

# **Written Public Comments**

**IACC Full Committee  
Meeting**

**July 26, 2017**

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**Marian Dar**

**July 26, 2017**

Thanks for your support of “As One” on Tuesday evening and the “UJA Hilibrand Symposium” on Wednesday -- two events that focused on the challenges and successes of living with autism at different life stages.

Both events brought different cultures and religions to the fore: autism does not discriminate, its impact is felt around the globe.

My now-adult son with autism was born in Asia to parents of 2 different nationalities and attended preschools where he was the sole American. When we were living in the Far East, my son was the requested friend and therapy partner of children who, with their mothers, had been abandoned by their traditional families.

It is hoped that this film, families and self-advocates depicted in a visual and personal way reduce the aloneness and despair of so many and increases the hope, knowledge and opportunities that now may be possible --

Thank you IACC,

Marian D

**Nathan Olson**

**July 26, 2017**

I am interested in potentially serving as a public member on the IACC (in the future. And also want to receive email updates of IACC. I also want to take this opportunity to say that when I came in APR 2016, and shared my story it was one of the highlights of my life and to this day I am so grateful to have had the opportunity.

I look forward to coming to a future meeting of the committee!, and sharing on the issue of collegiate admissions difficulty (and barriers) I recently faced. Thank you for giving me the respect and dignity as one who has autism. Its a memory I still think about and which indeed changed me as a person. It proved my knowledge and experience is WORTHY of itself and never have I forgotten that lesson learned back in Washington, D.C. in April 2016 at the meeting of the IACC I spoke to.

**Note: Profanity has been redacted in this document**

**John Best**

**July 26, 2017**

You [profanity redacted] are the most despicable group of psychopaths on the planet.  
John Best

**Noelle Aloe**

**July 26, 2017**

I am writing to you as a parent of a child with autism to request support for an extremely promising medical research program at UCSD School of Medicine led by Robert Naviaux, MD PhD. This program investigates the potential for an existing drug to treat the core symptoms of autism.

Dr. Naviaux's research suggests a biochemical cascade, the Cell Danger Response, underlies autism and that disrupting it with an existing drug, suramin, can treat autism's symptoms.

Dr. Naviaux has successfully demonstrated in peer-reviewed journals that suramin completely reversed both the behavioral and metabolic abnormalities seen in autism in TWO, unrelated mouse models both the MIA & Fragile X mouse models and is now testing this in a clinical trial with results to be published later this year. #NCT02508259 Despite this extremely promising start, Dr. Naviaux has been repeatedly turned down for NIH funding for suramin and his research is in jeopardy if he cannot receive additional grant funding.

I am asking the IACC to prioritize emergency funding in support of this highly promising program which could offer a 1) readily available treatment to mitigate the core symptoms of autism 2) dramatic advance in our understanding of the core BIOLOGY of autism.

While there are many worthy funding priorities in autism, the potential for a biological breakthrough that could lead to near-term treatments has to represent one of the highest priority investments that our government could make. Time is of the essence for families like ours living with autism,, and this offers real hope for the first time.

**Caryn Harb**

**July 26, 2017**

I am writing to you as a grandparent of a child with autism to request support for an extremely promising medical research program at UCSD School of Medicine led by Robert Naviaux, MD PhD. This program investigates the potential for an existing drug to treat the core symptoms of autism.

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**Joni Iqal**

**July 26, 2017**

I am writing to you as an aunt of a child with autism to request support for an extremely promising medical research program at UCSD School of Medicine led by Robert Naviaux, MD PhD. This program investigates the potential for an existing drug to treat the core symptoms of autism.

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**Lauren Harb**

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Hello,

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Sincerely,  
Lauren Harb

**Gina Jaber**

**July 26, 2017**

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**Marc Spilo**

**July 26, 2017**

I am writing to you as the uncle of a child with autism to request support for an extremely promising medical research program at UCSD School of Medicine led by Robert Naviaux, MD PhD. This program investigates the potential for an existing drug to treat the core symptoms of autism.

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**Helen Zhang**

**July 26, 2017**

Dear Sir/Mam,

We are Makeblock, a DIY robotics company specializing education products. The reason we reach you is that we are doing an educational program for Autism Children.

mBot - Autism Children Special Edition is an ideal entry-level programming educational robot kit design for autism children. It provides an entertaining learning experience for autism children by integrating robots and programming, and eventually through the program, they are able to become a successful programmer!

Many technology companies that need to perform high-load, high-repetition tasks, such as identifying data patterns or repairing software vulnerabilities (such as McNabb), autistic patients will be good employees. At present, companies such as Microsoft Corp., SAP SE, Freddie Mac and HP Australia are planning to hire autistic patients.

**Kellen Smith**

**July 26, 2017**

I'm reaching out to you today as someone responsible for disseminating autism resources to families and individuals. Given that studies have shown upwards of 80% of young people diagnosed with autistic spectrum disorder (and that number is equally bad for adults) aren't getting the necessary amount of sleep, my team over at the Tuck Sleep created a new guide to help.

Our guide covers everything from a comprehensive overview of ASD, how it affects sleep, expert sleep management information for people with ASD and much more.

Check out our guide here: <https://www.tuck.com/autism-spectrum-disorder-and-sleep/>

We're trying to raise awareness and need your help in this effort. We've been lucky enough to be featured on NPR and TedEd, as well as referenced by organizations like the ADAA and the American Sleep Apnea Association to name a few and were wondering if you would consider utilizing our resources as well.

Best,  
Kellen

**Stelios Georgiades, PhD**

**July 26, 2017**

I would like to bring to your attention an editorial perspective we wrote on the topic of autism heterogeneity over time:

- Scientific publication: <http://onlinelibrary.wiley.com/doi/10.1111/jcpp.12690/epdf>
- Lay article: <https://spectrumnews.org/opinion/viewpoint/tracing-autisms-trajectories-help-explain-diversity/>
- Research snapshot TEDx: <https://www.youtube.com/watch?v=lxCpR7AzOWQ&list=PL6YxDLuEsji7ZmSibAwfLRYtUvVV8HVxR&index=10> )

We think that the ideas discussed in this editorial may be of interest to the IACC.

Happy to provide additional information and will make sure to keep you posted on our progress as we empirically try to test the idea of chronogeneity using our longitudinal datasets.

Best wishes for a productive meeting,  
Stelios

**Stelios Georgiades, PhD**

Assistant Professor, Psychiatry and Behavioural Neurosciences  
Co-Director, McMaster Autism Research Team (MacART)  
Scientist, Offord Centre for Child Studies  
McMaster University & McMaster Children's Hospital  
[www.macautism.ca](http://www.macautism.ca) | [www.offordcentre.com](http://www.offordcentre.com)

**Note: Profanity has been redacted in this document**

**Anonymous**

**July 26, 2017**

Why won't you lying [profanity redacted] tell the truth about how mercury in vaccines mangles brains into autism? How long do you [profanity redacted] think you can keep lying about this? Thank you.

**Jamie Juarez**

**July 26, 2017**

I would like to meet with someone regarding my 20 years of research while I collaborate with USC, UCLA, UCI, and Stanford on my study please. Attached is my son with severe autism, grand mal seizures book that is the training manual as Whistleblowers in the State of California we used to settle over 30 million in wrongful denials of children that STILL CONTINUES TODAY by California Department of Education and local law enforcement.

<http://amzn.to/2uvJ2NN>



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

**Eileen Nicole Simon, PhD, RN**

**July 26, 2017**

Eileen Nicole Simon, PhD, RN  
[PII redacted]  
Cambridge MA  
[PII redacted]

Following are comments I would like to hear discussed by members of the IACC, at the meeting to be held on July 26, 2017:

### **1. Please Discuss**

When parents submit comments for IACC meetings, why are they only summarized and not discussed? Members of the committee are asked if they want to discuss our comments, but most are ignored.

Can discussion of all topics summarized be required, and moderated by a committee member familiar with each topic? Can more time be scheduled for discussion of public comments? If not, why?

### **2. Childhood Disability**

Can brain injury in the disabling form of autism be made a priority for discussion? The purpose of the IACC was to investigate the huge increase in autism first noticed in the 1990s. Neurological impairments are evident from early childhood. They cannot be overlooked, by parents or pediatricians. Language disorder is the most serious affliction of autistic children, and it prevents normal intellectual development.

Language is the defining feature of the human species.

Aphasia following stroke or head injury in adults is rightly recognized as a tragic debilitating condition. No one tries to minimize the seriousness of aphasia, and its sites of damage in the brain have long been known [1, 2].

The language disorder of autistic children is even more debilitating than aphasia, and denying brain damage in autism is absurd. Language disorder cannot go unnoticed until late childhood, adolescence, or early adulthood. Euphemistic speculations about "social disorder" or impairment of "shared interest" are not helpful.

No! Autism has not always been here, and only recently noticed.

The neurological signs of autism are (1) language disorder, (2) repetitive movements, and (3) diminished environmental awareness. Autism diagnosed in early childhood, on the basis of neurological signs, must be discussed at IACC meetings. I will continue to ask for this focus.

#### **References**

[1] Broca, P (1861). Remarques sur le siège de la faculté du langage articulé, suivies d'une observation d'aphémie (perte de la parole). *Bulletins et Mémoires de la Société Anatomique de Paris*, 36, 330–357.

[2] Wernicke, C (1874) *Der aphasische Symptomen-complex*. Franck and Weigert, Breslau.

### **3. Battle Over?**

I posted my website [conradsimon.org](http://conradsimon.org) 17 years ago (April 2000) to discuss research relevant to the brain disorder in autism, and especially the language disorder. I pointed out that damage of the inferior colliculus (plural colliculi) was discovered in monkeys subjected to asphyxia at birth [1]. The inferior

colliculi are relay centers in the midbrain auditory pathway, and I discussed why I thought they might be essential for language development.

Within a few months, I received email from many midwives asking how soon after birth my son's umbilical cord was clamped. Clearly it was clamped before he began breathing, and I can never forget the anxiety I felt as a team of people on the other side of the delivery room worked to resuscitate him.

Another correspondent was Dr. George Malcolm Morley, a retired obstetrician who had become outspoken against the protocol adopted in the mid-1980s to clamp the umbilical cord immediately after birth [2].

I received an email recently (May 4, 2017) from Dr. Morley informing me that the battle is over, "The American College of Obstetricians and Gynecologists (ACOG) has a 'practice opinion' that all births (term & pre-term) should have clamping delayed at least one to three minutes. It took them 20+ years to find out! Birth statistics should show a large drop in cases of neonatal encephalopathy, and soon a drop in reported cases of autism."

Yes! I found ACOG committee opinion 684 in Google. This comes two years after being adopted by the Royal College of Obstetricians and Gynaecologists (RCOG) in the UK. Hopefully five years from now there will be a decreased need for special education.

#### **References**

[1] Windle, WF "Brain Damage by Asphyxia at Birth". Scientific American 1969 Oct; 221(4):76-84.

[2] Morley GM., Cord Closure: Can Hasty Clamping Injure the Newborn?" OBG MANAGEMENT July 1998, 29-36.

#### **4. Auditory Processing**

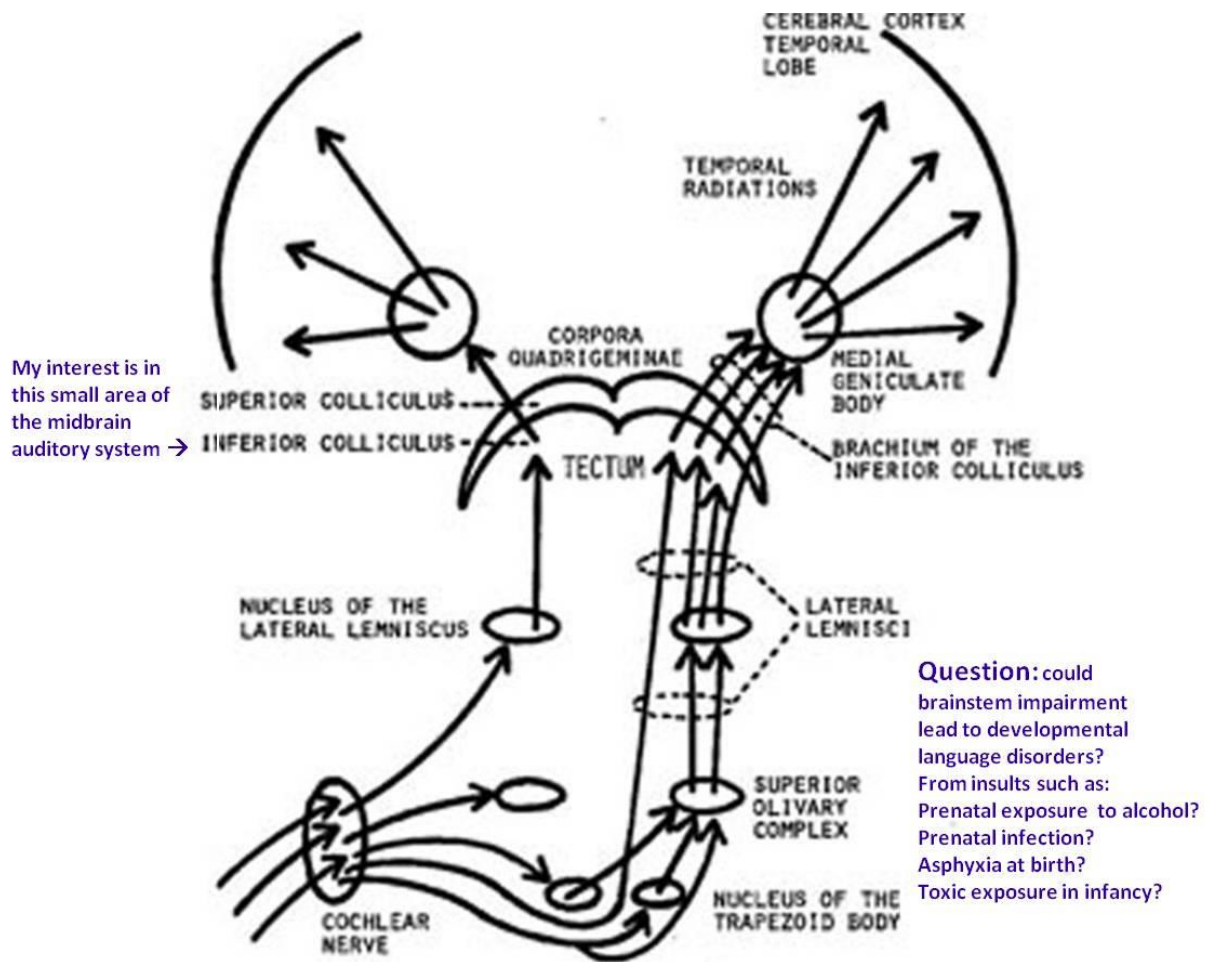
I have repeatedly tried to point out that damage of the inferior colliculus (plural colliculi) was discovered in monkeys subjected to asphyxia at birth [1], and discussed why I think these tiny midbrain nuclei might be essential for language development. Complications at birth have been reported more often in cases of autism than any other environmental factor; see my comment #3 (p28) submitted for discussion at the IACC meeting on October 26, 2016.

I drew the diagram below for my doctoral dissertation [2]. Note the cochlear nuclei, trapezoid body, superior olivary complex, lateral lemniscal tracts, inferior colliculus, brachium of the inferior colliculus, medial geniculate bodies, and auditory radiations to the temporal lobes. Within this circuit, distinctive features of language must be extracted from all other sounds arriving at the ears.

Superior olive damage has been described in brains from autistic patients [3, 4]. Superior olive damage has also been caused by administration of valproic acid (Depakote) to laboratory rats [5].

Signals from the superior olives arrive at the inferior colliculi via the lateral lemniscal tracts. Severing the lateral lemniscal tracts in cats led to dramatic behavioral changes described as strikingly reminiscent of autistic children [6].

Components of the auditory pathway are metabolically more active than any other region of the brain [7]. Can members of the IACC discuss auditory system injury, and recommend it as a priority for research?



## References

- [1] Windle WF. Brain damage by asphyxia at birth. *Sci Am.* 1969 Oct;221(4):76-84.
- [2] Simon EN. *Long-term Effects of Neonatal Asphyxia in the Rat.* Doctoral Dissertation, Boston University, Boston MA, 1974. available at <http://disexpress.umi.com/dxweb> (UMI Publication Number 7505520).
- [3] Rodier PM, et al. Embryological origin for autism: developmental anomalies of the cranial nerve motor nuclei. *J Comp Neurol.* 1996 Jun 24;370(2):247-61.
- [4] Kulesza RJ Jr, et al. Malformation of the human superior olive in autistic spectrum disorders. *Brain Res.* 2011 Jan 7;1367:360-71.
- [5] Lukose R, et al. Malformation of the superior olivary complex in an animal model of autism. *Brain Res.* 2011 Jun 29;1398:102-12.
- [6] Sprague JM et al. Attentive, affective, and adaptive behavior in the cat. Sensory deprivation of the forebrain by lesions in the brain stem results in striking behavioral abnormalities. *Science* 1961 Jan 20; 133(3447):165-173.
- [7] Sokoloff L et al. The [14C]deoxyglucose method for the measurement of local cerebral glucose utilization: theory, procedure, and normal values in the conscious and anesthetized albino rat. *J Neurochem.* 1977 May;28(5):897-916.

## 5. Speech Understanding

In Comments I submitted for the IACC meeting in April 2017, I cited Isabelle Rapin, who pointed out that "auditory agnosia" underlies language problems of some autistic children [1]. These are children who are able to hear, but unable to identify distinctive features of spoken language.

Agnosia is often described as reaching into your pocket but being unable to recognize which objects are your keys, coin purse, or dollar bills. By the second decade of life we outgrow the ability to learn a new language "by ear." Are we all victims of a progressive auditory agnosia, possibly due to a diminished ability to detect syllable boundaries in a foreign language?

The only site of visible brain damage in monkeys subjected to asphyxia at birth was in the inferior colliculi [2]. We cannot follow language development in monkeys, but areas of the temporal and frontal lobes did not follow a normal course of maturation in the monkeys subjected to asphyxia at birth.

In my presentation to the IACC on November 21, 2008 (nearly nine years ago), I cited several case reports of people who lost the ability to comprehend spoken language following injury to the inferior colliculi [3-16]. I cited these case reports again in April 2017, as I had for many previous IACC meetings. How much more serious this injury should be for an infant, who has not yet begun to learn to speak.

If this evidence is not important for understanding the language disorder of autistic children, please discuss why not?

**References:**

- [1] Rapin I. Verbal auditory agnosia in children. *Dev Med Child Neurol*. 1988 Oct;30(5):685.
- [2] Faro MD, Windle WF. Transneuronal degeneration in brains of monkeys asphyxiated at birth. *Exp Neurol*. 1969 May;24(1):38-53.
- [3] Joswig H, et al. Reversible pure word deafness due to inferior colliculi compression by a pineal germinoma in a young adult. *Clin Neurol Neurosurg*. 2015 Dec;139:62-5. 31
- [4] Poliva O, et al. Functional Mapping of the Human Auditory Cortex: fMRI Investigation of a Patient with Auditory Agnosia from Trauma to the Inferior Colliculus. *Cogn Behav Neurol*. 2015 Sep;28(3):160-80.
- [5] Kimiskidis VK, et al. Sensorineural hearing loss and word deafness caused by a mesencephalic lesion: clinicoelectrophysiologic correlations. *Otol Neurotol*. 2004 Mar;25(2):178-82.
- [6] Pan CL, et al. Auditory agnosia caused by a tectal germinoma. *Neurology*. 2004 Dec 28;63(12):2387-9.
- [7] Musiek FE, et al. Central deafness associated with a midbrain lesion. *J Am Acad Audiol*. 2004 Feb;15(2):133-51
- [8] Hoistad DL, Hain TC. Central hearing loss with a bilateral inferior colliculus lesion. *Audiol Neurootol*. 2003 Mar-Apr;8(2):111-3.
- [9] Vitte E, et al. Midbrain deafness with normal brainstem auditory evoked potentials. *Neurology*. 2002 Mar 26;58(6):970-3. (2 cases)
- [10] Masuda S, et al. Word deafness after resection of a pineal body tumor in the presence of normal wave latencies of the auditory brain stem response. *Ann Otol Rhinol Laryngol*. 2000 Dec;109(12 Pt 1):1107-12.
- [11] Johkura K. et al. Defective auditory recognition after small hemorrhage in the inferior colliculi. *J Neurol Sci*. 1998 Nov 26;161(1):91-6.
- [12] Hu CJ, Chan KY, Lin TJ, Hsiao SH, Chang YM, Sung SM. Traumatic brainstem deafness with normal brainstem auditory evoked potentials. *Neurology*. 1997 May;48(5):1448-51.
- [13] Meyer B, et al. Pure word deafness after resection of a tectal plate glioma with preservation of wave V of brain stem auditory evoked potentials. *J Neurol Neurosurg Psychiatry*. 1996 Oct;61(4):423-4. Free PMC Article
- [14] Nagao M. et al. Haemorrhage in the inferior colliculus. *Neuroradiology*. 1992;34(4):347.

[15] Jani NN, et al. Deafness after bilateral midbrain contusion: a correlation of magnetic resonance imaging with auditory brain stem evoked responses. *Neurosurgery*. 1991 Jul;29(1):106-8; discussion 108-9.

[16] Howe JR, Miller CA. Midbrain deafness following head injury. *Neurology*. 1975 Mar;25(3):286-9.

## **6. Male Metabolism**

I submitted the comment below for the IACC meeting in October 2016 on greater vulnerability of males. I resubmitted it again for discussion at the meeting in January 2017. Once again, can I ask why simple explanations are not considered before elaborate new plans for research are proposed?

Metabolism is higher in males than females. Muscle strength is greater in males than females. Women do not compete with men in most sports, and separate records are kept for running, swimming, and skiing competitions. Even events like figure skating, gymnastics, and springboard diving are separate for men and women.

During the process of birth, the aerobic needs of males are greater than females. I remember this being part of a discussion of cooling caps for infants who suffered anoxic-ischemic encephalopathy during birth, at a meeting of the Fetal and Neonatal Physiological Society I attended in 2006 (<http://www.inferiorcolliculus.org/fnps.html> ).

The 5:1 male to female ratio of children who develop autism has long been discussed in the medical literature. Following are a few citations on this subject, including my own dissertation research back in 1976:

[1] Dunn L et al. Gender specific intrapartum and neonatal outcomes for term babies. *Eur J Obstet Gynecol Reprod Biol*. 2015 Feb;185:19-22.

[2] Diepeveen FB et al. Among perinatal factors, only the Apgar score is associated with specific language impairment. *Dev Med Child Neurol*. 2013 Jul;55(7):631-5.

[3] Nagy E et al. Sex-differences in Apgar scores for full-term neonates. *Acta Paediatr*. 2009 May;98(5):898-900.

[4] Simon N, Volicer L. Neonatal asphyxia in the rat: greater vulnerability of males and persistent effects on brain monoamine synthesis. *J Neurochem*. 1976 May;26(5):893-900.

Thank you for the opportunity to submit written comments.

The Autistic Self Advocacy Network (ASAN) remains extremely concerned about how funding for autism research is allocated. The IACC's 2013 Autism Spectrum Disorder Research Portfolio Analysis Report reports that only 2% of all federal funding in 2013 went to research on the effectiveness of and access to services and supports (research that addresses the IACC's 2013 Strategic Plan Question 5, "Where Can I Turn for Services?") and only a fraction---1%--- went to research into lifespan issues (Question 6).

Lifespan issues addressed by Question 6 include everything from research into the effectiveness of all employment supports to the impact of services received during childhood on the quality of life of autistic adults. It is absolutely critical that we have research on these subjects available to us, and yet this research is consistently underfunded. By contrast, 32% of all federal autism research funding in 2013 went to research on the biology and causation of autism. This gross imbalance in research funding directly harms autistic people and does not serve the many very real needs of our community. ASAN implores the IACC to prioritize lifespan issues in the anticipated 2016-2017 update to its Strategic Plan.

ASAN appreciates the inclusion of research in the 2016 Summary of Advances that addresses substantive issues of concern to autistic people, particularly the study on whether access to Medicaid home and community based services (HCBS) waivers improves our health. The work of the IACC, and the funding of autism research that supports autistic people alive today, is more important than ever.

### **Lifespan and Quality of Life**

The IACC regularly presents studies in its Summaries of Advances which show that autistic people have much higher mortality and much higher rates of co-occurring physical and mental disabilities than non-autistic people.<sup>1</sup> The authors of one of the studies suggested that, because autistic people tend to have co-occurring psychiatric disabilities, one of the reasons we may have higher mortality is because people with psychiatric disabilities consistently get poorer quality care for their co-occurring physical conditions.<sup>2</sup> The study emphasized that, since "most individuals living with ASD today are adults, the support and interventions need to extend beyond paediatric and early education."<sup>3</sup> Given this, ASAN is discouraged to see that research funding is still disproportionately focused on early interventions in autistic children and pharmacological treatments for autistic traits. A lack of *disability-competent* primary and preventive care could also be responsible for the increased mortality from co-occurring conditions that we experience. There are very few primary care providers that are able to understand and effectively treat persons with complex medical conditions, psychiatric disabilities, and developmental disabilities.

ASAN encourages the IACC to emphasize research that investigates which treatments for co-occurring physical and mental disabilities work best for autistic people. ASAN has found that many treatments (such as medications commonly used to treat a specific psychiatric disability) may have different effects

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<sup>1</sup> Croen, L.A. et. al. (2015). The health status of adults on the autism spectrum, *Autism* 19(7), 814-23; Hirvikoski T, Mittendorfer-Rutz E, Boman M, Larsson H, Lichtenstein P, Bölte S. (2016). Premature mortality in autism spectrum disorder, *Br J Psychiatry*. 208(3):232-8.

<sup>2</sup> Hirvikoski T, Mittendorfer-Rutz E, Boman M, Larsson H, Lichtenstein P, Bölte S. (2016). Premature mortality in autism spectrum disorder, *Br J Psychiatry*, 208(3):232-8.

<sup>3</sup> *Id.*

on us than they do on non-autistic people. Research which shows us what we can do to best manage these conditions has the potential to vastly improve our quality of life.

## **Supports and Services**

Research on services and supports continues to be underfunded. Research into programs that promote community inclusion, for instance, represented only 2% of the total funding for services and supports research. We appreciate the increased focus on studies that examine the effectiveness of the supports and services available (18% of funding) and studies on the federal programs that cover services and supports for (as indicated in the articles selected for the 2016 Summary of Advances). This is research is even more critical at a time when many federal programs are threatened with significant budget cuts. However, if services and supports research continues to be underfunded it is unlikely that we will see the significant improvements in the quality of services and supports that our community needs to live fully independent and productive lives in the future.

ASAN urges the IACC to continue to prioritize research into the employment supports that allow autistic adults of all abilities to be gainfully employed in the community. The growing focus on community-based supports that help autistic adults navigate transitions into postsecondary education and employment, as indicated by the Portfolio Analysis and the articles selected in the 2016 Summary of Advances, is particularly promising. As the GAO articulated in a May 2017 study, the IACC should coordinate with the federal departments that typically provide transition services or financial assistance to youth with disabilities (such as the Department of Labor and the Department of Housing and Urban Development) in order to develop best practices.<sup>4</sup> This important work will remain undone if employment support research remains only a small part of what is already extremely limited research funding for lifespan issues in autism.

ASAN reiterates our interest in research which examines assistive technology used to improve the independence and communication ability of autistic people. ASAN strongly encourages the IACC to advocate for research studies similar to five of those listed under Question 4 of the Portfolio Analysis, which examine the impact of access to AAC devices on the quality of life of nonverbal autistic adults. We also encourage the IACC to invest in studying modern-day smart technology such as smart homes and other smart devices, which can reduce the use of aides and could make community living easier and more affordable for autistic people in the future.

We could also benefit a great deal from research that examines how to make commonly-used internet services (such as Google Suite and Facebook) more cognitively accessible to us. Full access and use of the Internet has become a critical component of independence for all people, and yet people with developmental disabilities are often unable to make use of the technology due to either accessibility barriers or stigma. The President's Committee for People with Intellectual Disabilities (PCPID) recommended that federal funding for cognitively accessible interfaces for mainstream technology should be greatly expanded.<sup>5</sup> The IACC should ensure that future cognitively accessible interfaces are also accessible to autistic people.

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<sup>4</sup> U.S. Government Accountability Office. (2017, May). Youth with Autism: Federal Agencies Should Take Additional Action to Support Transition Age Youth (Publication No. GAO-17-352). Retrieved from: <https://www.gao.gov/assets/690/684484.pdf>

<sup>5</sup> President's Committee for People with Intellectual Disabilities. (2015). Leveling the Playing Field: Improving Technology Access and Design for People with Intellectual Disabilities. Retrieved from: <https://www.acl.gov/sites/default/files/programs/2017-03/PCPID-2015-Report-to-President.pdf>

## **Diagnostic Disparities and Prevalence**

People of color may be diagnosed at a higher rate than non-Hispanic white children due to implicit and explicit bias, not just due to a lack of knowledge of autism in minority communities. Researchers and clinicians also often lack training on how to identify autistic traits in these populations. Autistic minority children, including women and girls, are typically identified as having another disability well before they are diagnosed with autism, such as attention deficit disorder or conduct disorder.<sup>6</sup> More research is needed on why these diagnostic disparities occur and on what practices increase the accuracy of diagnostics. Research is also needed on how to identify autism in adolescents and adults, who may go undiagnosed for years due in part to these disparities.

## **IACC 2016-2017 Strategic Plan**

We are pleased that IACC intends to revise its Strategic Plan for re-release in Summer 2017. As we noted in our April 2016 comments, ASAN has significant concerns about the Questions the IACC uses to direct research prioritization under its Strategic Plans. The current Questions (as reflected in IACC's 2013 Strategic Plan) are unnecessarily and excessively focused on the prevention and potential causes of autism.

We propose that IACC create new Questions that do not suggest that autism should be “cured” or “prevented,” but instead focus on researching: the services and supports we need to live full and independent lives; the diagnostic and other disparities in service access among autistic people; access to effective disability-competent treatment for our co-occurring medical conditions and psychiatric disabilities; how autism presents across the lifespan and what services are most effective at what times, and other concerns of autistic people.

## **Working with the Autistic Community**

The allocation of autism research funding has a real impact on the lives of autistic people. For that reason, ASAN believes that this funding should be allocated with the input and involvement of the autistic community. We urge the IACC to promote the involvement of autistic adults in grant review and other aspects of the research process, including through the use of Participatory Action Research models. We also urge the IACC to collaborate further with the Patient-Centered Outcomes Research Institute (PCORI), which nationally promotes research into the subjects of greatest concern to patients and people with disabilities.

Again, ASAN appreciates the opportunity to provide comments on the important issue of autism research. For more information on our comments, please contact Julia Bascom, Executive Director of ASAN, at [jbascom@autisticadvocacy.org](mailto:jbascom@autisticadvocacy.org).

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<sup>6</sup> David S. Mendell et. al. (2009). Racial/Ethnic Disparities in the Identification of Children with Autism Spectrum Disorders, *Am. J. Public Health*, 99(3): 493–498. doi: [10.2105/AJPH.2007.131243](https://doi.org/10.2105/AJPH.2007.131243).



**My statement and public request of the IACC board is once again, being repeated to address my previous letters from the last THREE meetings (that have gone unaddressed).**

**I have a 5-½ year old moderate / severe ASD son with tics and PANs.**

**1.) Speak with parents more and focus research on their feedback. There is truth in the herd.**

I request that the IACC facilitates a survey the parents of ASD children in the United States. I request that this survey is over 50 but under 100 questions pertaining an ASD child and overseen and co-managed by a third party foundation, or organization for Autism that is recommended and voted on by the public. I request that the IACC proposes and allocates funding for this study in the fiscal year of 2016 to be published no later than the spring of 2017.

Over the past 28 months since my son's official diagnosis we have invested all free time, over \$100,000 out of pocket on ABA, OT, Speech, accessories, learning aids, medical tests and vitamins. In addition to 28-32 hours a week of ABA in-home he is also attending a special education class 5 days a week, 4 hours a day. We've done the EEG's, 4 rounds now of different gene testing as well.

23 months ago we finally gave in and had allergies, hair, stool and urine tested? My son is allergic to many items. He's off the charts in aluminum, copper, lithium, rubidium and cesium. Then he was diagnosed with PANs and had a scare of Lyme as well.

We immediately started natural chelation with nutrients. We went GF/CF/SF and eliminated all sugars. We went 100% organic and juice every day. All chicken is free-range, antibiotic free and expensive. All beef is grass fed, non-GMO and expensive. Every bit of food that enters his body is known to the source and purity.

Results::

- any gluten, any sugar causes extreme aggression and yeast flare
- any "normal" produce produces foul stool, changes behavior and increases stims

What I also learned:

My road has many miles to travel, but I've covered more ground with natural healing than I did with any Dr's 7 minute consultation or prescription recommendation (what the hell is Marinol anyways and why would my child be prescribed this and not natural cannabis oil?) I'm not the only one. My path was paved by many, walked by thousands and is continuously modified with new tests, strategies and nutrients.

Parents live autism. They see changes that are microscopic. They notice what causes changes. They talk to one-another and compare notes. Compare Dr's. Compare protocols. Compare results.

**2.) Glyphosate. What are the affects on the human brain? What are the affects on the human ASD brain? Are there correlations, that have been studied between Glyphosate exposure and Autism Spectrum Disorders?**

Why would a 5-½ year old child on the spectrum whop was breast fed for two years and ate a natural, healthy diet have over 3x the normal levels of Glyphosate in his blood? We do not live near a farm, he does not work in produce, nor a processing plant.

Can the IACC to investigate how Glyphosate is affecting children with ASD vs. Non-ASD in the fiscal year of 2016, now 2017 or 2018?

**3.) The IACC makes a formal request to Congress to subpoena Dr. William Thompson at the CDC.**

Since his admission of falsifying tests, at the request of his superiors on how children receiving the MMR vaccine before 36 months were 340% more likely to receive an autism diagnosis or develop tics. Dr. Thompson made admissions to Biochemical Engineer Brian Hooker in a series of phone calls and not only gave specifics on how to obtain the correct data but also expressed remorse in his cover-up.

I ask: why hasn't the IACC been concerned with this information? Why hasn't the IACC even asked for clarification from the CDC and response been made public?

I request that the IACC makes a public, formal request to Congress to subpoena Dr. William Thompson of the CDC.

I request that the IACC makes a public, formal request to Nancy Messonnier, MD at the CDC for a full debriefing of the study to be included in the next IACC Summary of Advances in Autism Spectrum Disorder Research: Calendar Year 2016 that Dr. Thompson authored and the allegations of the link between autism and the MMR.

I request that the IACC demand retraction of published study (PubMed 2004 Feb;113(2):259-66.) at the AAP of the MMR/Autism paper co-authored by Dr. DeStefano and Dr. Thompson.