Note: This document contains reference to sensitive topics that may be triggering for some individuals. Comments containing sensitive material are indicated within the document.

IACC
INTERAGENCY AUTISM
COORDINATING COMMITTEE

Public Comments

October 11, 2023

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Oral Public Comments

Nicole Corrado

Moving Out as an Autistic Adult

I, like many adults, have wanted to move out independently to my own home. As an autistic person, this was harder to do than the average person. I was on ODSP, unemployed , and living with my parents and siblings. I had lived in Toronto all my life, but found Toronto to be rather busy. I wanted to move to somewhere else, where I did not have any baggage from my past. Moving to another city, where I never lived in before, would allow me to reinvent my adult self. I had lived at the same Toronto address for 25 years as the "autistic kid". Moving out to another city felt like the only way to move forward.

It was very difficult to find anything affordable in Ontario, but I found affordable apartments in Beaconsfield Quebec, a suburb of Montreal on the West Island. A province that speaks French rather than English feels different from where I used to live, which further distances myself from negative associations with my home in Toronto. The memories I have as a child visiting relatives in Quebec were positive, associated with happy memories of vacationing and visiting my extended family.

The first apartment I moved to in Beaconsfield did not work out. My grandmother, who lived in Montreal West Island, died shortly after I moved to the first apartment, which augmented my stress and separation anxiety of moving out on my own. That apartment was in a condo owned by a board that did not understand autism and my unique needs. My parents later found a basement apartment in Beaconsfield on Facebook Marketplace in a residential neighbourhood that was owned by a laid back person who lives upstairs. Having less people involved in the rental process was the key to success.

Connecting with the right people allows me to access support when I need it. The place I am living in now is very close to churches, parks, a local farmers market, a library, and other "third spaces" to meet people who can support my needs. I also live five minutes away from relatives who can support me. Being independent from my parents involves being interdependent with caring neighbours, some of whom are neurodivergent themselves. I walk everywhere, so having everything close by is really convenient. Navigating the city by transit is something I still need to learn, and I intend on doing that with my cousin, who loves transit and is also autistic.

For the most part, I find living on my own both exciting and rewarding. I find Beaconsfield very friendly. Beaconsfield is small, so everyone knows their neighbours, who introduce me to more neighbours. Being a small city connected to a large city means that it is quite navigable by foot and by transit, without having the sensory overload of of a large city.

Going to local churches has reduced stress. The churches in Beaconsfield are very accepting of a variety of people. The church that is five minutes from my house has a pastor who is accepting of everyone. I do not feel I need to mask my autism as much at these churches, (though no one has asked about my autism either). Not only does going to church provide a social opportunity, it also encourages me to bring my worries to God, rather than deal with them myself. I know I could pray anywhere, but there is something comforting about praying with other people.

Meal planning is a bit of a challenge, as I have trouble with money and often overspend at the farmers market. I find an organic outdoor farmers market, while expensive, is far less overwhelming than a conventional grocery store. Since it outside, it is less crowed, less bright, and less sensory confusing than a grocery store. There are buskers playing live music, and I love talking to the venders and meeting up with neighbours. I am vegan, so having access to organic fresh produce bought directly from the farmers is important to me. I need to learn how to cook, but right now, I buy ready made vegan meals from a South Asian vendor and eat raw organic vegetables. My parents still drive in from Toronto and bring me groceries and other essentials, though I would like to get executive functioning support in shopping with one of my friends and neighbours from church.

I still need to find a source of income; I am no longer on ODSP, and am relying on my parents to pay the rent, groceries, toiletries, and other essentials. Finding a job, and supplementing with Quebec disability pay would take some of the burden off of my parents. Although Beaconsfield is anglophone, I need to learn French in order to find any work in Quebec. Learning French would help increase my social skills too, because I could connect with a lot more people.

I still have issues with keeping a good schedule, since I do not have another person keeping me on task. Transitioning from wake to sleeping at night, and from sleeping to waking in the morning is hard. I have been walking to a daily church service; it keeps a routine, it is social, and reduces my anxiety. The daily exercise in the morning removes some of the stress that I experience from the transition to living alone. Creating a routine and developing good time management is something I am working on. I hope to continue to make connections with the community as I settle into my new living arrangement as an independent adult.

Written Public Comments

Research and Service Needs, Resources, and Policy Implications

Note: The following comment has been redacted.

Autistic Teenager, 16-Years-Old

Hello! My name is [redacted]. I'm currently a 16-year-old living in Bellevue, Washington, only 12 minutes away from the Microsoft Headquarters, 16 minutes away from the Facebook Reality Labs, and 10 minutes away from Nintendo of America. I've been surrounded by tech all my life and have noticed the distinct culture this area has compared to areas that are less tech centered.

I've read your work in the study "Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2018" and I found your findings that only 1 in 44 children have ASD surprising, because it seems I know far more people in my life who are eligible for diagnosis. However, seeing how much these results ranged by state, specifically less tech centered states like Missouri and states with a prominent tech industry like California, I noticed a pattern. Based on this research, I've developed my own hypothesis: computer programmers and those in stem fields are more likely to fit the criteria for ASD, and therefore tech hubs most likely have higher rates of people with ASD. By proving this hypothesis, we could lay the foundation for further research into autism as not just an individual's disability but also the impact of different neurotypes on various societies.

I have a couple of ideas for methodology, but my main idea would be to take a cluster sample from one programming team in a tech company and one marketing team from a non-tech company, to administer a self-assessment that can measure autistic traits. While this wouldn't be a formal diagnosis of any individual, we could get a general idea of if it's statistically probable that the average computer programming team is more likely to have more autistic members than a team unrelated to computer programming. I would love to get the help of a professional institution, especially one that has already done such extensive research on ASD such as as yourself. Please email me back if you're interested at [PII redacted]. Thank you!

Anné Hill

I believe that more resources on abuse of disabled people are needed. I've looked far and wide and found very few. I looked up abuse of disabled persons, and all I got were a bunch of articles about caregiver burnout. That is not helpful at all. Considering it is easier to isolate disabled people, there should be many resources on this. This bothers me a lot, so I decided to make this comment. Thank you.

Brittany Daniels

Why do most state autism insurance mandates not get rid of age limits, meaning that all ages of autism can get their needed therapies (OT, PT and speech therapy including dir Floortime) are all covered under health insurance up to a certain amount each year?

Rachel Kubiak

As a PhD epidemiologist and mom to an autistic child, I see a strong need to invest in occupational, speech including AAC, and mental health therapies that support people with autism. Alternatives to ABA supported by robust research are needed. Research groups that include, or better yet, are led by autistic people should be prioritized over others. At a minimum, the research must be a collaborative effort with all parties having a seat at the table. Anything less risks being ableist or irrelevant, both of which are a waste of funds. There are far too many small, poorly designed, and/or poorly analyzed projects and far, far too few robust studies assessing neuro-affirming goals.

Lisa Cooley

Increase participation in research on autism with non speaking people who are on the autism spectrum to support learning more about their needs.

Gwendolyn Harper

My name is Gwendolyn Harper. I would like to talk to you today about autism research. I think the IACC should tell the government to pay for autism research conducted by autistic researchers and that is primarily intended to benefit the autistic population.

I think this kind of research is important because we know so little about the phenomenon, and what we do know is generally fenced in by older scientific models. We need a totally rethink!

Only six of the 41 individuals responsible for making decisions that affect thousands of us are actually on the spectrum and of them, none of them are with the Federal government. As an American citizen, tax payer, writer, poet, artist, and activist with ADHD, who is on the Autistic Spectrum, and who has years of childhoood medical trauma associated with medical and psychiatric abuse at the hands of those who wanted to know "what was wrong with me," I urge you to strongly reconsider any funding or authorization for any research that is not conducted for the primary benefit of the autistic community. Ideally that research would be conducted by those of us on the Spectrum for our benefit; not the benefit of Pharmaceutical manufacturers or other High Dollar Political Donor Groups.

I think the IACC should listen to the voices of autistic people the most. Good and valuable research can be had and it can improve the lives of autistic people and the communities in which we belong. Research that is more directed rather than at some global “solve” is far more important to the public good and the benefit of all. It is important to autistic people, and it might answer questions we have about our lives. It could solve problems autistic people have, so we can live the lives we want.
Thank you for reading my comment. Sincerely, thank you.

Kathryn Hedges

I am an Autistic adult who is frustrated by seeing our limited research dollars wasted on yet more genetic "causes of autism" studies and other deficits-based research. What I support is a new generation of studies exploring how to make Autistic people's lives better today, designed in collaboration and consultation with Autistic people. We know that sensory sensitivity can be very distressing--what interventions are effective? We are beginning to prove that Applied Behavioral Analysis has many deleterious effects, but we don't have scientific support for alternatives yet. We know that many Autistics fall through the cracks of the social safety net because they are "too high functioning" for state developmental disability supports under criteria written during the DSM-III Kanner era that only included 1:10,000 Autistic people (and only males). We know that the ASD screening tools often overlook girls and women--how do we update those measures? How do we educate medical professionals about the changes in ASD criteria over the past four decades and how to support Autistic patients? These are the research issues we need to study, not whether a certain gene makes mice "act autistic" when mutated.

Lean Firestone

I am an autistic adult. I think the funding for autism research should be targeted at early identification and the delay in primitive relfexes. More pediatricians should be aware of these differences in development and Occupational therapy should be contacted. Speech therapy, maxofacial therapist, physical therapist and other medical professionals could be involved infant or toddler development aiding in growth. This would not remove autism symptoms but could help to encourage more "typical " curve of developemtal growth.

Finn Gardiner, Autistic People of Color Fund

I am writing as the director of policy and advocacy for the the Autistic People of Color Fund, an organization that promotes the advancement, inclusion, and integration of autistic people of color through microgrants and systems change advocacy. We engage in policy research and community-led advocacy to advance more just outcomes for disabled people that affirm our humanity and respect our dignity.

As an organization led by autistic people who live at the intersection between disability and race, we encourage the Committee to adopt policies and recommendations that are based on autistic people’s needs, priorities, and interests, rather than focusing primarily on our supporters? needs.

For this series of recommendations, we will focus on community living, healthcare access, and education, though these are far from the only issues affecting autistic people.

First, we recommend research on community living services and outcomes for autistic people, including supportive decision-making for autistic people, especially those with intellectual disabilities or higher support needs, case management and other services, and the transition from guardianship or institutionalization to community living. All these research projects should consider the effect that systemic racism has on accessing services for autistic people. We would also like to see research about racial disparities in guardianship, institutionalization, and other restrictive settings, and how advocates, nongovernmental organizations, and policymakers can mitigate those disparities to improve outcomes in community living.

Second, we encourage IACC to promote and pursue research about healthcare access and outcomes for autistic people that (a) takes into account racial disparities in diagnosis, treatment, and outcomes, (b) considers the influence of disability and health stigma on healthcare (e.g., general disability stigma, weight stigma, intellectual disability stigma, and (c) acknowledges the intersection between autism, race, and other social factors, including gender, sexual orientation, cultural background, immigrant/refugee status, socioeconomic status, and educational status. This work should draw on critical perspectives on medicine and health, including principles of epistemic justice that treat disabled people as valid knowers of themselves, their conditions, and the help they need.

Finally, we call for more and better research about educational attainment and experiences, with a focus on disproportionate discipline, the school-to-prison pipeline, and segregated special education programs. Black and Brown students in particular are already more likely to experience discrimination in the classroom than their white counterparts, and these disparities are only compounded when we also consider disability. According to research from the National Council on Disability and other government bodies, students receiving suspensions and expulsions are more likely to have disabilities. Systemic racism also increases the likelihood that students will be in segregated special education classrooms where they are unable to learn alongside their nondisabled peers. Using disability as a pretext for racial segregation is not a new practice: it was common in post-Brown v. Board schools, and it is profoundly saddening to hear that these methods of exclusion persist.

Christina Augliera

I urge the continued pursuit of funding for autism research to discover causes of autism and potential treatment for individuals impacted by autism.

Daniel Koizumi

Many autistic people have difficulties hearing people speak, even if hearing problems are not directly present. In my own experience as an autistic person, I don't have any hearing problems but frequently have issues hearing people speak when there is background noise. Most of the time, I have more hearing issues than the people I talk to, indicating that this might be an issue particular to me. I would like for the IACC to fund more research into the ability for autistic people to pick up voices when there is background noise like din. I believe that such research would allow me and other autistic people to understand hearing needs that conventional hearing tests may not detect.
Thank you for reading my comment.

Amanda Tipkemper

Cross-coordination of services and funding is unique across states and sometimes within[cross counties], creating inequities as well as issues impacting care, safety and welfare. Families continue to be primarily responsible for system navigation, if they are aware of the existence of some systems. System navigation requires a level of prowess from trained individuals who talk the talk and can translate the acronyms, and can be next to impossible for a parent who does not [or cannot] develop the skillset. Autistic youth in foster care are falling dangerously through the cracks. Add race, mental health condition, etc., and there are cracks within the cracks. Systems in Ohio refuse to work together to

ensure the highest quality of care. For example, county developmental disability board refuses to qualify a youth who is currently in the care of foster care, resulting in the youth being a hot potato that gets passed with little to no coordination. How are we supporting the youth who do not have parents/caregivers who can serve as advocates?
Aging parents continue to be the fail-safe for their adult autistic children, which has an impact that ranges from terribly unaffordable to down-right dangerous. Supporting the Lifecourse [e.g.] is a great tool, however, the onus remains on the autistic individual and their family/ network.
There is little to no assistance for older autistic adults who did not qualify for services in their youth, prior to IDEA applications. Without a formal diagnosis prior to age 22, these individuals aren't even able to try to qualify for eligibility at the county developmental disability board. I have witnessed this too many times- a parent in a nursing home and an adult with undiagnosed or late diagnosed autism who does not have the right support, resulting in homelessness, hospitalization, dangerous behavior, etc. Instead of staying on the surface of this landscape, let's dig deep to the most challenging situations and create supports and a safety net that will ultimately create a more universally designed system.

Jim Mavity III

I feel that I have deserved a lot of respect from everyone in the autism advocacy network and help I need. I have not arranged any time or place to be involved in certain meetings but there has been so much I have made improvements on. Therefore I feel like it's best to help autistic people understand certain things especially we don't live in a reality we use to live in but we should always provide tools to understand these thing's.

Tracy Moniz

I miss out on a lot of content because I don’t live in Massachusetts. I live in New Jersey and I still have trouble navigating the website to find some sort of community connection while also facing economic hardships. I am an autistic non-binary person who simply would like some closer representation, especially in the northeastern part of the United States.

Research, Services, and Supports for Adults with Autism

Brittany Daniels

Why do most states in the USA not include anyone diagnosed with autism of any age and just include autistic people up to 16, 17, 18, 19, 20 or 21 when it comes to these Autism Coverage Bills that require autistic children's therapies be covered up to a certain amount under health insurance? I am asking the previous question, because as a 36 year old autistic woman diagnosed with four other disabilities can currently only get limited amounts of needed speech therapy, 40 sessions per year covered under health insurance here in Georgia especially when I need more than 40 sessions of speech therapy covered by health insurance which may not happen at all.

Josh Irby

I would like to talk to you today about
autism research.

I think the IACC should tell the government to pay for autism research about autistic adults. Most autism research gets done just about autistic kids. But autistic kids grow up into autistic adults. It's important to do research about autistic adults, too, especially those that present differently than the outdated stereotypes traditionally associated with autism (male, early childhood, white). This kind of more expansive research would help many people understand themselves more and to shed light on a subject that little is known about currently.

I think the IACC should listen to the voices of autistic people the most. And include autistic people as researchers.

Thank you for your time

Ruth Horowitz

When will services be available fir adults? So many adults get missed as children. When we get diagnosed we are often in crisis and there are no services for us. Those who self diagnose can't find a way to get diagnosed because options for adults are so few and do costly.

The following comment has been redacted.

Rick Grossman

Diversity is important in all areas of service and research. Then why is 2/3 of the Autistic Community completely ignored?

Adults on the Spectrum receive no services. There is no research. No one even bothers to find out what their needs are. Even when there is a focus on adults, it is merely the transition to adulthood.

We don't ignore adults with physical disabilities. But for some reason, once someone has reached the age of majority, they are invisible as Autists. Find a doctor for an adult on the spectrum. Find a social service agency that offers some help in relating to neurotypicals.

Adults on the spectrum have higher physical and mental health problems. There are higher rates of divorce, isolation, homelessness, poverty, police abuse, depression, chronic diseases. They earn less than others. And no one [redacted]. Find a penny spent to help adults on the spectrum--you will need to look hard.

Is there any other disenfranchised community that ignores those who become 21? Do we stop addressing racial discrimination for POC over 21? Do we ignore the needs of the hearing impaired who need translation once they are no longer teens? Do we ignore diabetics past college? Are ramps unneeded in senior communities?

And even though 2/3 of the Autistic Community is over 18....they are completely ignored. OARC must be inclusive in all of its work. Autistic children become Autistic Adults. We do not graduate. We are not "cured." We exist. To ignore us is as eggregious as if you were to ignore Autistic POC.

Please address the institutional prejudice. At least accept we exist. And take responsibility for completely ignoring the needs of 2/3 of the community.

Kris Grenier

I am writing as an autistic adult who is deeply invested in the advancement of autism research and the improvement of services and support for individuals on the spectrum. I would like to emphasize the importance of allocating resources to investigate two critical areas that have profoundly impacted my life and the lives of many in the autistic community.

Autistic Burnout and Employment Strategies:
It is a stark reality that the autistic population faces disproportionately high rates of unemployment and underemployment compared to other disabled populations. I speak from personal experience when I say that autistic burnout can be a debilitating and pervasive challenge. During my 20s, I endured a period of autistic burnout that confined me to my bed for 17 months. This phenomenon is vastly understudied, and its effects on the well-being and employment prospects of autistic individuals are profound.

I urge the IACC to support research initiatives that delve into the dynamics of autistic burnout, seeking to understand its causes, triggers, and consequences. Furthermore, it is crucial to explore and develop strategies that can help autistic employees prevent burnout and thrive in workplace environments. By addressing this issue, we can work towards creating inclusive employment opportunities that empower autistic individuals to fully participate in the workforce.

Alexithymia and Chronic Illness in Autism:
Many autistic individuals, myself included, face challenges with interoception and often experience alexithymia-a condition characterized by the difficulty in identifying and articulating one's emotions. Simultaneously, a significant portion of the autistic community struggles with chronic illnesses, which

may be exacerbated by heightened anxiety or other emotional states. The overlap of these conditions is an area of research that holds immense potential for improving healthcare and mental health support for autistic individuals.

I implore the IACC to allocate resources towards research efforts aimed at understanding the complex interplay between alexithymia and chronic illness in autism. Such research can lead to the development of tailored interventions, enabling healthcare providers and mental health practitioners to better address the unique needs of autistic patients. It could ultimately improve the quality of life and well-being of those facing these intersecting challenges.

In conclusion, I want to express my gratitude for the work that the IACC has done in advancing autism research and support services. However, it is essential to recognize the urgent need to investigate and address these critical issues. By prioritizing research into autistic burnout and the intersection of alexithymia with chronic illness, we can take significant steps toward fostering a more inclusive and supportive society for autistic adults.

Thank you for your dedication to advancing the understanding of autism and for considering my input in this crucial matter.

Justin Acta

I'm writing as a person who has been twice diagnosed with autism both as a child and adult. Unfortunately Autism does not get the research that the Autism Community needs. Much of the research that does exist is focused on children with Autism with little research done for Adults with Autism. We need to expand research on Autism to study challenges adults with Autism face and to better understand the needs of Adults with Autism and to understand associated health conditions that affect people with Autism.

Sacha Greer

There is a paucity of research focusing on autistic adults, especially regarding the intersections of autism, race, gender, and class. Furthermore, resources for autistic adults are either extremely hard to find or prohibitively expensive. Getting a diagnosis for autism is required for accommodations, yet getting a diagnosis as an adult is exorbitantly expensive ($1500 - $5000) and it is rarely covered by insurance. Please devote more funding to research, resources, and diagnosis accessibility for all autistic adults. Thank you.

Rebecca Derr

Hello, I am autistic and have a comment.
First, while looking at research on autism I noticed a lot of it was on white, male kids. I am neither male nor a child, and am a little concerned and wary with the prospect that no physiatrist, or anyone for that matter, has any idea how a person like me functions in everyday life. I understand that autism presents differently in females, and would love to see more work to better understand these differences. How much is biological or social! Anyway, I would also like to know more about autism in those with

intellectual disabilities; I am curious. I would like some research done on different methods to raise an autistic child so that the child is most likely to be functional; that is, the adult can make their own food, do their own laundry, clean their own house, what education level was achieved, what is the average income? Well, some of those questions could be answered by a study that only focused on adults, but I would like a general consensus on best methods for raising a child with autism. I feel that my own upbringing could have benefited from such knowledge, since my mother basically had to figure it out on her own and, according to her, she did get some things wrong. In general, I would like more information about how an autistic adult would function in society. I have heard that autistics deal with grief differently, and am curious about that. I would also like more information about those who can not speak and how they communicate. I am curious about autistic education of facial expressions and body language, information I mostly gather from reading about professional interrogators. I am curious about neutral facial expressions and emotional stimming and if there are commonalities in the emotion that produced those actions among diverse autistic people; I hear the facial expressions are not universal, and hear a lot about happy flapping hands, and I would like more studies done than the singular one I read because it sounds so cool and I would love to know more! In short, I want more information that would make it easier for an autistic person to function in daily life.

I don’t think I should have to say this, but I don’t care what caused my autism, that has no impact on my daily life. The idea of someone removing my autism is frightening and sounds like assault and I wish people would drop it already.

Thank you for reading this, have a nice day.

Inclusion of Autistic Perspectives in Research

Lisa Cooley

Including more people who have autism spectrum disorders in research as subjects throughout the lifespan means that more research could be done to help determine the cause of autism spectrum disorders and improve understanding of autism spectrum disorders and other developmental issues that may be associated with autism.

Tanya Shields

Hello. I am the mother of an autistic child. I think it's very important that autistic people should be consulted in autism research. It's best to speak to those who are most affected by it to have accurate research that benefits both the autistic community and those who care for them. Cooperation is truly, truly important for the best results possible. I have become a better mother to my child by consulting autistic people on social media, who have helped me better understand my child and the autistic community as a whole. Thank you for taking the time to read this.

Julie Jones

I would like for autistic people to be included in the writing of the DSM and any/ all legisation that affects us.

Sikiti Toga

I believe hearing from professionals will boost my services,empower,enable me to advocate ,elleborata and implementing quality education for inclusion with a sustainability development.thanks.

Joshua Susser

I have read the recent report from the Surgeon General on "Our Epidemic of Loneliness and Isolation", and was disappointed that the focus was on so-called "normal" people who are lonely because of circumstance or breakdown of social infrastructure. Autistic people are arguably far more affected by isolation and loneliness than most people, but somehow are entirely omitted from the report. This seems outrageous. We are so easy to exclude that we are left out from the report about people getting left out.

We know that applying Universal Design concepts to accessibility creates environments and systems that work better for everyone. Curb cuts allow wheelchair users access to sidewalks, but also improve things for people with baby strollers. We know that making things better for the most vulnerable and most impacted often makes things better for everyone. If we work to reduce loneliness specifically for Autistic people, it's quite likely that will help lonely people of all sorts. But leaving Autistic people out of the conversation means nothing will get better for us, because the things that help most people won't necessarily help us. Creating more ways to do social activities with strangers is not the benefit for us that it might be for allistic people. It might actually make things worse for us, by shifting resources to programs we can't use at the expense of things that might help us.

Autistic people are desperate for help and support, but we and our needs are repeatedly ignored, even by initiatives that should be prioritizing us. It is demoralizing to see a major initiative like the Epidemic of Loneliness exclude and fail us so completely.

Ashia Ray

As a speaking Autistic adult and parent of a speaking Autistic child, I call on the IACC to hire non-speaking Autistic people into actual leadership (not token, not as unpaid labor) positions in designing policy around education, job creation, and community involvement.

We must also hire non-speaking Autistic adults to create curriculum and education materials for our public schools educating special education teachers on how to desegregate our classrooms and general classroom make public education inclusive for all types of communicators.

Educational Needs and Workforce Training

Angie Vigliotti
Advocate and IISS services for Celebrate Ability

Background Information:
With the budget discussion on the national level, Medicaid has been greatly affected (Senate Bill 202). This in turn has affected the Autism Waiver, as it lives under the umbrella of Medicaid. Celebrate Ability has voiced what we have heard from families and how this will affect us as an autism provider to our Autism Provider Liaisons the Waiver.

The Appendix K flexibilities that will end on June 30th, 2023 includes:
Transitioning youth 2020 to Jun 2022 will be disenrolled on June 30th, 2023 IISS hours will decrease from 40 to 25 hours per week.
Hours for other services, including FC, ALP, and respite will move back to pre-appendix K hours.
Families not utilizing at least 1 hour of IISS/TI/respite services per month will be disenrolled.
Participants who were deemed technically ineligible (due to being home schooled or not having enough IEP hours, etc.) will be disenrolled from the waiver.
With the passage of Senate Bill 622, ending the wait for families on the Autism Waiver waitlist, and with the shortage of staff in the state presently, this will create a critical shortage of services for our children.

Dear Representatives,

When my child finally received the Autism Waiver, we had just found out that the Department of Justice had investigated Frederick County Public Schools for unlawful restraint and seclusion of children in special education programs. My child had been on the autism waiver waitlist many, many years and was now 16 years old. I needed these benefits for transition into adulthood.
I applied for IISS services with an organization but they struggled to find a provider for my son in the area. Partially due to Covid but even before then, educators were lacking across the country due to school shootings and salary cuts. Service providers in special education can not be found and most people are not consistently trained.
I went back to my liaison and jokingly stated that I might as well quit my job to help my child. He had undergone a bunch of trauma in the public school system and I was worried about anyone ever working with him on life skills. The more information I discovered in his educational file, how he had given up a lot in middle school from being continuously thrown in a closet for hours on end just for shuffling his feet or because he didn’t have the right paper, I wasn’t sure he would ever heal from this. Reading restraint papers from third grade of him yelling, “I’m gonna tell my mommy.” He never told me, his mommy. Back then, even as a stay at home parent being very involved and educated about my child’s special needs, people handling him out of my sight were harming him.
My liaison came back and said I could work with my child under the Covid appendix k and in October 2022, I quit my healthcare job and started to work under Celebrate Ability after the application process and was able to be directly with my child again.
My son is currently on one medication now. He has a part time job and while he is struggling with the classes, he is taking 2 college dual enrollment courses virtually. He has 3 blossoming friendships, one rekindled from public school, and is attending camp for a second year. He is a completely different child now in the short time I have worked with him.

Why?
Because I meet with my family consultant weekly and take her advice. We brainstorm and work on life and social skills. I am able to see and speak with him about his triumphs and faults and help him work through them. We also get exposure to fellow parents for support and are able to help socialize our children that way. I also have been taking courses to become a Certified Behavior Technician, because I want to understand my child in every way possible.
Part of the reason we do not have educators or providers is because IDEA is not getting the funding it deserves. Special needs children are being abused in the public school system right under our noses.
As the fastest growing county in the state of Maryland, we do not have resources to sustain our children. We cannot continue to keep growing at an exponential level, without the continuation of parent support and parent educators. And while I firmly believe that all of the students have undergone some type of trauma due to Covid, and that we as educators should be approaching our children that way always, our neurodiverse community is at risk the most because it is overall a large minority.
I implore you to reconsider the current status of the appendix k for parent staff and make it permanent. A lot of us are scared to send our children with strangers that could possibly sexually, verbally, physically abuse or take advantage of them. Even if we were to trade with other parents, some of them may not be located in the same area, transportation may be limited, finances and resources to start over. Then it would take a long time for our child to become comfortable with that new person, if he or she even respects the new provider. A lot of us are running out of time for that and need help now in the adult life planning stage. Please allow us to continue for our children’s health and safety in the special needs community.

Addressing the Needs of Autistic Individuals with High Support Needs

Shaji Haq

We need more research for individuals with profound autism; we cannot assume that voices from the broader autism community, often fully verbal, applies to those who cannot voice their opinion (non-verbal). We cannot overlook the barriers that this marginalized population (i.e., people with profound autism) experiences in accessing services.

Stacy Dallss

I am the mother sole caregiver to my 28 year old daughter diagnosed with profound autism and intellectual disabilities as well and EDS hypermobility syndrome and histimine intolerance. She requires 24/7 care,she struggles with sleep and sensory overload... she has the mentality of a 4 year old. This population of people on the spectrum gets lost in the system, there are no community supports that fit her needs. Day support programs are 1 staff to 5 clients. However while she was in school she required one on one support and at home she requires 1 on one so how is it that now one on one is not offered ? Her care requires constant intervention and observation. And a 5 to 1 or even a 3 to one is not safe. So as a parent a concerned parent this is not good enough. This needs to change. Persons with profound autism should have the right to continue school for life. A safe consistent environment to be that suits their continues need for engagement and a safe environment to go. Where she can learn and reinforce her learning. This is a life long condition that is progressive especially when consistency is required. Autism is a spectrum disorder and needs to be looked at that way. The ones on the far end of the spectrum is extreme under served and even over looked. This is not right nor is it fair not only to her but to the caregiver who actually cares for them. Please consider making better accomodations for this small yet under served population.

Wilhelmina Murray

I have a profoundly autistic son in a residential setting. The turnover in his residence is rapid. These people desperately deserve a living wage. Most of them are from Ghana. Many of them are wonderful people. Others have given my son black eyes.
I pay $70 per hour privately to see my son 4 hours once per week. These are the only people who can work with my son since they know how to de-escalate his aggression. I have been hiring people privately for 10 years. I am Divorced. I cannot be alone with my son. Only recently my ex-husband and I have been working together with my son for 4 hours on Sundays. We are 61 and 68.
We always have PRN valium with us in case our son loses control.
My biggest concern is when we are gone. Without private pay for highly qualified autism pros, I am afraid my son will never get out. He does not gave day habitation services. He would need 2:1 staff and we are lucky to have 1:1, given Opensky chronic staffing shortages. Outside the US I AM CERTain Dean would not be alive today. I a eternally grateful to DDS, USA

Trigger warning: The following comment contains references to aggression, self-harm, and other sensitive topics.

John Saito

I am parent, guardian, and caregiver to an adult child with Profound Autism. To my part of the Autism community, that means . . .

Head-shaped holes in the drywall.
Boarded or blocked windows.
Bruises.
Bite marks and scars.
Concussions.
Detached retinas.
Months-long waitlists for medical services.
Years-long waitlists for social services (depending on state policy).
Emergency room visits that turn into stabilization unit admissions.
Anti-psychotics and anti-depressants.
Caregiver shortages.
Understaffed and undertrained special education teams.
Underfunded adult day programs.
Unsafe residential care facilities (with high risk of loss of placement).
Lifelong isolation and exclusion.
Parents afraid to die before their children.

For those like my daughter with little to no language, severe cognitive impairment, and unsafe behaviors (self injury, aggression), service shortages for Autism are much more severe, severely felt, and consequential to their very safety, let alone quality of life.

I urge the IACC to create a workstream or task force focused exclusively on the challenges, needs, and priorities of those with Profound / Severe Autism, because people like my daughter are at risk of being left behind and forgotten.

Kimberly Dick

I recognize and commend the IACC's pivotal role in coordinating federal efforts and providing advice on issues related to autism spectrum disorder (ASD). However, I feel compelled to bring your attention to the unique and pressing challenges faced by those living with profound autism. These individuals require 24/7 care, have a severe to profound intellectual disability, and have minimal or no language. They often face exclusion from disability programs, and there is a scarcity of appropriate educational interventions, adult programs, and supported housing tailored to their needs.

As a parent of a child diagnosed with autism, I have witnessed firsthand the benefits my son has received from available opportunities. However, I have also seen these same opportunities denied to the children of my friends, who struggle with profound autism. These dedicated parents have been advocating for the autism community for decades, yet their efforts have yielded little progress for their own children. The well-being of these devoted caregivers is also a growing concern, as they bear the heavy burden of care and face mental and physical stress without adequate support.

I urge the IACC to recognize the distinct needs of those with profound autism and to allocate resources accordingly. A focused approach towards profound autism, I believe, can lead to more effective policy-making, better targeted research, and ultimately, improved outcomes for those affected.

Thank you for considering my perspective.

The following comment has been redacted.

Robyn Johnson

My name is Robyn Johnson. I'm the mother of six children, including [redacted] who are identical 23-year-old twin girls with Profound Autism. [redacted] functions on 2-year-old level and is nonverbal with many self-injurious behaviors. [redacted] functions on a 7-year-old level with behaviors that are injurious to herself and others. Both require 24/7 lifetime care. There are so many current and future needs, but I'll focus on 3 things that could help right now:

1) Problem: The girls were approved in 2004 for funding and support under our state waiver program but we had to wait for the funding on list for 18 years (too long!). We are one year into being approved but the rules set in place are not in the best interest of [redacted]. I visited 10 day-programs and only one would accept my girls after meeting them. Sadly, it did not work out as it was not a good environment for their needs, they did not want to go, and they were suspended monthly anywhere from 3-7 days at a time due to behaviors. This became impossible for my husband and I to manage because we both worked full-time and we were in danger of losing our jobs. Due to the twins? challenges, requirements, and behaviors, we have not been able to find and then hold onto staff to come into our home either. There is also not enough funding to support the number of hours required. After taking family medical leave I had to leave my job completely, which has been a financial strain on our family. Waiver rules are set up where I can pay others to care for the twins, but I cannot be paid myself as their guardian. Sadly, this is what the girls request, and they are going to get better care from me than from anyone. I also cannot own or be on the deed of my house to do this. This puts all our future living security at risk. Solution: Have waivers allowing guardians to be paid to care for those with Profound Autism. Many of us must leave our jobs, which causes great monetary strain and then we cannot be paid for our caregiving of our adult children with Profound Autism. In my case I've had 23 years of training and experience and my girls are more comfortable with me and ask me to do it. Also, allow paid guardians the ability to own or be on the deed of their home. Providing a safe and stable residence for those with Profound Autism, and their caregivers, keeps those with Profound Autism out of facilities longer and is a more cost-effective option.

2) Problem: We cannot leverage respite because we cannot use family hires per our waiver rules. Our girls' behaviors and anxieties preclude them from being accepted and going into a center or having

strangers coming into the house. Solution: Allow family members who have spent years with these individuals who were specifically trained through us on how to manage them to be paid to stay so we can take a break. I cannot stress the importance of this. Those of us who are on call 24/7 for the needs of Profound Autism, sleep deprived, have other children, and work are desperate for help!

3) Problem: I cannot secure dental care for [redacted]. I am told by all [redacted] must be sedated in a hospital setting because of behaviors. Currently, there are only three dentists in the metro Atlanta area who will do this. All three don't take insurance, charge a $2500 fee to close their offices, and then the cleaning and hospital costs are on top of that. We realized we would have to pay over $5000 for one cleaning which we cannot do. This feels almost criminal to us, or at least like these dentists are negatively praying on special needs people. We live in fear of a simple cavity. This type of problem is a small issue for typical people and yet is monumental to those of us with loved ones with Profound Autism. We feel like they are denied basic human rights. Solution: Ease of dental care for Profound Autism that includes a covered annual hospital visit if needed.
I will stop here but I hope the little I've shared about our experience helps as you consider funding and legislation. If you would like to speak or meet with me, I am always happy to do so.

Thank you for providing a platform for my voice on behalf of [redacted] and our family.

The following comment has been redacted.

Leslie Lussier

My 20-year old son [redacted] has profound autism, requiring 24/7 care. I request that you please keep people like him, and my family, in mind as you complete your important work. [Redacted] is non-verbal and requires assistance in all his daily living skills, including dressing and toileting. He will never be able to hold a job or have a true friendship. He is a very sweet and affectionate young man. He loves to watch Sesame Street on his iPad, play in sprinklers and splash pads and go for walks at the mall with us or a caregiver.
Sometimes it feels like "autism awareness" has turned into "autism acceptance", and we can never accept the lifelong disability that autism is for [redacted] and about 30% of others diagnosed with this broad term. He will need care around the clock for his entire life. Who will care for him and other like him after parents die? This chilling question keeps me up at night. Again, all I ask is that you please think about this population and their needs as you do your important work.

Brandon Becker

People who require 24x7 care need additional, individual consideration. Broad obligations that "require" various types of care for everyone labelled "autistic" often don't address (and, indeed, are counterproductive) the needs of those children & adults who require 24x&7 care. Indeed, my experience is that the various "reform" movements have deprived my son of a meaningful work environment & instead substituted custodial care for a robust "community" engagement environment. It is a tragedy that some in the neurodiversity community choose to attack those of us who deal daily with the needs of those who require 24x7 care. I only can hope that the Committee will rise above the rhetorical posturing &, instead, address the the lived lives of the 25% (according to the Lancet study) of the community that require 24x7 care. Thank you for not leaving our loved ones on the dustbin of history.

Jill Escher, National Council on Severe Autism

As a preliminary matter we wish to express our skepticism regarding the value of submitting a public comment to the IACC. Despite voluminous submissions over the course of this iteration of the IACC from parents, community members, and even elite scientists, we see little attention to the concerns they express and almost no meaningful responsive discourse in the committee. Efforts to voice important ideas and draw attention to serious crises seem to be rather in vain. We consistently hear how the community feels its priorities are ignored and marginalized by the IACC.

That said, we submit the following.

Nearly 30% of autistic children (the percentage among adults may be higher) suffer from Profound Autism according to the CDC. In addition, 61.4% of children with autism have intellectual disability (ID) or borderline ID, according to the CDC (38% have full ID).

Yet the IACC spends a disproportionate amount of time on issues and concerns from those with the privilege of self-advocacy, self-expression, and strong cognitive abilities. The needs of those who cannot effectively self-advocate and who need the highest levels of services and supports seem to be de-valued and ignored.

We therefore request that 30% of each IACC meeting be devoted to the urgent concerns of children and adults disabled by Profound Autism (IQ under 50, or non- or minimally verbal) and at least another 30% be devoted to the concerns of those with ID and borderline ID that does not meet the stringent criteria for Profound Autism.

These topics include: medical interventions for treatment of severe behaviors; the desperate need for more inpatient and outpatient programs for both children and adults; the need for crisis interventions in all communities; the need for more residential programs to serve children with severe behaviors; the tremendous need for more options and models for housing and long-term care of adults with Profound Autism, particularly as autism parents are aging; among others.

To underscore this point, it is unclear from the October 11, 2023 agenda how the featured topic of "Mental Health" will be addressed. The mental health concerns of those with normal IQs typically differs considerably from those with ID. For the former, issues around depression, suicidality, gender dysphoria are often prominent. For the latter, issues of aggression, self-injury, property destruction are often prominent. Anxiety, OCD, and sensory sensitivity seem to be areas of overlap, however, the experience of these pathologies across the groups tend to diverge very substantially. The agenda as currently written does not provide any indication of what is covered under "Mental Health."

Moving forward, to ensure the IACC is properly addressing the needs of those disabled by autism, IACC meetings should very clearly delineate the forms of autism they are addressing with their chosen subject matter and ensure proportionality. The desperate and growing needs of those with Profound Autism, ID and borderline ID deserve full and urgent attention by this committee.

Deborah Gill

I fully support the statement from the National Council for Severe Autism requesting that time spent discussing issues be proportionally allocated so that the majority of the committe's time be spent discussing the huge gaping holes in services and supports for people with significant support needs. My son has Autism and ID characterized by screaming, aggression and self injury. We urgently need attention to topics such as community placements that will successfully support people like him. Psychiatric and other mental health supports to help decrease aggression and self-injury. Those experiencing significant challenges are the majority but are ignored to privilege the voices and needs of the cognitively intact and verbal members of the Autism community. Please devote proportional time and effort to the rest of the community as well.

Jacqueline Ceonzo

I have a 28 year old son with profound autism. He has a seizure disorder, is non verbal, can be self injurious, can be aggressive. He is in a cocktail of medications to control his seizures and behavior. He requires 24/7 care and always will. We shower, shave, dress him - he can feed himself and walk. The government has failed him. Under IDEA he was entitled to a free and appropriate education. There was no public school but we were able to sue and place him in an appropriate setting in 6:1:2 classroom with an aide. When he turned 21 he was no longer entitled to anything - his options? Adult day care with a ratio of about 6 participants to 1 staff ??? He is and has been a residential candidate. You need to pass legislation that will protect my son and others like him after parents die. Sen. Schumer has introduced a bill http://www.disabilityintegrationact.org/ I beg you to consider this or a version.

Jamie Cullen

I am the proud parent of a 21 year old son who was born with profound autism, developmental delay, chiari 1 malformation, sleep disturbances and aggression. We have been sued due to my sons aggression , We have had to sue to get him the services that he needs and he will never go to Harvard. Please don't forget about him. I'm a Mom but also a Social Worker, fierce advocate and worked in a level 4 Therapeutic day school for over 10 years but my journey started when I was 15 years old and worked at my first large group home. I am writing to say do not forget about our kids. By glossing over the word autism and my sons and thousands of others with autism and developmental delays you are not respecting these individuals, their families, the Doctirs and all the mental health and school employees that work with them besides the group home and home health care workers. Our kids need help and we need it yesterday. Is it fair that my son with profound autism cannot even find a hospital that will care for him in Illinois? We often hear we are not able to care for his mental health and high care needs so we are sent out of State. We need you all to start supporting us. Autism was 1 in 150 when my son was born 21 years ago. It is now 1 in 44. You cannot continue to ignore these numbers. We need change and we need it yesterday. Please remember all these people and their families matter. My son has to attend an out of State School Bc of his needs, he will never sit on your Board or attend College. He will always need 24/7 support and their are thousand like my son. I know bc I've worked in this field since I was 15 years old. I am now 52. Let's not forget about these individuals, please. Thank you for listening.

Gene Bensinger

Thank you for an opportunity to offer a comment at today's full committee meeting. But first, congratulations to Dr. Daniels on her recent, and well-deserved, appointment as our official HHS National Autism Coordinator. Coordinating, finding common ground, and advancing the voices of our diverse community of stakeholders, with its often conflicting priorities, is growing more complex by the day.

Federal activities and research around autism rest on a foundation of shared notions about the diagnosis and features of autism across the lifespan. Recently, these notions are struggling (and failing) to keep up with the pace of new discovery. Autism across the lifespan has been revealed as far more complex and dynamic than historic understanding. Diagnostic categories are proving to be fluid. Developmental trajectories are varied and unpredictable. Tools at hand are often employed with a disturbing randomness relative to individual need. This is no surprise to the IACC. You've heard from global experts about the inadequacy of the current diagnostic framework and often absent, or misdirected, systems of support typically triggered by an autism diagnosis. The complexity and dynamism of autism not only challenges the IACC to continually adjust its thinking to advise better approaches and best practices, it demands that stakeholders evolve, too.

The newly formed and rapidly growing, Profound Autism Alliance (PAA), an organization I've joined as a volunteer leader, reflects this evolving approach to autism advocacy. We're a large community of advocates and self-advocates focused on advancing ethical, evidenced based "Inclusive Research and Targeted Advocacy" for profoundly autistic people.

The term, "profound autism", is not a new, or separate, diagnostic category. Rather, it describes the typically unaddressed and intensive impacts that challenge the health, well-being, and lives of some autistic people 24/7/365. Despite representing over a quarter of the total autistic population, the needs of people with profound autism have been historically, and provably, subordinated in autism related research, clinical care, and community supports, and public policy. The PAA advocates solely to achieve equitable treatment and long term progress in these domains.

We encourage other underserved constituencies to overcome barriers in research, supports and services through targeted advocacy like ours. Going forward, the Profound Autism Alliance looks forward to offering the IACC, elected officials, and policy makers our deep and useful subject matter expertise and input on issues affecting profoundly autistic people. Thank you for your time and attention.

Katherine Durden

The need for permanent, stable housing and care for those affected by Level 2 and Level 3 autism is not being met now and will become more acute as parents of such people age and pass away. The neuro-divergent movement does not address this, but it is one of the main sources of economic and emotional stress for autism families, and puts the very lives of many autistic people in danger.

Angela Behrend

I am an aging parent of a beautiful young man who is severely impacted by autism and will need 24/7 care for the rest of his life. I am haunted wondering who on earth will care for him in the way that I have? He will outlive me and is extremely vulnerable.

Beth Lambert

Please advocate for research into the cause, prevention and treatment of autism. My adult son has severe autism. He is nonverbal and requires supervision throughout his day. When he was younger, he displayed SIB and aggression to the point where he had to be restrained in order to protect himself and others. He received quality ABA services as a child, so he is now able to hold a subminimum wage job where he is happy. I can't help but wonder how much more he could have done and how much better his life would be if he didn't have autism. Finding a cause and cure for autism will prevent others from struggling the way my son did.

Niria Alvarez

I have an autistic son who has profound autism and developmentally delayed. We live in the Central Valley Fresno and we have a nonprofit on behalf of my son called the Possibilities Center Empowering families through Autism resources ; we need more resources for our children a safe environment where they can socialize and come together their own recreational center we have a hard time finding grants to help raise the money we need; I'm asking for more grant money being used for servicing our autism community with educational and recreational resources . It's crucial to sustain a productive life for all our families .

Leigh Powell

I have a 29 year old son with Autism, ID, and Bipolar Disorder. His future seems hopeless to me. The systems currently offered within the Medicaid Waiver Programs are not appropriate for my son. He has severe and complex behaviors which would be escalated in the current offerings. I hear story after story of others like my son that end up dead, in jail, and more likely left to languish in emergency rooms or mental health hospitals for months or years because there is no other place that will take them. Adults with severe developmental disabilities need different options than are currently available. Please help address this service gap. The most vulnerable and needy citizens are not having their needs met. We need a continuum of choices so that everyone can have their needs met. So that everyone can truly have choice. "Progress" should not come at the expense of the most vulnerable and needy!

Karen Lepak

As adult children (with severe autism)age out of education resources,they are left behind mainly because they require 1/1services. Many have been at home in a " holding pattern for years and years with aging parents parent. Inadequate resources and years of waiting lists. Parents have quit their employment and many one one income. This is a disgrace and neglect to our families.

Raymond Lepak

The picture says it all. The pure love,the sadness, the constant on duty and the many sleepless nights, required to bring up a child with severe Autism. What does it take in the early years (pre-kindergarten) when your child screams, bangs his head in the wall or pushes his food to the floor. Is he in pain? (He's non verbal and cannot tell you) Finally in grades 1-5 what is he taught? (still non verbal he's kept in an isolated area so as not to disrupt other students. Does he know he can't read or partisipate?) He wants to have friends and have fun but cannot connect with his peers. From grade 6 to graduation he still hasn't been taught any life skills on how approach other children or behave in front of police. (does not know how to raise hands) Our politicians are walking our State but still cannot Help the severe Autistic children in their 20s, there are no programs to help these loving soles.

Melodie L Sharp

My 30 yr old nephew has profound autism. He requires 24/7 support. His family has worked very hard to ensure he has had the best education and support available. He is a very nice young man but is also basically nonverbal. More research is needed to understand more about autism.

Alexander MacInnis

I am writing to focus the IACC's attention on all the individuals severely impacted by autism and their families. These are primarily people who were either diagnosed with Autistic Disorder or who would have received an Autistic Disorder diagnosis but were diagnosed after ASD superseded Autistic Disorder in 2013. These days, commonly used labels include severe autism or profound autism. This is a heartbreaking, debilitating disorder.

By definition, the people I am talking about have severely impaired communication. This is not only, and not necessarily, a lack of speech. Some can spell but still cannot communicate. They cannot tell you their own stories. Many of them cannot care for themselves and cannot live independently. They need intensive, loving, specialized care all the time , 24/7/365. They cannot be left alone at all. Many show frequent signs of pain but often cannot indicate where it hurts. Severe sleep disruption is common and affects the whole family. Other symptoms are too disturbing to mention here.

Their immediate families and caregivers are the only people who know these individuals well and can communicate about them. Yet, they are often excluded as if they were not part of the autism community.

Life for these individuals and their families is very stressful and difficult. They need solutions now.

Even the best doctors have a limited ability to help these individuals, primarily due to the lack of research into effective treatments.

The vast majority of individuals with severe or profound autism will outlive their parents. We need a real plan for caring for them when their parents can no longer do it. The data on young people already diagnosed clearly show that the number of adults with debilitating autism will grow dramatically over the next few decades.

The IACC should actively seek more information about people with severe or profound autism. That means reaching out to their parents and siblings.

The IACC should study the trend in the rate of occurrence of new cases (incidence), preventable causes and effective treatments. Congress in 2006 mandated the NIH to do this work. People severely affected by autism and their families are still waiting.

Justine Neely

I beg the IACC to listen to the families of people with Profound Autism. Our loved ones will need 24/7 care through out their lives to stay safe. They are people who deserve dignity and need systems and resources for their lifetime. My son is 13 and I am terrified of the future and finding a place that will keep him safe and create meaning for him. Thank you for your attention and care.

Heidi Mann

I beg the IACC to listen to the families of people with Profound Autism. They are people who deserve dignity and need systems and resources for their lifetime. Thank you for your attention and care.

Rachel Nathan

It is essential that families get help caring for their loved ones who need 24/7 support. Having a family me we who needs this much care is overwhelming and they need as much public and governmental support as possible. The accessibility of care is extremely limited and it s very scary for families.

Gauri Govil

People with Autism need 24/7 care for their entire life. Please create policies to listen to the needs of People with Profound Autism so they get care 24/7. They have the right to dignity and care too and need a helping hand.

Rebecca Persson

I encourage the IACC to listen to the families of people with Profound Autism. Their loved ones will need 24/7 care through out their lives to stay safe. They are people who deserve dignity and need systems and resources for their lifetime to keep them safe and help them lead meaningful, engaged lives. Thank you for your attention and care.

Alessandra Di Credico

Dear members of the IACC, please consider the needs of people with profound Autism and IDD. My son, who is 17, will never be able to live alone and needs assistance 24/7. If left alone, he may wander in a street and get killed because he has no sense of safety. If left alone anywhere, he could collapse due to a seizure and nobody would notice. He cannot understand time and everything is scary when you don't know when it is going to happen. He cannot write and cannot read, but he's the most generous and endearing soul you will meet in your lifetime. I am utterly terrified at the thought that, when his parents will be gone, he's going to be alone in this world. Please consider his needs in your discussions. Thanks!

Darlene Borre

My son is 22 years old and has profound autism. He cannot read right or speak but he can use his iPad to request certain things that are important to him. He is very impulsive and will grab food off of a strangers plate or run across traffic without regard to danger, this makes community outings very difficult. He has severe self injurious behavior and has bloodied his nose repeatedly. He will not tolerate blood draw or vaccinations. He was forcibly restrained to get a Covid shot. Most medical professionals are afraid of him most medical professionals that we have dealt with have a little to no understanding of profound autism. He was rejected from several day programs when he turned 22. The day programs said they do not do one to one. It is the worst time to be an adult with profound autism And it seems that no one cares

Linda Cox

A 24-year old has the desire to communicate, to be engaged, and be respected for presumed competence. My son does not have these opportunities. He has profound autism and is non-verbal and his AAC device is never part of his engagement either in his group home, at his day program or out in the community. He is driven around in a van for community inclusion. He is suffering and now the medication for mood stabilization needs to be increased. I am advocating the best way I know how to provide insight into his needs. I am not able to get his vision even close to what he desires. As he molds into a new person, unable to communicate or find passion in his desire to be active, I worry about his mental health and his future. We need more training for those in the system of adult care to understand and raise the bar of accountability for themselves with proper training so our citizens with profound autism are able to be engaged in society at a level that provides good care and participation in society.

Rosamond Delori

As the grandmother of a child with profound autism, I urge you to provide support and appropriate resources for all children who have this condition. It has been heartbreaking for my husband and me to see the stress profound autism creates for the parents of a child with profound autism. It is a continual exposure to trauma, fearing for this child, who cannot communicate or keep him/herself safe without 24/7 supervision. Respect and support for the entire family system is crucial. We believe individuals with profound autism deserve care that allows them to live with dignity.

Rick Grossman

There is no doubt that children and those with more profound Autism need additional support. Even though there are twice as many adults with Autism than there are children, most commumities provide no support. Rates of homlessness, suicide, chronic illnesses, lack of medical attention, poverty, victimhood, shorter lifespans would receive major focus in any other community. But by pretending they don't exist, there's a pretty good chance they will be dead by the time someone checks.

Ignoring 6.2 MILLION Adults wtih Autism is the legacy of this commission. Count the extra deaths and ruined lives.

Jennifer Hayward

I am the mother and provider of all services for my 22 year old son with profound autism who requires lifelong 24/7 care.
He is currently at home and my husband and I worry constantly about his future.
When he turned 22, I was forced to quit my job as an RN to take care of him, as there were not any programs offered in the state of Maine that provided the level of care he needed. He is non-verbal, has bipolar disorder, epilepsy and phelan-mcdermid syndrome. He is incontinent, has limited safety awareness and cannot be in any of the day programs offered in our state due to the ratios of 3:1, as he requires 1:1 support. While I see the benefits of HCBS for the majority of those receiving waiver services, those benefits do not apply to my son. Under HCBS, my son has the choice to decide what he wants to do, however if given to his own device he would sit on a computer all day 24/7, how is this adding to his quality of life?
Even though my son has severe autism and cannot ever be left unsupervised, he still does not receive the comprehensive waiver in our state due to my husband and I being "young" enough to take care of him. If he even qualified for his waiver, we don't know that we would be able to find adequate help for him- we don't have any ICF's, intentional communities, etc. offered. What we have are group homes with a 3:1 ratio. Somebody needs to start looking at the needs of those severely impacted by autism and figure out another route for them, to help them when their parents are no longer able to. Please take a look at this underserved population and start having a discussion about how to best help them. Thank you.

Andrea Roell

Please support the people and the families affected by Profound Autism. They deserve dignified and compassionate care.

Gretchen Mather

My son is 13 and has autism. He will need care for the rest of his life. Please provide help for those who need 24/7 care for the rest of their life..

Amy L

As a mother of a 13yo boy with profound autism I am terrified of the future and pray that my husband and I will grow old and in good health as long as we can to care for our boy. It takes a village to care for the most vulnerable. Please help us ensure our children are not left behind. Help us keep them safe, healthy and care for. Alone we are weak but together we are strong. Thank you

Note: The following comment has been redacted.

Adrienne Benjamin

I am the Mother and guardian of a 27 year old woman whom I adore. She has Profound Autism and Intellectually Disability, and her needs are very significant. [Redacted] is totally non-verbal, nor is she able to effectively use a communication device. She needs help with every aspect personal hygiene, and is very active. Unfortunately, she has no safety awareness. Obviously, she needs constant care and will for the rest of her life.
I know that Autism is a Spectrum Disorder, currently diagnosed by the DSM 5 with 3 Levels. Those with Level 1 have very few needs, are fortunate to be independent and successful. I have observed your meetings in the past, and I am gravely concerned that the IACC puts its focus on Level 1 Autism. According to the CDC and the American Academy of Pediatrics the percentage of those with Level 3 Austin is between 25-40 %. I hope you begin to recognize the intense challenges facing these individuals and their families. We desperately need more resources, and more choices for our loved ones.
Thank you for this opportunity.

Nancy Maserejian

I am writing to ask the IACC to listen and help the families of people with Profound Autism. My good friend has a son with Profound Autism, and I see how worry and fear for his future strikes her and her family every single day.People who need 24/7 care through out their lives to stay safe, need our society and support groups to provide systems and resources for their lifetime. Help people with Profound Autism to live and age with dignity

Trigger warning: The following section contains references to suicide and other sensitive topics.

Mental Health Research, Services, and Treatment

Jess Cox

I am an autistic adult who was not diagnosed until I was in my late 30's. I have experienced chronic suicidality since I was an adolescent. I have struggled to find therapists who are competent and comfortable working with autistic folks and the particular struggles they encounter. I am also the group leader (mental health therapist, MSW) for an LGBTQIA+ IOP. We have a high density of autistic group members with high suicidality. When we discharge group members, we struggle to find austic (and queer and trans) competent providers for follow up care. There is such a dearth of resources, research, and understanding about how to autistic folks. If thinking about public (read financial/economic) impact, the majority of these individuals are incredibly intelligent but struggle to engage effectively and meaningfully in a world that was not built for them. The majority of them are unable to maintain employment because the environment and requirements are not accommodating of their sensory and capacity limitations. 90% or more are on medicaid and SNAP benefits and are applying for disability. This is the case despite the fact that the majority are very capable and have interests and skills they could use in employment if only there was space made for them. Meanwhile, the isolation and alienation they experience because they are not able to engage in the world meaningfully and effectively is the source of their chronic suicidality.

Jessica Tschida

In alignment with the University of Pittsburgh Autism Center of Excellence, I would like to submit a comment encouraging emphasis on better understanding of suicidality in neurodiverse communities of color.

Tosha Brothers

I have painstakingly prepared new recommendations for you, the members of the IACC, to consider. These are grave and pressing matters I wish to address that have not yet been discussed. My primary focus will be on the unique mental health struggles autistic adults face, and the dearth of research in areas where more targeted intervention is greatly needed.

I have provided two studies linking autism and anxiety. Although they support my points, I noticed an ableist assertion in this research that autistics with intellectual disabilities are less likely to experience mental illness than those without. Before advancing, I must say that more inclusive research into the mental hurdles those with intellectual disabilities face is crucial. Their struggles should not be overshadowed, misreported, or deemed irrelevant simply because of their intellectual disability. Better numbers around their experiences will assist us in understanding the full breadth of needs people have across the autism spectrum.

Now, I will illustrate how anxiety affects autistic individuals differently than neurotypicals. Especially regarding high sensory sensitivity. Despite searching, I did not find any study explaining the possible complications of having anxiety and sensory sensitivity simultaneously. Given that, I will relay what I have learned on my journey. While anxious, I felt my sensitivity go up manifold. I sensed wind in my head, detected different chambers of swirling vortices like an irrigation system in my brain, and, most notably, felt negative thoughts shape my grey matter in unproductive ways. It was a sensation of damage to my neurons, where one hemisphere would be hurt, only for the other to follow suit days later. These changes were permanent, with the only way of undoing them being to exactly retrace my steps and unwind each point of contact my brain and the thought had made. If I didn't, then my brain would suffer serious, lasting mechanisms that pervaded my mind and caused continual mental pain flooding out indefinitely.

This is an area that is lacking in both disability support and research. There are no known solutions, other than recognizing reactions and lowering the anxiety so the dangers of extreme sensitivity can be avoided. Although early intervention and integration therapy are valuable tools, more research into targeted techniques for dealing with high sensory sensitivity is imperative to those struggling.
There are little to no resources available for autistic adults who are suicidal. I have attached another study that explores this concept well. There are many reasons why autistics would be in more danger of having suicidal thoughts. Lack of support from peers, no belonging, and being at a higher risk from all forms of abuse. We are expected to navigate a neurotypical society and these complex challenges of the mind ourselves with no outside assistance. Autistics have a lower life expectancy because our needs are ignored. There should be a hotline or a website where autistic people can connect with someone who understands their neurodiverse hardships. A lifeline for those who desperately need a community to recognize their humanity.

Artificial intelligence could be hugely beneficial in helping autistics with suicidal tendencies. When used appropriately as a tool adjacent to regular therapy conducted by a human being, we could help bridge the gap in communication caused by social difficulties. Being careful not to fully automate the process by replacing valuable human connections entirely with AI, I feel the help could go beyond detecting traits of suicidality, but evolve into more broad applications such as diagnosis and specialized education. Custom education for autistic children who may not be able to grasp concepts being taught to them in a conventional school paradigm could benefit from an AI's objective feedback free of conformist judgment. The AI could help guide a child step by step through teachings without tiring. It is a remarkable technology that should benefit the diverse learning requirements of everyone. But, even so, a balance of human connections is key to developing well-rounded social skills that are applicable in real-world scenarios.

Autistic autonomy and the lack of respect for it is where I will end today. Although there is rising support for our rights, I must address the problems still present in the way institutions approach therapy and the language surrounding our identities. I have found that, despite popular practice suggesting otherwise, my unique form of stimming helped alleviate my depression. The sensation was apparent, and I was able to practice it first in my mind. I would imagine hand flapping in my neurons, and they would come back to life. Beyond that, I found more physical movements like jumping around helped immensely in reanimating my deadened connections. Unfortunately, I have no studies, as it is underrepresented in the research. This is my account.

As is my earnest call for more identity first language. Just because saying 'with autism' has always been the norm, autism is still a new concept, and things can and will change around it. Saying 'with autism' is damaging, as it sounds like referring to autism as an affliction. Just because it is accepted as the inclusive thing to do, doesn't mean it is right. This language is allowed to be harmful under this guise, and I will never accept it, instead hoping to portray autism as an integral part of my personhood. Please center the autistic community in these discussions, lest there is anything overlooked about our lived experience. Our voices deserve to be heard.

https://trialsjournal.biomedcentral.com/articles/10.1186/s13063-020-4161-2

https://europepmc.org/article/MED/31621020

https://scholar.utc.edu/mps/vol29/iss1/23/

Cheryl Chafos

My name is Cheryl Chafos and my 19 year old autistic son died in 2021 after placement in a neuropsychiatric bed at a facility in Maryland. He waited in the ER for four weeks and then again seven weeks without getting basic needs met. His story is tragic and should never have happened. Our country has a national mental health crisis and no person should have to languish in an ER waiting to get mental health services especially a nonverbal autistic adult. I am urging our medical communities to help address and fix this process so no other family has to suffer such a loss.

Employment

Rick Grossman

The differences between Autists and others can be very subtle, including body language, tonality, facial expressions, word selection, usage, etc. We recognize these subconsciously to help us identify members of our tribe. AI can compare behaviors and subtle identifiers. Autists spend a great deal of energy masking, yet only a tiny subtle change may be needed. But more important would be self-discovery. Rather than changing, self-awareness could allow an Autists to tell others the differences so they develop a conscious understanding. An autist could also "coach" their supervisor at work, after discovering patterns of behaviour. The concern that this could be used to teach Autistic people to act like others is legitimate. I propose that information be made available in large numbers (untaceable) to researchers. Individual Autistic people would have an id/password to allow them to generate reports on themselves. Eventually, lists of characteristics could be made available for Autistic employees to discuss with their supervisors. Accommodations can't be made until they are understood and expressed. Extensions could include the use between husband and wife to improve communications, etc. It might be used to help someone select a field of work, and help those who are less verbal and would not be able to describe the characteristics thjey want in a job. It is also possible that when this is miniaturized, someone could wear it and would communicate for the person. It could be like a futuristic mood ring. It could also identify subtext from others, explain metaphors and parables, etc. Autistic people often describe themselves as aliens. They can hear and understood the words spoken and take them in a literal manner. This could broaden communication, improve working conditions, raise salaries, allowing the person to become self-sufficient. When workers realize that what they think is a "keepaway from me face," is merely a neutral expression, they can make work better for the Autistic person. It might produce realtime translation or a running commentary. "When he asks 'Hot enough for you?' it is not a question. It is more of a statement. You can reply to this by rolling your eyes, and moving your hand across your brow to show you are hot, too." All of these are several years out. But now is the time to interest researchers into recognizing subtle behavior. This is also going to be needed should we ever encounter alien species.

Note: The following comment has been redacted.

Abe Shapiro

My name is Abe Shapiro and I am 25 years old. I am on the Autism Spectrum, but do not speak on behalf of all persons with autism as each person's story is different. But I am here to speak on an issue that has been the talk of the community. My email is [redacted] and number is [redacted].
As an advocate who has assisted individuals with Autism in obtaining and retaining employment, I am writing to urge you to please support the Transition to Competitive Employment Act. In the disability community, being paid a living wage is more than just one’s way to earn a living. It is a mark of self-determination and signifies an individual's right to life, liberty, and the pursuit of happiness. But recently, this pursuit has been limited because of the Department of Labor’s provision of 14c certificates to employers. Under 14c of the Fair Labor Standards Act, employers possessing such certificates can use these certificates to pay their workers a subminimum wage, oftentimes within sheltered workshops. According to a 2023 Government Accountability Report, “out of 120,000 workers surveyed, half of them

were working for a wage of $3.50." The Act assists disabled individuals in obtaining and training employment and therefore higher wages by awarding grants to states and employers currently in possession of 14c certificates to assist them in the process of transitioning their employees with disabilities to integrated employment, thereby ensuring such employees are paid the federal minimum wage. The State of Oregon began a transition plan similar to that stipulated in the Transition to Competitive Employment Act back in 2015 following a settlement in Lane V Brown, a class action lawsuit against the state for violating the Americans with Disabilities Act by segregating individuals in Sheltered Workshops. The state partnered with the National Center on Leadership for the Employment and Economic Advancement of People with Disabilities (LEAD) to create an initiative known as Guided Group Discovery (GGD). The goal of this partnership was to create a multitude of systems in which individuals with disabilities could participate in programs geared towards their eventual gaining of employment. It began with the state's Vocational Rehabilitation (VR) Center collaborating alongside the Department of Education to establish the Transition Technical Assistance Network, made up of eight transition plan teachers known as the Transition Network Facilitators (TNFs). This network informs local school districts throughout the state on the best practices for transition plans for students with disabilities. From there, the network recruited schools to participate in the GGD program. After the schools were chosen, the TNFs worked with the state's American Job centers and school district administrators to implement the GGD curriculum, consisting of 1-2 hour sessions of 5-6 weeks to help students develop their own blueprint to employment. 3 According to Disability Rights Oregon, as of Aug 2022, the State has provided integrated employment services to over 7,000 Oregonians, including providing competitive integrated employment to 1,138 Oregonians working in sheltered workshops, which all closed in 2020. By supporting the Transition to Competitive Employment Act, you would not only be creating better systems for disability employment but would also demonstrate solidarity for the well-being and success of the disability community so that they too can achieve their own version of the American Dream and self-determination.

Thank you. The link to the aforementioned GAO report and all sources used in this statement are linked below.

1.Subminimum Wage Program: DOL Could Do More to Ensure Timely Oversight.| Subminimum Wage Program: DOL Could Do More to Ensure Timely Oversight | U.S. GAO, January 25, 2023. https://www.gao.gov/products/gao-23-105116.

2 Cornett, Jake. "Lane v. Brown Frequently Asked Questions." Disability Rights Oregon, May 27, 2022. https://www.droregon.org/litigation-resources/lane-v-brown-faq.

3 Salon, Rebecca S., Nancy Boutot, Keith Ozols, Beth Keeton, and Janet Steveley. "New Approaches to Customized Employment: Enhancing Cross-System Partnerships." NDSCC.org, November 2018. https://www.ndsccenter.org/wp-content/uploads/Customized-Employment-article-June-2019-in-JVR-author-copy.pdf.

4 Pinedo, Tina. "Final Ruling Issued in Employment Case for Oregonians with Intellectual and Developmental Disabilities." Disability Rights Oregon, August 17, 2022. https://www.droregon.org/releases/august-2022-lane-v-brown-final-ruling-issue.

Kaitlin MartinezHall

Invest in more post-secondary options for people who use supported employment to pursue goals that lead to long-term economic self-sufficiency. Placement in minimum wage jobs without a plan for the decades to come doesn’t set supported employment clients up for success. But investing in the programs above will at least help because they motivate people to pursue careers, and get on the path toward economic self-sufficiency.

The Role of the IACC and the Federal Government

Lauren Agoratus

In light of the TN shooting, there has been backlash to both the LGBTQ+ and autism community. FACT people with disabilities and the LGBTQ+ population are more likely to be victims rather than perpetrators of crime. We would hope that the IACC would issue a statement to this effect.

Anna Gray

HOW MANY OF YOUR MEMBERS ARE ACTUALLY AUTISTIC??? Is your organization another one of those About us without us? I could not find any actually Autistic members. Of course I have Class 3 ASD and am dyslexic so I might have missed some. Please state how many members are Autistic.

Now to the comments:

1. It should be a federal crime to have organizations on topic of Autism and especially collecting funds in the name of Autism without any actual Autistic board members. That will get rid of haters like Autism Speaks really fast. Over 90% of our community hates and despises Autism Speaks. They do NOT represent Autistic people. They represent hateful portion of caregivers who hate Autistic people. Organizations like this should not be allowed to exist. You yourselves must have at least 80% of Autistic board members. So either enlarge the organization or fire people. It is a despicable and 100% wrong and evil notion that neurotypical people should make decisions about Autism. You have NO right.

2. You must have a guide on neurodiversity written by actual Autistic people. You must study this guide until it REALLY sinks in. That will help you overcome your ableism and neurotype bias. When you think that are ready we Autistic people will test you to determine if you are actually ready.

3. It should be a federal hate crime to subject Autistic people with sensory sensitivities to sensory stimuli that cause them pain and harm for example to subject noise sensitive Autistic people to loud noise. I develop seizures convulsions and paralysis from loud noise. I had a stroke from exposure to loud noise. I have mobility impairment. It was caused by a military helicopter pilot that flew across my yard at low altitude. Loud noise causes unbearable pain. All of the noise regulations were adopted in direct violation of Convention on the Rights of Persons with Disabilities and must be rewritten including regulations on construction aviation train gas powered lawn equipment car loud music dogs children screaming and other sources of noise. What is it? Construction noise is allowed between 9 AM and 5 PM?.. What a load of BS! I develop seizures from anything above 60 Db and these seizures will occur whether it is 9 AM 2 PM or 3 AM! There needs to be rapid noise response force that will stop abuse within minutes and impose heavy penalties on abusers. Fines collected from abusers MUST be used to fund programs benefiting Autistic people. My Autistic family has been abused FOR MONTHS. Miserable good for nothing DC government 100% failed to protect us. I am now having to sue DC government. In Alexandria VA non emergency police operator mocked me for my disability and told me to move. 911 operator threatened me with criminal persecution for daring to complain about abuse. I am now having to sue city of Alexandria VA.

4. Housing is a human right. I have to live in quiet places. They are more expensive. My noise sensitive Autistic family was outbid by able bodied neurotypicals who had more money than we. For them it was nice to have. For us it was MUST HAVE due to our disabilities. Useless politicians refused to help including mayor of DC. THIS DISCRIMINATION MUST STOP. There MUST BE sensory friendly housing accessible to people with sensory sensitivities. There MUST BE sensory friendly hotel accommodations available to Autistic travelers AT EVERY LOCATION! Hilton caused me seizures with gas powered lawn equipment. I will now have to sue Hilton. Hotels that do not provide sensory friendly accommodations should have higher taxes imposed upon them.

5. It should be a federal crime to not provide EMAIL or even PICTURES as a form of communication. This ableist neurotypical BS about telephones MUST DIE. I am having to sue ADA administration and VA DMV for disability discrimination. I should not have to do that. If your committee were actual Autistic people this horror would have ended LONG TIME AGO.

6. There MUST BE activities for Autistic people with sensory sensitivities in every city and every town. There must be safe public utilities for Autistic people. Like public toilets. Nothing like sitting on the toilet having a seizure and slowly suffocating to death from it because some moronic neurotypical decided it was a good idea to install 85 Db hand dryer and supernova blinding lights in the toilet. Hand dryers MUST DIE.

7. I have been turned down by multiple legal organizations including those that claim to represent Autistic community such as disAbility Law Center of Virginia (dLCV). Some such as ACLU did not even bother to reply. Those who did bother to reply told me that they concentrate their work on Autistic people in institutions. First off institutions are a form of state sponsored abuse and simply MUST DIE. Second my family is an example of how Autistic people SHOULD LIVE. We run a business we financially support our elderly disabled parents we live independently. At some point being continuously and severely abused on a daily basis and continuously denied justice I tried to take my life. After that I was abused and tortured even more by Alexandria police and Inova Alexandria staff who experimented on me denied ADA requests and requests for alternative communication. DO NOT call 988. 988 MUST DIE. I am now having to sue all these monsters and I am having to do it ON MY OWN. My Class 3 ASD dyslexic self. FREE LEGAL HELP or very low cost legal help MUST BE provided to ALL Autistic people WITHOUT discrimination. And those who cannot provide it are welcome to stop lying and GET OUT.

8. Work to overcome your ableism. This form is a form of it. TINY dyslexia unfriendly font and TINY boxes to tick underneath it. So you just assume here that all people with severe cognitive and neurodevelopmental disabilities have the required eye to hand coordination to be able to do that?.. Tells me that you do not really know what you are doing. Forms like this is a disrespect to our community.

Jennifer Tarbutton

I recently read that there was a new early diagnosis screening tool called Earlipoint approved by the FDA that could diagnose autism in babies as young as 16 months. I would appreciate it if the IACC could host a full presentation of this new technology so that the broader autism community could learn about its use.

James Perkins M.D., Ph.D.

Please ask this Agency and NIMH to provide more Free CEUs on the area of Autism. This would be beneficial too all . Thank you

Grace Ogden-Parker

My name is Grace Ogden-Parker, and I am Autistic/Disabled. I am writing to you today to discuss the need for the United States Congress to ratify the Convention on the Rights of People with Disabilities (CRPD). In 2008, the United Nations ratified and adopted the CRPD. President Obama signed it in 2009 but Congress has yet to ratify it.

The CRPD is an international treaty with the purpose:
to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.
Being inclusive in the definition of disabilities the treaty defines persons with disabilities to:
include those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

In Article 3 the CRPD outlines the general principals as follows:
(a) Respect for inherent dignity, individual autonomy including the freedom to make one?s own choices, and independence of persons;
(b) Non-discrimination;
(c) Full and effective participation and inclusion in society;
(d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
(e) Equality of opportunity;
(f) Accessibility;
(g) Equality between men and women;
(h) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

The CRPD outlines the general obligations of the parties of the treaty in Article 4. Article 4 section 1 specifies that the parties will undertake:
(a) To adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognized in the present Convention;

(b) To take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities;
(c) To take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes;
(d) To refrain from engaging in any act or practice that is inconsistent with the present Convention and to ensure that public authorities and institutions act in conformity with the present Convention;
(e) To take all appropriate measures to eliminate discrimination on the basis of disability by any person, organization or private enterprise;
(f) To undertake or promote research and development of universally designed goods, services, equipment and facilities, as defined in article 2 of the present Convention, which should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities, to promote their availability and use, and to promote universal design in the development of standards and guidelines;
(g) To undertake or promote research and development of, and to promote the availability and use of new technologies, including information and communications technologies, mobility aids, devices and assistive technologies, suitable for persons with disabilities, giving priority to technologies at an affordable cost;
(h) To provide accessible information to persons with disabilities about mobility aids, devices and assistive technologies, including new technologies, as well as other forms of assistance, support services and facilities;
(i) To promote the training of professionals and staff working with persons with disabilities in the rights recognized in the present Convention so as to better provide the assistance and services guaranteed by those rights.

Some important highlights (but not all encompassing):

Article 7 describes the responsibilities toward children with disabilities:

1. States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.
2. In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.
3. States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.

Article 8 Awareness-raising
1. States Parties undertake to adopt immediate, effective and appropriate measures:
(a) To raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities;
(b) To combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life;
(c) To promote awareness of the capabilities and contributions of persons with disabilities.

2. Measures to this end include:
(a) Initiating and maintaining effective public awareness campaigns designed:
(i) To nurture receptiveness to the rights of persons with disabilities;
(ii) To promote positive perceptions and greater social awareness towards persons with disabilities;
(iii) To promote recognition of the skills, merits and abilities of persons with disabilities, and of their contributions to the workplace and the labour market;
(b) Fostering at all levels of the education system, including in all children from an early age, an attitude of respect for the rights of persons with disabilities;
(c) Encouraging all organs of the media to portray persons with disabilities in a manner consistent with the purpose of the present Convention;
(d) Promoting awareness-training programmes regarding persons with disabilities and the rights of persons with disabilities.

Disabled people nationwide, and even worldwide, need our basic human rights secured.
You are in a unique position to affect real lasting change for the better for all Disabled people. Please consider supporting the ratification of the CRPD.

Potential Causes of Autism

Donald Sutherland

Is the IACC reviewing prenatal, child dietary dietary exposure to neurological harming organophosates pesticides in food residues and their contribution to Autism in the US?

Albert Enayati

This a published artic regarding the connection between autism and Nitric Oxide which has been broadly coved by all the newspapers in Israel including Times of Israel, Jerusalem Post and other Israeli newspapers. Below is an article by Times of Israel.

https://www.timesofisrael.com/new-israeli-study-shows-link-between-autism-and-nitric-oxide-levels-in-brain-neurons/

Fred Brown

Autism Ruined My Life

The autistic can be identified thru a simple questionnaire. I encountered many mental health professionals in my long life but none ever gave me that questionnaire.
I had to find out on my own, and I did not find out until I was 85 !! Autism is treatable.
Broccoli works better thn any drug they have been able to come up with. Now, because of broccoli, a vegan diet, and self-knowledge, There has been a profound transformation in personality.

Now I am normal. I am willing to
work with anyone doing research in this area.

Maurine Meleck

This committee continues year after year knowing that the autism rates are sky-rocketing every year. I have raised my vaccine-injured grandson who has autism for 23 years now. When will the committee come up with the reasons(besides better diagnosing)for the massive increase in autism every year and literally do something to stop it?

Increase Autism Acceptance and Reduce Stigma

Tony Sandy

Untypical by Pete Wharmby is one of the best books I have read about autism from an insider perspective, characterising the symptoms that make up the condition. For friends and relatives of those living through such a neuro diverse state, this explains behaviour traits in a thorough and diverse perspective that covers most if not all areas that perplex the neurotypical population. As a tome it therefore is invaluable in relieving the mystery that surrounds this condition.

Alice Stobart

please please please stop torturing people because the world isn't designed for them

Inclusion of Underrepresented Groups

Whitney Voltz

Research that is needed comprises identifying non-male and non-white autistics as early as possible. It is unacceptable how many women, non-binary and BIPOC individuals go unidentified long into adulthood or are never identified. We also desperately need research in environmental modification, i.e. structures and architectural constructs that are designed with autistics in mind. In addition, please consider researching autistic mothers--we are a vastly overlooked population in need of not only identification, but of knowledge and support. Parenting classes at local Childrens' Centers focus mainly on the education of neurotypical parents. However we autistic mothers comprise a significant yet underserved portion of the parent population. Another area of research: please consider researching and supporting autistic medical school students. The more autistics we have in the field of healthcare, the better the outcomes for autistic patients are likely to be. Thank you!

Amina Ahaddad

My name is Amina Ahaddad. I would like to talk to you today about autism research. I think the IACC should tell the government to pay for autism research about autism presenting in adult women and people of color. These two groups have been far underrepresented in autism research for far too long. The current DSM-5-TR is not up to par with what many of us are experiencing or presenting as. We are instead having to rely on books such as "Unmasking Autism" to self-realize because therapists are limited by the DSM-5-TR to diagnose us as it contains outdated information. Instead many of us are being diagnosed with depression and/or anxiety and being treated using methods that can actually be detrimental in the long run. There is also a huge lack of therapists that are trained to recognize the signs, especially in women, POC, and individuals who are working in high-level roles.

I think this kind of research is important because if something isn't done soon, you will have a sizable population that is burnt out, stressed out, and contemplating suicide and will not have the tools to revive themselves. Please take into consideration how much benefit funding more research on these overlooked groups would have. I am a 30-year-old woman who has always been high-achieving and gifted from a young age but I've always known I was different as I've struggled with social communication. After experiencing what I can now refer to as "autistic burnout", I found a community of people online going through the same thing and then I read "Unmasking Autism" by Devon Price, which completely changed my world. Most of the traits commonly associated with "female autism" explained me to a T. However, this isn't a diagnostic tool and is just a list of traits in a book. This is why we need a professional diagnostic tool. So we can receive the help we deserve and the help that's been offered to cisgender white boys for years. If I wouldn't have had "Unmasking Autism" or an online community, I most certainly would have contemplated leaving this Earth because I would have just thought I was a misunderstood nuisance to the world. So, this truly is a life-or-death situation for many people. I know I'm not alone in my experience and I am thinking of the thousands of others out there who may not have this new-found knowledge and may resort to the extreme. In this day and age, there is absolutely no reason why funding shouldn't exist for this and I'm surprised at how long it's taking.

Although, maybe I shouldn't be, considering how many of our systems and governments continue to repress women, POC, and queer people.

I hope that the IACC will listen to the voices of autistic people the most. It might answer questions we have about our lives and it could solve problems autistic people have, so we can live the lives we want and deserve as a human being. Please help autistic people by asking for more research on underrepresented groups. Thank you for reading my comment.

Karina Rodriguez

Not enough support for early diagnosed girls. No one actually helps and only keeps referring.

Sascha Sealie

My name is Sascha Sealie. I'm reaching out regarding research on autism. Many adult females struggle in their everyday lives, not knowing that they are autistic. The lack of research surrounding this group, and just females with autism in general, is astounding. There are so many questions that have been unanswered within out community. As a female adult with autism, it is not easy to get the resources I could use to live more comfortably. The IACC needs to listen to those who go through their daily lives adapting with autism. What I previously mention is important to us and with more research surrounding autism, many questions we have may be attended to. Asking for more research on females with autism would be incredibly beneficial to the autistic community. Thank you for taking the tine to read my comment.

Christine Preimesberger

I think it's important to focus on the experiences of autistic people with other marginalized identities. Like studying the experiences of autistic people of different races and cultural backgrounds, different queer identities, or other forms neurodivergence. Also, I would interested in research on how autistic people experience physical pain. Mostly because I struggle with finding pain medications that actually work and most of the research I found on this topic were by and for allistic people.

Communication and AAC

Note: The following comment has been redacted.

AJ Link, Autistic Self Advocacy Network

The Autistic Self Advocacy Network appreciates the opportunity to submit comments for October 11, 2023. In our last comments to the IACC, we recommend that the IACC advise HHS on its implementation of the Home and Community Based Services Final Regulation (HCBS Settings Rule) and protect HCBS funding and funding for Medicaid. We also urged the IACC to notify the public about, and share accessible resources describing, the end of the COVID-19 public health emergency (PHE).
For our current comment, we are providing our response to the recent the nonspeaking RFI by the National Institute on Deafness and Other Communication Disorders (NIDCD). Our comment looked to answer the four categories presented by NIDCD in the RFI.

1. The biggest communication needs for minimally verbal/non-speaking people

Communication is a human right. People with speech-related disabilities, including nonspeaking autistic people, need immediate access to robust Augmentative and Alternative Communication (AAC.) As the largest self-advocacy organization representing the autistic community, including nonspeaking autistics, ASAN witnesses routine and widespread deprivation of this basic human rights. Nonspeaking people often go many years without any access to AAC; when AAC is provided, it is often extremely limited, cannot be used across multiple communicative functions, and fails to support language development. Frequently, AAC systems are provided without any meaningful support for the nonspeaking person or their family and support system to learn to use the system or expand communication. Routinely, nonspeaking autistic people are expected to “prove” their interest in and capacity for communication, language, and social interaction under these insulting and inaccessible conditions before they will be granted access to robust communication. This approach is obviously ineffective; ASAN believes it is also a violation of the individual’s rights.

Instead, AAC should be considered as the first option when someone has a communication disability. This includes access to AAC for people who can speak but cannot rely on speech for their only communication. Early Intervention providers should be comfortable matching toddlers with robust AAC and supporting families in this process. Every time a nonspeaking person interacts with the service system, from Early Intervention through adult services, the service provider should have as a first priority ensuring that they have access to effective communication. AAC and related communication supports should be covered equitably by every payer; Medicaid, Medicare, private insurance, public schools, vocational rehabilitation, and any other applicable party. There should never be a financial barrier to communication.

ASAN emphasizes that AAC must be robust and enable effective communication as defined by the Americans with Disabilities Act.

By “robust” we mean an AAC system that:

Contains thousands, not dozens, of words
- Is language-based
- Supports language development and the full use of syntax and grammar
- Enables a person to communicate across the full range of communicative functions—not just requesting and labeling
- Is accessible to the person and adapted to their specific accessibility needs
- Matches the individual's communication preferences

In other words, "robust" AAC enables the person to express anything they might be thinking or feeling. The vast majority of nonspeaking autistic people, including those who have some access to AAC, do not have access to robust AAC. ASAN believes this is a human rights crisis.

2. The greatest roadblocks to supporting and improving communication for minimally verbal/non-speaking people

Once an individual has access to robust AAC, they are rarely given sufficient access to the support necessary to learn to use the system. AAC systems are complex, and, even in the absence of other language disabilities or trauma, overcoming a history of communication deprivation takes time. AAC users often need years of dedicated support across settings (school, home, the broader community, etc) before they are able to fluently use their devices to fully express themselves. This support is rarely provided. Speech Language Pathologists often do not have sufficient training in supporting AAC use; even when an individual has access to a trained SLP, they are often only served for an hour or less a week. Others in their lives-teachers, paraprofessionals, direct support workers, family members, etc-are often not given information about best practices for supporting AAC users. It takes thousands of hours and several years with constant support for humans without speech-related disabilities to learn to speak; AAC users are routinely given a small fraction of that time and then deemed to have "failed" AAC.

Nonspeaking people deserve the presumption of competence, which includes the presumption of the ability to learn when given the right support. They deserve effective support to communicate, across settings, for as long as it takes-even if that means their entire life. Communication is a human right.

Nonspeaking people also urgently need access to literacy instruction rooted in the science of reading, as well as access to inclusive education. Every AAC system is limited if the user does not have a basic ability to read and spell; literacy instruction is key to ensuring truly robust, effective communication. Nonspeaking children are routinely segregated in schools and denied access to the general curriculum. There is an urgent need for teacher education and system change to ensure that every student, including nonspeaking students with the most complex disabilities, has access to literacy instruction, the general curriculum, and effective communication. These needs go hand-in-hand.

ASAN stresses that these principles apply to all people with speech-related disabilities. Many nonspeaking people, particularly nonspeaking autistic people, are presumed to have intellectual disabilities and additional language processing disabilities. But it is not possible to truly assess for these conditions if the person does not have fluent access to robust communication. ASAN acknowledges that some nonspeaking people do have intellectual disability and/or language processing disabilities, as do some autistic people who communicate effectively with speech. Nonetheless, we urge that these labels not be assigned until they can truly be assessed. Furthermore, we know that people with intellectual disabilities or language disabilities are also deserving of, and benefit from, robust AAC, accessible literacy instruction, inclusive education, high expectations, and the presumption of competence. Communication is a human right.

3. The highest priority research targets to advance communication for minimally verbal/non-speaking individuals

The highest priority research should focus on the quality of life for people with speech disabilities, this includes research on if access to robust AAC impacts the quality of life for people with speech disabilities. There also needs to be more research focused on effective systems transformation. It is important to understand the most effective ways for schools, school districts, states, service agencies, and other stakeholders to change how they offer and provide AAC and alternative communication methods, as well as how they provide support for AAC users. There should be research focused on the scaling of different supports, especially to nonprofessionals and intentional matching of the right supports to different people. Research needs to prioritize matching the right supports with the right people. This means research to understand why some people do not use AAC or prefer alternative communication methods and also providing better access to assistive technology lending libraries and trials of different methods of communication and communication devices or applications.

Additionally, there should be an increase in research focused on supporting AAC users in utilizing the whole range of communicative functions to communicate. Another area of research that should be prioritized is the impact of access to effective communication supports on individual outcomes like self-determination, education, community inclusion, mental and physical health, reduction in self-injurious or aggressive behaviors, ability to report abuse, etc. particularly for people with the most significant disabilities.

There needs to be research focused on getting accurate demographic information on the number of people with speech disabilities in the US, how many people with speech disabilities actually actually receive AAC services, and how many people with speech disabilities are not receiving AAC services when they would like to have access to them. Research should prioritize understanding the disparities that exist in AAC service provisions between different age groups, different races/ethnicities, groups who speak different language(s) at home, and provisions of special education and disability services. There should be more research into affordable solutions to provide access to robust AAC that meets the needs of people with speech disabilities when they or their families have very low income or are un- or underinsured. There should also be research focused on what features AAC users want or do not want in their AAC systems, with emphasis on how AAC users feel about incorporating machine learning into their AAC systems.

4. The best ways to increase partnerships between researchers and minimally verbal/non-speaking people to guide research projects

There must be community-based participatory research (CBPR) and research led by AAC users and people with speech disabilities. AAC users and people with speech disabilities must be included on research teams and study advisory boards. There should also be multiple accessible pathways for people with speech disabilities to get involved in research, both now and in the future. One way to accomplish the goal of increasing the number of accessible pathways for people with speech disabilities to be involved in research is to have requirements for research projects to include people with speech disabilities as part of the core research team in order to get government funding. An additional requirement to receive federal funding should require research projects to recruit and train people with speech disabilities in research skills, these trainees could be students at universities or community members.

There needs to be more effective AAC mentorship led by AAC users. This mentorship should be for both AAC users and professionals, communication partners, and family members. These mentorship programs must include more collaboration with organizations led by people with speech disabilities and AAC users, like CommunicationFIRST. One resource that is underutilized by the research and professional communities is the Facebook group "Ask Me, I'm An AAC User!" This group provides answers to a wide variety of questions about AAC use from various stakeholder groups. This informal resource exists because there is currently no other adequate resource that is training professionals, communication partners, and family members on how to support AAC users.

There should be funding specifically allocated to CBPR. There should also be funding to support foundational work and grants, the implementation of accommodations, and Easy Read development. There needs to be better standards on what is, and is not, acceptable in terms of AAC practice. These standards need to be developed and defined by AAC users. Community-based participatory research must be a priority for research projects.

We again thank the IACC for inviting interested stakeholders to comment and help the IACC direct the future of autism research. For more information on ASAN and the autistic community's research priorities, please contact AJ Link, Policy Analyst, at [redacted].

Parent/Caregiver Support Needs

Fenna Blue

I am an Autistic person who has been pregnant, labored, and birthed another Autistic human. I now handle my own care though the medical community as well as my child's. I'm continually surprised at how poorly trained the medicos community is and how much they lack and understanding that Autistic people can be parents. I would like to see research that hopes to understand what Autistic people who are parents may need and how we can be supported.

Language Regarding Autism

Lauren Agoratus

The month of April recognizes autism. We would suggest moving from autism awareness to autism acceptance.

Concerns About Medical Practices

Note: The following comment has been redacted.

B D

I think that in some cases "profound autism" symptoms including learning disabilities seizures, permanent dyskedisa, mania, self harm, tics, aggression catatonia, vegetative state, death etc. are being caused by psychotropics including Risperidone.

Please please look at undesirable effects. For people with kids on the medication how do we know what is the medicine and what is the autism? We don't. Because the side effects of the medication are the same as the side effects of profound autism.

https://www.medicines.org.uk/emc/product/11560/smpc#gref

In other words big pharma is stealing people's kids from them and depriving them of a life. I think you guys are actually right that profound autism is a tragedy but I think that many cases are not the symptoms of autism. I think all the high functioning people are those who have never been on the drugs while some profound cases occur naturally but most are the drugs symptoms. I know this sounds crazy but I have a lot of proof.:

https://www.thecut.com/2017/04/why-are-doctors-giving-anti-psychotic-drugs-to-toddlers.html

https://www.salon.com/2007/05/18/autism_misdiagnosis/

https://www.reddit.com/r/radicalmentalhealth/comments/10sfh3q/risperdal_and_autism_this_is_what_makes_me_sad/?utm_source=share&utm_medium=android_app&utm_name=androidcss&utm_term=1&utm_content=share_button

https://m.facebook.com/groups/autismparenting/permalink/1168248967432757/?mibextid=Nif5oz

https://www.spectrumnews.org/news/risperidone-use-in-children-with-autism-carries-heavy-risks/

https://www.drugs.com/comments/risperidone/for-autism.html?search=&sort_reviews=lowest_rating#reviews

https://link.springer.com/chapter/10.1007/978-981-13-8437-0_4

https://www.huffpost.com/entry/15-million-award-in-child_b_4861391

https://www.millerandzois.com/products-liability/drugs/risperdal/

[redacted]

https://medium.com/@Drug_Justice/why-are-children-prescribed-risperdal-bddd9409001e

This study also proves it to me. Why would people's brains suddenly shrink? How do you explain a suddenly shrinking brain?

https://www.spectrumnews.org/news/brain-expands-too-fast-shrinks-too-soon-in-autism/

The exact same thing happens when the same meds are used for schizophrenia actually.

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3476840/

https://www.sciencedirect.com/science/article/pii/S2352853222000165

Abi Bartley

I do not support JRC or their practices of use of electric therapy.

Bianca DiRuocco

I am writing to urge IACC to issue a public statement condemning 2021, July 6th's reversal of an FDA regulation that would have banned use of the Graduated Electronic Decelerator (GED) for use in behavior modification at the Judge Rotenberg Educational Center in Massachusetts. This device issues extremely painful skin shocks for the purposes of behavioral modification and has been named a device of torture by the United Nations. Importantly, the Judge Rotenberg Center houses students primarily disabled students of color from New York City, making the ban on the GED a pressing issue of disability and racial justice.
Urge the legislature to cut the funding of the Judge Rotenberg Center.
Please include an amendment in the Keeping All Students Safe Act (KASSA) that would expand the bill's prohibitions to include aversive interventions and pass this Act.
How can it be illegal to so torture prisoners or animals, but perfectly legal to do this to the disabled? This is horribly inhumane and MUST be stopped.
I urge the leadership of IACC to stand against the use of this device at the Judge Rotenberg Educational Center, a center that has been at the center of controversy for many years because of its continued use of this barbaric practice. We cannot profess to do the work of equity and remain neutral in the face of such violence. When can I expect a statement from <organization> on this issue?

Elissa Hunt

The #STOPTHESHOCK Coalition against the Judge Rotenberg Center, in Canton, MA, is working to put an end to use of the GED SKIN SHOCK device used as an Aversive "therapy" on Autistic and Disabled individuals to control behavior. In 2013, the Special Rapporteur declared that the use of the GED device violated the United Nations Convention Against Torture.

Behaviors that the JRC has used GED shock include but are not limited to: hand-flapping, standing, making noise, and screaming in pain from the administered shock. The GED has been known to burn skin and is traumatic for individuals exposed to the device.

In December of 2022, after decades of persistent advocacy work, the FDA was finally granted the right to ban this device but has taken NO action.

While this is disappointing we have other options. Bill H180 An Act Regarding The Use of Aversive Therapy, currently in the house, if passed will FINALLY put an end to this BARBARIC practice!

We will be protesting the JRC again and showing our support for H.180, in September, on the day that the bill is going to be heard in the House Joint Committee on Children, Families and Persons with Disabilities. (exact date TBD) Danielle W. Gregoire, presenter of the Bill, will be in attendance to speak.

Please consider joining us in our efforts! You can fill out this Google Form or just reply to this email. I look forward to hearing from you.

With Official Partners: OccupyJRC, Alliance Against Seclusion & Restraint, ICAPA, END The TTI,ICARS -Int. Coalition Against Restraint and Seclusion (ICARS), Autistic Self Advocacy Network, The Autistic OT, 11:11 Media Impact (Paris Hilton), Autism National Committee, Humans Make Art, apexart, Baystate Learning Center, Massachusetts Advocates Standing Strong, Justice For Our Angels, Autism Career Pathways, New Haven RTC Voices, Lives in The Balance, Thinking Person's Guide to Autism, The Autistic People of Color Fund, National Youth Rights Association, NAMI Massachusetts, Neurodivergent Liberation Coalition, Massachusetts Assoc. For Mental Health, Restraint Free World (List in Progress).

Sarah Fox

I am a member of the Autism Self Advocacy Network and I want to emphasize the harm that ABA Therapy has done to the autistic community. Autistic people need access to alternative services that do not try to "cure" autism.

The model of ABA therapy is outdated and harmful to the community. The IACC should prioritize research into alternative therapy options that do not rely on Lovass' conversion model. Even "new" ABA therapy practices are harmful to autistic people because they emphasize compliance above all else. No child should be in 40 hours a week of treatment. Autistic children deserve to be children, not robots that spend 40 hours a week training in compliance.

For example, this might look like increased funding for research on DIR Floortime programs, AAC communication programs, and increased occupational therapy access for sensory regulation.

I urge you to listen to autistic voices in your decision making process, not just parents who have autistic children. Autistic parents care deeply about their children, but they have not experienced the pain of being subjected to behavioral therapy.

Please consider the voices of the Autistic Community in your decision making process, not just the neurotypical caregivers of autistic children.

Kaitlyn Ballenger

I would like to see less research on harmful autism treatments like ABA and more research in areas that will actually benefit the lives of autistic people, rather than focus on the convenience of their caregivers. I would like to see more research on associated co-morbidities with autism, such the correlative and/or causal links between autism and tinnitus, Ehlers Danlos syndrome, increased risk of childhood ear infections, thyroid disorders, PMDD, sleep apnea/insomnia, and other related issues. We know these occur at higher rates among autistic individuals, but research has yet to tell us why or illuminate effective treatments that benefit the autistic people these effect. Additionally, I would like to see more studies focused on improving diagnostic evaluations and support opportunities among/within historically marginalized communities, including BIPOC autistic individuals, and those assigned female at birth and transgender autistic individuals.

Mary Mulherin

15 years ago because medical care is soloed in the US, my son was " committed" for being "mentally ill" when in reality he is autistic. This mental health court has been traumatic for him and debilitating to his sense of dignity as a person.When, as a parent, I suggested he was autistic, I was told, " well, we treat it in the same way as we treat mental illness." I was incredulous then & am still incredulous. No one ever helped him find meaningful employment with his college degree & all the positive work habits he'd bring to a work place with his attention to detail & keen memory.I wonder how many other young & now aging adults have similar stories?

Needs of the Direct Support Professional Workforce

Kate Semple

I am a mental health therapist, and I want to call attention to the limits to training, resources, and advocacy regarding working with folks with autism within my field. We need to be better equipped to provide adequate support for members of the autistic community - including communication considerations, safety planning and assessing specific risk factors, and even identification/diagnosis of autism and other ND traits. I have learned the most from folks with lived experience, particularly those with intersecting marginalized identities, and would like to see more opportunities for these folks to be heard and to have their needs, wants, and concerns appropriately valued.