



Public Comments

July 21-22, 2021

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Oral Comments

Christopher Banks on behalf of The Autism Society of America

The Autism Society of America appreciates the efforts of IACC and its committee. Our organization, with its 74 affiliates throughout 33 states, has traditionally had representation on IACC. Since 1965, the Autism Society of America has worked tirelessly to support the autism community through advocacy, education, information and referrals, support and community building. We have made it our mission to improve the lives of all affected by autism, alongside our affiliates nationwide.

Through the decades, the Autism Society has proudly served the autism community and established itself as the nation's oldest and leading grassroots autism organization. Together, we are creating a more inclusive and accepting society full of opportunities for autistic individuals to maximize their potential.

The COVID-19 pandemic brought unparalleled challenges and grief to the global community, and our autism families were disproportionately affected. Through service interruptions, school closures, job loss, isolation, lack of respite care, and regression, many autistic individuals and families were left with few support options and increased worries.

The Autism Society and its network of affiliates served over 668,000 individuals and families affected by autism in 2020. 154,000 people called or emailed Autism Society helplines across the country; 124,000 people attended events, mostly virtual, to gain connection and community; 26,000 people attended online and live support groups to battle isolation, stress, and grief.

While we do not have a representative voice on the committee, we appreciate the opportunity to offer our concerns and ideas for which we would like IACC to focus some of its efforts.

In addition to the legislative agenda of the Consortium for Citizens Disabilities which the Autism Society supports and is working diligently to see achieved, the Autism Society would like IACC to encourage other federal agencies to work with us in the following three areas which are strategic priorities for the Society:

1. First Responder Training (Law Enforcement, Fire, EMT)

The Society will develop a process for creating teams to provide training locally through our affiliate network. The teams will include representatives from law enforcement, clinicians (i.e. Social Worker), Self-Advocates, parents, and researchers.

In addition, there will be subject matter experts included in the training and certification process for police departments, first responders, criminal justice professionals, district attorneys, and other law enforcement entities. The certification program will provide an Autism Society stamped certificate and will require a renewal.

Efforts in this area will result in a reduction of injuries, a reduction of fatalities, and a reduction of arrests within the autism community.

2. Water and Wandering Safety Programs

The Society recognizes that drowning is among the leading causes of death in the autism community. A study from the Centers for Disease Control and Prevention (CDC) found that children with autism

spectrum disorder (ASD) were significantly (60%) more likely to wander than children in other study groups. Furthermore, children with ASD are at a substantially increased risk of injury and mortality from drowning.

This, coupled with the perils of wandering for the more vulnerable members of the community, necessitates the establishment of a Water and Wandering Safety program. The Society will build a curriculum for water and wandering safety based on research and best practices. The Society will use a “train the trainer” model where we will arrange for Affiliate training. Ideally, Affiliates will complete a comprehensive training on water and wandering safety.

3. Employment

Recent data indicated that unemployment and underemployment in the autism community is as high as 90%. The Society recognizes the need for a systemic change that provides opportunities for professional and non-professional employment, as well as the need to increase opportunities for competitive integrated employment and other services and supports in the community. Working with collaborators nationwide and members of the autism community, the Society will gather government officials, organized labor, educational institutions, employers, and individuals from the autism community to address this issue in a comprehensive approach.

The Society will provide the venue for conversation that leads to more autistic individuals being gainfully employed; this effort will look to increase opportunities, encourage job development, train companies, managers and coworkers, prepare qualified candidates and support individuals in their personal pursuit of success.

The Society will devise an approach to explore the issue of unemployment and underemployment in the ASD community. The outcome will be an executable plan that can be implemented to reduce unemployment and underemployment. The Society will develop ideas for national programs that significantly improve services to help people with autism find and retain work in their community.

These are not the only concerns for the autism community. We are also concerned with other issues including vaccine hesitancy, housing, transitional services, diversity and inclusion.

Jill Escher, J.D., M.A. on behalf of National Council on Severe Autism



Re: Priorities for the federal response to autism

The National Council on Severe Autism, an advocacy organization representing the interests of individuals and families affected by severe forms of autism and related disorders, thanks you for your service to the IACC in effectuating the congressional mandate to further federally funded autism-related research and programs, and ultimately improve prospects for prevention, treatment and services.

Dramatically increasing numbers of U.S. children are diagnosed with — and disabled by — autism spectrum disorders. In the segment we represent, those children grow into adults incapable of caring for themselves and require continuous or near-continuous, lifelong services, supports, and supervision. Individuals in this category exhibit some or all of these features:

- Nonverbal or have limited use of language
- Intellectual impairment
- Lack of abstract thought
- Strikingly impaired adaptive skills
- Aggression
- Self-injury
- Disruptive vocalizations
- Property destruction
- Elopement
- Anxiety
- Sensory processing dysfunction
- Sleeplessness
- Pica
- Co-morbidities such as seizures, mental illness, and gastrointestinal distress

Given the immense and growing burden on individuals, families, schools, social services and medical care, the autism crisis warrants the strongest possible federal response.

Parents are panicked about the future. Siblings are often terrified about having children of their own, and/or the burden of providing lifelong care for their very much loved but highly challenging brothers and sisters. Schools cannot recruit enough teachers and staff to keep up with growing demand. Adult programs and group homes refuse to take severe cases. Vastly more must be done to both understand the roots of this still-mysterious neurodevelopmental disorder and to prepare our country for the tsunami of young adults who will need care throughout their lifetimes, particularly as their caring and devoted parents age and pass away.

With that in mind, we ask the members of the IACC to understand the priorities of our community. While this list is not exhaustive it represents many of the issues our families consider most urgent.

In the course of committee deliberations:

The amorphous word “autism” should never obscure the galactic differences among people given this diagnosis. The construct of “autism” — and it is just that, an artificial human invention contorted by political and historical forces — has thrown together into one bucket abnormal clinical presentations that often have nothing in common. A person in possession of intact cognitive abilities and/or adaptive functioning who suffers from social anxiety and sensory processing differences has no meaningful overlap with a person with severe intellectual impairment, little to no adaptive skills, and aggressive behaviors. The IACC should take care to make distinctions at every juncture where “autism” is invoked in a general way.

Zero tolerance for anti-parent prejudice. It has been alarming to witness the re-emergence of parent-blaming in some sectors of the autism community. Parents provide the lion’s share of support for both children and adults with autism and have been at the forefront of reforms aimed at improving the lives of those disabled by autism. Parents also most reliably speak out on behalf of the best interests of their non- or minimally verbal children. We ask that the attitude of the IACC be one of zero tolerance for the disturbing trend of anti-parent prejudice.

Honest language to communicate realities. It is crucial that discussions at the federal level retain the language that reflects our clinical and daily realities, such as the following examples we commonly hear from our families and practitioners: abnormal, maladaptive, catastrophic, chaos, low-functioning, suffering, devastating, panicked, hopeless, desperate, exhaustion, overwhelming, anguish, traumatic, bankrupting, financially crushing, suicidal, epidemic, tsunami. We stress this not to detract from the many positives found in every person disabled by autism, of course those also exist, but to ensure that the challenges of autism are never semantically erased.

As federal priorities are developed:

The ever-increasing prevalence of autism must be treated with the utmost gravity.

Rates of autism that meet a strict definition of developmental disability have soared 40-fold

in California over the past three decades. Rates of autism now exceed 7% in some school districts in New Jersey. There is overwhelming evidence for growing rates of disabling autism, and little evidence this has been caused by non-etiological factors such as diagnostic shifts. We have both a pragmatic and moral duty to discover the factors driving this alarming, unprecedented surge in neurodevelopmental disorders among our youth and young adults. Clearly, vaccines and postnatal events are not responsible for the surge in autism, but many other factors warrant urgent attention so we can finally “bend the curve” of autism.

Maximizing the range of options available to our disabled children and adults. We need a broad range of educational, vocational and residential services to meet the very diverse needs and preferences of the autism population — and this includes specialized and disability-specific settings that are equipped to handle the intensive needs posed by severe autism. The post-21services “cliff” is a gut-punching reality across our country. Lack of non-competitive employment options. Lack of day programs. Few or no housing options. No HUD vouchers. Little to no crisis care. A healthcare system and ERs utterly unprepared for this challenging population. Aging parents. Lack of direct support providers. Lack of agencies willing to take hard cases. All of this amounts to a nightmare for our individuals and families. Clearly, massive policy changes are needed across multiple domains to maximize options for this growing population.

A desperate need for treatments. Regrettably, the therapeutic toolbox we have today is largely the same as two decades ago. While a cure for autism is unlikely to ever arise owing to the early developmental nature of the disorder, the IACC should push for research on potential therapeutics that can mitigate distressing symptoms such as aggression, self-injury, anxiety, insomnia, and therefore improve quality of life while decreasing the costs and intensities of supports. The research may include medical treatments such as psychopharmaceuticals, cannabis products, TMS, and others, as well as non-medical approaches.

We appreciate this committee’s commitment to autism prevention, treatment and services, and for your consideration of our community’s priorities.

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

Bin Feng

I would like to make some comments on the employment for Autistic adults. I am a parent of 21 years old Autistic young [name redacted]. I have been helping him to keep his job as a janitor. Even during the pandemic he still keeps working. We are very proud of him. We now truly believe many of the young adults on the spectrum could become valuable and capable workers as long as we give them the right training, give them the right job and help them with the right people. To have a job not only just get a paycheck, [name redacted] also learned how to manage his time and routines around his working schedules, learned how to travel independently, how to follow instructions and how to learn from his mistakes and bounce back. The confidence he gets from his working experience is the greatest reward we could imagine. From now he is willing to cast his votes, he is willing to join the advocacy group, he is thinking one day he can live by himself.

But the journey to employment for Autistic adults are far from easy. We know about 80% are unemployed, the highest among all the other disabilities. We need investment more on their pathway to employment. The Federal government should be the leading force to collaborate with all aspects. The Medicaid services should have started as early as 14 years old for them to start career exploration and pre-vocational training. There are many jobs in the community would be a perfect match for Autistic young. The employers could get incentives to open and keep employees on the spectrum. Those investments are very crucial to the Autistic adults since they can have a pathway to gain independence and self-esteem. We have done so little on this in the past, it is our time to do now.



Kelly Israel on behalf of Autistic Self Advocacy Network

Thank you for the opportunity to submit written comments. The Autistic Self Advocacy Network (ASAN) is pleased that, after an absence of 2020 meetings due to the coronavirus pandemic, the Interagency Autism Coordinating Committee (IACC) will resume its efforts to ensure that funding for autism research is properly allocated. New meetings for the IACC represent an opportunity for the committee to further commit to the values articulated in its 2018-2019 Strategic Plan, namely to “accelerate and inspire research, and enhance service provision and access, that will profoundly improve the health and quality of life of every person on the autism spectrum across the lifespan.”¹

In particular, the reconvening of the IACC represents an important opportunity to reform the federal government’s autism research *priorities*. The priorities of the federal government set a standard for the direction that privately funded research should take. Research into intellectual and developmental disabilities (IDD) - particularly research on the supports and services that best enhance living, learning and working in our communities - has the potential to improve the lives of millions. Nonetheless, autism research in the past has been excessively focused on the cause and prevention of autism, as well as medications and coercive therapies designed to make the autistic person appear less autistic. The IACC’s 2021 meetings could, instead, pave the way to a better future for *all* autistic people.

The Autistic Self Advocacy Network (ASAN), a 501(c)(3) nonprofit advocacy organization created by and for autistic people ourselves, shares the IACC’s commitment to better autism research. ASAN’s primary goal is and has always been to ensure that research funding is directed towards high-quality research with the highest potential to directly benefit autistic people. ASAN has commented on many of the IACC’s full committee meetings in the past in order to provide the committee with input on the values and interests of the autistic community as a whole. ASAN’s comments on the current meeting are below.

Directing Autism Research Towards the Priorities of Autistic People

ASAN supports research and workshops included in the IACC’s 2018-2019 Strategic Plan that address important priorities of the autistic community. The Strategic Plan included a comprehensive September 2018 workshop on the co-occurring disabilities most common in autistic people (for example sleep, epilepsy, and gastrointestinal and connective tissue disorders). It additionally included a 2019 workshop

¹ Interagency Autism Coordinating Committee Interagency Autism Coordinating Committee Strategic Plan for Autism Spectrum Disorder (ASD): 2018-2019 Update at IV (Jul. 2020), available at: https://iacc.hhs.gov/publications/strategic-plan/2019/strategic_plan_2019.pdf?version=3.

on mental health in autistic people, a subject sorely in need of attention from the research community. These workshops examined the trajectory and impact of these conditions across the lifespan - a significant improvement upon prior work in this area - and included the perspectives of autistic people ourselves. Several of the workshops, projects, and studies described in the Strategic Plan either interviewed or worked directly with autistic adults. Our inclusion and investment in autism research is critical for ensuring that future research aids autistic people. ASAN also appreciates that the IACC's 2019 Summary of Advances includes research on important under-researched topics, such as the impact of home and community-based services (HCBS) waivers on racial disparities in service needs and the lack of adults with intellectual disabilities included in many ASD-related research studies.²

Nonetheless, there is a significant gap between the IACC's publicly stated *commitment* to autism research focusing on the real needs of autistic people and the funding actually directed towards this work. According to the 2017-2018 IACC Portfolio Analysis Report,³ which summarizes federal and private funding directed towards autism research, as of 2018 a mere 3% of total autism research funding went to research on the quality of services and supports. Although the 2017-2018 report again states that 6% of autism research funding went to services and reports (research which falls under the Strategic Plan's Question 5, "What Kinds of Services and Supports Are Needed to Maximize Quality of Life for people on the autism spectrum?"), *nearly half of that limited funding in 2018 -46% - went to the "practitioner training" subcategory*. Practitioner training is *not* research on which services and supports work best for the diverse needs of autistic people - which is research our community urgently needs.

Research Question 6, the only question to focus specifically and exclusively on lifespan issues ("How Can We Meet the Needs of People with ASD as They Progress into and Through Adulthood?") is similarly underfunded. Funding directed towards Research Question 6 accounted for only 3% of all funding for autism research. Additionally, a full 39% of this funding went towards research into only one age group and type of lifespan issue: effective transition services for young adults and adolescents with disabilities.⁴ While ASAN agrees that the transition into adulthood is a critical period, funding imbalances shortchange other critical lifespan research. Autistic people undergo the same range of life events as non-autistic people and spend the majority of our lives as adults. Our needs in mid-life, our experiences with marriage and parenthood, the ways our health and disability might change as we age, and our experiences with aging itself deserve serious consideration, research, and support.

ASAN recommends that the IACC prioritize the use of longitudinal aging-related studies of autistic people of a wide variety of backgrounds, socioeconomic statuses, genders, and ethnicities. In particular, ASAN emphasizes the need to ensure racial, ethnic, and gender diversity in future autism research. As a study in the IACC's 2019 Summary of Advances notes, Black, Indigenous, People of Color (BIPOC) individuals are

² Interagency Autism Coordinating Committee, 2019 Summary of Advances in Autism Spectrum Disorder Research 28, 38 (May 2020), available at: https://iacc.hhs.gov/publications/summary-of-advances/2019/summary_of_advances_2019.pdf.

³ Interagency Autism Coordinating Committee, 2017-2018 Autism Spectrum Disorder Research Portfolio Analysis Report (Apr. 2021), available at: https://iacc.hhs.gov/publications/portfolio-analysis/2018/portfolio_analysis_2018.pdf?ver=2.

⁴ *Id.*

historically under-identified as autistic people, and there are often disparities in the services that they receive. Any study which includes autistic adults but fails to include BIPOC people will dramatically reduce its efficacy to the autistic community.

Critical research largely remains underfunded in large part due to an excessive and often ethically questionable focus in the autism research community on the biology and causation of autism. The IACC research questions which represent research on these two topics (IACC Question 2 and Question 3) together accounted for more than half of all research funding in 2018 - 61%. While some issues important to the wellbeing of autistic people, such as epilepsy and other co-occurring physical and mental health conditions, require traditional biomedical research, the overwhelming majority of the research represented by these two questions transparently aims to identify and modify the biological mechanisms underlying autism in order to ultimately reduce the number of autistic people in the world. ASAN, and the autistic community as a whole, strongly opposes such research. ASAN urges the IACC to utilize its first committee meeting in more than a year to lead a change in focus for autism research; from research that aims to eliminate us, to research that aims to help us live good lives.

Avoiding an ASD Diagnostic “Research Silo”

Autistic people have a great deal in common with other people with intellectual and developmental disabilities (IDD). We tend to experience many of the many of the same academic and social differences, many of the same executive functioning impairments, many of the same lifelong support needs, many of the same issues finding and securing employment as adults, and a similar array of co-occurring disabilities. While there are some research priorities and concerns that may be specific to autistic people (ex. our high suicide risk), these are rarer than concerns that are common to all people with IDD.

Nonetheless, historically many of the researchers, agencies, and educational institutions which develop effective services and supports for people with IDD have few connections with siloed autism-specific research and do not receive autism research funding. The workshops and presentations listed in the 2018-2019 Strategic Plan indicate that this discrepancy still exists. For example, the September 2018 co-occurring disabilities workshop and the May 2019 mental health workshop do not reference research in these areas performed on people with other developmental disabilities, or generalist research on all people with IDD in these areas, even though this research exists and should inform research on autistic people. Similarly, the 2019 Housing Working Group largely ignored decades of research and practice showing the efficacy of community living for all people with intellectual and developmental disabilities, including those with the most significant support needs. ASAN recommends that the IACC discuss situations in which autism research could be better informed and improved in quality by consulting with the agencies, educational institutions, and researchers working on research on people with IDD generally and other groups of individuals with IDD. Autistic people are not served by research that reinvents the wheel or that views us as a separate category entirely, rather than a subset of a common group of people with disabilities.

Inclusion of Autistic Adults in Autism Research

While some researchers have begun partnering directly with autistic people ourselves in the design, production, and analysis of their research, most autism research is still “about us, without us.” ASAN

recommends that the IACC use its unique role to promote the inclusion of autistic adults ourselves in *all* forms of autism research. Autistic adults can provide input on not just our co-occurring disabilities and lifespan issues, but on communication access, the design of studies on the neurology of autism, studies on which services and supports work best for different groups, and indeed on any aspect of autism research.

We particularly encourage the IACC to recommend the use of community-based participatory research which works directly with autistic self-advocates ourselves (including non-speaking self-advocates and self-advocates with intellectual disabilities), rather than acquiring study participants solely by contacting parent representatives or our service providers. We possess firsthand knowledge and experience of our own bodies and minds that other stakeholders lack. High-quality research done in partnership with autistic adults ourselves is the only way to reduce gaps in the knowledge base.

Communication Access

Access to communication is a vital human right. Autistic people may use a wide variety of possible forms of communication, including verbal communication, behavior as communication, and augmentative and assistive communication (AAC) devices. At least one-third of autistic people are not able to rely on speech to communicate. Nonetheless, much of the current research *on* communication and autism largely does not reflect the diversity of communication styles in autistic people. Instead, it tries to determine how to get us to communicate through speech.

ASAN is concerned about the excessive focus on only verbal speech reflected in the IACC's Autism Research Database entries for 2018, the latest year available.⁵ While there were nearly 13 pages of research which examined the impact of autism on verbal language and the best means of facilitating its development in autistic people, there were only a few entries on the best ways of facilitating the development of AAC use or other alternatives to verbal speech. ASAN therefore recommends that the IACC prioritize significant additional research into how autistic people may best establish other forms of effective communication. This research has immense potential to profoundly impact the quality of life of autistic people who do not currently have access to a robust method of communication. More research is urgently needed to establish which methods work best for which autistic people, and how to best support every autistic person to access communication. Communication is a human right, and Nonspeaking autistic people deserve research that prioritizes their needs and interests.

ASAN again thanks the IACC for the opportunity to comment. We hope that the IACC is able to put forth new frontiers for autism research, rather than retreading upon the old. For more information on ASAN's positions with respect to autism research, please contact Julia Bascom, our Executive Director, at jbascom@autisticadvocacy.org.

⁵ IACC Autism Research Database, Interagency Autism Coordinating Committee, <https://iacc.hhs.gov/funding/data/> (last visited Jul. 1, 2021).

Noemi Spinazzi on behalf of M.D., Down syndrome-Autism workgroup of the Down Syndrome Medical Interest Group

Autism occurs more frequently in individuals with some genetic disorders, including Down syndrome. The prevalence of autism spectrum disorder in individuals with Down syndrome has been estimated to be 16-18%, based on a recent meta-analysis, though estimates in the literature vary due to differences in diagnostic approach and methodology. When autism co-occurs in a patient with Down syndrome, it leads to a complex neurodevelopmental profile, in which characteristics of autism - communication impairments, social impairments, restrictive patterns of behavior and interests - are superimposed on common challenges in Down syndrome, such as intellectual disability, speech impairment, short attention span and memory impairments. Due to diagnostic overshadowing and the lack of evidence-based guidelines for assessment, the diagnosis of autism is often significantly delayed in persons with Down syndrome, therefore delaying the start of targeted therapies that can improve the functioning and quality of life of a child with a dual diagnosis. There is also inadequate research on which educational and behavioral interventions are most successful in supporting children with a dual diagnosis. Given the high prevalence of autism in Down syndrome, the significant impact that this additional diagnosis has on the life of a child with Down syndrome, and the paucity of evidence on best practices for evaluation, diagnosis, and intervention, more attention needs to be directed to this underserved patient population.

Written Comments

Oren Evans

Finally, after more than 70 years of worldwide research the two main pieces of the puzzle can be put together and then all the other pieces fall into place. At first glance the answer seems improbable but after 70 years of research it was obvious that the answer wouldn't be obvious. There are several reasons that the answer wasn't found before, all mainstream researchers are medically trained and autism is not a medical problem it's more of a physics problem. These researchers are extremely fact resistant and refuse to consider anything but a medical cause. Another reason is that one of the two main pieces was unrelated to autism and had no connection to autism at the time and finally the data from the second piece was considered a symptom of autism and not the genetic factor.

In 1998 a study using EEG technology was conducted to determine the impact of fluorescent flicker (strobe) on humans. The flicker distorted every one's brain waves but the most notable finding was that the faster your visual response time (VRT) the GREATER your distortion became. This is the environmental component of autism. It has the capability to distort brain waves enough to cause autism in a fragile developing infant brain.

In 2013 the University of Rochester did a study on a group of autistic people and found that their VRT averaged twice as fast as normal. The fast VRT allowed for large brain wave distortions and is the reason they are autistic. This is the genetic component of autism that researchers have been looking for. An infant that inherits a fast VRT is predisposed to becoming autistic. Their fragile still developing brain is receiving very distorted information when exposed to fluorescent flicker causing improper neural connections and pathways leading to autism.

Major studies around the world prove that vaccines do not cause autism yet parents continue to see their children regress into autism after being vaccinated. This understandably drives the anti-vaxx movement. What they have no way of knowing is that the exam room with the door closed is the most concentrated flicker environment possible. This is what's causing the regression, not the vaccine.

It's well known that males (hunters) have a faster VRT than females (gatherers) which means that their brain waves are distorted more than females. Bell curve calculations indicate that about 6% of males and 1.5% of females are predisposed or 4/1. However the slower flicker in countries that use 50 HZ electricity put more children at risk but the percentage gain for females is greater than males making the ratio closer to 3/1 in the UK, this has been confirmed by the University College of London.

There are 350,000 Amish, some vaccinated and others not, no electricity, no autism.

An increased exposure to fluorescent light, an increase in autism, NICUs and day cares or just the need for more illumination, short winter days resulting in a seasonal variation or the abnormal amount of overcast days of the Pacific NW causing an increase in autism.

I could go on and on but if you're not convinced by now there's no point.

Ramey Chisum

Really need to focus on hyperthyroidism too. It caused my daughter's autism and it's nearly impossible to research it when added to the fact that health sites can't tell the difference between the two. I of course don't lump your site into that category, not at all.

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4196309/>

Resa Warner

Please recommend to the Secretary of Health and Human Services independent replication of the subject research as priority in autism research budgets. What issue could be more important than identifying the biological cause of 80% of autism cases? I am not asking you to manage individual projects or research portfolios. I am asking you to set a research agenda based on a biologically plausible explanation. (increased uptake of lead) Autism cannot be prevented without knowing the biological mechanism.

Kevin Tallman

The International Brotherhood of Electrical Workers (IBEW) offers a self-funded health plan to its local unions. The health plans offered are part of the Family Medical Care Plan (FMCP). Since the health plans are self-funded, they are governed by the Employment Retirement Income Security Act (ERISA) or in other words the US Department of Labor (DOL). Every plan offered by the FMCP has an exclusion against developmental delays and does not cover speech, occupational, or physical therapy for those who have a developmental delay. States mandate this coverage in private health plans but since the health plans are self-funded, they are governed by the DOL. To this date the DOL has not mandated self-funded plans to require speech, occupational, and physical therapies for those with developmental delays. In the FMCP plans they specifically state one is entitled to speech/occupational/physical therapy unless you have a developmental delay. What this means is children with autism are denied Applied Behavior Analysis (ABA) therapy along with speech/occupational/physical therapies. We need help, this discrimination can no longer be acceptable. Please reach out to your resources and advocate for the DOL to mandate self-funded insurance plans to not allow developmental delay exclusions.

Link to the NECA/IBEW health plan.

https://www.nebf.com/fmcp/documents/plan_documents/

Page 12 of PDF is one of many pages that has the developmentally delayed exclusions

https://www.nebf.com/assets/1/7/Plan_16_SPD_May_2012_11.30.18.pdf

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

Blesse Fields

Blessings I will make this short and include my phone number [PII redacted] I live in TN and have concerns after my son has been charged at school in Hawkins Co Juvenile Court for behaviors due to autism. I will not go into more details here but wanted to voice that until the charges I was unaware that the SRO in the schools have no access to Behavior support plan on Special needs children. Unless the parents give consent which I plan to do tomorrow at our IEP meeting for [PII redacted]. I want to keep this short but I was shocked to find this out. I also believe that law enforcement officers should have some way (license ID) or something to inform them to protect adults with behaviors so they know how to properly approach them. I have watched videos online and pray something can be done about both the SRO in the schools mandatory training with NASRO would be amazing! Thanks for reading all this I hope it was alright to send this by this route.

Marc Lefebvre

As a parent of a teenage child with both development disabilities and mental health issues I appreciate IACC's chairing committees to address housing/independent living because it is a goal, I think, for every parent with a disabled child for that child to eventually live independently and hopefully have some level of happiness in their life.

Housing issues is one of many concerns parents have but I think many would agree that the biggest challenge is that therapies, treatments and medication are hit or miss and there is no coordinated effort regionally or nationally to track persons and provide help to those who are treatment resistant and/or whose presentations are very complicated making treatment difficult. It is a tragic missed opportunity for information sharing and learning but most importantly help. This concern is compounded by the fact that absent electronic medical files allowing care providers to access full medical histories easily that care providers are missing possibly critical information, making therapies possibly less effective and this is coupled with the fact that loved ones wonder if current privacy laws make it overly burdensome for care providers to easily communicate with each other on histories and prior therapies. For many of us, there is a view that science is just reaching the frontier of understanding the brain, resulting in hit or miss drugs and therapies. Having said this, however, tracking and attempting to treat those who have no true relief should be a national priority.

Jobie Steppe

It appears that those diagnosed with ASD possess some characteristics such as seeking order similarly as is required in the programming of computers, or who seek perfection. It also appears silicone valley and other tech locals seek out and hire thousands of those diagnosed with ASD. This makes me conclude those diagnosed with ASD should be utilized to seek out the root cause of demyelination classifying them as researchers or should be hired as such. Is this being done?

Rob Avina

Facts are important. There is an idea that they are becoming bifurcated and will soon be obsolete. I think this is a false idea. A truth is only as true as the ideas surrounding it.

Following are 5 links. In order of creation and a short description of each. They are hosted on Google servers, so they should be safe and work. Take the time and precautions you see fit. I have.

Disney Disabled Services Letter.pdf A letter to Disneyland's disabled services:
https://docs.google.com/document/d/1Qc2h_Z5ZYKefjRgJ_Ahfp0uU8r2O5-JV-R_SvbDVf6A/edit?usp=sharing

1fTx0DDN.txt & dontdoanythingaboutthisplease.txt are the same document, a letter to CIA Director Haspel:
https://docs.google.com/document/d/1DlaL5oONIH0mB_vUamNbcMLrmwsPbhttfzTVILgiNXc/edit?usp=sharing

jiminiproject.pdf
https://drive.google.com/file/d/15t_fHDgwa06bB4w0tWkoZZR8kjrYxeB/view?usp=sharing

Business letter.pdf a letter to Chelsea Manning sent to her jail cell in Virginia by mail, with a copy sent to her lawyer via twitter messenger:
<https://docs.google.com/document/d/1CsvbTWchuMlaJLlb06iqKfRIImG1tC3p6uZVZU0wil0Y/edit?usp=sharing>

A list of Fax numbers I have sent these documents to. Sorting by Date or phone will give you a good idea of where I was trying to communicate to. The "Done - Good" tab at the bottom is only successful faxes with page count confirmations as copied from my account:
https://docs.google.com/spreadsheets/d/1bexjO2Q_Zyd3Y15DpuC6xWuD6VitzWWn0SwSaBtaM0/edit?usp=sharing

There are other facts, but these are some of mine. Please look into this.

Note: Attachments are available upon request.

Elissa Leonard

You have a duty to warn: this is the differential diagnosis for every single thing you label Autism Spectrum Disorder. Pediatric B12 Deficiency misdiagnosis in the age of folic acid interventions that mask B12 deficiencies in moms and babies.

Chaudhary H, Verma S, Bhatia P, Vaidya PC, Singhi P, Sankhyan N. [Infantile Tremor Syndrome or a Neurocutaneous Infantile B12 Deficiency \(NIB\) Syndrome?](#) *Indian J Pediatr.* 2020 Mar;87(3):179-184. doi: 10.1007/s12098-019-03117-w. Epub 2020 Jan 27. PMID: 31984470.

Malhotra S, Subodh BN, Parakh P, Lahariya S. [Brief report: childhood disintegrative disorder as a likely manifestation of vitamin B12 deficiency.](#) *J Autism Dev Disord.* 2013 Sep;43(9):2207-10. doi: 10.1007/s10803-013-1762-6. PMID: 23334842.

Note: Attachments are available upon request.

Elissa Leonard

Show me where there was an "autism epidemic" anywhere on earth, before we added high-dose folic acid to the womb (80s) and instituted food guidelines disparaging meat (80s) and then added more synthetic folic acid to all carbohydrates (90s) that mothers and growing children eat all day, every day.

Too many women have been convinced it is safe to be "plant-based" in the era of folic acid fortification where their B12 deficiencies will go undiagnosed, and therefore acquired by their babies. Too many women have the sense it is safe to begin pregnancy after decades of either a vegetarian diet or history of taking any of the many medications that can cause B12 insufficiency: hormonal birth control, metformin, antacids, statins, alcohol, antibiotics. Too many doctors still think B12 deficiency is ruled out by lack of macrocytosis.

Not educating the public about this lockstep time line (excessive folic acid and concomitant low vitamin B12) is akin to being part of a coverup.

Common gene variants like MTHFR have long existed. What hasn't existed is opposite extremes of B12 and folic acid deranging one carbon metabolism, as was forewarned to happen but went unmonitored. Is it ethical to medicate everyone with a form of folate that is not well-metabolized by everyone? Now we know it can change DNA methylation. Air pollution used to be worse, but as you know nutrient status is crucial in dealing with pollutants and toxins. Blaming genes or toxins for what the "B12 deficiency and excess folic acid" does (raise the metabolites homocysteine and methylmalonic acid and also cause abnormal brain growth and/or cerebral atrophy) is pure obfuscation.

Check Homocysteine, Methylmalonic Acid and treat all patients with signs symptoms and risk factors of insufficient B12 immediately or they will suffer serious permanent neurological harm including cerebral atrophy. A multivitamin may raise the blood level, contributing to misdiagnosis. That does not mean it reached the brain.

Guez S, Chiarelli G, Menni F, Salera S, Principi N, Esposito S. [Severe vitamin B12 deficiency in an exclusively breastfed 5-month-old Italian infant born to a mother receiving multivitamin supplementation during pregnancy](#). *BMC Pediatr*. 2012 Jun 24;12:85. doi: 10.1186/1471-2431-12-85. PMID: 22726312; PMCID: PMC3407531.

Kocaoglu C, Akin F, Caksen H, Böke SB, Arslan S, Aygün S. [Cerebral atrophy in a vitamin B12-deficient infant of a vegetarian mother](#). *J Health Popul Nutr*. 2014 Jun;32(2):367-71. PMID: 25076673; PMCID: PMC4216972.

Richmond RC, Sharp GC, Herbert G, Atkinson C, Taylor C, Bhattacharya S, Campbell D, Hall M, Kazmi N, Gaunt T, McArdle W, Ring S, Davey Smith G, Ness A, Relton CL. [The long-term impact of folic acid in pregnancy on offspring DNA methylation: follow-up of the Aberdeen Folic Acid Supplementation Trial \(AFAST\)](#). *Int J Epidemiol*. 2018 Jun 1;47(3):928-937. doi: 10.1093/ije/dyy032. PMID: 29546377; PMCID: PMC6005053.

Note: Attachments are available upon request.

Elissa Leonard

The Boston Birth Cohort study that came out last month shows high levels of Unmetabolized Folic Acid (manmade synthetic form of folate, hidden by law in all flour products) in Black babies with autism.

This is an explosive healthcare story with roots in the well-meaning but unmonitored universal intervention in the food supply to combat neural tube defects with synthetic folate. Sadly, adverse effects were predicted by experts and their concerns were ignored.

The intervention is lockstep with exponential growth in the autism epidemic. The story is nuanced with a number of variables, most notably vitamin B12 status. We cannot metabolize folic acid without sufficient co-factor B12. Babies need B12 and folate working in synergy for normal brain growth and development.

I have been studying the unintended consequences of excessive folic acid and concomitant B12 Deficiency for a decade. I attended a workshop at NIH last year on Folic Acid Excess and Vitamin B12 Deficiency. <https://www.niddk.nih.gov/news/meetings-workshops/2019/metabolic-interaction-folates-folic-acid-vitamin-b12-deficiency>

Attached is my report with footnotes to current research. In 2018 autism researcher and pediatrician Dr. Walter Zahorodny from Rutgers told me that the CDC was purposely obscuring the links to excessive folic acid and autism epidemic.

Folic acid is not the same as folate from whole real food. News hook for this article is the Boston Birth Cohort Study:

Raghavan R, Selhub J, Paul L, Ji Y, Wang G, Hong X, Zuckerman B, Fallin MD, Wang X. [A prospective birth cohort study on cord blood folate subtypes and risk of autism spectrum disorder](#). *Am J Clin Nutr*. 2020 Nov 11;112(5):1304-1317. doi: 10.1093/ajcn/nqaa208. PMID: 32844208; PMCID: PMC7657337.

If you want to watch real injured patients I interviewed as research for my feature film Sally Pacholok, you can see them here: <https://youtu.be/BvEizypoyOO>

I am a philanthropist not selling anything. Just interested in public awareness of something that has been causing serious permanent harm to all age groups.

Note: Attachments are available upon request

Elissa Leonard

Children with Autism in this study have low vitamin B12 -- but unrelated to absorption (not autoimmune pernicious anemia.)

They have acquired deficiency, presumably from undiagnosed moms and/or diet.

Why are moms undiagnosed? Because for 40+ years of folic acid, no one has been checking for B12 deficiency in absence of the anemia you were taught to look for. And a prenatal vitamin cannot reliably replete B12... could be not enough, could be an analogue. Raising blood level to "normal" does not necessarily address deficiency in growing brain.

Erden S, Akbaş İleri B, Sadıç Çelikkol Ç, Nalbant K, Kılınc İ, Yazar A. [Serum B12, homocysteine, and anti-parietal cell antibody levels in children with autism](#). *Int J Psychiatry Clin Pract*. 2021 Apr 6:1-6. doi: 10.1080/13651501.2021.1906906. Epub ahead of print. PMID: 33823740.

Additional Citations

Ozyurek H, Ceyhan M, Ince H, Aydın OF. [Vitamin B12 deficiency as a treatable cause of severe brain atrophy](#). *Neuro Asia*. 2021; 26(1): 187 – 191.

“Early diagnosis and treatment in infantile vitamin B12 deficiency are important to prevent the irreversible neurological damage.”

Metyas MM, Abdelhakim AS, Ghandour HH. Screening of vitamin B12 in children diagnosed as Autism Spectrum Disorder. *QJM*. 2020 May 5; 113(Supplement 1). <https://doi.org/10.1093/qjmed/hcaa063.006>

Trenton Ashizawa

I am someone who has been diagnosed with Autism, and have almost always felt left down by the climate of our culture in America, especially with some of the jobs I have applied for. I have felt discounted, because of my disability, including jobs that work with clients who have Autism Spectrum Disorder. I feel like those around me either make jealous reasons to kick me out or don't want to even hire me, because I have Autism. I had one instance where I was working as a Behavior Technician, and the job knew that I had Autism Spectrum Disorder, so they gave me the second hardest client and graded me more harshly than other people being hired. I not only would like to make you aware of this discrimination, but I would like to be proactive towards research within the topic of Autism to combat against the negative stigma I have been dealt.

In the near future, I really want to work in research, because there is a large hypothesis on happiness I have had for years that to my knowledge hasn't been researched. I have a plan of how I can not only test it, but think of ways to overcome the tested negative behavior. Though, some days I feel like I won't make it to where I want to be and before I could take one step forward I have to complete 50 longitudinal puzzles to get there. I don't enjoy griping about my problems, but I would like to make you aware that this has been an ongoing problem I have been dealing with. Also, I would really like to work under one of you, so I can follow my passion of psychology research as a profession.

Thank you in advance for reading what I have to say.

Note: Attachments are available upon request.

Harold Frost III, Ph.D.

I have information bearing directly on what new research to consider doing or sponsoring in the next funding cycle, to be done along untapped lines of theoretical physics and mechanical engineering analysis, to open up a new and potentially fruitful pathway to finding and quantifying an important environmental causative agent for or correlate of autism spectrum disorder.

That information is shared via (1) the attached stand-alone *pro bono* Treatise I've worked on as a professional physicist over the past 15 years (mostly as a retiree of the University of California), plus (2) the attached 1977 Letter to the Editor of *Lancet* magazine published when I was a GS-13 federal employee at the old BRH at the FDA in Rockville, MD, a unit now replaced by CDRH in Silver Spring, MD.*

This analysis bears on the overlooked action of medical diagnostic ultrasound (MDU) as longitudinal waves for producing shear deformation and damage on vulnerable interfaces in biological tissue modeled as a solid (such as a soft solid) having a non-zero shear modulus of elasticity. The physics concepts contained in the Treatise are simple enough to be taught in undergraduate physics and engineering courses at a U.S. university, such as in the continuum mechanics and dynamics of solids including the use of tensor analysis in rectangular Cartesian coordinate systems.

Accordingly, it is my assessment that the staff rosters for the IACC and the OARC fail to bring in the academic expertise needed for optimizing the opportunities created by the reauthorized Autism CARES Act of 2019 for finding out more about the causes of ASD (with or without simultaneous comorbidity like ID) and thus providing parents more hope through consequent discovery of more effective interventions. For example, physics and pertinent engineering disciplines are not represented in the bios of their members. That is not only poor policy but also a mistake that should be corrected.

Incidentally, I am sensitized to the challenge of ASD as an important public health matter by having our own 55-old son (and only child) living in his own apartment under the roof of our stand-alone house here in Sheffield village. Besides LD and AD he is diagnosed with autistic disorder. But also I bring to my assessments a high degree of objectivity and methodology in my research, such as learned from my physics dissertation advisor, Prof. Wesley L. Nyborg (1917-2011), who chaired Scientific Committee #66 of the NCRP also headquartered in Bethesda, MD -- a committee which issued three report volumes. He in part is 'where' I'm coming from. His Memorial Tribute which the NAE invited me to draft and includes a few details on those reports such as NCRP No. 140 (2002), is also attached, as published in 2012 by the NAP.

In closing, I am 78, in a neurocognitive decline. So what I've done is all I can do now. Yet the Treatise is solid, clear and engaging enough to help motivate another scientist who reads it while engaging his or her own unbiased intellect such as to identify any mistakes made in it but then to take the analysis to the next level of making quantitative predictions of thresholds for damage via the newly proposed bioeffect of MDU termed (purely) solid-state mechanical shear stress or strain (SSMSSS). Physical experiments and animal model studies should then be designed and funded to test those predictions.

I've done all that I can do with this matter, having regarded it as a moral imperative to bring my slow but steady work on it to a finish line so that someone else can now take up the torch.

Please respect the information offered in this message and its attachments, as developed in the disciplined tradition of the Scientific Method. It stands on its own. My only funding for it was, indirectly, my small pension from UC plus SS income. I had no co-author for the Treatise. I had no grant to sponsor my work on it and was interested in only bringing the physical truth out into the open. Thank you.

Note: Attachments are available upon request.

Harold Frost III, Ph.D.

Following your directions, please accept the two attached PDF files for the latest version of my *pro bono* physics-based technical treatise and of my CV, the later for credentials beyond those given in the treatise. The treatise and CV are meant to be conveyed together as a unit (along with this cover e-mail) to members of the IACC before their first meeting (in 2021?), as you indicate. Thank you.

For those members of the new IACC lacking but wishing any needed physics background, a suggested reader's *vade mecum* for my treatise is the textbook *Intermediate Biophysical Mechanics* by Wesley L. Nyborg (1917-2011) [Cummings Publishing Co., Menlo Park, CA, et al., 1975; hardcover; ISBN: 0-8465-4860-7], cited and used in the treatise. The author was my physics dissertation advisor over 1970-1974 at The University of Vermont. That dissertation was the starting point in 2005 when I began my *pro bono* investigations into a new and overlooked physical mechanism for the action of ultrasound in biological tissue when cavitation and strong heating are absent.

The treatise is not definitive on its topic but does introduce a sound, fresh line of thinking for the etiology of and interventions for idiopathic ASD and ID, mentioning ASD in "Addendum E - Postscript" on pp.77-78 and on pp.1-2, 15, & 66. Autism is mentioned on pp.66 and 91.

Nonthermal, non-cavitation low-intensity MDU does not have the energy density needed to break the macromolecular backbone of a DNA molecule but does have the energy density needed to break the weak cross links that provide the basis for secondary and tertiary structure of DNA. Thus MDU can affect DNA and protein conformational states and so the folding/unfolding process important for gene expression within the paradigm of gene-and-environment interactions, with ultrasound constituting a man-made environmental factor.

Over 2005-2010, Prof. Nyborg was my part-time scientific collaborator on this unfunded project. Published examples of our collaboration over the years include the references in the treatise of Frost and Nyborg (1973) and Nyborg and Frost (2006). Otherwise, I've had to work alone, due mostly to a major disability limiting some of my life's activities.

In closing: I hope my public comment will be treated respectfully and responsibly by the new IACC and by NIH, even though there may be IACC members and others who disagree with it.

With best wishes then, as you forge ahead. Thank you for your service to the public health of the Nation.

Note: Non-Latin characters were not rendered correctly and have been removed

Harold Frost III, Ph.D.

TREATISE ? CASE FOR PREDICTING ADVERSE BIOEFFECTS OF MEDICAL DIAGNOSTIC ULTRASOUND (MDU) AS BASED ON MISSED PHYSICAL ACTION OF RESOLVED SHEAR, by Harold M. "Hal" Frost, Ph.D. (HMF). A pro bono white paper dated April 29, 2021. 139 pp. total. HMF is a University of California (UC) retiree since 2008 via Los Alamos National Laboratory managed then by UC, as well as an IEEE Life Senior Member since 2017 and a Foundation for Science and Disability Member since 2008. A CV in PDF is available on request by e-mail. Synopsis (following the "Notes") indicates that the Treatise deals on the basis of simple classical physics principles and math with a possible link between fetal medical diagnostic ultrasound and autism (ASD, with or without IDD).

"Notes": Subscripts were not rendered properly during the copy and paste operation from the source document (PDF) to this message box. Today's date is Thursday, April 29, 2021, and this present posting is the second one posted by me today via this "Public Comment" form. Thank you very much, OARC and IACC members 'at' NIMH/NIH for your consideration of this public comment.

"Synopsis" follows:

This independent & original Treatise presents evidence for Hypotheses A and B (HA and HB) being true, based on over-looked action of B-Mode & Doppler imaging, elastography & other medical diagnostic ultrasound (MDU) in biological tissue assumed for simplicity to be an isotropic solid with Lamé parameters [non-Latin characters removed], with MDU as uniaxial longitudinal elastodynamic waves (ULEW's) governed by a wave equation (WE) in the uniaxial particle displacement vector u [non-Latin characters removed]. Here, [non-Latin characters removed] is a unit vector and [non-Latin characters removed]; a shear modulus of elasticity or viscoelasticity. For ULEW's, the linear strain tensor [non-Latin characters removed] is uniaxial (and stress tensor triaxial) per Kronecker delta functions [non-Latin characters removed], with [non-Latin characters removed]. Linear transformation of a rank-2 tensor [non-Latin characters removed], by rotating its associated Rectangular Cartesian Coordinate (RCC) axes to a new set RCC' resolves from ϵ_{11} a shear strain [non-Latin characters removed] and so by use of Hooke's law, such as Eq. (1) or (2) in this Treatise, resolves the stress tensor [non-Latin characters removed] in an RCC system with [non-Latin characters removed] into shear stress [non-Latin characters removed] in an RCC' system. With principal stress axes coinciding with principal strain axes in isotropic solids, shear strain & shear stress coexist on planes only with normals tilted from the propagation direction coaxial with ULEW's polarization direction parallel with u found by spatial integration of ϵ_{11} .

HA: ULEW's induce either force-relaxation or creep retardation in biological tissue or interfere with their natural versions. HB: Interaction basis is resolved solid-state mechanical shear stress or strain (SSMSS), material nonlinearity and entropy production. HA and HB posit a theoretical analogy between (1) newly proposed ULEW effects of 'recording' and 'erasing' of residual stress & pre-stress in soft solids obeying nonlinear constitutive equations for retardation from mechanical creep, with (2) known ability of ultrasonic Uniaxial Extensional Elastodynamic Waves (UEEW's), governed by a WE in longitudinal stress, to do this while breaking weak chemical bonds (e.g., hydrogen bonds) and thus changing material structure and creep compliance in tissue and plastics [Schnitzler (1969); Frost (1974)]. In contrast to case for ULEW's, stress is uniaxial for ULEW's such as for a stress tensor [non-Latin characters removed] (and strain is triaxial). Hypothesis examination was guided by the GREST framework & other formal methods [Frost (2010)] & mentoring of W. L. Nyborg (1917-2011), a National Academy of Engineering member

[Frost (2012)]. Accordingly, HMF uncovered evidence for a third possible set of adverse bioeffects of MDU based on a physical mechanism of purely solid-state mechanical shear strain or stress (SSMSSS) missing from the status-quo duo of accepted physical mechanisms of just heating and cavitation by MDU. Such solid-state effects have been long known as ultrasonic UEEW interactions in metals & alloys via resolved solid-state mechanical shear strain (SSMSS). Their subtlety was foreseen by Prof. Nyborg in his published lectures on physical mechanisms for ultrasound bioeffects [Surles (1977; 1978)] cited in the Treatise sub-section, 'Preliminary Matters...'

Yet today's expert analyses, position papers, and tutorial book chapters on the physics of ultrasound in biological tissue and phantom materials still hew mostly to that duo of MDU's fluid-state effects, with 'fluid' referring to gas and liquid phases of matter, 'effects' to all 3 phases including linear & nonlinear deformation and flow, and MDU limited to acoustic pressure waves (APW's) governed by a WE in excess pressure $p = [\text{non-Latin characters removed}]$ with $[\text{non-Latin characters removed}]$ the frame-invariant trace of the strain tensor. (Other terms for APW's are dilatational waves & P-waves.) The literature often describes APW's as examples of longitudinal elastodynamic waves (LEW's) ? untrue as they travel in media with $[\text{non-Latin characters removed}]$ so in fluids offering no resistance to shear deformation & thus unable to sustain shear stress [p.25, Achenbach (2003)]. So APW's have indeterminate triaxial polarization with both longitudinal & transverse parts, as opposed to uniaxial (longitudinal) polarization of ULEW's with frame-sensitive components. With MDU mistakenly taken as APW's (in still fluids) which cannot be resolved into shear via a coordinate transformation as opposed to ULEW's which can be in solids, physicians, ultrasonographers, researchers & other members of the medical ultrasound research and practice (MURP) community argue on that false ground that MDU is safe, even in OB/GYN practice. Other issues with their reasoning include the logical fallacy of excluding possible presence of adverse bioeffects of MDU when the canon of heating and cavitation effects is absent.

Rather than attack their POV, HMF instead developed without funding this inaugural pro bono counter case so that readers looking at both POV's can judge for themselves whether HA and HB need to be tested via new-start sponsored research, with ultrasound as mechanical radiation more carefully and holistically identified in the spirit of GREST as a triad of APW's, UEEW's (and other guided waves), and ULEW's (and other bulk waves), for a broader framework within which to make judgments on ultrasound safety & efficacy. Evidence given here for a third major physical mechanism includes data, concepts and other verbal, numerical and math content like (1) a tensor analysis formalism better tying knowledge of the mechanics of continua to that of thermodynamics [Gurtin, Fried and Anand (2013)] and (2) gene-and-environment interactions to help frame & explain the etiology of disease states involving environmentally induced protein folding, unfolding and misfolding in biological tissue [Buchner and Kiefhaber (2005)], with prenatal ultrasound a man-made environmental factor. Credibility and thus admissibility of that evidence is heightened by HMF's pertinent work experience spanning over a half century of research, and thus his call for new research to test & validate his predictions with observations, as on the central nervous system (CNS) including the brain vulnerable to exposure from prenatal MDU or MDU acting on the Blood Brain Barrier (BBB), adult or fetal ? or on phantom samples or animal models. Detecting & visualizing physical effects of resolved shear seems achievable by using 3D MDU methods with tomographic capability to image any plane segment in a total volume scanned (see 'Addendum E: Postscript'), and searching for human disorders & diseases due to mechanically-induced protein misfolding [e.g., Ch. 31 in Buchner and Kiefhaber (2005)] as by SSMSSS resolved from ULEW's, viz., idiopathic neurodevelopmental disorders like autism spectrum disorder (ASD; autism) occurring with rising incidence rates in recent decades, with or without comorbid intellectual developmental disorder (IDD).

Harold Frost III, Ph.D.

It is my hope that at least one of the new members of the IACC is a physicist. That is because physics is needed for making analytic assessments about the effect of radiation of any type in the environment on interactions with the human genome and concomitant gene expression. Radiation can be elastodynamic or electromagnetic as well as nuclear. Exposure can be prenatal as well as after birth. However, if none of the members of the new IACC is a physicist, I hope that at least several members of the new IACC will establish or continue close ties with one or more physicists (excluding myself, who am disabled and in failing health), and seek advice or other information when needed. Thank you for listening.

Affiliation: Retiree since 2008 of the University of California, as a former Technical Staff member at Los Alamos National Laboratory in Los Alamos, NM.

Qualifications include a Ph.D. in physics awarded in 1974 by The University of Vermont, and election in the IEEE as a Senior Life member.

Harold Frost III, Ph.D.

At least 10% of the federal funding total estimated or otherwise known by the IACC as available for autism programs of any kind in the U.S. should be recommended by it to be applied in the next practicable federal fiscal year cycle (FY2022 or FY2023) to fund new-start grants (both intra- and extra-mural to NIH) in response to formal RFP's issued to attract proposals whose sole purpose or at least primary deliverable is testing of the validity of as-of-yet untested but known hypotheses based on available evidence presented to it for ASD causation in scenarios made plausible to some through analyses based in part on overlooked radiation physics and chemistry principles expressed mathematically within a thermodynamics framework and employed at multiple size and time scales for physical and chemical interactions within biological tissue. Radiation is that present in the environment from either natural or artificial sources, and can be acoustic or elastodynamic as well as nuclear or electromagnetic. Interactions are to include those between the environment, and gene integrity and gene expression, as well as the dynamics of protein folding, unfolding and mis-folding in response to radiation inputs with energies sufficient at nano-size scales to break hydrogen bonds like those present in DNA, RNA and protein macromolecules. Such broken bonds may then reform but only after a solid-state order-disorder transition has occurred that affects the in situ, in vivo structure and functionality of those macromolecules. This effect may be strong enough to contribute in turn to a delayed adverse bioeffect of the radiation at a higher level of size scale, even macroscopic. Thank you for listening.

Nayeema Bashar

I am a single mother of an autistic boy, 18, who has been adversely affected by the pandemic. I am working to support my son's special school - SAND - that delivers educational and vocational support to children with various special needs.

Please find attached a proposal that outlines some initiatives for this school where I am a parent governor.

We urgently need your help to provide life opportunities for those who receive so little support from elsewhere.

I will be in touch to discuss this soon.

TD Wallin

Last year, I watched the videocast from the NIH titled "Addressing the Mental Health Needs of People on the Autism Spectrum." It was six hours long, and in it was a woman who had been diagnosed as psychotic when she really should have had a baseline diagnosis of a social developmental disorder. After diagnosis, she was able to come off a majority of the medications and learned to love her whole self. Too many medical professionals believe that if someone has a PTSD diagnosis, they are psychotic. Not true. People with a PTSD diagnosis will develop psychosis IF they are treated with antipsychotics or antidepressants instead of given compassionate dialectical or neurofeedback therapies.

I have two sisters who have suffered from misdiagnoses of Asperger's for women, considered parts of a "lost generation" of women by Dr. Tony Attwood of the UK. Over 700,000 female respondents tested positive for Asperger's which was misdiagnosed in the country.

One sister has shown a lifetime of definitive traits of Asperger's for girls. I have asked repeatedly for the psychiatric hospital to court order her for neurofeedback and trauma therapy. I assume it's because of state law, they cannot and will not do so. They also refuse to give her the appropriate diagnosis of primary Asperger's in women, because they are not familiar with the diagnostic guidelines. When my sister was in court to be court-ordered for drugging which caused horrific side effects, I met a gentleman whose wife was in the same predicament.

My daughter had to go into the evaluator's office and explain the diagnostic differences between men and women affected in order to receive a correct diagnosis. Even then, our state does not offer covered services for adults with Autism.

Since people with autism have genetic mutations and deficiencies due to mitochondrial dysfunction, they are not able to metabolize medications without suffering further harm to their gut microbiomes and their central nervous systems.

In raising twins with high functioning autism but never having received appropriate diagnoses (we were told Tourette's, ADHD, and OCD,) we feel betrayed by systems who seemed desirous of hiding their true diagnoses. What we couldn't understand then was that the most dangerous side effects of autism are metabolic and neuroimmune in nature. This means that they were given medications for years they could not metabolize well, which led to gut dysbiosis and worsening encephalopathy as a result.

My son ended up in kidney failure at 25 before I learned from all the new information coming out about why and how he developed the condition. I also learned how he might heal, since it was saline solution pushed through his system at too high a rate for too long that caused thrombosis to develop in his kidneys and a clot to form a stroke in his eye. Doctors didn't believe me when I asked for an ophthalmologist to come and look at his eye. Because of their hesitancy, (he was in hospital for 7 weeks) he still has a blind spot in his eye.

Doctors instead seemed to believe us hysterical when it was the saline that caused the problem.

I need help getting this information out, as well as forming a non-profit that would put together access to non-invasive therapies not easily afforded by autism families. The information included in the videocast I mentioned prior is what is needed for all placed in inpatient facilities across the nation. It's called EASE and was piloted by some wonderful doctors at University of Pittsburgh.

What can I do in helping children and adults alike have access to appropriate diagnoses and therapies in our state? Everyone I've called has said they don't diagnose adults, and they certainly aren't treating them at the root. The appropriate therapies and doctors are not covered on insurance in our state, which is and has been decidedly discriminatory in light of the above information. In our families' cases, it's rather urgent.

Please let me know to whom I can speak about getting funding for my non-profit to help families as well as how I can help change insurance coverage to include coverage for more than just ABA therapy for children, something for which those who have had it, say is detrimental in the long run, because it is a reward system like for dogs. We were told to give our children things to take them away as punishment. It and so many other disparities throughout our systems caused our children to think we were selfish and cruel in disciplining them, and to believe us to be bad "helicopter" parents instead of parents of high-functioning autistics with metabolic health and gut issues that to this day still have not been appropriately addressed or accommodated.

The truth is, women are more often affected because of the development of PTSD from not being heard or believed. I know this first hand. PTSD should be considered a physiologic diagnosis rather than a purely psychiatric one, in my humble opinion. Part of the problem lies in lack of resilience from within the immune system, which causes the development of neuroimmune developmental disorders and syndromes that are labeled Autism or "mental illness."

I'm not a doctor, but I am an Asperger's sufferer who never received appropriate diagnosis or therapy either. People with Asperger's tend to overcompensate with research into areas of interest, and I see clearly what is missing: listening to and hearing patients themselves. Once someone is stigmatized with a psychiatric diagnosis, they are discredited and dismissed. This must change.

People with PTSD have been injured and have had no support to show value for their lives. That's what leads to the development of psychosis - not being believed or supported, but being feared and medicated instead. If a person has mitochondrial dysfunction (susceptibility to develop Autism and chronic illness) they cannot metabolize synthetic drugs and quickly develop unwanted responses to them. Yet the long term physical effects are equally devastating.

Our systems are set up against us by not allowing families to participate and have input as to what therapies should be court ordered, because any non-invasive therapies besides drugs are not covered under insurance. My loved ones have been on the merry-go-round for decades, and it's time for new understanding and consideration. This is especially true for my son, who has suffered static encephalopathy from both cause and treatment in the form of dialysis for almost a decade. Saline solution which was the standard of care in 2013 caused thrombosis of his kidneys; something which I know could be reversed with the right interventions, has been missed by every doctor he has seen. So he has suffered needlessly all these years.

Our systems could save millions if they help people recover rather than masking the symptoms with side-effect laden drugs. They are far more expensive in the long run, as the kick the can approach leads to serious complications with age.

One of the most marked things for me was the SSRIs caused me to lose my compassion for both myself and others for years. We need more compassion in this divided world. Now I live in constant severe unrelenting pain from trauma combined with the neuroimmune effects of CFS/ME.

I look forward to hearing from you and the new committee. If I may be of any service to the committee in any capacity, I hope you will call on me as a citizen advocate. I believe I have a lot of experience, knowledge and information that might be useful.

I'll go talk to Congress if need be; I look forward to hearing from you soon.

Thank you for listening.

Paula Notarino

I am very disappointed in my state of Connecticut not giving mentally disabled people quicker access to the covid vaccine. Our Governor changed his mind the other day and now my son (age 36, mentally disabled with autism) has to wait until April. They were supposed to receive the vaccine shortly, but the Governor allegedly went against the advice of the Advisory committee. I will never vote for him again.

Ann Lindsey-Frost

Additional support, advocacy, and assistance needed on behalf of individuals on the Autism spectrum in this area. Especially during this season of COVID-19. Housing referrals in the Findlay, Ohio area at the Metro Housing Authority Office are not addressing applications submitted. A long, drawn out process for over 9 months include not answering calls, or returning messages to help this group of individuals. While funds are allocated to help those in need of housing during this Pandemic COVID-19 season, this area is not being of any support to the individuals with Autism or on the Spectrum. Thank you for any assistance you can provide during this time!

Note: Non-Latin characters were not rendered correctly and have been removed

Happy Bird

Hi, I'd like you to create a series about U.S.A. families struggling to raise severely autistic individuals of various ages, both sexes, and in various states. With a Japanese language full dub.

I'd love all IACC materials and website in full Japanese ([non-Latin characters removed]) and Irish translations.

I'd also love a multilingual, new, nationwide AAC app - hiring Japanese artists from Pixiv to create cute, relevant illustrations for the apps, as well as full Japanese translations and sentence formation, grammar, furigana.

And also, create Japanese language ADL (daily living activities) cards and pamphlets.

Jean Public

i find the blithe way that members of this committee seem to be so committed to vaccinating everyone no matter the cost for some of them in lifelong horror or death to be upsetting to me.

vaccination and alteration of the body with the vaccine is a huge event for somebody's body. you may be in perfect health and something about that vaccine can put your body off so that it doesn't work right for the rest of your life and that is a life ruined not only for the child so injured, but for the father the mother, the siblings, the grandmother, the grandfather, all are impacted by a body harmed by a vaccine. i think you all forget that.

\one person injured can and does cause injury to another 6 people at least and maybe more.

that is a good reason to become more understanding of the horrific impact for many millions who have already been injured in this USA by the push push push to get any vaccine at all and the push from alleged "science" has become more and more pronounced.

we need to step back. we need to re-evaluate. we need to go over safety and we can't be as negligent as we have been in safety. the safety levels have been very low with vaccine administration and they need to go back and redo all steps for this vaccine which is primarily a vehicle for big pharma to get rich on, as well as doctors.

the money involved seems to have altered good judgment imo.

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

Martha Gabler

Thank you for this opportunity to comment on issues of concern to the autism community. We have a 25-year old son, [name redacted], who has severe autism and is profoundly nonverbal. He requires 24-hour care. We are extremely worried about his future, particularly because we have no idea who is going to take care of him after we die.

We have two over-riding concerns:

1. Access to a variety of housing options, based on the person's needs
2. Access to Applied Behavior Analysis (ABA) support services

At the present we see no pathway to a reasonable future for [name redacted] in relation to housing and lifelong care. The superficial language of "community integration" does not address the intensive support needs of the population with "severe" autism, and even fails to appreciate the complex needs of some of the "higher functioning" individuals. People with autism, whatever their presentation of the condition, must have access to a *variety of options* for housing and care supports.

Each person needs to be in a setting that meets his or her needs, as documented in the Person-Centered Plan. Some individuals will be successful in more independent community settings, and some, like our son, desperately need a communal setting with well-trained staff and supervision by compassionate professionals.

Our son needs lifelong access to ABA support services. We know that people respond and behave in accordance with the treatment they experience in their day-to-day environments. [Name redacted] needs to be in a setting where people know how to build positive environments and maintain productive behaviors using the principles of positive reinforcement. He thrives in an environment with structured positive behavioral supports. He will suffer, fail, injure himself, and may even die, in an isolated, restraint-oriented setting.

Thank you for your attention to our concerns.

Connie Louderback

our sons almost 50 & over, severe, with autism. No services now for year 3 mos. Husband & I home, no breaks to take care of our medical or other needs. Due to aggressive, noncompliant behaviours, we are hostages in our own home & still are.

Now with Justice dept requiring they be in community, our son totally blind lost his day program because they are deemed similar to institution. They are not, & are much needed. He was there almost 30 yrs> Dealing with unpredictable noises in community are impossible, His once better life is now back and forth- bed to couch & back. real shame & his behaviour had gotten excellent as he could predict his daily ritual, Other son loves people but can hit & getting staff can be difficult & he don't like change. He has not left house in over a year. Right now programs cannot get staff, have not opened. Huge, Huge gap in services for more severe. They Need a program that Works for them! There is no respite, no emergency backup. Please help those who nobody really wants! Thanks

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Francine Hogan

Pennsylvania

Mother to [name redacted] (21 yo) who experiences autism and requires 24/7 care

It is paramount that the IACC sets the narrative for the autism Spectrum. In recent years the "neurodiversity movement" has staked claim on the voice of autism. They have vilified the family voice claiming families of severely autistic individuals are hurting them by seeking appropriate therapies, services, and programs. This movement is led by self diagnosed and Level 1 autistics who are functioning independently, working, living on their own, and do not want to be labeled as disabled. These individuals are minimizing the lived experience of Level 2 and Level 3 autistics and their families, who struggle to get through one day at a time. The legislature, professionals, Intellectual Disability systems, and the broader community are now questioning why people with autism need so many services. They are seeking advice NOT from the families who care for severely autistic individuals 24/7 for decades, but from the neurodiversity movement who has gained credibility by discrediting the voice of those who live the experience of severe autism each and every day.

The neurodiversity movement DOES NOT speak for the whole autism spectrum. Please consider reinstating the Asperger DX and removing it from the autism DX.

Thank you for the opportunity to comment.

Lisa Elliott

There is a Need for viable long-term programs, supports, and housing options for adults with autism, especially those living with parents who are aging or otherwise incapable of meeting their substantial needs.

My son is 30 and autistic. He has trouble communicating. He needs constant supervision. He can not even do daily living tasks for himself. We love him, he is one of the greatest gifts of our lives. He is funny and sweet. He brings joy to everyone who meets him. The thought of him going to public-run programs terrifies me. Do you see the horrific things that happen to disabled individuals in these settings? It's cruel. We need tougher laws for abuse and as families, we need our right as advocates to protect our family members in these settings. We need to back these bills like the Billy Crow Law in NJ.

Jane Kleiman

I am the parent of a 20 year old with autism, global apraxia and OCD. Combined, these diagnoses mean my son has a severe communication disorder that can result in aggression toward others and himself. The options for his adult life are limited, especially in NJ where we live, to group homes with no choice of housemates or staff or staying home with us as we age and providing a fulfilling life for him becomes more and more difficult. He is an adult who deserves a dignified adult life. That means, he should be able to work in an environment that is suited for him. That is decidedly NOT competitive employment as he would always need 1:1 support and redirection. It also means safety in community with well paid, reliable staff of our choosing, developmentally appropriate housemates and a custom designed adult program in which he can continue to develop his independence, have friends and feel happy and proud of himself. That means 24-hour monitoring, scheduling and support and what that looks like should be developed by his team. There are many, many parents who are each trying to put together adult housing/living communities for their children, but we shouldn't all have to re-invent the wheel. It would be so beneficial to these families if there existed a tier of templates for adult housing that could be followed, that the federal dollars that states must administer could be easily funneled into so that families could more easily create the housing that is appropriate for their adult children.

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Karin Lunsford

Our family of five includes one young person with autism named [name redacted]. His behavior over the years has included wandering, self injury, and property damage. During puberty he had a big regression and lost many of his independent self help skills. We spent over a year homeschooling and working to retrain the lost skills. [Name redacted] cannot have a conversation nor can he tell you what he did an hour ago. He cannot be left alone in any room of the house beyond his own.

[Name redacted] will start his last year of high school in August. While he will be eligible for a transition program we are already bracing ourselves for the cliff that awaits him once he ages out. Will there be a day program suitable for his needs then? Will there be any options for work that will be safe for him?

We have very limited family activities because of [name redacted]'s behavior. Respite is not easy to find so we typically have to leave one person home with him. Higher pay and better training for respite providers could make this less of a problem.

[Name redacted] can be dangerous in public if we're not taking precautions. This has gotten especially concerning as he's grown into an adult sized male. We wear ID to show we are caregivers and only visit familiar places to keep him safe. We wish that more of his community was accessible to him but worry about incidents that might be misunderstood. Will first responders know how to safely assist him and de-escalate a crisis?

As he approaches 18, we are thinking a lot about the conservatorship process and financially planning for his future. He will need new doctors and a new dentist as pediatrics no longer applies. Will we find new practitioners to accommodate his special needs?

[Name redacted] lives at home with two parents and one sibling, for now. We have no immediate intention of him living away from home but that has a lot to do with the quality and availability of options for him. Someday he will have to live without us and we fear that there will be even less choice then.

Thank you for your time.

David Kassel on behalf of Massachusetts Coalition of Families and Advocates, Inc (COFAR, Inc)

We are submitting a link to our latest blog post in advance of your July meeting. Our post details a mother's battle to ensure adequate care for her son in the Massachusetts Department of Developmental Services system.

Our post is at: <https://cofarblog.com/2021/06/29/a-mothers-lonely-battle-for-appropriate-care-for-her-son/>

We are a statewide nonprofit organization in Massachusetts that advocates on behalf of families and guardians of persons with intellectual and other developmental disabilities.

Thank you for considering our comments.

Lin Zhang

Hope there is more help on self-employment for autistic adults.

Rita Whitney

My son is 22 and has severe non-verbal autism. He has aged out of public school, and now attends a dayhab program every day. He requires a lot of support to keep him engaged in any activity, and to keep him safe. The dayhab is a nice facility, but with so many clients, it is impossible for them to keep him appropriately engaged in activities, as that would require a lot more intensive instruction pertinent to just him.

I do not know what the future holds for him when the time comes that we cannot care for home at home. My son is 6 ft tall, 200 lbs, very active, has maladaptive behavior and has no safety awareness. During his lifetime, he has been thrown out of preschool programs, Sunday school, classes and camps for special needs children, and most recently summer camp programs for special needs adults due to his high level of needs. His hyperactivity, sleep disruptions (sometimes only sleeps a few hours a night, on occasion stays up all night), his wandering, and his occasional aggressive behavior with biting or pinching, make him challenging to care for. Because of these behaviors, and his inability to communicate, he is considered high risk for abuse and neglect.

It is essential for individuals such as my son that there be a full range of services to meet the full range of the autism spectrum. That should include dayhab programs that can provide the necessary supports to individuals with higher needs, and a multitude of living options that could meet his needs. Since he is not welcome at most dayhab programs or camps for individuals with autism/special needs, the chances of finding a safe and appropriate group home setting is highly unlikely. I personally know families whose loved ones with similar needs were physically abused in group homes due to the lack of oversight of these secluded and privately run homes. It is dangerous to have my son secluded in such a home unlikely able to meet his needs. When we can no longer care for him at home, I hope to find a full range of living options, including farmsteads, congregate living facilities, and ICF facilities so that I can determine which one of those will be able to provide for his needs, keep him safe and allow him to live a life to his fullest potential.

Dawn Sikora

Lately, I have noticed that there is increasing intolerance in the Autism community towards people diagnosed with Asperger's Syndrome. The discrimination and psychological abuses towards us as people on the spectrum and as older adults diagnosed with Aspergers is nothing short of Agist attitudes, Ablism and Racism within the toxic advocacy section of online advocacy efforts. These attitudes are not helpful and actively harms our community. These attitudes further stigmatizes us as older members of the Autism community and has become increasingly prominent and problematic.

This toxicity within the Autism community is directed not only towards those with Asperger's, but also parents, providers and other allied professionals, such as researchers. It hurts the progress in our community and shuts out and intimidates some voices which with they disagree.

This toxic behavior also undermines the unique biological, social, and emotional needs of persons of different support levels on the Autism Spectrum, and effectively erases advocacy voices (both of self-advocates on the spectrum and also parent-advocates).

I would like to see a stronger stance taken against the deleterious effects on mental health that the kind of toxic advocacy in the ASD community is exhibiting towards older persons on the spectrum and their families.

Especially where by Autism and Asperger's diagnosis becomes integrated into the person with ASD's identity, it is only our decision for how we self-identify and our self expression of our diagnoses. No one else, who is not our personal doctor, should be telling us that our diagnosis does not exist or that our diagnosis is outdated or invalid. Or worse.

And if I have Asperger's Syndrome and disclose and self-identified as having Asperger's, I would ask for this to be respected and not be a homing beacon to target me, and others like me, for harassment.

Thank you to the members of IACC for allowing me to express this concern with you.

Actionable objective:

I would like to see a stronger stance taken against the deleterious Agist, Ablist, and Racist effects on mental health that the kind of toxic advocacy in the ASD community is exhibiting towards older persons on the spectrum and their families. That regardless of diagnosis, age, or time period when the person on the spectrum was diagnosed, that they are treated with dignity, respect, and compassion in all communication.

Possible outcome: A statement that states that Agist, Ablist, and Racist harassment based on diagnosis should not be tolerated in our community as people with Asperger's Syndrome and Autism.

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

La Donna Ford, M.D.

Foster City, CA

I am writing to urge that your committee recommend federal funding to investigate a question of urgent importance in autism etiology: the genetic and epigenetic impacts of halogenated anesthetic gases on the germ cells (egg, sperm, and lineage of precursors) of the parent generation, and the ensuing impacts on offspring neurodevelopment, in particular the early transcriptional dysregulation of brain-related genes.

Last year I co-authored a commentary on this topic, "General anesthesia, germ cells and the missing heritability of autism: an urgent need for research," in the respected peer-reviewed scientific journal *Environmental Epigenetics*, with Jill Escher, a well-known autism research philanthropist who has been raising questions about this and related matters for many years (Escher and Ford 2020).

I am a retired anesthesiologist and mother of a young man, [name redacted], who has a severe form of idiopathic autism. Based on my experience as a physician with extensive experience in clinical practice and my keen interest in autism causation research, I can say with confidence that this hypothesis, which has gained enthusiastic attention from molecular biologists, germ cell toxicologists, and reproductive biologists, is likely the most important one yet raised in the history of autism. Allow me to explain as best I can, briefly, and in layperson's terms.

Every year more than 50 million inpatient surgeries are performed in the United States, including procedures on pregnant women, neonates, young children, older children, adolescents and pre-conception adults. Since the 1960s, my field has adopted waves of new agents to induce the state of anesthesia, including but not limited to intravenous agents like propofol and halogenated anesthetic gases such as halothane, enflurane, isoflurane, desflurane and sevoflurane (which I will call "GA"). These drugs are nearly miraculous in their ability to induce global suppression of the nervous system in the patient so as to enable the myriad procedures of modern surgery (anything from neonatal hernia repair, to plastic surgery, to heart surgery, to orthopedic surgery, to appendectomies, among countless others).

That's the good news. The bad news is that these agents are highly toxic. In their ordinary doses they are of course lethal, with patients kept alive only via intubation and careful monitoring. They are neurotoxic - in fact, the FDA has issued a warning regarding neurotoxicity in patients under the age of three. They are genotoxic — seen to induce DNA damage at the site of contact and peripheral blood. They are reproductive toxicants -- which can damage sperm and egg. More importantly for our purposes, a rash of new studies in mammal models show they can induce epigenetic changes in germ cells that can result in abnormal neurodevelopment in the offspring. These papers are cited in our *Environmental Epigenetics* paper, and I will not repeat them now, except to add that a remarkable newly published study in *Biology of Reproduction* has shown how fetal exposure to sevoflurane can induce abnormal binding of transcription factors in sperm DNA, resulting in dysregulated transcription of autism-related genes in offspring -- and abnormal brain and autism-related behavioral phenotypes (Wang et al. 2021). In other words, it appears, based on animal studies, that germ cell exposure to GA agents can exert an adverse intergenerational impact.

In hindsight, this hypothesis strikes most people as rather obvious. And indeed researchers first noticed these heritable effects via mouse experiments in the early 1980s. But regrettably, no heritable-effect

studies were performed again until a few years ago (Escher and Ford 2020), and the FDA does not test for germline impacts of GA. As a practitioner neither I nor my colleagues gave any consideration to our patients' germ cells. This facet of GA toxicology has languished in a blind spot for nearly 4 decades.

While I believe that surgeries under GA are likely benign to germline in most cases, I am deeply concerned about certain exposures, for example, exposures to GA in infancy and childhood, as well as repeated or prolonged exposures, including in adulthood. And while GA likely poses little absolute risk to a patient's germ cells, the population level risk may be substantial. If just 1% of U.S. patient exposures result in an adverse heritable effect, that could result in 500,000 cases of some level of abnormal neurodevelopment per year.

Through the years I have watched many hypotheses of autism causation come and go. The current trend is to presume autism's strong heritability "genetic" -- an idea that seems sensible on its face but is lacking in actual molecular evidence except with regards to rare de novo germline mutations which can only explain a fraction of the cases. And while I have no way of knowing what subsection of autism cases may be explained by heritable impacts of parental exposures to GA, I must point out the unprecedented power of this hypothesis to explain a great number of unsolved mysteries of autism, including the following:

- The tremendous increase in prevalence in recent decades, particularly in industrialized countries
- Autism's strong heritability (via broad impacts across parental germ cells)
- Strong sibling recurrence
- The genesis of autism in early abnormalities of transcription of brain-related genes, impacting neurogenesis, neural migration, and synaptic function
- The heterogeneity of autism spectrum disorders
- The skewed male-to-female ratio (males are markedly more affected in the mammalian experiments)
- Regional and demographic variations in prevalence
- The "broader autism phenotype" seen in parents and siblings

The IACC was created to push federal agencies to finally answer questions about autism, and I can think of no other question in autism research that deserves more attention than this. And this attention is 40 years overdue. If the committee wishes to learn more about this important emerging hypothesis, please do not hesitate to contact me or my co-author. Thank you for your attention.

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Alexander MacInnis, M.S., M.S.

My name is Alexander MacInnis. I am an epidemiologist specializing in autism. The IACC has established laudable goals in its strategic plan, including understanding preventable causes of autism, its biology, effective treatments, and the needs of the burgeoning population of adults with autism. We have a great need for solutions to these problems.

For any disorder, disease, or condition, investigation of questions like those in the strategic plan relies on knowledge of the rate of occurrence of new cases. That is a fundamental descriptive measure, usually called incidence. Unfortunately, we currently lack high-quality, widely accepted estimates of the rate of occurrence of new cases of autism. For disorders like autism, the occurrence of new cases is not directly observable, so measuring incidence is not practical. The appropriate measure for the rate of occurrence is birth year cohort prevalence—the proportion of each birth year cohort with the disorder [1]. There are various abbreviations, including “birth prevalence.” Birth prevalence is similar to incidence. It is quite different from general prevalence, which is not specific to birth year, despite sharing the same word, which can be confusing.

Birth prevalence, like incidence, is important for studying associations with potential causal factors. Also, it is directly useful for predicting the future caseload of adults with autism based on individuals who have already been born.

The IACC can provide a great service by addressing the current deficiency in knowledge of the autism birth prevalence trend. Further, the IACC can use that information to inform research projects tied to the strategic plan and prioritize projects accordingly.

Some of the best autism birth prevalence estimates available now are from CDC’s Autism and Developmental Disabilities Monitoring Network (ADDM) project [2 - 10]. The numbers in those reports are called “prevalence” but actually represent birth year cohort prevalence. The plain prevalence terminology is commonly used to imply we are simply counting greater shares of a constant rate of cases without evidence supporting that hypothesis. If we labeled the CDC estimates correctly as birth year cohort prevalence, that would go a long way towards improving our understanding of autism.

The Autism Society San Francisco Bay Area recently published a report to the public on autism in California [11]. It addresses birth prevalence both in California and the CDC reports.

Most publications that approach the relevant questions about autism rates focus on general prevalence and not birth prevalence. There is a well-known controversy about comparing different prevalence estimates [12]. Such comparisons are not a valid substitute for examining birth prevalence. There may also be some controversy about the true values of birth prevalence. However, an exhaustive search did not find substantive reasons for such controversy.

Please see this paper for those interested in technical details about this problem and a robust solution to it [13].

I respectfully request that the IACC make it a high priority to establish robust autism birth prevalence estimates. These should cover a wide range of birth years and be fully supported by data and appropriate analysis.

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

Mary Barbera, Ph.D.

My son, [name redacted], who was diagnosed with moderate to severe autism in 1999, is turning 25 years old this week. In addition to autism, [name redacted] also has an intellectual disability, medical and behavioral issues and needs 24/7 supervision and care. He is not able to be competitively employed. His pre-vocational program [name redacted] attended closed during Covid and is no longer appropriate. [Name redacted]'s father and I are co-guardians and we speak for him. Adults with high-functioning autism do not.

I'm also a Board Certified Behavior Analyst, RN with a Ph.D. I've published two best-selling autism books including my recent publication: *Turn Autism Around: An Action Guide for Parents of Young Children with Early Signs of Autism*. Parents and early intervention professionals need to learn how to detect and treat the earliest signs of autism. They can't afford to wait and worry as I did and let years go by without the most effective therapy.

We need research on autism prevention, treatment, education, and long-term care for those with significant needs.

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

Alicia Mesa

Freedom, California

I am the mother of a young man with extremely severe autism, [name redacted]. I am writing to you to strongly support the letter submitted by La Donna Ford, MD regarding the idea that autism can be the result of past general anesthesia exposures to a parent's sperm or egg.

[Name redacted] has no genetic conditions and my family has no history of anything like autism, nor does my husband's. But my husband underwent many successive surgeries after he suffered a gunshot wound at age 9 (he was shot in the eye with a BB gun). The surgeries occurred at age 9, 11, and 18, plus wisdom teeth removal under general anesthesia at 21. In total, 5 surgeries before we had children.

I know of many other autism parents just like ours, where at least one parent had intensive exposures to general anesthesia. This includes my late friend Feda Almaliti, who underwent many surgeries as a child, including when she was 2 days old. She called this the "[Profanity redacted]Eggs" hypothesis of autism (pardon her colorful language). If she were still alive I know she too would be supporting Dr. Ford's important suggestion.

Deborah Blair Porter

I am grateful you are meeting. I am grateful this committee is again working and underway. I became aware the committee would start up again through a recent article.

<https://www.disabilityscoop.com/2021/06/28/federal-autism-committee-to-reconvene-after-going-dark-for-2-years/29395/> I learned about the opportunity to provide comments in advance of your next meeting. I am providing these comments without citation due to the deadline for filing them, but am happy to provide backup upon request.

I am writing about significant issues postsecondary students and adults with autism face with colleges and the courts in California. Rather than ensure access to education and not discriminate, postsecondary education agencies misuse the court system and uneducated judges to effect a “school to prison pipeline”, which results in the removal of students from their education and the opportunities for access and education both state and federal laws were enacted to provide.

All in all, the needs of individuals who are diagnosed with autism have for years been underaddressed by California’s education system and now these students are beginning to progress into adulthood, unprepared and unsupported. As a result they are now being victimized by California’s judicial system and related agencies, the very agencies that were supposed to protect and serve them and ensure their rights under the law. Unfortunately, this has been our experience for the past five years of our son’s life, on top of the multiple years prior seeking to obtain the minimum of services, only to have his needs and rights ignored.

Knowledge of autism, despite years of research, is nonexistent in many colleges where they refuse to address the effects of autism in a manner that will ensure access and accommodation. Such postsecondary institutions do not adequately support the needs of students on the autism spectrum or recognize their varying needs to ensure access. They prefer to use a “one size fits all” approach that ignores the complex needs of students who have an autism diagnosis combined with language challenges, including expressive/receptive, language comprehension, auditory processing, etc. Such needs often compound a general failure to teach students with autism in California’s schools.

As a result, such students are denied their right to access education under ADA and Section 504 through meaningful accommodation and services, and then when issues arise, rather than understand and address issues as the ADA contemplates, these colleges fail to assess students and offer necessary supplementary aids and services, including when students manifest stress and distress, and rather than use their own procedures and the ADA assessment procedures instead simply remove students from education through suspension and expulsion and in many instances through the misuse of the restraining order process, i.e., they resort to the courts.

Even when courts order these colleges to use their administrative procedures, they fail to follow the law and court orders, instead preferring to misuse their relationships with local courts to get the outcome they want, i.e., the removal of a student with disabilities, including obtaining multiple restraining orders to keep students from accessing the school campus to avoid having to hold required discipline proceedings, for they know the student would prevail. Such colleges, guided by the school’s legal counsel, even collaborate with local district attorneys to bring false charges to keep the student from accessing discipline procedures the college is obligated to ensure.

Unfortunately, these colleges find a ready collaborator in California's court system, which often does not comply with California's most basic procedures regarding accommodation, including under Rule 1.100. They also do not comply with 28 CFR 35.160 and ensure effective communication in such courts or recognize the need that students with autism and other language-based challenges require and are entitled to facilitation in what are high-stakes settings. This is a problem at multiple levels of California's court system and is not only the case in the Superior Court in civil and criminal proceedings, but also in the competency and conservatorship areas.

California's judicial system allows courts to fail to rule on or otherwise grant accommodations and then when the individual is denied access because he could not overcome a restraining order and is expelled from college because of it, they consider that "harmless error", ignoring the educational deprivations that have resulted. This disregard goes all the way to California's Supreme Court which does not consider such issues worthy of review.

California's competency process, despite specific laws on the books, are routinely ignored by California's judicial officers who ignore their obligations to involve California's Regional Center and the expertise of legislatively-appointed experts. Judicial officers often seem to believe that a person with a developmental disability is mentally ill, thus clearly demonstrating the lack of education on the part of such judicial officers and the need for greater training, despite research having been done involving individuals on the autism spectrum. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4392381/> ("Purpose The purpose of this paper is to explore how judges perceive High Functioning Autistic Spectrum Disorders (hfASDs) and the disorders' effects on an offender's ability to formulate criminal intent and control behaviour."). In the judicial system, the state's committee on Access and Fairness has not engaged in any meaningful studies since 1997, so that the benefits of research in the area of autism is virtually ignored.

Courts engage in biased conduct, essentially seeking to "punish" such individuals, without regard to the harm it does to such individuals or how it places them at risk, particularly when parents refuse to allow the court to criminalize behavior that is a function of disability and not a function of crime.

Individuals with disabilities generally are denied access to complaint procedures and those with developmental disabilities or intellectual disabilities have no way of accessing such complaint processes, even if they are able to find out information about them.

When a parent tries to facilitate communication including by providing assistance in accessing a complaint process, the parent is accused of engaging in the unlicensed practice of law and in our experience, the agencies, including in our son's instance the Los Angeles Superior Court and the District Attorney of Los Angeles, engage in retaliation in response to complaints filed, and threaten to institutionalize the individual because of the advocacy of the parent in order to bury the problem, as well as accountability for their misconduct, further.

Although the ADA Grievance process in the Los Angeles County Superior Court is ostensibly through Los Angeles County, it is our experience that the office of the ADA Coordinator collaborates with the courts and when it does not serve their purpose to further communicate, they just stop communicating, despite the continuing failure of judicial officers to accommodate. As a result, there is no resolution of issues outstanding and the individual is forced to continue without accommodation and unheard, which

leads to a deprivation of the right to due process in general. Fundamentally, there is no working ADA Grievance process in Los Angeles County's court system.

In addition, the judicial complaint system at the Los Angeles County Superior Court level is rife with cronyism and corruption at the same time it fails to conduct even the most basic investigation that includes the issues raised. Instead, its process uses a form of discriminatory gaslighting that blames the individual for the discrimination they are experiencing and when parents complain, ultimately asserts we are just "unhappy" or "disappointed" in their rulings.

At every agency level, we have experienced the practice of ignoring disability so as to avoid having to be accountable to the laws that do exist with regard to disability, including the protections such laws provide. We consider this a form of "disappearing" to avoid accountability, the greatest form of bias there is. This bias exists throughout the judicial system in California, which while purporting to collect data on "protected classes" does not collect such data on individuals with disabilities generally, and thus does not know that any of the problems we have described even exist.

Ultimately this system is founded on a cottage industry of lawyers who act as education agency legal counsel, who at the same time they are supposed to be advising school districts and post-secondary education agencies how to comply with the law, counsel violations of the law that lead to denials of access and education.

At the same time school districts are annually required to provide assurances to both state and federal authorities that they are ensuring student rights, including that they ensure FAPE for all of California's K-12 children, such attorneys regularly push the envelope and through their advice, seek to advise districts to circumvent their obligations to ensure FAPE and educate their students, and such attorneys collect California's tax dollars in payment for such violations of the law.

Because there is no central accounting for sums expended for such legal fees at the state level and as each district is to account for such expenditures through their Boards of Education, the total amount of public funding that is spent is unknown and even at local education agency level, school districts do not share actual figures in a way that ensures transparency or meaningful accountability.

In conclusion, the needs of individuals diagnosed with autism have for years been underaddressed by California's education system and now these students are beginning to progress into adulthood, unprepared, unsupported and being victimized by California's judicial system and related agencies, despite the obligations these agencies have to such individuals as part of the larger community. There is no advocacy presence in this state that I am aware of which speaks to these issues in a comprehensive and cohesive way, so I wanted to bring these matters to the Committee's attention and ask that they be raised and addressed, for I am fear what we are experiencing is happening in other states across the nation.

Thank you for your time in reading these comments and for the time you devote to this committee and its important focus. It is direly needed. I apologize in advance for any typos or grammatical errors my comments reflect as I was rushing to prepare them to meet the timeline on the website.

<https://iacc.hhs.gov/meetings/public-comments.shtml>. Again, thanks for all you do.

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

Stephen Wallace, J.D. and Debra Wallace

Red Rock, Texas

Father/Co-guardian of [name redacted], Austin State Supported Living Center

ICF Advocates for Choice

Parents and Allies of Remarkable Texans

IACC Workshop- Keeping the Olmstead Promise

My name is Stephen Wallace, and I am first and foremost the father and co-guardian of a forty year old son with severe autism. As I thank you for the opportunity to address this committee, I want to note that while I have been a father dealing with autism for nearly four decades, I have actually been confronting the issue of autism for at least a decade longer. I volunteered and later continued to work as a teacher and daily living trainer for autistic children in the late 60s and early 70s. In a cosmic case of irony, in 1980, our son [name redacted] was born. By 1983, he had received multiple diagnoses and confirmations as having a pervasive developmental disorder with autistic tendencies.

Our son, the fourth of five children, remained home and a vital part of our family for the first 18 years of his life. But as the years progressed, he became more aggressive and self injurious. We fought for inclusive programs with behavioral interventions at school, and even obtained the highly sought after and coveted in-home waiver service, which provided the latest and best services available. By 1998, all of the providers the state could offer refused to work with our son, and his school had long given up being able to deal with the increase in his aggression. After multiple near death experiences and almost regularly scheduled visits to the emergency room, we realized we had no other option than to place him in a highly structured residential facility with 24 hour a day protection and supervision.

The day we placed [name redacted] remains the darkest day of our lives to date, but that previously unthinkable option was the only one left that offered the hope of keeping him alive.

When the time came, we had to fight to achieve the very thing we had most feared. The movement toward community placement had already begun in earnest, and congregate care was already seen as an outdated concept.

Many of those who parent, protect, or love someone with autism will unfortunately face that same dilemma that confronted our family. Those on the severe end of the spectrum who demonstrate aggressive or self injurious tendencies continue to grow in numbers which exceed effective service provision available in the home or community. The simple fact is, thousands upon thousands of families will shortly be confronted by the need for more intensive care and treatment for their loved ones with autism. Growth in effective residential services has been stymied by a lack of resources, and compounded by the growth and acceptance of a mythical notion known widely as the "Olmstead Mandate". The myth grows from a 1999 Supreme Court decision rendered in ***Olmstead v. L.C. (527 U.S. 581)***, which held that unjustified segregation for persons with disabilities is a violation of the Americans with Disabilities Act, but stated the ruling was conditioned upon three factors which must be considered in each case; the treatment team responsible for the care of that individual agreed that appropriate services could be offered in a less restrictive environment, that the individual receiving services did not object to being relocated to a less restrictive environment, and that the state could offer those same services in a less restrictive setting without undue hardship. **The very conditional and specific holding**

has, over the last 22 years, been transformed by community advocates, and agencies on the federal and state level, into a mythical tool to indiscriminately close needed residential facilities, or at least demonize their very existence.

The narrative created and enhanced by this myth is now leading to, for many of us who rely on the intensive care offered by congregate facilities, a dystopian future where our loved ones have no refuge. Currently, thousands of individuals exist in our communities, languishing with unmet needs and protections, isolated in plain sight of a society that has little understanding or tolerance of the needs of the profoundly or severely afflicted. Even more will follow as increasing numbers age out of the education system and are thrown into the void of non-existent services for adults with autism.

It is time that the dangerous narrative of independence or bust be revealed for what it is; a notion fitting some, but leaving so many more without even the most basic services to keep them out of harms way. A realistic but compassionate view of the difficult futures faced by those with severe autism, must be adhered to, and it must contain the realization that some of our numbers will never develop the skills or capacity to protect themselves from abuse, exploitation, hunger, neglect or death. If not, then the current trend of community for all will result in an abandonment of our obligation to care for those who cannot care for themselves and end with the most profoundly impacted individuals being lost as collateral damage to the movement. True advocates for all of the disabled, and agency officials who create and administrate must awaken to the coming tide, if the most needy on the autism spectrum are to thrive and survive. Now is the time for those who can mold the future to realize that more intensive services such as ICF congregate care facilities are not only still relevant , but will be even more essential in the future. The myth of the Olmstead Mandate must be counteracted by an intelligent and responsible provision of services for a population which will not cease to be just because we deny their existence.

Adrienne Benjamin

Thank you for the opportunity to write. I am hopeful that the IACCP will devote more attention to the problems faced by those with Severe Autism.

While I am happy for those who can advocate for themselves and articulate their struggles with autism, it seems much less attention is being paid to those on the more severe end of the spectrum.

My adult daughter is one of those who cannot speak, nor use a communication device. She's active, loves her Blues Clues and toddler toys. She's DSM Level 3 Autism, and like over 30% of those with Autism, also has an intellectual disability. One step that could possibly make those who are severe more visible would be to correct the DSM and keep those with high IQ who can accomplish college and careers, in a separate diagnostic category. The depictions on TV of the autistic doctor and the autistic physicist have nothing in common with my nonverbal daughter who has no safety awareness and needs help with all aspects of personal hygiene. Lastly, there needs to be more options and resources for residential placement for our severe family members. Many are too unpredictable, disruptive and sometimes violent to live successfully in regular neighborhood group homes. A larger, exclusive, campus-like congregate setting would provide a safer option.

Rachel Johnson

When I was 22 I gave up an admission to graduate school in order to move home and care for my brother, then 15, who in the course of 6 months had gone from the happy, smiling boy everyone knew and loved to someone I no longer recognized. It was July of 2016c what should have been a time to celebrate my graduation from school and start my career. Instead the next six months was spent being hit, bit, slapped, having the hair ripped from my head and emotional turmoil that affect decisions I make today. The police were called, in the end, almost nightly. Psych evaluations were a pointless exercise as most nights we brought him home. There were no resources. Only “have you tried” and deflection of responsibility.

It wasn't until Thanksgiving, a week where the police came over 20 times in a span of three days, that by pure luck we were able to send my brother out of state to a hospital willing to keep him. 72 hours later he came home. When again his behaviors started he was sent back where, as exhausted of this cycle as we were, he had his first inpatient behavior resulting in his stay until January. Again by pure dumb luck, not a system designed to protect him or my family, a social worker from Kentucky was able to leverage his resources to get him on a waiver which could result in admission to a residential facility in our home state of Indiana.

But before he could get the help he needed, his prescribed insurance days ran out resulting in his discharge and a nearly \$15,000 medical Bill for the days Our Lady of Peace was willing to keep him based on his needs.

His final trip home as a minor lasted only a day. It ended with his hands around my neck and another night waiting, desperately, in a hospital for someone to help.

Before turning 18 my brother spent a year and a half in residential treatment. His behaviors lessened, but never went away enough to warrant his treatment team recommending he come home. But, just like insurance had decided the best course of action, 30 days before his 18th birthday the state made the same crass decision. He came home. And I quit the brief career I was able to muster, and followed him through the door with no services, no supports, only my mother and I back in the nightmare that had resulted in severe PTSD for my one year of freedom.

A brief, 5 day respite where a group home placement was attempted allowed him onto the CIH waiver. Later I would learn that a failed group home experiment is one of the only ways for families to access the services he needed.

I was hired to be his caregiver. Despite my education and being his only service provider for most of that first year, I earned only 10.30 an hour of his massive budget. And that was how I spent 24, 25 and 26. Taking him to school. Picking him up. (An hour round trip so he could continue at the school he'd begun while on campus) and doing my best to keep him out of behavior.

As I exited my mid twenties and he entered his early 20s; the behaviors decreased at the sacrifice of my every waking moment. Finally, again through pure luck rather than a set system, we found a roommate and our patience on waiting lists to have my brother enter a waiver home were answered. And just as I tasted for the first time freedom, the pandemic took away all sense of self once more, and I resigned myself to doing what needed to be done.

Due to a bad roommate, my brother's behaviors began to regain frequency. His life taken away. Again in a place without supports. To this day we struggle to keep a behavior specialist, not even to name the lack of staff to meet his needs. (And to say nothing about quality staff).

I still dread answering my phone. Afraid it means the police are there again. That there is another hole in his wall that another broken window has sliced his hands and feet. The infrastructure which should meet his needs are non existent. For families like mine, caring for someone with severe autism requires an entire being. Now at 27 my goals are as far away as ever. I have not finished graduate school, am allowed as far away as a supervisor in the company providing his residential services. For if I am not here I know he will not be taken care of. There is not the staff or money or professionalism to ensure his needs are met. And until they are, I can not begin to even think of mine.

Brita Darany von Regensburg

I am Brita Darany von Regensburg, founder and president of Friends of Autistic People - FAP.

I am writing today to ask you to urge our Federal Legislators to enact a bill to mandate improved training of Direct Care Workers who support individuals with Autism in group homes and other congregate settings. Such a mandate would guarantee a better quality of life for our most vulnerable children with Autism. These are our adult children who have profound, usually nonverbal, Autism and/or have severe speech or language based communication challenges and depend on the staff.

I am moved to speak about the invasive gap in the quality of life of our adult children with Autism as I, myself, have an adult daughter who lives in a group home in Connecticut.

The improved training should be given by professionals on a regular basis. It should address the following issues:

- Training to teach the caregiver how to support with more sensitivity and understanding our individuals with profound Autism & disabilities (sensitivity training)
- Training to learn body language and recognize an outburst as communication
- Training to teach staff how to use the iPad with their charge for more than 4-word "conversations" such as "what do you want?" or "what is the matter?"
- Training to make them aware that they must involve the group home resident in activities of daily living (ADL) to avoid increased dependency and learned helplessness;
- Training staff to have more confidence to take the group home residents into the community, participate with them in Yoga and pizza, etc. making classes, take them to the pool and to festivals;
- Training staff not to balk at medically prescribed walking and visits to the rehab therapist.

I repeat: At the root of a better quality life for our individuals with ASD in group homes lies improved regular training of the Direct Care Workers (Staff).

Please support this part of our national Infrastructure and fund the Budget accordingly.

Another major issue is Transparency.

With improved training staff will not hide behind Hippa regulations and try to cover up mistakes in medical and programs implementations.

In my daughter's case, due to an all new untrained staff who forgot to give the daily medication, my daughter suffered a grand mal seizure. Subsequently, the group home manager tried to conceal this from her PCP and from other medical providers.

Again, transparency and improved staff training in how to support individuals with profound autism are of major importance for a better life of our adults with profound Autism in congregate settings.

Joy McDaniel

My son, now 26, has been home 24/7 since he graduated from school 5yrs ago in 2016. To date, there are no day programs that will accept him due to his level of complex behavioral needs. The community component of Final Rule makes him a liability for day programs. HCBS has all but taken every option away from him with their "Final Rule" and due to those policies no traditional provider agency will take him on. Sure, they promise the world because the thought of Consolidated Waiver as a client perks them up but ultimately they fail to provide the staff and the turn over is horrific. We chose the only option left to us (minus residential/NOT WHILE I'M BREATHING) Participant Directed Services and use a Vendor Fiscal Employer Agency as the Financial Management to hire staff on our own but there again staff is hard to find, harder to keep even when you can pay them a much higher wage than a traditional provider model. So I am his staff. Myself and my sister get paid through his Consolidated Waiver to work as his In Home and Community Support 1:1. We get told by ODP "Well you do make a nice wage" which is so condescending. Yes, it is nice to not be poor anymore!! Age 3-21 all through his school age years we were poor. Not poor enough to qualify for any additional financial support because we were a donut hole family but were poor. I couldn't stay employed and not because I didn't want to work, I love working and having an opportunity to be JOY, A WOMAN, A PERSON, AN INDIVIDUAL!! My son required a bus aide, yet when aides didn't show up I couldn't go to work, can't go to work you don't get paid. Can't go to work too many times you get fired, one school year I was fired from 22 jobs!! Can you even imagine the morale crusher of a year that was!?!? Sadly, it wasn't the only one. So, yes, I do make a nice hourly wage to work as HAB staff for my son. I get paid for 40hrs and my sister gets paid for 20 so there's 108 hrs that are all on me as his only reliable natural support. I'm not complaining but the "powers that be" need to stop that "nice wage" narrative because me being me and fighting to guarantee my boy stays with me in our home is saving HUNDREDS OF THOUSANDS OF DOLLARS!!

I have never complained about my son's autism nor the severity of the complexity of his behaviors. I never asked God "why" and I'm not searching for a "cure" All I do ask is when a service is needed for my son, that he beyond qualities for and the need of the service is proven WHY should he have to give up his dignity and privacy in order to receive the service he needs? WHY must his most vulnerable moments be tallied and reported weekly? Shouldn't the knowledge that these behaviors occur daily be enough!?! Why can't a collection on the interventions and strategies used by staff suffice as the "required" data and it can allow for services without a violation of his privacy nor an assault of his dignity. When aggression (headbutts hitting tapping, SIBs etc.) occurs regardless of the type of mood he may be in and will happen regardless if his supports are 1: or 2:1 or 25:1 because those behaviors are natural. It's his way to communicate, to get his sensory input need filled. So how can counting natural behaviors benefit him. IT CAN NOT!! Might as well also ask on the data sheet "are his eyes still brown" because it is HIS NATURAL MAKE UP!! Don't forget, although he may wrap himself up in his favorite Sesame Street whoobie but make no mistake, my son is A MAN!! No neurotypical adult would allow this micromanagement to happen to them so WHY is it POLICY for someone who is Intellectually disabled? Especially when the services he needs isn't to "HABILITATE" his behaviors. The services he needs (Enhanced) is to be able to take all that is ALREADY KNOWN about this perfectly imperfect MAN with ALL of his complexities and still integrate him in his community in the capacity that best suits him. He receives 60hrs of regular non Enhanced HAB which keeps him safe and maintains him, he's merely dwelling NOT living. HE NEEDS ENHANCED SUPPORTS TO LIVE A QUALITY LIFE!!

The disconnect of information and communication between HCBS, ODP, AE, SCOs, SCs is AWFUL and there's no accountability for that disconnect. It's horribly unfair to our families that are just trying to get through our REAL LIFE/IN TIME day and doing our damnest to provide some kind of life for our severely

autistic behaviorally complex Loves!! That disconnect lands on our shoulders!! Policies cater to the higher functioning because tag lines, applause lines, and click bait showcases individuals with autism graduating from college "against all odds" or "living independently with supports" "working with supports" "embraced by community?" are the feel good stories yet the demographic of autism no one talks about gets ignored. The "Every Day Lives" Conference in Pennsylvania provided excellent resources stories and plans that will again benefit many and their work deserves praise. Sadly very very little was presented even remotely pertained to what a day in the life of my son or frankly any one else's son that is severely autistic with complex behavioral needs.

I use the words SEVERELY AUTISTIC deliberately. I'm told I'm an ableist for using the spectrum labels. ABLEISM DOES EXIST and it shouldn't but creating policies that benefit individuals with disabilities that can attend college, work in their community, live in their communities with supports and those policies get followed by decision makers "according to policy" SEVERELY AUTISTIC INDIVIDUALS WITH COMPLEX BEHAVIORAL NEEDS ARE THE REAL VICTIMS OF ABLEISM!! THEY ARE BEING EXCLUDED or the services THAT WORK FOR THEM are being dismantled because SOME self advocates are being showcased as the representatives of all individuals with autism!!

Apologies that this long and rambling. I am finding it difficult today to organize thought. Perhaps the stressors that are causing me to loose sleep, causing chest pains and migraines are the cause of my scattered word salad. Ironically these stressors aren't the daily stressors of caring for my SEVERELY AUTISTIC son OR my HIGH FUNCTIONING AUTISTIC daughter OR my SPECIAL NEEDS brother with Cerebral Palsy who's under my care now that our mother passed away. Yes, those stressors, are HEAVY but it's all handled well. The STRESSORS I'm speaking of are the unbearable never ending battles getting the NEEDED services FOR them!! I am currently in an appeals process against Allegheny County over these policies and I'M SPENT!! I AM TIRED!! FAMILIES ARE SPENT!!

Jennifer Degner

I am an Early Childhood Special Education (ECSE) Teacher in Olathe, Kansas. I have been an ECSE teacher for over 21 years. I want to share my grave concerns that I have regarding the Autism silent epidemic. The increase of my students entering my classroom at 2 years 9 months-5 years-old that are suspected of having autism or are diagnosed has dramatically increased in recent years. I have had to seek out autism resources and practices and hone my skills in this area. I have grave concerns that follow:

1. lack of autism screenings at well child check ups.. skilled staff
2. lack of daycare for child with autism (skilled staff and therapy)
3. lack of developmental evaluation opportunities (wait is 6-15 months at KU and Children's Mercy Hospital)
4. lack of affordable respite services for children
5. lack of parent knowledge of characteristics of autism
6. lack of autism services in the school districts
7. lack of convenient medical and mental health services for families, need more mobile units that can come to schools.
8. There needs to be a more continuous sequence of route to get services.
9. More mental health services for families with young children on the autism spectrum.
10. lack of autism specialists and autism programs in school tailored to help students be successful
11. more parent supports... I have exhausted parents that have their children kicked out of daycare.
12. The Kansas Autism and Intellectual disabilities waivers waiting list is over 9 years long.
13. We need district, community, and state agencies to get the help for both the young ones (identification), next educational supports, and then vocational, work and housing supports.
14. Family supports for Special needs trusts and ABLE accounts awareness and planning.

I am passionate about my work with children with disabilities and their families. I see needs everyday. Most lately I have seen children and their parents don't even suspect autism.. The doctors are missing opportunities to evaluate kids and get them services long before the age of 5, 4, or 3 years -old. Early intervention is so powerful. We need to leverage that learning time to support our children and families. Any supports that you can provide to help families day to day lives would be greatly appreciated.



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Background: Autism Spectrum Disorder (ASD) and developmental disorders (DD) can severely impair a person's communication abilities and social skills. ASD affects virtually all aspects of everyday functioning to some degree. Difficulties are seen in communication, social interaction, adaptive functioning, and self-care skills. Many people with ASD engage in behaviors that jeopardize their safety and health, i.e. self injury, pica (ingesting inedible items), elopement (running away), flopping (throwing themselves on the ground), aggression, sleep disorders, and severely restricted eating. **ABA therapy** or Applied Behavior Analysis is recognized by the State of Washington (SOW), Federal Employees Health Benefits, TRICARE for active military, CHAMPVA and most other 3rd party payers as a safe and effective treatment for ASD and related disorders¹; it's a *covered service under all forms of state and federally funded health benefits*.

Most people with autism have psychiatric symptoms that are separate from autism itself. About 70 percent "may have" another mental disorder and 40 percent "may have two or more" such disorders, according to the fifth edition of the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders, or DSM-5.

SOW is home to 142,864 children, adolescents and adults on the spectrum. Of them 51,096 are under 21, and 106,180 are adults 22 and older. All those under 21 and only 9,400 over 21 are accessing ASD specific intervention services.²

The Problems: Nationally there is a large gap between the supply of Licensed Behavior Analysts (LBA) and the demand for ABA services. None of the current education and training programs in SOW & a miniscule group of national training programs offer coursework in human development, child development or abnormal psychology. There are very few LBAs nationally that have the training or desire to work with teens and adults with ASD around severe disruptive behavior, feeding disorders, Activities of Daily Living (ADL), and Social Sexuality and of the dismal subset that do, all are dually credentialed as psychologists, in addition to being behavior analysts. We cannot rely on minimal BACB education and training to design, implement, and oversee changes to an ABA program for a population with such a high rate of co-occurring mental health conditions.

Agencies and third party payers are looking to professional behavior analysts to work with a wide range of patients, including those with very complex clinical and mental health needs. The

¹ <https://www.hca.wa.gov/billers-providers-partners/programs-and-services/autism-and-applied-behavior-analysis-aba-therapy>

²Based on data from Washington State Health Care Authority

same agencies and payers do not have an effective mechanism in place to evaluate those who claim to have credentials and expertise in designing, overseeing or implementing behavior analysis for patients with co-occurring mental illness. This gap is leading to psychiatric boarding and extended stays in ER's without suitable discharge options for hospitals³. Here in SOW, Seattle Children's Hospital is no longer accepting any patient with ASD over 17 at their inpatient psychiatric unit⁴ as patients are inappropriately dropped off at hospital emergency rooms for nonmedical reason and left to languish in ERs for extensive periods of time. There are currently only 31 master's and doctoral programs accredited by the ABAI nationwide (none in Washington State), only 6 of the programs reside in a traditional Department of Psychology⁵.

Since its passage (2006) & multiple reauthorizations, the [Autism CARES Act \(formerly CAA\)](#) has primarily funded early childhood autism screening and diagnosis. Little to no funding has been given to:

- Establishing best practice guidelines and evidenced based interventions for adolescents and adults
- Nationally inclusive research that establishes innovative and empirically validated vocational training such as NSF funded research under way at the [Frist Center for Autism & Inivation](#) at Vanderbilt University)

Future Outcomes: Establishing *Behavioral Center for Autism & Related Disorders* (BCARD) that are housed within the Departments of Psychology at University Centers of Excellence for Autism, which aim to remain at the forefront of promoting the highest standards of education will lead to:

- a. Hybrid programs that allows graduates to be dually licensed as behavior analysts as well as mental health professionals
- b. Improved knowledge and capacity of healthcare providers to serve more individuals who have co-occurring mental illness for this growing and vastly underserved population.

About Washington Autism Alliance (WAA): We provide Civil Legal Aid, Insurance and Family Navigation to an average of 3,100 families a year, in every county in Washington. We want more children, youth, and adults to have an equal chance to thrive and succeed in life, regardless of their socioeconomic status. WAA is dedicated to improving access to healthcare, education & social services for children with ASD/IDD and has been instrumental in passage and funding of critical legislation that improved access to appropriate education and intensive behavior supports. Since 2007 we're actively involved in statewide patient and provider education to improve access to health benefits.

³ <https://khn.org/news/for-thousands-of-autistic-teens-hospital-ers-serve-as-home/>

⁴ See "Stuck in the Hospital," December 2018, Office of the Developmental Disabilities Ombuds available at <https://ddombuds.org/wp-content/uploads/2018/12/DD-Ombuds-Hospital-Report-12.10.18-Final.pdf> see also Senate Health & Long Term Care Committee Testimony, Feb. 6, 2019, available at <https://www.tvw.org/watch/?eventID=2019021093>

⁵ <https://accreditation.abainternational.org/apply/accredited-programs.aspx>

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

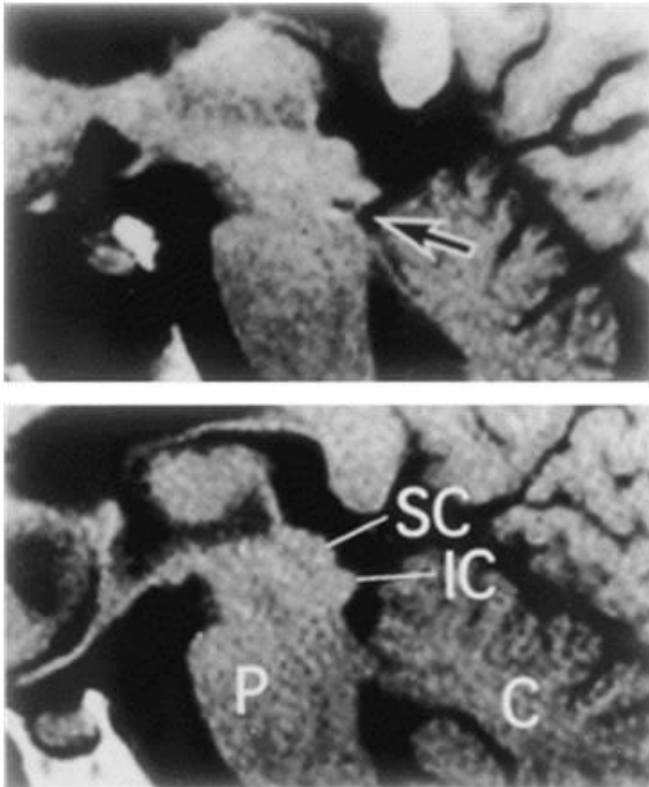
The inferior colliculus in the midbrain auditory pathway merits consideration as the site of injury that leads to difficulties with language development in childhood autism. Loss of speech understanding following injury to the inferior colliculi has been described in several case reports. I provided a list of these reports in a Public Comment I submitted for the IACC meeting held Nov 21, 2008.

Johkura et al. (1998) provided the photograph below of injury incurred in a skiing accident.

Damage of the inferior colliculi was found in the brain of monkeys subjected to asphyxia lasting 6 to 8 minutes at birth. Resuscitation was not possible if asphyxia lasted longer than 8 minutes.

How much more serious injury of the inferior colliculi would be for an infant, by trauma and/or asphyxia.

The image below from Johkura K et al. (1998) shows injury of the inferior colliculi from impact with the cerebellar tentorium. Location of the superior and inferior colliculi, SC & IC, in the tectum (roof) of the midbrain, above the pons (P) and forward of the cerebellum (C).



Johkura K et al. Defective auditory recognition after small hemorrhage in the inferior colliculi. *J Neurol Sci.* 1998 Nov 26; 161(1):91-6.

Heather Gordon

As the parent of a 9 year old, non verbal child who has incredibly high support needs, I would like to lend my full support and agreement to the letter by Jill Escher on behalf of the NCSA. Most notably, I believe that we MUST look forward to multiple levels of housing options for adults based on individual needs, rather than a one size fits all approach. I appreciate the goals of "inclusion," however, my son has absolutely thrived in a private school for children with autism, whereas he languished in a more "inclusive" public school setting, spending years where he did not acquire skills. Similarly, when he is an adult and his father and I are dead, I want options available to him that fit his needs. These options needs to include residential facilities with oversight that are tailored to his needs. Please do not allow his future options to be limited "group homes" in private neighborhoods with a rotating staff. Such a living situation would be catastrophic for him-though, for others, it may be fine.

I'm short, I'd like to advocate for a broad range of options that take into account those who will have lifelong support needs.

Kim Oakley

Good Afternoon, my name is Kim Oakley and I'm the mother of an amazing adult child with severe non verbal autism and self-injurious behavior. Let's talk about self injurious behavior, aka "SIB"-- to those of us who revolve inside the behavioral world of autism. Too many times we've been told by doctors that our children's self injury is "just part of their autism." This is a complete falsehood. People with autism aren't born with self injurious behavior. It's a learned behavior. A desperate way to communicate, often rooted in frustration or a cry for help. There are different levels of self injurious behavior (SIB), in the same way there are different levels of autism. The most ACUTE or chronic severe SIB seen in people with severe autism is almost ALWAYS rooted in underlying, undetected and UNTREATED MEDICAL and dental issues. "People with autism don't just go around all day smashing their fists into their head because they are autistic," I had told one doctor after he insisted my son's acute agitation was simply "part of his autism." Turned out my son had kidney stones. I wouldn't have known this had I not gone into acute advocacy mode and kicked the garbage bin over in the Emergency Room. I was nearly escorted out by security, so I don't recommend this advocacy tactic, but I was beyond fed up and wanted answers. I wanted x-rays and an abdominal ultrasound for my son, not a referral to psychiatry. As a mother, I knew my son's SIB was rooted in pain. I knew the pain was somewhere below the neck, given my son was punching himself in the chest and flanks. An abdominal ultrasound revealed several kidney stones. It took weeks to get into surgery. One doctor had dismissed the need for surgery saying, "he can just pass some of the stones." A person with non verbal autism doesn't simply "pass a stone." My son wasn't going to perch up on some patio swing, drink a Coors and pop a Tramadol. My son has routines. As in walking 5-7 miles a day. He's not the type of patient to wait something out, especially if it's painful. Thank God we had a compassionate urologist who advocated for an earlier than scheduled surgery. After the stones were removed, by son's severe SIB disappeared. This isn't to say it won't reappear if he gets a sinus infection, strep throat or some other medical issue causing temporary discomfort, but at least we know severe SIB is never just part of our son's autism. His baseline behavior is mild intermittent SIB used to communicate hunger, thirst, constipation, escape getting dressed or avoiding moving from one spot to another, thus when SIB becomes hours and hours of screaming and crying, we know it's medically related and time to see a doctor. This is the message we must send to the medical community. Severe self injurious behavior is not part of autism. We must encourage doctors to go above the standard of care and think outside the box with non verbal severely autistic patients. Otherwise you are leaving them tortured in a state of medical neglect. You can't tell an autistic child or adult to simply wait 3 weeks to get into surgery because if you do, they may slam their fists into their head for the next 3 weeks, refuse to take pain meds and end up dehydrated and sleep deprived due to being in constant pain. This knowledge comes from personal observation and experience with my son and other people's children with autism. Prompt medical treatment is therefore a matter of health and safety for these vulnerable autistic patients. I don't know if anyone outside of California knows this, but California has a unique law system for the developmentally disabled. It's called the Lanterman Act. No other state in the USA has these laws. California is the leader when it comes to caring for developmentally disabled citizens. Other states should look at the Lanterman Act. One of the laws in the Lanterman Act is Welfare and Institutional Code (WIC 4502 (b) (4)) states, "Persons with developmental disabilities shall have...a right to PROMPT MEDICAL CARE and TREATMENT." Shouldn't this same right be part of the USA laws governing healthcare in hospitals and dentistry? Speaking of dentistry for autistic patients: Let's not forget we still need to encourage HMOS like Kaiser to offer dental services for patients with autism and

other developmental disabilities who require SEDATION DENTISTRY IN A HOSPITAL. Did you know many hospitals do NOT allow dentists hospital privileges? Thus, thousands of dentally insured autistic patients are denied access to dental care because there are no dentists on many plans that can get into a hospital to perform needed dental work. Ironically, this costs our nation MORE in the long run, as untreated dental work in people with severe autism often leads to dental infections, which lead to repeated trips to Emergency rooms. It's also led to thousands of people with autism having their teeth EXTRACTED instead of treated, as if we're living in the 1700s. Surely, we can do better, specifically with increased education and collaboration between HMOS and dental plans to facilitate access to better dental care for autistic patients who require sedation dentistry in hospitals. If America wants to be a world leader, there is no greater privilege than to care for those who need to be led. Our children with severe autism may need 24 hour care and have the minds of children, even in their late 40s, but they are worthy of our advocacy and love and we must never give up making this world a better place for them. Thank you for you time.

Note: After the IACC public comment deadline we received over 120 comments related to Graduated Electronic Decelerator (GED)s. About half of those emails were from three different e-mail campaign form letters, which are below. Names of individual commenters are listed. The rest of the individual, original comments related to this topic will be included with comments for the October meeting.

Email Campaign Form Letter 1

I am writing to urge IACC to issue a public statement condemning 2021, [July 6th's reversal](#) of an FDA regulation that would have banned use of the Graduated Electronic Decelerator (GED) for use in behavior modification at the Judge Rotenberg Educational Center in Massachusetts. This device issues extremely painful skin shocks for the purposes of behavioral modification and has been named a device of torture by the United Nations. Importantly, the Judge Rotenberg Center houses students primarily disabled students of color from New York City, making the ban on the GED a pressing issue of disability and racial justice.

Urge the legislature to cut the funding of the Judge Rotenberg Center.

Please include an amendment in the Keeping All Students Safe Act (KASSA) that would expand the bill's prohibitions to include aversive interventions and pass this Act.

I urge the leadership of IACC to stand against the use of this device at the Judge Rotenberg Educational Center, a center that has been at the center of controversy for many years because of its continued use of this barbaric practice. We cannot profess to do the work of equity and remain neutral in the face of such violence. When can I expect a statement from IACC on this issue?

Sasha P.
Kerry Recht
Ariana Uriati
Holly Manning
Quin Potter
Veronica Poquette
Caden Mclsaac
Magdalene Ho
Athithya Aravinthan
Ivan Corn
Vanessa Matelski
Nicole Dannen
Baker Kipping
Ulysse Bartolomey
Kristy Dodds
Mirphy Harrison
Sara Rocha
Sophie Hughes
Emily Chicklis

Anish Krishna
Cypher Chu
Beatrice Augustine
Liz Franzone
Mark Blokpoel, Ph.D.
Rebecca Margolick
Dan Schwartz
Emily Sandford
K.E. Eckerman
Sandy Avrutin
Kate Murphy
E. Gill
Alexandra Bance
A. Héraud
Sherry Midi
Aminata Camara
Frank Corso IV
Samantha Ayala
Sathya Siddapureddy

Carolina Semedo
Lydia Jung

Gareth Jones
Shoshana Levy

Email Campaign Form Letter 2

I am writing to urge you to demand that the FDA ban the use of the graduated electronic decelerator (GED) on individuals with disabilities.

The GED is a device that delivers a powerful and painful shock to wearers. The GED has been condemned by the United Nations as a weapon of torture against particularly vulnerable populations. The severely painful device is primarily used at the Judge Rotenberg Center (JRC) on autistic individuals who behave in ways that are deemed inappropriate by staff at the center. Behaviors that the JRC has used GED shock to discipline include but are not limited to: hand-flapping, standing, making noise, and screaming in pain from the administered shock. The GED has been known to burn skin and is traumatic for individuals exposed to the device.

Last year, the FDA successfully implemented regulations that banned the use of the GED on individuals with disabilities with the support of over 300,000 caring individuals. However, the JRC successfully lifted the ban in a lawsuit against the FDA. The unfortunate success of the lawsuit occurred because the FDA solely banned the use of the GED for behavior modification purposes. The court ruled that the FDA did not have authority to implement the regulation because the FDA did not completely ban the device overall.

I am therefore calling on you to support autistic individuals and people with cognitive disabilities by encouraging the FDA to produce a total ban against the GED. Your support is necessary to protect the well-being of vulnerable individuals residing in the JRC and susceptible to grueling abuse.

Urge the legislature to cut the funding of the Judge Rotenberg Center.

Please include an amendment in the Keeping All Students Safe Act (KASSA) that would expand the bill's prohibitions to include aversive interventions and pass this Act.

Thank you for your time and consideration. Please feel free to keep me informed on your decision to act on this matter.

Hannah Judson
Kelly Stanton
Janine Briones
Kristin M. Paschall
Ella Ward
Ivy Schmid
William Spangler
Anne Sydor
Megan Denardo
Grecia Negra
Brianna Mau
Sarah Showich

Bashirat Oladele
Belle
Lydia Jung

Email Campaign Form Letter 3

["As a Massachusetts resident, I support Bill H.225, which if passed, will prevent the use of aversives, including the GED device, on disabled students."]

I would also like you to push for an outright ban on the Graduated Electronic Decelerator (GED) device. Please include an amendment in the Keeping All Students Safe Act (KASSA) that would expand the bill's prohibitions to include aversive interventions and pass this Act. The FDA previously banned the use of this device only in relation to behavior modification, which has just been overturned by the D.C. Circuit Court. The GED devices (GED-1, GED-3a, and GED-4) need to be outright banned as they serve no purpose other than to provide pain and therefore torture to the person receiving it.

The Judge Rotenberg Center tortures autistic people, people with intellectual disabilities, and people with mental illnesses with this shock device. They currently use the GED-3a and GED-4 devices. This GED-4 device gives out up to 90 mA current, nearly up to 3 times over the maximum current limit of the FDA. The GED-3a and GED-4 devices **are not approved by the FDA and never have been.**

The GED devices accidentally discharge, staff accidentally shock the wrong student, and the students are forced to wear these devices 24/7, including while bathing or showering, which has caused 2nd-degree burns due to malfunctioning in water.

The GED is abusive. Shocking autistic people and people with intellectual disabilities for not taking their coat off fast enough is abusive. This device should not be considered a medical device or a "treatment" in any way. This device is torture.

To learn more, please follow the [#StopTheShock](#) hashtag on twitter.

Please push the FDA to ban the GED device outright, and to prevent the restraint and abuse of all autistic people and people with intellectual disabilities in the US.

Urge the legislature to cut the funding of the Judge Rotenberg Center.

Here is a quote from Jennifer Msumba who went to the Judge Rotenberg Center describing the electric shocks that she endured: "It lasts 2 seconds but it feels like 10-15 seconds. The feeling is like this pulsing, pulling, yanking, burning sensation that they get in your arm, leg, whatever spot they shock you in. It doesn't go through your whole body. It will just stay on that one spot where they shock you, but it will tear into it and your whole muscles will clench up and raise up, and you have no control over your muscle for that period of time. It's a terrible pain. I have no idea how to describe it. They describe it as a bee sting, but some people will say it's like a hundred bee stings, it's not just like a little bee sting, it's like a bunch of bee stings. Unless you've been tasered or something, or electrocuted by something, I don't know how to describe the feeling. The pain is really bad." - Jennifer Msumba, from the Youtube video entitled "Escaping The Judge Rotenberg Center" - www.youtube.com/watch?v=A7hklHN-qqY

Tristen Koffink
Emma Fixmer
Karli Hayden
Ira Kraemer
Ryan Robinson

Shannon Cardinal
Stephannie Bethel
Nicholas Smith
Hayden Day
Sara Rocha