July 23, 2026 Independent Autism Coordinating Committee (I-ACC) Meeting Written Public Comments

1. Carolyn Krug

Dr. Phan asked a question during the July 23 meeting about data for preferences of autistic adults. On the subject of housing, there are housing market analyses being coordinated by First Place Global that include preferences of autistic adults in their analyses. This data is from survey responses from the autistic adults and/or their families and/or caregivers. I am not affiliated with First Place Global. I have only read some of the analyses and hope to help with one in my metro area in the near future. Here is the website with details if anyone is interested: https://firstplaceglobal.org/housing-community/housing-market-analysis/#main

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2. Lori DiBartolo

Thank you for your continued commitment to improving the lives of individuals with autism spectrum disorder and their families. As someone who works closely with children and families affected by autism every day, and as a mother of a child on the Autism Spectrum, I would like to encourage the IACC to prioritize research that explores not only behavioral interventions, but the biological and medical factors that may contribute to symptoms and quality of life for some individuals with autism. Autism is a highly heterogeneous condition. While behavioral and educational supports are essential, many children also experience significant co-occurring medical concerns, including gastrointestinal symptoms, sleep disturbances, immune dysfunction, nutritional deficiencies, metabolic abnormalities, and chronic infections. Some families and clinicians also report concerns related to environmental exposures, including mold, although more high-quality research is needed to better understand when and how these factors may be relevant. There is an urgent need for well-designed studies that investigate questions such as: How common are nutritional deficiencies among individuals with autism, and which deficiencies are most clinically significant? What role do gastrointestinal health, the microbiome, and chronic inflammation play in behavior, cognition, and overall functioning? Under what circumstances do chronic infections or immune dysregulation contribute to symptoms, and which interventions are effective? How should environmental factors, including mold exposure and other toxins, be evaluated in children with autism, and what evidence-based treatments improve outcomes when these issues are identified? Which biomarkers can help identify subgroups of individuals who may benefit from personalized medical approaches? Many families are searching for answers beyond symptom management. I can help them, but they want and deserve the rigorous scientific research that helps distinguish effective interventions from ineffective ones and identifies which children may benefit from individualized medical evaluation and treatment. Expanding research in these areas does not diminish the importance of behavioral therapies. Rather, it recognizes that autism is complex and that many individuals may benefit from a comprehensive, whole-person approach that considers both neurological and physical health. My hope is that future IACC research priorities will include large, multidisciplinary studies examining nutrition, metabolism, immune function, environmental health, gastrointestinal function, sleep, and other potentially modifiable medical factors that may influence health and functioning in people with autism. Thank you for your dedication to advancing autism research. Families across the country are counting on continued scientific exploration that seeks not only to better understand autism, but also to improve health, quality of life, and long-term outcomes for individuals on the spectrum. Sincerely, Lori DiBartolo

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3. Charmaine Porter

My name is Charmaine and I am a self-advocate—an adult with autism. I am also a parent to an allistic child. A public comment during the March 19th meeting named the need for applied research methodologies to be centered in efforts to approve the lives of autistic individuals. I would like to add that Participatory Action Research (PAR) is a particular applied research methodology that I believe should be supported by the I-ACC in order to ensure that autistic people are shaping the outcomes determined by said research. PAR is an essential practice that names those who are directly impacted by an issue as experts with the necessary tools to address its root causes. What research is being done to support autistic adults beyond young adults? What therapies are working for adults with autism? What issues are adults with autism facing—sustaining employment, establishing autonomy, accessing services, navigating parenthood, etc. What are adult AFAB (assigned female at birth) autistic people experiencing? How do conditions such as PMDD and PMOS interact with autism? Is postpartum depression exacerbated within adults with autism? What supports do autistic parents need to navigate burnout while raising children? What is the transition into seniorhood for autistic elders? I'm also curious to know how autistic meltdowns / shutdowns and cyclical burnout affect our bodies long term. This particular topic should include disaggregated data—how are different identities affected (gender and race in particular) so that we can get a fuller understanding of how we are experiencing the physiological existence and functioning of autism.

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4. Steven Kapp

The draft of the (federal) IACC's Strategic Plan appears to abandon the topic areas focused on in past versions (Screening and Diagnosis, Biology, Genetic and Environmental Factors, Interventions, Services and Supports, Lifespan, and Infrastructure and Prevalence). I encourage the I-ACC and its member organizations to advocate for the IACC to have such or a similar wide-ranging focus. While research on biology and co-occurring conditions may have merits, we autistic people and our loved ones and we autism researchers know the practical benefits of more immediate and practical research in areas such as communication, mental health, education and employment, and services.

While we do not know how the IACC will respond to public comments, and as the I-ACC considers strategies for drafting its own Strategic Plan, similarly consider a diverse focus of topic areas. This can be research from augmentative and alternative communication and otherwise research on investigating reliable means of communication, to investigating the amount and effects (including adverse effects) of interventions to maximize benefit, public trust and community take-up, and cost effectiveness. I agree with my understanding of Professor Helen Tager-Flusberg's remarks that I-ACC might not have the resources to focus on policy and practice beyond research, and that these are more the domain of the IACC.

I hope the I-ACC maintains a focus on autistic people as a whole. Individual studies may involve autistic people with severe to profound intellectual disability for example as relevant to the study's purpose, or a subset of autistic people that does not necessarily match official or proposed categories. People with complex or high support needs should receive a disproportionate amount of research funding and services, while there are still countless issues from a lack of valid subgroups to a lack of reliable means of identifying them in community practice. The aim is person-centered planning and care responsive to contexts and the dynamics in one's life, but again my understanding is the I-ACC will focus on research rather than policy or practice.

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5. Matthew Belmonte

I want to take up an observation voiced in the previous meeting by Dr Insel, on the difficulty of getting innovations commercialised to make an impact with stakeholders. A few years ago we had a grant from the UK National Institute for Health Research to evaluate an iPad-based intervention to develop visuomotor skills prerequisite to keyboard communication in minimally speaking autistic children. We hit all our pre-registered benchmarks in that trial, and the project won a Trophée de la e-santé in France, but despite these successes and recognitions we have been unable to find interest from any commercial partners. Four months ago I was chatting with Isabel Dziobek and she voiced similar obstacles to adoption of her technology. Instead, the space of autism technologies is all too dominated by apps backed more by marketing and name-dropping of neuroscientific terms than by actual neuroscience. The field needs a mechanism to connect evidence-based new technologies with companies willing to bring these technologies to market, in ways that preserve and enhance socioeconomic accessibility of these technologies. Scientists haven’t the spare time to implement such a mechanism, or to work around its absence. The resulting vacuum cries out for an open collaboration, organised by governments or by a consortium of corporate social responsibility schemes. The gap is evident; the question is how to bridge it.

6. 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. As the Committee develops recommendations regarding autism research priorities, we encourage it to ensure that the needs and perspectives of autistic people with motor and communication disabilities are fully reflected throughout its work. Communication Access Must Be Recognized as a Research Priority Communication is fundamental to nearly every aspect of life. It affects access to health care, education, employment, relationships, community living, self-determination, and civic participation. Yet communication disabilities often remain underrepresented within autism research despite their profound impact on quality of life. We encourage the Committee to recognize communication as a research priority that should inform every area of the Strategic Plan rather than being treated as a narrow intervention topic. In particular, future research priorities should include: Communication development across the lifespan; Augmentative and alternative communication (AAC); Implementation of communication supports in health care, educational, employment, and community settings; Communication access during emergencies and medical care; Equitable access to communication evaluations and AAC services; and Outcome measures that reflect autonomy, participation, and quality of life for people with significant communication disabilities. Research Must Continue to Advance Understanding of Communication and Motor Disabilities CommunicationFIRST is concerned by statements made during the Committee's March discussions that appeared to dismiss or minimize the role of motor disabilities in communication, and in autism as a whole. We are particularly concerned by suggestions that acknowledging the role of motor disabilities somehow redefines autism itself or is inconsistent with established understandings of autism. Motor disabilities are well documented among the autistic population, including but not limited to the autistic population (Miller et al., 2024; Piccolo et al., 2025). Although many important scientific questions remain regarding their causes, mechanisms, and interactions, decades of research have documented that many autistic people experience disabilities affecting motor planning, motor coordination, speech production, and expressive communication. Continued research is needed not because the existence of these co-occurring disabilities is in doubt, but because important questions remain regarding their prevalence, underlying mechanisms, assessment, and implications for support and long-term outcomes. The Committee should therefore be cautious about dismissing these areas of inquiry based on anecdotal observations or individual experiences. Scientific research priorities should be guided by the weight of the available evidence rather than isolated examples. Autism is an extraordinarily heterogeneous disability, and this individual variation should motivate further research. We therefore encourage the Committee to support research that improves understanding of: Developmental motor coordination and motor planning differences in autism; Childhood apraxia of speech and other speech-related disabilities among autistic individuals; Relationships between motor function and expressive communication; and Methods for accurately assessing cognition independent of speech or motor ability. Communication Research Is Essential to Improving Health Outcomes Communication barriers contribute to significant health disparities experienced by many autistic people. Individuals who cannot expressively communicate with health care providers face increased risks of diagnostic overshadowing, delayed diagnoses, inadequate treatment, preventable hospitalizations, and poorer overall health outcomes. We encourage the Committee to prioritize research examining: How communication barriers affect health outcomes; Interventions that improve communication access in health care settings; Clinician training regarding communication disabilities; Strategies for reducing diagnostic overshadowing

among autistic people with significant communication disabilities; and The impact of communication supports on health, autonomy, and quality of life. This research has the potential to improve not only communication itself but also broader health and participation outcomes across the lifespan. Conclusion CommunicationFIRST appreciates the Committee's commitment to developing an evidence-based research agenda that improves the lives of autistic people. As the Committee continues its work, we encourage it to ensure that communication is recognized as a foundational component of autism research. We also urge the Committee to ground its recommendations in the full body of available scientific evidence, including the extensive literature documenting communication and motor disabilities among many autistic people. Whether a particular intervention ultimately proves effective or ineffective should not diminish the importance of continued research into communication disabilities themselves. Research on speech, language, motor planning, AAC, literacy, communication access, and related topics is essential regardless of debates surrounding individual intervention methodologies. Finally, we encourage the Committee to ensure that autistic people with communication and motor disabilities are not only the subjects of research but active participants in shaping, conducting, and benefiting from it. Thank you for the opportunity to provide these comments. Sincerely, Sam Crane, JD Director of Policy and Legal Advocacy CommunicationFIRST Works Cited Miller, H., et al. (2024). Motor problems in autism: Co-occurrence or feature?. Developmental Medicine and Child Neurology, 66(1), 16-22 https://doi.org/10.1111/dmcn.15674 Piccolo, A. et al. (2025). Motor Coordination Assessment in Autism Spectrum Disorder: A Systematic Review. Diagnostics, 15(17), Article 2118. https://doi.org/10.3390/diagnostics15172118

7. Tanya Marquette

Having followed the issue of vaccines with their adverse effects particularly autism for many decades it is encouraging that this committee may actually do the serous research on such a high govt level that has been needed. Many medical practitioners, medical researchers, medical journalists and, of course, parents have been speaking out on these serious affects of these drugs. If it weren't for the powerful drug lobby this issue would have been addressed from the inception of the creation of these drugs. People like Suzanne Humphries, MD, a nephrologist documented much of this history in her co-authored book Dissolving Illusions. People like Neil Z Miller has been writing about this for decades. Doctors like Toni Bark and Joseph Mercola faced themselves to admit the harm they were doing with these drugs and stepped outside the mainstream medical dogma to change their practices and speak out against the harm. Paul Thomas, MD and Lawrence Palevsky, MD, both pediatricians saw the harm and changed their practices, Dr Thomas stepping out of practice altogether but not out of speaking out. Medical journalists like Gary Null have testified to NYS legislature some years back and Lawrence Palevsky did to the Connecticut Legislature within the past 6 or 7 yrs. The medical industry has a long and sorry history of foisting toxic, harmful, and worse than placebo drugs on the public with almost total impunity. With vaccines they were awarded total immunity for the damage they cause. This immunity was used to label the covid mRNA drugs as vaccines to free the drug corporations from lawsuits. This issue is a corollary to the issue of vaccines and autism as these corporation are free to promote barely tested drugs and drugs that they know cause numerous adverse effects including autism. Reading the drug inserts that are required with every dose of every drug so often includes autism as one of the dangers. Without getting too long let me simply state my very strong concern and recommendation that this committee pull off the blinders and take a deep look at the century of evidence of harm. Mandating these drugs along with the 'held harmless' status for drug corporations must be stopped. Parents and all people must be free to chose whether they will accept these drugs into their body and that of their children. This would be the minimum change to be made. Serious information must be given to people before vaccines are pushed on them. Paul Thomas, MD did an excellent brochure on informed consent for his patients. Doctors are horribly uninformed as they are never trained in this in medical school. This void in education is aggravated by the government financial incentives given to doctors to push vaccines and insurance companies do the same being known to set target goals for financial benefit. This must stop. States must cease with their draconian mandates as in California and New York (my State). On another level, protocols for treating damaged children and adults must include non-pharmaceutical protocols as well as the use of drugs which often cause more problems. There are numerous protocols for addressing autism that include serious dietary cleaning up eliminating all chemicalized foods and promoting organic diets. Ketogenic diet is very helpful with many brain injuries. Homeopathy has been getting used for many years to undo the damage of autism quite successfully. Behavior modification has been useful. This is just a partial list of known and successful paths to healing or amelioration. I do hope this committee will avail itself of people with experience in using these methods, both practitioners and parents and adult victims of these drugs. Of course, environmental toxins are equally important as they have gross impacts during pregnancy as well as after birth. This aspect of concern brings up the need for cleaning up the food sources in the US. People need re-education on what they are eating. Even people with good incomes who may think they are eating well, are not. They are not paying attention to the effects of GMO food and Glyphosate on reproduction, for example. This country needs a serious overhaul on so many levels that the problem can feel overwhelming. However, these arenas of concern must be called out being identified existing under the same umbrella and being related. Solutions must include all government agencies which need to be relieved of their corporate controls. I do hope this committee will prove itself serious in the work to be done. I do hope the voices of parents and those harmed will be elevated in importance. Thank You

8. Jill Levy

You started your own IACC group before the government's first IACC meeting even took place, claiming you weren't aligned with the new IACC. What exactly were you disagreeing with before the committee had even met? It seems like the decision to split was made before giving the new committee a chance. And if your goal is to help autistic children and families, what meaningful progress have you made in autism or related research over the last twenty years? If you're positioning yourselves as leaders or mentors, what recent accomplishments or measurable impact are you bringing that benefits the community?

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9. Amina Ammoura

I am a parent of 12 year old nonverbal boy with severe autism. I would like to share my life experience of what I have gone through with my son.

Before he was diagnosed, it took me going to 9 different pediatricians just to get a blood test to find out that he also has a genetic duplication of 22q11.2. I love advocating not only for my son but for other kids with special needs as well. I am a clerk at Children Youth and Families and see a lot of youth having special needs as well.

If possible, I would like to become a member in the future.

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10. Lori McIlwain and Dr. Caleb Hudgins, National Autism Safety Council (NASC)

Chair and members of the I-ACC, thank you for the opportunity to comment.
My name is Lori McIlwain. I'm the parent of a 26-year-old son with a long history of elopement, a co-founder and former founding board member of the National Autism Association, and founder and president of the National Autism Safety Council (NASC). I am joined in these comments by Dr. Caleb Hudgins, NASC's Vice Chair. Together, we write on behalf of NASC. For the past twenty years, I have worked as an independent researcher and advocate on autism elopement. I have studied thousands of cases spanning five decades, published three studies on elopement-related fatalities with a fourth underway, consulted on state and federal policy, and have developed national programs, including the Search Water First campaign and Big Red Safety Box, its booklet, among many other resources. I began collecting cases in the 2000s, originally to bring to Individualized Education Program meetings at my son's school in an effort to advocate for his safety following repeated elopement incidents. Over time, this grew into a national dataset, which I maintain and cross-check with federal collaborators. It was from this dataset that I first approached IACC in early 2010 via a written statement. I thank all IACC members, past and present, for their direct and indirect work on this issue, including hosting a live DOJ panel, which was a critical step in the passage of Kevin and Avonte's Law. The collective work over the last sixteen years has led to research, tools, programs, education, initiatives, policy, and training, forming the foundation for any and all work on this topic moving forward. Most of us have seen or heard of at least one case where first responders credited training or awareness, specifically around water risk, with safely recovering a missing person with autism. I believe the fatality numbers we share with you today would be higher without that work. However, even with these expanding resources, since June 1st, at least 24 individuals with autism have died as the result of elopement, 21 from drowning. This includes multiple cases of adults who left a group home or community outing. Among all 2026 elopement fatalities with race reported, nearly four out of five involved a child or adult of color, suggesting a unique and elevated risk for this population and potential gap in existing resources needed to keep Black and Brown members of our autism community safe. A collaborative commitment across organizations and agencies for targeted prevention strategies is needed to help address this gap. Without addressing it directly, these fatalities will likely continue. In April, IACC under HHS, delivered a presentation on the topic of autism elopement, and from that, submitted a federal document referred to as Attachment D, which proposes safety measures and policy objectives to address elopement related fatalities. However, Attachment D does not acknowledge this racial disparity or recommend targeted prevention strategies. HHS and other agencies are uniquely positioned to provide focused outreach, support, and prevention resources. Future state and federal surveillance systems would also benefit from more consistently collecting race data so this disparity can continue to be monitored and addressed. Because Attachment D relied extensively on my surveillance research, and referenced both me and NASC multiple times, I was surprised that neither I, nor other subject matter experts from NASC, were asked to review it before publication. When presentations and supporting documents are used to develop federal policy recommendations, they should identify the authors responsible for all underlying research, surveillance, and writings, not simply the organization through which that work was published or presented. Doing so promotes transparency, allows committees to recognize the appropriate subject-matter expertise, and helps ensure that future guidance is informed by leading experts who have actively maintained and advanced this work. While NASC's current, and my past, research was the primary reference for this report, it is our opinion that Attachment D does not accurately or adequately reflect the scale and scope of this current crisis. The report, along with messaging on this topic from HHS, includes specific errors and mischaracterizations of the research, provides certain recommendations that go against the data, and leaves critical gaps unaddressed. In addition to adding language about the disproportionate risk facing autistic children and adults of color, we offer the following recommendations so that the final guidance is as accurate,

complete, and useful as possible for the autism community. Recommendation 1: Present surveillance statistics as a single dataset, not separate sources. Both the April presentation and Attachment D cite NASC and National Autism Association drowning statistics as though they are two separate sources reaching the same conclusions. In reality, both originated from the same underlying surveillance dataset that I developed and have maintained. I now maintain this dataset exclusively through NASC. Hence, NASC and National Autism Association are not separate sources for this dataset. Likewise, the averages of seven and eight elopement fatalities per month represent 2024 and 2025 findings, respectively, from that same dataset, not separate national estimates. When these data are presented as differing estimates, and not as a sequence (2024-2025), it obscures the potential increasing trend. Also, the recent HHS public service announcement that referenced eight average drowning deaths per month should also be corrected. The accurate figure is an average of eight autism elopement-related fatalities per month, of which drowning accounts for the majority (over 80%), but not all, fatalities. Recommendation 2: Incorporate the existing national Wireless Emergency Alert (WEA) work already underway. While Attachment D suggests the need for an improved alerting system, it does not recognize the national multidisciplinary working group that has already completed extensive work in this area. This effort resulted in the Autism Wireless Emergency Alert template, which was made available to jurisdictions in June. This template was developed over the past year by recognized national experts in Wireless Emergency Alerts, emergency communications, missing person response, missing and exploited children, and autism elopement. Fatality surveillance data, operational review, and WEA technical requirements were also considered while developing this tool. As such, we recommend that this existing template should inform Attachment D rather than be recreated through a redundant parallel process. For those unfamiliar with the term, Wireless Emergency Alerts, or WEA, are automatic phone alerts, similar to AMBER Alerts and severe weather warnings, that reach every wireless phone in a targeted area without requiring an app or signup. Recommendation 3: For WEA language, avoid listing water and traffic as equal co-hazards. In the current report’s recommendations for the WEA language template, Attachment D currently presents water and traffic as equal co-hazards. The surveillance data do not support equal weighting. Additionally, "High-risk traffic" is not operationally defined, making it unclear what areas need to be prioritized. Roadways are dangerous, but they also typically have drivers and bystanders already present who may observe and assist an individual before a fatal outcome occurs. Traffic-related incidents also often unfold within seconds, leaving little opportunity for a public alert to change the outcome. Water environments, by contrast, frequently lack bystanders and offer a greater opportunity for alert systems to lead to a successful rescue. Given the limited character space available in Wireless Emergency Alerts, every word should reinforce the action most likely to save a life: searching nearby water first. As it stands, across the complete surveillance dataset spanning more than five decades of cases, approximately 82 percent of known elopement fatalities resulted from drowning, while vehicular fatalities account for only 12 percent making a drowning fatality nearly 7 times more likely than a vehicular fatality. Recommendation 4: Strengthen surveillance while preserving existing expertise. A surveillance snapshot alone does not produce the depth of understanding this issue requires. Expertise comes from years of memory of idiosyncratic circumstances from individual cases, pattern recognition, repeated analysis, and institutional knowledge which only comes through long-term surveillance and study. As an example, one isolated report noting that a parent was unloading the car may seem insignificant on its own, and hence not systematically collected in standardized surveillance data. Though, seeing that same circumstance recur across additional past cases reveals a potential preventable pattern that can be communicated directly to families. Any future surveillance system should build upon the existing body of work while expanding standardized reporting nationwide, including models such as Florida's diagnosis-inclusive child fatality reporting system. Surveillance should also explicitly include individuals awaiting diagnosis, young siblings of autistic children, and autistic adults in group homes, day programs, residential schools, and other high-sensory settings, where elopement risk persists but remains underrepresented. Recommendation 5:

Update registries, emergency profiles, emergency dispatcher protocols, and clinical guidance to reflect the evidence. Many existing registries, emergency profile forms, and dispatcher protocols ask caregivers to identify favorite places or preferred destinations. For children with autism, surveillance data consistently demonstrates that nearby water should remain the immediate search priority regardless of reported attractions, preferences, or aversions to water. Tools, guidance, and dispatcher protocols should therefore be revised to direct callers, communities, and responders to immediately search nearby water by default when a child with autism is missing. NASC has also been working to develop a standardized clinical autism elopement risk screening tool grounded in this surveillance data, and we welcome the committee's participation and support as that work progresses. Recommendation 6: Build upon existing national initiatives through earlier expert collaboration. Those with longstanding, documented, and demonstrated expertise on the various aspects of autism elopement should be engaged early in the development and review of federal guidance. Likewise, NASC’s national working group is currently developing a standardized school emergency response plan following multiple school-related fatalities and serious injuries in 2025. This work, along with the Wireless Emergency Alert initiative, dispatcher training, and clinical risk assessment tool, among other initiatives, should inform future federal guidance rather than proceed on separate tracks. Thank you for your continued commitment to improving safety for autistic individuals and their families. We hope the committee will take this opportunity to ensure any federal recommendations reflect the strongest available evidence and expertise so that additional oversights, gaps, and errors do not occur.

Thank you, Lori McIlwain Founder and President National Autism Safety Council
Dr. Caleb Hudgins Vice-Chair National Autism Safety Council

11. Wensheng Li

As a parent, science communicator, and autism advocate, I am so thankful the commitment of this committee to science. I sincerely hope the committee will make the following projects a top priority 1.Build a trusted hub for evidence-based autism science communication. Autism interventions based on pseudoscience not only strains familial and social resources, but could cost lives. In 2025, a 5-year child died from Hyperbaric Oxygen Therapy in Michigan. In China, the body of an 8-year boy was found in a mountainy area when receiving interventions based on pseudoscience. It is extremely important to educate parents about evidence-based interventions for their loved ones. For the past decade, I have been promoting autism science within the Chinese-speaking community by writing articles and debunking pseudoscience in this field. And in 2024, China's Huaxia Publishing House compiled ten years of my writings into a book titled This is Autism: the Science, the Data, and the Rumors. When working on my book, I have been reading research papers, as well as reports from open resources including CDC and the website of spectrumnews.org (now the transmitter) from Simons Foundation. However, in the last couple of years, the CDC's authority has been complicated by public trust challenges, and the Transmitter is more for the research community, not families and general public. It is urgent to establish a new trusted hub dedicated to autism science communication for parents and general public. 2.Continue the efforts to classify autism into sub-groups. Over the past few decades, the autism community has become so deeply divided that it has reached a point of hurting each other. This is mainly due to the different perspectives from different groups. It is essential to sub-group the broad autism spectrum disorder and allocate different resources to meet the needs of different groups. Sub-grouping is also important for autism research. For example, metabolomics has been employed to identify biomarkers for autism diagnosis, but has made very limited progress. Metabolomics is a powerful tool to distinguish distinct phenotypes—a component that is lacking in current autism research. We are glad to see progress has been made. In 2025, a research team led by Olga Troyanskaya, a computer science professor at Princeton University, used artificial intelligence methods to classify autism into four types based on behavioral and genetic data. And just this past June, Alison Singer of the Autism Science Foundation and her collaborators reached a degree of consensus on the defining characteristics of profound autism. But the efforts should be continued to ensure that no individual is left behind in both research and public service. 3.Unite Autism Advocacy and Autism Science I went to Capitol Hill to advocate for the Autism CARES Act, which was a very rewarding experience. However, I am also worried that all the efforts to fight for the budget might be used for interventions and therapies with very limited scientific evidence. I hope the IACC can unite most autism advocacy groups to advocate for autism and autism science together instead of separating them.

12. Dave Justus

Good afternoon, and thank you to the committee for the opportunity to speak. My name is Dave Justus. I'm the father of a 17 year old son with profound autism and Fragile X, and I'm also the founder and CEO of NeuroQure. Like many parents in this community, my family's journey with autism began with uncertainty. We spent years searching for a diagnosis, and we were not alone in this diagnostic odyssey. Most autism evaluations rely on observed behavior, which often cannot be reliably assessed until a child is 18 months old or more. This means families often spend years waiting for clarity, like we did. We know that evidence-based early interventions can change life trajectories, yet the average age of diagnosis and commencement of therapies across our nation has stubbornly remained way to high, way too late. For decades, families and clinicians have hoped and searched for scientific tools and biologic markers that could identify autism risk earlier, before behavioral assessments are possible. Today I want to share a scientific development that contributes to that goal. Researchers at UC Irvine identified a measurable biological marker related to calcium signaling in skin cells that correlates with autism risk; and is present at birth. At NeuroQure, we are working to translate this research into something that can help families and clinicians access earlier insight into a child's autism risk, with ASD Insight™. I've linked here both the peer reviewed scientific literature on ASD Insight and a video explainer prepared by our cofounder and Chief Scientist, Doctor Jay Gargus, who is the principal inventor. • 5-minute science overview (Dr. Jay Gargus): ASD Insight™ Explained • Key publications underpinning the biology: • Intracellular calcium dysregulation in autism spectrum disorder: An analysis of converging organelle signaling pathways - PubMed • High-throughput screen detects calcium signaling dysfunction in typical sporadic autism spectrum disorder - PubMed • Shared functional defect in IP■R-mediated calcium signaling in diverse monogenic autism syndromes - PubMed As the committee continues its work on the Strategic Plan for Autism Research under the Autism CARES Act, I respectfully encourage the IACC to consider the crucial role that biology-based markers and early risk detection may play in the future of autism research and intervention. Continued progress in this area could expand the tools available to clinicians and provide families with earlier insights as they navigate their child's developmental journey. Thank you for your time and for the work this committee does on behalf of individuals with autism and their families.

13. Emmet McManus

Dear I-ACC committee, ~Developmental Origins of Health and Disease. I am writing to ask that you consider or advise me on, the possibility that some complex traits (INCLUDING AUTISM) may be influenced by a certain unconsidered epigenetic mechanism operating at conception; that is, the laterality of gamete origin, and their combinations. Understanding '1 of 4' (LL;LR;RL;RR) gamete pairings takes place, NO EVIDENCE exists explaining whether there are any detectable compatibility differences between each of the 4 nor whether there could be any potential ramifications, depending on which 1 of the 4 combinations establishes. This astounds me, leaving me compelled to ask 'Is this 'science' that needs to be considered deeper?' As you well know, advancing discovery requires investigation and validation, and it begins by asking challenging questions, such as above. One can't help but wonder: could there be a connection regarding what impact these combinations of lateral gametes could have on aspects of human development. Perhaps none, but also perhaps something reliable and consequential. However, I can find NO EVIDENCE that any scientist has yet looked at this pretty simple question. This invites other associated questions such as: Can an experiment be designed to test this hypothesis? / Are you, or is anyone, interested in exploring this possibility? / What means are available or what resources would be required to help 'kick-start' an experiment to test the hypothesis that lateral origin of gametes, and their combinations, can have some impact on the epigenetic profile of resulting cells, and traits in an organism? Essentially, this is an appeal for scientific review and to engage in meaningful discussion. Thank you for your consideration and I welcome your advice or any comments, Emmet McManus.

14. Shari Bailey

Thank you for the opportunity to provide public comment regarding the important work of the IACC and its continued commitment to improving the lives of individuals with autism and their families. I respectfully urge the Committee to prioritize elopement and wandering as a national public health and public safety issue within its strategic discussions and future research agenda. As the founder of The LEAD Act (Laila's Elopement Awareness and Dissemination Act), my advocacy is deeply personal. My daughter, Laila, lives with a rare syndrome, has autism, and is nonverbal. After experiencing a frightening elopement incident, I quickly realized that our family's experience was not unique. Thousands of families across the country live every day with the fear that a loved one may wander from safety, often with tragic consequences. Elopement is one of the most significant yet under-addressed safety challenges affecting the autism community. Research has shown that nearly half of children with autism have attempted to elope, and drowning remains one of the leading causes of death following an elopement event. These incidents also place tremendous demands on first responders, schools, healthcare providers, and caregivers while creating lasting emotional and financial impacts on families. The LEAD Act was developed as a comprehensive, bipartisan framework to address these challenges through three core pillars: Access, Coordination, and Training. Maryland has already enacted portions of the LEAD Act legislation that expands access to resources, improves public safety training, strengthens emergency response, and recognizes that wandering is not solely an autism issue but a lifespan issue affecting individuals with autism, intellectual and developmental disabilities, Alzheimer's disease, dementia, and other cognitive disabilities. This broader perspective is especially important. Through our partnership with AARP Maryland, we have worked to elevate wandering and elopement as a shared public safety concern across generations. While the underlying conditions may differ, families often experience the same fear, uncertainty, and urgent need for coordinated community responses when a loved one goes missing. The work of the IACC has the opportunity to influence meaningful national change. By elevating elopement as a research, policy, and public safety priority, the Committee can help reduce preventable tragedies while improving outcomes for individuals with autism and their families. I would be honored to meet with the Committee in person to discuss the LEAD Act, the collaborative framework we have developed, and opportunities to build upon this model at the national level. I believe the lessons learned through our legislative efforts can help inform future federal research, policy, and cross-agency collaboration.