

Written Public Comments

**IACC Full Committee
Meeting**

October 26, 2016

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Andrea Colburn

October 26, 2016

Given the incident in FL where the police shot the unarmed black therapist of the individual with autism, along with other incidents where the individual with autism himself was killed, I think one of the topics for upcoming meetings needs to be training and community interaction between all first responders and individuals with autism. Especially, what a meltdown might look like - what it might look like when a family member or aide is trying to de-escalate a meltdown - and the fact that individuals with disabilities may not understand or respond to verbal directions and this does not mean they are being defiant but it is part of their disability.

Brian Kelmar

October 26, 2016

One of the biggest issues I have found over the past 10 years looking for help, there are numerous organizations seem to be doing similar things but very little coordination is seen from us as parents point of view. This is the first I have heard of your organization

Teresa Horowitz

October 26, 2016

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.

Jeff Belloni

October 26, 2016

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Mary Barto

October 26, 2016

My husband and I are caring for our niece on the Spectrum, who is now 28 years old. Her parents did not take advantage of any social services offered them as [PII redacted] was growing up.

When we took control over caring for [PII redacted], she was already 25 years old. We had her officially diagnosed by a Physiologist, who determined that [PII redacted] had Asperger's, with a verbal IQ of 160.

Because of this IQ, we had great difficulty getting her an SSI benefit. We were told to NOT even try.

We found two jobs for [PII redacted], which she manages very well. Unfortunately, neither job is even classified as 'part time'. So she has no benefits. She is on Medicaid, but because of her ability to work well at both organizations, she is now beginning to make sufficient monies to pay her living expenses. But because her one job is 'contract' based, if that company has no contracts, [PII redacted] will have NO work. Her 2nd job is at Chicago City Colleges, where [PII redacted] is a note-taker for 'disabled' students. Again, if no students are asking for that service, [PII redacted] is not working.

As you can see, my husband and I are very nervous for [PII redacted] future. We are aging and there will soon come a time when we cannot manage her 'activities of daily living', which is where her primary deficit exists.

We have her living in a small studio apartment, near a transportation hub, which [PII redacted] manages quite nicely.

We have all of her bills set up to pay automatically, but this is where the trouble begins. If one of these bills increases in any given year, [PII redacted] would neither understand that this increase has happened or what to do about making the correction, within her bank account.

If her GP doctor ever leaves her practice, [PII redacted] would have no clue as to be able to find a replacement. [PII redacted] has not been to a dentist in 3 years. Even though we make the suggestion to find a dentist who will take Medicaid, she has not been able to find one, since navigating these Service Based systems is not in her wheelhouse.

As she continues to earn more income, I fear that Medicaid will be taken off the table for her.

Her Student loans for 6 years of college (\$30,000+)...yes she does have a BFA degree and a TA Certificate, but she's not going to be able to navigate through the process of requesting a 'deferment', etc. for paying off these loans.

She does have a DHS go-to person, but that doesn't seem to be of much benefit in helping her get more services or a FT job with benefits.

We've researched the cost and availability of a Community Based program to manage her activities of Daily Living and/or have her move into one of the available apartments within such a community, but the cost for this is 'way' beyond her means.

So when somethings happens to us (and it will..!), [PII redacted] will be without any person who can 'protect' her from dangers that she is unaware of and/or 'manage' her ADLs.

So...I'm asking for the creation of the kind of help that [PII redacted] needs, which is primarily the ADLs...she can't be the only person on the Spectrum that requires this kind of help.

Or is this kind of help already exists, that would be 'affordable', we'd like to know where to find it. We've been working to assist [PII redacted] since 2013 and have not yet found a solution for getting her settled somewhere, with a job that has 'security' and 'benefits' and someone who can take over the task of watching over her and managing her ADLs, before we pass away.

In case anyone can help us, please contact us through my email address. [PII redacted] lives in the Northern side of Chicago, where Loyola University is located. She works at Aspiritech, a company which hires adults on the Spectrum and Chicago City Colleges, on the northwest side of Chicago proper.

I'd be grateful for any suggestions.

Callie Mitchell

October 26, 2016

As a parent of a child with ASD I worry about safety especially in the community. With a recent event in Florida with an Autistic young adult and his behavioral therapist. Many ASD children and adults will not be cooperative and may even become combative with unfamiliar people and not responding appropriately to questions whether law people are wearing a uniform or not. I can get my son a bracelet and a laminated card to carry in his pocket but ultimately training community agencies and law enforcement to be sensitive to identifying and working with children and adults with ASD is necessary to prevent trauma, injury, and death.

It should be recognized by doctors, therapists and others involved in the screening and diagnosis of toddler's suspected of being on the autism spectrum that a parent may try to manipulate that process to aid that parent's quest for custody of the child. Even a parental suggestion that his or her child could be autistic may be motivated by a parent's ulterior motives. The courts will usually grant primary physical custody to the parent who can provide the greatest stability at home for an autistic child. A child with special needs in family court is often considered not suitable for joint physical custody. That reality, unfortunately, is occasionally used in a child custody dispute by a parent who would promote a diagnosis of autism and is likely to gain custody if the child is diagnosed as being on the spectrum.

Those involved in the diagnostic process should be above the fray and be cognizant of, and on the lookout for, such potential manipulation. The answers on an ASD parental checklist can be skewed to obtain or influence an autism diagnosis. That checklist should contain an inquiry about a pending or future custody issue in court. Parents should confirm if they plan to use this diagnosis in a custody battle. A provisional autism diagnosis may be most appropriate in these borderline cases, especially when the child is a toddler and is high functioning. An autism diagnosis should not be allowed to be used as a weapon in court by one parent, given the toddler is in a provisional autistic state and can blossom before they get to kindergarten.

In my situation the mother's case in court was based on an autistic 4 year old special needs child that cannot handle living in separate homes. However, the child thrived in public school kindergarten socially and is a happy child. Although the mother's case to win custody was based on the child being autistic, there is literally no treatment for this diagnosis. Health practitioner's must gather how this diagnosis will be used when there is a pending custody case. The court awarded the mother primary physical and legal custody largely based on the fact a special needs child needs stability. However, at age 6 he was awarded camper of the week in a large mainstream camp for his participation skills. That award is inconsistent with an ASD diagnosis.

Physicians and clinicians need to be on the alert to the exploitation of children by parents who would benefit, as in custody disputes, by a diagnosis of autism. The ASD screening process must acknowledge their bearing on pending custody cases.

J.N.

Sandi Marcus

October 26, 2016

Independent researchers to review of the data was submitted in 2004 and 2011 to the Institute of Medicine's Immunization Safety Review Committee by CDC for data accuracy.
This needs to be done soon!

AnnMarie Sossong

October 26, 2016

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.

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Carmel Lozano

October 26, 2016

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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](#); I have an autistic son (31) and also a nephew (24) with severe autism. Since Dr. Naviaux has a potential treatment that looks extremely promising, using an existing drug - it must be pursued and given grant money!

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.

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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.

Thank you for your attention to this!

Carmel Lozano

April McKay Dudsic

October 26, 2016

i ask the IACC to retract the American Academy of Pediatrics (AAP) 2004 Pediatrics article "Age at first measles-mumps-rubella vaccination in children with autism and school-matched control subjects: a population-based study in metropolitan Atlanta".
Please amend this overdue travesty to our children & future children.

To Whom it may concern,

Any research program(s) should include representatives of parent's organizations who believe vaccines contribute to autism.

A controlled study on autism risk among children given the recommended vaccine schedule compared with those not so vaccinated.

A controlled study on autism risk among children given the recommended MMR vaccine and age effect, race and gender effect(s).

A controlled study on autism risk among children given the recommended DTaP vaccine and age effect, race and gender effect(s).

2009 National Vaccine Advisory Committee (NVAC) recommendation to IACC .

Independent researchers to review of the data was submitted in 2004 and 2011 to the Institute of Medicine's Immunization Safety Review Committee by CDC for data accuracy.

Aluminum in vaccines may have direct association with the increased rate of autism.

Increased risk of autism from the birth dose of Hepatitis B.

Vaccines have been found to increase the risk of seizures, tics and mitochondrial collapse, all of which commonly co-occur in autism.

Epidemiologic and Molecular Relationship between Vaccine Manufacture and Autism Spectrum Disorder Prevalence.

To assess the public health consequences of fetal cell line (MRC-5) manufactured vaccines that contain residual human fetal DNA fragments utilizing laboratory and ecological approaches including statistics, molecular biology and genomics.

Molecular mechanistic functions of vaccine-induced autoimmune disorder.

Christine Gilles

October 26, 2016

I am writing to provide input about services for people with Autism.

The services that I feel are severely lacking are places where those that have reached the age 21 can go to belong and interact with others during the day. When people with Autism transition out of the school system, there is nowhere for them to go. Gains & strides toward acquiring social skills that were made during their time in school can fade away if they are subsequently left isolated and on their own without continuing reinforcement of their social skills. Please direct focus to this very important area that will affect many, many people with Autism. Thank you

Shirley Farrior

October 26, 2016

You can help my autistic son and me by visiting my Facebook page (Shirley Farrior) and my Twitter page (@farrior_I). These pages contain facts about how those with autism in Illinois are grossly violated by the system. TRUTH is my complete defense against a claim of defamation. My logo is "Autistic Lives Matter."

There should be some policies in place regarding oversight for agencies who provide and/or coordinate services for the autistic. Autism appears to be the most exploited disability in the nation. My grandson was exploited out of a \$47,000 grant provided by the state of California and his social security. This was done to him by the state of Illinois. DayOnePACT in Lisle, Illinois purposely placed fraudulent medical records in his file. My Facebook page (Shirley Farrior) tells all. TRUTH is my complete defense. @farrior_I tells of autism in Illinois.

Sean Kelly

October 26, 2016

Retract the American Academy of Pediatrics (AAP) 2004 Pediatrics article "Age at first measles-mumps-rubella vaccination in children with autism and school-matched control subjects: a population-based study in metropolitan Atlanta?"

Kyle Bryan

October 26, 2016

Dear IACC,

I thank you so much for taking the time to reach out to us in the autistic community. As an adult that suffers from ASD, I know all too well the struggles, the pain, the fights, the anger and confusion that families and those who suffer with autism face every day. And it's not just merely an issue of critical need in Delaware. Autism has become a global issue. Japan, Canada, the United Kingdom, France, Germany, Iraq: all of them and perhaps many more have had to face this condition in their own homelands. And for many nations, they simply do not have the resources, the training, or the direct service professionals on hand to properly aid those affected and those suffering.

The need is growing! And the time is now for people who are willing to step up to plate to lead, to reach out, to listen, to love, and to act. Because you may never know if the efforts made through you; through families, communities, state services, non-profits, businesses; and yes, through those who suffer with autism. You never know if the efforts made in the present may catch the attention of the global community in the future. How a simple light in an overwhelming darkness can provide guidance and hope for a people who otherwise have nowhere else to go.

My blessing is with you:-)

Ann Lindsey Frost

October 26, 2016

I am a family member, advocate, and mentor to two individuals with Autism and I have extensive experience, knowledge and skills from interacting with this person with Autism. I am very interested in the future of all who have Autism because the risk factors are great, screening and diagnosis is complicated to detect and the doctors present different reports conflicting the outcome. There is an underlying biology to Autism, as also with the preventions, medications, treatments and surveillance of these individuals with Autism. The schools alter the records, miss important and many of with Autism fall in the cracks when it does not have to with the correct measures.

One of the persons I worked with for 20 years who has Autism has made tremendous success and the outcome with their Autism is hardly recognized, unless there is an emotional event or trauma to bring on symptoms. On the other hand, the other person with Autism experience huge pitfalls, and struggle only because of not being recognized early on with Autism and labeled with other diagnosis.

Laws need to be changed and guidelines need to be put in place. I am grateful that this is being addressed. Thank you and I look forward to a new strategic plan.

Ann Lindsey Frost

Jessica Simpson

October 26, 2016

Hello IACC I am a underserved adult with autistic spectrum disorder I have a hard time in getting my needs met with my autistic spectrum disorder in the state of Washington it has been really difficult for me . I was denied services through the developmental disability service agency in are area of Washington state . Can you help me to get the services I need for my underserved needs we have a broken system in this country . Ms. Jessica Simpson

Tilley Steven

October 26, 2016

My son wife has Hepatitis B My grandson was born last year June 2015. Her doctor said it was okay for her to breastfeed and she did. My grandson just had his first Hepatitis B test and they say he is testing positive for Hepatitis B antibody. We are extremely worried. He is only 22 pounds and does not have an ounce of fat on him. What is going to happen to him? the Doctor said There is no cure, is there? Will he get progressively worse? Is it possible he contacted it because of the breastfeeding? Or was it through birth, i was so confused and i did not know what to do lucky i met a friend of mind who introduce me to a clinic called medication clinic located in South Africa who help her during her pregnant stage .i contacted the clinic and in the period of 2 days ,i was so surprised when the courier service delivered the medication to my door step.thanks to medication clinic for there highly recommended herbal healing medication because now my grandson is hepatitis B negative here is their email CONTACT THEM IF YOU ARE diagnosed OF HEPATITIS B VIRUS or any other sickness ..their email = medicationclinic@gmail.com

Patrick Feeney

October 26, 2016

This is a copy of an email I sent to the school district, principle, department head and Local advisory board and of course was given absolutely no response from any member in the district.

October 11, 2015

Dear Director of Special Education Cheryl E. Coogan , Interim Superintendent Michael Convery:

I am contacting you with great concern with the direction of the Special Education services my son is receiving at the Coventry High School. I know that these changes were being put in the works at the end of last school year but letters were not sent out to the student's families until 5 days before school started with mailing time. Coventry School District purposely held out on informing parents knowing that they would not in any way shape or form agree with what you are doing with the special needs children in self contained classrooms.

I have spoken with at least 50% of the parents that had students last year in the 9th grade self contained classroom. Not one of them was happy with what has been done. Obviously you did not talk to the parents or the special education teachers to see what kind of feedback they could give you on possible success of such drastic changes to the special education system.

Let's look at the high quality of instruction and new structure of delivery. Last year my son and his classmates had one special education teacher for math and science and another special education for English and another for reading. As I spoke with each of the other parents of students in my son's class we all eluded to that our children worked at a 3-4 grade level in their school work. I am not a teacher but I would think that a high school level special education teacher would be capable of teaching these students at their level of education and understanding. I will say the teachers that I am speaking of were phenomenal with my son and immediately responsive to any concerns I had with his education in school and at home.

The second part of what I mentioned previously the delivery of special education services. I requested the student to teacher ratios along with number of students with IEP's in each class. The special education department at the high school sent me the information promptly. All the core class's that you have moved my son and other students to have between 35%-50% of the students in these classes working with an IEP. With one typical teacher and one special education teacher. These classes are level 3 class's witch I have been told are considered college prep classes. Makes me ask a question of how can students working at a 3-4th grade level could learn in a college prep class, with one special education teacher instructing the class and another one trying to aid 35-50% of the class? And how does this not take away from the typical students receiving their instruction in class? Most parents have had difficulty getting their child into a self contained classroom were the teacher can stick to basic concepts and move ahead at a rate that the class can handle. Now they all have been removed from the one service that we as parents could see results for our children. The self contained classroom is the least restrictive environment for these students; they get exposure to typical school experience in their elective classes as long as there chosen properly.

As the letter Coventry School District sent to parent's states Least Restrictive Environment that is the question? I would think the parents of the students and the special education teachers who saw them on a daily basis could give you the best recommendation for environment for these students. Placing them in a typical college prep class has opened them up to a much higher exposure of bullying and peer pressure. These students along with their academic deficits all have some social/awareness deficits as well. My son showed this in an elective class last year and at open house with a question a teacher asked him about a power point presentation. My son answered yes to the teacher or typically will say I

understand or I'm all set, when in reality he has no idea and needs direction repeatedly through his school day. These students will not self-advocate when they may stand out especially in a class with typical students. My son did this in an elective class last year and was greatly stressed by this class. I expressed more than once at the beginning of the school year about him being placed in this Elective class. All of the other parents I spoke with agree that unless you have a special needs child and see the result from that stress when they come home every day, you really don't get the effect on these students.

The guidance department was not responsive until I raised my voice. Then I had a vice-principal tell me, well he does need to learn how to write better. Again they really don't get it, they think these students are being typical teenagers and just don't want to do their work when they have cognitive deficits. The writing class my son was put into along with another student was an absolutely ridiculous choice of an elective for them and the teacher had not even bothered to read their IEP's. Reality check, my son is never going to write a novel or a 3-paragraph essay correctly. I understand they do not have electives specifically for these students but really a writing class, who's the rocket scientist!!! Stressing him out over an elective class is not conducive to him learning new things.

These students along with my son are most likely not going to grow up and be a teacher, lawyer, doctor, policeman or fireman. They will be lucky if they can hold down a 40-hour-a-week job and take care of themselves while not being taken advantage of. The Coventry School district insists on teaching them certain curriculum in preparation for PARQ testing. The students don't learn the material, the teachers know they can't learn the material, as well as administration, and they score far below the average on the test results dragging down the district score. Again where's the Rocket Scientist!!!

As a parent it seems that the School district has thrown them into the general population and written them off. These students need consistency more than ever, bouncing them around to 4 or 5 different special education teachers in college prep classes is setting them up to fail. It appears that the Coventry School district has broken and/or disregarded all the IEP's of these students and I'm sure you're hiding behind some legal letter of the law to protect the school district. The biggest thing I guess that is lacking in this issue is the people with all the education at the top seem to lack in the common sense department that applies for these students or that the district really doesn't care.

Concerned Parent Patrick W. Feeney

There is a large group of learning disabled students who cannot process or remotely come close to being taught to the standard of the high school grade there in. The policy set by the state to be taught in the least restrictive atmosphere in an inclusive classroom is not obtainable for some students that the state has ripped their self-contained classrooms out from under them. The sad thing is none of the district superintendent's will fight for these students to stay in the self-contained classrooms that many parents fought to get their children into.

Peter Mazure

October 26, 2016

I am the parent and caregiver for my 26 year old son with autism. My state (Virginia) does not pay for 24 hour residential care under Medicaid. My son needs 24 hour care. I am not the only person in this situation, yet we are left without options. At my age (68) and with my health, I wonder what will happen to him when I can't care for him. Our government has money for many projects, yet my son is without long term support. When will we put people first?

How can the government even begin to help people with autism when the NIH doesn't even know how many people have autism?
The government is totally behind the curve on taking care of its most needy citizens.

Question 6. The law requires schools to refer all high school students receiving special ed services to VOCATIONAL REHABILITATION. The Social Security Administration is also tasked with referring all SSI and disability applicants with a referral to Vocational Rehabilitation.

Even though Voc Rehab is available everywhere, most young adults with disabilities say they've never heard of it.

VOCATIONAL REHABILITATION is a federal program that provides JOBS to people with impairments. Job training, job placement, job coaches, college (including grad school in some cases), psychological or physical evaluations, case management and help with group homes, money management, transportation, etc. The case managers at Voc Rehab are some of the best-trained people in any agency.

Problems:

-Schools are giving students a pamphlet rather than facilitating a meeting between the student and Voc Rehab.

-Social Security is sending letters suggesting people call Voc Rehab but some disabled people, especially young people, aren't really skilled at navigating agency services and making appointments.

-The word "rehabilitation" means to the general population a program for drug and alcohol recovery or a program for injured people to recover skills they lost.

-Voc Rehab offices are hiding. States may put this agency under the umbrella of another agency and may move or rename it. It may be called DRS, DARS, Rehabilitative Services, VR, VRS or it may be part of a Workforce Onestop office in some states. It may be in the Department of Labor or the Department of Health and Human Services. The office may not be labeled except with an abbreviation. It may be in the middle of nowhere. It's not always on the map.

-Schools may think Voc Rehab services are only for profoundly disabled and/or impoverished people.

Wrong.

Vocational Rehabilitation should be required for all special ed high school students by age 16 and for all recipients of SSI after age 18 except in extreme cases.

Question 6.

Although colleges are required to provide disability services, they say that the additional services needed for students with autism are not covered by the law and are not part of the reasonable accommodations they're required to provide.

Many colleges now have new federal funding for programs for students with "Intellectual and Developmental Disabilities." A requirement for these programs is an intelligence test showing an IQ under a certain number (I think 75 or 80). Info about these programs here:

<http://www.thinkcollege.net/component/programsdatabase/>

Other colleges provide programs appropriate for students with Asperger's or High Functioning Autism. However, these programs for Aspergers are not funded by the government. They cost students thousands of dollars on top of their tuition and other college expenses.

Here's some info about these programs: <http://www.collegeautismspectrum.com/collegeprograms.html>

My child can get into college, but to succeed she'll need some additional services, especially help adjusting to the new environment, living in a dorm, dealing with social situations, communicating

effectively, and participating fully in the community. But I can't pay \$5000 a year on top of the regular fees.

I think addressing this issue would help college students become self-sufficient adults and help colleges fully accommodate students with Asperger's and similar conditions even when these students do not have IQs under 80.

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

Eileen Nicole Simon, PhD, RN

October 26, 2016

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

#1 What is happening? (Question 2)

In the conference call held September 7, Strategic Plan Question 2 was discussed: How Can I Understand What is Happening?

The statement was made that more is now known than in 2008. I disagree. Please look at the presentation I made in my public comment at the IACC meeting held in November 2008:

https://iacc.hhs.gov/meetings/iacc-meetings/2008/full-committee-meeting/november21/slides_eileen_simon_112108.pdf

#2 IACC, 21 Nov 2008 (Question 2)

(Question 2: How Can I Understand What is Happening?)

At the IACC meeting in November 2008, I pointed out my discovery of the Scientific American article on asphyxia at birth [1]. Damage was found in the inferior colliculi in the brainstem auditory pathway.

I also pointed out the research by Seymour Kety that revealed blood flow to the inferior colliculi is higher than in any other part of the brain [2].

Then I cited 12 reports of people who lost the ability to comprehend spoken language following injury of the inferior colliculi. I recently found two additional reports [3, 4].

Complications at birth have been reported more than any other environmental factor in children who develop autism. Shouldn't causes of autism related to brain injury be as much a focus as genetic research?

Clamping the umbilical cord immediately after birth became a standard protocol in the mid 1980s, whereas traditional textbooks taught that an infant should be breathing before termination of placental respiration. Shouldn't increasing need for resuscitation at birth be considered as a possible cause of the increase in autism prevalence beginning in the 1990s?

Can I ask for discussion of the presentation I made back in 2008?

References:

[1] Windle WF. Brain damage by asphyxia at birth. Sci Am. 1969 Oct;221(4):76-84.

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#3 What Caused This to Happen? (Question 3)

(Question 3: What Caused This To Happen and Can This Be Prevented?)

I read the transcript of the phone call on Question 3, What Caused This To Happen? I want to ask if, in addition to genetics and exposures, how the brain is affected can be included? Since 2003 I have pointed out at IACC meetings that complications at birth have been reported more often in cases of autism than any other environmental factor [1-37].

Birth injury is a taboo subject. It should not be. Clamping the umbilical cord immediately after birth is a medical error. Termination of placental respiration (with a surgical clamp) immediately after birth is an obstetric protocol that should never have been adopted. Clamping the cord before the first breath runs the risk of inflicting asphyxia resulting in damage of brainstem structures in the auditory pathway and basal ganglia [38, 39].

Diethylstilbestrol (DES) had to be discontinued for prevention of threatened miscarriage. Daughters and sons developed genital cancers, and litigation followed [40]. Funds for lifespan care of the developmentally disabled could be designated, and lawsuits disallowed for individual victims of umbilical cord clamping.

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#4 Teach Words (Question 4)

(Question 4: Which Treatments and Interventions Will Help?)

Language is the defining characteristic of the human species. Its failure to develop is cause for grave concern. Failure of language development is the most serious problem for autistic children; it cannot be dismissed as part of an underlying social disorder.

The comparison should be made with children born deaf, for whom the cochlear implant has been a miracle. Cochlear implant surgeon Dana Suskind explains the importance of learning words from an early age in her book, *Thirty Million Words: Building a Child's Brain* [1].

Names for objects, actions, attributes, and concepts are acquired with maturation of circuits in the brain that connect hearing to vision and sense of touch [2]. Maturation of the brain continues after birth. Myelin formation within the language areas continues during the first three to four years of childhood, and as language development takes place [3, 4].

Trophic neurotransmitters produced in the brainstem auditory pathway appear to be crucial for development of target areas for hearing speech sounds in the cerebral cortex [5]. The language areas appear to also influence how sounds are processed in brainstem circuits [6].

Damage of small brainstem auditory relay centers by prenatal exposure to toxic substances or asphyxia at birth cannot be dismissed as minimal.

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#5 Language and the Inferior Colliculus?

The article on asphyxia at birth, in the October 1969 issue of the *Scientific American*, was of great interest to me. In monkeys subjected to asphyxia at birth, damage of the inferior colliculus was where the most prominent injury of the brain was found [1].

The inferior colliculus? In the brainstem auditory pathway? The tiny pair (plural colliculi) of relay centers were shown in one picture, and their deep midbrain location in another. Yes! I realized this could explain my son's difficulty learning to speak!

Children learn to speak by ear. The ability to hear syllable boundaries appears to be most important for detecting words in streams of speech [2]. Loss of the ability to understand spoken language has now been described in several case reports following injury of the inferior colliculi [3-16]. Can my comments on language and the inferior colliculus be discussed? If not, why not?

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#6 Wernicke's Encephalopathy

Wernicke's encephalopathy (WE) was described in 1881, as a pattern of bilateral and symmetric hemorrhagic damage within the brainstem [1, 2].

The subcortical systems affected in WE were found, 80 years later, to be sites of highest blood flow in the brain. Measurements of cerebral blood flow were reported by Seymour Kety in 1962. Blood flow was found to be higher in the brainstem auditory pathway than anywhere else in the brain [3].

WE has long been recognized as: (a) The neuropathology that results from chronic use of alcohol, and (b) the pattern of damage caused by thiamine (vitamin B1) deficiency [4].

Asphyxia at birth causes an ischemic form of WE [5, 6].

Damage was not at first evident in monkeys subjected to asphyxia at birth. Seymour Kety suggested looking for damage in the inferior colliculus (plural colliculi). Only then was the severe ischemic injury found of these tiny auditory relay centers in the midbrain.

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#7 Language Disorder and Diminished Awareness?

Can Wernicke's encephalopathy (WE) be discussed as the neuropathology underlying the neurological signs of autism?

Damage of the inferior colliculi in the midbrain auditory pathway should be of special interest as: (a) a possible cause of developmental language disorder, and (b) diminished awareness.

Diminished awareness? British audiologist Ladislav Fisch pointed out that the auditory system of the brain is continuously active, even during sleep. This is why we use alarm clocks. The auditory system is the vigilance center of the brain [1].

The centers of highest blood flow in the auditory pathway are also the sites of highest aerobic metabolism in the brain. This has been reported in numerous investigations using carbon-14 labeled deoxyglucose [2].

Functional magnetic resonance imaging (MRI) has confirmed that the auditory nuclei of highest blood flow are the inferior colliculi in the midbrain [3]. The tiny size of the inferior colliculi is also revealed by MRI.

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#8 Thiamine Deficiency and Poisons

Wernicke's encephalopathy (WE) caused by alcoholism is believed to be the result of thiamine (vitamin B1) deficiency. This idea is based on the observation that alcoholics are often malnourished.

Thiamine is an essential co-enzyme in the pathway for aerobic metabolism. Thiamine deficiency was discovered to be the cause of beriberi, an affliction of people (primarily in Asia) who adopted refined white rice as their dietary staple. Thiamine was eliminated in the refining process [1, 2].

However, WE is also caused by many poisons.

One poison is pyriothiamine [3]. Pyriothiamine has been used in research as an experimental method to produce WE in laboratory animals. Pyriothiamine displaces thiamine at its sites of enzyme action.

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#9 Hemorrhagic and Ischemic Damage

Wernicke described pinpoint hemorrhages in a symmetric bilateral pattern within the brainstem [1, 2]. Alcohol causes increased blood flow. Small hemorrhages can occur with dilation of capillaries.

Relay centers in the brainstem auditory pathway have higher blood flow and metabolism than any other structures in the brain [3, 4]. Injury within the auditory pathway (especially the inferior colliculi) is prominent in Wernicke's encephalopathy [5, 6].

Increased blood flow and hemorrhage (especially in the inferior colliculi) have been described following exposure to other chemical substances [7-9]. A brief episode of asphyxia (suffocation) damages the same brainstem sites affected in Wernicke's encephalopathy, but the damage is ischemic rather than hemorrhagic [10-14].

Causes of autism include prenatal exposure to alcohol or valproic acid [15, 16]. Both alcohol and valproic acid disrupt development of the auditory pathway [17, 18]. Complications at birth have long been documented in cases of autism (see citations above in note #3). The most serious effect of asphyxia at birth is damage of the inferior colliculi in the auditory pathway [19, 20].

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#10 Infant Formula Deficient in Thiamine

In 2003 a soy-based infant formula was sold in Israel [1, 2]. Within four months beriberi (Wernicke's encephalopathy) was diagnosed in 15 infants for whom this formula was their primary source of nutrition. The formula was found to contain no thiamine (vitamin B1) [3-5]. The manufacturer (Humana in Germany) assumed the soya beans used would provide sufficient vitamin B1.

Wernicke's encephalopathy (WE) in infants fed the thiamine-deficient formula was confirmed in MR images [4]. Permanent disability has now been recognized as the sad outcome of brain damage suffered by many of the infants who were fed the thiamine-deficient formula [6-12].

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#11 Brain Imaging of Wernicke's Encephalopathy

Six infants, aged 2 to 10 months, were admitted between September and November 2003 to intensive care from the neurology clinic of the Schneider Children's Medical Center of Israel. All suffered signs of encephalopathy. After the 5th admission the cause was discovered. All of these gravely ill infants were being fed a soybean formula manufactured by the German Company Humana. Testing revealed the formula contained no thiamine (vitamin B1).

Wernicke's Encephalopathy (WE) injury in the brain was revealed by Magnetic Resonance Imaging (MRI). The youngest infant (admitted at 2 months of age) appeared to make a full recovery after thiamine supplements were begun. The other five suffered permanent disability. Injury of the frontal lobes and basal ganglia were found in addition to the pattern of brainstem damage seen in adult cases of WE.

An estimate of 600-1000 children were fed the thiamine-deficient formula. The children were all given thiamine supplements as soon as the error was discovered. Use of thiamine-deficient formula varied from 2 to 4.5 months. Infants were 2.5 to 15.5 months when the formula was discontinued.

Reference: Kornreich L, et al. Thiamine deficiency in infants: MR findings in the brain. *AJNR Am J Neuroradiol.* 2005 Aug;26(7):1668-74.

#12 Thiamine Deficiency and Developmental Delay

Development was followed between 20 and 39 months of age in a group of 20 children given the thiamine-deficient formula for at least one month during the first year [1]. Eight were delayed in motor development, and were older than 18 months when they began walking. All had language delay.

Cognitive development was assessed as a Mental Development Index score (MDI). Low MDI scores were related to language delay. None of these 20 children was assessed as having autism according to two standard scales (CARS and M-CHAT). However, from the descriptions of the children included and excluded from follow-up, I believe it is possible that signs of autism would be evident to someone unaware of the early thiamine deficiency.

Reference: Fattal-Valevski A, et al. Delayed language development due to infantile thiamine deficiency. *Dev Med Child Neurol.* 2009 Aug;51(8):629-34.

#13 Thiamine Deficiency and Language Problems

Language problems were investigated further in 59 children aged 5 to 7, who had been fed the thiamine-deficient formula for at least one month within their first year of life [1]. All, 39 boys and 20 girls, appeared neurologically unaffected, were not intellectually disabled, and had no hearing loss. Ten children with sensorineural hearing loss, one with cerebral palsy, and one with autism were excluded from this study of language development.

Tests to identify specific language impairment (SLI) were used: lexical retrieval, syntax, phonology, semantics, and pragmatics [2]. In the thiamine-deficient group, lexical retrieval and syntax were impaired in 57 of the 59 children. Tests of lexical retrieval reveal ability to distinguish subject from object. Tests of syntax determine comprehension of object, subject, and or verb in different positions of sentences.

The investigators planned further testing to determine whether the thiamine-deficient children would catch up. How thiamine deficiency could affect brain systems required for language development was discussed, and compared with cognitive decline in Wernicke-Korsakoff syndrome.

The brainstem auditory pathway is prominently affected in Wernicke's encephalopathy, and auditory system dysfunction was shown to be another problem of some children fed the thiamine-deficient formula early in infancy [3].

References:

[1] Fattal I et al. The crucial role of thiamine in the development of syntax and lexical retrieval: a study of infantile thiamine deficiency. *Brain*. 2011 Jun;134(Pt 6):1720-39.

[2] National Institute on Deafness and Other Communication Disorders (NIDCD). Specific Language Impairment. <https://www.nidcd.nih.gov/health/specific-language-impairment>

[3] Attias J, et al. Auditory system dysfunction due to infantile thiamine deficiency: long-term auditory sequelae. *Audiol Neurootol*. 2012;17(5):309-20.

#14 Research Priorities?

"Neurodiversity" as an explanation for the autism spectrum has thankfully not become widely accepted by medical experts. More should be done to stop promotion of this idea to the non-scientific public. Nearly everyone recognizes the seriousness and increasing numbers of language-impaired children. Were this many in the past really hidden away in institutions? Where are census reports cited?

The increase in numbers of autistic children is clearly evident, and frightening. The suffering of families who bear the burden of caring for an autistic child cannot be denied. "Acceptance" is cruel advice.

Diagnosis of autism later than early childhood must be viewed as something different. "Social disorder" in people whose language development was normal in childhood is not part of the spectrum described by Kanner or Asperger. How disabled are those first diagnosed in adolescence or early adulthood? How great are their lifespan care needs? Why are their opinions valued more than those of grieving parents whose children are unable to speak?

Should federal spending all go into "services" for the disabled?

Form letters I have received from president Obama, state legislators, and HHS state that the "playing field" must be leveled for all people with disabilities. We should just be accepting of disabilities? Was polio acceptable? Is Alzheimer's acceptable? Are addictions acceptable?

Central nervous system disorders must be made a priority for research. Could autism, addictions, and Alzheimer's all derive from injury of the same brain circuits during different stages of life? Wernicke's encephalopathy should be considered as a common underlying neuropathology. Can I request this as a topic of conversation by members of the IACC?

References:

[1] Murphy CC et al. The administrative prevalence of mental retardation in 10-year-old children in metropolitan Atlanta, 1985 through 1987. *Am J Public Health*. 1995 Mar; 85(3): 319–323.

[2] Gesell, Arnold. The mental growth of the pre-school child; a psychological outline of normal development from birth to the sixth year, including a system of developmental diagnosis. New York, Macmillan, 1925.

[3] Barr MW, Maloney EF. Types of Mental Defectives. Philadelphia: P. Blakiston's Son, 1920.

[4] Barr MW. Some notes on echolalia, with the report of an extraordinary case. *Journal of Nervous and Mental Disease* 1898; 25:20-30. Online at:

<http://www.conradsimon.org/BarrEcholalia1898.html>

#15 Male Vulnerability and the Inferior Colliculus

I see that at the October meeting of the IACC, a presentation "Autism in Women and Girls" is planned. For the July meeting I submitted the comment below on the greater vulnerability of males to oxygen insufficiency at birth. I also submitted this comment to the NIMH in response to their request for research ideas:

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 a topic of discussion at a meeting of the Fetal and Neonatal Physiological Society I attended in 2006, part of a discussion of cooling caps for infants who suffered anoxic-ischemic encephalopathy during birth.

What alternative ideas are there that might explain the 5:1 male to female ratio of children who develop autism?

Following are citations to the medical literature 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.

#16 Brain Damage?

I listened to the second conference call on Question 3: What caused this to happen? Why was brain damage not discussed? Prenatal and postnatal influences were proposed for discussion as environmental risk factors. Why were complications during birth not proposed? Why was cesarean birth not discussed?

Need for resuscitation is recognized as a priority for infants with a low Apgar score at birth. Low Apgar scores have been reported in numerous research reports on autism associated with complications at birth. What are the dangers of a low Apgar score?

Should preventing autism be a priority? Should failure of language development in childhood be a priority? Language is the defining characteristic of the human species. Autism diagnosed later than age 5 in a child who speaks is something different. Can evidence that "social disorder" prevents normal language development be discussed?

Language delay, seizure disorder, repetitive movements, and diminished level of awareness in young autistic children are signs (not just traits) of neurological impairment. Could a diminished level of awareness underlie social disorder? Causes of neurological impairment at any age must be looked for in the brain.

#17 Elephant?

In the conference call on Question 3: What caused this to happen? Discussion of public comments began by noting the "elephant in the room" polarization over whether (1) prevention should be a priority or (2) prevention is not a valid goal. Then it was suggested there is no clear way to adjudicate these opposing viewpoints. What?

Someone pointed out that families with more seriously affected children want to find the cause. Yes!

When your physically perfect (even especially beautiful) child does not learn to speak, shouldn't you be concerned? Shouldn't you bypass your smiling pediatrician, and seek the opinion of a child neurologist?

Wasn't the IACC formed to look for reasons for increasing prevalence of childhood autism beginning in the 1990s?

The elephant in the room is, in fact, all of the efforts made to ignore possible medical errors: Folic acid? Micro-biome? Exposures? Are the disabling core symptoms the result of a social impairment?

Language disorder, repetitive movements, seizures, environmental obliviousness must be investigated as a serious neurological disorder.

A 2016 report from the UK charity Autistica indicates that in autistic adults without intellectual disability, suicide is the highest cause of death after heart disease. Autistic adults without intellectual disability are nine times more likely to die by suicide than the general population. In a Lancet Psychiatry study from 2014, 2/3 of adults with Asperger syndrome reported having suicidal thoughts. 1/3 made specific plans or attempted. Anecdotally, I am an autistic adult without intellectual disability who has attempted suicide. Several of my friends have, too. Even more have confided in having suicidal thoughts.

Alarmingly, there has been little to no American research on the topic. What steps can and will the American research and provider community take to address the pressing issue of suicide in autistic adults? More funding is vital to discovering how to reduce suicidality in my community.

Whatever steps are taken, I think that it is absolutely vital to take a holistic approach to the issue -- High unemployment rates and social isolation seem like probable contributors to suicidality in autistic adults. It is not and must not exclusively be treated as a psychiatric problem. Personally, difficulty getting and keeping gainful employment and interpersonal difficulties were major contributors to one of the worst weeks of my life.

There is often a strong ideological split between the parent/provider community and the Autistic adult community. I think the issue of reducing suicides and suicidal thoughts is an excellent opportunity for collaboration to reach a shared goal. I hope this will be considered a priority in the coming years, and that we can all work together to address it.

Julia Lynch

October 26, 2016

Please discuss options for long term care of aging autistic adults.

Most societies are still speaking about research and early intervention strategies; however, the critical need is for appropriate long term care for those unable to be independent.

Respectfully,
Julia Lynch

Question 3. What are the most significant barriers to progress in this field.

Listening in today on October 12, 2016.

I would agree with the entire conversation that took place. However, prevention methods in most people's minds is not the same as cure; (ie) People with cancer are not labeled as Canceristic, however those who have had cancer and have been cured of cancer may feel that having cancer has provided them with personality "growth", but not a change of self.

So if you cured Autism, you would make the entire essence of what makes that person a person (body, mind, spirit) go away, as Autism or being Autistic is the whole person being.

So, I would not state in the document that because those with Autism may not want to be "cured" (as they know of no life or self without Autism) is a barrier to progress in the field - as stating that as such is really close to disability.

However, maybe it should be stated that the barrier to progress in the field really is - How do you mediate those behaviors that are of difficulty to the person or are challenges to the person, without making or wanting the person be a different person is really the barrier to progress in the field.

Lori Kay

October 26, 2016

As the parent of a 25 year old young man with severe "classic" autism, I am concerned that resources for understanding and treating symptoms in people like my son are not being adequately addressed nor funded by the government. My son suffers on a daily basis with self injurious behaviors and has little access to community based activities because of autism related issues. I would like to remind the committee members that there are others like my son who need research into severe autism. They and their families pray and hope that research will help them someday too.

Thank you for the opportunity to submit written comments.

The Autistic Self Advocacy Network (ASAN) continues to be deeply concerned by the allocation of autism research funding. According to the Office of Autism Research Coordination (OARC), the vast majority of NIH funding for autism research goes to investigating the biology and causation of autism, and its diagnosis and treatment in young children. In 2012, the most recent year for which data is available, only 1.82% of NIH autism research funding went to research on services, while less than one percent of this funding went to studying issues facing autistic adults. As long as research funding continues to be skewed in this way, many pressing questions with real implications for the lives of autistic people will go unanswered. There is an entire world of data which needs to be collected and analyzed before we will have a solid scientific understanding of what autistic people are experiencing throughout our lifetimes, and what will truly make a difference in our quality of life.

Lifespan and Quality of Life

Currently, there is little research on outcomes throughout the lifetime for autistic people, be it in terms of health, safety, life satisfaction, self-determination, or other measures. Yet research on quality of life and lifespan outcomes is literally life-or-death for our community. A recent study revealed that autistic people have a markedly lower life expectancy, and higher suicide rate, than the general population. Of this study, lead researcher Tatja Hirvikoski remarked, “We observed [an] increased risk of death in all categories that we could analyze — we don’t really know why.”¹ This concerning finding, and lack of related knowledge, highlights the need for further research in this area.

The study’s authors have hypothesized that a lack of disability-competent primary and preventive care could be responsible for increased mortality due to medical issues ranging from cancer to circulatory diseases. Given this, there is an urgent need for research into whether autistic people are accessing appropriate, competent health care, and receiving recommended preventive health services. Co-occurrences between autism and other conditions (such as epilepsy, depression, anxiety, disordered sleep and eating, compulsive skin-picking and hair-pulling disorders, connective tissue disorders, and others) have been entirely under-researched, particularly as applies to adults. Insight into the prevalence of these co-occurring conditions, and how they can best be managed, could help to improve the health outcomes and quality of life of autistic people.

Supports and Services

Services research has long been a priority of ASAN. The 2012 OARC data demonstrates that this continues to be one of the least-funded research topics in the field of autism. However, research can and should play a crucial role in identifying effective services for those on the autism spectrum, including supports for inclusive education (from pre-kindergarten through postsecondary), transition services, employment supports, and services that allow adults to live independently in their communities. It is critical that any research agenda prioritizes the needs of autistic people who are here now; unlike research that seeks to discover the causes of autism, services research can make a crucial and positive difference in the lives of autistic people and our families.

¹ Ann Griswold, “Large Swedish study ties autism to early death,” *Spectrum News*, December 11, 2015, <https://spectrumnews.org/news/large-swedish-study-ties-autism-to-early-death/>.

In addition, we urge more research on assistive technology, including alternative & augmentative communication (AAC). Many autistic people rely on text-to-speech devices and other forms of AAC to communicate, but little research has been funded regarding assistive technology for communication. Many non-speaking autistic people have been denied access to promising communication methods due to the lack of research in this area. Beyond communication, many autistic people use assistive technology such as specialized timers, apps and online programs to support executive function, memory, travel and navigation, independent living, decision making, community integration, education, and employment. Research examining how autistic people are currently using assistive technology, how effective current assistive technology is, and what possible innovations might be helpful, will have real benefits for autistic people of all ages.

Diagnostic Disparities and Prevalence

While improvements in diagnosing autism have been made for some populations, considerable efforts are still needed to make diagnosis and services available to all. African-American and Hispanic autistic children continue to go under-diagnosed, as do girls on the spectrum. In addition, girls who receive an ASD diagnosis are more likely than boys to have been identified as having an additional disability, and children of color diagnosed with ASD are more likely than white children to have been identified as having an additional disability. This suggests that there are many undiagnosed autistic girls and autistic children of color who are currently either assigned a different disability level or who are being missed entirely due to not being male and white. More research is needed to determine what factors are causing these diagnostic disparities, identify methods of combating bias, and to identify and develop diagnostic best practices which increase accuracy and ensure that all children are able to exercise their rights and access needed services.

Research is also needed to develop effective diagnostic practices and tools for autistic adolescents and adults, many of whom go undiagnosed because clinicians are not trained in identifying autism in these populations. Additionally, more data is needed on the prevalence of autism in adults. When the United Kingdom conducted an adult prevalence study, it found the same rate of autism in adults as children, helping to debunk public hysteria over a so-called “autism epidemic.” A similar study could be helpful in the US as well.

We also urge researchers to include a more accurate representation of the autistic community in their studies. Many autism studies only include white, male autistic people in the study cohort; data from such studies may or may not be applicable to the broader autistic population.

Working with the Autistic Community

ASAN is often approached by autistic people looking for information that can help them make decisions and plan for their futures, and we are often unable to provide this information because the research has not been done. The autistic community is asking for research into issues that some autistic people face, including motor planning difficulties, skill loss, struggles with nutrition, atypical response to medications, unusual pain perception, and difficulty with executive functioning. These issues are challenging to many autistic people across the lifespan, yet they are rarely studied, particularly among adolescents, adults and seniors. Additionally, the experiences of autistic people during common life events such as pregnancy, parenting, and aging have not been studied. Many autistic people have asked us for such information in order to understand what to expect as they grow older or start a family, but little to no

research is available. The priorities of the autistic community - the most impacted stakeholders - are not reflected in the current research agenda.

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.

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, Deputy Executive Director of ASAN, at jbascom@autisticadvocacy.org.

An ASD diagnosis should not be for sale. A practitioner that screens for this diagnosis should ask if the diagnosis will be used in a pending child custody battle. A parent can skew the child's performance in screening to benefit them in such a battle, so they can benefit with this diagnosis in court. A special needs child with ASD is not a candidate for shared parenting, and the screening practitioner should be made aware of this. That practitioner and child could be exploited by the parent using the diagnosis as a tool to win in a custody battle.

Therefore, I propose that screening should filter if this diagnosis will be used in such a battle. The screener can therefore make final ASD recommendations with such motives in mind.

comments from a beleaguered mother of a 15 year old non-verbal autistic son

Today I searched PubMed for autism clinical trials over the last year (less than 40). Behavioral hypotheses outnumber biological research two to one. If you discard the recycled hypotheses it is three to one. It shows a lack of interest, let alone progress in understanding the etiology of Autism.

I believe my non-verbal 15 year old son is part of a wave of severe autism that peaked in 2002, based on the number of autistic kids in the school district before and after his year group. I have also noticed the younger kids I see in ABA therapy waiting rooms are less severely affected (if at all). Who on your committee can explain that to me? It is not addressed in the literature.

Continuing to fund studies through NIMH has created industry of psychologists, ABA therapists, Speech Therapists, Occupational Therapists, Music Therapists, Dieticians etc., producing and re-producing useless descriptive studies or rehashing the use of Risperidone, diets and other less than mediocre therapies.

Since those with ASD have longer than typical DNA strands and the majority of these differences are de novo, why don't you fund studies to find out why?

While you are at it, here are a few more questions:

1. What is the involvement of Human Endogenous Retrovirus in ASD?
2. Where is the follow-up research on serotonin transporter and serotonin receptor binding?
3. Why do post mortem brains more closely resemble Parkinsons?
4. Does rubella cause ASD even in vaccinated populations?
5. Where is the research on abnormal fatty acid metabolism in ASD?
6. Where is the research on enzymes?
7. Where is the research on congenital rubella infection? How many ASD have elevated Rubella titers?
8. Where is the research on mycoplasma ssp. Chlamydia pneumonia and human herpes virus-6 coinfections in ASD?
9. Where is the research regarding virus induced autoimmune response in ASD?
10. Is it true that 70% of ASD are positive for folate receptor alpha autoantibodies?
11. How often temporal arachnoid cysts associated with PDD NOS?
12. Where is the food allergy research in relation to ASD?
13. What causes higher Glu/Cr and lower GABA+/Glu concentrations in ASD?
14. Why do ASD have higher peripheral blood levels of Brain-derived neurotrophic factor?
15. Can inhibition of the mTOR pathway using methoxyluteolin be treatment for ASD?
16. Is there a rational basis for specific therapeutic intervention in restoring gut homeostasis in ASD?
17. What is the biological signature and why is severe food selectivity found in only 10% of ASD? Why isn't this considered a sub-type?
18. If sleep problems are only reported for 5% of those with ASD, why isn't it considered a sub-type?
19. Is there a connection between ASD and parasites?
20. Are IL-6 and TNF cytokines markers for beneficial effects of luteolin?

21. Why do ASD have decreased plasma thiamine pyrophosphate concentration?

Sincerely,
Resa Warner

Kristie Sepulveda-Burchit, on behalf of Educate. Advocate.

October 26, 2016

Our organization is Educate. Advocate. We educate ourselves as parents and caregivers so we can advocate for children with special needs including autism. We are California statewide organization. We are a member organization with the Lanterman Coalition.

The purpose of submitting public comments today is to alert you once again as did almost a year ago now to a whistleblower at the CDC, Dr William Thompson. There was a rally held once again in Atlanta at the CDC over this last weekend <http://cdctruth.info/> . Dr. William Thompson gave data to Congressman Posey who spoke on the floor of Congress testifying that scientists at the CDC were instructed to trash data that showed a link between the MMR and autism with African American baby boys under age 3 (36 months). Here is Congressman Posey <https://youtu.be/qxr-cv-Jul8>

We want the IACC to reach out to legislators to get them to subpoena Dr. William Thompson so we can get the truth in a hearing. We want IACC's assistance in making certain both the states and federal government cease the coordinated efforts in pursuing vaccine mandates when the truth about the safety of vaccines is being suppressed and vaccine manufacturers face zero financial liability when vaccines injure our children or kill them. Many of our families with children with autism were injured by vaccines.

Because of this information that has come to light the Autism Omnibus cases that were tried need to be re examined. The data used to try these cases, according to whistleblower Dr William Thompson at the CDC was fraudulent and therefore these cases need to be re examined. We need the IACC's assistance with this.

We also request that the IACC request through legislators that congress repeals the 1986 National Childhood Vaccine Injury Act so that we can finally hold manufacturers liable for injury caused by their vaccines.

We request that the IACC request through legislators that all vaccines are classified as pharmaceutical drugs and tested accordingly.

Additionally a film called Vaxxed <http://www.vaxxedthemovie.com> is one every member of the committee should see. The Vaxxed bus is going around the country and getting stories from families of vaccine injury including those diagnosed with autism. There is a map available by state where you can pull up the stories of families from that state of vaccine injury and most features those diagnosed with autism. Please see the map here vaxxed.us

Families with children and adults with autism deserve the truth. At long last. It is time.

Thank you for your attention to this issue.

On behalf of the families we serve,
Kristie Sepulveda-Burchit
Executive Director, Educate. Advocate.

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

Linda Varsou

October 26, 2016

LETTER OF DESPAIR: WHERE THE IACC AND AUTISM RESEARCH ARE GOING?

10 Facts: **1)** Autism prevalence dramatic increase. **2)** Children with autism become adults with autism while remaining children. **3)** Suicides or suicide attempts are on the increase among adult children. **4)** Scarce services able to help autistic adults. **5)** The Health System, Hospitals, Emergency Rooms, etc. fail or refuse to treat autistic adults. **6)** The Judiciary System ignores the insights and special needs of autism with devastating and dramatic consequences. **7)** In 50% of families having children with autism, at least one parent (usually the father) remains in chronic denial with an attitude of *“flight instead of fight”*, which has detrimental effects on the child. **8)** The exponential increase of autism publications and research, besides the enrichment of researcher’s CV, doesn’t show any positive impact in autism. **9)** Autism societies and organizations have become more bureaucratic and money collectors than to offer advice or services to persons with autism without discrimination. **10)** Poverty afflicted families having a child with autism is the worst mirror image of any civilized society.

I am the mother and guardian of a 31-year-old brilliant and genius autistic son with the maturity of a 12-year-old, a scientist in academia for 40 years, associate professor in medicine, hygienist, immunologist, clinical biochemist with 2 PhDs, etc., an advocate for the rights and strengths of people with autism in Europe and US as well, promoting the true concept that ***“An Autism Friendly Society which will benefit us all”***. Despite all my endless efforts to fulfil the needs, wants and wishes of my son and not only, I have experienced firsthand all the above 10 facts with no help from anywhere.

I have followed the IACC’s efforts since day one, with at least 7 presentations and many comments online up to now. Despite all the federal money and time invested to these absolutely necessary and important IACC’s goals, when I see my son in his eyes, I can’t tell him: *“My dear son, you are better off today due to the IACC efforts and strategic plans”*, because he is the victim of the judiciary and health system, of a millionaire father in total and chronic denial, in poverty and food stamps, an honor student who dropped off from college just before his graduation with a degree, and in a totally dramatic condition, in and out from the emergency rooms. He told me yesterday: *“Mom, I am not coming with you at the NIH next week because I don’t expect anything from them; I rather prefer to stay home and watch my DVDs”*.

Is there any hope for the IACC and autism research? Yes and absolutely, but only if we start thinking and acting *“out of the box”*; if we leave bureaucracy and implement new rules, legislation and directives everywhere. Here are only a few examples addressing the 10 facts here above:

- 1) Address the environmental pollution and epigenetic factors which will benefit us all and not only autism.
- 2) Acknowledge that an adult with autism still remains a child although he can play a productive role in society and join (the workforce with special protection and services).
- 3) A suicide being the tip of the iceberg, mental health services and not poisonous drugs could reverse the situation.
- 4) Any service with human approach, understanding and compassion can be beneficial to autism, regardless the titles and certifications related to different autism educational programs. Autism needs first of all sensitive humans.
- 5) Instead of forcing hospitals or emergency rooms to put a label *“We don’t accept patients with autism”*, IACC could implement detailed directions on how to treat a patient with autism and

enforce every hospital, ER or health facility to strictly follow them; if not, some legal actions and sanctions must be taken against them.

- 6) As for the judiciary system, some Autism Law Centers must be implemented in every State where attorneys and judges must take an educational course about autism, pass an exam and only then can they continue their practice. The other alternative would be to separate them in two categories: autism educated and not. Also, autism organizations must have a list of autism educated attorneys who take pro bono cases, contingency cases or both.
- 7) Regarding the dramatic issue of parental chronic denial, please read my detailed written comments of 1/12/2016.
- 8) The voluminous amount of publications and research articles fails to give solid results as many confounding factors have been omitted leading to fast, conflicting, misleading and non-reproducible results. The IACC could implement strict regulations and rules for the IRB committees, when an autism study is to start and be funded.
- 9) Autism societies must become less bureaucratic, more human and in contact with the families and people voting for their board. If not, they lose their role and perspective.
- 10) Poverty has a negative effect on everyone, but in case of autism it becomes devastating. In a period of economic crisis, I am not asking for more federal money (SSI, Food stamps, etc.), but rather to implement measures to avoid poverty.

Note: For all the above mentioned facts and solutions, I have a huge amount of documents, photos, witnesses, websites and experts and I am willing to present them to any forum or federal NIH committee.

From Dr. Linda (Angelique) Papadimitriou-Varsou, PhD, MPH, DABCC, Immunologist, Hygienist, Clinical Biochemist, Associate Professor in Medicine. *Mother and legal guardian of a 31-year-old college student with autism; advocate for the Rights and Strengths of People with Autism, a fervent supporter of the concept: “An Autism Friendly Society will benefit us all”.*

SHORT BIO: Long-standing member of different autism related organizations and scientific societies in the US. Founding and board member of the Greek Society for the Protection of Autistic People and founding member of the Greek Scientific Autism Network. Long-standing member of “Autism-Europe”, and elected member to its Council of Administration. MSc in Biochemistry and postgraduate studies, Paris University; Specialization in Immunology, Paris Institute Pasteur, France; MSc in Public Health with honours; Diplomate of the American Board of Clinical Chemistry; Two PhDs in Diagnostic Laboratory Medicine; Research Associate at the University of Maryland School of Medicine, Faculty member at Johns Hopkins University School of Medicine where I studied neurosciences and initiated the “**fever study in autism**”. Current position: Associate Professor at the University of Athens School of Medicine in Greece, responsible for teaching 3rd year Medical students and graduate students in three MSc Programs at the Departments of Biology, Chemistry and Clinical Pharmacy -a position which allows me to spend more than half of the year in the US with my son, while continuing my teaching online.

Address: [PII redacted] Baltimore, Maryland [PII redacted]

Contact: [PII redacted] and avarsou@med.uoa.gr

In this presentation, I plan to teach awareness of how a subculture and community in the United States—the Japanese anime fan community—has worked to create effective social teaching strategies for people with autism in their community.

The information I am sharing here is based on my experiences within this community, and what I have learned and witnessed from them.

I have been a member of the anime community, and an attendee at anime conventions, since 2010. My first anime convention was Anime Central in Rosemont, Illinois, the third-largest anime convention in the United States by average attendance. I have also served as a volunteer at anime conventions since 2012, starting with Kitsune Kon in Appleton, Wisconsin. In 2015, Animecon.org, an organization that plans and runs anime conventions in Illinois, Iowa, and Minnesota, hired me to work on their staff. Finally, I have been an active presenter at anime conventions since 2013, performing as a musician, and presenting on autism awareness at anime conventions around the country.

Many people with autism enjoy anime, and belong to the anime community. Thus, the community has had to accommodate their unique needs. People with autism enjoy anime for many reasons, but three “core reasons” have been identified by such individuals I have met while working within the community. First, they have explained to me that anime serves as an escape from struggles and unpredictability people with autism endure in real life. Second, anime shows and films are often a predictable interest with understood storylines and plotlines. And third, talking about an interest in anime represents a simpler way for many people with autism to make friends without small talk.

However, people with autism do not always understand the social expectations and unwritten social rules when associating with other anime and manga fans, which can result in rejection from fandoms even when they are enthusiastic fans of specific types of anime and manga. They can unintentionally break anime convention rules and policies due to misunderstandings that can result in their expulsion from an anime convention. At anime conventions and fandom group meetups, they can engage in behaviors mistaken as intentional harassment and/or potentially leading to abuse that can upset other anime fans and, even when no harassment is intended. Yet on the flipside, “creepy” and “bad” anime fans tend to target them more frequently. They suffer the risk of being harassed and potentially abused by them, while simultaneously finding themselves accused for harassment.

Because of this, and to make sure that everyone understand the rules and regulations, very few social rules at anime conventions are unwritten at most anime conventions, which makes things much simpler for people with autism who struggle with instinctively “knowing” unwritten rules the way neurotypical individuals do.

So what do the typical rules at anime conventions consist of? One category of social rules has been categorized by my people in the anime community as the “Cosplay is NOT Consent” social “curriculum.” This curriculum teaches appropriate social boundaries in relationships and friendships by teaching that people’s boundaries need to be respected regardless of the costume they are wearing or their physical appearance. It also teaches that NO social boundaries can be violated on the grounds of a person’s physical appearance, and that NO one can be bullied or judged based on their costume. And finally, it

also teaches that a person's costume or appearance can not be used to assume a person's age, or ability to consent to any undesired behaviors.

Although rules vary at anime conventions and fandoms, a few rules appear at ALL anime conventions, such as:

No harassment, stalking, and unwanted interaction is permitted between conference attendees.

All weapon-like props must be approved by convention staff before being allowed to be carried at the convention.

Any activity illegal outside of a convention is illegal at a convention.

Finally, most anime conventions also require their attendees to carry a photo ID to identify if they are over 18 so they do not accidentally engage in any illegal activities with minors.

Meanwhile, many anime-themed video games and computer apps have been created that teach social thinking skills. Many of these games appear in the "visual novel" genre of gaming, such as the fantasy and anime-themed visual novel "Long Live the Queen." In these games, a player controls the main character through a visually-based, novel-like story, and as the character progresses through the story, the player decides what social decisions the character makes. They may also control certain activities or things the player does during the course of their daily life, within the story. The decisions that the player decides to have the character make determines their fate throughout the game. And if the player doesn't make the right social decisions, you may lose the game or even die before the end of the story.

In addition, the genre of "dating sim" games, such as "Eiyuu Senki," involve players navigating characters as they date romantic interests within the game. These games teach appropriate social behaviors in dating relationships, and games have been created that encompass all forms of romantic relationships (such as straight, gay, lesbian, etc.). In order to win the game, you must successfully date your love interest and make sure that he or she does not perceive you as "creepy," and you must engage in appropriate dating behavior. If you fail to behave appropriately, you lose the game.

These observations within the anime community, based on my experiences and work within this community, have enabled me to conclude that anime conventions, and the work in the anime community can serve as a great resource for fostering social development, social skills, and social independence for people with autism.