

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



Public Comments

April 13-14, 2022

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Oral Public Comments

Stevie Mays

Hi my name is Stevie Mays, I currently work at Reach Every Voice and AAC education and Activist Group. I have previously worked as a Registered Behavior Technician, a supervised therapist in the field of Applied Behavioral Analysis (ABA), for four years. During that time, I found that the Behavior Analysis Certification Board (BACB) demonstrates extremely poor critical analysis of the morality and ethical responsibility of its practices regarding student's access to appropriate modalities of communication. I believe children deserve access to education and language using the communication method best suited to their needs, but the practices in ABA do not reflect this belief. Here I will focus on the BACB's lack of research and education for the use of Augmented Alternative Communication (AAC). AAC refers to any method of communication that does not rely on spoken language or verbalizations. This may include signed languages, use of gestures, picture boards, or a large number of devices designed to assist individuals that may not be able to communicate using speech.

I ultimately left the field of ABA after my four years. I saw a pattern of students working in therapy for years and not making any gains in verbal communication—and yet, the program forced these children to continue with only verbal communication goals. According to the Autistic Self Advocacy Network (ASAN), 1/3 of autistic people fall under the category of non-speaking and would need AAC to support or supplement their communication. The autistic students have a difference in their brain-body connection, which affects the control of their bodies. When muscle control is minimized, the resulting behaviors are considered an inherent trait in autism, and this difference in muscle control is also seen in the use of voice. In ABA practices, children that have some verbal capability are forced to prioritize their limited verbal communication, when they could have full range of communication if simultaneously provided the access to AAC teachings.

I called a friend who is a registered Board Certified Behavior Analyst (BCBA), the trained and certified therapists in ABA therapy. She commented "I have to work within my education, but I have seen children make major communication gains when given access to AAC—both in vocal/verbal improvements and in AAC gains. However, the BACB does not have curriculum and training on AAC. I try to mimic what I have seen speech [language] pathologists do but I have to work within my training that the BCBA provides. There is little AAC [training], and I wish I had access to more."

If the BACB wishes to show a conscious effort towards ethical and morally responsible practices, there needs to be a shift in the consideration of more intensive AAC in ABA practices when targeting communication and providing access to language and education. This can be done not only by providing training to the therapists, but also by conducting research into the functional communication benefits for AAC use with students who show little to no progress with previous intervention efforts. A long term study could be done to examine functional communication outcomes of students who are otherwise not showing improvement in communication goals. Having worked directly with young adult AAC users, they have directly expressed that access to AAC has "Opened the world to them" and I believe all students should have access to AAC education when beneficial.

Lisa Morgan, M.Ed.

As an autistic, self-advocate, diagnosed later in life at 48 years old, I have routinely experienced people who do not understand what it's like to live with autism both in professional and personal situations, yet these people are still considered to be the authorities on autism and autistic people.

While autistic people have been invited to the conversation more and more now a days, I also strongly feel we are not being taken seriously.

I believe being given an invitation to join in the conversation ends there with us just sitting at the proverbial table, but not being listened to in any meaningful way Or, even worse, being given a pat on the back for showing up so it can just look like we are there participating and being part of the solution to the many issues autistic people face in our society.

We, autistic people, must be the ones who drive autistic research priorities, participate in developing resources, and effect social change in collaboration with professionals, researchers, and other stakeholders.

Professionals must listen in order to truly, fully, collaborate. Lived experiences of autistic people need to be regarded as a valuable, important part of understanding challenges and developing solutions that really make a positive difference in the quality of our lives. We autistic people know what it's like to live with autism. We know what works, what doesn't work, and our experiences must be the most important part of finding solutions.

No amount of book learning, training, or any number of years of experience in working directly with autistic people can come close to the knowledge and experience of living with autism... of being autistic. Although our invitation to the conversation was late coming, we can make up for lost time by working together now with autistic people fully involved and completely accepted as competent , knowledgeable collaborators.

Thank you

Edlyn Peña, Ph.D.

My name is Dr. Edlyn Peña. I am a professor at California Lutheran University and the Director of the Autism and Communication Center. I served on the IACC committee from 2016-2020. As the editor and author of the books, *Communication Alternatives in Autism* and *Leaders Around Me*, I am thrilled that IACC has decided to focus on supporting augmentative and alternative communication (AAC) among nonspeaking and minimally speaking individuals.

One of the major debates in the AAC world is whether parents and practitioners should support text-based AAC methods that require a one-on-one communication partner to prompt and support minimally speaking individuals to communicate. Some of the common methods under this umbrella include facilitated communication (FC), rapid prompting method (RPM), and spelling to communicate (S2C). The chief question defining this controversy is: Who is the author of the message being typed? Is it the facilitator/communication partner? Or is it the student? Thus far, experimental studies published in research journals indicate that typed responses using FC methods were either influenced by the facilitator or communicators were not able to independently pass messages.

In some cases, the bad rap these methods have received is fair; in other cases, it is not. There is no question that these forms of communication can be subject to influence, and yet, the research studies alone offer an incomplete picture. There is evidence of students and individuals who use these various methods and become independent in their communication. That is, their communication partner sits or stands near them, but does not hold the letter board or provide physical support. I have witnessed this myself. In addition, there is documentation of individuals who use FC, RPM, and S2C methods who have communicated medical conditions, even ones that led to diagnoses as severe as cancer. And yet, critics of FC, RPM, and S2C refuse to admit that what is being typed in these circumstances is authentic communication from the person typing or spelling.

I implore any researchers, task forces, or committees focused on AAC to explore questions beyond authorship. First, what are the circumstances under which a communicator becomes independent in their communication? What sorts of supports, fading of prompts, user profile, communication partner training, etc. lead to individuals becoming progressively independent? A longitudinal study would be required for this since it takes years for individuals to become independent. Second, nonspeaking and minimally-speaking autistic individuals contend with a number of underlying challenges and symptoms that play a role in the dynamics of communicating on keyboards and letter boards. Research must continue to uncover answers to sensory differences, motor planning differences, and anxiety, all of which have been documented to some extent in the autism literature. The relationship among these experiences and alternative communication is not yet well understood. Doing so requires researchers and practitioners to consider multiple sources of data (e.g. interviews, narratives, field notes) to give us a more holistic picture beyond what can be revealed through quantitative methods within the context of experimental studies. Engaging in research studies to address unanswered questions will help the autism community determine the conditions under which FC, RPM, and S2C, when done ethically and with rigor, can be successful. Further, the answers to these questions will enable the FC, RPM, and S2C communities to move past the question of authorship toward addressing sensory, motor, and anxiety challenges that impact communication as well as improving training of communicators and facilitators. Rather than determining that a form of communication which is subject to influence is therefore dangerous and should thus be stopped, professionals should be committed to understanding ways in which to reduce influence and to support the progressive independence and reliability of the communicator. Thank you.

Eileen Nicole Simon, R.N., Ph.D.

Failure of language development is the most disturbing concern of parents who seek help for a child, and sadly they are often given a diagnosis of autism. Difficulty learning to speak is not a sign that is ever missed.

Language is the defining feature of the human species. Social development cannot advance far without language.

In October 1969, I read the article by William Windle in the Scientific American, on asphyxia at birth, and I burst into tears. My sweet autistic son, Conrad, ran to the Kleenex box and brought me a tissue.

Windle described damage of the inferior colliculus, in the auditory pathway, of monkeys subjected for only 6 to 8 minutes of asphyxia at birth. Conrad had required resuscitation at birth, and then he displayed severe jaundice during his first week of life.

Conrad's developmental milestones were all right on time, and he began to speak near the end of his first year. Our relief was short-lived. It was Conrad's nursery school teacher who suggested he be evaluated by a psychiatrist.

Conrad's speech was clear with good articulation, but he used the pronoun "you" instead of "I" or "me." Autism was the diagnosis he was given shortly before his third birthday.



- (1) **ABOUT CommunicationFIRST:** CommunicationFIRST is the only organization focused on the rights and interests of the estimated 5 million people in the United States who must rely on communication tools and supports to be heard and understood. We are led by and for people with speech disabilities, including Board member Jordyn Zimmerman, who will be presenting during the afternoon IACC session on April 14, and Policy Director Bob Williams, who will present brief comments by Zoom at 1:00 pm ET on April 14. CommunicationFIRST is cross-disability in focus, representing people who have had speech disabilities since birth, as well as those who acquire speech loss later in life, for example, due to ALS or Parkinson’s. Autistic people are one of the largest segments of our community.
- (2) **IACC STRATEGIC PLAN PRIORITY COMMENTS:** CommunicationFIRST submitted comments on the IACC’s Strategic Plan last November. Those comments, which are focused on nonspeaking and minimally speaking autistic people and their communication and other support needs, can be accessed here: <https://bit.ly/3iRwefT>.
- (3) **RECOMMENDATIONS:** We encourage the IACC to take the lead on the following efforts:
 - (a) **Representation in IACC Work:** Increase the representation of nonspeaking autistic people and other users of augmentative and alternative communication (AAC) in the work IACC engages in relating to nonspeaking autistic people and those who must rely on AAC to be understood. We wish that more than 15 minutes of a 2-hour IACC session on the topic of “Perspectives on Addressing Diverse Communication Needs in Autism” involved getting the perspective of an autistic person with communication support needs. We strongly urge that the IACC hold additional listening sessions and other means of soliciting the views and insights of nonspeaking autistic persons. Time limitations are one of the greatest barriers that all people who use AAC face when expressing themselves. The IACC should seize on this opportunity to demonstrate how government and others can alleviate these hurdles.

1629 K Street, NW, Suite 300, Washington, DC 20006
<https://CommunicationFIRST.org/>
 - (b) **Representation in Research:** Include people who cannot rely on speech to be understood in research about them. Such research should be guided and advised by people who use AAC. Research funding priorities should be dictated by those who most stand to benefit from such research. This is one of the most neglected populations in terms of

federal funding and very little government-funded research on our population has actually improved our lives. We call on the IACC to urge government funders to include AAC users as reviewers on all relevant grant applications. This will help ensure research funding is prioritized for studies that have the potential to improve our lives.

- (c) **Improve Population and Demographic Data:** There is very little data on the numbers, characteristics, and unmet needs of people who cannot rely on speech to be heard and understood. CommunicationFIRST is helping to lay the groundwork to remedy this (see <https://communicationfirst.org/aac-counts/>), but the IACC can and should play a leading role in this effort, especially as it pertains to the autistic portion of this community.

- (d) **Improve AAC-Related Research Generally:** We know that AAC is in its infancy. Compared to the communication tools and supports available for those with the other two main types of communication disabilities – vision (Braille) and hearing (American Sign Language) – AAC is slow, clunky, expensive, unreliable, difficult to use, and generally inadequate to ensure communication equity. We know it is difficult to do this kind of research given how heterogeneous our characteristics and support needs are, but this is not a justification for opting not to conduct it. Such research is necessary and must be done. Great strides are being made on brain-computer interface technologies, but it will likely be decades before those tools are deployable to the average person who needs them. In the meantime, we need to improve AAC tools and supports. Equally importantly, we need to improve our understanding of why so many existing AAC tools and supports do not adequately meet the needs of people with speech-related disabilities. Too many people with significant speech-related disabilities are given up on when they don't intentionally use basic picture cards to request items. We need research that sheds light on the undoubtedly many factors that help explain why this appears to happen and what we can do to better understand and support these individuals. Too many educators, family members, and professionals assume that a lack of reactive or intentional movement means they are “noncommunicative” or “nonverbal” and cannot use more robust, language-based AAC, when nothing could be further from the truth.

- (e) **Improve AAC Deployment:** We believe that the vast majority of the nonspeaking one-third of autistics in this country—hundreds of thousands of people—have not been given access either through the education system or the adult services system to the tools they need to communicate agency, autonomy, self-determination, or to participate in appropriate educational and employment opportunities. As a result, we believe this is the largest underserved population of autistics in the United States. Autistic people of color, or those whose primary language is not English, who need but have been denied access to robust AAC face even greater inequities and marginalization. AAC should be introduced to everyone who has any kind of a speech delay as soon as the delay is evident, as

early as 18 months. Researchers at Pennsylvania State University are successfully introducing AAC to infants as young as 6 months, but most people aren't given access to robust AAC until they enter school or even later (if ever). Late and inadequate introduction of AAC causes a vicious cycle where students are given insufficient tools and supports to communicate, and then are blamed for not having the capacity to learn to communicate using language. They should also be provided with age-appropriate literacy instruction no later than their nondisabled peers. Developing strong reading and writing skills is essential to everything else these kids will aspire to and achieve in life. The goal should be that anyone who can benefit from AAC is proficient at using robust, language-based AAC by the time they enter kindergarten, if not sooner.

- (f) **Improve Research About Nonspeaking Autistic People:** So much of the existing published research on nonspeaking autistic people continues to baselessly conflate lack of speech with intellectual disability. We know that speech is a motor function and language is a cognitive function, and that they are processed and generated in different parts of the brain. But researchers continue to assume, without anatomical basis, that someone who cannot speak or move their body reliably also has a language or intellectual disability. All current standardized measures of cognition and “intellectual ability” assume the student or research subject can either speak or move their bodies in intentional ways. There currently is no standardized way to measure intelligence that does not involve planned and initiated movements. We know from countless studies published over the past 20 years that sensory and motor-related disabilities are a core feature of nonspeaking autism. Previously published research about nonspeaking autistic people that discounts the sensori-motor disability elements and assumes intellectual disability without valid proof should be viewed with caution at the bare minimum. Additional research on this front is desperately needed. History is replete with examples of how the research got it terribly wrong about autistic people. We need to constantly seek greater understanding of the abilities and need for communication support of all nonspeaking autistic persons.
- (g) **Stop Funding Research that Utilizes Existing Standardized IQ-Type Measures on This Population:** Nonspeaking autistic people and others who need AAC but are not yet proficient with robust, language-based AAC should never be assessed using standardized IQ-type measures, which are discriminatory and not evidence-based for people with motoric disabilities who cannot speak. Inaccurate low IQ scores are routinely used to deny such people access to robust AAC, creating a vicious cycle and leading to segregation and denial of educational opportunities. There are dozens if not hundreds of nonspeaking autistic people, including our Board member Jordyn Zimmerman, who is presenting to you on April 14, whose IQs were assessed in the “severely” intellectually disabled range before they acquired access to AAC. The existence of a single nonspeaking autistic person who has proved the IQ construct

wrong should serve as a caution to researchers. Moreover, federal agencies that fund such research must reconsider the discriminatory consequences of such research and whether it should continued to be underwritten with federal funds.

- (h) **Be Careful About Terminology:** Finally, language matters. The terms “nonverbal,” “minimally verbal,” and “noncommunicative” to describe people who cannot depend on their natural speech to be heard and understood are inaccurate and harmful. They are inaccurate because they imply that the person has a language disability, which is impossible to know if the person has not been provided with adequate language-based communication tools and supports. They are harmful because that embedded assumption results in a denial of access to robust, language-based AAC for those who need it. Terms like “severe” and “profound” are vague and dehumanizing. Like the terms “special needs” and “complex communication needs,” they are also othering. Every human has a need to be heard and understood, and those needs fluctuate from time to time. Some people may require substantial supports to be understood, but the need to communicate is not “special” or “complex.”

(4) CONCLUSION: We ask the IACC to provide bold leadership in supporting this neglected portion of the autism population by working to ensure that every single person is given the tools and support they need to communicate effectively. Introducing robust, language-based AAC is essential for anyone who cannot rely on speech to be heard and understood. When a person is provided access to (including the necessary support to use and learn to use) robust AAC tools, the most significant barriers to education, employment, social engagement, self-determination, decision-making, and community living are alleviated.

Thank you for your consideration.

Written Public Comments

Research and Service Needs, Resources, and Policy Implications

Trigger warning: The following comments contain reference to self-harm and other sensitive topics.

Karen Barrett, B.B.A. M.S.

ProFound Autism is an extremely complex human cognition condition.

Life cannot be stopped.

Abortions are deferring life, until it is possible, creating anxious infants, then violent children.

My now 18you Male with a 132 IQ was pushed through the system by our education system. One year, ten months ago my son began living in my rental house adjacent to my home. My daughter, today, shared how this week is the best week yet, of her life.

Family Services are DESERVED as we ARE the PEOPLE.

It is a CIVIL RIGHT.

I need to be part of these ongoing discussions and subsequent reports to the public.

Grateful Heart!

Agreed wholeheartedly with Dena the IQ and language does not correlate with SELF HARM, My son has been self-harming since the education system denied correct school, then I attended SPAN hoping to fix that issue, not possible due to dereliction of duties on behalf of our community supports put in place by our government grants which are assigned based on irregular types of measurements that only this population can define.

Apologies. Please read for me, grateful. I have been my son's cheerleader. A ratio DOES EXIST, thank you Susan, for reading these comments of functioning levels.

Profound autism is to be respected as per Ivanova's comments, and my ABA companies lead BCBA in NJ.

My son may or may not be one of those people as he requires aloneness and needs it to be FUNCTIONAL at the 132 IQ level. Please listen to your people.

Apologies, but I have to say what I am feeling due to my AUTISM, Joshus emits from his presence the fact that he does not believe her. Regardless of reconfiguration. Help us by

putting the right people in the right places at the right time to effect positive change. I believe these breaks are for the people, like Joshua, change it up and make these meetings representative of ALL the people we are paying to serve us, grateful.

Each speaker is awesome and I wish I could congratulate each one personally as I have pioneered in silence for so long in Ocean County NJ, NY first. Thank you kindly for your help!

Joshus used the word 'entertaining', which is to be removed from all language concerning Heathcare.

Note: The following comment has been redacted.

Lena Reardon

I'm a recently diagnosed 40+ year old woman with ASD. More people with ASD need to be included in policy making and research (as in conducting research, not only as studied participants). There are many Autistic people who are active in the scientific, medical, and education communities who can be leaned on to develop programs and support services that meaningfully help the Autistic community. ABA is abusive and should be stopped immediately. [redacted]. Autistic burnout among those who are able to work in high stress/demanding jobs is very real and debilitating. Employment opportunities and necessary accommodations should be readily available. The most important aspect of anything to do with Autism is that we must meaningfully include members of the community with all levels of research and decision-making.

Note: The following comment has been redacted.

Arabella Sterwerf

My thoughts as an Autistic person is that there should be a priority of including Actually Autistic voices within your work. To not do ABA which has been shown to 1) cause an increase in PTSD for Autistic people and 2) an increase in Autistic masking which causes harm later on down the line. I would suggest doing research on how to better support or create better systems for Autistic people. Work to research how to create safer work environments that centers Autistic people's experiences and trauma around the workplace. Study how ableism especially from Allistic parents and family members causes harm for Autistic children and adults. Do more research on how being Autistic as an adult can be different from being an Autistic child in ways. Work on getting rid of functioning labels that are inaccurate and ableist. We have spiky skill sets. Recognize that! Please recognize that a majority of Autistic people prefer Identify First language for us not person First language. We aren't separate from our Autism as people. Being Autistic is how we interact as people! Learn and do research about the unique and fascinating

ways Autistic people communicate differently from Allistic people without looking down on us communicating differently. Do more research about more of the many things that connect Autistic people with Autistic culture. Research and put funding towards Autistic included therapies that help us while recognizing we are inherently Autistic people who don't want to be cured or made Neurotypical. We deserve the right to act and be Autistic without shame. [redacted]. Research and examine how our sensory differences are different from Allistic people with the good and the bad.

Autumn Scheske

Hello

I am a formally diagnosed autistic adult, and I'm writing to request that Alternative Augmented Communication be prioritized as standard care for non-speaking autistic people. Thousands if not millions of autistic people live trapped in silence, assumed to be incompetent because their body may not do what they intend for it to do, or they don't use speech in the way that most people do, if at all. AAC has freed many autistic people from these lives of assumed incompetence, and non-speakers are now proving that they have a lot to say. In relation to this, I also ask that there is more emphasis on the fact that autism is not its common comorbidities. People regularly confuse autism with common comorbid conditions, like learning disabilities, dyspraxia, or motor dysfunctions. This confuses people into believing that autism is a scale ranging from "severe" to "mild" (or, seemingly, ranging from "looks obviously different" to "probably faking it"). This is harmful to all autistic people, regardless of our comorbidities.

I also would like to request for autistic people themselves to be leading these discussions - not caretakers. While our caretakers are precious to us, and while many of us are grateful to them for the love they have for us, they've been steering the conversations for a long time. Their misguided advice & interpretations of their loved one's behaviors have proven damaging to both public and professional perceptions.

We also need to address the lack of funding for autism therapies outside of ABA, which may be helpful for parents and caretakers but shows little efficacy in enriching autistic lives. It's common for therapies that are not ABA to classify themselves as such in order to gain funding or be approved by insurance companies. The confusion and damage this precedent causes should be obvious.

I think it's worth mentioning that autistic people are at a disproportionate risk of incarceration, especially if they are multiply marginalized and even more so if they are undiagnosed. Something needs to be done about this.

Finally, I'd like to ask for the prioritization of neurological autism research over genetic research. Financing incentivizes researchers to focus on genetics, but this does little to improve the lives of autistic people in the here and now. More and more research is showing that we should be looking at the brain - not the DNA -- to understand how conditions like epilepsy and dyspraxia are related to autism. Whatsmore, this research should include and/or be led by autistic people themselves, wherever possible.

Thank you for your time.

Trigger Warning: The following comment contains a reference to eugenics.

Note: The following comment has been redacted.

Hailey Teusink

As an Autistic person who is a survivor of applied Behavioral analysis (ABA) "therapy" I wish to point out that it is no better than conversion "therapy" which is indeed backed by research (source: <https://catalystjournal.org/index.php/catalyst/article/view/29579>) and that we should make any and all efforts to ban applied behavioral analysis on all levels local, state, and federal.

Additionally, I would appreciate research that promotes the human rights of Autistic individuals, including:

- The impact being forced to mask our Autistic behaviors has on our mental health as a community
- The under-representation of Autistic PoC in diagnosis; how the DSM itself is centered around the white, non-LGBT, christian male and how this further marginalizes Autistic cultures.
- The intersection between multiplicity/plurality (<https://www.youthandpolicy.org/articles/young-people-with-multiplicity/>) and autism.

I would also like funding and support for:

- AAC and other alternative communication methods for Autistic people, especially those most vulnerable in our communities such as nonspeaking Autistic people.
- Pro-neurodiversity, anti-eugenics (so: anti-[redacted]; anti-ABA; etc) narratives within the classroom, starting within elementary school.

While there is likely more that the Autistic communities need, I am sure this makes a good starting list to look into if you care about us and our wellbeing.

We sincerely hope progress can be made for Autistic communities.

Mary Russell

I am a wife and mother of four children, two of whom are autistic. I am also a family medicine physician, and was recently diagnosed with autism spectrum disorder with a fairly typical childhood history of intense and restricted interests, social isolation, and sensory sensitivities. My diagnosis has allowed me to find other autistic women who share my communication style and profile of difficulties and support needs.

What should be the research priorities of the IACC? Currently, very little is known about how autistic people parent or age. We have little practical guidance for how to recognize and treat "autistic burnout", and how it is different than major depressive disorder. How can we prevent suicide in autistic

people, who are at very high risk? What can we do to keep autistic people OUT of institutional care which too often controls and dehumanizes?

As both an autistic physician and the mother of an autistic daughter with high support needs, my hope is that autistic people will be involved from top to bottom in key decision making positions creating autism policy and research priorities. Parents of autistic children and nonautistic researchers can and must defer to the community they seek to serve.

Ross Cameron

All policies and procedures surrounding autism and autistic research should be lead and directed by the Autistic community. Allistic individuals, including parents of Autistic Children, should not be allowed to silence Autistic voices as it has led to horrendous abuses against Autistic people time and time again.

Nothing about us, without us.

Research and efforts should be focused on providing help and support to ensure Autistic people are able to live freely in society without fear of abliesm and be provided the help needed to succeed and prosper in society.

Trigger Warning: The following comment contains references to abuse and other sensitive topics.

Cornelius Hecker

We need more done to prevent autistic voices from being silenced and abused, from more access to communication that works for them, to more autistic people involved and in charge of research-services-priorities and access to services without giving up autonomy (so ability to get help with disability that is not institutionalization, and support with decisions that isn't guardianship, and no ABA). Also it's important to look into the criminalization of black autistic people, as seen with the treatment of Matthew Rushin and Champ Turner. And finally- the Judge Rotenberg Center is still open and still shocking people and using behaviorism so extreme people don't want to believe it exists when shown- it needs to close and autistic people need to be protected from such extreme "treatments".

Brennen Balsamo

Hello there. I am on the Autism Spectrum and please, I implore you, please consult Autistic people with any research done. Get Autistic people to research Autism alongside non-Autistics. The voices of the Autistic people are what matter most.

Emily Swaim

Speaking as someone who is often deep in the weeds of research: there need to be a lot more studies that speak to autistic people directly rather than using parent surveys. Parent input is nice, but it can't give insight into subjective experiences like autistic burnout or sensory pain the way a first-person interview can. Also we really need a lot more racial minorities in autism research, because too often the participant population is all white, which doesn't represent the autistic community at large.

Kris Guin

I am a queer, trans Autistic man who lives and works in Washington, DC. I strongly urge the IACC to prioritize home and community-based supports and services, paying disabled people the same wage as non-disabled people, ending restraint and seclusion, shutting down the Judge Rotenberg Center, support for competitive, integrated employment, support for more inclusive K-12 and higher education, and research into the psychological impact of ABA therapy on those who receive it. I also urge the IACC to support the expansion of Medicaid/SSI/SSDI to middle-income disabled people without regard for their employment status, marital status, or asset limits.

Trigger warning: The following comments contain reference to cures and other sensitive topics.

Theia Ware

First and foremost, thank you for taking the time to read this. I am an autistic adult who was professionally diagnosed late in life after a long series of misdiagnoses in the mental health system. I have suffered most of my life with severe depression and anxiety and I am only now reaching a spot of stability and mental health where I can see myself having a future beyond next month. I am not writing today for my future though, but for my autistic siblings of the United States and beyond. I want all autistic individuals to have the ability to thrive and live a fulfilled life and not just the appearance of one.

I fear that research is done about autistic people does not care about the lived experience of the autistic person.

Do we want to be cured?

No, we want to live as ourselves and many of us take... great... offense at the notion. Please do not fund any research that attempts to 'cure' us.

What will help us?

Not ABA or any therapy whose goal is a performance of behavior the neuromajority wants. I ask that you do not fund research that aims to erase me and people like me. I ask that you fund research that actively seeks to truly listen to autistic experiences.

Are there behaviors that need to be addressed to literally save the lives of autistic children?

Yes, absolutely; we must stop our dehumanizing treatment of children. Fund research that seeks to improve the ability of neurotypical people to communicate with autistic people: children and adults. There are reasons for meltdowns and stimming. They are part of the autistic's communication skillset. Ignoring why those things are happening is like me ignoring your yelp of pain as your hand is touching the hot stove. Please foster communication in your funding decisions.

Do we outgrow autism?

No. Autism changes with age. We learn how to cope in a world that is not built for us. We are aliens gasping for breath being told to just 'breathe'.

Please fund research of and support for autistic in all stages of life. Help fund research that seeks to understand what autistic mental health and development actually looks like.

We are different. We are not like allistic individuals. Neurotypical development is not autistic development. We suffer, but mostly from a hostile world that teaches us to ignore our needs and refuses to learn how we speak. Fund research that allows us to understand our mutual differences and shortcomings. Fund research that builds bridges between two types of human and not research that seeks to mutilate one to look like the other.

Thank you for reading this, members of the IACC. You have my gratitude.

Brooke Nixon

Research and support organizations should be led by Autistic people, not their families. Compliance based "treatment" like ABA needs to be thrown out. Research should focus around what Autistic people say they need, how they see and experience the world, and what supports they need to reach their goals and contribute to our society. Getting AAC to everyone that needs it should be a priority. Research needs to go into how to get Autistic people mental health support that is effective for their unique needs, views, and approaches, as there are almost no Autistic therapists or allistic therapists that understand autism outside of a neurotypical, deficit view, using techniques that are often harmful to us. Currently the supports and information that exists is available for children only and when that child turns 18 they disappear. This needs to change. Legal discrimination against Autistic people needs to end. Stop shocking kids. Stop dangerous restraints.

Amy Schmidt

I am an autism mom. I would like to support responsible autism research, which does not ignore autistic people. I would like to support healthcare that does help autistic people, like occupational therapy, and well educated psychotherapists. ABA is abusive. Adult autistics still need support. Thank you.

Note: The following comment has been redacted.

Trigger Warning: The following comment contains references to abuse and other sensitive topics.

Amber Pepper

I wanted to start this by saying "Please consider us," but that seems wrong. Please respect Autistic perspective and recognize that we deserve dignity. You have the power to ensure that we are represented by yielding your voice to an autistic person.

[redacted]

Please take a long look at ABA therapy and the tyrannical, abusive, and demeaning practices they utilize to make Autistic children obedient. We do not need training, we need support.

Please enhance support services to include any Autistic person, regardless of how "able" they appear. Our support needs can change dramatically given multiple factors, and the vast majority are disabled by our symptoms at some point in adulthood. There should be easier access to adult diagnostic testing, especially for marginalized communities and people of color.

We need new standards of continuing education for general doctors, therapists, and teachers. These professionals have a huge impact on access to testing and support services for Autistic children and adults, and need to have more of an understanding on how autism can present differently for everyone. They need to understand our needs, and the onus should always be on us to advocate for ourselves - especially given how difficult some social situations can be for many of us.

Please prioritize standardized education for non speaking Autistic people. Just because a child doesn't want to speak, doesn't mean they aren't verbal. Many nonspeaking Autistic people have emphasized that they do want to learn how to read and write, and many were able to accomplish this despite people around them assuming they weren't capable.

If all else fails, please just listen. We can and will find our voices, or our non speaking words, and communicate what we want and what we need. Don't assume, even for a moment, that we aren't capable of understanding what's best for us.

Jasper Hardin

You shouldn't research a cure for autism, or gene therapy. You should research ways to make AAC financially available for autistic people who can't afford it, how to make the transition process accessible for autistic trans people, the negative affects of use of the prone restraint on autistic youth, and the long term harm lack of accommodation in schools.

Tori Madway

Please listen to autistic adults & stop prioritizing non-autistic parents & professionals over our own communal efforts to understand autism from the inside. Outside observations of behavior are rarely accurate to what's going on inside our heads & this disconnect means our actual needs are ignored consistently in favor of responses aimed at making us act "normal" until we learn to mask our pain. This is traumatizing. It's why we have such high rates of mental health issues. Whether through formal ABA based programs or by social conditioning, we are taught from a young age that our feelings are wrong, our needs are unreasonable, & we need to change our fundamental selves to receive love. Because old theories about our brains (hypothesized by non-autistic professionals without our input) are still entrenched in the industry, it's difficult to find good healthcare or services that don't treat us as if we need to be "cured" of our neurodivergence.

Please stop funding/prioritizing ABA. Please support AAC & communication accessibility in schools. Please seek out actually autistic professionals to draft policy. Please listen to our community; we're hurting & current policy is a big factor in that pain.

Trigger Warning: The following comment contains references to sensitive topics.

Ari LaTourette

I am an autistic adult and I would like to see more research on the benefits of social supports for autistic people.

Being autistic comes with both inconveniences and benefits. I would like to stop seeing so much money going towards a "cure for autism", which honestly would not help most of us even if it did exist, and instead go towards things which improve our quality of life.

For example, maybe treatments for symptoms that are most harmful to us. Like gut issues and sleep issues, and how to treat those things in autistic people specifically.

There has been research on how autistic people have different sensitivities to nerve receptors (A-beta vs C nerve fibers) and perhaps looking at medications which can calm oversensitive nerve fibers.

I also think action should be taken to stop human rights abuses like using electric shocks to the brains of autistic children.

Trigger Warning: The following comment contains references to abuse and other sensitive topics.

Kristen Gorman

As an autistic adult, I'd like to weigh in on the number of issues affecting my community.

First and foremost, I think a greater priority needs to be put on expanded access to Augmented and Alternative Communication (AAC). In many cases, children who gain access to communication devices are better able to regulate their moods, since they now have the ability to state their needs. Essentially, AAC is a 2 in 1 solution to some of the most common problems faced by autistic kids and their families.

It is upsetting to me that speech is still considered more important than just communication in general, and that the words of AAC users are treated often with suspicion, as if they've been plagiarized. For people whose motor control issues are severe enough to make AAC use difficult, there needs to be more research into developing supports that would remove all doubt that the words being shared come from the autistic person and not their aide. Communication is a basic human right, and it should not be denied to anyone on account of the fact that they need to communicate in a different way.

Secondly, although I work in biomedical research myself and prize the advancements in genetic understanding that we have collectively gained in my lifetime, I must insist that research into quality of life topics is of equal or greater importance to autistic people and their families than knowing every possible cause of autism. Ultimately, I strongly suspect the leading cause of autism is just unprotected sex between two people with autistic traits who wish to become parents. Assortive mating has only become more common in the past 50 years- I know anecdotally, I have only ever dated men who were weird enough to enjoy my own strangeness.

Whatever the cause of autism, unless we are talking about gene therapy for a Shank3 mutation or the like, I don't see these findings having an immediate impact on autistic people in either a positive or negative way. It is, however, painful to still read constant headlines about the race to "cure" what makes me, me. I would gladly treat the trauma that came from being treated as a freak of nature by most people during my childhood, but I am happy to be autistic. The harm that came to me wasn't from my autism, but by other people's fear and loathing of it.

On a related note, I also have to advise extreme caution on the use of Applied Behavioral Analysis on children. While behavioralism has led to a better understanding of why it is people react to certain situations and stimuli, ABA seems to oddly enough ignore autistic children's need to be understood in favor of training them to be indistinguishable from their peers. The result is often children who actually grow to be less independent than they would have been had they not become prompt-dependent. Worse still, many children have their notion of consent trained out of them, leaving them vulnerable to bullies and sexual predators, who would be delighted to find a child who would do anything for a piece of candy and some words of praise.

The potential for abuse here is utterly horrifying, and it reflects societal dehumanization of autistic people that it isn't taken more seriously. While I certainly don't object to teaching daily living skills by breaking them down into steps, the other components of ABA (particularly the social skills training that has almost no relationship to how people interact, or context) are profoundly disturbing to me. Autistic people, and autistic children, generally stim, ask weird questions, avoid certain stimuli, speak with directness, and hyperfocus on our special interests because we have autistic brains and these things just feel right to us. Changing the software will not change the hardware, it will only make us confused about whether or not we are "allowed" to feel our feelings.

Finally, I think there should be more of a focus to help autistic people build their communities up. I mentored a girl with some executive function problems, and I was able to share with her some strategies that had worked for me. Autistic-led mentoring and therapy for autistic people by autistic people are two things that could help many of us understand how to make the most of our abilities in a world that often doesn't even understand what those are.

Thank you for reading my comments.

Allison Mercer

We need funding for AAC, comprehensive in-home & community supports, for services over the lifespan. Listen to actually autistic people for our needs.

Trigger Warning: The following comment contains references to restraint, shock, and other sensitive topics.

Criss Ittermann

I'm an autistic mom of adult autistic children in their mid 20s. This is more common than folk might think reading the comments by other parents of autistic children.

And I don't want people to change my children, torment my children, or force my beautiful children to become someone else, or conform to society. That's their choice. Their brilliance, their hearts, their minds, are their own. Their bodies are their own, even though I gave birth to them. I am so glad I never subjected my children to ABA, that I cherished their differences and their not fitting in was society's issue, not my children's issues.

Autistic children shouldn't be sidelined, tormented, restrained, shocked, forced to mask or pretend to be someone they're not. It's horrifying. Parents can get additional supports for the added energy and learn to be better parents for autistic children. Children shouldn't be made to pay for a society that fails to

accommodate them. So many of my adult autistic peers who went through ABA now have PTSD and other trauma disorders for the torment they went through in ABA programs.

That said, one of my children was mainstreamed and now needs a lot of supports they're having trouble getting. The younger was in special ed and had accommodations for most of his childhood and is more easily qualified for adult supports. We need better tools to identify autistic children and give them accommodations when they struggle, regardless of gender. Autistic "girls" like me and my older trans son (who went through elementary education apparently female) are being overlooked. It means we're struggling without supports and then continuing to have our needs overlooked and unaccommodated as adults.

We don't have paper trails to qualify for services that you need to prove that you acquired an issue before age 22. Of course the issues were there already, and they're not going anywhere. But the criteria are already biased against the full range of autistic presentations, and then it's doubly challenging to get services and accommodations later when you struggled with school and socialization, organization, various subjects, only to figure out why later, then be brushed off, still under-diagnosed.

And then there's the issues of folk who are non-verbal or inconsistently verbal. I'm not always verbal, and looked into AAC for myself and it's far too expensive to get any AAC accommodations. These need to be expanded and funded for those who need or prefer to use them - in any case where it will expand a person's ability to communicate. It's all too common to force people into society's norms and not pay attention to the individual's needs. This is one of those areas. Working on affordable and fully-funded AAC will help countless autistic folk communicate more readily and fully.

Parents struggling with autistic children in the home could use in-home supports to help learn how to take better care of their child, to give them a break, help them adjust their home environment to be more suitable for an autistic child in case there's say sensory issues at home that can be adjusted for the comfort of all involved, etc. Personal care assistants to help with chores, parenting consultants, etc. Instead of tormenting the child, help everyone learn how to respond positively and lovingly to their child's needs.

More community supports for autistic families and children. Like when movie theaters have low sensory viewings of movies, more supports and accommodations for autistic children & adults throughout the community. And with such a large aging population, of course many autistic folk are aging up. I'm 53, and will need some housing supports & accommodations. My kids need supports & accommodations in their 20s - work supports, housing supports, adulting skills supports, etc.

And as autistic folk mainly get along with, communicate with, socialize with, other autistic folk better - we need national recognition and removal of any and all eugenics practices and marriage penalties for folk with disabilities, including autistic folk. It's disgusting that there's additional penalties and discouragement of folk dating, marrying or having children with people they get along with better, who understand them, who are amazing partners for them - across the board. This should stop for autistic folk as well.

Thank you for this opportunity to comment. Please help take better care to assist and protect beautiful autistic children, adults & elderly persons.

Lisa Jeanne Graf

Please center autism research and policy on priorities from the autistic community and not parents, doctors, educators and autism charities (not run by autistic individuals) or the ABA business.

Personally I would welcome a new way to diagnosis autistic individuals based on things like a spikey profile, preferences for straight forward communication, overwhelm from sensory (including others emotions), etc. the fact that so much is based on external behavior misses the many individuals who have masked for survival.

I would also like research done on children who did not have ABA compared to those who have to see differences in self esteem and mental health.

Please no more studies to end autism and search for autism genes.

Heather Foxing

I am a neurodivergent adult, advocating firstly that decisions involving us should always be advised by those who have firsthand experience and understand what it means personally to be autistic. Autistic individuals have highly important experience and understanding that should be listened to, sought, and taken with utmost seriousness when it comes to making decisions on any matters of autism and neurodivergence.

The discontinuing Applied Behavior Analysis (ABA) is one of the Autistic communities' commonly discussed goals, as well as discontinuing electroshock therapy. These practices are consistently regarded as harmful and unhelpful if not also abusive.

"ABA is unfair, confusing, abusive, and it leads to feelings of inadequacy, increased anxiety and depression, sometimes even PTSD."

The desired outcomes of ABA training are not there for Autistic People. They still suffer low intrinsic motivation, and lack of independent functioning if not more so upon ABA's usage. Neurodivergent individuals being expected to Mask natural non harmful behaviors for years and years of our lives is emotionally draining if not self destructive.

We desperately need those with autism to have a voice and a hand in what is shared as acceptable support. If we are misunderstood, it is because we are not being listened to, not being given agency over the conversation which involves us first and foremost.

Please consider and advocate for those with neurodivergency and autism to have a larger role in deciding how we provide support to Autistic people.

Ira Eidle

Greetings. I am an autistic person. I could write about myself, but today I really want to emphasize the work of other autistic people.

For decades, autistic people have organized to advocate for a better world for them. This can be traced back to the early 90s with Autism Network International, and the conference Autreat, which was started

because the existing autism conferences would not give meaningful leadership roles to autistic people, so they decided to start their own conference. This kind of advocacy is built off of the work of the Disability Rights Movement that preceded it, going back to the Deaf and Blind communities that date back to the 1700s. The individual priorities differ between these sub-movements, but there are a few universal principles. Two of those being to end mistreatment of their population, and the idea of "Nothing About Us Without Us".

The statement "Nothing About Us Without Us" itself originated in South African Apartheid protests as well as Hungarian labor organizing, but has since been adopted by the Disability Rights Movement. It means that nothing about a given population should be done without their meaningful inclusion. What this means for the IACC and for anything autism related is that not only should autistic people be included, they should be the ones in charge. As the late Roland Johnson emphasized at a conference in the 90s, "who is in control? Are you in control or is staff in control?". "Staff" in this context is the staff at institutions, though it could also mean any kind of aide or support a person with a disability receives.

The IACC has a record high number of autistic people in the current committee. This is an ample opportunity to shift priorities and put the control of federal autism funding into the hands of the very people impacted by these policies. It always was an ample opportunity, but since it has yet to happen within this committee, and there are a growing number of autistic people on it, it is time for the IACC to live up to the phrase "Nothing About Us Without Us". We have many disagreements, even amongst each other, but one thing is for certain-the sooner autistic people are put in charge, the better off we all will be.

Adam Knapp

I want to take this opportunity to urge your team to listen to autistic adults when creating new guidelines around autism policy. While I understand that the parents of autistic children have a unique set of challenges, those children grow up to be adults like me - adults who should be listened to when we say what worked and what did not. Please remember this isn't something we "grow out of," nor do we simply get filed away in a facility never to be seen again - we have lives, loves, jobs, (tons of) hobbies, and a good portion of your tech/IT infrastructure is thanks to us too!

Please be mindful that us autistic adults are watching and listening, and that the policies and statements released about autism do affect us. We don't "suffer" for the most part (except when dealing with "normies" who have trouble with our differences), we don't need "cures", we need simple accommodation that can be fairly easily provided if anyone actually wants to.

Thank you for reading my message!

Ira Kraemer

Autism is not a separate entity. I am an autistic person. There is no "autism" without autistic people.

Autistic people are not burdens, deficits, severe, or low-functioning. Focusing on gene therapies or the genes that cause autism will not support the autistic people in the here and now, and I would argue, would not support autistic people in the future.

Many autistic people have co-occurring conditions. This does not make their autism "severe" - it means they are autistic and nonspeaking, or autistic with intellectual disability, or autistic with epilepsy.

Autistic people deserve to be listened to in all aspects of their lives and including in areas that affect their lives, such as autism research.

Some autistic people are parents, researchers, autism professionals, and more. Autistic people who are nonspeaking, minimally speaking, and/or have situational mutism deserve AAC devices. Autistic people who need 24/7 care deserve that support, and full-time caretakers for disabled people who need full time care should be covered by insurance in the US, rather than pushing disabled people towards institutionalization and often ill-suited care facilities.

The narrative of what is autism, who can be autistic, and who deserves support should be driven by autistic people themselves, not non-autistic people who are adjacent to our experiences.

Occupational therapy for autistic kids should not be limited to covering 60 sessions total for a child's lifetime on insurance plans. Applied Behavioral Analysis is often covered by insurance yet has been shown to be ineffective in helping autistic people through the 31-page 2020 The Department of Defense Comprehensive Autism Care Demonstration Annual Report 2020 (link here - <https://therapistndc.org/wp-content/uploads/2020/08/Annual-Report-on-Autism-Care-Demonstration-Program-for-FY-2020.pdf>).

What follows is a written comment made by ASAN from the July 2021 IACC meeting, which I wholeheartedly agree with: I would like IACC to use its unique role to promote the inclusion of autistic adults ourselves in all forms of autism research. Autistic adults can provide input on not just our co-occurring disabilities and lifespan issues, but on communication access, the design of studies on the neurology of autism, studies on which services and supports work best for different groups, and indeed on any aspect of autism research. We particularly encourage the IACC to recommend the use of community-based participatory research which works directly with autistic self-advocates ourselves (including non-speaking self-advocates and self-advocates with intellectual disabilities), rather than acquiring study participants solely by contacting parent representatives or our service providers. We possess firsthand knowledge and experience of our own bodies and minds that other stakeholders lack. High-quality research done in partnership with autistic adults ourselves is the only way to reduce gaps in the knowledge base.

Jo Adell

I am presuming that at least 60% of the people participating in this discussion are autistic adults between the ages of 21-75. We have lived experience of autism that many people do not.

Trigger warning: The following comments contain reference to torture.

Kimberly Miller

Researchers need to involve actually autistic people in development of the protocols, especially non speaking autistic. And ABA is torture. It's based in the same as conversion therapy.

Trigger warning: The following comment contains reference to sensitive topics.

Sarah Gillis

I am an Autistic/ADHD employee, and formerly an Autistic professional caregiver who specialized in Autistic patients.

What has horrified me in my previous career have been the attempts to remove self-determination from members of our community.

We need marriage equality. Disabled people should not have to worry about losing our benefits if we decide to get married.

We need reproduction freedoms. I have heard Autistics being denied treatment because the OGBYN believed Autistic Women and non-binary persons couldn't consent to sex.

The same is said about Autistics planning to become parents themselves.

We need to have our gender identities respected, and not be misgendered or denied gender-affirming treatment because we are Autistic.

We need AAC devices to become much more readily available, and covered by insurance. There should be policies put in place to prevent removing said devices in hopes to encourage speaking language.

We need professional diagnoses of autism to become more easily available, especially to adults.

We need appropriate workplace accommodations. If we ask for training, we should be provided with it.

And we need to make sentences harsher for caregivers who murder us.

We need society to stop trying to prevent us from existing, and start making society Autistic-friendly.

Trigger warning: The following comment contains reference to eugenics and other sensitive topics.

Fiona Burgess

My name is Fiona Burgess, and I am an autistic adult. I have been afforded many privileges as a white person from a wealthy family of mental health professionals that has insulated me from the worst abuse the United States has to offer autistic people. I have a college degree, a full time job, housing security and loving family and friends. I still have my struggles socially, psychologically and with my physical health, but I cannot in good faith center those needs when I know those same ableist influences are pushing down on people who have not been afforded the same protection as I have, and it's quite literally killing people.

* Your number one priority at this time should be putting an end to institutional abuse of autistic people of color (and other developmentally/intellectually disabled people) in schools, hospitals and prisons. Shut down the Judge Rotenberg Center, ban the use of electric shock aversives, seclusion and restraint,

and launch investigations into the practice of ABA and other behaviorism-influenced therapies that traumatize autistic children into compliance with arbitrary and unsustainable standards that we don't even impose on non-autistic children.

* Fully fund home and community-based supports (HCBS) for autistic people and others with disabilities. I have friends and family (autistic and non-autistic) who rely on home-based caregiving and similar supports to complete basic daily tasks, and they have been subject to abuse and neglect from caregiving professionals/agencies on a regular basis that has worsened during the COVID-19 pandemic. This isn't even getting into people who are stuck on waitlists for basic necessary care.

* Insurance providers must be required to fully fund Alternative and Augmentative Communication (AAC) supplies for nonspeaking autistic people, people with apraxia/dyspraxia, cerebral palsy and other people for whom speech is not accessible due to disability or illness.

* Autistic children grow into autistic adults. Any services, supports and accommodations provided by the government to autistic people must be available to us throughout our entire lifespan.

* All public policy, research funding and other actions that will affect the lives of autistic people should be made by consulting autistic people first. Recall the famous phrase "nothing about us without us." I find it disgusting that there are entire lobbies' worth of sadistic academics and bitter family members who are pushing to tell us and people in power that autistic people do not possess the proper expertise on living life as an autistic person. I understand why politicians look to people with certain types of education as an authority on matters they do not personally understand, but it is not uncommon for academics posing as authorities to dedicate their life to suppressing the people they claim to support, or at least be an "expert" on.

This is how states across the globe have implemented policies to advance eugenics, mass incarceration, and systemic oppression more generally. By privileging higher education, you are not only excluding the voices of a large majority of autistic people, you are also excluding the voices of people who are already marginalized and oppressed by other US policies and who often struggle to be heard even in the autistic community-- Black autistic people, autistic immigrants and refugees, queer and trans autistic people (speaking for myself), autistic people from lower income families, autistic people with higher support needs and/or multiple disabilities/illnesses, and all those who share different combinations of these experiences. It feels a bit trite for me to go down a list like this, but I implore you to remember who most often has access to higher education and the resources to complete it. Even as one of those people myself, I don't think I should require a degree in developmental psychology to convince someone I know what difficulties I face in my own life, or that I have no ability to research how different policies affect my life. For most people, it is as simple as seeing what everyday barriers they face that others do not (e.g., marriage equality on disability).

Some parents may push for a "cure" for autism because they see their child suffering. To me, this is like asking for a "cure" for left-handedness because your left-handed child is being abused by schoolteachers, or perhaps even focusing on a cure for COVID-19 because their child is immunocompromised while refusing to vaccinate themselves or wear a mask.

I am not struggling as a human being because I have issues making eye contact with people; I struggle because society (and job interviewers) has been taught not to accept it. Nonspeaking autistic people do not struggle simply because they do not speak, but because they have been deprived of other means of communication. Autistic people who suffer from seizures, dyspraxia or similar comorbidities need a

cure/treatment for those comorbidities, not autism. Any research that goes into the autistic brain must be used first and foremost to aid autistic people and build a world where we can thrive, not relegate us into sheltered workshops, psychiatric wards and prisons until someone finds a "cure" for us. Even if you consider autism to be a disability, remember that disability is a natural variation of human life that should not simply be sidelined or condemned because it is inconvenient for the culture and systems we've built. I honestly feel a bit foolish repeating these relatively basic common talking points about autism and about disability more generally, but perhaps a day will come when I no longer have to explain to someone why electrically shocking a child will not somehow make them less autistic.

Chloe Davis

Greetings. I am an autistic person. I could write about myself, but today I really want to emphasize the work of other autistic people.

For decades, autistic people have organized to advocate for a better world for them. This can be traced back to the early 90s with Autism Network International, and the conference Autreat, which was started because the existing autism conferences would not give meaningful leadership roles to autistic people, so they decided to start their own conference. This kind of advocacy is built off of the work of the Disability Rights Movement that preceded it, going back to the Deaf and Blind communities that date back to the 1700s. The individual priorities differ between these sub-movements, but there are a few universal principles. Two of those being to end mistreatment of their population, and the idea of "Nothing About Us Without Us".

The statement "Nothing About Us Without Us" itself originated in South African Apartheid protests as well as Hungarian labor organizing, but has since been adopted by the Disability Rights Movement. It means that nothing about a given population should be done without their meaningful inclusion. What this means for the IACC and for anything autism related is that not only should autistic people be included, they should be the ones in charge. As the late Roland Johnson emphasized at a conference in the 90s, "who is in control? Are you in control or is staff in control?". "Staff" in this context is the staff at institutions, though it could also mean any kind of aide or support a person with a disability receives.

The IACC has a record high number of autistic people in the current committee. This is an ample opportunity to shift priorities and put the control of federal autism funding into the hands of the very people impacted by these policies. It always was an ample opportunity, but since it has yet to happen within this committee, and there are a growing number of autistic people on it, it is time for the IACC to live up to the phrase "Nothing About Us Without Us". We have many disagreements, even amongst each other, but one thing is for certain-the sooner autistic people are put in charge, the better off we all will be.

AND END ABA

William Anderson

For autism research, we need studies that examine the quality of life from the perspective of the person with ASD. Areas to explore include 1) studies on PTSD symptom rates with respect to early therapies and "therapies." 2) How to improve quality of life for adults diagnosed with ASD. 3) Due to studies

suggesting 70+% comorbidity with anxiety and depression, studies assessing the efficacy of treatments for anxiety and depression among patients with ASD. 4) the double empathy theory.

Additionally AAC devices, and the requisite education necessary for their use should receive more funding.

Lydia Kolibar

The complete lack of any kind of genuine treatment for Autism concerns me. I do not consider teaching a child that their no is invalid, that they should not tell an adult not to touch them, any sort of valid treatment.

What are things that negatively impact Autistic people? For many, its sensory issues. It would be nice then for current research on sensory issues to be made available. If there is some tie to vitamin deficiencies, then parents should know that, ya?

I would like some of the more concerning medical practices to be addressed. All autistic people deserve the same amount of medical resources to be used on them in an emergency as any other person. Medical professionals often times operate under the assumption that "autistic people just suffer" and that when an autistic person comes to them with a problem, it could be largely ignored.

I apologize for the accusatory tone. Autistic people are much more likely to be labeled as drug seeking because their pain does not display the same as a typical person. If a patient tells a medical provider that they have autism, that should change the protocol for how things like body language are read. Having autism means they are more likely to be telling the truth, for a multitude of reasons.

If you want to teach someone how to fit in, put them in acting class. It is wrong to force someone to ignore their pain, to obey everything without pause and to let someone touch you when you don't want it.

Acting classes and the like actually give the skills-and you can choose when to implement them.

So things like occupational therapy, speech therapy, and maybe DBT could be helpful.

Not ABA.

Alex Bassi

Autism is not a separate entity. I am an autistic person. There is no "autism" without autistic people.

Autistic people are not burdens, deficits, severe, or low functioning. Focusing on gene therapies or the genes linked to and/or that cause autism will not support the autistic people in the present, and I would argue, would not support autistic people in the future.

Many autistic people have co occurring conditions. This does not make their autism "severe" - it means they are autistic and nonspeaking, or autistic with intellectual disability, or autistic with epilepsy.

Autistic people deserve to be listened to in all aspects of their lives and including in areas that affect their lives, such as autism research.

Some autistic people are parents, students, researchers, autism professionals, and more. Autistic people who are nonspeaking, minimally speaking, and/or have situational mutism deserve AAC devices so that their voices can be heard. Autistic people who need 24/7 care deserve that support, and full time caretakers for disabled people who need full time care should be covered by insurance in the US, rather than pushing disabled people towards institutionalization and often ill-suited care facilities.

The narrative of what is autism, who can be autistic, and who deserves support should be driven by autistic people themselves, not non autistic people who are adjacent to our experiences. No one can most tell what is going on inside ourselves than...ourselves.

Occupational therapy for autistic kids should not be limited to covering 60 sessions total for a child's lifetime on insurance plans. Applied Behavioral Analysis is often covered by insurance yet has been shown to be ineffective in helping autistic people through the 31-page 2020 The Department of Defense Comprehensive Autism Care Demonstration Annual Report 2020 (link here - <https://therapistndc.org/wp-content/uploads/2020/08/Annual-Report-on-Autism-Care-Demonstration-Program-for-FY-2020.pdf>).

What follows is a written comment made by ASAN from the July 2021 IACC meeting, which I wholeheartedly agree with: I would like IACC to use its unique role to promote the inclusion of autistic adults ourselves in all forms of autism research. Autistic adults can provide input on not just our co occurring disabilities and lifespan issues, but on communication access, the design of studies on the neurology of autism, studies on which services and supports work best for different groups, and indeed on any aspect of autism research. We particularly encourage the IACC to recommend the use of community based participatory research which works directly with autistic self advocates ourselves (including nonspeaking self advocates and self advocates with intellectual disabilities), rather than acquiring study participants solely by contacting parent representatives or our service providers. We possess firsthand knowledge and experience of our own bodies and minds that other stakeholders lack. High quality research done in partnership with autistic adults ourselves is the only way to reduce gaps in the knowledge base.

Robin Bond

I am an autistic woman who was not diagnosed until age 47. Part of the reason for the late diagnosis was, no doubt, my ability to mask; autism is woefully under-diagnosed in women. I would love to see more research on how autism manifests in women/girls.

I am frequently told, "You can't be autistic," because I hold down a fairly demanding job. I believe my autism makes me better at some aspects of my job (the research component; I'm a professor). Despite autism being a protected disability, I'm constantly hassled about being unprofessional for behaviors which are clearly autism symptoms--like stimming and not giving enough eye contact. (I also see colleagues who hassle students about similar behaviors.) I would love to see research on what institutional behaviors provide the best support for autistic individuals.

Trigger warning: The following comment contains reference to sensitive topics.

Morgan Stallard

I'm an autistic adult with substantial support needs. I live with family, need support in daily tasks most days, and frequently become non verbal when stressed. I also write well, and am active in my community. This sort of contrast is very common among autistic people. I want more lifetime services for autistic people that center our autonomy and place in the community. I want an end to regressive, coercive "solutions" that work by punishing us into compliance with other people's idea of a good life, or by hiding us away where non disabled people don't have to look at us. I want more accountability for autism service providers who abuse autistic children and adults, and comprehensive review of autism interventions focusing on the testimony of the people who have experienced them. I believe that autism is a natural and worthwhile part of the human experience, and while autistic people should have access to help for the things that distress us, such as comorbid conditions and PTSD from systematic social rejection and normalized abuse, the primary strategy for "dealing with autism" must be social. A huge amount of our suffering comes not from autism itself, but from how we are treated by non-disabled people. The cruelty and rejection we experience is not a fact of life, it's a choice being made by individuals and by society as a whole. We have the power to make better choices about how we treat people who are different.

Trigger warning: The following comment contains reference to sensitive topics.

Laura Comfort

I'm being tested for autism in my 30s, and the professionals in my life are convinced I have it. I've spent my entire life feeling different but not knowing why, and now that I know, I can't help but look around and try to figure out why it took 30 years to find. The most obvious answer is because the autism research available is biased and written by people who aren't autistic, and in fact seem to think of us as a burden or an inconvenience. It seems to be mostly non-autistic parents of autistic children. I've noticed throughout my life that NT people hate me. I haven't spoken to my mother in 10 years because she is abusive. Because of my experience, I don't think ANY autism programs or "support" networks should be filled with ONLY abusive parents of Autistic people. How about bringing in some actually autistic people? If not, maybe your program shouldn't exist.

Roxanne Blask

As someone who is not autistic, i use my comment to boost the words of someone who is. Even as someone with autistic family members, i know it is not my job to speak for them, or to assume i understand their experience or the experience of any other autistic person. You dont help by saying your giving autistic people a voice, you must have their voices be heard. Dont speak on behalf of people you pretend to understand the experience of. You only know what its like to interface with someone, a single dimension of an entire way of being.

Autistic people are not burdens, deficits, severe, or low-functioning. Focusing on gene therapies or the genes that cause autism will not support the autistic people in the here and now, and I would argue, would not support autistic people in the future.

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Jay Kristensen

I'd like to see more community resources for the autistic community, both in terms of more opportunities for social and community engagement, as well as an increase in human services overall, particularly among the aging autistic community. Also, I'd like to see the govt take steps to eradicate violent and psychologically damaging so-called "treatments" like the ones at the Judge Rotenberg center. Autistic folks shouldn't have to learn or be forced to conform to neurotypical standards in order to exist.

Heini Natri

- Autism research must be geared towards the intrinsic view and the needs and wellbeing of autistic people. Autistic people must be adequately represented at all levels of research, starting from leadership, with a focus on true equity, inclusion, and ethical engagement.
- Autistic-led research and peer-led support for autistic people must be supported and prioritized.
- Stakeholder engagement must be centered around autistic people, not non-autistic caregivers or professionals. Autism research must prioritize safety and informed consent, this includes open and transparent reporting and communication of possible group and individual harm.
- The diagnostic classification of autism and the assessment process must be recentered to emphasize and respect the intrinsic view, away from the deficiency-based view. Further pathologization and creating new, pathologizing diagnostic classifications must be resisted, as pathologizing, stigmatizing labels have been and are still used to deny autonomy and agency and to dehumanize autistic people, particularly those who are most vulnerable, e.g., autistic people with intellectual disabilities and non-speaking autistic people.
- In research and in clinical practice, access to basic human rights, such as communication and autonomy, must be prioritized and respected. Autistic communication style must be acknowledged as equally valid as non-autistic communication, depathologized, and respected.
- Autism research and advocacy must acknowledge and work towards dismantling the negative bias and harmful attitudes and structures that continue to negatively affect autistic people.
- Autistic people of all support levels must be protected from institutionalization and harm. Respecting autonomy, allowing autistic people to live their lives as their most authentic selves, and supporting autistic people's journeys towards self-actualization must be prioritized.
- We must work towards banning restraint and seclusion, all forms of conversion therapy, all harmful behavioral modification approaches, such as ABA. Those subjected to these approaches must be provided reparations and the institutions and companies developing and providing these harmful "interventions" must be held accountable.
- We must create clear guidelines to guide research and clinical practice away from the harmful, pathologizing, stigmatizing view towards acceptance and acknowledging autistic people as equals. This includes clear guidelines and regulations on ethical community engagement, transparency, equity and inclusion, and changing the language around autism from deficiencies and prejudice towards differences and respect. Autism research and clinicians must acknowledge and address harm and commit themselves to fight the negative bias that has caused and continues to cause irreparable harm to autistic people.

Lillie Ameling

I am 33 years old, I've been living on my own since I was 17. I have a job, a long-term boyfriend, and (albeit few) friends. I'm independent. I am also autistic. I found out I was autistic at 32 years old after deciding to go to therapy to finally try and figure out why so I've struggled my whole life in certain areas that the people around me don't seem to relate to (everything from hating school, needing sameness and routine, struggling to acquire friends, and hating bright lights, grocery stores and sheets that aren't perfectly flat and smooth.

I would like researchers themselves to understand that they operate on bias and preconceived notions of what Autism looks like, on what Autism is. I would like research to focus on this question: Why are there so many adult women who only find out after decades of struggling that they're autistic? Why are there so many adult autistic folks who only ever discover they're autistic when they have a child that's diagnosed? Why did they fall through the cracks? Why were they not seen?

I can't imagine how different my life would have been if I'd be given support and accommodations from the beginning.

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I would like IACC to use its unique role to promote the inclusion of autistic adults ourselves in all forms of autism research. Autistic adults can provide input on not just our co-occurring disabilities and lifespan issues, but on communication access, the design of studies on the neurology of autism, studies on which services and supports work best for different groups, and indeed on any aspect of autism research. We particularly encourage the IACC to recommend the use of community-based participatory research which works directly with autistic self-advocates ourselves (including non-speaking self-advocates and self-advocates with intellectual disabilities), rather than acquiring study participants solely by contacting parent representatives or our service providers. We possess firsthand knowledge and experience of our own bodies and minds that other stakeholders lack. High-quality research done in partnership with autistic adults ourselves is the only way to reduce gaps in the knowledge base.

Trigger warning: The following comment contains reference to sensitive topics.

Nikki Satterlund

I feel that, in conversations about autism, actual autistic people are too often ignored in favor of non-autistic family members or “professionals,” who treat us as burdens to be “cured.” Autism is a disability, and I do struggle with many daily living tasks. But it is also part of who I am. I love who I am. Being autistic makes me unique, kind, creative, funny, and passionate. I cannot be cured of who I am, and I don't want to be, even if that means there will be things I'll struggle with and be frustrated by my whole life. Trying to be normal has only ever caused chronic exhaustion and anxiety. Allowing myself to engage in autistic behaviors like stimming, special interests, social/sensory breaks, avoiding eye contact, etc., has made me much happier. My whole life I've been told by society that I have a deficit in communication and socialization. But to understand autism, we need to understand the double empathy problem. <https://www.autism.org.uk/advice-and-guidance/professional-practice/double->

[empathy](#). I have a difference—not deficit—in the way I communicate and see the world. Just as often as I fail to understand non-autistic people’s communication, they fail to understand my communication. The problem is a two-way street.

I would like research to collaborate with autistic people, to consult us as key stakeholders in any and all studies on autism. (Not as free labor, too many autistic people get used without compensation). I would also like it to be easier for disabled people to access support and accommodations in adulthood necessary for us to be independent. This might include things like help with driving, cleaning, finding jobs, making doctor appointments, etc. I’m lucky enough to have a good support system between my amazing friends and my wonderful family, and am able to get accommodations at college. Not everyone has that. Further, people who have to rely on disability benefits have restrictions put on them, such as how much they can save or if they can get married, and that’s not ok.

Recently, there has been discussion around words like “severe,” autism and “low-functioning.” It is true that autistic people often have a wide range of support needs and co-occurring conditions. However, just because someone needs significant support in their lives does not mean that they are “low functioning,” or need to be “cured,” or that they are a burden. What they need is to be properly supported, and to do that we need to listen to autistics. Not just autistics like me who can go to college and “pass,” as neurotypical (albeit, with significant background support), but all autistic people, including those with intellectual disabilities and non-speaking autistics. Non-speaking autistics can often communicate with AAC, and many are advocates in the autistic community who are often overlooked. We desperately need to invest in giving non-speakers access to AAC. The ability to communicate is a basic human right.

I also want to put an end to support for ABA therapy, and to invest in more research on the traumatic effects of surviving ABA therapy. There is evidence that ABA causes long term damage that lasts into adulthood, such as trauma, prompt dependency, learned helplessness, and anxiety
<https://www.tandfonline.com/doi/full/10.1080/23311908.2019.1641258>.

ABA was founded by a man, Ivar Lovaas, who was involved in the creation of gay conversion therapy, who thought that autistic people were not really people, and who used physical punishment to correct behaviors. I recognize that modern ABA is different than that, but it still corrects behaviors without understanding them, urges compliance, and does not allow for autistic behaviors. As a queer autistic person, I have this to say: any therapy founded on Lovaas’s principals cannot be reformed, even with physical punishment removed, and no matter how much “positive reinforcement,” and “fun,” is used instead. I understand that a lot of parents are worried about their children, that a lot of ABA professionals think they are helping and have good intentions. Good intentions do not undo harm.

Furthermore, physical aversive punishments are still used by places like the Judge Rotenberg Center. The JRC urgently needs to be shut down. They psychologically and physically torture autistic people—disproportionately those of color—with electric shocks and restraint. People have died and been seriously injured at the JRC. We need to ban physical punishments, like the GED shock devices used at the JRC.

We can support autistic people without controversial and abusive practices. That includes providing access to communication, whether that is spoken, typed, a picture board, or any other form of AAC. It includes understanding a person’s sensory needs. It involves understanding that stimming is a coping strategy that should not be stopped unless someone is being physically hurt (and even self-injurious

stims often have a motivation behind them, such as feelings of anxiety or overwhelm). It involves therapies that emphasize support, consent, and accommodation over treatment or cure. It involves knowing our triggers and our limits. It involves allowing autistics to be ourselves, even if we play different than other kids, or seem weird to you. It involves understanding that a lot of non-speaking autistics have dyspraxia. It involves access to services and accommodations in both childhood and adulthood. It involves having options besides restrictive guardianships and institutionalization for autistics with a lot of support needs. It involves listening to a wide variety of autistic people, autistic people with intellectual disabilities, autistic people of color, autistic non-speakers, autistic people with marginalized genders and sexualities, autistic people with other co-occurring conditions such as chronic pain, physical disabilities, mental illness, or ADHD.

This written comment does not even begin to scratch the surface of the issues faced by the autistic community, but I hope that it provides some insight to how to think differently about autistic people. We are not broken. We are not burdens. And we are the most important stakeholders in any and all conversations about autism.

Sarah Seigel

Thank you for providing me the opportunity to comment. I am a non-autistic parent to an Autistic child.

I want to share with you that the most valuable insights and information I have received regarding how best to support my child, including how to build a respectful and trusted relationship with him, have come from members of the Autistic community. While I do value the expertise of non-autistic therapists and healthcare providers, I always check in Autistics working in the fields of therapy, education advocacy, scientific research, and self-advocacy for guidance, to make sure that the decisions I make in support of my child are safe and appropriate. What I feel all parents of Autistic children desperately need is for non-autistic therapists, scientific researchers and all healthcare providers and organizations to be required to consult with members of the Autistic community to ensure best practices. Their input is critical to ensuring the health and happiness of Autistic children like my son. Children also must be communicated with respectfully, yet research on autism early intervention therapies notably do not include adverse events reporting (see study authored by Kristen Bottema-Beutel, Shannon Crowley, Micheal Sandbank, and Tiffany G. Woynaroski titled Conflicts of Interest (COI) in autism early intervention research- a meta-analysis of COI influences on intervention effects). More input from Autistic researchers would be a safeguard to ensure that all supports are humane. The lack of input from Autistic children, as well as from the adult Autistic community is alarming. We desperately need to add more seats at the table for Autistic and to reform models of support for Autistic children.

Thank you for your time.

Amanda Thomas

I'd like research on autistic masking and burnout to be prioritized as well as studies on the harms of ABA to be conducted. Of high priority is centering lived experiences of autistic persons when conducting any studies and research on autism.

Trigger warning: The following comment contains reference to eugenics.

Amaranthe Zinzani

It's invariably most ableist people (as well as the most selfish and underhanded) whose words about Autisticness are given most credence. The time has come for Autistic people, NOT our parents/carers, to be considered the experts on Autisticness and what support we need.

The attacks on Autistic activists are led by martyr parents who are more invested in protecting their narratives and their egos than they are in helping Autistic people, their children included. (Note: these martyr parents also frequently can't tell the difference between Autisticness and co-occurring conditions like epilepsy and intellectual disability. This is a HUGE problem.) We #ActuallyAutistic people are accused of faking or called "high-functioning," a meaningless and dehumanizing term. All we want is an end to the ableist abuse. Stop hurting us. Stop trying to "fix" us. Stop killing us (Google "Disability Day of Mourning").

#WeAreLikeYourChild #ABAIsNeverOkay #StopTheShock

Trigger warning: The following comment contains reference to aversives and other sensitive topics.

Courtney Johnson

My name is Courtney, and I am an autistic adult who needs a lot of supports to live independently. I have caregivers every day who help take care of me, use an AAC device to communicate because I am nonspeaking, and am in my state's home and community-based services program for people with intellectual and developmental disabilities. I wanted to write in hopes that the committee will focus on a few very important issues: stopping the use of aversive shocks at the Judge Rotenberg Center in Massachusetts, funding for home and community based services to help with waitlists, improving access and funding for assistive technology and AAC devices to help us communicate in ways that are best for us, helping us access better healthcare and expanding information in plain language, alternatives to guardianship, and more research on autism for how it impacts us throughout the lifespan. I also hope that there is a push for more representation of autistic people themselves and a focus on self-determination and advocacy, including us nonspeaking autistics and those of us with significant support needs - because we are often underestimated and spoken over, but we have a lot to say. Thank you for your time.

Trigger warning: The following comment contains reference to ableism.

Lucy Greenwood

As an autistic person I would like more research on the following -research into why ABA is harmful to autistic children -how workplaces can be accessible (I've faced so much ableism in all my jobs) -why as an autistic person I have undiagnosed gut problems -why autistic people suffer from extreme insomnia and night terrors -research into why so many autistic people are sectioned by the NHS and why so many die or face abuse whilst in that care. Why is it they are in there for 5+ years and their family aren't given any care at home plans?

Shereese H

The link between ODD, ADHD, AUTISM and how anxiety effects them and what other alternatives besides prescribing medication, because its not for everyone and each person and their needs are different

Darin Pyatt

I urge you to fund research that addresses the lived experience, needs and concerns of autistic people throughout their lifespan. Autistic children, teens and adults do not benefit from research for cures or causes of Autism. Largely, this is considered an insult, as they value their lives. I work in the field of autism health care and I see every single day that there are not enough supports, or the right kinds of supports. I urge you to include Autistic researchers in your research. Research alternatives to ABA treatment, because many parents are seeking alternative treatments as ABA is not for everyone. Many autistic adults report ABA was harmful to them. Additionally, more research is needed on autism in women and people of color as well as issues impacting autistic adults as they age. Please include the perspectives of the neurodiversity paradigm in your research as well. Thank you.

Alexandra Carter

I would like to see more research done on why women with autism often go undiagnosed, what symptoms are different for them, and what kind of evaluations can be used to specifically diagnose women.

Trigger warning: The following comments contain reference to cures and other sensitive topics.

Alex Sprague

One thing I realized about my autism is that it makes me who I am. I can't cure it, I've tried so many times. But I don't need to. I can just work with it and surely enough, I'm able to recognize small details that my family and friends otherwise would never have seen.

Autistic people deserve to feel welcome and not like they're being taken advantage of.

Erin Jonaitis

I'd like to see funding for researchers interested in applying what is known about autism to educational settings, in order to help teachers better understand how to work with their autistic students in the least restrictive environment possible. I'd like to see at least some of this work draw on the lived experiences of adults with autism, who may have ideas of what would have helped them struggle less in school. Relevant outcomes for this work might be school failure/grade retention, student academic performance, and student and teacher satisfaction with the classroom experience.

Tamara Griesel

As an autistic educator of postsecondary students in technical college, I would like to see research into how we as educators can best support these young adults in obtaining their degrees and reaching their

goals. Research into the most effective accommodations and supports, the role of facilitating community among these students, and better ways to support executive function is greatly needed.

Clarissa Nielsen

I think we should do more research about autism in women and non-binary people, why they tend to be diagnosed less and how they might have different symptoms or do better with different treatments.

Judy Ferry Rohlfig, M.S. Ed.

More funding is needed to provide support for students who are on the spectrum and who are included in general education settings.

Barb Schneider

RE: Future research funding: Late life diagnosis and life navigation. There are myriad losses of age that can create havoc for those with Asperger's, especially late diagnosed, who lack a support system. Health care workers and the public need education on this population for appropriate intervention. Testing for ASD along with dementia and other illnesses to make a correct diagnosis is vital.

Adam Brabender

Back in 2011 when I was first put on Risperdone. I could tell a world of differences. I was a lot more organized and started making my bed a lot better. I was aware of my surroundings and could literally see how people acted with another and observed they were walking. I was totally aware of senses for a brief moment in time, but the side effects wore off a couple of weeks later. I was chewing slowly and taking my time eating. In addition, I was more aware of nature and felt the sun on my body and enjoyed getting wet in the rain. It felt wonderful to finally being aware of all of my senses for the first time and being more aware of my surroundings. I think the IACC should look into researching new drugs with minimum side effects, something similar to Risperdone that help improve the systems of Autism much longer than Risperdone ever did for me. In addition, I think the IACC should have more clinical trials for adults, instead of just children and not limit it to a certain age group in adults.

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

Sondra Hardgrave

I would like IACC to prioritize research on health and mental health issues that are common for autistic people, including autistic children. Do research on how many autistic people have sleep disorders and what treatments are effective. Do the same type of research on mental health issues, such as depression, anxiety, ptsd and ocd. Focus on effectiveness of treatment, since many autistics are more sensitive to meds. Research how common neurological illnesses are for autistic people and focus on if they may need different treatment strategies. Research how to make schools and other educational settings less stressful for autistic students. Focus should be on causing less trauma for autistic people (including children) rather than prioritizing training autistic children to hide their autistic traits, which causes trauma. Too many of our community end up with PTSD and commit suicide.

Benjamin Kerensa

I would like to see more autism research funded that addresses sleep disorders for people with autism and diabetes.

Brittany Daniels

I wish there was research on why autistic people without any intellectual disabilities and no language processing disorder don't get along with autistic people with any intellectual disabilities and has a language processing disorder. I also wish there was research into why autistic people who need written instructions at the same time as images, photos, etc.... struggle to get that type of learning in the college/university classroom when auditory (spoken) lecture is the preferred teaching method in a lot of college/university classrooms.

Robin Atlas

I would like to see some research dollars go to fund how diet and nutrition can help alleviate some of the anxiety and other issues related to autism. FOOD ALLERGIES and POOR QUALITY DIET have an effect on the general population and it's exacerbated in the autistic community. Creating a baseline chemical assessment at birth might go a long way in helping to identify and treat some symptoms with improved diet and supplements...

Pandora Willcutts

The IACC should research autistic burnout and how to treat it.

Jodie Rosenblum

I would like more research to address why females are being diagnosed at greater wait times and at higher ages than males. I would also like research to address if and why suicide rates may be higher in autistic females than males and what we can do to reduce the number for all autistic people.

Corben Havener

I would like a study on Autism accommodation in the workplace as well as the recruiting process. There is too much underemployment in the autism community and career recruiting and advocacy should focus overcoming the challenges to let some of the known autistic strengths shine through.

Marja Erwin

I would like to see research into safety and accessibility for people with sensory processing issues. For example, current infrastructure often puts crosswalks at intersections, with turn signals, hazard lights, crosswalk lights, flashing left turn lights, etc. Buses and bus stations add more loud noises and flashing lights. School buses, ambulances, county maintenance vehicles, police cars, and so on, all fire strobe lights. State and county websites are full of animation, and often use animated zooming maps.

Advertisers add flashing billboards. Other websites and apps often include blinking cursors, animation, flashing, and more animation.

Anonymous

Hello. I am an autistic person, and I substitute at a school in a life skills classroom. I have started to have troubles at my job because I am burnt out in a way that my disability exacerbates, and it is becoming more and more difficult to take on shifts as the demands of the work day and surrounding aspects of it in relation to my being autistic mean I am very close to melting down by the time I get home, particularly if something unexpected happens (for instance, expecting to have a ride but instead having to take the bus). In fact, I have been working less and less because of this.

I think IACC should prioritize research on the way day-to-day demands in things like jobs can weigh on autistic people (i.e. because of things like social situations outside one's skill level, masking, routine changes, etc.), as well as what can be done to mitigate these issues, whether at home, on the job, or anywhere and anyway else. In the long term, the best option for the vast majority of autistic people is to be able to work without pushing ourselves to the brink, as it allows us to use our skills, earn our own money, and be more independent. I would like to be able to work without it being unhealthy. Thank you.

Julia Simko

I would like to see the IACC prioritize research on how many people across the autism spectrum--both with and without government benefits--are parents raising at least one child, and how to best support them. In considering this, I would like the IACC to remember that there a lot of parents out there who didn't even know that they're autistic until a son and/or daughter was diagnosed.

I would like the IACC to prioritize funding to train therapists and teachers how to implement the SCERTS Model, and to encourage the use of SCERTS consultants in therapeutic and educational settings.

Yamen Staniford

As an autistic adult, I would like IACC to prioritize research on the following:

- Alternatives to behavioral therapy to help autistic children cope with sensory, emotional regulation, and communication challenges.
- The disparities in diagnosis and treatment of Black autistics and other autistics in communities of color, and how to improve equity.
- Pathomechanisms and effective treatment of gastrointestinal disorders, sleep disorders, anxiety, and depression in autistics of all ages.
- Finding appropriate levels of respite and community support care for families and individuals caring for autistic people.

Richard Gallo

I would like IACC to prioritize research on how many autistic people have sleep disorders and what treatments are effective is more clear than “I want IACC to prioritize research on sleeping.”

Frank Carrillo

One focus of research should be on prevention of autism.

Yuliya Thomas

I would like more autism information from other autistic individuals/adults to be available especially to parents/caregivers of young and newly diagnosed individuals with autism.

Audre Wirtanen

Autism, hypermobility, POTS/Dysautonomia, and mast cell activation syndrome. A genetic connective tissue mechanism impacting systems in a way that makes sensation different and people neuro divergent. hEDS/HSD might be a good screening tool. hEDS/HSD prevalence has not been done scientifically well, but it is much more common at least 1/500, and the chronic illness connections to neurodivergence as a part of managing the whole experience is really important.

It's important to remember that the Beighton score, the only measurement of hypermobility, does not correlate with symptom severity or injury risk from hypermobile tissues, and as an inclusion/exclusion factor is not going to provide accurate information. Peoples symptom burdens are more important and scientifically relevant than the Beighton (which was developed on Black and Indigenous people of color but only used to screen white people in the US who have access to physicians who Dx hEDS/HSD). Please go to www.Hyp-access.com and email me if there are questions or you would like me to send references, etc.

Zachary Inkeles

I would like autism research funding to be allocated to study how cognitive impairment affects people with autism and how autism affects people with cognitive impairment. Schools often focus on behavior, which can impact how much effort is put into academic teaching. Is cognitive impairment created by focus on behavior, or is the cognitive impairment ignored in order to spend school time on behavior rather than cognitive development?

Katie Goidich

I would like to see more research on the sleep needs and sleep disturbances of autistic children and teens (including girls), and what treatments/therapies are effective in helping improve their sleep.

I would like to see more focus on improving the learning environment for autistic children in public schools, with equal representation of girls in the research.

Please do more research on the impacts autism has on nutrition and health, including women's reproductive health matters.

I would love to see research on effective treatments/therapies for autism and mental/emotional/learning comorbidities (eg ADHD, anxiety, depression).

Carmen Sweitzer

Please direct funding into research of how to make school and work more accessible to autistic people. Thanks!

Andrew Baxter

As a special education teacher who works closely with students with autism, i feel that mental health related issues are usually not addressed with autistic students. It can be very difficult for health professionals, teachers and other service providers to accurately identify what areas of support are needed; many times certain behaviors are attributed to autism, when in actuality the challenge may arise from other co-occurring disorders that have not been properly identified. This is just a broad observation that I feel needs more research. Thank you for providing this opportunity to comment.

Elizabeth O'Leary

I think it's important to reconsider the entire framework used when studying autism and related conditions. I think the broader Autism phenotype has to be studied alongside autism itself because autism is only diagnosed when it creates difficulties (and often, even when it causes difficulty it is misdiagnosed as something else). If so many people have gone undiagnosed into adulthood there may be situational things that make living with autism easier. Masking, of course, but I don't believe that masking is the whole story, perhaps growing up with certain privileges makes it easier to "escape detection". Or having certain supports, character traits, or types of intellect.

As far as a direction for research, I think health, especially mental health needs to be prioritized. I have never seen a mental health treatment that was designed for people with autism. I do think basic research is important, but not on the physiology and genetics of autism, but instead on how autistic people navigate and view the world, how trauma affects us, how many undiagnosed autistics are there, what do we consider important measures for success, and how do we define autism as distinct from other similar neurodivergencies and if overlap is appropriate. And again, we need to consider the BAP to see if people have come up with solutions that work well aside from masking.

And at the same time, use what we know to enhance quality of life for people in the present and near future. How can medical treatment be made more accessible, what types of living situations and supports lead to increased well being, what types of communication devices are most helpful. Clear information that will hopefully lead to policy changes so that quality of life can be enhanced regardless of finances.

Shari Chase

My comments will be on the lack of training programs for those with Autism and housing, with a few ideas to share with the audience. I would like to challenge attendees and committee members to try to create a national job skills training program and living environment that can create a campus with jobs, residential options continuing education, and businesses much like a retirement community.

Additionally I would like to advise that there had been abuse in the NBU programs with Flooding to try to overcome Hyperacoustics. in our state creating a public safety problem. I will go into brief story so this is avoided.

Tosha Brothers

As an autistic woman, I would like to give my personal suggestions for how research provisions should be used in the future. Specifically to benefit autistic voices, and to help us advance society past its current ableist state. To preface, any research that comes from the angle of proving our many strengths as autistic people is appreciated. But because there has been such gross negligence in assisting us with the debilitating parts of our condition(s), I think it would be best to focus on those things going forward. To start, I'd like you to delve more into helping autistic people with immune disorders to better function in their daily lives and look into the role the brain has in regulating the body via interoception, or lack thereof. Interoception research of any kind could lead to some promising findings. There are many hidden senses of the human mind and body that could unveil some answers. I'd like more research into reducing symptoms of general irritation and anxiety within autistic people, as well as depression and PTSD. Possibly through methods of interoception and other undiscovered senses.

Especially with anxiety, I have personally used methodologies such as deep breathing patterns, meditation, hypnosis, and psychedelic intervention. Psychedelic therapies are gaining traction with good reason, so in the future, it may be an easy solution for many common medication problems involving the strength of drugs. There is also, more popularly, cannabis. But these should not be stand-alone solutions, by any means. There should be more intervention, as I said before, to improve the quality of our lives. I find the rigidity that comes with being programmed with anxious mannerisms intertwined with OCD cannot be solved through conventional means. Research into these comorbidities and how they all link together synergistically would be appreciated.

This leads me to the effects of masking. Please research what effects masking has on autistic people based on their lived experience related to feelings of guilt, shame, or lack thereof. As some masking comes commonly to some autistic people, while in others it is oftentimes actively detrimental. I believe the systems of learning are closely interlinked with how we view the world through masking and pretending to be neurotypical. It is never as simple as putting on a front when it comes to our psychology. These things get actively integrated into how we personally express ourselves. It would be classified more as a basic survival instinct. That's why more research into it would help to discern these things becoming a heinous problem like I already believe to be true.

Empathy has been another popular point of contention, even within the autistic community. I would like more studies to be done into the 'double empathy problem'. A phenomenon where neurotypical people think we lack empathy based on us not expressing our feelings in a conventionally neurotypical way. Specifically, research that proves there is a miscommunication between our two brain structures; thereby proving we have empathy and that it is just commonly misunderstood. Going in and studying

how we express individual emotions such as sympathy, empathy, awe, and love would be a good start to understanding that autistic people very much have their own language of communicating that is distinct from neurotypical customs.

Along the same vein of proving our good qualities, I'd like more research to be done into the basis of what our brain structure even is exactly. At the bare minimum, I'd like plenty of noninvasive methods like scanning to be used to further clarify how we have extra neurons than most people and more grey matter that sets us apart from neurotypicals. Because there haven't really been many clear indications that people even know what an autistic brain structure even is. So more clarification of the official type would be helpful for confirming these things. If you could just get something down on paper for sure, that would be illuminating. I know autistic people have different kinds of grey matter, and it might not be easy to discern directly because of that. But we all share the most basic common differences. So that should be enough to go off of to get a commonplace answer that cannot be easily disputed.

Jay Jackson

I would like to see more research focused on the specific ways autism affects females, how autistic females present differently due to socialization, how that prevents us from getting diagnosed - usually either at all or until we are adults, research into how we can combat the male-only stereotype that many doctors and the general public still has - that prevents us from getting diagnosed or the help we need, and on the specific needs of autistic girls and women to help us live successful lives.

Keith Halperin

Please research the prevalence of mental health co-morbidities in AS individuals and whether the comorbidities or autism itself tends to play a dominant role in AS individuals' outlook and behavior.

Em Johnson

Do you think you could prioritize looking into why so many Autistic people struggle with sleep, and how to fix that?

Trigger warning: The following comments contain reference to sensitive topics.

Bianca DelVecchio

I would like the IACC to investigate the following:

-self injurious behavior and long term use of restraints in autistic adults with co-morbid mood disorders, barriers to fading use of restraints (bipolar, etc) -use of/barriers to use of AAC devices of non speaking/limited verbal abilities of autistic adults in group home/developmental center settings -barriers to community engagement and meaningful occupations (leisure, household management) in autistic adults in group home/developmental center settings -reasons for staff high turnover and neglect/abuse allegations in group home/center settings, quality of life of residents and staff in these settings- how that contributes to turnover of staff.

Rowan Briglevich

I want IAAC to put research into how many autistic people assigned female at birth have menstrual problems and what treatments can help.

Evander Smith

I am an Autistic young adult in my twenties. I would like to see more funding go towards certain research about autism and some funding be lessened to specific other research about autism.

I would like to see more funding go towards:

1. The effect of autism on sleep issues
2. The overlap of autism and hyper-mobility/chronic pain
3. How autism effects mental health and how to cater mental health services towards autistic adults with mental health concerns.

I would like to see less funding go towards:

1. Finding a cure for autism
2. Finding the causes/genes of autism
3. Anything that could add to the eugenics/abortions of possibly autistic fetuses like what happened to people with Down Syndrome

Matthew LeFluer

I. Support. Any. Or. All. Of. Above. Research institute technology advancement. Support. For. Citizens. Within the. Autism spectrum communities. In. The. United States of America Because. We. Deserve respect kindness compassion determination diversity equity and inclusion for all. Within. Social society services.

Rebecca McCabe

I would like to see research on technology to combat sensory overload, such as wearable devices that use pressure or other means to respond to and soothe moments of sensory stress.

Trigger warning: The following comments contain reference to suicide and other sensitive topics.

Anna Haugen

For too long, research on autism has ignored the needs and wishes of autistic people. I hope that you will move to include more autistic perspectives in the studies you fund. Here are some specific things that I, as an autistic, wish were better researched:

Suicide rates and suicidal ideation in autistics. The suicide rate is much higher for autistics than the general population, and I want to know why and what can be done to change this.

Alternatives to ABA. Meta-analysis of studies on ABA, as well as a recent DOD study, have shown that ABA is not effective, which autistics have been saying for a long time. I want research into alternatives. What works, what doesn't, and why?

Note: The following comment has been redacted.

Rebecca Tienhaara

[redacted]

Study Autistic People are marginalized by and in society by using a survey. [redacted]

Do a survey asking Autistic People how emotional they are and also a survey centered around sensory issues and how they effect Autistic People and ask which material or thing bothers Autistic People in the survey.

David Shuck

Much progress in society and technology comes from autistic people. To enable more progress, it would be helpful to educate NTs about environments conducive to the health of autistic persons. The current design of the world generally harms this group. Much available "information" on this group in this country is wrong. Much correct information comes from this community. New Zealand and the UK seem to be more advanced in this respect.

Please direct more funds towards helping this group, not finding causes or "cures". The world is better off with this group. This group would make great consultants for many aspects of government as they can often see much better through social noise.

Thanks for reading this.

Trigger warning: The following comments contain reference to abuse and other sensitive topics.

Sheri Waddill, M.A., LMHC

It would be useful to have more research on the intersections and differences between ASD and PTSD. This quandary often comes up when Im talking to/treating someone who is undiagnosed until either early adulthood (often college) and later adulthood (30+ years old). Currently there appears to be a paucity of research.

When considering "children with disabilities are almost two times more likely to be physically or sexually abuse[d] or neglected than children without disabilities", <https://disabilityjustice.org/justice-denied/abuse-and-exploitation/>, it is of significant importance to our community to have a better understanding of the differences between ASD and PTSD in adulthood. I say adulthood anecdotally bc in my personal experience as a mental health therapist many people don't seek help with symptoms of PTSD until they are adults, perhaps due in part to caregivers not recognizing or not acknowledging their child's suffering for a variety of reasons.

Many thanks for the opportunity to be heard

Nik Castle

Please be sure to include autistic researchers and contributors at all levels of research that is being conducted. I would like the IACC to explore autism and attention, co-morbidities with ADHD and other disorders, presentations of autism across genders, races, ages, and other demographic factors, and I also would like the viability of different communications styles to be studied bringing the double empathy problem to greater understanding. Thank you.

Trigger warning: The following comments contain reference to suicide and other sensitive topics.

Hana Gabrielle Bidon

I would like IACC to prioritize research on the representation of autistic people in mainstream media in the United States. Typically, American TV shows and movies portray autistic characters as middle-class cisgender heterosexuals white men with special interests lying in STEM. As far as I am aware, there few shows and movies about autistic women and nonbinary folks along with autistic people of color plus people at the intersections of these marginalized communities. American books and literature are not that much better. Though there are plenty of memoirs of autistic people, there are few fictional works with accurate representation of autistic people, especially those from other underrepresented groups, such as being a person of color or a member of the LGBTQ+ community. I would like to see how researchers can increase the diversity of representation of autistic people in American media so allistic people, especially neurotypical individuals think that autistic people are different from each other.

Additionally, I would like IACC to focus on research of autistic people in higher education, specifically with their university studies and graduate studies. For example, I would like to know what obstacles and challenges autistic people in higher education face whether it be not receiving their approved accommodations from their professors or not fitting in their university because people think that they are freaks and too socially awkward to fit with them. Moreover, I wish to see how autistic students receive academic and emotional support during their post-secondary studies from support groups, individual therapy, advisors, friends, and family.

Finally, I would like autism researchers to focus on the mental health of autistic people, especially how the COVID-19 pandemic impacted their ability to concentrate on their studies and work. I also wonder if the autistic population compared to the general population in the United States are more likely to experience symptoms of anxiety and depression, plus the suicide rates (attempted and successful attempts) among these populations before and during the pandemic.

Emma Wilkinson

I would like IACC to prioritize research on supporting the mental health and quality of life of autistic individuals, particularly by identifying better measures of depression, trauma, and anxiety in ASD as well as effective treatments and supports.

Trigger warning: The following comments contain reference to abuse and other sensitive topics.

Kenyon Chapman

There are a few topics of interest I would like to see studied. Foremost, I believe it would be in the best interests of autistics if research were to be done into specific environmental changes that can be made in school and the workplace so as to best accommodate those who are hypersensitive to stimuli.

Furthermore, I believe research into the development of Augmentative and Alternative Communication should be done so as to give all autistics who are semi/nonverbal the best opportunity to communicate their thoughts, needs, desires, and beliefs to others.

Another issue of particular importance is Special Education. Specifically, it is my and others desire that you would look into the outcomes of those in Special Education (isolating certain variables so as to see the effect of special education itself), the reports of abuse in Special Education classrooms, and ways in which "typical" classrooms can be made to be inclusive of those now put in Special Education.

This goes along with what I believe to be a broader necessity for research into methods of recording and counteracting discrimination and unequal employment/underemployment among autistics.

This is all.

Katie Gatto

I would like IACC to prioritize research on how many autistic people have sleep disorders and what treatments are effective and other quality of life research.

Barbara Goldman-Sherman

As a newly diagnosed autistic person in my late 50s, I was shocked to find out how little is available to me in terms of what to expect as I age. I am also surprised that so much public funding goes to research that is completely irrelevant and unnecessary in terms of how autistic people live our lives and what we actually need to know. I'd like more information on the effect of oxalates in both neurodivergent and neurotypical people. I'd like more research on women and gender non conforming people with autism and how we can live better lives with autism, how we can get past the debilitating suicidal ideation I struggled with through my 30s, how we can create better, longer lasting relationships, and how we can use our strengths better. When I think of the contributions of Einstein, Noether, Jobs and others, curing autism is an idea that stinks of ableism. We should not waste public funding on research like this but use public funds to educate and help those of us with autism to be able to live full lives. How did I spend 37 years in therapy with "professionals" without a proper diagnosis? Bias! Ignorance! It's about time there was equity, diversity and inclusion in the public funding of neurodivergence.

Matthew James

I would like you to implement the following research practices:

1. How to find a partner and get married if you are autistic. It's so unfair how everything, especially the whole process of finding a match is designed exclusively for neurotypicals.
2. How to make workplaces more accessible.
3. How to help people who struggle with noise sensitivity like me.
4. Educating the public to stop viewing autism as an evil curse and autistic people like me as dangerous subhumans.
5. Stop funding ABA and institutionalisation.
6. Make the school systems more accessible, including universities.

Monique Taylor

I would like IACC to prioritize research on how many autistic people have sleep disorders and what treatments are effective

Lisa Kriegel

I would like the IACC to prioritize research into music and how it helps our brains regulate stimulation during meltdowns or shutdowns.

Jared Stewart

As an autistic adult, parent of an autistic child, and a professional serving adults with autism for over 20 years now, I simply want to make a plea for focusing research and funding dollars on real-life, here-and-now projects with immediate potential for impacting quality of life. How do we effectively improve job finding and job keeping for autistics? What characteristics of housing and transportation create the best chance for autistics to be able to live independently? Why do some autistics succeed in college, and others in trades? How do we reduce the rates of suicidal ideation and suicide for autistics? What accommodations and environmental characteristics make public school less traumatic? How do we help autistics protect themselves from sexual and other abuse? What kinds of programs best bridge the gap between high school and independence for people with autism and other developmental delays? And so forth. Please consider giving priority to research that will actually make a real difference. Thank you.

Michael Rathbun

We very much need additional research that establishes the physical/structural underpinning of autism as a distinct and denominated condition. The current standards for identifying autism are almost entirely behavioral, which is at best unreliable.

Jane Patrick

I would like IACC to prioritize research on how many autistic girls are being overlooked in primary schools and how to effectively identify them and offer accommodations.

Todd Woodward

Research should be focused on helping autistic individuals to live productive and supported lives fully integrated into society. That may include education and training for non-autistic society.

Irene R

I want IACC to do research on the long-term effects of consistent masking, ex. dissociation.

Leanne Claire Civiletti

I am a 66 year old woman who is still struggling with explaining my communication disorder. I have nothing wrong with my intelligence or comprehension or long term memory.

The physician notes after I leave a new provider make me want to throw sand in someone eyes.

I personally feel that it would benefit the community to spend money on education for the few minutes of time Autism is given in medical school.

It's difficult enough having Ehler- Danlos hypermobility Syndrome, CCI, mast cell activation disorder let alone attempt to educate providers about my physical conditions when my Auditory Processing Disorder is not accommodated.

I need to see studies for accessible communication methods which will take in the understanding of a decent explanation of why one needs this and how to provide the accommodations.

Sensory overload issues, lights and EMF , noise etc

What is available to use for lighting that will not trigger reactions ?

Lighter weight noise cancelling headphones?

Perfume , fragrance, more literature on accommodations

Environmental triggers can be incredibly difficult to function around for me

How does one

Aleksandra Ruminska

I believe that research is needed on the educational needs of autistic students with language development challenges. Often, linguistically delayed autistic people have fewer development opportunities due to the fact that communication in educational institutions is not adapted to their needs. It affects their whole life, their understanding of their emotions and needs, and their independence.

Madeleine Calvi

I would like IACC to prioritize research on how many autistic people have sleep disorders and what treatments are effective.

I would like the IACC to prioritize research on the effects of cannabis use for autistic adults, and the potential of cannabis as a tool for coping with and/or treating sensory overwhelm.

I would like the IACC to prioritize research on the prevalence and manifestations of autism in women, trans, and nonbinary people and effective solutions for increasing awareness and inclusivity for them.

I would like the IACC to prioritize research on the prevalence of autism in people of color, the differing barriers they face as autistic people of color, and effective solutions for increasing awareness and inclusivity for them.

I would like the IACC to prioritize research on PTSD and other negative mental health impacts in autistic people who have undergone ABA therapy, especially autistic adults who experienced ABA therapy as children.

I would like the IACC to prioritize research on best practices for meeting the accessibility needs to autistic adults in the workplace, with an emphasis on preserving their privacy with regards to their diagnosis.

I would like the IACC to prioritize research on best practices to mitigate the negative effects of the food sensitivities and relatively restricted diets many autistic people have, particularly ones that do not require a diet overhaul, such as vitamin supplements, probiotics, specific food eliminations, etc.

Kaitlyn Ballenger

I would like IACC to prioritize research on how many autistic people have sleep disorders and what treatments are effective. This impacts the lives of so many autistic people.

Anne Patton

I would like to see research dollars spent on the benefits of organic foods and nutrition for people with autism. Additionally I would like to see the benefits of holistic, integrative therapies such as massage, acupuncture, chiropractic, energy work, mindfulness, yoga, and meditation on people with autism, rather than the more typical pharmaceutical route. I have found all these techniques to be very beneficial to my adult son with autism over the years.

Caelan Thorne

As an autistic adult, I would like to see more research into the following. Why do autistic people have difficulty falling asleep and what can help us fall and stay asleep?

What supports/factors allow us to find and retain meaningful employment and how should employers better accommodate and include autistic employees? On a related note, how can discrimination against neurodivergent employees be reduced so we can be considered for employment in the first place? Could programs or grants be created to help autistic people start their own businesses? Particularly those with financial obstacles like being on SSI.

And lastly, given the many conflicts of interest surrounding ABA, it's roots in conversion therapy and how many autistic adults report C/PTSD, depression and anxiety after having gone through it and the studies backing them up, I'd like to see more research into the long term effects of ABA on the mental

health of autistic people and whether it has a significant impact on our suicide rates and susceptibility to further abuse down the line. The research should be conducted by a third party completely independently (especially financially) of any ABA organizations and with the involvement and input of autistic researchers and autistic adults who went through it.

Rob Lagos

I wish to point out that Social Security has long demonstrated itself as autism unaware. It is run very dysfunctionally - this is especially bad for those on the spectrum as we are expected to know the unwritten rules involved. We are made liable for things for which we are not given the proper disclosure. Social Security seems to enact rules to only protect themselves which may be at the expense of beneficiaries.

We need more representation and more say in government institutions, particularly including Social Security - how to make the system work better and how to treat people better - and this before any funding increase. It involves honesty, disclosure, and employee accountability. Up to now, Social Security has been very neurotypically run - meaning, it seems to be run and designed by people of one type of neurology.

I cannot forgive or forget how brutally and disrespectfully we were treated by the system - we have no voice - and it is, in addition, dictatorially run.

Along with full disclosure, we need specific instructions and procedures on what to do when the administration is not doing its job, or to prevent problems, and not to be blamed when it does not. One of the worst abuses of all is overpayments (and underpayments), and not starting and stopping checks when they are supposed to be - and then finding ways to inflict blame on the beneficiary for it. (I am talking about many such incidents, not just one or two.) Disabilities where autism plays a role and pertaining to the interaction between autism and the neurotypical world have also been poorly understood.

One comorbidity which disproportionately affects those on the spectrum is trauma or PTSD. I was very much affected by it and it rendered me unable to get the proper legal help, due to being retraumatized.

I am an autistic adult, first diagnosed with autism in 1980 by an autism specialist at the UCLA Neuropsychiatric Institute. I am a co-author of the book "Older Autistic Adults in their own words - the Lost Generation", and facilitator of our autistic adult support group. One thing that our book demonstrates is that PTSD is about 4 times more prevalent in the autistic community. Autism related sensitivities inflamed by the interaction between this and a non-empathic neurotypical environment contribute heavily to the prevalence, and awareness for this also needs to be gained.

I have seen much positive support from neurotypical families of members in our support group, but there is also substantial on-going abuse of others, who are part of this vulnerable population. Ignorance and dominance may be what contribute most heavily to this vulnerability. I think it is very true that early intervention, identification, and acceptance are key.

Thank you for reading.

Samantha Hua

I would like IACC to prioritize research on how verbal and nonverbal language is processed differently for autistic people

Logan Hau

I would like the IACC to prioritize research on mental health disorders within autistic people, for example depression and anxiety. Mental health plays a large role in the overall wellbeing of a person, and because people with autism are prone to such disorders, its crucial that they can get the support that they need.

Duncan Park

I would like more research to be done about autism and epilepsy and the connection. I know that epilepsy is shown to be more common in autistic kids, but I would want to see more research to be done in order to have a better understanding of how it affects autistic people.

Jenny Tan

I am aware that autistic people tend to be more selective about their food, and that nearly 20% of anorexics have autism. I would like IACC to prioritize research on how the autistic people's food choices and thought processes might affect their eating habits, specifically eating disorders.

Eugene Lam

I would like the IACC to prioritize research on what isolation and being alone does to an autistic person.

Ellen Yu

I would like the IACC to focus on research about whether it's more likely for autistic people to develop disorders, if it's caused by autism, and if so, which disorders.

Joyti Nath

I want medicines for treating autism to be studied, and possibly what are some ways we could regenerate pathways to make it easier for them to communicate. I'd also want to study how autism affects someone's daily life.

Elissa Leonard

1. Synthetic Folate (folic acid) added to the food supply and vitamins can build up as Unmetabolized Folic Acid UMFA, which the Boston Birth Cohort has linked to the highest incidence of Autism in Black babies.

<https://pubmed.ncbi.nlm.nih.gov/32844208/>

It is significant that Autism epidemic began in prosperous educated women receiving medical care (presumably taking prenatal folic acid, but perhaps at risk of B12 Deficiency from diet and use of medications). No one checked B12 in these women and children because folic acid corrects the anemia

of B12 Deficiency, and doctors were taught that B12 deficiency is rare in this age group. The autism epidemic has spread exponentially-- post-folic-acid-fortification-- to children of women who most rely on cheap carbs now fortified with folic-acid-only. Population that eats folic acid every single day at every single meal. They may not get any quality animal protein. And public health messaging has been to avoid animal-sourced foods. As you know, B vitamins must work in synergy to keep toxic Homocysteine down. There has been an Epidemic of deranged one carbon metabolism from lifelong single-nutrient food fortification and dietary guidelines to avoid meat, that were never based in sound science.

2. Longterm Synthetic Folate (folic acid) changes DNA Methylation of the unborn, affecting generations to come. <https://pubmed.ncbi.nlm.nih.gov/29546377/>

"Conclusions: The results of this study suggest that maternal folic-acid supplement use is associated with changes in the DNA methylation of the offspring that persist for many years after exposure in utero. These methylation changes are located in genes implicated in embryonic development, immune response and cellular proliferation."

OOPS. We are changing the DNA of babies.

3. Babies who don't get enough vitamin B12 suffer cerebral atrophy on a spectrum from mild to severe. As we have known for decades. CDC put this out in 2003:

<https://www.cdc.gov/mmwr/pdf/wk/mm5204.pdf> "If lactating mothers are cobalamin deficient, their infants should be evaluated for cobalamin deficiency and treated appropriately" but didn't add this to webpage until 2019: "If left untreated, vitamin B12 deficiency in infants can lead to permanent brain damage." NIH ODS updated in 2022: "In pregnant and breastfeeding women, vitamin B12 deficiency might cause neural tube defects, developmental delays, failure to thrive, and anemia in offspring [7]."

4. In other words, epidemics do not come from no where for no reason. Public awareness is needed: Dangers of now unprecedented opposite extremes of too much folic acid masking and exacerbating not enough primordial vitamin B12. Which also leads to other nutritional deficiencies... low B12 and excessive folic acid causes stomach and digestive problems. Cells of mucous membranes cannot properly replicate without sufficient B12 (GI tract literally disintegrates). And there is a known toxicity of folic acid that has gone ignored, which begs the question How much Lifelong Folic Acid is Too Much in Babies? [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(70\)91845-3/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(70)91845-3/fulltext) Symptoms of folic acid toxicity are Mood and Cognitive Disorders, Sleep Problems, GI Distress.

Trigger warning: The following comments contain reference to abuse and other sensitive topics.

Keane Jones

As a social worker for people with disabilities, an autistic adult, and as a person who graduated from a social science program with high honors after having conducted and published anthropological research, I believe there needs to be a stronger focus on the sociological factors that contribute both to the expression of autistic traits & to the public perception of autism and autistic people. There are a number of specific ways in which I'd like to see this implemented.

The 2022-23 executive budget for medicaid in New York State includes an increase in the rate of reimbursement for Applied Behavior Analysis therapies "to incentivize providers in managed care." This is despite the fact that the autistic community largely agrees that ABA therapies, when applied according to traditional guidelines, are abusive and traumatizing(<https://journals.sagepub.com/doi/abs/10.1177/0952695117702571>)(<https://www.tandfon>

[line.com/doi/full/10.1080/23311908.2019.1641258](https://doi.org/10.1080/23311908.2019.1641258)). This is especially troubling given that people with disabilities already experience abuse at a higher rate than abled people. A recent study (<https://onlinelibrary.wiley.com/doi/full/10.1002/aur.2162>) reported child abuse rates of 30% among autistic people. This rate raises to 51% if you consider physical abuse among their peers, and even higher if you consider emotional and psychological abuse. Increasing avenues of abuse under the authoritative mask of mental health treatment can only further victimization and erode our already battered understanding of personal boundaries.

ABA prevails as a practice in part because practitioners claim it is an 'evidence-based' treatment. However, this is because the outcomes they use to define efficacy are based on acquisition of socio-cultural norms. In order to provide evidence that ABA intervention can be considered therapy in the truest sense - that is, in the sense that it supports people's sense of well-being and provides healthy tools for overcoming obstacles - More studies need to be done examining the effects of ABA on individuals' emotional stability, self-confidence & self-worth, and sense of agency & bodily autonomy, as well as examining if there is any correlation between childhood ABA intervention and PTSD, anxiety & depressive disorders among youth and adults.

In the past, the IACC has prioritized the study of gender differences in presentation of traits among autistic people as well as rates of diagnosis, and the relationship between these two topics. However, often studies addressing these topics follow a model of gender that is based on biological - especially neurobiological - essentialism. This perspective disregards the statistically significant proportion of autistic individuals who identify as transgender, nonbinary, or gender-nonconforming. There needs to be more of a focus on this demographic, with inclusive methodologies with autistic and gnc individuals as collaborators, instead of merely test subjects. I believe such a focus would reveal not only aspects of autism that are new to the scientific world, but would bring a fresh perspective to the scientific discussion of the psychosocial components of gender identity.

Among the autistic community, there is a general understanding of autism not as a biological or genetic disease but as a disorder (or a benign neurological difference, depending on who you ask) in the enculturation process - that is, the way in which individuals gain understanding of and interact with their predominant culture as they progress through childhood. This understanding is available to those outside of the spectrum; Oliver Sacks was so taken by Temple Grandin's description of her lived experience as an anthropologist on Mars that he used it as the title of what would arguably become his most famous book. This was 27 years ago. It is high time that scientific canon reflected this perspective.

Adriana Oliveira

I would like IACC to prioritize research on autism and suicide prevention

Rachel Bussan

I would like the IACC to study the gut microbiome and how it impacts people with autism, as well as how we can improve it. Thank you!

Ryan Peng

Something I would like researched is minimizing or erasing the effects of autism through brain surgery, as this could make many children's' and family's lives less strenuous with fewer required checkups and therapy sessions.

Note: The following comment has been redacted.

Ellen Alexander

FC, RPM and S2C are methods that work for some non-speaking autistic people. The nay-sayers MUST to silenced and stop depriving these people their only means of communication. Our 53 year old autistic son has a beautiful mind that remains 'locked' in most of his days due to lack of acceptance for his method of communication and therefore lack of trained people to assist him. It took 100 years for braille to be accepted and now it is happening to these newer methods of communication. Our son doesn't have time to wait. As we age we need to know he will have 'his voice heard' through his only true method.

Kelly Israel, Autistic Self Advocacy Network



April 1, 2022

Thank you for the opportunity to submit written comments in advance of the IACC's public meeting on April 13-14th, 2022. In prior comments to the IACC, the Autistic Self Advocacy Network¹ has continually emphasized the need for research concerning high quality, individualized services and supports for autistic children and adults. Specifically, we have encouraged the IACC to determine which services and supports are effective, evidence-based tools for supporting the daily living, health, communication, and community integration related needs of autistic people across the lifespan, including autistic people with the most significant support needs. However, ASAN has continually opposed attempts to split autism into multiple diagnoses. These attempts will not improve services for autistic people, and are largely based on the desire to segregate autistic people with the most significant cognitive disabilities and support needs.

We submit this comment in response to the growing desire of some stakeholders in the autism community to adopt a new diagnostic label of "profound autism." ASAN opposes this attempt to reclassify some autistic people because of its high potential to further segregate autistic people from our communities. The term, rather than expanding the knowledge base on autism or accurately categorizing autistic people, would merely retread old ground by bringing back old conceptions of functioning labels with a new name. We call upon the IACC to reject these attempts and to focus its attention on providing recommendations and support for high-quality autism research.

¹ For more information on ASAN, please visit <https://autisticadvocacy.org/>.

The Background Behind “Profound Autism”

On December 6, 2021, the Lancet Commission, a group of 32 autism researchers, clinicians, and advocates, released a report that laid out their vision for the future of autism services and research over the next five years (Lord et. al, 2021). The vast majority of the report addressed important topics such as the need for individualized services, as well as research that prioritizes the quality of life for autistic people (e.g., Lord et. al., 2021). Unfortunately, the report also included a recommendation for a new “administrative term” called “profound autism” (Lord et al., 2021, p. 278).

Lord et. al. (2021) stated that this new term would be applied to autistic people who require 24-hour support, are not able to be left alone, and are not able to take care of basic adaptive needs (p. 278). The authors (Lord et. al., 2021) opined that these specific support needs are primarily associated with autistic people with intellectual disabilities and/or limited spoken language ability (p. 278). This proposal is a recast of past attempts to divide autistic people into “low-functioning” and “high-functioning” groups. These attempts are based on the mistaken belief that autistic individuals have impairments and support needs which are fixed and uniform across multiple dimensions, including IQ, speech, language, daily living skills, social communication, executive functioning, emotional regulation, and sensory processing (e.g., Gardiner, 2018; Zeliadt and Spectrum, 2016).

Media coverage of the report zeroed in on the term “profound autism,” which quickly overshadowed the rest of the commission’s work. Some proponents promoted the new term extensively as a means of segregating a subset of autistic people into a “severe autism” category mandating separate and highly restrictive services (Lutz, 2021; Singer, 2021a, December; Singer, 2021b, January). There have been calls by these individuals to include the term “profound autism” as a separate sub-category in the DSM-V (Bernhard, 2021). This is the case even though the Lancet report explicitly stated that they did not intend to introduce a new diagnostic term (Lord et. al., 2021, p. 278).

Functioning Labels Like “Profound Autism” Are Not Helpful to Autistic People

Autistic self-advocates and people with intellectual disabilities have spoken out for years about the harm caused by functioning labels like “severe autism” or “low-functioning.” Parents of autistic people with complex needs, additionally, have stated that functioning labels fail to help their children access supports and services (Shannon Des Roches Rosa, 2021). For example, the “profound autism” term conflates needing 24/7 support, “being unable to be left alone in a residence,” and “not being able to take care of basic daily adaptive needs” --and conflates all of these things with speech ability and IQ (Lord et. al., 2021, pg. 278). But the reality is much more complex. Someone may not be able to take care of their basic daily adaptive needs, but be able to be left alone. Someone may not be able to be left alone, but may not require 24/7 support. Someone may be able to take care of their basic adaptive daily needs, but require 24/7 support for other reasons. These differences matter. Furthermore, someone can be autistic and have an intellectual or speech disability *without* requiring the level of support with daily living described by this term--and there exist autistic people with high IQs and fluent oral speech who nonetheless require this level of support. These individuals are not exceptions to the rule, but common expressions of autism's famously "spiky" profile.

The Lancet report (Lord et. al., 2021) itself acknowledges that someone can have these needs without having correspondingly "severe" autistic traits--but it fails to recognize that people fitting any of the above descriptions can *and do* have any IQ and any communication profile. Substantial research shows, for example, that cognitive and adaptive functioning can be quite different within the same autistic person, regardless of intellectual disability. Bottema-Beutel et. al. (2021), for example, summarized research showing that autistic people tend to have "spiky" cognitive profiles, wherein their "intellectual and adaptive functioning can vary significantly across domains" (pg. 24). Researchers in 2019 found that, for individuals labeled as "high functioning" based solely on their IQ, that this was not an accurate predictor of their adaptive functioning skills (Alvares et. al., 2019). In other words: individuals who supposedly do *not* have "profound autism," according to proponents, may require the same level of services described by the Lancet Commission nonetheless.

Rather than trying once again to divide up the autism spectrum with old, flawed assumptions, we should focus on ensuring that every autistic person has access to an individualized, person-centered service plan that identifies our specific needs and connects us to appropriate, personalized supports.

Intellectual Disabilities and Being Nonspeaking Are Not Predictive Labels

The push to create a new "profound autism" designation also rests on flawed assumptions about intellectual disability. These definitions explicitly conflate intellectual disability with specific support needs for daily living and a lack of speech. However, this does not actually reflect what the evidence says about people with intellectual disabilities or nonspeaking autistic people.

Nonspeaking autistic people are impossible to place in a narrow box. In fact, there is "no single set of defining characteristics or patterns of skills or deficits..." (Tager-Flusberg and Kasari, 2013, pg. 468). Nonspeaking autistic people have diverse disabilities and communication profiles, including but not limited to: the extent to which they can speak any words and what kind of speech they can produce in what context, their overall verbal and nonverbal IQ scores (ranging from very low to very high, although IQ tests lack validity for nonspeakers), their overall motor abilities (which greatly impacts the reliability of any assessment), their overall communicative abilities outside of speech (ranging from limited ability to robust use of Augmentative and Alternative Communication (AAC)), their social cognition, and their underlying language processing (Tager-Flusberg and Kasari, 2013, pgs. 468-470). Most importantly, there is a tremendous amount of variation in whether or not nonspeaking autistic people have been given access to best practices and evidence-based supports, including inclusive education and robust, language-based AAC. This lack of consistent access to high-quality support calls into question any attempt to globally summarize the abilities of nonspeakers, or predict their future abilities and outcomes. (Tager-Flusberg and Kasari, 2013; see also TIES Center, 2022). Nonspeaking autistic people would be greatly harmed by the creation of a "profound autism" designation.

Autistic people with intellectual disabilities have historically been referred to as "low-functioning." The idea behind this type of functioning label, similarly to the current argument over "profound autism," is that a person's IQ is predictive of their ability to perform activities of daily living. Nonetheless, as noted earlier, research on this issue has shown that "intelligence estimates are an imprecise proxy for functional ability in ASD" and that similar executive functioning difficulties exist in autistic people with

and without ID (Alvares et. al., 2020, pg. 227; Panerai et. al, 2013). Credible resources on intellectual disability, such as the American Psychiatric Association and American Association on Intellectual and Developmental Disabilities, as well as many studies, indicate that a wide variety of inclusive supports may be required by people with intellectual disabilities and that support needs are individualized (American Psychiatric Association, 2021; American Association on Intellectual and Developmental Disabilities, n.d.; Thompson et. al., 2009; Dew, Collings, Savage, Gentle and Dowse 2018). Indeed, most people with intellectual disabilities do not require the level of support described by the Lancet Commission (American Association on Intellectual and Developmental Disabilities and Association of University Centers on Disability, 2016). It therefore is profoundly un-useful and inaccurate to categorize autistic people with intellectual disabilities as a single sub-population that by default requires specific types of supports, such as 24/7 care.

Although research does exist which indicates that autistic people with intellectual disability may as a whole have worse outcomes than autistic people without intellectual disability, this research has not been performed in a vacuum. For example, although some research shows that autistic people with higher Verbal IQs specifically tend to achieve more positive outcomes, such as competitive integrated employment or friendships (McCauley, Pickles, Huerta & Lord 2020; *see also* Anderson, Liang & Lord 2014), all studies on the subject have been performed among a group of people who vary significantly in the extent to which they have received high-quality, inclusive support. It is entirely possible - indeed, likely - that providing consistent access to supports that reflect best practices throughout life would alter outcomes for autistic people with ID. It is therefore premature to state that the presence of an intellectual disability in and of itself is fully predictive of outcomes for autistic people. Over the past 50 years, we have seen expectations about other developmental disabilities such as Down Syndrome radically change as the people with those disabilities were provided with improved supports. There is no reason to think that the autistic community is any different.

Finally, the conceptualization of “profound autism” also rests on the assumption that having an intellectual disability and being nonspeaking are two conditions which invariably occur together. This assumption is not supported by evidence. Autistic people with intellectual disabilities have a wide range of communication profiles, and include many individuals with fluent verbal speech. As described above, nonspeaking autistic people have a range of assessed verbal and nonverbal IQs, and IQ tests lack validity for nonspeakers. Both populations do share one key aspect—they have a wide range of support needs that can only be truly ascertained by knowing the specific individuals. The variance of supports used by both people with intellectual disabilities and nonspeaking people show that these labels do not singularly illuminate the support needs of any one person. And considering the lack of predictive power of these traits, it begs the question of what utility there is in placing these traits into an even broader and less defined category such as “profound autism.”

We are not arguing that autistic people with high support needs do not need and deserve access to better services than they currently receive. However, the way to improve services is not to create a label that does not provide any actionable information about why a person needs support or what support they need, while encouraging low expectations and restrictive services.

This is not simply a disagreement about what language to use. Functioning labels often dictate whether an autistic person will be given the support and encouragement to live a life of their own choosing. Labeling a young person as “profoundly autistic” could be the difference between them getting to be a full member of their community or ending up in an institution.

We Should Promote Community Inclusion for All Autistic People

As we have established, the label of “profound autism” does not accurately describe a particular group of autistic people with particular support needs. We are also disturbed by arguments from some proponents (and others who have made similar arguments) that people with this label require not merely *more* services, but fundamentally more *restrictive* services than people with other developmental disabilities (Together for Choice, n.d.; Escher, 2021a, August; Escher, 2021b, December; Lutz, 2015; Lutz, 2017; Singer, 2021b, December). Indeed, proponents have been explicit that their underlying motivation for supporting the “profound autism” designation is to justify funneling certain autistic people into these services (Lutz, 2021).

Research overwhelmingly supports one central idea: that people with developmental disabilities - including those with the highest support needs - can not only live in the greater community of people without disabilities, but *do better* in the greater community (American Association on Intellectual and Developmental Disabilities and Association of University Centers on Disability, 2015; Esteban, Navas, Verdugo, and Arias 2021; National Council on Disability, 2015). Research has shown that community living improves factors as seemingly unrelated as social skills, number of friends, language/communication, overall well-being and employment (Lakin, Larson and Kim, 2011; National Council on Disability, 2015). Furthermore, the benefits are not only limited to people without ID or people with lower support needs. In fact, people transferring from institutions into the community - people who by definition require a high level of support due to service eligibility requirements - show very high gains in all of the above areas (Lakin, Larson, and Kim, 2011). People with intellectual disabilities tended to have a higher self-reported quality of life in community-based settings, greater control over their lives, and higher-quality and larger numbers of friendships and social connections (Kozma, Mansell and Beadle-Brown, 2009; Noonan Walsh et. al. 2010).

The overwhelming majority of evidence over a period of decades shows that community living and inclusive services are a *necessity* for a high quality of life for people with developmental disabilities, including autistic people with high support needs. We urge the IACC to follow the evidence and recognize autistic people as one diverse population of people with IDD who need a range of individualized supports to live in the community. The IACC should reject any arguments that a separate group of people with “profound autism” require institutionalization or similarly restrictive services. Instead, we encourage the IACC to lead the call for substantive and non-duplicative research which builds on the existing evidence base with regards to people with developmental disabilities broadly, and looks further into which specific inclusive services and supports will best help autistic people with complex support needs of many types thrive in the community.

We Should Focus on Improving the Services Available to All Autistic People

Lost in the discussion of “profound autism” was the fact that the Lancet report was written to help illustrate how services for autistic people could be improved. There are too many autistic people who do not have access to the supports necessary to live full, self-determined lives. Research needs to focus on matching services with individual needs, and not segmenting autistic people into groups based on unfounded assumptions. Therefore, instead of drawing arbitrary lines between people with developmental disabilities to segregate services that are not evidence-based, the IACC should instead continue to focus on which services and supports are effective for *all* autistic people and others with IDD across the lifespan.

ASAN will continue to advocate for research and services that meet the needs and promote the dignity of all autistic people. For more information on our positions on this topic, please contact Julia Bascom, our Executive Director, at jbacom@autisticadvocacy.org.

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I am autistic, can hear, and am verbal. As someone who wears earplugs and noise cancelling headphones due to sound sensitivity, I may come across as deaf or hard of hearing. I may not answer a person right away. I often rely on reading lips when I wear ear protection. I also often put closed captioning on TV to focus on the dialogue. The accommodations for the Deaf community can benefit hearing persons as well. Reading things out helps with auditory processing, especially in a busy environment. I can take in written instructions even while others are talking, but I can not take in two auditory input channels at once.

Nicole Leblanc

CMS Needs to order states to eliminate IQ limits in HCBS waivers, States need to make systems proactive for all adults with ASD

Kathryn Hedges

Research on Autistic people needs to prioritize the needs Autistic people have identified and studies must be developed by (or in close collaboration with) Autistic people. Some areas of research that I support would include:

Investigating the prevalence and types of sleep disorders or dysregulation in Autistic people, developing appropriate interventions, and identifying any links to other medical issues that are common among Autistic people;

Investigating the prevalence of and types of eating disorders in Autistic people, and developing interventions that take sensory issues into account as well as proper nutrition;

Developing best practices for Augmentative and Assistive Communication, including how to ensure it is offered as early as possible when a speech delay is diagnosed rather than waiting for speech therapy to "fail";

Investigating the role of dyspraxia in Autistic speech delays or lack of oral speech;

Investigating cost-effective supports (low-tech, high-tech, remote access, etc.) to maximize independence of Autistic people and reduce reliance on group homes, living with family, etc.;

Developing best practices for teaching family practitioners and other primary care providers how to communicate with Autistic patients (speaking or non-speaking) and provide optimal medical care, including knowledge of conditions commonly found in Autistic people;

Developing best practices for full integration of Autistic people into the workforce without segregation, bullying, discrepancies in compensation, etc.

Investigating the prevalence of abuse and filicide against Autistic people over the lifespan and how to prevent it;

Researching occupational therapy and other alternatives to Applied Behavioral Analysis for teaching Activities of Daily Living, social skills, etc. that avoid the shortcomings identified by Autistic people who

found ABA problematic, with the goal of providing evidence-based alternatives for those who need them.

Star Ford

I believe the objectives of research in autism should be framed by the word "accessibility". Important areas are communication (devices and techniques), transportation solutions, social models of supported empowerment, medical equity, and the connection between autism and mental health issues like depression, anxiety and PTSD. Any focus on genetics and causes of autism takes away focus from things that actually help autistic people.

I'm an autistic New Mexican and I'm increasing marginalization and fragmentation of our community and supports.

Cara Krebs

We desperately need more research on PDA, Pathological Demand Avoidance. Even awareness of PDA is severely lacking in the U.S. If PDA can get into the DSM or simply on the minds of U.S. professionals, so many misunderstood autistics will begin to get the understanding and support they lack.

Note: The following comment has been redacted.

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

Ange Marie

Firstly, "autistic individuals" is better language than "individuals on the autism spectrum." The autism community overwhelmingly prefers identity first language over person first language, as person first language stems from a place of ableism (separating autism from the person as if it's something to be ashamed of, and stems from cure culture). I'd also like to state that "opposing opinions" should only be between autistic people. People who are not autistic do not have opinions regarding anything autism related. Especially parents. Parents often traumatize their autistic children with their parenting and vilify autistic adults. The "autism mom" mentality is that of a martyr; they want recognition for how "hard" it is to parent an autistic, yet they do nothing to identify their child's source of stress and they do nothing to make their child's environment more suitable and comfortable. They allow their children to suffer in constant meltdowns, and if given advice from autistic adults as to reducing triggers, they argue and vilify them. There is no empathy for how much the child is suffering because of their parenting. There is no concern for the child when the parent constantly discloses their child's diagnosis in very public spaces such as social media. There are parents that record their children having a meltdown online to show how "hard they have it," with no empathy for how difficult of a life the child has due to the adult caregiver. People think that autistics that constantly meltdown are "low functioning" but functioning labels are harmful and no longer used in diagnosis. Functioning is fluid. Meltdowns are not our baseline. We can be very capable one day, and when under stress, incapable the next. Parents complain that their non speaking child has constant meltdowns and they don't know why, and when asked, their child doesn't have access to AAC device and doesn't have a means to communicate. The parents have

allowed their child to go years without being able to communicate, a basic right that many autistics are denied due to [redacted] parents.

ABA is the first line of “treatment/therapy” for autistics post-diagnosis and it is inherently abusive in all forms. This is a huge issue for the autism community because many of us come away from ABA and similar therapies traumatized. ABA teaches us that compliance and suppression is more important than bodily autonomy, it turns us into people pleasers and teaches us that saying no means punishment - making us more susceptible to abuse. This increases our risk of suicide.

[redacted] we don't want a cure. [redacted] We want society to realize that if it accepts us and accommodates us, that we will thrive. [redacted]

Barbara Leaf

I am a 52 year old female who was formally diagnosed with autism in 2019. I am also a veteran Special Education teacher. The following areas of research are critical to enhancing understanding of autism and providing meaningful supports:

1. What are the unique characteristics/presentation of autism in girls, and how can we adjust diagnostic tools to better identify autistic girls earlier in life?
2. How does menopause affect autistic women, so that health care providers can provide the most appropriate care?
3. What are common health effects of long-term "autistic burnout" (especially autoimmune disorders)?
4. How can corporations leverage the talents and strengths of autistic people in the workplace? (Tech companies have led the way...expand the thinking to ways in which, for example, the design, engineering and architecture sectors can utilize creative autistic thought processes and help "translate" their ideas into reality).
5. How can the education community attract, support and retain autistic/neurodivergent teachers?

Asher Gutman

I would like to see more work to educate the public on how to communicate with and respectfully assist autistic people.

Kenny Dalton

I would recommend IACC prioritize research on challenges of needs of autistic individuals that are multiply marginalized, such as in the LGBTQ community, autistics of color, and autistics with multiple disabilities. I also recommend including autistic researchers in the collaborative process and not only as research subjects.

Max Shinske

I am an autistic person and many members of my family as well as friends are autistic. I would really like to see more research going into things such as the digestive issues many autistics have, as well as sleep issues, and changing the focus from “early interventions” to what services do autistic people need to thrive without trying to act as non-autistic. I think it is important to continue to involve the autistic community and listen to more autistic voices. I would also like to see more research going into the link between autism and other common co-occurring conditions such as Ehler's Danlos, epilepsy, Tourette's, and ADHD. Little is known about the link and why autistic people are more likely to have these.

Maggie F

We need more research about the harm caused by ABA and especially research that prioritizes the perspectives of autistic individuals (NOT non-autistic caregivers and professionals). We need research about gestalt language processing and about robust AAC options. We need research that either supports or disproves authorship for RPM, S2C and similar "assisted" communication methodologies, via other means than message passing tests.

Jennifer Dekany

Please prioritize research regarding which services and supports maximize quality of life and well being for autistic people of all ages, demographics, and support needs. Please involve autistic people in all stages of the research.

Jessica Weiler

I would like to see funding to support the lived experiences of Autistic adults.

Christopher Merchant

Future funding for autism research should be focused on inclusivity and how to improve quality of life for autistic people. It is time to eliminate the antiquated thinking that autism is something to be cured and instead we should recognize the diversity of thought and livelihood strategies that autistic people represent. IACC should be seeking to support people with autism rather than cure them. Any other course of action is bigoted and generalizes the livelihoods that neurotypical people tend to lead as the only acceptable path in life.

Jane Horn

30 to 40 percent of people with autism are nonverbal or have great difficulty with oral communication. Research into the difficulty of acquiring normal speech is needed. What is echolalia? Why can some children parrot speech, but not use it for meaningful communication?

Alex Zheng

I believe it would be interesting to look at the the effects of race, ethnicity or family history on autism. Perhaps also the severity of the autism.

Annalise Bussewitz

I would like to request that the IACC divest funds into research over the amount in the autistic community that live with comorbid conditions, disorders, and additional disabilities; as well as what therapeutic treatments, supports, and resources are effective in aiding them. Please also take care to prioritize diversity of the wide ranging populations & experiences that have historically and are continually heavily underrepresented.

For example, in terms of both data collected and collaborating research with autistic people of color, autistic women, and nonverbal autistics or autistics who use AAC.

Trigger warning: The following comments contain reference to trauma and other sensitive topics.

Stephanie Huffaker

It's imperative for there to be more research into how trauma affects autistic folks. We may become traumatized by events that wouldn't have the same impact on someone who isn't autistic. We may exhibit the signs of trauma differently, cope differently after the fact, and need different kinds of support. Everyone deserves access to trauma-informed mental healthcare that is appropriate for their neurology, including us.

Cassidy Whipple

I would like the IACC to prioritize research on the efficacy of different therapies for children, adolescents, and adults that are NOT Applied Behavioral Analysis (ABA). While it may be seen as "the gold standard" in Autism therapy, ABA is at its core just obedience training for children. Many autistic adults who underwent ABA as children have lasting trauma from this therapy and struggle with the negative psychological effects on a daily basis. Alternatives such as Cognitive Behavioral Therapy, Dialectic Behavioral Therapy, and Occupational Therapy have had a much more positive effect on the lives of autistics and I would like to see more research done on these therapies.

I would also like the IACC to prioritize research on how autism presents in girls, women, and folks assigned female at birth (AFAB). Currently, much of the diagnostic criteria is based on the presentation of autistic white male children making it very difficult for AFAB folks, adults, and People of Color to be diagnosed. Diagnosis of AFAB folks as teenagers is considered early, whereas folks assigned male at birth (AMAB) are typically diagnosed by age 2! I am an autistic woman and wasn't diagnosed until the age of 29! I attended mainstream classes in public school as a child and adolescent and went on to earn a Bachelor's of Science degree in college. All of those years could have been made easier with the proper accommodations had I known I was autistic. Not to mention the difficulties I faced navigating the job force post-college. I spent most of my life in sensory overload and burnout with no understanding of why, concluding that something was wrong with me. After learning about autism and getting my own

diagnosis, I finally feel free! I now have the information and tools to help myself, ask for help when I need it, and get the accommodations I need to pursue my unalienable right to Happiness. Unfortunately, my story is not the norm. I'm privileged in many ways that have allowed me to dedicate time, energy, money, and other resources to learning about autism and seeking a diagnosis. Many people do not have the same privileges to even get started.

The lack of understanding about autism in AFAB folks also allows health care professionals to quickly dismiss the concerns and experiences of their patients, leaving them demoralized and closes the gate to resources and support. The more we understand how autism presents in AFAB people, the easier it will be for those people to get a diagnosis and/or receive the resources and support they need to live happier, healthier lives.

Note: The following comment has been redacted.

Ava Gurba, Elliot Gavin Keenan

We are two autistic researchers. **We urge the IACC to prioritize strengths-based approaches to research, in contrast to models founded on deficits-based approaches.** We ask this for two reasons; one, it conveys the belief that autistic people deserve dignity, respect, and are valuable members of our society. Two, it is important for advancing our autism science (Burack et al., 2016; Gernsbacher, Dawson & Mottron, 2006; Happe, 1999).

The shackles of deficit-based approaches condemned several major schools of thought surrounding autism to a position of controversy and perhaps an ultimate disregard; this includes the “theory of mind” etiological model (Baron-Cohen et al., 2001; Livingston et al., 2019) which posits the core deficit in autism to be in mentalizing, or the ability to represent the mental states of others in one’s own mind. These models are encapsulated in both psychological and neuroscientific research (Hu et al., 2021).

However, theory of mind as an etiological model fails to explain the restricted interest/repetitive behavior features of autism, which constitute a key symptom domain (Frith & Happe, 1994). Also, some people with autism consistently pass false belief tasks (Frith & Happe, 1994). Weak central coherence emerged as an alternative etiological theory to explain these gaps (Frith & Happe, 1994; Happé & Frith, 2006). Over the past 25 years, various refinements have been made, leading to the Enhanced Perceptual Functioning approach (Mottron et al., 2006). These are strengths-based theories; they noticed that autistic people sometimes showed superior performance at local processing tasks. More recent research has suggested that in autistic cognition, global processing is delayed – but not impaired – leading to a unique perceptual style (Van der Hallen et al., 2015). Other perceptual theories, such as the veridical mapping hypothesis, set out to explain autistic strengths and even unusual abilities (Mottron et al., 2013) – such an illuminating mechatognitive (an approach using higher order mechanisms, such as cognition, and translating them to understand lower order mechanisms, such as cellular mechanisms; Bonsall et al., 2015; Holmes et al., 2016) understanding of the autistic mind simply fails to be reached by deficits-based studies with the same objective (Heaton et al., 2008).

The ripples of these deficit-based approaches can be felt throughout society. These have led to many common myths about autism, including the idea that autistic people lack empathy and that the core issue autistic people have is a lack of social knowledge (knowing what to do in social situations). Myths coming out of these approaches have had lasting negative consequences on the public perceptions of autistic people (den Houting et al., 2021; John et al., 2018). As a result, autistic people can experience

stigma and prejudice and lead to major mental health challenges (Botha et al., 2020; Botha & Frost, 2020). These approaches have also shaped the types of interventions provided to autistic individuals. This belief that social knowledge is the main struggle autistic people face has driven the development and implementation of social interventions that teach explicit social skills without examining if this translates to real-world usage of skills and outcomes in social relationship development (Bottema-Beutel et al., 2018; Lerner & Mikami, 2012; Marro et al., 2019).

Strengths-based approaches can be of benefit to all forms of autism research. Recent clinical studies based in these approaches have examined attention (Burack et al., 2016) and the social interactions between autistic and non-autistic people (Davis & Crompton, 2021; Heasman & Gillespie, 2017; Morrison et al., 2020; Sasson et al., 2017). In recent years, the double empathy problem has emerged as a leading theory utilizing a strengths-based model (Milton, 2012). This theory posits that social challenges arise due the social communication differences between autistic and non-autistic people rather than within the autistic person themselves (DeThorne, 2020). Recent research has empirically demonstrated that the double empathy problem is an important contributing factor to social communication and interaction differences in autistic adults (Crompton, Ropar, et al., 2020; Crompton, Sharp, et al., 2020; Rifai et al., 2022). This has implications for the ecological understanding of social differences and the value of community for autistic people (Crompton, Hallett, Axbey, et al., 2022; Crompton, Hallett, et al., 2020; Crompton, Hallett, Mcauliffe, et al., 2022).

We urge the IACC to strongly encourage the use of participatory research methods that actively include autistic and other community stakeholders and prioritize research that does in funding decisions. Participatory autism research (PAR) with members of the autistic community can facilitate strengths-based research. PAR has many benefits: 1) ensure that research questions align with the needs and values of the autistic community and its allies; 2) improve the quality of research methodologies; 3) translate research findings into real-world practice; and 4) build trustworthy relationships between researchers and autistic people (Fletcher-Watson et al., 2019; Jose et al., 2020; Keating, 2021; Pickard et al., 2022). Participation in these methods should come from a diverse representation of stakeholders, including racial minorities, gender minorities, and those from low socioeconomic status. Several autism research organizations have taken steps to increase PAR and develop frameworks that support the active involvement of stakeholders in research, including INSAR (*INSAR Community Collaborator Request (ICCR)*, 2022) and AASPIRE (*AASPIRE Collaboration Toolkit*, n.d.; Nicolaidis et al., 2019).

In summary, we urge the IACC to prioritize strengths-based and participatory research approaches in considerations for research prioritization of funding.

Thank you for all your consideration and for your work in supporting the lives of autistic people. If you would like information or have any questions, feel free to contact us at:

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[PII redacted]

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The Autistic Avenger

AAC communication belongs in the hands of all Autistics, young and old. Software and devices are expensive for the individual and expensive for many families as well. Behavior is communication but Autistics deserve their Human Right to communication in whatever way works best for them. I'm compelled to add that does not include ABA, which studies show causes PTSD, not speech. AAC, letter boards, et cetera, for every Autistic please!

Amanda Whitaker

I'd like to see the money for research to towards how to make work or school more accessible for autistic people. I am a school speech language pathologist and I see my Autistic students struggling on a daily basis to fit within the mold of the academic environment currently in my school district.

Ken Thomas

I would like IACC to prioritize research on autistic suicidal connections. The research should be heavily dependent on real dialog with autistic people - not on check-the-box questionnaires.

Lee Rodman

I would like the IACC to prioritize research to identify A) how people with autism feel that autism impacts their lives, B) what impacts they appreciate or enjoy most and what impacts they find most challenging, and C) what tools and strategies have felt most helpful to them in uplifting the advantages and navigating the challenges of living with autism.

Jack White

I appreciate the IACC's work in making autism research more inclusive and helpful for autistic individuals.

I would like the IACC to prioritize research on autistic neurological/neurochemical differences that may influence effectiveness of and reactions to psychoactive medications, especially those intended to treat common comorbidities.

I would also like the IACC to give preference to autistic input and involvement in all steps of the research process for all research topics, not just as subjects participating in data collection. Including many and varied autistic minds and voices, not just as subjects but as researchers too, ensures that the needs and interests of people with all kinds of autistic experiences are being prioritized.

Oleksandr Kurtianyk

I believe that the IACC should listen to the voices of people with autism and reflect from those. According to Cambridge.org, many autistic people and the caregivers of those who are in need of one, would like the communication differences and the difference in prioritization of things studied. Many would also like the similarities between autistic and neurotypical people studied, "while allowing autistic differences." The topic chosen to research should be according to the wanting of people with autism and should include perspectives and stories from them directly as well. The voices of autistic people should be heard especially since this research is supposed to help them and I hope that whatever is researched helps people understand more about autism and the stories of people with autism.

Note: The following comment has been redacted.

Jhi-Young Joo

Please include autistic people and people with disabilities when you make policy for them. [redacted]. I recommend including ASAN (Autistic Self Advocacy Network) as a stakeholder.
From a neurotypical (non-autistic) parent of an autistic child

Addressing the Needs of Autistic Individuals with High Support Needs

Note: The following comment has been redacted.

Theodore Seeber

The profound autism debate is directly related to the DSM-V combining "profound autism" with "Asperger's" into one ICD-10 topic. There is a profound difference between people like me- high functioning and self-supporting; and people like my young friend [PII redacted], who has maybe a 200 word spoken vocabulary and a history of violence and running.

In Oregon [PII redacted] is currently in the home he grew up in, but both his parents are showing signs of serious caregiver fatigue. I can see the day coming when [PII redacted] will need more service.

I do believe, however, there needs to be a halfway point- perhaps private companies that can provide a menu of support activities, funded by specific grants to autistic adults themselves. This would provide the safety that Yetta was talking about, while also providing the freedom that Innova was talking about.

Ok, I'm just an autistic systems engineer. But I had to write, to provide a third model.

Trigger warning: The following comments contain reference to abuse, institutions, and other sensitive topics.

Kat Bjornstad

I don't support subminimum wage or institutionalization. Also alarmed by the fact that non-autistic voices are being centered because people like me have the most to lose. I am under guardianship and I can't even get disability payments or food stamps, and I would literally run away and live in a tent to avoid slave labor or institutionalization. I was threatened with sexual abuse in one mental hospital and I have been told that institutions are full of predators. The parents commenting in favor of these things care about themselves and not their kids.

Robin MacDonald

Please review future options for gated communities that can focus on and house adults with ASD. Those that need 24 care. Perhaps also with a mix of caring retired folks. A true supportive community.

Alison Boyce

I want the IACC to center autistic individuals with high support needs, including those who are non-speaking and require high levels of daily support. These are the most marginalized members of the community, and if they're not explicitly centered they are likely to be left out or even harmed by the initiatives.

Trigger warning: The following comments contain reference to self-injurious behavior (SIB) and other sensitive topics.

Jamie Cullen

I am a parent of a son who has severe autism. He put me and 2 hospital employees in the Emergency room this last year because he unlike the people you see on TV, has autism so severe that 3 grown men could not get him off me when he bit me so hard through my Jean jacket that he ripped the skin off my shoulder. I also work in a level 4 Therapeutic Day School where I have worked for over 10 years with students just like my son. This population of people will never be able to have a voice and rely on us their parents and educators to be their voice. We are so busy caring for our children and students that it leaves us exhausted and our ability to talk about the issues so heartbreakingly hard that we fear the negative comments about the children we love so much would ultimately break what's left of our spirit and so we protect ourselves, our children, our students, their families who are already living day to day in crisis situations and we say nothing. That is changing. By the age of 4 my son had put over 25 holes in our walls in our home. He had not only bit me hundreds of times, pulled my hair out, scratched me until I was bloody and bruised but he also would hit himself so violently that he's been hospitalized, the first time by the age of 5 and multiple times thereafter. He will be 20 this month. The number of people diagnosed with autism is 1 in 44 per the CDC and half they project will have severe autism. Since my son was born the rates have more than doubled. What will happen in another 20 years. You may all have someone in your own lives in years to come that will suffer with severe autism and you have the chance now to help. Our children are aging and states are taking away any ability for children like my son and their families to find appropriate education, living services that will give my son the best quality of life and ultimately maintain the safety of their caregivers. Not everyone fits in the same box. My son spent over 100 days in restraints in a hospital for lack of services in my State. My son currently lives in New York for lack of services in my State. We need to support all people born with autism. How is educating my son in another state better for him? How is it better for our family to not be a part of his daily life? Please recognize that every individual is different. If you take away further necessary supports for individuals with severe autism you limit them in their ability to live their lives. I brought my son to visit legislators in our state but not 1 had the courage to do what was necessary to help him or students like him ourthe staff that try daily to educate them as they are kicked, hit or even hospitalized due to injuries caused by students with severe autism. The legislators go for the "popular" idea. They want their name in the paper at the expense of my son and the people we count on to help him. Will you do the same or will you stick up for everyone with autism and recognize the differences? Will you stand up and say that all individuals with autism are different as is every person and therefore recognize that the parents who

live with children with severe autism need help not ignorance? We need understanding and more than anything we need you to help our children to have a voice at the table. Your committee should want representation from a diverse group from everyone not just the autistic adults that can speak for themselves. My son has no voice at your table. He mentally would not be able to. I am his voice along with thousands of parents and educators who are their child's or student's voice. I speak truth and I hope your committee does to. Thank you.

Concerns About Medical Practices

Mara McLoughlin, M.S., C.C.C.-S.L.P.

ABA is a pseudo-scientific, abusive intervention approach. The goal is compliance and to make children "indistinguishable from their typically-developing peers." Autistic people like me and the families my neurodivergent team serves do not need to be fixed, because they're not broken. Other strengths-based approaches exist that do not abuse and dehumanize humans.

Courtney Munnings

End ABA therapy. It is conversion therapy and it causes harm to autistic people.

Morgan Gunn

Educator and FORMER ABA technician, ABA is harmful to autistic people. #saynotoaba masking behaviors are harmful! There are many other therapies, resources, and ways to figure out a WHY to the behavior that is being displayed. Why does stimming, scripting, or any other way of how they are expressing themselves "wrong?" Why does it make YOU uncomfortable? Us neurotypicals need to fix our perspectives and feelings towards autistic people. PLEASE listen to real autistic people when they say something is harmful and doesn't work. Their voices are the only ones that are VALID when making choices for autistic people! Autistic people do not need to "fit" into our neurotypical society. US neurotypical people need to find a way to change how we communicate and change our society for autistic people to feel comfortable being HUMAN. There is no fixing needed! There is no puzzle piece missing! No one is high or low functioning! Their brain is functioning!! There's nothing wrong with how their brain works!!

Please use actual autistic people to research, create policies, and expand the beautiful autistic community.

Rebecca Gladu

I hope you will prioritize alternate communication methods (AAC) for non-speaking and minimally speaking autistics and therapies that are not ABA, like OT, etc. In terms of research, less emphasis on cures or pre-natal testing, more on improving quality of life for autistic people.

Cinta Reyes

Defund and abolish ABA. Charge practitioners, build on laws that actively protect autistic people from abuse such as pseudoscience practices, physical/emotional/mental abuse and more. Have autistic voices

work for the autistic children and not non-autistic people who try to traumatize them. Arrest chelation and ABA practitioners, make it easier for non white people to get a diagnosis and access support.

Peter Kelly

Close the Judge Rothenberg centre. Ban aba. Take autistic people, not their parents, seriously

Trigger warning: The following comments contain reference to abuse and other sensitive topics.

Lyric Holmans

ABA is abuse? yes all ABA.

Because:

The ultimate objective of ABA is to make the Autistic child indistinguishable from their peers. This holds NeuroDivergent People to NeuroTypical standards, which is cruel and sets us up for failure.

We are not and will never be NeuroTypical - ignoring this fact helps nobody.

ABA's messaging suggests that natural Autistic ways of doing things are wrong and you are broken, and therefore must be corrected - that the Autistic Person is broken and must be molded to be more palatable to non-Autistic people.

This harms Autistic people's sense of pride and identity.

ABA forces, autistic people to communicate, socialize, regulate, and move in ways that are unnatural and sometimes even uncomfortable in order to ease the lives of people around them or make them more attractive to their peers.

ABA teaches Autistic People that their own needs are less important than pleasing and making people around them comfortable. Making us overly compliant, leaving us more vulnerable to manipulation and abuse. ABA teaches children by rewarding them for "acceptable behaviors" - regardless of if these behaviors are natural or even comfortable for the autistic child.

For example, let's take eye contact. As an Autistic person, eye contact can feel like a very intimate experience (an experience that I wouldn't feel comfortable sharing with someone I did not know very well). Forcing me to make eye contact with a stranger can make me feel very uncomfortable almost as if they're looking at me in my underwear. We wouldn't and ask a child to let an adult touch them in a way that made them uncomfortable.

ABA teaches Autistic people that it's okay if you are uncomfortable, as long as you are pleasing other people. The goal for autistic people should be to help them express and get their needs met, not to teach them that their needs are less valid than the needs of people around them.

Even the sales pitch, ABA uses as manipulative, ABA uses fear mongering tactics to scare parents into unnecessary early interventions for Autistic children.

They scare parents by telling them all the things their kid may never do because they are Autistic and set up ABA as the only solution to the “problems” of having an Autistic child.

They guilt trip parents. They claim that you need to start ABA as soon as possible to give Autistic children the best chance at life and if you don't do ABA, they're going to make you out to be a bad parent, because you “must not want the best for your child.”

ABA is expensive. I poked around online for just a few minutes and I found a bunch of different prices that range from \$15,000 a year to \$50,000 a year.

Services can cost from \$100 to \$120 an hour. And so if a family is even paying for 10 hours a week, that's easily \$1000 a week, times 50 if we give the kids a couple of weeks off in the year, that's \$50,000 right there for just 10 hours a week of ABA.

Some kids are in ABA for 40 hours a week or more on top of school or during school. These poor kids have no childhood. They are constantly under this behavior modification framework and the costs for Autistic Conversion Therapy can be astronomical over an Autistic Person's lifetime, when there are better things parents could spend their money on that would actually help their child, instead of this horrible abusive manipulative “therapy”.

Autistic people do not need therapy just for being Autistic. If you want to help your Autistic child and you are being pressured into ABA therapy, please remember the following: There is no way to know what your child will be capable of as an adult.

ABA doesn't ONLY do Autistic kids wrong, it also does the parents wrong. It uses manipulation & coercion on the children in the “therapy” then uses manipulation & coercion to scare parents into choosing it, telling them their kids will be harmed without it.

Parents are terrified that their kids won't be able to “attend mainstream schools” “live independently” & “may face physical harm, abuse, & bullying” if they don't put them in to Autistic Conversion Therapy as soon as possible.

Often parents are told it's the ONLY option.

Then what do these desperate parents do, when doctors are pushing ABA so hard?

“Don't you want what's best for your child?” they ask, knowing parents typically want to do what will give their children the best shot at a “successful” life.

Parents are willing to fight for their children - they will fight to protect them & fight for what is best for them.

If they are told ABA is best (& believe the lie) they will FIGHT for ABA and anyone who stands between them & it.

Kay Hardy

Look, I don't have any ABA horror to tell you but I can tell you this: my parents raised to say no and it's saved mu butt more than once. I also know far too many autistics taught the opposite who weren't do lucky.

ABA doesn't teach kids to say no, only yes, and that's no way to live your life.

Trigger warning: The following comments contain reference to restraint and other sensitive topics.

Flora McNamara

I'm an autistic adult. I am horrified at the use of ABA, restraints, and other force instruments on vulnerable autistic people of any age. As a parent, an autistic, and a community member, please join me in condemning these practices. ABA is abuse. Full stop.

Trigger warning: The following comments contain reference to eugenics and other sensitive topics.

Jamie Atkinson

I'm actually autistic, and can say that ABA and shock therapy are needlessly traumatizing and we need to be focused on solutions that make the world more accessible for neurodivergent people rather than trying to force them into a mold to better fit in the world. A mold that does lifelong damage and won't last, likely resulting in burnouts later. In addition funding places that are looking into cures - that's just pretty eugenics. We are different but not lesser.

Christina Gleason

I am an autistic person who was first diagnosed with "Asperger Disorder" not long before the DSM-V came out and removed the diagnosis in favor of "Autism Spectrum Disorder." At that time, I would have agreed with other people who said I was a "high-functioning autistic." I had not yet learned how much of a misnomer that was, nor how it dehumanized people who were considered "low-functioning."

It took me a few years to understand what being autistic meant for *me*. I'm still learning new things about myself as I also continue to learn about the greater autistic community I belong to.

About a decade after my initial diagnosis, I can no longer be considered "high-functioning." Not only are functional labels ableist, but they are also inaccurate. "Functional" status is fluid over time, not just across years, but day to day and hour to hour. Any type of treatment or "therapy" that focuses on "functioning" is doomed to fail.

Because I wasn't diagnosed until adulthood, until I had a child of my own who was diagnosed autistic, I was not subjected to formal Applied Behavioral Analysis (ABA). But having earned by Master's degree in Psychology, I learned all about ABA and could have become an ABA practitioner before I even knew I was autistic. I'm very glad that I didn't go that career route. My childhood, however, could be considered "ABA in the wild." Every person I ever interacted with - peer or adult; family, friend, or stranger - "rewarded" me with acceptance any time I tried to "act normal" and punished me when I acted "weird," which was a synonym for autistic. As a result, I learned to "mask" my autistic traits so that I tried to appear neurotypical. I often failed, because it was obvious to other people that I was trying to

be something I was not. And yet I continued to mask even after my diagnosis because "friends" started treating me differently and I didn't want to lose them.

Trying to feign neurotypicality for decades is ultimately what led to my current inability to function. I'm barely able to work, though I was able to write client work for 10 hours a day, thousands of words daily, when I was first diagnosed. Now it's difficult for me to edit what my team of writers submit to me, unable to focus for more than 10-15 minutes at a time. My husband acts as my caregiver. My doctor wrote a note for my husband's employer stating as much, in order to get work schedule accommodations so he could be home in time to feed my daughter and me. All because of the collective trauma (C-PTSD) I experienced living in a world that is hostile to autistic people.

And that is why I must express how very harmful current "autism therapies" for autistic kids are. ABA doesn't make a child "less autistic." It forces them to suppress their autistic traits, ignore their own pain and distress, for the comfort of the non-autistic people in their lives. It may provide short-term "behavioral improvement," but in the end, it's the trauma that will remain when the child becomes an adult. There are, after all, no services available to autistic adults except for people who also have intellectual disabilities. Even then, day treatment programs are often infantilizing, and sheltered workshops exploit the labor of autistic or otherwise disabled people, paying far less than minimum wage for work they profit from.

Taryn Rosner

I am an occupational therapist who works with pediatric patients. I am submitting this comment to urge the IACC to recognize the harm ABA causes children and families. As published by the Autistic Self Advocacy Network, ABA has significant ethical issues that make it impossible to use ABA services ethically. ABA is linked with PTSD in autistic adults. The evidence base for ABA is poor, despite claims by ABA providers, and studies supporting ABA are often measuring unethical outcomes and/or outcomes that are irrelevant to autistic people's quality of life. The IACC should advocate for funding and support for neurodiversity affirming services that focus on increasing quality of life and center client autonomy.

Stephanie Singer

I went through ABA when I was 5 years old. I still remember the forced "sensory exposure" and restraints when I would refuse or say no. I remember being punished for speaking out about my sensory needs. I remember how my friend in the group was yelled at for talking about his special interest (outer space) and stimming. I remember how I didn't have the right words to tell my parents how bad it was. But more than all of that, I remembered the locked door. I had no escape. While I was pulled out within a year because I wasn't reaching the goal (acting neurotypical), other autistic children are still put through ABA year after year. Autistic children will grow up into autistic adults. No amount of "treatment" will change that. Ban ABA, and least fund better options that actually help autistic people.

Trigger warning: The following comments contain reference to suicide and other sensitive topics.

Roa Demille

Autism isn't a bunch of deficits, nor are we defective or robots. We're human.

ABA = eugenics: to break and kill us (suicide is high with us): its goal is to justify we're a burden and their unholy jobs, and so the cycle continues.

It's systematic gaslighting where 'therapists' profit from our suffering.

Do you have any autistic speakers aren't cis, white, and male? Any at all?

Sheila Majumdar

The current therapies and treatments for autism are largely harmful to the autistic people who are subjected to them. Formalized practice of the Applied Behavioral Analysis methods forces the children to suppress their personalities and distrust their own instincts and disregard their own needs for other's comfort. It is a manipulative practice that serves to endanger those it claims to serve.

Furthermore, what is blatantly unacceptable is the torture practiced at the Judge Rotenberg Center, where the people in its care are shocked for noncompliance with orders. People who are in evident distress need to be handled with sensitivity, not punishment, and recognizing that would go a long way.

One thing that I would like to see is a path towards making non-ABA supports for autism more accessible to people, in terms of location and cost (including coverage).

Trigger warning: The following comments contain reference to abuse and other sensitive topics.

Sarah Joyce

Thank you for the opportunity to comment. I was recently diagnosed with Autism as an adult and I have many autistic family members I love. Please do not allocate funding or time to ABA.

ABA is unethical and abusive. Regardless of whether or not electric shocks are being used, the basic premise is conversion therapy. The inventor of it, Lovaas, even laid the groundwork for conversion therapy!

ovaas stated in an interview for Psychology Today, "You see, you start pretty much from scratch when you work with an autistic child. You have a person in the physical sense. they have hair, a nose and a mouth" but they are not people in the psychological sense. One way to look at the job of helping autistic kids is to see it as a matter of constructing a person. You have the raw materials, but you have to build the person.? This is explicit: we are not humans, we need to be reshaped into someone else or suffer.

In an opinion piece in Indian Country Today, Jules Edwards makes a chilling comparison: "In 1879, an army officer named Richard H. Pratt opened a boarding school for Indian youth in Carlisle, Pennsylvania, which became the model for other boarding schools. His motto was "Kill the Indian, save the man."

These horrifying quotes reveal a similar intent. Both are dehumanizing, relegating Indigenous and autistic people as "other" subhumans who need to be trained to be real humans."

Please instead allow us to move into the future with humanity and autonomy. Help us to make our communities more accessible and accepting. Put more funding and focus on de-colonializing autism research and treatment. Put more funding into helping autistic people in minority groups, rural areas, historically under-served areas with sparse resources. Not into something that just traumatizes people and is proven to be ineffective.

Thank you for your time and attention.

Natalie Smith

I would like for autism-related funding and research to be focused on the needs of autistic people themselves. There are many "treatment" practices in use that are incredibly harmful and distressing, the most extreme being shock treatments at the Judge Rothenburg Center, which the UN has labelled as torture. The desires of caregivers are prioritised to the point where torture is administered as "treatment", and that is inhumane, and needs to end. I understand that these caregivers are faced with difficult choices, as their options are limited, but this should not be a route we go down, as it is completely inhumane.

I would also like for research and funding to go into supporting autistic people to maximise their quality of life, rather than looking at ways to minimise their "autistic behaviours" and genetic research. Practices like ABA need to come to an end. Diagnostic criteria for autism should look at the experience through the autistic point of view, rather than be determined by how good or bad the individual is at communicating with neurotypical people.

Skyler Sheldahl

Please do not fund ABA it is harmful and traumatizing to autistic people.

James Pope

Enforce the united nations ruling against the Judge Rotenberg Center and similar torture institutions

Priscilla Eyles

As an autistic person I would like to call attention to the well-documented physical and psychological abuses of ABA for example as described here:<https://neuroclastic.com/invisible-abuse-aba-and-the-things-only-autistic-people-can-see/> and in Steve Silberman's Neurotribes where the therapy is described as deriving from the same thinking behind gay conversion therapy.

And how much is being done to combat autistic people (and a majority of Black autistic people) being treated like cattle with electric prods to enforce ABA at the Judge Rotenberg Centre:

<https://autisticscienceperson.com/2021/07/10/yes-it-really-is-legal-to-electrically-shock-disabled-children-in-the-us-as-punishment-stoptheshock/>.

I would also like to know how you are communicating our communities' 'realities' as was stated by the NCSA (national council on severe autism) in July 2021 as being important. What real co-production work are you doing with autistic people in the community to really reflect and represent their realities and needs? How much consulting is done with parents of autistic children and adults rather than autistic people themselves? How much work is done with multiply marginalized autistic people also to look at intersectional issues with not getting diagnosed or misdiagnosed with diagnoses like schizophrenia and severely treated by the medical system (forced sedation, sectioned etc) police and law systems who fail to understand their autistic behaviour?

Thank you.

How much is being done to challenge the pernicious and harmful stereotypes of autistic people that result in films like 'Music' by Sia.

Trigger warning: The following comments contain reference to abuse and other sensitive topics.

Jake Morse

Please remove ABA as an available therapy option. All it does is make autistic people less bothersome to the people around them. It doesn't help them. Growing research is showing that ABA participation is linked to depression, suicide, and relationships with abusers later in life.

Sage Rusboldt

I am an autistic adult. Shocking people is torture, end of story. Stop torturing children and adults, stop torturing my autistic family. We are people and we are not broken, we do not need to be cured, we need autistic people making the laws about autistic people, not “mothers of autistic kids” they do not speak for us.

Sam Agnew

Ban ABA it disempowers the agency and authenticity of autistic people

Ryan Bingham

Stop ABA. Listen to autistics' needs, and focus on acceptance of autistics

Bethany Cattell

Please centre autistic voices. Fight attempts by eugenicists to wipe out our existence. ABA is abuse. Autistic people do not need to be trained like a dog to behave in a way that makes non autistic people more comfortable. This causes long term harm to our mental health and is partly responsible for our high suicide rate. Let autistic people be autistic, and listen to us, not our parents, or abusers, or “experts” who treat us like lab rats. We are the experts of our own experience. Can you imagine someone coming along saying “my son is gay and I force him to do conversion therapy and now he is in a relationship with a woman so I am an expert in homosexuality” and that person’s voice being elevated above their gay son’s? Do you see how absurd this is? Yet this is exactly what is happening to autistic people. You need to do better, so that we can live without all this trauma.

Note: The following comment has been redacted.

Jamie Diamond

Please ban ABA as it is harmful to autistics [redacted]. We are not sick or broken, we do not need cures, we need to be accepted as we are.

Radiance Sheppard

ABA/Autistic Conversion is barbaric. It is embarrassing and disgusting this even needs to be "debated". You can not change who a person is. We should be supporting everyone to be the best they can be not what others want to torture them into. Regulate it out of existence. Thank you for your time.

Kelly Vest

Most if not all autistic behaviors are done to help cope with having autism in ways that are not very obvious to the outside, and ABA takes those coping mechanisms away from autistic people to make them appear healthier despite having a more unhealthy mental state inside. So if we're to give parents the ability to choose what behaviors they want stamped out of autistic kids, I really, really hope they at least understand that as an allistic you really don't have the tools to understand what is going on inside the mind of an autistic person to really understand the cost/benefit, and are prone to highly underestimate the cost.

So, when everyone from moderately low to extremely highly communicative autistic people speak to the damage ABA has done to them across the board, and extremely few come out in support of ABA, I think it's extremely likely non-communicative autistic are suffering the same problems, just without the ability to advocate for themselves. Remember, communicative autistic people have parents just as well meaning when they got sent to ABA training too.

So I ask the committee please take autistic people seriously and do whatever possible to limit ABA for the benefit of all autistic people.

Sarah Longstaff

It's so important to know that autism is a neurological condition, not a "behavior." Autism is neurological, like epilepsy or migraines or hard-of-hearing or blindness. Those aren't behaviors either. Would you try to use "behavior therapy" to stop a seizure? Of course not. Behaviorism as a model is 100 years out of date. It's time to throw it out completely. Move on to neurology and socio-emotional models and attachment theory. Help autistic children feel safe, not "wrong."

It's important to consider autism as a disability, because that is how we can use the ADA for accommodations.

Please also look at who is profiting off autism. Are certain therapies (ABA) being pushed because of their marketing and manipulative, aggressive business models?

JP Mackey

ABA is abusive.

Nikki Satterlund

I feel that, in conversations about autism, actual autistic people are too often ignored in favor of non-autistic family members or “professionals,” who treat us as burdens to be “cured.” Autism is a disability, and I do struggle with many daily living tasks. But it is also part of who I am. I love who I am. Being autistic makes me unique, kind, creative, funny, and passionate. I cannot be cured of who I am, and I don’t want to be, even if that means there will be things I’ll struggle with and be frustrated by my whole life. Trying to be normal has only ever caused chronic exhaustion and anxiety. Allowing myself to engage in autistic behaviors like stimming, special interests, social/sensory breaks, avoiding eye contact, etc., has made me much happier. My whole life I’ve been told by society that I have a deficit in communication and socialization. But to understand autism, we need to understand the double empathy problem. <https://www.autism.org.uk/advice-and-guidance/professional-practice/double-empathy>. I have a difference—not deficit—in the way I communicate and see the world. Just as often as I fail to understand non-autistic people’s communication, they fail to understand my communication. The problem is a two-way street.

I would like research to collaborate with autistic people, to consult us as key stakeholders in any and all studies on autism. (Not as free labor, too many autistic people get used without compensation). I would also like it to be easier for disabled people to access support and accommodations in adulthood necessary for us to be independent. This might include things like help with driving, cleaning, finding jobs, making doctor appointments, etc. I’m lucky enough to have a good support system between my amazing friends and my wonderful family, and am able to get accommodations at college. Not everyone has that. Further, people who have to rely on disability benefits have restrictions put on them, such as how much they can save or if they can get married, and that’s not ok.

Recently, there has been discussion around words like “severe,” autism and “low-functioning.” It is true that autistic people often have a wide range of support needs and co-occurring conditions. However, just because someone needs significant support in their lives does not mean that they are “low functioning,” or need to be “cured,” or that they are a burden. What they need is to be properly supported, and to do that we need to listen to autistics. Not just autistics like me who can go to college and “pass,” as neurotypical (albeit, with significant background support), but all autistic people, including those with intellectual disabilities and non-speaking autistics. Non-speaking autistics can often communicate with AAC, and many are advocates in the autistic community who are often overlooked. We desperately need to invest in giving non-speakers access to AAC. The ability to communicate is a basic human right.

I also want to put an end to support for ABA therapy, and to invest in more research on the traumatic effects of surviving ABA therapy. There is evidence that ABA causes long term damage that lasts into adulthood, such as trauma, prompt dependency, learned helplessness, and anxiety <https://www.tandfonline.com/doi/full/10.1080/23311908.2019.1641258>.

ABA was founded by a man, Ivar Lovaas, who was involved in the creation of gay conversion therapy, who thought that autistic people were not really people, and who used physical punishment to correct

behaviors. I recognize that modern ABA is different than that, but it still corrects behaviors without understanding them, urges compliance, and does not allow for autistic behaviors. As a queer autistic person, I have this to say: any therapy founded on Lovaas's principals cannot be reformed, even with physical punishment removed, and no matter how much "positive reinforcement," and "fun," is used instead. I understand that a lot of parents are worried about their children, that a lot of ABA professionals think they are helping and have good intentions. Good intentions do not undo harm.

Furthermore, physical aversive punishments are still used by places like the Judge Rotenberg Center. The JRC urgently needs to be shut down. They psychologically and physically torture autistic people—disproportionately those of color—with electric shocks and restraint. People have died and been seriously injured at the JRC. We need to ban physical punishments, like the GED shock devices used at the JRC.

We can support autistic people without controversial and abusive practices. That includes providing access to communication, whether that is spoken, typed, a picture board, or any other form of AAC. It includes understanding a person's sensory needs. It involves understanding that stimming is a coping strategy that should not be stopped unless someone is being physically hurt (and even self-injurious stims often have a motivation behind them, such as feelings of anxiety or overwhelm). It involves therapies that emphasize support, consent, and accommodation over treatment or cure. It involves knowing our triggers and our limits. It involves allowing autistics to be ourselves, even if we play different than other kids, or seem weird to you. It involves understanding that a lot of non-speaking autistics have dyspraxia. It involves access to services and accommodations in both childhood and adulthood. It involves having options besides restrictive guardianships and institutionalization for autistics with a lot of support needs. It involves listening to a wide variety of autistic people, autistic people with intellectual disabilities, autistic people of color, autistic non-speakers, autistic people with marginalized genders and sexualities, autistic people with other co-occurring conditions such as chronic pain, physical disabilities, mental illness, or ADHD.

This written comment does not even begin to scratch the surface of the issues faced by the autistic community, but I hope that it provides some insight to how to think differently about autistic people. We are not broken. We are not burdens. And we are the most important stakeholders in any and all conversations about autism.

Bernadette MacDonald

Please. ABA is conversion therapy. Cruel to even consider let alone conduct it on people. It creates long term harm and no genuine changes in behaviour. It causes painful experience in those it's directed at. I object in the strongest terms. Parent of an autistic child who I love dearly and never want to change. We need to act differently and understand autistic people's needs instead of trying to change them. ABA should be banned.

Monique Marsten

I am an adult, recently diagnosed with autism. The lack of autistic voices in the conversations and discussions about autism is harmful. ABA is abuse, and beyond that it has been proven to be ineffective in multiple studies. Autistic people need support and acceptance, we do not need training on how to act neurotypical. The focus on white male autistics with a specific set of autistic traits has done a great deal

of damage to autistic people who do not fit into that small box. Please listen to us before you listen to neurotypical people talking about us. Do not exclude non-verbal autistics from the discussion, difficulty speaking does not indicate an inability to understand language. Listen to those who can speak with the assistance of AAC, read the words written by those who favor writing over speaking. Stop assuming our distress is anger and aggression, our emotions should not be invalidated by our inability to emote in a way that neurotypicals approve of. Those who accuse us of lacking empathy treat us with little to no empathy, they harm us and say that they are helping us, they refuse to listen to us because we aren't communicating in the right way. This results in frustration, and yes, anger. For a good reason. Being different isn't wrong, and it shouldn't be punished.

Note: The following comment has been redacted.

Trigger warning: The following comments contain reference to lived experience with ABA.

Anonymous

Hello, I saw a tweet about comments on ABA, and I would like to make one, as someone who worked for an ABA agency for over a year. I only ask if my comments are to be made public, please keep my name anonymous.

My name is [PII redacted], and I worked for a company called C.A.R.D. or Center for Autism and Related Disorders. I worked there from around February 2020 to around November 2021. I initially signed on because I have had experience in the psychiatric field and an interest in growing my career. I had never heard of ABA before I started, but I was diagnosed with autism some years ago, and I felt that I had this opportunity to help other autistic kids and adults. It was over that year I realized that what I had signed up for was a place full of abuse and vile methods of coercion to have children act neurotypical. It haunts me to this day and it will probably never leave me, but I want to use this opportunity to speak openly about what this company did, and the programs I participated in.

At this job, everyone was equipped with iPads. The basic idea is that when a child has a response to a behavior or stimulus (or SD), you would mark responses as correct, in correct, or no response. A side note, but therapists were often expected to be tracking behaviors, in some personal instances, nearly 70 times an hour, or at least 1 response per minute. It was draining to say the least, to constantly track dozens of behaviors that ranged wildly in scope and expectation. Sessions could last for over 4 hours at a time without a sanctioned break time or lunch period. While I was working part time, some days I would have to rush between two clients' houses with literally minutes to spare. I could not get lunch or take time to breathe between these often intense sessions. Shifts were calculated to the minute with no room for error. The children would often be forced to be exposed to this therapy for over 30 hours a week, often more. The drain and stress on these children was palpable and heartbreaking.

The sessions themselves would basically be a rapid collection of pointless data that only served to appease parents and management. In truth, I would often lie about the data I collected because I feared reprimand. This was during the early days of the COVID-19 pandemic and work was scarce. Part of why I felt like I could not leave, in spite of terrible hours, no benefits, and lousy pay, was because I had rent to pay. I felt this pervasive sickness every day I woke up, knowing that my meager income was the result of children being tortured for the sake of people who refuse to work with their autistic children. I often felt like some kind of babysitter who made children suffer through truly absurd tests of neurotypicality.

For example, I remember one set of lessons revolving around the act of choosing which toy the child wanted to play with. I would present the child with a preferred toy and a deemed neutral object (puzzle piece, jenga block, etc). However, as the instructor, I was only allowed to accept certain target responses, such as vocalization of the "mand" for the preferred toy. This test would be ran 10 times in a row, with an expectation of expediency and not allowing for alternate expressions of desire, such as reaching for the toy or pointing to it.

Trigger warning: The following comments contain reference to lived experience with ABA.

Anonymous

On some level, I can understand the desire for autistic children to be able to be independant and be able to express themselves freely. But ABA is not the way. I remember the moment I realized it was all a farce in the name of "helping" children when, at a time I was covering for another therapist, the lesson involved not allowing the child to pick their favorite character in Mario Kart. They wanted to pick "Kitty Mario" all the time, and apparently this was deemed enough of a problem that it needed "fixing." It would be one thing if the child had trouble sharing toys, but it's picking a character in a video game that carries no restriction on character choices. Every player could be "Kitty Mario" and the game wouldn't bat an eye. There are adults who make a pretty good living picking the same character in competitive video games, why should anyone care if the kid loves picking one character?

I can share more. I have in my possession materials used to train countless people on this cruel practice. I cannot say every person who I worked with was a bad person. People are complicated and have complicated motives for working in such an industry. But that really is the insidious part: ABA surrounds itself in the veneer of helping autistic children succeed and grow and learn. But that was never the intention or the point of ABA. It's a practice that must be stopped and I hope that my insight into this can help lead to public understanding of this practice.

Thank you for taking the time to read my message. If you have any follow-up questions, please contact me. I am willing to speak more on this subject, or if you have any questions or need any clarification.

Imene Saidi

Please focus efforts on listening and learning from actually autistic adults on what therapies other than ABA worked for them and they didn't have access to because of systemic barriers.

Brandon Lorrekovich

Too often, treatments like ABA are considered "successful" by neurotypical researchers, but are actually very detrimental to autistic people. I would love to see treatments and coping strategies studied that improve the quality of life of autistic people by their OWN self-determined metrics.

Oscar Hughes

Many autistic advocates have been sharing how Applied Behavior Analysis (ABA) denies their agency and in some cases has been traumatic and abusive. As a special education teacher, I worked for years at the May Center, where ABA was the core approach and where much research on the "effectiveness"

was produced and circulated worldwide. Daily, ABA was used to physically and emotionally control students and demand their compliance. Students were not allowed to advocated for themselves, and were instead taught that they must do whatever the teachers said or they could not do the things they enjoyed. I have since seen ABA used similarly in many public school settings. As a doctoral student I have learned that many ABA researchers profit from their findings and thus there are many conflicts of interest with researchers who feel they are proving ABA effective. Please provide funding into autism research that examines alternatives to ABA. Floortime, trauma-informed practices, and other approaches to education and supporting autistic students are needed. Please also fund research examining the potential harms of ABA which autistic self-advocates have described (e.g PTSD, susceptibility to abuse, etc.)

Caroline Rodgers

A great deal of study has focused on the maternal, pregnancy and neonatal factors that may increase the risk of having a child diagnosed with autism. So far, these studies have found only weak or no association in the wide range of potential risk factors studied, none of which fully explain the increasing prevalence of people on the spectrum. I would like to bring your attention to the possibility that the key is not a single risk factor but the combination of two maternal and obstetric trends that have both increased over the last five decades For a variety of reasons, both the average and extreme length of labor duration have increased at the same time that continuous electronic monitoring, which uses Doppler ultrasound, has become the standard for deliveries. Animal studies have shown that fetal mice exposed to ultrasound for the mouse equivalent of 12 human hours exhibited brain pathology and some behaviors consistent with people with autism.

There is an alternative to continuous electronic fetal monitoring that has already been identified as safer for mother and child because it results in fewer cesarean sections: intermittent monitoring, which is accomplished with a handheld Doppler device at intervals. For a detailed explanation of the above and the studies that support this concept, please see my open-access paper, "Continuous electronic fetal monitoring during prolonged labor may be a risk factor for having a child diagnosed with autism spectrum disorder" published in the December 2020 issue of the Elsevier journal "Medical Hypotheses."

Coral Treasures

Help lower the minimum age for autistic transgender men (FTM) from age 21 to age 19, for gender affirming hormones and surgeries such as oophorectomy and donor/lab grown testicle and spermatoc cord transplants. Especially in Florida where i have extreme ovary pain on both sides daily.

Cecilia Stonebraker

We need more research on how ABA causes trauma/PTSD in children.

Barry Prizant

For too long now, approaches based on applied behavior analysis continue to be put forth as the gold standard, with many insurance companies only funding ABA services both for young children all the way through adulthood. Although some recent research has debunked these claims, there needs to be more research on alternative developmental and relationship based approaches. There needs to be clear

statements about the unsubstantiated claims made by ABA researchers. Additionally, there is a need for significant more research on emerging practices for non-speaking individuals, including approaches such as spelling to communicate. Demonstrating efficacy of such approaches is best done through qualitative research, and not context-stripped experimental research.

Carl Muhlbauer

I find many autistic adults have serious concerns about the long term, mental health effects of ABA. I would like to see more research on this topic.

Increase Autism Acceptance and Reduce Stigma

Julie Luepke

When researching autistic people, of any age, please put their well-being first. Please understand that being or appearing “normal” is not always in the best interest of their well being

Mindy Sebastiani

I'm autistic. My husband is autistic. We have autistic children. We do not want a cure for the way that we experience the world, what we want is to have our experiences and ways of existing acknowledged and centered in discussions and research on autism. Non-autistic people--regardless if they have children who are autistic--do not have a right to dictate how we are treated, how our condition is approached. We do not have a disorder. We do not have a disease. We are not a burden. Asking to be treated with respect and to have autistic voices centered in autism research is not unreasonable. We exist. And we are willing to speak openly about what we need and want. Who is willing to listen to us?

Sarah Boon

Autism research is focused on how I'm broken, need interventions and ultimately, how people like me can be prevented from existing in the future.

My question is why does autism research see me as a problem? And by that I mean my existence as an autistic person.

For 20 years I did what society told me to do, hide the autism and pretend to be normal. Although this provided superficial results, the cost to my mental health was dramatic. I had no quality of life and my physical health was significantly impacted.

I'm proud to be autistic and I want to live in a world where my differences are accepted. This is the only way people like myself will feel accepted by society.

I want a cure for society's ableism, not my brain because it's different to others.

Laura Camacho

I am autistic and have three thriving autistic children. Being autistic is only hard when neurotypical people can't be flexible enough in their expectations or demands for others to be just like them. This happens more with the collective than with individuals, although the most rigid and inflexible assumptions about us are found in those trained to work with autistic people. The prejudice is very high amongst the therapists, SLPs, etc.

I hope that, moving forward, organizations such as yours will help remove the stigma of autism, rather than perpetuate the myth that it is such a disabling condition that we need to be treated as "less than." Autistics are far more accepting of neurotypicals' quirks and social "insufficiencies" and we deserve to be treated with equal care and compassion when you don't understand us.

Whitten Steele

It is of the utmost importance for educators, parents, and autistic people themselves to have current information about autism that is not rife with dehumanizing stigma. All too many of the various agency websites, at state and local levels, contain the same deficit-based language and rely on the same research that also uses stigmatizing and dehumanizing language. I am in the final semester of my Masters of Arts in Teaching program in Special Education and while every course I take reminds us that we must write all IEPs and other documents from a strengths-based perspective, every piece of research I am assigned on autism (and most other disabilities) is exclusively written in negative, deficit-based terms. This is incongruent with my values as an educator and with the stated values of every professor, school, and district I have ever worked with. Autistic peoples lives depend on reducing stigma (our life expectancy in the US is 38, the age I am now) and it should be a matter of course for government agencies to be working at every angle to ensure that we are able to live long, healthy, happy, and less traumatizing lives. Choose research by autistic researchers and their allies. Choose to place autistic people at the forefront of the agencies meant to serve us. Give us a chance to see ourselves successful and working to ensure others like us can be successful, too.

Samael Wolf

Please stop trying to "combat" autism. Autism isn't why I'm broken. I'm a square peg being hammered into a round hole by an alienating and uncaring system designed to extract as much value from humans before discarding them like unwanted filth.

Jacob Spanbauer

Autistic people deserve the same treatment as the rest of the population, the unfair treatment they receive by our laws are unjust. Autism is not a disease, it does not get "cured", instead it is a trait that some have and others do not, we must all see this && treat them as just and equal members of our communities.

Kevin Roach

Concerning the US Federal autism IACC meeting that is planned for April 2022, I ask that we have addressed how ill-equipped we have been for accommodating the needs of autistic people, along with other neurodivergent groups, and resolving them, along with ending the dehumanization of autistic children and adults.

While we appreciate more research being put into understanding autism, we deserve to be accepted as functional members of society than simply be made aware of.

More resources that are easy to access need to be made available for non-autistic people to understand correctly what autism is and what it really means, while autistic people deserve to have easier accessibility to accommodations in order to properly participate in society, and to be heard properly in the conversation without being talked over by non-autistic people

Lena Hearn

Hi! I would like to see more emphasis on how autistic people and allistics actually have a LOT in common, instead of treating us like a diseased Other. Non-autistic people get IBS, brain fog, allergies, hEDS, and all kinds of things. I don't need or want a "cure" for autism. I want to talk about a cure for things like seizures, which lots of people have, from things like poorly maintained street + gas station lights that rapidly flicker. I want curiosity in people to explore my strengths, like admin paperwork when I'm extremely organized and literal to a system, instead of getting upset at me for a migraine causing vomiting from pain because someone decided to wear strong lavender perfume in the office. You know, like lots of people might. I want conversations to shift from stereotypes of us being robotic and black/white thinkers to being paralyzed like a deer in headlights because actually, this instruction needs nuance and directions I don't have, but if I get it wrong, it'll mean my job. I don't think in "black and white"; I need everything to have an asterisk, to be explicitly clear.

It's time to change research from "cure autism" to "cure celiacs", which anyone can have. Or "cure hypermobility." Or anything else. I didn't appear different in Japan because it's rude to stare at people's eyes and you're SUPPOSED to keep your socks on indoors. American focus of autism traits are cultural and therefore incorrect. So correct them.

Talia Flah

I am an adult who only recently learned of my autism. Autism is part of who I am, as much as my height or eyesight. I was only able to learn of my autism and take steps to better my life once I heard about the internal experiences of other autistic people. It was by centering the voices of actual autistics that I finally became able to learn a deep truth about my way of interpreting the world. Every time I was told what autism was by allistic people, I thought "that can't be me." Only when I read autistic authors and watched videos from autistic creators was I able to recognize my way of thinking. Please do more to allow me and my fellow autistics to direct the conversation.

Trigger warning: The following comments contain reference to eugenics and other sensitive topics.

Lindsay Mohler

Autism is a natural variation in the brain AND a disability. It is something that cannot be cured, fixed, or treated in medical settings and in therapy. I am a therapy student and am autistic. We need more acceptance! There are plenty of reasons why. Autism is not a "burden" to society, it is not a disease. We are not diseased and ALL autistic people who are nonspeaking deserve just as much equity as other autistics equitably. We do not, as a majority of the community has stated, want Eugenics. I have co-

occurring conditions that do not make me "severe", as I am a person with medium level support needs and am partially non-speaking. I cannot speak for those who are completely nonspeaking but what I will say is that they deserve equity to autonomy acceptance. Autism is not anxiety, depression, etc. It is not a type of epilepsy. It is not an intellectual disability. Things can co-occur but autism is its own disability and does not fall under the medical model of disability. I ask those who have done disability studies research to speak up as well. Please understand that disability, disorder, disease, and condition ALL academically have different definitions. Autism is a disability, but it disables my environment, not my identity.

This means that autistics deserve to be heard in all aspects of our lives, and in autism research. I am a part time researcher, and want to be more supportive of the IACC, but in order to do so, we need people to stop relying on the medical cure model of disability, as that model is hegemonic and does not value humanity in the ways it could. Some are therapists, researchers, parents, students, etc. Some of these people are minimally speaking and use AAC! We have AAC users that go to colleges as well. Is that "high functioning?"

Autistic people that are in a dire need of nonstop, 24/7 care do deserve a lot of support, and full-time caretakers for disabled people who need full time care should be covered by insurance in the US, rather than pushing disabled people towards institutionalization and often ill-suited care facilities. These ill-suited institutions have been shown through history and still in 2022 to do more harm than good.

The decision on who is autistic should be decided by autistic professionals and their allies. ABA Therapy, including Early Interventions, and ABA-induced therapy techniques through other therapies have been shown through several research articles. The United States Department of Defense has stated that Applied Behavioral Analysis does not work. Applied Behavioral Analysis is often covered by insurance yet has been shown to be ineffective. Here is the 31-page 2020 The Department of Defense Comprehensive Autism Care Demonstration Annual Report 2020 (link: <https://therapistndc.org/wp-content/uploads/2020/08/Annual-Report-on-Autism-Care-Demonstration-Program-for-FY-2020.pdf>).

Even the Autism In Adulthood Journal has an article that talks about IPT, and DV, in relation to the autistic community ([link](#)). and IPT is something that autistics do experience through ABA, especially Black, Brown, Indigenous, and Asian autistic children.

I would like to see IACC use this opportunity for change by promoting the inclusion of autistic adults, and promoting an acceptance of Neurodiversity. We need to start listening to autistics, as autistic voices matter. We do have the lived experience of being autistic, as well as neurodivergent. And there are plenty of autistic parents who speak up about this all the time. High-quality research done with autistic researchers is key to this as well. Having autistic researchers being the primary authors on research articles, including Black, Brown, Indigenous, and Asian autistics. Please consider this and reach out to the community for constructive feedback! Culture is important in improving research equity. Thank you for your time.

Note: The following comment has been redacted.

Rebecca Tienhaara

[redacted]

Study Autistic People are marginalized by and in society by using a survey. [redacted]

Do a survey asking Autistic People how emotional they are and also a survey centered around sensory issues and how they effect Autistic People and ask which material or thing bothers Autistic People in the survey.

The Role of the IACC and the Federal Government

Inmara Fenumera

As an autistic person who has not had enough support throughout their life, neither as a child nor an adult, I would like to remind the IACC members to please, please, please work to preserve the human rights, autonomy, and right to consent of all autistic individuals, children and adults, regardless of apparent ability to function.

Note: The following comment has been redacted.

Jo Choto

I'm glad you have some autistic members on your team, but why aren't we even better represented? It's like having a Black caucus with mostly white members. Yes, of course we need professionals who have worked with a wide range of people on the spectrum. That insight is valuable. But at the end of the day, I am not interested in a bunch of neurotypicals determining who I am, what I'm worth and what should "be done" about me. Ultimately, if you are not engaging and communicating with autistic groups and individuals ([redacted]) then really, what are you doing and why?

Bonnie Johnson

I would like the IACC to focus research on prevalence of PTSD in autistics, and specifically it's relationship to ABA therapy.

Michelle Skigen

I would like IACC to focus research on the use of CBT and other therapies to replace ABA, across all age groups. I also would like there to be research on how autistic people communicate their distresses so that medical practitioners will be less dismissive of early signs of serious illness.

Georgia Wilson

I would like the IACC to focus on what actual autistic people care about, rather than what others think we want. I would like funding for research to go to research on helping autistics transition to college and the labor force.

Florence Lin

Trigger warning: The following comment contains reference to eating disorders.

I want IACC to focus on how autistic people experience eating disorders. For example, anorexia diagnosis is currently based on whether or not the avoidance of food is from body image concerns, however, autistic people can have anorexic behaviors that stems from other difficulties, not body image concerns. This is largely underexplored and help is limited because practitioners don't understand it.

Tomas Vanhoof

I would like the IACC to focus research on what aspects (job skills/training as well as physical+organisational accommodations in the workplace) permit persons with ASD to have fulfilling jobs they can do & keep for yearson end without burning out or being let go.

Isabel Yopp

I would like IACC to prioritize research on how to develop accommodations to help autistic people to experience more sensory-taxing occasions.

Adam Henderson

I don't know the specific statistic, but a very low number of autistics are able to stay fully employed (full time) for more than a few months in the same job. Many are chronically unemployed. I would like IACC to prioritize:

1. Researching how working from home can help autistics thrive in the workplace.
2. Researching hiring initiatives specifically targeted towards autistic adults.
3. Researching the root causes of unemployment in the autistic adult population.
4. Researching what employers can do to make workplaces less hostile to autistic adults.

Suzanne Leber

I would like IACC to prioritize research on what treatments actually improve quality of life for autistic individuals (especially adults) based on metrics developed by autistic people, rather than by neurotypical observers.

Riley Cruickshank

I would like IACC to prioritize research on how autism presents in people who are AFAB (assigned female at birth), including how the way AFAB children are taught to behave influences how autism presents in them. I think this would lead to greater diagnostic accuracy for AFAB people, and help AFAB people learn earlier in life that they are autistic.

Kristina Hawley

I would like the IACC to prioritize research on: how many autistic people have sleep disorders and/or digestive problems and what treatments are effective in this population for each; what proportion of adults who self-diagnose as autistic later seek professional diagnosis, and what the outcomes of those

inquiries are (how often are they right?); and how autistic people respond to various mental health treatment modalities (CBT, DBT, exposure therapy, etc.) differently than neurotypical people.

Siyu L

I would like IACC to prioritize research on how many autistic people have sleep disorders and what treatments are effective!

Robert Rice

My name is Robert, I am level 1 autistic & have struggled with mental health all my life. I think the IACC should allocate funding to study the causes of health disparities between autistic people & the general population, such as suicide, insomnia, and life expectancy. Thank you.

Jenn Smith

I would like IACC to prioritize research on how many autistic people have sleep disorders and what treatments are effective.

I would like IACC to prioritize research on direct more funding towards how to make work, school, college, graduate school, and Federal Student Loan repayment options more accessible for autistic people.

Julia Simko

I would like to see the IACC prioritize research on how many people across the autism spectrum--both with and without government benefits--are parents raising at least one child, and how to best support them. In considering this, I would like the IACC to remember that there a lot of parents out there who didn't even know that they're autistic until a son and/or daughter was diagnosed.

Theo Szpakowski

I want the government to prioritize funding research that is conducted by autistic people.

Yesined Ajete

I would like IACC to prioritize research on sensory processing differences. I believe that if we had a sensory room in every store, doctor's office , or even a classroom in schools, kids and adults would have a place to self soothe before coming home thus possibly avoiding meltdowns or autistic burnout. If we research the sensory differences many autistics have maybe we could make better accommodations in public spaces and start transforming society into a more comfortable and accessible society for Neurodivergent people.

Jennifer Brooks

I would like IACC to prioritize research on how many autistic people have sleep disorders and what treatments are effective

I would like IACC to prioritize research on social emotional learning for K-12 and college students on the autism spectrum, and how to incentivize schools to stop looking only at test scores and make social emotional learning a priority

I would like IACC to prioritize research which job prep and placement programs for adults on the spectrum are most effective at helping these adults find AND retain jobs and what makes some programs more effective than others

I would like IACC to prioritize research into the effectiveness of use of psychiatric drugs for patients on the autism spectrum

Trigger warning: The following comments contain reference to abuse and other sensitive topics.

Sebastian Rubino

To me, I really hope the IACC focuses their research on treating seizures and GI issues, as those cause the most physical pain amongst autistic people. We need to stop looking into genetics, as it will open the door for designer babies, which is wrong and creates unnatural human beings as a result. Research must also be directed to better accessibility in special education, as well as making sure all educators across the country treat autistic people in a humane way that takes their sensory needs, as well as needs for frequent breaks (and respecting those breaks) into account. There have been studies into how autistic people develop PTSD from undergoing ABA and behaviorism itself, and those studies must further be expanded upon. When there are better alternatives in place such as TEACCH, there is no viable reason behaviorism should still exist, given the awful psychological impact it has had on the autistic population, turning them into people-pleasers who are forced into compliance rather than allowing them to be defiant and create their own path in life.

Samantha Perry

I am autistic. I would like the IACC to firstly respect the wishes of the autistic community and use identity-first language (autistic, autistic person), as well as use the term 'autistic acceptance month' as opposed to 'autism awareness month'.

For research, the IACC should prioritize studies on cultural competence/the state of disability representation in corporate diversity initiatives, as well as the double-empathy problem (how neurotypical people can modify their communication to better interact with autistic people).

Additionally, please look into federal funding for assistance with executive function issues relating to home care tasks. Please make it easier for autistic people living independently to access housekeeping services through state governments. I live in Florida and have been trying to access this for months and have been brushed off and sent to other agencies multiple times. It should be much easier for me as a diagnosed autistic person to send an email or two and coordinate these services.

Research, Services, and Supports for Adults with Autism

Trigger warning: The following comment contains reference to sensitive topics.

Aleksandra Witkowska

As a late-diagnosed (38!!) autistic woman, I would kindly as we do more to assist autistic adults, particularly women. And stop spreading the false 1:4 female:male ratio of autism by gender. That's the diagnosis ration which just means for every boy, you miss four girls.

Also, once I received my diagnosis and started to research what that means, I was bombarded with pathologizing language that left me feeling SUICIDAL. Please stop dehumanizing autistic people in your "scientific" research. I use the term science loosely here as the researchers are completely wrong on a lot of aspects of what it means to be autistic. We have imaginations and empathy. We just express it in different ways. We are not all the same either. Hiring autistic researchers and advisors of different races and both sexes would go a long way to correcting the bigotry. Thank you for reading this far.

Julia Sevin

Thank you for existing. I am an adult, self diagnosed autistic with a mother and teen son in the same positions. I hope you can work to broaden resources for diagnosis. I also hope to see opportunities for federal grants and loans to autistic professionals. A lot of the time, I can operate brilliantly and lay down big smart detailed schemes. Other times I am disabled by autism related dysfunctions and other comorbidities. I want a future where my natural work/rest balance provides enough income for me, and I want the same future for my son. I hope you work with autistic adults to find out what career support is most needed. We are capable, creative, driven, and have lots to contribute, we just need slightly different circumstances offered to us.

Elle A

As an autistic adult and sibling of a late diagnosed autistic adult, my comments remain about the expansion of disability support services that include job coaching for adults. Too many times these services including testing centers for Autism are focused on children and preventing autism from continuing into adulthood. While we all know that is impossible as Autism is a life long diagnosis. I also push for more autistic input in psychology standards and testing when it comes to therapy that best benefits us. It is impossible to find any services for myself or my sibling that do not involve ABA therapy, which is a harmful therapy that is meant to change autistic behaviors causing trauma to natural behaviors in autistics. There needs to be more resources for adults and less focus on adults taking care of autistic children, or even caregivers. Job coaching, insurance seminars, housing help, and disability accommodation discussions. As a disabled adult I do not know what is required for accommodations for a workplace, I have not been guided on how to navigate that and I hit road blocks when researching on my own. I am capable of living on my own and have been, but organizations do not recognize me as having needs.

My brother was not diagnosed until age 30 because of the lack of research of autism and different presentations. He was constantly told he was too smart to be autistic despite hitting criteria for social deficits. That is a problem within the psychology community and tells us that the divergency within autism needs to be addressed, not to mention the need for studying autism presentation in the female sex along with multiple gender identities.

My goal for the future of the conversation around autism is less prevention, less solving, less curing and more ways to lend a hand to autistics struggling in a society not built for them. We do not need ABA therapy to teach us to stop flapping our hands, swinging our legs, or to learn social cues with rewards like a dog. There does not need to be a way to find out about autism in utero. Less eugenics, more mutual aid.

Jessica Burde

I am an autistic adult with autistic children. I am very worried about the lack supports for adult autistic people. If we are not disabled enough to require 24/7 care, we have no care or support at all. This has severely impacted my own life and my ability to care for myself and my children, hold a job, keep house, etc. I very much fear for what my children will face in ~10 years when they 'age out' of the supports they have now.

I am also very concerned with what I have heard about how many many autistic people with intellectual disabilities are being silenced. We have all been treated to a front row view of Brittany Spears conservatorship and how harmful it was. People with IDD, whether they are autistic or not, are people, with rights, and agency. Getting power of attorney, putting someone in a 'group home' or other 'nice' version of an institution where they need to live like children perpetually under the rules of 'parents,' and other acts of stripping people with IDD of their legal rights and agency should not be easy or routine.

Autistic people with IDD suffer from the lack of support as adults too. If there was more support, they would be better able to take care of themselves, have more options, and their parents and loved ones would not need to live in fear for their long term well-being.

Rick Grossman

There are twice as many adults on the autistic spectrum than there are children, yet 95% of all funds go to children. I don't want to take money from them, but adults cannot be ignored.

Potential areas for research:

- 1) Alternate assessment tools.
- 2) Teaching Autists Emotional Intelligence.
- 3) Does having a coach for a few hours a week improve their lives?
- 4) Which styles of therapy seem to be a better match?
- 5) Developing tools so Autists can explain to others about their styles, sensitivities and issues.
- 6) What tools/techniques can help Autists avoid problems with family, friends and coworker
- 7) How companies can make accommodations for Autists.
- 8) Are governments and businesses creating barriers for Autists?
- 9) Estimates as to the number of Autists.
- 10) Comparative rates of homelessness, suicide, physical illness, depression, anxiety, joblessness, income, and loneliness.
- 11) Techniques to teach social skills and to develop friendships.
- 12) Survey to find out how Autists feel their needs are met by friends, family, social service agencies, and governments.
- 13) Surveys to determine how many people on the spectrum work for or are on the board of directors of Autism agencies and charities.

- 14) Requirement that any study involving Autists have an advisory panel made up of Autists.
- 15) Survey of adults asking their opinions on how they were helped as children.
- 16) Tools to help Autists understand their special power.
- 17) Tools to help Autists find employment to match their skills.
- 18) Tools to help companies adjust job responsibilities based on unique needs and skills.
- 19) Does it improve the lives of Autists to have Ombudsmen or Advocates to help them with governments, schools, insurance companies, etc.
- 20) What self-help techniques do Autists find most helpful?

Crystal Root

I would like IACC to prioritize research on adults and particularly adult women rather than placing all research funding on young children and adolescents. Because there is still a wide gender gap in diagnoses, particularly early diagnoses, there will continue to be adult women in need of services in progressive generations.

Samantha Frie

I want the IACC to prioritize research on autistic people outside of childhood (preteen, teens, adults) and of genders other than cisgender boys (cisgender men, women and girls in general, trans men and boys, genderqueer kids and adults) I want them to focus on research that helps us learn how to accommodate, live with, and accept autistic traits instead of erasing them.

Gretchen Frankenstein

There are now probably more adults in the autism community than children, yet children get all of the attention. Adults need jobs, places to live, living support. Instead of just more research, how about some help? I am currently listening to two adults who cannot find work and who have nowhere to turn. They are both about to lose their housing and don't have anywhere to go. This should not be happening. One of them was told to "work for yourself" which is not possible in his case. This kind of blowing off impending disaster (from a state department of vocational rehabilitation) sends our mental illness and suicide rate already higher than it is. If it needs to be research focused, how about researching how to build systems to provide good paying jobs so autistic people have a fighting chance of living like everyone else?

Joshua Bernard

Projects meant to address autistic adults' service needs and lifespan issues are relatively underrepresented and underfunded, and these facets are among the least understood. The oldest among the first generation of autistic children to mostly grow up with early-childhood or adolescent diagnoses, and with mainstream awareness of autism, are now in their thirties.

A recently published BLS news release (hyperlink: <https://www.bls.gov/news.release/pdf/disabl.pdf>), using Census data reports that in 2021, the unemployment rate for persons with disabilities was approximately double that for persons without (10.1% and 5.1%, respectively). The Census's disability survey data includes at least some autistic adults, given they asked whether responders had a mental or

emotional condition that affected executive functioning (e.g. running errands, concentrating, making decisions).

Autistic children and youths are offered early intervention, accommodations, and IEPs during their K-12 education (and even accommodations during post-secondary education!) in line with the Americans with Disabilities Act. Autistic adults, however, lack similar support and thus struggle with the transition from education to the workforce, even if they had thrived in school. Using 2009 survey data from the National Longitudinal Transition Study-2, Roux et al. (2015) report that only 58% of autistic adults worked at all from high school to their early twenties (hyperlink: <https://drexel.edu/~media/Files/autismoutcomes/publications/LCO%20Fact%20Sheet%20Employment.ashx>).

An autistic worker lacking the cognitive empathy required to successfully navigate a workplace's social environment and acclimate to company culture is left at the mercy of employers who can hire and fire at-will, usually offering no useful feedback to the worker to avoid a discrimination lawsuit.

Given autistic workers in the workforce are less likely to be employed than neurotypical workers, many autistic adults lose out during prime earning years. The opportunity cost extends to lost opportunities to save for retirement, which either lowers living standards throughout the autistic adult's life if consumption is smoothed as the life cycle hypothesis suggests, or ensures that living standards discretely plummet when the autistic adult is too old to work.

Having outlined some of the stakes above, I would like to see the IACC prioritize research to determine the effectiveness of methods to reduce unemployment and underemployment among autistic adults, e.g., through pilot or experimental employment assistance programs targeting unemployed or underemployed autistic job-seeking adults in a specific city or neighborhood alongside placebo or control groups as the basis for a case study.

I would also like to see the IACC prioritize identifying the most common barriers to obtaining and keeping employment (e.g., self-reported difficulties in a survey of autistic job-seekers). Ohl et al. (2015) (hyperlink: <https://content.iospress.com/articles/work/wor2492>) includes some literature on this topic.

Speaking as an autistic adult with an economics background, I appreciate this opportunity to offer feedback.

Citations:

Bureau of Labor Statistics News Release (Feb 24, 2022). Persons with a Disability: Labor Force Characteristics ? 2021. Washington, D.C.: Bureau of Labor Statistics.
<https://www.bls.gov/news.release/pdf/disabl.pdf>

Ohl, A., Grice Sheff, M., Small, S., Nguyen, J., Paskor, K., Zanjirian, A. (2017). Predictors of Employment Status Among Adults with Autism Spectrum Disorder. *Work* 56(2), 345-355.
<https://doi.org/10.3233/WOR-172492>

Roux, Anne M., Shattuck, Paul T., Rast, Jessica E., Rava, Julianna A., and Anderson, Kristy, A. (2015). National Autism Indicators Report: Transition into Young Adulthood. Philadelphia, PA: Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University.
<https://drexel.edu/~media/Files/autismoutcomes/publications/LCO%20Fact%20Sheet%20Employment.ashx> on Mar 22, 2022.

Lisa Cooley

Please consider researching autism spectrum disorders and the aging process.

Jay Wilson

I would like to see prioritized research on the ways to reduce administrative burden and support autistic adults and families to access needed services, diagnosis, and supports. I would like to see research on how healthcare providers can increase accessibility, access, and reduce barriers to healthcare that meets the needs of autistic people of all ages.

Pauli Gomez Cockerham

As an autistic person with autistic family members and as someone who works with autistic people of all ages, I would like IACC to prioritize research on aging and autism, specifically the phenomenon of burnout/regression that seems to affect many autistic adults, including but not limited to stress tolerance in autistic people, signs and risk factors that one may be headed towards burnout, and what supports can be put in place to prevent or lessen the effects of burnout while allowing people to live as independent, autonomous, and fulfilling lives as possible.

Brian Galloway

I would like IACC to prioritize research on why fewer services for adults with autism and how to make it easier for adults to get diagnosed in the first place. Many of us had no chance for a diagnosis when we were children.

Catherine Cox

I am a 66-year-old retired college educator. When I was a child, an autism diagnosis was given only in rare cases, mostly to non-verbal boys with extremely severe social deficits. But as we know more and more about autism, it has become an increasingly common diagnosis - not necessarily because the incidence is increasing, but because we recognize subtler presentations of it, including in people who have for one reason or another found a way to order their lives in a way that suits their brains.

I am one of those people. I have at least 8 or 9 relatives who are autistic, including my daughter, two nieces, and a cousin, and while I don't yet have a formal diagnosis I am very likely autistic myself. But more to the point, so is my 93-year-old mother. And that brings me to the point of this comment.

There is very, very little research into autism among the elderly. Autistic research has focused largely on children, with some work done on adults of working age. But more and more adults in middle age are being diagnosed, often when their children are assessed. It seems highly likely that there are a large

number of older individuals in the population who, for one reason or another, have never been assessed but who are autistic. Whether or not that is true, it is certain that many of the newly diagnosed working adults will age over time . . . and that having a better understanding of the way autism affects an aging individual will be important.

Will older autistic individuals be able to work as long as neurotypical workers, or are they more prone to disability as they age?

Will older autistic people have more cognitive impairments?

Are there diseases that they are more likely to develop?

What types of living situations do most older autistic people find themselves in? What types of living situations would work best for them?

These are only a few of the questions that should be studied now, so that we will have the answers before we need them. Thanks!

Please prioritize research into the connection between Parkinsons and autism in people over 60.

Emmett Perkins

I'd love to see some research on adults and alternative and augmentative communication devices.

Nimbid Ditavi

I think there should be an emphasis on research on how to achieve outreach to autistic adults that aren't able of achieving full independence. Thank you

Jack Schak

As a ASD adult, I appreciate this committee's work in planning and coordinating research about Autism, and the experiences of autistic people. I think it is important to fund research that is centered around the aspirations, challenges, and voices of people who are neurodivergent. Effective research must be grounded in the human dignity and vast diversity of Autistic people.

Doing so requires researchers to better support ASD people of all demographic and social backgrounds. In particular, it is critical for Federal agencies to invest more in research about ASD during adulthood, because past and current research has excessively focused on children diagnosed with ASD. While all well-executed research has value, much more work needs to be done to understand how Autism manifests itself in adulthood, and how we can improve the quality of life for ASD adults.

To help create better conditions for millions of ASD adults, I ask the committee to facilitate and advance several specific areas of research:

* True prevalence of ASD among adults (and the general public). I believe that a very large fraction of ASD adults are undiagnosed, especially among women and BIPOC adults. Part of this under-diagnosis has to do with older adults (including myself) growing up prior to when practitioners modernized their

diagnostic techniques. Bias and inequitable access to educational and psychological services has further compounded under-diagnosis among people who are women or BIPOC. Diagnostic criteria have historically relied on indicators that worked better for evaluating White boys, and tended to exclude everyone else. Too often girls with autistic traits were explained away as just having “quiet” personalities or being “tomboys.” This injustice needs to be addressed with a more accurate accounting of who and how many adults live with autistic traits.

* Autism, sexuality, and gender identity and expression. Incomplete evidence suggests a disproportionate share of people who identify as transgender, gender nonconforming, and queer are on the spectrum. Since sexuality is a major part of adult life and influences mental and physical health, research is needed on how ASD may intersect with nondominant gender and sexual identities, and why such a correlation may exist. More broadly, research should examine how to create the conditions that allow ASD adults to thrive in healthy romantic relationships, while staying true to their personal and social identities. This work would advance our understanding of ASD and help improve the lives of Autistic adults.

* Autistic burnout. Common stressors may be undercutting the social autonomy and mental health of autistic adults, even those who are relatively well-educated and independent. This burnout is characterized by ASD adults losing skills they had previously mastered, and withdrawing from spaces dominated by neurotypical institutions, such the workforce. This condition, if common among ASD adults, suggests ASD may become harder to self-regulate as people age, contrary to much of the conventional wisdom that Autistic people “get better” as they get older. Some have even suggested that “passing” as a neurotypical adult hastens cognitive fatigue and burnout among ASD adults. This hypothesis is also worth pursuing since it could have far reaching implications for the continued use of therapies that try to suppress autistic behaviors, without having a clear understanding of the underlying biological mechanisms that drive neurodivergent thinking. To this end, research is needed to study how prevalent autistic burnout is, how it is triggered and aggravated, and how it impacts ASD adults.

I thank you for considering these areas of research highlighted above. Better understanding ASD in adulthood is a critical step toward improving interventions among practitioners, educating the public, and moving away from the stigmatization that has harmed neurodivergent people. I post this comment as a non-expert in this space, but please feel free to reach out with questions or responses to my specific recommendations.

Lydia Schiedermayer

I'm an autistic person and someone who has spent a lot of time in the wider autistic community talking with my peers. From that point of view, one of the most helpful things to direct research funding towards is things that directly help autistic people. Things that make it easier to navigate our ableist society, things that help us function better, and most importantly things that help us function more comfortably.

From a personal interest standpoint, I'd be interested in more studies about autistic modes of communication. Many people in the autistic community feel that rather than a lack of social skills, we people simply have a different set of social tools, as we communicate and socialize easily with each other.

I am strongly against research funding to identify the specific genes associated with autism, as it's almost entirely geared towards prenatal screening technology and the eugenics implications that carries. It does nothing to help autistic people, it only works towards making sure we don't exist. Thank you for taking the time to seek out feedback from the community, I appreciate it!

Roberta Walker

I would like funding directed toward increasing opportunities for people with autism in the workplace, and for the study of effective interventions to help adults with autism socialize and develop meaningful relationships. There is a lot of programming and funding directed toward children, but it seems that once someone reaches adulthood, the availability of programming and research stops.

Valerie Louis

Research on autistic women and aging. Being menopausal and autistic has a very specific set of challenges...more research on neurodivergence and aging.

Joel Wilcox

Please commit to creating equal and accessible job opportunities for autistic adults. A disproportionate number of autistic adults are unemployed but capable of working when proper help and support is provided. Fund and promote job coaching and similar resources that many people on the autism spectrum have difficulty getting.

Please focus on autism acceptance and focus attention on the potential benefits of autism instead of just potential negative impacts.

Jennifer Husek

Post-secondary transition is still a harrowing time for young adults with autism who are college-degree capable. While progress has been made in educational policy, too many students who would like to plan for college are being left in the dark and unsupported in their attempt to apply to college and seek degrees. School districts are not held accountable to strong transition practices such as those seen in PA's Transition Discoveries and the NTACT tools that can lead to positive outcomes. Often the only thing that is accomplished for students with autism, particularly those who attend regular education classes, is a minimal referral to OVR. These students are fighting for a place amongst their peers at college, and the process is arduous and full of roadblocks for them and their families. We must hold school districts accountable to better outcomes, as desired by their students and families.

Needs of the Direct Support Professional Workforce

Shahnon Hawkins

I'm an autistic educator who recently had to quit mid-year due to severe burnout, like many educators in the country today. My burnout was also due to the lack of information educators and administrators have about autistic adults (and still, autistic children). How can we provide school staff and admin the resources to accept and problem-solve with autism rather than perpetuate stigmatized practices?

Anya Ashouri

Research to support teachers reaching and engaging autistic learners is fundamental in a step forward towards inclusive education. The "autism specific" classrooms and schools are unsupportive of the integration of all students. Furthermore, long term placement of youth in these classrooms leaves them bereft of opportunities with non autistic peers and leave non autistic peers little opportunities to understand and embrace neurodiversity. Last, these separate autistic schools and classrooms does not provide enrichment opportunities these learners are entitled to and would benefit from. Let us advance our practices to understand and reach ALL.

Naomi Hickey

I would like the IACC to do more research on how to teach math, reading and writing in the most inclusive ways. I want adult autistics co creating curriculums for schools and work place. I want employers and colleges on board w accommodations to best support autistics.

Employment

Stephanie Tong

I would like IACC to research what percentage of autistic people gain meaningful employment in their adult years and what approaches are most effective at reaching that goal?

Emily Nguyen

Making sure all employers are willing to accommodate adjustments for their autistic employees so they're able to do their job and keep an eye on those who seem to be ableist.

Also, please discuss about the importance of neurodiversity and that not all of the exact same nor think and do things the same.

Diana Allen

A vital topic for research that would support autistic people and reduce many forms of discrimination is: What are the unwritten social rules that result in discrimination against autistics (and others--people of color, other disabilities) in the professional working world? Why is "strong interpersonal skills" required on the jobs that most often result in advancement? How could professionals be measured on their job effectiveness regardless of social skills?

Allen Smith

I am on the autism spectrum. I do not have some of the severe difficulties that others on the spectrum have to deal with. However, that does not mean that it is not difficult for me, being in between being severely disabled and perfectly "normal", but still having some degree of trouble connecting with neurotypical individuals in social settings. I would like to see more of a focus on helping those on the spectrum gain meaningful employment that helps connect people with their unique purpose. Everyone

has something incredibly valuable to offer. Too often, the focus on helping people on the autism spectrum find employment is relegated to just any employment.

There is not a focus on quality and what is going to be the best environment to allow purpose and special interests to really thrive. I would like more research focusing on how best to see the unique contributions that people on the spectrum have to offer through providing the best opportunities to help those on the spectrum find real purpose and connection, often connection related to tackling deep and relevant social, cultural, and environmental issues over simply contributing to an unsustainable and materialistic economy.

Potential Causes of Autism

Harold Frost, Ph.D.

Comment title: Notice on valuable recent background open-access Review Article* on multi-factor causation of neurodevelopmental disorders (NDD's).

Comment: The review article cited* is current, thorough (396 references), scholarly, and partially funded by the NIH. It addresses risk factors for NDD's (such as ASD with or without co-morbid IDD) Last sentence of Abstract of paper: "An understanding of the development and evolution of the PFC [prefrontal cortex of the brain] provide[s] insight into the pathogenesis and treatment of congenital neuropsychiatric diseases as well as idiopathic developmental disorders that cause intellectual disabilities." See Fig.[5] of paper for mention of risk factors in PFC development.

Full contact and affiliation information on commenter: Harold M. Frost, Ph.D. // P.O. Box 162 // Sheffield, VT 05866 USA // Tel -- (802) 626-3508. Retired from University of California (USA), a Life Senior member of IEEE, a former Health Physicist at FDA (USA), and a Viet Nam Era veteran.

* S.M Kolk and P. Rakic (2022). "Development of prefrontal cortex." *Neuropsychopharmacol.* 47, 41?57. <https://doi.org/10.1038/s41386-021-01137-9>. Content at URL of: <https://www.nature.com/articles/s41386-021-01137-9> includes link ("Download PDF") to full text of paper.

Edward Starr

In the past ten years on the radio with an actress (Braxton) I keep hearing the same ratio of one in 66 children have autism. Do you think that the general population believes that autism is a genetic disorder? As a scientist I believe that autism is a disease caused by Big Pharma.

When young children have very weak immune systems and a series of vaccinations are blasted into their bloodstreams then those children may get the altered genetic structure from these

Note: The following comment has been redacted. Additional materials are available upon request.

Richard Williams

The attached papers examine an environmental aspect of autism, deficiency of the nutrient sulfate. One study looks at beverages consumed during pregnancy by mothers of children with

autism. The second study correlates low sulfate in New Jersey tap water with autism prevalence. Together, these studies suggest that autism may be largely preventable by simply supplementing with sulfate during pregnancy. Of course, correlation does not prove causation, but it should spark curiosity. I urge the committee to consider the implications of these studies and act if appropriate. This is not mainstream research, but perhaps it should be.

[Sulfate Deficiency as a Risk Factor for Autism](#)

Journal of Autism and Developmental Disorders
(DOI: 10.1007/s10803-019-04240-5)

Abstract: This is a study of water and beverages consumed during pregnancy by mothers of children with autism. Materials included vials for water samples and a survey to describe the water and beverages. Samples were tested for sulfate and surveys evaluated for average daily levels. Results were stratified for selected regions of the United States. Areas with the highest rates of autism showed a trend toward lower levels of sulfate compared to areas with low rates of autism (28% sulfate, $n=45$, $p=0.059$). Severe autism was associated with low sulfate levels while mild symptoms were associated with higher levels of sulfate (-0.32 correlation, $n=86$, $p<0.01$). The results suggest that sulfate may be helpful in reducing both the incidence and severity of autism.

[Autism Prevalence in New Jersey Correlates with Low Sulfate in Tap Water](#)

Biomedical Journal of Scientific and Technical Research
(DOI: 10.26717/BJSTR.2021.39.006372)

Abstract: We examine autism prevalence in New Jersey (USA) and its relationship to sulfate in local tap water. Our previous work indicates that sulfate deficiency during early development increases the risk of autism. In this current study, prevalence is obtained from the report “New Jersey Autism Registry” on the state Department of Health website. The report analyzes prevalence for eight-year-old children born in 2006. The sulfate concentration of public water is calculated from test data reported in the Drinking Water Watch database. Counties are grouped into five prevalence ranges and tap water analyzed for the years 2005-2008, a period covering pregnancy through infancy. For this data set, the population weighted sulfate means correlate strongly with prevalence (correlation $r=-0.94$, $n=10$, $p<0.001$). This correlation, the literature and previous work suggest that increasing sulfate may help reduce the incidence of autism.

The full papers are attached as PDF files.

Daisy Tealer

I would like the IACC to conduct research on the genetic factors that play a significant role in autism being passed on by a parent.

As well as having studies done with more females present to prove that autism is not just prevalent in males.

It has become increasingly apparent that autism is presented differently in women and many of us are barely finding out of our neurodivergence only after learning about it mostly from our children who are autistic yet adult testing remains outdated or unavailable for a majority of us who continue to be invalidated of our autism simply because we are women / adults and have masked all of our lives despite it being known that autism is genetic.

I believe the autistic community would greatly benefit from this research not only to provide better evidence of autism being genetic but also to improve diagnostic tools for adults on the spectrum

Charles Heiner

Two things that have helped me deal with my autism are the diagnosis and treatment of my intestinal candidiasis and the substance triacetyluridine. I first started having gastrointestinal problems in middle school, a few years before I was diagnosed with autism, and they gradually worsened until my candidiasis was treated in my early twenties. By the time it was diagnosed, I was nauseous every day, and also had psychological symptoms like grogginess and confusion. I was mentally and physically slow. My head felt like it was full of rubber, almost numb around the edge of my skull and back of my neck. When I was 23, my doctor recognized the link between my autism and my gastrointestinal problems and tested me for candidiasis. When I tested positive, he prescribed the antifungals Diflucan and nystatin. I started with Diflucan, and within seconds of taking the first dose, I felt something like a static electricity charge in the middle of my head, similar to the sensation John Elder Robison describes getting from transcranial magnetic stimulation in *Switched On: A Memoir of Brain Change and Emotional Awakening*. My head became more sensitive to touch. I began to perceive my surroundings more vividly, in a way that felt more immediate and connected to myself. The feeling of having my skull encased in rubber was gone. In the most physical way imaginable, my brain was functioning better. I felt more awake and alert than I had in years. I took the Diflucan for about a week and nystatin for a few years afterward, stopping by 2007, and I have never since regressed to the poor mental and physical state I had been in before taking the antifungals. Cellulase and probiotics have also helped with the candidiasis.

Triacetyluridine, a more bioavailable form of uridine, has helped me feel calmer, especially in social situations. It has even made my head feel more physically stable. Before I began taking it in 2005, I would have strange sensations in my head, sometimes like balls were rolling around inside my skull. That has not happened since I started taking triacetyluridine. Also, unlike many substances used to treat anxiety, triacetyluridine is not a benzodiazepine. It does not cause inebriation and I have never heard of any instances of abuse.

Joseph Warren

I would appreciate it if there was more research that focused on which genes contribute to the development of ASD, how specific genes contribute to the development of specific traits in autistic people, and how to reliably identify those gene changes in a diagnostic setting.

Improvements in that understanding could help to further individualize the treatments and accommodations that autistic people receive, which appears to be increasingly important as more and more people are diagnosed.

Eileen Nicole Simon, R.N., Ph.D.

Following is the abstract of a paper I wrote back in 1975, on a possible cause of "echolalic speech" in young autistic children. I still believe this is an idea worth investigating, especially now, using functional-MRI (fMRI):

The speech of echolalic autistic children is (1) specifically lacking in appropriate use of expressive-intonational features, but (2) the echolalic child's clear articulation of words and phrases indicates that discrimination of phonemic features is intact.

The impairment in aphasic disorders is just the reverse. Failure to attend to auditory stimuli and the characteristic language disorder are among the most consistent findings in autistic children; they could be related.

Discrimination of differential stress emphasis is the way the normal young child extracts major morphemic word stems and syntactic features from environmental speech; this may be a primitive perceptual function of brain stem auditory centers. The brain stem auditory system is especially vulnerable to perinatal injury. Damage to this system is an example of the kind of lesion that might lead to behavioral handicaps without neurological signs.

Simon, N. (1975) Echolalic speech in childhood autism. Consideration of possible underlying loci of brain damage. *Archives of General Psychiatry*. 32, 1439-46.