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

IACC
INTERAGENCY AUTISM
COORDINATING COMMITTEE

Public Comments

October 26, 2022

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Oral Public Comments

Shannon Des Roches Rosa, Thinking Person's Guide to Autism

I am writing to you both as the parent of an autistic adult who requires full-time support and supervision, and as the senior editor of Thinking Person's Guide to Autism, which is an autism research and advocacy community with large and active Facebook and Twitter communities, which I moderate. This means that, all day long, I hear from parents, autistic people, professionals, and researchers about their priorities for autistic people to live safe, healthy, fulfilled lives.

I also participate in several initiatives for best health care practices for patients with neurodevelopment disabilities, in which participants discuss many of the same themes but in more formal ways. The lists of concerns are endless, but priorities include:

-Research on how autistic people can process medications differently than non-autistics. The medical community seems largely unaware that autistic people often have paradoxical or atypical reactions to commonly prescribed medications, such as not reacting to, or being overstimulated by, drugs classified as sedatives. In the worst case scenarios, this lack of knowledge can be (and has been) fatal.

-Research on why sedation for medical care is an access need. Many autistic people, whether they can communicate effectively in medical scenarios or not, require partial or full sedation to be able to tolerate medical procedures such dental exams and MRIs. Yet this type of sedation is rarely covered by insurance. Research demonstrating the necessity of sedation in these circumstances would not only lead to more access to health care but to better health care outcomes.

-Research on competing sensory access needs. Autistic people don't only have sensory systems that differ from non-autistic people, they often have sensory systems that differ from each other. We need research that demonstrates, for example, why it is not sufficient to hand every student with an autism diagnosis a set of noise-canceling headphones (many autistic kids can't tolerate wearing them, others can still hear disturbing noises when wearing non-professional-grade versions), and it is certainly not appropriate to put autistic people together in classrooms, or other settings, without fully evaluating and accommodating their individualized sensory profiles.

-Research on improving access to autism diagnoses across age, gender, class, and racial gaps. Too many autistic people are being misdiagnosed, categorized as having "behavioral disorders," resorting to self-diagnosis, or being overlooked altogether. They are suffering as a result, leading to avoidable anxiety, depression, isolation, poverty, and suicidality.

-Research on the transition from the school system to the adult world, especially for autistic people with the highest support needs. "The Cliff" is a real thing for students like my son, who is currently facing a complete lack of programs that can enroll an autistic adult with full-time support needs. Even those programs that are *in*appropriate for him currently have interminable wait lists. To compound matters, even though we are fortunate to have funding for home aides, there is currently a shortage of such workers, to the point where my son does not have the staffing he needs and deserves (and has been allocated). If families like ours, which have the language, class, and cognitive advantages that make it easier to navigate often labyrinthine and impenetrable public disability supports systems like Regional Center respite, SSI, and IHSS, still can't find any support, then families that don't have our advantages are certainly worse off.

A final note: I am gladdened about the IACC's current membership, inclusive as it is not only of autistic adults, but of autistics who use AAC to communicate, who have intellectual disability, who are parents, who have family members with intensive support needs similar to my own son, and/or who are people of color. It is hard to have faith in an advisory body that does not resemble the population for whom it is responsible, and it will be useful to see future iterations of the IACC reflect the autism communities to an even greater degree. Also, as someone whose autistic son has limited language, it is important for me to know that autistic IACC members, people who understand may son's life experience in ways that I as a non-autistic person never can, are looking out for his interests as a human being.

Judith Ursitti, The Council of Autism Service Providers

I write to you today on behalf of The Council of Autism Service Providers (CASP). CASP is a non-profit association of organizations committed to providing evidence-based care to people diagnosed with autism spectrum disorder across the lifespan.

CASP represents the autism provider community to the nation at large, including government, payers, and the general public. Our membership includes multi-specialty clinics, adult-service providers, applied behavior analysis clinics, and schools.

Our goals are to:

- Ensure quality, safe and most effective care
- Promote continuous quality improvement
- Help to ensure that the money spent for care and treatment is directed to the most effective, evidence-based practices
- Represent providers of care to government, payers, and the public
- Write and share public policies that balance effective treatment and economic principles

As the committee take on the important work of finalizing the strategic plan, we respectfully request your consideration of the following:

Prioritization of Generally Accepted Standards of Care (GASC)

Recent activity in the courts (i.e., *Wit v. United Behavioral Health*) and in state legislatures has emphasized the need to implement **generally accepted standards of care** for mental disorders as defined in the Diagnostic and Statistical Manual of Mental Disorders, including autism spectrum disorder. Additionally, the Department of Labor and CMS have been working to ensure that health plans are in compliance with requirements under the 2008 Wellstone Domenici Mental Health Parity and Addiction Equity Act.

CASP is home to the practice guidelines for applied behavior analysis, Applied Behavior Analysis Treatment of Autism Spectrum Disorder: Practice Guidelines for Healthcare Funders and Managers ("guidelines"). These guidelines, which have been recognized by payers and state agencies, most recently were proposed by the California Department of Insurance as generally accepted standards of care related to SB 855, California's recently implemented mental health parity law. **SB 855 requires that plans not only implement the guidelines but are trained in their usage.** Similar legislation has been passed in other states and is being considered nationwide.

As you develop a strategic plan specific to interventions, we ask that you consistently refer to generally accepted standards of care, i.e., the CASP Practice Guidelines referenced previously.

Need for Quality Assurance in the Provision of Autism Services

Over the past decade, state legislation and regulation have increased funding of applied behavior analysis services when considered medically necessary through health insurance and Medicaid. In response to the growth in this field of autism service provision, in 2022, CASP founded the Autism Commission on Quality (ACQ) to establish and promote organizational standards that improve the quality, effectiveness, and outcomes of applied behavior analysis services for autistic people. ACQ's vision is for all recipients of applied behavior analysis services to reach their full potential through access to organizations offering the highest level of care.

As you grapple with the balance of access and quality in the strategic plan, we encourage you to review the ACQ Applied Behavior Analysis Accreditation Program Standards and Guide.

Ongoing Consideration of Military Families

CASP is actively advocating to improve access to care for active-duty and retired military personnel and their families. **It is critical that the Autism Care Demonstration (ACD) recognize previously mentioned generally accepted standards of care as well as applicable CPT coding that has been published by the American Medical Association.** This will help protect against fraud and will also ensure meaningful outcomes for the autistic population the ACD is intended to help.

We are regularly engaging with members of the House and Senate Armed Services Committees but ask that the IACC work to specifically address the needs of this unique population.

Thank you for consideration and for your commitment to the communities we serve.

Amy Lutz, Ph.D., National Council on Severe Autism

The National Council on Severe Autism is extremely alarmed at recent efforts to cleanse the IACC, its Strategic Plan, and autism research more broadly of basic, accurate and meaningful language like "behavior," "risk for autism" and "quality of life." The clear trend here is to mandate language that treats autism as a neutral condition or difference. But Congress did not pass the CARES Act and allocate hundreds of millions of dollars to research because autism is a neutral condition.

That an autistic child cannot learn to speak or develop abstract thought is not a neutral issue.

That an autistic individual engages in self-injury or perpetually elopes or destroys property is not neutral.

The abnormal neurogenesis, neural migration, synaptogenesis, and neural connectivity evident in autism are not neutral biological phenomena.

That countless siblings live in fear of being attacked by their autistic brother or sister is not neutral.

That an autistic individual faces life-threatening seizures, pica or gastrointestinal distress is not neutral.

That an autistic child suffers unrelenting insomnia causing family-wide sleep deprivation is not neutral.

That parents must sacrifice careers, incomes and their own independent lives to permanently care for seriously disabled autistic children and adults is not neutral.

That autistic children lack basic safety awareness, to the extent they may rigidly refuse to exit a burning house, is certainly not neutral.

That growing numbers of adults lack basic cognitive functions to live independently is not neutral.

That we suffer a terrible shortage of inpatient placements, crisis care centers, child and adult psychiatrists, medical personnel trained in autism, and residential support centers to treat the surging population disabled by autism is not neutral.

The steady growth of autism prevalence, now closing in on 3% of U.S. children (and 5% in some areas) is a national crisis and not remotely neutral.

There is nothing inclusive about neutral or strengths-based language that specifically excludes or denies realities of autism, particularly severe autism. This is a high-stakes debate. We must ensure all federal efforts relating to autism are based on reality, not fantasy. If we must be neutral about autism we cannot emphasize the most urgent priorities facing our community.

We urge the IACC and its Strategic Plan to fully include *all* realities of autism, including, *especially*, its most severe manifestations, and to focus on true community priorities using language that accurately and meaningfully captures our community’s desperate needs.

Thank you.

Amy Montimuro, Abilis

Abilis is a Connecticut nonprofit supporting over 800 individuals with disabilities and their families. 45% of the adults we support have Autism. We launched our Supported Typing Program, (STeP) after incredible outcomes from a small sample in February 2019.

A STeP participant whose life has been transformed because of our program typed:

"I am free now of the frustration of not being able to tell you my thoughts and that has made a huge difference. People see me differently and I think differently. I now have hope for a freedom in my life that I have never had before. Please give me and others like me the chance to be the people that we really are."

We strive to build a community of typers and well-trained facilitators using best practices to ensure words being typed are the person's own authentic voice**.** For three individuals who were part of our 2019 sample, independent typing is now an emerging skill.

In March of 2020, with the onset of COVID, STeP moved to online coaching, training, social groups, and workshops. This unexpected shift allowed us to reach way beyond our catchment area. We have worked with typers and facilitators from 18 states, and from 5 countries. During the past 2 years, via Zoom, we have trained over 175 facilitators - which includes parents and staff members of agencies like Abilis from around the country. In some states there has been government funding for initial assessments, on-going coaching, and social group fees. Some states reimburse services provided by our program through self-determination.

Our clients and their families often describe the significant life changes that occur when someone learns to type to communicate. However, many school districts deny access to these typing methods even after parents and therapists have demonstrated successful communication when their autistic child is paired with a trained communication partner. Policy statements from some professional organizations, stifle educational opportunities for many. Their arguments rely on dated, limited, flawed research to deny services. Communicators feel unseen, disrespected and incredibly frustrated.

We ask that the IACC recognize that some forms of AAC such as FC, RPM and S2C are currently being utilized and are worthy of further scientific inquiry.

<u>We suggest the following research opportunities</u>

1. How can we better identify individuals who will benefit from FC, RPM and S2C?

2. How do individuals with a communication partner learn independence?

3. How can we measure the cognitive and social-emotional growth of typers and the impact on independent life skills?

Amy Montimurro, President & CEO, Abilis Inc
Susan Nisinzweig, Coordinator of STeP and parent
Deborah Hilibrand, Board Member and parent

Rieko Shepherd, J.D., Autistic Women & Nonbinary Network

The Autistic Women & Nonbinary Network (AWN) and the Autistic People of Color Fund (the Fund) appreciate the opportunity to submit commentary to the Interagency Autism Coordinating Committee (IACC). AWN is a national nonprofit that supports autistic women, girls, transfeminine and transmasculine nonbinary people, and trans people of all genders. Together, AWN and the Fund direct policy research and community advocacy to advance the health and independence of all disabled people.

All autistic people are at a higher risk of unemployment, poorer health, and other adverse outcomes than their nonautistic counterparts. However, they face further oppression on account of racism, anti-queer discrimination, and anti-immigrant prejudice. When research studies do not include or focus on diverse populations, this lack of information can be misinterpreted as indicating a lower prevalence of autism, which in turn can lead to underfunding services that could best support and respond to the specific needs of these marginalized communities.

We urge IACC to prioritize the following research topics and also ensure that this research is informed and led by autistic principal and co-principal investigators:

1. Exploring the impact of racism and anti-immigrant discrimination on the mental health of autistic people. Systemic racism and anti-immigrant discrimination contribute to increased rates and severity of psychological distress**,** but we need more empirical research to provide appropriate supports.

2. The prevalence of school exclusions and court-involvement for autistic students of color. Most research focuses on students with disabilities as a whole, but autistic students of color may need tailored strategies to protect them from criminalization, suspension, and expulsion.

3. Health disparities focused on autistic people of color, LGBTQ+ autistic people, and autistic immigrants and refugees, with a goal of developing guidelines and standards in cultural competency and communication access.

4. Prevalence of housing instability for autistic people, with additional demographic analysis across race, LGBTQ+ status, and immigrant and/or refugee status.

5. Employment rates for autistic people with additional demographic analysis across race, LGBTQ+ status, and immigrant and/or refugee status with a goal of developing strategies for increasing competitive, integrated employment.

6. The effects of linguistic and cultural barriers on autistic immigrants and refugees adjusting to life in the United States.

7. Research exploring negative repercussions or “permanent punishments” for formerly incarcerated autistic people, including but not limited, to housing and educational options or health outcomes, with additional demographic analysis across race, LGBTQ+ status, and immigrant and/or refugee status.

8. Access to alternative and augmentative communication (AAC).

Elliot Gavin Keenan

My name is Elliot Gavin Keenan. I am a doctoral candidate at UCLA and a visiting scholar at Stony Brook University; I study autism, and I am also autistic. I was diagnosed at the age of six. My parents were told that I was “high functioning”. I want to talk about this concept – what does it mean to be high or low functioning (or to have “severe autism”)?

For me, what my parents were told when I was six was, in important and meaningful ways, a lie. I have bipolar 1 disorder. When I was nine years old, I fell into a dark depression that lasted several years. This was due to the genes I was born with – and many of those genes are the same genes that cause autism.

My “normal” is far from the normal day-to-day life parents envision for their children. Over the past several years, I have been hospitalized 20 times in a locked inpatient psychiatric unit. Whenever people post guidelines on what constitutes “low functioning” I can’t help but compare myself to whatever arbitrary metric is being touted today to capture what is, really, an ineffable sort of quality. Independent living? We tried it, and failed – my parents now keep me in their home. Personal safety, or need for supervision? I’m chronically suicidal and have a history of medically serious drug overdose. Hygiene? Showering once a week isn’t that bad, and I won’t brush my teeth unless someone physically forces me to.

It may seem odd to include bipolarity in our assessment of functioning, as it relates to autism. But that’s just the thing. We’ve been bundling intellectual disability together with autism like a buy one-get one gift for years. True, not every condition that a person can experience is comorbid with autism at the population level – but many are. I’m talking about almost every psychiatric disorder, epilepsy, GI problems, and more. If these conditions impact level of functioning, is that not the severity of autism? By dissociating the constituent parts of one greater entity from each other, we can fit them into neat boxes and minimize the importance of some.

I humbly ask the IACC to consider, in the context of modern controversies, the role comorbid conditions play in the “severity” or support needs of autism – and how functioning categories may be misleading. People don’t follow straight lines – a lot of rhetoric plays on the perceived impossibility of a “high functioning” adult regressing into “low functioning” territory. But these labels aren’t individuals, they’re states of experience that we may live in, or pass through on our journeys. Finally, we need to study comorbid conditions in autism across all levels of functioning.

Written Public Comments

Research and Service Needs, Resources, and Policy Implications

Karen Barrett

In the spirit of collaboration: There is a segment of the autistic population that needs a mentor during the transition years of 18-21(2). All medical and psychological service providers should be aware of this need and encouraged to include this staff and service. The mentor would focus on all transition needs, especially financial, as the specialized school does not wish to take on these tasks. Please make this happen now, thanks.

Andrea Halliday

Please provide people with disabilities to have jobs learn how to use public transportation, have affordable housing

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More funding on transportation/ housing

Nancy Cheak-Zamora

It seems like several topics like "social and behavioral science" are being folded into Question 6. This seems inappropriate as it is a separate topic from lifespan issues and might degrade the important and expansive topics already included in Question 6.

Kathryn Parsons

1) Review data collection practices for determining autism, and developing testing protocols not just at early childhood but all stages of life. Add quantitative, biofeedback on sensory processing challenges and rigor towards qualitative, removing where possible analyst bias that views differences as deficits.

2) Workforce support towards managing all neurotypes. Setting standards for work accommodations that are reasonable for employers to implement. Update compliance standards towards accessibility for "invisible" disabilities.

3) Identify key "danger" zones where autistics are having their human rights violated and seek ways to remove these dangers:
   A) Police - conflict resolution based on neurotypes to avoid tragedies. Advocates for violators to help them navigate the system. Update training to remove neurotype bias (i.e. not looking in the eye = lying).
   B) Legal - standards for determining competency that doesn't put autistics at a disadvantage. (i.e. custody hearings, fighting parental controols/emancipation, etc.)
   C) Medical - different neurotypes may respond differently to medications (i.e. local anesthia) and creating protections to avoid trauma.

Justin Acta

I would like IACC to prioritize research on the following:
1. Autism and Type 2 Diabetes and challenges faced by people with Autism and Type 2 Diabetes.
2. Insomnia and Sleep Disorders and Autism and how sleep disorders impact people with Autism.
3. Autism and Incarceration specifically how common it is for people with Autism to be incarcerated and challenges people with Autism face while incarcerated.
4. Autism and Activities of Daily Living and how Autism impacts activities of daily living

Eleanor Wildflower

My name is Eleanor Wildflower. I would like to recommend that the IAAC request government funding to research sleep and stomach problems in autistic people, in order to help autistic people sleep better and have healthier stomachs. This is important because sleep and stomach disorders are very common in autistic people and we don't know why, or how to help. The IAAC should also request funding to research ways that autistic people can use Augmentative and Alternative Communication in order to help autistic people easily and effectively communicate. This is important because many autistic people have trouble communicating. The IAAC should also research ways to make employment and community living easier for autistic people to access. This is important because many autistic people are unemployed and/or live in an institution, but want to be employed and/or live in the community.

I am an autistic person. Some of my friends and family members are also autistic. This kind of research could solve sleep & stomach problems my community and I have. It could make it easier for us to be financially independent adults. That is why these issues matter to me.

The IAAC should listen to autistic people like me, including non-male autistic people, autistic people of color, and autistic people with intellectual disabilities, when doing this kind of research, because this research affects us more than anyone else. Nothing about us without us! We don't want to be cured. We just want to live long, happy lives and make choices about our own lives.

Kate Davis

I would love to see more research done into how to best support autistic people with sensory processing challenges. What can be done to minimize the stress caused by sight, sound, smell, touch, and taste - is there a way to treat that one aspect of autistic experience so as to make the world less overwhelming?

I would also love to see more studies done on the rates of sleeping disorders amongst autistic people, and the best strategies for treating them

Marc Rosen

I want IACC to require that all grant proposals must be under the authority of an IRB for which at least 50% of the board members must openly identify as autistic. Autistic representation is essential at all stages of autism research, and especially crucial in ensuring proper autistic cultural competence, in order to preserve our dignity, humanity, and most importantly, our LEGAL RIGHTS. Past funding has primarily been in the context of "curing" or "erasing" autistic life and autistic culture, viewing our divergence as pathological. Thus far, IACC's "Spirit of Collaboration" has been woefully insufficient to uphold our legal rights or our human dignity within any research or advocacy circles other than those which are autistic-run.

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

Nina Tobin

I would like the IACC to prioritize research on inclusion initiatives and education at all school levels, from pre-k to higher education. Bullying, exclusion, and marginalization are enormous issues for so many students who tend to "fall through the cracks" when it comes to "inclusion" with the general education population. The results are significant mental health issues, increased rates of suicide, isolation, and so on. I also hope that more work will be done on the harm of ABA misuse and overuse for individuals of all ages with ASD 1

Julia Simko

I would like the IACC to prioritize research on the number of autistic adults who are parents who have dealt with child welfare services due to false assumptions and/or lack of resources and what kind of help could assist them with raising their children. I'd like a separate study on this for autistic parents who receive public benefits due to the fact that they have even less resources than autistic parents without public benefits.

Anne Xie

I would like the IACC to prioritize research on helping autistic people manage their own physical and mental health, especially since autistic people experience co-occurring physical and mental health conditions as well as trauma at a higher rate than the general population. This research should result in publicly accessible, clear and concise health guidance and resources for autistic people.

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

Tosha Brothers

This October, I would like to bring attention to many issues the IACC have been overlooking.

Firstly, autistic people with complex sensory issues should have research done in order to navigate ways to mitigate their unnecessary pain and confusion. Therapies that involve redirecting our attention and energy away from the negative stimulus would be the most noteworthy that come to mind. Reinforcing positive thought patterns through therapies like acceptance and commitment therapy, otherwise known as ACT. Or cognitive behavioral therapy, known as CBT. Please study these in place of harmful therapies like ABA and RBT.

Behavioral therapies as a whole are not evil, and, when used properly, have the potential to heal instead of harm autistic individuals. An example of this is how many people use inspiration from the famous cult bite model, invented by Steve Hassan, to curb their addictions and make positive behavioral changes in their lifestyles. I myself have tried these techniques with great success. But, like I said. There is an undeniable dark, negative aspect to these methods, which is already used in ABA today. They are preformed with the wrong intention of controlling the targets everyday mannerisms to invoke total obedience. Yet if you take out fear inducing mind games from the equation, along with the induced feelings of shame, you will find a wonderful therapy that many autistics can use. Like ACT or CBT. So please focus on those from now on, as they are already done with the intention of empowering patients.

Alongside that, I want to explain how I, as an autistic woman, disagree with genetic research of any kind, and feel that it is the wrong path to take entirely. I disclose this opinion with the mind that we should deviate from genetics completely in the future, until we as a society can put rules in place that safeguard autistic genetic information from eugenics. Autistic people are not a mutation. We are not a chromosome gone wrong. We are perfectly natural in the eyes of nature. Therefore, we should not, and cannot advance in this conversation if curative efforts are still underway. I want to make that abundantly clear. In my opinion, there should be no genetic research of any sort until protections are guaranteed, otherwise autistic people should start their own research organizations and study ourselves as retaliation for all the crimes against humanity committed against us over the years. It would only be fair.

A more unpopular opinion I have is that pretending to be neurotypical is okay. It is a defense mechanism that many people have, not just autistic people. And that, in order to safeguard our own mental health, it is crucial to mask. I have been covertly masking all my life. It never felt wrong. It always flowed naturally. Because of this, I had the best childhood imaginable. Nobody ever picked on me, or treated me differently. Because they didn't know I was autistic. And I think saying it's okay to unmask is putting children in harms way. All throughout evolution, we were expected to adapt to our surroundings this way. Saying we can just stop is silly and dangerous. There are serious consequences to not masking. Like developing C-PTSD in early childhood from bullying. We are sensitive people by definition, and not masking, although it's a nice thought, it holds no real merit in reality. That is my stance. Teaching autistic children to mask is a good thing that protects them.

I also want more studies into proprioception and interoception. Especially through the field of neurology. Autism would be taken more seriously if there were more concrete neuroscience involved in it's existence. There are still many things that we don't understand about the human brain. It would be pure stupidity to write off autism as a defect when there are so many good qualities to it that neurotypicals don't get to see. Autism is a neurotype, and good science would help to prove that substantially. Right now, we just see autism as a set of behaviors that are problematic. And more study into neuroscience would change that. Then we could finally get to focusing on the more human aspect of our condition.

Emma Villa

I believe there should be a law for the right of people with Autism and other developmental disabilities to literacy; reading skills at their level. The literacy crisis in California's nuerotypical population is well documented. However many lawsuits and settlements there might be for this population, there is NO state-wide systemic advocacy and direct legal help for all people with Autism and other developmental disabilities to exercise their "right to literacy;" to have equal access, equity, full inclusion and the opportunity to learn to read at their level by appropriate individualized evidenced-based assessment, modality, methodology, and/or program they need. Without literacy, how does the autism and developmentally disabled community ever have equal access, equity and full inclusion in education (pre and post secondary), vocational training, meaningful employment, independent living, health/safety, housing and self-advocacy? I believe their right to Literacy is a civil right's issue.

I would like to see a Bill to:
(a)ensure and protect the right of people with developmental disabilities to have the opportunity to equal access, equity, and full inclusion to literacy at their level; to learn to read by whatever modality, evidenced-based assessments, methodology and program they need cat their level in elementary through adult school.
(b) allocate funds for direct legal representation, advocacy and support to those individuals to secure and protect that right.

There are several lawsuits regarding literacy, but none specific to the developmentally disabled community; a recent 2020 Lawsuit by Public Counsel in Ella T. v. State of California included disabled students but then limited settlement to only specific schools. Another in Student A. et al. v. Berkeley Unified School District filed in the federal court for the Northern District of California, Case No. 3:17-cv-02510) which again settlement was limited to Berkeley schools. Another federal lawsuit in Michigan, also filed by Public Counsel, in which the plaintiffs argued that it is impossible to be a productive member of society if one is not fully literate.

My child has a developmental disability and is very bright, but has not been provided the opportunity to learn to read due to his disability. He is in third grade and reading at a kindergarten level. I cannot access appropriate services for him to learn to read or appropriate reading intervention or legal help for him. I know I am not alone and have spoken with other similarly situated parents with children and family members similarly situated in K-adult. I believe the right to Literacy is a civil right's issue.

I would like IACC to prioritize research on how many autistic people have clinical processing issues in language processing, auditory processing, visual processing, sensory processing, and cognitive processing, and how they are diagnosed and what treatments are effective.

Silvia Rodriguez

I would like to see IACC prioritize research on novel interventions for bettering the quality of life of autistic individuals. I feel we need more options that have an updated understanding of autistic behavior, and that is respectful of neurodivergent minds. I feel ABA needs to be replaced as the gold standard.

Eli Estrin

I would like the IACC to prioritize research into the pain and discomfort experienced by many Autistic people when under or around fluorescent lights and possible ways of solving this or finding alternatives.

Katya Siddall-Cipolla

I would like the IACC to prioritize research on treatments for inflammatory bowel diseases in autistic adults and ensure that autistic people are collaborators on the project, not just research subjects.

Linnea Wickstrom

Please look into supporting research on the etiology of gastrointestinal difficulties in people with autism. In particular, please initiate research into gabapentin as a regulator for the gut.

Jane Horn, M.A. (Psychology), M.S.W.

We need to have greater definition of the many disorders that are collected under the umbrella of ASD.

This includes non-speaking people who understand what is being said, but are unable to speak because of lack of motor control. The ones who have learned to type, and to use a voice synthesizer, have communicated the suffering they experienced being treated as if they can't learn anything, and being physically restrained when their efforts to communicate by physical means have been misinterpreted.

There are others who are nonverbal because they have auditory processing problems which prevent them from getting much meaning from the speech they hear. Some of these children are able to parrot whole sentences and songs, with varying degrees of understanding. Some never speak at all. Many will never be able to tell us what they experience or what their frustrations are. Some of these children could learn language from sign language, but never get the chance.

All instances of non-speaking and other poor communication disorders are due to some kind of neurological problems. There are ranges of severity and degrees of disabilities. But the lived experiences are highly varied. We do a disservice if we consider that the lived experience of any single person, is relevant to others who have completely different lived experiences.

People who are too disabled to advocate for themselves are the people who need the most help. But at present, it seems that these people are not getting the services they need because they are not able to advocate for themselves.   This needs to change.   Parents need to be respected as advocates for their severely disabled children.   Also more opportunities for the evaluation of the problem(s) need to be available to families.

More research needs to be done on the neurological problems underlying each kind of disability.   And more needs to be done to find treatment modalities for each type of problem.

Careful and timely evaluation of each child who does not develop normal speech on time needs to be done.   "Wait and see" causes critical delays in treatment.   In some states the wait time for evaluation is so long, that early intervention that could make a big difference, is missed.

Appropriate remediation and special education is based on good evaluation of the problem(s).   IACC needs to address all these issues.

Allyson Raines

I am the parent of an autistic child. I would like research focused in on how school districts allocate special education funding and what supports best engage autistic children.

I would also be very interested into more research on the long term use of melatonin or other sleep interventions. It would be good to research why so many autistic people struggle to calm down for sleep.

Michelle Davidson

I would like IACC to prioritize research on how effective the support systems that are currently in place can help autistic people get and maintain jobs.

Anthony Vizioli

I believe that it is of the utmost importance to prioritize research into a CURE for autism. Like most people who have been labeled autistic from early childhood, my son cannot advocate for himself. Indeed, he is totally dependent on his family. I further believe that this condition is not "Kanner autism" but an illness, likely a neuro-immune dysfunction, and hence not a "developmental disorder" and should be curable.

Nathan R J Destler, Ph.D.

Cognitive Psychology, Rutgers University, New Brunswick

I'm writing here to support research aimed primarily at improving the quality of life for autistic people of all ages. I suggest to the Committee that this effort would be best served by investigating topics such as: What educational environments enable autistic people to learn real-world skills? How can workplaces be made more friendly to autistic employees without negatively impacting neurotypical coworkers? How can we build better systems for social and medical (including, but not limited to, mental health) support for autistic individuals of all ages?

I would also suggest to the Committee that researched based on pure behaviorism (an outdated and overly-simplistic paradigm in psychology) has been broadly disadvantageous to autistic quality of life, and should be subject to increased scrutiny. In particular, efforts that aimed at altering or concealing stereotyped autistic behaviors through conditioning, and not through the conscious, free, and informed decisions of the autistic person in question, have done considerable harm and should not be supported by the Committee.

Steven Bruce

Historically Autism was thought of as a childhood disease. It was not until approx. 2000-2010 that the tools to diagnose ASD were sufficiently developed to diagnose all individuals, both children and adults. Thus, there is a wave of previously undiagnosed individuals who are still not yet diagnosed after which time many will be in need of treatment.
Resources are needed to help not only parents but the public at large including educators, professionals, and self-advocates answer their immediate questions related to safety, transitions, research, professional development training, and to also diagnose and treat people over 18.

Emily Wilkerson

I am a parent of a wonderful 5 year old Autistic child. My child was diagnosed at 3 1/2 years old. Since their diagnosis, we have become apart of awesome communities focused on helping families who have an autistic child. This has opened my eyes to how incredible my child's brain is, but also the struggles that they face every day. I would like funding to focus on emphasizing how wonderful and amazing Autism can be. Stop focusing on how to "cure" Autism as it does not need a cure. Also, to have funding that increases accommodations for Autistic individuals instead of funding that forces them to be neurotypical which is traumatic and unfair. Listen to voices of Autistic individuals, they are the ones that should be determining where the funding needs to go.

Whitney Voltz Voltz

I would like to see more autism research focusing on how to improve the quality of life of autistics, specifically how to improve longevity outcomes. It would be interesting to study a cohort of autistics who have lived long lives (70s, 80s and beyond) and attempt to identify what factors have contributed to their living longer than the tragically short average lifespan of autistics. This information could then be used to inform policy, practice and to educate communities and individuals. I'm not at all interested in seeing any research or funding allocated towards such silliness as finding a "cure" or towards toxic therapy procedures.

Naomi Hickey

My hope is that there are more autistics and adhd people who are able to co-create curriculum to best support neurodivergents in schools and moving forward in the work force/university.

Marylyle McCue

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

Sarah Gromko

I am female, late-diagnosed (38) on the spectrum and would especially like research to be done regarding the correlation between masking and substance abuse.

Melanie Franklin

Autism research, along with the ability to define services and support systems, has never been more important. Millions of families struggle to get medical as well as appropriate, safe educational access for their autistic children and adults. Research into autism development, differentiation, and the types of support/educational programs likely to provide the safest, most engaging environment for children and adults cooing with autism would be invaluable to our autistic community and their families.

Alexander Bishel

I'm an adult with autism. There's a study from the UC Davis mind institute that found that people with autism aren't impaired but rather use "proactive control" processes differently by preparing for easier tasks instead of harder ones. I related to this study a lot. I get analysis paralysis and breaking tasks down from easiest to hardest makes it easier for me to make a decision about how to organize my tasks. I'd like the IACC to prioritize more research into how analysis paralysis relates to the findings in this study

There's another study from Europe that found that early intervention with infants helps reduce the severity of some symptoms when they're older and I'd like to see more about that too

I'd like to see studies on if Dialectical Behavioral therapy and learning to play music improve neuroplasticy and cognitive flexibility in people with autism

I'd like to see research on how well k-12 classes on communication skills would help neurotypical and neurodivergent people communicate meaning, and emotion effectively. It should include skills and exercises on the subjects like tone of voice, pitch, rate of speech, body language, facial expression, volume control, breathe control, self awareness, active listening and emotional intelligence, and the context on when to use them.

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

Community Funding?

Can members of the IACC request sufficient funding for community group homes? Complaints about institutions stemmed from poor funding. Funding of care in the community is even more insufficient.

"Too many trouble-makers live in your son's group home," the police chief in Weymouth MA told me.

"We have to go over there almost every night," he added.

Most of the residents in my son's group home have schizophrenia. They were all discharged to "the community" at the same time, when Westborough State Hospital was being closed. Nurses and mental health workers at Westborough understood how to manage interpersonal problems in my son's hospital unit on the Westborough campus.

Parent support groups at Westborough were also helpful in understanding patient conflicts on the hospital units.

Sadly, nursing care and family support groups are long gone in community group homes in Massachusetts.

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

Derek Dunagan

I would like to see investment in treatments (especially non-drug-based) and strategies for: calming extreme internal sensations/emotions experienced by Autistic people; evenly dampening external sensing for Autism-specific perceptual sensitivities; as well as preventing and managing Autism-specific social anxiety, insomnia, burnout, etc.

I would like to see investment in making public spaces (likely through building codes and licensure) more accessible to Autistic people, in particular by controlling for sound and light pollution. As an example, restaurants and cafés with only hard surfaces (which are easier to clean, so this is very common) and little-to-no soundproofing or sound absorption create a hurricane of acoustic waves that make these places of business un-enterable for many Autistics. When there are open kitchens, it's much much worse. The same happens with large windows and white/bright walls and ceilings: a hurricane of electromagnetic radiation that feels like walking "into the light".

I would like to see investment in syntactical/lexical patterns for and structuring of government forms and websites to be more accessible to Autistic people, so that they are easier for us to use when they are inevitably written and maintained by people who are neurocognitively dissimilar to us.

I would like to see research into how to effectively fund and disseminate high quality AAC devices to all American non-, selectively-, and unreliably-speaking Autistics, at no cost to the user of the device or their families. Communication should be a right, not a privilege under "the right circumstances", which often includes wealth and/or access to information.

I would like to see investment in understanding Autism through the lens of monotropic cognition and the effect this has on social, linguistic, psychological, intellectual, etc development.

I would like to see Autism research limit, but not eliminate, genetic research that seeks to predict or "better understand" Autism, as it offers little direct benefit to actual Autistic people, and treats us more like interesting biological specimens, rather than simply human. When there is much preventable suffering in the Autistic community, this type of research disregards our community's needs and prioritizes the majority's desire for knowledge over the minority's well-being.

I would like to see committees and labs that receive funding to be composed of a majority of Autistic people as a requirement for being a funding recipient (not unlike how groups whose mission is scoped by gender, race, generation, religion, etc would be composed of people in that group, often exclusively). As groups that receive funding under the purview of the IACC make decisions that profoundly effect us, these groups should not be composed of out-group observers that lack the neurobiological prerequisites to comprehend the Autistic interior landscape and are therefore unable to reach a true understanding of or even accurately describe the Autistic experience or Autistic habitus. Nothing about us, without us.

Betsy Cardenas

Families with autistic children need additional support to navigate a complex system of service providers that require time and money. Currently we are self employed and pay almost 2k per month in health services for our child to receive ABA , OT and other therapeutic services. But being self employed is the only way to have time needed to take him to receive services. Rather than focusing on examining the why of autism we should focus on how to ensure the next generation of autistic kids and families can thrive

Rebecca McCabe

I am a female autistic PhD student in engineering. I would like the IACC to prioritize research on how to best support autistic people who come from backgrounds other than the stereotypical white male child from a wealthy family. This includes female, nonbinary, people of color, queer people, adults, and others. These people need to be included in autism research, diagnosis, and support programs with significant emphasis. There should be research about identifying who these people are, what unique challenges they face, and how to adapt diagnosis tools and supports so these people are not left out. I am one of the countless late-diagnosed autistic people who went through the US public education system and was never identified as autistic and given supports, likely due to gender. There are many others less fortunate than I am, who are still being misunderstood and not adequately supported. After the diagnosis gap is closed, more research is needed on how to support and include these autistic people who may have different needs due to their intersectional identities, which calls for interdisciplinary research.

Next, I would like IACC to prioritize research related to therapies and supports that do not force autistic people into uncomfortable situations or try to make people look or act neurotypically. This is because some research suggests that ABA and sensory exposure therapy can cause trauma and are not affirmative of autistic needs. Some alternatives could include researching ways to manage sensory discomfort in an affirmative way, such as assistive technology and wearable devices.

Next, I would like IACC to prioritize research on how to make the public system more accessible for autistic people, including healthcare and services access, creating buildings standards for sensory-friendly spaces, and how to best address the needs of autistic people who are homeless, jobless, or in prisons. I would like the IACC to decrease its support of research related to cure and causation.

On the methodological side, I would like IACC to create incentives for researchers of all autism-related topics to adopt CBPR (community based participatory research). CBPR is a long-overdue method that involves autistic people in the research process, from conceptualization to data interpretation to communicating results. IACC should create incentives using funding, endorsement, dedicated research working groups or conferences, or any other tools at the organization's disposal to encourage this important research practice.

Finally, I have read the public comment from the Autistic Self Advocacy Network (ASAN) and I agree with what they recommend too, especially their idea of researching AAC and effective methods of communication for autistic people who cannot speak or have difficulty speaking, and non-medication mental health concerns.

In summary, please prioritize diverse and intersectional people, affirming therapy/support, public system accessibility, CBPR, and ASAN's requests.

Jennifer Degner

I wish to share concerns. I appreciate the collaborative efforts and recent report and vision about the work that needs to be done to support families and communities. However, I still see in Kansas few opportunities for families to high quality daycare for their child with needs, doctors that do autism screening on a regular basis that are embedded in well child checks. I see state disability waivers that are over 10 years long. Families are in crisis (birth-6). My student’s families struggle to get into developmental evaluations in a timely manner. The wait is 9 months to over a year. We have school systems in which special education is not fully funded, school systems are not in place to best support under diagnosed and under served students.
To sum up
1. No conformity in medical community among pediatricians preforming autism screenings 2. Lack of evaluation teams set up to provide timely evaluations 3. Lack of trained Daycare staff 4. Lack of coordination in communities to provide awareness and access to services for individuals with autism 5. Teacher shortages, Special education teacher shortages 6. We need PSA’s

I appreciate your work. Wishing you well.

Courtney St. John

I am the mom of a 16-year-old daughter with autism. I am deeply concerned about the lack of assistance and resources for helping individuals who have behavioral and mental health challenges in connection with their autism. Far too often, as I've seen with my daughter, children and teens with autism have mental health crises, and there are not enough places to go for help. I would appreciate more resources being allocated to help families in the middle of a crisis. This is very personal to me, as I have had to call the police when my daughter was aggressive, and there should be other alternatives. There should be crisis teams with compassionate, trained individuals, and appropriate places for kids to go when they need help. The ER is not a place for a child with autism, yet that was the only option we were given. This must change, as kids with autism deserve kindness, caring, and empathy, and they should never have to go to the ER because of their behavioral challenges. I am grateful my daughter is now getting the help she needs, but there are so many other kids and teenagers who are not, and who still need more assistance and care.

Thank you for the opportunity to share my experiences and suggestions. I am very grateful for your time and for all that you do.

Finn Gardiner, M.P.P., Autistic Women & Nonbinary Network (AWN), the Autistic People of Color Fund (the Fund)

The Autistic Women & Nonbinary Network (AWN) and the Autistic People of Color Fund (the Fund) appreciate the opportunity to submit commentary to the Interagency Autism Coordinating Committee (IACC). AWN is a national nonprofit that supports autistic women, girls, transfeminine and transmasculine nonbinary people, and trans people of all genders. The Fund promotes the advancement, inclusion, and integration of autistic people of color through microgrants and systems change advocacy. Together, AWN and the Fund direct policy research and community advocacy to advance healthy outcomes for disabled people, including high-quality and community-based services and supports, accessible housing and healthcare, integrated employment, and inclusive education.

We encourage the Committee to prioritize funding for research on the disparities and inequities in service provision and outcomes that autistic people of color, queer and transgender autistic people, and autistic immigrants and refugees face. All autistic people are at higher risk of unemployment, poor health, and other adverse outcomes than their nonautistic counterparts, but racism as well as anti-queer, anti-transgender, and anti-immigration discrimination worsen these struggles. When research studies do not include or focus on diverse populations, this lack of information can be misinterpreted as indicating a lower prevalence of autism among these populations. This in turn can lead to underfunding services, programs, and research that could best support and respond to the specific needs of autistic people in marginalized communities.

We urge IACC to prioritize such research topics, including the following:

* The mental health of autistic people of color, autistic immigrants, and autistic refugees. Although some studies exist on the prevalence of psychiatric disabilities among autistic people, very few examine the relationship of race, autism, and mental health together. Studies have shown that autistic people, regardless of race, are already at higher risk of anxiety disorders, depression, suicidal behavior, bipolar

disorder, obsessive-compulsive disorder, and psychotic disorders.[1] We hypothesize that systemic racism and anti-immigrant discrimination contribute to increased rates and severity of psychological distress among autistic people of color and autistic immigrants and refugees, but we need more empirical research to test this hypothesis and support appropriate funding allocations in the future.
* The effects of school disciplinary policies and the school-to-prison pipeline on autistic students of color. Students with disabilities are disproportionately likely to be expelled or suspended from schools that use zero-tolerance disciplinary policies, as are students of color.[2] Most research focuses on students with disabilities as a whole, but autistic students of color may need tailored strategies to protect them from criminalization, suspension, and expulsion.
* Healthcare experiences of autistic people of color, LGBTQ+ autistic people, and autistic immigrants and refugees. These experiences can include interactions with medical professionals and other clinicians, hospitalizations, accessibility in hospitals and clinics, communication barriers, denial of care, lack of parity in insurance coverage, and affordability of healthcare services, among others. Racial disparities negatively affecting Black, Native/Indigenous, Latine, and Asian communities in healthcare service provision and health outcomes are well documented.[3] Additionally, as the Committee may already know, researchers from the University of Cambridge published findings only last year that autistic people were more likely to identify as asexual, bisexual, and “other [LGBTQ+ identities].”[4] Health disparities negatively affecting LGBTQ+ people are also well documented.[5] For that reason, funding research on development and use of guidelines and standards (for example, on cultural competency and communication access) for providing healthcare to autistic people would be beneficial.
* The rate and effects of homelessness and unstable housing on autistic people. Some research has shown that autistic people are more likely to be homeless than nonautistic people, but there are relatively few studies.[6] Most of this research has taken place in the United Kingdom, whose sociocultural context is different from that of the United States. Researchers should pay particular attention to the prevalence of homelessness among autistic people of color, LGBTQ+ autistic people, and autistic immigrants and refugees, since they experience multiple forms of marginalization at once. Since Black, Latine, and Indigenous people are already overrepresented in the U.S. homeless population, autistic people of color may be at a higher risk of homelessness than their white counterparts.[7] Homelessness also increases the risk of incarceration, police officers often arrest or fine people for sleeping outdoors or lying on benches, which also disproportionately affects people of color.[8]
* Employment rates among, and effective strategies for, increasing competitive, integrated employment for autistic people of color, LGBTQ+ autistic people, and autistic immigrants and refugees. Some research on autism and employment rates exists, but there is comparatively little research that considers the relationship between autism and race and their relationship on employment rates. A meta-analysis found that autistic people of color were less likely to be employed than white autistic people, but this meta-analysis included only five studies.[9] It would also be helpful for IACC to fund research into autistic people’s experiences during the hiring process, including writing résumés and cover letters, completing and submitting applications, hiring tests, communicating with prospective employers, and interviewing. IACC should also fund research on work environments, retention, promotion, and relationships with supervisors and colleagues.
* The effects of linguistic and cultural barriers on autistic immigrants and refugees adjusting to life in the United States.
* Reentry outcomes after incarceration among autistic people of color. Rejoining mainstream society after incarceration is difficult for any former prisoner, but the combination of autism and racial discrimination may add to reentrants’ difficulties.
* Access to alternative and augmentative communication (AAC).

* The effects of incarceration on the health of autistic people of color, LGBTQ+ autistic people, and autistic refugees and immigrants.

We hope that these recommendations lead to increased research that improves policies, services, programs, and outcomes for autistic people, especially those of us who experience multiple forms of discrimination, marginalization, and oppression.

Sincerely,

Rieko Shepherd, J.D.
Policy Manager, Autistic Women & Nonbinary Network

Finn Gardiner, M.P.P.
Director of Policy and Advocacy, Autistic People of Color Fund

Natalia M. Rivera Morales, M.A., Ph.D.(c) Research Coordinator, Autistic People of Color Fund

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Tiffany Plato

The subset of PDA in autistic children absolutely needs more resources and advancement in the United States. We are woefully behind other first world Countries.

June Zhu

I would like the IACC to focus its research more towards improving the lives of autistic people than towards identifying causes or cures to autism. Identifying causes does little to improve out quality of life, and movements to identify cures to autism have historically been and currently are fronts for anti-autism sentiments.

Lori Torres

I would like each child/adult with Autism to be given more reSo & therapies not based on income of household. The deserve to be accommodated for all of their needs. Social Security has been nothing but a nightmare for us and trying to get therapies and meds approved have been a day to day fight. Parents of Autistic children need help and tools for their kids. We don't need hassles & barricades.

Help us, help our kids!

Megan McLaughlin

I am the neurotypical mother of a remarkable adult autistic daughter. I believe there should be more research on two subjects.
(1). Autistic sensitivities to medication, and specifically the need for better dosage guidelines.
(2). The impact of polypharmacy on autistic children and adults,not just the fact that many are taking multiple medications (already well documented), but the ways in which autistic people, specifically, react to the commonest drog combinations.
Thank you.

Dana Carroll

Many autistic people have a hard time getting quality health care. Doctors tend to treat people with "large swath" methods and refuse to handle outliers and edge cases. Describing compulsions and blocker conditions to physicians many times results in the provider simply reiterating the instructions or offering unsuitable alternatives. It would help increase the horrendous life expectancy of autistic people if physicians had special training or even the creation of specialty providers.

Nicole Corrado

While many autistic adults are capable of living on one's own, and are quite employable, most are unemployed, and living in poverty either with family members, or do not even have a home. We need to have disability supports that are not clawed back when one earns money. We need disability supports that allow for housing, food, and decent living. We do not need claw backs when one gets married and/or has children. While there are housing programs to teach one to live independently, these are unaffordable and do not give a person a home. And the autism specific housing projects tend to be in very small municipalities that do not have transit systems. We need access to the broader community, with housing and municipalities of our choosing, and accessible transportation to work, school, and social activities. We need access to healthy, affordable food. We want employment that reflects our true abilities, and is in the real world, rather than a sheltered workplace or an expensive learn to work program.

We would also like to see free autism specific mental health services, starting with a 24/7 dedicated autism Crisis Line. I have looked online and found no Crisis Line for autism, only information lines to learn about services. Every other minority group has a specific crisis line. Numbers like 1-800-AUT-HELP are still available.

We need real mental health and safety services. Investing in tracking devices in case a person "elopes" is very limited, and does not look at why the behaviour occurs. The trouble with tracking devices is that they give a dangerous message in that it is OK for someone to stalk you. There is a growing trend in Canadian cities to ask a found missing person why they went missing; sometimes the person had a very good reason for running away. Sometimes the person is fleeing abuse. If a tracking device is to be used, then it should be with consent (let the person know the device tracks them, and give them the option of opting out), and use a normal device like an Apple Watch, Fitbit, or phone app. Many people like to track their exercise.

Instead of using Kevin and Avonte's Law funds to pay for tracking bracelets that are annoying, ugly, and only track, please use Kevin and Avonte's Law to invest in free or subsidized cell phone coverage for autistic persons. We would be a lot safer if we all had phones in our pockets which also double as AAC devices.

Please invest in free communication devices for all autistic adults who use AAC.

We would also like there to be inclusive sexual education and dating education. We all need to know about consent, and many autistic adults want long term relationships. Please subsidize dating apps, and matchmaking services, and develop singles clubs for Autistics.

Please also invest in parenting supports for autistic parents who have children and want parenting supports. Most autistic parents are just as capable as other parents, yet may want support regarding finances, social skills, and sensory issues regarding parenting.

E F

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

Trigger warning: This section contains references to suicide, abuse, and other sensitive topics.

Co-Occurring Mental Health Conditions and Negative Life Experiences

Note: The following comment has been redacted according to public comment guidelines.

Tosha Rollins

I am a licensed professional counselor and autism mom to two adult sons on the autism spectrum. I also specialize in working with autism. I want to request a call from someone or email reply to voice my concerns regarding mental health and accessible services. Research shows that only 2 out of 44 mental health clinicians feel competent working with autistic clients. I don't know of any research regarding primary care physicians, but I can tell you from personal experience with my son's physician, autism training is limited to none. In my professional experience it has been impossible to find psychiatrists willing to work with autistic clients and accept state medicaid insurance. I am concerned about the growing gap in communication between mental health and the department of disabilities and special needs. I am also concerned about the delivery of services through DDSN in terms of assessment and eligibility for services in the autism division, and who can administer an ADOS assessment (and get reimbursed by state medicaid insurance). It is very apparent with the very long wait lists to get a diagnosis, qualify for services, meet eligibility requirements, and wait for waiver eligibility, and ever increasing rates of autism diagnosis (1 in 44) that our medical personel are not qualified, trained, or in a lot of cases lack interest in serving the autism population. There is a lot of research coming out which is wonderful, but who is going to integrate the research into practice and provide services or continuity of care for consumers like my children, and the clients I serve? [redacted].

Helen Leung

I would like the IACC to prioritize research on what causes depression, anxiety, and suicidal ideation in Autistic people, and what treatments can be successful. In addition, I want more research on how many Autistic people have been abused and in what ways, what we can do to prevent abuse, and what supports work for us during or after the abuse.

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.

Emma Wilkinson

I would like IACC to prioritize research on how many autistic people have depression, anxiety, and commit suicide. I would like research to focus on what prevention and treatment efforts may be effective, as well as creating valid assessments for these conditions in autism. I also think research should focus on what coping strategies autistic people use, and how these can be promoted in treatment settings.

Anna Tanksley

I would like IACC to prioritize research on rates of suicidality, including suicidal ideation, among rates of autistic individuals who identify as LGBTQ+.

Morgan King

i was diagnosed Autistic by a young white male psychologist with a PhD in Autism Studes just over 4 years ago. i am also a survivor of intergeneration family violence like many women and gender non-conforming humans. during that process, he demanded access to my abusers leading me to believe it was necessary for the assessment. then he acted on information from at least one of my abusers giving them access to me to further abuse me, and for the psychologist himself to abuse me. my current understanding that there are many in the Autism sector who continue to believe that Autists are incapable of feeling trauma, and that it is acceptable to breach client confidenitalty and privacy, put clients at risk, in their demand for the completion of family questionnaires. i would like to see future research address this problem and prevent future occurrences.

i am 71, and have spent the last 4 years in trauma counselling to recover from this psychologists's abuse, and i know i am not the only one. can anyhting be done to address this problem in future research? it seems this is a global problem not limited to australia.

Sheri Waddill

It may prove beneficial for IACC to prioritize research on the aftereffects of physical, emotional, and verbal abuse, parental rejection and neglect experienced by autistic children and adults. So many times what is unspoken, and underreported, in childhood is felt in adulthood. The development of PTSD treatments specifically for the full spectrum of autistic adults experiencing the residual aftereffects of childhood maltreatment may prove useful. There are some scant research articles regarding PTSD developed from an autistic child's sensory overload and social struggles, yet there is paucity of research for PTSD treatments for autistic people specifically for the above abuses. This is curious considering children with disabilities are recognized as a population at increased risk for maltreatment. "On the basis of national data from 2015, child victims with a disability accounted for 14.1% of all victims of abuse and neglect". (1) Although, this percentage is older than five years it is assumed abuse would have likely increased before it would decrease, therefore indicating a significant need for investigation.

1. The American Academy of Pediatrics, “Maltreatment of Children With Disabilities”. Volume 147, Issue 5. May 2021, page 1

Meggan Armiger

I would like the IACC to prioritize research on the intersections between autism, PTSD (both standard and Complex), and Childhood Emotional Neglect.

Jax Bayne

I would really like to know what efforts are being made to separate out developmental trauma traits from Autism.

Addressing the Needs of Autistic Individuals with High Support Needs

Allison Leavitt

As a parent of a child with severe non-verbal autism, I live every day with the reality of caring for my son long term. He will never be able to live on his own, may never be potty trained, may never be able to sleep Without fear he will elope and get hurt or worse. We live in a constant state of alert and guard. Resources are poor or non-existent and the only thing that provides any respite is school. What happens when that is over? What happens when we get older? What will we do, who will care for him when we can't? Our country needs to see us and know we are here. Or there will be An increasing number of families in perpetual crisis. Thank you for your time.

Trigger Warning: the following comment contains references some may find upsetting.

Leslie Lussier

I am writing to advocate for individuals who are severely affected by autism. I would like the council to consider overweighting its support for this population that is most profoundly disabled yet often overlooked when policies and funding are made available under the broad umbrella of "autism"
My son is 19 years old and is nonverbal and developmentally tests in the 2yo - 4 yo range. He and others like him don't need "acceptance" or want to celebrate neurodiversity. He will need 24/7 care for his entire life. Individuals affected with severe autism deserve to be brought out from under the broad umbrella term of "autism" and recognized as profoundly disabled people. I love my son. I hate his autism. He cannot advocate for himself and I spend all my time caring for him, so I am hoping you can be his advocate.
Please can him and others like him.

Cove Rathbun

I would like to see more research on dissociative disorders & autistic people. Do autistic people have higher rates of dissociative disorders? Which ones are most common in them? Are dissociative disorders in autistic people more likely to go diagnosed, & vise verse? Is the treatment plan for autistic people different? Does treatment have a different success rate in autistic people vs non-autistic (allistic) people?

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

Jill Escher, National Council on Severe Autism

The Interagency Autism Coordinating Committee's recent discussions, including those regarding development of the Strategic Plan, have been a disappointment. The sessions were often dominated by issues relevant only to the highest functioning slice of the autism population, with scant content devoted to the realities, needs and priorities of the great majority of U.S. autism families.

We were also alarmed to see members angling to cleanse the Committee's (and Plan's) language of basic, accurate and meaningful terminology like "behavior," "risk for autism" and "quality of life," suggestions which were treated seriously by IACC leadership. As Dr. Daniels stated, staff was actively working to remove words like "risk" and instead highlight resilience and strengths-based language in the forthcoming Plan. The clear trend here is toward a Plan that treats autism as a neutral condition or difference. But Congress did not pass the CARES Act because autism is a neutral or strengths-based condition.

Congress allocated millions of tax dollars to research because it is increasingly urgent to identify causes and treatments for the serious disorder of autism that imposes incalculable costs on our families and service systems, not because it is a neutral variant of brain functioning.

That a child with autism cannot learn to speak or develop abstract thought is not a neutral issue.

That a child with autism engages in self-injury or perpetually elopes or destroys property is not neutral.

The abnormal neurogenesis, neural migration, synaptogenesis, and neural connectivity evident in autism are not neutral biological phenomena.

That countless siblings live in fear of being attacked by their brother or sister with ASD is not neutral.

That a child with ASD faces life-threatening seizures, pica or gastrointestinal distress is not neutral.

That a child with autism suffers unrelenting insomnia causing family-wide sleep deprivation is not neutral.

That parents must sacrifice careers, incomes and their own independent lives to permanently care for seriously disabled children and adults with autism is not neutral.

When children autism lack basic safety awareness, to the extent they may rigidly refuse to exit a burning house, their disorders are deadly and certainly not neutral.

That growing numbers of adults lack basic cognitive functions to live independently is not neutral.

The steady growth of autism prevalence, now closing in on 3% of U.S. children (and 5% in some areas) is a national crisis and not remotely neutral.

That we suffer a terrible shortage of inpatient placements, crisis care centers, child and adult psychiatrists, medical personnel trained in autism, and residential support centers to treat the surging population disabled by autism is not neutral.

There is nothing inclusive about neutral or strengths-based language that specifically excludes or denies realities of autism, particularly severe autism. This is a high-stakes debate. We must ensure all federal efforts relating to autism are based on reality, not fantasy. If we must be neutral about autism we cannot emphasize the most urgent priorities facing our community, to wit:

- What is causing the continuing surge of autism cases, particularly moderate to severe cases requiring lifelong intensive supports?
- How can we characterize the different segments of the autism population by level of adaptive function, behaviors and other characteristics so we can project nationwide care, support, and housing needs 5, 10, and 20 years out?
- How can we reduce risk for or prevent autism in successive children, and in later generations?
- How can we bend the course of autism to ensure the best, most functional outcomes possible?
- How can we stop severe life-ruining and sometimes lethal behaviors such as aggression, self-injury, pica and elopement?
- How can we address the autism services, housing and staffing crisis affecting every state?

While the IACC neutralizes language about autism, families on the other hand rely on medical necessity, and the neural and behavioral impairments, disorders and pathologies underlying it, to attain desperately needed supports. For most of us in the real world, impairments, dysfunctions, deficits, disorders, dependency, and not “strengths,” define the daily experience of autism.

The IACC was intended to encompass the representation of the entire population disabled by autism to tackle the serious national crisis engulfing our families and communities, but the unbalanced slate of membership of the committee has led to a highly distorted discussions about priorities for federal agency efforts.

We trust that in spite of this, the IACC and Strategic Plan will be fully inclusive of all realities of autism, including severe forms of autism, focusing on true community priorities, using language that accurately captures our community’s dire realities, and that has not been sanitized.

Thank you for your consideration of our concerns.

Signed,

Jill Escher, President
Amy Lutz, PhD, Vice President
Gloria Satriale, Secretary
Denise Lombardi, Treasurer

Arthur Westover, MD, Board Member
Lee Elizabeth Wachtel, MD, Board Member
Pankhuree Vandana, MD, Board Member
Alison Singer, Board Member
Lisa Parles, Board Member
Judith Ursitti, Board Member
Maysoon Salah, Board Member
Eileen Lamb, Board Member
Kelley Bermingham, BCBA, Board Member

Note: The following comment refers to the letter from the National Council on Severe Autism.

Justin Meade

As a parent of a autistic child who requires 1 on 1 24/7/365 constant support and assistance with all aspects of daily life for not only health and safety. But to thrive! And as a autism advocate I agree with the following letter 100% I ask you to please read it. Think about it and keep it under serious consideration. Because for the individuals and families autism affects, this is their daily lives and well-being we are talking about!

Trigger Warning: the following comment contains language some may find upsetting.

Chaula Gupta

The IACC's attempt to cleanse and neutralize language related to autism is reprehensible and cowardly. You are penalizing and harming kids and adults who cannot use their voice by erasing their experiences in favor of using strengths-based language that appeases a vocal minority. Your work is excluding the voices that anyways find it hardest to be heard. Please step up and have the courage to acknowledge the experience of those who are severely impacted by autism and of their caregivers.

Nancy Boyer

The IACC was intended to represent the entire population of those disabled by autism and to tackle the serious national crisis engulfing our families and communities.
Our family is begging the IACC to ensure that Strategic Plan will be fully inclusive of all realities of autism, including severe forms of autism, focusing on true community priorities, using language that accurately captures our community’s dire realities, and that has not been sanitized.
Please make sure all voices are heard. Federal dollars belong to all. Families need help and are counting on you.

Robin Suzelis

Severe autism must always be a priority when discussing the needs of the autism population. Yes many individuals with autism can thrive with supports in their life, but with moderate to severe autism we are talking about life long intensive supports needed. These supports need to start earlier to make sure all children have access to therapy and health needs, including low cost inclusive health care options, some respite care and more. Then into adulthood support so parents can keep their adult children in their homes when it's best for all but also into group living when needed. The system already is denying children basic health needs, I can't imagine the very near future and the needs.

Johanna Cascione

I am the parent of 26 year old twin daughters with severe autism. The autism spectrum umbrella has often failed to include my girls with respect to support services. A new diagnosis for high need individuals is needed to specifically support the needs of this ever growing group

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

Michelle Trenk

I lay here listening to my husband try to calm my severely autistic non verbal 6 year old and I am enraged. He is neither represented nor considered by the council. People "identifying" as autistic and then celebrating it, pushing to normalize autism, are completely ignoring the community actually affected by severe autism. Self harm, no dignity with personal care hygiene, no functional language, these are not things to be swept under the rug. This is the population most vulnerable for abuse, mistreatment, and death and they are being shuttled along by "actually autistic" people claiming that they have autism so they speak for all. This needs to be rectified and these kids and their families need to be able to access the help they need to live the best life they can.

Lori Kay and Alex Kay, M.D.

We are writing to implore you to "stop sanitizing autism" as described by the national association of severe autism.

Our adult son with severe autism has struggled his entire life and is currently in the hospital awaiting a placement which is not currently available due to his severe behaviors. We love him more than anything but his autism is severe and should not be glossed over with language which is inappropriate for him and others like him.

Concerns About Medical Practices

Trigger warning: The following comment contains references to abuse.

Ben Hattingh

The Judge Rotenberg Center in MA is the only place in the US using GEDs on children and adults with autism and developmental disabilities. The use of this practice has been branded breach of the United Nations Convention Against Torture by the United Nations. Despite the FDA issuing a ban on use of the device, following the investigation requested by the UN, the JRC continues this practice due to an aspect being overturned.

How is it that a practice deemed to be torture is being permitted when there are several centres across the country that work with students of similar needs, but instead of electrocuting them, they provide more staff, proper protective equipment and instead of punishment they use reinforcement?

This center has a history of several deaths, with investigations finding it inhumane; working with psychologists who do not hold a licence; and disproportionately targeting communities of color, with statistics from 2014 showing that 90% of students were people of color.

Online, there are videos of former students describing their horrific experiences at the hands of JRC, receiving these torturous shockings, as well as one of a student being tied and an repeatedly shocked for not removing his coat. This is not how any human should be treated, nor any leaving creature for that matter!

Please support the passing of H.225 Bill in MA!

Paityn Bowen

The Senate needs to be more heavily pressured to act on H.R. 7667, which would ban graduated electronic deceleration completely if passed. This bill has been sitting dormant for four months, which is absolutely unacceptable. The Department of Health and Human Services needs to do everything in their power to bring this to light.

Carl Muhlbauer

I believe with all the money being spent on the highly questionable ABA treatments, money should be allocated to do a quality study of the long term effects of ABA. Including mental health, employment and social functioning of autistic adults who received ABA compared to those who did not receive it.

John McAllister

I would like research conducted on the psychological impact of ABA and behaviorism in schools in the short and long term on autistic children. There have been little studies here and there, but I want studies that survey thousands so research is more conclusive. I worked in group homes and the presence of ABA therapists makes clients' mood shift and become more aggressive. I also have friends with PTSD from ABA when they were kids. Try to compare behaviorist settings against alternatives like the SCERTS model and speech and occupational therapy. ABA is called the "gold standard," but the research that's out there has incredibly small sample sizes. The ABA industry must be held accountable and autistic people's lives count on it.

Chad Hansen

I would like to see more research into alternative treatments to Applied Behavior Analysis (ABA) therapy that takes into account the experiences and preferences of autistics with lived experience. As a parent of a child with autism, a disability rights attorney, and an ADA Coordinator, the only available options for children that I see promoted or covered by insurance seem to involve ABA therapy, while the stories coming from the autism community detail painful experiences from ABA therapy largely based around training children to act neurotypical. More research into alternatives that work with autistic children's sensory and information processing would be welcome.

Increase Autism Acceptance and Reduce Stigma

Benjamin Edwards

I want to see more research that treats autism less like a disease. I want it to make a world where we can be accepted and thrive as who we are. Research into stopping domestic violence against autistics. Research driven by autistic people. Less research that is more of the same, causes, cures, how we can act 'less autistic.' Stop making us hide who we are and instead let us thrive showing who we are meant to be

Merlin Star, M.S.

I would suggest in the future to not have an autism awareness month, but instead an autism acceptance month. Most of the time, awareness months are not to the advantage of those that are autistic and instead center allies. They also tend to not empower autistic individuals and focus on deficits rather than strengths.

There also needs to be more focus on autistic adults and to ensure that it is not unintentionally perpetuating further inequalities in doing so. Include Black, Indigenous, Asian, Hispanic, and other minorities that are frequently left out in autistic research. Please also have autistic researchers involved in said research so that everyone is heard.

John Espinosa, Esq.

I am 40 years old and I am currently battling a reccurence of a rare cancer in my lungs called synovial sarcoma, after the first one took my left arm to save my life back in 2015). My condition is now terminal and I've already outlived my oncologist's expectations. And I'm taking the time to write this, because it's that important. As an educator and attorney I have had the pleasure to both teach and represent a variety of autistic people over the last 12 years I've been practicing law and teaching. I've seen autistic college students of mine go on to law school. As an attorney, I've helped autistic children advocate for their wishes in school truancy, runaway, and child welfare cases where no one else wanted to hear them. I've helped autistic adults start their own businesses and protect their legal interests. Please, hear me now. Listen to autistic people, always. Believe them. Trust them. Don't supress their behaviors, ever. Don't try to change their tone of voice and make them ask for things nicely or not at all. Don't force them to make eye contact or stop moving their body. And don't ever make them believe that they need to change themselves in order to live in the world in any way at all. Let them flourish as themselves. Autistic people need to feel that it's safe to be themselves in the world, not like they have to change who they are just to be accepted. Please, focus your research on what life is like for autistic people from an autistic perspective, which will vary greatly. Please, stop framing autisim by how inconvenient the person is for others. Autistic people matter. Autistic voices matter. Don't try to make autistic people like everyone else. Everyone else could learn a lot from autistic people.

The Role of the IACC and the Federal Government

Damon Kirsebom

As a nonspeaking autistic person, I really appreciated hearing from Jordyn Zimmerman, Hari Srinivasan, and from Dr. Edlyn Pena. Each of them captured what is true for the nonspeakers I have communicated with (and there are so many of us!) For me, my journey to independent communication began at more than 14 years of age, after years of silence--and after being completely underestimated in school. I finally learned to type independently, but first, I needed to use a letterboard, in order to gain motor control. I then accessed academic testing, and scored 8 years above my age. I was also diagnosed with extreme movement disorder. Traditional methods and Apps weren't easily accessible for me. Please meet with and listen to nonspeakers. It is too long that we have been left us out in the cold, because people believe us too cognitively damaged to even care to communicate.

JaLynn Prince, B.F.A.

The Interagency Autism Coordinating Committee (IACC) is an important asset to individuals on the autism spectrum, their family members, autism professionals in the field of autism who provide services, collect data on the impact of autism on individuals and the community and for scientists and researchers who are trying to understand the complex nature of autism to accommodate issues that may surround the many aspects of autism in the same way there is research of health and lifespan for the neuro-typical population.

The IACC provides many different viewpoints from stakeholders of many types. This is a channel to inform policymakers as well, many of whom are imbedded in Federal agencies that may have discussions and input that may impact the future of autism, yet they may have little knowledge of how their actions may be impediments to moving forward rather than being constructive.

The IACC members have an obligation to those they represent to be civil to one another, especially during a national era where people have been denied face to face, interpersonal, interaction due to Covid restrictions. We all have a lot to say. Let us be respectful to all to all positions, stances and strategies.

Trigger Warning: the following comment contains language some may find upsetting.

Su Smith

With due respect, the IACC cannot allow a VERBAL, high(er) IQ group of people diagnosed with ASD LITERALLY speak for those who CAN NOT SPEAK and thus, drive your planning, writing style and influence. You are ignoring the "diverse view" of people with severe/profound autism. I fully expect for the IACC to include in your planning the use of REAL language that reflects the reality of severe forms of autism, including behavioral challenges, significant dysregulation, self-injury, extreme medical co-occurring conditions as well as the needs: community needs, housing, worker/staff training, safety precautions (cameras, door alarms) and so much more. The IACC cannot use "soft language" to placate those who are less affected. Those with severe ASD cannot WRITE to you so those of us who see the trend are reaching out to you. Please listen. Thank you for your consideration.

Trigger Warning: the following comment contains language some may find upsetting.

Jane Mccready

I feel that the top 5% of folk on the autism spectrum are taking up 95% of IACC airtime. Of course all have needs, but in what other disability forum would the mildly affected set the pace for and even talk over/cancel those most severely afflicted? For a diagnosis of autism, it is required that impairments are present. If they are not, it's not autism. You may think you are being kind or autism-friendly by sanitising the language used. But in fact your circumlocutions benefit only grateful cost-cutting authorities. Please speak up for severe autism too.

Patrice Rohde

I am concerned about lack of voting representation by members of the Autism community on decision-making boards and other policy-driven forums that directly impact their lives.

Research, Services, and Supports for Adults with Autism

Brittany Daniels

I would like to see research into why most of states in the USA don't require that autistic adults like me to have our needed therapies covered under health insurance.

Kaitlyn Ballenger

I want to see studies on autistic ADULTS and how we can help them thrive and create environments that are neurodivergent friendly. I also want to see more studies related to co-occurring conditions that commonly affect autistic individuals and how we might treat them: like the relationship between autism, Ehlers Danlos syndrome, and hypotonia, the relationship between autism and sleep issues, why so many autistic individuals had frequent ear infections as children, etc. Please stop putting research toward harmful ABA therapies and trying to "cure" autism. Autism is a different way of being. It is not a disease. We do not need to be cured. We simply need to be properly nurtured and have our unique needs met and accommodated. Listen to autistic adults like myself and so many others!

Joy Schneider

Research is needed on older adults who may be or are on the spectrum. There are many late life issues that are impacted by spectrum symptoms. Housing, new late life relationships/friendships, succession planning, navigating legal and financial anxieties, caring for adult children on the spectrum, fractured families and disintegrating support systems are areas where compassionate help is needed. Best practices must be developed.
I am a gerontologist on the spectrum, Medicare age, there are a great many of us and we need help. Thank you.

Sigrid Ellis

I urge the IACC to support and encourage research on older autistic people. To wit: what are the difficulties in being correctly diagnosed as an adult after decades of masking; what are the therapy needs of those lifelong-masking older adults; and, what does autism present as and what are the diagnostic criteria for older adults who have learned to behave appropriately-enough over the years?

Skyler Irons

We need to know how to rectify the damage we have done in the absence of equitable research over the past few decades so we can address the needs of now adult Autistics who never learned to accept themselves or adapt to a world that wasn't created for us. I am a clinician (LCSW-C) and a Neurodivergent. I have no community resources or supports for the Autistic community, especially for adults, especially in my rural area. No competent clinicians with experience in the area and no competent/current/equitable training available for services/support to adults either. This is what I need.

Tasha Hansen

I am a LICSW in WA state and specialize in treating adults who have been referred to me by primary care and mental health providers who are struggling to delineate a diagnosis of a neurodiverse condition or Autism Spectrum traits.

Two main areas of concern about Autism Research are as follows:
1) Research that is inclusive of CITED Autistic Adults on the study design for both observation, interpretation & report of participation and results.
2) Research on Autistic adults that distinguishes diagnosed before 16y and after 18y; as well as inclusive of a balanced ratio (ie 18%+) of at least 5 ethnicities and at least 5 gender identities (ie 18%+) in an effort to improve data for evaluating access to care, efficacy of behavioral interventions and qualitative recommendations to identify statistically significant gaps to create new behavioral interventions and treatment approaches or modifications for Autistic Adults

Caroline Pavlecic

I would like to see IACC prioritize research on the most effective ways of supporting autistic people during and after college education. I am an autistic young professional, and very few resources and support providers with expertise working with those in similar situations to me are available because so much autism research and general understanding centers on children. I would also like to see research on autism-friendly workplace policies being implemented company-wide and their effects versus merely accommodating autistic employees on an individual level.

Viola Sanchez

I have a grandson who has lived with me and also has autism and was diagnosed at the age of 2 1/2 and has been on an IEP the whole time he has been in school, he also got SSI to help with his living expenses and at the time he turned 18 SSI sent him a noticed he needed to get an updated evaluation that they sent us with a date and time to get it done, well I didn't have no doubt. but then we got a letter saying he has been cured he does not have autism anymore. and his checks will stop. but we filed an appeal, with no luck. I called and explained that (he is still in school) the lady said oh well he can go to school and get a job. I said he has a hard time with his daily assignments already to complete them and turn them in on time. And if he quite school what kind of job would he be qualified for without an education? Well our Rent also considers his portion of his SSI, and it helped him buy some of his expenses. SSI has no heart they are done with helping him. a person with a disability and not enough schooling and no help paying his rent what kind of life will he have. Just because he turned 18 doesn't mean he can get a good paying job. He still needs school and an education with the supports.

Cox Amy

PLEASE focus some effort on adults,. especially older adults like me, with autism, particularly those who are considered "high functioning", who must work to support themselves, and who are constantly subject to harassment, bullying, underemployment, unemployment, and harsh environmental sensory conditions. Also, perhaps there could be research into what, besides psychotropic medications, would help ease the incredible stress that sensory overload/sensory processing disorder (also hyperacusis and misophonia) places on individuals. In the 4 years since l discovered I'm autistic, l have found exactly no help with these issues. I'm consistently referred to agencies that work with children, despite telling them that I'm 65 and working full time. Thank you.

Bill Wong

One area that needs research is autism and productive aging. There are some coming along and I am contributing to such. But, we need more!

Carol Greenburg

I’m the autistic mother of an autistic son who is now taking a big step from school to the adult world. While I think it’s a good start that there are resources for autistics of his age, we as a society need to provide respectful, research-based, structures for autistics at all stages of our adult lives too. We need to take into account not just autistic children and teens, but also autistics going through all stages of the human lifecycle.

Kellyann Wolfe

As a 45-year-old autistic woman, one of my greatest desires for autism research is in the area of aging. Autistic women have collected much anecdotal evidence that our experience of menopause is different from neurotypical women, and that deserves research. I'm also concerned about ableism in hospitals, nursing homes, and home-health care workers. Educating medical professionals about the needs of autistic patients - especially with regard to communication, pain, and sensory needs - is critical to supporting autistic people of all ages, but especially elders. As I age, I find myself less able to tune out or ignore painful sounds, and because of that, I fear needing hospitalization. Even visiting my spouse in the hospital last year was difficult; how would I survive as a patient there? Moreover, it is exhausting to need to explain autism and common autistic experiences to every doctor, nurse, and dentist I see. Better education of medical personnel is crucial.

Our sleep patterns have a huge effect on our general wellbeing, but there's very little research on supporting healthy sleep for autistic folks, and that needs to change. Why do we get less REM sleep, and how can REM sleep be encouraged? Does our greater propensity for lucid dreaming explain why we feel less rested? How can we promote more restful sleep, and how might medications be used to that end, since behavioral therapies that work for non-autistic people often don't work for us?

I am also concerned that schools - most infamously, the Judge Rotenburg Center - are still using painful electric shocks as a method of behavioral correction and punishment - and the tying together of those two things itself betrays the harm done by the shocks. No child can learn to moderate their behavior well or sustainably while being punished.

Thank you for eliciting and reading our comments.

Trigger warning: The following comment contains references to death and abuse.

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

BLAMING PARENTS

"Conrad is dead!" my husband cried over the phone.

Two co-workers drove me home. I called the medical examiner's office.

"The remains have already been bagged," he told me.

Staff at Conrad's group home had not allowed me to visit Conrad. A facilitated communicator had determined that Conrad's autism was due to my having abused him. I never got to speak with her.

Education of group home staff is badly out of date. But many are high school dropouts, because, of course, they already knew more than their teachers. And, they knew I must have been a bad mother, for my son to have become autistic.

But the medical doctor should be serving a life sentence in jail, for prescribing Thorazine at a higher than recommended dose. Plus she prescribed many other drugs too. Conrad's death certificate gives cause of death as toxic blood levels of Thorazine.

Please invite more parents to participate in IACC conversations. We need to be listened to.

Corinne Fisher

I would like the IACC to prioritize research for late diagnosed and undiagnosed adult women and people assigned female at birth.

Autism Housing Pathways, Catherine Boyle

Autism Housing Pathways (AHP) has released the results of its 2021-2022 housing survey. The survey focused on Massachusetts adults with autism, and updates the results of AHP's 2011-2012 survey.

The data, elicited from 359 respondents, shine a light on gaps in the current menu of services in Massachusetts, including:

* Half of the individuals represented in the survey have too many skills to qualify for 24/7 residential supports from the Department of Developmental Services (DDS) or for MassHealth's state plan services but lack the skills to live independently.

* There is no housing pipeline for individuals with intensive support needs who lack an intellectual disability.
* Residential staff need training to work with individuals with intensive support needs.
* Drop-in services for prompting through daily living activities are not available in most housing situations.
* Workforce shortages impact the ability of individuals to live with support in the community.
* Innovative approaches are needed to support those who have difficulty with initiating skills or who freeze when something goes wrong.
* Without adequate support for appointment, paperwork, and money management, individuals risk falling through the safety net.
* A lack of environmental modifications in rental housing puts individuals and families at risk of eviction.
* People lack awareness of existing benefits, and especially of affordable housing programs.

The results paint a detailed picture of housing needs. Some sense of the scale of the demand can be seen in AHP's previous extrapolation from special education data and the CDC's autism incidence data: https://autismhousingpathways.org/supported-housing-demand-for-autism-in-mass-estimated-at-600-units-per-year/. That calculation indicated that 625-650 adults with autism per year are likely to need affordable, supported housing beyond that provided through the Department of Developmental Services and MassHealth's Adult Foster Care program.

The survey report also considers options for remedying the gaps. These measures would require legislative, regulatory, and procedural change. Examples include:

* Modifying the MassHealth Personal Care Attendant program to cover drop-in services for prompting.
* Making accessory dwelling units created to provide housing for persons with disabilities exempt from local zoning.
* Requiring a percentage of units in new multi-family rental housing to include the most commonly needed environmental modifications.
* Requiring that a percentage of housing funded through the Qualified Allocation Plan and/or the Facilities Consolidation Fund (a state loan fund) serve DDS clients who do not require an institutional level of care.

AHP is a Massachusetts non-profit dedicated to helping individuals and their families to identify or create sustainable, supportive housing options for adults with developmental disabilities. Founded in 2010, it is a membership organization run by and for families.

Housing needs and desires in the Massachusetts autism community: 2022 survey results:
https://autismhousingpathways.org/wp-content/uploads/2022/10/Housing-needs-and-desires-2022.pdf

Autism Housing Pathways 2022 housing survey: Executive summary:
https://autismhousingpathways.org/wp-content/uploads/2022/10/Autism-Housing-Pathways-Housing-Survey-Executive-Summary.pdf

Key takeaways from Autism Housing Pathways, 2022 housing survey (a one page summary):
https://autismhousingpathways.org/wp-content/uploads/2022/10/Key-takeaways-one-pager.pdf

Employment

Traci Collins

Please fund research that explores how to increase employment for autistic adults.

Justin Robbins

Research about autism should focus on ways to boost employment, independence, and improving quality of life. This is critically important and under-funded. It is high time the federal government stop spending billions of dollars annually on the fool's erand of trying to "cure" millions of autistic Americans of our existence and start helping us live lives of productivity and dignity.

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

Jason Brown

Please investigate exploitation, manipulation, and abuse of autistic individuals in the workplace. ASD individuals are often gifted with heightened abilities and interests which can be extremely lucrative for employers. A deficit of certain social skills, awareness, and other understandings leaves this minority group extremely vulnerable. A broad study to examine the treatment of people living with this disability by employers is needed.

Corben Havener

I would be interested in exploring if asking a job candidate if there is any accommodation they need would be helpful as standard practice for all applicants can make a meaningful impact in gainful employment among autistic populations.

Potential Causes of Autism

Elissa Leonard

Not only do babies with acquired B12 deficiency (from mom) have that strike against their brain health, they can also have impaired GI tracts predisposing them to further lifelong malabsorption of other nutrients... hence malnutrition.

Starting out with low B12 means the need for lifelong supplementation.

B12 deficiency harms young children's development, and the food relief we provide isn't good enough -- ScienceDaily

VICIOUS CIRCLE

- B12 deficiency can be transmitted from mother to child. If a mother is B12 deficient, her child will be born B12 deficient as well, before receiving breast milk with too little B12 in it. A child's B12 deficiency can affect the formation and regeneration of their intestinal cells. Consequently, the child's capacity to absorb B12 and other vital nutrients will be reduced. In this way, B12 deficiency contributes to the development of malnutrition.

Even after three months of food relief, one third of the children continued to have low or marginal levels of B12 stored. The unfortunate explanation is that there is a cap on how much B12 can be absorbed.
"A child's gut can only absorb 1 microgram of B12 per meal. So, if a child is lacking 500 micrograms, it will take much longer than the few weeks that they have access to emergency food relief," explains Vibeke Brix Christensen, a pediatrician and medical advisor to Médecins Sans Frontières and co-author of the study

https://www.sciencedaily.com/releases/2022/05/220503141353.htm

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

QUESTION 2, BIOLOGY:

Inferior Colliculus?

The inferior colliculus (plural colliculi) was the only site of injury found by WF Windle in his research on brain damage caused by asphyxia at birth. Windle's finding was confirmed by RE Myers (Am J Obstet Gynecol, Jan 1972; 112:246-76).

Myers found brain damage characteristic of cerebral palsy was caused by partial oxygen insufficiency in the prenatal period.

SS Kety (1962) discovered that the highest blood blow in the brain is to the inferior colliculi.

The inferior colliculus is damaged by 6-8 minutes of asphyxia, beyond which a newborn cannot survive. I suggested looking for injury in the inferior colliculus, as the cause of autism (Arch Gen Psychiatry, Nov 1975; 32:1439-46).

Syllable Detection

Roger Brown (A First Language, 1973) described baby-talk, use of stressed syllables, as the essential first stage of language development.

"Echolalic speech" is characteristic of autistic children, and accounts for pronoun-reversal.

"You want to go to the playground?" my autistic son, Conrad, would ask.

"Wanna go playground," his brother, Matthew, would tell me.

Matthew's request reveals use of syllables plus "grammatical transformation" as part of normal language development.

Language Disorder

Language disorder is the most serious impairment of autistic children. Injury of the inferior colliculus by a brief period of asphyxia at birth should be considered as a possible reason for failure to detect syllable boundaries.

Failure to detect syllables afflicts us all by about age 5. This is why learning a foreign language becomes difficult past early childhood.

Brainstem Abnormalities

Kulesza and Lukose (2008 & 2011) reported abnormalities of the "olivary complex" in the auditory pathway of people diagnosed with autism in childhood. They undertook this investigation based on a case report in 1996 by Rodier and Romano at the Rochester NY School of Medicine.

Dr. Romano had this patient's brain preserved after her death at age 21. The patient's mother was alcoholic. This suggests damage of brainstem pathways similar to that described by Wernicke in 1881.

Malformation of the superior olive in the auditory pathway was found. Kulesza and Lukose discovered similar brain abnormalities in brains they examined. Dr. Kulesza replied to my inquiry about the inferior colliculus. He told me they had only asked for brain-bank sections from the superior olives.

Prenatal Depakote

Kulesza et al. published reports in 2019, 2020 and 2021 that the inferior colliculi and other brainstem auditory centers are injured in laboratory rats exposed to Depakote during gestation.

Autism has been reported in many cases of prenatal exposure to Depakote, taken during pregnancy to prevent epileptic seizures.

Following are citations to the report of superior olive malformation by Rodier et al., and the reports by Lukose and Kulesza, and their students:

1. Rodier PM et al. (1996) Embryological origin for autism: developmental anomalies of the cranial nerve motor nuclei. J Comp Neurol. 370:247-61.
2. Kulesza RJ, Mangunay K (2008) Morphological features of the medial superior olive in autism. Brain Res. 1200:132-7.
3. Kulesza RJ Jr et al. (2011) Malformation of the human superior olive in autistic spectrum disorders. Brain Res. 1367:360-71.
4. Lukose R, et al. (2011) Malformation of the superior olivary complex in an animal model of autism. Brain Res. 1398:102-12.
5. Smith A, et al. (2019) Structural and Functional Aberrations of the Auditory Brainstem in Autism Spectrum Disorder. J Am Osteopath Assoc. 119:41-50.
6. Mansour Y et al. (2019) Auditory Midbrain Hypoplasia and Dysmorphology after Prenatal Valproic Acid Exposure. Neuroscience. 396:79-93.  

Brain Injury?

Brain injury that might disrupt language development must be included in The Strategic Plan.

In 1975 I proposed the inferior colliculi (in the brainstem auditory pathway) as a possible site of injury in autism (*Arch Gen Psychiatry* 32:1439-46). The only damage found, in monkeys subjected to a brief period of asphyxia at birth, was in the inferior colliculi (Windle, Scientific American, October 1969). Death from asphyxia resulted after 6 to 8 minutes.

In 1962 Seymour Kety reported highest blood flow in the inferior colliculi, in the brainstem auditory pathway, http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1804882/?tool=pubmed.

In 1981 Louis Sokoloff reported, “The inferior colliculus is clearly the most metabolically active structure in the brain” (*J. Cerebral Blood Flow and Metabolism* 1:7-36). In tables compiled by many users of Sokoloff's method, the inferior colliculi are always listed as the most metabolically active site in the brain. And note, the auditory system is rarely the focus of research using Sokoloff's method.

The research of Kety and Sokoloff should be discussed by members of the IACC. Why are my comments on brain damage not worthy of more than brief mention in summaries of public comments submitted???

Note: Additional materials for the following comment are available upon request.

Hal Frost, Ph.D.

(1) Thank you for adding to the NIMH budget the funding and NIMH infrastructure and giving the extra attention needed over the years to take, compile, collate, disseminate, and publish online the solicited public comments, both oral and written (latter type of which I earlier gave in three sets prior to two full-membership IACC meetings in 2021 and 2022 as well as earlier on the Strategic Plan and now are given in this fourth set).

(2) My credentials for submitting public comment in a professional way, with a respect for physical truth, are given in attached CV. I am a retired theoretical physicist whose prior three sets of public comments [per (1) above] related to my recently completed, unfunded (and thus independent and unbiased) *pro bono* research on possible physical risk factors for early-age ASD/IDD that others had not yet looked into.**

(3) Physics considerations in ASD-etiology-scenario thinking can be relevant to the operations and activity of the OARC and the IACC on behalf of the autistic child and adult, as only a physics or related engineering approach can correctly identify the physical mechanisms underlying the physical effects of radiation of any type on matter of any type including biological tissue considered as a solid-like medium 'marbled' with liquid-like regions. Obviously, the biology and the clinic have to be brought in by other experts to interpret impacts of these physical effects that may or can evolve into bioeffects, to assess whether the bioeffects self-repair or not and whether the non-self-repairing effects lead to adverse outcomes for the patient. Indeed a broader multidisciplinary approach is needed to see if there are any overlooked causative factors in future etiology studies for ASD. Such causative factors do not necessarily require gene mutations induced by ionizing radiation, as a physical analysis points toward

the ability of non-ionizing radiation to break weak bonds such as hydrogen bonds in proteins, DNA, RNA, etc. which could result in non-repairing mis-folds as topological defects in secondary and tertiary structure of such large macromolecules, which in turn would or could adversely affect the biochemistry (proteome) or morphology (e.g., fibrils or not) of tissue and thus the phenotype of the person so exposed (while leaving the genotype unchanged). That is, the phenotype could change as the result of a gene-environment interaction. And the child in the womb, as the mostly invisible patient in Ob/Gyn medical practice, is exposed to an environment of penetrating radiation, of which directed ultrasound or MDU is one kind. But, ultrasound is only one form of manmade radiation and many types exist of both manmade and natural radiation, whether ionizing or not (airborne noise or sound, UV, RF as from MRI's or smart phones or 5G or in the next decade even 6G, x-rays such as in airport scanners, dental xrays or CT scans, nuclear such as from PET scans, nuclear power plants, or background cosmic rays, etc.). And while children, especially their central nervous systems (CNS's) are or may be most susceptible to adverse bioeffects of radiation, whether *in utero* or *post partum*, many more adults are so exposed, so that a body of research already exists that the IACC could take advantage of when assessing whether a new, radiation-induced cause factor or at least a new radiation-related risk factor may be involved in causation of ASD and other neurodevelopmental disorders. The relatively high vulnerability of the CNS including the brain to radiation is also well established in the literature, lending credence to utility of this approach to the meetings of the IACC and oversight activities of the OARC.

(4) Is there an ultrasound gene? I do not know but it certainly seems reasonable to search for a biomarker for permanent radiation-induced misfolds in the genome. (Of course, in terms of aforementioned topological defects, the unaided eye in the office or at home can immediately tell or not if there is a frustrating 'mis-coil' in the coiled black cord between a standard telephone set and the hand-held unit.)

Emmet McManus

How well do we understand our TRUE 'bilateral profiles' in relation to how they are established and how they must subsequently function & perform within our body systems?
Attached, a resolute theory concerning many health matters including AUTISM(L?) /ADHD(R?), CANCER, M.S, DEMENTIA, ANXIETY/DEPRESSION and so on, possibly even SUICIDAL IDEATION!, might shine some much needed innovative light on this question.
Chirality isn't genetic, genetics must surely be chiral, more specifically - 'homochiral'
But how/why & to what extent?
The attached attempts to explain the 'how/why' aspect, but we're going to have to dig deeper to better understand & work out the 'to what extent' aspect! - maybe even fine-tune and apply a little flow cytometry technology along the way, see what that would highlight!
In the interest of addressing possible causes of and therefore a plausible explanation for many neurological (mental health) & physiological (disease) conditions, kindly review this novel insight.
For now, the MO is politely asking somebody to consider, just for a moment, regarding a particular detail within a process, that no one has ever before considered, though are aware it must take place but completely oblivious to its reality. Then, draw your own conclusions.

A sincere thank you & hope to hear any views you may have on this matter.

DOI: 10.31038/PSYJ.2021352
Published: 31/12/21
Citation: McManus E (2021) Be True: A Theory on Bilateral Sway. Psychol J Res Open Volume 3(5): 1-3.
https://researchopenworld.com/be-true-a-theory-on-bilateral-sway/

Inclusion of Autistic Perspectives in Research

Dr. Scott Frasard

One of the most fundamental aspects of culture and relating to one another is language. How language is used to communicate thoughts and feelings. Language can also serve to differentiate and even marginalize people. As an autistic person, there is a dramatic difference between person-first language (PFL), which is the accepted language by the vast majority of the world, and identity-first language (IFL), which is the preferred by the vast majority of autistic people. One of the main reasons for that is we see/experience PFL as pathologizing; that there is something wrong with us that needs to be fixed. On the other hand, IFL language acknowledges that our way of experiencing the world and our very existence is not faulty, but rather is a valid existence.

My ask is that we fundamentally change how we speak about autism by using identify-first language. We ARE autistic; we do not HAVE autism. The former honors who we are while the latter paints the picture that we are broken. We are not broken; we are just different.

Priya Sall

Please ask autistic people when your doing a study with autistic people.

Heather Ricks

First and foremost, I would like to urge the IACC to include autistic people (particularly autistic people with co-occurring mental health or intellectual disabilities, autistic people who use AAC, and autistic people of color) in the research process as collaborators, not just in the data collection phase.
I also urge research into:
1. All life stages with Autism (it can be hard to find evidence-based info beyond childhood).
2. Female/POC presentation (again hard to find evidence-based info).
3. Better options for addressing challenging behaviors in schools and at home.
All of these items will be better served if the first one is addressed.

Miyako Jones

I would like the IACC to collaborate with actually Autistic people from diverse ethnic minorities/genders/sexualities/disabilities/etc. on research and to also include nonspeaking Autists.

Jennifer Broekman

I would like IACC to prioritize research that includes autistic people, particularly autistic people with co-occurring mental health or intellectual disabilities, autistic people who use alternative and augmentative communication, and autistic people of color, in the research process as collaborators

Reilly MacDonald

I would like IACC to prioritize research in implementation science and studies that include either autistic researchers or partner with autistic individuals during the research process. I would also like IACC to emphasize the importance of compensating autistic participants in research studies.

Wandering and Safety

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

Missing Children?

My autistic son was 47 years old when he climbed out of his group-home window, and was missing for 7 weeks and 2 days. My husband never recovered from the trauma of searching everywhere for him.

"If he jumped off the Fore River Bridge, his body would have been recovered within a week," we were told by the police.

Wandering is often broadcast on TV and radio stations., Many missing children are therefore found within a few hours. These cases are not always published in newspapers. Those autistic from infancy, rarely develop skills sufficient for self-care in adulthood.

Who other than family members can stand up for the needs of an autistic child or adult? More than a third of people on the ASD spectrum have severe language disability, and are unable to advocate for themselves. We need more parents and other family members on IACC. Few people, obviously, appreciate the difficulty of parenting an autistic child.

Augmentative and Alternative Communication (AAC)

Amy Montimurro, LMSW, Alibis

Abilis is a non-profit organization in Connecticut supporting over 800 individuals with disabilities and their families from birth through the senior years. Since 1951, Abilis has been a leader in providing state of the art, progressive services and supports meeting each person where they are.

As 45% of the adults we support have Autism, we are always looking for ways to engage and to increase communication with non-traditional communicators. We launched our Supported Typing Program, (STeP) after incredible outcomes of a small sample in February 2019. STeP has received enthusiastic support from our board.

A STeP participant whose life has been transformed because of our program typed:

"I am free now of the frustration of not being able to tell you my thoughts and that has made a huge difference. People see me differently and I think differently. I now have hope for a freedom in my life that I have never had before. Please give me and others like me the chance to be the people that we really are."

“It is new to me to think this much. I was stuck in ways of thinking that was old and dead with no hope of doing it differently. Good life is here now. Yes, hope is the new feeling that I have in my life."

The mission of STeP was to support the non-speaking and minimally speaking in Lower Fairfield County, CT. We strive to build a community of typers/communicators, and to develop a growing community of well-trained facilitators with capacity to support individuals using best practices in FC to ensure words being typed are the person’s own authentic voice. For three individuals, over the age of 30, who were part of our 2019 sample, independent typing is now an emerging skill.

In March of 2020, with the onset of COVID, STeP moved to online coaching, training, social groups, and workshops. This unexpected shift allowed us to reach way beyond our catchment area. In addition to working with local families and clients from Abilis, we have worked with typers and facilitators from 18 states (AK, AL, CA, CT, FL, GA, IL, IN, MA, MI, MN, MO, NJ, NM, NY, OR, VT, WA), and from 5 countries, (US, Belgium, Canada, UK and India). During the past 2 years, via Zoom, we have trained approximately 175 facilitators - which includes parents, and staff members of agencies like Abilis from around the country. We have held close to 100 individual coaching sessions for families, worked with clients in group homes, provided training and coaching to several schools, and held over 85 sessions for the two thriving social groups that have met twice per month virtually since COVID began. In addition, we have provided virtual educational workshops with guest speakers attracting 85-140 registrants from around the country. In some states there has been government funding to reimburse families for initial assessments, on-going coaching, and social group fees. The State of Connecticut Department of Developmental Services has recognized our efforts and funded the program through self-determination

ensuring everyone has a voice and means of communicating with those around them. We are determined and committed to respecting each person and their means of communicating.
Our clients and their families often describe the significant life changes that occur when someone learns to type to communicate. However, many school districts deny access to these typing methods even after parents and therapist have demonstrated successful communication when their autistic child is paired with a trained communication partner. Policy statements from some professional organizations, stifle educational opportunities for many. Their arguments rely on dated, limited, flawed research to deny services. The fear of losing their license has intimidated professionals in the field from being willing to meet with and listen to typers share their thoughts and wishes. Professional therapists who observe the success of these methods when used properly (FC, RPM, S2C), are unable to publicly acknowledge the benefits and forced to work with clients privately, without the full team. Communicators feel unseen, disrespected and incredibly frustrated.

We ask that the IACC:
1. Acknowledge the basic right of individuals to choose the form of AAC that works best for them.
2. Recognize that some forms of AAC such as FC, RPM and S2C are currently being utilized by many individuals and are worthy of further scientific inquiry.

We suggest the following research opportunities
1. How can we better identify individuals who will benefit from FC, RPM and S2C?
2. How do some individuals who type with a communication partner learn independence?
3. How can we integrate typing methodologies into educational and community settings?
4. How can we measure the cognitive and social-emotional growth of individuals who type to communicate? How does this gain impact their independent life skill acquisition?
5. What tools do we need to help families and individuals of all ages, once they emerge to open communication to adjust socially and emotionally to create more independent, productive lives?
6. How does research on individuals who type to communicate inform our need to change cognitive, social-emotional, and academic assessments?

We would welcome the opportunity to present our outcomes to the IACC.

Thank you for your consideration.

Amy Montimurro, President & CEO, Abilis Inc
Susan Nisinzweig, Coordinator of STeP and parent
Deborah Hilibrand, Board Member and parent

Ileim Moss

As an autistic AAC user, I urge the IACC to prioritize research aimed at identifying disparities experienced by Autistic AAC users compared to other Autistic people (as well as our allistic peers who both do and don't use AAC). Such research should examine the ways participants, their families, and care teams report on the participants happiness, healthiness, satisfaction with life, agency in decision making, and perceptions of social fulfillment. It must also identify other ways in which participants are marginalized and seek a diverse sample to study, including people of varying class, ethnic, racial, linguistic, disability, and gender. It is crucial that autistic people who are racially marginalized, both those who do and do not use AAC, are sought out, centered, consulted, and compensated for said research.

Marrok Sedgwick

I want IACC to prioritize research on best practices for supporting robust and effective alternative and augmentative communication (AAC) for autistic people, as well as cultural competency of alternative communication methods. I also want the IACC to include autistic people, particularly autistic people with co-occurring mental health or intellectual disabilities, autistic people who use AAC, and autistic people of color in research as collaborators. I want the IACC to reserve 51% of its total available seats for autistic researchers, educators, parents, and otherwise unaffiliated autistic people. I want the IACC to prioritize educational research that utilizes modern methods from cognitive psychology and learning sciences, and to ban funding research from the behaviorist psychology fields (which have been proven to be empirically false, and considered out of date, since the 1950s). This ban should include a ban on research about applied behavior analysis, which is not empirically supported, despite the advertising campaigns claiming otherwise.

Iris Warchall

Topics that need research: 1. How to train healthcare providers in mitigating access barriers to receiving healthcare for autistic patients. 2. How to match autistic adults with support services to improve access to employment and community participation. 3. How to provide neurodiversity-affirming mental health care to autistic adults. 4. How to identify the need for assistive and augmentative communication (AAC) modalities in autistic children and adults and provide AAC devices and training as indicated

Kerry Sheehan

Listen to autistic adults. Learn about marginalized folks that aren't being recognized. Look for the holes in diagnosis processes that are missing marginalized folks. Stop ABA. Stop abusing us. Presume competence. Everyone gets a AAC device no prerequisites required. AAC is good for all autistic folks not just non-speaking autistic folks. Many of us can't communicate under stress and when we're traumatized. Most autistic folks are traumatized because of how society treats us. Did I say presume competence. Presume competence. Give us better tools to homeschool because you're not hitting it in public schools. You are harming us so bad You need to start over from scratch. Stop putting us under ages that we won't achieve past. Y'all are so wrong about that. So many of my friends and I were assumed We wouldn't achieve much and we've done above and beyond that. Presume competence. Our parents often are autistic themselves. Stop limiting us. Give us a robust AAC. Start using sign language from infancy. Multiple modalities of language is so important. Read to us starting in infancy. Presume competence. Let us stim. Let us lime things up. Let us just be ourselves. We communicate fine in our communities. Teach communication skills for being friends with autistic folks to non-autistic children. Teach social skills to non-autistic children about being good friends to us. Teach non-autistic children not to abuse us. Learn our communication styles. We aren't rude. We are direct. Y'all are rude. Y'all have communication issues and beat around the bush. Say what you say mean what you mean. Stop code with us. Give us Robust AAC and sign language right away. Make it fun don't make it work add it to our regular lives. Don't make it separate work. It's language skills you do it while living. Stop stealing our childhoods. Stop abusing us. Abuse meaning everything you're doing now. Stop it. Presume competence. We hear you even when we don't speak. We learn language even if we can't use it through speech. We've learned despite being held back with your 'ages'and denying education. Read publishing works by non speaking folks. Talk to us. If you're making decisions about us make sure we are present. Make sure a majority of us are making the decisions.