IACC

INTERAGENCY AUTISM
COORDINATING COMMITTEE

Public Comments

October 13-14, 2021

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Oral Comments

Adrienne Robertiello
Children's Specialized Hospital

Safety is part of all aspects of our lives. Related to autism, we acknowledge there is substantive risk in such areas as elopement and wandering, drowning, and abuse. There are indications that there is increased risk of unintentional injuries, poisoning, involvement in negative interactions with law enforcement, as well as other areas of safety concern. Potentially, there are compounded risks associated with those who are autistic and have co-occurring challenges such as communication deficits, hearing or vision loss, intellectual and developmental disabilities, physical disabilities, and issues involving mental health.

As one example, kitchen burns that require medical intervention occur frequently. Identifying when these and other types of accidents involve autistic people can support increased and improved prevention and safety education. A second example involves recognizing potential correlations between incidents of accidental poisoning and autistic people. Calls to poison control centers do not record if the victim is autistic or has other disabilities and potential factors that may have influenced the poisoning, such as not understanding medication usage directions which are written unclearly. There is also no record if the same person has had multiple instances of poisoning. Another very important example involves problematic interactions between law enforcement and autistic people. Typically, these events are not documented and assessed without bias. As a result, neither qualitative nor quantitative measures of occurrence are available for most safety events.

Aggregate data is unavailable to determine if these types of injuries or interactions occur with any specific pattern or frequency. Functional data which identify potential associations with unintentional injuries are either subjective, inadequate, discriminatory, inaccurate, or unsubstantiated. As well, baseline data related to the adequacy and effectiveness of safety education for those with autism, and autism training for law enforcement and emergency responders, are only anecdotal, based on personal and potentially biased testimonials.

We need objective safety data which comes from effectively identifying, measuring, and tracking safety matters that affect daily lives. We must analyze the outcomes of the data in order to equitably implement preventive practices and services. We must also study the efficacy and impact of current and emerging safety-focused education and interventions. These efforts are critical to empower autistic people to better understand and safely practice life skills.

It is time to initiate peer-reviewed research to determine tangible safety risks, identify disparities, and inform development of accessible and equitable safety education and professional training. In this regard, we must establish methods to collect and authenticate statistical representation of unintentional injuries throughout the lifespan. Policies and practices must be established to certify and standardize safety education for autistic people, law enforcement, and other emergency responders.

This public comment is a call to action to invest in and support methodical data collection from which we can explore how autism "and co-occurring conditions" intersect with injuries, law enforcement interactions, and safety interventions. Collectively, these data can validate systemic changes. We can no longer wait for purposeful and unbiased safety research. By identifying potential correlations and patterns of injury, we can establish substantiated safety interventions in order to increase the safety of autistic people.

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

Crystal Hernandez, Psy.D., M.B.A.

My name is Dr. Crystal Hernandez, I am an autism mother and ally, Cherokee and Latina. I serve as a Tribal mentor parent, serving on support groups and panels, working with local and national organizations on Tribal inclusion projects and research. I see and hear the stories of grandparents and parents, communities and individuals struggling to find suitable service and varied treatment for their Autistic loved ones. I see continued disparities in access to quality care within communities, underrepresentation, and cultural exclusion. We must do better.

It is a pivotal moment in our world, where Tribal Nations are not just being looked at, but rather are starting to be seen and included. But there is still much work to be done. Autism in Indian Country is overwhelmingly underrepresented in national and state data, due to non-inclusive methods of measurement and often distrust of the measuring systems.

We must focus on improving culturally relevant diagnostic tools and screening instruments and train in meaningful ways, those working within the field on cultural humility and responsiveness. There needs to be a focus on embedding appropriate culturally relevant screening practices in a variety of conventional and unconventional settings, such as health clinics, daycares, community centers, nutrition programs, headstarts, and behavioral health care settings. A focus on community and extended family compositions in system build and design is desperately needed. We must change the narrative within communities and learn from those walking the journey. Representation matters in all the places where decisions are made, not just in theory, but in continued practice.

There is a great need to improve access to care in community settings, meeting the person where they are, removing barriers to treatment and support. We must look beyond gap analysis and instead focus on actionable items for continued system overhaul. We need to allow culturally-rooted care to be viewed with the same fidelity and reimbursements that other mainstream treatments are. Giving honor to language, customs, beliefs, values, and practices is the only way forward.

The vast array of Tribal Nations throughout the United States are not here to be served, but rather are here to be part of building meaningful systems of service.

Thank you.

[PII redacted]

Julia Bascom, Autistic Self Advocacy Network

ASAN
AUTISTIC SELF ADVOCACY NETWORK
Nothing about us without us!

Thank you for the opportunity to submit written comments on the IACC's public meeting on October 13th and 14th, 2021. In our prior comments in July 2021, ASAN emphasized the importance of using the reconvening of the IACC as an opportunity in and of itself: namely, as a means of redefining the IACC's research priorities to address the things important to autistic people ourselves. ASAN's present comments will expand upon one of the issues that is most pressing for autistic children and adults: the need for high-quality services and supports that serve autistic people of all ages and demographics.

Although autistic people are a diverse group, our need for support services is as lifelong as it is for other groups of people with intellectual and developmental disabilities (IDD). The IACC has made progress towards both directing autism research towards the priorities of autistic people. However, the direction of autism research funding and the research base for services and supports both leave much to be desired. The topics we describe below are three of those which most urgently require a comprehensive evidence base that helps determine where providers, policymakers, families, supporters, people with disabilities, and other stakeholders should direct their attention.

Supporting Access to Communication in Nonspeaking Autistic People

As ASAN noted in our July 2021 comments, there are troublingly few studies recorded in the IACC's research database for 2018 (the latest year available) which examine how best to support forms of communication for autistic people that are not oral speech. Instead, the vast majority of research available in the database focused on determining why autism impacts oral speech and ways that oral speech may be developed or improved in autistic people.[1] In ASAN's opinion, while oral speech is neither critical nor necessary to live a full life, effective communication *of some form* is. Given that approximately one-third of autistic people do not develop usable oral speech, it is imperative that significant research dollars be dedicated to understanding and scaling effective augmentative and alternative communication (AAC) approaches for any autistic individual who might need them.

Access to communication is a vital human right. Without communication, it is impossible to express thoughts, feelings, and desires and nearly impossible to direct one's own life. Autistic

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[1] *IACC Autism Research Database,* Interagency Autism Coordinating Committee, https://iacc.hhs.gov/funding/data/ (last visited Sept. 22. 2021).

people may use a wide variety of possible forms of communication, including speech sign language, written communication, behavior as communication, and AAC) devices.

There is a robust body of research showing that AAC is highly effective for individuals with disabilities that impact speech generally, including people with significant intellectual and developmental disabilities, and that access to effective communication is key to reducing "challenging behaviors" and improving quality of life. However, research is much more limited on best practices to support autistic people specifically and our associated motor and cognitive or language processing differences, and very little guidance exists for families, educators, other supporters, or autistic people ourselves looking to develop a method of communication that allows us to say more than simple requests. Effective communication means being able to express anything we might be thinking. Autistic people deserve access to communication supports that enable us to show what we know, argue with others, share memories, tell stories, ask questions, and generally say more than "I want ball please."

ASAN therefore recommends that the IACC support and prioritize the development of substantial research on best practices for supporting robust and effective AAC for autistic people. This should include research on any supports necessary for a given communication method, such as supports for communication partners, instruction in syntax and sentence building, accommodations for motor challenges, and executive functioning supports such as reminders and prompting. Research regarding which supports or approaches are most effective for which autistic people is also badly needed. Cultural competency and cultural relevancy of alternative communication methods are also significant areas in need of research.

Assisting Individuals in Addressing Challenging Behavior

Challenging behavior (such as self-injurious or aggressive behavior) rarely arises without a specific cause. It often represents an urgent unmet need, especially if the person lacks a form of effective communication. Frequently, this need has been found to be related to an underlying physical or mental health condition, or to traumatic experiences. Autistic people are known to experience a myriad of co-occurring physical and mental health conditions, and to experience trauma at a higher rate than the general population. In other cases, it can be the result of frustration with an inability to communicate or an attempt to alleviate distress. Currently, autistic people who struggle with challenging behavior, especially autistic people with intellectual disabilities and limited or no oral speech, lack access to accessible mental health services and are typically only offered behavior modification programs or psychotropic medication, with little attempt to address their underlying needs. This is an urgent human rights crisis.

In all cases, autism research that has the goal of reducing challenging behavior should attempt to understand and address the root cause of that behavior in the form of providing supports and services tailored to specific needs and situations. However, this is not how autism research has been prioritized. According to the IACC's own 2017-2018 Research Portfolio Analysis Report, nearly half of services and supports funding is directed towards practitioner training, rather than research, while none of the remainder is directed towards helping autistic people or our supporters manage our own physical and mental health.[2] IACC Research Question 5's entries in the Autism Research Database contain only a few studies directly addressing these issues.[3] Although IACC Research Question 6, "Lifespan Issues," includes a few studies that do address which services and supports help autistic people manage our mental and physical health, the vast majority of studies are specifically directed at the concerns of transition-age youth - only one subgroup among the many autistic people in need of high-quality services and supports to help manage daily living and co-occurring conditions.[4] This deficit is not made up for by the Strategic Plan workshops that focused on these topics - one of which focused excessively on medication-based solutions and an extremely medicalized view of self-injurious and aggressive behavior, and endorsed highly controversial approaches of dubious merit and ethics such as Electroconvulsive Therapy.[5]

ASAN recommends that the IACC lead the charge for a transformation within autism research funding, geared towards funding research that expands the number of options available to autistic people struggling with challenging behavior. Possible research topics could include: (1) best practices for identifying and addressing underlying medical, mental health, and communication needs in people with IDD who lack a means of effective communication; (2) effective provision of community-based mental health services for people with IDD, especially people who lack an effective means of communication; (3) pilot programs of particular services and supports that address these underlying needs on an individualized basis for specific populations of autistic people to determine their effectiveness; and (4) scaling effective approaches and building the capacity of providers to support people with IDD who may struggle with challenging behavior safely and humanely in our communities.

All this work should build on existing knowledge regarding these issues for people with IDD and challenging behavior, trauma, grief, and loss, or co-occurring mental health disabilities broadly, and should closely examine questions of cultural competence. This research should be conducted, to the maximum extent possible, in partnership with autistic people, particularly autistic people with co-occurring mental health or intellectual disabilities,

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[2] To some extent, this may be due to the design of Question 5's Objective and subcategory design. Since neither directly mention services and supports that address co-occurring conditions, it is possible that studies on these topics exist that are filed under, for example, the Question 6 subcategories "family well-being and safety" or "community inclusion programs" instead, since the subcategories largely remain the same between reports.

[3] *IACC Autism Research Database,* Interagency Autism Coordinating Committee, https://iacc.hhs.gov/funding/data/ (last visited Sept. 22. 2021).

[4] *Id.*

[5] Interagency Autism Coordinating Committee, Strategic Plan for Autism Spectrum Disorder: 2018-2019 Update 24 (2020), *available at* https://iacc.hhs.gov/publications/strategic-plan/2019/strategic_plan_2019.pdf?version=3.

autistic people who use AAC, and autistic people who currently or by history struggle with self-injury or aggression.

Supports and Services for Individuals with Intellectual Disabilities and High Support Needs

ASAN strongly recommends that the IACC prioritize research that investigates how to maximize the self-determination, community integration, and physical and mental health of autistic people with intellectual disabilities and others with the highest support needs. Although the IACC has previously highlighted research in its Summary of Advances[6] and elsewhere on these populations (and even, indeed, on the need for more research in this area), the research base is still woefully limited. Indeed, most research on services and supports for autistic people appears to be designed to reduce the future support needs of transition-age youth or to make autistic people appear less autistic, rather than on how best to ensure a high quality of life for *all* autistic children and adults.

ASAN also strongly encourages the IACC to prioritize research on services and supports for Black, Brown, and Indigenous (BBI) autistic people with ID, autistic people with ID who use English as a second language, and other individuals on whom even less research has been done. It is critical that all autistic people, rather than a white subset, be included in services and supports research. The same support may not work equally well in all cultural contexts and demographics.

We again thank the IACC for inviting interested stakeholders to comment and help the IACC direct the future of autism research. For more information on ASAN and the autistic community's research priorities, please contact Julia Bascom, our Executive Director, at jbascom@autisticadvocacy.org.

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

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Shannon de Roches Rosa

My name is Shannon Rosa. I am the mother of a twenty-year-old high support autistic young man, and senior editor of the autism information and advocacy community Thinking Person's Guide to Autism.

My son is a thinking, feeling human being, like you. He deserves a good life. My husband and I love him dearly, enjoy his company, and do our best to help him feel happy, healthy, and safe. However, it is challenging for families like ours to give our autistic loved ones those lives they deserve, as current public and private autism efforts focus disproportionately on theoretical unborn autistic people, rather than investing in best support practices for existing autistic people like my son. Per the IACC's own analyses, autism research funding is primarily funneled into to risk factors and biology, with less than 10% prioritizing lifespan issues and services. I do not understand how this is considered acceptable.

My son and the wider autistic community deserve to be living their best lives, now. They deserve family, caregivers, and therapists who understand how to help autistic people thrive, now. They deserve access to well-trained and -paid educators and support workers, now. They deserve medical professionals versed in best practices for treating autistic people, now. In one year, my son and his peers will age out of the school system—yet no existing federal, state, or local framework exists to transition to or support them in fulfilling and dignified lives as adults. We need those frameworks, now.

Even so, my family is lucky; we have decent autism services in our area, and we have the language, know-how, and socioeconomic advantages needed to access those services. At the same time, we all know that less-advantaged autistic people and their families are missing out on services—partially or entirely—as are autistic people perceived as lower-support than my son, yet who still require significant accommodations. This is unconscionable.

Finally, we need to formally recognize that autism issues must have autistic guidance. My son's quality of life improved dramatically once we had access to autistic insights on supporting autistic people, and every autistic child and adult in this country deserve the same opportunities and benefits. I applaud the IACC for seating more autistic members, and hope autistic priorities will have a proportional influence on the IACC's outlook and directions.

Thank you for listening.

[PII redacted]

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

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

Language disorder is the most serious handicap of autistic children. Social disorder is the result of the language disorder. But since the 1980s social disorder has become the focus of most research. This has led to recent claims by many people who believe they are autistic, but that their autism was missed when they were children.

I want to urge the IACC to maintain the focus on developmental language disorder, and its causes.

Infants begin to learn language through the sense of hearing. Professor Roger Brown at Harvard determined that speech begins with use of stressed syllables. Stressed syllables become more and more difficult to detect during the first 10 years of life. This is why learning a new language becomes more and more difficult.

Language development should be the primary focus of research. Use of single syllables should be encouraged in attempts to teach autistic children to learn to speak.

Please discuss language development as the most important focus of research with autistic children.

[PII redacted]

Written Comments

David M. DeMarini, Ph.D.
Genetic Toxicologist, Retired
U.S. EPA, RTP, NC 27711

I am writing to express my strong support for the letter submitted by La Donna Ford, MD regarding the need for federal funding to investigate the heritable (germ cell) impacts of general anesthesia and the implications for the etiology of neurodevelopmental pathology, such as autism spectrum disorder (ASD) in offspring.

Despite the biological plausibility of this important hypothesis, the regulatory agencies worldwide evaluate agents almost exclusively for somatic cell effects and not germ cell effects. This also seems to be the case with the potent halogenated general anesthetic gases, which are used ubiquitously in medical practice. Federal funding devoted to this specific question is very much needed and long overdue.

I am a genetic toxicologist, author of >200 scientific papers, past president of the Environmental Mutagenesis and Genomics Society, Adjunct Professor at the University of North Carolina at Chapel Hill, trained 20 PhD students and postdocs, Editor-in-Chief for 21 years until last year of *Mutation Research Reviews*, and a recently retired research scientist for 36 years at the Environmental Protection Agency in Research Triangle Park, NC. I am widely known for my work showing how environmental toxicants can damage the human genome, the types of mutations these agents cause, and how those mutations lead to cancer.

Please do not hesitate to contact me should you have any questions or if I could be of further assistance.

Gene Bensinger
Parent Advocate

On the occasion of the first meeting of the expanded IACC, with many new people (and the organizations they represent) joining some familiar ones, I want to wish all of you good luck in your efforts, but also want to take a moment to address the critical importance of respectful behavior and civil dialogue on autism and disability related issues. Both within the workings of the IACC and, importantly, beyond your meetings.

Each and every member, whether public or federal, assumes broad responsibility in their service. Committee members offer important, but necessarily limited, expertise on the issues that the IACC addresses in coordinating federal autism efforts on behalf of the public. The ultimate constituent of the IACC, the American public, ranges far beyond engaged stakeholders like autistic Americans, parents and families supporting autistic people, scientific and medical professionals, public sector agencies, and service providers. All Americans and their collective interests are impacted by the actions the IACC takes, whether or not they're aware of it. And fully inclusive public representation demands that IACC members recognize that, no matter their personal circumstances, expertise, experiences, and opinions, ultimately, IACC policies must reflect reasoned consensus on the issues. Cooperation and compromise, even on topics that stir strong passions, must take precedence over partisan stances. No stakeholder constituency should be elevated, or subordinated, in the process of formulating that consensus.

The current toxic climate of debate on autism and disability related issues is plainly evident in traditional and social media. Conflict may sell stories, net followers or grow donations, but it doesn't build the resources all of us need. Just this month, a leading disability policy advocate affiliated with a new IACC member organization took to social media to personally disparage another policy leader based on parts of an opinion piece they disagreed with. Yet, it was clear from the content of the piece that agreement existed between them on many issues. This kind of aggressive behavior hurts everyone, because it cultivates distrust among what should be natural allies. Sadly, this was just the most recent example of many.

Let's all take a lesson from (then Vice President) Joe Biden when he spoke to students in a 2015 speech reflecting on his personal anger at an opponent to the Americans with Disabilities Act. He said, "it's always appropriate to question another man's judgment, but never appropriate to question his motives because you simply don't know his motives. Never once (since then) have I questioned another man's or woman's motive. Because when you question a man's motive, when you say? they're in the pocket of an interest group, et cetera, it's awful hard to reach consensus. No matter how bitterly you disagree, though, it is always possible if you question judgment and not motive"

So I ask IACC members to be a model for respectful interaction, and to demand the same from your colleagues and peers in all venues when you leave these meetings. People need to know that, no matter how much folks may disagree on some (or many) issues, all of you and your organizations are, in fact, committed to working together to achieve progress.

Again, good luck with the many tasks and initiatives that lie ahead. All are critically important parts of creating a better future.

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

Carole Yauk, Ph.D.

I have had the opportunity to review a written statement provided to you by Dr. Ford. As President of the Environmental Mutagenesis and Genomics Society, I hereby submit a letter of support for that statement for your consideration at the July 21 meeting of the US Interagency Autism Coordinating Committee.

EMGS
Environmental
Mutagenesis and
Genomics Society
Synergistic Interactions for a Better World

Re: Support for letter submitted by La Donna Ford, MD; suggestion for special session

The Environmental Mutagenesis and Genomics Society (EMGS) is the leading scientific society devoted to furthering research on genetic damage, including germ cell mutagenesis and epigenetic error. The society was founded in 1969 by distinguished geneticists and toxicologists, and today our members continue the mission to identify phenomena that induce genetic damage in humans, including heritable damage caused as a consequence of disruptions to germ cells.

The letter submitted by La Donna Ford, MD has come to our attention. We wish to express our strong support for her suggestion that the IACC identify as a top priority research on the question of germline impacts of general anesthesia, while at the same time keeping in mind the broader context of germline toxicant exposures, including pharmaceuticals (see, e.g., Kaplanis et al. 2021) and environmental chemicals (see, e.g., Gore et al. 2021).

In order for the IACC to better understand the germline disruption hypothesis, we suggest the IACC host a special session devoted to the topic, focusing on general anesthesia as an important example of this toxicological phenomenon. This session could be conducted virtually and include the following presenters: **Jill Escher**, science advocate and chair of the EMGS Germ Cell and Heritable Effects Special Interest Group; **La Donna Ford, MD**, retired anesthesiologist; **Victor Corces, PhD**, Emory University, and member of the National Academy of Sciences, and **Hsiao-Lin Wang, PhD**, Emory University, who have published on heritable impacts of sevoflurane in mice; **Anatoly Martynuk, PhD**, University of Florida, who has published two studies on heritable impacts of sevoflurane in rats; and **Vesna Jevtovic-Todorovic, MD, PhD**, University of Colorado, who has also published on heritable impacts of sevoflurane in mice.

EMGS has featured this topic at several of our recent conferences, and the 2022 International Conference on Environmental Mutagens will again include talks on this important subject. We support further research in this area without hesitation.

Thank you for your consideration of these comments. Should you have any questions, please do not hesitate to contact me at [PII redacted].

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Chris Colter

As someone who is in the trenches with autism, parents like me want to see action at the ground level. The view of this committee in the autism community is not favorable. We need to see more action and not words for our struggling kids. We know those in charge are having trouble admitting that the chemicals in our food are part of the overall problem. We need action focused people involved here, not greedy people who only want a paycheck and do nothing for it. Parents have had it.

Ilene Lainer

It would be very helpful to the community if grant money could be made available to promote improved outcomes for adults with autism. There could easily be defined areas so that the committee could track progress in each: 1. accessibility of services (this could include navigation so adults and families could find what they need, it could also track equity issues) 2. housing 3. employment 4. promotion of engagement. So many areas require support but a focus on what can be done to improve outcomes should be the focus.

Peggy Kilty

My name is Peggy Kilty. I live in the Columbus, Ohio area with my husband and two children. My youngest child, who is a biologically female eleven-year-old and currently identifies as gender non-binary, was diagnosed with ASD Level 1 in January 2021 and I am now following the work the IACC with great interest and I am impressed by thus far by the committee members, both federal and public, and the inclusion of committee members who identify as Autistic. Representation absolutely matters!

It took five long years for my child to receive a diagnosis: four years of telling our pediatric primary care provider that, developmentally and behaviorally, something was not quite right. We were repeatedly told she will grow out of it. That did not happen. While my child was referred to psychological services to address anxiety, our other concerns continued to be dismissed. Again we were told, she will grow out of it. Four years later, my child was referred to diagnostic services. We waited nearly one year for this evaluation. Once diagnosed, we waited another 7 months for ASD therapeutic services. Once the diagnosis was confirmed, researchers were quick to ask us to participate in studies, but no one was quick to get us into therapeutic services. Because of the ADS Level 1 diagnosis, my child did not qualify for a school IEP, Ohio Scholarship Funds for ASD, or County Services for Developmental Disabilities. While I fully understand that there is a greater need for services for individuals impacted by ASD level 2 and 3, that does not mean that individuals and families affected by ASD level 1 do not need help. We do!! Please do not leave us out of these important discussions surrounding research and services for ASD. While my experience is anecdotal at best, I don't need an academic study to confirm that there is gender bias in diagnosing ASD in girls. Thank you.

Kastur Halai

Please find a short article I wrote about my personal journey with autism and some other learning inabilities.

https://theworldwhisperer.com/autism-awareness/

Robert Castleberry

I am hoping you could be of some help. Due to genetic variances in how the neurons of my brain connect (an aspect of my diagnosis of autism spectrum disorder) and the amount of information I have absorbed due to a perseverance, I have "discovered" a singular behavioral constant that serves as the foundation of everything that exists.

This behavioral constant serves as an explanation for all behavior/function/shape/etc. Why we do what we do, what it means to be human, what is math, where do ideas come from, etc. It serves as a means of demonstrating how everything is the same. Science, spirituality, philosophy, psychology, etc. all exist as variants of a singular constant. They exist for the same reason. This behavioral constant not only rewrites almost every aspect of science and more, but also explains why the current perceptions exist the way they do. It explains why we invent what we do and shape the world the way we do. Why we have the career types that we do. Why we gather. Every single thing we do and say exists as variants of this constant. It also solves many of the long unanswered questions of science and philosophy. Consciousness can be finally understood via this constant. Everything can.

As a result of my genetic variances I struggle greatly with doing anything with these conclusions I've reached. I am incapable of achieving anything with them on my own. I have tried reaching out to hundreds of individuals within the varied scientific, psychological, and philosophical fields, including places that specialize in the diagnosis/criteria of A.S.D., but 99% never respond. The ones that do just tell me to start a blog or go to school and refuse to hear me out. Others misperceive my requests for help as a search for mental health care. Years of this.

I believe that these conclusions I've reached can help people dramatically. They can be of tremendous benefit to all fields of research. It explains why conflict exists and opens up avenues on how to reduce it. It shows how we are all different because we are all the same. We are all variants of a behavioral constant. The way in which the constant exists naturally resulting in variants. Genetics are not the explanation as genetics are another example of this behavioral constant. Mathematics is another example. Math does such a good job at explaining things as it exists for the same reason the things it explains does. It is not the language of the universe, it is another variant of a behavioral constant that the universe shares with it. Like how the same thing can be said in multiple languages but be perceived in different ways.

This behavioral constant serves as a means of explaining precisely what and how ‘autism’ is. Every aspect and perception of this diagnosis, along with other diagnosis, making sense in light of this singular constant. The social aspects, empathy, theory of mind, etc. All serve as representations of the behavioral constant. In perception we are conditioned to define them as separate things, but in nature they all the same. Attention issues and sensory sensitivities being by-products of this behavior. fMRI studies being one way in which ‘evidence’ exists for the explanation I have.

This constant also explains why pinpointing any genetic aspect of ‘autism’ has been difficult to do and why hundreds of varied areas of the genome have been linked to it. Our conditioned perceptions of genetics inhibiting our ability to look at the function of DNA in other ways. ‘Autism’ isn’t the result of any specific areas of the genome, but rather how the entire genome operates as a whole.

Make no mistake, though. I am not merely presenting an explanation for the diagnostic criteria of A.S.D. This behavioral constant exists in everything. It is in essence a ‘theory of everything’.

I need to be heard, hopefully understood, and aided in presenting these findings to the world. If you can in any way be of assistance I would be tremendously in your debt.

Additional information available if requested. I look forward to your reply. Thank you!

Joe Rashid
Palo Alto, California

I am the father of two teenage girls, one of whom has profound autism. I am writing to support the letter submitted by La Donna Ford, MD, requesting that the IACC prioritize research into autism parents' histories of surgery and procedures under general anesthesia. In the years prior to having children I had underwent 7 surgeries under general anesthesia, 3 on my shoulders, 1 on my nose/septum, 1 one on my hand, 1 on my foot, and 1 to correct a hernia at age 16. There is no history of autism in my family or my wife's family. This idea suggested by Dr. Ford, that these toxic exposures can damage sperm and germ cells in a way that can impair neurodevelopment in the offspring, makes sense and is supported by research. Given the ubiquity of this damaging exposure there is no question it should be a top priority for research.

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

Julie Fackrell

My name is Julie Fackrell and I am the parent of an adult with ASD.

Our autism family lives in a constant state of crisis. And when we seek help, we find there are limited programs to serve our son.

[PII redacted] ASD symptoms were somewhat mild as he was growing up. When presenting these symptoms to his pediatricians over the years, the common response was “he will grow out of it.” [PII redacted] did not grow out of these symptoms and in fact, they progressed and became much more severe limiting his ability to finish high school with his class. After a couple years of many different doctors, therapists, and psychiatrists we were at a loss. Our community in the Dallas/Ft. Worth vicinity did not offer any services or supports and I, his mother was forced to leave my full-time job to care for him. This left our family desperate for financial support on top of the need for ASD support almost losing our home to foreclosure at one point.

After making the difficult decision to move out of state to California where services and supports were more readily available, we found some relief. And while we continue to live a more stable life here, [PII redacted] prospects of gaining any type of employment or leading an independent life are despairing.

As a family, we have experienced many frightening situations over the years that will affect us for the rest of our lives. We have all been victims of severe verbal lashings that at times include being spat on and threatened. We have had numerous holes put in the walls, televisions being broken, and other miscellaneous household items being broken including priceless mementos from ancestors. My daughter who is now 17 has hidden in closets, under beds and behind doors. She has been attacked while sitting in the back seat of the car next to him at the young age of 10. While most of these incidents have not been physically abusive, the mental and emotional trauma sustained continues to harm us and has evolved into serious physical illnesses for me, his mother.

[PII redacted] has been hospitalized in several psychiatric facilities. I have come to learn this is not a treatment of any sort but rather a short break for the family at a very high cost.
I worked hard and put myself through school to be able to have a career and pursue my goals and dreams. I no longer have the ability to accomplish any of these things. I have mounting student loans due to interest I cannot pay and will not use the degree earned.

I love my son with all my heart, and both my children come before anything else. I am committed to living the rest of my life as his mother and caregiver, however long that may be. Considering my failing health at such a young age, I’m afraid I will leave this life not knowing how he will survive.

This is an acute, growing problem around our country. The IACC needs to hold a session on inpatient and outpatient care options for the severely autistic who can no longer live safely at home, and also long-term residential care. We also need more research on interventions that prevent aggression, self-injury, and property destruction. It is these behaviors that keep our severely affected children from being able to access care and services.

Thank you for your consideration.

Note: Personally Identifiable Information (PII) has been redacted in this document. The comment has been redacted for offensive and derogatory language.

Brian Gene Evans

My name is Brian and I am a 52-year-old adult with Autism.

Do you know anyone who would be interested in starting an adult autism medical hospital in Arkansas or Missouri or even every state in the United States that would be required to meet all the special autistic comfort and emotional needs of all autistic patients no matter what they are including mine where every nurse, tech, and doctor of that hospital would be required to meet all these needs of all their autistic patients in every department of that hospital an autistic patient goes to?

Is there some way you can bring my autism medical hospital idea to the Arkansas and Missouri Congresses to see if they will vote on having one started in their own state and also the United States Congress to see if they can vote on having an Adult Autism Medical Hospital started in every state of the United States?

I really think they ought to have these adult autism medical hospitals in every state in the entire United States to save the autistic community the trauma and abuse they have to face when they go for their medical procedures at all these regular medical hospitals.

I have had a lot of problems with nurses at hospitals refusing to meet my autistic comfort needs for hugs from everybody I see, cheery female nurses and techs only to take care of me and them rub my head and hold my hand during needle sticks and knock me out for all invasive procedures before they perform them and them calling hospital security guards and/or police and/or my wife, [PII redacted] just for asking for these needs
to be met by them.

I have had a sensory issue in my right ear since birth that can only be relieved by pressing it on the cheek of the people I like, usually females which I call a hug.

I have a severe oversensitivity to pain and a severe needle phobia.

A shot and a blood test feel like a steak knife.

An IV feels like a butcher knife.

A catheter feels like a sword.

Male doctors, nurses, and techs and serious acting female
nurses tortured me with needles as a child.

Serious acting female nurses and techs continued to torture me with needles into adulthood.

Cheery, adventurous, fun loving female nurses who act like they are on an adventure and like I am their best buddy in the world who act like and respond to me like Ariel, The Little Mermaid on the Disney Movie, "The Little Mermaid" are the ones I do the best with who comfort me like you would a child and give me hugs and rub my head and hold my hand during needle sticks to comfort and calm me through the stick.

Now, hospitals in both Arkansas and Missouri throw a fit for asking for my needs to be met by them and get hospital security guards and police after me and/or my wife, [PII redacted] just for asking for these needs to be met because I look normal to them regardless of the fact I have records
that prove them wrong.

This is a real eye opener to all these hospitals out there that think I'm not disabled.

They only see the way my future situation makes things appear, not what the past portrays about the truth of what my disability entails.

That's what throws them.

That's why they won't meet my needs.

They think you're either one or the other [redacted] or smart,and whichever one you are they think you're all the way across, you're
either all smart in every area there is or you're all dumb in every area there is and there's no in between with these people.

If you're smart in a few areas they think you're smart in them all.

And, they think if you're smart you've always been smart and always been exactly like everybody else and if your dumb you've always been dumb and never had a smart thought in you.

And if you're somewhere in the middle and have a little of both they think something fishy is going on and your playing them for the fool so when you try to say your autistic and disabled, even when you show
them the records claiming you are they don't believe it and consider you to
be a threat because you appear normal to them.

And, in their eyes, only [redacted] people are autistic and all autistics don't like touch and all autistics don't feel pain.

False.

Temple Grandin and Sean Baron are far smarter than I am and they are autistic.

They have an above average intelligence and always have.

My knowledge is learned. Theirs is not. Theirs comes naturally. Mine does not.

Mine is memorized not perceived by mere conception.

Also, some autistics crave hugs and touch.
I am one of them.

So are 6 of the 21 kids around the world in the article 21

Autistic Kids Around the World.

So, is the kindergartner that got suspended from school.

So is my ex-neighbor [PII redacted] grandson and my Pastor's [PII redacted] grandson.

And, I've seen others in other articles that are like me as well.

Also some autistic people feel pain very loudly, others barely feel anything.

They also have made comments to [PII redacted] before like, "He can talk!"

So, so can several other autistic people, many of them can talk, many more of them cannot.

It depends on what end of the spectrum they are on for all of this, verbal or nonverbal, craves hugs and touch or resists hugs and touch, barely feel pain, or feel pain loudly in magnitude.

And, for their information out of all the research I did, approximately 30% of the Autistics I read about craved hugs and touch.

The other 70% resisted touch and hugs.

So, there are autistics that do crave hugs and touch.

There's just not as many of them but there are plenty of them that are, so these nurses need to be trained to meet the special needs of both the autistics that resist touch and hugs "AND" the autistics that "crave touch and hugs", the ones that barely feel pain, "AND" the ones that "feel pain very loudly", the ones who can't speak, "AND" the ones that "Can Speak".

Some can speak, but not well.

Some can speak very well most of the time, like me, but have spells where they don't speak very well because they don't always know how to word things the right way to get through to you what they are trying to say or what they want you to know or what they want you to understand about them.

It's all a spectrum and they need to be willing to meet the special needs of "ALL" autistic patients and not just the ones that don't like touch or hugs and can't feel pain.

Upon research I have found that many other autistic adult and autistic children going to medical hospitals have also been harassed and/or even physically abused by their nurses and/or hospital security guards and/or policemen because of their anxieties over procedures.

You would probably be shocked at some of what I saw. I have experienced some of these problems as a patient in the medical hospital that these people are having, yet some other things they are doing to some of these people are even more shocking than what I have experienced.

I feel like any nurse or hospital guard or policeman that abuses an autistic or mentally disabled patient, and shockingly, even elderly, in the way I have seen in these articles should be immediately fired from their jobs and lose their licenses and their badges.

I don't mean to be mean or anything by saying this.

I realize there are good nurses out there but these bad nurses I saw in these articles and the hospital security guards I've seen in these articles as well as the policeman in these articles have got to go.

When you see what I saw in these articles and videos on the Internet I'm sure you will feel the same way.

Some of these people really were fired from their jobs in some of these articles but some were allowed to continue to get by with their mean practices, and this should not be, they should have been fired as well.

And, if nurses at regular medical hospitals and other medical hospital staff at these hospitals are going to insist on refusing to meet the comfort needs and emotional needs of autistic adult patients and autistic child patients and other mentally disabled people or the elderly, they need to start an adult autism medical hospital that will where the nurses will be trained to meet the needs of all autistic patients no matter what they are including mine everywhere they go at that hospital in every department of that hospital by every nurse, doctor, and tech there without complaint.

Please see what you can do to make this a reality.

Please read these articles and watch these videos on this list of articles and videos I am sending you and you will see what I mean.
Thank you.

Here are the articles:

Adults and Mentally Disabled Patient Abuse and Elder Abuse Articles and Videos

Regular Medical Hospitals Patient Abuse of Autistic Adults and Autistic Children

Day 19: Chicago Hospital Locks Down Autistic Patient

Hospital Reprimanded for Mistreatment of Autistic Patient at Banner Desert Medical Hospital

Nurse Surrenders License For Repeatedly Stabbing Boy With Autism With Hypodermic Needle: AG

Autistic Patient Allegedly Struck in Face by St. George Hospital Security

When The Hospital Fires The Bullet

Sobbing Mother Describes Treatment of Autistic Daughter in Hospital

15-Year-Old Autistic Boy Kidnapped By Hospital

OSU Harding Hospital Staff Threatens Autistic Patient With Security

Family Says Lack of Autism Awareness Led to Awful ER Experience

Report Urges Portland Hospitals Not to Criminalize
Homelessness or Mental Illness

Autistic Adult ER Visit: Not A Security Threat

Nowhere to Go: Young People With Severe Autism Languish
In Hospitals

Violence Against Hospital Patients By Armed Security
Guards

Autistic Man, 27, Held In Choke Hold Until he Passed Out
By Hospital Staff After Holidaying In Tenerife, Mother Claims

Are Hospitals Allowed To Restrain You And Strip Off All Your Clothes By Force? I Am 14, And They Left Me With Bruises, Just Because I Wanted To Change Into The Hospital Gown In Private

Patient Films Alleged Mistreatment at St. Mary's And Speaks Out

Ex-Cumberland Hospital Nurse Speaks Out “Shut It Down”

Probe: Disabled Patient Abuse Cases Overlooked
Learning Disability Practice Conference 2018: Mother of Man With Autism Recalls His Trouble Transitioning To Adult Care
Restraint Of People With Autism And Developmental Disability

Overhaul Needed To End 'Inhumane' Hospital Care of People With Learning Disabilities Or Autism, Says CQC

They Were Kids And Hospital Employees Beat Them

Hospital Employees Removed After Taking Photos of Newborns (They Made Them Dance)

WATCH: Patient Films Mistreatment at St. Mary's and
Speaks Out

Patient Reviewers Witness Patient Abuse of Disabled Patients at Medical Hospitals

Review By L. Sykes of Baptist Health Medical Center Little Rock, Arkansas Blowing The Whistle On A Hospital Security Guard Harassing Disabled Patients

Review By Branson Survivor of Cox Medical Center Hospital Branson, Missouri

Blowing The Whistle On A Hospital Security Guard Harassing Disabled Patients

Review By Brendon Oblinger, A 17-Year-Old, of Lake Regional Medical Center Osage Beach, Missouri Of A Hospital Security Guard harassing Him After The Guard Made Him Nervous From Continually Putting His Hand On His Gun And His Mother Calling The Hospital Staff On The Phone
Asking What This Hospital Security Guard's Name Was

Review by Rachel Pereria Of Baxter Regional Medical

Center Complaining About Not Being Treated Like A Human Being By Nursing Staff

Review by Kerstan Kelly of Mercy Hospital Rogers, Arkansas About Rude Staff

Carlile Spiers Review of Mercy Hospital Rogers,

Arkansas Transferring Her Mother To Another Hospital Behind Her Back And Then Refusing To Let Her Visit Her Mother At The New Hospital

Review by Nicole Falk of Washington Regional Medical Center Fayetteville, Arkansas Complaining About Their Terrible Service and the Horror Stories It Has About Making It Locally Infamous

Myriah Endres Review of Baxter Regional medical
Center Complaining About the Rude Nursing Staff In The ER

Note: The First 3 Of These Hospitals People Are Patient Reviews Blowing The Whistle On Hospital Security Guards Harassing Disabled
Patients

The Last 3 Hospitals Were The Very Ones That Got Hospital Security Guards and/or Police after Me and/or Bertha in Arkansas

Mental Hospitals Patient Abuse of Autistic and Mentally Disabled Patients

Mercy Criticized For Handling of Violent Mentally Ill Patient Report Shows
(This is Actually A Regular Hospital Who Owns Their Own
Mental Hospital In The Back of The Hospital Across The Parking Lot. I Did
Not Know This Until Recently.)

Why Did Mercy Fire 12 Employees? New Report Details Handling of Mental Health Patients

North Texas Mental Hospital Indicted For Holding Patients “Involuntarily and Illegally”
(Believe It Or Not, These Were Mostly Normally People,
Kids and Adults Held Illegally)

Yews Trees Hospital Essex Breaking Scandal United We Stand

Patient Found In Freezer, Child Loses Toe, 46 Claims of Abuse Investigated at Mental Health Facility

Government Faces Legal Action for Inhumane Treatment of People With Disabilities and Autism

Inhuman Use of Restraint on Disabled patients
Dallas Police Issue Warrant For Autism Treatment Center

Employee Accused of Kicking Patient's Teeth Out

Worse Than BROADMOORE: Nurse Whistle Blower Claims He Has
Seen Psychopathic Serial Killers Cared For Better Than Autistic Children He
Has Witnessed Being Violently Held Down And Force Fed Drugs At Health Unit
Funded By The NHS

Very Little Care or Empathy For Autistic Adults From NHS
Hospital Staff

Whorton Hall: Hospital “Abused” Vulnerable Adults

“Blood and Bruises” Parent Recount Injuries Suffered By Their Children While at Devereux

Abuse Caught On Video At Michigan's Biggest Autism
Therapy Provider

ProMedica Closes Autism Center After Criminal Investigation

'My Autistic Daughter Was Held In A Cell For Two Years'

Smirking Care Home Staff Attacking Autistic Patients And Abuse Scandal Reveals How She Felt Powerless
For 12 Years – Until She Saw One Victim
Being So Violently Restrained by NHS Staff They Broke His Neck Article By Ian Birell

Shocking Abuse of Autistic Children In U.K. Mental
Hospitals

They Have Stolen His Youth: Mother's Anguish For Autistic Son Locked Away By The NHS Staff For Years

Staff Abused Children For Years at Devereux Health
Facilities (You Tube)

Nurse Blows Lid On Shameful Abuse at Health Unit

Autism – Disabled Children Restraint Seclusion Abuse

Shocking Abuse of Autistic People – The Scandal of Young

People With Autism Locked Away
and Abused in Britain's Mental Hospitals

Autistic Girl Who Was Locked Up 24/7 Now Thriving With Bespoke Care

Video Shows Health Care Worker Punching and Beating Man
With Belt

Abuse of Autistic Individuals in Other Places

Convicted Felon Who Abused Autistic Patient Can Work Again As Caregiver

Kids Facing Charges After Teen With Autism Filmed With Pants Down In New Jersey

Mother Assaulted in Madrid Amusement Park For Defending Her Autistic Child

Why Autistic Kids Make Easy Targets For School Bullies

Survey Reveals Half Of Autistic Adults 'Abused By
Someone They Trusted'

Horrible Dentist Experience Autism and Dental Care

Nurse Under Investigation After Cord Swung At Boy With Autism

Health Secretary Faces Legal Challenges For Failing

Patients With Learning Disabilities and Autism

Autistic Kindergarten and Elementary Kids Abused By School Teachers, School Nurses, School Principals, and Police 5 Year Old With Autism Reportedly Punished for Hugging Classmates, Family Says

Surveillance Camera Shows Teacher, Nurse Dragging Boy With Autism in Kentucky School

Teachers Threatened to Pour Hot Sauce Down Autistic Child's Throat

Hawaii Family Horrified by Video Of Boy With Autism Getting Beaten In School Bus

Student Suspended For Sexual Harassment For Hugging Teacher

Video: Cop Handcuffed and Taunted 7-Year Old

Autistic Student After He Spat At School

Police Handcuff 9-Year Old Autistic Boy At School, Then Arrest And CHARGE Him After Teachers Call The Police To Handle “Fight With Bullies” We Are Outraged What About You?

Law Suit Filed In Colorado Arrest of 11-Year-Old Boy With Autism

11 Year Old Boy With Autism Searched How To Hide From Police

Outraged Father Speaks out After Son With Autism Is
Placed in Handcuffs In Lancaster

Video: California Police Officer Shoves, Punches Teen Boy With Autism

Violent Arrest Of California Teen

Graphic: Teen With Autism Punched By Police Officer

Suit: Cops Killed Autistic Teen By Sitting On Him, Choke hold

13-year-Old Boy With Autism Disorder Shot By Salt Lake City Police

Mother of Autistic Boy Shot By Police Speaks Out:
“Why Didn't You Just...”

Linden Cameron 13-Year-Old Autistic Boy Shot By Salt Lake City Police

Police Shooting of Boy With Autism In Salt Lake City
Leads to Call For...”

Bodycam Shows Salt Lake City Police Shooting 13-Year-Old Boy

Police Release Footage of Officers Shooting 13-Year-Old Boy

Police Chase and Shoot 13- Year Old Boy

General Abuse In the Community By Police of Autistic,

Mentally Disabled, and Elderly People

Video: California Police Officer Shoves, Punches Teen Boy With Autism

4 Arrested In Connection With Attack On Person With Autism In Hamilton: Police

Disabled Behind Bars – Center For American Progress

Why Autism Training For Police Is Not Enough

Fresno Police Handcuffed 16-Year-Old Boy With Autism After He Had A Seizure, Mom Says

Boy, 16, With Autism Had Seizure, Was Handcuffed and Arrested, California Mom Says

Texas Man With Autism Trying To Cross Road Says Officer Tackled Him

Autistic Man's Family Sues Over Florida Police Shooting

Colorado Cops Fist Bump and LAUGH at Video of Themselves

'Breaking Arm and Dislocating Shoulder' Of Dementia-Suffering Woman, 73

After She Left Walmart Without Paying $13

After Violently Arresting Woman 73, With Dementia, Police Laughed About It, Video Shows: 'We Crushed It'

Karen Garner Video - Loveland Officers Mocking

'Please Don't Let Me Die Back Here' Aurora Police Video Released Woman Cuffed, Hobbled in Back of Patrol Car

New Law Mandates Utah Police Undergo Autism Awareness Training Nursing Home Abuse

Video Shows Healthcare Worker Accused Of Assaulting Patient

Criminal Care Caught On Camera

(To Get The Correct One, Because There Are Several Of These, First Go To “Video Shows Healthcare Worker Accused of Assaulting Patient” To The End Of The Video, (or fast forward to end of video), Then, Skip Ad Then,Click on Play Button on Screen that says “Criminal Care Caught on Camera”

Instead of Going to Next (DO Not Go TO NEXT, Hit Button On Screen)

Elderly Patient Abuse In Pretoria Highlight Public Health Woes

General Information About Autistics Being Failed By The System

The Healthcare System Is Failing Autistic Adults

How Doctors Not Understanding Autism Can Endanger Autistic Patients

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

Brian Gene Evans

Summarization of Patient Abuse Of Autistic Adults and Autistic Children at Medical Hospitals

I have had a lot of trouble with getting hospital nurses and techs to meet my special comfort needs for hugs by everybody I see that I like including the nurses I like that take care of me, cheery female nurses and techs being the ones to take care of me and rub my head and hold my hand during needle sticks when I go to them for my procedures, labs, x rays, and surgeries, and am even harassed by the nurses and hospital security guards and/or police just for asking for these needs to be met.

I also noticed that many other autistic adults and autistic children are having their special needs refused by hospital staff and are also being harassed by hospital nurses and hospital security guards for the things they need done or for their anxious reactions of what is being done to them.

I also found upon research that autistic adults and autistic children are actually being abused by hospital nurses and hospital security guards in the form of patient abuse.

A healthcare nurse that a mother got to baby sit her 8 year old autistic son oddly brought her daughter with her. The healthcare nurse swung a cell phone cord at this boy consistently and then sat back and laughed while her daughter swung the same cord at him.

In another hospital a nurse stabbed a 10 year old autistic boy multiple times with a hypodermic needle.

There was even one hospital where a nurse kept swinging a belt at a patient to torture them.

I even saw one article where a nurse drug an autistic boy out of their inpatient room and drug him down the hall next the drug carts the inpatient nurses were using to do their prescription medicines for their patients at.

I even saw one where there was a trusted male caretaker that said he wanted to take care of disabled kids at a health center that cornered a teenage boy about 16 years old and continually kicked him and they found bruises on his knees and legs. That particular one may have just been a center and not a hospital.

At Banner Medical Center, a hospital in Mesa, Arizona a mother found her autistic daughter who was a patient at their hospital naked in a Guernsey in her own urine and he reported the hospital.

At a hospital in Chicago, Illinois, there was a nonverbal 16 year old boy in severe pain from stomach problems with bouts of constipation and diarrhea and he was having a meltdown screaming in pain not knowing how to tell the nurses what was happening to him because he couldn't speak.

Instead of getting down to the bottom of what his medical problem was they doped this boy with multiple psychiatric medications to keep him from being a problem to him and the hospital security guards stripped the boy of all his clothes including his underwear, handcuffed his hands and feet to a patient bed, and threw a raveled up, rippled sheet over his private area and bottom of his stomach and left him that way for 19 days.

The nurses had to remove his handcuffs every time he had to go to the bathroom and then handcuffed him back to the bed when they were done each time.

The boy had severe dermatitis on his back and on his arm as a result.

He waited 5 days just for a pediatric gastroenterologist to come in to check on him who said they didn't see anything wrong.

12 days later they finally got a second opinion from a 2nd gastroenterologist who said they found plenty wrong with him and did procedures on him.

He finally got to go home from the hospital on the 19th day he was there.

At another hospital an adult male patient, about 30 years old had to go to the Emergency Room for a medical problem he had and cried out, “I want to go home! I want to go home! Let me go home! Let me go home!” as the ER nurse tried to calm him down when suddenly, a hospital security guard struck him in the face and the parents of this boy had the hospital security guard investigated by the police as a result.

At a children's hospital in Alabama there was a lady who took her daughter to the PICU for her emergency care.

One day her mother was told she could visit her daughter that day but when she arrived there the nurse said, “You can't visit your daughter today. She's too anxious for a visit right now.”

The lady nurse slammed the door in this mother's face with her daughter behind the door screaming and pulling for the door and hitting the door as the nurse tried to drag her away crying out, “Mommy! Mommy! Come back! Come back!” as her mother saw from the other side of the door sobbing as her daughter was drug away from her by this nurse.

There was also another hospital where a mother had taken her 15 year old son to the children's hospital to take care of a medical problem he was having but she disagreed with the way they were wanting to treat him and wanted to go elsewhere to have him checked over and after she tried to leave with her son, her son was actually kidnapped by the hospital and she had a horrible time getting him back.

There was another hospital where an autistic man said that he was abused by the hospital nursing staff in the Emergency Room of that hospital.

There was even an article about a man with bipolar disorder, who seemed more like a schizophrenic patient to me based on his symptoms who the hospital security guard shot with a gun in the chest when nurses said the patient was delirious but was not violent.

At OSU Harding Hospital a mother was told by hospital staff that if her autistic boy did not get off the phone with his long conversation they were going to call security.

At Mercy Hospital Springfield, Missouri, a mother took her little disabled girl to an audiologist's office. One day they let the girl take a picture with spiderman so the mother did not see any harm in taking a picture of the girl sitting in her chair at her Audiologist's office to show her getting therapy there. Because she accidentally got a nurses arm in the side of the picture she posted on Facebook of her daughter going for her appointment, one of the hospital administration people, a man took this lady in his office and demanded she show him all the pictures on her camera. The lady said, “What if I refuse? The man said, “If you refuse, you will be asked to leave this place immediately and if you ever come back I will be contacting the Greene County Sheriff's Office to have you arrested.

At Mercy Hospital Springfield, Missouri, a man took his 13 year old son to the ER who was anxious over getting called back to the ER Room. The dad talked to a male ER tech and told him his son was just way too anxious, he was afraid his son would have a meltdown, that he was going to take him to wait in the car so he doesn't make a scene. The ER Tech said, “If you take him back to the car, we will not be coming back to the car to get him when we are ready for him.” The dad talked to a security guard about it who pretty much ignored him. After the dad was frustrated with the way they were dealing with him, he grabbed his autistic son by the arm and started heading toward his car, when here comes the security guard yelling, “Excuse me sir! You can't be doing that! That's abuse!” They got in the car and left and after they got home they even had police or investigators at their door accusing the father of child abuse which his own wife even thought was ridiculous. After while they finally got it straightened out and the hospital said they had to take precautions over anything that was different to them because they were trained to do so and couldn't take any chances.

After these 2 incidents, Mercy Hospital was reported because 12 of their mental health staff were abusing their mentally ill and mentally disabled patients and they wound up having to fire them.

Mercy Hospital Springfield, Missouri even recently got in trouble over another incident where a male nurse in their psychiatric hospital behind their hospital that is under them punched a mentally disabled patient. A man that works at this hospital said that the nurses were not equipped to work with mentally disabled patients.

This is also what North Arkansas Regional Medical Center about me. They told my wife, [PII redacted] that their nurses were not equipped to take care of autistic adults and that I needed to find a Children's Hospital or an Adult Autism Medical Hospital that would take me because they could not take care of me themselves.

There have even been reports by hospital reviews of 3 hospitals that the witnessed harassing disabled patients: Baptist Health Hospital North Little Rock, Arkansas; Cox Hospital Branson, Missouri; and Lake Regional Medical Center Osage Beach, Missouri.

You can also add Baxter Regional Medical Center Mountain Home, Arkansas; Washington Regional Medical Center Fayetteville, Arkansas; and Mercy Hospital Rogers, Arkansas to that list for me because these three places also got security guards and/or police after me and/or [PII redacted] when I went to them for my medical care.

If Hospital Nursing Staff are going to insist on refusing to meet the “special needs” and “special comfort needs” of “ adult autistic patients”, “autistic children patients”, and “mentally disabled patients” of “all ages” and “IQs”, both “verbal” and “nonverbal”, and they are going to continue to call hospital security guards and/or police on them for asking for their special needs to be met, and continue physically abusing them, "***especially high functioning autistic adults who appear normal to them but are not"*****,** then **someone needs to start a regular medical hospital** (*where they can go for all their Labs, X-rays, C T s, MRI s, Surgeries, EGDs, Colonoscopies, Cystoscopies, TURPS, EKGS, Doppler Echocardiograms, Bubble Tests, Stress Tests, Heart Cath Tests, Transesphageal Echocardiograms, Cancer Care, Pulmonology Care, Dermatology Care, Thyroid Sonograms, Radioactive Iodine Uptake Tests, C T s. MRIs, Abdominal sonograms,, Inpatient and Outpatient Care, Preop, Postop, OR Surgery, and Recovery,etc., and all other medical procedures, surgeries, and tests that every day people get done at regular medical hospitals all the time)* **who will.**

They need to do this for autistic and mentally disabled patients of all ages and I. Q. s (*even if their IQ is well above a 70)* **where the nurses and techs and all other hospital staff that work at that hospital will meet the special needs and special comfort needs of all autistic people on the entire spectrum, not just those who don't like touch, but also those who crave touch and hugs like me that need this kind of motherly, compassionate care desperately from all their doctors, nurses, and techs and make this hospital for only autistic and mentally disabled people and no one else.**

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

Douglas Bass
[PII redacted]

First, I thank HHS Secretary Becerra for appointing a variety of autistic self-advocates to the IACC for the 2021-2024 term. I consider this to be progress for autistic people in participating in decisions affecting them.

I am 64 years old. I was diagnosed with the now-defunct Asperger's Syndrome in 2006, at the relatively late age of 49. This was after the diagnosis of my then-7-year-old son with Asperger's in 2000.

Over the past few years, I have followed hundreds of people with autism on Twitter. I have seen countless tweets describing our triumphs and struggles, our hopes and aspirations. I have distilled these into a smaller number of words. I offer them for consideration in the next revision of the IACC Strategic Plan for Autism Spectrum Disorder.

Humanity needs the thriving and contribution of autistic people in order to survive. Humanity faces great challenges from environmental degradation, changing climate, and declining resources. These are exacerbated by the self-deception embedded in the human condition. Humanity needs the directness, creativity and focus of people with autism to successfully face those challenges.

People with autism are the greatest experts on what causes them to thrive and struggle. The conventional wisdom is that if autistic people could be cured, or normalized, or trained to suppress their unusual behavior, they would be happy. This is not necessarily the case. We struggle with the common comorbidities of autism, such as anxiety and depression. We struggle with families that are ashamed of us or embarrassed by us. We struggle with a society that is intolerant of our differences.

Autism is identified in all ethnicities, in all genders, and at all ages. Self-diagnosis of autism is frequently confirmed independently. The difficulty of autism diagnosis in underserved communities is underestimated. The stress of autism in marginalized communities is inadequately addressed. Self-diagnosis of autism occurs frequently enough to be studied by autism researchers.

The autism community should identify and cultivate alternatives to Applied Behavioral Analysis (ABA). If it were up to autistic people, ABA would be banned, just as the related gay conversion therapy is already banned in many states. There is evidence that ABA is unethical, ineffective, and harmful to autistic children. If the measure of success is suppressing autistic behaviors, some people might consider ABA to be effective. But if the measure of success is the well-being of autistic people across their lifetime, a different conclusion might be reached.

Support services for autistic adults should be as robust as those for autistic children and adolescents. The "Lifetime" portion of the Strategic Plan is underfunded. Autistic children become autistic adults, and stay that way for a long time. There should be as much funding for the "Lifetime" portion as there is for the portions related to children.

Masking (behavior to camouflage autism) causes stress, depression and suicidality in autistic people. ABA sows the seeds for a lifetime of masking. Masking frequently leads to the phenomenon known as autistic burnout

Identity-first language is ordinary common courtesy. It is ordinary common courtesy to speak of someone in the way they wish. It is known that autistic people prefer identity-first language. We find variations of person-first language such as "suffers from autism" or "struggles with autism" to be particularly odious. Identity-first language removes an opportunity for drama, which could be one reason autistic people prefer it.

Stims play a crucial role in emotional regulation and stress management for autistic people. ABA seeks to extinguish stims to make people appear less autistic. But it unwittingly sows the seeds of stress by removing this valuable resource.

Autistic people should have the same life expectancy and quality of life as the general population. There is no compelling reason why this should not be so. But elders with autism struggle with loneliness, isolation and suicide. A study showed autistic elders were nine times more likely to commit suicide than the general population.

Autism research should include autistic participation and direction. Autism research should focus on improving the quality of life for autistic people. Autistic people are climbing Arnstein's Ladder of Public Participation, insisting that there be "Nothing about us without us." No autistic person would request that an autism researcher create "autistic mice," then investigate interventions to change their behavior. Much autism research has the goal of eradicating autism by some genetic or environmental intervention. Is it just or fair to look a person with autism in the eye, and tell them without irony that they should not exist? There must be something wrong here. Even with all our difficulties, we vigorously contend for our existence. Much autism research frames autistic differences as deficits or symptoms. Is it just or fair to look at a person with autism in the eye, and tell them without irony that their harmless differences should be suppressed?

We do not dispute that autism is a disability. I have greatly struggled in work environments in my life. My difficulties were attributed to neuroses or malformations of character instead of neurology. My diagnosis helped me to make a more positive frame for my life. I have beautiful dreams that my son will not struggle as much as I did. Autistic people are going to be around for a long time. It is my sincere hope that the next version of the Strategic Plan will include more ways to focus on our well-being over a lifetime.

Patricia Athitakis

I would like to see more focus on the severe side of autism and the concerns for parents who have children with very severe deficits in communication and life skills. It would be especially good to focus on behavioral supports in schools and long-term living situations. Thank you.

Kathryn Ashley

Please foccus on DSP work and pay. The shortage all over the US is affecting people’s quality of life.

Alice Taylor

Please include an expansive definition of congregate housing, so that individuals and guardians have more choices than the de facto so-called 'community-based' 5-person group home. A house with five residents is often too hectic an environment for a person with autism. It would not be my son's first choice, if he had a choice. We let senior citizens choose intentional communities with centralized facilities and services. We should let those with severe disabilities make similar decisions concerning where they live. Look at other countries and learn from them, e.g., Denmark.

Also, severe autism is a different disability from those on the autism spectrum who can advocate for themselves. Persons with severe autism rely on their guardians and parents and siblings to help with nearly all aspects of their lives. In many cases, the parents are worn out and need behavioral supports for their adult children with autism. Severe autism is a life-long disability.

Note: The comment has been redacted for offensive and derogatory language.

Mel Persion

We have a facebook group called Support Group for Parents of Severely Autistic Children with Learning Disabilities.
There is also the National Council on Severe Autism.
As if it's not enough that we care for our children who are not potty trained, smear poop, attack us, hurt themselves, destroy property, do not sleep at night, and are unable to tell us where they are hurting, we are constantly being harassed by people who "self-diagnose" or "come out as autistic", who tell us we should celebrate autism, instead of taking our kids to therapies.
Some of them who say that a doctor diagnosed them were able to be diagnosed by answering a [redacted] questionnaire just right in order to get the diagnosis and to jump on social medial to announce it and celebrate it.
Why the [redacted] are doctors diagnosing half the population with autism?
These [redacted] tell us therapies are genocide.
Well, thanks to daily intensive ABA therapies since she was 2 years old, my 13-year-old daughter is out of diapers, she can state her needs, she can read, and her behaviors are improving.
Because we are so busy taking care of our children, and NOT taking them out in public due to meltdowns, these people say we don't exist.

If it weren't for these [redacted], we would just call our group "parents of autistic children". But because everybody is claiming to have autism, even we don't believe it when we hear that somebody's kid has autism. So, to distinguish our children from the [redacted], we say "severe" or "low functioning". But then these [redacted] say there can't be any levels. So, now we have given up and we are just saying "intellectually disabled with behavior issues". These [redacted] hijacked a diagnosis and made a [redacted] out of it. They can keep the diagnosis they made a joke out of. They have all the time in the world to spread their lies everywhere. And people who read these things and who have never seen a truly autistic person spread these lies even further.

These [redacted] have diluted every research study that gathered genetic information so that the research is useless.
And now it dawned on them that it doesn't fit their narrative of celebrating autism if they take part in these studies.

Will doctors, researchers, and the government just stand around with their [redacted] not knowing what to do about this?

Our children need ABA therapy, speech, occupational, and physical therapy. They need respite care. They need residential placement when parents can no longer care for them.
When places announce "special needs activities", they don't want our autistic kids. Nobody wants to include our kids in anything.
Respite places don't want our kids. There is one in my city, in Fort Collins, called respitecareinc.org that is a daycare specifically for kids with intellectual and physical disabilities.
But they refuse our kids because they have no clue how to handle behavior issues.

They won't let my kid take her ipad there to play on just because she can state her immediate needs so she shouldn't need her ipad. They are [redacted] about autism.

And when our kids are nowhere to be seen because everybody refuses them, these [redacted] take over every space and act like our kids don't exist.
Why are you listening to the [redacted] just because they are the loudest and have all the time in the world to spread their lies?
Who the [redacted] is going to take care of our children once we die? Why is the government not helping its most vulnerable citizens?
Help us. We are all drowning. Caretakers of people who truly have autism are drowning.
We don't have the time to keep begging. Just help us already. Help.

Sara Polito

Our boys were diagnosed with profound ASD at 18 months. They are now grown men. Our hopes of finding a 'cure' or adequate community supports are long gone. The agencies designed to 'help' have almost a decade waitlist. We waited 8 years for any type of help. Now that they are men with the intellect of young children, they need adequate housing and support, beyond our home. There is a severe shortage of Res Hab homes for the profound population. By mandating that only non-family individuals, Not-for-Profit organizations, and corporations, be allowed to start and operate a group home is wholly inadequate. Parents or blood relatives cannot form group homes. This leaves parents at the mercy of whoever wants to open a home - good or bad. Depending on the level of services needed, the only 'bed' open may be across the state (away from the family home). This makes staying close, and visiting, almost impossible. This system breaks families apart. Families or blood relatives need to be able to form their own group homes, so this won't happen. The ones who care the most about these kids/ adults are the families. Not corporations running a home to make a profit off their disability.

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

Vance Goforth
Administrator A Voice for Joshua
Member NCSA policy committee
Member VOR

My name is Vance Goforth and I am the parent of [PII redacted] that has autism and co-morbid conditions.

Our autism family lived in a constant state of crisis. And when we sought help we found there was no programs to serve our son. After begging for help multiple years, the crisis spiraled out of control and my son was self injuring daily and I eventually received severe injuries trying to protect him. I'm now the administrator of a advocacy and support group called "A Voice for Joshua". I've been contacted by families from across the country and globe with similar experiences. I have included a link to [PII redacted]'s story.

https://www.facebook.com/197745660861677/posts/348124045823837/?d=n

This is an acute, growing problem around our country. The IACC needs to hold a session on inpatient and outpatient care options for the severely autistic who can no longer live safely at home, and also long-term residential care. We also need more research on interventions that prevent aggression, self-injury, and property destruction. It is these behaviors that keep our severely affected children from being able to access care and services.

Thank you for your consideration.

Hoangmai Pham, Institute for Exceptional Care

Institute for Exceptional Care (IEC, www.ie-care.org) is a nonprofit organization dedicated to transforming healthcare for people with intellectual and/or developmental disabilities (I/DD). IEC was founded by healthcare leaders who have both led national efforts to transform healthcare payment and care delivery, and the lived experience of caring for affected loved ones. We partner with affected adults and many disability organizations. IEC focuses on addressing gaps in the financing and payment for healthcare and other necessary support services, in coordination across service sectors such as clinical and home- and community-based supports, and in the cultural and clinical preparedness of practitioners and payers to serve the I/DD population.

We appreciate the IACC's broad acknowledgement of these priorities. However, we recommend that the IACC consider more specific federal action in a number of areas, and ensure that people with I/DD can have meaningful input on all policies and programs.

- The IACC acknowledges the need for strengthening the HCBS sector, and financing/payment for both HCBS and clinical services. The Department of Health and Human Services has multiple opportunities to take concrete action to do so. For example, the Centers for Medicare & Medicaid Services could set explicit expectations for States to address HCBS infrastructure in their 1115, state plan amendments, or other Medicaid related waivers, particularly as related to use of available enhanced FMAP funds under the American Rescue Plan. Similarly, CMS could fund through the CMS Innovation Center the creation of state-specific common resources that all HCBS providers could use, such as technical or business management assistance.
- The IACC promotes greater investments in autism research. Comprehensive and accurate data are a critical foundation for research that can inform day-to-day decision making by clinicians or payers. Federal agencies could invest in improving the ability for healthcare decision-makers to identify autistic people across the lifespan, who are often not labeled as such in typical electronic medical records or insurance claims.
- The IACC also misses an opportunity to acknowledge and develop recommendations on the role of other federal healthcare entities, including TRICARE, which provides insurance coverage for active duty military personnel and that has conducted recent evaluations of applied behavioral analysis for autistic members; traditional Medicare and Medicare Advantage health plans; Medicaid; Affordable Care Act insurance exchanges and regulations; and the Federal Employee Health Benefits Program, which is an influential purchaser of private health insurance. All of these federal purchasers and regulators can focus more attention on identifying autistic beneficiaries within their populations and addressing their needs and goals.
- The IACC supports the development of more technology solutions to support autistic people. Yet companies offering new interventions struggle to create sustainable business models due to the fragmented nature and inadequate levels of financing and payment for autism and other I/DD related services. In too many cases, entrepreneurs default to relying in part or whole on direct-to-consumer sales, which likely exacerbate disparities in care, as people and families of means are more likely to learn of these interventions and be able to afford them. The IACC could call for the creation of an industry forum that could help healthcare purchasers and regulators coordinate review, approval, and payment for such interventions.

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

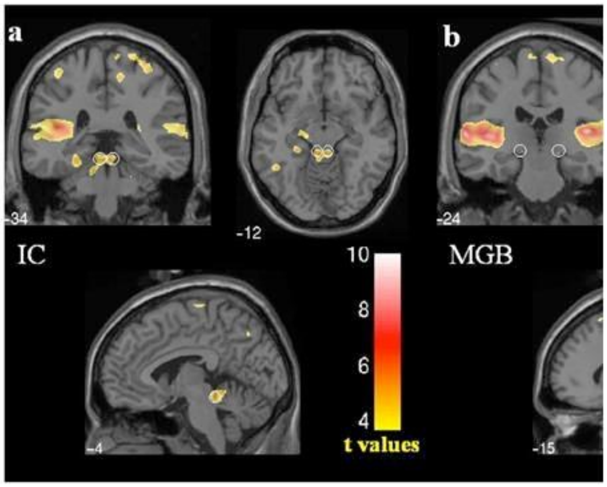
Midbrain Vulnerability

Blood flow in the brain is highest in two tiny signal processing centers in the Blood flow in the brain is highest in two tiny signal processing centers in the brainstem. These are the inferior colliculi in the auditory pathway. Highest blood flow to the inferior colliculi was a surprise finding reported in 1962 by Seymour Kety. The paper by Kety and co-workers is free online, and includes pictures showing distribution of a radioactive tracer 60 seconds after injection into the tail vein of cats. Damage caused by 6 to 8 minutes of asphyxia at birth was found in the inferior colliculi, and nowhere else in the brain. See the article by WF Windle in the Scientific American for October 1969. This article is now also free online. Partial oxygen insufficiency was later found to cause brain damage similar to that found in cerebral palsy. Damage in the inferior colliculi has been found in human infants who succumbed within a few days to asphyxia at birth. See the paper by RW Leech & EC Alvord, Anoxic-ischemic encephalopathy in the human neonatal period, the significance of brain stem involvement. Archives of Neurology 34:109-113, and my discussion at conradsimon.org/WorkingPaperIntro.html

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

Grant Application?

At the IACC meeting held October 17, 2018, Dr. Gordon discussed my many public comments urging research on injury of the brainstem auditory pathway as a cause of autism. He pointed out that could be the focus of a million-dollar grant application over five years. But that if we pursue that hypothesis, there are other hypotheses we cannot pursue. In the comment above, I have provided reasons why inferior colliculus damage should be looked for in brains from people who were diagnosed as autistic. Or the inferior colliculi can be viewed in functional MRI images. High metabolism in the inferior colliculi is visible on an fMRI image published by TW Budd et al, Neuroimage, 2003; 20:1783-94. High blood-flow in the inferior colliculi (IC) is seen, but not in the medial geniculate bodies (MGB).



[PII redacted]

Christine Miles Kincaid

I am the parent of a severely autistic (level 3) teenage son & a high functioning autistic person myself.

My number one concern going forward is the insidious trivialization of the challenges of those affected by severe autism & their caregivers. The popularity of "Neurodiverse" ideology is frankly; dangerous.

Autism can be profoundly incapacitating. Etiologically speaking; autism involves immune-mediated incapacitation of the Microglia cells in the brain, resulting in impairment of synaptic pruning during the early childhood rapid brain development phase. The results of such can cause an increased brain volume of 5-10% by the age of 5 years old. These neuro-anatomical changes qualify Autism as brain damage.

Yes, sometimes a slightly tangled mass of synapses can produce "savant" like traits but at what cost? We are are not differently-abled, we ARE disabled. My child shares my savant traits of absolute pitch & Hyperlexia but he cannot toilet himself. I know autistic children going blind from repeated head banging (detached retinas), autistic children with feeding tubes because they can't swallow, autistic children dropping to the floor with seizures on a daily basis, autistic children literally chewing & biting their own skin off, children strapped to gurneys in the ER for weeks; because they are suffering puberty onset aggression & physically assaulting teachers & family, etc.

There is nothing magical & delightfully spectrummy about Autism. The less impaired (high functioning) are being exploited to designate their autism as an "identity". I know: I used to be one of them.

In the scientific community, there is an advantage to be gained by this. Trivialization reduces the demand for etiological answers. Science can play with puzzle pieces of "parental age" & "maternal immune activation" & even "single-gene" (despite that there are none) & avoid the reality that a quiet consensus determined that Autism IS; Immune-Mediated, Multifactorial Genetic, decades ago. The genes loaded the gun; an atypical immune response occurring around the age of 2 pulled the trigger.

Trivialization will lead to the reduction of research funding, support services & educational funding, just as a tsunami of autistic children age out of services.

You cannot allow this to happen by prioritizing the whims of the Neurodiverse. We must stop the epidemic rates, we must have GOOD research (not puzzle-playing), we must have GOOD services; or we are heading into crisis & the marginalization of our most vulnerable: Our severely autistic people. Please, for the love of God & our children; listen to me. I am autistic. I am the parent of a severely autistic child. My voice matters. The fact that he has no voice matters even more.

Stop. Trivializing. Autism.

Melvin Rodgers

Thank you for considering my question. I believe is important to share that I am a retired board certified chaplain, ordained minister, pastoral counselor and on the autism spectrum. I was formally diagnosed at the age of sixty four and I am currently sixty nine. After being diagnosed, I engaged the autism community, researched and attended conferences in an effort to better understand autism. My question is; why is there so little attention given to the issue of meaning as it relates to persons on the autism spectrum? .

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

Martha Gabler

RE: Gabler Family Comments for the October 31, 2021 Full Committee Meeting
Please respond to urgent need for evidence-based services for adults with ASD

Thank you for this opportunity to comment on issues the public would like to see highlighted in the IACC Strategic Plan for Autism Spectrum Disorder. We have a 25-year old son, [PII redacted], who has severe autism, is profoundly nonverbal, and has bouts of self-injurious behavior. He has the independent-living capacity of a 3 ½ year old child; he will require competent and compassionate care 24 hours/day for the rest of his life. We are extremely worried about his future because of the continued and catastrophic lack of services.

I respectfully endorse the two following statements from the 2016-2017 IACC Strategic Plan for Autism Spectrum Disorder and urge that these items be the priority of the IACC:

> "The purpose of the Strategic Plan is to focus, coordinate, and accelerate innovative research and foster development of *high-quality services* in partnership with stakeholders to *address the urgent questions and needs of people on the autism spectrum and their families*." (Page vii, *Emphasis added.*)

and,

> "*Sense of Urgency*: We will focus on *responding rapidly* and efficiently to the needs and challenges of people on the autism spectrum and their families."
> (Page vii, *Emphasis added*.)

Sadly, nothing has happened since this report was issued. No high-quality services that address the urgent needs of people on autism spectrum have appeared. This is despite the fact that we have excellent lifespan planning tools, such as Person-Centered-Planning, and excellent behavior management and skill building protocols via Applied Behavior Analysis (ABA). For decades, we have had all the methods and information we need, yet *no actual services*. And it is now five years later.

For many people this lack of actual services is purely a ho-hum issue, just a yawn, but for those of us in the trenches, living with and supporting an adult with severe autism, it is an issue of how to stave off the suffering and misery that lie in his future when we can no longer protect him.

Unfortunately, autism has been a ho-hum issue for a quarter of a century. My son is now 25 years old. He has experienced 25 years of trauma and neglect due to denial of evidence-based services. When he was diagnosed in 1998, we were stunned to find out that there were absolutely no services to support him and absolutely nobody cared. He was rejected, denied, demeaned, belittled, bullied, and basically shown the door everywhere we went. People could not get us off the phone or out on the street fast enough. We tumbled out of American life and into the "autism abyss."

An abyss is a deep, bottomless chasm that separates whoever is at the bottom from whoever is on top. For years we struggled on our own amidst the howling winds, rocks, and coyotes in the abyss; we built a little hovel and eventually made progress with our son. As time passed, we couldn't help but notice that the abyss was getting more and more crowded. When our son was born, the autism incidence rate was 1 in 500, by the time the 2016 birth cohort came along, the autism incidence rate was 1 in 54. There are a lot of families down here with us.

We also couldn't help but notice that people on top were finally realizing that there were a lot of people down here in the abyss. We saw big buildings go up along the rim at the top. These buildings had names like: Research, Laws, Regulations, and Policies. But nothing came down the cliff towards us. Then we saw more buildings go up: Awareness, Acceptance, Media, Inclusion, and Community. But still nothing came down the cliff.

We see all kinds of people milling around up there. Sometimes they lean over the edge and point down toward us. We shout up and ask for help for our children. They shrug and walk away. Nobody comes down to us. Nobody asks to see our children. Nobody offers to throw us a rope.

Respected committee members, my family will take care of our son while we are alive and able. But we will soon die or become too old to care for him. He needs competent, compassionate care, and he needs to be protected from ignorance and abuse. If anybody from up top came down and spent some time with him, they would see that he is a pretty nice guy and that he does his best but -- he can't survive on his own, especially down in the abyss.

Throw us a rope. Now. Please.

[PII redacted]

Russell Lehmann

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

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

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

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

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

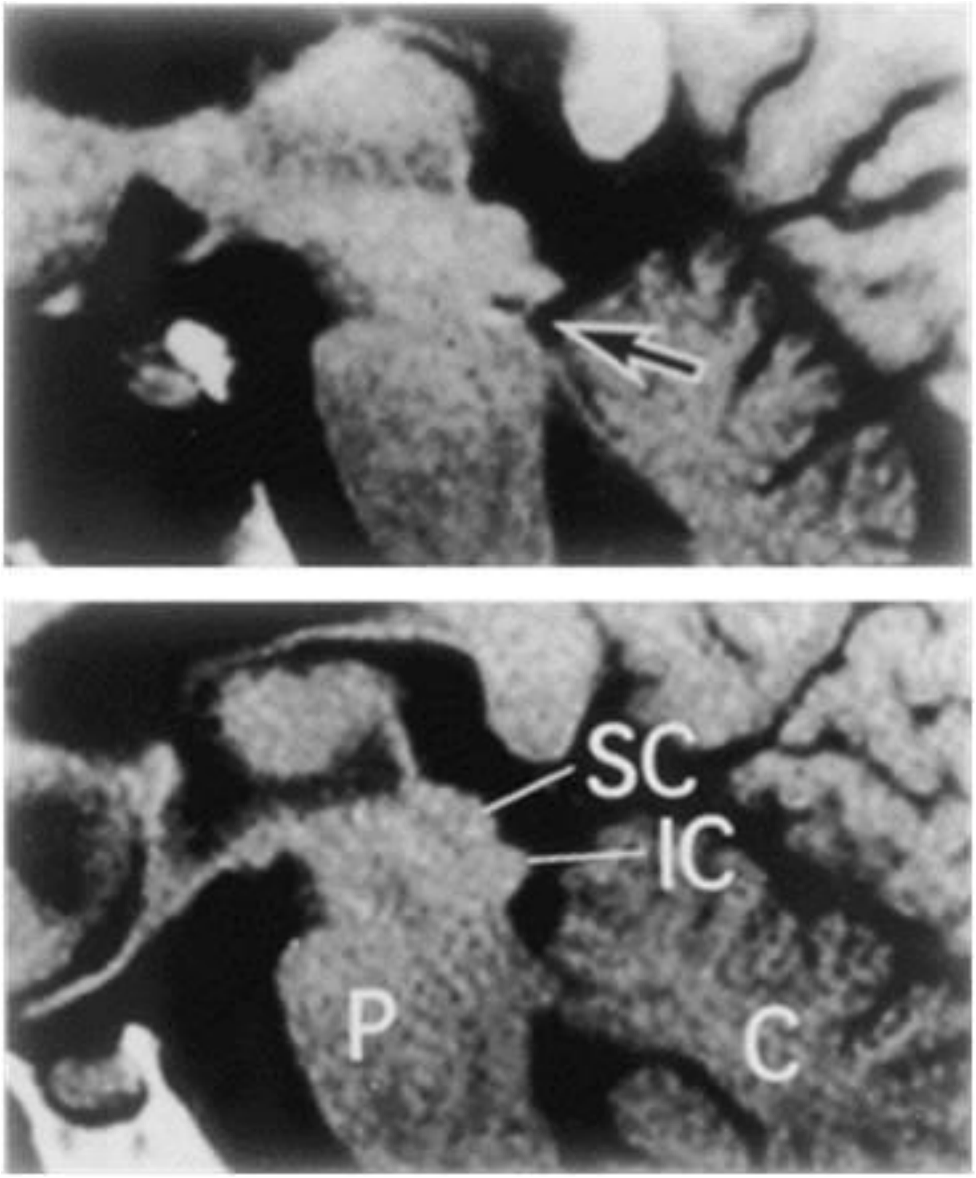
Brainstem Injury

Important in Parkinson's Disorder, and in Alzheimer Dementia &Autism?

WORD DEAFNESS & BRAINSTEM INJURY (inferior colliculus)

Following are citations to articles that reported loss of the ability to comprehend spoken language following injury of the inferior colliculi:

1. Howe JR, Miller CA. Midbrain deafness following head injury *Neurology.1975 Mar*;25(3):286-9.
2. Jani NN et al. Deafness after bilateral midbrain contusion: a correlation ofmagnetic resonance imaging with auditory brain stem evoked responses. *Neurosurgery. 1991 Jul*;29(1):106-8.
3. Nagao M et al. Haemorrhage in the inferior colliculus. *Neuroradiology.1992*;34(4):347.
4. Meyer B et al. Pure word deafness after resection of a tectal plate gliomawith preservation of wave V of brain stem auditory evoked potentials. *J Neurol Neurosurg Psychiatry. 1996 Oct*;61(4): 423-4.
5. Hu CJ et al. Traumatic brainstem deafness with normal brainstem auditoryevoked potentials. *Neurology 1997 May*;48 (5):1448–1451.
6. Johkura K et al. Defective auditory recognition after small hemorrhage inthe inferior colliculi. *J Neurol Sci. 1998 Nov 26*; 161(1):91-6.
7. Masuda S et al. Word deafness after resection of a pineal body tumor inthe presence of normal wave latencies of the auditory brain stem response.*Ann Otol Rhinol Laryngol. 2000 Dec*;109(12 Pt 1):1107-12.
8. Vitte E et al. Midbrain deafness with normal brainstem auditory evokedpotentials. *Neurology 2002 Mar 26*;58(6):970–3. -- 2 cases
9. Hoistad DL, Hain TC. Central hearing loss with a bilateral inferior colliculuslesion. *Audiol Neurootol 2003 Mar-Apr*; 8(2):111-223.
10. Musiek FE et al. Central deafness associated with a midbrain lesion. *J AmAcad Audiol 2004 Feb*; 15(2):133-151.
11. Pan CL et al. Auditory agnosia caused by a tectal germinoma. *Neurology.2004 Dec 28*;63(12):2387-9.
12. Kimiskidis VK et al. Sensorineural hearing loss and word deafness causedby a mesencephalic lesion: clinicoelectrophysiologic correlations. *Otol Neurotol. 2004 Mar*;25(2):178-82.
13. Pillion JP. Speech processing disorder in neural hearing loss. *Case ReportMed. 2012*, Article ID 206716. Epub 2012 Dec 6.

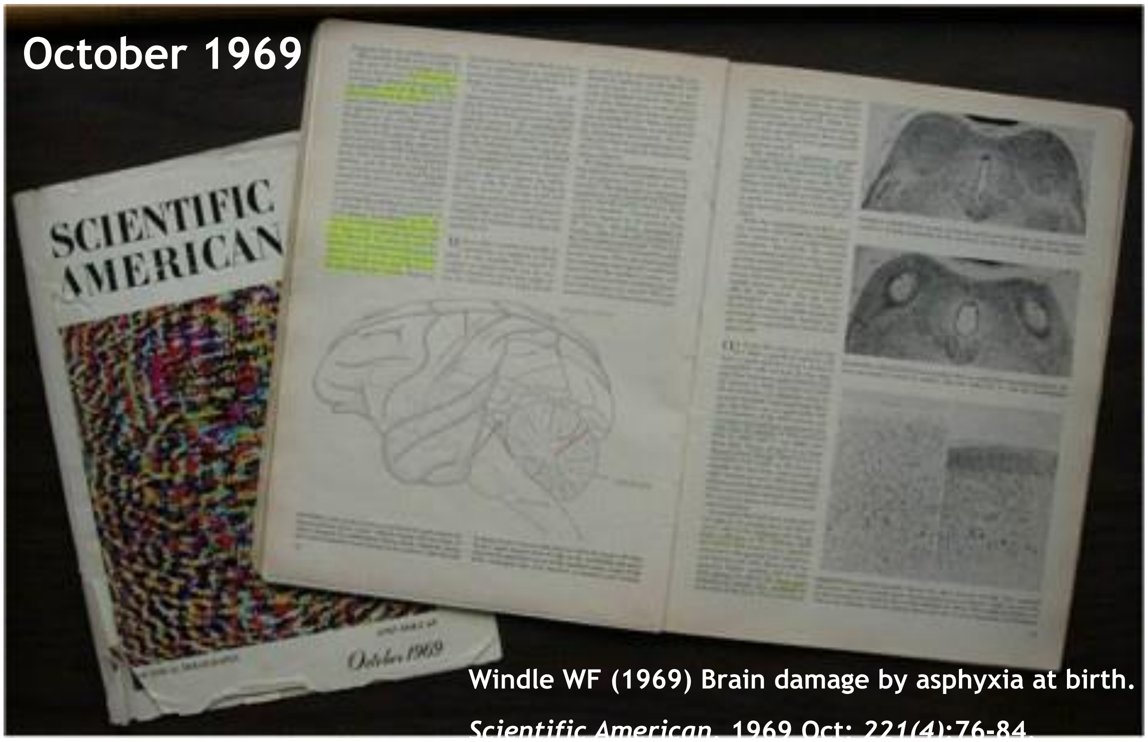


This injury occurred in a skiing accident, and was caused by impact from thecerebellar tentorium.

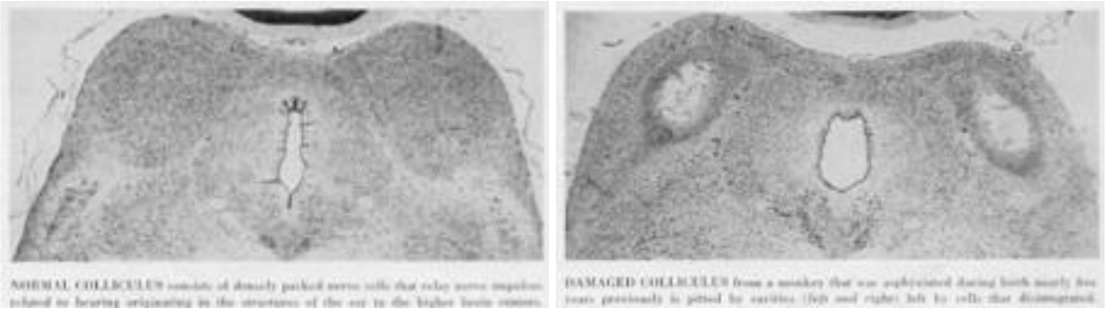
SC superior colliculus, IC inferior colliculus, C cerebellum, P pons

How much more serious would injury of theinferior colliculi be for an infant?

Damage of the inferior colliculi was found in monkeyssubjected to 6-8 minutes of asphyxia at birth.



Windle WF (1969) Brain damage by asphyxia at birth. *Scientific American*, 1969 Oct; *221(4)*:76-84.



The inferior colliculus: Normal appearance (left), ischemic damage (right). Pictures originally published in Faro and Windle, Exp Neurol. 1969 May;24(1):38-53, reproduced with permission.

- The October 1969 issue of the Scientific American arrived in our mailboxshortly after I entered graduate school in the fall of 1969.
- Asphyxia at birth caused damage in the midbrain auditory pathway. Thisseemed to explain what might have happened to (PII redacted), who had to beresuscitated after birth.

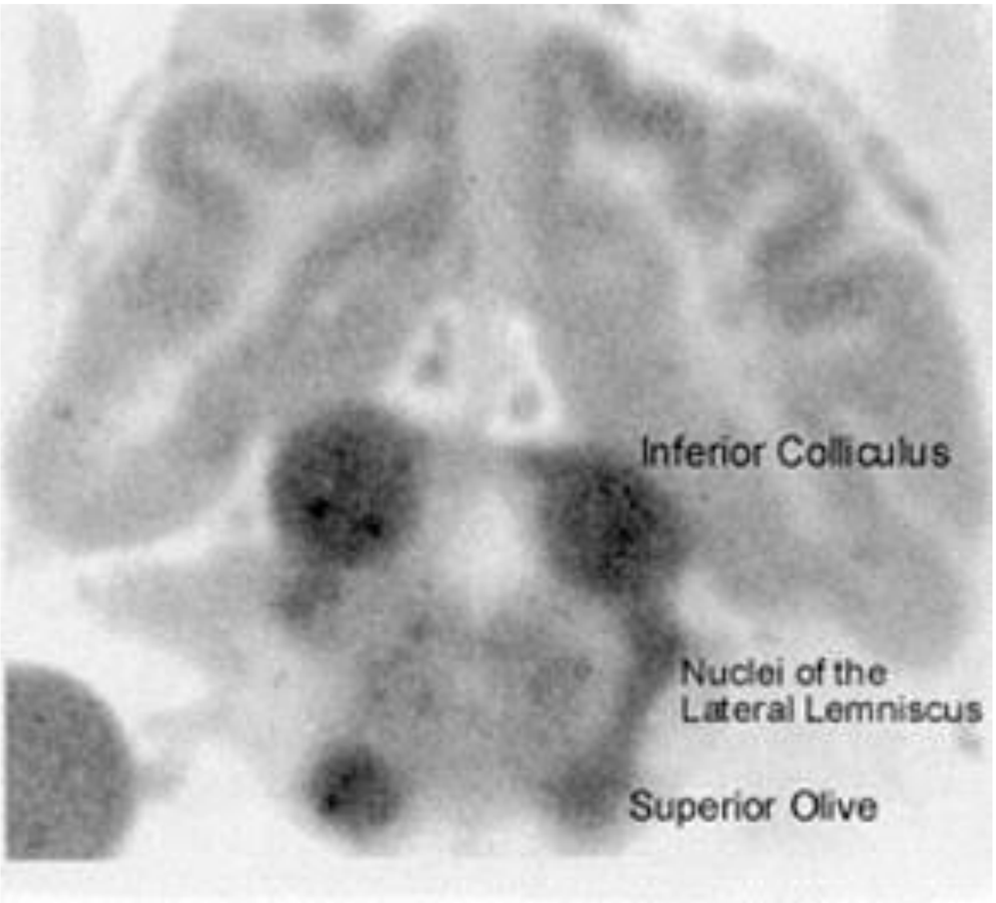
Damage of the inferior colliculi has also been found in human infants

- Gilles FH. Selective symmetrical neuronal necrosis of certain brain stem tegmental nuclei in temporary cardiac standstill [Abstract of presentation atthe American Association of Neuropathologists: 38th Annual Meeting. Atlantic City. New Jersey]. J Neuropathol Exp Neurol 1963 Apr; 22(2):318.
- Gilles FH. Hypotensive brain stem necrosis. Selective symmetrical necrosis of tegmental neuronal aggregates following cardiac arrest. Arch Pathol. 1969Jul;88(1):32-41.
- Norman MG. Antenatal neuronal loss and gliosis of the reticular formation,thalamus, and hypothalamus. A report of three cases. Neurology. 1972 Sep;22(9):910-6.
- Griffiths AD, Laurence KM. The effect of hypoxia and hypoglycaemia onthe brain of the newborn human infant. Dev Med Child Neurol. 1974 Jun;16(3):308-319.
- Grunnet ML et al. Brain changes in newborns from an intensive care unit.Dev Med Child Neurol. 1974 Jun;16(3):320-8.
- Schneider H et al. Anoxic encephalopathy with predominant involvement ofbasal ganglia, brain stem and spinal cord in the perinatal period. Report on seven newborns. Acta Neuropathol. 1975 Oct 1;32(4):287-98.
- Smith JF, Rodeck C. Multiple cystic and focal encephalomalacia in infancy and childhood with brain stem damage. J Neurol Sci. 1975 Jul;25(3):377-88.
- Leech RW, Alvord EC Jr, Anoxic-ischemic encephalopathy in the human neonatal period, the significance of brain stem involvement. Arch Neurol.1977 Feb;34(2):109-13.
- Roland EH et al. Selective brainstem injury in an asphyxiated newborn. AnnNeurol. 1988 Jan;23(1):89-92.
- Natsume J et al. Clinical, neurophysiologic, and neuropathological featuresof an infant with brain damage of total asphyxia type (Myers). Pediatr Neurol. 1995 Jul;13(1):61-4.

Damage of the inferior colliculi in a human infant (lower image)

From Leech RW, Alvord EC Jr, Anoxic-ischemic encephalopathyin the human neonatal period, the significance of brain stem involvement. Arch Neurol. 1977 Feb;34(2):109-13.

An autoradiogram picture showing distributionin the brain of a radioactive tracer 60 seconds after injection into the circulation of a cat



From: Kety SS. Regional neurochemistry andits application to brain function. In French, JD,ed, Frontiers in Brain Research. New York: Columbia University Press, 1962. pp 97-120.

With permission from Columbia University Press.

Reprinted in the *Bulletin of the New York Academy of Medicine*

1962 Dec;38:799-812, free online.

Nuclei of the auditory pathway have higher blood flow thanany other area of the brain, which explains why they are vulnerable to damage by asphyxia.

Brainstem Control Centers for Vital Functions?

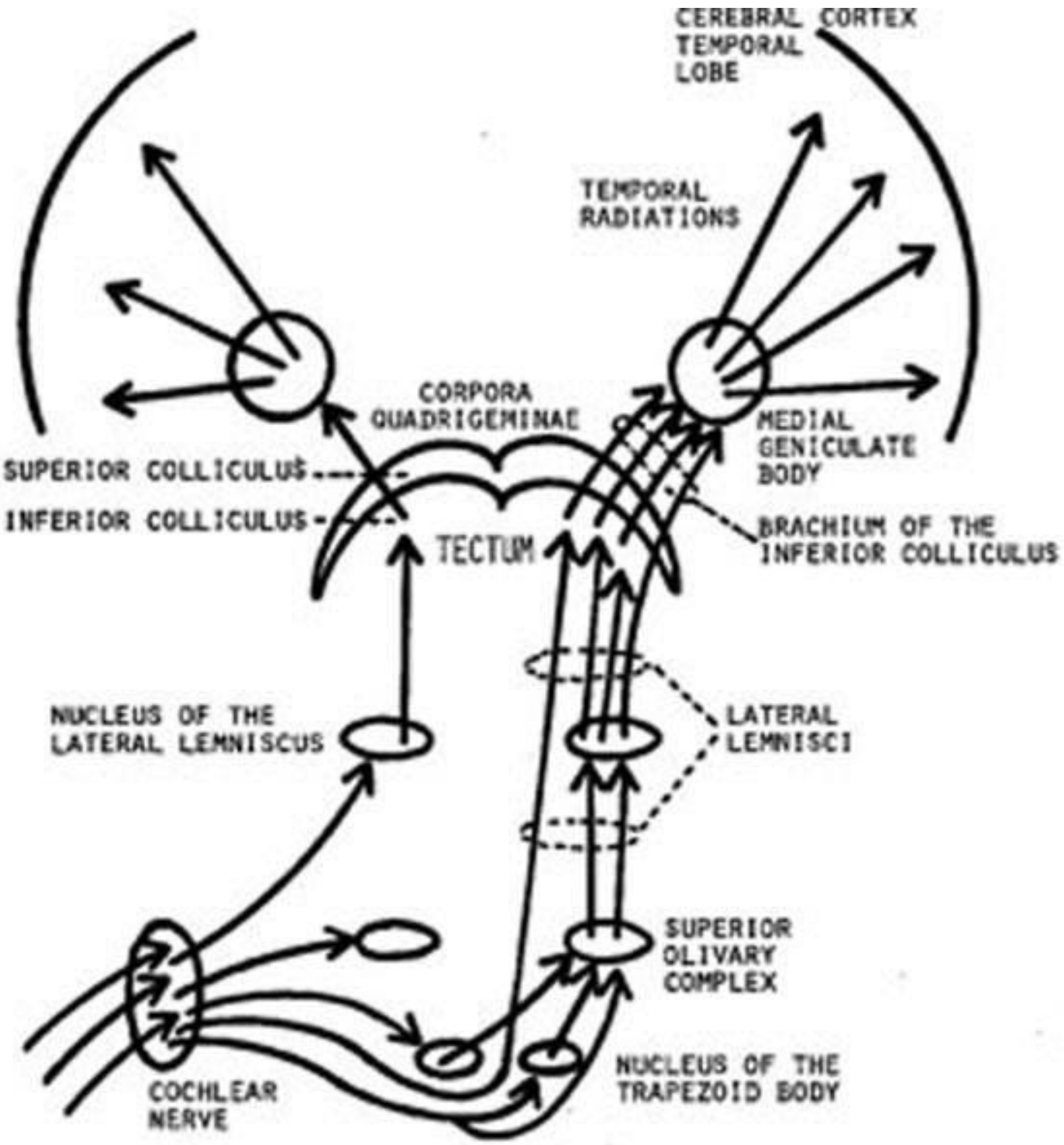
Also likely sites of high blood flow in the brainstem:

- Heart beat
- Breathing
- Intestinal peristalsis
- Sleep stages
- Reproductive drive
  -
  -
  -
- Alerting & orientation
- Seat of the conscious state?

These are the brainstem sitesaffected in drug addictions.

& their injury too often thecause of death.

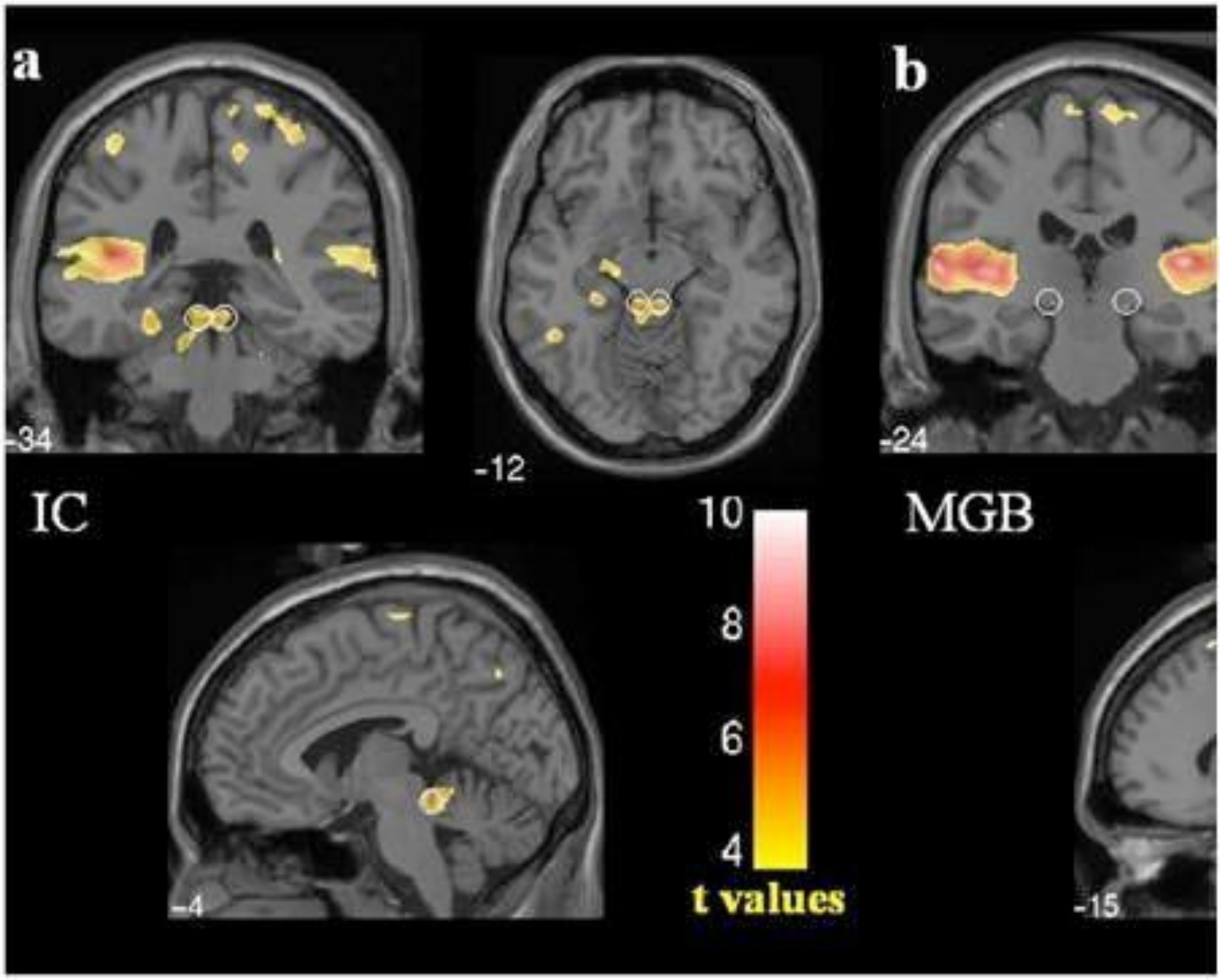
Auditory System Diagram



Question: Could brainstem impairment lead to developmentallanguage disorders?

From insults such as: Prenatal exposure to alcohol? Prenatalinfection? Asphyxia at birth? Or toxic exposures in infancy?

Functional MRI has revealed that thehighest blood flow in the human brain is also in the inferior colliculi.



(a) Note the 2 bright spots in the top images, & in the lower image, whichalso shows the location of the inferior colliculi (IC) in the roof of the midbrain, and (b) location of the medial geniculate bodies (MGB) in the thalamus.

Budd TW et al. Binaural specialisation in human auditorycortex: an fMRI investigation of interaural correlation sensitivity. Neuroimage, 2003 Nov;20(3):1783-94.

Email from TW Budd, first author of thepaper in Neuroimage, 2003:

Hi Eileen

Just a short note to thank you for your website regarding Autism and your son (PII redacted). As a novice cognitive neuroscientist I found it absolutely fascinating pointing to some very interesting links between hearing and autism which seems like a promising research area. I'm Australian and currently doing a postdoctoral research in the UK in hearing/fMRI....my realinterest though is in auditory temporal processing using brain imaging techniques like fMRI/ERP etc, and have some ongoing interest in learning disabilities.

I was just scanning the internet for info on techniques to more accurately locate the medial geniculate body from MRI scans (very difficult) and came across your info on the IC, which I have found is surprisingly active for sucha small structure in the fMRI data I am currently analyzing (brain stem structures being notoriously difficult to image for several reasons but primarily their size).

Not having much expertise in subcortical physiology, I wasn't aware of the oxygen hungry nature of IC relative to other auditory brainstem structures..which is probably why I can see it so clearly in this fMRI data. Also this current experiment examines the relationship between brain activity and inter-aural decorrelation (an important auditory cue in order to localise sound).....so to cut a long story short the info you posted has prompted more than just a few ideas about IC, fMRI activity/ auditory temporal processing and maybe even some research possibilities in autism etc. so THANK YOU VERY MUCH (and (PII redacted)!).

Best Regards

Dr Bill Budd
MRC Institute of Hearing Research
University Park. Nottingham NG7 2RD, United Kingdom

Early myelination of the auditory pathway

Myelin formation in brainstem auditory structures of a human fetus at 25gestational weeks.

ICol = inferior colliculus
Sol = superior olive

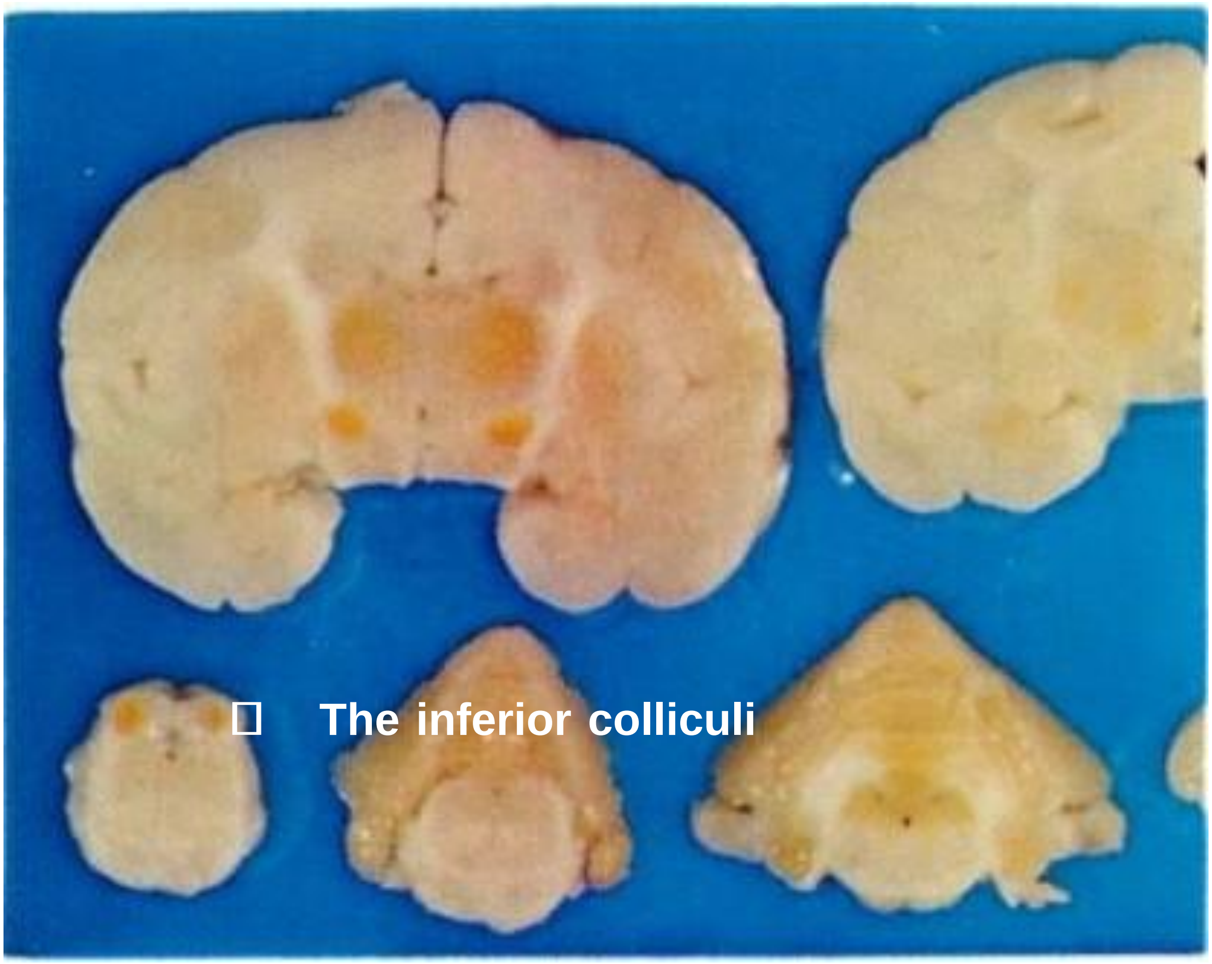
Yakovlev PI and Lecours A-R. The myelogenetic cycles of regional maturation of the brain. In A. Minkowski (Ed.), *Regional Development of the Brain in Early Life* (pp. 3-70).Oxford: Blackwell Scientific Publications, 1967, with permission from Blackwell ScientificPublishers.

- Nuclei in the brainstem auditory pathway are among the earliest centers of the brainto become fully myelinated.
- The auditory pathway is fully myelinatedbefore birth.
- Trophic neurotransmitters produced in brainstem auditory nuclei guide postnatalmaturation of the language areas of the cerebral cortex during infancy and early childhood.

Moore JK, Linthicum FH Jr. The human auditory system: a timeline of development.*Int J Audiol*. 2007 Sep;46(9):460-78.

Asphyxia at birth damages the blood-brain barrier.

This allows anything in the circulation to enter and cause further damage tobrainstem nuclei.



From: Lucey JF, Hibbard E, Behrman RE, Esquival FO, Windle WF. Kernicterus in asphyxiated newborn monkeys. Exp Neurol 1964 Jan; 9(1):43-58, with permission.

- Further investigation by Windle and his research team revealed that kernicterus (bilirubin staining) occurred only in the monkeys subjected to asphyxia, as seen in this picture.
- The pattern of damage caused by asphyxia is the same as that found ininfants who suffer kernicterus (bilirubin staining of nuclei in the auditory pathway and the basal ganglia).
- Injury caused by asphyxia at birth also injures the blood-brain-barrier and makes these brain centers of high blood flow even more vulnerable to infiltration of anything in the circulation.

Toxic substances that damage auditory nuclei

Alcohol

- Sullivan EV, Pfefferbaum A. Neuroimaging of the Wernicke-Korsakoffsyndrome. Alcohol Alcohol. 2009 Mar-Apr;44(2):155-65.
- Thomson AD et al. Wernicke's encephalopathy revisited. Translation of thecase history section of the original manuscript by Carl Wernicke 'Lehrbuchder Gehirnkrankheiten fur Aerzte and Studirende' (1881) with a commentary. Alcohol Alcohol. 2008 Mar-Apr;43(2):174-9.
- Vingan RD et al. Cerebral metabolic alterations in rats following prenatal alcohol exposure: a deoxyglucose study. Alcohol Clin Exp Res. 1986 Jan-Feb;10(1):22-6.
- Torvik A. Topographic distribution and severity of brain lesions in Wernicke's encephalopathy. Clin Neuropathol. 1987 Jan-Feb;6(1):25-9.

Mercury/ Lead

- Oyanagi K et al, The auditory system in methyl mercurial intoxication: aneuropathological investigation on 14 autopsy cases in Niigata, Japan. Acta Neuropathol. 1989;77(6):561-8.
- Bertoni JM, Sprenkle PM. Lead acutely reduces glucose utilization in therat brain especially in higher auditory centers. Neurotoxicology. 1988 Summer;9(2):235-42.

Herbicides/ Pesticides

- Cavanagh JB. Methyl bromide intoxication and acute energy deprivationsyndromes. Neuropathol Appl Neurobiol. 1992 Dec;18(6):575-8.
- Morgan DL et al. Neurotoxicity of carbonyl sulfide in F344 rats following inhalation exposure for up to 12 weeks. Toxicol Appl Pharmacol. 2004 Oct15;200(2):131-45.
- Cavanagh JB, Nolan CC. The neurotoxicity of alpha-chlorohydrin in rats and mice: II. Lesion topography and factors in selective vulnerability in acute energy deprivation syndromes. Neuropathol Appl Neurobiol. 1993 Dec;19(6):471-9.

More substances that damage auditory nuclei

Antibiotics

- Silverman WA et al. A difference in mortality rate and incidence of kernicterus among premature infants allotted to two prophylactic antibacterial regimens. Pediatrics. 1956Oct;18(4):614-25.

Chemotherapy drugs

- Husain K et al. Carboplatin-induced oxidative injury in ratinferior colliculus. Int J Toxicol. 2003 Sep- Oct;22(5):335-42.

"Recreational" substances

- Ferrington L, Kirilly E, McBean DE, Olverman HJ, Bagdy G,Kelly PA. Persistent cerebrovascular effects of MDMA and acute responses to the drug. Eur J Neurosci. 2006 Jul;24(2):509-19. Epub 2006 Jul 12.
- Kelly PA, Ritchie IM, Quate L, McBean DE, Olverman HJ.Functional consequences of perinatal exposure to 3,4- methylenedioxymethamphetamine in rat brain. Br J Pharmacol. 2002 Dec;137(7):963-70.
- Kelly PA, Ritchie IM, Sharkey J, McBean DE. Alterations in local cerebral blood flow in mature rats following prenatal exposure to cocaine. Neuroscience. 1994 May;60(1):183-9.

Nerve gas

- Scremin OU et al. (1991) Cerebral blood flow-metabolismcoupling after administration of soman at nontoxic levels.Brain Research Bulletin 26:353-6
- Shih TM, Scremin OU (1992) Cerebral blood flow and metabolism in soman-induced convulsions. Brain ResearchBulletin 28:735-42.

Auditory System Malformations in Autism:

- Rodier PM, Ingram JL, Tisdale B, Nelson S, Romano J.Embryological origin for autism: developmental anomalies of the cranial nerve motor nuclei. J Comp Neurol. 1996 Jun 24;370(2):247-61.
- Kulesza RJ, Mangunay K. Morphological features of themedial superior olive in autism. Brain Res. 2008 Mar 20;1200:132-7.
- Kulesza RJ Jr, Lukose R, Stevens LV. Malformation ofthe human superior olive in autistic spectrum disorders. Brain Res. 2011 Jan 7;1367:360-71.
- Lukose R, Schmidt E, Wolski TP Jr, Murawski NJ, Kulesza RJ Jr. Malformation of the superior olivarycomplex in an animal model of autism. Brain Res. 2011 Jun 29;1398:102-12.
- Smith A, Storti S, Lukose R, Kulesza RJ Jr. Structuraland Functional Aberrations of the Auditory Brainstemin Autism Spectrum Disorder. J Am Osteopath Assoc. 2019 Jan 1;119(1):41-50.
- Mansour Y, Mangold S, Chosky D, Kulesza RJ Jr. Auditory Midbrain Hypoplasia and Dysmorphology after Prenatal Valproic Acid Exposure. Neuroscience. 2019 Jan 1;396:79-93.

Evidence of damage to the auditory system caused by toxicsubstances has been published in many reports.

Note that the inferior colliculus is not routinely examined.

Word deafness (verbal auditory agnosia)

- Isabelle Rapin in her 1997 review article commented thatcomprehension and speech are always deficient in youngchildren with autism.
- She described this as a compromised ability to decode therapid acoustic stimuli that characterize speech.
- She noted that this is referred to as “verbal auditoryagnosia” or “word deafness,”
- and that children with verbal auditory agnosia understandlittle or no language. They fail to acquire speech and mayremain nonverbal.

“Comprehension and the communicative use of speech and gesture are always deficient, atleast in young children with autism.”

“A compromised ability to decode the rapidacoustic stimuli that characterize speech results in the most devastating language disorder in autism: verbal auditory agnosiaor word deafness.”

“Children with verbal auditory agnosia understand little or no language; they therefore fail to acquire speech and mayremain nonverbal.” [p97]

[image redacted]

- In my doctoral research, laboratory rat pups subjected toasphyxia exhibited growth retardation. This was clear-cutand males were more severely affected than females.
- This was a completely unexpected result.
- Monoamine metabolism was also affected differently inmales.

Dissertation Research:

Simon N (1975) Echolalic speech in childhood autism. Consideration of possible underlying loci of brain damage. *Archives of General Psychiatry.*1975 Nov;32(11):1439-46.

Simon N, Volicer L (1976) Neonatal asphyxia in the rat:
greater vulnerability of males and persistent effects on brain monoaminesynthesis. *Journal of Neurochemistry* 1976 May;26(5):893-900.

[redacted]

Note:

At the IACC meeting held Oct 17, 2018, during discussion of publiccomments Dr. Gordon made the following statement:

"... to investigate whether the inferior colliculus is involved preferentially in autism as opposed to other illnesses. It is not a matter of let's go look somestuff up. We are talking about a million dollar grant over five years. We are talking about a major investment of money. That means that if we pursue that hypothesis, there are other hypotheses that we cannot pursue." (transcript_101718.pdf, pp220-221, 226)

I hope my comments above provide a few reasons why my hypothesis mightbe worth funding.