

Note: This document contains reference to sensitive topics that may be triggering for some individuals.



Request for Public Comments on Co-Occurring Conditions

Responses

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Name	A.S.
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I am already perpetually exhausted and feel I never get quite enough sleep, rest, or recovery time from my obligations. Adding in the co-occurring physical health conditions exhausts me further. I have to push back on the idea that sensory challenges are some separate, co-occurring condition rather than something baked in to autism. Sensory challenges are just a part of autism, and those have to be mitigated with aids such as headphones/ear protection and sunglasses. Creating a world in which people are not so controlling of others that they balk at someone wearing headphones should be the ideal goal. I'm also concerned that scientists think they can or should make our sensory challenges go away because in the correct environment those can be an asset. It's just that none of us lives in the correct environment. Motor differences are interesting as not all autistic people have them. I certainly do and it would be nice to fall down less I suppose. Dyspraxia is the one piece of my autism I'd like to completely jettison. It's legitimately dangerous and I've had so many injuries over my lifetime that would not have happened if I didn't have motor challenges.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	These conditions for me have only ever occurred because of people systematically bullying, abusing, and ostracizing me just for being myself. They're all literal trauma responses, trauma of being abused. Being autistic is not inherently harmful and the autism phenotype has been found in prehistoric human remains. Something tells me it's a trait that can be useful. Some people are hunters and some are farmers, right? They're both important. Why are people so horribly abusive and awful and violent towards autistic people? I think that's the more important question to explore. Also, ADHD is a developmental disability, not a mental health condition. I don't understand why you lumped it into this question and then also included it in question 3. That seems really contradictory.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I have ADHD and it's difficult to "do capitalism" very well. Traditional employment is hard for me. I can swing it okay, but I'm often extremely exhausted and feeling resentful that our world doesn't afford other ways to survive aside from having a job. I can't force myself to do anything immediately and it takes me a long time to get anything done. I get distracted and derailed by other "side quest" sort of tasks along the way.
What additional research is needed to help address co-occurring conditions for autistic people?	Just acknowledging it exists and making the distinction between co-occurring and something inherently part of autism is important for dispelling myths and information (like people thinking if someone stops eating gluten their autism will magically go away). Some people think autism and ADHD are the same thing, some people think they're two distinct conditions that can occur in one person at the same time. Also approaching research from a compassionate and humanistic space instead of treating us like your little lab monkeys and like we're just a "research subject" would be the bare minimum. Switch to respectful and affirming, non-pathologizing language for starters. Pay autistic people to participate in studies and pay them handsomely. Don't collect DNA samples because the human rights violations implication of doing that is enormous. Basically don't be unethical eugenicists and don't see researching us as instant dollar signs. We are human beings, treat us as such.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access	Actual equitable treatment. Supports that aren't conditional on us being perfect with being on time and filling out dozens of forms. Supports that don't restrict our lives or strip us of any autonomy whatsoever. I'm radical enough that I want this for all disabled people. Nobody should have their

<p>to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>right to make decisions about their lives stripped away from them just to receive help. For those whose disabilities make decisions challenging, I think guided decision making is an equitable and compassionate middle ground so the person still retains autonomy and gets to have a full range of human experiences. Basically disabled people are treated as subhuman and deprived of life experiences because it's thought that we "can't handle it" and that's just gross.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>So much. COVID has so many neurological side effects, so it's not just an upper respiratory disease. The number of people with long COVID being basically ignored by the CDC, NIH, and medical profession at large is no less than criminal. When you already have disabilities and co-occurring conditions, this just adds another layer of pain and exhaustion to your life. I mask to protect myself and vulnerable loved ones, and the social and political nonsense people have around wearing masks has prompted strangers to harrass me in public over simply trying to protect myself. Autistic people are already targeted and bullied, so this adds another thing that people bully me over.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Remote work was good for me because I could regulate myself in my own, quiet room at home and could work a flexible schedule and got a lot more done. Luckily I live in a household that was conducive to me getting things done at home. I didn't have to mask (camouflage autistic traits) for the benefit of everyone's little feelings at work. I do miss the concept of "third places" where you could just go hang out and "people watch" for awhile, just simply exist somewhere without having to pay lots of money to do so. The disappearance of third places has been slowly happening since suburbs were invented, but COVID accelerated their death. You can't even go to a park without there being hostile architecture, or you're lucky to even find a bench to sit on and watch the day go by. It's sad. But the elders want to yell at younger people for being "inside" all day, but there aren't any good and safe places for people to hang out outside, either.</p>

Name	Aaron
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My sensory issues make it harder for me to stay calm out in loud public spaces like clubs/bars without being overwhelmed. I have trouble falling asleep and staying asleep most nights between sensory issues and insomnia. I also have to be near a bathroom most times of the day in case my stomach issues flare up.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My mood swings drastically some days due to feelings of anxiety or depression. It's harder to work through the feelings I get and figuring out why I have them. When I get them they also hit hard. At work it causes me to have trouble focusing on my tasks, and at home I can become despondent with my partner. Even with medicine the ADHD and anxiety aspects I have to put in extra effort to overcome. It's exhausting, but in order to function in society I have to put in a lot of effort masking my symptoms.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I have trouble communicating with my partner on occasion if we aren't directly blunt or specific about our topic. I have to ask extra questions and take a moment longer to think and process what is being communicated to me sometimes which can cause me to miss details. I tend to have to ask a lot of questions to make sure I'm doing something correctly, and will often repeat myself to make sure I get my point across.
What additional research is needed to help address co-occurring conditions for autistic people?	More research on undiagnosed adults would help. Just anything that can be found to make our lives easier or a better way to understand ourselves and our place in the world would help.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Making disability services more accessible to autistic people who are able to maintain a job. Just because we can, doesn't mean we aren't struggling daily with maintaining other aspects of our lives as well as masking our symptoms in order to stay employed. My disability is debilitating when I put all of my effort into masking at work or in public, and I get home unable to do chores or basic tasks to care for myself being burnt out.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Just being afraid of getting sick or getting someone else sick. I'm worried about the long term effects the virus has on the body and it adds another thing to be anxious about in my life.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Being able to stay home and not interact with anyone face to face was honestly one of the best things I ever experienced in my life. It's hard to always be social and sociable especially when working or in public, and the pandemic at least temporarily helped that aspect and allowed me to not be anxious about social interactions or masking all the time. I was finishing college and working remotely when it started. Since coming back to work and obligations in person again, I've noticed how drained I always am masking compared to when I was able to just do everything from the comfort of home and on my laptop.

Name	Abby Schindler, Institute on Disability and Human Development
Demographic	Autistic individual; Family member of an autistic individual; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory challenges seem to be most significant in both children and adults with autism. While the school system is improving in providing sensory accommodations for children, it seems most adults don't know how to advocate for this in the workplace and/or are not allowed sensory accommodations in the workplace.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The co-occurrence of autism and ADHD seems to be a significant challenge, and the term "AuDHD" is frequently used by autistic advocates surrounding this phenomenon. The research doesn't tend to treat these as distinct separate disorders. I believe research and clinical practice could benefit from understanding ADHD and autism more fluidly, as intertwined aspects of neurodiversity. The numbers on suicidality among autistic people is alarming. Efforts to educate crisis line operators on autism would be helpful. Some sort of crisis line by and for neurodiverse people would be even more helpful. It seems many autistic people, who are already familiar with mental health systems, fear they will be involuntarily admitted to a facility if they reach out about their suicidality. Because of this, they don't seek out help when struggling with suicidal ideation. There should be more ways for autistic people to receive safe and anonymous help. Having the option to communicate through writing when seeking help might make more autistic people feel safe seeking help as well.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I am a verbal autistic adult, but recognize that many people with autism have communication disabilities that limit their lives significantly.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Services and supports for late-diagnosed autistic adults which are covered by insurance plans.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	The reduction of social gatherings has made many people with autism regress in their social skills.

in-person social interactions and obligations)	
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Name	Abi
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	It varies for each autistic person. Personally, my biggest challenges are all sense related. The world is loud, like my sound sensitivity has been turned up to eleven, but the sounds all get jumbled in my head so I often can't understand spoken words. I also can't tell the direction sounds are coming from.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The hardest thing I've had to deal with would be self harming behaviors and suicidal thoughts. I still feel like those were largely my own fault. If I hadn't been so focused on being normal, I might have never done that. Other than that, ADHD has been troublesome because I can't perceive the passage of time. This makes academics difficult even when the subject matter is easy.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I don't understand tone of voice very well and I can't read between the lines. I'm very gullible and I take things at face value. People have taken advantage of this before. People have gotten angry at me for this. I get looked down upon for asking clarifying questions, but when I don't ask them I don't do things exactly how they were intended to be done. It's like everyone else is a mind reader and I'm just doing my best to keep up. I've also offended people by talking to them the way I am talked to. I mimic the way I am spoken to during conversation and I have been told that I sound incredibly condescending when I'm trying to be comforting.
What additional research is needed to help address co-occurring conditions for autistic people?	I think our development needs to be researched more. There is something different about the way we develop that causes these co-occurring conditions.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance for sensory needs would be huge. I am fortunate enough to afford high quality headphones that don't press on my skull and even play music so I can regulate my emotions. But there are a lot of people in America who can't even afford adequate food. Additionally, education for parents and children would help so many autistic people grow up without the same alienation issues I struggled with. My parents were always worried that my brother and I would be bullied by other kids who didn't know about autism. I have a very vivid memory of my brother being scolded for flapping his hands. I tried to be a chameleon when I was younger. To this day it is my deepest regret.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	I really struggled with school due to the lack of structure. However, my depression actually got better during the pandemic. The overstimulation of a classroom caused me a lot of distress, and social distancing allowed my brain to get a proper break.

in-person social interactions and obligations)	
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Name	Abi Lea
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	A lot of autistic people have mobility issues caused by co-occurring conditions like dyspraxia and connective tissue disorders like HEDS (Hyper-mobile Ehlers Danlos Syndrome) and HSD (Hyper-mobile Spectrum Disorder). This can cause significant challenges, such as difficulties driving or obtaining a drivers license and difficulties maintaining employment. For me personally, poor co-ordination and spatial awareness has meant that I have never been able to drive. Joint pain and mobility issues caused by connective tissue disorders can make working very difficult, painful or impossible for some autistic people. Sleep disturbances like insomnia, vivid nightmares, having Delayed Phase Sleep Syndrome, and sleep apnea, can seriously impact our quality of sleep and make it more difficult to participate in and handle the activities and stressors of everyday life. This can in turn impact our ability to work, complete daily care tasks and lower our overall quality of life.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	OCD causes me a significant amount of added stress as an autistic person, and can make it more difficult for me to participate in every activities. For example, I often get repetitive intrusive thoughts about jumping in front of the train and so this makes traveling by train much more difficult and the stress has a big impact on my mental health. ADHD compounds my difficulties with executive dysfunction making completing daily self care tasks, organizing my life and doing executive tasks like paperwork much more challenging. ADHD also makes it a lot more difficult for me to regulate my emotions and emotional responses. This makes me more likely to have meltdowns in public that can effect my employability and relationships with peers. I have gone through periods of depression and suicidality, as well as experiencing constant high anxiety, due to being overwhelmed by many aspects of life and feeling that not being alive would be the most peaceful option. It is depressing and demoralizing to feel like you are always battling upstream, in every aspect of your life. Everything (looking after myself, working, traveling, housework, socializing etc) is more difficult, overwhelming and exhausting for me than for my peers and this has a negative impact on my mental health.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Dyspraxia has made it very difficult for me to learn how to drive, and as a result I cannot drive and do not have a drivers license. Some of the challenges experienced by other autistic people with co-occurring disabilities, especially those with high support needs, include: not having access to AAC devices and therefore not being able effectively to communicate with others. Other people assuming incompetence because of their multiple diagnoses and therefore not providing them with access to the same educational recourses or activities as their peers.
What additional research is needed to help address co-occurring conditions for autistic people?	More research into HEDS and HSD, there is very little research on these conditions and therefore very little therapies or treatments available. More research into mental health conditions and how they impact autistic people.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More financial aid to help autistic people who cannot work because of co-occurring conditions, better insurance coverage to help access the medical care that autistic people need. More access to neuro affirming therapy for autistic adults.
What lasting impact has COVID-19 infection and illness had on co-	A lot of autistic people who were already impacted by auto-immune diseases and connective tissue disorders, have had increased struggles with their

<p>occurring physical and/or mental health conditions for autistic people?</p>	<p>physical health because of the impacts of COVID-19. Long COVID can cause muscle and joint pain as well as a compromised immune system- issues a lot of autistic people already face due to co-occurring physical conditions. Many autistic people also with executive function and focus because of co-occurring ADHD, and COVID has been reported to cause brain fog and executive function, which can therefore exacerbate these struggles. This causes even bigger obstacles to stable employment, ability to perform self care tasks, and overall good quality of life for autistic people.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Some societal changes because of COVID-19 have had a positive impact on the autistic community. Events, services and therapies being held online often makes these things more accessible for many of us. Working from home is also a great benefit for many autistic people who find working at the office taxing due to things like sensory issues and social challenges. However the change caused by the pandemic has been also created issues for many autistic people due to an increase in feeling socially isolated and difficulties processing and handling change.</p>

Name	abirami duraiswamy
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	There is lack of interdisciplinary study of neurodevelopmental disabilities (NDD). There are studies of higher lead level in autistic individuals, but yet, there is no mandatory lead tests, no interventions. Most people on the spectrum have low skeletal muscle mass and there are studies correlating poor skeletal muscle mass and executive functioning, which most autistic individuals struggle with. Poor muscle mass also leads to other health problems and physical disability. Most children on the spectrum are sensitive to certain food groups and are likely to have nutritional deficiency and gut issues. However mainstream medical community does not address this. Same with sleep issues. Studies point that individuals with NDD have sleep issues including sleep apnea. There is not cultural competent interventions to ethnic minorities. Most families struggle to access services. Waitlist for diagnosis is almost a year long, and same for most of the services. Most individuals with NDD and their families struggle with poor mental health, mostly due to lack of support.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My son has zero social life. Aggression, anxiety are the two most common issues. There is no awareness about sexual development and needs for the NDD population. Accessing mental health care is difficult for this population. There are hardly any mental health providers trained to work with profound autism and intellectual disability.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Life skills training is very poor and many adults with NDD are restricted to live at home.
What additional research is needed to help address co-occurring conditions for autistic people?	Since the diagnosis of autism is increasing every year, we have to find the cause and also identify parents/mothers who are at risk. We also need cultural competent interventions. The behavioral interventions rarely help and are very difficult to access. Policies to help promote mother, parents and family functionality is the key to improve outcomes for the NDD individuals.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	The gap between research and practice is atleast 10 years long. We have to bridge this gap. Maternal health care is important, and should include pre-conception, pre-natal and post-pregnancy.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	COVID-19 has affected the NDD individuals and their families much more than the general population. Most programs for the NDD community are still impacted with long waitlists. More children are diagnosed with behavioral issues than pre-COVID-19
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal	Positive - As a parent I have come to accept that my son is better off in a small social circle than in the community. Negative - I lost trust in the system, in the government and policymakers.

changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Adam
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	It is harder to keep a schedule because of my sleep issues. early mornings I have lots of energy but by mid day I am drained and can not keep up with social demands, My sensory system gets overwhelmed easily it affects the type of food I can eat to the fact I can't swallow pills , I have to have soft things to keep me calm, and I can't handle large crowds.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety: keeps me from driving, work it makes it hard I have always been harassed for being different then others so large crowds are a no go for me, Suicidal; no I do not want to kill my self but I do feel like life would be easier if I was not here, it is deferent then wanting to kill oneself, I try is a desire to have never existed
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Learning: for me in K-12 and in college, the harder part for me to all of it was the pace and the memorization they did not give me ample time to learn it, and digest it. Trying to memorize things just to pass a test for me and the other people I knew that are autistic. Just does not work. Communication: communication is very hard. I do great on a one on one basis, put me in a group chat with three or more people and I freeze because I don't know the proper way to react or the proper way to engage in conversations:
What additional research is needed to help address co-occurring conditions for autistic people?	we need to start by studying females and and continue the studying into adults. A lot of research and effort is put in the children. I grew up in a family that did not believe in mental illness so I was not able to seek help until late in my 20s and it was extremely difficult to find. a lot of the therapist that I have tried to see for the research I've done are uneducated on the subject.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	it is very difficult for me dealing with people that are supposed to be professionals when they do not understand traits of autistic people it would be helpful if there was some sort of training that you guys could do specially around Social Security departments about autism and how to talk to them and ask them questions appropriately. I tried to apply for disability a few years ago and was unsuccessful. At that point in time I had not been legally diagnosed with autism. I am in the middle of going through the process right now and it is very difficult. I am locked out of my online. I went into the office and explained that I need help and they just keep telling me to do it online. They do not truly understand the struggles that come with autism .
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	One of the nice positive things from Covid was when I had to go into public. There was way less people, so I greatly enjoyed that, the other part that was very beneficial, and I hope it stays is the ability to go to my doctors and therapist, online and virtually that helps with the anxiety of driving And appointments . The other thing that was very beneficial for me and I feel for a lot of people with the ability to work from home I had my cat and my sensory been available when I got overwhelmed
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services,	

increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Adam Wehn
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression, my depression is not caused by any clinical(chemical imbalance) source I have come to realize. The primary source of my depression has been infantilization, refusal to accept or understand my needs, and dismissing or downplaying my stated needs or struggles with meeting the expectations that societal pressure places upon me. Such as the societal expectation that I live in my own apartment and manage my own finances(one of my biggest struggles) with no other housemates(or community mates) leaving me feeling isolated and unwanted.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication difficulties, for me I am best able to communicate my feelings and needs in writing. But it has been a struggle to get so many people or organizations to allow me to interact/interface with myself through written communications such as email. With a healthcare provider I had to reach out to their umbrella healthcare group disability resources customer service section to get them to stop calling me, which is something that while I can do it speaking over the phone is very nerve wracking for me and induces anxiety and stress.
What additional research is needed to help address co-occurring conditions for autistic people?	I don't feel additional research is needed, what I do feel is needed is more support options being made available to the neurodivergent community. Especially in the form of housing options of a communal nature, either small communities where each individual has their own living space with a communal space for them to choose to socialize with others. Or a home setting where each individual has their own space to sleep in and retreat to if the stimulation of the world becomes too much for them.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I have previously stated prior but more support systems that do not apply additional pressure on individuals to conform to societal expectations.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	

in-person social interactions and obligations)	
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Name	Adriene Fern
Demographic	Family member of an autistic individual; Service provider, health provider, or educator; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gastro issues interfere with work consistency impacting performance reviews
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The anxiety in the world at large creates repetitive behaviors, may require prescription medication and service animal to be able to effectively manage and maintain mood
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Your panel asks how autism services could be improved to better address co-occurring conditions in this population. It must include changes and training to the social security phone and direct customer support staff. Social Security's inability to efficiently process and assist their most vulnerable consumers with consistent and knowledgeable information is deplorable. The maze of paperwork and lack of county/state sharing information creates a maze of misinformation, leaving many without funds. In April 2023, I contacted Congressman Jared Moskowitz's office for HELP! My son with autism had his benefits rescinded in February 2023. With his office's intervention, he was reinstated in July 2023. What will it take for the Social Security Administration to be able to talk to the other sub-departments of Social Security? We live in the 21st century with computers, email, and advanced technology, yet Social Security cannot streamline from one department to another. How many requests did your office and colleagues have to interfere with on behalf of your constituent's Social Security matters? Reform is required; we must do better for our most vulnerable. A broken system is no longer acceptable. Thank you for your consideration in this critical matter.
What additional research is needed to help address co-occurring conditions for autistic people?	Your panel asks how autism services could be improved to better address co-occurring conditions in this population. It must include changes and training to the social security phone and direct customer support staff. Social Security's inability to efficiently process and assist their most vulnerable consumers with consistent and knowledgeable information is deplorable. The maze of paperwork and lack of county/state sharing information creates a maze of misinformation, leaving many without funds. In April 2023, I contacted Congressman Jared Moskowitz's office for HELP! My son with autism had his benefits rescinded in February 2023. With his office's intervention, he was reinstated in July 2023. What will it take for the Social Security Administration to be able to talk to the other sub-departments of Social Security? We live in the 21st century with computers, email, and advanced technology, yet Social Security cannot streamline from one department to another. How many requests did your office and colleagues have to interfere with on behalf of your constituent's Social Security matters? Reform is required; we must do better for our most vulnerable. A broken

	<p>system is no longer acceptable. Thank you for your consideration in this critical matter.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Your panel asks how autism services could be improved to better address co-occurring conditions in this population. It must include changes and training to the social security phone and direct customer support staff. Social Security's inability to efficiently process and assist their most vulnerable consumers with consistent and knowledgeable information is deplorable. The maze of paperwork and lack of county/state sharing information creates a maze of misinformation, leaving many without funds. In April 2023, I contacted Congressman Jared Moskowitz's office for HELP! My son with autism had his benefits rescinded in February 2023. With his office's intervention, he was reinstated in July 2023. What will it take for the Social Security Administration to be able to talk to the other sub-departments of Social Security? We live in the 21st century with computers, email, and advanced technology, yet Social Security cannot streamline from one department to another. How many requests did your office and colleagues have to interfere with on behalf of your constituent's Social Security matters? Reform is required; we must do better for our most vulnerable. A broken system is no longer acceptable. Thank you for your consideration in this critical matter.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>The isolation find many to home, therefore propagating disengagement with others. Regression and social skills</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	

Name	Adrienne Benjamin , Parent/Gaurdian
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disorder: My daughter has Level 3 Autism, she is currently 27 yrs old, totally non-verbal. For most of her life she has had a severe sleep disorder, waking up after an hour like it's morning, or not falling asleep till 2am. She is currently on a lot of medication to help her sleep. Ambien, Estazolam and Melatonin. Irritable Bowel Syndrome: Terrible episodes of diarrhea for years. Allergy testing revealed lactose intolerance. Changes made did not solve IBS. Currently on Viberzi which helps. Self Injurious Behaviors: Hand biting, hitting her head when frustrated, or annoyed. Obviously related to her non-verbal autism.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	For parent caregivers: Sleep Disorder meant chronically poor sleep for parents, and my child. IBS: Significant hygiene challenges dealing with chronic diarrhea, as well as discomfort in my child. Difficulty planning activities out of the house. SIB's and Aggression: Episodes of SIB and aggression cause both pain and chaos, broken furniture, wounds to my daughter. Home doesn't feel safe. My other child also had to be hyper vigilant about my daughter's SIB;s and violent outbursts.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Intellectual disability plus autism creates a situation of chronic difficulties for my child. Developmentally, she remains a 2-3 yr old. She will always need 24/7 care, cannot be left alone, needs help with all aspects of personal hygiene. Level 3 Autism is present in approximately 25-35% of those with Autism. Once these kids age out of school (22yrs), there are no mandated services. Nor are there many agencies that have staff trained to work with people on the severe end of the spectrum. Parents dont live forever. Most agencies are desperately understaffed (primarily because of low pay).
What additional research is needed to help address co-occurring conditions for autistic people?	Great question. First, there still is no answer to explain why there has been and still is a massive increase in the number of children with Autism over the last 25 yr or so. That's important. Very important to study. And, usually, people with severe types of Autism are excluded from research. Yet, it is those with Level 3 Autism who seem to have the most co-occurring conditions. Research that too.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More funding for programs, higher wages for DSP's (Direct Support Professionals). More training for DSP's to improve services as well as to create a career path for DSP's. More training to the medical and dental providers so that they can effectively treat our population. More housing options, so people have a whole range of choices to meet their needs. Including congregate communities.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	

in-person social interactions and obligations)	
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Name	Advocates of Autism of Massachusetts
Demographic	Representative of advocacy organization
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>This comment is submitted by Advocates of Autism of Massachusetts, a state-wide grassroots association of self-advocates, families, service providers, and concerned citizens advocating on behalf of autistic people in our state. Many people with autism face a diminished quality of life on a daily basis due to co-occurring health conditions. The impact of certain co-occurring conditions can even result in premature death (e.g., catatonia, epilepsy and seizures). Moreover, due to communication difficulties and other manifestations of autism in an individual, these conditions can be challenging to diagnose and treat, leading to chronic discomfort and pain and a worsening of the co-occurring conditions. Medical conditions are not always observable, and many individuals on the spectrum cannot describe their discomfort or pain with any specificity. Due to sensory challenges, many devices and tools used for diagnosis and treatment may be unavailable (e.g., inability to tolerate attachment of leads to complete an EEG in connection with seizures). Oftentimes, the symptoms of co-occurring conditions are dismissed as “just part of autism” and go untreated, are treated with inappropriate behavioral interventions, and may worsen and lead to further complications.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>Higher rates of co-occurring mental health conditions among people with autism (including various types of anxiety, obsessive compulsive disorder, depression, aggressive or self-injurious behavior, and suicidality) are well documented and create significant challenges including impairment of sleep and appetite, irritability, repetitive movements, insistence on sameness, isolation, severe meltdowns, and self-harming behavior. These challenges in turn contribute to and cause spiraling of further mental health pathologies and behavioral issues, as well as physical health challenges, and may severely degrade well being and become life-threatening. Pica and elopement, experienced by some in the autism population, are extremely serious and dangerous, as are aggressive and self-injurious behaviors which result from both autism and co-occurring mental health conditions. These conditions frequently lead to bruising, lacerations, scarring, broken bones, ripping out of hair, skin infections, detached retinas, and concussion. In many cases involving aggressions, the person’s caregivers sustain these injuries. Obviously such injuries can be lethal and short of that frequently require emergency medical treatments, surgeries, and hospitalization.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>This question is confusing as it is difficult to separate these “co-occurring conditions” from autism, which is a developmental disability and in many on the spectrum is characterized by cognitive challenges and communication and learning disabilities. Depending on the severity of a person’s autism, their ability to live independently and engage in meaningful employment is significantly challenged. It is hard to designate certain challenges as more or less significant when one has a pervasive disorder that affects all aspects of one’s life and relations to other human beings and the environment.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>Notwithstanding research into the causes and characteristics of autism over the past several decades, investigations of the manifestations of autism, co-occurring conditions and effective interventions has barely begun. This research is particularly limited for those with profound or severe autism. Much of the research undertaken to date excludes participants who are nonverbal or those who cannot tolerate the conditions, procedures and environments involved in the studies. An important focus of research going forward should be on better understanding and addressing severe behaviors</p>

	<p>such as aggression, self-injury, pica, and elopement, and identifying more effective treatments (medical and behavioral). Much more research is needed on psychiatric medications and other therapies. Given the characteristics of autism in many people (sensory issues, communication challenges, etc), research is necessary to develop technologies, instruments, and techniques to allow people with autism to better access primary care and preventative screenings, as well improve the diagnosis and treatment of chronic and serious co-occurring conditions.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Private and public insurance for children and adults should cover medically necessary treatment of autism, including treatment for behavioral conditions (e.g., aggression and self-injury); such treatments must be recognized as medically necessary under mental health parity. The number of physicians and other healthcare providers who are experienced in delivering primary and specialty care to children and adults with autism must expand to meet the needs of this ever growing population. There should be greater coordination among state agencies that fund and oversee the delivery of healthcare and long term services and supports so that co-occurring mental health concerns, in particular, can be addressed in a less difficult and more coordinated fashion. The Medicare system (not just the Medicaid system) must become familiar with and adapt to serve this growing population as the large numbers of children with autism born in the past few decades become adults and they become eligible for Medicare themselves or through their parents' eligibility. Collectively, we must develop technologies, instruments, and techniques to allow people with autism to better access primary care and preventative screenings, as well improve the diagnosis and treatment of chronic and serious co-occurring conditions.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>We are not in a position to comment on this and are not aware of research on the lasting impacts of COVID-19 infection and illness on such co-occurring conditions.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>COVID has had a devastating health impact. Reduction of workforce and number of viable LTSS providers, exacerbated by the pandemic, continues to date. Many autistic adults have yet to return to services, particularly those with severe behavioral or medical challenges with more intensive staffing and those transitioning from education to adult services during and after COVID. (The vacancy rate in direct care positions in MA in Oct. 2023 averaged 24% (Association of Developmental Disabilities Providers survey).) Reduction in services has increased isolation, loneliness, skill regression, lack of exercise, and lessened overall well-being. After COVID closed in-person gatherings, some autistic people became anxious to leave their homes - even for school - due to social anxiety or fear of germs, leading to worsening mental and physical health. One positive outcome of the pandemic: an increase in telehealth services which can be a real advantage for some with autism. Some telehealth flexibilities have since ended, however, e.g., no more billing for remote CBDS services. There are circumstances when this would be beneficial to ensure continuity of care. e.g., when a participant is not in person for medical reasons, but still could participate in some activities. Also, some individuals are more comfortable participating in certain services online versus in-person. Eliminating such flexibilities fails to recognize that online communities are a new reality and provide benefits.</p>

Name	Aidan
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I have intense bodily pain and joint problems from the co occurrence of hEDS. I struggle to be able to work not from home because of this. My gastrointestinal issues make it difficult to live my life and little my diet beyond the sensory issues autism causes.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have anxiety, depression, PTSD, anger issues, and ADHD. All of these made it extremely difficult to thrive to school, and continue to make it difficult to work and have social relationships. I have to fight my own brain every day for the bare minimum of not simple curling up and dying.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I struggle to express myself verbally and am significantly behind socially.
What additional research is needed to help address co-occurring conditions for autistic people?	More research needs to be done in the effects of autism on women, people of color, various socioeconomic classes, and lgbtq+ individuals, as the majority of research and the most commonly used diagnostic tools were only tested on cisgender, white men and boys. New diagnosis tools would be amazing. It would also be useful to find the best ways for parents to raise children with autism without causing additional trauma and mental health disorders simply through not having the knowledge.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	All insurance should cover therapy, simply put, but accessibility is also a big issue. Public knowledge of co-occurring conditions is next to non-existent, and many providers brush off concerns of these issues.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	We were able to see the benefits of work from home and how much better that was for us, but that option has been taken from many people, and the same goes for telehealth. I personally found quarantine to be a healing experience., with less physical and mental pain and overstimulation. I was able to get good grades, thrive in my job, and maintain friendships all virtually much better than I did in person.

Name	Aimee Doyle, Autism Mom/Disability Attorney
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	One of the most significant challenges is recognizing that these co-morbidities are common with autistic individuals - and that these co-morbidities affect both health and the quality of life. Research on how to treat co-morbidities has been sparse. Here is a list of co-morbidities that I have observed after 30 years in the autism trenches. 1. Gastro-intestinal Issues. A sizeable percentage of individuals with autism have issues related to eating, digesting, and eliminating food. For eating, this can include everything from severe allergies to foods, to extremely restricted diets (malnutrition), to pica (eating non-food objects and needing surgery to remove them). I've seen problems with explosive diarrhea, fecal smearing, and constipation. 2. Epilepsy and Seizures. One key point is that seizures affect approximately a third of autistic individuals - and seizures are rarely perfectly controlled. 3. Sleep problems. 4. Hypo-Hyper sensory sensitivity. Many individuals with autism have difficulty with sensory overload due to inability to handle light, sound, or texture. Others have "hypo" systems - like my son, who didn't feel pain.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My son has experienced severe anxiety which compromised his ability to learn. He resisted all efforts at learning life skills. He had, self-injurious behaviors - in adolescence, he hit his leg so many times the hair fell off, and he walked on his knees until one knee became horribly inflamed. At times he has been aggressive (hitting others, punching me and my husband, poking me in the breasts). From my reading, I know that anxiety, depression, self-injury, and aggression affect a sizeable percentage of individuals with autism.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Approximately a third of individuals with autism are non-verbal, or semi-verbal, and cannot communicate effectively with even the best augmentative communication technology available. Approximately a third of individuals with autism (not necessarily the same third) are intellectually disabled.
What additional research is needed to help address co-occurring conditions for autistic people?	We need additional research on the co-morbidities that affect individuals with autism - both the physical co-morbidities and the mental co-morbidities. I think there should also be research into what causes they co-morbidities, and what causes autism, since it is always easier to treat something if one knows what causes it.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance could and should cover more autism treatment. We have spent hundreds of thousands of dollars on both conventional and alternative therapies for my son, without that much in the way of results. We have tried EVERYTHING. And almost none of it was covered by insurance. Insurance companies rarely cover even standard helpful therapies like speech therapy or occupational therapy and never cover newer therapies like biomedical intervention, sensory-integration therapy, vision therapy, or auditory integration therapy. There really hasn't been a new, effective treatment or therapy for over 15 years. And there is very little research on effective treatment for those who suffer from severe autism. There is little research on effective treatment for the co-morbidities of autism. Doctors don't seem to want to deal with either autism, or the co-morbidities.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I know individuals who responded poorly to the Covid-19 vaccinations. In some, it seemed to worsen their immune capacity. The vaccinations certainly didn't prevent infection, re-infection, or transmission.

<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Service disruptions in day programming were terrible due to Covid. Many people with severe autism just sat at home. Most were not able to work with any on-line services. Negative behaviors increased due to the lack of routine. Family members had to "pick up the slack." I know people who dropped out of the workforce or retired because they had to be there for a disabled child or adult.</p>
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Name	Aimee Mingone, Teacher
Demographic	Autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	All of these and I didn't know they were related. Sensory issues are probably the worst.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety and ADHD. I used to really struggle with depression and suicidal ideation, but that nearly non-existent since my diagnosis. This helped me escape a lot of unhealthy situations too.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Auditory processing and executive functioning
What additional research is needed to help address co-occurring conditions for autistic people?	More public acknowledgement of autistic voices
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage for diagnosis, autism support animals for adults, and workplace acceptance of accommodations.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I never had COVID
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Weirdly, the resulting cost and scarcity of safe foods for my digestive issues. I can't even afford most of what I can still even find since COVID.

Name	Akash Dey, ASD level 1
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory challenges. Ringing in the ears from hearing multiple frequencies affects concentration and wears you out. It is like you using energy when you are doing nothing. This is especially bad when multiple noises overlap or you need to concentrate on multiple things. It can affect your sleep as well. I have sleep apnea, but in addition to that the ringing from a previous over stimulation can affect my sleep and as a result the next day I could be more tired. It is very frustrating that when I am off of work I still have to expend energy from being constantly overloaded during driving or doing tasks I cannot control.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety. For me my autism manifests as anxiety. I make impulsive decisions when my head is overloaded by sensitivity because I just want the noise to stop. It is too difficult to think on top of dealing with all that is going on. Most times I do it but there is no time without a challenge. During driving my autism manifests as anxiety. The headlights on the road, the noises from the car, focusing on small details. Anxiety is also caused from introducing new tasks or changing routine.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I have difficulty visualizing things that are not definite. I failed college because I was struggling with communication and reading comprehension. I now know I can understand and trust numbers more.
What additional research is needed to help address co-occurring conditions for autistic people?	I think a study where you have adults with autism who have jobs write a daily or weekly report in their schedule and challenges they faced regularly as to when changes happened would be good. As well as how well their coworkers and workplace understood and supported them.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I got diagnosed as an adult and it was extremely hard. It was a battle. I hope adults can have easier access to being diagnosed and covered by insurance. Kaiser in San Jose said they do not diagnose adults with autism and only have group therapy services for anxiety and depression. I think there is a huge lack of services for adults with autism. I had to pay out of pocket and get a diagnosis as well as help.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I got some heart problems after covid, I think it increases anxiety.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I think the introduction of remote work and school are of great benefit. I never thought I could go back to school due to being forced into a crowded classroom with multiple noises going on and trying to focus. I am learning programming on my own in a nice quiet environment I can control. Having a hybrid schedule really helps me rest from sensory overload.

Name	Alan Owen
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory issues. Many meltdowns and difficulties with work are caused by sensory issues, and they exacerbate social difficulties, making it harder to interact with others
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Suicidality, depression, and anxiety can be explained somewhat by interactions with other people. When somebody is constantly told that they are acting weird, or strange, and are ostracized, then depression and suicidality are an expected result, and anxiety can come from interacting with those same people.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I personally only have issues with communication, so I can't comment on the others. That said, communication can be difficult sometimes, especially when social anxiety is playing a part. Not having my voice be heard because I'm not making enough sense to the listener is probably the biggest challenge I face.
What additional research is needed to help address co-occurring conditions for autistic people?	More studies of autistic brains in detail. One study I saw showed that the amygdala is enlarged in infancy in autistic people, and that it could be responsible for increased sensory issues and emotional dysregulation. This information, combined with the negative effect of cortisol on the hippocampus, led me to realize that interacting with people damages my brain. This was information that I myself had to piece together. Research showing the why of autistic issues, explained in a neuroscientific way, would do wonders.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Some ability to ensure security would be a good start. I'm thinking about universal basic income, which would allow autistic people to try out different areas of employment, and to find a place that works with them. Were I to not fall into a position where I could resign from my job safely, I would have committed suicide within the next year due to my co-occurring conditions. This position was living with my brother, who doesn't charge me any bills. Now, I can focus on trying to find a job that works with me, that I feel comfortable in. Before now, I had to work to survive, and my job was what was causing the problems.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	For those with social anxiety, the lockdowns were a blessing. Remote work and schooling were a benefit as well, and not worrying about social responsibilities was also good.

in-person social interactions and obligations)	
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Name	Alessandra Stark
Demographic	Autistic individual; Service provider, health provider, or educator; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disorders, eating disorders, sensory processing disorders, OCD
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, self injury behaviors, ADHD/ADD, low self esteem
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Behavior disturbances, communication delays, limited functioning, lack of understanding social cues, lack of environmental awareness, lack of self awareness, sensory processing disorder
What additional research is needed to help address co-occurring conditions for autistic people?	Additional research is needed on how to better treat anxiety when it comes to potty training and other tasks that are related to hygiene. Also there needs to be additional research on how to treat different eating disorders and sensory processing disorders that are involved in this
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage, free and equitable access to services, more services in low income and rural areas, more communication between patient and provider, mandatory consent procedures before implementation, more schools receiving funding for ABA services/other services in schools (especially schools in low income areas), more funding for ABA centers and agencies (BCBA's have to pay out of pocket for materials and that should not be the case, this should be funded by the ABA agency but agencies cannot afford it, therefore there needs to be more funding), free and affordable access through insurance to environmental modification at home, schools, center, etc for safety reasons and needs of that individual
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It's greatly impacted children's attention span to task and activities that are not related to screen time. Also lack of socialization with peers has impacted children to not socializing as much losing those skills and unable to communicate effectively and endgame with their environment.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	It has negatively impacted their development for socialization, environmental awareness, sensory input, and generalization of skills across different environments and people. Things have gotten a little better now but people with autism continue to struggle more than ever before on these important skills because the lack of interactions and going to different places was cut during covid. Some of the most detrimental years of development were cut for children that impacts their development.

Name	Alex
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbances which cause emotional disturbances, sensory over load, gastrointestinal disorders, heightened sense of touch, Ehlers danlos syndrome, hyper mobility, hypothyroidism, struggle with allergies to the point of avoiding vaccines due to allergies.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, depression, adhd, self harm as a form of sensory overload management, low patience, low tolerance of sound
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Intellectual disorders that cause us to process things faster, however people don't appreciate that we process things faster so they fire us from jobs. Communication struggles. Learning disabilities due to lack of leeway in the standard school system
What additional research is needed to help address co-occurring conditions for autistic people?	Research on the impact lack of sleep has on an autistic individuals daily life.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More leeway when it comes to the standard work schedule. An autistic person has to use 2-3x the amount of energy as a neurotypical person for the same job. We are managing our our senses while as someone without autism doesn't have to manage that at all, nor put any brain power towards it. Insurance coverage for things to help an autistic person. Medication research to lower the sense would be phenomenal to the autistic community and individuals.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	The Covid 19 vaccine, specifically Pfizer vaccine has given me an allergy that is unavoidable, propylene glycol, which is in everything down to city water and has made living my life nearly impossible without n allergic reaction, which makes attendance at work difficult, and then in turn makes keeping a job more difficult than it already is for an autistic individual.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Positive, less people approach us. Which creates less of an overload on us. Negative, people are more likely to reject each other which is something we already struggle with and it makes it harder on us to ask for help and get the help we need, even if it's just asking where something is in a grocery store.

Name	Alex
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The most significant challenges are receiving care insurance forces doctors to listen so little they dismiss or refuse to test or treat these conditions confusing pattern recognition ans years of research for trend following. Having these symptoms untreated also leads to an inability to work or an inability to work without being discriminated against. Only 15% of diagnosed autistic adults carry on successful stable careers while most are unemployed and chronically l'll despite having the ability to be incredibly diligent and overworking employees.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The issue here is the same as untreated physical illness, increased unemployment, increased discrimination in both the medical field and the job field. Untreated, mistreated or under-treated care also leads to a shorter lifespan with the average lifespan in autistic adults being drastically lower which can itself increase depression and feeling unwanted by society as it reflects society as a whole viewing us as expendable and disposable simply for communicating differently.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	More Autism run studies. A recent study at Harvard found Autistic people especially those with high pattern recognition are more accurately diagnosing themselves than doctors. This comes from a fundamental misunderstanding of the neurodivergency that textbooks and studies are overlooking based on outdated information from dangerous medical ideals similar to ABA or Conversion therapy. Research also needs to focus more on how socialization affects those with autism as it prevents vastly different in feminine raised people who as a whole are almost always late diagnosed if they get a diagnosis because the diagnostics are based on young boys only.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Better protections from workplace discrimination, too many symptoms of Autism are considered acceptable reasons to harass or fire someone. More aide services, something as simple as a care coordinator who actually shows up had changed my life. Having access to Autism friendly instructions on paperwork as many government forms are vague and confusing for someone who needs direct instruction. Easier or permanent accesses to things like Medicaid with an increased risk of medical and mental co-morbidities many autistic people have to choose between neglecting their health and having shelter or food especially when working many days in a row or many hours can take our entire energy reserves leave us to pick between working or caring for ourselves. Overall accesses to UBI or Medicaid or assistance in having basic needs met would help autistic people flourish and be able to participate more in the economy and bolster the workforce in a way that would greatly benefit our own health as well as the US
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to	Having an increased option for work from home where I can control sensory overload and reduce burnout has been greatly beneficial the same goes for

the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

higher access to delivery and telehealth appointments. The ability to move about with people distancing and masking has also greatly reduced the burnout I'd experience before the pandemic making it easier to retain a home and a job. I'd love to see these things grow and continue so that when there is space for it more people can enjoy more 3rd places more often without causing total shutdowns due to being repeatedly sick or overwhelmed

Name	Alex
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	In my particular case, sound and (non-epileptic) light sensitivity are on the severe side, causing pain like stabbing needles in my brain, eyes, and ears. Base from heavy machinery and loud music can cause crippling discomfort, even in my own home without significant recourse. I can wear earplugs and sunglasses when I can reasonably predict it, but i cannot wear both all day every day.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The whole of society is built in a way that shames and alienates autistic people. Much of the mental health issues stem from that simple truth. People intrinsically know that something is wrong with me and with that gut feeling ostracize and criticize me behind my back. There are no repercussions nor recourse for this. Even if I claim discrimination, how could someone prove anything? How can I access services via customer service when I have to sell my personality like a salesman to even be treated like a human being? Finding doctors specialized in autism is also a challenge. Even in mental health specialties, many doctors avoid learning about or diagnosing it. For people like me, these challenges manifest as agoraphobia and misanthropy.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Many learning disabilities associated with autism aren't screened for early enough (if at all) thereby permanently stunting our full potential. This impacts our economic success as well as our self esteem. Even worse disabilities can put us at the mercy of whomsoever has the shortest patience that day.
What additional research is needed to help address co-occurring conditions for autistic people?	We need AUTISTIC led research to examine the connections/causations/correlations of autism and its comorbidities. We DO NOT WANT AUTISM SPEAKS to have any involvement in this process due to their intense stigmatization of autism. If we understand the methods by which autism causes distress, we may yield therapeutic treatments for sensory issues, shutdowns, meltdowns, and more. If we can diminish the more destructive elements, the creativity, joy, and diversity of thought that autism can bring can take center stage.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	One simple to implement accommodation is to allow for more Healthcare and government services to be accessed non verbally. This means via a website, app, or other written or typed medium. The main issue overall is access at all. Many Healthcare providers have very little knowledge of autism. Specialized autism care is practically nonexistent to most people. Ideally, reasonable access to diagnosis with a protocol to refer out for comorbid condition screenings would be a start.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I think that because of my agoraphobia and higher degree of education, i was able to accept and understand the conditions of the pandemic and follow protocols easier than most allistic (non autistic) people. I also find that many are still struggling with a return to pre-pandemic life because the lockdowns actually allowed us to work in our own homes and have more agency in our day to day lives. Masks hid flat expressions. Work from home let us control our environment (sound, temperature, lighting, etc).
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal	The increase in remote work and services was a huge, but short lasting win for autistic workers. We're largely disconnected from society by non autistic people, so the mental health impacts didn't hit our community as hard. I wish remote work was the standard.

changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Alex Curtis
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory, motor, and sleep disturbances are the most common I have found. I take melatonin at night to help avoid waking up repeatedly, not being able to sleep, etc. For sensory I wear sound canceling headphones and avoid certain textures. Sometimes this makes it difficult to go to certain loud places.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	For me, the most is suicidality, self injurious behavior (self harm), depression, and anxiety. I've been to a mental hospital before and were/am going to therapy to help these things too. These challenges cause me to struggle with motivation, relationships, and self-esteem. It can be hard to escape these at times.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Learning disabilities
What additional research is needed to help address co-occurring conditions for autistic people?	I think the additional research needed to help address co-occurring conditions for autistic people is not just bringing awareness but acceptance of autism. Please research more into biological women (AFAB) with autism because it makes it very hard to get a diagnosis. Also, into other mental health conditions/disorders and how they can come from or relate with autism.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I think the ability to have access to earplugs/sound canceling headphones/quieter space options, and overall equity when accessing and using the same services as atypical people.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It has spread more awareness about mental health, but it also shut us in and made people see us differently.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	There is an increased use of remote work and school, and disruption in in-person therapy or other resources.

Name	Alexandra Carlson
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I can only speak to personal experience. It can be hard to sort out where the problem is. And a problem with one part can cause a cascade of problems with the others. Am I depressed because there's no sunlight? Because my thyroid is low? Because my insulin resistance is graduating to diabetes and I'm starving while gaining weight at the same time because government nutritional information told us fat is bad and shoved tons of extra sugar in all foods? Or is it autistic burnout... which was never a possibility because nobody recognized I am autistic until I was 30. Getting anything diagnosed and finding a treatment was difficult because of this. My pediatrician told my mother being moody at age 10 was normal, but then we discovered my thyroid was low, so solving that should have solved everything, but it didn't... etc.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	In my case, because my autism was not recognized, my psychiatrist accused me of lying. I was convinced I was lazy and unable to handle pressure. A lot of situational depression occurred due to feelings of ill-fit, being forced to pretend to be 'normal', not given space when I needed it, etc. Which then was a feedback loop between depression and burnout. When indications of self-harm were discovered, I was harassed by professionals, which only made me want to hurt myself more because now I was overwhelmed. Meltdown could trigger self-harm but it was treated as depression-led suicidality rather than a case of being overwhelmed, so the "solution" was to keep bothering me instead of letting me cool down.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	In my case, it's all about recognizing autism as separate from the co-occurring conditions. And that the solutions to problems need to take into account the autism as the standard solutions may be wrong or incomplete.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Screening and recognition for autism itself. Mental health support in general. For everyone, regardless of income. Ways to connect with medical professionals that does not involve being on hold for two hours and speaking to a receptionist who cannot help you. MyChart is awesome for this - I can send an email type message directly to my doctor who can respond for non-emergencies. I have excellent insurance and live in a place where I can access good care. Many people don't. Universal healthcare, please.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	I love video meetings (vs in person). I love being able to order food. I love self-checkouts. I love the explosion of discussions about mental health and recognition that addressing it is important. I worry that many children weren't socialized properly during lockdown and remote learning. They didn't get support services or testing and there are still shortages. Poverty here is still awful - mental health suffers when people's needs aren't met. Problems that existed prior to the lockdown still exist. Universal healthcare. Universal basic income. Universal Housing. Hell, universal internet access. Still upset that my city didn't figure out how to give all kids access to the

in-person social interactions and obligations)	internet during remote learning - that the school district had to shell out for hotspots rather than access to information and education being treated like a basic human need.
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Name	Alexandra Hathaway
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Understanding of complex health needs by medical professionals, lack of autism accessibility in physical health care providers offices and lack of physical condition accessibility in mental health care provider offices,
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Lack of autism education in therapists and other mental health care providers, understanding the difference between your diagnoses and not having another condition misdiagnosed because of overlapping conditions
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Difficulty understanding education and care information that is not written in plain language or in an accessible way
What additional research is needed to help address co-occurring conditions for autistic people?	Understanding why autism Co occurs with certain conditions
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Lack of accessibility because of a lack of wide spread masking and following proper protocols to avoid mass infection. Aggravation of symptoms from covid-19 infection.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increase in remote access which is a good thing

Name	Alexandra Hayman
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Undiagnosed Ehlers Danlos syndrome or HEDS, possible POTS, sleep problems (getting to sleep), sensory issues.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety disorder in my case Generalized anxiety disorder and bipolar 2 and a past history of NSSI and past suicidality prior to my clinical diagnosis/identification as autistic.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Learning disability in mathematics since childhood, intellectual impairment and was speech delayed in childhood and fine motor skills delayed.
What additional research is needed to help address co-occurring conditions for autistic people?	Research the prevalence of autism and Ehlers Danlos syndrome/HEDS, POTS, in autistic people, study more women and girls so that future generations can get identified younger than I did.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Equitable access and more services for autistic adults in all 50 states and make it easier to get SSDI, make it less difficult for renewing Link cards, decrease the wait time on the PUNS list and time waiting for funds from the state.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	The covid 19 pandemic caused me to isolate myself so much more and thus my mask slipped and my therapist/psychologist suspected that I was autistic and wanted to get me assessed again in 2021. I also immensely became depressed when we were home for so long and couldn't function at all. I also got covid in April 2022 and after I had covid I started having signs and symptoms of Ehlers Danlos syndrome or HEDS and POTS.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Telehealth/virtual therapy sessions, decreased socializing in person, forced isolation, increased depression.

Name	Alexie Herrmann
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Epilepsy, connective tissue disorders, hypotonia, fine and gross motor challenges, sleep issues.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD, trauma, suicidal thoughts.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communicate issues and lack of access to accessible communication options Lack of appropriate educational support for co-occurring disabilities
What additional research is needed to help address co-occurring conditions for autistic people?	More research into connective tissues disorders, the cause of connection between autism and epilepsy, therapies that aren't ABA that are helpful, what educational strategies are effective.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More ABA alternatives, insurance not requiring so many prior authorizations, insurance allowing sooner refills, more Medicaid covered providers, more Medicaid waivers, creating better living spaces that are accessible, easier access aac devices, more training to SLPs on aac devices, more Neurodivergent Affirming practices and trainings for the medical field, increasing help so wait lists aren't so long, covering hippo therapy under insurance.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Lost motor skills that weren't able to be gained. Mental health struggles. Social skills struggles.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Lack of access to stores being open 24/7. Pharmacy hours being limited. More difficulties getting medicine filled in a timely matter. Less support people in schools.

Name	Alia Campagnone
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gastrointestinal disorders, vascular compressions
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Stress,aggrivation, adhd, suicidality
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication disabilities.
What additional research is needed to help address co-occurring conditions for autistic people?	Research needs to be done on treatments& cures to help manage these co occurring conditions. Vascular compressions need significant research.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Provider patient interactions. Also to encourage autistic individuals to go into healthcare since a lot of the wording we use neurotypical cannot understand.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It added to the tipping point of my body.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Positive impact on telehealth Negative impact on providers thinking we are faking even worse.

Name	Alicia Whaling
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Insomnia, sensory issues, food sensitivity, digestive issues, headaches, widespread pain, functional regression
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression, anxiety, OCD, ADHD, PTSD, night terrors, sleep paralysis, suicidal ideation, self harm
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	not being able to socialize without extreme effort, never feeling accepted/constant fear of rejection, unable to maintain employment, all side effects from medication, broken relationships,
What additional research is needed to help address co-occurring conditions for autistic people?	Study all ages, all genders, actually use a spectrum instead of a line to measure, research masking
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Make a diagnosis accessible and affordable, widen the assistance available both physically and financially, force insurance to cover co morbidities, institute job security measures
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	People started unmasking during lockdown and isolation. Now it's too hard to mask again, so mental health issues are made worse

Name	Allison Barcott, Parent
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Our son's sleep challenges began in infancy when we had to resort to using the sound of a hairdryer to soothe him and continued into adolescence with significant anxiety at bedtime every night. At age 15, prescription medication finally brought it under control. However, that medication has side effects that we must continually watch. Diagnosed with Sensory Modulation Disorder at age 4, he put in 3+ years of OT work, yet still struggles to cope with the noise, smells, and visual overwhelm of everyday life. As a hidden disability, it is particularly insidious at school, as staff don't understand how difficult just being at school is for him.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The most significant challenge for our family has been the lack of psychological therapies (and practices) that have been adapted (or created for) autistic individuals (let alone Neurodiverse informed!) Our son had been diagnosed with ADHD, LDs, and Sensory Modulation Disorder by 3rd grade; however, his ASD was missed until he was 14. Over that time, his anxiety grew into depression, school avoidance, and suicidal ideation. As we sought treatment for him from well-respected psychological practices, he continued to (scream) that they didn't understand. After receiving the autism diagnosis, I began looking deeper into scientific studies on these therapies (CBT, DBT, etc.). I saw that while some have been found to be "helpful" for those on the autism spectrum, it is typically at much lower rates than neurotypicals. However, when those therapies have been explicitly adapted for neurodivergent individuals, the rates are much higher. Our son's mix of diagnoses makes this kind of individualized support imperative. However, finding clinicians who use or even know about these adaptations is like finding the proverbial needle in the haystack. We've learned this the hard way after putting our son into programs that may have actually done him harm. While we have found a therapist who we think will be helpful, uncovering anything like an IOP or PHP is beyond hope. Without that, his return to school will be an excruciatingly long and arduous process at best.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Our son's learning disabilities contribute significantly to his anxiety/depression on a daily basis. He continually hears and sees that he is slower and less able than his peers. When supports that help him have been found, staff has not been helpful in making it easy for him to access them. IEPs do not seem to get read by anyone other than the RTSE. Because we remained in the dark for so long about his ASD, he struggled on his own with social communication, both with peers and adults. When he needed to break-off from a friend who had become a bully, trying to do so put him in a traumatic meltdown. When overwhelmed by school, he was often unable to speak, so he could not advocate for what he needed with adults. When he would try to do so, the typical response was that he was overreacting and should just "get over it." Better paraeducators were at least kind, but others were not only untrained and uneducated enough in the subject but uncaring as well.
What additional research is needed to help address co-occurring conditions for autistic people?	We need more research on what WORKS for those with ASD, not just what we can adapt for them. (Both in meds and psychology) We need to train all behavioral health clinicians in everything about ASD!!! From diagnosis to therapy, there seems to be a massive lack of understanding in the field of what researchers have learned about ASD in the last 20 years. I recently read a bit of research done on how clinicians felt regarding treating those with autism, and it all came down to how much training they had had on ASD. More research in this area will help clinicians understand how important that

	<p>training is. We are sick of being told we are helicopter parents and need to tough it out when what needs to happen is that they need to learn how to slow down, be explicit, precise, and earn patient's trust. Without proper training, they should not be working with neurodiverse patients. We need research to show the lack of availability of specialized behavioral health care for those with ASD. Thus far, I have yet to find an IOP or PHP appropriate for the neurodiverse community. My husband and I live in fear of the day that we are forced to take our son to the emergency room for psychological evaluation--we've seen all too well how wrong it usually goes for anyone who is not neurotypical.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Insurance: Currently, if you have co-occurring behavioral health conditions (say ASD and anxiety,) you will need to pay from a clinician who is either "Out of Network" or out of your own pocket. The vast majority of clinicians trained in more complex conditions do not currently accept any insurance. Autistic advocacy needs to be done to push insurance agencies and clinicians to allow those with ASD to access full coverage for more highly trained personnel. Services: As I've stated earlier in this questionnaire, there is a significant lack of behavioral health clinicians trained to work with neurodiverse patients. Somehow, many professionals seem to think that those with ASD can leap the hurdles to access the therapy they are offering.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>My autistic son was completely unable to interact with tele-school during the 2020-2021 school year. However, it is the increased use of tele-everything that is negatively impacting his overall development. While he enjoys conversing with friends over "discord," I've seen that the benefit to him from services like behavioral health therapy are cut in half when done on screen. He is at a point where he'd like to improve his social skills but programs like "PEERS" are only being offer virtually now. If he is eventually able to attend school again, he will need tutors to support his academic losses. I have only found one agency that is still operating in person, and their rates are almost double.</p>

Name	Allissa
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	To me keeping calm when it is needed by others. To be experiencing issues caused by or in tandem to autism and then having others not understand and now have to shove it down and essentially pretend they aren't happening or to have a doctor tell us there is nothing wrong its in your head.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The depression that is constant and the anxiety that has been there for as long as I can remember. The attention issues that have just been dismissed by every doctor. It all always feels dismissed by all professionals.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Never understanding the social situations no matter how they are explained. Constantly being/feeling on the outside. No one seems to care.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	having doctors who don't have a stigma against autism and will listen and hear the patient.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The option to work from home has helped immensely for my mental health. The social expectation when in the office is so draining and makes me want to not work. Though I do appreciate that I go in once a week. Any more than that is draining. The options for no face to face interaction in most places also helps me when I want to go out for food or shopping but having an option where there is no talking is helpful.

Name	Allyson P., Autistic Adult
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Fibromyalgia/chronic pain, ME/CFS, dyspraxia, insomnia, IBS, food intolerances, and misophonia/sound sensitivity.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression, anxiety, social isolation, ADHD (forgetfulness and disorganization), OCD (having to have things just so), and PTSD from mistreatment or abuse by others.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Research to find out more about how ASD is connected to other mental health disorders, but especially ADHD and OCD; and to find out how it relates to eating problems such as ARFID.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Provide more support for adults on the lower needs end of the spectrum. Educate more providers on how autism presents in women and girls so that they don't fly under the radar. Put more money towards therapy other than ABA.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It's made it a lot harder to go out and interact with others, which we need just as much as neurotypicals. If anything it has stunted my social development.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Positive: more opportunities to work from home, more access to telehealth. Less pressure to perform socially. Negative: less opportunity to make connections with people, lots of disruption to routines, people seem more hostile.

Name	Alycia Halladay, Autism Science Foundation/Alliance for the Genetic Etiologies of Neurodevelopmental Disorders and Autism
Demographic	Researcher; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	<p>This response is being submitted on behalf of AGENDA, or the Alliance for the Genetic Etiologies of Neurodevelopmental Disorders and Autism, a group of patient advocacy groups, parents, researchers, and stakeholders with rare genetic forms of autism, many times either de-novo or recessive inherited mutations. Almost all these individuals meet the criteria for a neurodevelopmental disorder, which is not surprising because of the function of the genes impacted. A high percentage also meets the criteria for an autism diagnosis. These genes are pleiotropic, and in many cases are biologically linked to the co-occurring conditions. Therefore, it is critical that those with these conditions have genetic testing to better understand and possibly treat the condition.</p> <ul style="list-style-type: none"> • Epilepsy / Seizures • GI • Catatonia • pulmonary/respiratory • Hypotonia - scoliosis, difficulty coordinating cough response, musculoskeletal issues • Susceptibility to infection • Sleep problems, • Pain tolerance
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	<p>Meng-Chuan Lai wrote an excellent review last year of these co-occurring (or co-morbid, depending on the condition itself) mental health issues in ASD. This review highlights an often overlooked issue, which is catatonia. This condition is seen more often in those with rare genetic disorders and is often deadly. In addition, intellectual disability and being minimally verbal can straddle the border of physical and mental health conditions. The stigma associated with IDD and MV ability is delaying appropriate treatments and supports and leaves families feeling isolated. Being intellectually disabled and/or minimally verbal may lead to behaviors such as aggressive behavior and self-injury. While mentioned in this RFA, these two things are not in themselves mental health conditions, they may be behaviors that are the result of mental health or even physical health (for example GI) disorders. Other behaviors include elopement and parental abuse. Parental abuse is often stigmatized, exacerbating mental health issues across the family. There is a limited understanding of the most effective interventions to help non-speaking individuals communicate, and many are turning to non-evidence based and potentially harmful interventions. Part of the problem is that AAC devices, which are helpful if used appropriately are not accessible and training is poor.</p>
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	<p>In people with ASD/NDD, there is an especially complicated interplay between the behavioral phenotypes of autism and other health conditions. For example, the inability to communicate discomfort or pain can lead to delays in receiving treatment for things like earaches, dental problems, appendicitis, or other conditions, leading to unnecessary suffering and worse outcomes. The inability to understand language or follow instructions becomes especially dangerous when individuals with ASD have other conditions like epilepsy. This can lead to any number of additional problems, such as poor compliance with treatments or injury from falls. In fact, this can be what necessitates having a caregiver within arm's reach 24-7. Sleep problems and behavioral challenges are an especially difficult combination. Individuals with self-injurious, aggressive, destructive behaviors, or other challenging behaviors, require a very high level of support in the middle of the night, when parents need sleep and other caregivers are not available. The real issue is that autism greatly magnifies the impacts of other health conditions.</p>

<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<ul style="list-style-type: none"> ● Studies that address a direct link, not indirect assumptions, about the mechanisms of co-occurring conditions linked to autism. ● Genes are not just in the brain they are all over the body. Better understanding of genetic underpinnings may lead to interventions that target body parts other than the brain. ● Genetic findings could lead to preventative medications or direction on the right behavioral interventions. ● Gene therapy to treat comorbid conditions are necessary. ● Important to include patient-reported outcomes rather than just traditional outcomes. ● It is also important to explore the mechanisms of co-occurring conditions whether a genetic lesion can be identified. There is insufficient funding and no coordination across NIH institutes to advance ASD GI research, sleep research, or even epilepsy research. This is where we really see the unintended consequences of silos of expertise by the institutes. It would be transformative if there were trans-NIH initiatives that could bring together, say NIDDK, NIMH, NINDS, and NICHD to advance GI research in ASD.
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<ul style="list-style-type: none"> ● First and most importantly, we need better training and more clinicians and educators to deliver interventions and support. There are not enough clinicians and child psychiatrists are rarely trained to work in autism. ABA therapists are not available. ER doctors are not trained to deal with psychiatric crises, they focus more on the proximal physical conditions, and have a more “treat-em and street-em” philosophy. That’s the nature of an ER. It’s not meant to be an inpatient facility and is often the last hope in critical situations. Schools should also ● Because there are so few well trained clinicians long waitlists for trained clinicians who are experienced to help families (neurologists, developmental pediatrician, GI doctors, etc.). ● Family training, support for caregivers ● Mental Health Support for families - potentially through patient advocacy groups? ● Increased opportunities for socialization of families who feel isolated. ● Medicaid Reevaluations for autism/genetic conditions are unnecessary. Severe IDD rarely changes after the age of 8. The money and time that is being spent on re-evaluations, what are the purpose of these re-evaluations?
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>Isolation and masking during COVID (while necessary to prevent the spread of infection) was especially difficult on people with autism, who found themselves further isolated and had difficulty engaging socially. Additionally, social cues and expressions can be difficult to read on Zoom.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>One bright spot in the pandemic was the expansion of telehealth opportunities for families. In fact, telehealth was a blessing for some families (and found to be helpful for autistic adults with mental health issues) but after the pandemic, the ability to cross state lines for interventions/support via telehealth stopped. Accessibility to telehealth and to clinicians across state lines should be re-introduced and encouraged. In fact, some people got more access to services during the pandemic and now that has ended. Also, the ability to prescribe controlled substances across state lines should be reinstated.</p>

Name	Alyssa J. Pearson, New Mexico Department of Agriculture
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gastrointestinal disorders make it difficult to work outside of the home. Sleep disturbances make it difficult to reliably make it to work at 8 a.m.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD - makes it difficult to act appropriately in extended social interactions and meetings. Anxiety makes it so that inappropriate behavior in social interactions leads to even less of an ability to act appropriately in future social interactions. This ultimately causes rejection sensitivity dysphoria where it becomes difficult to have professional relationships in the long term with neurotypical people.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Research needs to be done showing that teleworking/working from home is a valid disability accommodation for people with autism to improve their job outcomes and employment satisfaction instead of being perceived as an attempt to goldbrick.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Accessibility of employment and improvements to the disability reporting services to avoid retaliation.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Exacerbated depression. Also made it so that I realized how much happier I am working from home which has made returning to office absolutely terrible.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increased remote work and school was a positive development until it started to be taken away. However, I appreciate the drastic uptake in the use of asynchronous and written communications methods such as Teams/Slack, as well as digital record keeping.

Name	Alyssa Stephenson
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gastrointestinal issues, sensory needs, sleep problems, issues with eating
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I'm adhd with depression and anxiety as well as being autistic. My personal biggest challenge is that few mental health providers realize that my treatment plan has to look different from non autistic people with these same issues or it's not going to work.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication issues are the hardest for me. Partly due to trouble recognizing facial expressions and tone and partly due to auditory processing disorder
What additional research is needed to help address co-occurring conditions for autistic people?	Research how various mental disorders effect autistic people differently than non autistic people
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Allow more options for therapy for families on medicaid that isn't aba, start allowing self diagnosed autistic people to access therapies that may help them
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Telehealth access, remote work access, and reduced social interaction for me was positive

Name	Amanda
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbances are very challenging as a lack of sleep makes it impossible for both the child and parents to function well. Sensory challenges are also difficult to carry out daily tasks and have children calm.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	One of the biggest challenges is PDA and how it presents. It is not recognized as well as other conditions and needs to be added to the DSM. It creates significant challenges around aggression, child to parent violence, school, and sibling relationships. It is also difficult finding professionals who know about it. FASD is another difficult one as many people will not diagnose both FASD and Autism, even though it can be quite common to have both. More assessors and professionals need to be aware of PDA.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Intellectual disabilities and learning disabilities make school very challenging. They often don't get the support they need in the school system. Social challenges can also be difficult if they are not able to keep up with their peers.
What additional research is needed to help address co-occurring conditions for autistic people?	More research is needed on PDA, how it presents, how to assess, and how to support. Additionally, more research needs to occur on hard-to-spot autism, as well as how autism presents in girls.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Have more coverage for assessments, as private assessments are very expensive. Supports should also be covered just like diabetes medication is, as they are both health conditions.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Many parents lost their jobs over ridiculous mandates so were unable to afford services for their children. Many autistic children also couldn't manage masks due to sensory needs or language needs, and were ostracized at school or kept from public places.

Name	Amanda
Demographic	Autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	sensory challenges, especially overstimulation of noise and touch. I also work with patients who seem to have much more serious/common hypermobility disorders that greatly affect their functioning.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I am a mental health counselor, I am autistic and work with quite a few patients on the spectrum, the vast majority of them experienced trauma based on their social behavior and/or limitations vocationally/academically with peers through their lives. Many of them have had higher incidences of suicidal ideations and self harm due to burnout.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Social isolation and loneliness, stereotyping about what is and what is not a sign or aspect of autism spectrum disorder, time management, hygiene skills, and emotional expressiveness.
What additional research is needed to help address co-occurring conditions for autistic people?	I know I personally would have benefited from more research into the emotional depth of autistic people, as I believe the stereotypes often frame us as cold/without empathy when I have found this very untrue in my professional work as well as with myself and family members on the spectrum. I think understanding how it is linked with physical issues (hypermobility, POTS, GI problems) as well as the impact of "masking" would be very beneficial.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	It is almost impossible for anyone over 18 to get a thorough assessment and diagnosis of autism in the state of new york without paying exorbitant prices out of pocket (over \$6000 in general). When I was in graduate school, the only training available was ABA style therapy which I feel is inappropriate, and neurotypical providers are at a loss as to how to help their patients.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	increased social isolation, more difficulty finding meaningful work.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Amanda Halloran
Demographic	Family member of an autistic individual; Service provider, health provider, or educator; Representative of advocacy organization; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	co-occurring illness is a huge issue for my family member who has both autism and mental illness; finding treatment is next to impossible as doctors want to treat one illness/symptom at a time rather than treating the entire person. They have gastro issues, a sleep disorder, sensitivity to chemicals against their skin & additional sensory disturbances.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My family member with autism also has bi-polar disorder and ADD. She has a history of trying medications that do not work or exacerbate some symptoms while treating others. It feels like a merry-go-round of puzzling symptoms with no answer as to what is going on. She is also extremely sensitive to making and keeping friends, especially love relationships.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	For my family member, we had a tough time finding answers to her physical, mental, and learning disability in the education system. Tight schedules, as well as expectations that everyone learns the same, pushed her into private schools. They also had no answer, and she graduated with a GED rather than a high school diploma. It has been hard on her self-esteem and in her job search as a young adult.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	In the state of SC, there is no safe place for the mental health treatment for those with co-occurring disorders, most especially autism. Patients in search of help from state agencies are tossed from agency to agency as no one agency wants to take responsibility for them. In addition, SC does not have Medicaid expansion so access to proper treatment is decreased for the entire community.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Increased isolation
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I would say that a lack of treatment for mental illness (along with autism) is the biggest challenge. For those of us in SC, treatment of those with co-occurring disorders is bleak as the state agencies offering the answers are the same: they throw their hands up and act as if treatment for these folks is not their responsibility.

Name	Amanda Kulesza
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory and motor challenges
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression, anxiety, ADHD
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication disabilities
What additional research is needed to help address co-occurring conditions for autistic people?	Autism in women/girls
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage for testing, service systems issues, and patient-provider interactions
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Amanda McCray, Autistic mom raising autistic kids
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory processing disorder. The feeling of a shirt can feel like you are physically on fire. Eating challenges. Being physically incapable of eating because food is the wrong texture for days. The inability to find something to eat is maddening.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression and anxiety from having to act like a neurotypical. Masking is exhausting. Not knowing why you don't understand what the right behavior is in the situation. The mental load to pull out that learned information in the rights Ettinger at the right time is exhausting. The strong sense of justice too. The world is on fire and we have to go to work?
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Auditory processing disorder. Sometimes the words just are not wording. "Can you hand me the remote" should not sound like "The cat became a stripper". Why does that happen? Also, why are most of us dyslexic? And why isn't this being screened for in the classroom?
What additional research is needed to help address co-occurring conditions for autistic people?	The neuroscience behind it. What is different in neurotypicals and neurodivergents? What is caused by the trauma society creates, ie depression and anxiety verses what is caused by different neuropathways like sensory processing disorder and pathological demand avoidance.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Better trauma responses by the mental health community. ABA needs to go. We need to teach people with autism how to be themselves within society and not try to fit into a society that is not accepting. There needs to be evidence based therapy that teaches coping mechanisms to deal with the social backlash from society. Until society changes.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It made it hard to reintegration to society. Social skills are learned from experience. With autistic people, they have to understand they "why". We understood the why with covid. The problem was, there was skills that were lost with the lock down. Resources were greatly reduced. The world became an autistic person's playground. It was quiet and there were a lot less people to try and fit in with. Then you took that away and expected a person who can't do change to just reintegrate.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I think covid gave some people an opportunity to educate themselves on autism. Many people came out of it with a different understanding of society and how they fit in. I think remote work/school was a good thing and a bad thing. Autistic people need social interaction more so than neurotypicals. But they need it calmer and quieter. It gave them a space for that, but took away the much needed face to face interactions. It's easy to hide when you don't have to and that's not healthy.

Name	Amanda Saffell
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep apnea, insomnia, ARFID, sensory sensitivity, ADHD are all often co occurring. Sleep apnea and insomnia limit the sleep necessary for functioning. Autistic people do not rely on 8 hours of sleep and can often function extremely well with 6 or less. Autistic people may sleep in short intervals more frequently. ARFID and sensory sensitivities make eating more ritualistic. Autistic people often prefer the same foods and textures over new options. They will have patterns of eating because the brain will eventually process the food as “different” and a new cycle will start. This is most likely due to our evolutionary history as hunter gatherers when a bison could last weeks, or we were in an area with more edible vegetation. Co morbid ADHD points to this ancestral commonality as well. The intervals of sleep, food and sensory intake, and ADHD functions would have been highly beneficial in humanities primitive development. I would argue that a lot of our “challenges” are only challenges in our current society and environments. In the right environment most autistic people would not see them as challenges but beneficial skills.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The overwhelming sense of justice. It causes an enormous mental and emotional toll on autistic people to see the injustice that continues to happen in our world. For thousands of years humans have been war stricken by that hands of other humans who made up something the other guy didn't like; see borders, races, money, etc. We see the cycles of every past civilization, we know where changes should be made, yet they never are and because such it weighs significantly on us. This is where depression, anxiety, suicidality stem. Per my last response a lot of “challenges” are only challenges under our current leadership and society.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Consider the possibility that some conditions are not co morbid but rather the symptom of society. Also research the impact of society on autism and how our role would be more significant in a society that encourages differences instead of belittles them. Research how the end of war, increased healthcare, removal of excessive wealth would impact autism. I'd bet there would be significant data that shows autistic people thrive in a peaceful society with community based environments.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	See all previous responses. The best way to help autistic people is to create a society that cares more about people than money. Healthcare, free education, and more services will do nothing if we continue to be forced to pay taxes to fund wars, it means nothing if we don't have good healthcare, infrastructure, or education (see our laughable world rankings), it means nothing if your social services do not operate well (SSI, SSDI, DHS), it means nothing without the prerequisite of a well functioning society. You can put glitter on a pile of [profanity redacted] but it's still a pile of [profanity redacted]. When the [profanity redacted] decomposes it creates a beautiful flower though, isn't that funny?
What lasting impact has COVID-19 infection and illness had on co-	The lasting impact is the realization that our society is extremely fragile and ignorant.

<p>occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Quarantine showed us that if everything stopped we'd all still be ok. It showed us that our government is fragile and we have a huge impact on its functionality. It allowed most of us to truly discover life without built in systems, and how much better society would be without them. It showed us that our "challenges" are only challenges to NT people in a NT world.</p>

Name	Amber Robertson
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The most significant challenges I face daily are sensory issues, sleep challenges, and gastrointestinal problems. I am hyper aware of every sound and feeling in my environment, and am very sensitive to light. It's like my nervous system is constantly on high alert. The sensory overwhelm from leaving my home to do basic tasks like grocery shopping or sitting in the parent pickup line can cause me to be extremely anxious, exhausted, and frustrated. Meanwhile I struggle to sleep when I'm supposed to, and generally can't sleep until I'm too exhausted to be upright anymore, and then I struggle to wake up. Unfortunately I have paradoxical reactions to medications I've been prescribed to correct this. Finally, my stomach is always upset. If I eat anything, I'm nauseated. These things together make it challenging to function daily.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I am not only autistic, but also ADHD, and I have clinical depression, anxiety disorder, panic disorder, and cPTSD. One of the symptoms I live with is suicidal ideation. My mental health suffers when I spend too much time masking, or in a place where I have a lot of sensory overwhelm, and I find I experience burnout more easily than my neuro-typical peers. I also live with chronic illness, which impacts my mental health, and unfortunately living with chronic pain is a constant source of sensory stimulation that can trigger burnout and shutdown.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I have the learning disability, dyscalculia. I am struggling to get through college, and unfortunately my health insurance won't cover an adult diagnosis so I can get accommodations. Healthcare and mental healthcare in the US is so expensive, and insurance companies do the bare minimum, so unfortunately people like me just try to struggle through it. I'm honestly considering dropping out of college at this point.
What additional research is needed to help address co-occurring conditions for autistic people?	I think it would be beneficial to look at the paradoxical reactions a lot of autistic people have with medications. For instance, I was put on a stimulant to help me stay awake during the day, and it only makes me more exhausted. Certain antidepressants do the opposite for me and make me less functional, more depressed, and more suicidal. It would be helpful to know why that's happening and if it's possible to avoid those medications without having to try them first.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Literally every aspect of autism services for adults needs to be improved. My insurance didn't cover my diagnosis, and I'm still paying that off. It doesn't cover diagnosis for a lot of co-occurring stuff, either. Healthcare is absurdly expensive, and that includes mental healthcare. Providers need to be better educated on what autism can look like, especially in women and girls, as it's often misdiagnosed or underdiagnosed in us.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I developed chronic illness caused by the lasting effects of covid-19, and it's made me unable to work full-time, my mental health is in horrible shape, and I'm in constant pain. As an autistic adult woman who has autistic children and works in mental health extended services, I can tell you 100% that covid has set autistic people back mental health-wise.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal	I think a lot of positives that have come out of covid include the addition of more remote work opportunities, increased options for telehealth, fewer social obligations, and more understanding toward those who are struggling mentally. That being said, I would have preferred to not have chronic illness and worse depression than ever. It wasn't a good trade.

changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Ambree
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	With ADHD you're stuck in this paralysis on a lack of motivation. I need to do something but it's too understimulating and disturbs the routine. Nothing gets done. Then when you add mental illnesses like anxiety and depression it gets even worse because then you start hating yourself for it.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Possible causes and solution to the juxtaposition of having cooccurring disabilities
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Some kind of money and compensation for those of us who can't do traditional jobs that pay enough for us to live. Also lowering the cost of accomodations amd diagnoses!!!
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The push for online school and learning on your own. They say it's "at your own pace" but in actuality they're not because the idea that you can do it whenever makes them a lot less sympathetic when you miss deadlines.

Name	Amelia
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I have difficulty working in group settings due to physical pain, need for urgent bathroom breaks, and the sensory problems that come with hearing others fidget/chew/cough as well as the lighting and temperature. I have terrible sleep habits and often either need to work night shift which lowers my life expectancy or I go to work tired everyday on day shift. With my constant physical pain, I can't do a lot of manual labor jobs but am also told that sitting jobs are bad for me too. I feel like I cannot succeed in my own country.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have had depression, anxiety, ADHD, PTSD, and suicidal ideations since I was a child. I was a gifted student until highschool graduation and I floundered in college due to extreme depression, anxiety, and ADHD. I have tried to take my own life many times. It is difficult waking up everyday. To get mental health treatment, I have to have a job (not designed for me to succeed in) and then I have to wade through long waiting times, terrible insurance authorization issues, high costs of medication that I can't afford even with a job even if it means I could eventually earn more, and it is nearly impossible to get good treatment without trying multiple providers which each have long waiting lists.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I learned how to hide my communication problems very young, but I still struggle to understand rules and social norms that aren't expressly stated. This often leads to me being an outcast at work and school because people don't like me, no matter how hard I try. When I manage to fake my way into having friends, it makes me so tired that I can either do the things I need to do in order to be healthy or I can socialize. I don't get all of the above. It makes me so tired that I get burnt out and stop enjoying things or engaging with things and my depression gets exponentially worse. I often have to isolate for long periods after social interaction to try to recover.
What additional research is needed to help address co-occurring conditions for autistic people?	A lot. There is a massive connection for autism and trauma and it seems like no one knows which one comes first. For the majority of my 10+ years in therapy, I was treated with ABA therapy which is the equivalent of telling someone to "just do it", even if it makes them sad, makes them feel like they're lying to everyone, makes them tired, or makes them want to kill themselves. If you're honest about it making you feel bad, you're given more medicine to make you not kill yourself but then you're just an emotionless robot, fulfilling their capitalist duty to earn money and not complain. It's soul sucking.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverages need to be improved a lot. Medication is not affordable in the US whereas it is in most other major countries. Patient-provider interactions need heavier regulation. I had a psychologist tell me I was fine and had "smart people problems". I had no idea how to report him or get better quality help. Autism training should be given to all practitioners and not just ABA. Recognition in classrooms needs to be improved. If I was diagnosed sooner, I may have had access to more supports. I don't even know what options I have and since I was diagnosed so late and have to survive on my income, I can't get on disability or any services because if I quit I will be homeless and I have no family or friends. I feel like I will never get healthy here. More publications and early intervention will help people like me from becoming people like me.
What lasting impact has COVID-19 infection and illness had on co-	Since having COVID, I have had persistent sinus issues and congestion problems which exacerbate my colds, my bad sleep, everything. I think having masks and being encouraged to be respectful of people's space

<p>occurring physical and/or mental health conditions for autistic people?</p>	<p>honestly helped me. I like not having to police my expressions and masks made that possible. People being afraid of COVID meant I could walk in a grocery store and not get bumped or have someone invade my personal space. I felt more productive publicly, but that is going back to normal now and people are just as rude as before. I think it would have been worse if I was in school during COVID because I needed that forced social interaction to learn about people and, without that, my more difficult years would started earlier.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Reduced public transit meant I had to drive more, which is hard for me. I am still scared of public transit now because of how unsafe it seems to be and how everyone seems sick so often. Increased remote and hybrid work has been a godsend. I am often overstimulated in offices and by others, so having my own self-designed workspace where I can thrive is amazing and has helped my sanity tenfold. It allows me to take better breaks where I can try to manage my household chores better too. Increased telehealth has also been amazing. I no longer have to plan long commutes or worry that someone in the waiting room will get me sick. I also get to be in my safe spaces with less sensory input and focus on the appointment rather than my discomfort. Reduced social obligation has been a nice break, but the obligation part is what kept me social. I am learning how to be social on my own terms, but it is more difficult now than it previously seemed.</p>

Name	Amelia Cruz
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I have a long history of gastrointestinal issues that went largely unexplained for most of my young life, as well as lifelong issues falling and staying asleep. My primary concern when it comes to co-occurring physical health conditions and autism is the tendency for the symptoms of autistic people to be ignored or not believed. I am a late-diagnosed autistic (diagnosed in my early 20s). When I was growing up, the things that bothered me were often written off as me being "too sensitive." The lights hurt my eyes? That's me being dramatic. The TV is on too loud? I'm the one being disruptive. This principle also applied to physical health issues. I would complain about gastrointestinal problems and I would be dismissed. Several years later, I discovered that my gallbladder wasn't working correctly, but I didn't learn about that until I had to get it surgically removed. Many autists have severe co-occurring conditions such as epilepsy, but I do not. There should be ample resources for those who do.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have both autism and ADHD, but I didn't receive these diagnoses until I was an adult. As a late-diagnosed, high-masking, AFAB autistic, depression and anxiety were by far the most significant challenges I have faced. In middle school, I noticed that I was different from my peers. My need for a specific fabric texture to fall asleep and emotional outbursts went from being quirky to bizarre. I paid attention to other girls – how they spoke, what they talked about and liked to do. Every waking moment of every day, I monitored and manipulated my behavior. This required a lot of energy, but I believed that I was "normal," so I berated myself for faking depression despite feeling a gnawing emptiness inside. When you play the part of an emotionless robot for 10-15 years, waking up to the realization that you were not a freak, but a perfectly normal autistic girl is earth-shattering. Yes, my autism is a disability, but it also saved my life. I no longer have passive suicidality. The take-away is that early accurate diagnosis is crucial, especially for high-masking, AFAB, and people of color. There need to be more clinicians trained with neurodiversity rather than pathology who understand that the autism spectrum is a color wheel of differences. More funding needs to go to studying girls, nonbinary folks, and people of color. The earlier autists are given language to describe themselves, the less likely they will be to experience the gut-wrenching emotional pain that I did.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I do not have any accompanying intellectual or communication disabilities. The only learning disability I have is ADHD, but my autism compensated for that just as my ADHD compensated for my autism. Where my ADHD couldn't focus, my autism usually could, and my ADHD allowed my brain to have an easier time switching between subjects. Because I was hyperlexic and have high verbal faculties, I don't experience many of the communication issues that other autists do. That being said, I want to highlight that just because an autistic person may seem unresponsive, that does not at all mean they are not experiencing a rich inner life nor does it mean that they are not communicating. Every autistic person communicates in their own way - gestures, AAC, echolalia, neologisms. All autists should be given the time and space to communicate in any way they see fit.
What additional research is needed to help address co-occurring conditions for autistic people?	Funding needs to be reallocated away from searches for a cure/cause of autism to studies on how it presents in underrepresented groups. Also, research into new ways for autists to communicate with each other as well as with allists. There is a lot of time and money spent trying to find ways to force autists into communicating as allistically as possible. I believe this is a

	<p>grave error. We do not need to train the autism out of autists. There is much to be learned from autistic people about the nature of language, speech, communication, and semantics. Instead of researching ways to "fix" us (with a cure, phony vitamin supplements, and/or Applied Behavior Analysis 'therapy', etc.), let's work together to find out more about autism as a valid way of life, so we can ease some of its more disabling aspects. More funding can also go into how allists perceive and respond to autists. The research lens is more often than not trained on the autistic child, and not on those holding the lens. How much of autism's disabling effect is a result of allistic people's treatment of us? Not all, of course, but I believe it's worth looking into. Finally, more attention should be paid to autistic adults. Despite popular belief, autistic children do in fact grow up to become autistic adults (if we're lucky).</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Most of my concerns when it comes to this issue are more widely applicable than just to autistic people. For example, I believe the American healthcare system needs a massive overhaul from just about every aspect possible. Insurance companies are greedy scalpers, medical professionals are either not given the time or are not interested in working with patients as individuals, and trained providers are few and far between in certain areas of the country. Fixing these things would be great for autistic and allistic people alike. For autistic people specifically, my concerns lie primarily with inclusive access to housing, education, and employment. The US tends to segregate autistic people from the general population - think of special ed classes, isolated housing institutions, the fact that most public spaces are not autism-friendly. Part of the stigma around autism comes from the fact that most allistic people have not met an autistic person. Their only frame of reference is Rain Man or The Good Doctor. So, while money should go to more accessible services for autistic people, I think it's equally important to find ways to provide these services without separating autistic people from everyone else. Allistic people have a lot to learn from autistic people; Finding ways to better incorporate autistic kids into the classroom, autistic adults into community spaces and neighborhoods, and all disabled people into public spaces might be a good start.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>I've had Covid-19 twice. My long-Covid symptom was some nervous system irregularities. Autistic people are already prone to having issues with their nervous system, so I wasn't shocked by this. I have mitigated this issue with some supplements.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Speaking solely for myself, the aftermath of the pandemic has simultaneously improved several aspects of my life and highlighted how little most Americans care about disabled people. On the one hand, the pandemic allowed me enough time to think and feel for the first time in over a decade. If it hadn't been for Covid-19, I'm not sure I would have figured out I was autistic. It would certainly have taken a lot longer. For me, being allowed to stay home and attend/teach classes when overstimulated has been incredibly useful. I don't have to hem and haw as much about advocating for myself in that regard. On the other hand, the blatant disregard for mask mandates and Biden's eager declaration of the end of the pandemic has solidified for me how America thinks about its disabled citizens. If it weren't clear before 2020 how expendable disabled people are to the rest of the population, it is certainly clear now. Just because the pandemic is over for able-bodied people doesn't mean it's over for immunocompromised people. The lifting of pandemic protocols has contributed greatly to the segregation of disabled people, and I think that is a real shame.</p>

Name	American Academy of Pediatrics, American Academy of Pediatrics
Demographic	Representative of advocacy organization
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>One common challenge is delayed access to care related to the misinterpretation of physical symptoms that present in an autistic individual. Co-occurring physical health conditions can cause pain, but pain can be difficult for autistic people to communicate, which often results in delays in care and delays in intervention. Additionally, metabolic syndrome and obesity are significant challenges as a result of nutrition and/or feeding difficulties and side effects from medications. For example, weight gain and metabolic issues are common in older youth and adolescents, as food is often used as incentives for desired behavior, which can be exacerbated with poor access to recreational activities. Other co-occurring physical health conditions that coincide with many individuals on the spectrum having fine motor deficits, sensory sensitivities and oral motor deficits include gum disease, tooth decay, and total tooth loss. These conditions create challenges with eating, communication, socialization and their overall physical health. These conditions also coincide with access challenges because many individuals on the spectrum do not have the appropriate access for medical or dental treatment for these conditions and/or their autism-related symptoms, such as behavior issues, or touch, taste and texture sensitivities. This makes it very difficult for them to receive appropriate medical care, preventive care, or other programs and services needed to address these conditions.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>Similar to the challenges caused by co-occurring physical health conditions, co-occurring mental health conditions can also cause diagnostic overshadowing for clinicians including inadequate or inaccurate prescribing of psychopharmacology, and delayed access to behavioral health services or other treatments. Due to siloed systems of services for mental health and developmental disabilities, autistic individuals with these co-occurring conditions frequently experience inequities in access to care, financial burden, and loss of employment for autistic people and/or their caregivers. Further, these conditions can cause isolation from community supports and community inclusion because of a lack of understanding about disabilities and mental health conditions. Co-occurring mental health conditions can also result in school avoidance and decreased learning. Anxiety, depression, and dysregulation interfere with optimizing learning and developmental outcomes over the course of childhood and adolescence by leading to school avoidance, missed instruction, and external behaviors that stimulate placement in separate classrooms and programs. Children need to feel safe, connected, and well-regulated to learn. The AAP recommends increasing focus on mental health and emotional regulation starting in early childhood and at the time of diagnosis in order to improve educational and developmental outcomes of children with autism.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>Overall, comprehensive oversight is a significant challenge. Coordination between settings such as schools, behavioral health care, mental health care, and pediatric care is a challenge as complete data and information is not always in one place to be able to make the right decisions in each setting. Lack of inclusion, communication access, and transition to adult services are significant challenges caused by co-occurring conditions in autism. Employers and educational systems are ill-equipped to support people with multiple disabilities in various settings, particularly in providing adaptive transportation. The presence of an IDD can result in bias and presumption of incompetence in people with lower cognitive and/or communication skills</p>

	<p>leading to a lack of inclusion. Families also often experience significant challenges in accessing augmentative and alternative communication or appropriate speech therapy support for children and youth with high communication support needs. Finally, better support through early adulthood is needed in recognition that developmental timelines can vary greatly and many people with autism continue to progress developmentally beyond the typical school age years. Some adults reach milestones such as driving, attending higher education, employment, or living independently at later ages than 18-21, yet school and adult transition programs end at these ages, leaving families with few supported options to help individuals continue to make progress.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>A clearer understanding of the real-world frequency and fluctuation of symptoms on a patient level is needed to obtain a more practical data set for clinicians to see patterns of behavior/symptoms associated with various co-occurring conditions. Most of the existing research is in “controlled” or non-real-life structures and is often too far delayed from the patient’s real experiences. Improved data collection processes including innovative tools like sleep tracking, urine/stool output, heart rate, and other forms of at home monitoring would significantly improve the ability to conduct research. Research on depression and suicide risk among autistic youth and adults, including causes and incidence, would help to address some co-occurring mental health conditions. Additionally, research on ways to prevent wandering, which is exacerbated by co-occurring mental health conditions, would be beneficial in reducing dangerous situations and outcomes such as drowning. Regarding development, further research on puberty in autistic youth, and reproductive health, would help determine the best treatment and prevention practices to address the increase in mental health conditions during and after puberty, specifically related to medications. Similarly, further research into effective behavioral strategies and/or medications to improve anxiety, aggression, self-injurious behavior, and obesity/metabolic syndrome would help address co-occurring conditions for autistic people as well.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Autistic people often receive late evaluations and interventions, resulting in poorer health outcomes. This inequity is caused by access issues, ableism, and bias in the healthcare system, which exacerbates challenges related to co-occurring conditions, deficits in communication, and differences in expressions of pain or other sensations. Autistic people need access to the same level of preventive services such as well visits and dental visits as everyone else in the United States. This requires a trained workforce that understands the IDD/ASD population and inclusive practices within therapy, medical care, mental health care, and dental care. Health care providers need better education on neurodiversity and ableism, and better support on how to help families navigate complex systems. Additionally, to achieve this, payer reform and differential payment structures are needed to allow for payment of support services so that people with IDD/ASD experience equitable care. Because it takes more time to modify clinical practices and procedures to include people with IDD/ASD, payers need to recognize this and allow for a modifier to be applied to serve this population equitably. Many healthcare systems are eliminating extended visit times in primary care, but even for providers who are allowed to give extended time for complex visits, knowing how to bill appropriately for their time is a complex skill and as a result, many end up not being compensated for the extended time.</p>

<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>Two of the main impacts of COVID-19 infection and illness on co-occurring physical and mental health conditions for autistic people are weight gain and increased anxiety which can cause difficulty with social re-integration. The delay in care due to the pandemic resulted in challenges related to feeding, constipation, and nutrition going unaddressed. Additionally, the pandemic increased the already lengthy wait times for specialty care, resulting in delayed autism diagnoses and services. Because of these challenges, the AAP recommends further research into increasing autism diagnoses within the primary care setting. Overall, there has been a decrease in health care services, with people leaving the health care field as a profession, resulting in a decrease in progress toward goals related to co-occurring physical and/or mental health conditions. Both caregivers and individuals on the spectrum have shown decreased mental and physical health since the onset of the pandemic.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>One of the positive impacts is the increased use of telehealth which helped improve access to medical and mental health care for some autistic people, but some payers and states are reversing some of the increased telehealth access and flexibilities from the pandemic. The increase in access to virtual school and work options has proved to be a benefit to some individuals, as more robust online communities and communication tools became available during the pandemic. Additionally, these remote options have helped reduce access barriers such as transportation. One negative impact is the decrease in social experiences. For example, remote school learning can work well for some individuals, but can also result in increased feelings and reality of isolation for others. Additionally, some of the social experiences that autistic people participated in before the pandemic have not resumed due to a variety of reasons including lack of funding. Additionally, many autistic people have increased anxiety as a result of the pandemic and societal changes related to the fear of being exposed to or getting sick from COVID-19. The pandemic also significantly impacted access to healthcare services, which has resulted in delayed diagnoses, delayed behavior services, and a loss of healthcare providers. This has created a rise in behavior symptoms due to the delay in services, which has impacted social re-integration and increased caregiver burnout.</p>

Name	American Association of Psychiatric Pharmacists, American Association of Psychiatric Pharmacists (AAPP)
Demographic	Service provider, health provider, or educator; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Given that many physical health conditions co-occur with autism, one of the most significant challenges is increasing medication complexity (PMID: 28750547). This represents clinical challenges for the individual taking medication due to high pill burden as well as for providers prescribing medication who must manage complex drug-drug interactions and drug-disease interactions. Co-occurring physical conditions may limit medication options available to treat symptoms of autism or co-occurring mental health conditions. Additionally, increasing the number of medications can lead to more side effects, which can lead to a medication prescribing cascade where medications are added to treat a side effect from a medication. Another significant issue is the difficulties in communication between specialties, which could potentially lead to drug interactions or a fear of making medication changes to avoid exacerbating a physical condition. Board Certified Psychiatric Pharmacists (BCPPs) may serve as the bridge between multiple specialties to assist with medication management for autistic individuals in outpatient and inpatient settings. This public comment response has been compiled by BCPPs who work with autistic individuals, on behalf of the American Association of Psychiatric Pharmacists (AAPP).
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Similar challenges occur with co-occurring mental health conditions, including the number of medications prescribed and the potential for a medication prescribing cascade. Studies suggest individuals with a diagnosis of autism may be more likely to have certain side effects with psychotropic medications (PMID: 27592097). This highlights the importance of close monitoring and specialized care for autistic people with concurrent mental health conditions. Furthermore, autism may impact individuals in a variety of ways including sensory sensitivities. This may result in the need to pursue unique medication formulations like liquids or patches to align with an individual's needs. An additional challenge is the high prevalence of supplements (e.g., vitamins) that are used in this population (PMID: 26366192), resulting in drug interactions or side effects. Supplements may not be mentioned in a medication history which results in an incomplete medication list for providers to review and assess.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Given the treatment complexity that can occur with the combination of autism, co-occurring physical health conditions, and co-occurring mental health conditions, medical decision making can become a significant challenge. Depending on type of learning disability, developmental disability, intellectual disability and/or communication disability, extensive visit time may be needed to thoroughly review all treatment options in a way the individual can participate in their own medical decision making. This highlights the need for team-based care, but unfortunately, access to team members like BCPPs remains limited by variability in state legislation and reimbursement. Additionally, some individuals may have guardians who act as medical decision-makers. In these cases, coordination with guardians, caregivers, and the individual is crucial to ensuring successful treatment and monitoring of all co-occurring conditions.
What additional research is needed to help address co-occurring conditions for autistic people?	Research addressing co-occurring conditions in this population is minimal. Major pediatric clinical trials have clear exclusion criteria of ASD diagnosis. The wide spectrum and degree of clinical manifestations makes this population challenging to study and generalize treatment for. This has led

	<p>researchers to exclude certain levels of functioning or co-occurring conditions from clinical trials and introduce study biases. A meta-analysis of >300 studies pertinent to ASD found only 2% of participants to be nonverbal or minimally verbal, while the real-world population estimates 25-30% (PMID: 30867896). There are currently only 2 FDA-approved medications to treat co-occurring conditions specific to ASD (irritability; risperidone and aripiprazole). This means that medications are often used off-label in this population, increasing risk for inappropriate polypharmacy, lack of symptom-based prescribing, and overprescribing. Utilization of available resources such as BCPPs to conduct research in this area critical, as BCPPs are skilled in clinical trial evaluation and coordination.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>With a national average of only 14 child and adolescent psychiatrists per 100,000 children and ~800 board certified developmental-behavioral pediatricians in the U.S. for the 19 million children with developmental differences, addressing the increasing mental health and complex psychotropic medication needs of this population is difficult. While Innovative services have been created, they need to be expanded (PMID: 34210189). AAPP advocates for the inclusion of BCPPs in interprofessional teams that care for individuals with ASD to support these demands. Examples of services that BCPPs can collaboratively support include: 1) Care coordination/delivery: support transitions of care, coordinate care among service providers (e.g., school, community supports, ABA therapist), provide medication education, ensure timely access to medications (DOI: 10.1002/jac5.1880); 2) Access to care: BCPPs can help mitigate the provider shortage through collaborative, innovative, and practical strategies to improve quality of care; 3) Evidence-based use of psychotropic medications in the setting of high rates of psychiatric and medical comorbidities, increased risk for adverse effects, and increased likelihood of being prescribed high risk psychotropic medication regimens (e.g., more than three medications). Specific strategies can include psychotropic stewardship and comprehensive medication management (DOI: 10.1002/jac5.1880, PMID: 37063939).</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>Autistic children are twice as likely to have an underlying condition that places them at high risk for severe illness from COVID, have orofacial sensitivities that makes wearing a mask challenging, and may be among family networks with higher vaccine hesitancy increasing their risk for contracting COVID-19 (PMID: 36799305, 36483100, 37147338). Young people's mental health was particularly impacted by the COVID-19 pandemic with increases in suicide attempts and related emergency department visits seen (PMID: 37910582). Autistic children had an increase in aggression, behavioral outbursts, and regression during COVID-19 restrictions (PMID: 32503172). Autistic children often struggle to communicate medical illness, and feeling physically unwell can lead to an increase in behavioral symptoms such as self-injurious behavior or aggression towards others. It is important to ensure treatment teams complete a thorough assessment to appropriately treat the underlying condition causing symptoms, potentially including COVID or other medical co-morbidities.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services,</p>	<p>Telehealth care models were fast tracked at the start of the pandemic and have continued to be used as they provide many advantages such as savings on the cost of travel, reduced time away from work, and access in rural areas. With increasing prevalence of ASD, access to diagnostic assessments is crucial. Telehealth evaluations for children with suspected ASD can be completed effectively and have been shown to leave both providers and</p>

<p>increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>caregivers satisfied with the experience (PMID: 35579789). Family-centered interventions focusing on physical activity, executive function, and social skills have also demonstrated efficacy via video (PMID: 35184077). Innovative treatment delivery methods have been developed to remotely enhance social communication skills in autistic children, such as at home electronic games (PMID: 34788890). Psychiatric pharmacists are well positioned to complete medication management via telehealth appointments. BCPPs can reduce medication-related problems that autistic children have higher rates of, such as polypharmacy, and side effects from psychotropic medications. Additionally, telehealth visits can be utilized to answer patient and caregiver medication related questions, and support medication adherence (DOI: 10.1002/jac5.1880).</p>
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Name	Amy
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Maintaining gainful employment is difficult because of sleep issues. Also, getting accommodations for sensory issues is difficult as employer's see noise canceling headphones as a safety issue (not able to hear fire alarms).
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD co-occurring with Autism has the individual always battling with themselves. We need routine but also crave novelty. We need some foods but get bored of them quickly. Its a daily battle
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	No matter how hard we try to be clear with what we say other people add implied meanings that aren't there so we're never understood.
What additional research is needed to help address co-occurring conditions for autistic people?	Research focused on the voices of Autistic individuals and NOT the perspective of those administrating the Research
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Access to services for Autistic adults, we don't grow out of Autism and adults with Autism need support services too
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Being left alone has been great, people keeping there distance from me has greatly improved my mental health. Not being expected to go to gatherings has also helped

Name	Amy Acevedo, Mother
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Visual impairment
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	suicidality
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Emotional intelligence
What additional research is needed to help address co-occurring conditions for autistic people?	public school involvement, resources, and diagnosis recognition
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	public school knowledge, acceptance, and recognition
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Amy Cox
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Severe sensory issues, rampant anxiety.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Much more research needs to be done on people like me, who weren't diagnosed until age 61ans were misdiagnosed and mistreated for decades with harmful drugs, and have absolutely no way of accessing any sort of meaningful help. 99% of services are for children. It would be a good idea to ask autistic people what they need. And finding out why so few physicians know anything about autism and related concerns.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	There are hardly ANY practitioners who work with autistic adults, and Medicare doesn't cover much if any of the care. And most know nothing about autism and related issues. More informed doctors, insurance coverage by Medicare, MUCH more help for adults, including people over 50.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Self checkout and mobile apps have been great! Less human contact and much faster service. Covid was great for me, because of enforced social distancing and more self serve options that lessened interpersonal contact.

Name	Amy Fowler
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Trying to walk a tight rope to manage competing needs followed by an exhausting cycle when I inevitably slip on the rope.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	This varies but for me as a caregiver it is the level of support and follow up needed to help my person needs to complete simple activities of daily living
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Not knowing what my son is thinking, if he is hurting, what hurts and how I can help
What additional research is needed to help address co-occurring conditions for autistic people?	I think instead of research caregivers need a menu of supports and services
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More of them and available during a variety times.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I feel fortunate that I was able to cobble together supports for my son. But the pressure of managing the services and supports have left me exhausted.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Positive: more curbside pick up makes it easier for me to get goods more easily Con: the staff shortages has made longer waits for even less services

Name	Ana Pereira, Mother of an amazing autistic boy
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My son is three years old. He does not sleep thru the night, I don't know what a full nights sleep feels like anymore and that causes issues in the family. He has GI-issues and is very picky eater. he also self injures himself. Cant be taken out in public without some sort of restraint (due to eloping). We have not had the ability to rest or vacation in years. Also deters us from family reunions or functions that have a lot of people or noises so we don't have much of a social life as he begins to scream or hurt himself.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	he has self-injury behavior (bangs his head a lot). he is still too young to show any other mental health issues
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	He has very limited one word vocabulary. due to communication issues he has many break downs (tantrums) and displays frustration and impatience.
What additional research is needed to help address co-occurring conditions for autistic people?	There should be more parental outreach and information. almost like a autism 101 guide for parents of newly diagnosed children.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Medicaid should be allowed to be a secondary insurance coverage. Financial thresh holds should be increased. (personal example: my husband are in the middle class financially, due to the increase of prices in the recent economy we are not poor but also not rich. My primary insurance covers some of the therapies he needs with daily co-payments. there are other things that we need to provide for him but we cant add any more to our plate. we have not had the ability to vacation in years because we use all of our extra for his care. Diapering, speech and OT therapies, sensory items for home, however the fear of losing my job and not having insurance anymore at least for him to continue to cover his therapies is a very real and scary thought. We are having extreme issues getting Medicaid for the disabled to even approve coverage for him at any level. I am not looking for "free" I am looking for affordable. Someone to work with us. There are so many other things he will need as he gets older and I am not sure how we will be able to provide them for him. It was also very hard to get him diagnosed and for someone to follow his care. i was on a wait list for over 8 months and had to drive 1.5 hours to a hospital that provided this service.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal	

changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Ananya Rishi
Demographic	Autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	- Healthcare management. - Routinely self-care once provided with treatment plan. Organising and adjusting schedule based on sudden health flare-ups. - Commitment to preventive care. - Managing health-care and daily life. - Communicating accommodation needs.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	- Accommodations needed to perform at work/school/social settings. - Communication difficulties to healthcare providers. - Consistency in routine and medication. - Managing autistic burn-out alongside co-occurring mental health conditions. - Preventing traumatisation.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	- Accommodations in school. - Feeling understood and fitting in. - Feeling behind compared to others in social settings. - Difficulty accessing same events, opportunities, experiences as neurotypical individuals. - Time management.
What additional research is needed to help address co-occurring conditions for autistic people?	- Accommodating to needs without segregating. - How to respond to difficulties being faced at school/work. - Benefit of diagnosing comorbid conditions alongside autism diagnosis. - Healthcare courses for doctors to understand and address comorbid conditions when they know patient is autistic.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	- Insurance coverage. - Access to specialised neurodivergent health-care providers. - Removing disability-related discrimination.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	- Social anxiety. - Behind on social norms. - Antisocial behaviour. - Fear of being in public. - More comfort in virtual/indoor settings.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	- More remote opportunities. - AI assisted schedules. - More access to people online with similar conditions.

Name	Andie
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My sensory challenges cause significant challenges during my day-to-day life. College classes, especially those in large lecture halls with very close proximity to peers and lots of sensory stimuli, can be very difficult and can cause long lasting dysregulation. Many social events are simply not doable for me due to loud and unpredictable volumes and crowded conditions. This has made forming connection and friendships difficult.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety poses significant challenges in my life as an autistic person. I experience immense social anxiety related to my autism and struggling to understand social expectations, as well as immense anxiety stemming from any change in routine or expectation. Such anxiety can be very disrupting to my day and sense of well-being and make it difficult to complete regular tasks. In addition, I have obsessive compulsive disorder that has had a significant impact on my life and well-being. I experience depressive episodes in addition to heightened anxiety when I am experiencing autistic burn-out, as well.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Greater access to services, and greater education and awareness of support services is needed. As an autistic person it is difficult to grasp where to start to begin searching for resources that could assist me. I, personally, could benefit from more accessible and sensory friendly spaces and clear, direct instruction in daily life and tasks and know that many other autistic people struggle similarly with feeling as if we were not given the instruction manual for everything from social interaction to paying bills and doing taxes and this makes initiating such tasks very difficult. Greater insurance coverage is an absolute must, as well. Many autistic people, myself included, have to incredibly high prices out of pocket just to get a diagnosis, making it completely inaccessible to many. In addition, insurance coverage for support and services such as various forms of therapy and training should exist.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	

in-person social interactions and obligations)	
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Name	Andrea Barlass
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I have observed to see several children diagnosed with Autism Spectrum Disorder (ASD) also have a diagnosis of a developmental disorder, speech delays, sensory related concern and delays in ADL's (which are common symptoms/characteristic associated with ASD).
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have seen several co-occurring mental health diagnoses of ASD and ADHD, ASD and Depression and/or anxiety. I have occasionally seen co-occurring mental health diagnoses of ASD and Oppositional Defiant Disorder.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I think that the symptoms/behaviors/characteristics that are common or typical of individuals with ASD often get misdiagnosed as ADHD, anxiety, and ODD. I also think that ASD can be misdiagnosed for some individuals who may struggle socially, be anxious, or not fit the stereotypical "norm". A diagnoses of ASD can lead to difficulty in relationships for children, teens, and adults which is challenging and can lead to additional mental health conditions like depression and anxiety. The symptoms/traits/characteristics of ASD also create challenges that require alternative interventions for teaching. If someone isn't skilled in working with an individual living with ASD or understand that person's developmental capacities, the individual will have barriers to learning.
What additional research is needed to help address co-occurring conditions for autistic people?	Better screening measures and assessments, increased education for parents and care professionals, increased training for mental health professionals who work with this population, and more availability for testing to clarify diagnosis.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Access to services Affordability of services Public education/awareness of services available Providers educating caregivers and assisting with referral process or referring to a care coordinator who can assist caregivers who may not have as much health literacy as others. Insurance coverage abd removal of prior authorization for services. School assistance in educating parents (if there is a trained, licensed mental health clinician available). Normalizing utilization of asking for help and use of community resources.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	unsure
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	Lack of availability of mental health care and or physical health care in general. - longer wait lists, disruptions in services, provider burnout/transfer of care to new providers because of burnout reduced social interaction and increased isolation limited opportunities to practice skills in community settings increased challenges in school settings Increased use of telehealth/video appointments

in-person social interactions and obligations)	
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Name	Andrea Dahlberg
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep challenges ongoing (my child is 13), early gastro issues lasting until age 8, misophonia
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, ODD, misophonia, aggression
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication, socialization, isolation
What additional research is needed to help address co-occurring conditions for autistic people?	More research within families, families have more insight and direct knowledge. They live with autism and the affects 24-7. The educational system needs more training and resources. Try researching where our children end up and ask yourself why? We need less research and more action. My child goes to a school for children with autism and I fight everyday to understand why they don't do more to help my child socialize within the community and/or as a typical child would. Everything is left up to the parents and if you're not an educated parent, then quite frankly you're screwed. Research why my child cannot hear or read the word quiet, see the gesture that represents that word, or listen to the sound "shhhh". Then find someone that will help me with that. That would be nice.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	It would be great to get autism services and supports. Could I get help finding a psychologist that understands autism and also have them to insurance. And I'm not talking crappy insurance, I have Cigna. Get my dental plan to cover nitrous so she can get dental work comfortably.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Heightened anxiety, increased isolation, decreased socialization
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school,	My daughter received school services and school related speech and OT via zoom for almost a year. Her summer program removed community activities and socialization for 3 summers. Nothing has been done to rectify all of the progress lost and the dive that my child took.

increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Andrea Davis, Ph.D., DIR/Floortime Coalition of California
Demographic	Service provider, health provider, or educator; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Mental health needs of autistic people are underserved due to the great divide between developmental disabilities services and mental health systems. We recommend: 1. Social-emotional developmental models of intervention such as DIRFloortime should be core curriculum for all professionals working to provide services to autistic people in order to flexibly support people with developmental disabilities, including those with mental health challenges. 2. Professionals in the developmental disabilities field must be educated in cross-system collaboration, core mental health awareness, and mental health triage. 3. Training for mental health providers must include assessment and intervention for people with developmental disabilities, especially autism spectrum difficulties to properly serve the high percentage of clients presenting for care who are autistic. 4. Healthcare providers must be trained in identifying and treating co-occurring conditions including anxiety, depression, sleep and eating conditions, and sensory processing difficulties with non-pharmacological efforts first. While the two FDA-approved medications, risperidone and aripiprazole, may be very helpful, clinicians must be educated to use extreme care, given their significant risks of metabolic and neurological side effects. 5. Policy makers must work to integrate the divided systems for people to have smooth experiences of adequately comprehensive and accessible care for co-occurring conditions.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	

What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

Name	Andrea Hammond
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Personal Experience: Sleep Disturbances, mainly insomnia. This makes it hard for me to enjoy life and hold down a job, and even drive. Sensory. Noise and light are my greatest struggles though I do struggle with the other senses as well. Constant exposure to noises and light cause me to have migraines and feel physically fatigued. I also struggle with motor like challenges, for example, I struggle with vertigo and balance, perceiving the distance of objects correctly, like running into walls, accidentally hitting my head on cabinets and counters, parking away from other cars because I can't tell how far they actually are, etc. This causes me to accidentally injure myself constantly or damage my car on curbs, poles, etc. if I am not very cautious. Other physical health conditions I struggle with are tinnitus and ear aches, and GERD. To my knowledge, other Autistic individuals have a high comorbidity of things like Ehlers Danlos Syndrome and POTS. I personally have not been diagnosed with these but I know of many other's who have.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Personal Experience: My greatest mental health struggles are general anxiety and social anxiety. These make it difficult for me to find community, socialize and find a job, hold down a job, or excel in a job. Autistic burnout from things like meltdowns and masking should be considered as well since it is very similar to depression. Burn out makes it extremely hard for me to care for my basic needs such as hygiene, eating, keeping my environment clean and working. It causes me to have more meltdowns often times leading to scratching myself and feelings of hopelessness. For others, it is important to note that depression is extremely prevalent in the autistic community and one of the leading causes of deaths for autistic individuals is suicide. Our average life span is significantly less than others because of this.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Personal experience: For me, communication disability is where I struggle. I am much better communicating via writing. I struggle to retain spoken instructions and struggle with Auditory Processing Disorder which makes it hard for me to understand spoken words quickly. This makes working hard as I am expected to listen and understand at a quicker pace than I am able. It affects my social life as others don't often have the patience to give me the time I need to understand, or the extra effort it takes to give written instructions.
What additional research is needed to help address co-occurring conditions for autistic people?	More research needs to be done with autistic adults of all genders and races. It is hard to find resources as an adult, but especially for women and people of color.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	My greatest struggles is finding support as an adult. Everything is geared towards children or the family of autistic individuals. Therapy is so inaccessible to me yet is something I desperately need. I haven't found a doctor who understands autism beyond stereotypes. When looking into services that might be of help to me a lot of them were inaccessible, they didn't have options like online applications. A lot of them needed phone calls or in person visits. Both of which are a huge struggle for me but also for those who are Non Verbal and the stigma we all face but especially for those with higher support needs. Autistic adults could really use more support as we are often forgotten about once we are no longer children even though we are still autistic.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I don't have much to say on this but the struggle I faced most was the reaction to parents not wanting to give their children vaccines because they feared it would cause autism, even though that has never been true. It was hard to face a world that would rather see their children sick or dead rather

	<p>than be like me. The other affect it had on me was my job. Because of my struggles I was unable to obtain a degree but work had become out of homes, but work from home jobs almost always need a degree. So I was forced to find a job that I was constantly exposed to others and at risk.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Positive impacts I had was things like social distancing and services like grocery delivery. There was also a lot less societal pressure to go out, to interact, and to touch (such as handshakes or hugs). Negative impacts would be things like a massive increase in changes surrounding things like businesses. There were rules that we had to follow but not everyone followed them, hours changed and you could no longer go later at night when less people were around (even my 24 hour gym is no longer 24 hours and closes early).</p>

Name	Andrea Webber, Mom
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	He has not lived with me in a long time but I do know that he can be up all night.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	He was self injurious a few years ago. Because I haven't seen him with short sleeves I don't know if he still is and he wouldn't answer if I asked.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication disabilities. Because there is no medication that I'm aware of to alter the mind to understand societal restrictions and laws and because there is a common denominator for people on the spectrum to not understand these laws, what can we do for them? They often appear to look and act strange. And although there is no intent for foul play; rejection, isolation and bullying can cause a meltdown because of misunderstanding. I was told by someone who works with my son that he needs to reside in a place that doesn't exist. Unless he is in a safe place, not to just protect unknowing people in the community but mostly to protect him from retribution from the community he is just being set up for failure or worse. My 43-year-old son with autism and co-occurring mental health issues was in county jail from 4/7/22 until 9/2/22 when he was moved to Ann Klein Forensic Hospital in Trenton until 10/13/23 when he was moved to Trenton Psychiatric Hospital where he remains. The optics of the police report has been misinterpreted and exaggerated, being seen outside the realm of those familiar with ASD/MH. There's so much more but I'm over my limit. The legal system needs to get on board with professionals in the field of Autism.
What additional research is needed to help address co-occurring conditions for autistic people?	It should be individualized based on the case. As Dr Steven Shore said "If you've met one person with autism, you've met one person with autism." The legal system with ASD people.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Housing and different supports. The people on the spectrum that I know of don't do well in a group home or with others, granted that's only the few I know. I don't know if anyone knows what they need. I think program/housing using Jespy House as a prototype but with changes would be a good start. There is also Mt. Bethel in Warren NJ which was originally supposed to be for people that were intellectually high functioning but socially and most every other way low functioning. From what I understand as one of the original founders said they could not find enough people to fill the Mt. Bethel so it was opened for ID people.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Prior to COVID I had 2 support staff, students attending TCNJ, working with my son. One was going to have him interview at the school for food service as they had special needs people employed the other was going to have him interview at the ShopRite she worked at, all of this and then COVID lockdown. Not that I know what the outcome would be but it was close to hopefully having a chance at a job as they would have been his job coaches.

<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>He was already being ostracized by the community, COVID just made it that much worse. In fact that was when he started to get into more trouble being totally on his own. Also he thought COVID was just another excuse for people to treat him as bad and worse than they always have.</p>
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Name	Andrew James Sanchez , Social Optics
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	To be completely honest there are quite a few. 1. Hyper photosensitivity allow sudden bright flashes of light or glare to cause me physical pain and even temporarily stun my body physically I call it the "Flashbang" affect. 2. Poor Interception and Proprioception, Random Spasms and Affects on Motor Skills. Autism has many physical effects people don't see, everything from issues which slack muscles, to the inability to sense when you need to go to the bathroom until it's too late or not sensing it at all until it's already happened. This is why many autistic youth and adults wear incontinence products / diapers some adults may have an issue with it their entire life with it worsening into adulthood. You can imagine what this does to on social life if you don't find people who accept you. One of the bigger problematic things is how it affects your ability to move through the physical aspects of executive dysfunction.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Many autistic people deal with some kind of trauma disorder as a form of mental health issue. These trauma disorders can be manageable while others can be heavily debilitating due to the increased likelihood of autistic people be traumatized physically or sexually. This is how somebody who could be working through PTSD can end up with cPTSD after significant A.C.Es or Adverse Childhood Experiences when coupled with adult traumas. Age regression is also extremely common amongst autistic people along with a kind of unidentified split between what some of us describe as our neurological age which can be much much younger than our physical body and our physical age. This can cause a great deal of suffering for autistic people with that split growing if certain support needs surrounding housing, therapy, and community aren't obtained.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Two big ones can be dyscalculia, and dyslexia. Often these will manifest as a learning disability or be labeled as such, there is often developmental delay in stunting with physical manifestations of age not showing up until much later. For example we may get our teeth very late, we may go through puberty very late and when it manifests it's a bizarre situation where we'll go through it multiple times in our life. To those who aren't autistic this won't make sense Extreme difficulties with math for a major problem for autistic people with learning disabilities being extremely common many of them centered around math. This in terms creates more educational trauma in which the autistic person will become fearful of going to school. Anxiety which presents itself through increase likelihood of medical and in school trauma are also common.
What additional research is needed to help address co-occurring conditions for autistic people?	One on one interviews, preferably paid research speaking to autistic people about their understanding of the following concepts within themselves. Age and how age is perceived. Their struggles, autistic people need to be asked "what are the things you have difficulty achieving?" Many of us will answer things like "gainful employment tell her to our specific and extremely challenging condition, housing that is affordable for someone on an autistic income which is usually below the poverty line, in an understanding of food sensitivities in society. One-on-one research is vital because each autistic person and the physical and mental toll on their body is completely different. You're welcome to contact me as an advocate.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access	The biggest would be access to housing, housing that is supportive without feeling like a prison. Housing that doesn't assume that all autistic people have the same support needs which doesn't have a curfew but supports are readily available should we call and need them. The other is access to

<p>to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>mental health services that are trauma-informed and seek to help rather than punish. An autistic meltdown is not a crime, and autistic shutdown is not a moral failing. When we do not address these issues we fail not only autistic people but society as a whole.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>Covid-19 was extremely dangerous for autistic people as most of us tend to have extremely sensitive immune systems and were prone to being killed by it. No one spoke about this. Many of us use places like zoos and aquariums and even some amusement parks where possible as places of vital systemic regulation and sensory regulation. This also included parks and certain businesses that brought us a sense of comfort. Covid-19 not only left many of us in undesirable situations struggling with housing but the shutdowns also endangered our mental health when the places we frequent are closed. Because autistic people have a lifespan of about 40 to 42 without support needs. Being stuck into one place, wouldn't inability to obtain certain foods our body won't reject and certain replacements for medical products and sensory items covid-19 left a lasting effect on those of us whom survived it. From mental health aspect many autistic people thought of taking their life during covid's highpoint.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Each Autistic person is different. For some autistic people like me, asking people to quarantine during covid and stay indoors unless absolutely necessary for work made for a quiet commute, free from many types of smells, loud noises and radio playing, and inconsiderate people on the subway system. For people that are hypersensitive to sound, light, and smell this was a blessing at times for me and others. Being able to go and work from home, and the Advent of hybrid education is taking society in a more inclusive direction even though people have tried to force human beings back into the cubicle, back into the hustle and bustle that degrades our mental health.</p>

Name	Andrew, Spouse of person with autism
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Of the examples listed, my spouse displays issues with her gastrointestinal system and bowel movements on a regular basis, great difficulty getting meaningful sleep due to waking up (and also frequent heartburn), has issues with sensory overstimulation (particularly noise, but also the taste and feel of certain foods). She also experiences minor issues/"klutziness" with general motor functions on a daily basis.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My spouse experiences constant anxiety over manners large and small, even worrying if I'll suddenly dislike her after 3 years of a happy marriage. She also experiences depression frequently which exacerbates her anxiety and often leads to suicidal ideation, but with no plans. My spouse also exhibits symptoms of ADHD, tho she is not diagnosed, in having an extremely hard time focusing even on activities she enjoys, inability to sit still for any period of time, and having a hard time committing to tasks around the house.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My spouse struggles with dyslexia, which has impeded her in school and even in her previous career work as a teacher. Physical books have words that are cramped and more difficult to read, so she usually utilizes audiobooks or a tablet, which has greater spacing. My spouse frequently flips words in sentences around and also has a lot of difficulty with even simple math, especially multiplication and division. My spouse struggles with some communication. She has a hard time reading and understanding social cues and sarcasm. Her thinking is also literal so I have to try avoiding metaphors or speaking around a subject.
What additional research is needed to help address co-occurring conditions for autistic people?	Finding earlier symptoms of autism in women, rather than being mistaken for symptoms of bipolar or borderline personality disorder.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I am unsure just yet as her diagnosis was recent.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	The lingering threat of COVID, along with seeing loved ones who did or did not take the risk of getting COVID seriously, made it difficult for my spouse to trust certain people. Her black and white thinking makes it a challenge to empathize with family members who deliberately didn't wear masks or believed COVID was a hoax due to political or religious reasons. The distrust has lingered in COVIDs wake.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	My spouse has enjoyed the reasons to stay separate from crowds of people, and it hasn't been easy getting back to "normal" with going back in public. It causes her anxiety just going to the store. She would love to find remote work after discovering the peace of mind that staying home each day afforded.

Name	Andy
Demographic	Autistic individual; Family member of an autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>When I was much younger, I struggled with insomnia. Sometimes, it would take hours for me to fall asleep. When I was about 16, I started to have the opposite problem where I could easily sleep for up to 14 hours straight. I also have sensory issues such as extreme sensitivity to sunlight, sensitivity to sound, and a strong aversion to the sensation of being wet. I also can't stand the sensation of my skin touching grass. And yes, walking in the grass with wet feet is a literal nightmare for me. In fact, just writing that sentence makes me cringe so hard that I viscerally feel the need to throw up. I always carry some kind of noise reducing/noise cancelling device with me at all times and I wear sunglasses religiously. The most difficult sensory issue to live with is my aversion to getting wet. This makes it incredibly difficult to shower, wash my face, do the dishes, wash my hands, and/or brush my teeth (my personal sensory hell). Unfortunately, I also struggle with an obsessive need to constantly rinse or wash my hands which I believe is OCD. In eighth grade, I washed my hands so often that they would crack and bleed. One of my biggest struggles, though, is my digestive system. When I was about 14, I started experiencing constipation, gas, bloating, inappetence, occasional nausea, occasional diarrhea, and all sorts of abdominal pain (dull, sharp, chronic, etc). I'm 22 now and I still deal with these symptoms almost daily (not all at once, usually 2 or 3 at a time).</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>I have a long history of self-harm, suicidality, and several mental illnesses, including but not limited to, major depression, generalized anxiety disorder, obsessive compulsive disorder, ADHD, gender dysphoria, and an eating disorder that I have struggled with off and on since I was 12 years old. As you can imagine, these all blend together with my Autism to make a hellish concoction of misery. All of these conditions have caused me so much suffering that I made the decision long ago that I will NOT be having children (at least not biologically). I don't think I could live with myself if I passed all of that [profanity redacted] onto another innocent little human knowing full well how terrible their life is going to be. On a brighter note, I am doing much better now for the most part. Don't get me wrong, I still struggle with everything I mentioned, but to a lesser extent. Additionally, this March 5th will mark 3 years since I last self-harmed. I'm still tempted to occasionally, but I also want to keep my streak going.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>There are many things that make living with Autism incredibly difficult, but the problem is NOT that I'm Autistic. The problem is the lack of patience, willingness to learn, and a severe lack of resources (at least here in the U.S.). There was a study done where researchers observed allistic participants' reactions to an Autistic person. They found that the allistics (on a scale of likability) assigned a lower rating to the Autistic participants as opposed to their allistic counterparts. This study supports the hypothesis that allistic people are more likely to dislike us rather than see us in a favorable light. Now, to be fair, the person doing the rating was not informed about who was Autistic and who wasn't. This could mean that their distaste for us occurs subconsciously. So, the hardest part about being Autistic (in my personal opinion) is how much everyone dislikes/alienates you for literally no good reason. They don't even know WHY they don't like you, they just know that they don't like you. Here is the URL address to the study: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8992906/ A lot of us Autistic folks struggle with rejection sensitivity dysphoria which basically means we can't help but take rejection VERY personally. This includes being</p>

	<p>rejected by potential employers, potential friends, family members, universities, potential romantic partners, etc. In other words, we are naturally more sensitive to rejection, yet we experience it almost everywhere we go.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>Oh honey, We've only studied Autism about as much as we've studied the 7 oceans. The first "studies" done on Autism only included young, white, male participants which is obviously incredibly biased. Fun Fact: the "evaluations" that Hans Asperger performed on Autistic children were actually just a test to see if (in his imbecilic opinion) the children were "functional" enough for society. Oh, and if Hans didn't deem them "functional enough," then they were sent to a nazi "asylum" where many of them were starved and/or abused until they died. So, all the research needs to be done! Considering the fact that earlier "treatments" for Autism included electrically shocking the patient, I'd say we need to take a VERY different approach to researching Autism (and it's co-occurring conditions) in the future.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Where do I even begin? First off, getting evaluated is not feasible for the majority of Americans since it costs anywhere from \$2,000-\$6,000, and there is usually an extensive wait list. The first goal should be to make an autism evaluation more accessible for EVERYONE. Insurance usually does not cover an evaluation, and the clinics that do the evaluations usually don't take insurance. We need to make EVERY insurance plan cover an Autism evaluation since so many idiots want to argue that self-diagnosis isn't valid when it ABSOLUTELY is. Also, the actual evaluation criteria should be developed by Autistic Neuropsychologists, not Neurotypical people, like hello? Who is going to be able to accurately identify Autistic folks better than Autistic folks? Also, accommodations on the job are basically non-existent. We need to promote the normalization of disabled people using accommodations. I have had jobs in the past where customers clearly mistreated me (while I was wearing a pin which disclosed that I'm Autistic), but I couldn't stand up for myself because I know that management would NOT have supported me. A lot of us feel pressured to work without accommodations because we have been made to feel like a burden in the past. We also need to have more services that help us get hired. MANY interviewers have rejected me purely because I seem "awkward" in their opinion. Keep in mind, I'm talking about places like gas stations and Taco Bell, not fancy office positions.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>I can only speak for myself, but I actually enjoyed quarantine for the most part. I know that might sound crazy, but after 18-19 years of masking, saying "I'm tired" would be a gross understatement. I loved not feeling that intense, relentless anxiety I always feel whenever I leave the house. It was also nice to not get judgmental looks from strangers all the time since I'm "odd-looking." I haven't worked a remote job, but that sounds like a literal dream come true for me, personally.</p>

Name	Andy Shih, Autism Speaks
Demographic	Representative of advocacy organization
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>Constipation, celiac disease, catatonia, obesity, restricted eating and sleep disorders are just some of the health conditions that commonly affect the autistic community. Restricted feeding in particular can lead to more medical issues, specifically lower bone density causing concern for osteoporosis. Often, the symptoms of physical co-occurring conditions can lead to diagnostic overshadowing, a clinical error wherein physical symptoms are misattributed to autism, leading to inadequate treatment. Sensory sensitivities further complicate matters, as they can alter the expression of physical symptoms and pain, making diagnosis and treatment for co-occurring conditions more challenging. Autistic people may also experience medication sensitivities, further complicating treatment plans. Health disparities in autism, coupled with increased risk for conditions like epilepsy and GI disorders, underscore the need for timely and appropriate medical intervention. Failure to address physical health conditions can lead to early morbidity and mortality. But accessing care remains a challenge for many. Addressing complex needs requires a team of specialized physicians who understand autism and can provide a level of care that is inaccessible to many autistic people, particularly in underserved communities. Many are forced to seek care in the ER, where staff often lack the necessary expertise to serve autistic patients.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>Co-occurring mental health conditions can lead to difficulty with work, school, community engagement, employment, post-secondary education and potentially run-ins with the justice system, greatly affecting quality of life. Limited evidence-based psychological interventions and stigma surrounding mental health exacerbate the difficulty of managing conditions like ADHD, anxiety, OCD and aggression. Moreover, treatment for these conditions often requires significant social interaction in settings that may be overwhelming for autistic individuals (e.g., hospitals), presenting additional barriers. Oftentimes, autistic adults in healthcare settings struggle to communicate their experiences, leaving them feeling misunderstood and unheard. Access to appropriate care and in-patient treatment facilities remains inadequate, particularly for autistic adults, increasing the burden on autistic individuals and their families. Non-specialist providers are not trained in autism, resulting in a lack of providers across specialties who are aware of the unique needs of the autistic community. Particularly in cases where an autistic person is experiencing severe aggression or self-injurious behavior, lack of adequate care can have a significant impact on their and their family members' quality of life. Family members may experience threats to their physical safety, mental health issues and lowered community participation.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>When these conditions co-occur with autism, differential diagnosis can be particularly challenging due to overlapping symptoms. Additionally, addressing the needs of autistic individuals with intellectual or communication disabilities poses unique difficulties, as understanding and responding to these needs can require specialized knowledge and accommodations. Unfortunately, many autistic individuals have limited access to specialized care, hindering timely intervention and support. Co-occurring intellectual, developmental or communication disabilities can also cause challenges in school, employment, post-secondary education, and community programs. Tailoring educational plans to accommodate diverse</p>

	needs requires specialized expertise and resources often lacking in schools and community programs.
What additional research is needed to help address co-occurring conditions for autistic people?	Addressing co-occurring conditions in autism requires research focused on the real-world effectiveness of interventions outside of controlled laboratory settings. Research should also prioritize understanding the social determinants of health, quality-of-life indicators, and predictors of community integration to better inform community-based support strategies. Research on co-occurring conditions like anxiety, ADHD, catatonia, and irritability is also needed, as well as research into validated treatments for these conditions and methods for disseminating these best practices to community providers who feel ill-equipped to treat individuals with ASD. Aging-related research is crucial for understanding the evolving needs of autistic individuals over time. Finally, there is a pressing need for research on behavioral interventions tailored for adults with autism. All this research needs to be codesigned alongside autistic people and their families and prioritize enrolling a sample of diverse populations.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Improving services and supports for co-occurring conditions in autism will require capacity development across all specialist levels, from peer supports to highly specialized professionals. Increased reimbursement for primary care providers and specialists caring for autistic individuals may allow for greater accommodations and increased staffing in these fields. The priority should be to improve access to qualified healthcare providers who feel comfortable treating co-occurring ASD and mental and physical health conditions. A multi-disciplinary approach to care where healthcare professionals coordinate with one another to support an autistic person's needs is also essential, particularly in complex cases. Many autistic people wait for years on waitlists to access care, so expanding insurance coverage to include group interventions would greatly increase access to care and support services. Expanding access to community integration opportunities can also enhance the overall well-being and quality of life for autistic individuals. To accomplish this, it's necessary to increase staffing for respite care providers, adult care programs and other supports, and improve training for these service providers.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	The COVID-19 pandemic has had a significant and ongoing impact on the autistic community. Many autistic people have family members and/or caregivers who have experienced death, disability or long COVID symptoms, affecting their ability to provide care. Many are struggling with decreased availability of support personnel (e.g., therapist, respite, school staff) due to illness. Fear of infection has also exacerbated anxiety and stress, particularly for those with co-occurring mental health conditions. This often results in lack of service utilization, decreased social connections and increased emotional distress. In children, disruptions in school routines have led to potential regression and loss of skills in children. Across the Autism Speaks Autism Care Network, some clinicians have observed abrupt worsening of behavior following COVID infection (e.g., sudden increase in OCD type behaviors).
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school,	The societal changes brought about by the pandemic have had both positive and negative impacts on the physical and mental health of autistic individuals. The widespread acceptance and use of telehealth has increased access to care and support services. Similarly, the flexibility of remote work and tele-education have provided new opportunities for individuals with autism. However, for many, increased social isolation and reduced in-person interactions have negatively impacted mental health, leading to

increased use of telehealth, reduced in-person social interactions and obligations)	regression of skills in some individuals and heightened anxiety and stress for both autistic individuals and their caregivers. Service disruptions and staffing shortages for treatment personnel have also directly impacted quality of life for many people.
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Name	Angela Close, Parent of adult with ASD
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Obesity due to lack of activity, social engagement, and sensory issues. Partially addressed during school years with PE and Unified Sports programs. Need additional programs to promote life long physical fitness. Hiking, biking, swimming, pickleball groups for adults with ASD.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety is most problematic for my son. Processing news, media, health issues and even weather can be anxiety inducing.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Learning differently!! It saddens me that we barely capture their potential because we can't seem to put enough resources to teaching and training differently. My son learned to read early with musical videos. But this method is not available in other areas.
What additional research is needed to help address co-occurring conditions for autistic people?	We need to research what the physical health implications are for ASD. Are gyms and fitness centers ASD friendly? Are their classes and programs. What educational and vocational teaching aides can we create for better learning.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Transportation to access services. Many adults with ASD do not drive and public transportation is limiting. It limits their availability to health care, counseling, social programs and employment. Too many unemployed or underemployed!
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I can't imagine what it was like for those fearing vaccinations. My son overcame his fear of vaccinations just in time. Luckily his sensory issues did not prevent the use of masks. The anxiety must have been tremendous. The long COVID must be worse amongst the ASD population.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	My son's internship with the local hospital was delayed, but they were able to train in a food bank and hotel instead. Eventually they had access to the hospital program with all the necessary vaccinations and precautions. As caregivers we had to be extremely cautious not to contract COVID. Our lives were greatly impacted, minimizing social interaction to remain healthy. Parents of ASD children cannot get sick. We have few options in caring for our children.

Name	Angela Hilbert
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gastrointestinal disorders. It's not just an upset stomach. Crohns' disease, in particular is a serious auto-immune disorder that shortens one's lifespan and puts them at high risk for cancer. I am autistic, my daughter is autistic as well. My daughter has had 2 surgeries for Crohns and has also had cancer twice. She is only 36. My own greatest struggle is the sensory problem of coping with light and noise. I am a high-masking autistic person but too much noise, light, or garish color can rob me of my ability to mask or even speak. Bright, noisy public environments are not accessible to me unless I can prepare to navigate them and allow recovery time after.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I am Autistic and have ADHD and Anxiety. It took me 12 years and 5 schools to complete my bachelors degree. I've been suicidal every time I've been through a burnout. When I meltdow, I beat my hands against tables, desks, door jams, and peel my own skin off my arms. This happens when I have deferred my own needs to accommodate the neurotypical people around me for too long at my own expense. Neurotypical people will not allow you to participate in society unless you can successfully pretend you are not autistic around them. You have to pretend light and sound doesn't hurt, that you don't need to rock. That you are "trustworthy" enough to make just the right amount of eye contact (even though eye contact feels like physical touch to you.) You have to translate everything through your best neurotypical lens or they won't understand you, you have to clarify the meaning of their raised eyebrow, the mis-match between their words and body language, monitor your face to be sure what your own facial expression is communicating is congruent with your intention for them. All this is in addition to the ordinary stress of everyday professional life. It's exhausting and when the mask inevitably slips, you are shamed, shunned, and excluded. This kind of hypervigilance is deeply unhealthy, but fundamentally necessary to participate in society as an Autistic person. And it is deadly.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I am fortunate that I do not have co-occurring intellectual disabilities. While my natural communication is "Autistic" I have studied communication obsessively to be able to "speak" the neurotypical language. I have a second degree in communications. I consider this essential to my ability to communicate professionally. I always have to go the extra mile to communicate with neurotypical people because they are too inflexible and self-centered to meet me half way and learn my language. Autistic people do not have a social communication disability. They just socialize and communicate differently. Autistic people communicate perfectly well among one another, just like neurotypical people do. But because neurotypical people are the dominant culture, they force Autistic people to do all the code-switching. (and they have the nerve to say WE are the "inflexible" ones?!) Autistic people HAVE to accommodate neurotypical social and language norms and be empathetic enough to recognize them. Meanwhile, neurotypical people are remarkably obtuse about recognizing Autistic communication and empathizing with Autistic people.
What additional research is needed to help address co-occurring conditions for autistic people?	Research on the double-empathy problem and Monotropism Research on Diversity, Equity and Inclusion programs that work for making professional settings more accessible and safe for Autistic people.
What could be improved in autism services and supports to help address co-occurring conditions for autistic	Do people with ADHD really have to see their doctor monthly for a non-renewable prescription of basic ADHD medication? I live in a rural area and have a 56 minute drive to my psychiatrist's office. I miss half a day of work

<p>people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>every month for this. I use up all my PTO just to keep medicated and in command of my own executive functioning. If I have to miss that appointment for an important work issue, I don't get my meds and have to work scattered. It reflects on my job performance and how I am judged and evaluated. If I use up all my PTO just managing my basic medication requirements, I don't have any for "mental health days", or a vacation to recover from chronic overstimulation and masking. This leads to burn out and job loss. I can't win. If I opt for using FMLA I have to disclose my Autism which can be career suicide. Even in a place where that would be safe, I would still have to take half-day without pay every month to use FMLA. It puts people with Anxiety and ADHD in an impossible situation.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>I LOVED IT! Shut downs were awesome! No pressure to socialize or meet for lunch. I've been working from home for the past 15 years, but for many of us, working at home meant we were finally able to control our own sensory environment at work for the first time! It created an increase in digital and written communication, which is a much more level professional playing field. Closed captions assisted those of us with auditory processing problems in meetings. I could flap my hands and rock my chair all day without looking "unprofessional." Even now, that shut downs are a thing of the past, I still have things like being able to order my groceries and just pick them up instead of wasting my saturday in the loud, chaotic market. Covid also brought to light how much EVERYONE's mental health was suffering at work. A new focus on the importance of mental well-being in the workplace is a tide that lifts all ships.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>see my previous entry. But Covid showed society that their addiction to in-person work and social structure was just an un-necessary preference, not a vital need. We can work, shop, meet, learn, play, and engage in so many more ways. Covid changed society to be more inclusive of a wider range of engagement methods and strategies.</p>

Name	Angela, Autism caused from brain damage at birth.
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Just some of my everyday personal physical health challenges: Sleep Issues, Sensory Issues (Sound and Touch), Speech Issues, ect.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have been informed I have ADHD, PTSD, Depression, Anxiety, and OCD Tendencies.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Math and Reading are given issues when dealing with Autism, but the hardest part of being Autistic for me is communication. It always feels like I am trying to translate a foreign language into another language without ever even knowing the original language.
What additional research is needed to help address co-occurring conditions for autistic people?	More research is need on Communication and speech therapy for Autistic people.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	We need more person to person options. A lot of my Autistic friends have issues when dealing with strangers/people on the phone. This is how their social anxiety show themselves.

Name	Angeline Low, Apt Fitness, Inc.
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I have ADHD, SMDD, PTSD, OCD, GAD, and other chronic mental and physical health conditions. I only sleep 0-90 minutes daily, which greatly inhibits my cognitive window, my body's rest and digest, and resetting my system through restorative sleep. There are many foods I cannot tolerate either due to anaphylaxis or texture / taste, which impacts my diet and weight. People often yell at me to stop stimming, which increases anxiety and depression. I am hyper flexible / hyper mobile, which impacts my stationary stability and agility.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I cannot sustain employment. I cannot retain relationships. I cannot assimilate. I wish I was dead, but I am not suicidal. Each morning is a struggle to get out of bed and face the world. It is too overwhelming. I miss a lot of work and get fired for it. Without a way to pay bills, I sink deeper into depression and anxiety.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I have difficulties reading and retaining what is read. I cannot understand people outside of a certain IQ range, because they seem illogical. It is a struggle to mask, and exhausting, because everyone expects me to be "normal," but I am different. Intellectually it is a challenge to communicate with others as they do not process their environments through logic, reason, critical and analytical thinking, and factual basis. I feel alone and struggle in school even as an adult. My social anxiety is so bad, I have a form of anxiety induced mutism, alexithymia, mobius syndrome, and people often misunderstand me.
What additional research is needed to help address co-occurring conditions for autistic people?	More awareness must be raised. People need to stop believing "everyone has a little autism." The condition needs awareness not desensitization. More research must be conducted on the links of autism and other conditions both mental and physical. Employers need to be more sensitive to the needs of autists as we are excellent employees when we are able to focus on performance.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Access to autism related services. I founded Apt Fitness, Inc., to help disadvantaged individuals affected by autism and ADHD, so they could afford to learn coping strategies, fitness, and social skills. We need more focus on nonprofit organizations such as Apt Fitness, Inc., which provides outreach support and services. When people are diagnosed late, they have missed a majority of their lives, where they kept thinking they were the problem, that something was wrong with them, when they were only autistic and needed to be shown coping strategies.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I have had long COVID-19 for two years, and it has exacerbated both my Autism, ADHD, as well as depression, weight, anxiety, and all of my other issues. Chronic fatigue, insomnia, my brain will not calm to sleep. I can go for 30 days without sleep, but my body is tired. I then start crying, curled in a ball, wishing I was dead, because I'm so exhausted and want to sleep but cannot fall asleep or stay asleep.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal	Telehealth is a positive. I was unable to go to the gym during COVID-19 and now cannot return due to long COVID. I am returning to school for a graduate program, but my attention span is nonexistent. I cannot sit still and continually fidget. I cannot concentrate at work. Increased remote services

changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	are a bonus, but some employers do not believe in remote, even during the pandemic they operated fully staffed in person.
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Name	Angie Gorz
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbances, sensory motor challenges and trouble addressing them due to housing inequity and noise pollution, and epilepsy.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression, obsessive compulsive disorder, mood disorder NOS
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication disorder, intellectual disability, developmental disability, movement disorders, mobility disorders.
What additional research is needed to help address co-occurring conditions for autistic people?	What is needed is actual support, not research into cures. Autistic adults and families need support. People who don't have multiple diagnoses need access to counseling, not constant denials.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Equitable access to mental health counseling for everyone, training in med to avoid patients being treated poorly, equitable access to all care, access to leisure activities to those who have co-occurring diagnoses, and more.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	More depression, increase in anxiety, increase in obsessive thoughts, decrease in happiness, increase in sleep disturbance,
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Reduced in person interactions because no one takes covid seriously

Name	Ann
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Overstimulation causes me to be very tense and in physical pain. Very sparse sleeping hyper mobility and joint issues. Can not stand for very long
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety Depression Suicidality Chaotic substance use as a way to cope
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Often I shut down and am unable to speak, especially when confronted by a police officer. Communication Delays make simple tasks such as paying for groceries difficult for both of us.
What additional research is needed to help address co-occurring conditions for autistic people?	Research how to support the Autistic community, especially in the areas of the medical industry, and law enforcement industry. These are the two industries that I struggle the most with.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Diagnosis availability for adults. many of us were overlooked as children.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Extream impact. I experienced 3 covid infections even with vaccines, because the timing of vaccine availability left gaps of exposure I am unemployable now because of my poor physical health and Autism but do not qualify for disability
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Isolation from support Hard to breath and move More sensitive to the environment than before

Name	Ann Glynn
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	For our son sleep disturbances and sensory challenges have been a constant.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	at the age of 13-14 our son's aggression toward others and self injury was off the charts. Even with intense interventions, behavior therapy and medications the challenges still exist. His behavior can be very unpredictable and stressful for himself and those around him. While he is learning to self-regulate (will be 20 in July) and we as his family are very in tune with his cues and triggers it has been in our experience one of the most challenging parts of his autism. There needs to be more awareness and help for families.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Our son is biologically 19, almost 20 however with his significant developmental delays he is more on the level of a 6-7 year old. He is not always aware of the dangers around him and needs constant supervision. He is a wonderful young man but this does present many challenges for day to day life.
What additional research is needed to help address co-occurring conditions for autistic people?	I would love to see more research on the sensory implications and how the mind is processing the world around the autistic individual. I feel if we could get a better understanding of how the individual was feeling in the world around them it would give us a better understanding of understanding what may be the root cause of some of the extreme behaviors that many of these individuals face on a day to day basis.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Now having an adult child with autism there needs to be life long support available for these individuals. Many if not all the services in most areas drop off when the person ages out at 21 or 22. Many will still need support for the remainder of their life. While they may not be able to go on to work they can lead a very full life with the right services in place for them to continue to teach them life skills and coping skills. Many family members need this to be available as it is devastating when there child ages out to go from a very detailed, routine schedule to days filled with nothing. There also needs to be more training and guidance for parents & caregivers.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	That was extremely hard for our son who thrives on routine and in the span of moments their life changed with no alternatives available to fill their lack of routine. My son went from school, aba, speech, ot, special needs swimming & adaptive tennis and golf to nothing available at all. Not even being able to go in many places comfortably. It truly left many families with a void and scrambling with how to create a new routine that would help their child process the world around them. Also when the world switched to virtual learning it was a literal joke for my son. The support wasn't there to keep him engaged and as a parent it seemed as though most of these individuals fell through the cracks.

Name	Ann Titus
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Pathological Demand Avoidance, also known as Persistent Drive for Autonomy
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Loneliness -- difficulty making friends
What additional research is needed to help address co-occurring conditions for autistic people?	Not only are the mental health care system and schools failing autistic people, but society as a whole doesn't value neurodiversity more generally. So, how can non-autistic people do a better job at accepting those who are different into their lives, places of work, etc.? Also, what information is being given to parents who have just learned their child is autistic? Why is ABA the go-to therapy when so many adult autistic people report that it is abusive and traumatizing? How can mental health professionals who diagnose autism better serve parents, and provide more appropriate resources? Are some "early interventions" actually harmful, especially to PDA autistics? Why isn't PDA in the DSM?
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Most providers are unaware of Pathological Demand Avoidance and therefore give poor advice. Therapies can be counter-productive. Also, if a child is diagnosed with autism, he/she/they should automatically be offered an Individual Education Plan. There should be no question or assertion that a child doesn't have "educational autism." Schools should be resourced adequately, so that they don't reserve IEPs for the toughest cases only.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It's been devastating. Screen addiction, weigh gain/obesity, lack of friends, a disruption in my child's routine and sense of security and well-being. And when kids suffer, parents suffer.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	All of the above. Disruptions have negatively affected every aspect of life. Remote work and remote school simultaneously was impossible. Mental health suffered enormously. Reduced activities, reduced interactions. On a positive note, Telehealth was a major bright spot! We continue to use Telehealth to access care with our son's neurologist, and we were able to get parent coaching through Telehealth that we wouldn't have been able to do otherwise, with our busy work schedules.

in-person social interactions and obligations)	
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Name	Ann, Parent
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Inability to communicate results in aggressive behaviors and undiagnosed medical conditions.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Training group home staff to be understand these conditions.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Really?! How would you feel if you were unable to speak?
What additional research is needed to help address co-occurring conditions for autistic people?	More emphasis on severe autism. Research on organic causes of speech apraxia. "Speech therapy" is ineffective.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Liaisons in emergency rooms to help parents overcome the implicit biases by doctors in understanding autism. Appropriate long-term housing for people with severe autism who are unable to communicate and left isolated and defenseless to protect themselves against abusive staff. Until appropriate housing is available people with severe autism need video monitoring for protection.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Covid19 isolated people living in group homes from their families. Please pass the Essential Caregivers Act.

Name	Anne Cuvellier, MSW
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I work at two jobs with children, adolescents and young adults diagnosed with Autism. One a school that requires a diagnosis of Autism and the students also have extreme behaviors and clinically at an inner city clinic providing individual and family therapy to persons diagnosed with Autism. Physical issues related to sleep, gastrointestinal and seizures seem pronounced but certainly sensory issues are present with many. Challenges encountered by the individuals that I work with are most times related to an interference in the individual's ability to socialize (sensory and communication), engage with others (communication, social skills), maintain emotional control (sleep, communication, coping skills). Judgement within the community is prevalent related to repeated behaviors/self-stimulatory and self-soothing behaviors which often are age-inappropriate and inability to self-regulate in the community. Sleep is significant in supporting self-regulation but seems challenging to treat. Gastro issues are often managed with diet and medication but put demands on families financially and to maintain consistency. Seizures seem common among those with whom I work but most respond favorably to treatment with medication but place stress on families. Most sensory and motor issues are treatable but finding replacement behaviors is difficult, coping strategies require CBT training and treatment and with non-verbal persons, this is more challenging.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD seems to be utilized as a diagnosis with little regard for the primary diagnosis of Autism and the overlap with criteria in these areas. Depression is more frequent but difficult to actually diagnosis if the person is non-verbal or withdrawing as a symptom of depression vs. autism. Isolation due to limited social interactions and limited ability to develop friendships/relationships contributes significantly. Aggression and self-injury are pronounced among person I see in the school and clinical setting. Self-injury - biting hand, head banging. Poor communication skills, impulsivity, intolerance of discomfort and lack of coping skills are often the cause. Suicidality is not seen in my practices.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Persons diagnosed with Autism who have higher cognitive functioning even when they are academically and vocationally delayed have more opportunities however, the challenges related to social functioning can interfere both with success at a job and with building relationships. Education is mandated to provide educational opportunities for people with disabilities but resources in the community based programs are often lacking, particularly with the many states now experiencing teach shortages, it is predictable that the students with intellectual disability will suffer from this. Communication is HUGE. Persons diagnosed with Autism are limited by the pervasive communication deficits that they experience. While technology is becoming an increasingly more important and useful tool, many times, persons with cognitive limitations are challenged to effectively and efficiently operate their devices. Being unable to communicate feelings, wants, needs, desires, in my opinion contributes significantly to behavioral challenges and is a major impediment to independent living.
What additional research is needed to help address co-occurring conditions for autistic people?	To have persons with Autism viewed as everyone else - a contributing member of society if they choose to do so. It is unfortunate to me that while schools are mandated to provide needed educational services, often at a significant cost, State Agencies that are SUPPOSED to provide adult services are not entitlements. By Departments of Developmental Services (in CT it is a 14 year wait for services under the Autism Waiver) lacking funding,

	<p>resources, organization and programs, many persons who enter their post-graduate life are left with no services, inadequate services and forced to continue to live with their parents/family members as though they have no right to an adult life. I liken this practice of mandating services until 21 or 22 through the education system and dropping the entitlement for continued services at age 21 or 22 to teaching someone to read and then taking away their books. There is no way for a student moving into their young adult life to maintain and gain skills without MANDATED programming in adulthood and without being provided the dignity of adulthood by the opportunity of living independently from family. Lastly, the current system requires that those individuals who are living with their family and require care, continue to live with family despite the age of the caregivers, this too is inhumane for both the caregiver and the person with Autism.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>funding Adult services is essential to improving the quality of life for persons diagnosed with autism. researching and developing specialized models for treating individuals with Autism to help address their mental health issues without solely relying on medication to manage mental health. providers should be required to have a specific certification in working with persons with Autism because as someone who has been practicing in the field for years, there are many unqualified providers out there and agencies who send them out. Insurance is good to my client base.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>I want to comment that it is unclear beyond that I think the families and the person with Autism in many cases have increased isolation wanting only in-home services and not wanting to go to a provider as well as preferring telehealth appointments. There is a place for both of these services with all persons in need but for some aspects of the population, what serves others well, does not always ultimately help everyone. Remote learning, I am confident is saying, did not serve most of those I work with well. For a variety of reasons: talking to a screen, inattentive due to lack of interpersonal exchange, confusion re: game vs. school, confusion re learning environment home vs. actual classroom, learning deficits/lack of progress and/ or regression most likely occurred during COVID</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Isolation, depression, anxiety all appear to have increased. While some contend that telehealth and remote learning prevented a disruption in services, minimally it caused a difference in services that has never returned to pre-COVID. As mentioned, requests for in-home services/telehealth continue which promotes isolation and is frequently driven by anxiety and fueled by depression. Anxiety related to fear of contamination/illness which has compounded existing concerns about navigating the social environments of the community depending on the severity of the person with Autism's social judgement. Socialization is critical for all humans and COVID has markedly changed our patterns of socialization. I go into homes now because clients won't come to the clinic. Many only leave the home for school and an occasional outing. In many ways, this is not solely an issue regarding the person with Autism but more a statement about how culture in general is more isolated.</p>

Name	Anne Marie Price
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep..sensory sensitivities, stomach issues and joint issues.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety disorders. Depression.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Learning disabilities.
What additional research is needed to help address co-occurring conditions for autistic people?	RESEARCH AUTISTIC WOMEN.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Late diagnosis therapists and doctors who understand the difference in women autists and men. Insurance coverage. ADULT ANYTHING SERVICES.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anne Nagel
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The biggest challenge is that many healthcare providers focus on my autism and downplay any other medical condition. By attributing everything to my autism, other medical conditions get worse. Sensory dysregulation is the biggest thing. My old doctor attributed increased sensory issues to my autism. I got a new doctor who did a cheap blood test and found a bigger physical issue that had nothing to do with autism. I wasted two years of my life dealing with a problem that was solved by a cheap medication because my old doctor only saw my autism.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Annettr
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory challenges, sleep disturbances
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, attention deficit hyperactivity disorder. Meltdowns
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Service accessibility, more services and teacher education in the school setting,
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Terrific impact- all negative. Magnified existing anxiety, My grandson was 18 months at beginning of Covid. Isolation definitely hindered his social awareness,
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous, public schools
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	picky eaters Sensory challenges
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety Loneliness
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication Disabilities Learning Disabilities Social challenges
What additional research is needed to help address co-occurring conditions for autistic people?	Basic understanding of frequency of co-occurring conditions
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Community Education
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I think it is too soon to say how long lasting the impact will be. At the present time, I think emotional regulation, learning delays and struggles with social interactions are still be impacted for many.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Tele-instruction and tele-health are both positive and negative. Depends on the individual. Disruption in services during critical learning windows is a negative impact. Reduced community interactions results in less practice in social exchanges and less opportunity to learn about your sensory reactions and adaptations to a variety of settings.

Name	Anthony
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I struggle with sleeping consistently and find myself in a complete sensory overload state when around other people
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Suicidality is a normal part of life in a way that isn't threatening. Self-injurious behavior for me consists of nail biting and scratching to my previous injuries
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I have dyslexia and in general have a hard time with social interaction and with normal conversation
What additional research is needed to help address co-occurring conditions for autistic people?	I think that a better understanding of autistic burnout specifically will be beneficial for others who are high functioning like myself
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Covid made it easier for us to isolate and not be questioned by society around us
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I think that the examples all have implications both positive and negative. The big change that is a relief is that the social contract of physical contact(handshakes and hugs)

Name	Arianna C
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	It is very common for autistic people to have issues with our joints and stomachs. Gastrointestinal diseases as well as Ehlers-Danlos, scoliosis, and hypermobility are common.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Disorders associated with trauma. In my opinion as an autistic person, being autistic in and of itself is traumatic and can explain the link between autism and trauma disorders.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	ADHD is one of the most common disorders that is diagnosed alongside autism
What additional research is needed to help address co-occurring conditions for autistic people?	The link between connective tissue and autism, improving education for autistic and neurodivergent students, lgbt+ identities and autism, the digestive tracts of autistic people, autistic eyes and ears.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Make more of them
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Ariel Taylor
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disorders and sensory needs
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, depression, a sense of loneliness
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Developmental disabilities and learning disabilities that are overlooked because everyone is just ascribed to the autism
What additional research is needed to help address co-occurring conditions for autistic people?	We need to start differentiating between autism and FASD. The most recent research shows that FASD happens at a much higher rate than autism but people with FASD are often diagnosed as autistic because of stigma/autism being more widely accepted
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Providers who take a neurodivergent acceptance approach to treatment instead of a medical model. Providers who accept Medicaid. Providers who are specifically trained in the most recent modalities for autism and not just ABA
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Longer waiting lists and services being interrupted by providers leaving and not being able to find replacements

Name	Arushie Nugapitiya
Demographic	Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	The issue is not so much co-occurring conditions that you list it is the coexisting conditions (lack of a better term) like DD and mental health that create a disparity for the DD population to receive Mental Health services that create barriers
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Isolation. Limited to zero mental health and medical service access for the DD population
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The individual support was not available

Name	Ash Keen
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Autism impacts my interoception making it difficult to sort out what I am experiencing in my body. It also impacts communication which makes it hard to communicate with my doctors
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	It's hard to find mental health providers who are trained and comfortable working with autistic adults
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	For me it's my physical disabilities and how my autism makes it harder to get diagnosis and treatment
What additional research is needed to help address co-occurring conditions for autistic people?	Research links between autism and conditions like OCD, POTS, EDS, and migraines
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Providers need more training on how to interact with autistic individuals. Autistic patients could benefit from a social worker or other support person to help them navigate the healthcare system
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I don't know
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Remote work and telehealth appointments make employment and healthcare much more accessible for some autistic people

Name	Ashleigh
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	For me the biggest issue is whilst we are more likely to have these conditions e.g: epilepsy, the doctors who are more likely to deal with those kinds of things don't understand how autism works.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Same as last one but also there isn't information out there for autistic people to know how these conditions present in us or if it's just one of our autism traits being extra full on.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Ashley
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory challenges, focus and attention, pica, sleep issues
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Self injuring Stims. Eating non good items
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication
What additional research is needed to help address co-occurring conditions for autistic people?	A lot!!!! We need an understanding of the mental health needs of au people
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Not having to fight insurance for therapies, cutting down on the 15 yr wait list for ssi
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Tons! Virtual.therapy and one on one aba therapy do.not.work over video
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Ashley Bayles, Autistic Person
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Need for accommodations and compassion from allistic people.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Trying to push yourself past your limits in an attempt to meet unreasonable expectations from allistics and being unkind to yourself when you fail to meet those expectations.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Accessing community life. Autistics with additional disabilities, especially in cognition or communication, are often shunned by their peers and community.
What additional research is needed to help address co-occurring conditions for autistic people?	Research into the biases and behaviors of allistics when they are interacting or interfacing with autistics and how to mitigate/reduce the harm caused by allistics against autistics.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Provider education that humanizes autistic people and the cessation of attempts to eradicate natural autistic behaviors/ways of being.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Many of us are afraid to leave home for fear of becoming more disabled through COVID infection and post viral illnesses. We struggle to trust our communities/peers because we know they consider us an acceptable loss and will do nothing to try to protect us.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Remote work and telehealth have made things much more accessible for autistics. But lack of clear guidance and rules and education regarding the seriousness of COVID has made it difficult to know what is and isn't safe or reasonable to ask of people.

Name	Ashley Daly
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Finding doctors who are familiar with autism and not just focused on their one expertise. Going to and through appointments, procedures and medication with an autistic individual who needs routine, familiarity and doesn't like unknown experiences.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Autistic son already feels "different" and has trouble emotionally regulating, so anxiety is overwhelming. When looking at medication to address anxiety and depression you have to consider possible other medications being taken and hard to navigate effectiveness if individual has a hard time expressing feelings.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Additional frustrations causing emotional dysregulation.
What additional research is needed to help address co-occurring conditions for autistic people?	If you're autistic, what additional testing should be automatically considered. Public school knowledge on what else to test for and funding to do so. Schools will only test for what you argue and push for them to test for.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Training and information for parents. More knowledge and training for pediatricians on what doctors to refer out to. Providers who take insurance and do the breadth of neurodivergence testing - dyslexia, speech, adhd, etc - we paid out of pocket for a full evaluation.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Delay in testing during height of Covid/2020. Most of the neurodivergent testing needed to be done in person - Dyslexia, for example.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	A positive is increased telehealth.

Name	Audra Olazabal
Demographic	Family member of an autistic individual; Service provider, health provider, or educator; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Helping people understand the interrelated dynamics between their symptoms and experiences. Help provide effective and sustainable improvements/outcomes.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Lack of providers, lack of education/awareness among existing providers, lack of funding for supports. Many people are under-served and greatly in need of targeted and knowledgeable support.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The invisible disabilities aspect. The general public assumes the average person is capable of a lot. Many of these challenges are cognitive and abstract/soft skills that people are just expected to be able to do. It's hard to accommodate when you're unaware and when the person may themselves not be able to inform you. Requires observation and thoughtfulness from caregivers and others in one's life.
What additional research is needed to help address co-occurring conditions for autistic people?	I'd like to see more research on mental health and autism, on women who are autistic, on parents who are autistic, on gender identity and sexuality, on undiagnosed or self-diagnosed adults, on supports and services for autistic populations from teenagers through old age (i.e. beyond early intervention), on what service providers (medical staff, emergency responders, educators) are seeing, and needing, and how to best support and train them, on developmental/play based approaches, etc.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	All of the above. Training for first responders, support workers and families. Mental health and community building resources.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Audrey
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	It is most challenging to deal with the mental toll of trying to exist in a world catered to allistics people and extremely hostile to autistic people. It's extremely hard to keep a work life balance that does not immediately drain all of my mental and emotional resources but allows me to provide for myself and my household. The exhaustion is the worst part, which leads to depression and anxiety about keeping up with the demands of life
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I struggle the most with communication "disabilities", however I would argue that my communication gets misconstrued but allistics people trying to read more into what I am saying than what is actually being said, yet I'm the one who "struggles with communicating effectively" despite saying EXACTLY what I mean, and nothing more or less
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Remote work has done more for my mental health than therapy ever could!! Being able to stay in my safe safe, surrounded by comfort items and with support people has been MONUMENTAL in allowing me to find a day to day equilibrium with fewer meltdowns and fewer sensory interruptions. Venue caps on attendance are fantastic to make sure things will not be overly crowded and I know how many people to prepare to be around!!

Name	Aurora
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Some of the most significant challenges caused by co-occurring health conditions in autistic people includes gastrointestinal disorders such as IBS (Irritable Bowel Syndrome), issues with chronic musculoskeletal pain, and disordered sleeping, like insomnia and narcolepsy.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The most significant challenges caused by co-occurring mental health conditions in autistic people are depression, disordered attachment styles, Obsessive-Compulsive disorder, personality disorders (especially borderline and schizotypal). It's very common for autistic people assigned female at birth to develop a borderline personality disorder in response to the trauma of being raised as a woman in a household with a narcissistic individual. The connection between autistic people and narcissistic abuse needs to be explored in more depth.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The most significant challenges caused by other conditions that co-occur with autism is the socialization aspect of it. This is to say, autistic people tend to feel very alone in the world, and many of their symptoms contribute to this being the case. Not being adept at socialization leads to numerous problems in spaces where social interactions are required, such as school settings or work settings, which leads to potentially fatal burnout.
What additional research is needed to help address co-occurring conditions for autistic people?	The connection between personality disorders (especially but not limited to borderline and schizotypal), gender dysphoria, and dyslexia with autism needs to be explored.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Many autistic people are not diagnosed with autism because of the many barriers involved in seeking healthcare, finding a care provider willing to diagnose you, autistic tests often being made for children, or made without masking in consideration. Adult autism needs more attention, especially services designed to help adults with autism navigate the complicated healthcare system and get diagnosed with autism, and if needed apply for disability services.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Autism high functioning, with Heds
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I have severe GI track issues which cause severe pain and can cause me to be bed ridden by Dr orders. Along with getting too much sensory input causing me to get overwhelmed very easily when in public places.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I've severe anxiety and depression since I was a young child, due to not knowing how to cope with over stimulation and social constructs that can be hard for me to understand or know what's expected.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	For me it's communication and social stimuli; holding basic conversations is very challenging for me. Plus I get very overwhelmed by the amount of info when in social settings.
What additional research is needed to help address co-occurring conditions for autistic people?	I have HEDS, GI track issues, and possibly peds. I've been in constant pain since elementary possibly sooner. Numerous joint and muscle problems along with losing vision etc...
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Having it de stigmatized so that autistic can feel comfortable getting help with mental difficulties and health issues, without being dismissed by medical professionals.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Mental health and struggle with depression and re entering society
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	It being more social acceptable and the online resources to help with coping mechanisms

Name	Autism New Jersey
Demographic	Representative of advocacy organization
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>Many individuals with ASD must grapple with increased prevalence of co-occurring medical conditions but experience more unmet health needs. Some cannot find a provider to care for them or they report lower satisfaction with healthcare provider interactions. Their healthcare costs are higher, and their outcomes poorer. There are many challenges to diagnosing/treating medical conditions in ASD patients. Without formal training to treat ASD patients, healthcare providers struggle to effectively provide even basic ASD-friendly care, let alone diagnose/treat co-occurring conditions. Communication differences make it difficult for many ASD individuals to give information vital to diagnosis/treatment. ASD patients without speech may be unable to express internal states/pain or may be unable to use nuanced language to accurately describe symptoms. ASD individuals without speech may express pain behaviorally and potential medical causes for challenging behaviors are commonly overlooked. ASD patients may also receive substandard care because they cannot tolerate the needed procedures. The persistence of undiagnosed/poorly treated medical conditions has more negative impacts than physical deterioration. Pain expressed as challenging behaviors may have a significant impact on educational, vocational, and living options for the ASD individual. A condition undiagnosed/untreated may require more intensive and expensive treatment and may be more difficult and traumatic for the patient.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>Additional research into the cause of increased co-occurring medical condition prevalence is needed. A study using a large sample size of SPARK data found that 74% of individuals with ASD had at least one comorbidity and had a greater average number of comorbidities than their non-ASD siblings (Khachadourian et al., 2023) which would suggest that something specific to an individual's autism diagnosis is correlated with the presence of the co-occurring medical condition. Second, while many caregivers report atypical symptoms among their children, there is limited professional understanding of these idiosyncratic symptoms or their etiologies. Knowing more about the cause of and presentation of co-occurring medical conditions in individuals with autism can result directly in improved care and outcomes.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services,</p>	<p>First, effective medical care for autistic patients can be improved by requiring formal education and training for healthcare providers on the complex presentation of autism in their patients and the most common co-occurring medical conditions. Healthcare providers who are well-versed in autism-friendly practices will provide better care resulting in better health outcomes.</p>

<p>insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Also, systemic changes in healthcare administration and third-party payor policies can result in improved care and outcomes. Providing adequate funding for hospitals and other medical providers to implement autism-friendly practices would incentivize healthcare organizations to take on these efforts. Changes to reimbursement rates and billing codes could allow for longer medical appointments for autistic patients, more case collaboration among professionals, and billing by behavior analysts in medical settings. When any of these things are piloted as quality improvement projects or via grant money, they show positive results (Boston Medical Center (n.d.) Autism-friendly initiative); the ability to expand and sustain these efforts can improve the health, safety, and quality of life for the autism community.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	

Name	Autism Society of Idaho
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Epilepsy Low Tone
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety and depression
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Lack of accommodations in the workplace or by the states in the case of licensing requirements
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Workplaces should accommodate neuro-divergent individuals
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Autistic Adult and Autism Researcher
Demographic	Autistic individual; Service provider, health provider, or educator; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	An under-recognized and often overlooked challenge caused by co-occurring conditions is food selectivity (picky eating), as well as restrictive eating and trouble recognizing hunger cues. Eating difficulties arise as early as 6 months of age in some individuals with ASD and frequently persist into adolescence and adulthood with few options for intervention and support, sometimes associated with gastrointestinal health issues, nutritional deficiencies, and increased stress among individuals and their families. The act of eating is not just a necessary behavior for sustenance but is also a crucial component of social and sensory development. Research is needed to better understand the impact of prolonged eating challenges in autistic adults, how eating challenges relate to co-occurring disorders such as ARFID and anorexia nervosa, how such challenges develop, and how treatments and supports can be developed and refined for autistic children and adults alike.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Significant challenges include eating and feeding disorders such as ARFID (more common in children) and anorexia nervosa (more common in adolescence and adulthood). Autistic individuals are more likely to be resistant to typical treatments for eating disorders and may require unique supports. Given that anorexia nervosa has an extremely high fatality rate, it is important that autistic individuals struggling with this disorder are given effective treatment. Other impacts of such eating disorders in autistic people include difficulty and avoidance of eating in social environments, gastrointestinal health issues, nutritional deficiencies, invasive medical procedures (e.g., feeding tube insertion), and being over- or under-weight. Additionally, attention-deficit hyperactivity disorder is a commonly co-occurring condition which can impact learning outcomes and ability to form and sustain social relationships.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Eating disorders, which are often overlooked as commonly co-occurring with autism, impact physical health (e.g., dizziness, fainting, weight), ability to concentrate, and social relationships. Many social interactions occur over a shared meal, and eating disorders can limit a person's social opportunities.
What additional research is needed to help address co-occurring conditions for autistic people?	Research is needed to better understand how eating challenges relate to co-occurring diagnoses and symptoms of ARFID and anorexia nervosa. Research should also examine how eating challenges develop and how treatments and supports can be developed and refined for autistic children and adults alike. Longitudinal studies are needed to understand how eating challenges change throughout the lifespan, as there is very little research in this area. As a result, it is unknown what the long-term impact of food selectivity is on autistic adults and adolescents. Additionally, there should be research into the potential role of gender and eating difficulties in autism, as autistic girls may be more prone to anorexia or food selectivity than autistic boys. Finally, research should explore the value and efficacy of food supports such as food delivery apps, personal care attendant to prepare food, etc to determine whether such services should be made more publicly and financially accessible to autistic adults.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services,	Providers should be trained in the care of autistic people and should understand the heterogeneity of the autism spectrum. As an autistic adult, I have had my autism needs dismissed in the medical setting when a doctor who is treating another one of my conditions does not "see" me as autistic because I am a high-masking, intelligent adult with low support needs, but

<p>insurance coverage, service systems issues, patient-provider interactions)</p>	<p>needs nonetheless. Services for co-occurring conditions should be made more financially accessible for autistic people, especially regarding insurance coverage. It has been difficult for me to access services because my psychologist specializing in both autism and ADHD in adults is not in-network despite this psychologist being the only neurodiversity-affirming adult specialist in my area. It would be very helpful to have access to food and item delivery services without paying an added cost, as co-occurring disabilities like ADHD and eating disorders can make the process of shopping in-person very difficult.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>As an autistic adult, I felt very isolated when COVID-19 began and have still struggled to make friendships since. My social anxiety increased due to the pandemic.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Increased remote work has helped me decide whether to go to work in-person or remote according to my social battery. This has helped me prevent autistic burnout.</p>

Name	Ava
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Chronic overwhelm from sensory overload - leading to daily headaches and fatigue. Also comorbid conditions: hyper mobile ehlers danlos syndrome, POTS, MCAS etc.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety - constantly overthinking and analyzing and planning ahead (because of fear of limited energy levels), which is incredibly stressful and draining
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Often being misunderstood or tone of voice being taken as aggressive. Trying to communicate and be received properly is very taxing
What additional research is needed to help address co-occurring conditions for autistic people?	Studies on females specifically. Extra high rates of reproductive issues, hypermobility, brain issues (inflammation), overlap with adhd etc
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Absolutely insurance coverage, but also more training in Med school. So many "experts" don't know what high masking autism looks like, especially in those assigned female at birth. racial minorities deal with the impacts most
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I've been infected 4-5 times. I'm sure it has only negatively affected my cognitive + fatigue issues
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Azure
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I have EDS which is more common in autistic people. The physical pain it causes me significantly impacts my life. My autism makes me more sensitive to pain in some ways. Many people with higher support needs, who would likely have difficulty finding out about this survey and possibly completing it, have more severe comorbidities.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have PTSD because of the way I was treated due to symptoms of autism and ADHD in k12 school by my teachers. It makes it incredibly difficult to navigate the world because I am constantly on guard. The people who caused this trauma will have long careers because nothing they did was technically illegal. Better protection for autistic (or potentially autistic) students in schools would be incredible.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Due to the format of this questionnaire it will likely be difficult for many people with intellectual disabilities to find and respond here. I personally have dyscalculia and my problem has always been getting colleges and schools to respect my request for accommodations. Professors who do not believe me will do everything possible to not allot me extra time for tests and due to their tenure or time at the college will face no consequences for it.
What additional research is needed to help address co-occurring conditions for autistic people?	There is a tremendous lack of research for high support needs autistic people that addresses their own concerns about themselves and not the anxieties of allistic people.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I have a horribly difficult time with paperwork that often leads to difficulties in my life. A service where an aid helps walk me through the process would be incredibly helpful for me.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I have social difficulties due to my autism but I love to go out and I love to be around people who are understanding. I was also born with orthostatic hypotension. This condition can be caused by COVID 19. Should I ever get COVID 19 mine would likely get worse, permanently. The lack of precautions has forced me into isolation.

Name	B
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Co-Morbid disorders. I have Insomnia, IBS, Gluten intolerance, sensory issues that relate to touching things and eating them. Long term motor and physical issues, like toe walking turning into issues with my knees and collapsed arches when standing. Hypermobility is also an issue. I have issues not understanding my body cues, such as hunger, bathroom use, water intake.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have ADHD, anxiety, social and generalised, impulsive and intrusive thoughts. Issues reading social cues and understanding normal behaviour that leads to isolationism among peers or only being sought out for a purpose. It can also risk my safety in public if I misunderstand someone else and their intentions which has lead to me responding improperly and getting assaulted. I also have issues understanding my own emotions which can look like apathy to others.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I was too advanced in something and delated in others resulting in not getting a diagnosis based on childhood criteria. I picked up reading took quickly but jot speech. I was good at maths and sciences because they're hard facts but failed at language arts and social studies because they're often more nebulous in context and harder to understand and communicate on, compared to solid facts. That, along with social issues, anxiety and other co-morbid issues already talked about make school not a good place for people like me. I've tried college four times and didn't finish.
What additional research is needed to help address co-occurring conditions for autistic people?	Research into groups beyond white males. You need other minorities, women, queer folk, all across the spectrum of society to understand these issue. Especially those diagnosed as adults because we didn't present with typical white male child symptoms.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Testing that doesn't rely on childhood things, especially for those seeking a diagnosis as an adult. Less hoops to jump through to get coverage. More health insurance options that don't have us paying out of pocket for testing or support because we're not children. More training for the in authoritarian positions like doctors and nurses and psychologists on how to interact with us and mandatory reading of the internal DSM and US DSM latest copies.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Some of it was good. A lot of us who suffer from social issues were able to use written forms of communication versus trying to understands someone's tone, body language, facial expressions, etc. A bad thing would be the anxiety caused by the country's poor handling leading to a lot of misinformation and misunderstandings, especially regarding autism and vaccinations. Again.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	It was good for a while, a lot of jobs were letting people work remotely or hybrid but now a lot of companies are backpedalling on that and requiring documentation despite productivity being up for a lot of these companies. Which ahas then led to issues with people scheduling appointments, increased social interactions and misunderstandings and obligations which lead to burn outs.

Name	B. Blair Braden, Arizona State University
Demographic	Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Lack of autism-informed providers or tailored interventions/approaches.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	There is a huge need for large-scale clinical trial funding. Many of the NIH ICs will not fund autism efficacy trials. This is particularly problematic for adults as interventions tailored to adults is only a recently emerging field. Yet, the opportunities to fund research that can build evidence-based interventions for autistic adults is severely lacking.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More funding for large-scale clinical trials. There are a plethora of pilot studies that show promising effects for addressing co-occurring issues, especially in autistic adults. But there is very little funding to execute large-scale clinical trials that can establish efficacy and move these interventions into services.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Barbara Baker, parent
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My daughter has gastrointestinal issues, poor sleep, epilepsy and sensory challenges. All of these variables are constantly changing. It is difficult to tell which of these (if not some or all) are contributing to her changing behaviors and moods. I am constantly in "fix it" mode, trying to figure out where to focus attention. It is extremely complicated and something that only I can do. This makes me nervous as we think about her living away from us. No one else will know her and be able to help her like I can.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Along with all of my daughter's "health issues" she also has intellectual, communication and developmental disabilities. This makes figuring out her needs even MORE difficult as she cannot tell me how she feels or what is bothering her. Also, she cannot read or write. It is a constant guessing game caring for her.
What additional research is needed to help address co-occurring conditions for autistic people?	I would like to see more research in the area of biomedical issues for people with autism. We seem to have good success when we treat her health issues -- this results in improved behavioral issues and better learning. I don't think a lot of practitioners believe it, but it just makes sense. Pushing heavy drugs on people with autism is not always the answer. Getting to the root of their behaviors needs to be better researched.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	For many of the biomedical interventions we have had success with, they are not covered by insurance because they are deemed "exploratory". I would like to see more insurance companies recognizing that all care for complicated individuals with autism is worthy of coverage. Especially since no one knows for sure what works for this population. It's truly all still trial and error. So do not dismiss possible treatments as not worthy of insurance. Also, more practitioners need to be trained to care for people with autism. There are not enough and there is a great need for them for the future.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I only gave our daughter 1 vaccine (J and J) because she her immune system is very compromised and I didn't want her to have too many injections. I am more afraid of the artificial vaccines for her than the virus itself. I think that as a general rule that many individuals with autism have regressed after having numerous vaccines. Many are very sensitive to the vaccine and the ingredients due to over active immune systems. Also, in general, being even more isolated during covid has led to many challenges for autism families related to housing shortages, staff shortages and the inability to practice skills in the community. Much regression has occurred for people with autism as a result of the pandemic.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal	See questions 6 response

changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	BAT
Demographic	Autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Co-occurring health conditions are especially difficult for some autistic people to manage. This is especially significant for individuals that suffer from the sensory, communication, and poor interoception. Autistic folks may have difficulty realizing there is something wrong and even more difficult deciphering what the location or body system is affected. Even if they know what's wrong they may not have access to medical care or the communication supports needed to access care. Further, because medical professionals have little, wrong, outdated, and/or (often) bigoted views of autism, the patient might not be believed. Autistic patients have medical trauma from being denied informed consent and not being believed. Autistic folks may not reach out for help due to all of these issues which can make comorbid conditions much more significant without intervention.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Because of the way that the DSM and psychological research is (by this, I mean it pathologizes any behavior that does not conform with conservative cultures and capitalist values), many autistic folks have been misdiagnosed and therefore been given improper intervention/treatments. The main treatment offered to autistic children is ABA which is described by most autistic adults as torture. So, even if an autistic child is offered early intervention, their life-long mental health is affected by that treatment. This makes it difficult to parse out what conditions are co-occurring or which behaviors are just a result of being insufficiently supported.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	It is often assumed that non-speaking autistic folks have developmental disabilities which affects their independence. Often teachers and therapists are taught to consider ONE disability at a time. Children who have more than one diagnosis or educational disability label are often mysteries to school and intervention staff and often mis-served.
What additional research is needed to help address co-occurring conditions for autistic people?	The relationship between autism and gender differences. The relationship between autism and Ehlers-Danlos Syndrome. ABA needs to be looked at without submitting more individuals to the torture. What are the long term affects of children being treated like dogs for hours every day? More research into neurodiversity affirming care and interventions. Clinicians need to find ways to help autistic folks navigate the world instead of trying to "fix" them. Autistic folks don't want to be cured.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More access to augmentative and assistive technology (especially communication), neurodiversity affirming therapists, insurance coverage (more than just ABA), more clinician education on co-occurring conditions.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Anxiety, depression, isolation, flares of co-occurring chronic illnesses making supports harder to access. Clinicians ignoring the pandemic and blaming anxiety.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services,	

increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Beatrice Alvarez , Parent
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Consistent GI issues that require prebiotic & probiotics, sensory issues with clothing softness, not able to tolerate socks, hair intolerance
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety in New places. My son has trouble using a single stall bathroom for the 1st time in a new place e.g., hotel, visiting home. He has to talk himself thru it or need someone to help him get past the threshold that he's going to be ok. Once past it, it's fine after that
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	IDD but my son also has Downs. It's hard to tell from which of these it came from.
What additional research is needed to help address co-occurring conditions for autistic people?	Mental health help, talk therapy, social group therapy, social stories, social practices, behavioral therapy
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage of mental health therapies
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Reduced social interaction and setback in terms of social progress

Name	Bella
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Definitely sensory and motor condition's. Mainly because for major stuff like learning how to drive, leaving the neighborhood on my bike, etc. I have a literal mental blockage that prevents that ability from happening unless I physically push pass it. Along with the fact that I have meltdowns from time-time if something acts as a trigger. Caffeine & sugar also make me pass out.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Definitely depression, anxiety, and ADHD. The ADHD more specifically because of the fact that ADHD symptoms tend to be the opposite of autistic symptoms. Which means you have to attempt to find a balance.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	All of the above in all honesty. The learning disabilities makes math extremely hard for me. And communication disabilities is worse because it means, in combination with my ADHD, I can't keep friendships because I literally forget to message people. Or don't because we don't have similar special interests.
What additional research is needed to help address co-occurring conditions for autistic people?	Just, talking to autistic people. There's different things that help all of us because not one autistic individual is the same.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	All of the above
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Bella Taylor
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Fibromyalgia
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD BPD
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Chronic pain, overlapping diagnoses of ADHD and BPD
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Bellamy
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I have a lot of sensory issues that affect my ability to take care of myself as well as perform the requirements of my job. Smells, lights, and sounds, and textures all become overwhelming very quickly. When my nervous system gets overwhelmed I usually begin to experience muscle ticks that are involuntary and have resulted in dangerous working conditions for me in the past. I also get what I call "tick attacks" where a particular tick gets stuck in a loop and I am unable to stop it for a length of time usually resulting in joint and muscle pain.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Before learning I was autistic I had a very confusing mental health journey. Between the ages of 12-18 I've had so many diagnoses thrown at me, anxiety, major depressive disorder, narcissistic personality disorder, bipolar personality disorder. I believe I would have had a much better childhood if I was able to be diagnosed correctly before going through all sorts of treatments and therapies and group homes I could have avoided so much trauma and emotional dysfunction. My working memory is in the 30th percentile due to PTSD. This makes keeping track of conversations difficult. I tend to forget what I'm doing as I'm doing it. I have struggled for a lot of my teen and adult years with self-harm and suicidal ideation a lot of which stems from feeling like my brain is broken and there are no good options for me.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	If I was given a learning environment better equipped for my sensory and learning needs my life would look SO MUCH DIFFERENT. I struggled a lot in school both academically and socially. However I only struggled academically when I couldn't understand directions and no one would take the time to explain it or was too overwhelmed with sensory issues to do the work.
What additional research is needed to help address co-occurring conditions for autistic people?	Please please please study more into autistic women and autistic individuals assigned female at birth. I was tested as a young child and found to not have it. Likely because I had a huge vocabulary for my age and appeared socially secure. (Both changed quickly as I continued to struggle through school and a world that wasn't built for my brain)
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Medical staff should be trained to slow down and explain what needs to be done and leave room for questions and accommodations. Hospitals are quite traumatizing for me and I think it wouldn't take a lot for them to be a whole lot better for folks with autism. Many autistic people can't drive, me included. We should have transportation available for those who can't drive themselves. (I cannot ride the bus alone because when I disassociate and hallucinate I become incapable of recognizing where I am in the world and how to keep myself safe in public.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I don't believe that COVID has had a significant effect on my autistic symptoms.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	I have found that the decreased social obligations due to COVID have allowed my nervous system a bit of a rest. Telehealth has been wonderful. Before I would opt to not address medical issues because hospitals and clinics are so overwhelming (bright lights, noise etc.)

in-person social interactions and obligations)	
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Name	Ben Yerys, Children's Hospital of Philadelphia
Demographic	Service provider, health provider, or educator; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	One of the most significant challenges is identifying speciality care providers who treat co-occurring physical health conditions. The lack of access to care is a major barrier across the lifespan, but felt the most in adulthood.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	-Access to trained providers, particularly med management for adults - Increasing awareness of co-occurring mental health in autism+ID populations—the potential for diagnostic overshadowing is large in this segment of the autism population -An absence of gold-standard treatments/supports that help autistic people manage co-occurring mental health conditions and also focus on positive mental health (e.g., decreasing ADHD symptoms does not automatically equate to a greater life satisfaction) -Insufficient characterization of how co-occurring mental health conditions impacts daily functioning - A patient told me "Don't treat my autism, treat my social anxiety" because his anxiety was a rate limiting step for friendships, self-advocacy, going to college -Depression and suicidal behavior is growing exponentially in the autism population without intellectual disability. Autistic people, particularly autistic women and nonbinary people, should be identified as a 'high risk' group for depression and suicidal behavior
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Research to establish gold standards for screening/diagnosing, treatment, and treatment outcomes related to co-occurring mental health. The greatest gap is screening and diagnosing co-occurring mental health conditions, because most clinicians use tools developed in non-autistic populations and assume they work the same for autistic people. On the whole, this is not true and may lead to over- or under-identification depending on the specific condition. The ability to screen/diagnose co-occurring mental and physical health conditions is compounded in those with autism+ID.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	-Equitable access to psychiatric medication, particularly for adults -Enhance autism services (Medicaid Waivers, vocational rehab) by providing support for mental health accommodations in addition to physical health accommodations -Identify opportunities to enhance research on self-advocacy/self-determination among autistic people of all ages, so they can advocate for their mental health needs.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic	

people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Berkeley Fisher
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep challenges, sensory issues.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	depression, anxiety, ADHD/concentration issues
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Research women with autism!!! Research the FULL spectrum!!! As a woman, I wasn't diagnosed until I was 26. I struggled my whole life with learning differently, feeling alone, sensory overload. I also think it would be EXTREMELY beneficial to conduct study on social impact on autism. It's a huge challenge being in a social situation/society that does not acknowledge sensory issues, or a society that thinks directness is rude. We are ostracized and it can impact our ability to work. Another good study could be autistic adults in jobs - corporate/desk jobs specifically and reasonable accommodations. Or autistics in post-secondary education. In grad school and corporate America, I was often given poor reviews because I couldn't grasp certain things. There needs to be a better understanding of what autism looks like and the limits we have.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage for the full ASD spectrum, providers (medical and mental health) get better training on ASD to combat overall ignorance, and some type of policy that builds on ADA to incorporate sensory accommodations
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services,	This is not applicable for every autistic. Not all of us struggled during the pandemic. Please don't focus the entire research on COVID-19 impacts on autistics. PLEASE. THERE ARE MORE IMPORTANT THINGS WE NEED YOU TO COVER AND UNDERSTAND.

increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Bern.W
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Dyspraxia Dysgraphia Sensory Processing Disorder Rejection Sensitivity Disorder Tourettes Syndrome Food allergies Asthma and sinusitis chronically Unable to make enough melatonin, serotonin Depression and high anxiety Demand avoidance
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety Demand avoidance ADHD Suicidal thoughts Chronic burnouts Frequent meltdowns Fluid adaptability that can look like regression during burnout Losing the ability to speak in high stress periods
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	ADHD Dyspraxia affects posture and balance Difficultly crossing the midline which affects reading and writing! Poor muscle tone in hands Auditory Processing Disorder Cerebral Visual Integration challenges the eyes can see but brain can't interpret Apraxia
What additional research is needed to help address co-occurring conditions for autistic people?	Please we need research so that medical professionals will understand Pathological Demand Avoidance is a disability under the autism profile. It is not a choice it is Pathological. It is very difficult for young Pda'ers who can not cope in schools and parents have no support without an official diagnosis. Include actual PDA identifying ppl to get the best info about it.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Chronic fatigue Weakened immune systems
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Remote working Flexible hours Homeschool support More contact via email

Name	Bernadette
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The motor and sensory issues affect one's ability to retain employment and the people they live with.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	All of the above issues affect employment and social interactions. Also, obsessive-compulsive disorder with disturbing thoughts makes it difficult to complete tasks.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	They have difficulty with executive functioning which means can't prioritize, plan, organize or be dependable.
What additional research is needed to help address co-occurring conditions for autistic people?	More community based or closer programs for individuals to find environments that are unique to one's needs. Supportive housing so they can develop confidence and feel responsible and productive for their own life.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Supportive housing in or near one's community and employers that will hire and support individuals with their specific issues.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Unemployment, excessive loneliness, and boredom is what they get up to every day.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	My son's life already had negative impacts before the pandemic, and nothing has improved for him and the stress on the family.

Name	Beth Greenspan
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	1. Getting the medical care I need including: support to and from doctors, hospitals for non-drivers, support at the medical facilities, and dealing with medical staff. Because I am not getting the treatment I need, my conditions are worsening as I age. I am sixty now and I have more ailments and less care. 2. Paying for care. As a person on a fixed income with Medicare and Medicaid, and they do not cover many things, such as many good quality dermatological care, dental care, progressive lens eyeglasses, etc. 3. Doctors who have no understanding of challenges for people on the autism spectrum. Doctors who will not work with my needs. And insurance companies, who do not care about actual human beings at all. For instance, I know I have sleep apnea. It was long ago witnessed by a relative. But my doctor says I must go to a sleep clinic, which I cannot do for so many autism-related reasons.. So I am not being treated for this disorder. 4. Self-care. I have so many challenges in this area, and I have no way to improve them. No adequate support, no money, and a whole long list of aversions, rituals, sensory issues, that prevent me from taking better care of myself.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The medications I take for my mental health issues cause extreme lethargy, and they are also damaging my organs due to long time use. Being caught in the psychiatric system for most of my life, when what I needed was care for my autism. Being overmedicated, and misdiagnosed for many decades. The psychiatric models of treatment do not work well for people on the autism spectrum, and in the long run, ended up doing more damage to my brain by constantly overloading it, and constantly focusing on goals that were unachievable for me.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	There has always been such a strong emphasis on being social, and communication skills. I have no desire or need to be social, even though I can communicate well. But it is entirely exhausting and overwhelming for me to be forced into being more like others.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Drastic improvements in care for low income people with autism, specifically with Medicaid. I am forced to follow the cookie-cutter rules of the autism waiver I receive in order to receive services. The waiver should be flexible to allow for the widely different kinds of people on the autism spectrum. And being able to find good quality doctors in all fields who also have knowledge or training of how to treat people with autism. How to adjust to our needs. Also, much better (reliable, consistent) accessibility for people who do not drive to get to these services. And finally, better wages for providers working with autistic individuals with low incomes.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	The pandemic has caused me to become even more home-bound than I was before. It has made being in public so much more challenging than it was before. Not only because of sensory issues, but because I am at high-risk for catching viruses, so it is easier and more comfortable to just stay home. And receiving healthcare has become more challenging, more challenging than it was before because I have less support due to staffing shortages and staff being out sick with viruses. As a low income disabled person with many needs, I have become even more low income due to rising prices, lack of resources, and lack of decent affordable housing in my community. Also, a

	widening gap between the "haves" and the "have-nots". And the technology gap has widened also.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Beth Malow, Vanderbilt University Medical Center
Demographic	Service provider, health provider, or educator; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep problems affect 50-80% of autistic people. They not only impact health, but also daytime behavior for the autistic individual and quality of life for the autistic individual and their family. It's a terrific opportunity to be able to impact daytime functioning through improvement in sleep and should be given full consideration in research.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Treatment trials, particularly of sleep problems, are critically important for autistic people.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Bethany Coop
Demographic	Service provider, health provider, or educator; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gastrointestinal issues can make it difficult for families to go out into public. Having a child with incontinence, reflux, and other health related conditions can cause embarrassing situations such as vomit on a restaurant table. We have sought out medical support for these issues and have been told that "its just something children with disabilities must learn to live with." My child has constant sores in his mouth. We never know from day to day if he will be able to keep food down. He has constant stomach aches from the symptoms of encopresis. These physical health conditions can also lead to mental health and behavioral issues.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My child suffers from social anxiety, depression (uncontrollable crying), aggressive and self-injurious behaviors. He has scars all of his body from things he has done to himself. We never know if we will be able to enjoy family events or if he is going to melt down as a result. When walking down the street things like a car or motorcycle can send him in a panic. He grew up at a time that ABA was not available and as he is "non-verbal" mental health providers couldn't help him either. Schools don't have the capacity for these kids.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My child is able to communicate only through his made up signs. He becomes frustrated and upset when other people don't seem to understand his needs. He has global delays which prevent him from being able to transition throughout the community without assistance, and we have to front load everything. He will never be without supports. I do honestly believe the science is out there which could have helped him become more independent. There just isn't enough providers, funding, or supports.
What additional research is needed to help address co-occurring conditions for autistic people?	EVERYTHING! We need more research into all the mental, physical, and developmental issues which face these children. I believe there are providers out there who have barely touched the edge of the iceberg. These children deserve to live happy, independent, safe lives just like everyone else. It is the lack of understanding and treatments available which hold them back.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	We need access to services which are in alignment with best practices rather than being controlled by other variables. Wait list and the silo's covering government service providers need to be eliminated. We need cooperative treatments, where therapist, physicians, social services and educators work together to address all of the needs of the child together. One contact to help families navigate all systems and work as the go between to improve provider relations.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	The most common mental health/behavioral issue I have noticed as a professional is social anxiety. People spent two years locked in their homes. For the first time in 15 year we are treating children who are unable to be outside of their homes and away from their families.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Providers are unable to attract quality service providers. And the providers they do have are more susceptible to colds and other illnesses. There is also an increase in mental health and capacity related issues among providers. This has led to long wait list, inconsistent application of therapy, and increased burnout.

Name	Betsy Pilon, Hope for HIE
Demographic	Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Etiology of autism is incredibly important. Neonatal hypoxic ischemic encephalopathy is an understudied etiology for autism, but we know that HIE increases the incidence of autism and autistic traits. In HIE, co-morbidities include a wide range of impact areas including cerebral palsy, epilepsy, autism, hearing and vision issues, learning and attention issues, GI, speech, swallowing and feeding, dysautonomia, and more.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	All of the referenced challenges exist with HIE as an etiology for autism.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	All of the referenced challenges exist with HIE as an etiology for autism.
What additional research is needed to help address co-occurring conditions for autistic people?	Etiological research is needed, and especially focusing on mild HIE cases that have a higher than average co-occurrence with autism.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Go back to known etiologies and educate families early on with the prevalence and services.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Isolation has been extremely difficult for patients and families, as well as exacerbated illness and impacts from COVID-19 itself.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	All of the above referenced.

Name	Betty Lehman, Lehman Disability Planning
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gastrointestinal disorders: especially in nonverbal; much suffering leading to self-injurious behaviors Hypotonia resulting in kyphosis: low tone is very common yet gets no attention to long term disabling outcomes
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Workplace anxiety is not sufficiently addressed or supported
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Some profoundly affected can speak but don't have abstract thinking - so they can't understand or communicate about information that is not within their lexicon and are misunderstood
What additional research is needed to help address co-occurring conditions for autistic people?	More research on methods to address public and workplace anxiety for those who employ or support people with IDD
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance and Medicaid often denies coverage for more extensive physical examinations for GI related disorders
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Those who don't understand why they need to protect themselves against spreading disease become anxious because they don't understand why their Day program closed, for example, or why they can't behave in ways previous to Covid precautions.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Some on the spectrum are germaphobes. Their anxiety and fears about germs have escalated and not come back down.

Name	Beverly Frost, parent, autism advocate
Demographic	Family member of an autistic individual; Service provider, health provider, or educator; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory and motor challenges, specific learning disabilities, despite high IQ inability to care for self, mental illnesses, depression.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The most significant mental illness problem is lack of understanding mental health professionals and the state to refuse mental health care for those with autism. Autistics may have one or more mental health conditions such as anxiety, depression, ADHD, aggressive or self injurious behavior, suicidality and as in my 58 YO son all of the above many due to lack of appropriate care.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication, LD, DD, IDD
What additional research is needed to help address co-occurring conditions for autistic people?	Vermont does nothing for adults with autism Yes, they spend huge sums of money but have no one in the AHS system with any knowledge, training or expertise in ASD. The most needy are placed in rural isolation with caretakers with no autism knowledge or training. Needed are comprehensive centers of autism excellence that treat the whole person using real professionals. I just about lost my son, now 58, had to find out of state services.and pay for them, then develop a program and implement it myself. He was able to become productive and work but had so much higher potential with better services.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Medicaid must not be the only requirement for developmental services. My son managed to have just a little too much money for developmental services. There was no way he could "lose" the income. Yet, his private income was just over Medicaid levels and certainly was not enough to provide for private services that didn't exist anyway. He could only get mental health care by providers who knew nothing about autism. A comprehensive approach was needed. Vermont and especially my rural area has no qualified autism experts in DD care or mental health.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Much less care and much more isolation.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school,	I eruptions in service care and isolation.

increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Beyza
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	when you don't have enough information on autism, or cannot get help from others there is really no way of escaping depression & anxiety. I am gonna continue in turkish. doktorlar çoğunlukla otizmli olduğumdan şüphe ettikleri için açıkça otizm semptomlarımın görmezden gelinmesinden kaynaklı sorunlarıma yanlış tanı koyabiliyorlar. mesela otizmli olduğum için beni mutlu eden şeylerden bahsetmek beni çok heyecanlandırırsa da sırf bu yüzden manik olduğumu sanan doktorlar vardı. (özel ilgi alanı vs.) [Translation: Because doctors often suspect that I have autism, they can misdiagnose my problems, which are clearly caused by ignoring my autism symptoms. For example, although I was very excited to talk about the things that made me happy because I have autism, there were doctors who thought I was manic just because of that. (special interest etc.)]
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	iletişim farklılığım yüzünden insanlarla kolay kolay arkadaş olamıyorum çünkü beni yanlış anlamaya çok meyilliler. bu durum beni çok üzüyor ve bu yüzden sıklıkla depresif hissediyorum. [Translation: Because of my communication differences, I cannot easily become friends with people because they tend to misunderstand me. This situation makes me very sad and I often feel depressed because of it.]
What additional research is needed to help address co-occurring conditions for autistic people?	otizm, özellikle kadınlarda bipolar bozukluk veya BPD gibi kişilik bozukluklarıyla çok karıştırılıyor. bu çok büyük bir haksızlık ve beni AŞIRI rahatsız ediyor!!! [Translation: Autism is often confused with personality disorders such as bipolar disorder or BPD, especially in women. This is so unfair and makes me EXTREMELY uncomfortable!!!]
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	insanlarla fazla iletişim halinde olmak zorunda olmamak rahatlatıcıydı. maske taktığım için yargılanmıyordum çünkü herkes takıyordu. (daha önce yüzümün görünmemesini istediğim için maske takmışım ve bu yüzden zorbalığa uğradım) [Translation: It was a relief not to have to interact with people so much. I wasn't judged for wearing a mask because everyone was wearing one. (I wore a mask before because I didn't want my face to be seen and I was bullied for it)]

in-person social interactions and obligations)	
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Name	BJohnson
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The biggest challenge is a lack of knowledge and screening of some of the co-occurring conditions of autism. Namely, Ehlers Danlos Syndrome- Hypermobility Type is a co-occurring condition to autism, and, although my family member had loose joints, frequent subluxes, loose, stretchy skin, and extreme hypermobility, no one ever mentioned it until they had multiple dislocations. Screening would have gotten us PT interventions sooner. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7711487/ The same can be said for a lack of both knowledge and screening of POTS (postural orthostatic tachycardia syndrome). https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8756818/ These common co-existing conditions can be rare in the general population, but are not as rare in the autistic population and therefore there should be screening and education. For our family hEDS has profoundly impacted our lives and we are constantly educating physicians who are unfamiliar with it and/or best practices for treatment.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The female presentation of autism often looks more like generalized anxiety disorder in the earlier years. This may be due to extreme masking. PDA (pathological demand avoidance) is a subtype of autism and is, by far, the most challenging, and least understood condition in our experience. Understanding PDA as a nervous system disability is crucial when working with Autistic patients who present with a PDA profile.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	For us, verbal processing delays present a significant challenge and show up at school, despite high cognitive abilities.
What additional research is needed to help address co-occurring conditions for autistic people?	By far, Pathological Demand Avoidance (PDA) is not widely understood as a subtype of autism and is often thought of as a character flaw or bad parenting. PDA is the number one challenge in our family and needs so much more research on amygdala response. Even in autism circles it is not widely understood or researched.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Better screening for co-occurring conditions, and then better multidisciplinary support among specialists treating patients with several co-occurring conditions. It is hard to go from specialist to specialist when they are not communicating with each other.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal	Some autistic students thrive in remote schooling when in person school was hard to access due to social and sensory challenges. COVID-19 actually made school MORE accessible for a subset of autistic students. This should be a lesson not lost moving forward. Remote schooling should be a viable and equitable option. Remote therapy has created more options for families to

changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	access mental health services as well, giving families much needed time back into their day that is not spent driving family members to appts.
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Name	Blair
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Pathological Demand Avoidance, or Pervasive Drive for Autonomy (PDA) Somatoform disorder Non epileptic Seizure disorder
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Pathological Demand Avoidance, or Pervasive Drive for Autonomy (PDA) Somatoform disorder Anxiety disorder
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Pathological Demand Avoidance, or Pervasive Drive for Autonomy (PDA)
What additional research is needed to help address co-occurring conditions for autistic people?	Pathological Demand Avoidance
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Accessible social programs, education accomodation, in home support,
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Increased anxiety and nervous system dysfunction
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Brandi Johnson
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	In my 10 year old it would be his sleeping patterns. He is able to stay up for days
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Comprehension issues triggers behaviors and causes severe meltdowns
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Comprehension is always a top concern because it hinders him in learning settings also communication and staying on topic holds my 10 year old son back
What additional research is needed to help address co-occurring conditions for autistic people?	School grade kid and parents need more support when dealing with schools "IEP"
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Services like ABA need to have real life environments centers plus the in home services More programs like IHSS PROTECTED CARE services so parents with autistic kids can provide care 24/7 without the stress of finding someone to watch/care for these certain kiddos
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The online schooling was a big set back. Learning and social skills suffers a lot

Name	Brandy Joy Leigh
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Finding providers who are trained/specialise and are sensitive to providing comprehensive care across disciplines.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Isolation, lack of opportunities to participate in community on their terms and sensitive to their needs
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The systemic attitudes that view autism as a pathology. We need services and providers who do not pathologize behaviors and are more accepting.
What additional research is needed to help address co-occurring conditions for autistic people?	Research the behaviors/attitudes of allistic people and how they negatively affect those with autism
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	All of the above
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Breana Turic
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbances impact me on a daily basis. I cannot fall asleep like a neurotypical person, sometimes my brain will not stop working for 2-3 hours after laying in bed. Other times I will wake up to use the bathroom and then be unable to fall back asleep for the remainder of the night. These disturbances lower my threshold to adapt to everyday environmental stimuli and social situations making it easier for me to get overstimulated or have a meltdown during situations I may have been able to adapt to if I had proper sleep. For my autistic daughter, motor challenges are one of the issues that impacts her attempts to interact with other children the most as she is unable to play sports, run, do kart-wheels, etc. like the other children. She still cannot grasp riding a bike while all of her peers can. Being unable to engage in many activities that her peers are doing makes the already difficult process of making friends even more challenging for her.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My daughter and I both have comorbid diagnosis' of autism with ADHD and while the ADHD may hide many of our autistic traits, it also causes some of the biggest mental health hurdles for us both. ADHD paralysis makes completing daily tasks such as hygiene, chores, or classwork a huge struggle. We both have to increase environmental stimulation to optimal levels in order to achieve normal productivity, while at the same time battling the overstimulation this can cause at the same time. We both also present in a pathological demand avoidance profile of autism meaning that our autism manifests in extreme anxiety oftentimes by something as simple as the thought of being perceived by others which makes tasks such as running errands a very stressful event for our bodies.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Research on the effects of ADHD medication for people with AuDHD is my biggest request! Many ADHD medications do not work the same for people with autism and ADHD so researching which uptake inhibitors are affected by medications for us is extremely needed at this point.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I would love to see the United States catch up with the UK for financial disability assistance for people with autism. The state of the economy necessitates a two-income household to be able to meet middle class living expenses so couples with one or more partners on the autism spectrum unable to meet the typical eight hour per day, five day per week, work schedule are under extreme financial pressure. Most workplaces are a sensory and social stimulatory disaster for people with autism leaving us a choice between masking with extreme mental and physical health consequences, or choosing alternative work from home options which are not financially stable. We need more financial assistance from our government.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	In many ways COVID-19 improved mental health for people with autism as it offered more work from home options as well as contactless services and delivery options reducing social pressures. If these options could remain open to those with disabilities I believe it would greatly improve the mental health of the autism population sustainably. I have a reduced immune system correlating with my disability so as far as physical conditions go,

	<p>COVID-19 reduced my body's already lowered ability to fight upper respiratory illnesses and I often get sinus infections, ear infections, walking pneumonia, and other related issues due to the constant re-occurring upper respiratory infections.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>As I mentioned previously, the societal decrease in social pressures and demands has greatly improved my mental health and the mental health of all my peers on the autism spectrum. We are grateful for remote work and school options and reduced social obligations. If these options could be continually offered for those with disabilities I believe it would be a huge step in aiding mental health for those with autism spectrum disorder.</p>

Name	Brian
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Physical health - from pain to GI, all of it.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Suicide isn't an issue until it's followed thru on. Support should be able to help prior to that becoming an issue.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Learning disabilities with language disorders. I'm already stuck in my own head most of the time. Add to it the issue with learning/and language and it's even worse. You say and think one thing yet the wrong thing gets output.
What additional research is needed to help address co-occurring conditions for autistic people?	A way to read thoughts to translate into text or speech.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Stop forgetting that we grow up! When we turn 18, or 21, that doesn't mean we are magical turn into normal people. Stuff needs better access to adults too.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Unfortunately it made stuff better. Things were more obtainable from stores, and messaging drs and even the delivery stuff. It is horrible that a pandemic had to happen for this stuff but it made stuff more easier to access.

Name	Brian Foti, Non-Speaking Autism Presenter
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The belief that we are not capable of autonomy and independence. We are more capable than we are given credit for and we can and want to be included in decisions that affect our life. I would like more emphasis on how apraxia interplays with autism and how we can work in partnership to develop solutions to this non-talked about challenge among me and my friends. The stress of being "judged" and labeled causes so much stress which then causes sleep disturbances and other physical struggles
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I am very impulsive and I feel the professionals may believe that I can control this through verbal prompts. This is not true. I need more concrete instructions on how to stop - Not things like: "We don't touch our friends." OR "Use your quiet voice." These terms are insulting - I really want to be able to control my reactions.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I can communicate through a spelling device YET I am not believed and that is horrible. I worked so hard to learn how to spell my thought and my determination is dismissed by those that have never met me or had a conversation with me. Spelling IS a form of communication and they way I can have control in my life and live safely.
What additional research is needed to help address co-occurring conditions for autistic people?	How Motor Challenges affect people with Autism and Down Syndrome. We are important members of the community and many of us want to be tax payers rather than tax takers.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Believe in us and allow our voices to be the driving voice in systemic policy. Many Autistics are misunderstood and until folks that develop policy accept us as content experts - the system will remain unsafe for all of us. We need thriving and accommodations that many general community based environments are lacking - such as more family bathrooms. Do all events really need to have the volume at a unsafe decibel? My friends and me want to be included - but we have sensory differences that can be addressed. For instance - an Autism Awareness event at a sporting event that demonstrated the sensory needs of Autistics.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	We are tribal by nature and need to be social (at some level) to thrive and have our nervous system engaged in a positive way. Taking all social interaction away is much more harmful than the health system accounted for. There is physical and mental health - they live together not separate. Taking our physical interactions away had a grave effect on our physical health. The emphasis on physical safety became the ONLY focus and there was not a solution for how it tore down our mental health. I, personally, now live in fight/flight.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	Socialization is so so so important. Isolation causes long lasting mental anguish because we did not have choice - government made choices for us and shamed those that chose not to have vaccinations. Covid shattered by trust in people. Please note - I am a non-speaking Autistic and answered these questions through Spelling on a letterboard. Please, Please listen to us - we have the lived experiences that the decision maker do not have. I struggle to speak - but my thinking and understanding is fulling functional.

in-person social interactions and obligations)	
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Name	Brianna Kerchner
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	There are so many diet restrictions for my son's gastrointestinal issues. Sensory Processing controls his life. He has to wear headphones and have a chew anywhere we go. The public isn't educated enough on these issues.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety & ADHD are huge struggles in school settings. These kids are supposed to act like "normal" functioning. But they aren't and don't function as such. School in general causes so much anxiety. We need to go back to a more natural learning setting. Kids aren't meant to sit in desks all day.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My son is still labeled non verbal. However still has some language. It is hard to keep up such an intensive therapy schedule. He is far behind most of his peers. There doesn't seem to be enough government or state assistance.
What additional research is needed to help address co-occurring conditions for autistic people?	This is a funny question. There is no single person/doctor/place to get all of this information. It takes years of research and different specialists/doctors before you feel like you have even simple answers. There needs to be MASS studies of autism and correlation and better treatments. My child has spent all 9 of his childhood years in therapies that show just a slight growth every year.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	A program like California. Where it helps parents with the costs to give families more access to more/different types of therapies. To give your child the support they need we have to be a 1 adult working household. So the other parent can stay home and make sure our child gets to all of his therapies. And fights insurance on a daily basis for coverage for what a doctor has already deemed necessary. Also making it to where insurance can't deny treatments that a doctor has deemed medically necessary.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Absolutely, they lost out on so much therapy and socialization. Children that are already years behind their peers are now even farther behind their peers. There was nobody looking out for our kids during the pandemic. Our kids could not sit in front of a computer for remote learning. So he was just held back a year. Also sensory wise excluded my kid from the public in many occasions for not being able to tolerate a mask.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Disrupting his school was the biggest. He was pushed back a year because he couldn't sit in front of a computer for remote learning. There was many many disruptions in therapies due to outbreaks. And his regression a consequence of that.

Name	Brichard Brummel
Demographic	Autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>Some of the most significant ones in my experience have been structural disorders (I have genu valgum "knock knees", medial plica "excessive inner knee tissue", scoliosis, anisomelia "short leg syndrome") Although they've been more minor in treatment, living in society where the symptoms are not as accepted has been very difficult, time consuming, and costly. I've had to see 4 orthopedists before being properly diagnosed for many of my conditions and have been put through physical therapy to no affect to be able to get insurance coverage for my specialist visits and treatments. Being low-income, self-supporting, and a full-time student, this is especially challenging. I would say almost worse than dealing with the conditions themselves. However, the conditions do make it especially hard to work entry-level jobs as often I don't receive physical accommodations and have to do physically intensive labor for several hours, making these co-occurring conditions worse. With sensory issues, I've been able to manage, but as for many of my friends with autism, I know that they have been discriminated against in the workplace, such as being fired or denied a job for having sensory/motor challenges, even when the job was not physically demanding.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>I have co-occurring ADHD and generalized anxiety disorder. With this, it has been hard to learn to self-regulate emotions and express them properly and in healthy ways. As a child, I would have very explosive swings of anger and was not able to learn coping strategies which devolved into me hitting myself, others, and objects out of anger and having emotional meltdowns. In adulthood, although I don't hit things anymore, I still have explosive emotions (anger and otherwise) related to ADHD and find it very hard to process and express them through words or helpful coping strategies and often breakdown, cry, withdraw from social situations, swing my limbs, engage in SIBs (self-injuring behaviors, such as hitting my thighs or gripping my fists very tight). With this, because the emotions are so big and with ADHD I have a shorter-term memory, it is very hard for me to express these emotions even after the fact. I have this as well with positive emotions, including engaging in SIBs. Outside of emotions as well, I'm very scatter brained but can sometimes focus in on the most minute things for hours or days on end, neglecting my basic necessities. I have a interest-based focus and things that don't interest me or serve a priority are very exhausting and taxing to do. It is very hard to get "invested" into something otherwise without instant gratification involved.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>In school, many teachers didn't understand my conditions to be able to properly accommodate me, and/or ignored my conditions all together. Although college is better than public K-12 was, I still face discrimination due to needing accommodations for these and have been denied them, against ADA. As I did well in K-12 generally, I was never granted a 504/IEP either despite showing great struggle at home with schoolwork. The biggest roadblock is the mental struggle of having to be without the accommodations because it is so difficult that I often break down emotionally from mental exhaustion. Outside of education, navigating social situations is difficult as I often get misunderstood for being rude because of my tone. Or being undermined for having "childlike" and "impulsive" traits related to Autism/ADHD. I have been socially exiled in my youth and adult life because of my neurodiverse behaviors. It is often hard for me to make eye contact, sit still, not bite my lips or fidget which give the impressions that I could be impatient, afraid, or even implying something</p>

	<p>sexual which is not the case. I also find it hard to navigate systems and paperwork due to the confusing nature of the setup but also due to my struggle with pattern literacy. I also struggle with somewhat of a speech disorder where I will mix consonants and often trip over my words, making it hard to say things clearly the first time and it taking it awhile for me to sound things out.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>I think it would be helpful to conduct studies by those who have similar conditions and on a variety of demographics. Much of the more significant studies on autism were done by White neurotypical (not having mental conditions) researchers on young White boys, when symptoms of autism and its co-occurring conditions appear differently in other demographics. Especially, without White neurotypical bias. This is especially significant as many girls, people of color, and adults go underdiagnosed and those who do receive treatment are treated with the intent to "fix" and not with the intent to support positive livelihood.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>All of the examples listed would be great. I wish there were more autistic-made resources available though and I could see more autistic providers as I feel they have a greater understanding of my condition, and I will have to explain less to be understood. Overall, however, treatment for autism is very VERY inaccessible, very costly, and incredibly skewed by neurotypical bias leading to misdiagnosis anyway. On top of those as well, there is an immense amount of stigmatization and I've recommended that many those suspecting they have autism NOT get tested due to the discrimination they can face (medical, disability in workforce, deportation from certain countries, etc.)</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>I feel COVID-19 has only made it harder for autistic people to get treatment and care for co-occurring conditions. As from my perspective, prices have raised for insurance and treatment, and appointment availability has been horrendous making care much more inaccessible than it already was. It has never been worse, but it was already terrible before.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>I feel it has made people more aware of their autistic behaviors and existence and really united the community. Especially in their co-occurring conditions. New research has been able to come out due to people self-isolating, allowing them to "unmask" (not hide autistic symptoms) and being more aware of their condition(s). At the same time, I feel it has made people painfully aware of how much our society does a disservice to people with autism and its related conditions. In general, there has been more individual improvement, but more mental exhaustion from society at large.</p>

Name	Brittany
Demographic	Autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The most significant challenge is expressing those conditions in a way practitioners hear, understand, and will follow through with. Because people with autism, including myself, sometimes express symptoms in way others dont understand - theyre often over-looked or minimized. Something my clients and I have heard a lot it "Oh, thats common for Autism" blaming whatever ailment on having ASD, with no desire to investigate.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The most significant challenge is expressing those conditions in a way practitioners hear, understand, and will follow through with. Because people with autism, including myself, sometimes express symptoms in way others dont understand - theyre often over-looked or minimized.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Interventions are generalized and applied indiscriminently across the spectrum. There is no distinguishing of support levels needed, or even change in modality.
What additional research is needed to help address co-occurring conditions for autistic people?	Adults need a greater representation in Autism research as well as assessing HCP's for their understanding in Adults with Autism experiencing Mental Health challenges.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Have MH interventions be 'evidence-based' for autism, not generalized to the majority and try to force autistics in that box.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Health services across the board are more difficult, many places lost funding, resources are strained or completely gone. This is a mess.

Name	Brittany
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The most significant challenge is medical providers not having an understanding that everything is linked (I.e POTS and EDS impacts all systems and are not properly diagnosed nearly enough) misdiagnosis and inappropriate treatment plans from GPs who treat every system separately (GI, Neuro, musculoskeletal, Gynecological, etc.)
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	That because someone is Autistic it's assumed they should also have mental health challenges (I.e anxiety). Use of treatment plans that don't work for Autistic brains (CBT). Not recognizing the difference between Autistic Burnout and depression/anxiety disorders as both have very difficult approaches to care.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Outdated "supports" in school systems. Not being provided with appropriate communication devices/techniques early on. Believing that complex responses to unmet needs or overstepped boundaries are "behaviours" and creating cruel "behaviour support plans". Having higher expectations of how an Autistic person should act/react written into "treatment plans" than would be expected of anyone else.
What additional research is needed to help address co-occurring conditions for autistic people?	Any research that provides explanation that a co-occurring conditions is what it is and a "behaviour" is actually a stress or trauma response rather than Autism itself. This will lead the way in ridding the world of cruel and inhumane "behavior therapy" still seen as the normal practice today. It's scary how the general public sees these (I.e ABA, PBS) and think that this is a reasonable way to treat a developing child.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Literally everything. Rid all coverage/access to behavioural therapy and place that into accessibility to actual needed supports like OT/SLP for apraxia. Access to proper Autism education for caregivers (parents, guardians, families) provided BY Autistic sources to better understand. Mandatory upgraded education to any medical practitioner who support Autistic individuals.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Covid has actually improved a lot of Autistic's mental health because we as a society have learnt that work from home and hybrid options are actually very do-able. I'm not sure if it's from Covid (have had twice) or age but my POTS symptoms and shortness of breath have worsened the past few years. I have also been struggling more with swallowing (oropharyngeal dysphagia & aerophagia)
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	As per previous comment, a positive has been the implementation of virtual/remote options for appointments, school, and work. Not having the obligation to attend uncomfortable functions was also a benefit. I feel more Autistic people have been able to set better boundaries since the pandemic.

in-person social interactions and obligations)	
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Name	Brittany Daniels
Demographic	None Indicated
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	What about getting needed OT (occupational therapy), PT (physical therapy) and/or needed speech therapy covered under health insurance including Medicaid for autistic adults 21 years old and older?
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Brittany Shidham
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbances - I can't figure out how to get my kids the sleep their bodies need. They just don't sleep well.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety - many people with ASD have high levels of anxiety which can be easier to notice than ASD. I showed signs of OCD from preschool age and was treated for that until my mid-30s when we realized I'm autistic. The ASD was missed. I noticed a similar trend happening with my kids but was able to help them pinpoint the ASD diagnosis to get them the best help for their self confidence.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Pathological Demand Avoidance (PDA) and other potential undiscovered tangential disorders - The UK and Australia have a robust understanding of PDA that's missing in the US. PDA is similar to ASD but has nuisances that leave these children and adults with misdiagnoses and few tools for support. I imagine there are other similar disorders that don't have a name - again leaving children, adults, and families without support. Strategies for ASD support can make PDA more challenging instead of helping.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage for mental health support More availability of in-home services like speech and occupational therapies for children.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Brixton Moss
Demographic	Autistic individual; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I have POTS (postural orthostatic tachycardia syndrome), and I have noticed that many other autistic people do as well. I have had lifelong insomnia issues, a lot of problems with digestion when I was a child. I have always been extremely sensitive overall. I can feel everything in my body way too intensely all the time. I almost never feel “good”, I’m always uncomfortable and feeling something too much. I have a lot of sensory processing issues. I have to wear noise-cancelling headphones and/or earplugs (Loop earplugs, specifically) when I’m in public, especially places like grocery stores with a lot of ambient noise. I also have sensory seeking behaviors and stim, which helps the stress of sensory overload/“bad” sensory input. I’m not diagnosed with these, but EDS (Ehlers-Danlos syndrome) and MCAS (mast cell activation syndrome) are also extremely common.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	There are few autistic people that are not living with a tremendous amount of trauma, because society refuses to accept and accommodate us as we are. We are also more prone to getting into abusive relationships and situations, which can also lead to trauma. I have C-PTSD, ADHD, MDD, PMDD, and various varieties of anxiety. I have tried antidepressants and ketamine infusions for my depression, but it’s still there. I’ve been in therapy for nearly a decade. I continue to find this world very hard to live in.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	We need to acknowledge the connection between autism, POTS, EDS, and MCAS. There is an undeniable overlap, especially in autistic women and AFAB people, who have been very misunderstood/ignored.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I hate that everything requires phone calls. I cannot make phone calls to access healthcare. I put this task on my partner, which I shouldn’t have to do. I know this is common among autistic people, and not just me. Services should be more accessible through apps like MyChart, texting, email, etc. Health care providers should be more aware of our comorbidities, and test for them once one thing is discovered. Most people that have the conditions I mentioned find out on their own, slowly realizing they have multiple conditions, when their doctors completely miss the signs.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I appreciate that we have more alternatives to interacting with people and going into stores. I like that we can have most things delivered, groceries brought out to our cars without having to shop for ourselves, and that work from home and online education is more common now. I don’t like going out in public for sensory reasons, and thanks to all of these things, I am finally feeling less burnt out.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	I mentioned that stuff in the previous question. I feel that the increase in remote services has been extremely beneficial for me. I dread the idea of things “going back to normal”.

in-person social interactions and obligations)	
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Name	Brook, No Pressure PDA
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Demand avoidance affects all autistic people, especially when co-occurring conditions accumulate stress. Pathological Demand Avoidance especially needs more research to help clinicians differentiate between extreme demand avoidance that occurs during burnout and the unique neurotype of PDA.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Lack of effective treatment, misunderstanding, judgment, isolation from community, parental guilt and blame when typical treatment plans don't "work"
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The lack of research into the different styles of demand avoidances cause confusion and stumbling blocks toward finding emotional regulation.
What additional research is needed to help address co-occurring conditions for autistic people?	As I've stated, clear research that explores what the PDA community has been saying for years: there are different kinds of demand avoidances, with different challenges. We need dollars spent exploring this as families are suffering.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage, access to disability supports, awareness in the cumulative affects in burnout and functioning, how co-occurring conditions can mask unique struggles.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I do appreciate that it is more socially acceptable to school from home now. Families are seeing the benefit of being able to meet their kids unique needs at home with less stigma.

Name	Bryanna
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Underdeveloped fine motor skills Food sensitivities Sensory processing disorder Comorbidities such as Adhd or Ocd Insomnia Gluten intolerance Lactose intolerance
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety Adhd Difficulty handling stress Conflicting symptoms Depression Difficulties finding meds that helps manage symptoms
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Stutter and other speech impediments Developmental delay in age (5 to 7 years behind)
What additional research is needed to help address co-occurring conditions for autistic people?	More therapists and psychiatrists with more knowledge and personal experiences associated with autism More autism friendly jobs and career opportunities
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Life coaches and supported/assisted living resources and programs
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Bryanna, self
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I have Migraines, Dysautonomia, Postural tachycardia syndrome, Attention-deficit/hyperactivity disorder, Pervasive Developmental Disorder – Not Otherwise Specified, Attention Deficit Disorder, Depression, generalized anxiety disorder, level one autism, Asperger's syndrome, Obsessive-compulsive disorder, Post traumatic stress disorder, panic disorder, Rejection sensitive Dysphoria, Unspecified Mood disorder, Alexithymia, Oppositional defiant disorder, disruptive mood dysregulation disorder, Pathological Demand Avoidance, insomnia, parasomnia, dream-reality confusion, Body Dysmorphia, Polycystic ovarian syndrome, tachycardia, Pseudobulbar Affect, Premenstrual dysphoric disorder, Premenstrual syndrome, dyspraxia, sensory processing disorder, Avoidant/restrictive food intake disorder, pill dysphagia, Chronic sinus infections, Allergic rhinitis, Orthostatic hypotension, Metabolic syndrome, Insulin resistance, Mixed hyperlipidemia
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	being unable to hold down a job, being unable maintain relationships or friendships between peers or adults, suicidality, only one in four autistic people graduate from college.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	severe anxiety and self esteem issues, as well as depression eating disorders, and suicidal tendencies
What additional research is needed to help address co-occurring conditions for autistic people?	1.) there is no medication specifically for autism. 2.) autistics are more likely to be unable to finish high school. 3.) private schools discriminate and kick students out for having disabilities 4.) 75% of autistics do not finish college 5.) the mental stigma of the label 6.) autism speaks is a hate group 7.) more accessible public spaces 8.) sensory overload solutions
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	special education degrees being required to work with students with special needs, more insurance coverage, doctors have no idea what it means to be autistic, other forms of taking medication besides pill form or liquid form(for example Tylenol used to have a dissolvable strip that you could put under your tongue that was grape flavored), therapy being covered under medicare and medicaid, special education classes being required to be a doctor.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	The Covid-19 pandemic has increased my anxiety to being around people being sick and has given me increased Dysautonomia, Tachycardia, and Postural tachycardia syndrome
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	increased remote work and use of Telehealth services have been magnificent with helping me with my ability to work however after 2022 those options started to disappear from the realm of possibility

in-person social interactions and obligations)	
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Name	Caesar Augustus, Autist Advocate
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator; Researcher; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Bpd, ocd, cyclothimic d, traits, adhd impulsiveness and dysphoric dysregulation. Al dough I still live in a terrifying day to day due to sensory issues and social phobia my greatest challenge from co-occurring conditions is in this lifelong social disabling, which bans me from any kind of co-op on every project I've ever started (as an adhd they mostly never see conclusion 😞 anyway)
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	We tend to live in permanent depression, anxiety, somatic life threatening disorder, RAGE towards people (for being ever neuro typical noisy indifferent non solidaire people) to suicidality on later ages; (have in my skin a couple of this “;” 😞) From desperation and tiredness of ever fighting for everything, from communication barrier to facial and body language barrier and cero interest sharing to anybody nor cold-chat (cheap-chat) able Not counting spoon lacking from those “social interactions” and/or sensory issues, and/or internal ableism tensions
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Talking from my own exp... my developmental and intellectual disabilities are not as disabling or serious as the Autist ever enemy of life, communication, from the dullest, smallest of duties to the important business, we always lose chances, my personal score of communication success in sadly low and literally lost every important chance on the past and not seems to get any better or me any younger, just by that double empathy very Real barrier.
What additional research is needed to help address co-occurring conditions for autistic people?	We need to know about a lot of things of course, NOT for autism screening for eugenic birth control like some places are doing today 😞 but for making accessible in real world to all of us the gift of brain functioning at functional rates, adhd meds are life changing and those must be accessible as a human right, so price must be accessible or state financiated, meds state occultation due to stimulant drug addict craving is leaving the really needy serious user at despair. Cannabis thc and cbd, both and other terpenes must be in study for adhd autistics in serious big budget studies on functional-mri at during, after and before, measuring basal and on duty mind states, we must have more information, again, due to drug addict craving we as socially disabled people are left at despair.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	We need trauma treatment as first approach on public services which is long lasting, multidisciplinary and performed by a team, on that matter state doesn't pay for any longer than a couple weeks, like giving aspirins and two days license to shellshocked soldiers on the sixties all over again. Not saying fast therapy, mindfulness or cbt is not useful, it's not useful on us, experts already on ever dissociating from overwhelming environments and body callings, we don't need to reconnect to the environment but our own body and our subconscious crying for help through self awareness and trauma reconnection, say long term therapy from neurodiverse trauma experts, only ones with truth empathy.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Among already spoken health issues are the bodily ones, like the very common concurring of iron deficit syndrome for life, the autistic celiac disease which includes serious issues with dairy, egg calcium causing internal non visible chronic disease like permeable intestine, psoriasis and adult acne, migraines, mood disorders, chronic articulation pain (very similar to arthritis), all of this debilitate the person to points of break where an

	<p>opportunistic infection like a respiratory one like covid takes a high life threatening toll on us, vaccinated or not.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>As an outside ever alienated citizen, tele socialising and tele schooling, even tele working and self tele employing is the VERY BEST thing ever to happen as a reasonable adjustment we (I) needed from 20 years ago. I will ever keep saying Covid lock down and all post keep safe protocols saved my life.</p>

Name	Caitlin
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Doctors are unfamiliar with co-occurring disorders and can be dismissive of autistic individuals self reported symptoms. Our family struggles with gastrointestinal issues which impact our ability to participate in the community. SLEEP IS HUGE. It impacts every facet of life. It is so hard for us to get good sleep. I have spent HOURS trying to find a doctor to listen about my 4yo lack of sleep. No one wants to prescribe anything due to her age. So our family is left not sleeping. This means missed work and school and well as impacts our general health.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety is huge in our household. It impacts us all significantly. It interrupts sleep, nutrition, and bathroom usage. Our daughter fits the profile of pathological demand avoidance. Our day is full of anxiety. It runs our lives. Everything from putting on clothing, eating, using the bathroom, sleep, taking medicine, getting in the car—EVERYTHING in our life revolves around our 4yo anxiety. We need help. We are drowning. No health professionals take us seriously. They are dismissive and lack understanding. Help us please.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Pathological demand avoidance needs more attention in the US. We are drowning as parents. Health professionals and educators do not take our needs seriously. They lack understanding and often empathy for our situation. Our child appears “normal” outside of the home. She comes home and falls to pieces. She doesn’t sleep. She won’t use the bathroom. She cannot leave our side. She is suffering. We are suffering. Help us, please.
What additional research is needed to help address co-occurring conditions for autistic people?	Pathological demand avoidance needs attention in the United States.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	The costs of services for my children are outrageous. We hit our out of pocket maximum very quickly each year. There are waiting lists for everything including financial support. We are drowning. Our children deserve better. There are no services for adults. There are waves of parents figuring out that they are autistic as they learn more about their children. There should be far more options to support us, though life and parenthood. We need more occupational therapists familiar with autism in adults. We need more support groups. We need more community support.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Autistic children and adults are at a far greater risk for developing long covid. More research is needed to learn how this will present and how it could impact someone through their life. More information is needed and resources are needed to stop the spread of Covid in ABA centers. Surgical masks aren’t enough.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Calen
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I struggle with fine motor skills and I am easily overwhelmed by loud noises and bright lights
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have always struggled with anxiety, depression, self harm, and multiple suicide attempts throughout my life
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I don't have any other co occurring disabilities
What additional research is needed to help address co-occurring conditions for autistic people?	autistics and suicidality, causes + solutions
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	free healthcare for everyone, increased disability awareness + acceptance, research + policy led by people with autism and supported by neurotypical people
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	expanded access for telehealth + remote work, contactless delivery

Name	Cali Hayes
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Connective tissue disorders. Gastrointestinal problems.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	PDA. ADHD.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication struggles. Emotional regulation challenges. Sensory issues.
What additional research is needed to help address co-occurring conditions for autistic people?	I would love to see more research on PDA (Pathological Demand Avoidance). There is not enough official information out there.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Better education and training for professionals who work with autistic people. Broader insurance coverage to access diagnosis, and more professionals able to diagnose. Currently very few places accept insurance for evaluations and many have them have multi-year wait-lists.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Positive: Increased accessibility of communication, work, and service options. Increase in remote work, online school, online communication, and alternative school offerings. Negative: Significantly longer waits for medical and mental health support. Much harder to find and access care.

Name	Cali, Worker/Student
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	a big problem i have is that autistic people experience pain and sensory stuff differently than other people and i've never met a doctor informed in how to treat me as an autistic person. for example: i had very rare chronic appendicitis and they thought i was dehydrated for 5 years when i was experiencing what some people call the worst pain of their life
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	i've attempted suicide 3 times. 16 having emotional outbursts and migraines from overstimulation. it started affecting my grades. parents weren't happy. When I stopped being successful they weren't so forgiving. I felt shame in losing my one good quality. The more I tried to improve my grades the worse i got. distress led me to attempt suicide during a meltdown. 18. was being bullied. I was away from my abusive family but everyone around me still hated me. & i tht they should. i had to be a bad person if so many people agreed. No money for therapy, so i decided to do the world a favor My last attempt was this year. been in therapy regularly. was diagnosed with autism. I had developed an understanding of myself and challenged my guilt and shame. But new problems presented. I had to confront that autism means being disabled. The future that was promised to the able-bodied is not promised to me. I am unable to work like other people w/out relapsing into painful meltdowns and self harm. So I have to work less. When I work less I cannot afford my rent or medicine. When I work more my mental health declines rapidly towards the suicidality that i've worked so hard to move past. I didn't want to live my whole life like this, always exhausted, always in pain, fearing homelessness, fearing starvation. nobody to help me. i'm scared. death had to be kinder to an autistic girl than life. Came close this time. In the past 2 years i've lost 4 people to suicide. they were all autistic.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Autism in adult, autism in women, autism under capitalism. autism in the 40 hr work week, autistic disease v allistic.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	1. govt paid for therapy 2. real labor rights protections for autistic people 3. improvement of currently disability aid 4. Required in-school education about autism 5. Requiring autism informed and educated medical care.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	A bad one. covid has seen massive skill regression which has caused higher autistic unemployment and lower graduation rates
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on	

physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Callista Markham
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	In my experience the most challenging co-occurrences are with Ehlers Danlos Syndrome. The condition when combined with neurodivergence are crippling, that initiates a cycle of pain and inflammation that drastically decrease movement and negatively effect digestion to the point that I would rather starve than make myself food. In addition to EDS, POTS makes physical exertion almost unbearable. Having communication deficits increases the potential harm of both of these by not being able to properly communicate needs.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The most significant issues caused by co-occurring mental health conditions are; depression that makes wanting to stay alive a constant and demanding task requiring a lot of mental stimulation and support, anxiety of being perceived that dictates actions, movements and thoughts, OCD that makes already physically and mentally demanding tasks even more so, and ADHD that works directly against autism demanding novelty while autism demands consistency.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	There must be more research done on AFAB individuals as well as adults with autism. There are little to no good or helpful resources for struggling adults with autism, let alone help for any co-occurring conditions. There also needs to be a concentrated effort in research about the treatment of individuals affected, and mental health.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Providers need to be more educated on autism in general and how to be accommodating. It would also be prudent to have better communication accommodations for anything health related like having text based options for dealing with providers. There need to be more services in general, and they need to be created with autistic people, not just allistic people and not with just one or two autistic consultants.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	The onset of the pandemic is when I first lost my job due to overwhelming anxiety that led me to discovering that I was autistic. Since then I have terrible anxiety every day because of the laxity of public restrictions and overall neglect in my part of the country. Knowing that COVID-19 could further disable me while still not receiving the help and accommodations that I need paralyzes me with dread.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I think that the pandemic has mostly affected positive societal changes in my life, with concerted effort to make modified communication more accessible and acceptable than ever. I think work and school should be more disrupted by health and environmental factors than it is.

Name	Candice
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gaslighting from medical community because of communication differences, stereotypes and lack of education on neurodiversity.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression from seemingly haven done all the correct steps demanded by society only to be still ostracized and treated poorly by most people for just existing.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	With a spiky learning profile it's hard to get adequate supports since you excel in some areas but need a lot of support in others. Also with daily challenges changing capacity it leaves many without support or being believed that they need support.
What additional research is needed to help address co-occurring conditions for autistic people?	Whole person, trauma informed and ND affirming medical centres maybe? So often when looking for support we are misdiagnosed, gaslit and told it's all in our heads. If there were a place with trained professionals who cared about patients and wanted to help them live their best lives. Mental health, physical health and community programs under one roof who all communicate together cutting red tape for patients.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	No autistic programs without autistic people being a part of the process to ensure we aren't forcing theoretical strategies based on stereotypes. Care given to those who need it without waiting years to prove a diagnosis because insurance companies say that's the way it has to be.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Personally my health has declined as my child's mental health is struggling. We saw through the pandemic that we don't have to be forced into environments that take all of our energy just to satisfy societal pressures. Life has gotten harder but so much happier knowing ourselves and getting to know the neurodivergent community. We have never met such an amazing group of welcoming and non judgmental humans as we have since discovering our autism and adhd. Knowing that you aren't a broken human and only wired differently helps to get through the hard days. The biggest struggle is ableist attitudes and people who would rather make assumptions and be mean to one another than to try and understand and show compassion to a story that seems so unbelievable to you.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal	Our life has turned upside down since the pandemic. Trying to endure the distance learning and covid scares/tests increased our child's anxiety and getting back to public school has led to burnout twice now. We are on waiting lists for an autism assessment and have been about 2 years now. We

changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	now once again rest to heal our child's nervous system since the school couldn't support her properly and we had no proof of her struggles on paper.
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Name	Carey Holm
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gastrointestinal, mental health, sensory processing, motor challenges, sleep disturbances. These all effect my son and the lack of research and provider services for a person effected is completely unacceptable.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Mental health (anxiety, OCD, attention, aggression)
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Intellectual disability, communication disability, learning disability (dyslexia, dyscalculia, dysgraphia)
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More providers that are educated and experienced in care of individuals effected by the most challenging co-morbidities of Autism (physicians, dentists, mental health, gastroenterologists, neuroscientists, and care providers)
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Covid 19 lockdown brought on highly aggressive and OCD behavior that has continued to this day.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Disruption of speech and occupational services caused regression of years of gains. Social isolation and tele-health has caused extreme anxiety when we now visit in person. Missed years in school instruction do to inability to tolerate online education.

Name	Caroline Rodgerss
Demographic	Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	<p>Most health issues co-occurring on the autism spectrum inspire compassion in the community at large. An exception is the higher percentage of people with autism who experience gender dysphoria. Gender dysphoria can make them targets of harassment and discrimination, making it even harder for them to create successful lives. People with autism are three to six times more likely to experience gender dysphoria than the general population (Warrier V, Greenberg DM, Weir E, et al. Elevated rates of autism, other neurodevelopmental and psychiatric diagnoses, and autistic traits in transgender and gender-diverse individuals. Nat Commun. 2020 Aug 7;11(1):3959.) The same study found a higher incidence of gender dysphoria in people with ADHD, depression, and learning disabilities, each of which co-occur in people with autism at a higher rate than in the neurotypical population (Medical Conditions Associated with Autism Autism Speaks), suggesting that these conditions may have a shared etiology. In contrast to the groundswell of community support inspired by autism, the debate over gender identity, care, and treatment has become an explosive political issue throughout the country. While it can be argued that the increase in people who do not accept their birth-assigned gender is due to increased tolerance, support and services, the possibility that some portion of its existence is a consequence of gestationally induced epigenetic changes cannot be overlooked.</p>
What additional research is needed to help address co-occurring conditions for autistic people?	<p>People with autism have a higher co-occurrence of health conditions such as ADHD, anxiety, depression, epilepsy, GI conditions (Medical Conditions Associated with Autism Autism Speaks, and gender dysphoria than the population at large (Warrier V, Greenberg DM, Weir E, et al. Elevated rates of autism, other neurodevelopmental and psychiatric diagnoses, and autistic traits in transgender and gender-diverse individuals. Nat Commun. 2020.) These co-occurrences provide researchers with a potential Rosetta Stone for understanding the mechanisms at work. Since current understanding of DNA explains only a fraction of these conditions and many are early onset it is possible that they share a prenatal etiology. Since DNA alone does not explain the conditions, epigenetics – a term that encompasses a variety of DNA methylations, histone modifications, and RNA silencing that affect gene expression (Kanherkar RR, Bhatia-Dey N, Csoka AB. Epigenetics across the human lifespan. Front Cell Dev Biol. 2014) -- may provide the key. It is these</p>

	<p>chemical occurrences at various and specific locations on DNA that are the likeliest cause of phenotypes and health issues that cannot be explained by DNA alone. It would be worth revisiting whether certain obstetric practices unwittingly cause epigenetic changes during labor (Rodgers CC. Continuous electronic fetal monitoring during prolonged labor may be a risk factor for having a child diagnosed with autism spectrum disorder. Med Hypotheses. 2020.)</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	

Name	Carolyn Holston , Democrat
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I worked as an aide for the teacher of this 1 child. I worked with him directly for several weeks. The way that the program was set up, I engaged him, & she observed, most days. Then he went home early & she & I would discuss what we thought. He would only speak in quotes from Disney movies. I would try to point out other things that had nothing to do with those movies. The family had 3 other children. I felt like he got parked in front of a tv a lot. It was like he was talking to the only people who "spoke" to him. Just a feeling that I got. He ended up permanently institutionalized. I'm not sure that we could have reached him.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	All of the above come into play at any time.
What additional research is needed to help address co-occurring conditions for autistic people?	I would look at the numbers of those people, & distribute the funds equitably
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	All of the above. There are many safeguards to eliminate fraud.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	As COVID only continues to mutate, fear. It depends on their ability to understand that.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Routine is often quite important to many on the spectrum. It was more traumatic to them than us, if they didn't understand why they just couldn't go to the store.

Name	Carolyn T
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The most significant challenges caused are through the lack of consideration of these conditions and resources to foster inclusion or assistance.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The most significant challenges caused are largely based on the male-centric evaluation process; the mere presence of a co-occurring mental health condition has the ability to lead to misdiagnosis, late diagnosis, or no diagnosis – all of which are hard to traverse and lead to improper treatment, whether it be medicinal trials to see “what works” or a lack of supportive services because the individual didn’t present as autistic in a certain way.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Again, the most significant challenges here are in the lack of services for all individuals, and professionals capable of providing said services.
What additional research is needed to help address co-occurring conditions for autistic people?	To fully understand autism and co-occurring conditions, research must be conducted on a larger, more inclusive scale. As an adult, I have been able to identify as autistic through resources provided by other countries, but I am unable to obtain a diagnosis because the “experts” don’t work with adults.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Autism services and supports require more experts to be able to provide proper and quality care. There should be universal healthcare for individuals with autism so that they can continue to receive care should they become unemployed, or otherwise lose coverage. Also, there should be options provided to accommodate the comfortable communication level for people on the spectrum (ex: My dealership has texting so I could ask questions and not get overwhelmed.)
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Like many neurotypical individuals, COVID has effected both physical and mental health in individuals with autism. It caused a disconnect within safe communities, changed routines for those who rely on them, put immunocompromised at risk, and I’m sure over all caused fear and possibly took the lives of their loved ones/ care takers.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	While remote services may benefit some, increased remote interactions have also lead to isolation and probable depression in individuals – these aspects are not inherently related to the autistic community, but this community is more vulnerable to change and emotional dysregulation which could lead to self-harm or suicide.

Name	Carolyn, Parent
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The biggest challenge are behavior related issues associated to Pathological Demand Avoidance. More definition and explain on ways to support these nervous system issues and greatly needed.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety and aggressive behavior associated to PDA
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication and social anxiety
What additional research is needed to help address co-occurring conditions for autistic people?	pDA needs its own research and DSM evaluation and diagnosis
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage for more modalities of therapy and education with the schools.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	The anxiety relating to social interactions suffered. They lost skills and have reverted to connection through screens.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The lack of qualified experts and technical service providers have created long waitlist and delays in getting services. Medication shortage is by far the worst part for kids that need the meds.

Name	Caryn Cramer
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep deprivation. Also, when the PDA profile of autism is involved, it overrides a person's ability to eat, have hygiene (bathe, brush teeth, etc), toileting, be properly clothed, have basic needs and safety
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	For PDA autism profile, all of the actual "demands" expressed through language as well as energetic and perceived /felt demands mean 70% of autistic PDAers can't access a school environment. it would be extremely helpful to do teacher trainings about declarative language and develop school programs that work to keep PDA autistic people able to handle a school environment. a lot of educators are aware of the sensory needs of an autistic person, but considering that PDA affects about 20% of autistic people, we need to have more awareness about what is perceived as a demand to them - as it sends them into nervous system activation/limbic system. We can train teachers and schools to work with this nervous system sensitivity/disability
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	PDA autism profile can lead to severe nervous system activation - it affects about 20% of autistic people, so it's a very common comorbidity. It can be debilitating and even harmful/unsafe if PDAers are not accommodated to keep their nervous system regulated/ stay out of fight or flight mode. Lowering demands for students (use of declarative language and more self-guided learning), would help them in both school and career - and greatly help their quality of life overall
What additional research is needed to help address co-occurring conditions for autistic people?	We need more research about PDA and autism. it affects one and five autistic people, so it is one of the most common comorbidities. And 70% of PDA kids cannot access regular school because it is too demanding on their nervous system. It's a serious issue that we need to put attention and resources into. Lowering demands through language style and teaching style and classroom environment would help these children greatly.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Parents of autistic children do not have a good enough financial system to help them cover the costs of therapies. we need more programs to help parents of special needs children pay for therapies. Health insurance often puts very arbitrary caps on what they will reimburse, etc. so the true cost of being a special-needs parent is very high, and there are some services that wouldn't fall under the scope of the OT or the SLP at a school - since school services are focused on helping kids achieve in an academic setting. There are many children that need more well-rounded life skills that would come from other therapies outside of the school. it would be particularly helpful to cover DIR Floortime!!! This method has extremely good results, far outperforms ABA results, is healthier psychologically for children, and teachers children skills in a way that helps them generalize and grow
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on	

physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

Name	Casey Foster
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gastrointestinal disorders can cause alterations of blood sugar levels leading to behavioral challenges as well as risks for other associated health complications. Sensory challenges associated with diet may make having a balanced diet more difficult and often there is increased cost burden to accommodate food related sensitivities. Sleep disturbances can affect relationships, place additional burden on care givers, and cause challenges with blood sugar levels and other dietary difficulties.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Co-morbid ADHD and its associated rejection sensitivity dysphoria place additional mental strain on autistic individuals and their care givers. Anxiety associated with OCD is a very difficult challenge to parents and care givers as well as the autistic individual. Depression can result from unaccommodated anxiety and RSD.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Non-typical communication styles and un-recognized common social constructs make it difficult for Autistic individuals to be accepted by allistic individuals
What additional research is needed to help address co-occurring conditions for autistic people?	Greater teaching of social, emotional, learning to the general population and how it impacts the acceptance of autistic individuals.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increased telehealth and remote work during and after the pandemic have made the world easier for neurodivergent people at large.

Name	Cassandra Mccarthy, Self, diagnosed Autistic
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Public spaces are often too stimulating in both a visual and auditory manner. I rapidly become overstimulated, leading to extreme agitation, lack of focus, and headaches.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My autism exacerbates my already existing severe problems with anxiety and depression, as well as my ADHD. Being overstimulated rapidly uses up my energy because it causes me to get anxious very quickly which prompts frustration which prompts exhaustion. My memory issues from the ADHD are also often exacerbated by my autism's extreme need for a consistent routine. When I can't remember or focus on my daily routine, I get more stressed out and more dysfunctional. When all of this accumulates into an autistic meltdown or shutdown, I inevitably wind up completely drained of energy and burnt out, which triggers a severe depressive episode. It also often interferes with my sleep because my brain is too active to quickly go to sleep without pharmaceutical aid.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	As stated before, my autism intersects hard with my ADHD. The symptoms of both often clash in such a way that I spend a lot of my time at a severe rate of dysfunction.
What additional research is needed to help address co-occurring conditions for autistic people?	More research into effective treatment methods, more research into effective support methods, more research on how to communicate with autistic people, and more research into how to teach skills and knowledge to autistic people.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Everything. For one, it NEEDS to be made far easier to apply for and get onto SSI/SSDI when you only have developmental disabilities. It should not be the case that something like nine out of ten disability cases get turned down because judges hearing our cases think that our lack of a 'visible' disability means we are either lying, exaggerating, or faking it. More doctors, dental, and psychological/psychiatric professionals also need to receive mandatory training on how to work with autistic patients. Far, far too many professionals have dismissed me, manipulated me, or written me off the moment I told them I was disabled. Anti-discrimination protections in employment need to be more codified, too, because I'm at the point where I refuse to willingly divulge my disabled status to potential employers because I KNOW they will turn me down for a job, or fire me if I already have one. And they'll get away with it, because burden of proof is on the autistic individual, and proving discrimination in hiring/firing is nigh impossible as it is.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Personally speaking, being forced to work through the pandemic to support my family was traumatizing. It has permanently impaired my ability to seek further work because I spent a full year at minimum having to risk my life working with the public every single day because I knew I wouldn't be able to get approved for disability insurance so that I could quit my job and take care of myself properly.

<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>There was temporarily a positive change in that remote work became normalized, but that positive change is rapidly disappearing because executives are trying to force everyone back to the office, which is eliminating a lot of remote work roles.</p>
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Name	Cassandra Rooney
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The biggest challenges faced are both within and outside the home. Having a child with comorbidities makes it harder to determine which behaviors/ conditions to manage first, as well as what strategies to use based on said comorbidities (ADHD vs Autism vs PDA vs treating for sleep apnea). Outside the home, the challenge is the constant educating of other people about Autism/ADHD/PDA and dispelling incorrect information of such.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The challenges are the same as mentioned in the first question: figuring out which to treat first, and finding mental health professionals that are knowledgeable in autism vs professionals that are misinformed.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	There needs to be more research on the co-occurrence of ADHD and Autism. In addition, more research is needed on information regarding PDA (pathological demand avoidance). Lastly there needs to be more research on the biological/hereditary component of autism.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	The supports and services offered within the public school system needs major improvements for the needs of children with co-occurring conditions.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Quarantining during COVID severely impacted the development of socialization skills for children with comorbidities, especially within early childhood. Continuously getting sick thereafter has impacted the ability of autistic people to function at their highest potential, in addition to missing school and/or work.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The reduction of in person health appointments, increased use of zoom meetings for school, and the inability to get needed services greatly affects children who are in desperate need of in person health services, schooling, and physical/occupational therapy.

Name	Cassandra Stanolevich, Mother of autistic child
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	1) There is the issues of reoccurring ear infections, resulting in several sets of ear tubes, or the concern of it turning to a staph infection..Im speaking from experince. 2) Child having nerve pain. 3) Another issue is GI problems. 4) Being nonverbal, having to have speech therapy, OT as well 5) ADHD/Anxiety 6) The issues of elopement are very scary for a parent. 7) Sleep issues, Sleep Apnea
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Aggressive behavior, anxiety, ADHD, and now self injurious behavior
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Trying to make sure that my kid has a updated IEP for school along with a behavior plan.
What additional research is needed to help address co-occurring conditions for autistic people?	Reaching out to families and individuals to ask them.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance not covering aba therapy or a special bed for a child.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Therapist were not able to work with your child. Having to stay home with kids and help them work from home. And reduce interaction with others

Name	Catherine
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gastro and toileting issues are the biggest challenges for us
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	We experience the world so differently, and we are not understood or given consideration or empathy
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	We can't put our feelings into words, so we can't begin to describe how we're struggling
What additional research is needed to help address co-occurring conditions for autistic people?	Speak with parents of autistic children, guaranteed they know more than the 'experts'
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Supports must be more readily available for lower income families
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	We are not 'allowed' to visit the doctor when unwell anymore, and cannot afford mental health support
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Being isolated when you already have a tendency towards shutting yourself off socially is damaging to the psyche and can be extremely hard to break

Name	catherine martell
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	sensory and motor challenges
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	suicidality, social phobia
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	learning disabilities
What additional research is needed to help address co-occurring conditions for autistic people?	how to change attitudes so more accommodations are voted for.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	medicare expanded to include dental, vision, and hearing FOR ALL.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Catherine Nimmons, Parent of a child with autism
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Self injury behavior
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Self injury behavior
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Intellectual disability
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More response or awareness and more support for parents of a child with profound autism who have self injurious behavior. More support is needed for parents
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Affected education. Our daughter was home for 6 months. Was a nightmare
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Telehealth is used way too much. People with profound autism don't respond well to telehealth

Name	Catherine Slocombe, Mother
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My son has had gastro issues most of his life. He also has sensory challenges, mostly that he does not like anyone too close to him. He also has to have socks on at all times, and will not go barefoot.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My son has all of it. Besides the Autism, he has severe Anxiety, Depression, OCD, ADHD, Self-Injurious behavior and Disruptive Mood Dysregulation Disorder. He stabbed himself a few years ago, hits himself in the head and pounds his fist on tables and in walls when he is angry or upset. He can't control his behavior and it can come on suddenly. He talks to himself constantly. We are senior parents and he is 28. We don't know if he can ever fully take care of himself in life. He cannot get a decent job because he can never get past the interview, even though he is smart, been to college and has a skill. Speech/Language and communication has always been a problem for him. ADHD causes him to not focus and getting him to pay attention is difficult. All of these conditions impact his life on a daily basis and have only gotten worse as he ages.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	He has a hard time communicating, finding the right words he should use. Speech/Language therapy all through school helped somewhat, but he still struggles even today.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Help finding a good job should be priority. We are working with the Dept of Rehabilitation, State of Michigan. It is a joke! He completed his schooling in September and got his last Certificate he needed. This is February, and he still does not have a job. His counselor went on leave, then the next person took over. He had a few mock interviews with her, and then she went on leave. The next person took over, and all he is doing is sending him jobs that he finds on Indeed, which we could have done ourselves. The system is ridiculous! My son has been on Social Security Disability on/off for many years. He applied again, but he was denied. Then he lost his Medicare insurance. Now he has to work a part-time job he hates, just so he can have health insurance. All these people should have health insurance provided to them. They suffer every day with all these co-occurring conditions, yet they are not eligible to have Medicare. They said my son's condition has improved. He has only gotten worse. Does someone who stabbed himself sound like his condition has improved? They don't care. They only see that he has a job and can work. That's all they care about.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	

<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>An increase in telehealth is a problem. My son has had therapy for years, but it has done nothing to help him. He needs, and wants, to have therapy in person, but nobody does that anymore.</p>
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Name	Catrina
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep Disorders Gastrointestinal disorders Sensory POTS Ehlers danlos syndrome PMDD
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Suicidality Anxiety Depression ADHD Self-injurious behavior
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication disabilities and developmental disabilities
What additional research is needed to help address co-occurring conditions for autistic people?	More research into how autism and all co occurring conditions presents and affects the lives of women, afab and bipoc people in general. How ADHD medication affects AuDHDers compared to ADHDers Who in the autistic community is affected by co-occurring conditions and what treatments, therapies, and accommodations help improve quality of life.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More help for autistic adults Access to healthcare for everyone More education into autism and its co-occurring conditions to general practitioners, nurses, surgeons and doctors. We are sometimes not believed when we describe our symptoms or tell a doctor we believe we have a certain condition because they are unfamiliar with both autism and its co-occurring conditions. Autism advocacy in doctors offices and hospitals from people who are autistic or at least have an understanding of autism. More protections for autistic people. Mothers are afraid to disclose they are autistic because they don't want to risk losing their children. Autistic people are also underestimated and neglected as parents, patients, and employees.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Isolation from lockdowns had a lasting impact on mental and physical health. Depression and anxiety remain high. Covid still causes a lot of illness and is unpredictable in how it affects anyone. But co-occurring conditions can make autistic people more at risk. Unmasking at home and late discovered autistics are having trouble integrating back into society now that there is a push to return to normalcy. Sensory difficulties are more difficult and old coping mechanisms are not working. Lack of insurance creates barriers to therapy and other services.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services,	Positives: reduced in person interactions, virtual appointments, increased access to remote work and school Negatives: More sensory overstimulation, unmasking complications, people are less likely to be understanding of social and political differences after the political conflict over the pandemic and other policies. The world feels less safe. It is harder to trust people.

increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Celestine Cookson
Demographic	Autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep issues (insomnia, delayed sleep phase syndrome, restless leg syndrome, etc), Ehler Danlos Syndrome and other connective tissue disorders (VASTLY underdiagnosed), chronic pain, sensory issues, POTS, PCOS, PMDD, Mast cell activation syndrome, motor challenges tied to EDS and hypermobility, muscle differences resulting in issues with gait, breathing, strength, back pain, joint issues. None of these issues can be separated from the massive rated of co-occurring issues related to complex PTSD and somatic expressions of various additional mental health struggles, including dissociation, nervous system sensitivity and regulation issues, etc.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD. Lack of diagnosis resulting in suicidality, anxiety, depression, substance abuse, and vast amounts of complex PTSD often as a direct result of lack of diagnosis, education, and appropriate support. Most Autistic individuals endure vast amounts of trauma due to lack of diagnosis and education in the medical and mental health fields about Autism and what it actually is. For women and girls, they are frequently misdiagnosed and put on inappropriate medications than can cause long term damage. Even with proper medication for co-occurring mental health issues there are insanely high barriers to getting access to their appropriate stimulant medications (most Autistic 40-60% people have co-occurring ADHD) which is incredibly challenging to get prescriptions filled due to laws around schedule II drugs, lack of informed and appropriate providers, cost, etc.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Learning, developmental, and communication disabilities. Autistic people require clear, direct communication and do not communication or often read subtext. This wouldn't be a challenge if the majority of the population did not avoid direct communication. The have cognitive processing differences, such as primarily bottom up thinking patterns that can take them more time to process new information or adjust to changes. Most Autistic people have learning or processing disorders, including dyslexia, dyscalculia, dysgraphia, auditory processing disorder. They can also experience different needs in order to learn most effectively. Developmental disorders can vary certainly, but issues around interoception, proprioception, can impact walking, crawling, and fine motor skills. Many autistics have a high tolerance for physical pain, but heightened sense of pain related to other sensory issues (heat tolerance).
What additional research is needed to help address co-occurring conditions for autistic people?	The BH4 pathway and co-occurring disorders, including have Autistic people have issues breaking down various vitamins and chemicals in the body. Autistic females especially have extremely high rates of CPTSD, and some studies have shown rates as high as 90% for those who have experienced sexual assault. Research is fine and good - but we need adequate and appropriate funding and support. Better education for parents, educators, medical providers about identifying and screening for autism. This is especially true for those who tend to fall through the cracks, especially girls, those with higher than average intelligence, hyperlexia, and heightening states of emotional sensitivity and empathy.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage should be guaranteed lifelong for all which includes the following treatments: -Patient advocacy services or support workers (for making phone calls, addressing daily tasks that are especially draining for autistic people) and in help navigating anything related to the legal system, education, employment, insurance, taxes, or highly bureaucratic systems. - Access to providers who are trained appropriately in trauma informed care and working with Autistic people including Occupational Therapy, Speech

	<p>Therapy, Physical Therapy, Chiropractors, Massage, Rheumatology, Geneticists, Gastroenterologists, Neurologists, Psychiatrists, Therapists. - Improve access to services that don't require phone calls, but offer texting/email options, including online scheduling, with more forgiving cancellation policies. -More options to include telehealth and inter-state access to providers as possible, especially mental health providers. -Require providers to stop providing ABA therapy. It's been shown to be harmful and have long term side effects and only encourage autistic masking. -Greater community supports for Autistic people that includes mutual aid and social supports. -Education systems and plans that have adequate providers for testing, providing appropriate accommodation and support plans in school which also factor in social supports.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>Vast amounts of Autistic people with comorbid disorders (which is all of them) have suffered increased issues related to long Covid, and increase activation of morbid disorders related to having had COVID infections. This includes worsening sleep issues, executive functioning struggles, worsening depression and anxiety. This also is greatly tied to more physical issues related to increase fatigue, chronic pain, memory issues, and activation of various disorders including POTS, PCOS, food intolerance, and immune system issues.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Greater access to remote access to services, including work/school have been especially useful. However many services are no longer being covered. This includes getting access to stimulant medication which requires in person visits again after the COVID 19 emergency measures expired. Increased access to services that allow for delivery or decreased social interaction have been useful, but are often very expensive. The disruption of routines and coping skills has been both positive and negative. Many undiagnosed Autistic people have begun self-identifying due to the disruption and getting supports. However getting diagnosed is time consuming, expensive, often comes with long wait lists, and many providers who are not appropriately trained or qualified to diagnose high-masking adults, women, BIPOC, and people with extensive trauma and other cooccurring conditions. Many Autistic people have sought out testing and diagnosis to only be dismissed and increased experiences with trauma from medical providers dismissing their experiences.</p>

Name	Celine Fortin, The Arc of New Jersey
Demographic	Family member of an autistic individual; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Co-occurring physical health conditions add another layer of complexity to the challenges already facing those with autism. Appropriate diagnosis is challenging, leading to misdiagnosis or a person with autism not getting the appropriate treatment. They may experience pain or discomfort which makes it more difficult to complete everyday tasks and if their expressive language skills are poor they may not be able to convey how they are feeling. Undiagnosed issues can lead to significant health issues later. Certain issues like sleep disturbances disrupt the entire household and can affect a parent's ability to work or care for other household members.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Many people with autism have co-occurring mental health disorders. It is extremely difficult to find specialists to properly diagnose and treat them. Traditional forms of treatment need to be modified or new treatment models need to be developed to be effective. My son with autism has been diagnosed with depression, anxiety, PTSD, and OCD. The anxiety is the most debilitating condition he faces. It is so severe he can not leave the house. No professional we have consulted has been able to treat him effectively. They either don't understand autism and how it affects his ability to participate in treatment, or they don't understand the unique way he processes his anxiety and depression. Another issue is that individuals with autism and co-occurring mental health issues are often found not eligible for traditional IDD services such as housing or employment supports. The individual is shuttled back and forth between IDD services and mh services with neither one taking responsibility for their care.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication disabilities make it very difficult for people with autism to participate in treatment modalities addressing mental health challenges or to inform their health care providers of issues and concerns. Therefore many co-occurring conditions go undiagnosed and/or untreated.
What additional research is needed to help address co-occurring conditions for autistic people?	There needs to be more specific research on effective treatment modalities. There also needs to be more effective methods for communication to help people with autism better express their issues and concerns. There also need to be a better integration of systems - IDD, mental health, physical health and behavioral health systems working together to develop and provide holistic care.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	All of the above mentioned examples would be beneficial. There also needs to be increased cross training of professionals across systems as well as increased services overall.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Unfortunately the pandemic has isolated people with autism even further than before. Individuals who experienced anxiety regarding social situations became even more isolated and now have an even more difficult time interacting in social situations. Also, anxiety over getting sick still keeps many people at home. If they are not utilizing hard won skills they are losing their abilities to communicate and participate in everyday activities.

What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

Thank goodness for telehealth. My son would not be able to have any health or mental health appointments without it. It is still limiting as his communication skills are poor but it is better than nothing.

Name	CFT
Demographic	Autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Can't speak for the majority, but based on personal experience and clinical observation, concurrent conditions with ASD create diagnostic complexity that causes some professionals to misdiagnose individuals (as in, diagnostic overshadowing). Concurrent conditions create the opportunity to do things in different ways than others, but they also create problems of feeling more physically and mentally exhausted, and misunderstood by others.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I'd say my response is the same as the prior question. Additionally, an internal sense of disconnectedness from others due to feeling so complex and different.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Again, same response as the prior two questions, with the addition that the combination of these conditions can lead to feeling incapable, condescended to, left behind, inferior, inadequate, and frustrated in a world that is not accessible to us.
What additional research is needed to help address co-occurring conditions for autistic people?	Research on a greater variety of overlapping conditions. For example, survey of Autistic people about their concurrent conditions). For instance, my unique assortment of conditions is: Leber Congenital Amaurosis / Cone Rod Dystrophy (autosomal dominant CRX mutation with nystagmus); essential tremors; asthma, reactive airway disease, & seasonal allergies; pelvic floor dysfunction, urinary retention, & overactive bladder disorder; ADHD inattentive type; functional dyslexia; Social Anxiety Disorder; OCD; C-PTSD; Persistent Depressive Disorder. Research on accommodation and advocacy strategies, especially that autistic individuals would endorse the need of, rather than just what others think we need. Research on concurrent conditions in autistic minority individuals, (E.G., those with physical disabilities of various kinds, people of color, women, those in poverty).
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Mandate that government services (E.G., SSA, TWC-VRS) accept diagnostic reports of ASD from LPCs, LCSWs, and other masters level clinicians, not just doctoral level, regardless of the level of clinician that made prior misdiagnosis / diagnosis disagreed with by the client). If a clinician is qualified, they're qualified, end of story. There should be access to free or affordable, insured, proximally accessible mental health, physical / medical, and specialist evaluations and prescription services for autistic and other disabled individuals due to such variable and high concurrence of conditions.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	The obvious response would be increased isolation and loneliness. Other responses are autistic burnout, autistic skills regression, financial hardship, chronic fatigue, reduced social connections, increased mental health issues.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal	Positives: The ability to say no to social gatherings. The ability to wear a mask or practice sanitation precautions, and the ability to distance without as much judgment in certain settings. The stimulus check and free Covid tests. Negatives: Disruption in services because people with disabilities (including Autistics) always have to wait ridiculous amounts of time to move forward

changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	with basic life needs anyways due to societal barriers. Barriers to ASD diagnosis in adults and adolescents especially because some professionals assume that Covid caused socioemotional developmental delays.
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Name	Charles Coleman, The Arc Massachusetts
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My daughter suffers from Autism, Intellectual Disabilities, gastrointestinal disorders, sleep disturbances, many other medical and behavioral condition as some described in the question. My daughter suffers from transitioning impediments and communication delays. We live in Massachusetts. The ASD and IDD adult services are diminishing and, in some cases, non-existing. Presently the adults in our population are not covered by MassHealth for Applied Behavioral Analysis therapy which is a critical Home Base ABA therapy program. When she matured to the adult system MassHealth doesn't cover ABA therapy for adults. ABA therapy is very effective for individuals, their caregiver and families in understanding behaviors and how best to treat the client, their environment, caregivers and families. DDS has been unable to provide a Day Placement. DDS states lack staffing for no opening of Day placements and some cases closing of day placements. It has been reported that there are at least 6,000 people in need of services. This number will continue to grow as what happen to my daughter when she moved to the adult system in Massachusetts. We have tried to find a private day placement; however, we are having extreme difficulty in the state of Massachusetts Transportation Department providing a van transportation company with a driver and female monitor which our daughter requires to travel for safety and decency issues resulting from potential disrobing incidents.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Massachusetts needs consistencies of services, MassHealth needs to cover adults for Home Base ABA therapy, safe and appropriate transportation for the ASD and IDD community to travel to day placements, doctors' appointments, and other places of importances. We also need a better adult system that directly services the cliental and the adult system must have transparency and accountability to the people that the system serves.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My daughter and others that are in ASD and IDD community in our state of Massachusetts have impediments of acquiring and delivery of services, even when medical necessity requires. For instance, we have been waiting for approximately at least 3 years for DDS Day placement, the state transportation department has been unable to this date been able provide a van, driver and female monitor for transportation to a private temporary transitional day placement; MassHealth doesn't cover adults for Home Base ABA Therapy. DDS and IDD departments in the state is supposed to be dedicated to providing services and supports to the DDS and IDD population. The systems are convoluted and lacks accountability to their cliental. The patent response for lack of services provided no staffing however they provide no direct, plan of action of improvement and accountability. Our community is the most vulnerable.
What additional research is needed to help address co-occurring conditions for autistic people?	Massachusetts Department of Developmental Services (DDS) and Intellectual and Developmental Disabilities (IDD) systems need to be evaluated, analyze, identify the deficiencies and establish a new and improve system to provide needed services to each person that is deem medically necessity to have the appropriate services. There also needs to be a vital component of accountability to the clients which they serve.
What could be improved in autism services and supports to help address co-occurring conditions for autistic	Equitable to and accessibility of services, for instance my daughter has been waiting for a DDS Day placement. for 3 years. We have applied numerous known DDS Day placements. Some of these placements have supposedly

<p>people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>placed her on a waiting list or just stated that they have no opening. To my knowledge there is no criteria in place verifying if there are in fact establish lists, if there are in fact lists, are they being honor and strictly adhere to as placement positions or are people be chosen before other arbitrarily. There is no transparency and accountability in the system. MassHealth doesn't cover adults for Applied Behavior Analysis this needs to be changed immediately this a critical service that is needed. ABA is a cornerstone of success for ASD and IDD clients. etc.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>Personal none however I don't know the impact on others.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Definitely disruptions of services, increase in remote work, school, therapies sessions, and some doctors' appointments whether medical or psychological.</p>

Name	Charli Barraza
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Autoimmune diseases are incredibly common among us and pose a very real threat to our well-being, functionality and livelihoods. Connective tissue diseases, Poly-Cystic Ovarian Syndrome, Celiac and other gluten sensitivities are anecdotally too common in our community to be a coincidence, and tend to flare up later in life after decades of unsupported and unaccommodated attempts at living.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Rejection Sensitive Dysphoria is a community-given name for a symptom that is so common among both Autistics and ADHD people, even without co-occurring mental/behavioral diagnoses and it is still so unknown and entirely untreated despite being both a potential threat to our lives, but also a large part of the anxiety that prevents the majority of us from being able to work, even before we hit Autistic burnout or autoimmune diseases in our late twenties and beyond.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Children identified as either female, high IQ, POC or all of the above get overlooked so often it's become a nihilistic joke in our community. We can't even begin to get an idea of what those disabilities look like until this discrepancy is addressed. Everyone needs access to mental Healthcare and diagnostic opportunities, as well as support.
What additional research is needed to help address co-occurring conditions for autistic people?	Autism from our own perspectives, especially those of AFAB, Black, Queer and/or Disabled people. Diagnostic tools that speak a language we (Autistics) understand. Anything that includes our voices as captains, or at least co-captains, of the metaphorical ship. We don't need a cure, we don't need Autism Speaks, we need a voice in what we have a stake in.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Equitable access to diagnostic opportunities. Increased, more readily available access to all disability support- adaptive technology, mobility aids, closed captions and auto-generated captions, public transportation services, legal support, living support, occupational and disability therapies
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	COVID has exacerbated at least one autoimmune disease, if not brought another one out entirely, for the majority of us who were already living with one. We literally will never be the same after a single infection.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Many of us experience agoraphobia, either chronically or temporarily, and now we have a very real threat to our well-being that reinforces our fears, especially for rural, poor, and/or disabled Autistics who may not be able to receive immunizations for access or medical reasons

Name	Charlie B
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My insomnia makes it very difficult to navigate 9-5 professional life
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Social isolation from not understanding social cues can lead to crippling depression and anxiety for me
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I have memory issues from ADHD
What additional research is needed to help address co-occurring conditions for autistic people?	Research on autism in understudied populations ex women, queer people, people with co-occurring disabilities
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Removing the marriage inequality for SSDI
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Chris Bruner, Family
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The biggest challenge facing autistic children is a comorbidity of symptoms that is always changing. Example: Comorbidity of sleep disorder, find an effective treatment for sleep, patient then has flare ups in mood control, self stimulation, information comprehension, binge eating, or any multitude of other symptoms. The Dr then treats the newly flaring symptom(s) and then the patient goes back to having sleep disturbances.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	1. Finding practitioners 2. Finding practitioners who have experience with autism in combination with other types of disorders. 3. Finding treatments that work, to help both patients and caregivers, in obtaining positive outcomes.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Overall education challenges are the biggest challenge. There is a lack of funding. Funding to help teachers teach autistic children, funding for aides, and smaller classroom sizes. A continued lack of understanding regarding autism and autistic spectrum children. A lack of accommodation for autistic families, especially as children reach middle and high school.
What additional research is needed to help address co-occurring conditions for autistic people?	Research that shows how different teaching styles and classroom environments affect autistic students and their ability to learn successfully.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage for all of the services needed would definitely be a big relief. My nephew needed braces for his feet. Insurance only covered 200 of the 1200 service. The braces will need to change as he grows and our family can't afford the services that are needed for his success.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	C19 definitely put a hole in his learning and treatment plan. Lack of access to healthcare therapies and therapeutic services set him back substantially. The switch to electronic education also made it easier for him to be left out and behind.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I believe that it will take a great, maybe insurmountable, effort to help my nephew catch up. Because education is not funded appropriately, and there is not funding for additional treatments, he will be further left behind, and it will be harder for him to succeed

Name	Chris Knobel
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Anxiety and Pathological Demand Avoidance
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Aggression and anxiety
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	The U.S. is extremely lagging, compared to the United Kingdom, on clinical research of Pathological Demand Avoidance.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More analysis needs to be done on the determinantal aspects of ABA on individuals with Autism with the PDA profile. Traditional autism therapy, behavior modification can cause traumatic experiences for individuals with the profile
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	chris patton
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	badass needs in me fearful, hard to get my body moving, nasty beastly body is shadow of me.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	fearful nasty needs in me, yipping in my meaty mind is bad, bad, bad.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	i typing my heartfilled words, cave in my bad mind, haha, needs full safe life.
What additional research is needed to help address co-occurring conditions for autistic people?	research in milling minds
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	nasty needs in me get worse in covid time. fast heart, anxiety is great
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	vast bad needs in covid nasty for both physical and mental health. i learned to do zoom, safe great needs met in zoom.

Name	Christi Caprara
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory issues make it difficult to focus and can also push me to avoid situations that lead to overload. Public transportation to a job (that likely has its own sensory challenges) is often too loud, crowded, and smelly. Throw being exhausted from sleep disruption in there and it's a perfect storm for task avoidance and meltdowns or being worn out from coping and masking to the point where it's hard to enjoy personal time.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD and depression make it super difficult to start and/or finish things. There's a lot of stigma and shame associated with needing help. Help also costs time and money. The fear of being judged or having your mental health held against you can trap a person in an unhealthy mindset, environment, relationship, or family situation.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Well it's frustrating to have a difference of ability labeled a disability when it sometimes can be an asset. College programs should take this into consideration. Engineering students shouldn't waste academic time on Chaucer and Sociology majors will really never use algebra. Dyslexics have excellent spacial acuity and visual memory. That's not a disability if teaching takes the proper approach.
What additional research is needed to help address co-occurring conditions for autistic people?	The overlap between autism and adhd as well as how digestive and metabolic differences contribute to both. And more understanding of how these things present differently in people who aren't white and male.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Any state sponsored insurance requires a daunting amount of paperwork that those of us with adhd will often avoid. These are lifetime diagnoses. Regardless of whether we have more or less income and stability we should receive continual medical coverage. Once enrolled it should require no annual stupid human tricks to keep it. Also, meds for adhd, depression, anxiety, etc. should be free. Everybody benefits from those of us who need them taking our meds.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Fewer social obligations- such a relief!

Name	Christie Long
Demographic	Autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	-Absences (school/work) - Issues in any of the above exacerbate the Autism (ie., less sleep, higher tendency for communication issues, dysregulation, etc) - Cultural stigmas
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	-absences from school / work - accessible treatment - discernment of when it's mental health vs when it's Autism - communication deficiencies affecting the ability to clearly communicate feeling in an efficacious manner (perhaps related to alexithymia)
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	- seeing relevance in the learning - navigating rigidity of thought in learning - testing iq in students with limited language - need for individualized instruction that is holistically provided, rather than broad statements, following medical model - weakness/deficit model over strength based
What additional research is needed to help address co-occurring conditions for autistic people?	-implications of medical model in schools (as opposed to social model) - chicken or egg? Learning how to address need- Autism or mental health need - assessing iq in nonverbal students? Is there a better way? - complex trauma - late dx in autism - outcomes: are current inclusive models making the cut or hindering growth
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	- education & research into treatment, ie., autism causing the depression/ anxiety or vice versa - continued culture/community work to build tolerance in community to consider and include individuals with autism - you cannot systematize autism; this has to be considered when building systems - screeners
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	All of the above mentioned have been helpful for the autistic community

Name	Christie Patterson
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Chronic fatigue, asthma, loss of functioning of daily duties, muscle pain
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression, ADHD, anxiety
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication and learning disabilities
What additional research is needed to help address co-occurring conditions for autistic people?	More focus on undiagnosed adults especially women
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Social safety net. It's difficult to get diagnosed as an adult especially without health insurance. We need help accessing basic needs of survival.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Chronic fatigue, loss of skills, depression and anxiety
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Difficulty obtaining income and health insurance

Name	Christina
Demographic	Family member of an autistic individual; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Doctors do not look past autism to understand behavior is communication and a person who has limited verbal communication may self injure or exhibit other maladaptive behavior when sick or in pain. They dismiss people who have autism dx. If a neuro-typical person came to an appointment with same symptoms they would run diagnostic tests.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	There are many people on the spectrum who have co- occurring OCD, anxiety, SIB to the point of debilitating their quality of life. Please hear and see the population who are most profoundly affected and can not advocate for their self. There is a need for self contained adult programs catering to profound and severe autism.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The most significant challenges occur in the most significantly affected population. They are isolated due to their fear of social norms and expectations from unknown people and places. This population needs routine and some type of control over their environment. They can not advocate for their needs and wants in a way that is convenient to others and so they get pushed into settings that can trigger a meltdown that then labels them with behavioral issues.
What additional research is needed to help address co-occurring conditions for autistic people?	There could be a deeper discussion about seizures, PANDAS, PANS, DNA mutations including MTHFR, GI issues, food allergies, paradoxical reactions to medications, high titers from childhood vaccines, HBOT treatment, inflammation and oxidative stress, toxic and autoimmune encephalopathy, sensory processing disorder. People need to be looked at as individuals and do not dismiss their behaviors because they have autism. The growing autism crisis is going to require more health care workers and out of the box ideas. Some ideas to share include drive through clinics for health care. Home visits and sedation for dental care. Community safe homes for respite and health care/ medical intervention that does not require a hospital bed.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I gave a few suggestions, see question #4. Accessibility of services is a huge obstacle for the non verbal population who must rely on their parents/guardians to find providers who have experience and can provide special accommodations. Then compound this with trying to find providers who accept the medicaid waiver. Some information to keep in mind for potential providers is wait time in the lobby, extensive waits in patient room and an office that is not autism friendly. Maybe make one day per week only for special needs patients.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	COVID-19 infection did not cause physical or mental health problems. The COVID-19 restrictions and school closures caused anxiety, fear, confusion, routine disruption, isolation, loneliness, lack of support and staff shortages.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services,	There is a placement shortage for adults who have autism that need extra support. There is a staffing shortage that is preventing agencies to move forward on new CILAs, day programs, community outings etc. Remote learning did not work for school. We have used telehealth due to debilitating anxiety since lockdown restrictions caused so much confusion and disruption.

increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Christina Stearns
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	When my son, now 19 years old (Level 3 ASD), was about 15 months old, he began to exhibit severe gastrointestinal symptoms as a sensitivity to dairy. We switched pediatricians several times after being dismissed and advised things like, "He's probably drinking too much juice". We were finally referred to a pediatric GI specialist. While we waited for doctors to take this issue seriously, I researched and tried an elimination diet, which worked (with agreement from the GI specialist afterwards). We were eventually able to reintroduce some dairy foods. I felt very alone in my journey to help my child. In addition, my son has epilepsy, which started when he was 9 years old. He must take medication several times a day to keep seizure activity under control, and there are times that he refuses to take his medication. We have limited ability to explain how important his medication is because his comprehension of language is low. In addition, his expressive language has huge deficits, and he is unable to express words/details about how his body and mind are feeling, so with medical/psychiatric symptoms, we are always guessing how to change/modify his treatment.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My 19-year-old son (Level 3 ASD) has several mental health diagnoses that are layered on top of his autism. His most challenging is schizoaffective disorder, which was diagnosed after his antipsychotic medication (prescribed for aggressive behavior) stopped working. His child psychiatrist struggled to find a medication that would work for him. During this time of constant trial and error, he displayed manic behavior, went multiple days in a row without sleep, and started to exhibit a lack of interest in most of the things he normally talked about. A previous inpatient hospital admission had confirmed that he was having auditory and visual hallucinations. These become worse when his medication is not working. Once we got him on the right medication (over a year after the original one stopped working), his quality of life drastically improved. However, due to his limited expressive language, he was unable to express how his body/mind felt while trialing different medications. These medications are already a huge challenge to prescribe, however, autistic individuals tend to react differently to a wide variety and combination of them. The communication barrier makes this exponentially more difficult. In the last 4 years, he has displayed significant self-injurious behavior in the form of skin picking. He currently has a wound that has required medical attention for the last eight months. Again, the communication barrier makes this much more complex.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My 19-year-old son (Level 3 ASD) has autism (developmental disability), intellectual disabilities, and communication disabilities. I would say without hesitation, that these impact his experience at medical facilities including hospitals, and especially in emergency situations. When he is frightened and confused, he has the potential to become physically aggressive, not specifically with the intention of hurting others, but as a flight or fight response. When hospitals respond by calling security personnel, this diminishes my son's dignity as a person. There are a handful of staff and facilities that have taken the time to understand disabled individuals like my son. When we encounter experiences where he is not understood and handled with patience, it normally escalates to a situation that interprets him to be a threat, when he is the one who is in desperate need of medical treatment.

<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>Include the expertise of autism behavior specialists, neurologists, and psychiatrists/ psychologists who have experience working with these dually diagnosed children and adults. Some of the leaders in this industry are at Bradley Hospital in Rhode Island, and the Kennedy Krieger Institute (The Center for Autism Services, Science and Innovation/CASSI) in Maryland.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Patient-Provider interactions including education for medical staff who work with the public, and developmental disability liaisons in hospitals/facilities, who can assist with advocacy for individuals and their families/guardians.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>My 19-year-old son (Level 3 ASD) lives in an Intermediate Care Facility (ICF) in upstate NY. When lockdown of these residences happened in our state, we could not see our son from mid-March through mid-June of 2020. This created a mental health burden for both our child and our family. I understand that this was a state pandemic response, but it went on for so long and did more harm than good.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Positive: Telehealth whenever appropriate is a wonderful thing for this population and those who care for their medical needs. Negative: Health care providers and facilities experiencing long wait lists for services. For several years, my son has not been able to get an appointment with his dental clinic (specializing in treating the developmentally disabled). There are few options in Upstate New York for dental providers who are knowledgeable and willing to work with individuals like my son. Also, staffing levels have plummeted for Direct Support Professionals at residential programs, and these are the people who supply 24-hour care for our residential children/adults.</p>

Name	Christine Buffington
Demographic	Family member of an autistic individual; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory and motor because they are not addressed by doctors whereas GI issues, sleep and others are. Also a mainly mental health issues. It is hard to find and retain a good psychiatrist and/or psychologist. It's hard to get medications filled and heaven help you if there is a problem
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Self injuring behavior/suicidal tendencies that could and should be avoided if the anxiety and depression were controlled
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Wow- all of the above but if I had to pick just one intellectual because the others can generally improve
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Access to services. What is offered in Pa is much greater than what is offered in Florida. There are better and more doctors in Pa than Fl. I am certain that this can be said of other states/areas as well.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I still can not get my sons out of the house. This has increased depression but when I try to push they become super anxious and it just goes round and round.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The ability to get out and do things with other people

Name	Christine Conway, Parent
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gastrointestinal Mental health
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	All of above
What additional research is needed to help address co-occurring conditions for autistic people?	More training to medical and psychological professionals
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More classes and health related workshops and specifically mental health professionals for this population to treat them appropriately to work thru issues
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Increases anxiety, regression and medical issues
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Permanent Reduction of services

Name	Christine Crum, Professionally Diagnoses with ASD Level 1
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I have trouble sleeping which affects my mental health, relationships, physical health, and ability to focus and function. My autism makes me hyper sensitive to sounds and textures and small irregularities with either one will wake me up throughout the night.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I've been diagnosed and treated for anxiety, depression, and self harm symptoms. IMO these were caused by the autism and the lack of a formal diagnosis for years. Now that I'm diagnosed, just the anxiety persists. My autism makes me hyper aware of any and all factors and possibilities. I have anxiety if things are not in an ideal order or schedule to eliminate possible difficulties. The anxiety affects my relationships, physical health, and gives me fatigue. The anxiety also takes a toll on my nervous system.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I've been diagnosed with selective mutism. From the ages of 10-20 I was physically unable to verbally speak from time to time. This affected my social life, relationships, self esteem, studies, work, led to self-harm, suicidal tendencies, anxiety, and depression. Being unable to speak was terrifying. As an undiagnosed child it led to a lot of confusion about whether or not there was a place for me in society, whether or not it was worth living, and whether or not I was a truly damaged person with no future. I needed a diagnosis.
What additional research is needed to help address co-occurring conditions for autistic people?	Do more research on autistic females. I know a lot of people are trying.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Programs for autistic adults; Insurance covering THERAPY for autistic adults. I'm barely able to afford my therapy and it's the only service I can find for adults on the spectrum. Services for autistic adults, especially if they have a job and/or a family. Their families will suffer if they don't have support. Education for adults with autism about what's going on in their brain and nervous system and how to tackle day to day challenges. Continuing education about the updated information on female ASD symptoms for medical providers.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	None for me. I had Covid twice and it was hard but I wasn't diagnosed then so I don't remember it because I was dealing with so many symptoms alone and blocked it all out.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	It's nice to be able to work from home. I have a college degree and my father gave me a work from home job in his company because I'm very privileged.

Name	Christine Deitcher, Mother of a 9 year old boy DS-ASD
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Allergies to skin and many food intolerances, GI issues, getting them to take their medicines, toilet training (or lack thereof), sleep disturbances like sleep apnea (there's no way my son would sleep with a c-pap mask), we haven't been able to even complete a sleep study in years. Dangerous and Aggressive behavior towards people and property, which I detail in the next answer block.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Dangerous and Aggressive behavior towards people and property. In my experience with my son who also has Down syndrome, this aggression can come out of nowhere and often occurs as part of a perseveration cycle of requesting or demanding something that is not available and bullying me to make it available. When there is no compromise to be had his aggression will escalate to the point where I need to seek safety and then risk him damaging our home. We've been working ABA for years and he's on Abilify and Guanfacine and I'm a mindfulness meditation teacher. I cannot accept this miserable existence we all have to tolerate until death. There has to be something we can do to calm him down. I feel for him. No one likes being a prisoner to their mind. He can't help that these thoughts come up and the strength of the desire to get what he wants, like to go to summer camp on a winter night. His emotional mind just grabs hold of an idea and puts him and the whole family through horrible experiences as it tries to get what it wants. ABA doesn't fix this...mindfulness doesn't fix this. I know because I've been trying them everyday for years.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	All of the above. My son's brain simply does not work in a way that will enable him to function in the world without a 1 to 1 aid, ever.
What additional research is needed to help address co-occurring conditions for autistic people?	Physical research of what's happening in the brain. I would like to look at everything from brain scans to surgical options, CRISPR, pharmacology interventions, gut micro biome studies... I would gladly participate in research studies if we can get my son to comply with the study requirements.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Availability and reliability. We've been receiving services (speech, OT, and PT) since my son was only a few weeks old. He's been receiving behavioral intervention services since he was 2, but they have never been adequate. The providers don't last long because they're always moving up to higher paying jobs and the one who was actually helpful didn't last for a similar reason. I feel like it's a constant cycle of over promising and under delivering. The provider organizations simply don't have what they need to acquire and keep staff. It's not surprising. These kids are some of the toughest kids to work with. My son is in 4th grade and has had the same teacher since kindergarten. She knows him better than anyone besides my immediate family and I can tell you he's still very much a mystery to all of us. She refers to him as her "little tornado."
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	My son has had Covid-19 at least once. It is not clear to me that any physical medical conditions he is experiencing are a direct result of infection from Covid-19 at this time.

<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Lockdown was an absolute nightmare. I had to bear hug my son to attend zooms. It was awful to have to try and force him to be in front of a screen. On the positive, my husband now works from home and that has been such a blessing. I'm not sure if I would still be married or alive today if not for his presence to support me and keep me safe from Caleb's outbursts.</p>
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Name	christine smallin, orange county dmh
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	significant mh concerns including psychosis diagnostic overshadowing
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	differential diagnosis
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	omh and opwdd working together and not in silos; both taking responsibility instead of trying to get the other to take responsibility.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I do not think we know the full effects yet
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	significant reduction in opportunities for community integration, socialization and work

Name	Christopher M Sculley
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I was always different and I never seemed to fit in. So I became very reclusive into my adult life. At 51 years old I still bight my nails and am very fidgety. It's very hard for me to even write this. But if there is anything I can do to help I will do what it takes.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I can never get respect that I think i deserve.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Fitting in with pears.
What additional research is needed to help address co-occurring conditions for autistic people?	Bullying we are a great resource for them to make them feel better about themselves. Some of us don't look like we are disabled.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Into adulthood a lot of us have been denied lots of things that we worked for thing's like education and financial literacy and other services.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	For me I stayed mostly isolated as an introvert and recluse it worked out for me.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	CJ Morefield
Demographic	Autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Pain, Illness/Injury, and Fatigue - caused by sensory overload, social and professional masking, POTS, Hypermobility Ehlers Danlos Syndrome, Mast Cell Activation Syndrome, insomnia/circadian rhythm disruptions, etc. Many autistic people experience fatigue at significant levels, but also desire fulfilling and meaningful careers. Currently, the system is set up to where if you want to achieve "the American dream," you must also ride the line of burnout while working full-time. Riding that line is extremely difficult and requires foregoing much of what makes life itself meaningful - time with family and friends, traveling, creating, etc. One's life is relegated to strict systems and strategies to merely survive. Autistic people are also more likely to acquire all different kinds of illnesses, some mentioned above, that require significant time off of work for surgeries, illnesses, and flare-ups.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Many autistic folks have experienced a great deal of social rejection and exclusion, which is inherently traumatic in a social species. I have never met an autistic person who did not have significant symptoms of trauma. One of the hallmark traits of autism is having sensory systems that are hyper and hypo sensitive, then having trouble integrating all of that extreme sensory information, and responding in the environment in optimal ways -- insert awkward pause here --. Having a nervous system that has experienced reoccurring traumas in addition to challenges in modulating behavior causes or reinforces a lot of depression and anxiety, including suicidal thoughts and behavior. So basically, one of the biggest challenges with co-occurring conditions, in my opinion, is that society (school, work, media) still normalizes one type of brain and pathologizes and "others" different ways of being. What is challenging is working on your depression and anxiety and trauma only to go out into the world and have it reinforced again and again that you're not "good enough." The other is lack of affordable access to treatments that actually help the root nervous system issues that truly disturb quality of life.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	More research into trauma and autism - specifically the effects of social trauma, the rate of experiencing of other types of traumas, and the similarities between PTSD and autism, the short and long term effects of any early intervention trauma (caused by holding therapy/food reinforcements) or interventions that had non-autistic affirming goals (making eye contact, reciprocating, etc) More research into early interventions and treatments for hypermobility/EDS.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Equitable/affordable access to adult autism evaluations! Adult evaluations cost thousands of dollars and are completely inaccessible to most people. Research on "the lost generation" shows that there are many undiagnosed adults who would benefit from access to services and accommodations, most of which are made up of gender, racial, and ethnic minorities as well as people of lower SES. Policies that prevent discrimination based on autism diagnoses, particularly in the military or government work. Equitable/affordable access to nervous system treatments like TMS, Safe and Sound Protocol, etc. Equitable/affordable access to trauma therapy.

	Secondary insurance/medicaid for disabled adults who are working without the requirement that they be on disability first.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Those of us with POTS that I have spoken with have experienced worsening of their POTS symptoms - increases in frequency and intensity of flares. Post-infection, it takes much longer to get back to being able to work than is likely average.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Telehealth has been a huge positive that has come from COVID in general. It has increased access for so many people with multiple conditions that make it harder to get to multiple physical appointments. My flexible, hybrid work schedule has been a big improvement for me in terms of sensory overload and my physical health has improved some over time.

Name	Claire
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Ignorant and prejudice institutions e.g. schools, mental health services, doctors, police, social services
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, depression, suicidal ideation, deep shame and fear
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication issues mean we cannot tell others what our needs are so others just do what they want based on prejudice and stigma
What additional research is needed to help address co-occurring conditions for autistic people?	Research into the PDA (pathological demand avoidance/persistent drive for autonomy) occurrence
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Listening to those who have it. Funding diagnosis to reduce waiting lists (UK). ABOLISHING ABA
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	A lot of people are experiencing chronic fatigue without recognition and support. Businesses need to allow work from home option
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increased remote work during covid proved helpful for many then it was taken away due to prioritising investments in business workplaces. Severe isolation from lack of informal social access has hurt many people.

Name	Claire Rattey
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Pathological demand avoidance
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Pathological demand avoidance
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Pathological demand avoidance
What additional research is needed to help address co-occurring conditions for autistic people?	Pathological demand avoidance
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Any service providers having knowledge of Pathological demand avoidance
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Clayton Oliver
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	This is a broad generalization because autism presents differently in each autistic person, and each autistic person receives a different slate of co-occurring conditions. Speaking solely for myself, the most significant challenges I face from co-occurring health conditions are related to sensory processing issues and sleep disturbances - though the latter may be connected to co-occurring mental health concerns rather than a direct product of my autistic neurology.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, depression, and suicidality are probably a cluster of co-occurrence that should not be assessed in separate silos. If we don't solve the problem of autistic suicide rates, autistic people will keep killing ourselves, rendering solutions to the other problems rather irrelevant. This, in turn, needs to be examined in light of how autistic individuals experience and process trauma differently from neurotypical individuals - and why we marinate in lifelong trauma simply from existing within modern mainstream culture.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I suspect that a lack of research and understanding around communication disabilities is responsible for a great many sources of autistic trauma - and a large number of situations in which the scientific community doesn't actually hear what autistic people are saying.
What additional research is needed to help address co-occurring conditions for autistic people?	It would be nice to see some practical social science focused on improving acceptance and understanding of autistic people in social, educational, and occupational settings.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Until providers are trained to recognize and interface with autistic communication styles, autism services will continue to miss the mark because neurotypical providers will force neurodivergent clients through neurotypical processes.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Again, this is an awfully broad brush. For some of us, particularly those with co-occurring autoimmune disorders, it's still a lethal situation, as it is for all other individuals with autoimmune concerns. For others, a year of social distancing was great because the stress and trauma of dealing with neurotypical society was reduced, and we wish we could keep working remotely and having a valid reason for declining most social invitations.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	See previous - it depends on the autistic person.

Name	Cody Rabalais, Parent/Autism Society of Acadiana Board Member
Demographic	Family member of an autistic individual; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The inability for public school systems to provide the care and support for children with co-occurring conditions without outside professional assistance.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Children with co-occurring conditions too often lose out on receiving a proper education due to the lack of ability, knowledge, and training required to ensure these children can be included, understood, and cared for based on their individual diagnosis.
What additional research is needed to help address co-occurring conditions for autistic people?	School districts that allow outside services to come into the schools to help children versus schools districts that do not. Services such as Applied Behavioral Analysis (ABA)
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Access to Behavioral therapies in the school setting to help address behaviors that are affecting the children's ability to receive an education.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	With the tendency of Autistic children to gravitate to electronic devices the requirement for remote learning further embedded screen time into their daily lives. The lack of peer interaction during periods of mental development has forever affected all children especially autistic children who often learn by observing others.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Colette
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I was diagnosed with autism at age 72 and I am now 78 and have just been diagnosed with sleep apnea. I started to use cpap 11 days ago. My memory has been deteriorating since 2002 when I first complained to my doctor about it. A at home sleep study was done and I was told I did not have apnea but I had fragmented sleep. Likely this was an incorrect diagnosis and my memory has continued to deteriorate and it is quite bad presently. It is my hope that using the cpap will cause my memory to improve as it usually does but my apnea has likely been present for 22 years so.....
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I also have amblyopia with sight in left eye limited to motion. I have known of this condition since childhood and have accommodated to it. The minimal sight in the left eye does allow me to know a car is approaching on the left when driving. Fortunately my right eye has strong and near normal distant vision and is now accommodated by bifocals with age. I understand that a greater percentage of those on the spectrum have amblyopia than the general population and the same is true for osteopenia which I have. Neither of these conditions is debilitating presently and I exercise aerobically and do strength training to try to keep the osteopenia from worsening.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I do not have any of the above conditions.
What additional research is needed to help address co-occurring conditions for autistic people?	I am not a researcher so I do not know but I think the medical community should be more knowledgeable about level one autism and also co-occurring conditions for autism.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	We need doctors who understand autism and will listen when symptoms are given and not tell the patient that they are wrong about the symptom they are describing. The doctors are not knowledgeable that ND individuals have different symptoms than NT individuals. I have a very high tolerance for pain. I was at the emergency room as I knew something was wrong but I did not have pain. I had an inguinal hernia and 2" of my bowel had to be removed as it was incarcerated. The ER doctor did not physically exam me and finally understood that I had a hernia, etc when he took a CT scan. He told me I should have told him; I think he should have examined me which he did not and he would have found the hernia. In 2002 I told the doctor my memory was affected and he sent me for testing. I said to him but you do not have a baseline as I knew my memory was above average. The neuropsychologist said my memory was within "normal" range, etc but likely the incorrect diagnoses of no sleep apnea and "normal" memory progressed to my current memory difficulties and I lost the enjoyment of my good memory for the past 22 years. Some of my other senses differ from NT patients and again doctors have not believed the symptoms I have given to them.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I do not have a direct answer to your question. I had all of the vaccines and boosters so I never dreamed I had covid on Oct 7 2023. After having a variety of symptoms for some time my daughter suggested I test for covid and yes, I had it. It appears it was present for about 6 weeks and then for about another month my capacity was not what it used to be. I am now just getting back to having my "normal" amount of energy. Since about age 50 I have exercised aerobically and done strength training and my HDL recently

	<p>was 67 which is quite high and likely a result of my enjoyment of gym activities. But, I guess my age of 78 caused the covid too really “sap” me.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>I very much like having telehealth and hope the government continues with it indefinitely. I think covid was less mentally detrimental to me because I need less social interaction than a NT. I isolated at home and I live by myself. I had an elliptical machine and I increased my aerobic to 1 hour on it and it strengthen my legs. I also have a full set of dumbbells and love lifting weights. I have a balance pad so I do balance exercises weekly also as well as strengthening and range of motion.</p>

Name	Colleen
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep always running believing people was used as a mule for drugs
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	All of them .. he has been placed in jail Maximum security Elmira 26 guards beat him bad now Wende. The Judicial system, attorneys, judges all failed. Been in and out of system since he was 9 awful
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Authority figures that don't understand autism ... Family court, judges, attorneys, probation, addicted to drugs, was raped it's has been awful ... Was Summitt until he was able to talk.
What additional research is needed to help address co-occurring conditions for autistic people?	Education...school, police, judges, jails, guards, attorneys, it's awful. Due to high functioning Summit learning picked and chose who to keep and sent the high functioning into the world to fail. The whole system has failed badly.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Have services that stop quitting on my son [PII redacted]. Community waiver based program failed miserably, waiting lists that you will never get called. Due to transition to adult they lost my son the courts family Judge [PII redacted] uneducated about any disabilities kept asking why he was acting the way he was and then put him in secured it's been horrible...the services failed summit failed the schools failed all due to Autism and behavior due to him being raped after he was raped is when he was in trouble with the law ... NO one cares NO one so he's in jail Maximum security...I have messages he lost part of his ear was beat so bad. He now has serious issues has mental health seizures so much neglect by jail court it's unreal ... I'm so upset I have 3 kids and 4 grandkids.. pat only child/Adult with Autism !!!
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	He went to jail due to waiting list OMRDD services years on waiting list housing etc.... the system has failed my son ... His civil rights have been extremely violated ... City honors refused to educate him saying he was unable to learn.... Due to behavior then police courts etc... failed failed failed ... My son almost died Oct 13, 2022 at the hands of inmates and guards!!! he had broken finger NO EAR LOBE has extreme pain ... Neglect of medical neglect all around ..
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	Waiting lists failing services OMRDD services are fully responsible for the neglect and community waiver program never coming due to COVID never calling it was unreal my son still receives NO disability from NYS ... Community waiver program stated due to covid they must not of received it. So [PII redacted] is in jail !!!

in-person social interactions and obligations)	
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Name	colleen allen, autism alliance of michigan
Demographic	Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Access to healthcare - providers and health systems trained in autism to sufficiently support need for services - informed/trained providers, ADA accommodations, sensory friendly environments, reimbursable (private insurance & Medicaid) extended visits for people with autism. Access to quality crisis care - psychiatric, trained behavior analysts, facilities, etc.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Management of aggressive/self injurious behaviors; people with autism are ending up in emergency rooms, restrained and sedated when a behavioral escalation exists versus being directed to trained professionals who can manage behaviors from the earliest point of escalation to situations that become unsafe
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The behavioral health workforce shortage that existed before COVID has become significantly worse.

Name	Colleen Floyd
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My 19 year old daughter with Autism suffers also from Generalized Anxiety Disorder and Schizoaffective Disorder. This comorbidity is complicated by her developmental disability resulting in a low IQ of 67. Fortunately she is verbal and can articulate the horrors (psychosis) she experiences so we can prevent her from harming herself or others but it certainly makes out of home placement (for her safety) very difficult as a youth and soon as an adult. There is an overwhelming need for specialized homes to accommodate people with Autism with severe mental health co-morbidities.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The most significant challenges occur as the child matures into adulthood as there are limited placements for these individuals who present with a complicated set of needs and abilities. It is not a one size fits all so it must be tackled on a case by case basis. It is hard to plan ahead, not just because of the emotional component faced by parents, but because as these affected individuals mature their needs change. Community housing and knowledgeable caregivers to run that specialized housing is needed at every level of care for this community. It is a heartbreaking societal reality that must be addressed.
What additional research is needed to help address co-occurring conditions for autistic people?	When my daughter with Autism presented with Psychosis in 2019 I had doctors and therapists and psychiatrists and school counselors and caseworkers tell me that they had never seen that co-morbidity before. That tells me that more research needs to be done in this area because as a society we need to be educated to understand, for example, that often "Autism" is not just "Autism" as most people understand it, but instead a complicated set of issues that need to be understood and embraced as part of the diagnosis and therefore part of that person. We need to accept and help one another as these same people still have a lot to offer society.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I made a conscious decision when my daughter was diagnosed with Autism and Schizoaffective disorder to actually say the word Schizophrenia out loud instead of whispering it -which was my initial instinct- because I wanted to in my small way attempt to break the stigma that surrounds mental illness. It was especially hard in my case because my daughter also has a low IQ so she could not articulate what she was experiencing for a couple of years, until we all understood the extent and seriousness of her condition. Once this type of thing is understood and accepted then services can offer more as needed such as specialized group homes that offer intense support. My daughter will be 21 soon so this issue is front and center for me.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on	

physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

Name	concerned citizen
Demographic	Autistic individual; Service provider, health provider, or educator; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I think the most significant challenge to physical health is that we approach healing conditions from a top down, rational to body approach when the problem is in the body. Cardiac health perhaps being chief among the most potent risk factors to autistic health and lifespan continues to receive little funding and remains deeply misunderstood in our population. Additionally there are an increasing number of grant applications seeking to see polyvagal theory research in autistics, but there is little to no guidance on what is considered accurately captured Respiratory Sinus Arrhythmia. Solutions ranging from bleach consumption to behaviorism make these claims with little to no knowledge of how to actually collect or current neurophysiological literature. What may be helpful is research to establish non-autistic baseline data across ages 3-18 for heart rate benchmarks to serve as a measurement for heart rate against.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The most significant challenges are cardiac in nature, which effects all other systems within the body of a person with ASD. Thus a problem with anxiety and loss of consciousness might be based in period cycles. There is minimal understanding taught to professionals in the mental health space of autistic bodily function and how it influences mental health of autistic individuals. This mirrors the history of mental health which was largely cognitively oriented before it began to focus on the role of the body in trauma treatment. We need to side step this historic mistep, and begin to look for solutions to autistic mental health that take a body, to emotion, to cognition approach. Or stated more succinctly, a bottom-up way of working.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I would argue shortened lifespan. The commonly held view is 17 years shorter than the average american male.
What additional research is needed to help address co-occurring conditions for autistic people?	Research cardiac health and autonomic functioning in autistic individuals for the safe of increasing life expectancy. I'd like to live as long as someone without autism, why can't we do that yet? Cardiac health would be a really decent place to begin.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Mandating that insurance companies treat autism as a mental health condition not a physical health condition. Requiring schools to take an autism diagnosis from a licensed mental health provider, not solely psychologists under reform to IDEA. Medicaid and medicare policy revisions to allow psychological testing to be performed by mental health professionals like LPC's, LMFT's, and LCSW's who undergo adequate training to administer such tests as the ADI-R, or ADOS-2. This would go a super long way in reducing waitlists to diagnosis and still retain the integrity of testing, if not improve it. Differential diagnosis practice guidance and research in this area to prevent more false positives on the ADOS-2 and ADI-R.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic	greater flexibility to remote work possibilities has been realized for the disability community. On the contrasting side, loss of basic social functioning has appeared across nearly all age ranges.

people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Connie Fidler
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Our son has tried to commit suicide many times. He is currently on the correct medication and counseling regime and successfully completed a course of ECT. The challenging part: This is after YEARS of trying to get treatment successfully. Many physicians and/or facilities do not want to deal with the Dual Diagnosis of Autism and Mental Health. It is like a stop sign is held up and you are told to seek treatment elsewhere. The other issue is cost. We are paying out of pocket for counseling and psychiatric care because in order to find a qualified practitioner in both mental health and autism, you need to look as they do not take medical insurance. We have had many practitioners say they understand autism, but after a visit, you realize they do not know how to deal with an individual with autism and you are searching again for someone to assist your family member.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I will answer the learning/communication disabilities portion. We have an IEP and know the methods that assist educating our individuals with autism. The school district and/or classroom employees, frequently, do not understand the importance of following the IEP. For instance, when our son was in 3rd Grade, most of the children with autism missed a question on a fill in the blank/answer with a sentence because of the way the question was worded. The special education teacher did not seem concerned. This happens frequently.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Accessing services is the most difficult part. I am my son's advocate. If he did not have me advocating for him, he would not be able to navigate the healthcare system using insurance and making appointments and finding the correct practitioners for his issues.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	

in-person social interactions and obligations)	
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Name	Coordinated Care Alliance
Demographic	Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Based upon our membership data, over 12% of all individuals with Autism also have a chronic gastrointestinal or genitourinary tract disorder or disease. In addition, approximately 20% of our Autistic population, have a co-occurring respiratory or circulatory disease.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	According to our member data, over 40% of our members have been prescribed an ADHD, Antidepressant or Antipsychotic medication, indicating difficulties maintaining a consistent mental state, potentially creating barriers to employment, education, social interaction and self-care.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Individual with Developmental Disability are who we directly serve. Having severe and profound intellectual disabilities, create significant barriers and restrictions for an individual to be self-sufficient and safe. Often times, IDD can be taken advantage of by "caregivers" or misdiagnoses, mistreated or overmedicated due to communication and cognitive issues. This may be a reason why over 25% of our population with Autism, have not seen an outpatient medical provider in the past 12 months.
What additional research is needed to help address co-occurring conditions for autistic people?	Diagnostic criteria, equal access, Medicaid advancement and increased funding.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	By increasing funding and reducing administrative costs, an enhanced Medicaid system would increase the availability of physician and specialty clinical services such as PT, OT, SLP. Currently, there is a massive discrepancy between Medicare and Medicaid in providers who accept them, same for commercial insurance.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	During the pandemic, resources were limited creating gaps in care plans, leaving people at higher risk of adverse health effects. While those gaps are narrowing, many providers have not fully recovered, creating a myriad of underserved populations, including Autism and developmental disability.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increased remote services does hold promise for individuals with Autism as well as other chronic conditions including mental, behavioral and physical disorders. However, improved reimbursement and availability is paramount to long term success.

Name	Courtney, Parent of diagnosed child
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gastrointestinal disorders Sensory integration challenges Motor planning
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My son has diagnosed ADHD (combined type) and Generalized Anxiety. His ADHD affects him almost more significantly than his ASD -- especially his impulsivity and aggressive behavior (controlled largely by ADHD medication). His anxiety has him worrying about social relationships, which because he is Autistic, he is not well-equipped to navigate. For example, when he can't get a peer's attention, or he perceives he has been wronged, he will lash out. He perseverates when he perceives he has done something "bad" to a friend (out of impulsivity or inability to navigate the social situation). The rigidity from his Autism exacerbates his ability to navigate friendships. And everything can spiral. I worry about his long term mental health and his risk for depression.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My child has above average intelligence and is highly verbal and communicative. The ADHD and Anxiety mentioned earlier are the larger concerns for me.
What additional research is needed to help address co-occurring conditions for autistic people?	We need more research on the efficacy of clinical interventions to better inform school-based accommodations and professional development for schools. For example, I find that the use of Declarative Language with my child has made mountains and lasting positive impact. Study this approach among other alternatives. Also, occupational therapy-based therapies should definitely be studied more! Public policy should most definitely look at the connection between sensory regulation and academic performance too. The schools seem to be in the dark ages when they look only at whether or not the child can "access the curriculum"
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	See earlier response on school-based interventions. Also, the level of training general pediatricians can't be much. I actually had a pediatrician say to me that she wasn't worried about my son's symptoms because Early Intervention was following him. I changed pediatricians. I can also confidently say that I know more about practical presentations/symptoms of ADHD and Autism than my son's current pediatrician. It's mind boggling.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services,	I was lucky. My son got diagnosed at 22 months in May 2020 and amazingly got some in-person services during lockdown.

increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Crickett Ravizee
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The most significant challenge for autistic individuals with co-occurring conditions is receiving diagnosis and receiving and maintaining care for those conditions. It can often be difficult for autistic individuals to navigate the medical community in order to be diagnosed formally with many co-morbid health conditions. In the case of my own child, because of his communication differences, his complaints were not taken seriously until I had to push for testing after 6 months of active GI symptoms. The GI at UK was more concerned with my son's psychiatric state. My son did end up having a condition called Eosinophilic Esophagitis and a lot of internal damage. He has dealt with diet restrictions, daily medication's, and regular endoscopies since which are necessary, but cause him additional trauma. My son is verbal but as many Autistic people do, he doesn't make consistent eye contact and can be selectively non verbal and unwilling to engage with new people. This has regularly led to difficulty dealing with physicians as many providers feel he should be at an age to speak on his own behalf. My son also struggles with communicating his general health, because he only discusses the symptoms he is immediately experiencing and will not take into account symptoms he is having off and on or the night before which makes it difficult to be screened for regular illnesses. My son also has a sleep disorder and a genetic Allergy trait
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The most significant challenge autistic individuals face with co-occurring mental and behavioral health issues is lack of understanding of their conditions from people in positions of power over them, such as teachers, physicians, employers, police, and even sometimes mental health providers. This is often due to misconceptions about autism or misinterpretations of autistic behaviors. For example, my child's anxiety was often seen as defiance in the school system, because he would freeze followed by a meltdown when continually pushed.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The most significant challenge autistic individual's face when it comes to other co-occurring conditions, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities is finding people who have the ability to properly assist with these struggles. Autistic individuals with higher IQ are often not given Adequate support for these conditions and autistic individuals, lower IQ are not always encouraged to work with these challenges. Assistive technology would make a big difference in this area, but are often cost prohibitive.
What additional research is needed to help address co-occurring conditions for autistic people?	There needs to be more research on best practices to educate people who are likely to care for autistic individuals but not necessarily specialize in caring for only autistic individuals. I believe, researching techniques, and then implementing them, would improve the experience of the community as a whole.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Having an autism, sensitive advocate, available and covered by insurance would be life-changing for many individuals.
What lasting impact has COVID-19 infection and illness had on co-	Covid has further isolated many people with autism. The waitlist for care has only grown and many community supports are gone. Smaller programs that were beneficial to autistic individuals mental health often were not able to

<p>occurring physical and/or mental health conditions for autistic people?</p>	<p>stay open during Covid. I have also noticed a decline in my son, overall health since having Covid in 2020 that has impacted his quality of life and his ability to stay mentally healthy.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Disruption in services, and a move to more telehealth services has been a major area of concern with my autistic child. In his case, he does not respond well to telehealth services and disruption of services dis-regulates him. I am grateful for the ability to access telehealth services despite my son, not responding to them as well, however, because it makes it easier to at least access services in times of emergency.</p>

Name	Crow
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbance, sensory and motor challenges
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Suicidality, self injury
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Ids
What additional research is needed to help address co-occurring conditions for autistic people?	Mote research into sleep disturbance would be lovely, especially into circadian rhythm disorders. Lots of autistic people have them and they are commonly misdiagnosed.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Accessible services (text instead of phone call, maybe), less infantilization by medical professionals. Also more financially accessible services, autistic people are significantly more likely to be unemployed
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Services are harder to access due to more precautions with no alternatives for alternate access. Plus long coverage making chronic conditions worse
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Options for remote appointments is good. But only remote can cause problems for people who cant make phone calls or cant speak. Supply chain issues causing problems for people with restrictive needs like specific food, specific medical supplies etc.

Name	Crystal Neihart
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My son has sensory issues (sounds, new surroundings, etc.) I try to bring him places for example the zoo, or family gatherings, birthday parties, train expos, he loves trains. He gets overwhelmed by all the people, the noises. He has on multiple occasions ran away in fear and put himself in dangerous situations or has panicked so bad that he falls and hurts himself. He has run into the road with traffic not realizing that he could get hurt.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My son will get so nervous around new people, and in new situations that he doesnt enjoy himself at all, infact I feel like I am torturing him by bringing him to do what other kids would view as fun.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My son has a hard time communicating with people. Often times when he talks to people besides me, they look my way and ask what is he saying. This puts a strain on relationships with family and friends. It's hard to bond with family and friends when you can't communicate. For example, my sons cousins can call eachother, grandma/grandpa on the phone. When my son calls on the phone, he is not understood. Nobody calls him on the phone. Which is stark difference to my other children when they were his age and a stark difference to his cousins. It is sad he doesn't get the same relationships as other children his age.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	My son is attending ABA therapy. The center he goes to is not "in network" with insurance. Clinics that are in network have years long wait lists. Because of this medical will not provide transportation to and from ABA therapy. I have to leave work 2 times a day to transport him myself. I either take sick time, unpaid leave or i balance my hours (for example; start work at 6:30, leave work from 7:30 - 8:30 to drop him off, work from 8:30 - 3:30 leave work from 3:30 - 4:30 to pick him up, work again from 3:30 - 5:30. I work 9 hour shifts so that I can have every other Monday off for speech, OT therapy, ABA therapy, and my bi-weekly meeting with ABA staff and whatever other appointments are needed for myself and family. I am not currently being reimbursed for gas or unpaid leave etc. I was denied Social Security for my son as I make too much money (I am a single mom with 3 children). I requested a MNCHOICE assessment. It took 2 months for someone to call me back to get it scheduled. The assessment was finally done in Oct. I started the process to have him SMRT'd right away. That is still in review. It is now Jan. and since he was not certified disabled in the short 90 day window after the MNCHOICE assessment, I have to start the process over to get services through Dakota County. I am now out of sick time at work.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	

What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

Name	Crystle
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Managing multiple conditions and trying to figure out which one is causing symptoms. A stomach ache because you have anxiety isn't treated the same as an IBS stomach ache because you ate dairy.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	When they all are acting up at the same time and make life harder.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Providers who don't think you can have multiple diagnoses. Having no resources as an adult. It's very difficult having to work a full time job as it's mentally draining, but I can't not work.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Don't assume we will ask for accommodations when we don't even know what accommodations we can have. Depending on my energy levels, I can not and will not read the reams of paperwork that comes with governmental and healthcare care work. My brain won't absorb the information correctly. Case workers should automatically be assigned when applying for governmental programs and healthcare settings. They should give you the option to opt out if you don't feel you need it or for them to periodically check on you.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Wearing a mask for so long is over stimulating. Certain sensory conditions can make repeated touch feel painful and that makes wearing a mask, even for short periods over whelming. If you have a job that requires mask wearing, that can make over stimulation happen quicker and burnout worse
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I'm happy to have more tele health options. I'm glad to have less stress on social obligations.

Name	Cullen Forster, Veteran
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Hypermobility disorders are common among people with autism, and have wide-ranging ramifications, because ALL connective tissues in the body are affected. Ironically, this may manifest as restricted range of motion, as the muscles tighten under the burden of compensating for loose joints and ligaments, to protect against injury. This hypermobility can also affect the vascular system, up to and including Postural Orthopedic Tachycardia Syndrome, a posture-based increase of the heartrate to compensate for a drop in blood pressure when blood pools in the elastic vessels of the legs – most experience this drop in blood pressure as a faintness upon standing, without loss of consciousness, and as a sudden onset of anxiety due to the biofeedback of the racing heartrate. Hypermobility can also cause sensorimotor challenges for hand-eye coordination and balance, because the loose joints deprive us of useful feedback about the orientation of our limbs – this leads to a general lack of bodily coordination, which may cause accidental injury at a disproportionate rate for autistic people.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Autistic people are trained by society from a young age to behave in a specific way, forcing themselves to hide the way their acute senses present information differently, and to consciously mimic the behavior of others in a bid for social integration. These efforts to mask their differences are frequently unsuccessful, aggravating a social ostracism by those who do not experience these things, and who socialize in a natural way by instinct alone, without conscious effort. A rapidly-growing population of young adults, around the age of thirty, are forced to come to terms with the emotional and physical toll of the excess effort required to socially integrate, and the social mask irrevocably disintegrates under the physical exhaustion. The exhaustion is aggravated by the onset of depression, due to the act of conducting your life counter to your core beliefs, while masking. This subtle development over years of failed attempts at socialization becomes an acute onset of neurological decline and a loss of valued life skills – the common term is “autistic burnout,” but the wording leads outside observers to assume the autistic person is experiencing short-term exhaustion; in reality, this neurological decline takes 3-5 years of applied effort before any degree of recovery occurs.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	A complicating factor is the frequent co-occurrence of ADHD with ASD, which have contradictory traits, resulting in an approximately-normal person with unusual habits – both developmental conditions tend to mask the contradicting traits of the other, until one or the other is detected and addressed. From the dopamine-deficient neural condition of ADHD, and the excessive sensory input of ASD, the individual endures emotional distress when under-stimulated, and physical distress when over-stimulated, requiring a careful balance of stimulus to retain functional behavior. This co-masking nature of the dual conditions leads to a large population of adult individuals who are unaware that their daily struggles to function are not experienced by the majority, and they suffer in silence, ignorant of both disorders they’re experiencing and trying to compensate for.
What additional research is needed to help address co-occurring conditions for autistic people?	Co-screening for ADHD and ASD may help identify individuals who are experiencing and enduring the contradicting traits of both; additional effort needs to be made to consider populations of persons of color and for female patients especially – the stubbornly-prevailing belief about autism is that it only affects young, white, male children, when that is simply the population least-strongly conditioned by society to hide their autistic traits from scrutiny.

	<p>Autism and ADHD are far, FAR more prevalent than current figures depict, especially when considered as a co-occurring condition; the CDC lists a figure of 1 in 36 individuals, while the apparent prevalence – in the university setting – is much closer to 1 in 10, by visible behavior signs alone. Add to that figure the number of individuals who have become adept at adapting their behavior – by conscious effort – to societal expectations, and the figure rises sharply; they are still autistic, and still suffering difficulties not shared by the majority. Updating current institutional knowledge about ADHD and ASD, to reflect the actual lived experiences of autistic people, is critical to helping autistic individuals find community and support from their co-sufferers, who have learned effective coping skills for the struggles involved with their unique neurological development.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>The capacity of screening and diagnosis for adult autism desperately needs to be expanded, nationwide. The waiting lists to receive a screening or diagnosis is months at minimum, years at the worst, which can have negative results as the person awaits receipt of official documentation, to receive accommodation in the workplace or scholarly setting. The cost of the screening is also excessive, at approximately \$3000 out-of-pocket, especially considering the possibility of receiving a false-negative diagnosis from a provider with outdated, male-centered education about autism.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>Under the acute sensory environment of autism, the altered senses invoked by “long COVID” may be especially disabling for autistic people; previously-acceptable foods may no longer be edible with an altered sense of taste, further limiting their access to adequate nutrition. Under long COVID, the reduced lung capacity may compound with the effects of POTS to induce struggles to remain conscious after standing, at lower thresholds than previously endurable. The disproportionate injury rates for autistic individuals with hypermobile joints – and the problems with hand-eye coordination that accompany it – may be negatively affected in the rate of healing, with a hindered cardiovascular capacity under long COVID.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>The increased access to and acceptance of remote work is almost certainly of most benefit to autistic persons, allowing them to better function in a sensory environment tailored to their needs. A cultural drive to “return to the office” may deprive opportunities for employment for individuals who were previously able to provide labor – an internet connection is much more accessible than a functioning car and a suitable commute. Additionally, forcing autistic people back into the workplace, when remote work was previously feasible, subjects them to sensory environments they can’t control, negatively affecting their capacity to work, and hurting the output of the workforce in aggregate. Hostile social work environments are especially detrimental to autistic people, who struggle with performing the correct body language, and who are not naturally adept at operating within the confines of social hierarchy; these are learned skills that take time and patience to cultivate, and inadequate management structures lead to failures to mediate social conflict – the figure of only 15% of autistic people maintaining steady employment is directly reflective of a near-absence of effective support within the workplace in Western society; autistic people bear nearly the entire brunt of trying to maintain safe, productive workplace relationships, or face chronic unemployment.</p>

Name	Cyndi
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety is extremely high in some, especially when someone is non-verbal or minimally speaking. More focus on how to help this vulnerable population is important.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Autism at its core, is a social communication disorder and a developmental disorder. This questionnaire is very misleading, since these are not “comorbidities”. All of these issues cause significant negative impacts on many with ASD. We need to bring even more focus on the people with ID and severe communication challenges. They are being left behind and spoken for by verbally-privileged advocates. Their experiences are very different. More families need to be listened to so our loved ones will stop being put in the dark.
What additional research is needed to help address co-occurring conditions for autistic people?	More research on gestalt language processing, AAC, different therapies for autistic people.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More everything. Children and families are suffering. They have waiting lists up to 2-3 years in some places for diagnosis, as well as several months for therapy. High needs adults are suffering. Lack of day programs, group homes, therapies are a very huge burden on families.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	My adult son developed Autistic Catatonia during the pandemic and is still recovering. All of the day programs in our area are still functioning at minimal capacity due to losing so much staff during the shutdowns. Most clients haven’t been able to return. I have been told there has been a spike in catatonia diagnoses in our area due to the loss of services. My son was severely injured in a day program that reopened at minimal capacity after the pandemic. He has been home with me ever since. Safe options are minimal, and that is inhumane. The high needs community are not properly being represented by your verbally -privileged self-advocates and that needs to be fixed NOW.

Name	Cynthia L. Reed, Parent
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Epilepsy, Celiac and Diabetes mean that we need to constantly monitor all food/drink intake and be sure that meds are taken regularly. Any GI or A1C disruption means poor sleep which triggers seizures. Constant observation for seizure activity. Our son's life is monitored every hour he is awake and we sleep with an ear to any unusual sounds/activity. We need to remind day staff about his dietary restrictions. Group home providers in our state will not accommodate his diet restrictions so he remains at home as we age.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	He is self-injurious when he does not feel well. It is one sign that we need to check his health status more closely. Usually gut related and sleep deficits lead to these behaviors. Close observation and management to prevent these issues requires full time caring and he is now 31 yrs.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Our son is non-verbal, so relies on speech output from his augmentative device. He has no ability to describe pain, feeling poorly or respond to medical questions. He has developmental and intellectual disabilities. Family members accompany him everywhere when not attending his day program. He does not drive, cannot work independently, and has no safety awareness, so parking lots, exiting a building, danger from strangers are ever present.
What additional research is needed to help address co-occurring conditions for autistic people?	Research that explores the connection between gut health and developmental delays. New approaches to speech and language acquisition. Look into why cancer rates in people with Autism is so low and what else may be connected to that "protection" as a way to unscramble some of the associated comorbidities.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Easier access to regular meds so that prescription renewals are not an anxiety producing event as insurance companies have tightened the window for refills. Medical and behavioral teams that do home visits for routine medical procedures and behavioral interventions/trainings. Housing for adults with Autism!!! Provider training for more effective care. Recognize that "community" is the place that welcomes our son, his posse, NOT forcing him to be part of the broader community. Have program providers understand medical comorbidities and train staff to make appropriate accommodations.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It was a re-set. More online programs were offered which was a huge bonus. Forcing autistic people to attend in person classes, recreation etc, is not always in their best interest. Online classes (yoga, dance, strength & conditioning) are accessible and cost effective. Every state should offer them statewide. The resultant online community is amazing. Train more providers of these services. Huge fall off in community work opportunities, volunteer and paid. Need to regain and expand those opportunities.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school,	Telehealth and online programs have been wonderful and should be expanded. In person opportunities are growing, but can be over-rated. Social interactions should be meaningful rather than just more time in a van going from A to B. "Social" needs to be re-examined to include what is meaningful for autistic individuals, not what the general population considers social. Overcoming sensory issues in many public settings makes it not worth participating as the rest of the day becomes a nightmare.

increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Cynthia Macluskie, Autism Society of Greater Phoenix
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gastrointestinal disorders, feeding issues due to sensory issues resulting in limited diet and interfering with social relationships, ADHD, Obsessive Compulsive disorder, epilepsy, mitochondria issues and genetic abnormalities, sleep issues, sensory issues, epilepsy that presents as violence, motor planning issues, articulation and social pragmatic issues,
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	1. Aggression and self injurious behavior often as a result of pain or seizures and inability to communicate the pain. 2. Anxiety and it inferring with building social relationships and participating in social activities. 3. ADHD 4. Executive functioning and planning skills 5. Depression.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I think the medical co occurring issues are the most important as they impact the ability to participate in life and live pain free. Often they are mislabeled or misdiagnosed and many professionals do not validate or listen to the family or the individual. Learning disabilities such as dyslexia can impact how they learn and their success. Often the global diagnosis makes getting additional services for learning disabilities difficult. Communication disabilities can be profound. Many believe that people who are non verbal are also not very bright and do not have thoughts or feelings. This is not true.
What additional research is needed to help address co-occurring conditions for autistic people?	the biggest issue is raising awareness with the mental health and physical health professionals that work with those on the spectrum. There is so much discrimination and lack of knowledge around comorbid conditions. We need to use research to inform and educate professionals.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Education of professionals at ERs, behavioral health facilities and medical professionals. Allow for complete medical evaluations in behavioral health facilities instead of saying these evaluations are outpatient services. Allow ERS to do complete medical comorbid evaluations for those with complex symptoms whose behaviors may prevent them from getting outpatient evaluations. Fix billing issues that would allow for both behavioral and physical health evaluations at the same time.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Cynthia Tyler
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	As the mother of an autistic child, I have witnessed the co-occurring physical health conditions from nearly the birth of my child. Sensory and motor challenges, including potty training, food aversion, educational structure challenges, and lack of societal support and understanding abound. As my child has grown and aged, it has changed to include gaining a tremendous amount of weight, which has contributed to sleep apnea. Food aversion means that there are only a limited amount of foods my child will eat, and those have become more expensive. The types of food also can't be swapped out for cheaper brands, due to the additives like bleached wheat flour and high fructose corn syrup which contribute to heartburn and reflux. Sensory issues also cause skin-picking, which can become infected. We have to carefully monitor hygiene, in order to prevent any further hygiene related issues. Dental problems have occurred, as tooth brushing is its own type of sensory issue, which have only resolved through therapy work and supports. It also extends to psychological health, as media has to be carefully curated to prevent exposure to concepts that my child does not have the current capacity to process, understand and interpret. These will only continue as my child ages into adulthood. This will impact my life as I age and will have to care for him until I die.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I am fortunate that my child is relatively mentally healthy. He has been surrounded by a positive and supportive environment, which has contributed to that. However, that is an outlier in the statistics. An autistic child will thrive in an environment that supports them, and many many autistic children do not have that, which results in poor behaviors that they model, or react to, as they have no other source to draw from. Regardless of how positive my child's family support is, my child still will experience over-stimulation from stress, environmental changes, sickness, hunger. The reactions to these include jumping, hand flapping, audio-visual stimming, and occasionally a rare meltdown.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My child will not have a robust social life, nor an independent one where he can live fully on his own. It is difficult to connect with other peers, and it will not be possible for him to live independently. With supports, he will hopefully be able to have a happy and full life, but without supports he will wither. There is no way an autistic child will be able to thrive without supports.
What additional research is needed to help address co-occurring conditions for autistic people?	All of it. More funding is needed. A more comprehensive understanding from society that autism has profoundly changed the fabric of how we live our lives together. More research in how autistic individuals can be critically important in understanding the use of higher-level algorithmic thinking that is now employed in most of the technological applications we use daily. And you must include autistic individuals in a collaborative way while completing research. Autistic people are not diseased and unaware lab rats. Listen to autistic voices FIRST.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Autism is as common now almost as common as wearing glasses- which is the most common disability in the world. It should be as easily adapted to as that. Disability services in this country are abysmal and need a massive update. Ask autistic persons FIRST and LISTEN to what they say they need, involve them in designing the access to services and supports.

<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>In a way, it was a quieter world during COVID. Autistic people were more isolated, but some (not all, as not all autistic persons are the same) were more able to regulate their environment due to the isolation. But autistic persons with higher-support level needs also experienced a struggle as their caregivers experienced that isolation as well, which did become overwhelming in cases. Remote access jobs are a boon to the disability community as a whole, the technology removed the mobility requirements and access requirements, and as we have shifted back from that in the following years, that has negatively impacted disabled Americans, not just autistic persons.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Remote work actually benefited many disabled individuals and autistic persons. The remote work allowed them to interface and interact in more accessible ways. The disruption of schedules was disastrous, however, as structure and schedules are the backbone of many autism families.</p>

Name	D. Buzz, guardian and SDE Supervisor
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Lack of quality and qualified services. Critical lack of individuals properly educated and trained to care for autistic individuals with co-occurring physical and behavioral needs. There is a critical need to develop college-level curriculum that focuses on caring for these individuals.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Lack of access to what I call focused services both medical, educational, vocational, social and community. The generic education and training that so called professionals have is inadequate. There have to be doctors, teachers, social service staff and, most importantly, personal care companions that have very specific training and skills in this area. More money needs to be directed to paying these individuals an appropriate and livable wage and FAR LESS on administrative positions. In other words, too many dead wood at the top and not nearly enough hands-on workers where they are desperately needed.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Too many administrators and not nearly enough thoroughly educated and properly trained care givers
What additional research is needed to help address co-occurring conditions for autistic people?	No more research is needed. Let's apply what everyone knows about this situation to creating more jobs and wages to the people desperately needed to do the hands-on, every day care.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	All of the above. And those supports and services need to be implemented immediately. The time for talk and discussion has long passed. These individuals need ACTION!
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Another excuse to funnel money away from where it is needed and another excuse to undermine the work force needed.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Simply put, STOP USING COVID-19 AS AN EXCUSE TO NOT DO YOUR JOB.

Name	Dale
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Constipation creates enormous discomfort and makes life and learning miserable and difficult. Limited motor skills, apraxia, dyspraxia, means inability to complete everyday self-care and basic tasks required to live independently. It also leads to inability to communicate verbally and makes communication using AAC difficult.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety is clearly a massive problem for many with autism. Life with severe anxiety is extremely overwhelming at times. Self-injurious behavior is quite common, even for those who are considered higher functioning in the autism world. In my experience, it increases along with physical problems such as constipation, or any pain, and of course, inability to communicate which is immeasurably frustrating.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	communication is most important. Even those with intellectual or developmental or learning disabilities can communicate verbally. But if you have motor issues, it is much more difficult to communicate verbally or using AAC.
What additional research is needed to help address co-occurring conditions for autistic people?	Study people with autism who have learned to communicate by using a letterboard or keyboard (S2C or RPM). There are a number of people with autism who can type independently. They should be approached and the issue of how to research and study this form of communication should be discussed.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	All of the above are needed. People need to be trained to provide the medical care as well as learn to support people to communicate using various types of AAC
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Many programs for adults with autism have disappeared since Covid. Transportation services have ended in some areas.

Name	Dallen Williams
Demographic	Autistic individual; Family member of an autistic individual; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The most common conditions I see in myself and other autistic people, as well as those in the community are ADHD, sleep, sensory and gastrointestinal disorders.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	With each co-occurring condition, the autistic person becomes less independent. This can lead to a host of mental health disorders in addition to the autism diagnosis. Co-occurring mental health disorders also make autism and the co-occurring disorders harder to diagnose. This often leaves the person with the co-occurring conditions under- or over-treated. These individuals may struggle with greater instances of self-medication in the form of drug or alcohol abuse. They tend to engage in riskier behaviors and have a smaller support network, especially if they are late diagnosed. The individuals typically suffer low self-esteem and have difficulty maintaining gainful employment. Personally, I have co-occurring ADHD, depression and anxiety. I was late diagnosed with ADHD (28) and Autism (35). Treatment of ADHD was only partly successful because the autism went undiagnosed. While I have maintained employment my entire adult life, it has been well below what I should be earning. I find that I burn out at about 6 months regardless of the work and struggle with attendance. These are things I have witnessed in other people with similar co-occurring mental health conditions.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The most significant issues I've seen caused by other co-occurring conditions tend to be attendance issues, disciplinary actions taken against individuals because they struggle to communicate in a way that is easy for neurotypical people to understand which can cause anything from minor squabbles to actual fights. Gainful employment is hard to obtain and maintain because of the interview structure and the lack of accommodations in roles that are better compensated for people with communication difficulties.
What additional research is needed to help address co-occurring conditions for autistic people?	Adult and female autism should be researched extensively. Current autism models are based primarily on studies of male children, same as ADHD. With the general lack of study of female autism and ADHD, women are often left to self-manage and many are never diagnosed in part due to the different social expectations on females. This leads to lifelong self-esteem issues and often abuse. The separate disorders and the way they interplay to become somewhat invisible in women should be a major focus of study.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	One thing I've found particularly helpful is software to "read" text to me. One on one training on the job is also helpful. More community resources that focus on adult life instruction. Many of us grew up with parents who also did not possess the skills to lead a successful adult life as many of us inherited the conditions. Things like balancing a check book, paying bills, filing taxes, and generally organizing life in some way, down to cooking and cleaning do not come naturally and were not taught to us.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	As an Autistic ADHDer with anxiety, depression and a host of other conditions, I found that the lasting impact is anxiety so severe surrounding doctors' offices and anything that involves going into an office where a sick person might have been causes not only anxiety attacks but also meltdowns. I have not seen a medical professional in person or had blood work done since late 2019. This is particularly dangerous since I have multiple medical

	<p>conditions that require better monitoring, but doctors' offices have not been accommodating of the mental health reasons, I have not been able to go in person. Odd hours or booking so that I can go straight into a room even if the visit takes just as long.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>The most positive effect COVID19 had for autistic people is the restructuring of society to allow autistic people to be in public with things like masks, headphones, sunglasses and hoods up on hoodies. All of these help with sensory issues. There are also more work from home jobs which allow an autistic person to create their own work environment. The negatives include having these accessibilities removed, particularly work from home jobs as many employers feel the need to micromanage. This adds back multiple layers of stress and may result in the person leaving employment or losing employment due to meltdowns. Examples of this include significantly increased social interaction which typically requires masking, increased uncontrollable sounds, fluorescent lighting, close proximity to others, and the commute.</p>

Name	Damaris Hadayia , Parent
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Insurance coverage for the conditions and the availability of therapies on public insurances. The availability of resources for families, to make all the pieces fit together (work and home life) while still providing the needed care for person.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Lack of money and resources to properly manage the comorbid conditions within the families. More conditions cause more absences from work which places families at risk for homelessness and hunger.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Finding the suitable treatment to help with the host of the challenges listed above. Constantly trying to improve education and treatment through the school systems as they constantly try to cut services.
What additional research is needed to help address co-occurring conditions for autistic people?	The benefits of therapies like ABA, benefits of comprehensive IEPs families don't have to fight for, and the affects that more resources would have on the improvement of comorbid conditions and overall wellbeing/ life satisfaction for people who have them.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Equitable access to education and services based on the person, not on school systems/ insurance companies estimation of the cost and the "percieved benefit" of someone they don't know. Better access to programs that help with the cost of having an autistic loved one. Better programs for parents who work and support an autistic loved one. Better transparency in the SSA system and claims through them for assistance! Getting your child the right care/ education and resources should not be an uphill climb made more difficult by those who are supposed to be helping.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It gave my child asthma, which he didn't have before. It also halted all of his therapies, caused me to loose my job, then my apartment trying to care for him during covid as schools and therapies were basically nonexistent. It destroyed my family's life, and eventually cause our homelessness! This should never happen to a family, because of autism!
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Negative- disruptions in services, years of waitlists for therapies and treatment that didn't exist before. Employers attitudes towards parents with children who are disabled has changed for the worse. Theres no longer an ability to balance work and care for severely disabled children. Less resources!

Name	Dana Haff
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Autism is frequently associated with hypermobile Ehlers-Danlos Syndrome (a genetic link is being studied). I have been diagnosed with autism, hypermobile Ehlers-Danlos Syndrome, hyperadrenergic postural orthostatic tachycardia syndrome, mast cell activation syndrome, myalgic encephalomyelitis/chronic fatigue syndrome, nonepileptic seizures, metabolic syndrome, a multinodular goiter with carcinoma that required a complete thyroidectomy, degenerative disc disease, an annular tear of a disc, adenomyosis, an adrenal adenoma, and more. I have yet to see a provider who has any understanding of autism and frequently associated comorbid conditions.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression-like disorders and anxiety-like disorders are rampant in autistic people. However, many of us get minimal relief from standard antidepressants or anti-anxiety medications, raising the question of whether it's really depression or anxiety as currently understood, or whether there's a different cause for these symptoms.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Sensory integration and processing are huge issues and are ignored in adults. It's like the assumption has been made that autism magically vanishes at age 18. It's appalling that services for adults are almost nonexistent.
What additional research is needed to help address co-occurring conditions for autistic people?	Genetic research to provide a better understanding of the common comorbid health conditions, especially as a consequence of hypermobile Ehlers-Danlos Syndrome. I have had several relatives die of strokes due to vascular disorders. I don't want to be next.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Teach providers about comorbid conditions. No physician I have seen has even a rudimentary understanding of the health conditions that frequently co-occur with autism.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Many of us have developed post-viral sequelae because hypermobile Ehlers-Danlos Syndrome is a common pathway to a virus causing ME/CFS, Long COVID, and other post-viral illnesses. I can't say this often enough: no doctor I have seen has any understanding of this.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I had Medicaid for a while and was granted 40 hours a week of caregiver services. The public health emergency ended, I was removed from Medicaid, and now I have no services. I've basically been left to die.

Name	Dana Holz, Center for Drug and Health Studies, University of Delaware
Demographic	Autistic individual; Family member of an autistic individual; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I have concerns about mental health conditions and people with autism. There are problems integrating developmental disability systems and mental health systems. I worry about suicide in the autism community, lack of good crisis response systems for this population, and long ER stays while autistic people wait for mental health treatment. I also think more attention should be paid to substance use prevention and sexual health promotion for autistic people.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Systems do not talk to each other. Mental health needs are too often defined as behavioral challenges.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	There is a lot of attention on so called "high-functioning" autistic people, as well as people with very severe needs. All three of my sons are autistic. Two are minimally verbal and are in autism classrooms. They kind of fit in the middle of both of these populations, and I feel like the people in the middle are kind of left out of the conversation.
What additional research is needed to help address co-occurring conditions for autistic people?	Research on substance use, sexuality, victimization, crisis response, mental health.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Reduce silos in governmental agencies so that funding can be directed to this population, and so that programs are inclusive to autistic people and other people with disabilities. For example, SAMSHA could require states to report disability status in mental health and substance use treatment data and/or provide funding for programs that would be more disability inclusive.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Dani
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory challenges and gastrointestinal problems
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety and depression for me
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication difficulties
What additional research is needed to help address co-occurring conditions for autistic people?	Firstly, more available assessments for adults
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage and access to services
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Danica Allen, Educator
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Limited ability to accomplish the things I want to accomplish.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Difficulty being taken seriously, autism being dismissed as symptoms of cooccurring mental health issues. Doctors trying to medicate my neurotype.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Limited access to resources, community involvement, education.
What additional research is needed to help address co-occurring conditions for autistic people?	More research into real lived experiences.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I like the example given. Also—more individualized support for each unique individual. More funding.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Daniele Armstrong
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	All of co-occurring physical health that are specific to each individual affect them differently and to varying degrees. Focusing on a few specific conditions does a great disservice to autistics who have other conditions that they need more medical, emotional, physical and tangible support needs.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Sadly these questions want to separate different types of conditions, physical, mental and emotional, etc. into groups that will disservice great numbers of autistics. Just because one autistic isn't affected as much by one condition as another autistic will be, does not devalue other mental health conditions that need just as much if not more support a few selected conditions.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Like many people, needing to compartmentalize to break things out and make it easier. I understand why these questions are so specific. Although, since we are looking for ways to service autistic community this is another question to devalue a great number of autistics with the co-occurring conditions.
What additional research is needed to help address co-occurring conditions for autistic people?	Looking at individual conditions with every autistic is the best way to assess and filling those needs. Not a lump sum survey, that will serve very few. Any services will be greatly valued, but still nonetheless, leaving many autistics, isolated and excommunicated even more in our society.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Sadly we need to address the bias within most people who are allistic or those were those who have been mold to believe there is no such thing as autism(even if they are unknowingly Neurodiverse themselves) they are just spoiled and demanding attention, and just need to conform to social ideals. Second, would be addressing the compounded complications of functioning in our society when autistic. For those who have high needs, disabilities that are diagnosed or undiagnosed, along with co-occurring conditions, make it nearly impossible to confirm and work to provide for ourselves in our already failing economy. We have those who are extremely fortunate, looking down at all people with less resources, just telling them to work harder, save more when they are unable economically with the funds, they have to take care of themselves in any capacity with a system stacked against them. This is strong and probably a word solid to most but there's only so much you can express in little boxes.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school,	

increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Danielle Christy, Private Practice psychologist
Demographic	Family member of an autistic individual; Service provider, health provider, or educator; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbances, seizures due to epilepsy
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Co-occurring mental health issues including anxiety, depression, ADHD, and other mental health diagnoses. These can cause debilitating symptoms for people with all degrees of verbal fluency and cognitive ability. There are not enough mental health providers with evidence-based training in both the medical and educational systems.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Lack of training and evidence-based practices by schools to support language (AAC devices), behavior, and learning.
What additional research is needed to help address co-occurring conditions for autistic people?	Research that is led by and organized by autistic individuals. Less research about etiology and cause. More research about how to support this wonderful group of people in the way they believe is most effective.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More training for all medical providers and educational service delivery systems. Move away from deficit driven medial model to a social model of disability where we look more at environmental modifications instead of changing the person. Less funding of ABA and more funding of interventions consistent with the social model of disability.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	For many with co-occurring anxiety and depression, the isolation has continued and caused significant impairment in daily life activities.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Some people and children found remote or virtual work/learning less anxiety-provoking and were able to switch to jobs or schools where this was more of an option. That is a positive. Some people and children had increased anxiety during COVID and due to the isolation did not leave the house, which reduced their social interactions and actually heightened their anxiety so they are still living in an isolated state.

Name	Danielle Mays
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Being developmentally behind; not learning or grasping things the same way others do; unable to communicate verbally; intellectually stunted in areas.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage, more accessible information, programs for all age ranges, services and therapies more widely available, education for both neurodivergent and neurotypical people on autism and other conditions
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Danielle Terrell
Demographic	Service provider, health provider, or educator; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Challenges caused by co-occurring physical health conditions can significantly affect all activities of daily living. The need for families to change their environment to adapt to the needs of this autistic children and family members. Co-occurring conditions can lead to significant challenges accessing appropriate healthcare, & financial barriers.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Access to mental health care resources and services. Limited mental health providers who have experience working with autistic people. Limited professionals trained to work with challenging behaviors. Injury liability. Not enough staff to support individuals with significant needs.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Lack of resources throughout the lifespan.
What additional research is needed to help address co-occurring conditions for autistic people?	Research for autistic adults continues to lack. Addressing gaps in research and increasing studies for non-white cisgendered males. Research on co-occurring mental health conditions. Supporting autistic adults throughout their lifespan. Future planning. Research around co-occurring PANDAS and PANS as diagnosed children become autistic adults. Healthcare access and training of healthcare professionals to support autistic people.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Address staffing issues that have existed for decades. Equitable access to healthcare services, and therapeutic services. Increased training and support for parents and caregivers.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	COVID-19 has impacted individuals, hypersensitivity to infection, increased behaviors, increased anxiety, changes in routines, identify crisis, limited access to services, increased barriers to service.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Disruptions in services, switch to virtual modalities/tele-health, changes in routines, regression, agoraphobic thoughts and/or behaviors. I have a client who was diagnosed with PANDAS as a child, and developed OCD. Their OCD was described as moderate, and they was able to manage his OCD and live a routine life, attend school, social events etc. Since getting the COVID vaccine, and tested positive for COVID there was been a significant spike in their behaviors and OCD tendencies, increase in agoraphobia, and limited social interactions due to heightened anxiety, multiple hospitalizations, denied access to services, financial burdens on the family. Health and safety risks for the autistic person and their family.

Name	Danielle Willsher-Goodman
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Ehlers Danlos connective tissue disorders, joint laxity and instability, problems with dislocation, subluxions, poor skin healing, bruising easily. Fibromyalgia, pain in muscles and chronic fatigue. Issues with POTS balance / dizziness, palpitations varies with degrees of nutritional deficiencies at time as to how bad suffer. Gut biome issues and gastro issues like IBS, constipation, problems with internal organ and soft tissue issues, GERD Sphincter not closing, gas, bloating, chronic coughs, sore throat. Often issues with allergies. Issues with gut also play into being able to digest/swallow food . Also gynecological problems extremes periods menorrhagia bladder problems . Back / neck and muscular skeletal problems in general after poor posture strength in muscles and soft tissue impacted by stress and strain and also inability to gain right nutrition. Also, stress and strain impacts peoples ability to utilize and digest the necessary protein and aspects of lactic acid for collagen production from Lysine. Also issues with dyslexia and dyspraxia can cause terrible self worth and issues feeling like failure or not able to do things and problems with parents, peers and teachers when not seeing or understanding hidden disabilities and thinking lazy and getting punished. Also sleep disturbances, issues with ADHD and concentration too. Sensitivity to foods and ingredients and also medicines.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Mental health, coordination, challenges in school, bullying, concentration, masking from dyspraxia to fit in end in disasters in relationships mistakes, challenging peer relationships, dangerous behaviour, self hatred, blame, scapegoating, suicide and self harm in later stages after years of misunderstandings, blame, ill treatment, bullying and not being listened to
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Misunderstanding, poor diagnosis in time, being bullied in interim, lack of support, lack of group support, too much pressure, not being understood by schools, parents, support services, mental health people, all leading to breakdown and blame, internalizing suffering.
What additional research is needed to help address co-occurring conditions for autistic people?	Listen to peoples experiences, read, lots of helpful diagrams online, many people disbelieved all life. Need to be heard and believed. Text book conditions do not always catch people who are on periphery but they suffer all the same and should be listened to even if do not tick all boxes and criteria. Sliding scale and spctrum with veying degrees depending of diet, coping mechanisms, gut health, life experiences, support. Many struggle to speak their experiences and need support helping to express what they are going through. Very distressing when had lifetime of other stressful and strenuous experiences
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Client centred support built and designed around them and their needs as all individual with individual interests, experiences, preferences and had lots of bad experiences with services already. Need more gentle, tactile, compassionate, trusting and reliable access with colour, safety nets with sensory considerations factored in and no hard and fast expectations.
What lasting impact has COVID-19 infection and illness had on co-	Lock down increased stress and anxiety and brought new level of threats to those suffering with compromised immune systems

<p>occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Less trust, less freedom, more judgement from society and newspapers which is very unfair and increased anxieties and stresses with schools, parents, exams, work, people not understanding fears over germs/virus and issues it has on disabled community</p>

Name	Danni Zou
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disruptions, sensory processing Would also love to see research into any connections with hypotonia and hyperflexibility
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	PDA!
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	More research into PDA, including emphasis on how to best serve in the school system
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Supports to improve education for very high cognitive autistic individuals
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	remote appointments with providers that do not capture the individual

Name	Danny Schaible
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Hyperactive catatonia that co-occurs in ASD, particularly with individuals with profound autism. We need better identification, treatment, access to treatment including ECT, and better catatonia scales for neurodevelopmental individuals.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Aggressive and self-injurious behaviors, in many instances it is believed, associated with catatonia.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Much much better recognition of and early intervention of autistic individuals with catatonia. Any individual that engages in chronic aggressive or self injurious behaviors should be screened and potentially treated for catatonia, but this often does not happen or happens way later than it should. How can we develop better protocols for screening and intervening in this treatable condition?
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Danyale Sturdivant
Demographic	Family member of an autistic individual; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gastrointestinal disorders because they are often overlooked and can cause issues such as sleep disturbances as well as behavioral issues. Additionally, ADHD is another co-occurring disorder that is often missed
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD and Anxiety is often misdiagnosed in black children and other children of color and can be mistaken for other disorders such as ODD
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Learning disabilities
What additional research is needed to help address co-occurring conditions for autistic people?	Culturally responsive research needs to be included to address the intersection of RACE, GENDER AND AUTISM
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Culturally Responsive Research, Diagnosis and Treatment
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	The increase in a lack of skilled service providers who are able to provide telehealth services
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Disruption in services

Name	Darcy Janowski , parent
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	We had to start my son on antipsychotics at age 3 because he was walking my countertops and would not sleep. No safety awareness,elopement
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	aggression when frustrated or doesn't get what they want. self injury bites himself,hits head,breaks windows. pulled a chunk of hair out of my head and has bitten me causing severe pain and scarring
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	nonverbal so uses sign language but increased chances of frustration because others don't know or understand what he wants
What additional research is needed to help address co-occurring conditions for autistic people?	medicine that is safe in children and has less long term side effects
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	psychiatry available and knowledgeable about autism and mental health conditions with it. more school day programs and residential options. paying staff well and educating in care for the disabled individuals
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	my daughter was very social before covid but such a long time with masks and separation from others took that away. She has never returned to the social butterfly she was. just starting to improve recently
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Staff stopped working with individuals during covid and staffing has never recovered. People can make more money at mcdonalds. remote education doesn't work in autism. totally ineffective. no day programs available for my son who has aged out of school and is sitting home doing nothing.

Name	Dave, A citizen from Oregon
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	<p>Dear National Institutes of Health, I write to share my struggles with autism, epilepsy, severe sleep disturbances, and sensory issues. These affect my communication, privacy, and work life significantly. Explaining health issues is a major challenge. For instance, mentioning a generalized seizure is often necessary to justify absences, requiring detailed explanations unfamiliar to most. This issue extends to the workplace, especially when seeking ADA accommodations. The process often feels like a battle, making it hard to ask for what I truly need without feeling cornered into accepting less. Moreover, epilepsy-related executive function deficits limit my economic contributions. In a predominantly able-bodied world, these challenges are magnified. Autism affects communication, so clear understanding of my needs, like missing events due to seizure risks, is vital. When these are overlooked, it exacerbates my struggles. I urge you to consider these experiences in your research and policy-making. Understanding the unique challenges of co-occurring conditions like autism and epilepsy is essential for a more inclusive society. Thank you for considering my perspective.</p> <p>Sincerely, Dave</p>
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	<p>To Whom It May Concern, I am reaching out to share my lifelong journey with autism, epilepsy, anxiety, depression, and ADHD. These conditions intertwine in complex ways, deeply impacting my daily life. My autism has led to social isolation, intensifying my depression. Additionally, the interplay between seizures from epilepsy and ADHD symptoms creates unique challenges. Frequent focal seizures disrupt my focus, and when combined with ADHD, it becomes increasingly difficult to complete tasks. This struggle is often misunderstood, especially in social interactions. Communicating effectively is a hurdle due to my autism, leading to skepticism when I explain issues like memory lapses caused by seizures. There's a significant distinction between having a disability and being disabled. A disability doesn't always lead to debilitation unless it hinders one's ability to live life as desired. In my experience, autism often shifts my other conditions from mere disabilities to a state of being disabled. It amplifies the difficulties I face, turning manageable issues into significant obstacles. I hope this insight helps in understanding the multifaceted nature of living with multiple co-occurring conditions. Recognizing and addressing these complexities is crucial for providing better support and fostering a more inclusive environment. Thank you for your attention to this matter.</p>
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	<p>There needs to be evidence, and easily accessible literature around 1. antecedent interventions in epilepsy. like https://www.tandfonline.com/doi/abs/10.1080/028457199439955 In my life there is a Skinner paper on the possibility of antecedent behavioral interventions can help with epilepsy, this study is an expansion but doesn't go far enough, the science needs further exploration - this hits the nexus between epilepsy and autism in that most treatment for autism is based in behaviorism 2. Some work needs to be done to figure out better tools for job hunting for this cohort. Low paying, stressful, ill fit, and mismatched jobs</p>

	<p>lead to a reduction in the health and well-being of folks experiencing these challenges. That is a health crisis. Researching what happens when the job acquisition process is handled for the subject/patient/autistic person and seeing what happens to their quality of work would be useful. It would also be interesting to see what happens to their earnings v. their allistic or fellow autistic cohort.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Career Placement and Housing first.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>It set me back 6 months on fitness training, it worsened social isolation, it increased anxiety, and the fighting to get insurance to pay for the missing time was terrific, and was made harder by the executive function issues. I had an enormous number of focal and complex partial seizures caused by the infection, and I still am not back to baseline for respiratory health three months later. Beyond that, it has made networking to advance my career much harder, even in the face of the extraordinary challenges that already exist for folks with disabilities. The social isolation and failures of institutions worsened anxiety - seeing the government be inaccurate repeatedly, and the social instability caused by people pretending science didn't exist, seeing 1/5 of americans just call the deaths of the weakest among us an inconvenience, and throw violent tantrums because they couldn't get their hair cut. I live in a nation less safe for me and folks like me than it was 10 years ago.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>On the up side - Remote work has been life changing in so many positive ways. It gives me the opportunity to better manage my epilepsy and do so more responsibly. It allows me to control how much human interaction I am required to have. My institutional trust has been devastated by half of the government showing that they are nudging genocidal by minimizing the deaths of millions of americans because they weren't "The right kind" I feel less safe in public. Particularly when masking. I experience belligerence and denial of access to some businesses because I am wearing a mask, and folks only care because it got politicized by losers. I feel as though the actions of the government during covid emboldened the worst of our society, and I look back at the folks Nazi's started killing and I check more than one of those boxes. The government's complete failure in these matters has worsened my life immeasurably and killed millions. The psychological and social impact of these things cannot be overstated. It is the responsibility of elected officials to act like adults. Their failure to do so endangered and killed millions.</p>

Name	David
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory issues. Smell. Taste. Touch. Over react to loud noises. May be trauma. Sleep issues. Often average 3 to 4 hours pn for extended periods
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Professionally Diagnosed Cptsd Ocd Bipolar Adhd Social anxiety Suspect Pathological demand avoidance Rejection sensitivity
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication my biggest problem. Excel at intellectual by myself. Understanding and being understood tough for me
What additional research is needed to help address co-occurring conditions for autistic people?	I think I was diagnosed in wrong order. Only recently autism but many of my earlier diagnosies may have been due to my behaviors caused by autism. Suspect trauma (cptsd) centered in struggling as autist. All anxiety. Not sure if bipolar mere symptom of my autism but working with docs to establish
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Everything. Healthcare companies dont take seriously and even some providers. Get far more help from peers. I suspect addressing autism more proactively will actually reduce mh costs due to other morbidities that result or misdiagnosis.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I was only diagnosed post covid. But the extra frustrations from covid brought out the worse in my autistic self as things even more chaotic and illogical than normal
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I was working remotely before. Less socializing work of otherwise, was actually easier for me.

Name	David Gartland, Father
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory Issues Sleep Disorders
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD Anxiety
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Learning disabilities Developmental disabilities Intellectual disabilities Communication disabilities
What additional research is needed to help address co-occurring conditions for autistic people?	Early Diagnosis Sensory issues Causes of autism Cure for autism
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Doctors acceptance and patience with unique autistic behaviors
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	None
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Stopped working due to COVID-19 and never got reemployed Remains at home 24/7

Name	David Grady, California State Council on Developmental Disabilities, Central Coast
Demographic	Representative of advocacy organization; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	All issues are important. Also important to consider is the severity of the autism diagnosis. Reports of sleep disorders and its impact on family is significant, but dietary needs/restrictions, behaviors that have a link to obsessive compulsive disorder needs consideration.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Co-occurrence is significant. Data about co-occurrence is limited and scarce. The issues are complex and interrelated. Autism awareness is required by crisis response and intervention, de-escalation, 988 and 911 responses, particularly by underserved populations, and appropriate documentation need addressing. Psychiatric holds, emergency room, transitional housing needs to be adapted to the population. Community awareness building is essential, is needed to shift thinking to those with autism also have behavioral health needs. Special and General Education need to address bullying and other trauma experienced in school and community settings. Education programs and clinicians need training and develop to offer treatment. Research needs to identify the most appropriate levels of care. Language needs to be developed around the levels of autism, with recognition that those with autism Level 3 have requires levels of support often including family, different than those with Level 1.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Recognition that some behaviors might be compensatory and necessary as a coping mechanism. Recognition that ABA might be enhanced with application of social learning theory. Recognition that intervention and treatment modalities may differ for those with autism. Recognition that many behaviors might be associated with anxiety and treatment interventions should include stress management. Development of best practices that promote inclusion, and socialization with others including that without an autism diagnosis.
What additional research is needed to help address co-occurring conditions for autistic people?	Causation. Social Learning vs. ABA. Best practices in treatment & stress management. Vocation development and training. Importance of early diagnosis and intervention.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Person Centered intervention. Vocational Discovery. Peer and ambassador programs. Community Awareness Building. Celebration of the Autism Identity.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Advantages and disadvantages of virtual education. Over-reliance on technology (social media) and how it might lead to isolation. Inconsistent special education practice. Impact on school attendance.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services,	All types of intervention needs to be individualized. For each improvement in response to Covid and the current culture, there may be an equal and opposite set of disadvantages. For example use of gaming as a reward or stress reduction technique can lead to a dependency that is counter productive.

increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	David Kaufer, Parent
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	1) Motor challenges 2) GI disorders 3) Sleep disturbances (usually tied to GI disorders it seems) 4) Sensory 5) Epilepsy/Seizures
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The most significant challenge caused by motor issues is that it makes communication very difficult for many individuals on the Autism Spectrum. Many are non-speakers and this, combined with their motor/sensory challenges, creates a brain/body disconnect that doesn't allow them to accurately/reliably take standardized tests. So they are inaccurately labeled as cognitively deficient and placed into intensive ed programs - even though their cognitive skills are strong. They need support with AAC devices and support for training/communication partners.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication disabilities is the key problem in my opinion. The inability to speak/communicate reliably creates a number of problems/assumptions that harms the individual. Our son was diagnosed with an intellectual disability - but he is now taking high school algebra and other courses.
What additional research is needed to help address co-occurring conditions for autistic people?	We need research demonstrating that spelling-based communication is credible and reliable. There are thousands of case studies now of spellers who have been able to communicate for the first time (and demonstrate their intellectual capabilities) but there is a very vocal minority who opposes this methodology that is trying to discredit this population with outdated and misleading statistics in a propaganda campaign. We need credible organizations/institutions conducting research that shows that this population is clearly capable of independent thoughts/responses.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Greater support for schools to provide individualized assistance to students in need.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	None for us.

Name	David McWaters
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	1. Diminished mental and emotional resiliency that limits time able to do tasks and perform work tasks 2. Dysgraphia affecting ability to write
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	1. Executive functioning disability resulting in inability to keep things clean, organized, and tidy 2. Anxiety over minor health episodes and injuries 3. Excessive shyness making finding friends difficult
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	1. Executive function disability affecting ability to focus and take organized notes in class
What additional research is needed to help address co-occurring conditions for autistic people?	Need a new focus on adults with autism living in society and working for a living wage
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Social interaction can be difficult in the best of circumstances and for many became impossible during the pandemic
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Dawn Werner
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	GASTROINTESTINAL DISORDERS
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ANXIETY
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	ALL OF THE ABOVE
What additional research is needed to help address co-occurring conditions for autistic people?	I don't know where to begin with this one. As a parent of an autistic child I "know" these conditions are "co-occurring" but only because I've read it online, but we've never had much help or success on how to improve the conditions or how to help navigate it.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Better access to care. Appointment times take forever and many doctors aren't much help. Better insurance coverage to gain a diagnosis.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Day, Autistic, ADHD, Dyslexia, and co
Demographic	Autistic individual; Representative of advocacy organization; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	sensory- constantly overwhelmed and overbearing feeling sleep disturbances- causes extreme fatigue or insomnia motor challenges- shakes, twitches, paralysis gastrointestinal disorders
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	attention-deficit hyperactivity disorder, anxiety, OCD, ticks
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	dyslexia, migraines, Tremors, dissociation
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Equitable access to and accessibility of services, insurance coverage, service system issues, patient-provider interactions
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	harder to mask or function regularly in public
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	people are more aware of their health so, make it safer for me and mine, i was forced to mask less so now i can breath, triggered my tics are more noticeable and paralysis worsen

Name	Dean
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Being able to communicate these difficulties to a doctor. Being able to engage in therapy
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I am partially sighted, have cerebellar palsy, borderline learning difficulties and PDA. By far the most disabling of these co-occurring conditions is PDA. It stops me functioning and very few people understand
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	PDA means I cannot do things I want to - I haven't bathed or washed my hair in a year. It took me months to get my hair cut. I don't take medication that literally keeps me alive because of pda.
What additional research is needed to help address co-occurring conditions for autistic people?	We need to focus a lot of research on pda - it is crippling and costs the country a fortune - 70 % of children with pda cannot access school. Pda ers often end up in institutions or needing round the clock support yet it still isn't diagnosed in most areas.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	PDA diagnosis being widely available. PDA awareness and training for all healthcare professionals
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	It was good when social stuff like church and also appointments were online but as soon as Covid was done they went back to face to face and autistic people were excluded again. Need the choice of online or face to face.

Name	Deb
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Epilepsy - adherence with medication administration Fibromyalgia & Osteoarthritis - pain management and reliable assistance as needed
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Attention deficit - teaching new skills need to be small steps at a time Anxiety - maintaining scheduled routine with teaching on dealing with interruptions as life deals
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communications- Daily calls to check on status. Provide support and patience. Encourage with open ended questions.
What additional research is needed to help address co-occurring conditions for autistic people?	Survey mailings to autistic individual households and provide opportunity for questions, support.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Improved Accessibility to insurance covered services
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Less accessibility for person to person assessment for planning, teaching, supporting and arranging services
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Reduced person to person interactions

Name	Deb
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Mental health
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	adhd depression ocd anxiety
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More mental health support for high functioning citizens with autism.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Deborah Bilder, University of Utah Huntsman Mental Health Institute
Demographic	Family member of an autistic individual; Service provider, health provider, or educator; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Mental health crises have a substantial impact on the well-being of autistic individuals. For children and autistic adults with high support needs, this impact extends to the affected person's family and caregivers. Psychiatric and physical conditions contribute to crises, yet most medical providers are poorly-prepared to evaluate the broad range of conditions that could be causing or exacerbating crises. While agitation, aggression, and self-injury are not core features of autism, autistic people presenting in crisis are at risk for disruptive behaviors to be attributed to autism rather than being evaluated for underlying medical and psychiatric disorders. The Sources of Distress Survey (SDS) is a screening questionnaire developed and validated to assess individuals with neurodevelopmental conditions presenting in crisis. Using online, branching logic, the SDS extends the breadth of symptoms that can be screened. It has been used over 500 times in medical settings. The most profound effect of SDS's clinical use occurred from identifying discrepancies between medications prescribed and psychiatric disorders present: > 50% of individuals with severe psychiatric disorders were taking medications that likely worsened these conditions. Over 70% had insufficiently treated medical problems that could contribute to crisis. Further refinement of SDS items and algorithms is ongoing. A prospective evaluation of its impact is needed to extend its use and inform standards of care.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	A prospective evaluation of screening tools for mental and physical health conditions in autistic people presenting in crisis is greatly needed. Additionally, measuring their impact on assessment results, treatment recommendations, and clinical outcomes will inform policy and standards of care.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Improvement of crisis evaluations by medical providers.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	

What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

Name	Deborah Gill
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	When sensory issues trigger aggressive behavior it is difficult to help my son manage his behaviors. He is often triggered by rain which we cannot control. He also is frequently up a lot at night which is hard on his staff in supported living and even harder on us when he lives with us as we still need to work the next day.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Keeping him safe and keeping staff to work with him are the most significant challenges. He has had very significant anxiety which triggers aggression and self-injury behaviors. Because of limited verbal ability he cannot participate in regular mental health treatment for anxiety. As a licensed Marriage and Family Therapist I know those treatments well and do use them with individuals with ASD who do not have the intellectual disability and language disabilities my son has. We have used ABA but it is also of limited use. When he is anxious he has behaviors. This has caused him to have a revolving door of caregivers. It is extremely difficult to create a stable, well trained in his PBSP staff at his house.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	His intellectual disabilities paired with his Autism means those around him need to be trained to help him manage his emotions and behaviors. He needs the support. But his staff is paid so poorly that they leave quickly and we cannot keep the staff adequately trained to support him. This is not a low skill job!
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Better pay and training for support staff. Better day services to engage him. When he is bored he acts out.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	My son was so isolated and bored during Covid that he developed aggression for the first time in his life. He was nearly 30 when this happened. He became very anxious and self injurious, also much more than prior to Covid.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	He is still very isolated and unable to work or have an interesting full life.

Name	Debra Yurschak, NCSA member
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My son [PII redacted] is 22 and his significant challenges caused by co-occurring conditions include everything mentioned plus self injurious behaviors & sudden loud explosive outbursts which is his common response to these challenges. These make it difficult for [PII redacted] & his caregivers (me) to participate in our community, visit the grocery store, go to church, visit family & friends, etc. All of that but especially GI disorders, sleep disturbance, & sensory challenges
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My son [PII redacted]'s (age 22) most significant challenges caused by co-occurring mental health conditions include everything mentioned except suicide but especially self injury, aggression & anxiety. We struggle to find effective psychiatric treatment such as meditation for these conditions. My son has been on several medications since age 10.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My son [PII redacted]'s most significant challenges along with autism include intellectual disability, global deficits in all areas including speech, OT, self care, activities of daily living, self advocacy, etc. He is mostly nonverbal and also refuses to use a communication device or a PECS system as both make him anxious & cause meltdowns. He is dependent on caregivers for almost everything. Severe frustration when my son can't communicate his needs which leads to self injury, aggression & property destruction
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	State & federal laws should allow employers of record to be added as paid staff since they are the ones who do the bulk of caregiving for their individuals. Also all name brand medications should be covered by insurance vs mostly generic for those with stubborn to treat behaviors that don't respond to generic meds. Also insurance should cover a yearly MRI, CT Scan, X-rays as part of their annual physical for those with severe self injurious behaviors & pica to catch broken bones, swallowed objects, brain injuries & other physical conditions caused by the individual that could be causing chronic pain. Self injury is more often than not a sign of chronic pain. It is also a cry for help and should be taken seriously by doctors. Usually they won't order additional testing because of insurance. Only the most wealthy can request any and all tests and pay out of pocket for these tests for their individuals to rule out anything physical. Same as any thoroughbred owner would do for a prized racehorse. Humans deserve the same treatment, in fact to give better medical treatment & care to animals over human beings seems a tad unethical, if not borderline illegal. More respite providers, weekend camps, more day programs that don't exclude because individual needs 1:1 support
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on	Negative. Programs like Kennedy Collective have greatly reduced the number of program locations following COVID shutdown. My son's autism school Giant Steps School closed permanently because of COVID. Far fewer day

physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

program opportunities & many do not accept participants who need 1:1 support. Hours of operation for day programs are shorter. My son does not have transportation to his program in Wallingford. We live in Milford.

Name	Delia Ruiz
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My 10yr has sensory challenges. He constantly has to smell my cheek or my pillow. I have been unable to find resources or any types of supports or replacement behaviors. It can be frustrating for me and embarrassing for him.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD has been challenging for my son. He struggles to sit still and has had injuries due to this, ie falling off chairs and beds.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication disabilities has lead to behavioral challenges for my son.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Equitable access to and services and insurance coverage and high quality parent trainings.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Deon
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	GI issues have caused sensory issues, but because GI issues were constant I didn't realize something was actually wrong until almost 30. I've developed ARFID due to long term sensory issues with food possibly due to unconsciously labling foods as unsavory because of GI upset
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I've been misdiagnosed as depressed and anxious my whole life, when those are only symptoms of undiagnosed autism and ADHD. I didn't know I was autistic until my mother informed me at the age of 26, she refused an official diagnosis when I was young. I've dropped out of college twice, and I know if I'd been diagnosed I would have grown up with the correct supports I needed and would have been better able to succeed. I've struggled with self-harm since I was about 8. I believe this is in part due to undiagnosed AuDHD and also a religious upbringing while being a closeted queer child.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Comorbidities. ADHD both goes hand in hand with my autism and contradicts it (ADHD wants spontaneity but ASD needs structure and routine to thrive). EDS is another common comorbidity that causes a lot of body pain and can sometimes make physical exertion harder than it already is. GI issues are also common, I personally have Celiac disease
What additional research is needed to help address co-occurring conditions for autistic people?	Research about common autoimmune diseases within autistic communities
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Care-providers should listen to autistic people and get information from autistic educators whenever possible. Often times I see a sense of superiority from doctors when discussing autism and they act like they know more about autism than those actually experiencing it.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Increased fatigue and inability to perform basic tasks necessary for daily living. Far more dependent on others for basic needs. More avoidant of people/infection
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increased isolation as a result of more remote interactions. Decreased tolerance for sensory input. Increased emotional overstimulation due to more time spent online

Name	Devorah, mother
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	anxiety, social challenges
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	anxiety
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	learning challenges especially reading comprehension
What additional research is needed to help address co-occurring conditions for autistic people?	research on medications and treatment for moderate to severe anxiety, the first line ssri have terrible side effects and many others as well.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	ABA as a related service that is covered by the school district is desperately needed, education to teachers in schools both private and public about autism especially the high functioning kids how to address behaviors how to help the kids navigate school and social integration withing the school setting. I would love to see coaches in schools to be a point of contact for staff and the child.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	loss of year of therapy and learning
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	ability to do remote work and therapy

Name	Diana Gonzalez Madin
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbance, anxiety and sensory challenges are the most challenging.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	anxiety, ADHD
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	communication disabilities, not being able to socially connect with people although connection is desired and looked for.
What additional research is needed to help address co-occurring conditions for autistic people?	Genetic factors to discard or analyze the origin of the condition and confirm whether or not can be treated.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	the social/communication progress was affected during COVID
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	reduce in person social interactions and obligations

Name	Dongmei Li
Demographic	Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Linguistic intelligence is one kind of human's multiple intelligences. Language development is very important, especially when a child is young, because a child's language develops along with his/her brain /cognitive development. Without language competence, children will not be able to learn new things, and without language competence, children will never be fully competent communicators. That is why almost all students with special needs are accompanied with language problems.
What additional research is needed to help address co-occurring conditions for autistic people?	A person's brain weight develops primarily during the first three years of life. Babies are equipped with hearing at birth, even in the mother's womb, and officially begin to speak between 1 and 3 years old. For young children without congenital hearing diseases, autism and input language errors, confusion, and language input It is related to insufficient input volume and incorrect language input method. Once a child develops language problems, it will in turn affect intellectual development, social problems and psychological problems. This challenge is particularly acute for bilingual children. I am opposed to prematurely labeling children as autistic. I believe that bilingual children whose English development is delayed due to unfamiliarity with English and are labeled as autistic are pseudo-autistic. I believe that because public school education in the United States begins at the age of 5, strengthening research on effective language input for children under 5 years old and improving related education and government strategies are the most effective ways to avoid childhood autism and adult psychological problems.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I think family care should be promoted for children aged 0-3, and I recommend a set of English DVD textbooks designed by Harvard University - Disney-world of language; and 3 years old is a critical period for children to begin to adapt to society, so I advocate that The age of compulsory education is raised from 5 years old to 3 years old, ensuring that children, especially bilingual children, can enter full-day preschool from the age of three.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	

What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

Name	Donna Costello, Private practice. Retired from public school as school psychologist working with students K - 12 with what was formerly known as Asperger's
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Significant sensory sensitivity which tend to diminish with age since family/school personnel stop trying to force the individual to deal with noise, lights, fabrics, et al. Lots of gastrointestinal issues noted, almost like some kind of autoimmune disorder. Often have sleep disturbances - worse when autism co- occurs with ADHD.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Undiagnosed ADHD as well as diagnosed ADHD. Given that ADHD doesn't hang out alone, there is a significant amount of anxiety and depression. Research suggests that individuals with ADHD have worse problems with attention and focus. Those with ADHD have more issue with planning.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication. Most individuals with higher levels of intelligence have average to above average language skills, assessed as vocabulary et al. Many educational speech and language therapists do not look at social aspects of communication, although this is changing. Interesting, when I get a possible autism assessment, not all school districts include a Speech and Language assessment if the student has a good vocabulary.
What additional research is needed to help address co-occurring conditions for autistic people?	More research on assessment of autism of students with high levels of intelligence, especially in girls who present differently. Also, research on assessment of high intelligence in adults w/ autism, that includes functional assessment of daily living. I assessed a 22 yr old woman with verbal IQ of 160, perceptual IQ of 145, with co- occurring ADHD, depression, high levels of anxiety, who could hardly get out of bed, work at a low level job, etc. The discrepancy between her high level of intelligence and poor functioning in everyday life was debilitating. AND it was impossible to find supports and services for her that were affordable for her and/ or her family. We need more support and services, similar to what is offered to those with intellectual disabilities.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage for one on one coaching and other services for developing daily living skills for independent living, plus career counseling and support. Most important are service providers who comprehend the depth of the underlying issues that renders a high intelligence individual with suboptimal to poor functioning in everyday life. These individuals have amassed much specialized knowledge and could be supported to be productive in their areas of speciality. They want the support.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	My client dropped out of college one year from graduation during the pandemic due to isolation. It was actually easier (more motivating) for her to get to class, focus, and complete assignments (mostly papers) in person than online.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic	Reduced in-person social interactions - although social communication is an area of deficit, there was an expectation that the AS individual had to be around others and required them to rise to the occasion (so to speak). The isolation resulted in a loss of social communication skills due to lack of

people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

opportunity for something that was difficult to deal with, making it easier to opt out and stay alone. I noted lots of deterioration. I worked with a group of 8 students/ families from K - 12 and college. I still am in communication with some of them.

Name	Donna Johnson, Parent
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory challenges and sleep disturbances
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, depression, hyperactivity, aggressive or self-injurious behavior, and obsessive compulsion disorder
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	executive planning, communication and developmental disabilities
What additional research is needed to help address co-occurring conditions for autistic people?	Research on the impact of challenges with executive planning disorder
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Services to support young adults and adults who receive a late diagnosis and missed the window of opportunities that exist for younger children. Training workforce to support youth and young adults who receive a late diagnosis when the manifestation of symptoms appears to be more visible (e.g., depression, anxiety, executive planning disorder) System of services challenges
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	COVID-19 has had a lasting impact on co-occurring conditions such as anxiety, depression, sleep disturbances, and executive planning.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Social changes related to reduced in-person social interactions exacerbated isolation for autistic individuals. Making the transition back to being socially engaged is a challenge and in some instances caused a setback of gains previously made for autistic individuals. The impact of being in isolation has also caused increased anxiety and depression as autistic individuals readjust and navigate their environment.

Name	Donna Narey
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Being nonverbal and having issues with sensory processing is very difficult. When your child cannot express what he is feeling and cannot process that feeling at the same time it is very frustrating!
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	In addition to the autism and down syndrome, my son has ADHD and anxiety. The anxiety causes him to become overwhelmed, and ADHD causes impulsiveness, which then leads to expressing his anxiety by scratching anyone in his space.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Besides autism, my son has Down syndrome, which combined causes his developmental age to be between one and three years despite being 18 years old.
What additional research is needed to help address co-occurring conditions for autistic people?	Not sure.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I think equitable access to services. My son doesn't fit in the Down syndrome world, and he doesn't fit in the autism world. Services tend to be for one diagnosis or another.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	thankfully, my son School realized that zoom didn't work for him and brought him and a few other kids back in person while keeping the majority of kids online. Now most things seem back to pre-covid.

Name	Doreene Donald
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory and motor challenges
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Hyperactive disorder
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication disability
What additional research is needed to help address co-occurring conditions for autistic people?	There should be more programs that help parents with kids who are autistic
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage for aba therapy plus more help to help parents rest sometimes. Parents with autistic kids most of us don't rest. There should be counseling for parents with autistic kids
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Dr Christopher Pyne and Holly Swan, Parents
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Our son has not slept through the night but possibly once or twice a year since he was a baby. He is now 26. He wakes every night and is up for a couple hours, so we are up. He walked in the house today and fell asleep in a matter of minutes because he is so sleep deprived. This causes the sensory issues (needs trampoline, etc inside and outside) to be even more extreme as well as his motor challenges.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	One of the more significant challenges is his self injury (with medicine , he has not been aggressive for a few years) but he is currently bruised all over his right arm and some on his chest from his pinching self so hard when he upset. He is so hyper it is hard to do things with him as he has to jump around so much.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	He is profoundly autistic and does not have much communication at all. It is extremely worrisome as he ages and can't tell us when he doesn't feel good/something is the matter or is constipated or has a headache. Or if someone has hurt him. It is heart breaking.
What additional research is needed to help address co-occurring conditions for autistic people?	Where is the research explaining the tsunami of autistic young people that is obviously growing at a frightening rate???
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Until we start paying people equitable rates to help our guys, there will not be trained people to work in this field or help our guys in a way they deserve, rather than pay employees less wages than those who serve us at McDonalds.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It has made hiring people to work in this field even more difficult, thus, many with autism haven't even been able to get the services that have been PROMISED to them.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Our son cannot easily sit still so he could not really participate in virtual learning. And would add his hard earned skills regressed.

Name	Dr Jessica Myszak, Help and Healing Center PLLC
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Unspecified auto-immune conditions, Ehlers Danlos and other hypermobility problems, POTS, IBS, sensory sensitivities (including ARFID) are all areas of significant concern for many autistic people and need more attention and research. Because some of these conditions are difficult to assess for and treat, many people experience these conditions and have no idea why, or that it can be related to autism. These can impact a person's ability to maintain employment and meet their financial needs, thus putting them in an even more precarious position.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety and depression are huge areas that are often present in autistic people, and these can worsen during autistic burnout, even to the point of suicide. Trauma often co-occurs, and it is likely that autistic people are more likely to experience both acute and complex trauma. There needs to be far more attention paid to autistic burnout and masking. These can impact a person's ability to maintain employment and meet their financial needs, thus putting them in an even more precarious position.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Many of the conditions that can co-occur with autism negatively impact a person's ability to maintain employment and meet their financial needs, thus putting them in an even more precarious position. This is why appropriate supports are so important, and why a safety net would be important for our community.
What additional research is needed to help address co-occurring conditions for autistic people?	There needs to be much more research on autistic adults, and the supports needed over the lifespan. Research on masking, PDA, the impact of an affirming environment, the impact of various supports should be considered. Even more important, this information needs to be disseminated to providers and trainees that work with autistic people.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	All areas of autism services and supports could be improved to better support children, adults, and families of autistic people. Currently, waiver programs are inequitable across states and have very long wait times for services. Because of the variability in individual needs, the offered services are not always what is needed by the individual. Services and supports for adults are minimal for all but the most significantly impacted individuals.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	COVID-19 infection and illness has created more isolation for many autistic people, and added yet another layer of challenge onto a community of people who already experience numerous additional obstacles to societal participation.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	For many autistic people, COVID-19 was a turning point in one way or another. For some people, the loss of existing structure and supports was terribly difficult and resulted in losses in functioning. For older autistic people with fewer support needs, the increase in access to telehealth and reduced in-person requirements. Many of my clients have thrived with remote work.

Name	Dr. Autumn Dae Miller
Demographic	Autistic individual; Service provider, health provider, or educator; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The assumptions that service provider staff make regarding behaviors/actions as a choice rather than seeing them as expressions of excruciating pain and discomfort related to digestion, exhaustion from sleep disturbance, and unbelievably irritating sensations from movements that bodies need to make. It's not JUST the physical health experiences, it's that professionals honestly believe there is a way to "just get through it and move on" that Autistic people are choosing not to do for the sake of making that person's day more complicated.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	1) The DSM-5-TR and the DM-ID-2 are both extremely limited. They were written by people without lived experiences and therefore can only be taken as books of assumptions based on assumptions. 2) Psychiatrists-by and large-are not diagnosing using the most updated versions of the DSM nor are they doing copious amounts of research on new caveats to mental health diagnoses and their treatments. 3) Most evaluations are 10+ years old and professionals refuse to take a FRESH look at a person; however, we all change and so do our experiences. It's a harmful practice. 4) We COMPLETELY miss how trauma masks other symptoms and shifts the way co-occurring MH presents in anyone! 5) Autism can quiet typical MH symptoms and exacerbate others. What looks like X in theory can be expressed very differently in an Autistic client.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The most significant challenge in this arena is that people supporting this person assume the following: 1) That this person is somehow always going to be childlike, which is absurd. 2) With that, that this person is not able to safely navigate social, romantic, employment-based, etc. relationships because of these "childlike" assumptions (also untrue). 3) That there is something WRONG with this person so they are unable to learn. This one is extremely problematic as it perpetuates the assumption that someone is expected to learn in ONE way - the way the EDUCATOR WANTS TO TEACH; rather than meeting each person where THEY are and teaching them using the methods that work best for them.
What additional research is needed to help address co-occurring conditions for autistic people?	Let's first look at WHO is doing the research, who is FUNDING the research, and HOW that information is going to be used. Once that is completely transparent and confirmed for the good of humanity rather than the perpetuation of stereotypes, then the following research foci would be helpful: 1) The effect of holistic bio-psycho-social treatments working in tandem to support Autistic people with health needs of any sort. 2) More research on Autistic Adults! People don't STOP being Autistic at 21! 3) Trauma and Autistic survivors 4) The effects of big-pharma psychotropics as compared to supplemental (natural) medications on neurodivergent brains to see what is ACTUALLY most beneficial for anyone with co-occurring mental health diagnoses and what the long-term effects of those medications are on the body and mind.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	1) Stop antiquated forms of ABA services (we have to stop telling people it's ok to force someone not to be themselves when we know this has caused physical and emotional pain). 2) Create & fund programs that have combination skills including professionals with LIVED EXPERIENCE where insurance and/or waiver funding can be tapped that would support the need for bio-psycho-social centers (NOT antiquated inpatient hospitals who do NOT know how to support Autistic clients or typical ERs that restrain clients they cannot chemically control) where folks would be able to safely seek NEURODIVERGENT-AFFIRMING support...this has NEVER been done outside

	<p>of the "private pay/elitist-funded" world. 3) Requirements that ALL providers who say they offer services to Autistic clients to go through training run by Autistic individuals every year with regulatory requirements based on the parameters of that care. Ex: If you say you serve Autistic clients at this ER, your response to someone who needs to scream and run when touched better not be to tie them down and give them IM injections!</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>You are asking what COVID-19 has done to physical and mental health for Autistic people...similar to what it gave & took away & made messy for everyone... 1) Remote work: finally people got the chance to work from home...where the food I can eat is, where bathrooms that feel safe are...where I can move, jump, fiddle with a fidget and not be judged. This has completely changed the game and made it possible for people to be more authentic and safe(r). 2) People are so stressed with the way the world is these days, the expectations are off the charts (do more with less than half of what you had before...of everything), and we expect folks to just KNOW how to survive it all. 3) For those who DO reach out for help, the BEST providers refuse to put up with the harassment and belittlement of insurance-funding or waiver-funding. To get the best, you have to bit rich and that's absurd in a world where those who need the most qualified cannot access them. It's not the fault of the therapist who would only get paid \$45/hour from Medicare when their time is worth \$150-\$250/hour elsewhere. They went to school, they have bills to pay, and the clients NEED them. COVID showed us that we treat the people our world needs the most like crap; hospital workers, therapists, teachers, human service workers in general...this negatively impacted us all.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>I'll answer just as an Autistic person and not with my professional hat on. I'm tired of people PRETENDING that actions that taken during pandemic and as part of the ongoing COVID19 effects were JUST because of a virus. A huge part of the last few years of our lives is that we also realized that: black lives STILL didn't matter and they MUST, people only value helping professions because they don't want to DEAL with the messiness of humanity themselves, that wars are happening and our country is too stubborn to care about any other humans unless it directly benefits them or makes for a great social media campaign, that people still do not believe WE are having a negative impact on the health of our planet, and that disability as a whole is a social construct where someone is only DIS-abled because society doesn't accept, adapt, and appreciate the all-natural variety of humanity. The worst part during COVID-19 is that we learned large parts of our country HATE anything that is different. I'm different. I've always been different. I thought that was a STRENGTH in this world but so many people said no, we hate you because of that and all your other identities. THIS is what affects my MH, my physical health, and the health of all the people I love and care about - even those I've yet to meet. Remote work is great; social media is a space where those without microphones in their faces can be recognized, and hate has no place here. Thank you.</p>

Name	Dr. Bernadette "bird" Bowen (She/they/Dr.), Media Ecology Association
Demographic	Autistic individual; Service provider, health provider, or educator; Researcher; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	For more of my life than not, I have been the bad guy, and it didn't have to be this way. One of the major findings of my PhD dissertation, about sociosexual ecologies in the algorithmic age, was neuroqueer self-realizations on platforms, like TikTok. This summer, I published books about why there are massive queerness and neurotype (in other words, neuroqueer) self-realizations happening. Within the last 10-15 years research has shown that millions, if not billions, of AFAB (assigned "female" at birth [ideas of "biological sex" and "gender" are built through language usage]) autists have been missed, and the world is still too discriminatory for us to safely be open about our neuroqueernesses. We also have high rates of substance abuse, 9 out of 10 AFAB autists experience sexual violence, and we have exceptionally higher likelihoods of suicidality. Research shows that, especially Black and Brown AFAB folks, are dreadfully undiagnosed, leading to additional

	<p>discrimination(s) and unemployment. Whether formally diagnosed or not, many autistic individuals are also high risk for significant health complications, including severe (short and long forms of) COVID-19. And, many, likely don't even know it, due to self-advocacy challenges and/or normalized medical gaslighting. Our community is not a hivemind. Many of us, however, have exchanged unprecedented solidarity regarding uncanny similarities during the most connected time in human history, and changed our lives for the better.</p>
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Name	Dr. Henny Kupferstein, Doogri Institute
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator; Researcher; Representative of advocacy organization; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The most significant challenges is a prognosis of premature death. There is so much gaslighting by primary and specialist physicians, that autistic people often quit asking for help. As neuromuscular disorders are so prevalent, little research is done to manage the progressive decline in adulthood. For example, I can no longer toilet independently due to complete bowel dysmotility at age 37.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Aggression and self-injurious behavior are not in the DSM-5 criteria for ASD. In fact, these are signs of PTSD. the same is true for property damage, elopement, and school shootings.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The primary diagnostic criteria of communication disability is grossly overlooked. We have a right to accommodation, but the law still requires us to communicate about our need for communication support. This is a catch-22 that any other population would not be silent about. The other concern is that generic social workers are tasked with making service decisions while lacking the expertise to review medical documentation of need; the due process is not accessible.
What additional research is needed to help address co-occurring conditions for autistic people?	There is a known trifecta of EDS, MCAD, and POTS. There is also a known comorbidity of mitochondrial diseases, and genetic metabolism errors. As long as this is not linked, we will be forced to seek out treatment from multiple specialists who do not communicate with each other, and run the risk of 'doctor shopping' or 'malingering'.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Licensed Clinical Social Workers and Medicaid Service Coordination to advocate in a case management position. The access issue is solely based on breakdowns in communication within a broken system. The autistic person shouldn't be burdened with calling to see if a referral arrived, and should benefit from service professional to ensure Timely and Appropriate access to care. We can't do it alone.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Autistic people for the most part have been surprised by the pandemic where non-autistic people were forced to adopt our lifestyle. Social distancing gives up the space to flourish. Zoom calls gives us an opportunity to have realtime captioning. Telehealth gives us an opportunity to be in our sensory friendly space while having a potentially traumatizing encounter with a generic provider.

Name	Dr. Karissa Burnett, Divergent Pathways: A Psychological Corporation
Demographic	Autistic individual; Service provider, health provider, or educator
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>Co-occurring physical health conditions are prominent in the autistic community and warrant extensive research, as they exacerbate challenges across domains and significantly impact quality of life. Some of the most common physical health challenges faced by autistic people include gastrointestinal disorders (e.g., IBS), dysautonomia (e.g., POTS), mast cell activation syndrome (MCAS), hypermobile Ehlers-Danlos Syndrome (hEDS), fibromyalgia, chronic pain, myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS), autoimmune disorders, asthma, allergies, and sleep disturbances. When any of these conditions are present, physical discomfort can be amplified by autistic people with sensory sensitivities, which can include heightened interoception. When this occurs, attention tends to shift toward pain/discomfort, stress levels increase, and the bandwidth for navigating daily stressors decreases. For those with less access to interoceptive cues from within their bodies, these physical health conditions may not be as apparent until they become worse. Autistic people with limited or no speech can have difficulty sharing their physical experiences with providers, especially if the environment is not accommodating of their communication and sensory needs. Also, many autistic people describe not being listened to or believed by their providers (“medical gaslighting”), which is a major problem that is important to address through further research and education.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>Many autistic people put extensive energy into “masking” their struggles to try to fit in, which can lead to misdiagnosis regarding autism and underdiagnosis of co-occurring mental health conditions. Masking also inherently means there is shame about the true self, which can lead to increased stress, anxiety, and depression. The prevailing behavioral treatment for autistic children often teaches masking and compliance, which can have significant negative impacts on their development (e.g., one study suggested that ABA correlates with increased PTSD symptoms in autistic people (Kupferstein, 2018)). Challenges in navigating neurotypical social norms can lead to and become intensified by mental health conditions, leading to increased feelings of isolation, misunderstanding, and loneliness. Sensory processing differences and challenges with emotional regulation can be exacerbated by mental health conditions (e.g., anxiety often seems to increase sensory overload, and vice versa). Finding mental health support that understands autistic people is difficult, especially through a neurodiversity-affirming lens. Traditional mental health treatments do not often consider the unique perspectives and experiences of autistic people, leading to less effective or even harmful care. It is especially rare to find providers who are able to conceptualize the nuances involved with co-occurring mental health conditions. More education is sorely needed.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>Autistic people with co-occurring learning, developmental, or intellectual disabilities may face heightened difficulties in traditional educational settings. These challenges can include struggles with information processing, memory, attention, motor coordination, and problem-solving, which may require specialized educational strategies and supports to facilitate learning in a way that works best for them. For autistic people with additional communication disabilities, expressing needs, thoughts, and feelings through speech can be particularly challenging, especially when they do not have access to alternative modes of communication (e.g., AAC). These compounded communication barriers can lead to misunderstandings,</p>

	<p>frustration, and increased difficulty in forming social connections and accessing needed support. Additionally, misconceptions and stigma surrounding these disabilities can lead to social exclusion, mistreatment, and isolation.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>A recent study from researchers in Scotland asked autistic adults what their research priorities are, which mirror what I see from the autistic community in the United States. According to these autistic adults, the least important things to research are “genetics, treatments and interventions, and cause [of autism]” (Cage et al., 2024, “What are the autism research priorities of autistic adults in Scotland?”). Instead, there is a call to research “mental health/well-being, identification and diagnosis of autistic people, support services, knowledge and attitudes toward autistic people, and issues impacting autistic women” (Cage et al., 2024). Fundamentally, research focusing on the subjective experiences of autistic people with co-occurring conditions is essential. This includes studies that prioritize the voices and perspectives of autistic people to inform practices and policies that genuinely reflect their needs. Studies that explore the impact of cultural, socioeconomic, and environmental factors on the prevalence, identification, and management of co-occurring conditions in autistic individuals are also needed. Of note, Pathological Demand Avoidance (PDA) is a unique profile of autism that has research backing in the UK but has been minimally-studied in the US. It is imperative that more research is done in this area to increase understanding and provide more effective support.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Autistic people should always be actively involved in decisions about their care. However, navigating systems of care and self-advocating can be daunting. When accommodations are not in place and environments are not affirming, challenges in communication may hinder the ability to access support. Across services, it is important to enhance accessibility, promote inclusion, and ensure that services are responsive to varied needs. Creating sensory-friendly environments across settings can make a significant difference. Training, ideally by those with lived experience, is needed for healthcare providers, educators, and support staff on autism and co-occurring conditions to improve patient-provider interactions and quality of care. Ensuring that all autistic people, regardless of their location, socioeconomic status, race, or gender, have equal access to services is crucial. This includes expanding services in underserved areas and reducing financial barriers to care. Insurance policies should be more inclusive and flexible to cover a broader range of services and interventions for autistic people with co-occurring conditions. It is imperative that the neurodiversity-affirming framework is integrated into services, and that they are covered by insurance. Currently, many insurance companies and service facilities will only accept autism assessments that use the ADOS-2, which can under-identify high-masking autistic people.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>I know many autistic people who have been dealing with long-COVID, which seems to exacerbate many underlying conditions (e.g., MCAS, dysautonomia/POTS), with significant impacts on daily functioning and limited treatment options. Lingering symptoms like brain fog, chronic fatigue, and other physical and cognitive challenges can further complicate existing co-occurring conditions and impact quality of life. Additionally, autistic individuals with pre-existing mental health conditions like anxiety or depression may have experienced intensified symptoms during and following the pandemic.</p>

<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>For many autistic people, the disruption of routines, social isolation, and the general uncertainty of the situation (which continues on some level) have contributed to worsening mental health conditions. However, there have also been some positive impacts from these societal changes, especially through revealing preferences/needs related to working from home, becoming more aware of social bandwidth and sensory challenges, and increasing access to neurodiversity-affirming providers through telehealth services.</p>
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Name	Dr. Marcy Epstein, University of Michigan/Athena Autism
Demographic	Autistic individual; Service provider, health provider, or educator; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Our diagnostic protocols need review, based on client report, especially for girls and women, BIPOC, and older people. I have gastritis and IBS and compulsion to eat as a stim. So eating disorders. I have a delayed sleep cycle of 3-5 hours, even with CPAP, Trazadone, and cannabis. Sensory issues include high volume or shrillness; not being able to smell or smelling synaesthetically; skin sensitivity to chemicals (hives and rashes) and materials (synthetics); attraction to certain food textures and unable to tolerate food smells and tastes; and most of all, needing music or solitude in order to self-regulate. Midlife onset (H)EDS; this seems to be the internal version of what's developed differently in me: I bruise, sprain, pull, and break my limbs and spine often, despite flexibility and attention. My skin is a strangely soft texture and is elastic. My hair follicles are perfectly round. Essentially, my body and brain design in all ways seems slightly off the norm. I think EDS and ASD are related. The trauma of being autistic in the world has long confused me and had an impact of my mental health. Most of us have developed full blown mental illness, spurred by this stress. We need a better understanding that ASD in itself is neurological difference, not the same as mental illness, but our experiences in this world is so difficult as to cause strain and burnout.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I'm sure that we vary. Poverty definitely plays a role in labeling without support. In every dimension. For me, I cannot seem to keep a job. Traumatic stress caught up with me, and each job takes a toll on me. I work hard, but I make people uncomfortable-- even when I've done nothing wrong. I really struggled in my career and now, I cannot see myself returning full-time to work. It's too stressful. But then how can I support myself? Some of our community really suffers from lack of real support, in their homes and in the work place, because of their aggression and injury to self/others. Also, understanding us as a variation, interesting and not always the same in our mental illness.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	We must correct the DSM for its narrow understanding of our spectrum divergence. High and low functioning needs dissolving-- i.e., my high intelligence has been hampered by unknown developmental disabilities. I learn differently. I age differently. There is so much room for more complex research. One of the worst challenges in our community is being researched without our direct representation in the research process. I've also been "managed" in clinics rather than listened to. So we tend not to seek help for ourselves enough from the allistic world, which somewhat obscures ours. So we feel despair in not being understood
What additional research is needed to help address co-occurring conditions for autistic people?	I covered this in another question, but we need a lot of new empirical, observational, and narrative research (that's my specialty) on autism itself, understanding the spectrum and our divergence, since all areas of health, including mental health, are based on a neurology, on pharmaceuticals, on a medicine based on allistic knowledge and allistic experimentation. We need research in these areas, too: autism and social difference; autism constructs in Medicine and other health fields; autism and self-immolation/addiction/compulsion; autism and early childhood, autism and aging, autism and sexuality/relationship; mental illness.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access	Much more funding for families who care for autistics, especially those with violent or aggressive reflexes. Situate autism more clearly within ADA, covering autism in its rearticulation. We need jobs and job protection. We need to afford independent living, wherein we're most at peace. We need

<p>to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>everyone trained in autism access-- allowing for non-use of telephones, giving us quiet, quick, and on-point interactions, low conflict, listening to us, not engaging in immediate dislike or rejection, microaggressions based on the perception that we are rude, etc. We need a different kind of unemployment insurance, better health coverage for diagnosis and trauma therapies, EMDR.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>Overall, we've suffered along with everyone else. More people at home means more opportunities for overwhelm. Masks can make our skin break out. When we got sick, we were in a hospital emergency, in all sorts of chaos, with communications gaps and highly variable pain thresholds. For the first two years, I was glad to be home, though, because I finally could do some overdo calming. But I had some major traumas, too, and every change from routine felt scary. I got Covid at the end of Year 2, and it came with terrible gastritis and brain fog. I still have flareups and don't know if it's all post-Covid or part of my autism journey.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Everyone in clinical health is exhausted and less patient with us. It's harder to see psychiatrists and neurologists. It's been impossible to get Autism-HEDS diagnosed because of instability in the field. For me, I've become so stressed out that I feel safe mainly at home. The public feels less thoughtful, more hostile, less hopeful, and inconsolable. Positive impact? For a while, the world felt quieter.</p>

Name	Dulce
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbances, sensory issues, motor control caused by spasms, muscle and joint pain, the inability tell internally what's wrong, and fatigue both mentally and physically.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression, anxiety, ADHD, complex post traumatic stress disorder and suicidal ideation is common but not always in tandem.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication disabilities such as due to sensory issues seem to be a common occurrence within the autistic community. As well as a few learning disabilities like dyslexia and dyscalculia.
What additional research is needed to help address co-occurring conditions for autistic people?	Treatment and support for autistic children and adults with other genetic disorders that seem to be linked to autism such as: Ehlers Danos Syndrome, it's umbrella subtypes and comorbidities.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Provide sensory bins so autistic individuals can stim without stigma, ear plugs for sensory overload, and access to a weighted blanket or stuffed animal. Make ear plugs weighted blankets and sensory items available to be covered under insurance or HSA. And optionally provide tablets with communication capabilities for partially mute and fully mute individuals.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	COVID has overall been good to us mentally due to the physical masks and physical distance we don't have to mentally mask and preform for all the steps of regular socializing. Though physically infection and illness has rendered many of us with significant chronic conditions like POTS, ME/CFS when many have not had them beforehand.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Most of the societal impacts caused by COVID-19 have been positive throughout the community since we don't have to be around a lot of people in person. Though in the beginning the disruption of services especially within the medical system was not ideal when it came to needing help with therapy for example.

Name	Dylan M. Fish, Disabled Autistic Student at RIT
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Autistic individuals often face challenges associated with co-occurring physical health conditions. Examples, such as gastrointestinal disorders, sleep disturbances, epilepsy, and sensory and motor challenges, contribute to a complex set of hurdles. These challenges can significantly impact daily life, comfort, and overall well-being, requiring tailored approaches in healthcare and support services.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The intersection of autism with mental health conditions like depression, anxiety, aggressive or self-injurious behavior, and suicidality adds a layer of complexity. Autistic individuals may encounter difficulties in expressing and managing their emotions, requiring nuanced mental health support that acknowledges and addresses their unique needs.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The co-occurrence of autism with learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities creates multifaceted challenges. Tailored educational strategies, inclusive communication approaches, and comprehensive developmental support are essential to address the diverse needs of this population.
What additional research is needed to help address co-occurring conditions for autistic people?	There is a crucial need for further research to understand the intricate interactions between autism and its co-occurring conditions. This includes investigating effective interventions, identifying risk factors, and developing targeted strategies for improved healthcare, education, and support services.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Enhancing autism services and supports necessitates a focus on equitable access, service system improvements, and positive patient-provider interactions. Addressing disparities in accessibility, insurance coverage, and eliminating barriers to services are vital steps toward ensuring comprehensive and inclusive support.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	The COVID-19 pandemic has likely had lasting effects on co-occurring conditions for autistic individuals. Disruptions in services, increased remote work and school, and reduced in-person social interactions may have exacerbated challenges or, in some cases, provided new opportunities for support and adaptation.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Societal changes resulting from the pandemic have both positive and negative impacts on the physical and mental health of autistic individuals. Increased remote work and school might offer flexibility, but disruptions in services and reduced social interactions may pose challenges. Understanding these impacts is crucial for shaping post-pandemic support strategies.

Name	E.R
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Pathological DEMAND Avoidance struggles & managing as well as anxiety
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	PDA
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	ADHD
What additional research is needed to help address co-occurring conditions for autistic people?	Acknowledging and understanding more about pathological, demand, avoidance (PDA)
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Consistency across-the-board with practitioners and diagnosis. As well as our support systems in the autistic community acknowledging this is on the autism spectrum and a subtype. With PDA we have had autistic therapists cause more damage, because they are ignoring that it even exists and needs very specific treatment plan
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Elena, Mother
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My 30 year old “child” has co-morbid conditions that overlap or are in addition to his autism. He has ADHD, which causes difficulty focusing and/or hyperfocussen, making him inconsistent when performing tasks. He’s sensitive to sudden loud noises, exacerbated by a past experience of being sat under a bell in a school, while it was being tested and suffering PTSD as a result. He also has a sensitivity to tags in clothing, which need removal before holes are torn. He also has mild OCD and gets obsessive about things in his surroundings. He also suffers from mild depression. Sleep has always been an issue: he cannot close his eyes to rest and will not sleep until exhausted. Due to his ADHD and OCD, he awakens often and runs through the living area to check on things before going back to bed. Gastrointestinal issues include Proctitis (in remission), and a years-long battle with IBS- which makes carrying a second pair of underwear a necessity. He is also lactose intolerant, and takes lactase enzymes before consuming dairy. He can and will eat everything. However, he has difficulty knowing when he is full. Twice in his life he has eaten until he vomited, but fortunately has a better handle on it as an “adult”. As an aside, he also has developmental issues, processing difficulties, and speech problems that make it difficult for him to make himself understood at times. All of the aforementioned mean that finding a job (and he is a hard worker) somewhat impossible.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	See aforementioned response, it includes most, if not all co-morbid conditions.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	See response to first question. But, to clarify, all of his co-morbid conditions, which I consider to be common in people on the spectrum that I have met (and having a 30 year old son means I have met many- including a husband who has mild spectrum-like qualities), means that living and working situations are the most difficult things we face with our son. There needs to be a larger choice and variety of living options, and more education in the total employment field about how to integrate these wonderful and special people into the workforce.
What additional research is needed to help address co-occurring conditions for autistic people?	Research into better living and work options- which should include in-field research amongst employers in what they would find helpful to encourage them to hire people on the spectrum. Naturally, a revamping of employment education for those on the spectrum is important as well.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	For people that do not have a support system, such as my son (who has me and his father, as well as a wonderful community habilitation worker, Medicaid service coordinator, etc), insurance covered advocates that work for autistic individuals - not the school system, not the medical community, no one but the individual in question, would be a good place to begin. However, even those on the spectrum, such as my son, who has had me as his lifelong advocate, still need more assistance in order to have their living and working situations, not only improve, but be more ‘normalized’ as well. As for issues with members of the medical community- across the board- education on disability, including case studies in medical schools, etc. that

	include people on the spectrum as well as those with other disabling conditions needs to be made mandatory.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Change in routine can be more difficult for those on the spectrum. My son, who had previously volunteered at a Nursing Home for five years and traveled locally on his own (thanks to a great public school for special needs populations, as well as a great travel-training instructor), has not wanted to think about looking for another volunteer or work opportunity since Covid. He is still frightened of getting sick and of not finding something that will last. He has only just began going places on his own again (like to the local barber shop) these past two months. Now with rising infection rates in NY, he is growing worried again, as are we all, and is more hesitant to go out, even with a N95 mask on. We have all gotten the latest vaccine, but unfortunately, too many others have not.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	My son used to have regular weekly in person social gatherings at his local YAI. However, Covid ended that. On-line social meetings have been a lifeline, as have been the few and far between in person gatherings - which I fear may dwindle again if infection rates continue upwards.

Name	Elenna
Demographic	Autistic individual; Family member of an autistic individual; Other
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>Gastrointestinal distress is a very serious issue between both my brother and I. My younger brother has Celiac which is more common in autistic people and access to safe food in public services is a major issue for him. He also has a very restricted diet due to sensory issues. Food labeling and standard care is an issue as some foods labeled as "gluten free" are not celiac friendly and my brother's other difficulties are less manageable when he is in pain. Additionally, my own sensory issues are aggravated by my own menstrual cycle which makes it difficult to work, complete daily tasks, and take care of myself. I alleviate this by taking hormonal birth control at a low dose continuously, which helps, but birth control access is frequently at risk due to decisions by Federal and state lawmakers or my own access to insurance. This medication makes it possible for me to function without aid and is critical to my survival. Additionally motor challenges are an issue as they make driving difficult or impossible for some people - my younger brother cannot drive and paratransit is unreliable as is. Alternatives to driving are necessary to help autistic people participate in society.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>Depression, anxiety, and suicidality have been extreme challenges in my life. During pandemic lockdown it wasn't that bad but once things cleared and people started returning to normal my anxiety was very high. When I had a recent suicidality episode I decided to seek psychiatric care and I was on a 6 month waiting list for a psychiatrist because so few were accepting new patients or even work with autistic or suicidal patients. When I last needed a therapist it took me almost 9 months to find someone remotely qualified who was accepting new patients and I had to attend therapy with two different therapists and call many more to find one who was qualified to treat me. Therapists and psychiatrists are not trained to work with autistic adults as a general rule. Grants towards therapists who want to learn to specialize or research autistic adults may help. Additionally after a layoff this year I became very depressed and anxious despite finding another job quickly. My new work situation is really not a good fit, which is aggravating my symptoms. My younger brother, meanwhile, requires assisted communication and did not receive it when he was younger. I believe if he had received more consistent access to AAC when he was younger rather than pushing for him to speak he would have stronger communication skills and be able to convey his needs, which would lessen aggressive and self-injurious behavior. (In the past, helping him to use them has helped.)</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>Communication is the single most significant thing that has followed me into adulthood. Learning and developmental disabilities get better with time and accommodation, but not being able to speak (in the case of my brother), and not being able to maintain relationships due to communication issues is a major issue for me and contributes to my depression, anxiety, and suicidality. The social skills class I received as a child did not help and in fact the people providing it were abusive to me and the other students, did not allow us to socialize with each other, and pathologized us for age-appropriate interests like Dragonball Z and Pokemon (we were 11-13). I've heard that other people have had different experiences since then - my main issue is that what I needed was a place to regularly socialize with my peers that was somewhat structured, I needed community with other autistic students who were in a similar ability range, and I needed adults that had appropriate training on how to help autistic teenagers. Unfortunately I did not have any of these</p>

	things and ended up finding them on the open internet, which is questionable.
What additional research is needed to help address co-occurring conditions for autistic people?	There needs to be more research on the current status and needs of autistic adults of all support needs. Autism research primarily focuses on young children - there are few resources for autistic adults who have moderate or lower support needs and standard therapy and psychiatry often does not support us effectively. Research into the effectiveness of DBT and EDMR for autistic adults may help. Additionally research into the effectiveness of Occupational Therapy. Additionally, research into chronic pain disorders may be helpful. More diagnostic capabilities towards a non-speaking population who struggle to communicate in other ways could help improve quality of life for autistic adults. Surveying the availability of ingredient-restricted foods may be a good first step to address co-morbid food intolerances and celiac disease. Surveying the availability and efficacy of public transit and paratransit may be a good first step towards improving integration for those with co-occurring conditions that make driving difficult or unsafe. (I know that personally I would prefer to take public transit rather than drive but it is not available where I am.)
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Providers often do not have training to work with autistic adults. Most training is geared towards young children. This is slowly starting to change but providing incentives for providers to pursue additional training to qualify themselves to work with autistic adults could help. Insurance is extremely important - however, insurance companies are incentivized to fight against covering care (mine randomly dropped the only therapist who is qualified to treat autistic adults that I have found). Publicly-funded health services are necessary to improve the quality of care for any chronic or permanent condition. That or insurance companies need strong penalties for refusing to cover care arbitrarily. Public transit and more effective paratransit is an accessibility need for autistic individuals like my brother who cannot drive at all. It is not appropriate for my brother to be in-transit for 4 hours on a trip that would take 30 minutes by a standard bus, but that has happened repeatedly.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	COVID-19 taught me that my quality of life is mostly better when I am able to perform most tasks remotely. Being able to access telehealth made it easier for me to receive medical care because I was not restricted to doctors within a commutable distance. I was also able to access a doctor for basic care when I would otherwise feel too sick to take myself to the office which is about 40 minutes away.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I think that increased remote work, school, and telehealth improved my quality of life drastically. I do not feel much need to go out and do very public events and usually can not handle them anyway. Shifting back to in-person was a much more negative impact on my quality of life because insurance is now fighting me on my doctor's appointments and I am struggling to find work in my field in my area, so shifting away from remote-work really impacted my ability to find a job. My brother, on the other hand, is already limited in how he can get out of the house so removing his in-person services really impacted his quality of life negatively during the pandemic.

Name	Elio McCabe, Autistic Women & Nonbinary Network
Demographic	Autistic individual; Representative of advocacy organization
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>Weight discrimination has made multiple headlines this year thanks to the AAP’s decision to encourage intentional weight loss for young children. For autistic people who experience multiple forms of discrimination and are more likely to experience abuse and violence, a punitive attitude toward food and nutrition adds insult to injury. The practices used to get larger people to lose weight are counterproductive and demeaning. There is an increasingly large body of research suggesting weight discrimination itself explains some of the adverse health outcomes associated with high weight. This is a form of allostatic load. We recommend that researchers conduct more participatory action research about autistic people, weight discrimination, racism, and other factors that lead to detrimental health outcomes. It is time for researchers and practitioners to rethink their vocabulary for larger people. We encourage autism/IDD researchers to lead the charge in changing the way we talk about weight and health. The first step is to end the use of the word “obesity.” For people with IDD, this term is analogous to terms like “idiot,” “moron,” or “imbecile.” It is rejected by the people it describes, especially Black people—just as the word “[redacted]” was rejected by people with intellectual disabilities. Listening to disabled people, or people thought to have health problems because of their weight, means using vocabulary that affirms their humanity. Anything else is epistemic injustice.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>Nine out of ten autistic women have experienced sexual assault or harassment—and most of them experienced their first sexual abuse before the age of 15. ABA may increase this vulnerability. ABA, especially in its traditional form, teaches children to comply with parents’ and teachers’ demands using operant conditioning. ABA is especially dangerous when used in the hands of adults who take advantage of autistic children’s compliance training to sexually abuse them. Research needs to be conducted about autistic people’s response to sexual trauma and its possible relationship to compliance training. Studies exploring child abuse and autism should note that primary caregivers can and do sexually abuse their children. There is a known link between neurodiversity and gender diversity. People diagnosed with gender dysphoria are eleven times more likely to also be diagnosed with ASD. Numerous studies show that LGBTQ autistic people experience greater barriers to healthcare access than their allistic cisgender peers. This means that even when healthcare is available, autistic gender-diverse people’s experiences drive them away from it. More research is needed into improving barriers to care for gender diverse autistic people. IACC needs to take a public stand against the incredibly harmful myth of rapid onset gender dysphoria. Finally, research which takes into account the voices of autistic people should examine the link between gender dysphoria and autism.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>We encourage researchers studying autistic people’s health outcomes to consider the intersection between autism and other forms of marginalization, oppression and maltreatment. Autism researchers should listen to the experiences of autistic people. Far too often, the voices of</p>

	<p>parents and nonautistic people are treated as more important, more relevant than those of autistic people themselves. In her book of the same name, the philosopher Miranda Fricker introduces the concept of “epistemic injustice,” or the idea that marginalized people are unable to know their experiences because they occupy a low status on the social ladder. Although she focuses primarily on misogyny and racism, this principle can be applied to autistic people, too, as well as disabled people generally. Research that serves the autistic community should emphasize quality of life for autistic people, rather than the convenience of parents or practitioners. Co-occurring psychosocial disabilities and autism. Although some research on autism and co-occurring mental health conditions (e.g., PTSD, bipolar, generalized anxiety) exists, it is relatively scanty. Since autistic people experience stress and trauma in a world that was not adapted for our needs, it is likely that autistic people are more likely to develop psychosocial disabilities in response.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>There is a serious access need for autism screening in racially and socio-economically diverse settings. Although the prevalence of autism does not differ across racial or socioeconomic boundaries, diagnosis has consistently occurred earlier and at higher rates among white male children from higher socioeconomic backgrounds. It is only against the backdrop of COVID-19 that the Autism and Developmental Disabilities Monitoring Network saw its first year in which children from minority backgrounds were diagnosed with ASD at a higher rate than their white peers. Even then, male-identified children were still four times as likely to receive an ASD diagnosis as female-identified children. This is not an accurate representation of autism diagnoses. Female-identified children are often misdiagnosed, or not diagnosed until much later in life, missing out on early intervention and critical support. Estimates of the “true” number of female-identified people with ASD diagnoses vary, with one recent study suggesting as many as 80% of autistic women are not being diagnosed until adulthood. More research is needed into the current diagnostic systems in place that are creating this racial, socioeconomic, and gender divide. It should not take a mass disruption on the scale of COVID-19 for children of color to receive autism diagnoses at a rate equivalent to their peers. We must not wait for something even greater to address the gender divide.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	

Name	Eliot C., Disability Network Washtenaw Monroe Livingston
Demographic	Autistic individual; Service provider, health provider, or educator; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I believe more research should be done on the co-occurrence of joint hypermobility disorders (like Ehlers-Danlos Syndrome) and autism. Many autistics experience lack of coordination or underdeveloped muscle tone, which affects the way we move. Additionally, we often desire physical pressure like hugging ourselves or stretching our bodies in atypical ways to regulate anxiety. Bringing one's legs into one's chest or other ways of over-extending our muscles might lead to greater physical joint pain down the road. Ehlers-Danlos Syndrome often features gastrointestinal issues, which may contribute to its greater prevalence among autistics.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Non-autistic people underestimate how much of our emotional disturbances are triggered by overstimulating, unsafe, or otherwise uncomfortable environments. Meltdowns or shutdowns often seem to come from nowhere from the outsider's perspective, but often they are the result of failing to keep ignoring the things that bother us that others don't seem to mind (bright lights and colors, intense smells, crowds of people, noisy environments, etc.). Mental health "treatments" for autism still focus on diminishing the behaviors that non-autistic people find disruptive or weird without regarding what is happening psychologically that causes us to produce those behaviors. Autistic people may end up traumatized from therapies that force them to hide their true feelings to appease authority figures. Even if we don't end up in ABA, we absorb social messaging that similarly suggests conforming to others' standards is the only way to be taken seriously in life. We need more research into trauma-informed treatments for mental illness among autistics, and into what mental health professionals need to know to be more responsive to autistic clients.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	How autistic sensory experiences contribute to mental illnesses like depression and anxiety Outcomes of autism-affirming mental health care Substance abuse treatments that are most effective for autistic clients In other words, anything that involves talking to and listening to autistic people (whether we communicate verbally, with AAC, in written language, or trusting that when we show emotional distress, there is a reason behind it)!
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Person-centered planning Coordination of Community Mental Health services (Michigan claims to have universal mental health care through CMH, but the same treatments are not available in every area) Provider education on autism acceptance and neurodiversity Insurance that covers autism services beyond ABA
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to	Telehealth and telework has been a positive outcome of the pandemic for me as an autistic adult. My psychiatrist's office had electronics that emitted a

the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

high pitched frequency that interrupted my concentration. Now, I can attend my appointments in a comfortable, familiar environment, and our sessions have become more productive.

Name	Elise Aguilar, ANCOR
Demographic	Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	<p>The Medicaid Home and Community-Based Services (HCBS) program is integral in improving the lives of people with autism. The HCBS program furthers the independence and empowerment of people with autism in their homes and in the community by offering person-centered habilitation supports designed to assist in acquiring, retaining, and improving the adaptive skills necessary to support community inclusion and integration. Yet, waitlists for HCBS programs for people with I/DD can be years long. Underinvestment and inadequate reimbursement rates have left providers unable to offer competitive wages, which has led to high turnover and vacancy rates. As a result, providers report higher rates of program closures and an inability to take on new referrals. The workforce shortage causes tangible negative effects for people with complex and co-occurring disabilities. A lack of consistency among staff severs bonds that have been created over time and leaves individuals without a person who is familiar to their unique needs. Without stable support in the community, individuals are at higher risk of hospitalization and institutionalization. The IACC must support policies to address the direct support workforce crisis, including increased investment in HCBS and guidance to states to support reviewing reimbursement rates. Strengthening access to person-centered supports furthers the IACC’s commitment to supporting services to maximize the quality of life for individuals with autism.</p>
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	

What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

Name	Elizabeth Bennett, Children's Hospital Colorado
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I think sleep has the most immediate and profound impact on families. It's hard to ask them to work on anything else when everyone's sleep is disrupted.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety. I think anxiety underlies many of the other hard things and certainly requires a great deal of management from families and results in avoidance of important things like vaccines and routine lab work.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The combination of ASD & ID is an especially difficult one that results in fewer choices for autistic people when they reach adulthood and increases the need for lifelong family supports.
What additional research is needed to help address co-occurring conditions for autistic people?	More work is needed to best understand how to reduce anxiety in autistic people. More work is needed on how to treat trauma in autistic people.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Colorado services are a mess with all the changes to CCBs. Getting services requires parents to have time and skills and access which are things not distributed equitably across all families. Kids with parents who are good case managers appear to have better outcomes than kids whose parents don't have the means to manage their child's team, for whatever reason. Rural areas have terrible access and few choices for many of the services we recommend. The inability to provide telehealth across state lines is an enormous barrier in the West where services are spread out and providers are few.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Elizabeth Doolittle
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbances as younger child Has Rectal Prolapse as a consequence of trying to force his stool out which then became a behavioral issue he could not stop doing Skin sores from picking at skin or picking at wounds which makes them bigger and take longer to heal
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD - severe inattention to anything that is not a topic of interest, gets lost in his own thoughts TICS - has motor and vocal tics Irritability - can be extreme when things are not going as planned or he gets interrupted doing something he is engaged in
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Has co-occurring dyslexia and dysgraphia (although the dyslexia has been mostly remediated with intervention)
What additional research is needed to help address co-occurring conditions for autistic people?	More awareness of how this presents with type 1 autism - kids are not getting diagnosed and most people do not understand masking and how skills are present one day and not the other or how it depends on the situation. Kids that are high IQ are judged for not trying or as behavior problems and not kids with disabilities. My son's rigidity gets in the way of the help we try to give him. He is resistant to any help and does not see his behavior as a problem to the extent that it is. We struggle with school issues related to his inattention and there are interventions that could help him but he will not accept them. I would like to see research around working with our kids with Autism and learning disabilities (yet high IQ).
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	patient-provider interactions, teacher-student interactions
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It seems like after COVID my son withdrew socially more. He was not super social before COVID but he lost his confidence after not getting as much exposure to friends from school - birthday parties etc during this time.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	reduced in person social interactions and obligations

in-person social interactions and obligations)	
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Name	Elizabeth Emen, Emen Counseling Services
Demographic	Family member of an autistic individual; Service provider, health provider, or educator; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	More research/validation in the US mental health system is needed for the PDA profile of Autism. This is an underlying nervous system difference that is not embraced or known for many of the individuals seeking psychiatric services and dealing with persistent mental health conditions. When Autism is unrecognized, which is due to many societal factors such as stereotypes about autism, limited diagnostic criteria that focus on deficits and miss other differences, and the reality of high masking and low social support needs, harm is done. To answer this question accurately, there needs to be a focus on accurate training and evaluation of autism that is non pathologizing. The PDA profile of Autism is at the root of complex persistent individual mental health and substance use disorder problems as well as systemic challenges, as unidentified autistic individuals who are high masking often have not been identified as having a disabled nervous system, and instead are viewed through a neurotypical lens so that when they experience social stressors or stressors to their nervous system they are pathologized in the behaviors that result. Most people are not aware that biological experiences that differ from what we are typically taught to expect, (sleep, eating, stress response) impact behavior and that these behavior differences can be indicators of autistic neurotype traits that mean other physiological differences in how the individual exists in the world.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Systems of care need to catch up to better understand the overlap and connections between ADHD and Autism. The evaluation and treatment of anxiety has different origins and treatment needs depending on whether there are underlying ADHD and Autism traits. Nervous system biology is not at the center of mental health diagnostic systems and treatment services and this is an enormous disservice to the autistic community and others. The assessment and interventions through a nervous system and neurotype lens yield drastically different results for an autistic individual than if they are assessed and viewed through the traditional behavioral health model- this is a form of ongoing oppression and harm to all, specifically the unidentified community of autistic individuals that are socially high masking/low support needs and often do not even know that they themselves are autistic. They many diagnoses they've often been given are typically inadequate external assessments about the symptoms that have resulted from not being accommodated and supported with their biological differences, and do not account for internal experiences and true differences in biological needs.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	In the case of PDA Autism, when nervous system activation occurs in response to perceived demands or losses of autonomy, stress accumulates and has the individual constantly in survival mode, when not being accommodated they are rarely using logic and frontal lobe processing to communicate and lots of blaming and misunderstanding result from the nervous system reactions that others observe and judge in the context of viewing them as NT individuals. This behavior is often misjudged as disabilities in learning, intellect and communication when in fact nervous system activation and flooding are at the root. The deficit model contributes to this inaccuracy and misunderstanding by teaching providers to look for limits to communication instead of differences. Learning disabilities are characterized based on assumption of underlying abilities- and the impact of being in a demand that is activating stress due to unique threat perception- is not accounted for in evaluation. In the presence of seemingly typical verbal

	communication, assumptions that the individual is sensing and perceiving the same as their peers is wrongly made.
What additional research is needed to help address co-occurring conditions for autistic people?	Research and data that conveys the reality that autistic traits present in a variety of ways, that shine a line on true neurodivergence and move common understanding beyond the limited historical viewpoints that expected to see verbal and social deficits, or high intellectual functioning but low social motivation. Research that supports the idea that social motivation and the desire to connect socially cannot be adequately measured through neurotypical standards and when individuals are not accommodated or supported to develop positive self-identity. All individuals need and are motivated by human connection, inadequate understanding of autism leads to stereotypes that autistic people are not social humans and deficient in skills. What people have been conditioned to understand and look for as autism both in professional and layperson circles is a barrier to truly understanding autistic neurotypes and the co-occurring differences, experiences and symptoms that result from being different and misunderstood in the world not designed for them.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Focus research and understanding that informs services and supports on the lens of the nervous system rather than behavioral and compliance based models of functioning. Services and supports need to emphasize the importance of internal experience over external signs of neurotype differences. Prioritize putting PDA, Pathological Demand Avoidance/Persistent Drive for Autonomy in the DSM or find an alternative way to standardize the awareness and inclusion of PDAers and other high masking autistics in all communities of life.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	The pandemic resulted in a collective prolonged anxiety that had impacts on every systemic level of daily life for US individuals. The access to social and economic resources was a potential mediator for the individual/family experience of stress. For those highly impacted by stress prior to the pandemic, the pandemic contributed to the accumulation of dysregulation and lessened capacity for many that may not have manifested as quickly or in the same way without the global experiences related to COVID-19. For all individuals, cumulative anxiety and prolonged dysregulation has significant impacts on physical and mental health experiences. For autistic individuals, this experience from the pandemic was superimposed on other layers of prolonged anxiety and distress that were already present related to neurotype and environmental interactions.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The accumulation of stress leading to chronic dysregulation often leads to a greater need for reliability, predictability and management of changing social and environmental experiences- this is theorized as a significant underlying experience in the perceives social and cognitive differences of the autistic individual. While there were opportunities for Autistic individuals to be more accommodated in their differences, such as with flexible telework schedules and use of technology to communicate, there were also sweeping changes in the way day to day life was managed and ambiguity in these experiences that increased unpredictability and forced change for folks before they may have had ample time to process or adapt. More research is needed to explore the nuances of these experiences of accommodation and adapting to changes and how they impacted Autistic individuals overall.

Name	Elizabeth Larned, MA, LMHC-A
Demographic	Family member of an autistic individual; Service provider, health provider, or educator; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	ehlers danlos syndrome, a connective tissue disorder commonly co-occurring with Autism. It's underdiagnosed, and is usually written off as laziness in adults, or an unwillingness to try physical activities in children. They're not lazy, they're undersupported.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The anxiety that comes from thinking they should "just have it right by now"
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Perhaps the most challenging is the lack of opportunity to learn social skills. Autistic people are often raised by autistic people, the only chance at "normal" socialization is through school and community. While some communities know how to support people with autism, most write it off as character deficits. This can cause issues at school, in the work place, and with loved ones.
What additional research is needed to help address co-occurring conditions for autistic people?	Research on the actual number of people with hEDS (hyper-mobile Ehlers Danlos syndrome) versus the previously estimated numbers. It's a connective tissue disorder, as mentioned above, which is highly correlated with eating and feeding complications, speech, heart health, all the joints. It's sorely under-researched and most physical therapists aren't trained to recognize it well.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	advocates in medical spaces would be a big deal, it's difficult for folx with autism to relay their experiences in a way that most medical professionals are receptive to, as they can be seen as "argumentative". Remaining employed is the biggest challenge for adults with autism. I'm a mental health professional so I can't speak to how to address that, exactly, but lack of income is really crushing for someone who can't work due to their disabilities.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Anxiety, weakened immune systems, social phobia. Depression, anxiety, lack of confidence.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	More remote services and work options is helpful for a lot of folx with autism. Disruption in services is dependent on the state, as many states don't have sufficient or clear resources for autistic individuals.

Name	Elizabeth Olson
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	It's very difficult to operate in society when you have co-occurring health conditions with autism. The health conditions are often not taken seriously by doctors or by society at large making it difficult to get accommodations, diagnosis and support. It's also very expensive and difficult to get medical care in this country.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Very difficult to work and to maintain a job with autism and mental health problems. Working tends to make the mental health problems worse by overstimulation and ableism at work. Work also takes all of the energy we have and we don't have any energy left for things we enjoy so that also adds to mental health deteriorating. It's difficult to get accommodations at work for mental health struggles, and once we tell our employees we are autistic we are often subjected to abuse.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication disabilities make communication ever harder, communicating is hard enough already but add not being able to form sentences to it and trying to communicate with bosses or coworkers becomes difficult and at times dangerous.
What additional research is needed to help address co-occurring conditions for autistic people?	More research on why we have different bodies compared to neurotypicals. It's hard to get a diagnosis as an autistic person because doctors often can't figure out what's wrong with us. more research on how jobs can be more accommodating to autistic people, and designing buildings to be sensory friendly (minimizing echoes, natural lighting)
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	There needs to be a way for autistic people to get more help financially, almost like a universal income. Working while being autistic is extremely difficult and there needs to be a way where we can work half time and then receive a supplemental income, or an entire supplemental income . I've been denied for disability income twice, and I would only receive \$800 a month if I got approved. That is not enough to live off of. Disability income is designed to keep disabled people in poverty, and there needs to be a reform where it's easier for people to get help and receive enough money to live off of.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Working from home has been an improvement for a lot of autistic people.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increased remote work has helped a lot of autistic people. I think things being more accessible online has helped a lot of us as well.

Name	Ellen
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep, sensory problems, auditory problems
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression, anxiety, adhd, disregulation
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication & learning
What additional research is needed to help address co-occurring conditions for autistic people?	1. Do traits increase or decrease with age? 2. Do traits increase or decrease based on level of support needs? 3. What are college & job statistics? 4. Housing? 5. What is the likelihood of co occurring?
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	1. Services for all ages & levels of support 2. More support for caregivers 3. More healthcare providers with knowledge about autism & co occurring
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	1. Stuck inside more 2. Change of routine 3. Not able to see normal help or support
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increase remote work Masks Reduced in-person interactions More empathy

Name	Ellen Kopel-Puretz
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	EPILEPSY!
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	PTSD
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	link between epilepsy and autism - perhaps it can lead in the right direction for a cure for epilepsy the effects of ABA - and resulting PTSD
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	get quantified data to encourage universities to properly educate teachers, therapists, and other medical professionals on HELPFUL accommodations and supports
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Elyssa Bolt
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	People in the autism community report a higher incidence of gastrointestinal problems than the general population. Autism correlates with delayed development in gross motor skills, which most of us outgrow eventually but not before sustaining negative childhood experiences of physical education and participation in sports. As a result of these frustrations, autistic people are likely to avoid exercise and physically demanding recreation, which makes the consequences of insufficient exercise not an inherent symptom of autism but another dimension of how many of us experience alienation from important areas of life.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Many autistic adults with a co-occurring bipolar diagnosis argue that this link needs to be better understood by educators, parents, and eventually employers. Being constantly in trouble for time management and mood dysregulation throughout childhood and well into adulthood takes a considerable toll on most bipolar individuals' mental health, an impact that is felt especially hard by people who also struggle with the sensory and social struggles associated with autism. The distinct yet probably related condition of borderline personality disorder, or BPD, is thought by some experts to ultimately be a self-preserving response to adverse childhood experiences, which autistic individuals are more likely to experience. Another mental health condition often experienced by autistic people is post-traumatic stress disorder, or PTSD. The same question of whether one causes the other or some other factor causes both applies to the link between autism and PTSD, but in any event autistic people are more likely than the general population to report PTSD symptoms and diagnoses. Among the autism community, the general consensus is that we are more likely to experience traumatic events than allistic people due to sensory overloads and trouble reading social situations that are prevalent autistic traits.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	As one of the major symptoms of autism is difficulty with sensory processing, many autistic adults – especially if undiagnosed – develop substance use disorder because alcohol and drug use can dull the sensory distress that many of us feel in environments that allistic people would find comfortable or neutral. Engaging in substance use can also break down social barriers that autistic individuals feel constricted by; not only does drinking help us fit in more with neurotypical peers, it also allows more flexibility of behavior that means that visibly autistic traits are often more tolerated in an alcohol-infused environment than in other situations. Statistics vary on the exact percentage of autistic adults who are unemployed at any given time, but some estimates put it as high as 85%. The expectation in much of the modern work world that employees simply continue to generate some unit of productivity at a continuous, linear rate does not mesh well with the abilities of many autistic people, especially with the co-occurring mental health conditions identified earlier. Job interviews are stressful for most people, but more so for people with visible struggles in displaying expected behaviors such as eye contact. Many autistic people, though by no means all, are naturally inclined to either answer questions very briefly or at great length, both of which are detrimental to success in job interviews and in situations regularly encountered in many jobs.
What additional research is needed to help address co-occurring conditions for autistic people?	Research needs relating to autism include, but are not limited to, appropriate pedagogical methods, the phenomenon of masking autistic traits, giving priority to autistic voices when we speak about ourselves, the exact nature of

	the bipolar-borderline-autism dynamic, factors that differentiate success from struggle within the autistic population, the impact of media portrayals of autism, the different expression of autistic traits in different genders, and the impact of aging on autistic traits.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Service needs sometimes overlap with research needs. I identify four areas of need for increased services: first, the abolition of Applied Behavioral Analysis (ABA) practices that are often wrongly perceived as therapy; second, the establishment of appropriate supports in school settings; third, greater visibility in all areas of life of diverse experiences of autism; fourth, funding for social support groups for a greater range of ages.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Emilee
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory issues, sleep disturbances, but usually society in general causes the most issues
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	All of the above. Mostly depression, which can be caused by a lot of comorbidities
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Stereotypical work/school week.
What additional research is needed to help address co-occurring conditions for autistic people?	Have people with autism conduct the research and come up with the study questions.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Humans instead of automated services, better public transportation
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It has shown that too many people do not care about their community and people with illnesses, and only care about themselves. This makes me fear being around others more than I did previously
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Positive: more remote options

Name	emily
Demographic	Autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>Much of my physical distress is disabling due to treatments administered under the assumption of inaccurate diagnoses. Key realms of distress: GI - unbearable esophageal spasms. Mobility - impaired by normalized abuse. Obesity - unable to thrive nutritionally or with regards to physical fitness after misguided pharmaceutical treatments. A way that all of these issues are made further distressing, however, is the emotional impact of my awareness of rejection from others around me. This becomes a prominent issue in my physical reality because of rejection I faced from a thin mother as a fat child. It may seem silly, but because the rejection has been felt by my body physically, it manifests in disease. I'm not exaggerating when I say acceptance changes the experience of my physical symptoms. The threat that rejection from others poses to my body and its ability to survive has kept me indoors. I am in very poor health from the isolation. These confluxes of emotional and physical symptoms also present a risk to me when it comes to seeking any medical guidance. The emotional reality of medical gaslighting is not something my body can survive. I hope this makes sense. I'm not claiming that autists experience a different mind-body connection than allistics, rather, that connection is more sensitive, and therefore plays a role in autism as a disability.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>I would say the hardest part of having any issue while being autistic is that the people whose job it is to help you truly believe that you can't possibly mean the things you're saying to them directly. There have been times in my life I was given harmful treatment because doctors and adults believed that my self-reporting and observable behavior were closer to manipulation than a genuine prompt for a child's needs to be met. In my generation, lots of people embodied a haunting image to adults - cutting our wrists, choosing drugs over consciousness, and so many children we lost to opiates. The ways we were treated for the methods we found to soothe ourselves and survive our environments were damaging in all the the ways that adults can carry damage from childhood experiences. I think to help us, the goal shouldn't be to have a kid who doesn't hurt themselves. It's to take it seriously when they let you know why it is they're hurting themselves. I honestly can't understand what adults thought we were doing - trying to be cool? Our pain was being dismissed as misbehavior - it was a disaster. The gaslighting is a physical threat as it is to any trauma survivor. I know you need to address pressing and tangible issues, but I also know I'm not alone when I say that I told the adults the first time. I told the adults directly. I used my words. And they just... thought I meant something that I didn't mean. And I never got a chance in this world, because of it.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>I can answer regarding learning disabilities and communication disabilities. Regarding learning disabilities, the way that autism has affected me deals with communicating the ways that I learn. People are often confused and don't allow me the time to explain in full that what I require in order to learn how to do something is to see someone do it, try doing it myself, ask questions, usually get some help from someone who knows how to do it, and then after that I can pretty much always do that thing - or, at least, to the extent that my body is able to that day. The knowledge of how to do the thing is permanently learned, though. I am so often excluded, though, when it seems to others that my sentences have too many words in them, or that my thoughts have too many sentences. It is very painful to be dismissed and assume ineligible in this way. It is so painful that it has impacted my</p>

	<p>central nervous system greatly, and I have been unable to seek medical care because of the recursive issue regarding the lack of patience in the medical industry for well-informed patients. And so this is really more of a communication issue, and this is not a disability for me; it is a shortcoming among allistics. I am a very effective and talented communicator. Allistics become angry and confused when my sentences are long or challenge perceived societal hierarchies. I am a very invested and skilled communicator. I have been disabled by the inability of others to hear me.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>More professionals need to be trauma-informed and stay up to date on best practices for complex trauma - in fact, all medical professionals should be required to keep their education on this topic active and ongoing. The amount of harm that is coming directly from the medical industry to autists - for whom chronic illnesses are statistically more likely - is demonstrative that a broken system can be repaired by accommodating the most vulnerable members of a community. I believe that by giving (needs-based) spaces to autistic people to explain in more depth what our experience is like, the whole of society can improve our infrastructure to produce better outcomes from infancy - both psychological and physical. Our species is in a crisis of empathy, and to draw the line at doctors hurting patients and facing no consequences for permanent nervous system damage would be a world-saving move, on a historical/ideological scale. Be kind. Listen. Believe. Respect. Care. This is research that takes place in the heart, and in the determination to see a better world, which I know we all do.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Like I've said, a lot of the obstacles come down to autistic styles of communication being dismissed, disrespected, invalidated, and pathologized. While I could write out extensive suggestions for improvements to every system we interact with, this text field only allows 1500 characters. ([profanity redacted] decent of you to let us navigate between answers, though.) And so again I believe this comes down to a matter of acceptance. We need for skilled allistics to become more willing to translate what we are saying, and that requires acceptance that we are who we say we are and we mean what we say we mean. If a broadly applicable protocol can be adopted by allistics (trauma-informed practice in all fields) then autistics will be more able to communicate. When we can communicate accurately about our sensitivities, those sensitivities can illuminate needs that extend beyond our community. It is the acceptance of the systems as they exist, to the detriment of autistic loved ones, that prevents allistics from being able to hear us when we talk.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>I will keep this one simple: I have a worse case of long covid than anyone i know. I can feel myself dying. And after screaming for help from my community for years now, stating my needs directly and deteriorating in front of their very eyes, I know what the idea behind chewing one's own tongue off is.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>This one i'll also put quite frankly, sirs and madams, and I think you'll catch my drift here: if y'all let us die out like it has seemed might happen, you could be making things worse for yourselves in the long run - I don't think any of you understand that an alternative to dystopia can exist, let alone map out the moving parts necessary for change for sixteen hour stretches at a time. But we both knew that, didn't we?</p>

Name	Emily
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I have IBS and i recently had two polyps removed in a colonoscopy that were precancerous. I have a hiatal hernia that was discovered in an endoscopy. I have irregular sleep patterns, and I experience sleep paralysis and night terrors. I've dealt with depression and anxiety for as long as I can remember and have autistic meltdowns frequently do to exhaustion. I have sensory sensitivity to lights, sounds and texture and have a hard time focusing and executing tasks because of it and it makes it difficult to communicate my discomfort.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I've dealt with depression and anxiety all my life, but it wasn't until I was 16 when I noticed I've become more aggressive, almost like how it is with Borderline Personality Disorder. I've always experienced ADHD symptoms, but never was treated for it because I was diagnosed with autism at the age of 3 and that was the primary focus of my care. I've never self harmed but I've definitely felt suicidal at times when I'm burnt out and spiral into a depressive state, usually around my menstrual cycle.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I was never diagnosed with hyper mobility/Ehlers Danlos Syndrome but I suspect I have it, which might have caused me to develop a hiatal hernia. It also affects my digestive system. I also get dizzy spells and have migraines from dehydration and have to over compensate with my sodium intake.
What additional research is needed to help address co-occurring conditions for autistic people?	Shift your focus away from young, white boys and focus on women, people of color and different age groups as we experience the world differently and have to adjust to social norms that white men don't experience.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Easier accessibility to insurance, not just Medicare/Medicaid. Improve ethics in healthcare.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Regression in mental development, brain fog.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	It has all been negative. My work load has increased but my pay has not, and I am burnt out constantly and have had to go to therapy because of it.

Name	Emily
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	gastrointestinal distress, sleeping too much or too little, vivid dreams, lights being too loud especially in public places, lighting in general being wrong in most places, makes it difficult to focus on anything else.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD, depression, anxiety, low self-esteem
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Autism and ADHD have made reading difficult. Dyslexia and dyscalculia are common. Then frustration with not knowing how to communicate what the issues are.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Easier online options for communication and access to services. I don't want to talk to people. I will avoid many things if it means I have to speak to a person. Texting options would be helpful.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Isolation was not stressful. However, coming back after isolation, I realized my 'autism mask' has come off. I didn't have to 'act like a normal person' for so long I sort of forgot how to. Ive finally allowed my natural self out and as a result my anxiety has decreased. The options for being able to do more things online has helped as well.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Telehealth and work from home have been the best things ever. Delivery services are great as well. I don't need constant human interaction to survive like neurotypicals do. I prefer isolation and am better mentally because of it.

Name	Emily Garris
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My son has autism and multiple co-occurring health conditions. He has sleep disturbances, sensory issues, and mental health issues. These make it difficult or impossible for him to have a job, maintain his hygiene, have relationships with others, attend school, drive, and live independently.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My son has multiple mental health diagnoses that co-exist with autism. He has schizoaffective disorder, depression, and anxiety. It is difficult or impossible for him to understand the point of view of another person, he can be paranoid, he gets overly anxious about minor health concerns, he has had several hospitalizations for suicidal ideations, he handles transitions poorly, he has demand avoidance, he freezes under any kind of pressure, he is socially anxious, he sometimes sees and hears things that aren't really there. All of these things affect his ability to live independently and have a fulfilling life.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	I'd love to see more research into the concept of demand avoidance. Where the brain and nervous system sees all sensory input as a demand and therefore the brain is constantly in a state of fight/flight/fawn/freeze. Also it would be great if some of the "branches" or "offshoot" phenotypes of autism could be classified as disabilities and have actual medical diagnoses.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The covid pandemic and shutdown was the catalyst that led to us seeking an autism evaluation for our son. The sudden shutdown of school, classes via zoom, the fear of catching and dying from covid, isolation from friends and extended family really caused his mental health and autistic behaviors to worsen and his quality of life hasn't recovered.

Name	Emily Paige Ballou
Demographic	Autistic individual; Family member of an autistic individual; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	While I'd consider sensory and motor challenges intrinsic to autism and not "co-occurring," inertia and auditory hypersensitivity/auditory processing challenges are the most significant physical challenges related to autism I face. Of conditions I would consider truly "co-occurring," personally, I would say gastrointestinal pain, sleep disturbances, and for most of my life although not currently, painful menstrual periods.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Personally, the most pervasive challenge is anxiety, related to any number of challenges and uncertainties that affect me as an autistic person far more than they do most people, and for which I have very little support available. I don't know whether I'd consider this more of a mental health condition or a social factor, but I'd also say loneliness. For autistic people in general, probably depression and suicidality.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Research into autistic experiences of movement differences/motor challenges that might improve knowledge of both social communication difficulties associated with body language differences, and how best to serve autistic people in services like physical and occupational therapy, support those with complex communication needs, and better support autistic people in gaining the skills we need to live autonomously (meaning: not necessarily "independently," but best able to direct the course of our own lives). Research into the safest and best-tolerated treatments for anxiety, depression, as well as epilepsy and heart disease (which are common causes of early death in autistic and developmentally disabled people).
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Availability of one-on-one assistance navigating the healthcare and health insurance systems.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Personally, while the lasting impacts of Covid-19 infection itself on my physical health are yet to be clear, the experience of the pandemic in a multitude of other ways has left me suffering from heightened anxiety, isolation, and loneliness, as well as overwhelming circumstances at work (understaffing, erratic schedules, physical stress associated with mask-wearing requirements, poor physical working conditions).
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services,	To some extent, the increase in remote work has been a positive, which allows me to avoid sensory overloading public transit use more days of the week. There was a period of time, however, in which the increase in online compared to in-person work was incredibly stressful for the amount of screen time required, learning curve involved in learning virtual systems, etc. To some extent I've experienced a relief from financial pressures due to

increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	enhanced unemployment benefits available during the pandemic. In both the short and long term, the pandemic has complicated my access to health insurance. Relaxed eligibility requirements, the 6-month federal COBRA subsidy, and short-term bridge plans made available by my union's health and pension fund helped keep me insured for the duration of the pandemic, but impacts on my career field and the finances of our health and pension plan have made our insurance more difficult both to qualify for and to keep.
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Name	Emily Ransom
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Communication challenges with an individual with autism can make self reporting difficult.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	If communication is a barrier for an individual with autism it may make it harder to work with a mental health professional to address the co-occurring mental health conditions.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication plays a big barrier for individuals with autism and/or other disabilities to seek the right treatment and/or medication from a professional because of the lack of communication or understanding.
What additional research is needed to help address co-occurring conditions for autistic people?	Additional research needs to be investigated on the individuals with autism who are nonverbal or lack of communication skills.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	The improvement for individual's with severe autism and their families more resources to help with the challenges. Improving waitlist for therapies to help address the self injurious behaviors or challenging behaviors. Providing families with professional mental health therapists to help address their needs as well. Being an autism parent to a child with severe autism can take a toll on parents mental health. It's vital the support is there for the families as well as the child and/or individual.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Covid-19 has made a huge impact for families to seek early intervention care on their young child showing signs of "autism" because the world was shutdown for months. Waitlist became even longer. The child continues to struggle and intervention is put on the back burner because of the waitlist.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	One positive impact Covid-19 had on my son with autism and has his mother is working hard to get him to wear a mask. Imagine having a child that is nonverbal and intellectually disabled be forced to wear a mask or they won't see your child. The hours upon hours working with my son we were able to have my son wear the mask without displaying challenging behaviors.

Name	Emily, Autistic individual
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Depending on the meaning of the term “most significant”, whether it refers to “most serious” or “most prevalent”, I would conclude that epilepsy is the former, and sensory processing disorder, the latter. I do not have epilepsy, but I experience significant challenges accessing public spaces due to the severity of my sensory processing difficulties. The fluorescent lighting, overhead music, and bright white walls and floors that are most commonly observed in large department stores or grocery stores, are too much for my sensory system to integrate appropriately, and I am prevented from remaining in these spaces long enough to complete errands without getting overwhelmed, even when I have my support worker with me to help me manage my sensory responses.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Self-injurious behaviors are one of the most serious symptoms of challenges related to emotional self-regulation, anxiety disorders, and depressive episodes. They can have physical medical consequences that reach beyond an immediate moment of dysregulation. Personally I have experienced at least three instances of ER admission and CAT scans due to acute head trauma caused by my own uncontrollable self-injury. Self-harm such as head banging, scratching, biting, hair pulling, etc. are common in those with developmental disabilities, because our brains lack the capacity to respond to socially, emotionally or physically challenging situations in a measured and rational way. The self-harm is not deliberate or calculated, it is an automatic, unmanageable response to distress that we do not have the skills to navigate in a cognitively appropriate way.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication difficulties are a common and serious concern for those with autism. An estimated one third of the autistic population is either nonverbal (no functional verbal speech) or minimally verbal (fewer than 30 words of functional verbal speech). As a level 2 autistic with moderate to high support needs, I rely on a speech generating device (alternative and augmentative communication, abbreviated AAC) for much of my interaction with others. Without it, I would struggle to get my needs met, my emotional experiences understood, and my ideas heard. A greater emphasis on supports specifically for autistic adults (as opposed to autistic children) who need more communication support, is, I believe, a high priority need.
What additional research is needed to help address co-occurring conditions for autistic people?	Really any research on autism and its comorbidities that focuses specifically on adults, especially women and individuals of minority ethnicities, is critically needed at this juncture. The vast majority of autism research is conducted on young children, and that which is conducted on adults, invariably includes primarily or exclusively white males as its experimental group participants.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage for autistics, especially autistic adults, is critical. I depend on Medicaid and my state’s SLS waiver to cover every one of my autism-related supports and services, including my in-home caregiver who supports me with the tasks of daily life, and the day program I attend, which is my only source of non-professional social interaction outside of the family members with whom I live. So many autistic individuals who have lower support needs than me, who are able to work to the degree that they do not qualify for Medicaid, struggle to find supports and services that meet their needs at all, never mind services which their private health insurance will cover, and whose copays and deductibles they can afford. A greater emphasis on affordable health insurance, and on services to meet a wide severity spectrum of needs, is of paramount importance.

<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Disruption of services was hugely impactful to myself and many other autistic individuals during the pandemic. Many of my services paused entirely, and others were not conducive to a telehealth format (for instance, occupational therapy). That said, the increase in the use of telehealth appointments has been very beneficial in the long run. It allows me to attend my appointments without having to overwhelm my sensory system on days when getting out of the house is too overwhelming. I have also heard other autistics who work more traditional office jobs say that they have benefitted greatly from their new ability to work from home.</p>

Name	Emma
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The lack of medical providers with awareness of autism when seeking care for related conditions (in my case, hypermobility, POTS and MCAS). Simply knowing that someone is autistic can tell you a lot about what their immediate and potential future health concerns might be, including important stuff like how we metabolize medications, and how difficult lifestyle changes are for us, but this is not taught in med school or in training for most specialties, and this is a factor in our life expectancies being so much shorter than allistics’.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Not being able to access treatment from providers who understand what it’s like to be autistic—I’m lucky to have found an autistic therapist and I’m never going back. Also, the most common treatment paradigms, such as CBT, have not been studied in autistic populations, which means that there is literally no evidence based psychotherapy available to us, and while many in the autistic community are aware that CBT isn’t effective for most autistics, and that we need different approaches to mindfulness techniques, the approaches that work better for us, such as DBT and existential therapies, are much harder to access—and still have the drawback of not being designed with our neurotype in mind. Another issue for autistics with co occurring mental health concerns is that for a lot of people, especially women and people of color, have their mental health problems diagnosed first and then autism is overlooked. Many of us end up on dangerously high doses of medications we don’t actually need and are doing more harm than good for years. I interacted with dozens of mental health providers over the course of almost 20 years, I worked with some of them for 5+ years, and none of them figured out I was autistic. How many people just like me will never get the help they need because the people they ask for help can’t recognize obvious autism? What could my life have been if I had known sooner?
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	More research needs to be done on autistic burnout, because it triggers a lot of co-occurring chronic illnesses, especially those involving autonomic dysfunction. How to recover from autistic burnout needs to be explored as well.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Make funding available for individuals for services that are considered luxury amenities, like grocery delivery, home repair, yard work, housekeeping, tax prep, a personal assistant, etc. There are tons of professional services already available that could make our lives so much easier, but most of us can’t afford them.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on	Increased availability of virtual options for healthcare and employment is a good thing.

physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

Name	Emmett Lockwood
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I have Ehlers-Danlos Syndrome in addition to Autism. Ehlers-Danlos Syndrome is a connective tissue disorder, the most significant challenge cause by it is mitigating the ease with which my joints dislocate or go into subluxation. Because of this I have to walk with crutches, forgo different types of physical activity - eg running or weightlifting- that put excess strain on my joints. One thing is that because of Autism I have worse proprioception then other people with Ehlers-Danlos syndrome this means I get less of the feedback from my body about when I am about to dislocate or sublux a joint and often push by body harder than I should. I also have Celiac's disease which leads to a lot of gastrointestinal problems especially in settings when others are cooking for me and are as not careful with my dietary restrictions as I am.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have been diagnosed with PTSD, anxiety, depression, and ADHD. I have had my anxiety, and PTSD diagnoses since age 13, I got diagnosed with depression at age 17 and with ADHD at age 20. One of the major challenges I have had with my co-occurring mental health diagnoses other than the symptoms of the diagnoses themselves is how because of Autism my presentation of them is slightly different - for instance I have had to explain to mental health professionals that there is a felt difference between sensory overload and needing to not interact with people to preserve my own energy versus not feeling apathetic towards interacting with people because of depression. In addition during therapy I have found while I am really good at rationalizing and understanding why I am feeling that thing because of childhood messaging that I needed to have smaller emotions I am not good at actually letting myself feel my feelings without getting anxious about how I am masking my autism in front of others.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I have Meares-Irlen Syndrome - and optic nerve disorder that affects depth perception, and my ability to read that I was diagnosed with at the age of 7. One of the main treatments for this disorder that allows me to read and gives me some frontal depth perception back is glasses, however unlike other glasses these glasses are dark -meant to block out the wavelength of light my optic nerve struggles with processing - and look a bit like sunglasses on first glance. While people can see some of my eyes through them one thing I struggle with is that when I am attempting to show emotion often people have a harder time reading me - harder than normal when I am masking my autism - because they can't read the emotion coming from my eyes.
What additional research is needed to help address co-occurring conditions for autistic people?	I think more research and training should go into the interaction between autism and specific co-occurring conditions. To be clear I would never wish to get rid of my autism or any of my other conditions, many of them I consider inherent parts of my and while some of them can be a pain in the [profanity redacted] I would not know who I am without them. What I would want to see though is not having to explain or work through with every one of my doctors how a condition affects me because of my autism, and while there is different experiences because Autism is a spectrum I would want more research into where these interactions are so it feels like less guess work.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services,	I didn't get my autism diagnosis till age 19 because I grew up with parents who due to the forced sterilization of my great grandmother and forced institutionalization of my great great grandmother were worried about how a diagnosis would mark my life and peoples views of my potential. What could be improved in supports is really any support for individuals diagnosed in

<p>insurance coverage, service systems issues, patient-provider interactions)</p>	<p>adulthood with Autism and the elimination of autism registers in states such as New Hampshire that scare parents out of seeking diagnosis and currently leave children without answers and without help. Insurance coverage for supports other than Applied Behavioral Analysis therapy - which has been shown to lead to increased rates of PTSD in autistic individuals who endure this therapy that seeks to make us neurotypical - is the bare minimum. Also equitable access to services to communities of color, individuals assigned female at birth, and impoverished communities. As a mixed white and indigenous trans man I have experience first hand how some providers still believe that white cisgender boys have autism this blocks access to diagnosis and access to services for many individuals.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>I have not had a COVID-19 infection at this point - knock on wood- but as someone who was diagnosed with autism during the COVID-19 pandemic and as someone who has experienced healthcare systems both in the rural Vermont town I am from and in my college town is a small city in Wisconsin I can say the waitlists for seeing providers have ranges from months to years long (I have been on waitlists for an appointment for a specialist for Ehlers Danlos Syndrome for over a year and have been told I will probably have to wait a year and a half before I see the provider). Wait times aren't just annoying but often because there is the administrative burden of having to call providers every month to make sure my name is still on the waitlist (a requirement by many providers) it adds an administrative burden for autistic folks.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>I have been lucky that it feels like my social circles have become far more well versed in online communication and online meet ups as a form of socializing - note most of my friends are also disabled and this has opened our worlds up in many ways. While it was nice to see increased accessibility at the start of the pandemic - finally it felt like my own variable ability to attend in person events was being accommodated through online options - I was worried like many people about when this accessibility would end. I did not experience this same flexibility in university or high school settings and it has now felt like people react negatively to being asked if there is a virtual or hybrid option offered. I also really enjoyed masks as it put less pressure on me to preform emotions with the lower half of my face but it has become hard as I now receive increased questions about why I am still masking - despite having individuals in my close friends who are immunocompromised.</p>

Name	Erin , Parent/guardian
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My son has never slept through the night. He is 24 years old. He has OCD in addition to many other manifestations of autism and OCD. He can't be left alone due to his OCD- accessing food, technology, a want to leave the house.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	There is no help for the 24/7 care our loved ones need in so many aspects
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	the most significant challenges are the lack of help and services, especially once individuals age out of the school district in the state of Washington. There are no services available
What additional research is needed to help address co-occurring conditions for autistic people?	Profound autism needs to be acknowledged. Not everyone has exceptional skills that make them a wizard with technology numbers. Individuals with profound autism, often have self injury, OCD, anxiety that keep them from being able to access the world, keeps them at home, keeps caregivers in a constant state of emergency. My own son ended up stuck in the hospital for 47 days a year ago with no support or services and no way to safely. Bring him home. It's a crime to not acknowledge This group of individuals who desperately needs services isn't support as well as their caregivers
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	There are no current services or access for any actual care for our loved ones with profound autism. Once they fall off the service cliff which is finishing the school district programming, they're left with nothing but to sit at home. Caregivers and those with profound autism struggle equally trying to keep the left one safe Well also, the provider trying to work and keep a roof over their head. These are individual who cannot be left alone. Ever. They need 24 seven care! Often times they're larger than us parents stronger than us parents. We have no help except for to go to the emergency room. My son was stuck in hospital last year for 46 days with nowhere to go. No help no services. We need day programs Because on DVR employment does not work for these individuals! I will say that again, Washington state state thinks, sending individuals to work with a job coaches, even feasible. It is not! Our loved ones are stuck, hidden away home from the world. They must have access to a day program Like so many other states! It's an absolute crime the way Washington state discriminates within the disability community. If you are not able to hold a job, then you get no services. It's a simplest that
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	The real impact on Covid was all the programming closing. The very few things that were available no longer are. Our loved ones sat at home with no services for almost 3 years! And as a result of no more programming, They are continuing to sit at home in crisis. State of Washington must create some

	<p>sort of deep programming for those High, profound autism. Employment is not the answer! That's a feel good statement that ends up discriminating within the community those who were too disabled to be in the workplace end up, sitting at home for their entire lives!</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Complete cut off from services during Covid. My son actually had a crisis. I have stated before he ended up in the hospital for 46 days</p>

Name	Esther Caletka, HOME Incorporated
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory challenges. However, impairment in their ability to communicate any type of pain may result in behavioral outbursts, as well as self-injurious behaviors. My brother would kick walls - this resulted in wounds which would not heal for years. The inability to communicate dental pain, as well as other types of pain, could result in the complication of sepsis, requiring hospitalization (a very unpleasant experience for them), or even death.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Concomitant Bipolar disorder. When in a manic phase, aggressive behaviors are more predominant. Depression has challenges of its' own.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication disabilities further hurt these individuals. My experience, (working in a Day Hab program), has been; that while individuals are in school, they have the benefit of Speech Therapy, and all sorts of assistive communication devices. The minute they graduate - this all goes away! WHY????? It's not as if suddenly they are "cured" when they graduate! Their communication needs not only persist, but even increase, as they are expected to become more independent! THIS NEEDS TO CHANGE!!!!
What additional research is needed to help address co-occurring conditions for autistic people?	pre-natal identification Early Childhood diagnosis More education, in this area for all teachers - not just Special Ed More education for society, and neurotypical kids. More support for these individuals and their families, post graduation More training for doctors - in the 1980s I provided a clinic site, and taught Pediatric Residents about autism and D.D. One of the OPWDD MDs, recently referred to this as a positive experience, which paved his path to his current career. Training for Law Enforcement.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Greater research into, and greater understanding for all of society of Sensory issues, and sensory needs. We need more housing, as well as supports for older parents who choose to care for their adult children. Many cultures do not believe in sending their kids out to be cared for by "strangers". We have CDPAP for certain populations - why not for those with autism/DD/ ID
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Programs shut down. Some with autism were not able to receive remote services due to their disabilities. I, personally saw a decline in their cognitive function, behaviors, some becoming more "institutionalized" - not wanting to leave home. And many of our individuals never returned to receiving their day treatment services.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	Please refer to last answer. But, individuals who are already challenged with social and communication skills, were further hurt after we shut everything down. Also, many with hearing impairment, and other communication impairment rely on reading lips. Masking further disabled and hurt these individuals.

in-person social interactions and obligations)	
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Name	Ethan, Care Giver/spouse
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	GI issues, Sleep, Sensory over stimulation with day to day things.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression, anxiety, aggression, suicidal thoughts,
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Effects of stimulus. effects on Adults (separate for both male and female).
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage. Support systems, therapy, Schooling, Accessibility of services to adults instead of just children
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	When everyone is inside, it was easier for my spouse to feel less pressure/stimulus when we were to go out of the house. Was also easier to maintain a routine in daily life easier.

Name	Eugenia Ramsey
Demographic	None Indicated
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Health issues become acute as early signs are not addressed because the person with autism is not understanding them to let a person know that something in their body has changed. Acid reflux learned from enamel on back teeth were etched. Constant bowel movements with no control found person with autism had Chrones disease. Testing in blood can help diagnosis. Please study sounds, body positions of the autism person to give doctor clues as to what area to examine and test.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Evren Wiech-Barnes
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	GURD/IBS, sleep difficulties, GAD (generalized anxiety disorder), PTSD, most of which occurred after the age of 18 after years of trauma from parental abuse and school mistreatment. These compounded by office politics and other neurotypical niceties, backstabbing, and other nonsense that creates a toxic environment to get work done. Masking becomes a necessity to survive, but ultimately causes burn out. After years and years of burn out after burn out this causes severe disability. Parenting, schooling, and work life needs to change for us to function. Medication is NOT the answer.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have PTSD and GAD. Neither happened in because I am Autistic. They happened because of the neurotypical world does not accept an honest, justice-seeking, uncompromising, feminist woman that doesn't waste her time kowtowing to men or people-please to be liked, nor did my parents like a child that smarter than they were. In a supportive environment, it's highly unlikely that my gifted natured would have resulted in disability.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I don't have intellectual disabilities. I have a very high IQ. I did, however, have delays in understanding neurotypical communication, but I believe that is a two way street. I believe it should be both parties that need to learn each other's language, not just treat me as deficient for not being, thinking, or communicating like you. That is outdated thinking. I am not a defective neurotypical. I am a perfectly normal autistic neurotype person. I don't suffer from Autism; I suffer from a world not built for me to thrive, and because that the world was robbed of my intellect and capabilities. I have a master's degree I cannot use because bubbly dispositions are favored over genuine work. Absolute waste.
What additional research is needed to help address co-occurring conditions for autistic people?	Stop treat us as if we have "deficits" because we are not like you. Improve how you recruit Autistic people for studies. Regularly ask the community what we want and need. We desperately need services to help adults that are LEVEL 1 on our career and life path. We want to work. We want to function. We need workplaces to take accommodation and staff education seriously. We should not be paid less for our labor when we give equal work as any other. We should also have training to start our own businesses if we cannot function in an office setting. The goal should be to allow each Autistic person to be all they can be and tailored to their specific needs and challenges. Please put money into researching this. Stop trying to "fix" us and start trying to work with us. Maybe put money into researching parenting practices. Or even better stop funding ABA because it's nonsense. Teaching us to obey is not teaching to do more than mask to make others feel more comfortable around us. I don't see how their comfort is worth my mental health.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Fix the world you throw us into and leave us to the wolves to survive in. I wouldn't need anxiety meds at all if I didn't constantly live in fear. I lived in fear of my father, my classmates, my bosses, etc. I am stuck in fear. Now that I'm here, maybe take klonopin off the "controlled substance" list because it makes getting the one simple dose I have been on since 2001 a nightmare each month. Chasing down doctors for scripts, fixing communication between dr and pharmacy, dealing with my own executive dysfunction to remember to start the process each month is all a nightmare and exhausting. So the world messed me up and now it is my job to fix your systems to make sure I can cope? Maybe fix that.

<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>I believe I may still have a lung infection a year and three months after my Covid infection. I may have heart damage. It is unclear. Tests are on-going. I am extremely angry at the bungled handling of Covid from the previous administration. Each body is different. I don't know what others are facing.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>I love tele-health. I dislike people. I was fine with isolation. It didn't bother me a bit. I do like that some work from home jobs have remained, but there should be more. The idea that overhead or micromanagement is necessary for quality work was proven false. Yet tons of companies are demanding a return to the office. It's bad for all disabled people (social model or otherwise). This should be addressed with corporations. Remote work could mean less reliance on social security.</p>

Name	Ewa Omahen, PhD, Retired school psychologist
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	In addition to co-occurring medical conditions listed, communication and language challenges are a significant issue that needs to be addressed more effectively.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	There needs to be more research, training, funding and resources allocated to AAC. The current emphasis is on behavioral treatments, such as ABA. These treatments are inadequate in addressing complex communication needs of autistic individuals. The AAC methodology and best practices need to be taught to all professionals, including educators, private providers and medical providers, caretakers and families in order to support access, introduction and development of authentic and robust language system to all complex communication learners throughout a lifespan. This access is currently limited in spite of the technology being available (communication apps, devices, etc).
What additional research is needed to help address co-occurring conditions for autistic people?	*More research, resources and training dedicated to AAC *There is limited evidence of the effectiveness of ABA in this population. Other therapies need to be explored and studied. There needs to be better funding in special education and private therapies beyond ABA, including OT and speech and language therapy. *More emphasis on the interplay between diet/gut amend brain/behavior
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Better training of all educators and professionals in autism Partnering with and empowering families and autistic individuals Better funding for therapies other than ABA, such as speech and language and AAC training for all Easier access to quality comprehensive medical care including mental health.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school,	

increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Fin Finney
Demographic	Autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I struggle with vertigo, joint pain, pelvic floor dysfunction, and untreated eyesight dysfunction due to passing regular exam methods.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The most significant challenge is provider bias against treating multiple issues. If I have one thing down, I feel locked out of treating the other. For example, being diagnosed with anxiety and not receiving any additional diagnoses or treatment after suicide attempt. As an autistic adult I have had to self advocate to even discuss autism in an evaluation setting, and have been met with direct opposition to more than 1 diagnosis (in addition to PTSD). As a public health community advocate and educator, the number one complaint I hear in relation to autism is inability to get a diagnosis. The second complaint is the risk of violence that comes with diagnosis with a primary concern for Black children.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	It feels impossible to get them treated if you don't present in a very specific way. As an adult I have to bring these topics up to my provider and build my case, despite the fact that I was (improperly) screened for these issues as a child. Providers universally lack an understanding of autism, and I as an autistic person have had to dedicate multiple years to fully understanding how to navigate my condition without causing myself further harm.
What additional research is needed to help address co-occurring conditions for autistic people?	Lived experience data from autistic people both qualitative and quantitative and always paid. Study pilot programs that create greater accessibility of autism diagnosis and greater accountability of provider harm.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Access, consideration of SDOH, challenging requirements for formal diagnosis at the funding level and provision level, communication training for healthcare providers, consideration for autistic equity in development of mental health processes/funding/resource development. At all levels, treating autistic people as collaborators and leaders in their own care.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I have no more trust in service providers. I have wasted so much time and money trying to be treated only to find myself making more progress at home with no support than I did while trying to navigate seeing multiple providers. I am burnt out on having the same conversations about weight and diet, anxiety and depression, and mild exercise. Understanding polyvagal theory and treating my nervous system as a real part of my body took ONE book and a few minutes of research to do. Why aren't providers trained to provide care that has been proven to increase self efficacy? I want to trust my providers but I am overwhelmed by the grief of all my failed care. The provider in these situations will face no harm at their actions, but I will lose all of the resources that could improve my life outcomes. When people come to me seeking support getting an autism, or any diagnosis, I feel fear for the misdiagnoses from provider bias they might face, and I feel hesitant to encourage conversations with general physicians whose advice on mental is, in my and my communities experience, not helpful at best on mental health topics.

<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Untreated long Covid and the exacerbation of existing untreated conditions Lack of health equity programs and lack of development of real plans that involve community collaborators at all levels. Loss of valuable social autonomy. The groups and programming that were once available online too have gone mostly in person with no mask requirements. As someone with multiple conditions and a history of provider bias I am hesitant to raise my risk of experiencing long Covid symptoms when I have seen the real harm it can cause first hand in my community.</p>
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Name	Firos Shamsudeen
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	my daughters 14 year, most challenging part on physical health, she is not able to tolerate any pain and become very hyper active if she has any especially during her periods. Lack of eye contact, have sleep problems.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	facing lot of behavioral issues including hyperactivity and not willing to interact with anyone and always want to spend time alone in any corner.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	have communication disabilities since not good in English and her native language is different. Comprehension is very poor.
What additional research is needed to help address co-occurring conditions for autistic people?	No much therapy option found for children more than 9 year. We are facing this issue to get her any services like speech or behavioral therapies. Also looking any occupational therapies. We have good trainings in public school under Rockwood school district, however we are unable to find any resources on how we can improve her through extra services outside of school hour.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	1. Need to have more sport programs to participate for autistic children. We found one basket ball training but trainers were not sure about to give training to autistic children and we didn't go. 2. Insurance should be covered more for autistic children with lower copay. 3. More sessions and awareness is required for parents and family members who has autistic children. Frequent sessions create a supportive community where parents and family members can connect, share experiences, and provide emotional support. This sense of community can be invaluable in coping with the unique challenges of raising an autistic child.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	since autistic children and other differently abled people will have limited communication ability it is good to have special covid-19 clinic or service for them.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	service availability is very important

Name	Fraida Flaishman
Demographic	Service provider, health provider, or educator; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory challenges, motor challenges, sleep challenges, gastro intestinal challenges and feeding and eating difficulties, social engagement difficulties, self regulation difficulties.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	anxiety, aggression, self-regulation challenges
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	learning difficulties, language and communication deficits, developmental delay, self regulation challenges, social engagement difficulties.
What additional research is needed to help address co-occurring conditions for autistic people?	1) auto immune and gastro intestinal prevalence with those with autism to identify if they are at risk for occurrence of autism based on their physical related issues to determine early prevention methods. 2) The difference between individuals born with autism or those that developed autism in early childhood 3) How to differentiate autism for other similar presenting conditions 4) Determining which interventions are most helpful for individuals with autism 5) Identifying the possible causes of autism including if environmental toxins may be causing or exacerbating individuals with a predisposition for the disorder
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	parent and physician training for identification of autism and related symptoms, education about services available for diagnosis and intervention for those with autism including the related deficits, education about the different diagnosis and interventions families can access to support individuals with autism as well as their family members.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	This is an individual question based on the personal experience and environment of people during that time period. I have seen cases were families and children struggled during the time that schools and program and support were put on hold including those that recovered quickly and others where they are still struggling including needing psychiatric supports because the change of routine was difficult. It was most difficult for families to cope when their support outlets including school and vocational programs were not available for the individuals with autism.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal	Change of routine, lack of family support, and disruption of service has been difficult for families. Remote therapy and telehealth are a positive alternative but does not work in all cases and cannot be compared to in person treatment.

changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Frank Camilleri
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	From my lived experience as an autistic person with an autistic father and autistic friends, sleep issues are a core, if not the core issue with being autistic. Yes, sensory challenges can be disabling, but putting on gloves and noise cancelling earphones are viable treatments for those issues. If I can't sleep (which I can't, as autism has blessed me with treatment-resistant insomnia) then all the other challenges that come with being autistic become impossible to navigate. According to recent meta-analysis of autism sleep studies, there are no treatments outside of melatonin that have been researched for autistic minds, and most neurotypical methods won't help because of the changes that autism brings to the Default Mode Network of the human brain. Currently, I am a college educated software developer that was making 150k+ in 2022, but could not work in 2023 because I cannot functionally sleep. That's ~30k in tax dollars that the government has missed out on.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	From my own lived experience, ADHD, chronic fatigue, and the isolation brought about by the proven Double Empathy phenomenon have posed significant challenges to how I'm able to interact with the world. The fact that autistic people and non-autistic people have completely different non-verbal languages and mannerisms is a very hard barrier to overcome.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication disabilities, by far. Most autistic people I've worked with don't actually have learning disabilities or intellectual disabilities, but have been labeled as such because the world will not work with the method of communication that they are able to employ.
What additional research is needed to help address co-occurring conditions for autistic people?	Sleep research most importantly, and how to teach autistic communication to non-autistic people, and vice versa.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Get rid of private insurance entirely. As a nation, we will have no motive to solve any of these problems if we're not able to prioritize it as a common goal that all people need to deal with. Also, it's extremely hard to navigate a system when every bone in your body is telling you "this is morally wrong, and logistically inefficient."
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	The reduction of in-person business interactions and obligations has been a massive boon for autistic people, especially when paired with the massive improvements made to online systems during the pandemic. However, the reduction of in-person non-business interaction has made socializing as an autistic person [profanity redacted] near impossible. We live in a country of only work and sleep, there is no joy.

in-person social interactions and obligations)	
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Name	Freya
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory issues Behavioural challenges Sleep trouble Disordered eating
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety Extreme mood lability ADHD Aggressive and violent behaviour Social difficulties Low self esteem
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication disabilities Learning difficulties (attention and concentration)
What additional research is needed to help address co-occurring conditions for autistic people?	More research into pathological demand avoidance profile of autism and presentation in girls
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Cost of assessment, diagnosis and services Equitable access to above Wait times to see Specialists and Allied health professionals
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	negative impact on routines More ability for carers to work from home and flexibly to be present and support

Name	Gabriele Arnhold
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gastroenterological comorbidities (in my case CIPO). And I am prone to (vasomotor) migraine attacks
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, depression, attention-deficit disorder (without hyperactivity), skin picking, Morsicatio buccarum, thoughts of "wanting to die" (not planning suicide, but I always wish I were dead, because the thought of having a longer life without any help and without any familimembers is unbearable)
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I will never have enough money to support myself because I will never ever get a paid job. And I will always be on my own and will ever be in danger of being abused by other people.
What additional research is needed to help address co-occurring conditions for autistic people?	Research. Just resarch. Especially on rare diseases like CIPO or Mitochondrial Disease. But our lives don't count. We are irrelevant to (our) society. So you will never do research that will help us autistic people.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Service that is tailored to my needs would be of great advantage. Unfortunately, there is no help in my area for autistic people who do NOT have an intellectual disability. I was told that because I was highly gifted, I could not get help. They also said it wasn't okay that I also have a physical illness/disability, that would be "too much", I was told that it would be cheeky and brazen for me to go out in public with this multiple disability and ask for help.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	All help I got was canceled. I was cut off from medical help and my condition worsened. Health service for people like me were never established again like before. After the pandemic was over people were more selfish and I was told I should go to gas, I should die, I was not worth living, my life would not matter. The pandemic taught me that I won't get any help if it gets really bad. I lived more isolated during the pandemic and never got an infection until in 2023 kind of all inhabitants of the nursing facility my father was in were infected by a a doctor who did not follow the precautionary measures. I was infected by my father. My father died. We were both vaccinated.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The pandemic taught me that I won't get any help if it gets really bad. And I learned that remote work is possible, but not for individuals with disabilities because nowadays many people want to work from home and people with disabilities are just too much now.

Name	Gabrielle Connelly
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Food. Extremely restricted diet, a lot of struggles around eating. Losing foods. Struggling to eat a healthy balanced diet. Limited food choices under 5 options for a non speaking autistic child. Need better development in food programs. Sleep. Years and years without proper sleep. Needs medication to sleep. Up frequently. Toileting, suffers from constipation issues constantly because of inability to use the toilet.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Aggression and exhaustion when hungry or tired. Physically uncomfortable when constipated. Fighting constipation daily. Food we have to drive to get specific foods so that he will eat. Self injures when frustrated due to sleep, hunger and physical discomfort
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Developmental disabilities, no awareness of danger. Not aware of others near him. Hazards near him he will trip and fall. He also injures himself trying to regulate himself. Communication cannot tell us what he needs if he's hungry or hurting or upset
What additional research is needed to help address co-occurring conditions for autistic people?	Food therapy, sleep disorders, swimming lessons need to be offered through health insurance to prevent the leading cause of death for autistic individuals which is drowning
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage, access to autism schools for all children who need it. Swim therapy. Food therapy. Better research on sleep disorders.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	When COVID-19 hit, we lost a lot of foods that my son used to eat due to people stocking up in their freezers and the inability to get his preferred items. we have not gained those foods back, and it's been years. it took us years to get him back on track from potty training when COVID-19 hit he started urinating everywhere and anywhere with no rhyme or reason. we are still trying to undo what the pandemic did for his development
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	we are still seeing a disruption in his services. We are still seeing a huge lack of staffing that has just not been back to what it was before the pandemic.

Name	Genevieve Chaput, mother of 21yo with autism
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gastrointestinal disorders, sleep disturbances, sensory issues (from my experience with my son).
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Severe anxiety, depression, paranoia, outbursts of anger and frustration, thoughts of suicide
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Learning disabilities, SOCIAL disabilities (my son does not understand context at all and cannot read a room), developmental disabilities in early childhood, communication disabilities (many autistic adults that I have met have stutters and obsessive thought processes). Intellect is not an issue. These people are just as intelligent as others, but a disconnect occurs between the brain and the mouth or motor control.
What additional research is needed to help address co-occurring conditions for autistic people?	Comorbidity of autism and schizophrenia, comorbidity of autism and depression from inability to socialize with neurotypical community
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	The biggest issue is accessibility to services like respite, GROUP HOMES for adults, social security disability services and Medicaid. My 21yo son holds a part time job (with great understanding that his outbursts are from autism) but cannot get Medicaid or social security services because he is not physically disabled. We have been fighting this for 3 years now!!! He will NEVER be able to afford his own place and is unable to understand how to pay bills. What will happen to my son when I die? He won't be able to keep the house. Who will take care of him? How can I teach him to be independent without social services and available group homes for him to live in with a CNA to check in on him or group mom to ensure the place is clean, bills are paid, etc.???? Adults with disabilities are often abused and have little to NO ACCESS to services. Their parents take care of them until they pass away and then these adults are left homeless and without access to help if they are trying to hold a job and be a functioning member of society. PLEASE HELP!!!! My son must hold a job with routine and feel useful or he has additional mental health issues. I cannot allow him to stay home 24/7 just to get social services. He would hurt himself and others without having his job. Please, please help fill this gap for those who are trying!!!! I am so scared of what will happen to my son when I'm no longer around to help him and all my family is gone.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Increased risk of cardiomyopathy, anxiety and paranoia
What lasting positive or negative impacts have societal changes due to	Severe PTSD from being quarantined for a year with little contact with the outside world has given my son increased paranoid delusions of "other

the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

people coming to hurt/get him". He regressed in his social skills because this occurred during his senior year in high school, reducing social interactions in-person. He is very anxious and medicated for his anxiety which I believe was exacerbated from being quarantined during BLM protests, the Trump/Biden election, and the insurrection. The inability to decipher what is realistic versus what the news/social media put out is an increasing concern. His paranoid delusions are fueled by the inability to communicate and socialize with peers, accompanied by outrageous claims by social media and news from the fear-mongering used to get "watches", "clicks" and "likes."

Name	george knoth
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	sleep disturbances and severe aggression
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	aggression and self-injury
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	can not live independently needs 24 hours a day care
What additional research is needed to help address co-occurring conditions for autistic people?	what is causing severe aggression in this population, what meds work best to control these behaviors
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	need for better services for housing especially when family is gone, no place for these individuals to live and then when family is gone the state needs to place in a emergency shelter, no long term planning for this aging population
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	support staff is exhausted from pro-longed care when agency's were shut down
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	disruption in level of service no opening in group homes to provide 24 hr care or to provide direct care, shortage of staff

Name	Gerald Wilgus
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Issues with proprioception. This led to poor coordination and was a barrier to play and sports.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Paralyzing social anxiety. Especially during teen and young adulthood this kept me from realizing benchmarks for social involvement and relationships.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I was highly intelligent and at a time when autism was rarely diagnosed people thought that I was normal and that my social isolation was a choice.
What additional research is needed to help address co-occurring conditions for autistic people?	Don't know about research. Rather appropriate help for ASD-1 individuals in social coaching would be good.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Easy access to services that would provide ASD-1 individuals having challenges with delayed social maturity.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	None. However, I think it is scandalous that effort was made to help NTs with mental health issues stemming from isolation especially when no effort has ever been given to provide autistic individuals with help when they were isolated.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Social isolation of children. Welcome to my world. I have no empathy towards those people when the message I have always gotten was "deal with it."

Name	ginamarie
Demographic	Other
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>finding doctor in home area base that function my needs level to safe guard and health care me proper. i be the told go to morristown for my complex health needs so i be have better quality life... no transport services to get me there never the mind there be hospital 3 miles from where i be lives and many network doctors. this no okay. blue envelop for the police - this be wonky no train inform proper and u poop the bed thinking when we stress trigger etc that we be remembers calm blue envelop give police never the mind the police lack of training for us this be sensory stress direct relates back our health. if we no feels safe and have proper doctor we no have quality life. sleeps extreme import, isolation connection to health conditions, my function level impair to receive understanding doctor to listens. i be go ER and no respects no have call button ask for social worker - it no until the doctor come down visits me - he be say i be see you here want come check in you and then the care improve for me why no treat with the same respects - it no matters be on the spectrum label. and yet you wonders why people of color have more complex health issue - it be yet another box that be dismiss no respect proper.... snowball hurt our health complex issues etc</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>behavior and having my boundaries violated - my health file must be disgusting . here be one sample. blood works i be ask butter fly needle my hand please - (note it be the prime office so they be awares me have do the bloods before) the person say oh the no we like do the arm. then they poke me both arms no vein and then wants try fish around my upper arm above elbow - as the if. so i repeat my hand please use butter fly - again the health worker dismiss my request. so then i be have the behave issue irrate label other negtives cause why i no want be human pin cushion and no respects my ask. consent dismiss in health care setting has the many negtives that give us triggers of depress anxiety adhd etc.... labels but please over drug us that then snowball side effects - which many cause other health probs concerns even the behavior issues..... least we keep you making money the system right....</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>the intellect - communicates and learns be extreme hard. i be got the covid again and stress so bad i be no remembers just take aspirin for my fever.... many the doc office no use simple word language break down repeat steps need for care level for when we alone... there be a disconnect in the understandings of level care requested that especials the push for use on the line - that no options proper for me so many my basic needs no go connect proper. like when got the stitches i ask for instructs and still need call office i be got infect cause i take longers to heal - another snow ball health concern.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>i feels the services and resource and doctor office and teachers area be more worse to so the call encounter help empower my life then the complete strangers be. these folks be trained vetted degrees etc - so why the moron oxy? when i ask for write down please take notes please record app please - i get push back dismiss. and then when need questions ask help like with the stitches it be alarming the responds i receive. another be the abuse we be receive from same areas of the services resources in place to allow us full function. i feels some times the label cause more damage and the judging of the box slam me in relates. i feels many the research and grants no go deep enough - the impact be yet another island to self - no deeper connection to make a true impact for those us on spectrum in this nation. we be a money making machine - and u be over drug many us that be have another entire area need of research side effects etc. sample u put me on a cheap</p>

	[profanity redacted] drug predzone and at no time relates that to me now have sugars health probs until i see a differ doc that tell me stop take the predzone and oh my my sugars go back normal range.....the level of basic disconnects over site be hurtful cause it be hinders our life level function - a life function that already considers not normal
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	all samples you be listed and heal our nation to actual care for the living..... another trigger moron oxy - abortion become much illegal but the abuse and dismiss and departmental no qualty level care connections for my life be alarming. some the system created and set up to be islands of money making machines so i no sures how to improve this without stop the cash cow greed and thinking for some reason we be less than human cause we be have a label and differ needs. last time check ever person be differ and ever person be have the unique needs
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	i be have more visits the doc office - my function level be less - i be told it no more safe me try push self do many the things cause my immune be the low high risk of ables get the infect. yet the mores isoates be the more i becomes the high risk to have infect illness.....i be got the covids more one time now and i take longers since the covids for health improve ever thing. the stitches take longer close heal. a bruise.....sleep less....get more alergys....another snowball result that no make the since and it wonky cause many docs no respects to answer my questions and the or take times - sevral them want just pill me - like oh you no ables sleeps we give you the sleeps pill yet i be test and told i be hypoxemia so is the sleep pill make health care wellness me a good option???? alarming
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	the telheath no option good for me - when covids come in no have intrnet so how gonna do that. making big assumps that we ables app on phone to with our differ function levels. services stop and still stop and the or change for less, i less physcial connect to others and i be hard time many things. i feels i be much worse my functions cause of the covids and i live in new jersey - it extreme wonky depend where in state lives for so the call state program resources service cause the limits be no active yet service be state wide program then i be have no helps. lost my case worker - then new one be part time and send me wonky text then ignore me when i ask no text me call me please. etc just hurtful

Name	Glen , The Jewish Guy Business venture PTY LTD
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Indeed, knowledge is power and malongi ma ndona madungu... positivity is accepting reality rather than living in false hope
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Indeed
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Glenda Hayes, Grandparent
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Textural issues related to types of foods eaten. He tends to only eat certain foods which creates concern with getting a balanced diet. Other issues include the "walking chicken gait" and uncoordinated chewing which causes bits of food to be expelled during meals.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	There is anxiety about social issues and making friends. There is great sensitivity and worry about health of beloved grandad who has health problems.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Grandson learns easily but is convinced/very resistant to homework that he sees as totally unnecessary "because he has been in school all day". Test grades very good but homework grades poor. Probably related to desire to play video games after school.
What additional research is needed to help address co-occurring conditions for autistic people?	Education for parents to avoid issues of video games or create video/educational programs to address problems seemingly from autism. Also for kids with gait or stemming issues, physical education teachers could employ PT or OT techniques in helping those students. Ex: That could be exercises to strengthen the core.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Special Ed teachers might have training in these areas to address particular issues. A school which has special ed classes, might also employ a PT or OT to serve students with necessary therapies without taking child away from school, for regular treatment.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Our students in SC did not lose as much in-person school time as many states. The stress and anxiety increased over Covid in parents, grandparents and friends.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Doing school at home was very challenging to keep on task. New math for an old grandparent 🤔. Talking with a therapist over the phone seemed ok. The child was open, maybe due to not having to look directly at the therapist.

Name	Gloria Derosa
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My daughter has Pitt- Hopkins , a rare severe form of autism she has severe gastrointestinal issues, needs daily medication, and a bowel program.suffers quite a lot of daily physical pain due this She also receives daily medication for a sleep disturbance, sometimes it works, sometimes she will be awake 24 hours a day for 6-7 days per month She is non verbal, has no communication system, despite many years of efforts by therapists and teachers She takes medication for a type of seizures She in not mobile, uses a wheelchair
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Angela has periods of anxiety, aggression and some self harm behavior.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I think the most significant Challenge is communication She has no means to communicate her needs and wants, she cannot tell us what is wrong or what is bothering her medically. It is difficult to form relationships with other people, because she lacks the reciprocal communication with others
What additional research is needed to help address co-occurring conditions for autistic people?	I think a big one would be researching the gastrointestinal disorders that people suffer from it really has a negative effect on their quality of life. another area of research should be communication for non verbal persons with Autism. Many of the speech therapists are only being trained for working with “mild” speech disorders but lack any training or expertise in working with non verbal individuals.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	One big issue is how services, therapists, doctors etc disappear once an individual turns 21 and leaves school. Another issue has been access to health insurance. Angela has a Medicaid waiver which we are very grateful for, but often doctors will tell me they are not taking any more Medicaid patients. I am paying for private insurance that is \$ 1,200 a month out of pocket along with other medical costs. Because of the intensity of my daughter needs , the shortage of caregivers, I retired “early” after 30 years of teaching, a living wage for caregivers would encourage others to become caregivers.. There is also an unintended consequence of the tax laws concern ing parent/family care providers 2014-7, difficulty of care payments, they do not take federal income tax out of our checks, but they also are not taking social security taxes out , which will cause some parents not to be able to earn enough quarters to qualify for retirement benefits and/or their social security checks will be greatly reduced.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Covid terrified us, we didn’t take our daughter out in public for 2 years. Disabled people are more likely to die from Covid or suffer lasting effects. My daughter missed 2 years of schooling, and vital communication and physical therapy, and 2 years of transition services. the district offered a couple hundred dollars in compensation but that would pay for MAYBE 2 therapy sessions .
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on	All of the above were affected! Zoom dr appts, Decided not to pursue Department of vocational Rehabilitation services. On line school & services did not have any benefit for her. Less social interactions

physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

Name	Grace, Autistic person
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory sensitivities can exacerbate physical health conditions and also cause the individual to experience conditions more severely.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Alexithymia can make emotions hard to identify and understand for autistic people like myself. Additionally perseverance and literal interpretations can cause negative thoughts to spiral for us and we can take our own thoughts as absolutes. Additionally we have variances in neurotransmitters and therefore are prone to complex experiences with mental health and emotions.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication disabilities face significant exclusion in all areas of support and rights. AAC users can communicate yet are often on the fringe of society being left out of all relevant discussions.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Providers need person centered training to help autistic people with co-occurring health issues as they currently disregard our own lived experiences and our conditions go undiagnosed and untreated or misdiagnosed and inappropriately treated. Additionally we need better insurance coverages for diagnosis, and supports that are NOT ABA.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Grant D. Sparks, MS
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory overstimulation stands out as the most impactful physical health condition that autistics experience, as the overload of the nervous system dysregulates all other physical, mental, and emotional systems within the human body. Overstimulation often leads to “meltdowns”, which leads often to the inability to regulate whatsoever or a complete shutdown of outward functioning. This impacts hygiene, health and wellness, diet, exercise, communication, sleep, motor function, and all other elements of a person’s physical health. Often, overstimulation leads to a state of catatonia that renders all other elements of physical wellbeing moot.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	As one might assume, having a nervous system reaction that forces shutdown has drastic impacts on a person’s mental health. Depression, anxiety, self-harm, obsessive-compulsive disorder, and unstable attachments are a common experience of the autistic community, due in no small part to the impact of their nervous system responses. Being forced out of work, social interactions, passions, hobbies, or often basic activities of daily living by one’s own brain has significant mental and emotional impact. Self-harm and detachment from loved ones are often used to wrest some semblance of control over this experience, often only complicating matters further for an autistic in a spiral.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Unfortunately, considering the last two entries, I suspect the most significant challenge regarding other conditions that co-occur with autism is misdiagnosis and the resultant inaccurate treatment planning. Given that much of an autistic’s ability to communicate, self-express, and engage in the environment around them is contingent on the cooperation of the nervous system, I believe that many individuals with ASD are misdiagnosed with other disabilities because they are not able to accurately replicate standards of “ability” that are set by individuals with self-regulating nervous systems and the average neurotype. Many an autistic has been labeled intellectually disabled by undertrained or misinformed diagnosticians, not due to a lack of content understanding or intellectual ability on the part of the autistic person, but due to the inability to communicate this understanding in a way that is deemed “appropriate” by the governing bodies of medicine and psychology.
What additional research is needed to help address co-occurring conditions for autistic people?	Research is needed on autism as whole, and how to work with autism rather than how to force autistic people to function “normally”. As well, we require more research on effective ways to help regulate the autistic nervous system in a way that is not suppressive or harmful. Additional therapies, medicines, and systemic approaches should be studied, and these studies should, whenever possible and with the highest priority, be orchestrated, lead, and overseen by autistic people. Neurotypical bias needs to be removed from research into autism. Focusing on developing methods for coping with the resultant depression, anxiety, and other disorders that stem from the debilitation of the autistic nervous system would be of major benefit in the treatment and care of autistic people.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services,	First, autism should be wholly recognized as an immediate qualifier for disability services, social security disability insurance, and subsidized healthcare. Far too many autistic people exist in state of perpetual agony due to their forced participation in a society that does not provide adequate accommodations for their needs, often suffering in silence due to an inability to adequately portray their internal experiences. Research suggests that

<p>insurance coverage, service systems issues, patient-provider interactions)</p>	<p>something like 85% of autistic people are unable to maintain employment, which in turn leads to the exacerbation of all the symptoms listed above due to reduced or removed access to care. It is notoriously difficult to qualify for social security disability with a diagnosis of autism spectrum disorder, stemming from the inaccurate attitude of many neurotypical agencies of “if you’ve held a job once, you can do it again.”</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>Simply put, Covid has mostly made everything much worse. Those autistic people who had successfully learned to mask adequately enough to function in a neurotypical society have regressed substantially due to the social isolation of lockdown; and while from a mental health perspective, living an unmasked life is substantially less draining, it also means living with more pronounced and impactful symptoms. Those without that ability have found themselves even more isolated than before, and with more restricted access to the limited services available to them in the first place. This has led to a net worsening of the autistic experience overall.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>On a societal level, one positive is that people who have existed with undiagnosed autism are starting to recognize their need for care and support. The idea that remote work or school is a fix for autistic engagement is rooted in the neurotypical mindset and extreme capitalist values. Just making a job more accessible to someone doesn’t mean working will be any less overstimulating or agonizing for them. Telehealth has been somewhat beneficial; however, the problem remains that nearly 85% of autistics are unemployed, meaning access to services is restricted to those who show extreme disability.</p>

Name	Greg
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep and eating. If I manage 6 hours of sleep it's a good night. Once I wake up I cannot go back to sleep as my mind snaps awake and nothing short of chemicals can shut me off. Avoidant eating and maintaining weight is difficult.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety and depression. Creates a loop in my head and I end up coming to the worst conclusions of every interaction. Makes me see knives where there aren't.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication. You don't know how important it is until you are literally unable to express your feelings
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Any service for autistic ADULTS would be nice. I wasn't diagnosed until my 30s and it's impossible to get real help at all.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Positive to a degree. Work from home is a perfect environment

Name	Gretchen Stewart, Center for Learner Equity
Demographic	Family member of an autistic individual; Service provider, health provider, or educator; Researcher; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Co-occurring health conditions can be significantly downplayed given an ASD overarching diagnosis. For instance, neurodevelopmental disruptions that manifest in motor differences which are in turn required for many mind plus body actions linked to independence (driving, hygienic, writing, etc.) can be under treated or ignored. For school aged children with Autism in K12, many states have guidance that prevents school based therapists from working holistically with children as they are restricted to narrow clinical focus. Too, given the dearth of developmental pediatricians available to families, parents are often directed to ABA as an end all be all therapy, rather than therapies that include a range of treatments for co-occurring conditions.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	For an individual with Autism, all of the above listed alone without Autism are know to be correlated to lower quality of life - under or un employability, social stratification, and mental health concerns. With Autism, those effects are intensified.
What additional research is needed to help address co-occurring conditions for autistic people?	I would start with more funding for neuroscientific root cause research that results in translatable intervention for co-occurring conditions. For instance, motor differences. Researchers, including those seminal in defining the characteristics of Autism more than 60 years ago, have been evidencing links between brain plus body both structurally and functionally. Put more RFPs out for this kind of work in conjunction with practicers to develop new approaches to intervention.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Remove therapy session limits from insurance. Widen insurance approvals for holistic modalities (music therapy, hippotherapy, chiropractic, etc.). Encourage new pediatricians in training to become developmental peds.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	

in-person social interactions and obligations)	
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Name	H
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Anxiety, demand avoidance or inability to do most things during times of shut down or burnout, sleep disturbances
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Heightened anxiety that doesn't respond well to CBT and leads to depression
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	School not working and exacerbating challenges
What additional research is needed to help address co-occurring conditions for autistic people?	How to effectively treat anxiety in people with different social/emotional awareness levels. Where demand avoidance and inertia comes from and how autistic people can accomplish their goals while dealing with the challenges of demand avoidance.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Where we live, there is a big push towards ABA as the main "evidenced based" treatment that government funding money can be spent on. This needs to change so that autistic people can allocate their funding allotment towards a wide variety of supports that they choose according to what they know would be of help to them, this should include things like using funding money to pursue special interests.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increased used of telehealth and remote school options is something we continue to enjoy and make use of on a regular basis.

Name	Harriet Stuart
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gastrointestinal issues, migraines; allergies Child can not express pain and acts out with SIB or grabbing others.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Inability to express discomfort leading to inappropriate behavior.
What additional research is needed to help address co-occurring conditions for autistic people?	Connection between gut and brain; behavior analysis to help communication.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Appropriate residential and training services.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Since COVID, there has been a serious shortage of direct support professionals.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Service disruption for those who need structure more than typical age peers

Name	Heart of Texas Behavioral Health Network
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	A large majority of mental health care providers are uncomfortable or unwilling to work with individuals who have an intellectual or developmental disorder. Many individuals who have IDD have co-occurring mental health conditions including autism.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	A large majority of care providers are uncomfortable or unwilling to work with individuals who have an intellectual or developmental disorder. Many individuals who have IDD have co-occurring mental health conditions including autism. Communication is a significant challenge.
What additional research is needed to help address co-occurring conditions for autistic people?	Additional research is not the most pressing issue. Putting into practice what is already known must occur ASAP. Provision of mental health treatment is seriously lacking. There are not enough providers, and evidence-based training is needed.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	All of the above examples. Access to care by providers who are well-trained in evidence-based treatments would improve outcomes and satisfaction with services.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Heather
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	It can be difficult to get adequate help for them because of difficulty communicating; doctor's not really paying attention to us when we talk; lack of understanding. a HUGE problem are self-diagnosed autistics completely changing the conversation on these things, denying they are related in any way to autism, and damaging public perception on what autism is and how it impacts us.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Being afraid to be open about what we are going through out of fear of being put into a hospital or removed from the surroundings we know / placed on medications / not being taken seriously or having these issues approached in a way that causes more damage than it does help. Also, self diagnosed autistics are harming autistics by conflating other mental health issues with autism.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Lack of access to proper supports, help, resources; especially for autistic adults.
What additional research is needed to help address co-occurring conditions for autistic people?	stem cell therapy, research in general. We need more funding for actual help, in our day to day lives.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Services right now are mostly 'resources' that provide the numbers to other places that provide numbers to other places - it's a circle jerk of 'resource' places, with very very very few actually providing real world help/resources/supports. More benefits through health insurance for in home help, help managing day to day life.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	100 times worse. Everything is worse.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I felt more normal because more people are shut ins like me; increased remote work.

Name	Heather
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Inclusion in tasks such as going to the grocery store, or leisure activities. Not enough places are doing sensory hours, all grocery stores do not offer Caroline's carts making it near impossible to take some autistic individuals to the store. My daughter cannot go to Chuck. E. Cheese because they don't have sensory friendly hours at our location for example. More businesses need to have sensory friendly hours. Gastrointestinal issues and incontinence. Many public spaces will prohibit use of their restroom and you have nowhere to change a diaper for an older autistic child or adult who is unable to hold their bowel movement or urine. We were refused the bathroom at a Family Dollar when I needed to change a diaper.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Daycare personnel are not trained to handle aggressive or self-injurious behaviors. Kids are often kicked out of daycare and it's difficult for parents to work, but SSI is not enough to live off of to stay home with them. Autistics that elope and flop are difficult to manage in stores and stores need Caroline's carts in them so we can keep them safe and secured.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Needing assistance with using utensils, getting dressed, toileting and not being able to communicate wants and needs, but having to go to a daycare that isn't trained on how to handle autism, because we can't stay home with our kids because there isn't enough financial assistance to do so. Autistic females statistically have only a 10% chance of NOT being sexually assaulted in their lifetime due to communication disabilities.
What additional research is needed to help address co-occurring conditions for autistic people?	Take a level 3 autistic child or adult that is too old to fit in a grocery cart seat to a grocery store. Then try taking them to family fun events like Chuck. E. Cheese, Theaters, Amusement Parks, Arcade Centers etc. and document the experience then implement some means for inclusion. Provide free training to daycare centers on autism behaviors, communication and ABA therapy basics.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Provide free training to daycare centers on autism behaviors, communication and ABA therapy basics. Make it mandatory for state licensed daycares. Increase the income limits to qualify for financial support for parents of autistic children and autistic adults. Provide more financial support for sensory regulation needs and items and safety items for elopers like fence installation and GPS tracking. Having an autistic child should automatically qualify you for the childcare voucher. Due to the amount of work that we miss for our children but still have to pay childcare providers whether our child was there or not.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	Disruption in services

in-person social interactions and obligations)	
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Name	Heather
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory processing issues have been the most significant difficulty in my own experience and in the experiences I have observed in other autistic/neurodivergent individuals.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety and depression associated with the difficulties of being autistic in society have been the biggest struggle in my personal experience. I am also diagnosed with ADHD and this causes difficulties in daily activity and socialization.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The biggest struggle that I have and that I have noticed in others is communication difficulties and being able to read social cues. It is difficult to “fit in” and try to navigate a world that seems to think and act so much differently than I (and other autistics) do.
What additional research is needed to help address co-occurring conditions for autistic people?	More research into how autism develops through adulthood when someone is not diagnosed or recognized as autistic as a child. More reliable and research-based therapy to handle the anxiety and depression that comes with learning late in life that you have autism.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Reliable doctors and a more affordable option to seek diagnosis and treatment for adult autism. Better resources and services for people who need more help in their daily lives. Laws and regulations to protect those on the autism spectrum from job and housing discrimination. Though there are laws that currently do that, in my experience, many job opportunities lack the accommodations that many autistic people need, such as being able to wear headphones or bring fidget toys to work with them to help with the overwhelming sensory issues we experience at a typical 9-5 work environment.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I am autistic and had covid-19 and in my experience I had a very hard time with my memory and orienting myself even at home. The brain fog had a lasting affect on me for over a month.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increased remote work I think has made a difference for autistic people seeking jobs because they have been able to get an income while being in a place they feel is safe. I have not personally experienced this, but the community I talk to has said this. I also personally think that social distancing and mask wearing has helped me to feel more comfortable leaving my house and going to crowded areas such as grocery stores.

Name	Heather
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory, GI issues, Sleep issues, anxiety, ADHD.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD, Anxiety, Depression
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Sensory issues
What additional research is needed to help address co-occurring conditions for autistic people?	Gifted. Many that are Autistic are also gifted and not just with disabilities.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More access to Mental Health
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Heather Bourne
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	the narrow range of tolerable foods can present nutritional challenges
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	executive functions weaknesses/ frequently comorbid ADHD can present a double barrier to accessing learning in and outside of schools-- the autism profile can impact HOW one can access interventions for ADHD, and vice-versa. My daughter has dyslexia, and her autism/ pathological demand avoidance PROFOUNDLY impacts how hard it is for her to engage in dyslexia interventions-- and in turn, her anxiety skyrockets and she feels terrible about her brain. The intersections here are each something to understand and separate out.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	executive functions weaknesses/ frequently comorbid ADHD can present a double barrier to accessing learning in and outside of schools-- the autism profile can impact HOW one can access interventions for ADHD, and vice-versa. My daughter has dyslexia, and her autism/ pathological demand avoidance PROFOUNDLY impacts how hard it is for her to engage in dyslexia interventions-- and in turn, her anxiety skyrockets and she feels terrible about her brain. The intersections here are each something to understand and separate out.
What additional research is needed to help address co-occurring conditions for autistic people?	Please: Research Pathological Demand Avoidance My daughter qualified first for a social communication disorder diagnosis, then an autism diagnosis. Yet the behaviorally-based autism interventions actually made her anxiety, depression, and family relationships worse. Only after I stumbled upon the concept of Pathological Demand Avoidance -- an autism profile, or perhaps a separate disorder-- did I find interventions that actually brought more peace to my daughter and our family. It's recognized as a mental health/ neurobiological condition in the UK and Australia but not in the US---making it so much harder to access information.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	To develop and then pay for interventions, Pathological Demand Avoidance needs to be characterized and recognized.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Over-reliance in schools and socially upon screens has brought out-of-control and unavoidable hours of screen use, and autistic brains having greater trouble disengaging from screens. We need more outdoors, in-person interventions and so many are now delivered remotely, reducing opportunities for organic, real-time social learning
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal	Increased remote work and school. VERY hard to activate to do things in person when remote is less of an emotional and cognitive demand-- but SO much less enriching. My daughter has both figuratively and LITERALLY developed myopia during the pandemic.

changes: disruptions in services,
increased remote work and school,
increased use of telehealth, reduced
in-person social interactions and
obligations)

Name	Heather Cellini , SLP
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Diet and gastrointestinal challenges and sleep disturbances impact nutrition intake as well as energy requirements for daily functioning
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety and PDA cause meltdowns and impact participation in ADLs
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication disorders and lack of access to AAC impacts autistic self-advocacy and participation
What additional research is needed to help address co-occurring conditions for autistic people?	Research on how PDA (pathological demand avoidance) and other co-occurring conditions exacerbate challenges to participation in activities of daily living
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	access to support and education for families supporting Autistic members. Insurance coverage for non ABA supports such as speech, occupational therapy, and neurodiversity affirming therapy for anxiety, etc...
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Not sure but isolation and a higher level of overall anxiety in the population can't have a great impact. Plus access to medical care is challenging even when there isn't a pandemic
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Remote learning has been beneficial for some Autistic students. Being able to learn in a more suitable environment is one of the few positives that has come from COVID

Name	Heather Gray
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gastrointestinal issues, sleep disturbance, sensory and motor challenges
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Major depressive disorder, anxiety, ADHD, suicidal ideation, elopement
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Learning disabilities, development disabilities
What additional research is needed to help address co-occurring conditions for autistic people?	Anything. Access to materials, access to assistance, more neurodivergent acceptance in the workplace
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage, knowledgeable providers, optional treatments not including medication, knowledge throughout healthcare
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It has exacerbated my symptoms and made it borderline impossible to function.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Going from a more controlled environment back into the work force made me feel like a failure. During COVID, I had time to exist and create a functioning routine for me. Being forced to be in public often and without choice is debilitating.

Name	Heather machin
Demographic	Family member of an autistic individual; Service provider, health provider, or educator; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The lack of understanding regarding how cooccurring conditions impact the way an autistic individual interacts with the world, how they experience things and therefore how they may behave in their interpretations and responses to what is happening around them. If there is no insight into what other factors influence and compound some of the struggles autistics face, then limitations will remains with how to actually help support them in the most optimal way.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	As prior comment, without a comprehensive perspective of potential cooccurring conditions, a deep understanding of each individual condition and the intersecting points of the person's environment, culture, personal beliefs and supports, we have limited ability to offer the most help in supporting these individuals to have the optimal quality of life and feel productive in their communities.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	There is difficulty in educational systems with being able to truly accommodate individuals since there seems to be siloed and fragmented understanding regarding how conditions impact each other. Similarly, treatment is generally aimed at treating symptoms but if symptoms are overlayed by a different condition or a similar symptom origin is misunderstood, the therapeutic target may be missed.
What additional research is needed to help address co-occurring conditions for autistic people?	We need to exercise more observations and interviewing of autistic children and adults to gather a much wider net of what the experience is like, then account for the surrounding circumstances such as culture, beliefs, gender, concurrent conditions, etc, then tease apart how some of these factors might work together. We have to ask more questions.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Certainly equitable access to and accessibility of services and complete, total coverage of services. More importantly, the quality of services - after personally and professionally interacting with support services, it is breathtaking to see how different the same professionals can operate in their education, thinking and treatment execution. The quality of care can be very poor despite how it is advertised.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I think there have been clear benefits and drawbacks from the pandemic in terms of help with autistic people, and these may be quite different depending on individual circumstances. It's hard to make a generalization. Some kids have thrived remarkably well once remote learning was started and they were finally able to have some relief from systems that were traditionally seen as best practice. Of course, suspension of services for some kids was difficult and lead to possible regression, but to others, it allowed some relief again. Ultimately, I think the effect of the pandemic would need to be clarified on a case by case basis.

Name	Heather margiotta
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My daughter was diagnosed 2020 with schizoaffective, 2023, gastroparesis and rheumatoid arthritis
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Aggressive and schizophrenic
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication, speech. Intellectual disability.
What additional research is needed to help address co-occurring conditions for autistic people?	Adult behavior programs 18+, doctors that have more training dealing with special needs,
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance acceptance by providers, specialist, adult services, ABA therapy
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	My daughter became schizophrenic when covid shut down all programs . I truly believed her beeing isolated for over a year caused this mental brake. It's now 2024 and still dealing with voices, fine motor skills decrease during that period and an adult, 25 with limited help.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Negative impact. My daughter needs to be physically present, zoom sessions are useless. Mentally she will never recover from covid.

Name	Henrietta Reder, Friends of Ann Kiley Center; Parent
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Aggressive behavior and conditions such as intermittent explosive disorder accompany many people with autism. Aggression hinders these people from being able to live in group homes and to work either in the community or in a sheltered workshop. Research is desperately needed in order to curb aggression and to find ways to address it successfully.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	As I previously stated, severe aggression and self-injurious behavior seriously prevent individuals with these conditions to live in less restrictive settings or to work at all. Research must continue to help these individuals and their families to address these behaviors. Medication as a solution must be explored as a way to contain these behaviors. The effects of these behaviors are devastating for the individual and his/her family and last a lifetime. I cannot stress this enough.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My family member has little to no speech and functions at a 2 year old level for speech but at a higher level for self-help skills. Pair this with severely aggressive behavior and intermittent explosive disorder and the result is devastating for everyone. The public must realize that all people with autism do not perform in a Broadway show or act like the "Good Doctor" on TV. Our needs are minimized and not addressed at all by the media.
What additional research is needed to help address co-occurring conditions for autistic people?	Research on how to treat aggressive behavior - whether it's through medication, behavior analysis or a combination of both. I cannot emphasize how much my family member's co-occurring conditions have negatively affected his and our lives. Not enough services exist to help these individuals.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Access to services is needed. Just trying to find any are consuming. Residential services are few and far between. My husband and I were fortunate to have extra speech and occupational therapy paid by my husband's insurance when our son was young (He was born in 1981.). Not everyone had this option.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I know individuals who have become so depressed they do not want to even get out of bed. Medications provide little in the way of helping this individual. After having to go into isolation at the center where they live, trying to get these individuals back into attending the sheltered workshops is very difficult. As a result, aggressive behaviors are surfacing again.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Isolation during Covid caused disruptions in attending workshop sessions and even having visits from parents/guardians. Visits now can be done at anytime, if using the proper PPE equipment.

Name	Holly
Demographic	Service provider, health provider, or educator; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Its effect on everyday functioning - but more specifically the effect on challenging and severe behaviors (aggression, self-injury).
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	They inability to access education and safe places to live.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	More research is needed on systems level changes in schools, for example, on how to best support students with severe behaviors. The training doesn't exist, the expertise doesn't exist, and its failing the high needs students. We need more behavioral interventions that work across various environments.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Holly Connor
Demographic	Family member of an autistic individual; Service provider, health provider, or educator; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The conditions all get lumped together and not addressed as its own issues. Not saying it's just a symptom of autism. For our son the challenges with sleep have been ongoing since birth. Resources to have accurate sleep studies are needed. Lack of specialist that are willing to take on the unique needs of ASD and trying to take further diagnostic test to find any underlying causes. Distinguishing between lack of sleep or underlying cause of behaviors. Another issue is having to travel to an office that only causes more stress and anxiety that then alters the outcome of any testing or diagnostic tool. Having option for house calls that could provide a more relax and natural state, might lead to less testing needed and better results to then develop a treatment plan. Sensory issue and food aversions is the need for more testing on Nutritional needs and depletions. Families should be able to get regular testing done of gut biomes, vitamin and minerals, and in-depth analysis on a functional level to be able to best support their nutritional needs. Then consideration of if diet changes are even possible and alternatives for supplementing nutrition.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Again, most mental health conditions are brushed under the primary diagnosis. The assumption that those on the spectrum do not have feelings. Taking the time to understand their perspective and then try to be diagnosed based off that and not "traditional" or "typical" ideologies.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The fact that diagnostic tools look at IQ and adaptive behaviors scores. Testing used does not look at the individual's motivation of learning things that interest them. Testing is not adapted to offer the means to understand the way they process the world. Although IQ is still a needed number, just like with autism having various levels, breaking down the cognitive ability if various categories that give a better picture of ability and needs.
What additional research is needed to help address co-occurring conditions for autistic people?	How to categorize the spectrum to best understand how autism effects each individual. The spectrum is too large and too many assumptions are made on ability based on one word, autism. When the DSM changed to autism spectrum disorder, losing Aspergers as a way to see an autistic person as cognitively able, but still needing social, behavioral, or communication supports lumped the diagnoses all together and many assume that all have low IQs. Or the contrary and people assume they are all astrophysicists. Looking at IDD-intellectual and developmental disabilities and the definitions of the moderate, serve, profound, and taking it to the other side of gifted and seeing that as a cause of issues as well could be helpful. More research into the brain and how it processes information. Finite answers on the genetic side of causes of autism. Finite answers on environmental causes of autism. Research into why the rate of autism is highest in our military families.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services,	Insurance needs to see that ABA is not the only treatment. Looking at Medicaid models that offer a larger variety of services such as respite, skill building, developmental therapy, social skills, community inclusion, CHILD CARE after the age of 12. Before and after school care for kids over 12 and summer camps. Better collaboration with schools on getting services that wrap around a student and provide whole person and family support.

insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	<p>People should now understand what it feels like to be controlled and isolated against their will like many on the spectrum. One would hope there is some actual empathy that has developed on having to be forced to change to fit the "new model of norms" that autistic face every day!</p>

Name	Ian Morris
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Strangers incorrectly judge us. When a therapist told me in 2000 that I am autistic, I said that I want to keep it a secret because people will misjudge me. Since we autistics are considered freaks, we waste tons of energy masking. Masking is exhausting. Some individuals who know I am autistic tell me to mask all the time. That is ableism. We autistics deserve to be treated fairly in society.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Terrible parents who wanted me to appear "normal" kept trying to reshape me into someone people who judge them would find "normal". Normal is a setting on the dryer. We autistics are weird. I considered suicide years ago, but I got myself psychologists and psychiatrists instead. We autistics deserve to be accepted for who we truly are, not what a popular worldview considers us to be. In order work against ableism, we need to have a society with a better understanding of who we autistics are.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Some autistics have learning as a hindrance, but sometimes we autistics have an advantage in learning. The lowest my IQ has ever been measured by a psychologist is 145. My sort of autism leads me to go to the library and read as much as I can. I have had discussions with other autistics, and they tell me about the difficulty they had in school. In order to prevent ableism in schools, we need to have a broader understanding of autism.
What additional research is needed to help address co-occurring conditions for autistic people?	In order for fair research to be done on we autistics, we need to first be accepted by society as equals. We autistics are not better nor worse than anyone else in the US republic. When we are accepted as weird bu tequal we can then dp proper research on how we autistics are perceived.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	We autistics are often overlooked as differently abled. We want to be accepted as part of society, and recognizing us as being different but good people will help knock down access to service systems issues. I used to work for a police department, and answerng 911 calls taught me that my autism came with plusses and minuses. I sometimes did not perceive tacit messages callers were trying to purvey. However, I could sometimes hear when someone was in trouble of physical violoence or was considering suicide in a way that neurotypcial individuals did not always understand. We autistics can help society.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I was fortunate to not get COVID-19 during the hottest years, but I understand that it could still happen. I was homeless just before the pandemic hit, and there were fellow autistics sleeping on the street. I don't know, personally, how the pandemic hit them, but since we were sleeping cheek by jowl it seems likely that fellow autistics were more likely to be positive with COVID-19.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I have discussed COVID-19 with my psychiartist and psychologist. I have monthly sessions with the psychiatrist and weekly sessions with the psychologist. Since I live on disability and spend most days at home, I am not certain how COVID-19 has affected fellow autistics.

Name	Ilana Gruber, Pennsylvania Advocates and Resources for Autism and Intellectual Disabilities (PAR)
Demographic	Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Many challenges caused by co-occurring physical health conditions in autistic people stem from difficulties communicating pain, discomfort, symptoms, or side effects from treatment. For example, challenges communicating sensory sensitivities during medical procedures can be an issue. Difficulty separating autism spectrum disorder (ASD) signs and symptoms with symptoms from undiagnosed or undertreated medical conditions is also a significant issue and can severely impact quality of life as well as delay diagnosis and medical interventions. Other challenges include disruptions in daily routine due to physical health issues and difficulty with transitions between home, school, work, or other programs while also managing visits to health providers. Many autistic people also struggle with falling and staying asleep, which can impact physical and psychological well-being and can also exacerbate ASD symptoms, such as aggressive behavior. Sleep problems also greatly impact parents' sleep, which in turn can impact a parent's ability to co-regulate and utilize treatment plan interventions.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	A. Understanding of mental health needs: Aggression, self-injurious behavior, and suicidality are symptoms of Autism and co-occurring mental health conditions that are not always received in a supportive manner among mental health care providers. Autistic people are often dismissed when presenting with mental health symptoms, leading to delays in diagnosis and treatment interventions. Many providers lack understanding of how mental health conditions are expressed in autistic people and are not adequately trained to treat these co-occurring conditions. B. Obsessive Compulsive Disorder (OCD): Research suggests that autistic people are more likely to have co-occurring OCD. Some symptoms of ASD and OCD overlap, such as compulsive, restricted, and repetitive behaviors, making diagnosis more challenging. C. Communication Challenges: Autistic people may struggle identifying or communicating emotions or trauma, making therapeutic interventions more challenging. Difficulties with social skills and self-reflection can also hinder therapeutic relationships with mental health providers and may call for tailored strategies for rapport-building, support, and interventions. PAR also recommends that the IACC reconsider listing "aggressive or self injurious behavior" as a mental health condition. Aggression and self-injurious behavior are potential symptoms indicative of mental or physical health disorders rather than disorders themselves.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Day services, schools, and other programs are often ill-prepared to adapt to the needs of autistic individuals with co-occurring intellectual or developmental disabilities. Providers are often not adequately trained to understand how these additional disabilities impact autistic individuals and how to adapt treatments and interventions to better serve this population. Other challenges that potentially affect quality of life are challenges with social growth, interpersonal effectiveness, sense of self-efficacy, ability to cope with change, and the need for increased housing supports and employment supports.
What additional research is needed to help address co-occurring conditions for autistic people?	In general, more research is needed around evidence-based diagnostic and therapeutic interventions for autistic individuals with co-occurring mental and physical health disorders. Below are several specific areas for consideration: A. Sleep disorders, including sleep medication aids and sleep hygiene. B. How to best support autistic individuals who are gender questioning or gender nonconforming. C. Treatment for OCD for individuals

	<p>with Level 2 and Level 3 ASD diagnosis. D. Effective staff training methods for supporting autistic individuals across settings in the community, day services, and employment. E. How to best support transition age students (school to adulthood). F. Genetic and environmental factors influencing co-occurrence.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>A. Training & Education: There is a significant gap in training and education for professionals working with this population, including teachers, therapists, psychiatrists, law enforcement officers, nurses, and physicians. Updating curriculum and continuing education programs to include information on how to best communicate with, diagnosis, and treat this population is crucial. B. Diagnostic Practices: There is currently greater demand for qualified autism diagnosis providers than there are providers available. Delay in diagnosis can have serious consequences for this population and additional resources are needed to address this issue. C. Hospitals: Current practices often leave individuals without proper care and discharged prematurely from hospitals. Many of the people who experience aggression, self-injurious behavior, or suicidality are heavily sedated and/or confined in restraints instead of provided appropriate supports and treatment. Policies must be implemented to ensure this population receives adequate care. D. Guidance for Parents: Many parents struggle to navigate multiple service systems for their children with co-occurring autism and other conditions. Greater resources for how parents can access services through the lifespan are needed to ensure parents can easily navigate and access services for their children.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>Many individuals experienced disruptions in their routines due to the pandemic and are still building new routines or getting back to their pre-pandemic routines. These disruptions have caused social isolation, which has negatively impacted the mental health of many individuals. Furthermore, the pandemic limited access to essential services and therapies, resulting in delayed diagnoses, interventions, and increased/prolonged symptom intensity. Lack of medical care and mental health care, as well as the inability for teachers to observe students in-person, has also decreased identification of symptoms.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>A. Telehealth: Increased access to telehealth has been a significant positive change from the pandemic and has reduced barriers diagnosis and treatment. PAR recommends that the IACC consider looking at ways to protect individual's access to telehealth services including, but not limited to, advocating for the amendment of 42 CFR § 440.90 to allow for greater flexibility of the practitioner's and individual's location. B. Remote Activities: Remote activities have provided flexibility and convenience, but have also decreased face-to-face social interactions, limiting opportunities for individuals to build communication and social skills. C. Program Closures: Many community-based programs that closed during the pandemic are also still closed or are operating at reduced capacity, limiting opportunities for skill development and structured socialization. D. Social Isolation: Disruptions in school, work, and social engagements not only increased social isolation during the pandemic, but also has continued negative effects today. For individuals with tendencies to avoid social situations due to social anxiety, anxiety symptoms have often only increased or intensified after the pandemic.</p>

Name	Ines Echegaray
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator; Researcher; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The fact that when co-occurring physical health conditions do present themselves, they lead to Autistic Shut Downs that are interpreted as Depression, when they are not Depression. And that leads to worsening shut down and/or health conditions. It's a serious vicious cycle that needs to be addressed.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Again, that Autistic Shut Down is mis-diagnosed as Depression and this leads to ineffective and injurious treatment plans, instead of working with us to address the Autistic Shut Down to begin with...that is the most significant challenge. The general ignorance about this is profound, even in the Medical and Behavioral Communities where we have to seek assistance for our sensory challenges. And then we have to explain to service providers the difference, while we are shut down! It's an impossible situation you're putting us in.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	If I had to choose one among those listed, Communication disabilities are the most challenging for me. Because I am educated, and can advocate for myself with proper preparation, people assume I can always advocate for myself. And I cannot. It takes a lot of emotional and physical energy to self-advocate, and even then, I need processing time to respond to new information. I am consistently required to make decisions on the spot, despite my requesting time to process, all the time. It's profoundly able-ist. I'm also required to engage when I cannot. I have to reschedule appointments all the time, and it's not because of an oversight. It's because some days are too sensorily challenging and impede my ability to engage others.
What additional research is needed to help address co-occurring conditions for autistic people?	Ask Autistic People and not in survey form with time limits. Create something in Praxis that allows us to engage when we can with you, instead of creating an opportunity for us to do on YOUR Time Line. We can't, oftentimes, on anyone else's time line but our own.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	All of the listed options above (Equitable access to and accessibility of services, insurance coverage, service systems improvements, patient provider interactions) would help us. Most imperative is patient-provider interactions being less able-ist and more focused on what we say we need from service providers. And, of course, education, so that others can see us without our having to explain ourselves, which we often cannot do.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Slow COVID has made an impact, and worsened an already challenging ability to respond. I am slower and I have fewer resources to call upon. And when I ask for help from my medical provider, I am dismissed.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school,	Disruptions of service and reduced in-person social interactions continue to affect us even after the pandemic. We have yet to recover from the Mental Health impacts. And while some services have increased, it is still very difficult for those of us who were diagnosed as adults to receive supports and services.

increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Irene Tanzman, parent/guardian
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I am the almost 70-year-old mother and guardian of a thirty-five-year-old man named Isaac, diagnosed with severe autism, intellectual disability, and Crohn's disease. Isaac's individual support plan (ISP) and his Home and Community-Based group home placement is not adequate to support Isaac's needs and keep him safe. This is particularly true in terms of accommodating his inflammatory bowel condition, a serious and chronic problem. His plan does not include a clinical assessment which explores his medical needs. The Massachusetts Department of Developmental Services has been aware of Isaac's issues but sees no need to address these. Isaac is also at high risk of developing colon cancer due to family history on both sides of his family and because of his inflammatory bowel disease diagnosis. Isaac's Home and Community Based placement does not have the health services essential for addressing his special health care needs. There is currently no plan in place for his need for regular colonoscopies. When I am no longer able to prepare him for colonoscopies, there is nobody with the expertise to do this in his current programming.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	There is no plan in place to discern a Crohn's flare from a psychiatric or behavioral issue.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Isaac cannot describe pain or tell a physician where it hurts. This is also one of the many reasons that speech and communication interventions are an essential accommodation for him. The community-based placements available to him do not offer speech and communication therapy or communication therapy based on the behavioral principles of verbal behavior. They do not have a mechanism or a plan for upkeep of augmentative communication devices. No allied health professionals are involved with his individual support plan development or were present at this or any of his thirteen ISP meetings. No nursing staff has ever been involved with Isaac's ISP development or present at any meeting. I have never received any nursing or medical evaluation from anyone at his Home and Community-Based group home placement.
What additional research is needed to help address co-occurring conditions for autistic people?	Research whether community-based placement are adequately addressing special healthcare needs.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Give families a choice of service models. Expand and offer public intermediate care facilities (ICF) to families who need this.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	

What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

Name	Izabella Pulvermacher, Dental Coordinator Department of Developmental Services
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	When discussing co-occurring conditions and autism most agencies forget oral health. There must be programs that address oral health for individuals with autism,
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Oral health - dental care is omitted....
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication disabilities - not able to communicate pain....
What additional research is needed to help address co-occurring conditions for autistic people?	We need to create space where all specialties work together to accommodate proper medical and dental care
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Supports need to start when they are young and build on successes and not to wait until the person is an adult. Also, children with autism become adults with autism.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	J Maust, HUB 302
Demographic	Family member of an autistic individual; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbances, sensory & motor challenges, diabetes, GI issues
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, bipolar, schizoaffective, ADHD, suicidality, frontal lobe dysrhythmia
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication disabilities, medication balancing & dosing, impulsivity, certain areas intellectual disabilities,
What additional research is needed to help address co-occurring conditions for autistic people?	The medication game of balances of dosages & kinds when involving several co-morbidities. How to control the anxiety & thus control the ability to respond to a situation instead of spiraling. How independence may be achieved using technological aspects which calm anxiety. Beneficial in-patient & availability. How addressing social & physical needs lessens emotional disorder distress. Best job settings, if any.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Patient provider services (esp upon death of primary caregiver), service system issues, Life-skills needed for the comorbidity issues, many types of medications, get rid of Paratransit for some & give a car service to cut down on anxiety, nursing
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	The good lasting impact is availability of mental providers' telehealth. It aids in assuring appointment will be kept. No need to figure out transport.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Positive is availability of telehealth , ability with zoom to now connect in a much broader way.

Name	J Olson
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Co-occurring physical health conditions exacerbate Autistic/sensory challenges and affect every aspect of the child's life. A major lack of understanding and acceptance, particularly in the educational setting. People are not understanding of what they can't see and have the mindset that the challenges caused by these co-occurring health conditions are willful and purposeful because they are not always apparent.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Again, lack of understanding and acceptance. Particularly in the educational setting. Watching your Autistic child have panic attacks every morning because they are petrified to go to school and become so depressed that they question their own worth because when they go to school they are taught that everything they know, think, feel, do, are is wrong is an all consuming feeling of helplessness and soul-crushing as a parent.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Understanding and acceptance. Autism is a dynamic disability. People do not understand this. They do not understand why an Autistic person may communicate verbally one day, but be unable to communicate verbally and need to utilize sign language, gestures or a communication device another. It is viewed as willful and purposeful manipulation (actual terminology noted in my child's educational file).
What additional research is needed to help address co-occurring conditions for autistic people?	Research is desperately needed for the PDA (Pathological Demand Avoidance) group of Autistic individuals. Both adults, but especially adolescents. Students are being mislabeled as willfully defiant, behaviorally challenged, socially ostracized, discriminated against, and being deprived of the right to a free and appropriate public education in the least restrictive environment because of a lack of understanding and unwillingness to work through the challenges that PDA Autistic students face. PDA is widely recognized and diagnosable (therefore able to be supported) in other countries, but not in the USA.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Accessibility and access to services and supports. Increased understanding, awareness and acceptance of these co-occurring conditions. Parents have to go on a wild goose chase to find what their child needs. Services and supports that are backed by Autistic individuals, and not traumatic to Autistic individuals like ABA therapy. Not a one size fits all support plan for all Autistic individuals. Neurodiversity affirming supports and services.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	Increased acceptance of remote work/school has been both a positive and a negative. It allows parents to better support their child at home when need be (so long as the school is willing to work with the family), but it also exacerbates a lack of social interaction.

in-person social interactions and obligations)	
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Name	Jack Brownn
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbances, Visual Snow Syndrome, Sensory Issues
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, BPD, Depersonalization
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Dyslexia, Stuttering
What additional research is needed to help address co-occurring conditions for autistic people?	Research those who are also self-diagnosed autistic
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Restricted access to services due to diagnosis.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	My asthma has worsened
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Wearing masks is very hard to manage. The sensory sensitivity makes it difficult to wear them although they are a line of defense against COVID.

Name	Jackie
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Workplaces are not equipped to accommodate autistic individuals in most cases. Disability is hard to get so most of us end up working jobs that severely overestimate us and lead to melt/shut downs. These episodes are unpleasant and exhausting, for me personally it's affected my depression and anxiety negatively. I've also had to call out a lot due to the reasons above.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My depression makes it hard for me to clean, take care of myself, eat. My anxiety makes it hard to sleep and do things outside my house. My adhd craves structure and balance but everything is out of whack because I haven't been able to clean or get things done like I need to. I get overestimated by all the tasks and chores I have to do, sometimes causing a melt/shut down, not to mention the daily normal stressors the average adult has like affording rent, food, and bills.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication is the most difficult as most places of employment are not willing to make adjustments in Communication methods so that the autistic person can fully understand what is expected of them. Many of us experience a heightened reaction to being in trouble or doing something wrong and being criticized. Getting an official diagnosis is almost impossible as an adult thus making it even harder to get services and accommodations.
What additional research is needed to help address co-occurring conditions for autistic people?	Research in adult females or AFAB people, people of color. The connection between hypermobility and ASD, whether there is a link to Ehlers Danlos Syndrome
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Education on effective communication methods, understanding when a shutdown or meltdown occur it IS NOT the autistic person throwing a tantrum. Access to disability for autistic adults and improved access to pathways to get an official diagnosis as an adult.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Disruption in services, isolation. It's lead to some skill regressions and then to be thrown right back into society like nothing has changed has been very triggering and scary.

Name	Jackie Ceonzo, Parent
Demographic	Family member of an autistic individual; Service provider, health provider, or educator; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep deprivation I believe causes so many other challenges with autism. I feel it exacerbates all the other issues- certainly can make epilepsy worse, no one has a good day when they have not slept. The other big issue with sleep issues is this affects everyone caring for the person also. An exhausted caregiver can't really do their best. I often say to people let's deal with the sleep issue first and then we can deal with everything else.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Aggression and self injury are the most isolating for our family and the most challenging to deal with kids I have worked with - it makes your world so small. As kids age so do their parents and when you reach the point that they can physically hurt you it becomes such an unmanageable situation so quickly. Self injury is heartbreaking - to see my son bite his wrist til he bleeds, or kids hit themselves, especially when the hospitals are not really equipped to deal with treating the individual so most kids are probably over medicated to avoid an outburst. With these two issues it becomes very hard to be in the community - programs won't take them so we have all folks suffering at home with too few capable psychiatrists trying to manage the behaviors with trial and error medications. It's awful and there are way too many people living like this and they afraid to talk about it.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	These just add to the issues and make caring for these individuals without tremendous support impossible. My son has epilepsy, I/DD, aggression, self injury, Mood disorder, non verbal he's 28 and we are 60 - we live one crisis away from it all falling apart every day and the future - biggest fear. The I/DD component makes all the other issues so much more complex - he has no sense of danger, can't communicate his needs, make for a very complex plan.
What additional research is needed to help address co-occurring conditions for autistic people?	The seizure component and gut component need to be part of the screening process upon diagnosis We need more medications with less side effects especially weight gain We need best practice for caring for these individuals - this caring for those with aggression should be trained to handle it like professionals are We need more settings where care can be administered and monitored to many people are handling these issues at home and doctors don't have a clear picture of what's happening with meds prescribed etc. We need places for these guys to live and be cared for because too many are affected and I dare say won't be cured.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	We need treatment facilities covered by Medicaid. We need dental care with sedation. Dental issues are cause of many behavior problems. We need better meds and better oversight and distribution. We need quality day and residential programming to flourish with funded by self directed Medicaid. We need a professionally trained workforce to care for these guys in community settings most appropriate to their needs.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	The pandemic was devastating - the little we had is still disrupted - so much regression occurred for so many - lost caregivers, loss of routine, setback in future planning, inability to return to volunteer or work program. Progress lost - hard to know with my son as he doesn't talk but he is not the same post Covid none of us are
What lasting positive or negative impacts have societal changes due to	Telehealth is a major plus in some cases it exposed so many flaws in a very frail service delivery system - the system is now officially broken but it's an

the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

opportunity to fix it. I say to many - now that everyone has had to isolate they have an idea of what life living with a profoundly autistic person is like - we never go anywhere crowded - we are home more than not - it was hard to believe our world could be any smaller Many of our guys like my son did not do well with virtual stuff but many did.

Name	Jaime
Demographic	Family member of an autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>Sensory and motor Challenges for my child. He doesn't sense things as a normal child and he lacks the normal motor abilities of a normal child. For instance: Myself and wife have struggled since his early childhood to assist him to illustrate him to objects and physically point his head into the correct direction of things as he's constantly looking up in to the empty air, directing him while he's walking as his attention is limited and he is constantly looking up, playing with his hands or looks back as he walks and is constantly stumbling. We have struggled teaching him over and over how to hold on to a spoon, difficulties in getting him to sit still when is time to eat, teaching him how to hold a pen in school, making him to pay attention to teachers-to boards- or screens. Difficulties to get dressed as he's 5 and I still have to help him dress and he doesn't distinguish a right side from wrong side, constantly and countless trips to the bathroom potty training him which has turned to be one of two most difficult tasks so far as well as getting him to talk or communicate as he has a short attention span and it is hard for him to pronounce many words. This is not only a difficult challenge but an endless mission which doesn't have an end date to be completed. The challenges are countless and constant.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>Anxiety, attention-deficit and hyperactivity in our child brings significant challenges. His anxiety drives him to clap his hands in an unstoppable manner and endless and sometimes as he sleeps his hands seem to move causing him to be restless and sleepy at school. His attention-deficit has brought him many challenges at school as he tends to direct his attention anywhere but the things he's supposed to be learning. He is a very smart child but his lack of attention distracts him from his full learning capacity and delays his learning and this retreats him from being at the same learning level from a normal child his age. He has to have a special individual education plan developed specifically for his needs and sometimes the resources are limited and the specialized parties are limited in some schools and this arises challenges to communities that deal with the spectrum. He is also very hyperactive and there have been reports from school where he climbs chairs/desks and jumps and runs in the class. He is always so hyper at home and he climbs objects which is dangerous as he has fallen a couple times and is a constant vigilance we have to put up with every single day and is time and energy consuming. Is hard to visit places and have quality family time as he can't endure long waiting times. We have limited places we can visit and we always have to choose nearby locations since he can't sit for long periods of time inside a car.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>His learning is very periodic and delayed. He faces constant learning struggles which seem to take a toll and frustrate him causing irritation periods and periods of isolation and bringing swing moods. He is developing at a much slower pace than other normal kids and we see the differences between him at five years and our child being only four and we can see the huge differences in both of their developmental stages. The communication portion has been so difficult and is hard for him to express what he wants and it's hard for us to know or identify his needs and this also provokes his tantrums and mood changes. There are times when out of the blues he starts crying and is hard to understand what causes these reactions. This brings sadness and disappointment to me and my wife and we feel helpless and feel that as much as we want to help him there's just things we won't be able to do for him.</p>

<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>Full extent research needs to be done on two things: Research needs to be done on how these conditions can be prevented before birth and if the conditions can't prevented before birth: Research needs to be done on the possibility to eradicate these conditions once they appear. The biggest challenge us families with a family member in the spectrum have to face is being heard and agencies understanding this is a real critical condition affecting our nature, our surroundings and poses many obstacles to the family's and child's well being. The families dealing with a family member in the spectrum are constantly questing for answers to our questions as to how does this happen and when it happens how can these conditions be eradicated. Team-work makes the dream-work and I'm sure all agencies working together is crucial to develop the powerful component that will identify a real live solution to the problem rather than just an ongoing treatment. Now that these conditions have spun in such incredible high numbers and many important agencies are finally realizing and accepting - I'm sure the correct intelligent minds working together will be able to focus and identify great techniques to help make these conditions minor, almost seamless or even eradicated. My child needs it and I'm almost positive the cure is already working it's way through!</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>More clinics, centers need to be facilitated. More educational programs on the issue. More personnel need to be capacitated to be able to provide spectrum services . More schools with special intelligence should be built for kids on the spectrum so families don't have to travel long distances to find these services. More equipment and tools need to be developed. Reliable and reduced means of transportation for all families assisting with the education of a child on the spectrum. More economic assistance/resources need to be made available to the families or to the child alone as soon as there is a disability diagnostic. The sooner any child in the spectrum has access to these benefits would be crucial to the child's well being.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>Covid caused more anxiety and more frequent allergic conditions. I perceive more anxiety in my child after enduring such long periods of time being enclosed at home. Post covid also brought more constant allergic reactions in my child's health not perceived prior to covid.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Disruptions in crucial services. Scheduling conflicts with doctor visits. Limited availability to live personnel and the increased reliability to remote resources.</p>

Name	James V. Bradley
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Clumsiness, sensitivity to light and sound, difficulty becoming physically comfortable, nausea from gastrointestinal discomfort.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Major depression, severe social anxiety, ADHD (combined type: both inattentive and hyperactivity), suicidality.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	It is difficult for me to communicate and express myself verbally; I do not organize my thoughts in a way that can be easily conveyed in a real-time back-and-forth conversation.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Access to and availability of services: housing, food, and health care without being limited to a geographical location, the lack of government-issued identification, or length of employment. A lack of the aforementioned items does not mitigate the need to have a safe place to live, food to eat, and health care.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	James Weingardt
Demographic	Autistic individual; Family member of an autistic individual; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory motor preferences and differences are grossly not understood especially by school and medical personnel outside of sensory based occupational or vision therapy. Gastrointestinal disorders are not understood by general practitioners. Referral to specialist with emphasis on gasterolintestinal is rarely given. Slipped disk from not knowing boundaries or pushing self to limit/dangerous behaviors leads to obesity or heart disease.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, self injurious behavior, aggression, suicidality, chronic traumatic encephalopathy, wellbeing, happiness, rejection sensitivity dysphoria, flourishing, social inclusion without masking,
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Sensory processing, developmental disabilities, neurological functioning (dysgraphia, dyslexia, dyscalculia, spikey profile), executive functioning (remembering, planning,), rejection sensitivity dysphoria, Trauma, complex trauma,
What additional research is needed to help address co-occurring conditions for autistic people?	nonspeaking, minimally speaking or unreliable speaking individuals are ignored or projected onto, discriminated against when not taught to advocate effectively for self. Study on reduced anxiety and depression by using Ayers Sensory Integration or other neurofeedback approaches during emotionally exhausted or traumatic times. autistic youth or adults whom grew up in an alcoholic family or in a family where they are systematically not listened to. stigma of autism vs neurodiversity. Study of neurodiversity models from autistic community, neurodiversity model shaped by typically developing professionals and community members with consultation of neurodiversity individuals (IE Boulder Valley School District may pass 1st (known to me) neurodiversity policy in the nation. Further studies expanding sample size, etc: A Sensory Integration Intervention in the School Setting to Support Performance and Participation: A Multiple-Baseline Study how to implement Ayers Sensory Integration Intervention on a larger scale at the state and district levels. Study on using Ayers Sensory Integration for children 0-3 yrs old, 9-13 yrs old, 14-21 yrs old, adult and geriatric populations.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	School based education of peers of autism, nuerodiversity, functioning including randomness and noise in joints Autism, Micromovement approach (Torres et al 2013). Training people how to respond with non-speaking, minimally speaking and unreliable speaking individuals rather than "he/she didn't tell me" Behaviorism trauma due to increased understanding of physiology and the polyvagal theory. Youth sports how untrained coaches often parents and organizing bodies do not understand early childhood development and how youth sports system systematically excludes autistic children based on perceptions of behavior vs physiology as well as limit setting. stadiums, concerts and events can be more neurodiversity friendly including entry into parks, low lines or crowds, trained staff or an independent neurodiversity entrance. Difficulty getting needs addressed

	<p>due to unreliable speech in the short 15 min window. providing sense of safety and assurance that what is said will be further looked at with provider and that they don't get to decide whether they will listen or not to us including recommendations for specialists.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>Societal interactions have been less. Raise in obesity. unknown increased anxiety and depression or suicidality</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Increased use of computers, reduced sleep.</p>

Name	Jamie Cullen, Parent
Demographic	Family member of an autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>My son has autism and other commorbidities that makes it impossible for him to email you, speak at a conference and get his needs met without 24/7 help. When Aspergers was taken out of the DSM is when things became progressively worse for people with severe and profound autism who will NEVER attend Harvard. Please do not minimize my son by saying to me "how do I know that he cannot attend Harvard". He has global developmental delay and needs 24/7 care. He is 21 years old and still needs help with daily living needs, will elope with no safety awareness and has been hospitalized without proper healthcare his entire life. When we lived in Minnesota we had to travel to Prairie St. John Hospital in North Dakota for sub par care. Now living in Illinois we have had to go to Indiana where our son lost over 50 pounds in 3 weeks and at discharge the nurse asked us what medication to give him? What? We had left a full page list on what to do and what foods he will eat and even bought the foods and told them about his restricted diet. His needs were once again not met. We had to get an attorney to get him appropriate education and in the least restrictive environment for him after he ran away from a licensed school and was lost in the same month the Heartspring School had a death of an autistic adult student due to elopement. Please we need knowledgeable medical Doctors, services and housing.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>My son will hit his eyes until they are swollen shut. He elopes into traffic, water and has no awareness of safety. He cannot talk other than Bathroom Please and short needs. He will become so aggressive we have been sued by school staff who personally sued us while he was at school when the behavior happened. We have had to hospitalize him since the age of 5 and have tried every other therapy and service we have known about with no success. We need knowledgeable Doctors, more help for adults for housing and services because when they graduate their needs do not change and they still need to learn. My son has autism and other commorbidities that makes it impossible for him to email you, speak at a conference and get his needs met without 24/7 help. When Aspergers was taken out of the DSM is when things became progressively worse for my son who will NEVER attend Harvard. Please do not minimize my son by saying to me "how do I know that he cannot attend Harvard". He has global developmental delay and needs 24/7 care. I will be his voice as long as he is not treated in the way that is humane. He was restrained in a Hospital for over 3 months. Please do not forget about the adults who are not attending Harvard and never will. Please remember EVERYONE is important. The best compliment I received in my life was the fact that I never treated my special needs son any different than my other 2 boys. I have fought long battles for him and fought law suits. I have watched him hit his eyes until they were swollen shut and he had to be restrained in a Hospital.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>My son cannot talk and tell people who he is, what is wrong and what his needs are. People may not know that if he runs into traffic he has no awareness to safety. The staff that work with him are not paid enough. He cannot live without 24/7 care. He rarely sleeps through the night. I could go on and on. I have a son with autism and other co-morbidities and I am his voice. He cannot advocate for himself but that does not mean he is less than and his needs shouldn't be considered. When the DSM was changed and Aspergers was taken out of the diagnostic manual is when my son and all of his friends lost their spot at the table. To consider my son in the same</p>

	<p>category as a student who can attend Harvard is the most gross discrimination there is. The levels in the manual have not changed the fact that #actually autistics are trying to lead any and all discussion to say I shouldn't speak for my son. If I don't who will. He cannot and would not be able to text, send an email, etc. That does not mean I treat him differently and in fact one the the best compliments I received in my life was how I didn't raise my son any differently than I did my other 2 boys. I have a degree in Social Work and I am a fierce advocate for anyone that doesn't have a voice or doesn't know how to use their voice to make changes.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>We need to find out why aggressive behaviors occur. What will medically help our kids so they do not hit their eyes or bite their skin until it is bloody. I was walking near my Dad's farm in South Dakota. I saw a bright green piece of corn and brought it to a farmer and asked what it was. They said it was the pesticide that is put around each piece of corn so it kills worms that attack it. These pesticides are in our ground, food and water. Is this causing our kids to have autism and co-morbid conditions? What is this doing to all of us? Is this causing cancer. We need to start researching all of these terrible things that no one realizes is going on and causing so many issues.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Doctors with the knowledge of how to help. More Hospitals that can care for individuals who need both psychiatric care and health care. People to be paid better so we have more housing and care for our kids. I had to quit my job to find long term care for him and I have to move to a state in order to find that care which is away from the family and friends that have helped us throughout our lives. These are the decisions I make because this country is not waking up to the fact that in 2002 1 in 150 babies were born with autism and now the CDC predicts in 20 years 1 in 3 babies born will have autism and half of them with other comorbidities. What will happen when all there people needing services cannot get them and there is no now able to help. We need help now, We cannot continue to wait while our kids are in hospitals that do not understand how to care for them so they are restrained? What are you doing now to help all these individuals?</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>My son lived at home until covid. He became so adisregulated because he didn't understand that he was hospitalized for 3 months restrained to a bed with the State Crisis Team telling us to keep him in the Hospital so he is first to get Transition Housing, That Housing never came and we had to place our son who does not speak in an Illinois State Approved residential School that was not appropriate for him because we had no other options. He eloped from the school and this is when Heartstring School had a student death due to elopement so the school kicked our son out after losing him and we had to get an attorney to get him into a school in New York. We had to send our already challenged limited speaking child out of State to a school and drop him off and go back to Illinois. I had to quit my job to find someone who would help get him back to Illinois. In the 2 years I have searched I found 1 place in Wisconsin willing to take him. We are having to move to Wisconsin for help. It's insane and I am thankful we can afford to do this but what about all the people who can't??</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school,</p>	<p>We have no workers to help care for our kids and governments do not seem to grasp the need and complete desperation of our families.</p>

increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Jamin Johnson
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Significant challenges with co-occurring physical health conditions: depression lack of interest in speaking more than 1-3 words sound sensitivity Biggest challenge with co-occurring conditions-- a. finding doctors who know anything about serving our kids/adults with these challenges. b. finding doctors willing to serve our population
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	depression anger self-injury ADD
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Challenges-- all of the above-- learning, developmental, intellectual, and communication disabilities.
What additional research is needed to help address co-occurring conditions for autistic people?	YES... an it needs have on-going funding!!!! Band-Aids are not going to help the 1 out of 6 kids with autism and co-occurring conditions. We need more research and support!
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Better pay for support providers-- the agencies take the dollars and pay the staff what they can, but they have to hire anyone willing to work with our challenging family members. So, we get unskilled, bidding their time, workers that turn over ALL THE TIME! Training and \$upport to doctors willing and able to work with our kids/adults with challenges to find solutions.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	NA-- my daughter didn't get Covid! YAY!
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	NA

Name	Jana Young
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	PDA, Anxiety, sensory
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	PDA & ADHD
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication challenges, emotional dysregulation, learning difficulties (literacy)
What additional research is needed to help address co-occurring conditions for autistic people?	PDA! It's so hard navigating support for my PDA autistic son with ADHD ... especially as PDA is not in the DSM yet so it's discounted as a contributing factor by his doctors, and ADHD is not given support in our school system, so he's faking through the cracks in both public institutions.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Acknowledgment that PDA is real and legitimate
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Massive increase in childhood anxiety, particularly in my son's grade 2 cohort... the number of neurodivergent diagnoses at his school ballooned for his age group, which started kindergarten during the pandemic

Name	Jane Horn
Demographic	Family member of an autistic individual; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Echolalia is a significant barrier to communication for many autistic children. It is not unique to autism, but often alerts providers that the problem may be autism.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	For the child who uses echolalic speech, there is often great frustration that his/her speech is not understood. It is very frustrating for parents and caregivers.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Most education is very difficult with a child whose language is severely echolalic.
What additional research is needed to help address co-occurring conditions for autistic people?	Research is needed to understand what is going on with a child who only speaks in irrelevant phrases. When a child speaks clearly, words that he/she has heard, but do not fit the present situation, the problem is not hearing. Does this child have any comprehension of the words he/she speaks?
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I know examples of very early speech therapy getting a child past echolalia. Too often, speech therapy is not available until a pattern of echolalia is established. Research on what treatment, and how early is needed. Parents have too often been told "let's wait and see." Referrals and treatment are too late. Sometimes parents wait for YEARS for waivers or vouchers to come through. If early intervention is to work, providers need to know about it, and parents need to be guided to the resources EARLY.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Jane Roberts, University of South Carolina
Demographic	Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Anxiety is an early emerging feature that has significant negative effects on these children, their families and the communities that support them. Intellectual impairment (ID) is a huge factor that constrains all areas of function, and sensory issues are pervasive.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	early and valid diagnoses are a huge challenge as diagnostic overshadowing can result in delayed or invalid determination (mistake fear and anxiety for autism features). Anxiety will effect employment, academic achievement and social competence.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	lack of functional independence, poor services in school or communities and the need for housing. transitioning to adulthood is a tremendous challenge for those with ASD who have co-occurring conditions.
What additional research is needed to help address co-occurring conditions for autistic people?	sex effects in anxiety, brain based and ANS function as potential bio behavioral mechanisms.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	integrated care particularly in rural areas,
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Jane Seymour
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Pathological Demand Avoidance profilr
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Understanding Pathological Demand Avoidance
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage for treatments such as neurofeedback therapy, more mental health coverage, respite support, educational support when the child can't be in a public school
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Jane, County AE
Demographic	Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The individuals that have a diagnosis of Autism with higher IQs and open in ID ODP waivers, providers are struggling to support these individuals in our current service system with Individuals diagnosed with ID. Some of these individuals have severe mental health issues and are not wanting to be supported in the MH system because of their Autism diagnosis.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	It's not those individuals that providers struggle to support, it's the Autism only individuals with the high IQ's. Are system is based on supporting individuals with an intellectual disability. Question is are we stifling the individuals with Autism with normal to higher IQ's to their full potential.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	The individuals that have a diagnosis of Autism with higher IQs and open in ID ODP waivers, providers are struggling to support these individuals in our current service system with Individuals diagnosed with ID. Some of these individuals have severe mental health issues and are not wanting to be supported in the MH system because of their Autism diagnosis.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Janet Callahan
Demographic	Autistic individual; Family member of an autistic individual; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Doctors often refuse to look for reasons other than autism. For example, we have heard, "well, all autistic kids have X, so there is no solution" even though there are known treatments and other possible causes for X that are being ignored.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	It is <i>*extremely*</i> challenging to find appropriate mental health care at all, especially for children in our state. Finding any mental health professional willing to work with an autistic child, much less anyone who actually knows how to do so effectively, is nearly impossible. It took 5 years to find a therapist to see one of my children who has severe anxiety, presumed PTSD, ADHD, probable OCD, and self-injurious behavior. My children's psychiatrist, who it took over a year to find, no longer accepts any insurance; my children's medicaid case worker told us they cannot provide a referral because the medicaid provider wait lists are too long. There is no facility in our state who will take inpatient mental health clients who are autistic or have other medical issues. So...if we cannot manage my daughter's needs at home, there is no other option.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	First, people's assumptions that any of these things mean that someone is incapable of learning has been a bigger impediment to my children's learning than their actual diagnoses. My children had IEPs (we currently homeschool because there is no reasonable way to send them back to school and get what they need). Their IEPs did not result in academic progress, even though they were quite capable of it. We spent hundreds of hours negotiating how to get needed services and supports. My son has substantial communication disabilities. We were told when he was in 4th grade that he would not graduate from high school. In part, he could not participate in foreign language classes, because he couldn't "speak English," and those foreign language credits are a graduation requirement. At home he's learning a 2nd language quite successfully.
What additional research is needed to help address co-occurring conditions for autistic people?	Research is needed to first prove that medical and educational and mental health professionals are ignoring all these things and that they should be treated. Research is also needed to sort out how much of these things are "just autism" vs actual conditions that could be resolved, and thus might improve people's lives and outcomes. The list of co-occurring conditions is long, but professionals often don't know the list is as long as it is.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Equitable access to mental health treatment is a problem for everyone, but autism makes it even less equitable. Insurance companies need to stop saying "well they're autistic so this won't benefit them." Providers need to stop assuming that something is "just autism."
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It has made it worse for many people. Fewer supports exist now than pre-covid. It took us 2 years to hire someone to cover my children's state-approved support hours because so many caregivers left the field due to covid. They were not provided appropriate educational supports for virtual learning during covid, and lost ground. They were not offered any additional

	<p>services when things started to return to normal. And because of their medical histories (all those co-occurring conditions), their medical providers did not feel returning to in-person school was a viable option. They lost out on things that were assisting their mental and physical health when things were locked down, and getting therapies back on track has been challenging.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Disrupted services have not been un-disrupted, which is a problem. Virtual schooling is not good for everyone, nor are telehealth appointments. Increased remote work has been good for me as an autistic adult. It's been good for my kids because I am here and can step in when things are not going well no matter what time of day it is. On the whole, though, I think it's mostly been negative.</p>

Name	Janet Shouse
Demographic	Family member of an autistic individual; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Many individuals on the autism spectrum have physical health conditions that cause pain and distress to themselves and their families. These include significant sleep disturbances, seizures, gastrointestinal conditions such as constant constipation, chronic diarrhea, and reflux, feeding issues and food aversions/restrictions, sensory hypo- and hypersensitivities, and catatonia. These physical health conditions negatively impact the quality of life for the individual and their families. In some cases, these conditions lead to premature death.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Among those with intellectual disability and limited communicative abilities, aggression, self-injury, elopement, pica, and property destruction are often present. Every year multiple children with autism wander from home and drown. Less dire, but much more frequent consequences are bruises, cuts, skin infections, and broken bones for the individual and often their parents, siblings, and support staff. Repeated self-injury can cause detached retinas and concussions. Pica causes individuals to ingest all types of inedible objects. Such behavior can require emergency medical care, surgeries, and costly hospital stays, and often these individuals require extraordinary measures to ensure that they adhere to treatment plans and can heal. Such conditions also often lead to out-of-home placements, as most families don't receive the needed supports to keep their loved ones at home. Among those with higher cognitive abilities and fewer communication issues, anxiety, depression, obsessive-compulsive disorder, ADHD, and suicidality are found at much higher rates than the general population, yet effective treatments and counseling are extremely short supply. Not only are these conditions traumatic for the individual, the family, and support persons, they often impose enormous costs on families and ill-equipped systems of care. Reducing the frequency and intensity of these mental and behavioral health conditions should be a key goal for autism treatment and research.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	For approximately 30% to 40% of individuals on the autism spectrum who have severe communication impairments and intellectual disability, they often require near-constant supervision, which means one parent may have to quit work and stay at home, if the child or adult is still in the family home, or a paid staffer is needed around the clock, if the person is living outside the family home. Such an individual is unlikely to be able to live independently nor to earn enough to pay for their own housing and upkeep. Families often face huge financial costs—the possible loss of a parent's income as well as costs for multiple types of therapy, respite care, in-home supports, specialized equipment, medical care, and often replacing or repairing property destruction. And state Medicaid waiver programs often have huge waiting lists, limited funding, and chronic and severe staffing shortages preventing such adults from being able to move out of their family home and to be as "independent" as it is possible for them to be. Also, since Medicaid dollars cannot be used for housing, a huge challenge is for these individuals is being able to afford decent housing on an SSI check of \$943 a month, particularly if the individual's behavioral needs require the person to live by themselves (with 24/7 staff).
What additional research is needed to help address co-occurring conditions for autistic people?	A top research priority for those with the most significant impairments should be the alleviation of aggression, self-injury, pica, and elopement. There are seemingly very few truly effective medical and behavioral treatments, and we need research into ways to prevent, if possible, these behavioral health conditions. We need more research on effective

	<p>medications, cannabis, electro-convulsive therapy, and behavioral/sensory approaches. We also need research into effective counseling and talk/play therapy for those with significant communication limitations. We need a greater emphasis on the needs of adults who often lack access to appropriate care—both mental/behavioral health and physical health—and whose distressing and dangerous behaviors cause great trauma for the individual, their families, support persons and other care providers. For those with higher cognitive abilities and fewer communication issues, more research is needed for effective treatments, including medications, for anxiety, depression, and OCD, so individuals won't have to face multiple medication trials to find one that works well. We need hospitals—both primary hospitals and psychiatric hospitals—to be accommodating to the needs of autistic adults who have medical complexities, intense sensory needs, and/or intellectual disability. Too often autistic individuals with ID or co-morbid medical conditions are not accepted by hospitals or stays create trauma for the individual.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Insurance, both private and public, should cover both outpatient and inpatient care for those behavioral health conditions associated with individuals with the most significant impairments. Medicaid reimbursement should cover the costs of treatment, so that health care providers are willing to accept Medicaid recipients, particularly adults. Treatments for such behavioral health conditions must be recognized as medically necessary under mental health parity. Currently finding willing and knowledgeable health care providers for this population is extremely difficult. There are vast “health care deserts” across the nation for this rapidly growing population. For many people, there are no in-state options for a teen or an adult with autism, intellectual disability, and severe behavioral health conditions. Families struggle to find and fund distant hospital stays for loved ones who may not be able to communicate except in person. We need an intense effort to educate health care providers on the needs of individuals with autism across the spectrum. Medicaid waivers should be portable, so that families can move to another state without a child or adult losing their supports and services or having to go to the bottom of a years-long waiting list. Medicaid and other funding should enhance payments for supporting and serving those 30%-40% of autistic individuals with the most significant challenges. Enhanced funding is vital for waiver providers as well as health care providers.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>Given how long COVID manifests itself in multiple ways, it's extremely difficult to know the impact on those with autism who are not able to communicate effectively or to articulate their internal states. The mental and behavioral health impact of the pandemic itself was distressing to large numbers of autistic individuals. We do know that COVID-19 was far deadlier for individuals with intellectual and developmental disabilities than any other group. Additional research in those areas is needed.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced</p>	<p>The COVID shutdown has had a devastating impact on programs serving individuals with autism and intellectual disability. Many programs were unable to keep staff during the pandemic and closed their doors, leaving many adults isolated with little or no access to day services or community engagement. An already severe shortage of direct support professionals has become even more dire, and many individuals who ostensibly have waiver supports cannot get those supports because there simply are no DSPs or personal assistants or job coaches to provide those services. This is sometimes referred to the “shadow wait list,” as these people are enrolled in</p>

in-person social interactions and obligations)

waiver programs, but they aren't being served. While the increased use of remote work has helped some autistic individuals and their families, for many families, remote school was a nightmare, and their children lost enormous ground. The disruptions to child care programs, and now the loss of pandemic funding to help stabilize them, has exacerbated the huge issue of finding appropriate child care for autistic children and teens for working families. The federal government should take action to facilitate the use of telehealth across state lines. At this time, many areas are not served by autism specialists, and telehealth can provide access to many more people. However, while many autistic individuals can benefit from telehealth, for many others, virtual options simply do not work, and telehealth cannot be seen as a panacea.

Name	Janice
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I would say motor skills and joint pain
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety is the most for my daughter
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My daughter is very smart but often has trouble finding the right words. Expressive verbal skills have a problem since she was a preschooler. She can function in the world and has a job but sometimes it takes a little bit to get context and details on things she's talking about
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Better insurance coverage. It seems like all the psychologists and psychiatrists who don't accept insurance are the best and the ones who do are subpar
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	My daughter has gotten Covid twice (she works in an after school care program) but I don't see any long lasting issues.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Remote college classes have been a good thing for her. It decreases the anxiety and since she doesn't drive requires less coordination to get her there. However she does better with the structure of a zoom class vs pure online go at your own pace class.

Name	Janice, Parent
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My daughter did not sleep well even as an infant. Could not nap, difficulty falling asleep, frequent stomach aches.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression and anxiety were diagnosed at age 13, but adhd and autism were not identified until she was 25.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	She is very intelligent but easily overwhelmed by noise, crowds, etc. Which may cause temporary inability to speak.
What additional research is needed to help address co-occurring conditions for autistic people?	Early screening and diagnosis for girls, how to create sensory friendly environments.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Financial assistance for autistic individuals to access appropriate medical care, including physicians and disability resources.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The availability of telehealth has been helpful.

Name	Jared Goodrich
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory Issues with crowds.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have ADHD, I have social anxiety etc it can be difficult but manage.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Social interaction
What additional research is needed to help address co-occurring conditions for autistic people?	Understandings
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Treat us like any other individuals.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Stress
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Telehealth has been so useful

Name	Jason B, Self
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep, sensory, gastrointestinal, diabetes, eating / nutrition / weight, stress, lack of physical activity.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Burnout, depression, anxiety, meltdowns, suicide, sleep deprivation, sensory triggering, can't leave house / interact socially.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication, learning things a different way, non-accommodation for outliers in just about every facet of life.
What additional research is needed to help address co-occurring conditions for autistic people?	Research burnout, shutdown, PDA, depression, anxiety. Research how to support adults who disconnect from society. Research support for untreated chronic medical problems due to communication issues and resources. Research how to help adults with daily tasks like meals, chores, maintenance, etc. Research how to provide jobs that accommodate autistic people. Research how to fight exploitation of autistic people.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Outreach programs, autistic communication specialist that can "translate" for medical staff, affordable direct services or insurance, accessibility for people with sensory and social issues, being patient and providing accommodations, resources / staffing, not waiting six months for an appointment!
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Since the pandemic I can't leave my house most days and don't interact socially. I do live with my autistic partner, we are in our 40s. We have little support for chronic medical issues due to communication issues, depression, anxiety, burnout. We both lost our jobs and are unable to function. We struggle to do many daily tasks like meals, chores, basic shopping, maintenance, etc. These things are not due to severe financial issues, we just can't face the world and are in severe burnout. We started having issues like this in our late 30s but the pandemic made it so much worse.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	Deaths, changes at work and then layoffs, refusal and reversal of accommodations, exploitation and scams, people seem more greedy / mean / selfish / violent, reduced interactions, widespread depression / anxiety / fatigue, no meaning or purpose.

in-person social interactions and obligations)	
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Name	Jason Montgomery
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The most significant health challenge I see in my son who has autism is his sleep schedule. He is 23 and unable to keep a normal sleep schedule. He often sleeps 12+ hours, and his schedule shifts from sleeping in the morning to sleeping at night to sleeping in the daytime. It seems to be his biggest challenge, and he is often exhausted.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I am not a doctor, but I believe that my son is mildly depressed. He also doesn't have good executive functioning skills, or the ability to make plans, remember them, and follow through with them.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My son finds it difficult to function in social settings. He can mask, but his desire is to exit the situation as soon he can. I think his difficulties with executive functioning also fit in this category.
What additional research is needed to help address co-occurring conditions for autistic people?	I think there needs to be research aimed at the common issues that autistic people deal with: - social deprivation - sleep deprivation - executive functioning issues - sensory issues
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	All of the above listed in the questions. I think that those with autism need services in school, in college, and in living situations. Having someone that can assist a person with Level 1 autism can change that person's life. Insurance coverage for these services (or government coverage) is critical.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	For my son, similar to what other have seen.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I would say similar to non-autistic individuals.

Name	Javier, Advocate
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gastrointestinal issues, anxiety and learning disabilities.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression, ADHD
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Learning disabilities
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage, I myself as an autistic adult and also a parent to my child who is also autistic, we should receive more help and insurance coverage to have access to more counseling and psychology help.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	COVID was a very frightening experience, I was very depressed during the initial start of the pandemic.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increase use of Telehealth

Name	Jeanine Castagna
Demographic	Autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Autistic people have deficits in communication skills to express pain, discomfort, or other issues related to medical conditions. As a result, conditions are usually not caught as quickly as when it affects a neurotypical person which affects treatment. Also, the healthcare system or lack thereof for these issues make getting treatment difficult
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Autistic people face ableism and struggle with social situations. These usually result in low self esteem and loneliness. With a lack of appropriate coping skills, it can get exhausting and mental health can be affected
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Interviews with autistic people and families are necessary for research to identify barriers.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Pay autistic workers minimum wage, recruiting and retaining qualified providers for autism services (right now lack of staffing is a huge issue across agencies), increase job opportunities and employment services for autistic people
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	COVID 19 made child find and crucial early intervention very difficult to find and access for autistic people. Which overall affected development
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Autistic children had their routines thrown off completely and suddenly which put a pause on learning. They also struggled with remote learning.

Name	Jeannie C
Demographic	Autistic individual; Family member of an autistic individual; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory processing disorder completely distorts reality and makes noises seem louder and scarier and lights at night are too bright for me to drive safely. I also have OCD and anxiety which significantly impacts my day to day executive functioning.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Having ADHD and Autism is very confusing because while one disorder pulls at the side of our brain that likes routine and structure the other seemingly disorganized part of the brain craves spontaneity and newness.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The most significant challenge is the communication and social disabilities. There are a lot of non verbal social cues that we are expected to know and use in order to navigate social situations. While I have learned how to get by with small talk and socially acceptable scripts, I require a lot more down time and recovery time from social obligations than most neurotypicals. Also, growing up and not having a sound understanding of my differences played a huge part in me being bullied for being perceived as different than my peers.
What additional research is needed to help address co-occurring conditions for autistic people?	SO MUCH RESEARCH!! Right now we operate in small online communities where we share our own lived experiences as autistics. We need people from and within the community who are on the spectrum to be apart of this research. We need to be testing children at young ages to detect early childhood autism which then can link that child with occupational therapy and other services; NOT ABA (basically conversion therapy to appear more neurotypical while harming the autistic individual immensely) and the child can build on their skills and find areas within their development that might need more assistance and guidance. The goal is not for the child to be less autistic but to be more educated in their autism so that the individual/parents can find useful accommodations to make their day to day lives more bearable and enjoyable.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Having a thorough screening process for all children whether or not they present early autistic traits or not. Most parents are not aware of the signs or symptoms of early childhood autism so they miss these children completely and the children grow up feeling inherently different than their peers so they begin masking at young ages and begin the slow descend into what I believe manifests early anxiety related to social situations. We need equal access for all children in public schools to early autism testing. From there we need accessible and affordable services for these children and their families. We need education GLOBALLY on autism and how common it is and the ways to nurture our community. We can and will save lives with early detection of autism.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	

<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>The reduced in person social interactions and obligations have been a reset for my nervous system. Making health/store systems more accessible to disabled people has been one of the positive outcomes of social changes post COVID-19. Being able to do pick up orders and avoiding the dreadful overstimulating stores has been helpful.</p>
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Name	Jeffrey Poms
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	many autistic people experience physical illness among which are sleep disturbances which can lead to a lack of focus, mental fortitude and ultimately burnout. Sleep disturbances are also a large contributing factor to persistent, treatment resistant depression and anxiety.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	statistically 85% of autistic people are unemployed or can not maintain a job. this is often because workplace accommodations are not readily offered, available or granted when requested. Depression can be so severe that the individual may not be ABLE to get out of bed to go to work, even those who work from home. This leads to self harming behaviors and even suicide as the autistic person can't get or maintain employment and if they lack a sufficient social structure which most do, suicide rates skyrocket at the thought of not being able to pay bills, afford healthcare, support services etc. one becomes hopeless as its a never ending cycle that when not escaped many feel there is no other option then to end it themselves.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	a lot of autistic people are very intelligent but may struggle to communicate in ways well received by their allistic counterparts. We have regulated trainings in every major employer for workplace violence, harassment, diversity including now the trans community, why can we not add regulated information on neurodivergence?
What additional research is needed to help address co-occurring conditions for autistic people?	Autism research has really only just begun! It started with Dr Asberger who only believed boys were affected. Most with autism have been misdiagnosed with personality disorders like narcissism, anti social disorder, psychopathy, sociopathy and borderline/bi polar... there are even cases i've found where in the early 1900's through to the 40's many boys were institutionalized as they were thought to have schizophrenia. Girls have only just recently in the last 20 years begun to see how they present differently than boys. much more research needs to be done on the genetics, family history.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	All of the above examples! but a particular point that i've encountered is that at 44 years of age and having suspected for YEARS that i had autism its taken 2 years to find a provider that was 1 in network and 2 which was most difficult available who did ADULT assessments. people in my generation were often overlooked especially those in the autistic community who are high masking and have communicative skills because well, we figured out how to "make" ourselves fit in but this of course comes at a great cost to our energy and mental health.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school,	

increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Jeffrey Reeves
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	For me it is a struggle with alcohol issues. I so wish that it made me a dominant alpha male tough guy, but it makes me more depressed and confused and it is chemical dependency and not a fun party. That's all that I can think of for myself.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have been afraid of my own shadow for most of my life. I was always easily intimidated and dominated. Anxiety and depression has ruled my life. I can't concentrate because I have been gaslighted and betrayed so much. I am cursed with Dyslexia also, and a Dyslexia of thought as well. I have always been easy prey for predators and parasites. Everyone for the most part is plotting against me also. I am cursed with ADHD also. And no one likes me and everybody is against me.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I have tremendous difficulty with following instructions. I am totally [redacted] at Math. I am constantly tortured with "Remembrance Of Things Past". In a battery of test it was observed that I cannot learn from visual instructions. Something to that effect. I say the wrong thing to the wrong person. I don't react quickly enough in social situations.
What additional research is needed to help address co-occurring conditions for autistic people?	I read that the Amygdala part of the Human brain is more accelerated in autistics. That has been my lifelong curse of being afraid and hopeless. I've not had anywhere near enough sex. Young Women need to have sex with me and we will discover if that cures the Aspergers/Autism.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Vitamins are what make me functional. Tell autistics to try vitamins. Equitable access to and accessibility of services, and service systems issues too. Vitamin B-100, Magnesium, Fish Oil, Flaxseed, are beneficial.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	The vaccines that I received seemed to benefit me in recovering from the China Plague.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I really need Human contact and the China Plague prevented that.

Name	Jeffrey Slater
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Anxiety/depression, ADHD, alexatymia
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Managing mental health amid coping with autism-related traits
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Overall mental health, for me anxiety and alexatymia
What additional research is needed to help address co-occurring conditions for autistic people?	Better understanding of autism-related traits specifically in adults and how they contribute to co-occurring conditions
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Better awareness and knowledge among providers of autism in adults
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I see this is the last question, so let me take this opportunity to say that these questions are ridiculous. You're asking me to describe the entire autistic community, even though that's literally the job of the research you're wanting me to comment on. Furthermore, these questions betray a fundamental lack of a modern understanding of autism. Spend some time on online forums where autistic adults share experiences and further their understanding of themselves. You'll quickly see how far ahead of your studies we are. We still need the scientific rigor, but wow, you all have fallen behind even the most obvious of areas.

Name	Jeffrey Thomas
Demographic	Autistic individual; Family member of an autistic individual; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory and motor challenges, creating comorbidity of eating disorders or substance use disorders to ease the sensory input. .
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression, social isolation, ADHD.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication disabilities that result in an inability to express needs to doctors/healthcare professionals.
What additional research is needed to help address co-occurring conditions for autistic people?	We have plenty of individuals such as myself who have had to live with this condition and make due. I will never be successful because I am unable to hold a high responsibility job, so I am only able to work as a teacher aide or gas station attendant and have been stuck in this cycle of poverty due to my disability.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage, stipends, accessibility. Things that normally insurance would cover (mental health therapy, physical/occupational therapy) haven't been covered by my insurance in the past because supposedly my issue is not "severe enough"
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Humans are complicated and social creatures. The pandemic completely changed how we interact with each other, And now we essentially have to entirely relearn every new societal norm and social interaction queue that has come about because of COVID and the isolation we all faced during quarantine.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	During quarantine in the pandemic the remote work and a remote doctor appointments were a lifesaver, but we have begun making a shift away from that because able-bodied people are able to and it's better for company's bottom line.

Name	Jemima J
Demographic	Family member of an autistic individual; Service provider, health provider, or educator; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Some of the most significant challenges I have noticed, as sensory issues and GI issues
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, hyperactivity and aggressiveness
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Some of the challenges I have noticed are problems in socialization and inappropriate social approach. Communication problems are also common.
What additional research is needed to help address co-occurring conditions for autistic people?	Research looking into deviations in development of speech that contributes to inappropriate social approach. Memory processes that may play a role in repetitive and ritualistic behaviours.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	-Caregiver training programs that are aimed at early detection and intervention. -Developmental monitoring that collaborative in nature, involving all stakeholders in the child's life, parents/ therapists etc. - Community level interventions. -Access to free resources.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Anxiety and delayed achievement of developmental milestones
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Positives: Parents/ caregivers became more proactive in the child's life/ more aware of their functioning and needs. Perhaps even more creative in meeting these needs without access to regular facilities. Negatives: Disruption in services vital for them/ disruption in play opportunities and avenues for socialization.

Name	Jenise Woolf, Parent
Demographic	Family member of an autistic individual; Service provider, health provider, or educator; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I have an adult son who has had multiple ED visits as well as inpatient psychiatric admissions. I have had to beg, usually unsuccessfully, for physical health issues to be evaluated. I'm quite certain many incidents of crisis behavior are due to dental problems, constipation, and/or other health issues. It is not possible to get him to a dentist if there was one. We rely mostly on telehealth for doctor visits due to behavior. My son has ASD, bipolar disorder and IDD.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	There continues to be confusion between symptoms and behaviors. The DD system is not equipped or trained to deal with mania, psychosis, etc., and the BH system has not done well with adapting therapies and clinical resources. Most of all there is a huge lack of integration between the systems!!! Hospitals are ill-equipped to provide inpatient admissions, medical or psychiatric. Sensory equipment and basic behavior modification should be included in treatment and OTs / BCBA's should be part of treatment teams.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Mental health conditions are so pervasive in ASD (OCD, anxiety, bipolar, PTSD), yet there is so little treatment being provided. Clinicians and medical professionals MUST be trained not only to recognize this, but also learn how to adapt treatment interventions.
What additional research is needed to help address co-occurring conditions for autistic people?	The NADD is a wonderful resource for information and data, but more needs to be done to disperse the information and bring about change to the way states, agencies and hospitals provide services. There needs to be more research into effective therapeutic interventions. ABA is not the solution to a manic episode. Approximately 90% of individuals with ASD have experienced some type of trauma, more research needs to be done on prevention, self-advocacy, and most importantly, treatment.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Better integration between DD system and BH system within State Dept of Mental Health. Doctors and especially psychiatrists should receive training in dual-diagnosis. There should be standard protocols for dually-diagnosed individuals seen EDs to rule out physical causes (dental, constipation) with each evaluation. Early intervention services should be more accessible, no wrong door, whether entering through BH system or DD system, and individual should be able to receive services without being screened out.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	My son will no longer leave the house. He was on a wait list for a day program, which had to close during COVID. Staff turnover has, and continues, to disrupt programming.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Telehealth has been a wonderful tool that allows appointments to occur, which we would otherwise have had to cancel due to behavior issues. The disruption in services during COVID definitely derailed things. My son has become used to sitting at home and it is a struggle to get him back into any type of routine.

Name	Jenn
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Anxiety
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, aggression
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Adequate supports and accommodations in schools. Most schools do not recognize a medical diagnosis of autism and do not have the funding to provide adequate supports, so they refuse an IEP to autistic people on the grounds they do not have an « educational diagnosis » of autism.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Additional educational and employment options
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Jenn Raley Miller, Parent
Demographic	Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Differences in sensory processing, sensory integration, and sensory perception.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My child, now age nine, has been assessed by a pediatric neurologist as "twice-exceptional": sensory processing disorder + ADHD + gifted. In the primary grades, we had conflicts with therapists and educators who insisted that the diagnosis must be ASD. Yet the ADOS result was "minimal-to-no evidence of autism" and the SCQ score was 11. Our family is only one example in which different providers have different interpretations of neurodivergence.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	There is very little understanding of how the spectrum of intelligence, from ID to profound giftedness, interacts with other dimensions of autism.
What additional research is needed to help address co-occurring conditions for autistic people?	- Research is needed to establish better definitions and measurements for ASD vs. ADHD vs. SPD etc. Overlapping behavioral definitions are causing confusion. - More research is needed into how the spectrum of intelligence, from intellectual disability to profound giftedness, interacts with the forms of neurodivergence listed in the DSM.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	- Policy and systems change is needed so patients can access Occupational Therapy regardless of whether they "come in through the autism door". The OT community has established excellent assessments for sensory needs, including interoceptive, proprioceptive, and vestibular. - Insurance plans should be directed to approve Occupational Therapy without conditions, as a first-line therapy for individuals with sensory differences. - Funding is needed to attract practitioners to specialize in pediatric and/or sensory integration OT.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Jennifer Colberg, Grandma
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory and motor issues, sensitivity to food and safe foods they are willing to eat, stomach issues
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Self injury, anxiety
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Non verbal, cognitive delays
What additional research is needed to help address co-occurring conditions for autistic people?	There is so little being done and with the rise in level 3 autistic children we need to catch up sooner rather than later
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Services available especially in rural areas, insurance for families that don't qualify for assistance but don't make enough to purchase good insurance
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Early intervention delays and set backs. My grandson had just started early intervention when the shut down happened and we are still playing catch up because none of the services were available and none of the services were made up after shut down so he lost so much
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Disruption in services and no attempt to make them up

Name	Jennifer Higgins
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	anxiety, depression, sensory issues, repetitive behaviors, noise sensitivity, intense, eating disorders, narrow interests, acting without thinking, emotional dysregulation, OCD, over eating
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, social phobia, excessive worry, OCD, hypervigilance, mood instability
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Pathological Demand Avoidance
What additional research is needed to help address co-occurring conditions for autistic people?	Pathological Demand Avoidance
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Equal access to services for all who are labeled as autistic rather than based on income level. Standard level of care or therapy for those diagnosed with autism.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Jennifer Proffitt , Parent and Teacher
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My son has gastrointestinal issues, as a child he had baby hemorrhoids and bloody stools. He also has a hard time using the restroom as a teenager. He slept so hard that he could not wake himself up to use the restroom and would wet his bed until age 14. We have had him on medication now that helps with that. He also has sensory sensitivity to sounds and needs to wear headphones. He does OT, ABA therapy, and mental health therapy.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	He has depression, anxiety, adhd, when he was younger he had aggressive and self-injurious behavior. I feel like he has RSD rejection sensitive dysphoria. It's intense anger when someone hurts your feelings or rejection or criticized assume no one likes you and is overly sensitive. So far none of the doctors I know have anything to help me with this.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My child has dyslexia as well as autism and adhd. He has been in Reading tutoring since third grade that we have had to pay out of pocket for because public school does not do the Barton reading method. He is in high school now and still working with his reading resource teacher. He goes twice a week and has since third grade he is now in high school. This not only costs a lot for us but because of the autism and the ADHD it is taking him a long time to finish the program. My sister's child with dyslexia attended a private school in LA where they had the burden reading method. They worked with him everyday for about a year and a half and he can read fine now. Why can't public schools use the Barton method?
What additional research is needed to help address co-occurring conditions for autistic people?	There needs to be more research into RSD rejection sensitive dysphoria. There needs to be more research done on dyslexia and programs implemented in public school systems. There needs to be emotional support and mental health counseling for students in every grade level every week. My son has not had any friends other than the ones I have helped him make. It is very lonely at school for him and others with autism. Best buddies did not do anything for him. There needs to be a system in place for helping children with autism integrate into the social aspect of their schools by having a peer mentor, a group, or other Outlet so that they don't feel alone.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance should cover every aspect of autistic care. Whether it's doctor's appointments, medication, tutoring, therapies, and especially respite care. There needs to be After High School additional schooling that is publicly funded. There needs to be support with going into Community College for autistic adults who can handle this. This should also be funded by the government. Parents should be reimbursed for being caregivers for their own children. There should be screening through every Milestone doctor's appointment for autism and School screening starting in preschool.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Autistic individuals should not be required to take mandatory vaccines. When the government wanted to make it mandatory that everyone got the covid vaccine this was not an option for our child. Their immune systems and body chemistry are extremely sensitive to medication, food, household cleaning products, etc. Forced vaccines are never an option. Government needs to realize that especially for people who have children on the Spectrum as well as other impairments such as ADHD etc.

<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Reduced rigorous educational activity, disruption in therapy services, disruption in regular schedules which is a huge deal for people on the spectrum, reduction and social opportunities for them to grow and learn.</p>
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Name	Jennifer Quigley
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	For my child, medications for autism has caused significant weight gain leading to increased isolation and decrease in social skills. His gastrointestinal concerns have also caused him to miss school and have issues fitting in with his peers. Sleep disturbances causes troubles meeting a normal school schedule. For my son he gets up at 5am and is ready to start school and can get frustrated by having to wait.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The aggressive behavior and lack of impulse control have caused him to be totally secluded from peers in school. It also led to a large number of restraints, lock downs and seclusion rooms.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My son is 2E and has a very high IQ learning isnt difficult for him. People are.
What additional research is needed to help address co-occurring conditions for autistic people?	More about medical implications.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Eliminate Medicaid waitlists and income limits. No wrong door is important for families without knowledge of the systems that support people.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Significant for my son. It derailed his early advancement and stopped his learning do to requirements to be on camera.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Jennifer Reppond, autism parent
Demographic	Family member of an autistic individual; Researcher
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>The biggest challenge is that the medical community cannot get on board for treatments that are outside the box. To get actual healthcare therapies and protocols, we have to seek those doctors who have taken it upon themselves to delve into the medical treatments that are out there and the new research that is coming out every day. They don't take insurance because insurance stifles the healthcare that our children need. Our son had gastro issues when he was younger, and we took him to a gastro doctor - he said there were no issues, take some laxatives, and sent us on our way. The "in the box" doctors check their boxes and shuffle us out, not helping us AT ALL! So I pay monthly for pharma-grade, highly bio-available supplements because the gastro issue stems from gene issues called MTHFR. No doctor checks for this EVER unless you ask, and some refuse. It turns out that both my autistic son and my ADHD son have this problem. So, they cannot dispense toxins from their body or ingest the proper nutrients from their food. Many of these nutrients are imperative for the GI system to work correctly. How about the medical community catch up to where we are? I'm tired of fighting with our medical professionals because they have ZERO clue. The GI tract is essential to the other examples listed above - sleep issues, skin issues, stemming, and brain issues due to substances getting into the blood and ultimately breaking the blood/brain barrier.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>The biggest challenge is that society needs to understand how these things are intertwined. I have a son moving on from 12th grade who is not ready to enter adulthood. I am doing my dissertation on cooperatives between ISDs and the community they serve. Most of the community (businesses, organizations, etc.) need to learn about people on the spectrum. They need to learn how to handle them or work with them. With 80% of this population doing nothing after their public education ends, they become severely depressed because there is no more interaction. And not that public school interaction is much better since most school kids ignore them, but someplace to go and something to do is better than sitting at home. Depression and bad experiences lead to a host of issues with this group because it is hard to find dedicated, caring, and compassionate people with patience. So far, I have run into no one that even knew that there was a problem, and I did not know that the ISD I am looking into have programs that they could work with to help in the experience and education of this population. Most of them are anxious due to the impatience of others not understanding how to take the time to educate, explain, and show them (as many times as it takes).</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>This goes along with the last question. But many of these kids (young adults) do not understand how "humans in society" work. They don't see the logic in anything people do, and parents so desperately try to make their children fit the "humans in society" mold. When they can't, the child (young adult) gets frustrated, depressed, and angry because they cannot understand or express things to get their point of view across. They also do not know why things are done the way they are. My son understands that you need money to buy things, but that is about the extent of his understanding of money; many people on the spectrum are the same way. They also do not understand figurative language (which is almost 100% of how Americans communicate). This is why my husband, I, or my other son needs to be with our autistic son so that we can explain things to him. The people dealing with him don't know how to communicate. Some people tend to be leery of the bluntness</p>

	<p>of autistic people. We always tell people that if you don't want to know the truth, don't ask your son. Unfortunately, transfer of learning is almost impossible with persons on the spectrum. That is why teaching them is hard, and patience has to prevail. Lack of training and knowledge for people not on the spectrum.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<ul style="list-style-type: none"> • Professional development for general education teachers, para-professionals, staff, and administration currently in the classroom. • Proper education at the university level for ALL teachers - not just those choosing special education. • More training and education for doctors, etc. so that parents aren't left feeling like they are alone. What I learned about autism did not come from any of our mainstream doctors. It came from hundreds of hours of interviewing professionals in the field as well as reading and researching journals, articles, and research materials. • Training and education that is manageable to the parents. Lots of great things are going on, but I was never told about one. I know them because I stumbled upon them. Most parents are not working on 3-4 advanced degrees; they want to know what the path is. • There needs to be a path - to some degree - that is standard - to some degree - that parents can be led to - and helped along the way - with people who can guide them. Governmental entities are a joke and a waste of time - and chances of anyone getting services after years of waiting to come up on a list - are slim to none. • Training and education for the community – employers – organizations – churches – etc.
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>1. Disabled people are the most discriminated people in the world. Put focus on the outlandish discrimination experienced by disabled people. 2. Medical therapies, etc., need to fast forward and intersect where research is today. The medical community needs to admit that they have no clue how to treat people on the spectrum. And in doing so, make the changes necessary to help parents. 3. Education needs to get on the ball in the public education classroom and the university lecture hall. 4. Insurance needs to stop dictating what treatments are acceptable. Last time I checked, doctors are supposed to decide what treatments are best for each of their patients. 5. Community education (all the community - employers, local governments, churches, civic organizations, non-profits, etc.). Sponsoring conversation cafes would be a start - to get movement at the local level.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>My son was distraught with the whole COVID-19 pandemic. He still cannot get off talking about how this entire thing ruined his life. It stopped his life as far as he was concerned. He hated being stuck at home all day and not going to school. Our son is a planner, and this ruined all his plans. He had outbursts of anger that we had never seen from him. When he wasn't angry, he was weeping because he did not understand, and when we couldn't answer his questions or give him understanding, he was just depressed. I know some who did not want to rejoin society after the pandemic and secluded themselves. Our son is still mad at what he considers lost time and moments. One way or the other - mad that life stopped or not wanting to rejoin life - is terrible. So, I believe it did have mental health ramifications as well as ramped up more physical ailments. Stress, anxiety, anger, and confusion all mess with the mind and, if prolonged, can mess with the physical body, causing all sorts of problems. When you don't feel good physically - or mentally - you act out and behave differently.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on</p>	<p>The reduced in-person social interactions hurt the most. Most children on the spectrum regress when they are not consistently in their schedule. Taking them out of their "known plan" upsets and possibly scares them. They</p>

physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

cannot take change. Aside from a known schedule, they need interaction with others. My son needs interaction with others. The daily interactions with his peers, teachers, and staff members at the school help him grow and learn.

Name	Jennifer Sibley
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My son has significant issues with sleep and having Autism. He does not have a regular sleep schedule and has to rely on medication in order to fall asleep at night. When he does sleep, he often does not sleep through the night. He also has significant sensory challenges that make going in public difficult. He is challenged by noises that most of us would not be troubled by and because of this, he looks for those sources when he goes out and avoids them to the point of disrupting his day.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My son has Autism and Anxiety. We have not been able to successfully help him manage his anxiety as he has limited verbal skills and is not able to participate in traditional talk therapies and there is no medication management that we have found so far that helps to decrease the symptoms of his anxiety. In our area (rural Northern New York) we also lack providers who are able to treat individuals who are dually diagnosed with I/DD and Mental Health disorders.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My son with Autism has significant challenges with communication. While he can speak, and answer basic questions, he cannot carry on a lengthy conversation, answer questions about his health or well-being or his wants, needs and desires about living independently. This limits his choices as an adult for independent living.
What additional research is needed to help address co-occurring conditions for autistic people?	More research needs to be done around effective treatment for individuals with Autism and co-occurring anxiety disorders (or any mental health disorders), particularly, those with communication challenges, so that these individuals can participate actively in their own treatment.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Expanding medicaid services for individuals with Autism would be a step in the right direction. Medicaid reimbursement rates, compared to the rates for commercial insurances, are not even close to comparable, which drives many medical practitioners to not accept Medicaid reimbursement. This in turn, limits the providers that individuals with Autism can choose from for medical services. There should also be some work into incentives for new providers to set up practices in rural settings. More providers equals greater access to services for individuals across all disabilities.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	COVID-19 has made it more difficult to retain talented staff to maintain the services that my son requires in order to live in the community. He has been through 5 care coordinators since 2020, and this is a low number compared to some of my friends and their family members. I am pleased with the increased access to Telehealth services as it does make it easier to attend services and medical appointments. This has eliminated the need to travel from work to home to get my son, then travel to his appointment and then back again. Telehealth means that I can attend from work and my son can attend from home with the support of his paid staff member.

Name	Jenny Folley
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gastro discomfort nausea IBS symptoms migraine symptoms insomnia nocturnal body clock fatigue
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	adhd depression anxiety pda
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	adhd pda
What additional research is needed to help address co-occurring conditions for autistic people?	more surveys more info to gps
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	more info to schools and gps
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Long term fatigue long term chest pain long term asthma symptoms long term cramps
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	positive- people are more aware of diversity and needs in adults negative - children are under more pressure to catch up and school is seen as a cure for everything

Name	Jesenia, NeuroSpicy Networking
Demographic	Autistic individual; Service provider, health provider, or educator; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	EDS, sleep disturbances, lack of supports for adults, late realized, lack of access to official diagnosis, danger of obtaining diagnosis and social determinant of health as well as medical gaslighting, medical trauma, ableism and racism in they system and the individuals in the medical system, lack of reproductive care, lack of agency, lack of access to thriving wages, lack of stronger ADA protections. Many employers allowed to discriminate because most of us can't afford to sue or have the energy to do so while we are trying to survive and not become homeless, which is on the verge of becoming illegal so they can criminalize us and put us into modern day slavery (aka the prison industrial complex). Lack of access to Occupational therapy's and accommodations in everyday public life including mask mandates, ADA compliant spaces, broken equipment, untrained staff, equipment not withing accessible range (aka miles away), no reliable public transportation, no funding for in home care, no funding for transportation, no funding for adaptative supplies, or prohibitively priced, and unable to be gainfully employed or keep employment due to lack of all accommodations and supports and ablest employers and coworkers.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	lack of support from they system designed to keep us in poverty and in the conditions of death. depression from not being able to afford to live. 85% of autistic people are unemployed or underemployed AND have college degrees. anxiety from being gaslit by providers that won't take our conditions or health seriously by believing us or wearing a mask to protect us from covid. ADHD which is not well managed by med, hard to access due to barriers and bias of providers, and unaffordable since we don't have access to job and thus healthcare. suicidality because the systems keep us in the conditions of death and no community support due to eugenics and ableism pervasive in our oppression.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	lack of knowledge by the general public, trained practitioners, and psychiatric professionals about how the inter-play of co-occurring conditions AND cultural heritage play into the presentation and affects of ASD with other conditions. Most times we are spending time teaching rather than being treated. Also the pathologizing of our condition rather than listening to our lived experiences and to the now emergent Autistic researchers, pathologizing language and "deficits" instead of realizing that we are multi-lingual, we have been learning how to speak in "allistic" allistilese for our whole lives and masking is draining us. Lack of consideration for our skillful communication within our own community, not having any failings but rather focusing on the social model of disability and the 10 principles of disability justice.
What additional research is needed to help address co-occurring conditions for autistic people?	All autistic research teams AND they must be DIVERSE in culture, ethnicities, genders, and avoid replicating the issues of dominate culture and white supremacy culture. Until we listen to all autistic stories, we are not including the most marginalized or being intersectional in understanding the spectrum. This includes non-speaking and non-verbal autists. Also, need to look into the interplay of nutrition, AND co-occurring conditions such as EDS, Marfans, hypermobility, POTS, MCAS, IBS, Fibromyalgia, MFCFS and Long Covid.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access	UBI, universal healthcare, food is human right, autonomy is a human right, access to sexual reproductive care and offering housing is a human right, education and training made by autistic adults, removing childism and ablism from structures and resources, creating Autistic sensory compliant laws and

<p>to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>enforcement for workplaces and all public spaces and venues. Remove the institutionalization and incarceration of autistic and disabled people, remove modern day slavery allowed in the 13th amendment. Offer advocates and trained support specialists for all autists regardless of age and abolish hate groups such as Autism Speaks and ABA therapies on autistic people, especially children. Require cultural competency, and sensitivity training, DEI, and CRT to ALL staff engaging with disabled people. Require continued training for all medical staff on infectious diseases, care work, and latest research on autism and comorbidities. Require patient-advocates for all interactions with the medical, education, judicial systems. Require employers pay for and provide third party legal services to all disabled employees to incentive them to not discriminate their employees. Require affirmative action for employers making over 5 million in revenue to require at least 40% or more of their workforce be disabled employees or pay 40% more in taxes to cover disability health costs. Remove limits on asset building for disabled people to have access to healthcare.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>covid like HIV has been horribly handled by the governments and politicians politicizing a deadly cumulative auto-immune disrupter. The misinformation and disinformation has deadly consequences on an already vulnerable population and social determinates of health are even more impacted by the lack of precautions, we also have to deal with minor co-occurring physical and mental health becoming flared or activated by degrading and dysregulated immune systems. Then add to that the lack of care from healthcare providers to believe us or take us seriously in knowing our own body-minds. It is a MASS DISABLING EVENT. It is not a matter of if you will become disabled but when. The future is and will be disabled by the our lack of care towards disabled people. eugenics runs deep in this colonized society and we must center care and compassion if we are to survive as a whole.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Positive for a short while was the access to remote work, but as the society continues to gaslight and remove access to remote work and access to public spaces with out covid precautions we are again entering the age of the ugly laws returning. The understanding that our systems are not meant to protect us.</p>

Name	Jess Butler
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Joint pain/hypermobility causes SEVERE pain. Esophagogastric dysmotility causes swallowing difficulties, gastroparesis, SIBO, malnutrition, leaky gut, constipation, bowel impactions, bowel obstructions. Sleep disturbances cause daytime sleepiness, preventable incidents/accidents, brain fog, cognitive dysfunction. Sensory challenges cause SEVERE meltdowns if not appropriately prepared for: everything is either TOO or NOT ENOUGH. Too bright, too loud, too smelly, too scratchy, too much in general causes overloaded senses. OR not enough stimulation causes the "stims" that non-autistic people hate so much and wish to "treat out" of us. Things like hand flapping, finger flipping, toe and foot movements, spinning around, watching spinning things, fascination with little parts of objects, lining things up by color, category, etc. Motor challenges cause instability, lack of coordination, and result in falls, dropping things, etc.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression and anxiety begets suicidality or SIB. Depression and anxiety are often very difficult to treat and the meds have pretty significant side effects: emotional numbness, apathy, sedation, weight gain, high blood glucose readings, flat affect, etc. ADHD causes impulsivity in many forms (overeating, oversexualized status, overspending, etc.), inability to focus (makes us seem "stupid"), hyperactivity makes us unable to remain still when required to do so, etc. Aggressive behavior makes us look "mean" "unpredictable" etc. SIB may cause us to get committed to mental institutions, cause infection, etc.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Learning difficulties: render us "unable to be taught" and result in us being put into life skills classes and being given up on by teachers. Developmental disabilities, depending upon WHAT is disabled, can be detrimental to mobility, communication, etc. Intellectual disabilities: everyone just eventually "gives up on" us, thinking that we "cannot learn, so why waste time trying" Communication difficulties can lead to a whole other set of difficulties, especially when NO effort is put into trying to obtain some sort of communication device (or when the insurance repeatedly DENIES the purchase of a communication device)
What additional research is needed to help address co-occurring conditions for autistic people?	STOP with the "biological" research--just take it that we HAVE autism and help us try to live with it, do NOT attempt to explain it away, and possibly raise the issue of EUGENICS: breeding out autistics by pregnancy termination, fertilized egg cell selection, etc. Research medications that will help treat the symptoms of autism: there were promising oxytocin research trials--what happened to that? Research ethical treatment/therapies for the symptoms of autism--STOP using/recommending ABA and behavioral modification therapies because they are DEGRADING to autistic people! Research the gut-brain connection and immune response system to see where treatments can be aimed (like the microbiota transfers) AND force the insurance companies to cover these procedures! And actually, THAT would be another MAIN concern--forcing insurance companies to actually cover any medications, procedures, or treatments discovered by thorough research!!!
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	FUNDING. Plain and simple. Cut some of the military trillions and throw like a few billion at the autism industry for once. There is a dire shortage of experienced, tolerant service workers. They don't want to work because their wages are PATHETIC for the jobs that they do. There is high turnover, which is detrimental to getting treatment to "stick." Service organizations go out of business for the same reason. There is a total LACK of understanding that ABA and other behavioral-based therapies are DEGRADING to autistics. We are NOT "broken" so we do NOT need "fixed," what we NEED most is

	<p>help to live in a "foreign" world. We need funding for supportive housing, funding to pay the workers who support us, funding to pay for employment services, funding for AAC, funding is the key. But we KNOW we will NEVER get it from the US Govt.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>Probably not a whole lot, you see, because many autistics LIKE to stay home, so the whole "stay home" thing was not like the punishment that the NTs thought it was. It actually SPURRED on things that HELP us, like telemedicine, remote work/work from home jobs, etc. I don't know any autistics who had COVID-19, possibly because our immune systems work differently than NTs.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>As I stated in the last answer, POSITIVE impacts: MORE telehealth, MORE remote work and school (MY kids THRIVED during the school shutdowns and hated to have to go back to the classrooms!), LESS social interactions and obligations is ALWAYS a good thing for us, because we see those things as AWFUL, not enjoyable.</p>

Name	Jesse Scott
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory overload from public restrooms (toilets and hand dryers) being too loud, sensory awareness of the urgency to go before an accident happens, bladder and bowel incontinence. Chronic constipation.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Significant challenges with mental health include ADHD, Anxiety, aggressive behavior under stress. General anxiety in social situations.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Ability to self-advocate, knowing when to ask for help when having challenges. Processing too much information independently can lead to stress without support.
What additional research is needed to help address co-occurring conditions for autistic people?	Causes of incontinence, sensory overload, lack of body awareness. Research investigating autonomic nervous system dysfunction connections between incontinence, GI issues, seizures and other physical health concerns. Neurodiversity-affirming intervention models addressing mental wellness challenges exacerbated by incontinence-related anxiety, depression or trauma.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Increased insurance coverage for specialized products, prescription diapers/pull-ups, assistive devices and mental health counseling related to incontinence management. Mandated accessibility standards so facilities have ample family/accessible restrooms, changing tables and sensory-friendly spaces for intimate care needs. Cultural competency training so providers understand autism-incontinence intersections, ask appropriate questions, and accommodate appointment structure/environment needs. Self-advocacy and system navigation training autistic voices are centered in informing policy improvements over time.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Isolation/changes in routine/structure disrupted established incontinence management plans for some, potentially exacerbating physical symptoms. Loss of employment/income led to inability to afford specialized products for incontinence/prescriptions, worsening well-being. Overstimulation/distress from extensive safety protocols/PPE requirements made it harder to self-advocate needs and tolerate intimate assistance if needed.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	Positive impacts: Increased telehealth access has benefitted some by improving continuity of care during isolation through virtual appointments/services. Work/school accommodations allowing remote participation have enhanced inclusion for individuals whose incontinence may be exacerbated by traditional in-person settings. Reduced social/sensory obligations gave respite to exhausted caretakers and those whose mental health relies on low-pressure environments. Potential negative impacts: Prolonged isolation has worsened anxiety/depression for individuals reliant on

in-person social interactions and obligations)	community support systems and face-to-face interaction. Disruptions in daily routines and structure removed important coping mechanisms and management support for physical health conditions. Transition challenges reacclimating to pre-pandemic expectations have taken both physical and emotional tolls, especially without adequate accommodations.
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Name	Jessica
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Since childhood I've had sensory issues which made it impossible to wear certain fabrics and eat certain foods. I can remember varying forms of insomnia as early as elementary school. These problems have persisted into my thirties where I experience difficulty falling asleep and staying asleep. Before falling asleep I also often have an extreme falling sensation which causes me to jerk violently. I also have gastrointestinal problems which include constipation, and as I've aged, severe heartburn. I needed glasses before the age of 22 due to nearsightedness and an astigmatism, and I experience something known as visual snow. My bladder also hurts, and I pee ALL THE TIME. The problem I deal with most, however, is constant pain. Since I am also female this pain is often ignored, and I'm often treated as if I'm drug seeking so I've learned to just deal with it. My joints used to be hyper-flexible, and some still are, but they are now locking up as I'm aging. Doctors don't seem to care. These are not my only issues unfortunately. At 18 I had a tonsillectomy. At 22 and 23 I had vascular surgery to remove varicose veins from my legs. At 29 I was diagnosed with PMDD and at 32 had a hysterectomy because my periods got so bad I was passing blood clots the size of tangerines for days each month. When I was 33 I was diagnosed with IHH and had brain surgery to treat the underlying venous stenosis at 36.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression. We are criticized by others CONSTANTLY our entire lives and struggle to make friends. If it wasn't due to brain chemistry then being neurodiverse in a neurotypical society does the job. Anxiety. Our nervous system is constantly bombarded by demands it isn't equipped to deal with. This, in combination with the living in a world not built for us, often makes us really anxious. ADHD is commonly co-occurring. I'm and AUDHD'er myself. I know many autistics who struggle with BPD although I am not one of them.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I can't speak for everyone but I can tell you that my biggest challenge is socializing. It is a misconception that we prefer to be alone. We learn to prefer to be alone because people treat us so badly. We annoy neurotypical people just by being ourselves. I will never know how to comfort someone, and I will never be comfortable in a room full of people. Everyone speaks a special social language that my brain doesn't. If we could educate others on autism and eliminate stigma, society as a whole would be more accepting and kind.
What additional research is needed to help address co-occurring conditions for autistic people?	We need to research how girls present since most research is based on boys presentation. We also need to better understand the relationship between ADHD and ASD.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	We need to have access to friends. Autistic people often die by suicide because we lack social supports. A social worker assigned to us, friendship groups, support groups, and group classes would be so helpful. Most helpful, however, would be educational requirements in all schools teaching people who aren't autistic about our lives. If they understood that we weren't all the same but experienced similar trauma we might have a fighting chance at living healthier lives. We really need more understanding and support from society.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	We often struggle with physical difficulties so for many autistics long COVID is a huge fear. The stress of politics and illness has made our anxiety worse. We also have a high sense of justice so bitterness has also been a side effect of feeling disliked and not cared for yet again.

<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Personally, I'm more socially isolated. My husband is military and they stopped all the wives groups during COVID. I haven't been able to rejoin and making friends post COVID is somehow more nightmarish than before. I like telehealth. Now when I'm ignored at least I'm at home in my pjs. Plus I don't have to deal with people. I just really wish I could make friends and that there were things to do. Lots of businesses shut down. As far as services go... what services? There are no services for adults. If they did exist they are so difficult to access that someone with a nervous system disability won't have to capacity or desire to obtain them which is a huge barrier to care.</p>
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Name	Jessica Bearden
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The most significant challenges in my work as a counselor include the self-injurious behavior that is a result of sensory processing issues
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The challenges are often getting school systems to make appropriate accommodations for co-occurring disorders. My experience with Alabama schools and mental health is that they do not have the proper training, understanding, and resources to meet the needs of autistic individuals
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	These challenges include communicating with autistic individual about their needs. Resources for alternative methods of communication would be helpful
What additional research is needed to help address co-occurring conditions for autistic people?	There is SO much research still needed. As a counselor, I see that autistic individuals have difficult processing traumatic events. What takes 3 months for neurotypical individuals takes double for neurodivergent. There needs to be mental health research regarding how to speed that up. Needs to be reseath in schools about their methods of addressing behavioral concerns. There needs to be research for families and what resources they need.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More insurance coverage. Insurance companies often will not reimburse for autism because it is not curable. However, there are ongoing needs that can be addressed with therapies. The lack of coverage restricts access to services... putting professionals in a bind to choose between steady, healthy income, and meeting the needs of the community. Alabama needs more support for families, more options for respite. The lack of community resources and access to care are causing chronic stress in families with autistic children... leading to chronic illness and burnout. Therefore, costing more money long term for insurance companies.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Jessica Blackmon, Just an ADHD dyslexic autistic girl
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I deal with problems with sleeping racing thoughts during nights where I'm so exhausted that I cannot fall asleep though.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I suffer from depression, anxiety, attention-deficit hyperactivity disorder, aggressive, and suicidality
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I have ADHD and severely dyslexic I would love to take the time to be able to take classes to help me learn how to read and write so that way I can actually go back to school actually learn something that's not a trade skill, but unfortunately for my age I'm too old to get any assistance so I'm stuck working to pay bills and I do not have the time nor the money to afford such education I grew up it is School District that if you were failing any of your classes instead of finding out what was the matter with that student they would stick you in a autistic class where I fell behind multiple years because of it and yet I never had an issue with anything else besides my reading and writing so now I am stuck in a manual labor job and barely able to make it. So yeah adults that have ADHD and dyslexia on the autism spectrum we need help desperately none of us want to be in the position that we are we can do so much more in this world but it's not made to accommodate us so we are just left behind. PS please don't mind the grammar this is being written through speak to text on my phone.
What additional research is needed to help address co-occurring conditions for autistic people?	The correlation between families and their conditions along with the studies with the long psychological trauma that occurs in children to adulthood as well as the adults that are currently along with this is a huge can of worms honestly there's so much that it needs to be done that I can't fit in this message.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Yes there is a ton that needs to be done for autistic ADHD dyslexic adults. (1) Due to my financial problems of struggling I can't work and go to school at the same time it would not be possible to pay my bills and to do school it will take me too long for school and I would fail it because it takes me much longer to intake what I need to learn. (2) the expense to get a specialized tutor to help me with my reading and writing skills is the cost of rent at this current time of this questionnaire along with every tutor that I spoke to they want me because I'm severely dyslexic to be there 3 days out of the week for 7 hours I would not be able to work enough to pay my own bills and this tutor it would be impossible. I have much more to say but I can't fit it in your limit of characters
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I can only speak for myself on this one and only with some limited knowledge of what others told me. For many of us that suffer with executive dysfunction disorder from our ADHD are places became tombs of our own messes as much as we tried we got to clean a little bit took care of things

	<p>that we can take care of but there was not much to motivate us and so with many of the issues that come with ADHD and then coupled that with the autism we self-sabotage ourselves mentally I continuously talk down about myself beat myself up mentally because it made me feel entirely worthless that I could not achieve the simplest tasks with so much time that I am stuck with along with not being able to being the ability to learn a new skill due to my severe dyslexia going online to read and learn a new skill was more challenging and stressful it got to a point where I threw my own work desk across the room and had a nervous breakdown so yeah that's my story and quite similar to several others that have told me there's.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>We definitely reduce social interaction and obligations due to the fact that that was something that helped motivate me to be on time and get things done because I had to physically be there in the breakdown of routine was devastating because my loss of time became so bad that several days I wouldn't realize that it could be 8:00 at night and yet it was only one in the afternoon to me there is nights that I would stay up until 4:00 in the morning because I didn't realize that it was 4:00 in the morning for me and my brain even though I woke up at 9:00 in the morning it was still 7:00 in the afternoon so now I have days where I would wake up before my alarm for work just because I'm terrified that I might miss work and get in trouble I have to set an alarm for even more things than I did before so I can have some reassurance that I am not feeling at my job because I can't afford to lose it.</p>

Name	Jessica Iverson
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Even more time home alone and resting than participating in society. Communicating with healthcare staff to get needed care, including diagnosis and treatment. more brain fog from chronic pain and fatigue, symptoms of many if not most physical health conditions.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Regular treatments and therapy are not as helpful or accessible for people with autism. It is logical that someone with autism or other condition would also experience depression and anxiety due to social stigma and bullying. And doctors over diagnosis anxiety and depression instead of investigating whether autism and/or ADHD may be the source of difficulties especially in women. They tend to want to prescribe antidepressants and anti-anxiety medications instead of stimulants that are proven to help ADHD which would then help the depression and anxiety. The medication shortages have caused ADHD people to quit or be fired from schools and jobs due to lack of medication.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	People with higher support needs are often labeled as having an intellectual disability simply because of their lacking communication skills.
What additional research is needed to help address co-occurring conditions for autistic people?	What therapies and medications help people cope with being autistic and other co-occurring conditions without forcing them to mask their symptoms. Why some autistic people aren't able to mask their symptoms even if they wish to. Diagnostic assessments that are more accurate. How abilities and needs change over the lifespan.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	If mental health therapists and psychiatrists screened for autism and ADHD symptoms and were better trained at recognizing it in patients. Insurance coverage of assessments and therapy options for all ages. More sensory friendly doctors offices and hospitals. More therapists that focus on addressing the needs of the autistic person as opposed to conforming to make things easier for family, school, and society. If someone is diagnosed with autism, all family members should be encouraged to be screened as well. more accountability and higher paid, better trained staff at schools and residential facilities for people with higher needs. More education around and access to augmentative and alternative communication for all autistic people especially higher support needs and nonverbal autistics.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	COVID affected those with physical health conditions that occur with autism, such as long term effects on mental clarity, migraines, respiratory and digestive systems. It also greatly impacted people with mental health conditions, either worsening pre-existing conditions or triggering new ones including agoraphobia, anxiety, depression, and OCD.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services,	COVID-19 caused increased isolation and worsened mental health in autistic people more than the average person especially due to difficulty adapting and lack of access to supports, consistent schedule, access to healthcare, and medication shortages.

increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Jessica Mullaney
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Joint hypermobility (i.e. Hypermobility Spectrum Disorder or Ehlers Danlos Syndrome) occurs more frequently in individuals with ASD than in the general population. The chronic pain and mobility limitations caused by these conditions can negatively impact mental health in individuals with ASD, as well as their ability to access needed supports in the community.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	A lack of understanding in how to accommodate these challenges in the workplace, leading to unemployment or underemployment of individuals with ASD
What additional research is needed to help address co-occurring conditions for autistic people?	A greater understanding of the links between ASD and conditions like joint hypermobility leading to better treatment options would be helpful, but the biggest issue is lack of awareness among healthcare providers currently. (It's great to do research, but if that information is not widely known by the people that individuals with ASD are seeking help from in a healthcare setting, then it doesn't do much good from a practical standpoint.)
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Patient-provider interactions could be helped simply by a greater awareness of co-occurring issues on the part of healthcare providers. I went undiagnosed with Hypermobility Spectrum Disorder for 38 years because healthcare professionals incorrectly assumed that my complaints were psychosomatic, due to my co-occurring ASB and anxiety diagnoses. Ultimately, I had to learn about this condition on my own and ask to be evaluated for it, rather than any physician identifying it, largely because they failed to take my complaints seriously. This led to significant medical trauma and needless suffering for many years. Sadly, I have heard similar stories from others with these conditions. We can do better.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	A high percentage of those in the Covid-cautious community are neurodiverse and/or diagnosed with ASD. When the medical community decided to "move on" even though Covid has not yet moved on and abandoned Covid precautions like masking in hospital and office settings, many Covid-cautious individuals, including those with ASD, were forced to start forgoing medical care whenever possible for our own safety. The long-term implications of forgoing preventative care can't be good, so the failure of the medical community represented by them giving up on Covid precautions is highly unfortunate, harmful and, frankly, ableist.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on	See response to previous question. The medical community's decision to abandon Covid precautions has led to some autistic people being unable to access needed care. We can do better.

physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

Name	Jessica Phillips
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My son is almost five and around 2/3 he was struggling with waking up 1am and want to start his day. Along with food diversions and will only eat limited food along with temper tantrums that can last two mins to thirty.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	He has a lot of aggression due to not being able to communicate his needs
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	He has social and emotional delay he has a hard time with his peers of his age. He tends to not want to be in unfamiliar places such as grandmothers house
What additional research is needed to help address co-occurring conditions for autistic people?	We need more people to provide services to special needs kids in sussex county.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	My son has regressed in what he has learned when time has been off and unable to receive support

Name	Jessica Smith
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	SPD (sensory Processing Disorder), Gastrointestinal disorders (sometimes caused by the trauma we get being autistic living in a world not designed for us) theres some research that being autistic effects us all the way down to how we breath, we could be breathing wrong a not even know it.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	BPD, CPTSD, PTSD, PTED, anxiety, depression, adhd. there are so many its almost hard to not list almost everything. phobias, fears, OCD, bipolar, (yes i have all) eating disorders is HUGE, they are all horrible. theres not really one is worse than the other they all play a huge role in how it effects us.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	learning disabilities. some people dont understand the differences between autism and learning disabiliteis and will treat us as if we are trying to cause problems when we just learn/ process/ understand not just diffrently but at a diffrent time line. For me it takes me a lot longer to grasp concepts but once i get it i get it. aullistics and neurotypicals loose thier [profanity redacted] if i eed longer than the time THEY would need to understand something. and then say we have beveral problems just cause they are projecting how they would understand something onto someone else. like mainly its how others react to our learning disability/ intellectual disabilities than it actually being a problem. as well as communication. autistic/ neurodivergent peole might use a form of communication called anecdotal communication. neurotypicals do not use this style of communication and accuse us of 'one upping' them in conversation when we are just trying to prove we relate, understnad, and empathixe and sympathize with thier story. but we are forced to not use that style of communication cause THEY feel uncomfterbul with it and try and change us to lacate thier feelings of uncomfternility instead of actually understanding diffrent communication styles exist.
What additional research is needed to help address co-occurring conditions for autistic people?	Listen to autistic researchers. stop going to aullistics for understanding us. They will never be able to ask the right quetions cause they do not have our disability(ies) they do not struggle with what we striggle with, they do not understand it the way we do. and they are not only truamatizing us but making living in this world so much harder. listen to autistic researchers, realize that one way is not always the right way
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Have autistics and neurodivergents be the main staff for autistic and neurodivergents in any setting. if you dont have the neurotype, disability, ect then they should not be helping us learn how to handle it. for the love of all things cute and fluffy END ABA or at least staff it with people who are actually trained and have overcome these issues so we can actually help autistic children navigate this world. instead of putting people in there that might never comprehend our neurotype thus forcing us t behave in ways they see as appropriate/normal instead of the children learning proper ways to handle their disability. A lot of autistic/ neurodivergents view allistics/ neurotypicals the same way they view us. strange, weird, extremely rude and struggle with the concept of empathy.

<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>i just like not always having to go in person. I wish there were more text services so i didn't have to call in or talk over skype (its strange and an invasion of privacy) i also dont like being precieved so having to be on camera, without a script, is horrid. there should be more remote work, more work done from home. ike no one really needs to be in the office and going to the office having to deal with a toxic work environment is not healthy for anyone. most if not all jobs can really be done from home and forcing us to go back into work is a living hell and causes a lot of issues. also school can be done from home as well, i get doing a test on site, but school work. like i learn better on my own anyway. i like having a teacher there for questions but id rather self study than listen to a teacher drone on for hours. plus student to teacher ratio is always off so in a classroom theres no time to ask questions and we usually get made fun of if we do, so id rather just type it to my teacher and get help that way then when they answer my question go back to independent study.</p>

Name	jewel brobst
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	depends on the day. (allergies can play a big role in some of the things i experience and how my body developed in incubation and growing up) but from say a scale on 1 (low) to 10(high) they tend to be around a 5 or 6.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	getting out of bed somedays. being able to calm my mind enough to sleep, the aggressive or self injurious behaviors for me happen during melt downs (that i have made categories for based on how they affect the people around me mostly but also how long the recovery time and how long / bad they normally are. these behaviors tend to happen in the 3s and 4s (higher ones) the suicidality is off and on with how bad the depression can get, very bad after bad melt downs (often caused by conflict) and i have to be able to bring myself back up from that low point and say their are people on this planet that still need me. depression & anxiety (same scale as before) from 1 to 10, lately is around a 4 or 5 adhd tends to be around that 8-10 (contributes a bit to the anxiety as well)
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	when i was doing in person schools. the fact not everyone believed I had my adhd, autism, and other learning disabilities. having many of my teachers not believe me meant that i wouldn't always get the accommodations that were in my iep or get new ones added. (yes i know illegal they still did it) i have 2 (both very similar) which put back my math and reading (what the state tests us for) which almost very easily could have put me back a few years in my learning. communication which is another thing i personally struggle with, effected my social life in school. having a small group of friends was better for me but we sometimes had a hard time understanding each other due to us all being neurodivergent and in diffrent grades. having friends in diffrent grades and not being able to make friends with those in a younger grade then me ment my friend group kept getting smaller. as well as having communication problems as in but not limited to: not understanding socail situations, social cues, hints, sarcasm, joking, body language, you get the point. having these problems makes it hard for me to understand and socialize with people not just my own age but people older and younger then me. more so if they dont understand why i stim, repeat words, figit, cant stand still, relate a story back so they know i understand.
What additional research is needed to help address co-occurring conditions for autistic people?	understanding that it may look like 1 person has 20 problems but 15 of those relate back to autism. understanding that as a autstic(spelled the way i normally spell it. idk why it says its wrong sorry) person you may have to get people to understand that what you have isnt just autism. in my 9th grade health class that was 1 semester long (half of a school year) we learned about depression, anxiety, some other common mental health problems, drugs. i feel like autism and adhd and some of the co occurring conditions should be added to that due to a kid might go their whole life thinking their just a bit weird and geitting bullied and having no idea why and never find out their autstic unless they go online or find someone who knows they are and relates to that. just make autism and its co occurring conditions normilized please

<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>maybe suggest to more insurance companies to cover tests. make the accessibility to services more known, like what we can get what we cant, what is around.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>both good AND bad. bad because during it i couldn't socialize with the friends i had made. (lots of ties that i NEEDED broke.) cant function as well as i could before. (basically i hid everything that made me autistic and after covid i couldn't shove it back into that bag.) good things are that many of my local stores do online shipping, and curb side pick ups now. meaning i dont have to wear sunglasses and earbuds when going in stores to HELP dull out the bad sensory (bright lights, crowds of people, and louds sounds msotly) and possibilty get asked why i need all of this. (or pay for sunglasses that have my prescription because i need glasses) so over all, things came out decently well, my mental health suffered like i seen alot of peoples mental health suffered. (and yes this goes for alot of my co occurring cuz they are all tied together)</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>we stopped wearing masks. i dont care i kept getting myself sick. i didnt have to express my thoughts or feelings on my face. now i have to AGAIN its annoying. the incress remote school given i got into the right one isn't fully negative. showed me their were other options i could do. for a long time i couldn't see my friends, even after the "dust settled" due to their being a stigma around having flu or covid like syptoms. (which i have year around due to allergies)</p>

Name	Jill Escher, National Council on Severe Autism
Demographic	Family member of an autistic individual; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Many in our severe/profound autism population suffer physical pathologies that can severely compromise well-being, to the point of being fatal. These include catatonia, epilepsy and seizures, gastrointestinal distress, insomnia and sleeplessness, and sensory overload. These pathologies can be ruinous to quality of life for the individual and family. They cause suffering and often, premature death.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	In our severe/profound autism population, behavioral pathologies are pervasive and can severely compromise well-being, to the point of being fatal. These include aggression, self-injury, property destruction, pica, and elopement. Aside from death, common consequences include bruises, lacerations, scarring, broken bones, ripping out of hair, and skin infections to both the afflicted individuals and their caregivers. Repeated self-injury can cause detached retinas, cauliflower ears, and traumatic brain injury. Pica can cause our children to ingest lightbulbs, rocks, toys, soap and countless other inedible objects. These are more than "challenges," they are lethal or traumatic injuries that often require emergency medical treatments, surgeries and complicated, costly hospital stays. Not only are these behaviors traumatic for the individual, the family, educators and caregivers, they often result in the need for emergency medical treatment, crisis and inpatient care, and residential placement. This imposes enormous costs on families and care systems. Reducing the frequency and intensity of these pathologies should be a preeminent goal for autism treatment and research, as they can result in death or further serious disability.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	In our severe/profound autism population, autism is in part *defined* by severe functional and communication impairment, so it is unclear why the NIMH considers these to be "co-occurring" conditions. Our population's functionality and independence is severely compromised by pervasive communication impairments, typically involving no or minimal language, and cognitive impairments so severe that they prevent any chance for independent living or meaningful employment.
What additional research is needed to help address co-occurring conditions for autistic people?	A top research priority for our severe/profound autism population is the alleviation of distressing and too-often fatal behaviors of aggression, self-injury, property destruction, pica, and elopement. There is a desperate need for more efficacious medical and behavioral treatments, and of course more understanding of routes for prevention. We need more research on: psychiatric medications; electro-convulsive therapy; other brain-activity modifying therapeutics such as TMS; and behavioral/sensory approaches. Much more emphasis must be placed on the needs of adults who often lack access to appropriate care and whose dangerous behaviors cause enormous burdens to families and care providers.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance, both private and public, should cover both outpatient and inpatient care for behaviors associated with Profound Autism. A new insurance code should be created to correspond with these clinical impairments (eg, aggression, self-injury, pica, elopement, property destruction), and treatments must be recognized as medically necessary under mental health parity. With urgency we must foster a much larger and more robust network of care providers in all states to address the care needs of this rapidly growing population. In addition, many suffering with severe

	<p>and profound autism require a therapeutic model of long-term residential living with onsite or collaborative psychiatric and medical care. Medicaid and other funding should directly and realistically address the needs of those suffering with the most severe forms of autism.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>The Covid shutdowns have had a lasting devastating impact on programs serving individuals with severe and profound autism. Many programs, particularly those serving high-needs adults, have shuttered, leaving many adults almost completely isolated with no access to day habilitation or community engagement. We also believe that the federal government should take action to facilitate the use of tele-health across state lines. At this time, many regions are not served by autism specialists and their only hope for reasonable treatment access is through tele-health.</p>

Name	Jill Ide, University of Washington Autism Center
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	for my son and most of the people I serve, it is sensory challenges, followed closely by sleep disturbances, and then gastro disorders.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	communication disabilities
What additional research is needed to help address co-occurring conditions for autistic people?	unsure
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	service system issues
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	reduced in-person social interactions and obligations

Name	Jim MacNaughton, parent
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My son has a high level of anxiety in part due to his life experiences through ASD and the world around him. He is constantly learning (and re-learning) the unwritten social rules.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	For our son, it is definitely anxiety, which makes it harder for him to interact with others. He also has dyspraxia and ADD.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	communication - his ASD and dyspraxia creates a frustration with him, which creates behavioral concerns. He often communicates through his behavior.
What additional research is needed to help address co-occurring conditions for autistic people?	anxiety reduction.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Schools moving to virtual model created a large socialization learning loss in our son.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Negative: Disruption in social learning via the virtual model.

Name	Jimee
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory & motor challenges. Sleep disturbances. Additionally UTIs and incontinence due to interoception difficulties. **Dental issues from executive functions struggles.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD (all types) Dyslexia Especially in girls: depression & anxiety from misdiagnosis and/or from internalizing struggles
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Especially in girls: Speech Impairment can be only diagnosis given by public schools if any giving young girls access to special education services...but not all that they need. Dyslexia (can be compensated at young ages at the expenses of individual) Personally I was *lucky* to get an ADHD inattentive type diagnosis in the 90's. My IEP also supported my gross and fine motor delays.
What additional research is needed to help address co-occurring conditions for autistic people?	Research in AFABs!!!! Continuing research on how ASD presents differently in all individuals! The DSM-5 doesn't support women or other minorities... More training for providers on MASKING and compensating (which can be in boys as well as girls)
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Access to Providers that are well trained in the research surrounding Autism in AFAB & minorities! So they aren't given inaccurate diagnosis. My late grand mother was treated for Bipolar Depression when she was Autistic!! This would have alleviated so many of her depressive symptoms!!
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Thankful for telehealth. This makes mental health care more accessible and accommodating. Also the ability to work from home. This helps so many autistic & adhd individuals do quality work and lesson risk of overstimulation and burnout
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Postive: Remote work Telehealth Online scheduling Reduced unnesesary social obligations No contact deliveries Negative: Denied access to safe and prefered or established providers due to covid scheduling

Name	Joanna
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Poor sleep , general crippling anxiety , poor diet , sensory issues such as struggles bathing and hygiene , changing clothes , brushing teeth . My boy has PDA which should have its own recognised profile under the ASD diagnosis as it has its own set of traits , these traits to manage need different strategies than an individual with ASD alone . Professionals are not aware of PDA even in SEN schools which makes our kids unable to manage in mainstream or SEN schools and parents have to home Ed instead .
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Generalised anxiety , extreme responses to frustration due to ADHD , makes him aggressive . His PDA and anxiety makes it hard for him to leave the house and experience new things . Poor self esteem , extremely attached to care givers . When overwhelmed it can take a long time to calm down and due to the panic attack he is exhausted the day after . His nervous system disorder (pda) makes every day asks turn into a fight / flight response . Managing this is extremely tricky as other ways of parenting , rewards , punishments do not work but upset him more .
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication , speech delay , poor understanding of how he feels , very black and white understanding of emotions which makes it extremely difficult to understand how he's feeling and for us to understand how he is feeling . Can't have a 'normal ' conversation 2 way as he only talks about what he wants too and doesn't listen to others opinions . Interrupts , talks over people . Also selective mutism due to his anxiety and social difficulties. PDA means asking direct questions turn into a demand and his nervous system gets triggered .
What additional research is needed to help address co-occurring conditions for autistic people?	PDA needs to be recognised and diagnosed alongside the autistic assessment . It is a specific set of traits and relatively easy to spot from a young age . It would help parents get support and SEN schools to use a different approach to these kids . Autistic kids without pda have a different set of needs , PDA needs to be identified and recognised to enable our kids to receive actual support and access SEN schools they have an entirely different approach to allow our kids to thrive . Parents must stop being blamed for professionals not understanding their kids needs . Parents have to research and understand their kids themselves in order to get any kind of support . As PDA isn't recognised parents receive damaging advise on how to handle these kids that absolutely doesn't work . The system needs to recognise that pda is very real and unlike other profiles . Parents and kids need support not blame . Education for professionals is key , CAMHS needs to identify and diagnose PDA profile .
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Faster assessment times for kids with a diagnosis already of ADHD or ASD so parents don't have to struggle . More thorough OT sensory assessment through NHS so parents don't have to pay private to access their kids sensory needs . Access or an option of insurance to access private therapies , more access to play therapists . For paediatrics to recognise anxiety in children and to help parents to help their children without assuming the parents are to blame . autistic kids need more therapy options in general .
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	My child loved Covid as everywhere was quiet so he felt more comfortable accessing the outside world . For others I understand Covid will have had a negative impact effecting their daily/ weekly routines and they will have felt trapped .
What lasting positive or negative impacts have societal changes due to	Assessments through OT on NHS were done via phone call and the outcome was underwhelming and very poor . May aswell have not bothered .

the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

Name	Joanne Miller
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Professionals often do not see beyond the autism diagnosis to consider any other medical condition/issue that the person may be experiencing. Professionals often attribute any physical health condition to "autism" and do not spend the time or effort to listen to what is occurring.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Professionals do not see beyond the autism label. They attribute any mental health condition to being part of the autism diagnosis, instead of looking at the person from a holistic viewpoint to consider all variables that may be interacting for the person.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	If a person with autism experiences issues with expressing themselves/is non-verbal, people assume they aren't intelligent, which is a false assumption, and write off anything they might say/do as "being a part of the autism". Many, many people with autism might not communicate verbally, but do use other forms of communication to relate to others. People who are not skilled in this or don't take the time to learn how the person communicates is not listening to the person.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Training on all facets of autism - from behavioral challenges, to communication methods, to simply "how do I interact with this person who has a diagnosis of autism", because if I've only met one person with autism, I've only met one person with autism. Insurance coverage needs to be beefed up to cover trainings and therapies for folks, and there need to be more providers who will serve the folks with the most profound disabilities, those who do require 24/7 care for the rest of their lives. We don't have enough qualified people for that very urgent need.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Joanne Van Hoosear
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory and motor challenges: sensory challenges that impact movement and balance, interoception. POTS: Dizziness, heat sensitivity, impact on self care when standing in shower is so exhausting. Ehlers-Danlos: Joint pain and needing joint replacement at a young age
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Pathological demand avoidance: this presentation of autism is not well understood and not a recognized diagnosis in the US. Especially given that typical approaches that are effective for many autistic folks can actually worsen PDA responses, this is an important area for study.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage for supports other than ABA.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	A positive for autistic people is the greater availability of remote work, schooling, health care, etc.

Name	Jobless autistic
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	GERD, gastroparesis, insomnia, POTS, epilepsy/ photosensitivity, sensitivity to stimuli, lack of balance, difficulty reading and writing, polyneuropathy, costochondritis/ tietze syndrome, slipping rib.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression, anxiety, bipolar type 2, BPD, ADHD, PTSD, C-PTSD.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Difficulties in communication, learning disabilities, uncontrollable extreme emotions, sensory struggles like overload or sensory seeking, stress induced seizures, constant burnout
What additional research is needed to help address co-occurring conditions for autistic people?	In general I don't think autism is researched enough, but I'd love to see research into the full capabilities of autistic people in childcare so we can adopt since we're already allowed to have our own kids by childbirth. I'd also like research into helping us at jobs and in the education system so we can get support because 60% of us are unemployed including me. I apply everywhere and can't get a job because I'm disabled and autistic.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	My social anxiety has gotten worse, I'm slightly agoraphobic now, I'm suspicious of everyone because it's like a long game of clue since I'm immunocompromised and therefore almost constantly sick, I'm mad at people for not wearing masks, I'm getting less exercise because of it and my physical health is suffering, and my depression is up because I'm trapped inside or else I'll get sick even with the necessary precautions
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	My final year of high school was disrupted, and so was my graduation. I had so many plans that year that never got a do-over because of covid-19 and it was really hard for me because that was my plan/ schedule! I also unmasked my autism while at home and now I struggle to put the mask back on. In some ways I don't even think I can mask again.

Name	Jody McCormick
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The most significant challenges I face is sensory overload. Being in a crowded space where there are a lot of different things happening around me often requires intense focus to be able to do the simplest of things. For example, when checking out at the grocery store all of the "boop"s of the scanners around me, the mom in line behind me trying to keep her kids from touching all the candy on display, and the facial expressions of the cashier... I notice all of them and more along with the thoughts they all produce in me. Why that *specific* "boop" sound? It certainly cuts through the noise. I'm sure that's why. Wow, being that mom right now looks hard. I remember being a kid in line and wanting some reward for not eating the blackberries I saw back there. I wonder what the cashier looks so aloof to it all. She's underpaid. The economy will probably get better eventually... All of the sights and sounds around me produce full-fledged, in-depth, internal discussions that I have no control over. My brain cannot cut the unnecessary connections between neurons as easily as others'. Getting through all of that sensory information to realize that the cashier is now staring at me because I haven't pressed "The Green Button" on the card reader can be very, very difficult.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	All of the above. From my family and friends to my bosses and coworkers, it can be extremely difficult to communicate effectively with them and feel like I'm being correctly understood. It's isolating. I'm not anti-social because I don't want to be known. I'm anti-social because I need to be known. I'm just usually the only one can. But I'm still human and still need real connections with people. Not being able to really have that without hiding myself by mirroring the speech cadences and, as closely as I can, the thought patterns of who I'm interacting with so that I can even somewhat be heard -- is tiring. It's so easy to get depressed and to feel so very alone when you have to constantly adapt yourself like that. Any excitement from getting to know someone or being in front of people can quickly turn to anxiety when you know that sooner or later something you will say or do is not going to mean what you thought it would to them, because you simply do not have the same toolkit for the way you cognitively process information. The consistency and pervasiveness of that experience is, well, depressing.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication disabilities. Hands down. I have learned that no matter how articulate I am I can never distill what is in my mind into words. What I see through the lens of my autistic brain almost never correlates directly with any word or phrase in my vocabulary. So I just try to get as close as I can. Imagine you're on the 20th floor of a building overlooking a crowded street below you. In the room with you are a 24in by 48in canvas, one fine-point brush, various paints in small bottles, and one person you know. The person, unable to come to the window, asks you, simply "what is going on out there?". You get one color for every word or phrase you know and as many strokes of your fine-point brush as the person with you has patience -- and they get to ask you clarifying questions while they watch you painting. The only thing you're allowed to say to them is "that's not really what I meant" and must adjust your painting accordingly to answer any questions they have about it. That. It's like that. Over time, you get better at it, but still. Communicating is hard.
What additional research is needed to help address co-occurring conditions for autistic people?	With the proper accommodations and support, autistic people can add truly incredible value to organizational goals. However, the typical expectations set in a working environment hinder us from being able to perform at our best. I have worked in many industries and by far the most accommodating and

	<p>supportive working environment I've experienced is in the software engineering space. Companies in that space tend to be much more flexible with time off, more understanding of the need for autonomy, More research is needed at a national level to assess what accommodations and what strategies are effective and what are harmful to people with autism in the working environment -- as well as the real impact to GDP provided by investing in effective accommodation and support strategies for people wherever they lie on the autism spectrum.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>* Regulations to reduce sensory overload from advertisements, especially when advertising to children * Regulations to effectively eliminate any practice employed by producers of any form of digital media (i.e. video games, applications, digital devices, music, video, etc.) that are specifically marketed to children, of utilizing the mental or cognitive disabilities (including, but not limited to, those that are co-occurring with autism) for the purpose of monetary gain. * Federal protections for taking "mental health" days off of work to protect the mental health of employees diagnosed with autism * Metal health service coverage should be considered as necessary care (both as preventative care and as treatment) and be required to be covered by both private and publicly funded insurance providers. * Educational reform to better address the social and interpersonal challenges faced by children on the autism spectrum to provide equitable access to education for all children in the classroom.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	

Name	joe valenti, parent advocate
Demographic	Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The biggest challenge for those in this category is the behavior challenges which occur. The staff training and education in the needs of those with co-occurring conditions is lacking with community providers.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Attention-deficit hyperactivity, self-injurious behavior, hurting of others. Our state has an interdisciplinary team which coordinates care which is not available in the community.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	all of the above especially for the most profound. Behavior.
What additional research is needed to help address co-occurring conditions for autistic people?	I believe CMS needs to understand one size does not fit all. We seem to think about autism with high functioning individuals. The individuals at the higher level of the spectrum have much different needs. More feedback from parents/ guardians
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	education and training. And then appropriate funding from the state and federal Medicaid.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	In some cases, they have become more isolated. Less social
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I believe individuals have become more isolated. I also feel it highlighted the significant staff shortages in the provider area.

Name	John
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	In addition to ASD, I also have ADHD, and find it very difficult to fall asleep & stay asleep, which result in lower energy and emotional regulation during the day.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have late-diagnosed (aged 49 years) ADHD & Autism, and significant monopolar depression. In the past, I have had significant challenges with executive function & emotional regulation, which I know has caused trauma for both of my children. Since my diagnosis, I now have the tools to manage my emotions, and am working to heal both my trauma, and that of my kids.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The ADHD, that I did not know I had, significantly impacted my education. Had I been diagnosed & accommodated, I suspect I would have performed significantly higher in school, and may have pursued a more advanced degree & career path.
What additional research is needed to help address co-occurring conditions for autistic people?	How businesses can better accommodate & include/reduce stigmatization of ADHD-Autistics in the workplace.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Protection from punishment in school & at work by non-autistics that do not understand the difficulties in communication faced by autistics. I have lost multiple jobs/promotions because bosses did not/could not understand my communication needs & style
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Reduced in-person requirements & fewer large meetings have resulted in a much lower stress level for me. Also, the emerging community of ADHD-Autistics that has grown on TikTok/Instagram would not have exploded without the impacts of the pandemic. There so many of us undiagnosed autistics who benefited from the additional time & space at home to genuinely evaluate ourselves & our interactions with others, leading to discovery of our condition, and allowing us to seek diagnosis & therapy. Without the pandemic, I would probably still be a burned out underperformer at work and in my relationships.

Name	John Collins, Mass General
Demographic	Family member of an autistic individual; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Finding clinicians experienced with profound autism, non-verbal. Coordinating care. Lack of research available on patients with profound autism with co-occurring health conditions. Lack of inclusion for profound autism people on public committees. Their challenges make participation nearly impossible, so they are ignored.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Getting through a day without injury. Having access to providers with experience with people with profound autism. Very few available. Lack of research on the underlying causes for profound autism and co-occurring mental health conditions.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Daily life!!! Fundamental safety issues, all activities require support and supervision. Where is the research to help develop more technology to make daily life doable for non-verbal people with profound autism?
What additional research is needed to help address co-occurring conditions for autistic people?	First recognize that people with profound autism are NOT represented in research! Focus on this population that needs the most help...but cannot ask for it. What causes autism and GI and autoimmune medical conditions in people with profound autism? Why do they have more co-occurring conditions and that develop earlier in life? Why do states have such poor data on autism, housing for people with autism, medical care use? We need better data in order to plan/provide adequate medical care, housing, transportation, work/volunteer opportunities.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Everything for people with severe or profound autism needs to be improved. This population is NOT represented by self advocates, and does not have a voice in research or policy. People with profound autism have been ignored and as a result none of their needs are being met in a systemic way in any state. National data do not reflect this group. This is an urgent request to include people with profound autism in all future research considerations.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Fewer opportunities for people with profound autism to be in the community. Insufficient staff has closed day programs and closed group homes, fewer jobs/volunteer sites. Families continue to be required to be home to supervise without support services. Need better supports for families, career paths for workers, training for staff and clinical staff working with people with profound autism, more telehealth, online healthy programs, alternative options for exercise. Have state universities open gyms and recreation facilities to these state residents for free use as part of a healthy living protocol.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal	Need research on what lasting impacts these changes have had! Families of people with profound autism have experienced loss of income, restriction of activities/movement as they care for their loved one at home due to loss of services and programs. Research on families, higher rates of mental health

changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

issues for family members. Research on profound autism is urgently needed to answer all the questions asked in this request for comments.

Name	John Saito, Oregon Commission on Autism; Washington County Developmental Disabilities Advisory Council; Oregon Home Care Commission
Demographic	Family member of an autistic individual; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbances and sensory challenges can interfere with and even prevent autistic people from engaging in valuable therapy sessions, medical treatment appointments, and day support activities intended to address their other diagnoses including autism. Losing eligibility for these services and having to constantly delay and reschedule them effectively reduces their efficacy.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression, anxiety, and unsafe behaviors all interfere with, delay or prevent use of valuable therapies and treatments, many of which are intended specifically to help alleviate these very conditions. Worse, many autism / IDD service providers are incapable, unwilling, and not required by law to accept autistic people with aggressive or self-injurious behaviors into their Medicaid-funded programs. This leaves the autistic individual insulated, and in greater danger of neglect or worse once their primary caregivers (parents) die.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	School and transition programs administered under IDEA / FAPE are not equipped to service people with severe / profound autism given their high prevalence of learning, intellectual, and other disabilities (usually equally severe). The result is an 18 year daytime respite program with very little value-add in key areas such as basic communication, social interaction, personal safety, and fundamental activities of daily living (ADL) skills development. Once such an individual ages out of IDEA/FAPE, adult programs for the underserved individual are all but nonexistent. In other words, I/DD social services are scarcest for those with the most significant needs.
What additional research is needed to help address co-occurring conditions for autistic people?	What are the drivers that result in the disproportionate amount of co-occurring diagnoses for those with a profound (level 3) autism diagnosis? What therapies and medications should be required mandatory coverage in Medicaid and private health plans for those with an autism diagnosis, given the higher likelihood of certain co-occurring conditions? What social service program enhancements (via Medicaid Waiver / HCBS) should be made to better address the comorbidities that occur most commonly with autism (especially those with severe / profound autism)?
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Medicaid Waiver funding should be contingent on requiring a state and its counties to guarantee accessible and appropriate capacity to residential care facilities, adult day programs (enrichment, recreational and employment), and in-home caregiver programs that must accept and support autistic people with co-occurring mental health and behavioral control issues such as self injury and aggression.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to	

the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

Name	John Yacks Jr.
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The biggest challenge is communication and management. Dietarily speaking, it is incredibly problematic to break bad habits or even have a desire to change, because at our core hate change.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	For me, I was very dependent on my mother. I didn't feel comfortable with being around new people or even getting help. I felt I didn't want to say the wrong thing.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication and understanding. I there has to be an understanding that we need the care to be explained concretely.
What additional research is needed to help address co-occurring conditions for autistic people?	Further behavioral and mental health research could be done to see how issues and policies that were in place, like the pandemic, would be beneficial
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I think more consideration could be given to the fact that virtual visits and telehealth aren't the same as being in person. I have cases that I manage where the provider won't hear what my member has to say half the time.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I have PTSD from having to isolate. I have resentment in my heart for a government that deliberate turned a blind eye to how all this could have been avoided. I have no faith in anything that is being done at a federal level. Physically? I have had COVID 3 Times while being unvaccinated and vaccinated and I don't feel any different. I can still walk talk and breathe like it never happened.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I can't ever be the same. What semblance of normalcy I have now is really the only thing keeping me from destroying myself. It would wreck my soul to have to go through that again.

Name	Jonathan Fratz
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	As someone who could not speak when I was younger, it was difficult to explain to caregivers and medical professionals that I was having issues with sleeping and eating as well as facing sensory and motor challenges. I still struggle to this day with these issues, which have impacted my quality of life and my ability to be among my peers and community. I have co-occurring physical health conditions such as scoliosis and hypopituitarism. Some of the symptoms are fatigue and muscle weakness. It is difficult to get others to understand that when I am tired, it is not because I am being lazy or that due to my autism, I am not following social norms and behavior when in public. My physical health conditions are also overshadowed by my autism as I have difficulty explaining what I am feeling or having issues with, which can make my conditions worse or left untreated. It was a challenge for my family to find medical professionals who understood both autism and could treat co-occurring conditions.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	As an autistic youth with ADHD, I suffer from anxiety and depression. I receive support from a behavioral aide in school due to aggressive behaviors that I had in the past and my inability to initiate and complete tasks. Being autistic makes it difficult for me to express myself and my feelings. I still have difficulty being understood by mental health professionals in both the school and medical communities. My co-occurring mental health conditions are underestimated, and their symptoms are incorrectly associated with being autistic. It was a challenge for my family to find medical professionals who understood both autism and could treat co-occurring conditions.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I was nonverbal until the age of 6. Being nonverbal and autistic presented many challenges for myself and my family, as well as accessing and utilizing supports and services from the school and medical communities. It also made it difficult to be among my peers and to be understood, which only increased my anxiety and depression. I have auditory processing disorder among other conditions, which still makes it difficult for me to understand what is communicated to me, which further complicates the things that I can do and how I interact with everyone around me.
What additional research is needed to help address co-occurring conditions for autistic people?	There needs to be research in establishing better practices to address co-occurring conditions in autistic people, particularly children and youth in receiving diagnoses and accessing services, as well as establishing guidelines in how medical professionals serve autistic people by addressing those co-occurring conditions without placing their cause under the scope of autism.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Autism services and supports could be improved by providing more training to medical professionals in how to address co-occurring conditions for autistic people, improving accessibility of services and supports from medical professionals that already have training and expertise in providing care to autistic people with co-occurring conditions, and providing training to increase positive patient-provider interactions in which autistic people feel seen and heard when it comes to communicating their needs, concerns, symptoms, and treatments for their co-occurring conditions. As an autistic individual, I have experienced not having my symptoms being taken seriously because they were viewed as an extension of my autism and not my co-occurring condition.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	In the winter of 2021, I was infected with COVID and had to miss school for a month. As an autistic individual, I already had difficulty socializing with my peers, which was made even worse through the need to social distance and attend school via virtual learning. I was attending a new high school virtually

	<p>and being sick delayed my return to campus. This negatively impacted my mental health, increasing my anxiety and depression, and making me feel even more socially isolated. In addition, I suffer from asthma and other physical conditions that were also negatively affected by my having COVID. I feel that my mental health never really recovered from the impact that COVID made, during the lockdown and when I got sick. I did not have access to my supports and services during COVID, including physical access to my behavioral aide. I had to interact with them virtually, which did not really help. I have severe anxiety and high level of frustration. The pandemic only made my anxiety worse. I received virtual services from my school psychologist, along with support from my family and therapists at home, but it was an extremely difficult time for me.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Telehealth and access to virtual appointments have been some positive impacts that the pandemic had on the physical and mental health of autistic people. Unfortunately, a lot of people like me never recovered from the disruption to supports and services that occurred during the pandemic. I depended on those supports to be a part of my school and neighborhood community and their disruptions put me further behind, both socially and academically, compared to my neurotypical peers. The reduced in-person social interactions made me feel even more socially isolated and hampered my ability to develop my social skills, skills that I need to depend on to navigate my community as a youth and that I need to develop. My depression and anxiety increased, and I never returned to the levels that I was before the pandemic.</p>

Name	Jonni Jordyn
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I'm highly masking which delayed diagnosis of my gender dysphoria for decades. I think my educators recognized in the 60's that I had (at that time) Asperger's syndrome, but not my doctors. I also remained undiagnosed for Ehler's Danlose despite many dozens of sprains and a recommended operation to shorten some ligaments. My autism mostly manifested in positive traits, gifts, but I do suffer from sensory overload and lack many social skills like the ability to recognize non-verbal communications.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My therapist has not related my anxiety with my autism, but I started suffering migraines at age three (although my physicians never actually admitted they were migraines until age twelve. They told us children don't get migraines because they are related to adult pressures.) My migraines had two main triggers, mint, even just the smell of a candy cane, and anxiety. The day before every new school semester would come with a migraine. I learned on my own how to recuperate from them by age eight and nearly eliminated them by college (through relaxation techniques.)
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I had no learning disabilities, in fact, I had just the opposite. My teachers never advocated skipping me ahead due to my social issues (of which I was completely unaware) but they did send me up for specific classes like math, english and sciences. My gifts are in creativity and logic, which paved the way for music, acting, writing and computers, when they became publicly available.
What additional research is needed to help address co-occurring conditions for autistic people?	There are so many co-morbid overlaps. I think the relationship to ADHD is well recognized, but other overlaps with Ehlers Danlos (connective tissue) need more research. This connection can be important for medical treatments, for example, before I had braces installed on my teeth, I forewarned the orthodontist that she may see some differences and her whole office is amazed at how quickly my teeth moved into place. Treatment options could be modified if these relationships were better understood.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	First, remove the stigma related to autism. Having an official diagnosis can follow a person around and may even prevent them from moving to some countries. Second, training to recognize that not all autism patients are non-verbal. Highly masking individuals with genius IQ's may also need mental health care to diagnose co-morbid conditions earlier in life.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I'm unaware that covid-19 had specific connections to autism or mental health. I've had two cases that were so mild, I had NONE of the classic symptoms (I had all my vaccinations.) I'm seeing my therapist today and will set her on the hunt to learn about these.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Although I had been noticing personal traits that were on lists of autism symptoms for decades, the quarantine period freed me to start questioning these with my therapist. As a well compensated technologist, I was able to perform all my duties remotely. I never suffered the shut-in symptoms that others have, possibly because I'm less social, in which case autism was a boon.

Name	gorja harper schall, OHSU lend
Demographic	Autistic individual; Researcher; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Schizophrenia anxiety
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Schizophrenia anxiety self injuring
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Development disability
What additional research is needed to help address co-occurring conditions for autistic people?	Housing group homes
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Housing group homes institutions
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Anxiety getting out
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Loneliness

Name	Josephine Weber
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Attending to task. My sons OCD like tendencies interrupt the smallest tasks. This makes getting through the school day very hard and increases anxiety.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The anxieties that come along with ASD often result in impulsive behaviors that make it difficult to interact in the community and classroom. For example, an impulsive behavior my son has when upset is grabbing hair or flopping to the floor.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication. My son has words but we consider him non verbal bc he is non conversational. He doesnt comprehend things bc he is severly cognitively delayed and also has Apraxia. This means he struggles to interact w peers and adults. He spends most time alone or w adults. He does not get to lead a typical childs life.
What additional research is needed to help address co-occurring conditions for autistic people?	More genetic research. We have 5 boys on my dads side diagnosed w autism or learning disorders.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance needs to cover behavior therapy and additional services outside school. The service school gives (speech, ot) is not enough. Pay providers more! We need more quality providers. Revamp the special ed public school system. Pay the Aids!! Train the aids!!!
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	None
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	My son started school post covid

Name	Joye, service coordinator in HCS program
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	who wrote these questions? we don't say autistic people. the question should be, "how does autism affect someone's physical health?"
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	communication. being non-verbal doesn't mean that the person has nothing to say. being unable to make yourself understood is the cause of a lot of aggression.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	language must be learned in a group, otherwise, who will you communicate with? Isolating the person who cannot communicate by surrounding them with people who are unwilling to learn their communication styles is counterproductive
What additional research is needed to help address co-occurring conditions for autistic people?	teaching sign language to the entire community. what would happen if everyone learns basic sign language? Cultures already use sign language like, high five, thumbs down, middle finger, shake your fist. Then, put the people together who pick up on the sign language and let them have their culture. let them learn together. What would happen if there were dorms or apartments that cater to people who sign? people who can hear should not be prevented from learning sign language.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	people who have autism have the same need for counseling as anyone who is going through stress and trauma. Counselors are needed who accept clients with autism. Also, the question should be " conditions for a person with autism." (who wrote that?)
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Jude
Demographic	Family member of an autistic individual; Service provider, health provider, or educator; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	As a 77 yr old neurodivergent woman with diminishing brain, due to 20 yrs paying financial, emotional, mental + social price for subsidiizing (lifetime undiagnosed) 77 yr old privileged white man. My naively/innocently/unknowingly/lovingly housing + feeding + tolerating his severe autistic dissociation which has disabled his ability to earn a living or to be father & grandfather -- his children's choice. Where cen he, where an I, get help? WE NEED HELP
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	EQ -- no EQ + his innate deep sensitivity has to be denied. my 77 yr old autistic partner of 20+ yrs his EQ -- lack of emotional quotient -- lack of ability to relate, or to see others, disables him from accepting reality and thus is unable to earn a living due to his self-protective ONGOING DENIAL of his disability of his never diagnosed somewhere on the spectrum.
What additional research is needed to help address co-occurring conditions for autistic people?	levels of lack of relatedness --- leading to fruitless dysfunctional (deeply denied painful) 77 yrs of life
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	understanding -- ACKNOWLEDGEMENT of some of the less overtly obvious -- but passively self-destructive life patterns which ripple dysfunction through a lifetime through familys and down through generations
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	more pressure on the 77 yr old autistic man of my references here apply to there being less empathy and understanding, less professional ability and time, and money within the mental health systems and social services here -- which of course are under huge ongoing pressure - to grasp the severity of autism for older people -- at least in my case for my 77 yr old partner whose brain -- like mine -- continues to deteriorate...AND THANK YOU ALL FOR CARING ENOUGH TO BE DOING ANY OF THIS IN THE DOMINANT POLITICAL SYSTEM FOR WHICH LOVE AND CARING OR ITS LACK -- COUNT FOR ANYTHING

Name	Judith Ursitti, Profound Autism Alliance
Demographic	Representative of advocacy organization
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>Because people with profound autism can't provide written comments to requests like this, we've attempted to convey their experiences through caregiver feedback: GI "It's challenging to determine what will help your children when they can't tell you exactly what is happening with their digestive systems. We have been through several specialized diets & supplements & have finally settled on what we think is helping them, but both have struggled with chronic constipation." "They dismissed my concerns because he wasn't celiac, but chronic constipation during early development prevented potty training; at 14 years old, he's still in pull-ups." Sleep "My kid used to sleep for 4 hours every 3 days. Almost 30 years into this, she sleeps 4 hours daily, sometimes in several pieces. Staying up through her insomnia has been soul-shattering & brutal. My health has deteriorated, as I was left to monitor her during all waking hours plus figure out how to work while sleep deprived." Sensory "It is hard to find a dentist who will adapt to sensory & behavioral issues & if you need sedation dental work. My son went without for years, & then when we found a dentist, he had to get 5 teeth removed at one time due to decay."</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>Because people with profound autism can't provide written comments to requests like this, we've attempted to convey their experiences through caregiver feedback: "Self-injury is so damaging to his body & mind. He will hit his head until his temples are swollen & blood vessels burst on the surface. He bangs the bridge of his nose & has created a bump. He has scars all over his hands, arms, & legs that are remnants of self-injury episodes. He picks his skin; he slams his hands to his chest; he has callouses from biting areas repeatedly; he has left me with scars on my hands & arms; he pulls hair so hard that my scalp throbs; he scratches, pinches, & is unpredictable. He has always had self-injury & aggression. However, as an adult, it is very life-altering. It affects services & his quality of life. I don't understand how services won't accept people with behavioral challenges." "Aggression towards others & herself- Biting, scratching, hitting, putting pressure on people with her hands or other body parts), hitting herself in the head, picking at her skin, bending her body into painful contortions, throwing herself down, using objects as weapons, breaking her teeth on objects, pulling out hair." "OCD - Constant ritual behavior, verbal ticks that must be completed, hoarding objects, shrieking at high levels at all times of the day & night if something doesn't go according to ritual, triggering violent episodes. Hand washing until she has severe eczema."</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>Because people with profound autism can't provide written comments to requests like this, we've attempted to convey their experiences through caregiver feedback: "Health care is generally difficult, so many adult providers do not understand how to interact or communicate with your children. My children are young adults now at 21 & 23, & they still struggle to tolerate basic medical exams--blood pressure cuff, otoscopes, thermometers, much less injections. Both boys have had to be sedated in the hospital to undergo what would normally be outpatient procedures: dentistry & dermatology, for example. My younger son just had to be sedated, which was a long, stressful process in the local hospital because the anesthesia professionals were not trained to work with this population. The reason? He needed to have plantar warts removed, which you would normally do in the podiatrist's office with a local anesthetic. My older son has a suspicious lesion on his scalp that I suspect is basal cell skin cancer, so</p>

	<p>we're getting ready to have to go through a similar procedure with a dermatologist. "Other issues, such as ingrown toenails or cavities, should be considered, too, since these are normally minor occurrences, but for someone who is non-verbal & doesn't communicate very well, they can lead to infections." "Prompt dependency gets in the way of authentic communication."</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>Autistic people who require round-the-clock care throughout their lives experience unique challenges that warrant targeted research. Additionally, a renewed focus on the meaningful inclusion of people of all ages with profound autism in clinical research is critical, as currently, they are severely underrepresented. Specific areas of focus that would benefit those with profound autism include: Research specific to communication as it is currently minimal at best. Research focusing on intense behaviors that people with profound autism experience, frequently resulting in injury and isolation.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>To improve health and connection, it is critical that clinical practice guidelines specific to profound autism are developed and implemented. Additionally, enforcement of protections under federal mental health parity law should be a priority. Because people with profound autism can't provide written comments to requests like this, we've attempted to convey their experiences through caregiver feedback: "Every hospital that receives federal funding (all of 'them) should be mandated to have a designated ER & inpatient care coordinator on staff for all patients with ID (including profound autism) & other disabilities. It doesn't need to be a separate position. The role can be a (trained) regular staff member. Hospital rules & procedures may need to flex for various reasons to improve the quality of care for our community, & management will need to approve changes. For example, a caregiver in the room overnight, dispensing regular (Dr approved) meds, consolidating scheduled tests & procedures. "He can never ever ever be left alone. That doesn't sound like a big deal compared to the myriad of other issues we've faced in the past and that other families grapple with now, but it's pretty major when you're talking about 66-year-old parents and a nonverbal 38-year-old guy who would not be accepted at any of the nonprofit residential programs in the area and is still on the waiting list for the most appropriate community-based Medicaid Waiver funding."</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	

Name	Judy Stoltz
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My son has motor issues and apraxia His body does things that he doesn't want it to do Sometimes minor like pacing or making involuntary noises But other times dangerous like jumping in front of speeding cars or throwing object at family members or self injurious behavior like hitting his head again the wall or door-jam When asked what he wanted to tell the regional center at his annual meeting, my son spelled "AUTISM IS NOT A COGNITIVE OR BEHAVIORAL ISSUE, IT IS A MOTOR ISSUE. WE NEED PEOPLE WHO KNOW HOW TO COACH OUR BODIES" Not people who are trying to teach us to talk "I AM NONSPEAKING, I AM NOT NON VERBAL"
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	For my son he is still learning to communicate openly. He has not communicated that he has depression , but he has been self injurious at times over many year, and occasionally been aggressive toward me/mom. He has spelled "IT DESTROYS ME WHEN I HURT YOU! BUT YOU HAVE NONIDEA HOW HARD IT IS TO BE IN A BODY I CANNOT CONTROL." The way autism is perceived is all wrong They are not mentally deficient In fact are some of the smartest people I know But they have been trapped in bodies that we dont understand What if we and by we i mean the entire system of schools, doctors, specialists, ASSUMED COMPETANCE
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I know know And any parent of SPELLERS know, But now YOU NEED TO KNOW there is not learning disability or cognitive issue, it is all motor issue Fine motor issues don't allow them to use sign language or writing or typing SPELLING moves their communication into gross motor and there are no limits what they can learn
What additional research is needed to help address co-occurring conditions for autistic people?	Study the motor issues, apraxia, dyspraxia, and assume competence
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	My son NEVER would have been referred to as cognitively impaired if experts were not worried about protecting their current standards The EXPERTS don't accept or acknowledge practices that would really help our autistic population Non speakers are graduating from high school AND COLLEGE Non speakers who the experts identified as mentally impaired As severely autistic As not being able to spell their own name Imagine if we all ignored ASL or Braille as a valid form of communication By denying autistic people communication partners and use of spelling boards, the EXPERTS are denying our kids and young adults the right to an education and a full life
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Lock down and isolation was not good for anyone But for an autism person who is also non speaking it was that much harder on them and their families
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	All of the above were an issue My son Had severe self injurious behavior with no social or physical stimulation Since starting to use SPELLING BOARDS, (only one yr ago) he has not yet spoken of his mental health, but he is no longer self injurious

Name	Jules Good, Autistic Self Advocacy Network
Demographic	Autistic individual; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	We thank the IACC for the opportunity to comment. We note that given the importance of these issues, it is unfortunate that the submission format for this RFI significantly limits respondents' ability to provide thorough, meaningful comment. Please visit https://bit.ly/48eGZzO to view our comments in full, including citations. Difficulties during pregnancy and birth are a common issue for autistic people. According to an NIH meta-analysis of 13 studies on pregnancy experiences in autistic people, we are more likely to experience "preterm birth, cesarean delivery, and pre-eclampsia". Given what we know about Black maternal mortality, we can extrapolate that Black autistic birthing people experience these issues at an even higher rate. More research is needed in this area. Forced birth is known to cause adverse health outcomes, especially for disabled people. Given abortion restrictions in the wake of Dobbs v. Jackson and the fact that many autistic people are on Medicaid/are, which does not cover abortions, these adverse outcomes are becoming a bigger problem for our community. Police violence is an often-fatal threat to the physical health of Black autistic people and has been recognized as a public health issue. Police violence is never the victim's fault and no amount of police training can solve this systemic issue on its own. To reduce this threat to our community, we must decrease police encounters and hold officers accountable for the harm they cause.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Many mental health conditions are inequitably diagnosed among autistic people. One study found that Medicaid-eligible Black children were 5.1 times more likely than white counterparts to be diagnosed with adjustment disorders before being diagnosed with autism. Labels of oppositional defiant disorder or aggressive, dangerous, & self-injurious behavior (SIB) disproportionately affect autistic people of color, especially Black autistic people. Misdiagnoses delay access to therapeutic support, leading to mental and physical harm. SIB is separate from suicidality. Studies from 2021& 2024 show disproportionate suicide attempts among autistic people. Suicidality is understood among those with lived experience as a "portal communicating to us what needs to change in society so that people want to live." Quality wrap-around services—not involuntary hospitalization—must be prioritized. The co-occurrence of gender dysphoria and autism is well-documented. Access to gender-affirming care is under threat, & it's of critical concern to the autistic community. ASD screening should never be required to access gender-affirming care at any age because it perpetuates the discriminatory myth that autistic people are "too disabled" to know ourselves. Avoidant/restrictive food intake disorder (ARFID) is common among autistic people, & leads to nutritional deficiencies. There is a lack of interprofessional education, training, & knowledge about treating ARFID in autistic people.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Lack of support for communication creates significant challenges for people with learning, developmental, intellectual, and communication disabilities—not just the latter. All behavior is communication and behavior labeled as "challenging" is often an autistic person communicating or responding to an unmet need. ASAN has repeatedly emphasized a need for widely available, robust communication systems, including access to AAC devices. As noted by Communication FIRST, only "some of this technology" is available "some of the time, in some states, for some people who can somehow navigate their byzantine, and often biased, processes and requirements." We must do more to increase access to communication technology. The lack of widely

	<p>available plain language (PL) and Easy Read (ER) materials creates barriers for many autistic people with co-occurring disabilities. PL and ER materials give us more agency in decision-making, which has implications on guardianship determinations. As ASAN stated in our comments on HHS’ proposed Section 504 changes, “guardianship is predicated on a ruling that an individual cannot make their own decisions or communicate them effectively. Providing disabled patients with health care materials in plain language and Easy Read would make these decisions substantially more accessible to those with a range of cognitive, developmental, intellectual, or neurological disabilities and thus reduce some of the impetus for guardianship applications.”</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>Existing research, including reports from the Department of Defense’s TRICARE Autism Services Pilot, has pointed to the inefficacy of ABA: “43% [of ABA participants] demonstrated no improvement or increased intensity of symptoms over a two-year period”. Other criticisms cite impacts like “consent violations and removal of autonomy, pathologizing unremarkable behavior, and interventions where the risks are greater than the benefits.” However, we lack research that focuses on (a) additional harms of ABA to multiply marginalized autistic people, including those who are POC, Black and brown, nonspeaking, IDD, women, non-binary, trans, and LGBTQ+, from the Global South, people with mental health disabilities, people with co-occurring medical conditions, and people with higher support needs and (b) additional benefits of occupational, sensory, and other therapies to those same groups., Until research fully addresses the ways in which ABA specifically harms multiply-marginalized autistics, we cannot understand how to equitably formulate evidence-based ABA alternatives for these populations. In general, autism research needs to be led by and developed with autistic people and address the needs of autistic children and adults across the lifespan. Autistic people need to be involved in all stages of research design and paid for our work. Research about our community must be made accessible to us by communicating key findings in plain language and Easy Read.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>There is a dearth of accessible, affordable, & quality mental health (MH) care for autistic people with co-occurring MH conditions. Providers lack the education & training, as well as competence & confidence, to serve autistic people of all ages, with or without intellectual disabilities. This service gap prevents autistic people from receiving necessary support. Network inadequacy compounds the issue; “83.86% of all US counties lacked any diagnostic resources [for ASD].” Provider quality & quantity need expansion. Punitive seclusion, restraints (mechanical or chemical), & other coercive measures create barriers to MH care for autistic people. These cruel anachronisms are used disproportionately on autistic people of color, particularly Black autistic men & boys. More retrospective research is needed on the long-term impacts of restrictive & coercive practices, like the incidence of PTSD. Behaviorist interventions such as ABA should never be offered in lieu of or foreclose access to MH support. Behaviors termed “challenging or dangerous” are often natural responses to dehumanizing service systems or unsupported needs. These approaches prioritize outward conformity with neurotypical expectations over addressing underlying emotional distress. Effective modalities center patient agency. MH support includes, but isn’t limited to, individual or group psychotherapy, peer support, social or affinity groups, & other types of therapy (physical, speech/language, sensorimotor).</p>

<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>Long COVID is itself a co-occurring health condition. Autistic people have been found to have significant sequelae after infection. More research on autistic post-COVID experiences is needed, especially for Black and Hispanic people who “are more likely to report symptoms of ‘Long COVID’ than their White peers” though “White people are more likely to have a documented case of the illness”. Because of the heightened risk to our health, many disabled people have continued to take COVID precautions while many nondisabled people have stopped. Many autistic people are dismissed as “overly anxious” about COVID-19 when we insist on PPE and other precautions. In some cases, disabled people have delayed medical care because their providers refuse to wear PPE at appointments. We would like to see acknowledgment of PPE in medical settings as a reasonable accommodation under the ADA. As public awareness and reporting on COVID-19 has decreased throughout the pandemic, vital COVID-19 resources have disappeared. ASAN had to end its COVID-19 case tracker due to lack of data. Project N95, which donated vetted PPE to those in need, had to shut down due to decreased public support for masking and a resulting lack of donations. The loss of crucial resources as COVID continues to circulate and take lives needs to be addressed. COVID is an airborne virus, and proven methods of transmission reduction such as air quality monitoring, HEPA filters, and respirators should be broadly used.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>The ongoing COVID-19 pandemic -as well as policies implemented to mitigate it- have had enormous impacts on autistic people for both good and ill. For example, the continuous coverage provisions authorized by the Families First Coronavirus Response Act enabled autistic people to maintain access to health care and services, and its expiration caused many autistic people to lose coverage. Provisions of the HCBS Settings Rule relating to community integration were delayed, which further heightened social isolation for those in congregate settings, while service disruptions put autistic people at further risk of institutionalization or reinstitutionalization. The provider shortage—while exacerbated by the pandemic—predates COVID-19 and must be addressed as a longstanding and systemic issue. In order for autistic people to receive higher quality care, direct support providers must be paid a livable wage, receive adequate training, & be free from workplace racism, sexism, & xenophobia. Increased use of and support for telehealth has expanded access to mental health providers and specialists, including for those who need specialist care that is not readily available locally. Efforts to preserve telehealth availability should ensure that they are and remain accessible for autistic individuals, particularly those with intellectual or communication disabilities.</p>

Name	Julie Bresette
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The most challenging part of co-occurring disorders is that often traditional treatments such as medication and surgery don't work or don't work well enough.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The most significant challenge caused by co-occurring mental health issues is that only the symptoms are treated and any correlation due to autism is often overlooked and merely treated with an antidepressant.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The most significant challenge is the way in which society feels these issues can be "trained" away. Meaning autistic individuals are required to conform.
What additional research is needed to help address co-occurring conditions for autistic people?	Additional research needs to be done on how autists respond to medication, the correlation between their nervous system and disease, treatments beyond antidepressants for anxiety and sleep, and how to better accommodate different learning and communication methods in everyday life.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Specifically, training the medical and mental health community as to how autistic bodies and brains function would be extremely helpful. Insurance coverage for autistic testing without stigma should also be made available. Access to and insurance coverage for physical and occupational therapy is needed as well.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Positive effects include more access and acceptance of remote meetings, acceptance of being germ-conscious, increased awareness of distance-learning opportunities, increased opportunities to work from home, and access to telehealth appointments. Negative effects include isolation, increased mental stress, and having to learn and navigate a new set of societal rules. An effect that has both positive and negative effects is the loss in masking skills.

Name	Julie Emig
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My child has autism. She experiences gastrointestinal disorders and sensory disorders.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My child is often anxious and can have a hard time focusing.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My child has difficulty connecting with peers.
What additional research is needed to help address co-occurring conditions for autistic people?	Any and all methodologically sound research is needed and applicable! The more we know about these conditions, the more we can be proactive in treatment.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage. Holistic approach from all clinicians.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Nothing in our family related to autistic child...just the standard need to adjust to the consequences of isolation from Covid. Plus my spouse suffers from long Covid. The ramifications of long Covid for families in general are desperately in need of study to garner education and support.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	For my family the most significant ramification has been the diagnosis of long Covid for my spouse. This affects the entire family and inhibits professional/work—not to mention lack of energy as a parent.

Name	Julie Lackey, OKIPSE Alliance
Demographic	Family member of an autistic individual; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	<p>Sleep Disturbances: Lack of quality sleep not only impacts the person diagnosed with autism but also the parent/family. Brain function, including emotional regulation, impulse control, ability to make decisions etc. are all negatively impacted by lack of sleep, including sleep with nightmares, which are often the side effect of medications. Example: when it is time to make a medication adjustment, if the person with autism is sleep deprived, you cannot tell whether it is a problem with the medication, or just because the person is sleep deprived, which then can cause an incorrect decision to discontinue a medication. In addition, when an individual is awake at night, that person is not necessarily safe, so that situation then impacts the family member who must also be awake. This in turn impacts the family member's ability to function. Innovative methods of treating sleep disturbances - could brain ultrasound be utilized as it has been for addiction for instance?</p> <p>Sensory Challenges: There is not enough research and new ways to work with individuals that have autism with sensory issues. Innovative new treatments are needed that are NOT medication based. Sensory challenges can impact literally every moment of a person with autism's life. Think about it, if your hearing, smelling, feeling, seeing, tasting and touching are all either on hyperdrive and ultra sensitive or muted which can set a person up for a dangerous situation, life gets very scary.</p>
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Innovative methods to treat both anxiety and ADHD that are not medication based are needed. For instance can ultra sound be utilized in the brain as it has for addiction? Co-occurring mental health conditions: Anxiety: anxiety affects everything in a life. If a person is anxious, they simply cannot engage in therapy, or any activity without being hobbled by fear. ADHD: In our son's 26 years, we have seen a definite loss of interest in the medical community to coming up with either more targeted medications or non medication based therapy. Particularly for young adults, there is practically nothing that is truly new and innovative to try to help these individuals. ADHD can make employment, social, sleep and interactions of every kind difficult or impossible to be successful. Think about it, the inability to modulate impulse control and stay on task is a recipe for failure in every area of life.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	<p>Intellectual disabilities - there are not enough therapy techniques that deal with the fact the intellectual disabilities often co-occur with autism, particularly with mild ID. There is more emphasis on severe ID, however mild ID with autism can hinder a young adult's potential success with employment as they tend to fall in the cracks between not quite "typical", but not impaired enough to be good candidates for the low level jobs typically ascribed to the ID population. These young adults can succeed if they had informed, educated support personnel and educated employers to provide minimal supports that can help them be successful and engaged citizens.</p> <p>Communication Disabilities- repeat of the above verbiage. Simply insert "Communcation Disability" in place of ID. With this addition: When a person with autism cannon communicate, which can happen even with a high functioning person under duress, that is a dangerous situation waiting to happen. Our first responders need more training to prevent negative outcomes with interacting with these neurodiverse individuals.</p>
What additional research is needed to help address co-occurring conditions for autistic people?	Studies beyond ages 0-14 that deal with everything I have referenced . Although there is not enough research for all ages, there is definitely much more research put towards young children. It is almost like the medical

	<p>community decides that once a person reaches high school graduation, they no longer have autism. In reality, young adults desperately need research on all the conditions I have listed in this survey. Once they no longer have the support of the K-12 system, they are often "on their own" as agencies are not equipped, understaffed, and working with old information that treats them like they are all the same and often do not assume competence with does these individuals a grave disservice. With the numbers as staggering as they are for autism diagnosis, it should be incredibly obvious that targeted research is desperately needed for these individuals. We have a young adult son, I used to run a parent group, have started social skills groups in multiple schools, have a non profit that funded 2 inclusive post secondary education programs, and now am the Director of a state Alliance that is all about inclusive post secondary education. I have direct experience and know what I am referring to in this survey.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Focused personnel that are trained to work with young adults rather than children. Studies that focus on young adults (ages18-26). The Inclusive Post Secondary Education initiative across the nation now lists over 300 programs in 49 states. Combining research with these IPSE programs to work on specific ways of supporting this population would be a natural fit for new frontiers to help young adults. See Think College.net for more information.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>The lasting negative impacts of increased remote work and school...rolls down to IPSE programs for young adults. The move to remote classes after COVID puts individuals with autism in a format that goes against their need to learn social behaviors as adults. Reducing everything that goes into being a successful member of society - including good hygiene practices, communication practice, interpersonal relationship practice, and beyond.</p>

Name	Julie Schweitzer, UC Davis
Demographic	Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Our research findings demonstrate a very high rate of symptoms associated with ADHD in autistic youth. This includes increased inattentiveness, impulsivity, challenges with emotional regulation, irritability, planning, organization and so forth. Similar to what we observe in ADHD, these symptoms, cause challenges in academic and occupational responsibilities and in their social relationships. Because we know that impulsivity in ADHD can lead to higher suicidality in ADHD it is worth exploring if this is also the case in autism. As autistic youth mature, their parents increasingly request assistance for these issues, particularly once they feel that language and other social challenges have been addressed. We have much to learn about how ADHD symptoms in autism differ from how they present in ADHD without autism. We do know that there is insufficient interventions to address these issues in autism.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Independence, physical health issues and others.
What additional research is needed to help address co-occurring conditions for autistic people?	Research into the causes, be they environmental, genetic, epigenetic. Novel treatments as many of the treatments seem to be variants based on some of the same ones used for decades.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insuring that the services are of high quality. Equitable access and services available through the entire life span. Making it easier for families to understand how to access services.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I cannot give a fully informed response to this question.

Name	K
Demographic	Autistic individual; Researcher
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>GI disorders, sleep disorders, and sensorimotor challenges affect almost all autistic people. GI disorders can be particularly frustrating because they stack on top of existing difficulties with food and eating. Similarly, sleep disturbances can worsen mental health, reduce tolerance for sensory stimuli and changes, and increase the risk of other physical health problems. Many of us also have issues with joints that are less often talked about. Headaches, including migraine, are also more common and can be triggered by or increase sensory overstimulation, and they might be under-recognized because of their seeming similarity to sensory overstimulation. Dysautonomia may also be under-recognized and can be very disruptive when present. Epilepsy is less common among high functioning autistic adults but very common among those with ID and is a potentially very serious issue when it is present. Finally, stress, poor eating, poor sleeping, and poor self-care can increase the risk of type 2 diabetes, autoimmune diseases, heart problems, or similar conditions.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>Depression and anxiety are extremely common mental health concerns for autistic people, especially autistic women. Another major concern is OCD, which can overlap significantly with autistic rigidity to the extent that it can be difficult to differentiate. OCD can interact with autism to cause severe daily life difficulties, such as worsened need for routine, difficulty with adaptive functioning, restricted eating, and social isolation. Finally, posttraumatic stress and dissociation are under-recognized despite autistic people experiencing trauma and specifically interpersonal violence at extremely high rates. Trauma can not only significantly impact mental health, including increasing self-harm and aggression, it can also contribute to social isolation, reliance on predictable routines, cognitive rigidity, and loss of skills. However, there are very few mental health providers who are willing to treat posttraumatic stress in autistic individuals, especially those who have higher support needs.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>A high proportion of autistic people have ADHD, and even those who aren't hyperactive, inattentive, or impulsive still struggle with executive dysfunction in the form of difficulty initiating, transitioning between, or stopping tasks. This can make autism much more challenging. ADHD can often lead to an overall more severe presentation, and executive dysfunction without ADHD is often offered no support. Similarly, "spiky profiles" often lead to overlooked strengths or unmet needs, including specific learning difficulties or processing weaknesses being ignored. Finally, individuals with co-occurring intellectual disability or language impairment are among the most vulnerable autistics, yet they're often overlooked because many of the most severely impaired individuals are unable to participate in self-advocacy, are difficult to research, and require high levels of support that many are not willing to acknowledge.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>More research is needed on autism and mental health, particularly PTSD and OCD. Additionally, more research is needed on managing and treating co-occurring disorders, especially GI and sleep disorders, as well as preventing chronic illness as autistic individuals age. Too many studies only include children, only examine prevalence, or are only concerned with potential causal mechanisms for autism. The focus needs to shift to how to improve quality of life throughout the lifespan. This includes improved assessment, medical and mental health professional interactions with autistic people, self-care and condition management, and long-term outcomes.</p>

<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>It's difficult for many autistic people to access services. Many autistic people do not work fulltime and cannot afford quality care. Inability to drive or use public transportation can also make accessing doctors difficult. Professionals, especially mental health professionals, may not work with autistic clients. Doctors may not be thorough in investigating potential problems in particular for autistic clients who have very unusual speech, no speech, or intellectual disability. Diagnostic overshadowing is a major risk, especially for autistic individuals with higher support needs. Doctors may be belittling to clients or ignore them in favor of only communicating with caretakers, leading to very negative perceptions of or fears of medical environments. Finally, autistic individuals may not have the support needed to appropriately take prescribed medication, struggle to change their diet as recommended, or otherwise be unable to follow treatment recommendations on their own. Increased access to services, professional training, and home-support or creative solutions to improve self-care are needed across the board.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>COVID-19 infection and illness worsened co-occurring conditions for many autistic people. Pre-existing fatigue, GI dysfunction, and dysautonomia could all be worsened, or they could newly develop or reach clinical levels. Additionally, the stress of the pandemic and quarantining worsened depression, anxiety, and OCD for many. Loved ones becoming ill could also severely negatively impact mental health, especially if the loved one died of COVID or a related complication.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>The impacts of COVID on society were mixed. Increased remote work and school could increase social isolation and negatively impact social skills, but they were also less cognitively demanding for many autistic individuals. Remote participation involves less sensory overstimulation, less need to cope with changes and transitions, and no need to worry about driving or managing public transportation. Similarly, increased telehealth expanded healthcare access. Many autistic people also find it easier to communicate through mediums such as emails than in-person conversations. Fewer in-person social demands also allows autistic people to interact on their own timeline and avoid overwhelming environments. More online social events could increase community inclusion and socialization. However, those who cannot reliably access or use the internet well may be more severely negatively impacted. Finally, disruptions in services are always a major problem.</p>

Name	K
Demographic	Autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>I find that I don't know everything about health related conditions to autism. There isn't enough available information for me to access, and when I've asked for medical advice I've been shoved to the side. I do deal with gastrointestinal problems, questionable sleep patterns, and as of lately, sensory issues are a huge problem for me. Some days I wake up with my senses in hyperdrive, and smelling anything is enough to make me throw up—even if I like the thing the smell is associated with. (Fried fish and lemon, espresso, coffee vanilla extract, etc) other times I have to wear sound-cancelling headphones because the sound of someone's breathing, another person's chewing, someone's laugh, the radio over the loudspeakers—is too much—and makes me want to tear my hair out. I also have audio processing troubles—if someone doesn't enunciate their words clearly or let me watch the way their mouth moves when they speak, I can't articulate a single thing they said. It's even harder when I'm trying to talk to people with stronger accents, and it's not their fault, but I feel absolutely terrible that I can't understand what they are saying.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>For me, depression and anxiety is a big one. I'm also trying to get an adhd diagnosis, but it's difficult because the medical field doesn't take me, a female passing person as seriously as they do a male. I can't get a diagnosis for something I clearly have, because it's just severe anxiety, and I'm shoved off. My anxiety makes it difficult to speak up about things that bother me, in relationships and in groups. This leads to severe miscommunication and extremely hurt feelings on both sides. I also have a severe case of abandonment issues—combined with the anxiety it's not great. I am constantly hyper-examining people and figuring out the best personality they would want around them, and I perform exactly how they would want me to. I've done this for so many years, I don't even know if I have a personality. I'm whatever anyone wants me to be. My depression makes it difficult to do literally anything. I'm grateful I'm on medication, it's easier, but it doesn't cover every problem. I'm constantly searching for my next source of dopamine, what will make me want to do something—and I'm incredibly grateful that those sources are found through media, and not abusable substances. I frequently worry I will become an addict in the future because of how strong my need for dopamine is.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>When I was a kid, I didn't know how to act. What was a normal thing to say. But I loved reading, I was hyperlexic. So I would become characters I read about or saw on tv—because it was the only representation I got as to behave. it got to the point where I had to sit outside of the classroom in kindergarten while I waiting for the class to finish reading Junior-B-Jones. And it was the reason I wasn't allowed to watch SpongeBob as a kid. I never had explicit issues in school. I was an overachieving kid, but when I got to highschool, no one cared about it, and I had no resource for when classes got harder. I didn't develop study habits, I got increasingly frustrated with everything. If something didn't immediately spark my interest—I didn't care about it. It was hard to pretend to be interested in conversations I could care less about.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>More representation in female studies. Most autism diagnosis go to people who have been socialized as men, however a majority of people socialized as women are also autistic, they have been taught their whole lives how to mask it better, and find it difficult to get valid support from medical professionals. I find myself dismissed and humiliated when I try for</p>

	<p>diagnosis, it's stressful, and discouraging. Sometimes even finding a female practitioner won't take you seriously. I got told I was too anxious and depressed for them to tell, and that I might be autistic, I might not—which isn't a solid answer. I can't get accommodations for that. How is it that everyone I knew as a kid could tell there was something different about me, something they couldn't describe that made it difficult to form relationships, but my own parents and people with doctorate degrees couldn't. TLDR: do more studies on women/afab people with autism.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>All of that. It's hard for me to make appointments and keep them, it's hard to phrase things to a doctor in a way that will make them see what I am saying and not what they think they are hearing. They often have selective hearing about patient issues, and I'm taken less seriously because of my anxiety, depression, and woman-passing appearance.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>I've loved the increased availability of remote work. It doesn't always work for me, I need to be in a physically different place I associate with getting work done, and my home doesn't really have that mindset. However I love that it is an option. Some days when I can't make myself get out of bed, it's easier to convince myself to do my work remotely then getting up and doing my get ready tasks. However, I found that the inability to rely on services, due to unresolved understaffing from poor management during COVID, is increasingly frustrating. That needs to be addressed immediately. Covid allowed a lot of people already in power to take advantage of it. And it's not okay.</p>

Name	K
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Maintaining a healthy diet while having GERD, food aversion, anxiety and ADHD as well as autism impacting ability to grocery shop. Hard to get consistent sleep due to sleep apnea and insomnia. Difficulty with fine motor skills, balance, coordination due to dyspraxia
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Social distress due to RSD as a result of social rejection and harassment due to autism. Lead to self harm, panic attacks and isolating.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Mostly executive dysfunction. I'm personally hyperlexic so I'm able to take in and understand information easily but starting and organizing tasks is a struggle
What additional research is needed to help address co-occurring conditions for autistic people?	I think there needs to be an understanding of the vast developmental differences in autistic people. Some people are non verbal, some are dyslexic and others hyperlexic. Some people suffer from dyspraxia while others suffer no coordination issues. It seems that autism is so vast that its really hard to encompass everything that can come with the label.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I think it shouldn't cost so much money to access an autism diagnosis. I think the opportunity to work with individuals to help them determine what career direction would suit their skill set and giving them the tools and resources to develop those skills such as working with trade schools or colleges or on the job training.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I think it sucks that remote work was only offered temporarily despite the fact productivity didn't decrease while people worked from home and allowed them to save time and money commuting. Telehealth is still available but now certain medications are not allowed to be prescribed via telehealth. These services were temporary and taken away so people could go back to micromanaging every aspect of our lives even though it doesn't improve productivity or morale or save money. I think things were better when we all had to wear masks and stay six feet apart and the rules were all black and white. Now it's mask if you want to and try to stay away if you have flu like symptoms but there are no actual rules.

Name	K
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I would say my biggest co-occurring conditions would be daily gastrointestinal issues including IBS as well as the overall joint and muscle pain. My closest comparison is HEDS right now but its immensely tight muscles that get pulled or strained due to weak joint that cant hold up. My hip has popped in and out since i was a teenager (~15) and i would say I pull a muscle weekly.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	On the mental health side my ADHD has had quite an impact on my life. I was diagnosed late in life which i heavily regard to my autism internalizing a lot of my symptoms making it less noticeable. This caused a battle with separating what is causing different symptoms which were commonly blown off as anxiety. I noticed my depressive symptoms only increased when overstimulation but were labeled as depression rather than a symptom of the stimulation
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My main challenges showed up in dyslexia and a disinterest in reading for most of my early education. This led to me being put in additional reading help. I also had a lisp and was in speech therapy for many years
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Coverage for every day consumables like KT tape, heating pads, earplugs as well support in work settings where accommodations may not be supported initially
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Kaalyn
Demographic	Autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Pain conditions, light sensitivity, auditory processing disorders, visual disturbances, and temperature dysregulation make outings, doctor's appointments, socialization, and general independence a near impossibility. The overstimulation maxes me out before I can even leave my home. The need for captions, low light, quiet places of reprieve, and operational hours later in the evening (the darker hours) are just non-existent in aggregate. I'm additionally a wheelchair user and that alone is a barrier to society independent of the autism.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Complex childhood trauma and autism go hand in hand like PB&J. The mistreatment by caretakers, schoolteachers and admin, doctors, psychologists, and larger society is everywhere. We are easy to abuse bc people assume we don't understand what's being done to us. That no one will find out. That no one will care anyway. That we deserve it. So much gaslighting, trickery, abuse of power, berating, physical violence, punishment for existing, and so much more. We are also extremely vulnerable prey to sexualization and predation. The overlap in symptomology between complex trauma and autism also makes many of us go misdiagnosed for decades (from either condition). Lack of education and awareness is terrible. ADHD and Autism also have competing symptoms constantly, but frequently pair together.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Auditory processing issues, dyslexia, dysgraphia, and speech conditions create an even greater barrier between us and the world we're trying to interact with. People assume we're dumb, slow, childlike, or require our parents to speak for us. Many of us are actually the most intelligent person in the room but can't get a word in edge-wise. But if we mask well and perform social norms beautifully people automatically flip the script and say we're lying. Self-diagnosing. "High functioning". Or other invalidating sentiments. We're caught in a double bind just to be heard. Let alone respected and valued.
What additional research is needed to help address co-occurring conditions for autistic people?	Research into the overlap between autism and (separately): - Complex PTSD and dissociative trauma disorders - queer and gender non-conforming identities - Ehlers-Danlos Syndromes - POTS - MCAS - perseverance on social injustice - delayed dx of female-presenting children - disparity of delayed dx in non-white populations - A re-examination of the spectrum gradient and the benefits/cons of functioning label use
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	- less focus and public education on things like vaccines, cures, and prevention - increased science communication to the public on the diversity of "what autism looks like" - WILDLY more accessible testing/screening for dx (i.e. cost, number and availability of physicians, insurance coverage, etc) - increased *accessible* transportation to appts (i.e. noise and stimuli controlled, RELIABLE pick-ups/drop-offs, services that extend to rural areas - ease of application process to receive social security benefits - more insurance and medicaid/-care approved tools and assistive tech (headphones, communication devices, motor skill and orthotic supports, etc)
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Vaccine hesitancy revived a reducing fear of autism being caused by them. Isolation massively hiked up the loneliness and ostracization of us from society Progress being made socially has regressed dramatically in 4yrs Masks make lip reading and auditory cues and more blurry/non-existent
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on	Truncated this answer with the response to the last one

physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

Name	Kacey M
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Ehlers Danlos Syndrome (hypermobile type), Postural Orthostatic Tachycardia Syndrome, Mast Cell Activation Syndrome, Gastrointestinal processing disorders, auditory processing delays, chronic fatigue, sleep disturbances, heightened nervous system reactions, dopamine driven addictions
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression, anxiety, C-PTSD, OCD, ADHD, unhealthy attachment issues for human connection, ARFID, eating disorders, suicidal thoughts, alexithymia, panic disorders, dissociation from stress, derealisation, insatiable urges, extreme impulsivity
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Sensory overload, dyspraxia, chiari malformation, apraxia
What additional research is needed to help address co-occurring conditions for autistic people?	Whether or not ASD has any different types of classifications regarding where peers might have common traits with bodily structures (beyond support needs). What type of environment is well suited for a student with low to moderate support needs, moderate to high support needs, etc.. commonality between types of passion topics. ways for medical, educational, and supportive professional to develop tools for autistic people. Learning why ABA therapy has been used, and how to learn tools to succeed without sacrificing our own wellbeing. Data collecting for which doctors know what undiagnosed autism can look like, and how to support the patient. Why hEDS is common, why dysautonomia is related, what happens during a nervous system “breakdown”, how ASD bodies react to different conditions (temperature, textures, overall senses and nervous system responses), histamine intolerance commonality rate, allergy rates, location and environmental factors during/post puberty
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Access to more support, more funding towards social services, including mental health and wellness services into the medical system and not a separate and exclusive services, public education training AND funding, systemic accountability for the failures of how marginalized people are treated, higher research rates in people who are not just white, male, young autistic people, updating the DSM and medical terminology for people who are autistic, reformation of testing for ASD to exclude biases of racism, sexism, ablism, non-abrahamic religious based discrimination
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I am often unable to breathe through my nose, constant nasal congestion, food processing issues has become more frequent, social isolation, chronic fatigue, constant anxiety for health
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on	Remote services /telehealth was a positive change. Destabilizing responsibilities and accountability (financial, educational), inflation of medical and professional costs, increase in unsafe behaviors (dopamine

physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	seeking), stress in overall state of economic collapse and societal instability due to COVID was a huge negative impact for the autistic community.
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Name	Kaela
Demographic	Autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>I'm extremely impacted by exhaustion, gastrointestinal distress, anxiety, migraines, and joint pain. I find it very hard to eat nutritionally consistently, not only because of sensory preferences, but also because I am often nauseous for no reason that doctors can figure out. I struggle to ever feel rested no matter how many hours of sleep I get. My anxiety has a negative impact on most areas of my life. My biggest source of pain is from migraines, and it has been a multi year journey to get any sort of reliable and effective treatment for those migraines. Part of it was discovered to be due to joint issues, but most of my bodily issues I learn about connections from people within the autism community and doctors never seem to know that information or how to help.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>Sorry I grouped anxiety in with the last question. Yes, I have severe anxiety and have found mild relief from an SSRI but it's still tough and the fact that my brain works differently always seems to be the problem and not just a symptom of the problem so many people invalidate it or just treat it as a normal and expected part of the autistic experience.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>PLEASE fund research done BY autistic researchers as all other research has so much inherent ableism and neurotypical bias it is so dismissive of the autistic experience and therefore does nothing to actually help others learn about and support the autistic experience in an authentic way.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>That would require such an overhaul. Increased testing for people who lack access to be able to get testing covered by insurance. Shorter wait times to diagnosis. More clinicians trained in late diagnosis and autism in women which is STILL missed so often. Training done BY autistic people not by neurotypicals who view us as incapable children. Insurance cover for therapy for autistic individuals. Insurance coverage for nutritionists for autistic individuals. I think being autistic should automatically qualify people for Medicaid as so many of us are multiply disabled and can't access the supports we need.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced</p>	

in-person social interactions and obligations)	
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Name	Kai
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disorders. Every symptom of my autism is exasperated by my lack of sleep but I have struggled my whole life to sleep more than 4 hours a night except rare days when I sleep 12 hours or more. I've been put on sleeping pills before but their effectiveness diminishes rapidly if they work at all. So much would be easier if I could just sleep
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Adhd. The symptoms overlap and conflict in the most annoying ways. I need routine but routine is nearly impossible for me which causes a ton of my anxiety and depression. I think I'd still have those if I was only autistic but being both autistic and adhd makes it worse I think.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Anxiety combined with my lack of understanding of general social stuff is absolutely terrifying and I'm often nearly paralyzed by anxiety in social situations to the point my stims turn self harming without me noticing. Me fingernail beds are often torn and bleeding from it.
What additional research is needed to help address co-occurring conditions for autistic people?	Sleep studies, more research on how many medications interact differently in our brains to find more effective ones, educational program development aimed at teaching autistic people to better read and understand social situations rather than just how to mimic them.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More general medical professionals knowing how to communicate with autistic people. I get so anxious going to the doctor and I don't know what I'm doing and they tend to rush appointments and then I don't end up receiving care unless I bring an advocate with me. Maybe making it easier to get a trained advocate
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Useful! Much less in person interaction required. I can order groceries online, I can wear a physical mask more so I don't have to think about my facial expressions so much. People respect personal space more

Name	Kai C.
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Personally I have a combination of autism and ADHD. The worst physical symptoms I deal with are in relation to things like my dysautonomia. I have a hard time sleeping and getting comfortable in bed. My heart rate is irrationally high at different times even when mentally I'm relaxed. I have frequent body aches and pains and I'm not sure if it's because of my dysautonomia or of some other medical condition like being so desensitized to pain at this point that I don't usually register it when I hurt myself.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Personally I have a combination of autism and ADHD. My depression was the absolute worst of my symptoms pre-medication. I really desperately used to eat my feelings as my coping mechanism and the only daily comfort I really had. Eating your feelings when you don't understand them and have no impulse control is often a central issue of people who develop eating disorders. Now my worst symptom mentally is my anxiety. I have horrible social anxiety as well trauma from decades of being bullied that I'm constantly dealing with, and the willingness to get out of bed sometimes is the biggest challenge of my day, because facing the world means another exhausting day of anxiety even with medications. When I am irritated or overstimulated I get very aggressive and often don't recognize why until I am out of the situation, and typically it makes me have intrusive thoughts of either harming others or myself that I need to get away from. At times I go into full manic episodes where I feel the impulse to drive on the interstate at 90mph. Others I fully lose all focus on everything except my anxiety and sensory issues and want to dig myself into a hole and just stay there. The anxiety medication helps a lot with this irritability as they limit external input to some degree and make it less overwhelming. I have struggled with suicidal thoughts because of all of the aforementioned things.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication is number 1 for me the absolute worst to deal with. Trying to convince neurotypical people that you literally say what you mean without ulterior motives or implied meaning is the most annoying and irritating thing in the world. Learning disabilities are usually at fault of the teacher in my experience if I get someone who can explain something or answer my questions in detail when they come up I don't have a problem. Personally the worst issues I have with this are with religious people who would rather preach at you than actually answer a reasonable question about the very thing they are attempting to teach you, as if I as someone who doesn't experience the world in the same way am to just accept everything they say as fact when they cannot back it up. This led to a lot of abuse as a child, and leads to a lot of assumptions on the part of others and miscommunication as an adult. If you give me the correct words to explain a feeling or you can draw me a picture I can better understand, but I don't understand irrational "emotions" when you only describe them as "I don't know, you just feel it." We need more education about neurodiversity in general in religious organizations.
What additional research is needed to help address co-occurring conditions for autistic people?	Research on how schools teach media literacy and doing it early. It is one of the largest things I have overcome in learning "Oh when people say this thing, they actually mean-" and outside of a realm of the scientific, even things like metaphor and hyperbole can often fall flat. Now, I am very good at understanding the nuances of things. As a child, I thought cartoons were real and I could chase someone with a hammer or a knife and them still be okay afterwards. You need to explicitly layout that there are more than just good

	<p>and evil in the world, and as such much like neurodivergence, good and evil exists on a spectrum. Black and white morals and a lack of nuance in early understanding of ethics creates a dichotomy where autistic people who take things very literally will only trust science and their own experiences until the point that they are proven wrong, and then are put in positions of direct opposition to those of faith at an early age because we seek clear and concise answers even though nothing is clear in actuality.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Understanding patients’ sensory needs in environments like doctor’s offices, hospitals, etc. and allowing them to carry sensory devices with them like headphones, fidget toys, etc. I don’t think I’ve ever walked into a hospital where I have actually felt safe in the cold sterile environment with the loud beeps and boops of the machines. We also NEED to allow for diversity in how doctors view autistic patients. We are not all [redacted] or savants, we are a larger more diverse group of people and deserve not to be treated like children and buffoons, or treated like we’re “too smart” or “too self aware” for mental healthcare when we may just have the language for what our issues are and not how to deal with them. Listen to people when they bring up problems, and trust that they’re smart enough to know what’s going on with their own bodies. I have been attempting to get treated for POTS for 10+ months now and none of the doctors believed my speculations aside from my general practitioner, and yet they put me through so many unnecessary expensive cardiological exams seemingly because they didn’t think my own interpretation and research of the symptoms was enough to go off of. Had they listened in the first place like my general practitioner did I could have saved somewhere in the range of \$750 of unnecessary medical bills.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>It’s scary because we are now seen and treated as second class citizens because we’re considered disabled. I don’t want to be the last person in the hospital to be seen because I have so many comorbidities someone thinks I’m better off dead. Frankly it’s awful how disabled people on the whole are treated in this country and how we’re frequently the least of anyone’s considerations.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Increased remote work. Decreased incentive to socialize in situations where I’m uncomfortable. Less talking to strangers. Increased boundaries in my general life being respected by more people as to where they were barely respected previously. Now I don’t have to worry about strangers in the super market putting their hands on me. I don’t have to worry about people walking up to me and harassing me for “looking weird” or “looking tired” as much.</p>

Name	Kaisi rolfe
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression anxiety adhd pda
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication and social skills
What additional research is needed to help address co-occurring conditions for autistic people?	Any research in to neuro diversity is needed
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Patient provider interactions. I believe all schools should be teaching the Ron Davis method for both neurodiverse and neurotypical. Far to many children/adults are growing , maturing with essential life concepts being missed
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Karen
Demographic	Family member of an autistic individual; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	For us the most significant challenges were and still continue to be behavioral challenges and the level of functioning due to intellectual disability. The lack of awareness of self and of danger significantly impacts my son.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The mental health conditions my son experiences are ADHD and depression, severe anxiety that is debilitating ..causes him to be unable to leave home. He has not been anywhere except a doctors office in many years.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The biggest challenge with intellectual disability relates to the level of functioning in all areas. Speech deficits significantly impacted his communication and developmental disability as well as intellectual disability affected quality of life and the entire familys quality of life
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	We did not have COVID-19 to my knowledge
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Karen Ashikeh, Registered Nurse- Health Adviser
Demographic	Family member of an autistic individual; Service provider, health provider, or educator; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Dental care is an ongoing and lifelong need that is not well served in the training of dental care staff, including dentists and is very hard to find in many communities. Often many miles away for dentist experienced in the needs and ways to provide basic care for this population, as children. Working with several other children in the room is problematic for these children but is often part of routine Pediatric dentistry. The need for sedation during some routine and many complex procedures is also a problem getting permission from insurance. Dentists with experience working with autistic children do not let their patient families know when they move to another practice. This should be done for consistent care and for best standards of care practices so families can find alternatives for emergencies and routine care.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Problem: Not using the training children get to express these conditions of concern, pain or fear, with clear and understandable communication leads to these other behaviors. Using, routine mental health check-ins, with devices available, is one way to encourage understanding, acknowledgement and empathy from care givers that may help reduce other, more unwelcome behaviors. The ways to express, sadness, pain, fear and concerns about self and others need to be incorporated into materials like tablets and electronics, pictures showing concerns that children can point to and should be used at the start of any major daily activity period, wake up time, school lessons, returning home, etc. can be starting points. "How do you feel this morning?" " Are you feeling well today?" Are you glad today? Sad today? Training for ways to reassure and assist when responses are not well or positive or secure, may be some of the most important "lesson plans" between parent/child and child/teacher or other adult or other child. The need for other ways of expression may be both less effective and more problematic for all. Focus on clear feeling and status of wellness communication sooner and more often to help all ask and know how the other is doing.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Inability to speak what is known, perceived and felt, observed and understood is a disadvantage to many children and their families. Everyone is happy when forms of communication are identified for needs, feelings and thoughts, even if the result is not what is popular or good news. Dealing with the news one has a hard time hearing is difficult part and more help and support for parents, families and other relatives is needed for the best outcomes. Support groups, on line, to allow parents and others to share information on techniques and problem solving, would be helpful during times children with these problems do not attend. Perhaps late evening?
What additional research is needed to help address co-occurring conditions for autistic people?	1.Support groups for parents and family- when should they occur. 2.Dental care training and Pediatrician training and webinars or CE credits for dentists and pediatricians and staff that care for these children. 3. Review of electronic learning systems to recommend ways for users to express feelings - happiness, sadness, anxiety, fear, worry about self or others, aloneness and feeling there are too many people to cope with. Also identifier of name and address, phone # Ideally, Small, hand-held devices or necklace-type units should accompany the child where they go so they can communicate clearly with those around them, at any time. A good device to point to when encountering police, if ever stopped. Police need to be trained to recognize

	such devices as identifiers for those with autism or speech or other disorders and how to use them to interact with that person to assist them.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Training and use of assistive devices to communicate by police, teachers and others to identify feelings and concerns could provide a standard and consistent ways for all who interact with the person, as well as to identify demographics and a listing of any co-conditions the person has and what help needed and who should be contacted in emergencies. These can be used by family, teachers and health providers or in community interactions and should be a standard part of the earliest interactions that a child is taught from early childhood. The regularity, use and consistent methods of such interactions is both reassuring and routine for child and for helpful to those interacting with them. It should bring reassurance, communication tool and increase understanding that allows best outcomes of whatever the situation or issue.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Options for home-schooling greatly improved. This individual learning could be augmented but group activities for small groups of home-schooled children with autism, in person play groups or discussion and activity groups for older students.

Name	Karen Barrett, Barrett Consulting
Demographic	Family member of an autistic individual; Service provider, health provider, or educator; Researcher; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Invisible disabilities such as a delay in executive functioning, and pathological demand avoidance predisposes the individual to the misguidance of well-meaning institutions, such as the education and judicial systems. As per atpeaceparents.com 'Pathological Demand Avoidance (PDA) profile is often missed by professionals or misdiagnosed. There are two reasons for this: It is not yet a category for diagnosis in Diagnostic Statistical Manual (DSM-5) and because PDA produces paradoxical behavior that challenges the conventional wisdom on what is defined as "Autistic" (e.g. These children can often make great eye contact, have strong verbal skills, and a strong interest in social engagement).' My son has several comorbid conditions enabling all of his functionality which includes being able to ace material on tests however is unable to fully implement the skills necessary to master material. This type of disability masks the true achievement level of the individual being evaluated and the evaluation criteria of eligibility requirements to continue to be able to receive a free and appropriate education are skewed, even bias, masking real results. We need to changes these violations of human rights asap, thanks.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Acceptance in social situations
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Existing misalignment of teaching skills impede human progress
What additional research is needed to help address co-occurring conditions for autistic people?	Empirical testing as per atpeaceparents.com and other organizations that continue to log results such as behaviorinterventionsinc
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Education to all administration managements and other employees and staff that directly or indirectly impact individuals with and IEP
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	regression
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal	regression

changes: disruptions in services,
increased remote work and school,
increased use of telehealth, reduced
in-person social interactions and
obligations)

Name	Karen Gee
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gut health, sensory issues,
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression. Anxiety. Loneliness.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Unable to have friends. Doesn't fit in with peers. Socially awkward. But wants to have friends.
What additional research is needed to help address co-occurring conditions for autistic people?	Identify why an increase in autism.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Government needs to give tax credits to Businesses that hire autistic individuals. My grandson is looking for work where he can excel. All he needs is additional training on the job and he will always show up
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Could make them more nervous to go out In Public
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Affected their group sessions which is sometimes the only in person contact they had.

Name	Karen Kaye, Executive Director, Foundation for Autism Support and Training (FAST)
Demographic	Family member of an autistic individual; Service provider, health provider, or educator; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	autism with psychosis and OCD
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The lack of ability to hospitalize someone with autism and psychosis in Maryland. Only 7 beds available and you can't get in unless your in an emergency room, and if they 'Happen to have an opening then" otherwise your only choice is to throw them into the emergency room for 2 to 3 months and wait for an opening, which is a non-starter. So I had to treat him at home on an outpatient basis and I have endured much physical abuse in the process, trying to stabilize him. He is 30.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Medications either don't work or they present onerous side effects that are so dominant, it is not worth any good they might do. How can anyone tolerate your childs head snapping forward constantly, ridgid posing, constant grimacing. The meds are just horrible.
What additional research is needed to help address co-occurring conditions for autistic people?	Much research is needed on medications without side effects. Risperdal and Abilify are non-starters in my opinion, but everyone insists on starting trials with these for autism.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Ability to have hospitalization for stabilization for autism/psychosis. He was on Thioridazine for 15 years and I never knew that when we had to wean him off, he would go into a psychosis and regress so extremely. Families need to better understand the risks of those heavy neuroleptics with autism.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It allows more remote services and that is a good thing
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	interruption of services, lack of socialization, tremendous regression being home 2.5 years.

Name	Karen P, Special Educator/Autism Consultant/BCBA
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The medical community acknowledging co-occurring conditions is a problem. Too often they just say "it's autism" and don't dig deeper. If the underlying health conditions were addressed, the "autism" often is easier to address. You must take care of basic needs FIRST before education/learning can occur, and those basic needs include dealing with underlying medical issues.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I work primarily with young children. I see most anxiety and ADHD issues in this population. In my limited experience with older children, I have seen anxiety have a tremendous impact, as well as depression.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The most significant challenge in this area is communication. Regardless of developmental disabilities, intellectual disabilities, etc., if an individual is not able to communicate effectively it will impact all other areas, including behavior, learning and mental health.
What additional research is needed to help address co-occurring conditions for autistic people?	How to accurately identify and treat co-occurring conditions
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	"buy in" throughout the medical community a tremendous lack of availability and long wait lists for any mental health treatment
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Telehealth services for this population are minimally effective, as a whole. Since COVID, with staffing shortages, sometimes telehealth is the only thing being offered. This is not effective or adequate for many of the individuals on the spectrum. The overall lack of staffing and long wait lists were bad before COVID but are significantly worse since COVID, with no end or solution in sight.

Name	Karen Scallan, Parent of Individual (22yo) with Autism and Down syndrome
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Increase in seizure disorders during puberty caused issues in our school because school was not knowledgeable of this increase in diagnoses at this age and they were not prepared with enough nurses available at the middle school level; sleep disturbance is extremely important and significant. Leads to other problems with behavior, health, desire to eat, increased depression, etc. Weight gain after exiting traditional school and not having as active a schedule.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Not enough therapists who understand neurodiversity/Autism and can provide appropriate therapy like trauma informed care or grief therapy; Not enough psychiatrists and long waits when you have to get a new psychiatrist for med management; not enough training for parents (early on) and school professionals in positive behavior support and how to identify what is a behavioral health issue and what is a lack of communication issue.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Regarding communication, schools give up too early on teaching whatever form of communication (device, sign, picture symbols, combinations) that the individual with Autism can learn. If they don't learn it fast enough, they just give up. Schools also don't provide enough communication devices and often bog down parents with agreements they have to sign that if it breaks they will pay for it.
What additional research is needed to help address co-occurring conditions for autistic people?	Lack of training and care in schools around behavior, communication, interaction in general. The research is there on what to do, but no one is researching just how bad the situation is and it is significantly bad.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Create incentives for states to recruit and retain psychiatrists that are Autism, trauma and grief informed; Create incentives for schools to take advantage of training opportunities ; funding opportunities for schools to use to train all school personnel; create incentives for middle school schools to hire additional nurses with caveats around number of nurses available per number of students with neurodiversity (both identified in IEPs and those under 504 plans/medical diagnoses of Autism).
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Isolation was profound and lead to depression in many.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	There are still disruption in services such as day habilitation and significant reduction in ability to hire. Wages are increasing in other sectors syphoning off good personnel that we could previously hire. Individuals who are in self-directed waiver services, those using agencies for care needs and agencies that operate day habilitation centers are all vying for the same workers and all are having grave difficulty in hiring. Wages need to be increased through Medicaid waiver programs.

Name	Karen Weigle, National Center for START Services and Chattanooga Autism Center
Demographic	Family member of an autistic individual; Service provider, health provider, or educator; Researcher; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Chronic illness leads to loss of income/work, loss of social support, and early morbidity. I have seen a high rate of stage 4 GI cancer leading to death in people in their 40's in this population; factors to consider include lack of close health care, unhealthy lifestyle habits, impacts of trauma and marginalization on health.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Our research indicates high levels of anxiety and depression as well as trauma-related disorders, all of which go unrecognized, misunderstood and misdiagnosed (and therefore ineffectually treated), or mistreated, both in regard to medication and outpatient mental health care (counseling, etc). Mental health care for his population is sorely lacking and many providers report "not having expertise" or knowing what is evidence-based and effective for people with autism. Outcomes related to this include: poorer health (often caused my medications and over-medicating), further traumatic experiences, worsening mental health, loss of vocation and income, loss of relationships, and earlier death.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Marginalization has a major impact on wellbeing; people having low expectations of you, leaving you out of decision-making and not being active participants in your own care and life decisions has major impacts on your sense of self, health and wellbeing. The same poor outcomes listed under the medical and mental health questions also apply here. All areas of life are impacted by how people are treated on a daily basis in their communities as well as by health providers, and how much self-direction people experience. Further, many school systems are not equipped to meet federal guidelines for adequate accommodations to ensure each student meets their potential. Lack of understanding, funding, knowledge, and acceptance all impact this.
What additional research is needed to help address co-occurring conditions for autistic people?	More research on all areas discussed is needed. We need to include people with autism in research design and implementation to ensure that what we research is important to the people we are "researching." People with autism should guide the research questions and design, as well as be asked to participate.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	All examples you listed are important. Another critical factor is including people with autism in designing improved supports and services; listening to their input and guidance and using it drive change. People with lived experience are our best allies in doing this work, and many would like to do it themselves. We need to do better at ensuring they are included and driving this work to ensure the "rest of us" know what is needed/wanted, rather than using our own biased lenses.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Our research indicates it parallels that of the general population with the caveat that the worsening of mental health is both more common and more intense for people with autism (as was the case pre-pandemic). We must remember that physical pain and emotional pain are biologically the same and that we must use multi-modal approaches to treat it, with less reliance on medications and more on building PERMA (a positive psychology term first defined by Seligman, which outlines "ingredients" necessary for health and wellbeing: Positive emotions; Engagement; Relationships; Meaning; Accomplishment) through a variety of possible supports and/or treatments.

<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Many people report positive outcomes around use of telehealth and remote engagement as normative (or at least more available); we need to ensure those remain available and covered by funding entities, especially for those who have other challenges to using in-person only services. More research is needed (and being done) on when and for whom and for what services telehealth leads to equal outcomes.</p>
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Name	Karey
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Digestive issues- constipation, sleep disturbances, Skin irritations (when washing is a struggle), teeth and gum issues (when tooth brushing is a struggle)
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Pathological Demand Avoidance causing anger, stress, anxiety and depression
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	PDA causes developmental disabilities and communication disabilities
What additional research is needed to help address co-occurring conditions for autistic people?	Research into PDA
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Kari Johnson
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory difficulties, hyper flexibility.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Autistic burnout, ADHD, anxiety, cptsd (which is not recognized in the united states yet). Also, how ADHD, anxiety, and autism are difficult to manage without exacerbating at least one of the conditions.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Ability to care for oneself or work without much support.
What additional research is needed to help address co-occurring conditions for autistic people?	Autistic burnout.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Right now it's very difficult to get disability even though most people with autism can't work. Functioning in autistic people can vary wildly and can't hold a job even though they might seem like they can at first glance. There are not enough social safety nets in place and there are enormous barriers in place to access what little support does exist. I struggle to get through all of the red tape because it's very confusing and causes meltdowns.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	None for me personally.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The cost of living crisis and being denied disability even though I can't work has caused me to become suicidal at times and feel like what little life I'm capable of might not be worth it. I like being able to have telehealth appointments.

Name	Kari Knutson, PathPoint
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	I would like to comment on the autism research possibilities. I work with a mix of disabilities and autism is one. I feel that the number one piece of the puzzle that needs to be addressed for autism is communication. As professionals, we need to look into ways to assist people with autism to communicate with who and what works for them. My program is vocational and a simple "good morning" can be triggering for some people. The multi layers of others voices and sounds, make what seems to us a simple action, a sometimes horrific moment for those with autism. In addition, finding jobs that meet the communication barriers and needs of people with autism is in high demand! Thank you for reaching out to those of us who work with people with disabilities.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school,	

increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Kari Schaer
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Demand avoidance, mood disorder, Pathological Demand Avoidance
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Aggression, meltdowns, depression, anxiety, ADHD
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Dyslexia, dyscalculia, dysgraphia
What additional research is needed to help address co-occurring conditions for autistic people?	Medication for PDA autistic children, appropriate and effective therapy for PDA autistic children, defining PDA vs DMDD in the DSM 6, determining if PDA is stand alone or a condition within Autism or a condition within ADHD.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage, provider accessibility (both diagnostics and therapy). We would also love family therapy at home (that is not ABA) to support our autistic child's struggle with demand avoidance and meltdowns. School systems are not set up to serve this community. Schools do not have the resources or knowledge to support autistic PDA kids who have the ability to mask their symptoms in public, and then meltdown all evening/night.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It's hard to know how we'd be without Covid, but I see so much more anxiety in my kids than I ever experienced.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	More acceptance in not showing up. More mental health acceptance in societal norms.

Name	Karoline Moxham
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Stomach related issues. My 2 ASD kids suffer from reflux and IBS related issues
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression, anger management & anxiety are the most significant challenges. My youngest suffers from both depression & anger management; it has been difficult to get the right treatment for him. It's a never ending struggle.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Learning disabilities are challenging, because on the surface, my son appears typical. People don't understand that it takes him a bit of time to process information. Society is not tolerant of that.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More services particularly as they age out of the school system; better insurance coverage.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Kat
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I have several autistic family members, and many of them really struggle with sleep disorders. They don't get enough sleep, which causes all sorts of long-term health risks and issues. My husband has comorbid ADHD, and his sleep issues complicate his attention issues and put him at huge risk for accidents and for long-term health complications like Alzheimer's. My son doesn't get enough sleep, despite his 90 minute long sleep hygiene routine and everyone working together to help him sleep. He's a young child, still growing, and we just cannot get him enough rest. I worry for him.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD in combination with autism is something two of my family members experience. It makes everything more complex to address, and finding ways to compassionately treat both conditions would help them so much.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	It makes helping them, empowering them so much harder. So many people demand that autistic folks communicate like neurotypical folks, putting a huge barrier between them and the treatment they need
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	STOP making them communicate in NT ways. It's so harmful.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Kate D
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory issues, gastrointestinal problems, anxiety, depression, delayed sleep cycles, chronic pain, chronic fatigue, ADHD, memory issues, low libido, low energy/motivation, audio processing issues, POTS, hypermobility, disordered eating
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression, anxiety, ADHD, memory issues, emotional regulation issues, pathological demand avoidance
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Trouble navigating social situations, dyscalculia, dyslexia, trouble verbalizing thoughts and feelings, trouble with interoception, disordered eating.
What additional research is needed to help address co-occurring conditions for autistic people?	Genetic testing, physical testing, researching the link with hypermobility and POTS
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I feel it made my physical symptoms worse
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I believe the increase in remote work and health options has been positive and helpful for autistics

Name	Katelyn
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Having gastrointestinal issues causes a lot of problems when in at work. I end up taking a lot of time out of my day for this issue and it's really distressing. I also have sleep disturbances and that causes me to be extremely exhausted starting my day and it causes a lot of issues at work and making mistakes because I'm so tired. Sensory challenges were also a huge factor when I was a teacher and couldn't function with all the noise and had to take time when I should have been working to calm down.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I struggle a lot with depression and it's hard to get out of bed and a lot of times it ends up with me being suicidal because it gets so bad. I have no motivation and I can barely get a shower let alone work a whole day successfully. I also have ADHD and that is a huge struggle as well. I can't concentrate on getting my basic needs done and I can't even focus on my hobbies most of the time. I also struggle a lot with executive dysfunction and it's really tough getting anything done.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I have dyslexia, dyscalculia, and ADHD and it makes it hard not to procrastinate which causes my anxiety to get bad and I get so stressed out I end up throwing up. I also have trouble with math and can only do multiplication up to 5s and I can't add multiple digits in my head. Dyslexia also makes it difficult to read and speak. I stumble over my words constantly when speaking or say the wrong thing.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	We need better access to insurance that's a given. Having accommodations at work is also a struggle. Companies with employers need training and knowledge on autism and co-occurring issues so they know and understand why they need accommodations.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I've has much more issues with memory and brain fog and it's made my learning disabilities worse.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I haven't been able to reap the benefits of the things mentioned above.

Name	Kathleen Meyer
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Impulsivity and sleep disorders come to mind. Having to watch someone every minute of every day to keep them out of harm's way is exhausting. Many families do not have the means or the opportunity to get help or relief to keep their loved ones safe. With sleep disorders this makes them unsafe even overnight.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	There are multiple challenges with many of our loved ones on the autism spectrum. Our first hand experience is observing anxiety, attention, deficit hyperactivity disorder, complete with auditory processing issues and impulsivity. Compounding all this is the lack of understanding outside of the school systems to accommodate the safe functioning of these adults.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Because of the multiple layers of impairment that include intellectual, developmental, self control communication and sensory differences (impairments) these innocent people are at high risk of abuse by everyone from caregivers to our legal system. It is a very scary world every day for families with loved ones with autism. Our higher needs adults are not represented in the "not about me without me" as they need proxies to speak for them. The low needs autistic people do not represent the high needs group.
What additional research is needed to help address co-occurring conditions for autistic people?	Research desperately needs to include the whole spectrum of autism. Currently about a third are left out of consideration for their needs or even research about the natural course of their lives and function. The co-occurring condition is severe disability that threatens safety and prevents true independence. To pose this as co-occurring conditions may be helpful for a researcher designing questions but feels far from the reality of our high needs population. DD/IDD is believed to be 20 to 40 percent of the homeless population. Many autistics are evicted because of their autistic issues. The incidence of IDD/ DD in the prison population is approximately twice the incidence in the general population. Research in housing issues and incarceration areas would be helpful as well.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	There is no housing vision for autistic adults with high needs. There is a shortage of affordable housing and a shortage of caregivers. A second significant number live with parents over 60 years old. Many are nursing home level of care but no nursing home would take them or care for them. Many of our adults can't wash themselves or brush their own teeth. It is difficult to get a haircut, doctor visit, dental cleaning. The questions of co-occurring conditions does not begin to touch on the challenges. What co-occurring condition makes it so difficult to cooperate with a physical exam? What is your definition of autism? In this spectrum some have relatively mild sensory issues, while others are debilitated by them. Is this a co-occurring condition or are you including it in the autism diagnosis? This line of questioning is not straightforward and will be of limited value to most people on the spectrum.
What lasting impact has COVID-19 infection and illness had on co-	I don't know. We were able to isolate and vaccinate.

occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	We were fortunate that some of our son's usual people came to our home dinner the pandemic. This was valuable. Other changes in routine were very painful. Work skill training came to a halt

Name	Kathleen Walker
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	From my personal experience, sleep has always been a significant challenge. I also have Type 2 diabetes and sensory issues make it harder to manage my diabetes. For example, it's difficult for me to get blood tests done and I can't tolerate many vegetables due to texture issues.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have experienced anxiety since I was a teenager. Recently, I learned that much of my anxiety is related to complex trauma, which stems from my experience growing up autistic and how my family responded to my disability. I think one of the biggest challenges is that many mental health professionals don't understand how autistic people are likely to experience trauma or what therapeutic modalities will be most helpful for autistic people. For example, a few years ago I learned that many autistic adults feel cognitive behavior therapy doesn't "work" for them. Even though I'd interacted with the mental health system since I was a teenager and even studied psychology in college, I'd never heard this perspective before. It would be helpful if therapists could have a deeper knowledge of autism so they could guide patients (even those who are undiagnosed) to the most helpful type of therapy.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	I would like to see more research about -sleep: identifying better ways to deal with insomnia or other sleep issues -mental health: identifying the most effective approaches for supporting autistic people who are struggling with trauma, anxiety, depression, or suicidal ideation -chronic illnesses: identifying ways that doctors can support autistic people who struggle to manage chronic illnesses like diabetes because of sensory issues
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Patient-provider interactions: -Make sure providers have an up-to-date understanding of autism and don't make assumptions based on stereotypes. For example, a provider once asked if I really believe I have autism. This was our very first interaction so I can only assume they were making assumptions based on my personal info (e.g., that I live alone and have a full time job, etc.). I think it would be helpful for providers to have some education from autistic people with lived experience, including people with different needs and perspectives. -Educate providers about what sensory issues look like, how they may affect patients' ability to care for their health, and solutions that can help. For example, I found that using a continuous glucose monitor has been really helpful in managing my diabetes, as it would have been very hard to cope with daily finger sticks. It would have been great if my doctor had proactively suggested a CGM as an option (I had to research it myself and bring it up during my appointment). If dietitians or nutritionists could have training on sensory issues, this would also be very helpful for autistic people managing chronic illnesses.
What lasting impact has COVID-19 infection and illness had on co-	

<p>occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Remote work and the increased availability of telehealth have been helpful for me. The reduced demand on my energy and having access to therapy via telehealth have contributed to a big improvement in my mental health. However, I feel that the COVID-19 pandemic revealed longstanding ableism in our health care and public health systems, and that has been detrimental for the mental health of disabled people overall. For example, policies that prioritized "getting back to normal" while downplaying the importance of protecting others sent the message that disabled people's health is less valuable. Since many autistic people have co-occurring conditions this messaging hit close to home.</p>

Name	Katie
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD: having my ADHD and autism constantly at war with each other. It becomes incapacitating. Anxiety: I am constantly socially worried about being “normal” enough PTSD: I struggle with meltdowns already. PTSD has really harmed my already difficult experience of regulating my emotions and irritability.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Research on how Autism and ADHD present when someone has both. It can look like one compensates for the other and then we get missed until adulthood. Also more research on women/girls, trans, and non binary people. I think this would help a lot of us be noticed sooner than someone who only has autism. Also PTSD and autism occurring together.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Mental health services covered by insurance better (I have Medicaid and almost no one is covered especially anyone who is educated in autism or trauma). I have so many therapists that have told me they’re on the waitlist for Medicaid and it’s so frustrating Medicaid won’t allow more providers. Also making all mental health providers (and doctors if possible) take courses on autism ESPECIALLY on what low support needs autism looks like.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Burnout from going back after a break. I miss the flexibility of working from home and going in. I now feel like I’m always burnt out and overstimulated. It’s like I notice my autism more now because I stopped training for a year.

Name	Katie
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My son and I both have trouble connecting with and using our muscles effectively. When we walk, we tend to just move our bones through space, instead of properly supporting our frame with flexed and toned muscles. This led to numerous joint problems and long-term chronic pain. After 1000 hours of yoga, I finally understand how to move.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Because symptoms of autism can overlap those with ADHD, OCD, bipolar, CPTSD, and other mental health conditions, it is <i>*very*</i> difficult to get treatment that actually helps. None of my formal diagnoses tell the whole story, and some accepted treatments (like ERP for OCD, or stimulants for ADHD) have actually done more harm than good. I went to psychiatrists for ten years before I got an autism diagnosis, and it was only because I took the test on my own and brought it up with my doctor. Now I have meds and therapies that work for me, but I am still unraveling years of harm.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	What treatments are actually effective, long-term, for <i>*holistic*</i> betterment (not reduction of a single symptom)? How does the diagnostic model (and poorly-educated doctors) fail people with complex needs? How many false or secondary diagnoses do people receive before they get to a label and treatment that actually helps? How does autism change mental health crisis signs? What does a manic episode look like for someone with an autistic brain? What assessment questions need to be altered, so doctors get a clear picture of what is going on?
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Autism testing costs a lot of money, even with insurance. My son needs accommodations for school, so we needed to pay a lot of money that insurance didn't cover. My son's brand new school building looks beautiful but is a nightmare for autistic people - loud and massive, with tall ceilings that echo sounds. No quiet spaces or breaks available for him to decompress during the day. His teachers won't even let him step into the hall or wear headphones. These are simple, human quality of life things that everyone needs - but if my son doesn't get them, his grades and behavior suffer. Doctors need to ask better questions on assessments. "Do you struggle with racing thoughts?" Is a difficult question to answer. "How many times a day do you feel like your thoughts are uncomfortably fast?" Is much easier. I always want to answer a question, "it depends - what do you mean?" And that isn't allowed. If someone is born with severe autism, their life is immediately very difficult and expensive. Parents of autistic kids need more physical supports - childcare, food, accommodations from work. It can be devastating, and it affects an entire family.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	

<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>I really love working from home and using telehealth. It's much easier than going into public spaces. Even grocery ordering saves me a meltdown.</p>
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Name	Katie DuPree-Magat
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbances and executive dysfunction make it hard to keep an hourly entry level job. I and my child thrive in environments where the quality of the work is what matters and we can complete it in our own time, such as in salaried positions. Sensory issues and low social battery make me require shorter but more frequent vacation times. For example, taking a 4-day weekend once a month as opposed to a 2 week vacation twice a year.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	These can make us more prone to disregarding our needs until we meltdown or burn out. OCD can make it harder for us to form relationships with allistic people who see us as weird because they do not understand our behaviors. It can exacerbate executive dysfunction challenges. We are more likely to require maintenance medications and services as in for ADHD.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Continue research on autistic presentation differences in adults. women and people of color compared to affluent, white little boys. Less abusive treatment alternatives to ABA. Continue research on overlap between ASD and ADHD.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Equitable access to diagnosis and coverage for OT, PT and Speech.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Showed us working in an autistic friendly way (from home) is possible and benefits the many people, not just Autistics. Companies just need to be held accountable to keeping these accommodations.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	See comment on previous question regarding work from home.

Name	Katya Siddall-Cipolla
Demographic	Autistic individual; Service provider, health provider, or educator; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Many co-occurring health issues are invisible disabilities, and autistic people may explain or experience symptoms differently than allistic people. Most doctors are completely inequipped to pick up on differences in symptom presentation due to sensory or communication differences.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Misdiagnosis of autism as depression or bipolar disorder.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The assumption that all autistic people have learning deficits, which excludes many autistic kids from diagnosis early, as well as the lack of understanding that autistic people can be highly gifted intellectually but still have deficits that need support. There are many gifted autistic folks who are also dyscalculic or dyslexic, but do not get any support because they're "smart."
What additional research is needed to help address co-occurring conditions for autistic people?	Research on adults, specifically those assigned female at birth, and inclusion of autistic parents in studies about children. We know nothing about autism and perimenopause, for example, but this is one of the hardest times for women with mental health and co-occurring conditions.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	ELIMINATE ABA COVERAGE REQUIREMENTS. Payers will not cover more beneficial services because they meet the regulatory requirements by only covering ABA, which is abusive and not affirming.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	There is a much higher rate of long COVID in this population, and people who were able to work and enjoy life are now almost completely disabled. It's a public health crisis.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Telehealth access has been a godsend, and remote school has been so helpful for our family to help reduce burnout in our child. It makes me sad to see so many beneficial policies of COVID be aggressively rolled back, like remote work.

Name	Kay
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I personally feel like the pain experienced from these conditions are amplified due to my autism and others don't understand that and think I'm overreacting.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Similarly to the last question, I feel that the hard parts of these conditions are amplified from my autism.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The hardest challenge caused by these conditions is that the majority of day to day activities in life are more configured to those without these conditions, leaving those with them alienated.
What additional research is needed to help address co-occurring conditions for autistic people?	I feel that reading different challenges faced by autistic individuals from reliable sources and how to help others with ASD can help.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I personally feel it's more complicated to socialize as an autistic person after the pandemic as the isolation hurt my ability to socialize in person.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The lack of a need to interact in person for most jobs due to working from home can be helpful for those who have trouble with socialization.

Name	Kayla Weant
Demographic	Autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory hyper/hyposensitivity, communication differences, sleep disorders
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD, anxiety, depression
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication differences.
What additional research is needed to help address co-occurring conditions for autistic people?	Updating the diagnostic criteria to better include girls, women, non-binary, and people of color. Look into the lasting harm of ABA therapy on the mental health of autistic individuals.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Lower the barrier of entry for adults, AFAB individuals, nonbinary individuals, and people of color to access diagnoses. STOP recommending the use of ABA therapy as the default treatment for autism.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Increased anxiety and depression
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Kayn L
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Hypermobility Syndrome: chronic moderate to severe pain in hips, knees, lower leg, back, elbows, and wrists
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD-C: medication makes autistic traits more apparent opposing stimulation, sensory, and energy needs, executive dysfunction and motivation issues Bipolar disorder type 2: co-occurring depression Bulimia: food, texture, and routine issues slowing recovery
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Research into comorbid biological and psychological conditions unrelated to a biological or psychological cause for autism
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More and easier to access services/testing for adults, especially those covered by insurance (state run and private)
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Kd
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory issues Seizures / epilepsy Genetic conditions Gastrointestinal disorders Migraines
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD — rejection sensitive dysphoria OCD Anxiety Depression Suicidality
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Dyslexia Social communication disorder sensory processing disorder Developmental disabilities— sometimes genetic disease linked Sensory processing disorder
What additional research is needed to help address co-occurring conditions for autistic people?	How these conditions overlap, how the symptoms differ, rates of concurrence, if there’s a genetic basis, difference between and alignment of autism and genetic conditions that mirror autism
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Improved patient and provider interactions for autistics with limited verbal language Equitable access to augmentative and alternative and communication devices— too much gatekeeping by service providers and lack of knowledge based on community, access, and privilege Equitable access to services based on geographical location How do we support those with genetic conditions which parallel autism? Do they also qualify for autism? How do we get providers and doctors on the same page about this? We need non behavioral based/ ABA treatment options for autism like Floortime, play therapy, etc. We need more public integrated preschool programs. In districts where there are limited spots (which is many) with the money For an advocate, get the preschool spots. That’s inequitable.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Autoimmune conditions, long covid, fibromyalgia symptoms are often worse for autistics. These have gotten worse with repeat covid exposure
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increased isolation; emotional dysregulation; lack of community connection could lead to worsening mental health conditions; remote services often offered first/ more available even when that’s not what is best for the individual; increased sensory issues

Name	Kelley, parent
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The inability to get medicine in a preferred form, such as having a sensory aversion to pills, yet cannot find medicine in any other form.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	1. Focus is in stopping the behavior instead of fixing the problem, or finding an alternative. 2. Society's view that problem behaviors, such as not paying attention, are something the person just has to learn to overcome, or that what works for a NT person (like a day planner), will work for the person with ADHD. When all it does is add another thing to do.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	1. In regards to intellectual disabilities, it is labeling people with severe IDD as severe autism. They may have autism, but the IDD is the significant issue. Not labeling the disability correctly tends to lump them in with everyone in the autistic population, and the strategies are often vastly different. 2. Helping with communication disabilities is too often focused on verbal communication, instead of all forms of communication. 3. Too often, the people helping are focused on what needs to change per their perspective.
What additional research is needed to help address co-occurring conditions for autistic people?	How the labeling of the disability affects the outcome and services. With everything being lumped under autism, research and services tend to lump very different disabilities together.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Kelli
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Getting overwhelmed and overstimulated very often. Eventually causing burnout and lots of stress on the body/mind.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Quality of life is poorer (or not being able to enjoy it fully), job difficulty with certain jobs causing extreme anxiety, difficulty communicating with coworkers and romantic partners, parenting is extra challenging, difficulty with friendships, people not believing or supporting you. Not enough mental health professionals that specialize in ASD. Or can't access the needed services as an adult.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Thinking differently, processing language differently, needing more accommodations etc in school. Having hard time articulating feelings and thoughts to NT people.
What additional research is needed to help address co-occurring conditions for autistic people?	More research is needed on women/girls with autism and co-occurring conditions. Also how not getting proper support early in life leads to these issues in adulthood. More on genetics and generational trauma and how that plays into it. How pregnancy affects autistic brains. And parenting as an autistic individual. And more psych training on how to support autistic people in therapy as we don't respond to same methods as well it seems.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage! Mental health services should be fully covered for autistic adults and the adult assessments as well. More teachers, psych professionals, and medical professionals need to be trained on supporting and caring for autistic people. Especially women and those who are high functioning because we are often missed/dismised. More supports for autistic mothers and parents. And more spaces for autistic people of all levels to find info, services, and friendship.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I don't have evidence, but my memory and anxiety/depression is much worse since having covid. And I'd assume it also has made my immune system worse. My knee joints also hurt for a very long time after covid.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Positive changes. Working from home has been life changing and helped quality of life so much. Much less anxiety about work. Like the not interacting with people as much and having to mask all the time is wonderful. I can take my time and make the work day how i want it to be. Don't worry about getting sick as much in the office.

Name	Kelly
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Difficulty falling asleep, audio and visual sensitivity, especially in places with fluorescent lights,
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, depression, postpartum depression, PMDD, ADHD (medication helps tremendously), cutting, alcohol use disorder, suicidal ideations
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Learning disabilities, social interaction disabilities,
What additional research is needed to help address co-occurring conditions for autistic people?	Research on the efficacy of assigning social workers to “functioning” autistic adults. I feel everything so intensely that it can become overwhelming. I just need someone to metaphorically hold my hand sometimes.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Social workers for autistic adults who are self-sufficient but could burnout at any time
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Severe anxiety and hypochondria, panic attacks, burnout, Raynaud’s Syndrome, tachycardia, increased sensory issues
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Kelly Howard
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Many of the co-occurring health conditions in autistic people cause aggression towards themselves, known as self-injurious behavior; or others like close family members, teachers, and therapists.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Many of the co-occurring mental health conditions in autistic people cause problems with memory and retention of skills learned; if they're even able to be taught.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	One of the most significant challenges caused by communication disability or developmental disability in an autistic individual is that they are not able to be tested on what they actually know. Expressive language is so low that you'll never know how much that person actually understands about the world or how they feel.
What additional research is needed to help address co-occurring conditions for autistic people?	As the mother of a nonverbal autistic child with a developmental delay, I'm actually not sure what needs to be done on a research level. I can tell you that as far as the medical community is concerned, including therapists, they need to listen to the parents more and stop throwing out the excuse "oh that's just autism."
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	My son's therapies were disrupted and his therapists were changed due to fear of cross-contamination of some kind. My son had a huge problem with the masks, as they block out social cues on somebody's face. It took him over 6 months to finally wear one but returning to school without the virus completely under control and having to go to school with a mask, started the ball rolling for me to completely withdraw him and homeschool.

Name	Kelly King
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	GI, lung differences, microbiome differences, lack of dental - particularly sedation dentistry, sleep issues, sensory and motor issues, intense behaviors of properly destruction, aggression and SIBs, speech and apraxia. Practitioners of all types commonly lack genuine care, flexibility and willingness to serve those with severe ASD, recognize underlying conditions, and to treat them holistically - they are unprepared. Diagnostic overshadowing is common and procedures, labwork and appointments can themselves be problematic. Facilities are ill-prepared to address the sensory, daily living and behavioral challenges. Hospitalizations add another layer of problems. Access to services, quality of life for the entire family, and health equity are all compromised. Waits for diagnoses and services can be long. School MH supports are variable and usually inadequate. Psychiatry, nursing, and density are a challenge; sedation dentistry means a year's wait. RTFs and ICFs have no space. Group homes are rife with abuse and neglect with low quality, poorly trained staff, lack transparency, and internal BS and incident handling are flawed. Group home to exclude and villainize families is commonplace.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	All of the above and trauma. Psychiatry has become psychopharmacology and the hypersensitive virgin system doesn't always deal well with the host of drugs prescribed. Psych hospitals add diagnoses - reportedly for insurance purposes - and meds for which other meds must be added to deal with side effects. It's the old throwing spaghetti and seeing what sticks idea; there seems little clarity on what will be effective for this population. Drug trials are often left to do in the family home.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	All of the above The shift of the childhood autism "developmental disorder" into the realm of labeling it a mental health condition simply because the individual turns 18 is concerning. Adulthood does not change history nor erase the developmental difficulties. A developmental disorder that persists into adulthood is no less a developmental disorder because one had a birthday.
What additional research is needed to help address co-occurring conditions for autistic people?	Much - with a focus on severe population. Physical lung differences; are there other physical differences Documented microbiome differences, how can these be addressed? Treating intense behaviors in effective ways. Medication research. Causal factors for common co-morbidities and how to treat effectively. ACEs, trauma and effective treatment (particularly to the non verbal) Investigative research, including surveys of staff, residents, and families around abuse and neglect, etc. in residential facilities.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Best practices are set aside at 18 - unless you are incarcerated. The neurodiverse fad backwaters the severe and nonverbal. Spelling to communicate is discredited leaving many without a voice. Trauma abounds with few of any skilled therapists to help the severe and nonverbal. Issues abound, the population increases, we're missing the mark.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	COVID left a mark: learning loss, ineffective remote instruction and telehealth, lack of exercise, isolation, habituation to the home and loss. Some have yet to leave their homes. Fears persist. Needed residential services (RTFs) were unavailable and remain so. Therapies ceased so treatment stopped. Teletherapy was most often ineffective and individuals disengaged. Is there effective grief counseling? Those in group homes were

	cut off from their family, many could not communicate and quality of care is questionable across the time period. Disruption of the schedule and routine precipitated an increase in MH issues.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Disruption in services Availability of telehealth, sometimes good, sometimes bad but available. Learning loss Job and skill losses Staff shortages and loss of support. Isolation, decreased social connections Supports systems cut off

Name	Kelly L. Nimitz-Rusch, DNP, RN, The Autism Collective
Demographic	Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	lack of understanding/education regarding what co-occurring conditions to expect/look for and how to treat effectively causing delays, under treatment or no treatment lack of care coordination of the co-occurring conditions lack of access to the services
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	lack of available services to manage co-occurring mental health conditions and support to families/caregivers we are seeing high number of children, young adults taken to the ED (family feels unsafe or the residential home they are living in feels outbursts cannot be managed). They are then boarded or inappropriately placed on an inpatient unit (not behavioral health unit) because there is not a safe discharge plan. There are no available beds at appropriate facilities (or facilities saying they are unable to take them because of their autism). We have seen autistic individuals in hospitals for months waiting for appropriate placement. It is horrific situation.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Lack of appropriate IEPs or adherence to IEPs Teachers tell us they have not had enough education on autism to understand how to best address or management within the classroom setting Classroom aides or assigned 1:1 have not had education on autism and while well-meaning often utilize interventions that exacerbate the behaviors rather than help. Lack of sensory or calm rooms in schools
What additional research is needed to help address co-occurring conditions for autistic people?	There is a need to identify individual autism genotypes that could assist in predicting symptom subtypes. This could inform targeted interventions for specific symptoms that much earlier.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	From my perspective there is a much needed overhaul in this area. The current healthcare system is not designed to address autism. There is a lack of support, access, knowledge, insurance coverage to support an autistic individual through the lifespan. We have a piecemealed system.... autism impacts each part of the co-occurring condition. The individual may have severe communication limitations impacting his/her ability to appropriately communicate stomach pain which may lead to delayed identification of GI issues. GI issues can directly impact sleep, and exacerbate behavioral and psychiatric disorders. While it is great to have autism centers, we need to transfer this level of healthcare expertise beyond the centers. ECHO Autism is a start but we need transfer of knowledge that provides the means for physicians, APNs to diagnose with confidence and understand the co-occurring conditions that should be considered. They need access to experts (physician to physician consult) so that patients can be managed by primary care with the comfort of know they have access to experts with a phone call. We need to think of out the box and identify way to expand access and ensure insurance coverage is there to support the interventions/care needed
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Not entirely sure we know at this time. We believe there was a delay in diagnosis as many of the gold standard diagnostic tools could not be administered with masks on. Needed early intervention services were delayed and early interventions result in better outcomes. As routine and structure is often important regulating factor, many found autistic individuals suffered from severe dysregulation, inability to understand the change in routine, and frequent meltdowns. This impacted the family structure as many were ill-equipped to handle this level of meltdown on daily basis.

What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

Name	Kelly Tabeling
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Accessing education in a school environment
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Accessing education in a school environment
What additional research is needed to help address co-occurring conditions for autistic people?	Pathological Demand Avoidance is an area that desperately needs further research. We have had a very hard time finding a provider who understands the unique profile of PDA, which makes it hard to get an autism diagnosis and the necessary services.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More education for teachers and providers.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Ken
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I do not know if this is related to autism, but I have three autoimmune diseases: Crohn's Disease Celiac Disease Type 1 Diabetes I attribute my autistic focus to learning the mechanism of action for each of these diseases in order to manage them to non-disease levels. My methods do not follow the medical establishment, however, they are successful, resulting in symptom and complication free.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I suffer from anxiety, depression and suicidality. Each of these is primarily due to society's rejection and bigotry of my social differences from typical. As such, I am fine when alone. I would be fine socially also if my differences were accepted. Society is a very rigid component of the human species. Members of most non-human species accepts me as I am, making me comfortable in their company. Interesting that that never occurs with humans.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Throughout school, I was regarded as [redacted]. However, I am now retired from a very successful career as an electronics design engineer. In school, I was considered to have a learning disability. The reality is that I have no problem learning, however, I have a problem being taught. Being taught is a social process inducing social anxiety making learning very difficult. On my own, I can learn just fine. Verbal communication disability is due to my lack of control of my tone and expressions. The other person includes tone and expression as part of the communication, but I have no control of that. They always interpret something more than the words I speak, creating confusion and frustration. This is a known issue called the 90 percent rule.
What additional research is needed to help address co-occurring conditions for autistic people?	Greater understanding of the social interpretation which induces social anxiety. Anxiety can be very debilitating and physically compromising. Many autistic's suffer from extreme sensitivities that can result in unhealthy lifestyles such as food, etc. It can also prevent some health related hygiene activities. Social anxieties can prevent autistics from visiting health care services, etc.In my case, social anxiety is my greatest issue. If left alone, I can easily and successfully take care of myself. I sent my primary care physician a letter describing my autism. She actually read the letter and changed her interaction with me to prevent traumatic social anxiety resulting in a very calm, successful appointment. Basically, what's needed is more understanding and acceptance. It is so often considered that if someone is "different" they are defective and need "help". Typically that help, however actually makes things worse - confusing the helping professional.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	For service providers to understand and respect autistics and learn how to understand and interact with them. A high percentage of early diagnosed autistics are tragically taught to be debilitated. This is typically due to misunderstanding autistic responses, mannerisms, etc. It also results in debilitating anxiety for the autistic. The goal is always to fix them and make them behave like "normal" people. This never worked for me, but leaving me to be me resulted in my very successful career and life. Just let us be us. We can do fine, if you just let us and avoid pushing us which only elevates debilitating anxiety.
What lasting impact has COVID-19 infection and illness had on co-	For me, the COVID-19 lock down was a great relief. The solitude was a great benefit to me. The isolation helped me build the strength to get all the

<p>occurring physical and/or mental health conditions for autistic people?</p>	<p>COVID vaccinations, boosters and tests. As a result, I never got the virus or any symptoms.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>The COVID-19 pandemic occurred after my retirement, so there was no work related issues. I found telehealth to be awkward, but functional. I prefer in-person visits as long as the doctor and staff understands and respects my autism and treats me accordingly. Reduced in-person social interactions and obligations was a benefit, dramatically lowering my overall anxieties.</p>

Name	Kendahl Damashek
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Nervous system disabilities presenting as behavioral challenges (Pathological Demand Avoidance), sleep disturbances (including narcolepsy), sensory challenges
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Pathological Demand Avoidance - behavioral expressions of this co-occurring nervous system disability, which is often misidentified as many of the listed mental health conditions, in addition to Oppositional Defiant Disorder and eating disorders, are incredibly destabilizing and disabling. Adaptive measures are also negatively impacted. This is made worse *because* PDA is understudied, and traditional guidance advises using behavioral modification strategies (like ABA or reward-sanction paradigms) that are contraindicated in PDA individuals and worsen the disability/push the autistic individual into trauma.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Many autistic people are gestalt language processors, but this is not taught in most speech pathology programs. Therefore autistic individuals are treated as though they are disordered analytic processors, when they actually have a different method of acquiring speech altogether. This means that resources are used ineffectively to apply moot strategies to the majority of autistic people with speech delays.
What additional research is needed to help address co-occurring conditions for autistic people?	Research on Pathological Demand Avoidance (see preliminary studies by Noelle Carlozzi at University of Michigan). It needs to be studied so it can be recognized officially as a disability and its parameters defined--for both internalizing and externalizing PDAers. Additional research also needs to be funded in Polyvagal Theory (Stephen Porges), which explains the suspected root cause of PDA. Research on gestalt language processing would also be incredibly helpful.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Many services are rendered through school districts, whose assessments target different goals than the actual autistic person wants. Respite should be provided to every family with an autism diagnosis, w/o additional bureaucracy. It has taken me years to finally be awarded respite; now that we have qualified (through OPWDD in NY), we are not given a case manager b/c my kids are too young. I have to do another application to receive funds I've already qualified for, after determining myself which agencies in my area are contracted. Pathological Demand Avoidance is not either heard of or respected by most professionals in the United States, so the guidance/support services offered--if at all--are inadequate/contraindicated. Insurance companies only cover ABA therapy, which the majority of autistic adults agree was abusive and traumatic for them. Diagnosis is a privilege; most insurance companies don't cover this, esp for adults, even though the diagnostic criteria in the DSM has changed since we were children. There aren't services available for "high functioning" adults. We have difficulty maintaining adequate work, but if we can't afford diagnosis, we also can't receive services/SSDI. Executive dysfunction is a symptom of autism, but the bureaucracy required to receive assistance is labyrinthian. Many people can't access resources *because* of their disabilities. Autism is genetic and it

	is highly likely that the parents of children needing support also need support.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Brain fog, inflammation that exacerbates diabetes
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Kenneth Kaye
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gastrointestinal disorders are one of the most challenging physical health conditions that affect me, followed closely by sensory issues. They have an immediate and daily impact on my ability to function as required by society and the quality of my life.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression, anxiety, ADHD, and the sub-categories of Autistic expression such as PDA make being a functional human being a challenge on the best of days and impossible on the worst.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Issues associated with the expression of ideals and the definitions of words and their meanings are the most challenging from this "other conditions" category. It's damaging to my mental health and well-being to live in a society that claims to value and respect fairness, equality, honest, and doing the right thing when all experiential evidence indicates that none of those things are actually valued or respected, but rather mocked and disrespected.
What additional research is needed to help address co-occurring conditions for autistic people?	Research about the origins of, treatment for (which doesn't indicate medication alone), and accommodations for autism that doesn't have any preconceived notions inherent in the research about age, race, gender, or other factors and treats it like a first-class issue that deserves the full attention and respect of the researchers involved.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Universal insurance coverage for autism diagnosis (heck, Universal Health for all for that matter), laws that protect and defend the neurodivergent in the workplace, and process and system alternatives that allow for differing sensory experiences for equitable access to services.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I don't have enough context to provide an answer for everyone, but for myself long term physical condition degradation as well as mental degradation are apparent, and affects me not only emotionally, but also in my ability to provide and care for myself.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The shift in the American workplace to remote for many technology-based jobs has been an incredible help for me, and people like myself, who get overstimulated in office spaces, who can't relax and focus in those spaces, and who get anxiety being around people. The improvements to telehealth, while modest, are also greatly useful and appreciated.

Name	Kerri Greig
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The biggest problem is being listened to and having these co-occurring physical challenges acknowledged. I wish there was more understanding and acceptance. Poor sleep and hyper sensory challenges mean being wiped out: physically, mentally and emotionally and therefore overly wired and on edge. This makes interacting and relating positively with others an additional challenge.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	For me and my family, it's running out of mental spoons that creates problems. For us, the anxiety (and some depression) is because it's just plain HARD to get through the day without feeling so depleted. It robs us of the joy of being laid back.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I don't like the term learning difficulties. If rather say learning differences. That's what suits myself and my family better. What would help, is to have explanations given in a logical sequence and then to go over it all once we have the whole story. So, maybe this will answer better - or is a significant challenge when information is presented in a way that only gives small pieces of information that seem irrelevant until afterwards. We need to know what info is the most relevant / important - and why. Knowing the 'why' can make a whole heap of difference.
What additional research is needed to help address co-occurring conditions for autistic people?	More surveys like this I imagine. Actually speaking with autistics who have the lived experience, and listening to all of our voices. It's only the people with lived experience that can be referred to as the real experts.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Administrative / executive function type of assistance. It's honestly so difficult to get through the red tape hoops and it's so draining, so some of us stop looking for official help or apply for services. And less feeling like we have to prove ourselves deserving of the help. Less judgementalism etc.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	No idea. I wouldn't think that would have such a significant impact as to warrant it's own question.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I think the main positive changes are more access to online meetings / telehealth appointments (& them being considered more acceptable in general society). The other main impact for our lives was having the time for self reflection which resulted in us realising we are in fact autistic with ADHD, which we weren't cognitively aware of prior to that. We knew we weren't like most other people, just hadn't been able to get to the bottom of it.

Name	Kerry
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gastro/metabolism of nutrients
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, adhd
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication disorder
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	My son spent nearly 15 years of his life suffering from anxiety and being medicated for anxiety at the highest adult dose. Only serendipitously did I discover that he suffered from low ferritin saturation-chronically. No doctor had tested this since his cbc was all within normal (though often right at the cut off number.) Once he began iron pills daily he was able to stop taking anxiety medication completely. His low iron status was causing the anxiety (and other problems) . Not one psychiatrist, psychologist or pediatrician tested his iron status despite it being a known ride along with autism and adhd. The government must mandate testing for known issues that co-exist with autism and recommend testing for immediate family, as well.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	None.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	None

Name	Kerstin Powell
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Other occurring disorders disrupts the patient's ability to self regulate. Sleep issues, anxiety, GI issues, even a common cold, can send an individual on the spectrum into a spiral. Many autistic individuals struggle to communicate discomfort, and, even if they can intimate that they don't feel well, they may not be able to tact body parts or conditions that are making them uncomfortable, adding to the communication frustration that manifests in maladaptive behaviour.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Many autistic people who have the official diagnoses are not treated for co-morbid mental health issues such as anxiety and OCD, depression and suicidal ideation. There is a tendency to see the autism diagnosis and pin everything happening with the individual on that ONE thing, despite evidence to the contrary. Pathological demand avoidance (PDA) and pediatric acute onset neuropsychiatric syndrome PANS/ PANDAS) are little understood to begin with, even moreso for individuals with autism.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	In my own experience, the mental health, learning disabilities, and, social communication challenges prevent many autistic individuals from being able to access care. Again, people see the autism and don't treat the co-occurring problems as a different set of problems for the individual.
What additional research is needed to help address co-occurring conditions for autistic people?	The institutions are 10 years behind the current research. A robust implementation of a sensible standard of care would be one thing, using research already done and getting up to speed with best practices is potentially helpful. Also caregiver support and helping families afford therapies that are salient would be nice.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Access to affordable healthcare. Coverage for ABA and other evidence based therapies. Access to affordable mental health coverage.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Everyone has mental health problems post covid. That whole thing did not have to happen, regardless, isolation and unpredictability, loss and pain, all of that has a negative impact on people in general. It was a struggle for everyone, worse for those who depended on their routines.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	All negative, disruptions in employment of caregivers leading to more poverty, not to mention the fact that people with special needs individuals in their families are hurting and struggling with basic daily needs. Childcare is a big issue with employment. Public schools are not properly equipped to deal with individuals with autism to begin with.

Name	Kevin Gerrity, Project Beacon TX
Demographic	Family member of an autistic individual; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My son is severely autistic/non verbal, and some of the co-occurring health conditions that he demonstrates include pica, self injury behavior, gastrointestinal disorders, (infrequent) seizures and inconsistent sleep patterns.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	To me, with my son, the most significant are the self-injurious behaviors and pica. While the others he displays (from my response to the previous question) are serious, these two are the most significant. He is rarely aggressive toward others and does not (currently) demonstrate any suicidal tendencies.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The most significant challenge is finding proper care and treatment that will allow him to become the best version of himself. My son can learn, and improve from these behaviors, but it takes time and the proper approach/treatment. He made progress while in his post high school special needs program but will age out this year and there are limited/no viable options post 21.
What additional research is needed to help address co-occurring conditions for autistic people?	There is all kind of medical and therapeutic research that can be done to help address/improve these conditions. Unfortunately, with autism, there is rarely "one answer" given the wide variety of issues and support levels in this community. At the federal level there should be a willingness to listen to parents and self advocates from across the spectrum to understand priorities and then work with private industry to launch some of these higher priority research opportunities.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	What (to me) is the most critical area for improvement is the post- 21 educational, vocational, social and (most importantly) residential opportunities for this population. It varies greatly by state, and even the most "progressive" states have backlogs, issues with the quality/pay of care providers, quality residential options, etc. We need to figure out where these guys are going to live/work/learn for the rest of their lives, after their parents pass, as a priority.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I do not have a view on this question...I do not see my son being impacted...more of an impact on the caregivers
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I think the biggest thing here is the disruption of services, and the slow rebound in getting quality staff back in sufficient numbers to support the population.

Name	Kevin Ryle, Association of University Centers on Disabilities and the Autism Society of America
Demographic	Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Research demonstrates that individuals diagnosed with Autism experience frequent gastrointestinal symptoms, and those symptoms are associated with “an increase in self-injurious behaviors, somatic complaints, reduced sleep duration, and increased parasomnias (Restrepo, et. al, 2020). Initiating sleep and being able to maintain sleep are known challenges for Autistic children, as is sleeping for excessive periods of time and night sweats (Romeo, et al., 2021). Epilepsy prevalence is much higher in the Autistic population than in the general population, and experts believe there to be a connection between the two disorders (Besag, et al., 2017). GI problems, sleep disturbances, and sensory differences all correlate with anxiety. Substance abuse and eating disorders have become more prevalent in the Autism community over the last few decades. While typically categorized as psychiatric disorders, these disorders clearly affect physical health and life quality when they co-occur with Autism.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	For decades, mental health needs of individuals diagnosed with Autism have been misdiagnosed, ignored, and misunderstood. About three-quarters of children diagnosed with Autism meet criteria for one mental health condition, while one-half meet criteria for two. Feeling one must blend into a neuro-normative society – called camouflaging, or masking – may create distress that leads to mental health conditions, including suicidality (Cleary, et al., 2023). Females and members of the LGBTQ+ community have reported the distress they experience with masking. Several studies, including Cassidy et al. (2018) have found that Autistic adults are at significantly increased risk of suicidality. Co-occurring mental health conditions can exacerbate challenges for individuals in school, social relationships, independent living, employment, and personal safety. Crisis beds for those experiencing a psychiatric emergency are limited in most areas, and not available in many areas of the country. Emergency room professionals are under-trained in how to identify and support the mental health needs. People with Autism experiencing a mental health crisis deserve a mental health response. Some families must resort to calling law enforcement to help with a crisis. These situations too often lead to unnecessary incarceration, harm, or even death. Community-based programs rely on funding from programs like Title XIX Medicaid Home and Community-Based Waiver programs with limited funding (waiting lists).
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Schools are often not equipped with the tools or personnel to help a child who has Autism and a co-occurring disability to manage their behaviors, and this results in a lack of access to an education with their peers without disabilities. When children reach a “transition period,” their school programs set up experienced-based learning experiences, like going to work at a local organization. Children with challenging behaviors are often not included in these learning opportunities because the businesses that contract with schools will not work with students. Students with Autism and behavioral needs are not given the same opportunity to learn about independent living skills or employment. Students with Autism and co-occurring conditions are often subjected to outdated discipline guidance, causing them to miss critical points in their education. Restraint, seclusion, and school dismissals are practiced around the country, and cause students to miss class time, thus falling behind in their education. Individuals with Autism and co-occurring intellectual and mental health disabilities too often end up in the criminal

	<p>legal system. Social and communication challenges present significant barriers to navigating legal proceedings as an Autistic person, and courts generally fail to consider Autism a mitigating factor in proceedings. This is especially true for individuals with Autism that intersect with BIPOC communities.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<ul style="list-style-type: none"> •Psychotherapy is not often available, nor is it effective when attempted. Counselors are taught to develop a therapeutic alliance through social cues, open-ended questioning, and reciprocal dialogue. This maybe a significant challenge for people with Autism. Identifying effective psychotherapeutic techniques is an important area of research, as is counselor education about Autism and effective therapeutic strategies. •More research into sexual and gender identity in the Autism community is needed to support health. •The needs of females diagnosed with Autism need to be better identified and understood. •Employment-related research, such as how to make the workplace “Autism-friendly.” •Strategies for effective transitions into adulthood, especially in rural areas needs more research. Research into using modern technology to better facilitate employment, housing, education, etc. – especially technologies and strategies developed after the pandemic – should be a priority. •A national task force of experienced clinicians should be created to develop a Gold Standard protocol for diagnosis. •A new intervention research network focused on communication needs, in particular, alternative augmentative communication (AAC) should be created. 25-30% of individuals are non-speaking or minimally-speaking. Individuals need access to communication assistants and/or devices. Additional research to develop evidence-based AAC devices and methods.
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Unintentional bias in the medical community – specifically the medical practitioner tendency to presume co-occurring physical and/or mental health issues are the result of Autism – is a well-known, long-standing issue in the Autism community. This presumption may occur inadequate medical and psychological training, inexperience of the physician, or even the communication challenges an Autistic person may encounter with contacting a doctor. Inequitable access to services often leads families to have to wait months to receive a diagnosis, and then sometimes years to receive services. A survey conducted by CMS showed that 60% of centers surveyed had over a 4-month waiting period, mostly due to workforce shortages (cms.gov). Additionally, the process of acquiring a diagnosis must be more affordable and accessible for Autistic people. Another important service that must become consistent across the country is Autism-specific training to law enforcement and first responders. Individuals diagnosed with Autism have unique communication and behavior that may cause those professionals to be suspicious of their behavior. It is known that about 20% of all Autistic people have an interaction with police by age 21; for the safety of Autistic people and those first responders, training is a necessity. A few states, such as West Virginia, have this training codified into legislation. Other states must, too.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>We need research into the impact of long COVID on this population as well as the general population. With increased anxiety of many Autistics, the fear of contracting COVID and fear of death of oneself and for loved ones has left an impact on people diagnosed with Autism. Anecdotally, Autistics have expressed significant trauma related to being isolated during the pandemic.</p>
<p>What lasting positive or negative impacts have societal changes due to</p>	<p>Anecdotally, numerous individuals diagnosed with Autism have experienced mental health benefits by being able to work remotely, as well as access</p>

<p>the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>health care via a telehealth option. A significant negative impact would be the lack of social skills that young Autistic children were exposed to during the pandemic, and those children now struggle able to integrate into what we would consider a traditional school environment (i.e. lack of social distancing, hugging/handshakes, masks, etc.). Doing school from home allowed students diagnosed with Autism to learn in a more comfortable environment, and many students are struggling with the transition back to more in-person scheduling. More Autistic students and parents are continuing homeschooling, despite schools going back to in-person.</p>
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Name	Keyunna Harris, Caregiver
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory and motor-challenges when the autistic individual is non-speaking and do not have the motor strength to work with a standard AAC device. Gastrointestinal disorders due to limited diet and sensory challenges, but no means of communicating those problems.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	High support needs/non-speaking autistics, for sure my daughter, face challenges as soon as she wake up until she possibly finds sleep. When there are communication deficits along with developmental and learning disabilities, teachers give up on the child. A difference in brain functions immediately equals intellectual disability because of the lack of understanding or training on autism in the public school system. For example, most high support needs autistics will not be able to fill out this survey because of the broad questions and no clear modeling of the answer. High support needs autistics with other conditions will still most likely not be heard.
What additional research is needed to help address co-occurring conditions for autistic people?	Patterns in learning for non-speaking high-support needs autistics. Research on how to teach and empower high support needs autistics to hold meaningful and influential careers. In addition, research on medical deficits and biomedical research on the cause and ways to alleviate some of the debilitating autism symptoms.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Accessibility of services and government funding for therapies and family care help.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	

in-person social interactions and obligations)	
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Name	Khalila
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Low energy, orthostatic intolerance
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Trauma caused by lack of childhood treatment or autism-based abuse/neglect.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Research on ADHD-autism connection, and autism-EDS-POTS-MCAS connections.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More providers for autistic adults, providers trained in autistic communications, less chances for one provider to prevent care.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	COVID-19 infections can cause worsening of physical conditions such as POTS, common in autistic people.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Emotional distress over gap between current data and public attitude.

Name	Kia Green, Emerge, Inc.
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	As a provider of services of some individuals with Autism who are also nonverbal, the most significant challenge is understanding when they are in pain and where the pain is. We are often unaware that someone is in distress until its really bad or too late. It is very frustrating and upsetting for the individual, their families, and loved ones. Many individuals have not received proper medical care from healthcare professionals who understand where and what to look for. .
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Medication side effects and desired effects in individuals with Autism are not the common effects. Person's with Autism are often outliers from what is considered the medical norm. Many of the symptoms of the co-occurring mental health conditions simply result in aggression as a result of the person's inability to communicate. Even in persons with Autism having language skills, it is often not the appropriate language which can be extremely frustrating and also dangerous.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	For persons with Autism and disabilities, stigma is still an issue. Housing for those who are in services and/or living with families, is still not comparable to society. Services are hard to acquire for those who were not identified in the school system as potential recipients of support. Services are almost non-existent in rural areas, in more populated areas staffing and support is a major challenge.
What additional research is needed to help address co-occurring conditions for autistic people?	More research regarding the GI sensitivities of those with Autism may help with understanding a lot about other co-occurring conditions.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Autism Awareness, Autism is a spectrum of disorders. Most people hear and see information about Autism but there are so many horror stories, old wives tales, and falsehoods surrounding Autism. The promotion of truth backed by evidence based research should be shared everywhere, in schools, in the workplace, on the news.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Many individuals in my care with Autism regressed. It have been very hard for them to return to life as it once was. Many preferred activities no longer exist. Many individuals just cant bring themselves to leaving the home. Many others have developed a change in compulsion and or obsessions.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Access to more of the world virtually has been a positive impact.

Name	Kris Guin, Queerability
Demographic	Autistic individual; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	As an Autistic person recently diagnosed with Type 2 Diabetes, I have found most forms of treatment for diabetes inaccessible to me.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Diabetes treatments often involve taking medications that require certain timing which is challenging for Autistic people who have executive dysfunction. Diet is also a way that diabetes can be managed, but many Autistic people have certain sensory sensitivities to different kinds of foods.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	More research is needed into how to treat diabetes in Autistic people.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More training for medical professionals in autism.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Kristen Brake
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory motor coordination
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Attention deficit disorder
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication and speech delay, learning disabilities, developmental disabilities, and intellectual disabilities
What additional research is needed to help address co-occurring conditions for autistic people?	Teachers need to study/acquire specialties in order to teach our students. For example: Wilson reading certifications, learn how to teach math to kids with dev delays and autism.../ education needs to be researched.... No one knows how to teach our kids. They just want to put them in self contained classrooms and teach them life skills which they can learn at home. They should be going to school to learn how to read write and add and subtract.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	General family practitioners need to learn about autism and how to interact with people with autism.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	The [profanity redacted] downs that occurred with the pandemic have been catastrophic for individual with autism. Telehealth is a joke and does not work with most children on the spectrum. Long wait lists have been made even longer since Covid pandemic.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increased use in telehealth is basically equal to no treatments or therapies. Prolonged remote school has completely negated learning for someone with learning disabilities and is way farther behind than she would be. Societal changes include lost time of in person interactions... making friends and experiencing social gatherings and learning how to interact with people in general.

Name	Kristin Botwinick
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Binge-eating/obesity
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Binge-eating, excessive eating
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Interested in interventions to assist in weight loss/excessive eating. Traditional interventions e.g. CBT, hypnosis, psychotherapy seem to elude my son due to his executive functioning issues and intellectual disability
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Simpler process to explain and facilitate enrollment in various programs eg insurance and self-direction. Fund initiatives that truly increase the wages of support staff and thereby improve the quality of workers
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Some young adults were left with nothing as far as programming, supports and services for years as there was a drastic slow down in processing applications
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Given the extreme delays in processing applications for supports and services, along with the shutdown of community based programs, young adults on the spectrum were left even more isolated and in turn more depressed

Name	Kristin H.
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbances - difficulty falling to sleep and frequently waking up in the middle of the night.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	OCD
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Finding the right educational resources to teach a non-verbal child how to read etc. more over, the right resources to test how to know what the person is cognitively capable of. For example, I know that my nonverbal autistic child is able to read as he can independently point to sight words, consistently even though he was never taught to read . I would love to find an educational program that allows him to further his literacy skills and also test his literacy skills so that I might know exactly where he is academically. Most of the assessments and curriculums out there require a verbal component.
What additional research is needed to help address co-occurring conditions for autistic people?	More research into the G.I. system, and its effects on autism
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	All of the above
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Covid took my then five-year-old out of a school environment and prevented him from having the education he needed at such a formative age. In addition, he regressed in terms of toileting, and went from almost 100% potty trained to not potty trained anymore At eight years old.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Academics were completely stopped for a period. My son was unable to attend school. He was unable to learn via telehealth models that were tried therefore, they disruption and services increased remote schooling an increased use of telehealth all affected him significantly

Name	Kristina Funk
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Pain not addressed or believed. Sleep disorder from childhood to late adult either never addressed or treated then medication removed. Various gastrointestinal problems. Hyper-mobility in joints becoming more disabling with age. Postural orthostatic tachycardia syndrome not addressed or treated.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression and anxiety that could be addressed with proper education for providers AND patients. Psychologists and psychiatrists who are not specialists cause distress in patients with inappropriate care.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication, whether lack of speech or gifted talent overlooked.
What additional research is needed to help address co-occurring conditions for autistic people?	How to support families and providers with education.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	The APA and AMA have acted to reduce specialists (for example, behavioral analysis) from the health insurance marketplace. Education professionals are not supported financially, and schools in the USA use up the lifetime insurance caps for individuals before they are out of elementary age.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Hypermobility joint damage and cardiovascular health
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Being able to work at home

Name	Kristina Tober, parent
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	sleep disturbances, dysregulation (both physical and emotional) that is unpredictable and can turn into dangerous behaviors (both self-injurious, to others, property damage) within seconds, seizures
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD, aggressive and self-injurious behaviors, loud outbursts in public, inappropriate sexual behavior (disrobing in public), elopement and complete lack of safety awareness, manic behaviors
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	inability to communicate, intellectual and developmental disabilities, behaviors that arise out of an inability to effectively communicate needs/wants
What additional research is needed to help address co-occurring conditions for autistic people?	We need to understand how the lack of acknowledgement around profound autism and deference for neurodiversity is impacting families, funding and supports for these individuals
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Access to high quality care, continuing behavioral supports into adulthood, safe residential placement where these individuals can still have access to the community, interact with peers, live meaningful lives, job training, FUNDING!!!!
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	The isolation and complete lack of services during the pandemic had a far greater impact on this population than the virus itself.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	If you look at the impacts of social isolation and discontinuation of services during COVID on typically developing kids, multiply that by 10x. How do you explain to a profoundly autistic individual with ID/DD that they have to stay in your home, no more access to the activities they relied on for support, development. These individuals required 24/7 care -- and families were left bearing the total burden and stress of that during COVID.

Name	Kristoff Furgiuele-Weis
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbances and sensory challenges. I've always had sleep issues since I was very little.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Aggressive self injuring behaviour, depression
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication disabilities
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Depression has gotten worse
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Disrupted schedule changes

Name	Krystin LaBarge
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	ARFID has minimal resources available to navigate nutritional deficits. Parents and individuals should have safe and neuroaffirming guidance available to help expand dietary options that may alleviate gastrointestinal issues, increase immunity, assist with interoception challenges, and lead to a more satisfying and fulfilling life. Motor differences such as apraxia and dyspraxia are often overlooked yet highly impactful. It seems everyone is focused on behavior but lack the understanding of motor differences that can directly correlate to intense feelings of frustration and sensory overwhelm that motor challenges and their being misunderstood or unrecognized can lead to.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The challenges are many in a population of people who have been understudied and underrecognized are vast. AI Depression, anxiety and panic were co-occurring in my life and largely overshadowed my autistic traits and masking. These impacted my ability to obtain a traditional education, access higher education, or enter into a reasonable career despite being targeted for accelerated and gifted programs. Self injury is also very impactful and often a result of unmet needs of the autistic individual who is misunderstood. It can often be a coping mechanism gone awry while the individual is compensating for an outside source of stress.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Learning disabilities being under resourced or misunderstood can lead to depression, anxiety, lack of self confidence, and feelings of hopelessness. The category of learning disability should also expand to include the ways that not only dyslexia is misunderstood but hyperlexia as well. Hyperlexia being seen as entirely strength based can be problematic in children who commonly struggle with comprehension to match their strong decoding skills. Learning disabilities need to be found and resourced at earlier ages, and supported throughout their time of need. Communication disabilities need to be resourced- no individual should struggle to access any multimodal system of communication. AAC and sign language should be commonly taught, funded and resourced in classrooms and public spaces. Non speaking advocates need to be at the center of policy and education.
What additional research is needed to help address co-occurring conditions for autistic people?	The research to address co occurring conditions needs to include autistics who have been historically understudied and dismissed from the data- individuals raised as female, people of color, socioeconomically disadvantaged, and those in the LGBT+ community. We need access to adequate and accurate assessments, resources to assist in our day to day lives, readily available and educated medical personnel, neuroaffirming mental health guidance, accessible education, and employment.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance needs to resource far more than ABA, which many autistic individuals find harmful and abusive. Access to services- including assessments needs to be more timely. Wait times for an initial evaluation are commonly 18 months +. In my family's case the overall process took 7 years to arrive at a diagnosis for a child, gatekeeping precious resources and educational support in the process. Therapies to assist with apraxia and dyspraxia should be readily available, and would inadvertently assist with common dysregulation struggles as well.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I am of the belief that we are not yet fully aware of the extent COVID19 and has impacted co-occurring physical and mental health conditions, but I have experienced odd health occurrences after having COVID myself, and have many family members who fall into the autistic realm. We have very little data on the experience of perimenopause for autistic individuals, so it is also

	<p>hard to differentiate that with post COVID or Long Covid possibilities. But symptoms pertaining to commonly co-occurring conditions like POTS have been far worse after COVID- more feeling faint, light headed. Very easily fatigued even after extra rest. Brain fog. Autoimmune responses with no prior history before COVID illness. Gastrointestinal conditions worsened and I received a diagnosis of EPI, among other increased infections. My autistic child has had recurring headaches and migraines after his illness. We all continue to struggle to fight viral infections with immunity theft. And all have far mentally weaker health than prior to COVID. Currently I struggle to leave my house and have anxiety attacks often.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>In my experience the changes brought about by the pandemic are the realization that we can be so accommodating for individuals who have social differences and challenges, offering zoom connections and digital schooling (which was a highlight for my autistic child who no longer had expectations held over him related to eye contact, fidgeting, or doodling), but then increasingly rolling those options for digital interactions back with an attempt to “return to normalcy”. It reverses everything the pandemic showcased about disparity for social demands autistics face. I do think a positive that came out of it are the agencies that have offered more flexible, at home career options. And some are understanding of the increased need for sick and personal time.</p>

Name	Kyla
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	PDA
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	PDA ADHD PTSD Complex PTSD
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The continued stigma that autism is an intellectual disability
What additional research is needed to help address co-occurring conditions for autistic people?	PDA research
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Easier access to supports- fewer barriers
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It has compounded significantly
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	That virtual services are possible - this needs to be an automatic accommodation permanently offered

Name	Kylie
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory motor and gastrointestinal issues
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety Aggression
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Learning, developmental, Intellectual, sensory overload
What additional research is needed to help address co-occurring conditions for autistic people?	More research needs to go in to the different profiles of autism so they can be more understood by the people around them. For example teachers and support staff.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Access to support services and accessibility to services in all areas. In rural areas there is not enough support.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Socialisation is much harder due to Covid 19 and being locked up all that time.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Definitely disruption in services and societal changes. Anxiety has increased as a result of not being able to go to school. Covid really had a set back for us as socialisation was already hard and it has exacerbated greatly since lockdown.

Name	Kym Pettitt
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	For my son, it is: Type 1 diabetes Celiac Disease
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Developmental disabilities
What additional research is needed to help address co-occurring conditions for autistic people?	How to improve medical care
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Patient provider interaction
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	L. Void
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gastrointestinal Disorders- IBS-D (Stress is a major trigger. Every day I go to work, I get sick to my stomach) Gerd Episodes of pancreatitis Sludge reported in gallbladder Other- Insomnia Deviated septum Impacted wisdom teeth Severe allergies
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have a 'good' salaried job, but my mental health is a disaster. Waking up- I'm always filled with dread and never well rested. I'm filled with fear on public transit, battling panic attacks and the urge to cry. My office stress causes severe physical illness, and I'm forced to work through it, fearing job loss. I suffer from PTSD, enduring & hiding my flashbacks throughout the day. Taking FMLA would mean a financial nightmare, and I fear resentment & retaliation for taking time off. At home, I'm crushed by depression, unable to handle basic tasks. This job is killing me, but I can't quit due to the need for health insurance. Alternatives like COBRA or disability are out of reach. The American worker's condition, especially for the disabled, is a cruel joke. I can only hope for an early grave.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I've lost months of memories this year recovering from ptsd. My short term memory was also massively impacted early on after the trauma. I needed direction from my employer in writing but my boss didn't understand. He just kept getting mad that I couldn't remember things he rattled off in passing the day before. I tried to explain that I was having flashbacks and crying spells, sometimes derailing myself from work for up to three hours at a time. He chose to believe that I've just become disillusioned with the job and I'm quiet quitting when I disappear during these episodes. No one gives a [profanity redacted] what I'm going through until I file the paperwork for accommodations. And as soon as that happens- I will be the bad guy. Sure, they'll comply. But they'll also be more critical of my work in other areas or maybe I'll be the next one laid off, failing to meet some new metric they've manufactured. No one cares about us. Everyone thinks their own battle is just as hard, so why should autists get special treatment and accommodations?
What additional research is needed to help address co-occurring conditions for autistic people?	-What's the deal with autism & connective tissue disorders -Why is it so hard to get special assistance? If I'm disabled to the point that I can't clean, health insurance could subsidize a weekly house keeping service. Insurance could cover quality of life items like noise canceling headphones, weighted blankets, sensor deprivation tank sessions. -Why is it so hard to get diagnosed with autism as an adult?
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Access to healthcare needs to be free and easily accessible over telehealth. People who mental disabilities don't always have the capability to plan ahead for appointments.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I was doing pretty okay health wise. Then I caught covid twice in one year. After the second round, I caught strep throat 9 times and had a hospitalization for a UTI. I think covid severely damaged my immune system.

<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>I felt safer on the roads with less drivers. Working remotely was amazing and the only way I want to work. Access to telehealth services increased and helped me see more doctors & therapists on a more proactive basis.</p>
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Name	Laura
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Misdiagnosis
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Not being listened to or taken seriously
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Increase autistic persons autonomy. Lower cost and increase accessibility of services.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Laura
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The most significant challenge faced by autistic people, in terms of mental health, is trauma -- whether we're calling it PTSD or its diagnostically nascent cousin, C-PTSD. Every autistic people I know experiences small and large injuries from being a mismatch with mainstream society. We know almost nothing about what it is to be autistic without trauma, because trauma is almost bound to happen to autistic people.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Autistic people need continued research into psychedelic-assisted therapies for trauma. As new modalities such as MDMA come online, autistic people need to be included in the first wave of patients. Trauma drives our suicidality the same way it drives the suicidality of combat veterans. It's the same, and it deserves and needs the same focus of treatment.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Autism should be covered by insurance at parity with other conditions when it comes to psychoanalysis and its related forms (NOT ABA). Avoiding and processing trauma are essential to autistic thriving.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Laura
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Celiac, leaky gut, EDS, autoimmune diseases, anxiety, depression, hyper mobility, fibromyalgia, chronic pain, GERD, insomnia, SPD, dyspraxia, ADHD, OCD, PDA
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	depression, anxiety, ADHD, aggressive or self-injurious behavior, suicidal ideation
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Both my son and I struggle with learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities. It is difficult for me to hold down a job, and I doubt my son will ever be able to have a job.
What additional research is needed to help address co-occurring conditions for autistic people?	There is currently almost zero support for parents of autistic kids with high support needs. We struggle to maintain a job while handling insanely high stress at home due to our high support needs autistic son. We can't afford or even find adequate childcare for our autistic son. I am forced to stay home to care for him and my home is essentially a prison because I can't go anywhere or do anything due to my son's challenges. It is deeply depressing and miserable
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	As a late dx autistic person myself, I still have zero support from the government. Most autistic support ends at 18 which is a joke. Like we ever outgrow autism? We don't. It is highly difficult to maintain a full time job due to zero accommodations in the workplace. It shouldn't be so difficult to get on disability. I can't even get insurance currently. I can't afford adequate childcare for my autistic son. I need a qualified person to accompany us on public outings to help keep my son from eloping. The only thing covered is ABA and that isn't a good fit. Parents of autistic kids desperately need more respite care on a weekly basis.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I am autistic. I have permanent Covid anosmia taste and smell distortion, as well as long Covid. I can barely function. I am weak and exhausted all the time. I never recovered after Covid. Yet I have to stay home and care for my 2 kids full time and I am suffering horribly
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	One of the best things to come out of Covid was curbside grocery pickup and grocery delivery. I wish more virtual health services were still offered. I shouldn't have to physically go into a doctor's office to get an antibiotic.

in-person social interactions and obligations)	
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Name	Laura Cosgriff, Lakewood
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbances, sensory integration, balance issues, and executive functioning.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression, anxiety, executive functioning deficits
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication disabilities, expressive language disorder, difficulties following multi-step instructions
What additional research is needed to help address co-occurring conditions for autistic people?	I would say more services and supports are needed in the areas of occupational therapy, speech therapy, physical therapy, and executive functioning in all these areas. OT and speech are the areas that have been the most successful for my child. Not sure if more research is needed. If you ask any parent, the needs are pretty well understood. The problem is only certain services are supported by insurance or by public agencies. If more research is needed to provide services to families and children, then those areas are the areas that are needed.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage of speech services and occupational therapy services. Equitable access to and accessibility of the services. Improvement in school IEP processes. My son wasn't identified until he was 15 years old because school staff never told me how to request services/evaluation from the school. I had to learn about it from people outside the district. I received strange feedback on and off for several years. I couldn't make sense of it and would talk to my son about it. Most of it I didn't understand as medical. These vulnerable kids and their families are dependent on the feedback from school staff. My son suffered unnecessarily for several years. This could have been prevented if one staff member could have simply said, "your son needs to be assessed for x, y, and z. This is who and how you need to ask for it."
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It's made everything more challenging.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services,	The process for finding appropriate help is difficult anyway. But, COVID made it that much harder. For my son, in-person meetings/appointments are the most effective.

increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Laura Graham Holmes, Silberman School of Social Work, CUNY Hunter College
Demographic	Service provider, health provider, or educator; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	When people experience physical health challenges, it is difficult to function at school, at work, at home, in relationships, as parents, and as community members. Suffering related to physical health conditions and difficulties fulfilling our valued social roles can then affect our mental health. In our field, we have often focused on academics, employment, and independent living, without the foundations of freedom from pain and physical suffering coming first, and I hope we put more focus into helping autistic people identify, manage, and cope with physical health conditions in the future.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I would like to highlight a particular condition that has been underaddressed: substance use disorder. Autistic people use substances for some of the same reasons that others do: for social lubrication, to overcome social anxiety, and to cope with physical and emotional pain. There is some evidence that those who use substances may be more likely than non-autistic substance users to develop substance use disorders. In my work with autistic people looking to gain more control over their substance use, I've learned that treatment for substance use disorder is even more difficult to access for people who are autistic, and particularly for those who rely on Medicaid. Substance use disorders are inextricable from issues of physical health, mental health, and everyday functioning and quality of life. We need more research investment to address substance use disorders among autistic adults and to treat them among autistic people who use substances.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Although there is a lively online discourse about autism and chronic pain conditions, the research literature on pain, pain conditions, and autism is in its infancy. However, there is some evidence that chronic pain conditions are more prevalent among autistic people who hold other marginalized identities (e.g., women, gender diverse people, and those who are gay, lesbian, bisexual, or queer). Basic qualitative and quantitative research is needed to understand the prevalence, mechanisms, healthcare experiences, and potential interventions for chronic pain management among autistic people.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Autistic people are being seen across specialists, whether or not they have an autism diagnosis. The ways in which people move through the healthcare system to receive screening and diagnosis for autism and common co-occurring conditions or needs (e.g., sleep disorders, GI issues, eating disorders, anxiety, gender-affirming care) is of great interest. Education and case management services targeting specialists could help more autistic adults be diagnosed, and a robust screening and referral service among autism diagnostic clinics could help more autistic people be connected with other services. Focus on training and supporting people who can provide adult autism diagnosis could also increase healthcare equity. For example, there is a huge labor force of social workers who speak languages other than English who could be trained to provide diagnostic services, but many of them are unaware of that fact and unable to pay for additional training; how can we provide scholarships and support for them?

What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	For the issues I am most interested in - chronic pain or other physical health conditions, substance use disorders, health disparities related to being LGBTQIA+ - there has not been research on the effects of the COVID-19 pandemic, but it is potentially relevant for all of these.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Laura Mansdorf, Mother of an Autistic Child
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My daughter has had casts, braces on her legs and botox to try and reduce the likelihood for surgery on her heel cords in the future. Her idiopathic toe walking and mixed muscle tone leads to unsteadiness, which results in falls. She has been diagnosed with insomnia. Her sleep issues make it difficult for her some days to attend to tasks and to learn. Her sensory issues and anxiety over food have required her to continuously work with therapists so that she doesn't backslide into only eating 3-4 things. She's made an incredible amount of progress, and it takes a lot of continual effort to maintain it.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My daughter has a limited ability to express herself using speech. She is verbal to an extent, with a handful of functional phrases. But you wouldn't be able to get her to elaborate past "I'm sad" as to whether she is hurt physically, emotionally etc... This inability to quickly express herself leads to frustration, aggression and self-injurious behaviors. She has a behavioral team of people in place at home and at school which have written behavior intervention plans to help reduce these behaviors. In addition she is also diagnosed with ADHD as a comorbidity. It makes it difficult for her to attend/focus on tasks she does not find interesting. Often times, people will discount her ability because of the behaviors surrounding her ADHD.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Often times, issues arise when my daughter cannot communicate verbally or using her AAC. Generally, when she cries spontaneously without a clear reason, she is unable to articulate complex thoughts. It is a challenge to be able to aide in her care. In regards to her school work, she is able to complete tasks with extra time, repeated refocus and an individualized approach to her learning. Standardized learning does not get through to her-- being able to teach her 1:1 has been the most successful way to help her gain skill. Teaching the basic skills in order to learn have helped her understand how to read, retain the story, and math skills. Spending time teaching her life skills has helped expand her view of the world. The goal is to teach her everything necessary to be as independant as possible.
What additional research is needed to help address co-occurring conditions for autistic people?	I think there needs to be research done to see how to reduce the amount of distraction in the mind of a person with autism and adhd. How medicines metabolize in an autistic person's system vs. a neurotypical person. More in depth research into what causes the sensory overload, how the brain reacts, and how to reduce the issues associated with overwhelm. Also research on how to best educate those who have the most support needs. I am a firm believer in "support needs" over "function." Had I just left my daughter without the most support possible, she'd be functioning at a much lower capacity than she is now. How do we bring the highest quality therapy to the most children possible? How do we ensure that its being done correctly?
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	It should not be a fight to attempt to receive services and assistance. The process taking so long, with so much paperwork that as a single parent, frankly I'm burnt out. There should be a easily attained standard level of care for all autistic people who require support. High quality ABA with focus on skill acquisition. Insurance has been a constant battle-- they deny our providers payment because my daughter also has Medicaid for Disability, so her primary insurance claims that Medicaid is the primary when it isn't. In regards to patient-provider services, I really just wish that medical doctors, police officers, EMS... would be better educated on how to compassionately and empathically assist autistic people. We've had an ENT want to hold my daughter down to do an endoscopy without anesthesia. In the ER in 2019, I

	<p>had a doctor be persistently rude when my daughter wouldn't give a urine sample or answer questions. She had the flu and a fever. I'll never forget the frustration and disgust on his face. In public school the school psychologist, when asked to give a Functional Behavioral Assessment, stated that "the function of her behavior is Autism" which is incorrect. The teachers keep her at the same level of studies for a year because they did not understand she knew the material they were teaching. I read stories of countless people tased and shot by police because they did not immediately comply. Since my daughter may elope, I constantly fear this may happen to her.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>We've had to reduce the amount of social interaction we participate in as a result of attempting to avoid COVID-19. There are times where staff is not available due to an outbreak.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>As said previously, we attempt to be as diligent as possible to avoid infection, because it is much more difficult to care for someone who is unable to articulate what is wrong. It causes us to reduce the amount of time in the community, and we are able to work on social goals less often as a result. My daughter cannot do her ABA therapy over the computer, so there is an increased risk of infection by allowing multiple therapists into our home.</p>

Name	Laura Mewbourn
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I think for both my son and I, our most significant physical challenges are related to sensory difficulties in the public sphere. This is one of the least understood yet aspects of being neurodiverse and can be frightening both for the person on the verge of meltdown as well as a stranger witnessing said meltdown. I would order groceries and have them delivered, but I cannot afford the extra costs associated with delivery fees, tips, etc.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My most significant mental health challenges stem largely from a lifelong, mostly untreated, anxiety disorder which I believe was born in part from a childhood of unrecognized autism and adhd. As an adult, I realized that all of my thoughts and feelings were not healthy and that there were resources available to get that anxiety under control. Unfortunately, as a low income person, I cannot currently afford my adhd medication or the in-person psychotherapy that I badly need at this moment. As a result, I also grapple with clinical depression and occasional bouts of suicidal ideation. I have struggled to find providers who are knowledgeable about psych med management or have had providers who treat me like a drug offender for wanting my prescriptions refilled. I left one such provider and gave up on treating my adhd after repeated conflicts over prescription refills. I struggle sometimes with daily tasks as simple as phone calls because I absolutely cannot have a verbal conversation in that moment. To explain it to an outsider sounds like whiny blame-shifting, so rather than explaining, I often withdraw into further isolation. In short, I think the biggest challenge are the compounding factors of living life as a neurodiverse adult. One thing piles on another, leading to being virtually incapacitated with no outside support (or inside support, since I'm a single mother).
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Diagnosis and support in the academic setting. My son and I are twice exceptional. I did fairly well in school, enough that any perceived gaps in my academics were considered a lack of effort rather than a lack of ability. My son's experience (he is 7) has been a little different only because I am hypervigilant. His school has actually declined testing (OT) because they decided he didn't need it, and yet we consistently receive feedback that WE need to work on his writing/fine motor skills. Because he is at least average in all markers, they have decided he does not need additional support services. I suspect he has other learning related challenges, but as long as he is doing okay unsupported, our only choice would be to pay out of pocket for further evaluations. I find the rigidity of school extremely difficult.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	There is a pervasive idea that autistic children grow up into fully functioning adults. While that's clearly not the case, support services for "high functioning" neurodiverse adults are minimal. I would LOVE to seek assistance with executive functioning. I would love a competent psychiatrist that doesn't cost me \$175 for every visit and meds that aren't \$300/mo. I would love therapy to help me process my day to day life. I find connecting with other neurodiverse adults to be INCREDIBLY helpful, and while I have a resource available for that, I know many people do not. I think society has convinced itself the problem does not exist when the "problems" have actually just isolated themselves to a degree that they are no longer noticed.

What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Laura Saenz
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Hypermobility and connective tissue disorders like hEDS contributing to gastro, sleep, POTS, MCAS, PMDD, endometriosis, poor healing of wounds, hernias, migraines due to cranial cervical instability and chiari malformation. But #1 is the medical gaslighting telling us it's just anxiety then prescribing meds that don't work for our neuro type.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety is the direct result of undiagnosed and "pushing through" all our issues. Burn out is waiting for all of us. I'm in year 3 of burnout at 55. The medical gaslighting and medical ignorance is causing us to leave the medical system entirely to self medicate. I bet more than half of homeless are neurodivergent.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	ABA is the only "treatment" in the school setting and its straight up abusive. It does not help with any learning disabilities. Most of us figure out our own "systems" for our disabilities bc of the unintended abuse within the education system. After figuring that out, later in life the physical symptoms flare up worse. Usually during pregnancy and menopause.
What additional research is needed to help address co-occurring conditions for autistic people?	The most detailed research right now is on Tik Tok. Yes, I read medical journals and desk references. But only Kimberly102347 has mapped out the co-morbidities and the triggers and deficits we need tested regularly by MDs. Her research answers all of these questions. And we need to get folate out of our food supply.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	#1 Eliminate ABA #2 put autistic people in charge #3 test all neurodivergent people for connective tissue disorders #4 test all hyper mobile people for neurodivergence #5 Create new specialty of connective tissue disorders so one MD can know about entire patient instead of subbing out to 10 other specialists. Which leaves us running our own healthcare. #6 re-educate entire medical system on what neurodivergence actually is so they stop infantilizing us and thinking we are not smart.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I'm autistic. I recognize patterns. I know covid never left. I am vaccinated and wear a mask. Although living in one of the largest metro areas in the country, and traveling internationally, I have not gotten COVID.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Remote school should be an ongoing option for all. When someone doesn't feel well, they can do on line school. It would be helpful when my autistic daughter is dysregulated. Sending her to "power through" at school is just cruel. She's in emotional and even physical pain.

Name	Laura Stoddart
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My PDA son's ability to access basic needs of sleep, eating, toileting and hygiene practices due to the accumulation of stress bought on by his nervous system threat response means that his disability requires increased amounts of care giving support.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	PDA being a nervous system disability means regular activation of the threat response which can result in explosive autonomic flight or fight behaviour beyond his control which impacts his relationships with peers and adults and his own mental health in terms of self loathing and low self esteem.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Getting others to recognise and acknowledge PDA in the DSM-V so that it is taken seriously by professionals and not responded to through a behaviour modification lens as this exacerbates the child's responses leading to burn out and trauma. Nervous system activation needs to be viewed as beyond the child's control with the understanding that adults need to modify their practices to accommodate the child if the child is to successfully engage.
What additional research is needed to help address co-occurring conditions for autistic people?	PDA recognised in the DSM-V as a nervous system disability that is not under the control of the child. That the cumulative nature of stored stress has a debilitating impact on the child's ability to access both basic and secondary needs which is beyond their control. Activation of the threat response needs to be viewed as a panic attack not a behavioural choice that can be conditioned. ABA therapy is highly damaging to the PDA child.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Care giving support in the home when cumulative stress activation impacts basic needs. Financial aid for parents who have to leave work to care for children in burn out or who cannot access education outside of the home. Raising the profile of PDA so that parents are taken seriously, believed and supported rather than being gaslit, isolated and shamed in society.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Access to services delay and increasing wait times for professional assessments etc putting more pressure on families supporting children in the home.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Access to support being delayed.

Name	Laura thimen, Parent
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Physical aggression to others s the worst in profound autism, inividualized care is important,. My son bites, kicks, push us.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Aggression, and ocd. Impulsivity with adhd is the worst. He can be super aggressive
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Medicines to reduce aggression, stomach issues,
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Proper care of behaviors, insurance, respite for parents it is 24 hours challenge, dangerous, more impatient behaviors unite, more group homes, better schools.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	My son aggression is worst, after the pandemic he is not able to be with others kids.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Lack of services during the pandemic, for servers cases online school don't work,

Name	Lauren
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I've had lifelong GI issues, disordered sleep, dander and pollen allergies, and migraines. The latter two get worse in periods of stress and often coincide with times when I feel overwhelmed. Eating can be difficult for me as well, which has worsened the GI issues. With the exception of the allergies, my autistic partner experiences all of these to a greater extent; she also has more sensory and motor challenges, which all impact her day-to-day life. Overall, I think that these all contribute to stress and anxiety; for example, when eating and food are already hard, GI issues make them even more of an ordeal. Problems with food, problems with sleep, poor self-care, and the stress caused by all of these compounding with each other, can lead to a general increased risk of additional physical health issues.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety and depression contribute to general difficulties around switching and executive functioning, to the point where basic ADLs can become an ordeal. Anxiety additionally compounds social difficulties that already exist around general communication, reading others' signals and expressions, initiating and sustaining conversation, and interacting in group settings. Co-occurring OCD has worsened my internal distress over breaking internalized rules and routines. My autistic partner's mental health is also significantly impacted by PTSD and dissociation, and the intersection between her ASD, PTSD, and OCD has led to significant daily life difficulties.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Autistic individuals with ID/LI are a vulnerable population who are at increased risk of victimization, but there are considerable barriers to their inclusion in research and in autistic self-advocacy. They also require a level of support that is stigmatized even within the autistic community, especially among those with lower support needs. Additionally, in my personal experience, ADHD compounds with ASD and makes task switching and executive functioning more difficult. Basic ADLs, like eating, brushing your teeth, or taking a shower, can become enormous tasks that are all the worse for their regularity.
What additional research is needed to help address co-occurring conditions for autistic people?	There needs to be more research that focuses on autistic adults, since a lot of autism research tends to focus on children or on potential causes of autism. I think that research that looks at autism alongside mental health conditions such as OCD or PTSD would be hugely beneficial, along with research that goes beyond prevalence or causality and has a more long-term scope, such as managing chronic co-occurring physical health conditions or improving general quality of life for autistic adults across all levels.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Even among professionals such as occupational therapists, there is still a lot of stigma around adults needing high levels of support, and they are often unprepared for addressing autism-specific issues, such as RRBs or cognitive rigidity, in adults in a manner that is compassionate and respectful. Professionals also need to be able to recognize and address the impact of trauma on autistic individuals. In addition, doctors and mental health professionals need to be prepared to communicate with patients with ID/LI, and to engage with them in a way that doesn't further isolate or belittle them. In the background of all of this, there are still fundamental practical barriers to accessing autism services, such as questions of transportation and money, and difficulty even finding professionals who are willing and qualified to work with autistic individuals.
What lasting impact has COVID-19 infection and illness had on co-	On the side of physical health, COVID-19 infection led to GI issues and constipation that lasted long past the initial infection itself. On the side of mental health, the pandemic has worsened my anxiety and depression. It

<p>occurring physical and/or mental health conditions for autistic people?</p>	<p>worsened my previously uncontextualized OCD symptoms to the point where they had to be addressed. It has made socializing and public gatherings even more difficult both because of the added fear of infection or infecting others, and because in-person classes, work meetings, and social events seem more intensive and tiring after I became acclimated to remote options.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>The increased use of telehealth services and normalization of remote work and school options have had a positive impact, along with the reduction of in-person social events. In an academic context, recorded lectures, flexibility with attendance, and increased teacher empathy for absences and accommodations also represent positive change. However, I believe that an uneven and unspoken, but still insidious pressure to transition back to “regular” life, despite the realities of the pandemic still persisting, creates a lot of negative stress even with the increased accessibility options brought about by remote work and school.</p>

Name	Lauren
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Fibromyalgia, sleep disturbance, AFRID, eczema, ehlers danlos
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Alexithymia, social anxiety, depression, adhd
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Specific learning disorder, below average working memory, gestalt processing, auditory processing difficulties
What additional research is needed to help address co-occurring conditions for autistic people?	Research based on autistic people's experiences. Most research is based off caregiver observations, so they aren't inclusive of how the autistic person feels or experiences the world (aka ABA is harmful to autistic people, but caregivers love it). Understanding autistic communication styles.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Improving awareness of autistic needs or communication styles. I have been fired or ostracized for my assertive communication and it's so frustrating. Help teachers and employers create affirming spaces.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Decompensated overall physical health due to inflammation from covid. Increased fibro flares. Chronic tinnitus and laryngitis. Improved mental health being able to work remotely and no forced social encounters.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Positive - work remotely is great! Negative - video conferencing is so exhausting for autistic people

Name	Lauren Agoratus, SPAN/Family Voices NJ
Demographic	Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	As far as physical conditions, the two most commonly cited are seizure disorder and gastrointestinal issues. In addition, health disparities and discrimination exist for people with developmental disabilities . We appreciate the NIH designation of people with disabilities as a population with health disparities. We participated and highly suggest IACC examine the Center for Dignity in Healthcare for People with Disabilities, now called Think Equitable, recommendations on prenatal, mental health, transplant, and end-of-life care. Finally, we would add the risk to children/youth with autism and other developmental disabilities having limited access to good oral health providers.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Regarding mental health, there is comorbidity between developmental disability and mental illness. In addition, dual diagnosis of DD/MI is difficult to find treatment for, especially in crisis. There is a shortage of specialists, hospital beds, and wait lists. This was well documented in the Family Crisis Handbook which we ask the IACC to look at with their recommendations.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	We also understand that there may be other comorbid conditions associated with autism such as LD, dyslexia, ADD/ADHD, etc. It is important for both educational and medical professionals to look at the necessity of additional interventions, although some developmental pediatricians may note there is nothing more that needs to be done medically based on if the child is already on medications etc.
What additional research is needed to help address co-occurring conditions for autistic people?	Research in autism continues to be essential due to increasing prevalence rates. We would suggest that more research be done on the comorbid conditions listed above. Note: Additional research should not take funds away from ensuring appropriate services and supports are available to people with autism and their families.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Services and supports are essential regarding comorbid conditions and autism. As stated previously, a secondary diagnosis may necessitate additional educational or medical interventions. In addition, not all states have ABA certification requirements. Some ABA practitioners use forceful manual guidance, restraints, and other aversive techniques. As members of the NAMI (National Alliance on Mental Illness) national restraints committee, we found that aversive interventions are ineffective as behavioral modification and experienced as trauma. Indeed, the U.S. Department of Education noted that these techniques are not evidence based best practices . There are alternatives to ABA such as DIR (Developmental, Individual-differences, Relationship-based) model which is child-led, otherwise known as FloorTime. In addition, many students with autism could benefit from sensory integration (by a specially certified occupational therapist) and social skills which are related services under IDEA (Individuals with Disabilities Education Act), but school districts may not readily offer and families may be unaware that these helpful therapies are available in addition to the usual PT/OT/speech (physical, occupational, and speech therapy).
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	The effects of COVID were two-pronged for people with autism. Physically, they were more at risk of COVID complications . Additionally, in some states there were actually injuries or even deaths due to health disparities, including for people with developmental disabilities, as healthcare was inappropriately rationed. Also, COVID exacerbated mental health conditions;

	<p>some people who didn't have mental health issues do now, and some of those with pre-existing mental illness worsened. Many people with autism also had difficulty understanding the changes, hygiene, and social distancing associated with COVID, and some were unable to tolerate masking due to sensory issues. Long term effects of COVID (including Long COVID), both in terms of physical disparities and inequities as well as increased mental illness, remain.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>In general, we would also highly recommend referencing "Educating Children with Autism" which has clinically researched interventions for effectiveness. We also highly recommend the NIH National Center for Complementary and Integrative Health as the NIH found almost 81% of families of children with autism used alternative medicine. We would also suggest consulting with the AAP (American Academy of Pediatrics) clinical guidelines and policy statements as they relate to autism. For example, AAP cites the dangerousness of chelation for autism, or that gluten/casein-free diets do not cure autism but may be helpful in identifying food allergies only.</p>

Name	Lauren Dehler
Demographic	Autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	PDA (Pathological Demand Avoidance) is a subtype of Autism that much more research is needed to understand and better provide accommodation and services for.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Trauma, anxiety, co-occurring ADHD, suicidality for untreated trauma and lack of access to accommodation, needs, and understanding by loved ones and community.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Nervous system dysregulation caused by overstimulation, lack of accommodation, lack of resources, neuromormative assumptions of health and wellness.
What additional research is needed to help address co-occurring conditions for autistic people?	So much! Include Autistic people in designing research, focus on PDA, focus on intersectionality of those with marginalized identities, focus on including medium and high support needs folks in research, gender and racial bias in research and treatments, ableism in fields of psychiatry and psychology.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverages for services, trainings for practitioners in the neurodivergent affirming model, awareness and training on PDA type of autism, support for Autistic folks with multiple marginalized identities, integrating physical health care with mental health care for Autistic folks, training medical doctors about the many co-occurring health conditions that Autistic folks have.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Many, increased health issues with autoimmune conditions and physical health issues, emotional health issues of isolation, trauma, anxiety, increased ableism and ignoring of calls from those in the disability justice movement.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The pandemic has allowed many Autistic folks to work from home and be virtual that has increased accommodations for many folks. During the height of the pandemic, much of health care was also accessible virtually, though that has been decreased and causes serious set backs for folks with multiple mental and physical distress.

Name	Leah Bennett
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	It is a challenge as these co-conditions often exacerbate and trigger the health/mental co-condition(s) that my daughter has. An example is she struggles and has since birth with sleep disturbances . When her sleep is sporadic it interferes with her abilities to manage anxiety/depression , ADHD . When she has gastro intestinal issues , she can not longer eat and doesnt feel well, retreats socially and this triggers her anxiety and affects her sleep
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety and depression make it incredibly difficult to be social and sociable . These in combination with ASD and ADHD make it incredibly challenging to have relationships with peers and or family
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The learning, developmental, intellectual and communications disabilities make motivation and goal setting incredibly difficult if not non existant . There is a huge struggle as my daughter ages to assist her to grow and be independant and enjoy her life and be responsible for her self
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	During the pandemic remote schooling had a very severe negative impact on my austistic daughter as the ciriculum changed and the online classes were unable to affectivly keep her interest . The lack of a support person and in person learning interaction also negativly affected her . Reduced in person social interactions and obligation are a lasting negative affect During the pandemic she did not have to interact with her peers , she did not have to keep a rigorous schedule (get ready , eat, breakfast , get on bus, arrive to school ontime) She has since graduated and I believe this has perpetuated the lack of social interactions and obligations

Name	Leah Goeres, Citizen
Demographic	Autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Collagen disorder - joints unstable and resulting chronic pain. Having to take weeks of disability off to rest hands, back, hips from seeming normal use. Postural Orthostatic Hypotension likely secondary to collagen disorder - unable to maintain adequate cerebral perfusion when standing. Fainting or "blacking-out" when changing from seated position to standing position.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression and Anxiety requiring two medications to treat. ADHD. Skin-picking disorder. Verbal outbursts.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Difficulty reading social cues
What additional research is needed to help address co-occurring conditions for autistic people?	Finding genetic markers for joint hypermobility. Understanding the pathogenesis of joint hypermobility and postural-orthostatic hypotension. Research describing the kind of supports hEDS people need to remain in the workforce. There is no specialty that "owns" hypermobility disorders in the same way the endocrinologists "own" diabetes or Rheumatologists own Rheumatic diseases. Research needs to be done around what training practitioners need to be able to treat and manage these conditions. Research describing the economic costs of untreated or under-managed hypermobility disorders and postural orthostatic tachycardia syndrome. Guidelines need to be developed for hypermobility disorders and dysautonomic disorders.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Easier access (easier insurance coverage and HSA reimbursement) to compression garments and braces to help joint hypermobility disorders and POTS. Easier access to massage therapy (easier insurance coverage and easier HSA reimbursement) Early intervention on hypermobile children, initiating physical therapy and strength exercise programs early in life (screening in schools)
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I have no suffered a lasting impact of COVID-19 infection.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school,	Longer wait times to get medical care. The healthcare system is crumbling, it is harder to get healthcare needs met. I work in healthcare and the mass exodus of early retirees has led to an extremely stressful work environment. Loss of work-place culture as most meetings are remote/virtual.

increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Leanne Maidment
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disorder has had the biggest impact on our family. Both I and my two autistic children have had problems with sleep and lack of sleep impacts so many other areas of life.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My youngest child is autistic and we believe PDA although they don't diagnose that here. He also has ADHD and poor mental health, which has led to suicidal behaviours. I think ADHD and ASD conflict in so many ways that it can be absolute hell for a person when their own brain contradicts itself on a daily basis.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My children are verbal which means people expect them to be able to communicate, but they are unable to communicate feelings and other things.
What additional research is needed to help address co-occurring conditions for autistic people?	I believe PDA needs to be more widely recognised and diagnosed and research is needed into how this differs from "typical" ASD, how it presents, strategies etc. I also believe that although ADHD and ASD are understood as standalone conditions, more research is needed into what it means when they are co-occurring.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Leanne-Claire Civiletti
Demographic	Autistic individual; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I find that the most challenging aspect is the lack of education and experience in the medical profession of Ehlers Danlos Hypermobility and autism. I have always had sensory difficulties with sound and fabrics, light , the inability to hear and process information over the phone. I'm 67 years old, I was adopted at birth and I wasn't diagnosed with Autism until I was into my late 30s. I learned to mask my symptoms , since I have become profoundly sick with CFS-ME and have been with several unknown rare diseases. My psychiatrist has diagnosed me with delusional disorder thinking that I have diseases that most medical professionals have not had experience treating. My visits have all been over the phone, when I requested that my psychiatrist look up Ehlers Danlos syndrome she couldn't understand why that disease has anything to do with psychiatric disorders. Trying to educate individuals on the complexity of the inter connected relationship of systematic diseases.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Not being able to locate appropriate physicians who understand sensory overload and how this can trigger physical symptoms. I can't afford to pay out of pocket for specialists any longer. I'm on Medicare and SSI. I suffer from anxiety and fear of seeing a new provider to the point of refusing to go to the ER. I have Dysautonomia and when I stand up my heart rate goes sky high, legs swelling and compression to my spine. I cannot verbally answer rapid paced questions over and over and am refused using my communication IPAd. Dismissed with anxiety. Really frustrated when you're physicans does a EKG and tells you you have a heart attack. Emergency rooms need protocols enforced for people who have hEDS and Autism. I have no support system and my inability to communicate to medical professionals who know very little about the complications and symptoms of hEDS is baffling.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The inability to answer questions and explain symptoms. I expect to much and assume that my symptoms will be believed. I go into absolute panic at the idea of filling out. Medical intake only to be dismissed , lack of awareness. Invisible. Just because I can talk and respond does not mean that I don't need to use my communication assistive technology. I'm so tired of being told I'm doing fine when I'm not and speaking caused physical pain and anxiety as I can read what I'm saying or what's being asked of me. Then I'm labeled with a description which I would not have if my disability was accompanied as asked.
What additional research is needed to help address co-occurring conditions for autistic people?	Research ? I wish that more education and awareness was made to the medical community. Ehlers Danlos Syndrome and Autism isn't rare. I personally know over 18 people in my city that are diagnosed with both and are struggling to get appropriate medical care.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Medical care and insurance would be a start. I've tried to fill out the Calif rare genetic disease program paperwork. I can't do forms. I've never been able to do forms. I personally need more help with getting my medical records and history of my prior diagnostic records in one system of care. I need help is amending misdiagnosis and MIs interpretation of what I did not say but is quoted in medical records. Lack of understanding and communication with doctors and staff. The energy I have to communicate with individuals lasts about one hour. I'm in recovery from that hour for weeks. I replay the interaction over and over trying not to blame myself for being denied accommodations for my communication difficulties.

<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>Lack of support and care during the COVID pandemic. Isolation and masks and inability to see or “ read” the person examining me.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>I do like having zoom appointments with medical care. If I know the physician prior and there is a established relationship. Masks and disinfecting which triggers mast cell activation reactions. Challenge. I don't recognize medical professionals when they don't have a mask on. I can't communicate. I can't recognize the affect or response in a person who is wearing a mask that I don't know well.</p>

Name	Lee S.
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Honestly, the health effects of the items listed (stress created, lack of sleep and sudden, severe conditions that can occur in random situations), coupled with the challenges Autism already presents can make processing one's environment nearly impossible in both the short and long term.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Speaking only for myself, I would say depression is paramount, along with anxiety and aggressive behaviors brought on by frustration and confusion. It is safe to say that all of the mental health conditions listed above are going to be tremendously significant to a variety of people, some more than others based on their experiences.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	In my experience, each of these can take their turn as being the most significant depending on the situation at hand. Communication disabilities occur daily, whether recognized or not, but the developmental, learning and intellectual components may not even be know to the person who is dealing with them and each of those can create incredible challenges in ordinary situations.
What additional research is needed to help address co-occurring conditions for autistic people?	There is a wide gap between neurotypical and divergent individuals mostly because both of these conditions are life-long and are nearly impossible to comprehend without experiencing them yourself. Research would be useful in pinpointing the specifics that each of these types of people has in variance and developing simple mechanisms to mirror more easily sustainable traits.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	All of the above and, and I cannot write this in bold enough letters, SERVICES AND HELP FOR AUTISTICS ADULTS ACROSS THE SPECTRUM. Autism is not a condition that goes away, it is one that some of those who live with it have been able to cover up due to intellectual capacity to formulate behavior patterns in typical interactions with people around them.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Those were terrible times as the typical social structures, general scheduling patterns and behavioral processes that many of us studied for years to try and accommodate all changed overnight. This still continues to this day, since it has been noted that people are continuously recovering from the changes brought on by Covid, so to are many Autistic individuals who must now start from square one or risk negative impacts from their new inability to fit in.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I personally found the distance between people and the decrease in crowding very positive, however not having the opportunity to distance oneself from family, etc. was difficult. One thing that is a negative consequence is that, while Autistic people would have less contact and hence less need for altering their behaviors and dealing with difficult situations, we also move further out of the culture and so societal norms have changed. This means, when Autistic folks have to re-engage the public, they are now at a significant disadvantage of trying to figure things out as they go, even the older individuals with more experience.

Name	Leeann
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	There are many physical ailments that effect the autistic community ranging from gastro intestinal issues to ehlers danlos syndrome. I suffer with many and find that it is difficult to keep up with a regular 9-5 work week and keeping a consistent routine due to the inconsistencies that coincide with these ailments. Regular daily functions become almost impossible at times because these ailments also affect our mental well being and ability to form a healthier lifestyle
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Autistic Individuals find it difficult to advocate for themselves because of the constant misdiagnosis received by medical professionals. There is just not enough research or trustworthy resources specifically in regards to autistic women so we are misdiagnosed with BPD, bipolar disorder, as well as depression and anxiety. The root cause of those SYMPTOMS are not addressed due to being overlooked and we are often misguided.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	There needs to be more research on autistic women and the differences associated between male and female autism. Autistic women are very often overlooked or misdiagnosed due to the similarities between previously thought "female mood disorders" such as BPD and bipolar disorder. In turn, we are misguided or medicated for an ailment we do not have.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I've found in my experience that many medical providers carry outdated or misinformed information in regards to autism. Regular revisions and information should be shared with family providers/primary care providers as they are discovered and/or questioned. This, I believe, will help the issue of patients being misdiagnosed and/or overlooked.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Leigh Powell, NCSA TN Chapter
Demographic	Family member of an autistic individual; Service provider, health provider, or educator; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Bipolar and significant sensory challenges, in addition to autism and ID, cause my son to have severe behavioral challenges. There are no programs and services in ECF that are remotely appropriate for my sons needs. By their design, the day and supported living services in ECF will NOT be able to manage my son's behaviors. Sadly, they will cause him extreme mental anguish and duress that will escalate his dangerous behaviors over and over again. He needs supports designed for lifelong high behavior support needs. This does not currently exist.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	As per previous response, there are no appropriate day/supported living models in ECF to deal with lifelong high acuity behavioral individuals. Current models will provoke extreme stress and sensory overload for my son, severely escalating his behaviors. I cannot send him to camps or day programs for those with disabilities because they cannot manage his behaviors. He is isolated and he wants to be around others. It is also very difficult to find people to come into my home to help with him because they are scared of his behaviors.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	For those with autism and intellectual disabilities it is almost impossible to find psychiatric facilities/stabilization units that are equipped to help them. It is hard for people to learn what my son is saying even though he is verbal. The constant revolving door of staffing issues will ensure that much of the time the staff that will care for him will not be able to understand his communication.
What additional research is needed to help address co-occurring conditions for autistic people?	What I do know is that the bigger issue is that no one will step up to the table to address viable appropriate options for those with lifelong high acuity needs. When Tennessee's most fragile, vulnerable, and needy are ending up being warehoused for months or years in hospitals, mental institutions, out of state placements, or jail it is clear that different options are needed. Recently, Jordan Allen of DIDD said that solutions for the high acuity cases were "unsolvable." I don't believe that is true. Tennessee needs to involve the families of those with high acuity to help design appropriate housing and support systems for them.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Allowing Sheltered Workshops and Farmsteads/Alternative Housing models that are environmentally modified to support those with high acuity behavioral needs. That would not mean that they could not access the greater community when or as their behavior would allow, but it would ensure regular structure and social interactions for them in a much safer environment. There also needs to be options for 1 on 1 or 2 on 1 staff for those with high acuity needs. There needs to be specialized transportation options as well in order to keep driver and/or others safe.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I stayed home with my son with no help for over a year and a half without going out in the community at all in fear that if I got Covid and died or were in the hospital there would be no one to care for my son. If I died and he was placed in ECF it would be so cruel for him as it would increase his aggression and he would end up hurting someone and in a very bad situation with no viable solution in sight. Literally torturing my son because there are no appropriate long term housing/supports specially designed for those with high behavioral acuity needs.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on	It has further heightened the staffing crisis for DIDD/ECF Choices Waivers. The safety, stability, and security of those with disabilities is disrupted by lack of staff, untrained staff, and constantly revolving staff. Some families are

physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	being told to come get their family members because there is no staff available to care for them.
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Name	Lekeisha Williams
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	my son has a sensory delay, and also sleep disorder
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Self injury
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Developmental
What additional research is needed to help address co-occurring conditions for autistic people?	Self harm
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I don't know
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Mentally
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Disruption in service

Name	Lesley
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Epilepsy, sensory and motor challenges and anger
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	depression, aggressive behavior, suicidal, anxiety. Doesn't fit into this world.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	communication, learning, intellectual and developmental disabilities. I have twins...they are 15, one is like a 3 year old and one is like a 9 year old...with men bodies. Can hardly find any help
What additional research is needed to help address co-occurring conditions for autistic people?	More education for our schools...anything that has to do with autism needs to be highly researched. 1 and 30 something kids is an epidemic
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	We need help for when our kids age out of school programs. More insurance coverage, but mainly safe places for kids that are not high functioning. Any and all help will do!!
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Leslie
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Communicating clearly. Doctors like make up their own idea what I'm saying
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	No useful depression treatment. The pills make me sick
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I'm fortunate in that I am verbal. Others are not so.
What additional research is needed to help address co-occurring conditions for autistic people?	People that are nonjudgmental, fair treatment.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Now it is psychologically difficult to go to places .
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Leslie Lussier, Parent and Guardian
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Epilepsy is the most severe challenge for us bc my son has been hospitalized 3 times for uncontrollable seizures. He's on 3 medications now to prevent them but we are worried about his risk factors each day (is he overtired? Overstimulated?) and managing his medication is complicated w 5 doses daily. We cannot bring him to events past 6pm due to seizure risk. He also has GI issues - obstipation - do watching his intake and output each day and managing GI meds too. He cannot speak or indicate if he is in pain so often we are guessing about how he feels.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	His self injury is mist challenging. He bangs his wrists/back of hands in table tops, walks or anything with a sharp corner. He also bites his hands. He has swelling and bruising as well as callouses on hands from biting. We've tried so mushy interventions (gloves, wrist bands, competing items to hold etc) and nothing stops this behavior. We fear he will injure the nerves in his hands.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My son has intellectual disability. He is a 6' tall 250 lb man body with the mental development of a toddler. He cannot speak, read, count. Etc. He uses an iPad communication system to make simple requests for food or daily activities. However he cannot express emotions, recall and share his experiences or interact in most basic ways with us.
What additional research is needed to help address co-occurring conditions for autistic people?	We need to understand underlying brain disorder that causes autism. I suspect it's related to the gut. We need to focus on the profound autism population to address these most severe needs of these individuals and their families. People with profound autism suffer from physical and intellectual disability and require 24/7 care which is devastating to the family. When families are no longer able to care for these people they require tremendous resources for care that lasts many decades. It's a huge cost yo the system that we need to address as the surge in population begins to age out of home care.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	People with profound autism face a crisis at age 22 when school services end. Many are left without programming or support. It's been called the autism cliff at age 22. Please please guarantee and find day programs and residential as needed to provide needed supports for these people and their families. Human services workers need to make a fair wage and have a career path. Oversight is needed to be sure adult placements are safe. Video cameras need to be allowed everywhere including bedrooms to protect our profoundly autistic adults from neglect and abuse.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	There is now a human services worker shortage that leaves to few day placement programs understaffed s d has created waitlists lasting years for services. We need to train and pay the direct care workers much more for the important work they do and attract them back to this field of work.

in-person social interactions and obligations)	
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Name	Leslie Welch, parent of adult with autism
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Have to keep on a strict diet so they don't get sick, which means hyper vigilant monitoring of all made and purchased food and drinks. Getting to see the right specialists when dealing with bi-polar disorder as well as autism and medication. Very hard to get in with a provider who doesn't just throw medications at you.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	General public understanding of meltdown behavior so not to stigmatize both the person with autism and the family/caretakers. Getting to the best medical provider to treat the person on the spectrum, not just throw medications at them. There are very few people who truly understand the medications and how they should or should not be used in people with autism. Having general providers who understand that "typical" treatments often don't work for our family member and have strong connections with specialists and will refer you out to someone who knows better.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	children and adults with significant IDD or DD are much less able to access the trained care takers they need for 24/7 care. They often cannot be left alone for any length of time and need to be cared for by highly trained individuals. The individual may not be toilet trained -- and may not be able to be --- which means caring for a 6'3" 2 year old man in all bathroom related ways. Finding someone who is trained, caring and willing to do all these things, is rare. Determining and then finding the right placement, after they leave their parent's home, is extremely difficult. The facilities often exist but there are very few good ones. The parents do not live forever, and often shouldn't be caring for autistic adults as long as they have to, due to lack of care options.
What additional research is needed to help address co-occurring conditions for autistic people?	Care Training medications really everything
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Well funded services where the actual person supporting the individual is well trained and paid and valued. These services need to be person-centered at all times and wrap around the person needing service. They should start at diagnosis and go until death with natural progressions built in.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	During covid, the isolation was incredibly hard on our son and we couldn't explain it to him. He lost his entire world, except us, and he depends on the consistency of that world to be able to function. It was hard to access his typical drs and sometimes his medication as well.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	see previous response

in-person social interactions and obligations)	
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Name	letitia smith
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	constipation (gastrointestinal)
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety ADHD RSD
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	in particular need more understanding about PDA. it is becoming a more common diagnosis but understanding still very low, especially about how it different from autism
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	access to public services to be offered when quieter and less overwhelming so actually get to use them. however this should not be shoehorned into ridiculously early or late times so as not to impact anyone else. that is not inclusive
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Lewese, Child with ASD with PDA profile
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Severe Sensory and emotional anxieties linked to PDA profile, mismanaged at school leading to violent outbursts to the point my son is now refusing to attend school due to extreme anxiety. Locks himself in room, and barely interacts even with me. It is very stressful with no support as a single parent, while waiting for NDIS .
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Extreme anxiety with any demand leading to anger frustration and violent outbursts to myself, teachers, students, and damaging property. This reduces dramatically if my son has limited demands.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My son had emotionally shut down and will not communicate his needs to others or myself, which makes it extremely hard to help him. No eye contact, barely talks despite being very intelligent
What additional research is needed to help address co-occurring conditions for autistic people?	Not just autistic children, but those with other barely recognised forms such as PDA, so it is finally recognised as a very difficult condition to manage. It's great ASD components added to schools, but not necessarily ok for children with PDA. There needs to be PDA programs as well, as it is a special way of managing them .
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More training in schools and PDA support people at each school, maybe a classroom for those children . Better and quicker access to supports. In Home Care Support on average had a years wait time for help, NDIS, 3 months just for a planning meeting, then how much longer until funding given, and no one to support me in the applications or planning meeting prep, so better access to supports to enable parents abd especially the child get the support they need. More providers, and regulations on costs, so prices are more regulated. Currently my son is on multiple waitlists for therapy, which I cannot afford to pay for until finding approved. Standardised funding for certain conditions, cause if you don't know how to prepare, or what to ask for you just don't get it.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	No idea
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	Recent diagnosis, so not sure

in-person social interactions and obligations)	
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Name	Lilja
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Our family deals with sleep issues - both myself and my child, and PDA (Pathological Demand Avoidance) - my child.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	First of all, as someone with an AuDHD brain, I do not consider ADHD to be a mental health condition. It is a difference in brain structure and behavior - just like autism is. That said, I do suffer from anxiety. Crowds, driving, loud unexpected noise, grocery shopping, etc. all heighten my anxiety.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My child deals with PDA (Pathological Demand Avoidance) as well as an intellectual disability, ADHD, and autism impacts his ability to verbally communicate. He did not speak until he was 3 1/2 years old, and utilizes scripts often. When he is unable to articulate clearly what is going on in his head, it can trigger his PDA responses (screaming, hitting, biting, breaking things, destroying things). When he doesn't understand something, it can trigger his PDA responses. When things don't go the way he planned or expected, it can trigger his PDA responses.
What additional research is needed to help address co-occurring conditions for autistic people?	PDA needs to be recognized in the USA. I believe most cases of PDA in the US are misdiagnosed as ODD. We badly need more studies in this area. Children are being punished for the way their brains and nervous systems react to a perceived threat. It is cruel and unfair. Both to the children (and adults) that deal with this, and the parents that are desperate to help them - like me.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage of course. Insurance is terrible in the US. Fewer barriers to diagnosis for both children and adults. We waited 1 year and 6 days for my child's evaluation and that was considered fast. We need more diagnosticians, and they need to be up to date with the many ways autism presents - especially in a person assigned female at birth. Far too many AFAB children who are autistic do not get their diagnosis or are misdiagnosed because they do not present like 4 year old boys. Far too many adults that slipped through the cracks as children do not get their diagnosis because they also do not present like 4 year old boys. Services cannot be accessed without a diagnosis. SSDI reform! No one can live on what the SSA expects disabled people to live on. Destigmatize Autism. Far too many people in the medical community disregard or infantilize autistic people.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic	Grocery pickup/delivery has been a huge benefit for our family. I no longer have to deal with the anxiety that grocery shopping induces. My child is no longer tempted by all the colorful things, so there is not a subsequent meltdown or PDA response when he is told he cannot have something.

people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Linda
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Other conditions" all of the above
What additional research is needed to help address co-occurring conditions for autistic people?	Other research should include what services can be provided to assist those with autism
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	All of the above should be employed
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Linda , parent of adult with autism
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My son has severe constipation, and apraxia which makes it impossible for him to communicate verbally and perform daily care tasks. Both of these conditions lead to extreme anxiety at times and difficult behaviors. My son is on a very special diet which requires cooking most food at home and can limit opportunities for social activities. He needs support 24 hours a day to help with cooking and shopping and self-care. He cannot drive or take public transportation. He cannot communicate his wants and needs verbally. He is learning how to communicate more by spelling out words and this gives us some hope.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety is pervasive in the autism community. Living with someone with autism and anxiety also increased anxiety in parents and siblings. My son has had very serious SIB. The teenage years are SO difficult for many people with autism. The SIB has decreased over the years but still appears during stressful times or when the stomach issues get worse.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The inability to communicate is a horrible situation to be in! We make assumptions based on peoples behavior that is often completely wrong! There should be a much greater emphasis on teaching communication skills in school. Part of this process also required the necessary motor skills to accurately point to pictures, words or letters. We also make assumptions that people with autism who are non-speaking, are not intelligent. That has not been shown to be the case in most instances. My son has been able to communicate by spelling and proven to us that he is smart and funny.
What additional research is needed to help address co-occurring conditions for autistic people?	The focus now needs to be on motor issues and apraxia. Not just gross motor ability but fine motor including ability to speak. We need to understand what the issues are and figure out the best ways to teach people with autism other ways to communicate using AAC, including spelling out words.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Better coverage from insurance for Occupational therapy to improve motor skills. Also, there need to be more developmental optometrists as there seem to be a lot of issues with eye tracking. My son has had difficulties reading and following the words on the page. We have done eye exercises to improve this. In general, programs for adults with autism suck and are just babysitting and wasted time.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Lots of programs and services have shut down. Transportation is terrible. Programs have all been forced to become community based which is pathetic and with covid, was and still is dangerous at times.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Telehealth has been a positive change. Sometimes you do not need to see a doctor or mental health professional in person and it makes it much easier to access the support needed. In the past those telehealth sessions were not covered by insurance.

Name	Linda Gone , Parent
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Mental health disorders, gastrointestinal disorders
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Aggression, self injurious behavior, anxiety
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Being unable to participate or have any involvement in the outside world
What additional research is needed to help address co-occurring conditions for autistic people?	There's no research in the adult population
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Equity with services for individuals with severe and intense behaviors is nonexistent. Providers will not take them
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Better hygiene
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Telehealth has been great

Name	Linda Jones
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My daughter has a profile of autism called Pathological Demand Avoidance (PDA). We have been struggling to find providers who are aware of and able to support my daughter who is 7 years old. Many of these providers who are supposed to be helpful have failed to help her and have inadvertently made things worse, due to their lack of knowledge. The school system called into question my credibility when I mentioned that she has a profile of PDA as there is no formal diagnosis available in the US at this time. We are struggling with her behaviors and obtaining services from knowledgeable professionals. Our family as a whole has experienced a decrease in our quality of life because of the lack of research and information available on PDA, which presents dramatically different from typical autism.
What additional research is needed to help address co-occurring conditions for autistic people?	Research that would determine effective treatments and strategies for managing PDA is needed to provide children and families the relief that we need. Also, research that proves the existence and develops diagnostic criteria for PDA is absolutely critical. Without legitimizing PDA, there is no real way for my daughter to receive treatment and support for her condition which looks very different from typical autism.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Training and knowledge about PDA for service providers is the most important factor in addressing the needs of PDA autistic individuals and their families. Having a list of diagnostic criteria that is widely accepted among professionals as well as criteria for managing the disorder would change lives. It is extremely frustrating to reach out to professionals who are supposedly knowledgeable about autism only to find that they are absolutely useless, if not harmful in their ignorance. As a parent, being the one who has to inform providers about my daughter's needs is extremely frustrating and disheartening. We need real advice, real support and real treatment for our daughter.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic	

people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Linda Kline, DDA SDS Family As Staff Direct Support Staff
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	When staying overnight with Special Olympics they have a no prescription medical cannabis regulation which is problematic because conventional prescription drugs didn't work for my son's sleep disorder and off of those pills he was lucky to get 0 to 3 hours of sleep per night, prescription medical cannabis always 6-10 hours.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I am lucky, my son has no mental issues, he is only Neurological as that is what Autism is, neurological not mental.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Proper social and keeping the conversation going.
What additional research is needed to help address co-occurring conditions for autistic people?	Well, number 1 the schools need to put Music Therapy in the school setting and number 2 the schools need to have Recreation Therapy and eating therapy. My son had all of 3 of those therapies in the school setting from 1990-1996 and when I moved back to Maryland and was told he couldn't have Music or Recreation Therapy in the school system I was crushed, thankfully Huntington Autism Research Institute and Ewing School in Marietta Ohio trained all of us parents to perform these 2 therapies, so my son was still getting it even though the state of Maryland is way behind Ohio. Put that [profanity redacted] in the schools for our Autistics the way Ohio had it.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Permit family as staff to work over 40 hours per week whenever the need is there, I am my son's only staff and I can tell you he has way more than 40 budget hours per week and I do them all but only get paid for 40.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	We are tired of people trying to get us to take the [profanity redacted] jab. After I watched the 3 shots my mom take kill her immune system, and after the 2nd shot my dad had a massive stroke that sent him on a life flight to Altoona PA 4 weeks before Christmas in 2022....and after having 4 of my own physicians tell me NOT to get it, trust me I don't need it. I haven't had Covid the entire time, not once, I don't mask either, I refuse to as it was causing my Rosacea to go up into my eyes and had constant eye styes, so them [profanity redacted] face diapers are trash.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on	There is a Head Coach in Washington County Special Olympics that wants my son jabbed so bad with the Covid injection, he refuses to invite him to State Competition using the excuse you aren't injected, well that's nice he don't

physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	have to be to participate at state level and that's discrimination and our representatives got an email about this.
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Name	Linda Luxenberg, Parent and Professional
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Lack of understanding of processing, sensory and communication sensitivity which effects behaviors.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Communication by behavior when accommodations are not provided. Self injurious behavior requires adequate support to understand and treat issues such as OT/PT and, of course, communication.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Medication used to treat rather than evidence based interventions such as structured, predictable and consistent treatment. Poor staffing leads to poor programming.
What additional research is needed to help address co-occurring conditions for autistic people?	Vermont is at the bottom of the learning curve; yet, boasts its philosophy is superior. When families express concerns the VT system, rather than addressing the systemic failures, retaliates against parents by taking over guardianship. States lacking expertise should send not receive Fed funds. Money talks.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Vermont is administrative heavy and direct service provider light. Furthermore, the administrators lack knowledge about autism.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	More reasons for the vermont system to whine about the "staffing crisis," which was problematic prior to Covid.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Less large social gatherings is a plus for some people, particularly true of those on the autism spectrum.

Name	Linda Schepis
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory regulation challenges impede attention and learning.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD, again impacting attention and learning.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Feeding disorders.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Automatic referral for evaluation and treatment by Occupational Therapy. I have yet to meet an autistic child and family who does not need this. Get rid of ABA (see all the mental and physical health harm it causes). Provide respite care to families that is not ABA-based. Help families navigate the process of entering preschool as soon as they turn 3 years of age.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Linda, Parent
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	GI problems- co Stilton and GERD mainly Sensory and motor challenges. Unsteady gate. Sleep issues. Too little and trouble sleeping. Frequent pain. Headaches and stomach aches mostly.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Self injury, irritability and aggression/violence toward others. High anxiety.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Can't speak, Incontinent, difficulty learning to use communication device. 19 yo with developmental ability of a two-three year old.
What additional research is needed to help address co-occurring conditions for autistic people?	We need research In The causes and treatments for autism and their co occurring conditions so we can improve their health and quality of life.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Private insurance needs to cover things that Medicaid does for those that can't get Medicaid. IE therapies, pull-ups, diapers, OTC meds that help. Long waiting lists for help needs to be resolved and/ or at least decreased. Don't make us jump through hoops and all kind da of red tape to get help.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	None for us.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Hard to get help, waiting lists, telehealth has been a benefit bc it's hard to go places and waiting is always an issue due to hard time waiting.

Name	Lisa
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I personally experience gastrointestinal issues, motor challenges, and insomnia
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I personally deal with anxiety, burnout, ADHD, processing issues, and have dealt with suicidal ideation
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I personally also h
What additional research is needed to help address co-occurring conditions for autistic people?	Hearing from the personal experiences of those who have autism from different settings and demographics
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Services that focus on bettering the individuals life such as life skills, job help, making sensory management more accessible. Currently behavioral management helps but many use it as an end-all. Many individuals both children and adults are left helpless when it comes to anything other than correcting behaviors. Sensory management can become more accessible with making items like noise cancelling headphones, weighted items, sensory tools etc more affordable and accepted in professional academic settings. Many individuals especially adults also do not have access to accommodations in higher education or professional settings. Accommodations that allow individuals to perform better help such as longer test times, staggered deadlines can help.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Positive: remote options, telehealth as these can be accommodating to autistic individuals. Negative: reduced in person interactions have caused many including myself to regress.

Name	Lisa Graf
Demographic	Family member of an autistic individual; Service provider, health provider, or educator; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The biggest physical impact on my son is gastrointestinal, hypermobility, weak muscle tone and sleep issues. I am undiagnosed but likely on the spectrum. I also have gastrointestinal issues, chronic pain issues, hypermobility of joints, and migraines.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Executive functioning and anxiety are the two biggest issues.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I've worked with students on the spectrum with a wide range of abilities and additional disabilities. The additional layer of autism primarily adds social/communication issues. Sometimes students do not understand instructions or explain things unclearly. Sometimes it is the uneven maturity (young socially but knowledgeable). Sometimes it is the inability to verbalize when frustrated or distressed.
What additional research is needed to help address co-occurring conditions for autistic people?	I think a medical records study looking at different rates of people with autism, people with family members with autism and people without to identify what truly is common.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Better access to disability services and better supports for employment.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	My son has a lot of anxiety about the epidemic. He still masks in school by his choice. He has had covid several times. We think he has PANs now but not sure what virus caused it.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Access to mental health services has been limited here in Indiana with very long wait lists, It seems to be getting better. Telehealth has been great as has remote schooling when ill. He has been sick more this year.

Name	Lisa Jeanne Geaf, 2023 LEND fellow
Demographic	Autistic individual, Family member of an autistic individual, Researcher, Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	autistic burnout because it is so common and impacts so many people
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Autistic burnout
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Lack of accommodations for communication differences. Accommodations include written notes and communication and closed captioning.
What additional research is needed to help address co-occurring conditions for autistic people?	There is too much focus on changing autistic people and not enough on changing environments and expectations to make relationships and spaces more welcoming and accepting.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I would love access to services like house cleaning, Acupuncture and financial support to pursue and enjoy special interests. Improving quality of life is important.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Better access to closed captioning, community meetings and written communication accommodations. Problems are less safe access to the gym for exercise. Would love wood land hiking clubs as an option.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Largely positive but lately I am craving and sealing out more one on one visits in real life not virtual.

Name	Liv
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Not being taken seriously by medical professionals and the cost of healthcare
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	not being taken seriously by medical professionals and the cost of healthcare
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	cost of seeking help
What additional research is needed to help address co-occurring conditions for autistic people?	how to provide free healthcare to all
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	reducing cost barriers by giving everyone free healthcare
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	its too expensive to live a life

Name	Liz
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Epilepsy, anxiety taking medication
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety taking medication for epilepsy
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Dyspraxia, comprehension issues
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage, staff that understands epilepsy, not being ignored or treated like everyone else that may not have epilepsy with autism
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Staffing issues have changed dramatically since Covid 19,

Name	Liz Martineau, Nashoba Learning Group
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Many in our severe/profound autism population suffer physical pathologies that can severely compromise well-being, to the point of being fatal. These include catatonia, epilepsy and seizures, gastrointestinal distress, insomnia and sleeplessness, and sensory overload. These pathologies can be ruinous to quality of life for the individual and family. They cause suffering and often, premature death.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	In our severe/profound autism population, behavioral pathologies are pervasive and can severely compromise well-being, to the point of being fatal. These include aggression, self-injury, property destruction, pica, and elopement. The underlying cause may be anxiety or simple frustration at an inability to communicate. Aside from death, common consequences include bruises, lacerations, scarring, broken bones, ripping out of hair, and skin infections to both the afflicted individuals and their caregivers. Repeated self-injury can cause detached retinas, cauliflower ears, and traumatic brain injury. Pica can cause our individuals to ingest toxic inedible objects. These are more than "challenges," they are lethal or traumatic injuries that often require emergency medical treatments, surgeries and complicated, costly hospital stays. In addition, OCD is often co-occurring and can cause individuals to engage in rituals and routines that are dangerous and engage in dangerous behavior if those routines are interrupted.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Profound Autism, by definition, includes intellectual disability and communication disability. This combination of disability leads to profound challenges for individuals and their caregivers and a need for individualized teaching and behavior support. This segment of individuals has dramatically different needs than others with Autism and research should be directed to the specific needs and challenges of this population.
What additional research is needed to help address co-occurring conditions for autistic people?	A top research priority for our severe/profound autism population is the alleviation of distressing and too-often fatal behaviors of aggression, self-injury, property destruction, pica, and elopement. There is a desperate need for more efficacious medical and behavioral treatments, and of course more understanding of routes for prevention. We need more research on: psychiatric medications; and behavioral approaches. Much more emphasis must be placed on the needs of adults who often lack access to appropriate care and whose dangerous behaviors cause enormous burdens to families and care providers.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	With urgency we must foster a much larger and more robust network of care providers in all states to address the care needs of this rapidly growing population of individuals with Profound Autism. In particular Adults with Profound Autism need funding and access to intensive supports. We provide these supports at NLG but incur a substantial financial deficit because funding doesn't contemplate the intensive needs of this population.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to	The Covid shutdowns have had a lasting devastating impact on programs serving individuals with severe and profound autism. Many programs,

the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

particularly those serving high-needs adults, have shuttered, leaving many adults almost completely isolated with no access to day habilitation or community engagement. This also causes their families/caregivers to be isolated and often unable to work. Our program remained open but the costs of hiring and retaining staff with the appropriate skills have skyrocketed and are not adequately reflected in the funding we receive.

Name	LizC12, Self
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I'm currently getting further testing due to chronic pain. Part of said pain is severe gastrointestinal pain that also causes extreme nausea and even severe vomiting. I do not sleep well. I also. Have sleep issues, either i cannot fall asleep or I cannot stay asleep without the aid of a prescribed muscle relaxer. Not to mention certain textures, sounds, smells, flavors, and lights make me extremely uncomfortable, or icky
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have ADHD, Generalized Anxiety Disorder, and Major Depressive Disorder. I have difficulties staying g on topic when speaking or jumping from topic to topic rapidly, or getting stuck on a particular topic. There are days where I have panic attacks that are hard to get through. The days where the depression hits hard... it hits HARD. Combined, it's as if the whole world is sitting on my chest. I don't want to wake up
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I find it difficult to tell if people are being serious with me. Sometimes I don't know how to think of a good response to things people talk to me about. I always had issues with numbers in school, terrible at math.
What additional research is needed to help address co-occurring conditions for autistic people?	Definitely more research on women and girls. Testing for these things earlier. Believing the things a patient is saying, not gaslighting them or making them think they're just crazy.... I was a late diagnosed autistic female. If I had earlier testing, doctors who listened sooner (and parents who believed in these things), I might not be as bad as I feel I am today.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More coverage from insurance for tests, for accommodation tools (walkers, therapies of any kind, etc). Better access to these tools, not having them cost more then, a minimum at best, a third of average rent in one of the most expensive cities in the US. Thousands should not have to be spent by a disabled person to have an accommodation or test or procedure that they need
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Lori Hogenkamp, Center for Adaptive Stress
Demographic	Autistic individual; Service provider, health provider, or educator; Researcher; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The Evolutionary-Stress Framework (ESF) from the Center for Adaptive Stress views autism as part of a complex adaptive system, focusing on neurodiversity as an adaptive response to environmental and internal stressors. In this context, co-occurring physical conditions in autistic individuals, such as gastrointestinal issues, sleep disturbances, epilepsy, migraines, and sensory or motor challenges, are deeply intertwined with mental and cognitive health. These conditions are seen as part of a spectrum of inflammatory regulation issues, reflecting neurotype-specific stress responses and trade-offs. Understanding these conditions through the ESF lens suggests that both physical and mental health issues are interconnected, necessitating a calibrated approach to treatment. This involves fine-tuning various health aspects to achieve a balanced state, recognizing the unique stress adaptation patterns of each individual. An ESF-based approach to care emphasizes ecosystem-focused, personalized interventions, considering the complex interplay of factors influencing health in autistic people. This perspective shifts the focus from treating isolated symptoms to addressing the broader adaptive context of health and well-being of emergent allostasis.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Addressing challenges faced by autistic individuals with co-occurring mental health conditions requires a nuanced, systems-based approach. Key challenges: Complex Neurodevelopmental Interplay: Autistic individuals experience unique interactions between their neurodevelopmental traits and mental, developmental and cognitive health issues, necessitating dynamic understanding and treatment strategies. Individualized Stress Responses: These individuals often have distinct stress response patterns, which are further complicated by mental health conditions like anxiety, depression, or ADHD. Standard treatment approaches may not be effective, highlighting the need for personalized care. Access to Tailored Healthcare: There's often a lack of healthcare services equipped to address complex needs of autistic individuals with co-occurring conditions. Quality of Life Impact: The combined effects of autism and mental health conditions significantly affect social interactions, education, employment, and daily functioning. Healthcare Navigational Difficulties: Families often struggle to navigate healthcare systems to find comprehensive care. Integrated Care Models Need: There's a crucial need for integrated care that addresses the interconnected health needs of autistic individuals. Addressing the significant challenges faced by autistic individuals with co-occurring mental health conditions requires a nuanced, systems-based approach.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Autistic individuals often face complex challenges due to co-occurring conditions like learning and communication disabilities. The Evolutionary-Stress Framework (ESF) views these as part of a complex adaptive system where each condition interacts dynamically, akin to varied weather patterns in different climatic zones. Traditional healthcare approaches tend to treat these conditions separately, leading to suboptimal care for autistic adults, who commonly have intertwined health issues. This fragmentation overlooks the interconnected nature of these conditions and their collective impact on an individual's health and well-being. The Center for Adaptive Stress advocates for a systems approach, treating these co-occurring conditions as a cluster or constellation. This shift from a fragmented to an integrated treatment model focuses on emergent allostasis, recognizing the adaptive stress responses unique to each neurotype. By understanding the interplay

	<p>of these conditions, healthcare providers can tailor interventions more effectively, aligning with the diverse neurotypes of individuals. This approach, considering the interactive nature of disabilities and societal influences, promises more effective, personalized care and fosters a society that values neurodiversity and resilience.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>To enhance research on co-occurring conditions in autistic people, it's essential to integrate complexity and systems models. This approach would focus on the unique manifestations of conditions across different neurotypes, rooted in their distinct neurobiological configurations. Research should particularly explore non-linear patterns and stress mechanisms, understanding conditions like depression or anxiety as integral components of the neurodiversity spectrum, specific to the neurotype's adaptive responses. Reframing the narrative around these conditions is pivotal. Instead of viewing them as deficiencies, we should consider them as part of a spectrum of adaptive-maladaptive trade-offs. This perspective aligns with principles of complexity, evolution, and neurodiversity, paving the way for a transformative model in medicine. Here, conditions are recognized as inclusive and evolutionary adaptations. Further, studies should delve into individualized health concepts like 'emergent allostasis', investigating neurotype-specific stress responses. By viewing co-occurring conditions as interconnected elements within complex adaptive systems, we can gain a deeper understanding of neurodiversity and its implications for health. This approach not only promises targeted interventions but also informs policies that support a more inclusive and nuanced healthcare system.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Improving autism services for co-occurring conditions involves:</p> <ul style="list-style-type: none"> Integrated Care Models: Collaboration among healthcare professionals to address both autism and co-occurring conditions comprehensively. Personalized Treatment Plans: Emphasize emergent allostasis by tailoring support to individual neurotypes and stress responses, considering the dynamic nature of each person's health. Professional Training: Enhance training for professionals in systems-based approaches, emphasizing the complexity of neurodiversity. Develop holistic assessment methods for accurate identification of co-occurring conditions, respecting the interconnectedness of neurodiverse traits. Family and Caregiver Support: Provide resources, education, and support networks, acknowledging the crucial role families and caregivers play. Accessibility of Services: Ensuring all individuals can access necessary care, reducing financial and geographical barriers. Inclusive Education: Tailored educational strategies and support within schools for diverse learning needs. Mental Health Support: Adopt specialized therapeutic approaches that view common mental health conditions as part of the neurodiversity spectrum. Research Investment: Broadening research to include community-based studies on stress and quality of life, alongside top-tier research. <p>Collaborative, interdisciplinary efforts are key, respecting self-determination and providing continuous support.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>The COVID-19 pandemic highlights the need for comprehensive stress models, particularly for individuals with long-term impacts like autistic people. Key insights:</p> <ul style="list-style-type: none"> Physical-Mental Health Interconnection: The pandemic shows the link between physical conditions (obesity, heart disease) and mental and cognitive health impacts through proinflammatory responses. Inflammatory Regulation and Trade-Offs: The Evolutionary Stress Framework developed by the Center for Adaptive Stress suggests stress responses, including inflammation, are neurotype-specific adaptations.

	<p>Understanding these as part of a broader health system is crucial.</p> <p>Calibration in Treatment: Current models often oversimplify stress as a direct cause of health issues. ESF advocates for a calibrated approach, adjusting various health factors for optimal support. Chemical, Physical, and Social Stress Factors: Factors like cytokines (IL-6, IL-7, IL-15) are significant in stress adaptation and immune response, especially under social isolation. These should be integrated into health support models. COVID-19 underscores the need for dynamic stress models in healthcare, accommodating the complexity of individual health responses, especially in autistic individuals and those with neurological disabilities.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>The COVID-19 pandemic has profoundly impacted the physical and mental health of autistic individuals, highlighting the necessity for neurotype-specific care and a deeper understanding of stress mechanisms. Autistic people's unique responses to stressors like a global health crisis require personalized healthcare approaches, especially considering the varied symptoms and recovery patterns in 'long COVID.' Mentally, the pandemic has intensified stress, anxiety, and isolation, disrupting routines and increasing sensory challenges. This situation calls for a reassessment of mental health support, focusing on interventions tailored to the specific stress response patterns of different neurotypes. The pandemic also presents a chance to reform healthcare systems, emphasizing integrated care models that concurrently address physical and mental health. For the autistic community, strategies informed by the complex interplay of neurotype, stress mechanisms, and environment are crucial. In summary, the lasting effects of COVID-19 on autistic individuals emphasize the need for an ESF-aligned approach in healthcare, focusing on neurotype-specific care to effectively address the unique challenges of this community</p>

Name	Lori, mother of 32 yo with autism
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	trouble sleeping due to compulsive thoughts; motor challenges, particularly when walking (sometimes just falls down)
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	depression, anxiety, self-injurious behavior
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	When my daughter is overstimulated, she often cannot speak as her brain cannot formulate words to speak. Also, during times of overstimulation (meltdowns), my daughter, if she can speak, must talk very, very slowly to be able to articulate every word as it forms in her mind and flows to her mouth (this is how she explains it to me)
What additional research is needed to help address co-occurring conditions for autistic people?	So much research needs to be done to help health and human services providers better understand that, although a person with autism may seem to be able to function independently, often there are areas of gray where their independent abilities fall short. Along this line, research that really focuses on the multitude of ways a person with autism may present themselves both to people they know and people they don't know. Any research would be good - oh yes, and, really important to me is research on adults with autism. I am so tired of reading about all the new research and practices for infants and children that it seems like people forget that children with autism grow up to be adults with autism.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	First, I would say more funding needs to be made available. My daughter has been on a wait list since she was 18; she is now 32. Because she can "cook, clean, and bathe herself," no one thought she needed support, such as independent living skills. I guess they thought I would take care of all that, which I did, out of my own pocket with money I don't have. Insurance coverage - Medicaid - ugh. Why are there so many different Medicaid choices? If a doctor takes Medicaid, then they should be required to see any client who has Medicaid as their insurance coverage. Education of any/all health or human service providers. If a person with autism says they don't understand a question, don't just repeat the question - rephrase the question. Finally, even though we are on a wait list - no one follows up. I, as her mother and caregiver, have to make all the effort to get information about whether or not she might now qualify for assistance. In the meantime, I'm all she's got and, like many aging parents, I lose sleep at night wondering how she will ever adjust after I'm gone since no resources have been made available to her at this late stage in her life.
What lasting impact has COVID-19 infection and illness had on co-	My daughter is a rule follower. It makes her very nervous when/if people didn't wear masks. Research said we should wear masks so she couldn't understand why people weren't doing what was best for them and everyone

<p>occurring physical and/or mental health conditions for autistic people?</p>	<p>else. This caused her a great deal of anxiety and made it hard for her to venture back out after the pandemic was considered over.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Loss of direct care workers - even though my daughter is still wait for services, the loss of the direct care workforce and other service providers will probably delay even longer the amount of time we/she waits for the assistance she actually needs, despite what they said when she was 18.</p>

Name	Louis
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator; Researcher; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	As an autistic adult, some of the things I struggle with most because of my current co-occurring conditions are pain, fatigue, motor control issues , and worse quality of life. The symptoms that I have make it so it is difficult for me to hold a job, to focus in school, to maintain an income above the poverty line, be mobile around my daily tasks, and I struggle with activities of daily living. Other experiences as an educator and advocate support many of these same struggles, though the reasons behind the struggles may differ slightly. For example, while my gastrointestinal issues do cause me great discomfort and can interfere with life, I have seen other autistic individuals who have lack of bowel control or extreme pain. This, similar to my co-occurring conditions causes dysfunction in both basic and instrumental ADLs.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	In my personal experience, anxiety especially social anxiety, can be incredibly debilitating in interacting with others. ADHD also makes it difficult with executive dysfunction and added difficulty with social interaction. I have a number of different co-occurring mental conditions, which in of itself presents a lot of challenges as many providers do not know how to help my case, and I've seen the same issue in many of my autistic friends and family. Another major struggle that I see in the community is the prevalence of trauma. The effects of trauma can create a lot of dysfunction and heightened sensitivity to the environment. There are not many good medications for this, so I know many people are left without good treatment. I think another problem that arises with more externally presenting behaviors like self injury and aggression, that this comes with a lot of stigma and lack of education on the sensory conditions that lead into these meltdowns. This can cause interactions with police officers that are incredibly damaging, interactions with peers that are ostracizing, interactions with educators that are punitive. There needs to be better measures and education on this behavior to help destigmatize these conditions.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I think one of the biggest places I see problems with co-occurring disabilities in learning, communication, and intellect is education. Education systems are set up to teach neurotypical students, and so those with co-occurring conditions are subject to isolating environments, where individuals are not learning at the same level as their peers, and not given the proper accommodations to meet those needs. I also think a big problem is undiagnosed learning, communication, and intellectual disabilities as this is met with more punishment from the school system and internalizing negative self-esteem. I've seen autistic adults who have co-occurring conditions who have deep wounds and Trauma from their time in the school system. We need a major reform to both mainstream and special education classrooms to better accommodate students with co-occurring conditions. Another issue I see, is people who have co-occurring conditions in Care Homes where they are privatized, creating a highly restrictive environment. Individuals are not given the level of autonomy that they could be given. For example, many individuals in care homes with these co-occurring conditions, are not allowed to go out and engage in adult activities like going to a bar or club, they are required to abide by strict curfews, and because of poor working conditions see a high turnover in caregivers creating an unstable environment and escalating meltdown behavior.

<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>There needs to be more research from the perspective of autistic individuals, including opportunities and grants for autistic researchers and specialists who have a particular interest in autism. I see a major need for more research into treatments of co-occurring disorders, instead of individual disorders. Often, studies are separated into autism as a condition, or a co-occurring condition as a condition of the study. This ignores any synergistic effects of having both and how they affect one another. For example, major attention needs to be drawn to how autistic individuals communicate with care providers and how that affects their treatment. Also needs to be more research on adults, with attention paid to diversity as currently much of the research is fairly homogeneous in its sample.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Expanded services for adults as there is currently little support for autistic adults and their co-occurring conditions. More attention to how diversity impacts co-occurring conditions, especially the impacts of race, sex, gender. Insurance coverage through universal access for autistic individuals is necessary considering the number of co-occurring and conditions that complicate the lives of autistic individuals. Government sponsored Healthcare is a major step in the right direction, as is many autistic individuals utilize government support because of the disability that co-occurring conditions with autism causes. More education in the school system, doctors offices, and at a university level needs to happen in order for autistic individuals to receive proper treatment for the co-occurring conditions that often they have to bring to people serving them. Additionally, there needs to be more consideration in counseling for autistic individuals as currently many autistic individuals feel they cannot find a therapist who understands autism and co-occurring conditions. Another major change that needs to happen is better Social Security Programs, for income accessibility for autistic people with co-occurring conditions is attainable. Considering the high number of unemployment among autistic individuals, it is absolutely crucial that there be safety nets in place so that a vulnerable population is not marginalized further.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>In my experience, I have had long covid and chronic fatigue syndrome as a result of the covid-19 pandemic. Myself and many people I know have really struggled with returning to social life even years after the pandemic, and feel there's been a sort of loss of social skills and regression of other skills mental and physical as a result. I think many are still feeling the fall out of the isolation, causing increased anxiety and depression. As for existing conditions prior to the covid-19 pandemic I and the many other autistic people have experienced increased symptoms of these conditions like increased pain, fatigue, musculoskeletal issues. Another effect that I have seen is anxiety around sickness and health.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Some positive changes as a result of the covid-19 pandemic is that many providers now offer a Telehealth option and a lot more jobs ate remote increasing the ability to work from home which is often necessary with co-occurring conditions. Another positive, is is expanded access to online ordering decreasing social interaction which reduces social anxiety. I was able to get an undergraduate degree during this time because of the increased access to online school and that wouldn't have been possible previous to the pandemic . I think several autistic people got some social advantage during the pandemic as these opportunities became available. Some of the negative impacts that I've seen, is the pressure to get back to work and recover the economy when many of us have new conditions. The increased prices of everything makes it harder for autistic people with co-</p>

	<p>occurring conditions as many of us were already living below the poverty line and that has only increased after the pandemic. A lasting social impact for minority stress, is the knowledge that many providers could do Telehealth because they did during the pandemic, but now they've refused to do it, showing a lack of accessibility. Another lasting impact is the provision and removal of government services, where many services were expanded during the time of the pandemic which helped many, but now the services are reduced again making it very difficult for those who are reliant on services because of the strict regulations.</p>
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Name	Louise
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	A lack of understanding from healthcare professionals. Difficulty in using verbal communication to give a clear history to healthcare professionals. A tendency to underestimate the severity of symptoms due to the different ways autistic individuals communicate.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Lack of understanding from healthcare professionals regarding the difficulties in communicating distress. The expectation that people will automatically engage with a neurotypical approach to assessment, No understanding of selective mutism, alexithymia or interoception.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Having no learning / developmental or intellectual disability underplays the significant, yet hidden disabilities that autistic people experience. Looking “normal” and assuming neurotypical characteristics is highly distressing.
What additional research is needed to help address co-occurring conditions for autistic people?	Gathering the information from healthcare professionals about their preconceived ideas about what autism is and how it presents. These assumptions and preconceptions need to be challenged.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Reduced waiting times for assessment in the first instance. Post diagnosis support, advice and information, with practical examples of how to navigate the system of health and social care.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increased waiting times for assessment. Lack of available support without a diagnosis.

Name	Luca Hardt
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Scoliosis and other skeletal differences are more common in people with autism. I had a full spinal fusion when I was 11 due to severe scoliosis. I have chronic pain twenty years later and permanently limited mobility. My liver is unable to process certain medications. A low dose of sertraline caused me to enter serotonin syndrome. My concerns were dismissed by my psychiatrist as my flat affect led her to doubt my self-reported symptoms. I suffered sterile meningitis. I was unconscious or in status epilepticus for 2 days before being found and taken to a hospital. I still have seizures and must take medicine. My diet and behavior are limited due to sensory issues. I love to cook well-rounded meals, but I am not able to eat them. My diet is mostly processed foods as they are uniform and consistent. I eat too little and my digestive system is slower than most. I am frequently bloated and constipated. I must plan my errands for when there will be little traffic, and when stores will not be busy to accommodate my sensory needs. I can only manage one errand a day usually, and must nap after. I sleep approximately 3 hours at a time, with a few hours of wake time between. This is incompatible with work or life, but I am not able to make myself sleep more. 1.5mg of melatonin leaves me tired the next day, more gives me night terrors, less and I will not stay asleep. My brain's preferred sleep schedule is 2-4 hour naps, 2-3 times a day.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I am constantly made to second-guess my perceptions and feelings. I have been labeled depressed because of my flat affect and frank way of speaking. When I say people seem to distrust or dislike me upon meeting me, neurotypicals hear negative self-talk. My lived experience is that people think I am weird, I make them uncomfortable. My diagnosis helped to confirm that. The problem was not depression, it was that I was treated differently because I am autistic. The problem was not anxiety, it was that I have sensory issues. Being gaslit or dismissed by authority led to poor mental health and self-doubt. My seizures are primarily triggered by stress, made worse by lack of sleep or food. Unfortunately, the world stresses me out. I am constantly afraid to trigger a seizure. I can't afford another emergency. I have lost multiple jobs because I couldn't drive, even working from home. I have worked in disabilities social work, mental healthcare, and behavioral health. Never have my seizures been accommodated. I know better than to report my autism or ask for accommodations. I have always been passively suicidal. I have been told, directly or indirectly, that the world does not care about my needs, and will not accommodate them. Every day is difficult. Every day is exhausting. I want to live in a world with mutual aid, community, support, but that's not the reality. I am an adult that struggles to keep a job, and for that I will never thrive.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I was forced to mask from an early age. Masking is exhausting. It is taking years to unlearn and find myself again. At 30, I hit autistic burnout and entered major skill regression. I was nonverbal for six months. I was unable to leave the house or care for myself, or reach out for help. My partner has been my lifeline. I'm still recovering. I'll take any chance to rant or write about my interests - like autism, especially my own autism. Still, this form has taken me six weeks to fill out. And there are so many autistic voices who cannot contribute. I was diagnosed in my 20s. As a child I was hyperlexic, teaching myself to read before I was forming permanent memories. But there was no comprehension, I was stimming on letters. School was a game, memorizing information just long enough to get a high score. But I refused to

	<p>do busywork. Beating or failing me didn't motivate me. Still I have no tolerance for things that aren't my current hyper-focus. Because I did well academically, my lack of social skills was overlooked until I was a teen. Overnight I went from genius child to social pariah, without having changed my behavior. Miscommunications are seen as malicious, asking clarifying questions is questioning authority. I don't know how to close this gap. I'm not confident I've answered these questions in any sort of competent way. I struggle to know what is obvious, what is only personally relevant, what is fluff, and what is vital to the reader's understanding.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>The hoops one must go through to obtain a research position are incredibly difficult to overcome for many autistic people. Support in all levels of education for people who are neurodivergent could lead to better research. Autism research done by neurotypicals often borders on hatefulness. Starting with autistic researchers will help guide research on autism in positive directions. No one knows our needs better than us. Research on supports needed by otherwise employable autistic adults needs to be furthered. For many positions, there is no reason that working hours couldn't be more flexible or for employees to be constantly plugged in and ready to chat. These expectations have me in constant fight-or-flight. Even in a job I enjoyed and felt supported in, my office hours became closed-door spiraling on the floor while waiting for an approaching meeting. Positions that promise autonomy still keep tabs on you during working hours. These positions are unobtainable for the autistic people who weren't able to go to college. There are many brilliant minds not being put to work because of the antiquated expectations of work. Also further research into the outcomes of ABA therapy needs to be funded, as it is dog training for disabled children and abusive. It leads to adults with crippling PDA profiles because it is abusive. It is militant abuse to force children with autism to ignore their needs for the comfort of the neurotypical people around them.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>It currently costs approximately \$3000 out-of-pocket to be officially assessed for autism. At the point when assessment is accessible, it is likely already more or less confirmed by a therapist that one is autistic. Talking to a doctor is very hard for me. Things that may be different about my body are all I know, so when the doctor asks if I have any questions or concerns, I draw a blank. I'm not given dialogue options in the exam room, so I have no idea what I need to bring up. I am not able to argue with a claims adjuster on the phone, I know they are attempting to take advantage of me and I know they are easily able to. Because of the unexpected charges I may incur at any step of the process of receiving healthcare, I am more likely to simply never see a doctor. Just making the call to make an appointment triggers a vasovagal response. I am not able to navigate the healthcare system, especially as a labeled disabled person. I was told I qualify for disability, but every attempt at seeking help has been in vain. Social workers don't respond to phone calls, when I tried to do it myself, I was rejected. I was told that accessing disability would leave me unable to marry my partner and that a case worker would have to monitor me to ensure I was really disabled (hell). I stopped pursuing help, because I could not handle the social, hierarchical, performative process of being helped. There is an overwhelming impression of the system wishing I simply did not exist.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>I was working in a group home for teenage boys with autism when the pandemic began. Their routines were severely disrupted and they did not understand why. This led to high stress and restlessness in all of the boys, which led to violent behaviors. Staff were frequently injured, and the use of</p>

	<p>safe restraint became a daily occurrence. With a lack of previously available options due to shut downs, damaged property and sensory equipment, lack of maintenance workers, and shipping delays, fighting staff to invoke safe restraint became a sensory activity. There was an incredibly high rate of turnover at the house, meaning the boys could never form necessary bonds with new staff. We were frequently understaffed. Female staff were assaulted while working with boys who were supposed to be male staff only due to a history of inappropriate sexual behaviors. Multiple established staff members had to leave due to injury. The trauma of the pandemic set those kids back years and created many, many dangerous habits. My persisting brain fog is potentially linked to multiple exposures to COVID. I have received every booster and vaccine, but still I have had COVID 4 times. The virus seems to affect me worse than others. In the last four years, I have declined in functioning. My relationships and ability to work have suffered. I had to drop out of my MSW with only 6 months left. Due to the way I was treated once I was obviously disabled, I will not go back.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>The pandemic demonstrated that capitalism does not care about disabled people, especially those with high support needs. COVID is mostly fatal for those with pre-existing conditions, after all. Corporations raise prices arbitrarily while wages stagnate. Companies demand loyalty and productivity without returning it. People do not feel safe in or appreciated for their work. COVID protocol was lifted prematurely, leading to surges in infections and more people permanently disabled. Disability services were deemed essential but the pay was made unlivable. Many of the systems adapted during COVID showed us that society actually could be more accessible to disabled people. Telehealth was a good option but is no longer offered. Healthcare workers no longer mask. Remote work is nearly impossible to find. My city council member ran on a campaign of filling downtown office buildings and ending remote work. Given a remote position with autonomy and limited communication, I could thrive. During the pandemic, many people stopped working long enough to consider their health. Many found out they were autistic. They found out they were disabled during a mass disabling event in which our government and culture demonstrated it did not care about people with disabilities. I believe this too has led to a surge of support for Palestinian resistance, as their genocide is another mass disabling event sponsored by our government. COVID changed everything.</p>

Name	Lynn Cass
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My situation with son is 2-fold. His epilepsy, sleep disorder, sensory challenges and self-injurious behaviors cause his pain and discomfort as well as significantly limit the activities, even so-called disability friendly activities, that he has available to him. He in turn becomes more isolated and less likely to do any activity. In addition, due to the fact that he's nonverbal is it very difficult to find a medical practitioner who is willing and able to treat him and take our concerns seriously.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	For our family self-injurious behaviors and anxiety significantly limit our son's ability to participate in many activities outside of our home.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My son is nonverbal, along with intellectual disability. This makes it almost impossible for anyone but his immediate family to be able to understand and communicate with him.
What additional research is needed to help address co-occurring conditions for autistic people?	I think the best research you can do is to actually listen to families like ours who live this reality every day. We can certainly tell you what is needed to improve the quality of life for our family members.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	It would help to make it part of the priority to address the individuals on the more severe end of the spectrum; those with significant behaviors, nonverbal, not candidates for competitive employment, those who require 24/7 specialized care.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Several day programs, including the one my son attended, have shut down or decreased capacity since the pandemic. Those programs that still exist are not suitable for an individual with needs such as my son's.

Name	M
Demographic	Autistic individual; Service provider, health provider, or educator; Researcher; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	getting accommodations discrimination Sensory challenges finding healthcare
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	depression anxiety ADHD
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	intellectual disabilities
What additional research is needed to help address co-occurring conditions for autistic people?	barriers to accommodations
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	access to accommodations
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	depression anxiety lack of financial support
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	lack of boundaries and structure increase workload lack of in person interactions when it comes to requesting accommodations. prejudice by services that are available to provide accommodation in certain educational field such as the USMLE disability boards and Law School Admission Council (LSAC) disability boards.

Name	Mabel Thomas
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Restricted eating, interrupted sleep, sensory and motor challenges, behavioral expression of disability
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety and self injurious behaviors, as well as injurious behaviors towards others
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Developmental and communication disabilities
What additional research is needed to help address co-occurring conditions for autistic people?	PDA as a nervous system disability and its supports
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	All of the above.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Maci Barbour
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Joint dislocations, Gastroparesis, chronic pain
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression, anxiety, social anxiety
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Speech impediment, dyslexia, selective mutism
What additional research is needed to help address co-occurring conditions for autistic people?	Genetic links to comorbidities (eg: Ehlers-Danlos Syndrome and Autism link)
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Equitable access to public transit, pictures at public offices/facilities for nonverbal communication, insurance coverage of adult autism testing/services
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Increased social anxiety and compulsions around germs
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Reduced social interactions and availability of services for adults, changes in routine

Name	Madeline Lodge
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The most significant challenges are sleep disturbances and sensory challenges. The autistic mind is always going at high speed and thus needs heavy sedation to fall asleep. In regards to sensory challenges, our senses are so fine-tuned that we are very selective with our food and drink (which means that we are choosy even when we are beggars) and we find bright lights overwhelming (like the ones in every public place ever)
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	When combined with autism, any benefits ADHD might have are nullified, and it just makes things worse. Anxiety is also common because of how the autistic mind thinks so quickly and the conditioning and paranoia many undiagnosed and allistic parents impose on their autistic children. Depression and suicidality in autistic people are NOT caused by the condition itself, but by the fact that it is one of the most oppressed groups in the United States. You see similar results among LGBT individuals.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	We need to find ways to manufacture ADHD medication cheaply and quickly so that everyone who needs medication can readily get it.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage, accessibility and access to services, and lower lights and less sound in their areas to make autistic people more comfortable.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The increased remote work and reduced in-person social interactions have benefitted autistic people greatly because they can now earn money in low light environments without interacting with other people who they cannot understand and who are very likely to be ableist towards them.

Name	Madison
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory processing issues, sleep disturbances, stomach and bowel complications, co-occurring Ehlers-Danlos syndrome, co-occurring Postural Orthostatic Tachycardia Syndrome, panic attacks, autistic meltdowns, extreme periods from PMDD
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD, major depressive disorder, generalized anxiety disorder, PTSD, OCD, emotional regulation issues which lead to autistic meltdowns, self-harm issues, panic disorder, suicidality, self-harm, monthly meltdowns due to PMDD
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I struggle to maintain relationships with others due to social struggles, I have a hard time keeping a job due to my constant overwhelm, I can't maintain a romantic relationship due to communication issues, I can't travel or participate in activities I would like to due to sensory issues
What additional research is needed to help address co-occurring conditions for autistic people?	There needs to be a deep dive into co-occurring issues for female autistics - in particular PMDD. There is a 92% comorbidity rate, but little to no information or support. I think research needs to be done to see how ovulation impacts those with autism. There also needs to be research on emotional regulation and how we can assist those who are constantly living outside of their threshold.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Easier access to therapists educated on autism, more resources for those with autism seeking to get an education, more support in the workplace for autistic adults, assistance with medical paperwork/insurance/logistics
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Isolation exacerbated my symptoms
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Being able to work from home has allowed more flexibility, and telehealth has helped me a lot as well to accommodate my sensory and travel issues.

Name	Maegan Hayes, Social Science Specialist
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The significant troubles I suffer from are gastrointestinal issues. My ulcerative colitis becomes hard to manage when other aspects of my mental health are suffering, such as my depression and ADD.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I believe the lack of representation when needed for advocacy. Yes the union is available, but a committee to support other neurodivergent individuals would be awesome. As often times, without this representation or knowledge of how to engage, individuals can leave feeling dismissed and misunderstood. Having a person with lived experiences would help create a safe place for individuals to feel included and heard.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The lack of representation to provide guidance through processes. As often times, repetition is the hallmark of understanding many difficult and confusing processes within the VA systems.
What additional research is needed to help address co-occurring conditions for autistic people?	Is there representation provided at every VA? Also, does every VA understand neurodivergent and co-occurring disorders? This is important, as often times the best employees are viewed as lazy or unmotivated.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Education of stigmas associated with autism and how to utilize support if colleague or participants are struggling.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Maeve Sherry, Pan-End-It!
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Long Covid
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	self-injurious behavior
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	The link between autism and susceptibility to long covid and covid mortality
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Education for healthcare providers about how autism may present in different ages, genders, support needs levels, etc. Healthcare providers often perceive me as deceptive and I frequently experience discrimination in emergency medical settings because they profile me as someone who is "drug seeking."
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Long covid
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Long covid

Name	mags, diagnosed autistic
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	As I understand it, many autistic folks develop joint problems, namely a higher likelihood of ehlers-danlos syndrome.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Medication resistance has led me to have Medication resistant depression. BH4 controls (among other things) for the porosity of the Blood Brain Barrier and many autistics have a BH4 deficiency I'm also disabled to the point I can't work and I'm on Medicaid and state insurance. There are treatments for depression that have shown to be effective in treating treatment resistant depression (ketamine therapy, transcranial magnetic stimulation to name a few) but my insurance won't cover them. They come out to thousands if not tens of thousands of dollars. Also included are a myriad of other health issues along the B4 pathway. I would refer you to the work of Kimberly Kitzerow's "Map of the Biochemical Biomechanics Behind Invisible Illnesses"
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	We experience a sensation of being on the other side of a window than the general public. We are manipulated more likely than our allistic peers and taken advantage of as well. the difference of being welcome in community and being treated like we're wanted there runs deep for us.
What additional research is needed to help address co-occurring conditions for autistic people?	Please read Kimberly Kitzerow's work. I'd stake my like on her work helping understand underlying facets of the Autistic condition.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance often won't cover treatment I need because the treatment is for my comorbidities, not directly my autism. That just isn't good enough.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Nobody is the same as they've been before Quarantine. My CPTSD has evolved into something much more life-defining since quarantine. If I didn't have my 40-hour comhab support I couldn't function either in society or here alone.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I have close friends I haven't seen in years because of quarantine. My services are at times a nightmare to navigate, and moreover, people are less willing to be patient with autistic folks and I think it's because for the duration of quarantine nobody was patient with themselves.

Name	Maija Vance
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The inability to attend school due to a nervous system disability called PDA. My son is unable to access school due to Pathological Demand Avoidance. This has caused our family to have to rearrange our lives including dropping my work so I can stay home with him. It also disturbs his sleep and can cause him to stay up all night.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	PDA causes my son to feel different from his peers. He wishes he was able to attend school with his friends. He experiences anxiety and also ADHD. He has low self-esteem.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The inability to attend school and also to participate in a home school curriculum makes learning challenging for my son with PDA. He is behind his peers in school for this reason.
What additional research is needed to help address co-occurring conditions for autistic people?	More research is needed into PDA so that professionals and families can understand the root cause of the behaviors in PDA kids. Behavioral approaches actually cause more harm and led my kid into nervous system burnout.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	First off, just recognition of PDA as something real. And educating schools and healthcare providers of this profile in order to create interventions that actually help a PDA child and the family, such as much greater flexibility within a school regarding attendance. Once a child reaches burnout and can't attend school, and a parent has to stay home with them, support for the family during this time would be helpful. Insurance coverage for service dogs who could accompany a PDA child at school would be excellent. Financial assistance or home services for the family of a PDA child in burnout would help greatly.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Mara LaViola
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I believe for many autistics the sensory issues are significant, global, and often overlooked. Much like Blindness and Deafness, autism is a sensory based disorder that is minimized, but the visual and auditory deficits that co-occur with autism are severely disregarded. Many autistics have visual and auditory impairments that make accessing the learning environment extraordinarily difficult and they need explicit and intentionally designed instruction in concept development, auditory listening skills and other items blind and deaf students get from the Expanded Core Curriculum. My son has cortical vision impairment and a functional loss of hearing that is so severe it is analogous to deafness. Both are functional losses of sight and hearing that are significant and woefully unidentified in individuals with autism. My son just got DeafBlind eligibility at the age of 19 because everything was attributed to his autism. I know you will hear more about the other physical health conditions so I wanted to emphasize these as they are severely underidentified and significant. In Europe, 40% of autistics also have cortical vision impairment.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The utter failure of our mental health professionals to know how to effectively address autism and the lack of appropriately trained mental health professionals and supports for these individuals and their families. Also, these often result from the failure of our educational system to appropriately address social, emotional, and communication needs.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The failure to presume competence, teach multi-modal forms of communication, and the significant educational loss experienced by late identification of autism itself or the many co-morbid physical and mental disorders that can occur. This leads to significant educational loss. These individuals need real opportunities for life long learning that is meaningful, accessible, and built on strengths.
What additional research is needed to help address co-occurring conditions for autistic people?	Look at the co-morbidity of autism and cortical/cerebral vision impairment and other brain based visual impairments. Many autistic individuals are losing out to a life time of an education because of these missed diagnoses. It is said that 80% of learning is what we gain through our sight through incidental learning. Autistics with vision impairments have no access to the visual world if their CVI is not addressed. Autism itself leads to diminished access to incidental learning, so I would argue that much like the educational loss associated with a dual sensory loss such as DeafBlindness has a multiplicative effect on learning, adding autism into the mix only exacerbates the lack of learning opportunities and the appropriate explicit instruction needed to address these functional losses of vision and hearing.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Easier access to meaningful compensatory services due to late identifications or inappropriate educational instruction and/or environments. Special education needs to go beyond the age of 22. Insurance coverage for brain-based sensory losses like CVI and auditory processing disorders. Adult services that are more than baby-sitting and provide meaningful opportunities to continue to learn, engage in the community, and make joyful and purposeful contributions. Re-vamping of our criminal justice system so that it better understands the manifestations of autism and its co-occurring disabilities. Long term supports and services that pay commensurate to the level of training needed to ensure purposeful, joyful,

	<p>and meaningful lives where learning, growing, and maturity are expected and nurtured. Creating meaningful employment opportunities for the neurodiverse at all levels of support. Physicians who truly understand the disorders and appropriately advocate for the needs of their patients. A meaningful governmental response to the tsunami of youth with autism who will soon exit our public school system with nothing to do and where regression is expected because there are no long term supports and services. Support for their families who often have to give up on employment opportunities or social connections because they are left to care for their family members, extending the cycle of poverty beyond just the individual with autism themselves.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>Educational loss and social isolation severely exacerbated and no compensatory services as a result</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Disruption in services has been severe with no governmental response that is anywhere near appropriate. Much outcry over the isolation and educational regression of neurotypical children with no reflection on the fact that this is actually how our autistic children have experienced the world both before and after COVID.</p>

Name	Marcella Schieffelin, Member Colorado Developmental Disabilities Council
Demographic	Family member of an autistic individual; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Over 40% of individuals with a diagnosis of ASD also have a major mental health diagnosis. The healthcare system aims to provide whole person care while also stating it is concerned with continuity of care yet behavioral health is separated from medical care. One effects the other and there cannot be true whole person care when the needs of the individual are treated separately. Additionally, there are typically more than one co-occurring condition with people who are autistic. For example, my daughter has a mental health diagnosis, she is autistic, has GI issues, connective tissue issues, learning disability, to name a few.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Each individual with autism presents differently. Even so, there are people who are diagnosed with bipolar who also experience depression & anxiety. There are high levels of people with ADHD. Again, my daughter is diagnosed with bipolar disorder, adhd, and has been treated for depression.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	All of the above. For example, my daughter was born with a rare genetic disorder. Under that genetic disorder, she has multiple diagnoses that effect every aspect of her life. I'd also like to point out that ob/gyn and reproductive health is grossly overlooked. Case in point, this survey so far has not addressed that issue.
What additional research is needed to help address co-occurring conditions for autistic people?	Since I am not a physician or medical researcher, I'm not sure how to answer this question other than to review responses and analyze the data to create a plan of action.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Increase the length of time a provider is allowed to care and treat for an individual. The individual has complex needs that cannot be addressed in one short visit (typically 20 minutes at the most). The more complex the individual, the more time should be allotted for care. Transportation to appointments is already a barrier and if a person needs to return for an appointment because not everything could be addressed at one appointment, there is a lack of continuity, the risk for more problems later and cost to the individual, family, and society increases. That makes no sense.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I'm not sure.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The pay for support staff is abominable. There is lack of good, quality and qualified professionals who serve people with I/DD and therefore causing decrease continuity of care, lack of services that an individual qualifies for but not available, Another disparity is people having aging primary caregivers or primary caregivers who have died of Covid or now disabled or daily functioning limited as a result of Covid. Domino effect.

Name	Maresa
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbances and sensory and motor challenges
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD and anxiety
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Down syndrome with co-occurring autism presents significant challenges, because it causes many of the issues faced by autistics, combined with intellectual, speech, and processing difficulties found in those with Down syndrome. There needs to be more research dedicated to this dual diagnosis, and more resources for parents and caregivers of those with both diagnoses. Their needs are complex and cannot be easily addressed by knowledge or resources that target only one of the diagnoses.
What additional research is needed to help address co-occurring conditions for autistic people?	Sensory processing difficulties and mental health issues, including anxiety and depression.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage could be improved, as well as accessibility of services, especially in more rural communities.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I feel that all the examples listed above have had negative effects on autistic people's physical and mental health.

Name	Mari Savickis
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Treatment that works
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Education system not equipped to handle growing numbers of kids with autism, ADHD, and other special needs. Also housing for once they become adults.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Traditional medicine simply does not always know how to treat beyond the typical ABA, OT, speech, etc.
What additional research is needed to help address co-occurring conditions for autistic people?	Believe it would be highly beneficial to study alternative medicine to establish an evidence base. Example - I noticed years ago that my son who has both autism and ADHD had increased lucidity when he had a fever. After doing some research I learned that this occurs with other kids with autism. Also turns out there has been some study of this involving broccoli sprouts. See: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5672987/ But, my experience with traditional doctors (ie Kennedy Krieger) is they acknowledge but have zero advice on how much to take of a supplement. Studying more alternative therapies and educating clinicians about recommendations would be very helpful. My son takes medication and receives ABA which has helped a lot but I am always looking for what else I can do for him. Frankly, most clinicians I've encountered seem ill-informed about anything beyond this. I also strongly support investing more in functional medicine. Very hard to find these practitioners.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More funding for a high functioning education system. It is broken. It feels like glorified daycare. These educators are severely underpaid, they are under-staffed and the populations of special needs kids is only growing.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I can only speak for my son, but he could not do Zoom. We are fortunate in that we have the resources to help him and get ABA in the home during the pandemic to work on social skills and needs. He was already behind to start and this just set him back further.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic	It's been widely document that it has been bad for children in general (i.e. increase in mental health, lower school scores, less social interaction) - it seems reasonable to posit that that kids with autism would be equally or more so impacted.

people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

Name	Maria Garritt
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I am a bilingual Care Manager for people with Developmental Disabilities and receiving OPWDD services. The physical health conditions presented by individuals in the Autistic spectrum are: 1. Gastrointestinal disorder 2. Sleep disorders 3. Allergies 4. Epilepsy 5. Skin problems
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	1. Social Anxiety 2. Anxiety 3. Depression 4. Learning Disabilities 5. ADHD
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	1. DISCRIMINATION 2. Social isolation 3. Anger issues
What additional research is needed to help address co-occurring conditions for autistic people?	1. Educating individuals on their own condition of Autism and what to expect for others. 2. Educating public in general about the characteristic of Autism 3. How to build self-esteem in the population in the Autistic spectrum.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	1. Mental health providers well-versed in Autism. 2. More community activities directed to people in the Autistic Spectrum and with co-occurring mental health conditions. 3. More staff in agencies providing services for population in the Autistic Spectrum 4. More resources/staff for non-English individuals and their families.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	The impact was HUGHE!!! By being isolated, individuals with Autism stopped receiving services and most of them regressed in their progress. Also, MANY individuals did not return to receiving services after the COVID-19 the emergency period was lifted. Another terrible consequence was losing many direct providers as people had to find other jobs and the vacancy positions were not filled out. Many positions were closed.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	There are MANY negative consequences I cannot think of any positive consequence to the COVID-19 pandemic emergency period.

Name	Maria Maiorano
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	In my experience as a classroom teacher, the most significant challenges caused by co-occurring physical health conditions in people who are autistic vary widely and are extremely individualized. All of which have had a critical impact on their cognitive, academic, and behavioral needs. Many children will come into school and fall asleep due to not sleeping at night, making it difficult to learn anything during the school day, others may have sensory and motor challenges making it difficult to show safe behaviors throughout the day. The most significant I would say are any co-occurring physical health conditions that present to be frequently dangerous based on the individual person.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	In my experience as a classroom teacher, the most significant challenges caused by co-occurring mental health conditions in people who are autistic vary widely and are extremely individualized. All of which have had a critical impact on their cognitive, academic, physical, and behavioral needs. The most significant challenges within the classroom, I would say, is aggressive and/or self-injurious behaviors because it makes it difficult for staff to help build critical life skills. This also makes recruiting staff that want to help children with this level of need a real challenge. Aggressive behavior makes teaching a simple basic need such as toiling challenging. On the other hand, it also is a challenge to teach children who are cognitively capable how to read.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Some of the most significant challenges caused by other conditions that co-occur with autism in my experience are communication problems. This creates many barriers for the individual to express themselves leaving staff/families/doctors guessing what the needs are that have not been met. Building communication and social skills takes many years, and the intellectual disabilities vary widely, therefore, this is definitely a significant challenge.
What additional research is needed to help address co-occurring conditions for autistic people?	Continuing to help us understand more about what in the brain is wired differently, and if there are any preventative ways we can address autism through possible vaccines, medications and holistic supplements etc. and/or continuing to understand what could be causing autism. Also, experienced doctors and teachers who help treat people with autism should in some way work together to understand different perspectives. This may help to find better ways to diagnose, educate and treat patients. Also ask better questions, take specific data, and/or prescribe better medications to treat individuals with autism. I also believe that more affordable brain scans should be performed. I do understand that this does create challenges for some individuals, but it is necessary in our research to find ways so that we can also see what the brain looks like, and where the deficiencies are present. Understanding more about the brain we can also holistically help through vitamins, healthy foods etc... Taking medication and/or supplements create many challenges. Continued research to help with medications in liquid and or chewable forms that can be easily placed in foods or have a good taste to them may help ease the burden for some. In my opinion, doctors who do holistic research and medical doctors coming together for internships in a balanced way to address issues may help as well. Then finding ways for insurance companies to cover costs would be great too.
What could be improved in autism services and supports to help address	In my opinion, like most things in life, everything can be improved. The more we continue to learn, understand, and truly accept individuals with autism,

<p>co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>they will continue to teach us how to improve ways we can help them. I think one way is to continue to ask those individuals that can communicate and their families how we can service them better. Continue to recruit , train and learn new ways through professional learning communities online and in person. If diagnosed through early intervention, I believe definitely giving them equitable access to same aged peers to learn better communication skills when they are not that far behind their peers so we could help improve and increase skills needed for a lifetime of learning. This will help us build better programs within their schools and communities, and create empathy and acceptance among everyone.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>To be honest, I am not sure. I think that we will need many many more years to even begin to understand the lasting impact of COVID -19 infection and illness for people with autism. But the loss of learning through direct instruction in schools may show to be significant as these individuals get into their later school years.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>In my opinion, some lasting positive impacts we have societal changes due to the COVID–19 pandemic are that we do not have to do as many face to face social interactions leaving the many people who have autism communicating no differently behind a computer and/or phone as the rest of us. By reducing the social interactions for some, may reduce the anxiety many people with autism have on their mental health. I think with more and more online platforms becoming normalized in our society we will see people with autism meeting people across the world giving them a sense of belonging. Although, I do think there may be many negative effects that will come of the COVID -19 pandemic. Time will tell, like anything else it is extremely individualized and we will have to wait, ask and learn more through continued research.</p>

Name	Mariana Romano
Demographic	Family member of an autistic individual; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I think that many of these co-occurring health conditions are caused by the extreme anxiety that many autistic individuals suffer in navigating a world that seems hostile to how their brains and nervous systems function. My teenage daughter has two gastric ulcers, trouble maintaining a regular sleep schedule, AND sensory and motor challenges. It seems that perhaps these co-occurring conditions might be part of being autistic?
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Related to my previous answer, these co-occurring mental health conditions seem inextricably linked to autism. Depression, anxiety, ADHD, aggression, and self-harm appear to spring from the hostile world ASD individuals are expected to navigate. This heightened nervous system engagement should be the focus of new research, looking to the work of Elizabeth Newson and others in the UK who have identified this presentation.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	It is important to look at the links between the co-occurring conditions, both mentally and physically. Is there there an inherent link between ASD and the co-occurring conditions caused by biological reasons only, or does the environment in which ASD individuals are expected to navigate trigger certain co-occurring conditions. How does Pathological Demand Avoidance fit into these co-occurring conditions? How can we better serve these individuals to have fulfilling lives as integral parts of our communities?
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	For school-aged children, helping learning institutions understand how these co-occurring conditions affect children's ability to function in a system that is biased toward "neurotypical" kids, but that inability to function does not mean the student is intellectually incapable or "lazy." Research also needs to challenge itself to discover best practices to elicit the gifts these ASD individuals have. Also, perhaps if our systems worked differently, some of these co-occurring conditions might "disappear" or at least be reduced in severity.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	It is difficult to tease this out, but it would be worth looking into. For my daughter, our proximity to her daily functioning and her interactions with the demands of school, allowed us to better see the issues that she had been masking for 15 years. In mentioning that, I also think it is important to continue to study and publish about the differences in how males and females present with ASD. Our daughter had plenty of issues, but it wasn't until the pandemic that we began to add up the sensory sensitivity from birth, the slight lack of coordination, the executive functioning issues that have been with her for years in spite of her sweet nature and her "seeming" ability to get along socially that she was in fact on the spectrum.

Name	Mark Byam
Demographic	Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Severe Mood Swings, Learning challenges, attention-deficit, aggressive conversation, depression, difficult to keep relationships
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Reading, staying focused.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance Coverage, accessible services for everyone
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increased telehealth appointments

Name	Marnie Morneault, University of Maine Center for Community Inclusion and Disability Studies
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Mental health is health, which is more often than not is separated out in terms of looking at the complete health picture. Challenges for people with Autism are health/mental health professionals both recognizing how someone may be affected by mental health, versus challenges being related to Autism.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Lack of professionals to pull apart what is happening, for each person, as an individual.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Not seeing each part of a person through the lens of the separated and layered challenges that they are experiencing.
What additional research is needed to help address co-occurring conditions for autistic people?	Research should be around supporting professionals to know how to separate each condition, how it is affecting the person, how to support the needs both separately and collectively.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Service specific respond to people with Autism. Plan development to address access needs, needs related to patient/provider interactions to support each person as an individual.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Unbelievable. Because mental health services are broadly more challenging, even more so for people with disabilities.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	More challenging to see person as a needed, and fundamental part of society.

Name	Martha Gabler, Mother and Legal Guardian of nonverbal adult son with severe autism
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	In response to this question, the IACC may wish to review the following article, Al-Beltagi, Mohammed. "Autism medical comorbidities." World Journal of Clinical Pediatrics, 2021 May 9: 10(3): 15-28. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8085719/ . Accessed January 10, 2024. This excellent article provides a detailed list of autism comorbidities. There are 205 articles on this topic in the PubMed database at the NIH National Library of Medicine, National Center for Biotechnology Information. In the PubMed Central database at NIH there are an additional 22,227 articles on this topic. Thus, there is plentiful information about this important topic. A very important outcome of these medical comorbidities is that they are difficult to diagnose because the child is often nonverbal, plus there may be competing behavioral problems which mask, or are the result of, underlying medical comorbidities. A huge and significant impact of these problems is that they deny children and adults with autism access to medical and therapeutic treatment and impose a staggering care burden on the family. Parents face huge obstacles in getting access to coordinated medical care for their children, and in having the child's problems properly treated.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Our son has had life-long problems with Self-Injurious Behavior (SIB). The most significant challenges of mental health conditions in autistic people are that they have no access to quality medical or behavioral treatment (ABA: Applied Behavior Analysis) to determine the function of Self-Injurious Behavior (SIB), and thus there is no way set up an appropriate and comprehensive care plan to assist the person. Please see this article by the renowned Dr. Brian Iwata: Iwata, Brian A., Dorsey, Michael F., Suifer, Keith J., Bauman, Kenneth E., and Richman, Gina S., "Toward a Functional Analysis of Self-injury." Journal of Applied Behavior Analysis, 1994, 27, 197-209. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1297798/ . Accessed January 10, 2024. The Abstract of this article states, "... higher levels of self-injury were consistently associated with a specific stimulus condition, suggesting that within-subject variability was a function of distinct features of the social and/or physical environment. These data are discussed in light of previously suggested hypotheses for the motivation of self-injury, with particular emphasis on their implications for the selection of suitable treatments."
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Please see: Gehret, Melissa. "Autism and Learning Disabilities." Spectrum of Hope, August 6, 2020. https://spectrumofhope.com/blog/autism-and-learning-disorders/ . Accessed January 10, 2024. "Autism Spectrum Disorder is not a learning disorder. However, ASD's impact on verbal and language skills, social interaction, executive function, and motor control can all cause significant developmental obstacles to learning. Children with ASD may develop language at a later age than others, use language differently compared to their peers, or may not communicate with language at all." Another huge and frustrating problem regarding learning disabilities for children with autism is that most school systems refuse to implement research-validated curricula and methods for teaching these students. For example, Direct Instruction (DI) curricula, while initially designed for typically developing learners, are so well-structured that they have been proven to be effective for learners with autism as well. Please see this article, "Direct Instruction," at the Association for Science in Autism Treatment (ASAT), https://asatonline.org/for-parents/learn-more-about-specific-

	<p>treatments/applied-behavior-analysis-aba/aba-techniques/direct-instruction/?fbclid=IwAR3dDD_YIkJ5RdO0BhMxHigSHuPs3C-YodApa9AgsypCy8SkdUa6VvjcW3g</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>Please see the excellent position statement below developed by the National Council on Severe Autism: NCSA, “NCSA Position Statement on the Need for Innovative Research.” https://www.ncsautism.org/innovative-research. Accessed January 10, 2024. “NCSA Position Statement on the Need for Innovative Research In spite of considerable investments in research, a decreasing proportion of autism studies focus on the severe end of the spectrum. Profound impairments in communication and disruptive behaviors often preclude cooperation with necessary assessments and procedures. Meaningful accommodations must be developed and implemented to make autism research truly inclusive. The NCSA recommends that research intensify efforts in the following areas:</p> <ul style="list-style-type: none"> • Medical and nonmedical interventions to address the needs of those affected by severe autism. • Comorbidities that frequently afflict those with severe autism, such as seizures, insomnia, mental illness, pica, anxiety, oppositional defiance, immune disorders, gastrointestinal distress, and others • Etiological factors, including gene-environment, epigenetic, and environmental factors • Prevalence and demographics, including better population data on qualitative characteristics, family characteristics, and birth year, to facilitate better policy and service planning
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>People with autism need much more coordination of care between medical, behavioral (ABA), and educational professionals. Nothing like this exists and, again, parents have the extremely difficult burden of trying to create a coordinated system of care from these disparate fields, each one of which has unique obstacles that need to be overcome. Health insurance codes need to be modified to address problems such as the fact that many people with autism need anesthesia to undergo dental treatment; many people with autism cannot tolerate shots or invasive screens and may need sedation or some other type of diagnostic process. Please see: Pinals, Debra A., M.D., Hovermale, Lisa, M.D., Mauch, Danna, Ph.D., Anacker, Lisa, M.D. “Persons With Intellectual and Developmental Disabilities in the Mental Health System: Part 1. Clinical Considerations.” <i>Psychiatry Online</i>, 4 Aug 2021. https://ps.psychiatryonline.org/doi/10.1176/appi.ps.201900504. Accessed January 10, 2024.</p> <ul style="list-style-type: none"> • People with intellectual and developmental disabilities (IDD) often have co-occurring mental health conditions. • Getting treatment for co-occurring IDD and mental health conditions typically requires accessing bifurcated care across two siloed care systems. • Even though the lack of integrated care options for individuals with IDD and mental health conditions and the need for a skilled workforce have long been recognized, system structural problems and professional training gaps persist.”
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>COVID-19 exacerbated every single one of the many difficulties already faced by this population.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services,</p>	<p>The lockdowns severely limited access to community and recreational activities and shuttered the “adapted” activities that are so necessary for people with severe autism. This has had a colossally negative impact because almost none of the activities have come back. A FINAL COMMENT: The wrong and misleading media narratives of the last 25 years claiming that autism is a “super-power”, people with autism are “different but not</p>

<p>increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>disabled,” parents of children with autism are “bad and evil” because they seek treatment for their children’s conditions instead of accepting them “as they are”, ABA is “bad”, etc., have had a devastating impact on access to care. These media narratives have denied and trivialized the stark reality of autism, the difficulty of getting quality, coordinated care in medical, educational, and therapeutic settings, and they deny children and adults with autism the opportunity to learn the skills that everybody else learns (communication, reading, writing, math, appropriate public conduct, etc.), and they deny and minimize the crushing round-the-clock care burden placed on exhausted and maligned parents. The result is that the past 25 years, which could have been devoted to research and improved care for this growing population, have evaporated. POOF. We are still in the Neolithic Age when it comes to autism, with continued stone-throwing at these suffering children and their families.</p>
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Name	Mary
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Day and night are turned around for my 42 year old son. Concern with early onset dementia.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication disability
What additional research is needed to help address co-occurring conditions for autistic people?	Wish I knew, but wonder if more needs to be done with early onset dementia and autism and also if more needs to be done to not label folks with dementia as schizoaffective.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	My observation as a mother of 42 years of a son on Spectrum is that he is "normal" to himself, so labeling him otherwise is not of service to him.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Mary Jane Reis, Parent
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	In infancy and early childhood, my daughter struggled to sleep, often getting in fewer HOURS of sleep than the minimum number of hours suggested by pediatric guidelines. More research into infant and toddler sleep is desperately needed, as less sleep suggests less time for necessary brain "wiring." Could it be that sleep disorders in early childhood exacerbate or even cause autism? Today, my daughter's sleep is much closer to norms, but she still struggles to fall and stay asleep (see next section, anxiety) Note: My daughter was treated for infection/ spent 10 days in NICU - is there a link between infant infection, autism and / or poor sleep?
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	OCD, anxiety. People think autism is hard, but autism combined with OCD is a nightmare. People with autism need better interventions, both behavioral and pharmaceutical. OCD can unravel years of good therapy, leading to a cascade of developmental losses - in terms of social skills, intellectual growth, and adaptive living skill development.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Autism seems to have a big impact on reading comprehension. More studies needed to identify what reading programs are evidence-based to improve comprehension. Also, more work at the intersection of ASD and auditory processing disorders.
What additional research is needed to help address co-occurring conditions for autistic people?	Evidence-based sex and relationship education might help alleviate feelings of aloneness and co-occurring depression. There are many social skills programs for kids, but very few resources for adults seeking safe, fulfilling adult relationships, including partners. Harvard is test driving an adult relationship program but it's a one off. We need more of these types of programs.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Housing, job support that takes into account the limits places by autism and resulting comorbidities (for example, job coaches that can help with anxiety, housing that is on public transit, etc). Maybe somebody should also research the positive impact of work - and how the social support system sometimes undermines the ability of disabled people to work due to the threat of losing government benefits. The income limits now in place seem designed to keep autistic people in poverty or to encourage them to work minimally. Yet I would bet, should studies be done, that working autistic people fair better than those who are home alone collecting their SSI. My daughter might be better off financially if she worked minimally and collects her dad's SS but her mental health might be better if she worked - but then she might lose her benefits. I know this is a congressional issue, but seriously something needs to be done.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	For kids and young people, the COVID-19 epidemic gave them less time to work on social growth. I would say the pandemic set my daughter back at least one year, probably two. Also, the pandemic exacerbated her anxiety and depression. Like typical people, autistic people also do worse when they are isolated. They might not need as much interaction, but they do need some - which is why so many adults with autism struggle with depression once they age out of services / especially if they do not have meaningful employment or day services.

What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

Name	Mary Jo Cooper, Bay Cove Human Services & Boston Architectural College
Demographic	Service provider, health provider, or educator; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	universal access, space for durable medical equipment, and assistive technology. Built environments that are not person centered or not trauma informed causing the physical environment to exacerbate behavioral responses instead of facilitating independence and agency
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Especially in the transitional age youth population there is very little planning for going from entitlement (school systems) to need base systems (HCBS etc). They often will fall through the cracks and mental health conditions are exacerbated or worse, the individual will self medicate with drugs/alcohol. Because the ASD isn't always readily evident, they often fall into the Criminal Justice system instead of an actual service system that can help facilitate work, skill development, meaningful engagement and agency over life choices etc.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The greatest challenges are those that are born of not recognizing the full spectrum of conditions an individual presents with and only treating the most evident. For instance if someone presents with I/DD but also has autism, the service system may predominately focus on the I/DD and not appropriately consider the autism as influential. The whole person (holistic approach) is not always considered given the social service system design being more compartmentalized than most people...
What additional research is needed to help address co-occurring conditions for autistic people?	How do medical and social service systems interact How to look at a person, their environment, and co-occurring conditions in a holistic manner.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	community education including the medical system and school systems. trauma informed approaches including trauma informed design for physical spaces Assistive technology
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	continued and exacerbated isolation
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Virtual appointments & therapies have made specialists and engagement more accessible.

Name	Matthew Janicki, National Task Group on Intellectual Disabilities and Dementia Practices
Demographic	Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	We recommend a comprehensive and targeted program of research on the intersection between autism and dementia. Research should encompass epidemiology, presentation, assessment approaches, and disease trajectory for dementia in autistic individuals, considering variations in intellectual disability. This should include comparative studies with the general population and individuals with other intellectual and developmental disabilities. Research is also needed to enhance our understanding of the cognitive aging trajectory in individuals on the autism spectrum, factoring in variables such as intellectual functioning. Investigating prevalent types of dementia among individuals with autism is essential, acknowledging the varying degrees of risk associated with the underlying neuropathology of autistic behaviors. To improve research quality, methodological enhancements such as better research designs, larger sample sizes, and representation of diverse groups, including older adults, are crucial. Concrete recommendations include extending autism research from childhood through the lifespan, establishing a dedicated funding stream for research on aging adults with autism, and on the value of providing education for both paid and unpaid caregivers. Recognition of the disproportional funding for childhood versus adult autism research underscores the need for ongoing advocacy and resource allocation to meet the evolving needs of this population across their lifespan.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	We recommend a comprehensive and targeted program of research for advancing our understanding of the intersection between autism and dementia. This should include comparative studies with the general population and individuals with other intellectual and developmental disabilities. Research is also needed to enhance our understanding of the cognitive aging trajectory in individuals on the autism spectrum, factoring in variables such as intellectual functioning. Investigating prevalent types of

	<p>dementia among individuals with autism is essential, acknowledging the varying degrees of risk associated with the underlying neuropathology of autistic behaviors. To improve research quality, methodological enhancements such as better research designs, larger sample sizes, and representation of diverse groups, including older adults, are crucial. Concrete recommendations include extending autism research from childhood through the lifespan, establishing a dedicated funding stream for research on aging adults with autism, and on the value of providing education for both paid and unpaid caregivers. Recognition of the disproportional funding for childhood versus adult autism research underscores the need for ongoing advocacy and resource allocation to meet the evolving needs of this population across their lifespan.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	

Name	Matthew LeFluer , Vermont Legends of Cities And Towns
Demographic	Autistic individual; Researcher; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Everything including individuals of color suffer the most from every condition possible Know To Man
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Everything including individuals of color knowing every condition exists within individuals with autism
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Everything from accessibility and combinations from buildings transportation energy climate change etc everything is a definite challenge for individuals with autism and other learning needs
What additional research is needed to help address co-occurring conditions for autistic people?	First would be data research on marginalized communities communities of color that's also been left out of data research or knowledge systems we need more data of individuals on autism or autistic personnel live data so we can address the issues concerns conditions as soon as possible for everybody to meet their access need
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Equity and equality access for individuals with autism communities of color with autism other marginalized communities with autism to help address systemic barriers of culture of a system-wide privilege systems of white People researchers institutions and other factors of challenging barriers
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Health related issues with individuals with disabilities or Autism has brought forward in it inequities against individuals of color with autism and covid-19 long covid has significant damage to individuals with autism across the board of every health related issues .
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Positive is continue the hard work of addressing accessibility and accommodation barriers to A system that has not have that opportunity to grow from and Nativity is what I see not continue to move forward and understanding individual access need of autistics individuals across the board from health-related problems and issues to mental health related problems and issues to society health and problems issues and to Transportation barriers to solve Health disparity issues across the nation's Nationwide

Name	Mattie Wentz
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	hypermobility is a big issue for me. doctors are too quick to dismiss our complaints or blame them on autism/gender/other things.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	i have both adhd and autism and i think there should be more research around their similarities and differences
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Hypermobility/Ehlers-Danlos syndrome should be looked into
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	a more organized medical system would be so helpful. i like the MyChart app and it would be more helpful if more providers used it AND if it presented info from different provider groups (virtua, penn, etc) im the same place so all of my medical info is easily accessible
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I have not been able to “bounce back” from isolation like everybody else seems to. I tried to go back to my job but I haven’t been able to handle it for a while

Name	May
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory voices, texture
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	depression, behavior issues and hyperactive
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	communication disabilities, developmental disabilities
What additional research is needed to help address co-occurring conditions for autistic people?	How can we skill up their strength, for example at art or other mental skills?
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	- How can the system be Quicker to deliver the services?
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The negative was reduced in-person interactions, the remote work was really challenging.

Name	Meg Collier
Demographic	Autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I am a socialized female Autistic person and my co-occurring physical conditions include; Sensory sensitivities (light, temperature, noise resulting in burnout. Sleep disruptions, food allergies, Autoimmune Condition (Lupus + Hashimotos), POTS,
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	As a person with ADHD-Combined, persistent depression and generalized anxiety disorder in addition to ASD - I find the largest challenge is the lack of research and studies that center on Black women or Women of Color. Many socialized females, like myself, present with Autism or AuDHD differently and are often dismissed with a sort of "hysteria" or generalized anxiety making it more difficult for people to be taken seriously and diagnosed. With Co-occurring Mental Health conditions I am unable to meet the demands of the regular 40-hour work week and stay gainfully employed. I have been underemployed due to my health challenges my entire life - and almost always too employed to access benefits.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I found it almost impossible to work in the typical American corporate workplace. the 40-hours+ per week, the socialization expectations, and the generally unhealthy environments of the workplace were entirely disabling for me. I felt perpetually misunderstood and told I was "too ethical" and "too sensitive" - When in all reality I was an Autistic Adult experiencing undiagnosed justice sensitivity and rejection sensitivity dysphoria resulting in major meltdowns that would be misdiagnosed as panic attacks for years.
What additional research is needed to help address co-occurring conditions for autistic people?	Research specifically center Black children, gender queer children, in addition to research that focuses on specifically women and girls. There is some research that needs to be done to understand the relation between queer identity and Autism. I also believe research into how society can adapt to Autistics and not the other way around is much needed.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Equitable access to Healthcare and behavioral healthcare services with an ANTI-CARCERAL lens - we DO NOT need to be institutionalizing children and adults or involuntarily committing them for ASD. I think more education addressing the SPECTRUM of Autism as opposed to the non-verbal stereotypes are important , especially as more adults are diagnosed. Education on how to self-advocate and legal resources for taking action against discriminatory real estate agencies. landlords, businesses and employers
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I have been unable to work outside of my house since the Covid-19 pandemic. As an immunocompromised person with autism and ADHD, my entire way of life has changed since Covid-19. Since the CDC and the American government could not continue mitigating the pandemic and dropped mask mandates, people like myself have been left behind. I can not do many things I did before the pandemic including gather with people, eat out in restaurants, or shopping in crowded places. I worked for a radio station for many years and attended many concerts before 2019, now I couldn't possibly imagine being able to attend a concert because of an airborne pathogen that could cause me to be even more permanent.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on	I have had almost no in-person interactions and social interactions since the COVID-19 pandemic. I've had to move my housing multiple times to stay safely housed and have relied on family members and friends to supplement

physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	my income as I closed my self-employment business in 2023 because it is too much to manage and too expensive to run. The inflation has smothered my ability to stay afloat both emotionally and financially. I am not able to see my parents or friends. I've only been able to access behavioral healthcare via telehealth and I feel it's a different type of therapeutic benefit being in person. I no longer feel safe in the general American society because generally, Americans don't seem to value or care for communal care or the elderly or disabled communities.
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Name	Megan
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	We see some random gastro issues, but the families we work with access medical care for that. Sleep, or lack there of, is most common. This can cause mixed moods each day with a person who is not able to communicate being tired or not able to recognize less tolerance of triggers due to lack of sleep. We also struggle with participants not being able to identify and then communicate pain/discomfort/problems with their body. e.g., tooth pain, headaches, upset stomachs, etc.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	This is a primary area of concern. I have worked with Autistic people for 3 decades and there is sooo much confusion about given Mental Health diagnoses, e.g., anxiety, psychotic dis., etc. when some of the symptomology echoes Autism. There needs to be more research in this area. There is so much variation as some people get a MH diagnoses for exhibiting the same symptoms as someone who's medical professionals relate, say an personality disorder related to an inability to display empathy, as 'just autism'. The professionals are not equitably trained. Also, where are all of the Psychiatrists who are IDD trained/educated? Autistic people don't have many options.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	This question is applies to the non-autistic community equally. I think this is more about our education system, not the individuals. All of these conditions co-occur with some part of the Autistic population, but access to individualized schooling with professionals who can identify the individual learning style is lacking.
What additional research is needed to help address co-occurring conditions for autistic people?	Autism and mental health diagnoses. Better education systems to truly engage Autistic people in learning in the way they can.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Limits to Medicaid, medical professionals guiding care not the government. Education systems that work for all Autistic people, not just those with access to special schools. Better trained and more accessible Psychiatrists to offer specialized services, not just "let's try this new drug", so pairing with skilled Psychologists as a proper/effective treatment style. Medical appointment time limits prevent families from getting the time they need to really assess the individual within their communication style. 15 minutes for a person who needs time to process questions and responses is not enough, so relying on the support person to answer for them means they aren't advocating for themselves.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Fear. Quite a few of our participants now have an overwhelming fear of the world and what being 'sick' means. School age participants missed out on education, as virtual was not effective for them. They were not given the opportunity to make up for that missed time, plus the regression that occurred. We are seeing less people willing to be caregivers since COVID, so many of or participants are without the supports they needs to progress and be successful in life. There is a general shortage of medical professionals as well.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services,	all of the things mentioned in the question. Although, the use of virtual visits has been good for individuals who may not like strangers or having people in their homes. BUT this also means that that social skill is not being exercised.

increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Megan
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Constipation, insomnia, poor coordination
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, ADHD, PDA,
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Dyslexia
What additional research is needed to help address co-occurring conditions for autistic people?	More research on PDA (Pathological Demand Avoidance) and helpful interventions. More research on types on useful if any probiotics.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More options for covered support services covered by insurance. Covered family therapy and parenting training. Better in school trained individuals.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	My son has gotten COVID 19 twice and both times it increased his meltdowns, irritability, aggressiveness towards others While physical symptoms of COVID have been mild
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The decrease in opportunities to have social interactions has negatively impacted my son. They option of hybrid school learning maybe beneficial in the future

Name	Megan Arbour, PhD, CNM, CNE, Frontier Nursing University (and a mom)
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbances, restricted eating (ARFID)/ disordered eating, pathological demand avoidance
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, ADHD, highly reactive behavior to sensory stimulation or perceived loss of autonomy as in Pathological demand avoidance
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	learning disabilities, social interaction challenges. It is especially hard to natively interact socially in a way that seems "weird" or "different" to the norm. A cultural shift towards acceptance of people and behavior that is neurodivergent needs to occur. People don't need to be fixed, but supported.
What additional research is needed to help address co-occurring conditions for autistic people?	auditory processing disorder pathological demand avoidance genetics for learning disabilities, auditory processing disorder, pathological demand avoidance as a presentation of autism
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	A school system that does not "other" autistic people through pull-outs and shaming of behaviors. Primary care provider increased education regarding developmental disabilities. Alternatives to ABA. Acceptance. Unschooling. Parent and caregiver support.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	COVID-19 has changed the world 100% for our vulnerable population. Work, school, interactions made available at a distance via telehealth have helped. School, healthcare, mental healthcare structures that are in place are decidedly not supportive of autistic people.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increased use of telehealth has been good. Access to remote school was terrible in the public schools- the assumption of ability to hear and understand with headphones, etc., caused major trauma.

Name	Megan McLaughlin
Demographic	Family member of an autistic individual; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	In my experience, sleep disturbances and sensory challenges cause the most problems. No one can function well without enough sleep, and sensory issues can cause all sorts of problems in school, the workplace and at home.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Based on my personal experience as well as the research I've done, a disproportionate number of autistic people suffer from Post Traumatic Stress Disorder, due to the multiple forms of abuse they suffer from institutions and individuals over the course of their lives. Physicians and psychiatrists are insufficiently skilled at distinguishing the symptoms of PTSD from the characteristics of autism, so the condition often goes untreated, with disastrous effects on people's lives. It is already well known that depression, anxiety, and suicidality are major problems for autistics, but in my view insufficient attention has been paid to the cause of these problems--are they inherent in autism or can they be attributed to our society's treatment of autistics? Regardless, people are dying.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	In my experience, teachers don't recognize many of the learning disabilities autistic children have to endure (auditory processing disorders, visual processing disorders, as well as dyslexia, dysgraphia, etc.) So the children are labelled intellectually disabled, or are treated as troublemakers. Some never get the education they deserve. The challenges caused by communication disabilities seem obvious: social interactions at all levels are affected, and the result is often rejection or victimization
What additional research is needed to help address co-occurring conditions for autistic people?	More research is needed on the causes of these conditions (intrinsic to autism or caused by society's response to autistics?) and above all on autism-specific treatments for physical and mental conditions and work-arounds for learning disabilities.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	All of the above. But a greater emphasis on teaching budding physicians to understand autism and autistic people would be the most important. Only five years ago my daughter was incorrectly diagnosed with a personality disorder, simply because a psychiatrist didn't believe she could possibly be autistic (she had been diagnosed at age 3, and rediagnosed repeatedly afterwards).
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	On the one hand, many autistics reported feeling much lower levels of stress, since they could go to school or work on Zoom and avoid dealing with unforgiving people in person. On the other hand, people often report being highly stressed by the unpredictability of another, similar illness arising. The nation's treatment of autistics during the pandemic was shameful--as witness the catastrophically high death rates within this population. But so far as I can tell, no research has been done on the incidence of long Covid within the autistic population. Given their other vulnerabilities, it seems likely that long Covid would be an especially grave problem for this population.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic	Remote work and schools generally, but not always, good. Disruptions of life patterns generally very bad.

people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

Name	Megan Mitchell
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	You are doing this public comment for autistic people, yet these questions are not worded in plain language to make it accessible to answer them, so I will do my best. The most significant challenge is accessibility to be at work and school. There is a huge lack of accommodations for these issues. The need for flexible schedule, mobility devices, sensory aids, access to bathrooms. Autistic individuals like myself are unemployed at a high rate. Things like making remote work the norm would greatly increase the ability of autistic individuals to work and go to school.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Access to care. This year I spent months trying to get my son a therapist, and would be turned away because he is autistic. I had to stop telling therapists he was autistic to find one to take him on. Therapists should not be able to discriminate against autistic people. It should be protected that you get access to therapy if you are autistic.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	There are significant challenges in access medical care and government assistance. The lack of communication accommodations leaves autistic individuals like myself without proper care. Our symptoms often get dismissed as anxiety without doing any testing you would do on someone that was not autistic. Instead of investigating symptoms and pain, you are told its anxiety. Doctors do no testing to verify this.
What additional research is needed to help address co-occurring conditions for autistic people?	How to best get the resources available to be actually accessible to autistic individuals. If you have autism and struggle with communication you can't just fill out an online application for assistance and then easily understand what happens from there. For people requesting disability, food stamps, TANF, Medicaid, etc, if you have autism, you should have access to an aid to help you navigate the system. Much like they already provide interpreters for people with hearing disabilities or that speak other languages, there should be aides for individuals with intellectual disabilities that can go on the calls and help explain things.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Accessibility to services. When you speak another language you can get an interpreter on the line when trying to access government services, you can also get interpreters for having a hearing disability. There should be aids that can be called onto the line for people with intellectual disabilities and autism who are trained to explain it in a way the person can understand. This small change would hugely help autistic people get access to services and healthcare.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	For me personally I have not physically recovered. Since having COVID I went from making over 46K per year, to making 25K per year. I have had so many absences for my health that I am regularly taking unpaid leave. I went from a thriving family to struggling to make ends meet. I don't know how to access the government systems to possibly go on disability, or how to get help.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	Increased remote work has hugely impacted the autistic community. Autistic people are highly unemployed due to the lack of accommodations in the work place, and other limitations like often not having a drivers license. Access to remote work improves so many employment options for autistic individuals, as well as all individuals with disabilities. Employers should be required to have remote positions available if specific criteria are not met that would require a person to be in office, like needing to open and scan mail, be present to sign in packages or greet customers, etc.

in-person social interactions and obligations)	
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Name	Megan Tomhave, PA-C
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My insomnia has caused significant disruptions to my ability to work as I often have periods of insomnia that go on for weeks at a time with little to no sleep. I found that the primary reasons for my insomnia were my sensory sensitivities: small noises in the house, light peeking through my window, or temperature changes. The solutions have been: trying a weighted blanket, playing white noise at night, wearing noise-cancelling earplugs to bed, and having a separate duvet from my partner. I work with autistic patients and many including myself have GI issues - most commonly IBS or GERD. I find that supplementing with a probiotic helps both my emotional regulation, gut regulation, and social anxiety. I also find that I have vestibular issues - it is hard to keep my balance. My noise and light sensitivity make it essential for me to work from home or in an office with dim light. I must wear noise cancelling headphones when going to an overstimulating environments such as the grocery store. My tactile sensitivity makes it difficult to have jobs where I must shake people's hands or wear tight clothing. I have poor interoception and this makes it difficult to identify my own emotions - I do not realize that my heart beating faster for example is happening because of anxiety. There is a disconnect between my physical body and my emotions.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression happens naturally as an undiagnosed autistic woman as everyone around you assumes you to be a bad person or a narcissist and you internalize this instead of recognizing that you simply have a different brain and communication pattern. You develop anxiety because people assume things off of your non-verbal communication that you had no idea you were communicating. People get offended easily but will not tell you directly and instead act passive aggressive toward you or bully you. ADHD is very co-morbid - I have both and find it to be a good combination as my autism keeps me motivated and my ADHD allows me to be fun, but ADHD is also the reason I turned to drugs and sex as a means for connection when I couldn't understand how to connect with others otherwise. I have been suicidal at times due to lack of friends and community. I have been abandoned and isolated by many allistic people for my autistic traits.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The inability to properly communicate sensory needs. Most people don't know the reason a lot of Level 2 and 3 autistics have so many meltdowns is because they are overstimulated in some way. Too much sound, light, emotion, etc. All they need is to stim freely, have their sensory needs addressed (either by giving them stimulus or removing stimulus), spend time in their special interest, be allowed to do repetitive behavior, and be understood by their caregivers. ABA therapy is awful and tells autistic people they shouldn't be themselves which can lead to low self esteem, depression, and suicide. Going non-verbal occurs in all levels of autism and makes it difficult to communicate when emotions are high. I am a level 1 autistic with no learning or intellectual disability, yet cannot communicate at all when I am overwhelmed by emotions or feeling misunderstood by the person I am talking to.
What additional research is needed to help address co-occurring conditions for autistic people?	Research on allistic communication that can be interpreted for autistic people: non-verbal communication, social hierarchy dynamics, etc. Research on the gut-brain axis: probiotics can help autistic people, autistic people can theoretically be diagnosed via fecal sample Research on profiles of autism, including pathological demand avoidance Research on sensory hyper- or hypo- sensitivities in interoception, proprioception, empathy, or psychic

	<p>abilities Research on psychedelics and autism - apparently autistic urine contains more DMT Research on sociocultural influences on autism presentation (race, nationality, and gender) Indigenous perspectives on neurodivergence and autism Masking and autistic burnout What benefits neurodivergent communities - individualism vs collectivism I would love to help with any of these topics; I have a BA in neuroscience and I work with autistic patients as a physician assistant in a functional psychiatry clinic.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Training medical professionals in identifying level 1 autism / late-diagnosed autism especially in AFAB individuals Training employers in autism accommodations (focus on sensory accommodations, like dimming the lights, ability to wear earplugs, noise-cancelling headphones, working from home) Training teachers and educators in all of the above, putting autism education in schools</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>It has been positive in my situation: I can work from home now and don't feel as bad when I do not want to leave the house or socialize.</p>

Name	Meilin Zarnitsyna, Chicago Counseling Associates
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Epilepsy GI disorders (e.g. IBS) Sleep disturbances Hypermobility spectrum disorder / hypermobile Ehlers-Danlos Syndrome Chronic pain / Fibromyalgia Chronic fatigue POTS / dysautonomia Long COVID OSA ME/CFS Migraine Vitamin deficiencies Metabolic disorders Mast cell dysfunction / mast cell activation syndrome / mast cell activation disease Sensory/motor challenges
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Pathological Demand Avoidance (PDA) profile ADHD OCD Self-injurious behavior, suicidality Depression and anxiety Autistic burnout
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	More research into the Pathological Demand Avoidance (PDA) profile. Autistic people with this profile experience many traditional teaching/parenting/therapeutic techniques (as well as many techniques typically used for "general" autistic clients) as traumatic. Because of this, these people are at risk of being harmed (pushed into greater anxiety, aggressive/self-injurious/suicidal behavior, and reaching autistic burnout) by the very strategies intended to help them.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Equitable access to/accessibility of services Centering autistic perspectives / educating providers on co-occurring conditions (specifically helping providers understand the prevalence of co-occurring conditions so that they don't dismiss everything happening with a patient as being caused by autism) Insurance coverage
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Mel Houser, M.D., All Brains Belong VT
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I am an Autistic family physician, providing primary care to Autistic patients across the lifespan. I am the founder and Executive Director of All Brains Belong VT, a nonprofit 501(c)(3) organization in Vermont that is pioneering a novel model for neuroinclusive healthcare delivery. We integrate medical care with social connection, employment support and community education so as to holistically address multisystem barriers to health and quality of life. With support from the Organization on Autism Research and the Health Resources and Services Administration (HRSA) of the US Dept of Health and Human Services (HHS) under the Autism Intervention Research Network on Physical Health grant, All Brains Belong’s task force of interdisciplinary clinicians and 100+ neurodivergent people co-created a free resource about the constellation of intertwined medical conditions commonly afflicting Autistic people. This includes hypermobility, mast cell dysfunction, dysautonomia, pain syndromes, gastrointestinal conditions, sleep disorders and more. The constraints of the healthcare system often interfere with clinicians addressing multiple medical problems at a time. Often the standard management of some parts of the cluster makes other parts worse. When viewed as a whole, many patients make more progress. This free resource presents content in text, graphics and video, and includes content for both patients and primary care clinicians: https://allbrainsbelong.org/all-the-things
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	As an Autistic physician caring for Autistic patients throughout the lifespan, I encourage re-consideration of the distinction between “physical” vs. “mental health.” In my professional experience, Autistic patients often accumulate a range of mental health diagnoses without professionals considering that the nervous system goes throughout the whole body. For example, what dysregulates the nervous system can directly impact the immune system, and vice versa. Zooming out, I believe that fragmenting physical vs. mental health sets us up to miss the big picture where everything is connected to everything.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Autistic adults die on average by age 36-54. The main reasons for this are early heart disease and suicide. 69% of autistic adults have untreated health problems. 80% of Autistic adults struggle to access primary care. This is not a foregone conclusion. Research to explore pilot healthcare delivery systems, such as that modeled by All Brains Belong VT, can identify practical strategies for expanding healthcare access. For example, our medical practice uses universal design principles, and invites patients to co-create a customized healthcare experience, choosing from a range of options: environmental conditions, communication, sensory, and executive functioning supports. All of this was designed in consultation and collaboration with our patient community. Given that 85-97% of autistic people are dyspraxic, I would like to see research regarding motor coordination and sequencing differences; in particular, given the high rates of connective tissue disorders (ie, hypermobility spectrum disorders / hypermobile Ehlers-Danlos), the

	<p>interactions of motor coordination, proprioceptive feedback and that which is contributed to by hypermobility. I think this has broad implications for autistic people's quality of life.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>The deficit-based medical model of autism is itself a systemic barrier to health equity. My medical training focused on the triad of impairments and a rote list of co-occurring conditions without anyone zooming out to wonder why. Medical education needs to include the knowledge, skills, and attitudes required to provide neuroculturally competent care. Particularly now that we know about the constellation of intertwined medical conditions – which is NOT part of standard medical conditions – these physiological changes need to become part of medical education for all healthcare professionals. Recognizing that many Autistic patients are not identified as such, recognizing these physiologic patterns may even contribute to earlier identification of Autistic people. As mentioned above, with support from the Organization on Autism Research and by the HRSA under the Autism Intervention Research Network on Physical Health (AIR-P) grant, All Brains Belong's free resource - Everything is Connected to Everything: Improving the Healthcare of Autistic & ADHD adults - includes evidence-based guidelines for primary care clinicians: https://allbrainsbelong.org/clinician-resources Moreover, given that Long COVID risk is higher for Autistic people, absence of a universal mask mandate in healthcare settings is a clear systemic barrier to healthcare access. When we make patients choose between "health" and "healthcare," everyone loses.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>As an Autistic physician caring for Autistic patients, my personal observations are that Long COVID has had a devastating impact on Autistic people of all ages. We know that Autistic people have higher rates of Long COVID. What we see is that Autistic people with an underlying vulnerability to multisystem neuroimmune conditions, that may or may not have yet manifested, COVID can put them over the edge. Given that Autistic adults already have a 2.5-8 times increased rates of being unemployed or underemployed, and the known relationship of unemployment to chronic illness, the role of Long COVID in this equation becomes even more concerning.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>One size fits all does not work for all. While flexible adaptations for the healthcare, education, employment, social connection have been innovated and disseminated since 2020, access to these options is a privilege not available to all. Part of holistically addressing the health of all Autistic people requires zooming out, offering services, programs, etc. in multiple different ways, and giving people freedom and choosing to identify what works best for them. If the IACC is interested in learning more about an Autistic-led movement to incorporate universal design principles into the delivery of healthcare for Autistic people, I am available to provide additional public comment.</p>

Name	Melanie Del Ponte
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbances, motor challenges, physical growth of tongue/mouth muscles (from lack of speech) ADHD
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I believe the most significant challenges would be community-related, societal, and learning difficulties. I had to switch my sons school 5 within 3 months of starting kindergarten because he had so many challenges adapting, sitting still, and was unable to learn even in classrooms that were special education oriented. We moved across town literally so that he could attend a school that would work for him. I think these co-occurring mental health conditions impact them in such a huge way that it makes life even more difficult for them than it already is.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I would say the most significant challenges caused by his learning, communication, and intellectual disabilities may be informational processing, sensory challenges, lack of social skills, which leads to anxiety. I think the anxiety that comes along with these would probably be the greatest challenge. Meltdown due to inability to communicate or interact the way they wish to, and just everyday living activities. Something as simple as waiting in the line at the store is difficult sometimes because of his lack of understanding. Taking trips is difficult because he gets thrown off when his schedule changes. Every day activities become a significant challenge when you lack verbal communication and an understanding of social expectations, etc. trying to explain why we have to wait in line or why we're going on a trip is impossible, so it's almost like he's just being told to do something, and go somewhere. But can't understand why he has to do it, or why he's expected to act a certain way if that makes sense.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage, support for after-school and school programs, daycares, etc. many daycare programs will not accept a child with autism, and are unable to care for him- this is a huge gap in services for autistic children. Insurance coverage and additional special needs training for everyday pediatricians would be great as well.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school,	My son was unable to attend OT, PT, and speech therapy. The services were all virtual, and he was unable to participate because it was difficult for him to sit still and learn anything through a screen or zoom meeting

increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	melany hansen, parent
Demographic	Family member of an autistic individual; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	not sure if depression would count as the co occurring physical health condition. My son has Developmental Delays, depression and autism (and a host of other things). The challenges come in interpersonal relationships at school, work and home. Also challenges finding employment when skills are compromised and interpersonal and judgement and attitude is compromised. The world is always correcting and fixing his behavior which leads to greater depression and hopelessness.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The world is always correcting and fixing his behavior which leads to greater depression and hopelessness. my son has add,depression and anxiety. The constant corrections by the "world" have caused manic depressive episodes. Hopelessness.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Honestly differentiating between all of this is complicated. My son has add, anxiety, depression, autism and learning and developmental delays. I could use training and resources which could help me help him. It's complicated. Consequences and behavioral management can't be done as easily.
What additional research is needed to help address co-occurring conditions for autistic people?	a knowledge database that when you put in conditions you can customize how to handle things.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I designed surveys for a living for awhile (and i have 2 masters degrees) . This is confusing to me. No idea what you are asking. we have services and insurance.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	isolation. "online" issues. interpersonal skills.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	reduced in person social interaction practice (in a safe caring environment). increased remote work/school.

Name	Melissa
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I have always had trouble sleeping , getting restful sleep, staying asleep, sleeping too much. I have joint hyper mobility, my knees have been dislocating since I was 12. I have chronic pain that treatment doesn't help. I have stomach issues. I have severe CPTSD from abuse. The world feels like it was not made for me.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I find it hard to leave my house because of anxiety. My baseline every day is that I don't want to be here and I have to consciously talk myself into keeping myself going. I have serious executive functioning issues because of the CPTSD . I struggle so hard everyday to just exist.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I find it almost impossible to talk to people. I have no desire to interact because I am often misunderstood because of some subtext that is added to my actions that I did not even know about and didn't intend. I also struggle with numbers as I can't see them in my head .
What additional research is needed to help address co-occurring conditions for autistic people?	Have actual autistic people do the research on how to better our lives and not neurotypical people who have no frame of reference for how it is for us to exist everyday.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Doctors that listen and don't infantilize us and just tell us we're crazy or just anxious. More access to help and more doctors. If you're diagnosed autistic you should automatically be tested for anything that is considered a co-occurring condition.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It's traumatic for me when I get sick because of the overstimulation of my bodily functions. Not being able to breathe well or coughing constantly or having pain I can't do anything about is enough to cause me to go into an autistic meltdown. It's almost impossible to function when I'm sick.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Telehealth has improved significantly and is more widely accepted and offered which is Amazingly helpful to me .

Name	Melissa Foster
Demographic	Family member of an autistic individual; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	sleep disturbances and behavioral issues.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	behavioral issues: adhd, inappropriate behavior in the community.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	communication disabilities. There are few options besides the standard speech therapist. We need practitioners that understand all the other disabilities and how they can impact speech and how that should impact how they approach speech therapy. For example trying prompt therapy, understanding hyperlexia, autism and adhd together and how that impacts an individual.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	They three major issues that I see as a self direction broker and mom of an autistic child are the following: -access to insurance that will cover additional therapies as self-direction does not. I have very few clients with good insurance to help cover the cost of things such as aba and behavioral therapy. - After school care for special needs individuals. Currently in rochester there is a waitlist and the providers are currently on the east side of rochester only. This is why so many families have one parent that stops working in order to provide after school care. - reliable transportation to and from work or out in the community for special needs adults.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	my son has a harder time out in the community. Can only stay out for an hour tops.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	fewer respite workers as most want to do com hab as the pay is better and the hours are during the day.

Name	Melissa McKenzie
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The most significant challenges relate to activities of daily living which can include education, work, social connection - the toll taken on emotional well-being can be high.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The most significant challenges connect with activities of daily living - work, education, friendships, romantic relationships. Difficulty or inability to engage with others can make mental health challenges even more severe.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Challenges related to pathological demand avoidance can be significant when interfering with activities of daily living - as mentioned in previous responses, the inability to engage with others and find meaning through education, work, relationships can be an extreme drain on individuals and their families.
What additional research is needed to help address co-occurring conditions for autistic people?	More research on pathological demand avoidance! Awareness of PDA is growing quickly with communities coming together to support individuals and families within this domain. We need a solid research base to assist in understanding the mechanisms driving such extreme demand avoidance and to also provide evidence based prevention and intervention strategies!
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	A primary area, especially for young children is with education. Many IEP and 504 supports do not provide helpful accommodations that children need to engage with the learning process.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Melissa Sanchez
Demographic	Family member of an autistic individual; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory challenges. Much of the world is not designed to accommodate people with sensory challenges. Or we have to jump through hoops too be accommodated.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety and depression. I have been diagnosed with ADHD, anxiety, and depression. I'm fairly certain I actually have ADHD and Autism and experience anxiety and depression because of lack of accommodations and treatment. But my insurance says because I'm an adult, they will not screen me for autism.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication disabilities. Sensory overload can make it difficult to communicate. Both to express communication and to take in communication from others.
What additional research is needed to help address co-occurring conditions for autistic people?	Woman need to be included in the research more! Especially adult woman.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage. My insurance won't even screen me. I am fairly certain I have autism. I think they completely missed it when I was a child. Because I'm not medically diagnoses, I do not qualify for services or accommodations that would make my life so much more tolerable.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	MG Chappell
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	In my experience as an autistic individual, I have gastrointestinal issues as well as sensory challenges. The sensory challenges sometimes make participating in public settings difficult. My issue is primarily with scents. Experiencing things like vape and cigarette smoke make it very challenging to interact with people emitting it. This has even impacted my marriage and other interpersonal relationships. Having to mask or fight through the need to lash out at the disturbance causes me anxiety and stress. I also have sleep issues, including chronic fatigue and sleep apnea. My gastrointestinal issues include having trouble if my diets varies in any way. In my children, they have textile sensitivities, including not being able to wear certain types of fabrics. My daughter needs chewy devices for her oral needs while my son prefers weight and pressure for comfort.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Myself, as well as my children, have ADHD. I also have anxiety, PTSD and struggle with wanting to throw fits when I feel so overwhelmed with frustrations or emotions I cannot process.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My son is dyslexic. I have communication issues and do not understand social cues as easily as others. I also have trouble with understanding and expressing emotions. It makes for difficult situations as I am intelligent but do not understand why certain communication protocols make no sense.
What additional research is needed to help address co-occurring conditions for autistic people?	Autism in girls. More research is needed to identify it earlier in girls/women. I was not identified until an adult and it would have been extremely helpful to have that knowledge and supports years ago. The toll it took on my interpersonal relations including my marriage. The medical field seems to think it is a one size fits all for children and getting a diagnosis or for a physician to listen, especially in smaller, rural areas like where I reside.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I feel that there should be more supports and services available in rural locations. There is so little mental health support in this area that it is very difficult to get care and therapy, including travel costs.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	The increase in working from home and remote schooling actually helped a lot for me. I was previously a teacher and was very stressed by how students would not follow directions when given and I could not understand why that was. Being removed from the interpersonal aspect of the classroom was life changing. I loved creating and leading remotely. I taught music at the time. It also helped with my overstimulation of sound and activity. I am very sensitive to sound and quantity of types of sounds. All this led to changing work fields after going back to in person teaching. The increase in telehealth services

in-person social interactions and obligations)	opened the door for mental health support and I have kept that going even afterwards since we don't have local supports in my area. The closest is 30 min drive away. However, not having our normal routine was difficult for myself as well as my children, resulting in behavioral issues and depression. My daughter is a people person and was very down with not being able to see friends.
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Name	Mia
Demographic	Autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>I personally have hypermobility and an unspecified dysautonomia. Hypermobility has caused chronic pain for me. Walking as much as a typical person results in my knees/ankles aching at night, so I avoid it as best I can. That avoidance has caused deconditioning and probably has contributed to my depression. I have not been diagnosed with a sleep disorder but I very frequently do not feel rested after I sleep. I dealt with hypersomnia for a while (1-2 years) where I'd sleep 12+ hours and still want to sleep more. I am particularly sensitive to some sensory inputs, such as bright lights, noise, and smells. I cannot relax in most stores, school, or work. There is a great sense of anxiety that I get from that kind of overstimulation. I am uncomfortable going most places. Having to mask sensory overwhelm is exhausting, and when I return home from doing so my energy levels are very low, and can very well stay low until the next day. Consequently, I stay at home most days to avoid feeling so depleted. I will also get meltdowns when sensory overwhelm becomes too much.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>I have PTSD from multiple sexual assaults. I believe me being at the hands of so much abuse is directly correlated with my autism and my inability to discern when someone has bad intentions. I struggle with addiction as do many of my autistic friends. I feel like I need substances to socialize/exist without feeling such intense anxiety. I have ADHD which makes life feel like a nonsensical dichotomy, I feel at war with myself a lot of the time. ADHD craves novelty and autism craves predictability and structure. I have never been able to create the structure I crave for myself. I feel depressed and hopeless for more days than not. I've been suicidal most of my life and it is exhausting trying to keep those thoughts at bay. (MDD) I had excoriation disorder in adolescence and still struggle. I have an eating disorder from me constantly procrastinating eating, as accommodating my palate feels impossible at times. (EDNOS) I have a disorganized attachment style, constantly craving yet pushing away intimacy. I have been severely anxious for as long as I can remember. My anxiety causes a lot of avoidance. Lately my high anxiety has made it hard for me to clearly/articulate verbalize my thoughts. (GAD) I headbang during meltdowns in attempts to get myself back into my body. I used to cut myself during adolescence in an attempt to make my struggles more visible and tangible.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>I struggle with communication difficulties. It takes me a bit to hear what is being said, formulate a response, and then tailor that response to the relationship dynamics of whoever I'm talking to. It's often hard to articulate what exactly I want to say to someone and I often don't know exactly what the other person is looking for in a conversation with me. I often don't know how honest to be and don't understand/conform to the silent, implied emotional boundaries of a relationship, especially new ones. I've lately been feeling like a deer in headlights with most conversations and tend to stumble over my words. It is very frustrating feeling like I cannot articulate myself and I find most people do not give me enough time to process, breathe, and find a flow.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>Researching what intrinsically motivates autistic people would be helpful, as I and most other autistics I know struggle a lot with motivation. I would love to see more research looking at people with both autism and ADHD and how to accommodate that dichotomy. Researching autism specifically in women and people of color (who's experiences are criminally under-</p>

	researched) could prevent many co-occurring mental health conditions from developing due to misdiagnosis/no diagnosis.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More support specific to autistic adults would also be much appreciated, as a lot of the current help available is catered only to kids. Service dogs can be helpful both for autism and many co-occurring conditions like PTSD, anxiety, panic disorder, and some physical health problems. I would love to see them become more accessible, as right now they are very expensive and difficult to come by. More education about autism in mental health facilities. So many autistic people struggle with mental health, but so many providers do not adequately understand autism. Autistic people also tend to need a different type of therapy than neurotypicals, and treating them with the same therapy could lead to more mental health issues. Also adequately educating professionals on what co-occurring conditions are commonly seen with autism could be helpful getting more people a diagnosis as well. More intersectionality in services and research would drastically improve quality of life for many, as leaving women/POC out of the conversation allows for so many to go mis- or undiagnosed, allowing them to acquire likely preventable co-occurring mental health conditions. Insurance coverage for psychological testing would make it so much more accessible for so many people. I paid around \$10,000 for 2 assessments over my life, both weren't covered by insurance. Many never pursue a diagnosis because of the high price tag.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The pandemic has exponentially increased my social anxiety. The unpredictability of it all made life so difficult to adjust to and I can confidently say my mental health has never fully recovered. I felt so isolated and alone and still do. I'm scared to talk to people. My anxiety when talking to people is palpable. I was anxious before, but now it is paralyzing. It is much harder for me to leave the house. My body feels like it's unsafe when I leave the house. I grew accustomed to living isolated. I got comfortable with being depressed and doing nothing most days. I felt so disconnected having every interaction through a screen. Reading people's body language allows me to contextualize their facial expressions more accurately, which I could not do from zoom.

Name	Michael
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	For me personally, I have mobility and pain management issues from an injury so each day is quite painful physically as well as stressful. My work environment is extremely loud, which causes me stress and hearing loss. I am burning out faster as I get older.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The main challenges involve maintaining employment while desperately managing your symptoms. The hostility and aggressive rejection of autistic coworkers has grown increasingly intense as everyone struggles to make a living...more of us lose jobs and become unemployed.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I have a hearing deficit which is worsening as I age. It causes problems at work. I get dirty looks if people have to repeat things. I can't have more problems at work.
What additional research is needed to help address co-occurring conditions for autistic people?	How ADHD and autism correlate, how anxiety impacts both. How our brains metabolize/process sugars. How unreasonable pressure to work causes depression and suicide among autistics.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Anything to help with maintaining employment and an income. Legal protections a working class person has access to, not what wealthy folks buy. Access to medical care and counseling...I want to say especially for adult males.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	The job market is tighter and more aggressive. Coworkers are the biggest threat to us frequently. I cannot hold on to a job long. The fear and risk from COVID is an ongoing concern as I work in healthcare. Stress from being sick has been significant.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	My anxiety is through the roof every day. I think many autistics are just overwhelmed by the number of alarming issues looming over us at all times, but this last year has been quite bad. I'm not sure how long I can keep this up.

Name	Michael Confoy, parent of child on the spectrum
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Needing speech therapy
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, ADHD
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Slow learning to speak clearly, slow learning to walk and crawl
What additional research is needed to help address co-occurring conditions for autistic people?	How to treat all conditions together as a whole recognizing how they interact with each other
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance doesn't address the existence co-occurring conditions as something to address, just each individual one. Also, insurance is difficult to get coverage for high performing individuals on the spectrum.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Lack of social interactions
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Disruption of in person services, lack of social interactions

Name	Michael Raney
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Anxiety and stress on nervous system
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety and depression, particularly with regards to what is known as the Pathological Demand Avoidance profile in the UK.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	One area of concern for my family is school refusal (related to what is known in the UK as the Pathological Demand Avoidance profile). Class sizes as a factor in autistic students feelings about school and willingness to attend school within a mainstream setting.
What additional research is needed to help address co-occurring conditions for autistic people?	Any and all research related to what is known in the UK as the Pathological Demand Avoidance profile.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Ways to improve understanding of atypical presenting autism within schools and other places that diagnose autism. For example, my child's school evaluation disregarded autism because he can make eye contact. That is an outdated belief which seems to still be disturbingly common, even among providers who should know better.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Michael Rathbun
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I experience GI disorders, motor challenges, prosopagnosia/prosopamnesia, topological agnosia, aphantasia, and Severely Deficient Autobiographical Memory (SDAM), various manifestations of executive dysfunction.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	For me: Major Depressive Disorder, clinically diagnosed in 1987, likely due to executive dysfunction, with frequent suicidal ideation since age 7. Social disconnection as a result of inability to properly interpret communications, especially nonverbal.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Human communication involves many factors that are not apparent to the casual observer. Learning involves discovering that what is important for you is what is important for the teacher.
What additional research is needed to help address co-occurring conditions for autistic people?	We need an understanding of autism based on measurable structural departures from "typical" rather than largely subjective behavioural observations.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	For autistic adults, the ability to detect autism without years of effort and thousands of US\$, after which some reasonable accommodations should be discussed.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	This needs to be understood. I personally have had novel, apparently COVID-19-related adverse experiences that are outside my experience over the past 70 years or so.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Michaela
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	It's definitely difficult to get to sleep. I've had to medicate and do deep breathing exercises just to get my body to go into sleep mode. "Sensory challenges" is the biggest thing. If I become overstimulated, it can lead to severe irritability, up to a meltdown, in which I need to separate myself from any company in order to just let it out. Overstimulation can be caused by loud sounds, too many different sounds at once (i.e. several people talking while the tv is on, an itchy tag on a shirt rubbing against my neck all day, conflicting scents, etc.)
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I've also been diagnosed with general depression and anxiety disorders as well as ADHD. Self-injurious behavior and suicidal ideations were more of a problem when i was younger (pre-diagnosis) but they were definitely a problem. These cause more significant roadblocks in my life as I'm constantly having to battle them just to get through the day-to-day.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I personally didn't have any handicaps with learning. As far as development, my parents say i was slower to learn how to talk. I was, however, quicker to learn to read and am an avid reader (i believe the term is 'hyperlexia'). Communication is a thing i stumble over, however. I find it difficult to use the correct 'tone' when speaking and completely miss when people are trying to make a joke unless explicitly told. I don't understand when people try to 'hint' at something rather than saying it outright. To be honest, i still don't understand WHY people don't say exactly what they mean.
What additional research is needed to help address co-occurring conditions for autistic people?	Self-diagnosis, especially in cases where there is no pathway for someone to get official diagnosis (such as a lack of insurance) or where it is unsafe to obtain an official Dx (such as states that legally discriminate based on mental illness; for example, in some states autistic people cannot adopt children).
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increased remote work has definitely helped/been a positive in my case. I can control my environment and since everyone uses text-based communication, people feel the need to be clearer in their words. I also don't have to "mask" (hide autistic traits) for ten hours a day when I'm working from home, which is really nice.

Name	Michelangelo molina
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The interplay between autism and co-occurring mental health conditions introduces intricate challenges. Depression may intensify social withdrawal, anxiety can heighten sensory sensitivities, ADHD may exacerbate attentional difficulties, aggressive behavior poses safety concerns, and suicidality demands urgent intervention. Recognizing the unique experiences of each individual is crucial in navigating these complexities. Tailoring interventions to their specific needs ensures a more effective and empathetic approach, aiming for holistic well-being.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	For individuals with autism, co-occurring conditions like learning disabilities may pose challenges in academic settings, developmental disabilities can impact daily life skills, intellectual disabilities may affect cognitive abilities, and communication disabilities might hinder effective social interaction
What additional research is needed to help address co-occurring conditions for autistic people?	Research is needed to delve into effective interventions, such as exploring how tailored therapies can alleviate the impact of co-occurring conditions like anxiety and depression in autistic individuals. Understanding the role of environmental factors and genetic predispositions in the manifestation of co-occurring conditions can guide personalized approaches to treatment. Additionally, investigating the long-term outcomes of individuals with specific combinations of co-occurring conditions, and assessing the efficacy of support systems, will contribute to a more nuanced and targeted approach in addressing the complex needs of autistic individuals
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	

in-person social interactions and obligations)	
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Name	Michele Brady
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	It is very hard to get comprehensive care for autistic individuals. Parents must coordinate care with many specialists who are not autism specialists and do not understand how these health conditions interact on the individual as a whole. Pediatricians and primary care doctors are very under educated in treating autism and co-occurring conditions. It is very hard to get medical guidance that considers the whole child or adult.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	It is difficult to find neurologists, psychologists, and psychiatrists that are knowledgeable about treating mental health issues in the autistic population. And insurance does not cover these services.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Once a child leaves the school system, it is hard to continue growth and learning. These young adults are still learning, but there are very few programs that support continued growth and learning. It falls to the parent to drive this process and it is a full-time job.
What additional research is needed to help address co-occurring conditions for autistic people?	We need to research best practices for treatment of mental health conditions in the autistic population and train more providers of these services.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance needs to cover treatment for these conditions and we need more providers who specialize in these conditions in the autism population.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Regression in skills and increased mental health issues have occurred in this population. Anxiety and depression are still at a high level. And skilled specialists are hard to find for treatment and support.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	My son graduated from high school in 2021 and it was very difficult to find a post-high school program that was open and accepting new students. These programs are still having issues retaining staff and returning to regular activities. Being forced to stay home continues to cause anxiety and depression.

Name	Michele Lappin, The Center for Exceptional Families
Demographic	Family member of an autistic individual; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbances, sensory processing disorders (including Avoidant Restrictive Feeding Intake Disorder), gastrointestinal disorders (including Acid Reflux, GERD, Chronic Constipation), Gross and fine motor issues
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety Disorders, ADHD, Aggression, Self-injury, Depression, PDA (Pathological Demand Avoidance), PTSD
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Intellectual disabilities, significant communication disorders and deficits
What additional research is needed to help address co-occurring conditions for autistic people?	I think there needs to be more research on how co-occurring conditions can present differently in Autistic individuals compared to neurotypical individuals.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I think there needs to be more training and resources to help the medical community look past a patient's Autism as the reason for all their ailments. For example our Autistic son was irritable and throat clearing for a year. Our son could not communicate what was wrong. We went to numerous doctors who said it was because he was Autistic and stimming. I knew something wasn't right and took him to an ENT. Our son had tonsil stones which were irritating and causing him to constantly clear his throat. He had his tonsils taken out and he stopped throat clearing and was less irritable. This is the norm in the Autism community. Similar things have happened to everyone I know who is Autistic or has an Autistic child.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It has definitely made accessing healthcare more difficult. Mask wearing is extremely difficult for some Autistic children and adults. It is also hard for them to understand language when other people wear them and talk. Virtual options for speech, physical, and occupational therapy did not work for our Autistic children. Hospitals only allowing one parent with a child in the ER made accessing care difficult because some Autistic children need 2 people for safety purposes. Overall it made accessing healthcare for anything including co-occurring conditions challenging.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school,	Negative: Disruptions in services, more specialists leaving the field or moving, less options for services, remote school and therapy were inadequate for our Autistic children. Positives: Mobile patient intake processes, waiting in care to be called, telehealth options, reduced numbers of people crowding together, sensory sensitive times at many businesses, increased availability for curbside and delivery for grocery and take out

increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Michelle Goldberg
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Constipation, lack of sleep
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Crying, depression, aggressions towards others and self, adhd, vocal stimming
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Lack of Communication which causes anxiety and anger
What additional research is needed to help address co-occurring conditions for autistic people?	What is causing the emotional breakdown and how to handle it.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Make it more comfortable for someone with autism to be examined and being treated by a doctor.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I do know that it was difficult to get back into a routine
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	See previous answer

Name	Michelle Grochocinski
Demographic	Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I want to elevate that hypermobility and associated disorders, including hypermobile spectrum disorder (HSD) and Ehlers-Danlos Syndrome hypermobile type (hEDS), is significantly more prevalent in individuals with autism than the general population. EDS is a genetic connective issue disorder that can impact all bodily systems and cause a variety of symptoms, including joint pain, chronic pain, fatigue, sensory issues, GI issues, and sleep disturbances. MCAS and POTS are frequent comorbidities. EDS is underdiagnosed and frequently misdiagnosed. It is important to educate providers about hypermobility disorders and screen individuals with autism for hypermobility and EDS.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I want to elevate that hypermobility and associated disorders, including hypermobile spectrum disorder (HSD) and Ehlers-Danlos Syndrome hypermobile type (hEDS), is significantly more prevalent in individuals with autism than the general population. EDS is a genetic connective issue disorder that can impact all bodily systems and cause a variety of symptoms, including joint pain, chronic pain, fatigue, sensory issues, GI issues, and sleep disturbances. MCAS and POTS are frequent comorbidities. EDS is underdiagnosed and frequently misdiagnosed. It is important to educate providers about hypermobility disorders and screen individuals with autism for hypermobility and EDS.
What additional research is needed to help address co-occurring conditions for autistic people?	Hypermobility and associated disorders, including hypermobile spectrum disorder (HSD) and Ehlers-Danlos Syndrome hypermobile type (hEDS), are not well understood. More research is needed to understand the link between hypermobility disorders and autism (as well as ADHD).
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Providers should be trained to recognize and, if appropriate, diagnose hypermobility and associated disorders, including EDS.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	

in-person social interactions and obligations)	
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Name	Michelle Harris
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gut/GI issues, motor coordination and low core tone, sensory aversions.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Cognitive impairment, anxiety and OCD.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Difficulty communicating needs/preferences and internal sensations including emotion, pain and other symptoms (nausea, dizziness, fatigue etc). Difficulty accessing appropriate screening for vision care, dental care, other health services. Dependence on adult/aging parents. Lack of community support/funding as autistic individual ages.
What additional research is needed to help address co-occurring conditions for autistic people?	Allow parents/family members to speak on behalf of our children. The disservice done by the "neurodivergent" community means research will have to focus on those autistics who are able to communicate either verbally or in some other way. What happens to the rest of the autistic community? My son has autism and cognitive impairment - he was turned away from research studies (NIH) for not being high functioning enough. This is not our preference - we would much prefer to allow him his own voice. There are NO services for him once he turns 21.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Options for those who are not high functioning and those who are not from wealthy families - what happens after 21? Services are woefully inadequate, challenging to navigate. Services must include medical/health but also allow for these young adults to maintain and continue to develop life skills - why would it all stop at 21? The insurance system in this country is so broken, I wouldn't even suggest coverage. We need infrastructure for our more dependent individuals - in education, vocation, health and welfare.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Basically 2 years of little to no schooling - the burden on parents was intense. The autism community was shameful in it's shunning of vaccines leading to continued outbreaks (in January 2024) of Covid-19.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The pandemic was extremely hard on our teenage son with autism. The burden (financial, emotional, physical) toll of providing 24/7 care was very tough on parents, and has continued to lead to health issues for older parents. The pandemic led to a total disruption of services (in home techs) and educational and recreational services.

Name	Michelle Jace
Demographic	Autistic individual; Service provider, health provider, or educator; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	sleep disturbances, gastrointestinal, anxiety
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression & anxiety are constants because society sees many autistic characteristics as laziness or stupidity instead of a legitimate disability. The depression and anxiety conditions developed due to these societal factors along with the possibility of depression and anxiety from additional factors catapults many autistic individuals into self-injury and suicidality. These challenges are significant because they don't arise in a vacuum. Autistic people are constantly having to adapt and readapt to societal norms while trying to meet the needs of their disability that directly contrast those norms.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	There are many comorbidities that impact the lives of autistic people, but to answer this question specifically I think the most significant challenges for autistic people are found in communication disabilities. I think we need more education and support in education, medicine, human resources, law enforcement, and government, on alternative communication styles and to help squash the myth that spoken speech is the only valid type of communication. More people outside of DEI, special education, and other disability work need to be comfortable with AAC, speech differences, and body language differences. If communication needs are better met, then treatment and support for the other co-occurring challenges like intellectual, developmental, and learning disabilities will suite the needs of the autistic individual better providing them the most opportunity for independence.
What additional research is needed to help address co-occurring conditions for autistic people?	Out of all the answers received for this question, please prioritize what autistic people with high support needs share. The voice of the autistic individual far outweighs the perspective of any caretaker, educator, parent, or practitioner. The biggest thing needed is more support for autistic adults particularly in the workplace and other areas of life like home ownership. Any research done should be to survey or interview the perspective of autistic adults on this, or autistic teens moving into adulthood. This research should not be done with the intent of providing autistic people with more training on how to exist in a non-disabled world, instead it should focus on ways to provide more disability support within the workforce, universities, and other adult community services. I think research on disability and homelessness needs to be done as well, specifically examining antecedents to a disabled individual becoming unhoused. Those findings should be used to propose programs and legislature to help support disabled individuals into adulthood.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	A massive training effort needs to take place across healthcare, government, law enforcement, education, corporations, and communities lead by autistic people who are also practitioners. This unique perspective will address the realities of their field and expertise while also taking the autistic perspective into account. Autistic teachers and professors should lead trainings on teaching autistic students while autistic doctors are given the floor at medical conferences to speak on the unique qualities of trauma and sensory

	<p>processing differences in their autistic patients. Financial aid and disabilities services shouldn't have so many hoops to jump through to prove that a disabled person is in need of support. Since the US is a country that does not provide healthcare to their citizens, it is incredibly difficult for many individuals to have the funds to not only seek a diagnosis, but also continue paying for the care needed. As more research comes out supporting the accuracy of self diagnosis for autism spectrum disorder, financial and community supports should be available to autistic adults without a formal diagnosis.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>I think many autistic people thrived in the solitude of lockdowns due to Covid19 and they are hoping to get back to a quiet environment like they had before. However, many autistic people also struggled significantly during lockdowns because their routines, education, medical needs, and social plans were stopped and they have been unable to catch up or really find their stability again. I think more work from home and telecommunication opportunities need to be implemented particularly in healthcare, school, and the workforce. Governments should find incentives for businesses to hire more disabled employees as well as incentives for providing disabled employees with work from home positions. The impact of long covid is concerning for everyone, but for people already living with a disability like autism, the comorbidity can further impact ability to function within society.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Many services were interrupted for disabled individuals and the efforts to get the back on track are almost nonexistent. Working in early intervention with public schools, there was already a long line of children waiting to be evaluated for an IEP and covid19 shutdowns made the list even longer. Currently there are many children that should have been evaluated already, but haven't been because the wait is so long or parents are at a loss of what to do next. Autistic adults are struggling to navigate this post shutdown world, as many of us are in tune with disability rights and advocacy and when we look around we see almost nobody wearing a mask to protect themselves and the individuals within our society who have disabilities and weak immune systems. Better covid19 safety measures need to be put back in place to make disabled people feel like they can go participate in society safely. Autistic people need more opportunities to continue school and work remotely as well as telehealth and other obligations.</p>

Name	Michelle Linn, Parent, Provider
Demographic	Family member of an autistic individual; Service provider, health provider, or educator; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Headaches, neurological issues (epilepsy), gastrointestinal, and sensory and motor difficulties are all significant challenges for us. Autism needs to be diagnosed biologically, not through the subjective DSM-V. We need science to distinguish between autism and the co-occurring health conditions with specificity. As it stands, there really is no hard science to differentiate between autism, epilepsy, or any other psychiatric disorder. It's a subjective pile of nonsense. All research should be directed toward biological markers and the cause of autism. The fields of psychiatry, psychology, and neuroscience should not be involved in or directing autism research. Unfortunately, these professions have monopolized most what has been published on autism, which is why we have had such little progress during my son's lifetime (he is 29). We need a radical shift in the autism research strategy.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Aggression and self-injurious behavior have been my son's (and our family's) most significant challenges. Had we not had our own, substantial financial resources, our son would be homebound and we would all have a horrible quality of life. Many families are suffering with the debilitating and isolating behaviors associated with autism. More must be done to support families, find the cause, and develop actual treatments and prevention based on causality. The current trial and error use of psych meds and intensive behavioral intervention (when it's even available) is insufficient.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My 29 year old son is completely non verbal and uses an ipad (ProLoquo) to make basic requests and choices. Consequently, his functioning and quality of life are very limited. Many individuals with profound autism have been helped with Spelling 2 Communicate, which is a very painstaking process to overcome motor deficits in order to teach typing and, subsequently, significant communication. There are very few providers available and therapy is not covered by insurance or recognized by ASHA (American Speech-Language Hearing Association)
What additional research is needed to help address co-occurring conditions for autistic people?	Autism needs to be diagnosed biologically, not through the subjective DSM-V. We need science to distinguish between autism and the co-occurring health conditions with specificity. As it stands, there really is no hard science to differentiate between autism, epilepsy, or any other psychiatric disorder. It's a subjective pile of nonsense. All research should be directed toward biological markers and the cause of autism. The fields of psychiatry, psychology, and neuroscience should not be involved in or directing autism research. Unfortunately, these professions have monopolized most what has been published on autism, which is why we have had such little progress during my son's lifetime (he is 29). We need a radical shift in the autism research strategy
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Quit calling them co-occurring conditions when there is no science to distinguish between the disorders biologically. Acknowledge we don't really know what autism is and therefore need a significant research effort to identify autism and its cause. All parents providing care for their adult children with profound autism should be compensated at the rate for nursing home/institutional level care until such a time that adequate, high quality residential care and treatment are available. Individuals with profound autism need high quality, 24/7 care across their lifespan. Society isn't currently paying this high cost, the burden is laid on families at the expense of their livelihoods, quality of life, and their own health. It is a heartbreaking

	tragedy that requires an effective and adequately resourced and organized response (something we have never had).
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	COVID-19 infections were mild and did not affect our family at all. Since we help run the day treatment facility that supports our son, it did not close or discontinue services to any client. The isolation of COVID-19 was business as usual for us, as we did not go out in the community with our son due to his aggression and self-injury.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	COVID-19 infections were mild and did not affect our family at all. Since we help run the day treatment facility that supports our son, it did not close or discontinue services to any client. The isolation of COVID-19 was business as usual for us, as we did not go out in the community with our son due to his aggression and self-injury. Autism already devastated us, COVID-19 therefore had little effect.

Name	Michelle OConnorTeklinski
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The lack of practitioners with specialized training to support the adult autistic population. Parents and caregivers seem to continually dismissed as historians for their adults with autism experiencing co morbid issues
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Our healthcare and mental health system are short staffed and lack specialists to address scaffolded issues such as anxiety, OCD, ADHD, depression and autism. We don't look at the big picture and write off behaviors as autism. A family in Michigan called their psychiatrist after hours emergency on call line and it took 5 days to get a call back.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Since our support models are driven by diagnosis, interventions are driven by the same model. We need access to services based on need not diagnosis or severity.
What additional research is needed to help address co-occurring conditions for autistic people?	How anxiety, OCD, ADHD can be diagnosed better and what treatments will be most effective.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Appropriately trained and staffed clinics offering timely access to diagnosis and services. We also need a safety net for families dealing with physical aggression and not sending autistic adults to the ER or inpatient psych
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	There seems to be increased aggression and behavioral changes. Is this tied to the vaccine or illness?
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Lawmakers and providers were forced to adopt practices that they would not traditionally embrace as an option. IE remote, eligibility requirements. Take time to look at outcomes before adopting the status quo

Name	Michelle Skigen, M. A.
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Anxiety, depression, PTSD autoimmune issues (higher stress levels tied to genetic predisposition)
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	PTSD, depression/anxiety
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	This is individual, just like for non-autistic people. What needs to be researched is how to separate any challenge from autism when evaluation is occurring... recognizing that it is a condition expressed autistically, rather than saying it is all autism. For example, self-injury is an anxiety/PTSD behavior (seen in people who aren't autistic as well who have undergone severe trauma). It is a HUMAN response, not because of autism. The stresses that bring on the PTSD may differ from what is considered "normal," but it is the stresses, not autism, that are causing the PTSD behaviors.
What additional research is needed to help address co-occurring conditions for autistic people?	Research into how thin-slice judgements by neuro-normative people affect social, economic, and personal-interest access to opportunity and resources. Separation of various conditions that are being expressed autistically, but are separate conditions because neuro-normative people also have those conditions. Research into supportive rather than remediative resources for autistic people in all areas - medical, psychological, employment/school, etc. Research into the best ways for professionals to decipher and accurately assess autistic people's needs, comorbidities, acute illness, etc. A big deal is that autistic people often go untreated, undertreated, or mistreated for medical conditions due to staff misjudgements regarding both what the autistic person is experiencing and the autistic person's motivations. See my earlier comments about thin-slice judgements.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	See my earlier comments.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Access to regular supports, accommodations, etc. has varied due to the strain on the systems that normally provide them. Now that COVID-19 is less of a concern in general, the shift back to on-site employment is interfering with many autistic people's ability to self-support, and increases stress which exacerbates medical and mental health issues. Family stress because of other members of the family having cabin fever, anxiety over lack of rule compliance, etc. also contributes to stress levels.

<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Increased remote work and school has improved things for many autistic adults, and some kids. Some of the kids had increased stress instead... it all depended on family engagement and collaboration with staff. Disruptions in services was huge, especially when dealing with accessing medical care, and most especially with accessing specialists... but that is also the case for neuro-normative people with illnesses/conditions requiring that access.</p>
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Name	Michelle Surgenor
Demographic	Family member of an autistic individual; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbances, sensory challenges
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	All the above mentioned
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	All the above, plus pathological demand avoidance
What additional research is needed to help address co-occurring conditions for autistic people?	Micro level research to understand what help and challenges families face when raising someone on the spectrum
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Patient/provider interactions, equitable access, appropriate accommodations, more advocacy services
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It has desperately made mental health problems worse
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Disruption in services, less help and more isolation,

Name	Michelle, LMFT in California
Demographic	Autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Managing care with providers that do not have enough training or knowledge in neurodiversity. Doctors, primary care providers and therapists do not use a neurodiversity affirming lens and it creates a huge medical bias that harms neurodivergent individuals and creates more disabled people.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The significant challenges is how these conditions further disable autistic individuals yet they are caused by ablesim, sexism, racism, disability discrimination, and neurotypical spaces that are harmful. We are blaming the individual but doing nothing to fix the system
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Appropriate resources, access to those resources and community support.
What additional research is needed to help address co-occurring conditions for autistic people?	How we can shift systems in our society to better support neurodivergent folks
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Equitable access, increase/development of resources for autistic adults who don't fall under conservatorship or supported care programs (those who function in life ok), systems issues, healthcare inequity
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Increased social distress and anxiety
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Those people who are still at risk, including disabled autistic folks, are not getting any precautions anymore. Positives: easy access to online services like therapy

Name	Mikol Bailey
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	GI disorders, EDS, Sensory and motor challenges.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety and depression (from living in a world not built for us), executive dysfunction, ADHD.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Research that takes into account the diversity of the population of autistics, including age, race, gender identity, socioeconomic status, etc. And the different ways autism presents for different people.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Equitable access above all. Accessibility to even receive diagnosis is honestly a huge barrier. People who weren't diagnosed as children also basically have few options to access diagnosis and care as an adult.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Covid-19 has disabled autistic people, along with the broader population. The effects of the pandemic have worsened health outcomes for autistics.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increased telehealth is helpful, as is the increase in the availability of telework.

Name	Mimi Rankin Webbq, Parent of 3 with Autism
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	These co-occurring conditions amplify each other & show up in asd trait presentation & the standard is to keep throwing medications at a person to try and stop the worst of the behaviors & trait presentations that cause problems for them in society instead of treating the actual problem from an asd standpoint. Mine have the toileting/gastro problems, sleep disorder, extreme sensory disorder, dyspraxia(medically klutzy but meant they also have problems writing/rendering) one has epilepsy, another has a seizure disorder, extreme migraines, and require therapies as older teens even. We need ABA access as adults, social skills help too
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Mental health conditions are oftentimes simply autism trait presentations being mislabeled by the neurotypical community.The lack of accomodations & understanding lead to much of this being labeled as self-harming/emotional disturbances when stimming behaviors are done as a coping mechanism & could be rectified with slight accommodations & aba therapy to help find better coping skills/techniques. We need specialists who understand this & can help from an autism standpoint not neurotypical as this is hurting us! Aggression can come from high doses of medications which could be avoided if a person had been equipped with coping skills & treated humanely in the first place. NOT providing these things is leading to the problems you list above. Depression happens when people are mistreated- & society mistreats autistics for kicks & this is condoned by even policymakers which is wrong. or rather especially policymakers.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Lack of providers trained & equipped to treat & head off these problems. We need longterm access to treatment, therapies & services as adults not just young children! YES early intervention is key, but a person doesn't stop being autistic when they are sent to school or stop being autistic when they graduate high school or age out! Where are the services for adults with autism & where is the coverage for them?Schools fail them as they often don't recognize medical dx's parents bring them as valid which needs to be stopped in practice. Every student with an ada recognized medical dx needs a base level iep or 504 to help meet their ever evolving needs.Parents should not be fighting months before graduation to get a child help because schools pretend good grades are all that matter datawise when a child is bleeding on the floor in the middle of class from self injurious behavior caused by failure to accomodate or recognize medical dx that has amplified anxiety and functioning capabilities in trying to navigate school environment.
What additional research is needed to help address co-occurring conditions for autistic people?	Monitor&hold schools accountable for NOT recognizing medical dx & for not accomodating autistics appropriately & for allowing bullying of these students unnecessarily.We need providers to be taught & trained about autistic trait presentation&behaviors especially with regards to mental health & counseling as they do the most damage to autistics by not treating the actual root cause of the behaviors that brought the patient to them in the first place.It is especially bad with all things mental health related & first responder related. Deaths could be avoided if only training were embedded into certificate & graduate programs medically on autism. Teachers, medical providers of all types dental, counselors/mental health, physicians, people who work with autistics in any facet ALL should have autism training with relevancy to their fields and how it applies & that isn't happening. Our numbers are growing & there are far more unidentified autistics out here trying to muddle thru life- training for every aspect of the community as a standard norm would go a long ways towards inclusion for all.

<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Mandate insurance coverage for ALL ASD related services for ALL ages.STOP making school IEP/504 qualifiers to access social security & waiver services for the disabled when they've valid medical dxs! Mandate schools be required to accept medical dx's on parent request for sped/iep/504 help-refusing medical dx's is HARMING students! Service system is broken if you require school documents to access medical services. My own daughter isn't considered severe enough to need iep/504 thru school because she is straight A(ocd trait presentation of an autistic female who cannot allow herself to fail/be less than perfect) @17, she has spent the past 2yrs with severe anxiety /self injurious behaviors IN CLASS due to extreme sensory overload & stress caused by schools refusal to acknowledge her medical dx of asd, anxiety & epilepsy w/severe sensory disorder on file since age 4 She was institutionalized for suicidal ideation due to the cutting self in class when it was ASD TRAIT PRESENTATION School wrote it off as emotional disturbance & enabled bullies to continue bullying Hospital had less knowledge on asd than the school & did nothing but enabled bullies instead of helping!Training on all levels would have resolved this</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>Society deems us lesser beings even more now than ever due to Trump & Repub policymakers openly allowing blocking access to healthcare,education & community with refusing to even simply mask up & get vaccinated. The anti-vaxx movement is openly anti-autistic people. You should know that already. We are dangerously close to prewwII level treatment of the disabled as nonhumans & worthy of experimenting on & expendable. Basic rights are being stripped & access denied to education, community &healthcare almost daily in the current political climate.This makes people even less inclined to accomodate, or care to provide access to services and education than ever. Sometimes its a fight just to access the grocery store without being made to leave.Same thing happens with healthcare & education.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>virtual participation in all things has made things more accessible, only there is this weird far right/republican refusal to allow these things as a norm that continues to block adopting these as standard norms.We changed the open meetings laws here in louisiana with specific carveouts for the disabilities community YET the Disabilities Council still is under a specific cease & desist virtual meeting participation as a direct result of driving the need & changes to the laws successfully.</p>

Name	Mina
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	<p>I think the prevalence of trauma in autistic people should be studied to better understand how we may need different care. Difficulties with communication and connection can make getting help difficult. Modalities like CBT, a common starting point in therapy, is not as effective for autistic patients. Trauma is also a near universal experience for autistic people, who often face discrimination, abuse, and bullying from peers, families, and authorities. I also think that trauma can contribute to the high rates of depression and anxiety in the autistic population, which is often treatment-resistant because the root trauma is not addressed. Additionally, Complex PTSD is an important lens for many autistic people, as it is often caused by long-term neglect or abuse that is more subtle. Models for diagnosing and treating PTSD should be expanded to account for complex trauma, which sometimes appears atypically. I also think that the overlap between autism and ADHD deserves more attention. The dual diagnosis has not existed for long, but estimates suggest that a large percentage of the autistic and ADHD populations have both conditions. Despite this, there are few resources addressing the nuances of this overlap and how it may present differently.</p>
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	<p>Co-occurring conditions can exacerbate the struggles autistic people already face. Our systems are not designed to account for people holistically. Practices that are meant to accommodate autistic people might not be sufficient for autistic people who are late-diagnosed, queer, women, or POC, let alone those of us who are multiply disabled. Access to disability support is a significant issue. For example, SSDI applications are almost always rejected by default. A process that already demands executive function and communication (which are already difficult for autistics) now also requires follow-up and possibly legal representation. On top of the fact that this will take time, meaning the disabled person who has been rejected is forced to work at their own detriment or risk running out of money before back pay arrives. These same issues apply to other resources like short-term disability support. Autistic burnout also needs to be recognized as a disabling condition, it is not discussed in current medical models for ASD, but it affects every autistic person in my life. I personally had to take six months of leave from work when I could barely manage to keep myself clean and fed, but I was unable to get disability support because of the reasons described above. This severely affected my financial situation and cost me savings from 18 months' full-time work.</p>
What additional research is needed to help address co-occurring conditions for autistic people?	<p>The overlap between the autistic and transgender communities has been known for some time. However, this information is primarily used to discount autistic, trans children's identities, when it should affirm them. Our disabilities do not prevent us from knowing ourselves, and evidence is needed to prove that autistic children who are transgender persist at similar rates to allistic trans kids. We also need to better understand how co-occurring conditions interact from both medical and psychiatric standpoints.</p>

	<p>Diagnoses are created and applied as if they exist on an island, and do not account for the whole human as a system or the intricacies that entails. As an example, I went to visit a doctor to address symptoms of fatigue, brain fog, dizziness, and weakness. Tests revealed nothing but that I had a high white blood cell count, so my doctor referred me to a hematologist. She ran more tests, saw there was nothing else unusual, and referred me to an endocrinologist to check my hormone levels. Well, those looked fine, so I was sent back to my PCP. My symptoms remain undiagnosed and untreated, despite clear evidence that something is wrong. This reliance on diagnostics means that atypical presentations or uncommon conditions are seen as exaggerated or psychosomatic if professionals can't relate it to a specific diagnosis.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>ASD makes medical settings difficult. facilities are not sensory-friendly. Bright lights, loud noises, and chemical smells cause overwhelm. Social anxiety makes communication harder. We also respond differently to pain. Doctors do not understand us, hence our worse healthcare outcomes. We need PCPs who specialize in caring for neurodiverse patients. Their practices could accommodate sensory needs, give patients more time to communicate with their provider, and help them schedule referrals or tests. There is also a lack of therapists trained for autistic patients. Let alone co-occurring conditions, mental health models fail to account for interactions between conditions. Disability services fail to meet our needs. Access requires repeated communication and executive function demands, unfair rejections, and lengthy appeals. All of these are hard normally but nearly impossible in a crisis, when support is crucial.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>I have found the effects of long COVID to have a significant impact on my life. Fatigue is now a constant. Executive dysfunction and brain fog have worsened. My performance at work has decreased measurably and I cannot communicate as effectively as before. Anxiety and depression have also intensified. Additionally, despite dozens of visits to PCPs and specialists in the 18 months since infection, I've not been able to find a single medical professional who will agree that my symptoms are related to long COVID. Even though they've been unable to find any other conditions that could be causing such chronic fatigue.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Increased remote work has made some aspects of employment more manageable. It is more flexible, so I can take time for my mental health without missing a full day of work. However, it also leads to more demands for communication by phone/zoom/email, which can be more stressful than in-person communication due to the different expectations of communicating virtually.</p>

Name	Minela Fernandez MD
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	When I was running a feeding clinic, many infants were sent to me around 9 mos of age with feeding difficulties, and most of them, during the f/up period with their feeding therapist, were then diagnosed (or referred for further evaluation) with Autism.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	All of those listed. Anxiety about new foods. Aggressive when being asked to eat.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Oral sensitivity leading to malnutrition. I had a 10 yo who only ate FF's. Parents refused to f/up/ take recommendations. about 3 yrs later, had a blood count so low he had to be admitted to the PICU for a blood transfusion. They finally got a GTube placed- which should have been placed much earlier. So getting PARENTS to understand the complications of malnutrition before it is too late. Reminding them that GTubes are for Longer term but still TEMPORARY while the child undergoes ABA/ OT therapy for feeding.
What additional research is needed to help address co-occurring conditions for autistic people?	Follow some Feeding d/o clinics and get some statistics from them regarding success of therapy, length of therapy to achieve oral success, and need for GTube placement, if at all. Consider CPBH, Center for Pediatric Behavioral Health in Wilmington NC who works with these types of children all the time.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Knowledge of these types of feeding disorders and how severe they can be/get. And ways to treat them before it gets to the point of needing a GTube. Ie, Parents not catering to the child from the beginning, and NOT seeking help early. Gen Practitioners and pediatricians alike do not refer early enough, and just call it "picky eating," thereby delaying the parent seeking help, until it is too late and more difficult to treat.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Missy Garcia
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	For me, the most significant challenge lies in diagnosis. There are so many overlapping symptoms, so it's hard to tell what is the autism showing itself and what is an actual physical health condition. I think, second to that, is the paralysis that comes with trying to figure it out. That can lead to missed diagnosis of medical conditions that do need to be treated.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	This is where the most challenges exist, in number, magnitude, and importance. I believe those challenges mostly arise from lack of information and research. We are left to do our own research, and when we can't find what we need, it starts to affect our mental health in a new way, on top of the struggles we're already having. The most under examined co-morbidity is ASD & trauma. And I think it may be the co-morbid condition with the highest overlapping traits. Again, diagnosis is at the root of the problems.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I feel like the most significant challenge in this area is not the ASD community. It's the lack of knowledge outside the autistic community. The condition itself makes it very difficult for the person with autism to make the adjustments for the non-autistic person. So it's not logical to expect the change in communication to happen on the autistic side. It makes more sense to create change in the neurotypical world, because they have the ability to do it. People on the ASD spectrum are actually very easy to communicate with, because they are so literal and logical. They get emotionally dis-regulated. When people aren't like that with them. The problem is, most people do not mean what they say, so they don't understand a person with autism being literal. Most people are defensive about the truth. People with autism can only handle the truth. We all need to understand that there are two very different types of communication happening so that we can understand each other.
What additional research is needed to help address co-occurring conditions for autistic people?	All of it. Each co-morbidity needs to be researched. Starting with trauma. I'm not an expert, but I am very intelligent with outstanding pattern recognition. It is my belief that the research in the co-morbid state of ASD and trauma would well inform the other co-morbid conditions.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Mental health centers that specialize in this area and are subsidized to be affordable. We have places like this for sexual assault victims, we need places like this for people with autism. It's a mental condition that cannot be changed. Therefore, we need the resources to learn how to deal with it for both people with autism and everybody else.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services,	

increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Misty Cameron
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Hypermobile Ehlers-Danlos is really difficult to deal with as it causes increasing joint pain and stiffness; many doctors know little to nothing about it and I have been medically gaslit by my providers for years bc they did not recognize what was happening to my body. I might have been able to get help sooner and not be in as much pain as I am if doctors were better educated on this.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression and anxiety are often the result of untreated ADHD, yet women who have co-occurring Autism and ADHD often have to fight for diagnosis and treatment bc our providers yet again do not recognize that our depression and anxiety are secondary to our Autism and ADHD. Providers need to be better educated and should be forced to specialize if they want to treat these issues - way too many providers are far behind on the research and have no idea what they're looking at or talking about; they then tell us we're "just depressed" or "it's just anxiety" when it's not. Once I was properly diagnosed and medicated for my ADHD, my depression and anxiety significantly improved, and I no longer meet diagnostic criteria for either.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Honestly the biggest challenge is ignorance on the part of providers and the general public. When your patients have to be better educated on their condition than the providers are, there's a serious problem.
What additional research is needed to help address co-occurring conditions for autistic people?	PLEASE do more research on late diagnosed/self diagnosed women. When providers cannot even properly assess and diagnose, self diagnosis is valid; the neurodivergent clinical community recognizes this and it's time for the rest of the world to catch up. Stop allowing providers without specialized training and certification to assess and diagnose. I cannot tell you how many women I have treated who have been gaslit to the point of suicidality by ignorant providers who think they have nothing new to learn. Autistic/ADHD women are completely neglected in the research and it needs to change. We KNOW that our "knowledge" of autism comes from highly flawed research. Do something about it.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	All of the above. It should not be a privilege of those with money or great insurance to get adequate diagnosis and treatment. Providers are not properly educated and do more damage in the end by not assessing correctly or even entertaining a patient's concerns that they may be autistic. Women are constantly misdiagnosed - and incorrectly medicated - for things like bipolar disorder and BPD, which can have devastating consequences to them and their families. Educate your providers better. Require them to have training that is backed by CURRENT research before they can even think about assessing for autism. Include ADHD in these provisions and restrictions. Require rheumatologists to be educated on the overlaps and comorbidities.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Since many of us also have autoimmune issues, once again, ignorance on the part of providers and the public is the biggest challenge.

<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Being able to work remotely has done wonders for my mental health. Employers should not be able to require in person work if they cannot adequately show that someone's job cannot be done from home.</p>
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Name	Molly
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My son who is autistic with a PDA profile (pathological demand avoidance) exhibits many very challenging behaviors for school and caregivers. He has severe anxiety and depression and ADHD and makes suicidal comments. I believe the majority of his mental health struggles are rooted in navigating a world that does not understand his needs are vastly different from his peers.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My son has a higher than average IQ, and yet he is reading well below grade level, despite 3 years of one on one tutoring. I wish there were support for research of PDA in the US--this is the first disorder I have ever learned of that PERFECTLY fits my son and provides explanations that help me and others find solutions that actually work for him.
What additional research is needed to help address co-occurring conditions for autistic people?	The US needs to get on board with affirming PDA as an autism profile, as other countries have. Parents whose kids have PDA resoundingly find relief in this diagnosis, as it is often the only one that provides logical explanation for confounding behaviors.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	We need more great providers who are in network for services such as occupational therapy and speech therapy. It seems more and more of the best providers are dropping insurance since insurance is not adequately paying them.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	COVID lead to deep depression in my very young child.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Molly Schenker
Demographic	Family member of an autistic individual; Service provider, health provider, or educator; Researcher; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	As a parent of an autistic child, sleep and sensory challenges have been the most difficult to help my child manage and have created major stressors for our family.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD, anxiety, aggression have greatly affected our family. Aggression has been particularly difficult to manage. We believe it is related to sensory issues, ADHD/impulsivity, and constant activation of our son's sympathetic nervous system due to sensory and anxiety. Our son's aggression towards both objects and people has made it difficult for us as parents to keep our house in the order we would like, fulfill responsibilities at full time jobs (due to exhaustion, school removals, etc), and participate in community activities as a family.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Education, for sure. Communication is difficult in particular. Many people surface-judge a person's "level" of autism on how much a person speaks, but this is not enough information to determine how affected/disabled a person is by their differences. For example, my son speaks fluently and has a large vocabulary, but it is still difficult to understand his message. School tried to place him in gen ed as much as possible, stating "least restrictive environment." The problem is that "least restrictive environment" means the least restrictive setting a child can be successful-- and he was not successful in general education settings. He does much better in self-contained classrooms where teachers have the time to communicate with him and he has an environment where he can process. The overall push to get him into general ed settings was not a good fit for him and I believe it contributed to an increase in behaviors, particularly when he was placed in an "emotional-behavioral unit" that relied on ABA principles. I think educators need a much stronger understanding of neuroscience before working with autistic children, so that they can understand there are layers of functioning that contribute to observable behaviors.
What additional research is needed to help address co-occurring conditions for autistic people?	Where to start... Caregivers of autistic children are struggling. There is not reliable daycare for many of our kids and virtually no options outside of school once the kids get older (e.g., summers are a major struggle). I would love to see more research on: year-round school models, center-based early intervention, the effects of respite on individual and family QoL. For autistic and other neurodivergent individuals, I would like to see research on "convenience" services like laundry/drycleaning, cooking, house cleaning, etc. and how these services affect quality of life and ability to retain employment.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Extensive service coverage for services other than ABA. I believe a big reason parents like ABA so much, despite that it is not favored in the autistic community, is that it provides insurance-covered respite and daycare for parents who have no other choices. Autistic kids are often removed from daycares and private preschools, or these agencies encourage parents to remove them due to behaviors or lack of training, and parents have nowhere to turn.

What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	A positive is that I think a lot of autistic people discovered they can function pretty happily in society when expectations are adjusted. A negative is that now that the pandemic is no longer a global emergency, we have gone right back to the old systems that have excluded autistic people for ages.

Name	Monica Allen
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	All of the examples that are listed for co-occurring physical health conditions, my daughter has experienced or has currently - GI symptoms, sleep disturbances, epilepsy, sensory & motor challenges. I think there needs to be more education about these conditions available to the public and health care providers. The specialists for these conditions must have training about all of the other possible comorbidities that Autistic people experience, and better tools and understanding for working with Autistic people (attention to sensory factors in a clinic, understanding possible differences in pain tolerance, longer appointment times to allow for better communication, trauma-informed de-escalation strategies, and more).
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	All of the examples that are listed for co-occurring mental health conditions need as much attention and support as co-occurring physical health conditions - depression, anxiety, ADHD, aggressive or self-injurious behavior, suicidality. I think there needs to be more education about these conditions available to the public and health care providers. The mental health field is grossly underfunded and understaffed. The mental health field needs to do better with trauma-informed care and culturally-relevant care for people of color, immigrants, and others who are marginalized by white supremacy. There must be more training about all of these possible comorbidities that Autistic people experience so health care providers will not miss connections or additional diagnoses. All providers and settings must have better tools and understanding for working with Autistic people (attention to sensory factors in a clinic, understanding possible differences in pain tolerance, longer appointment times to allow for better communication, trauma-informed de-escalation strategies, and more).
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Again, health care providers and settings must understand more about these conditions (learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities) to provide more accurate care, referrals, and communication. School settings must be more equitable in providing services for these conditions, making sure each student gets what they need. Public life needs to be set up to better support Autistic people, especially those with these additional disabilities. We need more support care workers (HCBS) so our loved ones can stay at home with proper support, or live independently with support, avoiding institutional and segregated settings. We need more availability and understanding about Augmentative and Alternative Communication (AAC) devices, training, and usage for individuals, providers, and families.
What additional research is needed to help address co-occurring conditions for autistic people?	The Autistic Self Advocacy Network would like to see more research for Ehlers-Danlos Syndrome (EDS). I'd like to see more research on options (and availability of these) besides guardianship for Autistic adults who need a wide range of supports.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I touched on some of this already and will add more here: -equitable and affordable access -trauma-informed care -culturally-competent care -anti-ableist care -anti-racist care -insurance coverage for all needed specialists, therapies, medications, sensory tools, and more -communities and states need Autism offices with more funding and staffing to help with connecting to services, providers, peers, work opportunities, and more -telehealth coverage must continue -a better understanding and awareness of COVID and long COVID in the Autistic community, including access to testing, vaccines, high quality masks

<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>I do not have data to support this but I imagine the Autistic community suffered a disproportionate amount of deaths and long COVID compared to the general population. This issue again supports the need for funding, education, retention, PPE for home health workers under HCBS (home and community based services), so Autistic people and disabled people are not forgotten and neglected. In general, more training about long COVID symptoms is needed across the board, especially for people who may experience symptoms and/or communicate differently.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Telehealth must continue indefinitely. Online options for arts events and social interactions must continue. Wider access to high-speed, affordable internet continues to be needed in rural areas. Due to the ongoing pandemic, many people are delaying necessary health care. Providers, hospitals, clinics, MUST reinstate and require precautions against COVID and other airborne illnesses, so Autistic and disabled people can get the care that they need and deserve. Examples of precautions: air filtration and ventilation, easy and free access to vaccines, PCR and RAT tests, 94 and 95 high quality masks for free, offering early appointments to those who need more safety, isolation recommendations that are based on facts of how long people are still contagious (including asymptomatic people), and more. COVID is still active. Lastly, our family learned that schools are not equipped to offer special education virtually. Instead of forcing disabled children to come into schools, or forcing them to withdraw and homeschool, public and private schools should proactively prepare plans for distance learning, before it's needed again in the future.</p>

Name	Moriah Adamick, parent of Autistic child
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Our son demonstrates the PDA (Pathological Demand Avoidance/Persistent Drive for Autonomy) profile of Autism. His nervous system disability causes him to perceive threats to his safety in common/banal everyday situations that neurotypical or non-demand avoidant individuals do not perceive. This greatly compromises his functionality and causes a great deal of anxiety for him. It affects some of his access to basic needs (hygiene, toileting, sleep, protecting his own safety). It has profound effects on the mental and emotional health of his family members (parents, sibling, extended family).
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	We are observing anxiety and ADHD-like behaviors in our son who has the PDA profile of autism. He has at times exhibited aggression or mild self-injurious behavior, but he is still very young (4 years old). For us, the biggest challenges are access to basic needs like toileting, hygiene, safety and sleep.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	PDA affects Everett's trajectory in society. The world is not build to accommodate his oversensitive neuroception. He has challenges in all realms, social, intellectual, emotional, etc.
What additional research is needed to help address co-occurring conditions for autistic people?	It is clear that our society in the United States has not embraced or studied the PDA profile and leaves a huge portion of individuals without the accommodations or services they should be entitled to as a part of our disabled population. Families are suffering with an often insurmountable burden and these PDA autistic individuals are often traumatized by society's structure repeatedly trying to hammer their square pegs into round holes. We need lots of research and the establishment of a diagnostic criteria in any manual that informs access to supports and services.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Across the board, providers, educators, service systems, insurance coverages, support services are not educated or informed about the PDA condition. We need more services in terms of educational formats that increase autonomy for PDA autistic individuals, respite support for families who often have to pour all efforts and attention into regulating the nervous system of their PDA family member, widespread belief and understanding of the condition and affirmation of the fact that there are many different kinds of brain-wiring and minds in the world.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Absolutely. Many of the services and supports have been ineffective during COVID
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	increased use of telehealth is often missing details in assessments that are obvious in in-person assessments.

in-person social interactions and obligations)	
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Name	Mother of an autistic daughter
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	abdominal pain and trouble digesting (gastrointestinal disorders) especially connected to preferring only certain kinds of foods and textures, and connected eating disorders, Extreme/Pathological Demand Avoidance
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	anxiety, depression, eating disorders, ADHD, self-injurious behavior, suicidality
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	communication disabilities -- ability to communicate socially and self-regulate within those social situations, social-emotionally effective communication, especially difficult for those with Extreme Demand Avoidance and Pathological Demand Avoidance, a subset of autism fixated on social relationships
What additional research is needed to help address co-occurring conditions for autistic people?	-more research on Extreme/Pathological Demand Avoidance -more research on women with autism -more research on previously undiagnosed autism in adults -research initiated and led by autistic individuals -research into Montessori techniques of inclusion in the classroom as a constructivist critique to the behaviorist methods primarily used with autistic people and abhorred by them -research into giftedness/precocity and its connection to autism (eg hyperlexia)
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	-funding for transportation to appointments -ability to choose private effective alternative schools using public school funding (school choice) for disabled/autistic people -- ease of doing this without requiring lawsuits -- not forcing disabled/autistic people to go to educational institutions using a 150-year-old model (requiring 6-year-old children to sit still at desks and listen to lectures) or use pullout services that shame students and are ineffective - holistic model rather than forcing autistic people to go to interminable different services (OT, speech therapy, social skills groups, etc.) -services provided in nature (outdoor schools) -- also based in gardening/farming/practical life skills -- time spent outdoors is more effective at reducing sensory loads and has other benefits that are dismissed by traditional services -abandoning behavioral techniques, listening to autistic adults about the effect those techniques have on them, using self-driven methods that tap into internal motivation, a scaffolding, connection-centered, attachment model rather than punishment/rewards (treating disabled people like dogs)
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Primary effect is increasing social isolation.
What lasting positive or negative impacts have societal changes due to	Societal changes decreasing the amount of physical time people spend together has had lasting negative impacts in socialization.

the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

Name	Myles Davis
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Low energy caused by insomnia/sleep disturbances, and higher possibility of meltdowns or shutdowns from poor sensory and motor function/regulation
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	high suicidality rates, lack of focus and joy out of life because of anxiety and depression, and difficulty trusting due to trauma and rejection-sensitive dysphoria
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Lack of respect from allistic people who view intellectually or developmentally disabled people as less than, or do not make an effort to find alternative communication styles with communication disabled.
What additional research is needed to help address co-occurring conditions for autistic people?	identification of the most frequent co-occurring conditions, tracking of pertinent symptoms, and designing specialized treatment plans for autistic people.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	easier insurance coverage and appointment scheduling, better training of therapists and autism professionals to better engage with autistic people, and easier access to services for marginalized communities
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	isolation has increased anxiety and depression rates and worsened certain sensory deficits and internal functioning due to changes in routine
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	N Miller
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I personally have dealt with chronic pain, stomach issues (IBS, reflux, stomach pain), a weak immune system, joint pain, and chronic insomnia my whole life. It's also important to understand that the sensory issues associated with autism itself can be experienced as physical or somatic symptoms. For example, when I am in a noisy place my ears and head hurt, my eyes burn, and I often feel nauseous. This can make it difficult to differentiate between symptoms caused by overstimulation, and those caused by other health conditions. It also makes it very difficult to get accurate diagnosis from doctors, who often will say the physical symptoms are "just stress" for example. For my daughter, who has had sleep issues her whole life, we cannot parse whether her insomnia is caused by physical conditions like apnea and asthma, or by her autism. Personally, I have gone undiagnosed with medical conditions like anemia because I thought my exhaustion and dizziness were caused by autistic burnout.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	(This is another case where it can be impossible to separate autism from co-occurring conditions. The question assumes that autism is a "condition" whereas many autistic people feel that it is inseparable from their entire existence.) I went undiagnosed until adulthood because doctors always assumed my sensory and emotional regulation struggles were "just" depression and anxiety. Misdiagnosis is a huge issue. I have been told I can't be autistic because I am also ADHD, which is not accurate at all. Many autistic people experience anxiety and depression because their sensory needs are not accommodated. If you go an extended period in constant sensory overwhelm, you are inevitably going to go into burnout, which can cause extreme depression and suicidal symptoms, or meltdowns that can resemble panic attacks. The biggest problem with this is that traditional recommendations for these conditions DO NOT WORK for autistic people. When I am in burnout and feeling depressed, trying to socialize or get exercise will send me into deeper burnout and could lead to suicidal ideation.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My daughter and I both have ADHD, which can often mask or complicate our autism struggles. My ADHD makes it hard to focus on my special interests. It akes me feel like I need novelty and am frequently bored but trying new things often leads to meltdowns or burnout. It also makes it very difficult to do things like FILL OUT THIS FORM. On top of that, treatments for ADHD have made my sensory symptoms even worse, even if they address some ADHD symptoms.
What additional research is needed to help address co-occurring conditions for autistic people?	We need more focus on how autism is inextricably linked to many co-occurring conditions. Too many studies try to compartmentalize these variables, but you cannot separate autism from an autistic person, and therefore you cannot separate the conditions that autism can cause from the autism itself. There also needs to be more studies on how autism changes the efficacy of traditional medications and treatments. There needs to be more education in the medical community on how co-occurring conditions can often mask or obscure autism symptoms, leading to misdiagnosis and under diagnosis, especially in female presenting and non-white individuals.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services,	Increased supports for autistic adults is a major need. Often autistic treatments only focus on children, and only focus on "behavioral issues" rather than addressing underlying causes of those issues. For example, you cannot treat toe walking in an autistic child without also addressing issues with EDS, chronic pain, vestibular problems, or potential muscular issues. We

insurance coverage, service systems issues, patient-provider interactions)	need fewer behavior based treatments and more treatments focusing on treating the whole body, and approaching the patient with the assumption that there is very often a physiological reason for many symptoms that are assumed to be behavioral.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I personally have struggled with more chronic pain and immune deficiency since contracting COVID, and experienced pretty severe depression and anxiety symptoms during the height of the pandemic. I cannot "mask" socially the way I used to due to lack of social interaction during lockdowns and experience more social burnout and more difficulty regulating sensory needs now. My daughter has been constantly sick with many viral illnesses since contracting COVID in 2022 and now is often fatigued, and her growth has stalled as a result.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	One negative effect from COVID for me is that I am constantly distressed and dysregulated due to my heightened sensitivity to justice. Seeing the government and people around me refusing to mask, get vaccines, or take care of each other caused me to have intense meltdowns on a regular basis. Positively, I liked wearing masks because it meant I didn't have to make myself smile or stress about my facial expressions as much, and I liked the peace and quiet of being able to go into public spaces without everyone crowding together and getting in my space.

Name	N/A
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory challenges has to be one of the most significant challenges for me, I can't count how many times I get overstimulated on a daily basis weather it's because there's no many things happening around me, too much sound too much light the way that my clothes feel ect it is truly hard to learn how to cope with these things and the feelings that come with being over stimulated in normal everyday life.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I feel as if I've learned to cope better with anxiety and I've come along way but it is still a struggle, adhd hasn't necessarily been a con for me but it is quite strange to see how other neurotypical people think or do things compared to how my mind works. Another struggle is being diagnosed, I am self diagnosed it is very far and few that a woman gets diagnosed with autism and I think that needs to change, I was diagnosed with bipolar in remission, ocd, adhd, and depression although I'm hardly ever depressed but I soon learned those could all just be symptoms of autism. I feel like I was wrongly diagnosed just like lots of other people are everyday that autism isn't studied better.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Growing up I struggled in school because I stopped applying myself once I became an adult I realized this was burnout, except when it comes to autism it doesn't just go away after a relaxing evening it stays with you. I've even experienced this in multiple jobs where I just didn't/ physically couldn't do it anymore I don't want to do anything unless it's something that I want to do if that makes sense. As far as communication goes sometimes I feel different or weird compared to my peers this could also be because of anxiety but I often question if my peers think I'm weird, i wonder if the responses I give or the way I react to things are slightly aloof compared to other people.. it's a very confusing and sometimes lonely situation
What additional research is needed to help address co-occurring conditions for autistic people?	Research on the behavior of autism in adults not just kids, and the various levels of autism on the spectrum you should be studying people with low to medium level autism just as much as people who are severely autistic/ severely autistic non verbal because autism looks different in everyone. And real adults real people that you and I see everyday at work or church or at the grocery store are living with autism right now experiencing similar issues I just mentioned and going completely unnoticed because it's not always visible unless you take the time to learn the traits andthe thought patterns of the person(s), like I said I didn't even know I was autistic until I was 22 and I still haven't received a diagnosis; but I'm learning now on my own how to cope and live my life fuller.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance covered Counseling counseling is a good way to learn how to cope and adjust to everyday life with autism as long as the counselor is educated. Providers need to be educated on autism to be able to fully understand and care for their patients. Disability for those who struggle with working and doing everyday things with autism not just high spectrum autism but low spectrum as well, being self aware and autistic is just as hard as being unaware. And treating autistic people like people and not like disabled individuals or children, personally I believe that organizations like autism speaks has the right intention but is actually doing more harm than good because of the lack of education and understandment of the spectrum that is autism.

<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>Personally no physical impact but mentally after the lockdown it has been harder to get up everyday at a scheduled time to work, I want to be able to fulfill my days with what I want to do I don't want to be required to do a job for 8hours everyday. I want to wake up and make breakfast for my family and clean and go do something fun or draw it's also really hard to balance work/home life it's like I can't dedicate myself to both I always end up losing myself in one or the other usually it's in work when I'm home I'm doing my best at work I'm giving barley anything, I recently had to cut back to 32 hrs a week instead of 40 because I wasn't able to be a human outside of work all I did was come home eat and sleep now I have more time but it's still not enough.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>I think an increase of remote jobs has been a good impact however myself I've had trouble finding those jobs, there's always a catch like you have to meet a quota to be able to stay working remotely I personally think any job that is on a phone or computer should be remote and there shouldn't be a goal you have to meet either you do good and you work or you don't and you get fired and that's that</p>

Name	Nancy
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Motor challenges, epilepsy, sensory and motor challenges are some of my son's challenges. He also has very limited speech. Difficult to communicate needs. My biggest concern (we live in Massachusetts) is the horrifying lack of staff in adult day program. The system has fallen apart due to a few reasons. Health and Human Services have deserted the Disabled, autistic and other disabled adult citizens. Prior to Covid they had barely acceptable services from staff that had none to limited training. After Covid many potential and entry level staff "went away", left their jobs for more pay. The problems are astronomical. The whole Federal/State Human Services needs an entire overhaul. That includes Ma Dept. Of Developmental Services also. My son has been out of his day program for 4,4,4, I'll say it again FOuR YEARS. A SIN
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety takes medication for it Behaviors takes medication for it Seizures takes medication for it
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My son is also cognitively disabled. He functions at 3-4 year level in learning, speech etc
What additional research is needed to help address co-occurring conditions for autistic people?	That is a tough question me not being a doctor, researcher. This is a pervasive affliction. Coordination in medical research needed, sharing all information among ALL professionals. Also need is a ONE National Autism institute which gathers all research, houses it in one place, and connects all professional looking for Autism cure. Research in genetics, cross over and information sharing with other disease centers, ie parkenson+ Alzheimer-in other words all BRAIN Research and findings.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Biggest thing. Access and accessibility to day and residential services for under and over 22 years old citizens. Adult day programs are not taking new clients that turn 22, they can not service prior clients (after Covid). We do not know where to turn. There is No sign that things will get better. These are citizens born in the great USA. Start revamping the entire system. The American with Disabilities Act mandates this
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school,	All of the above And no start on improving services, putting much more money in budget for HIGHER PaY for staff who work with Disabled

increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Nancy D Miller, VISIONS/Services for the Blind and Visually Impaired
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I have 52 years of experience working with people of all ages with legal blindness, total blindness and partial sight (low vision). Approximately 15-20% of the people we serve identify on the autism spectrum with the highest percentage of people under age 30 and the lowest percentage of people age 60 and older. Two big problems are that people who are receiving services or enrolled in programs for their autism who are also blind, do not routinely get referred to the blindness services. If they do get referred for blindness services, the blindness service system is often not prepared to serve them appropriately. If they start in the blindness system, they may not get properly diagnosed on the autism spectrum losing out on those services. There needs to be increased funding and adequate number of trainers for cross training between the two service systems and funding streams.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Most staff in the blindness system are unprepared to deal with some of the co-occurring conditions and behaviors so people who are blind and autistic are not enrolled in services or do not have the proper supports to gain the most from training. There is not enough access to counselors and/or applied behavioral analysts for school aged children and youth and especially young adults that have have aged out at 21 years.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	If you have met one person with autism you have met one person with autism. Every person with a disability is unique and needs a truly individualized service plan to help them transition from school to work and independent living. Our current education, workforce and independent living systems are often too bureaucratic for truly individualized attention and training which is more time consuming.
What additional research is needed to help address co-occurring conditions for autistic people?	It is very important to study co-occurring disabilities and publish results on demographics as well as training outcomes. Make sure the disability questions remain as is in the American Community Survey.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Screen for co-occurring conditions and make sure appropriate referrals are made into the other service systems that are often siloed. Even within a state, the services networks for people with disabilities do not always cross refer or know about each other. Strengthen the requirements to assess and refer for whatever training the individual will benefit from.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Access to the internet, assistive technology and affordable connectivity is crucial. Social isolation is a huge issue for both people with autism and people who are blind. It is double the problem if they are co-occurring conditions.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The internet is both a positive and negative for people with disabilities in general. It is a necessity but can often disrupt in person social interactions. There needs to be choices for both internet based and in person based social interactions.

Name	Nancy Hauprich
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Finding providers/physicians that are trained to treat individuals with autism.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Difficulty finding appropriate placement/facilities to bring individuals with autism during a crisis. Emergency rooms are not equipped to handle individuals with autism when they are exhibiting aggressive and self injurious behaviors.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	The isolation of not being able to get out in the community has caused long term anxiety issues
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Nancy Williams
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory issues are challenges including food textures resistance, sensory pressure seeking, sensory movement seeking for regulation and sensory seeking for close, tight spaces.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD, Anxiety and constant hypervigilance in unfamiliar settings. Also perhaps more likely to become addicted to an activity or substance due to being hyper focused on it.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Intellectual disability and lack of communication avenues.
What additional research is needed to help address co-occurring conditions for autistic people?	Finding accessible solutions across the spectrum and sharing the positive results.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Access to better mental health treatments that are evidence based, beyond ABA. Connection between behavioral health services and developmental disability services. They act very separately in AZ currently and the disconnection is not serving individuals well.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Ability to use telehealth for those who do not want to go out in large spaces or with lots of people. Perhaps decreased interest in in-person interactions is a negative to some.

Name	Naomi Mittet, Circadian Sleep Disorders Network
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The most significant challenge for my child's life has been her Non-24 Sleep-Wake Disorder. This condition is more common in the blind population, but over the past five years I have seen that there is a large segment of people with Non-24 who are not blind and are autistic. Non-24 is a circadian rhythm sleep disorder which affects the person's sleep and wake times since their days are over 24 hours long (often 25-26 hours long). When a person is able to follow their own body clock and sleep when needed, their sleep/wake times will go around the clock. For my own child, she goes to sleep and wakes up an hour later each day. She has had sleep issues since infancy and I believe she's lived with Non-24 her whole life. It wasn't until I was able to let her sleep as needed and kept a sleep log, that I noticed the typical Non-24 pattern. After 4 years of keeping records, I was able to get a diagnosis from Dr. Bushnell at UW Medicine here in Seattle. My daughter has been homeschooling since I understood what Non-24 was and concluded that receiving accommodations from the public school system would be difficult. There are other co-occurring health issues, such as gastrointestinal problems (GERD, hiatal hernia), and sensory overload. But her Non-24 has had the greatest impact on her daily life.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	For us anxiety has been the most challenging. Depression has also been difficult, but anxiety affects being in public and can cause meltdowns and/or shutdowns. Aggression diminished once able to free-run with sleep and was no longer chronically sleep-deprived.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	I would like more funding to help those researching the connection with Non-24 Sleep-Wake Disorder and autism. I feel once the connection is proven and accepted, it will be considered a symptom for sleep issues such as insomnia. Typical sleep studies will not help, a person would need to free-run with their sleep and wear an actigraphy device at home. There is also genetic research currently happening, but again funding and outreach is needed.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	The first helpful support would be for sleep specialists, neurologists, and those who work with the autistic community to be aware of Non-24 Sleep-Wake Disorder. Unfortunately circadian rhythm sleep disorders are still not fully understood by those who it would help to know. After there is more knowledge and acceptance about Non-24 (especially in sighted people), the next step is easier access to getting diagnosed. Insurance coverage for an actigraphy device, as well as time off from work and/or school so that the patient can free-run with their sleep in order to get a true reading of their sleep cycle. Once diagnosed, schools and workplaces need to allow accommodations for those with Non-24. Flexible work and study times, allowing for some days to be spent at home when sleep/wake time doesn't

	follow a typical 9-5 day. Video recording of classes for classes or offering all classes online would also be beneficial.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Reduced in-person social interactions and obligations were actually beneficial for my child. Having telehealth as an option was very helpful.

Name	Natalie
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	For me it is sleep disturbance and ADHD. I consider ADHD a physical issue because it is, as I understand it, a wiring/neuron occurrence and not a mental health problem. Furthermore, ADHD is not a mental illness.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD being called a mental health problem feels wrong. That makes it sound like an emotional disturbance and not a neural disorder. But yes, ADHD is perhaps even more difficult because there is no real relief from it, whereas with autism you can potentially find comfortable balance a lot of the time. Girls and women need more ADHD screening. Also, anxiety.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication disabilities... They persist even in so-called high-functioning individuals. They are the one thing on this list that I think every single autistic person struggles with.
What additional research is needed to help address co-occurring conditions for autistic people?	Coping with these issues as adults, discussing them respectfully with adults who are autistic. If you can learn to frame the conversation in a way that is acceptable for autistic adults, you can learn to not leave parents feeling like they have a defective child. Language matters. Qualitative analysis of how adults are treated and spoken to regarding autism and ADHD would change the quality of care dramatically.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Patient-provider interactions. I have been refused ADHD medication because I didn't want to see a new therapist. I already had a diagnosis and previous therapy. I was only filling one month of medication per year, and my dose is low. I have no history of drug abuse of any kind. The doctor had no reason to try to force me into mental healthcare over this. I'm autistic. I don't want to meet a new therapist who probably knows little or nothing about autism. In this case, I didn't even want to tell the provider that I'm autistic. I almost never tell because it can only make the interaction worse, not better. Doctors aren't really going to do anything with that information, so why bother?
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	COVID has made me realize how absolutely minimal my socializing can be and still feel ok. This is good and bad. If I ever have to go back to work in an office instead of working from home, that will be very difficult. Then again, it was always difficult. Working from home has helped me tremendously.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I love remote work. I love that delivery is available for pretty much everything now, even more so than before. I like telehealth. Some things are obvious and no longer require the added burden of calling for an appointment, talking to several different people in the process of the appointment -- all just to spend 5 minutes or less with a doctor to confirm what you could have told them over the phone (especially for common recurring things). I would not say service disruption is an issue because I never have had any services, nor do I even know what services are available.

Name	Natalie
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I have chronic gastrointestinal problems and my lack of interception often exacerbates the problem because I don't feel internal body sensations until they turn into pain. For example I don't feel hungry until I'm sick and my head hurts. On top of that I also have eating disorder ARFID so my diet is lacking in proper nutrients.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	As a child going undiagnosed, I was addicted to self harm to release the negative feelings I had in my body. I was suppressing meltdowns in that way and now have to fight the urges forever. I think the lack of care and understanding that comes with not receiving a diagnosis could have caused or at least intensified my depression and anxiety throughout my life.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication disabilities are extremely hard because you can't actively describe the things you need from others. People misunderstand your words, tone of voice, or body language and that changes their perception of you without you even noticing.
What additional research is needed to help address co-occurring conditions for autistic people?	Speaking to late diagnosed autistics, because they have often analyzed their entire life and actions
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage, low income options, cheaper diagnostic appointments and tests
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Having less people in public places was an unexpected positive. The changes in my work within the healthcare field were close to unbearable. The masks gave me sensory overload.

Name	Natalie , Woman
Demographic	Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, A.D.H.D, Depression,Suicidality, aggression, learning disabilities, manic episodes
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Struggling with learning disabilities developmental disabilities intellectual disabilities and communication disabilities is a war in itself
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Natalie Mason
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep difficulties. I'm seeing a large number of anecdotal reports of a connection to Ehler's Danlos, POTS, gastroparesis.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Eating disorders. My youngest child developed ARFID and a fear of food and had to be fed via nasogastric tube. There is such little information out there on ARFID and how best to manage it. The connection to anorexia is also needing more research, as is the role of faulty interoception in the development of obesity.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Schooling and employment. Schools are not equipped adequately to provide for autistic students. The high unemployment rate of autistic people is also a huge issue.
What additional research is needed to help address co-occurring conditions for autistic people?	Pathological Demand Avoidance. ARFID.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Access to NDIS and cater supports made easier and user friendly.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Covid 19 itself had little effect on my family. The fear, social isolation, lock downs, wearing of face masks in schools led to massive anxiety issues in my youngest daughter around school attendance and possibly played a part in her developing ARFID.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Love telehealth. See previous comment for mental health issues seen in my children.

Name	NaTasha Turley
Demographic	Family member of an autistic individual; Service provider, health provider, or educator; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory challenges, mental health challenges, poor dental hygiene, lack of effective treatment options
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression, anxiety, self harm, suicidal ideation
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Co occurring intellectually disabilities and communication disorders are significant barriers to skill acquisition and maintenance of skills
What additional research is needed to help address co-occurring conditions for autistic people?	Effective treatment approaches for autistic individuals who are experiencing depression/anxiety. Purely ABA approaches are lacking in this area, but often most accessible. CBT is not often effective and finding an experience practitioner and DBT who has worked with autistic individuals is almost impossible for families
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More accessible services and less bureaucracy around what is considered "medical necessity ". Additionally, we just need more providers as well as training for human service personnel in general who may be interacting with our community. Most individuals in the broader medical community are not well trained and how to support autistic patients in their care.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Many individuals lost access to their service providers, and thus experienced regression or exacerbation of behaviors of concerns and co occurring symptoms. It was during the pandemic, that my own autistic Child begin having suicidal ideation.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Because so many people begin offering telehealth services, it now feels like it is more difficult to get in person appointments because lot of providers have chosen to maintain telehealth. This is often not the most effective way for us to receive care

Name	Nathan Blenkush, The Judge Rotenberg Educational Center
Demographic	Service provider, health provider, or educator; Researcher
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>In many cases, co-occurring physical health conditions affecting people with autism spectrum disorder are addressed in precisely the same way such conditions are addressed in people without autism spectrum disorder. However, for patients with autism spectrum disorder and concurrent, severe, treatment refractory aggression, self-injury, and other destructive behaviors, receiving routine medical care or medical care for physical health conditions can be complicated and challenging. First, such patients are often difficult to transport and require restraint, protective equipment, and high levels of staffing simply to safely bring the patient to the outpatient appointment. Second, some patients do not tolerate routine diagnostic and assessment procedures including venipuncture, x-ray, dental exam etc. Third, some outpatient offices do not tolerate disruptive behaviors in their waiting room or offices and ask the patient with autism spectrum disorder to leave. In many cases, patients with ongoing aggression self-injury receive less than optimal care because of their severe problem behaviors. Creating situations where medical specialists can assess and treat patients in environments comfortable for the patient (e.g. day/residential treatment program) may be helpful for such patients.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>Treatment refractory self-injury and aggression are often exhibited by patients with autism spectrum disorder and intellectual disability and present significant challenges. Treatment refractory means the violent behaviors continue despite reliable implementation of standard psychopharmacological and behavioral interventions. The behaviors persist for years, decades, or even throughout the lifespan of the afflicted patient. Such behaviors are devastating and adversely affect co-occurring physical health conditions (e.g. by creating extreme difficulties in accessing outpatient care or by interfering with diagnostic/treatment procedures); result in physical health impairment (e.g. blindness, traumatic brain injury, chronic wounds, fractures, loss of body parts); result in or exacerbate symptoms such as anxiety, depression, and other psychological symptoms (i.e. because of physical isolation and family separation); and interfere with skill acquisition (which affects communication, education, vocational achievement, and independent living). We recommend research efforts focus on defining and classifying severe aggression and self-injury in this patient population. There is presently no agreed upon criteria for what constitutes treatment refractory aggression or self-injury. Such definitions also assist in weighing the risks of inaction versus the risks and benefits of existing therapies.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>The Judge Rotenberg Educational Center, Inc. (JRC) has treated thousands of patients with autism, co-occurring conditions such as developmental, intellectual and communication disabilities, and treatment refractory self-injury and aggression. JRC patients are admitted from inpatient psychiatric settings; jail settings; residential treatment programs; or directly from home where family members struggle to care for them because no treatment facility will help their loved one. Programs are reluctant to treat such patients because they do not have the ability to control ongoing self-injurious behaviors and maintain the patient's safety; the patients require extraordinary level of treatment resources (e.g. 1:1, 2:1, 3:1 staffing; highly trained treatment staff); and/or patient's behaviors are extremely dangerous to others resulting in frequent injuries. JRC has found that providing the least restrictive, most effective treatment for aggressive and self-injurious behaviors requires individualized assessment and treatment. Unfortunately,</p>

	<p>providing such treatment has become increasingly difficult because of misguided restrictions on treatment procedures force patients into restrictive hospital settings. Consider restrictions that limit the use of emergency restraint for patients living in community settings in certain states. Such restrictions have unwittingly caused patients that require occasional restraint to receive far more restrictive treatment in hospital settings.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>In order to improve autism services for people with severe problem behaviors, treatment providers need access to a full range of treatment options with appropriate safeguards to protect the patient and allow them to live in the least restrictive environment possible. Instead of regulatory procedures that seek to eliminate treatment options for all individuals, the laws and regulations should provide realistic pathways to various treatments appropriate to the needs of individual patients. One example model can be found in Massachusetts where extraordinary treatments like antipsychotic medications, planned mechanical restraint, and contingent skin shock (CSS) are available through a substituted judgement process. We recommend research efforts focus on defining and classifying severe aggression and self-injury and identifying the risks and benefits associated with existing therapies through direct comparisons with reliable and direct dependent variables. There is presently no agreed upon criteria for what constitutes treatment refractory aggression or self-injury. Yet, it is abundantly clear that current therapies, except CSS, are inadequate. Classifying and defining treatment refractory problem behaviors allows direct comparison of treatment approaches within and between participants. Such definitions also assist in weighing the risks of inaction versus the risks and benefits of existing therapies.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Individualized Treatment is the key to effectively addressing severe self-injury and aggression exhibited by people with autism spectrum disorder. Unfortunately, decisions about how to address clinical problems are increasingly made by rule or legislation instead of by clinicians, families, and individual patients. Treatment refractory self-injury and aggression are real clinical conditions that often require extraordinary management procedures including long-term hospitalization, residential treatment, and restrictive interventions with significant side effects. Remarkably, the very existence of these patients has been questioned by advocacy groups and ideology derived from proponents of positive behavior support and other advocacy groups. These assertions that all problem behaviors can be treated effectively with psychotropic medication or non-restrictive behavioral interventions are false and patients with these conditions suffer because such assertions.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced</p>	

in-person social interactions and obligations)	
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Name	National Council for Mental Wellbeing
Demographic	Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	<p>Individuals with autism commonly experience co-occurring mental health conditions.¹ While identifying the exact prevalence of individuals with autism and comorbid mental health conditions can prove to be difficult, studies corroborate that children and youth with autism often experience higher rates of mental health conditions, such as depression and anxiety, as compared to the general population.² Measures of suicidality in people with autism have been found to be variable, though studies have suggested that adults with autism experience suicidal ideation at a much higher rate compared to the general population.³ Contributing to the difficulty in identifying the exact rate of co-occurring mental health conditions is the lack of access to appropriate and validated screening tools for individuals in this population, as well as the potential for overlapping characteristics that exist between autism and some mental health conditions.</p> <p>1. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6669096/ 2. https://www.sciencedirect.com/science/article/abs/pii/S175094672300034X https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6162511/#B13-children-05-00112 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5772195/ https://jamanetwork.com/journals/jamapediatrics/fullarticle/2755414 3. https://molecularautism.biomedcentral.com/articles/10.1186/s13229-023-00544-7#:~:text=An%20influential%20study%20of%20late,a%20suicide%20attempt%20%5B10%5D.</p>
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Additional research in the field of autism and co-occurring mental health conditions is needed to ensure and advance appropriate and validated tools for screening, cost-effective and readily accessible assessments, and pharmacological and behavioral interventions for individuals with co-occurring mental health conditions.
What could be improved in autism services and supports	For children and youth, access to health care providers that have specialized knowledge in addressing specific needs of people with autism and co-occurring mental health conditions may not always be readily available. For example, it can be challenging to find a

<p>to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>developmental pediatrician who specializes in autism and co-occurring conditions, and there is a well-documented workforce shortage of child psychiatrists. There is also a significant shortage of applied behavior analysis (ABA) therapists, which is considered the gold standard treatment. Additionally, barriers to accessing care can often include a lack of resources and adequate insurance coverage, lack of awareness of autism, stigma, and lack of linguistically appropriate resources. Furthermore, given potential impacts from other co-occurring conditions such as sleep difficulties and gastrointestinal considerations, the intersection of co-occurring conditions should be considered in providing quality, responsive behavioral health care that meet the needs of individuals in this population. Challenges can further arise if an individual is prescribed multiple psychotropic medications which can result in a drug interaction and metabolic syndrome. The need for collaborative care emphasizes the importance of care coordination and integration across a multidisciplinary treatment team.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	

Name	Nele Van hemelen
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbance ARFID/eating disorders Hyperactivity Sensory overload
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD PDA (so anxiety is a big thing Here, and when needs are not met: aggression, depression and autistic burn-out)
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	PDA stops my child with an above average IQ, from developing and from learning...
What additional research is needed to help address co-occurring conditions for autistic people?	PDA research because PDA NEEDS, however the condition is an autistic condition, are different from the needs from people who have classic autism disorder or Asperger's
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Professionals who know that PDA is a form of autism... getting it in the DSM
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Before lockdown: scared to get the virus, it was difficult for them to go ahead with things. Lockdown At that moment most felt safer, not only because they were safer, being deprived from the virus, but because they could stay home, with less stimuli... They experienced a new way of living that suits them more... After lockdown it is more difficult to get out of the house, because they experienced during the lockdown how safe they felt at home...
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Disruptions in services, now for all services you have to have an appointment, which is okay, but the appointments you can make , are dates way toooooo far ahead... Less social obligations are better

Name	Nellie
Demographic	Family member of an autistic individual; Service provider, health provider, or educator; Representative of advocacy organization; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disorders Gastrointestinal issue, constipation, cyclic vomiting syndrome, food aversion Stim vs Tic : tourettes Speech development: nonverbal Sensory needs : proprioceptor stimulus input demands
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Aggression Self injury Alienation from community Anxiety and depression All of these will coexist and build up a wall between the person, the family unit, their community, and services available. The asd individual loses services and connections, while the family loses community resources. The system becomes smaller and smaller..
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Schooling becomes extra difficult. Schooling centered and focused on academics, while the child has no understanding of what you want them to do, so they become aggressive. School unable to provide behavioral therapy, it leaves the child unable to attend school without issues. The school staff is unable to intervene or handle the child. Therapies have long waiting lists. Now what?
What additional research is needed to help address co-occurring conditions for autistic people?	More research that addresses recent anecdotal findings. More research in masking.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More system resources and more services being offered that are covered by insurances including medicaid! Less municipal and county barriers on access to these services and resources. More services, less paperwork and requirements.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Interruption on face to face services, loss of services when virtual services were not able to be accomplished. Resource gaps. Loss of staff and providers. Loss of opportunities that were opening prior to covid.

Name	Neoli Hernandez
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory issues, electrolyte imbalance, insulin resistance, memory issues, fainting, muscular pain, anxiety, gastric issues. Please refer to the research completed by Kimberly Kitzerow, writer of <i>Discovering Autism and the Comorbidities Along the BH4 Pathway</i> .
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Fear of medical gaslighting, being told I'm sensitive then experiencing minimization of symptoms, misdiagnosis of bipolar, sensitivities & expressing adverse reactions to anti depressants then being medicated with them anyway, complex ptsd, non selective mutism, agoraphobia.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	There are currently extremely minimal resources, therapy, supports and insurance coverage for autistic adults to be diagnosed, receive any type of support unless you have very high support needs. I am late diagnosed, I paid thousands out of pocket. Psychiatrists and therapists also struggle to treat autistic patients, more often than not I am educating them myself. It is at a detriment of the autistic individual to always be prepared and well informed when interacting with doctors at risk of serious harm or costly mistakes. For example before I became unconscious I clearly explained I am autistic & needed electrolytes, but because my sugar was high from a high carb meal they wrote high insulin & I was left unconscious for hours until someone gave me an IV. This was an educational issue because the emts were not trained on communication & I have experienced this many times and this has almost caused me great harm. I have been left dehydrated in the ER numerous times due to lack of training & procedural issues.
What additional research is needed to help address co-occurring conditions for autistic people?	Kimberly Kitzerow & her research on the BH4 Pathway. Please don't steal research and findings, just fund some research for once. Some of us with Comorbidities would like some peace in this lifetime. Also yes DMT can be extremely beneficial for autistic individuals with complex ptsd. This could be an incredible therapy for autistic individuals and I hope more funding goes towards this not only for autistic people, but for anyone with ptsd. It helped me survive healing after being kidnapped & tortured. I no longer have access & the treatments are so expensive, inaccessible for autistic people who struggle with steady incomes.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Equitable access. Right now late diagnosis for adults is incredibly difficult to afford. Diagnosis questionnaires discriminate against neurodivergent women & non binary people. Doctors do not have access to up to date research, practices and the resources they are told to suggest are aimed towards children. Nothing is really covered for autistic adults when it comes to services offered by charities either. Very difficult to get help or get therapies to help on the journey towards autonomy if they are inaccessible & unaffordable. It is a harmful cycle and can be very traumatic.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Potential activation of dormant familial health issues: immune system flares, skin issues, gut problems, sleep cycle disturbances, food intolerance, heightened sensory sensitivities, metabolic disorder, familial hypercholesterolemia

<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Disruption in support services, reduction of service access, more unexpected/unplanned obligations, reduction of work from home time, forced in person interactions</p>
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Name	Nicholya Crockett
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	For my child, diagnosed with autism with demand avoidant profile, we have found sleep disturbances to be the top physical condition that affects him daily. He will stay up late every night, despite being very tired. This is not something he chooses.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My son has Autism with Pathological Demand Avoidance and ADHD. I do feel like a lot of times these all go hand in hand and what we use to treat or address one of them is counter indicated for the other, all the way around. For instance, what works for ADHD individuals might set my PDA son into a pattern of burnout, or cause him to have a nervous system reaction such as flight, fight or freeze.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Because my son has PDA, a nervous system disorder, any time he perceives a loss of autonomy, or perceives a demand, he goes into fight, flight, or freeze. This is not behavioral, so traditional behavior correction systems and traditional education even fail him because his nervous system is constantly being activated. This leads to autistic burnout, school refusal, lack of eating, lack of sleeping, and more frequent meltdowns. This affects my son's daily life at school, home, and play.
What additional research is needed to help address co-occurring conditions for autistic people?	My son has been diagnosed with Autism with Pathological Demand Avoidance and ADHD for just over a year. In that year, I have only met three people who even know what it is. One is the psychiatrist who diagnosed him, one is his teacher who had researched it in regards to her own daughter, and the third is the school's psychiatrist, and he thinks that because it is not recognized in the DSM-5, that it is phony. I have had to educate about PDA to my son's entire circle of people that interact with him, from his pediatrician to the special education team at his school because NO ONE KNOWS IT EXISTS! Of all the things that I advocate for my son, my number one goal, wish, hope, is for PDA to be recognized as a diagnosis worldwide. As I said, I am just one year in to diagnosis, and have already felt and faced this immense uphill battle for not only PDA awareness, but to have my son's differences be taken seriously.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I think it would be really helpful for certain conditions, such as PDA to have more awareness so that better services for this nervous system disorder can be made available to those who need it. So many kids are currently being misdiagnosed or go undiagnosed because they don't fit any of the current diagnoses.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic	

people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Nick McCurdy, Patient/Advocate
Demographic	Autistic individual; Family member of an autistic individual; Researcher; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Dealing with disability, overwhelming stimuli, and loss of executive function with medical issues
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Dealing with mood swings and balancing conflicting cognitive symptoms of autism and ADHD
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Getting left behind in education and socialization, resulting in more difficulties integrating and communicating later in life
What additional research is needed to help address co-occurring conditions for autistic people?	Get more information about life struggles from the patient's perspective at varying levels of the spectrum, especially with autistic adults
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More funding for disability services would result in shorter waitlists and easier application processes for necessary aid. It would also be helpful if more services were available with accessible websites for those with communication or other difficulties.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Increased anxiety in public environments and potential cognitive impairments from COVID infections (still being researched, but there seems to be ties to existing neurological disorders like autism, ADHD, FND, and schizophrenia)
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Overall I believe the pandemic has made society much less accessible for disabled persons. From a cognitive science perspective, highlights include difficulty safely going out in public to access healthcare, work, social, and other needs, and feelings of not belonging or falling behind. Additionally beyond public spaces not being safe for disabled people, not enough jobs and services are available online or over telehealth (which can also be challenging for autistic patients with language issues, to be fair).

Name	NICOLAS LINARES-ORAMA, FILIUS CENTER-UNIVERSITY OF PUERTO RICO-MEDICAL SCIENCES CAMPUS
Demographic	Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	All these co-occurring conditions manifest themselves in personalized ways for each individual.. This means that, in addition to a clinical diagnosis, we need to assess the interactions among them.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression, ADHD, oppositional behaviors
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The impact these have on the individual's potential for independent living and employment.
What additional research is needed to help address co-occurring conditions for autistic people?	We need to investigate on the challenges faced by health and special education systems for personalizing care, particularly for Hispanic individuals.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	The training and follow-up of family members who are poor and poorly educated; the requirements of Early Head Start & Head Start systems towards very early diagnosis/assessment and inter-professional intervention; with continuous family follow-up and participation.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	A high prevalence of ASD in Puerto Rico after the pandemic, perhaps due to lack of pre-natal visits of mothers afraid to be sick with COVID, and the extreme tension in mothers that could have changed their immunology and affect the baby's brain.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	A lack of services for very early diagnosis and assessment due to the insufficiency of health personnel and teachers who have left Puerto Rico.

Name	Nicole Corrado
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My menstrual cycle disregulates my mind and body. I get very emotional, cry easily, get more stuck, and more agitated. I often make poor decisions around that time. I also have a lot of anxiety and OCD.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD is not a mental health condition. It is a neurodivergent difference. I am AuDHD so I get hyper and distracted easily. I find this can be a problem with executive functioning, but the AuDHD made me tired of living with my parents and got me to move out. OCD, suicidality, self injury, etc were more problems when I was living with my parents. I have more of a sense of control now living by myself. I still have a compulsion to check negative things about animal rights and that can derail me for hours.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I have some math LD so my parents manage my money. I was homeschooled because I was too overstimulated in school. I need to get an adult high school diploma to get into university.
What additional research is needed to help address co-occurring conditions for autistic people?	There is a need for surveys like this one. Talk to autistic people directly. We are the experts.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	A universal basic income, free budgeting courses, free dental, medical, mental health preventive care, etc. And train medical staff at universities. I participated in an event at University of Montreal Medical School in which neurodivergent people played patients and were paid for it.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	The pandemic delayed moving out, which caused incredible stress for me as there was a high profile very negative news portrayal of autism at the time in the city I was living in. But Zoom was the best thing that happened because it allowed social interaction and education from the comfort of one's own home.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Zoom and videoconferencing was the best thing for accessibility to ever happen. It opens up possibilities for work, education, social interaction, all with the option of various methods of communication.

Name	Nicole Collings
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Mental health, sleep, and sensory
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, ADHD, suicide. Pathological Demand Avoidance (PDA) is characterized by high anxiety but this is not the only feature—we desperately need better understanding of PDA and how to support PDAers in the United States.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication
What additional research is needed to help address co-occurring conditions for autistic people?	Research on Pathological Demand Avoidance (PDA). We need more autistic-led and autistic-informed research if we want to really understand the issues impacting autistic individuals including ensuring reliability and validity.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	“Nothing for the person without the person.” We need autistic voices informing changes/improvements in supports and services. We also need to follow a neurodiversity-affirming model where we get away from the traditional medical model and instead depathologize differently wired brains and different ways of learning, communicating, experiencing the world, socializing, and behaving. We need to create environments where people feel safe to unmask and can be open and honest with their providers. We need providers who are educated about non-stereotypical presentations of autism as well as the high rates of co-occurring conditions which should be screened. We also need to consider other barriers in accessing services including phone calls, paperwork, waiting rooms, etc—can accommodations be offered to help improve access to services?
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I’m not sure about the infection and illness itself (I think the long-term impacts are still being investigated); however, the pandemic itself resulted in high levels of anxiety/panic for many, exacerbated mental health conditions, delayed access to health (and mental health) services resulting in worsening/compounding conditions. The pandemic caused trauma for many, and we are still suffering the consequences of that trauma. Autistic individuals have been more vulnerable to the aforementioned due to their neurobiology and high rates of co-occurring conditions.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal	Autistics are a heterogeneous population and different individuals will have been impacted differently and have different needs. For some, increased/improved telehealth and other remote services has actually broken down barriers and improved access to services. For others, the heightened stress of the collective nervous system (of society) and persistent

changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	instability in various systems (healthcare, education, social systems, etc) continues to takes its toll.
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Name	NICOLE LEBLANC
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	LONG COVID IS A BIG CHALLENGE IN AUTISM WORLD, COVID19 CAN CAUSE PTSD WORSENING ANXIETY, GUT THYROID DYSFUNCTION IN AUTISM WORLD. TMJ, HIGH RISK GLACOMA, WEIGH GAIN. INSOMINA, UNRESTFUL SLEEP, FOOD ALLERGIES, INTOLERANCES
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	POOR SLEEP CHRONIC FATIGUE BURNOUT, LOW STAMINA, LOW MUSCLE TONE MOTION SICKNESS LEAKY GUT GUT IMBALANCES CAUSING SEVERE COVID, COMPLICATIONS LACK OF ROBUST TRAUMA TREATMENT
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	ABLEISM IN HEALTCARE SYSTEM DOCTORS DIAGNOSTIC OVERSHADOWING DOCTORS ARE POOLY TRAINED IN AUTISM DOCTORS REFUSAL TO ACCOMODATE NEEDS OF ASD MANY PEOPLE WITH AUTISM CANT ADMINISTER AT HOME COVID TEST INACCESSIBLE REMOTE PLATFORM FOR MEDICAL VISITS] FUNCTIONAL MEDICINE NOT COVERED MY MEDICARE MEDICAID
What additional research is needed to help address co-occurring conditions for autistic people?	LONG COVID IN AUTISM PTSD IN AUTISM TRAUMA MODALTIES TO RELEASE TRAUMA , HEAL LONG COVID LONG COVID TREATMENTS, GUT HEALTH AND PROBIOTICS IN AUTISM
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	WE NEED ALL DOCTORS, THERAPISTS TO TAKE MEDICAID MEDICAID WE NEED FUNCTIONAL MEDICINE TO BE COVERED BY INSURANCE MEDICAID SHOULD COVER MASSAGE ACUNPUNCTURE, ZERO BALANCING, REIKI, HYPNOSIS, ALL TOUCH THERAPIES WE NEED CLINICS FOCUSED ON AUTISM , NEURODIVERSITY FOR LONG COVID
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	COVID19 CAUSES PTSD , WORSENING SLEEP, FATIGUE, ANXIETY, TRAUMA SYMPTOMS IN AUTISM, LOW THYROID, BLOATING, GI ISSUES, HORMONE IMBALANCES, WORSENING AUTISM ADD, ANXIETY SYMPTOMS, DISRUPTS FIGHT FLIGHT. LONG COVID HAS COST ME 8+ GRAND OVER THE LAST 2+ YEARS
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	HAVING TELEHEALTH AND REMOTE WORK HAS MADE LIFE LESS STRESSFUL FOR THOSE OF US who dont drive or get HCBS support and are low income has made it easier to get things done. Its much more cost effective to do therapy, go over lab results with doc over computer than spend another 30-60 \$\$ on LYFT.Its nice not having to always wear DRESS CLOTHS, SIT IN TRAFFIC EVERYDAY. We need to allow therapists to see PWD ACROSS STATELINES. ON DOWNSIDE SOCIAL ISOLATION, LACK OF HCBS FOR ADULTS WITH AUTISM

Name	Noemi Spinazzi, MD, FAAP, Down Syndrome Medical Interest Group (DSMIG), DS-ASD workgroup
Demographic	Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	<p>Autism is a common co-occurring condition in individuals with Down syndrome, with estimates ranging from 4-39% and meta-analysis data indicating that between 16 and 18% of individuals with DS meet criteria for autism spectrum disorder. Individuals with Down syndrome who are also autistic present significant challenges in their communication, adaptive functioning, behavior, and sensory processing. While communication impairments are very common in individuals with DS, they are much more profound in those who also have co-occurring autism, often with very limited verbal abilities or gestural communication. Delays in self-care, including independent dressing, bathing and toileting, are more pronounced in those with DS+ASD. Common behavioral concerns in this population include elopement, self-injurious behavior, aggressive behavior, and sensitivity to sensory triggers leading to restrictive feeding repertoires and difficulties with loud and unpredictable environments. When tested for cognitive abilities, individuals with DS+ASD demonstrate more severe intellectual disability; additionally, attention-deficit hyperactivity disorder (ADHD) co-occurs more frequently in those with DS+ASD than in those with DS alone. Children with DS+ASD struggle to remain up to date with recommended medical care (hearing and vision testing, bloodwork monitoring, dental treatment, immunizations) due to significant difficulties during medical visits; additionally, it is often very challenging for them to tolerate prescribed medical equipment (glasses, hearing aids, sleep apnea treatments, etc). Families of individuals with DS+ASD consistently report that autism is the more disabling condition, and report elevated levels of stress due to their loved ones' need for continuous supervision.</p>
What additional research is needed to help address co-occurring conditions for autistic people?	<p>Over the past few years, members of the Down Syndrome Medical Interest Group have formed a workgroup aimed at catalyzing research in the field of Down syndrome and autism, as well as improving provider and family awareness, education and outreach. Despite these efforts, there continues to be very little data on interventions that are most effective in supporting this vulnerable population of patients. Research from the general population of individuals with autism is extrapolated to those with DS+ASD; commonly recommended strategies include applied behavioral analysis, occupational therapy, augmentative communication, special education programs with an</p>

	<p>emphasis on TEACCH methodology, and psychotropic medications to address the co-occurring behavioral challenges. However, there are no studies that prove that these therapies and techniques are truly effective for individuals with DS+ASD. Tests used to define IQ are not only culturally bias, but the added layer is that they are not specifically designed to identify the strengths and challenges of individuals with genetic conditions like Down syndrome. Floor effects result in limited information to be drawn from these measures from an intervention standpoint. Most individuals with DS+ASD are not even able to participate in the assessment which further limits access to care if a provider is not comfortable with making a clinical determination outside of standardized assessment.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Families experience significant challenges in accessing services due to a paucity of providers, hesitancy by these providers to care for individuals with both DS and ASD, lack of linguistic proficiency for those families whose primary language is not English, and many other barriers to accessing care; this is more pronounced in those who are uninsured or underinsured, who identify as racial/ethnic/linguistic minorities, and/or who experience poverty and housing insecurity. Challenges in accessing services and therapeutic supports have gotten worse since the Covid-19 pandemic, as many therapeutic providers have stopped accepting insurance or have transitioned their service to telehealth, a service delivery modality that does not work well for a majority of individuals with DS+ASD. Additionally, schools have seen tremendous turnover in educators and paraeducators, especially in special education classrooms and programs, and children with DS+ASD who rely on consistency, continuity, and expertise are bearing the brunt of these challenges. Notably, most individuals with DS do not live near a specialized Down syndrome clinic, and really struggle to obtain adequate evaluations, diagnosis, and treatment recommendations. There is currently little incentive for healthcare institutions to support Down syndrome clinics, and the lack of government funding to support these clinical programs leads to barriers to opening or expanding these important programs. To truly support individuals with DS and co-occurring ASD, governmental organizations need to provide additional funding to programs that care for this vulnerable population to enable them to expand access and enhance their care coordination abilities.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	

Name	Olive
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I would say emotional dysregulation is a big one. I have many autistic friends who talk about how this is one of the biggest things they struggle with, and I do as well, it probably impacts me the most in my day to day life
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I can only speak for myself but I found schooling and education in general was a hardship for me because of my autism, largely because of the lack of resources and stigma preventing me from getting a diagnosis even to this day.
What additional research is needed to help address co-occurring conditions for autistic people?	I think a large thing that needs to be addressed when it comes to autism and comorbid conditions is accessibility to care and quality of care as so many people myself included simply can't access the care we need to properly get diagnosed or end up in situations where we are made to feel less than for not being able keep up with medical care or not being taken seriously in medical settings. There is an overall lack of understanding when it comes to autistic patients and so many suffer because of it.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	A large part overall is education as so many allistic people don't understand autism especially in a medical setting, it should be mandatory to learn about autism and how it can affect medical care. That and making services more accessible and less stigmatized, a huge barrier for many autistic individuals like myself is lack of access to resources in adulthood or being shamed for needing them. Autism doesn't magically go away once we become adults and so many people lose access to resources they had if they had any to begin with once they reach adulthood
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It's hard to say the full extent the Covid-19 pandemic had on autistic people but I know for myself there was a huge adjustment in social norms and this caused a lot more stress and emotional dysregulation making a lot of tasks more difficult as I lacked resources and were surrounded by people who didn't understand and expected me to just get over it.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	I can't speak to the full extent but I know a large part that impacted many people myself included was being disconnected from community and major changes in routine. Paired together it brought out a lot more depression and anxiety and it's taken us longer to bounce back than our allistic counterparts, I know a lot of people struggled maintaining an education as all of sudden they were no longer able to be accommodated do to the shift to online schooling. It felt very much like we were being left behind and having to fend for ourselves because a lot of the resources that were available became harder to access

in-person social interactions and obligations)	
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Name	Olivia
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory challenges
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	PDA
What additional research is needed to help address co-occurring conditions for autistic people?	PDA
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Wider understanding of PDA
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increased homeschooling and more use of telehealth.

Name	Pamela Bows
Demographic	Autistic individual; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	It is very difficult to get crisis support and educational support for kids with mental health needs co-occurring with autism. Kids with this profile board in emergency departments and bounce from school placement to school placement. We need professionals to be able to accurately differentiate autism traits from mental health needs, and we need more effective interventions to be able to teach kids, not just relying on ABA to mask needs.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	We need more extensive and inventive communications strategies. The biggest barrier is when professionals are unwilling to learn different modes of communication and resist the presumption of confidence. We need higher standards about communication and it should be the first stop on newly diagnosed kids' plan of action.
What additional research is needed to help address co-occurring conditions for autistic people?	Communication methods research, effective educational best practices, how to educate providers and educators to presume competence, differentiating autism traits from mental health symptoms.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Meeting of basic needs including housing and communication, education for professionals regarding autism traits compared to symptoms of co-occurring needs— how they may interact or increase severity of symptoms. Removing barriers to care like siloed state agencies (in Massachusetts you can't functionally qualify for both DDS and DMH)
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Personally it has allowed me to perform at a higher level in my career because I now work from home and have the personal space I need to mask/perform and recover privately.

Name	Pamela MacAllister
Demographic	Service provider, health provider, or educator; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Behavioral challenges where they have socially unacceptable behaviors including physical aggression against others, yelling, throwing things, eloping, hygiene concerns.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	These challenges often create social isolation for the person with autism and their family.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The biggest challenges can be lack of programming after 21 if that person is not employable. Many times by 21 families have exhausted all their resources both financially and socially.
What additional research is needed to help address co-occurring conditions for autistic people?	Institutional abuse accountability for the service providers for people with autism and co-occurring disabilities. There is such a money grab to provide services and abuse is rampant.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Services should be provided in community settings. So many programs are in isolation and only serve people with disabilities. This does a huge disservice to the learners and participants. They remain isolated and therefore do not progress or are in danger of abuse.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Not as much as people would think. However in NJ the over 21 programs have become very selective of participants. So less is available.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	parent
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbances affect every aspect of a person's (and family's) daily life. Our child is almost 6 years old and has never been able to sleep more than 1-2 hours without one of his parents with him. He just doesn't feel safe alone or with a pet, stuffed animal, with or without nightlights, etc. Consequently we are all tired all the time. It's well known that sleep issues can also negatively impact behaviors and ability to self soothe, etc.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication difficulties seem to be the most significant challenges since communication affects a person's/ community's ability to function. If you struggle to communicate your needs, wants, goals, etc then you certainly will have a hard time getting those met. That's not even to mention struggling to meet your own basic health care and mental health needs, sensory sensitivities, etc.
What additional research is needed to help address co-occurring conditions for autistic people?	The USA is significantly behind other well- developed nations in the area of the PDA profile of autism. This is incredibly important since these individuals require a very different approach than other autistic individuals. My child would likely benefit from some Occupational Therapy if we could only find a provider who understands and works well with PDAers. Our last OT was not able to accept that our child was PDA because they didn't see it during therapy sessions.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Patient- provider interactions could be much improved if/when more providers update their understanding of autism, in general, and especially PDA.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I think that, to some degree, the COVID-19 pandemic has led to some autistic people having increased anxiety around germs and illness.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	It seems that lasting impacts of the pandemic have had some positive impacts on autistic people, including increased opportunities and acceptance of remote work/school as well as reduced in- person social interactions and increased use of telehealth and services such as curbside grocery pick up.

Name	Parent
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbances, avoidant restrictive food intake, sensory and motor challenges,
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, self-injurious behavior, ADHD, aggression, Dentophobia
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication and emotional disabilities
What additional research is needed to help address co-occurring conditions for autistic people?	Supports and Treatments for psych and dental. Are these conditions truly co-occurring or part of the autism diagnosis; how many individuals with autism do not have a co-occurring diagnosis? What education do medical professionals receive about autism and intellectual and developmental disabilities?
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Access to adult psych and dental providers! Insurance coverage for psych and dental! Education to ALL types of medical professions about autism and intellectual and developmental disabilities
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Disruptions in services, ability to access the community, isolation

Name	parent
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Autistic individual not being able to recognize or communicate the symptoms and/or discomfort of the experience. The result can be awful constipation that is hard to control, vomiting or diarrhea without any notice. After several years, I now recognize that my daughter has awful pms and accompanying pain. But she was never able to tell me. She no longer has seizures, but some of the behaviors related to past seizures remain, eg. night wetting. Sleep disturbances are particularly difficult as she wanders around the house and tries to get out. We had to lock all the doors, refrigerators, food and toiletry cabinets, and of course, everyone is tired.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	First, as with health conditions, the autistic individual often cannot explain what he/she is experiencing. So, we may not know what to treat. When we can tell, eg my daughter is very anxious and has been diagnosed with anxiety and OCD as well as pica, it is pretty much impossible to attempt verbal behavior therapies as these are just not effective or understood by the individual. So, treatment is most often through medication, many of which have their own side effects/complications. For example, my daughter's constipation is much worse since being on meds for anxiety and OCD. She also now wets herself during the day (and always at night).
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My daughter is diagnosed as having IDD and poor communication. Again, this makes it almost impossible to figure out when she does not feel well or what she wants/needs. My experience is that it also makes treatment very difficult as we are just guessing from her behaviors how the treatment is going. The staff has to be really well-trained and sensitive to be able to assist this population, and there are very few such staff members. My daughter had an undiagnosed UTI and was being prevented from going to the bathroom because the staff thought she was just avoiding doing her work and also were worried she was trying to clog the toilet. A dr visit detected the UTI.
What additional research is needed to help address co-occurring conditions for autistic people?	I am not sure, but I know the gastrointestinal issues (particularly constipation and food distress) can be debilitating. So, why is this happening? Can we control some of these symptoms with diet? Definitely need more efficacious medication and interventions. It takes a lot of time to know the person well enough accurately to tell what he/she is communicating through their behaviors. For example, my daughter constantly pulls up her pants when she is experiencing menstrual cramps. It took a long time to figure that out. If we could have a long-term study of behavior-association with malady, we could provide a list to family and staff members as possible explanations for behaviors.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance is a nightmare and an ongoing battle. Dental care is a big challenge. As my daughter gets older, there are fewer doctors/services for her. One office outright said "we have reached out quota of government contracts." She has Medicare and Medicaid. NONE of our drs participate in Medicaid. ALL of our psychiatrists have NOT accepted any insurance. Clearly reimbursement of specialists is insufficient, and these patients really need specialists. They actually need more treatment than normal peers as their treatment takes longer, typically for lack of compliance by the patient. My daughter's podiatrist had to stop treatment for plantar's wart as it would no longer be covered by the insurance. Yet treatment was longer than usual as my daughter pulled off the medicated pads. This type of situation (individual needing more visits and more time to treat) is typical for this population. So,

	<p>many are actually being undertreated. Need more insurance coverage for longer treatment periods. Also, coverage for non-typical treatment. My daughter has to be put under for some dental care. Insurance does not cover full anesthesia. And we were extremely lucky the dentist is patient and was creative in coming up with a treatment plan. Other dentists did not even want to see her. Training physicians on how to treat these individuals is not enough, you have to PAY them for the extra effort and cost they experience.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>We lost all of our supports and many never returned. My daughter's day program closed for 14 months. She still has not gone back to her regular schedule. She was so disrupted by the change, that she is just not the same person. She remains afraid of masks. Also, we lost about 1/3 of the staff in her program. The program is still understaffed AND the new staff members are not as well-trained or liked by my daughter. We also lost all weekend programming and most of that has not come back. Her anxiety levels are clearly higher and staying that way. Physically, her psychiatrist believed some of her newer and more disruptive behaviors were triggered by inflammation resulting from covid. She did have covid, and while the expected symptoms (eg. cough, fever, etc.) were unremarkable, her disruptive behaviors increased markedly and quickly. Antibiotics helped, but her base line remains worse than before the pandemic.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>See response above. Most of the impact for us has been loss of services and increase in disruptive behaviors. We have fewer supports. We cannot tell if she has permanent physical or cognitive damage. On the positive side, we learned about new activities that our daughter likes. She is very active and her anxiety is reduced with physical activity like long walks, particularly outside, bowling, etc. She has a greater tolerance for different foods. She ate at home exclusively for over a year and we learned she can be a very healthy eater. So, we learned that some of the "behaviors" and preferences were actually made worse by her pre-pandemic setting. These individuals benefit from being out-door and not cooped up. They will eat fruits and vegetables if offered, not just pizza. But good food is expensive and not often offered in institutional programs.</p>

Name	Parent
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My 16 year old son has always had sleep difficulties and was diagnosed with severe sleep apnea last year. Had his tonsils out and just got retested for apnea and is now considered moderate. Will definitely need a CPAP because he falls asleep in school.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Bipolar disorder is likely but not yet confirmed. Son has been on an antipsychotic for 4 years now.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Pragmatic language/social communication appears somewhat advanced at times but son likes to dominate every conversation. He will ask a conversation partner a question because he wants the same question asked back. At home gets very stuck on topics of interest, often repeating the same news or set of facts. Recognizes he should stop because it is causing frustration but is unable to stop.
What additional research is needed to help address co-occurring conditions for autistic people?	More studies on effectiveness of medications for ASD and co-occurring conditions is desperately needed.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Specialized job coaching
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	My son struggled tremendously during shutdowns and with restrictions. He entered high school with wider social gaps than prior. He worries significantly about the world shutting down again. Schools are still going easy on students since reopening, not holding students accountable for their work or lack of. Not helping prepare these students for college or work.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Parent of Young Adult with Autism
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Our son was born with significant neurological deficits, swallowing & GI issues. Sensory and motor issues were so pronounced, he had total head lag and didn't use his right arm at all. Later came the expressive speech issues. All these improved (except the food allergies) due to access to therapies beginning at 8 months & because we had health insurance & received help from UHC Foundation. He could use more therapy for gait issues, stamina, postural and oro-motor challenges.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Our son also has had severe and debilitating anxiety throughout his life, now manifesting as OCD. He also has both forms of ADHD. It's a spider web in which all the strings are interwoven together; you can't pull out or try to affect one string without affecting all the others. Any approach trying to isolate any of these factor and ignoring the "interconnectedness" of him as a person with particular wiring will not bring positive change. We do know other young adults who have some of these co-existing challenges but not others. Treatment and resources must account for the whole person.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	These are not simply co-occurrences , but are part and parcel of who an individual with autism is and how it expresses itself. We could ask the same question of any given population group at large and try to categorize, essentially slice and dice a person's challenges as if we can "treat them" in isolation. Our son with the severe expressive speech delay as a baby and young toddler, was saying his food was scrumptious by age 3. Someone could have assumed this was an intellectual or learning disability. But for adequate & high quality speech therapy we might still be wondering. Gifts & challenges, no 2 kids alike, need therapies & education that doesn't "box in" assumptions about categories that define approaches & outcomes. It treats the whole child with an array of approaches to see what is effective.
What additional research is needed to help address co-occurring conditions for autistic people?	As a psych major who worked with children with autism in the 1970s, my focus would not be on research. Perhaps in the individual disciplines of speech, occupational and physical therapy, etc., but not anything that will delay actual treatment. Compared to the 70s, we have a myriad of approaches and therapies. It might be appropriate to report on successes and what doesn't work, say in a particular classroom, or school. But no traditionally academic approach with control groups is going to help children who are highly individualized responders to any sole therapy or teaching style. I taught 2 of our children at home. Both had special needs and were very different. I had learned many educational skills, but then had to learn the skill of constantly adjusting to meet each child's needs. The desired outcome is setting a child free to utilize his/her gifts, not to validate some specific numerical result. See Temple Grandin's recent books.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Our son would not have improved without access to excellent therapies. Even with employer coverage, we could not afford the co-pays. A healthcare foundation granted funds that enabled us to continue the therapies. This is simply not available to every person in every state all the time. Equitable access is vital. That means doing serious oversight of a given state/county Child Find programs. And appointing independent advocates for children in the IEP process which is heavily weighted *against* finding a child needs an IEP. Further, school respond terribly and consistently to actually providing these services. Governmental entities must have the ability to reward and punish school districts who comply or not. These 2 steps along would greatly

	expand access to every child in every neighborhood in every state regardless of demographics.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I can only opine, but significant changes of any kind disproportionately affect the most vulnerable among us. Anything that results in less predictability and fewer services has likely wounded the autism community greatly.

Name	Patricia Quinn, Mental Health Asso of O.C. and Dept of Mental Health of O.C.
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	While all of the COD above are challenging to individuals with ASD, I think the larger problem is the lack of clarity of how COD mental health challenges are identified and treated. In my work I am surprised that it is not seen that there are high rates of sexual trauma and PTSD in this population, emotional dysregulation, etc, and a lack of attention to this side of the person. In addition there is unevenness, even among certifying professionals of what constitutes autism. There are some psychiatrists with post doctoral training that disqualify highly intelligent people from an ASD diagnosis on that basis.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	In my work I am surprised that PTSD symptoms are not explored. This population and IDD people are susceptible to sexual trauma as well as emotional dysregulation, and all of those diagnoses due to sensory reactivity, difficulty with transitions, and ineffective parenting. Attention to this side of the person with better assessments and more consistent training is needed. In addition there is unevenness, even among certifying professionals of what constitutes autism. There are some psychiatrists with post doctoral training that disqualify highly intelligent people from an ASD diagnosis, primarily for that reason.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	1. Lack of adequate and effective assessment 2. Lack of education and respite for families and caregivers 3. Lack of in school support professionals to identify and address these learning challenges 4. Lack of support for evaluating youth, and even fewer resources or none for assessing adults who eluded detection, leading to entrenched isolation and depression.
What additional research is needed to help address co-occurring conditions for autistic people?	That which: Takes stock of the adequacy of resources, anticipating they are inadequate to address the burgeoning need Includes promising therapies that stimulate social interaction and positive self image like the creative arts Explores how sensorimotor approaches may help Identifies the needs of support staff and families to reduce family causes of dysregulation and iatrogenic injuries from from staff Looks at the adequacy of psychiatric/psychological training of those who assess and confer a diagnosis of autism.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	There needs to be better coordination between Office of People with DDs and OMH Better diagnostic categories and nomenclature that fits the range of need and ability of those with autism Guidance for NP-Ps and psychiatrists in medication considerations as well as use of things like hallucinogens for people with autism
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Loss of support staff Increased isolation and regression socially and emotionally Loss of educational resources
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	People are more guarded and there may be fewer sports and other in person meeting and interacting opportunities Many small programs have closed and the emphasis on self direction vs. congregant care activities (to eliminate expensive programs and employee benefits for states?) mean that there are fewer social opportunities. There are also not enough residences for people who cannot live with families. The socializing activities levels in these homes that exist are nil due to lack of training and adequate treatment planning.

in-person social interactions and obligations)	
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Name	Patricia Thomason, Parent
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The treatment and services of these issues, are not the same for the neurotypical population. The autistic thinking processes are different, and therefore must be treated and serviced differently. Communication can be limited, both receptive and expressive, which means traditional procedures, need to be adapted. It can be difficult for someone to find the words to describe what they are feeling when recovering from or beginning to have, a seizure. The sensory input received from the autistic individual can be greatly exaggerated and painful/confusing/traumatic for the individual. When providing services, all environmental conditions need to be considered and understood, to allow for a successful experience.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Many treatments for mental health conditions to include verbal and medicinal therapy, needs to be adapted to the autistic individual. Understanding how their thought processes and triggers affect their behaviors, can lead to more successful treatment. In my experience, when the anxiety/aggressive behaviors are adrenaline filled and impulse controlled, the considerations of the personality, past traumas, and the environment are paramount for a successful deescalation of the event and behaviors. The autistic mind does not respond typically, so many considerations and knowledge of the individual is required by the staff and services they receive.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Research should include studies, treatments, and adaptability/differentiation of common treatments should all be considered. In my experience, the autistic person can not always perceive and/or process thoughts and rationalizations due to the mental health components they are experiencing. The autistic mind, again in my experiences, prevents them from processing sense or rational thoughts from a situation because adrenaline and fears from anxiety and anger, which leads to aggressive behaviors or fight/flight reactions. Research in dealing with anxiety/anger in the autistic mind would be helpful. Finding the differences or adaptations in current treatments could be beneficial to many in the community.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance companies should be accommodating and approve services for the treatment of adults with co-occurring conditions. The fight for these services for the diagnosed autistic adults is yet another brick wall to climb that families and providers have to fight for.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic	The positive is the creation of social "zoom rooms" for members of this community to interact from different parts of the country. And the telehealth component can be very accommodating to the individual and their families to receive some services.

people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Patricia Wright, Proof Positive
Demographic	Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Proof Positive: Autism Wellbeing Alliance is grateful for the work of IACC, as demonstrated in The Summary of Advances of the Interagency Autism Coordinating Committee. Still, there is much more to do as these issues and others remain: -Families and caregivers report tremendous stress and lack of access to services and supports -Community service providers struggle to attract and retain talent Higher prevalence of mental health disorders and difficulty accessing mental health support
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Learning the science and skills of positive psychology may help address the physical and mental health issues many autistic individuals experience. The autism community has an opportunity to address mental health conditions through the application of wellbeing practices. Wellbeing skills can work in tandem with existing autism services and can help address co-occurring conditions in the autistic population. Though not widely applied in autism services and supports, positive psychology interventions, including wellbeing practices, can benefit mental health (Chakhssi et al., 2018). Autism service providers can take action by incorporating mindfulness practices for those for whom they provide service and for their employees. The autism community deserves to benefit from the wellbeing practices established in the field of positive psychology. Deploying research dollars could help establish the efficacy of wellbeing practices in the autistic population.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Social policies can indeed transform the lived experience of marginalized groups, including those living with autism, and that includes addressing wellbeing in the autism community. The PERMA Model (positive emotions, engagement, relationships, meaning, and accomplishment) is one of the most widely accepted and utilized models of wellbeing (Seligman, 2018); the model is a core component of positive psychology. Using the PERMA model, the government can take action to promote the wellbeing of the autism community. As one of the current IACC Committee Members, Hari Srinivasan, recently wrote, "All humans, disabled or not, yearn for human connections that enrich their lives beyond a mere fulfillment of basic needs." Increasing the frequency and intensity of these five building blocks of wellbeing increases access to a high-quality life. Addressing access to care is a reasonable first step to promote wellbeing for the autism community. Families report the burden of accessing care for their autistic children as tremendous. Promoting the social service workforce's wellbeing through established practices that promote engagement and meaning could be one

	<p>component of addressing low job satisfaction that leads to high turnover. Corporate America has been incorporating wellbeing practices into its talent management strategy and operations for years; it is time for social services to join in understanding wellbeing's importance in recruiting and retaining a high-quality workforce.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	

Name	Patricia, Student
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory related disturbances can stop an individual from engaging in necessary day-to-day tasks, and impede regular and necessary function. Some affected areas are personal hygiene, excursions (grocery shopping, appointments, etc), work related tasks and socialization.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	As an autistic individual, I have struggled with depression and suicidal ideation from the beginning of adolescence, 10 years old, and still continue to struggle with my mental health. I was diagnosed with persistent depressive disorder at 11 after attempting to take my life at 10, and was diagnosed with autism at 14. I believe that my depression is a result of being an autistic person in a world that is made for non-autistic people, and is hostile towards those with perceived differences.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	As a child I had great difficulty making friends, forming bonds and communicating with my peers because I am autistic. I was outcasted, isolated and bullied because I couldn't pick up on the social cues that others were displaying.
What additional research is needed to help address co-occurring conditions for autistic people?	There needs to be more research into co-occurring disorders in autistic women. Every autistic woman I know, myself included, suffers with one or more of these conditions: POTS (postural orthostatic tachycardia syndrome), hEDS (hyper-mobile ehlers danlos syndrome), PCOS (poly-cystic ovarian syndrome), endometriosis and mast cell activation syndrome. And yet there is so little research regarding the co-occurrence of any of these conditions and autism. I also believe that the occurrence rates of autism in woman vs. men needs to be readdressed, just because more men and boys receive diagnosis doesn't mean there are more autistic males overall.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Most of the specialists and providers specifically for autism only know how to treat and interact with autistic children. During my diagnostic at 14 I was asked demeaning questions that would be more appropriate for a young child or toddler, and most of the questions were deferred to my mother as though I were not in the room. The tests themselves were also for children, involving picture book, building blocks, and toys cars. When receiving care for chronic pain it is also imperative to keep in mind that autistic individuals process pain differently, I personally don't show many external signs that I am in pain, unless it is incredibly severe, so much so that I cannot sleep due to joint pain or headaches and I begin to cry. I have been accused of drug seeking and faking simply because I have a monotone voice and don't show much expression.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I developed juvenile arthritis after having COVID-19, due to a predisposition to auto immune conditions. And I became significantly more depressed due to the quarantine, ending up in an inpatient acute ward for a suicide attempt in August 2021. I have only recently returned to the same headspace as before covid.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on	Remote school work nearly caused me to repeat a year of high school because I benefit greatly from having a specific space just for school work, as I cannot get into the same motivated headspace at home as at school or

physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

work. I benefit greatly from a structured routine, and deviations from it can be damaging. Telehealth is convenient because of transportation concerns and the difficulties that come along with going to new places and meeting new people. I have mixed feelings about the social obligation part of this question.

Name	Paul Ridikas
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The most significant challenges that are caused by co-occurring physical health conditions are sensory circumstances, motor challenges, loneliness, and sleep disturbances.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The most significant challenges that are caused by co-occurring mental health conditions in autistic individuals are anxiety, aggressive behavior, and depression. I do admit that I sometimes struggle with these circumstances.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The most significant challenges that is caused by other conditions that co-occur with autism are low comprehensive levels, lack of focus, and struggling with communication.
What additional research is needed to help address co-occurring conditions for autistic people?	I think that there needs to be footage of videos or images that might cause a dignosis of autism on an individual.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Have more support and inclusion for people with autism when it comes to improvements in autism services and supports to help address co-occurring conditions for autistic people.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It had a tramuatizing impact on physical and mental health conditions for autistic people for COVID-19 illness and infection.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	When it comes to COVID-19, the positive impacts were increased remote work and school, the rise of Telehealth, and feeling more connected with people while the negative impacts were isolation, delays of services, and not enough support.

Name	Payton
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Some of the common challenges autistic people face in physical health is usually a heightened sensory experience, meaning that people on the autism spectrum are more sensitive to sights, sounds, smells, and sensations than the average person. This obviously has a wide variety of ways that it displays in others but it does limit experiences for a lot of people, movie theaters are too loud so they never go, clothes with tags cannot be worn, certain foods can't be eaten because of the sensory feel in one's mouth. This can obviously lead to dietary restrictions and dietary issues that can lead to gastrointestinal problems, and the sensory around hearing can prevent one from having a proper deep sleep and in some cases develop insomnia. These all lead to more extreme results but ultimately the cause is heightened sensory awareness and sensitivity to the point one can hear the sound of electricity moving through lights and other equipment.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Autistic people can definitely experience an influx of depression, anxiety, and other issues relating to these disorders. Autism carries a lot of overlapping symptoms with ADHD so they share similar traits and both can lose their train of thought easily and forget things that were important. The depression and anxiety is not directly linked to autism but more likely linked to the environment around the autistic person experiencing them. "Masking" is something that a lot of autistic people do (ie behaving and acting the same way neurotypical people do, often at the expense of their mental and physical energy) and that fear of being rejected (rejection sensitivity is also heightened among autistic people) drives an anxious need to be seen as the same. Autistic people are often bullied for being different, for seeming "off" in comparison to their other peers without knowing the difference. This leads to depression, in extreme cases suicidal ideations and actions, violence is rare but possible as well. These need to be addressed not only within the autistic community but also within the allistic community that it goes beyond just educating the public.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	There are autistic people who are nonverbal and do not speak at all, there are also autistic people who are selectively mute and find that easier. Communication is not always clear, autistic people require direct speech very often and don't always understand social cues. At best, it results in some embarrassing story that they can laugh about in a year. At worst, it results in losing relationships and community entirely just for saying one thing and not realizing the weight of their own words. It can also be difficult for autistic people to focus on things that are outside of their interest range. For example, if one is inclined towards creative interests such as art and literature they would find it difficult to focus on STEM subjects such as Algebra and Physics.
What additional research is needed to help address co-occurring conditions for autistic people?	There should be research involving alternative forms of communication for autistic people, as well as helping to lower the sensitivity of one's sensory experience so they can be more on the levels of their adult peers. Research should also be done on the way schools are handling not only IEPs for autistic students but also how their peers approach the subject. Schools are the foundational ground of development for many autistic people and it creates many of the environment conditions that lead to anxiety, depression, and other mental health problems. There should also be research conducted into the mental health solutions that some charities such as Autism Speaks offer as they have been known to abuse those who have come into their care looking for help with their autism symptoms. I understand that there is little

	influence publicly over private institutions but there should be a vetting process in place to ensure that autistic people aren't being given electroshock therapy to force their brains to "rewire" and "become normal" or something similar.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	If someone is offering autism services through private means, such as Autism Speaks, I would greatly prefer seeing such companies put to a specific standard that guarantees not only that no abuse is taking place but that the services are actively improving the life of the autistic person receiving them according to the patient and not the institution. In terms of public services, the main issue is simply a lack of staff and a lack of education about available services. I think a financial incentive to potential therapists, doctors, and teachers would help to better increase their education regarding autistic people as well as helping to increase staff for such endeavors.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	COVID-19 was an event that shocked the country and we are still currently recovering from. There are many autistic people that watched the government put out the order for a 2-week quarantine to be met with people dismissing and outright disobeying this order in order to fulfill their own wants and needs. For many, it was simply a shift in the view of the world that became much less hopeful now that they know the selfishness of the average american. I don't know that much can be changed in regards to that.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The increased remote work can be a benefit to most autistic people and undoubtedly helps those in fields where they would be working with customers and clients to keep their distance and maintain a greater amount of energy by staying home and working on their projects in the comfort of the familiar rather than going into work. While routine is important, and sometimes essential for the average autistic person, ultimately social distancing has made life easier for the average autistic person and an option should be available to continue doing so without risking their job or their education.

Name	Penny, Autistic adult
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	orthostatic intolerance (POTS and non-specific) & pre-/syncope, disordered sleep, GI disorders, disordered eating from sensory limitations and/or poor interoception, proprioception deficiencies and hypermobility-exacerbated injuries
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	autistic burnout (especially for high-masking individuals), ADHD, sustained/complex trauma from sensory issues, bullying, etc., passive suicidal ideation
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Deficient social capital often leads to deficient financial capital, Lost income potential for inability to 'play the game', Excellence is less rewarded than change (e.g. 'promotion'), and change can be difficult for autists.
What additional research is needed to help address co-occurring conditions for autistic people?	Causation/correlation research is great, but unapplied knowledge is just a trinket. Research must be geared toward effective, affordable, and universal accommodations to ensure that folk on (and off!) the spectrum have a fair shot at a satisfying (or at least minimally traumatizing) life & career.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Steps toward universal accessibility will help everyone, including autists. Ensuring that important (dare I say all?) documents are available in multiple modalities to accommodate different cognitive strengths/processes. Focus on output rather than input in any workplace where physical presence is not a true requisite of the role and significant allowance for respite from stimuli where physical presence is a key responsibility (manufacturing, retail, in-person service desk, etc.).
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Alone time, increased opportunities for remote or hybrid work, social distancing/personal bodily space (all positive).

Name	Person with Autism
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	sleeping disorders, co-existing mental health conditions and epilepsy
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression, Anxiety and ADHD
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Learning Disability, Hand Writing, Developmental Disability
What additional research is needed to help address co-occurring conditions for autistic people?	1. I think more research needs to be done to help educate mental health practitioners both about autism and co existing mental health conditions. Many mental health practitioners do not have the education and training to diagnose autism and yet they often are dismissive of such diagnosis of their clients even when made by an autism expert. Normal mental health therapies do not work well for people with autism so there needs to be new approaches to counseling and therapy for people with autism. 2. More research about learning disabilities, sleep disturbance etc
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	1. States Medicaid programs should cover seeing autism expertised therapists and getting autism related services for adults. Most states don't cover these for adults. 2. People who receive autism related disability services should be entitled to privacy. As a disabled person with autism I have a host of issues with privacy each year. My state (Oregon) requires my home to be visited each year just to get services but people on other safety net programs have no such requirement also there are other intrusive requirements that really make it feel like I give up privacy for very basic services.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Honestly the biggest issue for me is that society has now acted like Covid is over and with co existing health issues I feel at risk of Covid. Providers and agencies no longer affordable to ability to do things remotely instead wanting to come to my home or me to go into an office and this is especially worrisome for me during the winter when Covid cases rise. I feel like my own safety from Covid has been jeopardized by the return to normal attitude.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services,	Telehealth has been great

increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Peter Brown
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	In my son's case, sleep disturbance followed by sensory concerns followed by motor challenges. Sleep disturbances probably have the greatest long term impact to variable mood, anxiety and depression.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety leads to demand avoidance, difficulty with social relationships, aggression, depression etc. It is a downward spiral toward self injury and suicidality.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My son is a verbal thinker. He is gifted in his english language ability and as a result was miss-diagnosed as not autistic as a child. I suspect there is a link between verbal thinking autistic people, anxiety and pathological demand avoidance. Pathological demand avoidance should be recognized and researched as it is exceptionally difficult for families to understand and deal with, upending normal parenting strategies.
What additional research is needed to help address co-occurring conditions for autistic people?	There is tremendous variability in presentation of autism. Research should focus on groupings. Pathological Demand Avoidance (PDA) appears to be a grouping or profile with similar characteristics where common strategies may exist for parents and for adults living with the profile. Temple Grandin identified three different thinking styles, visual, mathematical/musical and verbal. Maybe these thinking styles could be related to profiles with similar characteristics. Research should look for common characteristics which could allow other profiles to be developed. PDA needs more research.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Many autistic people are extremely capable in certain fields but are unable to gain employment because of poor social skills. Employment services are critical to a positive trajectory in adulthood. There is much to be done to overcome biases in hiring and interviewing practices that lock autistic people out of quality employment.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Covid-19 lead to further social isolation and greatly increased anxiety with long term consequences.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increased telehealth may be a positive impact. Increased internet services in general have probably had a positive impact in our case. Paradoxically reduced social interactions and obligations may have had a negative impact.

Name	peter mazure, parent
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Anxiety is a major issue, particularly regarding large crowds, loud noise, and small spaces (inside a car). Skin disorders are also a problem.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety is a significant problem.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Lack of expressive language skills is a major problem.
What additional research is needed to help address co-occurring conditions for autistic people?	Increased attention to non-medication approaches to anxiety.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Better trained doctors and nurses; most are poorly prepared to treat patients with Autism and ID.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Pon kavitha Anbarasi, St. Mary's College
Demographic	Family member of an autistic individual; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Physical illness include : motor challenges, unable to respond quickly, digestive problems, urinary tract problems.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD, Learning disability,Intellectual disability, Specific learning disorder, Motor disorders,anti social personality disorder.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Intellectual disability is the most common challenges an autistic individual can come up with.
What additional research is needed to help address co-occurring conditions for autistic people?	Awareness and studies related to the autistic individual.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Giving proper treatment of counselling and clinical assessments.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Learning disability, communication problems,
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	It created a negative impact during the COVID 19 , as some children's have affected by prone to the screen which led to develop some development problems .

Name	Priya
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	People with autism are unable to communicate how they are feeling or talk about their symptoms and this can be really challenging not just for them but also for their health care providers. This can cause a delay in accurate diagnosis.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Their SIBs can be mis- interpreted as a " behavior" rather than them trying to communicate a need. Meds used to treat behaviors , can cause patients to gain weight and asking patients to follow a certain diet for weight loss can be challenging for patients and this can be a source of anxiety for them.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	It can cause a lot of frustration. There r a lot of non verbal people with Autism who are able follow commands but unable to speak which means they have the ability to understand what is being told to them, however have difficulty responding verbally and speak what's on their mind.
What additional research is needed to help address co-occurring conditions for autistic people?	Why do a lot of patients with Autism have oropharyngeal dysphagia
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	It's really difficult to find hospice services for patients with Autism More funding for special education services in schools Parents of children with Autism need more community support and accessibility for services More daycare centers for children with Autism/ ADHD etc so parents can get a break Temporary Respite Care services where parents can drop off their children if they need to go on vacation or take care of their own health More " In Home" workers who can help on a PRN basis
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Some patients have developed severe cardiac and respiratory illnesses. Lot of patients do not like to wear oxygen masks and it's challenging to provide oxygen therapy. Isolation during COVID was difficult
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Telehealth services have been very helpful. Not being able to see parents or guardians over extended periods of time was difficult for them Not being able to go out to restaurants and fun activities was tough as well

Name	Purna Waldow
Demographic	Autistic individual; Family member of an autistic individual; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Based on observations of people in my personal life, former patients and my own lived experience, I would like to see more research into Ehlers Danlos, chronic pain conditions, sleep apnea and other parasomnias, sensitivity to fluorescent/LED lights, Sensitivity to mold and sensitivity to synthetic chemicals. As more studies come out about the prevalence of PFAS and forever chemicals, I think we will see sensitive populations, such as autistic people, be negatively impacted first.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Based on observations of people in my personal life, former patients and my own lived experience, I would like to see more research into the abuse of autistic people which yields to co-occurring mental illnesses, specifically PTSD, depression, anxiety, suicidality, self harm, and addiction. I see all of these mental illnesses that often affect autistic people as connected to each other and correlated to the treatment received by others combined with sensory overwhelm of one's environment. I would also like to see research into agoraphobia, especially during and since the pandemic. There also needs to be more research into gender dysphoria in neurodivergent people, and how restricting access to reproductive healthcare impacts them specifically.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I would like to see more research into different learning styles of autistic/neurodivergent people and ways providers and educators can help them accomplish their goals in life. More research into masking, burnout and their connection with sensory and social overload is needed. Though not necessarily a “condition”, I think research focused on introverted people and how to meet their needs would be beneficial. I see people around me who haven't had a need to be diagnosed as autistic or having attention issues because they are extroverted and can function adequately in job positions and at school versus introverts who seem to burnout faster and more frequently if they don't have accommodations.
What additional research is needed to help address co-occurring conditions for autistic people?	In general, we need more equitable research that utilizes inclusive population samples of all races, sexes, genders, ages, and economic classes. I'd like to see research about how accommodations improve outcomes, which would bolster the populations' ability to access them at work and school settings. Research also needs to be conducted regarding the number of autistic people being incarcerated, likely due to other unaddressed mental health conditions, and how addressing their support needs could prevent incarceration.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Equitable and affordable care and accommodations need to be available to all autistic people, including those who are considered “level 1” or appear “high functioning”. These labels have left a massive gap in support for these people in particular. Affordable diagnostic services need to be available to adults who are high masking and have struggled their entire lives. More providers need training in what it means to be autistic/neurodiverse and that this population cannot be reduced to a stereotype, especially when considering other co-occurring conditions. States that restrict access to Medicaid or intentionally refuse to fund it also create a lack of available services to autistic people, as many are unemployed/underemployed and poor.
What lasting impact has COVID-19 infection and illness had on co-	I have witnessed long COVID in one neurodiverse person I know. I have personally isolated, stayed current on my vaccines and have yet to contract a symptomatic case or test positive for COVID. I have not heard much from

<p>occurring physical and/or mental health conditions for autistic people?</p>	<p>others around me how they were directly impacted by having the illness in relation to being autistic.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>I observed enjoyed the decreased social expectations during the pandemic. The increase in available telehealth services made accessing care easier and less stressful. The increased availability of remote work also made life easier and work sustainable. I was, however, disheartened to see the utter selfishness people exhibited during the pandemic and their willingness to put others in danger, especially people who were already vulnerable due to pre existing health conditions. It contributed to me leaving my career in healthcare to pursue work I could perform remote and I have no desire to work directly with the public anymore after the way I was treated during this time. It's also been disappointing to watch the spike in corporate ableism as companies try to force people back to in person work, regardless of the benefits remote work brought many people, not just autistic people.</p>

Name	Quinn
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	When an adult with autism is tasked with assimilation to an allistic (non-autistic) society, not built for their needs to begin with, the navigation of symptoms and inherent ableism they face at home, school, work, or even the doctors office is not aware of the possibility for autistic co-occurrence, we are doomed to be symptomatic. How can one manage symptoms if the underlying issues (both autism, and implied co-occurrence) is not noted? How are you to heal? How are you to cope? How can you ask for help, if your providers and peers and colleagues do not understand that these things are connected? It is alienating. I have been sickly my whole life, and been told numerous times that it is based in mental health; not neurodiversity, nor underlying co-current conditions. I wish more providers knew to even consider the physical aspects of living with autism; and the trauma that lives in your body, alongside it.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Almost all of the Autistic Adults I know have co-occurring mental health disorders. Most prominently, ADHD/ADD. I also have found throughout my own life that my autism makes the average therapies nearly impossible. I am not going to therapy to fix my autism, to assimilate, to “get better”. I’d like to cope with it. Alongside it. Alongside all of my disorders. I did not ask to be labeled “mentally ill”. I did ask repeatedly if autism & ADHD/ADD could be the main connection between my mental health issues. And as an adult, I have found that yes; my autism touches all of it. My brain is all connected. So to be asked the worst struggle... of being mentally ill, & autistic? It is that providers, peers, anyone could assume I am “simply” “just” “mentally ill”. When in fact, I just operate differently from an allistic; and the mental health issues I face stem from masking, hyper vigilance, hyper criticality, and a poor understanding of how to comfort or even just speak to an autistic person. I wish more people understood. I am not simply anything. I am an autistic individual, and that effects how I think and feel, across all expressed emotions and traumatic events.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Homelessness, addiction, isolation/loneliness, lack of access to support that is understanding of autistic proclivities.
What additional research is needed to help address co-occurring conditions for autistic people?	Female autism needs to be researched. The cross section of autism & ADHD/ADD needs to be researched. Our diets as an American society and how that affects one’s brain chemistry, hormone production, insulin levels... it all needs to be looked at. Where is the connection between these things? & what can we, as the autistics, actually tangibly control and change for the better?
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	The idea of a Personal Aid needs to be much more normalized; I wish so badly that the school and health systems had departments, manned with employees who have an understanding of or even certification for working with autistic adults. And another for autistic children. There are options for people like us; as a hyper verbal/higher functioning autistic, I wish I could work with my fellow man, and let them know we have options and capabilities. Even if they do not align with the same things from allistic communities.. we need more people who understand. To take the human aspect of it and be a person to a person. We are simply just people, with a different way of

	<p>thinking of things. I think we need more diplomatic interpreters essentially. :,)</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>The massive disruption of social routine. Most autistic people (not all!) appreciate and thrive through a similar routine, as it brings a sense of normalcy to us as we fluctuate internally. Another aspect that is not inherently tied to covid itself, but more so the internet/Information Age, is that the amount of misinformation and infighting that is both documented and spread without question. I am a proponent of self diagnosis; as getting an autism diagnosis can lead one down a path that is not entirely positive (as it can effect adoption; immigration; employment; social standing; etc), I do find it disheartening that so many people, young and old, find untrue or misconstrued information online about autism. I think we need to do two things; to help both of these issues. 1. We need a truly unbiased, humanized and yet scientific, database or news outlet or nonprofit to share current/modern autistic data & information... and it needs to be accessible to the average autistic. We can not continue to live in the dark about our own experiences. Thousands upon thousands of people have been different over humanity's life span; we are no different. We must just come to an understanding. And our information must be provided by an unbiased, scientific but feeling perspective. 2. There needs to be a AA/AI-Anon type group/nonprofit that is created entirely for the sharing of the information</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	

Name	Rachel
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Makes treatment difficult
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	makes treatment difficult...what are we treating, ADHD? ASD? Depression? anxiety? anger? they can look alike but sometimes causation is related to treatment
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	again, makes course of action difficult specifically, i'm thinking about the school setting. can impact how others view the individual and understand the "why" of the individual's behaviors
What additional research is needed to help address co-occurring conditions for autistic people?	i've heard about ultrasound to rewire the brain for parkinsons, dementia, drug addictions. wondering if there is a potential for this with ASD
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	absolutely insurance coverage guidance, perhaps a case manager, a "go-to" person to help the family navigate and develop a course of action - someone who is COVERED UNDER INSURANCE a designated medical professional who specializes in ASD - so far we have seen a neurologist, psychiatrist, psychologist, pediatrician,
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	the isolation for a group of people with social challenges has caused a negative impact the increased use of technology as a substitute for in-person interactions has its place but can be overused
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	i actually addressed this in the previous question

Name	Rachel
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	For myself I struggle with my sleep, sensory and gastrointestinal issues. Which all have made my life very difficult. I can't sleep through the night, I struggle with falling asleep, which when I'm not sleeping well my sensory issues are harder to cope with. I also have migraines, which are also disabling. It gives me vertigo, nausea, throwing up, changes in my vision, etc. My sensory issues have made my life extremely difficult between becoming over stimulated with simple life, but I do not handle change well. I need a rigid routine or I have meltdowns. It's exhausting and frustrating.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My son is extremely hyper active. It makes it hard for him to eat, sit, read books, etc. when he becomes overwhelmed he will harm himself or run away. For myself I have had Major Depression since I was 13. I've had anxiety my whole life, I've been diagnosed with OCD. When I am overstimulated I will harm myself without thinking.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I have a learning disability and it's made my life very difficult, I can't count money, I struggle with reading. It's frustrating.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I wish more professionals understood what I can look like in different people. I wish there was more professionals who diagnosed there should be more Support systems. Whether that be autism coaches, someone who can check on you and see if you need additional support. Someone who can help clean your house or make meals for you occasionally. Therapist who can help you with social problems.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It's made it harder for me to leave the house
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Rachel
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I have a gastrointestinal disorder called irritable bowel syndrome. In my experience, it causes random vomiting and stomach cramps. It can be one of the reasons I stay up at night. It can also add to my selective diet because something's hurt my stomach more.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	There is a huge struggle with anxiety in my experience. My anxiety gets so big that I can't sleep or sit still. I have to move a lot and sometimes have panic attacks. Anxiety prevents me from leaving my house, making friends, and sometimes even talking. It's hard when I am anxious and have things to say in my head, but I can't get them out of my mouth.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I have situational mutism. It is a real thing. For me, it's not a choice not to speak. Sometimes I can and sometimes I can't. Situations where I can't speak are usually when I'm very anxious or the situation is new. Sometimes it's also in random situations when my voice turns off. I open my mouth, but no words can come out. This can lead to a panic attack.
What additional research is needed to help address co-occurring conditions for autistic people?	Research is needed not to cure autism but to help us function in a neurotypical world. We need research on why anxiety is heightened in autistics and what skills can help autistics with their heightened anxiety. There are some general coping skills for anxiety, and they do not always help autistic individuals because their brain functions differently. This also goes along with GI issues. Autistic individuals are more sensitive to medication so what medication is helpful for autistics with gastrointestinal issues and even anxiety.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Researched therapy needs to be available to autistics after they reach adulthood. Many of the services that are credible and have been backed by large autism researchers are not as available to adults. This can include occupational therapy, physical therapy, play therapy, and talk therapy.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	There has been a big positive impact of COVID-19. It has provided online pickup for groceries so an autistic person does not have to shop inside. It has provided a six feet recommendation so people do not get too close to autistics who can be sensitive to their personal space.

Name	Rachel brown, University of Kansas school of medicine
Demographic	Service provider, health provider, or educator; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Many autistic individuals respond to pain differently including with severe behavior. I have seen horrible self injury and aggression in autistic individuals experiencing pain and discomfort. Understanding more about why this happens and why resources for physical care including dental care are difficult to access is a priority for me
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Severe self injury including tooth removal and aggression limit the ability of many autistic individuals to live full lives and challenge their families caregivers and communities. Have been a relatively neglected area for research including research into the implementation of existing effective interventions
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Focus on severely impacted autistic individuals and on severe and intense behaviors; use of implementation science to explore barriers to intervention; we need to understand why autistic children are still prescribed antipsychotic medications, often by midlevel practitioners, don't get known effective behavioral supports and what negative consequences result. We need research into care delivery systems to establish which patients can be safely cared for in primary care settings, which need specialist interventions, which need residential care and what kind of settings can support the highest quality of life
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Equitable access to high quality care delivered by those with the highest levels of training and expertise. Every individual on three or more psychotropic medications should be evaluated by an MD psychiatrist with expertise in this field. Psychologists with training in behavioral interventions for severe behaviors should be available to patients everywhere. Hospital care can be accessible with safety teams focused on those needing more support because of challenging behaviors.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	

in-person social interactions and obligations)	
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Name	Rachel Goodman
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	medical professionals lack of knowledge about co-occurring conditions with autism is the biggest challenge. I wasn't diagnosed until age 40 after suffering a lifetime with known co-conditions. It makes me think why didn't my physicians put it all together? It wasn't until I was diagnosed with ehlers danlos syndrome that I found out about the co-conditions of autism. Suddenly my list of conditions were no longer occurring independently but they were now part of a whole series of connected conditions.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	For me it's sensory issues & anxiety.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	First, getting diagnosed with autism as a female. Second, getting diagnosed with co-conditions as a female.
What additional research is needed to help address co-occurring conditions for autistic people?	To me I see the biggest thing needed is research & then educating medical professionals so they know about the do-occurring conditions.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Services & supports can't happen without early diagnosis followed by interventions. And for those diagnosed as adults access to services & supports needs to be available - but I've found those things are mainly offered to kids & families.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It's kept us from living our lives the way we want to.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	All of the above. It has been a huge issue.

Name	Rachel Payne, PhD, Didlake, Inc.
Demographic	Service provider, health provider, or educator; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	<p>Didlake is a nonprofit rehabilitation services organization that has been creating and promoting opportunities that enrich the lives of people with disabilities for almost 60 years. Some significant challenges associated with other conditions that we see and support in employment and community settings include challenges with following multi-step directions, sensory challenges, and biases/misconceptions that people have about their abilities that impact the level of interaction and support they receive. Collaboration and coordination between various service systems and providers (e.g., education, human services, healthcare) are essential for providing comprehensive support to this population. In adult rehabilitation services, we work closely as a supportive team to help meet the support needs and goals of everyone we serve. Outside of the services and support that autistic people need, there is also a need for comprehensive training on autism and co-occurring conditions for healthcare providers and first responders. Increasing community awareness is a crucial step toward creating a more inclusive society. This approach not only aligns with Didlake's commitment to advocacy and support for individuals with disabilities but also ensures that individuals with autism and co-occurring conditions receive the comprehensive, respectful, and effective care and support they deserve.</p>
What additional research is needed to help address co-occurring conditions for autistic people?	<p>Our research recommendations include more comprehensive studies on the prevalence of co-occurring conditions in autistic individuals across different age groups, genders, and cultural backgrounds. Research is needed to identify barriers to service provision for individuals with autism and co-occurring conditions. This may involve studies on access, disparities in care, and the effectiveness of different service delivery models in meeting the needs of individuals with autism. We recommend expanding on and strengthening the research on models that have been studied in this population. Additionally, research that examines the intersectionality of autism and co-occurring conditions with other factors such as race, ethnicity, gender identity, sexual orientation, and socioeconomic status could help with informing more equitable and inclusive approaches to research and practice.</p>
What could be improved in autism services and supports to help address co-occurring conditions for autistic	<p>Improving autism services and supports to help address co-occurring conditions for autistic people is paramount. Understanding the barriers individuals face in accessing appropriate services due to factors such as</p>

<p>people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>location, socioeconomic status, and cultural differences is critical. The impact of co-occurring conditions presents additional barriers that people with autism already face in many areas of their lives, including employment and participating in their communities. Our experience at Didlake underscores the necessity of individualized, evidence-based approaches that respond to individual needs. Autism services should be tailored to address the specific needs and challenges of individuals with co-occurring conditions. This may involve specialized training for service providers to support individuals with autism and co-occurring conditions. The staff and employees working directly with individuals need specialized skills and training to meet the needs of the population they serve. Individualized treatment, support, or employment plans should consider the unique strengths and support needs of each individual.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	

Name	Rachel Spencer
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbances are quite traumatic on the caregivers, feeding concerns affect our quality of life a lot, and being non-verbal is the 3rd most Difficult comorbidity of autism.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Attention deficit is the most difficult co-trait to handle
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Because there are so many varying degrees of autism, no one “plan” to help overcome developmental deficits fits all. Someone needs to take the time to get to know the person with autism in order to be able to help developmentally and most kids get 30 minutes in front a doctor, not nearly enough time to get to know when or help
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	We have a lack of services in rural counties. No autism centers within an hour drive from us.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Lack of in person services and therapies for a long time delayed any progress in speech
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Rachel Swisher
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	For my son, it is the GI issues. Sensory and motor challenges are difficult, but with therapies can be managed.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	In my limited experience, ADHD and aggressive behaviors have been the most challenging. Mental health issues among people on the autism spectrum tend to be ignored because of their overarching diagnosis. This is cause for concern.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication continues to be a barrier for many people on the autism spectrum. Because of this, engagement, employability, and general ease can be difficult for people on the autism spectrum.
What additional research is needed to help address co-occurring conditions for autistic people?	I would like to see double-blind studies on physician and therapist interaction with children on the autism spectrum. Are their mental health needs being addressed as well as their physical needs? Is there a checklist to go over with children on the autism spectrum to adequately address their mental health needs? If not, or if the child is unable to communicate, can one be offered to the caregivers? This issue seems daunting to parents with children on the autism spectrum and would benefit everyone involved.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Oh my goodness, insurance coverage. The insurance coverage through my husband's employer is incredibly lacking in mental health coverage. We pay over \$200 a month for our son to meet with his psychologist. The lack of benefits for this health issue is dreadful. Patient-provider interactions can also be lacking. I believe providers could benefit greatly from CSE on working with clients with autism spectrum disorder.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The increase in telehealth has benefitted my son tremendously. Though the disruption in his schedule was a challenge, the availability of his doctors, nurses, and specialists via telehealth was a godsend for him. He does well with telehealth appointments, sometimes better than in person.

Name	Raine
Demographic	Autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>These conditions are frequently under diagnosed. Many go through their entire, if not, most of their academic experience without receiving a diagnosis for their co-occurring physical disabilities. This means they will not receive any accommodations. This creates the opportunity for extremely poor learning experiences. Health insurance will sometimes not cover, or only partially cover an insignificant amount of these appointments to the doctor for getting these conditions examined or appointments for receiving treatment. Doctors are also often dismissive because their patient is autistic. They frequently will misdiagnose them or they will not receive any diagnosis, treatment, or insight for their problem at all. Jobs will not allow enough time off or breaks to allow the autistic person with co-occurring physical health conditions to recuperate. This limits a vast amount of job opportunities to an already vulnerable group. Social challenges include employers not hiring due to our disabilities because they would have to accommodate them. This causes autistic people to stretch ourselves beyond our natural capacity. This often causes burnout, which, there is not accommodation for an autistic person experiencing burnout despite how likely it is to occur and how debilitating burnout is.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>These conditions are frequently under diagnosed. Many go through their entire, if not, most of their academic experience without receiving a diagnosis for their co-occurring mental disabilities. This means they not receive any accommodations. This creates the opportunity for extremely poor learning experiences. Health insurance will sometimes not cover, or only partially cover an insignificant amount of these appointments to a psychologist/therapist for getting these conditions examined. Psychologist are also often dismissive because their patient is autistic. They frequently will misdiagnose them or they will not receive any diagnosis, treatment, or insight for their problem at all. Jobs will not allow enough time off or breaks to allow the autistic person with co-occurring mental health conditions to recuperate. This limits a vast amount of job opportunities to an already vulnerable group. Social challenges include employers not hiring due to our disabilities because they would have to accommodate them. This causes autistic people to stretch ourselves beyond our natural capacity. This often causes burnout, which, there is not accommodation for an autistic person experiencing burnout despite how likely it is to occur and how debilitating burnout is.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>These conditions are frequently under diagnosed. Many go through their entire, if not, most of their academic experience without receiving a diagnosis for their co-occurring learning disabilities. This means they will not receive any accommodations which creates the opportunity for an extremely poor learning experiences.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>Observing the differences in autism and all it's relate co-occurring conditions and disabilities between male, female and intersex people. This research should include varying age groups (children, teenagers, and adults) as well as different races and ethnicities.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services,</p>	<p>Health insurance will sometimes not cover, or only partially cover an insignificant amount of these appointments to receive diagnosis or treatment for getting these conditions examined. These need to be covered better by insurances, and not just for children but also for teenagers and adults. Service-providers are also often dismissive because the care-</p>

<p>insurance coverage, service systems issues, patient-provider interactions)</p>	<p>reciever is autistic. They frequently will misdiagnose them or they will not recieve any diagnosis, treatment, help, or insight for their problem at all. They need to know what these conditions present as in autistic individuals. Jobs will not allow enough time off or breaks to allow the autistic person with co-occurring health conditions to recuperate. This limits a vast amount of job opportunities to an already vulnerable group. There needs to be more tolerance for the accommodations needed for autistic people. Employers often will not hire an autistic person with co-occurring conditions because they would have to accommodate them. This causes autistic people to stretch ourselves beyond our natural capacity. This often causes burnout, which, there is not accommodation for an autistic person experiencing burnout despite how likely it is to occure and how debilitating burnout is.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	

Name	Rainier, Endeavor to Hope Counseling, LLC
Demographic	Autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	There is a lack of knowledge from some practitioners about the correlation of physical conditions and autism, which can lead to specific treatment styles that end up not working, as there can be an improper case conceptualization. The strongest conditions I see are ARFID (often mistyped and treated as anorexia), GI issues due to lack of appropriate nutritional care and understanding, hypermobility disorders, dysautonomia, and mast cell/histamine conditions.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	In my lived experience and practice as a therapist, I see a high rate of perfectionism, people pleasing, masking, and feeling burdensome or unknown to themselves. All of these experiences often lead to suicidality and substance use. I see many individuals misdiagnosed with borderline personality disorder, psychotic disorders, and bipolar disorders due to the lack of understanding of how autistic people think concretely and mood shifts leading from overstimulation.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I often see dysgraphia, dyslexia, dyscalculia, alexithymia, and ADHD (the combo known as AuDHD).
What additional research is needed to help address co-occurring conditions for autistic people?	Research needs to be done on the ACEs and autistic people, the correlation with hypermobility, the impact of being “autistic coded” and mistreated pre-diagnosis (AKA being treated differently without knowing why), and the impact of black and white thinking.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance needs to cover autism assessments, especially those done by LMHCs, nutritional care, occupational therapy, mental health therapy related to living with autism and the societal stress, adult autism services of all sorts, adult peer support, and much more.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Many autistic folks lost some of their peer support and consistently used social skills from meetings, school, and otherwise, creating more “bridging of the gap” to renew the skill sets. However, many autistic folks enjoyed the reprieve and the normalization of technologies that allow for our comfort, connection, and ease of life. Many believe that some options “enable” people, however, I am of the belief as a therapist and autistic human, that we need only challenge ourselves to our passions and necessities. If it does not impact our life whether we, for instance, order groceries online or shop in the store, it doesn’t need to be an issue.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	The ability to work from home, use accommodations, and normalize a life that many disabled people live already has increased access and freedom in ways that technologies are cheaper and options for work, support, therapy, and more to be online or hybrid are available.

in-person social interactions and obligations)	
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Name	Rajarshi Rit, The University of Burdwan
Demographic	Autistic individual; Family member of an autistic individual; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Being victim of bullying and infantilization, being called in derogatory terms, being advised, spoken over, and misguided.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Self hatred, Rejection Sensitive dysphoria
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Society does not provide us the appropriate communication mode. People use their expectation, their definition of age-appropriateness. Anything we want to communicate that does not fit the social format, is not listened.
What additional research is needed to help address co-occurring conditions for autistic people?	COMMUNICATION. AAC ASSISTIVE TECHNOLOGY Presume competence. Understand cognitive style, and ask the questions in appropriate format. Frame the questions in culturally relatable way.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Ban the ABA therapy. Throw away the ABA therapy. DITCH the ABA therapy. There is NO such thing as "inappropriate play". Don't poison our livelihood with "intervention". We are not criminals. We are human.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	The LOCKDOWN taught us several things. Firstly, flexible work schedule is possible. Secondly, Advanced countries can put "Do not resuscitate order" on learning disabilities, which means your Authority believes our lives are "Less worthy" than yours, which harms us the most.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Definitely, Flexible time schedule has been a good thing. Do not resuscitate orders were bad thing, as if Autistic/dyslexic lives are less worthy

Name	Raliat Bello
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory and motor challenges
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Hyperactivity disorder
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Learning disability
What additional research is needed to help address co-occurring conditions for autistic people?	Unsure
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Access to support within the community
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Support in the schools for their education has declined for this group.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Support in schools has declined for this group

Name	Rashelle
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I suffer from depression and anxiety that has made it difficult to function in day to day life at work and in society. I get massive panic attacks in form of dreams that have me waking up tired and exhausted, usually not ready to function in the day.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have depression, anxiety that effect my ability to socialize "normally". I get anxious in social situations and get overwhelmed into exhaustion despite being an extrovert. I used to have suicidal ideation but after I got COVID a second time it changed how I function. I became more anxious and reactive to people. My autistic differences became more apparent in social situations.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	As a child, I was considered "gifted" but over the years burn out occurred. I couldn't read without getting distracted easily. I have a hard time with math and writing in "proper structure". I am trying to improve my communicative abilities as an adult but I also see the lack of "proper communication" in allistic people. Lying is considered normal. Understanding sarcasm is considered normal. You're supposed to "know" these things which is difficult. I have found out that I am good with remembering small numbers and patterns, but sometimes reading people is hard.
What additional research is needed to help address co-occurring conditions for autistic people?	Research I believe needs to extend to individuals. The effects of COVID changed my personality causing my depression to ease but my anxiety to go up. Different meds are required to keep me stable. Autism isn't a problem but people treat it like it is. Empathy in allistic and autistic people need to be researched too
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Equitable access to medications that help with related issues. Police and Doctors should be trained on how to deal with people with autism (anxiety attacks, meltdowns, etc)
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I was isolated which caused my depression to worsen. But when I caught COVID the second time I was in a non-functional fog that sent me to the hospital and I could not stop crying. I couldn't do anything for myself. After a month I realized my depression was mostly gone but my anxiety became a lit worse. I couldn't hold down a job, I couldn't finish duties. I needed a change in medications
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	Many are introverts, but it made needed social interactions worse among ballistic people. People effected forgot how to interact properly.

in-person social interactions and obligations)	
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Name	Reagan
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I suffer from sensory issues on a constant basis. It has given me anxiety that I've been diagnosed with. Sounds are often too much, especially when it's as a surprise.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have depression, adhd, anxiety, and ocd. I struggle on a day to day basis to get up and be functioning. I'm unable to work, due to my issues. And I haven't been accepted on disability because of my mental health struggles.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I really struggle to process instructions, often times miss understanding and taking it too literally. I struggle to be able to communicate effectively, due to late diagnosis and neglect in childhood. I can never formulate words, to describe anything.
What additional research is needed to help address co-occurring conditions for autistic people?	For the love of god, safe spaces for autistic people to be able to work. And get paid equally. Treated equally. I feel so inhuman because I struggle to have a job.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I feel truly as an outcast in every sense of the word. Medical care was absolutely abysmal. I can't get insurance because I can't work. I can't learn how to hold down a job. Can't afford therapy. Disability doesn't pay enough. And won't allow me the privilege of disability either.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Best thing to ever happen. I felt safe for once. Not having to socialize. Most people couldn't work. So I felt human I felt normal. Many of my autistic friends totally felt the same. I wish we could go back in that time. Just without all the deaths.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	It's been 100% harder to even find a job. I applied to over 237 last year. And I never got anything back. No calls backs, even when I tried to call for updates. People have treated me worse since the pandemic. Everyone seems more hurt or something.

Name	Rebecca
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep, stomach, and attention issues along with sensory. My husband and I are both autistic and both have various traits. He has adhd for example as well and I'm the one with the sleep and stomach issues. I'm on a journey of discovering all what is wrong but I have many stomach conditions diagnosed such as diferticuli, esophogitus, history of ulcers but no H pylori, so on. I've had many surgeries as well, Interesting note was my autism was diagnosed well after all these issues. My husband got his diagnosis much earlier in his life
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The urge to hit yourself, sounds weird right? It is I agree. I also feel great shame when I feel that urge. It's usually shame that brings it on as well, like I made a mistake or I feel great anger. I never want to hurt anyone else, and in the past as a child I have on accident. My emotions feel so strong and in my arms I feel this overwhelming urge and I also even feel in the spot I plan to hit, a sense of it NEEDS to be hit. My leg or my head. Mentally I feel better doing so. Attention, my husband for example has a very hard time depending. Some subjects hours can be spent while others it's a struggle to stay. We both need different ways of multi tasking or background interaction for different tasks
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	As a woman that was diagnosed late, I was put on so many medications as a child. Instead of understanding why I did or said anything I did I was always punished via family or peers/public. I've had a lot of physical and mental abuse over tiniest things. Shaking my leg as I sit or bouncing it, twirling my hair, clicking my tongue, walking on my top toes. I never learned to express myself I only learned to mirror those around me. And being in a bad area bad town bad part of town, mirroring those around me was NOT a good thing. Instead of helping me learn to cope, I was medicated and I had to teach myself to cope in my younger years
What additional research is needed to help address co-occurring conditions for autistic people?	Genetics. Autism is genetic put research into the families with it. It's so clear it's genetic and it's shamed heavily and punished and thus we are forced to hide ourselves
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Stop treating autistic adults as idiots. Believe what we say. And stop gaslighting women and young people. Just because we might speak well, have a friend or be married or even parents does not mean we are not autistic. If you bothered to read any of my previous comments you would realize the abuse from real world has a lot to do with us hiding our traits. As it has become more acceptable of course you are seeing more autistic people. We were always here you just either hid us away in horrible medical facilities or we had to learn to fake it.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Positive in some ways I believe. It gave some of us undiagnosed individuals time to assess and realize our entire lives were essentially a lie and us struggling and thinking we were some stupid freaks that is different from everyone else, THERE WAS A REASON we felt that. But, negative in that public services that previously were there were deemed a threat due to Covid 19 and is no longer here
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school,	

increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Rebecca
Demographic	Autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Not being believed by health professionals. Not being offered treatment. Conditions being labeled psychosomatic.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Lack of support. Lack of diagnosis in AFAB people. It's hard to get disability and if you do it, it's not enough to live on.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Allow people to self diagnose and then listen to their description of what it's like having autism. The diagnostic criteria is too slim and does not allow for adults to be easily diagnosed. If dx was missed during childhood it's almost impossible to get as an adult. Free screenings need to be made available through health department for adults.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Free access to diagnostic screenings. Insurance coverage. Disability access. Better disability pay. Doctors need to be better educated on spotting autism in adults.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	COVID has made my health issues much worse. And doctors are not taking COVID seriously anymore. The public health concern over COVID is basically nonexistent. Those of us with chronic health conditions are extremely isolated because we feel we are the only ones taking precautionary measures anymore.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Autistic people already feel isolated. Working from home is better for us. But not feeling like we can go back into society without jeopardizing our physical and mental health is taking a huge toll. We live with fear of ourselves or our loved ones dying from Covid complications daily.

Name	Rebecca Bowen, American Speech-Language-Hearing Association
Demographic	Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory and motor challenges that impact feeding and safe swallowing. Challenges in conducting evaluations for AAC and other communication interventions, requiring additional time and observations to provide comprehensive and person-centered recommendations for individual needs. Hearing loss or other hearing-related challenges may impact the delivery of services. Equipment must be available, individualized, and tolerated due to sensory needs. If physical conditions impact overall health and ability to attend therapy sessions, progress may be interrupted or slowed.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Professionals are not consistently applying knowledge of how “masking” autistic behaviors impact the autistic person’s mental health. Anxiety impacts receptive and expressive communication, slows response time and could reduce the person’s ability to accurately and effectively communicate safety needs and/or sensory supports that would improve or reduce negative [feelings] experience. Impact of not having access to communication supports, AAC, or the ability to functionally communicate orally and be understood could exacerbate anxiety and contribute to other mental health conditions. Between masking and lack of familiar communication options, there is a cycle of impact that can be a constant stress or burden on the autistic individual. Speech-language pathologists and other professionals working with clients must be informed of best practices and apply that support consistently to address their autistic client's needs. Time spent counseling families on how to support communication impacted by the mental health condition may reduce the time in direct service to the client with autism. (this supports the new CPT codes for parent/caregiver training)
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Childhood apraxia of speech impacts reliable oral speech Ability to participate in treatment protocols not normed on persons with co-occurring intellectual and learning disabilities Fewer employment opportunities K-12 education and placement decisions Limited opportunities for higher education Independent living Independent participation in health care Impact of ADHD on learning and function Executive function difficulties impact problem solving and independence Literacy skills Timely and accurate diagnosis Limited funding options for interventions across the lifespan
What additional research is needed to help address co-occurring conditions for autistic people?	Evidence-based comparative effectiveness research is needed to: determine which intervention(s) yield clinically significant improvements in speech, language, cognition (e.g., memory, attention, executive function), and social communication and address the unique challenges associated with the various comorbidities; understand which intervention approaches provide the most meaningful communication and social interaction outcomes for various age groups; identify which interventions are most beneficial for which sub-groups of individuals with specific co-occurring conditions including responsiveness to treatment at different times during the lifespan; examine the impact of changes in frequency, intensity, and duration of treatment; identify screening and assessment tools that are most effective at accurately diagnosing autistic individuals with co-occurring conditions, especially differential diagnoses.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services,	-Care coordination and health care access across the lifespan particularly during times of transition (new living situation, employment) -AAC/assistive technology supporting communication and adequate time for direct instruction for the individual and communication partners -Spectrum of need for autistic individuals is a barrier to equitable access. Providers implement

<p>insurance coverage, service systems issues, patient-provider interactions)</p>	<p>prescriptive treatment protocols without adapting to the individual's needs and preferences -Caregivers often become decision-makers without considering input of the individual with autism, specifically with choosing AAC vocabularies and devices that limit access to other options for communication. Some institutions provide only one type of communication support due to funding needs rather than individual needs -Treatment should be individualized, considering all the areas of need, including communication and AAC for those who are non-speaking or part-time users. -Treatment should address family and community knowledge and acceptance as part of service delivery and goal setting to decrease stigma. - Improving models of interprofessional collaboration that includes time for training, information sharing, collaboration without the patient present. Billing pressures can disincentivize high quality care that teaming produces. - Consider how social determinants of health impact autistic individuals over their lifespan. People with communication disorders have poorer health care outcomes than people without.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Positive impacts include increased access to telehealth services, when appropriate, and increased acceptance of social media and alternative communication means (e.g., text, videoconferencing) improved assistive technologies like word prediction, voice banking, voice assistants, speech to text, and text to speech. A negative impact is delayed access to services resulting in language and learning loss post pandemic.</p>

Name	Rebecca Dosch Brown, Parent advocate
Demographic	Family member of an autistic individual; Service provider, health provider, or educator; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Accessing mental health practitioners and other health professionals willing to see (feel confident and trained) in seeing adults with autism. Many refuse, especially mental health therapists who can do adaptive CBT and Exposure and Response Prevention (ERP) for people with autism AND OCD and anxiety. They actually can treat folks with ASD. Our family found that all it takes is a therapist who uses creativity, visuals, and trial and error like any good therapist they work with families and they can do it. Sadly too many just say NO and families are left without help when their children are in worsening mental health crises. We need to train MH therapists to have confidence and some proven tricks of the trade we have from the skilled educators out there of autistic children/adults.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Lack of professionals willing to see our children. They think because they didn't get specific training they can't know how to work with them. Not true. They can do it. They dehumanize autistic people, especially people who are not conversational or who do not use words for communicating. We need more messages that they CAN treat and work with autistic people. It's not rocket science and with following the lead of parents and the person in need they can figure out options that are more step by step, visual or music-based that still fit into their standard ways of treating people.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	diagnostic overshadowing that it all ties to ASD. Teachers assuming all autistic people are x (low) or y (high) functioning per their academic (testing) abilities alone and not really honoring the real complexities in how each autistic person is as a wholly complex person with the same range of human emotions and skills as anyone else w/o autism. The dehumanizing of people with ASD is so sad to see as a parent. The lumping children into categories and not seeing nuance or possibilities if they get the "low" label. I hate those labels.
What additional research is needed to help address co-occurring conditions for autistic people?	Most just say anxiety, OCD, depression etc. is common co-occurring (and typically searches for biomarkers or genetics for this). Why not ask: wouldn't you have anxiety if you constantly had people telling you want to stop doing, telling you to sit still, and yelling at you and talking about you as if you are not there all day? That alone would cause these co-occurring MH conditions. Its traumatizing being misunderstood so much by adults who are supposed to care and love children (not berate and control them). I'd love for researchers to look at the behaviors of the adults surrounding the children with as much scrutiny as they give to the people with ASD's behaviors. How they treat our children is often traumatizing and damaging to our children's development as people.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	demystify the stigma and prejudice around serving people with ASD. Teach practitioners disability history, the social model vs. the charity/pity and medical models, how society is wrong to categorize normal so narrowly and expand acceptance of behavior that doesn't harm others are okay and not in need of constant harping to try to change people whose minds are just wired a little differently. What if we see could as adults interpret these differences as strengths to build on and develop rather than to extinguish? Most things can be seen as strengths. If someone is in crisis help/show you care for them and don't berate and punish them. I really think practitioners need to shift their attitudes before the systems can hope to change (vs. fix the person not in need of "fixing"). Attitudinal shifts of neurotypicals are needed about disability writ large.

What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Compounded social isolation.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Rebecca Faith Crews, Autistic adult
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Significant sensory challenges, especially when out in public with large crowds Pain and discomfort from comorbid Ehlers Danlos syndrome
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Severe depression, anxiety, self injurious behavior and suicidality
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	ADHD makes learning and focus difficult
What additional research is needed to help address co-occurring conditions for autistic people?	Where do these co occurrences come from? Why do they occur? How can we better treat them to make them less impactful on an individual's life
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance, advocacy in medical care, advocacy in legal networks. Having better access to information on how to do these things
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Severe depression, ptsd, and new cooccurring chronic health issues
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	More people were educated on autism during the pandemic, leading to more awareness and acceptance.

Name	Rebecca Farrell
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	In our household, sensory and sleep disturbances are the most common challenges faced by our 10-year-old son. He requires a long bedtime routine, melatonin, and still wakes as early as 6am, even on weekends. His sensory issues cause problems with noise, even those that are pleasant, e.g., seeing a musical. On a recent trip to Disneyland, he constantly had his fingers in his ears.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	All of these mental health issues are very serious, especially in autistic people who are so often ill equipped to process their feelings. Our son is very anxious, has diagnosed ADHD, is extremely aggressive when upset and is difficult to control. Medication and therapy can only do so much.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	For our son, who has autism and ADHD, he must attend a very expensive private school that can help him learn the way he needs to learn. He also struggles with communication, was a "late talker" and often refuses to engage in conversation that is sensible. Most of what comes out of his mouth is related to his hyperfixations or is rubbish.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Everything! We need more paraprofessionals in public schools, we need therapists in schools, we need FREE public schools dedicated to serving children of ALL AGES with ASD and ADHD.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Rebecca Jukes, Mom of Autistic Child
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Disordered eating that creates a host of issues ranging from only eating a certain number/type(s) of foods, eating all day or not at all for days and those issues create weight, mental health issues and nutrient deficiencies. ADHD and anxiety goes hand in hand with lots of autistic people. Medication backorders, the lack of support in the school systems, wait lists over a year long, lack of staff and income restrictions make it hard to find support workers, therapies, doctors, aides and education.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety in groups of more than 5 people, social issues like refusing to talk to unknown people even if needed (stores, doctors, restaurants) impulse control issues leading to safety and welfare issues or injurious behaviors such as jumping off high places and running in parking lots. Reliance of caretaker/parent to guide them through daily life causes caretakers/parents to need mental health care for anxiety, depression, PTSD. Being able to get care is nearly impossible when someone relies on you 24/7 and there are no resources.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Lack of social skills that restrict peer interaction, the anxiety of things changing and moving too fast for their understanding, ADHD causing disruption in classroom/hallways/public areas, speech issues, gross/fine motor issues resulting in teacher complaints and bad grades, cognitive understanding and the ability to retain information resulting in bad grades. These are barriers to learning in the mainstream classroom but you have to be severely autistic to not be in mainstream education, get an IEP or qualify for an aide.
What additional research is needed to help address co-occurring conditions for autistic people?	Autism presents differently in everyone, there are 100's of conditions that come with autism but within those conditions is another scale you need to qualify for to have autism. For example (A) has anxiety can be managed with meds (B) has anxiety can not be managed by meds (C) has anxiety but does not qualify for a diagnosis (D) does not have anxiety. But in order to qualify for autism services you need to have anxiety? Half of those people are being misdiagnosed.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Access to care in smaller areas some areas have year long waitlists for services, doctor/therapy participation in state insurance, required autism training for public service workers (any one in a doctors office, therapies, dentists, police, rescue, everyone in the school system including support staff), insurance requiring proof to approve medications, therapies, support people after the doctor says they need it or income restrictions where you make just a little bit too much to qualify for this service but they need it.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Covid restrictions has resulted in more anxiety over going out in public, fear of getting sick, less social interactions compounding the existing social issues, failure to be able to separate from caregiver for long periods after public restrictions were put in place which also results in mental health stresses for caregivers.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	During remote learning and telehealth the stress of social interactions and going into the public decreased and made things easier, the ease of self paced learning, shorter hours and being able to be in a safe, comfortable and familiar environment where they were not restricted to social norms, strict schedules and the distraction of others and fear of upsetting their teacher they thrived and were happy. Once things started moving back into normal routine it became stressful, the anxiety and ADHD meds increased, the stress of homework being counted as part of the grade compounded with 5-6

in-person social interactions and obligations)	hours of needing to be normal, calm, quiet and pay attention increased behavior problems at home as well resulting in bad grades and social issues.
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Name	Regina Conti
Demographic	Family member of an autistic individual; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My son has been home from school since October (4 months) due to severe GI symptoms. He has regressed in his skills over that time and has been very uncomfortable. He also has epilepsy, which is scary, as it can cause brain damage and even death.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My son's severe anxiety has made it extremely difficult to access medical care.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My son's medical issues are extremely difficult to address because he can not communicate his symptoms or follow directions. He can not swallow a pill. We can not get a blood pressure reading on him. He requires around the clock care and is often unable to participate in activities he enjoys and school due to these symptoms.
What additional research is needed to help address co-occurring conditions for autistic people?	Practically-oriented research with human participants. Research to develop approaches to dealing with the challenges of profound autism, and capture the perspective of the valuable people living with it.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Improved support to provide families with paid caregivers. Agencies that advertise, screen and train qualified applicants. While families deserve a choice in caregivers they should not be burdened with the work of searching for, screening and training applicants.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	COVID-19 was more dangerous for autistic people. My son was sick with COVID-19 for several months on multiple occasions.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The labor shortage has made it difficult to find qualified direct support professionals.

Name	Rex Frasier
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Trying to get treatment for the co-morbid health issues has been the biggest hurdle. Most autistic people seem to be hyper aware of where their ailments are coming from and what the cause might be related to through communicating with each other and heavy research. Sometimes the tests involved in this is less focused on what the individual NEEDS to be tested for and instead doctors want to test for EVERYTHING ELSE it could be FIRST. It has been my experience to strongly and calmly suggest to my doctor that I am acutely aware of the situation and that the combination of certain symptoms relates to these more "Rare" medical cases that are actually QUITE COMMON across autistic and neurodivergent people alike. Most of us, especially late diagnosed individuals, have spent MOST of our life trying to identify what is causing our issues just to find that the issues we have are very common across our neurological community even though the things being diagnosed are listed as RARE amongst neurotypical communities. People tend to infantilize us and not take what we are saying at face value because they assume we are just overreacting when we are not.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	As for myself, one of the most significant challenge is societal perceptions. This is a HUGE problem that can actually cause several others to happen. The world isn't made with disabled people or divergent neurotypes in mind and it shows. This can cause a snowball effect leading to an increase in depression, self-harm, harmful stimming, being perceived as violent, being attacked and abused by others, others perceiving you as untrustworthy, suicidality, public "meltdowns," and other similar events and happenings. I live in constant fear of being in public spaces with people I don't know. I get so nervous around cops that I have panic attacks when they talk to me. I feel like I can't use mobility aids without people around me making comment's about how I'm "taking away from people who need it" and that I "Look too healthy" to use it. I choose to go places when I know it won't be busy so I don't have to deal with comments from strangers.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I have a hard time processing things that I read or hear. The best way I can describe it is that it's like having a computer for a brain that is full of viruses while using dial-up connection and you are trying to search for the words while an endless stream of pop-ups keeps blocking what you are trying to do as well as someone keeps calling and disconnecting you from your ability to search while also trying to get rid of the pop-ups.
What additional research is needed to help address co-occurring conditions for autistic people?	GENDER RESEARCH!!! Not all autistic people are the same for their perceived gender/sex. We are all individuals. 1 out of 7 autistic people experience some type of gender dysphoria or identify other than what they were assigned at birth. These people also more closely diagnose with what is true for the opposite of their gender assigned at birth. I have more typical identifiers with female autistic adults than I do the males. I myself am also gender-fluid leaning more towards feminine than masculine. Autism is exceedingly more varied than what is currently being researched.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Accessibility, Incurance, Services, Service Provider understanding/interactions, Affordable Healthcare, cheaper testing and therapy, life coaching that IS NOT ABA(ABA is abuse and forces harmful masking strategies instead of how to exist as yourself in a world that is not designed with you in mind just to make everyone around you more comfortable, most autistic people who have endured ABA "Therapy" grow up to becoming more depressive and suicidal than those who were taught to

	embrace themselves). The entire system needs a kick in the pants to do better, if I am being honest.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Increase in avoidance in social settings, being a "homebody" or "shut-in" is more common, myself included. A lot of autistic people also have co-morbid immunocompromised health conditions that limit their ability to go into public spaces as safely as they used to since the country was so divided on the entire Safety Protocols for the pandemic.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I think employers that were more willing to adapt to remote work and schooling were beneficial for autistic people who are immunocompromised as well as those who have social phobias or are distracted easily when surrounded by other activity going on in a work space that can cause them to lose focus on their duties. This also comes with a decline in ability to be in social settings or how to respond to people during person to person interactions.

Name	Rhonda Moore
Demographic	Autistic individual; Family member of an autistic individual; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Chronic Pain Hypermobile Ehlers Danlos Sleep disturbance obesity menopause
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD Bipolar Disorder Suicidality Depression Anxiety Emotional regulation challenges we know very little about menopause, mental health in Autistic women across the lifespan
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Sensory Self care Emotional regulation communication difficulties and challenges menopause
What additional research is needed to help address co-occurring conditions for autistic people?	We need more research on menopause and mental health across the lifespan we need more research on strategies for healthy aging across the lifespan We need more research on chronic pain disorders, mental health and autism across the lifespan we need more research on Autism and ehlers danlos
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More research on late diagnosis, sex, gender and autism in women more research on service systems issues more research on lessons learned from patient-provider interactions. we need to know what works and what does not
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Disruption in services (including services to get a diagnosis and management) reduced in person social interactions which may lead to loneliness and isolation Obesity Loneliness, depression and anxiety

Name	Rick Grossman
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Adhd Insomnia. Isolation leading to emotional problems
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression Anxiety Loneliness ADHD
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Our strong dexication to truth honesty and facts. Inability to handle conflicting information. Not able to navigate many web sites Inability to interact with bureaucracies—can't complain or request help causing victimization
What additional research is needed to help address co-occurring conditions for autistic people?	Any research about autistic people should have autistic people on the review board to determine how ethical it is and how the autistic people are being treated. Today, most research is done on 'the cause' of autism. We don't do research on the cause of homosexuality, or left-handedness, or political persuasion. Research needs to be done based upon what autistic people want and need. There's absolutely no work out there. That is what autistic people need. It's patronizing. And immoral. Hundreds of thousands of people in this country are desperate for services and no one has any idea because they're not asking as a result we have not been able to utilize the skills and talents of these people and society is a hole is operating at a deficit. How can autistic and non understand specific differences. This should be applied from an anthropological Approach. We know that people from country x have differences and forgive them- but not autistics.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I teractions between Autists and Allistic people is much rhe same as watching an immigrant communicate with a native speaker. Exceptt the Allistic person does not understand that there is a language and culturaal barrier. This should be studied by linguists, anthropologists, and socologists. These problems are not psychiatric issues.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal	if someone lived in the community where they were services for artist who were adults, they don't exist anymore. Suicidal changes have made it more difficult to communicate with businesses, and to get a helpful response. Businesses are only providing phone numbers which make it very difficult for

changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	autistic people to communicate And people are flawless tolerant, and angrier today our problems have magnified and there's nothing or no one to help
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Name	Robert Briskie, U.S. Citizen
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Challenges for autistic people exacerbated by co-occur physical health conditions, revolve around daunting diagnosis process&barriers to healthcare access. Financial constraints due to insurance hurdles lead to hopelessness &mental paralysis in diagnostic journey. Privilege of diagnosis compounded by complexities in co-occur conditions, results in arduous path. System's inadequacy in providing immediate &compassionate aid hinders ability to function/thrive. Interplay of autism &co-occur physical health conditions complicates matters. Trigger events, like lacking time, energy, support for diagnosis process impact mental health. Gaslighting w/in the healthcare system exacerbates situation leading to conditions like PTSD. Persistent issues at root level including insufficient financial aid &restrictive regulations, perpetuate crisis for the diagnosed &undiagnosed. Repercussions of systemic failures contribute to alarmingly high suicide rates among autistic individuals. Research shows higher prevalence of suicidal thoughts/actions. Mental disorders, particularly depression/anxiety linked to unaddressed co-occur conditions, contribute to suicide attempt. A proactive approach to aid is essential, involving unrestricted monetary support, accessible healthcare practitioners embodying empathy, awareness/understanding. Redefining &implementing genuine "help" is crucial to addressing the urgent needs of autistic individuals, promoting well-being&preventing tragic outcomes.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Healthcare system must adopt proactive stance in addressing co-occur mental health conditions in autistic individuals, emphasizing empathy, kindness&understanding from healthcare professionals remains a determinant factor for such conditions. Another significant determinant is necessity to devise aid methods independent of monetary paywalls controlled by insurance comp.'s, ensuring autistic people proceed w/out fear of financial persecution&mental harm. Complete removal of gaslighting by healthcare practitioners (common occurrence of autistic individuals seeking diagnosis) crucial in minimizing co-occur mental condition flare-up. Could be addressed via empathy training/seminar&ASD training from autistic perspective. Unlike DSM-5, which lacks empathy, awareness&open-ended answers, these trainings should focus on the psych impacts of words w/in question formats, promoting appropriate language use, particularly in mental health questionnaire. When autistic people seek help, healthcare professionals must listen, acknowledge potential co-occur symptoms that may impede communication efficiency. Conditions like Apraxia &Selective Mutism, require tailored precaution, especially for highmask people. Recognized challenges faced by these people, is crucial for effective support. Proactive measure, training&language sensitivity are integral for a healthcare system that addresses unique needs of autistic people fostering supportive environment&minimizing mental health challenges.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Societal expectation: numerous challenges for autistic people, lead to co-occur conditions. Challenges: difficulty asking for help, self-isolation, communication deficiency, task paralysis, emotional outbursts&misunderstood. Significant hurdle: assumption of issue by people or health workers, lack how relate to ASDpeople. Financial struggle, compound by unemployment rate reach 85% (barrier). Easy/access monetary support w/capitalist framework:crucial. Neurotypical society categorize perpetuate societal hierarchy. Health workers influenced by-may overlook unique abilities&heightened processing of ASDpeople. Despite societal

	<p>assumption ASD people often operate on higher processing lvl, analyzing info quicker. Forced need to navigate society that doesn't cater their needs activates fight/flight, causing depletion of focus&burnout. Necessity: patience&time in analysis essential. Neg. attitude/hierarchy approach bring frustration depression&diminished trust, cause co-occur conditions. Sci. research indicates ASD people have higher gray-matter vol., allows enhanced awareness of surroundings/analysis. Healthcare must prioritize aid>money, consider unique communication style/analysis. Care provided to extend to undiagnosed&highmask. Imperative health workers acknowledge/respect authentic communication style of ASD people, fostering supportive env.. Paradigm shift in healthcare-crucial to address distinct needs&mitigate risks of co-occur conditions.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>Research focus on ASD has predominantly centered on children, but a critical shift is needed towards comprehensive studies on adult ASD people. Exploring dietary needs for both children&adults, particularly those diagnosed later in life: crucial. Understanding how their brains adapt&potential harmful effects due to societal impacts on high-masking individuals are vital research areas. Regular surveying of ASD people(beyond multiple-choice formats) can provide valuable insight. Investigating role of money in co-occurring conditions, rates of ASD people below the poverty line&surveying parents, especially those whose children have experienced suicide, can unveil critical data on manifested co-occur conditions. Examining connection between ASD&physical conditions like Ehlers-Danlos Syndrome, Binocular Vision Disorder& dental & bone manifestations is essential. Research should explore potential treatments for individuals facing painful conditions, seeking avenues for healing, aid, & regeneration. Exploring homeopathic, non-evasive, frequency/tone/laser/Chinese medicine, &naturopathic therapies, & collaborating w/countries holding extensive info., can pave the way for innovative treatments in these areas. Overarching goal is to enhance understanding, provide holistic support&discover effective treatments for the diverse challenges faced by individuals w/ASD.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Ensuring equal access to ASD services is paramount, encompassing free & accessible insurance coverage & healthcare, as well as easily accessible therapy. Naturopathic & homeopathic practitioners should be available to aid autistic (ASD) people. Implementing a support system akin to student aid, offering one-on-one guidance in tasks like resume drafting, job hunting, & advocating for employment, contributes to their well-being. Assistance with finding housing, teaching life skills, & aiding in paperwork for social security disability benefits ensures survival & independence. Free tax assistance & rent stipends facilitate secure living. Educational programs on meditative practices benefit ASD individuals. Legislative changes, including the removal of marriage & income restrictions, combat ableism & mental abuse, fostering autonomy. Eliminating paywalls is vital for autistic individuals to thrive & learn self-care, empowering them to lead fulfilling lives. Also, you could allow more than this measly 1500 character restriction for these answers. I have had to sacrifice grammar to get my point and theme across in this commentary.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>Covid-19, unexpected cured my severe asthma. Opting for the Covid-19 vaccine felt safe until after Pfizer booster triggered chronic fatigue, pain, migraines&more. Diagnosed w/Factor V Leiden, Myocarditis, vasculitis onset&VITT, health workers offered no aid beyond diagnosis if at all. Despite healthy&exercising regularly, the booster's aftermath left me</p>

	<p>bedridden for 6mths. Conventional medicine provided no solution, turned to homeopath. Nattokinase:enzyme that dissolves blood clots, brought relief. Asked primary phys. to review any scientific studies done on enzyme to deem it safe. After proper review, got green light to use. All symptoms went away in month. I continued to see the homeopath Dr &we continued to see improvement. Still take Nattokinase b/c of the benefit that I continue to exp.. Still if decide to take break from it, will feel heart palps come back gradually, so I assume the booster caused irreversible dmg. Sci. study on mRNA vacc. hint at potential clot issue, echoing findings in ASDpeople regarding weak blood vessel function. I criticize govt's failure to warn those w/mental illness about potential harm&lack sharing importance of research/preventative care. The personal journey shows the need for informed decision-making in vacc. &comprehensive support for those w/ASD. I believe that the DNA based cov. booster causes the issue of VITT as well as the mRNA based. That is what my doctors told me, suppression of info. is causing lack of research.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>The question seems designed to emphasize the negative impact of the U.S. government & societal systems on ASD individuals. The lack of positive experiences & pervasive maleficence towards autistic people in this country are highlighted. Service disruptions persist, with limited options due to legal restrictions. Remote work opportunities for autistic individuals are scarce, and the brief respite from in-person interactions was short-lived. The hope for positive change through commentary is overshadowed by a sense of hopelessness & past trauma by the system ASD people live within, I am anticipating continued struggles for all autistic adults. The analogy of autistic individuals as the canary in the coal mine reflects ASD peoples role as indicators of societal health. A thriving society is evident when ASD individuals face fewer challenges, while a corrupt one manifests in their daily struggles, co-occurring conditions, and trauma. My contribution may be futile, but it underscores the urgent need for systemic improvements to support & uplift ASD individuals. More help. You asked for our commentary? We don't have enough help monetarily and empathetically to function as adults. Do something to actually help, please.</p>

Name	Robert C Bransfield, MD, DLFAPA, Hackensack Meridian School of Medicine and Rutgers--Robert Wood Medical School
Demographic	Service provider, health provider, or educator; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Please read my recent article that addresses the cause of autism spectrum disorder: Bransfield RC, Mao C, Greenberg R. Microbes and Mental Illness: Past, Present, and Future. Healthcare (Basel). 2023 Dec 29;12(1):83. doi: 10.3390/healthcare12010083. PMID: 38200989; PMCID: PMC10779437.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Autism, as well as schizophrenia and bipolar illness, are multisystem illnesses that often have an infectious disease contributor and an immune mediated pathophysiological process.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Research the cause of autism.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Roberta Kane
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Our son is 44 years old, lives at home, and has autism as well as anxiety disorder. It has been difficult to have a consistent practice prescribing his medication because after a few years, they seem to close the practice for outpatient services. This has happened with Rowan University as well as Bancroft. Their clients are left with finding a new practice which often has a waiting list. This is our present situation. We are told that the office is not able to remain open due to funding and low payments they receive from the insurance companies. We used to receive counseling as well, but this service is also no longer available. This is a very frustrating as well as frightening situation for caregivers. It should not be difficult for people with autism and other mental health disabilities to see those who know and understand their disability, and who can prescribe their needed medication.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Roberta Lincoln, Parent Advocacy Group and lived experience
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	SPD, gastrointestinal, seizures, MH issues, behavioral health issues, asthma, ADHD, learning disorders, anaphylactic food allergies, seasonal allergies, enuresis, hypoglycemia
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression, suicidality and suicidal ideation, homicidal ideation, ADHD, self-injurious behaviors, unsafe distressed behaviors, abnormal sexualized behavior, belligerent verbalizations, dysregulation,
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Specific learning disabilities, developmental disabilities, intellectual disabilities, communication disorders, challenges with “how he learns” (very verbal and articulate and above grade level reading, but has no receptive verbal “understanding” and requires visual aids to fully comprehend. Has NO concept of the passage of time.
What additional research is needed to help address co-occurring conditions for autistic people?	The processing time delays not only on verbal reception, but also in the length of time to learn/understand “everything-more delayed than neurotypical... unless it is a distinct area of interest (both time as in a classroom, and time as in 6 months for typical peers, 18 months for those with high functioning autism; also, how and why ABA is so damaging to higher functioning autistic people... and Collaborative Problem Solving is so much better.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Yes to all your examples above! Add more direct services and supports in-home, and intensive in-home behavioral treatment; anti-racism supports and services; training for schools, school systems and educators about Collaborative Problem Solving. MOVE AWAY FROM PBIS WHICH CAUSES TRAUMA AND PTSD in the educational systems! Teach educators not to use restraints and seclusions.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	The lost a year of social/emotional learning and development.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Lack of access to ADHD meds

Name	Robin Baumeister
Demographic	Autistic individual; Family member of an autistic individual; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	In addition to those listed above: -Disorders related to autonomic dysfunction/dysautonomia -Neurologic conditions, including migraine - Connective tissue and autoimmune disorders, including EDS, arthritis, lupus, etc. -Metabolic disorders -Endocrine disorders, including thyroid disease The interactions/relationships between these disorders is also noteworthy.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	In addition to the above: -trauma, including PTSD, complex trauma, and traumatic situations not typically defined in the DSM -substance dependence/abuse -OCD -psychoses -dementia -personality disorders Of note is the potential interplay of these conditions not only with each other, but also with co-occurring physical conditions (e.g. the influence of elevated/chronic stress response on immune dysfunction)
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Each of these conditions cause unique challenges. Most significant is probably the increased likelihood of self-injurious behavior, comorbid psychiatric disorders, etc. Comorbid psych disorders may exacerbate symptoms and/or lead to the development of more symptoms, including suicidality and general decreased quality of life. Conditions that inhibit motor skills may make alternate forms of communication difficult or inaccessible, which is another challenge. Co-occurring conditions also often get de-prioritized when autism is also present. This is a major issue, as these conditions are oftentimes more serious and/or treatable. Considering co-occurring conditions and helping autistic people recognize them for themselves is a major current challenge. In the same vein, barriers to care for co-occurring conditions are a significant challenge. Realistically, each individual is going to have a different scope of challenges. Personally, my greatest challenges are dismissal of physical symptoms or other mental health concerns, as well as access to care in general. Additionally, I have had a hard time identifying health concerns and knowing if they are worth professional consultation; this is a barrier to care that should be addressed.
What additional research is needed to help address co-occurring conditions for autistic people?	I think a really under-researched avenue is the etiology of these conditions in the context of inter-relatedness. Rather than focus solely on individual conditions, their holistic relationship to other physical or mental outcomes should be considered. Stress and trauma are important avenues for consideration. Additionally, more research needs to be done with adults. Longitudinal designs across the lifespan are needed. Diversity in race, location, gender identity, etc. is also necessary in future research. Also important is more research investigating early mortality among autistic adults; protective factors should be investigated further. In general, any research in this broad field is warranted.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Universal insurance is the biggest one. Not only does the current system leave gaps in coverage, but navigating the private system is monstrous to understand. Current systems are not at all close to friendly to autistic or other neurodiverse people. Guides and trainings on how to navigate systems for autistic people and caretakers are also needed. And on the provider end, there needs to be better knowledge of autism and its co-occurring conditions. Generally, more services need to be created in

	<p>general to ameliorate the service cliff into adulthood. Adult transition services would be incredibly helpful, including online and in-person systems.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>Given high stress and common co-occurring immune dysfunction, COVID-19 has impacted many autistic people. In my own personal experience, I am still recovering from an infection, and the illness was incredibly stressful; the sensory overload from illness can take a mental and physical toll. It is likely that many have experienced trauma from the situation. On the flip side, the move to more online/remote services has been very beneficial in improving access to care.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Negative: -increased stress, trauma, and potentially worse outcomes/regression -difficulty wearing masks, while simultaneous stress when others disobeyed rules regarding masks -loss of autonomy, especially for those stuck in controlling or abusive environments Positive: - WFH/remote access increased accessibility -online interactions are generally also more accessible</p>

Name	Robin Blitz
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disorders are a significant co-occurring health condition because they can negatively affect an individual's physical and behavioral health, as well as the impact on the family and caregivers. Access to in-home behavioral health providers that can be present around bedtime is unavailable for many, due to lack of providers and access to payment for this.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Access to coordinated care for co-occurring mental health conditions and access to insurance coverage, especially when needed in the home.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	State Medicaid Waiver programs provide coverage and access to individuals with ASD, often above and beyond what commercial insurance covers. However, some states, such as Texas, have very long wait-lists for these Waiver programs. Eliminating the waitlists in each state would provide improved equity and access for individuals across the US.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Robin MacDonald, Parent and Conservator
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Dental care
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Dental care
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Housing as adults.
What additional research is needed to help address co-occurring conditions for autistic people?	Housing options
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More case workers and caregivers are needed.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Not able to attend school due to chance of exposure to virus.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Disruption of services. Changes to daily routines, vacation plans, family functions.

Name	Robin Rhoades
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory challenges and sleep disturbances
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, ADHD, aggressive behavior
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication disabilities, developmental disabilities, intellectual disabilities, learning disability
What additional research is needed to help address co-occurring conditions for autistic people?	Need more research with high needs non verbal level 3 autism individuals. Ways to improve lives of the most severely impacted individuals with profound autism.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Equitable access to early intervention and accessibility of services throughout a profoundly autistic individual lifetime. Insurance coverage for all. Service system issues, patient provider interaction. safe and accessible quality group homes for adults with profound autism. Livable wages for lifetime of caregivers of individuals with profound autism.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Severe delay of development. More behaviors and aggression
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Severe disruptions in services and school. Loss of any supports and schooling for 2 years. Caused even more developmental delays. Can't do distance learning. Reduced in-person social interaction and obligation.

Name	Robin Weisman
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory. The multiple sensory impacted areas, some researchers now say 9, can create significant challenges and impact behavior, communication, emotional regulation, employment, etc.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety can manifest itself through behavior. Communication, social interaction, etc regardless of what level of autism a person is considered to have. In times of stress and trauma, anxiety is increased and the factors above are intensified. Mitigating anxiety is often not something people consider when working with people who have an ASD
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication can be impacted regardless of whether a person is verbal or not. Communication is behavior. Behavior is communication. If a person does not have a method to communicate, this can impact all parts of their life. Providing a method to communication should be priority.
What additional research is needed to help address co-occurring conditions for autistic people?	Yes. Co morbid conditions are often not identified or underidentified. We have to be able to identify and treat these. There is no ASD pill. People with ASD can have other conditions just like others. We treat symptoms not just medically but also with teaching skills. If we don't understand how these conditions work together, then we are not supporting, teaching and treating ASD as effectively as possible.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	All. It should be required that all in the medical community participate in a training. Not virtually. But hands on training to understand what works.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Robyn Linscott , The Arc of the United States
Demographic	Family member of an autistic individual; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Many individuals with IDD have gastrointestinal disorders and frequently experience inadequate treatment for abdominal pain. This problem is especially acute for individuals with communication challenges. For example, the mother of a nonspeaking autistic individual in Milford Connecticut reported that, after a sudden spike in self-injury behaviors indicated her son might be having GI related abdominal pain, numerous GI doctors refused to run tests or provide treatment. People with IDD report that their pain is often discounted by medical staff, they are not considered to be ‘reliable’ judges of their pain, prescriptions for pain killers and/or muscle relaxants are often denied, and they are frequently accused of drug-seeking behavior. In some cases, medical staff assume that people with IDD cannot consent to treatments that could potentially address their pain. For example, one individual with autism in Milwaukee, Wisconsin reported that it took 20 years for medical staff to diagnose and treat her severe menstrual pain. They said, “I was refused a hysterectomy and told I had to try every birth control available multiple times because I couldn’t be trusted to choose the hysterectomy for myself.”
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	More than a third of people with IDD have a co-occurring mental health condition, but they often experience barriers to accessing appropriate mental health services.[iv] This includes several assumptions that people with IDD cannot benefit from mental health services, that nonverbal individuals cannot participate in therapy, that multiple medications are needed to control the behavior of some people with IDD, and that mental health professionals do not have the competency to serve people with IDD. Many individuals with IDD are also improperly prescribed medications for mental health conditions despite not having any psychiatric diagnosis.[v] Examples include: · New Hudson, Michigan: An autistic individual reported that after being discharged from a hospital stay that included psychiatric care, they could not find a psychiatrist in the hospital’s network that would provide outpatient services to them due to their disability. · Bedford, Massachusetts: An individual with autism reported they were not allowed to join a therapy group due to their disability. They said: “A psychiatrist I was seeing at the time had referred me to the group, and I'd had a successful interview with one of the group facilitators. However, the person leading the group, who I'd never met, decided I wasn't a good fit because my autism prevented me from picking up on non-verbal communication.”
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access	A common theme raised by individuals with IDD and their families is that they are often considered by medical staff to be “too difficult,” “uncooperative,” burdensome, or a ‘waste’ of limited time and resources. Conscious and unconscious bias, lack of disability competency or training in

<p>to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>care for people with IDD, and resource constraints impact healthcare access and quality. Individuals with IDD that experience compounded discrimination include those with multiply-marginalized identities, and those with communication and behavioral challenges. Examples shared with The Arc included challenges accessing a broad variety of services from diagnostic testing, to preventative screenings, primary care, vaccinations, speech language pathology services, physical therapy, pain management, gastroenterology services, surgeries, mental health services, reproductive health services, oral health services, eye exams, emergency room services, and end-of-life care.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	

Name	Rose Baumann, Parent advocate
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	When an individual with profound autism is unable to reliably communicate, it becomes very difficult even to assess what issues might be impacting their physical health. This often results in self-injurious behaviors that only exacerbate the condition. For example, toe walking causes misalignment in the joints of the feet, legs and hips often resulting in pain. Some individuals, like my son, will kick or punch the areas that are painful as a way to either communicate that the pain exists or to try and change the pain experience in some way. Without the capacity to understand that hitting the affected body part will only cause further damage and pain, caregivers are forced to use padding or other restrictive means to protect the individual. When restrictive means are not possible, are not tolerated by the individual, or are prohibited by existing policies, the self-injurious response to bodily discomfort often requires medical treatment. More research on self-injurious behavior as a coping response to physical health issues needs to be done in order to save individuals with these behaviors from serious health outcomes, which may include death.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	OCD, anxiety and depression are not uncommon amongst individuals on the autism spectrum. While all individuals with autism are more vulnerable to trauma and abuse, those on the profound end of the autism spectrum who are unable to communicate and process their adverse experiences are especially vulnerable to a myriad of mental health issues including PTSD. As autistic children become autistic young adults who age out of the school system with few appropriate supports available to them, the isolation, anxiety, and despair they feel at not being able to engage in life as their non-disabled peers have adds to their mental stressors. Young adults on the profound end of the autism spectrum are "graduating to the couch" in record numbers. They are languishing at home without the full spectrum of services they need because employment, social, and residential options that should be available to them through HCBS waivers often exclude them. Aggression and self-injurious behaviors preclude these individuals from living safely in their communities. The IACC needs to do more to address SIBs and aggression, particularly in the adolescent and young adult population.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication challenges are probably the single biggest barrier to favorable outcomes, particularly for those with profound autism. And as Mr. Anthony Tucci suggested in his oral comments at the Jan 24, 2024 IACC open meeting, a particular method of communication, chosen by the individual because it works, should not be legislated, dictated, or negated because peer-reviewed literature doesn't endorse it. Many tragic outcomes result from not having an ability to use language, however that language is generated,
What additional research is needed to help address co-occurring conditions for autistic people?	Research on the causes of and treatment strategies for pica, self-injurious behaviors and elopement, which are common to those on the level 3 end of the spectrum is necessary to support not only the health of individuals on the spectrum but to preserve their lives.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	We need more physicians, particularly in the adult space, who have knowledge of autism best practices and awareness of ongoing research on the co-occurring conditions. As it stands now, individuals with co-occurring conditions wind up with referrals to psychiatrists who treat with multiple psychiatric medications that ultimately land the individual down the slippery slope of polypharmacy. These meds add more co-occurring conditions due to

	their interactions and known side-effects, causing further suffering for the individual.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The negative impact of COVID-19 is seen in the worsening of an already barren landscape of Direct Support Professionals willing to work with autistic people in the home and community. Post-COVID, it has become even harder to find qualified individuals to support individuals on the spectrum because higher wages are paid for easier jobs.

Name	Rosemary
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep is challenging in young people pre diagnosis because melatonin and support in general can only be accessed via a paediatrician. Waiting list are very long
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Just identifying each separate disorder can be very challenging and getting professionals onboard and understanding is very challenging as they are not up to date. Knowledge is often by 50 years out of date. School staff especially need training as they can easily break the trust needed for an AUTISTIC/ADHD child to attend
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	RSD is extremely difficult to overcome and prevent my child from accessing activities they want to attend and enjoy. It feels impossible to overcome and is preventing her from fulfilling her dreams.
What additional research is needed to help address co-occurring conditions for autistic people?	I think research in to RSD trauma and how to identify and the then treat would be amazing. Our child had experienced traumatic events both as part of being undiagnosed autistic at school and life events. Trauma and RSD (reaction sensitive) means she can experience a paralysing fear which prevents her enjoying life. Very sad to watch so my life potential and fun pass her by
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Identification, step by step effective treatment plans. And a road map for parents and professionals.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It has made our family more isolated. School is no longer an option. It was described as 'unsafe' and that in combination with previous school experiences has now made it a place my child cannot go. There was no transition, no gentle start, no explanation as to how this 'unsafe' place is now safe. There is an explosion in non attendance due to unmet needs. Also, we had lost the 'habit' of going out and meeting friends. Habit forming is so challenging with ADHD and object permanence issues means we have forgotten our friends and families, lost the habit of going out and meeting up.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school,	Working from home is a positive for people with ASD and other conditions. For ADHD we need some routine and the structure and a slight pressure to get anything done. So I think identification of conditions like ASD/ADHD etc is vital and at an age before working life starts so we can know ourselves and what works for us. Early intervention is vital to live a good life knowing yourself and what works best. We want to do well, we want to work and have families and thrive, but that is very challenging without diagnosis in a

increased use of telehealth, reduced in-person social interactions and obligations)	world that is not designed for our needs or with flexibility. To survive we have to know early on our diagnosis and put strategies in place to navigate the world.
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Name	Rosemary Brierley
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep and sensory issues -struggling in school and work places due to this
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Regular meltdowns and low mood. Aggressive outbursts and low self esteem. Many end up feeling suicidal
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Needs not being met in educational and work settings. Being seen to not be trying hard enough
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Education for all staff and additional support in settings
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Changes in routine are challenging. Trauma from the pandemic not being addressed or supported
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Huge disruption in services

Name	Rosemary M. Morgan
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I have a hard time with both too much noise, and too little noise. I find it very hard to concentrate when I can't have my noise canceling ear phones on. Many times I've run into not only jobs, and testing centers, but also other spaces where I've been asked to remove them. They are literally keeping me from hearing EVERYTHING around me that leads to over stimulation and meltdown. I also have to deal with some undiagnosed gastro issues, sometimes I need to find the nearest restroom to deal with the pain I am in. Sometimes, the toilets are set too high for me to clean myself correctly (I am also obese), and that's just embarrassing.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have some pretty bad depression and anxiety. These have made my life very insular because of my fear of how humans will react to the way I act sometimes. Some of this is due to sever bullying as a child, by other children, some is due to how I was treated while trying to hold down a job. I have a hard time finding work that I fit in well with the other staff and supervisors and such. I have been so far into the dregs of depression that I have just wanted to die, because of my feelings of inadequacy due to my being in perpetually low end jobs and losing them and not being in the same place as many of my peers. With a lot of therapy, I have reached a space where I am doing much better, but this is an issue that will NEVER go away. I will always have to take the meds, and will always have to deal with my depression, anxiety, and anger issues.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I think that there needs to be more research into how to support adults on the spectrum. The unfortunate saying is that we don't just spontaneously grow out of autism. With the correct support, I feel I'd have been in a better situation now, than what I am at. I know other people that could use more help as adults, some of them can't just jump through all the hoops that finding and funding the help they need. We need to simplify some of the processes, and also help with healthcare costs would be nice. Even with insurance it is nearly too expensive to talk to healthcare professionals. Educating employers about autism and how to handle those of us on the spectrum might be nice.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school,	I like that I can wear a mask if I find that a place is too smelly, IE too many strong perfume smells. I also like the social distancing is still kind of a thing and it makes shopping better. I have more anxiety over shopping in person now, especially if the store is hard to get out of, like my local Smith's. I am sad that telehealth is less likely going to be a thing now, I enjoy being able to have an appointment in my office rather than having to leave work and drive halfway across town to see my doctor.

increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Rowan Gibson
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I am a 27 year old autistic adult. I am nonbinary, and was assigned female at birth. Due to sexism in the medical and psychiatric fields, my myriad symptoms and presentations of autistic traits were ignored, dismissed, and undiagnosed until I advocated for myself to receive a diagnosis at age 22. There are many conditions or disorders I experience that are often comorbid or co-occurring with autism, including: chronic migraines, sensory processing issues, anxiety, brain fog, depression, dyspraxia, sleep issues, vitamin deficiencies, and potential OCD. I also have experienced gender dysphoria, although this has lessened since I was able to receive gender affirming surgeries such as a double mastectomy and a hysterectomy. In general, many of these issues are not fully studied in autistic adults, especially when it comes to the inclusion of trans and nonbinary autistics.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	More research needs to be done on these topics; specifically, how health practitioners can better support autistic people with these physical and mental health struggles.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Rowan Leshy
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My ability to work full-time, maintain relationships, and my ability to have joy in life.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Same as question 1
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Same as question 1 but also my ability to attain an education any employer gives enough of a [profanity redacted] about to pay me an actual living wage.
What additional research is needed to help address co-occurring conditions for autistic people?	How best we learn in order to foster better education. What our best skills are so that we can get jobs we're a good match for so we don't have such a high career turnover.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Everything listed in the examples. Exactly. Yup.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I'm afraid to find out. I did have ling covid at least once.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I don't need more isolation, i need more connection. Especially with compassionate employers and coworkers.

Name	Ruby Bard
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The biggest issues with autism are the lack of accomidation and the wide discrimination for the health issues not the issues themselves. I have Ehlers Danlos Syndrom, Ulcerative Coitus, Postural Tachycardia Syndrome Mast Cell Activation Syndrome and Ulcerative Coitus. I already deal with the classics "Loud noises and bright lights hurt" but when my whole body is in pain at all times and I'm always on the edge of a meltdown. Its the fact that I am not accommodated for in public or professional settings. Doctors dont believe me when I say anything, or if they do they infantilise me about my own conditions and think im being over dramatic. Its hard to explain how a sound or texture or bright light can cause actual physical pain. Its the public reaction (and beliefs) that causes me the most harm. I don't feel supported in my disabilities. Nor do i feel like I have assess to the accommodation I need to have a healthy workplace. Ive lost jobs because they don't want to accommodate my needs.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I would say ADHD, Anxiety and Depression. Tho it should be taken into account the high levels of PTSD in Autistic individuals due to a multitude of reasons but one stands forward for me, abuse. The hardest part is the Depression and Anxiety that comes with living in a world that is not friendly to you. A world where people are confusing and often cruel to you for not being able to understand unless they are clear. You then punish yourself and get frustrated because "Why cant you figure it out on your own" and hopefully some day get to the point where you can accept your different way of processing but its hard to get there and oftentimes we just cant. I get hit with that two fold due to the ADHD making it more complicated when you get hit with both Autistic and ADHD mental needs. PTSD is such a common condition among those I know with Autism because we are often abused in the name of teaching us how to mask normality. Neglect is also a huge issue particularly in late diagnosed autistics because caregivers refused to adapt there parenting to accommodate our nuro-divergence. Im also terrified of the police finding me in a verbal shutdown/melt down because they have been known to get violent and even kill Autistic people in those states. I have a fight response when restrained. For that reason and other health issues I never go out alone.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Being AuADHD I think the biggest thing I get hit with is that people don't understand when you say "I need clear communication to know what you want of me. " you fully mean it and do need it. My Dyslexia, Dysgraphia, Auditory Processing Issues all can be accommodated in physical ways but people refuse to do simple things like explain what they want of you. They assume you understand them and there implications and the complex public rulse in place but you cant unless you are told what they are. The whole world seems like a game with a rule book everyone else can read but you cant. And If you could you would happly follow it but like the english language, even when you know a rule it can be broken under specific circumstances you may not know. We are flying blind and nobody wants to accommodate us with guidelines. and when we break a rule we didn't know existed we find ourselves fired from the job, or in trouble with doctors or the law, or with troubled relationships.
What additional research is needed to help address co-occurring conditions for autistic people?	I think that wide spectrum demographic reasurch including these things would be super important to guide what reasruche would most benefit the auttistic community including stuff like: Age Sex at Birth Current Sex Hormones Gender Other Conditions (Physical, Psychological, and Social)

	<p>Work Status Work History Location Previous locations lived (To better understand the nurture parts of autism) Number of Close friends Family History of health issues and autism Dates of Diagnosis for health issues (Later Diagnosis comes with worse symptoms and worse symptom management) Access to Snap Access to Disability Benefits Access to Public Education and Jobs training Access to Mental health care and resources Access to Medical Health Care and Resources Social Network Support Discrimination history (Have you felt discriminated by X/Y/Z in your interactions with them) Abuse History And having free fill boxes for Autistic people to be able to better explain themselves and there answers because we tend to like to be clear about why we chose what options we chose.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>The listed suggestions all sound amazing, the main one i think is important is access to Supplemental Security Income, Snap, and Medicare due to being disabled. 38% of Autistic people are unemployed and more than half report job instability according to the research paper "Predictors of employment status among adults with Autism Spectrum Disorder". Its incredibly difficult to enforce anti discrimination legislature so the better option is to make it easier for Autistic individuals to assess support outside of jobs that will be unstable no matter how hard we work to make it Illegal to discriminate (Millions of Cases of Workplace discrimination due to disability go unreported, its almost impossible to prove). Widening Disability wealth caps for Social Security Support for married and unmarried disabled people so we are able to invest in our futures and purchase much needed gear or additional healthcare (therapy both physical and mental) would not only help us participate in society. It would help us gain the stability to do more than just survive hanging on by a thread. We could much better become productive members of society and eventually gain the infrastructure to get off of government assistance.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>My immune system has only gotten worse since the pandemic. I normally would get sick once or twice a year (maybe an additional cold here or there). After getting COVID before we knew what it was, my body started falling apart. The MCAS and Ulcerative Colitis I probably had very minor before put me in the hospital. Ive been to the ER for one issue or another at least twice if not three times a year since the pandemic. My asthma has also been a wreck and Ill often get bad chest colds that need Prednisone to go away (Instead of one a year Its been three this year). I now get the Pneumonia Shot along with the Covid and Flue boosters every year because if I get pneumonia im in the hospital. Covid took all my problems and made them twice as troublesome.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Ive found that social anxiety has increased and loneliness, but honestly the original pandemic was really scary; I was really glad I didnt have to go out and interact. Im aloud to be more rude and go home because im sick or overwhelmed I can just say "im not feeling well" and go home. A quick covid test will tell me how dangerous a cold is and I can move on from there. Getting back out in the world is the hardest part because people get more pushy, or maybe I just wasn't used to it like I had been. I was severely burnt out from masking at the start of the pandemic and went through a major depressive episode. It took a very good ESA Rat, Trained to alert to psychiatric episodes, to get me back to a new normal. Im still very dysfunctional in public and can barely step foot into a grossery store without cringing but my Service Dog helps loads and grounds me and lets me stimm on her when i get overwhelmed. I already had a special interest in disaster</p>

	preparedness and Medical emergency care and triage so I quite enjoyed being able to use my knowledge.
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Name	Ruth Hevelone, PDA North America
Demographic	Autistic individual; Family member of an autistic individual; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	nervous system challenges due to pathological demand avoidance (PDA) create severe functioning issues for anyone with this co-occurring issue. It creates severe eating, toileting, sensory & sleep issues which make it challenging for PDA people to function in society.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	the most significant co-occurring mental health conditions are the nervous system disability that happens with autistic people that fit the PDA profile. They are severely riddled with anxiety, depression, aggression, and sometimes self-harm.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	There is no research done in the USA to support people with PDA, the profile of autism that so many people have, so thousands of people are left with no supports. The UK found that 70% of PDA children cannot access school due to their PDA. The UK has been researching PDA for 30+ years but without any research in the USA, supports are very hard to acquire for our children (and selves).
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Awareness of PDA is KEY to set up the right supports for PDA people. Education in schools and therapies as to how to support PDA people is absolutely crucial in their success.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Ruth Horowitz, Author of Living With Autism Undiagnosed
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Insomnia, and severe pain create increased risk of autistic burnout and suicidality. Loss of executive function. Physical challenges in general impede coping skills and increase risk of autistic burnout.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I developed CPTSD in my forties. My anxiety levels skyrocketed, I started having autistic burnouts, got misdiagnosed with major depressive disorder and was forced to take ssri anti depressants for six weeks while hospitalized for an attempted suicide that was driven by autistic burnout not major depressive disorder. Misdiagnosis led to mistreatment. I started vomiting blood and my metabolism has never recovered. Lack of regulation over who can work with what conditions in the mental health field has led to mistreatment. Improper diagnosis has let to gross mistreatment. Since developing CPTSD my overwhelm meltdown shutdown cycle has become more pronounced, when I start to lose Executive function it becomes worse as my executive function gets worse.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication difficulties because my brain processes information differently, and miscommunication because I don't understand nuanced speech, and others interpret my speech as nuanced when it isn't. Now that I am finally diagnosed I hope to be able to navigate things better.
What additional research is needed to help address co-occurring conditions for autistic people?	When is it depression and when is it shut down/autistic burnout. And effects of menopause on autistic women, and autistic burnout.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Neurofeedback treatment through insurance. Better awareness of autistic needs in mental health settings, and execution. Home help for autistics who live alone and are going through autistic burnout. My house was an absolute disaster for several years. As I am recovering it's getting better but I couldn't get any help as I went through it. I slept on the same sheets for almost a year. My floors weren't cleaned for several years. I had to eat frozen dinners because I lost my ability to cook even though I started learning to cook at age six. Wellness check ins for autistics who live alone. When we are in crisis we are unable to ask for help. Doctors need to be aware that we may be reactive to things at lower doses. And that we have a different pain scale.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	Losing the social life I had developed over the last 15 years was devastating. It was a level of change I couldn't handle. If I hadn't been making enough money to afford neurofeedback sessions I would have become suicidal. Now that I'm on federal disability I can't afford neurofeedback to help me recover from this last autistic burnout that is NY far worse than anything I have experienced before

in-person social interactions and obligations)	
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Name	RuthAnn Winschel
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gastritis makes it painful to eat at times and can make me feel full after I've only eaten a little bit. When I was in high school I was misdiagnosed with anorexia. It was just painful to eat so I often didn't eat for many days because it felt better to do that. I also wouldn't always eat because of my depression. It took many years for me to get a GI doctor because my doctors always said the pain was just psychological. About a week before my first appointment with a GI doctor I was in the ER because I had lost 15 pounds in 2 weeks because my esophagus was extremely swollen so I was even choking on cheerios so I could only eat liquid like stuff. Since I'm autistic my sensory system does work differently but I don't feel like that is a bad thing. I am sensitive to loud noises, too many smells, certain textures but I mostly able to deal with the things. Sometimes brushing my teeth can be difficult thing to tolerate. But in middle school I started using an electric brush and that helps me tolerate it much more. Also sometimes my GI stuff causes me to vomit a lot and have reflux. Back in October I had vomited constantly for 3 days and lost 3 pounds and then the first day I wasn't vomiting I had a 45 minute meltdown (with hitting my head, rocking, banging my head on the wall and screaming) which I think happened because my GI system was messed up. I also have Klippel Feil syndrome which causes chronic neck pain.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I've been to a psychiatric emergency room which is called CPEP multiple times. I was told I look too happy to be there. But I remember feeling extremely frustrated that they would say something like that since I was taken by police so obviously I wasn't ok. So the staff need to understand that some autistic people may not be aware of their facial expressions I remember when I was first placed in the inpatient psychiatric unit I was really freaking out and slamming the doors of the unit and crying and all the nurses did was threaten me with a shot which would have obviously been something sedating or putting me in a room I wouldn't like. That night no one ever told me anything about the unit or the schedule. I've never been officially diagnosed with PTSD but I do believe I do have trauma from being hospitalized because for a few years after it happened I would have severe panic attacks in the same days each year and I'm terrified of ending up back at that hospital which is the only one police take people to in my area so it prevents me from being fully honest at time about how I'm doing. The hospital was St. Joes hospital in Syracuse NY. I do get overly attached to people who make me feel genuinely cared about and have abandonment problems so it was hard because I was very attached to a nurse.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The challenges I experience with being autistic are often related to external environments which cause sensory overload or if my GI system is messed up then I may have a large meltdown. Also growing up in a world that does not value autistic people can be challenging and lead to internalized ableism. Also at times it can be frustrating that I have slow processing because that impacts so many things in everyday life.
What additional research is needed to help address co-occurring conditions for autistic people?	More research on autistic adults experiences of meltdowns and how to best support them and I'm saying this because I'm a high masking adult so many people would never know I am autistic but at times I can have extreme meltdowns that I have no control over. Research on education of psychiatric/ mental health professional education/ knowledge of autism. Self acceptance/ internalized ableism. Research on how often autistic people are restrained when they can't control their meltdowns like if people

	<p>are responding in the wrong way and causing more trauma instead of assisting them with their sensory needs.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>For the suicide hotline 988 it should have a specific part to talk to a person educated about autism in an autism affirming and neurodiversity affirming way. Just like there are specific hotlines for veterans, LGBTQIA+ and some other groups there needs to be something for autistic people. It needs to be something that is not controlled by state disability services because in NYS OPWDD does have some crisis counselors educated on autism but only autistic people who qualify for OPWDD can use the service. For NYS OPWDD needs to change their rules about who can qualify for services. I was denied any support services because my adaptive functioning score was 4 points too high. It is really hard not getting the services I need with independent living. I was late diagnosed at age 21 and I think if I was diagnosed younger I may have been able to get help because one of my friends got services at age 2 and we are very similar. Also all mental health workers like therapists, nurses, care managers need to be educated about autism in a neurodiversity affirming way. Even doctors need to be educated about autism. I'm always nervous about possibly being in the ER and having a meltdown and being physically and/or chemically restrained because that would cause more trauma for me. Psychiatric hospital workers need to be educated about how the environment of being locked up in a psych unit is not sensory friendly and can be extremely stressful and traumatic.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>Covid did make things difficult in some ways. At the beginning of Covid it was extremely hard for me to wear masks especially disposable ones. The sensory feeling of the masks would cause extreme meltdowns for me. I was able to tolerate the fabric masks better but of course eventually learned that the fabric masks are not effective. With my mental health Covid made it a little challenging because I have been living with my parents who are emotionally abusive and Covid made it so I had to spend more time at home. Especially in the beginning when there was strict rules about times to be out in public and not being allowed to be out between 9pm-6am unless people were working. I never really had too much anxiety about covid and had accepted the possibility of dying from Covid. All the changes and uncertainty was a little difficult.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>When covid first happened my college classes became virtual for the rest of the semester which I really enjoyed and it helped with my energy level since I didn't experience as much sensory overload. I have never had remote work unfortunately. My mental health therapy did become virtual which I was really nervous and hesitant about at first because of possibly not having a private space to do it. But now my therapist has in person or virtual option and I have chosen to continue virtual because with my chronic neck pain from my rare disease it is more accessible. I have done physical therapy virtually at times which was more difficult.</p>

Name	Ryan Bradley
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression Anxiety, Attention-deficit Disorder suicidal (fleeting moments with myself although not in months)
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Learning Disabilities
What additional research is needed to help address co-occurring conditions for autistic people?	Isolated one self from a party unless interest me Sensitivity to Certain levels of sounds Feel relax when entering a dark room after sound periods of time in the artificial light What senior citizens with autistic need to survive and be independent Genetic screening but only forward Type 2/3 and not Type 1.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	All the examples Job Training and placement Social Gatherings Money
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Depression Suicide Loneliness
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increased remote work Increased Telehealth reduced in-person obligations Increase in depression, self-afflicted harm, suicide, dietary problems, loneliness

Name	Ryan Erdozain
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I walk, talk, and write differently than my neurotypical counterparts due to my co-occurring conditions. My co-occurring conditions also make it hard to get around because I have a delayed reaction time and I choose not to drive for the safety of myself and others on the road. My disabilities affect many other parts of my body such as my eyes. They make it hard to see fine print when reading things from across a small space and from farther distances.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Gullibility is a big issue when it comes to my challenges. I have been scammed on several occasions and as an autistic adult without any support from other adults, I have no way of knowing when I am being taken advantage of. My anxiety and depression also work in tandem. After I experience any slightly stressful situation my body and mind will begin to shut down. I have less energy than others because of my mind working overtime on every single detail of my life. I've also been told by my therapist that I have ring-of-fire ADHD, I haven't learned much about it yet but I get bursts of energy sometimes where I feel like I can do anything such as cleaning my room in the middle of the night or organizing my bookshelf for the millionth time when in actuality I don't have the energy to be doing any of that.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Compared to my peers I talk way less and I am unable to properly express my thoughts and feelings on certain things. They always come to me and when I am unable to give them a proper response, I just give them the answer I think they are looking for. I have done this in job interviews and in other situations which can make forming a stable relationship difficult. The tangled knot of disorders I present with can make many other things challenging for me such as dealing with math and other language systems especially times and dates like my work calendar. I struggle with change as well which makes it extremely hard when my normal schedule is changed, and I am unable to compute the change properly so my mind tricks me into thinking the schedule hasn't changed.
What additional research is needed to help address co-occurring conditions for autistic people?	It makes me angry that ASD and some other common disorders are mostly advertised like they only affect children and by organizations like autism speaks who make people like my dad think autism is something that can be or needs to be cured and that it isn't a lifelong disability. I also find it strange how we are in the 21st century and yet BIPOC individuals, woman and young girls, and individuals in other small communities are treated differently even though they aren't any less likely to have autism as the rest of the population. I think the standards for diagnosis need to be reevaluated to fit a wider demographic including adults who are mostly finding their way into the neurodivergent community through social media platforms like TikTok and individuals in the minority who are often told that they don't fit the outdated criteria for autism just because they aren't the average white autistic child.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	School services could do more to include neurodivergent kids in activities with neurotypical kids. When I went to school, I felt isolated after having to stay after school for math class because I was much slower than other kids and I could never catch up. I would have to cheat by taking tests with a counselor where she would go through every step with me. I would also be invited to socialize with the neurodivergent kids instead of being able to communicate in the cliques people separated themselves into. I was an

	outsider who tried to join as many clubs as possible to fit in but could never really find my place due to the inadequacies of my social life. I also think that neurodivergent individuals should have an easier way of accessing funds from the government to navigate daily life.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I had a really hard time with Zoom school. Many panic attacks happened on camera, and it was very draining. The pressure to succeed when I didn't understand the rules of the game was exhausting and trying to wrap my head around it all was mental agony, to say the least. The rapid change in my schedule was hard but after a couple of years, I started to get used to things. The social effects are still damaging as I still only have contact with a handful of people and am unable to reliably travel to hang out or meet new people on a whim.

Name	S
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	EDS, gastroparesis, POTS, sensory processing disorder,
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	PDA, ADHD, PMDD,
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	PDA needs to be separated from the useless diagnosis of ODD
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Separation from behaviorist techniques
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Yes, many autistic individuals are prone to developing pots after covid.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Remote work is great.

Name	S.
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Finding proper help
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Finding proper help. Some people Don't know how to get proper help. Some people can't get access to proper help
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Most significant challenges is getting proper help.
What additional research is needed to help address co-occurring conditions for autistic people?	There needs to be more research on gender dysphoria and gender incongruence in autistic people. There needs to be more studies on trans people and non-binary people on the autism spectrum in particular. Since being both autistic and nonbinary is stigmatized, more research on nonbinary brain and autism may help lessen stigma against nonbinary and trans people.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage for sure. There needs to be better accessibility of both services and information.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It has had horrible impact, especially mentally. Many autistic people are already isolated, the COVID 19 pandemic made it worse.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The COVID-19 pandemic had has a negative impact on socialization. As an autistic person, it is even more hard for me to socialize.

Name	Sabrina Par
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep, POTS (postural orthostatic tachycardia syndrome), hEDS (hypermobile Ehlers Danlos) and dysregulated nervous system
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	depression, anxiety, executive functioning and dysregulated nervous systems
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	executive functioning
What additional research is needed to help address co-occurring conditions for autistic people?	research regarding PDA (pathological demand avoidance) and EDS (Ehlers Danlos)
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Having a team of people who support the autistic individual as a whole - not segmented parts that each specialist addresses without looking at the whole individual. Access to services that are not dependent on IQ/cognitive functioning as the uneven development of skills can be as debilitating as an intellectual delay. Supports for independent living skills. Supports for employment/volunteer.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Covid has drastically affected my son's depression and anxiety level in a negative way.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Positive: more online/phone options for doctors's appointments. Negative: fear of leaving the house and getting sick

Name	Sacha
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Pathological demand avoidance and constant nervous system dysregulation
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	PDA needs to be more recognized within the healthcare and educational community and better understood so children and adults alike can be properly supported rather than punitively punished for what is effectively a nervous system disorder.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Neurodivergant affirming practices and the elimination of ABA and other abusive methods to avoid traumatizing patients.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It is very hard to access support, respite care, social interactions, and therapies without risking your long term health because covid has been downplayed and not taken seriously for years.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The only good thing from covid is more availability of telemed and other virtual events which help make them accessible for autistic people.

Name	Sam Stern, either individual person or democrat-center
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	getting people, even medical professionals, to believe you long enough to let you speak your piece.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	a mix of a few things : - since I cannot drive, arranging and funding transportation is often challenge especially if I need to move to maintain a relationship and end up too far from a city. - I often have problems with requesting accommodations some thing like "I am autistic, please turn off the flashing light over there" vs "I cant read that light up sign, may I a menu" have vastly different outcomes. - just determining which symptom vs diagnosis to quote on some single choice form or conversation really is madding.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	- finding work around for things like the first time seeing some over complex restaurant gadget can cause a scene if I express myself wrong or poorly. - plotting courses via public or private transportation is a huge night mare - locating medical help that does not interrupt my work days all the time - funding transportation to accessible locations
What additional research is needed to help address co-occurring conditions for autistic people?	it would be great to form a list of guide for how to support your \$relationship who has multiple difficulties. something like "my person will not go into certain stores with me " or "my friend gets agitated/anxious/confused when they perform this action" etc.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	- update certain programs like transportation services, voting services, etc to include diagnosis like "multiple sub clinical presentations that prevent driving / entering crowded spaces" etc. - help public locations provide accessible menus/maps for folks with navigational needs and/or sensory needs - I would love to see stickers or notes on the outside of public spaces that rate things like visual complexity, floor patterns, flashing lights, mirror that catch glints etc. like a warning label on hmart! - craft services that allow me to "borrow " a guide from someone where to help me shop in otherwise inacceeeeible spaces . these service exist but are often very rigid and set to certain times, need weeks of planning etc. - expand hours that services are available so I do not have to plan to be available at certain (often early) times just to get a ride someplace
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	- By increasing the discussion of mental health it has made discussion of accessible locations and services a bit more normalize. - by giving folks a taste of what it feels like to suddenly have to enter crowded spaces after being in less busy places covid has helped give a common experience to describing the problem I face with busy places. - oddly folks now have a strange time table in their heads for adapting to changes that I can not meet which makes for negative impacts.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services,	- stores do not stay open late anymore seriously restricting access to wall mart, home depot and ote4hr stores that I used to be able to goto late at night to avoid crowds. - COVID helped normalize work from home, making it teaser to discuss those alternative experiences and seek them out - the anti vax movement has added to the language bank of words that indicate that I

increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	should not ask for help from or should seek out help from specific folks depending on how they react to masks, hand washing etc.
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Name	Samantha
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	These conditions cause us to disconnect from ourselves, others and the environment. They make normal daily living more of a challenge and necessitate more support and rest.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	These conditions serve to further isolate us from society and even our own families and support systems. Solutions to mental health problems are nearly impossible to find. We're left to spend our energy tending to our troublesome feelings or becoming overwhelmed by them because we haven't.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The hardest thing is finding others to relate to or be helped by. These co-occurring conditions get in the way of a true understanding of autism.
What additional research is needed to help address co-occurring conditions for autistic people?	I wonder if more research might be needed looking at undiagnosed autism. Autistic people who have learned to fit in could be a vital resource as well as a demographic in need of more support and understanding. How many of those suffering with mental illness are also autistic and would be served by better understanding the roots of their problems?
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Perhaps if more people who identify as autistic were in positions to provide these services, they would be more compassionate and effective. Our bodies, like our minds, are not operating in a "typical" fashion. As such, the typical recommendations and assumptions proven by studies on "normal" people are not always relevant or fully informed.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	In some ways, the societal changes after the pandemic have increased resources and opportunities available. However, the increased isolation may only serve to exacerbate problems that can be worked on with diligent effort and proper support.

Name	Samantha
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	EDS, POTs, sensory issues, gastrointestinal issues Tongue tie - needing therapy pre/post surgery, benefits of surgery as adult Dyspraxia-coordination fine motor skills issues.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	PDA - internalized expression especially. Chronic ervous system dysregulation Overstimulation / understimulation Suicial ideation
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Dyspraxia, directional dyslexia Overstimulation Bottom-up processing needs with learning Rejection sensitivity dysphoria
What additional research is needed to help address co-occurring conditions for autistic people?	Internalized PDA General/subclinical PDA Dyspraxia awareness Tongue tie surgery benefits for adults, therapy benefits for pre and post-op Autism not as a disability but as a neurotype, actual prevalence rates.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Okay to take more than 20 minutes per appointment. Clear charges for services.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increased remote work Increased understanding that matching external expectations for socializing can be unhealthy for some.

Name	Samantha
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	For our case, severe ear infections landed us in the hospital many times. He had four sets of tubes. Many times due to him being non-verbal he could not even tell me he was sick until his fever was high. He also has many sensory issues which his preschool did not address and when his public school wanted to instill a uniform he was not able to wear it.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	He has extreme OCD, which many educators and therapist do not understand due to his age. They would lose their patience with him and not let him get the time he needed to complete tasks. They want to jump to medication instead of therapy and increase his communication.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My son did not start to talk until he was almost 5 years old. He needed support with communication and using a AAC device. He also has apraxia, many speech therapist were not trained in supporting him with his device and apraxia. I struggled to find him a good therapist who could support him and make progress.
What additional research is needed to help address co-occurring conditions for autistic people?	Research in other behavior strategies than ABA like floortime and sensory based practices. Also, providing supports at a younger age so children have the early intervention that research suggest.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	access to transition and work services once they leave school as many students cannot work or go to school. Additional supports and training for staff to support inclusion in schools. Insurance coverage for things other than ABA. support for families who are caring for individuals like respite
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	absolutely, more providers have gone to practicing on zoom which is not always a good thing. So many children missed school time and need services, so the waitlist are long and families are waiting up to two years. More therapists and teachers are leaving, which means students are not getting quality education or the services they need. Not enough staff trained to provide mental health for students with autism, they may be hiring...but no one applying
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	cannot find providers, long wait list, staff leaving the profession due to long hours and lack of funds those who could do therapy on zoom have been able to get services without leaving their home which is nice for some.

Name	Samuel Pehrson
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Addiction to multiple substances. Sleep disturbances due to constant overstimulation. Low energy levels in the day due to the resulting insomnia. Frequent headaches. Frequent anxiety attacks.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Mixed Anxiety and Depressive Disorder, Attention Deficit Hyperactivity Disorder, Insomnia. Work is almost impossible without medications. Not being able to focus while severely depressed is often a debilitating mix of comorbidity.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Not understanding cues or having any kind of social skills in general made me feel very isolated as a child. Though I was quite intelligent, even then. Today, I still struggle a bit in social situations (I tend to avoid them due to high levels of social anxiety) but find my most significant challenges would be emotional dysregulation. Followed second only to my severe mental health challenges.
What additional research is needed to help address co-occurring conditions for autistic people?	Research into psychedelic therapy. More specifically, psilocybin. Though any psychotropic which acts on the serotonin 2A receptors would be greatly beneficial research, not only for those with autism but depression as well.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Better access to proper medications such as cannabis, amphetamines (the adderall shortage is hurting the autistic/ADHD community greatly), norepinephrine reuptake inhibitors, etc. These medications also need to be significantly cheaper. Autism must be understood to be the disability that it is, and the policies of government agencies must begin to reflect and address the needs of those with it.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Worsened depression and insomnia.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Disruption in access to medications has been a serious negative impact. The post-pandemic economic greed of massive corporations has crippled the mental health and positive outlook of most autistic individuals. Medications are too scarce and far too expensive, often I have to choose between my meds and food for the next few days.

Name	Sandra
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gastrointestinal issues, Sleep disturbance, Sensory issues with just the sleep disturbance along not including any other issues it is hard to make plans and abide by them.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, ADHD, Aggressive also behavioral. Its like walking on a land mine waiting for any moment for one to go off..
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	the developmental and intellectual along with the communication disabilities makes it not only hard to them to tell us what is going on but us knowing what is going on to where we have to do a process of limitation.
What additional research is needed to help address co-occurring conditions for autistic people?	Needs more research defiantly but also more resources for this population
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	All across the board from medical to dental to behavioral, this population gets gas lit and or discriminated against which makes things harder on families and caregivers.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Didn't really matter before covid , we live a secluded life due to the disabilities.

Name	Sandra Doyon
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Not always being able to determine that I'm having a bad day because my stomach is upset. Or not being able to express it.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Being misunderstood in the workplace. There needs to be more information out there about managing an autistic employee
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Making autistic adults eligible for Medicaid automatically so we can access services would be great
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I liked the isolation aspect but did not like wearing a mask so much.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	There are even fewer options available for diagnosis which is very limiting

Name	Sandy
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gastrointestinal issues. Hypermobility issues. Sleep issues
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Pathological Demand Avoidance Anxiety
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Pathological Demand Avoidance
What additional research is needed to help address co-occurring conditions for autistic people?	Into Pathological demand avoidance
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Sandy Wormald
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I find that for those of us who are high masking we have no extra energy to mask. This can add more stress as those who are close to us try to make us mask back up instead of helping when we need it most.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I don't know as I've always had adhd and autism and often depression. I think it makes me feel as if I'm torn in many ways unable to do a lot of what I want or what is expected of me.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I found that I am very intelligent.. I got things much quicker than my classmates, and easily learned things well above my grade. Unfortunately, because of my ADHD side, it was never noticed. I was so bored once I got the lesson, that I would end up being disruptive. If my intelligence had been noticed, it would've been best for me to learn at my own pace in a quiet, but stimulating atmosphere with a bit of freedom. Possibly I could have been contributing more to our world than I am now if I'd had the opportunities instead of people just trying to make me be and act like everyone else.
What additional research is needed to help address co-occurring conditions for autistic people?	I think when you're dealing with autistic people because there's such a range, you need to have someone with empathy and intuition dealing with and researching us. Otherwise they're always studying us to get the results they want or to prove judgements they have about us rather than learning to help us and understand us as we are. Everything is always done so we act and look more like "normal" people but we each have gifts and sometime we are so gifted that if we were properly understood and cared for we could be a benefit to the world and give what no one else can. If you make us mask all the time it takes so much energy that we don't have the time and energy to express our giftings. Besides that we still fail and the mask inevitably falls off often because we're not build to wear one. It wastes time and effort of all those involved.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I wish I would have known earlier. Not so I could be medicated or pitied, but so that people would have encouraged and helped me in my giftings instead of always shaming me and getting mad at me when I couldn't be "normal". I think there needs to be more research without conformation. I think there needs to be help with understanding patience and compassion. If we were understood and cared for we could find out what we need. The current system just wants us eliminated and conformed. Many breakthroughs we need globally are just beyond the compassion and understanding of "normal" people for those of us who are gifted.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	A lot of times because we're more sensitive to everything, food is a huge thing and connected to our ability to handle illness like Covid. Refined sugars, highly processed foods, foods with chemicals, meat and dairy usually overwhelm our bodies as is. If our bodies are already taxed by not eating properly for us we are more likely to be sicker longer and more intensely. Same thing if we've been taxed also with the stress of having to wear a mask

	<p>all the time. It runs our bodies down so we're more susceptible to illness. I think what's really important for helping us be able to go through times of illness, is learning how to cope with stress, eating a clean diet, and compassion and understanding from those who are dealing with the autistic person.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Personally I've found it better for me. It stopped the world and I was able to find out what personally worked for me in regards to living life. Instead of trying and failing to do things as others told me I should i just did what I enjoyed and I found new ways to make money and use my giftings. Instead of fighting my audhd I now have learned how I like to do things and I enjoy everything I do. This makes it easier to deal with everyone else and my quality of life has improved. In some ways I go at a slower pace and I now have grace in that. I also have many giftings and now I'm able to express them instead of being forced to focus on only one or a few and being frustrated and bored all the time. I deal better with things being alone so Covid was good for that. It's not truly that I like being alone, it just wastes a lot of time and energy when people enter your space but consistently try to force you to mask with policing and judgements. It's easier to be alone and just get done what I need to without the control and judgements because I don't do things like others or care for what others care for.</p>

Name	Sara
Demographic	Autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory differences, ADHD (which I believe is on the same spectrum, not a co-occurring disorder), and differences in anesthesia! Pain meds and surgery meds work SO DIFFERENTLY! It is quite painful and frightening.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety and ADHD. The anxiety is adaptive, from masking and functioning in a neurotypical-centric society.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	More info on neurological aspects. Personally, none of my neurons are where they should be, and anesthesia doesn't work right on me. I'm sure those pieces are interconnected with the over and under perception of sensory stuff, and hyper-focus parts, which then impacts anxiety and mental health.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	A variety of ways to seek help, some of them not involving direct interaction. More training in medical professionals about what Autism is and the many ways it can present. Also, much more neurodivergent-affirming language.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It seems anxiety may be higher now. Remote work and social suited me very well, and I am having a hard time re-building my tolerance for going out.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Sara
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I didn't know I was autistic until I was 48. The same year I saw a rheumatologist because I thought I had Lyme disease. I was tested for all auto-immune disorders, and tested off the chart positive for Celiac disease. I also have hEDS, and have had a multitude of physical injuries because of it (ankle rolling, unexplained bruising/cuts, thin, stretchy skin, LOTS of dental issues).
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have ADHD, PTSD, C-PTSD. All of these conditions make daily life quite difficult. Sometimes my ADHD makes me crave outside stimuli, and other days my Autism makes me not want to leave my house. The two conditions fight with one another, regularly.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I was a C student. I talked a lot. I was labeled as "disruptive", but didn't understand why, because I wasn't malicious in my intent. I never felt like I belonged in any academic setting, even though I am aware of my intellect.
What additional research is needed to help address co-occurring conditions for autistic people?	Attention needs to be paid to women who went undiagnosed, or who were misdiagnosed with things like Bipolar, Borderline Personality Disorder, etc. Many of us are just Autistic, and could really use resources to prevent meltdowns, burnouts, and further traumatic experiences.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I paid \$700 to be assessed by a "medical professional", who said to me "You just have C-PTSD, which can mirror the markers for Autism." It would have been helpful for her to realize that I have C-PTSD because I am Autistic, and no one takes it seriously, even though I have spent the last 14 months researching Autism in adult women, masking, etc. Lived experience is the best assessment, and the testing models are STILL geared toward young boys. Take into account how women/girls are socialized, and realize that we are pros at masking. It's a way of self-defense. The whole testing model needs to change. Acknowledge the racism present in our medical industry.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Covid has shown us just how self-serving many of us are- controversies around masking, judging people who wish to remain remote workers, and a general lack of empathy, something Autistic people have an abundance of.

Name	Sara Brown, Prevent Blindness
Demographic	Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Prevent Blindness is the nation’s leading nonprofit, voluntary organization committed to protecting and expanding access to sight-saving care for patients of all ages who live with a multitude of diseases, conditions, and circumstances that may affect their eye health or impair vision. Children with neurodevelopmental disabilities (NDD), including those with autism spectrum disorders (ASD), are at increased risk for vision disorders. Studies show that children with ASD have a number of visual system processing disorders and are at greater risk (up to 5 times) for refractive errors, strabismus, and other eye diseases such as optic atrophy and retinal dystrophies. Vision care is one of greatest unmet needs for these children. According to the 2022 National Survey of Children’s Health, only 41.9% of children with special needs ever (if under age 5) or in the past 2 years (ages 6-17) had an eye exam. Barriers to eyecare for children with ASD include: ☐ Poor fixation and challenges with wearing eyeglasses for children ☐ Lack of knowledge, skills, and equipment for examining children with ASD ☐ Family lack of awareness of the importance of vision care ☐ Lack of uniformity in requirements and guidance for eyecare for children with ASD ☐ Lack of education for special educators and healthcare providers around the need for a comprehensive eye examination for children with ASD
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Recommendations for improvements of vision and eye health services and systems for children with ASD include: ☐ Parent/Guardian education around the risk for disorders among children with ASD and the need for eye examinations. ☐ Support and case management to help families find available eye care, make appointments, and prepare children for the examination. ☐ Professional education for special educators, healthcare providers, and others around the need for a comprehensive eye examination for children with ASD, how to make effective referrals, and how to support children with ASD in wearing glasses. ☐ Integrating vision and eye health into home visiting programs to help prepare families as they navigate the eye care referral path (this should also be part of professional education). ☐ Performance metrics for MCHB grant programs to ensure that children with ASD receive eye examinations at the frequency determined by the eyecare professional. ☐ Support for training of eyecare professionals on how to perform eye examinations on children with ASD. ☐ System

	<p>changes that support flexibility in completing the eye examination over multiple visits, flexibility in scheduling, increased time for appointments, and providing at least two pairs of glasses to accommodate frequent eyeglass breakage with this population. This includes requiring Medicaid and other insurance companies to allow the flexibility recommended here.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	

Name	Sara CdeBaca
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep issues.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety and adhd
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Intellectual disabilities
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Education- special education for kids with multiple disabilities is a joke. It's babysitting. Teachers are not equipped or paid enough to understand how such individuals learn. So they just babysit them.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Sara Trovinger
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory and motor challenges lead to increased anxiety with our son. This makes it hard for him to leave the house and participate in normal activities that he should otherwise be able to be a part of. This increases the isolation of our family and just further compounds the problem. It is seeming impossible to break out.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression has hit our family hard this year with our son telling us he wants to "go to heaven". Though he is 13 and can talk and walk, we can't leave him by himself sometimes. He has so much anxiety about everything outside of a couple activities at home (like playing video games) that he won't engage in anything he hasn't done before and will ask us repeated questions about things he has done in the past.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Anxiety
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	We are lucky that I make enough money for my husband to be a stay at home dad, but I have no idea what we would do if that weren't the case. We live in a rural area where we don't have access to any sort of school option for children with autism other than a public school, but my son was getting bullied so bad that we had to pull him out. Support for families to allow one parent to be a stay at home care giver for his child is ESSENTIAL.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Sarah
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I am a behavior analyst who has focused primarily on individuals with autism for almost 30 years. In my experience, there seems to be a sub-set of individuals with ASD who also experience severe OCD. These obsessions go beyond just ritualistic routines, narrow interests, and a need for sameness. These obsessions tend to be extreme and often destructive in nature, and when interrupted, can lead to severe aggressive behavior. Some examples include obsessions with ripping, breaking items, or knocking things down (often "big ticket" items such as toilets, televisions, etc.), arranging or placing things in odd locations, then becoming extremely aggressive if the items are moved, and obsessions with watching people bleed or picking other's scabs. These behaviors require intensive intervention and highly skilled professionals, typically beyond what traditional ABA programs, schools, and other interventionists are able to provide.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Sarah
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I believe a large proportion of autistic individuals are also experiencing hypermobility disorders which cause a constellation of other physical symptoms such as joint pain, allergies, GERD, insomnia.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety is the biggest challenge, followed closely by depression. PTSD is present in many ASD individuals as a result of chronic, lifelong trauma.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Some of the learning disabilities include dyscalculia and dyslexia. The pace of learning is challenging. There is little room for alternative learning styles. Sensory overwhelm does not help. We're so focused on learning social skills, we miss out on the learning happening for our neurotypical peers.
What additional research is needed to help address co-occurring conditions for autistic people?	I truly believe that connective tissue disorders are going to be the big break. I think it's the source of a lot of debilitating problems. Heds is associated with the MTHFR gene. Even one copy of a "broken" variant can impact how one can utilize B vitamins. Of which are fundamentally required for so many body systems to work correctly. Some 40% of the population has at least one bad copy. And there's already a cheap, readily available OTC supplement that bypasses the deficit cause by the MTHFR genes. The impact that could have is astronomical. Similar to how we don't even think about our fortified cereals at this point.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	We need more access to services in general. We need to catch it earlier so we have the information nessasary to support the early and higher education required to live an independent life. We need doctors to take our concerns seriously. Caregivers need more respite and education. We need more community outreach. The problem isnt autism. It's living in a system that isn't built for us. A system that turns into a meat grinder for anyone who doesn't fit a specific standard. I do just fine, until it's time to perform for others. I've never been fired for job performance. It's always because of office politics. I don't enjoy going to the doctor or the store. I can always tell when they've pegged me as "other" and it's a race against that invisible clock to get my needs met before thier attitude blocks me out. We need more community.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It makes it harder to access care. It diminishes endurance for tasks required to maintain independence. I actually found I was more socially successful when everyone wore masks. Now that no one is wearing them, I'm back to struggling and it's not something I enjoy.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic	The single best thing has been the rise of telehealth appointments, contactless delivery, and curbside pickup.

people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Sarah K.
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Working in community mental health as a licensed psychotherapist (in practice 14 years), I often seem to encounter individuals that seem to fit within a triangle of diagnoses. Common triads I notice are: -ASD, ADHD, and PTSD -ASD, Schizoaffective Disorder, and anxiety disorders -ASD, OCD, OCPD Some of this I've attributed simply to the overlap of traits/symptoms across diagnoses while also questioning more over time whether I am seeing this because these diagnoses truly occur along the same spectrum. This is simply speculation and curiosity however as I am not a researcher.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	I am interested in research that might help better distinguish ASD and Schizoaffective Disorders.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	There can be complications providing services when insurance limits coverage based on whether ASD is a primary diagnosis versus a secondary diagnosis.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Sarah Kelly
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	A lack of resources to help autistic individuals manage co-occurring conditions. A lack of public knowledge that the typical/well known autistic challenges do not encompass the challenges that occur with comorbid conditions.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Isolation and a lack of inclusion. For example, my son's former school only had general ed specials (art, PE, music, library). Students with outbursts or aggression were not allowed to participate and no special ed specials were provided. Sometimes people in public are scared of us when my child has an outburst. In some settings, the autism is the focus and the other mental health concerns go unaddressed.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	A lack of resources to address learning challenges. I would be as bold as to say that most severely autistic children who have learning disabilities will be given preschool material for the bulk of their education with minimal attempts to help them move to higher level material.
What additional research is needed to help address co-occurring conditions for autistic people?	Outcomes of autistic children who have a 1:1 aid to help with academics vs those who do not. We have a couple of FDA approved meds to treat autism related irritability. We need more. The current meds have the possibility of fairly significant side effects.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I would like to see a nationwide program as opposed the individual states running their own problems. This leads to a lack of equity. We recently moved from PA to NY. A couple of months before our move, the rules changed. All those who came before my son are grandfathered in. They are allowed to spend thousands of dollars a year of the government's money on things like trampoline parks and zoo memberships. My son can't even get Medicaid. He's a level 3 autistic with adhd and developmental delay. The New York State government does not consider any comorbid conditions when applying for Medicaid.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I don't think there is a way to measure this. The IEP was not followed during the COVID lockdowns, so I'm sure there has been a lasting effect on my son's learning disability.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Positive- greater access to telehealth, which can increase equitable access to services as long as Medicaid is providing phones (as they do in Pennsylvania) and those who are autistic with comorbid conditions can access Medicaid.

Name	Sarah Lau
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Elhers Danlos Syndrome
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Pathological demand avoidance
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	ADHD
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Acceptance of different presentations of autism
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The ability to get more telehealth visits has made it possible to keep more appointments.

Name	Sarah Marlowe
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Hypermobility including chronic pain and frequent injury and postural orthostatic tachycardia syndrome - these have caused far more distress, grief, difficulties with school attendance for my 15 year old than direct autism or ADHD challenges
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My 17 year old has a PDA profile which has made life extremely difficult for them and the family, and causes debilitating anxiety and depression, esp as it is little understood and only recognised very recently.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I don't know where you could put PDA but it had an extremely challenging impact on my child's development from infancy and through early childhood, esp the emotional dysregulation and fight response - this also impacted enormously on their two siblings.
What additional research is needed to help address co-occurring conditions for autistic people?	Building our understanding of PDA is the most urgent as it is so little researched. I have learned most as a parent from lived experience educators but the research must catch up as the consequences for PDAers - 70% of children not being at school for example - are extremely serious. This reflects my child's experience despite great family support, a supportive school and access to good health care providers. This autism profile is extremely challenging
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Health care providers having a neurodiversity affirming approach, equity, greater understanding of diversity within autism and the comobid physical conditions require multidisciplinary approaches
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	The years of lockdowns - though we supported them from a public health point of view - were devastating to the mental health of my two autistic teens, and delayed both their diagnoses
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increased Telehealth options eg it's counselling has been excellent for my PDAer as they find it very difficult to leave the house. Long term the increased flexibility of remote work may also be helpful to thrm, but remote schooling was a disaster for both my Austistic kids

Name	Sarah McCarthy
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gastrointestinal
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Agressive
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication
What additional research is needed to help address co-occurring conditions for autistic people?	Studies on people of colour links between sensory issues
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Hearing issues
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Reduced interaction and disrupt ion in services

Name	Sarah Miller
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	PMDD, allergens & food sensitivities, gastrointestinal disorders, sensory overstimulation, weak immune system/ prone to illness & infection, injuries from lapses in motor functions, fatigue, adverse effects of burnout and meltdowns
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD, major depression, suicidal ideation, executive function variability, alexithymia & access to emotions, anxiety, dissociative identity disorder, body dysmorphia, antisocial vs isolation, mood disorders, communication & processing disorders, learning disabilities
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Learning disabilities (e.g. dyslexia or dyscalculia), delayed processing of auditory information, struggles forming thought to speech, nonverbal episodes, social difficulties
What additional research is needed to help address co-occurring conditions for autistic people?	More research into late-life diagnoses/ adults with autism, more research into undiagnosed autism in women (AFAB), more research on the commorbid symptoms between ASD & ADHD, more research on the relationship between autism and hormone functions, improved accessibility for self-reporting/ contributing autistic experiences/ symptoms/ behaviors to research (or more frequent research with larger sample sizes & visible ways to contribute personal experiences)
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Better support for autistic adults/ late-life diagnoses, easy-to-find access to self-reporting tools or provider outreach for research purposes, insurance coverage, reformed social services, better academic opportunities, better understanding of medication sensitivities (and more careful prescription practices) for patients with co-occurring conditions, improved accessibility to therapy
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Loss or damage of sensory function which has led to further difficulties with sensory processing, extreme fatigue, more stress due to worsening services/ increasingly convoluted processes/ under-funded institutions that don't provide stable environments for work or learning
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Disruptions in services, increase in remote school and work without adequate training or infrastructure to compensate, more convoluted systems in place to get services, technological advances moving faster than are taught/ processed

Name	Sarah Mouser
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbances, eating disorders, constipation, failure to thrive, low weight
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Aggressive behaviors, anxiety, attention deficit, mental retardation
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Inability to communicate basic needs. Being on waitlists for therapies.
What additional research is needed to help address co-occurring conditions for autistic people?	Research the “spectrum” aspect. Level 1 & 2 autism is NOT the same as level 3 autism. Level 3 autism needs more funding. People with the inability to communicate need the research funds.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Accessibility for therapies, more accurate diagnosis, insurance coverage
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Lack of therapy accessibility
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Disruption in services, increased telehealth

Name	Sarah Muecke
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Differing circadian rhythm, anxiety and depression, having to be around people, work life balance while maintaining daily life tasks.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I am burnt out all of the time with no opportunity to recover and no help.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I have to work twice as hard as neurotypicals.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I went through a period where I was actively suicidal, reaching out to programs and no one even called me back. I have a diagnosis on record. They want us to die in america.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Sarah Peitzmeier, University of Michigan
Demographic	Family member of an autistic individual; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	There is increasing interest from many parties lately on the intersections between autism and transgender identity. I urge any work on the topic to include a trans- and neurodiversity-affirming expert on the topic as it has been seized upon by anti-trans groups of late as another fabricated reason for legislation putting up barriers to medically necessary care for trans individuals. John Strang and Finn Gratton are two names I hear a lot with expertise in this area as a trans health researcher.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Sarah Stewart
Demographic	Autistic individual; Family member of an autistic individual; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Myself and quite a few other autistic individuals I know of have hypermobile Ehlers-Danlos Syndrome and associated comorbidities like POTS, MCAS and spinal instability. This affects my entire nervous system from seizures to gastroparesis. As a life sciences research director and rare disease patient, I see from both sides how disconnected our medical system is. I'm uniquely qualified to navigate the diagnostic/treatment process and still feel completely lost trying to get care.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	A lot of it boils down to trauma
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Self advocacy and representation
What additional research is needed to help address co-occurring conditions for autistic people?	Not only research on the actual conditions, but the diagnostic journey and where diagnoses are being missed
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Care coordinators and patient outreach
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Covid has increased the volume of patients with co-occurring conditions like POTS to the extent that many existing patients aren't able to get appointments with their specialists.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Savannah Higgins
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator; Researcher; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	In a clinical setting, providers may focus too much on behaviors and social skills. There is this notion that if autistic people can socialize in alignment with societal norms and expectations, mental health concerns can be alleviated. Let's consider that pushing for this social/behavioral assimilation may be contributing to other adverse mental health conditions.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	We need more inclusive and intersectional research. Autism research has been narrowly focused on the experiences of white, cisgender, males. This leaves autistic people living at other intersections without access to adequate, evidence-based services. Services and support should not be one-size-fits-all, especially in a sociocultural context.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insufficient access to services and support is a major barrier for many, but an added layer of concern here is that once services and support are secured, the support may not be culturally responsive. Cultural competence needs to be taken more seriously among service providers and their education/training programs. This can lead to a better understanding of behaviors and diagnostic criteria within a sociocultural context for autism and other co-occurring disorders.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	One positive (perhaps also negative) aspect that came out of the COVID-19 pandemic was the reality that remote work has always been a feasible accommodation. It just took non-disabled people needing the accommodation for it to become a broadly acceptable one. Many of us are grateful for this option, but it's truly unfortunate that it had to come down to a global pandemic to witness change in this area on such a large scale.

Name	Scott Jones
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	research has shown joint issues, gastrointestinal issues, and sleep issues are the major physical problems affecting autistic people
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	there needs to be more research done in this field, as our current research is showing these and more are related to each other.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	adhd and autism are being found to be incredibly linked together and we need to view autism not as an isolated thing as it previously has been seen as.
What additional research is needed to help address co-occurring conditions for autistic people?	ties to adhd and ties to intestines' issue. there needs to be more research in this field in general.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	first more research needs to be done. this research needs to influence the policy in the service of autistic people in the k-12 system. but then there needs to be even more resources given to autistic adults out side of the education system. there is virtually no programs out there helping autistic adults outside of social security, which has it own issues.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	many of these comorbidities also cause these individuals to be more susceptible to more severe cases of covid 19. there is also the issues of social isolation causing issues of socializing that way and then having to go back to office and recharge their schedules and patterns they just got accustomed to.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	resocialization, changing in patterns and routines,

Name	Sean Heupel
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The patterns I have seen remarked within the autistic community are as follows: - IBS (commonly attached to the word 'stress'). - Sleeplessness. - Stimulation issues surrounding having to 'pretend' during work or social interactions (in the community, we call this 'masking'. Masking translates over time into 'burnout' and significantly decreases quality of life. To put simply, imagine an actor that never gets a day off for years. - Hypertension often results from the stress of masking and having to perform socially as expected. - Eating comorbidities, whether it be overeating/comfort eating to compensate for stress or lack of eating due to stress. - Dysregulated personal connections. Personal Story: During my 20's, I worked 2 jobs almost constantly plus a full social life. It was an average of 18 hours per day of masking, followed by an immediate 3-4 hour nap then house chores. This grueling pace is common throughout the autistic community, because we collectively want to be involved socially, but we only hold so much capacity. My imminent break-down occurred in 2018 at the age of 33, after a major life event tipped the scale of personal balance, and recovery spanned 4 years.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression - Often centered around forced social interactions and a lack of acceptance by others for our natural personalities. Hopelessness - Social Security Disability does not compensate the cost of living, society continues to depict autism as something negative translating into personal relationships and perceptions. Fatigue - Constantly masking is mentally exhausting and psychologically harmful/traumatizing. PTSD/CPTSD - Both occur in higher frequency within the autistic community when compared to the general populace. ADHD - This is a common co-occurrence with autism. Self Harm - Many of us do this for various reasons. Suicidal Ideation - I have yet to meet an autistic individual absent controlled suicidal ideation (i.e. avoiding being in rooms with knives and/or other harmful tools)
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication challenges are the most frequent, given that autism entails direct speech with fewer social filters. Interpretations and conveyances tend to be very literal more often than not. Self-esteem has been shown to impact intelligence and processing/response to local environment. Autistic individuals do not feel safe as themselves in the workplace, and every autistic individual I have spoken to surrounding occupation has a story about being fired for being 'different'. This is the basis, early on, for us collectively and individually learning to 'mask'. NOTE: It is worth noting that autistic individuals collectively do not favor every aspect of our lives being labeled as 'disabled'.
What additional research is needed to help address co-occurring conditions for autistic people?	The evidence and consensus within the community is to answer need, versus speculation. At present, autistic individuals are the most unemployed/underemployed demographic in the United States, mostly due to not adhering to social expectations (i.e. the 'mask' slipping off). Prior to exploring co-occurring conditions, it would be more relevant to educate the masses on autism as a condition, not a disability, focusing on acceptance of differences. This can prevent homelessness, self-harm, self-resentment and promote quality of life. Save the co-occurrence research for 'after the fire is put out'. NOTE: I offer to contribute resources toward this endeavor.
What could be improved in autism services and supports to help address co-occurring conditions for autistic	Improvements could be made through workforce education. Many autistic individuals would benefit from their co-workers being educated that while there may be ticks, we hold equity as human beings. This would allow for

<p>people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>corporate acceptance of the need to 'stim' to self-regulate and the need for 'sensory breaks'. Education toward the strengths of autism would also be beneficial, such as a keen eye for detail and the obscure (that which stands out), our ability to do what is colloquially known as 'deep diving' into our 'special interests'. Our attention to correlations and patterns is also a strength, which many of us use for survival (i.e. how we learn to 'mask')</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>I asked this of the autistic community on TikTok, and overwhelmingly the answer was: the ability to be myself more often. Those working COVID-remote jobs usually stated greater productivity and job satisfaction. Many reported symptoms of stress being greatly reduced and enjoying remote conversations, versus in-person dialogue. The consensus overwhelmingly points toward a higher quality of life when working remotely. This information was gathered by inquiring of my own followers on social media and mass exploration of platforms, such as YouTube and TikTok.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Increased remote work has held a major impact by reducing commutes and in-person social interactions. 'Masking' requires a great deal of effort. To do so properly, one must be constantly vigilant of their surroundings and social interactions to include context interpretation, tone, facial expressions, gait and body language/proximity. Masking for 8 hours per day could be held akin to walking with an 80lb backpack for 8 hours, every day (exhaustion and muscle fatigue, translated into mental fatigue known as 'burnout').</p>

Name	Shannon
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I have two children with autism. They both have gastrointestinal disorders which require special diets and medications. They both have difficulty falling asleep and require supplements to fall asleep. They both have sensory challenges which can trigger each other in to very challenging behaviors which result in agitation, aggression, violence, self harm, elopement, property destruction, depression, anxiety, tics, etc. We have had to call the police for help only to find their only answer is to have the children committed, mobile crisis wouldn't come out and only suggested having children taken to ER to be committed. HBCS services have been non-existent since covid due to no staff, vocational training no staff, community Networking no staff, respite no staff, day program not enough staff. We have absolutely no help.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have two children with autism. They both have gastrointestinal disorders which require special diets and medications. They both have difficulty falling asleep and require supplements to fall asleep. They both have sensory challenges which can trigger each other in to very challenging behaviors which result in agitation, aggression, violence, self harm, elopement, property destruction, depression, anxiety, tics, etc. We have had to call the police for help only to find their only answer is to have the children committed, mobile crisis wouldn't come out and only suggested having children taken to ER to be committed. HBCS services have been non-existent since covid due to no staff, vocational training no staff, community Networking no staff, respite no staff, day program not enough staff. We have absolutely no help. My children cannot swallow pills/capsules and insurance company refuses to cover liquid or patches unless they try/fail the formulary medication that they cannot swallow. Milk intolerance makes it difficult to find medications because 45% medications available contain lactose and the majority of medications are only available in pill/capsule form.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My children cannot communicate their needs/wants, frustrations and most importantly ailments or side effects of medications. Most doctors want to put your children/adult children on antipsychotics that carry very heavy side effects that our children cannot communicate if they are experiencing. My son was having hallucinations and it took awhile before we figured it out. How frustrating and frightening for him. The oral surgeon punched my son in the face and left a black eye and we had no idea until we got home 20 minutes later and the bruising was evident.
What additional research is needed to help address co-occurring conditions for autistic people?	Better access to quality health care, medical care, alternative medication options, day programs for socialization, vocational training, staff to help them, relief for caregivers, actual crisis intervention that doesn't just send you to ER to dope up your kid and send them back home. How is that helpful. It completely traumatizes the child, family and you lose your child's trust, creates PTSD and makes things worse. Train police departments, medical staff, families, etc. Too many children are being diagnosed and are turning in to adults with no help out there. This is a crisis that needs emergency funding. It is unfortunately only getting worse.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services,	Staff is non-existent. We have been without staff for any services for 3 years.

insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	My children have developed anxiety, depression, socially withdrawn, lost interest in things they use to enjoy.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	We have no services. I had to quit my job to stay home and be a paid caregiver, increase use of telehealth, increase in medical visits, increase in medications, increase in medical bills, increase in mental health diagnoses, reduced social interactions, reduce obligations, reduce outings, reduce social activities, reduce tasks, basically reduce productivity in life.

Name	Shannon Crandall
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The most significant challenges I face are sensory, gastrointestinal motor skills as I also have ehlers danlos and sleep disturbances.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My most significant mental health challenges include adhd, anxiety, and depression.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I have found communication to be my biggest challenge. Misunderstanding the subtleties that language can cause. I need direct instruction as to what is expected. I can't always discern gray areas with ideas.
What additional research is needed to help address co-occurring conditions for autistic people?	I would like to see research done on the connections between adhd, ehlers danlos and autoimmunity with autism. I have all of these co-occurring conditions and feel that I had a late diagnosis for autism because of these co-existing conditions.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I found it quite difficult to get a diagnosis for autism as my insurance wouldn't cover it. Finding neurodivergent specialists has also been extremely hard.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I feel covid-19 caused even more isolation for neurodivergent individuals. It exacerbated anxiety and depression.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Finding services was hard before Covid-19 and even harder during and after.

Name	Shari Washburn, COPAA
Demographic	Family member of an autistic individual; Service provider, health provider, or educator; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	sensory challenges
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	depression and anxiety
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	communication disabilities and intellectual disabilities (e.g. processing deficits, working memory deficits)
What additional research is needed to help address co-occurring conditions for autistic people?	More research on earlier identification of girls with autism as a way to address pervasive depression from masking; research into how to regulate disinhibition
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	better screening and assessments for girls with autism
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	increased virtual services

Name	Sharon Anderson
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Chronic/severe constipation. Requires medication to have movements.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	There is some aggression particularly when introduced to new things; environment, people, transitions, etc.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Developmental and deficit learning disabilities. Non-verbal. Inability to perform basic and routine daily life skills. Inability to communicate. Have not been taught signing. Has no communication device despite requests. Only receives 40 minutes of speech each week.
What additional research is needed to help address co-occurring conditions for autistic people?	When a child is IDD, I ponder the need for education, in terms of math, reading, etc. It seems there should be dedicated learning opportunities that focus on survival and daily life tasks such as eating, dressing, putting on outer garments, putting on/taking off shoes, feeding, brushing teeth, etc. It seems the education dollars are moot. Children with severe or extreme IDD will benefit very little with classroom studies. I feel teaching them basic daily functions and signing, i.e., help, eat, drink, danger, etc., would serve them far better. I am not opposed to an education, however I think the focus should be primarily that of self care.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Provide them with the services that they need. Schools do not provide true occupational therapy even when it is requested by a physician. The OT Teacher provides aides and classroom teachers with things to monitor rather than being hands-on. That is a travesty and disservice to the individuals. I know finances are an issue, but it seems the system is not serious about improving the lives of those impacted. As a caretaker who has been able to teach a few things by religion, I feel an individualized plan that is executed to meet the daily deficiencies would result in marked improvements.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	There really was no remote work. Parents were not trained on how to work with students who were Autistic and had IDD. Students in self-contained classes were not afforded Chrome books to work with. Papers were sent home. A student in 8th grade and who cannot talk, write, communicate, hold a pencil, crayons, or scissors, etc. meant that the parents or another family member was physically doing the work; and without pay. The struggle was real for students and families. The lack of social interaction I feel impacted everyone then and I feel we are experiencing residual effects now. People are

in-person social interactions and obligations)	still uncertain in large crowds. When someone coughs, people become afraid. I think Covid-19 will impact our lives for years to come and I don't think most of us will feel "normal" ever again. I think we will all be on alert. The damage has been done. I and have long term implications. Thank goodness the physician still saw us as needed.
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Name	Sharon Saavedra , Parent
Demographic	Family member of an autistic individual; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep deprivation impacts everything else ! Aggression Being non verbal and having limited cognitive capacity ; self injurious
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Isolation Lack of social skills Lack of communication skills Limited community involvement or interest Anxiety/ ADHD / intellectual disability along with autism Limited ability to communicate and self regulate leading to aggressive behaviors / meltdowns
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Making friends Community inclusion Informed adults Working Isolation Intellectual disabilities Non verbal ; low IQ Quality of life impacted
What additional research is needed to help address co-occurring conditions for autistic people?	Medical and therapeutic interventions that work Making communities aware Accessible to our folks
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Increasing the number is Educated experienced professionals working with our population Better trained workforce Staffing for group homes Special education services in public schools ; Medical professionals trained specifically in autism Affordability of services
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Isolation Skill regression
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Disruption in services such as day programs for adults with autism Skill loss Isolation Social interactions became more difficult

Name	Shauna Ikahihifo
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I experience significant challenges due to co-occurring physical health conditions like Polycystic Ovarian Syndrome (PCOS), hypermobility, acute eosinophilic asthma, seasonal allergies, sleep disturbances, and gastrointestinal issues. A flare-up of any of these conditions has causes significant distress by amplifying my sensory issues and flooding my nervous system with cortisol making me much more easily prone to meltdowns. I also deal with chronic pain which makes working even a part-time retail job very difficult as I cannot stand for long periods of time without experiencing significant pain and my many physical symptoms are a constant distraction from my duties.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I was diagnosed with Premenstrual Dysphoria Disorder at the age of 11. This means that from the time I started menstruating, I have experienced significant bouts of dysphoria, suicidality, and self-injurious behaviors. By the time I was diagnosed with autism at the age of 32, I'd already been diagnosed with major episodic depressive disorder, acute generalized anxiety, and panic disorder. This often puts me in a state of emotional dysregulation that makes me more prone to meltdowns and burnouts which are traumatic and can cause significant skill regression. As an autistic person, driving was always a stressful endeavor, but my anxiety has made it impossible. I also am unable to hold a typical job because my moods can be very unpredictable limiting my ability to perform the duties of my job.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I did not mature at the same rate as my peers and that caused significant distress and was very isolating. Looking back, I can see how opportunities and relationships were denied to me because of disabilities that may be invisible but significantly affect my ability to connect with others.
What additional research is needed to help address co-occurring conditions for autistic people?	Most research on autism is conducted on autistic children, ignoring the fact that these children grow up to become autistic adults with very little supports available to them. We need more research done on the lives of adult autistics and how to best support us not only in the transition from adolescence to adulthood, but also throughout the remainder of our lives. This is especially those of us who were missed as children and only became diagnosed after experience significant mental and physical health problems that had devastating effects on our professional and personal lives.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	There need to be more resources for autistic adults that are accessible to those of us able to travel and for those hospitalized or housebound. There also needs to be more funding to support autistic adults in being able to live independently, regardless of whether they come from wealthy families. We need job training initiatives within social services that aren't limited to those of us fortunate enough to be discovered and diagnosed before the age of 18.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	An autistic young woman was one of the first COVID casualties in my small town. She had developmental delays that made her reliant on her caregivers and community to protect her and we fell short of that commitment. This was a devastating loss for our community, but also greatly impacted the emotional and mental wellness of her friends and classmates as well. My younger brother, who is also autistic, was unable to make the transition to online schooling and has had to repeat two years of school to make up for time lost during the pandemic. We are hopeful he will be able to graduate

	<p>this year, but not being able to graduate with his peers really impacted his confidence and sense of self.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>The increase in remote work and more options for remote schooling are very positive impacts for those of us who struggle working in traditional environments. Another positive effect was the availability of take-out and other delivery services that make the world much more accessible to those of us who are often stuck in our homes.</p>

Name	Shauna, Mother of ASD Adults
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My son has moderate to high functioning Autism and co morbid diagnoses of ADHD DSM-F90.2, Other Specified Disruptive, Impulse-control, and Conduct Disorder DSM-F91.8, Other Specified Trauma/Stressor-Related Disorder DSM-F43.8, and Other Specified Anxiety Disorder DSM-F41.8. When my son is having a mental health crisis (threatening suicide, having suicidal thoughts, or homicidal threats) he is turned away by all in patient hospital programs because he has autism too. We are often told "we do not have the level of supports he needs". The Centers for independent living (CILAs) do not provide the level of care needed for his mental health crisis. When there is a crisis, the CILAs have months long wait lists to even get a bed for him to attend a 90 program for assessment and treatment. No CILA is able to handle my son's outbursts and violent behavior. This puts him at a greater risk for abuse in these environments. In our state, all state government developmental facilities have been closed or have had their funding minimized to where they can not take new patients. The non profit crisis centers send my son home from the ER with "coping skills" instead of putting him in patient in a mental health crisis. One of my friends son's had to sit in the local hospital ER for 3 weeks because Illinois does not have any place for Autistic individuals who also have mental health issues.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The schools still just pass these kids through k-12 instead of educating them. My son's learning disability was not even discovered until he was over 18. The schools did not catch that issue.
What additional research is needed to help address co-occurring conditions for autistic people?	We need more direct funding to in patient sites for people with co occurring conditions that specialize in mental health and autism. We need more funding for adults with autism and co occurring conditions. Funding for autism programs stop at age 21 to providers. Insurance companies also do not pay for a lot of programs and treatment after the patient has turned 21. The current non profit funding strategy does not help.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Equitable access by regions of high prevalence of autism. Montgomery county Illinois has a high prevalence of autism but we only have a day program and cila for 21+ patients. We have to leave the state to get inpatient mental health coverage. Every state should have at least 2 inpatient programs for adults with autism and mental health disorders. When my sons were diagnosed with autism the prevalence of autism diagnoses were 1 in 157 boys would be diagnosed with autism (2005). Now the prevalence of autism is 1 in 36. Our country and states and regions do not have the supports to this aging population. They are falling through the cracks. As the parents of this population age, these children have nothing but a broken system to support them when their parents are gone.

<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>I believe Covid exacerbated my son's trauma. It also impacted his ability to be social which caused a regression in his social and communication development. This has made it very hard for him as is now out of high school.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>For our family there were some positive impacts, I am now able to work from home all the time which allows me to be at the ready when my son needs me. Covid opened the door for employers to really see how challenging it can be to be a parent of a child with a disability. Policies are changing for employees because of Covid. Our biggest negative impact for my son with autism is I believe Covid exacerbated my son's trauma. It also impacted his ability to be social which caused a regression in his social and communication development. This has made it very hard for him as is now out of high school.</p>

Name	Shawn Sullivan, Autistic adult
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The most significant challenge is finding medical providers who believe us. Most of my medical needs are not met. I have a lot of physical health conditions that persist because I have yet to find a doctor or insurance that will treat more than one problem at a time. Medical providers do not provide accommodations for people on the spectrum. They insist on verbal communication and will not provide follow up in writing. It is impossible to find a medical practice who will not discriminate against us because we are autistic.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The problem is a lot of medical providers still do not believe co-occurring mental health conditions are real. There is a provider in rural Oregon who is in charge of almost all of the autism diagnostic evaluations who does not believe a person with autism can also have ADD or ADHD. There are not providers with experience in assisting adults on the spectrum, and if they exist we have to private pay because they don't take insurance. Suicide is a significant issue. A lot of that stems from our inability to be accepted for who we are.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Research should be focused on helping us navigate the world so we are not experiencing poverty. Most of us are in poverty because the system is designed to keep us from being successful. The biggest barrier to success is the job interview process. The current system is designed against how our brains work. You are asking us to do things we simply cannot do. Can we research how to make our lives better rather than focusing on a "cure" or how to "change us." You can't "change" a broken arm. You treat a broken arm. You can't "change" being in a wheelchair. You create an environment where people in wheelchairs can access the same places.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Stop allowing insurance companies to dictate the care of people. A for profit company should be the one deciding who gets treatment and who does not. Train people who do evaluations better. Can we create a better system of diagnosis that allows for co-occurring conditions to exist. Can we get sensory processing issues tied to autism diagnosis?
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	

in-person social interactions and obligations)	
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Name	Shawna Strickland, American Epilepsy Society
Demographic	Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	For those with autism and epilepsy, the ability to obtain a history directly from the patient and to perform a physical examination in those with limited communication skills can be difficult. In such cases, the providers rely more heavily on objective testing. For example, EEG to establish epilepsy diagnosis from behavioral outburst is common. In addition, some patient behavior will limit obtaining standard testing without extreme methods (e.g., sedation for brain MRI or EEG). Another significant challenge is trying to figure out how often they are having seizures. For adults with autism who live in group homes and may not always be observed or be interacting with others, subtle seizures can easily be missed. Also, if staff are not diligent about writing down seizures in a log, it's quite difficult to know the seizure frequency. Group homes can also have trouble distinguishing seizures from various types of behaviors.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	It can be difficult to identify clinicians who are trained to provide care for these conditions in this special population OR who feel comfortable providing care for this special population. There is a delay in starting therapy due to a shortage of healthcare professionals (e.g. neuropsychologists) and developmental-behavioral pediatricians. The current path for board certification in developmental-behavioral pediatrics requires completion of a pediatrics or combined internal medicine-pediatrics residency program followed by a 3-year developmental-behavioral pediatrics fellowship. Upon conclusion of this 6-years of training, the average starting salary for a developmental-behavioral pediatrician is often lower than their general pediatrics colleagues who only complete the 3 years of post-graduate pediatric training. To address the shortage of developmental-behavioral pediatricians required to care for the increasing population of children with autism, reimbursement for developmental-behavioral pediatricians and the duration of training should be reassessed.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication disabilities and intellectual disabilities are the most encountered challenges in this patient population.
What additional research is needed to help address co-occurring conditions for autistic people?	a. Additional research is needed in the following areas to help address co-occurring conditions for people with autism: b. Identifying the EEG markers for diagnosing the onset of autism at the earliest possible age c. Identifying biomarkers in evaluating seizures in autism. This could include EEG, MEG, etc. Identifying the presence of epilepsy and instituting strategies to minimize progression could help in minimizing long term neurocognitive sequelae in patients. d. Establishing criteria/ biomarkers for identifying psychiatric conditions in children with autism. Additional research falling under this umbrella includes developing a structured format for identifying autism in youth with intellectual disability, identifying overlap in symptoms in autism and schizophrenia in youth, differentiating tics from stimming behaviors individuals being evaluated for autism, and identifying eating disorders in autism (when symptoms of anorexia and sensory sensitivities (i.e., food textures) overlap).
What could be improved in autism services and supports to help address co-occurring conditions for autistic	The time to diagnosis of autism comes with a waiting list ranging from 1- 3 yrs, depending on the patient's financial situation and location. The diagnosis of autism spectrum disorder necessitates genetic testing, which not only

<p>people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>benefits the patient but also allows parents to plan further pregnancy. Autism requires a significant allocation of public health funding, and genetic testing should be easily accessible, enabling us to address the issue at a certain level. Clinical resources and social support could both be improved. A network of resources for affected patients and clinicians would improve care. Patients often want referrals to specific services or practitioners with experience/knowledge. There are limited resources outside of academic centers in many cases and finite resources at academic centers, which exacerbates the problem for patients and clinicians. An additional void is that once patients graduate from high school and post-high school programs, there may be limited opportunities for them to remain engaged with the community. Some day-programs don't allow patients with epilepsy, and the same is true for some work programs geared towards individuals with autism. Even if the program does admit a person with autism and epilepsy, the staff may be anxious as they are not appropriately trained in epilepsy care and, as a result, restrict the person's activity within the program, depriving the person of activities that could be of benefit.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>COVID-19 limited routines and access to programs that were getting these patients outside of their houses. These programs are significant chances for social engagement and support for care givers. Some children with autism had regression secondary to discontinuation of therapy in a pandemic.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>One of the lasting impacts from COVID is that many day-programs were stopped, which was a big loss for people who attended them. Patients are often in group homes or at their own home without any structured social or work programs to attend. A lot of patients really enjoyed the social interaction that their day-programs offered, and not having this has left a big void in their lives.</p>

Name	Sheila Bell
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Inability to function in everyday life. One of the main issues we face is the lack of diagnostic criteria for the Pathological Demand Avoidance profile of autism (PDA). It is debilitating and schools will not recognize it forcing youth with autism to go through traumatic truancy court processes. Also, so few doctors know about PDA making it doubly difficult. We have no doubt our daughter has a PDA profile and desperately need help and have so few places to turn. other than PDA support groups and websites.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, Suicidal ideation, depression
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Autistic burnout
What additional research is needed to help address co-occurring conditions for autistic people?	Research and strategies to work with PDA autistic individuals and autistic individuals in burnout. Research on autism in girls vs boys and updated diagnostic tools to catch it in girls sooner.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Recognition of PDA as a profile of autism. Early identification of autism in girls. Tools need to acknowledge masking.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Covid exposed how our daughter was masking in school and now she cannot do it, leading to lack of education. We have recently learned that she has PDA.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Disruption of education and friendships.

Name	Sheila Judge Leonard
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Emotional regulation & sensory challenges
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Regulating emotions to manage social situations
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	ADHD and challenges with executive function skills. Highly intelligent individuals who are unable to demonstrate their skills & intellect because they struggle organizing & keeping track of things
What additional research is needed to help address co-occurring conditions for autistic people?	Research into effective ways to help ASD people reduce sensory overload and manage emotional stress so that they can more comfortably exist in the society
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Free services & coaching to help these people with skills needed to better navigate & participate in society
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Remote working & schooling has been difficult for some because it requires skills in being organized & self motivation

Name	Shelby crane
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The inability to fall asleep, sensory issues that make you physically sick.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression caused by the fact we mask after years of bullying making people think we lie about our disability, anxiety from the pressure of constantly getting yelled for not having something explained good enough. Adhd, ocd. Suicidal ideation from professionals and peers dismissing our disability as manipulation
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Learning disabilities the educational system would rather fail us then help us learn in way we understand. Communication, people don't understand what we say is said in a literal sense and dismiss anything serious we say in regards of asking for help. Work places discriminate and exploit us to the point we burn out and become unable to be functional and productive. Getting diagnosed in a timely manner for girls is impossible because they don't study autism in girls . There are not enough autistic people in the research feild, autistic people can quickly identify other autistic people while nerotypicals can not .
What additional research is needed to help address co-occurring conditions for autistic people?	More studies on female toddlers, children, adolescents, teens and adults . Most of us don't get diagnosed until it's to late for us to receive help resulting in ruined futures because they lack the diagnosis to receive help in school to be successful. Having classes tailored towards the way ASD minds learn in public schools could raise graduation rates most schools would rather bulky kids out of the school vs take time to help.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Better special Ed resources in all schools that are tailored to the way people with ASD learn, having researches diagnosed with ASD lead studies and research would help uncover characteristics that NT people can't notice. Doing studies on girls with ASD so girls don't have to go undiagnosed till they are almost adults or middle aged . Research ways to help people with ASD who suffer from dyslexia and are discalcuate learn , start acknowledging that hyperlexia is one of the biggest telling signs that girls have ASD.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	The pandemic gave some of us the chance to take care of our mental health the way we need for others it made it worse because of how rude customers where, and how demanding and abusive employees where and still are and how they took advantage of our determination to not prove their ideas about our disability right.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	It made getting a job as a disable person really hard, and if you do get a job they exploit you by making you think your about to get fired because of your struggles do to your disability, making you ever work yourself. But it also has given us the courage to call in sick when we need. The biggest issue in the work force now is lack of mental health assistance and the unaffordability of Healthcare to receive medical help to get therapy and medicine to be our best selves

in-person social interactions and obligations)	
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Name	Shelby Shifflet
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Being an autistic individual, I face many physical challenges as well. For example, I experience gastrointestinal pain and sensitivities, trouble falling asleep/staying asleep, nightmares and night terrors, auditory/visual/touch intolerances, and many more. My cardiologist has stated I present textbook POTS and am referred to a facility for a tilt table test for the official diagnosis as I faint if upright or walking too long. I cannot be standing/walking long.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Along with my autism, my major depressive disorder, generalized anxiety disorder, ADHD, and PTSD causes many obstacles in my day-to-day life. Working in a society is difficult as I am semi-verbal. Talking and socializing is expected and necessary to function in today's world. I struggle to perform these social tasks without facing a deep depression, burnout, and meltdowns from overstimulation and anxiety.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	With my autism, I struggle to be outside of my home or my safe places such as my favorite low traffic nature spots. School had always been a struggle with the communication and participation expectations/requirements. I preferred solo assignments and non-public speaking as I do not wish to speak. I become extremely overwhelmed and cannot process anything. This causes me to panic and meltdown as I cannot understand the situation.
What additional research is needed to help address co-occurring conditions for autistic people?	Research into autistic needs to help us fulfill them ourselves, along with making a society more accessible for autistics. Crowds, with people and cars alike, cause us to remain at home because buying groceries and getting book from the library can be too overbearing. Doing just one of those tasks can cause an autistic, from my experience, to spiral into a depression.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Equitable access to grocery stores, retail, and places like the airport or schools, would be amazing for the wellbeing of autistics. An inclusive way of including us without making us feel alienated or uncomfortable. Such as a room where we can go for a break or quiet as to calm ourselves to avoid overstimulation. Better insurance coverages for doctors, specialists and dentists. The wait time for disability is damaging. I have been waiting for even a decision on disability for my autism and co-occurring conditions since they make my mind and body struggle to keep up with even a five hour shift. Being expected to force myself through agony to make an income is painful and torture.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I have not experienced a COVID-19 infection.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I genuinely felt better during the COVID-19 lockdown as I did not have to leave the house and when I did, did not have to interact with many people. It was less stressful to grab feminine hygiene products and bread when no one approached me every thirty seconds.

Name	Shellie Rubin, speech language pathologist
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Trying to medicate or treat both physical / emotional conditions without causing autism symptoms to worsen
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety symptoms in some children/teens, aggressive behavior or self-injurious behavior increases in other people
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	All conditions in autism have children/teens not able to verbalize /explain show their learning differences/difficulties
What additional research is needed to help address co-occurring conditions for autistic people?	I do not know, that is not an area I am comfortable with offering thoughts.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I am sure insurance coverage and state options for increased or any services as well as services in the educational setting
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Doing tele speech/language therapy is more difficult than in person, but the decrease of Speech language pathologists overall makes tele services better than none.

Name	Shelly Glennon
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The autism dx is primarily what unlocks resources and support, but sometimes it's the co-occurring issues like PDA that require higher support levels, which can make it tricky navigating support systems when the autism dx says "level 1" but the PDA requires much more support than level 1.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	PDA and the root anxiety
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Accessing school while struggling with PDA
What additional research is needed to help address co-occurring conditions for autistic people?	More research on PDA please! And more broad communication on what PDA is, how to deal with it in therapeutic, school, and home environments.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Again, having a dx of autism level 1 tells many of the systems "low support needs" but having the PDA profile of autism means higher support needs. Also, in general the "allotted" amount of services is basically bare minimum to try to keep kids from ending up in an institution. We really need insurance to cover what is needed to set these kids up to thrive.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Unknown to be honest.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The entire medical industry is a disaster such that getting ANY services has months, even years long waitlists! We currently have zero options for in-network psychiatric services for medication management because the major group that provides it is so impacted that they aren't even taking people on a waitlist anymore.

Name	Shelly Moss, Atypical
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The most significant challenges in my experience has been the unwillingness of the medical community to acknowledge that I have co-occurring conditions. I was diagnosed with SIBO and then told by my primary that I needed to lose weight before they could treat my bacteria overgrowth. My primary said "you don't have sleep disturbances" despite my sleep study confirming it undeniably. I still have yet to be referred to ANYONE to confirm or deny whether or not I have Ehler's Danlos Syndrome because "we don't know how to diagnose that." There should be a standard of practice and treatment for these well known common issues for people on the spectrum. As a female, I have had so many issues getting any kind of diagnosis that didn't pertain to my weight or gender. Everything gets blamed on those two things.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	These issues often go overlooked as individual conditions and are lumped in with autistic traits or behaviors which is infuriating. The conditions should be treated as individual conditions AND as co-occurring conditions with a team of providers who are dedicated to the overall health and wellness of the individual. Suicidal ideation can be both a physical ailment (lack of vitamin d, lack of sleep, nutritional shortcomings, etc) and a psychological issue that needs more than one provider to approach treatment. ADHD on the other hand is often unincorporated from Substance Use Disorder even though they go hand in hand when the ADHD is undiagnosed. The need for certain drugs to regulate themselves is intuitive to them; yet providers are incredibly reluctant to prescribe what is necessary for an unregulated brain. Aggressive behavior is often a result of the lack of understanding of allistics communication or lack thereof in the way of the autists inability to read between the lines, not understanding social norms or cues and feeling set up by people who don't shoot straight. Truth is subjective for allistics as well as integrating subtle undertones of suggestion that are infuriating to people on the spectrum.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The fact that it is a spectrum is the challenge. People tell me that I "don't look autistic" or act autistic but the truth is we are all so incredibly unique and the face of ASD has drastically changed. I have unique skills and unique disabilities. I have a high IQ, eidetic memory and high retention of information but often suffer from face blindness and read lips because my ears are too sensitive that words are often drowned out by cars and sirens and barking dogs. I have been trained to be high masking as to not elude to my differences yet people inherently sense that I'm not like them. I enjoy concisely communicating yet it's often perceived as being short and rude to people. My ability to mask often leads me into leadership roles but my inability to regulate after long periods of masking lead to bouts of isolation and depression because I need to recharge and I can't be myself. Developmentally challenged until my late 30's, I had no idea how far behind I was in comparison to allistic peers until presented with the comparison. We don't know what we don't know until we realize that we don't know it. The learning and intellectual disabilities are wild. My granddaughter didn't speak until she was 4 years old and she had a tight grasp on language. She taught herself how to read so when she started speaking it was at a second or third grade level of grammar and comprehension.

<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>Genetic testing and researching the genetics, assessment should come with assessing known co-occurring cases and general health studies of gut health, gut-brain link in autism, absorption and malnutrition issues, sleep issues and how sleep deprivation make other conditions worse .</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>An across the board overhaul of assessment and treatment for people on the spectrum. My daughter had to drive hundreds of miles to have my granddaughter diagnosed because they were not able to in our county. That's ridiculous! As an adult I have been denied assessment because I already have the "atypical" diagnoses from the 90's, that is also ridiculous. These should be accessible to everyone despite insurance coverage in my opinion. They should also be accessible everywhere medical treatment is offered. Training and education are imperative.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>My family has yet to fully recover physically since having covid and have been denied medical treatment due to provider gaslighting and inability to believe that we still have issues. Both of my grandkids have been persistently sick for years now and not much help from the medical providers.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>I believe it has damaged social structures beyond repair for allistics and autistics alike. The isolation caused many to become feral and unhinged socially.</p>

Name	Shelly Witte
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep. Schools start too early. My son has a difficult time getting to sleep and then can't get up and going for school. If we force him out the door then he won't function in class. So if he doesn't sleep well, he stays home.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety and from that depression and self injurious behavior and suicidal ideation. Most autistic people know they are different. We explained autism to our son the summer before he went to middle school. We wanted him to know why he stims and why he has other behaviors. We have also spent his life pointing out behaviors in other people and what is socially acceptable and what isn't. But my son now sees when people are making fun of him or his autistic peers and can stand up to them. This makes him very anxious still because he wants people to follow the rules all the time. And when they don't follow the rules, he gets Anxiety, and when the Anxiety goes on too long he gets depressed.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication is key. I've seen a lot of speech apraxia. It's very difficult to teach a child when you can't communicate with that child.
What additional research is needed to help address co-occurring conditions for autistic people?	We need better ways to teach autistic students. Not all schools have autism only classrooms. Do students taught in these classrooms fair better? How can we push this across the country?
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Why can't we start a guardianship at a sooner age? Why can't I still access my son's medical records since he turned 13? He's autistic. Why couldn't we get life insurance for him? We were told too many autistic children grow up and end up in jail so he is uninsurable.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I don't think covid has a lasting impact on autistic people specifically. The vaccine caused massive nosebleeds in my son though.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	It was a disruption in people's schedules. If only online school was available many autistic people either thrived or did horribly and there was no middle ground.

Name	Sher DeGenova MS CCC-SLP, Flemington-Raritan School District, NJ
Demographic	Family member of an autistic individual; Service provider, health provider, or educator; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	-Anxiety (often not diagnosed) -feeding disorders; restricted diet -auditory processing disorders -apraxia -sleep disorders -OCD -difficulty learning due to lack of attention
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	-anger, explosive behavior, aggression -self-injurious behaviors -depression -lack of social peers -inability to gain employment and/or hold a job - inability to keep roommates -inability to continue in day programs (due to mental health issues)
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	When communication is affected, frustration and aggression occur. Learning is affected negatively. Emotional and cognitive delays definitely affect social interactions and can even cause criminal behavior as the person becomes an adult. All of the above mentioned disabilities will certainly affect independent living and employment in a negative fashion,.
What additional research is needed to help address co-occurring conditions for autistic people?	Doctors, specifically specialists in psychiatry, neurology and developmental studies must do better in treating individuals with autism in order to know them and help them. Autism must be included in medical school curriculums. Specialists in other areas (psychologists, pediatricians, social workers, LDTCs, Speech and Language pathologists) must equally be involved.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Better medicaid rates, since no one wants to accept it for medical care. Better transportation to get around in our communities, esp to doctors.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Complete stop to services, if you were lucky enough to get any services. That says it all.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Disruptions to services and community activities turned into permanent termination of many services. Lots of programs still do not have enough staff.

Name	Sheri Mills, Prader-Willi Association USA
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Rigidity and repetitive behaviors. These can be debilitating and hard to move on to another task and just get through our day.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, which leads to excessive questioning and repetitive behaviors. Anxiety also leads to aggression and self harm.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	All of the above. My child struggles with very delayed speech. But, the intellectual delay is growing, or the gap with her peers, as she gets older. Not being able to communicate, and the rest of her peers are growing developmentally or intellectually is very hard. Frustration, anxiety, and aggressive behaviors occur when she doesn't understand what everyone else is doing.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	We need more providers, and access to providers. We live in a rural area and do not have a lot of support. But, even in larger areas, should we drive, the waiting lists are so long. We need help now. Not in 3-5 years. We also need frequent help. We need to educate schools, but we need the staff too. More funding to schools needs to be a priority for our states. Special education is suffering. And, yes insurance coverage.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Covid-19 completely upended routines and structure for our kids. Our kids who also have complex medical needs, do not feel safe, because everything (and I mean everything) takes more planning just to go somewhere. Fear leads to anxiety, anxiety leads to certain behaviors, those may lead to aggression and self-harm.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Well, our kids need more support in the home. We just do not have people who can do it. We have a lot of kids in my county who need home-bound school services and have been waiting 6 months for them because there is no staff to do them. Without a structure to our kids day, and then them continuing to learn when they already have a developmental delay, holds our kids back even more. There is so much stress on a caregiver, and now we are to be teachers, therapists, be on the phone with insurance all day, etc. It's too much. The mental toll on a caregiver also affects our children with autism significantly.

Name	Shiloh
Demographic	Autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Not only the above mentioned, but also looking into the way medications can affect us differently. Especially, with mental health conditions and demand Avoidance.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	For myself, it's depression and the ever present anxiety. I'm also diagnosed with PTSD.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Looking into PTSD, Anxiety treatments that are effective and coping skills for demand avoidance and executive functioning.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Equitable access and expansion of services that Autistic people approve.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Shonda
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Motor, sensory and sleep disturbances
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	self-injurious, anxiety and adhd
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	ID and communication
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I would have to say all that was given in the examples. Especially services needed of teens with severe autism. There are quite a few programs for "higher functioning" kids but what about the population that are left out the equation. MORE services, programs on weekend and after school events in PHILLY
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	disruption in services, home health aid workers shortages due to low pay

Name	Simcha Weinstein, NYADD & FTNYS
Demographic	Family member of an autistic individual; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	It's common for autistic individuals to be diagnosed with concurrent mental health issues, like depression and suicidal tendencies. In fact, statistics show that as many as 80% of autistic people carry at least one comorbid psychiatric diagnosis, like attention-deficit/hyperactivity disorder (ADHD), obsessive-compulsive disorder (OCD), or anxiety disorders. Of that population, 40% are estimated to experience two or more such diagnoses. Statistics upon statistics underscore this reality. One study reports that autistic youth are nine times more likely to present to the emergency department for psychiatric reasons than their neurotypical peers — and that number has almost certainly increased since the study's publication a decade ago. Autistic individuals and their families continue to face massive and seemingly insurmountable challenges as they try to access much-needed mental health care in community settings. For example, finding a mental health provider who is equipped to work with autistic teens is virtually impossible. Youth who experience autistic meltdowns end up in psychiatric wards that can't treat their unique needs — as faced by my own family's Lived Experiences.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Autistic youth aren't just disproportionately affected by mental health diagnoses; they're also at higher risk for factors related to suicidal thoughts and behaviors and non-suicidal self-injury suicidality. Bullying is near the top of the list, with statistics showing that bullied youth are, in general, at a higher risk for suicidal thoughts and behaviors — and children with autism are far more likely to be bullied than their neurotypical peers. There's also the fact that when autistic teens face mental health challenges, they're often less able than their neurotypical peers to verbalize what they're going through, which makes the challenges significantly worse. These are challenges that my family and I know all too well. But we also understand that it is not our son or his diagnoses that are the problem. The problem is that the very systems designed to help him are still not equipped to do so.
What additional research is needed to help address co-occurring conditions for autistic people?	This means that our systems must be structured to distinguish between neurotypical and neurodivergent needs — and accommodate them accordingly. It means understanding that autistic youth are often unable to express themselves in the way neurotypical kids are and recognizing that autistic meltdowns are usually the result of unmet needs. It means adapting our existing teen mental health resources — including suicide prevention resources and screening and intervention tools — to accommodate the evidence-based mental health needs of neurodivergent populations. Recognizing the intersection of neurodiversity and mental health is paramount. Lisa Morgan M.Ed. CAS, a board-certified Autism Specialist and suicidologist, writes: "An autistic person is not a neurotypical person with a little autism. Autistic people have a different brain. Their brain is structured differently. They think, communicate, and experience the world

	differently, so they need support that meets their needs, not standardized, evidence-based, best practice support for non-autistic people."
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	We reside in New York State, where there's seeming confusion over which actual system is responsible for providing mental health services to the autistic population, as case management is separated between comorbidities, requiring an impossible choice of attaining services of the Office of Mental Health or the Office for People with Developmental Disabilities when in actuality one needs both. Different offices mean systems, which means different case managers, leading to a massive resource duplication. It suggests that case managers' purviews are distressingly limited in scope, never enabling them to provide whole-person care. And it means that all the while, the medical systems buckle under the weight of all the progress notes — and all the actual lack of progress
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Addressing these challenges will require a shift in discourse that moves away from siloed systems and fragmented services and instead prioritizes comorbidities. Labels are for insurance companies, not humans. This urgent, collective challenge calls for the commitment and work of self-advocates, healthcare professionals, lawmakers, and caregivers/families all working together — and the outcomes will define the mental health of a generation.

Name	Sleep Research Society
Demographic	Other
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>Sleep disorders are very common in autism, affecting up to 80% of individuals. Sleep problems are one of the most common co-occurring conditions that parents report to children’s pediatricians. Improving sleep is not only an avenue to improve health, but has profound effects on daytime functioning for the child and family. For example, daytime alertness and attention are higher with better sleep, and aggression is lower. Lower family stress and higher parenting sense of competence are also affected when sleep is better We would like to advocate for more research to address sleep problems in individuals with autism across the lifespan, as well as improved access to treatments, such as cognitive behavioral therapy for insomnia, in this population.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	

Name	Sloane Walters
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I struggle with insomnia and IBS but the most difficult are my sensory issues. My sensory issues make it difficult to go out in public with bright lights, loud noises, babies crying, or even the hem of my pants getting the slightest bit wet from a rainfall. All of these things will send me into sensory overload and makes me never wanting to leave my house.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	As someone who struggles with depression, anxiety, ADHD, and suicidal ideations, it has been impossible to live a “stress-free” life. Doctors always tell me to do something relaxing or not allow stress to affect me, but it’s not as simple as a snap of the fingers.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	School has been incredibly difficult as I have always been on a constant state of masking which impedes my ability to retain the information I learn.
What additional research is needed to help address co-occurring conditions for autistic people?	How autism presents in females needs to be researched more. Too many girls go under the radar until they’re adults who cannot function due to doctors using male diagnostic criteria.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	COVID-19 has impacted therapy availability and autistic people are left having to “figure it out” until they can be seen by their therapists or doctors. This is incredibly damaging to the continuity of care we need.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	A very positive impact is the widespread acceptance of telehealth, which allows people with sensory issues to seek care from their own house.

Name	Sonia
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	How expensive it is.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Sonja
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Difficulty obtaining diagnosis and treatment for co-occurring physical health conditions due to 1. Doctors do not give diagnoses even when symptoms are presented, and may make the autistic person think they are over reacting to "normal" health experiences, and/or the symptoms are due to a lack of self-care and good health behaviors. For example I was told to eat a balanced diet, get enough sleep, and exercise when I presented all of these symptoms: fatigue, back pain, menstrual pain, pain during sex, frequent UTI's, frequent yeast infections, frequent upper respiratory infections, hair loss, heavy periods, stomach aches, bloating, constipation, rosacea. I was later diagnosed with multiple chronic health conditions and auto immune conditions. 2. The autistic person is not aware that there symptoms are abnormal and/or important. For example, stomach aches, severe period pain, fatigue. I thought "doesnt everyone have that?" about a lot of my symptoms. 3. Its hard just keeping up with day to day life so autistic people have less time and energy to seek out diagnosis and treatment for health problems.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	1. Misdiagnosis, due to ignoring ways autism can present (esp in a highly masked individual) 2. Assuming that depression and anxiety are the primary/only problems a highly masked autistic woman has, and then treating those problems only 3. Treating mental health problems in a neurotypical way, when a neurodiverse friendly approach is needed. For example CBT and analytical approaches were detrimental to my mental health. It caused rumination, disconnection from my environment, guilt and shame becuase I thought I was not working hard enough at CBT, sadness becuase I thought I was broken after years of therapy and I am still depressed.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	As a parent, my son's learning disabilities were missed or ignored due to his having autism. The autism/adhd was the only focus. He had a full eval at public school age 5, age 8, age 11 and we were told he was average IQ, below average in some areas. At age 12 we took him to a private speicalty clinic and he was diagnosed with 3 specific learning disabilities and given specific supports for each and he is now reading at grade level, doing math at his grade level, and confident enough to participate in class.
What additional research is needed to help address co-occurring conditions for autistic people?	Health provider bias and Autism (ignoring, dismissing, or making incorrect assumptions about physical health symptoms in autistic people), Co-occurrence of Auto-immune condtions and autism, the effect of chronic stress and anxiety in Autistic people and how it relates to physical health conditions, the efficacy of treatments to lower anxiety, reactivity, fight/flight, cortisol, on autism and co-occurring mental health conditions, vagal nerve interventions and autism and co-occurring medical conditions.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Providers being trained in diagnosing chronic health conditions and auto-immune conditions. Providers validating symptoms, taking symptoms seriously, being aware of their own biases, not assuming people are not taking care of themselves and this explains symptoms. Providers being aware of the co-occraence of physical health problems in autistic people, especially women with autism. Providing care and treatment in a more neuro-diverse friendly, sensory friendly way.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	

What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

Name	Special needs mom
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Chronic constipation.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Intellectual disability ADHD Generalized anxiety Aggressive behavior This affects outings/gatherings, being able to find a safe babysitter, going out in public, etc. My child oftentimes doesn't have a sense of safety awareness
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Intellectual disability Developmental Disability and delays Academic challenges, reading/writing. Ensuring my child is being taught according to their level but also being challenged to perform to the best of their ability. Why are special needs children required to take end-of-year tests? Traditional classroom educators need more education regarding special needs children as well
What additional research is needed to help address co-occurring conditions for autistic people?	More non-white families need to be studied. More families that have girls with autism need to be studied as well.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Definitely adequate insurance coverage, once the diagnosis is given, the individual diagnosed should automatically qualify for Medicaid to cover costs that private insurance does not. Often times even physicians are a bit nervous when interacting with a patient with special needs who may be anxious and their anxiety can cause the special needs individual to become agitated and/or aggressive
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	It was a bit frustrating due to change in routine, children missing their friends, virtual learning being absolutely ineffective

Name	Stacey Senn
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbances impact his day to day most. He is unable to sleep until 3AM on some nights
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	For our son, anxiety impacts his health the most. He has difficulty accessing school and activities outside the home. Feels like people are looking at him.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	More research on Pathological Demand Avoidance since strategies are so vastly different than typical strategies used with autism. Without research, educational settings are difficult to access because administrators refuse to make accommodations for something that is not research backed.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage is our biggest issue as a family. Our insurance is through my husband's employer, and they deny us access to services despite state laws that are in place.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Delayed diagnosis
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Positive: telehealth and accessing services remotely are much easier Negative: reduced interactions outside the family delaying diagnosis. Hard to see impact on socio-communication if not around people

Name	Stanley Jaskiewicz, Parent of adult child with autism
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I cannot speak to autistic people generally, but I can speak about my son. At age 26, his greatest challenge is his anxiety, which has affected his ability to obtain full time employment. I think it also has contributed to high levels of stimming, including at work, which have affected his life.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	As noted in my response to question 1, anxiety. I have seen my son reveal layers of anxiety that my wife and I would never have imagined, but which affect his daily life.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My son's communication disabilities can limit his ability to interact with others, and obtain assistance when he needs it. For important interactions - job interviews, for example, or, when he was younger, his Eagle Scout Board of Review - we practice the conversation in advance. I feel that such practice gives him confidence in the moment, and helps him overcome possible mental processing delays (because he has already worked out answers to questions at his own speed, a phrase he has used often). But such practice is not always possible.
What additional research is needed to help address co-occurring conditions for autistic people?	1) Effective training for persons with autism on managing anxiety. 2) Promotion of workplace interventions to promote hiring of persons with autism, accommodation of their disability, and, most importantly, employer training to support and retain employees with autism.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Greater availability of mental health/anxiety counselors, skilled in developing trust with adults with autism. We have struggled to find a provider who can work with our son on anxiety issues. (His medical provider had spoken with him about them, but she recommended that he transition to a psychiatrist or psychologist. However, both work through talk therapy, which has not been an effective intervention with our son (other than informally with particular teachers with whom he had developed a relationship of trust while in school).
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Our adult son's aunt's husband died from COVID-19. As a result, I take great precautions. (I have a medical condition.) I think my son sees this level of concern, and has anxieties about being in certain public situations.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Our son graduated from college in May, 2021. He had not been on campus since March, 2020. As a result, he did not have an opportunity to use his school's career placement services to find a position in his field of study (and still has not found one today, almost three years later).

Name	Stephanie
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep difficulties like insomnia often poses a significant challenge in autistic individuals. Sleep disruptions can intensify core autistic traits, influencing communication skills, social interactions, and emotional regulation. Simultaneously, the challenges inherent in autism, such as sensory sensitivities and repetitive behaviors, can contribute to the development or worsening of insomnia.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression poses a significant challenge for some individuals with autism when it comes to co-occurring mental health conditions. The blend of autism and depression deeply affects overall well-being. Autistic individuals are at an elevated risk of depression due to challenges in social communication, sensory sensitivities, and the potential for isolation.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The co-occurrence of autism and intellectual disability presents some challenges such as communication, daily living skills such as self care, social interactions and adaptive behavior.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I think improvements in healthcare, Insurance, government benefits, transportation and access to services would be very beneficial to the autism community and for those who have co-occurring conditions.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I think the changes from Covid-19 have affected lesser access to services, City Transportation, doing online work and school, more online doctor's appointments and using online communications for friends and family.

Name	Stephanie Dulawa, UCSD
Demographic	Family member of an autistic individual; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	sensory challenges ADHD Growth hormone deficiency small anterior pituitary
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	communication
What additional research is needed to help address co-occurring conditions for autistic people?	more genetic testing more drug trials find biomarkers
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	more educational options more community activities
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	devastating for school and education
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	All.

Name	Stephanie Ranno
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	GI disorders causing severe constipation. Sleep disruption causing lack of focus and irritability. Sensory processing- leading to binge or overeating and health issues like obesity, diabetes, and fatty liver. Restricted eating leading to nutrient. Rejection sensitivity dysphoria which lead to explosive anger and mental health issues and affect social interactions. Echolalia which can severely limit communications and the ability to creat connections.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	adhd and RSD can lead to isolation, anxiety, acute mental health issues.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Echolalia can make sharing your knowledge and thoughts very difficult and can impede social connection. dyslexia, dyscalculia, and dysgraphia can lead to underperformance in academic settings not because the person isn't knowledgeable or capable but because they process differently. It can severely and negatively affect an affinity for learning and one's self esteem.
What additional research is needed to help address co-occurring conditions for autistic people?	We need to take a full-system, integrated medicine approach as well as highlight other non-drug related therapeutics that can help with the challenges.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	All of those listed - schools, insurance companies, service providers, healthcare organizations are all very quick to "not cover" or "not my problem to solve." It can be overwhelming and complicated for individuals and families to navigate to determine what's best. It can also be very expensive. And waiting lists are too long and services often too limited.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	The ability to work from home was very helpful but also led to back sliding for our kiddos in academics.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Some of the impacts were positive- remote work allowed for more line of sight into the challenges for my kiddos in the classroom. It also was a challenge for social connection and increased isolation and computer device usage which was a negative.

Name	Stephen Silva
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory issues and anger issues. Not being able to regulate emotions.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, stress, aggression.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Development delays(behind in reading and math).
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More coverage on how to help people interact with others.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It has lead to more anxiety and stress. With COVID, kids were at home so they couldn't get the social interaction they need to succeed.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increase in telehealth and decrease in social interactions due to events, services being shut down.

Name	Steve
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	That medical carers neglect or dismiss our symptoms, because we're autists ... and no-one likes autists, do they? Autists are got rid of ASAP, hence neglect.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Like all invisible disabilities, people don't believe they're there, and see no reason why they should care. They don't understand, but they judge us anyway, despite their profound ignorance of our condition(s).
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I have none of the above, happily. Note: our difficulties in social communication with NTs are due to NTs not knowing or understanding that we communicate differently. Between autists, there are no such problems; between NTs there are none; only cross-neurotype communication is affected. We don't have "communication disabilities", generally. [Except those of us who are non-verbal, of course.]
What additional research is needed to help address co-occurring conditions for autistic people?	A simple list of commonly co-occurring conditions would be a good start...
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Knowledge, by medical carers, that these conditions exist, and are associated with Autism. My doctors didn't know the gastro-intestinal complaints are very common among us, and hypermobility syndrome too. I have both.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Lockdown was a joy. My NT partner didn't find it so easy... Actual infection and illness? The same as for NTs, I think?
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	None that I can think of.

Name	Steven Lunseth
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	All in all my biggest challenge is sleep and sleep is my worst enemy. For all my life sleep has been a major struggle and has directly effect every facet of my life negatively.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression and Anxiety have been the biggest demons I have had in my entire life. They have been such a challenge that it is hard to do many thing without them trying to rule my life. While I have ADHD as well it is not as bad as the issues caused by Depression. Depression has led to suicidality and self-injurious behavior that had caused a myriad of problems in my life.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Social Developmental Disabilities have been a big problem for me. Even at 35 I am still developing social abilities that neruotypical individuals learned in childhood and in there teens.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Adult social support is one of the biggest issues with autistic adults at this time. Autistic people have a tendency to be rejected by society as a whole leading to mental health issues being exacerbated.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Personally COVID-19 lead to developing Fibromyalgia. Fibromyalgia has cause difficulties with getting proper medical care. It has caused my depression to get worse leading to greater suicidal ideation because of the fear it causes and the loneliness during a flareup. It is made worse by social isolation that comes with Autism.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	It is harder and harder to try and make any connections with people. It is also harder to get proper medical care. I moved into a independent living apartment run by Fraser which is a company based in Richfield MN. They said they had social opportunities that are just starting to come back but vanished during COVID. It made it harder to leave the home during COVID leading to a increase in Agoraphobia. As for positive things. Some companies are actively trying to hire neurodivergent people.

Name	Stevie Aubuchon-Mendoza
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Working is very difficult. Noise and sensory issues and sound processing, overwhelm and GI issues causing me to find coverage or leave clients to use the restroom. I also have POTS which sometimes makes me lightheaded, dizzy and leaves me feeling like I will pass out. Driving is also difficult with sensory overload and processing. It's almost impossible or at least extremely unsettling to drive at night. Sleep. I sleep with earplugs and a eye mask. I need brown noise going in the background to drown out any sounds I can hyperfocus on. Relationships. Unless we have a long history because of being family or childhood, I can't ,maintain friendships and sometimes feel very lonely despite not wanting to socialize.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression and anxiety.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication is difficult. I can mask really well but it is incredibly draining and usually have to nap after periods of forced socialization (work) or spend time alone for days. I have a very hard time with math, or tasks like reading instructions that cause informational overwhelm and analysis paralysis.
What additional research is needed to help address co-occurring conditions for autistic people?	More research on and for autistic adults and afab individuals.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More services for adults with autism.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It has made me more agoraphobic. Not clinically, but it is a lot harder for me to go out and do the things I was able to push myself through before.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Summer Bammes
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbances make it difficult to keep a schedule that can support education, employment, etc. Having more than one autistic person in the household can exacerbate sleep problems, because household members will keep each other awake. Pain from physical conditions can also disrupt sleep. Lack of sleep can worsen autistic challenges.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Research sleep! Both in autistic individuals and in their households. Research the relationship between autism and chronic pain. Research the effectiveness of different accommodations in schools and workplaces, both for autistic people and for their peers, teachers, and managers.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Medical case management for autistic individuals and their families. Proactive screening for co-occurring conditions in autistic people.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increased use of teleworking and remote educational programs have been an absolute godsend for me, but have also worsened my social isolation and resulted in some lost skills (e.g. planning to get to a workplace or an appointment on time). I dealt with agoraphobia for a good year after the first vaccine came out.

Name	Susan
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I've suffer from gastrointestinal issues that have sent me to the ER more than once. I have had sleep difficulties fir most of my adult life. The stresses of growing up undiagnosed in the 79s and 80s and being bullied have ked me to develop fibromyalgia. The comorbid conditions along with anxiety and periodic depression have led me to be underemployed. I live my job the the stress of trying to make ends meet, paying more than 1/2 my taxes home pay on rent, the stress if working in the care during the pandemic and dealing with long haul covid issues have probably shortened my life.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Periodically suffer from anxiety and ir depression most likely due to the stress of growing up undiagnosed. Getting a diagnosis in middle age was very helpful in understanding myself and eventually others. This improved my quality of life.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I do not understand why there are communication difficulties between nuerotypicals and myself but I know that there are. Also sensitivity to noise, fabrics etc have impacted my daily life.
What additional research is needed to help address co-occurring conditions for autistic people?	I would find training on communication for both those on the spectrum and nuerotypicals to be very helpful. More sensory friendly spaces would be wonderful as well. In addition better access to more comfortable clothing would be a boon.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Better, more thorough explanations of benefits, increased benefits for job trading and mental health too.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It ruined my physical health which impacts my mental health.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I can see that as a benefit for many but not myself as NY job is hands on.

Name	Susan A. Fowler, PhD, University of Illinois, College of Education
Demographic	Family member of an autistic individual; Service provider, health provider, or educator; Researcher; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Co-occurring mental health conditions (depression, anxiety, anger management) are common and yet not acknowledged by many agencies serving individuals with primary diagnosis of disabled or cognitively impaired. Individuals with autism can range on the intelligence scale from gifted to average to below average to showing intellectual deficits. Support services must acknowledge the importance of "dual" diagnosis and services that address mental health and quality of life regardless of assessed intellectual skills. Too often services are siloed as for developmental disabilities or for mental health-- these must be merged or at least coordinated to accommodate the "whole individual and address range of needs. Specifically my son has been turned away from DD services and community supports for individuals with DD because of mental health concerns and has been turned away from mental health supports because of perceived cognitive impairments--this is a no win situation. Individuals with autism can have complex needs across multiple domains--all should be addressed and not discounted as the responsibility of a different agency or specialty.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Those with co-occurring mental health conditions are often excluded from supports and access to services traditionally developed for those with only developmental disabilities. They are left with no supports.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Failure to recognize that people with autism can have complex needs which cross ability and disability categories. Autism is not a stand alone disability but often part of a range or continuum of disabilities (including learning disabilities, pervasive developmental delays, social interactions and communication). Services cannot be categorized only into speech language or psychiatry or physical therapy or digestive health. We have a desperate need to integrate services and to manage (case manage) the array of services needed by many individuals with autism, who have other co-occurring diagnoses.
What additional research is needed to help address co-occurring conditions for autistic people?	Post education resources for young adults who are not being served by Vocational Rehabilitation Services or traditional DD services and are unable to attend usual trade courses or community college without supports provided when enrolled in k-12 education. The loss of all supports typically provided through an IEP must be recognized and included in future planning documents that have legal standing to support the future employment and steps toward community living of all people with autism. Research should identify exemplary programs and how they work, are funded and supported and we need R&D funds to support the development of post education work and life programs to support and increase moves toward independence for those with autism. Family members (parents in particular) may not outlive those with autism and the loss of private or family support can leave them without resources in their communities.
What could be improved in autism services and supports to help address co-occurring conditions for autistic	Insurance coverage for mental health related services, equitable access to Voc Rehab Services, community college, trade schools with embedded supports to ensure successful engagement and completion of post secondary

<p>people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>training. Independent living and group homes in the community are desperately needed to house and provide socialization opportunities. Medical providers outside of the DD or autism field often treat an individual with autism as fully competent adults when in fact they may not understand or comprehend the medical plans, prescriptions or services recommended. Advocates or supports are needed to assist many individuals with autism to negotiate much of daily life.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>It has increased isolation and reduced opportunities for nearly 2 or more years for individuals with autism to participate in society. This loss of opportunity has significantly impacted any progress made prior to covid in terms of education access, job access, etc.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Services were disrupted for 2 years and have not been re-established; job opportunities have disappeared;</p>

Name	Susan Sigersest, Retired Autism Professional
Demographic	Family member of an autistic individual; Service provider, health provider, or educator; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Anxiety and sensory issues
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication
What additional research is needed to help address co-occurring conditions for autistic people?	How much time and support it takes to make sure a person with ASD is comfortable and able to perform in a new environment - school, work, social settings.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Support sisters for new environments - school, work, social settings.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Not sure - but isolation is always a problem.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Disruption in service and isolation

Name	Susannah Fields, Parent
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbances, aggression, danger to self and to others, elopement, impulsivity, chronic pain.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD, bipolar with psychotic features along with autism (no intellectual disability) causes constant challenges in a social/emotional level. She becomes verbally and physically aggressive, elopes from school and home, is bullied at school - and sometimes is the bully as she is not in tune to social cues. Suicidal and homicidal ideation when manic. Depression and anxiety are common along with self harm and feelings of worthlessness because she knows she's "different". She's been hospitalized psychiatric inpatient 16 times now. Only one hospital in the Phoenix metro area has focus on autism and the beds are always full. She was denied DDD coverage the first time due the fact her afflictions are mostly 'invisible' as she is fully mobile, able-bodied and intelligent.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Autism + ADHD + Bipolar Disorder combine to make a child who is never at ease, is always overwhelmed and primed for a meltdown. Her bright mind can't calm enough to properly learn or function in school. When manic, she's in and out of hospitals for months at a time until her meds are straightened out. She currently resides in a group home due to hurting her attendant care providers - she's been aggressive with her parents for years.
What additional research is needed to help address co-occurring conditions for autistic people?	Hospitals: Research the need for psychiatric units that also address the autism factor, not just the bipolar or adhd. Govt Agencies: Research ways to educate decision makers that lack of intellectual disabilities does not equal lack of need for services. Genetics: Research the correlation with genetic Ehlers-Danlos hypermobility syndrome. There is a subset in those with that syndrome who have multiple psychiatric comorbidities. Psychiatrists: Teach doctors to quit saying, "It's so rare". Even though things are going very wrong very quickly. Schools: Research into how to best support bright but severely affected kids. My daughter hates being lumped in with those who also have intellectual disabilities - she says she feels like a 'showoff' for being bright when in those groups - and just shuts down.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Health insurance is abysmal at coverage for mental health and psychiatric care. My daughter was on her dad's corporate insurance but it didn't cover almost any of her needs. It cost two thousand a month for her meds and tens of thousands for each hospitalization. Once accepted to DDD/AHCCCS we had to drop the corporate insurance which felt really uncomfortable/vulnerable but we were going to be bankrupt otherwise. Service providers for behavioral therapy and respite care (etc) are sorely lacking and wait lists are long. Part of that is covid, but part of it is minimum wage for those dealing directly with kids who have complex diagnoses.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Thankfully our family has been spared for the most part.
What lasting positive or negative impacts have societal changes due to	Negative: disruption in services across the board, including therapy and psychiatric hospital bed availability Positive: Reduced social interaction was

the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

actually very helpful for my daughter. Increased use of telehealth was great, fewer appointments away from home to affect her schedule and overall ability to cope with new situations.

Name	Suzanne
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My son is challenged by sleep disturbances, gastrointestinal, and epilepsy co-occurring conditions. He is non-verbal, which means we have to rely on our instincts when it comes to how he is feeling. If he has not had good sleep or feels off at all it affects his entire day. Which means he does not get anything out of his therapy or school for that day. If he doesn't sleep, I as his caregiver doesn't get and it means we both have a hard day.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Currently my son chooses self injury as his mode of regulation when he's upset. My greatest fear as he grows is he will begin to hurt himself in more harmful ways or begin to harm others.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Being non-verbal and not being able to know what hurts when my son is upset is the hardest piece of his autism currently. This means I rely on my knowing him, and run through a checklist of possibilities. Has he had a bowel movement? Could he have fluid in his ears? This then leads to multiple doctor appointments, and phone calls to discover the root of the problem and the route we then take to address his ailments.
What additional research is needed to help address co-occurring conditions for autistic people?	There should be more done genetically, and if stem-cells are proven to help some of these co-occurring conditions that come with autism. Imagine, if stem cells is something we could utilize in treatment early on in a diagnosed child's life? The possibilities that exist here need to be better understood and tested. Then provided and covered by insurance.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I am lucky to be able to be able to be home with my son. We are a one income household. If we did not make sacrifices so I could be home my son could not get many of the services I transport him to. In my opinion for my own personal situation. If caregivers in my state could get some form of income for being home, it would make for a better financial environment for our family. Daycares are needed that are equipped to care for autistic children. If these existed parents could continue to work, but subroutine choice sacrifice has to be made. Student loans, if a parent can not work due to caregiving for an autistic child some relief with regards to repayment would be life changing for many families.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Access to telehealth has been amazing for my family. Less travel when it comes to making appointments saves us on mileage, gas money, and stress of getting our kid ready and in a state where he can have a successful appointment. Traveling 3-4 hours one way for 15 minute appointment and then 3-4 hours back is hard on all involved.

Name	Sym Rankin RN, APRN, CRNA
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Autoimmune problems, gut health problems, neurological problems.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	OCD , anxiety, seizures
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication
What additional research is needed to help address co-occurring conditions for autistic people?	Research into the insane practice of vaccines during pregnancy, the effect of double doses of antibiotics before the incision is made and the baby is delivered in a c section. It Research into the insane practice of vaccinating a baby within an hour of birth with a vaccine for sexual transmitted diseases and drugs. What effect the aluminum has on the infants brain and immune system? Studies about all the vaccines given at 2, 4, and 6 months before the immune system is fully developed. Studies about the effects of giving a vaccine with another vaccine that is a live virus vaccine. The package insert says not to give a live virus vaccine with others but it is done all the time.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Stop using drugs to treat symptoms and use a functional medical approach to heal their immune system and their gut health. Make insurance companies pay for this treatment. Stop poisoning our food and environment. Stop the overuse of antibiotics and other drugs.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Treat the damage done by those who got the vaccine. Catch up the children who went without services during COVID. Get the insurance companies to pay for the therapies that work, not just medications to treat the symptoms.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	Disruptions in services. Their needs were ignored during COVID.

in-person social interactions and obligations)	
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Name	T. Gittleman
Demographic	Service provider, health provider, or educator; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Binary thinking as if something cannot be more than one thing (such as Borderline and ASD), having research predominantly on a certain demographic (white men) rather than more holistically reflective of the general population, and lack of in-person communities.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication and regulation
What additional research is needed to help address co-occurring conditions for autistic people?	Differentiating between ASD and OCPD, how ASD impacts AFAB/higher IQ folx differntly, gender dysphoria and ASD
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Free education for providers outside of a ABA lens of ASD, ongoing webinars about relevant advancements, such as what PDA is and how to work with it
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Tanina Cadwell, Unaffiliated
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I was born with a congenital diaphragmatic hernia (CDH) which came with a number of co-abnormalities (a likely origin of where my autism came from). My most severe physical challenges can be boiled down to autistic burnout, leading to fibromyalgia, difficulty going to sleep / staying asleep, adrenal fatigue, maintaining personal hygiene, and gastro-intestinal troubles. I work myself too hard in order to maintain a semblance of a neurotypical personae. As a result I completely exhaust my body and manifest a slew of physical and mental issues, many of which are difficult to resolve in the small amount of time I have available to recuperate. I have much more to put here, but the character limit 1500 is incorrect. I had a long passage under the limit, and it refused to accept it.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My co-occurring mental symptoms are as follows: Autism Spectrum Disorder, ADHD, Generalized Anxiety (GA), Obsessive Compulsive Personality Disorder (OCPD), cPTSD, panic attacks / meltdowns, and insomnia. As a result: - I live in "extremes" - it's very difficult for me to calibrate to the middle ground in anything I pursue - I often overwork myself to the point of burnout / flare-ups when given a novel and/or exciting task (e.g. If I go unmonitored, I will work a 12-hour day with one restroom break, will not eat, and will complete a task meant to be completed over the course of a week within one sitting. Afterwards, my brain/body will shut down for several days). - I struggle to deliver on tasks in a timely manner due to a rigid, compulsive need to deliver only my finest, most perfect work - I also struggle due to a perseveration on the "research" phase and an inability to follow a single, direct path (I hop all over the place). - I am often overwhelmed by strong emotions, especially in events that normally do not affect other people - I experience high levels of fatigue, bodily inflammation, and burnout from masking in different social environments, especially when I am overstimulated - I have lost my sense of self and identity. - I experience severe episodes of anxiety, shame, and depression when unable to complete what I perceive to be the workload ("day in the life") of an excelling, neurotypical person.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My co-occurring mental symptoms not previously mentioned are as follows: extreme Rejection Sensitive Dysphoria (RSD), extreme Justice Sensitivity (JS), pathological demand avoidance (PDA), oppositional defiant disorder (ODD), cognitive rigidity, perseverative cognition, emotional dysregulation, oversharing, and masking. My most severe challenges (at work & home) are predominantly triggered by (or are a result of) my (1) extreme Rejection Sensitive Dysphoria, and (2) extreme Justice Sensitivity: - I overwork myself often to the point of extreme burnout, hospitalization, or near hospitalization in order to maintain the ruse of an "exceptional neurotypical individual" - I will quit / end things abruptly - there is no changing my mind once it has been made - I stay in traumatic & stressful situations for far too long - I avoid confrontational conversations in order to avoid being "found out" as neurodivergent - I will "dig my feet in" when I disagree with something, to my own detriment (especially problematic when coupled with my PDA and ODD) - My perspective/relationship with others depends almost exclusively on my internal gauge of justice / injustice - I struggle to regulate my emotions when a less logical decision / path is taken - I often challenge others use of language, making it very difficult for them to engage with me - I actively avoid verbal conversations, preferring text to the point of skipping medical appointments to avoid phone calls / zoom meetings

<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>1. Burden Analyses for Late Diagnoses of Autism in Women: Societal pressures have made it much easier for us to fall “under the radar” when it comes to diagnosis, and we’ve lost years of resources and early development tools that have resulted in an innumerable number of mental and physical comorbidities as a result. Late diagnosis for women with autism has effects on the quality-of-life at the individual & population level, but also has innumerable effects socioeconomically. 2. Comprehensive Diagnostics for Women with AuDHD: Clinical diagnosis for women with autism (even ADHD, and especially AuDHD) is exceedingly difficult, and wrought with antiquated biases. 3. Tools for High Functioning, Level I Autistics: We need tools & resources for those “under cover” in the workforce / homestead. Many of us struggle with comparing ourselves to perform at the level of a neurotypical because we have no other quantitative / qualitative measure to compare ourselves to. Therapeutic approaches like CBT, exposure therapy, etc. can often be harmful to individuals with autism, while therapies more specialized to autistics are focused on Level II / Level III diagnoses. 4. Evaluating Misdiagnoses of Autism / AuDHD: Many of us struggle with misdiagnoses of bi-polar disorder, anxiety, depression, etc. This has led many of us through cycles of unhelpful medications / therapies, delayed our true diagnosis, and an extreme misrepresentation of autism (especially in women) nationally.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<ul style="list-style-type: none"> - Increase Financial & Service Support for Evaluations: children & adults can expect to wait several months for an eval, and many insurances do not fully cover it. A formal eval would cost me well over \$3K, despite being a “cut and dry” case. - Expand Financial & Job Search Support for Disabled Individuals: we keep ourselves trapped in unsafe jobs because the job search process is nigh impossible for a neurodivergent (even a high functioning one) to navigate. We often do not vocalize our disability due to the very clear ableism that still exists in the workforce, and sharing our diagnosis is incredibly risky when it comes to job security. - Tools for High Functioning, Level I Autistics: Already discussed in question 4. - Regulations to Better Protect Autistics in the Workforce: The existing regulations enable companies to work around accommodations for diagnosed autistics. Autistic employees are also at high-risk of being fired / not hired after disclosing a diagnosis, because companies do not explicitly state the diagnosis as the cause. - Expand SSDI/SSI to consider cases where “severe and frequent episodes of autistic burnout” meets the criteria: Many of us CAN perform the tasks defined as limitations under the SSA Blue Book. However, we can only do them for a short amount of time before we find ourselves in extreme cases of physical and mental duress due to autistic burnout. This leads to a cyclical spiral until we are no longer able to work, or even live.
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>Surprisingly, my mental health and physical health were drastically improved during the mass quarantine due to COVID-19. Because I was allowed to work from home, everyone had to wear masks, and many social / professional events were cancelled, there were fewer triggering stimuli and traumatic / stressful events to push me towards burnout. I very quickly deteriorated when people were starting to pick up conferences & hybrid work again - April of 2023 was when I ended up quitting my job of just over 3 years due to severe mental & physical symptoms of burnout. I’ve been unemployed since.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal</p>	<p>Same answer as previously: Surprisingly, my mental health and physical health were drastically improved during the mass quarantine due to COVID-19. Because I was allowed to work from home, everyone had to wear masks, and many social / professional events were cancelled, there were fewer triggering stimuli and traumatic / stressful events to push me towards</p>

changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

burnout. I very quickly deteriorated when people were starting to pick up conferences & hybrid work again - April of 2023 was when I ended up quitting my job of just over 3 years due to severe mental & physical symptoms of burnout. I've been unemployed since.

Name	Tara
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	For myself sensory processing can lead to extreme headaches, dizziness, nausea so environments that are loud and/or have strong smells and bright lights can trigger a very exhausting anxiety attack. It is currently making my job search very difficult.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The biggest challenge is to fulfill very specific needs in order to fight depression and anxiety. When I am forced to mask I become deeply depressed. Having to apologize for who I am also causes deep depression and the anticipation of this scenario also causes panic attacks. With my inattentive ADD I can become lost because my brain just leaves reality.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I did not find out that I had Dyscalculia until my 30s but it is clear that my autism made it difficult to get help and I ended up failing classes and scoring low on SATs. Anytime money or numbers are involved I can have a meltdown because I have a hard time communicating that I'm struggling.
What additional research is needed to help address co-occurring conditions for autistic people?	Keep asking different groups of people about their experiences. Especially women, BIPOC, LGBTQIA+ individuals. Not enough information because they are not getting the support they need.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Definitely easier access to support services and more knowledge shared with general public about autism and what accommodations we might need.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	What has been helpful is the increased use of Telehealth and work from home. It illuminates some stress. Normalizing this gives disabled people better care.

Name	Taylor Sweeting, Autism/ Marfan Syndrome Self-Advocate
Demographic	Autistic individual; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The challenges associated with autism and my co-occurring conditions (Marfan Syndrome, GI issues, sleep disturbances, diabetes, and high blood pressure) are synonymous with my behavioral challenges. For example, lack of sleep, high glucose levels, high blood pressure, and or GI issues can add to my irritability and make it more difficult for me to function in an overstimulating environment. Marfan Syndrome also contributes to my challenges in that my physical well being is compromised due to the complications associated with Marfans and that autism is now being identified as a co-occurring diagnosis along with other connective tissue disorders including but not limited to Marfan Syndrome.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	In my personal experience anxiety, depression, and ADHD are my most prevalent challenges. My autism causes me to over-think and be very hyper-focused on certain situations and issues as they occur. My anxiety as well as other hyper-focused emotions can be heightened because of this. Also, because of my autism I am overly critical of myself and hyper-exam myself and my introverted perspective is thrown into depression and critical self-doubt and my self-confidence can plummet because of this.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	In my personal experience my interpersonal communication skills can be significantly debilitated by my autism. Communication is a key skill needed for all ADLs and basic functioning, when it is impaired all other aspects associated with this are affected as well. I may very well be very gifted and or knowledgeable regarding a certain subject but because my communication is affected and more difficult to convey and or interpret that expertise is significantly impaired due to lack of communication.
What additional research is needed to help address co-occurring conditions for autistic people?	To address this issue it first has to be established that each case of autism is truly unique, and no two cases are the same. One way to unlock an autistic person's potential is by utilizing their special interest(s). By using the special interest of the individual you can almost guarantee that you can have their complete undivided attention and that they will be engaged in the conversation at hand. The special interest can then be utilized to illustrate specific learning points and objectives (for example: if a child's special interest is trains use that to illustrate a math problem "if one train leaves from Boston and another train leaves New York and they are both going to New Jersey how many trains will end up in New Jersey?"
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More accessibility to services that are geared to aide us in understanding those services and specific assistance from people to help us navigate those services as well. Also in addition, more training geared toward services provided to autistic consumers provided by autistic self-advocates (Nothing about us without us!).
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	For me personally COVID-19 has had lasting affects in co-occurrence with my Marfan Syndrome, diabetes, and high blood pressure. Lasting lung complications, long COVID symptoms, and respiratory system irritation. On the mental health side of it, COVID left me with a strong sense of isolation as well as lasting anxiety and depression as a result of not only having the infection but due to the reaction from others from me having the infection.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on	The use of remote work and services have been a tremendous asset for the autistic community. Being able to reduce the amount of social interactions

physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

one has to endure daily to remote access has been very positive and I have for one been very active using remote services in response to the pandemic.

Name	Tempest
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Some Autistic people are hyposensitive to stimuli and struggle with interoception which can make identifying issues and symptoms difficult. Personally, I tend to be more hypersensitive and am almost always over-aware of any discomfort in my body which can make managing symptoms difficult as I don't tend to get much relief, especially with my sleep disturbances. I struggle with insomnia, sleep-paralysis, and nightmares that regularly affect the quality of my sleep most nights, which makes managing sensory overload more difficult. My GI tract is also sensitive and nausea, constipation, and diarrhea are common issues that affect my life daily. I also have POTs syndrome which contributes to my sensory issues (temperature dysregulation, "air hunger" aka feeling like I can't get enough oxygen, racing heart rate, etc) and exacerbates my GI issues.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My ADHD consistently butts heads with my Autism (ADHD wants novelty and spontaneity while my Autism craves familiarity and routine, for example.) So I often struggle to keep a routine and end up falling into depression and worse anxiety. When I do accommodate my Autistic need for structure and routine, I thrive. My meltdowns tend to be self-injurious, even as a 22-year-old adult. I often come out of a meltdown with self-inflicted bruises and marks. Suicidal ideation often accompanies my meltdowns. Depression and anxiety have plagued me for years. The first time I showed signs of social anxiety, I was three and it ended up causing me to drop out of dance lessons (something I regret to this day) as I would refuse to go in. Depression first started to plague me around middle school after years of bullying that continued even in middle school, leading to self-injury and suicidality. I also struggled with anorexia in high school, it started because I needed a sense of control and I knew no one would bat an eye because I had been a lifelong picky eater with sensory issues around food who didn't enjoy eating very much anyway. I also struggle with OCD and hypochondriac tendencies which impact my daily life greatly.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	More research on Autism in BIPOC communities, the LGBT community, as well as for women. These communities are under represented in overall Autism research, especially BIPOC communities. Research into the way co-morbid Autism and ADHD present as the two often contradict and the AuDHD (Autism and ADHD) person often may not relate to a purely Autistic or purely ADHD experience as their comorbidity interact in such a way that makes their AuDHD experience unique.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More support and resources for Autistic adults. Many of us are left with no supports. 85% of Autistic adults with a college education are unemployed. I am Autistic and an adult with (currently) no college education and am unemployed as my Autism makes holding a job extremely difficult and leads to Autistic burnout and suicidality. How many other Autistic adults without a college education do you think are struggling to find community and resources to help them?
What lasting impact has COVID-19 infection and illness had on co-	COVID-19 is the cause of my POTS syndrome and as I said in the first question, it can exacerbate my sensory issues. Subsequently, the lockdown

<p>occurring physical and/or mental health conditions for autistic people?</p>	<p>had an extreme effect on my ability to mask and cope with my autism symptoms.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Negatives: The masks, while necessary, prove to be a sensory issue for me and many other Autistic people. Service disruption could upset an Autistic person's schedule which may be extremely rigid (Mine tends to be flexible to accommodate my ADHD, even though I would prefer a rigid one. However, I am still distressed by schedule changes.) Positives: The chance to unmask, telehealth options, remote work/school options, reduced obligations, and the ability to stay home to mitigate sensory input.</p>

Name	Tetyana Davis
Demographic	Autistic individual; Family member of an autistic individual; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The most significant challenges caused by co-occurring physical health condition is blurring of the lines between causes of each symptom and gaslighting of the medical community.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Misdiagnosis.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Social perception that autism is equal to learning disabilities or intellectual disability.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Trained liaison or patient representative that will help communicate with health providers and remind them to not blame everything on autism.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Remote education and job opportunities are the biggest positive impacts of Covid-19.

Name	TG
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Delayed sleep phase syndrome Postural orthostatic tachycardia syndrome Due to these I not only function on a much later schedule than others, i also have at times extreme fatigue. This makes life very difficult and the judgement from others is debilitating because they think I look fine and should be able to do everything they can do.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Pathological demand avoidance This autistic profile is so misunderstood.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Thomas
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	It is very hard to plan a day. I get anxious about having to run to the bathroom or some stomach pains. It is hard to plan for that as my body can be unpredictable so surprise plans give me anxiety. Also my sensory issues can make going new places hard or overwhelming. High Support needs so it is often hidden from others. I
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	anxiety, depression and cptsd. A lot of anxiety from being hyper aware and making sure everyone is not mad at you and that you are not acting weird in public. cptsd is because of being criticized for everything you do differently.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Speak more to low support needs autistic people. The research is way too focused on childhood. Most high masking autistic adults do not realize until they get burned out. We've always felt something was wrong with us so we kept quiet.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Make it easier for us to ask for help. When autism is described only in children, many adults won't be able to recognize that. Overall more training on dealing with anxious people would help many autistic people. We are constantly worried someone is mad at us or we will mess something up. Also worried about being told we are lying about our issues or accused of having ill intent.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Negatively it has impacted how people treat one another. They are much more hostile to everyone. It felt easier at first since everything was remote and social interaction was not required. It did cause a lot of emotional weight with watching the virus kill, shut down places and cause a huge rift that is still not fixed.

Name	Tiana
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Lack of understanding and lived experience information guiding practitioners/providers and immense stigma around autistic experience with co-occurrence of other neurodivergencies/conditions.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Stigma, insufficient awareness and not understanding autistic experience to ensure link in of appropriate supports.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Lack of flexibility to pre-existing structures, stigma, unrealistic expectations and lack of willingness to implement adaptations because it is just too hard for them supposedly.
What additional research is needed to help address co-occurring conditions for autistic people?	Lived experience research consulted/designed by and run by autistic individuals to guide change within different communities of autistic people such as young, older, rural, lgbtiqa+ etc. Also more research about neuro affirming supports and supporting those with PDA presentation within different settings
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Equitable services, mandatory lived experience training, shut down of harmful neuro conforming services, autistic representation within all industries to ensure only beneficial support provided that actually supports autistic people be authentically them instead of the current ones that traumatise them, gaslight them and exploit them.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Minimisation of experiences due to "shared experiences" during covid.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Remote learning and working options however a lot have reverted, more connections made between neurokin and some improvements in less pressure to be doing more out and about.

Name	Tiffany Marie Ryan (Brittingham)
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator; Representative of advocacy organization; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gastrointestinal conditions Sleep disturbances Sensory and motor challenges Anxiety PTSD/C-PTSD Epilepsy Alexithymia ADHD Pre-eclampsia and premature birth Substance use disorder Asthma Allergies Obesity Psychosis Postpartum depression Fibromyalgia Hyper mobility
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression Anxiety Self injurious behavior Suicidality Repeating the above because they also cause mental health concerns: Gastrointestinal conditions Sleep disturbances Sensory and motor challenges Anxiety PTSD/C-PTSD Epilepsy Alexithymia ADHD Pre-eclampsia and premature birth Substance use disorder Asthma Allergies Obesity Psychosis Postpartum depression Fibromyalgia Hyper mobility
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication disabilities- hard because society at large isn't flexible
What additional research is needed to help address co-occurring conditions for autistic people?	Research should be led by autistic people with intersectional lived experiences. This is URGENT.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Start with urgent care to prevent harm for the future and go from there. Expand disability services to reflect market rates (instead of forced poverty). UBI preferred because how many folks are undiagnosed? Statistically, UBI is more effective. Universal intersectional healthcare Universal intersectional mental health and spiritual care Prenatal and family services Educational supports Educate everyone in public service and healthcare in neurodiversity and divergence
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Who knows. Probably a lot of us triggered with OCD. Personally, knowing the data I'm concerned.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increases in remote work and telehealth

Name	Tosha Brothers
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	As an autistic individual who has navigated severe anxiety, depression, and OCD, I emphasize the need for tailored mental health support. Meditation and mindfulness were instrumental in my recovery, offering separation from destructive emotions. Autistic brains process information with detailed exactness; therapies must respect this intricacy. Personal autonomy is crucial in treatment—every reaction in an autistic mind has a domino effect. My journey from deep despair to a place of continuous improvement underscores the potential for resilience and recovery in the autistic community. Our experiences are nuanced and deeply informative for mental health research and practice.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My learning disability, dyscalculia, has inhibited my ability to do math beyond a fourth-grade level and held me back from graduating high school. Though I did the tutoring the school provided, it was insufficient and led to feelings of worthlessness. If they had accepted my learning disability, along with my autism without pushback, I would have been able to home-school instead. Sometimes there should be more of a focus on a student's strengths, rather than their weaknesses. That way, autistic children with learning difficulties could go into society feeling confident instead of ostracized. Above all, IEPs must be upheld for these vulnerable students.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Tova
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	For my kid, PDA, Sensory issues of putting things in mouth and fidgeting roughly to break or tear apart most items picked up, and picky eating to an extreme.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	PDA, ADHD, suicidal ideation
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	struggles with handwriting and converting ideas into writing
What additional research is needed to help address co-occurring conditions for autistic people?	PDA
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	school services for 2e neurodivergent kids are hard to get
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	big gap in socialization for children

Name	Tracey MacDonald, Profound Autism Alliance
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbances/insomnia is one of our more pressing issues with our 26 yr son with autism. This past weekend he decided he wanted to go swimming at 11:30 pm in our community pool. My husband and I had both gone to bed but I was able to hear the door chimes after he left the house. Although our son is "water safe" he is unable to differentiate when the water is too cold or too hot. He also makes loud stimming noises and plays his videos somewhat loudly. We have had neighbors complain due to the noise and the late hour. If we were not with him, he would be unable to answer any questions, handle an angry neighbor, respond to police or heaven forbid if he fell, hit his head or was hurt in any way - he does not have the communication skills to come tell us. His inability to sleep "normal" hours causes us undue stress related to his safety and requires us to be "on call/awake/responsive" 24 hrs a day. Despite our efforts to utilize as many safety net features as possible (door chimes/alarms on every door, Ring cameras, endless social stories and reminders to not leave the house without mom or dad, our son continues to have sporadic episodes .
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Our son has limited to vocal ability so I am limited in my ability to respond to this. I wish I knew if he was depressed, had anxiety or wanted to hurt himself. He does seem to be OCD and will roam the house moving and replacing items throughout the house. Currently every decorative vase, jar, and bowl - along with all of our glassware are stacked up in his room. Any attempts to move any of these items causes him distress. These hoarder-like tendencies are becoming a health issue as he will not allow us to move, touch or clean any of these items without getting upset and anxious. If we try to do while he is out at an activity, he will be obsessive for several hours to make sure everything is in its place.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication disabilities - with a very limited vocabulary (1-2 word responses or "video speak"), our son is unable to tell us when he is not feeling well, hot or cold, tired, hungry, sad or happy. He seems to have a high tolerance for pain and we will not know anything is wrong until the situation becomes critical.
What additional research is needed to help address co-occurring conditions for autistic people?	Cross functional teams that speak to each other. More experts available. Shorter wait times (currently waiting 6-24 months for appts). Access to crisis care beyond emergency rooms/police - once a situation gets to this level, it is difficult to get our son to comply with emergency personnel.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Access to knowledgeable, local doctors/therapists - especially those that work with adults. We had more medical support when he was able to see a pediatrician but once he became an adult, their were no drs. that could address his autism. Reduced wait times for appointments. Education of emergency response personnel. Cross functional teams that work together with each other. With limited verbal ability, and lack of medical knowledge, it is hard to know what to ask for. We have been referred to doctors, waited months for appointments only to be met with blank stares as to why we are seeing this doctor. (Example: sent to endocrinologist who asked us why we were there - said we were referred and our son is obese. These said until he is diagnosed with diabetes (he is pre-diabetic) they could not help us. This out of network, \$500 appointment which we waited for 3 months left us feeling hopeless and stupid.
What lasting impact has COVID-19 infection and illness had on co-	

occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	We had to provide all services ourselves as no options were available for over 18 months. My husband and I work full time and it was difficult to provide activities

Name	Tracy Dixon-Salazar, Lennox-Gastaut Syndrome (LGS) Foundation
Demographic	Family member of an autistic individual; Service provider, health provider, or educator; Researcher; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Co-occurring epilepsy is a major issue in autism community and nearly always represents a worse course of the autism, including risk of premature mortality.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Aggressive behaviors are a major concern in the autism community and are a huge danger for people with autism and caregivers.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	One of the major issues is that caregivers and programs designed to help individuals with autism may be prepared to deal with the autism, but when you add in seizures and intellectual disabilities it becomes nearly impossible to find a carer or program that can assist. This causes families with all 3 of these issues to self-isolate at home because their loved ones don't "fit" anywhere.
What additional research is needed to help address co-occurring conditions for autistic people?	Further research is needed to understand what type of live individuals with autism, epilepsy and IDD are experiencing and what the impact is on the carer.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	For our Lennox-Gastaut Syndrome (LGS) community where co-occurring autism/autistic features, epilepsy and IDD are in nearly all individuals it is difficult for carers to find services that can help. Respite carers are inadequately trained, group homes can not often handle the excessive seizure burden, and hospitals divide each of these issues into separate health conditions requiring multiple specialists. This leads to the carer having to "quarterback" all of the specialties and the individual is not treated holistically. This is especially true in adult care and in rural pediatric care. The end result is that many of our families self-isolate out of necessity, which causes even further social isolation for carers, siblings, and the person with autism.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	In many cases, COVID has worsened the epilepsy and aggressive behaviors in those in our community. My daughter developed long COVID and her seizures went from 2-3 a week to 30-40 a week with multiple episodes of status epilepticus each week. This has been her new seizure baseline since getting COVID 2 years ago.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	

in-person social interactions and obligations)	
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Name	Tracy Johnston
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Severe, chronic GI issues Severe Anxiety Emotional outbursts, meltdowns rigid thinking Chronic ENT issues
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety depression aggressive behavior destruction of property
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Learning issues Executive functioning issues
What additional research is needed to help address co-occurring conditions for autistic people?	Lots -- until there is real help readily available
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	New therapies and treatments that acutally help and actual access to said treatments.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	It seems like access was as bad as it always is.

Name	Trayle
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The fact that co-occurring physical conditions are dynamic, i.e., they change over time and space, and can be more/less debilitating depending on the situation. It is complex and difficult (impossible) to predict.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The most significant challenge caused by co-occurring mental health conditions of autistic people is that mental health for autistic folks is difficult to evaluate, i.e., such conditions may not be apparent or exhibit themselves differently than for typical folks. Important to notes that it is often difficult for autistic individuals to describe or explain their lived experience of depression or anxiety etc., or even to name it. Also - existing treatment (e.g., CBT) can harm autistic well-being. Lastly, mis-diagnosis, of course, incl. marginalized folks (people of color, poor families) are apathologized more than more privileged folks.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Researchers and health professionals often presume incompetence because communication with autistic people can be challenging. someone with impaired brain function is still competent- it just might take longer to communicate.
What additional research is needed to help address co-occurring conditions for autistic people?	Research with a critical lens that questions the status quo, research with and BY autistic researchers.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Patient-provider interactions is the basis of many challenges - when a patient and doctor TRUST each other, it is a solid base to address other conditions and find effective care solutions. It could be improved by raising awareness with providers about autistic experiences (and the diversity therein), and providers need to be supported to take more time with patients (the are overworked).
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Positive: More options for participation in society - online or remotely. Negative: death. folks with mental health or neurological conditions at the bottom of the triage.

Name	Ty Shields
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My autistic daughter gets gastrointestinal issues frequently. We have to make sure her fiber level doesn't drop below certain levels or she could have physical discomfort which leads to emotional dysregulation, which leads to getting in trouble in school. If we had more research (preferably including input from autistic people), we could solve so many problems.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My AuDHD daughter has emotional dysregulation and sensory issues. Talking and working with autistic people in research will do so much to help her to focus and succeed in school, not to mention the mental health toll it takes on her to be told she is "disruptive" and "attention-seeking" to the point where she feels she is terrible and that "no one likes" her. She is an elementary school student. My ADHD (possibly AuDHD) niece is already experiencing this same trauma, and she just started kindergarten.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Letting the autistic community have more say with the research. Don't just see what "works", such as in the case of ABA; also ask how they feel and what effects such things have on their mental health.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Don't treat autism as a "behavioral" issue. It's an emotional regulation issue. They are having trouble with self-regulation. The answer isn't giving them sweets and stickers and punishments. It's sitting with them, talking with them, helping them find coping techniques that work for them and not against them. Some of the traditional things don't work, like breathing exercises. Sometimes thinking of things that are their special interest (sometimes called hyperfocus by "experts"). Don't take those away. Also, meltdowns and tantrums are two different things, not the same, as autism "experts" refuse to believe/understand. Listen to the autism community.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Val
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep issues - not being able to get to sleep or sleeping too much. GI issues - specifically from dietary issues.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression and impacts of relationships issues, bullying, low self esteem. Anxiety specifically PDA driven anxiety Suicidality
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	PDA. Impact on relationships, learning, education, communication, understanding of the impacts of this on the child and the adult .
What additional research is needed to help address co-occurring conditions for autistic people?	Further research on PDA with a view to inclusion as a diagnosis within ICD and DSM, that will allow educators and social services an understanding of the impacts of this condition and provides genuinely helpful advice and interventions that support people with this condition
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	As all cited above - when our grandchild was diagnosed we were offered education on autism broadly but the suggested interventions do not work for PDA That's not equitable
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Val Luther
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The lack of understanding and recognition of Pathological Demand Avoidance in the US has negatively impacted how my son is treated by health care professionals and in school.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The first recommendation from healthcare and even some mental health care professionals for Anxiety-like symptoms are treating with medication rather than recognizing that accommodations, supports and changes to the environment are considered.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Ableism has been the biggest challenge for my son. Others view that what he is being asked to do is "not that much" and therefore withhold accommodations and use behavioral interventions.
What additional research is needed to help address co-occurring conditions for autistic people?	Research about Pathological Demand Avoidance and researching updated, Autistic-led training for health care professions (including Developmental Pediatricians!)
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Access to neuro-affirming care. In NJ I had to opt out of my son being put on a state registry of individuals who are Autistic and despite my written request, the doctor's office still had him registered. We must protect children's privacy. Also, updated services so ABA is not pushed on families.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Positive effects for our family have been Telehealth appointments

Name	Valerie Beckwith
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Balance and coordination issues, insomnia, sensory overload in public spaces (aggressively brightly-colored advertisements, harsh lighting, lack of personal space, too many smells etc)
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression, lack of self esteem and confidence due to social isolation, suicidal ideation, OCD
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication is difficult and frustrating due to the nature of our speech patterns (and unwillingness to lie, it can cause literal pain in some people).
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Basic universal income, make public spaces more accessible, better insurance coverage & designated public transport
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	The lockdowns made socially isolated people even more isolated. Many of us who were in school during the pandemic feel “stuck” and are developmentally behind where we should be because we missed necessary coming-of-age landmarks
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Valerie W, Self and child
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disorders. Learning disabilities. Eating improperly. Lack of drive to want to learn. Not being seen in the classroom my child is high functioning and gets treated like a burdon and like they are in the way in all 3 public schools they have attended so far. Staff like to act my child is just constantly overreacting. Educators need to be better trained. The attendance policies are counter productive to our specific needs.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression ,anxiety, self harm, negative self talk adhd my child has attempted suicide twice since returning to in person school. My child has stopped attending class 2 months ago due to mental health reasons we are waiting to be accepted into the virtual program but it is taking forever.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The lack of support in public schools. The stigma that surrounds the label andvasking the schools to be patient or to try and include a child that has missed any amount of class is ridiculous. The schools are underfunded. The teachers are unwilling to reteach anything. I suggest that all public schools classrooms be filmed and that days recording be sent home to any child that missed that day. Teachers are public servants just like police men sho have to wear body cams. The same principle should apply. My childs inability to communicate their needs leads to even further division, separation, and animosity towards my child and it's not right. Staff need better tools better funding and better education.
What additional research is needed to help address co-occurring conditions for autistic people?	Speak to the schools ask why the animosity. Why are us parents asking for help always met with such tremendous push back. Especially when our children are high functioning and need to be with other children that function on a normal level and not in special needs classes. Do better.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	The public school systems need better funding, less restrictive policies that allow for a little give in places like attendance or a better way to deal with absences, and the staff need better training to learn how to deal with children that they deem "difficult" . Insurance needs to cover high functioning just as well as others and need to pay for any tutors or outside that any child not just mine needs.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	My child has had worsening depression. The attitude of faculty and staff at Education fatalities has become less tolerable more quick to snap back and place blame on my child for being in hospital and missing school. The overall attitude of all people involved with my childs health and well being have drastically gone down hill since the pandemic. The world is on fire, the functionality of our government is laughable at best and nobody seem to give a crap about another human because they are all miserable facing their own issues, climate change, us funding a genocide against our will. I get it. But its in our governments hands to fix it because we are all powerless but it seems more concerned with showing naked pics of our President's son on the congressional floor than doing anything for the American people and everybody everywhere is tired of it. Tired of not being able to afford basic needs, tired of our voices falling on deaf ears. Tired of fighting "mom's for

	liberty" and the like for our children to have some semblance of a future yet here we are and its only getting worse.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Bad. very very bad. I don't want to admit to any of it being lasting because I have faith that our government is going to get its [profanity redacted] together and Fix it.

Name	Vanessa Farrand
Demographic	Autistic individual; Family member of an autistic individual; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory processing issues are something that I see troubling children and adults. And are not receiving enough support.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD and anxiety are the biggest mental health conditions that I see troubling much of the autistic community.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication can be such a struggle. Even in higher function individuals. The ability to understand how to communicate effectively with others and in turn understand the unspoken within a conversation. This is something that also needs to be addressed and can help tremendously, especially if supported at an early age.
What additional research is needed to help address co-occurring conditions for autistic people?	Addressing the differences between male and females with autism. It can present so differently. Educating others about how broad the spectrum is. More supports in schools to help.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage for less traditional methods of helping individuals. Easier access to testing for adults.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	More opportunities to work from home.

Name	Vanessa Smith
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have seen all of these issues in my 14 yr old autistic child. I also believe PDA (pathological or pervasive demand for autonomy) is an area that needs more research. My child experiences many of the characteristics of being "demand avoidant" and it is a source of much distress for him, me as a parent and other professionals working with him who don't have an understanding of it.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My child experiences problems communicating with peers but it isn't clear to see. He presents as "typical" because of masking so he just looks to the outside world like he has bad behavior when it is really due to the limited social skills and anxiety.
What additional research is needed to help address co-occurring conditions for autistic people?	I would like to see more research into PDA as a possible autistic profile and more resources to help people with this profile.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	If there was a clear diagnosis for PDA and understanding of it by professionals then it would be easier to get both the services and insurance coverages needed to help children like mine.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The ability to have more services available online has been both a positive and negative for my child. It does allow him to meet with therapists from further away and also in a convenient and comfortable setting for him (home) but there are times when in person services are really the only effective option and making them available remotely simply isn't good enough.

Name	Veve Crowe
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The most significant challenges would be everyday life. I can't be independent, I can't work as I'm in constant pain and have very limited energy(this effects me physically), I can't sleep as much as I need due to insomnia and when I finally can sleep, I can't do anything when I do wake from an appropriate amount of sleep because everything important(ie postal services, dental services, hospitals, etc) closes at 4/5/6pm, I have a very limited amount of food I can eat due to sensory issues. Eating and talking and socializing can put a strain on my body, put me in more pain than I already was in. A single bad sensory experience could ruin my entire day and make it so I can't do anything, especially if it causes a migraine, for the whole day.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My Anxiety prevents me from having a job, from eating certain foods, from cooking certain foods, from sleeping in the dark, from having someone behind me or talking to me or perceiving me. My OCD makes it so I need to have things in a specific way or I legitimately can not function. I can't use dishes that I haven't cleaned two or three times, my food has to be on the dish in a certain way. My Speech Impediments make it difficult to talk and communicate to get what I need which, paired with my monotoned "sarcastic" voice, cause people to believe mocking, insincere, or rude which leads to a hostile encounter despite it just being my voice. Something close to Dyslexia makes reading and writing difficult, making words fuzzy or double or change or disappear, which in turns gives me migraine. Migraines. I can get them from everything which makes our loud, cacophonous world hell to live with. A change in temperature, the cold or heat, a sudden loud noise or repeating loud noises, people talking too loud, people talking too quietly, bright lights, allergies, smells, myself talking. Sensory Processing Disorder makes sensory input either limited, which means I sometimes don't notice I'm being harmed until several seconds later, or too much, which means even my clothing hurts to touch my skin no matter how soft. I could touch a hot stove and not notice until a few seconds later even when I'm looking at it, injuries go unseen until blood is or some pain is finally felt.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	It's difficult to speak to people verbally. I can never find the right words as they're either the wrong ones or they're too simple to properly convey what I want to say. Words are said wrong way round, the words get caught in my throat, all the words I know disappear when I have to speak. My thoughts are rarely verbalized as they should be which often causes fights, irritation, and hostility because my brain I can't properly word correctly. Even typing is difficult. I often repeat my words or phrases, sometimes I echo the person without knowing and that also starts hostility. I'm unable to live on my own due to not being able remember to eat or clean or recognize the passing of time or remember any important facts about being independent apart from maybe some cooking and doing the laundry(which I then forget I ever did until I pass it). I can't remember things that will help me live once they leave my sight, including my phone.
What additional research is needed to help address co-occurring conditions for autistic people?	There needs to be more research into why caffeine and other stimulants affect us differently, more research into autism symptoms amongst ALL genders(get as many as possible, Cis and Trans, and include POC) to see why autism could present differently in people based on gender and race(social factors. always social factors), why we need to build a society where autistics who can work CAN, research into uncommon autistic traits and why these are often over looked or underdiscussed outside of ASD circles.

<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Equitable access to/accessibility of services, better insurance coverage, proper training for service workers regardless of "how often" they work with autistics, better public transportation services that allow us to get to and from appointments(works for disabled allistics as well), more understanding from providers, better awareness about how autism presents and that not all us are cis white men/little boys.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>There's been disruptions in routines, disruptions in services, caretakers can't take their clients out with how everything is and the reduced interactions has just isolated many who usually were able to socialize outside before. Sure, reduced social interactions can be nice but we need to socialize every once and while as we are a social species. Without it, we become withdrawn, depressed, poor in most mental senses of the word. Caregivers must be allowed to accompany their client, especially if said client needs them for everything. Isolating them further does nothing but harm the community.</p>

Name	Vicki Markowskin, Mother
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Anxiety and how it can affect an individual that is neurodiverse . Both of my children developed debilitating OCD that required hospitalization. I think parents need to be educated about the affects of untreated Anxiety . More mental health providers are needed . It took me 3 years to find an ERP therapist . We had to leave the state for treatment for my son.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	For me it is figuring out what disorder is the cause of the behavior . I need support that is not available . Many times teenagers with Autism rage and are abusive and destructive.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	How they are treated there needs to be more understanding and inclusion .
What additional research is needed to help address co-occurring conditions for autistic people?	How to alleviate anxiety , provide needed therapies . Earlier and better diagnosis .
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Definitely patient provider interaction - I have had experience with providers that dismiss my child's health issues , even ones that have been cruel .
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I feel Covid-19 destroyed my children's lives and mine . My son was a happy child , playing soccer , scoring well on speeches for 4-H , taking I swimming lessons , having a routine helped him . Then he was isolated .All the media , fear , his anxiety increased , his therapist could not see him for months so he lost treatment for his OCD which became debilitating. He is not the same child he was before . My daughter still wears a mask ,is afraid to eat out in public - she also had no access to therapy . When Covid struck she was attending an inclusive college program and learning independent skills .
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The lack of routine , social interaction increases anxiety. Isolation lack of therapy , use of electronics to try to find social interaction .

Name	Vicky Scollay , Parent
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory challenges and demand avoidance- my son has PDA profile and hasn't attended school since 2021.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Huge anxiety and demand avoidance stop my son attending school and taking part in any activities
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Demand avoidance impacts our entire family: can't go out, go on holiday, do any activities
What additional research is needed to help address co-occurring conditions for autistic people?	Research into Pathological Demand Avoidance
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More creative ways to access support ie CAMHS when young person unable to engage
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	My son stopped going to school and didn't leave the house for nearly a year- catastrophic
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Victoria Miller, TCCMO
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory challenges which impact food acceptance, hygiene, getting dressed, specific activities, i.e. being outdoors, being wet, enjoying music or activities with loud sounds.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Often OCD, ODD, ADHD are overlooked as components of ASD in younger youth and older youth/adults are often overlooked as at risk for depression/anxiety and SI...
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Inadequate educational services
What additional research is needed to help address co-occurring conditions for autistic people?	Effect of diet/specific foods or additives, impact of overstimulation or soothing behaviors utilizing screen time/electronics
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Access to interventions, particularly early interventions, better screening in school settings and more support in public school settings for individualized education
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	The multi-year gap in interactive opportunities in community has been a setback, dependent on age at time of social disruption.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Many individuals became much more isolated and socially regressed

Name	Vienna
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Constipation, sensory and motor challenges, hyperactivity and learning disability
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication challenges
What additional research is needed to help address co-occurring conditions for autistic people?	Metabolism, connection between brain and gut and overall inflammation in the body and the need to make it accessible
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Equity and doctors that listen to caregivers, not being dismissed and denying information and beliefs
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Learning in isolation was hard. Not having access to medical providers and therapies
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Viki Quirk
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My son does not sleep through the night and never has. He struggles to fall asleep and even with supplements and medications to help, he is still unable to sleep independently.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My son has very high anxiety which makes it very difficult for him to go to school. He refused to attend school for over a year. He acts very aggressively with his brother which has caused a lot of damage to their relationship and my younger son now needs therapy to address the harm it causes him. Despite all of our best efforts, we don't have therapists who truly understand our son's autism presentation. As a result, they give us all the traditional tools that don't work and sometimes make matters worse. Our own research has lead to better results but as burnt out parents, we need experts and professionals who can guide us.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Our son has struggled dramatically with social interactions with peers. He relies heavily on adults for companionship which is not healthy but we haven't found the right support to help him with his socialization skills. Many groups and resources don't work well for his presentation and super high anxiety that leads to demand avoidance.
What additional research is needed to help address co-occurring conditions for autistic people?	A deep dive into Pathological Demand Avoidance and strategies to support children with this presentation and their parents. There needs to be more therapists and other professionals who understand this presentation and can help parents learn how to accommodate their child's unique nervous system disability.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Equitable access to and accessibility of services, updated best practices for ABA and other techniques being implemented so ABA is not the only therapeutic option, insurance coverage for various services, providers getting continuing education on the various presentations of autism, more support for parents and siblings
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Increased anxiety in social situations
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The disruption of services and schooling made it very challenging for my son to return to in-person activities. I believe it impacted his social development dramatically

Name	Viktoriia
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I dont know a lot of autistic people outside of my family. Of the things, mentioned above, I do have insomnia from time to time, and symptoms, similar to irritated bowel syndrome, I think, it is related to me stressing out all the time. Also I am pretty clumsy and often get injuries like burning my skin or sprained joins, bruises. Also I have a hear loss.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have experienced eating disorder, depression, depressive-anxiety disorder, self harm. I also was diagnosed with ADHD.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I think, my cognitive skills are above average. It was not a problem to obtain 2 university degrees. I am fluent in 3 languages(my native language is Ukrainian, 2 others are English and Polish), and understand 4 more. But I have issues with becoming part of the groups all the time - there are people around me, but I don't know what to do with them. Also I have issues with being overstimulated all the time - I stop perceiving speech and not able to talk if the meetings at work are too long or a lot of things are happening around me
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	That would be great if there were silent hours(no music) in the supermarkets, shopping malls (preferably always). Quiet corners available everywhere. Also access for good noise cancelling tools and sunglasses. That would be great if autistic people have access to therapy.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I am considered to be a healthy person, but I hit me a bit. I had a fatigue, which lasted for a few weeks if not months. It took time regain my sense of smell. I gain a lot of weight, mb because of covid, mb because I had to take antidepressants, because I got a depression appr. at the same time
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	it was better actually - I love working from home. And I was happy to stay there most of the time

Name	Virginia Fox
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression from feeling like an alien and lonely and not understanding why you're different. It makes you isolated and depressed and it is very hard to recover from. This in combination with autistic emotional experiences like meltdowns leads to more frequent occurrences of self-injurious behavior and suicidality. ADHD contradicts autism a lot which makes your brain feel at war with itself
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The fluctuations in skills and abilities make it hard to be able to reliably depend on things like communication. Sometimes I can speak and I can tie shoes and follow my face wash routine and sometimes I can struggle to do a number of those things. It's very frustrating when it feels like your abilities get snatched away intermittently. I do not have learning disabilities, but I know they add an additional layer of struggle to regulate and understand and cope and increase social stigma and judgement, which is a huge challenge
What additional research is needed to help address co-occurring conditions for autistic people?	We need to understand the overlap of things like EDs/connective tissue conditions, POTS, etc. we also need to research how differences in processing in autistic people (including under/over registration of stimuli and neural integration miscommunications) may be connected to so many co-occurring conditions and may require a modified treatment plan for the co-occurring conditions when they're present in an autistic person
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Autistic adults have for so long been underrepresented in services and support. It is often treated like a childhood disorder and the only adults included in supportive services are parents and caretakers. But once we (autistics) grow up and become adults (specifically those that have lower support needs I believe), all access to support services feel absent. We're largely left to our own devices. And insurance does NOT like to cover any services or diagnostics autistic adults seek
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I worked daily for years to learn and practice my social and communication skills, and during Covid and the lockdown I had a major regression in skills and my ability to cope with and function in social situations. I had a hard time getting back to my level of socialization pre-pandemic and a lot of autistics shared the same struggle. I lost a lot of time. I was in high school at the time and spent the last 2 years trying to get back to where I was socially instead of continuing to maintain and improve my social skills throughout high school. I'm still coming back from what I lost.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school,	Increased use of telehealth is nice because it makes doctors appointments easier. Reduced in person interactions made my social skills suffer and I got unhabituated with coping with social environments. Increased remote school/work has helped schools and companies be more flexible with accomplishing tasks in person or at home, and that flexibility has helped autistic people.

increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Vista autism services
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disorders
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety OCD Self injury Aggressive
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Lack of communication skills to say their wants and needs
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Enough staff to be able to pay attention to each child's needs. Diverted attention leads to the most self injury and aggressive towards staff
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Social interaction in younger students
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	School being so easily canceled now that it messes up their schedules

Name	Vittoria Cristoferi, Medico Neuropsichiatra infantile
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I problemi mentali dipendono in gran parte dal fatto che il soggetto autistico non può comunicare (parlare) con chi gli sta accanto [Translation: Mental problems largely depend on the fact that the autistic person cannot communicate (speak) with those around him]
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	La disabilità nel comunicare verbalmente è alla radice della disabilità intellettiva, spesso conseguente a pregiudizio del contesto sulle capacità cognitive di chi non può parlare in modo ampio e articolato [Translation: The disability in communicating verbally is at the root of intellectual disability, often resulting from the prejudice of the context on the cognitive abilities of those who cannot speak in a broad and articulated way]
What additional research is needed to help address co-occurring conditions for autistic people?	La ricerca sulle cause e le conseguenze dell'impossibilità di esprimere il proprio pensiero con la voce è troppo limitata. E le modalità alternative sono limitate a immagini e ai segni e non alla scrittura [Translation: Research on the causes and consequences of the inability to express one's thoughts with the voice is too limited. And the alternative modes are limited to images and signs and not to writing]
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Manca spesso la proposta o possibilità di poter imparare l'uso di modalità alternative, non limitanti la qualità del pensiero da esprimere, come può essere l'uso della scrittura per comunicare, con le dovute facilitazioni tecniche e umanamente personalizzate [Translation: What is often missing is the proposal or possibility of being able to learn the use of alternative methods, which do not limit the quality of the thought to be expressed, such as the use of writing to communicate, with the necessary technical and humanly personalized facilitations]
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I cambiamenti sociali legati al Covid dovrebbero aver fatto capire anche alle persone non autistiche e verbali che si può comunicare in modo efficace anche senza la voce e l'interazione sociale stretta, ma con l'aiuto della tecnologia e della lettura-scrittura se c'è interesse e attenzione al valore delle persone, anche di quelle autistiche [Translation: The social changes linked to Covid should have also made non-autistic and verbal people understand that they can communicate effectively even without the voice and close social interaction, but with the help of technology and reading-writing if there is interest and attention to the value of people, even autistic ones]

Name	Walter Newsom, Newsom Psychological
Demographic	Autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Co-occurring conditions are often more impairing than the Autistic characteristics. For instance, most Autistic people also have ADHD and that interferes with Autistic goals as much as it interferes with neurotypical goals. Motor coordination problems can impact speech, language and the perceptions of others, inviting rejection and negative impressions before people even get to know the Autistic individual. This happens in very important environment in the Autistic person's life: family, school, work, recreation, and of course social. Low IQ is not a part of autism, but when it is a co-occurring condition it makes life much more difficult.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Almost all Autistic people are born with dysregulated emotions due to differences in the amygdala and associated emotional circuits in the brain. This causes Autistic people to be more vulnerable to all emotional problems and to difficulties with self-regulation. Not recognizing this as a core cause of Autistic differences creates massive problems obtaining adequate therapy. Imposing manipulative therapies like ABA just make this worse. Instead of focusing on helping with emotions, ABA tries to train children as if they were dogs. It is shameful this is still allowed.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	One of the biggest problems Autistic people face right now comes from a politically motivated group that is conflating low IQ with autism, and trying to call it profound autism. This is disinformation and propaganda that misleads people about the nature of autism and continues to feed the stigma autistic people face, including those who have co-occurring intellectual abilities. Most of the less disabled Autistic people I evaluate in my practice have speech and communication problems that are obvious until I do the cognitive testing. This core aspect of autism explains much of the difficulty Autistic people have with communication, but it isn't recognized as a core Autistic characteristic any more.
What additional research is needed to help address co-occurring conditions for autistic people?	Any additional research should focus on the priorities of Autistic people. So much money is spent on things that have little meaning or benefit to Autistic people that it is just shameful.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Providers need to listen to Autistic people better to understand our needs. So much of the available resources are spent trying to change us instead of supporting us, that it is a constant fight to get even the small changes we have been asking for. Autistic people need smaller classes in school with more self-directed focus, we need more supports through major changes and an understanding that our typical developmental stages are going to differ in regard to timing/age compared to more typical norms. We are not herd animals, but we are often treated that way.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It has vastly increased the severity and prevalence of agoraphobia. On the the hand, it helped Autistic people and their employers understand that Autistic people can be more productive working from home without all of the inappropriate social, emotional and sensory demands of the workplace. Autistic people who can't work from home are able to better understand the accommodations they need to be successful in the workplace.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school,	As I previously noted, increasing work from home and a better understanding of Autistic needs for accommodations in the workplace are a positive. Telehealth is preferred by most Autistic people and the increasing availability of this has been very positive.

increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Whitney Lee, Neurodiverse UT
Demographic	Autistic individual; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	1.Lack of awareness and research in to hypermobility conditions in Autistic women and people assigned female at birth. 2. Healthcare professionals not being educated on helping Autistic clients and how the spectrum is multifaceted and dynamic. Including not being equipped for AAC, and that speech does not mean communication.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	1. ABA, behaviorism, and behavior being prioritized over mental and physical health especially in those who are nonspeaking and or have an intellectual disability. (finding the root cause(s) of self-harm/ injury needs priority over simply stopping self-injury) 2. Finding neurodivergent affirmative mental health professionals. 3. Minimal research and awareness into complex PTSD and the impact of ableism on our (autistic people's) mental health. 4. Side effects of psychotropic medications. 5. Lack of research into Neurodivergent affirmative mental healthcare.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	1. Gaining Oral speech being deemed more important than communication access. 2. Segregated Education. 3. An education system that ignores both childhood development, health, and neurodiversity. 4. Lack of access to important facets of education including social issues and sex education.
What additional research is needed to help address co-occurring conditions for autistic people?	Problems with conflating autism with co -occurring conditions (like saying autism is bad because a lot of Autistic people have epilepsy). Systemic issues like healthcare disparity. Research in to drug addiction and homelessness.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	1. Universal and single payer healthcare including dental, vision, and mental healthcare. (Not requiring people to do paperwork to qualify like they do for medicaid and medicare) 2. Replace ABA with services from neurodivergent affirmative providers including speech therapy, physical therapy, occupational therapy, and support aids or care aids (who assist with people who need more 24hr type care. 3. multiple options for making and cancelling appointments (including telehealth and online scheduling) 4.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I have a long covid and am now on supplemental oxygen 24/7. I have post exertional malaise. I live alone and I am only 30 years old. I got long covid in 2021. While I don't need daily assistance, I do need weekly assistance for cleaning and even some meal prep. I don't have access to transportation (short of friends). Public transit isn't reliable and too exhausting for people with PEM especially without a wheelchair.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Whitney Storey, University of Louisiana at Lafayette
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The focus on the co-occurring condition apart from the neurodivergence is causing myself, my peers, and my clients a lot of issues. Specialized medical professionals do not have the training and competency on autism in order to best understand the context of the co-occurring condition, let alone the impacts of the specific differential biological function related to neurodivergence (which affects both the way that medications/treatments work/don't work on ND individuals and also the way that the co-occurring condition appears for ND people as compared to neurotypical folks). This is especially problematic for gender/sexual minorities, women, people of color, and folks whose autism looks atypical (for example, those with a pathological demand avoidance profile).
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	In addition to the previous response, mental health professionals do not have an accurate understanding of autism and neurodivergence in general. As an autistic clinician who is also female, I do not fit the typical look of autism and also do not qualify for a diagnosis to a clinician who is not well-trained on the differences of autism for women. Regardless of the specialty/license of the mental health professional, without updated understanding of neurodivergence (which goes beyond the DSM), they are causing harm to their ND clients.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Most school systems are missing autism diagnoses (and specific learning disorders, etc.) because the behavioral repertoire of the kids does not match the stereotypical view of autism. In working at our local mental health clinic doing assessments and diagnosis clarification, almost all of the minors I assessed came to me with a history of diagnoses including oppositional defiant disorder, conduct disorder, ADHD, bipolar, borderline personality disorder, etc. Our school systems are not prepared to properly work with folks with these diagnoses, so what has been happening is these kids end up being expelled and/or sent to alternative schooling and get a label of being a bad kid. Autism looks different than people and school systems think! And this is especially true for Black and Brown children.
What additional research is needed to help address co-occurring conditions for autistic people?	Where to begin - the US needs to catch up with other places in research on "atypical" autism (e.g., autism in women, autism in people of color, autism in adults, etc.). We also need research on the prevalence of autism within these more realistic bounds (apart from the DSM) and across the lifespan. So many adults are being diagnosed and needed help but didn't receive it in childhood because they didn't fit the stereotype and/or because they were so good at masking. We also need research on the prevalence of autism in the justice system - preliminary research suggests that the rates of ND among justice-involved folks are higher than expected, especially those who are undiagnosed ND. The system is not set up to work for and with ND people, furthering their trauma and limiting their ability to effectively rehabilitate.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Providers, school systems, and medical systems need updated training on neurodivergence and the impacts of ND. This requires funding and access to folks who have lived experience AND the ability to communicate the information in a way that works for these different power systems. Access to services that are helpful for ND kids are extremely limited in the school systems overall, but especially for those systems in marginalized areas. Insurance coverage for mental health issues overall is incredibly limited - and even if the coverage exists, mental health providers are extremely

	<p>limited/misguided in their understandings about neurodivergence broadly. The medical system is extremely unfriendly to neurodivergent patients.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>Many autistic people are talking now about how the period of lock-down and social distancing was helpful for them. Now that we are back to "normal," autists report feeling very discouraged and high levels of stress over the push to be in public, the lack of space, the social pushback over choosing to wear a mask, and the movement away from tele-health, tele-mental health, and remote work. Personally, I am burning out, and my clients say the same thing. The collective trauma of COVID has not been dealt with, so that is being compounded by a return to a very neurodivergent-aversive world and way of being.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>See my previous response - social distancing was overall experienced very positively for autistic people, but the return to "normal" has been traumatic.</p>

Name	Whitney Voltz
Demographic	Autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The most significant challenges caused by co-occurring health conditions in autistics include the limited ability to engage in meaningful, paid work and the ensuing stressors of material and financial instability.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The most significant challenges caused by co-occurring learning disabilities include the paucity of supportive resources in the school system and the centering of responsibility of management within the family. Some families can afford to pay for adequate services without strain. But far too many cannot.
What additional research is needed to help address co-occurring conditions for autistic people?	Research that centers the lived experience and knowledge of actually autistic individuals.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	All of the above. Where I live (Louisiana) there is almost nothing. I have to pay out of pocket for a therapist who respects autism. None of the so-called providers within my network (that I've found) are qualified to work with autistics. I've experienced a spectrum of unhelpful "treatment", ranging from outright dismissal and medical gaslighting to providers minimizing my autism and not understanding its importance in relation to co-occurring conditions and a history of trauma.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	For me it has been largely positive. I LOVE telehealth visits. I understand that sometimes I must go into the clinic (for blood draws, for example). It is much more bearable now that I can do the majority of my clinical visits virtually. I've also worked 100% virtually the last few years. The reduced need for in-person interaction has been a godsend. I'm physically, mentally and financially better off. Leaving the house 5-6 days a week, dealing with sensory overwhelm, transportation, unaccommodating coworkers and having to mask were horrible for my health and felt like they were shortening my life span.

Name	Wilhelmina murray
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Aggression
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Dissatisfied staff. Underpaid. Constant turnover
What additional research is needed to help address co-occurring conditions for autistic people?	Anticipation of aggressive response (monitoring blood pressure, brain wave changes)
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Patient provider improvements. Protective gear when necessary, improved pay, acknowledgement that small female staff should not be hired to work with strong aggressive male staff This happens all the time since finding staff is so difficult.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	My aggressive son, 25 yo, lives in a residence. Still no day hab Being in house all day leads to irritability, increased aggression, calls for increased psych meds
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	William Bryan
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	ARFID is one of the most significant, particularly in individuals with PDA profile, as it may cause significant issues due to malnutrition. *Consistently* exercising in any capacity is also extremely difficult, which leads to many other health difficulties.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Getting access to medical help of any kind is head and shoulders #1. Let alone keeping track of it. Be it psychologists or psychiatrists, general practitioners, dentists or other specialists. Affording that help is #2. Concurrent/comorbid disorders make working at all extremely difficult, let alone full-time, and in a field or industry that pays you well enough to live.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Being dyslexic and hyperlexic makes communicating difficult, especially because we can sound so eloquent over written word, but speech being orchestrated by different parts of the brain/anatomy means we may sound far less “conventionally,” intelligent out loud. And with my particular profile, it may mean a significant amount of re-reading and re-writing of formal responses. Apologies.
What additional research is needed to help address co-occurring conditions for autistic people?	Other ways to test for/perhaps treat connective tissue disorders. Particularly Ehlers-Danlos. Hypermobility cases seem to have a wide gamut themselves from blatantly obvious to deceptively mild. Neurological mapping of individuals with the condition(s) to increase sample size to better understand.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Examples given are quite good. Other additions such as access to public exercise facilities would be incredibly helpful, as would access to physical therapy. Publicly funded doctors being permitted to prescribe certain controlled substances, (e.g ADHD medications,) would remove many a roadblock to effective treatment for millions of autistics. Patient-provider relations *MUST* be addressed. Treatment is not dictated. Treatment is a two-way street, and it must be collaborative. Not authoritative.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	A dramatic and potentially lifelong one. I have become less certain of my own health after recovering from it a little over 1 year ago. I haven't ever really felt like I'm physically back at 100% since getting it. If anything it's more like 85% is my new 100%.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Tele-health and work-from-home positions have been of incalculable benefit to us at large. I have not worked a remote-work job, but being able to communicate with my doctor via worded messages OR video call was a tremendous relief and incredible convenience, during the short time I used them.

Name	William Spell
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I am prone to gastrointestinal issues like acid reflux and irritable bowel syndrome as well as difficulty sleeping. I also sometimes get sensory overstimulation.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	When I was in college, I got such severe depression I was considering suicide. I'm in a much better place now. Also, in elementary school, I was diagnosed with ADHD, though now I question the validity of that diagnosis.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	When I received my official diagnosis as an adult, it stated I have poor short-term memory, which probably had an impact on my education in primary school and college.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Having been locked up in the house for most of the week due to quarantine has denied me opportunity to develop my social skills.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I had used more telehealth, and there are far less in-person interactions nowadays.

Name	William Stillman
Demographic	Autistic individual; Researcher; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Proprioception, gastrointestinal issues, allergies of all kinds, issues with sleep (insomnia or hypersomnia) symptomatic of a mental health issue.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I would strongly suggest revision to listing "aggressive or self-injurious behavior" as these are descriptions of potential symptoms indicative of a mental health syndrome and are not "behaviors." As such, it would be incorrect to include these in a list of legitimate mental health diagnoses. Please know that I have spent my 37-year career in the field of supporting individuals with developmental differences and autism demystifying the stereotype that autism necessarily equates to violently aggressive "behavior," and am the award-winning author of ten autism and special needs parenting books.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Intellectual disabilities in individuals with autism is a complete myth. The most prescient and respectful alternative is to presume the individual's intellect and interact with and educate them at their chronological age. Full demonstration of intellectual capacity is possible with communication technology for those not capable of producing speech reliably.
What additional research is needed to help address co-occurring conditions for autistic people?	Not research, education of those who are operating with a belief in myths and stereotypes about individuals with autism being void, vacant and unaware.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Stability of staff, programming and living environment would nearly eradicate all manifestations of anxiety and insomnia not otherwise attributable to legitimate mental health diagnoses.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Isolation and social deprivation along with COVID compromising individuals' already fragile physiology has had a lasting impact.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Wyatt Miller
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Difficulty articulating emotions translates to difficulty explaining what is wrong and/or why when sick or impaired.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	It feels like a 10-car pileup in your brain. so many things are wrong and they work together to make each other worse and more difficult. Specifically the combo of Autism and ADHD makes it so very difficult to do anything, the lack of motivation can easily become depression and every day feels like an uphill battle.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	I believe it would be helpful to know why these disorders and disabilities tend to overlap with Autism, better understanding would be somewhat comforting at least and would open up the world of treatments and prevention. I don't want to eradicate autism but I would want my children to have less issues than I.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I'm not sure there is any service that goes out of it's way to help autistic people, and if there is, there is not enough awareness of it. Disability services has helped me as a result of my autism on occasion, but overall there seems to be a large wall between people and any kind of help.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	COVID was so long ago that it's hard to say, but I do distinctly remember feeling like a different person after recovery. There may be something to that.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Social life is much more atomized, there are little to no public social gatherings in my area, and even large cities like Chicago, which I live near, have lost their sense of community. When people do interact, such as in school, no one speaks, it's deathly silent. While I'm sure many autistic people may find comfort in a more personal and intimate social environment, for me and those around me the stink of death and the eery silence are nearly impossible to cut through, and it leads to incredibly diminished mental health. I have no idea what solution you could have that would encourage social gathering but life is just so empty now, and I'm sure people who have difficulty talking to people or making connections are more lonely than ever.

Name	Wylder, Autistic
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I have a lot of gastrointestinal problems, making it hard for me to function in public without knowing exactly where a bathroom is. I also have Ehlers-Danlos which makes my joints very painful, preventing me from participating in many activities
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My anxiety has greatly impeded my life. Before receiving treatment I could barely leave the house at all. Even with treatment, many social situations are horrifying for me, and make any interaction ridiculously difficult.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	More information needs to be gathered on co-occurring conditions of all types, and finding the best ways to support people with autism and other conditions at the same time
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Providers need to stop treating adults like children, even if they have developmental delays. Providers should be more easily accessible to people without or with limited health insurance
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Virtual appointments for school and medicines are much much less effective in my experience. Specifically, my psychiatric care has decreased drastically in quality. It is much harder to say what I need to say virtually than it is in person, making it much harder to have my needs addressed.

Name	Yasmine
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Co-occurring issues can be more debilitating than autism. Ibs and POTS can stop you from living normally before any autistic trait.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety keeps me living inside my house. And mostly im anxious about my ibs. My adhd, sensory processing disorder, synesthesia, OCD are less of an issue.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Social isolation because these topics have been taboo and ignored. And there are no social structures for the autistic community to really thrive. Everything is made for neurodivergents.
What additional research is needed to help address co-occurring conditions for autistic people?	a wide spread of research needs to be done that includes people who are autistic with various different needs, ethnic backgrounds, genders, and sexualities. Autism isn't black and white and researchers need to understand the complexity of it. Better research lead by autistic people on co-conditions and needed support would be great.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Better insurance coverage and more work related support accommodations would help so many. More public acknowledgment of the various lifestyles autistic people can live and achieve. Highlighting autistic voices and people so we are seen as equal and valued.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Telework has been a major improvement and wearing mask.

Name	Yesenia Aviles, Caregiver
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Finding adequate professional compassionate caring therapists, as well psychiatrists. I continue to see immense lack of training in this area and it is extremely upsetting. Myself trying to get my master because of this in healthcare management and policy.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	All of the above- mentioned examples. Mainly when it comes to OCD and impulsivity.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Inability to stay on task and function on very minimal life skills.
What additional research is needed to help address co-occurring conditions for autistic people?	I think we need to collectively focus more on brain function relating to gut, ineffective medications making those behaviors worse, and also lack of training as well in that specific area.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	All of the above- mentioned examples are extremely indeed part of the issue. No doubt. No one should go into this field if you do not take insurance neither underserved communities should have to face challenges to have access to adequate care from providers.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	All of the above- mentioned examples can be part of the overall systematic issue we continue to face without the adequate effective long term treatment models we need to implement, in order to see positive long term changes.

Name	Zachary Kopel
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Epilepsy
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, depression, ptsd
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Not understanding social cues or how to interact with others
What additional research is needed to help address co-occurring conditions for autistic people?	The link between epilepsy and autism Effects of applied behavior analysis therapy and ptsd
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Dealing with less people

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I wasn't diagnosed w Autism until I was 44. I'm a cis white woman. The understanding of autism in women/girls is woefully inadequate. I have been misunderstood my whole life by others AND myself- I've been labeled as aggressive, combative, aloof, weird, awkward. I've had to be medicated for the anxiety this causes. I've suffered from periodic depression because I become exhausted. I'm a hermit because I am so afraid of human interaction, and only JUST learning how to interact with the world comfortably
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I'm incredibly bright and sharp. I spoke in full sentences when I was 9 months old. Early and advanced language skills is one of the first flags of Autism. Evidently in 1979 no one cared. I both excelled and struggled through my entire academic career because I learned in a specific way. Some teachers taught in that way. Some didn't. If I had access to the support I needed, I can't imagine how much that would have benefitted my life. Instead I now awkward spout off slightly related facts in conversation, then elaborate on what I've said like I'm a live wikipedia, because I cannot connect the excitement of information properly in a social setting.
What additional research is needed to help address co-occurring conditions for autistic people?	Co occurring conditions are clearly important, but these questions are clearly leaning toward the robust body of knowledge about men/boys. Focus on better understanding of women/girls, and stop leaving us in the dust as if we don't matter. We have Autism too.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	My health insurance policy had no one available to do testing. Not only did I have to pay \$6k out of pocket for testing, I then maintained a relationship with that provider for treatment. Again, OOP. The mental health services in the US are abysmal- and I have insurance. Reimbursement for this provider is embarrassing- I was reimbursed about \$2400 of the \$6k I spent for diagnosis. The reasons mental health professionals DON'T take health insurance are good ones- they are not the problem.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I can meet w my care team virtually. This access improvement is immeasurably positive. Being on lock-down and working from home were the best thing that has ever happened for my mental health. Just the mere presence of people is painful. Having to be back out in the world is the absolute worst.

Name	Anonymous
Demographic	Family member of an autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>Our response focuses on the impacts of residential care over ten years for our severely autistic and developmentally disabled child. We have observed the following co-occurring health conditions as a result of our child’s residential care: (1) health issues related to hygiene while in residential care, including a neglected MRSA infection and an ongoing e-coli contamination (EAEC). (2) sleep disturbance issues for which he is treated through off-label prescription of a blood-pressure medication. Environmental factors contributing to successful sleep management are more challenging to execute in institutional environments. Physical impacts: (1) medications were prescribed that were effective in reducing maladaptive behavior but which also exacerbated his tic disorder. The increased frequency and severity of violent head and neck tics has resulted in permanent musculoskeletal damage which has now been diagnosed as a source of chronic head and neck pain; (2) from time to time our son has needed to be physically restrained, which has generally been well executed by trained caregiving staff but which occasionally has resulted in significant injury. (3) neglected hygiene during the pandemic that led to chronic physical pain (e.g. ingrown toenails; chronic diaper rash; (4) significant motor challenges which require constant and significant attention by caregivers to monitor (e.g. fall risk).</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>Our child has been under psychiatric care most of his life. We have come to believe that this care is often misguided, mistaking behavior-as-communication (as described above) for symptoms of psychiatric disorder. The side effects of many of psychiatric drugs commonly employed to address perceived disorders can have profound effects on persons such as our son, who are unable to communicate (except through behavior) the adverse impacts of these side effects. Examples include: weight gain, lethargy, “disturbance” (hallucinatory or similarly distortive perceptive effects that are sometimes side effects of SSRIs and other advanced psychiatric drugs), and involuntary tics. The role of off-label psychiatric medication to treat conditions co-extant with severe autism, developmental disability, etc. needs to be re-examined. The medications are given ostensibly to treat mental disorders that are only co-occurring with autism, such as maladaptive behavior, when they may in fact be reactions to poor care conditions, regimentation, etc. much as they are for the inmates of maximum-security prisons. These medications also create their own knock-on effects, e.g. morbid weight gain, permanent tic disorders, etc. that have not been adequately studied. As described above, these effects have led to permanent co-occurring physical and psychological conditions.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>Our child is functionally non-verbal and has an IQ that cannot be measured. He lives by routine, familiarity, and habit. Because he is non-verbal, he communicates needs and emotions, including comfort, satisfaction, and love, but also pain, confusion, and anxiety through his behavior. This behavior can be inappropriate (e.g. loud), intrusive (e.g. disrespectful of normative personal boundaries) and disturbing to someone in his proximity who does not know him or other persons like him – which is our societal norm. He can also be aggressive, self-injurious or injurious to others around him. It is in part for these reasons that he has been in residential care. The impact of these conditions is very great – he must live the rest of his life in constant and careful supervision, for which current resources are inadequate, and current research can do more to address.</p>

<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>The role of off-label psychiatric medication to treat conditions co-extant with severe autism, developmental disability, etc. needs to be re-examined. The medications are given ostensibly to treat mental disorders that are only co-occurring with autism, such as maladaptive behavior, when they may in fact be reactions to poor care conditions, regimentation, etc. These medications may create knock-on effects, e.g. morbid weight gain, permanent tic disorders, etc. that have not been adequately studied. These effects have led to permanent co-occurring physical and psychological conditions. Research should be done to identify and address co-occurring conditions that result from inadequate staffing, training, and housing. There is a desperate shortage of direct support professionals (DSPs) and job coaches, many of whom don't stay long enough to learn our child's behavior or how he communicates. We need to realize greater efficiency in how they are employed. Using smart-home monitoring technologies coupled with artificial intelligence (AI) could assist in monitoring resident safety (e.g. preventing elopement) and improving communications (e.g. interpreting non-verbal communication and "behavior as communication). We also need to research how technology can assist in supporting the non-verbal. A personal AI could study our child's behavior and routines, learn his communication style, and act as translator. Privacy would be an issue here but we feel it is our only option.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>The side effects of the common use of psychiatric drugs to control behavior may lead to physically or psychiatrically adverse impacts which nonverbal persons may be unable to express to others except through maladaptive behavior, which not only may be overlooked in treatment or care, but may be interpreted by medical personnel or caregivers as symptoms of a psychiatric disorder to treat with more medications. In our view, this creates a vicious cycle (where the medication becomes the primary driver of the condition being treated by medication) that needs to be looked at from a medical and public policy perspective. There need to be tiered services for autistic persons across the spectrum based on need just like there are for the elderly. There are few appropriate communal living situations for the severely autistic. Group homes that are adequate for the less severe do not have appropriate staffing or safety supports, and those historic institutions for the severe which remain have insufficient staffing and transparency. There are no jobs or recreational programs for the severely autistic because they need too much support. We need trustworthy data on outcomes vs. expense across the autism spectrum, and to encourage appropriate public housing, technological innovation, and development of an effective, efficient and well-incentivized workforce that values and rewards those who work with the disabled.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>We are not sure that the direct effects of COVID-19 on the health conditions of the autistic have been substantively different from those of the general population, and so defer our answer to question 7.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced</p>	<p>The current spectrum of housing, vocational and care options for adults with severe autism is that most participants want to solve problems for the easiest-to-manage people, maximize profit for minimal effort through this strategy, and ignore the most vulnerable who are also the most difficult and expensive to support. This dynamic results in the least vulnerable taking all available public support for housing and care, leaving the most vulnerable underserved and endangered, and placing an undue burden on their families. As parents of a severely autistic adult child, we expect to commit all</p>

in-person social interactions and obligations)

of our remaining years and resources to his care, because there is no other viable option. Policymakers and legislators do not understand this, and there are too many actors in the autism community who are only too happy to victimize the vulnerable to gain greater resources for the less vulnerable (who are more numerous) and to resist changes to the status quo from which they prosper.

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbances associated with sleep apnea are an issue for me. However my need to sleep more hours than most is likely not only related to apnea. This is an issue that interferes with me being able to work all of my scheduled hours at my University research job. I have a very flexible schedule and am able to work from home or in my office but needing a nap for several hours many days of the week is difficult to manage with a full-time job. I have GERD that is managed but it does not cause any challenges. My sister and three of her six adult children have ASD. All are obese, none have been screened for diabetes. None have had regular physicals as adults, though they all have medical coverage.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have ASD, major depression (recurrent), and generalized anxiety disorder (all treated). I have a PhD and work as a researcher. I use weekly therapy and medication management support. I struggle at work when my social skills are inadequate, and I make social mistakes. My sister and three of her six adult children have ASD. All graduated HS. My sister has significant anxiety and depression that is keeping her employed as a personal care attendant even though she has a 2 year RN degree. She had a serious suicide attempt when she was in her 20s. One daughter with ASD was employed as a railroad conductor but lost the job when she started having seizures. She is frozen by her anxiety and has been unemployed for 18 months. She has a BA but most recently worked mucking stalls at the horse ranch. The second adult failed her driving license test four times due to test anxiety and relies on her parents to transport her to her full-time job at Walmart. She has significant untreated anxiety and depression. She will not make medical appointments for herself. The third works full time in a warehouse and of the three is the most independent, driving himself to work and working full time. But he talks about how his limitations in social skills have made it difficult to make friends. All have insurance that would pay for supports but they have not sought mental health treatment for their anxiety or depression.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	People with ASD who have ID or DD often are eligible for Medicaid and SSI and are more likely to get their needs met. People with ASD who do not also have ID struggle alot more to get their needs met. Access to augmentative and alternative communication supports for people who do not communicate verbally are scarce and help to maintain systems set up for children and adolescents while they are in school are rarely available. The severe shortage of speech and language therapists limits access everywhere but most accutely for adults.
What additional research is needed to help address co-occurring conditions for autistic people?	Research on the long-term support and service needs of adults with ASD is extremely limited. This is especially true for adults who do not have co-occurring ID. I work at a University center that offers evidence based social skills training for adolescents and their families. However, the evidence base for social skills training interventions for adults across the IQ spectrum is very limited. Access to social skills training for adults without ID is very limited in my community. A few very expensive programs are available but the costs are far out of range for most adults with ASD. There is not much research on employment outcomes for adults past the transition age group. Because ASD dx has only been available in the US for a couple of decades, many adults with ASD have never had a formal dx. Given the pervasive shortage of assessment resources for people with ASD of all ages, it seems unlikely that this situation will change, especially for people born before 1990 or so. This

	<p>makes research more challenging for middle age and older adults with ASD (especially those who do not have ID).</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Access to services requires a sufficient number of appropriately trained clinicians which we do not have. In addition, even people who are eligible for Medicaid funded LTSS struggle to get the supports they need because of the shortage of direct support professionals. Adults with ASD who have not been formally assessed often end up having a long list of incorrect mental health diagnoses before finding a clinician who has training in identifying and treating ASD in adults. Many of the federal ASD initiatives focus on providing insurance coverage and services for children with ASD. People with ASD do not turn into people without ASD just because they graduate from or drop out of high school. Both clinical and social services for adults with ASD are very insufficient. Learn the signs act early is a great outreach effort to identify young children with ASD. We need a similar outreach effort to help adults who may have ASD identify and name the condition that is negatively impacting their lives. Adults whose social skills are not at the level of neurotypical people often face discrimination at work because employers misinterpret their behaviors. Even though I work in a disability related center, I have faced illegal discrimination because of my ASD or related to the medications and their side effects that sometimes affect my job performance.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>I doubt anyone can reliably answer that question. One might suppose that covid exacerbates depression, anxiety and other mental health concerns amongst people with ASD of all ages. This is an area that requires research investments.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>I have heard stories from the Competitive Integrated Employment experts about how people with disabilities who were employed during the pandemic sometimes thrived with remote supports in a way that far surpassed expectations. The shift from exclusive in-person medical and mental health services to remote services has been a huge boon for people with ASD and other disabilities, significantly improving access to supports (particularly when the providers and the clients are physically distant from one another). I love that most of my many weekly meetings are now held via Zoom. It puts me on a more level playing field because some of the nonverbal messages that neurotypical people use to their advantage are not available. Obviously covid continues to be a top cause of morbidity and mortality around the world. Long-covid can interact with ASD and other common comorbidities to make life more difficult for people with ASD. This is another area that is ripe for research. We know that the prevalence of depression, anxiety, nonsuicidal self-injury, and suicidality has increased dramatically since covid amongst adolescents. We don't know the situation for people of all ages with ASD.</p>

Name	Anonymous
Demographic	Family member of an autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>My son has autism with a PDA (pathological demand avoidance) profile. While its not recognized in the DMS, there is a very significant difference between "standard" autism and autism with a PDA profile. First of all, its hard to diagnose, especially since providers aren't aware of it. It often gets mistaken for ODD or DMDD which has recommendations that are the polar opposite of what a child with autism needs. I've found success using "low demand parenting". My son is highly intelligent, and high masking. However he struggles with emotional regulation due to the every day demands placed upon him. He can be explosive when people aren't expecting it. He also struggles greatly with sleep. He is medicated to help him relax at night and on top of that we have to use melatonin to help him sleep. If he does not sleep well, he is unable to function at school. I cannot send him to school when he does not sleep well. There are no social supports for these challenges and without education about PDA, no one understands. They just see a lazy, angry child and a parent who just needs to show him who is boss.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>The most significant challenges we see are driven by autism with a PDA profile. My sons anxiety levels are high. In second grade he learned that adults do not listen to kids. He would tell the teacher that he was too tired to do something, they would encourage him to try anyway. He would repeat that he was too tired. They would encourage him again...and he would explode. He would flip desks, throw things, the classroom would be cleared out to keep the other kids safe. He was restrained a few times. It's been 5 years and he is still feeling the effects of the trauma of being restrained/secluded. He recently confirmed that he learned that when adults don't listen, the only way to get them to listen is to get aggressive. While the scenario described above probably happens in schools all over the country everyday, most of the time the kid pushes through and gets through the day. Uneventful. "Normal". With PDA, my son doesn't understand or see the social hierarchy. He views himself as an equal or peer to any teacher or adult he interacts with. He is unable to comprehend why an adult won't listen to him if he says he's too tired. He's now in 7th grade and we're struggling to break him of the habit of throwing things when he perceives that no one is listening. He lives on edge. he is easily overwhelmed when he perceives a lack of respect from an adult...and very few adults lead with respect when it comes to kids.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>My son has autism with a PDA profile. He struggles with communication and learning disabilities. His IQ is very high. In CT, he will not qualify for benefits due to his high IQ. However, he also has slow processing speed, which has become more of an issue as he's gotten older. He has high expectations of himself, and so do his teachers. He struggles with self confidence when another peer answers before him. It's challenging to find adults who are patient enough to work with him and who understand that while he did something yesterday, due to his PDA his nervous system may not allow him to complete the task today. He is very honest. But he will sometimes perceive a situation in the wrong way. When this happens and someone accuses him of lying, he does not respond well. This is very triggering to him. He needs to work with adults who trust and respect him. And who give him the time to process a situation. He is always apologetic after a violent outburst, but never in the moment. He needs to wait for his nervous system to settle back down. Once he is calm, sometimes it can take a day or 2, he will be remorseful.</p>

<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>Additional research is needed to help education doctors, therapists, teachers and society. I'm not at all worried about the cause. I need help finding treatment and supports now. For school and later for work & living supports. I think ODD and DMDD need to be reexamined. My son was previous diagnosed with DMDD. I have a friend whose son is diagnosed with ODD. Both of our kids present in a similar fashion. Neither "treatment" for ODD or DMDD is effective for our kids. These approaches have the opposite effect. The suggestions of reward charts and printed schedules are laughable. They have the opposite of the intended impact on my son. Professional need to be educated about autism with a PDA profile. Professionals are still refusing to diagnose kids with autism because they make eye contact. My kid learned how to fake eye contact before he entered school. The lack of professional understanding is appalling and is doing a disservice to our children and society. Once a kid is labeled with ODD or DMDD, even parents assume that they've got a "bad" kid on their hands. The facebook support groups are full of parents with no hope and no supports. Parents and professionals need education about different parenting approaches.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>More training & education for therapists & doctors. I recently had a therapist recommend ABA for my child. Research into PDA has determined that ABA will not work for these kids. (I personally would question if it's really working for anyone. But that's a different debate.) I had to pay \$5k out of pocket because it's hard to find a knowledgeable professional willing to acknowledge PDA. Many of the professionals who will "diagnose" PDA don't take insurance. This "diagnosis" is only available to people with cash. I am privileged to be able to afford this access. This diagnosis has helped us write a better IEP at school. It's helped his teachers understand that he's not a "bad" kid. Without this diagnosis, this kid could easily be on the school to prison pipeline. We've been lucky to avoid police interaction at this point, but I'm scared for what a simple traffic stop could lead to. Police are not educated about PDA. They'll see his defiance as a threat. We recently hired a SRO at our local school. My son is more likely to be negatively impacted by the presence of a SRO than he is to be helped by one.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>He struggles to attend school full time. His school stamina was negatively impacted by the long break. He is more likely to need a mental health day now than prior to covid. The 5 day school week is too overwhelming. The state has recently started to crack down on truancy and attendance. This is very unhelpful. My child frequently stays home from school because his nervous system is unable to function safely. I cannot send him to school if I think he'll become explosive at school. I cannot get a doctors note for each absence. Even with a 1:1 paraprofessional, it's still unsafe. (Also the pay for paras is so low, it's hard to hire quality staff when Target pays more.) We're currently unable to find quality therapy close to home. When we originally switched to remote therapy he refused to participate. He lost a couple years of quality therapy time. There's only a few therapist in CT who are educated in PDA. Remote therapy & Psychpact(?) have increased option, but most of them don't take insurance. Access to quality treatment should not be dependent on having excess funds.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services,</p>	<p>Increased remote work has actually been very helpful to me. I would have most likely lost my job due to the amount of school refusal we've had to deal with over the last couple year. As companies are starting to push for employees to return to the office, I'm concerned about the potential negative impact on my career that his PDA diagnosis could have (and I carry our health insurance). Telehealth has been great for quick doctor</p>

increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	appointments, but it's been ineffective for therapy for my son. (I personally have found it very helpful for therapy for myself).
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Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The co-occurring physical health conditions I would recommend focusing on are sleep problems, sensory regulation and processing, bullying, intersectional identities(e.g. race), and poverty. Yes, I consider poverty a physical health condition given it's a primary social determinant of health(SDOH). The challenges caused by sleep and sensory issues are the ones that, in my opinion, cause the most problems in interactions with neurotypical people. Sleep problems are a particularly nasty set because sleep problems go undiagnosed, have no physical manifestation like a rash, and have such a dramatic effect on mental and sensory processing. Similarly, the challenges caused by under or over stimulation are mentally taxing to attempt to balance, usually include factors completely outside of an individual's control, and are best handled through isolation, which causes other problems.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	In my opinion, the most challenging co-occurring mental health conditions in autistic people are depression and anxiety. These are generally not caused by autism but rather by how neurotypical people treat autistic people. Gas-lighting, hate, ignorance, incompetence, lack of respect or care, inflexibility, harmful treatments, and more contribute to isolation, fear, powerlessness, and knowing it won't get better.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Navigating the neurotypical world.The lack of autistic specific and/or friendly spaces/towns so there is respite available.
What additional research is needed to help address co-occurring conditions for autistic people?	How to train medical providers that a)more than one thing can be a problem at the same time, b)sometimes a spade isn't a spade, c) doing more tests earlier decreases negative outcomes, and d) believe women, people of color, and other under-appreciated people when they say something is wrong. At the same time, an autistic person may be so used to an issue they don't know it's a problem anymore. MDs, APNs, nurse practitioners, and other health providers need to be taught how to be diagnosticians again instead of antibiotic pushers, pain minimizers, and those that automatically do referrals to psych when they don't want to deal with something. Medical providers are a main challenge for autistic people, especially those with co-occurring conditions and the answer is to make medical providers better. So please research how the medical profession can do that.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Please see previous answers. In addition, stop infantilization, stop pity, stop ABA, stop giving up on treatment of autistics because "it won't make a difference" or someone else is more deserving, single payer healthcare, teach the public what autism and autistics are really like, care coordinator or service to make phone calls for us since medical providers are dead set on doing everything by phone, making or supporting software that lets a patient manage and control their medical record in order to coordinate and share across specialists. Last, but far from least, autism does not end at 18. In fact, arguably, most don't know they are autistic until after they are 18. The lack of support for autistic adults is stark and avoidable if anyone with power would bother to care about autistic adults.

<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>I don't know what the overlap between long COVID conditions and autistic people is, but I would bet it's above that of the neurotypical population. We know COVID-19 drove "women" out of the workforce and had a dramatic negative effect on women's financial lives and economic outlook. That's probably exacerbated for autistic women, non-binary, and other identities correlated with negative SDOH, especially that of poverty and domestic violence. Then there's the increased anxiety - both from needing to go places that no longer require masking or other precautions and from having to be explicit and "difficult" about requiring COVID-safer options to participate. Stressors then exacerbate all medical conditions.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>The increase in acceptability of remote work and virtual presentations has been a gigantic improvement in the lives of autistic people. Transportation to and from work and being in offices, office buildings, and otherwise having to deal with the sensory and interpersonal experiences in an office are debilitating. Open offices, bad light bulbs, perfume, etc. are hell. And asking for accommodation meant a) giving HR a reason to target you for firing and b) having co-workers asking questions and resenting you. Now, we can self-select employers that have employees who can communicate without needing to do so "over a beer". In terms of virtual video of events there are so many more things to attend and participate in. The groups who cut out the accessibility of participation from home prove they don't want people who aren't like them and that they can and should be written off. The distinction that this type of inclusion versus exclusion decision draws in "post"-COVID-19 times is apparent and improves lives. It's also clear who does and does not still require masks, air filtration, testing, and vaccination. Some people care about others and some people don't. It's now very easy to tell the difference and stop wasting time on discriminatory groups.</p>

Name	Anonymous
Demographic	Family member of an autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>Physical health, autism, and mental health, it is ALL physical/medical health issues. All these conditions impact someone's physical health so no need for the false dicotomy just because our systems of care are siloed. The most challenging health/ medical conditions were a rare seizure disorder and early onset psychosis. The suicidality, depression, aggression, trauma, discrimination, have been more challenging then the autism which was also difficult. Mania and paranoia were the scariest and most life threatening. The state psychiatric hospital releases individuals manic and paranoid. We need to totally revamp how we deal with families and support networks. The Federal government MUST take a more active role in psychotic disorders and reclassify them as the neurological disorders they are. Individuals that have anosognosia are in grave danger and the Federal government needs to develop policies to protect these medically complex individuals and their families. These individuals deserve the same care as other individuals with life threatening medical needs. And early onset psychotic treatment programs should not exclude individuals with autism. Ohio State's early onset psychosis program excludes individuals with autism. This is not acceptable. We need Federal policy on ADHD/executive functioning. It is a neurodevelopmental disability and can significantly impact someone's life. Please develop a Federal policy paper and train your UCEDDs and LEND programs.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>Aggression, suicadility, anxiety, psychosis have been VERY challenging. Autism - sensory, communication, countless hours of OT, PT, speech, etc takes its toll. The most difficult medical issues to deal with have been the aggression, the depression, the trauma, the suicidality, the mania and psychosis- the DISCRIMINATION, and the absolute and ridiculous lack of services and supports. EVERY UCEDD and LEND program should be required to discuss these issues. They should have a curriculum to recruit and teach future leaders and practioners. The Federal government should ensure that every state stops forced child relinquishment due to disability. Ohio has established a specialized managed care contract and 1915(C) waiver with the goal to end forced child delinquishment due to disability. The Federal government needs to take a bigger role to make this happen. The autism community sould get away from high versus low autism and base classification on functional limitations and need for supports and services. A very significant number of individuals with autism have brain- based disorders such as schizophrenia, bipolar, and major depressive disorder. These individuals have very complex medical needs. They die at a MUCH earlier age of STROKE and suicide. And yet, they are discriminated against and left to die on the streets, institutionalized in prisons, and left homeless many of them psychotic.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>Autism with co- ocurring ADHD is more challenging. Add learning disabilities such as dyslexia, dyscalculia, dysgraphia compounds issues. Learning to read is a civil rights issue. I am happy to see all the work being done on structured literacy. I am so grateful to the work of journalists such as Emily Hanford and her podcast, Sold a Story, and the tireless efforts of parent-led groups that have ended up passing dyslexia laws requiring early identification of reading difficulties and revamping the choice of curriculum (goodbye Gay Su Pinnell/OSU and your bogus and non evidence- based Reading Recovery). The Federal government should have taken a much, more active role. It became a political issue and should not have. It is neuroscience and there are</p>

	decades and reams of research paid for by the Federal government on how children learn to read. And children with autism have much higher rates of dyslexia, it was important.
What additional research is needed to help address co-occurring conditions for autistic people?	There are huge gaps in providing needed supports and services for individuals with autism that have brain- based/psychotic disorders such as schizophrenia, bipolar 1, and major depressive disorders. There is a sizable group of individuals that are highly stigmatized and shuffled between systems of care. Some of these individuals have ID, some do not. All of these individuals are greatly impacted and have a great need for supports and services. Some of them also have SUD.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	First, until the private insurance debacle is fixed (doubtful), children and families that have serious emotional disturbances (dislike this term) need Medicaid. Very few states use BCMH to pay for medical/health needs for families and children with autism and co- occurring morbidities. States are very discriminatory. There is SO much work to be done. We need a Federal white paper on ADHD and executive functioning. We need to reclassify psychotic disorders as neurological. We need to have a campaign on Anosognosia. We need to recognize how serious mental illness impact health parameters, including cardiovascular issues and suicide. These are MEDICAL issues. The brain is a physical organ in the human body. We need biomarkers. We need to stop shaming mothers. We need to work more closely with families as support networks. We need to have caregivers and families at the table, because the most impacted individuals have a difficult time advocating so we are not hearing from the full spectrum of individuals and families. We need to provide evidence- ases family counseling and have Medicaid and insurance pay for it. Also, the Intergovernmental Serious Mental Illness Coordinating Committee needs to have more membership from the autism , academic, and medical community. A lot more money needs ro be expanded on these efforts.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	COVID impacted those with serious mental illness greatly yet there was very little discussion about this. In our state those with certain developmental disabilities and their parents were given early access to vaccines. The individuals with serious mental illness and autism were excluded.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Tele- health for mental health is one of the greatest benefits of COVID along with remote work for individuals with disabilities.

Name	Anonymous
Demographic	Autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>I have a connective disorder called hEDS, which is commonly co-morbid with other conditions. For years, I was misdiagnosed with Fibromyalgia, and my symptoms were dismissed as normal. Recently, I discovered that my lax connective tissue has caused visceroptosis, leading to chronic bacterial overgrowth and allergies requiring multiple bouts of emergency care. I also suffer from Mast Cell Activation Syndrome, which can trigger life-threatening reactions without true IgE allergies. Additionally, I experience adrenaline surges and high blood pressure when standing due to unspecified dysautonomia. I have undergone multiple surgeries for endometriosis and adenomyosis. Dyspraxia adds to my challenges, causing coordination difficulties and constant dropping of objects. Sadly, these conditions were not diagnosed until my late 30s, and I endured decades of pain due to medical ignorance and dismissive doctors. Living with severe sensory issues further complicates my daily experiences within my own body.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>I have been diagnosed with OCD, PMDD, ADHD, complex PTSD (unofficially recognized), PTSD, severe anxiety, and social anxiety. During meltdowns, I engage in self-injurious behavior. Severe trauma has left me completely isolated, as I was not diagnosed with autism until my late 30s. This late diagnosis brings its own set of challenges, as I grew up feeling constantly misunderstood and rejected. I endured relentless bullying from peers and even teachers, leading to a deep sense of being "bad" and not knowing how to fit in as a human.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>I experience verbal difficulties when overwhelmed or overstimulated, and my processing speed is delayed, making it challenging for me to keep up with conversations. This can sometimes frustrate others who may not understand my need for clarification. Despite these difficulties, I excelled in the gifted program and thrive when provided with a supportive environment. Unfortunately, many social and educational settings are not accommodating to individuals like us. It is important to recognize that people should not underestimate our capabilities simply because we are autistic. Additionally, autistic individuals with intellectual impairments often excel in areas that society tends to overlook, such as memorization and fact recall within our special interests.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>Although we do not yet fully understand the biological root of Autism, it is clear we tend to suffer with many physical manifestations outside of the behaviors we display (which is just the "tip of the iceberg"). I can only speak for my experience, but I hope to see research in the following: 1. Connective tissue disorders and how they are linked to ASD (see the Connectivome Theory of ASD: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8892379/) 2. Mast Cell Activation Syndrome 3. Dysautonomia 4. Complex Post-Traumatic Stress Disorder (which can exacerbate physical ailments)</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Autistic individuals require a dedicated case worker as a central point of contact for accessing medical and mental health services. The current system is fragmented, and a single touch point is necessary. With an established case worker, we can receive information on common co-morbidities, guiding us towards appropriate healthcare professionals. Additionally, there is a pressing need for increased public awareness. The autistic community, including caregivers, has been advocating tirelessly for ourselves and our children. It is crucial for the public to gain a comprehensive understanding of Autism.</p>

<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>In addition to the challenges of isolation as an autistic individual during the Covid-19 pandemic, my physical comorbidities further restrict my ability to leave the house. The ongoing health risks associated with the pandemic, coupled with my specific health conditions, make it necessary for me to prioritize my safety and minimize exposure to the virus. As a result, I have limited opportunities to engage in outdoor activities or access essential services outside of my home. This further exacerbates the feelings of isolation and impacts my overall well-being as an autistic individual.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	sympathetic nervous system (stuck in fight/flight/freeze/fawn), gastrointestinal disorders, sleep disturbances (not able to sleep through the night), sensitive to chemicals in the air like laundry detergent sheets (coming out of homes), chemicals worn like perfumes, deodorants, chemicals in homes like cleaning products, plugins, etc., hEDS (connective tissue disorders), extreme fatigue, physical pain walking, standing, sitting and lying in bed due to hEDS, hives, headaches from environmental chemicals, muscles clenching, jaw clenching, throat issues, sensory challenges
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD, social situations are tough to navigate due to high masking, causes fatigue, mental, emotional and physical. Not able to sit still, stand for long periods of time due to hEDS, uncomfortable in a bra so staying at home is more comfortable than leaving the house, anxiety when I am not able to get info about circumstances I will be moving through so I know how to best prepare and care for my needs
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I feel like I am very direct and clear with my communication yet I feel like I am always misunderstood or misinterpreted. Dyslexia, OCD, routines are necessary for stability. Socially awkward, not willing to conform so treated like outcast, direct, blunt, can hurt other people's feelings with my delivery, major communication breakdowns
What additional research is needed to help address co-occurring conditions for autistic people?	More research is needed on adults, especially adult women who were not diagnosed as a child. Need a broader understanding of comorbidities related to autistic genes so these conditions can be recognized sooner than later in our lives. High masking females are overlooked and need daily support even if they are considered high functioning and appear "normal", we need data collected from this part of the autistic population
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Better doctor care and knowledge, more training from autistic people and providers who are trained BY autistic people based on our perspective. More advocacy in doctor offices/visits, help from providers that understand how stress manifests in the body, somatic practitioners, trauma informed practitioners available for autistic people to help regulate the nervous system. Affordable access to foods that are free from pesticides, chemicals and preservatives. Health practitioners that coach autistics on how to eat better, move better and execute daily tasks with more ease and support. Have insurance cover these costs as part of disability services.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	None Indicated
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<ul style="list-style-type: none"> • Determining what behavior manifestations are related to physical conditions or pain • Increased aggression towards self or others and how to ensure safety for all • Lack of communication system related to pain, discomfort, or medication side effects • Difficulty with transitions between home/school/work/other programs which can be challenging in initiating and behaviorally managing visits to health providers. • Disruptions in daily routines due to physical health issues • Ruling out medical concerns/conditions and separating from ASD signs and symptoms increasing the possibility of diagnostic & Intervention delays • Staff training and consistency • Lack of parent support and resources • Communication difficulties about sensory sensitivities that occur during medical procedures
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<ul style="list-style-type: none"> • Determining what behavior manifestations are related to mental conditions and how to manage those on a daily basis • Expression of psychiatric symptoms may be limited, resulting in potential misinterpretations of behaviors • Lack of communication methods to identify feelings or emotions • Social interaction challenges can interfere with diagnosis as well as therapy • Increased aggression towards self or others and how to ensure the safety of all • Difficulty with transitions between home/school/work/other programs • Disruptions in daily routines due to physical health issues • Staff training and consistency • Lack of parent support and resources • Possible trauma • Difficulties with social skills, communication, empathy, and insight may hinder the therapeutic relationship and call for highly tailored strategies for rapport-building, support, and interventions
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<ul style="list-style-type: none"> • Staff training and consistency • Adapting to the person's needs in various settings at Adult Day Services/School/Work and other programming, especially when working with individuals with other support levels/needs • The most significant challenges potentially affect the person's overall quality of life: social growth and interpersonal effectiveness, coping with change, choices related to housing and employment as well as one's sense of self-efficacy.
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<ul style="list-style-type: none"> • Staff training methods • Supporting individuals with ASD across settings in the community, Adult Day Services, work, etc. • Transitional age of services – School age to Adulthood • Identifying evidence-based diagnostic and therapeutic interventions. • Exploring genetic and environmental factors influencing co-occurrence
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<ul style="list-style-type: none"> • Psychiatrist, Psychologist, and Nurse Practitioner interactions with providers/clients • Virtual visits versus a need for more In-person visits • Parent guidance for services available for the child from diagnosis through the lifespan • Increase funding of research (prevalence, disorder interactions, approaches to diagnosis, intervention, and outcomes) • Increased funding for training (providers, payers, and family members)
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<ul style="list-style-type: none"> • Disruptions in structure, routine, and social dynamics. Currently building new routines and getting back to former routines • Social isolation from the community • Worrying about exposures and infections thus err on the side of caution • Behavioral challenges such as mask-wearing • Access to essential services and therapies constrictions, potentially resulting in delayed diagnosis, interventions, as well as increased (and prolonged) symptom intensity

What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

- Disruptions in services (Adult Day services and community engagement)
- Continuity of care - increased use of telehealth, still experiencing virtual visits that do not capture the full picture of the person when reporting to the clinician
- Staffing shortage
- Caregiver and provider burnout
- While increased remote activities provide flexibility and convenience for some, they also reflect decreased face-to-face social interactions, which limits opportunities to build and refine skills related to communication and socialization increasing the need to adapt and be creative with social interactions and events
- Unwittingly promote social isolation

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	In addition to autism, my son has sleep disturbances, GI problems (acid reflux, frequent constipation, food sensitivities), sensory integration disorder, allergies (peanuts, eggs, soy), and asthma. He misses a lot of school due to these co-morbid conditions, especially GI issues and asthma (which prolongs his respiratory illnesses). Because he is nonverbal, he is unable to communicate effectively how he's feeling. This prolongs his discomfort and the resulting behaviors (like meltdowns and self-injury) until we figure out what's wrong and how to treat it.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	In addition to autism, my son also has severe anxiety and OCD, and exhibits aggressive and self-injurious behavior. Management of these behaviors has been an on-going challenge his whole life. Medications have helped a lot. He's also benefited from a switch from regular public school to a specialized outplacement designed for students with his behavioral challenges. Aside from school, his behaviors and severe anxiety currently limit what he's able/willing to do at home and in the community. He restricts his activities and avoids changes to his routine - deviations can bring on meltdowns and self-injury. As a family, our world has become very small.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My son has nonverbal autism and intellectual disability. He is able to communicate some basic needs through a communication device (ProLoquo2go), PECS, and some ASL signs. He can make a few approximations that only those closest to him will understand. His school program continually adds new words and phrases to his device as he's ready, but communication continues to be a huge challenge in his life. This is especially true regarding abstract things like emotions and expressing pain or illness. His lack of ability to properly communicate emotions or pain often lead to meltdowns, self-injury, and aggression. We also worry for his safety in the future.
What additional research is needed to help address co-occurring conditions for autistic people?	I believe more research needs to be done in regards to medication for anxiety, OCD, and challenging behaviors, especially in children and young adults. Many interventions for these behaviors involve some kind of talk-therapy, which obviously won't work for nonverbal individuals - especially those with intellectual disability. So medication is often the best option. However, finding the right medications with the least side-effects can be very difficult. At one point our son was tested to see what medications would match him genetically and which to avoid. This was helpful but not perfect. It would be great to explore this research further.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	There needs to be more training and better pay for those who work with autistic people, especially in the home. Although our insurance covers in-home ABA services, we are unable to find and retain well-trained therapists in our area. As our son has gotten older, this has gotten more difficult because of his size and behavioral challenges. The wonderful therapists who've worked with our son over the years often left for better paying jobs. So I think autism services would be improved by recognizing how difficult the job is, providing proper training and support, and paying those jobs well. Then hopefully it will become easier to hire and keep quality care workers.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I will respond with a positive impact, from our perspective. Covid-19 protocols made it acceptable to have virtual doctors' appointments and for insurance companies to cover them. For my son, going to a doctor's office can be extremely stressful and bring on anxiety and challenging behaviors. The ability to have a virtual appointment from home (for issues not requiring

	a physical exam) has been hugely helpful for him, as well as his parents, since he often needs both of us to accompany him to an office visit.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I already wrote in my last entry about the positive impact of virtual appointments from the pandemic. Another positive impact on our family was my husband's ability to work from home remotely during the pandemic, so he was available to attend appointments and help out when our son was experiencing challenging behaviors. The ability to have IEP and team meetings remotely was also a big help. On the negative side, my son's anxiety increased during and since the pandemic. He was unable to attend school in person for about 5 months, and keeping on a daily routine was difficult. He developed some bad habits of avoidance that we're still working on to this day.

Name	Anonymous
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	As a therapist at a public hospital, I work in a team of providers. We all treat individuals across a wide variety of presentations and identities, including many individuals with ASD. Numerous times I've heard therapists admit they feel they don't know how to work with Autistic individuals, including those they are actively treating. It has historically been seen as a specialty— only certain clinicians have special training in working with neurodiverse clients— but increasingly we see Autistic folks in therapy and a clinical workforce who is unprepared to help them. Self-harm, social anxiety, generalized anxiety, depression and trauma are all rampant in this population but clinicians haven't been educated in understanding how all these things may present a little differently and how to treat in an affirming way. One ACT clinician shared they were struggling to use their usual skills to help an autistic client they were working with; I mentioned that people on the spectrum sometimes struggle with abstraction, so ACT metaphors may not be supportive and it was the first they had heard about this. There needs to be movement toward all clinicians getting basic training in working with folks with ASD. We are doing a disservice to a large community by not.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services,	

increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Getting diagnosed. It took two years for my niece. She was lucky enough to be diagnosed young enough to have support. Not only that, I as a grown adult, am trying to get assessed and the process is so costly and long, and I have absolutely no support. A diagnosis should not be considered a luxury and it should be so much more available than it currently is to be assessed. I've struggled my entire life possibly being neurodivergent in an atypical society, and now things are beginning to make sense that didn't before. It is an injustice, how many people have gone undiagnosed just to have to figure it out alone.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	In my case, as one of many trying to see if we're on the spectrum. I've dealt with so many mental health issues that possibly could stem from being neurodivergent and possibly autistic. To the point of being suicidal.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	As someone who is trying to get assessed, I always struggled in school. There was a point where I was failing all of my classes and nobody batted an eye. I was even placed in ESL classes without being helped. I speak fluent English. Nobody cared enough to question my mental health, or to see if I could possibly have any learning or developmental or intellectual disabilities. My doctor was well aware of my situation with school, the school system failed me as well. It was so obvious that something wasn't right.
What additional research is needed to help address co-occurring conditions for autistic people?	AUTISM IN FEMALES. So many of us have slipped through the cracks. Way too many females go undiagnosed.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Accessibility for assessment. I could possibly be neurodivergent and the process to get assessed is made for people who are neurotypical. How does that make sense? Especially for people who are being diagnosed later in life typically don't have the support to follow through with the process of getting assessed. And that's even if they have the money to do so. ASSESSMENT AND DIAGNOSIS SHOULD NOT BE A LUXURY.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	I think more research into autistic people's relationship with food. The books I find about the subject tend to pseudo-scientific and focused on "curing" autism on some level. I think we would benefit from research about the connection between food and sensory and/or gastrointestinal issues with the goal of giving autistic people more tools to monitor their health.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Motor, sensory, and anxiety
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety that stops normal activities
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication issues
What additional research is needed to help address co-occurring conditions for autistic people?	Research into causes of issues
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Better access to diagnose and therapy
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The world is generally less stable and predictable which increases anxiety. Followed closely by issue caused by fake self dxers on social media

Name	Anonymous
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbances Sensory issues Social emotional issues
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Attention issues Nutrition Anxiety
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication disorders
What additional research is needed to help address co-occurring conditions for autistic people?	Mental health issues Adaptive to work
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Consider and Support natural healing and the arts
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Anxiety Fatigue Weak immune system
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	All if the above

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gastrontestinal due to low.lotility, poor.diet due to sensory issues, sleep disturbances, attention issues, impulsively related to sensory.motor.needs (running away, not standing still)
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD like symptoms, mood disturbance including anxiety and depression, aggressive and self.injurious behaviors that increase in severity related to ASD level of functioning and lack of clinical upper in-virtu for individual and caregivers
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	It can be difficult to tease out learning or developmental issues that co-occur but I believe there is a high prevalence. My son has experienced communication delays, learning delays and overall developmental delays.
What additional research is needed to help address co-occurring conditions for autistic people?	Research on effective.models caregivers can implement at home and in community settings to help navigate symptoms, ow to reduce caregiver burnout.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	We live in NY and developmental disability services thru Medicaid waiver are still silo'd under OPWDD. However, they can lit access based on "need" that is also impacted by complicating medical issues. I have avoided OPWDD services in fairer of other waiver service under DOH because I feel the OPWDD system is slow in determining need which can delay supports for a year or more. My son has other needs and I wish I could access some OPWDD services but won't give up his current eligibility under DOH because of the negative stories I hear about OPWDD. Too many hoops for.too little service. I would.like those waiver services under OPWDD to be accessible without additional bureaucratic red tape.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Disruption in services and access to community supports has had a significant impact. Many providers are short-staffed and appts stretched farther apart as a result. COVID resulted in my son losing a chunk of time in his integrated pre-k where he should have been in class with on-site therapies. This resulted in loss of progress for his speech and social interactions.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Most importantly is how we are treated by health care professionals. The second one finds out that I'm autistic, they immediately begin to treat me like an idiot who doesn't know anything. Second, we don't have the same scale of intolerance that neurotypical people use. I rated my meniscus tear as a 3/10 so I was dismissed, then I walked on it for 2 months until it required major surgery. Third, very rarely does a place accommodate people with multiple disabilities. If my wheelchair fits, it's too loud and bright. If it's a calming environment, the walls are too narrow or there are steps.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Misdiagnosis. Almost every autistic person I know was misdiagnosed at least once before getting their correct diagnosis. Panic attacks and meltdowns can look the same from the outside, but they are so different.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	It would be great if I had access to places and services. Insurance also won't cover very much. It would also be super cool if doctors would actually communicate with each other because I had to get a care coordinator to force them to talk.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	It's been very eye-opening seeing how easily society was able to adapt when THEY were the ones in need. It has made so many things easier for us. Not needing to leave the house removes some of the burden.

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	becoming overstimulated and not being able to move on with the day can be a real issue. bright lights, loud noises, or other specific triggers can absolutely halt an autistic person's routine, which has the potential to heighten chances of a meltdown or shutdown. not getting enough sleep leads to easier overstimulation, overstimulation leads to less sleep, it feels like an endless cycle.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	when anxiety rises, you become so much more aware of everything. a panic attack can quickly become a meltdown if you're not careful.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	as an autistic person who is semi-verbal, it is difficult for people to understand that just because i can talk sometimes, does not mean i can all the time. and i need help and accommodations to be able to properly communicate (ex. them learning sign language or at least not being judgemental when i use text to communicate)
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	remote delivery options have been a life saver, making trips for groceries is not ideal for me and if i have to do that it typically takes a long amount of time to recover/decompress (issues with lights, people, scanning noises, etc.)

Name	Anonymous
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbances, speech disorders, sensory and motor challenges, and multiple severe food allergies that could cause anaphylaxis cause challenges. All of these physical health issues greatly impact success with autism treatments and therapies. Many treatments and therapies only seem to work if physical challenges are not present.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Obsessive compulsive disorder, anxiety, and depression issues, combined with autism, are very difficult to treat with psychological therapies and medicines. It is difficult to find any combination that works to make individuals functional in the community so that they can begin to try steps to work toward getting a job.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Borderline intellectual disability and many communication processing disabilities make it very difficult to treat challenging behaviors and work on job skills.
What additional research is needed to help address co-occurring conditions for autistic people?	The development of tools to make treatment plans (psychological and medical) that better address all challenges of a autistic person are needed. The tool would need to include best practice treatment recommendations based on research.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage improvements for autism and co-occurring conditions treatments would be very beneficial. This would include medicines and therapies. Discrimination in health care services could be improved. In my experience, health issues often are not addressed in people with autism by "regular" doctors because "it's not worth it." Service systems are complicated and not all potential services information seems to be shared by case managers. Training and awareness for health care and other professionals in how to communicate with autistic individuals is often lacking in my experience. Since so many have autism, more training and awareness is needed. Since autism is at epidemic levels and rates continue to increase, it is a major national health emergency and a major problem for society in general. Additional funding and efforts are needed in all areas.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It has triggered more mental health conditions, like anxiety, depression, and obsessive compulsive disorder, that are not likely to go away after they have been triggered. All of these cause challenging behaviors, loss of functional skills, less employment, and more.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	Positive impacts are telehealth and general social communication "meetings" like Zoom, Teams, Meet, etc. Online communication is very good for those who find it difficult to travel to community locations. Negative impacts are reduced in-person interactions so that individuals do not get to practice those social skills.

in-person social interactions and obligations)	
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Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Social anxiety disorder - leads to difficulty advocating for ones' interests and participating in group activities.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Research into ways that non-autistic people can understand and include autistic people in complex social situations, rather than focusing on requiring autistic people to learn to mask and pretend to be "normal".
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Educate medical personnel (and mental health personnel) providing services to understand that autism isn't a disease to be "cured", and can significantly affect the presentation of co-occurring conditions, requiring different modes of assistance. When autistic persons are receiving assistance, if they suggest that their autistic traits may have to be considered, it is very unhelpful if the medical and mental health personnel respond by comments like "you don't seem autistic" or otherwise treat the autism as irrelevant. For example, at an audiologist, the structure of the actual hearing tests seem designed for people who are "normal" rather than "autistic".
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	telehealth and remote work seem to have benefited autistic people, certainly myself, by increasing acceptance of communications limitations.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I find that my sensory issues are the hardest part of day to day life. If I don't monitor my noise sensitivity, I could end up dissociating for an entire day and not really remember anything by the end of it. Similarly, my aversion to particular textures and tastes can make finding something to eat very difficult to do. As a result, I don't feel like I eat enough every day even though I want to be. My issues with sleep also do not help with all of this. Because I'm not getting enough deep sleep or restorative sleep, I often wake up with a lot of pain from muscles that never relax and tiredness.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I'm right in the middle of Autistic Burnout, and fighting my depression to get motivation to do things I love to pull myself out of burnout is [profanity redacted] near impossible. For example, I used to be a HUGE reader, but I can maybe only read a chapter before I start to read the same paragraph over and over again, even on my favorite books. My anxiety also has a part in it because I've found more things to enjoy, but pushing past prejudices to continue to enjoy them is really hard. I love a bunch of different anime shows now, but growing up, people who watched anime would get bullied and ostracized. I have to put forth a lot of effort to watch anime more in order to get past my defense mechanisms.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	There needs to be a lot more research done on autism with autistic people as advisors or consultants. I was trying to write a paper in college about the comorbidity of CPTSD and autism, and there wasn't a single paper that even attempted to link autistic burnout to CPSTD despite that being a fairly easy experience to see within myself and other autistic communities I follow on various social media platforms.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	The diagnosis process needs to be revised. Most of these tests are made by allistics for autistics and causes a lot of miscommunication that could result in misdiagnosis. The most common example I've seen is the question, "Do you struggle to put on shoes?" The autistic person would say no, because they have a system for putting them on so it's not overwhelming. Needing a system is part of struggling, but because it's worded in such a way, the diagnoser would've missed that information.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	People got a lot more involved on social media as it was the only way to connect with people while social distancing, and that opened up an entire WORLD of connections to multiple autistic people. It allowed easy access to autistic from autistic that helped to provide a lot of self diagnosis to something that people hadn't been able to understand within themselves before, especially for women. Because of the way autism is diagnosed, women are overlooked too often, and Covid finally gave some answers to people whom doctors didn't notice.

Name	Anonymous
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Seizure disorder, food allergies, Pediatric Feeding Disorders, Failure to Thrive, lack of coordination, hypotonia, sensory processing disorders
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, social anxiety, ADHD, SIB, aggression, sensory processing disorder
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Developmental disabilities, apraxia (motor and oral), communication, learning, and intellectual
What additional research is needed to help address co-occurring conditions for autistic people?	Infant and prenatal behaviors of fetus for predictive diagnostics
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Allow OTs to bill for mental health and physical health interventions for child and family for all insurances. Stop promoting ABA therapy on highly susceptible population
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Disrupted identification and access to educational resources. Schools delayed appropriate placements during pandemic for higher functioning children in TK, K, 1st and 2nd grades which meant a delayed participation in learning and use of resources
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Delayed identification or placement for school services support. Families are addressing behavior with ABA and sensory with OT but the anxiety continues to be neglected and untreated.

Name	Anonymous
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	One of the biggest challenges faced by people with Autism is that there is a misconception that this neurological developmental disorder is some sort of a mental or behavioral health problem. Like people with strokes, neurological damage and differences can be observed and have impacts on mental health (frustration, mobility issues, despair, etc.) but at its core, Autism is well recognized as a neurological disorder with developmental aspect that will not be resolved in talk therapy, group therapy, or with psychiatric medication. AN autism diagnosis must immediately be prompting a full medical work up for potential medical causes, genetically related causes and conditions, and proactive prevention of further physical complications. Endocrine, especially thyroid interactions as well as auto immune and immune deficiency concerns are critical elements, especially as sleep and communication disorders can be resolved in this axis, and are common among the autistic population. We have to look for these problems with the known statistical association to lessen their impact and resultant suffering and further damage.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	despair
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Hyperlexia and speech processing disorders and accommodations are poorly addressed in the field and this leads to a much lower quality of life and self direction for people with Autism. It is so important that behavioral communication be addressed as communication first and that all efforts to empower individuals to express and be understood so that their medical needs can be met and they can be safe.
What additional research is needed to help address co-occurring conditions for autistic people?	Thyroid axis and autoimmune interactions are a critical deadzone for understanding, while genetic and peroxisomal concerns seem clearly implicated, this is not well addressed.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	The barrier to social services is particularly high for individuals who lack the communication and mobility function to participate in safety net program requirements and as this population is so often lacking intellectual disability, yes has such high functional behavior impairment. yet deserve to live as free citizens but cannot process a simple trip to the food bank, or fast food restaurant for that matter, standing in line, making a dozen choices quickly or asking for help. Personal assistance, tailored to need and ability of each person on the autism spectrum, is critical tor keep individuals safe and meet basic needs.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Many people with autism are also immune impaired and are at increasingly higher risk for covid and less likely to have access to safe caregiving or alternative settings where n-95 masking is tolerated.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic	ending of services and a failure to adapt services to include reasonable ongoing infection protocol at a pre-pandemic level have caused many deaths in the autism community.

people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Anonymous
Demographic	Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	<p>The 3 questions in the survey posed to address 3 categories of co-occurring conditions in autistic people speaks to the core challenge which is the multiplicity of co-occurring physical, mental and developmental conditions in the same person. Focusing on a single condition/category misses the bigger picture of multiple, diverse conditions which poses the most significant challenge. Further work is needed to identify opportunities for secondary and tertiary prevention targeting co-occurring conditions over the life course. There must be better understanding of the dynamic patterns of emergence of the co-occurring conditions (patterns over time as well as associated risk factors/mediators/moderators of the patterns of emergence of potentially multiple conditions over time), including investigation of the genetic underpinnings (including g-e studies). Further work is also needed to better understand the sources of resilience in autistic people because the patterns of co-occurring conditions and their impact on health, well being and quality of life in autistic people are not uniform. Improved understanding of the factors associated with better outcomes among autistic people is understudied. Further research into improving health literacy of autistic people and their families and health communication with care providers may be an early step in improving outcomes in the context of co-occurring conditions (one means of secondary and tertiary prevention)</p>
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	<p>The prior suggestion for research into improving health literacy and health communication of autistic people and their care providers may improve the delivery of services and services satisfaction.</p>
What lasting impact has COVID-19 infection and illness had on co-	

occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	sleep disturbances and sensory & motor challenges
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD, anxiety, self-injuries behavior, and suicidality
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	intellectual disabilities and communication disabilities
What additional research is needed to help address co-occurring conditions for autistic people?	To identify caregivers' priorities for intervention endpoints To identify co-occurring conditions for which the improvement will enhance the overall quality of life of individuals on the spectrum
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	patient-provider interactions. Providers need to listen to the patient more and respect patients' lived experience.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	adaptations to new social and life/work routines
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	increased use of telehealth may create a digital divide among individuals with SES disparities.

Name	Anonymous
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory (integration) differences, sleep disturbances, AFRID, MCAS, POTS, Ehlers-Danlos
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD, Trauma, depression, Body focused repetitive behaviors
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Intersectionality between autism and adoption. More research on how autistic traits and characteristics manifest in BIPOC and LGBTQIA2+ communities.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Improved training of professionals in and outside of graduate school, uplifting voices and perspectives of those with lived experiences versus valuing research and training by those without lived experience, equitable access to and accessibility of services, increasing services for autistic folx who are 21 years old+
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gastrointestinal disorders; environmental and food allergies
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety; eating disorders
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Developmental disabilities, intellectual disabilities, communication disabilities
What additional research is needed to help address co-occurring conditions for autistic people?	Firstly, including participants with co-occurring conditions in the first place is a great start. Co-occurring physical, medical conditions are often overlooked by doctors who place everything in the “it’s just the autism” basket, leaving GI disorders, allergies, and possibly autoimmune disorders unaddressed. Autism and anxiety is huge because it can lead to other mental health disorders like eating disorders, depression and OCD. Please do more studies on those with more severe autism. The more severe the autism, it seems the more likely they are to have co-occurring physical and mental health conditions. But since they are often less verbal, they get less help.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Non-traditional educational options for those with severe autism. Special education in public school can be absolutely traumatizing for a kid with multiple conditions and who is non-verbal. Please expand access to alternative access to education such as online, independent studies, etc. Public online charters do NOT allow for mod-severe kids in need of special education, even if they did well on distance learning. Options should be at least statewide and not only if you get lucky in the right district with the right administrator.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	Positive: Many families learned that their kids did really well on distance learning and with telehealth for therapies. These options prevented disruptions in education and treatments during lockdown. Negative: the total removal of most of these options has unfortunately led to major disruptions and many children, including my own, have regressed drastically. More exposure to illness at school, loss of learned skills, and overall greater anxiety.

in-person social interactions and obligations)	
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Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gastrointestinal disorders, specifically constipation, and obesity resulting from aversion to appropriate foods
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety and self injury
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication disabilities
What additional research is needed to help address co-occurring conditions for autistic people?	Determine what causes gastrointestinal problems in autistic people. Determine better methods of overcoming food aversions.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Improve education of concurrent health conditions in autistic people for pediatricians and general practitioners
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Online school did not meet our needs for communication education. Being away from school also increased our son's anxiety.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increased remote education has decreased communication disorder treatments.

Name	Anonymous
Demographic	Family member of an autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>My 19-year old son has a Pathological Demand Avoidance (PDA) presentation of autism. The physical result of his continual heightened anxiety during puberty included debilitating GI cramping and vomiting that, after many invasive medical tests, was determined to be Functional Abdominal Pain. He missed most of several years of school due to both discomfort and extreme anxiety. Unaware of the concept/diagnosis of PDA, we essentially stumbled into creating a low-demand household and schooling situations that over time has enabled him to physically feel well most of the time. My son also has co-occurring encopresis and nocturnal enuresis (bed wetting). He was in pull ups until age 6 and continued to have embarrassing pee accidents until about age 10. At age 19 he still pees the bed several times a week, and has all of his bowel movements in his underwear. We suspect his PDA presentation of autism underlies why he isn't able to use the toilet. The shame of his encopresis has been immense and very impactful on his mental health and ability to try to fully function in society. He has been accepted to college, but has taken a gap year to try to figure out how to deal with these conditions in a dorm setting. He has not physically been able to make much progress and, due to the PDA anxiety and shame, is unable to access medical help (e.g. OT). These conditions cause huge amounts of laundry, which his PDA prevents him from being able to do. He requires extensive parental support.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>My 19-year old son has a Pathological Demand Avoidance (PDA) presentation of autism. His ability to do anything depends on his level of internalized anxiety at that particular moment. He has had multiple multi-month periods of burnout during which he was unable to do virtually anything, including attending school. Around age 10 he began showing signs of OCD. By age 12 the OCD manifested into obsessive suicidal ideation. He didn't want to die, but felt he needed to kill himself. He had not yet been diagnosed with autism, and we were unaware of the concept of PDA. [Typical of PDA, his eye contact was decent and he was able to develop friendships and appear sociable so multiple doctors and therapists had not diagnosed him with autism. They simply said he was a "complex kid" and difficult to diagnosis. None-the-less he was very confused by or unaware of most social cues, idioms, etc.] Due to the suicidal ideation and his impulsivity (potentially injuring himself), he went through several rounds of mental health hospitalization. During his first in-patient stay he received a clinical diagnosis of autism. We wish PDA was in the DSM then. It was another 6 years before we stumbled onto the term PDA. While a variety of medications and extensive mental health therapy had helped over the years, it has been our teaching ourselves about PDA and adopting a low-demand lifestyle for him and our household that has now enabled his OCD and suicidal ideation to dramatically improve.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>School is an especially challenging environment for autistic people with a Pathological Demand Avoidance (PDA) presentation. My 19-year old son has PDA. The social, prescriptive, and structured demands of school were essentially impossible for him. He is autodidactic and a very good communicator, so he was able to learn and progress through grades while frequently missing school or leaving the classroom throughout the day (even with an IEP, aide, social pragmatic, therapeutic, and social work supports). Virtual learning during covid lockdown was somewhat better for him because he could stay home, have more breaks, and be more in control of his time</p>

	<p>and tasks. He ultimately finished high school as a homeschooler using an “unschooling” approach in which he developed his own “curriculum” and pursued his intellectual interests. He was then accepted by a college. My son also has co-occurring encopresis and nocturnal enuresis. Coupled with PDA, it is extremely difficult for him to be without parental support for laundry. He is not able to manage washing the large amount of very soiled laundry he produces. He requires extensive protective bedding and extra clothes to get through each day. This all makes it very difficult for him to go away on a trip without multiple duffle bags stuffed with supplies. So far the PDA-based anxiety has kept him from being able to get professional help (e.g., OT) or being willing to work with a home health aide; therefore he has not started college.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>I beg you to develop/fund/advocate for research studies of the Pathological Demand Avoidance (PDA) presentation of autism – for child, adolescent, young adult, and adult stages. PDA is an official diagnosis in the UK, but it is not in the American DSM. Please work to get it accepted as a diagnosis in the DSM! Our 19 year was not diagnosed with autism until age 12. When we would ask doctors and therapists whether he may be autistic, we were told he had good eye contact so he wasn’t autistic, although they did recommend autism programs because he did have a very complex presentation that defied diagnosis. Last year I saw the term PDA and did an online search. I found a description on the UK PDA Society web site and was shocked to find that 5 of the 6 key features (except role play) perfectly described my son and the characteristics that professionals found so “complex” about him. Over the past year we have delved deeply into learning about PDA from the UK PDA Society, the nascent PDA North America organization, and various US-based PDA coaches and support groups. What we have learned has fundamentally made a difference to the quality of life for our son and our family. But there is so much more understanding, insight, guidance, and professional support we need, especially as he encounters the challenges of going to college and becoming an adult. We need the professionals he will need support from to accept, understand, and be able to work successfully with someone with PDA.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Research, validation, and inclusion of the Pathological Demand Avoidance (PDA) presentation of autism in the next edition of the American DSM is essential to improving services and supports for this segment of the autism community. PDA-ers desperately need providers at every level of the medical, mental health, education, social work, insurance, and employment sectors to first be aware, and then be well trained to support the PDA-er in an accepting manner that takes seriously their innate need for autonomy. Many medical, therapeutic, and education professionals are required to follow proscribed steps and show progress toward specific goals in order to be paid (by employer or insurance). These steps and goals work counter to the approach PDAers need to experience to feel safe and make progress. Autism services need to adapt to this paradigm shift.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic</p>	

people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

Name	Anonymous
Demographic	Autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>Personally I haven't had any nor has my family that aren't a result of increased sensitivities of negative influences (stress ulcers panic attacks etc) though there have been many of this nature when situations could understandably cause them. (Increased susceptibility to stress induced conditions). We do all suffer from difficulty with daily sleep routines demanding consistent times.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>Finding safe care and support: A lot is heightened with my autism, senses, emotion, trauma. I was misdiagnosed schizophrenic and prescribed antipsychotics like seroquel, trisidone and risperdol; all caused adverse reactions but geodon caused the most painful night of my life. I haven't recovered from the fallout of that night, after over twenty years of slow recovery. Autism NEEDS *affirming* care. The main downside of autism is the difficulty calming down after trauma (high glutamine vs low GABA in the brain) BUT we are also sensitive to medication that affects it, so transq or anti-anxiety meds etc quickly lead to dependency and even worse panic attacks, making them all but useless. Suppressing autism symptoms is removing coping tools and damaging capacity for calm. We need social support like group meetings and understanding therapeutic care. The side of the mental health care system that I've seen, the short time diagnosing and the subjective/unscientific means of assessment are not only despicable and pathetic but atrocious. I'm running out of words or I could tell you stories and you'd see why I see it in this light. I've seen many lives utterly ruined by cold uncaring doctors. I was committed by a judge the week of my 18th birthday while forced under the influence of high doses of meds that made me deeply confused and frightened. They heavily drugged me against my will before court to be assessed... think about that.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>I'm frankly deeply afraid of most people and always have been. This has always proved to be the correct way of thinking due to most people's behavior. I have instinctively avoided eye contact and am afraid of how to talk to people and am nervous around strangers. I get anxious when criticized and indignant when ordered around because I easily get tired of being manipulated by people who are not gentle or tolerant and who have earned no respect for no other reason than because they say so. This kind of social dynamic leads to countless problems in culture and society and a "strong survivor" is one who commands respect from people easily and copes with stress by taking the difficult path of least resistance and works well with a group and sees the goodness in others as that is how they stay strong. We need to work together</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>There needs to be a way of ingesting and supporting research and analysis of individuals that combines research already done and to incorporate autistic and other neurodivergents into the medical community. It needs to not be seen or treated as a disabling thing as much so that those with different neurologies are able to contribute and be part of the discussion. Yes it is challenging at best but in no way is it invalidating. The best therapists for NDs are themselves NDs, for example. Autistics should be the forefront of autistic research; this is necessarily true for many reasons.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic</p>	<p>Everything.</p>

<p>people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>The increased difficulty with cost of living is causing a massive and escalating homelessness problem and the stress is felt very acutely. As already being “bad at capitalism” the autistic community is doubly suffering from economic strain.</p>

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	in order of severity 1) Sleep disturbances = unavailable to appointments, school, social time, keeping other household members up and/or intermittent sleep 2.) Inability to live outside of bedroom if unregulated. 3.) Body cleanliness = skin issues, body odor, infections
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Unable to be outside of bedroom for very long most days. Extreme anxiety over: weather changes, how far away from home he is, experiencing something new, especially if far from home, needles (no vaccines, no bloodwork), medication-will not try or take any, hearing or viewing health concerns that are spoken about, or seen masking= extreme exhaustion, verbal abuse, misunderstanding between general society and what occurs within family/parents verbal abuse to family inability to explain feelings lack of accountability touching dirty dishes, garbage, dirt.... smelling most scents, but oblivious to own body odor inability to focus on school work
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Masking in public, especially at school = late diagnosis/IEP/no-knowledge/diagnosis regarding PDA Educational support that is capable, consistent, communicative (w/parents) concise, reliable, and trustworthy Lack of physical/team sport and social per-to-per connection opportunities if not in public school system
What additional research is needed to help address co-occurring conditions for autistic people?	Recognition of PDA (Pathological Demand Avoidance) within the USA How to supply the public educational system with collaborative, child-led education, so they are more able to learn and stay in the school building. Aid with increasing the amount of support- certified, Autistic specific, psychiatrists, psychologists and educators.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage for mental health care from a certified Dr who specializes in PDA (Pathological Demand Avoidance) Autistic specific Specialty Clinics to aid in medical visits. Disability Law to help with employment discrimination Funding for long-term financial support, housing, parental support, medical needs
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	extreme anxiety to go out in public incapable of receiving vaccinations = loss of job, immunity
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Disruptions with public education that led to staffing issues, less college graduates, lack of special ed support staff and teachers, that led to the inability to keep up with NT students. Now many are being home schooled or participating in on-line learning to catch up or re-regulate. On-line/home school education cannot replace social interactions with per's and team, school supported athletic activities.

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	a) communication between professional and care team b) as young person can read/write/talk (but may not fully understand) care team think she is deliberately naughty when having a meltdown.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	a) Getting timely help b) communication between professionals c) as can read/write talk, carers think her behaviour is deliberate
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	a) challenging behaviour b) anxiety c) depression d) query psychosis Being believed
What additional research is needed to help address co-occurring conditions for autistic people?	To be clear what the differences are/similarities are between co-occurring conditions Acknowledging PDA exists and the impact this has, especially for girls
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	communication between professionals better understanding by professionals
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Isolation wrecked her mental health. Coped fine at the time as no pressures to attend school/college, etc., But getting back to 'normal' life has just not happened
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Easy at the time as no pressures, but after the lack of support has been significant. The excuse for every failure by the services meant to help.

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Anxiety. Nutrition. Education. I am the parent of a 12 year old autistic boy with a PDA (pathological demand avoidance) presentation. My son has been "in burnout" for several months. During this time, he has not been able to access school; in fact, he has left the house only a few times. He struggles to eat, to get dressed, and to perform basic self-maintenance tasks like washing his hair and brushing his teeth. He has been able to do all of these things in the past, up until the burnout trajectory turned into a crisis and he became unable to do these basic things. He will now only eat a small number of foods and can only eat them in a very narrow set of conditions. We are concerned about nutrition. School has always been a source of anxiety for him, and he was misdiagnosed for years with performance anxiety and anxiety/ depression. He is a typical PDA child, in that he is extremely good at masking his autism and getting by-- we were not aware of his autism until he reached the burnout point, and so he has not ever had access to accommodations in his schooling up until this point. The most significant challenges are: eating. Accessing school. Managing anxiety in order to leave the house for basic things like doctors appointments. He has lost the ability to be in the same room as anyone besides immediate family, and even in those settings needs a lot of soothing and comfort.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety. Aggressive and self-injurious behavior. Inability of others to understand the root cause of anxiety and aggressive behavior. It is challenging to sift apart the behavior from the underlying need. Especially in a PDA autistic child, who is very good at masking and mimicking social behavior (despite being extraordinarily stressed by doing so)-- and thus may seem "normal," despite having the same needs and challenges as other autistic people.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Accessing school accommodations. Especially when the accommodations needed for a PDA-type autistic is different from those that might help other autistic people. Also, even more especially, when the accommodations necessary require a restructuring of the school day and accommodations more fundamental than seating changes or sensory breaks. A PDA autistic student needs education that centers their special interests and permits the student autonomy throughout their school day.
What additional research is needed to help address co-occurring conditions for autistic people?	How to feasibly educate PDA autistic children in a school setting. How to appropriately support parents if and in the times when the PDA autistic child cannot access the school setting.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Increased awareness of PDA type autism.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	In our household, the demands of zoom during the remote schooling period have made that medium frightening and have decreased my child's willingness/ ability to interact with others virtually.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on	Increased fear of in-person social interactions. Increased fear of zoom-based communication.

physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

Name	Anonymous
Demographic	Autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>When it comes to sensory challenges, everything is too loud and too bright. Certain textures are painful to touch. For example, the pockets of my favorite jacket feels like I'm sticking my hands in razor blades, so I can't use those pockets even though its not very practical. I don't recognize when I'm hungry until I'm starving. I don't recognize when I need to use the bathroom until I'm about to have an accident. I don't recognize when I am hurt or sick unless there is a serious problem, but even still I don't get taken seriously by caregivers and medical professionals because I don't express pain in a neurotypical way. The most significant challenges caused by epilepsy include seizure related injuries, confusion, headaches, and memory loss. Frequent appointments and EEGs are stressful. I stopped seeing my neurologist for many years because the stress of the appointments and EEGs became too overwhelming. We have our driver's licenses taken away after we have a seizure. There is a risk of drowning during seizures in swimming pools, bodies of water, or even in the bathtub.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>Anxiety and depression medication options are extremely limited. The "trial and error" method of finding the right medication for anxiety and depression management is lengthy and dangerous. When I was diagnosed with Autism as a child, I was put through ABA to learn how to mask my Autistic traits. We now know that lifelong masking causes anxiety and depression. The suicide rate among Autistic people is alarming and is something that needs more public awareness. We need depression medication that actually works and doesn't have "worsening depression" as a side effect.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>I was diagnosed with selective mutism as a child when I lost my ability to speak entirely, two years later I was diagnosed with Autism. We absolutely need more research in this area with this specific skill regression. When we start out our lives as being verbal and lose our speech at a later age everyone around us thinks we are doing it on purpose. We are punished by our families and teachers because they think we are being "disrespectful" or "rude." When in reality, we suddenly and without reason can no longer make words go from our brains to our mouths.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>Research why non Autistic people hate us. If we weren't hated for just simply existing, question number two wouldn't need to be asked. We wouldn't have anxiety from constant masking. Constantly surveying our surroundings to try to blend in just to avoid being seen for who we really are. Living in fear of making mistakes that we don't even know are mistakes. We wouldn't be so depressed if we were actually loved the way we are. We wouldn't have astronomically high suicide rates if we were just accepted as equal members of society, not any different from anyone else. At some point or another, we didn't know we were any different until an allistic person told us we were different. Autism awareness is not enough, we need equality.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>We need to be made aware of what services there are for us in all stages of life and not just childhood. We have support all throughout elementary, middle, and high school, and then not much support after that. This can lead to skill regression in Autistic adults. We need more services, supports, and accommodations for adults of all levels of the Autism spectrum. We need services in rural areas. We need better insurance coverage. When we lose our parent's health insurance at age 26 and only have government insurance, we can no longer see our specialists for many of our co-occurring conditions. This obviously keeps us sick and shortens our lifespan. We need our case managers, psychiatrists, therapists, doctors, teachers, and anyone else</p>

	<p>working with us to be educated on Autism with up-to-date information. Many Autistic people are LGBTQ+ and we need to know we're only coming in contact with safe people who won't judge us based on our gender identity or sexual orientation.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>The pandemic was a blessing in disguise when everyone suddenly became aware of germs and how they are spread. I'm not going to sit here and pretend I forgot the general public needed to be educated on basic handwashing. People started doing the things I had always been saying they should do, such as, social distancing, wearing masks, properly washing their hands, using hand sanitizer, and stores sanitizing after each customer. When normally I would get sick when anyone would so much as breathe in my direction, the world had finally become clean and I didn't get sick that year. Masks and proper handwashing for everyone in society are imperative to the health of Autistic people with co-occurring health conditions. Reduced in person social interactions and telehealth reduces social anxiety. Remote work and school lets us do things from the comfort of our own home while still being productive members of society. Unemployment is a huge problem for Autistic people, we need more remote jobs and we need Autistic people to be considered first for these jobs.</p>

Name	Anonymous
Demographic	Autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Connective tissue disorders, sleep disorders, anxiety disorders, pathological demand avoidance
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Inability to work, relationship issues, self harm
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Job related issues, challenges with living independently
What additional research is needed to help address co-occurring conditions for autistic people?	Study sleep, pathological demand avoidance, self diagnosis
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage, access to resources to pay for a wide variety of treatments
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Learning challenges
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, depression, aggression
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Learning and intellectual
What additional research is needed to help address co-occurring conditions for autistic people?	You need to focus on PDA, it is such a challenging condition and there is nowhere near enough research or understanding. As a parent of a PDAer, it has been an extremely challenging time. My son is extremely impressionable and as such has been drawn into so many problematic situations. We simply did not have the tools or understanding to support him and it appears nobody does for kids with PDA. As a result he has declined into alcoholism and drug use to self medicate. He is 19 years old.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Specialist services for PDAers
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	often misdiagnosed or missed in autistic people, i got misdiagnosed as bipolar
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	lower cost, better provider training *by autistic people*
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I have personally experienced gastrointestinal difficulties and sleep difficulties. I do not have any diagnoses for either of these issues. Possibly the problem is that I was not diagnosed with autism until I was almost 46 years old. It is also possible that it is not widely known that these conditions co-occur. Not having accurate diagnoses seems to have caused confusion and delay of treatment for me. I have no current resolution to my gastrointestinal or sleep difficulties.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The most significant challenge of my entire life has been that I did not receive my ADHD diagnosis until I was 44 years old or my autism diagnosis until I was almost 46. I was mis-diagnosed with mental health conditions and given medication that was not helpful to me or caused unwanted side effects. For example, depression medication caused me to become agitated and limited my sexual function. Mood lability medication was not that troublesome but it didn't help me and it cost me and my insurance a lot of money over time.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My main co-occurring condition is ADHD. It seems it commonly co-occurs with autism. Autism probably should have been screened for when I was diagnosed with ADHD in 2021 especially since I was presenting with high anxiety
What additional research is needed to help address co-occurring conditions for autistic people?	As much data should be collected as possible regarding co-occurring conditions with autism such as hypermobility and connective tissue disorders. This evidence will help doctors to be aware and look for these disorders together because a lot of people suffer from either or both greatly.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I think that changes that would help disabled people overall would help autistic people. Healthcare in general needs to be more accessible, more affordable, and more efficient. Public transportation needs to be much more comprehensive. Patient-provider interactions are rushed and impersonal for most people regardless of disability status.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It seems like long-COVID disease has many similarities to issues that autistic people already face as being likely to have connective tissue disorders. For example, one might experience disautonomia from either. For me personally, my obsessive compulsive disorder and health anxiety have become worse since there is a greater threat to my health from the virus. Prompt and competent attention to symptoms from both/either COVID-19 and/or autonomic disorders in the emergency care and primary care setting could be a game changer
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increased remote work and reduced in-person social interactions and obligations has seemed to have a positive impact on the physical and mental health of not only autistic people. I have heard women of color on social media talking about how they don't have to "code-switch" or worry about their hair because of being able to work at home. Working at home is a more flexible option for people who have special needs. For me personally, I prefer to leave the home regularly and I prefer to feel physically safe in the workplace. The COVID-19 pandemic has left me feeling more afraid to leave the home. I did contract COVID-19 in my workplace last year and I am concerned about what long term health effects I might encounter. A

	thoughtful, introspective autistic person is likely to be more affected by these concerns for themselves and others than the average neurotypical person. This is an overall negative impact of the societal “acceptance” and dismissal of COVID-19 as serious.
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Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Magnification and catastrophizing of physical issues. Physical symptoms overwhelm easily.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Untreatable depression and anxiety, obsessive thoughts lead to suicidal ideation.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	All areas that might address extreme levels of anxiety/depression and rumination.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Late diagnosis (26) creates a host of problems and extremely limited resources primarily to affordable access to treatment and supports.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Isolation creating major social anxiety
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gastrointestinal disorders, sensory challenges, and autoimmune conditions make it difficult to function in uncontrolled environments.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	People with autism are frequently perceived as lazy and uncooperative. This makes it particularly difficult to function in the workforce, which is a social requirement to justify our existence.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Many opportunities are disseminated in our society through charismatic in-person interaction, resulting in unequal opportunities.
What additional research is needed to help address co-occurring conditions for autistic people?	I believe long COVID to be a largely autoimmune condition co-occurring with autism. The healthcare system is, at present, unable to do anything in response to one of the greatest mass disabling events in modern history.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Working from home and hybrid work environments must be seen as not only a matter of employee preference or convenience but as a matter of inclusion.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Substantial exacerbation of health conditions persists more than three years after initial infection. Irritable bowel syndrome, fatigue, anxiety, and cognitive function are all worse in my case. Invisible disabilities such as these are difficult to document, impeding requests for reasonable accommodations. Before getting sick, my partner and i drove about 30 minutes and 50 minutes, respectively, to work at the office most days during the week, and worked a full-time schedule. Since getting sick, we've struggled to maintain a full-time work schedule, even entirely working from home, to the extent of one of us taking unpaid leave.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increase in remote work has been great. I was miserable conjuring into the workplace daily prior to the pandemic. But the more recent push by many for more presence in the office has been very stressful. We demonstrated that we can do our jobs from home, but management often wants to force employees into the office due to their personal preference.

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Fatigue and low energy, especially chronic fatigue and post-exertional malaise from long COVID. Also attention and focus challenges in the workplace - many autistics work better from home (when the position allows)
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Attention and focus issues, anxiety, and with long COVID brain fog and low mental bandwidth
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Workplaces and society more generally expect non-neurodivergent styles of communication, which can disadvantage neurodivergent individuals and unduly dismiss their ideas
What additional research is needed to help address co-occurring conditions for autistic people?	Effective treatment and/or a cure for long COVID is crucial
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Increase virtual and asynchronous interaction opportunities to improve accessibility - allowing telehealth and electronic messaging whenever possible is a great example
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Having long COVID has made my autism so much more disabling. Since March 2020 I've experienced a chronic post-viral illness, largely characterized by excessive fatigue and weakness. Before COVID I thought I needed just a bit more rest than the average person, but now that difference is dramatic. By depleting my energy, long COVID made my autism symptoms much more noticeable and disruptive in my life. I sought workplace accommodations for increased work from home and flexibility to use leave - and pursued an autism diagnosis for this reason. I didn't realize how much energy I was putting into managing my autism until my energy levels so drastically fell. I'm aware of thinking that long COVID disproportionately affects autistics, perhaps due to an autoimmune effect - I believe there could be merit to that.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school,	I now better appreciate how workplace flexibilities, including remote and hybrid work, are accessibility issues, and how unduly requiring employees to return to the office (without a business need) can unfairly disadvantage workers who do their jobs best from home. So to improve workplace accessibility for autistics (as well as many others), I want to see a greater push for and normalization of remote work flexibilities. I certainly work best from home - as someone who is autistic, I save physical energy by not

increased use of telehealth, reduced in-person social interactions and obligations)	commuting, experience less distraction within my home office, and reduce stress by having better control over my environment, including the ability to step away to rest on short notice.
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Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The most significant challenges caused by co-occurring physical health conditions in autistic people are many and may last or come and go such as tiredness, stomach aches, sensory and motor issues, stress, anxiety, being alone, ADHD symptoms, hearing problems, misunderstood, social and emotional problems, clumsy, lazy, snacking, Impulsive, not knowing what to say, social anxiety, not being diagnosed but knowing something is wrong as you age and you masked unaware to cope in the process you were drained. Reprimanded continually by anyone you came in contact with. Then shunned, mocked and ignored. It's extremely important to diagnose young children with any learning differences they may have so they develop their best potential.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Significant challenges caused by co-occurring mental health conditions in autistic people is getting mental health care services in place to support the needs of the autistic community.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	implementing learning programs that will help students learn coping skills for communicating effectively. learning disabilities, developmental and intellectual programs that promote growth and success.
What additional research is needed to help address co-occurring conditions for autistic people?	Additional research needed to address co-occurring conditions for autistic people, substance abuse, PTSD, diseases and child abuse, abandonment of a parent and other trauma. Trauma short circuits pathways in the brain. science says new pathways can build back in the brain over time and heal in part pathways.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	It's important to have a good fit patient-provider relationship. Resources to access support, internet, telephone, small groups.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	School children in general have been most affected by covid-19. Positive impacts, family time sometimes and a slower pace.

Name	Anonymous
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	GI issues and PDA stops the individuals capacity to deal with them
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Pathological Demand Avoidance profile (PDA) - makes traditional treatment options inaccessible and irrelevant
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Learning disabilities / school can't (too hard to fit in to neuronormative environments), social struggles and constantly being "second class citizenized" instead of celebrated for more unusual talents etc. Mental health and self esteem go down hard... lots of trauma.
What additional research is needed to help address co-occurring conditions for autistic people?	PDA!! It's in its infancy research wise yet far more commonplace than understood at present. Needs and deserves a lot more research
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	A willingness to learn from individual clients instead of textbook service provision.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Generalized anxiety increases and less general trust of people and the world around them
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	All of the above - more entrenched social isolation (and distrust)

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I have Autism and suffer from gastrointestinal disorders, sleep disturbances, sensory and motor challenges, along with memory issues, severe developmental delays and a lack of understanding social situations around me and what is appropriate. I also have many severe allergies , mental health disorders and time blindness.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I suffer from depression, anxiety, ADHD, suicidal tendencies and thoughts. I am also transgender.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I have learning, developmental, some intellectual, and communication disabilities.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Eliminate the \$2,000 SSI asset limit for those on disability and collecting social security. This would greatly reduce stress on the community reduce homelessness or save up for people to get cars to live in so you're not homeless on the streets.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	After COVID happened they started allowing virtual visits to be covered which helped my anxiety a lot and substantially reduced the amount of time I had to travel. Making healthcare more attainable. I also now have a personal live-in aid whose made a huge impact.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Disruption of services resulting in homelessness and loss of healthcare.

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	When our child is overstimulated from the external environment (school, friendships, sounds) her physical body can no longer tolerate clothing, sounds, the ability to rest and sleep, eat. This causes great distress to her as she desperately wants to eat or go to sleep but her body won't let her. She says that can't swallow her food. When it comes to bed, everything feels itchy and scratchy all her clothes her linen, she will end up crying herself to sleep on the floor. When her nervous system is so activated, there is no way she can brush her teeth. She will go for days without brushing. Brushing her hair can be very painful for her too. All of these sensory issues impact on her physically getting to school. At the moment she is not wearing shoes to school because her body is so overwhelmed with attending school. Lack of sleep, poor diet, poor hygiene impacts on her school and ability to develop friendships.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My daughter has a PDA profile. This is extremely difficult and she often tells us she hates her body for the PDA. PDA has stopped our daughter from doing things she loves and wants, like gymnastics, going to events. She describes it as her brain desperately wants to do something but her body won't let her. This can be something like going to school, birthday parties, she wants to go but she can't. She physically isn't able to push her body through it. If she tries she will eventually have a very big meltdown and then this impacts on her energy levels. Due to her PDA, she is an amazing master when she needs to be. Because of her "heavy masking" at school for year prior to her diagnosis, it led her into burnout in 2023. This was an extremely challenging time for our family. Our daughter (11 years old) was not able to move, walk, toilet, eat, talk for months. Someone had to be with her 24/7. Her mental health was so bad, her panic attacks were significant and frequent. She didn't participate in any form of education for most of 2023. Since burnout, our daughter is a different child. She is constantly anxious, always heightened, has frequent meltdowns and can be extremely verbally abusive to close family members especially her little brother (who is also autistic). Managing her anxiety is very difficult as PDA will not allow her to take medication. Our family life is completely different, it has impacted on all of our mental health and financial situation.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	More research into PDA and burnout. How masking causes burnout. How the education system causes significant distress of neurodivergent kids leading to burnout, self-harm or suicide.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service system issues, patient-provider interactions)	Systems need to come from a neuroaffirming perspective. The medical model needs to change and look at autistic people as people, not a deficit that needs behaviour skills to fit into a neurotypical world. More accommodations in schools and workplaces.
What lasting impact has COVID-19 infection and illness had on co-	Covid lockdown was good for my daughter as she felt safe and enjoyed homeschooling.

occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Flexible workplaces allow for us as parents to be able to WFH when daughter is not able to go to school. More people needing to access MH supports which leads to more pressure on the public system and less availability of good quality practitioners

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Doctors make inaccurate assessment due to patients' non-typical reactions to pain or other discomfort, thus providing inappropriate treatment. Our son would have been sent home from the ER with a constipation diagnosis had his group home nurse not insisted on an x-ray which led to the discovery of a perforated duodenum requiring emergency surgery.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Aggression can be a symptom of pain or discomfort, instead of a mental health condition. When the underlying medical condition is resolved, the aggression may stop.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication disabilities may prevent quickly identifying where the medical issues are and require additional testing. One patient with aggression went under colonoscopy and endoscopy to rule out medical problems and eventually the cause was found to be a cracked tooth. Patients are often terrified due to lack of understanding and need to be sedated.
What additional research is needed to help address co-occurring conditions for autistic people?	Better technology may provide ways to measure anxiety and stress, leading to more accurate diagnoses and treatment and new methods to reduce anxiety and stress .
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Better dental coverage, more dentists willing to accept special needs patients (waiting lists are often 2-3 years). Doctor training on diagnosing non-verbal patients. Simplify billing for patients dual eligible for Medicare and Medicaid so Medicare providers can be paid automatically by Medicaid for unreimbursed Medicare expenses; so more doctors would be willing to accept patients.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Diagnoses are delayed and treatment postponed due to lack of access and resources. Dental problems were not timely addressed due to lack of operating rooms for hospital dental visits. Job sampling in community was not possible.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory challenges, gastrointestinal issues, social anxiety.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Social anxiety, self harm
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	With learning disabilities, we need research on what is the best way for kids to learn.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	In high masking women who are undiagnosed, if we present to the doctor's office because we're depressed, this is a pivotal moment where we should be assessed for autism. It might not be depression, it could be burnout and finding out we're autistic could be helpful.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	None
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbances
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression and aggression
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Learning disabilities and social difficulties
What additional research is needed to help address co-occurring conditions for autistic people?	Research about treatment of PDA
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	At home mental health care
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Perhaps just the lack of knowledge of concurring disorders. I am also highly concerned about the inability to get my son assessed for EDS. We are on a two year waitlist. It's crazy
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have been asked by many about the overlap with adoption and autism. Jodi Moore has some interesting theories and anecdotes, but we would love numbers and more understanding
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Autism + Adoption
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Automatic Medicaid health insurance would be amazing... the multi year wait list for a waiver is not helpful
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory challenges ie; mouthing objects such as shopping trolleys and reaching out to touch objects with a lack of sense of danger, for example touching a sharp holly leaf or drawn to a flame to reach out to
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD and showing a PDA profile. With pathological demand avoidance the nervous system struggles and my child is very disregulated most of the time. This makes every day tasks/demands very difficult and simply saying no to something my child wants can cause a disregulation and “fight” response with explosive behaviours and words used
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Speech and language. Having a global development delay, specifically within the social/emotional area makes it difficult for my child to have friends, understand their peers or their peers to understand them. This has caused immense problems in the settling in of school and currently no access to full time education due to unmet needs. This has also put my child well behind their peers in a learning sense
What additional research is needed to help address co-occurring conditions for autistic people?	More research is required for pathological demand avoidance (PDA) which many autistic people show a profile of. It causes significant issues and can present very differently to a lot of advice currently available for autistic people. Also the link of ADHD and autism
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More specialist education settings, focused on autism/ADHD PDA to be a diagnosis that can be received More services in general available, especially paediatric.. currently very long wait lists in all areas
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbances, insomnia, ADHD, GI issues
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, depression, isolation, ADHD.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication issues, apraxia, Gestalt Language Processing
What additional research is needed to help address co-occurring conditions for autistic people?	Much more research, especially provided by Autistic voices - the CDC, HealthyChildren.org, and NIH have little to no information available that was clearly drawn from Autistic voices.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Equitable access, more accommodations as opposed to requiring masking of Autism/Autistic traits. Less "conditioning" to "train away the autism" and more empathy and neuro-affirming therapy.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Less socializing, which for some autistic people can be soothing, but for others it can be more difficult to learn more language and socialize (especially small children).

Name	Anonymous
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	GI and sleep problems; sensory hypersensitivities
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Pathological Demand Avoidance (PDA) must be acknowledged and addressed.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Isolation, shame, depression. I have a 7 year daughter with autism and a PDA profile. She currently cannot access school because she has developed such immense anxiety and fear from her previous school experience. Instead of respecting her needs, the staff tried to force her to adapt to things in her environment that were too much for her given her sensory differences. As a result, she experienced intense stress during the school day that eventually caused a mental health crisis. She is now home, and life is very hard for her. She doesn't understand why she can't go to school like her friends. She is a smart, motivated, kind child. She loved school early on. Now, it's become a place she fears immensely and a place that makes her feel ashamed of who she is ... all because the education system keeps thinking they can and should push neurodivergent children to adapt to neurotypical norms ... norms that frequently work against their own neurological needs.
What additional research is needed to help address co-occurring conditions for autistic people?	Please devote more research to developed autism measures that are sensitive for girls, especially "high functioning" girls. My daughter wouldn't have a diagnosis or any supports (which have been life changing for her) if I had listened to the first doctor who evaluated her using nothing more than the "gold standard" ADOS. Please, if you are a woman with some sort of decision making power here, please push for more funding for research autism in girls (and more research on PDA).
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	THE EDUCATION SYSTEM. It is appalling what's happening in schools. Ask any parent what they want fixed ... it's the education system. Also, please devote more funding to neurodiversity-affirming supports like DIR Floortime. Enough with ABA.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on	

physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Having these co-occurring conditions recognized, documented and known by professionals so that they can be screened for and addressed once you've been diagnosed Autistic. I have had to research them myself every time and educate the professionals I was working with for my own wellbeing. Some of the co-occurring conditions aren't even universally recognized (ie: PDA - Pathological Demand Avoidance) despite being very disabling in our current societal context.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Getting autistic relevant services for the co-occurring conditions and having them identified and acknowledged.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	That they cause differences in how each other present, and many are assumed only to effect certain autistics, where they may still affect all, just in different ways.
What additional research is needed to help address co-occurring conditions for autistic people?	Please focus on defining and validating PDA - Pathological Demand Avoidance. It is recognized in the UK, but not in North America, at least not formally, and therefore getting supports is nearly impossible. But it is debilitating for families, children, and especially adults in employment and education.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Professionals who are knowledgeable in a more holistic way and can identify and support the different conditions as a unified human - understanding they all affect eachother and therefore change the presentation and how they should be addressed.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increased remote educational opportunities and employment opportunities. More respect for personal space, and more acceptance of non-social time - those are all positives.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disorders. Because seeing a doctor for the chronic insomnia's pricey, I just have to knock myself out with Benadryl sometimes. I know that's not good for me, but I can't lose too much sleep or it'll affect job performance.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD and anxiety. Once again, I cannot afford any medication, which makes life hard. I could've finished college in half the time, if five cups of coffee per day wasn't my substitute for medication. The executive dysfunction makes me feel like I can't ever be a fully functional adult. Especially with tasks like cooking and cleaning.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Overstimulation and burnout. I'm sensitive to noise, lights and too many things going on at once, yet most jobs can't or won't accommodate for that. Not to mention the fear of discrimination, as people treat you differently once they know you're autistic. Even if workplace discrimination's illegal, good luck trying to prove it in court most of the time. Because of my job around loud machines where I have to mask all day, I'm in a constant cycle of burnout where I end up having to call off work. I lose pay by doing this, but I'm so scared of lashing out if I reach my breaking point. There's no relief. It's like being sick every few weeks, but you have to just pray you'll get time to actually recover. Many of us don't, so we become a shell of ourselves for years. It feels like I have to choose between working full-time, and being a functional human. But in this economy, the choice is pretty much made for me. I'm trying so hard to find a better job where I could still pay rent, and just can't right now. The job market isn't anything like current reports, and it's not just me noticing this. Just hoping I can hold on...
What additional research is needed to help address co-occurring conditions for autistic people?	Research autism in women, and the ways medications affect our bodies. Much of the research is so male-centric, and autism in girls is horribly under-diagnosed. Partly due to outright misconceptions and double standards by doctors with outdated ideas of the condition. (the same symptoms will get a boy an autism diagnosis, but a girl bipolar/BPD for example) The other reason is that we're taught to be very high-masking from a young age. "Boys will be boys", so they're allowed to act loud and weird for a little longer. Meanwhile girls must be quiet, responsible and obedient from the youngest age. For this and other reasons, autism often manifests differently in girls compared to the stereotype. More research and education MUST be done. I also think cannabis research on autism symptoms looks promising, whether that be CBD or THC or whatever else. I know cannabis isn't a cure-all and not everyone reacts well to it, but with all the other things it treats, maybe there's something promising?
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services,	-Low-cost/no-cost healthcare options for diagnosis and treatment. -Make it easier to get disability with autism alone. Make it easier for us to get around without a car, because many of us can't drive. -More jobs willing to be remote or hybrid-remote whenever possible. It can make it easier for us to accommodate ourselves. -Address the homelessness crisis disproportionately affecting neurodivergent people, including those with

<p>insurance coverage, service systems issues, patient-provider interactions)</p>	<p>autism. -Speaking of homelessness, remember how I said I often have to take days off work due to sensory burnout? Those days add up, as they are unpaid. Paid time off guaranteed to us, to recover from burnout, would be an absolute godsend to help keep a roof over our heads. -Educate on what autism actually is, break the stigma keeping many of us from seeking accommodations. Show what so-called “higher-functioning” autism looks like, and non-stereotypical symptoms. Educate on things like masking, overstimulation, etc. Most importantly, PLEASE let people who actually have autism speak. Let us tell our stories more, instead of just “autism moms” who sometimes infantilize us. -And remember: We’re not broken, we’re fish being forced to climb a tree. Near-sighted people without glasses. The world just isn’t built for us. And it gets more unforgiving by the year, as even neurotypicals struggle to afford basic food and shelter nowadays, and support networks erode. Many of the things that improve our lives, will also improve everyone else’s.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>Long COVID symptoms and COVID cases are just another weight to add to our load. Dealing with physical and mental health at the same time makes life even harder. Especially when access to care for many has all but disappeared, since the government just started pretending COVID went away.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Increased use in telehealth, availability of work-from-home jobs and classes, and no-contact services like store/restaurant pickup or delivery are all positive changes. It means better access to care, accommodations for work and school, and the ability to still get food if you feel overwhelmed, respectively.</p>

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	gastrointestinal disorders and sleep disturbances
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	emotion regulation, depression, anxiety
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	communication
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	equitable access to and accessibility of services, insurance coverage, larger service systems
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Service provider, health provider, or educator
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>The listed co-occurring conditions, and many others, are more prevalent in the autistic population. Our responses are not about any specific condition but rather the challenges that autistic people have with medical care. • The behavioral and communication challenges that accompany autism can lead to delays in diagnosis and to suboptimal management. • Autism and the needs of the autistic community are not taught in medical, dental, or nursing schools today. Nor are they taught in the allied health curricula. • We know from recent research we conducted that children with autism who are hospitalized are at risk throughout their hospital stay with:</p> <ul style="list-style-type: none"> o Delay in diagnosis o Greater loss of function o Longer and more expensive hospital stay <p>• Pediatric care is highly organized and coordinated, while adult care is siloed and fragmented. Unfortunately, this is the case for both primary care and for specialty care. • Studies have shown that autistic adults report suboptimal experiences with their healthcare providers – not getting enough time with providers, not having things explained in a way that they understand, etc. This leads to a poor experience and poor outcomes. • Autistic adults also have lower utilization of screening tests such as pap smears, mammograms, and colonoscopies. • People with autism have a significantly shorter life expectancy than their peers without autism.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>The most significant challenge is intellectual disabilities (ID), which are often ignored in the autistic population. As a result, we don't know the true prevalence rate. • The most recent pediatric hospitalization data (KID) show that only 10% of admissions with an autism diagnosis had a co-occurring ID diagnosis listed, so it is unlikely that hospitals are capturing ID. This is problematic as it is important for medical providers to understand patient care implications for co-occurring ID in autistic patients. • Russell et al., (2019) and others have found that individuals with ID are left out of autism research. • As the diagnosis of autism has increased across the nation, diagnosis of ID has decreased. It is more likely that individuals with ID are underdiagnosed or misdiagnosed than that the rate of ID is decreasing. Thrum et al., (2019) state that autism may have become the "preferred" diagnosis, accounting for the decreasing ID diagnosis rate. Ignoring ID or misdiagnosing severe/profound ID as autism to render patients eligible for services is a significant challenge that must be addressed. • Children diagnosed with autism and global developmental delay are often not assessed for ID at school age resulting in a growing number of youth/young adults seeking cognitive assessments (Carey et al., 2023). The sooner an individual can receive services and assimilate their diagnosis to understand themselves, the better equipped they are to live the life they choose.</p>

<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>We should clarify what we mean by “autism.” The heterogeneity of the population with an autism diagnosis makes it hard to determine who is included and what they need. The practice of diagnosing individuals with major genetic conditions associated with ID (e.g. 22q deletion) with autism further compounds this because these conditions create different needs. The fact that an ASD diagnosis renders a person eligible for more services creates further complication and inequity. The high ASD prevalence rate reported for California (currently 1 in 22 children) suggests over-diagnosing and makes it difficult to determine who needs which services. We recommend: 1) Ensuring that autistic children diagnosed with global developmental delay receive a cognitive assessment by age 6 years. 2) Continuing to research differences between individuals with major genetic disorders and those with idiopathic autism, particularly those with autism and average/above average cognitive abilities. The populations with genetic syndromes or “syndromic autism” often have multiple medical and behavioral health needs which are unmet. 3) Ensuring that diagnostic assessments are conducted by well-trained professionals who can provide differential diagnostic assessments. The movement towards early diagnosis using technology may increase already high prevalence rates in California and make it more difficult to determine co-occurring conditions and provide appropriate services.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>There are two subpopulations in the autism population (individuals without intellectual disability (ID) and those with ID, including “profound autism”). Individuals with ID, minimal language abilities, and extremely disruptive/dangerous behaviors need lifelong comprehensive services which are not typically appropriate for the subpopulation without ID. The subpopulation with “profound autism” has the highest needs and is often ignored. We recommend: 1) Tying services to intellectual and behavioral needs, not the diagnosis of autism. 2) Educating health care providers on the different subpopulations within the autism spectrum disorder diagnostic category. 3) Increasing respite and residential services to meet the needs of autistic individuals with ID and significant behavioral support needs. 4) Developing specialized support for siblings of autistic individuals with ID. 5) Focusing on wellbeing as a global outcome measure which all services should increase or maintain. The focus on individual skills as a measure of outcomes, while important for some with less severe disabilities, is often ineffective for autistic individuals with more severe intellectual and developmental disabilities unless the “skill” improves wellbeing. Insights from our tool, The Catalight Family Wellbeing Scale, show that parent wellbeing is negatively correlated with parent stress and positively correlated with parental self-efficacy, demonstrating the impact and importance of wellbeing as a focus.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced</p>	

in-person social interactions and obligations)	
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Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Co occurring physical conditions can be disabling by themselves, but when seen holistically/globally, physical and neurological differences exacerbate one another and each require specific supports.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	There is still major bias in the mental health community to pathologize neurodivergent traits. Much more research and work need to be done to improve differential diagnosis.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Again, there is a major need for improvement in differential diagnosis in the medical and mental health fields. Many neurodivergent traits could be unclumped from disabilities altogether.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Equity is huge. Knowledge and competence within and between providers in the various fields, as well as accessibility, inclusion, and reducing stigma and bias. Accessibility and inclusion should become the default, vs neurodivergent and disabled people having to seek out, ask for, or fight for basic needs.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	urine retention motor challenges (clumsiness) fibromyalgia common cold (chronic) sleep disturbances (hypersomnia)
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	dysthymia anxiety adhd ocd personality disorders (schizoid)
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	fear of people thinking the autistic is rude
What additional research is needed to help address co-occurring conditions for autistic people?	teaching psychiatrists specializing in adults with the increasing diagnosis rates at later age (i was diagnosed at 18 and many thought i am factitious due to physical problems and extreme side effects from medications such as ssri and neuropelctics [extreme irritability, restless leg syndrome or extreme tiredness]) as well as family doctors and pediatrics. For example my doctors keep telling me i have hypochondria even though gastrointestinal disorders have high co morbidity with autism.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	In Israel there is a major lack of experts in Autism in general, in psychiatric field, occupational therapy for adults, speech language therapy. and in general other fields have lack of knowledge as well (gastro, urology, nephology, ophthalmology) i dont know about neurology
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	disruption in medical services and increased use of telehealth fora few months overall it was minor

Name	Anonymous
Demographic	Autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>Every autistic person I know has suffered with insomnia or some other sleep disorder. This affects every aspect of daily life. The extreme exhaustion causes other problems to exacerbate. When you're so tired all the time, sensory needs can be overwhelming and food is difficult to consume. I have been on medication for my digestion since I was 15 years old and still cannot tolerate the texture of many foods. It is a challenge to function as an adult, as I cannot participate in any kind of food-related activities (luncheons, work dinners, even parties) without having to plan around my needs. Scheduling regular exercise is inhibited by low energy levels and chronic pain whose origins cannot be found. Autism is a painful disorder at its core, with the world being bright and loud, foods having too many flavors and textures, and our bodies processing stimuli on a different level. It is a challenge to do anything that isn't sitting at home in a controlled environment.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>For me, chronic and persistent anxiety has always been the worst part of autism. Fear and guilt are my most common emotions. It is a challenge to call and make appointments just as much as it is to go out into the world. Many times, I've avoided going to get what I needed from a store because I was too afraid to speak. I get stuck in anxious thought spirals that will overwhelm me for hours, forcing me to sit in a room doing nothing until something breaks me out of the cycle. When I was younger, I would hurt myself because my emotions were too much and physical pain helped relieve some of the pressure. When you're an independent adult who struggles to make phone calls and run errands, basic needs can become impossible to meet. Your health and problems become worse and worse until they are truly debilitating. ADHD adds extra layers of pressure. You have to expend extra energy creating systems so you can live on a basic level of functioning. I cannot work 40 hours, have friends, and take care of myself. Autistics have to sacrifice something in order to live without burnout, which can lead to more depression and suicidal thoughts. I am nearly 32 years old and will never have a proper family, simply because without supports I am not able to do more than work and stay alive.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>My skills are mismatched for my IQ and it was a huge cause for distress in my youth. I learned to read and write at an extremely young age, but I still can barely do basic math at nearly 32 years old. Having a communication disorder makes this extremely difficult to explain to others, which makes help less accessible. My schools were baffled and assumed I was just screwing around in math, which made my mental health worse. I couldn't properly communicate why language arts came so easily to me, while math felt like everyone was speaking Greek yet expected me to understand. It's also a struggle to get quality medical care, as doctors seem to be dedicated to misunderstanding me. One of the biggest challenges as an adult is simply living alone. Without outside supports or help from a live-in partner, ADLs can be difficult to achieve fully. If I cook dinner, I'm unable to shower. If I do laundry or clean something, that's the only chore I can do that day. It is expensive to rely on premade food/delivery services and I have to purchase extra hygiene items to make up for my personal deficiencies. This is all on top of being unable to work full time but denied services because I do not appear "disabled enough". To be autistic is to be poor as life is 10x more expensive.</p>

<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>So much that it is difficult to quantify. For example, these questions. The request questions are written poorly regarding autistic input. They are too open-ended and nonspecific. I spent weeks gathering my thoughts for this request and I still feel like I'm doing it wrong. If researchers feel they cannot write questions for the autistic audience, then they should hire autistic people. So much information about autism is really from an allistic viewpoint that it's often unhelpful to us. Even autistic testing is from an allistic perspective. Symptoms and behaviors that bother allistics are emphasized without considering why autistics have them. Autism research needs to be autistic-led. The spectrum is too large and co-occurring disorders too prevalent to rely solely on the research of people who do not experience them. We need better research on how to support independent autistic adults. Many of us work full time and live on the edge of burnout to do so, as we don't qualify for supports. We are too disabled to live full independent lives, but not disabled enough to get help.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>More autism services need to exist in general, especially for those of us late diagnosed. I am unable to work a full time job due to my sensory issues, chronic pain, and anxiety; however I do not qualify for disability because my developmental disorder wasn't caught in childhood. So many social programs seem to believe that autism goes away in adulthood except for those with pervasive mental/intellectual disabilities, despite all of us having unique needs. Providers also need to understand that autism truly is a spectrum, and the ability to hold a short conversation or eye contact doesn't mean the provider can assume the autism doesn't exist. More doctors also need to be aware that our disorders often cannot be treated normally. Medications and treatments work differently in an autistic body.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>COVID was a disabling event. We were more affected than the average person between having lower immune systems and people not following masking rules. COVID increased mental health issues by furthering isolation and creating more barriers to treatment and services. I know personally, COVID left me with sleep apnea and a potentially lifelong reliance on CPAP and my anxiety around health has increased exponentially.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>There have been some positives from COVID. The increase of curbside pickup and normalization of grocery delivery has been helpful for many of us. However, COVID did put in more barriers to access when we already had enough problems to begin with. Social programs lack workers, which makes our services (those of us who can get them) inconsistent and low quality. Many of us also struggle with long COVID. For example, I now need a CPAP machine and have had such an increase in general body pain I can no longer walk normally. I am lucky to have Medicaid so it will cover most of my needs, but others aren't.</p>

Name	Anonymous
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Autism with PDA creates challenges with sensory processing and motor development. The challenges created by these make it difficult for a child to understand their physical body, meet sensory threshold, and be able to perform appropriate age level motor skills.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Autism with PDA has created significant challenges in regulating anxiety. Their “meltdown” is not the typical meltdown. Often needing to escalate and not be able to calm. It is difficult to even co-regulate with someone who has PDA. As social emotional cognitive awareness grows the symptoms intensify. These children can struggle to understand/express emotions. Behavioral therapy often fails to help, as behavior modification tools do not consistently work, 1-2-3- magic does not consistently work, and consistency does not consistently work. In fact, most of these strategies make it worse. Occupation therapy can help with the anxiety created by impaired sensory or motor skills. However, social situations (like s at school) increase anxiety to the point they will refuse to attend. School staff often do not know how to assist child and often these children ended withdraw from the school and homeschooled. The school staff struggled because they fail to see the reality of what is going on with child. Many caregivers can relate to the book “My daughter is not Naughty” and feel understood and heard for the first time. Once child is diagnosed with Autism with PDA lives change. The family and individual with PDA begin to understand and are able to assist the child with PDA better. There are children who symptoms meet PDA over what most are diagnosed with. Many of the parents feel helpless, hopeless, and alone.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Autism with PDA has been challenging because most people (untrained providers, school personnel, community members) don’t see the challenges these kids suffer from. Many of these children are highly intelligent and know how to use autism masking to appear neurotypical. The intense anxiety felt often displays inward with subtle signs of struggle until it maximizes to the point the child cannot control it anymore. At this point the child often explodes in a highly destructive way. This leaves the child being misunderstood, misdiagnosed, and provided the wrong treatment all of which increases the anxiety, avoidance, and need for autonomy.
What additional research is needed to help address co-occurring conditions for autistic people?	Pathological Deman Avoidance needs to be researched here in the United States. Many people are impacted by this diagnosis and are not able to receive the needed and appropriate diagnosis, understanding, or treatments due to it not being recognized as a co-occurring condition.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	All of these services need improvement for individuals who are high functioning Autism. These individuals and their families need support and recognition. It is doing this group of individuals a disservice expecting them to function as neurotypical individuals with increased pressure to mask their true selves and ignore their needs, and for their caregivers to not be able to meet their needs due to the unrealistic expectations.
What lasting impact has COVID-19 infection and illness had on co-	

<p>occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>The increase in remote work, schooling, telehealth, and reduced social interactions and obligations has been helpful. The expectation to change from remote to in person has been challenging and difficult for many. Many with the PDA profile, find social expectations and experiences to be debilitating and traumatizing.</p>

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Losing a job due to running out of sick days or having too many "low performance" days, losing my insurance due to losing my job, not qualifying for disability and falling through the cracks of society. My condition being treated as an excuse, and not being provided the proper legal protection to avoid homelessness.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	It's often a challenge to leave the house, which greatly limits job opportunities, and social interactions. As time goes on and everyone else gets better jobs, and gets better at social interactions, we (autistic people) fall further and further behind our peers, which leads to worse and worse mental health outcomes as we feel more and more isolated and alone with little to no hope of ever catching up.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	More research into how autism affects young girls, and adult women differently than young boys and men, so less autistic women are misdiagnosed in the future. More research on how autism may look different in children vs adults, so more adults who weren't diagnosed as children can get a proper diagnosis now, later in life.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Better education on how to treat autistic people when interacting with them, so we (autistic people) don't feel infantilized by those that are claiming to help us. We already struggling with social interactions, and feeling talked down to instantly builds mistrust and deters honest communication.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The increase in remote work and school, and increased use of telehealth was positive for the autistic community, but unfortunately these were not lasting changes. More and more jobs that were remote during the peak of the pandemic are forcing workers back to the office or laying people off. Furthermore, more and more states are now greatly restricted what services telehealth doctors can provide, to the point of making it almost useless.

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Pathological Demand Avoidance (nervous system hair trigger) Sleep disturbances
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Pathological Demand Avoidance Anxiety ADHD
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Learning disabilities And communication disabilities
What additional research is needed to help address co-occurring conditions for autistic people?	Pathological demand Avoidance (PDA) is the biggest factor in my child's autism. His hair trigger nervous system leads to extreme anxiety and panic attacks. This is something that needs to be researched immediately. There are no medical, educational or community supports. The only support we have found is through grassroot parents/families and adults that are living with PDA, PDA North America and PDA UK society. This is an underserved and hidden part of the disability that needs to be researched and funded to support our families futures.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Access to a public education plan that can support a PDA child. Insurance coverage for support of mental health services. This is not a behavioral based disability. Anything ABA related or behavioral based does not support the autistic community and does not support an autistic person with a PDA profile
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Migraines
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	High anxiety, fight or flight responses
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Research done on Pathological Demand Avoidance autism!!
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Doctors/providers need to be more knowledgeable about different types of autism that do not like the stereotypical autism. It is a spectrum
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Less meltdowns because there are less social interactions, but that also means less opportunities for growth in such areas

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep is the foundation of health. The sleep disturbances I and my daughter experience are some of the most draining and difficult experiences of being autistic.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Complex PTSD needs to be researched as a comorbid condition with autism. Teasing out the difference between a trauma response to the rejection, misunderstanding, and aggression constantly directed at autistic people, and the neurotype itself could be of great benefit.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My daughter and I both have the PDA (Pathological Demand Avoidance) profile of autism. This profile has been known about decades and yet has received very little research. It is extremely debilitating and painful, and involves constant nervous system dysregulation. It interferes with all aspects of life, including eating, sleeping, using the bathroom, working, learning, and socializing. The symptom of "superficial social function" involved in PDA often impedes individuals with this profile from getting an autism diagnosis, leading to a complete lack of support that is devastating to families and individuals. For my daughter, PDA has led to her exclusion from school, as accommodations are unavailable given how little is known about PDA. For myself, this condition impedes my ability to relate socially to others and care for my body. The lack of professional knowledge about this profile has also led to me being misdiagnosed with multiple other mental health conditions and being subjected to treatments that made me worse.
What additional research is needed to help address co-occurring conditions for autistic people?	Ehlers-Danlos and other connective tissue disorders need to be researched more. Also, why a large subset of the autistic population has very high levels of serotonin circulating in our blood and the impact of this also needs to be researched further.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Patient-provider interactions are brutal for those of us who are twice exceptional and afflicted with the Pathological Demand Avoidance profile of autism. Giftedness combined with other forms of neurodivergence mean that some of us are "high functioning" enough to work and have some social connections, and yet our bodies and mental health are destroyed by living with our disability every day with no accommodations or safety net. When we attempt to get diagnosis, we are treated with disrespect and dismissal by providers because of the lack of research and understanding. We are often misdiagnosed, which leads to grave suffering.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic	The break from the need to constantly socialize in a way that is unnatural to me was very helpful to me as an autistic person. Working from home also allowed me to be much more productive and at ease, as I could control my environment and avoid sensory triggers.

people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Pathological demand avoidance
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Pathological demand avoidance
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Access to education
What additional research is needed to help address co-occurring conditions for autistic people?	Research in pathological demand avoidance
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Understanding of PDA by medical professionals, mental health professionals, and educators in order to create environments that facilitate well being and growth.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Increased anxiety and sleep disturbance
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Lack of exposure regarding social and anxiety leading to increased social avoidance

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Connective tissue disorders
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Pathological demand avoidance
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	More research on pathological demand avoidance (PDA)
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Migraines Gastrointestinal distress
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety PTSD
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Pathological Demand Avoidance ADHD
What additional research is needed to help address co-occurring conditions for autistic people?	Drug sensitivities Effectiveness of traditional modes of therapy
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Accessibility of doctor's offices More help managing multiple conditions, which is just an exercise in complex communication Most of all- More education for doctors on what autism actually is
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Positives: - normalizing not touching strangers - normalizing working from home - More widespread telehealth services - masks to reduce spread of germs Cons: - when care rationing is in effect, autistic people are more likely to be denied care - parks and other public spaces shut down - disruptions in supply chains

Name	Anonymous
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	GI issues, dyspraxia
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Pathological demand avoidance
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	I wish there was more information on pathological demand avoidance (PDA) as a profile of autism.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage for occupational and physical therapy, speech therapy, for adults and children, without capping sessions to 20 per year or something like that. It's very difficult to afford therapies.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Delay in diagnosis for some children. Limited access to therapies during height of pandemic. This has an ongoing affect for children who were late in getting supports.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	It is sometimes difficult to diagnose physical conditions co-occurring with autism because our somatic perceptions are different than allistic people's default description of a symptom, and we often have difficulty reporting length of symptom. This means we may receive the wrong treatment for our conditions. Sensory, motor, sleep, and gastrointestinal disorders all sap the energy of autistic people to cope with life, so learning the best ways to diagnose and treat these co-occurring conditions will improve our lives by a wide margin. I personally would like to see more research into fibromyalgia, EDS, and other chronic pain conditions, and how these present in autistic people.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Trauma is one of the key mental health conditions affecting autistic people, particularly because autistic people experience traumas that the general population often doesn't, and because autistic people experience things as traumatic that allistic people find just unpleasant. Treating and supporting trauma in autistic people will have a positive impact on the rates of co-occurring mental health conditions overall.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	More research is needed into how to update scales of pain, fatigue, and other internal symptoms to accurately communicate autistic experiences and help diagnose co-occurring conditions accurately.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Services and supports should be more aware of flat affect and atypical sensory responses when treating autistic people. Providers who are not well-trained in autism often cannot accurately triage or diagnose co-occurring conditions when they expect our responses to look allistic.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	COVID-19 has disabled and killed many autistic people, along with the rest of our population. However, the switch to having many more remote opportunities can be very helpful for autistic people, as they allow us to interact from a more controlled sensory environment.

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	GI, sleep, sensory, motor coordination/planning
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, depression, ADHD, aggression, suicidality. Most importantly - Pathologic Demand Avoidance. My high-IQ PDA son, diagnosed with autism with a PDA profile in the US, has suffered greatly by more traditional research-based autism strategies. These strategies have completely the opposite effect for him than desired. Their use at school by supposed experts at ages 6-7 (despite my best efforts to educate them otherwise), caused severe trauma and resulted in significant mental health challenges to this day, even though he is only 11 years old - he is unable to attend school any longer, has extreme anxiety resulting in near-agoraphobia, is depressed, believes he is "broken," and was suicidal at age 7.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	1) Stigma and misunderstanding in a world and culture designed around neurotypicals - even though there is the desire to be heard, seen, and fully accepted for who they are (isn't that one of the most basic human desires?), neurodiverse individuals are very often treated in a way that very often causes them to feel or be treated like "other," rather than a natural variation of humans, and that they have to either isolate themselves or act in ways that feel completely unnatural to them and do not honor their individuality. 2) Pragmatic communication challenges - even though there is a desire to connect with others (but may not be expressed as expected by neurotypicals), autistic individuals have so much difficulty understanding and being understood by others.
What additional research is needed to help address co-occurring conditions for autistic people?	1) Much more research into the PDA profile of autism so that it is more widely understood and honored. 2) Much more research into effective and tailored mental health treatments specifically for autistic individuals and the full spectrum of autistic people (including PDA), whose brains work in different ways - E.g., rather than CBT, more research is starting to emerge that approaches like ACT (Acceptance and Commitment Therapy) are more effective for autistics.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	1) More training of non-autism specific professionals (e.g., medical community, police/fire/emergency responders) in how to interact best to help autistic individuals feel more comfortable. 2) Insurance coverage - it is often difficult to find qualified providers who are covered and we often have to go to out-of-network private providers whose rates are only covered a fraction by insurance coverage. 3) Overall education, integration, and cultural change across all systems (schools, medical, public services). Rather than be siloed as different, greater integration can only help non-autistic people understand/accept autistic people more and help autistic people get services that will serve them better.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Covid has increased the mental health challenges of my 2 autistic sons. Although we have been fortunate to not have gotten Covid, the shut-downs and restrictions have negatively impacted quality of life of autistic people and their families. One autistic son was completely unable to access virtual school and therefore regressed, and the other autistic son was further

	<p>isolated as the few out-of-home experiences were cut down even further. If we are to get Covid, isolation periods for either autistic people or their caregivers will have similar effects.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Negative - increased isolation, inability to access virtual school and therefore causing regression, loss of/limits to services and community opportunities. Positive - less crowded and less overwhelming community interactions and events, greater understanding of mental health challenges overall (hopefully at least; everyone experienced isolation and difficult changes to routine which is a similar feeling that neurotypicals hopefully can use to relate to what autistics often feel every day), increased telehealth (helpful for both my sons who can struggle with in-person medical visits in less familiar environments with unfamiliar people).</p>

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	hygiene due to children not pooping, peeing
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	adhd
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	demand avoidance, such as found in the pathological demand avoidant profile of autism.
What additional research is needed to help address co-occurring conditions for autistic people?	pathological demand avoidance profile - effects on parents' well-being, parenting styles training, educational implications
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	educational supports for pathologically demand avoidant children, insurance coverage for services trainings for parents with children who are demand avoidant and fit in the pathological demand avoidance profile.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Deafness makes communication very difficult.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety and ADHD make it difficult for my daughter to enjoy her life.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More and better care givers in a group home setting.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Day to day function, such as taking care of basic needs, eating, using the bathroom, etc. Interactions in society, such as making friends, working.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Stuck in fight, flight or freeze, every action colored in trauma response
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Severe anxiety or a large spectrum of pathological demand avoidance
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Parent support
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increased work remote, families can be home and take care of autistic kids, also it's more acceptable that 0-7 can stay home instead of forced into daycare

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	PDA, anxiety, depression, ADHD, trouble with self regulation, anger, frustration,
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	anxiety, ADHD, anger, frustration
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Dis-regulation, trouble with short term memory processing speed, delayed executive functions, trouble with math anxiety, trouble with handwriting, trouble keeping organized
What additional research is needed to help address co-occurring conditions for autistic people?	PDA and co-morb with ADHD
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Better access to people who are trained and capable and knowing how to help kids, parents and schools. Yes insurance coverage
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Social
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	the lack of truly integrated care. Somatic health professionals who understand the connection between autism and chronic health concerns.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	the barriers between service providers. OMHCs who won't treat people with primary autism. ABA providers who fail to welcome the relational or trauma focused work. etc
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	research on people of color, women, LGBTQ
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	removing discriminatory exclusionary policies
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	isolation, inflammation, sensory overload, compounding somatic conditions, exacerbated burn out
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	inconsistent access to IEP services, long wait lists for various services, economic hardship,

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My son has co-occurring PDA, DMDD, GAD, and giftedness. He does not present the way people expect an autistic person to present. He doesn't have any intellectual disabilities and he has advanced communication skills. But under his intelligence and communication skills, he has lagging social-emotional understanding. Because he seems so smart and affable, people don't realize he needs accommodation to understand social cues and to manage his anxiety. That anxiety grows under the surface and then explodes in aggressive and often unsafe ways. People assume his explosions are behavioral and what he needs is discipline. But the PDA dimension of his profile precludes the efficacy of conventional discipline.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Support for differential diagnoses to identify kids with co-occurring ASD, PDA, DMDD, GAD, and/or BPD and better understanding of how these neurodivergent dimensions manifest in a unique profile for each kid.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More intensive in-home support. We need help where challenging behaviors happen.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	He still has anxiety related to high alert we were all on for two years.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The most significant challenges caused by co-occurring physical health conditions in autistic people I know and have worked with appear to be sleep disturbances, gastrointestinal issues, and sensory challenges.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression, anxiety, ADHD.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication disabilities
What additional research is needed to help address co-occurring conditions for autistic people?	Research is needed to support medical school training. There are no pediatricians and very few psychiatrists in our area (Washington DC Metro) as of right now who specialize in treating autism in an affirming way. Research is also needed to support and treat these medical issues that are causing physical impairment.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	All of the above!
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Covid-19 has had a lasting impact in the delays that my child, in particular, faced in school and in learning. This has contributed to increased depression, anxiety, and social isolation.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	All of the above.

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The most significant challenge is being heard and believed and then getting appropriate treatment
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Having a chance at success is a challenge when being heard and believed and getting proper treatment are utter failures
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Receiving proper services and setting a future for assistance
What additional research is needed to help address co-occurring conditions for autistic people?	Extensive research on PDA including dietary needs and genetic mutations
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Affordability of services, accessibility of services, getting the most current research and knowledge into the right hands, providers need to stay current
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Persistent feeling of being left behind, severe depression, anxiety
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Positive is more people seem accepting of those who don't prefer social interactions

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Finding providers who understand the complex dynamics involved in managing care for an autistic person in distress. Accessing care by professionals who will not simply say "it's anxiety" and gaslight either the patient or their parents. Not enough providers understanding atypical presentations of autism (such as being chatty, social, etc.) and minimizing the impact that autism has on such patients. Co-occurring conditions make many autistic traits worse, so it's a double-whammy.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Finding providers who aren't trying to use neurotypical metrics and methodologies for supporting autistic people. Therapists and other professionals pushing behavior modification and/or operant conditioning **does not** help to alleviate anxiety, depression, suicidality, etc. and yet these are the go-to methods at most therapy practices. We need more neurodivergent-affirming professionals. Finding intensive (acute care, PHP, RTC, etc.) level care that is neurodivergent-affirming and affordable/accessible. Mental health challenges are quite literally life threatening and yet **appropriate** care is often not accessible. Negative experiences with therapists and medical professionals turn off autistic 'black and white' thinkers and refusal of therapy becomes another roadblock.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Isolation is the first difficulty that comes to mind. Our teen's challenges in maintaining personal relationships and understanding others' perspectives has resulted in profound depression, low self esteem, school avoidance, and deep isolation. Another challenge is the way that allistic/neurotypical people treat those with this list of disabilities. Being ostracized, bullied, ignored, infantilized, and treated as less-than is inherently problematic.
What additional research is needed to help address co-occurring conditions for autistic people?	More research into PDA (pathological demand avoidance) as a legitimate co-occurring condition -- or even as a stand alone diagnosis. More research into how to settle overactive nervous systems when psychiatric meds are not doing the job (or are causing too many side effects). What adjunct therapies (not behaviorism based or ABA adjacent) are useful to help autistic folks regulate their emotions better? Is there a way for researchers to better understand and help mitigate the burnout/crashes that often occur for autistic teens when they hit puberty? A common theme seen across autism support groups is adolescents hitting rock bottom and burning out at the onset of puberty. Many fall into crisis. We need research into this ongoing and devastating phenomenon. What supports can we as a society put in place to prevent and to treat/support these kids and their families?
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	We need more access to neurodivergent-affirming providers who aren't using neurotypical metrics to treat autistic people. More ND input into models of care. More providers well versed in PDA. We need more providers who don't buy into ABA. "Just try harder" and tough love isn't treatment. We need more autism-informed schools. We need more trauma informed care. We need much more access to providers who take insurance, and more robust coverage. We need insurance companies held accountable for coverage for intensive support rather than receiving denials. We need more accommodations for autistic patients (dimming lights, asking what the patient needs to feel safe, finding sensory sensitive ways of providing care, etc.). Easier ways for autistic adults to make appointments. Compassion/training among nurses & office staff when patients may become overwhelmed. We need more professionals (doctors, therapists, teachers, school admin/counselors) trained by thought leaders like; Dr. Ross Greene,

	<p>Dr. Mona Delahooke, Greg Santucci OT, Robyn Gobbel (trauma therapist), and so on. We need more professionals looking upstream at the 'why' behind challenging behaviors or conditions and working to meet the needs of autistic clients rather than trying to reward or punish away challenging behavior. All behavior is communication, so we need to look at adapting and helping rather than just using dog training methodologies to extinguish what's seen as problematic.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>Increase in isolation, anxiety, and depression. The pandemic began a pattern of isolation and reduced social interaction with peers. Illness itself has increased fatigue and lower immunity (so more susceptible to illness). Possibly has led to higher incidents of burnout.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Benefits have been that we've been able to access more services remotely, which offers more flexibility when there may be struggles to leave the house or otherwise engage. Spouse has been able to continue working from home - which has been extremely helpful as our autistic/PDA teen has been struggling. The disruption of the pandemic but the breaks on our teen being able to attend school, led to reduced ability to engage socially, fear of crowded spaces, and an increase in anxiety, depression and isolation.</p>

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory - it can manifest in different ways- some children are more sensitive to lighting sources(overhead florescent bulbs used in certain stores or classrooms seem to be a biggie for my child), smells, tactile- this can include food textures which can present a whole issue of nutritional value of food intake.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	This is a huge question- it also highlights the importance of the need for services that are delayed (missing critical Stages of development or exacerbating the problem) the tax payers will pay more for institutional needs in the long term if remediation is not timely. We have 4 autistic children among 4 genetically related siblings - my child has ODD and ADHD ODD can escalate into conduct disorder which then involves law enforcement. The wait list and interminable wait times are grossly apparent
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Significance is the ability of the primary caregiver to maintain an income due to disruptions requiring immediate attention. Services that are not really Available in a timely fashion- lack of trained psychiatrists - lack of in person care and dangerously- mid Managed medications by professionals - my child was in ICU thanks to an incompetent med manager
What additional research is needed to help address co-occurring conditions for autistic people?	Use the families to get info - we need the help. When I went to an autism event - the majority of booths were manned by parents of special needs kids that needed to start their own groups to get proper care. Make nationwide resource terminals for parents (like CARD currently in FL). Listen to what needs are Being unmet by those of us in the trenches- lip service and waitlists create children who grow up ill- equipped to be happy productive members of society
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Psychiatric care in person teledoc is NOT a solution for the special needs sector- the average person also cannot afford certain services - if you are fiscally above average - your child will get the help- if you are middle class or lower- the fees associated with quality (Sress quality) services are insurmountable
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Made social skills Development more Of an issue
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Masks obliterated th e face - so verbal communication with enunciation is delayed in the elementary set- middle school Lacks social Skills and high schoolers cannot properly inference or utilize critical Thinking skills- all ages have issues with coping

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	For my five year old, sleep avoidance and sleep disruption are the biggest co-occurring physical health conditions. My son also has a very limited list of foods he will tolerate. Sensory sensitivity is also a struggle for him, due to his pathological demand avoidance.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety. My five year old had a panic attack today and could not attend kindergarten.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	PDA needs to be researched, and clinicians and doctors need to be informed. Several specialists who have worked with my son have done more harm for him than good simply because they won't acknowledge PDA due to the fact that it is not yet in the DSM-5. No child should have to suffer because adults are uninformed.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Research PDA, require clinicians and physicians to learn about PDA, and include it as a diagnosis in the DSM-5.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>I'm the parent of a young person who did not present as or similar enough to the commonly known traits of autism. To many they appear as regular, however he has some form of autism with PDA being the main component that caused so many issues but professionals could not (and maybe would not) see what I saw. The parenting skills required in this situation appears the opposite to what professionals want to see happening, ie low demand parenting is needed yet professionals see that as not productive, not using consequences, not controlling enough and not involved enough. However the parenting skills that professionals want to see create the very environment that causes more issues for a PDAer. Much more research is needed on PDA to ensure the protection of PDAers mental wellbeing.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory overload, especially sensitivity to scents and chemicals that cause neurological effects.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Not being able to function in society, but not disabled enough for support resources leads to isolation and desperation.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Misunderstandings, both personal and professional.
What additional research is needed to help address co-occurring conditions for autistic people?	How to build a safety net for autistic people, and how to build a common language between ND and NT people.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More understanding on the part of providers. Autism friendly medical facilities (for example, omitting the piped in music and air fresheners and fluorescent lighting).
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Reinforced overisolation, more communication complications.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory processing challenges make it hard for my daughter to participate in school. Her classroom, like many elementary school classrooms, is loud and chaotic. She wears noise-cancelling headphones but they are not enough to help her process all of the input from noise, kids moving around, multiple people talking at once, fans, overwhelming visual input, and trying to hear her teacher in all of the chaos. She is very smart and the school work is easy for her, but the school environment is not.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety and PDA (pathological demand avoidance) make it hard for my daughter to access school. The school environment is not accessible for her, and while her teachers are responsive, they know very little about supporting autistic kids with PDA profiles. She tries very hard to do everything right at school and is constantly on high alert to process all of the sensory input, the expectations, the social interactions, and the content. The school work is easy for her, her reading and math are above grade level, but school is very very hard. She masks extensively at school and her teachers say she is “fine”, but she comes home broken. Many days she is not able to go at all, and she spends those days huddled on the couch with a blanket over her head. Her attendance this year is around 80%. She loves learning and wants to do well, but school is hurting her. This has had a huge impact on her mental health, and it has also affected our family since we need to take unpredictable time off from work to stay home with her. Since she started school, one parent has dropped to part time employment. We are lucky that our jobs are flexible, our supervisors are supportive, and we are able to afford the pay cut.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	How to make school accessible for PDA kids. Schooling is compulsory but not accessible, and it is causing harm to mental health. Specifically, research into: 1: Neurodiversity-affirming practices. How to teach autistic PDA students without trying to teach them they should not be autistic. Autism is a normal part of human diversity and a valid way to be human. Providing equitable access to education for autistic children should be the goal, not teaching neurotypical behaviors. Research is needed to develop methods, curricula, and guidelines for providing equitable access to education to autistic students. 2: Education practices specifically for PDA kids. Many of the “best practices” for neurotypical kids, and even for autistic kids without PDA, are not effective for PDA kids. Some even cause harm, increase stress and decrease accessibility. Education research into effective, inclusive, and supportive curriculum and instruction for PDA kids is needed. 3: Policies that support school success for autistic PDA kids. Fluctuating capacity (ability to do something one day but not another) is common with PDA. Currently attendance, behavior, and performance policies assume that students generally have the steady capacity- if they can do well in school on one day, they should be able to every day. This ignores a key part of the disability, and reduces accessibility. Research should examine how school policies can accommodate fluctuating capacity so autistic PDA kids can succeed.

<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Integrate the Social Model of Disability into medical care and services instead of the Medical Model. Autism is not a disease and does not need to be cured. Autism is a normal part of human diversity and a valid way to be human. Services, insurance, education, and medical care should focus on making sure autistic individuals have equitable access, and providing support when society does not meet autistic needs.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	We suspect gastrointestinal disorders but have never been diagnosed because the symptoms weren't severe enough. Sleep disturbances, yes, due to restless legs and leg jerks, occur nightly. while trying to fall asleep
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Intellectual disabilities.
What additional research is needed to help address co-occurring conditions for autistic people?	Social and engagement activities to learn adaptive and tolerate and be a team players.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Group and team players. Learning to acceptance and giving and sharing equally with it others.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Not much ..only reinforcing personal hygiene and social distancing in group activities.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The lasting positive impacts on what I've seen, the willingness to participate in group setting like community engagement project. The negative parts are finding the activities they want to be involved and comfortable with. Why not start your own small group in community with the goals of Employment and Self-Advocacy.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The stress of not liking the way I am mixed with not wanting change but then hyperfixating on trends. Things like that combine I find difficult to manage
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Seeming like I'm stupid or don't know how to communicate when really I'm shy and struggle to articulate my feelings
What additional research is needed to help address co-occurring conditions for autistic people?	How late diagnosed affects people How there are many conditions that combine with autism
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More understanding and resources to help with service and providers
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Not for me
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Discovered how much I liked being at home

Name	Anonymous
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbances Sensory sensitivities Food sensitivity Fluctuating energy levels
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety ADHD Depression Suicidality PDA
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	PDA Processing speed differences
What additional research is needed to help address co-occurring conditions for autistic people?	PDA Interest-based learning
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage for occupational coaching and social opportunities Pathways to navigating services that decrease barriers caused by executive functioning differences Providers having up to date knowledge about autism Increased LGBTQ inclusion and awareness in services
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Huge setback in finding services Huge difficulties for families in taking on the load from lack of services for autism and mental health
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Disruptions in services for autism, mental health and transgender care overlapping to create negative outcomes Reduced in person social interactions

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory, sleep difficulties, interoception awareness and intense imagery movements.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Firstly, lack of SEND training for education professionals. I speak from experience as a teacher. I have had to educate myself. 2 of my children have suffered because of a lack of understanding by professionals. Masking is a big issue. Anxiety, suicidal ideations, self-injurious behaviours, ADHD etc.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Selective Mutism. Our local SALT team have no experts//specialists in SM. Recommendations have been inappropriate for the age and difficulties of my children. It has taken 2 tribunals to get them specialist support. My eldest is nearly 17 and has only recently received support. This vital support should have been provided years ago but wasn't, despite me referring twice to the SALT team. NHS statistics say that Selective Mutism affects 1 in 140 people yet there is little understanding of the condition in schools and other settings.
What additional research is needed to help address co-occurring conditions for autistic people?	More research is certainly needed in the areas of PDA and Complex Motor Stereotypies - Intense Imagery Movements. I would certainly love to support with any research if this would be possible.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Consistent treatment for all. Even within our LA who have accepted a PDA report, diagnosis and strategies for one child are discounting my daughter's report, diagnosis and strategies from the same professional which followed a previous multi-disciplinary autism assessment by the LA. It is an injustice and the consequences of the LA behaviour have impacted so badly on my vulnerable daughter. The referral pathway and wait times is not helpful. Having separate autism and ADHD assessments when one clinician said their service could have done them together saving time, resources and money. Better training with certain EPs and professionals around autism. Instead of a LA EP telling me my child is not autistic and refusing to refer them for an assessment when the assessment team agree there is plenty of evidence and they share my frustration is not helpful. My son has since been diagnosed with autism, ADHD along with various other conditions and complex needs. Professionals who are not trained to assess have blocked pathways for my child. Also, masking is a big issue and parents and children should be believed as we live with the reality. Better training for schools etc.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Lockdown alleviated anxiety for my autistic children as they didn't have to go out. Going back to school was difficult. One of my children has OCD so having a population being scared of germs is the reality for my child so it was like people were experiencing what it is like for her. My husband who is classed as vulnerable anyway due to health conditions worked in a covid ward and had inadequate PPE. The impact on his mental health was huge. He worked as a senior nurse but has left his role now. He has since been diagnosed with epilepsy. Obviously, this impacted on my family, especially knowing

	<p>neighbours were having parties even when their 3 children's bubbles should have been isolating. The whole situation re rule breaking impacted heavily on my family.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Professionals blaming covid for not doing what they should have been doing, e.g. ignoring EHCP provision, not following their promise of submitting an EHCP request for my son so I had to do that. LA using covid as an excuse. Especially when my husband and his work colleagues had to step up massively from 2020 with the spread of covid, certain LA and education professionals took a step back. Don't get me wrong, plenty of teachers went above and beyond but for 2 children who should have 1:1 support, my son got 10 mins a day and my daughter received no support. I have one child who has been failed by school and LA and now has EOTAC (Education other than at school). She can't leave the house. Anxiety has increased for all my children and I believe Covid has played a part in this although there are other more significant factors that have played a role.</p>

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Fibromyalgia, hyper mobility, sensory needs.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Suicidality, ADHD, anxiety, depression, eating disorders, PDA.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Pathological demand avoidance, ADHD.
What additional research is needed to help address co-occurring conditions for autistic people?	Further research on Pathological demand avoidance.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Accessibility of services, understanding of PDA, presentations, supports. understanding of how AuDHDers (Autistic and ADHD) present and support around managing neurotypes that often have conflicting needs.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Wait in services, diagnosis and support
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increased remote work and schooling, reduced in person interactions.

Name	Anonymous
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	PDA, seizures, sleep disorder, feeding disorder, sensory issues, fine motor issues cause my 3 boys significant issues. PDA based on anxiety is a major issue with no funding or help and we desperately need help in the PDA community
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	PDA, OCD, anxiety, ADHD, aggression, impulsiveness, depression, perfectionism, separation anxiety, ADHD are all things we struggle with. I think the root of the issue is anxiety.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Dyslexia, dysgraphia, dyscalculia, fine motor & speech issues are all things we deal with. New curriculum needs to be created for ND autistic LD kids. New curriculum ideas especially for PDA kids
What additional research is needed to help address co-occurring conditions for autistic people?	We need research around autism with a PDA profile. In the us there is zero help and a fairly large community.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Support that is of firming, not recommending ABA, more services, better insurance coverage, services for young adults, services for multiple functioning levels, affordable private school options, respite options, better education to providers from AA people
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	My kids have anxiety and trauma from it. It's hard to leave the house. We are high risk so we like virtual things a lot. My kids started homeschooling because of it and may always, since masking is not required any more and we are immunocompromised and high risk every time we go out we are in danger and no one cares
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Autistic people have multiple co occurring conditions and are higher risk than the general public. Bc of this, they are more likely to get long COVID, be hospitalized or die from COVID. Since masking is no longer used by others, those that find masking difficult for sensory issues are no longer protected. Society and the government has failed our kids.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	In my case it's insomnia, auditory processing disorder and suspected mild EDS.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	In my case it's anxiety, social phobia and cptsd.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Cognitively somewhat disabled since permanent autistic burnout, otherwise no disability.
What additional research is needed to help address co-occurring conditions for autistic people?	Listen to autistic experiences rather than label us incorrectly. Autistic burnout is not depression Meltdowns are not nervous breakdowns or dramatic behaviour Masking is not manipulation Autism is not BPD
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I'm still looking for professional support provided by autistic people. Counselling with an NT is useless to me because they cannot possibly understand what I'm experiencing.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Our basic human rights were taken from us for no reason and they threaten to do it again. I'm scared.

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Common concurring diagnoses like Hypermobility/EDS can have prevalence underestimated, and this makes it difficult to access diagnosis and treatment. Autistic people might be disbelieved about the impact on us because we don't present in typical ways doctors are expecting (when in pain for example it may not be obvious from our expression and behaviour). I also think our experiences can make it hard to tell how badly I'll we are, either because we are used to pushing through discomfort or due to poor interoception and this means delayed treatment and care. Co-occurinf physical conditions impact my ability to tolerate sensory stimuli and to communicate.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The way other mental health conditions interact with autism seems to be poorly understood. For example there is plenty of information on Autism alone and ADHD alone, but not a lot about the combined experience of both and what treatment/strategies will work best for people with both. Autistic people can be pushed into modalities that don't work for them, like CBT. The presence of trauma can prevent or delay diagnosis of autism, meaning it is longer before children get the support they need. It is difficult to find a psychologist or mental health service that is able to work with someone on different facets of mental health (ie I can help you with the trauma, but not the autism or ADHD) but it is hard to separate out our experiences into what is due to being autistic and what might be due to a other mental condition. Mental health professionals are not good at picking up where autism might be a contributing factor to mental illness. As an undiagnosed adolescent and young adult I interacted with at least 6 different mental health care providers for anxiety and depression, none of which picked up on autistic traits although undiagnosed autism and burnout was a big contributor to me experiencing these things.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Best treatment and management strategies for autistic people common concurring diagnoses including ADHD, particularly how this differs from standard advice. Barriers to accessibility of care.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Increase in experiences of chronic post infection illness such as ME/CFS, dysautonomia etc. exacerbation of mental health conditions due to uncertainty, isolation etc.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic	Reduced in person services has been difficult as Telehealth options can make communication more difficult, but at the same time increased flexibility with Telehealth and remote working arrangements has been very positive for

people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	many. Reduced in person interaction and environmental noise reduction during lockdowns were very positive.
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Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Pathological demand avoidance resulting in chronic nervous system overwhelm, aggression and shutdown.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Pathological demand avoidance. Caregivers are drowning. Please help provide resources and spread awareness.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Awareness/ support of PDA
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Keeping up with expectations of society, keeping a fulltime job
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Same as previous question + maintaining healthy interpersonal relationships
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Keeping up with school & society expectations, maintaining interpersonal relationships, keeping up with daily life administration, maintaining a healthy family balance
What additional research is needed to help address co-occurring conditions for autistic people?	Pathological demand avoidance (pda) linked to autism should be much better understood and regarded as real. The autism spectrum in general could be much better mapped, also with regards to overlap with other neurodiversities.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory challenges. Outside environments like schools, workplaces, shopping, parks, are so loud and bright and overstimulating. My child needs to homeschool in part bc of the overwhelm caused by the school environment.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	PDA (pathological demand avoidance/persistent drive for autonomy). Society's lack of understanding makes school, aftercare, extracurriculars, and workplaces inaccessible to many in this group.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	More research on PDA is desperately needed, as well as more research on service providers and parents knowledge and understanding of it.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increased remote work and school has allowed my AuDHD PDA child to homeschool and has allowed me to work almost entirely remotely. This is better for our sensory profiles and sleep patterns.

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	For my son: gastro difficulties: chronic constipation, soiling, small bladder, enuresis. Plus sensory processing difficulties, interoception difficulties and manual dexterity problems. For my daughter: severe sleep disturbances, sensory and interoception difficulties.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Son: anxiety/low mood. Daughter: severe anxiety, severe demand avoidance, low self-esteem, ADHD, aggression/violence, skin picking, over eating, suicidality.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Son: Gestalt language processor, communication differences, taking things literally. Daughter: inappropriate behaviour/communication, auditory processing disorder.
What additional research is needed to help address co-occurring conditions for autistic people?	The person needs whole person support so it's vital we understand the co-occurring conditions as well as their Autism or PDA.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Services, much more training for teachers, GP's, paramedics, dentists etc.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	No sure.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Reduced schooling

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I have POTS, gastroparesis, and hEDS and for me, it's very difficult getting the proper medical care when I cannot communicate to doctors in a way where they understand and want to help my physical health conditions. Allistic doctors have a hard time understanding what I mean by certain symptoms or taking their severity seriously when my pain tolerance is different than someone who's allistic.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	A lot of my mental health struggles were just signs of being autistic but misinterpreted because I was undiagnosed for almost 27 years. Like, I was misdiagnosed as having bipolar disorder when a lot of my mental struggles should have been correctly diagnosed as being autistic. Allistic mental health counselors also have a hard time understanding me or helping my depression and anxiety though still. Even when I disclose I'm autistic. They need more training on how to help autistic people, such as alternatives to CBT which I've found very unhelpful.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	There needs to be an entry on PDA in the DSM5 and more research on it. It's so under diagnosed or misdiagnosed as ODD or something else when it's something that effects me maybe even more than being autistic.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	We need more autistic providers who understand us more than allistics and aren't ableist or insensitive. Health care and services should be more accessible and with better insurance coverage but that's more of a systematic general American issue as well. But also more education for providers done by autistic advocates and more education on situational mutism or AAC as a valid form of communication.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I wish we could go back to the start of the pandemic *only because* there was higher tolerance for zoom or virtual appointments. The lasting effect for me is I realized how much more accessible appointments can be when I don't have to go into an overstimulating doctors office for a regular visit. We need to get back to how things can be more accessible and that's sometimes better than getting back to normal. Not sure if I answered your question exactly right, sorry.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I guess I answered the previous question more with what this one is asking. I think remote work and school is more helpful than society wants us to think. For me, it's helped to be more at home because it made me realize how dysregulated having to be in public all the time can be for me. I also think autistic children can benefit more from virtual school than some think, as typical classrooms are overstimulating and constricting. I've also been more lonely from less social interaction, but less lonely from more virtual communication and more regulated from less in person social interaction and obligations.

Name	Anonymous
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Pathological Demand Avoidance
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Pathological demand avoidance
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Pathological demand avoidance
What additional research is needed to help address co-occurring conditions for autistic people?	Adding pathological demand avoidance to the DSM-V. Children are being harmed and suffering greatly due to the lack of understanding of this condition. It is causing great harm not recognizing it in the USA
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Acceptance and training on pathological demand avoidance and it's co-occurrence with ineurodivergent disorders
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Delay in diagnosis and treatment. A lack of access to behavioral and developmental pediatricians.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Significant challenge for our child is being able to attend school.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Again, attending school
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Research into PDA and how schools can cater for these individuals with low demand and anxiety-aware classrooms
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Schools and teachers being informed of the latest research and evidence based approach to work with an autistic child
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Telehealth use has been great for families of children who struggles to leave the house/leave the house safely

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory challenges, nervous system constantly in fight or flight mode, hypermobility, fibromyalgia, scoliosis
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, ADHD, depression,
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Pathological demand avoidance
What additional research is needed to help address co-occurring conditions for autistic people?	More appropriate diagnostic criteria to identify autism that's not based on middle class white boys. More research into how incredibly disabling Pathological Demand Avoidance (PDA) is for individuals and how much this impacts on their nervous system and prevents them from carrying out activities they want to do and the crippling anxiety that comes with it
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Less judgement of how an autistic person "should look". Don't assume that the person you see, that looks "normal & capable" is tortured by the system or their parents are. Learn about masking and the fluctuating capacity of autistic people.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	More access to services from home, don't always have to leave the house for support. Increased opportunities to socialise online which is often a more comfortable environment for autistic people to connect with others

Name	Anonymous
Demographic	Family member of an autistic individual; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The common occurrence of Ehlers Danlos Syndrome in autistic people, which means many autistic people also have to deal with chronic pain and other medical symptoms. EDS has gastro symptoms, as on your question above. Often the medical profession is slow to recognise and diagnose EDS which means autistic people are gaslighted about their symptoms and need to advocate for themselves to get help and diagnosis.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, PDA. However its also important to study issues from a sociological viewpoint, as a result of living in a society built for neurotypical people, rather than as a pathology.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Not being accepted by society, isolation and segregation, lack of accessibility, lack of reasonable adaptations, prejudices, poverty.
What additional research is needed to help address co-occurring conditions for autistic people?	Research into everything I have mentioned in the other questions, especially Ehlers Danlos, and the effects of society on autistic people, including how this affects anxiety and demand avoidance. The research should not pathologise autism or treat being autistic as a disorder. Instead it should accept that being autistic is a naturally occurring neurological difference. It should never look for 'cures' for autism or support aba. Autistic people do not need 'curing' of who they are, they need changes within society to create inclusivity.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Active training and recruitment of neurodivergent people to become future professionals within research, medical, psychological and support professions. It us vital that autistic people are included in their own support industries. As above, stop pathologising autism. An inclusive society. Especially better support in schools, and in hospital/gp practice.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Others ignorance
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Others ignorsnce
What additional research is needed to help address co-occurring conditions for autistic people?	Inclusion education
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Lack of understanding of cumulative disabling effect of multiple co-occurring conditions. Difficulty obtaining diagnosis of co-occurring conditions. Inadequate general (public) knowledge of how cumulative effects can impact functioning.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Difficulty accessing neurodiversity affirming treatment for mental health conditions. Many approaches used in the neurotypical population are ineffective and can be harmful to autistic people. Oversimplification and misunderstanding of reasons behind mental health difficulties. Lack of understanding how sensory differences can impact both mental health and treatment for mental health.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Lack of presumption of competence. Infantilizing autistics with these types of co-occurring conditions.
What additional research is needed to help address co-occurring conditions for autistic people?	More research into neurodiversity affirming care. Not treating autistics as a monolith. Impact and harms of ABA. Lack of resources to address PDA traits.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	For myself the reduced social demands was helpful, as well as opportunities for remote work and telehealth.

Name	Anonymous
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Ability to access and engage with health services that do not accommodate different needs - eg where, when, noise, length of appointment - especially when these visits may involve touch and procedures. Symptoms of physical conditions causing more distress and harm through lack of interoception, increased anxiety and fear, avoidance of simple treatment options like pain relief, needing general anaesthesia more frequently
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Lack of understanding and compassion, behaviour seen as a choice rather than panic response
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	PDA.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increased use of alternatives like telehealth, awareness of neurodiversity and neurodivergent diagnoses, people having an opportunity to recognise some societal things that made life harder for them and that it wasn't their own fault, social media sharing of information. Negatives are reduced resources.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Ehlers-Danlos Syndrome is a big one!!
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Pathological Demand Avoidance!
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	communication disabilities
What additional research is needed to help address co-occurring conditions for autistic people?	Research on Pathological Demand Avoidance!
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	on why ABA is harmful AND alternatives
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbance (significantly delayed onset) has led to multiple health problems
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Pathological Demand Avoidance (an anxiety-based need for autonomy, an atypical presentation of autism) has led to severe strain on our entire family, including siblings and parents. It causes very significant stress to our autistic adult child. This leads to emotional volatility, and disruption to functioning of the whole family every single day. We have to walk on eggshells constantly to avoid exacerbating adult child's severe anxiety and consequent responses. In addition to this, our child is diagnosed with anxiety, depression, gender dysphoria, and ADHD. Each of these has an impact on daily functioning and the whole family. The biggest impact of course is on our adult child, who is currently experiencing autistic burnout and is unable to engage in any activities outside of their bedroom. They also have a history of self harm and suicidality. PDA is the biggest contributing factor.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	PDA as per previous question
What additional research is needed to help address co-occurring conditions for autistic people?	We urgently require extensive research on PDA, it's origins, potential treatments to alleviate the impact on the person and their family, most effective approaches and strategies for parents, educators and health professionals to utilise when supporting those with PDA profile.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Extensive education and training for all of those who work with children and adults with a PDA presentation. The lack of awareness and understanding contributes to judgement, criticism, blaming, isolation, seclusion and expulsion.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Just made everything worse
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	Increased use of telehealth has been beneficial for us as parents not needing to Endeavour to encourage, force, coerce etc our child's attendance at in-person appointments. The reduced social interaction, however, has not been beneficial.

in-person social interactions and obligations)	
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Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I have obstructive sleep apnea and must use a cpap machine every night. I am quite clumsy. I become overloaded visually and auditorily easily. These are my physical challenges.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have bipolar disorder, which is mostly controlled by medication, but still have symptoms of mania and depression from time to time. Also, I can be quite impulsive and even aggressive. I also have ADHD. I've never been self-injurious.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I struggle with Executive Dysfunction, especially from short-term memory challenges. I believe I may have a learning disability but managed to graduate with a master's degree.
What additional research is needed to help address co-occurring conditions for autistic people?	Thank you very much for NOT calling these conditions comorbid! They are simply co-occurring conditions, not a source of death, as the word morbid implies.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage for supports. Readily available career coaching. Having a liaison to help navigate the insurance system.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I can only speak for myself. I greatly enjoyed two years of working from home, being with my family, and being alone. I never missed work colleagues or friends for a moment. I made use of virtual solutions. The only real challenge was making sure I got myself to the clinic to get the vaccine regularly.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Again, I have no problem with increased remote work, telehealth, and reduced in-person obligations. The only thing I'm noticing is some business leaders seem to be having a negative reaction, and instead of compromising with hybrid work schedules, are demanding in-office only every day. It seems to be a backlash.

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Significant challenges include insomnia which might keep her up until 4am. Not sleeping well affects her ability to function and stay engaged in her day to day tasks. Gastrointestinal issues have landed her in the ER recently which is a challenge due to not having health insurance or Medicaid.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Most significant challenge is holding a job. Her anxiety prevents her from wanting to drive or be in crowded places such as a grocery store. Long history of self harm has led to multiple hospitalizations and deep scarring all over the body.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Misinterpretation of human behavior and what other say leads to the wrong conclusion many times. She gets flustered and confused. May retreat and have episodes where she cuts herself off from others, doesn't answer phone or wants to be in a dark room.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance through marketplace is not available with subsidies for the unemployed. Since she doesn't earn up to the threshold limit, she cannot get discount or reduced healthcare premium. She cannot hold down a job, and our state of South Carolina will not approve her for Medicaid because social security administration will not approve disability application. Insurance is too expensive and she cannot afford to pay for an individual policy.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gastrointestinal issues are a very common problem among autistic people. Learning more about why this is common co-occurrence would improve the lives of autistic people as me may be able to have better treatment for it. It is hard to focus on anything when your tummy is upset. EDS and other connective tissue disorders need to be addressed as well. I know many autistic people, myself included, who have issues with their joints and are constantly in pain.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I think researching the co-occurrence of C-PTSD would be worth while. Based on what I've seen in the community and as an autistic person myself, we all seem to ahve the endured life long trauma from having to conform and exist in a world that is not set up for autistic people.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Medical providers need to be better educated about common co-occurrences with autism. I have many things that my doctors seem to have not been able to connect the dots on but by being involved in the autism commiunity and speaking with other autistic people I am finding out they have the same issues. ie. EDS, C-PTSD, OCD. I also need to be believed when I bring up a concern with my providers. I am fequently brushed aside when I have brought up concerns realted to the aforementioned issues I experience. Autistic people are commonly, for lack of a better phrase, medical messes. We deserve better access and to be believed when we voice our concerns.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I think as a whole society has suffered trauma from the COVID-19 pandemic, not just autistic people. As we are speaking about co-occurrences, many disabled people, autistic or not, have co-morbidities that makes them more at risk if they contact COVID-19. As a society we have mostly moved on from masking and social distancing, this makes it difficult for our most vaulerable members of society to participate in school, work, and social events. Not feeling safe to participate in society makes it difficult to attend events and live a more normal life.

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	lack of sleep, pain, burnout, being misunderstood or not believed, fighting with doctors because I don't present typically.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	exhaustion, advocacy, looking after your own children, getting and keeping a job
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	none of the above. instead: physical health, mental health, executive functioning etc.
What additional research is needed to help address co-occurring conditions for autistic people?	more research is needed to identify the atypical signs, for both individuals and doctors; so they are able to be identified quicker and supported without being gaslit or disbelieved. what training doctors receive about all ND diagnoses. how different co-occurring disabilities present in autistic compared to ADHD, or compared to NT people, ask the patients what their experience is and how to help.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Disability services and tools are human rights services and tools. And yet insurance companies only cover things like abusive ABA or think that a wheelchair is a luxury item. No all tools are necessary and valid and covered under UNCRPD.... but the choice of service provider is also covered under UNCRPD - yet many countries still force people into certain therapies instead of allowing choice. There also needs to be more training for providers from actually autistic people. eg: an advocate needs to train the providers how to be neuroaffirming, do no harm and trauma informed. And the providers need to be audited by autistic advocates to make sure they continue this way.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	The world's demand to return to working in an office is the most ableist BS I've seen so far. They've proven that we don't need to work out of an office, that often we work better, have better outputs and healthier happier lives by working from home, and yet many businesses, including government businesses worldwide have ignored this and gone back to pre-COVID madness - why? because they like to torture people.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school,	COVID lockdowns were mostly beneficial to my family of autistic people, we loved it. But being forced back into society has caused massive problems, depression and anxiety as well as disinterest and hatred of work.

increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I have seen all of the above in my grandchild and a serious version of epilepsy and PTSD. Research in epilepsy must be elevated in importance. It is a great challenge to the patient and those who are caretakers for young and old.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression and ADHD
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Start with adult autistic persons and really listen to their experiences.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Of course all of the above is not available to all, starting with early diagnoses and school experiences from nursery through college. In fact, most do not have access.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	-Hypermobility issues (Hypermobility Ehlers-Danlos Syndrome or Hypermobility Spectrum Disorder) -Sleep Disturbances -PMDD and other issues with menstruating
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	-Depression -Anxiety -ADHD -OCD -PTSD
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	-Dyslexia
What additional research is needed to help address co-occurring conditions for autistic people?	How many comorbidities autism is linked to
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More access to resources to late diagnosed adults with autism. My personal struggles: -Lack of assistance and understanding for learning how to drive -Lack of assistance and understanding getting, holding, and maintaining jobs -Lack of assistance and understanding from medical professionals about adults with autism
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I personally have not gotten infected (yet) with covid-19. I know for a fact getting infected will cause life changing effects to my well being and quality of life. I live in anxiety every time I have to step out of my house, or when the people I live with go out into the world.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Having it be more socially acceptable to avoid social interaction and contact, more services are available online (telehealth, jobs, etc)

Name	Anonymous
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The way co-occurring physical conditions stack on each other make day to day living challenging. Maybe they didn't get great sleep because they were up with gastro issues. Now, they are going in to the next day at a disadvantage, and some of the tools that may work for managing say, sensory challenges, are no longer working due to lack of sleep and physical distress.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Again, the challenged stacking make them all the more difficult to deal with. Anxiety often leads to aggression or self- injurious behavior. Self- injurious behavior leads to depression. etc
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I think some of the most significant challenges are actually with the world assuming that ALL these conditions stack together. For example, a communication disability leading people to assume a learning disability. Though, trouble with communication can easily lead to difficulty learning if the proper steps are not taken to ensure they are able to participate.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Equitable access to and accessibility of services. A much lower bar for access to services. Many families of children with conditions that stack like this have vast expenses, costly equipment, constant appointments, inability for a 2 income household as one parent is full time caretaker. We need a lot more money going into these services so the bar for help is much lower. And insurance companies should be made to pay for MUCH more, if not everything! Families can't make it work and children are going without because of it
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	This question is hard to answer because it speaks to the lack of research and understanding of how autism impacts the physical body across sexes. We're only just starting to figure out those differences and it's difficult as autistic individuals to know what about yourself is a co-occurring condition, or even a condition at all, due to low interception and masking. I can only speak from my own experience since the autism spectrum varies so greatly. That being said: sleep disturbances, connective tissue issues, sensory challenges, hormonal disruption, blood sugar regulation, digestive issues, PMDD.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Speaking only of my own experience: depression, generalized anxiety, social anxiety, ADHD, self-trust and self-esteem, burnout/extreme fatigue.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	From my own experience: communication is one of the biggest disabilities; learning/slow processing; auditory processing issues.
What additional research is needed to help address co-occurring conditions for autistic people?	We don't yet understand the vastness of the spectrum itself - I'm positive it's much more prevalent than we know - so that seems to be the more pressing issue. How can we study the co-occurring conditions if we don't know enough to make sure the studies have a enough diversity and depth to their participant groups? We need to study mental health as it relates to autistic people living in a late-stage capitalist society; where so many of the struggles we face are directly related to the way society forces us to live. You need to study women and people of color to better understand how pain, hormones, sleep, digestion, connective tissue disorders are disrupting people's lives so greatly due the simple fact that the medical model doesn't have a clue what's going on or that it's connected. We need to study the experiences of autistic individuals navigating the medical world/healthcare industry; how, by this experience alone, is enough to create mental health problems on top of the physical ones. We need to study how female hormones wreak havoc on autistic women, causing fluctuations in pain, digestion, inflammation, sleep, mental health (and so much more) every day changing how they experience the world and their body. We need to study the internal experience of autistic people because only then can you really understand how they're experiencing their own pain/disability/difficulties.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Better access and affordability for adults to be assessed. Being asked to wait 18 months for an assessment that's going to cost several thousands of dollars, knowing the assessor may not be up to speed on (or believe) the ways autism presents in women/minorities/adults is a terrible experience and one many don't think it's worth having. Patient-provider interactions definitely need to be better, but the bigger issue isn't the individual interaction - it's the lack of understanding the interdisciplinary connection of these conditions co-occurring with autism. No one practices functional medicine - everything is compartmentalized - so even understanding if something *is* co-occurring is difficult. Most doctors chalk things up to

	anxiety or dismiss the stated reality of autistic individuals, especially women and people of color.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increase in remote working has definitely been a positive change, but autism can be very lonely to experience without at least a few solid relationships to lean on and COVID definitely took some of that away. Telehealth is a positive change, but the schedule II drug distribution issue for ADHD medications has been terrible. The strain of the economy has really hurt people with disabilities because so many of the accommodations needed are coming out of pocket and things are so terribly expensive now.

Name	Anonymous
Demographic	Autistic individual; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Personally, gastrointestinal disorders and insomnia
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Far more research is needed in the co occurrence of autism and avoidant restrictive food intake disorder (ARFID)
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Personally, I have had an even harder time reintegrating into society than pre covid. Once I was able to be comfortable with my mostly sedentary way of life it's still been really hard to get "back to normal" and engage with society in the level I used to.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Overlap in symptoms and effects can muddy the waters making it hard to determine what kind of help would be most beneficial and even identifying what the root concern is. E.g. depression or anxiety can come on as a natural result of difficult experiences that autistic individuals need to navigate on a regular basis. Without addressing the issues that underlie everything, you can't really help the person with their depression or anxiety. Indeed, anectodally those can clear up on their own or at least be much less severe if the other difficulties are effectively addressed. This requires mental health professionals to be better educated on this though and that's been severely lacking.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage. More affordable access. Financial support for services and aids that allow autistic individuals to more easily access other services and basic needs.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My son has a stutter. Communication is already complex enough for neurodivergent children, so adding a stutter is challenging. Communication via writing is also a challenge - the process of finding the words, putting them in a sentence, and spelling is challenging.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	My son was in early elementary education - so he worked on phonological awareness through virtual learning. The effects of virtual learning not being successful still is a challenge.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	My son was in early elementary education - so he worked on phonological awareness through virtual learning. The effects of virtual learning not being successful still is a challenge.

Name	Anonymous
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory challenges
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression and suicidality
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication challenges
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	All
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Impedes social interaction and supports

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	i have ibs and it makes it difficult for me to socialize normally and participate in classes. sometimes i have to go home because of abdominal pain or excessive gas. i also have back pain (unsure of cause, have ruled out scoliosis and eds) and have to spend 90 mins daily doing physical therapy exercises at home, and i go to pt appointments 2x weekly. i was always an active person and exercised / did sports but my back hurts and it's difficult to go out and socialize when lots of standing and walking is involved. i have sensory issues and can't enjoy busy places like malls or museums as much as other people, and have to go home sooner. after my classes, i can't socialize with friends because i am too exhausted from regulating my attention and sensory input.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	i have adhd and it impacts my ability to plan and organize my life. i often miss deadlines and make mistakes despite putting in lots of effort. i am currently trying to apply to schools and get a visa for studying abroad, and it's extremely challenging and exhausting. adhd also impacts my ability to socialize, because i accidentally interrupt people constantly when i get excited about what they are saying, and i forget a lot of what people tell me despite being very engaged and interested while they are telling me. it hurts people's feelings when i don't remember important things they've told me, and they often assume i didn't care or wasn't listening, even though i really did care. i have lots of social anxiety (i think as a result of growing up autistic) and find it very challenging to do basic things when i'm out in public, like ask an employee where to find something. i often don't understand how everyday things are supposed to work, like checking in at a doctor's office for an appointment, and get very anxious to enter the building and try to figure out where the front desk is and what to say to the receptionist. anxiety will prevent me from texting a classmate asking if they want to meet up, and will even make me doubt whether i'm remembering their name right or if i'm about to text someone random. i'm anxious to open texts because i'm scared of what they'll contain, and i don't know how to respond to them and am overwhelmed trying to put my sentiments into words.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	

What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety Rumination Executive dysfunction
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	learning disabilities
What additional research is needed to help address co-occurring conditions for autistic people?	Research needed for personalized medicine and AI powered diagnostics which may be AI powered neuroradiology or something else to help diagnose other conditions whereby those conditions share similarities with ASD such as NVLD, social communication disorder, ADHD/a.d.d, or other transdiagnostic information which is linked to some conditions such as transdiagnostic info for an auditory processing problem, poor self-regulation, memory problems, insomnia, sensory integration disorder, or slow processing speed.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Mental health services that have the training for disability (minority) related problems such as guardianship problems, unemployment, abuse in regard to lack of assistance with transportation or problems regarding other situations that involve self-care, and help with advocating for individual needs in regard to having a disability.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Each vaccination makes the problem worse. Unable to get the support needed from anyone makes life miserable.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	If the individual or parent was given the funds and resources instead of the vendors most of the problems could be managed.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	There are no online free K-12 schools for those with autism which makes it much harder and challenging.
What additional research is needed to help address co-occurring conditions for autistic people?	With the development of new technologies and advancements in medical science there surely should have treatments and help for individuals with autism but the truth is there is more money made in keeping people autistic than getting them out.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	1. Stop vaccinating. 2. Give the autistic person or parent the funds and resources. 3. Provide free school/ college for those with autism 4. Provide driving schools for those with Autism 5. Help develop communities for those with Autism. 6. Compel insurance companies to cover all costs related to autism.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Did not make any difference as I had very little social contact before COVID.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Had become autistic after a flu vaccine reaction. Have very little social contact so felt that others also got to experience what those with autism face everyday.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	All of the above
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Listening to autistic people
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleeping poorly is the worst. If you can't get enough sleep everything else just falls to pieces. My partner and I spend most of our time trying to improve our sleep and sleep hygiene (we are both autistic, and we both struggle with this).
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety is, I think, the biggest challenge, but since it's tied to environmental triggers, the challenge is really changing the environments. Autistic anxiety tends to not come out unless there's sensory overload and/or something triggering in the environment.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Please fund more studies on autistic women/girls and nonbinary folks with co-occurring conditions. We're underrepresented in the research.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	If you really want to strengthen services and supports you need to put more teeth into the ADA, tighten it up so that so many workplaces and institutions can't get around it. Insurance coverage certainly wouldn't hurt. Are physicians currently trained on how to help patients with autism? If not, they should be.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Remote work has been a blessing for those of us with sensory sensitivities. The year I spent working from home was the healthiest year of my life, ironically, especially on the mental health front. Since I have a co-occurring disability that prevents me from driving, I have also benefited from expanded telehealth services. It's interesting that the rest of the world got a taste of the environment that suits autistic people best and ran away from it screaming.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	It's a lot harder for me to function and go to work, acting completely normal when I have to not only mask my autistic traits, but also mask all of the chronic pain I'm in from my connective tissue condition, chronic migraines, and gastrointestinal issues. It's also incredibly hard to not get in trouble at jobs for calling out sick so often, but with my chronic illnesses and me regularly sleeping 0-2 hours, there are times when I simply can't function at work due to chronic pain, chronic fatigue, and lack of sleep. My sensory sensitivities also make being out in public (work, errands, etc) difficult due to the pain of bright lights and loud noises.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have several co-occurring mental health conditions including ADHD, depression, anxiety, PTSD, OCD, and a history of self-injurious behavior. The most difficult part of having autism on top of those for me personally is trying to regulate my emotions and do self-care when I'm in autistic burnout because those take so much energy to do. It's hard to consistently go to therapy appointments as well due to being so exhausted from masking my autistic traits and being in sensory overload all day at work as well. I'd also say that my mental health conditions can easily be triggered by things that my autism causes me to do like making social mistakes (oversharing, talking too much, missing social cues). This can lead to me falling deeper into a depressive episode, having heightened anxiety, and, in more severe moments, urges to self-harm.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My ADHD and autism make getting things done in my day-to-day life really difficult. For example, staying on top of chores is really hard because of my struggles with executive function (planning out what tasks need to be done, managing my time well enough to get all of them done, etc). I struggle to complete errands because of pushing them off due to being exhausted from sensory overload and masking my autism at work and then forget to do them later due to my ADHD. It also causes me to struggle to manage my finances. I'm impulsive due to my ADHD and struggle to understand how much money I'm really spending along with my special interests causing me to want to spend more and more money to be able to engage in those special interests. I frequently have had to be bailed out by those around me when I couldn't afford to pay my bills at the end of the month due to losing track of how much money I spent.
What additional research is needed to help address co-occurring conditions for autistic people?	I think there needs to be a lot of research to address how co-occurring conditions affect autistic people specifically. It's already really hard to be an autistic adult when there's little to no support for autistic adults. Add on other conditions that can interact with and be triggered by autism, and functioning as an adult (holding down a job, staying on top of chores and errands, paying bills) becomes incredibly difficult. It can lead to financial troubles and further mental health struggles or, in an attempt to avoid that, us having to overextend ourselves which can put us into autistic burnout.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I think it's super important for autistic people to have better access to services as adults. I'm not talking about ABA or anything like that. I mean access to those who genuinely understand autism and can help coach us through life as an adult and give suggestions on how to thrive better. I think it's also important to push for better workplace and school accommodations for adults like allowing autistic people to use sensory aids or fidgets and being more accepting of them needing to take more days off of school or work than non-autistic employees/students. I think doctors need to be educated on how autism truly presents rather than the narrow and

	<p>stereotyped view that a lot of them have so that autistic people can get the educated care that they need. I think insurance should cover more costs for autistic people such as sensory aids (noise cancelling headphones, for example) as a lot of autistic people are under- or un-employed and struggle to afford the things they need to improve their life.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>The increased use of telehealth has been huge for me as an autistic person. Being able to have doctors visits in my safe place (my home) makes them much more accessible to me. I'm not overwhelmed by things like the bright lights or sounds of a doctor's office, which allows me to focus better and form my thoughts so I can better communicate my needs to my doctors. Also, many more stores started having the option to place an order ahead of time and be able to just drive up and have the store employees bring your order out to your car. This has been life-changing for me as I can make sure I get all of the things I need due to not being distracted by sensory overload while at a busy store and it allows for less social exchange, which helps on the days when I'm really drained from having to script and mask all day at work.</p>

Name	Anonymous
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensorimotor skills are foundational for development of other skills. A child won't likely be speaking if they're still trying to activate their proprioception. Sensorimotor issues should be the highest priority of research in people with autism.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	I truly don't understand why the following article from years ago has still not become more mainstream. Future Research should focus on these findings. https://www.sciencedirect.com/science/article/pii/S0361923023000771
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Research and public education on sensorimotor system findings in people with autism.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Removed access to supports.

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleeping issues can be so bad. Many caregivers of children and adults with profound autism are running on little to no sleep
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Many people with profound autism are very aggressive. They get kicked out of programs and their parents are left to care for them alone as they age
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The communication aspect is the worst. If you can't communicate you get frustrated. This causes self injurious behaviors or aggression towards others at times.
What additional research is needed to help address co-occurring conditions for autistic people?	Better pharmaceutical research including MMJ.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Recognize that profound autism and high functioning autism are two different things with two different sets of needs and one set needs much more help and services.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It caused isolation where some now don't want to go out because they were stuck home for so long. It cut off services. It cut off lifelines.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The negative impact for sure is service disruption. It's an ongoing problem now. There aren't enough service providers and Covid made it so much worse.

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My child has experienced depression, aggressive behaviours towards me including some violence and has suspected EDD. The most significant challenges of these conditions have been fear and unwillingness to properly engage with us as a family within the education system and an unwillingness within CAMHS to prescribe until recently. The very minimal medication my youngest child now has, has made a world of difference. My child is now productive, positive and happy. All violence has stopped. I have also paid for my child to have counselling for the last 2 years and this too has had a positive impact. This is not something I should have had to pay for myself, but it was absolutely essential for my child's and my family's wellbeing and probably for society ultimately because my child now stands a chance of being economically productive and not a danger to anyone else. Lack of funding of mental health services means people are left to develop harmful behaviours. During my child's worst times, I was on the PEGS page on Facebook for support and the majority of parents on that site had children who were autistic.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My child has dyslexia as well as autism (undiagnosed). This has led to frustration and not helped in the onset of depression. After the pandemic, my child would not attend school and has now not been able to attend college. If diagnosis had been offered and good support given in school, they may still be learning now at 17.
What additional research is needed to help address co-occurring conditions for autistic people?	Research into effects of change of routine on the developing mind of autistic youngsters as in the case of the pandemic could be helpful, if there were to be another one. We all know that school attendance has plummeted since the pandemic and for my child that expectation to go back to school after such a long break in education was never going to happen, due to their autism.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Better educational support and awareness of the impact on co occurring conditions for all teachers and especially ALNCOs would be beneficial. Essential really for a child with co occurring issues to succeed. Education of teachers is always the answer
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	My child could not go back to school after the pandemic as already discussed. It was too big a change after being home after all that time. They were more depressed and more anxious and more fearful of change after being home for all that time.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal	My child could have been encouraged to learn more online after the pandemic on a one to one basis, but after the pandemic school went straight back to face to face and there was no acclimatising period allowed for. The child either complied or was left to fall by the way side.

changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Anonymous
Demographic	Family member of an autistic individual; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, ADHD
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Clearer understanding of the line between ADHD and ASD and how treatment of and recommended best practices in teaching and parenting and treating children with both ADHD and ASD would differ from those with just one or the other conditions.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Broader insurance coverage, including unconventional treatments such as equine therapy. Additional provision and coverage of social skills small groups and one on one treatment. Much needed is expanded services and insurance coverage for counseling and education of parents, other relatives, and educators working with people with autism and ADHD. Family systems training including providers who can come into a home and train household members should be considered for coverage.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Need more research to understand the longer term effects of the gap in social interactions because of long term school closures.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Reduced in person social interactions have impacted all people. There is a need to better understand the effects losing a year or more of education and services for children at every age. E.g. if a student missed all of kindergarten, how should that gap be addressed and how would it differ from a student who missed all of fourth grade? What should educators be considering for each cohort as they move up in grade levels?

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Learning to manage IBS has taken a long time and impacted my ability to work at times.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have been depressed bordering on suicidal and that has been a more significant problem than any physical health issues.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Most health and insurance services seem entirely based on phone skills, which is a huge obstacle for autistic people as well as people with anxiety or ADHD. More online systems and detailed information about what to expect would improve access tremendously.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Longterm fatigue after having Covid has contributed to depression.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increased virtual and work-from-home options have been very helpful and allowed me to have more self-direction and flexibility, which has improved my depression, especially at work.

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	anxiety, emotional dysregulation, sleep disturbances/circadian rhythm issues, collagen-related defects, Raynaud's syndrome, GI issues (constipation and diarrhea), allergies, altered pain perception
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Autistic "agitation" or irritability, ADHD/ADD, anxiety, impulse control, emotion regulation, depression
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication differences are No. 1, and the more the person experiences differences between their style/understanding and that of peers/family/society, the more it affects the person; learning disabilities; developmentally at least 2 to 3 years behind peers, often more, and it's difficult when they realize their cohort has moved on and they haven't
What additional research is needed to help address co-occurring conditions for autistic people?	anorexia nervosa and other eating disorders - the treatment models are a horrible match for most autistic individuals and exacerbate anxiety and other traits, difficulties
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	All of the above
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Speaking only from my personal experience, I struggle with sensory and motor challenges significantly in my daily life. It's important to note that the experience of this varies significantly day to day. This has lead some healthcare providers and support services to conclude that I don't need help (if they see me on good days), or for people to decide I'm unfit to drive (if they see me on bad days). There is a significant lack of understanding across the board for care and services in this regard. My experience of autism and related conditions is not perfectly consistent. Just like if you've met one autistic person you've met one autistic person, If you've seen me one day, you've seen me on one day.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have a diagnosis of depress, anxiety, ADHD, situational mutism, and sometimes suicidal ideation. But all of these take a back seat to PTSD. Living in a world designed for neurotypical people, where the experiences of autistics are rarely if ever considered, where our perspectives and input are values and integrated into decision making and space/service design, is a fundamentally traumatizing experience. The lack of inclusion of autistics within reach done *on autism* is a stark and painful example of this. The "care" provided to autistics at the Judge Rotenberg Center is undeniably traumatic. Having official diagnostic criteria describe our differences in terms of deficits, in terms of how uncomfortable we make neurotypicals feel, in terms of how inconvenient our behaviors are for neurotypicals, is fundamentally traumatizing. Just like autism is extremely underdiagnosed in women and non-binary people, PTSD is severely underdiagnosed in autistics, with devastating effects. This requires a two-part change. First, we must improve the diagnostic criteria of PTSD and train autistic support services and clinicians to identify how PTSD presents in autistics and equip them to help. Second, we must redesign the services we offer (eg the complete discontinuation of shock therapy and ABA for autistics), the care we provide, the spaces we create, the entire society we live in, to include the perspectives and needs of autistic people to prevent traumatization in the first place.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Speaking only from my personal experience. I struggle significantly with communication differences compared to neurotypicals. My facial expressions and body language are consistently misinterpreted by non-autistic people, often undermining the genuine and positive intent behind my messages. For example, maintaining eye contact is difficult, and a neurotypical may see my gaze shift and interpret it as eye rolling to indicate sarcasm or as a sign of guilt or untruth. Note that this experience doesn't happen with other autistics. The issue isn't in what I'm doing with my body, but in the ableist neuronormative assumptions that neurotypical people make about the behavior of others. I also experience situational mutism, which is often misinterpreted by non-autistics as belligerence (voluntarily refusing to speak, giving someone the silent treatment, etc), aggression, or insubordination when in reality I'm in a situation that has robbed me of my ability to communicate by not being accessible to me. Judgements that again I rarely observe when experiencing situational mutism among other autistics.
What additional research is needed to help address co-occurring conditions for autistic people?	This is asking the wrong question. You should be asking, how can we change the way we do research to improve outcomes for autistics. The answer is to stop framing autistic experiences as deficits to be fixed, and instead focus on changing society (including healthcare provision (including behavioral/mental healthcare), therapeutic interventions, the design of

	<p>spaces, ableism in society), and to include autistics in research that affects us (by including autistic researchers, letting autistics be PI on autistic research topics, focusing on the perspectives and experiences of autistic people rather than centering the voices of our parents and caregivers, and letting us describe ourselves the way we choose to (autistic person, not person with autism). Examine our experiences through a lens of intersectionality: autistics are also racialized, we're 6x more likely to be gender-expansive than neurotypicals, we're more likely to be romantically and sexually diverse, we're more likely to be socioeconomically disadvantaged. Reframe the way that research sees autism, not as deficits or inconveniences for neurotypicals, but as differences to be encouraged, celebrated, accepted and accounted for by society.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>The examples provided are all things I've personally struggled with and barely scratch the surface. But the single most important thing services and supports need to do is believe us at face value when we talk about our experiences. Just because I'm autistic doesn't mean I can't understand my own gender, and shouldn't be denied access to gender-affirming healthcare. Being autistic means that I experience and express pain differently, and that different presentation shouldn't result in me being denied pain management medication when I have a broken arm. Being autistic and non-speaking doesn't mean that support staff should speak to my caregiver instead of me as if I'm not present. Being autistic doesn't mean I'm incapable of expressing my own thoughts and feelings, so people don't need to ask about the experiences my caregiver has of supporting me as a proxy for understanding my experience.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>Speaking for myself, it has allowed me to experience what it's like to work from home, to have people respect my physical space boundaries, and a reduction of barriers to accessing care in a way that works well for me. Since I've been allowed to work from home, my productivity has improved, my mental health has improved in relation to my work, my job satisfaction has improved, I am able to contribute more to discussions at work. I attribute this to being able to fine-tune my working environment to meet my sensory and motor needs, as well as the changes in communication patterns as now people are more likely to contact me via text means than walk into my cubicle and start a face-to-face conversation. The same has been true in accessing medical and behavioral healthcare, where providers are much more likely to have online scheduling systems and offer telehealth visits. Conversely, since the ending of the state of emergency, I often encounter people who are uncomfortable with me continuing to wear a mask. Masking provides me with protection against NT misinterpretation of my facial expressions in addition to protection against deadly diseases (I haven't been sick in 4 years, compared to every 2-3 months before masking everywhere was possible).</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Speaking for myself, it has allowed me to experience what it's like to work from home, to have people respect my physical space boundaries, and a reduction of barriers to accessing care in a way that works well for me. Since I've been allowed to work from home, my productivity has improved, my mental health has improved in relation to my work, my job satisfaction has improved, I am able to contribute more to discussions at work. I attribute this to being able to fine-tune my working environment to meet my sensory and motor needs, as well as the changes in communication patterns as now people are more likely to contact me via text means than walk into my cubicle and start a face-to-face conversation. The same has been true in</p>

	<p>accessing medical and behavioral healthcare, where providers are much more likely to have online scheduling systems and offer telehealth visits. Conversely, since the ending of the state of emergency, I often encounter people who are uncomfortable with me continuing to wear a mask. Masking provides me with protection against NT misinterpretation of my facial expressions in addition to protection against deadly diseases (I haven't been sick in 4 years, compared to every 2-3 months before masking everywhere was possible). I wish that the benefits of masking as a common choice in society had been lasting.</p>
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Name	Anonymous
Demographic	Autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>Sensory challenges had long plagued me. It makes things like physical therapy problematic and leads to less treatment due to Medicaid requiring six weeks of PT before you can get things like MRIs. I have good strength and movement and thus, the main thing they want to do is lay hands on me. Stuff like that have always causes me significant pain and isn't the least bit helpful. At this point, I'm waiting until the problem is bad enough I have to go to the ER. This is especially true as I have systemic CRPS. It's far too risky to engage with PT and is likely to lead to flare ups and possible hospitalization. Sleep disturbances is a huge issue. I rarely sleep without having to take Benadryl or related drugs. Prescription sleep aids tend to lead to black outs. I have trouble keeping weight on and have dealt with stomach issues for several years now. Thus far, doctors have largely ignored the problem even though I've lost over thirty pounds while eating like a horse and wasn't big to begin with. My only way of managing the problem thus far is to restrict what I eat. In fact, so much as buying small bell peppers from Mexico doesn't work for me. They use too many chemicals apparently. Canadian bell peppers aren't problematic.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>I've suffered from severe depression ever since a severe TBI as a kid. I should have had a hole put in my head to relieve the pressure, but the doctors missed the problem because I was a girl and thus, apparently, was crying for no reason. They didn't notice I had no memory because they asked my brother the mental acuity questions first. Perhaps doctors, nurses and EMTs should ask different questions. However, even then, they should have noticed that I gave them four different birthdays, aka the one question I hadn't gotten the answer to. When it comes to depression treatment, all drugs and therapy have been useless. The only thing that has been useful was teaching myself how to carefully control my thoughts. My focus is on mood stabilizing. What goes up must come down and when I go down, it's very down. Why a doctor never suggested such a thing, I will never understand. Anxiety frankly causes me more trouble today than depression. Mainly because I was born physically anxious. I say physically, because it's not coming from stressed thinking like for most neurotypicals. No, my brain is about as zen as it can be at this point and yet, I still deal with constant body tenseness. No, thus far, I'd yet to figure out any work around other than staying away from things that might trigger increased tension. Doctors have been basically useless in this area. Most don't know anything about treating anxiety that isn't brain based and I can't take anxiety meds because I'm in pain.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>Communication is problematic mainly because neurotypicals refuse to take things at face value and always assume there's an agenda. Moreover, it doesn't matter how often you correct their assumptions, they just keep on going assuming that your brain works like theirs. However, the biggest problem is communication or so much as being around people is stressful. I'm too empathetic and most people are insecure and anxious. Perhaps if the medical industry figured out a way to deal with body-based anxiety, autistic people would be less reluctant to be around people.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>I'd love to know if CRPS happens more frequently for autistic people than the general public or perhaps autoimmune conditions in general. I'd put more effort into researching the different ways autism shows up across genders. I'd research all the reasons autistic people struggle in the workplace and take steps to correct it. You are wasting your most precious resource. No one</p>

	wants a company to do as well as someone who is autistic. We become experts at whatever we do. It just generally requires those around us to recognize that we aren't threatening their position but asking questions because we actually plan on doing what we've been told to do and thus, have no other option than speaking up.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Autistic people should be given exceptions for the PT requirements to get an MRI. Six weeks of PT would only be likely to result in my being hospitalized again. Plenty of conditions make no sense to send to PT. Perhaps try it once but if the patient reports no improvement, to keep requiring it will only result in delayed treatment. It's a waste and expensive for the country. It means more ER visits. Doctors in general need to understand that many of our problems aren't brain based but physical. They need to be told to trust our words and in no way are we slow. In fact, they're brains are 30% less active than ours. As mention prior, it'd be good to get nurses, doctors and EMTs to ask different mental acuity questions.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	It's been incredibly positive to have doctors do more virtual appointments.

Name	Anonymous
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	seizure disorders, motor dysregulation, compulsiveness
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	anxiety
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	communication disabilities
What additional research is needed to help address co-occurring conditions for autistic people?	Research WITH autistic people is a must - not just ABOUT them - and publications must be accessible and understandable by the general public
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	communication access
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Difficulty preparing, eating, and digesting food, sleep disturbances causing fatigue and difficulty dealing with day to day life, and when unaccommodated sensory issues can interfere with any type of functioning.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Difficulty determining which mental health condition is causing which symptom/how to manage it, anxiety and autism symptoms aggravating each other and making functioning and new situations much more difficult, depression and social anxiety being formed or made worse by societal treatment of autistic people
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I don't personally have much experience with these but communication difficulties have made maintaining a social standing difficult in every environment I've been in. Many autistic people struggle to get degrees or finish highschool because their learning disability may not be accommodated
What additional research is needed to help address co-occurring conditions for autistic people?	A good first step would be research on profiles of autism. The only one I'm aware of is the pathological demand avoidance profile and there isn't much solid medical information on it. Some people may be misdiagnosed as having a co-occurring condition when they may be dealing with a specific type of autism they're unaware of. In general more studies on co-occurring conditions, why they are common, and how to help autistic people manage them would be beneficial
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More therapists and support systems learning about co-occurring conditions and how the symptoms affect autistic people's thoughts and behaviors would be helpful as well as more resources for autistic adults, especially those who are diagnosed as adults, as they much more frequently have co-occurring conditions. As an adult who was diagnosed as autistic in the last year I've had a lot of trouble finding the right support for it, especially when taking into account that I have several co-occurring conditions.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I don't know much about that but I do know that when I had covid my autism and co-occurring conditions made it a lot harder for me to get back to my regular behavior and start being active again
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increased use of telehealth has been wonderful, but being used to being in my house all the time has made socializing and being active a lot more difficult. Some people may have been on track to get a diagnosis or specialized treatment but the shutdown made it more complicated to seek any type of help

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Insomnia, gastrointestinal issues, sensory issues
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Executive dysfunction (ADHD-i), depression, anxiety, emotional regulation issues
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Telehealth has been a godsend, as well as reduced in-person interactions.

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbances, sensory challenges.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	All of those listed.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	communication disabilities.
What additional research is needed to help address co-occurring conditions for autistic people?	Need evidence-based research for sensory challenges.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Incentives for doctors and especially psychiatrists to train in the needs of this population. Incentives for these providers to accept insurance.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Inability to find respite providers.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Everything is so loud and stores are overwhelming. Being in a crowded area is absolutely miserable. Being in public in general is stressful and overwhelming. And i have to work a job in the general public. I am in pain quite often because of health problems I'm pretty sure are related to my autism but I have no way of knowing that because I am way to exhausted to schedule a doctors appointment unless my organs are falling out of my body.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	So I have adhd in addition to my autism. That makes to it hard to focus, plan, and stay organized. Keeping a job is extremely draining and hard. Getting a diagnosis is almost impossible especially on your own as an adult. Nobody believes you either, you just get told your anxious. Most companies have a terrible attendance policy which is bad because if you have no concept of time and are always late you could possibly get fired. I also learn slower which makes it harder to keep up with my peers in my job field. College is taking much longer for me. Its also really hard to keep my tags up to date and I keep getting in trouble year after year for that. Its not even that I don't want to do it. I do. And don't even get me started on communication. I often struggle to be understood. It's hard for me to speak up for myself. I miss social cues quite often which gets me labeled as rude. If I'm communicating with my superiors I have to rehearse several times so hopefully I'll be understood and the changes I need will be made.
What additional research is needed to help address co-occurring conditions for autistic people?	I think it would be helpful to test people with adhd for autism and people with autism for adhd too. I also think if you get an autism diagnosis, you should get like a referral to be tested with some of the common health problems. And maybe the CO occurrence of personality disorders too. It would really really be helpful if more women with autism could be included in the research because we often get missed.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	The whole diagnosis process as a whole kinda sucks. You get put on a really long wait list and you get no help in the meantime. I think the process for adults should be a lot easier. Insurance coverage could be better.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic	I was not a huge fan of the telehealth thing because it resulted in a misdiagnosis. However since there was less social requirements it was better for me. The personal space I require was accommodated for. It was

people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

easier to interact because I only had to change half my face expression wise. And I found myself wanting to be more social because I had more energy.

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep apnea, gastrointestinal, sensory issues, high anxiety, verbal and physical stimming
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, ADHD, aggressive behaviors
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Access to services offered, especially local. Insurance coverage that covers more autism services, service system issues. Pay caregivers more than fast workers to stop them leaving because wages too low. Cover more therapies, ie social clubs, activities instead of squeezing what little money families have.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	No illness, however a 3 year lockdown was catastrophic and exacerbated their behaviors. Dismal failure.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	All the examples above. Harm caused was unprecedented, irreparable and inconceivable.

Name	Anonymous
Demographic	Autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>I can't speak for all autistic people, but I have noticed that Sleep apnea along with sensory overload caused by multiple sounds at once have been a pretty common problem (myself included). This can effect not only ones energy and performance at work, but it can effect ones ability to listen to someone talking to you but can lead to lashing out at people or objects out of frustration (especially when they your trying to focus on a task). This can also effect decision making such as when it's the right time too make a turn onto a highway when there are more then two lanes with a large convoy of cars moving in the same direction and you have to check for gaps and figure out how fast the next line of cars is coming up on you while also holding up traffic behind you. Your speech is also effected we're you trying to talk to someone and you either can't find the words or you don't think your sentence through it and it comes out jumbled adding to confusion or wrong and it offends someone.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>Depression and anxiety appear to be pretty common (at least from my experience). Its pretty easy to become deeply concerned over issues such as weather you turned the stove off or not or when you realize that you forgot to do something at work and are afraid of getting in trouble. Depression is usually the result of loneliness along with being disrespected by peers and employers. You feel that no matter how hard you try to be like a neuraltypical person and no matter how well you do your job and try to develop a close relationship...the autism is all they see at the end of the day. Words cannot describe the frustration, anger, and sadness that comes from that. I am aware that some of the issues can be dealt with through self-improvement, but the stigma and prejudice Is still there. The awareness is there, but the acceptance isnt.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>The main challenge is being taken advantage of by people that prey on us for money, real-estate, and other reasons. There are people in the spectrum that are placed in both private and state run "schools" by terrified and exhausted parents that are desperate for help. These people are supposed to be taught how to advance themselves, but in reality they hardly learn anything and are given "goals" that are made as a check list to get medicaid funding. The end result is lots of children and adults that are just left to stagnate and are at the mercy of these institutions that prey on them.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Specific legislation that actually protects people on the spectrum on a state and federal level from workplace discrimination along with the removal of questionnaires on job applications that are used to bar people that disclose that they have autism, abuse from parents and providers, as well as increased penalties for crimes against the community (physical and verbal bullying and murder). There should also be state services that provide therapy, actual life long skills, transportation if needed, job hunting (and assignment for lower functioning individuals), and just a sense of belonging as a member of the communities they live in and a citizen of the United States of America.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	

What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Access to proper healthcare and dismissive doctors. I have co-occurring mast cell issues, primary immunodeficiency, gastroparesis, possible Ehlers-Danlos, and possible POTS. The challenge is that most of these are rare medical conditions with few doctors who are willing to diagnose them in order to treat them. Then you have doctors who try to remove you from proven treatments because "you're just anxious." No, I nearly died from sepsis which is why I am now on that treatment. Because my immune system is trash due to underlying genetics. Doctors who don't get autism are also problematic. They don't understand our communication styles are different. And that makes it harder to self-advocate. We need advocates. We also need single payer and can't afford premiums when we are on plans that are not supposed to have premiums.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have ADHD in addition to autism. For this one, it is the lack of coverage for QUALITY mental healthcare with professionals who KNOW autism and ADHD.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Autism is a developmental disability. Lack of services, especially for adults who are no longer in college.
What additional research is needed to help address co-occurring conditions for autistic people?	Genetics testing should be available at no cost to everyone. But WHY are you asking this particular question and what are your plans for this feedback you receive? Autism does not need cures. We need acceptance no more services for adults. If the research will definitively prove beyond all doubt that autism is genetic or epi genetic in utero so we can stop the vaccines causing autism myth once and for all, great. Rubella babies have a high incident rate of autism. But antivaxxers are out here killing everyone by bringing diseases back. So figure that out.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Services need to exist in the first place. You cannot improve nonexistent services. Where are the services for autistic adults in their thirties and forties and fifties and sixties and seventies? We are waiting.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Loss of the few existing services for autistic adults. No services at all for autistic adults. No coverage for services for autistic adults. And lack of masking in clinics - CLINICS - and other such services can be a deterrent for autistics to seek care and services they need. Especially for autistics who also have co-occurring immune system issues. Not to mention that the current research on longterm effects of COVID is that COVID causes a dysregulation of the immune system. Repeat infections are going to wipe people out. We should have masking continuity in ALL clinics no matter the season. We should be masking on public transportation and in crowds.

<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>I faced loss of whatever few existing services for autistic adults we had. I had to move to another state to feel somewhat safer. People in general caused me to lose faith in humanity because they laugh about COVID vaccines, COVID deaths, COVID disabilities because our government dropped the ball and threw the vulnerable under the bus multiple times. We have more COVID deaths right now than during the entirety of the pandemic because we dropped masking in healthcare facilities - the last remaining safe place for the vulnerable. I worry what will happen as antivaxxers bring back measles and other diseases because they still push the myth about vaccines and autism.</p>
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Name	Anonymous
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory challenges, sensitivity to gluten dairy,
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	To obtain quality doctors and therapist who are TRAINED to treat autism and co occurring conditions, one must often pay out of pocket
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Explore effect of diet on autism, explore effect of vaccine on autism, explore effects of environmental toxins on autism.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Government should provide reimbursement for private pay practitioners that specialize in treating autisms and co-occurring conditions. Most "mainstream" medical practices do not address nuances of autism, biochemical imbalances, etc. forcing parents to pay out of pocket.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Personally and what I've observed in my family members (who would previously have been called high functioning), sensory overload leading to meltdowns and chronic gastrointestinal issues making everyday life/occupation difficult. Also, personally chronic fatigue and chronic lower back pain have caused me to lose jobs, and have severely limited my social life. Fatigue requires me to stay home and rest a lot. Sensory overload and pain make it hard for me to be in the car for long. Being thus homebound/socially isolated/at times underemployed have also contributed to depression.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety affects appetite and digestion, makes one "tired and wired" or deal with insomnia. Anxiety impacts substance use (I can rarely use any substance - sugar, caffeine, alcohol - without having a severe crash or starting to become addicted/dependant; have witnessed similar dynamics in family members). All of these make daily routines difficult to maintain. Also contribute to further social isolation and depression.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Difference in communication, e.g. one person uses language literally and the other relies more on nonverbals or implied/inferred meanings, cause difficulty with following instructions at work, getting along with coworkers or being accepted by peers. Difference in verbal or visual processing speeds can cause similar disconnect in communication.
What additional research is needed to help address co-occurring conditions for autistic people?	Research on subjects who went through formalized school and conventional (such as ABA) therapies vs. subjects who were home schooled/unschooled or in less formal settings such as Montessori, and/or less conventional and more permissive therapeutic settings, and the long term outcomes on their comorbidities.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Providers: listen (and observe) more and take more time before making prescriptions or decisions for treatment. Center the patient's goals (including children!) Stop expecting autistic people to conform. Recognize and affirm their differences as valid and equally worthy. Obviously universal healthcare would help with accessibility. Or having more insurance options for partially employed (or irregularly employer) autistic adults.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	In order? Sleep disturbances, epilepsy, sensory issues, gastrointestinal issues, motor challenges
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, Anger: outbursts that last all day, self injurious behavior & adhd
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication, Developmental, intellectual , leaning * in order
What additional research is needed to help address co-occurring conditions for autistic people?	Not all parents/ providers can tell which issue is the driving the behavior so they cannot determine the cause or kick off of the antecedent.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	holy heck.. you stepped in it with this question. The affluent parts of town get the services and the providers, the not so affluent parts of town are ignored, multiple call outs, or flat out dropped clients. I live in Peoria AZ.. middle of the road, we once lived in Tolleson (lock your doors) before the gentrification (?) providers would cancel, DDD S.C.s would vanish or never show up. Same thing with outreach services, they do not happen in bad parts of town, at all. Speaking as a parent with 4 on the spectrum the early years we were lucky to get through on one income, we had no car, I couldn't work.. no one would watch my kids (now 27 & 24) the affluent parts of town or getting there was a laughable impossibility.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	loss of acquired skills due to loss of ESY, or disruption in services, or their routine. Everyone handled covid in their own way neurodivergent or not.

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	POTs and EDs/hypermobility can cause significant limitations in accessibility of events and spaces as well as need for more significant work accommodations
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Untreated/undiagnosed ADHD and anxiety (especially combined with autism) can lead to alcohol abuse (to self-soothe social anxiety/rejection sensitivity dysphoria, help with masking, and to dopamine-seek). More research is needed on effects of stimulants for ADHD on people with both an ADHD and an autism diagnosis (vs ADHD alone).
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Dyscalculia seems under-studied, especially in gifted/high general intelligence autistics. It can impact self-efficacy in STEM careers even for high verbal ability students with strong interests in science/engineering. It can also impact social anxiety in situations when one is asked to tell time, make change, play board games etc. that compounds the existing social anxiety of autism. More research on what educational supports/accommodations would help those with dyscalculia reach their potential would be fantastic (given that already some are highly successful in advanced math even if they still struggle with mental math and arithmetic).
What additional research is needed to help address co-occurring conditions for autistic people?	The overlaps of autism, ADHD, and OCD still seem under-studied and the effects of various stimulants and anti-anxiety medications on different subgroups with different intersections of these 3 diagnoses would be very helpful.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Access to ADHD medication already being an issue, it makes it worse when providers are not educated about the overlaps of autism and ADHD. Some autistic people are afraid to disclose an autism diagnosis to their prescriber for fear of being categorized as "misdiagnosed" ADHD and losing access to medication. Also, it's currently much easier to find a neurodivergent-affirming therapist than medical doctor (doctors not believing patients with EDs/hypermobility/POTs about either their physical symptoms or their autism if they are level 1 continues to be an issue due to Drs not being up to date and informed).
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	Positive: increased remote work and school, increased tele-health, reduced in person social obligations.

in-person social interactions and obligations)	
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Name	Anonymous
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Pharmacologic treatment associated weight gain and metabolic toxicity
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Autism merging with psychotic illness: restricted interests--->over valued ideas--->delusions. Irritability and "outbursts."
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Inability to describe physical discomforts underlying impulsive aggression.
What additional research is needed to help address co-occurring conditions for autistic people?	Better diagnostic validity.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Establish facilities with wide access that provide all indicated services "under one roof."
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	No more so than that experienced by the neurotypical community
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I have not noted any decrement in the services I and our CHMC provide.

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Often misunderstanding emotional clues.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Aggressiveness, ADHD
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication
What additional research is needed to help address co-occurring conditions for autistic people?	Development of more non-addictive meds. Making educators and law enforcement more aware of ways to work with autistic individuals.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Reduced social interactions.

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My son has significant GI issues such as gastroparesis and colonic inertia. Both result in frequent nausea and pain. His weight has always been low and he has a diagnosis of malnutrition and anorexia. He has impaired gross and fine motor skills and received years of physical, occupational and speech therapy.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My son has been diagnosed with ADHD, MDD, anxiety And borderline personality disorder. He has been hospitalized for suicidal ideation and has self injurious behaviors. He was in a residential program for 4 month. His recent evaluation by a team of psychologists recommend long term residential mental health placement.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My son has dysgraphia and written output disorder. He is gifted verbally but has very low processing scores.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	My son receives services in the state of MA from department of disabilities as a person with autism without an intellectual disability. Those services are quite limited and unequal to the services one receives with an intellectual disability. My son’s functional abilities are quite low with acts of daily living but that is not taken into consideration when looking at services and needs. My son has significant mental health problems yet the department of mental has denied services since he has autism! The departments will not work with each other to serve this comorbid population. As you know the suicide rate is much higher in autistic adults but the state of Massachusetts refuses to do anything !
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	My son, as a lot of autistic people, tends to isolate. Virtual everything has made this much easier for him to do which is NOT a good thing. Isolation increases levels of depression and decreases motivation. I’m working against a tide of people wanting to provide services virtually while he needs in person interactions.

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	For me it's the GI issues. They have been a plague for the last 40 years.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	For 20 years I had OCD and GAO. It is incredibly difficult to navigate the NT world, with all of its inconsistent, irrational, unexplained rules. I found it to require constant hypervigilance on my part.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I do not have this, but my son, who I am a caregiver for, has ADHD and Autism, and the two are like a powerful supervillain combo. Each aggravates the other.
What additional research is needed to help address co-occurring conditions for autistic people?	Research needs to be conducted BY AUTISTIC REAEARCHERS
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	There is a desperate need for more organizations that can provide adult life coaching, adult peer mentoring, one-on-one peer-to-peer body doubling and executive assistance. The adult world is difficult for anyone. Young autistic adults need a huge range of skill assistance.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	About the same as most people, I think. Deeply reduced care and assistance options. A social system that doesn't give a [profanity redacted] whether disabled people die.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	In social situations or during extended activities like exams, I experience a 20 to 30-second tightening and occasional shaking in my hands, shoulders, and chest, making it difficult for me to write. While sensory issues aren't a significant challenge, background noises and loud voices bother me. My relationship with food is peculiar – I have a strong attachment to specific foods, consuming them daily. If these preferred foods aren't accessible, I find it difficult to eat, even when hungry, leading to challenges for my digestive system.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I've faced anxiety and depression in the past, but through learning what works for me and what doesn't, I've found a path that allows me to lead a fulfilling and happier life now.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	While I haven't encountered any learning disabilities, my ability to process information has improved with age by applying theories and research practically. However, during exams, issues with hand tightness and shaking sometimes compel me to provide concise answers, affecting my rank. Despite often knowing more than the top students, my scores remain above average rather than at the class's pinnacle.
What additional research is needed to help address co-occurring conditions for autistic people?	Hypermobility, causing sharp pain in different areas, is a common co-occurring condition with autism, challenging to detect through standard physiological tests unless physicians are particularly attentive. The unsettling aspect is that many autistic individuals receive generalized anxiety disorder (GAD) diagnoses. Reflecting on my mother's GAD diagnosis and past depression, I sometimes ponder the possibility of her being autistic. While I'm not a professional, the question of various scenarios often crosses my mind, acknowledging the importance of not imposing personal theories onto her. Children with autism in socially disadvantaged households require thorough assessment to ensure their unique needs are properly addressed. It's crucial to consider their environment and circumstances to provide effective support and intervention. Exploring additional research on the connection between hypermobility and autism, as well as the prevalence of GAD in autistic individuals, would be valuable for a more comprehensive understanding of these aspects.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I'm not sure how we can improve autism services. Improving autism services is a challenge, especially when individuals in influential positions, like college professors, lack awareness of autistic needs. I've experienced a professor who insists on constant eye contact and nods for comprehension, seemingly unaware that neurodivergence, including difficulties with non-verbal cues, is not yet normalized. This lack of awareness can lead to misunderstandings and discomfort for autistic individuals in educational settings thus, needs to be taken into consideration.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	The experience of Covid-19 was an emotional rollercoaster for me. I frequently cried while watching the news, witnessing the loss of lives and shattered hopes. However, there was a positive transformation. Prior to the pandemic, I was reserved, but afterward, it surprisingly facilitated a level of socialization I never thought was possible. I became relatable to others, and it's astonishing how my personality swiftly shifted from extreme social

	awkwardness to being a social butterfly. I haven't quite figured out how my personality changed on its own without any intentional effort on my part.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Throughout the Covid-19 period, I found myself grumpy and frustrated, possibly due to the overwhelming news and social media. To cope, I heavily relied on takeouts for comfort. Being a reserved individual since childhood, the solitude during Covid didn't bother me much, but I had a lingering concern about potentially reaching the end without forming any friendships. My academic performance suffered during online studies, especially in a stream I was forced into. However, I excelled in subjects I enjoyed, resulting in overall satisfactory scores. Post-pandemic, I dedicated effort to all subjects and achieved significant improvement in both academic performance and social interactions. Consequently, these changes had a positive overall impact on my mental health.

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>Gastrointestinal disorders, sleep disturbances, sensory processing and overwhelm challenges. So many of us have generalized anxiety disorder. Per information on the autism.org website, "Autistic youth are three to four times more likely than non-autistic youth to experience sexual victimization, and between 40% and 50% of autistic adults report experiences of sexual abuse during childhood." The fallout from childhood sexual abuse causes physical conditions, and this is certainly co-existing, based on the above quote. In California, it is challenging to impossible to receive autism services if you have a childhood sexual abuse history, because they say the symptoms are so similar that they can't be sure they are only covering the autism. This is not okay.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>The aforementioned increased likelihood of sexual abuse, and the additional emotional and physical challenges that causes. Many of us were not diagnosed until adulthood, sometimes late into our lives. This creates a situation where we do not understand ourselves and the supports we need to be successful. We often lose hope and fall into depression. We are under employed and unemployed at higher than neurotypical rates, even those of us with advanced degrees. If we have been stay at home parents, and then get divorced, we often fall into poverty because we have no access to supports that will help us to find and retain work that we can support ourselves with. This is not our fault, it is the responsibility of our social safety nets to help those of us born with neurological illness understand ourselves and learn strategies we can use to stay afloat in the shared economy.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>I'm 59. I was tested in school and my family was told that I am a near genius and that I wasn't trying hard enough. In reality, I was struggling with multiple sensory overwhelm, executive function differences, things that I didn't understand at the time. My parents certainly didn't understand either. I spent decades trying and failing and feeling ashamed of myself. Now I know that I am autistic, but I have not been able to find any help. I desperately want help to be financially stable. In Europe, there are studies of autistic people being a good fit for having small self owned businesses so that we can accommodate our different sensory needs. In the US (a country that uplifts entrepreneurism) I can't find any help for this. The fact that I was tested for intelligence and then left to fend for myself says all you really need to know about how we are failing autistic people. The imagined spectrum, which designates us as either high or low functioning is not an accurate description of our struggles. Some of us are brilliant and non-verbal. Some of us are hyper-verbal and struggling. We each have individual strengths and weaknesses. That should be the basis of our support strategies.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>We should be looking squarely at the higher levels of sexual abuse autistic children endure, and we should be acknowledging that documented difference in on-boarding a person for supports, instead of using it to deny access to life changing help. We should be doing elder outreach to find autistic elders who are currently falling through the cracks and living in our cars. Just because we weren't diagnosed as a child doesn't mean that we haven't had lifelong struggles. When autistic people are living in poverty, it is all the proof you need that we were left to fend on our own with significant neurological differences that we didn't understand and couldn't cope with.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic</p>	<p>Equitable access to services. Services to Black autistic people are even more of a struggle than for white autistic people. Make it easier for us all to get help. It should not be through a for-profit insurance provider. We as a group,</p>

<p>people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>have too much poverty and work struggles to make that a stable way to access help. We need help learning to run cooperatives or other business structures that would give us the autonomy to work hours we are capable of working. There are so many of us living in poverty, we need supports. We need better supports in transferring to college, in navigating professional relationships with neurotypical people. We need housing we can afford, just like neurotypical people. Using "natural supports" is fraught with power differentials, which make us less safe physically. Often in this country, churches are communities with hidden sexual predators. And yet, we tell autistic people to go find supports in churches, without any instruction or cautions, despite the overwhelmingly higher numbers of autistic people sexually victimized. These are not the ways to administer public health initiatives. It affects people's lives daily. It has affected my life. Legally, we recognize the responsibility to help autistic people navigate our lives, and yet we are letting most of the population fall through the cracks!</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>During the period where I wasn't working outside my home, I lost a lot of my social masking skills, and they haven't come back. I stopped wearing clothing that was a sensory distraction, because I didn't feel like I had to look a certain way to get along with people. I stopped forcing myself to make eye contact. I didn't even realize that I was doing it. Autistic people are systems thinkers, and we are concerned at what many of us see as a breakdown of public health structure. We are concerned about long covid, which many of us suffer from. We see our fellow disabled people, who are stuck with limited options for social gathering or for daily requirements like shopping and going into a work location. We see our government backing away from educating the public and rallying us all to work together for the uplift of us all.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>While so many of us were deeply relieved to have less in person interactions, it also created struggles for those of us who depended on day programs for social and emotional and physical needs. It has been a mixed bag. Overall, many of us feel the increased stress of the past several years, both in changed economic realities and in changed abilities to move more freely in the world.</p>

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gastrointestinal disorders, sleep issues, sensory issues, mental health issues
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression, anxiety, anger, self harm, suicide ideation
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Dyscalculia, communication disability, learning disability,
What additional research is needed to help address co-occurring conditions for autistic people?	Women, gender non conforming autistics, impacts of going undiagnosed, how others view autism
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Patient provider interactions could be improved so that autistic individuals feel seen. We need better access to care- many people don't have health insurance
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Positive: remote options for work and school, reduced in person obligations, mask removes perception issues Negative: disruption to normal service routines, restructuring of society, negative health perceptions

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I am an individual who is autistic who has obstructive sleep apnea. One of the most significant challenges that this causes is that those with Autism Spectrum Disorder are often susceptible to having a chronic mental health condition. It is not a causation, as ASD is a neurodevelopment disorder, but it very often happens. Sleep disturbances can absolutely aggravate symptoms of autism as well as co-occurring mental health conditions (whether chronic or not). The reverse can be true that it can create problems, but speaking from experience of having pre-existing conditions, having a chronic sleep disturbance, like sleep apnea, can aggravate the negative traits I experience.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I, personally, don't believe ADHD to be a mental health condition, as it is a disorder that is traced back to childhood. A challenge that can occur related to co-occurring mental health conditions, chronic or not, is lack of protection against discrimination in the workplace if they are hospitalized (voluntarily or otherwise).
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	In my own experience, for those of us adults who struggle with sensory issues related to food, there needs to be access to nutritional therapy as an option.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	One positive impact that, I think, has been helpful for us in increased access to telehealth services.

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep related issues, gastrointestinal issues, immune system issues, issues with feet/gait
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	More research should be focused on providing better medication management for externalizing violent behavior. Relying on antipsychotics isn't ideal because of side effects and not really being efficient
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	In this area, I think the problem is more so allistic people. Schools and the workplace need to quickly catch up in understanding and supporting the disabling aspects of the autistic people. Also colleges need to urgently update their curricula, and start studying the neurodivergent experience
What additional research is needed to help address co-occurring conditions for autistic people?	It's time to start listening to autistic people and really follow their lead. So acknowledge the criticism towards ABA, the hyperfocus on the childhood years at the expense of the lifespan, etc
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Encouraging bilingual individuals to pursue careers related to supporting autistic people. There's a huge need
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Virtual health appointments as well as remote work and school lessons on zoom have been very beneficial for many. Also a heightened awareness of mask use for protecting immunocompromised people

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Being misunderstood or written off by providers
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Being rushed Not giving enough attention to the individual to describe what they are experiencing Not taking us seriously
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Not identifying the problem until it's deeply ingrained
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Equitable access to services Insurance Providers getting better training
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Deep isolation and trauma from society not taking protective measures and precautions
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Negative

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory challenges with eating foods in the mouth and causing dental damage. Visiting the dentist is a challenge due to the sensory inputs and dentist visits are avoided.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety and hyperactivity affect a whole spectrum of my autistic child's daily experiences.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	ADHD affects the ability to focus on academic material being presented in school. Learning disabilities impact this as well.
What additional research is needed to help address co-occurring conditions for autistic people?	Assessment of learning disabilities and accommodations during the assessments to accurately tease out what is causing the specific challenge such as anxiety, sensory input, learning disability, brain functions.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Encourage more staffing and staff to work in the field. Pay for education of staff working with autistic. Encourage person centered planning and training of staff of person centered planning. Encourage private insurance to cover autism services.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Virtual schooling delayed academics for students with autism, especially related to social skills due to the social isolation. Provide more social skills programs to counteract these effects.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	negative effects-reduced staffing at existing programs, long waiting lists, virtual only/telehealth services that don't really improve skills and leave the burden to parents to provide specialized teaching, long waiting lists for behavioral health services/therapy/ABA positive effects-telehealth available when child is sick or can't handle sensory input from going into offices

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>They aren't recognized by medical professionals, and they have no idea how to handle it. Everything is siloed so no one talks to each other to understand what the complexities are. There needs to be cohesion in the medical field, as well as not having universal healthcare means many Autistic people won't get the care they need. Autistic people are mostly unemployed and relying on them to be able to pay for care, when they are excluded from society intentionally, means they won't get the care they need for co-occurring conditions. There are also many autistic people that aren't recognized as autistic, but have all the co-occurring conditions, and instead of saying maybe you are autistic because you have co-occurring conditions that might need to be evaluated, they just slap inappropriate labels on you like anxiety or depression. There needs to be a coordinated effort to remove the silos from healthcare and make it universal so that not only Autistic people, but all marginalized people can get the care they need. This includes instating universal masking in all healthcare facilities because we know Autistic people are more at risk and public health needs to actually do their jobs and prevent the spread of infectious diseases.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>That far too often Autistic people are missed because they majority of mental health professionals don't have any idea what an actual autistic person is. Instead they label us with anxiety, depression, etc. when we are responding to an unsafe world that continues to marginalize us. This is worse for genders other than male, and anything other than white. They are so afraid to consider Autism because of the horrendous stigma associated with it in our society, so they label you with anything else other than that. This means appropriate medical conditions will be missed because they won't see the connection because you are Autistic. Autistic people also lash out because society is not setup for us, so we are reacting to the oppression we are experiencing. This includes in legal circles where being autistic is seen as incapable of existing because it is seen as a mental health disorder. We are humans that deserve to be able to live the life we desire/need, without being oppressed.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>These are not seen as co-occurring in society, they are seen as integral to being Autistic, so they dismiss anyone that doesn't have them as faking. Many Autistic people experience these and should be supported in a way that works for them. Many Autistic people I know have experienced these things, but there just isn't appropriate support, especially if you are labeled with one of these and they won't consider you as being Autistic so you can get appropriate supports. So much is focused around child diagnosis, when so many Adults have been and continue to be missed. Even the CDC doesn't keep track of adults, they focus on kids.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>How to update current health professionals on what Autistic people are actually like. The past research has been done without Autistic people and is still being used to identify Autistic people, including using child evaluations to diagnose adults. This is harmful. There are many Autistic people entering the field and they need to be the focus of the research, because having an internal understanding of Autism is much more accurate than looking from the outside in. There are organizations like All Brains Belong in Vermont that are working to give integrated appropriate care for Autistic people, and it is a much more integrated and supportive way of helping Autistic people and identifying co-occurring conditions and how to support them. They have a program called "All the Things" that identifies so many co-occurring</p>

	conditions and we need more of that type of knowledge and understanding being researched and disseminated to medical professionals.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	First of all identify what they are, and educate current professionals. Universal healthcare because the majority of Autistic people can't work. Understanding that many Autistic people will need accommodations and they aren't wants, but needs. So many healthcare providers to this day refuse to accommodate Autistic people. Systems need to be integrated to support Autistic people because the systems are all siloed and no one talks with each other to support the person.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	First off, COVID-19 damages the immune system among so many other things and it should be prevented for all people and the lack of prevention from the CDC and federal agencies is horrendous. We already know Autistic people are more likely to have bad outcomes than the majority of people. Refusing to prevent infection in the first place is causing significant harm and is increasing the likelihood of them developing co-occurring conditions that may not have been triggered yet. Many Autistic people struggle with sensory issues, so they might not be able to wear respirators and by public health not doing things to clean the air like respirators, upgrading indoor air systems, requiring all buildings to display their air quality so people can decide if the air is safe or not. We do it with water quality, food quality, etc. so we should include clean air. This leads to isolation for many Autistic people leading to worse mental health. Both Trump and Biden administrations have failed in their ability to implement public health measures that actually prevent this deadly and disabling disease.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Inability to get safe care because the risk of infection is too high. Telehealth is being discontinued for Medicare recipients in 2025, so how are we supposed to get safe care when COVID-19 is still spreading uncontrolled through our society. If it isn't safe to get in-person care as well, then you have to forego getting care making any of your co-occurring conditions worse. We don't get to socialize as much as those going about life like there isn't an ongoing pandemic, and contrary to past research we understand how to socialize, just in the appropriate environments.

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Tics, stomach issues, poor proprioception
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Tourette Syndrome, Dyslexia, Dyspraxia, Dysgraphia, Dyscalculia, ADHD,
What additional research is needed to help address co-occurring conditions for autistic people?	Please research tics and Tourette Syndrome/other tic disorders
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Other
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>Sleep disturbances. Sensory challenges. Emotional and mental health conditions. All of these are triggered based on broader population expectations/definition. Without the need to conform to external standards, my sleep patterns would normalize in whatever way is normal for me whether I sleep in 4hr patches or only sleep post hyperfocus investment. I don't consider neurotypicals 'slow' because they don't process as quickly as I do or question their moral character because they seem to be able to lie or manipulate more easily. The more we expand our thinking to allow nuance and authenticity the more accurately we'll be able to assess, treat / avoid unnecessary mental/physical/emotional issues. This question is focused on symptoms, not root causes. Missing the broader health opportunity.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>Same issue as 1st question...focus is misplaced. I don't want more help dealing with mental health triggers. I want to avoid the triggers. If the expectations re: my frequency, pace and depth I'm able to contribute within group structures was adjusted I'd be able to self-manage and regulate.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>Communication, educational, societal and work expectations. Current standards are neurotypical based which is why I'm classified as disabled vs. appreciation for full spectrum engagement/experiences. Without these expectations, 'how I am' or how I function would be accepted. Example: peoples' communication preference could allow for individual capability/comfort. To require conformity creates unnecessary stress/decreases participation/excludes individuals.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>All health aspects need to be reconsidered with spectrum influence in mind. Without consideration for how I'm 'wired', I may not be receiving the correct diagnosis or treatment. Examples: 1) If my system is prone to vit d deficiency, don't just put me on high daily doses. Instead, understand where in the process there are issues. 2. Most behavior modification treatments aren't possible due to overwhelm and need to be prioritized, etc. 3. Understand every patient's capability of reading their own body's feedback. Without clarity at this level, assessment and treatment are mis-informed.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Workplace accommodation. Insurance coverage. Provider knowledge. Service system issues. Understanding of spectrum influence for all diagnosis and treatments is essential for proper care.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>Cognitive fog. Fatigue. Lingering illness symptoms. Have high concern of impact for any auto-immune, hormone disrupted patients, / uniquely neurodeveloped individuals.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services,</p>	<p>Positive - Fewer expectations for social & work engagement. Flex work timing and location. Teleheath removes all of the operational tax (mental and nervous system/sensory) created during travel to and from physical locations...and saved travel time opens new opportunities to receive care. Negative - sensing the strain the covid illness or societal restrictions placed</p>

increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	on extroverts, couples, families, essential workers or anyone who had mask sensitivities.
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Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	gastrointestinal issues, menstrual issues (pmdd, pcos, etc.), sensory differences (which needs accommodation and awareness and compassion)
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	anxiety (accommodation and compassion would help with this), ocd
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Demand avoidance (pervasive drive for autonomy), having communication differences but not having societal awareness and acceptance of AAC
What additional research is needed to help address co-occurring conditions for autistic people?	How do people experience autism and adhd together (as opposed to just autism or just adhd), how can society move to be more accepting of AAC, how can demand avoidant people use strategies to preserve/increase autonomy to reduce nervous system activation, what extra challenges do queer autistic people have to face in society, how can public places be more sensory friendly
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Availability of free resources without requirement of costly professional diagnosis that often gatekeeps certain demographics (e.g., poor people, people of color, queer people) from receiving assistance. Acceptance of autistic people without seeking to fundamentally change them through therapy or other means (being neurodivergent and being neurotypical are both valid and okay ways of existing!)
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Has caused sharp increase in anxiety and depression as autistic people were able to experience more accepting and sensory friendly environments when away from the public but then they had to return to trying so hard to be "normal"
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increased work from home, telehealth options, more flexibility, wearing masks (helps with not having to worry about facial expressions), all of that has helped autistic people, but not all of that is accessible for everyone (not everyone can just work from home and be able to afford their overwhelmingly high rent that way)

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The understanding and notion that these conditions can affect each autistic person in individualistic ways, that sometimes autistic people may communicate these co-occurring conditions that may not necessarily occur in a neurotypical manner or that these conditions may not even manifest in the same way associated with ableist views and so may require more clarity or ways in which autistic people can connect with their needs and communicate them that is more accessible and accommodating.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Co-occurring mental health conditions can occur as a result of burn out, overstimulation, clarity or knowledge on how to recognise what these symptoms look like in an autistic person and again is highly individualised, but that there can be clear and compassionate support and education that not only destigmatizes these symptoms by bringing awareness but also the importance of autistic learning and listening to how these needs are communicated and acknowledging the ways that these needs can not only be met but shared and expressed.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Challenges such as developmental, learning, intellectual and communication disabilities make it extremely frustrating and difficult to feel like there are resources in which to understand that there are different ways and accommodations for different needs and that not only are these resources more than possible and available, they are necessary in that they contribute to a fulfilling and productive life, expanding all different aspects of not only autistic but also neurotypical learning, are essential towards understanding greater humanity and interpersonal development and empathic interconnectedness.
What additional research is needed to help address co-occurring conditions for autistic people?	Ask autistic people about their experience. Ask questions. Ask and really listen. Offer kindness. Ask yourself how can you sit with your needs and recognise what is it that makes you feel that the needs and worlds of autistic people is somehow objective. Recognise that autistic experiences in a lot of ways are the same as yours, that it just looks and functions differently, and that's what makes it so interesting and important. That's what makes accommodating people and families with autistic experiences so wonderful.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Every resource and interaction is care. Anything and everything you can do to accommodate and support autistic needs is supporting their needs.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	The lasting impacts of COVID-19 along with the associated isolation, although the lessened pressure to have to socialise in a typically social environment or setting, still made it so that, although autistic people may have experienced more of the ability to be themselves, the need for connection and interaction is still crucial and in such isolated instances can almost make it more difficult to ensure that those specific needs are consistently addressed, and in ways made navigating more overwhelming and in a lot of ways traumatic, because the ability to have structure and consistency in ways that are important to autistic people, social settings and support included, wasn't available in the same way or at all due to COVID-19, but that it is necessary to have both, now the advancements in both technology and meeting autistic accommodations in addition to social, real-life interactions and connection.

<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>A combination of all of these, and that Telehealth is a viable resource but not a replacement for the very real support and services that are available for autistic people and more, but that these advancements do not have to take away from the benefits of either. That there can be a balance of both technological innovation and societal needs. And that autistic people should be able to have the resources and ability or should not have to feel obligated to either socially engage or distance, should not have to worry about disruption of communication, rely solely on technological means of medical care or have to replace already existing care, and that this is something that should be openly discussed, acknowledged and addressed as part of the autistic and autistic advocacy efforts.</p>
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Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	POTS/dysautonomia
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Having to adjust our communication to be understood by allistic people. The onus is on us to learn how we are misunderstood, to correct misunderstandings, to make our communications softer and more socially acceptable, and to learn social cues. Allistic communication is treated as the norm that autistic people must accommodate.
What additional research is needed to help address co-occurring conditions for autistic people?	The common co-occurring conditions for adult women: ADHD, anxiety, depression, hypermobility, POTS or other dysautonomia, endometriosis or other reproductive issues, chronic pain, GI issues, autoimmune disorders.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage and medical professionals that are knowledgeable about how these conditions present in adult women.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I have Long COVID which triggered POTS, chronic fatigue syndrome, and endometriosis. Learning that these conditions are common for autistic women was shocking. I've observed the patterns of my symptoms, researched possible conditions, and brought my findings to my physicians. They're often unaware that these conditions co-occur in women, especially women with Long COVID and autism. They want to treat each condition as its own separate thing, but they overlap in symptoms and treatments.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Negative: increased social isolation, disruption of routines Positive: ability to work remotely in environments that we've adapted to meet our sensory needs, reduced expectations for in-person social obligations, greater availability of telehealth services, more options for delivery and curbside pickup of food and goods, more services that come to your home or are available online.

Name	Anonymous
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	In my work and personal experience, I notice a lot of sensory processing issues. There's also a pretty significant link to Ehler-Danlos Syndrome in the autism population.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Thinking about impact, one thing I notice is that when you have these multiple disorders, it's really challenging to find strategies to address needs. For example, Caleb is diagnosed with autism, anxiety, and ADHD. But there are strategies that help with ADHD that are difficult to utilize when you have anxiety, for example. The combination of needs can get really overwhelming, and can also be difficult to explain to others when you are seeking accommodations and support. I think a HUGE need is for more education for neurotypical adults (employers, medical providers, etc.) to have a better understanding of neurodiversity and how to support neurodiversity (not through trying to force autistic people to act neurotypical, but by listening to the voices of autistic people about what would meet their needs). It's very difficult for autistic people to be employed, to access services as adults, etc. – often because of the stigma associated with the diagnosis or with needing any kind of supports or accommodations. I think all medical providers and community providers, as well as educational professionals, should have required neurodiversity-affirming training as part of their job preparation.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	It's very difficult to qualify for supports as an adult...for example, in Maine, you have to have ID to get supports as an autistic adult; but many autistic adults have normal or even above average IQ, and that doesn't mean they don't need supports! IQ testing is also a somewhat outdated way of looking at a person's functioning...there are much more comprehensive ways to look at what supports a person needs.
What additional research is needed to help address co-occurring conditions for autistic people?	I'd love to see more research into inattentive ADHD in general, and as a co-occurring disorder; it's much more difficult to treat with medication (most meds are more for hyperactivity) and common ADHD strategies, but makes success in school and life very difficult!
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Policy-wise, I think there needs to be advocacy to have better Medicaid and insurance coverage nationwide of services that support neurodiverse people (not more ABA, but things like executive function coaching, sensory supports, more sessions of OT/Speech therapy that is often really limited by private insurance, better coverage of AAC for all ages, more options for adults and not just children, etc.). It should also be easier to qualify for, and keep, Katie Beckett waivers, nationwide. Katie Beckett should really be an option in every state and run at least somewhat consistently between states for continuity of services when families have to move.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Some things have become easier; for example, more teletherapy and telehealth options make it easier for neurodivergent patients who struggle with getting out of the house to keep appointments and receive services. However, since COVID, previously existing shortages have been exacerbated in so many ways. Our state (and many others) have massive shortages of mental health professional, neurodiversity aware clinicians and medical providers, preschool slots for kids with special needs, etc.

What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Digestive conditions like GERD, sleep problems, migraines
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD, anxiety
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Treatment for co-occurring conditions that is appropriate for Autistic culture and ways of living
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Respect patients when they say no. No more restraint and seclusion and reparations for survivors. Make it more affordable for employees to choose their own health insurance carriers - I make too much money to get a marketplace subsidy but can't afford unsubsidized health insurance, and it is extremely difficult to find providers for some of my more specialized but medically necessary therapies that take my company's insurance.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	While the isolation of quarantine in the early days of the pandemic was necessary, I felt like I could not communicate as effectively when it ended.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I like being able to work remotely whenever I want because I can choose not to interact with others when I am feeling overwhelmed, I don't have to be interrogated every time I display Autistic traits at work, and I can move around as much or as little as I want which helps me focus.

Name	Anonymous
Demographic	Autistic individual; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Many autistic people happen to also identify as trans. As a trans autistic person myself who has conducted qualitative research to better understand how queer, trans autistic folks create and define their identities, I want to be clear that I believe that autistic and trans are two identities that a person can have, but are not co-occurring medical conditions. With that being said, there are many societally biases against both trans and autistic people, and we can see that in the legislation being passed preventing trans youth from accessing gender affirming care. Some states, like Georgia, even want to prevent trans youth from access gender affirming care because of the fact that there are trans autistic people. I believe that there should be more services and policies in place to protect trans autistic youth and allow them to receive the gender affirming care that they deserve.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Many autistic people happen to also identify as trans. As a trans autistic person myself who has conducted qualitative research to better understand how queer, trans autistic folks create and define their identities, I want to be clear that I believe that autistic and trans are two identities that a person can have, but are not co-occurring medical conditions. With that being said, there are many societally biases against both trans and autistic people, and we can see that in the legislation being passed preventing trans youth from accessing gender affirming care. Some states, like Georgia, even want to prevent trans youth from access gender affirming care because of the fact that there are trans autistic people. I believe that there should be more services and policies in place to protect trans autistic youth and allow them to receive the gender affirming care that they deserve.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Many autistic people happen to also identify as trans. As a trans autistic person myself who has conducted qualitative research to better understand how queer, trans autistic folks create and define their identities, I want to be clear that I believe that autistic and trans are two identities that a person can have, but are not co-occurring medical conditions. With that being said, there are many societally biases against both trans and autistic people, and we can see that in the legislation being passed preventing trans youth from accessing gender affirming care. Some states, like Georgia, even want to prevent trans youth from access gender affirming care because of the fact that there are trans autistic people. I believe that there should be more services and policies in place to protect trans autistic youth and allow them to receive the gender affirming care that they deserve.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Many autistic people happen to also identify as trans. As a trans autistic person myself who has conducted qualitative research to better understand how queer, trans autistic folks create and define their identities, I want to be clear that I believe that autistic and trans are two identities that a person can have, but are not co-occurring medical conditions. With that being said, there are many societally biases against both trans and autistic people, and we can see that in the legislation being passed preventing trans youth from accessing gender affirming care. Some states, like Georgia, even want to prevent trans youth from access gender affirming care because of the fact

	<p>that there are trans autistic people. I believe that there should be more services and policies in place to protect trans autistic youth and allow them to receive the gender affirming care that they deserve.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Constipation and sleep apnea are incredibly disruptive to daily life.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Aggression, self injurious behavior, and general lack of ability to regulate emotions is detrimental to daily life.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Intellectual disability means that child cannot possibly function in society.
What additional research is needed to help address co-occurring conditions for autistic people?	Do whatever research you want, but please just help. We need more services that are covered by insurance. Please help.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Better school supports. The school systems are completely overwhelmed and cannot possibly provide the accommodations children need. There's not enough money, there's not enough staff.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Delayed toileting is incredibly hard for young children and families. It inhibits kids' abilities to attend school and summer camps, and is very poorly understood by most care givers. Poor training means kids do not get evidence based supports and are often made to feel embarrassed or are excluded. Sleep challenges are also very hard with limited research on how to better help young children sleep
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD makes it very hard for other early interventions to work. It makes it incredibly hard for families. Finding care and therapies for both is incredibly time consuming and extremely expensive. Parents need someone to help coordinate care and only the very, very wealthy can afford that. Schools are poorly equipped to support students with these co-occurring conditions and they are not given adequate support to learn. There is poor understanding of this occurrence in girls, in particular. It is very hard to distinguish autism symptoms from ADHD from anxiety so diagnosis and monitoring is very hard and, again, falls so much on families. There are not nearly enough providers or affordable providers. Family stress is significantly amplified and good parenting practices are not just logical. Good approaches require unique training - and that training is very expensive, usually offered by private practices if available at all.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Developmental delays and communication challenges make learning very difficult for children and most daycares and schools are not equipped with knowledge, skills and resources to identify and support children with these challenges - especially girls. It is very hard for parents of first born children to identify delays when they are moderate. It creates a significant problem for child learning but standard development tools often do not suffice, especially for girls or for when parents do not know what is 'normal'.
What additional research is needed to help address co-occurring conditions for autistic people?	Medications for ADHD and anxiety Effective, widely available behavioral interventions for ADHD Effective parenting education to manage ADHD, anxiety and autism and effective implementation strategies to teach parents (and caregivers/teachers) Research on visual spatial disorders. This is a common co-occurring condition and the evidence based for vision therapy is promising but weak. Ways to diagnose this at an earlier age, efficacious interventions, and effective implementation. Once we understood this as a part of our daughters autism puzzle it helped to explain a lot of delays but we learned about it late, diagnosis and treatment is very expensive and the treatment evidence based is weak. But it can change a child's life and make other interventions possible if this can be helped in some cases
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance needs to cover services for occupational therapy, speech therapy, physical therapy, vision therapy. There are insufficient providers. Insurance needs to cover in and out of network. Fit of child and therapist matters. Many families sacrifice a lot to stay with someone who fits their child but may be out of network once networks change or all in network providers have a long waitlist. Early intervention is key, so waiting 6 months - 1 year matters. Rates need to be higher for insurance reimbursement. In 2023, An hour with a trained speech language pathologist was reimbursed at approx \$20 out of network and the rest of the cost fell on us. There is no trained professional who is charging \$20. It is absurd. Services are extremely expensive and only available to the wealthy. Finding and registering for and coordinating services is more than a part time job. Families need financial

	<p>help and service coordination help. It feels impossible. Trying to work to have money to pay for the services and arrange for the services and then have enough sleep and energy to appropriately parent very challenging children. Parents need more support. More schools need to be better trained to manage kids with ASD and co-occurring conditions.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	

Name	Anonymous
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gastrointestinal difficulties. Picky eating leading to nutritional deficits.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Pervasive Drive for Autonomy (PDA) profile of autism. Gender dysphoria. PTSD.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Gender and sexuality spectrum (i.e., transgender, asexual, bisexual, etc.) Intellectual developmental delays.
What additional research is needed to help address co-occurring conditions for autistic people?	Reach out to individuals who live these experiences and listen to their perspectives. Ask them what they see as a gap in services/understanding of autism and co-occurring differences. Also, do more research on implementation of supports at various levels, especially the public schools.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Give public schools funding to be used for student mental health, hiring autism specialists to address mental health of autistic/neurodivergent students as well as behavioral health in schools. Insurance barriers with providers who provide therapy for autistic individuals (several of the most qualified providers are not in network with insurances in the area we are in).
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbances and fine motor challenges. My son is 16 and still has trouble using scissors. Fine motor challenges affect basic life skills such as being able to open a package of food, brush and floss his teeth, etc..
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My son's most significant co-occurring psychological condition is intellectual disability. This affects everything from being able to learn, remember, hold a conversation, navigate public transportation, purchase something, etc.. He will never be able to live independently because of this. The second most significant condition is attention deficit disorder. This keeps him from following a conversation, learning in a classroom or other situation, and following directions, which could be dangerous when he's an adult.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The most significant challenge with my son's intellectual disability is that he will not be able to support himself with a job or live independently. He is able-bodied, but his IQ is about 40. He cannot write a sentence, let alone a paragraph. He would not be able to problem-solve if he were a clerk in a retail store, for example. He cannot correctly re-tell what happened to him earlier that day --either because it was not encoded or he cannot recall the events in order or understand cause and effect. I could write a book on this aspect; it is the most heartbreaking and terrifying aspect of his disability, and it is what holds him back the most (more than social deficits).
What additional research is needed to help address co-occurring conditions for autistic people?	We need an effective treatment for cognition (intellectual disability). The additional research required is (1) understanding how the brain represents and processes information in a logical, goal-directed way (eg problem solving / reasoning). (2) Treatments need to be developed to improve the information processing systems underlying cognition. There is a lot of emphasis on treating anxiety, depression, and other non-cognitive aspects. Those are important, but there is an absolute paucity of treatments that could address intellectual disability itself. NIMH has a few relevant programs, which could be leveraged much, much more to develop novel treatments.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	The myriad systems and their requirements are overwhelming to navigate, even for high-achieving parents. How will an adult with autism/IDD navigate this when the parents are not around anymore?
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	There were no lasting effects in my son's case, thank goodness, but the virtual school in Spring and Fall 2020 were completely useless for him. He was unable to engage at all with his teachers via Zoom, even when I sat right next to him prompting him to attend and respond to his teacher. After weeks of this, I gave up. It was a lost year where he just sat at home, watching YouTube on his phone until in-person school restarted. It was a very impoverished experience for him.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on	As I mentioned in the previous question, the virtual school was useless for my son; he was unable to engage via Zoom at all. For a while, his Applied Behavioral Analysis (ABA) services also stopped, which had been his only way

physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	of learning anything since he was 18 months old. (He is unable to learn at school because it's insufficient repetition, which ABA addresses). However, in-person school does serve the function of providing social interaction, so he missed that during the pandemic. During the shutdown phase of the covid pandemic, he had nothing in his life at all except interactions with me, who had to work remotely fulltime, and my daughter, who was facing her own struggles with virtual high school classes.
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Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory and motor difficulties
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety and ADHD
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication disabilities
What additional research is needed to help address co-occurring conditions for autistic people?	We honestly need more research on all fronts. Actual funded research, not just a million people telling their experiences
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage for all autism related support would be awesome. Being taken seriously by healthcare providers would also be great.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It has made it even more difficult as far as the communication and social aspect. I was terrible before and now I'm terrible and out of practice.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I like that telehealth is so much more common.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The most significant challenges I face physically are with gastrointestinal issues and sleep problems.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have struggled with suicidality and an eating disorder, but I think experiencing eating disorder treatment was the most challenging thing I've faced.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	I think research into treatable gastrointestinal conditions and sensitivities could be helpful. The research I see is often on the connection autism has with the gut biome, but I don't find it helpful because I don't know how I could use it to improve my digestive issues.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I think there should be more research on what treatments would help for autistic people with eating disorders. As I understand it, autistic people have higher rates of eating disorders, but I didn't feel like my personal challenges were taken into account when I underwent treatment. I think there should be more consideration for people who struggle with group based treatments but need more intensive care than once a week therapy appointments. I think research into how healthcare workers and mental health workers can better communicate with autistic people would be beneficial. Professionals failing to speak with me directly in a concise way is something I find very frustrating about pursuing treatment, and is often a barrier for me.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Being systematically dismissed by medical doctors for chronic pain, specifically in my experience, pain related to Ehlers Danlos Syndrome. I began having symptoms almost a decade ago, and am now close to getting a diagnosis and treatment only because I did the research myself on chronic pain conditions that co-occur with autism.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Being given the wrong treatment by mental health professionals, combined with (and likely caused by) a lack of mental health professionals who are themselves autistic, or at least educated about the autistic brain. I was diagnosed with depression and anxiety long before autism, but the treatments involved being more social, masking more, going to places with more sensory input, etc. I was also put on many SSRIs, which are known to affect autistic people differently. I now pay \$160 per appointment to see an out-of-network autistic therapist, because I don't trust non-autistic therapists to understand what's actually going on in my brain.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	There needs to be much more research into Ehlers Danlos system, a the EDS "cluster" in general: EDS, POTS, and MCAS. It would greatly benefit autistic people, particularly autistic women who are disproportionately affected by EDS, if the diagnostic process were faster and more available, and if medical doctors were actually educated about the process and willing to initiate it. It would also be extremely beneficial to understand what gene causes hEDS, and better treatments for the issues that faulty connective tissue causes. It would be fantastic if the treatments for the various EDS issues could actually be integrated into the various medical specialties, so that someone with EDS seeing a gastroenterologist for EDS-related issues would be able to get EDS-specific care from an in-network specialist, rather than resorting to their own research and out-of-network EDS specialists. Specifically for me, more research into how EDS affects TMJ and craniocervical instability, how to better diagnose and treat these problems, would be fantastic.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I, personally, have 0 services and supports, for autism or any co-occurring conditions. So for me, any services at all that could meet my support needs would be an improvement. I think the biggest issue for me is that I'm ASD Level 1, and therefore tend to be considered not disabled enough to get support. My support needs may be low but they aren't nonexistent. I personally, because of autism plus EDS, which are both "invisible" disabilities would greatly benefit from: Health insurance that actually covers autistic therapists and EDS specialists Doctors who are actually educated in EDS and how EDS affects their specialty Paratransit for getting to and from medical appointments No or low cost prescription and grocery delivery Doctors who are educated about the autistic brain, so I don't have to mask in order to get my pain taken seriously More places to sit down, especially with back and neck support, in public spaces Affordable treatments for the various issues that EDS causes, perhaps with no referral or prescription required

	<p>(pending safety issues of course) Policy of immediate referral for EDS evaluation for a female autistic who complains about chronic pain Policy of actually taking chronic pain, especially in women, seriously Free legal advice for requesting reasonable accommodations at work for chronic pain issues (and autism as well) Disability benefits that I can get even if I'm working</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Increased remote work and healthcare has been the single best thing that has ever happened to my mental and physical health as an autistic person. I wish that things would go even farther, and that the default (professionally, socially, and medically) would be that everything is done virtually, and move to in-person only if virtual doesn't work. However, I do find that it's harder to see a medical doctor now. Doctors are quite booked up and like to get through the appointment as quickly as possible.</p>

Name	Anonymous
Demographic	Autistic individual; Service provider, health provider, or educator; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbances
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	obsessive compulsive disorder, suicidality
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Expressing need for accommodations without receiving stigma
What additional research is needed to help address co-occurring conditions for autistic people?	Alcohol and substance use
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	insurance coverage for things that ARE NOT ABA. More provider education on best practices for supporting Autistic individuals of all ages.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Getting medical providers to understand that every single medical condition isn't always caused by autism.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Most people don't know how mental health conditions are affected by autism.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Doctors don't often know if other disabilities can lead to problems with autism.
What additional research is needed to help address co-occurring conditions for autistic people?	How co occurring conditions affect people who have autism in multiple ways.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Access to doctors who have an understanding of autism across the lifespan.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	They haven't been able to get access to information about the coronavirus that they can use.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	More use of video conferencing for meetings and some activities.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	It varies. All of us autistics are different.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Again it varies. But I do get anxiety and depression time & time
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Just uphold the not about us without us motto and understand that we're all different and that while autism itself isn't a mental illness, many of us autistics are prone to *getting* mental illnesses and that to get respect especially from us you have to give respect.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Well basically the same thing I said in the previous question. You can use that when training not just healthcare folks but also businesses, law enforcement, air travel workers, you name it.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Well for me, I just simply kept getting chills time after time even after my Covid wore off.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	All sorts of things for me. I struggle to find quality friends. Then again lots of people do regardless of neurotypical/neurodivergent status.

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Joint pain (EDS), dizziness/fainting (POTS), anaphylaxis (MCAS)
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	sensory and motor challenges
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	aggressive and self injurious behaviors
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	communication disabilities
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	insurance coverage and equitable access to services
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	disruptions in services

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gastrointestinal disorders, sleep disturbances, communication issues, sensory challenges
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, self injurious behavior
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Developmental disabilities, communication disabilities.
What additional research is needed to help address co-occurring conditions for autistic people?	Research of how we can benefit children at an early age with communication
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage, educational opportunities, alternative therapy access
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Furthered the gap of social and intellectual developmental and access to educational services
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	To me as an early interventionist, the biggest challenge faced by individuals with autism who also have co-occurring conditions is that client education on those conditions is frequently nonexistent. Client education on autism itself is infrequent as well, but if a second (or third) condition is present, I myself find it difficult to recall a time when I observed someone explain that condition to the client. Unexpected physical/mental sensations are frightening enough for neurotypical individuals. Providers and care team members need to take the time to explain all components of a neurodiverse client's medical history to that client, not just the client's guardian or caregiver. And after the client reports an understanding of their secondary condition (or their understanding is assessed), the client can be taught how to manage it and advocate for themselves.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Since there is such frequent overlap in symptoms from one mental health diagnosis to another, it's difficult to parse out which symptoms are solely "autism" symptoms and which are symptoms of another diagnosis. The DSM-V-TR has yet to catch up with self-advocacy efforts from those on the spectrum and living with other mental health conditions, and providers from all disciplines tend to not receive training on neurodiversity unless they specifically seek it out. Additionally, mental health conditions including autism are so frequently caricatured in various media that public misconceptions and judgments about this population abound. There is an insidious assumption within society in general that having a neurodiverse brain is somehow a comment on one's intelligence or capabilities, especially in the workforce. Finally, self-advocates tend to receive a lot of pushback, and mental health is regarded as an extremely touchy subject by a lot of people.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	fMRI, EEG, and other imaging data to capture structural variations in the brain among those with different neurotypes and conditions
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	See previous response. Also, the healthcare system in the US is, to put it mildly, difficult to navigate. Neurodiversity should be presented to every new patient along with an itemized list of resources, and they can disclose their neurotype if they want to. Self-advocates should be seen as the experts. Common behavioral variations such as speaking directly or louder than expected should not be assumed to be coming from a place of intentional hostility.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal	

changes: disruptions in services,
increased remote work and school,
increased use of telehealth, reduced
in-person social interactions and
obligations)

Name	Anonymous
Demographic	Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	sleep, motor challenges, eating, learning abilities
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	aggression, stressed, confused, anxiety
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	routines, how to handle outbursts
What additional research is needed to help address co-occurring conditions for autistic people?	communication with families, and individuals with autism
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	lack of resources accessible to all
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	academic skills are set back, reduced social interactions

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory and motor challenges
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Attention deficit injurious behavior
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Developmental disabilities and cognitive disabilities
What additional research is needed to help address co-occurring conditions for autistic people?	Visit families and know their experiences impacted by autistic people in the family
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Work collaboratively with family and school and see closely where they need help with Parent be educated
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	A lot they were home bound
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Break in providing regular service

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Diagnosis. Describing symptoms is difficult for many autistic patients so physicians need training on asking more specific questions and giving examples to help accurately assess a patient
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Lack of understanding in schools and the community
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Lack of support for individuals and their families. Getting appropriate behavior support is critical but very difficult. Most providers will not accept patients with both commercial and Medicaid coverage. It's impossible to find care
What additional research is needed to help address co-occurring conditions for autistic people?	Early diagnosis and treatment
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Dual insurance coverage needs desperately to be addressed! Families cannot find any psychiatric/therapy providers and cannot just pay out of pocket
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	More anxiety and isolation
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increased use of telehealth has been very positive. Insurance should keep covering that. The serious lack of behavioral staff is a huge problem. DSP, BCBA, RBT, etc are so hard to find and keep.

Name	Anonymous
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	One of the biggest challenges we face as parents is trying to identify what condition is causing a challenge so we know how to address it. For example, are we having difficulty potty training because it's our daughters personality (stubborn), is it related to her Autism (intellectually/developmentally and/or sensory), and/or is it related to her GI disorders?
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	When seeking out services of support, often they want to box people into neat categories. But when you have a child with Autism and ADHD, the boxes blend.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	It is very hard to find a community of support when you have a daughter with a rare genetic condition whose primary form of communication is using an Aug Comm device.
What additional research is needed to help address co-occurring conditions for autistic people?	Resources. Researching the brains response to different stimuli to help better understand how the multiple diagnoses play a part and which ones are the "cause" of specific challenges.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage is an ongoing battle because diagnoses blend into one another and they either don't cover a beneficial support (i.e. vision therapy) that is needed for autistic people. Or they want to limit the amount of support received (i.e. not allowing an ABA provider to work with a Hab provider to bring a team model to the autistic person and their family).
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	This is where research needs to be done. We have an almost 13 year old daughter who is incredibly bright but also significantly delayed and we are just guessing how/if Covid-19 impacted her emotionally and medically.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Before Covid-19 we had an incredible support system of providers in our home that walked alongside us and supported our family holistically. We lost those providers due to in-person services being suspended and we have yet been able to find replacements.

Name	Anonymous
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Continued lack of integrative treatment knowledge and approach between disciplines complicates care, confuses the individual and parents, and misses critical opportunities to address foundational health elements for quality of life.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The lack of entry into traditional mental health services is massive-every wrong door. Providers lack the knowledge, training, and willingness to serve ASD and SMI jointly, find reasons to prevent admission, and often find many ways to prematurely discharge patients if admitted. Environments of care are not set up to address sensory issues, provide for sensory regulation spaces, and often place this vulnerable population in a position to experience distress. Crisis systems, including 988 are not trained effectively (or at all) to address this population and instead further increase the likelihood of police response and a negative outcome. CCBHCs and URCs are not accessible to those with ASD and SMI, again, many of the reasons listed above. State mental health systems and statutes exclude treating patients with ASD-pushing their care to human services agencies who are not equipped to address the mental health needs. This leads to unserved needs and continued suffering. We have so much work to do and need to force government systems to integrate-not merely suggest or show this as best practice-because left to choose to do better-the have not and will not.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Incarceration
What additional research is needed to help address co-occurring conditions for autistic people?	Include diversity of location, culture, race, ethnicity.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Coverage for treatment-including access without barrier.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services,	

increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Anonymous
Demographic	Autistic individual; Other
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>There is significant indication that autistic individuals not only experience higher than normal instances of co-occurring physical health conditions, but that these instances contribute to an overall deleterious occurrence of allostatic load, an outcome that is now demonstrated to, itself, be a cause of continued co-occurring physical health conditions: https://www.nature.com/articles/1395453 Both my husband and myself suffer and struggle with this as a direct result of autistic burnout, caused by significant and harmful neuronormative bias in literally every aspect of our daily interactions with the culture and systems of our nation, but in particular, the workplace. Anxiety, depression, gastrointestinal disorders, sleep disturbances, high blood pressure, sensory and motor challenges are but the tip of this iceberg. I suffer with fibrillation, fibromyalgia. skin, joint, and soft tissue algias, and degenerative disc disease. Serious consideration needs to be given to allostatic load and its effects on autistic co-morbidities.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>They are ALL significant challenges in that this culture and society does not truly accept our neurotype and phenotypes are a normal and natural expression of human genetics. This means that, no matter our co-occurring mental health conditions, or their co-morbid physical health challenges, we are constantly beset by devaluation, dismissal, derision, gaslighting, and more and this is FROM THE MEDICAL AND MENTAL HEALTH PROFESSION, before we even GET to daily interactions and engagements. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8115954/</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>Allistic, ablest, and neuronormative biases in every interaction that is NOT with autistic humans. Active and often intentional discrimination over learning, developmental, intellectual, and communication differences in every avenue of engagement with the greater and majority neuronormative culture and society. I left the last job I was able to get over this and filed an EEOC complaint and they declined to even try to depose and discover the truth of it. According to them, because I didn't allow myself to be further abused, I didn't have a case. Now I'm out not only the job, but the ability to see this company brought to justice for bullying over my communication differences and the profound discrimination and denial of my autistic being.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>There needs to be a much deeper understanding of how allostatic load contributes to autistic co-occurring physical health issues and how this frequently causes on-going or extremes of autistic mental health issues. There needs to be a MUCH greater effort to integrate neurodivergent differences and eliminate neuronormative bias. There needs to be meaningful and prohibitive outcomes for those who insist and persist in discriminations against the autistic, and there needs to be accelerates education in all industry domains, but particularly the medical and mental health ones to assist autistic people in protecting their agency, autonomy, and lived experience authority (these being the first things that come under attack, which, frankly, should be viewed as human rights violations).</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>All of the examples you mention are highly needful and often overlooked today and in particular, insurance coverage for both child and ADULT assessment and support services. Elimination of the detrimental pathological model in the face of emerging neuroscience and neuroanatomy that demonstrates autism is a unique neurotype and phenotype, not an "abnormality". Education and a requisite minimum training for both medical and mental health professionals to attack and uproot the vestigial remnant of early American eugenicists and neuronormative supremacist bias</p>

	<p>so that autistic people are not regularly sub-humanized in their attempts to secure and enjoy the basic medical and mental health care they deserve and need.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>The impact of COVID-19 on individuals with autism spectrum disorder (ASD) is complex, involving heightened vulnerability to certain medical conditions, leading to severe outcomes if infected. Healthcare disparities and lack of insurance support compound challenges in accessing timely medical services. The pandemic introduces stressors like anxiety and depression, exacerbated by uncertainties and disruptions. Changes in routine and social isolation pose significant challenges, impacting mental well-being. Educational disruptions, including school closures and shifts in learning formats, create stress, while support services face disruptions. Personally, as someone with autoimmune issues, I feel unsafe in an unmasked and unvaccinated population, unable to risk adding COVID to my challenges. Addressing these issues requires strategies to reduce healthcare disparities, provide mental health support, and ensure educational continuity for individuals with ASD. Public health measures should prioritize vaccination for this vulnerable population, and awareness campaigns can foster understanding and support. A comprehensive, nuanced approach is crucial to meet the unique needs of individuals with ASD during these challenging times.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>See previous response. EXTENSIVE and life-altering, not to mention exacerbating to all existent, autistic challenges.</p>

Name	Anonymous
Demographic	Autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbances, co-occurrence of hypermobility disorders, autoimmune disorders, sensory sensitivities including food aversions (to food texture, etc.) which cause highly restrictive diets, GI problems, fatigue
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Trauma/PTSD; depression; anxiety; ADHD; suicidality; co-occurring developmental disorders such as Turner's Syndrome, Klinefelter's Syndrome, etc.; psychosis; bipolar disorder; dementia; intellectual disability, gender dysphoria
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Learning disabilities, developmental disabilities, intellectual disabilities, communication disabilities
What additional research is needed to help address co-occurring conditions for autistic people?	Research may be needed about how autism relates to different kinds of developmental disabilities. What does autism "look" like for each co-occurring developmental disability? Research may be needed about whether early autism diagnosis/intervention helps prevent additional mental health and physical health conditions down the road.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage, especially for psychological testing Education for clinicians about co-occurring conditions and easy access to this education (i.e., affordable classes/training) Funding for therapy and other services for people who make too much to qualify for Medicaid, who are uninsured, or who are underinsured (due to poor quality health insurance plans).
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Autistic people often have physical health concerns and anxiety about their health, they may have isolated more than others during the pandemic, and may continue to isolate, having a difficult time adjusting post-pandemic. This may have affected their self-esteem and anxiety levels. Autistic people may use face masks to try and mask their emotions, facial expressions, etc. without knowing that they are doing this. They may feel safer with a face mask in in-person social situations, and it may help them in some ways, harm them in others.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	Remote work, school, and healthcare may have helped some autistic people communicate and socialize more easily, learn more effectively, and get work done. For other autistic individuals, remote communications may have had a predominantly negative effect on day-to-day effectiveness, and emotional and social learning and growth. Many autistic people may have experienced both positive and negative effects from pandemic-related societal changes. Reading body language is harder to do when meeting with someone remotely. Autistic people's ability to read others' body language and be

in-person social interactions and obligations)	aware of their own body language and emotions (due to lack of feedback from others) may have been affected.
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Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Auto-immune, skin, and soft tissue issues (e.g., fibro, mcas, and polyalgias)
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Inability to hold jobs, discrimination in workplace, neuronormative bias, and failure of SSA to appropriately support these causes of autistic burnout and related depression.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Neuronormative bias causing autistic burnout, compounding depression and anxiety.
What additional research is needed to help address co-occurring conditions for autistic people?	Longitudinal study on allostatic load and its contributions to depression, diabetes (type 2), high blood pressure, afib, and auto immune disorders.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Everything. I have never been able to hold a job more than four years in my over 30 year career (now58), and am now utterly unable to work due to autistic burnout, cPTSD, major depression, and a raft of comorbid illnesses that include afib, fibro, diabetes type 2, and both joint and soft tissue algias, gastro issues, and intrusive, persistent tinnitus, and still cannot obtain SSI supports. It's like ya'll just want me to die.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Terrified to go anywhere because I am already immune compromised and no one will enforce public safety masking or immunization. Haven't left home but for doctor appointments in over eight years. This does NOT help my already struggling state of existence.

Name	Anonymous
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Feeding issues. Fine motor issues.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Suicidality.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication disabilities.
What additional research is needed to help address co-occurring conditions for autistic people?	Self advocacy
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Accessibility of services
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Increased anxiety.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Positive: increased remote work and increased use of telehealth. Negative: perception that Americans don't care enough about people with disabilities to use prevention strategies consistently

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My adult son has severe anxiety and multiple physical health conditions including Autism. Because he has IDD, his comprehension is poor, and he fails to understand what is happening. He has can suffer from insomnia, sleeplessness, sensory overload, and other issues. Then, he can rage, which results in potential harm to his caregivers, his physical surroundings, and his own well-being.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My son has behavioral pathologies that are pervasive and can severely compromise well-being, to the point of being fatal. These include aggression, property destruction, and elopement. Aside from death, these "challenges," are traumatic and potentially lethal. Besides being traumatic for everyone involved, this results in the need for emergency medical treatment, crisis and challenges locating staff assistance. This imposes enormous costs on families and care systems. Reducing the frequency and intensity of these pathologies needs to be a goal for autism treatment and research, as they can result in death or further serious disability.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication, finding qualified staff, retaining staff, finding, and retaining employment, burnout, finding medical professionals who are willing and qualified to treat, etc.
What additional research is needed to help address co-occurring conditions for autistic people?	We need help preventing aggression, psychiatric medications, and behavioral/sensory treatments. More emphasis must be placed on the needs of adults who often lack access to appropriate care and whose dangerous behaviors cause enormous burdens to families and care providers.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Both private and public insurance should cover both outpatient and inpatient care for behaviors associated with Autism. A new insurance code should be created to correspond with these clinical impairments, and treatments must be recognized as medically necessary under mental health parity. We need to create a much larger network of care providers in all states to address the care needs. Some individuals with Autism require a therapeutic model of long-term residential living with onsite or collaborative psychiatric and medical care. Medicaid and other funding should directly and realistically address the needs of those dealing with significant autism.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	A feeling of lack of safety, instability, predictability.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	My son lost his employment which he had for 13 years because of Covid. When it was over, because of staff shortages, he was unable to locate a job coach. His mental health and self-esteem suffered significantly. This has been devastating. My son lost his employment which he had for 13 years because of Covid. When it was over, because of staff shortages, he was unable to locate a job coach. His mental health and self-esteem suffered significantly. This has been devastating. He became more isolated and depressed. He cries a lot.

Name	Anonymous
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	lack of resources in school to help those with autism and co-occurring health conditions, lack of mental health professionals trained to help those with coping skills, lack of specialists who understand the multiple medical conditions in those with autism (more NPs and Drs need training on those with autism and developmental disabilities)
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	DDD needs to stop providing parents as paid providers to those under age 18 as it is causing mental health issues for the members. It is creating a reclusive environment, families quitting jobs and pulling kids out of school and day programs to get paid and capitalize off their children. Members deserve autonomy and need to be away from parents.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	lack of resources and trained professionals (doctors), no ABA programs or similar
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	more ABA and peer play environments, trained professionals, more specialized schools or more resources at the schools, pay more to entice people to move out here
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	parents as paid providers for underage kids has created a HUGE long term negative impact on the members, there is no more inclusion or autonomy, parents are greedy and just want a free paycheck, it should have never carried on this long, it is damaging the members
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I have not seen too much other than maybe a little regression in school or interaction with peers as people were not engaging much in person, lack of good medical care as it was all telehealth

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep Issues, Developmental Coordination Disorder, Expressive/Receptive Language Disorder
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD, Severe Intellectual Disability, OCD, Specific Phobias, Elopement, property destruction.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Severe intellectual disability impacting learning and quality of life. Severe expressive and receptive language challenges making it almost impossible to function in the world.
What additional research is needed to help address co-occurring conditions for autistic people?	We need all kinds of research across disciplines: 1. Better diagnosis 2. Better treatment
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Having trained providers who know how identify and treat autism and co-occurring conditions. Insurance coverage and access to treatment. In the DD system, they are not prepared to deal with co-occurring mental health conditions.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	COVID -19 caused a huge disruption in services that we have yet to recover from. The pandemic caused regression and huge loss of skills in our son.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	We had a provider shortage prior to the pandemic that is now exacerbated. Telehealth was helpful during the pandemic and still is. We are still in the process of recovery from the pandemic.

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Our daughter has gastrointestinal, sleep and sensory problems. These affect her daily life.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Our daughter is on medication for anxiety and depression. She did not like the side effects from the ADHD medication she was on. She also has thoughts of not wanting to be here any longer.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communicating her thoughts are very difficult for her.
What additional research is needed to help address co-occurring conditions for autistic people?	Additional research is needed in helping to identify autism in females. Our daughter was diagnosed at 17 because professionals were always looking for “other” things. At this age it’s very difficult to find services for her.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage, services for older children/young adults
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increased remote school was difficult for our daughter. Not being able to see a doctor in person and not being able to find doctors that help with autism in old teens.

Name	Anonymous
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Pathological Demand Avoidance
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Pathological demand avoidance and aggression
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Pathological demand avoidance
What additional research is needed to help address co-occurring conditions for autistic people?	recognizing, treating, and interacting with pathological demand avoidance.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Public and professional education on pathological demand avoidance. And services for severely behaviorally challenging individuals.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Those with autism, particularly those with severe autism often struggle with multiple co-occurring physical health conditions that makes them struggle more. My son is deaf and epileptic along with being non-verbal, has limited communication and often destructive behaviors that result from an inability to be understood and frustration at not being able to communicate his needs. His medications for seizures also cause constipation which can greatly affect his well being.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	my son struggles with aggression because of his limited communication skills and inability to focus on one task for more than a few minutes.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	More funding needs to be placed on those with the most severe autism needs. Those who cannot take care of themselves and will need lifelong care. How are we as parents supposed to ever be at peace knowing there may not be anything or anyone in place to take care of our children when we are gone.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage is a huge obstacle. So much of my son's ABA therapy gets denied and we are caught in never ending loops of appeals and denials. Also, there is no understanding of the individuals who review requests for things that help to make our lives easier such as specialized strollers and beds to keep them safe. We have been denied through insurance more times that I can count. Also, many providers have no idea how to address someone who is not only autistic but also deaf. I am always explaining and advocating for him.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Severe challenging behavior like aggression to others, aggression to self, destruction of property, eloping (i.e., running away)
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Many individuals with autism do not have communication skills, which is why they often resort to challenging behavior. Many autistic people cannot speak, contrary to what shows like Atypical and Love on the Spectrum and vocal autistic advocates would have you believe. These individuals do not have a voice to advocate for themselves and their needs are often overlooked and ignored.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	The resources required to assess and treat severe challenging behavior using evidence-based procedures (i.e., Applied Behavior Analysis) are often expensive and the current reimbursement rates for ABA therapy are the same as those that cover early intervention for younger learners, which can be provided with far fewer resources. Therefore, providing severe behavior services in ABA clinics is currently cost-inefficient.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	in both my professional work and experience in being a stepparent to an individual with moderate ID and Autism, I think gastrointestinal disorders (constipation primarily) and sleep disturbances are the most significant challenges health conditions impacting autistic people. In addition, I think sensory challenges related to ASD, make it more challenging for individuals to function in today's society.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Firstly, I do not see aggression or self injury as a stand alone mental health struggle, these are symptoms that are used to COMMUNICATE struggles. Anxiety is a MH condition that is commonly seen, this appears related to sensory needs, being overwhelmed in their environment, change and lack of structure or routine. Depression appears often and can be related to a lack of PERMA+ and the inability to engage in meaningful activities, build positive relationships with peers (as many relationships are with paid supports or family), and not being able to flourish in their life's. The lack of choice and decision likely also impacts the development of depression. In addition, I think the most underdiagnosed and often overshadowed MH condition that impact people with IDD is trauma.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I believe communication challenges is one of the most impactful, when they do not have a method to communicate what they want/need/think, they are more likely to utilize externalized symptoms (aggression etc.) to communicate that something is occurring for them. To co-morbidity of intellectual disabilities, also leads to additional challenges most commonly with their executive functioning.
What additional research is needed to help address co-occurring conditions for autistic people?	more research on the presentation of MH conditions for people with ASD is necessary, we know the symptoms present differently, but this needs further investigation that can lead to quality training for psychiatrists and NP and therapists. In addition, the same can be said for medical providers. research to better understand how symptoms may present, since the individual may not be able to clearly communicate their pain or symptoms, leading to effective training for medical providers.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	people with ASD often fall through the cracks between IDD and MH services. but the facts are, people with IDD have a higher rate of MH conditions than the neurotypical population, but the MH services are NOT prepared to support them.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	lack of providers virtual supports rather than in person lack of staff
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school,	provider changes increased virtual supports closed programs lack of staff

increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Anonymous
Demographic	Autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory processing
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication disability - lack of knowledge about aac, false idea that spoken language is best
What additional research is needed to help address co-occurring conditions for autistic people?	More research into hyper mobility
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Assistance navigating healthcare and insurance systems, improved provider knowledge
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Ehlers-Danlos Syndrome, POTS, autoimmune, chronic pain and migraines.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, depression, auditory processing issues, sensory processing challenges, suicidal ideation and ADHD.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Sensory processing disorders, language processing disorder, auditory processing disorder, reading comprehension challenges.
What additional research is needed to help address co-occurring conditions for autistic people?	Research in genetics and treatment options for co-occurring conditions. Especially in more natural, Integrative approaches.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Parent support! (Financial and physical support), more tax breaks for all the money spent on healthcare for children and self. Better insurance coverage for services that actually help autistic people (not ABA therapies). Therapies tht support and not try to change the autistic person. Trainings for providers who are directly working with autistic individuals. More trainings on high functioning autism autistic presentation in girls and women.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	After having covid 19 I developed an autoimmune disease.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Positive impact in increase in working remotely and telehealth services.

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep issues
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression Suicidal ideation Anxiety
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Dyslexia
What additional research is needed to help address co-occurring conditions for autistic people?	Personal conversations with the autistic community
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Support early in school and home life. Community support for all families regardless of income
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory processing(loud noises, bright lights, food textures). A lot of autistic individuals, including my high supports needs child have a very limited diet due to sensory overload with certain food tastes or textures. This can also lead to teeth issues due to the sensory issues with teeth brushing as well. Executive function problems (cooking, making phone calls, grocery shopping, paying bills, and keeping up with hygiene). Many autistics have trouble with sleeping, falling asleep and staying asleep. Gastrointestinal issues such as constipation is an issue due to limited foods eaten, ARFRID being an eating disorder that contributes to this. Many autistics have fine motor skill issues (struggling with food utensils, drinking from a regular cup, holding a pencil properly). Many autoimmune diseases tend to also be comorbid such as ehlers danlos (connective tissue disorder), epilepsy, thyroid disorders, Crohn’s disease, IBS. Other comorbid issues common include ADHD, anxiety and depression. Mental illnesses being a major factor in the high suicide rates for lower support needs autistics.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Executive dysfunction making it hard to take care of basic hygiene (brushing teeth, bathing). Having a hard time making phone calls for appointments, going grocery shopping, cooking, and keeping up and paying bills which further exacerbates depression and anxiety. The anxiety makes getting a job difficult due to having anxiety and having to have interview to which eye contact and certain characteristics being more appealing to an interviewer which furthers ableism. Meltdowns due to sensory overload can cause autistics to self harm. All the these issues go back to the case of high suicide amongst autistic individuals.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Lack of communication due to speech delays that can include apraxia of speech. This makes communication hard for the individuals needs and hard to determine needs by caregivers. This also makes it hard when going to school and being able to participate with peers (a truly inclusive environment) in social interaction as well as teachers and other care providers. The lack communication can lead to meltdowns that can sometimes cause self harm. Learning disabilities such as dyslexia, dysgraphia and dyscalculia make it challenging for the individual to succeed in their education while also causing self esteem issues and behavioral issues when not receiving proper supports and communication devices to have success.
What additional research is needed to help address co-occurring conditions for autistic people?	Further research could delve into identifying specific genetic and neurobiological mechanisms that contribute to the co-occurrence of conditions in autism. Understanding how these factors intersect may guide the development of targeted treatments. Additionally, exploring the role of early intervention and assessing the effectiveness of various therapeutic approaches for individuals with multiple conditions could enhance overall care. Investigating the influence of environmental factors, such as socio-economic factors or access to support services, is crucial to creating comprehensive strategies for managing co-occurring conditions in autistic individuals.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More awareness within communities such as school on neurodiversity. More education about how autism presents differently in females at birth in order to give assessments to those that might go unnoticed. Insurance coverage for autism evaluations as well as co-occurring conditions such ADHD and other learning disabilities, without any age restrictions. Insurance coverage for other therapies besides ABA. Additional covered therapies should include occupational therapy, speech therapy, DIR floor time therapy and any other

	<p>therapies that will work out better for the individual based on what works best. Insurance coverage for low support needs autistic adults such for therapy and/or coaching. Autistic burnout for low support needs autistics is a problem that also needs addressing. Autistic children become autistic adults. They don't disappear and neither do their needs. Health care providers should know more about autism than what has now become outdated and just include stereotypes. Autistic adults, even those considered low supports should have access to services to help individuals with jobs (accommodate for autistic needs), housing, mental health services, etc.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>High support needs autistics thrive in routine and can become dysregulated when those routine structures are taken away. Regression also tends to occur along with it. Some autistic people thrive in quiet environments without the loud noises and other sensory overload that comes with school/work. Autism is a spectrum so needs will vary on a case by case scenario.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>For some autistics a net positive during COVID-19 was remote work, remote schooling, more available grocery pick up and delivery options, as well as Telehealth appointments. Social interactions can be extremely distressing for autistics which can cause anxiety, depression and meltdowns. The ability to focus on work or schooling without distractions and the social interactions that can hinder the ability to succeed in those environments.</p>

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	sleep disorders, sensory processing issues, EDS/HDS
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, ADHD, Suicidality, depression
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication differences
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Joined up services, mentors to help navigate the system!
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Scarcer services (negative), more remote services (positive)
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Negative - disruption, increased health anxiety, more illness, longer waiting lists Positive - more work from home, more telehealth,

Name	Anonymous
Demographic	Family member of an autistic individual; Other
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>SAFETY HEALTH AND WELLBEING are severely compromised having a diagnosis of SEVERE/PROFOUND autism. You are ignoring this population and this needs to change. "Neurodiverse" folks needs support too but you need to see that given their social limitations, they are "hijacking" the important conversations. No-verbal/speaking people have been ignored for too long. Seizures, self injury, severe panic, OCD, GAD, IED, DENTAL PAIN that goes ignored, and PANS/PANDAS ignored testing is causing. This is not a life - these co-occurring conditions are a death sentence. No programming, no residential, no agencies will take severely affected people with ASD IN ANY STATE. Families are broken, taken out of the workforce, injuries, use of 911, psych hospitals that cannot "handle" ASD, ER rooms putting people in restraints, excessive use of antipsychotics with no efficacy- it has ruined our and many families, slowly or quickly killing us all with our own medical conditions brought on by our own PTSD and injuries cause by our wonderful loved ones.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>Aggressive behavior toward others, often intractable requires day and residential care from experts; not young people making barely minimum wage. Complex people need complex care solutions. Impulsivity leads to elopement and death. Self injury leads to blindness, skin injuries, open wounds - it is a terrible life for anyone and again, it is being ignored for deference to "neurodiverent" populations. They need to be heard, but those significantly impacted by ASD who cannot cross a street safely or be alone safely need YOUR attention - the federal government is ignoring this very difficult situation. Families need 3 or 4 people at home to be sure they can restrain their loved one when they become dysregulated. What does this mean? 911 calls, hospitals, ER - repeat. No one can work and can become bankrupted. It is happening every day throughout the country (and world). PAY ATTENTION. Write policy for increased funding and accountability to serve "complex autism" needs.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>IDD and DD combined with ASD has been a disaster. We all love our family members but when one cannot tell you what hurts, what is wrong, what they need - it leads to prolonged illness often too late to diagnose and treat successfully. Many have had to have multiple teeth removed under anesthesia due to a misunderstanding of aggression and self injury due to dental pain - yes, it is that simple. Toothbrushing, twice yearly dental appt and it can be prevented, but dentists do not want to serve this population. Most doctors do not want to. The reimbursement rate is low and, the needs to getting people with ASD in and out quickly goes UNHEARD and therefore, no care is sourced. Federal police should also consider creating legally binding policy, similar to that of an IEP (Individual Education Plan) so that agencies can be sued. Now, there are documents created constantly for "compliance" but families have no recourse when there is no progress or worse, abuse and neglect - do not believe anyone who tells you there is a system to report. For people who cannot be reliable witnesses - all allegations result in "unsubstantiated" results.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>Pediatric and Adult Docs need a new screening protocol that includes PANS/PANDAS, encephalitis, LYME and environmental screening for toxins such as mold. If these are found early it is better, but policy can push these screeners to begin now. The silos in medical are and mental health care in all candor are a joke. It needs to be a top down mandated structure. If these diagnoses are found and medical/MH care treatment are implemented, you</p>

	<p>could decrease the use of 911, psychiatric stays, ER us, admissions and more. Just get it right medically - you would be surprised. Also, psychotropic medications are used like candy - there is NO oversight and no clinical direction for people with ASD taking all these meds. Trials need to include neurodiverse who can report AND non-verbal non-speaking SEVERELY impacted people in these trials. Most families will tell you MEDS DO NOT WORK. Under this view, the question becomes... then what? Back to policy that provides true expertise and higher pay for those who care for severely impacted ASD people in day programming and residential settings.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Policy and funding. A top down screening recommendation that rules out medical conditions AT ANY AGE right now: PANS/PANDAS, encephalitis, LYME, environmental toxins such as mold. The medical community is living in the dark ages. It's time to truly look for root causes in addition to genetics and TREAT what is wrong. Policy creating and "IEP like" document that allows action for family members to use if those in care of their loved one accomplish nothing or worse, abuse or neglect their loved one. Policy increasing funding and creating professionals with true expertise to provide care in day programming and residential settings for those with the most complex issues - and provides for higher wages for this role. Policy that requires physicians to see complex ASD patients AND provide accommodations to see them quickly, "The Get In And Out" bill would work; happy to help write it.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>Where is the study? Shouldn't you know? This is your reminder that THIS is the kind of research that those severely/profoundly affected by ASD need to be in. Long COVID, increased encephalitis, heart issues - where is the federal government on this?</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>You need to do this research. It has been a tragedy. Absolute. While telehealth is really important, it is NOT an excuse to NOT get people engaged, active and happy.</p>

Name	Anonymous
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Working in a pediatric dental office, sensory challenges are the number one issue I see with this population. From a crowded waiting room, overbooked and long waiting times in waiting room, loud instruments, bright rooms, poor pre screenings, etc..
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Everyone has their own unique challenges. I don't think one stands out more than another
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Again, everyone has the own unique challenges and disabilities associated with their autism, it's hard to pinpoint the main one out of the options listed above
What additional research is needed to help address co-occurring conditions for autistic people?	I would love to see or hear research being done on how peoples energy and auras can affect our interactions with the autistic population. From my 10+ years of working with them, I feel like this population can pick up on peoples energy and this allows them to select who to avoid and who to open up to.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More coverage in the dental offices. I personally help and desensitize autistic patients who have a fear in the dental environments. My employers wish we could bill or get paid for these services, but it gets complicated and usually unsuccessful since it's considered an elective procedure
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Due to many closures and changes, this made the autistic population a sudden change in their normal routines. This also makes it difficult for the care takers of these kids
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My daughter has profound autism (Level 3) and doesn't understand medical procedures. She has co-occurring medical problems (e.g., heart conditions, epilepsy, sensory disorders, Duane Syndrome) and when we need to do medical procedures, she doesn't consent or allow them to be completed. She either needs to be sedated or restrained, which is terrible. However, we cannot have work done on her teeth, blood draws, or EKGs completed due to her not understanding why she needs to be still. I am lucky that she takes medication and allows shots to be given. I know others are not so lucky.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	These co-occurring mental health disorders add a layer on top of autism that makes it difficult to function.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	It is hard to know why my daughter does talk... is it because she has an intellectual disability or is it just her autism. I know she understands language, and she uses other means to communicate with us. However, I fear for her future, her livelihood and her safety as she ages.
What additional research is needed to help address co-occurring conditions for autistic people?	We cannot stop research to support autistic individuals. While some are able to live without high support needs and can even have relationships and work, many are underemployed, restricted in their rights and autonomy, and are at severe risk for being taken advantage of in their lives (e.g., sexual abuse, physical abuse, theft).
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Honestly more money needs to be allocated to individuals and their families. The cost of caring for someone with autism is astronomical and many of us cannot provide the care that is needed across the lifetime.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Being different is a challenge in its self but I do believe that this is one of the most significant co-occurring challenges with autism. Being recognized for having a difference from another individual doesn't feel great, I feel like people are always starring at me when I'm stimming. My behavior isn't seen as normal because everyone else is being recognized as normal behavior.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety is the most significant co-occurring health condition that causes challenges in autism. I struggle with mental health, and with my mental health a lot of the time it's simply a challenge to get motivated to do things in public. I think the anxiety sets in when there is a lot of noise and many people. This makes it really difficult to concentrate and it also makes you feel uncertain of your own feelings. Anxiety can make you feel inadequate and that can cause sadness.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	With my daughter's autism diagnosis I have noticed that her speech is always very random. She says what comes into her mind and most of the time it has nothing to do with what we're doing. For example we could be driving and she would say that the fish doesn't want to go to sleep. And although I don't completely understand why she is stating this I believe it has to do with communication. I'm not the greatest at communicating but I have found that writing helps me to express myself and my daughter loves to draw. I believe that these are positive ways for individuals that struggle with disabilities to express themselves.
What additional research is needed to help address co-occurring conditions for autistic people?	I don't feel that autistic individuals are the only people that need to be researched I think that it is a matter of perception. When you grow up and your told that something is different about you and your not like most children your age. It hurts. Then you grow up with this hurt of being different and not really fitting in with the other children which leads to you not having much of a social life. These things have already been researched. Normal people that don't suffer from disabilities or disorders need to be researched just as much as people that have autism or schizophrenia. Once your diagnosis with a disability the decision is made for you. You don't get to decide whether or not you want to be labeled. Not having a condition or maybe never being recognized for having a condition is really not fair. Many people never really are researched and get over looked for their condition because the symptoms are different.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	It's not a matter of the services not being available. Supporting the very issue of what is making me feel left out in the world hurts. I think we have to change the way we view people that are different. I'm not so different that I need extra help. Often I'm so different that I can help make a difference in the world simply by being excepted.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to	

the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

Name	Anonymous
Demographic	Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	As a suicidologist, we don't know much about suicide and autism. But casually we find that there are increased risks, and even more so if they also identify as a racial/ethnic minority or a gender/sexual minority.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep issues and behavioral including anger and physical responses to that anger
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anger
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	School districts response to needs of child
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Equitable access most notably from insurance perspective
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Social isolation has impacted social interactions
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Social interactions

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Three months of 24/7 colic at age one and a half months. No naps after one year old. Increase appetite, ate adult food at 1-1/2 yo--half again as much as I did. Dare-devil thrill-seeking during childhood. As a toddler, he'd sit on his parent's shoulder and suddenly dive forward, causing bystanders to scream. We, as his parents, quickly learned to hold his ankles while he was on our shoulders. Maybe related: he ate poisonous things like turpentine or other things he knew were dangerous. I once caught him with a twig in his mouth. I told him to remove it NOW. He quickly swallowed it instead. I had long ago memorized the phone number of Poison Control. A quick phone call confirmed that bush would cause paralysis, but, "It tastes so awful no one would swallow it."
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	As adult, developed schizophrenia, later, schizophrenogenic bipolar with seizure disorder. Never aggressive. Withdrawn and sensitive; could not tolerate any sight of aggression.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Held back in kindergarten because of failure to communicate with teacher, although quite bright intellectually.
What additional research is needed to help address co-occurring conditions for autistic people?	ASD needs to be better understood by more people. A diagnosis was requested of his psychiatrist who did a test and declared, " I see no reason to change his diagnosis." That wasn't the question. I wanted ASD as an additional diagnosis, not an exclusive one. He needed a developmentally delayed disorder diagnosis to qualify for dental coverage. Almost all meds for SMI cause dry mouth, which is hard on the teeth, yet they have no dental coverage other than to pull their teeth.. Our other son was DD (from infection, not genetic) and he had full coverage.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Better understanding of possibility of multiple diagnoses and, therefore increased services.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school,	Son died before covid. Since he mostly self isolated, didn't understand people and didn't know how to interact, I doubt covid would have affected him much except for wearing the masks.

increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Just naming one is not possible. But if only one is allowed I would say intellectual disabilities. I feel that this is not studied enough. Having a severely ASD child with intellectual disabilities that is nonverbal. Also, saying one challenge is not fair. My child also struggles with ADD/ADHD sensory issues, developmental delays, sleep issues, eating disorder, GI problems, requires OT for motor challenges. And again this is not all of his "documented medical" conditions. My main concern is that the committee does not focus on severely ASD children or adults with intellectual disabilities or severe ASD those who are nonverbal. I feel that we are forgotten.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADD/ADHD,. It is so difficult to get medication. We have an incredible doctor, but everything month it is so hard getting the Rx on time and the availability. My son's ADD/ADHD is very severe and the dose is not strong enough and trying new Rx and different doses. If it was not for Medicaid we would not be able to afford as one medication is \$700 for one month. And that is only 1 of his 5 medications.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Can I don't think it is fair to just name one. As my son struggles was all of the above. He is nonverbal and has developmental delays. But by far it is his intellectual disabilities. My son is 11 years old but developmentally 18 months old. We moved from Virginia to Delaware because VA school system did not support our child with intellectual disabilities. We discovered abuses, and he was locked in closets. Attending an public ASD School in DE has helped with son's treatment. Unsure about son's future has he has not improved or grown intellectually since diagnosed ; he has declined. It is not regression as he has never regained skills. (ie. he use to be verbal and now is non-verbal).
What additional research is needed to help address co-occurring conditions for autistic people?	I think there should be more research for those with severe autism and intellectual disabilities. I believe 30% have intellectual disabilities. It would be helpful if there were medical intervention for children that have severe behaviors that come with severe autism. Also, I am very scared about what will happen to my son when I am no longer able to care for him. There are not many or places long-term to care for severe autistic adults.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I am lucky that my son goes to a good public school that is an autism school. We were able to move to a different state. There needs to be support in school or systems outside of it. Because we were completely alone and scared. We did not find out about my son's autism about he was 5. His doctor had no idea, it is not fair that my son was not diagnosed.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	My son became nonverbal because of COVID.His school was closed completely. We were lucky we were able to move and all Delaware schools were open. But all his friends never received school in VA during the entire time of COVID. I know FCPS was sued by DOJ. Compensatory services do not make up for lost education of a special education classroom and OT, PT, speech services.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal	Many to most of autistic children require routine. Everyone's routine changed dramatically because many things could not be done in person. The closure of special education classrooms around the country impacted a generation of ASD children. Virtual learning does not work for a ASD child with intellectual disabilities with severe ADHD.

changes: disruptions in services,
increased remote work and school,
increased use of telehealth, reduced
in-person social interactions and
obligations)

Name	Anonymous
Demographic	Service provider, health provider, or educator; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	It is unclear that all autistic people have the same physical experience of these conditions (I.e., due to differences in interception or sensitivity to physical sensation), therefore treatment may be delayed / conditions exacerbated to more serious than otherwise Sometimes pain/discomfort cannot be adequately communicated, therefore this may contribute to aggressive or harmful behaviors directed to self or others. Extended physical difficulties without appropriate treatment will reduce mental health and quality of life.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Limits engagement with the community. (interferes with activities, impedes taking advantage of opportunities, etc) Lack of understanding by others / diagnostic overshadowing (people assuming difficulties are due to autism), which can result in improper treatment. Reduced quality of life and, in many cases, longevity. Extended mental health difficulties will also negatively impact physical health.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	There are a lot of assumptions surrounding ID and communication difficulties (e.g., minimally verbal), which result in people not being adequately supported. (I.e., assumed they cannot do something). there is also a significant lack of attention to development and change in this subgroup (I.e., opportunities that were presented during childhood but were not successful may not be presented again in adulthood, even though further development may result in the person later having the prerequisite skills learning) For Learning disabilities - I think people have a misperception that autistic people have "scatter" across their profiles and do not adequately test for / consider LD, which may preclude appropriate intervention.
What additional research is needed to help address co-occurring conditions for autistic people?	More consider of primary, secondary and tertiary care, rather than focusing mostly on adapting interventions (which tend to be tertiary).
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	All of the above need improvement. one major consideration in the US is the separation of behavioral (mental) health and DD services. because these are managed in different systems, it makes it very hard for autistic people to access the range of supports they need.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I do not think adequate research has explored this.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I think the greater integration of remote work/school has likely been overall positive by creating more opportunities / lessening in person demands that may otherwise impeded success. However, a negative issue is that by reducing in person requirements, we may be impeding autistic people's learning (in the way many students' socio-emotional development was impeded during the shutdowns). This could exacerbate / extend difficulties to engage "in real life" and I worry about the potential contribution to isolation longer-term for people who may still want to have in person contacts (but will have less 'practice' navigating such environments)

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	3. Sleep disorders cause severe sleep deprivation to caregivers and worsen emotional lability and ADHD sxs of ASD 4. OCD behaviors and verbal & motor tics cause delays and distress, and hinder transition in activities, distract others in classes or lectures 1. GI-abdominal pain, vomiting, constipation, overeating, food aversions, eating non-food substances, preoccupation with food: difficulty with eating out, going to camp or overnight events d/t sxs, behavioral issues with food-seeking in public places, church, school; emotional responses to not having food he is willing to eat. 2. Sensory-loud noise can cause distress and meltdowns, impair ability to learn and communicate, attend to the situation; vomiting at meals if presented with disliked foods; difficulty with clothing, shopping, uniforms, bathing, haircuts and nail trimming
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety leads to physical sxs, meltdowns, increased perseveration on feared situations Low frustration tolerance leads to feelings of hopelessness, SI and suicide attempts, flight behavior, aggression, self-harm; prolonged screaming in childhood made it impossible to go to church, shop, get a babysitter, have social playmates ADHD-impaired ability to learn and respond appropriately to situation, increased danger socially OCD-difficulty with transitions, increased agitation with triggers, delays in accomplishing tasks
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication - low frustration tolerance and meltdowns/screaming/aggression; increased escape into fantasy, checking out from the world around him Learning disabilities in communication and reading comprehension can cause impaired function in academic areas in which they have exceptional abilities. Social-Emotional delays become more significant as a teenager and young adult, impairing ability to interact appropriately physically, verbally, sexually. Poor awareness of boundaries and differences between people in different relationships (family, coworkers, classmates, supervisors). Impaired ability and motivation to start or try anything new- interview, apply for jobs. Poor tact, say whatever they think, even if inappropriate or would cause harm to self or others, or frighten people. As a parent of a now-adult that still acts like a 5 year old but is the size of a large grown man, I fear potential for indecent exposure, physical harm, sexual harassment, misinterpreted verbage or behaviors that can be misconstrued as threatening. Also, that my child could be manipulated to do something wrong by an unscrupulous person. Bullies of all ages can find out their triggers and use them to provoke a person with autism to aggression, flight behavior, suicidal behavior. I also worry about them taking food from anyone/anywhere because "I was hungry," and getting arrested for theft.
What additional research is needed to help address co-occurring conditions for autistic people?	The effectiveness of medications AND non-medication treatments for co-occurring symptoms specifically in people with autism. (Electromagnetic fields, vitamin and mineral supplementation, social skills groups, dietary changes, types of individual therapies, sensory diets, etc) Screening tools for co-morbid conditions specifically tailored for patients with autism. Effects of electronics on relational function, emotional well being, communication, empathy, academic performance specifically in autism cw typical peers. Best practice programs for evaluation and management of teens with autism to transition teens to adults and into the workforce-to address how to manage their developmental delays and disabilities.
What could be improved in autism services and supports to help address	1. Increased availability for autism evaluations. 2. Increased availability of developmental pediatrics and psychiatry appointments (9-12 mo wait for the

<p>co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>last 19 years). 3. Increased availability of ABA services (12 mo+) 4. Increased counselors willing to see children under 13. 5. Regular CME on developmental disabilities, comorbidities, and treatments in the ASD community for Family doctors and pediatricians, to increase their comfort and confidence in screening, diagnosis and treatment. 6. Programs to help cover the non-covered costs for therapies, especially once kids are in school. 7. Cognitive /behavioral classes built into the school curriculum- DBT, CBT, social skills, emotion management , conflict management, etc.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>The biggest impact of covid-19 was the social isolation and increase of electronics in schools which has reduced communication, social awareness, social skills, and overall emotional health.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>See prior question/answer. 1. We had multiple psychiatrists after moving to a new community who never once saw my child in person. Try doing telehealth with a ASD person and getting any meaningful interaction, a good assessment or plan. 2. I estimated all my kids were academically behind 18 months at the beginning of the hybrid year, and gained little academically during it, while suffering emotionally and relationally due to the isolation from peers. My child with autism initially lost all services during the shut down, and when he transitioned to online learning, he was 100% unable to stay on task, complete assignments, or perform on tests, he requires 1:1 for all computer based learning, or will accomplish nothing. Where he was on grade level pre-pandemic, He is now at least 4 years behind in reading and writing skills. Minimal improvements seen in social skills, and only in the last 18 months.</p>

Name	Anonymous
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory challenges and the lack of funding for OT. OT should be funded at a higher rate than ABA. OT has a neuro developmental background with an emphasis on generalization of skills to a variety of occupations and settings. ABA does not have this physical and mental health training.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	All of these co-occurring conditions mentioned can be addressed by OT and may be related to sensory functioning. ABA is trying to address these without proper training and causing detriment to children as a result. Anxiety is not a "behavior", nor is depression or ADHD. These mental health co-occurring conditions can impact every occupation and role in a child's day to day life- the occupation of play, leisure, sleep, daily living, reading, writing and the list goes on.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Not being able to perform a variety of occupations independently which when performed independently and successfully contributes to positive self esteem, self confidence and self worth. When we are not addressing their roles and occupations, we are not setting them up for success. Communication needs are also essential. ABA does not have training in acquisition of language skills. They should NOT be addressing communication skills.
What additional research is needed to help address co-occurring conditions for autistic people?	Do not fund more ABA single case study research. If they get funded it needs to be a large randomized control study that a non ABA IRB research institute manages. Remove the bias.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Cover OT at a higher rate. Remove the limits on the number of visits. Cover SLP services at a higher rate. Remove the limits on the number of visits. Find respite care for families. Defund ABA at its current level. NO child should be subjected to 40 hours of ABA a week. Nor should they get 20 hours of ABA while they also attend school. It is too much. These kids are stressed. Let them PLAY. That is a child's occupation.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I find a lot less engaged parents since COVID. Parents are on their phones. Parents plug their kids in. Play!!! Engage!!! Have parent night craft or game activities posted every week on a website for family engagement. Set up an obstacle course in your living room with pillows and cushions and sheets. Crawl, roll, hug. Get sensory input and be rewarded with hugs and happy faces and praise not reward charts, and edibles.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My son [PII redacted] is 8 years old and is autistic and has combined ADHD, central auditory processing disorder and is impacted by sensory and motor challenges. [PII redacted] is a sensory seeker and needs constant input to allow his body and brain to settle down and focus.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I believe my son's biggest challenges are tied to his combined ADHD. After [PII redacted] takes his extended release ADHD medication, he's able to focus for a few hours and really demonstrate what he knows and what he's capable of. Once that medication starts to wear off, he's unable to focus and to someone that wouldn't know him, they would think he can't do something (i.e. reading), but this isn't the case. As a mother of an autistic child and an employee of a nonprofit autism advocacy group, I see how challenging ADHD is for autistics with it. When their brains can't calm down, it makes it next to impossible to do things independently.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My son is developmentally delayed with fine and gross motor skills and is delayed in reading. Most of his behaviors come out during these activities. As he gets better in a particular are (i.e. handwriting) the behaviors start to go away. I wish more people realized that in order to work on behavior, you have to get to the root problem it stems from.
What additional research is needed to help address co-occurring conditions for autistic people?	I wish there was more research into the therapies and their effectiveness long-term on these co-occurring conditions. Autism is a life long disorder, yet there doesn't seem to be long-term research on these therapies and their effectiveness that are done in childhood. Also, I would like to see more research done on kids that take ADHD medication vs those that don't and long term what their outcome looks like.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I wish more funding would become available to help those with co-occurring conditions to help support them in the workplace. Autistics are still overwhelmingly unemployed and underemployed. Having a co-occurring condition like ADHD only makes it even more challenging to find and remain employed. I wish there was more funding available to provide job coaches and better educate employers. I also wish there was more funding available to educate medical providers on how to interact with autistics, especially ones with co-occurring conditions. It's very challenging to find providers who understand these conditions and can properly interact with someone who has them.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	We lived in Washington state when Covid-19 lockdowns occurred. Washington was one of the last states to make schools go back in person. We ended up sending my son to a private school that was in person because he couldn't do online learning. He went to kindergarten and first grade to this school. Although I believe it was the right choice given our options, he did fall behind in reading because they were not equipped to support kids that needed unique learning support around reading. My son is now in 3rd grade (we moved to Massachusetts for better education and support) and he is still significantly delayed in this area, but making progress. I believe Covid-19 has had a profound impact on social interactions for autistics with co-occurring conditions, but also for neurotypical people, especially in children. I see gaps in age-appropriate behavior and how to connect with others.

What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

The only positive I see from the COVID-19 changes was the access to telehealth. Although therapies like OT, PT and speech were super challenging for my son online (he was 5 at the time), it's been very useful for me for ongoing checkups on things like his ADHD medication. I no longer have to pull him from school and bring him to a doctor's appointment. I can have it after school and take it online from my home. The most negative impact from Covid-19 was the remote schooling. Both my NT child and my ND child struggled with this. Both are now academically behind in a subject area. In Washington state, we were the last state in the country to go back to being fully in person. When kids were sent home in March '20 in Washington, they did not return to in person learning (and it was only hybrid) until February '21. They did not return to being fully in person until August '21. Cushioned grades are not showing the true reality of the impact this had on academics and learning. Kids with autism and other co-occurring conditions will feel these delays and their impact even more.

Name	Anonymous
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	GI disorders (gastroparesis, reflux) Sleep disturbances Epilepsy Sensory processing disorder Fine and gross motor issues
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Agressive or self-injurious behavior, anxiety, trauma, suicidality
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Learning intellectual communication and developmental issues, excessive phobias, OCD
What additional research is needed to help address co-occurring conditions for autistic people?	Go into special services schools in NJ and observe and help rectify the educational economic social communication and medical gaps of this population
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Case management and navigation from 3 plus years, service system and insurance issues, provided training and social services training in IDD. More streamlined processes for all services. Crisis and mental health training for all personnel working with this population.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Long Covid, isolation, increased GI and brain heart stroke seizures , learning decrease and adl and social skills decreased sleep disturbances anxiety depression abuse increases
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increased use of télé health and increased remote work, lack of attending and family support and education for remote work, family obligations juggling, neglect reduced in person social interactions and work and other obligations disruption in services, nutrition snd food scarcity

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory processing issues, anxiety and co-occurring mental health issues
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, adhd, being a people pleaser susceptible to narcissistic abuse
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	All of the above
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Make the insurance provider search much easier to navigate. More support programs for adults that aren't ABA
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Increased anxiety and sensory processing issues
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Reduced social obligations in person

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory overload, difficulty processing information and emotions, anxiety, forgetfulness, disorganization, panic attacks, difficulty coping with change, communication difficulties, being misunderstood, physical burnout from trying to navigate a neurotypical society that's not built for me.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, panic attacks, ADHD burnout, forgetfulness, autistic burnout (physical, mental and emotional).
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Learning disabilities, concentration, executive dysfunction, confusion, difficulty understanding nuance, taking information literally, memory recall, struggle to contextualize information, communication difficulties
What additional research is needed to help address co-occurring conditions for autistic people?	Understanding the differences in the ways Autism presents in people based on gendered social expectations. People socialized as females have been entirely overlooked in terms of autism supports, because we were trained to be well behaved. The DSM criteria for autism is based solely on criteria for white males.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	equity in employment funding for social support programs, free access to therapeutic services (sensory therapy, autism friendly counseling). Patient provider training and awareness
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I haven't experienced lasting effects from the virus itself. The social impact of the pandemic has been much more significant.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The pandemic has reinforced my introverted nature as an autistic person. I am struggling to perform socially the way I did before COVID. The world feels louder, brighter and more chaotic than it was during lockdown. My threshold for coping has diminished telehealth care is harder to navigate with autism. I struggle to communicate over the phone

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My son has had severe GERD & constipation his whole life. He's unable to fall asleep without medication & has severe Sensory Processing Disorder which limits not only his diet but his ability to go out into the community
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD was a huge problem when my son was younger - it made everything school-related extremely difficult. He started having anxiety & depression in middle school due to bullying, and was admitted to a psychiatric institution in 9th grade for suicidal ideation. He still struggles with severe anxiety that keeps him from going out into the community.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My son doesn't have low IQ, but he is emotionally immature for his age. He didn't start talking until he was 3 1/2. He still struggles with a slight speech impediment.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Provider training on how to interact with patients who have autism
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	We love telehealth! It's improved our access to care

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	One of the most significant challenges is that many health care providers will not treat the physical condition if it is a co-morbidity with autism. We have flat-out been denied care because of the autism diagnosis even if the diagnosis for the other condition is within the specialist's field of training. They feel as if they are not trained or capable of providing appropriate treatment --- there is a general misunderstanding that autism requires some specialized training on how to accommodate the condition or misunderstandings about how co-morbidities interact.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	health care providers and social services agencies do not know where the autism ends and mental health concerns begin. This is especially relevant when applying for SSI since symptoms presented from the autism (an eligible disability) could be interpreted as stemming from an ineligible mental health disorder, resulting in an erroneous denial of benefits.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	again we have been denied services unless the provider specializes in autism specifically. Also I think because communication disabilities are not a recognized category of disability that prevents employment, it leads to denial of the public benefits which are based on disability. In other words, the agency/govt says the autistic person can work when they really cannot because no one will hire them due to communication disabilities. However, their communication disability was not part of the equation for determining eligibility or the autistic person's ability to work.
What additional research is needed to help address co-occurring conditions for autistic people?	to engage in AND proliferate results from research on how autism affects co-morbidities and how regular providers and agency caseworkers can indeed accommodate autism without much specialized training. More research is needed about how health care providers and social agencies can accommodate people with autism in simple, direct, tangible ways.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	there is a generalized stigma surrounding autism even among care providers that they would rather deny services completely than to deal with a co-morbidity of autism. This is especially true of mental health services. It took us a year to find a therapist to address depression in my daughter because we had to find a therapist that specialized in autism and depression together, and not just a general therapist. The lack of insurance coverage for the very limited number of providers who specialized in this was a huge issue. This is an issue of equitable access to services for people with autism and increasing public knowledge about autism to improve patient-provider interactions. I think offering system-wide training about autism for providers who are not specialists in autism would help address this.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	during covid, there was a drastic reduction in opportunities to interact socially. In some ways that provides comfort for those on the spectrum, but overall having limited opportunities to interact increased the symptoms dramatically. There was no way to mitigate symptoms and the autism got a lot worse. Also for a person who has difficulty reading social norms, covid19 represented a complete upset of social norms. It was already hard enough to gauge social norms before covid, and during covid when all previous norms of social interaction are thrown out the window and there are sudden changes in new social norms about masking and coughing in public and distancing, this was very disruptive. Because it is autism, it has taken a very

	<p>long time to readjust and regulate again, making co-occurring mental health conditions a lot worse.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>I feel that the lack of in-person social interaction has brought comfort to my autistic daughter, but at the same time, it reduces the opportunities to do social activities that would mitigate symptoms. She is very isolated and there are fewer ways to help her interact. In other words, she can't learn to act within social boundaries if she is not interacting with people. It has increased the mental health challenges. During covid, it was easy to not shake hands or not interact personally. Now that covid is not viewed as seriously anymore, people (especially potential employers) accommodate autism much LESS than in the past. They see her avoidance as rude rather than something to accommodate because of the autism disability. It is as if she has to deal with the stigma of autism in addition to the stigma of social avoidance behaviors post-covid.</p>

Name	Anonymous
Demographic	Autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>Gastrointestinal disorders and sleep disturbances tend to greatly affect an autistic individual's ability to function daily and can be intertwined with one another (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8608248/). For instance, if someone is a working autistic adult and has sleep disturbances, because they did not reach a full REM cycle, they will have a harder time to perform well even with a full 8 hours of sleep. They will most likely reach autistic burnout much faster than normal, which can impede their ability to successfully complete tasks. GI disorders affect an ASD person's ability to comfortably work and live in any public environment. They have to be especially careful with what they eat, which is difficult for many autistic people with sensory food issues, and will increase their stress due to lack of access to more gender neutral public restrooms that provide more privacy for autistic people. Lack of sleep combined with GI issues can lead to them drinking more caffeine or unhealthy stimulants to keep them focused and awake, therefore causing more GI issues and consumption of unhealthy nutrition.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>Depression and anxiety are the co-occurring mental health conditions that a majority of autistic people have, and those conditions greatly affect autistic people's ability to socialize, to find work, and to take care of themselves (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC335529/). Autistics tend to have higher anxiety due to sensory issues, communication issues, changes to routine, etc. Anxiety increases an autistic person's social ineptness, leading to social exclusion, solidarity, and seclusion. Because of social anxiety and a lack of community and support, autistic people, especially autistic women and those with comorbidities, have a greater risk of depression. ASD individuals have a higher risk of suicidality than those who are not autistic or neurotypical (https://molecularautism.biomedcentral.com/articles/10.1186/s13229-023-00544-7). Accessible neurodivergent-affirming mental health professionals, early diagnosis/ASD evaluations, and inclusive practices to diagnosis can help many ASD individuals receive the mental health care that can combat these growing statistics.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>Communication disabilities are significantly challenging for ASD people. ASD people who are nonverbal have limited resources to communicate to others, and because of a lack of resources, education, and healthcare services, families of non-verbal autistic children will struggle to understand non-verbal communication. Having a way of communicating (e.g. via visual communication board, Talkpads/AAC devices, sign language lessons, etc.) will greatly benefit and improve communication between ASD individuals, families, and other people within society. This is especially important to research and bring more social awareness to because autistic POC who are non-verbal can encounter a higher risk of stigma and discrimination (https://autismspectrumnews.org/rights-and-challenges-for-autistic-people-with-communication-disabilities-in-the-legal-system/). Also, creating more resources for non-verbal and high support needs autistic people can potentially allow them to live independently, if that is something they desire.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>More research is needed on finding more effective resources for high support needs autistic individuals and their families so that the ASD individuals can potentially live independently or not need as much support as adults. Research is needed to help address the comorbidities with ASD and other disorders like ADHD, bipolar, borderline personality disorder, OCD,</p>

	<p>anxiety, and depression and research devoted to improving mental health methods that are more neurodivergent-affirming practices. More research needs to be devoted to the ways intersectionality plays a huge role in POC autistic people and how it contributes to many of them not being diagnosed or being late diagnosed adults (https://pubmed.ncbi.nlm.nih.gov/36777375/).</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Equitable access to and accessibility of services and insurance coverage are the main supports that need to be improved. Black, hispanic, and Asian communities have a significant disparity in accessing healthcare and services to receive early ASD diagnosis, support services for their ASD family member, and especially support for late-diagnosed autistic adults (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8500365/). Also, because there are disparities in access as well as lack of inclusivity and understanding of how intersectionality affects POC autistic individuals, many POC autistic people do not and/or cannot be diagnosed until they are adults, and getting diagnosed as an adult is more challenging because most testing does not consider autistic adults, and it is extremely expensive for those whose healthcare does not cover the assessments. Accommodations for both diagnosed ASD children and adults is lacking and needs more coverage for both high-support needs and low-support needs ASD individuals.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>The positive impacts that societal changes due to COVID-19 have had on mental and physical health are the increase to remote work and school and reduced in-person social interactions and obligations. Because there has been a decrease in social expectations for frequent in-person interactions and increases to alternative online options, a few ASD individuals and adults have expressed a decrease in anxiety (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9887236/). Having more remote work options as accommodations and/or having more remote jobs available for autistic people will benefit the community who wants to and is able to work. Increased use of telehealth has both positive and negative effects. Telehealth has given autistic the opportunity to receive mental health care without having to leave their home and worry about transitions, but if they do not have good internet, a private room, and adequate equipment, this could be a negative outcome with the increase in telehealth. However, disruptions in services and more challenges to accessing healthcare have had greater negative impacts to autistic individuals and their families. Getting a hold of a person has become more difficult in general, but especially for healthcare services. Making phone calls, appointments, talking to staff, etc. are already daunting tasks for autistic people, but their anxiety, burnout, and frustration can increase when access to someone is stilted or never resolved.</p>

Name	Anonymous
Demographic	Service provider, health provider, or educator; Researcher; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	As a provider my answer would be that sleep disturbances are the most common physical health challenges that impair children's functional skills which I see in children with autism. When children don't sleep, no one in the family sleeps. When humans do not sleep, they do not perform at their best behaviorally, emotionally, physically or academically. While most of the children with ASD who I see have sensory concerns, these are much less likely to impair their ability to function effectively in the world.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	In the children and youth that I follow with ASD, their most common accompanying mental health conditions are difficulty with anxiety and with hyperactivity and focus/attention. Behavioral interventions and medication can be very helpful in helping the child cope with these conditions.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Challenges with communication - both understanding their world and effectively communicating their desires and needs are extremely impactful for most children with ASD. Lack of understanding in both directions is extremely frustrating and the source of many behavioral/emotional challenges. Helping them learn means of communicating effectively is an essential component of their education and their health and mental health care.
What additional research is needed to help address co-occurring conditions for autistic people?	We need to listen to children, parents and self advocates and understand their needs and priorities. Observational studies identify issues but intervention study is needed to find solutions. Curing ASD should not be a goal. Improving function and well being should be the goal.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	The co-occurring conditions (anxiety, ADHD, language delay, cognitive delay etc.) are typically more impairing than autism itself for most of the children I serve. Everyone - not only those with ASD- deserves access to an accessibility of services and adequate insurance coverage. Putting all resources in an ASD bucket has made this diagnosis one that is highly sought out and sometimes excluded individuals with other behavioral health conditions who are equally deserving of services and supports and would benefit highly from these. Services and resources should be based on the child's developmental profile and needs, not just an ASD diagnosis or lack thereof.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	During the pandemic many young children, especially those from underserved families, were not enrolled in EI or dropped out of EI due to lack of access to virtual platforms. This snowballed into not having a handoff into preschool special educational supports. A whole cohort was isolated, did not receive appropriate early intervention and remains without services. We will be paying for this for years. The pandemic stressed everyone's mental health - parents, children, providers and recovery has been slow.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services,	The main positive effect of the pandemic for care of those with ASD and other mental health conditions was that we learned how to perform and be reimbursed for telehealth. I do not think that remote ASD evaluations are ideal, however, virtual follow-up care for coexisting mental, behavioral and educational concerns can often be well addressed by telehealth. This is something we need to preserve. It allows parents who are coping with

increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	stresses at home to access services even if someone at home may need them or the weather is terrible or their car has broken down.
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Name	Anonymous
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	securing supports for youth with mental health needs and Autism. such as PHP for youth 18-21, that have aged out of children's PHP, programs but not appropriate for adult PHPS, that do not specialize for I/DD teens.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Appropriate emergency services, such as CCIS units, and PHP's for those with I/DD and metal health needs
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication needs, and those that are in hospitals not being trained to support those that need assistance communicating.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Service system issues, adding more specialized crisis beds and units for those with I/DD and mental health needs.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	skills regression, loss of services, reduced providers that will work in home with those in need.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	increased remote work and services which are not always appropriate for this population. Disruption in services, and therapies, increased telehealth treatment.

Name	Anonymous
Demographic	Other
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>Many people with autism are adversely impacted by chemical fragrances/scents and experience a neurotoxic effect even at very low concentrations. The NIH has epidemiological publications showing that environmental chemical exposures play a larger role in causing autism than previously thought. Multiple Chemical Sensitivity, MCS. "MCS is a complex chronic and disabling condition, which involves multi-system symptoms triggered by both scented and unscented chemical products used in everyday life, including fragrances, cleaning products, cigarettes, pesticides, petrochemicals, laundry detergents, personal care products and building materials. MCS is closely linked to environmental health inequity. Ubiquitous exposures create barriers to access and inclusion, including health care, workplaces, and barrier-free, safe housing." ASEQ-EHAQ website There is truly a GREAT NEED for healthy housing for people with chemical sensitivities. Currently there is only one HUD house in California that is fragrance and pesticide free. People with MCS are often forced to leave their apartments and live in their car or outside in the woods to get away from neighbors who use toxic fragranced cleaning products, air fresheners/sprays, fragranced laundry products, scented burning candles/incense, etc...that come into their apartment through shared heating units, shared hallways, shared laundry facilities, as the only thing that seems to mitigate the neurotoxic effects is total avoidance.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>The World Health Organization has declared air pollution as a top five risk factor for cardiovascular, respiratory and neurodegenerative disorders. The CDC has an indoor air quality policy. Scented or fragranced products are prohibited at all times in all interior spaces owned, rented or leased by the CDC. CDC Indoor Environmental Quality Policy.pdf (wsimg.com) There is an international prevalence of chemical sensitivity. Dr. Anne Steinemann has done extensive research on this topic. Please see her website: Home (drsteinemann.com) FAQs (drsteinemann.com) It is time for all hospitals, health clinics, doctors and dental offices in the U.S. to adopt and enforce the CDC's indoor air quality policy.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services,</p>	<p>The CDC has an indoor air quality policy. Scented or fragranced products are prohibited at all times in all interior spaces owned, rented or leased by the CDC. It is time for all hospitals, health clinics, doctor and dental offices in the U.S. to adopt and enforce the CDC's indoor air quality policy, so that individuals with MCS and fragrance intolerance can access health care without becoming ill and debilitated.</p>

insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Some people are unable to be vaccinated and are living with immunodeficiency disease (are immunocompromised). So, the pandemic precautions of masking in public and essentially avoiding the public are still in place - - for 3+ years now. The social isolation is challenging.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The increased expense to have groceries shopped for and delivered is not within the limited financial means of someone living solely on Social Security Disability. Plus, we miss out on all in store sales. Quality masks are expensive for someone living on Social Security Disability. Doctor and dentist office personnel disregard the risks for someone unable to be vaccinated, living with immunodeficiency and unable to afford immunoglobulin replacement treatment. They are unmasked and roll eyes if you ask them to mask up.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory challenges Anxiety (muscle tension, fatigue) Burn out
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Self harm (cutting, punching self) Inability to choose or decide Confusion Persistent feelings of rejection and isolation, social ostracization, anxiety depression
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Making decisions Planning, planning everyday activities Performing in school *****Accessibility to care ***** Communicating properly, how others would prefer it/ how they receive information Lack of accommodations everywhere **Lack of people's awareness and understanding of autism**
What additional research is needed to help address co-occurring conditions for autistic people?	Research on undiagnosed adults. Research on autism in females** Research on the effects lack of accessibility Research on burnout and how to properly cope
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage Patient provider interactions Information given to employer to adequately explain accommodations or even just to provide simple understanding not leaving all the weight on the autistic individual to explain themselves because communicating can be challenging Counselors in early age schools that specialize in identifying undiagnosed children
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Borderline personality disorder is co-occurring for me. The most significant challenges are the emotional dysregulation & interpersonal challenges that I experience from both Autism & BPD. This causes a lot of suicidality/injurious behavior for me. It's really hard to cope with these in the workplace
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	More research on how autism & co-occurring conditions show up in BIPOC women. Most BIPOC women don't ever get diagnosed with Autism as co-occurring. Only one or the other.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage for autism tests for adults. Many BIPOC fold are diagnosed later in life and tests are usually paid for out of pocket. Insurance coverage could help many BIPOC folks get the diagnosis they need in order to find skills and therapies to help them.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increased remote work has been so helpful. I don't have to worry about masking my BPD & autism symptoms nor receive micro aggressions about it. I like that I can also schedule more appointments online so I don't have to call and talk to someone on the phone.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory overload happens often to me. This means I have to avoid places that are too loud, too crowded, or too bright. Sometimes riding in a car is difficult because I get vertigo from the movement and visual of things going by too fast. I also have gastrointestinal problems and ARFID, so I can't always eat even when I'm hungry or eat proper food.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression and anxiety are constant and not even medication helps. I've already had 2 suicide attempts in my past. Alexithymia and depersonalization make it more difficult to understand what I feel.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I struggle the most with communication. I spend lots of time thinking about things, but I don't know how to get my thoughts out in words. People misunderstand me often or just think I'm cold and uncaring because I don't talk often. I also have dyscalculia and struggle with all math. I can't count out change or read a clock face properly. I can't see numbers in my head so I rely on a calculator for all things, even basic addition or subtraction. I also have aphantasia so I can't see things in my mind at all. This affects my communication with others because they always want me to make decisions about things I can't see or comprehend. I have short term memory problems and autistic meltdowns and situational mutism.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	There are no services for autistic adults. It's just expected that we have family to care for us the rest of our lives. This is not the case for most autistic adults. We are dying from homelessness or suicide at higher rates than others. We need services that provide education and incentives for businesses to hire and retain autistic employees. We need services for our basic needs like shelter, food, medicine security/procurement. We need affordable healthcare.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I got covid 2 years ago and I still have trouble with my lungs when the air is too cold. This causes me to cough a lot even when I'm not sick. It hurts my throat and is another sensory issue I have to add to the vast list of sensory problems I already had. Makes my depression worse because I'll never fully heal from it.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The only good thing that happened for me is that I can wear a face mask whenever I want in public and no one makes me take it off now. I would prefer to work from home, but I've never had that opportunity, even during covid. Most places want you to go back to work in person now anyway.

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My entire family has some sort of physical disability on top of autism. I have ankylosing spondylitis, inflammatory bowel disease, hypermobility syndrome, MCAS, ME/CFS, dysautonomia, long covid. All of my kids are autistic with ADHD, PDA, chronic pain from hypermobility syndrome, and long covid-which affected various parts of their bodies including making their cholesterol go very high and inflamed any other autoimmune disorders present. My eldest child developed Hashimoto's, PNES, MCAS, severe depression, and POTS. My second developed MCAS, ME/CFS, dysautonomia, POTS, severe depression, and has a congenital tooth agenesis. My third developed puberty at age 9, has developed dysautonomia and sleep apnea on top of unresolved issues with a positive ANA with a speckled pattern and PFAPA. My youngest has "stork marks" and a simple over his tailbone, so I am going to request an MRI of the area soon. All of my kids can hardly do the activities that they'd like to do because of emotional or physical impairments. I can't work anymore and am a full time career because they're all in severe burnout. PDA is not recognized in American schools, and they were put in burnout by the lack of appropriate accommodations in school and bullying for being transgender or nonreligious. We homeschool now.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My kids developed PTSD from an authoritative school program and seclusion and restraints and ABA. PDA hasn't been recognized here until very recently. They are all sad and triggered often and trying to recover from burnout. They can hardly tolerate going out much anymore either physically or emotionally. ADHD makes life difficult, especially with extreme executive dysfunction from ADHD and PDA. Demand avoidance from things that you WANT to do is distressing. It's worse in burnout. The emotional dysregulation is difficult. I've learned how to do drywall well.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My kids may not be able to earn enough income to live independently without a partner or room mates. They may not be able to travel. They may not be able to afford food or necessary medical care when I die.
What additional research is needed to help address co-occurring conditions for autistic people?	Ask autistic people. Make it truly accessible and not only asking adults and not only speaking and reading people. Amyloids GS224 Connective tissue disorder Mitochondrial disorders Long covid
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Universal basic income, ban ABA, universal healthcare, paid parental caregiver programs, automatically assigning autistic adults their own social worker if they're unable to choose on their own, free advocacy and gentle parenting education for parents.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It's changed our lives, and since it's been since December of 2020 already I'm assuming it's permanent unless our healthcare system gets better. We are all exhausted by basic living. I can't get home health care for myself. My husband makes too much for us to get benefits, but not enough for us to have what we need so he has to work OT and still be giving 100% at home as well. It's affecting his health, so it's all of us. Our family dynamic isn't as healthy as it was because everyone is in pain all the time and grumpy. There's not as much enjoyment or adventure like there was. It feels a little

	hopeless, but we are still finding studies and therapies that are helping a little at a time. We are just mostly having to do it all on our own.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	More telehealth is good. Reduced obligations were nice.

Name	Anonymous
Demographic	Family member of an autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>My sons are level 1 autistic and have different co-occurring physical health conditions. Both children have spatial awareness challenges and, for instance, might run into the path of a swing because they can't predict its trajectory. My older child has challenges with motor skills and physical strength. He is six, but has the physical strength of a child three years younger. He has been in physical and occupational therapy since he was 4 years old, and this is helping him develop more motor skills and strength. My younger son is three and has sensory sensitivities. He dislikes loud noises and dislikes certain textures. Both children do well when their challenges are communicated to and respected by adults. E.g., allowing them to take a break if an activity is "too much" or having them attend a sensory-friendly version of an event.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>I see signs of anxiety in both of my autistic sons ages 3 and 6. I think this is due to inflexible thinking and rigid senses of "right" and "wrong." They are both unusually distressed if there isn't a schedule or set of predictable and consistent rules. They feel comforted and confident when they know how things will unfold, or what they are expected to do. When this is unclear, they show signs of anxiety (e.g., wringing hands, holding breath, having an intense meltdown). Both children seem scared of making mistakes despite us as parents actively endeavoring to create a home life in which mistakes are seen as normal, as part of learning, as part of being human. An example involves our younger son. He went to a Montessori school when he was 2, and he sobbed and clung to his parents every time we dropped him off for almost a year. Eventually we changed to a preschool that had more structure, and on day two, he happily left us and he loves his school. We think that the Montessori environment overwhelmed him with choice and that he was worried about doing something "wrong." He needed more guidance (e.g., "now we're all going to play with blocks") and is now more confident in making his own choices. We as parents are worried because it seems likely that both of our boys are inclined toward anxiety BECAUSE their brains are inclined to black-and-white thinking.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>This varies from person to person but in our sons' cases, they have a hard time with social skills and communication. One son has speech challenges so he's sometimes hard to understand, and he doesn't read social situations easily. We have to overtly explain how to "read a room" and how to not monopolize conversations. He is highly intelligent, which is a gift, but his social skills are impaired. So we've got a child who taught himself to read at age 2, who loves learning and has a significantly higher-than-average IQ... but he struggles to fit in with other children due to his challenges with social connection. His motor skill challenges make it harder for him to participate in sports, but we encourage him to have fun playing vs be the best player. We notice that autistic kids who are diagnosed and supported do much better when their challenges/disability is acknowledged and openly discussed without shame or pity. They can thrive to the best of their abilities when adults focus on progress over perfection or aligning with the norm.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>In general I would like to see more research done that involves girls and women. Autism can look different in girls and women than it does in boys and men, and I think this leads to fewer girls/women being diagnosed and therefore supported. Looking back at my childhood, much of what defines my sons' autism overlaps with my own experience. Hyperlexia, toe walking, sensory hypersensitivity, rigid and literal thinking, a sense of observing a</p>

	<p>group rather than being part of it, enjoying alone time, not naturally "getting" social norms but being able to mask... this is all me as well. I think I would have had less anxiety and depression as an adult if I had understood that I am most likely autistic and indeed different than the majority of folks on that front.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Mandated ASD (and associated services) coverage within self-funded insurance policies. Our insurance changed this year and because it's a self-funded policy, it's not required to meet state or federal requirements for ASD services/coverage. This means that our son now has a cap on services each year and will not be able to get what is therapeutically recommended. Some policies cover only ABA, but not OT/PT/speech therapy despite them being necessary and caused by ASD. Our new insurance also has a \$40 copay for each service within each visit. So now we pay \$80-\$120 twice a week for our son to get the services he needs. And then we'll hit the cap and need to pay even more out of pocket. This is on top of \$600/month for our insurance. This is nuts and it's 100% based on corporate greed. We desperately need single payer health insurance for every American. Health care should not be a for-profit industry.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>Infection: none that we can see.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Our older son was 3 during the pandemic and that's when we realized that he was autistic. He was diagnosed during the pandemic, but largely unable to receive services due to wait list and the difficulty of remote services. Isolation, lack of peer interaction, and a pediatrician who insisted "it's just the pandemic" contributed to his ASD challenges being worse than they are now. The good news is that with services and support, our son is doing very well at this point. But he missed a year of important social development and peer interaction, and so he's playing catch-up. The other problem with covid is that anti-vaxxers often point to a discredited study that suggests vaccines cause autism. This is false but it causes some parents to avoid vaccination.</p>

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The inability to receive adequate mental health support for comorbidities like ADHD harms me and my family. Many professionals do not recognize that patients can have ADHD and autism simultaneously since the DSM IV was exclusive and many old school providers are unaware of the DSM V's joint diagnosis. Additionally, it is difficult to report to primary care providers the need for exploring related health conditions like EDS/Hypermobility, POTS, autoimmune disorders, migraines, epilepsy, etc. My family has a history of all the aforementioned linked health conditions and primary care providers are not good at recognizing the patterns proactively in addition to dismissing an autistic patient's concerns as hypochondriac paranoia. I feel that there are not enough supports for autistic folks to advocate for their health and health disparities result from miscommunication between the patient and the care teams.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Many concurring mental health conditions are difficult to address since mental health resources have generally been over capacity post-Covid. Getting ADHD medication and access to mental health care providers specializing in autism is impossible. We don't have enough access to specialized care in addition to having to wait for general care and supply chain issues. There are not enough general mental and behavioral health providers with experience treating autism (which I have seen first hand as someone working in primary care after working in hospital administration during Covid). That is, many behavioral health resources that are available and/or in network are not experienced with autism so autistic patients end up in referral hell. I had to wait almost two years for a neuro work up to get diagnosed with ADHD. By the time the referral processed, my insurance had JUST went out of network days before my appointment and I had to pay out of pocket. All of my mental health medications were difficult to figure out since my PCP was inexperienced with autism. I've had three new PCPs since 2020 and none of them have had long term experience with autistic patients, somehow.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I was lucky enough to get screened through the school district as a kid (circa 2010) and received decent accommodations. I feel that I wasn't equipped to do well in school unless I had accommodations such as extended testing time, closed captions for Zoom calls, note takers, etc. I wish it was easier to get accommodations at school and there was an external resource specifically meant to help with disabled students in school. Like, additional funding for a class counselor who would check in on me more regularly and advocate for me. I had a strong advocate counselor via Trio (as BIPOC first generation college student) and feel that neurodivergent students would benefit from a similar program. Time blindness is near impossible to get accommodations for and is a very real issue independently of work ethic. I struggled to communicate with many teachers and often experienced bullying from teachers all the way until I finished college. They would make passive aggressive or condescending remarks that I often didn't pick up on but heard from my peers. I felt like I was either going to be a halo effect student or golem effect, but never flew under the radar no matter how engaged or quiet I tried to be. I rarely felt I had someone I could talk to about problems I had with authority figures, and generally experienced similar social isolation from my peers to a less hurtful degree. I think it hurt less

	from my peers because they couldn't really mess with my life the way a teacher can.
What additional research is needed to help address co-occurring conditions for autistic people?	Research is needed on how to implement better societal supports such as parental education programs for autistic children, school based advocates for children and parents alike, research on what accommodations make sense for folks with ASD and overall more research on how ASD affects overall health considering there are a plethora of linked conditions. To clarify, we need research on how SBHCs affect autistic children's health in addition to how non specialized practitioners treat autistic patients compared to practitioners who have a background in autism. We need to know exactly how much the lack of training is affecting/driving health disparities. There needs to be more research on adult autism (society only supports autistic children as if turning 18 magically fixes us), and how we can better support adult diagnosis to help folks live healthier, raise their potentially autistic kids better, and find preventative health sooner. That is, we need to know WHICH co-occurring conditions are linked to autism so we can hassle our PCPs to get started on the process. We need more research on how autistic folks experience health inequities so the powers that be can break down those barriers. We need more community based research so autistic folks can share their lived experiences of managing co-occurring conditions. We need more research on how to better integrate community support systems for autistic folks in rural areas.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	We need more advocates who can facilitate difficult conversations and act as an interface between the patient and practitioners. We need insurance to be less difficult and less useless. Many insurance companies are no longer supporting ASD services and BH altogether. We need more equitable access to qualified ASD professionals and need to hold all medical professionals to some level of competency. Services for ASD folks should be available in rural areas, and remote options need to be made available in areas where service is unavailable or inaccessible due to staffing, coverage, etc. We need funding to get independent programs set up outside of general BH/psych services.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	As mentioned previously, there are major supply chain issues with medications like Adderall and referrals for BH/MH services are a year out in many places which can lead to health disparities or death for some patients. Many ASD folks are burnt out and self harm has increased dramatically since COVID.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Positive: new, more accessible modalities (namely telehealth). Negative: bottlenecked services and supply chain failure preventing much needed services/interventions/treatments; reduced masking demands=less burnout; social isolation; new paradigm shift of mental health awareness (self care movement supports mental health support)

Name	Anonymous
Demographic	Autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>Gastrointestinal disorders, like IBS and Crohn's. But also sensitivities to food that can restrict diet, and lead to nutritional deficiencies. Sleep disorders, like delayed sleep cycles, insomnia, recurring nightmares, and the resulting daytime exhaustion. Sensory issues, like discomfort from noise, smells, physical contact, like other people bumping into an autistic person in a crowded setting, or physical contact in inanimate things, sensations from clothing, furniture, etc. Muscle and motor challenges, including poor proprioception, but also postural issues that lead to chronic pain. A lot of the difficulty day to day with Autism is just being physically uncomfortable all of the time.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>Depression, general anxiety, social anxiety due to a lot poor experiences, ADHD, suicidal ideation. The physical discomforts that come with autism can have a seriously negative impact on mental health too. Specifically for people who are diagnosed later in life because their autism was simply missed due to lack of access to knowledgeable medical providers, mental health challenges are greatly exacerbated by knowing they are somehow different, but not quite how or why, and being surrounded by other people who are also aware of these differences without being able to name the how or why, and feeling empowered to mistreat autistic people because of it. Or more simply, bullying. Being subjected to bullying behavior, without understanding why it's happening, throughout childhood and into adulthood, is very hard on the mental health of autistic people. Constantly feeling depressed, anxious, unable to focus, etc. makes it hard to find and maintain stable gainful employment. And being underemployed or unemployed just compounds those mental health challenges.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>More research into possible metabolic differences, especially as they might relate to the metabolism of medications. More research into correcting postural issues that lead to chronic pain. Beyond just research into autistic people themselves, there needs to be research into the scale of gaps in knowledge in medical settings. Do doctors know the different ways autism can present in patients? Do they know how this can change over time, as people grow up and learn strategies for coping with, or even hiding their autism, often even without knowing they're autistic? If a doctor knows a patient is autistic, are they even aware of any co-occurring conditions their patient might need help with in the first place? Can doctors make recommendations that work for autistic people, like giving nutritional advice that can accommodate food sensitivities? Do doctors know that autistic people are capable of making decisions for themselves, including medical decisions? It won't help autistic people for there to be articles published about the gastrointestinal issues, metabolic issues, or postural issues, etc, if there isn't any work done to address whether that information actually gets disseminated to the medical providers autistic people actually have access to.</p>
<p>What could be improved in autism services and supports to help address</p>	<p>Access to services needs to be easier, and information about services needs to be more consolidated. A lot of information regarding autism support</p>

<p>co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>services tends to be directed towards an imaginary audience of only non-autistic parents caring for autistic children. But autistic people grow up, become adults, and need to be able to navigate these systems ourselves when we don't have care givers. Additionally, many parents of autistic children are autistic themselves. Autism related services need to be covered for adults. Often, insurers will have childhood diagnostic service providers, but adult diagnostic service providers, if there are any, aren't covered. This means autistic adults have to pay out of pocket for diagnostic services which is expensive, often between \$1,000 and \$3,000. Insurance carriers need to have service providers for adults in network, so that visiting service providers for autism isn't more complicated than any other health care interaction, rather than forcing people to pay out of pocket and then try to navigate reimbursement, if the insurance company even offers that. Providers need to make it easier to communicate in preferred ways, and to use those methods of communication reliably. It doesn't help to fill out a form and then see the provider hasn't read it, or for online patient portals to take much longer to fulfill requests, necessitating spoken phone calls.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>It just makes everything harder, more uncomfortable. Someone who already had chronic pain may now have additional long term symptoms. And when doctors don't know which symptoms come from where, they often don't seem to know what to do about any of it. Autism can be isolating, and spending long amounts of time in isolation due to COVID just exacerbates the negative impacts on mental health, like loneliness, depression, and then anxiety about going out into public due to the risk of repeating a painful COVID infection.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Increased remote work is helpful, although finding good remote work has been increasingly difficult as many push for return to office policies. For many autistic people, prolonged isolation during lockdown also meant getting out of practice masking. Masking isn't good for mental health, but it is often unfortunately required for gainful employment. Reduced demand for in-person social interaction is a mixed bag. The idea that autistic people don't want any social contact at all is misguided - the quality of the social interaction is important, and while lockdown and remote work reduced the kind of water-cooler office small talk autistic people tend not to like, it also reduced access to meaningful and rewarding social contact that everyone needs. During and post-COVID, there has also been a breakdown in some social norms about kindness, decency, politeness, etc., that is not about autistic people at all, but we especially suffer from people around us being more rude, impatient, or potentially abusive or violent where social interactions were already more difficult.</p>

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	They impair the quality of daily life. They take up extra mental energy that we don't have.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	They impact relationships, jobs, family life,
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	That most of the therapies/schools/jobs expect autistic people to conform to a standardized allistic way of doing things, instead automatically modifying to allow for learning, processing, and working to each individuals strengths.
What additional research is needed to help address co-occurring conditions for autistic people?	The positive effects of polyvagal and somatic therapies, along with EMDR. Being able to notice sensory overwhelm as it is happening and being able to calm down overstimulation/fight, flight, freeze, and faun for oneself in your body before burnout. EMDR does not need talking and is an incredible way to physical feelings in the body, emotions, as well as trauma.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	All of the examples above. Also, the issue of schools/providers seeing people with autism as less human or needing to be fixed to fit in, instead of compassionately supporting them in their learning of how to be successful individuals for the ways their brains work.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	For me I developed more exhaustion/braking fog, since I have more inflammation in my brain and body to start with. Providing people with health information on nutrition would be helpful.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Separating people increased fear, depression and anxiety. This and wearing masks have delayed speech and reading, as well as socio-emotional learning.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gut issues (IBS) Sensory issues around smell & bright lights/contrasting light levels The hyperosmia is especially distressing and isolating.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	OCD - skin picking OCD - contamination phobia Depression Anxiety
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Research on the gut biomes of autistic people Research on the neurology of sensory sensitivities
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Better access to autism diagnosis for adults who were “missed” as children Better expertise/awareness by health professionals about autism & related needs — some of them watched RAIN MAN & think they’re good Insurance coverage for autism-related mental health services AND home modifications Workplaces designed with consideration for neurodivergent workers — tbh this would make things better for neurotypical workers as well and could lower the need for autistic workers to disclose
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It has really been hell for the contamination phobia OCD. Also, realizing that the majority of people don’t care about helping protect vulnerable people in their community (by masking, staying home when sick, etc.) has made me realize what a selfish, cruel society we live in and they probably won’t look out for neurodivergent folks either. I would say that has affected stress and depression.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Most of the (temporary) positive changes were clawed away by institutions who want to get “back to normal” when normal was really bad for some autistic folks & others. Working from home, telehealth appointments, and remote options for attending conferences and other events are all things I had access to during the first 2 years of COVID but have now been dropped. One positive thing that has remained is that most work meetings are still via Zoom so we can stay in our own offices.

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My son has had terrible sleep issues since he was little. He would sleep very little and not continuously and this affected everyone in the house. Lack of sleep for everyone created a health issue for everyone. I could not work effectively on such a small amount of sleep. When he was awake it was not possible to sleep because of his behaviors. We tried all kinds of sleep hygiene and medication but only got hi, up to a reasonable amount of sleep by his early twenties. It still isn't enough sleep for me. I feel as if my life has suffered terribly from the lack of sleep as his caregiver.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My son has autism and bipolar disorder, adhd and has had aggressive and self injurious behavior. Getting help for him has been very difficult and we went through many providers before finding medications that have helped him. I think that most providers don't see coexisting disorders or they would be more helpful. Also, finding educational programs and activities has been difficult. We have had to get psychiatric assurances that my son can participate because of fears about his psychiatric diagnoses. Also, because he can't be responsible for his own medication he ends up in more restrictive programs than if he wasn't on the medication.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My son has intellectual disabilities but also has autistic fixations of certain subjects. He can therefor sound very knowledgeable about his fixations but is unable to function in other areas. This makes it difficult to convince providers of his abilities once they hear him talk at length about football. Many times we are assured that he can function in situations and the everything falls apart. The providers then get angry at us as if we misled them about his abilities.
What additional research is needed to help address co-occurring conditions for autistic people?	Research the training that providers receive to find out if more is needed.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance must be comprehensive and housing must be made available.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Much learning was lost during COVID lockdown. It was never made up.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I deal with sensory challenges which often cause extreme distress and discomfort including noise and textures
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression, anxiety, and ADHD are some things I struggle with for example self harm that comes with feeling depressed and increased sensory input from anxiety and lack of liquids and foods is a major issue with my ADHD due to hyper focus
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	More research into nonverbal and semi verbal behaviors and causes for it
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Having sensory kits and noise canceling headphones be more accessible for people with a diagnosis, extra support to working individuals with autism regardless of level (level 1, level 2, level 3) including payment benefits and insurance coverage especially for people with communication difficulties who either cannot talk or go nonverbal occasionally and better accessibility within loud environments for people who struggle with sensory input and overstimulation
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Finding proper medical care.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Finding a doctor to treat the whole person.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Finding support at school. The pay is so low that people can't afford to be a para or one on one support for these kids.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage and support services
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Disruption of services and classes

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	One of the biggest challenges that we have been faced with is aggression. Aggression is so difficult to treat and causes so much disruption in the life of the child and family.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Due to our sons lack of communication it is hard for our son to express his needs and wants which make the aggression worst.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I think that the crisis centers needs to cater more to behavioral challenges. Most of the crisis centers that we have encountered is experienced in dealing with other mental conditions, but not autism and the goal is to just stabilize the child and send them home. That is why many kids end up back in crisis months or even weeks later.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	COVID caused more son to have extreme OCD symptoms so it is definitely something that needs more research.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I think the COVID pandemic was tramatic fir children with autism and their families. Working remote with our son was extremely difficult. We had to be the teachers and therapist. There needs to be a better system set up when special needs kids have to work from home. There needs to be more resources available to the parents.

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I am having gastrointestinal issues and am not sure what causes them. I have been diagnosed with IBS and have had my gallbladder removed with no clear indication of what caused the chronic inflammation of my gallbladder. My brother has epilepsy and will have to take medicine for it for the rest of his life. My parents and I are in constant anxiety that he will have a seizure when no one is watching. We both have some form of insomnia.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have ADHD as well as generalized anxiety. I have had depression as well. Being a late diagnosed woman has a lot to do with this as I was not able to get the help that I needed or taken seriously as I didn't display stronger symptoms like my brother who is non-verbal. My sister who is diagnosed with level II autism has depression, anxiety, and OCD.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My brother has level III autism and is non-verbal. This is difficult when he has a tantrum or gets upset and we don't know the cause of him being upset. Especially if he is sick or god forbid has a serious illness he can't explain his symptoms. He does use his IPAD but uses it for smaller sentences.
What additional research is needed to help address co-occurring conditions for autistic people?	I think we need to study the physical symptoms or occurring that autistic people deal with and take them seriously. Listen to us when we say we think we have POTS and we think it relates to our autism. Also listen to Autistic adults.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage for sure. Many later diagnosed autistics are self-diagnosed especially people of color and women as we don't have the funds to get a formal diagnosis. More doctors who have studied and understand that autism comes with many co-occurring conditions.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I have a cough that comes and goes. I had asthma as a child so that doesn't help either. My recovery time from sickness such as a cold has also increased.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The positives are more things are online instead of in person. For me that means I feel more comfortable as I struggle with social settings and cues.

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Epilepsy Sleep disturbances Apraxia
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety OCD ADD Aggressive/self-injurious
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	intellectual disabilities communication disabilities
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Provide in-home/mobile medical treatment that is accessible to all and covered by insurance. Full medical coverage for OR time and anesthesia for sedation dental treatment. Training for new physicians in how to work with patients with autism
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Reduction in adult autism services due to staffing crisis. The government still has not learned to fund increased wages for this much needed profession.

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Seizures Sleep disturbances Sensory and motor challenges Visual acuity Diminished reflexes and ability to react
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression Anxiety Sudden mood changes ADHD
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Learning, Developmental, Intellectual and Communication Disabilities.
What additional research is needed to help address co-occurring conditions for autistic people?	More research needed into how their living environment (home, work, community) affects their lives and behavior
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	A lot more training is needed for their DSPs
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Introversion
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	All of those mentioned above

Name	Anonymous
Demographic	Family member of an autistic individual; Service provider, health provider, or educator; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The lack of support for treatment needed for families due to 1) low financial resources to afford doctor's visits and adequate medicines and on going therapies especially those from culturally and linguistically diverse individuals with autism 2) Inaccessibility to social services from language barriers/ lack of information/ technological barriers (e.g., computer literacy, wifi etc) 3) Mistrust for systems and staff due to fear of being judged or discrimination based on race or other social determinants
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Families of individuals with autism and co-occurring mental health conditions are overwhelmed by dealing with daily demands/ and other responsibilities to get through the day which can cause delays in seeking medical assistance. Parents are not always fully informed as to how to help and it can be difficult to sit down to do long term/short term support planning. Schools can be a great support in working with families.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Qualitative studies that highlights lived experiences of parents and individuals with autism and co-occurring disabilities to share. Investigation of IEP accommodations (special education, IDEA) that are frequently used to inform special education teachers and its correlation to improvement in any school related activities. Longitudinal studies that tracks accommodations and related services to investigate the magnitude of the effect on academic performance, personal satisfaction level at school and reduction of challenging behaviors from teachers's perspectives/ parents and students themselves
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	All those listed in the question and, additionally, providing informal and formal support networking system (including ethic societies in the local communities) between families who can share informations and strategies by efficient information sharing through creative platforms. Cultural liaison at each agency to build a bridge between families who lack self-advocacy skills or unaware of their right to receive social services.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	

in-person social interactions and obligations)	
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Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	For my daughter it has been physical activity such as walking as she gets severe pain. She has several physical conditions such as scoliosis, hypotonia, etc. When she was little, she had GI issues which interfered with her feeding resulting on a delay in her development
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My daughter has ADHD, SLD. She gets easily frustrated however, with therapy she has learned effective ways to identify and cope with her feelings (most of the time). Regarding ADHD and SLD, I am starting to notice (she is 14) that she struggles with grasping information from health professionals.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I have noticed that my daughter struggles with comprehending and grasping information provided by health professionals. Unfortunately, most offices do not have visuals nor are trained on how to better attend the needs of individuals with ASD and co-occurring conditions.
What additional research is needed to help address co-occurring conditions for autistic people?	Research in which the autistic community can express their needs and how professionals and neurotypicals can better satisfy those needs. Also, training and education to everyone: doctors, therapists, businesses, educators, etc. about ASD and co-occurring conditions.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Access to services not only for children but also for adults and seniors on the spectrum. More inclusion and less judgement. Insurance coverage for adults and children. Fair employment with fair wage (most people with disabilities live in extreme poverty)
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I have noticed that due to COVID-19 changes people with ASD (and basically everyone) avoid to have any social interaction. This situation impacts autistic social skills.

Name	Anonymous
Demographic	Family member of an autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>One of the most significant challenges caused by co-occurring physical health conditions in people with autism is the diagnosis and treatment of those conditions, which can be challenging and may result in delays. The person with autism may be non-verbal or unable to communicate what they are experiencing. They may be unwilling to cooperate with assessments or accept treatment. Because they may feel unwell, that may make their behaviors more difficult. We have also had providers who didn't want to pursue a diagnosis or adequately evaluate the situation because it was too hard. For our daughter, challenging behaviors and noncompliance made her physical health conditions harder to manage. When she was diagnosed with type 1 diabetes in adolescence, that was particularly difficult because it required repeated injections and finger sticks every day. Some of these became routine, but there were times when she needed an extra shot or an extra check of her blood sugars. That is the nature of type 1 diabetes. There were also ways in which diabetes affected what she could eat and when, which had to be handled delicately to avoid a meltdown. High blood sugars could affect her mood, and diabetes, in general, affected how independent she could be because emergencies could happen anytime.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>Our daughter's schizoaffective disorder made challenging behaviors that much worse. It was difficult to take her anywhere safely or leave her with a sitter, which was isolating. There was physical and emotional harm to us and our other two children. Our daughter also had multiple suicide attempts and inpatient hospitalizations. Most hospitalizations had no effect though. She had therapy that made little difference. Her psychiatrist tried a variety of medications, and they helped, but not enough. In short, we found that there were few resources or help available to us for decades. Another challenge we experienced was not being able to integrate our child into the schools we tried. She was in multiple different special programs, none of which worked for long. She would refuse to go, run away, or act out. She had a major crisis in early adulthood. One of her medications caused her to develop a complex delusion, and she was hallucinating daily. Her psychiatrist recommended a change, but she refused. It was impossible to put her on a 72-hour hold because she was not yet a threat to herself or others. We had to wait until a disaster occurred. When it did, she was arrested and taken to jail. Fortunately, no one was hurt, and she was released to a hospital where her meds were changed but we had to deal with the courts and legal system for a considerable time after that. The systems in existence simply don't work for individuals with autism and mental illness.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>Our daughter's autism affects her significantly in many ways. She does not read social cues, make eye contact, or understand social conventions. Her social communication is poor, and she struggles with communicating in complex ways. She is also very poor at reciprocal conversation and talks almost exclusively about her own interests and experiences. She wants friends, but these obstacles make that difficult. Feeling isolated and misunderstood is one of the bigger challenges for her. Another major challenge for her is her lack of functional skills. On the Vineland, she consistently scores in the very low range even though her IQ is intact. It is doubtful that she will ever be able to live independently. We have tried repeatedly to teach her these skills; however, her progress has been slow to non-existent. Not being able to live independently changes the game plan entirely. She will probably need to live in a host home and depend on others</p>

	to help her with almost all aspects of her daily life including getting out into the community since she doesn't drive. It means a less full and independent life for her.
What additional research is needed to help address co-occurring conditions for autistic people?	Perhaps we need to be researching integrated models of care specifically designed for individuals with autism. There are so many potential co-morbidities that can impact quality of life, independent living, and health. A multidisciplinary approach may be needed. I imagine a center where healthcare, different therapies, navigation services, and mental health services are all available. We probably need more research into how to meet the needs of autistic students with co-occurring conditions in the schools. For co-occurring psychiatric conditions, one of the most challenging co-morbidities, researching how the START model at the University of Vermont could be modified and expanded to meet the needs of children with autism could make a difference. For adults, research into how to help them avoid mental health crises or how to respond more effectively when these occur would be beneficial as well.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	What I really wish for is a single organization that could provide resources, help with navigation, give emergency support in a crisis, and provide access to a group of autism experts for managing physical and mental health conditions. Having one organization to call and that other professionals could refer families to would be helpful, improve access for all individuals, and make the process so much easier. Services are too fragmented and siloed now.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Connections with others, once lost, can be so hard to re-establish. Isolation is already a significant issue for many individuals with autism, and the pandemic only made this worse.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	All the examples given are things we experienced, too, and they did increase our adult child's isolation, which worsened her moods and anxiety. Her therapist even commented on how poorly Zoom calls work for her. It is as though she is watching a program on television, and she focuses primarily on watching her own image. As a result, communication is worse, and she is less likely to pick up on social cues.

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Anxiety, behavioral challenges and sleep disturbances.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My son is an adult and people have expectations of him as being "normal" or "typical"...but he doesn't always understand directions and cannot read the room. He gets frustrated and anxious and acts more like a 5-year-old when things get really difficult for him. This doesn't usually get a positive response. Some health care providers don't understand the impact of his literalness on his ability to follow their instructions. He has become aggressively agitated lately as society has a set of norms and standards he can't meet, and no one extends grace to him.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Again, as these are "silent" disabilities...at least initially...my son is very challenged by people who expect one thing from him but get another. Employment has been very difficult for him to attain as people can't...or won't...make room for additional support and understanding. He has three learning disabilities and an inability to read social cues. Makes it hard in the workplace. He has a HS diploma and is cognitively able to hold full-time employment, but he does need assistance occasionally that often isn't given.
What additional research is needed to help address co-occurring conditions for autistic people?	Would love to see someone looking into the interaction in the brain between the co-occurring conditions because what I often see is an approach meant to help with one condition....Adderall for ADD, for example...exacerbates another condition...anxiety, for example. If there were a Venn diagram(s) mapping out the brain, perhaps the therapies in the center of said diagram would yield a bigger benefit.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More training for providers. An understanding that HPPAA protects the patient but it is ridiculous that we have to jump through hoops to talk to providers even after it's in the records that we have permission (i.e., HPPAA shouldn't be a one-size-fits-all approach when it comes to folks with disabilities). More training for employers in ADA responsibilities. And of course, equitable access to services, which is a huge problem in Maryland, with an extensively long list of people waiting YEARS for DDA services. Real world: simply telling my son to do something doesn't work, nor does printing out standard pages of info about a condition and handing them to him. Checking for understanding, and or writing different instructions in a manner accessible to him would go a long way toward better care. And of course understanding his family members are equal partners in caring for my son.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	My son has never had COVID-19, but the isolation required to keep that true has sent him on a tailspin. He craves social interaction and the first 18 months of the pandemic were a disaster for him. He lost both jobs and sat at home, forgetting all of his manners and social skills. Still hasn't recovered.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services,	Ahh, answered this previously. The isolation and lessened in-person interactions have taken a heavy toll on my son's mental health and emotional well-being. He lost his jobs, and lost his way. Sitting home day after day after day with only his parents to interact with has led to major regressions in behavior, understanding and ability to perform adult tasks.

increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I've seen a lot of autistic people develop EDS and POTS, as a more extreme example. For me personally, I have N24, which is a sleep disorder, and it developed in early 2020. I also deal with misophonia and I've had gastritis, which will hopefully heal, since early 2022.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression and Anxiety are super common among autistic people, me among them. I'm also trying to seek a diagnosis for ADHD.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I have an autistic friend with dyslexia, but I'm not aware of anything else like this in my own personal life. I actually had hyperlexia as a kid.
What additional research is needed to help address co-occurring conditions for autistic people?	Gut health is definitely something to look into. But also look into how popular therapies like ABA affect the mental health of autistic people, because I've heard some very negative stories.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Medicaid could become easier to apply for as a provider, because I've heard the process is lengthy, confusing, and frustrating. And the poorer of us could benefit from more options. Also, it would be nice if SSDI offered a living wage rather than poverty wages.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	As far as I know, I was never diagnosed with COVID, but I could have caught it at some point and it went undetected. And it's possible my new sleep disorder is connected, but I can't say for sure.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	To those of us who become more distressed at losing their normal routine, it was damaging. But to those of us who struggle in highly social spaces, it was a nice reprieve. Seeing a therapist over telehealth has been helpful for me for sure.

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The most significant challenge is that Co-occurring conditions are underdiagnosed. This is primarily due to (1) the patient assuming everyone has their symptoms and (2) the symptoms being belittled/downplayed by healthcare professionals. A lack of diagnosis is the first barrier to treatment.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The most significant challenge is maintaining the energy required to participate in family life in a “normal” capacity. This can be keeping up with household tasks, maintaining relationships, caring for oneself, etc.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	The most beneficial research would be toward helping patients quickly identify any co-occurring conditions they may have quickly so that quality of life may be improved. Comprehensive screening test or a genetic test panel might be two ways of accomplishing this.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	(1) Improving access to diagnosis by increasing qualified professionals or incorporating genetic testing and diagnostic tests. (2) Removing stigmatized restrictions and policies on formally diagnosed autistics that prevent others from seeking a diagnosis. Some examples are autism registries and occupation restrictions. Services are inaccessible if you are not diagnosed.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Benefits: (1) Increased discussion of mental health in society (2) Increased remote work and work flexibility (3) Increased concern for spreading any illness Negatives: (1) Increased cost of living (2) Increased job market volatility (3) Increased mental health concerns Autistics sometimes struggle to maintain employment due to lack of accommodations, personality conflicts, and low energy.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I consistently feel too tired and too weak to keep up with the amount of tasks required to function as a fully independent adult due to my chronic exhaustion caused both by insomnia and sensory overwhelm. Things such as doctors appointments are consistently put off for dangerously long because I am simply too tired to do it.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I feel an immense amount of guilt and shame around my executive dysfunction. I feel like I am seen as lazy and entitled for all the invisible ways in which I struggle.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Extremely difficult to find and maintain employment due to my difficulty communicating with hiring managers and supervisors.
What additional research is needed to help address co-occurring conditions for autistic people?	Most research focuses on the needs of nonverbal autists, as communicated by their caretakers. Autistics who have the ability to understand and voice the accommodations they need should be more involved in the research and should be taken more seriously, as many of our needs align with nonverbal autists.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Increased focus on support for autistic adults instead of just children. These services can include things such as providing assistance for filling out complex paperwork and forms such as tax forms, applications, signing up for other government programs and services, medical paperwork, insurance papers, etc, disability benefits for autistics who do not have co-occurring physical disabilities, as sensory overwhelm can greatly reduce the amount an autistic adult is able to work, Communication accommodations for those seeking access to these services, as many autistics struggle to communicate over the phone. Improved education about autism amongst providers, as many are openly discriminatory towards autistics.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The increase in remote work has been extremely beneficial in the employment of autistics. The decreased care for public health has been very distressing for many autistics who use masks both to hide unnatural facial expressions and to avoid the spread of coronavirus.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Having Trouble sleeping due to a lot noises in my environment. I have gastrointestinal problems. I struggle to be around too much light.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have anxiety issues, ADHD, and recovering OCD.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I have learning difficulties, it takes longer for me to learn things than the average person, and have some difficulty talking once in awhile.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Adhd, depression and anxiety
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	How changing the overall environment in society can positively affect autism and society as a whole. Like lower lighting or quieter or no music in stores and restaurants.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Make autism testing something that can be done at the pediatrician at least on some level. Testing cost me 3,000.00\$ out of pocket because they didn't take our insurance.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Maintaining a job due performance issues caused by frequently having to use the restroom. Finding job appropriate clothing that is sensory friendly. Being forced to wear something that triggers my sensory issues causes problems at both the workplace and at home. Being able to fall asleep at a decent time.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	OCD, anxiety, and adhd make it difficult and at times impossible to start and complete everyday tasks such as cooking, cleaning, showering, grocery shopping, and making phone calls. They also at times make it difficult to socialize, fall asleep, concentrate, and affect short term memory.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	The severity of symptoms and effectiveness of treatment when comparing autistic people to non autistic people. I cannot find much information on this. Autistic people and non autistic people experience things differently because of the way the brain processes everything. If we were to find any differences in how autistic people experience co-occurring conditions compared to non autistic people, we may be able to better treat co-occurring conditions in autistic individuals.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	The two things I always hear and see people talking about are lack of services and accommodations in their area and being unable to access services due to income and insurance coverage.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Reduced in-person social interactions and obligations.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	ADHD Insomnia Restless leg syndrome EDS C-PTSD/PTSD(trauma of being autistic in a world that is designed for allistics) OCD Anxiety Sensory overwhelm LPRD/GERD/IBS ARFID Misophonia Dyspraxia Pathological demand avoidance Executive dysfunction Visuospatial issues Migraines POTS Emotional dysregulation Depression
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD Anxiety Depression OCD Visuospatial issues Maladaptive daydreaming Insomnia Misophonia Pathological demand avoidance Executive dysfunction
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Migraines Random loss of ability to speak Meltdowns Sensory overload Extreme fatigue Burnout
What additional research is needed to help address co-occurring conditions for autistic people?	The link between ADHD and ASD. Why 9/10 of autistic women have experienced sexual assault and ways to effectively teach the public about consent to prevent this. How to make society more inclusive so that PTSD and C-PTSD are not expected comorbidities. Ways to actually support autistics and NOT ABA. Why ABA is even legal(it should not be). Effective protections for ASD adults under ADA to help them keep their jobs and have support. Better methods of teaching doctors how to take the disabled more seriously as well as women and anyone who is not a neurotypical white man. How to help autistics get better sleep. Methods for teaching autistics ways to do everyday things like cleaning and house chores for themselves in a way that is doable and not overwhelming. Maybe more accommodative decides for Autistics that help them get these things done more easily without shame, or guilt, that are low executive functioning friendly.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Banning ABA therapy. Autistic therapy that addresses the needs of autistics and NOT focused on the erasure of unwanted autistic traits by neurotypical standards. Better education for the general public about autism because the people tend to be misinformed. More accessible autism assessments for adults(cost and availability to get in without waiting a year). More significant workplace protections. More research into autism that includes adults, women, trans, and BIPOC. Better diagnostic standards that can be done by GPs so access to a diagnosis is more accessible. Not allowing government or scholarly resources to recommend anti-autism things to be recommended to parents of autistic kids like ABA(dog training for Autistics) or Autism Speaks(hate group). Autism specific care that is covered by all insurance by law. Universal single payer insurance. This gives access to everyone, allows doctors to make decisions not health care, saves the taxpayers money, and will hopefully prevent people from going into medical debt for just trying to get the help they need to live functionally and have a better quality of life.

<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>Many people with ASD have comorbidities that make them more prone to Covid. We know long covid is having major and lasting impacts on the people who are struggling with it. With sensory issues from ASD alone being sick at all is even more overwhelming as you are constantly taking in all data from things around you(sounds, smells, feelings like textures, and more) and it gets to be overwhelming. Being sick is like having all of that intensified and being in a jail of your own body where the discomfort cannot be escaped. I find ASD people tend to be more empathetic and are more likely to get the vaccine, wear a mask, and social distance or stay home when they can afford to miss work. Often though neurotypical society is not willing to avoid going to outings, or out to bars, or go to other social gatherings and dismiss the pandemic as something that only effects those who are already at risk as though the people at risk are less deserving of being able to leave their homes or to be safe. I find this to be very frustrating and selfish.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Telehealth has been helpful so if I have a migraine I don't have to drive, and I don't have to be around people as much which feels safer. I like not having to be around people as much and used the pandemic as an excuse to avoid some social situations. I feel like people, especially allistics, don't really take covid seriously anymore though which is very unfortunate.</p>

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	This can vary, but many people have a issue with things like ADHD, OCD, sensory issues, and/or issues like Epilepsy. Weirdly, Epilepsy is more commonly a female Autistic issue compared to a Male Autistic issue. I'm one of those that has Epilepsy myself.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Again this varies - extra stress, anxiety, perfectionism, and extreme confusion (thanks to taking things too literally and/or not learning at the same rate as Neurotypical people) are all possible.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Learning disabilities are pretty common, but I'd say that contributes to all the other disability types noted. How can you communicate well and/or hit the intellectually expected points if you don't learn, period, or learn around the same rate as other people? I'm not saying that we can't learn - I'm just saying the learning rate would naturally vary a lot based off others around us and whether or not we'll have classes to help us learn more effectively.
What additional research is needed to help address co-occurring conditions for autistic people?	I'd say figuring out the rates of co-morbid conditions with: Level 3s autistics, Level 2s autistics, and Level 1s autistics. Is one co-morbid issue more common with a particular level? Does the person's level change how the co-morbid issue affects them compared to someone at a different level but same co-morbid issues? Does sex and/or gender change these as well? I think these questions need to be researched further.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Well, the biggest problem I have is not feeling I can be completely honest about my condition. Let me explain - I was diagnosed with Autism at 2 and 1/2. I was given therapy, put in Special Ed, was in Head-start, and was able to get out of Special Ed by middle school. I was good enough at masking and acting relatively "normal" that most people didn't realize I had Autism. My co-morbid issue of Epilepsy didn't start until my mid-20s, one month before my senior year of college. Due to this, I ask (and often get), accommodations as required for the Epilepsy specifically, since I don't ask for too much (just being able to take meds and not having to do certain potentially dangerous things). I feel I can't ask for accommadations for Autism, even if I needed it, due to the fact that most people don't understand and/or think in stereotype on what Autism is. If anything, as an adult, I've used certain traits involving my Autism to get promoted without saying that "I have Autism" at one job. Let's just say being able to figure out where around 3/4ths of a Super-Walmart's things are based on where are 5-6 items is a useful ability as a Digital Shopper.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I think it made some of us more stressed than we were before due to how much changed.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on	Increased Hybrid School was great for me, but the way things changed in retail was rather horrible. Zoom meetings are artificial but a little less stressful than in-person meetings. A lot of jobs can't go hybrid, and that's

physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

where people seemed to get worse to all employees, which made things worse for anyone there. Since, I was working retail and currently work at a car dealership, these are both included. Also, I hate telehealth - talking over a phone about your Epilepsy doesn't allow for legit medical tests that can help a doctor determine change in condition. I apply that same logic to a variety of chronic conditions.

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Everyone automatically blames autism for everything and do not continue to look for the root causes. They just see the autistic behaviors
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Getting FAPE. Often need to bring lawyers in. Schools will blame the child for not being able to learn when they are only looking at the autism diagnosis and ignoring the rest. Therefore appropriate accommodations are not provided for learning. It should be a daily fight for the parents
What additional research is needed to help address co-occurring conditions for autistic people?	Common coexisting issues and how they mirror autism. Listening to the child's advocate (parent or 3rd party)
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Many providers do not take insurance due to rates paid back. Therefore parents have to pay out of pocket or not provide
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Delayed schooling. Did not pick things up at same speed as neurotypical children did
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Being at home I was better able to see how my child was not leaning - and after 18 months of legal battles was able to achieve out of district placement and she is now where she needs to be

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Personally, I have multiple chronic illnesses including but not limited to Crohn's Disease and chronic migraines. I also experience minor sensory challenges.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Again, speaking for myself, I have ADHD, severe depression and anxiety, gender dysphoria (I am a transgender individual), as well as near constant chronic suicidal ideation. My suicidal ideation has never made me a danger to others, and has never even been a reactionary, "need to do something right now" type of feeling, but a drawn out, calm and conscious desire to not be alive anymore. This is largely a byproduct of having multiple chronic illnesses, compounded by extreme negative societal opinions and discourse surrounding my status as an autistic and trans individual. It should be no surprise that people like me, who feel both unwanted and targeted by the world at large, don't want to be a part of this world anymore. The only real solution to that is widespread acceptance and a constant, conscious effort to fight back against harmful, stigmatizing, and flat-out untruthful beliefs.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I struggle with communication and certain social norms, but otherwise I am a college-educated individual that has minimal-to-no intellectual disabilities. I had near straight A's through all of schooling, and I have an IQ of 160. There is a false belief circulating that autistic people cannot make decisions for themselves, completely stripping us of our agency and rights as human beings. Especially in regards to trans health care, many states are now pushing for a complete abolishment of gender affirming care for people who are also autistic. Not only is this unbelievably dangerous and tantamount to genocide, it reduces autistic people to be some sort of unthinking, unfeeling beings that can't take care of themselves. It is frankly sickening. Medical decisions concerning one's own body should be up to the individual, not a nebulous governmental entity that has likely never even interacted with trans people before.
What additional research is needed to help address co-occurring conditions for autistic people?	There needs to be more research all around, concerning mental health, autism, and co-occurring disorders. The DSM as it is now is grossly outdated, extraordinarily locked into a nonexistent gender binary. Our knowledge of how the human brain works is still extremely limited. We may know the names of some neurotransmitters and vaguely what they do, but we have no real idea of how the brain functions as a whole, and how it interacts both with the individual and the external societal context it exists in. Many existing diagnoses are immensely oversimplified, often overlapping with others in many significant ways, which to me makes the labelling of people using these disorders pure guesswork, and incredibly dangerous as any sort of foundation for legislature. We know nothing, and yet we find ourselves trying to put people in these boxes and subsequently make laws based on unproven and outdated science largely funded by cis, white, heteronormative financial sponsors. 50 years ago, being gay was considered a mental illness. What will change 50 years from now?
What could be improved in autism services and supports to help address co-occurring conditions for autistic	All examples already listed are valid. Equitable access would be ideal, and insurance coverage that covers most (if not all) medical treatments that the individual finds necessary would be even more ideal. Continuing to add

<p>people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>barriers and hoops to jump through in order for people to get medical care WILL kill people. Full stop.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>Covid has had a lasting impact on everyone's health, including autistic individuals. More than welcome realize, frankly. Little research has been done on "long covid," and anecdotally many of my friends are still struggling with their health as a result. Covid also had (and continues to have) a significant impact on the mental health and socialization of every person on this planet. And those with comorbid conditions will always suffer the most.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Covid has been a largely insulating epidemic, all new digital connection possibilities aside. There have absolutely been disruptions in services, including but not limited to mass shortages of medications, and the increased reliance on remote work and schooling has made traditional socialization much more difficult, especially for those who already struggle with social norms. Covid became an excuse to isolate oneself, making it exponentially harder for people with social struggles to get back into the world and be social again. Personally, I have much more social anxiety now than I ever did pre-pandemic. I find it much more comfortable staying at home by myself, when I know that pushing myself out of my comfort zone is necessary for my socialization and mental well being. But being immunosuppressed, I'm even less inclined to risk leaving my house in fear of exposing myself to the continuing ongoing threat of covid. The pandemic never ended, regardless of how people feel about it.</p>

Name	Anonymous
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Lack of understanding by providers Diagnostic overshadowing Lack of access to safe medical care Trauma
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Lack of understanding and education in providers Diagnostic overshadowing Lack of access to safe medical care, behavioral and psychiatric interventions
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Low expectations Infantilization of individuals with disabilities Lack of education Workforce crisis
What additional research is needed to help address co-occurring conditions for autistic people?	Research is needed to identify appropriate interventions and treatment and increase education of providers
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Provider education Access to appropriate trauma-informed treatment and services Significant investment in workforce expansion and education Anti-racism education for providers Behavioral supports in healthcare settings Sensory friendly and trauma informed environments Human rights
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Lack of access to services and placements Workforce crisis Trauma
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Access to telehealth has improved Provider burnout Workforce crisis

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The following neurodisabilities frequently cooccur with Autism, as they do in our family: Postural Orthostatic Tachycardia Syndrome (POTS), Ehlers-Danlos Syndrome (EDS), Small Fiber Neuropathy (SFN), Mast Cell Activation Syndrome (MCAS), and Gender Dysphoria. We have access to multiple specialists at Stanford, which is significant because many medical providers haven't even HEARD of these conditions. Further, schools and teachers disbelieve, doubt, and gaslight because these conditions are invisible. You cannot see someone's pulse skyrocket or one's adrenaline surge or brain fog settle in or gastrointestinal upset strike -- all for no reason at all other than one's autonomic nervous system malfunctions. Clueless physicians and educators will say, "You look fine." That ignorance is outrageous and the MOST significant barrier to appropriate healthcare and a Free Appropriate Public Education (FAPE) per the IDEA. Doubt and disbelief. The next challenge is that there is little to no research into these comorbid conditions and there are ZERO treatments. ZERO.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Imagine being chronically disbelieved by those whose job it is to provide medical care or to educate you. We have had to have the Office of Civil Rights, US Department of Education investigate our school district several time -- several times -- because they ignore 504 Plans and IEPs. The stress of having to cope with physical illness is difficult in and of itself, but to have physicians and educators compound that is overwhelming. So, yes, depression, anxiety, and more.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Unless a family has the financial resources to pay out of pocket for a private assessment, the special ed assessments tools that schools use identify next to nothing. Ever Autistic person is unique. Every person with learning differences is unique. Better, more nuanced, and more specific assessment tools will surface and identify each person's unique combination of learning differences and strengths -- but it costs a small fortune to do so. Most families have to rely on schools/school psychologists and many kids fall through the cracks as "fine," and don't get any academic or learning support or scaffolding.
What additional research is needed to help address co-occurring conditions for autistic people?	FUND RESEARCH for: Postural Orthostatic Tachycardia Syndrome (POTS) Ehlers-Danlos Syndrome (EDS) Small Fiber Neuropathy (SFN) Mast Cell Activation Syndrome (MCAS) There are NO TREATMENTS for ANY OF THESE. Find them.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Stop creating budgets that provide only for a few to be helped at the lowest possible monetary levels of assistance. Even the bottom of the barrel is higher than what's allocated to APPROPRIATELY help the disabled community.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on	Remote school was the BEST idea and plan of action in regard to protecting kids and everyone's health in the midst of the COVID-19 Pandemic. The DELIVERY of education during this time was the WORST. Teachers, tools, and

physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

technology were horrible. More than a year of education was lost. Teachers gave up. We saw it.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I have Hypermobility Ehlers Danlos Syndrome, POTS, & MCAS, all common alongside autism. Autism makes self advocacy in medical settings very challenging and almost no one knows how to approach management with sensory processing problems in mind. Navigating ER visits is nearly impossible on my own due to miscommunication and I think these challenges with doctors have contributed to more serious disability, as I now require use of a wheelchair, rollator, or cane, depending on the day and have severe chronic pain. I have non-verbal episodes and meltdowns, which most medical practitioners (aside from autism specialists) don't know how to deal with. The problems this causes can be very dangerous and I have been injured by doctors before as a result. All medical practitioners need to be able to navigate interactions with autistic people for our safety.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	It's very difficult to find a therapist who understands autism beyond a very specific stereotype of the high support needs young boy.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	-Medical bureaucracy is incredibly complicated and difficult to navigate, especially when you have significant communication impairments. This either needs to be simplified, or autistic people need advocates to help them navigate. Additionally, it would help to have more options for how to communicate with service providers. For instance, I struggle profoundly with verbal interactions, but not so much with written. However, it's rare for any bureaucratic institution to allow fully written communications. -Doctors need better training on how to communicate with autistic people and others who may not communicate in a typical allistic way. They need to slow down with us, carefully explain, respond to questions, and not think that questions are a sign of conflict or non-compliance. Alternatively, access to some sort of advocate or intermediary in medical settings might help.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services,	COVID-19 was a major disruption to the routines of almost everyone on earth. For autistic adults, like myself, who are heavily reliant on routine, this was and is a huge problem. I am 38 and have managed my whole life by maintaining strict routines and structures in order to function as normally as possible. That all collapsed in 2020 and now I'm on my own trying to figure out how to rebuild routines and support structure. I'm finding this to be

increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	impossible without help. But no help is available. This impacts my mental health, my ability to work, my ability to care for myself, and my marriage even ended. It's devastating.
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Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory and motor challenges in addition to things like PICA require the individual to be under constant supervision. A caregiver must stay home and not seek employment. Adequate and affordable care is not currently available. Gastrointestinal and sleep issues affect academic performance and school attendance. Public schools need to have the option of flexible schedules for those with serious conditions. Research needs to be done on sleep aides like light therapy and melatonin for children. Research into gut health should continue.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Many co-occurring mental health conditions exacerbate autism symptoms. Opposition to change can go from dislike to a panic attack due to anxiety and emotional regulation issues. In general the impulse control and emotional regulation issues present in conditions like ADHD make autistic tendencies more fraught. These co-occurring conditions also make misdiagnosis more likely especially in girls whose autism presentation is less obvious. The combination also leads to medication being used for the non autistic condition and nothing being done to address the autistic needs.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	In early years schools tend to address these conditions and ignore the autism. Communication issues and some of the other learning disabilities can lead to gifted children not meeting their potential. Schools need to address the needs of the twice exceptional individuals by providing the necessary accommodations and also providing an enriching learning experience.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage for an individual to see multiple mental health providers in order to meet all their needs. Insurance coverage for communication supports and devices. Teachers and administration in public schools need to be educated by health organizations on how to better meet the needs of the students with autism.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	The need for masks negatively impacted how well providers could support individuals with communication issues. Virtual schooling did not work for severely impacted autistic individuals even though it was sometimes beneficial for those with only social issues such as bullying and large class size.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	It provided alternative educational and work conditions that were beneficial to those that found the typical environment stressful.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory processing disorder(s), insomnia, hyper mobility, etc.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression, anxiety, ADHD, suicidal ideations and attempts, etc.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Developmental, cognitive, social, and intellectual disabilities
What additional research is needed to help address co-occurring conditions for autistic people?	Ask the Autistic person themselves about their struggles rather than their loved ones or caretakers. Every autistic person has different needs and accommodations that need to be addressed by researchers. Research on physical and mental health conditions faced by Autistic people needs to be expanded upon. Research on marginalized Autistic people such as women, POC, and LGBTQ+ needs to be expanded upon as well.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage, equitable employment opportunities, better physical and mental health services, etc.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Worsening of physical and mental health, less access to needed care, less energy, etc.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Positive and negative impacts may depend on each Autistic individual. Personally, positives include less face-to-face interaction with strangers and mean people and easier access to online school, health appointments, and shopping. Negative impacts include less face-to-face interactions with loved ones and worsening of physical and mental health symptoms.

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Very difficult to work full time. Also, very difficult to get any help or support as an autistic adult. The government (social security) does not help adults with disabilities, even after multiple applications and requests. The government thinks that autistics will magically not need support when they turn 18. As an autistic adult, married, raising a family, it is very challenging. I could use programs and support, both financially and socially.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Very easy to be anxious and overwhelmed by trying to navigate day to day life, especially with no support systems in place for autistic adults. There needs to be government funding for autistic adults because working full time is not feasible mentally.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Social and communication deficits make it difficult to navigate daily tasks, especially trying to maintain employment.
What additional research is needed to help address co-occurring conditions for autistic people?	Research how to get social security disability or some other government funding to help autistic adults survive and thrive. It is a joke that there aren't any support programs in place to help us.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Need to actually provide services, period! Autistic adults do not have access to any services or supports. No insurance, no income, no support systems! And when you apply for social security disability, that's a joke! They make it a game of dragging it out as long as possible and denying you as many times as possible, hoping you give up or go away!
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Covid 19 and the lockdown/isolation was a big tipping point that allowed many masked adult autistics to go into autistic burnout. The autistic burnout and mental health crisis of that caused many autistic adults to seek therapy and help of diagnosis to understand and support their autism.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The positive change from covid 19 is the increase in autistic diagnosis for adults, and seeking help for mental health. The increased availability of telehealth for doctors and therapy has been positive.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	One challenge is becoming overwhelmed by the amount of issues occurring at once on a day to day basis which can cause debilitating symptoms. Another challenge is being able to keep a full time job while also maintaining a stable living environment. All of the health issues combined tends to create circumstances in which holding a job becomes impossible.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Seeking professional help is a challenge due to many autistic children going undiagnosed. Professionals are unwilling to diagnose adults because they either believe all autistic people get diagnosed in childhood, or they have doubt as to their ability to diagnose an adult due to the diagnostic criteria being mainly for children. Seeking disability help without a diagnosis is impossible and discrimination because of a lack of diagnosis is extremely common.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Research into how autism affects women compared to men, how autism presents based on age, and how autism can differ because of race. Co-occurring conditions need research based in finding out if the cause is genetic or environmental.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Access to mental health care such as therapists and psychiatrists that are knowledgeable about autism and its comorbidities that are covered by health insurance. Having more widespread information about where to get help, and having more options and information about having patient advocates during appointments. Having easier access to case management options covered by insurance.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	COVID 19 has caused a widespread belief that autistic people will not be protected and will instead be left to die with other disabled people because non autistic people are unwilling to help make things more accessible to autistic people. And they're also unwilling to advocate for autistic people, especially those with conditions that lower the effectiveness of their immune system.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	It's much harder for anyone to get hired for a job, and autistic people are often not hired because hiring managers will favor non autistic applicants and discriminate based on requests for accommodations in the work place, as well as wording their rejection differently or not giving a reason at all in order to avoid lawsuit. Autistic people that are occasionally hired to a new job have a much harder time keeping that job due to the same discrimination. Managers will find a reason that is unrelated to autism to fire them for even if it's false, or in the case of at will employment they won't give a reason at all. Reduced in person interactions can help sometimes, but other times it means more phonecalls which can be a detriment because multiple phonecalls can be overwhelming due to being unable to understand tone and having no way to see the person on the other end to look for clues

	<p>in body language. Telehealth can be helpful in some cases but in cases like seeking therapy it can be detrimental to the treatment being effective and cause anxiety due to internet access, connection issues, and having a totally private space for a long enough time to talk about private health issues with no possibility of being overheard.</p>
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Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I suffer from insomnia and have such a terrible time sleeping at night. I don't feel rested when I wake up the next day. Sometimes I don't even sleep at all because of my insomnia. I also have gastro issues which make my stomach hurt frequently. I also have severe sensory issues which cause my diet to be extremely limited. I also cannot wear a lot of fabrics due to my sensory issues
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have anxiety, depression, and ADHD along with my autism. Anxiety is a big struggle for me because I'm always worried about something. I feel like anxiety crippled me and makes me feel almost frozen. My ADHD is also really bad. It causes my thoughts to race and I have a hard time with emotional regulation and executive dysfunction.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I have a hard time with conversations due to not understanding social cues and not being able to make facial expressions. It makes it difficult for me to make friends
What additional research is needed to help address co-occurring conditions for autistic people?	There needs to be more research on sensory issues and how serious they are. It's not autistic people being picky, it's a real and serious issue that we wish we didn't have. There also needs to be more research on autism in adults and AFAB people in general
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I think insurance coverage would be really good so that we can get the help we need. Also, educating providers on autism and what it actually means to be autistic. They shouldn't treat us any differently than someone who's allistic. They should take our issues seriously
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	COVID has made my depression worse. It has made it more difficult for autistic people to have close friends and be social than it already is. For a lot of us it has also made our anxiety way worse. I know that that's true for me.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I think the decrease in being able to go out in person and actually talk to others and do things we enjoy outside of the house has affected us very negatively. It's hard for autistic people to deal with change so taking that away and then giving it back, especially when we already have a hard time with social interactions is so difficult and hard for us to navigate.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Many comorbidities like EDS, POTS and Celiac are often difficult to diagnose, and require significant work on the autistic individuals part to advocate for themselves/get doctors to listen to them. Additional training for medical professionals about autism would help autistic individuals be taken seriously about their medical concerns. I was once told by a cardiologist that I was anxious and that was why my heartrate was abnormally high. I never indicated that I was experiencing any anxiety, nor was I. This is a very common issue.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Autistic individuals, especially those who underwent harmful ABA “treatments” often struggle to trust mental health professionals. In my experience, once I have built trust with a therapist, it is very common that they won’t be sure how to help me because I understand cognitively what happens in my mind. That does not mean that I can process or necessarily emotionally understand what I am experiencing.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I do not have any diagnosed learning disabilities, but as someone who struggles to understand mathematical topics significantly more than in any other subject, teachers often told me that I “was too smart to be struggling” and things along those lines. Schools providing individual tutors (who actually teach the student, rather than just giving the answers) would probably help way more than just one teacher can
What additional research is needed to help address co-occurring conditions for autistic people?	Any research not done by eugenicist groups like Autism Speaks.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Providing autistic adults with a social worker or advocate who can assist them with communicating with doctors, filing taxes, applying for social security, and other extremely complex tasks would likely be beneficial to many who do not have a care-taker who can fulfill that role.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I have been made fun of/harassed in public for wearing a mask and taking basic precautions to avoid getting sick. I caught Covid from work before the vaccines were available, and it permanently scarred my lungs, worsening my asthma. It has increased my anxiety from going places in public.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	PMDD, hyper mobility, chronic fatigue, high glutamate levels
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression, self injury, anxiety, panic attacks, fight or flight, migraine, burnout
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Elopement, poor interception, poor proprioception, disordered eating habits, language acquisition, sensory motor, bruxism, monotropism, auditory processing
What additional research is needed to help address co-occurring conditions for autistic people?	catecholamine and glutamate studies. Delineating differences between autism and cptsd, BPD, and other disorders that have comorbidities that are often used in misdiagnosis of autistic individuals.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Eradicating ABA therapy and instead focusing on guidance for accommodations rather than assimilation to allistic standards. Education in medical professionals for identifying autism in adults. Mandating public services like education to use up to date resources like the DSM-5-TR instead of the DSM-4, which was published in the 90s. Equitable and nondiscriminatory practice for immigration policies, job procurement, housing, etc.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Long-COVID susceptible, along with amplified sensory issues regarding its symptoms. Agoraphobia for a culture that's increasingly less covid conscious. Increased difficulty gaining or retaining employment due to COVID and corresponding symptoms. Lack of equitable access to testing and prevention due to out of pocket costs.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Covid presence interrupts routine, lack of focus conscious behavior amplifies concern of spread, lack of information literacy from allistic is deeply frustrating, mandating return to offices and in person interaction increases anxiety. Ableist policies on lax covid regulations extends to other disability inequities including autism.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The most significant challenges would be daily life struggles and also getting health care officials to take the struggles seriously.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Getting health care officials to take it seriously and being able to hold a job.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Being able to hold a job, keeping up with day to day life, and being able to have a support system.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	To have the health care system to provide affordable and accommodating resources for people in the community since everyone has different needs.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It has caused a major mental health crisis and also chronic health issues that left people in the community feeling helpless from not getting the help they need.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The positive would be more resources from home but that's about it. Life has got harder to navigate since 2020 and society is more difficult.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression, anxiety, burnout
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	More research with autism in women
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Easier access to accommodations
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Needing specialized medical care (we travel 90 miles to a hospital that can treat Eosinophilic Esophagitis). Needing all types of medical professionals to have experience working with special needs and making appropriate adaptations (eg. dentist).
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Finding a child psychiatrist with experience with intellectual disability and autism. Getting an appointment with that psychiatrist (there are too few). Finding the best medication (we have tried many and had some severe side effects). Treating someone who can't verbalize their experiences.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Finding good schools (especially pre-school). Figuring out the best placement within the school (regular classroom vs. special education classroom). Helping educators understand behavioral issues as communication of unmet needs.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Training requirements for all providers to work with disabled patients (eg. the need for extra time, sedation, etc.). Disabled people have all the medical needs as other people, but too few professionals are really capable of treating them.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Remote schooling is totally ineffective for my son. He should have compensatory time added after he "ages out" of school. Staying home caused a lack of physical activity, and increased separation anxiety on return to school.

Name	Anonymous
Demographic	Autistic individual; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Lack of mental health providers that understand dual diagnosis
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Lack of understanding from developmental disabilities providers
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Have direct support professionals understand mental health illness
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It lead to isolation
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	sensory challenges, attention deficits
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	anxiety, ADHD, depression
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	communication and social disabilities
What additional research is needed to help address co-occurring conditions for autistic people?	more research done with autistic females to help diagnose earlier
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	more supports available in rural areas
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	COVID isolation made it more difficult for some to get back out with people again
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	telehealth was helpful but reduced social interactions were detrimental

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The most significant challenge with the autistic family member is sleep disturbances, many nights were insomniac nights which give him anywhere from 4 to 6 hours of sleep. Also, since he doesn't have speech, it makes it very difficult to know his wants, needs, how he feels, if he's sick or can't express his moods. So, not knowing any of those, challenge his life and all those that are a part of his life.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Having to constantly redirect his attention significantly cause challenges, since he is non-verbal makes it difficult to keep from aggression, and self-injury. Not knowing if he is going to lash out or accept that redirection. That challenge is a day-to-day basis on the behavior he reacts to, if nonsufficient sleep or irritability.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	To this question, since the individual living in my house has all these needs it is difficult to say the significance of each challenge such as learning, developmental, intellectual and communication. All these are a significant challenge for him. Since he was diagnosed at a young age and there were no programs available for him, even there was actual diagnosis for him at that time he didn't get his needs for development. He tends to fare well in classes and programs available to at this time. But trying to find programs available to him isn't easy since they are only available to minor children and not much out there for young adults over 21 years of age.
What additional research is needed to help address co-occurring conditions for autistic people?	After them being placed in the school system with the programs available to them, there should be more programs available to them when they are done in the school system. My son is 38 yrs old and I still have problems with Dental, communication, and other programs that only allow up to 18. They should be more research as they age.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Every autistic person no matter what level they are at, should be able to receive all services to keep them healthy and have programs available for whatever their needs are. Plus, they should be treated as people and not lab rats, but to research more on how they can progress in society. They should have more programs to help support their health and social aspect.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	The impact that COVID19 had on my son was not being able to go out in public and trying to participate in social events have not been able to. so, he prefers to stay home, which before COVID 19 he was very outgoing. So, now I have to worry when out in the community for him to retrack all that was taught to him so we can get to that point again.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	His reduced in-person social interactions have changed and really doesn't like to go traveling like he used to in the past.

in-person social interactions and obligations)	
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Name	Anonymous
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	feeding, sleep, seizures
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	aggression/self-injury, elopement, anxiety
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	lack of language, ID
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Development of healthcare professionals knowledgeable and able to care for people on the spectrum over their lifespan; insurance coverage for school based services so ABA, ST, OT treatment are provided in adequate intensity, duration and dosage given the level of disability
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Skill regression due to lack of programming
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	increased isolation

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gastrointestinal disorders is something that all physicians and parents should be made aware of. Our son suffered for years because he wasn't able to tell us what was happening with GERD. Sensory disorders are also critical for medical, dental and vision providers to be aware of as well as parents/caregivers. Especially if the person with autism has communication issues. Self-injurious behaviors can result in physical injuries some serious that require hospitalization and treatment and some that require first aid. Research to identify and ameliorate SIBS is much needed.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Aggression and self-injurious behaviors severely limit inclusion and participation in community for people with autism. More research needs to be dedicated to these behaviors that will improve lives and reduce costs in emergency rooms and law-enforcement involvement. Much caregiver burnout is related to these behaviors. Constant vocalization is another isolating behavior that needs research and treatment options so the person can live and thrive in the community. ADD/ADHD needs better treatment options in this diagnosis. Medications that work in other populations sometimes don't help people with autism.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	LD and IDD are significant challenges that can be supported with many existing curriculum and strategies. Communication disorders are trickier in this diagnosis and require focus on pragmatics, social skills and fluidity rather than pronunciation. When combined with and IDD it needs focused attention and support from therapists and educators.
What additional research is needed to help address co-occurring conditions for autistic people?	Self-injurious behaviors Combativeness/aggression Constant vocalization
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Co-occurring conditions increase complexity of care. Parents and caregivers need much more support to insure that the person gets the care they need. Multiple systems of care: Medical/physical, psychiatric/psychology, dental, vision, hearing, IDD supports, communication and behavioral make it almost impossible for anyone to coordinate care for an individual. Many of these systems require excessive paperwork for eligibility and to maintain the service. Costs are exorbitant and unaffordable for most individuals and families. Highly trained and experienced care coordinators will be necessary until we can simplify these systems.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	More isolation
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Telehealth has been helpful. Remote work has been helpful for autistic individuals and their families. The acute shortage of disability services providers is at a crisis for people with complex autism that requires 24/7 support. Caregivers are burning out and quality of life for the individual is at very low levels.

Name	Anonymous
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Misdiagnoses like for instance Parkinson’s Disease when in reality mental health medication caused severe tremors for years when all patient needed was a DaT scan and taken off the effecting medication. Patient could no longer take care of own basic needs thrown out of AFC home into nursing home sent to hospital and died there from hospital acquired pneumonia & UTI/sepsis. In reality patient had spectrum disorder and malnutrition from neglect. The system failed him.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Finding a good caring doctor and follow up with medical staff on patient health by setting up appointments fir the patient with testing and specialists asap.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Testing for vitamin deficiencies such ss vitamins, minerals, protein and side effects of any medication that may be same as diagnoses like severe tremors, depression, seizures, confusion and the list never seems to end including death!
What additional research is needed to help address co-occurring conditions for autistic people?	Every patient diagnosed with mental illness, autism, intellectual issues needs to be screened for autism spectrum at least to rule it out like the do depression.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Find them the help they need housing, schooling, food, clothing, mentor etc. not just referral rabbit hole most caregivers get with no end in site.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Death
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Lack of experienced staff they are burnt out, inpatient, low income, low morale and lack empathy. On the job training is needed before the work alone by seasoned employees.

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	People with autism and adhd can have issues eating and providing essential self care resulting in becoming undernourished, not having clear thoughts, confusion, fatigue, low blood sugar, mood swings and other issues that come with not being able to care for essential needs of eating.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Not being able to advocate for medical treatment, disability, or other social services.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Not being able to adapt to a society where if you can't work or make money you will end up homeless.
What additional research is needed to help address co-occurring conditions for autistic people?	How to form outreach for people who can't advocate for themselves.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Not all people with autism understand that they have autism or know what's wrong with them. Providing resources that help people identify that they have autism. Assisting the people who are unable to advocate for themselves to get disability could help people who are unable to do so without assistance.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Long Covid effects such as brain fog and fatigue on top of issues from autism and adhd make it even harder to provide essential self care for individuals.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The Covid epidemic has caused many disruptions in community functions. With this lapse in people coming together some people are disconnected for their communities causing higher amounts of mental health issues.

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gastrointestinal disorders, sensory disorders and comorbid mental health challenges
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, ocd, hyperactivity
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Learning disabilities including hyperlexia
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Havin comorbid conditions covered by insurance. Additional information for parents and caregivers
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Has made it more difficult to get services
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Hyper mobility skin disorders sleep issues eating issues mobility issues POTS Ehlers Danlos Depression anxiety autoimmune issue sensory issues complications driving vision issues picking disorders Stimming work adaptations
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD depression anxiety temper issues meltdowns self harm picking disorders eating disorders learning disorders and also a different way of thinking and feeling that has to translate everything and it's exhausting
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Isolation codependency a need for a support net learning complications we just think differently and communicate differently and people don't like that in general how we act and how we feel and sense things how we perceive social structures can be different and not understanding that difference and forcing yourself and others forcing you to act differently to who you are is exhausting
What additional research is needed to help address co-occurring conditions for autistic people?	Therapy, medical care, school restructuring, disability representation and education on conditions and how they can be spotted in schools to notify students families on how to adapt to their child's needs and maintaining support over time
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage needs communication with patients and providers accessibility to services is difficult insurance also might not cover medicines we need and should be negotiated higher education is inaccessible to many including jobs that require such education and work cultures in most jobs are inhospitable to autism
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Advanced underlying conditions, new medical conditions, strain and stress caused many suicides, starvation, food and money insecurity, illness insecurity from repeated dosings of diseases. Physically and mentally exhausted and sick
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Telehealth is amazing life has changed, online community has been amazing, struggle socially anyways, remote work and school seems like a positive change revolutionary for this day and age

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The biggest challenge is energy management and perpetual burnout. Sensory overstimulation, anxiety and stress leads to perpetual burnout, chronic fatigue, headaches, muscle tension and insomnia. I also have had many GI issues. I've had issues with Proprioception/gross motor issues and gaining muscle mass.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Between the sensory overload from smells, lights, sounds etc. & social anxiety from always guessing how to respond correctly, I get fatigued easily. I miss out on many opportunities because of fatigue, headaches, & social anxiety leading to isolation. If I get overwhelmed by sensory input or large emotions, I lose verbal ability, shutdown & cry. I cry a lot & when in public, leads to more anxiety about not appearing normal. Masking takes a lot of effort to sustain otherwise I fear being rejected by others. I am hypervigilant of everything/one around me. When talking with people, I monitor sounds, lights, activity in the background, eye contact, how far away to stand, how uncomfortable it is in my body etc which is all draining on top of the pressure to respond verbally. I also process auditory input slower so I am slow to speak if at all, leading to isolation because of being so quiet. I have a hard time recognizing faces & voices so that gives anxiety when I feel expected to know someone. I also need to wear hats, sunglasses, carry water & coats around, medication, snacks, earbuds & other things to help manage sensory input that contributes to anxiety. In the past I've had depression but developed many special interests to fill the void of the lack of people. I feel sad when a social situation doesn't work out, if I embarrassed myself, or if I feel like there is no purpose to my life if it is this hard to even manage basic survival needs.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I have auditory processing disorder so I process auditory input slower. I miss some of what is said and it tires me out quickly since my brain is working twice as hard to process what is said. It is exponentially harder to process when there is background noise and causes a lot of stress. Often I am quiet and miss out on social opportunities or become isolated because of this.
What additional research is needed to help address co-occurring conditions for autistic people?	Idk what research is out there already. But maybe look into auditory processing disorder since not a lot of people know about it. Fatigue and severe anxiety could be researched too.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Accessing services, general public awareness and education, education for doctors and therapists, low cost support groups and therapy, low cost and easy access to getting diagnoses, educating autistic people on general and local resources they could seek, medical insurance since autistic people need more medical services and might not be able to work to afford them all (or to get all needed services while working), education around work search and accommodations, removing all florescent lights, lowering volume in places, being mindful and curious about autistic people
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	

<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Positive for telehealth, remote work, and anything that can be done online. Negative in that it increases isolation and misunderstandings if everything is online. As a personal preference a hybrid model with mostly remote is ideal.</p>
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Name	Anonymous
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	ESRD dialysis- esp group in center setting. it can be so loud disorienting and chaotic in general, can be awful for those that have mental health, cognitive and neurodivergent issues... having a companion trained to help and redirect could help, so could private settings not all can do self dialysis at home
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	ESRD dialysis- esp group in center setting. it can be so loud disorienting and chaotic in general, can be awful for those that have mental health, cognitive and neurodivergent issues... having a companion trained to help and redirect could help, so could private settings not all can do self dialysis at home dialysis needs ample communication abilities the clinic can not be conducive to this at times...esp when extra barriers
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	ESRD dialysis- esp group in center setting. it can be so loud disorienting and chaotic in general, can be awful for those that have mental health, cognitive and neurodivergent issues... having a companion trained to help and redirect could help, so could private settings not all can do self dialysis at home caregivers could help with that- funding , specialized training and supports
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My eczema, dermatographia, and mast cell activation syndrome symptoms massively impact my sensory sensitivities. My skin is legitimately more sensitive and easily irritated than most, but they interact intensely with my sensory overstimulation and cause significant distress. I also fall, bump into things, and drop things frequently which often worsens already overstimulating situations and leads to meltdowns.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I think one of the most significant difficulties is the invalidation of autism symptoms due to comorbid conditions. I've seen it with myself and others where if a person has ADHD everything is attributed to that and ASD sx are ignored. If a person has trauma, that is presumed to be the cause of everything and ASD sx are ignored. My ADHD symptoms and ASD symptoms are constantly co-occurring which can make both appear less impactful externally, but, internally, both experiences are exacerbated by each other. It is also difficult to engage in things like CBT due to my ASD. Attempts to reframe thoughts tend to only make them more intense, for example. Additionally, the combination of ASD and a restrictive eating disorder is extremely difficult. In addition to my typical eating disorder symptoms, I also struggle with extreme sensory issues that makes eating intolerable at times. Foods will shift from being a safe food to being completely repulsive quickly which can worsen my restriction.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	While I am not impacted by any of these excluding ADHD and ASD (neurodevelopmental disabilities, I have worked with clients with these disorders. In many cases, my clients were overlooked for either ASD or an intellectual disability since practitioners were unaware of the co-morbidity between them. Thus, they would assume that whichever they thought of explained all the symptoms. I think there is generally a lack of understanding of all developmental conditions especially among mental health providers. I think that efforts to bridge the gap between developmental disability and mental health work workers would significantly improve the underdiagnosis of ASD.
What additional research is needed to help address co-occurring conditions for autistic people?	Studies seek out participants from minority groups who have been excluded from ASD research and dx, but they require a formal diagnosis. It makes sense that they would want to ensure participants have the condition, but the disparities in accessing formal diagnoses lead to fewer qualifying participants which harms both the study and the autistic community. There also needs to be research on non-behavioral ASD supports due to the traumatic nature of ABA. It is unacceptable to justify the use of ABA with a lack of evidence-backed alternatives while failing to put resources into exploring trauma-informed alternatives. Research also needs to explore the psychological and neurological impacts of ABA rather than only the behavioral impacts since ASD is a neurodevelopmental condition, not a behavioral condition. I think it would be helpful to study the co-morbidity between ASD and PTSD. Again, this would be difficult to do if a formal dx is required for a participant to qualify as having both disorders. It could be helpful to explore the co-morbidity of participants who meet the dx criteria for both rather than simply relying on a formal dx. It's also important to explore the co-morbidity of POTS, MCAS, and EDS with ASD and ADHD would be beneficial since there are many anecdotal reports of neurodivergent people experiencing either one or a combination of these disorders.

<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Educate all providers on the risks associated with ABA as well as alternative tx options. Educate ABA providers on the psychological impact of ABA as well as the internal experiences of autistic youth. Stripping autistics down to their behaviors is dehumanizing and ineffective. Educate providers on the various ways ASD can look and how to support clients with ASD. Way too many providers are relying solely on stereotypes of autistic people rather than genuinely understanding the condition (i.e. "You can't be autistic because you make eye contact"). Universal healthcare which mandates that ASD testing and support are covered. More effectively educate parents on how to accomodate their child's needs rather than focusing on changing the child's external behaviors (internal dysregulation doesn't go away because a child is trained not to show they're upset).</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>While I did mask and continue to do so when COVID cases are high, it really irritates my dermatographia and eczema and causes me to break out in hives on my face regularly. It also caused me to overheat which caused MCAS flare-ups at times.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>I massively benefitted from the expansion of telehealth services. My executive dysfunction and difficult with transitions makes it very difficult to leave the house sometimes, and telehealth has been extremely helpful for me. I also benefitted from the expansion of curbside pickups and shipping options since I struggle with overstimulation in stores. I also found that masking made me feel less pressured to mask all the time which was a pleasant shift. I also enjoyed the increase in virtual interactions with friends since it was more comfortable for me. However, the way people responded to the COVID pandemic was extremely distressing to me. People refused to mask, were verbally or even physically aggressive to people who did mask or isolate, and generally expressed disregard for communal well-being. It caused an increase in my anxiety and led to a lot of rumination. The aversion to public safety measures made me feel extremely unsafe leaving my home and was very distressing to me.</p>

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I also have adhd and auditory processing disorder. It take someone repeating something a half a dozen times for me to understand what they have said sometimes and I cannot watch any show without captions.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have adhd, severe manic depression and cptsd. I struggle daily to regulate my emotions and panic attacks from people verbally and mentally abusing me for being different when I was growing up.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	The people that can mask to the point that they can function and get misdiagnosed with other disorders need case studies. I am 26 and just now got diagnosed because as a child my parents were told that my iq was too high for me to actually be autistic
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Disability coverage for autistic people needs to be broadened. I am not on disability because I am apparently ineligible but I've never been able to hold a job for longer than 2 months because of my autism.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep, noise sensitivity, and clumsiness: I have a very hard time falling asleep, staying asleep, and getting enough REM & deep sleep; have a severe sensitivity to noise; and am clumsier than most people, prohibiting me from driving in populated locations.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have severe depression due to a lifetime full of rejection/exclusion and so have persistent suicidal ideation. I also have a terrible memory, likely due to the sleep troubles and depression.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I also have ADHD-PI, which has left me unable to make up for the many deficits of having Autism.
What additional research is needed to help address co-occurring conditions for autistic people?	How to fix sensory sensitivity (e.g. noise, light, food). The world is a very loud place and due to my noise sensitivity, I am not welcome to many places in it. After that, researching how people with abnormal, autistic brains can properly sleep.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage/universal healthcare
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	COVID-19 further worsened my poor memory
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	What limited amount of social skills I had were lost through lack of social interactions. Remote connections are not the same as in-person connections.

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The most significant challenges I've seen with co-occurring physical health is POTS, HEDS, gastrointestinal issues, issues sleeping. The sensory issues that Covid and the long lasting effects of Covid have caused are too many to list.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The biggest challenge is being taken seriously and not looked at and dismissed because eye contact was made or certain characteristics were so heavily masked that the uncaring eye would miss. I have undergone a lot of abuse and my signs were missed or dismissed as "attention seeking." I had a mental health professional look at me and say "Why do you think its autism? Don't you think that is just anxiety?" after I asked for a referral for an assessment. I never went back to that doctor. I am a female adult, which makes it statistically harder for me to be diagnosed or taken seriously. After my son was diagnosed, I started seeing things from my past that were missed by my parents and those around me. I do have anxiety, but I have never found relief from medication at the highest dosage for years. I thought that I as really just making this up. I was taught to just sit down and be quiet and learn. I learned that self-diagnosis is valid, and sometimes that is all you have. The free tests online (RAADS-R among others) were how I realized that my experience in life was not normal. There are so many barriers to treatment, let alone diagnosis that need to be addressed before we can begin to heal.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication difficulties are my main issues. I find myself scripting out every possible way a conversation can go and then panicking when the conversation goes off-script. I have always had issues with math and reading and I am finding out that I am concerned with dyslexia and dyscalculia. I have always had issues with my attention span and having to practice my emotions in the mirror. There are so many other ways that this could be improved as well.
What additional research is needed to help address co-occurring conditions for autistic people?	I feel like we need to focus on the self diagnosis and how it IS a valid diagnostic tool. Autistic individuals are so scared of being perceived as an outsider that I would avoid all in person interactions. I would love to see more online and accessible care for all, not just those that have insurance coverage or money.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	So I had a really bad flare up due to stress of a job in January that caused me to have to spend \$2,500 on surgeries to find out that it was stress in a sales based job. I didn't meet my deductible, so now I have to pay these bills out of pocket and I have been unemployed since June. The health system failed me. Repeatedly. I have \$25,000 of medical debt and that was before my realization of self-diagnosis. I can barely make it paycheck to paycheck, let alone afford to pay for insurance coverage to go to the doctor. The copays alone are at least \$30 a visit on top of the monthly costs. In order for me, an adult female, to get diagnosed I would have to pay \$400 out of pocket to be seen for a 1 hour assessment. That price would not include a review of the results or anything else. The next assessment I found was foOr over \$1000 out of pocket. That is without insurance. No insurance I could find in my area would cover autism assessment and diagnosis anyway. I have been dismissed by a provider as having anxiety, even though I was on the max

	<p>dose of anti-anxiety meds with no improvement for over 5 years. I asked for a referral for an autism assessment and was told "Why do you think its autism? I think its just anxiety. Take your meds." That was the last time I went to a mental health provider.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>I got Covid in October 2020. Until about May of 2023 I couldn't taste anything. Now meat is almost impossible for me to eat. It either tastes spoiled or just wrong. Sensory issues are no joke and I feel like so many stigmas apply not only to sensory issues but mental health as well. I have an Associate's Degree in Social Work, I am a SUD Peer Mentor and I am a recovering addict as well with a clean date of May 2019. Losing my smell and taste has been the most challenging burden Ive faced in my life. I already had "repulsives" when it came to diet and I had worked through most issues with acceptable solutions. Now that I have regained some senses, none of them are correct. Everything is either dulled or so intense I throw up. I am a baker and I love to cook as well but my joy has died now. I have a cough that wont go away and I get so much sicker a lot more often now as well.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>I prefer virtual interactions over in-person, so this has been okay for me to transition to. Being isolated to lockdown wasn't that big of a deal for me as far as mental health goes. I love being by myself. I dont have friends and my soon-to-be fiance is a gamer so I just got a new hobby. I also started my journey of self-discovery and found the RAADS-R. I scored a 145 and sat there and cried. Everything made sense for once.</p>

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I think two of the most significant challenges in our (a family with multiple people who are “high-functioning” on the spectrum) experience with autism are the GI disorders, sensory challenges and hormonal issues. Many of us still lack specific diagnosis for the issues or it takes years of visits and testing to receive a diagnosis. Sensory issues are also very challenging. We are living in a world that feels created for neurotypicals. The lighting and music in stores and restaurants are often overstimulating. We avoid food textures/flavors/colors that don't feel "safe". If there is something sensory wise that I can adjust for myself or remove, I can often avoid the meltdown. Learning to identify the overstimulation and what the trigger is, greatly helps but sometimes does take a co-regulator to help identify and help. Based on my family as well as some patterns I have been seeing in general in society, I think menopause and hormones for autistic females is a huge challenge that deserves to be studied. I would say based on what I have experienced and observed, the rates of PMS, PMDD, PCOS and other hormonal based issues are higher in women with autism. Quite a few autistic women I know who have gone through menopause, have attempted suicide during this time, have had panic attacks/meltdowns more severe than earlier in life, and they all of a sudden have a harder time functioning through life tasks such as paying bills, having conversations, working, etc.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, depression and suicidality are some of the ones that have most directly impacted my family in relation to autism. A majority of my family (including aunts/uncles, grandparents, children and self) have all dealt with anxiety. This anxiety impacts social life, school, work and in some cases has resulted in several family members becoming more of what would be considered a reclusive person. Those people rarely leave the house and are prone to meltdowns/shutdowns if they attempt to leave the house or do leave the house. It has also resulted in them struggling to hold down a job or find a job. Depression and suicide attempts also has directly impacted our family with those with autism, especially with females who are going through puberty or menopause (please, please please someone study the impacts of puberty and menopause hormonal impacts on autistic women!!!). This has resulted in several family members requiring psychiatric or even hospital care and many were unable to work anymore during and after menopause.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	This is a harder to question to answer and really is hard to sum up because these other disabilities are part of what changes how high someones needs are if they are on the spectrum. I think one challenge overall, is “higher-functioning” individuals getting recognized for their additional disabilities because they can get overlooked by not appearing to be “as autistic”. We have these additional disabilities but are often right on the line of it being a disability or not. It would be better to be treated and have the services and resources for those disabilities than not have them and struggle a lot when it is too late to still receive the help in school.
What additional research is needed to help address co-occurring conditions for autistic people?	As mentioned before, the biggest thing I want to see additional research on is puberty and menopause and the impacts of those hormonal changes in females. I think this research could help shed light on the impacts I think this greatly has on this population. I think studying what is going on could also lead to treatments that will in turn allow these females to continue to have a quality of life, contribute to society still (socially and economically) and be able to continue day to day living tasks better without burdening resources.

<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Costs for getting evaluated & diagnosed needs to be addressed. Another resource that is needed would be a service similar to the telephone system that people who are deaf and hard of hearing have access to, but this would be a resource that could be utilized for people who need support making customer service phone calls, during doctor visits, etc. There are times we need to call or go somewhere (doctors, IRS, Insurance company) ask a question and it is hard to not have this task trigger a meltdown. Having a third party who could help communicate and direct the conversation would help make these needed tasks doable. This third party being able to identify the meltdown/shutdown starting and telling the other person that we need a moment or help sum up what we are trying to say when we aren't being understood, would be amazing. Overall more services in general for "higher-functioning" autistics is needed. There are resources to be found for higher needs, but it is harder to find help or support when we appear to be doing ok on the outside. Many "high-functioning" adults also hit a breaking point where they can no longer mask and function without higher support. Having services/support that are easily found for us once we no longer are fine, would be amazing.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>I think being able to work from home options have been super positive. Working from home allows us to avoid masking ourselves to the point of exhaustion. I find I am not as overstimulated and I have more energy to complete day to day "normal" tasks than before. I can still socialize over zoom/phone with work related people but also have more energy to socialize with friends/family. It feels much more doable and life feels more balanced overall.</p>

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	being accepted by society. Being hated for being "weird" or being told its bad, family members (specifically religious people) denying that autism is "a thing" or mental health is general, and overall having a bad reputation around the word "autism" when there is NOTHING wrong with autistic people, and we should be respectful to each other for our differences.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	When people who are more severely on the spectrum and need extra help and the general public doesnt understand and calls the police who then are not trained to handle mental health or any mental challenges and then the police hurt or even kill the autistic person simply for not understanding they needed extra help.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Stress and anxiety in autistic people is so high, they are constanly in fight or flight and the general public doesnt respect them or their boundaries and autistic people are left unsupported.
What additional research is needed to help address co-occurring conditions for autistic people?	Autism evalutaions shoud be standard and happen regularly in elementary schools the same way they check for lice, or eye sight, or scoliosis in public schools, they should inquire for autism and other types of nuerodivergence like ADHD in little girls specifically becuae the girls get left behind, I did.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More people need to go to school to be doctors and therapists for autism. This should be promoted the same way nursing school is promoted; everywhere! The lastest stats say 1 in 36 kids has autism. The autistic community KNOWS its much more than that-probably closer to 1 in 10. We NEED to have more education around this. as well as ALL mental health issues.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	The pandemic [profanity redacted] was the start of so many people waking up tot ehir own mental health and looking for help with diagnosis. The current wait for an evaluation is over 18 months. That is a nightmare when you need help today. especially for kids who need extra help at school or the kids who's families do not support them and they just get lost in the public school system. The red states need the most help with education, its embarrassing.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	with so many people staying home and getting their infomation first hand from tiktok or other places-where professionals and educators can educate us right there at our fingertips; we have been able to connect and educate ourselves within the autistic community, and help a lot of people get self diagnosed which turns to getting a formal diagnosis but again, the wait list for an evaluation is ridiculous. This is a great thing! But now the government(and education and medical boards) need to catch up!! We are angry with you.

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>Sensory issues cause significant challenges, such as with driving--too much sensory information that overwhelms the individual, thus causing anxiety. None of my autistic adult children are able to drive due to this sensory overload. This affects the ability to get anywhere on their own, since we don't have access to public transportation. Also, I think sensory issues, in general, are difficult for those who are autistic. It can make being in public spaces very uncomfortable, including classrooms, waiting rooms, crowded public spaces, etc. Sensory issues can also affect nutrition as some autistic individuals can't tolerate certain textures so they avoid many foods and have a limited diet. And lastly, trying to find a suitable job for an autistic person with sensory challenges (which in turn causes anxiety), is nearly impossible.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>Social anxiety and anxiety, in general, are huge challenges that affect ones ability to make and keep friends and relationships, and makes it difficult to find a job that doesn't exacerbate their anxiety and social anxiety. Depression is a huge problem for autistic people. All the other things that create anxiety and keep autistic people from finding a suitable job, making friends, being able to live on their own, living within limited financial means (on SSI/SSDI/Medicaid) all contribute to this depression. I see it with my adult autistic children--a feeling of hopelessness that life will never improve for them, feeling as if the assistance they receive and the lack of needed services (for us it's only SSI and Medicaid, no community services for them) only keeps them living in poverty and unable to climb out of it.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>Communication disabilities are very significant challenges. Two of my three autistic adult children have difficulty expresses their thoughts and feelings, and one of them is somewhat non-verbal--mostly with people they don't know. It makes it difficult to know how to help, if something is wrong. Also, being unable to talk about your feelings creates a sense of isolation, I think--those that can't are alone with their painful thoughts.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Adult services are severely lacking, and trying to access support to navigate the process of acquiring services and supports is challenging and frustrating.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>My eldest was terribly anxious during the pandemic--he wouldn't go out of the house unless absolutely necessary. When he returned to college and lived on campus, he couldn't handle that most people were not following the COVID protocols, which increased his anxiety and caused him to withdraw from school and come home. He was already over 6 years into trying to get his degree and this anxiety-provoking experience cost him his 4 year degree.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school,</p>	<p>One of my autistic adult children cannot interact online or on the phone--it is too anxiety-provoking for him. During the pandemic, he lost access to his psychologist for 18 months due to the counseling center using telehealth. Starting back up after that 18 months was difficult, and it was like starting all over (he does not like to leave the house, either, so after 18 months of being home, he experienced severe anxiety when it was time to go back to the counselor's office.</p>

increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	stomach disorders due to nervousness avoidance of new activities due to nervousness of meeting larger groups of people
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	For those who are highest on the autism spectrum. Extra help at all school levels. Many are brilliant but have trouble with daily living activities. Independent living facilities much like those for senior citizens with meal facilities and cleaning and laundry help would help those who can hold down jobs and are bright, but at the end of a day find household chores too physically exhausting.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increased ability to do remote work a huge benefit for those with Autism

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	There are two children (an adult & a teen) who are diagnosed as being on the ASD. They both have sleep disturbances which affects their daily functioning. The adult child is obsessed with his digestion, and has become restrictive in his eating habits
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The mental health challenges are the most significant co-occurring issues for my family. The older of the two children obsesses over washing his hands and his bowel movements. He can also become very anxious, by stressing over negative news in the media, as well as negative comments made to him. The younger child who is a teenager has been diagnosed as also having ADHD and depression. There has also been passive suicidal ideation utterings.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Developmental and communication challenges
What additional research is needed to help address co-occurring conditions for autistic people?	Research into what causes these conditions and how to alleviate them, especially the mental health and obsessive challenges.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Equitable access to insurance coverage and competent mental health therapists, psychologists, and psychiatrists.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	COVID 19 seemed to have triggered dramatically my teen son's depression. He might have been predisposed. However COVID meant that he spent a long time at home, being educated online. He was away from his middle school classmates and friends. The depression was so bad that he was taken to the mental health ER for an evaluation. He still suffers with the depression and is on medication now.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Definitely, heightened the anxiety and depressive states due to disruption in in-person school attendance, rupture in school friendships, being surrounded by family members who were working remotely, fear of the disease and death, being stuck in the house, and difficulty in finding an in-person therapist.

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbances that start in childhood and persist through adulthood. When able to get enough sleep we're better at staying regulated, able to pay attention and absorb information. Sensory overload makes going out to public spaces very difficult at times. It can be overwhelming visually and audibly and sometimes plans need to be abandoned in the middle of things happening because it's too much. Speech delays cause CONFUSION when it comes to assessing wants and needs of a child with autism.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD - because given tasks have to be novelty and interesting for most effective cooperation. If the task isn't interesting it becomes an uphill battle that can quickly cause dysregulation/meltdowns and make even participation difficult. Aggressive and/or self-injurious behavior is a big one for us. Emotions are driving force and self regulating emotions does not come naturally. It has to be taught and it starts early and needs to be consistent. It takes a lot of time and a lot of patience and compassion
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Developmental disabilities - your child isn't doing what they should be for their age and they are operating at a level far younger presents the challenge of how to enforce rules because there's an element of plausible deniability if your child is nonverbal like mine. So you are only working off of what your child is able to show you on their own and if they aren't ready or willing to try communicating, you can never be 100% sure they understand what you are trying to teach so you could be dealing with the same set of negative behaviors for weeks, months, years until it finally clicks. Will-power is a factor that I don't think gets talked about enough. What happens when you can confirm that they understand a rule or expectation and they express that they don't want to and commit to not doing it. Changing their mind? Buckle up.
What additional research is needed to help address co-occurring conditions for autistic people?	I think listening more to the individuals who can articulate these things for themselves and/or parents and caregivers who are doing their best to work through these challenges as you have done with this questionnaire. Yes, the doctors, Sped teachers, specialists, paraeducators went to school and studied all about autism and other disorders but they have a tendency to ignore and dismiss the very real concerns and suggestions of parents and caregivers. STOP THAT
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Low cost/no cost services. Stop making it so much harder for us to get the help we need for ourselves and/or family members. A lot of us need services outside of what is mandated through FAPE and we recently found out that even though our son is obviously autistic and has been since he started showing symptoms at 18 months, we need to have him seen by a developmental pediatrician. He already has a pediatrician who can confirm his autism he has been evaluated 4 times since age 3 (he is 8 now) and yet we need to get put on a wait list to have him seen by a dev. Peds. Physician just to be able to have things billed to insurance for him and even then those services are not affordable
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	My son cannot wear a mask and is frightened of people when they have masks on he can't see your face he doesn't know who you are or if you are safe. Personally, I hate going out in public way more than I used to. There is an element of paranoia as people have abandoned wearing PPE when sick, jobs are penalizing employees for needing to take sick time, and people are refusing to stay home when they are sick and refusing to social distance. I

	<p>hate when people get too close. I have a lot more anxiety about going out now and if i have to bring my son quadruple that anxiety because i now need to be prepared in case he disregulates while we are out. It isn't fun when he does.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Increased remote work in some areas has been a blessing. We don't worry about childcare. We are not comfortable having our non-verbal son in daycare (we have found that they cannot accommodate his needs in the way that we need them to to maintain consistency). A bit more compassion for workers in general came of it but that compassion seemed to have has an expiration date</p>

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The most significant challenges caused by co-occurring physical health conditions: 1) They can be exacerbated by mental health! Somatic disorder, for example, is often directly tied to anxiety disorder. 2) There are often multiple conditions that require multiple doctors and therapists. This can be very expensive for individuals and families. 3) There needs to be much more research done concerning how gut biome affects mental health disorders and what can be done to improve the biome. 4) Weight management, healthy eating, and ASD is a real issue. 5) As autistic individuals age, their health needs change. Robust research on autism across the lifespan, especially in older ASD individuals is required to determine how conditions such as, for example, dementia, affect ASD individuals and what preventative measures can be done to reduce/eliminate the potential for conditions common to people over 60.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	1) There are often multiple conditions that require multiple doctors and therapists. This can be very expensive for individuals and families 2) There needs to be much more research done concerning how gut biome affects mental health disorders and what can be done to improve the biome 3) As autistic individuals age, their health needs change. Robust research on autism across the lifespan, especially in older ASD individuals is required to determine how conditions such as, for example, depression, affect ASD individuals and what preventative measures can be done to reduce/eliminate the potential for conditions common to people over 60 4) Loneliness is a key driver of anxiety and depression for ASD children and adults. Continue finding and implementing solutions to help this population over the lifespan cope with social anxiety and feel engaged 5) The connection between gender identity and autism must be researched more robustly. This is a twice at risk population for harm and exploitation 6) Trauma informed care is vital for ASD individuals. PTSD, generational, and other forms of trauma are common in this population 7) Therapists, doctors, nurses, counselors, paramedics, social workers, etc. are not trained in how to effectively communicate with autistic individuals.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	1) Most ASD individuals have more than one co-occurring condition. Having several co-occurring physical, mental, and neurological health conditions is expensive!!! 2) Many co-occurring conditions happen simultaneously and it's often difficult to "tease" out and separate conditions. This in turn frequently makes it difficult to determine the best course of treatment. 3) Providers cannot treat autism as a one size fits all condition!!! Autism is an "all you can eat neurological buffet." Every ASD person's "plate" has different "items" and/or varying "portions."
What additional research is needed to help address co-occurring conditions for autistic people?	1) The connection and prevalence of Gender identity and co-occurring conditions. 2) The connection between environment/environmental factors and co-occurring conditions. 3) Best practices for providers to communicate with ASD individuals with co-occurring conditions. 4) How to make communities and society more understanding of how co-occurring conditions impact autistic individuals.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services,	Define what equitable access and accessibility to services means. Increase health insurance coverage and do not separate mental and physical health coverage. Create autism advisory councils at the state level that include autistic individuals, family members, legislators, and reps from autism, medical, and mental health organizations. Create autism certification

insurance coverage, service systems issues, patient-provider interactions)	programs for teachers (even general ed teachers) that include training of co-occurring conditions and best practices for working with these students.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	The Covid-19 pandemic led to increasing shortages in mental health providers, doctors, nurses, therapists, and teachers. This in turn has led to delayed support and services for conditions such as depression, anxiety, and led to increases in suicidal ideation. Research has shown that Long Covid led to increases in neurological conditions such as memory loss and "brain fog." ASD individuals with co-occurring conditions such as ADHD, bi polar disorder, Obsessive Compulsive Disorder, etc. who have had Covid are at increased risk of these conditions worsening.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	All of the above examples.

Name	Anonymous
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	few services provide integrative teams that can address complex comorbidities in autism autism
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	specialised multiprofessional teams working with patients and families,
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	equitable accessibility of services insurance coverage early detection and early intervention during the first year of life (for secondary prevention) Parents intervention , education about systems, supportive systems for families of autistic individuals, special complex education for families and the individual patient . etc
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Masking during work causes chronic stomach aches, migraines, PMDD, misophonia, never achieving REM sleep, sensory issues, light sensitivity (esp headlights at night)
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Suicidal ideation, depression, anxiety, adhd, sensory overwhelm
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	dyslexia, situational mutism, hyper fixation
What additional research is needed to help address co-occurring conditions for autistic people?	Expand research into bipoc and indigenous, women trans and nonbinary etc. Most research has been solely on affluent white boys/men
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Extra assistance with the ridiculous amounts of paperwork and phone calls to apply for disability Proper Accommodations
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I figured out I was autistic the summer before the spring 2020 lockdown. Being in isolation pretty much confirmed my suspicions. Working and autistic masking was causing physical harm to me. I got diagnosed asd/adhd 2022 and stopped working. I had been going to work sick most of the time.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Negative- Lack of resources and accommodations Positive- Telehealth therapy

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My son is also diagnosed with mental health and attentional difficulties. It has been difficult obtaining skilled and knowledgeable caregivers and group homes to address his social emotional needs.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My son is also diagnosed with mental health issues (aggression, auditory and visual hallucinations, anxiety disorder, mood disorder etc) and attentional disabilities. When he was younger it was difficult obtaining a psychiatric facility in PCG Maryland that could provide mental health services to him. We had to go to Baltimore to obtain inpatient and outpatient care for him. Also, his educational needs could not be met locally, and he also attended school in Baltimore.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Finding an educational program that could address his behavioral as well as his educational needs. Son was ASD Level one, but his attentional and behavior issues interfered with his learning.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Opportunities to interact with peers in social settings at a reasonable cost. High school programs better preparing students for employment, use of technology, life skills, and partnership with Department of Vocational Rehabilitation to pursue job readiness and employment skills and placements.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Son graduated with a high school diploma and lacked the opportunity for job training and placement. Due to attentional issues virtual learning was not a good fit for him. DORS has not been a good resource to him since they seemed overwhelmed by the number of their clientele seeking services.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	My son has been negatively impacted by the disruptions in services, reduced in-person social interactions, and ongoing discussions about Covid and RSV and other illnesses impacting our nation.

Name	Anonymous
Demographic	Family member of an autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>My daughter has trouble predicting when she has to vomit (either when sick or from GERD and post-nasal drip). She cannot get to a bathroom in time. She has missed significant time from her program this year because of this when her GERD was not well controlled. She also has obstructive and central sleep apnea, but she does not sleep well at the sleep lab (I believe due to her sensory challenges) so we often don't get complete results to fully understand the extend of her sleep conditions. I am not sure how much of some of her behavioral concerns might be due to her not sleeping well. Sensory concerns also make it hard for her to integrate into various environments. She has sound sensitivities, gets very overwhelmed easily, and is sensitive to certain smells and tastes. All of these limit what she is willing to do in a social setting.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>For my daughter, there are many challenges related to her anxiety and perseverating thoughts. She gets very anxious easily and that prevents her from trying new things. When she is really bothered by something, she will make up situations/stories to create a reality that she is more comfortable with to help her cope. She also tries to convince others to do or say what she wants by pushing on their shoulder or saying that they said things that are not true (e.g. "mom said she wanted me to do that," when that was not the case or "what you meant to say was [what she wanted instead of what was said]"). Transitions and change in routine are very difficult. Sometimes she will say things about people that are not very nice because she is upset about a change (e.g. about program staff or her family or her doctors because she does not like a proposed or actual change). It is very challenging to see her like this and also challenging to learn how to best help her get through these situations. She also picks at her fingers to the point of making them bleed or removing several layers of skin. She says it does not hurt, but her fingers are raw. She has tried multiple medication combinations, but none have seemed to really help all of this. I worry about the long-term effects of being on these medications as well.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>1) Helping people understand how to talk with her so she is comfortable and can express herself. Sometimes people don't understand she may need something rephrased or repeated to help her understand. Sometimes they don't explain things fully and take her first answer when maybe she didn't understand the question correctly and was just saying something just to get them to stop asking. Sometimes they just assume she cannot understand. 2) While inclusion is important, sometimes it is helpful for her to be around others like her. She was in inclusion classes throughout school and was never comfortable or accepted. She was bullied in elementary school and often ignored in the higher grades. She is now in a transition program and feels much more comfortable than she ever did because the students are like her. I wish there was more of a balance for her in school. It is important to feel comfortable and unfortunately, she never did in school until COVID when she did school virtually. 3) Finding programs to help young adults "in the middle" to develop job and independent living skills. She needs help with a lot of ADLs, but can do more than others with very low IQs, etc. I find that programs are either above her level (e.g. focused on college, which she is not interested in) or that they work on the skills she needs, but the other students are below her level so the program won't accept her. Also, the programs tend to be far away, and she does not want to travel far from home.</p>

<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>I think it is important to research ways to best support individuals with autism and their caretakers in finding ways to manage these co-occurring conditions. Accessing therapies and mental health services is not easy and while work is needed to improve access, perhaps researchers can find other ways to help in the meantime. Also, finding ways to increase job opportunities and explaining these conditions to employers. I often wonder if my daughter will be able to maintain a job or will she be let go because of some of these co-occurring conditions.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>All of the above. Insurance coverage is an issue. Many individuals have medicaid, but then many providers do not accept it. Also, the wait lists for providers (e.g. therapies, mental health, etc) are very long. I also wish there was someone to help caregivers navigate the systems. Case managers from DDD come and go and never formed a relationship. Our support coordinator helps with her budget related items, but not everything else. I wish there was someone who could help with everything - like the idea of a medical home, but specifically one person assigned to an individual to help point you in the right direction for things like accessing therapies, transition programs, transitioning to adult medicine, SSI benefits, etc. Also, the process of transitioning to adult medicine itself is challenging. She has been seen at a children's hospital system since birth. They understand all of her conditions. It is not clear where she should go next.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Online school was a huge positive for her as mentioned earlier. It was the only time she actually felt comfortable in school. She also likes telehealth appointments and not having to wait in busy waiting rooms. I do believe her overall anxiety has also worsened and she has not had the social interactions that she did in the past. There was a time she didn't want to leave the house. She is past that now and doing much better. However, it took a while. Also, if someone is sick she worries it is COVID. She is very cautious and it is hard for her to understand why some people don't wear masks when near her or things like that.</p>

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Co-occurring conditions can cause death, isolation, communication difficulties, missing work, self-esteem and self-efficacy deficits, reduced income potential, reduced perceived mate value, injury, disfigurement, increased dependence on others, direct discrimination (both for those which put you in a protected class (like motor challenges), and for those that don't (difficulty wearing shoes because of sensory issues)), transgressing societal norms (Tourette, sleeping at the wrong time), vulnerability to structural inequality in education, housing, transportation, nutrition, the justice system, and health care. Note: I believe that you are distinguishing between "mental" and "physical" health conditions based on whether the primary diagnostic criteria are behavioral. I will answer according to that rubric, though I think it is a poor one. From a naturalistic perspective, all health conditions are physically based. So, this is a distinction based on our knowledge about the condition and our measurement capabilities. It is not intrinsic to the nature of the condition except as far as that condition's etiology falls into the class of those that exceed our current diagnostic capabilities.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Co-occurring conditions can cause death, isolation, communication difficulties, missing work, transgressing societal norms, self-esteem and self-efficacy deficits, difficulty with keeping promises, reduced income potential, reduced perceived mate value, inability to improve your situation (because of lack of motivation, fear, or lack of focused effort), injury, disfigurement, increased dependence on others, direct discrimination (both for those which put you in a protected class (like gender dysphoria or same-sex attraction), and for those that don't (ADHD speaking speed)), vulnerability to structural inequality in education, housing, transportation, nutrition, the justice system, and health care.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Co-occurring conditions can cause death, isolation, communication difficulties, missing work, transgressing societal norms, self-esteem and self-efficacy deficits, reduced income potential, reduced perceived mate value, inability to improve your situation (because of lack of awareness, planning, or ability to communicate), injury, disfigurement, increased dependence on others, direct discrimination, transgressing societal norms (e.g., hugging too much/too little), vulnerability to structural inequality in education, housing, transportation, nutrition, the justice system, and health care.
What additional research is needed to help address co-occurring conditions for autistic people?	1. Identifying co-occurring conditions and why they co-occur, so they might be treated. 2. Identifying how the co-occurring conditions affect autistic people so environments can be adapted to better serve autistic people while still being useful to typically-developing people.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Improve insurance coverage. Use subsidies to increase the # of providers. (Coverage isn't treatment access. I've been trying to get treatment for several covered co-occurring conditions for over 2 years.) Tackle structural inequality. Promote valuing people rather than productivity. Mandate flexible work arrangements for disabled people. Ration healthcare based on something other than wealth. Enable users to copy this survey's questions so they can use assistive technology from outside the browser. Non-wealth-based rationing example: Give "health dollars" (\$H) to everyone. Each person, irrespective of socioeconomic status, gets enough that there's a 99% chance they'll have enough that month based on their health history (age, pre-existing conditions, lifestyle, amount owed last month). People may give excess to the 1% in need at the end of the month through a regulated

	<p>system. Unused \$H lose value over time to discourage hoarding, yet retain full value when donated. Fund with an automatically increasing progressive tax to avoid inflation. Refine the \$H percentage through regular analysis to ensure it meets everyone's needs. This example is incomplete. One could reduce corruption (investigate donation recipients, provide a low-% cash out to out-price the black market), inspire donation (community leaderboards), give \$H allocation advice, nudge prevention (extra \$H for checkups or fitness milestones), and encourage trust (audits, public reporting, education campaigns.)</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	sensory issues and motor challenges. coordination too. driving would be a problem. my son who 18 still can't properly ride a bike.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	anxiety and adhd for sure. he really has a difficult time with focusing and paying attention in class. he really is in his own mind. I would say adhd is really difficult.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	all the above for us. it makes it really difficult to have just about all the above to be able to live a productive life in the real world. Keeping a job. for example. being able to sustain the real life living that it takes to live somewhat a normal life. Some are more severe than others but it still impacts a person with autism. ID is tough too. My son almost tests to be ID but he really is not. His challenges are in-between which it makes it hard to get/find the right fit for him. School and social groups.
What additional research is needed to help address co-occurring conditions for autistic people?	The need for the person who has autism but does not fall in the low or high spectrum. Would benefit from being with typical kids but need the help to navigate yet would not benefit from the lower functioning people. It's tough to find programs that has a mixture of this kind.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	All insurance should have coverage for autistic people for therapy in all areas, speech, ot, social help ect. Help with patient advocates just like they have for the elderly. Including housing in the same manner would be helpful.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Being taken seriously Mis-diagnosis [autism not recognized due to other conditions] Effective communication of co-occurring health conditions Being provided with the time and opportunity to share information regarding co-occurring conditions
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Impacts access to education [and overall care] for school age individuals Lack of appropriate services available to individuals with co-occurring conditions Lack of trained professionals Mental health conditions and needs are commonly disregarded in nonverbal/significantly impacted individuals, and this contributes to a lack of services for those individuals
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Death Suicide being one of the leading causes of death among autistics Undiagnosed medical conditions in non-conversational/non-verbal individuals can result in significant behavior episodes, disruption of care, death in some circumstances Misdiagnosis- there are many people not receiving a diagnosis of ASD due to co-occurring conditions Females, black/brown people more likely to get behavior or mental health diagnoses due to the diagnostic tools being majorly biased towards the white male characteristics
What additional research is needed to help address co-occurring conditions for autistic people?	development of tools to ensure diagnostic tools are not weighted towards any one group [consideration of impact of gender, race, poverty, trauma, etc.] effective tools for primary care providers working with individuals on the spectrum when completing annual physical... question and response format that is supported by best practice
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	kids who are accessing private insurance do not get access to the continuum of resources available via public insurance, such as care coordination, med management, etc. or it is accessed with significant out of pocket, which is prohibitive to many middle class families who have more out of pocket burden youth with disabilities and especially co-occurring conditions should automatically qualify for public insurance
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Especially for those who do not have a consistent or well understood method of communication, seeking help from others and/or describing how the physical health conditions feel is extremely challenging. In the absence of communicating vocally, majority tend to display maladaptive behaviors as a way to communicate their discomfort. This may manifest in self injurious behaviors or physical aggression to gain attention. For those that have a consistent form of communication, some of these physical health conditions can be stigmatizing and differentiate them from their peers and exacerbate the socialization challenges. It may also be noteworthy that sometimes physical health conditions go undiagnosed because of someone's lack of communication abilities causing the individual to suffer for longer than their peers with the same condition/s.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The most significant challenges caused by co-occurring mental health conditions in autistic people is funding. Mental health providers argue that the individual needs to be served by developmental disability providers and developmental disability providers argue that the individual's mental health conditions also need to be addressed. Funding is typically at the center of this argument. Also, the prevailing methods of therapeutic intervention for mental health conditions is talk therapy and 30-50% of individuals with an autism diagnosis can't speak. Another concern would be that once individuals receive an autism diagnosis and gain access to ABA, their caregivers may feel like they have reached the end of their diagnosis journey and not consider a co-occurring mental health condition. Fewer and fewer mental health professionals are familiar with behavior modification and will not accept an individual where autism is the primary diagnosis for treatment.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Compare and contrast Medicaid utilization of both mental health and developmental disability services for individuals with autism and a co-occurring mental health condition. Additional research on prevalence of co-occurring mental and physical health conditions in autistic adults.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More behavior modification providers. More ABA providers, especially in rural areas. More training regarding autism and evidence based therapeutic interventions such as CBT, DBT and ACT for mental health professionals. More training for physicians and nurses on how to communicate with children and adults who don't use their voice to communicate to identify physical health concerns. More public information campaigns for parents and caregivers that in addition to autism they should be aware of common physical and mental health that are co-morbid.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic	

people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Anonymous
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Adhd hyperactivity, impulsivity and distractibility
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Adhd Aggression
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Intellectual disability Communication problems
What additional research is needed to help address co-occurring conditions for autistic people?	My concern is the DIAGNOSIS OF AUTISM when it is absent. Many people are worried they are autistic and are insisting on evaluation. Many evaluations are faulty unfortunately.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Telehealth is convenient for many families.

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Aggression and mood swings
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Behavior that might damage things and injure others
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Developmental and cognitive abilities
What additional research is needed to help address co-occurring conditions for autistic people?	Best supportive living situation for people with complex autism and co-occurring conditions to keep them safe but still offer a connected, meaningful life.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Best supportive living situation for people with complex autism and co-occurring conditions to keep them safe but still offer a connected, meaningful life. This would include access to healthcare, behavioral therapies and services, good food, vocational services, recreational activities, and access to the community with support if needed.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	The lack of services, isolation, loneliness, and then the illness Ireland disrupted our daughter's way of life that sent her down a violent spiral. It also fractured an already fragile system of caregiving support. She ended up becoming violent in the community, our home, and was ultimately placed in adult foster care - this took 15 months while we as a family remained in crisis and experienced PTSD.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	There needs to be more caregiving, respite, and supportive housing for those with profound autism and co-occurring issues. COVID has broken the fragile caregiving system in place - people need to paid more money, get benefits, and have caregiving serve as a real career. Families need more support if we are going to continue putting the burden on them - respite, caregivers, therapy, and skill building.

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	GI difficulties, malnourishment, ARFID issues, insomnia, connective tissue disorders, sensory challenges, motor challenges
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, burnout induced depression
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	About half the autistic people I know have dyslexia or disgraphia
What additional research is needed to help address co-occurring conditions for autistic people?	Insomnia research, GI research, connective tissue disorders research, ways to achieve nutritional balance on a limited diet
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More support for autistic adults outside of institutionalization
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	The same as it's had on non-autistic (allistics) people - respiratory issues, cardiac issues, brain fog. That's not to consider the effect forcing return to office has had on many autistic people who were suddenly able to work fulfilling roles in corporate due to flexible remote policies, and are now struggling as companies rescind those policies.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Greater access to remote work, greater flexibility on schedules, more awareness of remote schooling

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Physical health conditions are sleep disturbances, self-harm, harm to others, inability to brush teeth, inability to bathe, inability to sleep, nausea when stressed or dysregulated.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, ADHD, aggression, self harm, harm to others, trauma.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	PDA is the significant neuro-psych behavior that feels generally unknown in the industry in the US. Many clinicians treat it as a behavior issue which only makes it worse when the child masks.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Broadening the term disability to handle high functioning autistic persons because they are unable to go to public schools and require homeschooling which result in loss of income or additional cost.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>Adverse body sensations associated with physical health conditions prevent me from doing my usual self-care things like preparing food or showering. It also makes it more difficult to access medical care, which is already new and overwhelming on a normal day. Accessing medical care is also difficult when doctors don't factor in my sensory issues or how much they impact my life and instead just write off my situation as mild because I'm not having what they consider to be extreme symptoms, and they don't realize that I'm doing everything in my power to avoid those extreme symptoms because I would not be able to communicate verbally if those symptoms were happening. Multiple times I've been stuck in my bed and unable to reach out for help when things got that bad, and I just had to wait and hope that recovery was possible. Recently I've been having stomach issues that further limit my already limited access to food. It's been very distressing when my usual safe-foods like vegetable broth further upset my stomach, but food isn't something I can just stop doing because my body feels worse when I do. There's many things that can strain food accessibility (food allergies, financial problems, food shortages, the stress of going to the grocery store, my ability to prepare food once it even is in the house), and a stomach condition only adds to that list.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>I have ADHD, Autism, and Complex PTSD from my Autistic needs getting overlooked and dismissed as a kid. This led to me lacking a sense of self and feeling terrified of most things in the world. It got worse as I became an adult because all of a sudden I was expected to do things that I was not prepared for like navigate the doctor's office or apply for a job. I had never done these things before, and they were full of the most difficult things for me to do like navigating new systems, making phone calls, and talking to new people. It's taken me about 6 years to gain enough experience to start to feel competent in navigating some of these areas like managing doctor visits, but I still haven't been able to get a job. Before my Autism and ADHD were recognized, I burned out when attending college to the point of being hospitalized. No one understood why that had happened, not even the doctors at the hospital I was admitted to. It all makes sense now that I know about my Autistic and ADHD needs, and things are better now that I have more supports, but the strain I was under did lasting damage and I'm no longer able to do as many things before becoming exhausted and needing to stop. It's also a testament to how little is known about autism, even in the medical community whose job it is to know about things like this, that they would not have been able to recognize or troubleshoot an issue that culminated in me ending up in the emergency room.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>I've struggled most in areas that have little to no education infrastructure like how to navigate government systems, how to manage health issues and doctor visits, how to look for and apply for work. I also tend to get overstimulated by common things like the grocery store or other public spaces. Living in a suburban/city environment means I haven't been able to access many spaces outside my house because they're too loud, or too busy, or they stink so I can't breathe. That compounds other issues like physical conditions from not walking as much as I used to or lack of quality air. I haven't had the resources to move, so I'm stuck in an environment that is highly inaccessible and am reliant on my mom for food and shelter. Communication struggles have made it difficult to access what supports</p>

	could be there. I wish there was a consolidated Autism Community Center to help connect me to supports and offer ideas that I wasn't aware of.
What additional research is needed to help address co-occurring conditions for autistic people?	Much research is needed on the ways Autism presents in all marginalized groups--autism in the Black community and other people of color, autism in women and girls, autism among trans and nonbinary folk, high-masking autism, autism in adults and not just children, and autism as it intersects with other conditions that can mask it like ADHD. More research is also necessary into communication design that is more accessible--things like UI design and graphic design (both digital and physical) as well as increased written communication avenues like through text and email.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	- more supports tailored to autistic adults instead of just parents of autistic children - support designed for high-masking people (we are commonly denied supports because we meet conventional markers for success but struggle greatly in places that are conventionally out of sight, but that tends to lead to burnout and subsequent decreased abilities and increased health conditions) - having consolidated centers for autism support to help people discover what supports there are and navigate the systems that are otherwise inaccessible
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	New illnesses prompted by compromised immune system have been difficult to manage, and they disrupt my self-care processes which have already been difficult to manage.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Positive: - increase in remote-access services like self-check out, food pickup shelves, telehealth, more written chat or email communication options, online options for filing paperwork - decreased social obligations Negative: - increase in health issues from compromised immune system - medical system more full and less available - medical system more scary to navigate because of higher risk with COVID being so contagious

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	<p>I meet the criteria for a PDA profile of autism. I can make eye contact. I am social. I have special interests. I am mono tropic. I also have executive dysfunctions. I was born this way. I can not 'do' things when I am overwhelmed, which is a lot of the time. My childhood was a nightmare. I appeared super smart (with a high IQ) and was placed in a NYC tag program. I could 'not' concentrate of the teacher for more than a minute or two. I could 'not' learn' in a classroom. I melted down daily at home. I could 'not' make my bed or do my homework. I made a serious attempt on my life at age 16 because I could 'not' do almost any of the things I was expected to do. By age 19 I was homeless and an alcoholic and was shooting up heroin. The more declarative the language used the less able I am to 'do' the request. I finally managed to get into Antioch college which had no grades and I only had to attend the first and last class. I could work with the profs one on one and I designed my own major. I learned to love learning and eventually got a masters and a tenured job teaching adults in a college. I'm over 70 now and missed so many opportunities to have a way better life thanks to PDA. There is an official website for this profile. Please check it out. It is in the UK. https://www.pdasociety.org.uk</p>
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	<p>I have a PDA profile of autism and I find it a real challenge to 'do' anything, even things I 'want' to do. I sabotage myself. I also have many executive dysfunctions around time, working memory, impulsiveness and internal and external organization. I also have many social challenges, the biggest one being monotropism. It is almost impossible to get me to change the subject once I am 'hooked' into it. I also suffer from the 'double empathy' issue where NT and ND people just seem to 'miss' each other's communications. It is in the social realm that I fall down again and again. My impulsivity and tendency to 'melt down' when my anxiety level rises alienates folks from me and I do not have many close friends.</p>
What additional research is needed to help address co-occurring conditions for autistic people?	<p>Please check out the PDA Societies website https://www.pdasociety.org.uk They are the leading institution around PDA (pathological demand avoidance or pervasive drive for autonomy) This profile on the autism spectrum needs to be researched extensively because the strategies for autism actually worsen the symptoms of PDA! Only the strategies designed for PDA work with us and they make the difference between night and day. So many lives could be saved (I almost successfully killed myself at age 16) if this profile could be identified and interventions put in place. But it needs a lot of study and more research. Please! The first 20 years of my life with PDA were a nightmare for both me and my mom. I had to go to eight different high schools before I could graduate. We fought daily! I could not 'do' almost anything! BY age 19 I was an alcoholic shooting heroin and homeless. Fortunately things turned around but I am an exception! Thank you.</p>
What could be improved in autism services and supports to help address	<p>All insurance needs to cover autism assessments. Include profiles (like PDA) in the assessment process. There should be an online assessment option for</p>

<p>co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>the immunocompromised who can not catch COVID. All diagnosticians need to be aware of autism and its profiles. I was misdiagnosed so many time (adhd, bipolar, bpd, atypical depression, etc. etc.) and none of the strategies for those issues worked. Only the PDA interventions worked and now it's like night and day! But I am over 70 years old! So many lost jobs, and relationships. So much needless suffering!</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>Too many demands from Covid! As a person on the autism spectrum with a PDA profile the pandemic has been terrible. I have socially isolated for almost four years now. And I am constantly terrified. So many friends have had strokes, dementia, divorce, and exacerbation of their mental health issues, and long covid. etc. Several people I now 'died'!</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	

Name	Anonymous
Demographic	Autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>Some of the most significant challenges are being able to: - withstand long periods of standing without feeling lightheaded or getting irritable. - tolerate extreme heat and humidity without getting irritable or experiencing a meltdown - going longer periods of time without food and not getting irritable/becoming lightheaded - going a full week without having a night where I'm up until 3 am - being able to go into areas where there may be sudden loud noises or not having to cover my ears when that does happen - being able to go into/navigate crowds or tight spaces without getting irritable and anxious - not have gastrointestinal problems every time there is a stressful event or time period -not feeling nauseated when I eat something with a sandy or dry texture (i.e. sandy watermelon, bland chicken) - not get irritable when it is windy while attempting to do something</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>I have clinical depression, ADHD, PTSD, and CPTSD. The most significant challenges for me are: - not feeling motivated to do a task that needs to be done (i.e. finishing an assignment, doing chores) - maintaining structure to routines and punctuality - not getting anxious or getting aggressive/having a temper when there is a sudden change to plans - having a harder time confronting people due to past experiences - having intrusive thoughts that often involve harming others, especially to those that I feel have wronged me in any way even if we made up - perseverating on a situation for days on end - thoughts of suicide and attempting to do so - intrusive thoughts about memories from my childhood I'd rather forget - going into the same area as my ableist ex-roommates and their homophobic friends and having a panic attack - dissociating in loud, crowded spaces or certain social situations (i.e. going to a public event alone without friends)</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>The research that I feel is the most needed is how often PTSD/CPTSD occurs in autistic individuals and where that often stems from. Every single autistic person, especially early diagnosed, all have PTSD which can be traced back to early childhood. If left untreated, this can lead to other mental illnesses such as depression and even BPD, which is also caused by childhood trauma. This is unrelated to childhood trauma but how often ADHD occurs alongside autism and how that can impact the autistic individual growing up. This must also be researched for those with ADHD who have late/undiagnosed autism.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>- more intense and lengthy training for special education/autism based therapists/wrap around workers, paraprofessionals, and teachers all of whom should be required to take an ethics test every year before the start of the term. - if they fail the test at any point they are to be barred from working with any children - Along with a criminal background check, paraprofessionals must be required to have a psychology, special education, or a teaching degree along with the said above. - If reported by an adult or child & caught emotionally, physically, sexually, or psychologically abusing the child they work with or any child they must be fired, stripped of their license, and barred from working with kids again or the school will face a hefty fine. - Classrooms that have neurodiverse children should require wellness checks from the school psychologist where the neurodiverse child is</p>

	<p>to tell EVERYTHING about what goes on in that classroom. - ALL applied behavior analysis (ABA) practices and related/inspired practices within wrap around must be outlawed due to their abusive nature to convert autistic children into neurotypical kids and for inspiring gay conversion therapy - every autistic individual that is a victim of all or any of the said above, such as myself, should be paid FULL FINANCIAL COMPENSATION for every dollar that their family paid towards these schools and services from the school and the government.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Positives: - access to Telehealth appointments rather than having to schedule a time to meet then travel out of you way to see that person. - ability to take exams, quizzes, etc. remotely which is more accepted -within the safety of your home frequently Negatives: - limited access to friends &/or partner - lack of motivation towards classes/exams - harder to pay attention in said above and within job - changes to how frequently you can see friends - sensory issues with masks not fitting well (which is why I wear disposables)</p>

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	gi issues, physical fatigue from burnout
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Complex ptsd from being undiagnosed, anxiety, depression, suicidality
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Being gifted led to me not being diagnosed for years
What additional research is needed to help address co-occurring conditions for autistic people?	Look at high masking autistic individuals and the trauma and mental health destruction that can result, particularly high achieving, high masking females
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Disability for burnout
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	gastrointestinal disorders, (hyper mobile) Ehlers danlos syndrome, POTS, fatigue, sensory sensitivities, fine and gross motor challenges, dental hygiene issues due to lack of executive function or sensory issues preventing one from brushing their teeth or similar
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD, OCD, dermatillomania, trichotillomania, anxiety, social anxiety, depression, suicidal thoughts, restless leg syndrome, BFRB, skin biting, nail biting
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	struggles with communication with atypical or neurotypical individuals due to different communication styles
What additional research is needed to help address co-occurring conditions for autistic people?	when one comorbid diagnosis occurs others should be considered to fully support the autistic individual. there should be more research on ADHD and autism, what it looks like when they occur together (because autism symptoms can cover up ADHD symptoms and vice versa) and what they look like separate. also more research should be done on autism in AFAB individuals as they are often socialized differently and autism can be overlooked as simply being picky, shy, or "weird"
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	ABA therapy should not be the first choice of treatment for a child as it can be harmful and traumatizing
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Many people realizing that they were autistic over lockdown because there was less social pressure to act "normal" and it allowed people to discover who they are, and realize that they might be autistic. lockdown also created isolation and removed structure from many peoples lives so they began struggling more in social settings and became for fatigued when returning to society
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	Covid caused a disruption to routines and caused less social interaction which autistic people may thrive on, but it also created a more accessible world for many with telehealth appointments, other virtual gatherings, more people to relate to about their experiences online, etc

in-person social interactions and obligations)	
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Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory overstimulation causing physical discomfort and distress. Digestive issues such as slow motility or alternating between diarrhea and constipation and physical hypermobility causing painful or stiff joints
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, Depression often caused by overstimulation and burnout. ADHD. Suicidal thoughts
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Inability to respond appropriately in social situations, dyscalculia, inability to effectively communicate feelings, thoughts and boundaries with others
What additional research is needed to help address co-occurring conditions for autistic people?	More research in adult diagnosed individuals to determine support needs from years of trauma through undiagnosed years
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Ease of Access to formal diagnosis, less costly testing alternatives, formal work accommodation guidelines for autistic adults in the workplace, support services for autistic adults with low to medium support needs
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Positive remote work. Reduced in person interactions.

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Aggressive and self-injurious behaviors are the most significant co-occurring conditions in autism. They impact learning, interpersonal relationships, activities of daily living, and independence and are a significant safety concern for the individual with autism and their families and peers.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Intellectual and developmental disabilities that co-occur with autism significantly impact the ability to perform activities of daily living and limit independence.
What additional research is needed to help address co-occurring conditions for autistic people?	Research is needed to address the intellectual disabilities associated with autism, particularly in individuals with a co-occurring diagnosis of Down Syndrome and autism, who are significantly impacted in all activities of daily living.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Better pay and benefits for personal support individuals who play a critical role in supporting individuals with autism is imperative.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	In addition to higher COVID morbidity and mortality in individuals with autism than in the general population, regression in learning due to online format has been significant.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Societal changes due to COVID-19 have resulted in educational losses due to online learning, attrition of direct support professionals due to poor pay and increased risk for illness and fewer opportunities for in-person interactions resulting in loss of social skills.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbances.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADhD
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	There needs to be a recognized alternative to ABA (which is abusive and has primarily negative outcomes) that can be covered by insurance, so the people who have access to insurance and need help (whether parents of autistic children or autistic adults) can access therapy.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Chronic fatigue from COVID-19 can exacerbate negative aspects of autism and make common coping and executive function management skills more difficult to access.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Remote work, school & health services being normalized on a wide scale has vastly increased access to all three. Disruptions to public transportation and supply chains has decreased access to a wide range of goods & services.

Name	Anonymous
Demographic	Autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>As an autistic individual, I have additionally been diagnosed with chronic migraines. An overlapping symptom between these two conditions is sensitivity to sensory input, such as light and sound. My chronic migraines resulted from hormonal imbalances during puberty, but I have experienced sensory issues my entire life, though it was only during the period of time which my migraines were at their worst that I had my sensory issues taken seriously by family members, school officials, and medical professionals. Bright and flashing lights or loud and high pitched sounds can cause me high levels of anxiety and register as physical pain throughout my body, but this pain has only ever been taken seriously by medical professionals and family if I so happened to be experiencing a migraine at the same time that the overwhelming sensory input is occurring.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>As an autistic individual, I have additionally been diagnosed with CPTSD, anxiety, depression, skin picking disorder, and gender dysphoria and while it is not a formal diagnosis, I experience general issues with fine motor control. Of these issues, the most significant struggle of mine is CPTSD, or Complex Post-Traumatic Stress Disorder. I have experienced a variety of traumatic events within my life that have caused me to receive this diagnosis, but many of the traumatic events can be attributed to my experiences being autistic. Bullying and discrimination I faced from peers and teachers growing up, a lack of care and assistance in meeting my needs from family members, and infantilization and dismissiveness from doctors throughout my life have all contributed to the creation of the mental health conditions I have today. Additionally, my skin picking disorder occurs as I use skin picking as a self stimulating behavior and this has a negative impact on my physical wellbeing. Furthermore, I am a transgender man and as a result of my autism, people often believe that I am simply confused about gender and that I am just a confused woman. Finally, anxiety and depression stem from a wide range of autism related symptoms.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>I have issues with auditory processing capabilities and this can make it difficult to understand the verbal information being provided to me. This causes a variety of challenges in my life, from having issues understanding the words being spoken to me by a friend, to have difficulty comprehending information or instructions given to me by a professor or employer. As a result of these issues, I have had difficulties in certain classes throughout K-12 education and college education and I have been reprimanded by employers for not understanding instructions for a task given to me the first time they were given. Additionally, when I am able to ask for information to be repeated to me, the person to repeat this information will often either become annoyed with me or infantilize me as they interpret my lack of understanding as stupidity or laziness.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>Further research into CPTSD and how trauma impacts the brain is needed as a whole even for those who are not autistic, as while a great deal of new information has been learned over the past decades, there is still a great deal we don't understand about trauma's impact on the brain and many health providers have a limited understanding of CPTSD, if they know it exists at all, as many are only aware of PTSD, which shares many similarities, but has distinct differences as well. A further understanding about the social treatment of autistic individuals in our current society would likely shed light on the trauma this treatment can cause and the lasting mental health impacts this can have. Further study into the unique ways certain conditions</p>

	<p>occur with autism is needed as well, such as how eating disorders and addiction impact autistic individuals at higher rates compared to the neurotypical population. Overall, if further research is done on these co-occurring conditions, it is likely that more individuals may be diagnosed as autistic and given treatment suitable to their needs.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>A greater deal of education on autism should be provided to K-12 educators, physical health practitioners, and parents so that children may receive education better suited to their learning styles and so that treatment intervention may occur earlier on. Specifically, there should be better education regarding how autism presents differently in females than males, as it is believed many females go underdiagnosed due to the lack of education on these differences. Furthermore, additional education should be provided on autistic individuals who may have higher than average IQs or co-occurring conditions such as hyperlexia and proficiencies in certain subjects, as many providers see these traits in patients and believe that as a result of these "positive" traits, the patient must not be struggling with other symptoms related to autism. Additionally, as more information becomes accessible to the public regarding autism, better insurance coverage should be provided to adults who wish to seek an autism diagnosis. In terms of patient-provider interactions, a decrease in the levels of infantilization patients receive and a general increase in education given to providers would be appreciated, as well as how symptoms of autism may discourage individuals from seeking out various medical treatments (eg. sensory issues may provide difficulty for those seeking out dental procedures) in order to create a more sensory friendly environment.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>COVID-19 had caused a great change in presentation of symptoms of autism in me. During the time quarantine, without initially realizing it, I was given the opportunity to unmask in a way I had never been able to before. I began masking autistic symptoms as early as kindergarten in an effort to shield myself from bullying from peers and disapproval from various adult figures, but during quarantine, as I was a freshman in high school when it began, allowed me an extended break from regular interaction with peers that I had never before experienced. The only people I was interacting with daily was my parents and grandmother who lived with me during the time. This provided a great deal of improvement to my mental health as I was no longer expected to hide many of my symptoms, however when quarantine ended, I was thrown back into public education and as I had become accustomed to not masking my symptoms, I was regularly harassed and discriminated against by peers and staff for my symptoms, as I found it difficult to attempt to quickly hide them again. It is also worth noting that my depression did increase during the quarantine as many experienced with a lack of ability to leave the home and interact with friends and loved ones, and my physical health overall was negatively impacted as I began to exercise less.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Ability to work remotely and use of telehealth services have had positive impacts of my mental health, as they have provided a lesser deal of anxiety with interactions with medical professionals. One of the greatest challenges I have faced with in person physical healthcare was the distance I had to travel for specialized care, such as when I had to travel from my home in a rural area of New Jersey to the Children's Hospital of Philadelphia or hospitals in areas outside of New Jersey in the New York City area. This provided me and my family with higher levels of anxiety due to the need to travel and our unfamiliarity with traveling in more urbanized areas. About a year ago, I was involved in a serious car accident and have had anxiety regarding car travel</p>

	<p>ever since, so being able to have access to telehealth appointments has decreased that anxiety, the anxiety of in person social interactions, as well as anxiety that comes with spending money relating to the necessary travel to in person appointments. In recent times, many of my providers have repealed their use of telehealth services and my college no longer allows students to choose whether they may attend class in person or virtually as they have felt virtual options were no longer necessary and because many providers or teaching staff prefer the in person interaction, though it is important to recognize the benefits of virtual interactions for autistic individuals.</p>
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Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I can't walk in a straight line without intense focus and effort on gait. I fall and trip frequently, easily get extremely faint, and easily over extend my joints or sleep on them wrong and cause pain.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	my obsessive compulsive disorder, especially before medication, has a huge impact on my life. I am rarely free of intense and upsetting intrusive thoughts and compulsions, intense fear and unsafe, uneasy feeling.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	just...more. a lot more. larger, more diverse sample areas, autistic-led and autistic-focused research. and [profanity redacted] autism speaks and their "cure autism" goal and all of their [profanity redacted] "research". they are a hindrance, they fearmonger and suck up donations from well meaning idiots.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	TRAUMA INFORMED CARE PROVIDERS. CONSENT INFORMED CARE PROVIDERS. PHYSICAL/MOBILITY/COORDINATION/BALANCE DISABILITY ADAPTIVE PROVIDERS.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gastrointestinal disorders (IBS, sensitivity to foods, etc.), Sleep disturbances (unable to sleep, vivid dreams, waking up feeling tired, sleeping at unnormal hours, etc.), motor challenges (delayed speech, or highly focused thought patterns and having the inability to regulate the amount of speech, etc.) sensory (light sensitivity - causing headaches, nausea and eye pain), (temperature sensitivity- always cold/hot). (Food- sensitivity to texture, smell, taste. This causes a decrease in required vitamins which can impact the overall development of the brain and body organs, which in turn cause other disorders and delays in development.) Movement of body parts (walking on toes, flapping of hands, etc. due to stimming. This can cause soreness and joint pain. If at a younger age can cause the muscles/system to develop incorrectly causing long-term effects and the need for physical therapy).
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anger, depression (isolation), anxiety (fear of our self as there is little information on what the spectrum of autism is and how it impacts each person that experiences it. Also for females (women) the lack of diagnosis and the requirement to mask cause long-term anxiety that is not treatable with medication. Anxiety related to not fitting into society's requirements). ADHD, eating disorders, self-injury (hitting, cutting, picking as examples due to self-hatred and also stimming activities). suicidal ideologies and attempts. Educational disabilities, learning disabilities, executive functioning difficulties, and social difficulties lead to new disorders and can cause personality disorders. Substance Use disorders.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Learning disabilities, development disabilities, intellectual disabilities, communication disabilities, social interaction "disabilities", and unable to obtain and maintain a job/career. Sensory issues, executive functioning difficulties, impulse control, eating disorders, substance use, self-harm, OCD, inability to stim in public for fear of judgment, and lack of understanding from those around them. Isolation, lack of human connection.
What additional research is needed to help address co-occurring conditions for autistic people?	Brain research, vitamin research, body function research, what does the spectrum truly look like. Is autism the main disorder and other disorders are co-occurring but autism is not looked at because the other symptoms are only looked at because of the lack of research and information published on this type of neurodiversity. I believe all children that enter school should be tested for autism at a young age. School research needs to be conducted to change the way we teach our children. We know that brains are different and we should be educating our children and public on this. We cannot create a system where "one size fits all" because that is not the case. We need research looking at the increased rate of homeless, suicide rates and substance use disorders to see if they are tied to individuals masking their autism and using the tools society has given them because there is a lack of understanding of what autism is and how do we treat it. Research associated with overall assessment for autism in men and women, girls and boys, of all persons. Does autism look different in different locations of the world because of their environmental exposures. Research on how autism is developed (nature/nurture/genetic)? Is this a part of our genes? Can it be identified?
What could be improved in autism services and supports to help address co-occurring conditions for autistic	Testing, assessments from a younger age. Society having programs available, medical practitioners trained on neurodiversity and brain functioning. Insurance coverage, support service and insurance coverage for them. A

<p>people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>change in the educational system. We know that each child brain is different and we need to change our educational system to match science. There needs to be more support for all students, and teachers. Change how we teach, inclusion classes for the workforce (private and Federal).</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Delayed response, unable to properly regulate oneself, overstimulation, self detrimental
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Self harm, Regulation, Thought process, attention to a task, continued support for adults
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Educational support, access to communication tools
What additional research is needed to help address co-occurring conditions for autistic people?	How conditions may effect a Autism Diagnosis. Both mental and physical
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	All of the above, support for adults, access to additional financial support, aids, therapy, types of therapy approved
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Negative
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Access to services. In home support

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	GI issues, specifically low intestinal motility, combined with sensory issues (causing a narrow range of food consumption), resulting in severe constipation problems, amongst other GI issues. The GI issues ultimately affect the mood and sensitivity to the surroundings of an autistic child.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, showing up as hypersensitivity to noise, change in routine, crowd of people
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Developmental delays/disabilities, language disorders, socialization issues.
What additional research is needed to help address co-occurring conditions for autistic people?	Research that focuses on the cultural impact on autism, how different cultures treat people with autism, and how to effectively address each cultural implication in families to help people with autism in that family. Research that addresses sensory issues and GI issues in autistic people to better address the problem rather than a doctor saying, "Just eat more fiber."
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Children who were eligible for Early Start services for autism should be able to receive the same services up to age 8, not end at 3. Government-funded agencies, like the Regional Center, should be more proactive in providing and guiding resources rather than functioning on a "need " basis or "we'll look if you ask" basis as they are now. Eliminate the income threshold for families to receive autism-related services, especially from government-funded programs. The problem is that there are plenty of government-funded autism-related services out there. Still, there is no one providing a middle class or families between the poverty level and middle class with autistic individuals who cannot access resources because they make \$1 over the threshold. Private sectors are charging an insane amount per service.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Overall fragility to health. Non-verbal autistic individuals cannot embrace the full effect of a person's suffering, which is mentally exhausting to the caretakers.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	Positive impact: increase in app development that allows visual communication, like food ordering or purchasing things to be picked up curbside/drive up. Increased online business conduct will enable families to stay home and accomplish the same thing without minding autistic individuals in crowded places. Negative impact: reduction in places we can sit and enjoy. Therapists and other professionals wear masks that prevent autistic people from understanding/seeing critical non-verbal cues.

in-person social interactions and obligations)	
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Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>I have daily challenges with the food available, and how that food impacts my physical health, I can't eat most foods because of all the additives and unnecessary substances added to it, or the highly processed foods. I get physically sick and I become unregulated in managing my autism. Everything has to be balanced if I want to somewhat function "normal." Stress, overstimulated, senses overstimulated, and I cannot function. I shut down, and then barely can even care for myself, and yet then I'm expected to work and function like nothing is wrong. Everyday living, and life is a challenge with being autistic, and my challenges fluctuate daily, hourly, and minute to minute. One thing I want to make clear, most of the time, these challenges, I never know what they will be, because it is never the same. One day, I have diarrhea and can barely eat, next day every sensory, sound, taste, touch, sight...etc, is so overwhelming, I cannot live "being in my own skin" This effects my whole person, not just physical, but mental, because then my mental health begins to spiral, and spiral fast. Guess what? There is no one I can turn to, to get help. There is no community support, doctors gaslight me and don't know how to work with or treat autistic people, and therapists, mental health providers are much the same.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>Anxiety, depression, ADHD, C-PTSD, hitting myself when I'm in a meltdown. Lots of trauma. Being yelled at, being hit for not sitting still. Trauma of being excluded from basic aspect of society & social interaction because I was "too weird" or "there is something wrong w/ you" & I'd like to add religious trauma, & punishments because I thought differently, because I was defiant, because I wasn't obedient. Feelings of being a failure because I'm not trying hard enough, so then I'm not good enough & never will be good enough. & then high masking. Feeling all of that, & I have to pretend everything is fine, & smile to make everyone else feel better, but what about me? I'm forced to work because I have no other option, but my mental health is suffering. Again, there are no community support programs, or support in general for us autistic adults. Yet there are a for school age children. Again, in my experience, mental health providers just are not experienced to deal with us late diagnosed autistic people on the spectrum. My husband, dx ASD, his co occurring disorder is bi-polar. I can see the bi-polar developed out of being unregulated & misdiagnosed. I see this with a lot of the co occurring "other" disabilities with ASD. My anxiety, depression, & c-ptsd all from being undiagnosed. Now, I barely leave my house unless I have to, & I don't know how to get better. Anxiety going to the grocery store because it is crowded w/ people & it is too loud & over stimulating.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>Everyday is a constant battle of trying to understand and decode the world around me. I struggle to learn new things because I have this feeling that I can't make mistakes or I'll be punished, so I don't want to learn new things now. Communications is a struggle daily because I think I'm being clear and direct, and I'm being rude or blunt. Developmental delays? How am I supposed to know when I didn't know what was wrong with me until I was 40? Now I'm having skill regression, and I feel like I regressed back to childhood and now I have to relearn everything as an adult. I think I'm directly communicating, and yet I'm somehow not. I did learn American Sign Language and I communicate easier in that. Which kind of helps, but not everyone knows it. Guess what? There are no community resources or support for autistic adults. In fact, I had a health professional say, "you're to old, there's nothing to help you" Then you all are wondering and trying to</p>

	figure out why suicide is so high among neurodivergent adults? We have no support and no help!
What additional research is needed to help address co-occurring conditions for autistic people?	You need to start researching autism and other neurodivergent ADULTS! and research what community resources and support we need. Research and pass laws on how workplaces can be neurodivergent friendly. I can work, and I enjoy my work, I'm told I'm one of the best employees, BUT, when the work environment is not friendly towards me, I can't do the job I love. Autistic children grow into autistic adults, but us adults are forgotten and tossed aside. Researchers can learn so much from us, but we're never part of the conversation. We're never included in the decisions.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	First & foremost, physical & mental health professionals need to get out of their fixed mindset, & stop gaslighting us & actually listen to us. Neurodivergent bodies are different than neurotypical bodies, "normal" treatments & doseages don't work on me, or has adverse effects on me. We need community resources for autistic adults. Sensory friendly places for us to have a sense of community. We need to feel like we are accepted and belong in this world. Most of us feel like we are aliens living among humans. We feel we don't belong here. When anyone feels they don't belong, no hope, no support, no community they commit suicide. I would bet, the suicide rate is so high because it is neurodivergent people who are mostly unaliving themselves. I see patterns, and that is a pattern I see
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	They've gotten worse, and I can't mask anymore. When we went on lockdown, I had a nervous breakdown. I suffered, and mental health service I sought, made it worse. I didn't know if I would make it through alive. Socializing for ASD people is so difficult, then add onto it what our government did to us by forcing the lockdowns, and the vax mandates. The mask mandates as someone with sensory issues, no one knows or cares what that did to us. I'm even more mistrustful of our government and those in power. I'm even mistrustful of filling this questionnaire out. Then when we were told "everything's fine now, go back to work" & I could no longer mask or know how to interact with a covid/post-covid world, with 0 support. Let's just say, I'm still dealing with a lot of trauma from what the covid policies have done to me. I had covid twice, covid was just another sickness to me, and no issues from the virus. It was the social controls and hate from people that effected me the most.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The negative side of things, I'm even more mistrustful of our government, federal and state. I'm more mistrustful of doctors and mental health providers. I lost my ability to function like a "normal" person. I had a nervous and mental breakdown. I experienced skill regression, that of which I have no recovered from. If I wanted to access public services to get help, you have to wait 6 months to a year to see anyone. Everyone wants to stay home now, or doesn't have the money to go out, and we don't have community spaces, those all have been defunded. The American people are unwell, even the providers. Insurance is a joke, we keep paying more for less coverage. Work from home actually was fine for me. I wish I could still work from home, but my school district in fully in person now. What I also see with working in public education, the younger generations are suffering terribly, and don't care about an education. Again, these kids, and teenagers have no support. My outlook on our life is pretty negative since covid.

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory challenges create the most pervasive challenges. A great many places are both audibly and visually noisy, which is both distracting and overstimulating. This was particularly challenging when my Autistic son was in daycare and early elementary school, as finding daycare and after school care facilities that weren't overstimulating was difficult and significantly limited our options. For my son, sleep disturbance is a close second, as he requires 10-12 hours of sleep to do his best but requires medication to sleep at all.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	All of them, for different reasons. Aggression when my son was younger was very significant and disrupted his schooling for several years, until a combination of medication and therapy helped make it manageable, and what we are guessing is the onset of puberty has toned it way down. I had grown afraid of leaving him in the care of people I wasn't sure were equipped to handle him. ADHD in both of us has been another obstacle but getting him evaluated for it for an official diagnosis and supports has been impossible, due to his existing Autism diagnosis putting him at the lowest priority on waiting lists. Without diagnosis, we're locked out of medication as an option, and it's beginning to affect his grades. Anxiety for my son often leads to the meltdowns. He'll get anxious about something, and then the Autistic perseverance starts a vicious cycle that can be difficult to break him out of. Autism-related PTSD is the primary root of my depression and anxiety. As an adult woman, I went undiagnosed entirely until my late 20s. Jobs are difficult to retain, because people assume that because I'm smart and good at my core work, that I don't need support in other ways, and I end up failing to meet other expectations (and denied support for those things, because "you're smart, you can figure it out") or run afoul an unspoken cultural rule, resulting in me getting pressured out, if not outright fired.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The nuances of interpersonal communication is, hands-down the most significant challenge. While I'm very intelligent and articulate, I often miss particularly non-verbal cues, and I default to the literal interpretation of things. I frequently find myself processing things fundamentally differently, which very often causes communication breakdowns that I've yet to be able to prevent or mitigate. It's destroyed a great many personal and professional relationships, requires a great deal of emotional energy to handle, and is a large source of anxiety, depression, and PTSD.
What additional research is needed to help address co-occurring conditions for autistic people?	Quite a bit, especially in women and girls. Girls are very often diagnosed much later than boys, which results in girls having to mask more and for longer and requires us to find ways to manage it all on our own, taking a major toll on mental and physical health. In both, what are the effects on the central nervous system and the adrenal system, how do those differences contribute to Autistic perception of the world, and in what novel ways can we "turn the volume down" on the world? What's the toll on those who are "gifted" (as schools classify them) and also ND? What can we do to better support them?
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More diagnostic providers in general, insurance coverage of diagnostic screening. A diagnosis of Autism shouldn't disqualify a person from ADHD or other evaluations. Better training for teachers, psychologists, childcare providers, and others in handling ND kids. Better training for medical personnel in general in handling and listening to ND people. Better mental health services more generally. Better training for first responders in handling ND people in crisis. Teach sign language as a core part of school

	(and more sign language education accessibility for adults). Work culture that supports more breaks (both during the day and as Paid Time Off) and better work/life balance.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The increased acceptance of remote work has been a huge boon for me as an Autistic person. It greatly reduces the cognitive overhead of being in an office, around so many other people, and expected to follow certain social norms. Text communication works better for me generally, and it's more acceptable to use it in a remote environment. I can also set up my environment the way that makes me most productive. Increased telehealth has also been beneficial, as it's increased access to therapists, making it easier to find one that meets my family's needs. However, it seems to have decreased the number of diagnostic providers, who tend to be separate from the everyday providers, making an already difficult thing nearly impossible.

Name	Anonymous
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Due to sensory challenges with food textures, children getting adequate nutrition is difficult. Add in sleep disturbances, and the result is a emotionally and physically unregulated child. Emotional regulation is hardly a solution when they are tired and hungry, and unable to explain this to those who are trying so hard to help them eat and sleep. Any food that has varying texture, i.e any fruit piece that has pieces of pulp, rind, peel, or seed will cause gagging, so safe foods that are small and reliable in texture, shape, and color, i.e goldfish crackers, fruit gummies, and chicken nuggets are the only thing they will comfortably eat, which is not meeting their daily fiber, protein, or vitamin minimums. Without physical needs being met, emotional needs will be all over the place!
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The ability to emotionally regulate, and communicate their needs to others who can help is the most significant challenge. With anxiety, poor function/planning skills, and the aggressive behaviors resulting in the speediest attention, the skill of self reflection "What do I need?", then communicating that need to a caregiver or loved one comes second to having aggressive behavior outward or inward.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication disabilities bring the most challenges. These can be mitigated with technological speaking and interpreting devices.
What additional research is needed to help address co-occurring conditions for autistic people?	Research for Autism in connection with: eczema, ehlers-danlos syndrome, and ocd need further attention.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance has no reason to deny people with Autism services they received as children after they turn 21. With delays in many significant areas, it cannot be expected that once this population turns 21, they are ready to be independent adults with no support. Allow all individuals with Autism funds for self-directed or caregiver-directed supports that benefit the individual. Insurance denies those with Autism who display aggressive behaviors, towards self or others, to participate in group therapy. This is ludicrous- skills needed for group therapy are best taught in group, with 1:1 support for those who need it. This is neglectful to a group of people who deserve community, a chance to make friends, and a chance to encounter people of all ages and abilities. Companies working for those with Autism should be allowed and encouraged to make relationships with the individual and their family, not abide under strict ethics codes that don't allow for Christmas present swapping between caregivers and Autistic individuals. Gift giving is an appropriate part of social communities and those skills have to be taught- they are not innately learned.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on	

physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The co-occurring physical health conditions all contribute to making life more difficult and require more planning/adaptations. For example, I have to be particular with my diet to avoid gastrointestinal discomfort and I need supplements of particular minerals because my body does not absorb them well. Sensory issues, particularly hypersensitive hearing and sensitivity to heat, affect my ability to sleep. I use accommodations such as keeping white noise and a fan on at night, but sensory issues have also made it necessary to move from an apartment because the street noise was so bothersome I had chronic stress symptoms, which abated after moving to a quieter location. The world is much more overwhelming with the constant sensory input I have to deal with, and that can make doing even important things I want to do, like going to a busy academic conference for my career, difficult to manage.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I would hazard a guess a lot of co-occurring mental health conditions in autistic people are not because of autism, but rather because of how society today is built in opposition to autistic people. Besides the sensory onslaught from urban society, the complex social navigation required to really excel in a career can also be hampering. Is it any wonder autistic people are depressed or anxious when it is difficult to navigate society? I cannot speak to aggressive or self-injurious behavior as I don't experience that, but I have seen friends suffer social ridicule and physical injury due to it.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	While it is helpful to do medical research to determine the causes of various co-occurring conditions, I would like to see increased research on sustainable and equitable solutions for difficulties autistic people experience. While some of my difficulties could use medical interventions, such as the gastrointestinal issues, others involve things outside of my control, such as how society works in ways that are inherently not intuitive to me.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Expanded insurance and services would perhaps be the best supports. I do not currently know what my insurance would or wouldn't cover related to autism, but I do know it would require a formal diagnosis. Many people who could benefit from services are very much barred from access because of how inaccessible diagnosis is both due to cost and shortage of qualified providers willing to assess adults who may not have appeared "autistic enough" to get assessed as children. To really help access, either increased access to diagnostic services needs to happen, or removing the formal diagnosis requirement to access services.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I don't think COVID was helpful for anyone, but I wouldn't say personally it made any of my co-occurring physical conditions any worse. It certainly didn't help mental health, mainly due to seeing the lack of compassion broadly and the many avoidable deaths that happened because of that.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal	Having more access to remote services and increased normalcy of remote work has been very beneficial.

changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I find myself avoiding modern society due to sensory challenges. There is always so much going on, that my brain tries to process all at once. Shopping for groceries takes up much of my energy for the day. The lights, sounds, and simply trying to find what I'm looking for can be overwhelming. Socially acceptable clothing is rarely sensory friendly. I can only stand it for a few hours before I am overwhelmed. The feel of makeup on my face, and having my hair down is another issue. When I shave my hair off completely, I am judged by most people.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD affects everything in my daily life. I have to constantly repeat in my head what I'm about to do, so that I don't get distracted and start doing something else. If I add something new to my daily routine, I often forget to do something else. Finding a balance between self care, caring for others, and working can be quite challenging. Social anxiety can make shopping difficult. Shop keepers tend to notice that I am anxious and assume that I am going to steal things. One man followed and confronted me, causing a meltdown at a pet store. I was too anxious to explain and ended up calling the store after leaving. Depression comes from everyday life being so challenging, and the lack of understanding from most non-autistic people.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication is a huge problem. I've read books on body language to better understand people in social situations. Small talk feels like a lie, I avoid it. People are uncomfortable when you truthfully respond to the usual "how are you?", they don't actually want to know. I find myself auto responding to them now, which is what they want. In my day, school was not capable of teaching me. I did poorly in most subjects, because they did not interest me and I would forget to do the homework. I was overwhelmed by the large classes, and could not focus. I had frequent meltdowns and confrontations with bullies and teachers. My lack of education means that I have limited job opportunities. I have trouble learning visually and orally. I have to do something repetitively to retain it.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I have not even been formally diagnosed because of the cost. I don't have insurance. I have had to research for myself. So I haven't found any help so far. Considering history and how autistic people have been viewed as a problem for society, I am unsure if I even want to be diagnosed.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I believe Covid-19 social isolation and distancing was mostly looked on favorably by the autistic community. This is how we prefer to live. It is uncomfortable for strangers to enter my personal space. I want to be home and work from home. I prefer grocery delivery to the sensory onslaught that is grocery shopping. I believe Covid-19 affected autistic people much less than others in daily life. Cleanliness and OCD is common in autism, so we like the extra precautions taken. Masks are irritating sensory wise, but it does help my social anxiety to hide my face.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic	I think Covid had a positive affect on society with telehealth, work from home, and remote schooling. I can control my environment at home for my sensory processing disorder. It is much less stressful, and saves commuting.

people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Receiving initial diagnosis, especially for late-diagnosed autistic individuals; physical symptoms are frequently overlooked, often due to patient's communication issues
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Autism-informed treatment for adults is nearly nonexistent, especially when co-occurring mental health conditions are directly caused by unmanaged symptoms and experiences of autism
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Treatment for adults is nearly nonexistent
What additional research is needed to help address co-occurring conditions for autistic people?	Independence-based treatments for adults, especially continued occupational therapy
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Insomnia is incredibly difficult on caregivers, especially since folks with a lot of support needs can have no sense of danger and good motor control. They can easily do things like open a window and wander out of the home. It is difficult to figure out ways to always have someone monitoring a person that may not sleep for days and always need supervision. Spontaneous disrobing is a real difficulty as well, since it can happen at any time. Physical assault of caregivers and as self harm is terrifying. I remember being terrified that my child might pull out their own eyes, and have watched them break their teeth on furniture that they grabbed and bit into. I cannot think of anything more difficult than seeing your own child harm themselves. Fecal smearing is another difficulty, especially since it is often paired with gastrointestinal disorders. So, for example, my child experienced constipation and would then smear themselves with fecal matter they could pull out of their own body. Sensory issues make all moments stressful. You never know when something might happen and set off, for example, an assaultive behavior. That is the reason that many people with children that can become violent often become hermits themselves.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety and sensory issues often fuel aggression and self-injury. It is hard to pull these issues apart, even for professionals. I have a very small adult child, but they can still seriously injure me or themselves. I cannot stress what a frightening experience that is, to love someone that is not capable of understanding their behavior and can cause a lot of physical harm and destruction. This makes things like doctor visits incredibly dangerous. It can make getting simple lab work done impossible without sedation, and most places don't offer sedation. So, a lot of folks aren't getting the medical care that they need because it is impossible to get basic labwork done.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	It makes folks so vulnerable to exploitation, and it makes families vulnerable to misunderstanding. It is easy to have a kid that will (for example) always choose the second choice in a question. If someone knows that, they can use that to get whatever they want as an answer from a person. Having a nonverbal child can be challenging in so many ways. It is harder for them to advocate for their basic needs or even tell folks if they feel bad. I feel like government systems aren't adapted to handle different communication styles, that are often totally individual to the autistic person. This is understandable, but often makes government forms and questions always nonsensical and necessarily works of fiction. Example: How can a parent know if a child who is nonverbal, has intellectual disabilities, and never expresses things in terms of emotions is ever suicidal? They can be asked that by medical professionals, but there is no way to ever answer it factually.
What additional research is needed to help address co-occurring conditions for autistic people?	It would be useful if folks that had a formal diagnosis and qualified for public disability funds would actually get to describe the experience of their child in a way that could be used by folks like University of Washington Spark project. Also, if I'm being honest, I think we need more information about folks that need the most support needs. A lot of folks who are on the spectrum and do not need many supports are hogging the conversation. There are a lot of mothers huddled in rooms right now, isolated, and doing their best that are bullied by the state, medical authorities, and even vocal disability advocates that don't want to understand how difficult situations can really be out there in the real world. If you've met one person with autism, then you've met

	one person with it. Some folks are really in impossible circumstances. We need to address the practical needs of *those* folks.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Almost everything. The most important thing I can think of off the top of my head is access to anesthesia/sedation for medical procedures, and access to labs and lab techs that can make appropriate accommodations.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	COVID made it very clear that there were no real accommodations for my kid. It was difficult to get vaccines because I couldn't get her to wear a mask when places would only help her if she could keep one on. I had no access to sedation for her to get shots. I ended up having to get helpers from the fire department and EMT folks to bring her the vaccine after pulling a lot of strings. The situation has been dire for her. I've had to fight for any kind of medical help. Her anxiety has been through the roof due to the world acting differently.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Social distancing was a momentary boon. It was easier to manage things when folks kept their distance. It was difficult in pretty much every other way.

Name	Anonymous
Demographic	Autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>For me I have issues with my stomach. Doctor says it's stress and inflammatory diet. I have emotional dysregulation which adds to the stress and makes it hard for me to keep jobs and afford healthy food. Junk food seems cheap, to help I have tried switching to rice diet but its not easy. Also grocery shopping is hard for me in general because of sensory. I can't work many jobs because of noise, temperature, or texture of card board. Customer service can also be hard because I can't filter out information and can become overwhelmed. People will assume im being rude and write me up and sometimes I will get fired because I look irritated but it has nothing to do with them personally I even though it's hard I can still do the job. I do have trouble sleeping and sometimes I have issues with attendance. It is all related and accumulative. I wish people could trust and understand more. There are lots of things I can do, it may just look different.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>I have emotional dysregulation, sensory processing disorder, ocd, depression, generalized anxiety, and alexythymia. Because I have asd level one, I went undiagnosed for a long time and I get very little support, most of the work I have done including finding a useful therapist, finding a boss that will advocate for me, and getting formal diagnoses I have all done and payed for on my own with the exception that you could consider my income subsidized if you take into account my parents or my partner have always been there to take care of me with rent and food ect. I would like to become more independent and contribute to society more. I'm seeking professional help now because a lot of strategies I learned growing up have been maladaptive and held me back, and have become less useful as I have gotten older. Challenges include: 1. Attendance at work 2. Keeping jobs 3. Keeping a healthy social net work 4. Finding therapist who won't turn me down 5. Finding sensory friendly environments to improve and learn new skills 6. Attendance and performance at university 7. Maintaining client relationships at work 8. Executive dis fuction and trouble remembering anything outside or routine 9. Creating and keeping routine as an adult 10. Having someone to call when I'm having a melt down and I need to calm down. 11. Self harm 12. Bullying by others 13. Manipulation from bosses, Co workers or companies.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>Communication issues: 1. Will miss Important Information for a task 2. Will perform a task incorrectly 3. Trouble with directions 4. Offending others on accident. 5. Problems following directions from law inforcement or government officials 6. Knowing how to do things like buying plain ticket or mailing something or cashing a check. 7. asking for help is hard sometimes. Developmental disability: 1. Still have trouble tying my shoes. 2. Stiming can be disruptive to my task 3. Melt downs can be dangerous to me and others around me when I'm driving Or at a store. 4. People often mistake me for being on drugs.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>More research on antidiuretic nasal spray More research on adults. Most is done for and with children. More brain imaging Most studies between the effects of early diagnosis vs late diagnosis. More research on emotional dysregulation.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services,</p>	<p>More support would include everything mentioned in the example as well as: -More tested values of a solution of autism in the dsm 5. DSM 4 went from 30000 to 2000 in 2013 and people lost their diagnosis. - better operative definitions for autism. Levels don't work. It's too vague and to specific at the same time - More support for all levels of autism as it is defined currently</p>

<p>insurance coverage, service systems issues, patient-provider interactions)</p>	<p>in The dsm - More support for autistic adults - disability aid should not resign people to a life of poverty. Instead support should be geared toward helping people become stronger, more independent, and successful. Their need to be less financial restrictions to get aid and it needs ne Match the rate of inflation. - More education on what the core features of autism is for the general public.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Work from home is part of the reason I lost my job after 6 years. I do not work well at home it is not sensory friendly and not structured enough and i would have lots of melt downs. I like structure and organization. Politics made rules very confusing and I did not know what I supposed to do or not do and everything keep changing which I did not like.</p>

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator; Representative of advocacy organization
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Connective tissue disorders (Ehlers Danlos), muscle tone, apraxia, autoimmune conditions, POTS, Mast Cell, gastrointestinal issues, executive function disorder, ARFID, PDA, migraine, sleep disturbance, sensory, dyspraxia
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, depression, ADHD, PDA, restrictive eating, suicidality, aggression, alexithymia, Aphantasia, ARFID
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Cognitive disability, auditory processing, visual processing, dyslexia, dyscalculia, learning disabilities, process disorders, communication. Poor health leads to a greater struggle to perform life skills/goals. Intellectual disability - harder to learn and implement skills
What additional research is needed to help address co-occurring conditions for autistic people?	Researching life span issues, particularly aging well. Research on unconscious bias of medical professionals.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Equitable access to health care, gender affirming care, better Medicaid, neuro-affirming care, patient-provider interactions, dentistry!!! Equitable support for all individuals with autism, including those who don't make the cutoff for eligibility for state supported services. Women with Autism!
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Long Covid is certainly an issue for autistic individuals. Not being able to find direct service providers is a larger issue! Brain fog, fatigue, disruption of services across the board, lack of providers and staffing
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Positives - remote work Negatives - lack of remote work, low employment opportunities, long COVID, disruption in services, scarcity of providers, not being able to access support

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The most significant challenge is daily survival. Every day is different and overwhelming. I personally suffer with gastro, sleep, and pain issues (feet and wrists/hands as well as headaches and vision) - occasionally overwhelming/debilitating. It's exhausting and exacerbates mental health issues.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My most significant challenge is retaining consistent and supportive employment. Nobody really understands how difficult basic communication and participation can be. Prone to depression, anxiety, brain fog, distraction issues, and sound/feeling induced panic.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I am incredibly black and white in terms of processing and communicating. This can be very difficult for employers and co-workers to understand. More than capable of handling the work typically, but horrible at reading emotions and non-transactional details.
What additional research is needed to help address co-occurring conditions for autistic people?	Autism in women (including those that are diagnosed late) and particularly women heading into or in menopause. Whole different level of stress and emotional management and it is NOT discussed.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	You literally can't get an appointment for any relevant services. Emergency rooms and gp's do not take concerns or issues seriously. Constant struggle to be taken seriously and given overall avoidance/communication issues anyway...it's not worth the fight most days.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	For me personally, having had COVID-19 twice, definitely strange physical issues - hands/wrists/feet, exhaustion and/or fatigue, head and back aches. Metal health-wise...100% good with quarantine and isolation periods. Actually improved the level of social anxiety and participation. Embraced remote work and avoidance of others.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Since we aren't taken seriously 90+% of the time, remote work has been a good thing and limited interaction/communication has made employment easier. The isolation factor overall, the lack of social obligations, while temporarily a relief has significant negative long-term impacts.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Migraine Intestinal distress Joint aches Clumsiness/accidents
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety Inattentive type ADHD Isolation
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Isolation Unemployment
What additional research is needed to help address co-occurring conditions for autistic people?	Research into providing accommodations and facilitate making contributions
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	-offer options that allow time to reflect on answers (ie. Alternatives to phone and imperson access) -provider education -broader availability, outreach, testing
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	-disproportionate negative health outcomes
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	-New opportunities for employment and engagement as more services become available online and are not dependent on in person interaction

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Aggressive behavior, emotional disturbances, sleep disturbances
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	aggressive behavior, inability to communicate, emotional disturbances, elopement, sleep disturbances, inability to keep self safe
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Inability to participate with peers, inability to participate in services meant for children and adults with intellectual disabilities due to aggression and high level of care needed. Inability to self advocate and communicate needs and wishes.
What additional research is needed to help address co-occurring conditions for autistic people?	Research is needed to address the cause of autism and how to help those with high support needs, those that are nonverbal and those that display aggressive behaviors and those that cannot communicate using alternative communication forms.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Respite care, better paid and trained providers, access to in home care, payment for caregivers who take care of minors and adult children full time, access to services (medical, social, vocational, recreational) even for those that require a high level of 1 on 1 support and display aggressive behaviors towards themselves and others.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Covid further removed those who are unable to communicate and advocate for themselves from the public eye, it removed life sustaining services for the highest needs population and their families, further isolating them and increasing caregiver burnout.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increased use of telehealth left many medical services inaccessible to those that cannot communicate or advocate for themselves. It made in home caregivers and therapies harder to access, further isolating those with aggression from the community.

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	This is a very broad question that is a bit too in-depth for 1500 characters, but I will list some personal challenges as examples. GI disorders prevent me from engaging in activities/work/events/etc, often having to take long breaks or cancel plans entirely. Chronic fatigue is one of the most overwhelming problems that I have that affects literally every aspect of my life and I have yet to find anything that truly helps. Sensory and motor issues affect my work life as uniforms/dress codes cause disturbance, as well as having to mask when working with clients/families.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I've collected mental health conditions like stamps and all of them significantly impact me in different ways. ADHD makes time management or focusing near impossible (even with treatment), depression and anxiety (mostly stemming from PTSD) are extremely debilitating and prevent me from even being able to sit up in bed some days, I have suffered head trauma from self-injurious behaviors... I could go on forever, but the one thing I want to emphasize is that I was diagnosed with "High Functioning Autism," but it does not accurately describe my struggles and makes it even harder for me to find appropriate services because people assume all I need is social skills training or CBT, when in reality I'm in need of much more intensive supports. Just because I have a high IQ doesn't mean I don't also have a developmental disability that affects my brain functionality. I can't access my intelligence if I'm overwhelmed, stressed, or burnt out.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I worked as a DSP for about 3 years and truthfully the biggest issues I noticed for my clients with co-occurring conditions was that some of the people supporting them would outright refuse to try and learn new ways to communicate or work with the clients. All the people I supported had diagnoses of Autism and Intellectual Disability, but they were incredibly intuitive and intelligent in their own ways. They had to learn to adapt to a society that does not value them in order to survive, even in a group home setting where they should have received plenty of accommodations and services.
What additional research is needed to help address co-occurring conditions for autistic people?	Research needs to focus on how to support, serve, and intervene (when necessary) folks of ALL ages. Most research I see is focused on early intervention or transitional age/young adults, but there are so many school age children and older adults who are without resources. Additionally, please stop funding research that focuses on finding "causes" or "warning signs" of Autism. Autism is not a disease, it will never go away or stop existing. Frankly, some research I read comes off as trying to bring eugenics back in style. It's extremely depressing and disheartening to see that people like myself and the folks I used to support are viewed this way.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	It's extremely hard for me to find good Autism services as someone with private insurance, it's also extremely hard for folks who are on Medicaid because there aren't enough service providers or funding for these services. The biggest thing that I think would be helpful is having more case workers, and having them available to ALL Autistic folks, not just ones on the Innovations Waiver. For example, it takes all of my time and energy to work a full time job and take care of my home, I don't have anything left to give to trying to find services or schedule routine checkups, but because I work and pay bills, I'm considered completely independent, which isn't achievable even for able-bodied people/.

<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>There are Autistic people, especially those living in group homes/medicaid funded housing, who have not and are not receiving proper treatment for COVID or long-COVID (I personally know someone with long COVID who has been suffering for months due to there not being suitable resources for him). Medical and mental health providers as a whole are wildly unprepared to work with Autistic people (though that seems to be improving) and I believe misinformation regarding healthcare (medical, mental, and behavioral) is one of the biggest contributing factors.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Increased remote work and school greatly benefit those who aren't able to travel or live away from family/support people, but it's also being slowly stripped away as businesses are forcing in-person attendance again, even in situations where it's not necessary. Many services were also put on hold or shut down due to the pandemic and there aren't resources to start them up again.</p>

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Narcolepsy, IBS, clumsiness resulting in frequent cuts and bruises
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Social anxiety resulting in complete lack of desire to be out in public
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Few friends due to mutual misunderstanding. Frustration with trying to keep track of unwritten rules
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	A lot of organizations are streaming/meeting online now. I had stopped attending church because of the social anxiety. Now I can watch from home
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Less in-person interaction has been a benefit for me.

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Making money Filling out forms for transitional assistance
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Motivation for anything
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Difficulty taking care of body and home
What additional research is needed to help address co-occurring conditions for autistic people?	MCAS POTS EDS
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	To be able to get help easily and not have to reapply every 6mos-1 year. We miss out on services because of these forms. To get support if a professional in health care. For the government to help health care professionals to be able to take insurance so autistics can help broke autistics
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Long covid
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	It was much better during lock down. We were paid to stay at home which would be helpful to many of us

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	muscle weakness, muscle atrophy, strabismus, diplopia, lack of depth perception, light sensitivity, cognitive deterioration, stroke like symptoms, neurogenic bladder, incontinence, neurogenic bowel, chronic constipation, facial weakness can't hold it up can't make expressions people get mad at me because they think i'm disrespecting them makes it harder when i don't understand people, mobility issues, scoliosis, ichthyosis, muscle fasciculations and spasms, neuropathy, having an arrhythmia, having lung problems that cause congestion coughing sneezing randomly, fatigue
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	delusions hallucinations paranoia, ocd especially moral and scrupulous, anger, impatience, no tolerance for frustration, everything makes me mad everything frustrates me and i don't understand anything and no one's nice about it ever, lack of empathy
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	dyscalculia: hard to draw because i don't understand geometry, my brain mixes up numbers with other numbers like 0 and 9 are the same number to me, i don't know even basic math to the point that i now struggle with addition and subtraction when as a child i didn't used to cognitive deterioration: nobody is patient ever, people especially doctors make me do things i don't want to do, they're mean to me they don't understand don't try to, they make fun of me, they talk over interrupt me, i don't understand so many things and no one bothers to make anything simple anymore they always use big words i don't understand, even this form is worded confusingly, i don't know if i'm supposed to talk or just list, socializing is extremely hard because i don't know how to respond
What additional research is needed to help address co-occurring conditions for autistic people?	i don't understand this question
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	doctors seriously lack knowledge about congenital neurological conditions when i can't talk right doctors just talk over me and they don't help give me words which i'd like a lot if they would think about what i'm trying to say but saying ineffectively and they would be patient and help me talk i especially have problems wording what's happening to me. i wish doctors would help me say things i'm having trouble saying and actually listen to me instead of talking over me or talking to mom instead of me. a lot of symptoms i have especially with my heart are hard for me to describe i also wish more doctors would be like my urologist who actually treated me like an adult not a child and when i was scared of a test she explained to me how the test worked and told me she had been scared of it too in the past, instead of telling me i'm being childish and stupid or telling me that if i don't do the test she can't help me. i did the test and i felt better because she was nice to me. but nobody else ever did that it's also so hard to get diagnosed with a congenital condition if you weren't diagnosed as a child because doctors who only see adults don't know anything!!!!!! teach them about congenital conditions!!!!!!!!!!!!!! the only doctors who ever knew anything about my condition were doctors who worked in pediatrics too!!!!!!!!!!!!!!
What lasting impact has COVID-19 infection and illness had on co-	i can't go to the doctor because hospitals aren't masking anymore and i can't go anywhere in general because nobody is masking anymore i don't like being kept inside it makes me have meltdowns i'm really miserable

occurring physical and/or mental health conditions for autistic people?	my condition is progressing to the point that last year i went to the er for heart attack symptoms and my cheek has gotten hollower i haven't had an ecg or echo since early last year i am coughing up bloody mucus and i can't even be with my friends
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	can't go anywhere at all because no one protects people like me anymore

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Unable to eat solid foods
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Self harm, extreme behavior screaming
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication
What additional research is needed to help address co-occurring conditions for autistic people?	Cognitive developmental deficits
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Access to therapy
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbances- autistic child has delayed sleep, wakes up in the middle of the night and typically doesn't sleep more than 7 hours altogether. This presents difficulty for child bc of inadequate sleep, family has inadequate sleep, and family has difficulty providing engaging activities for this awake periods as well as appropriate supervision.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety- reduces opportunities for learning both socially and educationally. In our situation I'm not sure if it's anxiety related but child "picks", bites fingernails, lip for sensory input or anxiety management. This is complicated by the fact child will NOT take any medication and has a limited diet of less than 10 foods.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication difficulties- child has a severe phonological disorder and moderate apraxia of speech. Child is 10 and can't read on a K kindergartner level. Child has participated in private and school speech therapy. Educational speech/reading in public school is inadequate. Regular tutors ineffective and expensive. Educational system isn't properly funded to address issues AND school system's goals are NOT the same as family goals. Hard to find competent SLP's in school and medical facilities who know how to manage behaviors of autistic patients (esp ones with a PDA profile) and our knowledgeable about apraxia, prompt therapy and gestalt language processing. Clinicians do not teach parents nor do they give parents HW to do with child.
What additional research is needed to help address co-occurring conditions for autistic people?	Research how anxiety and pathological demand avoidance are related and how these interfere with learning, social relationships (making and sustaining), and employment. Figure out how to make these challenges into assets or at least mitigate some of the negatives
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Improve requirements for SLP training programs and/or have insurance pay for RBTs to correct with SLPs. Most SLPs will have autistics on their caseload and many are not trained to work with autistic people. As a generalization the SLPs my son has worked with requires me to manage child's behavior and help facilitate the session. This was common occurrence in early intervention, private practice (that takes medical insurance). Better pay and benefits for BCBA's and RBTs is needed to attract and keep competent professionals in the field. This would help improve accessibility to treatment.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	My child regressed socially, educationally and still has not regained skills lost.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	Structure and interpersonal relationships/daily interactions with people in and out of the home are what helps my child. COVID-19 shutdown was terrible; my child lost skills he still hasn't regained. Trying to get a neurotypical Kindergartener to attend to Zoom lessons is hard, but impossible for an autistic child.

in-person social interactions and obligations)	
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Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	It's a paradox for me. The intensity of the physical ailments is directly correlated to the level mental stress I'm under. The physical ailments I experience impeded my ability to function properly causing me more mental stress that in turn makes the ailments worse. hyper / hypotension Sleep apnea Inverse psoriasis Athsma Hidradenitis suppurativa Irritable bowel Arthritis / joint pain stiffness Joint hypermobility* Flat feet Sciatica Spinal subluxations Disautonomia Nausea Migraines Balance Fine motor control of hands Heart palpitations They can't be organized by what's worse because their intensities change and each effects daily life differently.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Adhd and ocd are my co occurring conditions. They are what i was born with and they are not in the same category as environmentally caused conditions. I experience anxiety, depression and suicidal thoughts. They come from living in an unaccepting, bigoted world thats conditioned to refuse to change their views when facts prove them wrong. Researchers need to listen to people like me and think about the chicken and the egg question.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I struggle with verbal communication, more specifically turning thoughts to words. Writing is my most effective method. My most effective method of learning is by working along side someone. My reading and auditory comprehension struggle. I feel I have average to above average intelligence in the form of problem solving, memory recall and pattern recognition.
What additional research is needed to help address co-occurring conditions for autistic people?	Researchers need to listen to the neurodivergent individuals and their lived experiences. Outward appearance has absolutely nothing to do with the world within. I believe that we're going to find that neurodivergence as a whole is one big spectrum of trait regulation and intensity. Certain things like anxiety and depression are tendencies that vary intensity by the environment the person is in. Researchers need to understand that some of us that made it to adulthood before diagnosis had really hard lives and had to figure out how to blend in to survive. Outward appearance CANNOT be a consideration as to how "functioning" someone is. *trying to make an neurodivergent individual more "normal" against their will is abuse and should be a prosecutable offense*
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Require all pediatric, family primary care and psychological providers to be fully educated and certified in the understanding of the internal lived experiences of neurodivergent individuals and to erase any preconceived notions of what they think these conditions are.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I am unvaxinated and have no intention of doing so. I had covid in December of 2020 and i still don't have full taste back yet. My smell seemed to have returned fully a few months ago. I experience colds and flus strongly in a physical sense. Covid made every part of my body sting and ache. Sound and light sensitivity were really bad. It essentially made my normal sensitivities extreme.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic	Telehealth has been great for improving access for me. Reduced in person interactions have been great because they're typically with people I don't want to talk to and in overstimulating environments that I don't want to be

people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

in. Autistic people don't necessarily want to always be alone, we like interactions with people we understand and understand us in return.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Difficulty falling asleep at a normal time, often not falling asleep until 2-3 AM. Difficulty processing loud, busy environments, and feeling inadequate for struggling in those environments. Slow to learn common tasks, like tying my shoelaces or riding a bike.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Extreme sensitivity to teasing, criticism, bullying, etc. Extreme social anxiety and difficulty making friends. Issues with confidence and self-esteem. Loneliness due to never having a partner. Depression and feelings of worthlessness.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication differences lead to being easily misunderstood. I am very blunt and straightforward in my communication style, and this often seems bothersome or even threatening to many people.
What additional research is needed to help address co-occurring conditions for autistic people?	Research is needed to give autistic people the accommodations they need to thrive in education, the workplace, and society in general. The public needs to be better educated on what autism is and how it presents. Sorry, this is not a very specific answer, but I strongly feel that we have done a terrible job of trying to understand and accommodate the needs and challenges of those whose brains work differently from the norm.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Better access to qualified mental health professionals for diagnosis and support, and better insurance coverage of mental health services in general.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The COVID-19 pandemic has resulted in mental health problems for our society across the board, autistic or otherwise. In my experience, this has led to a breakdown in civility and understanding in daily interactions and, as a result, feelings of being “othered” by people much more than before. My difficulty with expressing my own emotions seems to create the false impression that I’m doing fine, and seems to make me an easier target for those who are going through their own struggles.

Name	Anonymous
Demographic	Autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>Sensory challenges present the largest difficulty for me. Few workplaces support wearing noise-cancelling headphones or earplugs without disclosure of disability, and disclosing my autism typically leads to being treated as lesser by my employer and eventually fired for "issues" that did not exist before disclosure. The cost of not having these accommodations is total exhaustion and an inability to function once I arrive at home. It would help a lot if accommodations did not require disclosure of disability, and if disclosure did not mean that people treated me like a child. I wish that simple, non-obtrusive sensory tools like headphones were fully accepted and unquestioned. Gastrointestinal issues mean that I always need to know where the nearest bathroom is, as excess stress will cause me to have diarrhea. I'm often under excess stress from life demands and sensory issues, so this happens at least once a week. Otherwise, I'm often constipated to the point of nausea, which limits my ability to enjoy food and certain social events. I brought this up with my doctor, but he dismissed it and told me to eat more fiber, so I've been unable to get any kind of treatment. Taking fiber supplements has not resolved the issue. I'm also a type one diabetic. While I'm generally good at handling my own treatment, I could see this being a problem for some other autistic people. There's a lack of good education on diabetic self-care for the autistic population from what I've noticed.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>I almost died in high school as a result of autistic burnout, which presented similarly to severe depression and anxiety. The autistic community usually defines burnout as a regression in abilities along with intense mental, emotional, or physical exhaustion as a result of continual overwhelm. I was completely unable to function normally. Ordinary mental health interventions (medication, therapy) did not help much; I had to give my brain time to recover to resolve the burnout, and being pushed harder to just think happy thoughts didn't help. It took me a long time after the fact to realize that burnout was the problem. I wish that more research on autistic burnout was done, and that more mental health professionals knew it existed. Otherwise, anxiety is an ongoing struggle, as is dealing with the effects of trauma. I was diagnosed in adulthood, and the lack of awareness from family and friends in childhood about autism led to a lot of conflict and problems that still affect me today. The skills I learned to cope are the same skills I'm having to unlearn to improve my mental health. I learned to hide everything about myself to make others happy, and that my core self was wrong. The focus on assimilation over acceptance destroyed my self-confidence, trust in others, and sense of safety in the world. I wish that acceptance were the focus instead, and that autistic children were not forced to change themselves to be loved.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>I would like to see research on how autistic masking affects mental health, whether masking is correlated with self-reported trauma history via ACE scores or another metric, whether gastrointestinal conditions are linked to masking and/or distress in autistic people, whether sleep difficulties and sensory processing disorder are correlated in severity, and whether</p>

	<p>education on co-occurring conditions aimed at autistic people is sufficient according to autistic people (understood, effective in teaching self-care, comprehensive enough). I would also like to see more research into how to treat autistic burnout from a mental healthcare perspective, as mental health professionals in my experience are severely under-prepared to handle this issue.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Patient-provider interactions need major improvement. I've had my concerns dismissed by so many doctors that I've given up on getting any kind of help for gastrointestinal and sleep issues, and non-autistic mental health professionals are extremely unprepared to work with autistic patients. I've almost never had one help me in a way that worked for me. More provider education on autistic needs in general and on the negative effects of masking would make a huge difference. I don't feel understood by doctors and therapists and it feels like they would rather that I look normal than feel happy. More acceptance of sensory supports in the workplace without disclosure of disability would also be a great help, as would decreasing the effects of stigma in work environments. Disclosure usually results in people dismissing my strengths and only seeing my weaknesses at present. Accessible education on how to navigate insurance would also be very helpful, as that whole system is deeply confusing to me. Accessible sign language education would also help a lot. I think in gesture, and I've been struggling to learn ASL as a way to understand my own thoughts more coherently. It would also help with communication when unable to speak.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>The availability of remote work almost singlehandedly saved my mental health. I was able to get through a day without collapsing at the end of it for the first time in my life, and that gave me the chance to finally recover from burnout. I sincerely hope that remote work and appointments remain an accessible and equal option to in-person options. On the other hand, my therapy appointments stopped for several years, and I didn't get adequate support adjusting to changes caused by the pandemic. I still struggle with health anxiety caused by the COVID-19 pandemic as well. While I'm back to therapy now, the break in routine has made it hard to re-adjust, and the push to get "back to normal" is disrupting the routine I got used to during the pandemic. I don't want to go back to normal. I want to keep working from home and enjoying having the ability to get through a day without a mental breakdown from stress and overwhelm caused by sensory problems and high workplace demands.</p>

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Working full-time employment. Working with the general public. Care tasks like eating or showering—whether for yourself or someone else (eg, parents.) Chore tasks like dishes or laundry.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Working or going to school full time. Care tasks. Chore tasks. Social activities. Skill regression or skill loss.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Not being heard or fully understood despite using very direct and clear language. Not being given space when needing time to process how to respond—sometimes we are unable to respond right away or in the moment. But if these things seem to offend others. Not entirely sure why. Being infantilized if we are non-verbal—being treated as if we have no self awareness or ability to think or understand. All of this inhibits our ability to interact with others which is crucial in social, educational, or workplace settings.
What additional research is needed to help address co-occurring conditions for autistic people?	We need to make a better effort to understand the research that’s already been done. There are still too many “professionals” out there that do not understand Autism and ADHD; They only understand a specific stereotype of either of them and it greatly negatively impacts quality of care. Eg: Why are we gate keeping ADHD meds when we know it’s FAR more likely for them to fall into addiction if they aren’t vs if they ARE medicated? Why are we gate keeping AAC devices on the grounds that it discourages them from using verbal language when that’s not true at all? Why are we still calling everything “anxiety + depression,” prescribing SSRIs without doing any due diligence to make SURE it’s not an underlying neurological difference? Why are Neuropsych evals so difficult to get insurance coverage for?
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage is a massive issue. A lot of policies will not cover evals, but will cover dog training for Autism? Why are we gate keeping AAC devices and ADHD meds even when research shows that doing this is actually incredibly harmful? Medical/Educational professionals’ understanding of both disorders is abysmal-Especially in General Practice/Pediatrics and K-12th public schools. School staff seems to think that just because a doctor says your child is Autistic, that doesn’t mean they are at school?? A doctor diagnosis should be the only requirement to get support at school or work. Financial support for adults needs to be accessible and truly beneficial—most of us cannot work full time if at all, and the way benefits are set up make it difficult to qualify for them even if you have a confirmed diagnosis. PCA pay needs to extend to parents of Autistic children without applying for disability. This helps Autistic parents care for their Autistic kids and fills the financial void of not being able to work.
What lasting impact has COVID-19 infection and illness had on co-	a lot of us are dealing with co-occurring conditions that already cause chronic pain, fatigue, and illness at baseline. Dealing with infectious disease,

occurring physical and/or mental health conditions for autistic people?	especially to the degree that Covid has caused, makes life pretty bleak from a physical standpoint, but also an economic standpoint.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The rise in some remote services has helped, but others I think hinder. Eg, grocery pick up and remote work helps while trying to do OT via telehealth is not helpful.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory processing disorders, fine motor challenges, sensory challenges, gastrointestinal disorders, difficulty with spatial awareness that often results in injury, insomnia
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Lack of motivation to complete tasks, difficulty managing tasks, executive dysfunction (extreme difficulty completing basic daily tasks such as eating, sleeping, bathing, dressing, etc.), difficulty with focus, self-harm, difficulty in social situations, difficulty advocating for oneself, difficulty self-regulating, difficulty eating, difficulty navigating most forms of transportation, panic attacks, difficulty staying still for periods of time
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Difficulty reading, difficulty focusing, difficulty advocating for self, difficulty communicating needs/wants, difficulty learning in typical school environments
What additional research is needed to help address co-occurring conditions for autistic people?	There needs to be more research done that involves getting information directly from autistic people, rather than allistic (non-autistic people) who know someone who is autistic. There needs to be more research on how to make the world more accommodating for autistic people and to educate allistics on how to accommodate autistic people, rather than trying to make autistic people less autistic. There needs to be more research on the long-term effects of masking behaviors, as well as the long-term affects of ABA therapy (which is actually child abuse and is currently the main resource/"treatment" for autistic people. We don't need to be cured, we need acceptance, understanding, and accommodation.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Get rid of ABA services. Create more non-ABA resources that provide services that teach people how to make places/people autism-friendly. Create more services that provide things like peer mentors to help autistic folks with daily tasks. Create more programs that provide (free or inexpensive) accessible transportation. Create more programs that provide free housing for autistic individuals because working is often extremely difficult and sometimes nearly impossible for a lot of autistic people, and most of us who can work aren't able to earn enough money to support ourselves financially. Educate first responders and doctors on how to interact with autistic people (including those who may not "seem" autistic)
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal	Virtual interactions such as zoom meetings, online jobs, telehealth appointments, etc. were a lot more accessible for a lot of autistic people, because it limited the amounts and types of social interactions, it provided predictability, structure, and control to social interactions, it limited the need for access to transportation, and it allowed for multiple types of

changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

communication (for example, if someone is non-verbal, whether always or just sometimes, they could type instead of speaking if they were in a zoom call). Online ordering for restaurants and grocery stores was also helpful because of limiting social interactions and the need for access to transportation.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep issues and sensory sensitivity issues. It is extremely difficult for an autistic person to get good sleep because of our sensory sensitivity issues, and I believe anxiety and depression also play a role in this. Physically, the conditions need to be perfect in order for me to get quality sleep. Being overly sensitive to sounds, lights, temperature, and the tactile feelings of our pajamas and bedding, all of these contribute to a poor night's sleep. This is exacerbated by mental health issues as well.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression and anxiety from Autism affect every aspect of my life. Sleep, relationships, work, daily life, personal hygiene, and generally being a functioning member of society. My mental health has been a struggle my entire life, even as a child. The main challenge can be summed up by saying that society and the world in general is not designed for autistic people. The result is low self-esteem, depression, and anxiety which are caused by being different, misunderstood, disrespected, and ostracized by society. This even happens with family and close friends. Basically, we feel alone in every sense of the word. This escalates over time and begins to affect to every aspect of our lives. The result is isolation and being unable to work.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Research should involve asking autistic people themselves what would help them the most.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Professionals in the healthcare system and mental health system all need to be trained in autism. As an autistic person, I know more about it than all of the health professionals that I have encountered who tried to help me. It needs to be more understood before they can implement the changes that we need. Things that would help the most would be financial support and peer support groups in every city. SSI/SSDI is a flawed system that allows most autistics to fall through the cracks. Autistic people struggle to support themselves and most are unable to work, especially full-time. Anything at all that could help in this area would make a drastic difference in our lives. There is also an extreme lack of in person peer support groups, which leads to further isolation.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	

in-person social interactions and obligations)	
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Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory disorders - challenging when navigating the external world and shopping online can make it hard to determine good (manageable) purchases but shopping in the real world can be overwhelming /trigger sensory overload Auditory processing disorders - makes it challenging to keep and maintain a job, hearing problems that may or may not have physical causes or just be the way our brain processes make it hard to process the world around us Sleep disorders - we can be exhausted but necessarily know that we are. This leads to burnout at higher rates and can trigger worsening of comorbid mental health issues as well as degradation of physical health
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD - this and ASD are kind of at odds. I have two very opposite sides of my brain. One enjoys a gallery wall with no method to the madness or theme or layout, the other gets easily overwhelmed by a single image. Trying to balance these two- particularly during the recent medication shortage for ADHD meds, is a huge challenge in terms of just getting through a day and being able to manage yourself, or at a minimum, set realistic expectations for yourself. Autism - duh Anxiety - I never know if my anxiety is for a legitimate reason (I also have panic attacks and cardiac issues), if it's because I'm feeling insecure around neurotypical people, or if it's just my broken brain. I tend to overcomplicate things when I simply need to process them, which causes further anxiety. Bipolar disorder - hard to know how to manage appropriately between the highs and lows, especially with the self-regulation challenges that ADHD and autism present Depression - all of these things combined put me into major burnout mode where I cannot bring myself to do anything for days. Work is a challenge, but not an option because things like FMLA for conditions like this are next to impossible - and even if they weren't impossible, who can afford it?
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Just the humanity of it all. I'm a level 1, whatever that means, so I don't "need" support, but that also means I have everything delivered and I am rarely around another human being. Any length of time spent around another being physically puts me into a drained battery situation for several days. Needs look different for everyone. I'm still a human and need human connection, but I have no idea how to effectively navigate that without exhausting myself for the foreseeable future.
What additional research is needed to help address co-occurring conditions for autistic people?	Ask us. Talk to us. Help us figure out what support and accommodations look like across the spectrum. Understand that what works for one is not a universal approach. Implement more neurodiverse focused options when it comes to design for public spaces. Ask public service providers to provide better options (I.e. some retailers provide sensory friendly shopping hours/experiences, but it is so hard to find ones that do, or that have reasonable hours). Help us understand WHY our brains do the things they do - for most of us, not knowing the why behind things is a huge frustration. We may not understand the science, but you can bet we'll hyperfixate on it until we do.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	See previous answer. Medical providers REALLY need better training on what being on the spectrum means instead of assuming each of us is going to behave the same way. Just include things like sensory questions on medical questionnaires for a start. Employers need adequate training on this. Public service providers should have a better awareness overall of things like ADA in terms of service dogs, aids, etc. every time I go into a store that says bags are prohibited, I have to decide whether I bring it in (has my aids like a cane,

	<p>panic meds, headphones etc.), leave it to avoid the anxiety caused by the potential interaction, or choose just the MOST important items - which causes more anxiety.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>On the one hand, WFH and my anxiety about being in public etc have been eased with COVID. I joked that the pandemic was exactly what I needed as a wannabe hermit. It was fine for three years. Then I settled into it and I REALLY stopped leaving my house ever. I stopped interacting. On the one hand, I still enjoy that - but I have a hard time regulating myself and knowing my limits, and subsequently find myself a victim of burnout because I cannot tell myself when to stop. When I burn out, it isn't just being tired. It is complete and utter despair, a sense that nothing is ever going to change, and if this is all there is, why bother? To be clear, I don't have suicidal ideations. I literally just don't understand the WHY. If I'm working for money and health insurance, the money is for a house that I have or a car I never use, and the health insurance doesn't actually SOLVE my myriad health issues...why do it? It's been hard to get out of this mentality, especially with the inability to create an artificial work life balance. And going back to an in person job full time would be prohibitive and trigger meltdowns - what options are left? What do we do?</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>I miss the "vulnerable populations" shopping hours. I wish that hadn't been a thing just during lockdowns, because those were the best grocery shopping trips of my life, even if they were at 6am. I love WFH but again, it's so hard knowing how to set those boundaries when there's no "end of day leaving the office" to enforce it or the social component to help ease it along. I am home and alone and working, all the time it seems. I love the more prominent availability of telehealth, but it seems the quality of these providers is INCREDIBLY hit or miss, which is frustrating. The technology isn't always where it needs to be, which is maybe even more frustrating. Combine the two and I'd rather give myself a swirly because what is the point? Half of my conditions can't be managed via telehealth wholly because they're controlled substance refills or require actual medical tests, so it kind of negates the convenience of it.</p>

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	For me the most significant challenges are the unpredictability and unknown of things. its hard for me to keep to my routine with doctors appointments or when my symptoms are bad. Its hard when i have physical symptoms because it causes me to go into sensory overload.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	how autism affects the perception of symptoms and pain. Because often it's hard for us to describe or pinpoint where a symptom or pain is coming from within our bodies.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	services for autistic people over 18. a lot of services stop at 18 and this makes things difficult for those who still need services like aba, OT, and speech when they age out.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Not having access to services during the pandemic caused a lot of regression for autistic people who had to miss therapies for so long.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Some positive changes are; The increase in availability in things like; curbside pickup, telehealth appointments, pre scheduled appointments at places like the DMV, less people in waiting rooms. These changes have allowed me to be more comfortable and stick to a routine. The negative impact is from the lack of services causing regression.

Name	Anonymous
Demographic	Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Living life is more exhausting. I feel like I can't keep up/enjoy as much with my peers b/c of those co-occurring health conditions i.e. lack of sleep, lower tolerances for loud, or busy or crowd situations b/c of sensory challenges. It feels like there isn't space in society and therefore stay home a lot of the time.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety with co-occurring panic attacks has been the biggest challenge for me. They stop me for going new places, trying new things, or even doing basic things like seeking out a new therapist or doctor. The fear of being looked down on or shamed because of who I am keeps me away from people. The challenge here also extends to things I can't work around or find ways to make work. The most recent example of that was a summons to jury duty, there wasn't a safe place to decompress, there was a lot of waiting which gave me a lot of time to get more and more anxious, the building was so unfamiliar so i didn't feel like i could leave and grab lunch or find a place to decompress so even being given a map of the building would have helped with the experience.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	I think there needs to be more integrative research. By that I mean research needs to look at the whole person rather than a collection of symptoms because as i've found as i've gone along in life is that most things are interconnected. I had a lot of tummy troubles as a kid and it was just taken as that a kid with an upset stomach...it turns out that my anxiety was causing the gastrointestinal problems for years but nobody ever looked beyond that.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Education addressing the public at large as well as employers. Many accommodations that can help an autistic/neuro-divergent person are largely agreeable to the general public as well. Getting the public to see that things like remote work and flexibility help everyone not just the neuro-divergent person.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	

in-person social interactions and obligations)	
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Name	Anonymous
Demographic	Autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	In my practice as an SLP as an autistic individual I see sleep disorders and sensory challenges as the most impactful and gastrointestinal as second and hypermobility issues third.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	CPTSD often caused by long term ABA therapy (which more research needs to be done for the long term negative side effects). Anxiety/depression is often caused by long term masking (leads to suicidal ideation) and not being accommodated or supported. Autistic individuals are comfortable at home and feel less anxiety/depression when their needs are met (mostly sensory and executive dysfunction). ADHD also contributes a lot to the executive function dysfunction.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Autistic individuals who can not communicate verbally have the largest risk for abuse. They need access to care that enable them to communicate their needs and wants. Caregivers need education on therapy that helps not hinders mental health.
What additional research is needed to help address co-occurring conditions for autistic people?	The most research is needed on masking for autistic individuals (especially how to support in the public sector and reduction of ABA based therapy) and the effects of it long term on mental health. A neurodiversity affirming initiative made public like other countries have done such as Australia and Britain would help to reduce rates of anxiety and depression. This would help insurance to cover more speech therapy, mental health, and occupational therapy that does not promote masking. This would reduce suicide rates in autistic individuals.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More coverage for speech therapy, mental health, occupational therapy, and physical therapy. Less coverage for ABA. More respite care for care givers. Supports in the general public sector would be overall increased education especially with the police force to be trained on recognizing autism and responses to it.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Long covid may impact or increase already occurring conditions such as POTS and MCAS which are common among the autistic community.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Positive impacts were the increase in money for school services. When that support was taken away we felt the difference in being able to provide that amount of service. Negative were social isolation. Contrary to some myths about autism - autistic people like to socialize it's just different than neurotypical individuals.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	-Finding doctors that listen and take your health issues seriously without infantilizing adults with autism -Getting doctors to work together on a care plan when you see multiple specialists (gastroenterology, endocrinology, psychiatry, primary care) -Lack of understanding from the general public about autism -The pushed idea that only children are affected by autism/programs for individuals with autism that only cater to children -Not being believed by most people because your health conditions are not "visible"
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	-Having psychiatric conditions that exacerbate the symptoms of another - Being misdiagnosed due to the similarities between two coexisting conditions -Being prescribed overly sedative medication
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	-Knowing what you need but not being able to communicate it -Lack of adaptability from others for any form of communication other than verbal
What additional research is needed to help address co-occurring conditions for autistic people?	-Research done by autistic scientists -Just a better healthcare system in general
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	-Social workers for individuals with autism so that care is more coordinated and scheduled -Better patient-provider interactions -Doctors that actually want to help people and not just push medications
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	-Common viruses cause more severe symptoms -Chronic stress
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	-More people have self-reflected and researched autism -More people have gotten diagnosed due to increased awareness -Stigmatization that people are getting diagnosed because it's "trendy"

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Trouble falling asleep Extreme food pickyness Sensativity to fabrics and noises
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety Meltdowns
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Social awareness and social skill. Making and maintaining friendships. Responding appropriately and not having extremem reactions.
What additional research is needed to help address co-occurring conditions for autistic people?	Effective therapies for high functioning autistic kiddos
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Access - both location and not months and years long wait lists Affordability A resourched for what is available and how it could help, steps to tak with a new diagnosis, etc. Support for parents and siblings
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Less access to resources as there wasn't availability during Covid and now there is a backlog.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I struggle with intense sensory and sleep issues; I often struggle to fall asleep and wake back up consistently, and sometimes cannot fall asleep without melatonin. My sensory issues often cause secondary physical issues such as malnutrition from picky eating, UTIs from overcleaning, skin issues from washing my hands too regularly, ect. I'm also prone to feeling more anxious than most people due to fears of overstimulation.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Feeling isolated from my peers growing up has planted doubts in me about my ability to socialize, and more significantly how others view me. I'm very self conscious about my weight, how I look, what I'm doing, and I'm very prone to paranoia and rejection sensitivity. I was severely bullied despite my best attempts at masking/trying to appear "normal", and I developed suicidal ideation and manic depressive disorder as a result. I used to self harm, but more as a coping method with overstimulation (like biting, kicking, hair pulling) rather than self harming as a way to cope with depression.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Since I'm so sensitive to specific sensory information, it heavily impacted my ability to consistently focus on school. If my pants were too tight I couldn't focus, if someone had eggs in the classroom I couldn't focus, if someone was yelling or chewing too loud I couldn't focus, ect. My school had a difficult time providing decent accommodations, as my 504 was often ignored/denied simply if teachers didn't want to respect it. I wasn't placed in special education due to my assigned sex at birth as well as being labeled "high functioning" despite having much trouble functioning in a normal classroom setting. On the other hand, I had a great time learning in environments that were comfortable for me and did great academically (usually on the A/B honor roll) as well as exceeding in extracurricular classes. I graduated easily (aside from truancies from sickness) and am now enrolled in college courses.
What additional research is needed to help address co-occurring conditions for autistic people?	I feel like co-occurring symptom research and autism research in general should be geared more towards gathering information from autistic people rather than any caretakers/outside input, as that way we can more closely identify, describe, and provide input based on our co-occurring conditions. Up until I got formally diagnosed, my parents never noticed any of my sensory issues as being life-changing and thought it was me being silly/dramatic despite it drastically affecting how I operate in life, so I feel like there could be a lot of information missed if research is being done with the guardians or caretakers of autistic people rather than the autistic people themselves.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Early intervention and easier access to IEPs would exceptionally help autistic children I believe, and helping both the child and the parents understand what autism is and what it means for them going forward. Insurance coverage would also help because things like physical therapy, learning programs, ect, are incredibly expensive if not covered by insurance.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Aside from paranoia about catching it, I myself have never had any long lasting symptoms after I got covid. I have heard of people doing their sense of taste and smell though, which would have been devastating because most of my sensory coping skills rely on smell and taste (gum chewing, candles, ect) and would have changed my life significantly.

<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Online school helped since I was able to study and attend lectures in the comfort of my home without having to worry about being overstimulated or having a meltdown in class, but being suddenly cut off from my social group due to fears of infection negatively impacted my ability to socialize once things started opening up again, as well as my ability to mask or understand social cues as well as I did before the pandemic.</p>
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Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My loved one is often dismissed at the doctors for any health concerns, this has lead to several conditions going unchecked and getting worse.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety seems to be the most outwardly harmful issue. Their anxiety leads to isolation, which then leads to other issues. This is one of the problems discussed with a healthcare provider that was dismissed.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	While my loved one communicates clearly they do occasionally have difficulty processing information.
What additional research is needed to help address co-occurring conditions for autistic people?	We need more adequate health care. Research and updating the education of health providers needs to be a priority. We also need to give insensitive to good and qualified professionals so they remain within the field.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance tends to be very discriminatory for many mental illnesses, autism included. If we had access to better coverage perhaps they would not struggle so much with finding adequate care.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Both my loved one and myself still suffer high anxiety. While I am not Autistic I now suffer from frequent bouts of over stimulation in public. I cannot begin to imagine how they feel with their preexisting issues.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	My loved one lost contact with most of their friends, as well as lost their routine. This severely impacted their mental health and while we are recovering and rebuilding the affects are still felt.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression, suicidality and anxiety.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	We need to change our social construct as it is intentionally made to be over complicated and it doesn't help Autistic people at all as it opens them to be victims of abuse, scamming, to be used and taken advantage of, raped, etc. we need to quit the whole victim blaming/shaming and gaslighting that happens.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	All the above.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It had no personal affect on me as I don't socialize with people and keep to myself.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I experience a multitude of co-occurring conditions, but perhaps the most disruptive in my life has been insomnia and other sleep disturbances. Gastrointestinal discomfort has plagued me my entire life, and my sensory needs make certain spaces inaccessible. My eyes are quite sensitive to light, this makes driving at night impossible (especially now that lots of cars have LED lights). I find it difficult to remain in bright, loud, or dirty spaces for very long.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety and depression are unfortunately deeply connected to my Autistic experience of life and the trauma of growing up undiagnosed and unaccommodated. Depression makes any level of functioning difficult and anxiety is miserable and debilitating. I live with major-depressive disorder on top of my Autistic struggles.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication has always been a challenge for me, I understand myself and my own thoughts quite well I just have difficulty expressing thoughts in a timely manner. It is difficult to be intellectually or cognitively able but unable to communicate at a "normal" pace.
What additional research is needed to help address co-occurring conditions for autistic people?	I believe research on all things Autism is critically lacking. The interaction between Autism and trauma (cptsd & ptsd) needs to be explored further as many Autistic people struggle with some form of trauma. I am sure there is much to be understood about Autism and depression and anxiety, for me my Autism is strongly inter-linked with my anxiety. Research that focuses on making tangible changes to public or private spaces to better accommodate Autistic people is critical, we deserve to be able to exist in public spaces. Autistic people need more than just awareness, we need acceptance.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Equitable access to disability services and medical care is crucially lacking for many Autistic people. Health care of any kind is expensive, making cost a significant barrier. Autistic people often cannot work or cannot work "ordinary" jobs so money is tight already. A health care system that removes barriers to entry and use for all people is essential for public good and for Autistic people to get the care they need.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	COVID-19 has had a devastating impact on people with disabilities, and has itself disabled many. People with disabilities are vulnerable to COVID and special consideration for the disabled is necessary.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The increased use of telehealth has made mental health care accessible for me, and it has been life changing. Reduced in-person interactions and obligations has certainly been a blessing for me, but the sudden societal shift and disruption of services at the beginning of the pandemic was deeply damaging to my health, only now after years of recovery am I seeing light ahead of me. I feel very deeply for all those with disabilities and mental health issues, they are already vulnerable and in need of help the pandemic made things worse.

Name	Anonymous
Demographic	Autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>Difficulties monitoring thirst, hunger, and tiredness leave me physically exhausted but also drastically reduce my impulse control and executive functioning, leading to difficulty with behavioral addictions, especially in relation to screen usage which give me eye strain migraines and hand pains. All of these problems increase as the day goes on, which gives me insomnia issues. Sensory overstimulation also often leads to physical pain, such as nausea (especially smells) and headaches (especially visual overstimulation), and the stress of sensory overstimulation directly leads to teeth grinding, chest pains, and other physical symptoms of anxiety.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>For me there is significant overlap with the last question. Anxiety, depression, and ADHD work in tandem to make self care difficult. This combination makes navigating bureaucracy of any kind challenging, and often leads to decision paralysis that makes me miss deadlines. Behavioral addictions are easy for me to develop and difficult to stop, especially around video games and sex. This largely stemmed from childhood social isolation; as an adult with a stronger social network they are much more manageable. Periods of stress cause me obsessive thoughts about other people similar to OCD, largely involving sex and race. When I am more anxious, all of my sensory issues get significantly worse. Severity of sensory issues is tied strongly to my mood. Periods of loneliness significantly exacerbate all mental health issues. Many people on the autism spectrum have heightened empathy and acquire vicarious trauma quickly. They also seem to be generally more susceptible to PTSD. Changing behaviour through masking to adapt to social situations is highly stressful and physically exhausting.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>For people with fewer support needs, direct interviews and surveys are extremely useful, especially when designed by people on the autism spectrum. Most low support needs people are very self aware and articulate about their problems. Studies about trauma, repression, and masking. In my experience autistic people, due to stronger senses, experience trauma more acutely, and due to masking in social situations, experience higher rates of physical stress symptoms. Epidemiological studies about addictions, especially regarding social media, video games, etc. Autistic people are more susceptible to addictions and are a prime target for predatory marketing tactics and recruitment efforts and autistic children require stronger regulations in these industries for their own safety. Studies on mindfulness and meditation as a primary treatment for low support needs autistics. In my experience autistic people benefit tremendously from these treatment options because so many of their problems come from difficulty monitoring varying sensations in their bodies, and from dealing with constant states of high stress. Studies on exercise as a treatment option, for similar reasons to meditation. The mind-body connection of regular exercise helps us regulate senses better. Also do studies on our senses and healthy/unhealthy compounds. Autistic people are particularly</p>

	good at identifying rotten food, airborne toxins, etc. due to our heightened senses.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	The bureaucracy itself is a massive hurdle. Our executive functioning problems make navigating health insurance and government paperwork SIGNIFICANTLY more challenging than normal, the processes need to be streamlined and/or we need specialists to navigate us through the process. Many people on the autism spectrum especially struggle with phone calls, so having a text-based service would be very helpful. It's also particularly difficult to access workplace accommodations due to discrimination and lack of knowledge from both employers and coworkers. There needs to be more efforts around disability education and training. People on the autism spectrum also need more access to remote work. Remote work solves the majority of workplace problems.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I have issues with memory loss and sensory problems. Someone will explain something to me and I may forget 20 seconds later. I eat 3 prepackaged foods only on a regular basis because most foods are inconsistent.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I'm a very anxious and depressed soul. I have self injured in the past, but have learned coping skills to avoid this behavior.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	ADHD goes hand in hand with autism. This is a long survey and it's hard to focus.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Are there systems in place to help "high functioning" autists? Most of us are unemployed, we need financial help more than anything.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Covid-19 has made anxiety and depression worse.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Remote work/school is helpful, the constant fear of getting Covid well into 2023 is not.

Name	Anonymous
Demographic	Autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>Chronic fatigue. Sensory and emotional overload frequently and repeatedly pushing our minds to a breaking point. The massive amount of information, input, and processes our minds receive and experience is ridiculously higher than allistics, against our will. Our control over this is often none. What we feel, because of certain things our brain does out of our control, is something that can and often does ruin, destabilize, and choke our lives into constant minute by minute mental self care, management, and regulation. This leaves us with nothing left for the mountain of other needs our bodies and lives require. We run out of the ability to do anything at all extremely fast because of how constantly overwhelmed and bursting at the seams our brains are by nature. We can not function healthily underneath the society we have been born into. Unless the people in power see that they can help, and decide to. Support is our highest need, and it is your responsibility to provide it.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>Autistic people are extremely likely to have depression, anxiety, CPTSD, DID, BPD, ADHD, OCD, etc. Just as likely we have adopted dangerous coping mechanisms to soothe the overwhelming amount of pain we receive frequently in many ways due to our brain's needs, its environment, and trauma. When we have a mind that is constantly drained to empty all of the time, and we are put into the pressures of the world, with no help, no support, no one listening to us, no one believing us, no one showing us we are worth anything, everyone showing and telling us how much of a failure we are and constant insulting harassing attacking from people beating raping and killing us for being different, we don't want to be here. We cut, burn, drink, smoke, vape, attempt suicide, and have sex to soothe the mental pain, or to punish ourselves, or to try and feel some sense of worth or happiness for ourselves being alive. We are given and entirely negative self image from birth and it is ingrained into us which leads to the common co-occurring mental health conditions. We don't know how to help ourselves because no one teaches or helps us. We can't upkeep the amount of self care we need because our nervous system is sucked dry after one single task of the day. We deserve happiness and stability and we can not give that to ourselves without external support.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>It is disabling to be in a world of 90% normal people, who hate, reject, disown, deny, and ostracize us because that's what they are taught to do by everyone else. We need everyone to understand how we communicate and what we need to function "properly". The way we are treated by everyone who doesn't understand, doesn't listen, isn't patient, isn't compassionate, is a huge part of why living as an autistic individual is so painful. At times not being able to speak, communicate wants, needs, choices, feelings, makes people see us as walking vegetables. We are treated as not human. We frequently have difficulty using technology, reading instructions, reading maps or road signs, engaging in conversation, describing ourselves to others, reading walls of text, writing neatly or swiftly, listening to spoken words, retaining spoken information, understanding spoken information, understanding the pressure of being in the same room as someone we know doesn't understand us. Some of us are better with words than others, but those who can not speak for themselves have the same heart inside them as I do. They are smart and conscious and they feel things significantly more intense than normal people do. We just want to be treated like everyone else, not different.</p>

<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>Massive groups of autistic people of all levels of communicative ability coming together whether physically or digitally to all share everything they know feel and experience to people in organizations, doctors, politicians, who can document it and publish our suffering and struggles in the world to the government and medical field workers to help us with their resources.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>This entirely relies on getting the correct information in front of the eyes of doctors teachers and service providers who will be taught and required to follow rules and procedures specific to working with autistic people. This needs to be a law. They need to understand how we work different and what we need different. They can scoff at it as much as they want but if they act inappropriately and offensively to autistic people they should have their ability to work with us reprimanded and removed. Get people out of these positions and hire/elect those who are willing to follow procedure when it comes to providing care to autistic people.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Two most significant challenges from co-occurring disorders are sensory issues, mood dysregulation disorders and motor challenges. As an autistic person with Ehlers Danlos Syndrome, the motor challenges can further disturb my physical health, including the muscle, and for an able-bodied person it can severely affect your body's overall performance. Mood dysregulation disorders are a challenge for many autistic individuals, along with sensory issues due to the fact they amplify emotions, causing someone with autism, who is already hyperaware of their surroundings and oftentimes can have mood switches, to struggle even further.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	GI issues—ranges from general IBS to more severe stuff
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD is a big one. There's some real symptom overlap and it feels like most low support needs autistic people get an ADHD diagnosis at some point. Another weird overlap is bipolar 2—lots of us seem to wind up having bipolar 2.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Research into best practices for autism and co-occurring ADHD treatment. Are ADHD drugs appropriate?
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Patient-provider interactions are a tough spot. Most of my providers ignore my autism diagnosis. This is good in some ways because I'm treated like a competent adult, but I usually have to find out something is a common co-occurring condition from other autistics instead of my doctor.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Reduced social interactions has been helpful, as has *some* remote work. A quiet space I control is helpful, but video calls are very difficult—I feel under the microscope and like any flaw in my social skills will be blatantly obvious. Telehealth has been great—psychiatry access is easy now.

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I experience the following: Sensory Processing Disorder is a major issue. I experience extreme issues with various sensory inputs, including sound, light, smell, taste, touch Dyspraxia is major clumsiness to a point drastically more noticeable than most others. Insomnia is a daily occurrence. I have trouble falling asleep until very late at night, sometimes 2:00 to 4:00 AM, despite laying in bed before midnight and trying various methods to sleep(at various times: silence and black room, ASMR videos, soothing sounds, television).
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I experience the following mental health challenges: Complex-PTSD(CPTSD) resulted from persistent bullying throughout childhood, social rejection and isolation, being physically attacked and assaulted, neglected, and gaslighted throughout my life. Depression is persistent, and I have experienced ongoing suicidal ideation for most of my life. ADHD-PI causes issues with forgetfulness.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Situational mutism often makes it difficult to talk, most often in (1) conversations with more than one other participant, but also in situations involving anxiety. I literally lose the ability to speak, despite having the desire to speak and the will to speak.
What additional research is needed to help address co-occurring conditions for autistic people?	Research needs to be done to find connections with these conditions: Ehlers Danlos Syndrome, related to hypermobility and common among other autistic people I know POTS/Postural Orthostatic Tachycardia Syndrome, common among other autistic people I know
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Undiagnosed autistic people are in a Catch-22 scenario. 1. Autism creates problems with social interaction, which creates difficulty getting jobs. 2. No job can mean no insurance and no access to healthcare. 3. No healthcare means no ability to get diagnosis. 4. No ability to get diagnosis means no access to benefits. So undiagnosed autistic people can't get diagnosis without a job, but can't get a job without diagnosis. I spent \$3700 and got professionally diagnosed after suspecting my own autism for nearly 20 years. I went 20 years without diagnosis because of this problem, before I finally made enough money to pay for diagnosis out of my own pocket. ****Please make autism diagnosis free for undiagnosed people.***** The U.S. has millions of undiagnosed autistic people.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	1. Learned social skills suffered because of social isolation. This makes allowing autistic people to work from home even more important, and increases a need to consider whether this isolation may be even more disabling for many, in cases of work. 2. Long Covid seems to disproportionately affect autistic people, and this should be looked into.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	1. Work From Home has majorly benefitted autistic people. Autistic people's sensory issues and tendency to be socially rejected by others are unique challenges that contribute to preventing autistic people from succeeding in on-site workplaces. Work From Home needs to be an accommodation for autistic people, because it has allowed many autistic people to thrive and be significantly more productive in work. 2. Telehealth has been beneficial. I used it for part of my diagnosis of autism.

in-person social interactions and obligations)	
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Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	All of the above listed, along with increased substance use, high blood pressure, liver enzymes, and diarrhea.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	All of the above listed, and SUDs.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	All of the above listed, including dyslexia.
What additional research is needed to help address co-occurring conditions for autistic people?	Additional research requires additional funding. There isn't enough funding for those that have already been diagnosed. Universal healthcare would be more beneficial.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Universal healthcare and basic income would be the most beneficial.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Many with autism already deal with chronic illness. Long and short COVID increased those numbers.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	It depends on the individual. Increasing remote work and school, and telehealth was beneficial.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The most significant cooccurring physical challenges to my autism are: connective tissue disorder (unspecified), Mast Cell Activation Syndrome, irregular/heavy menstrual cycles, and sensory sensitivities to light and sound.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My largest challenges are caused by late intervention. I got diagnosed at 21 years old, so my support needs were not met. As a result, my cooccurring challenging conditions are: ADHD, EDNOS, OCD, C-PTSD, generalized anxiety disorder, depression, self-harm, trichitillomania
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I do not have any cooccurring learning disabilities
What additional research is needed to help address co-occurring conditions for autistic people?	Research is needed in two key populations: adults with autism, and those with level 3 autism/ higher support needs who cannot answer surveys such as these
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage, lowering prices, educating providers on autism. I have had medical providers miss key information because my symptoms present differently. For example, my face often goes slack when I am overwhelmed, even when in intense pain.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	The pandemic made life slow down, and when things started again I couldn't keep up. I still cannot keep up a high demand life.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increased remote work has allowed me to maintain employment

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep, and ability to work/attend school. I have insomnia and if I don't get a certain amount of sleep I can't function. I get so overstimulated I experience meltdowns where I can't stop crying and it can mess up weeks of my life. It also makes me unable to work and go to school because autistic traits that might be able be accommodated get so much worse. If I'm not on schedule because of one of my illnesses it ruins the day. Chronic pain I can't relieve adds to the sensory overload I experience at work/school, it's not uncommon for me to loose the ability to communicate to other people because of how much I'm experiencing in my body at once
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	It affects my social life the most. I already struggle to socialize, which flares up my depression, and my anxiety. I also struggle with emotional regulation and when my PMDD or MDD act up I compulsively self isolate out of fear of having an extreme reaction over something minor and having to face social backlash for it
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Social and school related issues. I tend to have a hard time reacting on the spot, teachers and students alike have made fun of me for responding in "weird" ways, and because I have a hard time understanding instructions I would be made to feel stupid if I asked for help which means I don't know a lot of what I should've learned
What additional research is needed to help address co-occurring conditions for autistic people?	Research into ways to treat/diagnose disorders as well as how to provide additional support in medical environments. I've been told over and over again that I don't express my pain or distress from symptoms the same way non autistic people do and that's caused people to refuse me help and not believe me until it's too late. I feel like if we had research on how autistic people experience, express, and report health problems it might make it easier to get help and treatment
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Making resources easier to access and more affordable. It's not uncommon for families like mine to pick and choose what we need to treat because it's too expensive to take care of my mental and physical health at the same time for long periods of time. Even though my parents are lucky enough to have good insurance insurance only pays for so many things and it gets us stuck in this cycle of prioritizing one aspect of my health until the other becomes so bad we have to switch. I wish I could treat both at the same time
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Made my mental and physical illnesses way worse. I was unable to leave bed for several months because my POTS got so bad I would collapse just getting out of bed, and as a result my depression and OCD went into remission flor what felt like the first time since I started therapy.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I can't work anymore. I worked before the pandemic but my health got so bad that now I can't. Even if I was able to I'd spend most of the day terrified I'd get sick and it would get bad again. I've gone to people's homes since but I think it made my OCD worse because now it has a "justified" reason to worry about how many germs I touch

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Stomach issues, insomnia, sensory issues, anxiety, depression and reading comprehension.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD, forgetfulness, anxiety and depression
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Dyslexia and general anxiety in crowds
What additional research is needed to help address co-occurring conditions for autistic people?	Mental health resources, work accommodations, diet, and sleep.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Equitable access to therapists, work accommodations, insurance and school accommodations.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Anxiety
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Positive- more at home options that reduce anxiety for work, school and medical. Negative- mental health decline in general and insomnia

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	hypermobility disorders and autism have a high comorbidity rate. as a person with hEDS and autism, i see a variety of specialists for my health needs. i frequently experience barriers when trying to access healthcare, such as appointments having to be scheduled via phone calls (i can't communicate well over a phone due to auditory processing disorder) and other things
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	being diagnosed with autism at a young age gave me nothing except for horrendous abuse from teachers and bullying from peers. i have dissociative identity disorder and one of my largest struggles with that is the lack of research and understanding from mental health professionals. there is also a great deal of stigma surrounding the disorder and it keeps me from being able to healthily express myself as a person
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	i have auditory processing disorder and cannot make phone calls because of it. i'm also struggling to learn a second language because i can't parse certain sounds, leading to incorrect pronunciation and can't differentiate between my mistake and the proper pronunciation. i also can't watch movies without subtitles, nor can i listen to a podcast without a transcript, which is incredibly inconvenient if i have it on in the background while working.
What additional research is needed to help address co-occurring conditions for autistic people?	a lot. research on the comorbodies should be done first and foremost, as many of them are heavily under-researched and underrepresented.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	healthcare providers need to find better ways to communicate with patients in ways that don't have barriers such as requiring phone calls. communication also needs to be more clear cut
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	i can't work remotely. it just simply isn't possible for my brain to process anything that way. jobs need to support both remote and in-person employees. the pandemic also affected a lot of peoples' ability to communicate effectively, and more support needs to be in place for people who have lost communication skills because of that.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	the employment market is largely not accommodating to my needs. i regularly need to devote an entire day to low-stimulation recovery (low-light, solitary quiet time) to avoid burnouts or exhaustion, which makes it hard to maintain a job where I'm expected to work consistently for 8 hours straight every single weekday.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	the Brain Soup of depression, anxiety, OCD, and ADHD (honestly better labeled as an executive functioning disorder) make it incredibly difficult to maintain a household, personal relationships, jobs -- it's often even difficult to maintain hobbies and things i find enjoyable. that there is no "safety net" if i were to lose my job means that in the back of my mind im often thinking "if i ever stop working myself to exhaustion like I currently do, I will probably lose my home and be unable to feed myself." so that's extremely stressful which only exacerbates the mental health conditions.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	during COVID and for a long time after recovering, my quality of sleep was much worse which significantly impacted how productive I was able to be at work, and made my mood more volatile + irritable. my GI symptoms worsened and it was common for me to be in the restroom once every hour or two. neither of these issues have fully resolved, and they currently affect my ability to work, participate in my hobbies, and maintain family/personal relationships.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	things are more accessible without face to face interaction now. practically every restaurant has online ordering options, many grocery stores allow for orders to be placed ahead of time and picked up without entering a crowded building, and telehealth appointments with physical and mental healthcare have allowed me to receive help in situations I would've previously been unaccommodated. negatively, the pandemic seemed to reignite the conversation about the long-discredited myth that vaccines lead to autism. ive noticed a rise in both general autism awareness (good) and hate speech/personal discrimination towards autistics, especially autistic adults (bad). the trend towards remote work is excellent, however it seems like many places of work are starting to reject it in favor of returning bodies to offices, probably to justify the overpriced real estate the business has leased.

	it's discouraging to see remote work as a concession to be made only when in-person work is verboten.
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Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory issues not being accommodated by employers, sleep disturbances causing major fatigue that can be debilitating in day to day life. Research shows links to autism and auto immune health that doctors need to be more educated on, such as hypermobility caused by EDS.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Doctors not understanding that there are physical side effects to anxiety, adhd, and depression. Doctors not knowing the full extent of those connections or the various symptoms such as the vast lack of knowledge or sharing knowledge on how impactful ADHD can be, with difficulties managing impulse, executive disfunction,
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Going non verbal from stress or anxiety is involuntary
What additional research is needed to help address co-occurring conditions for autistic people?	Research in the connection of auto immune disease, adhd, and autism so that doctors can identify and diagnose them
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	One positive is curb side pick up so that we don't have to traverse sensory overload in grocery stores. More options to reduce high volume people interaction. Increase in remote work. More remote options should be available to those with autism, adhd, depression, and anxiety, telehealth briefly being more accessible made healthcare more accessible

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The most significant challenges often
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	n
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	n
What additional research is needed to help address co-occurring conditions for autistic people?	n
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	n
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	n
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	n

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Chronic pain. Lots of conditions that cause chronic pain are heavily comorbid with autism, particularly joint hypermobility and sleep disorders. Autistic individuals are even less likely than the general population to be believed or taken seriously by doctors when they complain of chronic pain. This is doubled when the individual is a woman, a person of color, disabled, transgender, gender non-conforming, or any combination of the above.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	When you have autism, ADHD, depression, anxiety, PTSD and more, the worst part is not knowing which is which. We need much more study on what it looks like for symptoms of multiple disorders to show up all at once, otherwise we will continue to be put in the box of "we don't know what's wrong with you": a BPD diagnosis.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Autistic individuals are much less likely to be listened to or believed by doctors, and one of the reasons is communication issues. Autistic individuals can have a hard time making themselves understood by neurotypicals, especially in a situation with a person of authority where there is an underlying power dynamic. I've had some pretty bleak doctor appointments, and when I hear upsetting news I've been known to simply shut down. Even when I've had a hospital chaperone or family member present to help communicate on my behalf, they can't know what questions I have.
What additional research is needed to help address co-occurring conditions for autistic people?	Autism in women, people of color, LGBTQ+, transgender and gender non-conforming individuals, disabled individuals, etc. The current definition of autism (and ADHD, for that matter) is written solely to describe how it impacts cisgender straight white men. Autism in women and masking. Women frequently don't get diagnosed until adulthood if at all, and one of the main reasons is that they tend to develop better masking abilities to "fit in". The connection between autism and ADHD. Is ADHD somewhere on the autism spectrum? Transgenderism and gender non-conformity in autistic individuals Comorbidity with a variety of chronic pain and chronic health issues Connection between the uptick in autism prevalence over the last few decades and the rise in technological advancement. Essentially, are we becoming more neurodivergent as a society because we've gained a better understanding of neurodivergence in recent years, or is it because we're now seeing the impact of the first few generations having been raised with today's technology? (Ex. is ADHD becoming more common because children are now growing up with access to constant stimulation?) We need a trial on autism education programs for doctors. Would it lead to faster diagnoses and therefore better outcomes for patients?
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	ACCESS TO AUTISM DIAGNOSES THAT ARE FREE OR AFFORDABLE. Currently it costs at least \$1-2K to get diagnosed with autism, with or without insurance. This has created a climate where: (A) Treatment and medication are extremely difficult to access; (B) We have no idea what the actual prevalence rates are, let alone demographic breakdowns; (C) Self-diagnosis is extremely common with or without meeting the diagnostic criteria; (D) Self-diagnoses are recognized as valid by the autistic community out of necessity, but are not taken seriously outside the community; (E) the

	<p>primary source of information about autism for the youngest generations is TikTok, a social media company that is highly censored by the Chinese government and is also known to use highly unethical data collection practices. Tiktok is also how I heard about this request for public comment, by the way.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Returning to society was a really rough transition for almost everyone. For autistics, the change was nearly impossible. A lot of people I know, myself included, have had a hard time re-learning to handle overstimulation and understimulation in public spaces after being cooped up in our homes for several years. Telehealth, remote meetings, and increased work-from-home opportunities are the best thing to come out of the pandemic. This is how we all get our lives back in the current socioeconomic climate. In 2021 I had to change career paths due to serious health issues that left me disabled, so I found my first work from home job. Working from home is the only thing that allowed me to earn an income with my disability. I've also discovered that I'm significantly more productive, both at work and in my personal life, when I don't have to expend so much energy (spoons, if you will) on social interactions with coworkers. When these interactions are limited to messaging and remote meetings, I can use much more of my energy to do my job well and to maintain my physical and mental health needs. Having that extra freedom has truly changed my life, and I think it can for a lot of neurodivergent folks. Thank you for putting out this request for public comments. It means a lot to know that somebody might be listening.</p>

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I am autistic and I have adhd and treatment-resistant depression. The depression is a direct result of autistic burnout living in a fast-paced, inadequately structured, capitalist society. The lack of resources available to autistics who cannot afford the expensive process of diagnosis exacerbates this issue-- the less support available, the worse the burnout and subsequent depression becomes. Taking my ADHD medication, although it helps with focus, executive dysfunction, and energy levels, ultimately makes my sensory processing issues worse and leads me to burnout earlier Social anxiety accompanied by intrusive thoughts Burnout seeking some form of control- - I have used tattooing as a form of self-harm. A way of feeling in control over my body when I don't have the capacity for anything I need or want in that period of time. These needs and wants can include the most basic forms of self care such as feeding myself, brushing my teeth and taking showers, or going to class, work, or social functions. In these periods of extreme depression I have experienced suicidal ideations.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	- Autism and ADHD -- the effects of stimulus treatment of adhd on autistic/adhd individuals - "HSP" or "Highly sensitive people" - Autism and anxiety (often social anxiety) in girls specifically - Autism and chronic fatigue- - more research is needed on chronic fatigue in general
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	- EQUITABLE ACCESS TO AND ACCESSIBILITY OF SERVICES, ESPECIALLY EVALUATIONS -- insurance should be covering this, it is not - More therapists specifically specializing in "high functioning" autistic adults. I was incredibly lucky to find one with an opening, and honestly would be in a much, much, much darker place in my life - Education of educators, employers, and administrators on both "high" and "low" functioning autistic needs -- we tend to be ignored/not taken seriously because allistics simply don't understand how our processing can be so different from theirs.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services,	Honestly, quarantine was so healing for me. I had just graduated high school, was deep in burnout. My catchphrase was, "I don't want to die. I just need to be in a coma for a year." and that's essentially what covid quarantine was. The the reduced in-person social interactions and obligations was just what I needed. I was pursuing old and new hobbies, and was happier than I had been in years. This ultimately led me to my autism diagnosis -- for years I

increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	couldn't figure out why I was so depressed. Quarantine made me realize it was my sensory processing issues tied to autism. The increased access to services via telehealth has also been incredibly helpful. As part of my executive dysfunction issues, I have yet to get a driver's license or a car, so getting to appointments can be incredibly difficult for me. Telehealth, especially for therapy and psych appts, makes this process so much simpler for me. I also have issues with change and interruptions in my day-- not needing to leave my comfort space to go to therapy or a psych appointment allows for me to devote energy that would have been devoted to transportation/acclimation
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Name	Anonymous
Demographic	Service provider, health provider, or educator
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>As a Special Education Teacher, I am advocating for my students who are non-speaking with limited verbal language and high support needs who are unable to access and fill out this form independently who are Autistic as this is inaccessible for people with complex communication needs. Fine motor needs: Unable to write independently to express thoughts and academic capabilities. Difficulties in carrying out daily living needs such as zipping up coats, using the bathroom independently, typing on a computer, utilizing eating utensils Sensory Processing Disorder- affects capabilities of accessing the community due to oversensitivities to noise, taste and touch. Going to a restaurant and grocery store can be deemed impossible due to safety. Children may often elope out of buildings which causes major safety concerns. Anxiety- unable to attend doctor appointments due to high anxiety and oversensitivities to noise and touch. Speech/Language Disorder: non-speaking, no access to AAC devices due to financial reasons, advocate for body autonomy, express wants/needs/requests. Sleep Disorders: Days where child cannot sleep, disturbed sleeping patterns (sleep during the day, awake throughout the night, awake for days at a time)</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>As a Special Education Teacher, I am advocating for my students who are non-speaking with limited verbal language and high support needs who are unable to access and fill out this form independently who are Autistic as this is inaccessible for people with complex communication needs. Sensory Processing Disorder- affects capabilities of accessing the community due to oversensitivities to noise, taste and touch. Going to a restaurant and grocery store can be deemed impossible due to safety. Children may often elope out of buildings which causes major safety concerns. Unable to regulate and communicate emotions. Anxiety- unable to attend doctor appointments due to high anxiety and oversensitivities to noise and touch. Since many people with Autism are complex communicators, they may participate in self-injurious behaviors such as hitting other and self, banging head on objects or walls. May throw objects that could cause injury to self or others.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>As a Special Education Teacher, I am advocating for my students who are non-speaking with limited verbal language and high support needs who are unable to access and fill out this form independently who are Autistic as this is inaccessible for people with complex communication needs. Fine motor needs: Unable to write independently to express thoughts and academic capabilities. Difficulties in carrying out daily living needs such as zipping up coats, using the bathroom independently, typing on a computer, utilizing eating utensils Sensory Processing Disorder- affects capabilities of accessing the community due to oversensitivities to noise, taste and touch. Going to a restaurant and grocery store can be deemed impossible due to safety. Children may often elope out of buildings which causes major safety concerns. Speech/Language Disorder: non-speaking, no access to AAC devices due to financial reasons, advocate for body autonomy, express wants/needs/requests. Intellectual Disabilities: deficits in cognitive functioning that impact abilities to access the general education environment and acquire age appropriate academic, communication, social, behavior, and adaptive skills. Deficits in attention, sensory processing skills, and fine motor development also impact ability to attend to instruction, follow directions, transition, and participate in learning activities without significant support.</p>

<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>Research on alternate therapies besides traditional ABA Therapy. Less compliance, more on communication. AAC advocacy, listening to Autistic individuals, shared experiences, medication, support for families</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Flexible choices for health services, AAC access for all, insurance coverage for therapies not specific as ABA, easier access to paraprofessionals in the school setting, caregiver support in the home for families, respite care for families, education for government officials such as police officers, first responders, health providers. Sensory tools for homes.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>Staying at home has caused regression for individuals with social anxiety from being at home for years at a time. Educational regression from being required to access education at home. Inaccessibility for people with Autism to access online education during the pandemic without assistance from a caregiver. Sensory processing needs for student to be unable to wear a mask, therefor increasing possibility of infection from Covid-19 when out in the public. May be confined to home.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Some of the most significant challenges caused by co-occurring physical health conditions that we have experienced with my son is congenital heart disease which stems from some kind of a genetic condition that we still are trying to pinpoint, it has caused my son to have intestinal malrotation, mirrored organs(stomach on the opposite side) .Heterotaxy is the condition associated with his organs being rearranged and having congenital heart defects . My son was born with a complex single ventricle heart, has had three open heart surgeries since 2016. He also struggles with sensory challenges that causes him to cover his ears when there are loud sounds. The sensory challenges impact his ability to sleep comfortably, he ends up waking to any sudden noises. He was also born with some damage on his brain that was discovered during a Mri after birth.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The most significant challenges that have been caused by co-occurring mental health conditions are anxiety. My son struggles with social settings due to being seen by others, he doesn't like for people to see him if he is getting pulled from class or has to participate in a group where he is called on. Connections with other individuals is difficult as he shuts down around new people or in new environments. When he shuts down , he becomes nonverbal although he is verbal and can communicate with others he is comfortable with. When he shuts down, or is overwhelmed by sensory input he exhibits challenging behaviors that impact him in a classroom setting or even public setting. He will hide under furniture, he will lay on the floor and refuse to move even if the area where he is laying is unsafe due to other people potentially walking on him. When he is overstimulated additional behaviors are noticed such as escaping the area , being disruptive if he wants to be somewhere else or if there is a change in the routine that he struggles to transition with.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The most significant challenges caused by other conditions that Co- Occur with autism, are the combination of attention, deficit, hyperactivity, and attention, deficit, disorder with a mixed language disorder such as Receptive and Expressive language delays. My son has both ADHD/ADD and language delays that impact his ability to communicate and express himself while also comprehending the information that is given to him. Ever since my son was an infant there was always a risk for him to develop psychological impacts due to his physical condition with his heart . Lack of oxygen to his brain created issues in his early development . We saw developmental delays at a young age, which made it harder for him to learn and develop age appropriately .
What additional research is needed to help address co-occurring conditions for autistic people?	More research around physical health conditions that lead to an autism diagnosis as well as genetics . More research on public awareness of the causes of autism and the impacts of physical health impairment's on the brain leading to risks of autism.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More Accessible and Equitable access to services especially community-based services. My son has faced termination out of community programs prior to his autism diagnosis. He has also faced isolation due to his challenging behaviors and lack of resources for providers in community programs. There also needs to be more regulations around denial of services even before an autism diagnosis. More understanding on how Co-Occuring conditions impact our children and loved ones with autism . It's not them, it's their brain and how it is wired . Sometimes it's the story behind the behavior that a lot of people don't hear. My son spent his young infancy and toddler

	<p>years in and out of the hospital, on and off a Heart and Lung Bypass machine . PTSD from medical trauma can play a major role in the behaviors seen, but also his inability to communicate his feelings or being heard is another part .</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	

Name	Anonymous
Demographic	Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disturbances Gastrointestinal issues (including constipation) Motor issues Feeding difficulties Toilet training difficulties Epilepsy
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD Anxiety Depression Self injurious behaviors Passive suicidal ideation Misdiagnosis of personality disorders Misdiagnosis of bipolar disorder
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Learning disabilities Communication delays/ differences Motor coordination and strength issues Intellectual disability Tic disorders
What additional research is needed to help address co-occurring conditions for autistic people?	Awareness and research on impact these conditions have on autistic individuals. Implications and recommendations for treatment and treatment providers.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Disruptions in services, reduced socialization, increased demand for virtual learning which tends to be highly stressful for those particularly with cooccurring ADHD

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The hypermobility disorders so many of us have such as Ehlers Danlos Syndrome are the most disabling in my experience. I can't have most jobs because I can't do any sort of physical labor like standing in service industry jobs for 8+ hour shifts, and there are no jobs where you can lay in bed the entire time. I have plenty of GI issues as well which make holding down a job complicated too, but not as much as the EDS. But the government doesn't consider EDS disabling enough to give me disability payments, so I'm forced to work through excruciating pain.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The most obvious one is that suicidal ideation/depression makes every aspect of your life harder, you can't work if you can't get out of bed. My OCD is also very detrimental to my ability to work, there are some jobs entirely off limit to me because of my symptoms. Misophonia is one of the ones that seems like it wouldn't affect you as much, but if I can't even sit in a break room during lunch without being miserable and agitated at the sounds of people chewing their lunch, I can't further my connections in a place of employment.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Getting advanced degrees to get better jobs is much harder for us than for the average person, and disability accommodations at an individual school don't factor in the fact that we can't spend extra time studying because we have to work to feed and house ourselves. Many colleges don't even really have useful disability services even though they're required to by law, and even if they do, individual teachers sometimes don't care and won't follow the accommodations anyway.
What additional research is needed to help address co-occurring conditions for autistic people?	More research needs to be done on the connection between autism and Ehlers Danlos Syndrome, and also why we all have GI problems. I just keep getting told "yeah they're comorbid, that's all we know" but why?? How can we help manage the bad symptoms if we don't know the mechanisms by which they operate?
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance only exists in the US if you have a good enough job to get it, which is a huge obstacle for autistic people. We also have to address individuals at every point in the system not caring about their legal obligations to help disabled people and just disregarding us entirely.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	So many of us already struggled with social interactions and loneliness, and now we're further isolated because the government failed our country so badly on covid management and wants to pretend it doesn't exist anymore so nobody wears masks, nobody tests, etc.... I shouldn't have to risk my life in order to have a social life when it's already so much harder for me than for other people.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The reduction in my ability to safely do in-person social interaction has severely increased by depression and loneliness. If people were required to wear masks, I could actually go out and try to meet people in person, but my safety is important to me.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The most significant challenge caused by a co-occurring physical health issue for me is severe fatigue. I've had to cut out most things in my life that aren't work or immediate family, even long phone calls leave me needing rest. It's extremely frustrating.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The most significant challenges caused by co-occurring mental health issues would probably be the loneliness. Having autism or mental health issues (depression, anxiety, etc.) can be isolating, having both is extremely lonely. Also, as it relates to ADHD as well as autism (what many of us refer to as "AuDHD"), it's extremely challenging feeling pulled in such different directions. At times I can be meticulous and extremely rigid and other times I can be impulsive and careless, and there's not always a pattern or method to it. There's also a lot of executive dysfunction to contend with. It's a lot.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	It would be incredible to have more research done on diverse participants. I can't begin to tell you how many times I've heard "...but you don't look autistic". In fact, many people don't believe you if you don't look a specific way. I believe this is because so much of previous research was done on such a homogeneous group. It would be great to have research on participants who are women or other gender identities as well as BIPOC. I would also love to see some autistic people on the research team. The assessment process as it exists now is maddening and the questions don't really make sense when you consider the minds of autistic people and how we think. For example, "would you rather go to a party or a museum?" The writer of the question was perhaps trying to get at the person's relationship with simulation but most autistic people read that and probably think, "well, what kind of party? Is it loud? What kind of museum? Who's there?" Etc. More autistic people involved in the research could be quite useful.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Making it easier to get assessed would be helpful. Most the people I know who believe they're autistic have done a great deal of reading and reflection to come to that conclusion but have been unable to get a formal diagnosis. Also making services more accessible would be useful.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic	

people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The main issue that I have found both in myself and others is mainly the ability to take care of oneself.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Self-care tasks such as brushing your teeth, brushing your hair, taking a shower, and eating. Being able to communicate which directly influences the ability to have access to job opportunities, meaningful social interaction, and meaningful day today activities.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	The main research that needs to be occurred is how to help autistic people with these conditions as well as how to help autistic people in their day life in general. Whether they have high or low support needs.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Talking to low and high functioning autistic people about the relevance of the support that is being added, seeing if that support also works for intersectionality such as if the autistic person is a person of color or wheelchair bound, and openly listening to autistic people's feedback when it comes to the current system that is in place as well as any other systems that are added in the future.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I have personally not experienced any lasting consequences due to covid, but I've heard a lot of other autistic people have experienced dramatic setbacks socially and emotionally because of their experience with covid
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	From my own personal experience, I have not seen any positive lasting change. A lot of people experienced negative change because of it and a lot more ableism within their day-to-day life since COVID.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	There is a lack of knowledge of co-occurring health conditions by healthcare professionals causing autistic individuals to get misdiagnosed or not diagnosed at all. If an autistic individual gets diagnosed with a co-occurring physical health condition, it is difficult to receive aid for such, and the aid available is often not enough.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The symptoms are often mixed up within the common co-occurring mental health conditions, and not enough health care professionals are accurately trained to diagnose autistic individuals, often ignoring the co-occurring mental health conditions.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Lack of social knowledge and acceptance.
What additional research is needed to help address co-occurring conditions for autistic people?	We need more studies to better understand the links between co-occurring conditions, and to start a process where when an autistic individual is diagnosed, they get screened for any co-occurring physical and mental health conditions to help make sure there are less hoops to jump through to get the help they need.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	There is a lot of room for improvement in this area, the greatest of which being that people that work with autistic individual should better know their needs.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	COVID-19 exacerbated co-occurring physical and mental health conditions.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The COVID-19 pandemic helped many seek diagnosis, and the change of work styles and shift towards work from home has allowed autistic people to stay employed. increased reliance on online communication has helped autistic people make appointments, communicate more effectively with others, and take advantage of services not traditionally available to the social impaired.

Name	Anonymous
Demographic	Autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>I struggle most with insomnia, Ehlers-Danlos Syndrome and POTS. I know a lot of autistic people have different circadian rhythms so that can cause a lot of us trouble when trying to sleep at a “regular” time. A lot of us are also hypermobile and for me this causes a lot of nerve pain and keeps me from doing many different activities such as exercising, sleeping comfortably, lifting heavy things, writing or typing for long periods of time, playing piano, etc. One of the biggest challenges with EDS is that most doctors don’t seem to know much if anything about it. There is also very little research on it but it seems to be a lot more common than what was first reported in research because not many people were diagnosed with it before. It’s frustrating that there isn’t more research on the different ways in which an EDS person’s body functions differently from the average person’s aside from the musculoskeletal and gastrointestinal symptoms. POTS keeps me somewhat fatigued all the time and makes getting any amount of exercise difficult due to my high heart rate that won’t slow down for a long time after physical exertion. I don’t fully pass out from it but it’s really annoying and prevents me from doing things I want to do. As for sensory and motor challenges, I don’t have co-occurring disorders of those but the typical sensory issues related to autism are very disruptive in my life and affect every part of my day.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>I have ADHD, chronic depression, trauma, generalized & social anxiety, phobias & chronic suicidality. ADHD is difficult because of the stigmas about being lazy when I’m trying but my brain disagrees with what is highest priority (executive dysfunction & interest-based nervous system). Many ADHD people fail to meet expectations & are villainized for symptoms out of their control. Most neurotypicals don’t know what ADHD is, especially because the name suggests it’s a deficit of attention (which it isn’t & inattention is the least of our problems). Chronic depression & trauma are common in autistics because you grow up in a world made for neurotypicals. You’re lonely & upset that your life isn’t going how you had expected. I’m still grieving the life I thought I would have. Medication doesn’t eliminate my depression because it’s situational & the situation is permanent. Therapy never helped; I was so self aware that I already recognized how I functioned but still felt the way I felt. A lot of therapists don’t know how to work with a bottom-up processor who is so self aware that pointing out how they behave & think doesn’t give them any new information. Without medication, my anxiety is crippling. A lot of it could have been avoided if there hadn’t been so much pressure to act, speak & move a certain way (masking). Like my depression, my suicidality is difficult to treat because it’s permanently situational. I don’t want to die; I just don’t want to live.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>I personally struggle with dyslexia. It’s difficult to learn when you struggle so much with reading and most of schooling is reading things.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>There is definitely not enough research about Ehlers-Danlos Syndrome and how the bodies and minds of people who struggle with it are different from the average person’s. I also would like to see more research about the link between Autism and ADHD because they seem to have a lot in common.</p>

<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Insurance coverage. Getting diagnosed with autism is really expensive and most autistic adults are unable to hold a job. Getting diagnosed with ADHD is also expensive and should be covered. For that matter, getting diagnosed with anything should be covered because it's a necessity for most people with disabilities.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>For me personally, the changes were actually great because health providers started using telehealth instead of requiring in-person visits. However, going back to in-person appointments has been difficult for me because I struggle a lot with pathological demand avoidance and I also have a lot of trouble with changes to my usual daily schedule. Leaving the solitude and safety of my apartment is upsetting to me and I will avoid it at all costs.</p>

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The ineffectiveness of the healthcare system to help is most significant for me. All the time and 90 dollar copays spent on doctors that take 15 minutes to pick out one issue, rejecting the whole picture, then send you to someone else for that one issue, is frustrating, ineffective and financially devastating. The more wholistic healthcare professionals don't take insurance because they see how insurance ruined medical practices. They are even more expensive, but more effective.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Because Ehler's Danlos Syndrome is poorly understood and I find it difficult to verbally express what I experience, doctors have failed to even test for it. I've known for many years that I have EDS, and have not been able to get the healthcare community to work with me on it, even though I have asked for testing.
What additional research is needed to help address co-occurring conditions for autistic people?	Research on how many people go undiagnosed as autistic and undiagnosed with co-occurring conditions is an important basic step.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	A wholistic testing facility that can run a thousand tests on the entire body, during a one day to one week, annual visit would be beneficial to everyone, but especially autistic people.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>Some of the most common comorbidities in autistic people (like autism itself) are complex and multi-system conditions that healthcare professionals are uneducated about and ill-equipped to support. Many have a genetic basis. Many are compounded by the effects of trauma that seem to be more prevalent (if not ubiquitous) in autistic populations, and we tend to be more sensitive and susceptible to the trauma we do incur. Childhood trauma in the form of adverse childhood experiences (or ACEs) are the single greatest predictor of dozens of health outcomes, but trauma is vastly underrepresented in healthcare and research and its treatment isn't prioritized all because it's not profitable. I personally have had chronic respiratory infections and developed ME/CFS and FND with non-epileptic seizures, among other conditions, and 1500 characters is nowhere near sufficient to cover the range and severity of symptoms of my own, let alone for the gamut of autistic people. Medications corresponding to misdiagnoses (which are very common for autistic people) can cause further health problems, and often do, and only serve to compound the difficulties of those afflicted with the massive web of comorbidities.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>High self harm and suicidality rates are well documented, but what isn't is the ubiquity of trauma and its impacts on the mental health side of things. Trauma is a primary predictor of all kinds of health outcomes, and most autistic people I personally know have at least PTSD. Many (especially those of us who are more highly sensitive) have more complex traumagenic disorders. It's not studied yet, but based on my own experiences and the community that I engage with, I'm confident there's a statistically significant overlap between autism and DID, OSDD, and other conditions of complex trauma. DID as a condition on its own is already so widely misunderstood and misrepresented. The most significant challenges are varied and numerous, are often very individual in nature, but are compounded by the lack of trauma-informed healthcare, rampant misdiagnosis and prescription, and the negligence of healthcare professionals who aren't equipped to help autistic people but work with them anyway.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>I'll defer to autistic people with higher support needs and their caregivers on these specific conditions. I fear autistic people with less significant support needs will be more highly represented in these surveys, as they are in discourse in the public sphere in general, and I believe the comments of those with more experience with these disabilities should be especially weighted. I will say, though, that autism being understood so widely through the lens of research done by Nazis and the obvious implications of eugenics have allowed for the abusive treatment of autistic people (especially those who have difficulty self-advocating) for far too long, under the guise of medical support and intervention. Namely therapies like ABA and electroconvulsive therapy, but others as well. They often don't treat the root causes of difficulties autistic people face, nor view them holistically as a part of a complex and multi-system disability with many layers of cause and effect. Many autistic people are assumed to have lower intelligence and ability to interact with the world when the difficulties with communication, learning, and others can come from physical issues like facial hypotonia (for the sake of example).</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>Trauma research across the board is necessary. Trauma-informed healthcare would change so many people's lives, but undermines the profit motive that drives how so much of medicine is practiced, and it takes many years (if not</p>

	<p>decades) to receive proper support. Many never do. With that in mind, there NEEDS to be research on gender, racial, and other disparities in diagnosis and treatment, and in barriers to access. I've also seen many in the autistic community starting to understand the genetic and biomechanical functions that underlie the symptoms of autism (and its web of comorbidities) by connecting existing research to improve their lives and those of other autistics. I've seen research that seems compelling and promising about connections to many comorbidities relating back to BH4, and how its dysfunction affects several enzymatic pathways that use BH4 as a necessary cofactor. With the internet and community around autism, there are many who use what exist, to self experiment and reach conclusions that seem to be potentially decades ahead of existing research, even without the expected qualifications or credentials.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Just about everything. I don't even think too many would be mad if the diagnostic criteria and corresponding treatments at a foundational level was gutted and redefined by the autistic community. So much of what's widely accepted about autism comes from the perspectives of people who aren't autistic, and many with blatant histories of eugenics and abuses of disabled people, addressing how they're affected by autistic people rather than understanding fundamentally what necessitates certain behavior and what differentiates autism as a neurotype. Autism is highly complex and very individual, meaning it looks different in all kinds of people who have it. Diagnosis is often expensive, and even with the cost, most of the research done is on young white male children, so virtually every other demographic is underrepresented in research, diagnosis, and receiving proper supports and accommodation. Misdiagnosis (particularly in the vein of depression/anxiety, BPD in women, ODD in people of color, etc.) is rampant. Care providers are widely not trauma-informed, and don't understand how their treatment of autistic people can do more harm than good in many cases, and especially not of those who aren't properly diagnosed to begin with. Services and supports are among the least accessible and least trusted infrastructure in place for autistic people, and barriers to success exist at every step of the process.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>"Long COVID", a common form of long term post-viral illness, is just the tip of the iceberg of this mass disabling event. I was diagnosed with ME/CFS, and its onset was years before the pandemic even started. Millions of people, and I assume a plurality, if not a majority with neurodivergence, are affected and have virtually no infrastructure of treatment options in place to support. ME/CFS for the sake of this example, had its quality of life indexed against dozens of health conditions, and its outcomes were marked as worse than every other condition that was listed, including cancers, diabetes, brain stroke, and schizophrenia. It affects everything from energy levels and memory to autonomic functions, seizures in some, and many other symptoms. This is just one label/subsection of this phenomenon, and virtually identical to what "Long COVID" describes.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced</p>	<p>COVID has had a part in exposing glaring, widespread inequity and inaccessibility that has already affected disabled people as a whole, including those with autism. I've shared that being mostly homebound, little about my way of life had changed between pre-COVID and lockdown. In terms of positives, there's more of a social awareness of disability (although it's definitely lacking still), and using proactive, preventative health measures to protect many of the most vulnerable in our communities, and increased use of technology and remote communication to eliminate risks, with the added</p>

in-person social interactions and obligations)	benefit of increasing accessibility. We saw firsthand how our former way of life contributed to ecological degradation, needless extraction of resources and labor, and the exclusion of disabled people. Differences illuminated in that time helped us face the apocalyptic trajectory we all face and clearly outline changes in the sociopolitical order that would allow us to avoid that. People have become more aware and politically active. Part of the negative impact is that there's a greater divide than ever between the rich and poor, and the attitudes of younger and older populations on how to handle the existing decay of society and life as we currently know it. These aren't directly about autism, but sensitivity and susceptibility to trauma and stress are clear predictors of health, and these pressing issues are all many of us can even think about.
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Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Denial of request for Dx (not a white male), self-hospitalized twice for SI, refusal to identify as victim because of additional physical harm or social bullying based upon racial/ethnic culture, consistently told not ASD by GP and family because of physical appearance/athletic abilities in individual sports/academic abilities, high masking due race-culture-religion-sexism-homophobia-misogynoir-FOO-employment opportunities-corporal punishment, speech impediment, hyperlexia, dyscalculia, GT Kid, ADHD, SPD, CPTSD, anxiety/depression, Hashimoto thyroiditis, IBS, Ehler-Danlos, GAD, social anxiety, panic disorder, queer, bulimia during partner violence in college
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Parents gaslighting and hypercritical—in denial or lying due to respectability politics, ADHD, SPD, GAD, CPTSD, speech impediment and swallowing issues, ear issues, social anxiety, panic disorder, self-destructive behavior to avoid harming others, depression, SI (after a decade of being misdiagnosed in early 30s), bulimia during episode of partner violence, clinical PPD with dysphoria
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Labeled aloof-Oreo-blurd-nerd, geek-spaz-weird-eccentric-too sensitive-too smart-too quiet, hyperlexia, intense/encyclopedic special interests make social interactions difficult, labels such as INFP/HSP/GT only complicate Dx, truly never bored so intensifies isolation, intersectional identities, need for social justice and equity make friendships nearly impossible because of societal prejudices, biases, inequities, intersectional issues and pointing out employers violating employment law and intentionally discriminating in admissions and hiring and promotions and mentoring, all my life all friends are cousins I grew up with, extreme need for autonomy
What additional research is needed to help address co-occurring conditions for autistic people?	Cultural and class incompetence is MALPRACTICE: how to identify and address misdiagnosis in GenX women and minorities consistently and intentionally excluded from research, ASD-identity integration/coping skills, how chronic gaslighting by ignorant and biased GPs, ER physicians, specialists, nurses, therapists, psychologists, psychiatrists, educators, schools, and families lead to maladaptive coping and SI, how being undiagnosed through adulthood affects parenting abilities, class/economic issues of seeking Dx as adult even with health insurance, what are the psychological, social, intellectual benefits of ASD. What is the effectiveness of CBT, DBT, EMDR, transcranial magnetic stimulation, etc. for ASD. How does psycho-social-educational deterrents to stimming affect emotional regulation and ability to learn and firm positive self-concept? Especially for marginalized groups (race, class, gender, sex, orientation, etc.) being denied Dx or access to testing which self-tests are most reliable? How reliable is self-evaluation/testing?
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	IAT and Psych evals for ASD diagnosticians, honor requests for ASD testing, insurance coverage for adult testing, employer benefit-incentive for hiring/mentoring/promoting full-time ASD individuals (especially in their qualified, special interests), enforcing CROWN act nationally (Black women with ASD)—more Black psychiatrists and psychologists specializing in ASD and co-morbidities who are not religious, socially conservative, elitist, sexist, and homophobic—and do not espouse or engage in respectability politics. Also, young, inexperienced, and provincial educators and administrators are causing psychological harm and trauma, while impeding natural academic

	<p>gifts, talents, and ability to socially adapt while inhibiting students self-concepts. EXPLICITLY warning parents/guardians of the long-term effects of avoiding intervention or hiding their child's Dx from the child.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>Increased barriers to ASD testing, Dx, therapy, physical care, and coordination of mental/physical care/services. Remote testing for ASD unavailable, remote testing for adults IMPOSSIBLE. Constantly needing to teach providers about autoimmune Hashimoto, Ehler-Danlos, IBS, ADHD, SPD, anxiety, depression, insomnia overlap—and now officially menopausal at 55. However, the isolation of the pandemic provided a chance for my nervous system to rest.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Positive: reduction of obligatory social demands, greater equanimity, increased work/personal/creative productivity. Negative: autoimmune disease increased fear of interactions, reduced connection to FOO and extended family because of phone aversion (no non-verbal cues & PDA), object impermanence, very little desire for communication reciprocity</p>

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disorders are an almost nightly occurrence for me. Sensory overload is one of the worst challenges faced by the Autistic community.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression and anxiety, self harm and suicidal actions, aggression when misunderstood and/or belittled.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	A panic room. A quiet place to go with dim lighting should be included in all spaces that can become overwhelming
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Migraines/nerve pain and dysfunction as related to overstimulation. Sleep disturbances as related to overstimulation. Sexual dysfunction as related to overstimulation (getting physically aroused when not aroused otherwise, also relating to sexual violence against autistic people). Poor depth perception, clumsiness, high physical pain tolerance and low psychic pain tolerance. Gastrointestinal issues as related to overstimulation. Burnout as a whole and skill regression.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression, borderline personality if traumatized in childhood, attention deficit disorders. High risks of suicidal ideation during burnout or if overstimulated. Eating disorders and obsessive compulsive disorders both related to having inclinations towards special interest and excessive shame and guilt.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	As with everything related to autism, not being taken seriously and being infantilized. Taking things for face value (getting into dangerous situations or enduring sexual violence because because you misunderstood a social cue). Allistic people being extremely frustrated with you for not understanding or not complying to something you don't understand. Extreme rumination.
What additional research is needed to help address co-occurring conditions for autistic people?	How the stress of overstimulation and burnout effects the brain and body of autistic people. How autism ACTUALLY presents in women and people of color.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Actually being able to diagnose people who aren't 5 year old white boys. Patience. Kindness. Doctors to be trained on what autism actually is.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Possibly making migraines and nerve issues worse. Not sure. Definitely worried for all disabled people in this day and age, as insurance providers and medical institutions are extremely biased against disabled people in general, and especially if they think you're [redacted].
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	While being home, more autistic people were able to learn about autism and either self diagnose or seek medical diagnoses for autism and comorbidities.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gastrointestinal issues, migraines, hallucinations, ADHD, trouble moving when comfortable, short term paralysis, synesthesia, memory trouble short and long term, sensory overload or selective intake, differences in social expectations, realities, experiences and instincts, differing emotional and physical needs from the norm not being considered
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD, anxiety, mania, memory issues, long term hyper fixations, burnout, lack of ability categorize priorities
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Differing developmental goals and tracks, disabilities being hyper realized via official systems such as the educational or employment systems but otherwise manageable or invisible, trouble reading, memory issues, need for longer down or break time or other concessions
What additional research is needed to help address co-occurring conditions for autistic people?	Non biased research into autism in social settings whose conclusions do not end on a massive generalization, or infantilizing/hateful conclusion. On interacting with other social groups, on differences within the community, medical issues that are common and how they can be accommodated and much more
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Equitable access to services, insurance coverage, marriage equality, lack of withholding or societal mobility due to diagnosis, concessions in relation to demonstrated needs
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Long COVID comes in many forms that can add another layer of complications on top of already snarled medical conditions, and can involve intense sustained traumas that are nontheless going publicly unaddressed culturally and as a whole
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Better public awareness of how health issues impacts daily life, access to remote work/school without structural issues, then taking away of that option out of apparent pettiness, reduced societal obligations, severe social and touch starvedness becoming even more common, young people in crucial development periods during that time facing huge setbacks due to isolation

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Within my life, I have struggled with sleep, unexplained GI upset, and sensory issues. These have become moderately worse with time, although I have also developed ways to exist with this. I have trouble going to sleep, randomized GI issues that can be painful, and with certain textures/sounds. I also have a heightened heart rate, which I've been told could be related to being ND. I would call sensor issues the most prominent in the experiences of autistic people in general, but it's certainly possible many of us have health issues that are not discussed in the community that I've heard.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	In my life I have experienced depression, ADHD, and disassociation. Relatedly to the first and last, I've experienced periods of injurious behavior, suicidality, memory loss, and unresponsiveness. Several years ago when this was at the worst it's been, this provided challenges to my functioning.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I have found that I process information differently, although I can usually keep up or ahead of others with effort. I have also found that communication with neurotypical people is harder than with other autistic people, in a way I would compare to both of us being semi fluent in a second language and trying to speak to each other with slightly varying personal dictionaries and ideas.
What additional research is needed to help address co-occurring conditions for autistic people?	I think that physical conditions need to be looked into most pressing. For example, it is personally well known to me and in my experience to the community that autism is related to GI issues, but I'm not certain of scientific evidence of this. I also think that research that has been done has been disrespectful, disregarded, and/or undervalued.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I think that in a typical situation becoming diagnosed or receiving allowances for autism comes at the cost of societal respect. This is then reflected in the support we may receive and its effectiveness. I think in educational or working environments specifically more support is often needed, especially in terms of accessibility. I also think doctors and other professionals either ignore a diagnosis or discredit the autistic individual.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I've found that due to long stretches of remote work/school, my socialization skills have gone from mediocre to fumbling. I was however more comfortable/less stressed existing more privately.

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>It varies among Autistics. What family/friends of an Autistic person may view as significant challenges may vary from what the Autistic person perceives. Example: I have a gastrointestinal (GI) disorder that severely restricts diet. My relatives say it's "horrible" that I have to live with it, and menu accommodations distress them. But to me, my sensory challenges feel more burdensome than my GI disorder and insomnia. Example: I'm hypersensitive to auditory stimulation and subconsciously clench my jaw until I get out of the situation/environment. By then, I have a terrible headache from jaw and shoulder tension. I've had a WFH job for 6 years, but Zoom work meetings mean I'll get one of these headaches. Higher pitches, such as those of some female voices, cause sharp ear pains that result in me wincing and jaw clenching. Hearing back-and-forth conversations between 3+ people causes painful sensations of my eardrums "pulsing" with each word heard, which results in jaw clenching against pain. (Physically, doctors say my ears are fine.) My Autistic teen reports that her PCOS is a worse challenge than her tactile sensitivities and insomnia. (Source: autismparentingmagazine.com/autism-pcos-link.) Even an Autistic person can't say what a significant challenge is for another without asking. For non-Autistics answering this survey, the question should be "What do you PERCEIVE as the most significant challenges..." since they can only speculate.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>Self-reports for my Autistic self and my Autistic teen are for anxiety as the most significant co-occurring mental health struggle. As the parent of an Autistic teen, I would argue it's the suicidality that my child struggled with in middle school (pre-dating her autism diagnosis).</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>As an Autistic and the mom of an Autistic teen, we're fortunate to not have learning developmental or intellectual disabilities; I won't speculate on which is worse for other Autistics who have these disabilities. My teen and I do both struggle to a degree with communication, despite both of us being verbal.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<ol style="list-style-type: none"> 1. Medical provider education—Providers have said since my child and I are verbal and have gifted intelligence, there's no reason for them or any provider to ever know we're Autistic and autism co-occurring conditions "aren't a thing" 2. Patient-provider interactions—I'm fortunate in that I have a master's in healthcare communication, have gifted intelligence and worked in medical writing for 10+ years, so I have a high level of health literacy. But my Level 1 autism causes even me to struggle with medical interactions sometimes, and providers are clueless as to how to help or accommodations. I have Autistic family and friends who greatly struggle with patient-provider interactions. 3. Workplace rights & accommodations—Beyond only environment (e.g., low lighting, noise-canceling headphones) 4. Autism in adult females—Diagnosing, navigating relationships (friend and romantic), parenting, and career 5. Public education—Eliminating stereotypes & stigmas, as well as what to do/not do if an Autistic has a meltdown in public. 5a. Autism strengths—Internet focuses on negative aspects of autism. People have been shocked to hear that some Autistics can be 140% more productive in the workplace, are great at outside-the-box

	solutions, etc. (Source: hbr.org/2021/12/autism-doesnt-hold-people-back-at-work-discrimination-does). 6. Mental health provider education—Several psychologists refused to evaluate me for autism since I can make eye contact if needed and am female
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I can't speak to traditional autism services (e.g., ABA), as myself and my child were told we are both ineligible since we're Level 1 Autistic. My Autistic teen does need executive function coaching because she's struggling in school and with daily life functions, which I was told isn't covered under insurance. I'm paying for it out-of-pocket at \$100 per hour, which is a financial burden. The psychologist who did my autism evaluation said I need to find a therapist who specializes in autism masking. She said my masking score is the highest she's ever seen (160s) and I'm in Autistic burnout. Such therapists that she's knows of and that I've found are private-pay only, so I can't afford one.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I haven't had COVID-19 myself yet. My Autistic teen had COVID-19 in December 2022, but she and I are unaware of any lasting impacts she's had from it.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Negative impacts: Minimal for my Autistic self and my Autistic teen since we're both Level 1 autism (don't get autism services). Our largest struggles: not seeing family (our main support network) in-person each weekend during lockdown, and increased anxiety with worries about friends or family getting COVID-19. Positive impacts: 1. Remote school & work—Fewer in-person social interactions and struggles with time management/organization (AKA arriving to places on time). 2. More telehealth—Being in your home/familiar environment helps to focus on conversation (e.g., no overstimulating smells/textures/lighting/sounds, no stress of trying to navigate through confusing medical facility, no traveling unfamiliar routes). Telehealth also makes it possible to avoid eye contact, which can be so distressing or uncomfortable for some Autistics like me that I struggle to follow the conversation. People are used to eyes looking slightly above or to the side in video calls; it's socially acceptable. 3. Fewer social interactions & obligations—Being introverted and Autistic, people would judge myself and my teen for being homebodies and not wanting to do "normal" things on weekends (e.g., go to bars or mall for "girls night", have playdates where kids play while moms talk, etc.) 4. Curbside pickup—Store music, noise and lighting; navigating around crowded aisles; checkout lines; finding items in the store (especially if the store rearranged); etc.; can be overwhelming.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Many have depression, anxiety, and PTSD due to trauma (often from bullying or abuse). ADHD is also a common comorbidity. These conditions make it hard to function in daily life. We feel scared and stressed all the time.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Nonverbal autistics have a hard time communicating their needs and are often abused because they can't tell others what's happening to them.
What additional research is needed to help address co-occurring conditions for autistic people?	The research MUST listen to autistic voices and should never treat autism as a disease that needs to be cured. Autistic people with varying levels of support needs should be involved in the creation of research programs.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Services should be made accessible with accommodations for those with different ability levels. Autistic people should have advocates who are trained to understand the autistic experience.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The reduced societal habit of unnecessary touching is good. The introduction of telehealth and other online options for obtaining services is also good.

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep disorder -since birth. Nothing really shows on sleep study. Medication only partially effective. Sensory issues -sound and light sensitivity. Concern about safety with law enforcement due to hypersensitivity to loud voice and lights. Alexithymia- difficulty recognizing and communicating emotions. Also there is a physical version of this. They have trouble articulating physical sensations to health care providers. Difficulty quantifying severity of symptoms like fatigue, pain, or sinus congestion. Poor historians regarding current illness and medical history.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD is significant. It is difficult to differentiate between ADHD and autism as far as inattention and executive functioning. Depression including seasonal affective disorder. It is difficult to maintain a bright outlook when unable to function in our society that rarely provides adequate accommodations. Inability to work enough hours to self-support because of disability is a source of sadness and impacts self-esteem. Anxiety-overstimulation and hypersensitivity to environmental factors like noise and light combined with slow processing of verbal commands increases anxiety. A case manager would be helpful. The health care system is difficult to navigate. Autistic people with executive dysfunction face a lot of barriers to getting mental health care.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Auditory processing is a concern. As mentioned previously, there are safety concerns with law enforcement because of slower processing and need for concrete clear directions. This is also a barrier at work and can lead to overstimulation, meltdowns, and burnout. It is hard to get slow clear directions provided as an accommodation in the entry level type jobs that autistic people often have to work like in retail or food service. Written steps with verbal reinforcement and repetition is helpful but often not provided.
What additional research is needed to help address co-occurring conditions for autistic people?	Sleep in autistic people - do sleep studies and figure out where the problem is. Mood disorders and what interventions are effective for autistic people. Effectiveness of interventions that decrease sensory overload. For example, Walmart has sensory hours from 8-10am. This is a free and easy way to make life easier but is anyone studying it? Could we have more of this in the mainstream to integrate neurodiverse people into society? What about in the workplace and schools?
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Autistic adults have limited resources and many, even those without intellectual disability, are unable to work enough to support themselves. Some have above average to high intelligence but lack executive function or struggle with sensory and communication issues in the workplace. Adults need a lot and are not getting it. I meet with other parents of adults in a support group and we are all terrified of what happens to our "kids" when we are gone. They need: -Healthcare: they should qualify for Medicare and Medicaid. It is a lifelong disability with comorbidities. Make employers allow parents to cover autistic kids over age 26 on their insurance plan as a disabled dependent. This is currently optional, it should be mandated. - Workplace support and accommodations -Housing: if the autistic person qualifies for SSI (they should and often get rejected) the housing options are very limited and require navigating a system that is difficult for persons with executive dysfunction. At best, there are group homes living with intellectually impaired individuals. This is not a good mix for autistic people due to sensory issues and self-esteem/stigma. A care manager type or navigator to help with access to health and housing services is needed badly. I am afraid we are going to see autistic adults become homeless when their

	parents die. There is no support system in place for them. They graduate high school and there is nothing for them.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increase in remote work and telehealth has been positive. Social isolation was difficult. Autistic people have trouble making and keeping friends. The pandemic made that harder.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Co-occurring physical health conditions in autistic individuals can present significant challenges. Gastrointestinal disorders may lead to discomfort and impact overall well-being. Sleep disturbances can affect quality of life and exacerbate existing challenges. Epilepsy poses additional health risks and management complexities. Sensory and motor challenges may contribute to difficulties in daily activities. Addressing these issues requires a holistic approach, considering both autism and associated physical health conditions for effective support and management.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Co-occurring mental health conditions in autistic individuals can present significant challenges. Depression and anxiety may exacerbate social difficulties and impair daily functioning. Aggressive or self-injurious behaviors can emerge, necessitating specialized interventions. Suicidality highlights the critical need for tailored mental health support for individuals on the autism spectrum. Addressing these challenges requires a comprehensive approach that considers both autism and associated mental health conditions to provide effective diagnosis and treatment.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Co-occurring conditions like learning disabilities in autism can heighten educational challenges, while developmental disabilities may affect overall adaptive functioning. Intellectual disabilities may impact cognitive abilities, requiring tailored support. Communication disabilities can hinder social interactions and the development of essential skills. Addressing these co-occurring conditions demands personalized strategies to accommodate diverse needs and promote holistic well-being in individuals on the autism spectrum.
What additional research is needed to help address co-occurring conditions for autistic people?	Additional research is crucial to better understand and address co-occurring conditions in autistic individuals. Further exploration of the underlying mechanisms linking autism and associated conditions is needed. Research focusing on effective interventions and treatments tailored to the unique needs of individuals with co-occurring conditions is essential. Additionally, studies examining the long-term impact of integrated approaches, both medical and behavioral, would contribute to improved support and outcomes. Collaborative efforts between researchers, clinicians, and the autistic community can enhance our understanding and guide the development of more targeted interventions.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Improvements in autism services should focus on: 1. Integrated Care: Enhance coordination among providers for comprehensive support. 2. Tailored Interventions: Design interventions specifically for autism and co-occurring conditions. 3. Early Detection: Improve screening to identify co-occurring conditions early for timely intervention. 4. Professional Training: Provide education for professionals to better address co-occurring conditions. 5. Family Support: Strengthen resources for families to manage challenges associated with co-occurring conditions. 6. Advocacy and Awareness: Increase public awareness to reduce stigma and enhance understanding. 7. Research Funding: Allocate resources for research on autism and co-occurring conditions for evidence-based practices. These measures aim to create a more inclusive and supportive environment for individuals with autism and co-occurring conditions.
What lasting impact has COVID-19 infection and illness had on co-	The lasting impact of COVID-19 on co-occurring physical and mental health conditions in autistic individuals is complex. Pandemic-related disruptions, such as changes in routine and limited access to services, may have

<p>occurring physical and/or mental health conditions for autistic people?</p>	<p>exacerbated challenges. Increased stress and anxiety due to uncertainties could have impacted mental health. For those with sensory sensitivities, mask-wearing and hygiene measures might have posed additional challenges. Interrupted therapies and healthcare access could have affected management of co-occurring physical conditions. Research is ongoing, but understanding and addressing these pandemic-related impacts on the well-being of autistic individuals with co-occurring conditions is crucial for targeted support and intervention.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Societal changes from the COVID-19 pandemic have brought both positive and negative impacts on the physical and mental health of autistic individuals. Positive Impacts: 1. Remote Accessibility: Increased use of telehealth has enhanced access to healthcare services, potentially benefiting those with sensory sensitivities or transportation challenges. 2. Flexible Learning and Work: Remote work and school options provide flexibility, accommodating diverse learning styles and reducing environmental stressors. 3. Reduced Sensory Overload: Decreased in-person interactions may have alleviated sensory overload for some, providing a calmer environment. Negative Impacts: 1. Disruptions in Services: Interruptions in therapies and support services could exacerbate challenges associated with co-occurring conditions. 2. Social Isolation: Reduced in-person interactions may contribute to social isolation, impacting mental health and social skills development. 3. Increased Anxiety: Uncertainty and changes in routine during the pandemic may have heightened anxiety, affecting both mental and physical well-being. Understanding these impacts is crucial for developing post-pandemic support systems that leverage positive changes while addressing challenges, ensuring a more inclusive and supportive environment for autistic individuals.</p>

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My autistic child is still very delayed and fine and gross motor skills. There is not a school close by that can truly accommodate what he will need as he continues to grow and get into elementary. The only schools that seem to be available are ABA driven and this scares me knowing that some schools are still behind and their ABA practices. My child has to take melatonin every single night in order to fall asleep.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Speaking as my son's caregiver, I worry for his future, with his mental health in regards to anxiety and depression. This runs on both sides of our family, and he is non-speaking, which will make things 100 times more difficult for someone like him. I do my best to protect and navigate for him and his future but as he continues to get older, and when he hits puberty age, this is truly frightening for me as a parent. My child when he gets excited, he can show some aggressive behavior like grabbing or biting. You can see that his body doesn't know what to do with all that energy and since he's only four now, it's still considered to be appropriate, especially being non-speaking but what's going to happen as he continues to get older? We are always redirecting, giving him access to chews and Z-vibes.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	When your child first gets a diagnosis, you get thrown all these different options for therapies but there's truly no real guidance other than the hospitals social work department and they really just give you their specific list they offer. It's not always convenient to caregivers to be driving to a hospital or maybe the waitlist is too long to get into. So you find yourself scrambling for outside resources and different therapies that are offered or maybe even school programs but really you don't know what to expect. For a child like mine, who was a toddler when he was diagnosed, it's hard to see that most other time is spent in therapies instead of with his peers. my child is what is considered to be level three and he is non-speaking, he's been in therapy for two years now, and he is only four. Although there's been some progress on his ACC (which I had to buy on our own because insurance takes too long and pushes back) it's hard to know how to fully support him when he can't communicate it. he can't say his name he wouldn't be able to tell you what his names are, or how to identify himself to others if he was lost I will not know if anyone ever lays a hand on him if I'm not around unless there's visible markings. I have to worry on a daily basis, if my child is safe on a whole different level than a typical family worries because he can't tell me if someone does something inappropriate to him or hurts him.
What additional research is needed to help address co-occurring conditions for autistic people?	How can we build a better community to support our autistic community. How can we build better public school systems to include children with higher support needs so I don't get lost in the system. how can we get more inclusion for families with autistic kids in community. For me personally, my child is perfect the way he is what worries me is the lack of resources that are truly available and not being put on wait list. Or the thousands of parents being denied Medicaid for their autistic child because they aren't "autistic enough" or have enough "behaviors". The majority of autistic people don't want any research done on how to "cure us" we just need to be seen and supported without so much pushback.
What could be improved in autism services and supports to help address co-occurring conditions for autistic	My child only could receive 60 sessions for an entire year that combined all his therapies for Speech and Occupational therapy. we are pink so much money to have insurance just to be cut off even though we are told that our

<p>people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>son needs therapy on a weekly basis. Just because you get a diagnosis doesn't mean you have access to services which is absolutely disgusting. Having to fight for your autistic child is so exhausting. We were almost denied occupational therapy, even though my child is significantly delayed in all motor skills. This would cost us \$18,000 plus out-of-pocket. How can People sleep at night, knowing that you're denying a special-needs child to help they need. Or if my child doesn't improve enough during his therapies, he can also be denied because he's not making improvements... He's autistic and insurance expects miracles to happen when he just might need more time to master skills of his peers. ABA needs to listen to the autistic community, examples no hand over hand, or bribing with food, no stopping stims -unless harmful.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>Not knowing that my child was behind because we were practicing safe social distancing, my child could've gotten help sooner, but I didn't know. It's isolating and it's defeating</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>I don't think there's anything positive that came about for COVID-19.</p>

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	For me, the most significant challenges come from sensory and motor issues associated with autism. Many spaces aren't sensory friendly or have spaces to go to if the general area is too overwhelming.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Challenges come when there isn't a good resource to help those with autism who also have these conditions. Extra time and research needs to go into how being autistic affects treatments for those conditions.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	There aren't enough resources available for those with autism who also have interpersonal struggles / other disabilities. Having resources and correct information about these disabilities can help those with autism when they need the proper care.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Equitable access is probably the thing that could be most improved on. People should be able to have services readily available to help them, without too much expense.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	More social isolation probably.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Lots of changes very quickly. Not great. Now people also think covid is the only bad virus out there, and more people are willing to get sick and others sick because they don't have covid.

Name	Anonymous
Demographic	Autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>Lack of obligatory protected accommodations that call for flexibility and alternative approaches for neurodivergent individuals without causing "undo hardships". Implementing this as a hard requirement by law rather than a formality would help functional atypical people to live both successfully and independently. Without it this can contribute to poor mental health, self-care and overall well-being. Without it we're left to figure out how we have to navigate the world with our weaknesses instead of our strengths causing major executive function disturbances and sleep disturbances on a daily basis from induced stress and anxiety. For example, some one may have to learn career skills visually, hands-on, in smaller groups or one on one. They may require direct communication an open line of communication. If the system of beliefs can change for us in these environments, especially when multitasking they may also need more time, less rigid SOPs or clear cut expectations. Understanding that while we work for quality results we also cant always read inbetween the lines. This could look like reducing the quantity of tasks juggled at once although in return we'd see an increase in the completion time and quality of resolution.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>Similar to my last response, I believe that no matter the course of treatment that it will feel fruitless in the end. Despite finding productive therapists and/or medication, we're all still very different and have a different level of autonomy. Most are intelligent and misunderstood. A lot of us are gifted and if we are given the opportunity to carryout tasks in a way that allowed us to be productive we would be able to make large contributions and perform optimally. If this was all taken into considertion, I'd be willing to bet that most of us would easily out perform others neurotypical minds. Also, it'd likely alleviate pressure from any commorbidities.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>The real question is why atypical minds are only supported when they are children? Laws make it so that schools have to offer fundemental support in their education such as an IEP or 504. As adults we are unable to obtain the support or the style of learning and communication that we need when navigating life. People are just allowed to straight up deny our needs to save some time and a dime before accessing our real potential and contribution level. I also have ADHD, depression and anxiety.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>I think advocating to allow neurodivergent people to have a voice and the support they need through out life is complimentary enough. We have our own conscious and our own wants and needs. we dont need to be studied like rodents in a lab. We simply need to be included in society.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>not forcing people who may need support in any fashion including financial to be in section 8 housing when the reality is that they may be able to and want to work and only need supplemental support.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>developmental delays in adulthood, frequent stress induced sickness.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on</p>	<p>All of it i guess. People in business managment especially retail and remote work have gotten lazy in creating solid teams with proper training while remaining inclusive.</p>

physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

Name	Anonymous
Demographic	Autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My inability to fully process my environment makes it impossible for me to be aware of my physical needs. I am so consumed by over stimulation that my physical health symptoms go unnoticed for hours, sometimes days depending on the symptoms.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Having Autism and not being treated as a child lead to significant anxiety and depression issues. Trauma added to that eventually gave me the diagnosis of BPD. It builds difficulty in processing emotions and physical sensation for life.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The inability to express my emotions, so they are internalized. Extreme need for routine and a clean space, emotional outbursts when routine is changed. Difficulty in understanding and keeping interpersonal relationships. Rumination and obsession with trying to fit in to society.
What additional research is needed to help address co-occurring conditions for autistic people?	Borderline personality disorder, dissociative symptoms, the tie to somatic experiencing and trauma processing. The negative affects of societal expectation on the neuro divergent brain. Autism rate in unhoused people 👁👁
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More access to funding for experienced and licensed staff for community mental health agencies. Behavior coaching, not ABA. Housing for the unhoused, IQ/autism screenings for the unhoused, then follow thru with stabilizing the unhoused.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Brain fog. Neurological side effects and long term difficulties with rumination about getting sick.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Big question, small box. Disruption in quality services, socializing, safety in some cases due to DV issues or abuse at home. It's made it hard to get quality people hired in community mental health, which means less therapists and more people looking to pass the time.

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gastrointestinal and sensory.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I used to self harm for years. It was sensory seeking. When I was able to stim more freely I stopped. I don't even have a desire to now that I have other options. I have a lot of anxiety due to not understanding social situations. I have a lot of depression around being a liar. Having to pretend to be allistic (for example the way I choose to stand or my vocal range). I hate being a clown performing for others but it's the safest in many situations.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I can only speak for myself but I am autistic, dyslexic and a children's librarian. English is a Frankenstein's monster of a language and it is not given enough credit for the freakish creole that it is. I would cry myself to sleep at night because there was seemingly no logic behind letters and I hated it. I wish someone told me (as I do my kids) that language is a living thing that undergoes evolution like other living things. That goose and geese are Germanic which follows a different plural logic than cat and cats, the plural of moose is not meese because moose comes from a language with no plural system and was not introduced into the English language until Europeans made contact with the Americas. That each word has a story tied to its geopolitical context not an overt logic system. I wish someone told me that I could be apart of language evolution, that language was not something that controlled me, but something I was an active participant in.
What additional research is needed to help address co-occurring conditions for autistic people?	This. To listen to autistic people. To engage with our culture. Researchers do not understand enough for a survey or even a hypothesis. There needs to be more qualitative ethnographic style data, ideally done by researchers who are autistic themselves.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I don't know if this whole "co-occurring" thing is an attempt at intersectionality, but the answer is intersectionality. If something is racist it will negatively impact autistic folks. If something is sexist it will negatively impact autistic folks. Every single person in this country is less safe without universal health care. Every single person is less safe without universal housing. I will not leave anyone behind because my safety is dependent based on the quality of life of those around me. The best way to help autistic folks is to help everyone.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Well the initial isolation was wonderful for me. I was finally able to be authentic. But I don't know if I will ever be able to get that drive back.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal	After being unmasked for so long I will never get the ability fully back. And I'm not sad about it. I'm an adult now so fewer people can hurt me. So, I will be autistic fully and unapologetically, if they have an issue with that I am confident I can get out alive. Normalization of telehealth and other non-in-person social interaction has been helpful in maintaining old connections.

changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

However it has been harder in making new ones. Physically masking was LOVELY. Goodness, getting to hide half my face me me feel so much safer. But now wearing a mask makes you a target which makes me sad. I loved not having to think about and monitor the bottom half of my face.

Name	Anonymous
Demographic	Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory challenges and motor planning issues
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, adhd, and aggression (aggression caused by anxiety)
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Speech language deficits which can lead to academic challenges, social difficulties etc
What additional research is needed to help address co-occurring conditions for autistic people?	More research needs to be conducted to find a medicine that may help an individual with co-occurring conditions like anxiety/aggression and autism - not to completely solve all challenges but in combination with other therapies (Ot, pt, speech) to help the autistic individual reach his/her full potential.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More and better Insurance coverage so all individuals have access to the adequate and right services. Many autistic individuals require lifelong intensive therapies that go beyond what insurance will approve.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It has certainly led to regression and lack of services, huge gaps in services, and delays in services. Without the right and adequate support autistic individuals lost value able time and undoubtedly there was a huge impact for many.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Disruptions of services and lack of providers, remote services which were not suitable for most autistic individuals, and lack of social interactions and experiences to work through challenges and make progress.

Name	Anonymous
Demographic	Autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	As a services coordinator for autistic children, I would say the most significant challenges is a lack of medical providers that are willing and able to treat co-occurring conditions, especially for children with autism and intellectual disabilities. Personally, my most significant challenges relate to Ehlers-Danlos Syndrome and dysautonomia (autonomic nervous system disorder).
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Autism is under-diagnosed, especially in women. It is very common for women to end up being misdiagnosed as having highly stigmatized mental illnesses such as borderline personality disorder or bipolar disorder. I was never misdiagnosed, but feel that my anxiety and depression would have been better managed had I known I was autistic.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	As a services coordinator for autistic children and teens, I see that there is a lack of mental health and substance abuse providers that can successfully treat autistic children and teens, especially those with co-occurring intellectual disabilities. My clients are often turned away from mental health and substance abuse providers and treatment centers because they are deemed to be too cognitively impacted to benefit from their services.
What additional research is needed to help address co-occurring conditions for autistic people?	Research and funding into Ehlers-Danlos Syndromes.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Services and supports are not cognitively accessible for people with significant learning disabilities or intellectual disabilities. Moreover, many services are not financially accessible to autistic people living off of SSI/SSDI or who are otherwise poor.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	As a services coordinator for autistic children and teens, I have seen a lot of clinics that treat co-occurring physical and/or mental health conditions close down, often due to a lack of funding. Thus, waiting lists for other clinics have drastically increased.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Doctors not believing autistic people's symptoms causing years of battling to get diagnoses for co-occurring conditions like EDS or POTS.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Doctors are un-educated on the current research of co-occurring mental health conditions. Many still believe ADHD and autism cannot co-occur despite the DSM-5 having been released over 10 years ago. This issue is especially prevalent in the treatment of women and girls.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Personally, communication difficulties are most challenging. I do not have additional intellectual disabilities to my knowledge, so, I cannot respond in the superlative as the prompt requests. Still, I am often misunderstood or misunderstand in ways that have caused me significant problems in the workplace or social circles. For example: failing to recognize that a boss stating "let us know if you have any ideas" somehow does not mean that they want ideas. Letting them know when I have any ideas then repeatedly being accused of wanting to destroy organizations with too much change, which inevitably leads to job loss. This is a major contributing factor of why up to 85% of adult autistic persons are unemployed.
What additional research is needed to help address co-occurring conditions for autistic people?	Research into autism generally in females is lacking, but even more so when adding the co-occurring conditions aspect. Any research on any co-occurrences in biological females would help fill that gap.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	ADA protections that address communication differences. The way the ADA is written currently, almost no existing accommodations would be reasonable from the employers perspective obviating their legal requirements to accommodate.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Co-occurring EDS body pain worsening
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increased remote work and telehealth had significant improvements for autistic people by reducing the social requirements of work, school, and healthcare access.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Having to always be on alert for anything that may trigger a physical response, in terms of GI issues.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	More often, my ADHD diagnosis overshadows my autism diagnosis and prevents others from seeing my autism diagnosis
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	In terms of learning challenges, it can be hard for me to grasp certain topics that others can get easily, leading to me failing classes, falling behind in schoolwork, and heightened stress levels
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Being able to group together certain resources while also working with an individual on their conditions as needed versus trying to limp all conditions together under an umbrella
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	The level of social anxiety since Covid personally has gone up due to the lack of interactions. I am also now feeling anxious about people that I know interacting with me.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The increase in remote learning has really put a dent in the educational habits that I have. Not being able to physically interact with the work I am doing and having to talk through a screen has removed all connections I have with my professors.

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Autoimmune diseases have been a surprise. Not something anybody mentioned as a co-occurrence. But I've noticed in the population that they frequently show up. Children were much more prone to viral illnesses as well. Frequently sick as children with asthma etc. and connective tissue disorders that can lead to some really challenging problems. And more autoimmune diseases. There's a lot that doctors don't warn you about for the future but it has been changing so much and so fast.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I think the most dangerous mental health side effect with having autism is suicidal idealization. We are one of the top group most likely to commit suicide, even as children. most parents are not warned about that. With women there's so many of us that aren't even diagnosed that we fall under the radar and nobody notices that we may be in trouble. Autistics are frequently diagnosed with PTSD. constantly failing does damage our self-esteem. If we're at a job we constantly want to make it more streamlined and easier but others want to just do it the way it's always been done. we notice when somebody says that's not the way we do that around here. It hurts as if we were hit. with children at a young age we need more help learning how to manage our emotional barrage. We don't get help with that in elementary school. And we need it. Teachers don't have the ability to handle the emotional well-being of autistic children in school settings. Every elementary school should have its own psychologist. Usually one psychologist per district. They only handle things like diagnostics. not able to handle the emotional needs of these children.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Many don't realize that they hire IQ autistics frequently have learning disabilities. We are not Sheldon. We have intellectual abilities and intellectual shortfalls. We need comprehensive testing to find our shortfalls before we are defeated emotionally. Some things we just need to be led through and not expected to figure it out for ourselves. I never saw a testing for things like dysgraphia dyscalcula. People assumed because we are smart we can't have these. But some of us do. They don't test for irlens syndrome either. It's amazing how changing background color can suddenly make reading or math easier. Fixing that can suddenly change a child from looking like a 70 IQ to 130. Common core math is an issue for us. We are much more concrete brain.
What additional research is needed to help address co-occurring conditions for autistic people?	We need to lock down the comorbidities with connective tissue disorders. So many are not being diagnosed. DNA testing is not often available for ehlers-danlos kids. And connective tissue involves arteries, veins, hearts, skin, and not just joints. We need to know when these kids have asthma. We see a lot of that. Viruses are rampant in elementary schools. And these kids are always sick with something. But they want us in school even if we're sick.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance for autistic children is a must. With mental health coverage and dental services. These children with connective tissue disorders have high pallets and issues with teeth placement that need to be addressed. Depression anxiety needs to be dealt with as young children to help prevent PTSD as they get older. Parents don't know how to deal with IEPs and 504s and rely on teachers who aren't educated in how to deal with autistic children. Half the time you have to fight even to get services.
What lasting impact has COVID-19 infection and illness had on co-	Covid has been good and bad for people with autism. It's awful for our immune systems which are not up to par. But for most of us the isolation was a relief from the constant bombarded crowded rooms and crowded

occurring physical and/or mental health conditions for autistic people?	buildings. We control sound and emotional stimulus at home much better than in an office setting.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>Gastrointestinal (GI) disorders are the most common and over-looked issue. Many times these disorders are challenging to diagnosis and therefore mean autistic individuals suffering from these health issues are unable to get treatments and medications for it. There are many reasons why it is a challenge to get these diagnosis but a big problem is the way doctors treat autistic patients. Doctors either lack knowledge about how autistic individuals can suffer from these issues, or in some cases doctors do not understand or believe that their patient is suffering GI issues because they are seen as too young, and because many autistic children can have motor challenges they are sometimes unable to explain their symptoms to their doctors. Even when the autistic individual is old enough to explain their symptoms many times they are brushed off.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>The most significant challenges tend to involve interacting with people around you. Many people particularly teachers, bosses, and those in positions of power, don't understand why autistic people have special needs and react the way they do to things. Particularly though ADHD and autism tends to be the hardest to deal with because they work mix in a way that can make anxiety, depression, and insomnia worse, and also make it harder to function in day-to-day life.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>Research on women and how autism presents in them is sorely lacking as a whole. Research on how to help teach autistic children who are high functioning but need extra help and better ways to get them to learn is necessary since many times the way that other students are taught will not be as efficient for an autistic child especially if they are suffering from anxiety, depression, ADHD, etc. Research children who are autistic and have depression is also non-existent, despite many autistic children suffering the effects of depression and anxiety as children some as young as four years old. Also understanding how autistic people think and operate is desperately needed since many systems and tests are worded in a way that makes it hard for autistic people to understand what they are being asked to do, such as this survey.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>The services available to those who have autism are lacking particularly for those who are near or below the poverty line. Autistic children require more time and money to care for because they have special needs and requirements, which can be very hard to access if you are not in the middle class, and even then it can be a struggle. On top of that many times if a family has an autistic child or relative that is unable to provide for themselves they look for a care facility that can provide said relative with all the care and support they need. However in many states in the U.S. it may take years for a spot to be available, and if a spot does open up it requires that the guardian stays in that state. However if the guardian moves to a new state then they have to start the whole process over again. Insurance has a lot of gaps in it that make it difficult to get a diagnosis of autism, and even once you have it they also make it challenging to get medication and</p>

	treatments, it can also be more expensive and harder to get too, since it is seen as a pre-existing condition because it can cause health issues.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Covid-19 both helped and harmed autistic people. It helped because those of us who suffer anxiety from social interaction didn't have to interact with people and wearing masks and the emphasis on health has helped those who suffer from a weakened immune system. However it also hurt because it made depression worse for many people and because getting Covid had long-term impacts on our health.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The increase in remote school and work has been extremely positive because it allows individuals who either suffer from social anxiety to stay home and work, while also helping those who suffer from health conditions to have flexibility in their schedule and also allow them to continue to work even when they are unable to leave their house. Reducing the social interactions has also been helpful since the anxiety of talking to people has now decreased.

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	It's difficult to make it through a a full shift at work due to my insomnia, gastrointestinal disorder and sensory overload. The lack of understanding in society and workplace of autism and mental illnesses have made those spaces unsafe for individuals like me.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Having depression, anxiety, suicidal thoughts and so much more make even the simplest of tasks such as brushing my teeth, showering, cleaning the dishes, vacuuming, etc. impossible to complete.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communicating with a nuero-typical individual is very difficult because when I believe I'm being direct an concise in my word choice they still can't understand what I'm trying to say. This misunderstanding makes getting through the interview process, ordering food at restaurants, receiving medical care and so much more impossible because we are disregarded.
What additional research is needed to help address co-occurring conditions for autistic people?	I believe that should be more research in the link between autism and drug addiction. As well as the link between autism and chronic illness
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More training on LGBTQ+ issues in autism and more education courses being accessible for autism support providers.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I have not been physically healthy for longer than a week since the COVID-19 pandemic began due to having multiple co-occurring physical and mental illnesses with autism. I've attempted to go to the doctor multiple times and each time have been sent home being told I'm 100% healthy. Then to go home and take a COVID test and test positive. Simply because these medical professionals don't listen to the symptoms I'm experiencing because I speak different than them.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I personally have liked the move to a more telehealth based approach. I have agoraphobia and prefer to have as little face to face contact with other people as possible. But, by not having access to in person medical care my health has deteriorated drastically.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory issues
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, depression from loneliness and bullying
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Learning disabilities
What additional research is needed to help address co-occurring conditions for autistic people?	I hope they research about adaptive functioning and autism because it's hard for me.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More services for adults. Programs like self direction. More mental health care. Help with navigating through systems for parents of autistic kids and for autistic adults.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It was devastating for my mental health. I was hospitalized for 4 months and lost my supports I had in place like my day program and my staff.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Allowing some services to be virtual like meeting with my case manager.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	*autoimmune disorders *gastrointestinal problems *disautonomia *how our bodies process vitamins (BH4 pathway)
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	*depression/ anxiety/ suicidality- sensory needs are not met, natural stimming behavior is "trained away", and or a lack of understanding and resources about Autism. *poor executive functioning and slow pace of life are disabling in our modern society, and there is not enough actual help or resources to be able to live life as we need. *ADHD co-occurring in a high percentage of Autistics
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	extra processing time- our world is really fast paced and this is the biggest disabling factor in my own life misunderstood learning disabilities sensory processing disorders- sensitivities
What additional research is needed to help address co-occurring conditions for autistic people?	*studying Autistic nervous systems, sensory processing, they way C-PTSD ends up affecting us because of how we are expected to disengage from our own needs in order to better fit in society/ work, etc *co-occurring physical health concerns like EDS, POTS, disautonomia *studying the BH4 pathway and how it relates to our ability to process vitamins, etc
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	*good health insurance for the myriad of co-occurring health issues *support for executive functioning- help with scheduling and staying on top of appointments *easier and better access to disability funds, and allowing us to save money for the future. (the unemployed 85% of us don't work because we can't, not because we don't want to) *requiring medical professionals in the area of Autism/ ADHD/ neurodivergence to stay up to date with new and emerging research. *easier access for all medical providers to understand new research pertaining to Autism
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	*chronic fatigue *disautonomia
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	*positive: increased remote options! In medical appointments, work, shopping, etc *negative- we all slowed down for a bit which was wonderful, but we are feeling left behind as things speed up again

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Even with 10mg of melatonin every night, sleep lasts 4 hours or so. Awake for several hours and then napping throughout daytime hours. Typical wake-sleep hours not their reality. Sound sensitivity and headphones required all day every day. Social norms not observed or followed. Autistic adults report being traumatized by ABA therapy and being forced to “mask” who they are and how they behave. They seek acceptance just as they are, with all their individuality and unconventional behavior.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Other countries recognize PDA but the U.S. does not. PDA is pathological demand avoidance. We live this every day. The more we demand, the more he retreats. If we give choices, he is more likely to engage. We struggle with anxiety more than depression and also have ADHD. We have sought out education about demand avoidance and have tried to learn new communication methods that offer more choice.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Some Autistic individuals don’t “look” disabled. Because it is an invisible disability, it is often disregarded and disrespected. We struggle in so many ways and sometimes are not believed by the public.
What additional research is needed to help address co-occurring conditions for autistic people?	Please research PDA profiles in Autism by looking to other countries and the organizations serving the PDA community. Please consider studying unconventional schooling methods for Autistic individuals. Regular schools can’t always meet their needs. Higher education desperately needs more flexibility for Autistic kids. Taking 2 years of classes in subjects that don’t interest them is a huge deterrent to pursuing college education. They can be singularly focused and need the flexibility to dive into their special interests, not being forced into societal or educational norms.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Sensory rooms everywhere possible. Just like wheelchair ramps are required for accessibility, sensory rooms need to be more commonplace. The number of individuals diagnosed with Autism is significant enough to warrant a closer look at how we accommodate them. Low lighting, low noise, a place of refuge for sensitive individuals.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	COVID-19 drastically set us back in a variety of ways. All of the ways we could force social interaction and schooling became almost impossible once everything became accessible online. He isolated himself and even now, 3 years later, is not back to where he was before the pandemic.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Once everything could be done online, it became almost impossible to get him to leave the house. I think the fear of the pandemic also did emotional damage to him. He disengaged from the few friends he had and still chooses to be alone most of the time.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory Overload - Too much stimulus caused by things such as loud cars, electronic billboards etc Hypermobility - Joints dislocate frequently and constantly, see Ehlers-Danlos Being outside and/or being around too many people can cause sensory overload and makes it harder for us to function.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, PTSD, and disassociation. These are wrapped up together, most autistic people are traumatized because society is centered around things we can not do and we are forced to interact with that. It starts as soon as you're born as most parents don't know how to parent autistic children properly
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Misunderstandings, or infantilizing us. People often assume we mean something we don't or will treat us as children. Autistic adults are adults. We are treated like we can't make decisions or are incapable of understanding things. We are fully aware people.
What additional research is needed to help address co-occurring conditions for autistic people?	Most issues are caused by overstimulation and PTSD. Please do not listen to Autism Speaks. They treat us as a plague, something to be solved when we are really just people happily existing. We just have slightly different needs but other than that are like everyone else.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Have any. Autistic support is very rare, it's a joke within the autistic community that there is no support. We need understanding. Autistic people are extremely diverse as are their needs. Many doctors have very outdated information about autistic people and never bother to learn more. This outdated information is harmful. A course for any worker in medicine whether physical or psychological should be mandatory for longer practicing people
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Covid disproportionately affects disabled people as they often have autoimmune disorders. We need to call for masking again. To do otherwise is an attack on the disabled.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Remote work, telehealth, and reduced in-person obligations are very good for autistic people as we are allowed to accommodate ourselves, and work around what our body is wanting. Uninformed people cause most of our sensory issues.

Name	Anonymous
Demographic	Autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>For a lot of us, the biggest thing is pain. Pain from gastrointestinal issues, pain from Ehlers-Danlos syndrome, pain from fibromyalgia. Secondly, would be exhaustion. Between the amount of sensory input that we experience on a daily basis that we can't easily avoid, and the comorbidity conditions that we have to deal with, they are constantly causing exhaustion. Third would be lack of knowledge. Most of the conditions associated with autism are incredibly under researched and not well known. We end up having to teach other people about our conditions in order to get help and sometimes we are simply not believed or told that because we have one they can't treat another one because it's basically just symptoms of it. Often, we have to travel long distances to find the care we need.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>Awareness. It is extremely hard to get diagnosed with autism and ADHD even though it is very clear that the rate of autism in society is much higher than anyone ever thought. And that's just those two. Having a diagnosis of those two can make it both easy and hard to get diagnosed with other things. And once again doctors do not know the rates of comorbidity of anxiety and depression to be on the lookout for it and treat it as such.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>Finding the right accommodations to fit you and then getting those implemented. It is often a fight to find accommodations that help you, and then an additional fight to get them implemented. Things like virtual learning for a hyflex environment should be an easy adaptation for those that need it, but there is great resistance from people like professors and teachers. Even the simplest of things, like adhering to accommodations such as extended time for tests or assignments are fought.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>All of it. All the research. We now know that these conditions are incredibly common in society and yet they are some of the most under researched conditions. Hypermobility Ehlers-Danlos syndrome for example is said to be possibly one in five people and yet we still don't know what causes it for sure. I have been experiencing POTS symptoms all my life and didn't know anything about it until I started exploring EDS and started talking to other patients. Conditions this common should have more information about them. Also, ABA is the most common 'treatment' for autism, yet, we know that from lots of scientific studies that it is actually trauma-causing and simply causes autistic people to be forced to mask. We don't need to be cured, but we do need to know our options and how to decrease and treat certain symptoms that may be troubling to us such as intense sensory issues, including texture and food issues. For example, there is a medication that we now know used off label in low doses helps decrease autism symptoms. Yet we don't know why, and it's not commonly known. Also, the current testing for autism is beyond outdated. It is focused on what someone call low functioning people, and specifically boys, and specifically children. More and more autistic people are getting late diagnosed and a large percentage of them are women.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services,</p>	<p>Insurance needs to cover more than just ABA. It needs to cover physical and occupational therapy for autistic people as well as new and experimental treatment. ABA has been scientifically studied to show it causes trauma and does not help and yet it is generally the only treatment covered and suggested by doctors. There also needs to be far more education for the general medical population of comorbidities. If a patient is diagnosed with</p>

insurance coverage, service systems issues, patient-provider interactions)	autism, they need to be checked for EDS and POTS and mental disorders and vice versa. Anyone being evaluated for ADHD needs to be evaluated for autism as. These should be automatic processes.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I have heard from a lot of us that we are having a hard time adjusting back into society because we lived in a place where we didn't have to mask and the sensory intolerance was lower. We have become more introverted and are having a hard time succeeding, even more than normal.

Name	Anonymous
Demographic	Autistic individual; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	As an adult with autism and attention deficit hyperactivity disorder (hereby referred to as ADHD), the most significant challenges for myself include: Sleep disturbances; prone to being overstimulated or under-stimulated, causing issues in but not limited to anxiety, increased stress, severe inconsistency with energy levels, and major depressive disorder.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Due to autistic symptoms including problems in emotional regulation, it causes a larger struggle with managing mood disorders like major depressive disorder and anxiety, often causing either longer periods of time dealing with these symptoms or more severe and intense episodes of these emotional disorders. In terms of ADHD, it increases issues with regulating stimulation and stress levels regarding the ability to keep my attention on either hyper-fixations or special interests.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The largest challenge for autistic individuals facing interpersonal difficulties or other difficulties that can co-occur with autism is a large lack of public education regarding how autism can present in individuals (i.e. an autistic individual may have an amazing talent with communication, but horrible abilities with sensory regulation, while another may be able to regulate their sensory overload but be unable to pick up on any subtext, tone, etc. in communication) and a SEVERE lack of support for autistic individuals that both keeps in mind how unique autism may appear in each person and respects the autistic individuals knowledge of themselves and symptoms.
What additional research is needed to help address co-occurring conditions for autistic people?	There needs to be research addressing what co-occurring conditions autistic people are predisposed to, the interactions between the autistic neurotype and these co-occurring conditions, as well as how different and new treatment/support plans can help different individuals with managing their autism and other conditions.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Autistic individuals need explicit protections under federal law, including an equal minimum wage, accommodations for sensory or other issues that may come up during work/school/etc., a more expansive coverage to insurance, a fundamental change in school systems to normalize existing with autistic individuals in everyday life alongside ensuring they have the support systems needed, and an extensive education system for medical providers to better understand how autism manifests in individuals and how to respect autistic people while providing the medical assistance they are entitled to.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	The sharp change in societal expectations for one being sick, the increased unpredictability and lack of communication or transparency from officials who are able to help mitigate impacts of the pandemic, and the lack of more policies to ensure safe existence in society during the pandemic (i.e. mask mandates or isolation mandates, with strict regulations for monetary or material reimbursement for any losses due to falling ill with COVID-19) has created a much more stressful and intense experience with mental health disorders such as major depressive disorder or generalized anxiety disorder.

in-person social interactions and obligations)	
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Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>It is hard to work. although workplaces are "required" to be accommodating to their employees needs, the general public is not educated enough on matters involving disability, chronic illness or empathy. my mom and I both have gastrointestinal issues. they flare up unexpectedly at times and interrupt whatever we're doing. Personally, I have to take more frequent and longer bathroom breaks when this happens. Our employers and coworkers only assume we are purposefully "slacking off". I've been harassed by other coworkers for this. my mom and i both have trouble sleeping, I am especially sensitive to noise and light, and I was diagnosed with rheumatoid arthritis at age 21. I am now discovering that I may also have lupus. we are much more sensitive to stress and it takes physical tolls on us. there have been times where i am near ready to faint or throw up at work because of the overstimulation along with. i have been unemployed for a year now. i do not have the energy nor strength for entry level jobs which all require us to be good at repetitive, strenuous, or social tasks. i am not seen as an asset to any employers. I cannot work. my mom is good at being nice to people even when they are extremely rude and condescending to her. that's one of the only reasons she has been able to work.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>having an autoimmune disease and being on the spectrum has made life hard since i was a kid. I had suicidal thoughts by age 12 and since then have struggled with depression and anxiety to this day (age 22). I have always felt stunted in terms of social etiquette and am treated as if im stupid. there is no space for me at school or at work and accommodations still do not work for me. They are more focused on lessening the burden on the people who aren't ill or who are neurotypical. all throughout highschool i was seen as a lazy student. i was diagnosed with adhd after i graduated and i couldnt even go to college because I hadn't done well in highschool. my only option was to work until something changed. I couldnt hold a job more than 3 to 6 months. I could last longer at jobs that included my interests. I became a mural arts apprentice in 2021. My attention to detail and creative direction was something that astounded my peers and supervisors. after a month i became a teaching artist and mural designer. Still, i was expected to do the same work as everyone else. i ended up burning out and since then have not been able to work much. the only other job i had after that, i was fired from for having too soft of a voice. my anxiety makes it really hard for me to hold conversations or even speak sometimes. i dont leave my house very often. I cant tell when im hungry or when im hurting. if i fill a day with necessary tasks and errands, i cant do anything for about another week.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>I have trouble processing what i hear and speaking to people. when i attended school it was hard to follow what my teachers or professors were saying. If i missed one note i would be lost for the rest of the class. i usually have to teach myself the subject at home anyway but it's very hard to be present in the moment. in hand with that comes the speech issues. i usually have to think up scripts when i expect to speak to someone. once i say what i prepared myself to say, i cant follow up with the conversation because obviously interacting with people can bring the unexpected. its so hard to get noise out of my mouth and by the time i figure it out it's to quiet or monotone for anyone to understand my words or intention. a lot of what i say sounds sarcastic or rude when I don't mean for it to.</p>

<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>There needs to be more research on women and afab people with autism and there especially needs to be more research on people of color. most of the studies we have to work on, are made on young white men. we all come from different backgrounds and what a white woman experiences with autism will absolutely be different compared to what a person of color experiences. when i got tested I was asked so many questions that barely applied to me. for example i was asked if i ever disrupted classes or got up and walked around. being raised by immigrants i was disciplined in ways that most white people are not. I wouldn't dare move from my seat as a kid (i even have trouble with it now) even if i had to use the bathroom. i dont eat bland food because in my culture we dont eat bland food. i still have comfort foods but its nothing that white people would like. white autism is different than autism in people of color.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>First there needs to be research, then education. If no one is aware of our experiences and needs, they cannot so much as sympathize for us. much less accommodate for us. People with disabilities are treated badly by our government. They put caps on how much we can earn, keeping us poor. They make it hard for us to seek treatment and to continue it. There are problems in the work environment that extend beyond accommodations for people with disabilities. There aren't even accommodations for people without disability. A lot of it boils down to stress management. I got arthritis and lupus not only because it can be genetic, but because it was triggered by stress. Not being able to take time away from work was hurting my body. Pushing myself past my limits only made me more sensitive. Not stronger. This doesn't only happen to autistic people. It happens to others without them knowing. Allowing us to live would open the door for everyone else to ask for the accommodations that they deserve and that's not something that people want to pay for. Access to healthcare, coverage for that care, job safety so that we are not discriminated against, actual work accommodations like being able to sit, take breaks, take days off work without risk of losing our jobs. There are some tasks that some of us are just not able to do. We should not be forced to make ourselves seem less able. we should be focusing on the areas where we match and even exceed the abilities of others.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>It was just another thing that triggered my autoimmune disease. I had to quit my job after getting COVID-19 because I just couldn't perform at the level I used to. I was a teaching artist for a year designing and installing murals for schools across Chicago. It was meaningful work to me. My body was my tool. It broke glass and painted walls with sparkling tile. My creativity and direction flowed like fire. No one knows that my blood is everywhere. The underpass in Englewood. The Metra stop in Belmont Cragin. The cultural center in Austin. It was less than 2 years ago but when I think about everything my hands used to be able to do, I feel so inadequate. I was made to be small and miserable. I wasn't born like that. I've been depressed for a decade and supposedly my life is just starting and "it only gets worse from here." I might not be able to open juice bottles without help but my hands and eyes are still everything to me. So what if we need a little help? That doesn't mean we're nothing. It takes about 3 minutes within meeting someone for them to know something is wrong with me. I'm too tired to hide it anymore even if that's what helps me fit in the most. I can't pretend to be like everyone else. They don't know how drained we are.</p>
<p>What lasting positive or negative impacts have societal changes due to</p>	<p>telehealth has been extremely helpful for me. there have been periods of time where i could not leave my room, but i needed help. i sometimes prefer</p>

<p>the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>therapy in person but my mental health doesnt always allow for that. i appreciate being able to wear masks in public as it helps keep me comfortable. my mouth shows a lot of my emotional reaction so i like keeping that to myself. when i was employed the mask helped to comfort me. i also have contamination ocd so im happy about the increase in sanitary practices. I've been looking for some kind of remote work but there arent a lot of entry level positions that arent focused on customer service. my anxiety continues to hinder my ability to speak well.</p>
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Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	In general, lack of knowledge. Autistics are likely to assume what they experience is typical, and this includes disabilities. They may not think a difficulty is worth mentioning. Medical professionals also are not adequately educated on comorbidities and unfortunately may dismiss any alerts. This lack of knowledge prevents diagnosis, accommodations, and/or treatment.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	There is a lack of accessible resources and support.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Effective accommodations are unknown. It's difficult to ask for accommodations when you cannot imagine what will help. It also takes time to adjust, so results can be slow.
What additional research is needed to help address co-occurring conditions for autistic people?	I would be interested if it would be beneficial to include comorbidity screening in Autism screening and testing.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	It was wonderful for many activities to move online to accommodate social distancing. Telehealth is great, but I also mean museum virtual tours, online clubs and workshops, online support groups. My Autistic child struggles with agoraphobia, so this was much appreciated. His social life actually improved.

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	There is a fear to get an actual diagnosis for autism. This means that, instead of getting proper treatment for co-occurring conditions, many autistic individuals just live with these conditions. This affects their standard of living, and could potentially become worse as time goes on. Of course, this is just an observation as someone who is around autistic individuals. I, personally, have no data to back this up. It should also be noted that people tend to not get a diagnosis because of other parts of their identity. The medical field is biased against diagnosing POC individuals and women.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The autistic people in my life are the smartest people I know. However, the current schooling system does not accommodate properly for them. They tend to be left behind when they should be far ahead.
What additional research is needed to help address co-occurring conditions for autistic people?	More research into what autism looks like in girls is critical. From my understanding, most research into the topic studies exclusively men. There should also be research into how race plays a part in getting a diagnosis and proper treatment for autism. Many autistic POC are left out of conversations surrounding autism, which leads to discrimination in diagnosing autism. In turn, this can lead to these individuals not being treated for commonly co-occurring conditions.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	In my experience, I have seen how the traditional school system has failed autistic individuals. I think that autistic individuals are seen as less than because of their autism. I think that one of the biggest things that could help autistic individuals is a change in perception. There is discrimination against autistic individuals at every level. This leads to inadequate care for co-occurring conditions.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Covid was very isolating, and a disruption to everyday life. I think the social changes for autistic individuals should be looked into.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep is a common and very impactful issue for both my son and myself. We struggle to sleep, and often wake up very early with active minds. We both tend to get sicker more often than others, and our illnesses seem to last longer. Finally, the sensory issues can trigger aggressive overstimulation.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I struggle with anxiety, which can lead to meltdowns and aggressive outbursts.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Significant! Include multi-generational studies, multiple genders, from multiple ethnicities.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	There is a lot lacking in adult diagnosis. Mental health was so stigmatized, that many missed the diagnosis, and are now living a life without all the knowledge or tools that they need to be successful.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	YOU NEED CULTURAL QUESTIONS ADDED! PERIOD! THINGS THAY HAPPEN IN A CLINICAL SETTING TO BLACK AND BROWN FOLK EFFECT THINGS IN THEIR AUTIZZY WORLD BIG TIME. FIX IT. also FREE PALESTINE! CEASEFIRE NOW!
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	CEASEFIRE NOW FREE PALESTINE END MEDICAL APARTHEID IN USA FOR NON WHITE FOLKS
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	FREE PALESTINE FREE CONGO FREE SYRIA FREE YEMEN NO MO GENOCIDE JOE! END MEDICAL APARTHEID FOR BLACK AND BROWN FOLK IN USA! FREE HEALTHCARE FOR ALL!
What additional research is needed to help address co-occurring conditions for autistic people?	Free Falestine! Stop murdering babies! You're bombing children!
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Gun laws now!
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	End medical apartheid!
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Free Falestine!

Name	Anonymous
Demographic	Autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>Sensory issues cause a multitude of problems on the day to day. It's harder to drive at night, going outside in the day tends to hurt and in turn give headaches and quickly exhaust me. Too many loud noises makes it hard to enjoy certain events. Certain things make my skin feel like I'm under attack and all of these combined together makes it hard for me to get out the house or go to work without becoming quickly overwhelmed and in turn struggling to continue the day. I have Silent Reflux, and IBS which requires that I take medication everyday to avoid extreme stomach fluctuation and issues with any random food that I may not have realized would cause a problem. I've randomly thrown up without knowing why and in turn all of these things cause my body to grow weaker and more reliant on medication. Sleep-wise, I can't even begin to describe how much it impacts my day-to-day.. I never feel like I've gotten rest and am always tired even if I get 12 hours of sleep. This leads to constant exhaustion mental and physical that make getting through my days nearly impossible. I've had many days where the best I could do was get up and go right back to sleep. In turn this creates issues with holding steady work and hoping that if I do get a good job they will be reasonable to me randomly being sick in what seems like short periods of time when things are way worse than usual.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>I have ADHD, Social Anxiety Disorder, an unknown depression disorder. I've struggled with suicidal tendencies, and aggression problems. These things have made my life extremely difficult as long as I can remember from being seen as a rebellious youth and that causing friction in my household to struggling to hold friendships because of my behaviors. Over the years, the ADHD has made it nearly impossible for me to finish school and any effort I did make took significantly longer than the average or just outright failed. While I was lucky enough to get a job in something that I've been obsessed with my entire life, it doesn't mean it's easier for me to get through the day to day. Often, I just can't hold my focus no matter how hard I try and even with medication sometime it's just an impossible task to be able to get up and do the job. It's taken me years to get my aggression under control and to stop reacting physically to things that upset me for one reason or another and even longer to understand why I would get so angry all the time. I've tried to kill myself more times than I can count and in countless ways only being lucky enough to seem to be bad at it. While, I've gotten control of my suicidal tendencies I still struggle with passive suicidal ideation and don't have a great view of life and my reason for living.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>I'm lucky enough to not have learning disabilities, but as far as communication and developmental. ADHD is a nightmare on wheels on fire, but not being able to burn to death or crash. You're just forced to take the ride and scream into the void. It affects my work, my home life, my relationships and literally every and anything else one could think of. There's literally no aspect of my life that isn't somehow affected by it. I may not even remember to use the bathroom because of what ADHD does to my mind. I'm lucky that the people I do know are somehow understanding enough to not take offense when I forget they exist. All of this is just me being lucky because I know many people with no such luck in finding peers. Communication wise, I can be socially awkward and it's very difficult to maneuver those situations. I'm not sure what is the right thing to do and I certainly struggle to understand mannerisms of other people. I've learned some of the social scripts and use those accordingly, but it doesn't always</p>

	<p>work. Humans are unfortunately only sometimes as simple as reading a book. I have alexithymia which makes it nearly impossible to truly understand what other people may be emotionally radiating and I also barely understand my own emotions. Even as I'm learning and becoming more aware of my internal feelings it's still not perfect. I still very often miss my own emotional cues and for everyone else it's pretty much out of the question.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>ADHD and Autism is a huge one. I know many people in the community and we all feel like we're navigating our own complex psychological dynamic. A lot of the things that may be 100% true for Autism alone or ADHD alone are completely not relevant for AuDHD. Some of us love being social, some of us are really good at understanding and dealing with emotions, some of us are somewhat consistent and you just never know what you'll get. They say if you've met one person with Autism you've met one person with Autism. It's the same for Autism w/ ADHD. It feels like we've got our own condition going on because of how the two interact. Other than that PDA (Pathological Demand Avoidance), I've found there's significantly more research on this outside the US and that's unfortunate because it covers a subset of Autism that many of us fit more into than the standard pieces of the spectrum. The aspect that confuses a lot of assessors even. For example, many of us who identify as PDA have people as a special interest (myself included) and have spent our entire lives studying Psychology, Sociology, Philosophy, Religion and anything else that helps us understand people. That makes us anomalies often in the Autistic communities, but we're no less Autistic.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Insurance Coverage, Accessibility of Service, Service System Issues and Patient-Provider interactions. All of these things need help. Insurance doesn't always cover Autism diagnostics and they are extremely expensive. Even if your state has a law that requires it be covered you may still need to pay out of pocket and then attempt to be reimbursed which is a miserable experience. Other than that assessment services are hard to get because if they are covered under insurance the wait time can be months, on average, and if they're not, I refer back to the exorbitant cost. Service wise systems still require too much direct human contact. There's no real reason why someone should be required to call to setup certain things. We live in a day and age where accessibility is a Federal law and in my experience, working in the tech field, there's no rational reason why we cannot extend this to those who struggle with everyday interactions. Lastly, Patient-providers should be required to have certain understandings or do certain trainings before interacting with someone suspecting they may have certain conditions. I've interacted with many providers who are just completely lackadaisical when it comes to interacting to someone who says they have Autism. It's significantly worse if they don't feel like you seem autistic. Why bother trying to get help if you know that may happen?</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services,</p>	<p>Increased remote work was the best thing that ever happened to me. It makes it much easier to hold a job and not wonder if I'll burnout and stop going. The increase in these kinds of opportunity for remote interaction and less in-person obligation has overall reduced the amount of stress that I normally feel when doing day-to-day operations. My hope is that we further improve upon our ability to do things in this manner. It allows me to</p>

increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	reduce the burden on myself and keep some of that "social battery" for attempting to interact with friends and/or hopefully make friends.
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Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>I am diagnosed with PCOS (Polycystic Ovarian Syndrome) as well as being on the Autism spectrum. This means I have cysts on my ovaries that effect my hormones, period, ovaries, weight and fertility. One of the hardest things of having a co-occurring health disorder is how awful it can be sensory wise. I am already very sensitive to textures, sounds, smells and lights, but during my period it all gets 10x worse because of my PCOS, probably because of hormone imbalances. It is difficult to find the strength to get out of bed in the morning. It is very difficult to go to work and focus on my job because I am constantly bothered by my health issues, being in pain, losing lots of blood makes me anemic. It is also difficult to be able to see a doctor, because just going to a hospital and having to speak to another person takes a lot more emotional and physical labor for me than the average person. I have to prepare a script. I have to have my boyfriend come with me in case I am too overwhelmed to speak. I want help, but I cry whenever i am frustrated or confused. Doctors don't take me seriously because I am overly emotional, but they don't realize how scary it can be for an autistic person.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>On top of ASD, I am diagnosed with BPD (Borderline Personality Disorder) as well as DPDR (Depersonalization Derealization disorder), both stemming from traumatic experiences. I have been working hard to improve myself, but i have mostly had to do this on my own. I have been to many doctors and therapists and tried many mental health drugs, but I don't feel I am really taken seriously by doctors, especially after I disclose i am a diagnosed autistic. I feel as though I either get "babied" by doctors, who don't take me seriously that I have BPD, or the other way around, where I am treated like just another "crazy" woman and am making up having autism for attention. There is so much stigma regarding BPD even in hospital and mental health settings as well as autism and stereotyping. All I want is help, not judgement...</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>I struggle with reading as well as struggling greatly with math. I was in special programs as a child to help me, but the training for special education teachers has to be atrocious with the way me and my classmates were treated. Every autistic person I know has a horror story to share about life in special education. Being locked in "time out rooms" which were really dark closets, being screamed at for simply stimming or talking, being forced to sit and watch the same movies all the time instead of being taught anything. We are not lost causes! Just because i don't learn the same way others do, doesn't mean i don't deserve to learn at all. Even those of us who don't speak still understand. We crave learning. We just need teachers who care to teach us.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>I think we should research more on autistic Women, and autistic adults (also specifically women.) Autism can look different for us because we grow up with more pressure to blend in and be nice. This pressure can make our masking skills very good, which can hide our symptoms to others, leaving us in the dark about who we really are. I grew up thinking I was naturally stupid, and felt so much shame about myself because on the inside, I felt so different to everyone else. I didn't know what was wrong with me, just that something was. I was severely bullied in school for being Autistic, but didn't actually get diagnosed until I graduated early due to the bullying. If autism wasn't seen as a "boy's disorder", maybe I would have felt the relief i felt when i was diagnosed much sooner. I felt like a weight was lifted from me, that nothing was "wrong" with me, i am just Autistic.</p>

<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Insurance coverage! Therapy for autistic people is way too expensive! Providers also need to have more time spent with autistic adults!</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The unique barriers to seeking long term treatment for any condition in adults. Adult autistic folks, based on my experience, find the process of managing health care overwhelming and are less likely to pursue, start or stick with treatment plans. Aside from a general skepticism I think many autistic adults feel toward the industrial medical complex.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Because we are not so great at picking up signals including ones from our own bodies, we often don't recognize symptoms of mental health conditions. Lack of diagnosis and cynicism over diagnosis probably are the biggest factors in sustained mental health issues.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I chafe at the language used here. Autistic folks learn differently. yes. But is that a disability or just difference? Personally, I learned very slowly but once I finally got a concept. I really 'got it' to a depth beyond many others who 'learned' it faster. People said that was a disability. I disagree and at 50 years old I feel I've surpassed many of those 'normal' learners.
What additional research is needed to help address co-occurring conditions for autistic people?	It's not about any one co-condition. It about the support to identify them and the rigorous science around treatment that will satisfy the most literal, logical, and cynical person And the patience and time of the care giver to explain and listen and explain again.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I've hit on this as the primary challenge already. The whole system is not geared for people who need help identifying their own symptoms, who learn slowly and are less inclined to just 'do' what they are told as opposed to understanding thoroughly and agreeing to the course of treatment which takes longer and requires more patience from the provider. Don't get me started on insurance but that is a nightmare for anyone especially those easily overwhelmed. I suspect we pay more for health care cuz we give up or don't contest mistakes.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Personally covid led to many improvements. Previously overwhelming tasks like grocery shopping are now easily done online. Exhausting days in the office remembering to look up and smile are now working from home days. Video calls are awesome cuz I can see my face and modulate my expression in real time. And the emergence of tele-health has helped me diagnose a thyroid issue impacting my physical and mental health. Life is better than ever.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Oh, I answered this in the last question but the online world has been a boon. Online shopping, working, health care all reduce the anxiety of crowds, interactions and other ick. And I love video calls cuz I can see my face and adjust quickly.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory issues are by far my greatest and most apparent condition. It has made it difficult to get most daily tasks outside of the home done due to repetitive meltdowns. Grocery stores are far too loud, bright, and packed. By my senior year of highschool it was too overwhelming for me to make it through the day most of the time, I would end up so exhausted I would have to go home due to the pain and exhaustion. I also experience dietary restrictions due to sensory issues which makes it harder to stay healthy.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have depression, anxiety, and ADHD along with my autism which leads to extreme emotional instability that makes it excessively harder to function throughout the day. It makes it hard to be social. I have felt suicidal and used to cut myself in the past. Relating to self-harm, meltdowns often lead to repetitive self-injuring behaviors as attempts at regulation such as hitting myself and biting myself enough to leave bruises.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I have Dyscalculia and ADHD which makes it hard to focus and learn the way that others do. I find myself knowing information but not having the confidence to recall said information when it's asked of me, and my Dyscalculia has gotten me fired from workspaces before for being unable to reliably do basic treasury functions.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Personally, I didn't have the language, let alone the professional help or accommodations, to function with my autism for the majority of my life. Accommodations for autism aren't accessible in most places in the most places in this country what-so-ever. In addition, there's tons of resources and organizations that work actively against what would serve the autistic community. Tons of proven to be ineffective and harmful charities and therapy options, often targeted towards young children, are what's pushed to the forefront of Autism discussion and treatment. I think the way we discuss and navigate autism, as a result, must radically change and evolve as our understanding of Autism does as well.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I think the simply the period of quarantine offered a period to reflect. That alone shifted the perspective on autism a lot. The world has learned a lot about autism in the time we had to spend inside, and subsequently autistic people learned a lot about themselves. Being in the safety of our own homes for months taught us how to properly accommodate our own needs, and for some we learned that we may have needs greater than we knew that we were completely neglecting. We learned how to listen and work with our brains and our bodies when we were given time off to process and recalibrate.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I have 16 diagnosed conditions that affect nearly every system in my body. This has made it incredibly difficult to receive an autism diagnosis because every computerized test marks me as "malingering." These supplemental tools are a hinderance to autistic individuals with physical health conditions because they were not created with this possibility in mind. I am unable to work or participate in most activities I once previously enjoyed as my health has declined over time since I have been required to to work through any physical discomfort. Due to taking rules and instructions literally, as is notable in autistic individuals, I pushed my health to the point of no return. Not only is it difficult to navigate our society with physical health conditions, having autism on top of that makes our systems incredibly inhospitable for me and causes significant distress on a daily level.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have both autism and ADHD which can cause a distressing dichotomy. It often feels as if my brain is at war with itself and it is exhausting. I also experience self-injurious behavior in the form of skin picking caused by anxiety or OCD-like intrusive thoughts. The feeling of something "wrong" on my body like a bump or a flake can cause great distress until I can't control my actions. I also have been diagnosed with depression since a very young age that I only recently have realized, along with my doctors, was in reality a response to being undiagnosed autistic. The fundamental misunderstanding that we have of autism and subsequent ignorance of the neurotype caused me so much distress in my formative years that it led to suicidal ideation. It is not my autism that causes me distress, it is the systems around me that led me to believe I was fundamentally flawed.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I did not realize I was dyslexic or had dyscalculia until I was an adult and out of schooling. Once again caused by a fundamental misunderstanding by doctors and teachers that leaves many outside of the support systems we do have. The tendency to blame the child for difficulties instead of working with and learning from them causes incredible trauma on developing brains. Nonverbal support and understanding is minimal, especially when someone experiences it only some of the time. Suddenly shutting down and not being able to speak or only being able to speak with great effort is often turned against the person experiencing that distress as having behavior problems instead of empathizing with the situation.
What additional research is needed to help address co-occurring conditions for autistic people?	Understand that autism and co-occurring conditions are not a monolith. Each person (both children AND ADULTS) experience their own version of difficulties even if there are lots of similarities between them. Research to "prevent" autism is gross and ignores those of us who are currently living in a world that doesn't want us. Research the effects of growing up undiagnosed. Research autistic adults in the workplace and how social structures tend to alienate and exclude autistic adolescents and adults. Research the nervous system and common dysfunction of systems like the autonomic nervous system and how it could be related to the nervous system of autistic individuals. Why are we more likely to experience physical health issues such as neurological damage and autoimmune diseases? Relate it to the trauma we all experience as children and how it affects our health in the long run. Research why our society is fundamentally traumatic to autistic individuals and why so many "autistic traits" are traits of cPTSD.
What could be improved in autism services and supports to help address co-occurring conditions for autistic	It is incredibly difficult to find affordable healthcare for those of us with both autism and physical health conditions. Autism testing excludes the possibility that the patient could also have physical health conditions.

<p>people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Accessible spaces or entrances often don't have clear instructions or require calling ahead to request access which in turn makes it harder for those who may have difficulty speaking or making calls. It makes it harder for those of us who need clear instructions, have memory issues, or have difficulty completing tasks on a deadline. Having access issues already addressed that doesn't require waiting for the key to a bathroom (as many autistic individuals have trouble determining when they need to go) or waiting for a ramp to be put down would be better. If these accessibility needs were already integrated without having to "request" them, it would make navigating the world a lot easier for us.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>It makes health issues worse. We have known this for a long time and disabled individuals warned of the increase in disabled individuals that would occur from a virus that damages the nervous system and our government support systems are not equipped to handle it. Add on to it the fact that many autistic individuals find wearing masks to be difficult or even painful, it puts us at a greater risk of catching this virus and thus more at risk of developing COVID-related health issues. Treating this pandemic as if it is over and done with was the worst decision we could have made in these circumstances and it has made it very clear to us that the health and well-being of the citizens is not more important than the money we could possibly bring in as a workforce. Good luck paying for the social security of all the newly disabled folks that could have been prevented. Congrats. You got what you wanted.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>I can only speak on what I have personally experienced. Increased access to telehealth and remote work has helped me access more of the world. However, because we have access to the world through the internet, autistic individuals with justice sensitivity have been incredibly active in social movements like speaking up against our government's funding of Israel's genocide against Palestine. We have been active in speaking up against our government's treatment of disabled individuals. We have been active in speaking up against our government's treatment of Natives and other racial minorities. We have been active in speaking up against our government's horribly outdated systems, including both governing and schooling systems and because we experience great physical and emotional distress at injustices we will continue to speak up on issues like this. We are more physically separate from each other but more socially connected than ever and many of us wish to change things for the betterment of everyone.</p>

Name	Anonymous
Demographic	Autistic individual; Researcher
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>For me specifically, gastrointestinal disorders lead to nausea which leads to syncope episodes that may still be listed as epilepsy. I have to always be prepared for fainting episodes, and make sure that I am surrounded by those who will respect my wishes when I do faint. I have never slept "normally" and often end up in a cycle of awake in the evening, and fatigued all day. I also suffered from sleep paralysis during many transitional periods in my life, I am sure due to the unique challenges I face and how stress inducing it can be. I am highly sensitive to many external stimuli, especially light sensitivity, sound and volume sensitivity, misophonia or a sensitivity to chewing sounds and repetitive noises, as well as something that shows up similar to contamination OCD. These sensitivities come with intense skin reactions that appear more like an autoimmune disorder. I am also frequently bruised because of "clumsiness" and at age 16 I had surgery on both of my legs due to mobility issues and misalignment when growing.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>I must first list depression, as this is the number one mental health condition that seems to follow my entire life. I believe it stems from the exhaustion of never feeling normal, not accepted despite all my efforts, and my own intense standards placed on myself. I was also frequently isolated, as family did not understand my sensitivities for most of my life. As an adult woman now, I have always "hidden in plain sight," causing emotional distress throughout my entire life. I have always appeared to have "social anxiety" but my Dr. now calls this stage fright, from the performative nature of my outward personality. I have difficulties learning and focusing, but an intense need to learn which causes inner turmoil. I have never been aggressive, however as a teenager I struggled with suicidal tendencies and self-injurious behaviors, as I knew something felt wrong in me. Most people subconsciously try to protect me or shelter me from the world, which causes isolation. Mental stressors cause a great deal of havoc on my body, and I also can fall into executive dysfunction often. I work in the beauty industry because I try to hide this struggle, which in turn causes inner turmoil. Feeling incapable of holding a job, even when I am holding a job, is mentally taxing. I know that I have much to offer, but I am held back by this struggles.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>I struggle to communicate and always have. I look like someone who would not struggle, so I often appear rude, standoffish, or too confident. These are values I despise, so I become anxious when I am aware of this which is often when communicating vocally. I have always hidden my learning disabilities, but I know that due to my age and how public schooling was, I was separated as a "gifted student" which did offer me a chance to learn deeper in small groups, and that helps. I often can not focus or learn when being watched, and I can not perform as much as I know is possible when in a competitive environment. I do often feel developmentally delayed, but I have always hidden that. However, as I grow into adulthood I find new difficulties with every transitional period. I do not complete tasks as quickly as others, and I do not complete major life decisions in the time it seems I should. For example, I am not able to drive or get my drivers license.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>I feel that autism in women, and late-diagnosed women is extremely important. Because of the inherent need for women and girls in our current society to conform and perform, it is an easy skill for them to suppress or hide their challenges. Women also are easily convinced to shrink their needs, and again suppress them. Because of this, I have learned to hide very well, and even convinced myself for much of my life that nothing was wrong.</p>

	<p>There is research needed into high-masking individuals, because we are not seen. Even my Dr. claimed I could not have autism, because I made eye contact with him. We can make eye contact, that's absurd. I make eye contact because I know I am supposed to, even though I do not want to. Research is needed in identifying and helping such individuals who can mask sufficiently for long periods of time.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>I think education and accessible information on the vastness of autism is important. We can hope that this will help non-autistic people to better understand what it is like internally. Insurance coverage may also be helpful, as I often avoid medical assistance due to the cost. For example, I need to warn anyone around me to not call for an ambulance if I faint, because I can not constantly afford that bill.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>There are many lasting impacts, as I fear infection constantly. I have had COVID confirmed one time, and I was healed, however it can be difficult for me to know if I have suffered long term symptoms. Mental health has greatly decreased, as I am trying to re-enter the workforce and in-person spaces.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>I think that isolation offered me an increase in mental health, as it felt like everyone was feeling how I have always felt. Remote work does not work well for me however, as routine is important and executive functioning has decreased. I have also noticed something that may be referred to as skill regression, as I can not grasp the personality or performances that I could accomplish before the pandemic. Because I can not drive, the increase in food and grocery delivery services have changed my life, as I can not yet afford to live in a walkable city. Telehealth is not something I think I would ever use, instead I choose the stress of in person appointments, as I know I can mask my symptoms easier through the phone or video call. Reduced obligations seemed to save my life, but now I have trouble rebuilding my resilience to obligations and tasks. I also struggle to rebuild any coping mechanisms that helped me get through over stimulation. I did successfully graduate from university in 2021, fully online, however it was much harder than I ever thought it would be. I successfully completed trade school after, as I sought out more guided education to keep myself in line, however I found I was no longer able to mask as I was used to, and I was noticed as very different.</p>

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Myself and my father (now deceased) have always had sleep disturbances. He was unable to fall asleep without medication, and even then, was not able to stay asleep for longer than a couple hours. I typically only sleep in one-three hour bursts throughout the night. My father and my sister both had childhood epilepsy which was under control post puberty. I was diagnosed with celiac disease, postural orthostatic tachycardia syndrome, and ehlers danlos syndrome. Myself and my father have extremely weak joints especially in the knees requiring reconstructive surgery.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have combined type ADHD and a lot of anger issues, the latter likely stemming from childhood trauma. I also struggle severely with depression and anxiety, especially relating to the symptoms of my autism because I feel isolated/disconnected/incapable in comparison to non autistic people. My father had bipolar disorder and spent most of his adult life in active addiction. Both my father and I always struggled with skin picking.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I struggle to process new information that I hear, as it's very difficult for me to register the individual sounds as complete words. I also struggle to interpret vague or broad statements which could have multiple meanings and get into conflict because I don't understand what the other person is trying to communicate to me.
What additional research is needed to help address co-occurring conditions for autistic people?	Autism and PTSD. Myself and most autistic people I know suffer from ptsd. I wonder if autistic people may be more susceptible to developing ptsd or if the world is more traumatic to autistic people.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Access to diagnostic, supportive, and therapeutic intervention for adults
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	It has been very difficult to readjust to post-covid society. The disruption of life as we know it caused myself and many of my autistic friends severe mental distress and depression, which many of us have never recovered from. The lack of support for autistic people during lockdowns has caused lasting impacts on our ability to operate out in the world, especially for those who were in a period of critical development at the time

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Dysregulated Immune System and not being able to stay healthy. Ehlers Danlos and chronic fatigue and not having proper accommodations like extra sick days from my job as a public school teacher.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	All of the above.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I need extra time to complete tasks and my workplace closes early so always feel so much pressure to try to beat the clock. I benefit from direct and literal communication, most people do not communicate this way and am regularly confused by people. I also need space to be curious and ask loads of questions without being perceived as questioning authority. Due to how I communicate my directness has been viewed as insubordinate and had many issues staying employed in corporate settings.
What additional research is needed to help address co-occurring conditions for autistic people?	Research late realized/ diagnosed autistic folks who identify as women of color.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Universal healthcare so we can access the care we need without fearing for how we will pay for it. Help us get and retain employment which will allow us the conditions to survive capitalism.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I am constantly sick. I am healthy for 2-3 days and then am sick again. Chronic fatigue creates barriers to access my social support/ activities.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I am hypermobile, and because of a lack of interoception (the ability to sense internal signs from the body) i do not know when i am hurting myself by sitting on my joints in ways that could cause great problems down the line. i do not have this but my friends with autism all have sleep disorders/disturbances of some variety, constantly waking up at night and other problems. sensory issues are a huge part of why i cant do certain things, i had to quit a test i had for school cus the brightness of the room we took it in. i wear headphones constantly to help with noise
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have adhd, anxiety, mild depression, paranoia, and trauma associated with being autistic. Anxiety is the one that gives me the most issue, i cannot walk outside without panic. talking to people is something that takes 15 minuets to recover from and it stacks up every person i talk to.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	i could not multiply till i was in middle school. i have some dyslexia, and have difficulty reading even if i enjoy it a lot. i did well in school because i have good pattern recognition, and can use logic to make assumptions about the answer to questions, this was not good for me in the long run, because i never received accommodations or aid so my mental health suffered even if i could get by.
What additional research is needed to help address co-occurring conditions for autistic people?	research about how trauma effects autism would be useful. A lot of autistic people talk about how we cant separate our autism from our trauma, and it would be nice to learn about,
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	i would like for therapists and (some) doctors to not treat me like a child when i tell them i have autism
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Chronic fatigue means that the autistic individual, who needs more time to handle managing everyday life tasks, has even less awake time during the day to take care of the admin of life, from personal hygiene to keeping up with home repairs. Without significant support for the everyday tasks, there's little time to improve in any other area of life, including interpersonal relationships, which, for an autistic person, is difficult without time and energy constraints. Not having a safety net of relationships makes the person more vulnerable to other unfavorable outcomes, including domestic abuse.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Finding appropriate interventions for an autistic person can be very difficult. Their brains work differently enough that standard protocols need adjusting to prevent the autistic person could be harmed. Depression is common, but shouldn't be confused with autistic burnout.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication differences cause a lot of misunderstanding and mistrust as does having spikey skill sets. Being good at one skill and bad at a related skill can look like trying in the one case and not trying in the other, but the autistic person is trying and trying harder. Executive dysfunction is a huge problem. Without significant support, the autistic person may not be able to make or enact long term plans.
What additional research is needed to help address co-occurring conditions for autistic people?	There needs to be a better bridge between the autistic patient and their medical team for communicating about their co-occurring conditions. The pain scale 1-10 is notoriously confusing to an autistic person, so even just starting there might lead to better communication and better outcomes.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Universal healthcare, universal basic income, autism services for adults with all levels of autism, more autism education for service providers, less pressure and more pay for all medical staff, so they feel allowed to take longer to communicate with patients of varying needs
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Like most things, autistic people are experiencing the same difficulties as non-autistic people, but with more intensity and more frequency.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Having less pressure to attend in person events was positive. Services moving online was good. The pressure of the pandemic on people in general has made society as a whole less patient, less forgiving and more hostile, which affects autistic people disproportionately. The closing of smaller independent businesses and constant merging of larger companies leaves fewer to no employment opportunities for autistic people who need a little job in a little shop to get by.

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Some of the most common issues are comorbidities of connective tissue disorders, Ehlers-Danlos being the most common categorization, which causes widespread issues often misattributed solely to Autism without further medical evaluation. EDS is often the etiological baseline for GI Issues, autonomic dysfunction and dysregulation, as well as sleep disturbances, and autoimmune dysfunctions and disorders. The comorbidity of EDS with autism needs further evaluation and further study to correctly address the systemic concerns that present with this disorder, particularly in the autistic community.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The most challenging aspects are those that involve the schizoid or schizophrenic-type elements, for those who demonstrate that pattern of autistic overlap. These are disabling at a level that often prevents any kind of typical functionality. For those who do not have that symptom cluster, the comorbidity of ADHD and insufficient treatments related to it often become the most challenging. The lack of sufficient research of the patterns present in comorbid Autistic/ADHD patients when there is up to a 50% rate of comorbidity is near criminal. Undiagnosed, Untreated, and Under-treated ADHD is often what feeds into resistant "depression" and other forms of self-harm. Far too many clinicians still believe that people identifying ASD/ADHD is more of a fad or that you can only have one or the other and refuse to diagnose both despite the clear presence of both conditions.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication disabilities are often the hardest. It is often not just a measure of fluency in a language, whether written or oral, but that the way in which the autistic mind processes and uses language often demonstrates a systemic difference in categorization and clustering of language. As a PhD student in psychology, I can communicate at a very high level: Yet, I am often misunderstood in common contexts of communication due to the fact that my Autism does not encode implicit social implications and symbolism from the enculturated baselines that are standard within allistic communication patterns. As such, my intended meaning is often distorted through the translation and implicit social attributions that are interpreted by an allistic listener.
What additional research is needed to help address co-occurring conditions for autistic people?	We need further research to assist in generating profiles of what comorbidity patterns show up and provide doctors and therapists protocols of evaluation for both physical and mental health conditions upon suspecting any of the cluster of disorders with high comorbidity. For example: Suspecting Autism should immediately come with physical evaluations for hypermobility and connective tissue disorders like EDS, allergy testing, and for mental health conditions that are commonly comorbid. This also means more research to see how comorbidity alters presentation of single disorders, as there is a desperate need to have clinicians understand how something like ADHD might mask symptoms of Autism, particularly in low support need patients.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Accessing any services is a nightmare for anyone with autism, either as a parent or as a patient. The arbitrary forms and various levels of bureaucracy make accessing the very things we need almost entirely inaccessible by virtue of what we struggle with. Beyond that adult services outside the most extreme cases of complete disability with another caregiver need to exist. Services to help people fill out forms, services to help people navigate bureaucratic processes, to understand and gain help in the job search and application processes. Many of us live on our own, have families, and

	<p>otherwise are functioning adults who are endlessly burning out because there are zero supports for anyone who "looks functional" on a surface level. Asking for help filling out "simple" forms and melting down due to overload when you are a PhD student is something that you get laughed at for. Beyond this, navigating the healthcare system with two disabled children who are autistic and have health issues is a nightmare for even a neurotypical parent. I do this as an autistic ADHD parent with disabilities. Yet I am distrusted by professionals to accurately report about my children the moment I disclose my diagnoses to them. The lack of education about autism beyond stereotypes within both the medical and psychological fields is appalling.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>My chronic health issues worsened significantly from Covid-19. My children both had Covid as well: One developed significant schizoid traits in that timeframe after their first time having Covid; The other developed Tourettes after having Covid. From what I have seen in the wider community, many of us have had worsening mental health outcomes due to significant disruptions in our lives as well as the virus itself causing a significant worsening of neurological symptoms, autonomic dysfunctions, GI issues, and autoimmune disorders.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>The increased use of electronic options has been a mixed blessing. The option for Telehealth, for more online schooling, for online work options, and other similar baselines have helped me and many of my autistic friends and family. Our ability to engage the world digitally while controlling for our environment and adapting for our disabilities has been a massive improvement for many of us. Yet, the downsides have been that the increased fear in the world due to the pandemic and consistent social isolation have significantly reduced our ability to tolerate a lot of the environmental factors we previously had habituated to. This has increased a lot of overall anxiety, agoraphobia, fear of germs, and has lowered many of our abilities to effectively "mask" and engage in social niceties like we could prior to covid-19.</p>

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The trauma of being put in behavioral therapies that force you to mask your autistic traits. Pretending to be non-autistic can lead to severe anxiety and depression, and we need a serious look into the emotional health of those who received ABA as children.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	The link between masking of one's autistic traits, and anxiety/depression.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	The ability to make appointments through text message. Simplified wording on insurance and intake forms Greater understanding of what trauma can look like in autistic people Coverage of therapies besides ABA (such as speech, OT, etc.)
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	One positive change is the increase in telehealth and remote work. I hope those two things are here to stay. Not being able to see my friends IRL was hard on my mental health though.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Hypermobility Ehlers Danlos Syndrome and Dyspraxia
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Anxiety, PTSD, self injurious behavior, suicidality, substance abuse disorder
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	ADHD
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Mental health and well-being as well as identification and diagnosis.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Agoraphobia
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Lessened anxiety by working from home. Less likely to get sick working from home. Increased use of telehealth. Reduced in person interactions.

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sleep apnea has been debilitating at times, and took a long time to diagnose because as an autistic person, interception is limited, so it was difficult for me to discover cause and effect of the tiredness I felt for years. Sensory challenges make work and home life extremely difficult. Gastrointestinal challenges make relationships difficult, because it's hard to tell if I'm just experiencing the discomfort of digestion, or distress due to communication challenges (again, interception challenges and difficulty identifying cause and effect.)
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I don't experience these so much as just co-occurring, but as a result of living with autism for almost 40 years. Depression comes from the experience of always being misunderstood, having difficulty starting and maintaining connection, and things keep going wrong because you don't understand how things work.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Too many to include even a fraction here... This summer I went to the emergency room for a neck injury and because I was in so much pain, I lost my ability to speak. But I was crying and looked "hysterical" to the doctors and nurses. They gave me anti anxiety meds which did not help. What I needed was X-rays and treatment for my neck. Because people don't understand autism, they misread us as having mood disorders or being irrational, but really our needs are valid.
What additional research is needed to help address co-occurring conditions for autistic people?	We need to parse out a lot of details. First of all, make sure autistic people are involved in the leadership of any study about us, or there will be misinterpretations by the allistic people who are looking at us from the outside. Second, look at how much misdiagnosis of borderline and of bipolar are done to autistic people who don't have those disorders, but are misinterpreted in our behavior. We are confused and having difficulty expressing ourselves, so they believe they know what's going on inside when actually they just need to better understand autism. We also need more studies about how some ADHD meds like amphetamines can cause agitation and destroy the lives of autistic people. We have trouble communicating with the doctor about our symptoms, and connecting them to the meds. But this time I kept a spreadsheet and over the course of months it was clear that Vyvanse was making me not myself, I felt aggression and self harm, and anxiety like never before. Apparently there are limited studies about autistic people experiencing this, but we need more doctors to know about it and more studies, so people like me don't literally have our lives torn apart by "trying ADHD meds".
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Providers in general just know nothing about autism. As an autistic person seeking support from therapists and doctors, they have done massive damage to me because of their assumptions of what's needed, when what's needed for an autistic person is vastly different. The interventions designed for allistic people, when applied to us, harm us. Please educate all providers about how autism looks and what we need. For example, EMDR can be damaging if it becomes a type of exposure therapy, because many autistic people can't habituate. So instead of improving symptoms, it can worsen symptoms.
What lasting impact has COVID-19 infection and illness had on co-	Isolation during the pandemic was unbearably destructive. Public health responses should understand isolation is just as deadly as a virus, and be

occurring physical and/or mental health conditions for autistic people?	mindful of that in future interventions. (I am both autistic and a public health practitioner)
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Remote and hybrid work is life saving.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I don't like that. This question is phrased for individuals to speak for all autistic people. All autistic people are not the same and that needs to be recognized and it is harmful regardless of intention to ask when autistic person to speak for all autistic people. In my personal experience, the most significant challenge of having co-occurring physical health conditions as an autistic person is not being able to afford care that I know would help me. We can't get care for everything, but for the things that are physically accessible to us, it's important for them to be financially accessible as well. There's not enough financial protection for autistic people, especially those with co-morbidities
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The most significant challenge as a result of co-occurring mental health conditions that I experience as an individual autistic person is more so reflective of the amount of education and protections given in society to autistic people. Our country could do a lot better about educating people on the experiences of disabled people and people with autism so that we don't enter into unsafe environments because no one thought to consider helping people learn about what it's like to exist in a body that behaves like mine. This would help people give better accommodations for things that can't be changed
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	I wish that people would actually ask actually autistic people including self-diagnose autistic people what their experiences are and take it at face value cross-reference that data and actually do something to implement strategies that we know are likely to work. I don't think it's helpful to probe autistic people for more questions about autism and then not use the information in a way that actually supports us.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Literally everything. I got diagnosed two years ago and It should be a standard of care to give resources for people who are self-diagnosed or formerly diagnosed so that they can actually understand how to accommodate themselves and help themselves past a piece of paper saying that some individual with a bunch of experience says that you're not crazy. This stuff is actually happening to you. More financially accessible services and protections are always hopeful. We do not have enough currently.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	

in-person social interactions and obligations)	
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Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	POTS, this condition is well known to occur in neurodivergent individuals and women. It is grossly under diagnosed and has no cure. Physicians need more training in how to detect it and specialists need to learn how to not blame the symptoms of POTS on anxiety. A patient will see on average 7-10 doctors before receiving a diagnosis.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Suicide is a huge issue. Right now the average age of mortality is 30 years. Between autistic burnout to social isolation we are under supported and made to feel like aliens that are not good enough to exist in this world.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Social anxiety caused by autism is huge! People can just pick us out and it feels like I'm in a full performance of a play, but i missed every rehearsal and no one gave me a script. It's like there are rules for everyone but they only apply to me and I don't even know what they are. I want to have friends but no one wants to be my friend. I am constantly on guard for any social rule I might be breaking. But it makes me even more insecure and unlikeable. I wish that when I meet people for the first time I could say, "Hi my name is, blank, and I have autism." Then they would know I'm a bit different and then they might be able to make any adjustments for how they interact with me.
What additional research is needed to help address co-occurring conditions for autistic people?	We need more research on ME/CFS and long covid. It is well known people with autism are more likely to get these two conditions and they are grossly under researched and embarrassingly denied by members of the medical community. People are dying from lack of treatment. We also need research on the presentations of autism in females and changing the education of our teachers and anyone interacting with children so that they are not just taught the stereotypical form of autism. Unmasking and how to is so important. Masking leads to burnout which leads to disability which leads to the inability to work which requires more supportive resources. We also need research on how to diagnose autism. A lot of autistic people are very unhappy with how the process is not even made autistic friendly, like asking questions that are unclear or unnecessary and play to a stereotype.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	We need more supports for caregivers of autistic people. Caregivers can become isolated and overworked. It's not good for the parent or the child. We need better treatments that are not ABA therapy. It is often abusive and basically just teaching a child to suppress their autism rather than how to cope or manage it. We need to end the abuse that happens to autistic people in mental institutions. We need better support for those who are higher functioning autistic. Such as classes on how to socialize. This should be content found in a communications class in college. This is the study of how to have relationships with other humans! We also need to better educate students about how to treat autistic people. Because people often ostracize us without even telling us what we are doing wrong. We need more support in the workplace. Such as training for how to work with people

	<p>who have autism. Such as being specific and clear on how a task should be done.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>Yes. Like mentioned before autistic people are more likely to get LC and ME/CFS and dysautonomia. COVID has killed 6million people this year but it has taken the livelihoods of so many more. There are no treatments for LC and ME/CFS. People are dying because of it. Because physicians are not educated in and some don't even believe in these conditions patients are told they are just anxious or lazy. They go undiagnosed and miss access to treatment. It is imperative to do research on these conditions as it directly impacts many autistics.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	

Name	Anonymous
Demographic	Autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Managing co-occurring conditions can become a game of whack-a-mole, where you only have the energy to manage some symptoms at a time, leading whatever does not have your focus to become worse until you must direct your attention towards it. This is exhausting and pulls energy away from external responsibilities and self-maintenance.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	When it feels like you can not possibly manage ALL of the things wrong with you, managing anything can be discouraging. Being suicidal in particular, encourages you to ignore problems rather than work towards solutions that are kind to yourself. Also, many people do not believe you if you have "too many" things happening. Which can socially isolate you further. Many times, autistic people need change in structure or expectations, not to change their own behavior, and this is often not an option and can make mental health challenges more difficult.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I do not personally experience this but as a special education worker, I witness autistic students with comorbid cognitive and intellectual impairments struggling to gather information from the environment like their peers do, which means they need more one-on-one communication, even when they wish they didn't have it
What additional research is needed to help address co-occurring conditions for autistic people?	We need to look at WHY comorbidity happens. Is it genetic predisposition? Is it social consequence? Can it be prevented or is it inherent? But we also need to raise awareness for what comorbidity looks like, ESPECIALLY in women, and people of color, who are misdiagnosed due to lack of understanding of how the same condition can present differently based on cultural factors.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Better training for health and education professionals
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	For some autistic individuals, the increase in remote opportunities was a blessing, but for autistic children the transition back to school has been tough, and many are not recovering from the missed time.

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	The most significant challenge would be navigating the medical field. I've been advised that we "don't question the doctor" despite other factors. Doctors, in my experience, do not like patients who ask questions or who have researched their condition. They are deemed a challenging patient or "pill-seeking" because they know that ADHD is comorbid with Autism. I already have a hard time advocating for myself due to my own social adversions and add to that a professional who refuses to hear me or, even worse, infantilizes me? They here autism and start to change their behavior whether they think it or not.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Again, doctors. Doctors are the gateway to getting help. Being believed by doctors is very difficult especially since I am a cis female on top of it. I didn't get diagnosed with autism until I was 26 despite having very clear signs. And I STILL had to fight with the psychologist because I wasn't "autistic enough" for him. I have ADHD and IHH. He did diagnose me with autism but only after I had to question why he left the entire autism assessment out in the first place. Being believed and treated as a competent adult is another big one. I am 27 years old. I have been autistic my entire life. I have navigated this society without the tools I needed and it led to additional problems. Being treated differently because someone knows that I am autistic is a sure fire way to ensure I never go back there. I communicate directly and honestly. The around the tree talk doesn't work and usually ends up making my life more difficult in the long run. Communication is so much easier without interpersonal politics.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication is a science to learn and it always felt like everyone got a manual but me. I'd fight with my mom because we don't think alike and I'd take her words at their meaning and not search and hunt for a new one based on the person. What the person says is what they mean. I would say that undiagnosed ADHD as a child was a learning disability. I never functioned properly in a classroom. My partner suspects he is autistic due to his comorbid dx's of Dyslexia and ADHD. He struggled a lot with his Dyslexia. He also never functioned in a classroom well and while he's extremely intelligent, he was not given the tools to succeed. Neither of us were.
What additional research is needed to help address co-occurring conditions for autistic people?	Research women. Please for everything, research women. So much of what we "know" about autism is focused on the CIS White Male and that is partially why it's so hard to get diagnosed and get the help we need. Research how many women are autistic and get IHH. I have it and have no reason for it at all. I've dropped the weight, no tumor, and no vein issues. Look at ADHD and Autism but in women! Update the DSM to include things about masking and how women are more likely to mask because of the societal expectation. Look into how many women who've dropped out of school later were diagnosed as ADHD/Autistic. Just look into women and try to keep it fair. I'm so tired of finding so many doctors that think adults can't be autistic. That women can't. Or that it's just a "fad". It's real and debilitating.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services,	Providers need to be better trained. Autistic adults are not children. They may need some accomodations but there are 3 levels of autism for a reason. Talking down to a full fledged adult is beyond insulting and results in the provider refusing to hear the patients concerns. Infantilizing autistic adults is my #1 grief with the medical system. It sets off alarm bells when it shouldn't.

insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I did not have COVID. My partner had COVID twice and suspects he is autistic based on his dx comorbidities and his traits. He experiences lethargy, lower sex drive, and his heart races all the time. It's higher than a normal resting point consistently.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	After requesting to work from home for years, I have successfully worked from home for 4 years. Come June, it is being mandated to come back to the office 3x a week. I don't think I can handle that. The infrequent days I am in office leave me drained, exhausted, and I'm likely to pass out very soon after getting home. I do not miss the exhaustion or the forced social interaction. I also have been less sick while staying home and have a greater flexibility with doctors appointments that are offered via Telehealth. The idea of having to go back to the office 3/5 days honestly makes me feel a bit crazy. I have IHH and will experience migraines that require me to lay down for an hour or so. I have the flexibility to do that while working from home. At the office, I'd be forced to take FMLA (which I qualify for) and that would be a drain on my team, my time off, and my workload.

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	GI issues as well as hypbermobility and connective tissue disorders. The high comorbidity with Ehler Danlos Syndrome impacts all inner organs and especially the heart. POTS is also highly comorbid and can cause significant harm when left untreated. There are also significant instances of physical harm being misidentified by the autistic individual as a mental health issue (Ex: high blood pressure misidentified as anxiety), leading to long-term 'work' in therapy without progress.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression and rejection sensitivity lead to high levels of suicidal ideation. Lack of emotional regulation training that is effective for autistic individuals also leads to aggressive & self-injurious behaviors as well as self-harm actions. It's also an undeniable factor that miscommunication impacts things severely: we need things communicated in ways that often make non-autistic people uncomfortable because it 'breaks' unwritten social norms (ex: directness).
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The communication disabilities impact all of us severely and play into the experience of the other conditions. We often cannot effectively communicate our experience so that other people (even providers) can help us.
What additional research is needed to help address co-occurring conditions for autistic people?	The MTHFR mutation's relationship to autism.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Services for adults!!!!!!!!!!!!!! Especially adults not diagnosed as children.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	It compounds all autistic criteria and experiences. It makes everything so very much harder. Long Covid symptoms also seem to be aligned with autistic experiences, which is an interesting pattern. We're going to need support for adults who feel they have 'become autistic' after having Covid / Long Covid.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Negative impacts abound. The positive has been increased time to self-explore and identify effective supports.

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Gastrointestinal issues and sleep issues make it hard for me to be at my job consistently, as I don't get any more sick days than anyone else.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I've struggled with drug-resistant depression for my whole life. It made graduating from high school and college challenging, and makes it challenging to hold down a job. My partner, who is also autistic, has been hospitalized several times for suicide attempts. Obviously this makes work difficult.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication issues are often not "disabilities," in my opinion. They become disabilities when neurotypical people are not informed about how best to communicate with us.
What additional research is needed to help address co-occurring conditions for autistic people?	There needs to be significantly more research on the needs of autistic adults. The DSM doesn't even have a definition of autism in adults, making it extremely difficult for adults, especially adults assigned female at birth, to be diagnosed and get accommodations. By the time we're adults, we have learned to mask, and we need different kinds of help and accommodations than children do. We're tired of being infantilized. There needs to be research on how to best accommodate autistic adults in the workplace, what kinds of social support they need, and research into better diagnostic tools for female adults especially. There needs to be more research into how autistic adults mask, and the consequences of such masking. There needs to be research on how neurotypical people can be educated to better communicate with their autistic peers, family members and coworkers.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I don't even bother to tell doctors that I'm autistic, because I don't have a formal diagnosis and from what I've heard from the autistic community, it's unlikely they'll believe me. So the first step is making diagnosis cheaper and *way* easier to access so that doctors can even *know* that these are co-occurring conditions. The next step is a lot of doctor education about autism, how to treat autistic patients, and what kinds of conditions are likely co-occurring ones. Also, accessibility of what services? Services for autistic adults are few and far between and as far as I can tell, focused on autistic people who are non-speaking and/or intellectually disabled. Which is an important population to serve, but there are a lot of us out here who don't fall into those categories, and we need help too.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	COVID-19 further isolated autistic people who were already somewhat isolated. Some people have had serious physical side effects from it, and going to the doctor is a riskier thing than it was before, especially now that even doctors aren't masking all the time anymore.
What lasting positive or negative impacts have societal changes due to	I think the growth of remote work reduced frequency and size of social interactions was helpful to autistic people at first, but now there are big

the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

movements to return to the office, and in-person social interactions are no longer requiring masks or vaccinations, making the decision to participate or not all the more difficult.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory processing disorder makes life very challenging. Every new sound, smell, visual, sensation, takes energy out of me. When it becomes too much my brain cannot function normally anymore. I cannot think and all I want to do is hurt myself or run away. It is very physically and mentally draining, I have excessive sleepiness. It makes leaving my house difficult because I know any location could send me into a spiral. My gastrointestinal problems cause me discomfort every day. I get terrible heart burn where I am in so much pain I can't do anything.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have been hospitalized in a psych ward 5 times in my life, starting at the age of 12. Autism is a very lonely disorder. You experience the world differently than most people and therefore face challenges other people don't understand. Growing up autistic and trying to make friends is a minefield. I had severe anxiety since I can remember. It was so bad I would be too scared to ask to use the bathroom and soil myself. For most of my life my anxiety has been crippling and has kept me from leaving the house. I have been suicidal for most of my life and have struggled with self harm. It is painful to exist in society as an autistic person
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Research into alternatives therapies for autistic people. Therapies that address how autistic people feel and experience the world.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Having case workers available to help those with autism and other disabilities navigate the complicated system. They would help them apply, learn what they qualify for, and help them keep track of everything. As an autistic person it's very hard for me to navigate all the services. I rely on my family to help me but not everyone has that. There needs to be a third party available to connect people to services. More independent housing services for autistic people.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	All the delivery options and telehealth options have been amazing. I know autistic people who only shop through delivery because going to the store is too much. I still shop physically because I cannot afford delivery and I also have family to go with me and assist me. Being able to conserve energy by staying home instead of going out is extremely beneficial.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I have had two twisted blood vessels in my body. One in my brain which cause seizures and one in my right ankle which limits my mobility and ability to work. Also, my sensory issues which limits where I can work are bright lights at night, loud noises, and several textures that can cause meltdowns and shutdowns.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have depression, anxiety, and ADHD. My depression affects my mood, sensory issues, and ability to do hygiene things when it flares up. My anxiety is mainly social when it comes to talking on the phone, talking to new people, and public speaking. My ADHD makes it hard to keep routines and schedules.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Researchers need to talk and listen to actual autistic people and the autistic community. Especially, BIPOC and LGBTQIA+ autistic people. We know more about what we go through than allistic people.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	ABA needs to go away. It is abusive and more than half of autistic children end up with PTSD because of it. Quiet and sensory rooms need to be available in every school and place of business for autistic children, autistic adults, and autistic employees. Autistic and other disabled employees have to be paid the same minimum wage as their neurotypical and able-bodied coworkers.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I struggled with getting back into the real world and depression hit hard. I could not go shopping by myself for the longest.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Co occurring conditions exacerbate existing sensory issues, can lead to more instances of meltdowns, and can be increasingly difficult to manage because of executive dysfunction and the variety of ways autism can make it hard to manage daily life. It can also be especially challenging for example when it comes to food sensory issues that limit the diet that can directly conflict with the dietary requirements of some comorbidities like diabetes. Many safe foods are heavy in starch but that's not something a diabetic can process in significant quantities without big effects on blood glucose, and not being able to eat a safe food can mean not eating at all which is also detrimental.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Being autistic can make managing things much more difficult and when the thing to be managed is a mental health condition that has similar impacts on ability to manage medications and daily life compounds the issues of both and can make one unable to care for themselves in many, if not all, ways.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	It can be extremely difficult as an autistic person to get the help needed to manage life, home and work because of these co-occurring disabilities. When one has difficulty communicating, learning, managing documentation and understanding the processes we need to follow, it leads to us not being able to get help through assistance programs and if not diagnosed in childhood it is exceedingly difficult for an adult with autism to jump through the hoops needed to not only get a diagnosis but then also to get assistance or SSI. This leads to many becoming more and more burnout or worse, houselessness, substance abuse or even suicide. Without easy to aquire and understand advocacy, we go without critical aid potentially as long as our whole lives.
What additional research is needed to help address co-occurring conditions for autistic people?	The biggest issue with existing research is that it is largely designed, performed and interpreted by non autistic people. Those who are not autistic cannot fully understand or appreciate the challenges or experience of being autistic. It is necessary for autistic people to be included in research processes and for us to be the authority on our own needs and experiences.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	I think first and foremost ease of access is needed. The systems society operates on are inherently disabling to us, so any programs or assistance centered in those systems are more difficult for us to access than they should be. It seems there is more concern around making sure only those who really need help get it when it should be making sure anyone who might need help has the ability to get it. A net rather than a filter, in other words. Catch as many as possible, who could need help. Easier entry would look like anyone who suspects they qualify for assistance gets a neurological advocate who understands the process and can help get the potential recipient of services through any necessary assessments and form submissions.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on	I feel a lot of positive has come for autistic people, especially in terms of remote work, telehealth and even an increase in availability of delivery and

physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

pickup shopping services. For me personally, working remotely opened my eyes to just how disabling working in an office environment was for me.

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory issues with food, hypermobility, ehlers danlos syndrome, fatigue, migraine, visual disturbances, gastrointestinal problems, bladder problems
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD, intrusive thoughts, anxiety, depression
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Better diagnostic tools made readily available. I didn't get diagnosed until I was 44 and along the way was misdiagnosed as anxious, MS, arthritic, etc.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Single payer healthcare for all. Access to experts. Easy to navigate resources online developed and monitored by NIH
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Anxiety is worse. Long Covid has increased sensory issues and made eating and existing more difficult
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Remote work has been better for me. School has been difficult for my kids because cruelty from their neurotypical classmates has increased

Name	Anonymous
Demographic	Autistic individual; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Health providers dismiss symptoms of co-occurring physical conditions as being “anxiety” or other mental health aspect of Autism, and refuse to consider co-occurring physical health conditions as separate, treatable conditions. It’s treated like it’s all just the autism.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Mental health providers who are not knowledgeable about autism and who do not know or utilize neurodiversity affirming practices. Some aspects of therapeutic techniques may be inappropriate or even harmful to autistic people. Also it is nearly impossible to find a therapist who is knowledgeable about and willing to work with autistic clients.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Establishing a functional communication system for non-verbal individuals is critical and is NOT happening in schools. Too many non-verbal people lack a way to communicate and therefore engage in the only form of communication they have which is their behavior. As a teacher I am tasked with creating behavior plans for students who are physically aggressive because they cannot communicate what they want/need. They don’t need a behavior plan, they need an AAC device!!! AAC devices are too hard to get and there often isn’t knowledgeable staff who can teach them how to use it AND teach their parents or guardians so they can use it everywhere.
What additional research is needed to help address co-occurring conditions for autistic people?	More research is needed on how symptoms of co-occurring conditions present in girls and people of color and in people of other marginalized groups. Most of the research to date was done using upper middle class white boys as subjects.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	There needs to be an alternative to ABA services! ABA can be done in a way that is not harmful, but many times it is not and should be only for cases of extreme behavior or other challenges wherein not using ABA would be more harmful to the individual than the ABA itself.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Healthcare providers often fail to identify COVID related conditions or side effects because they assume everything is just related to the autism itself. People with autism are not receiving appropriate healthcare due to health providers lack of knowledge about autism and their inability to make a differential diagnosis in autistic people.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	The use of video conferencing and other means for communication that are not in person has been a positive change. Another positive change is that assistive technology has come a long way to support autistic people. Resources such as ChatGPT, text to speech with more human sounding computer or AI voices, apps that helps autistic people do things more independently are more abundant and freely available than ever before.

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>Extreme fatigue from constant masking. Gastrointestinal disorders, hemorrhoids & fissures Hyper mobility that NO ONE will acknowledge leading to repeated physical injuries/dislocations/surgeries. Inability to properly gauge pain. Skin picking and hair pulling especially when agitated. Inability to self-regulate body temperature - puking/lightheaded/full body muscle cramps. Burning tears, eczema, POTS, cluster migraines, ARFID - malnutrition, y'all messing with our food. Irregular mensuc/cysts leading to ablation. Inability to stand still without pain. Delayed circadian rhythm leading to sleep deprivation, irritability and decreased cognitive functioning. Easy bruising & falling, rolling ankles, back pain. PAIN, anxiety, depression, CPTSD, Suicidal Ideation, crisis. i've struggled hard to maintain the will to live since 2019. Easy victim for allistics/narcissists to hurt and take advantage of (rape, manipulation, abuse) terrible teeth even with good hygiene and regular dental visits (11 crowns, 2 root canals and TMJ that makes my dentist wince). auditory processing delay, hear everything and nothing. overall desire to escape capitlistic hellscape and rage over lack of bodily autonomy and yall killing women to protect parasitic tissue that is not viable Without the host. yeetus the fetus and codify it.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>I have 3 boys. i've struggled to maintain the will to live since 2019. I struggle with SI, Depression, Anxiety, CPTSD, ADHD and all the hoops to get [profanity redacted] meds. I think of ways to kill myself and escape all day everyday and i'm just waiting for my 9 year old to get a little older. i'm waiting to be another [profanity redacted] statistic and it disgusts me that every time i try to find something worth living for, i am surrounded by obligations to everyone but me. and then ppl say it's selfish? let ME be selfish for once! I don't want to live for anyone else anymore. i hate it here. ADHD costs ppl a lot of money. we throw away food we can't cook but bought cuz we know we need to take care of ourselves, we throw money at systems to help us be "Normal" only to fail cuz this world isn't made for us and we aren't welcome here I physically hurt myself during meltdowns and struggle to maintain relationships cuz meltdown me and normal me look very different and people can't handle that. my whole life i've been too much, too sensitive, too combative, too loud, too childish. i just want to be nothing.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>Learning process is too slow and boring. american school system is designed to teach hours of nothing and kids need to learn important things from those in their lives who were never taught in school or seek mentors (privledge) Extreme miscommunication, especially in writing and expressing things that affect me personally. social interactions are confusing and exhausting. many jokes need explained and i'm often funny when not trying or realizing i said something funny. Financial disability- manic spending for dopamine, inability to budget, paying more for paying late.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>co-morbidities. BH4 pathway could use a real good look. quit treating symptoms and treat the source. EDS, POTs, BVD, migraines, fibromyalgia, gastrointestinal issues. also maybe make health classes teach ppl what normal bodies should be doing instead of showing the worst case scenario pics of various sexually transmitted infections and trying to scare the hornballs into abstinence. teach about female condoms, why do we need an RX for them and u didnt hear of them til my 30s????</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic</p>	<p>Teleworking! we don't want to see people. MDMA and psilocybin therapy Job finding services at companies that pay 6 figures, not Goodwill. High-performing burnouts have capabilities when accommodated. Community</p>

<p>people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>food services. i struggle to feed myself and can't afford to eat out so i call it "fasting" to be socially acceptable. Abolish IVR phone systems - let me press the [profanity redacted] button yall can't hear me and i don't wanna repeat myself ADHD meds have too many controls in place for those who thrive on routine and struggle with executive functioning, waiting in lines (PDA), and time blindness. Also get off the marijuana high horse. y'all made getting diagnosed and medicated soooo [profanity redacted] hard we self-medicated for years with weed and then the Doc says ya gotta give up this thing you know works and been using for years so we can give you exactly 30 days of this med the manufacturer keeps messing with and works some days but not others and makes your body feel like it's jacked on speed cuz moving around like a chicken with your head cut off all day isn't gonna leave you in incredible pain!</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>mental trauma. the world is [profanity redacted] and people are selfish. we are worried bout women covering their nipples under their shirts but people couldn't cover their mouths to save lives. I never want to work in an office again. Corporate greed abuses us every [profanity redacted] day. and collectively our politicians stood up and said you know what, let's be divisive instead of doing our [profanity redacted] jobs. instead of taking a firm stand on covid they went after women's autonomy. EAT THE RICH, [profanity redacted] THE GOVERNMENT! pattern recognition has every autistic I know learning permaculture, preserving, bush-craft, foraging, self-defense and seeking to build isolated communities . yall deserve what is to come.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>[profanity redacted] Hybrid schedule. the absolute worst possible schedule for an adhd autistic who thrives on routine and systems to thrive. can't get a routine set to save my life. work days always rotating in the office and all work can be done from home. telehealth has made going to counseling feasible. i missed a lot of appointments i had to psychically show up for. teleworking brings work/life balance</p>

Name	Anonymous
Demographic	Autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I have had GI problems my entire life, specifically IBS, chronic functional abdominal pain, and gastroparesis. Each of these conditions are exacerbated by stress. I also have narcolepsy making my sleep quality very low. It impacts my ability to mask when I interact with others. My sensory issues were worse as a child than they are now. These issues were mostly sensory issues with clothes. I currently do a lot of sensory seeking behaviors and fidgeting helps. One of my sensory seeking behaviors that is negative is skin picking. The aftermath affects my self esteem and willingness to be social.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have depression, anxiety, and ADHD. I have a history of self harm and suicidal ideation. Occasionally when having a melt down I will hit myself and have racing thoughts of wanting to die. It makes my thinking black and white. My anxiety often leads me to avoid social situations
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Research focused on women and girls, beneficial supports and accommodations, education of those who likely engage with people with autism such as teachers, school admin, first responders, health professionals, and community transportation services.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance, accessibility to services that are friendly to people with autism (sensory needs), presentation of health information in multiple forms such as verbal, writing, visual, etc., patience from health providers to ensure good communication that allows both the patient and provider to understand what each other is saying, telehealth.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	My mental health and willingness to be social has declined drastically.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Positive: Telehealth services, optional remote work and school when needed, reduced in person interactions and obligations, grocery pick up, more awareness of mental health. Negative: fear of Covid, increased cost of living.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Many autistic individuals do experience anxiety and depression. This can cause suicidal thoughts and actions. I also notice many autistic individuals have other conditions such as OCD, ADHD, Sensory Processing Disorder, Bipolar Disorder, Eating Disorders, and in my own personal experience many autistic individuals including me have developed Tourettes Syndrome or some type of Tic Disorder.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	There could be more access to affordable sensory aids. I observed that although I can access aids such as noise canceling headphones, many people in the autism community who are low income can not afford to buy the aids they need. People with autism if included in Social Security benefits for disability should have a higher allowed income. The maximum income per month is only allowing for the individual to care for basic necessities, such as taxes/rent, groceries, and not much else.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory disorders. We have many diagnosed autistics in our family and some with only the sensory disorders. Also sleep disturbances. Also, from the outside, for the adult males, I would say bursts of violence or anger. I am self diagnosed, and something that I don't see anywhere but that other autistics do talk about are the nightmares that go all night. I have always had vivid nightmares, many each night, all night long, that I remember, ever since I was a baby. Another autistic adult male in my family has the same. Stays up all night and sleeps all day. Only one person has been clinically diagnosed so far but there are clearly others in my family that are "less severe" and yet have many issues, like meltdowns, depression, etc..
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression Nightmares all night Anxiety Severe sensory issues! Obsessive compulsive Meltdowns, even in adults Isolation
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication disabilities. Clumsy. Non-athletic. Most of the autistics in my family are very gifted intellectually. Neuroscientists, doctors, engineers, very high intellectual scores and IQs... Not all, but most. Even the most severely autistic child in our family that is non verbal scores ok on standardized tests. You would think he isn't picking up anything, but apparently he is.
What additional research is needed to help address co-occurring conditions for autistic people?	The tests to determine autism are extremely flawed. There are a million "it depends" running through my head with each question because they just aren't specific enough or clear enough. I like this one because it lets me write and isn't multiple choice. I would say that any test or research on actual people needs to eliminate the multiple choice, or always provide a place in which a person can expound.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Pediatricians and doctors should be trained in symptoms beyond early childhood and ESPECIALLY how females present, which can be completely different. They should be trained to see the non-obvious cases and we need WAY more testing. I have been on a waiting list this whole year for my daughter with no end in sight. I am also curious to know if anyone has a synesthesia link. I have numbers and calendar synesthesia. And I am curious to know the links with the scientific professions as well as professional musicians. It seems that a LOT of professional musicians have autistic children. Maybe the parents are also undiagnosed too?
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Well considering that Covid is a vascular disease and that studies have shown it causes significant grey matter loss in 100% of the people that contract it, I would guess it's not going too well for anyone. Honestly the autistic people I know were relieved when everyone went into isolation. We all are first to be boosted and all wear masks still. I would guess it's harder on children that need school support services, and their parents. I would also guess that autism is a bigger spectrum than suspected, meaning that so many people maybe only have sensory issues, and no social problems. But they wouldn't be diagnosed with autism. Yet people with only severe sensory issues really struggle, especially children, and there is no help or insurance coverage available.

<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>I think many autistic people may have enjoyed the reduced social interactions. Some haven't been forced to exercise enough, which is difficult and bad for physical health. Being on the screen for school for more than an hour was a nightmare for everyone. It seems the schools may have learned that. Not seeing everyone get vaccinated, boosted, and wear masks causes a LOT of anxiety for us because we understand how this virus is transmitted. The infected person is the person that needs to wear the mask. And with so many being asymptomatic, it's just horribly immoral to not wear a mask to a public place. It is also a crime that the federal government doesn't put out public service announcements that are clear, dry and unapologetic about the facts of COVID. Everything seems to be an apology for being the messenger, the bearer of bad tidings, instead of just giving us facts. We all need facts to be able to make good choices. And honestly, the government needed all along to have actual laws in place. But instead it was an allistic popularity competition. So Covid was and is frustrating, and shows us that we would have a much better and safer world if people were more autistic, literal, honest and ethical. This is where the allistic fail, in disseminating info and making good laws. It's been frustrating to watch most of society live as if things were the fairytale they wish it were, instead of in reality, where we can actually protect each other.</p>
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Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Getting a medical professional to listen to you and treat you for the things you're dealing with. I've been dismissed and misdiagnosed. And also being dismissed by co-workers and supervisors as if I'm just complaining or lazy. Not being taken seriously.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Finding anyone at all who understands and takes you seriously. Even medical professionals have a tendency to dismiss us. And employers don't seem to care or be willing to help or work with you to get help.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I tend to over explain everything in extreme detail and it's often treated as making excuses.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage and training that encourages medical professionals to take us seriously. And if they aren't willing, they should be encouraged to refer us to someone who is willing to help us.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My son has needed both clonidine and melatonin in order to fall asleep and stay asleep since he was 5 years old. He didn't sleep through the night until 17 months and barely napped. The lack of napping was commented on by the daycare provider when he went there at 3 months. He also has movement issues, specifically with bilateral movement and small motor skills. He also has trouble running.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	My son also has ADHD and General Anxiety Disorder. His ADHD is more an issue with focus and distraction and does not create any behavioral issues. He is also one of the most emotionally resilient people I know for major issues, but has complete meltdowns when needing to multitask because it's input overload for him.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My son has dyslexia and is a slow processor on neuropsych testing. If you look at his IQ without timing, he would be gifted but his processing is so slow an IQ cannot be accurately assessed. He struggles to get the thoughts out from his head, both verbally and in writing, unless he is repeating what he learned from another source which was audio. It's his original thoughts that can't get out cleanly. He also struggles to remember basic things like the order of the months on the calendar but can remember complex concepts. We have been told it's an issue of mind mapping and accessing parts of information. He also has trouble remembering peoples faces and names.
What additional research is needed to help address co-occurring conditions for autistic people?	Issues with mind mapping and memory in autism need to be expanded on, both in neurological and educational research. I had been complaining about the memory issue for years but neither my sons earlier provider and his IEP team in school knew anything. A change in autism provider and access to an educational consultant with experience with autism made all of the difference. They told me it seemed to be a common issue with autistic children.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	My health insurance doesn't have enough therapy appointments nor providers in my area for my sons issues to be properly address (despite what Cigna's website claims for providers in my area). I struggle and try to provide my own therapies at home to compensate (psychological, OT and PT) but I have no education nor experience in health or medicine. I am internet trained, observant and creative so I try to make it work on top of working and caring for my whole family. I am applying for state insurance for my son, which I heard has better coverage but I may make too much to qualify - even though I am the only working adult in the house and I don't make all that much.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	My son has remained COVID free so I cannot answer this.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal	The isolation from COVID 19 had a dramatic, negative impact on my son's communications and ability to socialize with non-autistic peers. He can't make friendships like he did. Academically he did much better with remote learning, but because I created an environment that was low disruption and used Alexa devices for transitions while I worked (time for a break, time to

changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

return to school and log into Math, time for lunch, etc.), I also make the return to school, albeit online, as something fun and special to make it seem exciting. Socially my son struggles. He is well liked but his limited interests in addition to struggling to remember people's details makes it harder to pick back up interpersonal communication and take acquaintanceship to friendship.

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Failure of medical professionals to understand the comorbidity of various physical conditions and autism. Lack of education on how autism affects bodily systems like the GI tract, or vision, or connective tissue.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Autism can make it difficult to communicate symptoms to a provider. Doctors expect an allistic description of a symptoms that may not be how an autistic person perceives their status. For example, the common pain scale used in most emergency rooms is too vague and doesn't correlate to how many autistic people experience or describe pain.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Because of a lack of education on the part of allistic people about autism, autistic people struggle to learn in traditional classroom settings and to communicate their needs. Autistic people expend a great deal of time and energy having to navigate systems that are not designed for them, and this requirement that autistic people accommodate allistics is exhausting and frustrating.
What additional research is needed to help address co-occurring conditions for autistic people?	Research into how autistic people perceive their body state and how they communicate their needs is needed. We don't have the same perception of self as allistics and that makes communication with allistics difficult and extremely dangerous when in a medical crisis.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Educate medical providers on how to evaluate and communicate with autistic patients. Address insurance companies that don't understand comorbid diagnosis and deny services coverage for them. Mental health coverage should not be separate from major medical coverage.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Some thrived in the isolation of the pandemic due to not having to attend appointments, meetings, etc in person and eliminating the sensory overwhelm of being in waiting rooms and medical facilities. Others were negatively impacted by the limitations of accessing online care and in-person care. Telehealth should be an option for everyone, and the interaction with medical services should be accessible in a way that suits the patient.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Reduced social obligations was a benefit. It is exhausting to be around allistic people in social settings. Disruption in services needs to be addressed as an equal access issue for all. Remote learning is not designed for neurodivergent learners, and failed many students who are allistic as well. Better understanding of how to deliver learning online that has flexibility for different learning styles is needed.

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	For me, it's gastrointestinal troubles.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	For me it's depression and anxiety. There's self-injurious desires and sometimes behavior, but that is sourced from depression and anxiety, and I feel like I have an okay handle on the ADHD.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I struggle a lot to communicate. I don't understand some social cues, have an understanding of "normal" behavior, and find I want to express how I feel in convincing ways that are also natural to me.
What additional research is needed to help address co-occurring conditions for autistic people?	How autism expresses in femme-coded people, and the mechanics of masking. No one could tell that I was autistic until I was near 30.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service system issues, patient-provider interactions)	Definitely access to services which includes things like transportation, financial ability, and autistic-friendly patient-provider communications.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I feel confused because I spent years concerned about the spread of COVID-19, and now every business and the government act as though it's not worthy of concern, and thus others around me handwave it more. I have become hyper-aware and fearful of getting sick in case I spread it to people, but no one else cares.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Remote work has been amazing, as has the reduced social obligations. The cons are how the world is trying to whip back into creating more social demands and ending remote work and services. The quiet is being taken away.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	sleep disturbances, pmdd, sensory issues
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	depression, anxiety, self-harm
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Having a job. Even when they say they will accommodate you the managers never do because "you can't be expected to have special privileges."
What additional research is needed to help address co-occurring conditions for autistic people?	It would be nice if they could do more research on autism in girls.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	My mental health was better / has been a lot better since covid. A lot of places made it so you could do more things online instead of in person. Social distancing helped me not feel pressured to communicate with people.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	GI disorders, sleep disturbances, epilepsy, sensory and motor challenges, Ehlers Danlos Syndrome, Congestive Heart Failure, POTS, low muscle mass, autoimmune, migraines, poor interoception
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression, anxiety, CPTSD, ADHD, schizophrenia, self harm, suicidal ideation, OCD, eating disorders, alexithymia
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	communication disabilities, learning disabilities, intellectual disabilities, developmental disabilities, chronic pain & illness, poor mental health
What additional research is needed to help address co-occurring conditions for autistic people?	more surveys and health screening for co-occurring physical and mental conditions in people diagnosed with autism, more research on women with autism and adhd since autistic traits are often overlooked with adhd diagnoses
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	equitable access to and accessibility of services, insurance coverage, service systems issues, patient provider interactions, health advocates to assist autistic people with doctor/mental health visits (someone to accompany them physically or virtually to appointments to help them express their issues to health professionals)
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	disruptions in services (negative), increased remote work and school (positive for many), increased use of telehealth (positive in the sense that more people are getting help, negative since its harder for doctors to assess patients online and many things go missed since autistic people have a harder time describing pain/emotions and advocating for themselves), reduced in-person obligations (positive, but it would be nice to have more safe spaces for autistic people to interact in person or virtually),

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>The most significant challenges caused by co-occurring physical health conditions in autistic people is being able to communicate a need or asking / needing assistance and all co-occurring physical health conditions not be brushed away as just another symptom of autism. The level an individual is at on the spectrum can affect their ability to communicate effectively based on their verbal ability, the way they communicate, etc. Another challenge is "is this a symptom of autism or is this something else all on its own?". Whether an individual can communicate verbally, through sign language, written word, tablet/ai, can significantly impact the individuals ability to live a life that accommodates their existence rather than alienating them for being different or incorrectly labeling them as defective.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>The most significant challenges caused by co-occurring mental health conditions in autistic people is the increased likelihood of having a co-occurring mental health condition such as anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality, etc. Aggressive or self-injurious behavior for example could be a symptom of autism and one's ability for emotional regulation or it could be a symptom of an anger problem or depression which, while neither can be cured it can be managed with affective therapy, medication and healthier ways of coping with aggressive or overwhelming feelings. It is more often that an individual is more likely to have an anger problem and have autism rather than the idea that the individual has an anger problem because they have autism. To effectively know the difference it must be known if the condition is linked closer to one's passed down in the genetic lottery or if it the result of the outside environment they have been subjected to.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>Listen to autistic people. Listen to autistic teens and adults. Do not base diagnose criteria based on biological sex but rather whether or not an individual regardless of biological sex exhibits those symptoms and or meets the diagnoses criteria for autism and it's co-occurring health conditions. Yes some thing may be more noticeable or prevalent in males than in females or vice versa but it is important to treat both as a whole and two separate categories.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>More services for autistic adults to transition from school and home accommodations to helping them successfully make their own appointments, hold jobs that pay them a living wage, assistance with housing and avenues to help house less autistic people.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to</p>	

the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I have a child that is 4 years old Level 3 autism. At the moment we are learning as a family how to navigate his physical health conditions. I would have to say the most significant challenges are differentiating between if my child is stimming or if he is having a seizure. He struggles to sleep. He can go days without sleeping well maybe an hour or two a day of sleep which doesn't help with his episodes of severe stimming. Or outbursts.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	With my child we struggle going out in public. If there is too many people he gets over stimulated this causes him to cry uncontrollably. He also self injures and anywhere we go we have to tie him in a seat or he will elope without any understanding of danger.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Some of the most t challenging things I would say is not knowing what my child feels, or needs. My child is non verbal and because of this I don't know what he feels. I don't know what he understands or doesn't understand. There is also lack of understanding from the community and in this case the world. There isn't enough resources or education. For example at the moment I have no idea what I am going to do for his education.
What additional research is needed to help address co-occurring conditions for autistic people?	I think most testing is needed on what is causing autism. I know that most people think it's always been here but I having a child with severe autism and working in the healthcare field see a high increase in which I dont understand why this sudden increase especially at this level. In the beginning of my healthcare career I met 1 child. And I worked in mental health. This was 1 child in 5 years I met then in 2020 I met 10 kids in the same state with severe autism. It could be a coincidence but I feel its increasing. I wish I could know what caused this in my child.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Encouraging more people (the right people) to become specialized in this. We have been on waiting list to get my son seen for a year and in the area we just moved were told the wait is Soo long it could take years because the kids that are being seen aren't kids that in a year get to graduate out of therapy they could be in therapy until they age out. There isn't enough places that offer therapy. Also many places don't take insurance why I am not sure. I've also had pediatricians who truly have no idea what to do. I have to tell them what I feel my child need because they are clueless in the matter. At most of all please I beg of you set up a type of schooling system. For example my son will be starting school next year and I have no idea what to do. There isn't enough schools that take children who aren't potty trained, are non verbal, elope, and can get aggressive. I wish there were more at home services and that people were paid more to offer these services or paid more to join this profession.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on	

physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Lack of care & treatment is a large hurdle. I have a gastroenterologist but insurance won't cover the medication prescribed. Insurance also won't cover treatment for sleep disturbances, primary care doctor is unable to treat balance/blood pressure (POTS). I'm not able to live in an environment where I can control the sounds, which can lead to dysregulation. My insurance also wouldn't cover physical therapy where they identified hip alignment/structural issues causing pain, though the physical therapists didn't seem to be trained to work with/identify connective tissue disorders. I am in constant pain, experiencing likely nerve damage, am constantly exhausted and unable to care for basic needs, having abandoned most self care so as to expend my little energy where I am barely work a job to survive. My brain is on fire, everything hurts, I am exhausted, & there is no help or assistance or relief.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The gaslighting by mental health professionals who don't know how to identify or treat autism, who don't understand the daily trauma of living with or masking autism or adhd and the impacts that has & how standard CBT/ACT can be re-traumatizing and invalidating and ultimately, leaves autistic/adhd patients worse off than if they'd never received mental health treatment—it leaves one feeling hopeless and alone, likely contributing to further mental health decline.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Just seeking help in the first place is difficult. Having to struggle with paperwork, phone calls, rescheduling, remembering appointments. Then, if you can make it to the appointment, having to struggle to be heard or treated; to communicate with the doctor in their very limited time what is wrong; they do not have time to properly listen and consider and communicate clearly with patients who are disabled. They do not know enough about these disabilities either.
What additional research is needed to help address co-occurring conditions for autistic people?	How do we survive? Autistic people need appropriate stimulation and ability to control sensory stimulation to some degree, but our economy/society will not "cater to"/meet the needs of autistic people; instead, forcing them to mask to fit in and survive (maintain employment)— until we can no longer do either. Our talents are vast and valuable— but we cannot pass the social/hierarchical litmus tests that all workplaces seem to demand (85% of autistic people are unemployed, but many are perfectly capable of working/learning; people just feel uncomfortable that we don't think the same ways). I want to solve problems, it's what I am good at; but I can't do that when the majority of my job is really "relationship management," not because my work requires it, merely because of social convention(?)/comfort of others. Finding solutions or treatment to help alleviate discomfort/pain of POTS, constant nausea & digestive issues / connective tissue disorders to would help. I'd say maybe I could mask better if I weren't in pain, but I'm too exhausted to even think of masking!
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Better training & information for care providers, particularly primary care and specialists of common co-occurring conditions; why does my insurance get to deny treatments my doctors prescribe? Mental health professionals also need better education and information to aid in identifying & funneling patients with autism to appropriate, non-harmful treatments that aren't akin to "think positive hard enough and you won't be disabled! C'mon! It's like you're not even trying!"... Perhaps just MAiD if that sounds too onerous. There are currently no supports or services even available to autistic people.

	<p>More time with a doctor who has some clinical awareness of the deficits that may come or some training in ascertaining those deficits (communication, interoception, neurological decline/dysregulation) would likely help facilitate medical care more effectively than the current standard (which likely isn't great for allistic patients either); remove profit motive from healthcare</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>I can't "mask" my autism anymore— social rules changed and then changed again and now I am exhausted. I must be solely vigilant against infection because no one else is taking precautions and I am vulnerable. That I cannot always clearly function or think compounds the stress of hypervigilance out of necessity. I will likely never recover; the community recommends total rest as the "treatment" for autistic burnout, but that is out of reach for many; we must work to survive, or die. There is now an additional, onerous obstacle. Tests are expensive & out of reach, proper respirators are expensive; even getting vaccinated was not straightforward and I had to pay out-of-pocket; \$190 I did not have to spare. I am exhausted and I cannot fight the insurance denials; the paperwork, the mental energy, the time, the effort... it's inhumane</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Telehealth and remote work/school are great! Stop trying to remove them, please. Less social interaction in-person, please. Normalizing respirators would help reduce social stigma for all vulnerable populations. Lasting negative social impacts from Covid— Covid made people I've served in my community for over a decade say the most horrific things about "Darwinism" to my face. While still expecting me to work & serve "with a smile on my face." Humanity is imperiled. Apathy has given way to direct cruelty. No one cares if we live; the least you could do is make it humane.</p>

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual; Service provider, health provider, or educator
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	If I'm listened to at all, it is after an exhausting amount of self advocacy that is only possible because I am high masking and a registered nurse. Cost of healthcare is a major issue as I suffered major burnout during/after the pandemic and cannot afford to recover. I remain undiagnosed for fear of losing rights. Our society has made it so that I am required to expend all my energy in order to feed the machine of capitalism. I have no bandwidth to include relationships, passions, hobbies, physical activities, or anything that could bring me joy. I hate it here so much.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have been in a constant state of burnout from the pandemic and I'm not able to recover because this country is demented and would rather me show up to work half dead every day than waste a dollar trying to let me have a life worth living.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I live in a society that is not only not designed for people like me to thrive, it seems to actively work against disabled people many times. I have been failed by the us healthcare system, the education system, everything.
What additional research is needed to help address co-occurring conditions for autistic people?	Research on WOMEN AND GIRLS WITH AUTISM. Links between adhd/autism/bpd.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Why can I only access disability services if I have -\$10,000 in the bank????
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I haven't known any feeling of peace, safety, or inner joy since the pandemic started and I spend most of my time outwardly and openly suffering from the ptsd and burnout that it caused. I haven't had a full time job or healthcare since last year. I had to move in with my abusive parents. I lost everything. My life is no longer liveable. I'm just here bc someone has to take care of my dog.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Class consciousness and the faint hope of a revolution before total climate collapse.

Name	Anonymous
Demographic	Autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>The health care system seems to be hostile to autistic people. Communication with health care providers is severely constrained, often limited to voice phone calls or face-to-face interactions. Interactions are usually very brief. Since I require some time to process information and perform best in written communication, this is a barrier. My attempts to get health care providers to accommodate my communication needs have mostly failed—and health care providers often claim (contrary to HHS guidance) that HIPAA prevents them from accommodating patient communication needs. Doctors and nurses don't know how to interact with autistic people, nor do I know how to interact with them. There isn't time for either of us to learn. Even when I tell them that this is not the case, health care providers seem to assume that the communication skills they've developed for interacting with allistic patients will still work just fine. The workload for coordinating care is offloaded to patients, but I'm not well equipped to handle that workload, particularly when my communication needs are ignored. There seems to be an assumption that patients have the social skills to navigate a byzantine bureaucracy that seems to confuse the health care providers themselves. There doesn't appear to be any system in place to help those of us who don't have that expertise and don't have close relationships with people who can provide it. We're just left to fail.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>So far as I can tell, existing mental health practices are based entirely on allistic people. There doesn't seem to be any recognition that common therapeutic paradigms like cognitive behavioral therapy often don't work—or are actively harmful—for autistic people. The impression I've gotten from therapists is that they're taught that viewing oneself as fundamentally different from or alienated from allistic society is a cognitive distortion that should be corrected—and that if we try new social experiences we'll have positive experiences. However, there's abundant evidence that this is incorrect for autistic people—we are different, we're frequently excluded or rejected because of it, our social experiences are often negative. We know it; therapists don't. Being told that your hard-won understanding is incorrect is invalidating and harmful. I've been able to access some useful medication related to mental health issues, but have not found any useful psychotherapy. Regarding suicidality—the risk of involuntary hospitalization is a barrier. I've never really talked to anyone about my suicidal ideation because it doesn't feel safe to do so. I haven't found anyone in the mental health care world who I trust enough, and who I think understands me well enough, to feel safe talking about things that could lead them to take this kind of action against me.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>Difficulty with communication has made it difficult for me to access health care, and difficult for me to deal with employment. A couple years ago I was forced out of a permanent federal position because of a hostile work environment related to systemic dishonesty. In short, I was hired to do work that I believe in, but which my co-workers did not, and the fact that I took my responsibilities seriously led to hostility and social isolation. Luckily, I ended up in a different federal position in which these issues are greatly reduced. However, for my prior position I had developed substantial expertise over nearly 20 years, most of it through unpaid effort on my own time, and now I find that this expertise is worthless. It's depressing. I thought I'd found my life's work, only to find that it was all a waste of time, that my efforts and expertise are not valued because of my social / communicative limitations.</p>

<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>Teach allistic people how to communicate clearly and directly. That is the biggest barrier. We're seen as "defective" and all the burden to try to "fix" it is placed on us. However, it's a double empathy problem—communication across the allistic / autistic divide is difficult for <i>*both*</i> parties, but only one of those parties is expected to put in the work. It would also be helpful to understand what kind of accommodations would work in this context. Existing concepts around accommodations seem to be based almost entirely on physical rather than social limitations. So, e.g., when the problem I'm facing is a work culture in which employees are expected to know when to follow and when <i>*not*</i> to follow stated policies, I don't know what the accommodation is supposed to be. What I really need is for people to just... not lie to me about expectations... but what's the non-antagonistic way to ask for that, and is there a reasonable way to address that when it's a systemic aspect of work culture driven by political pressures that my supervisor does not control? Educating employers, health care providers, etc., about accommodations for social or communication difficulties related to autism would also be helpful. When I've asked for communication accommodations in a health care context, I've just been told "we can't do that". I don't think they even recognized it as a legitimate accommodations request.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Teach health care providers how to understand and interact with autistic people. Also, require them to provide access to written communication in all contexts. (This is already required to some extent by HIPAA, I think, but health care providers don't know this and apparently the burden is on a patient to understand the rules and then hire a lawyer—otherwise, so far as I can tell, they'll just say "no" and you have no recourse. In any case, the requirement should be explicit, universal, and enforced.) Also, give us some tools to understand the system. Everything in health care is opaque. It's a maze of arbitrary and undocumented rules and misleading (or flatly dishonest) communication with patients. A random recent example—the hospital I go to has an online record request form, but that record request form only applies to <i>*parts*</i> of the hospital. If I request records from other parts of the same hospital they send a letter a couple weeks later saying the records don't exist—not "that part of the hospital doesn't respond to the records request, here's the alternate process", just "the records don't exist". This nonsense is surely frustrating for everyone, but it puts a disproportionate burden on anyone who struggles with social ambiguity and communication.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>I haven't had any direct experience with COVID-19.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Increased acceptance of remote work has been beneficial for me. Prior to COVID-19 I was starting to get panic attacks from having to visit my workplace in person, due to the hostility of co-workers. That said, I'm much more socially isolated after COVID-19 than I was before. I think it's still a net benefit given that my ability to tolerate long exposure to allistic social environments was breaking down, but it's definitely not ideal.</p>

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I suffer from migraines that often align with when I am very stressed out or am not getting quality sleep. Traditional migraine medications do not work for me and doctors don't seem to know the cause. I think it is related to autism because of my inability to relax muscles, so my neck and jaw are often very tense and I'm unaware. It may be a connection between hypermobility, autism, and muscle tension. The frequency and severity of the migraines make it very hard for me to work and financially support myself.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Having ADHD and autism is like having two people fighting all the time inside my head. My autism likes things to be a certain way and my ADHD likes it completely differently. Executive dysfunction gets more challenging I think. It causes a lot of self doubt which leads to anxiety. I think having better mental health services in this country would overall help. One condition can lead to another and lack of access can be deadly. I know the suicide rates for autistics are higher than gen pop. And it's under diagnosed in girls and women. Some people don't even want a formal diagnosis because of the loss of rights for disabled people in the US. That stuff contributes to poor mental health.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	So much research is needed. I'd love to know more about how autism presents differently in a diverse population than how it presents in young white boys, which is most of the research we have now. I think the diagnostic criteria needs a complete rewrite. I'd love to know if there's a connection between autism and hypermobility/EDS and migraines. As well as more research on how it interacts with ADHD, specifically in girls, women and trans/nonbinary folks. I think there also needs to be research on how the lack of rights for disabled people is ruining lives. Some disabled people need more support than others but that doesn't mean they should have their agency and dignity taken from them.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	There currently really are not any institutional supports available to autistic people. Access to validating care is extremely limited. Insurance is laughable. And it all hinges on getting an expensive formal diagnosis that could mean the end of your agency as an individual. Care and rights go hand in hand. And these decisions should be lead by the autistic community.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services,	Working from home is ideal. Reduced in person social interactions is also ideal but I still am able to get enough social interaction. Even wearing a mask is great because I don't have to worry about making the right facial expressions. But now it seems like there's less and less opportunity to work from home. Companies should be encouraged to allow anyone to work from home. It's better for productivity and for people with disabilities.

increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	
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Name	Anonymous
Demographic	Autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>Social isolation. By in large, being disabled is an extremely isolating experience. People do not care. People do not WANT to care. As much as we are taught that eugenics was a german mistake, and one long ago at that, we are still useless eaters to most Americans, not to mention government institutions. After that, it would be the complete absence of a serious social safety net. Yes, one TECHNICALLY exists but it is famously difficult to access and, even when you DO manage to get approved for government aid, your ability to actually live stably is, pardon the completely intended pun, crippled. You cannot save, you cannot work even if you wanted to and thus it is nearly impossible to meet people because most non-labor social spaces are not remotely disability friendly. Spaces like libraries are dying and it is because neoliberalism, policies of deregulation and the calcification of tech industry markets, are killing them. The hardest part of being disabled is living in America.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>Yes, it IS social isolation again! And the reasons are the same! Because mental illnesses are ALSO disabilities! Secondly part 2: Social safety net, death of communal life, etc etc. [profanity redacted] you, pay me; love me and never let me go.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>Im sighing right now. You're sighing right now. Everyone is sighing right now. Social isolation and the impossibility of even living. There's something to be said for the destruction of public schools, with inflating class sizes and shrinking teacher salaries here. Something else to be said about how neurotypicality is the social structure creating the conditions necessary for autism to even be considered a serious disability as opposed to a certain kind of neurological difference. But we don't mind that overmuch, do we? We'd rather let millions of immunocompromised people, who are disproportionately likely to be autistic mind you, die for the sake of SOME extra money for the people who'd hardly notice it missing if you stole their [profanity redacted] wallet. The hardest part is knowing most people do not care, do not want to care, and likely will not start caring in your lifetime.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>Funding existing research more would be helpful, for the record, but here goes: 1) Autism is not a disability. It is a SOURCE of disabilities. The field will never move forward until we contextualize traits in their proper context. 2) How disinformation about autism spreads through platforms like tiktok 3) The history of neurotypicality and what "abnormal behavior" actually means 4) How to teach already licensed doctors (MD & PhD) the basic qualities of autism 5) actually [profanity redacted] useful autism assessments. good god. It's bad out here. 6) what potential social safety net programs for autistic people could look like 7) how existing disability services could be updated for autistic perspectives 8) why autistic people have trouble recognizing their own divergence until forced to reckon with it? 9) what in the [profanity redacted] [profanity redacted] a "neurotypical" even IS?? Everyone's brain is made of jelly and smells. It has the voltage or a low battery. What do you MEAN "typical"? 10) the way autism's current disability status is being weaponized by oncoming anti-trans legislation and a million more. Won't matter if there's no money in it.</p>

<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>What autism services? There are no autism services. Is this a joke? Pls be funny next time.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>Made them worse. Killed a bunch of us. Long covid is probably worse for us somehow.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Unironically appreciate the way fewer strangers try to talk to me in public (I look like a white guy with a soft face, I assume that it comes with the territory). I barely noticed the pandemic because my parents are wealthy and I could afford to just stay inside the whole time. And then my friends started dying. And then the lockdown ended while infection rates skyrocketed. I think the deaths of innocents staining our hands at various intensities is probably the most lasting impact.</p>

Name	Anonymous
Demographic	Autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>Challenges I face are sleep disturbances with joint hyper-mobility, sensory and motor processing. With sleep disturbances I am only able to sleep for 1-3 hours at most a time and total 6-7 total hours of rest and this is typically due to my hyper-mobile joints being held into a difficult angle with consistent pressure, causing pain and small loss of circulation occasionally which wakes me up throughout the night. I typically can fall asleep after repositioning but immediately fall into REM sleep and will most often get to a deep sleep shortly before I need to wake up or not at all. This has led to processing of sensory information and motor skill to lack throughout the day, requiring more energy to complete 'simple' tasks and chores that after one or two tasks, my body is ready to rest and is worsened on days that my joint pain is exacerbated. I already have extremely slow processing speeds (per my autism evaluation) that is exacerbated when I have had little sleep and and no additional naps through out the early part of the day that it effects my ability to go to work some days. Resulting in needing to call in or work small amounts from home. The lack of rest also effects sensory processing and can in turn cause a much lower threshold for what I can tolerate either in lighting, auditory, or textile sensations which cause can a meltdown or shutdown at any given point but most often at the end of my day.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>Anxiety, depression, ADHD, and suicidality have all impacted my life in different forms. Anxiety and depression had led to an increase in suicidal thinking especially in younger years as I had only received and diagnosis in my early twenties. This did improve after starting therapy and medications to treat the depression and anxiety. ADHD has effected how i process information as well and made going through the k-12 education system difficult, especially since teachers had not caught on to my autistic or ADHD traits that held me from fully understanding and absorbing learning materials. I believe being female has impacted this as well, since I did not appear to be like other autistic/ADHD children or the boys with "textbook" traits. This also held me from perusing higher education as I had felt there was something wrong with me not being able to learn "properly" prior to receiving my diagnosis.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>More research on young girls and boys who do not exhibit the "traditional" autistic traits. Especially girls or those assigned female at birth who do not show "textbook autism" and autistic adults who have goin 20 plus years undiagnosed.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>I feel there needs to be more options or help, vocational, educational, etc., to support autistic adults who are not high support needs and diagnosed after 21 years old. At this time, many autism resources are geared towards younger children, parents of autistic kids or individuals with high support needs, but since individuals can make their whole lives being undiagnosed, they end up with little help understanding themselves as autistic adults with low to moderate support needs and no resources to easily locate that would help them as an adult over 21 years old. An autism diagnosis later in life puts an individual in the place of removing their "mask" and starting to see their</p>

	<p>traits as autistic which can cause lots of confusion and stress, especially if there's not any resources geared towards helping them fully understand and accept themselves. Personally, my diagnosis effected how i viewed my career but I quickly was underwhelmed when trying to find resources for understanding my options as an autistic adult as I was "too old and required low support needs".</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>I greatly reduced my social interactions since the beginning of Covid 19 societal changes. I developed OCD around cleanliness and illness and have since found it hard to go in public or be with friends/family. I did appreciate telehealth and work from home becoming more acceptable as it have helped reduce much of my anxiety around public and social interactions.</p>

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Severe constipation Depression
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression Anxiety
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Research on the best practices for treating depression and anxiety specific to autistic patients
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Better training for physicians regarding interacting with autistic patients & better training for physicians on common co-occurring disorders with autism in adults (especially GP's)
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Worsening depression in autistic people during the lockdowns due to isolation. Increased anxiety especially for autistic students
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Positive: Tele-Health appointments

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Ehlers Danlos syndrome often co-occurs with autism. It can cause physical joint pain as well as problems involving posture, exercise intolerance, and dental issues. Many people deal with stiff joints as a result of hypermobility.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	many autistic people consider suicide as a result of social isolation and unstable interpersonal relationships. They may also suffer from PTSD from trauma faced throughout childhood. Catatonic symptoms such as verbigeration, echopraxia, grimacing, and withdrawal can lead to further communication difficulty. dissociation/depersonalization can often disconnect autistic people from reality. And substance abuse leads to further feelings of emptiness.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Dyslexia and Dyscalculia lead to difficulty processing info especially at school/work. Dyslexia also affects ability to recall left from right. Auditory processing difficulty also can lead to issues when learning new information and will take longer to process what has been said.
What additional research is needed to help address co-occurring conditions for autistic people?	A better understanding of how autism can present differently based on cultural and gender differences. Researchers should help better inform the public on what autism can look like so high masking autistic people can also receive the help they need.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	many autistic people are LGBTQ+ and POC, and people within these groups often have a harder time receiving a diagnosis due to the bias among many psychiatric professionals. Autistic people are especially likely to have differences within gender expression and lack of understanding from professionals can be discouraging for people seeking help.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Many people post COVID infection have reported long covid symptoms such as changes in taste and smells. Changes in taste and smells often leads to changes in food intake as many people with autism deal with disordered eating as a result of ARFID. Even after the initial infection many people report feeling physically weak and much more easily exhausted.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	remote schooling has been very beneficial. Though the furthering of isolation and increased separation from those around us makes loneliness a much more common issue. Many people are severely depressed about the state of the world.

Name	Anonymous
Demographic	Autistic individual; Researcher; Other
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Personally, I struggle with insomnia, digestion, and joint pain.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	CPTSD, ADHD, major depressive disorder, generalized anxiety, and suicidal ideations.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Dyspraxia, ADHD
What additional research is needed to help address co-occurring conditions for autistic people?	Postural orthostatic tachycardia syndrome (POTS), Ehlers - Danlos Syndrome (EDS), and CPTSD
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Pricing and insurance coverage are big problems for a lot of people. Girls, PoC, and adults are likely to get overlooked in diagnosis, and if we are diagnosed we are infantilized and not believed when we need accommodations or co-occurring ailments.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	My bones hurt all the time now.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Pros: increased awareness of Autism, remote meetings, hobby time. Cons: Grown agoraphobia, mysophobia, and anthropophobia

Name	Anonymous
Demographic	Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	ADHD Ehlers-Danlos Syndrome Insomnia Sensory Sensitives
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression Anxiety Bipolar Borderline personality Disorder
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication Challenges for Autism- Level 1 Individuals
What additional research is needed to help address co-occurring conditions for autistic people?	Autism and Correlation with: Eating disorders , self harm, bullying, suicidality, and comorbidities
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Universal health care to cover all medical costs More training to health care providers (doctors, nurses, therapists, etc) More training for educators (birth through college) Work accommodation for autistic adults
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Covid exacerbatated mental health conditions such as depression and anxiety. Covid had a positive impact on expanding telehealth and teletherapy. Some autistic students also reported lower level of bullying during remote learning
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increase in remote work, remote learning, telehealth

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My child and I have hEDS, sleep issues, GI difficulties since birth, sensory differences, and difficulties with proprioception as well as interoception. The sensory differences and sleep issues make everyday life very challenging on their own. My child has to be homeschooled because they had so much trouble being in any school environment we tried. Between the noise being overwhelming, only having enough sleep to function in a school environment without having multiple meltdowns less than 50% of the time, and constant stomach aches interfering with their schooling... we had to accommodate them and home was the only place we could do so. We have also had to take my child to the ER multiple times due to accidents resulting from their lack of proprioception awareness. Working a 9-5 is not a viable option for me due to how inconsistent my sleep is as well. I have tried so many medical interventions and lifestyle changes but nothing helps enough to function like a neurotypical.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have PTSD, depression, anxiety, OCD, ADHD, and I have struggled with anorexia as well as dermatillomania. Finding treatments that works for me took over a decade as my depression is treatment resistant and that had to be treated before I could really work on everything else. My anxiety kept me from socializing with new people for 4 years at one point and even seeing old friends was hard. My mental health conditions keep me from feeling secure in any job I might have. My child has anxiety and is suspected to have ADHD (we're scheduled for testing). Their anxiety makes going anywhere impossible at times and contributes significantly to their sleep issues. They have had panic attacks since they started preschool at 3 years old.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	My child has dyslexia and a speech disorder. Reading is a constant challenge for them and most other parents and educators do not understand. Until a couple of years ago, my co-parent and I were the only ones who could understand our child's speech and we often had to act as interpreters for them as a result. Their speech disorder has also made it even more difficult for my child to socialize with other kids.
What additional research is needed to help address co-occurring conditions for autistic people?	Sleep research would be a big one for us. Also research on how to treat anxiety for children who are too young to safely take medications. Additionally, therapy services that do not involve rewards or punishments and respect bodily autonomy for autistic children in need of mental health support are desperately needed. It seems that everything that is currently available is ABA based. ABA may be widely accepted but it causes PTSD, increases anxiety, increases masking, and sets children up for grooming. It also has been shown to be ineffective by multiple peer reviewed studies, including the largest study on ABA recently conducted by TriCare.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Insurance coverage for Autism and autism related conditions would improve the care autistic people receive. Having service providers educated in the neurodiversity model of the autistic neurotype would improve autistic quality of life and make way for autistic folks to be better able to self advocate. Services aimed at helping autistic adults who have less obvious support needs are currently non-existent in this country and would benefit a lot of us.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	During 2020 I lost my ability to mask after being away from people for so long. That significantly increased my anxiety levels until earlier this year. My physical health has also declined significantly since catching covid in October of 2020 pre-vaccine. My sleep and hEDS joint issues particularly have become much worse. I have also developed POTS since having covid.

<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>The increase in remote work, remote schooling, homeschooling, and telehealth services over the last 3-4 years has been an immense blessing for me and my family. We are much more easily able to accommodate ourselves and thrive due to these changes. The lack of social obligations has been beneficial to our mental health as well. Additionally, we have been less “othered” in social situations thanks to the increase of people who have social anxiety now. However, due to the teacher and medical staff shortages that have occurred as a result of the pandemic, getting in person services we need has become much harder. In person school has become a non-option for us in part due to the lack of staff who see autistic people as people. Socialization anxiety has increased due to the cultural changes that we are unsure on how to navigate and due to being out of practice in dealing with humans.</p>
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Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Mouth breathing Trouble going to sleep.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD Aggressive behavior OCD Anxiety
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Communication disability
What additional research is needed to help address co-occurring conditions for autistic people?	Please do more research for women. I'm 28 and I've been masking my entire life. I've been tested and told I communicate too well to be autistic. There is not enough data on diagnosis women. Especially adult women.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	If autism is present in people with ADHD, I'd love if ADHD allowed me special services to prepare for job interviews.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I don't see any lasting positive or negative. I'd love more remote work but companies want us to go back in.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Physical health issues can contribute severely to overstimulation and the ability to do basic tasks. Being in pain can be either unnoticed or unbearable. Doctors do not take you seriously or believe any complaint you have.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Conflicting needs to cope or improve both conditions. Hard to find appropriate medication.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	People assume you are an [profanity redacted], get bullied, have to work twice as hard to communicate efficiently with many types of people and still get treated poorly for being autistic
What additional research is needed to help address co-occurring conditions for autistic people?	There are so many co-occurring conditions it seems impossible to isolate one way to improve. ARFID, EDS, seizures, and other conditions need to start being treated appropriately so that autistic people can function and not kill themselves before they reach 40 years old.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	There are no support services. Most insurances don't even cover neuropsych evaluations, so diagnosis is near impossible for most adults.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	I lost the little social skills I had before covid. I am severely isolated and lack any social interactions other than medical appointments (which are traumatizing). Nobody is covid safe anymore so I can't even try to do anything fun or make friends. Covid will likely kill me if I get it. Nobody cares and I'm told I'm paranoid and dramatic. I am traumatized by almost every social interaction I have.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	I can't get the appropriate medical attention I need because doctors give up when covid happened. Nobody cares about anything anymore. It used to be easy to use pick up services but now people assume you're just entitled. It's harder to do literally everything.

Name	Anonymous
Demographic	Autistic individual
<p>What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)</p>	<p>The challenges that come with having both autism and other physical health issues are really complex and deeply personal. For someone like me, who's autistic, everyday things can get a lot tougher when you're also dealing with stuff like acid reflux or sleep problems. These issues can make the sensory overload that's already a part of autism even more overwhelming. It's like you're constantly trying to juggle feeling uncomfortable with trying to cope with the world around you.</p>
<p>What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)</p>	<p>Navigating life with both autism and co-occurring mental health conditions like anxiety can feel like walking a tightrope. For someone who's autistic, the everyday social challenges and changes in routines become even more daunting when anxiety is in the mix. It's like being in a constant state of alert, where every social interaction or unexpected change can set off intense worry or stress. This heightened anxiety can amplify the inherent difficulties of autism, such as communication struggles or sensory sensitivities, making them feel even more overwhelming. Finding the right support can also be tricky; it often feels like you're trying to explain what's going on in your head to someone who's speaking a different language. So, dealing with autism and anxiety together is about more than just tackling each issue separately; it's about understanding how they intertwine and affect every aspect of life.</p>
<p>What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?</p>	<p>I feel like this is being answered in the other questions.</p>
<p>What additional research is needed to help address co-occurring conditions for autistic people?</p>	<p>To really help autistic people with other conditions they're dealing with, we need research that looks at the whole picture. This means understanding how different issues, like mental health or sensory sensitivities, really play out in day-to-day life for someone who's autistic. We need to figure out what kinds of help work best for each person, because autism is so different for everyone. It's also important to keep an eye on how these issues change as people grow up – what challenges do they face as kids, teenagers, or adults? We should also dig into how to make therapy and support more autism-friendly. Plus, it's not just about the individual; we need to think about their families and the people who care for them too. How can we make things easier for everyone involved? And hey, why not see if technology can lend a hand? Maybe there are cool new tools or apps that could help. Lastly, getting experts from different fields to work together could lead to some great new ideas. So, it's all about connecting the dots between different areas to find the best ways to support autistic people with the other stuff they're dealing with.</p>
<p>What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)</p>	<p>Improving autism services on a large scale, while keeping in mind the unique needs of each person, is like trying to solve a complex puzzle. One big piece is training: we need to get more professionals out there who really understand autism and the extra challenges that can come with it, like anxiety or learning difficulties. If doctors, teachers, and therapists have a better grasp of what autism looks like and how it interacts with other issues, they can offer more effective help. Another piece is about making services easier to get to, like having more centers in different places, and making sure they're welcoming and don't overwhelm the senses. We also shouldn't forget</p>

	<p>about the power of technology – things like apps or online resources can reach a lot of people and can be tailored to individual needs. Plus, we need to listen to what autistic people and their families say they need, because they're the real experts in their own lives. By putting these pieces together, we can create a bigger, more effective support system that really gets what people with autism need, even if everyone's experience is a bit different.</p>
<p>What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?</p>	<p>Not aware of any personally though I'm sure there have been and will continue to be.</p>
<p>What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)</p>	<p>Same response as last question.</p>

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Accessing necessary testing and treatment— it can be expensive, it can take considerable time to get diagnosed with co-morbidities, and then treatment is either minimal or just a bandaid. And then sensory and motor challenges then make it additionally challenging to access care.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Symptoms of ADHD can often clash with symptoms of autism— adhd asks for more stimulation which can set off autistic overstimulation. Most public spaces are not designed to accommodate the mental health needs of people with autism and co-occurring mental health issues; it's not even considered when planning spaces. Traditional and the most accessible forms of therapy also do not effectively treat mental health conditions plaguing autistic people.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	
What additional research is needed to help address co-occurring conditions for autistic people?	Obviously there are many strides to be made in research but the biggest issue is that so many health practitioners and counselors/therapists are not privy to or taught the findings of this research so they are unable to effectively help and treat their autistic patients. Particularly adults
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Making them free and widely available. That's the biggest hurdle.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	the glimpse into a world where we were provided with UBI without being required to work in overstimulating environments was really lovely as a neurodivergent person. But being forced back into public, removing all logical protections and seeing how individualistic people behaved absolutely made anxiety, OCD and depression worse especially amongst the neurodivergent population.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Increased remote work and remote access to public life was great, increased Telehealth services have been helpful as well. But the going against logic and pushing vulnerable people back into public without any real safeguards is a huge negative.

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I've had chronic insomnia since I was a child, as well as acid reflux, and hemorrhoids. I've had asthma since I was born.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	drug addiction and alcoholism.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I also have adhd.
What additional research is needed to help address co-occurring conditions for autistic people?	how the hell would I know I'm not an expert. if I had solutions I would be using them
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	there are multiple large companies in this country that have customer service so bad their reps can't even have a decent conversation with autistic people. it causes endless frustration. it should be part of the ADA that customer service has to be able to communicate with autistic people effectively
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	it's turned me into a recluse.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	you just asked that question

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory challenges have been the most significant for me, especially in workplace situations. I found it impossible to work in a noisy, artificially lit environment with people all around me. It takes enormous amounts of energy to keep on task and mask my physical and mental discomfort.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	The combination of anxiety, depression, ADHD, and autism wrecks havoc with my brain. I have never been able to sustain a relationship with another human because I'm terrified to be myself with them and hyper vigilant for bullying and betrayal. Bullying from other people is not listed, but the most devastating part of autism is how other people treat you. I find myself completely alone now and probably the most comfortable I've ever been.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I also have dyscalculia, which is a condition that is not widely known or understood. I didn't know it about myself until recently. It caused widespread financial problems for me, especially in conjunction with spending impulses and hyperfixation.
What additional research is needed to help address co-occurring conditions for autistic people?	Researchers should trust autistic people more when they are relating their own experiences. I spent 60 years without knowing what was going on with me because as a girl and woman, no doctor ever even suspected. No one ever talks about how strongly hormones affect autism and ADHD in women. We definitely need more research into fluctuations in estrogen, such as menstruation, pregnancy, and menopause, and how it affects us. Menopause tore the mask right off my face and I can no longer hide myself. Which makes work and relationships extremely difficult, if not impossible.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	The medical community needs to stop seeing themselves as the autism experts. They aren't. In fact, most have outdated, rudimentary ideas about what it is. Having to put our faith in some random medical doctor for diagnosis (and spending \$1000s to do it) is ridiculous. We need doctors who are certified by some method, and preferably, autistic themselves. Their understanding of women with autism and/or ADHD is especially bad. Actual people with autism are the experts and should have a larger role in formulating tests and treatments. Autism is not a disorder and should not be thought of as such. It is a neurotype.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	Thankfully, I have not contracted COVID. Being a hermit and working remotely counts for something!
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	My life was not impacted as much as allistic people. I was already working remotely and I live in an RV by myself. I'm glad to see more remote work available, although the number of applicants for each job has greatly increased, and because employers still put so much stock in how well we interview, rather than our skills, it's more difficult for an unmasked autistic person to gain and keep employment. It's also great that tele health services have increased. Doctor offices are sensory torture chambers for me.

in-person social interactions and obligations)	
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Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual; Researcher
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory and motor challenges, hypermobility and proprioception issues, IBS / IBD, autoimmune disorders. High lack of recognition for female autistic individuals and their different ways of displaying symptoms.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	ADHD, anxiety, PTSD (specifically from the need to mask AND high risk of early childhood abuse). All are federally financially unsupported past childhood / age 26, particularly when the person/person's caregivers cannot financially afford proper testing and assessments for autism and comorbid psychiatric disorders.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Lack of resources for alternative forms of learning and communication beyond K-12. California colleges (community through postgrad) have poor to no resources for ancillary courses such as basic arithmetic, social skills, and occupational therapy-based classes on writing / learning needs.
What additional research is needed to help address co-occurring conditions for autistic people?	Hypermobility disorders such as Hypermobility Spectrum Disorder and Ehlers-Danlos, stress-induced autoimmune disorders. Also, there is a need for affordable / free assessments for adults that specifically look for dissociative-type symptoms and recognize those symptoms and behaviors as low-support / Levels 1+2 Autistic people's masking.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Adult insurance coverage for occupational therapy, financial aid for community college / adult school classes NOT required for university but NEEDED for personal and academic success. Higher affordability / tax deductions for AAC devices / American Sign Language courses and greater access to specialists (Speech-language pathology, neurology, occupational and physical therapy, etc.) Specific resources allocated for Black, Brown, and Queer Autistic people and their families, as well as bias-sensitivity training for healthcare providers and teachers. More federally-covered options for alternative treatments beyond ABA therapy. Protections against being exploited via underpayment from jobs, stipends for small companies to create ADA-compliant workplaces. Federal housing specifically for low-support needs Autistic adults.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	PTSD, lack of timely healthcare appointments, housing insecurity, impediments from finishing school online and missing out on SLP / special education courses
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced	Increased telehealth, but decreased concern for immunocompromised individuals (including Autistic individuals, who are at higher risk of comorbidities). Increased wait times for doctors appts due to greater need for HCPs than the current amount of professionals available. Compassion fatigue from caregivers / lack of financial support for overnight and evening respite care. Burnout from underpaid and overworked professionals both in schools and in healthcare settings

in-person social interactions and obligations)	
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Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Inability to explain what is wrong, inability to verbalize how much pain we are in/our symptoms, increased pain tolerance that can lead to making injuries or illness worse, symptoms of illness/colds can cause sensory issues and lead to meltdowns, feeling useless and unable to do what everyone else can.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Inability to verbalize what is wrong, very self aware making it hard to change behaviors or thought patterns/attitudes, self-harming behavior caused by meltdowns, meltdowns in generally are traumatizing and physically exhausting, easily frustrated
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Never receiving aid for cooccurring disabilities, forced to verbally communicate
What additional research is needed to help address co-occurring conditions for autistic people?	Research done with actual autistic people running the research or at the very least consulted, focus on the autistic individual and not the family or caretakers
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	More financial benefits that are easier to live off of and get, more jobs that are doable and won't cause burnout or meltdowns and aren't exploitative, more care and support for autistic adults
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Extreme isolation, feeling like I'm younger than I am, loss of experiences and milestones, sudden extreme changes, frustration with technology/post-pandemic work life, loss of social skills

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	Sensory issues, changes in pre frontal cortex leading to lesser executive functioning contributing to difficulties managing daily tasks and creating delayed emotional processing (ie takes days to weeks to process a single highly emotionally charged event), constantly fatigued, POTS, Ehlers Danlos, Binocular vision disorder, PCOS, Hashimotos, Sjogrens, Auto-immune disorders, low immunity to common colds/flu etc
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Depression, Anxiety, ADHD, Suicidality, Schizophrenia, Bi-polar Disorder, NPD
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	Delayed speech, delays in learning to read and write, Dyscalculia, Alexithymia
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Equitable access to services, insurance coverage, patient portal with electronic communication to access services without needing to always directly interface with someone on the phone
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	

Name	Anonymous
Demographic	Autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	I don't feel qualified to speak on behalf of others experience. However, I can say that there are many autistic individuals who live with Ehlers Danlos Syndrome and its co-morbid conditions Mast Cell Activation Syndrome and Postural Orthostatic Tachycardia Syndrome. I am one of those individuals. For me my most significant physical health challenges are joints slipping out of place due to hyper mobility and Ehlers Danlos Syndrome as well as gastrointestinal issues related to both Mast Cell Activation Syndrome and Hyper mobile Ehlers Danlos Syndrome.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	Again, as an Autistic individual, I do not feel comfortable speaking on behalf of others but, my experience indicates that social anxiety has been the hardest as well as not getting a diagnosis until I was 31. I spent so long struggling and I did not know why.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	I also have ADHD I struggle between needing a solid routine and wanting spontaneity.
What additional research is needed to help address co-occurring conditions for autistic people?	
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	As a lower support needs autistic person, getting access to more supports in terms of learning how to access accommodations, and housing support as often our job can be put in jeopardy due to sensory aversions.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Less access to diagnosing providers and

Name	Anonymous
Demographic	Autistic individual; Family member of an autistic individual
What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)	My sleep disturbances and insomnia are some of the worst symptoms. Followed by gastrointestinal problems such as IBS, diarrhea, constipation. Sensory issues are also a problem but more manageable for me.
What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)	I have treatment resistant depression, anxiety, adhd, and very very bad suicidality. Because of the extent of my depression, I'm unable to get a job or finish my college degree even though I only need 5 more credits to finish. Getting up in the morning is nearly impossible as I'm immediately plagued by aggressive suicidal thoughts.
What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?	The most challenging aspect is not being able to go to school or work even though I'm an intelligent and once productive individual. It affects my self esteem that I cannot function in society.
What additional research is needed to help address co-occurring conditions for autistic people?	Research on how to train therapists to be autism friendly. Most CBT and DBT therapy modalities are useless for autistic people such as myself who have trauma.
What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)	Programs to help autistic adults integrate into society/ find community. Insurance coverage of more therapeutic services.
What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?	After I got covid, my brain fog and confusion got worse.
What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)	Positive impacts were increased remote work/school. However, this has not lasted as finding remote job opportunities is incredibly hard right now. Negative impacts have been increased isolation and disruption of services.