Written Public Comments Received for March 19 Meeting

Lisa Croen

I would like the I-ACC to increase representation amongst its membership of traditionally underrepresented persons in terms of race, ethnicity, and ability (verbal, intellectual). I would also like the committee to include more autism researchers with expertise in environmental science and epidemiology.

Alycia Halladay

Dear members of the I-ACC,

Thank you for the opportunity to comment to the I-ACC, and for the creation of a forum to help scientific studies on autism move forward by collaboration and engagement with the community. This offers a unique opportunity to stakeholders and also reflects this group's commitment to ensuring that scientific approaches for the benefit of all affected with autism and their families is advanced. It is important as we talk about science that we acknowledge that scientific findings build on one another, and that the scientific method ensures that mistakes are not repeated. It moves forward and not backward. There are scientific truths that have guided major accomplishments in understanding health and disease. Because of science, we know that illness is not caused by bad spirits, mental illness is not the result of "humors" or energies in the brain, that disease is not a literal curse and that autism is not caused by neglectful mothers or vaccines. Thanks to science, we know that autism starts at conception, or perhaps before conception, not when vaccines are given. We know that genetics plays an enormous role in the causation of autism, and there are in fact genes that confer a grater probability of a diagnosis than others. If we deny these truths, we waste the opportunity to gain an even greater understanding of not just what causes autism, but how we can help those with a diagnosis and prevent the debilitating features of autism.

One scientific topic that seems to be quite the controversy is the role of the environment in autism. Why? Because many people equate "environment" to the most studied environmental factor so far: vaccines. The number of studies looking into vaccines as a cause or even trigger of autism far outnumber any other environmental factor that has been studied, including examining the effect of family history on vaccine exposure and outcome. This means we need to move on. Science needs to utilize the scientific method to continue research into what causes autism, examining other environmental factors together with genetic background. Science should also think broadly about environmental factors as well. The community needs to have an open mind to relevant environmental factors that may not have been studied, and a flexible definition. The environment includes contextual factors like the neighborhood you live in, access to services based on whether or not you have insurance and what insurance you

have, it is the food we eat and yes the air we breathe and the medical care we get when we are pregnant. If we narrow the possibility down of environmental factors to those that have already been studied and ruled out, we will spin our wheels and waste opportunities to better understand what environmental factors contribute to an autism diagnosis. There are obviously questions to answer, but science is not served by rehashing questions that have been answered. We do not have time and patience ended years ago.

There are also many other scientific questions of priority that will be ignored if we continue to perseverate on vaccines. Some of these include how to better diagnose autism, understand different features of those with autism and how to best identify and support them, how to reduce waitlists and ensure all of those with autism receive a diagnosis, identify new technologies generate treatments that match individual needs and biology, understand how the brains work in people with autism, and figure out the best way to get those treatments to the most number of people that would benefit them. This committee should do what the federal IACC might not: develop and nurture scientific approaches that are used to help families, and that the needs of all individuals across the spectrum are supported by science, not just those who believe that vaccines caused autism. Thank you for your time.

Laura Anthony, PhD

Thank you for creating this committee and for your service on it. Please consider diversifying your membership to include more autistic members (autistic scientists, clinicians and self-advocates) and more members who focus on interventions, services and supports.

Katherine Troyer

Our loved ones with severe ID and profound/severe autism are so poorly understood by federal and state policymakers as well as state and community-based providers of services.

Many in this sub-group have co-occurring serious mental illness (including mood and psychotic disorders), and we know how our nation has struggled to provide appropriate services and supports for the seriously mentally ill. Behavioral challenges in those with severe ID and profound/severe autism reflect distress. Distress comes from unmet needs.

Distress can come from caregivers imposing unrealistic expectations on clients. Distress can come from untreated medical, dental and/or psychiatric conditions; hunger, thirst and other unmet basic needs; anxiety or confusion arising from a noisy, chaotic, environment, hostile, neglectful staff, and/or the anticipation of being physically restrained or isolated; lack of trusting, loving emotionally supportive relationships; lack of interesting, engaging daily activities that include access to nature and the out of doors.

It is up to caregivers to identify the source of the distress and to alleviate the distress, not punish it through rejection, isolation, use of physical restraint and/or sedating medications, criminal justice involvement, or other traumatizing measures. It is the job of caregivers to meet the unique needs of their clients. Once a client's medical and psychiatric needs are appropriately addressed, providing stability and a sense of well-being, the essential work of caregivers, providing 24/7 compassionate, continuous supervision, support and engagement, ensures the individual's safety, health and happiness.

Caregivers continuously lend themselves—their knowledge, abilities, judgement—to their severely disabled clients. They prevent health/mental health/behavioral crises by truly meeting their clients' unique needs and by interrupting problematic behavior and redirecting their clients to safer, more appropriate activities. This is very active, engaged work that should be supervised by educated professionals with clinical knowledge and experience. We need meaningful research to better understand the brains and bodies and service/support needs of those with profound/severe autism and severe ID. And

we need laws and regulations that establish a much higher standard of care for those with severe ID and profound/severe autism in all settings, including ICFs where “active treatment” is too often not provided.

One that mandates the active involvement of well-educated health, mental health and allied health professionals; appropriate staff/client ratios; appropriate eyes on supervision of clients; engaging programming in all settings that includes excursions beyond the residential setting and access to the beauty of nature; appropriate dietary and hydration and exercise standards; cameras in common areas with the consent of parents/guardians; the ongoing involvement of families/guardians in planning and oversight; the inclusion in service plans of all concerns that impact the well -being and safety of the client. And one that creates the expectation that once a provider takes on a client, they are fully responsible for that individual’s safety, health and well-being. One that stops the excuses, the gaslighting, the scapegoating, the diagnostic overshadowing.

Two trends, while well-intentioned, work against this complex population receiving appropriate care. One is the emphasis on a behavior modification approach as the preferred treatment modality, to the exclusion of more traditional mental health treatment approaches offered by social workers and mental health counsellors, and to the exclusion of ancillary therapies like OT, PT, Speech, Recreation, Art, Music, etc.

The other is the emphasis upon “independence”, self-determination and full community integration as the only worthwhile goals to pursue, hence federal and state regulations and guidelines that protect the “rights” of individuals with IDD while imposing little real responsibility for their overall safety and well-being on the providers of services. Those with severe ID and profound/severe autism can use community-based services and can enjoy community-based activities, but only with intensive support. Support makes possible inclusion.

I once had a conversation with a higher up in state government about the need for 24/7 support for those with severe ID admitted to hospital. Community-based providers are not required to provide such support. And we know we cannot count on hospitals to do so. He focused on the individual’s “right” to use a community- based hospital while acknowledging that, without support, the individual may have to be tied to their bed. His focus remained on the right to

use the hospital, and not on the individual's right to an appropriate level of support. Torture and neglect over support. That is the mindset we are confronting.

Thank you.

Greatness Adewumi

Dear Members of the Independent Autism Coordinating Committee,

My name is Greatness Adewumi, and I am the Founder and Executive Director of the Rare Neurological Disorder Foundation (RNDF), a student-led initiative focused on neuroscience education, rare disease advocacy, and global health engagement. As RNDF continues to grow, we are expanding our RNDF National Interest List, which currently includes over 170 students, professionals, and trainees from institutions such as Yale, the University of Pennsylvania, Dartmouth, the University of Texas at Austin, Baylor University, Stanford, Rice University, and others. The interest list connects individuals who are interested in neuroscience education, neurodevelopmental research, and advocacy for rare neurological conditions. Given the I-ACC's leadership in advancing autism research and coordinating national priorities across the scientific and policy communities, I would be grateful if the committee or its broader networks might consider sharing RNDF's National Interest List with interested students, trainees, program directors, laboratories, and academic or research communities who may wish to engage with our initiatives. We are also interested in connecting with professionals, researchers, and clinicians who may wish to serve on RNDF's advisory board as the organization continues to develop its educational and advocacy programming.

RNDF National Interest List: https://forms.gle/YpdZckK2mUeCkxRW7

Thank you for your continued leadership in advancing autism research and improving collaboration across the neuroscience and neurodevelopmental research communities.

Sincerely, Greatness Adewumi
Founder and Executive Director Rare Neurological Disorder Foundation

Blythe Corbett, Ph.D.

In response to the considerable changes at the Interagency Autism Coordinating Committee (IACC) in representation and approach to scientific inquiry in autism research, there is significant concern voiced among the established scientific community, families and autistic people. Thus, the formation of the Independent-Autism Coordinating Committee (I-ACC) is a necessary and formidable undertaking to put forth a scientific roadmap to inform the field of autism.

The appointed I-ACC leadership has the trusted background and expertise to recognize the foundation, discipline and rigor of science that has advanced our understanding and treatment of autism spectrum disorder for decades. I applaud and support the mission of the newly formed I-ACC with expert representation and respect for the dedication and productivity of clinicians, researchers and educators working in collaboration with stakeholders to sustain and advance autism research.

Cynthia Bjorlie MD

In Ms. Sassi's letter (3/10/2026) about vaccines and autism, she refers to "debates that have been settled by overwhelming evidence," I ask, "Where is the overwhelming evidence?" I cannot find it. There are studies regarding individual vaccines and studies about the measles, mumps, rubella (MMR) combination. But where are the studies that look at the whole picture of the combinations of the vaccines?

Here is the recommended vaccine list: • Diphtheria • Pertussis • Polio • Tetanus • H. influenza type B • Hepatitis B • Measles • Mumps • Rubella • Hepatitis A • Pneumococcal • Influenza • Meningococcal • Varicella • Rotavirus • Human papilloma virus (HPV) • COVID • (Respiratory syncytial virus).

There are 56 recommended doses (birth to age 18). Let us look at the Covid vaccines, for example. Most, if not all, of the published Covid vaccine studies have been conducted by the companies that sell the vaccine. The studies are months long and assure "safety and efficacy." "Efficacy" is often measured by testing positive for Covid, even if there are no symptoms. Efficacy is often not a measure of sickness. In 2013 the U.S. Federal government funded a major retrospective study by the National Institute of Medicine (IOM) to look at the safety of the entire vaccine burden. Here is what the IOM concluded:

"The committee generally found a paucity of information, scientific or otherwise, that addressed the risk of adverse events with the complete recommended immunization schedule." Yet, since then, more vaccines have been added. Do vaccines cause autism? They did not know. Something is causing a child born today to be 2000 (two thousand) times more likely to be autistic than a child born in 1980. That is 200,000%. Why are we preventing minor virus infections when we do not know the safety of the preventive measures?

Erin Lopes

Thank you to all the members of this committee for taking on this vital work on behalf of the autism community.

The mission of the Independent Autism Coordinating Committee is critically important, and I am grateful for your commitment to it. The harm done by HHS over the past year and a half has been real and significant. I have watched it unfold in my own family. My son Tom, a 26-year-old man with autism, has struggled emotionally with the negative statements about autistic adults that have come from HHS. Discussions about vaccines, Tylenol, and autism are deeply triggering for him—he feels these unscientific claims have served only to stigmatize people with autism, and as a result he is at times fearful of being openly neurodivergent. His experience is a direct consequence of HHS's failure to counter misinformation with evidence-based messaging. I am certain he is not alone.

I ask this committee to make it a priority to oppose HHS's proposed autism registry. Any national registry must comply with existing laws protecting patient healthcare data. The healthcare data of people with autism should be treated equally and should not be exempted from existing privacy protections in furtherance of HHS's agenda to find data supporting predetermined conclusions about cause. This committee should take a strong public stance in defense of the dignity, autonomy, and civil rights of autistic individuals and their families. I also fear that all the important work accomplished here will have diminished impact if we do not actively communicate it to the public. Unlike unscientific wellness misinformation, evidence-based research does not offer easy answers—it often generates more questions than it resolves, which is precisely the nature of scientific inquiry.

We cannot sit back and hope the science will speak for itself. We must actively promote it, with a positive and assertive voice. I urge the committee to identify and invest in novel communication strategies for the research agenda—strategies that utilize social media to cut across generations within the autism community and beyond, and to directly challenge the myths that have taken hold in public discourse. Evidence-based science must be communicated with the same energy and reach as the misinformation it is countering.

More than ever, we need a scientific research agenda held to the highest standards—one that is evidence-based, focused on treatments that improve functioning, and oriented toward meaningful inclusion and quality of life for all people living with autism. And we need the voice of this committee to make that agenda heard.

Thank you.

Alexander MacInnis

I am intrigued by the creation of the independent I-ACC. I am not sure what to think about it. I hope that the I-ACC will be successful in terms of the goals that I firmly believe are most important. I eagerly await the results from the inaugural meeting on March 19. Unfortunately I cannot attend. I submitted a comment letter to the HHS's IACC. Since almost all of it also applies verbatim to the independent I-ACC, I am copying it here. Please seriously consider it. Please don't hesitate to ask for items where I can help. That includes technical and evidential support for the key points, starting with the epidemiology. You can contact me at either a.macinnis@alumni.stanford.edu or agm@macinnis.org.

(This exact copy is for the I-ACC.)
Dear IACC members,
You have a unique opportunity to make a real difference for people impacted by autism, their families and society as a whole. You also have an opportunity to improve the public's trust in science.

I am both an epidemiologist studying autism and a parent of an adult with what is now called severe or profound autism. I became an epidemiologist to help find answers and solutions for autism.

People significantly impacted by autism and their families need solutions to multiple problems. The IACC can help by establishing priorities and coordinating research and related funding.

The word “autism” as used here means the neurodevelopmental disorder defined by official diagnostic criteria. It manifests in early childhood and is usually diagnosed by age 10. The word also has other meanings.

Here are three main problems that need solutions.

Treatments. We need effective treatments now. Common symptoms dramatically impair quality of life for both individuals with autism and their families. These go beyond the symptoms required by diagnostic criteria. They include problems such as cognitive impairments, significantly impaired sleep, gastrointestinal problems, inability to tell caregivers where they hurt, eloping and disruptive, self-injurious

and aggressive behaviors. The current medical standard of care is clearly inadequate. The lack of treatments leads people to try alternative or unproven treatments. Treatments should have high quality research showing effectiveness and safety. Such research requires funding.

The IACC should substantially raise the priority of discovering and validating treatments. These may include repurposed approved drugs, new drugs and existing over-the-counter supplements.

The development of treatments is likely to require a deep understanding of the biological mechanisms underlying the symptoms. There may be a large number of such mechanisms — we simply don't know yet. Researchers have developed multiple autism biomarkers. They could be useful for understanding the underlying mechanisms. But, oddly, papers on biomarkers typically describe them as aids for diagnosis rather than the more valuable purpose of understanding mechanisms. That should change.

Planning for the rapidly growing and future demand for housing and caregiving. The number of autistic adults needing intensive caregiving and housing is certain to grow dramatically in the coming years and decades. This is clear from the increasing birth year prevalence. The vast majority of people with autism are children now. They will age into adulthood and most will far outlive their parents. Their families cannot care for them forever. We must plan for it now. While this is obvious, it is rarely mentioned. The IACC can publicly bring attention to this critical issue.

Reduce and reverse the rapidly rising risk of autism. The probability of children having autism has grown each birth year. This clear from birth year prevalence, which is equivalent to the probability and to the risk. We must find preventable causes and prevent at least the worst symptoms. There must be environmental factors involved. Prevention is not eugenics. In general, we must always use the best available scientific methods and follow the evidence wherever it leads. Quality science is not a slogan. Beliefs should follow evidence, never the other way around. We must all resist the natural tendency to seek to confirm beliefs.

The Combating Autism Act of 2006 and subsequent reauthorizations (Autism CARES Acts) require the HHS to report on autism incidence. Incidence — the rate

of occurrence — is the fundamental descriptive measure in epidemiology for investigating the causes (etiology) of any disease, disorder or condition. The law specifies the correct measure. Prevalence is different: it is the current caseload. But the IACC's reports to Congress have not reported on incidence. Instead, they claim incorrectly that prevalence is a better measure, and point to the CDC's ADDM reports. What everyone seems to miss is that the ADDM reports measure birth year prevalence while misleadingly calling it "prevalence." Birth year prevalence is effectively the incidence of autism. While those words may seem confusing, the literature is clear on this point.

Here are some sincere suggestions to help you be as successful as possible:

- Don't blame vaccines for the increase in autism. That conflicts with the evidence. Worse, it causes denial of the increase and prevents progress.
- Don't deny the increasing rate of occurrence — the incidence — of autism. That conflicts with the evidence, and it prevents progress. Denial of the increase appears to be a response to vaccine blaming. As such it adopts the framing of vaccine blaming.
- Don't claim autism is almost all genetic, leaving little room for environmental factors. That conflicts with the evidence. Heritability does not mean inherited. And causality does not work that way — causal factors often add up to more than 100%. Most genetic factors are common in the unaffected population, meaning they are not sufficient to cause autism. The term for that in genetics is low penetrance. There must be significant environmental factors. Claims that autism is genetic are misleading and lead to unfounded fears of eugenics.

For more information: Autism Love and Science http://autismloveandscience.org Subscribe on Substack to get future updates on autism epidemiology.
National Council on Severe Autism https://www.ncsautism.org/ Profound Autism Alliance https://www.profoundautism.org/
The BRAIN Foundation https://brainfoundation.org/
MacInnis: Time-to-event estimation of birth prevalence trends: A method to enable investigating the etiology of childhood disorders including autism. PLoS One. https://doi.org/10.1371/journal.pone.0260738
Rothman and Greenland: Causation and Causal Inference in Epidemiology. AJPH. https://ajph.aphapublications.org/doi/full/10.2105/AJPH.2004.059204 Alexander MacInnis, MS Epidemiology, MS EE

Nicole Feaster, RN-C

Family Perspective on Severe Autism, Autoimmune Encephalitis, and Lifelong Support Needs

My name is Nicole Feaster. I am a registered nurse living in State College, Pennsylvania, and the mother of a 24-year-old daughter with autism whose life changed dramatically following a severe neurological illness. Before becoming ill, my daughter Rena was a joyful child who loved music, laughter, and the simple rhythms of childhood. Like many children on the autism spectrum, she experienced the world in her own vibrant way and was thriving within the supports we had built around her. Before a virus hijacked her immune system and led it to attack her brain, Rena was thoughtful and inquisitive, with her father's acerbic wit and her mother's generational stubbornness. She had beautiful red hair and a personality to match. Rena had friendships. She was a proud Girl Scout. She explored activities in our community, attended summer camps, and traveled with our family — including trips to Hersheypark and visits to family in Washington, D.C. She was living a good life.

Then in June of 2011, everything changed. After contracting Epstein–Barr virus, Rena developed autoimmune encephalitis. Almost overnight, the joyful rhythms of her childhood were replaced by a neurological storm that none of us could have imagined. The infection triggered an immune response that attacked her brain, altering her behavior, cognition, and ability to communicate. The daughter we knew was still there, but trapped behind a cascade of severe neuropsychiatric symptoms — profound obsessive-compulsive behaviors, relentless perseveration, and a loss of the functional communication she had worked so hard to build. What began as a viral illness became a life-altering neurological injury that continues to shape every aspect of her daily life. Over the years, our family has sought care from multiple specialists across neurology, psychiatry, and immunology in an effort to stabilize her condition. Rena underwent total body plasmapheresis in 2017 and again in 2019. Rituximab was attempted but had to be discontinued due to severe adverse reactions. Today we continue to navigate complex medical and behavioral challenges that dramatically impact her ability to function and communicate.

Despite the fact that I am a nurse and my husband is a child and adolescent psychiatrist, navigating the healthcare system on behalf of our daughter has been profoundly difficult. Families without medical training face an almost impossible task coordinating care across multiple specialties, managing insurance barriers, and advocating for appropriate services. Our experience has revealed significant gaps in the systems meant to support individuals with severe autism and complex medical conditions. These include fragmented care between neurology, psychiatry, and developmental medicine; limited research on autoimmune and post-infectious neurological injury in individuals with autism; and a critical shortage of services for adults with severe autism and high support needs. Families like ours often become full-time care coordinators, advocates, and caregivers simply to keep our loved ones safe and living at home. Rena's experience also highlights an important gap in autism research. Many individuals on the autism spectrum develop complex neurological or immune-related conditions following infections or immune dysregulation, yet these intersections remain under-studied. When post-infectious autoimmune brain injury occurs in someone who already has autism, the resulting symptoms can be devastating and extraordinarily difficult to treat. The systems designed to study and treat brain disorders often separate neurology, psychiatry, immunology, and developmental medicine into distinct silos. Families like ours live at the intersection of those fields.

Future research must better explore the relationship between infection, immune response, brain inflammation, and long-term neuropsychiatric outcomes in individuals with autism so that other families do not face the same uncertainty and lack of treatment options that we have experienced. Today Rena is a 24-year-old woman. She is still the same beloved daughter we have always known, but the systems meant to support individuals like her remain fragmented, underfunded, and extraordinarily difficult to navigate.

For Rena and others like her, a good life requires:
• Access to integrated medical care that recognizes the intersection of autism, neurology, psychiatry, and immune-mediated brain injury
• Research that includes individuals with severe autism and complex medical conditions • Reliable home- and community-based services that allow individuals with high support needs to live outside of institutions
• Stable, trained caregivers who are supported to remain in this workforce

• Recognition that autism is not a single experience — many individuals live with profound support needs and complex medical challenges

Families like ours are not asking for miracles. We are asking for research, services, and systems that recognize the full reality of severe autism and the lifelong needs of those who live with it. My daughter deserves the opportunity to live a meaningful life with dignity, safety, and appropriate care.

Thank you for listening to the voices of families caring for individuals with severe autism.

Nicole Feaster, RN-C State College, Pennsylvania Mother of Rena Feaster
nicole.feaster@icloud.com 814-441-1843

Caroline Rodgers

My name is Caroline Rodgers. I am a peer reviewed author who has been investigating autism etiology for more than a decade. Today I want to highlight a core autism developmental feature that deserves more focused attention: reduced synaptic pruning that results in an overabundance of synapses in early development. This is one of the most consistent biological findings across the autism spectrum, yet we still do not understand why pruning is reduced or how this developmental difference shapes the wide range of autistic outcomes. Several biological pathways that reduce pruning are already being investigated, including microglial mechanisms, autophagy and mTOR related pathways, and immune inflammatory signaling. Each of these can contribute to excess synapses, and each has been associated with autism. But what remains unclear — and what deserves greater attention — is what upstream factors create these conditions in the first place. Without understanding why pruning is reduced, we cannot fully understand autism's developmental origins.

In my recent preprint, Mitochondrial Dynamics in Regressive Autism and the Surprising Link to Genius (https://doi.org/10.32388/S5NHH0), I outline a conceptual framework that connects synaptic overabundance, mitochondrial capacity, and developmental outcomes. The model proposes that autism arises when the developing brain retains more synapses than the child's available energy supply can support. When this occurs, the system can either become strained or flourish. In some children, where mitochondrial capacity is insufficient, this imbalance leads to regression; in others, where there is robust mitochondrial capacity, it can lead to exceptional abilities. The common denominator is the balance between synaptic load and energetic resources. This perspective also helps clarify why sensory features are so prominent. If higher order circuits -- such those required for language and social behavior -- are shut down or paused, the surge of available energy may shift toward lower-level sensory pathways. These circuits then become highly active, and because pruning is activity dependent, this heightened activity can create a feedback loop that further reduces pruning. This may help explain why sensory hypersensitivity is common and why it often emerges at the same time as regression.

I applaud the new committee's dedication to science-based work and encourage it to highlight research that examines the upstream factors — energetic, cellular,

or environmental — that shape pruning during early development. By examining how synaptic load and energetic capacity interact, we may better understand the diverse developmental trajectories seen across the autism spectrum, from profound regression to the small percentage who attain exceptional abilities. Thank you.

Judith Ursitti

I appreciate the opportunity to provide public comment and write as cofounder and president of the Profound Autism Alliance, a nonprofit organization focused on improving the health and connection of people with profound autism and intellectual disability through inclusive research and focused advocacy. People with profound autism typically require continuous supervision and lifelong support.

Ongoing autism research addresses many important issues across the spectrum, yet people with profound autism remain underrepresented in research and priorities. This gap has consequences. When people with profound autism are not included in research, the field lacks evidence needed to advance medical understanding, services, and real supports for a substantial portion of the autism community.

The use of the term “profound autism” is about clarity, not competition. Greater clarity helps researchers, policymakers, and service systems better understand support needs and develop appropriate responses. Recognizing the needs of people with profound autism does not diminish the importance of any other part of the spectrum. Every part of the spectrum matters.

Research indicates that approximately 1 in 4 people with autism meet criteria for profound autism (Hughes MM, Shaw KA, DiRienzo M, et al., 2023, Public Health Reports), yet only about 6 percent of clinical autism research includes people from this population (Stedman A., Taylor B., Erard M., Peura C., & Siegel M., 2019, Journal of Autism and Developmental Disorders). As a result, many people and families are not represented in the research that informs policy and services.

The disparity also appears in federal reporting. In the 2019–2023 IACC Autism Spectrum Disorder Research Portfolio Analysis Report, employment was referenced 141 times, while profound autism was mentioned only four times. Congress has recognized the importance of addressing this issue. Fiscal year 2026 appropriations language tied to the Autism CARES Act of 2024 directs NIH autism research to reflect the entire autism population, including people with profound autism.

To support implementation of this directive, we respectfully encourage you to:
• Provide clear reporting on how autism research includes people with profound autism, including representation in study design, enrollment, and analysis.
• Align research portfolios with the full range of autism, including people who require continuous supervision and lifelong support.
• Continue use of the term “profound autism” in research, strategic planning, and reporting so that this population remains visible in policy discussions and research priorities.
• Encourage ongoing autism surveillance and reporting that clearly tracks the prevalence and characteristics of people with profound autism, helping policymakers and service systems better understand population needs.

People with profound autism and their families depend on research to advance understanding of co-occurring medical conditions, challenging behaviors, and long-term support needs. Greater representation in research design, funding priorities, and reporting will strengthen the evidence base and help autism research serve the entire community.

Thank you for your consideration and for your continued work to improve outcomes for all people on the autism spectrum.

Sincerely, Judith Ursitti
Cofounder and President judith.ursitti@profoundautism.org (508) 785-4074

Suzi Kyle

Is there funding to share success stories of high functioning people with autism-like Elon Musk, Darryl Hannah, Anthony Hopkins, Greta Thunberg, Albert Einstein, etc. that can be campaigned broadly to change the narrative of autism being a problem to solve, to an idea of a diverse community that adds value to society. (Would Elon Musk and his wealth contribute to such an idea). Hopefully counter misinformation/ panic with positive attributes.

Can we collectively present data that shares the importance of early intervention as beneficial, early diagnosis as the drive for increased rates via social media platforms to target young parents who are most impacted by the vaccine/ Tylenol scare.

Sam Crane

CommunicationFIRST appreciates the opportunity to submit the following comments to the Independent Autism Coordinating Committee (I-ACC). CommunicationFIRST is the only organization led by and for and dedicated to the rights and interests of the estimated 5 million people in the United States who must rely on communication tools and supports to be heard and understood due to speech disabilities and conditions. We advance our mission by educating and engaging the public, advocating for policy and practice change, and working within the legal system to protect rights and advance change.

CommunicationFIRST is cross-disability in focus, representing people who have had speech disabilities since birth, as well as those who acquire speech loss later in life, for example, due to ALS or Parkinson's. Autistic people are one of the largest segments of our community. Regardless of the reasons by which, or at what stage in life a child or adult first becomes unable to rely on speech alone to be understood, they routinely encounter similar prejudice and discrimination. Prejudice and discrimination result in lifelong low expectations, denial of equal opportunity, and denial of access to reasonable services and accommodations that could reduce or eliminate communication barriers.

Effective communication is a fundamental human right and a prerequisite for full enjoyment of other important rights, including the right to make decisions, participate in the community, and equal access to educational and employment opportunities. Of the 1 in 3 autistic people who are nonspeaking, however, many do not currently have access to any form of robust communication that facilitates a full range of expression. This is in no small part due to failures to invest adequately in research on the communication needs of nonspeaking people and promotion of robust augmentative and alternative communication (AAC) tools and supports.

I-ACC proceedings must prioritize the voices of people with disabilities.

Efforts to coordinate autism research funding and set a comprehensive research agenda have a long history of excluding those most affected by that research: autistic people themselves. Previous rosters of the Interagency Autism

Coordinating Committee (IACC) included as few as one autistic public member. It was only in 2019, following over a decade of advocacy, that the Autism CARES Act was updated to require that at least three public members of the IACC be autistic. The 2019-2025 roster included well above that required minimum of autistic members, including the IACC's first nonspeaking autistic member, Hari Srinivasan. The newly nominated roster of public IACC members has now been reduced to the statutory minimum of three; we have expressed our disappointment at this regression in our comments to IACC.

It is unacceptable that the I-ACC fails to meet even the IACC's minimal threshold of representation, with only one autistic member. This failure fundamentally undercuts the I-ACC's credibility as an advisory body. It is not possibly representative of the many ways autistic people show up, consider research, or think about what is needed. Additionally, when the IACC is overly dominated by non-autistic members of the public, its recommendations have failed to meaningfully represent the felt needs of autistic people themselves. We urge I-ACC to add additional autistic members, including nonspeaking autistic members.

Nonspeaking autistic people should not only be added to the membership of the committee but also meaningfully included. We therefore further urge I-ACC to commit to accommodating nonspeaking participants in proceedings, including members and those presenting public comments. In particular, time limitations for speaking are one of the greatest barriers that nonspeaking people, particularly people who use AAC, face when expressing themselves. We strongly urge that the I-ACC modify any such limits when applied to nonspeaking participants in committee proceedings and that the I-ACC hold additional listening sessions and other means of soliciting the views and insights of nonspeaking autistic persons.

I-ACC should avoid direct counter-programming with other advisory bodies.

We share the I-ACC's concern that for the first time in its history, the membership of the IACC lacks representation from the largest autism research and advocacy organizations. This lack of representation risks undermining the IACC's core mission to "ensure that a wide range of ideas and perspectives are represented and discussed in a public forum." Without broad-based buy-in across the community, the IACC's role will likely be severely diminished.

Nevertheless, by holding meetings simultaneously with IACC, the I-ACC has made it unnecessarily difficult for advocacy organizations to observe proceedings and present their concerns directly to both bodies through the public comment process. Smaller nonprofits may lack the staff to attend both meetings at once, and individuals will find it impossible to do so. I-ACC should schedule its future meetings to avoid such conflicts.

Support research that addresses the expressed needs of nonspeaking autistic people.

The newly constituted I-ACC has an opportunity to address longstanding disparities in research funding that fail to prioritize core quality-of-life concerns for nonspeaking autistic people. The autism research portfolio has, for as long as data has been available, included a disproportionate focus on topics that have no direct impact on the quality of life of autistic people. For example, in 2020, only 11% of funding supported research on services and supports, whereas 6% focused on the needs of autistic people across the lifespan. In contrast, over 50% was focused on genetics and biology. One result of this disparity is an alarming lack of quality research on effective communication supports. Nonspeaking people are frequently not offered any form of AAC altogether; are assumed to be incapable of using AAC because of assessments that have no evidence base for use in screening AAC needs; or are offered AAC that fails to facilitate robust communication or that fails to address their specific communication needs.

To ensure broader access to effective communication, researchers should prioritize:

- Working with nonspeaking populations to design, implement and interpret research;
- Achieving a better understanding of sensory and motor challenges that may affect communication Conducting and evaluating programs to support nonspeaking people with robust, language-based communication—including older nonspeaking people who have not previously accessed effective supports
- Improving timely access to robust, language-based AAC. Most people are not offered robust AAC until they enter school, if not later (if at all). This creates a vicious cycle in which students are deprived of language-based

AAC during critical developmental periods and then blamed for difficulty learning to communicate using language

- Achieving a better understanding of how speech-related disabilities can affect the accuracy of assessments, including IQ assessments Improving the collection, analysis, and reporting of demographic data on people who require AAC, as currently there is no comprehensive data on this population in the United States
- Reducing economic, racial, gender, regional, and other demographic disparities in access to AAC Identifying and ameliorating the disproportionate rates of trauma, abuse, loneliness, isolation, and mental health issues experienced by people who need but lack access to robust, language-based AAC, including achieving a better understanding of the impact of trauma on ability to use robust AAC and developing services and strategies to prevent trauma from communication deprivation
- Investigating the effectiveness of existing behavioral, educational, occupational and employment services and supports for nonspeaking autistic people. Without first addressing communication, these interventions may be ineffective and/or abusive to nonspeaking people
- Understanding and documenting the impact of effective, robust communication supports (or lack thereof) on community inclusion, medical, mental health, employment, and educational outcomes Ceasing funding for research that relies on methods that conflate speech-related disability with intellectual disability, as this often results in inappropriate delivery of services and supports

A. Support Community-Based Participatory Research (CBPR) Autistic representation is important not only in the context of I-ACC's own operations but also at all stages of the research process. Research funding priorities should be dictated by those who most stand to benefit from such research. Community-Based Participatory Research (CBPR) is a broadly utilized approach through which members of affected communities collaborate with researchers at all stages of the research process, from identification of priority research topics to interpretation and dissemination of results. The nonspeaking population is one of the most neglected populations in terms of federal autism research funding. With the exception of studies that meaningfully engaged nonspeaking people to determine which projects would have the greatest impact, very little of this research has actually improved lives. By prioritizing projects that follow CBPR

principles, funders can ensure that research focuses on those topics that have the biggest impact on nonspeaking people's lives—including prioritization of research on robust communication supports over interventions that inherently limit people's range of communication to basic requests or answers to questions. The I-ACC must also urge funders to include nonspeaking people as reviewers on all relevant grant applications to ensure that high-impact projects are prioritized.

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

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

D. Improve AAC Deployment and Implementation There are hundreds of thousands of nonspeaking autistic people, representing about one-third of

autistics in this country. We believe the vast majority of nonspeaking autistic people have not been given access either through the education system or the adult services system to the tools they need to communicate agency, autonomy, and self-determination, or to participate in appropriate educational and employment opportunities. As a result, we believe this is the largest underserved population of autistics in the United States. Autistic people of color, or those whose primary language is not English, who need but have been denied access to robust AAC face even greater inequities and marginalization. AAC should be introduced to everyone who has any kind of a speech delay as soon as the delay is evident. Researchers at Pennsylvania State University are successfully introducing AAC to infants as young as six months, but most people aren't given access to robust AAC until they enter school or even later (if ever). Late and inadequate introduction of AAC causes a vicious cycle where students are given insufficient tools and supports to communicate, and then are blamed for not having the capacity to learn to communicate using language. They should also be provided with age-appropriate literacy instruction no later than their nondisabled peers. Developing strong reading and writing skills is essential to everything else these children will aspire to and achieve in life. The goal should be that anyone who can benefit from AAC is proficient at using robust, language-based AAC by the time they enter kindergarten, if not sooner. Policymakers at the state level have begun responding to this need through legislation improving access to AAC at school. For example, in Virginia, new legislation requires that school staff be trained to understand and support students' AAC needs before the beginning of each school year. Research can support these efforts by evaluating the effectiveness of efforts to promote universal AAC.

E. Stop Funding Research That Uses Existing Standardized IQ-Type Measures on the Nonspeaking Population

Much of the existing published research on nonspeaking autistic people continues to conflate lack of speech with intellectual disability. We know that speech is a motor function and language is a cognitive function, and that they are processed and generated in different parts of the brain. But researchers continue to assume, without basis, that someone who cannot speak or move their body reliably also has a language or intellectual disability. All current standardized measures of cognition and "intellectual ability" assume the student or research subject can either speak or move their bodies in intentional ways. There currently is no standardized way to measure intelligence that does not involve planned and

initiated movements. The result is often provision of services and supports that do not reflect a person's actual needs.

We know from countless studies published over the past twenty years that sensory and motor-related disabilities are a core feature of nonspeaking autism. Previously published research about nonspeaking autistic people that discounts the sensori-motor disability elements and assumes intellectual disability without valid proof should be viewed with caution at the bare minimum. Additional research on this front is desperately needed. Many nonspeaking people have experienced serious consequences as a result of these failures, including our Board Chair Jordyn Zimmerman, whose IQs were assessed in the "severely" intellectually disabled range before she acquired access to AAC. Consequences may include failure to identify and address motor challenges and their effects on communication, as well as deprivation of appropriate educational opportunities.

We need to seek greater understanding of the abilities and need for communication support of all nonspeaking autistic persons. Moreover, federal agencies that fund such research must reconsider the discriminatory consequences of such research and whether it should continue to be underwritten with federal funds.

F. Be Careful About Terminology Finally, language matters. While we recognize that autistic people experience a range of support needs, terms like "severe" and "profound" are vague, dehumanizing, and ultimately contribute to decreasing access for those these terms purport to help. We urge the I-ACC to instead use language that describes specific disabilities and needs within the autistic population - such as intellectual disability, nonspeaking or speech-related disability, and behavioral support needs.

Conclusion

We ask the I-ACC to provide bold leadership in supporting this neglected portion of the autism population by working to ensure that every single person is given the tools and support they need to communicate effectively. This starts with the recognition that historically, when advisory bodies have excluded nonspeaking members, their recommendations have failed to meaningfully represent our community's needs. Introducing robust, language-based AAC is essential for

anyone who cannot rely on speech to be heard and understood. When a person is provided access to (including the necessary support to use and learn to use) robust AAC tools, the most significant barriers to education, employment, social engagement, self-determination, decision-making, and community living are alleviated. Thank you for your consideration. For more information, please do not hesitate to contact Policy Director Sam Crane at scrane@communicationfirst.org.

Karen Isaacson

I am 71, autistic, and older than RFK Jr. I have read two things that suggest that Vitamin D may have some involvement with autism: a Somali population relocated to Minnesota had a large percentage of first gen American-born children diagnosed with autism, and Scandinavia has a significant number of autistic people. My father and grandfather were of Scandinavian lineage and I believe both were autistic. If Vitamin D (which I've read is actually a hormone) has an effect on how autism presents, how severe the effect is, it would be nice to know that.

Mariel Fernandez

I write today on behalf of the Council of Autism Service Providers (CASP). CASP is a non-profit trade association of autism service provider organizations, with a demonstrated commitment to promoting and delivering evidence-based practices for individuals with autism. CASP represents the autism provider community to the nation at large, including government, payers, and the general public. CASP is committed to addressing barriers that impact access to quality services delivered by qualified providers. CASP and our member organizations are very interested in the I-ACC and its future activities related to autism spectrum disorder (ASD). We do not have official comments for the I-ACC today but hope to share concerns and recommendations with The Committee during future meetings. Thank you, in advance, for the support you will provide to coordinate activities and improve access to necessary services and supports across the lifetime and all areas of need.

Respectfully Submitted,
Mariel C. Fernandez
Vice President of Government Affairs
The Council of Autism Service Providers mfernandez@casproviders.org (334) 332-2504

Wesley Turner

80% accuracy from charts, 100% accuracy from retina images

"Machine Learning Prediction of Autism Spectrum Disorder from a Minimal Set of Medical and Background Information" (2024)
https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2822394
https://github.com/Tammimies-Lab/ASD_Prediction_ML_Rajagopalan - "AI Model Predicts Autism in
Toddlers with 80% Accuracy" (2024) https://neurosciencenews.com/ai-autism-detection-27556/

"Development of Deep Ensembles to Screen for Autism and Symptom Severity Using Retinal Photographs" (2023)
https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2812964 - "AI-screened eye pics diagnose childhood autism with 100% accuracy" (2023)
https://newatlas.com/medical/retinal-photograph-ai-deep-learning-algorithm-diagnose-child-autism/

Given the privacy concerns, Is it possible to identify subtypes of ASD with retinal imaging? (In the US so many of our health plans don't include dental or vision, though there is screening for scoliosis, hearing, and vision impairment in public schools) Couldn't ASD screening be integrated with automated refractometry and retinal imaging for clinical diagnostics? And how do retinal images predict also the subtypes of ASD and others conditions like diabetic retinopathy? Isn't there like a cell phone camera attachment for retinal imaging?

Jim Schulz

One emerging area of research within autism science is the microbiome–gut–brain axis, which explores how gut microorganisms may interact with the nervous system and immune system. Gastrointestinal symptoms are relatively common among autistic individuals, and researchers are increasingly investigating whether differences in gut microbiota, microbial metabolites, immune signaling, or intestinal permeability may contribute to certain symptoms experienced by this population. Although this field is still evolving, it has opened new opportunities to better understand how gastrointestinal health may influence broader physiological and neurological processes.

Scioto Biosciences has been exploring how its proprietary platform may contribute to this emerging area of research. The company's work focuses on understanding whether targeted modulation of the gut microbiome could help alleviate gastrointestinal symptoms while potentially influencing systemic or neurological outcomes through gut–brain interactions. To evaluate this hypothesis, Scioto Biosciences conducted and successfully completed a Phase Ib clinical study in autistic individuals, providing important early clinical insights into the safety and potential benefits of its approach.

Scioto's strategy is primarily aimed at improving gastrointestinal health, with the possibility that improvements in gut function could also positively influence broader physiological outcomes. This approach reflects a growing recognition within autism research that co-occurring medical conditions—such as gastrointestinal disorders—can significantly affect quality of life and may represent important therapeutic targets.

However, developing microbiome-based therapies presents significant regulatory challenges in the United States. When probiotics or microbial therapies are intended to diagnose, treat, mitigate, or prevent disease, the U.S. Food and Drug Administration (FDA) regulates them as biologic drugs, typically classified as Live Biotherapeutic Products (LBPs). As a result, these products must follow the same regulatory pathway as other biologics, including submission of an Investigational New Drug (IND) application, followed by Phase 1, Phase 2, and Phase 3 clinical trials to establish safety, dosing, and clinical efficacy, and ultimately submission of a Biologics License Application (BLA) for approval. This process can be complex,

time-consuming, and expensive, often requiring many years of development and significant financial investment.

Additional challenges arise from the FDA's Chemistry, Manufacturing, and Controls (CMC) requirements. Developers must demonstrate consistent manufacturing processes, confirm strain identity and genetic characterization, ensure product stability throughout its shelf life, and maintain reliable potency across production batches. These requirements can be particularly demanding for microbial products because they involve living organisms whose viability and activity can be influenced by growth conditions, formulation, and storage. Ensuring consistent potency and product characteristics across batches is therefore more complicated than for conventional pharmaceutical compounds. Another difficulty lies in defining and measuring potency for probiotic-based therapies. Unlike traditional drugs with clearly defined active ingredients and mechanisms of action, the therapeutic activity of a microbial product may depend on factors such as organism viability, metabolic activity, and interactions with the host microbiome. Because the precise mechanisms underlying clinical benefits are often not fully understood, developing standardized potency assays that meet regulatory expectations can be challenging.

Clinical trial requirements can also present obstacles.

The FDA generally requires well-defined clinical endpoints that demonstrate meaningful health outcomes, rather than biological changes alone. Because microbiome-based therapies often exert indirect effects through microbial or metabolic pathways, demonstrating clear and consistent clinical benefits may require large, carefully designed trials. These studies can be lengthy and costly, particularly when outcomes vary across individuals. Safety considerations add further complexity. Even when a microbial strain has a long history of safe use in foods or dietary supplements, the FDA evaluates safety differently when the organism is intended for therapeutic use. Regulators may require additional data addressing potential risks such as infection in vulnerable patients, horizontal gene transfer, antibiotic resistance, or unintended alterations to the microbiome. In addition, because live biotherapeutic products represent a relatively new regulatory category, limited precedent can create uncertainty regarding acceptable trial designs, potency measurements, and manufacturing standards.

If a microbial strain is well characterized and confirmed as Generally Recognized As Safe (GRAS) for human consumption, several regulatory adjustments could potentially help accelerate development while maintaining appropriate safety oversight. For example, the creation of a tiered regulatory pathway for GRAS microorganisms could allow products based on well-characterized and widely consumed strains to move through development with reduced preclinical safety requirements. When genomic sequencing confirms the absence of virulence factors or concerning antibiotic resistance genes, regulators could reasonably rely on extensive historical safety data to streamline certain aspects of development.

Development timelines could also be shortened through more flexible clinical trial designs, such as adaptive trials, combined Phase 2/3 studies, or smaller confirmatory trials for products with well-established safety profiles. These approaches are already used in other therapeutic areas and can allow developers to gather robust evidence of efficacy more efficiently. Regulators might also consider accepting validated microbiome-related biomarkers as intermediate or surrogate endpoints in some studies. For example, restoration of microbial diversity, suppression of pathogenic organisms, or production of beneficial microbial metabolites could potentially serve as indicators reasonably likely to predict clinical benefit. Recognizing such biomarkers could reduce the size and duration of clinical trials while still ensuring meaningful evaluation of therapeutic impact. Further efficiencies could be achieved through platform-based manufacturing approaches, in which validated production processes for a live microbial therapy could be applied to closely related strains or formulations. This would reduce the need to repeat extensive manufacturing validation for each new product iteration. Broader use of accelerated approval pathways could also help bring promising microbiome therapies to patients sooner, particularly in areas where treatment options remain limited. Under such models, therapies could receive earlier approval based on surrogate endpoints, with additional post-approval studies conducted to confirm long-term clinical benefit.

Finally, clearer and more detailed regulatory guidance specific to live biotherapeutic products would help reduce uncertainty for developers. More explicit expectations around strain characterization, genomic analysis, potency testing, stability requirements, and acceptable clinical endpoints could make development pathways more predictable. Companies such as Scioto Biosciences, with clinical experience and emerging data in microbiome-based interventions,

can contribute valuable insights to this evolving field by helping inform research priorities, supporting clinical studies, and collaborating with the broader scientific and medical community to advance safe and effective microbiome-based therapies for individuals with autism and related conditions.

Paul Silver

I was diagnosed with Asperger's at age eight, in the 1990s, when much less was understood about autism. Instead of allowing that diagnosis to limit me, I turned it into purpose.

In my twenties, I became a self-advocate and helped my home state of Georgia pass Ava's Law, which required insurance companies to cover ABA therapy for autistic individuals.

I have worked in the medical field for over fourteen years, including the last four as a Medical Coder. I understand healthcare both personally and professionally. The current misinformation about autism is deeply hurtful.

Comparing autism to deadly infectious diseases is not only inaccurate — it is dehumanizing. Autism is not a tragedy. It is a neurological difference. Autistic people deserve support, services, and respect — not fear-based rhetoric.

I am also Jewish. Over the years, I have witnessed disturbing antisemitic imagery used within segments of the anti-vaccine movement. I have seen Nazi-era propaganda depicting Jewish doctors as dangerous reused in modern contexts. I have seen activists wear yellow stars — symbols forced upon Jews during the Holocaust — repurposed to compare vaccine policies to genocide. I have seen conspiracy memes labeling law enforcement as "Zionist" while portraying families as victims of state violence. These images are not accidental. They echo centuries-old antisemitic tropes that falsely portray Jews as controlling medicine and harming children.

When Health & Human Service Secretary Robert F. Kennedy Jr. suggest that COVID-19 was caused by specific ethnic or religious groups, it reinforces dangerous conspiracy narratives that have historically led to discrimination and violence.

Vaccines are one of the most effective tools in the medical profession's toolbox for preventing deadly diseases. Calling vaccination "medical malpractice" is a misuse of the term. Medical malpractice occurs when a healthcare professional is negligent in caring for a patient. If anyone wants to understand what real medical

malpractice looks like, they can ask me about my brother Daniel, who passed away due to negligence during a medical procedure. That is malpractice. Public health prevention is not. I will continue to advocate for the autistic community, for evidence-based medicine, and against antisemitism wherever it appears. My identity as an autistic self-advocate, a Jewish man, and a healthcare professional is not something that can be weaponized — it is something that strengthens my resolve.

Steven Kapp

As a U.S. citizen and autistic autism researcher and advocate, I urge the I-ACC to commit to a formal policy of having at least three autistic members. It is important to represent the autistic community, beyond one white male academic psychiatrist. It is also important that not all autistic members are academic researchers, just as the lay broader autism community is represented by the historically non-autistic family-led organization Autism Society of America. This would be consistent with the Autism CARES Act for the IACC, which in 2024 had seven public autistic members and one federal autistic member, and still has three public autistic members, many of them non-academics. Currently there are at least three non-autistic parents of autistic people on the I-ACC and bringing in three autistic people would keep a balance, whether or not they have autistic children. I think it helps if they, like the autistic community, have ideological diversity (while all committed to science and the quality of life of autistic people and our families). I recommend Jenny Mai Phan, an autistic scientist who straddles between basic and psychological science, who had served on the IACC and has served on the Autism Science Foundation's HEARD (Healthy Engagement in Autism Research Dialogue) group. She is an autistic mother of an autistic son with intellectual disability and another autistic son without intellectual disability. She also is a bridge-builder (as seen through, but not limited to, HEARD and as an Assistant Director of Community Engagement at the Center for Adaptive Systems of Brain-Body Interaction). Groups such as the Autistic Women & Non-Binary Network and the Autistic Self Advocacy Network would be good to include under inclusive conditions. I-ACC will have more respect and influence in the diverse autism community (especially the non-MAHA parts) if it includes progressive pro-science autistic people. To do so, it must have a decision-making process that works toward genuine consensus through collaboration and compromise, or allow respectful disagreement at times from members (not suggesting all members sign on to a position they do not believe or to which they cannot commit). There is power and progress in truly shared goals. If the IACC acts beyond matters of science and treatment, in a manner with which I-ACC members disagree, it may be worth considering whether the organization takes a broader scope. Depending on the issue (services, employment, housing, etc.), it might not be an area that achieves consensus on the I-ACC, however

Emails:

It was disappointing enough not to have my IACC appointment renewed and be replaced with a committee void of diversity and in no way reflective of the demographic distribution of the US. It was more disappointing to watch ASF call themselves mitigating the issues presented by the new political administration, then immediately replicate that lack of diversity presented. I have no interest in attending the public meeting bring held on March 19th and providing these comments in real time because I'm exhausted with being marginalized and overlooked. Feel free to share my comments with the committee and program leadership.