Written Public Comments

IACC Workshop on Under-Recognized Co-Occurring Conditions in ASD

September 23, 2014

List of Written Public Comments

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

Teresa Arens

July 1, 2014

Subject: Autism Concerns

I am writing as a person who lives in a very rural area in Nebraska. I have a very hard time finding someone to help me with the care of my 11 year old daughter with Autism. I also have to drive over 3 hours to get to the nearest help for her.

We are very blessed that we have a school only about 20 minutes away that she can attend. They are very loving and very good with her. But any medical help we want/need is hours away.

I deal with daily "emergencies" from poop explosions (and played with) to what did she just eat. It is very exhausting. Anything that you can do to help us get some support for families that live a distance from help would be great.

We have been dealing with runny pants for the last few months. I have taken her to her pediatrician but we are at a loss there. It is getting very old and tiring changing so many pants and cleaning up the mess. In fact the photo I attached [Photo redacted] is one that I took while I was writing this.

I haven't had much time to really think about this and write it as well as I would like. If you have any questions about how you can help my daughter and our family better in the wonderful midwest please contact me and I would be very happy to talk with you, in between emergencies.

Teresa A. Arens

[PII redacted]

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

Bhagwan Mirchandani

July 9, 2014

Subject: My dad had Asperger's

My dad passed away last October at age 73. He raised my sister and me alone. In the last week, my reading has convinced me he had Asperger's. If you need information about NTs with a single parent father with Asperger's, you may contact me (and my sister). My e mail is [PII redacted]. Thanks, [PII redacted] I am looking forward to learning more for a deeper understanding.

Martin Theiss

July 27, 2014

Subject: Due Process

I want to say that I am glad that I can tell the Secretary of Health that I am enrolled in a pharmacy technician class. I feel it is an improvement over distribution work in the last seven years I have done and I would be very eager to be able to keep tabs on your business and development in the State of Nevada since autistic workers can be a key to our future here.

If you would like my opinion I would be very surprised if the IACC would be certified as part of the California State Workforce Investment Board if they try to gain certification under Section 503 of the Rehabilitation Act of 1973. The IACC would certainly have better chances if they redevelop their California objectives to cite Section 1 of the Americans with Disabilities Act or Section 7 of the Civil Rights Act of 1974. I appreciate this opportunity to share my thoughts.

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

Teresa Rietveld

[PII redacted]

August 4, 2014

Subject: HELP! Aid for Post Second. Education program for indiv. w/Autism

To the members of the IACC committee:

I am the mother/guardian of a 20-year old son who has been diagnosed with Autism for many years. I am also a professional in the disabilities field, just completing my 26th year with my employer. Legislation and laws for autism have my support. I am very concerned about the lack of appropriations for the children who have autism or their families on their behalf. For instance, our son was accepted into what we believe is a wonderful "college" training program for students with disabilities. It was the only one we were able to locate in our state. However, as it isn't a program that offers a degree or a technical license/certification, etc., there is $0 financial resources available to him/other students like him through the local, county, state, or federal government programs. As he isn't receiving a degree or certificate for specific area, he/the program is automatically disqualified for any of the typical college financial assistance programs such as through FAFSA applications. He is on a (Medicaid) HCBS waiver program as has always had private health insurance and for many years Medicaid as well. He further receives supports from Vocational Rehabilitation. Last year Voc. Rehab. did provide approximately $1,000.00 total for his first year tuition. For school year 2014-2015 he will receive approximately $300.00 total for the year. We strongly believe his attendance at the program he is enrolled in is making and will continue to make a marked difference in his abilities which will directly influence his ability to obtain "gainful" employment in order to assist him with being a "productive member of society". However, when the program cost alone is almost $26,000.00 for one year, it is not possible for a "middle class/working" family to provide. Remember these are the basic required costs and fees. This does not assist with transportation for the student nor any of the additional needs of a college student, especially one who has fairly significant disabilities. From reading and studying the Combating Autism Act, I do not see how individuals/families responsible for the individuals directly benefit.

The following is a copy from part of a document given to us by the program requiring parent/guardian and notary signatures. I have removed the name of the program.

Financial Statement of Proof for Iowa Residents Class of 2015

Note to parent(s)/guardian(s): As part of the enrollment process for year 2, xxxxxxx students and the family must submit evidence of adequate support to cover the costs of one full year of participation in the xxxxxxx Program. Be sure to attach the appropriate attested supporting documents. The student's enrollment for year 2 cannot be finalized, without proper certification of financial ability to provide support. Please type or print legibly.

Section A. Expenses--These are the 2014-2015 rates for the xxxxxxx Program and University fees.

$ 14,083	1) Resident tuition (program fee) for the academic year

$ 1,401	2) University Fees for the academic year
$ 9,711	3) Room and board costs (9 months)
$ 220	4) Estimated cost of textbooks, supplies, and activities
$ 120	5) Estimated transportation costs for bus pass ($60/semester)
$ 25,535	**Total estimated costs for 2014-2015**

Any/all IACC members, I would openly welcome any questions, comments, or input you may have.

SINCERELY,

Teresa Rietveld, Parent/Guardian of a child with Autism.

My Best Contact is Mobile # [PII redacted]

“Just living is not enough," said the butterfly, "one must have sunshine, freedom, and a little flower.”
— Hans Christian Andersen, The Complete Fairy Tales

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

Marian Dar

August 21, 2014

As the parent of [PII redacted], a now 26 year-old man with autism, I know first-hand and well the large and endless challenges of caring for an autistic individual.

Growing up, there were years of cleaning smeared feces off bathroom walls and floors at 3 am in the morning; then and still today there are rescue and pick-up calls from local supermarkets and candy shops about a "wandering person" covered from head to toe with Confectioner's sugar and crumbs and with pockets stuffed with stolen cakes and candies etc.

That said, I write today as I become increasingly concerned and exasperated with the deteriorating "management" of [PII redacted]'s life as a young adult. The State Agency working with my son has operated with an armchair mentality and model that is skeletal at best, uninspired and dysfunctional.

As a consequence my son's well-being and chances of a more independent and successful future are potentially forever compromised.

[PII redacted], like many with autism, has not insignificant behavioral issues and needs assistance managing them. However, in the past five years the only intervention he's received from his State-approved agency is —*increasing numbers and doses of medication.*

Despite repeated suggestions about a wider and more analytical, inclusive net (the state of the art in many States and agencies) — *no change in programming, management or approach has occurred*.

Despite repeated suggestions and now pleas that other mechanisms and monitors be in place, along with the State–funded *medications requiring no staffing or programming by the Agency (economic incentives misplaced)*, the woefully inadequate and unhealthy status quo endures.

We in the US and the State of "Anywhere" consider ourselves progressive. Yet and sadly, the proverbial system cliff for those over 21 with disabilities is alive and well. How can we allow our young adults with no voice to live like this — who is [PII redacted]'s advocate here?

STATE
: Case Manager
How frequently and what issues should this person be addressing, overseeing and following?
Does this person have *experience and/or any current specialization with this disability (autism)?*

AGENCY
: OVERSIGHT of staff (what is the obligation and role of an Agency Case Manager)?
: ACCOUNTABILITY?

María Luján Ferreira

August 21, 2014

Subject: Comment on next workshop on health issues

I don´t understand why the requests continue to be done to public inquiries when after the meetings, nothing is done, practically or efficiently related to these, extremely key topics to the health and progress of many children like my son. AS a commenter from a country outside the USA and a PhD in Chemistry, I simply can´t understand the situation.

However, for What is worth, I consider that the medical problems in autism -ASD and their importance is one of the key aspects forgotten in the current models that are being discussed as majority (genetics or epigenetics/prenatal determination of versus neurodiversity approach to disability).

The model of ASD-Autism as a chronic dynamic, systemic encephalopathy to be considered in the context of systemic pediatric (or teen or young adult or adult) complex pathology (many medical problems, biological, not neurological only, not brain only, not psychiatric only, not behavioral only, not genetic only and so on) was, is and will be the road to life quality with lower costs, suffering and higher efficiency, safety (if properly done) and functioning that any of the other models. In fact this new model includes the other ones.

About the different medical problems that are important to consider, this manuscript presents very well the situation Medical Comorbidities in Autism Spectrum Disorder. Unfortunately, this kind of material is not considered even in the formulation of models of contribution to symptoms and correlation with pain, aggression, self-aggression and many other" supposedly psychiatric" comorbidities.

Even more, the work about PANDAS-PITAND-PANS, especially in the context of the immune dysfunction many children have, is not even properly mentioned or analyzed. This work is key to be considered, especially when anxiety, aggression, irritability, TOC (as part of the presentation, individual in nature) are present as comorbidities.

Recommended speakers
-Dr Martha Herbert
-Dr Susan Swedo
-Dr Alesio Fasano
-Dr Robert Frye
-Dr Theoharides
-Dr Paul Ashwood/Judy Van de Water
-Dr Richard Deth
-Dr Richard Frye
-Dr Abba Chauhan
-Dr Jill James
-Dr Isaksen

Sincerely
M. Luján Ferreira
PhD in Chemistry
Mom of a child diagnosed with ASD -2003

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

Beverly Frost

August 21, 2014

My 49 year old son, [PII redacted], has diagnosed autism, mental illness, former substance abuse, learning disabilities, probable TBI (possibly from head banging) and is [derogatory language redacted]. Needless to say growing up for him was tough for both of us. He is also high IQ and managed to graduate from college with a BS degree in four years and earning it with distinction. Unfortunately he has not been particularly successful as an adult I think partly because of a total lack of appropriate support. Finally after letting him flounder on his own for many years I had to step in and he is doing somewhat better and he could work if only someone would hire him.

His early evaluations were unfortunately lost but he does have extensive testing as an adult confirming his disability. I am not sure if he would be of interest to someone working in this area but he would be very open to talking to or meeting someone to talk about his challenges. He is very verbal now, drives and travels. He is open to calls at [PII redacted] or email at [PII redacted].

Beverly Frost
[PII redacted]

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

Ann Z. Bauer

August 27, 2014

Subject: How to avoid the ensuing public health crisis of non-vaccination

Although the exact contributions are debated, it has become clear that both genetics and environmental factors play a role in autism etiology. One environmental factor that appears to be a plausible contributor and has not been thoroughly investigated is paracetamol/acetaminophen. Paracetamol is the most commonly used medication during pregnancy and given to young children- often in conjunction with vaccines. It can cross the placenta and blood brain barrier. A 2009 FDA report indicated that the therapeutic index of paracetamol is so narrow that many users receive a toxic dose in the course of normal use. Two prospective cohort studies have found that prolonged use during pregnancy increased the risk of adverse neurodevelopmental outcomes (Brandlistuen et al. 2013, Liew et al. 2014). Animal models have shown paracetamol and it's metabolites to have neurotoxic effects (See attached studies).

I implore you to advocate for further studies and to push for publication of the studies already underway. I obviously do not know if these studies will find an association but if one is found, all facets of the autism community may be appeased - the researchers who have shown autism to develop prenatally, as well as, the parents who are convinced their child regressed into autism after vaccines.

I spoke to [PII redacted] with the Danish Birth Cohort about three years ago to inquire about my participation in such a study. He told me the study was already underway. They did publish on ADHD (Liew et al., mentioned above), but have not published on autism. It should be close to completion. An inquiry from you may help push this along. I have been in contact with investigators from The Norwegian Mother and Child cohort (MoBa), used in the Brandlistuen study. The cohort is now old enough for a ASD diagnosis and it appears that the follow up study is just beginning. I have a collaborative agreement to use the Quebec Birth Cohort but this has yet to be funded.

I urge you to facilitate investigation of this hypothesis. Because paracetamol is largely an over-the-counter medication, exposure assessment must rely on self-report and requires a prospective study design. A study designed specifically around this research question would be superior to the mentioned studies but these can provide somewhat expeditious results.

Thank you for your consideration of this matter,

Ann Z. Bauer

(Attached Studies)

Brandlistuen RE, Ystrom E, Nulman I, Koren G, Nordeng H. Prenatal paracetamol exposure and child neurodevelopment: a sibling-controlled cohort study. *Int J Epidemiol.* 2013 Dec;42(6):1702-13. [PMID: 24163279]

Posadas I, Santos P, Blanco A, Muñoz-Fernández M, Ceña V. Acetaminophen induces apoptosis in rat cortical neurons. *PLoS One*. 2010 Dec;5(12). [PMID: 21170329]

da Silva MH, da Rosa EJ, de Carvalho NR, Dobrachinski F, da Rocha JB, Mauriz JL, González-Gallego J, Soares FA. Acute brain damage induced by acetaminophen in mice: effect of diphenyl diselenide on oxidative stress and mitochondrial dysfunction. *Neurotox Res*. 2012 Apr;21(3):334-44. [PMID: 22081409]

Viberg H, Eriksson P, Gordh T, Fredriksson A. Paracetamol (acetaminophen) administration during neonatal brain development affects cognitive function and alters its analgesic and anxiolytic response in adult male mice. *Toxicol Sci*. 2014 Mar;138(1):139-47. [PMID: 24361869]

Dean SL, Knutson JF, Krebs-Kraft DL, McCarthy MM. Prostaglandin E2 is an endogenous modulator of cerebellar development and complex behavior during a sensitive postnatal period. *Eur J Neurosci.* 2012 Apr;35(8):1218-29. [PMID: 22512254]

Blecharz-Klin K, Joniec-Maciejak I, Piechal A, Pyrzanowska J, Wawer A, Widy-Tyszkiewicz E. Paracetamol impairs the profile of amino acids in the rat brain. *Environ Toxicol Pharmacol.* 2014 Jan;37(1):95-102. [PMID: 24316461]

Liew Z, Ritz B, Rebordosa C, Lee PC, Olsen J. Acetaminophen use during pregnancy, behavioral problems, and hyperkinetic disorders. *JAMA Pediatr.* 2014 Apr;168(4):313-20. [PMID: 24566677]

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

Eileen Nicole Simon

August 29, 2014

Following are some additional comments (and many many questions) that I hope can be discussed:

SEARCH FOR A CURABLE CAUSE?

The workshop on September 23 is taking place I believe in response to so many stakeholder requests for co-occurring conditions in autism to be investigated.

How often I wished 50 years ago for a curable cause to be found that could restore my two sons to perfect health. I knew both of my children suffered trauma and anoxia during difficult births, but the doctors told my husband and me that most children do not suffer lasting consequences following a difficult birth.

I was hopeful that a genetic problem like PKU could be identified, which like PKU could be treated by diet or other means. We consulted [PII redacted] at Children's Hospital in Boston, who did extensive testing but could find no genetic defect in our children.

Then I found and read the article in Science Magazine (April 1968) on Orthomolecular Psychiatry by Linus Pauling, which I took to the first Association for Mentally Ill Children (AMIC) meeting I attended in a Boston suburb, and pointed out the recommendation of taking a gram or more of vitamin C every day to possibly correct a "scurvy of the brain." That was good for a laugh, but soon the mega-vitamin craze was the rage.

Then in October 1969 I read the article by William Windle on brain damage caused by asphyxia at birth. The most prominent damage was in nuclei of the auditory pathway. All I could do was weep. That was when I first faced up to brain damage as the cause of my children's language problems.

COMMENTS SUBMITTED FOR THE JULY MEETING

I submitted comments for the July 2014 IACC meeting on co-occurring conditions. I am told those comments will be posted online. Following are summaries or expansions of comments (1-9) I submitted for the July meeting:

1 - AUTISM'S MANY CAUSES

Many very different medical conditions are associated with autism, prenatal rubella infection, prenatal exposure to alcohol or valproic acid, asphyxia at birth, neonatal jaundice, and lead poisoning in childhood. And autism occurs in many genetic disorders, even Down's syndrome.

PKU (a former cause of autism) is treatable by a diet low in phenylalanine. Is there some metabolite or set of metabolites from aberrant enzymes in Down's syndrome that might affect the brain areas injured by other causes of autism? Wouldn't dietary treatment or even dialysis be preferable to abortion?

What is the final common pathway in the brain affected by all of the disorders that cause autism?

2 - BRAINSTEM SITES OF HIGH AEROBIC METABOLISM?
Similar patterns of symmetric bilateral brainstem damage are caused by (a) asphyxia at birth (reported by Ranck & Windle in 1959) and (b) alcohol intoxication (first reported by Wernicke in 1881). The research of Seymour Kety and Louis Sokoloff revealed the highest blood flow and aerobic metabolism in nuclei of the brainstem auditory pathway. See citations below.

Asphyxia leads to ischemic damage. Hemorrhagic damage is caused by alcohol and other toxic substances.

Autonomic centers in the brainstem must also be sites of high blood flow and metabolism, but perhaps too small to be revealed by Sokoloff's deoxyglucose method. Possibly these have been reported in some of the research based on the deoxyglucose method.

3 - BOWEL DISORDERS?
Those who work with alcoholics and substance abusers are well aware of the GI and bowel problems suffered by these [offensive language redacted] people. I have been royally criticized for suggesting that similar autonomic dysfunction might cause the bowel problems of children with autism. Parents desperately want treatment of the bowel disorder to put an end to the brain irritation caused by a "leaky bowel."

4 - AUTOIMMUNE DISORDERS?
Could autoimmune problems, like bowel problems, arise from the anoxic or toxic causes of brain damage? Damage to brain tissue is likely to evoke an immune response. As an immune reaction to host tissue, could this be an autoimmune reaction?

How much parents want to believe that treatment of the autoimmune disorder will stop its effects within the brain.

5 - MITOCHONDRIAL DISORDERS?
Mitochondrial disorders are likely to have their greatest effect in brainstem sites like the most metabolically active nuclei in the auditory pathway. Mitochondrial enzymes are the catalysts of successive steps in aerobic energy metabolism. Mitochondria are bacteria-like and may have originated as symbiotic infections of primeval multicellular organisms.

Mitochondria may suffer damage from antibiotics and other drugs. Mitochondria are unable to mutate the way modern wild bacteria do, so while bacteria are becoming more resistant to antibiotics, mitochondria remain vulnerable. Antibiotics may be overused in neonatal intensive care units. See papers by WA Silverman and AF Robertson (citations below).

6 - SEIZURE DISORDERS
Seizure disorders result from missed connections between sites of signal transmission and intended target areas of the brain.

In the experiments with monkeys on asphyxia at birth, prominent damage was found in brainstem nuclei, and maturation of the cerebral cortex did not progress normally in monkeys kept alive for many months and years. See the paper by Faro and Windle, 1969.

Brainstem damage leads to missed connections during maturation of circuits in the cerebral cortex. Rewiring, or “plasticity” may occur, but is likely to be aberrant. “Under-connectivity” seen in fMRI scans, and recent abnormal “patches” in the cortex of brains from people who were autistic, should be compared with the abnormal maturation of the cortex observed in monkeys subjected to asphyxia at birth.

Maturation of the cortical language areas continues for at least 4 to 5 postnatal years. Damage by oxygen deficiency at birth and toxic exposures during infancy are as disruptive as maldevelopment during early gestation.

7 - ATTENTION DEFICIT SPECTRUM?

Disturbed social attention is believed by many to underlie failure of language development in autism. Could this be another euphemistic way to deny maldevelopment of the language areas in the cerebral cortex? Social obliviousness in autism is part of a more extensive lack of general awareness, or deficit in consciousness.

Language is the defining feature of the human species. It is not completely abolished in most cases of autism. Children with ADHD are afflicted with language and intellectual deficits, but to a less severe extent than in autism. Should autism and ADHD be viewed as part of a spectrum of developmental disorders?

8 - SCHIZOPHRENIA SPECTRUM?

Schizophrenia appears in adolescence or early adulthood, following apparently normal development during childhood. However, uneven development, especially in school, is reported by mothers in many cases. I know this from my 23 years working at the state hospital for mentally ill prison inmates in Massachusetts (Bridgewater).

High functioning autistic people, like my oldest son, may get a diagnosis of “schizo-affective” disorder when they are apprehended by police, and presented to court evaluators. My son now lives in a “community” group home, with alarms on all the doors. Six men live in this house, with three shifts of 2 to 3 staff on each shift. Many residents of this house fit Kraepelin’s descriptions of “dementia praecox,” replaced by the euphemism schizophrenia a little over 100 years ago.

My son does not suffer from dementia. He continues to make cognitive progress. He is capable of doing useful work, but he is not being helped to gain skills for employment and independent living. He is a misfit in this house. I take him out several times a week to go to the library or a coffee shop to write. We have written two memoirs together, and are working on our third. Look for our series *Autism and the Inferior Colliculus* on amazon.com.

Autism should not be confused with schizophrenia. Both disorders may be initiated by the same disrupted systems in the brain, especially the auditory system, but childhood development and lifespan needs are different.

9 - DEPRESSION

Depression is the final common condition that afflicts many (if not most) who had developmental problems. This is especially true for those, like my oldest son, who overcame the most serious of his disabilities.

My son did not speak normally until he was almost six years old. By then he had been excluded from attending public kindergarten (in 1967). He was admitted to the children's unit, Ward 6, at the Massachusetts Mental Health Center at age 5. He blossomed with the gentle guidance of an inspired and dedicated special education teacher. By age 7 we thought he had overcome all of his problems, but by age 17 it was clear he would in no way be able to go to college.

"Not everyone goes to college," a social worker chided us.

What??? College, and saving for it from infancy is one of the great American expectations.

During his special education years, when asked where he went to school, my son replied on more than one occasion, "I go to the junkyard school for junked children."

Lifespan care for people with autism is in the news lately, "life after 21." Now we are up to life after 51. I started a whole new career (nursing) after the age of 50. My son wrote about Julia Child's career beginning at age 50. I still hope looking forward to greater productivity can be a focus of support for him.

Following is a brief chronology I recently provided to my son's case manager:

After 21 - was spent drifting from home to being lost, to state hospitals (Northampton, Taunton, Bridgewater), a group home in Boston, coming to the attention of the police, jails, and probation.

After 30 - began the greatest growth period, at Westborough State Hospital. Most important was the job he had at the Clarke Workshop. Seeing the bird feeders he assembled for sale at the entrance of Caldors as Christmas gift suggestions was a truly great emotional moment. "That's my work!!!" he exclaimed. For the first time in his life I think he felt like part of the real world.

After 40 - was his discharge to the "community" group home, with alarms on all the doors. He was so unhappy that he ran away, five years ago (March to May 2009). "He's not ready," was the response of staff during the 6 years (2003-2009) for everything, GED, supported employment, etc...

After 50 - what can we look forward to now??? It was very distressing to learn a year or so ago that the Department of Mental Health (DMH) cannot guarantee housing for everyone. "Recovery is real" is their [offensive language redacted] motto, which implies that substance abuse treatment is the new DMH mission. This is so infuriating. Substance abuse could be avoided with appropriate education in the schools. Students should graduate knowing that drugs damage the brain, and beyond dementia maybe the most disgusting outcome really is GI problems, with chronic constipation, laxatives, cathartics, and loss of control...

My son deserves better. He is now a published author. See our two memoirs on amazon.com; search for inferior colliculus. Still a part-time day-job would be helpful, as it is for me in my 70s still.

I too am sick with depression and grief. Stop smiling at us and talking about early identification and early intervention. My son has progressed more than most, but this has not been a happy life.

NEURODIVERSITY?

The euphemistic idea that language disorder in autism results from difficulties forming social relationships has led quite a few people to identify their shyness and problems with friendships as a form of autism. They strongly oppose the idea that autism is a neurological disorder. These are the self-advocates who want to promote the idea of "neurodiversity," and oppose funding of research looking for brain impairments that cause autism.

This form of autism must be clearly differentiated from the neurological disorder that disrupts normal language development.

Could "childhood aphasia" possibly replace "autism" as the diagnostic label for our severely afflicted children? Research on neurological impairments that prevent normal language development is urgently needed at this point in time when so many children can only attend school in special education classes.

The IACC should retain the focus of the Combatting Autism Act. More parents of children with serious developmental problems should be appointed as public members, and especially if more self-advocates are now to be appointed.

LANGUAGE, THE PRIMARY CONCERN?

Neurologic impairments must remain primary even in discussions of co-occurring conditions in autism. Since the first IACC meeting I attended in November 2003, I have raised the following concerns over and over (about language and brain injury):

(1) Language handicap is the most serious aspect of autism, and should be the first priority for research. Failure of language development is a neurological disorder.

(2) Nuclei in the brainstem auditory pathway are especially vulnerable to oxygen insufficiency at birth, and also to toxic substances. This is because aerobic metabolism is higher in the auditory pathway than any other area of the brain. Lookup some of the research done using the deoxyglucose method developed by Louis Sokoloff.

(3) Language development depends upon an intact auditory pathway.

(4) Maturation of the cortical language circuits depends upon neurotransmitters produced in nuclei of the auditory pathway.

(5) Loss of the ability to understand spoken language has been described in more than a dozen case reports of traumatic injury of the inferior colliculi in the midbrain auditory pathway.

(6) Complications at birth have been reported more than any other perinatal factor in children who developed autism. Low Apgar scores and respiratory problems are prominent in these reports. Nevertheless authors of these papers suggest some problem with the mother or baby as the cause of complications. Yes? Small pelvic dimensions, malpresentation like breech or occiput posterior...

(7) Since the mid-1980s clamping the umbilical cord immediately after birth has become a standard protocol in obstetrics. This is a serious medical error. Placental circulation does not cease until the fetal

heart valves have closed. Traditional textbooks taught that pulsations of the cord should cease before tying or clamping it.
(8) There is no health benefit from clamping the umbilical cord. The IACC should work with the American College of Obstetrics and Gynecology to get this procedure stopped.

VERBAL AUDITORY AGNOSIA AND APRAXIA?
Isabelle Rapin in 1997 pointed out that the language disorder in some autistic children could be the result of verbal auditory agnosia.

Since the advent of MRI many reports of verbal auditory agnosia following injury of the inferior colliculi have been published (see citations below).

In a recent discussion (August 21-24) on the Age of Autism blog it was suggested that the IACC should require funding of the Rapid Prompting Method (RPM) for all non-verbal children with autism. I expressed my skepticism, then I went to PubMed and put in search terms: apraxia speech autism. This brought up a very interesting article by Tierney et al. (cited below) that clarified apraxia of speech for me, which may represent failure of development of Broca's language area?

Language depends upon neural circuits between the auditory receptive areas of the temporal lobes and Broca's areas (left and right) in the frontal lobes. Auditory problems, including hyperacusis, are prominent features of autism. Even the briefest lapse in respiration at birth may cause damage within the brainstem auditory pathway, which in turn may impair normal maturation of Broca's as well as Wernicke's language areas in the cerebral cortex.

The oral presentation I plan to make at the co-occurring conditions workshop is on this topic. I hope the above comments on agnosia and apraxia clarify what I have to say. I hope language development and neurological signs will not be totally omitted from the workshop topics.

EVIDENCE?
What evidence can be provided that the neurological difference in autism is a normal natural variation in the human genome? Language is the defining feature of the human species. Its failure to develop is the result of abnormal brain development.

A great deal of evidence is available of neurological impairment in autistic children and adults. Very few children completely outgrow autism.

Anyone who claims to have recovered from autism must produce pediatric records of language delay, and stages of recovery from early difficulties learning to speak. Well documented stages of recovery from delayed language development should be of great interest to scientists engaged in research on language development.

REFERENCES
Bilaterally symmetric damage in the brainstem

Thomson AD, Cook CC, Guerrini I, Sheedy D, Harper C, Marshall EJ. Wernicke's encephalopathy revisited. Translation of the case history section of the original manuscript by Carl Wernicke 'Lehrbuch der Gehirnkrankheiten fur Aerzte and Studirende' (1881) with a commentary. Alcohol Alcohol. 2008 Mar-Apr;43(2):174-9. Free online at http://alcalc.oxfordjournals.org/content/43/2/174.long

Blood flow and metabolism in the brain

Kety SS. Regional neurochemistry and its application to brain function. Bull N Y Acad Med. 1962 Dec;38:799-812. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1804882/?tool=pubmed

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.

Damage by asphyxia:

Myers RE. Two patterns of perinatal brain damage and their conditions of occurrence. Am J Obstet Gynecol. 1972 Jan 15;112(2):246-76.

Miller JR, Myers RE. Neurological effects of systemic circulatory arrest in the monkey. Neurology. 1970 Jul;20(7):715-24.

Miller JR, Myers RE. Neuropathology of systemic circulatory arrest in adult monkeys. Neurology. 1972 Sep;22(9):888-904.

Abnormal brain maturation:

Faro MD, Windle WF. Transneuronal degeneration in brains of monkeys asphyxiated at birth. Exp Neurol. 1969 May;24(1):38-53.

Damage by antibiotics:

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

Silverman WA. The status of 2-year-old children who had received sulfisoxazole in the neonatal period after premature birth. J Pediatr. 1959 Jun;54(6):741-7.

Robertson AF. Reflections on errors in neonatology: I. The "Hands-Off" years, 1920 to 1950. J Perinatol. 2003 Jan;23(1):48-55. Free online at http://www.nature.com/jp/journal/v23/n1/full/7210842a.html

Robertson AF. Reflections on errors in neonatology: II. The "Heroic" years, 1950 to 1970. J Perinatol. 2003 Mar;23(2):154-61. Free online at http://www.nature.com/jp/journal/v23/n2/full/7210843a.html

Robertson AF. Reflections on errors in neonatology III. The "experienced" years, 1970 to 2000. J Perinatol. 2003 Apr-May;23(3):240-9. Free online at http://www.nature.com/jp/journal/v23/n1/full/7210842a.html

Verbal auditory agnosia in autism?

Rapin I. Autism. N Engl J Med. 1997 Jul 10;337(2):97-104.

Apraxia of speech?

Tierney CD et al. Clear as mud: another look at autism, childhood apraxia of speech and auditory processing. Curr Opin Pediatr. 2012 Jun;24(3):394-9.

Verbal auditory agnosia following injury of the inferior colliculi

Pillion JP. Speech processing disorder in neural hearing loss. Case Rep Med. 2012;2012:206716.

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.

Pan CL. et al. Auditory agnosia caused by a tectal germinoma. Neurology. 2004 Dec 28;63(12):2387-9.

Musiek FE. et al. Central deafness associated with a midbrain lesion. J Am Acad Audiol 2004 Feb;15(2):133-51.

Hoistad DL, Hain TC. Central hearing loss with a bilateral inferior colliculus lesion. Audiol Neurootol 2003 Mar-Apr; 8(2):111-223.

Vitte E et al. Midbrain deafness with normal brainstem auditory evoked potentials. Neurology 2002;58:970–973.

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.

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

Hu CJ et al. Traumatic brainstem deafness with normal brainstem auditory evoked potentials. Neurology 1997;48:1448–1451.

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.

Nagao M, Kita Y, Kamo H. Haemorrhage in the inferior colliculus. Neuroradiology. 1992;34(4):347.

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.

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

--
Conrad Simon Memorial Research Initiative
To seek understanding of brain system impairments in autism.
http://conradsimon.org/

Teresa Rietveld

September 4, 2014

Subject: Assistance to college student with Autism

Hello –

I am the mother/guardian of a 20-year old son who has been diagnosed with Autism for many years. I am also a professional in the disabilities field, just completing my 26th year with my employer. Legislation and laws for autism have my support. I am very concerned about the lack of appropriations for the children who have autism or their families on their behalf. For instance, our son was accepted into what we believe is a wonderful "college" training program for students with disabilities. It was the only one we were able to locate in our state. However, as it isn't a program that offers a degree or a technical licensure/certification, etc., there is $0 financial resources available to him/other students like him through the local, county, state, or federal government programs. As he isn't receiving a degree or certificate for specific area, he/the program is automatically disqualified for any of the typical college financial assistance programs such as through FAFSA applications. He is on a (Medicaid) HCBS waiver program as has always had private health insurance and for many years Medicaid as well. He further receives supports from Vocational Rehabilitation. Last year they did provide approximately $1,000.00 total for his first year tuition. For school year 2014-2015 he will receive approximately $300.00 total for the year. We strongly believe his attendance at the program he is enrolled in is making and will continue to make a marked difference in his abilities which will directly influence his ability to obtain "gainful" employment in order to assist him with being a "productive member of society". However, when the program cost alone is almost $26,000.00 for one year, it is not possible for a "middle class/working" family to provide. At this point, we have borrowed the maximum amount our bank will lend us. We have also assisted him to apply for 3 scholarships, 2 of which he was awarded, for a total of $2,500.00 for the 2014-2015 school year. At this point, we continue to be short on our total funds available for the 1st and 2nd semesters. We have been notified by the program that if we don't have proof of our availability to pay the rest of the amount by November, 2014, he will not be allowed to come back to the program following winter break.

Research, early child interventions, summaries of the prior and the IACC committees are all wonderful things. Additionally, in Iowa, the insurance laws for Autism were passed, but ONLY required for the insurance companies of the state employees. This doesn't help my spouse and I and ultimately our child in this situation either. I am at a loss and don't know where to turn. Any questions, comments, input or likewise you have would be greatly appreciated.

Teresa Rietveld, PC/QIDP

Christian Opportunity Center

1553 Broadway; PO Box 347

Pella, Iowa 50219-0347

Phone: Direct Dial My Office: (641) 628-8087, ext. 112; Main Office: (641) 628-1162

E-mail: trietveld@christianopportunity.org

“Just living is not enough," said the butterfly, "one must have sunshine, freedom, and a little flower.”

— Hans Christian Andersen, The Complete Fairy Tales

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

Shannon Rosa

September 8, 2014

Thank you for reading my comments today. My name is Shannon Rosa, and I am the parent of a thirteen-year-old, thoroughly wonderful, autistic young man who does best with 1:1 support. I believe it is the responsibility of all those involved in autism policy to work towards guaranteeing autistic people like my son the support they need to succeed in life, no matter their abilities.

For that reason, I would like to thank the IACC for the positive work it does in advising on autism policy. However, I'd like to speak out about what the IACC can do to help people like my son, and families like ours:

1) Focus on getting supports and resources to autistic people and their families. The CDC's 1 in 68 numbers for autism prevalence are an excellent opportunity to reinforce the message that autistic people of all abilities have always been part of our society, and that we will all benefit if the proper autism resources are allotted -- whether for housing, employment, respite, education, health care, or therapies.

2) Focus on research that helps the autistic people who are already here. We need to know more about autism and sensory issues, autism and anxiety, autism and co-occurring medical issues, and so on. This should be a higher priority than research into causation.

3) Recognize the agency of autistic people, and include more of them on the IACC itself. I have spent many years working with and learning from autistic adults regarding what my son needs, and how he experiences the world. While I support the involvement of parent advocates and autism professionals on the IACC, autistic people themselves should be the majority representation when it comes to advising about autism policy.

4) Finally, stop accommodating pseudoscience. I still keep seeing mentions of vaccine or mercury autism causation theory in the IACC proceedings. Such theories have been debunked repeatedly by legitimate research. Setting aside any time to discuss them is a waste of the IACC's resources, and does not help autistic people.

Thank you for your time,

Shannon Des Roches Rosa

Senior Editor, Thinking Person's Guide to Autism

[PII redacted]

Dawn Loughborough

September 9, 2014

My name is Dawn Loughborough and I am the mother of three wonderful children, one who has autism.

I am commenting on the workshop agenda and notice that it significantly strays from the original intent gathered from the community over the past many years. That original intent was sourced by parents of children who have often regressed into severe medical co-occurring conditions with multidisciplinary concerns such as brain damage, seizures, digestive disorders, bowel disease, metabolic issues, sensory concerns, loss of speech and eye contact and behaviors of elopement or dangerous self-injury again due to neglected physiological concerns. Many children who have these concerns addressed have a better quality of life.

Today's workshop agenda disregards the medically severe individuals with autism who could be served by translational research in these areas of concern.

Our families continue to struggle without regard from this very agency charged by congress to coordinate a strategic plan to address this. This workshop misses very critical topics such as medical standards for pain investigation and treatment. Congress has also requested insights into causation. Currently families are left without best practices and standards of care while leaving these individuals to be discriminated against by not activating these medical standards.

This workshop continues the complete disregard for medical concerns and the agenda instead spends too much time on genetics and mental health as opposed to environment and physiology. This has to shift into a new paradigm committed to the view that autism can be helped by addressing the underlying medical conditions of the whole individual.

I am deeply disappointed in this very misleading stance by the IACC which does not honor the lives of individuals with disabilities who are loved and cherished by their families who want to see them have access to medical practices that alleviate their suffering around these often treatable co-occurring physiological conditions.

Mike Hoover

September 10, 2014

Subject: Autism/Vaccine Inquiry

THE
MAKE IT FIT
FOUNDATION
WWW.MAKEITFIT.ORG
Michael Hoover
Founder, The Make It Fit Foundation
7385 N. State Rt. 3 | Suite 50 | Westerville, OH 43082

Dear IACC Panel,

You have spent 8 years and 1.7 Billion Dollars and have you saved even one person from this DX?... NO... Please study all causes of Autism including vaccines.

Sincerely,

Mr. Mike Hoover
/Mike Hoover/
President/Founder of The Make It Fit Foundation
Dad of 2 Boys on the autism spectrum

Heather Price

September 10, 2014

This is my second written comment to the IACC. I will reiterate briefly the points from my last letter:

1. The increasing numbers of autism diagnoses among the lowest functioning are not related to better diagnosis or to wider understanding of the condition. Where were the multitudes of nonverbal adults just one generation ago? Where were the folks who couldn't provide the most basic self-care for themselves?

2. To bring about tolerance and understanding, we need more awareness of the dirty, often shunned type of autism. You have the power to make people see ALL types of autism, not just the high functioning.

3. Medicaid waivers need to have portability between states. Parents waiting for residential treatment for their children or placement in group homes for their children are locked into their state.

And now I'll bring up vaccines, because most of you on the IACC don't seem to want to do so. The in-fighting in the autism community between those who want to repeat the same studies (84% of your research is duplicative in nature?) and those who want to take a serious look at vaccines and environmental toxins is astounding. We all need to work together to FIND the cause. If you don't believe vaccines and/or environmental toxins to be the cause, then why not prove it with the study (NOT associated with the CDC!) that hundreds of autism mothers want to see? This article: http://www.ageofautism.com/2014/09/katie-wright-iacc-public-members-disappoint.html#more articulates what I'm feeling about this issue: "Sure vaccine company research and patent holder research has been done and CDC research has been done and guess what – they all exonerated themselves!" We're asking for research on children who had an adverse reaction to vaccines and regressed INTO autism.

There are very few people on your panel who understand the type of life that the #hearthiswell community lives--- the daily seizures, the twenty year olds in diapers, the life of forced poverty (how can a mother work when there are very few people willing to babysit a nonverbal non toilet trained teenager for a reasonable price?) I've noticed in recent years that the number of people who see the correlation between toxins and autism is growing. I've also noticed that the majority of this group seems to be mothers of lower functioning children. The more severely affected a child is, the more the parent researches the ingredients in vaccines and reads the studies about pesticides. There is a reason autism didn't exist a hundred years ago. You have the power to make the studies happen which will show us why. Please do it before 1:68 becomes 1:25 or 1:2.

I just took a look at this: http://www.ms.academicjournals.org/article/article1409245960_Deisher%20et%20al.pdf They looked at 4 countries, going back 35 years, and saw that every time they introduced a vaccine that had human DNA in it, the autism rate went up starting with children born that year. I want to see more studies along these lines. We could GET somewhere, FIND a cause, and stop an epidemic in its tracks. But if we're not willing to take a serious look at vaccines or environmental toxins and we're not willing to see 1:68 as an epidemic, then soon there will be very few neurotypicals left to care for all of the severely affected autistics yet to be born.

Finally, why not invite parents of severely affected children to join your panel?

Thank you for your consideration.

Heather Price

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

Kathleen Levistein

September 10, 2014

Subject: Anthologies

My son died of an ABA related injury on April 1, 2014.

I am working on 2 antholgies- one of ABA survivors- entitled "At the Expense of Joy" and one entitled "Not Dark Yet": The Last Voices of Autism"- an attempt to record stories of Human Beings with Autism before eugenics results in our disappearance-

If you know anyone who wants to be included in either of these antholgies, pls ask them to contact me [PII redacted]. I can change their names when telling their stories if they do not wish to be identified for some reason-

Thanks-

Dr Kathleen P Levinstein, PhD, LCSW

Assistant Professor Social Work

University of Michigan Flint

[PII redacted]

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

Michelle Schneider

September 10, 2014

[PII redacted]

Affiliations: Parents for Ethical Research, TEAM TMR, TACA Parent Mentor, Autism Media Channel

While major news outlets and the vast majority of our legislative representatives have remained silent on the issue, my family and I have closely watched as the revelations of the CDC "whistleblower", Dr. William Thompson, have unfolded. We take a keen interest in this story because of its implications for future generations and the direct effect it potentially had on scores of children, including my own. Because the CDC allegedly participated in scientific fraud for years, in addition to continually ignoring thousands of parents' observations, subsets of children who are more susceptible to vaccine injury and vaccine-induced autism in particular, have not been addressed properly. In the minds of this federal agency's lead scientists, they suppressed evidence of a problem, therefore the problem did not exist and was not worth pursuing further in order to eliminate potential harm in high-risk populations.

As a result of what Dr. Thompson refers to as the CDC's paralysis regarding vaccines and autism, my daughter received multiple doses of several vaccines in her first year of life. I trusted that my government and her doctor had her absolute best interest in mind, and I did as I was told. After her second dose of the influenza vaccine at ten months old, we noticed some head banging and disruption in sleep. But, it wasn't until her one-year well child visit that we really noticed a change. On January 26, 2012, she received a dose of the HIB vaccine in order to catch her up in her series. Two days later, we celebrated her first birthday at an indoor playground. While her friends and cousins ran around, climbed, played, and screamed with joy, she sat clutching a balloon and staring blankly at nothing.

Within the following several months she experienced odd rashes, staph, otitis media, [PII redacted]'s dermatitis, and the onset of bowel disease. She lost her speech. She would spin in circles and put her fingers within centimeters of her eyeballs, repetitively climb up and down a slide, moan and groan and hum for hours on end, and often stare into space. She stopped answering to her name and would spend a vast majority of her day tantruming violently. She would lean over furniture to press firmly on her stomach. She would scream frequently throughout the night. She was diagnosed with autism spectrum disorder and encephalopathy at 27 months old.

Subsequent testing has revealed autoimmune cerebral folate deficiency, abnormal activity on EEGs indicating paroxysmal spells and absence seizures, gastritis, enteritis, chronic diarrhea, immune system dysregulation, nutritional deficiencies, thyroid issues, metabolic abnormalities and possible mitochondrial dysfunction. She should have never been vaccinated due to family history and underlying risk factors like specific genetic mutations.

I share her story not because I desire vindication or sympathy. I speak of her hardships for two reasons: (1) it is eerily similar to far too many other stories of children, children whose parents believed wholeheartedly in the benefits of vaccines and were not told of the real risks (because doctors are not qualified to attest to these risks and because risks were perpetually denied by our government) and (2) this must stop; we are damaging our children in the name of greed and pride. My daughter is nearly four years old and though she is making great strides thanks to biomedical interventions, I do not know for certain that she will ever fully recover from her injuries. Since biomedical treatments are not explored by the IACC and the committee refuses to appropriately research the vast environmental causes of regressive autism, including vaccines, parents are left without knowledge or direction.

How many more children must endure undue harm before our representatives and federal agencies decide this is worthy of a thorough review? You owe it to my daughter, the droves of children before her, and the millions of children whose parents are just now considering these issues.

Carol Fruscella

September 10, 2014

I am not sure if you have heard, because there seems to be a Media Blackout occurring about a CDC Whistleblower by the name of William W. Thompson. Please feel free to 'omit' his name as you see fit.

In question now is at least one study that he co-authored with at least one current member of the IACC panel. May I state that this seems to make the 'water' very muddy. See, I want to believe that this whole panel has spent 1.7 Billion Dollars wisely. I also know from attending one meeting in person and listening to several meetings on line that 'vaccines' are not being studied by this group as a possible cause. I also am aware that much duplicate research has happened.

I am not trying to insult anyone. I just hope you all know that if I can see a possible conflict of interest... I am probably not the only American who does.

Our Children and Adults with Autism deserve answers. At the rate of One out of every 68... is it not time to research every last idea including Human DNA in vaccines?

I just read a study a few minutes ago saying that 'Human DNA' in vaccines seems to coincide with the Autism Epidemic. And please make no mistake about this... there would be no 'panel' if there was not an emergency or an 'epidemic'... I know I can use that word... This panel dare not say 'that' word. 'Epidemic'.

Granted... some people with Autism do recover and thrive and lead productive lives. Sadly, I know more people who have their grown children in adult diapers than on the recovered side.

Does everyone sitting at this table today truly understand how sick and sickly our youngest generation is? Who will defend us as a country when we have no one able to serve?

I believe we have reached a point that History will record this panels response to the National Epidemic of Diarrhea, Constipation, Inflamed Colon's, Mystery Rashes, Disrupted Sleep Patterns, Tics, Stim, the Loss of Verbal and sometimes all Vocal Communication, Allergies, Seizures, Sensory Overload, OCD and ADD Disorder. Please study the Autism that is Medical. This is the 'form' of Autism that needs to be studied. More people than ever will be watching your every last detail. Please make this a good meeting... Do the right thing... Investigate all possibilities...

Ask yourselves why people have lost trust in this system... Then take that list and make positive changes starting today.

Sincerely,

Carol J. Fruscella

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

Rafael and Ada Sepulveda

September 10, 2014

[PII redacted]

On behalf of our non-verbal 15 year-old son [PII redacted], diagnosed with “autism,” and so many others affected in our population, we thank you for attending to this important matter. Thirteen years ago, during the Christmas holiday season, our son no longer recognized us. This was reciprocal. We no longer recognized him. He was not the happy, healthy, precocious child that filled our home with joy. He had deteriorated physically and mentally after having met all his developmental milestones. This regression journey followed a “well baby” visit for immunization.

Our son had fever, limping, rash, excessive drooling, and hand tremors accompanying body rigidity. His eyes lost all luster and appeared opaque. He had vomiting, diarrhea alternating with constipation, photosensitivity, and restriction of the visual field, hypotonia, and high pitch screaming every night with no sleep. He looked pale, jaundiced, and was just not thriving. He would jump if you coughed near him, yet not respond to his name. His little hands could no longer hold any object. His words became less and less, until no longer any. He stopped playing with toys. He spanned, stared at ceiling fans, rocked, and head banged. He walked the periphery of Gymboree and would crawl between people’s legs at home, only to resume a catatonic state on the floor. He no longer responded to the human voice. He no longer looked at anyone. However, the skin peeling, rashes, allergies, constant respiratory infections, sinus infections, and gastrointestinal pathology continued. My son was no longer with us.

This regression is not psychiatric. This is medical, biological, without a doubt. This is vaccine related, without a doubt. The vaccine studies are just not there. Can we honestly assure that the benefits of immunizations outweigh the risks? Where are the studies that address the synergy and interactions of this aggressive vaccine protocol? Where are the follow up long term studies? How utilized is the VAERS system? How effective and just is our Vaccine Injury Compensation system? Who is adjusting for genetic and environmental variability seen in our population, as should be done with pharmacological agents used in medicine? We did not hear any answers from the CDC or NIH experts. Now fraud being committed by CDC scientists?

My family is extremely grateful. You are asking the right questions and getting ambiguous, substance empty responses. Accountability and transparency are imminent. An investigation is mandated. We really envision the beginning of a new vaccine paradigm emerging that will really serve the “public good.” This can realize because you listen to “the people;” All this because of your initiative. Please keep in mind that in so many cases, like our son, “autism is really a misnomer for so many individuals that are suffering from vaccine injury. Thank You.
[Photo redacted] & [Video redacted]

Sincerely,

Rafael Sepulveda
Ada Sepulveda

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

Joyce Herron

September 10, 2014

Ten years ago my husband and I were blessed with twin grandkids. They were very much wanted babies and their parents had to wait several years before becoming pregnant. They were born healthy and grew and progressed meeting their developmental milestones. However, after receiving the MMR vaccine our grandson had a very high fever of 105. This was disregarded by the medical doctors (not related to the vaccines). He slowly began losing his milestones, he no longer responded to his name, he avoided eye contact, he lost the few words he had, all while his twin sister continued to meet her milestones.

It took another 2 years before any doctor finally said he had autism. His pediatrician, who had treated him from the time of birth, always dismissed our concerns of his loss of milestones and no longer talking as “boys are just slower”. His twin sister is still waiting to be able to talk to her brother. I am still waiting to hear him say “Grandma”.

Part of my grandson’s autism includes severe small bowel disease, body wasting,
PICA, elopement, drawn to bodies of water and he does not recognize danger. He must be watched closely 24 hours a day to keep him safe. The family must lock themselves inside to keep him from opening the doors and running down the street. The formal dining room has been converted into a safe area for him to “play” (a ceiling mounted taco type swing that meets his sensory needs and a small indoor trampoline). There is a camera there also to allow his mom to view his actions on a large TV screen while she is in the kitchen. At night he is locked into his room and monitored with a TV camera to alert his mom if he awakens during the night. She followed the doctors’ recommendations and the CDC’s for the vaccines because we TRUSTED these entities to keep our grandchildren safe from disease.

This email is to request that the IACC members immediately demand a Congressional hearing regarding the recent revelation by Dr. William Thompson that the autism study conducted over 10 years ago was manipulated with the data to get the results that the MMR does not increase the rate of autism. The data eliminated showed the rate of autism in African-American males who received the MMR vaccine as scheduled had a > 200% increase of autism. IF they received the MMR after 36 months that increased rate was not there.

Dr. Colleen Boyle was the lead researcher in this fraudulent study. I have watched the IACC meetings many times via the live web streaming and heard Dr. Boyle state to the committee that there have not been ANY studies done that showed an increase in autism rates associated with any vaccine.

Presenting false information in this committee meeting much less allowing the public to go on accepting the lies that vaccines are safe and effective is not acceptable to me as a grandma neither to my precious grandson nor to me as a taxpayer supporting the CDC.

How can the deletion of this effect on African-American boys be overlooked? In my opinion it was genocide.

It is long past time to have a true independent review of the entire vaccine program which seems to be based on fraud. How much longer will this committee allow this type of damage to be done to our children? The stench coming from the CDC can be sensed all the way to Texas.

If some questionable sports trainer could report a well-known baseball player's use of performance enhancing drugs and there be a Congressional hearing as a result, don't you think it is time to demand a Congressional hearing to investigate the possibility that over 1 million kids in this country have been damaged by the vaccines the parents agreed to thinking they were safe?

If a Congressional hearing does not take place, I am inviting each of the committee members to come spend a week at my daughter's home to see the results of vaccine injury in my grandson.

Joyce Herron
[PII redacted]

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

Kristin Kauffman

September 10, 2014

My son, [PII redacted], was born in August of 2004. We followed the CDC recommended vaccine schedule and my son saw a major regression in October of 2005 after an influenza vaccine and forty one days after his MMR. He began nursing all day and previously I had been down to a night feeding. [PII redacted] ignored us when we called him, lost verbal communication skills, began playing with toys in odd ways and dumping contents of our drawers and pantry. He had high anxiety and anything would set off temper outbursts that would last thirty minutes and longer. My son has the MTHFR genetic mutation, a mitochondrial disorder, which was unknown to us at the time of his vaccinations. His pediatrician recommended we give Tylenol before every round of vaccinations because he would spike a fever for days. Later we found that Tylenol is detrimental to those with MTHRF because it depletes the body's glutathione levels. [PII redacted] suffers from Encephalitis, Heavy Metal Toxicity and has PANDAS (Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal infections) as a result of his impaired immune system due to vaccines. We have worked with specialists for seven years and spent hundreds of thousands of dollars to restore our son's health.

I am concerned about the recent public statement of Dr. William Thompson and the fact that the CDC has manipulated study data. The 2004 study entitled "Age at first measles-mumps-rubella vaccination in children with autism and school-matched control subjects: a population-based study in metropolitan Atlanta" has been referenced/cited in 344 studies. This study affects an entire body of work. All of these studies should now be re-evaluated. I demand that the IACC appeal for a vaccinated vs. un-vaccinated study by and an independent party not related to the CDC or drug companies. In addition, the lack of lack of representation of the autism community, especially parents, on the IACC is laughable. What actions have you taken over the last few years except for yet another genetic study that has been fruitless? Real action and leadership is needed now! We are quickly becoming "America the Disabled" and I beseech the IACC to open your eyes and get to work helping families in America.

I am happy to speak with anyone with the IACC about my son [PII redacted] or attend any upcoming meetings.

Kristin Kauffman

[PII redacted]

Joseph Jackson

September 10, 2014

I have major concerns over the CDC Whistleblower exposure of CDC fraud. I am thankful for Thompson's regret regarding the manipulation of data and I hope everyone involved continues to be exposed and face the consequences of what they have done. My only son, born in 2008..... DID NOT HAVE TO HAVE "AUTISM".

Joseph M Jackson

Wapakoneta, Ohio

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

Katie Harris

September 10, 2014

On Sunday, August 17, 2014, my husband, 6 year old autistic son and myself arrived home midday from visiting family out of state. [PII redacted] was over-stimulated and was therefore repetitively stimming. A couple hours later [PII redacted] was quietly playing in his play room, my husband was in the upstairs office working on homework, so I ran upstairs to collect dirty laundry from the bedrooms. I came back downstairs to the front door standing wide open. My stomach hit my knees. I started yelling for [PII redacted] and ran out the front door. The whole time praying that he was just playing on the porch. I reached the edge of the front porch – no [PII redacted]. As I rounded the front corner of the house, I see my son skipping down the middle of our street, barefoot. He was 2 houses from the end of our street, a street that dead ends into a 4 lane extremely busy road. I was lucky on numerous counts that day: first, when he heard me calling him he had turned around and was heading back to our house; second, that I only was upstairs to gather clothes – a couple minutes. I do not know if I will ever recover from seeing that front door standing wide open. My son now wears a Project Lifesaver tracking device on his ankle that he cannot remove. All exterior doors of our home now have chains at the top and alarms. I cannot take any chances that next time I will be so lucky.

On July 8, 2014, as members of the IACC you were here for the last full committee meeting. Shortly before you broke for lunch that day in Cass County, Missouri an autistic boy named [PII redacted] walked out the front door of his grandparent's home. As you sat and ate lunch and listened to numerous recounts of duplicative research, he drowned in a neighbor's pond. He was 5 years old.

The government has given IACC 1.7 BILLION dollars. What have we, we meaning the Autism community, gotten for that 1.7 Billion dollars? I cannot answer that. Only the members of this committee can answer that. And we already know that the GAO said that 84% of federally funded autism research was duplicative. Sounds like the Autism community has not gotten their monies worth.

My July 8th comments discussed education deficiencies, health insurance discrimination as well as lack of support – specifically in Ohio. Today I would like to discuss life care, specifically after 21. The autism epidemic doesn't go away when our children graduate at age 21 – when they age out of the school district. The recent warning from MIT researcher, Dr. Seneff, stated autism will be 1 in 2 by 2025 is staggering and yet no surprise. At least not to me, not to the autism community. Is it a surprise to you?

How will the US have a military, after all boys are afflicted at a much higher rate and the US only allowed women in combat roles last year? Our national security woes aside, how will all these children with autism be cared for once their parents are gone? Where will they live? Who will care for them? Where is the vocational training? Many individuals on the spectrum are capable of having a job and being contributing members of society but they need assistance – assistance that appears to not be coming. There are few support options for autistic individuals after 21. This committee is "the federal panel responsible for coordinating the nation's response to autism." What happens as the care givers age? There are not group home equipped to handle this magnitude of autistic individuals. Specifically, I am asking "WHAT IS THIS COMMITTEE DOING FOR ADULTS ON THE SPECTRUM?"

1 in 68 today. 1 in 2 in 2025.

Sincerely,

Katie Harris

[PII redacted]

Eileen Nicole Simon

September 10, 2014

Researching and responding to public comments should be a priority for the IACC. Autism is an unexpected tragic catastrophe for families. As parents, we all reacted in unique ways to the shock of what we were dealing with. In my case I knew I had terrible experiences in childbirth.

More papers on complications at birth have been published than on any other medical problem associated with autism, but then difficult birth is blamed on “some defect” of the mother or child. Shouldn’t the next topic for research be how the brain might be affected by oxygen insufficiency?

My children were born before the increase in the vaccine schedule. What parents have to say about their experiences with vaccination must be looked into, not rebuffed, neglected, and omitted from all “professional” conversations about autism. Again, rather than more epidemiology, shouldn’t research on how vaccines might affect the brain be the priority?

Prenatal ultrasound, acetaminophen, soy products, and many other concerns are expressed in the public comments. Shouldn’t all of these possible causes of autism be investigated for their effects on the brain?

Autism is defined in terms of behavioral traits, impaired social interactions, diminished communicative intent, and repetitive behaviors. These traits are then looked for in the parents and siblings, to justify a “broader autism phenotype” (BAP), which can then be linked to genetic origins. I take offense at being labelled with the BAP. I had a 30-year career as a software engineer: Satellite orbit computation, submarine tracking, software control for imaging systems, and finally as a UNIX and C expert. Am I therefore a geek? Is this part of my being labelled a BAP parent?

I am not happy with people who claim they have autism. Did they have problems learning to speak? What evidence can they provide that autism is a matter of “neurodiversity” rather than damage to the brain? Why have their insights been valued more than those of parents who are trying to help children who remain nonverbal into adulthood?

Thank you again for beginning to include the ideas of parents, and grandparents. Some of us have spent decades working to help our children, and find out what caused their autism.

--

Conrad Simon Memorial Research Initiative

To seek understanding of brain system impairments in autism.

http://conradsimon.org/

Susan Wald

September 10, 2014

Autism needs to be declared an epidemic. The CDC stated that the rate of Autism is one in 68 children in March 2014. What will it take for the government to recognize Autism for the crisis that it is?

Also I am concerned about the recent public statement of Dr. William Thompson and the fact that the CDC has manipulated study data. The 2004 study entitled "Age at first measles-mumps-rubella vaccination in children with autism and school-matched control subjects: a population-based study in metropolitan Atlanta” has been referenced/cited in 344 studies. This study affects an entire body of work. All of these studies should now be re-evaluated. I demand that the IACC appeal for a vaccinated vs. un-vaccinated study by and an independent party not related to the CDC or drug companies. In addition, the lack of lack of representation of the autism community, especially parents, on the IACC is laughable. What actions have you taken over the last few years except for yet another genetic study that has been fruitless? Real action and leadership is needed now! We are quickly becoming “America the Disabled” and I beseech the IACC to open your eyes and get to work helping families in America.

Susan Wald

Leslie Phillips

September 10, 2014

My name is Leslie Phillips and I have two sons on the autism spectrum. My oldest son is diagnosed with Aspergers Syndrome and the youngest is diagnosed with Autistic Disorder.

For more than a decade, parents have been reporting that their children regressed into autism and make an association with vaccination. My youngest son, who is most severe, clearly was meeting developmental milestones until vaccines he received around 15 months of age. This began a downward spiral and loss of skills eventually labelled as "autism."

I believe the science cited to exonerate vaccines in the exploding prevalence of autism is flawed, deliberately misleading and downright fraudulent. The recent revelation by a senior sitting CDC scientist who admitted that at 2004 study showing no correlation between MMR and autism was fraudulent further solidifies these concerns. Years ago, Dr. Insel and others admitted both that there must be environmental factors contributing to autism, and that a study comparing fully vaccinated children to unvaccinated children was needed.

Public confidence in IACC is justifiably low due to the abysmal record in bringing to bear any useful methods to prevent, treat or serve the autism community.

As far as co-existing conditions, my youngest son is also diagnosed with mitochondrial dysfunction (confirmed by muscle biopsy), bowel disease (confirmed by scoping, including pill cam and biopsies), and cerebral folate autoimmunity. He is suspected to have dysautonomia and, because of the behavioral manifestations of his medical conditions, is also diagnosed with Mood Disorder NOS.

There are simply too many issues to cover in one comment that anyone will bother to read. To summarize my input, vaccines can and do cause autism, the vaccination schedule should be revamped and vulnerable populations identified, and every child with an autism diagnosis should routinely be screened for the myriad underlying medical conditions that threaten their health and life.

Regards,

Leslie Phillips

Katy, TX

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

Chanda Jackson

September 10, 2014

I am sure this board is very well aware there is a fraud sitting on this committee as a director. Until she is removed, she brings the entire committee down with her. My son has vaccine induced "autism" and I will share this from the highest mountain until my last breath as long as this sort of scientific fraud is being conducted at this level. [offensive language redacted]. Influenza vaccines are NOT SAFE for pregnant women AND YOU KNOW IT. It's blood on your hands.

Let's take a look at what occurred during your last board meeting on July 8, 2014.

[PII redacted] (2008-2014)

[PII redacted] was 5 years old and had autism. He lived in Cass County, Missouri. He wandered away from his home on July 8, 2014, when the door at his home was left open by a crew repairing the air conditioning at his house. He was found dead in a pond near his home later that afternoon.

So, hear this well, vaccines CAN and DO cause autism. My son's autism could have been prevented. Our children are not destine to SUFFER. And DROWN. So go ahead and DO SOMETHING FUNCTIONAL about it.

I also want my public comment to be just that..... PUBLIC. http://youtu.be/owuBeE1oweo

~Chanda Jackson

Ohio Families Affected by Autism

Courtneay Reid

September 10, 2014

This is not my first time submitting written comments to this panel. Since the panel was developed and implemented, I've seen a large amount of tax payer money spent and not a single child has been cured, not a single case of Autism has been prevented, and most importantly no one has found the cause for this Autism epidemic that we as a country are experiencing. I have a solution for a possible cause. Vaccines. I find it irresponsible that this panel has not taken a hard look at the vaccine-autism link. More so in light of recent events it is your duty to no longer turn the other cheek when the word vaccines is mentioned. William Thompson, a lead scientist with the CDC, has come clean about fraud on a research paper that the government continues to site as a source as being the reason vaccines cannot be a cause. If you as a panel want to be taken seriously by us parents who have vaccine injured children then you must look at ALL possible causes until you can come up with a definitive cause for ALL Autism.

In a statement from William Thompson he said

"The omitted data suggested that African American males who received the MMR vaccine before age 36 months were at increased risk for autism. Decisions were made regarding which findings to report after the data were collected, and I believe that the final study protocol was not followed."

Because of this statement I believe Coleen Boyle should resign from the panel since she is a co-author to the study that Mr. Thompson has exposed as being fraudulent. There should be no place on the IACC panel for anyone who has a conflict of interest, cannot be trusted to be transparent, and has everything to gain personally from keeping a possible vaccine - autism link buried.

Thank you for your time.

Courtneay Reid

Hockley, Tx

Tara McMillan

September 10, 2014

I am a parent of a vaccine injured child who coincidentally now has autism.

First he developed encephalitis. Then he lost his language skills.

Then he regressed into autism.

You will not see us going away.

You will only see an increase in irate parents because you chose to do nothing about the vaccine induced epidemic that we have in the United States.

The truth is coming out slowly but surely thru reluctant scientists that finally value their conscience over their pocketbook.

I thought that perhaps I was too harsh when I suggested Mr Insel be put in jail.

I was wrong It should be prison. Mr. Stefano, along with Collene Boyle and a host of others that are full of nothing but deceit---

Their time for paying for what they have done will come.

As far as shutting out the vaccine injured siblings from being able to comment-- we are all alive and well at youtube on hearthiswell.

Thanks

Tara McMillan

Mike Hoover

September 10, 2014

In early 2001, my beautiful, typical, normal baby boy was injected with autism. I vowed that day that I would fight to get him out of being trapped in his own mind, or that I would die trying.

Over the past 12 years, I've met thousands of parents with the same story, a completely typical, happy, healthy toddler that "suddenly" disappeared into the depths of autism within few days or weeks of receiving their vaccinations. I've learned more than I ever wanted to know about the level of lying and corruption in our system, and it's time to put an end to it.

It starts today.

It starts with YOU. YOU are the ones who have to look yourselves in the mirror and sleep at night. YOU are the ones who have the power to right a terrible wrong and the poisoning of an entire generation. All of you know a friend or have a family member that are affected by autism, and if the rates continue as they are, the ratio will be 1:1 in just 64 years. Then what will your children and grandchildren do? Who will run the country? Who will defend the country? Who will be left to take care of those with autism, when 100% of the population has autism?

Given the recent admissions of CDC Fraud by Dr. Thompson, as well as the lying that went on by CDC Members in front of the Senate during the Senate Autism Hearings in 2012.

I'm sure the Board is well aware that its own Director is the biggest offender, and she must step down, or be removed from Office, or the entire Committee will be seen as a sham. Thousands upon thousands of Americans already know the truth, because we've lived it.

It's time for it to stop.

You're all well aware of the truth, and it's long past time for all of America to know what we know. It's time that all of the secrecy, fraudulent behaviors, and cover ups to come out.

You see, nothing is stronger or more powerful than the love of a parent, and I made a promise to my scared to death 2 year old baby boy, some 12 ½ years ago, and I will fight for him until either YOU admit it and do something about it, or I take my final breath on this Earth.

The vaccines are NOT safe, and all of you [offensive language redacted] well know it. Don't get me wrong, I am not anti-vaccine, I'm anti-lying, anti-poisoning, anti-harming, and [offensive language redacted].

Do something right. Do something positive. Do something that your children and grandchildren will be proud of you for. Right a terrible wrong.

People are suffering, kids are dying, families are falling apart, society has a whole generation of kids with moderate to severe autism entering adulthood soon, with nothing in place for them.

Please remember that you work for us. America.

We won’t be silenced due to your greed, ignorance, and your inability to tell the truth.
A promise is a promise, and I WILL keep mine to that little boy, to the 1000’s of kids like him, and to the 1000’s of parents like me.

So “hear THIS well”…We’re watching you..

DO SOMETHING !!

Sincerely,
Mike Hoover
Westerville Ohio
Dad of 2 boys on the autism spectrum
#hearthiswell #CDCWhistleblower

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

Christiane Marshall

September 10, 2014

Subject: Comment on autism research

I am a special education teacher, parent and grandmother of two children (ages 1 and 3).

I have worked with children who have autism but my own children are not afflicted with it. However, the increase in autism is very concerning for me. It is alarming and I am concerned for my own grandchildren and all of the precious children I see every day.

I have only recently learned about this meeting and the opportunity to make a public comment, so I have not had time to research and prepare as much as I would have liked to. However, I trust that the committee cares about children and that members of the committee are most likely as alarmed as I am.

I've seen firsthand the suffering of the families of the lower functioning children on the spectrum. Even the higher functioning children present enormous challenges for both parents and schools. I am awed by many parents and wonder how they get through each day.

I have advocated for one child and was amazed at the lack of support and the how difficult it was to get the services she needed. I had to document with photographs and detailed descriptions of thrown desks complete with measurements.

Autism affects the child, the family of the child afflicted and everyone they come in contact with. Some children in my class were hurt by this child's unintentional behaviors. The loud screaming during meltdowns made teaching impossible. I was treated twice for injuries I sustained trying to protect my student and the student's peers.

This condition affects the mental health of families and their economic situation. And the behaviors can often be dangerous.

1 in 50? How will our schools cope with this when it took me an entire year to make a case for one single child in an entire elementary school?

Something needs to be done to identify what is causing this, and something needs to be done to create programs and community support for families and their children.

I understand that there is a crazy controversial polarization between anti-vaccination and pro-vaccination people. There is a lot of evidence that is being ignored and political positioning for something that should be purely scientific.

I am not a scientist but I know enough about science to know that this is not something that can be researched and decided as quickly as it has been. Anything having to do with the complex human body and brain can't be researched fully unless the synergistic aspects of the interaction of environmental toxins and pharmaceutical agents combined with the human physiology, biology and development can be factored in.

As far as I can see, this has not been done yet. So I shouldn't be hearing that anything is fully determined yet.

I've read that most of the studies so far done have been duplicative in nature. In a case like this, new research, out of the box methods and ideas should be pursued quickly.

Also, parents of the severely affected children should be part of the committee if it is not already the case.

I personally have heard many parents talk or write about a sudden change in their on track developed child. Somehow I suspect that there is either flawed reporting of vaccine accidents, or that many reported incidents have gone undocumented for whatever reason. My quick glance at the vaccine accident reporting system showed a very limited time frame for reporting these. I may have missed something, but if I have not, this should be changed.

I hope that a big change is coming! Because the epidemic is not slowing down.

Thank you for this opportunity to comment.

Christiane Marshall
[PII redacted]

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

Haven Delay

September 10, 2014

Subject: What "autism" REALLY is

Autism has been the least of my child's worries since he was horribly damaged by vaccines. Vaccines caused a metabolic disorder NOS and an immune disorder NOS along with severe gut problems. My son was damaged on March 7, 2001, and he was diagnosed with "Heavy metal Intoxication" in August of 2002.

He has suffered two many infections to count including nine bouts of pneumonia and two bouts of meningitis. Post his vaccine reaction, he could no longer so much as fight the bacteria introduced from a mosquito bite. He will get radiating staph form each bite which quickly turns into cellulitis, putting him at risk for MRSA, septicemia and death.

His gut problems caused mega colon. By treating him for mercury poisoning, the "autism" part improved, but his immune and metabolic problems will be for life. The medical mainstream has never been of any help with the medical problems. All they ever said was, 'Well, he has autism." As if his medical problems didn't matter. The only thing they ever offered for his autism was psychotropic dope. They never wanted to address his issue of mercury poisoning, though the neurologist admitted it had to have come from the vaccines.

His care in lost wages and out of pocket expenses for thirteen years has been 1.5 million dollars. How much for the rest of his life? No child should have to spend their childhood fighting their way back from vaccine damage.

Sincerely,

Haven Delay
Gerard Dziuba
[PII redacted]

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

Shannon Strayhorn

September 10, 2014

I am writing this letter as a parent of a child with autism. I would ask that you actually read it, as well as allow it to be viewed for public viewing, so that future parents, as well as our children, can see how very long it has been that we have asked you, the members, to actually do something productive to help our children and have been denied.

My daughter is almost twelve now. In this time period, not once have our governing agencies, or committees tasked to respond to this crisis, even considered her. If not for your [offensive language redacted] “new rules” on age you just enacted, she would be there to speak for herself and let you know that you have failed her. But the truth is, I understand your hesitation because I couldn’t look her in the eyes either, if I were you; knowing you have done nothing in over a decade that would help her understand why you continue to allow this to happen, why you refuse to acknowledge what happened to her, and have ignored every attempt by parents to make clear to you that there are answers and even ways to care for or recover our children. You can’t sit and look an eleven year old in the eyes and rush her through her story as you do us parents. You can’t fall asleep while she stands before you. You can’t tell her that there is no evidence when she stands before you as proof of both the harm and the opportunity to recover that you have denied. You can’t explain to an eleven year old that you haven’t figured out a way to even count her in the numbers of children effected, and that currently she doesn’t even exist in this epidemic after so much of her young life has been consumed with undoing the damage done to her little brain by those who are supposed to protect her. You can’t excuse yourself for babysitting duties or look across the room at the man on your own committee that spends his days spewing hatred at our families online and honestly believe that you are doing everything you can or that you deserve to be there representing our community. You can’t hear her words, even though she worked for years to gain them back, because you do not want to hear them.

On your agenda you are addressing co-occurring conditions and yet once again the agenda lacks biomedical representation, which seems rather odd considering story after story about children who have seen the most improvements have all been parents who used a biomedical approach. But for some reason again you do not listen to the families. You don’t hear our children. You don’t listen to the doctors and the science that backs up what we say. The disconnect is disturbing and has cost hundreds of thousands of children the opportunity to live healthy and happy lives. If the information was new, I could possibly understand (although if anyone should be on top of it, it should be this committee), however some of the basic information is now ten plus years old. And there is NO excuse.

The most common insult directed at us parents time and time again is that we are “just parents”. What I want to know, is that if we are just parents and can figure all these things out, then what is wrong with those on IACC that they cannot. EGO? LACK OF URGENCY? NOT YOUR CHILD? THE TRUTH WON’T GO OVER SO WELL? I don’t know, but what I do know is that we are tired of having to battle with you, the people who are in charge of this path, to actually listen for a change.

What should be being discussed is the current level of complete distrust in everything you are doing/not doing, as well as our governing agencies. But I know not a word will be whispered about how we now have yet another study on vaccines from multiple countries showing a vaccine connection. Not a public comment on the whistleblower story because you can't dare question the MMR or thimersol, or why our governing agencies are not following protocol and are manipulating data. Not a comment on the lawsuit against Merck going forth. Nobody will say a word about how hundreds of thousands of parents came out last week sharing the exact same story of how vaccines caused their child's autism. No, because we know right now there is a big push to control all this information in the public, and that this meeting will be recorded. We can't discuss why the majority of autism organizations backed dismantling this committee or firing those in charge because that is all moot now as we go forth for the next ten years chasing mystery genes again and talking about how we will now handle all the needs of our children who have now become adults. Instead of real discussions on changing this course, and how to build up trust, or solve anything; there will be pats on the back and words of how great you are doing. It's time to wake up, you are not doing great; you are failing us. You have failed us. You have failed our children.

I, along with all the other parents who have written and testified over the years, am tired of asking and begging you to hear us. We have been nice, and asked for your help. We have stood before you and shared our most private realities. We have come before you as parents, teachers, doctors, grandparents and siblings and pleaded with you to look at the information. We have wasted years hoping you would do the right thing. We have cried, screamed, and thoughtfully composed our words to express with you our frustration at your inaction. The time has come, we are done being nice. We are holding you and everyone else accountable. Now, I am only submitting this because I want my child and others to know that we never stopped fighting for them, that my legacy will be of someone who went to bat for our children. I don't expect you to do anything different this meeting, as I have watched every single meeting over the years and nothing is ever different. But I will keep doing so because I want you to know that we are watching you, we do hear you, and we know all the things that you could be doing and are not…and that will be your legacy.

Shannon Strayhorn
[PII redacted]

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

Lesa and Dave Walsh

September 10, 2014

Our son [PII redacted] was born on May 10th, 1992, approximately 3 weeks early. In spite of this fact, his Apgar scores were 9 and 10. He met all of his developmental milestones, usually "right on time". He was a very healthy baby and did not really get "sick" until he was 14 months old. Lesa, [PII redacted] and other family and friends were at Disney World in Orlando, Florida in July 1993. [PII redacted] was the last child in the group to get sick. Lesa was informed in the ER that both of his ears were infected and [PII redacted] was put on his first course of antibiotics ever.

[PII redacted] had a well-baby visit shortly after returning to New York. He was scheduled to get his MMR vaccine at that time. Lesa asked the staff if it was safe to give [PII redacted] the vaccine because he had just finished some antibiotics. She asked how long had it been since he finished and Lesa informed her it had been about 7 to 10 days. "Oh it's fine; it's fine!" As it turns out, it was not fine.

It took us some time to connect the dots and put 2 and 2 together. [PII redacted] was vaccinated again in December, 1993 just after receiving his second course of antibiotics. By February 1994 (about the time Lesa's Mom passed away), we knew something was now very wrong with [PII redacted]. He had changed from our bright, cheerful, coordinated, chatty, loving toddler to an overwhelmed, uncoordinated, minimally verbal, hearing sensitive, no eye contact, and GI system distressed toddler.

We held onto hope because [PII redacted] was still loving towards us. When we raised some of our concerns about [PII redacted]'s seeming loss of motor skills, apparent "deafness", serious GI distress and loss of words with our elderly pediatrician, the responses we were given were usually something like, "Oh, he may have some food sensitivities"; "Didn't you say one of his grandmother's had Crohn's disease", "Oh, boys mature more slowly"; "He may be going through a growth spurt"!

Convinced she was somehow subconsciously doing something to [PII redacted] to make him more dependent on her, we enrolled [PII redacted] in an educational program in Pearl River. We took the expense for this on by ourselves. No one told us about [PII redacted]'s rights, or Early Intervention or anything that would help us to help him. They worked with him for a year making minimal progress, when [PII redacted] received the Varicella vaccine in 1995. The regression that happened within the first 2 weeks after the vaccine was unreal.

That is when we began to become convinced that [PII redacted]'s problems were related to his vaccinations and we traced it's beginning back to his MMR vaccination. [PII redacted] was diagnosed with Autism in March, 1996. We have paid our way to Washington, DC at least 8 times to implore our elected officials to press for an unbiased, objective, non-pharmaceutical related study of vaccines, vaccinations with antibiotics, Autism, Autism rates of vaccinated and non-vaccinated children to no avail.

Paul Thorsen, the "catalytic agent" for almost all of the studies refuting a connection between Autism and vaccines is on the FBI's Most Wanted List. He was capable of committing mega-financial fraud, but he would never engage in research fraud? In light of the recent emergence of fraudulent practices from

Dr. W. Thompson, aka the #CDCWhistleblower, we are strongly requesting that your committee finally demand that an objective study of vaccines and Autism be conducted ASAP.

We were at Congressman Dan Burton's hearings in 2000 when the very same was asked for. How many children have been diagnosed with Autism since then? When are the rates, now at 1:68 going to be epidemic enough to move this committee to real action? How many times do you have to hear, "We don't know what the exact cause of Autism is, but we know it can't be vaccines?" How can every medical professional accept that most people can use Penicillin as a "Life-saving" intervention and they accept that there are people who are negatively sensitive to it, but the same cannot possibly be true of vaccines?

Our son is 22 and is at the start of the Autism tsunami that has blind-sided a generation of children for families, not only in America, but around the world. Will you let another generation perish? We thank you for your time, attention and cooperation in the matter.

Yours,

Lesa and Dave Walsh

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

Carolyn Gammicchia

September 10, 2014

Dear Chair Insel and members of the Interagency Autism Coordinating Committee,

We are writing to the members of the IACC with concerns we have mentioned in the past as well as concerns about the function of the current IACC and its membership. As you may recall we expressed concerns to you for the January 15th, 2014 meeting, and those still exist and have been unanswered. However now we have even more concern on the lack of coordinated research the IACC is using due to the recent revelations of Dr. William Thompson of the CDC. As you may know, Dr. Thompson disclosed information as a whistleblower and current researcher employed by the CDC, regarding research studies related to vaccines and autism. He indicated that in at least one of those studies, which IACC member Colleen Boyle also was involved in, pertinent data was left from the report. Specifically Thompson advised many media outlets that be believes his research found some correlation between measles, mumps and rubella (MMR) vaccine and an increased incidence of autism among African American children, however that data was left out which resulted in the findings being manipulated.

As a family that has lived now over twenty years with the knowledge that our son's vaccine injury resulted in inducing his autism, we felt that this perhaps was a light at the end of a tunnel. Now however, due to the fact that even almost two years after the federal Congressional hearing on Nov. 29th, 2012, where Ms. Boyle was asked about vaccinated vs unvaccinated study on children with autism, we still do not have such a study. We do however have several studies where Dr. Thompson worked alongside Dr. Boyle, as well as other researchers, to disprove the autism vaccine connection. It is our concern at this point that those studies too may be fraudulent or exclude data as the 2004 study that Dr. Thompson has reported. At this point it is therefore imperative, if this committee has in the past based their opinions on such research, that those studies are looked at and addressed as to how the data for them was interpreted. Additionally the IACC has heard repeatedly, since its inception from public members as well as those from the autism community of injuries sustained by their children. Several have been documented, unlike our son who was born healthy and in one day received a total of six vaccinations, including the MMR, and sustained a vaccine injury. Within a year he was diagnosed with PDD-NOS (autism) after losing all speech and the many of developmental milestones he had gained. Recently when there was discussion by the IACC that environmental matters would not be broach, especially vaccines, we felt once again we were not being represented by the representative body that has been formed to do so. Additionally now that this revelation by Dr. Thompson has been exposed, we feel it is time not only for the IACC to look at any and all research he was involved in, but consider those research results that you have used to make your decisions within strategic planning. This should be done so for many reasons including the fact the information and documents by Dr. Thompson is being investigated by Congressman Posey's office. Also thousands of family members from within the autism community has come forward with stories via the Hear This Well initiative. Over one thousand videos have been submitted to the YouTube site with individual statements regarding their child's vaccine induced autism. Those videos can be accessed on the Hear This Well: Breaking the Silence on Vaccine Violence page located on the link below. We would urge you to view those videos since they are from the community you all are supposed to be representing.

https://www.youtube.com/channel/UCFCrfK5rP_B6huriP1hLApw/videos

In the past we have also mentioned conflicts of interests and it seems more apparent now that these are present. We would like to ask that all conflict of interest statements of public and non-public members be posted on the IACC page.

Again we are also asking that all documents provided by those providing oral comments be posted on the IACC webpage as well as all of those being submitted to the IACC via Written Public Comments. Under the Open Meetings Act any public comments provided for consideration by a government entity are to be made available for public review. We've been requesting this now for over a year. There have been less than fifty public comments submitted in that time and they could easily be scanned and linked to the IACC website in less than a couple of hours. As for privacy of those submitting them, there is a realization that any document submitted within a Public Written Comment is done so knowing not only can it be FOIA'd, but as an attendee of meetings, we've obtained those packets.

Lastly we would like to again express concern regarding the lack of representation on the IACC by a public member that is serving individuals with autism and their families daily. There currently is not a standing public member from an organization that does so. Autism Speaks does not do so. The Autism Society of America does not do so. At this point in time the only national organizations that support individuals and families with autism daily, or have the capacity to do so are TACA, the National Autism Association, and The ARC. At least one of those agencies should have representation on the IACC because they are serving the community by answering daily calls, providing Parent Mentor support, as well as providing information and resources via a human connection. Those representatives too can be representative of the majority of the autism community rather that the minority which other organizations represent. It is time to look at the way in which choices are made for public members, their conflicts of interests, as well as how they are serving…if even in attendance at meetings.

We have several additional concerns, one being that oral public comments are limited to 3-5 minutes and this meeting having only fifteen minutes to do so therefore limiting those that can participate. Additionally there has now been a restriction that only one family member can speak as well as only those age eighteen and over. These seem to be new guidelines and we'd like to know how those were decided on, especially since the committee has not met to discuss such changes. Lastly we also like to know how we can have our questions answered on concerns from the committee. There does not seem to be a current process to do so.

Please know that we have read the charter of the IACC and do understand its mission and overall work directive. We however do not see the work of the committee meeting this need directly, nor acknowledging public concerns. Since the committee is to be representative of those it is aligned to serve, we'd like to know how to collaborate to make that possible so the autism community's questions that have been asked do not continue to go unanswered. Please feel free to contact us if you have any questions regarding our concerns.

Respectfully submitted,

Carolyn Gammicchia and Andrew Gammicchia
On behalf of our family including our son [PII redacted], a twenty three year-old young man living with autism
[PII redacted]

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

Alison Hoffman

September 10, 2014

In April 2013, I optimistically addressed this group and pleaded for a standard of care for diagnosed children with autism. I shared our experience with our son, [PII redacted] who is diagnosed with autism and viral encephalopathy, petit mal seizures, gastrointestinal issues, and hypogammaglobulinemia. It took our family seven years, four hospital systems, and many doctors to receive proper diagnosis and care. During this period of time, [PII redacted] was in pain and suffered. I'm back again to beg again on behalf of families like mine across the U.S. Since my last public comment, the diagnosis rate has gone from 1:88 to 1:68. Autism is an epidemic. I realize that many of you disagree with me on this point. I think the only thing lacking is care. You'd have to care about families with autism to acknowledge this is an epidemic. I've heard "we expect the number to rise so it's not an epidemic." Not one person on this panel can tell me exactly what autism is and how it develops. You can tell me how we diagnose it, one scientifically proven way to treat it but absolutely no process to pay for it, but no one here can tell me why. Until you can, how can you accept an increase? More and more families are receiving the diagnosis of autism for a child yet there is difficulty accessing care and treatment.

I volunteer in the community and mentor families. I meet families via friends who have a friend or work colleague seeking information from diagnosis to services to best areas to live in DC to access special needs education. Recently, I spoke to a Mom within the last month about her 2 and 1/2 year old daughter. As she described her journey, I was greatly saddened. She was experiencing barriers to diagnosis, treatment, and testing for co-morbid conditions. I told her to do her research and continue to make sure there weren't any comorbid conditions that needed concurrent treatment. I then told her if [PII redacted] at diagnosis received 48 hour EEG, petit mal seizure diagnosis, and a treatment protocol, he would be further in his development today. If [PII redacted] received a GI workup including scopes considering he was having constant explosive diarrhea and weight loss, his reflux and GI inflammation would have been addresses and treated five years earlier and he would have slept, grown, and experienced less pain during that time. If they ran an immune panel after noting his history of ear infections, strep infections, and herpetic eye infections, they would have discovered his prime immune deficiency and treated it five years earlier. I told her that I would have done things differently had I known. Even at that time, I thought the doctors were trained in autism and would make sure [PII redacted] had the testing required to treat. It was not the case. I left his hospital visit in 2007 with a stack of test results and absolutely no treatment plan. I followed the labs. Through reading and interpreting the results, I sought out experts, enrolled [PII redacted] in clinical trials, and received treatment for his comorbid conditions. The moment [PII redacted] was diagnosed with autism, it was if all his health issues could be explained by this mystery condition that didn't warrant diagnosis or deserve treatment.

Seven long years later, my son sleeps through the night again. His reflux and GI inflammation are healed thanks to a strict paleo diet and immune support. His seizure activity remains but is managed with medication supervised by a top local neurologist. His hypogammaglobulinemia is treated with IVIG infusions monthly and his overall health continues to improve. He attends school instead of staying home sick. As I look at [PII redacted]'s health progress, I realize it's nothing short of miraculous. After witnessing his regression and watching him rapidly lose skills, I quickly learned that we were on our own seek help and treatments for [PII redacted]. I am grateful [PII redacted] is alive and that he suffers less.

I’m grateful that my husband and I are still married and that we can afford [PII redacted]’s medical treatment co-pays, medication, and therapies. I’m devastated that families are experiencing the same disconnect and lack of support in 2014.

The reason that Mom of a two year is experiencing the same thing I did in 2006 is there is no standard of care to diagnose and treat comorbid conditions of autism. I’m disappointed but not surprised at the lack of action and progress from the IACC. We discussed standard of care and co-morbid conditions eighteen months ago but have yet to see an action plan. I want the IACC to partner with the AAP and the Medical Academy of Pediatric Special Needs physicians to develop the standard of care and required testing at time of diagnosis. I then want the AAP to develop training and a roll out schedule to train pediatricians across the country. I want families like mine with a child who regresses into autism to see specialists in gastrointestinal disorders, infectious disease and immunology, and neurology. I want standard testing of endoscopy/colonoscopy, immune panel, MRI, and EEG. Once tested, I want treatment protocols if required and for the patients and data to be entered into a national registry. We need scientists culling the data and using to design studies. Follow the data. Fund more trials. Find a cause and a cure. By 2015, I want a family who has a 2 year old to receive an autism diagnosis and comorbid diagnoses on day one thus reducing the time from diagnosis to treatment and supporting the child.

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

Donna Young

September 21, 2014

Subject: The issue of possible prevention is never discussed at Autistic Meetings, only care of the autistic children. Do Prevention plus care for those now afflicted.

Prevention is worth a pound of cure to contributing causes of any form of autism.

RE:
http://www.gopetition.com/petitions/stronger-babies-by-no-clamping-off-their-umbilical-cord.html

Please bring this Petition to the attention of the care givers of any impaired or compromised child. They do look normal and so cute when we take them home anemic.

We often blame poor genes when they have eating and sleeping and learning and behavior problems, or poor lungs or poor energy as to allergies. All may be contributed to what they all will have in common early umbilical cord clamping. The baby`s deprived placental blood is harvested and sold, when the full placental infusion should be inside the baby, as the lungs are expanding. The process time is different for all babies, so one should wait for the third stage of labor to be completed before cord clamping. That is the placenta is birthed or removed (if a C-section), and all pulsation has ceased in the cord. The placenta will then, in that time period, of twenty minutes, more or less, will be a flat cake. And the umbilical cord will be white or silver in color, and flat and not pulsating. Early clamping often called delayed, the cord is yet firm, red, and pulsating. This is a clinical standard of care that is the most evil of mankind in their method and means to sell the trapped blood in the placenta and some in the cord. It is most evil not to consider the clinical standards as the contributing cause, weakening babies for profit of selling their deprived and stolen whole blood, and selling the extracted stem cells, for more than $30,000 USA dollars. The collected unit will measure less than one ounce, but the baby has been wrongfully, and I alleged, criminally deprived up to sixty percent total placental blood volume. This is a known fact stated in most all editions of the Lippincott Manual of Nursing Practice.

http://www.gopetition.com/petitions/stronger-babies-by-no-clamping-off-their-umbilical-cord.html

I am a birth reviewer since, 1998, to the present date.

Ms. Donna Young
[PII redacted]

Canada

[PII redacted]

Kathryn Kelley

September 23, 2014

Mr Insel, today you are the straw that broke the camel’s back. If you are not willing to fight for our children then you need to get out of this job! You say we don't have money to do anything. "we hope some people around this room will want to fund some things". Are you kidding me? YOU, yes YOU should be in front of congress shouting what needs to be done. YOU need to tell them what studies need to be done and that they must mandate NIH or whoever to conduct them.. YOU need to tell congress what services our children need and that they need to mandate insurance companies to pay for them. You blew my mind today with your careless attitude about accomplishing anything with the IACC. ??"I am waiting for the cares act to state this more clearly" Is that what you really said? There were so so many individuals who spoke today who are passionate about our children and truly want to make a difference. It is that type of person who should hold your position. Is this a paid position? Because if it is you should be charged with theft. You've done nothing for our kids, and with your comments today you have proven you could care less! Please do the autism world a favor and resign.

Kathryn J Kelley