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

IACC
INTERAGENCY AUTISM
COORDINATING COMMITTEE

Public Comments

April 4, 2023

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Oral Public Comments

Geraldine Dawson, Ph.D.

Members of the Interagency Autism Coordinating Committee:

I am writing to draw your attention to a proposal by the Accreditation Council for Graduate Medical Education (ACGME) to make two changes to the requirements for pediatric resident training that would negatively impact the care of autistic patients and their families. The proposed changes can be found at https://www.acgme.org/globalassets/pfassets/reviewandcomment/320_pediatrics_rc_022023.pdf.

The first change - II.B.1).e. (p.15 of the document) would remove the current requirement to have a Developmental-Behavioral Pediatrician (among other subspecialists) on the faculty of the residency program.

The second change - IV.C.6.g).(2) (p.39 of the document) would remove the current requirement for ensuring "adequate" exposure to the spectrum of normal development, and the longitudinal care of children with special healthcare needs.

The U.S. healthcare system is currently inadequate for meeting the healthcare needs of autistic individuals. The primary care pediatrician plays a crucial role in autism screening, referral for diagnosis, and addressing the substantial health-related challenges associated with autism, including increased neurological, ophthalmological, and gastrointestinal problems. Primary care pediatricians are the medical home for autistic children and the entry point for early detection and referral for evaluation and behavioral and physical health services. Thus, medical training about patients with autism and other neurodevelopmental conditions is essential for our future medical workforce. Research has documented the substantial impact of co-occurring medical conditions on the quality of life for autistic individuals and the important role of medical training in addressing the complex healthcare needs of autistic patients.

Removing the requirement to provide adequate exposure to patients with neurodevelopmental conditions and other special healthcare needs during medical training would represent a significant step backward from reaching the goal of meeting the healthcare needs of autistic individuals, with significant long-term consequences on health, quality of life, and mortality in adulthood. As the national body that oversees research, services, and policy related to improving the quality of life for autistic individuals, I urge the IACC to provide comments to the ACGME about this proposal, which can be submitted directly to the ACGME at https://www.acgme.org/review-and-comment/320---pediatrics---major-revision/. The deadline for submission of comments is April 5, 2023.

Miya Asato, M.D.

With regards to Section II.B.1.e). Subspecialty Faculty, the removal of the requirement to have a developmental-behavioral pediatrician (DBPed) as part of training faculty is a reflection of shifting needs of pediatricians to be able to address more psychiatric issues than ever before and due to the shortages of DBPed faculty on the national level.

The essence of pediatrics residency training is to understand and treat the physical, emotional, and developmental needs of children from birth to the transition to adult care. Without understanding the template of what is within the range of "typical", there will be a *fundamental shift* in what pediatricians know about child development and may consequently impact the developmental health of generations of future children.

Pediatricians play the crucial role of being the gatekeepers. Without being trained what to look for as signs of autism, intellectual disability, and other disorders in the *context of pediatric outpatient settings* – pediatricians will continue to feel uncomfortable about developmental issues. This is already a problem across pediatricians and pediatric specialists. By diminishing the central focus of the pediatric resident training month in DBP and shift to other professionals to carry the curriculum may unintentionally create a generation of pediatricians who are unprepared for their important future role in developmental supervision. Without requiring DBPed physician role models as teachers, the positions for fellowships will continue to remain unfilled and will impact the teaching workforce.

When physicians are uncomfortable with what is being asked of them, they will refer to other professionals. Currently when a pediatrician is concerned that a child is delayed or may have a disorder such as autism, they refer to DBPed or other neurodevelopmental physicians. If they do not understand what DBPed physicians do or if there is not a workforce available, the referral pattern will shift to other professions who may be unprepared for this change. By shifting this role to others, this will add to already long wait times and may increase the age of diagnosis of ASD, and delay start of services. It is important to note that some of the alternate professions mentioned in the ACMGE document are not trained in typical development, and may have unawareness of the complexities of various pediatric diseases which may alter developmental trajectories. Children with medical complexity and their families need the combined expertise of pediatric physicians and developmental knowledge of DBPed or other neurodevelopmental specialists. Comprehensive programs, such as Down Syndrome centers are often led by DBPed physicians which provide a medical home and provide care supervision and management. These centers play important roles in forging pathways and standards of care for transition to adult systems, which remain a significant need for young adults with complex needs.

The workforce available to address parents' concerns around development is already at a crisis point. If pediatricians do not receive adequate training in understanding the complex needs of childhood disabilities, it is possible that the limited services and supports children currently receive may be under further peril due to limited understanding of the chronicity and extent of services children with disabilities need in medical and community settings.

I urge the Interagency Autism Coordinating Committee to express concerns about this change in pediatric training and consider advocacy for additional mechanisms such as federal and state funding to support existing clinics to identify and treat children at risk for developmental disorders. Developmental clinics do not fare well in terms of hospital-based economic metrics, so consideration of joint funding resources should be considered as a potential mechanism to support developmentally focused care.

Anthony J. Tucci, L.L.M., E.S.Q., C.P.A.

Thank you to the entire IACC for allowing me the opportunity to submit written comments. I am a parent of a 19-year-old son who has autism and is a non-speaker. I am also the executive director of Autism Awareness and Support Foundation a 501(c)(3) organization that has sought to advocate for autism awareness and support services.

My brief comments include the following concerns and/or recommendations:

I. **We need more research and NIH workshops that promote effective interventions to address the unique language and communication challenges of individuals with autism.**

The lack of sufficient research delays the finding of required insight related to communication challenges of children with ASD, delays effective interventions, and also delays indentifying prior research findings that may be inconsistent with newer scientific findings. Dr. Tager-Flushberg and Dr. Connie Kasari in their 2013 article entitled “Minimally verbal school-aged children with autism spectrum disorder: the neglected end of the spectrum” recognized the need for this important research (Autism Research 2013 468-478). I am hopeful that IACC will continue to play a key role in promoting and facilitating this vital research. It is of utmost importance that continued research continue to be performed to confirm that non-speakers with ASD can learn and achieve high literacy scores and robust communication development skills from interacting in the environment, without formal, guided instructions.

The recent January 2023 NIDCD conference entitled "Minimally Verbal/Non-Speaking Individuals with Autism: Research Directions for Interventions to Promote Language and Communication" is a great illustration of the type of workshops that are essential to explore the research needs of this population. I am hopeful these types of workshops will be replicated on an ongoing basis.

II. **The research direction for interventions that promote language and communication should be led by an independent and qualified team of multi-disciplinary experts.**

The Autism CARES Act of 2014 brought attention to the need to expand research and improve coordination among all NIH agencies that fund ASD research. The same logic which compelled coordination of agencies should hopefully highlight the value of applying a coordinated approach to research conducted by a team of multi-disciplinary experts best suited to address the unique and widely unknown challenges related to communication disorders of individuals with ASD. Research that seeks to promote effective language and communication must begin with a commitment to a best practice methodology that is rooted in integrity and wisdom. To foster and help promote independent and robust scientific research, this research should be undertaken by a team of multi-disciplinary experts who are able to offer competent and informed knowledge with respect to the unique language and communication challenges of individuals with autism. Research involving communication and language for individuals with autism should no longer be conducted via a silo approach of expertise. For example, speech and language experts are likely singularly ill-equipped to explain and analyze the current research and knowledge of the neuroscience involved in complex communication disorders. The National Center for Complementary and Integrative Health (NCCIH), National Institute of Health has offered amazing insight on the value of using a multi-disciplinary integrative medicine team in the treatment of many medical disorders.

Hopefully NCCIH and NIDCD can work collaboratively to identify the most appropriate teams of experts that are qualified to conduct meaningful research that will incorporate the highest level of available relevant knowledge within all fields of medical/health care. I have recently addressed these recommendations via email to these esteemed NIH divisions.

III. A humane and ethical foundation must underlie all applications of evidence-based practice models that seek to apply scientific research for the betterment of individuals with ASD

I am hopeful that the IACC can intervene and offer some form of independent governmental oversight to the unbounded actions of some professional and trade associations that seem to be pursuing a form of misguided advocacy against individuals that seek to merely exercise their human right to select a mode of communication that is effective for them. For example, I have carefully studied all aspects of the S2C controversy, and have sadly witnessed the inappropriate and hurtful conduct of select professionals that oppose it. It is my opinion that this form of misguided advocacy violates the human dignity of individuals with autism and displays a grave example of science and its greatest discontents. Professionals and trade associations serving individuals with autism would be well advised to recognize that their singular knowledge and experience as speech and language experts, ABA providers, etc. represent, at best, single spokes on a large wheel of unknowns. It is my opinion that the IACC goals for meaningful and accelerated scientific progress can only be achieved if all researchers and professionals work collaboratively with an open mind to learn from one another.

I respectfully request that the IACC seek to intervene to help ensure that all governmental agencies, educational programs, clinical practitioners, and relevant trade associations seek to implement evidence-based practice mandates in a manner which does not serve to undermine the human rights, ethical rights, and legal rights of minimally verbal/non-speaking individuals with autism. Human rights, equitable rights and civil rights must lead a proper application of the evidence-based practice model for all interventions aimed to promote language and communication for individuals with ASD.

The communication challenges of non-speakers should never fall victim to unreasonable turf wars between professionals and experts that have opposing views. Moreover, non-speakers should never be condemned for selecting a mode of communication that has proven to be effective for them.

Thank you.

Christopher Banks, M.B.A., M.S., Autism Society of America

Thank you for allowing me to speak before the IACC today. My name is Christopher Banks. I am the President and CEO of the Autism Society of America.

This April, the Autism Society of America is proud to continue its fifth annual “Celebrate Differences” campaign in honor of Autism Acceptance Month. Every day, we work to create connections, empowering everyone in the Autism community to live fully. We believe that acceptance is creating a world where everyone in the Autism community is connected to the support they need when they need it. And by everyone, we mean every unique individual: the implacable, inimitable, and irreplaceable you.

Today, I would like to share with you an overview of our health equity work and highlight our programmatic impact around accessible vaccination. Health equity is the foundation for a healthy life.

The Autism community faces unique barriers to accessible care, resulting in healthcare inequities which are exacerbated by social and economic factors. These inequities can result in differences in length and quality of life, disease rates, access to treatment, disability, and death. Too often, these barriers to care are viewed as patient barriers, when in fact, they are environmental, resource, training, and systems barriers - all which contribute to trust barriers. To realize health equity, we must work together to reduce these barriers and create accessible solutions.

In 2021, the Autism Society received funding from the CDC through a subgrant from the AUCD to address vaccine hesitancy - a longstanding issue within the Autism community that has been perpetuated by access barriers and trust barriers. The Autism Society developed its Vaccine Education Initiative, or VEI to advance health equity through a focus on education, confidence, and accessibility. The VEI is a tailored public health model that reduces barriers to vaccination faced by the Autism community by supporting Autistic individuals, their families and caregivers, and their healthcare providers and systems. We piloted the VEI with 12 of our affiliates, which allowed us to learn from our community, identify best practices, train professionals, and support individuals and families for an improved vaccine experience.

Through this work, we have an opportunity to impact lasting change, by:

- Promoting vaccine education within the Autism and disability community so that all individuals, families, and caregivers are empowered with the knowledge they need to make informed decisions
- Equipping healthcare providers with the training and resources they need to meet the unique and diverse healthcare needs in the Autism Community - which supports universal accessibility
- Creating community connections that lead to improved patient-provider confidence, communication, interaction, and outcomes

We are happy to report that earlier this year we received additional funding through the Administration for Community Living working with US Aging that will allow us to expand the VEI program within our network of approximately 70 affiliates in 34 states.

In the greater scope of our health equity focus, our policy work is currently spotlighting the crisis of understaffed and underpaid direct support professionals, inequitable access to home and community-based services, and systemic employment barriers among many other policy priorities that impact Autistic Americans. As you recall, Joe Joyce provided remarks at the previous meeting of this group on the crisis in our services system. We will continue through our public policy efforts and our national programs to address the needs of people with Autism in the community. Other areas of health equity in which the Autism Society is working include mental health, suicide prevention, and law enforcement and first responder training.

Lastly, I want to briefly echo the concerns regarding the issue of training for medical professionals to work with people with Autism. Improved training for healthcare professionals is a core area of need that has emerged from our health equity work. As others have mentioned, the recent changes in Pediatric Residency education proposed by the Accreditation Council for Graduate Medical Education (ACGME) will result in even fewer developmental pediatricians with the ability to screen, diagnose, and support individuals with Autism and other disabilities to achieve their full health potential. The Autism Society of America will be providing comments to oppose these changes.

Stakeholders have until April 5th to provide feedback on the proposal and hopefully bring about a course correction.

During Autism Acceptance Month, the Autism Society of America will be highlighting its work and impact to ensure accessible experiences in healthcare and other social determinants of health.

Thank you for allowing me to cover this important topic today.

Idil Abdull

Adults with Autism & Nonverbal/Minimally Speaking Individuals with Autism

Dear Mr. Chair and Members, my name is Idil Abdull; I am a Somali Autism Mom and retiring advocate. First, I want to thank Dr. Daniels for her support and guidance in the Somali autism community in Minnesota as well as all autism families across the nation.

I was lucky enough to be part of IACC almost a decade ago now, how time flies. We made a lot of progress back then and you all on the current committee have made even more progress. However, there are two areas that I believe we still need more work and support.

Let me start with adult services. My son is now twenty years old; he will be twenty-one in July of this year. There are almost no services for adults with autism in Minnesota and nationwide. Our children grow and become adults, but we as a nation are not ready for them. The system is simply not set up for adults with autism from employment to housing, to safety, and in between. One of my biggest worries is who will care for my son when I am no longer here.

I want to ask IACC members, particularly the federal agencies that oversee adult services to concentrate more on not just research, but on services and support for adults with autism. They will need housing that is person-centered and culturally responsive, and employment that is fulfilling and rewarding. They will also need to be safe in their communities including with law enforcement. We must make sure adults with autism are able to live and work safely in their communities with dignity and respect.
My second request is about the ability to communicate. As you may have heard, Somalis are an oral society. Sadly, most of our children, including my son, have nonverbal autism. In other words, autism is silencing a nation of poets who are known for their oral communication. I thank Dr. Kasari at UCLA and Dr. Helen at Boston University. We need more research into this area, particularly teaching our kids the ability to communicate from their hearts and minds via spelling. I think PECS is fine, but those are pictures and do not give our kids the ability to communicate their true needs and wants. It is a limited system.

I ask IACC to raise awareness of the spell to communicate method, to have insurance companies and Medicaid coverage, and to ensure we are giving every individual with autism the opportunity to be able to tell and say what they want, what they need, what they are thinking, and tell us their dreams.
I would give every organ in my body for my son to be able to speak orally. It is my hope that one day (God Willing) he will tell me his thoughts, wants, and needs. I would love to ask him and have him answer me why he likes to listen to 70's music such as the song – ooh child, things are gonna get easier while we are in the car and Bette Midler when we are traveling out of state. You see Mr. Chair and Members, individuals with nonverbal autism are smart, funny, thoughtful, and want to live a happy, healthy, and safe life just like all of us do. I ask IACC to tackle these incredibly important issues.

Mariam Egal

Challenges Parents are Faced with

I am a Somali elderly with a 25 years old young adult with an undiagnosed behavioral condition.

- On top of the list, I will say point blank racism/discrimination. Most service providers are not culturally inclined and tend to ignore communities other than the Caucasian community.
- Poverty, large household members, lack of knowledge of existing services and supports, single parent household with no family and community supports, ….this can go on and on!
- Lack of funding for grassroots community-based organizations that already provide culturally responsive services and supports to their perspective communities. Most funding goes to mainstream organizations that don't provide culturally responsive services.
- Lack of services for young autistic adults, no post-secondary educational institutions, and no adult day services available in Minnesota!
- Undiagnosed young autistics with no services and supports and pose a behavioral challenge to their care givers. No safety net!
- Housing poses a great problem for large families of individuals with special needs. Landlords tend to evacuate such tenants. No were to go!
- Undiagnosed mental health issues that goes untreated. Parents and siblings tend to manifest signs of depression, anxiety, chronic diseases, and other relating issues that are not a priority until it is too late.

Recommendations

- Resources and fundings targeting community-based grassroots organizations of parents with individuals with autism. These organizations thrive without funds and are doing astronomical community engagement activities in a culturally and linguistically appropriate manner.
- Change our communication strategies. It is not a one size fits all. Be mindful of culturally and linguistically appropriate communication strategies. Oral versus written, English vs other languages, through what channels…and more.
- Diversity our work force, be inclusive of minority communities, those with cultural and linguistic barriers, in particular. Incentivize scholarships, to recruit minority youth from these communities, in the area of Mental and Behavioral Health.
- Research in causation, addressing the request of the Somali Parents of individuals with autism in Minnesota, which by the way have the highest prevalence rate of autism coupled with Intellectual Disability ID.

References

Studies

Hewitt et al. (2013). Minneapolis Somali Autism Spectrum Disorder Prevalence Project. Retrieved from: **http://rtc.umn.edu/autism/**

Mcalpine et al. (2014). A qualitative study of families of children with Autism in the Somali community: comparing the experiences of immigrant groups. Report for the Minnesota Department of Health. Accessed from: **https://www.leg.mn.gov/docs/2014/mandated/140404.pdf**

https://addm.umn.edu/htb

Written Public Comments

Research and Service Needs, Resources, and Policy Implications

Hilary Martin

My name is Hilary Martin. I would like to talk to you today about autism research. I think that the IACC should tell the government to fund more research about sleep difficulties in autistic people, and digestive difficulties in autistic people.

Many autistic people, myself included, have challenges with sleep, whether getting to sleep, staying asleep, or getting adequate sleep. Many autistic people also seem to need significantly less or more sleep than most neurotypical people. This is also true for me--I seem to need much more sleep than most people I know. Many autistic people I know need much less sleep, sometimes only 3 or 4 hours a night. However, there is little if any research into why this is the case. By funding studies to find the cause of these sleep differences, researchers could also find ways to help autistic people get the sleep we need. This research could also help us better understand how autistic brains work.

Many autistic people also have digestive difficulties, such as IBS. Again, this is a poorly researched area. Figuring out why there is so much co-occurrence of gut problems with autism could help researchers find better ways to help autistics deal with those issues.

Most important is that the IACC listen to autistic people about where we wish to see research dollars go. The areas I discussed above are both areas of interest for many autistic people. Conducting research into sleep difficulties and gut problems in autistic people would help solve problems autistic people have, so that we can live the lives we want.

JL Angell

Right now, research funding on autism still disproportionately focuses on behavioral therapies, biomedical studies, and causation and “prevention.” Research priorities should reflect what the autistic community needs and wants.

Trigger warning: The following comment contains references to conversion therapy.

Kevin Hintzman

Hello to all. I run a series of 4 Federally Qualified Health Clinics in Northwest Indiana. We offer primary care along with behavioral healthcare both within our clinics and also within local schools. As someone close to an Autistic Person, I would like to advocate for 2 areas of focus. First, more research into the area of increasing the functionality of Autistic Adults through the use of psychedelic medicine seems quite promising. Additionally, ABA therapy is the half-sibling of Gay Conversion therapy. Why is this still the gold standard of care? Why aren't there adult-focused treatment options? I call for ABA alternatives to be studied and developed.

Robert Hackl-Blumstein

As an autistic adult, I support prioritizing research on support mechanisms that can improve autistic people's quality of life. While I believe that understanding autism from the perspective of neurology, genetics, and more has scientific value, these should be deprioritized by the committee, as they do not directly benefit autistic people and could even be used in harmful ways. Further, studies involving therapies with the reported goal of minimizing autistic traits should not receive support.

Marylyle McCue

Good Autistic research is based on the needs AND wants of the Autistic community. Research should most of all benefit the ENTIRE Autistic community. This includes children AND adults; ALL races and ethnicities; male, female, AND non-binary individuals; those with high, medium, AND low support needs; intellectually disabled autistics; etc. It does not try to make Autistic people act less Autistic for the comfort of non-Autistics. Behaviorism only looks at behavior and not at what is causing the behavior or what needs are not being met. Behavior is communication. All methods of communication should be a prime topic of research. This will help the Autistic community better advocate for itself.

Tosha Brothers

I want to preface that this is all understanding from my privileged, neurotypical-passing autistic experience.

Autism is, by definition, a different brain structure from neurotypical. However, there is one thing that makes our brains so interesting, and that is the length of our neurons. We are often seen taking too long to think about things and derailing conversations with our delayed thoughts. This is because we are drawn in by the natural processes of our brain to think about things more deeply and insightfully than the average person. Despite what it seems on the surface, we are not being slow. What happens behind our eyes is more complicated than it may initially seem.

The language in these studies I've provided is very ableist and curative based. Here's hoping future studies will alleviate that. If the researchers looked past their blatant hatred of autistic people, they would find that having long connections is the reason for our incredible abilities. I would like to suggest that extra neurons in the cortex, the area responsible for creating reality, as a good thing that helps the brain have a deeper, more complex sensory experience of life through an endless myriad of mental mechanisms and combinations. Qualia the likes of which cannot be accessed by a typical brain structure under normal circumstances. These studies tend to downplay the profundity of our experience. What if the recipient knew how to work with and control these extra neuronal connections to their advantage? That would give them a huge leg up in observing the true nature of reality as we know it?Aka, more sentience, which is seen in my case.

One study showcases more grey matter and the number of neurons as well. So what's wrong with being smarter while having longer neurons? There is no harm in extended memory, accelerated learning ability, and more sentience than what's considered normal. If you could bottle up and sell extra grey matter, people would gladly take it and call it a miracle product. But when it's from autistic people, it's seen as taboo? Why?

Functioning presents differently for each autistic. Not everyone can utilize the extra connections, as it can be a tremendous undertaking. The individual's self-esteem and perception also play a role. Although some abilities heighten, others are traded to make way for them. So there are definite disadvantages that can arise from this area of the brain being so malleable. For example, I have a talent for words. But also problems with math past fourth-grade level. That's why there's a dropoff in capabilities after some time because autistic people who perform well early on lack supports in school going into adulthood. However, there are no other challenges present in my experience. I am aware this makes me part of a privileged few. As such, unlike popular belief, autism is not immediately synonymous with brain damage and mental problems.

As for what these studies propose as "treatment," my quality of life decreased with clear-cut neurons. Even though I present as more neurotypical, I am missing out on my unique language and can't access emotions and knowledge as much as I should, which I had a full range of before. While it may be normal for neurons to prune themselves in neurotypicals, it is also normal for autistic neurons to grow indefinitely. These studies are simply instruments with which to illustrate my point. We have these connections, and they have, conversely, demonstrated themselves to be benevolent.

And, after all, is making one more neurotypical passing curing them? Not exactly. Where do we draw the line? Consent. We must always lead with the will of the autistic individual and what they wish to do with their lives. Our ultimate goal should always be to improve the outcomes of autistic people. Part of doing that is understanding what we experience through our lens. What can be seen by autistics is seen by neurotypicals, too, in particular circumstances. Those things include turbulence, waves, polarized light, and particles, to name a few. I saw them all sober while I had heightened nerves from anxiety. Most neurotypicals only see these things while high.

Visions of this nature are also caused by the length of our neurons extending outward infinitely. To describe it, it is like a warm rush of information cascading over the temples. First, there's a pull; then, it envelops the senses. The expanse is like an echo that floats and duplicates in zero gravity. Finally, the scene turns shiny, blending every sense into one. This is the art of the brain forming its reality. It is, above all, sacred. But to be frank, what is usually lacking is consideration or basic respect when conversing about autism.

People also widely disregard that the brain has sentience of its own, adding complexity to the equation. It has its impressions of experiences, needs, etc. And I do not know if this is the case for others, as everyone's brain responds differently to reality. I imprint inwardly, and my ADHD grandmother processes outwardly. There is no certainty that every experience is like mine, and I can't assume. The brain also has a built-in ability to stabilize itself. It is, indeed, something to talk about with respect.

The researchers in this study think autism equals bad. That is why I want more studies done that learn about autism with impartiality. So there are no obvious mistakes made in observation like this again. I admire autism acceptance as a concept because I alleviated my anxiety by loving and accepting it. If I had demonized it, I would still have severe anxiety. People tend to get carried away with the medical model of autism. But it is not the whole story.

As one last addendum, I also request to the IACC that these studies be human ones instead of those involved with animal testing. It is a more accurate and straightforward methodology. Otherwise, I hope I did autism justice.

https://www.cell.com/neuron/fulltext/S0896-6273 https://jamanetwork.com/journals/jama/fullarticle/1104609

https://i.pinimg.com/originals/f6/b1/2a/f6b12a781179c3f7a960682662131bd9.jpg

Trigger warning: The following comment contains references to suicide.

Elizabeth Carey

as a late diagnosed autistic, female, I truly believe that more research and funding needs to be allocated to the level one/"low support needs" autistics, whom there are very few resources for other than community boards and Facebook groups. Many of the late diagnosed adults, still struggle and really need support, but there are really few resources out there for us. our struggles are usually hidden under anxiety, depression, and other mental health issues that are not addressed from the artistic end

In addition, I believe that specifically for Female autistic's that have their period and or will have perimenopause and menopause I think it's incredibly important to focus research on how menopause affects the female autistic population. There's an incredible gap in research related to autism and menopause and perimenopause experts, that I've talked to believe said that because Autism hasn't been as prevalent, and only now are female autistic folks being diagnosed at a higher rate.

Very basic information about menopause shows that there's a drastic change in mental health status, suicidal ideations, and change in sensory processing and if that's true for Neurotypical's in the anecdotal evidence I have in the groups for autistics females with menopause it seems that the symptoms are significantly more prominent. I'm very concerned about the mental health aspects of it since there seems to be in general issues with menopause and suicide ideation.

I read somewhere that the stats on females who commit suicide are very high in the age group that is associated with peri & menopause. And since people with autism have a higher suicide risk to begin with I think this is very important thing to research so that we can get the support that our community needs at all needs levels.

Sameena Flinner

I'm Sameena Flinner and I am a current undergraduate at USM with a major in psychology. Throughout my studies and classwork, I have often written papers where I had the option to choose the topic of discussion. Nearly every single time, I would choose the topic of autism, as I am autistic with the intention of my future research in my further education to be focused on autism. While researching autism, I have found that numerous articles focus on possible future preventions and possible "cures" of autism. Of course, I acknowledge that this is not all of research, I have found some fantastic anti-eugenics, and anti-ableism research studies in my time. However, it seems like a disproportionate amount of funding goes to looking into possible preventions and cures of autism.

My recommendation for where funding for autism research should go is to look into why females have a significantly higher percentage of going under-diagnosed and late-diagnosed compared to males. In addition to this, I also think research should go into how can we adjust the criteria or diagnostic tools, so that autistic females can have a better likelihood of being diagnosed in early childhood, just like autistic men are.

I also believe that Intersectionality should be a bigger factor that is accounted for when conducting autism research. Women, LGBTQ+ individuals, and BIPOC have unique experiences in life that may impact them differently when they are also autistic, and I believe that this should be more looked into.

Overall, I believe research efforts and fundings should focus more as to how we can further help autistic individuals rather than try to figure out what is abnormal about them.

Charlotte and Trudy Dier-Chacon

Part 4: What does good autism
research look like?
25 Words to Know in
Part 4
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Communication
How we show others what we want and
need. Research A way that people learn new things about the world. Research happens when people try to answer questions or solve problems.
Researchers
People who do research as their job.
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What does good autism
research look like?
There are many things we think autism
researchers should focus on.
But these are the main things we think are important.
These ideas are a good start to figuring out what good autism research looks like.
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Good autism research focuses on all
autistic people.
That means research should get done
about autistic kids and adults.
Most autism research gets done just about autistic kids.
But autistic kids grow up into autistic
adults.
It’s important to do research about autistic adults, too.
29
Most autism research has only studied
white autistic people.
Most autism research also only studied
boys and men.
A lot of autism studies leave out people with intellectual disabilities.
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We need more research about autistic
people of color.
We need more research about autistic
women and non-binary people.
We need more research about autistic
people with intellectual disabilities.
We need to make sure people from
these groups have their voices heard in
research.
That is the only way we can know how to
help all autistic people.
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Good autism research focuses on all kinds of communication.
Communication is how we show others
what we want and need.
All autistic people communicate.
But some autistic people talk with our
mouths. Other autistic people don’t.
Some of us use words, while others don’t.
32
Most autism research about
communication focuses on talking with
our mouths.
It tries to make all autistic people talk with our mouths.
But we shouldn’t have to talk with our
mouths to get what we need.
Autism research should help us
communicate the ways that work best for
us.
It should focus on ways to communicate
besides using our mouths.
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Good research listens to autistic voices.
Good non-autistic researchers work with
autistic community members.
They help autistic people do research
ourselves.
They let autistic people decide how
research projects get done.
34
Most of all, good research focuses on what autistic people want.
We want help fixing other health problems we have.
For example, sleep problems or stomach
problems.
We want help living in our communities.
We want help getting the services we
need.
35

We want help going to school and getting jobs.
But most autism research doesn't focus on what autistic people want.
It focuses on trying to cure autism.
It focuses on trying to find out what causes autism.
It focuses on trying to make autistic people seem 'less autistic'.
36
Good autism research doesn't focus on
trying to 'cure' autism.
Researching a cure for autism hurts
autistic people.
It shows that researchers don't want to
accept us for who we are.
It makes us feel bad for being autistic.
37
Other research tries to make autistic
people seem 'less autistic'.
These research projects hurt autistic
people.
They punish autistic people for being
autistic.
They make autistic people scared to show we are autistic.
These projects don't make us 'less
Autistic'.
38
They just make us pretend to not be
autistic.
That hurts autistic people.
We should get to be who we are.
39
Autism is an important part of who we are.
We don't want to be cured. We don't want to be 'less autistic'.
And trying to cure us doesn't help us live our lives now.
It just takes money away from research
that can help us.

Megan Hrach

My name is Megan Hrach, and I have some thoughts on how autism research can be improved. I believe that autism research should prioritize enhancing quality of life for people on the spectrum, rather than seeking to cure or mask their autistic traits. I would like to see greater funding for research that examines quality of life of autistic adults. Additionally, I believe it is important to fund more studies that center on the experiences of autistic women, and explore how symptoms may manifest differently in female children. It is concerning that autistic girls are often diagnosed later than autistic boys, leading to a delay in necessary support. As someone with a loved one on the spectrum, I want to see research that will help the autistic community.

Emily DeFour

As an AuDHD (Autistic and ADHD) woman, I would like to see less research into causes, prevention, and pointed fingers. We need more research into helpful accommodations, especially for children in school and autistic adults. A large percentage of autistic adults are either unemployed or chronically in a state of burnout and fight or flight if they are employed. This is due to a lack of accommodations, a lack of u derstanding, and a largely neurotypically-based world. Neurodivergent people have been told that they need to change at the expense of their well-being, when in reality living in an NT world hurts us (whether we receive therapy or not). There needs to be less focus on how we can be changed to suit those who are not autistic and more focus on how we, as autistic people, can live comfortably without constantly being in crisis.

Megan McLaughlin

I would urge the IACC to prioritize research of value to autistic people in their everyday lives. That means research on better physical and mental health care, the lessening of discrimination, housing and employment opportunities, and similar subjects. Research on the genetic roots of autism and on ways to make people appear less autistic are undoubtedly fascinating to the researchers concerned, but have no real benefits for autistics themselves.
I am writing this as the mother of a brilliant, empathetic, hard-working autistic woman who is studying to become a social worker.

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

Kim-Loi Mergenthaler

I would like to advocate for more research into the following priorities:

-Trauma and past harms from ABA
-Long-term mental health outcomes of autistic people who have undergone ABA -Alternatives to ABA -Suicide in autistic people -Autistic burnout -How to reduce barriers to adult diagnosis -Employment supports for autistic adults -College supports for autistic young adults -Executive functioning supports -Supports for autistic parents

George Sumner

I don't think we should do any research. Autistics don't need anymore research, we need the world to be more accommodating and understanding. If you don't do this kind of extensive research for Neurotypicals, why do it for Autistics? We are just a Neurotype after all. Autism is just a difference and a needed one at that. What are you going to do with research? Does it change our quality of life one iota? Research, for me as an Autistic, is offensive. It is like a procrastination, redirecting your attention to anything but the real problem and that is society.

Whitney Geertsen

We need to fund studies that the Autistic community such as myself need and want, not studies that professionals and parents think are needed. Important topics that need research are:
Autism and Homelessness.
Nonspeaking communication.
Mental Health access and disparities in the Autistic community especially for those who are nonspeaking and or have intellectual disabilities. Also for people of color and those who are LGBTQIA LGBTQIA and Autism Access to Comprehensive, Inclusive, and Consent based Sex Ed.
Autistic parents
Quality of Living
Physical Health disparities and access to physical health care.
Suicide Prevention.
Access and barriers to jobs, higher education, and community.
Look at intersection treatment of co-existing conditions including Ehler's Danlos, Mental health problems, other physical problems.
Barriers and accessibility in schools.
Complex PTSD and Autism
Stop funding benefits of ABA studies causal studies. These don't help our community.

Julia Simko

There needs to be more data collected on the number of autistic parents who are under investigation and receive services from the child welfare system. There should be extra emphasis on autistic parents who receive government benefits in this data collection.

Natalie Dowd

Please consider funding studies that explore improving communication between autistic people and their school, work, and healthcare providers. Research is over-focused on prevention and should instead help the communities or people being studied. Pediatric research should involve input from a broad group of adults with autism, especially those who themselves participated in research or had interventions as children.

Shannon Shea

As a mother of an autistic child who is possibly also autistic herself, I care deeply about autism research and the autistic community. Autism research should focus on meeting the needs of all autistic people - including adults (not only children); women, girls, and non-binary people; people of color; and people with intellectual disabilities. It should respect people who are non-verbal or do not use speech as their main form of communication and explore effective alternative communication options. It should focus on the best types of accommodations and resources to improve autistic people's quality of life, rather than being focused on finding "cures" or making people "less autistic." Most of all, it should involve and follow the lead of autistic people themselves rather than non-autistic advocates.

Algernon Lutwak

Speaking as both an autistic person and a medical researcher studying autistic health outcomes, I'd be interested in more funding for research around causes of stress, depression, and burnout in autistic adults, especially those deemed to have low support needs. I'd also be interested in examination of long-term health outcomes, including depression, IBS, MSK disorders, and heart disease, in ABA survivors compared to autistic adults raised without ABA. Finally, more research on accessibility, particularly surrounding sensory sensitivities and communication access/AAC, of healthcare facilities (telehealth, pt contact methods, clinics, hospitals), educational institutions (including universities), law enforcement agencies, courts, and public utilities, would be useful.
Also, less funding needs to go to genetics research. The private nonprofits already disproportionately fund it, and it doesn't improve quality of life for autistic people in the slightest.

M Horowitz

Autism research should reflect what children and adults in the autistic community need.

We need more research about autistic people of color, women, non-binary folks, and other marginalized genders. We also need more research about autistics who have developmental disabilities.

Good autism research listens to autistic people, regardless of their mode of communication. In other words, non-speaking autistics should not have to talk. Autism research should instead focus on helping people communicate in the ways that work best for them.

Good allistic researchers work with autistic community members and empower autistic people to conduct their own research on issues that matter to the autistic community, such as sleep problems, social anxiety, stomach problems, living independently, and obtaining education, employment, and services.

The focus on research to cure autism, find the cause of autism, and make autistic people appear less autistic shows that researchers don't accept autistic people, just as the focus on conversion therapy reflected more about societal prejudices than it did about the needs of LGBT people and actively harmed the people it sought to cure.

Christina Capella

As ASAN outlined in our most recent comments submitted to the IACC, autism research spending remains heavily invested in research of dubious moral and scientific integrity, aimed at preventing autism and forcing autistic children to suppress their autistic traits. Only about 6% of federal autism research spending goes towards research to understand autism across the lifespan and support autistic people to live good lives. The autistic community has been calling attention to this imbalance for years. It is time for the IACC, and the federal government as a whole, to listen. The IACC should use its role as an oversight and coordinating body to change how the federal government funds research, and Congress should use the next reauthorization of the Autism CARES Act to do the same.

Tim J Klaas

Whenever researchers announce a "major breakthrough" in understanding autism, here is how it is received within the adult autistic community: "Yeah, we could've just told them that if they'd asked."

Research on autism without the direct involvement of actual autistics will always miss the mark. We don't need others telling us who we are -- we already know. We also don't need a cure. We need help navigating a world that seems to deliberately hinder us.

River Bradley

I would like to see more research on masking and the effects of masking. For example, is it possible that masking for too long might cause migraines?

I would also like to see more on misdiagnosis, especially for women/afab people.

Christine Preimesberger

Autistic research should devote funds to research about the intersections between race and gender and expressions of autism.

Kate Seader

We need more research on how to best support autistic individuals. Prevention should not be a priority. Increase research on the benefits of AAC devices for non-speaking individuals. Increase research into the long term negative effects of ABA therapy and include autistic adults as your research pool

Steven Bruce

As it is with psychiatric and/or developmental delay disabilities, People With Disabilities Foundation's (PWDF's) mission is through advocacy and education to ensure all people in this population have equal meaningful access throughout society.

For more specific information visit https://www.pwdf.org/resources/ and let us know what areas are of interest to you as PWDF decides on both Education/Public Awareness and Advocacy areas.
This month we filed a lawsuit of an individual obtaining equal meaningful program access to the Social Security Administration's (SSA's) work incentive programs and how an individual can try to work part time to make ends meet but too often ends up as a victimized person based on severe mental or developmental disability who is wrongly either terminated from the SSA's disability program or faces obstacles such as waiting 2 years for his first disability check due to lack of effective communication allowing for equal meaningful program access by affording him reasonable accommodations provided for under Section 504 of the Rehabilitation Act of 1973. See Ibarra v Kijakazi, Commissioner of the SSA, Case 3:23-cv-01037-SI in the Northern District of California.

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

Community treatment"?

There seems to be an assumption that "community" care is better than "institutional" care. I would like to draw some contrasts.

Before Massachusetts closed most of its state hospitals, my autistic nephew was receiving treatment in one. He was in a vocational workshop, the products of which were sold commercially. He earned some pocket money from his work. He had considerable pride in the work he was doing. The staff at the hospital were mostly long term with some training and lots of experience in dealing with the situations and conflicts which arose. My nephew had friends and the hospital also ran support groups for family members.

But then Massachusetts closed most state hospitals, coerced many families to take their adult, disabled children home, and the rest were placed in group homes.

There are many very unhappy stories about the families who took on 24/7 care of disabled adult children with little to no support from the mental health system. Why were often aging parents or single parent homes supposed to be able to cope 24/7 with erstwhile state hospital patients?

My nephew was placed in a group home which has high staff turnover, many staff hired on temporary basis, and most with little to no training. The staff who are good with the clients seem to move on to better jobs before long. The only programming I know of was having the residents coloring for hours a day. My nephew went along with that for a while, even producing some beautiful pictures. But then he couldn't see the point any longer and stopped taking part. As far as I know, there are no community programs that he is involved in

The untrained staff is not good at dealing with the difficulties in communication with the clients, and often resort to calling the police when fighting breaks out, a huge contrast to the state hospital.

Family members are barred from the house, and there is nothing to take the place of the family support groups. My nephew loses clothing, including his winter coat, and his mother sees no alternative to replacing such items. Last winter my nephew developed frost bite on his feet, and quite accidentally, his mother discovered that he had big holes in the soles of his shoes. That would not have happened at the state hospital where the nurses and direct care staff would have seen to it that patients were adequately clothed to go out in cold weather.

In 2021, David Axelrod wrote a Guest Essay for the New York Times entitled "When it Comes to People Like My Daughter, One Size Does Not Fit All", about the pressures to close institutions in favor of group homes in the community. His developmentally disabled daughter is in an institution with wellness facilities and activities as well as other opportunities and activities on and off campus. She has friends and is happy. This article is very thoughtful and details, better than I can, the causes, without blame, and the pros
and cons of the present situation.

I hope that members of the autism community will read David Axelrod's article as well as what I have written about the experiences of my autistic nephew. As far as I can see, my nephew was better off at the state hospital.   If group homes were organized to offer as good services in the community as my nephew   had at the state hospital, and/or connected residents to opportunities in the community, for true transition to the community, I would be better satisfied.   But true transition to the community would involve learning independent living skills.   I haven’t heard of any such programming.

Axelrod, D. (July 4, 2021), THE NEW YORK TIMES, When it Comes to People Like My Daughter, One Size Does Not Fit All.

Donna Murray, Ph.D., CCC-SLP

I am writing to express concern regarding the Accreditation Council for Graduate Medical Education (ACGME) proposed changes to the Pediatric residency requirements. The ACGME is proposing 2 changes that I believe may negatively impact the quality of medical care to autistic children and their families.

Proposed change in requirement **II. B.1 e)**, would change the current requirement for having a Developmental Behavioral Pediatrician (and other specific subspecialties) on faculty.

The second, **IV.C. 6 (2)** would remove the current requirement for ensuring “adequate” exposure to the spectrum of normal development, and the longitudinal care of children with special healthcare needs.

I believe these proposed changes are ill-advised and will negatively and disproportionally impact children with autism. The most recent autism prevalence number of 1 in 36 children, calls for increased education and training in the identification and care for autistic people. Loosening the training requirement for pediatricians at this time is not aligned with efforts to close healthcare disparities. Autistic children already experience healthcare gaps and these changes will likely widen those gaps, particularly those that live in under-resourced communities.

The majority of children with autism are served outside of subspecialty centers and fall under the primary care of pediatricians. Reducing training opportunities for pediatric residents creates barriers in accessing knowledgeable physicians, disproportionately impact those who are unable to access subspecialty care, and potentially delays identification and care.

I hope that IACC will review the ACGME proposal and formally request reconsideration of these changes that will likely increase gaps in care for an already under resourced community of children and families.

Research, Services, and Supports for Adults with Autism

Pamela Alston

How can my state allocate funding to provide inpatient hospital beds for autistic adults in crisis? My son has been hospitalized several times in the past 5 years and each time he is given medication but no real evaluation or assessment of need. Myself and several other families are experiencing this to no avail. Inpatient hospital centers are needed in Maryland as currently there is only one facility for adults and less than 8 beds. When Sheppard Pratt is filled where do our young men and women go? There is also a shortage of workers to provide services so families can get relief and much-deserved breaks.

Daniele Colozzi

Autism being a spectrum, it is very difficult to know exactly how to deal with it! Still, as the mother of an autistic man, I deplore the lack of resources and support that these individuals deserve! Please everybody! If you have a child on the spectrum, write a comment! A lot is done for the younger crowd and that's great, but the adults seem to be left behind! There is no cure for autism, so what will happen to them! It is frightening!

Kaitlin Walker

Too much research is focused on parents, on making autistic kids conform to neurotypical behavior, and on medical intervention or prevention. More research should be done involving autistic adults in order to find out what would help them survive and thrive, medically or with social supports or accessibility changes. Universal design, community integration, professional protections and supports, health concerns, should all be a focus. Autistic adults help parents like me understand our kids.

Nicole Corrado

I am autistic and am finally moving out on my own in my 30s. While there are transition programs to help younger autistic adults move out on their own, there are not many supports for adults over the age of 30 who are moving out for the first time. It can take some individuals more time to find independence, and the supports need to be there for all ages and support needs. There also needs to be support that is the same across jurisdictions, as some may move out of state or province. Some people move out to college, yet others move out on their own for other reasons. There needs to be support for all adults moving out for any reason. This support needs to be for as long as the person requests it, and not be cut off due to age, time constraint, marital status, children, or work. Housing is best near transit and in a neighbourhood or condo/apartment unit that is in the general population. The point of moving out is to integrate into the community.

Inclusion of Autistic Perspectives in Research

AJ Cho

Although I am not autistic myself, I firmly believe that all autistic people should have primary decision-making power in research and everyday affairs, including their healthcare and social/economic support. I urge the IACC to center the opinions and experiences of autistic people in their research, rather than relying on autistic-adjacent people (such as non-autistic/allistic caregivers and family members) to provide input.

Mental Health Research, Services, and Treatment

Anna Lauber

I believe very strongly that accessibility and prevention is incredibly important when treating people with mental illnesses. Having access to information is also critical in order for individuals, families, and their treatment teams to make informed decisions.

In the interest of improving the health and well-being of people experiencing mental illnesses on the Spectrum, I truly believe that research on the topics like comorbidity and intersectionality is incredibly important, particularly in cases where disorders are chronic and/or treatment resistant. People on the Spectrum also require different approaches from neurotypical folks when it comes to treatment for mental illnesses, but also other health concerns. I believe this is an area that has long been ignored.

I would ask that the IACC please consider further consideration into these areas:

Comorbidity between the chronic variations of anxiety and depressive disorders (or others such as PTSD or OCD related disorders) and those on the Autism Spectrum. Are there significant differences in mental health between late diagnosed and early diagnosed? How do treatment outcomes differ when there is a clear indication of what 'normal functioning' for an individual looks like, and are chronic conditions less likely to become treatment resistant? How do the outcomes differ from neurotypical and neurodivergent folks when treating them for similar conditions or with the same methods, and are there ways we can change our treatment standards and systems to accommodate for neurodiversity?

Are there any improvements we can make to the process for late diagnosis of undetected ASD? Ones that would allow people easier access to diagnosis/testing, and catch undiagnosed folks (particularly the less often noticed AFAB folks) more often? Why is it that the tests/diagnosis processes differ so much between disorders like ASD and others that have clear (or more extreme risks and/or potential positive results like antidepressants for example) treatment outlines? Criteria is of course different, but why is it that getting an autism diagnosis requires many more extra appointments, waiting times before getting answers (or access to resources), and less insurance coverage for tests? Or that more often than not, a late autism diagnosis requires a patient to begin the process by asking specifically for it.

I ask that the IACC allocate less resources into the biological causes and treatment of ASD itself. There have been improvements in this area in recent years, but the continued emphasis on these kinds of topics over others that need more attention or have clearer potential benefit is troubling.

I ask that research that has any focus on preventing or 'curing' ASD is not given any funding or support. This approach is harmful to people on the Spectrum (and related conditions), as treatment that attempts to remove Autism or 'autistic traits' from individuals are not only ineffective at doing so in any meaningful way and harmful to the people involved, but are also seen as unethical by those on the spectrum and many close to them. We should be focusing on helping people on the spectrum, and trying to erase their experiences from the healthcare they receive, or trying to find ways to avoid accommodating them by placing the burden of not needing support on them, does not do that.

I have seen changes in the language used by the IACC to refer to people on the Spectrum. It means a lot that there has been a greater push to avoid devaluing or pathologizing people on the Spectrum. I understand the complexities here, but I personally believe that the systems we use around disabilities in general are flawed, and that viewing people through a lens of ability: (especially productivity or ability to 'function' standardized by a neurotypical majority) is harmful to everyone in our neurodiverse world. This mindset can exist alongside realities we experience, and can actually help those who are unable to do things (or unable to do them the same way) as the people around them. Shifting the view here is something that can be done without ignoring the pain we experience or taking away resources or accommodations. Language is important when we try to improve equity.

Jeffrey Slater

Thank you for considering the thoughts of those like me who are directly affected by the research surrounding ASD and healthcare standards.

Research on psychological support for adult autism is sorely lacking. My son’s diagnosis led to discovery of my own autism, but now I find there is very, very little scientifically backed help available. While I am coping decently, I also know my son will one day be an autistic adult with no scientifically-backed support available to him. Please fund research in adult autistic mental health.

Employment

Bob Steinkamp

Subminimum wages. One of my pet peeves is when non-handicapped people want to help those with disabilities they look at an issue as that one size fits all. They forget that when they say let’s pass a law that helps people with disabilities. The subminimum wage is a prime example of this issue. People who have moderate to severe cognitive handicaps, from my 50 plus years working with folks with disabilities, are not interested in how much they make. They are interested in going somewhere to socialize and seeing their friends. What is happening now is that if they make minimum wage they usually work only one day a week when they used to work many days a week. What do most of them do when they are not working? They are sitting at home doing nothing. Is this helping people with disabilities?

The Role of the IACC and the Federal Government

Larkin Taylor-Parker, Autistic Self Advocacy Network

The Autistic Self Advocacy Network appreciates the opportunity to submit comments for the April 4th, 2023 IACC meeting. In our last comments to the IACC, ASAN supported research on communication access and different forms of augmentative and alternative communication for autistic people. We recommended that the IACC support HHS' implementation of the Home and Community Based Services Final Regulation when it goes into effect in March 2023. We updated the IACC on legislation banning the use of electric skin shock for behavior modification to "treat" aggression or self-injury. We asked the IACC to pressure the FDA to pass a new ban without delay.

We now recommend that the IACC advise HHS on its implementation of the Home and Community Based Services Final Regulation (HCBS Settings Rule). The HCBS Settings Rule lays out the minimum standards for home and community based services providers. The HCBS Settings Rule is in effect. We also recommend that the IACC advise HHS to protect HCBS funding and funding for Medicaid. HCBS and other services provided by Medicaid are vitally important for millions of people. There have been calls in Congress to freeze and remove Medicaid funding. Finally, we urge the IACC to notify the public about, and share accessible resources describing, the end of the COVID-19 public health emergency (PHE). Many government programs protecting the most marginalized individuals will end after the PHE is declared to be over. These individuals will need information and guidance on what to do to protect themselves and their rights, as well as how to obtain replacement funding for any services they lose.

Promotion of Full Compliance with HCBS Settings Rule

The Home and Community Based Services Final Regulation (herein referred to as the HCBS Settings Rule or the Rule) went into effect on March 17, 2023. The HCBS Settings Rule sets minimum standards for what a setting must do to be considered truly home and community based and not just an institution by any other name. We urge the IACC to promote full compliance with the HCBS Settings Rule.

The HCBS Settings Rule will have a marked impact on the lives of many autistic people who receive HCBS, as well as people with disabilities who receive HCBS more generally. The Rule sets basic standards for what kinds of protections and rights service providers must provide to their clients with disabilities. For instance, people who receive HCBS in residential settings (such as group homes or assisted living facilities) must have basic privacy rights, such as: controlling who can come into their bedroom or living space, having a key to their bedroom or living space, and being able to lock the door to their bedroom or living space. All people who receive HCBS have the right to respect and privacy, and the right to be free of restraint and seclusion. These are basic rights that most people without disabilities take for granted. These are basic rights that are currently being denied to many people with disabilities who receive HCBS.

States and service providers have had nine years to come into compliance with the Rule. There were multiple postponements of the Rule going into effect. HHS also included allowances for states to not implement all the parts of the Rule right away, so long as they have filed a Corrective Action Plan with the Centers for Medicare and Medicaid Services (CMS). Nine years is more than enough time for states and service providers to come into compliance with the Rule. We therefore recommend that the IACC advise HHS to pursue strong enforcement and oversight of the Rule's provisions.

Protecting Home and Community Based Services and Medicaid Funding

In his second State of the Union address, President Biden called for protecting Medicare in Social Security, but not Medicaid. Medicaid funding is vital for many autistic people, as well as people with other disabilities, to receive health care services. ASAN is concerned that multiple legislators have mentioned potential cuts to Medicaid. We call on the IACC to advise HHS to support full funding for Medicaid.

While Medicaid is a state run program, the federal government can still prioritize Medicaid access. Medicaid funding goes to support workers who provide people with disabilities home and community based services (HCBS). The IACC's recommendations for autism research on which services and supports are most effective will be empty recommendations if federal funding for those services and supports is limited. ASAN urges the IACC to advise HHS to support robust Medicaid funding.

Research has shown that Medicaid, and especially HCBS, improve health outcomes and reduce health disparities in autistic people. Improving health outcomes and reducing disparities are both core goals of the research IACC directs. IACC itself has highlighted research on the impact of LTSS (likely, Medicaid-funded LTSS) on autistic people in the past. An expanded coverage gap could have devastating consequences for individuals who need HCBS and would slow the pace of innovation in autism research. We call upon the IACC to communicate the importance of Medicaid funding for HCBS to HHS.

COVID-19 Public Health Emergency (PHE) Unwinding

The Biden Administration announced on January 30, 2023 that it would end the public health emergency declaration on May 11, 2023. The emergency declaration which has been in place for over 3 years, gave the federal government flexibility to waive or modify certain requirements in a range of areas, including in the Medicare, Medicaid, and CHIP programs, and in private health insurance, as well as to allow for the authorization of medical countermeasures and to provide liability immunity to providers who administer services, among other things.

Congress, in turn, passed several pieces of legislation, including the Families First Coronavirus Response Act (FFCRA), the Coronavirus Aid, Relief, and Economic Security (CARES) Act, the American Rescue Plan Act (ARPA), the Inflation Reduction Act (IRA), and the Consolidated Appropriations Act, 2023 (CAA), that provided additional flexibilities tied to the public health emergency and/or the national emergency declarations emergency declarations. These flexibilities are set to expire when the emergency declarations are over. The IACC can support people with disabilities by sharing information on the end of the PHE.

Some of these changes include higher costs for COVID tests, the end of government funding for COVID vaccines, tests, or treatments (if Congress does not make more funding available, and the end to continuous enrollment for Medicaid enrollees on March 31, 2023 - this means that some states can begin disenrolling people from Medicaid as early as April 1, 2023. We recommend that the IACC communicate these changes both to the broader public and to autistic people and our families. The IACC could use its website, which acts as a central repository and directory for both the IACC's work and autism research, to share one-pagers and technical assistance on the end of the PHE to the public, as it does on other subjects related to autism. We additionally encourage the IACC to prioritize the impacts of the PHE unwinding on autistic individuals in future study and closely monitor the impacts the unwinding has on access to services and supports for members of our community.

We again thank the IACC for inviting interested stakeholders to comment and help the IACC direct the future of autism research. For more information on ASAN and the autistic community's research priorities, please contact Larkin Taylor-Parker, our Legal Director, at ltaylorparker@autisticadvocacy.org.

Concerns About Medical Practices

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

Medical Error

Use of a clamp on the the umbilical cord at birth is a horrific medical error. Clamping the cord immediately after birth became widespread in the mid-1980s. This should be investigated as a possible cause of the autism epidemic, which began in the early 1990s.

Clamping the cord is likely to be done before the alveoli of the infant's lungs have been filled with blood sufficient to allow exchange of carbon dioxide for oxygen. Oxygen insufficiency will be greatest in brain structures of highest metabolic rate.

The auditory pathway in the brainstem has higher metabolism than any other area of the brain (Sokoloff 1981, J Cereb Blood Flow Metab. 1:7-36).

Diminished function in the auditory pathway should be considered a possible reason for language disorder, the most serious problem of autistic children.