



## **Public Comments**

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## Oral Comments

**Russell Lehmann**

My name is Russell Lehmann, and I'm a motivational speaker and poet with a platform of autism and mental health.

As an individual with autism and other mental health diagnoses, I've been admitted to three separate psychiatric wards in my life, each time leaving worse off than when I entered due to horrible treatment and severe lack of compassion.

With this personal context of the lived experience, and as an activist for those not seen or heard by society, I would like to express my view on the shock treatment at the Judge Rotenberg Center in Canton, MA.

## Nicole Corrado

I have lived experience with the missing persons/wandering issue.

<https://nicolecorradoart.wordpress.com/2019/01/29/how-to-report-missing-persons-with-neurological-differences-respectfully/>

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I am autistic, and have experienced wandering/elopement behaviour. I have written an article, based on lived experience, regarding missing autistic persons.

<https://nicolecorradoart.wordpress.com/2019/01/29/how-to-report-missing-persons-with-neurological-differences-respectfully/>

I do not agree with tracking devices, unless they can easily be removed, and are consented to. There may be cases in which a non consenting person (adult with dementia, or very young child) may wear a removable tracker, but the point of any tracker must be to improve independence. A tracking device should not be used to further restrict a person. Therefore, the default for tracking device purchase must be self sign up and self purchase for adults.

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I am autistic and live in Toronto, Canada. I am interested in the topic of elopement and Kevin and Avonte's law from the perspective of an autistic person. I am involved with an upcoming research project on elopement behaviour.

While tracking devices are one tool to reduce search and rescue time in finding missing persons, they are controversial, and do not always prevent elopement or drowning deaths. The funding from the Kevin and Avonte's Law grant program should be used to support swimming lessons, and other sports programs, (persons often run or swim to get rid of anxiety or other pent up energy), education programs to teach autistic persons the dangers of elopement, and healthy alternatives to the behaviour, mental health programs for autistic persons with various support needs and communication methods, (including an autism specific crisis phone line that accommodates spelling for communication), relationship support and education for autistic persons (including sexual education and consent education), a safe place for autistic persons fleeing abuse, mandatory autism education by autistic persons for all first responders, and housing/funding supports for persons who want to live independently.

**Karen F. Heffler, M.D.**

I am an autism researcher at Drexel University, and mother of an adult son with autism.

I ask you to please listen carefully to the research that I will briefly review and that you discuss this and act on it urgently in the Strategic Plan.

While autism prevalence rates continue to rise, there is ample research findings of an association between early-life digital screen exposure and autism outcomes. Additionally, there are growing reports of intervention including turning off screens and focusing on social engagement strategies in children 4 years old and younger with a history of high exposure to screens, resulting in more rapid and extensive improvements in autism symptoms, than is typically seen. Our work is additionally showing a decrease in parent stress related to the intervention.

These findings are consistent with child development literature. Infants and toddlers learn through parent-child interactions. Digital screens in the background, as well as parent focused, and child focused screens all interfere with these critical parent-child interactions. A landmark 2021 Australian study showed that parent-infant social communication training decreased autism outcome in infants who were showing early signs of autism.

Higher screen time is also associated with language delay, social impairment, attention problems, cognitive impairment, challenging behaviors, and dysregulation, all of which are co-occurring in autism.

In the US, toddlers average 2.5 hours/day of screen time and 50% have their own mobile devices. In Romania, 97% of children presenting with an autism diagnosis had screen exposure of at least 4 hours/day since infancy.

What can be done by the IACC? Provide an urgent recommendation in the Strategic Plan to provide a focus on research to study:

- 1) Parent education to expecting parents and new parents on digital screen time and social engagement strategies, with autism and child development as outcome measures
- 2) Parent education and support to decrease screen time and focus on social strategies in young children with autism and high screen exposure, with autism symptoms and child development as outcome measures.

As a parent of an adult son with autism, I understand the need for services for all impacted by autism. With rising autism prevalence, the need for lifelong services is astronomically increasing. Addressing this environmental risk factor from both the prevention and intervention pathways has the potential to significantly improve outcomes in the youngest children with this exposure, thereby leaving greater resources for other children and adults with autism.

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## **Alison Singer, M.B.A.**

I'm Alison Singer, President of the Autism Science Foundation and mother of a daughter with profound autism. I served as a public member of the IACC for 12 years.

In December 2021, The Lancet published a special report I co-authored titled "The Lancet Commission on the Future of Care and Clinical Research in Autism." In the report, the commissioners introduce the term "profound autism," which is intended to describe autistic people with intellectual disability, who are minimally verbal and who are likely to need 24-hour support throughout their lives. The goal of introducing this designation is to provide more specificity to the extremely broad autism spectrum - to equip parents, researchers, scientists, service providers and the public with the language necessary to ensure that all individuals with autism receive the accommodations and interventions they need. Concise, meaningful terms like "profound autism" will simplify the process of determining appropriate care, leading to quicker and more forceful interventions. For those who bristle at the use of labels to describe autism, it's vital to understand that the term "profound autism" does not seek to demean individuals in this group, nor does it seek to invalidate the experiences of those not in it. Instead, "profound autism" is meant to call attention to the unique needs of this vulnerable, underserved community.

A few days before The Lancet commission report set out a clear clinical definition of what constitutes profound autism, the Centers for Disease Control and Prevention (CDC) announced that autism rates are once again on the rise. The uptick in diagnoses makes the need to provide more specificity to the broad autism spectrum feel especially urgent, particularly given that the CDC reported that more than 58% of 8-year-olds with autism had intellectual disabilities or borderline intellectual disabilities. Similarly, the Lancet Commission, made up of clinicians, clinical scientists, high-functioning adults with autism and parents, reviewed several international datasets of people with autism utilizing the new clinical definition of "profound autism" (a term the commission worked on and debated for over 3 years) and estimated that up to 48% of the autism population falls into this category. In other words, for nearly every autistic person trying to get a job at Microsoft, there's also one who is nonverbal and is struggling to get through the day without peeling the skin off her arm or biting herself. Furthermore, these data indicate that for every high functioning adult with autism sitting at the IACC table, there should be a parent representing the needs of a child or adult with profound autism.

Autism used to mean something specific; until we moved to DSM5, autism described a consistent cluster of symptoms. But today the phrase "autism spectrum disorder" has become such a big tent term that the people under that tent often have little in common with each other. Autism can mean genius, or IQ below 50. Autism can mean highly verbal or nonverbal. It can mean graduating from Harvard Law School, or "exiting" high school with a certificate of participation. It can mean self-injury, sleep disorders, aggression, pica, wandering, biting, or none of these things.

If we are going to be able to personalize our approach to care and provide benefits to ALL people, we need terminology and language that are specific and meaningful. In fact, the DSM5 was supposed to do this—it was intended to provide greater specificity so that the diagnosis would point toward potential services—but because of the way DSM5 is applied, the opposite has happened. Everyone is lumped together as having ASD. To the broader public, the word "autism" only describes the more verbal, traditionally skilled, visible end of the spectrum, because those individuals are able to have a voice, represent themselves at meetings, participate in the IACC for example, and appear in the media. Unfortunately, television shows like *The Good Doctor*, *Love on the Spectrum*, *House*, and *Atypical* are broadcasting this brand of autism, and only this brand, to the world. The result is that autistic people with the most challenging behaviors have become invisible and are being left behind. Many of them cannot speak for themselves, and so this

task often falls to their family members. In fact, the basic civil rights of some people with autism are not being protected because the abilities and disabilities of each end of the autism spectrum clash, putting parents and caregivers at odds with those who can advocate for themselves, live independently, gain competitive employment and ultimately lead independent lives.

Since the publication of the Lancet commission report, I have heard from countless parents of profoundly autistic children who are scared about their children's futures and feel bullied into silence by higher functioning self-advocates who often have a fundamental misunderstanding of what having profound autism even means. These parents tell me they are exhausted, both physically and emotionally, by the work it takes to keep their children healthy and safe each day, and by the difficulties in securing quality care for their children. Most parents tell me they are terrified about what will happen to their profoundly autistic children after they die.

**I urge this committee to embrace the term "profound autism" and use it.** The positive response from the scientific community to The Lancet defining and calling for use of this term has been extremely gratifying. The term is being embraced because it's meaningful, much like the term "Asperger's" (which, unfortunately, we also lost with the move to DSM5) was also meaningful. Both terms describe clear clusters of symptoms, which is the key to determining and providing appropriate interventions, services and supports.

**I urge this committee to add additional public members who are parents of individuals with profound autism.** Specifically, the National Council for Severe Autism should be represented on this committee so that the needs of this population have a strong and consistent voice.

**I urge this committee to focus on this traditionally excluded population in the annual strategic plan for autism research.** People with profound autism are woefully underrepresented in research studies. Some of this is understandable, because of issues around consent and language, and because it's harder, for example, to get them to stay still in a scanner. But new PECS-based and social stories-based programs are being developed to help these individuals learn about research and prepare them to be research subjects. Excluding those with profound autism from autism research means the results of the research don't apply to them. I urge you to overweight and overrepresent those with profound autism in future research to compensate for past exclusion.

Thank you for your consideration and for your work to support the needs of all people with autism.

**Note: Personally Identifiable Information (PII) has been redacted in this document.**

**Michael Ha**

Consideration for additional resources on the study of reduction of screen time and increased social focus with young toddlers on the spectrum

My four-year-old Son [PII redacted] was born in the modern world of technology and social media where the physical and intimacy of bonding from birth was separated by nothing more than a WIFI connection.

So many of today's parents rely on lights, sounds, and lots of visual aid from devices that requires a power source to act as our babysitter while we busily continue our days, doing laundry, cooking, cleaning, shopping, fixing things, earning income for the family, tending to other children, or just having some alone time to recharge our own battery. We did this too, until 2 months ago.

My goal here today is to convey a message of hope and bring awareness of the detrimental effects of "tech" time, which takes away time from naturally occurring communication and social bonding, both of which is the core deficit of an ASD diagnosis.

To illustrate my own experience, [PII redacted] was diagnosed early, around 18 months old, and we had him started on Early intervention, with OT, SI, and speech, then on his 2nd birthday added more hours including ABA and daycare into his schedule all of which helped him improve his gross and fine motor skills and to some degree his receptive and non-verbal language... Despite extensive therapy for most of his waking hours, NONE of these services over 2 years significantly increased his social response to others. He had poor eye contact, no spoken language, played by himself, and did not engage with others.

However, about 2 months ago we were introduced to a Drexel researcher who compassionately suggested we might try some of the techniques that seemed to be beneficial in a recent pilot study. We agreed. The researcher taught us about how tech devices disrupt interactions between children and parents, and guided us and our team on strategies and techniques that involved intense social connections including strategies for eye connect and getting our child's attention. And one of the strongest suggestions was to remove all "tech" and screen time, cold turkey so that all available moments spent with [PII redacted] were dedicated to social interactions.

Within one week, we started to notice changes in his attentiveness to his family and his environment, within three weeks his respective skills took quantum leaps, and two months into this program, he has begun showing consistent signs of social engagement, parallel playing with his peers and some direct play at day care. He is producing vocal approximations of words, and now saying several actual words with meaningful intent. He giggles, looks at us, loves the attention from his parents, and points to objects he wants...

He has shown remarkable improvements since following these recommendations. This intervention is non-invasive, non-drug induced, scalable and teachable therapy that has tremendous potential to help others as it is helping our son.

So, what I am asking for isn't to help my son, as he is now making rapid improvements. I am asking that you provide funding and focus on this type of intervention so that other children and families can benefit from replacing tech time with social engagement strategies. Based on what we have seen, this is critically important. Thank you.

## Written Comments

**Lori Kay**

As the parent of an adult son who has moderate/severe autism, there is a great need to provide services and housing to people like him. Services are currently directed at the mild or higher functioning population and it is almost impossible to find adequate day programs and residential settings for those with greater needs.

**Zolfa Valiani-Merchant, M.D.**

This presentation from Drexel U on MH policy and analytics is extremely relevant and interesting. It definitely captures our experience with our teenagers, one with ASD/ADHD and the other with ASD traits and ADHD. I would like to hear more about how this data, other comments and work from this committee, etc. make more impact on best practices and professional education for special education providers in public schools. I'm new to the IACC, but given that the Department of Education is part of the federal government. Why has there been so little discussion about improving IDEA/IEP utility & section 504 plans and how the DOE can facilitate improved access and dissemination of information, especially to underrepresented communities? Please excuse my naivete on my part. Thank you.



**Zolfa Valiani-Merchant, M.D.**

Along the lines of what Dr. Piven commented on (affective, etc. disorders running in families) and in referring to previous comments about culturally competent care, please consider building into study design a way to reach subjects from non-caucasian populations with similar questions or a short survey to determine how they think more people within their communities might be reached more effectively. Study design that also provides information to give to subjects to widen their circles of participation and to encourage their family members/friends, etc, to participate in study may be another way to increase the diversity of autistics from underrepresented ethnic/racial backgrounds.

## **Nate Watkins**

I am here to speak about the issue concerning parents of children diagnosed with "severe autism". I sympathize with the struggles of such families, but I want the IACC to link such parents to articles such as "I Shouldn't Have to Dehumanize My Son to Get Him Support" by David M. Perry, published in The Nation Magazine. In this article, Perry, whose son is very much like the children diagnosed with "severe autism", criticizes the fact that the only way for him to get the kind of supports he needs for his son is to constantly refer to his deficits and the worst day he ever had with his son. I personally believe this is why parents of "severely autistic" children believe autism is a bad thing that needs to be wiped off the face of the Earth, either by 'getting rid' of their autism while they're still alive or by making sure no one is ever born autistic ever again. The only people who give said families any semblance of help go by a deficit model as a means of delivering services to them. Parents of "severely autistic" children put a lot of trust in the professionals going by this deficit-focused perspective because the parents are afraid that if they don't do as these professionals tell them to do, they'll be hurting their own children. To the parents I'm referring to, I will close out this comment by giving you some advice I don't believe anyone else has ever given you in your entire autism journey: It's okay to say no to professionals who are talking about your children like mistakes instead of the unique people they truly are. You don't have to ignore every professional, but if a professional is speaking about your child like they're a burden on society, you CAN tell that professional: "NO. This is MY child. YOU don't know my child at all. I do, and I'M going to help him/her achieve their goals. Believe what you want about my child, it's a free country, but I am telling you that as long as you're seeing me concerning my child, YOU are not going to talk about them like they're hopeless, and YOU can't tell me what my child's life is going to be like. My child is going to achieve SO much and when he/she does, YOU are going to regret talking about my child the way you have. Just you wait."

## **Rosalind Kaplan**

The brain is plastic (flexible) and more help for autistic people can be found. At any age. Repairs are possible for all Neurological Disorders. If the research is done.

Funding for research should be based on what has most potential not politics. Spectrum people never answers questions. This is very upsetting. My adult son made progress because of ABA. I want away to help him become more self sufficient. I do not believe all is being done that can be. Pharmaceutical companies oppose anything that does not require drugs. Parents know all that can be done is not being done. This is unethical and we are very angry. Autism can be cured.

What matters to me is that my son becomes self sufficient. I want answers.

**Note: Personally Identifiable Information (PII) has been redacted in this document.**

### **Edrick LaTrone Linston-Jones**

My name is Edrick LaTrone Linston-Jones and I was diagnosed with a disorder called Autism; more specifically called Asperger's Syndrome. Asperger's (Autism) has set up some pretty serious barriers in front of me throughout my life from school to home, from riding bikes, making friends and even dressing myself. In school, I struggled in specific ways. For example, I couldn't function in a loud environment, I was easily caught off guard and would easily forget what the teacher said, which caused me to fail tests. At home, I would feel uncomfortable staying alone because I would get nervous thinking someone would break into my home. My disability would increase my anxiety which caused me to become overwhelmed very quickly. I would get tasked with chores and couldn't complete step by step directions(two to three part directions) which was very challenging. I've also had trouble making friends because I wouldn't understand their social que's. Because of this, I was left alone, or I would always annoy others?.. I just didn't know. My family took me to several psychiatrists and the doctors thought I'd never learn how to ride a bike (I have the best grandmother who practiced daily with me and helped me learn quickly.) Throughout school, I had the best teachers in the Clarke County School District. My mother, Mrs. LJ, is a teacher in the school system. My mother was instrumental to me with my education. My mother would not allow my disability to stop or cloud my future. Because of her hard work along with the teachers, I graduated from high school May, 2020 and I'm currently planning to start college in the Spring, 2022. My major: Sociology Anthropology.

I always wanted a job so I could learn how to generate income. I applied to my local grocery store in my county. This is a great experience for me because I felt independent and self-sufficient. I met a lot of new people who were very patient with me and who also supported me regardless of my cognitive condition. The staff at the local grocery store showed tremendous support towards me and encouraged me daily. On Wednesday, November 11, 2020, I went to work in a great head space because I love what I do and the staff and customers are so kind towards me. I went to work and saw my friend "Bee" and I walked towards her and jokingly grabbed her neck twice(she and I always joke and laugh.) I didn't think anything of it because we formed a friendship and followed each other on more than one social media account so we were friends?.so I thought.

I was walking up to the front when the Clarke County Police Department approached me asking about "Bee." I thought she was in trouble but instead she had reported me saying how she felt uncomfortable around me and how I grabbed her twice. I was shocked that my friend would do this to me! I thought we were friends but instead I was completely shocked and confused as to why she would get me in trouble. Her parents rushed to the grocery store, not to mention her father is the captain of the police department. Her father(who wasn't in uniform and off duty) was persistent with arresting me when the police on the scene didn't want to. Her father began pulling "rank" and insisted I be arrested. I was arrested and very embarrassed as well as confused because I knew I didn't deserve what was taking place. I knew this was motivated by the election. She and I would disagree about political aspects of the world. I frequently would state my liking towards Biden and she was for Trump and against BLM. What "Bre" showed me was a very good reminder of the America I live in.

Throughout America, African American people, especially African American men have often been victims of the degrading stereotypes that we are subjected to constantly in our livelihoods. Stereotypes of being violent cause us to be feared in public spaces like stores, walking down streets, even so much as schools. African American men in particular are victims to the stereotypes that have indelibly

dehumanized our existence as black men, but also we have traditionally been victims of white women accusing African American men of untrue acts. These acts have roots behind it going all the way back to slavery when the whole Idea of black men being dangerous as well as sexual predators towards white women and how white woman have been depicted as the good and moral “right” in American society as well as helpless victims. Those two identities have allowed white women the power of using their victimhood to abuse black men and people of color in general. American society has allowed white woman that power which caused a huge injustice and proof of this country's history thus reinforces the system of white supremacy that still doesn't get addressed as well a systematic racism (black men being profiled more by police and more likely to get brutalized by police; immigrants of color are 7 times more likely to get deported than other immigrants.)

In conclusion, my story definitely has been A learning process for me. I've had to fully think about and process how some people are on the inside instead of what they present to you. My so-called friend was truly not my friend, and I didn't realize it but now I am more aware of who people really are. I've also learned that this country still has a long way to go in terms of meeting the quote that “all men are created equal.” Currently, that' S simply not true and it's never been true in a country that owned slaves or set up a system in which only the dominant white culture can benefit from. There is also something I'd do differently. I'd definitely get to know people a little more before calling them a friend.

Please read my son's story. An incident happened involving my son on November 11, 2020. My son was arrested and falsely accused of an act he did not do. We hired a lawyer and the case was dropped. My son's information is:

[PII redacted]

## **Daina Krumins**

How to hold a conversation with an NT? In Victorian England there were books written on etiquette and "proper conversation" which were probably useful for ASD people. But now, what do we do? At a job interview, for example, what should be said, and what should not be said? An ASD person with good intentions, a kind, concerned nature, and appropriate work skills and experience can still get it wrong. Why? Should we have acting lessons? It can't be all that difficult.

Maybe some movie directors should analyze how ASD folks interact with NT folks, moment by moment, word by word, expression by expression.

**Note: Personally Identifiable Information (PII) has been redacted in this document.**

## **Rick Grossman**

For several years, I and others in Seattle have searched for anyone who works with and has expertise in problems faced by Adults on the Autistic Spectrum. Many therapists can help in alleviating symptoms such as depression or anxiety, but that is merely a bandaid.

I believe we need to find a skill-based program that will help us identify those things that get in our way to create relationships, learn unwritten rules, and understand behaviors that make us outcasts. Once we identify those, we want to be able to choose when and where we adapt and have the skills to do so.

This is not held by all. Some call this "masking," the equivalent of being in the closet for gay people or passing for people of color. I contend that we should have the choice and that we cannot change the world around us, but can adapt without losing our identities. I also argue that everyone masks all the time, whether in a discussion with a best friend, or work supervisor, or in hostile environments. It is a skill needed for all to survive.

I am a member of a local self-help group called the Square Pegs. None of us have found any such support. Now as geographical limitations are being broken down by telemedicine, I was hoping there were additional resources. Of course insurance companies create limits, and in my own case Medicare has limitations.

The well-known national Autism groups have turned a blind eye on adult services. There is no funding for supporting Adults on the Spectrum. And doctors/therapists are not trained and have little expertise.

What we need are therapies/programs/therapists who help Adults on the Spectrum learn and understand what we do that is different, and can provide training and feedback to help us survive, and even flourish. I believe the area of greatest need is in communications and social relations.

Do you know of any such successful programs, therapies, agencies that have shown to be effective. We would even consider workbooks with exercises, even though they may not be able to provide feedback.

There are a thousand databases. We spend time searching them only to find we don't have the understanding to use them or to find nothing is available.

I know there are limitations. Medicare, for example, requires one be licensed in the state, and will allow MSWs to be paid but not those with MAs. There are ways around that including finding outside funding or requesting rule changes.

The high incidence of suicide, depression, unemployment/underemployment, loneliness, isolation, and homelessness among those who are on the spectrum is discussed with handwringing. The costs to all these is high. The ability to find effective programs and practitioners trained to help us address our real problems will benefit the entire nation.

We need leadership to address this, not more shoulder shrugs and telling us to look in places that merely tell us to look elsewhere. My voice carries no weight. We need someone who has the authority and

recognition to spearhead this. Barring that, we at least need some crumbs that help us and give just a tiny glimmer of hope.

There are many needs by individuals and I realize it must be difficult to realize that not everyone can be helped. CDC statistics were at 1.85% in 2016. Trending indicates that today results are over 2% and considering those screened, the number is closer to 5% of the population. All of society loses--valuable employees don't contribute, funds are required to take care of symptoms, families suffer.

The need is there. The impact will be huge. We need leaders to address this, and in the meantime, we at least need to know what we can accomplish on our own.

Rick Grossman  
[PII redacted]



**Rick Grossman**

In most of the country there is no support or programs for Adults on the Spectrum. Either they are all "cured" or they are ignored. How can we tell the parents of Autistic Children that once they reach 21, they are on their own? Is this part of the high rates of depression? Is all the government money and grants limited to serving children only, or is it redirected? Why don't the public agencies have staff, board members or advisors who are actually on the Spectrum? That would be like the NAACP only hiring white people.

## **John Saito**

I support the proposal to create a separate DSM category for "severe" or "profound" Autism as called for by the Lancet Commission and NCSA.org. It is my hope that service providers, policymakers and lawmakers will use this new category to craft targeted goals, funding, program planning and performance metrics for this high-need group.

My daughter has profound autism. She requires 24/7 caregiving, and is at constant risk of self-injurious and physically aggressive behavior. She has been unable to develop a sense of personal safety or hygiene despite all our efforts. She is incapable of communicating with anyone other than with caregivers who have spent years with her.

Unfortunately, all of her public service and support programs seem more geared toward those with some form of higher-functioning ASD. It has been a struggle to secure items as basic as appropriate clothing, safe home modifications, and in-school services such as behavior intervention and communication support. In terms of residential care and out-of-home day programs, none of the service providers in our state are willing or able to take on the challenges of the severely autistic like my daughter.

While the creation of a DSM category specific to the profoundly autistic does not directly address the problems they face, it does force us to acknowledge that they have distinct needs, and (I suspect) are decidedly underserved by today's policies and programs.

Recognizing there is a problem is the first step toward solving it.

**Note: Personally Identifiable Information (PII) has been redacted in this document.**

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

### **Season of Sorrow**

My son [PII redacted] died on January 17, 1995. He was 31 years old. Cause of death was found to be Thorazine intoxication.

The psychiatrist who prescribed 1500 mg/day of Thorazine (500 mg at 3:30pm, 7pm, and 8:30pm) should be serving a life sentence in prison.

She also prescribed Haldol 6 mg/day (3 mg at 8am and 3:30pm), Depakote 2000 mg/day (500 mg at 8am and 3:30pm), 1000mg at 7pm, and Chloral Hydrate 2 grams at 8:30pm.

[PII redacted] never had a seizure disorder. Depakote was uncalled for. A fuller description can be found at [conradsimon.org/Conrad.html#death](http://conradsimon.org/Conrad.html#death).

I was accused of being an abusive mother, and was not allowed to visit [PII redacted] at his group home. My husband told me to just stay away for awhile.

"They won't kill him," my husband assured me.

But they did kill him.

I hope members of this new IACC can come to recognize the seriousness of autism, especially the language disorder. And, to blame parents is wrong.

### **Inferior Colliculus?**

Please discuss my hypothesis that damage of the inferior colliculus (plural colliculi) could be the primary site of brain injury in infants who are recognized as autistic within the first 2 to 3 years of life.

Note paragraphs that follow on blood flow, metabolism, injury, vulnerability, plus evidence of auditory system dysfunction in cases of autism:

- 1- The inferior colliculi are the site of highest blood-flow in the brain.
- 2- The inferior colliculi are the site of highest metabolism in the brain.
- 3- The inferior colliculi can be damaged by asphyxia at birth.
- 4- Injury of the inferior colliculi disrupts language comprehension.
- 5- Case reports, loss of speech comprehension.
- 6- Photo of traumatic injury that led to loss of speech understanding.
- 7- The inferior colliculi are a site vulnerable to traumatic injury.
- 8- Damage of the superior olive in a case of autism.
- 9- Damage of the brainstem auditory pathway in cases of autism.
- 10- Brainstem (substantia nigra) defect in Parkinson's disease.

### **Brainstem Circulation (1)**

Highest blood flow in the brain is in the inferior colliculi. SS Kety reported this in 1962, and that it was a surprise finding! Kety's report is free online at <https://pubmed.ncbi.nlm.nih.gov/14032202/>, and includes an autoradiographic picture showing highest blood flow in the brainstem auditory pathway.

The inferior colliculi are pea-sized centers in the midbrain auditory pathway. How could injury of such a tiny site in the brainstem be of great importance?

Consider the size of insect brains. Consider brain circuits in tiny flies that make it so difficult to swat them out of existence.

Audiologist Ladislav Fisch pointed out that the auditory sense is the most essential for survival of vertebrate species.

## Brainstem Metabolism (2)

Louis Sokoloff worked with Seymour Kety and later developed the deoxyglucose method to measure metabolism in the brain. Sokoloff's method has been widely used to investigate actions of drugs in the brain.

The auditory system is rarely the focus of research using Sokoloff's method, but in tables compiled by many users of this method, the inferior colliculi are always listed as having the highest metabolism.

See: Sokoloff L (1981) Localization of functional activity in the central nervous system by measurement of glucose utilization with radioactive deoxyglucose. *Journal of Cerebral Blood Flow and Metabolism* 1:7-36.

Sokoloff commented, "... the inferior colliculus is clearly the most metabolically active structure in the brain."

## Birth Injury (3)

Damage of the inferior colliculi was the only injury found in monkeys subjected for 6 to 8 minutes to asphyxia at birth.

Lookup Windle WF (1969) Brain damage by asphyxia at birth. *Sci. Am.* 221:76-84 at <https://www.weisenborn-boer.nl/Geboorte/Windle.pdf>.

More extensive brain damage was found to be caused by partial oxygen insufficiency over longer periods of time. Difficult birth has frequently been reported in the records of children who develop autism.

Should inferior colliculus damage be looked for, by fMRI or neuropathology investigations, in cases of autism?

## Brainstem & Language (4)

Inferior colliculus damage has been reported in several people who lost the ability to speak following automobile accidents. Loss of the ability to speak has also been reported in people with cancerous growths in the midbrain.

## Case Reports (5)

In previous comments submitted to the IACC, I summarized the following reports of language loss following injury of the inferior colliculi:

1. Howe JR, Miller CA. Midbrain deafness following head injury *Neurology*. 1975 Mar;25(3):286-9.
2. Jani NN et al. Deafness after bilateral midbrain contusion: a correlation of magnetic resonance imaging with auditory brain stem evoked responses. *Neurosurgery*. 1991 Jul;29(1):106-8.
3. Nagao M et al. Haemorrhage in the inferior colliculus. *Neuroradiology*. 1992;34(4):347.
4. Meyer B et al. Pure word deafness after resection of a tectal plate glioma with preservation of wave V of brain stem auditory evoked potentials. *J Neurol Neurosurg Psychiatry*. 1996 Oct;61(4):423-4.
5. Hu CJ et al. Traumatic brainstem deafness with normal brainstem auditory evoked potentials. *Neurology* 1997 May;48 (5):1448-1451.
6. Johkura K et al. Defective auditory recognition after small hemorrhage in the inferior colliculi. *J Neurol Sci*. 1998 Nov 26; 161(1):91-6.
7. Masuda S et al. Word deafness after resection of a pineal body tumor in the presence of normal wave latencies of the auditory brain stem response. *Ann Otol Rhinol Laryngol*. 2000 Dec;109(12 Pt 1):1107-12.
8. Vitte E et al. Midbrain deafness with normal brainstem auditory evoked potentials. *Neurology* 2002 Mar 26;58(6):970-3. -- 2 cases

9. Hoistad DL, Hain TC. Central hearing loss with a bilateral inferior colliculus lesion. *Audiol Neurootol* 2003 Mar-Apr; 8(2):111-223.
10. Musiek FE et al. Central deafness associated with a midbrain lesion. *J Am Acad Audiol* 2004 Feb; 15(2):133-151.
11. Pan CL et al. Auditory agnosia caused by a tectal germinoma. *Neurology*. 2004 Dec 28;63(12):2387-9.
12. Kimiskidis VK et al. Sensorineural hearing loss and word deafness caused by a mesencephalic lesion: clinicoelectrophysiologic correlations. *Otol Neurotol*. 2004 Mar;25(2):178-82.
13. Pillion JP. Speech processing disorder in neural hearing loss. *Case Report Med*. 2012, Article ID 206716. Epub 2012 Dec 6.
14. Poliva O et al. [Functional Mapping of the Human Auditory Cortex: fMRI Investigation of a Patient with Auditory Agnosia from Trauma to the Inferior Colliculus](#). *Cogn Behav Neurol*. 2015 Sep;28(3):160-80.
15. Joswig H et al. [Reversible pure word deafness due to inferior colliculi compression by a pineal germinoma in a young adult](#). *Clin Neurol Neurosurg*. 2015 Dec;139:62-5.

### **Injury that led to loss of speech understanding (6)**

SC superior colliculus, IC inferior colliculus, P pons, C cerebellum.

### **Brainstem Vulnerability (7)**

The injury shown above resulted from impact by the cerebellar tentorium under the inferior colliculi in a skiing accident (Johkura et al. #6 above).

Please discuss this evidence of importance of the brainstem auditory pathway for language comprehension, and how much more serious injury of the inferior colliculi should be for an infant.

### **Neuropathology in Autism (8)**

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

Dr. Romano had this patient's brain preserved after her death at age 21. The patient's mother was alcoholic. This suggests damage of brainstem pathways similar to that described by Wernicke in 1881. Malformation of the superior olive in the auditory pathway was found. Kulesza and Lukose discovered similar brain abnormalities in brains they examined.

Dr. Kulesza replied to my inquiry about the inferior colliculus. He told me they had only asked for brain-bank sections from the superior olives.

### **Auditory Pathway Defects in Autism (9)**

Kulesza and his student co-workers published reports in 2019, 2020 and 2021 that the inferior colliculi and other brainstem auditory centers are injured in laboratory rats exposed to Depakote during gestation. Autism has been reported in many cases of prenatal exposure to Depakote. Depakote was taken by their mothers during pregnancy to prevent epileptic seizures.

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

1. Rodier PM et al. (1996) Embryological origin for autism: developmental anomalies of the cranial nerve motor nuclei. *J Comp Neurol*. 370:247-61.
2. Kulesza RJ, Mangunay K (2008) Morphological features of the medial superior olive in autism. *Brain Res*. 1200:132-7.
3. Kulesza RJ Jr et al. (2011) Malformation of the human superior olive in autistic spectrum disorders. *Brain Res*. 1367:360-71.

4. Lukose R, et al. (2011) [Malformation of the superior olivary complex in an animal model of autism.](#) *Brain Res.* 1398:102-12.
5. Smith A, et al. (2019) Structural and Functional Aberrations of the Auditory Brainstem in Autism Spectrum Disorder. *J Am Osteopath Assoc.* 119:41-50.
6. Mansour Y et al. (2019) Auditory Midbrain Hypoplasia and Dysmorphology after Prenatal Valproic Acid Exposure. *Neuroscience.* 396:79-93.

### **Brainstem Injury? (10)**

Brainstem dysfunction is recognized as important in Parkinson's Disorder. Brainstem sites are now also viewed as possibly important in Alzheimer Dementia.

Repetitive movements of autistic children are likely the result of basal ganglia abnormalities, as in kernicterus (damage caused by bilirubin).

Shouldn't brainstem injury also be investigated in cases of autism?

**Note: Personally Identifiable Information (PII) has been redacted in this document.**

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

### **Inferior colliculus**

Summary of comments I submitted Dec 10, 2021:

- 1 - Inferior colliculus (colliculi plural) are the site of highest blood flow in the brain. See the article on autoradiographic measurement of blood flow in the brain by SS Kety at: <https://pubmed.ncbi.nlm.nih.gov/14032202/>
- 2 - The inferior colliculi are the site of highest metabolism in the brain. Louis Sokoloff stated, "... the inferior colliculus is clearly the most metabolically active structure in the brain."
- 3 - The inferior colliculi were the only brain site damaged by 6 to 8 minutes of asphyxia at birth. *Sci. Am.* 221:76-84, online at <https://www.weisenborn-boer.nl/Geboorte/Windle.pdf>
- 4 - Traumatic injury of the inferior colliculi led to loss of the ability to speak in at least 15 case reports (dated 1975 to 2015).
- 5 - Inferior Colliculus "malformation" has been reported in cases of autism, and in laboratory rats exposed to prenatal Depakote.

### **Public Comments**

Can members of the committee be required to discuss public comments? Currently all we get is mention in a summary prepared by OARC (Office of Autism Research Coordination).

Oral comments are limited to 3 minutes or less. My husband pointed out that this is about the length of Lincoln's Gettysburg Address. I found this online, and it is 272 words. The request for the last meeting was to limit public comments to 2 to 3 minutes. I now aim for 2 minutes, or 180 words.

Members of the IACC rarely discuss my comments, or those of other parents. But they then often yarn on for much longer than the attention span of most of us.

### **Forgotten Comments?**

Following is the summary (from minutes of the meeting) of the comment I made at the IACC meeting on November 21, 2003:

"Ms. Eileen Simon asked the committee to consider the possibility that clamping of the umbilical cord immediately at birth might be an environmental contributor to autism.

She noted that the widespread adoption of this practice seems to correlate with the apparent increase in prevalence.

She noted that research on oxygen insufficiency in newborn monkeys might be relevant, as the sites of brain abnormalities resulting from the asphyxia is similar to those that have been talked about in connection with autism.

She distributed a summary paper of her ideas to the committee members."

### **Obstetric Protocols**

I posted my website in memory of my son [PII redacted] in April 2000. Shortly thereafter I was contacted by several people who were (and still are) working to change the obstetric protocol that mandates clamping the umbilical cord within the first 30 seconds after birth.

Since the mid 1980s, clamping the cord immediately after birth has become standard practice. The umbilical cord clamping protocol came as a complete surprise to me. My introduction to learning about delivery-room procedures came from reading the excellent paper by Mercer and Skovgaard (2002), two nurse-midwives.

### **Obstetric Error?**

"Immediately after the delivery of the neonate, a segment of umbilical cord should be double-clamped, divided, and placed on the delivery table pending assignment of the 5-minute Apgar score."

ACOG Committee Opinion No. 348, November 2006: Umbilical cord blood gas and acid-base analysis. ACOG Committee on Obstetric Practice.

*Obstet Gynecol.* (2006) Nov;108:1319-22.

A half minute wait is now recommended before clamping the cord. But can use of a clamp on the umbilical cord just be stopped? What other species subjects its newborns to use of a surgical clamp on the umbilical cord ???

### **Fear of Jaundice?**

Mercer and Skovgaard pointed out that the protocol for immediate clamping of the cord appears to have come from two papers that expressed concern that polycythemia and excess bilirubin result from allowing "placental transfusion" to occur:

Saigal, S. et al. (1972) Placental transfusion and hyperbilirubinemia in the premature. *Pediatrics* 49:406-19, and

Saigal, S & Usher, H. (1977) Symptomatic neonatal plethora. *Biol Neonate*.32:62-72.

### **Umbilical Cord Bloodflow**

Partial retraction of Saigal's ideas was published in 2004:

Philip AGS, Saigal S. When should we clamp the umbilical cord?

*Neoreviews*. 2004; 5:142-154. <https://publications.aap.org/neoreviews/article-abstract/5/4/e142/92122/When-Should-We-Clamp-the-Umbilical-Cord?redirectedFrom=fulltext>

My online comment remains online at this link, as does a comment by George M. Morley, a retired obstetrician who has adamantly stated that use of a surgical clamp on the umbilical cord is wrong, and that this practice should be stopped.

### **Latest Protocol**

The American College of Obstetricians and Gynecologists (ACOG) now recommends a "delay" in umbilical cord clamping for at least 30-60 seconds after birth. See: American College of Obstetricians and Gynecologists' Committee on Obstetric Practice (2020). Delayed Umbilical Cord Clamping After Birth: ACOG Committee Opinion, Number 814. *Obstet Gynecol.* Dec;136(6):e100-e106.

### **What are Parents Told?**

How many prospective parents are told that placental respiration is to be cut off so abruptly at birth, even before the first breath?

How many prospective parents have been encouraged to bank their baby's umbilical cord blood?



### **Asking for Help**

I have been attending IACC meetings since 2003, asking for help. Now nearly 20 years later I somehow try to hold out hope.

Being pointedly ignored continues to be the response too many parents endure from our attempts to be heard. Minimal inclusion in IACC meetings is all we are allowed.

I have continued to take the trip from Boston to DC. I will continue to work toward better responses of the IACC to parents of life-span afflicted children. Please consider a change in attitude.

My oldest son is very high functioning, and he deserves far more help than most "professionals" seem to deem appropriate.

### **Bullied Parents**

I am not the only mother who has been treated badly by "professional experts."

Would anyone think to treat parents of children with cancer with such disdain? Why isn't there an effort to raise money for research and lifespan care for people diagnosed with autism in early childhood?

Why do we have so many imposters now claiming they are autistic, but only learned in college that they have autism? How many of these "late diagnosed" victims of autism had difficulty learning to speak in early childhood?

Please discuss attitudes toward parents. Also, what purpose is served by so much attention given to late-diagnosed cases of autism? The focus of the IACC should be language development in the first 12 to 18 months of infancy.

### **Brain Research**

The cause of autism is brain injury, not vaguely presented genetic disorders. Genetic causes of brain injury should be better understood as in PKU disorder.

(1) Phenylalanine is not metabolized properly in infants with PKU. Research now shows this metabolic disorder is less problematic by age 5, with maturation of the blood-brain barrier. But a low phenylalanine diet must be reinstated when a woman with PKU becomes pregnant.

(2). Research on other genetic disorders should be done in the same way. What are the abnormal metabolites in Down syndrome? How can entry of abnormal metabolites into the brain be prevented?

### **Online Comments**

Following are the online responses by Dr. George Morley and me to Philip & Saigal's partial retraction of earlier ideas that early clamping of the umbilical cord might prevent brain damage from bilirubin.

Note the long history of published discussions of the importance of postnatal blood flow from the placenta:

### **We Should Not;. Physiology Clamps the Cord Perfectly**

December 30 2004

George M. Morley

The authors conclude that the answer to, "When Should We Clamp the Umbilical Cord" remains "enigmatic." It was no puzzle for Erasmus Darwin (1801) who wrote: "The navel string should be left untied until the child has breathed repeatedly and till all pulsation in the cord ceases." He described tying the cord before these events occur as "injurious," causing blood to be left in the placenta – blood that

ought to have been in the child. He recognized childbirth, umbilical cord closure, and placental transfusion to be physiological, normal, natural, healthy (and fragile) events.

The authors omit the one reference that clearly illustrates physiological cord closure (PCC) and placental transfusion – Mavis Gunther’s 1957 article in the Lancet. PCC involves reflexive initiation of crying, reflexive dilatation of pulmonary arterioles, erection and aeration of alveoli by pulmonary blood flow, establishment of the adult circulation by the placental transfusion that initiates function in all the neonate’s life support organs – lungs, brain, heart, liver, gut, respiratory muscles, kidneys and skin, and reflexive control and termination of the placental transfusion – after the child’s life support organs are functioning with a blood volume that is optimal for survival. PCC has produced healthy neonates for millions of years.

After the details of PCC are defined, the authors’ question becomes, “When should we disrupt this delicate anatomy and intricate physiology?” and the results of timed clamping (disruption) can be evaluated in relation to the physiological norm. There is no enigma.

The usual cord-clamping pathology is hypovolemia – blood volume clamped in the placenta; very occasionally, too much blood may be clamped in the neonate – hypervolemia. Common neonatal hypovolemic / ischemic disorders are anemia, hypotension, oliguria / anuria, pallor, hypothermia, IRDS (shock lung), hypovolemic shock and heart failure (retraction respiration), NEC (ischemic bowel infarction), IVH (ischemic hemorrhagic infarction of the germinal matrix), hypoxic-ischemic encephalopathy HIE / CP and mental deficiency / autism. All these injuries correlate with IMMEDIATE cord clamping, (ICC) done to obtain a cord arterial blood pH sample as promoted by ACOG, RCOG, and SOGC; they do not occur with PCC.

Similarly, ICC is a crucial error in neonatal resuscitation, done to rush the child to a resuscitation table. In the depressed child, if the cord is pulsating at birth, the placenta is its only functioning life support organ; it also contains the blood volume needed to establish lung function and function of all other life support organs of the neonate. After ICC, it is futile to ventilate lungs if the child does not have enough blood volume to perfuse them.

Rational resuscitation necessitates keeping placental life support functioning until the neonate reflexively closes the cord vessels after its own life support organs are functioning.

In conclusion, despite enigma, the authors seem to recognize that something is seriously amiss with current neonatal practice, and suggest a neonatology campaign to “WAIT A MINUTE”. The rational neonatology campaign should be: “DO NOT CLAMP THE CORD; I WILL RESUSCITATE THE CHILD WITH THE CORD AND PLACENTA INTACT!” Physiology should clamp the cord. A full, referenced answer to this NeoReview is available at [www.cordclamping.com](http://www.cordclamping.com)

G. M. Morley, MB ChB FACOG

### **Wait at least for the first breath**

December 30 2004

Eileen Nicole Simon, PhD, RN

I am glad to see the shift in opinion from immediate clamping of the umbilical cord to "wait a minute" [1]. Better still would be to wait until pulsations in the cord cease; this would ensure that transition from the placenta as respiratory organ to the lungs has completely taken place.

Philip and Saigal cite the important paper by Redmond et al. that demonstrated that the first breath redirects blood from the placenta to the lungs [2]. Most but not all infants breathe within seconds of birth, and continuing placental respiration is crucial for infants who are slow to begin breathing [3].

Over the past year I have made a systematic search of textbooks on obstetrics and midwifery to determine what the traditional teaching has been. Until about 20 years ago the teaching was explicit that the cord should not be cut until the infant was breathing; most taught waiting for the pulsations to cease. Clamping of the cord immediately at birth is a fairly recent addition to obstetric protocols [4].

If the immediate cord-clamping protocol is followed too literally, nature's intended shift of placental blood to the lungs with the first breath will be prevented in those infants who do not breathe immediately. Even a brief lapse in delivery of oxygen to the brain is detrimental.

A pattern of symmetric bilateral brainstem lesions was found in newborn monkeys subjected to asphyxia for six to eight minutes [5, 6, 7]; asphyxia was inflicted by delivering the infant head into a saline-filled rubber sac and clamping the umbilical cord [6, p247]. Damage was restricted to the brainstem, which led to the idea that a brief lapse in respiration was at most minimally harmful to the newborn infant [5]. However, growth of later maturing areas of the cortex was disrupted in the monkeys subjected to asphyxia at birth [7].

The thoroughbred foals delivered by human assistance (which included umbilical cord clamping) were later found to have brainstem lesions similar to those in monkeys asphyxiated at birth [8]. This suggests that a similar sudden cutoff of circulation and respiration had been inflicted on the foals. Seizure disorder as well as respiratory distress was part of the "Barker Foal Syndrome." Return to the tradition of waiting for an infant to breathe before clamping the cord might well reduce the rising numbers of mentally handicapped children.

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Submitted on December 30 2004

**This comment has been redacted according to IACC public comment guidelines.**

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

### **Parent Concerns**

Public comments submitted included many from distressed parents, like myself, who are pleading for lifespan care for their autistic children. How can this have been so overlooked by the IACC over the past two decades?

Please read comments, submitted for the October 2021 IACC meeting, by Shannon de Roches Rosa, Ilene Lainer, Julie Fackrell, Alice Taylor, Mel Persion, Sara Polito, Vance Goforth, and Christine Miles Kincaid.

Most are brief comments begging for lifelong care to be provided for their children who are now adults and remain severely disabled.

### **Medical Lobby?**

Brain damage is the cause of autism. Prenatal exposure to Depakote anti-seizure medication and oxygen insufficiency at birth are well-documented in medical histories of autistic children.

Is there a medical lobby preventing discussion of birth injuries at IACC meetings?

Use of a clamp on the umbilical cord is very dangerous. Veterinarians stopped doing this long ago. Descriptions of behaviors and brain injuries in thoroughbred colts are too similar to autism to be ignored.

In PubMed I have recently seen papers on malpractice lawsuits. Lifespan needs of autistic children are expensive. Government funding should be provided for care of autistic adults. And, use of a surgical clamp on the umbilical cord should be outlawed.

### **Productive Life?**

My high functioning autistic son has been abandoned since his discharge from Westborough State Hospital in Massachusetts back in 2003. Mental health "professionals" wanted him to return to live with my husband and me, where at age 40 he would again be put on waiting lists for services.

He now lives in a group home with five other very incompatible people. He should have been helped to find employment.

He puts on a suit jacket every day and goes into Boston, pretending to go to work. He attends meetings at places like the Parker House, where he says the refreshments served provide a good lunch.

Can the IACC finally do something practical to help people like my son?

### **Free Will?**

The Autism Self Advocacy Network, ASAN, advocates that autistic people should not have constraints placed on their wandering. Dr. Gordon read a comment from [redacted] about the possibility that some autistic individuals may become engaged in sexual relationships, or sex for profit out in the community? I hope so. [redacted]

Please set me straight if my grief has me horrifically off-track.

But aren't concerns about wandering really about young children who walk away, get lost, and often are found dead?

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

### **Wearing a Necktie**

I visited my son's school several years ago. Students discussed what they wanted to do in life.

"I love airplanes. I want to be a stewardess when I grow up," one young girl offered.

"It's cars that I love," my son replied. When I grow up I want to drive to work, and wear a necktie, like my father."

While a patient at Westborough State Hospital in Massachusetts, my son was employed at the Agnes Clarke Memorial Workshop. He assembled and packaged products to be sold in stores. He was paid for each completed package, and this was an incentive for him to work quickly.

Unemployment since his discharge from Westborough has been the worst aspect of my son's "community" placement.

### **Inferior colliculus**

Restatement of comments I submitted Dec 10 & again on Dec 22, 2021:

1- Inferior colliculus (plural colliculi) - site of **HIGHEST BLOOD FLOW** in the brain. See the article on autoradiographic measurement of blood flow in the brain by SS Kety at: <https://pubmed.ncbi.nlm.nih.gov/14032202/>

2- The inferior colliculi are the site of **HIGHEST METABOLISM** in the brain. Louis Sokoloff stated, "... the inferior colliculus is clearly the most metabolically active structure in the brain."

3- High blood flow & metabolism indicates important activity. Ladislav Fisch pointed out that **ENVIRONMENTAL AWARENESS** is maintained by the auditory sense. The auditory sense is constantly active, even during sleep.

### **Brainstem Injury**

The inferior colliculi are susceptible to damage by asphyxia and trauma:

1- The inferior colliculi were **DAMAGED BY ASPHYXIA AT BIRTH** for 6 to 8 minutes duration. Scientific American, October (1969) 221:76-84, online at:

<https://www.weisenborn-boer.nl/Geboorte/Windle.pdf>

2- **TRAUMATIC INJURY** of the inferior colliculi led to loss of the ability to comprehend speech in at least 15 case reports (dated 1975 to 2015).

3- Inferior Colliculus "malformation" has been reported in cases of autism, and in laboratory rats exposed to **PRENATAL DEPAKOTE**. Prenatal exposure to Depakote (valproic acid) is associated with development of autism.

**Nicole LeBlanc**

HHS Needs to push states to adopt Autism HCBS waivers for all adults with ASD regardless of IQ. Many of us w/o I/DD struggle with adaptive functioning and have Anxiety issues that make day to day functioning challenging.

**Karen Barrett**

As a parent and advocate of an autistic child whose diagnosis was not used in his IEP, I demand schools defer classification of students to the medical community support medical diagnosis. People should not have to use our judicial system to carry out basic civil human rights.

## **Parrish Hirasaki**

The pandemic caused an interruption in prenatal care that has produced a population of babies who were not scanned with ultrasound early in gestation. This creates an opportunity to conduct an epidemiological study of fetal ultrasound, the major change in prenatal care in the 2000s.

The increase in the prenatal exposure to ultrasound per pregnancy and the increase in ASD follow similar curves. The vibration and heating created during scanning seem a poor environment for the migration of brain cells which occurs during the first 20 weeks of gestation.

The FDA's regulatory designee American Institute of Ultrasound in Medicine (AIUM) formally states on its website that no epidemiological study has been conducted since the allowable intensity was increased (8-fold) in 1992. AIUM scientists cite the lack of a population of children who were not scanned as the reason.

IACC should request NIH establish a research grant for an epidemiological study that will build a database of children born in 2020 and 2021 who were not exposed to ultrasound during the first 20 weeks of gestation and will compare their health outcomes with children who were exposed.



**Note: Personally Identifiable Information (PII) has been redacted in this document.**

**Lori and Alex Kay**

On behalf of my son, who is profoundly affected by autism, my husband and I would like to advocate for the autism label to be changed to "Profound autism" for those like my son who requires 24 hour per day supervision and help with all daily life skills and is minimally verbal. We need research to focus on both preventing this type of autism and curing it. He needs supports which are entirely different than the supports he would need if he was "high functioning". Resources must be directed to this type of autism.

Thank you,

Lori Kay-Mother to [redacted] age 30  
Alex Kay, MD-father to [redacted]

## Tal Purk

Hi, Just wanted to put in some really important clarifications on what is needed in the Autistic Community, from a late-diagnosed Female on the Spectrum

\*Better access to late-diagnosis Autism Evaluations (and hopefully training so that more evaluators can be competent in how it presents in women and girls)

\*Access to a program to access Vitamins and critical supplements (different than medications)- similar to how food stamps works but for supplements- especially given many people on the spectrum suffer from Kryptopyrolle Disorder, undermethalation, or the MTHFR genetic mutation which dictates we need over supplementation given our body doesn't absorb certain vitamins, minerals and nutrients, given these genetic issues that we were often never told about until it was too late.

\*Access to individualized (not group homes/mass housing) housing options for those on SSDI/SSI or some sort of waiver to purchase small property- especially if High Functioning. We can get very sick living near or in groups of others or near loud noises...

\*Access for all children to be tested for kryptopyrolle disorder testing (urine test) as children in school to prevent a life time of health issues and poverty and struggle and mental health issues so they can be notified earlier on

\*Trainings for educators, and health professionals and even families in the community in what to look out for for ASD and how it presents in young girls, which is distinctly different than the past research and writings available which has only focused on boys- girls do not have as many obvious behavioral problems but their presentation is more overt, and also more critical to detect given ASD women have a very high suicide rate, and are often victims of sexual abuse throughout their lifetime at various ages.

\*Programs to teach ASD women and girls how to protect themselves from sexual abuse- the signs to look for, self defense training, and things of that nature.

\*Programs to educate the general public (By aspies for aspies) on how to not control, or abuse the average ASD person- how to not take everything that is done personally or through a neurotypical lens- education on the double empathy problem is critical since so much blame and shame and hatred gets pointed at us and thus prevents us from making the changes we need to make since we have to process so much hatred constantly

\*\*Access to communication tools for those that are non verbal as a basic human right

\*\*Access to kryptopyrolle disorder, MTHFR related, or MCAS, lyme, SIBO, inflammation and other related health care issues which are actually very common not just to ASD folk but generally- make that training for to all doctors- so that they do not dismiss, or discount our uncommon (or sometimes common) health issues and that our ability to get help and treatment for these issues is much more accessible to us and the general population.

\*\*Training programs for employers on how to work with our strengths given we are often over qualified (especially as HFAS) however, they need to understand we may not be able to adapt to their

expectations...it might only be able to be done the way we are understanding it to work... things like that..

or basic business classes that work with the Neurology of an ASD person- for instance, how to hire, how to manage emotional projections from non- ASD folk, things like that, ideally taught by ASD folk to ASD folk- and not NT's teaching us...

Last but not least:

\*Specialized training for ASD folk so we can work with our strenghts and own neurology and not adapt to models of neurotypical expectations, which we can never succeed in nor perform in. However we can succeed and perform in our own strengths but they need to be fed and encouraged and getting the proper structures in place- then we can overachieve and end up creating jobs for people- and then we are able at that point to work with different forms of help and appear "normal"- this could include nervous system training, somatic experiencing, vagal tone help, managing anxiety with certain substances or specialized supplements (most medication won't work depending on the ASD person) working with our neurology, treating kryptopyrolle disorder, or underlying immune issues, and helping us faciliate our own advocacy- helping us hire houseworkers after a baseline- so that we can focus on what we came here to do and make a difference for other lives that are in desperation as we once were. Unfortunately many NT people resist this so much, and as a result we are prevented from creating jobs and success for them which would make them happy and add the economy instead of just "appearing productive" we could actually be working with larger frameworks of achievement- but the image of an ASD person has to be changed in society- instead of this label of "non abilitied"- nor forced into false abilism, which back fires on everyone. These things are very critical but often misunderstood.

Ok that is all. Thank you so much in advance.

## **Jane McCready**

I am worried that the autism debate is being dominated by the most high functioning (level 1) autistic voices, to the detriment of profoundly (level 3) autistic voices such as my own son's. To add to the worry, those same autistic voices are insisting that only autistic folk can speak with authority on autism, meaning my boy's voice is twice lost: once because he can only communicate at a basic level, and twice because his mum - and main lifelong/legal advocate - is being pushed off the platform by a relatively privileged autism 'elite'. In no other disability would the arguably least needy be taken as the voice for all. It needs bodies such as the IACC to stop kowtowing to 'Twitter autism' and start standing up for more severe, real-world autism.

## **Anonymous**

We are reaching out to you as the parents of our sweet 3-year-old daughter who was diagnosed with Autism Spectrum Disorder (ASD) 8 months ago. Like so many other parents like us, we have worried so much about our daughter's development and the impact it will have on her current and future life. We have sought out care from multiple developmental pediatricians, speech therapists, occupational therapists, certified ABA therapists, and more. We have been repeatedly disappointed by the limited interventions available for our daughter and the potential impact that each will likely have. Nevertheless, we have enlisted her in each of these therapies and are thankful for the amazing clinicians providing these services.

We were surprised when our pediatrician suggested that we connect with Dr. Karen Heffler at Drexel University College of Medicine to learn about her cutting-edge research into the impact of screens on young children with ASD. Dr. Heffler informed us of research conducted by her team and others related to the impact of screen time on ASD symptoms and importantly the results from a pilot interventional study where they stopped screen time in a small cohort of children with ASD. We were interested to learn of this intervention, but skeptical about the impact it could have for our daughter. At the time, her favorite thing to do was to watch educational TV shows, including Sesame Street, Blippi, and Daniel Tiger. In fact, they appeared to bring her great joy and she asked for them constantly throughout the day, watching over 3 hours per day. Given her lack of speech, we welcomed the opportunity these shows provided to communicate what we perceived as valuable information to her.

Given our daughter's ASD-related symptoms, particularly a lack of speech, we decided to try to eliminate screen time for 6 weeks to see what would happen. Turning off screens led to more opportunities for us to socially engage with our daughter. We were amazed that within 10 days we began to notice improved eye contact, a stronger desire to interact with us and other people, and better ability to maintain that engagement. We also found that she was more interested in trying to speak words and sounds than she had previously. This improvement has continued and we have not turned our TVs or iPads on in front of our daughter for approximately four months. We can't put into words what it has meant to us to be able to see our daughter improve in front of our eyes with such a simple intervention. Not only are we so thankful for the improvements we've seen, we also have more hope for the future that our daughter will be able to achieve the milestones and life events that we dream of for her.

While we are excited about the dramatic changes in developmental trajectory we are seeing in our child, we are surprised to learn that screen time interventions are not being more widely studied or implemented in more children with ASD and saddened by the slow pace of research (slow publication rates and lack of funding) that we worry about the millions of children with this exposure whose families may not have the information that will help them while they are still young enough to benefit. As you know, the NIH currently has no ASD grants which cover this type of research. The prevalence of ASD has increased from a few in 10,000 in the 1980s to 1 in 44 children; 1 in 27 boys; and 1 in 16 boys in California in 2018 (reported December 3, 2021).

In the interest of helping others like our daughter, we are pleading with the IACC to recommend urgent research focus on this type of intervention. Specifically, we are asking the committee to urgently undertake measures to:

1. Inform your own committee members (through a presentation by Karen Heffler or another expert in this area) on research literature associating a) greater and earlier screen time in the first few years of life with ASD symptoms and diagnosis, and b) emerging literature showing rapid changes in developmental trajectory of ASD symptoms when screen time reduction is combined with socially focused therapy.
2. Suggest that you add to the Strategic Plan an urgent call for research to study a) Screen time as a risk factor for ASD symptoms/diagnosis, b) Potential of screen time/social engagement parent education as preventative strategy in ASD, and c) Difference in outcome with addition of screen time reduction to intervention in young children with ASD and high screen exposure compared to intervention without screen time reduction.

Thank you on behalf of us and our daughter,

Two anonymous parents in the Greater Philadelphia Area, who are requesting anonymity until we can have conversations with our daughter about her interest in our sharing her diagnosis publicly

## Gene Bensinger

Thank you for this opportunity to submit comment to the Committee. At your last meeting, ASAN submitted an important written public comment regarding IACC research priorities in three areas of particular urgency. I want to add my voice to theirs in support of immediate focus and enhanced research on these three topics: first, supporting access to communication for autistic people who are low or non-verbal or otherwise non-speaking; second, research geared toward assisting autistic people (and their communities of support) in managing violent, aggressive, self-injurious, or otherwise challenging behaviors; and third, inquiry that aims to improve the health, well-being, civil rights, and access to supports and services for autistic people with intellectual disability and high support needs. While I often disagree with ASAN's assertions, analyses, and policy recommendations on these and other topics, I think their letter demonstrates a broad consensus view among stakeholders that past and current research initiatives coordinated through the IACC have not adequately focused on autistic individuals and groups who don't enjoy an easy fit within existing research infrastructure, including people impacted by the topics listed above.

There are, naturally, many directions for research to develop in each of these areas. I'd like to see as many pursued as possible! But, in a desire to be brief, I want to highlight one much needed first step that sticks out to me above others.

In regards to research into tools and methods that support communication for autistic people with elevated challenges, the IACC should, with immediate effect, prioritize rigorous research that investigates the validity of, and serious questions of authorship in, certain methodologies promoted by their supporters and providers as Augmentative and Alternative Communication (AAC) tools, specifically, Facilitated Communication, RPM, and Spelling to Communicate. Intense controversy surrounding these physical partner dependent methods is not new. Each of these methods has strong and vocal critics as well as strong and vocal supporters.

However, given the known incapacities and vulnerability of the target population for marketers of these methods, there is, undeniably, an elevated risk that autistic people may experience civil rights deprivations and abuse from physical partners using these methods, even if these partners are family members or other well-intentioned individuals of good character. Rigorous, independent research, specifically on the issue of validating authorship, is an essential protective tool in this regard. The significant financial obligations associated with these methods (which autistic consumers, families, policy makers, other parties, and the public may need to consider), also demand that a body of well-structured inquiry should exist to help people weigh claims of effectiveness, and even their validity as an AAC tool.

Thank you for your attention to this matter. As the parent of a profoundly autistic adult who lives with many of the challenges listed above, I'm excited that research is starting to include inquiry that will better address my child's long term service and support needs. I hope to see much more going forward.

**Anthony J. Thompson**

I am a parent of a severely autistic 23 year old with a brain injury,Day Habs have been shut down for Covid-19's reasons. We have been stuck together for more than two years now 24/7 and we need a break from each other.We are triple Vaxinated. . Things are way out of control with the autism people that have aged out of the system ,they have no where to go for adult day hab services this needs to change soon . Thank you



**Melvin R. Rodgers, D.Min ACPE**

My concern with this committee and autism research in general is that there seems to be very little focus on the whole person. As someone on the autism spectrum, we are more than a physical body to be poked and examined. Granted the physical body is an important domain with respect to suffering but there are other domains. The social, psychological, spiritual and the family are also important domains. If you had a truly interdisciplinary team rather than multidisciplinary team these areas would be highlighted and respected. Moreover, this would suggest that there is a serious effort to reduce suffering.

Respectfully Submitted.

**Greg Robinson, M.P.H., Autistic Self Advocacy Network**



Nothing about us without us!

Thank you for the opportunity to submit written comments for the IACC's public meeting on January 19th, 2022. In prior comments in November, ASAN emphasized the importance of addressing diagnostic disparities in autism, as well as the need for more lifecourse-focused measures of autistic outcomes. As the IACC continues to develop its strategic plan for 2021-22, we wish to expand upon these previously discussed matters.

On December 2nd of this past year, the Centers for Disease Control released new autism prevalence numbers through its Autism and Developmental Disabilities Monitoring (ADDM) Network report. This report demonstrates what we have long anticipated- that improved knowledge of autism and improving access to diagnostic screening have led to more early detection and diagnosis, leading to greater prevalence numbers. To be clear, there is little evidence to support any claims that this increase is due to a true increase in the prevalence of autism, but rather, all evidence suggests that it is due to improvements in the effectiveness and availability of diagnostic screening. While this news is encouraging, as are the signs that some historic gender and racial disparities have begun to close, there is also ample evidence that substantial disparities continue to exist in autism diagnosis, and that these disparities lead many marginalized groups, such as individuals assigned female at birth and people of color, to be underdiagnosed or misdiagnosed, with many such individuals not receiving diagnosis until adulthood, if at all.

In light of this fact, it is imperative that IACC's strategic plan center efforts to reach and support underserved populations as a substantial priority. One element of this is recognizing that the path to diagnosis and support may differ substantially for underserved groups. Recognizing the importance of early identification for matching autistic individuals to supports, it follows therefore that those who are diagnosed later are more likely to have unmet support needs, and more likely to experience additional downstream impacts from these unmet needs. Where underserved communities are underserved due to lack of access to services and supports, this lack of access is likely to additionally manifest elsewhere in their lives, creating additional challenges around co-occurring diagnoses and health burdens.

All of this also highlights the importance of an improved access to diagnosis and support for autistic adults. Expanding access to diagnosis for adults is critical to ensure that under-served and underdiagnosed populations are able to receive needed supports. As these unmet support needs can also lead to worse life outcomes including housing and food insecurity, unemployment or underemployment, and greater risk of illness, injury and justice involvement, it is important to ensure that unidentified autistic adults have access to screening and supports as well. This is also important for expanding our understanding of autism, including its true overall prevalence in society, and for a fuller appreciation of the impacts of missed or misdiagnosis on the lifecourse of autistic individuals.

Finally, while the news that some of the diagnostic gaps in autism have begun to shrink is encouraging, it remains the case that significant gaps still exist, and that more progress needs to be made in ensuring that underserved populations are able to access providers and services that help them. Therefore, IACC must also be sure to focus on strategies to close this gap and ensure that underserved and underrepresented populations, including Black and Hispanic populations, as well as children assigned female at birth, have fuller access to diagnosis and services. In many places, this also means considering broader social and economic contexts. The CDC's ADDM report noted substantial variance in diagnosis rates by geography, for example. This suggests that some of the continued diagnostic gaps are a product of community-by-community variance in access to services and supports. Addressing these broader sources of care inequality are critical for continuing to address these gaps. Similarly, our knowledge-base concerning autistic English language learners, including their barriers to diagnosis and supports, remains woefully sparse. Ensuring that the English learner population is well understood, identified, and supported should be a priority for the IACC alongside other underserved populations.

We thank the IACC for inviting stakeholders to comment and help the IACC identify strategic priorities for the coming year. For more information on ASAN and the autistic community's research priorities, please contact Julia Bascom, our Executive Director, at [jbascom@autisticadvocacy.org](mailto:jbascom@autisticadvocacy.org).

**Cynthia Reed**

The housing and medical needs for people with severe Autism continue to grow as this population ages. Is IACC research, policy and awareness efforts focused on defining the housing and medical needs accurately? IACC's work should provoke states address these needs and to promote the expansion of housing options and training for medical professionals to meet the needs of this complex population. The work of this committee must inform states' regulations for direct services to provide the most appropriate services.

## **Musu Sesay**

As a parent of a child on the autism spectrum, I am concerned about administrative quotas for ABA services especially when it is supposed to be personalized to the needs of the child. Current recommendations call for minimum of 10 hrs of ABA, however, not all children on the autism spectrum need that many hours (and I can attest to it) if they are attending a school offering services and also getting private weekly occupational and speech therapies. The administrative quotas by service providers (requiring weekly minimum of 3 days between Monday & Friday) prevent a child from getting continued ABA services to complement other therapies and burden a family to choose between giving their child ABA therapy and making a living to provide for that child. Also, administrative quotas create an unnecessary delay of care and long waitlists that burden families needing crucial help for their children because a service provider is mandating a family on a quota not based on clinical needs.

**Lori Frome M.Ed.**

Early Interventionist/Behavioral Consultant  
York, Pennsylvania

My letter comes to you out of the concern of a parent of a child diagnosed with autism, as well as an early interventionist and behavioral therapist specializing in treating children with autism from a diverse background of cultures, socio-economic levels, and severity in their formative years of life before age five. What I am going to share with you today may seem trivial to some and vital to others. To me and the hundreds of families represented in the contents of this letter and call for your Strategic Plan, I ask you to consider providing funding to research why this protocol has worked for so many with a type of autism known around our world distinctly as “Virtual Autism.”

Most of you have probably never heard of this diagnosis or subset of young children that will meet diagnostic criteria of Autism when using standardized tools utilized around the world for testing in children such as one of the most popular; Autism Disorder Observation Scale (ADOS). This subset of the population of children diagnosed with ASD early has a different developmental history than their classically autistic counterparts. Their history is unique in that they have had exposure to high amounts of electronic screen media of two or more hours a day before the age of three. This high screen time then automatically and yet unintentionally relates to much lower levels of social interaction with the child’s primary caregivers due to having only so many waking hours in the day of a young toddler.

The American Academy of Pediatrics (AAP) calls for a child not to be exposed to any screen media before the ages of eighteen months and that video chatting is a permissible method of screen viewing approved for young children between eighteen and twenty-four months. It is not until age two that the American Academy of Pediatrics (AAP) considers co-viewing screen media with primary caregivers developmentally appropriate for one hour or less of their total day.

This population of children affected with Virtual Autism; a term coined by Dr. Marius Zamfir of Romania or how electronic screen media viewing may contribute to autism-like symptoms and how it’s removal and increased social interaction may help remediate the symptoms is studied by researchers, therapists and physicians around the world. Some of these are including but not limited to Dr. Marius and Ana-Maria Zamfir, Dr. Anna-Lise Ducanda of France, Dr. Hamid Pourtemad and Dr. Saeid Sadeghi of Tehran, Dr. Karen Heffler of Drexel University, and Michael Waldman Ph.D and Sean Nicholson Ph.D Cornell University.

These children display high efficacy of symptom reduction in a similar treatment protocol. Less therapeutic resources are needed from an already overly taxed system in every country with this protocol being applied to young children who fit the criteria for Virtual Autism. What is recommended by all these specialists is a protocol of extremely low or complete removal of all digital screen media from the child’s view to be implemented and a therapeutic, yet naturalized setting in which the primary caregiver high amounts of social interaction with the child is embedded into their daily lives. Many of the providers need only to coach the parents once or twice a week for about an hour at a time with easy intervention strategies imbedded into natural routines and play. These strategies help the child understand, communicate, and be socially motivated to participate at a developmentally appropriate

level over a few weeks' time. These activities provide many opportunities that allow the parent to have the primary focus of connection as they socially interact with their child throughout daily activities targeting of utmost importance eye contact and social environmental awareness of people, which is the foundation of much of a young child's social learning. For eye contact to be targeted before the age of five in utilizing this protocol it is recommended in my own practice that the child's hand be held to your eye as you talk to them with love and simple words according to their developmental understanding. If that does not appear to be effective for a child, holding objects close to your eyes and labeling the object can be used for natural motivation for connection and eye contact. Positioning yourself lower than your child during daily moments can also allow for easier opportunities to make eye contact and share joint attention between an object and your child.

Routines such as household chores of laundry, doing dishes, tooth brushing, and bathing can all be targeted in this way. It may take a little longer for completion of these common activities, and they may not be done to perfection, but the parents utilizing these techniques report lower amounts of stress over time and higher amounts of social connection and opportunities to bond with their child in my experiences with clients and families. The progress of symptom improvements can easily be tracked monthly on informal tools such as the "ASD Assessment Scale/Screening Questionnaire" developed by Dr. Rami Grossmann, a board-certified neurologist in New York which can be found on the website [childbrain.com](http://childbrain.com). These tools and parent reports tend to show profound improvements in core symptoms of autism within the first six weeks of protocol implementation and many of the first areas apparent to most parent are improved eye contact, desire to be near family members/primary care givers, higher environmental awareness, and less of the child's stereotypic and repetitive behaviors.

The following are unsolicited public comments that can be found across the web from googling the term "Virtual Autism" by parents who have tried this protocol all over the world and have found relief from the core deficits of autism for their young children whose developmental histories meet the criteria of Virtual Autism. These parents have set up a socially supportive and developmentally responsive relationship with the at risk or diagnosed child that is so very important for building the positive neural connectivity per the research on early childhood development and the environmental settings. The benefits have greatly paid off on their child's symptom reductions. Many of these children show a diagnosis of residual autism within the US in which all or most all symptoms have resided within 2.5 years and the child is able to attend kindergarten in a regular classroom setting with little to no support. My son was one of these children and hundreds of other parents report positive effects with their own children below...

- "...definitely improvements are there...she is having better eye contact and wants to go out of the home. We took her for a 3 day outing to kids of her age and guess what some of her words she spoke earlier came back..."
- "Now after stopping all screen time for 1 month and sending him a preschool (has) brought (a) change in eye contact and response when calling his name etc. He spoke a 2 word sentence in the last day."
- "...now after a little over a month she is starting to notice when we leave the room or if someone is leaving the house coming in and her eye contact is at least 60% better..."

I hope that hearing the term “Virtual Autism” has sparked your interest today and desire to learn more about what could save many children from a life that has the symptoms of ASD affecting their daily lives in a negative way to one that creates freedom from the symptoms and yet does not demean the diagnosis.



## Matthew Zeidman

I am an autistic American. Yes, I prefer identity-first language (e.g., "autistic person") instead of person-first language (e.g., "person with autism"), because identity-first language recognizes that being autistic is nothing to be ashamed of or feared and that, while it is not the entirety of my identity, it is an inseparable part of it.

I am writing to you today to highlight the importance of diagnostic and support options for autistic adults. I was not diagnosed as a child and only recently made the decision to seek a formal autistic diagnosis (not because I was unsure of my identity or needed an external source to validate it, but because I wanted access to the accommodations and support I should have had access to my entire life).

I thought obtaining such a diagnosis would be easy and immediate. I was wrong. The vast majority of medical professionals and facilities that offer diagnoses to the general public exclusively serve minors. Of the few that offer their services to adults, only a small minority accept insurance.

Those willing and able to pay out of pocket for a formal diagnosis can expect to fork over between \$1,500 and \$3,000. Those who cannot afford to pay out of pocket (or, like me, refuse to participate in such a predatory model of medicine) can expect to wait roughly a year or more to see a provider that accepts insurance.

I was able to locate only one diagnostic provider in my area that accepts my insurance and am a few months into a yearlong waiting list. Please keep in mind that I do not live in an area that is medically underserved. If I did, I likely wouldn't have any options at all.

To be honest with you, I find it deeply frustrating that I have to wait several more months to receive a formal diagnosis I've desperately needed and struggled without all my life. While an autistic person born today is far more likely to be diagnosed in early childhood, those of us who fell through the cracks before diagnostic measures were standardized and widely implemented are being left out in the cold.

I also find it deeply offensive that, instead of filling in the diagnostic and support gaps for adults and children alike, government and private resources are disproportionately being dedicated to genetic research and harmful treatments, like applied behavior analysis (ABA).

While, in a perfect world, genetic research would help us better understand ourselves, this is not a perfect world. The goals of autism-specific genetic research (whether those funding the research wish to admit it or not) are to "cure" living autistic people and develop a prenatal test for autism so that no more autistic people will be born. Until society as a whole accepts, supports and accommodates the autistic community, genetic research of this kind is dangerous and should not be prioritized over diagnostic and support services.

As for ABA, it frightens me how this quack pseudoscience has proliferated in recent years. It was developed by psychologist Ole Ivar Lovaas, who was also responsible for the development of gay conversion therapy. Its purpose is not to teach autistic individuals new skills or provide them with any kind of support or accommodation. Instead, its attitude is that autistic people should be compelled to behave like neurotypical people. It is basically a forced version of "masking" that many autistic people find themselves doing to hide their differences and "fit in" with neurotypical society.

ABA subjects spend up to 40 hours a week having their visibly autistic traits suppressed through a system of punishments and rewards, an extremely traumatic experience. In fact, autistic people exposed to ABA are 86 percent more likely to exhibit symptoms consistent with post-traumatic stress disorder (see link below).

[https://www.researchgate.net/publication/322239353\\_Evidence\\_of\\_increased\\_PTSD\\_symptoms\\_in\\_autistics\\_exposed\\_to\\_applied\\_behavior\\_analysis](https://www.researchgate.net/publication/322239353_Evidence_of_increased_PTSD_symptoms_in_autistics_exposed_to_applied_behavior_analysis)

I also recommend the article linked below, which was written from the perspective of a dog trainer, who has a bachelor of science in psychology and is herself autistic. She points out how ABA's ethical guidelines are virtually nonexistent and that, if she treated her canine subjects in the same way ABA practitioners treated their human subjects, it would be considered animal cruelty.

<https://neuroclastic.com/is-aba-really-dog-training-for-children-a-professional-dog-trainer-weighs-in/>

ABA is, for all intents and purposes, torture, no matter how its proponents portray it. Insurance should not cover it, and it should be outlawed. Imagine if every psychologist who currently specializes in ABA instead specialized in diagnosing and supporting autistic people. Perhaps then there wouldn't be such a gap in diagnostic and supportive care.

I hope you heavily weigh my perspective, as well as the perspectives of the autistic members of your committee. Quite frankly, there is no reason a committee focusing on autistic issues should not have a majority of autistic members. When it comes to such issues, we are not one voice in a chorus; we are the chorus. The perspectives of non-autistic doctors, caregivers and government leaders are valuable, but they should never be valued over those of the autistic community.

Thank you for your time.

## Matthew K. Belmonte

From Bettelheim all the way through to science's unnecessarily belated recognition of common autism comorbidities such as disordered sleep, gastrointestinal function, and immune function, autism research has been littered with instances in which failure to listen to stakeholders or to front-line clinicians has prevented our asking the right questions in the right way. Cross-disciplinary work on "patient and public involvement"

<[https://www.invo.org.uk/wp-content/uploads/2011/11/Involve\\_Exploring\\_Impactfinal28.10.09.pdf](https://www.invo.org.uk/wp-content/uploads/2011/11/Involve_Exploring_Impactfinal28.10.09.pdf)> shows that making health service consumers and providers part of the research team results in more honed questions, more acceptable and feasible methods, and greater clinical acceptance.

In particular, the question of keyboard-mediated communications from non-speaking or minimally speaking people with autism ought to have been laid to rest, yet persists because of a gap of communication and cooperation between families, therapists, and scientists. Stakeholders point to case reports of independent or apparently independent typing (as represented, appropriately, on the IACC itself), and claim that laboratory testing environments and binary outcome measures may lack validity or sensitivity. Behavioural scientists point to clear-cut Clever Hans effects and negative results from testing. And everyone points to marketers' conflicts of interest, not only in selling unproven typing methods but also in maintaining status quo therapies. Families resort to pseudoscience and to cults of belief precisely because they do not feel listened to. If we involve them from the beginning in formulating research questions and methods, though, they will own and accept the results and conclusions!

What is needed is a dialogue amongst stakeholders, scientists and therapists leading to a consensus protocol for rigorous, cooperative, advance-registered testing of claims of keyboard communication. Such a dialogue might begin in the setting of a retreat. This undertaking can include sceptics, proponents, and those with no position, the prime desideratum being an open-minded willingness to observe and to be convinced by evidence. It must address whether, how (mechanistically), for whom (which autism subtypes and developmental stages), and when (under what circumstances) typed communication is or is not valid. At the end of such an enquiry, either a class of invalid methods will have been soundly debunked with the participation of stakeholders who can better convince their peers of its invalidity, or a newly opened avenue of communication research may lead towards new authority, agency, and self-direction for some subset of non-speaking and minimally speaking people with autism. Indeed, both these scenarios might hold, for different subpopulations of autism and/or for different typing methods.

Either scenario would be a victory, allowing people with autism and their families to focus on interventions that work.

More broadly, the IACC must promote stakeholder involvement in the research team as a core aspect of institutes' and agencies' evaluations of the quality of research proposals. And it should facilitate formation of subcommittees and/or external working groups comprising stakeholders, front-line clinicians / therapists / educators, and basic scientists who can set research questions and methods of enquiry with advice of the experts on autism: the people who live with it or alongside it. As brother and uncle to two people with autism, and as an autism scientist, I for one stand ready to help.

[PII removed]

**Jill Escher, National Council on Severe Autism**

President

NCSAutism.org

Request for IACC to carve out specific recommendations regarding U.S. population disabled by profound autism

The IACC is congressionally mandated to advise the Secretary of HHS on matters regarding autism in the United States. Pursuant to statute, these matters include, among others, research on neurobiology, genetics and epigenetics, neurobehavior, causes (including possible environmental causes), prevention, services, supports, intervention, and treatment of ASD.

There is broad consensus among researchers and clinicians that "autism" is not a single disorder but rather a constellation of different impairments with varying intensities and functional capacities. Unsurprisingly, we see growing support for formally separating out subgroups in order to more accurately reflect clinical realities, improve validity of research, and facilitate identification of treatments, services and support.

In particular, the label of "profound autism" identifies a set of patients who suffer intellectual disability and such poor adaptive functioning that they require 24/7 support. This group likely exceeds one-third, and perhaps reaches nearly one half, of the autism population. According to CDC data, as well as data available from states such as California, U.S. autism rates continue to increase. Nearly 60% of children with autism have intellectual disabilities or borderline intellectual disabilities.

We urge the IACC to specifically attend to the needs of the profound autism population, needs which can diverge radically from others having ASD, particularly those who have the capacity for articulate speech, self-advocacy, and self-care.

As this body undertakes its congressionally mandated duty to advise the HHS Secretary regarding specified matters, we urge that it explicitly and intentionally identify research and activities targeted to the realities of profound autism. As mentioned above, pursuant to statute this should include, among others:

- neurobiology
- genetics and epigenetics
- neurobehavior
- causes (including possible environmental causes)
- prevention
- services
- supports
- intervention
- treatment

In recent years, several papers have been published pointing out the woeful dearth of research on this population. As one group of researchers wrote, "Those with intellectual disability or minimal verbal ability are often systematically excluded from research on ASD," resulting in "limited applicability to people who may need the most support." Greater attention to the unique characteristics of profound autism will lead to greater advances in science and society.

We also urge this committee to add additional public members who are parents of individuals with profound autism. Having strong representation for profound autism “which is notably lacking in the current IACC” is the best way to ensure that appropriate recommendations are made about those who have the least voice and most acute needs.

Thank you for your consideration.