Oral Public Comments

IACC Full Committee Meeting

July 19, 2016

List of Oral Public Comments

Katie Myers **July 19, 2016**

My name is Katie Myers. I am a board certified music therapist (MT-BC) and member of the American Music Therapy Association. Thank you for the opportunity to discuss the importance of music therapy for today's full committee meeting.

Music Therapy is the clinical and evidence-based use of music interventions to accomplish individualized goals within a therapeutic relationship by a credentialed professional who has completed an approved music therapy program. There is a growing body of evidence regarding the benefits of music therapy treatment and interventions for persons with Autism who have functional deficits in social, behavioral, cognitive, motor, and emotional functioning. Rapidly emerging science on the neurobiological basis of the influence of music therapy procedures on brain functioning attests to the viability of music therapy even in those who are resistive to other treatment approaches.

When individualized music protocols are designed by a MT-BC to fit functional abilities and needs, responses may be immediate and readily apparent. Music therapy provides opportunities for:

Increased attention
Decreased self-stimulation
Improved cognitive functioning
Increased socialization
Successful and safe self-expression
Improved behavior
Enhanced auditory processing
Decreased agitation
Improved verbal skills
Enhanced sensory-motor skills
All of these outcomes contribute to the well-being of persons with ASD, allowing them to maximize their potential and lead fulfilled lives.

Music therapy also helps families by providing structured opportunities to increase social engagement in the home environment and community.

Research among persons with ASD demonstrates that music therapy can:

Improve communication, interpersonal skills, personal responsibility and play in young children,
Elicit joint attention, enhance auditory processing and other sensor-motor,
perceptual motor or fine/gross motor skills,
Help identify and express emotions, and
Modify target behavior and teach new skills.

Music therapists offer services in public schools, family's homes, preschools and daycares, early intervention programs, treatment centers, support groups, hospitals, and various venues within the community, including music therapy agencies.

The U.S. Department of Education has provided written guidance that clarifies recognition of music therapy as a related service under the Individuals with Disabilities Education Act (IDEA). Qualified music therapists have been providing music therapy as a related service to literally thousands of children with disabilities in every state of the nation over the course of the 40 plus years since the passage of Public

Law 94-142. Through the use of the nationally recognized SEMTAP Assessment (Special Education Music Therapy Assessment Process), credentialed music therapists are able to determine if music therapy is "necessary" to assist a child with a disability benefit from special education.
The National Center for Complementary and Integrative Health at NIH has noted that, "Music therapy may have a positive effect on social interaction, and communication and behavioral skills in those affected by ASDs." NCCIH recognized the evidence base from several studies and a recent Cochrane systematic review. As a growing healthcare profession, music therapists need expanded recognition of the vital role the profession of music therapy plays in neurodevelopment.

I am requesting continuation of provisions related to advancing the understanding of the efficacy and effectiveness of music therapy interventions through research, education, training and information dissemination. Currently, the National Standards Project Phase 2 identifies music therapy as an "emerging intervention" as opposed to an "established treatment". The potential to make important contributions to help persons with ASD is large; however, the disciplines and stakeholders often work in relative independence. Therefore, I am asking for the recommendation to support music therapy researchers in multidisciplinary interagency collaborative work, including neuroscience research, to benefit basic, applied, and translational research as well as applied demonstration projects.

I look forward to providing additional input through future committee activity and thank you for consideration of our suggestions.

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

Albert Enayati **July 19, 2016**

Who should parents trust
Robert DeNiro or Centers for Disease Control

Testimony Presented By
Albert Enayati, MSME
Research Scientist, Senior System Engineer
Father of [PII redacted], who regressed into autism after his childhood vaccinations
[PII redacted]
Before the
Interagency Autism Coordinating Committee (IACC)
July 19, 2016
Bethesda, MD.

The movie Vaxxed is about fraud at the Centers for Disease Control (CDC), the federal agency in charge of the US vaccine program, because a whistleblower scientist (Dr. William Thompson) who conducted many of the studies used to “prove” vaccines don’t cause autism has publicly admitted data was hidden that actually showed a link between the MMR vaccine and Autism in African American Children. Now days It’s hard to take a defender of the vaccine program too seriously when they don’t address the existence of a senior scientist at CDC claiming the very studies they are citing as “proof” were done fraudulently.

Sorry, vaccines, but it’s just true: you may provide benefits to society in preventing certain potentially fatal diseases. But, you also have a dark side, too, like some pharmaceutical drugs: you cause brain damage in some of the kids who receive you. Don’t take my word for it — our federal government could not be clearer about this truth, the truth that vaccines cause brain damage in SOME children. Time and again, the Department of Health and Human Services makes it clear that “encephalopathy” is a vaccine injury, and they go on to define one form of “encephalopathy” from a vaccine injury table in the following way:

“Chronic Encephalopathy occurs when a change in mental or neurologic status, first manifested during the applicable time period, persists for a period of at least 6 months from the date of vaccination.”[1]

Like many children with autism, my son is suffering from a chronic encephalopathy that occurred after his vaccine appointments. I don’t really have to use that many of my IQ points to think that there may be a correlation between a product that causes brain damage (vaccines) and my son’s brain damage!

Historically vaccine are also guilty of poisoning our precious children’s brain by using the preservative Thimerosal a known neurotoxin.

The Eli Lilly Material Safety Data Sheet (MSDS) for Thimerosal acknowledges that exposure to Thimerosal in the uterus and in children can cause “mild to severe mental retardation and mild to severe gross motor impairment.” The Sigma Aldrich MSDS lists abortion and fetal death as possible outcomes of a uterus exposure. Thimerosal is a poison, neurotoxin, cancer-causer, and can disrupt the immune system and the normal development of an unborn baby or a child.

Here is what CDC website defines Thimerosal:

“There is no evidence of harm caused by the low doses of thimerosal in vaccines, except for minor reactions like redness and swelling at the injection site. However, in July 1999, the Public Health Service agencies, the American Academy of Pediatrics, and vaccine manufacturers agreed that thimerosal should be reduced or eliminated in vaccines as a precautionary measure”.

The very safety studies CDC are quoting were piloted by Dr. Poul Thorsen, who is indicted on 13 counts of wire fraud and nine counts of money laundering for financial research fraud and he is listed as a most wanted fugitive by the Department of Health and Human Services Office of Inspector General and was discredited in April 2011. It does not take a rocket scientist to comprehend who is being untruthful and misguiding the public.

Now a days It’s HARD to believe scientific studies, when it comes to vaccine-autism science, the general game plan of obfuscation by the CDC and AAP looks like this:

•Create a study in some way related to kids and vaccines

•Ensure the outcome will be one that exonerates vaccines

•Claim it proves vaccines don’t cause autism, details be damned

•Rely on the fact that journalists don’t read the studies

On no planet in the universe would anyone with a brain view these type of studies as in any way addressing whether or not vaccines cause autism, yet these studies remains cited on every list as “proof” that vaccines and autism are unrelated. It’s insanity!

It is true IACC, on your birth; you gave desperate parents so much needed hope but you also failed us. In space of six years you spent more than 1.6 billion dollars and you did not help our children not even one bit, no safe and effective medications, no prevention strategy, no conclusive biomarkers, no new treatments and autism prevalence continues unabated. You were cited by Government Accountability Office (GAO)[2] that Eighty-four percent of the autism research projects funded had the potential to be duplicative. In 2009 the National Vaccine Advisory Committee (NVAC) [3, 4, 5] recommended you a number of feasible research proposals on vaccines and autism, you did not implement not a single one. Please take note that a recent study among parents by the Simons Foundation found that 42% of parents felt vaccines contributed to their child's autism.[6], The IACC should not ignore this large segment of the community and observations by so many parents regarding their children's developmental history. IACC must and should include NVAC recommendation as a part of IACC new strategic plan and IACC needs to recommend to HHS that vaccine-autism safety needs to be addressed immediately. You constantly ignored petition of parents who their children regressed to autism through vaccination including myself. To keep the vaccine injured children voices silent, autism organization nominees for new IACC public membership were ignored instead, you reappointment three individuals from a single organization that known to have pro vaccine records in your committee voting.

1. http://wonder.cdc.gov/wonder/help/vaers/reportable.htm
2. http://www.gao.gov/products/GAO-14-16

3. http://archive.hhs.gov/nvpo/nvac/documents/NVACVaccineSafetyWGReport041409.pdf
4. http://www.huffingtonpost.com/david-kirby/cdc-to-study-vaccines-and_b_837360.html
5. https://snt153.mail.live.com/mail/ViewOfficePreview.aspx?messageid=mgTej-OXeB5RGKhgAhWtgZSg2&folderid=flinbox&attindex=0&cp=-1&attdepth=0&n=34466307
6. Goin-Kochel RP, Mire SS, Dempsey AG.. Emergence of autism spectrum disorder in children from simplex families: relations to parental perceptions of etiology. J Autism Dev Disord. 2015 May;45(5):1451-63. doi: 10.1007/s10803-014-2310-8.

Lori Frome **July 19, 2016**

Dr. Michael Merzenich a leader in neurocscience describes the period of neuroplasticity in infancy as "always on" (Soft-wired, 2013). According to most research, very young children are spending increasing amounts of time in front of electronic screen media. I ask you then, how is electronic screen media affecting our youngest children's brain development?

Many studies show that there are no benefits to watching television before two and that there is a negative association between screen time and attachment, attention, play, social and emotional interaction, language, behavior, and self-regulation These areas described also coincide as areas cited as deficits from children diagnosed with ASD. Zwaigenbaum et. al (2005) found that children with a predisposition to ASD have a more difficult time disengaging from a visual stimulus on a screen when another visual stimulus is provided than those without a predisposition. Due to this finding, these at risk children may be more fragile to developmental harm from early screen exposure.

Today, I come to request that further research be done regarding the topic of electronic screen removal in young children with ASD as a therapeutic treatment that may lead to a quicker achievement of developmental outcomes. I have been recommending screen removal in my own practice as an early interventionist who treats young children with ASD and pairing it with an intense focus on social interaction from the primary caregiver. I have witnessed seven children of varying severity levels make dramatic improvements leading them away from ASD and to a more typical developmental trajectory, including my own son's complete diagnosed recovery from ASD in just nine months' time. All of the children, including my son, were exposed to several hours of screen exposure in the first two years of life for various reasons.

With this method I recommend removal of all screen media such as television, tablets, DVD players, and smart phones including any background screen time they may be exposed to which is not directly programmed for their viewing. I also encourage the parent to involve their child in what they are doing and have their child be part of their routine to the greatest extent possible while labeling what they are doing as their child participates with the least level of prompting. The parent is also encouraged to hold the objects they label to their eyes and gives their child verbal praise, tickles, and encouragement when eye contact is made.

When using this method, parents have seen that their child begins to respond more typically, often in a period of weeks. Eye contact, joint attention, and physical closeness often are the first noticeable improvements using this method and the parents report feeling a deeper sense of connection with their child which encourages them to continue it's use. This method has also been effective in families where previous siblings have had ASD and the abstinence of screen viewing during the first year of life has produced no subsequently affected siblings with ASD in these families.

References

Merzenich, M. M. (2013). *Soft-wired: How the new science of brain plasticity can change your life*. San Francisco, CA: Parnassus Publishing.

Zwaigenbaum, L.,S. Bryson, J. Rogers, W. Roberts, J. Brain, and P. Szatmari, "Behavioral Manifestations of Autism in the First Year of Life," *International Journal of Developmental Neuroscience*, 23, 2005, pp. 143-152.

Carolyn Gammicchia **July 19, 2016**

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

I'd love to spend this three minutes allotted to discuss all that we are concerned about as parents of a now twenty five year old young man living with autism, however that would be virtually impossible. Each time members of our family have come before this committee, we've presented concerns we've felt have fallen mostly on deaf ears. Yet I still appear before you today, traveling from Michigan, with the hope that you will listen because our family's story is not rare. I'm playing this video for you to see as I speak because there are parents standing up all across the country who have stories just like ours and could not be here.

In 1991 our son was born a healthy child.

In 1992 our son was developing ahead of his milestones. He started crawling early. He climbed the stairs at six months. He started walking at nine months. He began saying two word phrases at a year old. His brother, fifteen months older, was his role model and they were inseparable.

In 1993 I took our two sons to the health department for their vaccinations. Our oldest had one vaccination that day without problems. The attending nurse advised me that to make it easier for us in future visits, I should catch up our youngest son to his brother current vaccine status. I asked the nurse if that was safe and what that would entail. She stated "He will be given four vaccines and this is perfectly safe, we do it all the time, and there is no need to worry."

That day still is as fresh in my mind as when it occurred. Our son sat in my lap and the nurse injected the first vaccination in his thigh. He cringed away and started to cry. The nurse then tried to grab his arm when she came back with another syringe and he pulled it away still crying. As he did so he put him hand to cover the other vaccination site which had now started to redden. She then grasped his opposite thigh and injected our son with his second vaccination. Our son began to scream and as I sat there trying to calm him I just knew something was not right. I again asked if we should be doing so and the nurse stated "This will be over soon and the kids cry all the time." The next shot was given to his original thigh which by now appeared to be starting to swell. Our son began screaming at the top of his lungs and his brother too was crying by this time as was I. The final vaccine was in his opposing thigh and by then our son was sweating and both thighs appeared to be red and swelling. At that point the nurse indicated our son was "caught up" and had been given six vaccines in one sitting because one of the vaccines was the MMR.

I was not told at the time that these vaccines our son was given were not tested for safety, especially when given all in one sitting due to the ingredients they obtained.

I was not told that giving him the suggested Tylenol to ease his pain and fever, which contains acetaminophen, could fuel to the fire of what was transpiring for him.

I was not told that we would lose our son that day.

That he would no longer speak.

That he would no longer be able to sustain being held.

That he would no longer play with his brother.

That he would no longer make eye contact.

That he would no longer be the healthy, happy, loving child we had known.

Within the next six months our son was diagnosed with PDD-NOS and we were told to concentrate on our other son because we would have to institutionalize this son by the time he was ten.

Within the following year, our son was diagnosed with Autism and we were told there was nothing we could do to alleviate his condition.

Nothing we could do to stop him from self-injury and head banging.

Nothing we could do to stop him from not sleeping more than two to three hours in a night.

Nothing we could do to stop him from lashing out and screaming at his older brother.

Nothing we could do to get our healthy, happy, loving child back.

Our child that did not have these challenges when he was born. These challenges were not present prior to his vaccine injury. They were not missed by us, nor was the diagnosis of autism, because our son was not born with autism.

Twenty four years later we now know that vaccines are not safe given in combination. (1)

We now that researcher Dr. William Thompson of the CDC has come forward and indicated that vaccine research associated with causation of autism he participated was flawed and has gone without investigation. (2)

We now have scientific experts, some in the field of autism, coming forward and indicating that autism is being caused by environmental factors. (3)

We as a family ask that you now revisit the fact that vaccines and environmental issues have been and will continue to cause cases of autism in the United States and include this in the research that has yet to be done. As Dr. Coleen Boyle testified before Congress in the past, we have yet to have a study done of children in the United States that have been vaccinated and have autism vs those who have not been vaccinated and have autism. Until that study is done, and at least replicated once, no one can say "Vaccines do not cause autism".

We will not go away. Our son will continue to seek remediation of his vaccine injury while an adult living with autism. This year alone he's been newly diagnosed with seizures and just this week was given the clinical diagnosis of PANDAS by his neurologist, after a sudden onset period of regression, which will require infusions of intravenous immunoglobulin (IVIG) due to this being caused by immune deficiency. This will minimally be over a six month period where he will have to be hospitalized for these infusions that will take hours.

So you see, vaccine injury is not something that can go away. It can continue to cause illness related to the immune system once that is damaged and is often difficult to remediate.

We will continue to think as well of all of the children who could have been spared vaccine injuries and the co-occurring medical conditions an autism diagnosis can bring.

If people had listened. That is why we will continue to stand up.

Thank you,
Carolyn, Andrew, Alexander, and Nicholas Gammicchia

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(3) Bennett D, Bellinger DC, Birnbaum LS, Bradman A, Chen A, Cory-Slechta DA, Engel SM, Fallin MD, Halladay A, Hauser R, Hertz-Picciotto I, Kwiatkowski CF, Lanphear BP, Marquez E, Marty M, McPartland J, Newschaffer CJ, Payne-Sturges D, Patisaul HB, Perera FP, Ritz B, Sass J, Schantz SL, Webster TF, Whyatt RM, Woodruff TJ, Zoeller RT, Anderko L, Campbell C, Conry JA, DeNicola N, Gould RM, Hirtz D, Huffling K, Landrigan PJ, Lavin A, Miller M, Mitchell MA, Rubin L, Schettler T, Tran HL, Acosta A, Brody C, Miller E, Miller P, Swanson M, Witherspoon. 2016. *Project TENDR: Targeting Environmental Neuro-Developmental Risks. The TENDR Consensus Statement. Environ Health Perspect* 124:A118–A122; http://dx.doi.org/10.1289/EHP358

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Heidi Scheer **July 19, 2016**

Good afternoon committee members. My name is Heidi Scheer and my son [PII redacted], was diagnosed with autism at age four. I am here to discuss the critical importance of research for biomedical treatments for children with autism. I have been an international autism advocate for 10 years and have traveled throughout the world meeting parents and caregivers of children on the autism spectrum.

The need for research of biomedical interventions for children with autism is critical, as we face the astronomical number of cases of autism, as well as the debilitating financial affect this is having on our country. I meet families every day who are unable to help their children due to the lack of funding and resources available to heal their medically ill children.

I speak from experience when I say that biomedical interventions have changed my son's life. After 10 years of treatments, he is recovering and no longer needs the tremendous amount of special services that were once required to help him function. When he was first diagnosed, he couldn't speak a sentence or interact with other children in a safe way. He would bite, scream, and run away from us as he had no comprehension of fear, danger, or safety. He was in three schools during the first two months of kindergarten where we tirelessly pursued many, many plans to educate him. We tried a "one on one" aid, and later found a self contained classroom for him where he would remain for 5.5 years. As you know, these self contained classrooms cost tax payers millions of dollars each year needing one teacher and two para educators in order run safely and smoothly.

Of course biomedical treatments do not work for all children on the autism spectrum (just like drugs and ABA do not work for everyone) however, they have been documented to work for thousands! I have personally met hundreds of greatly improved and recovered children who were once very sick and suffering in pain. Pain that emerged as self injurious behaviors, intense gastrointestinal distress, and the inability to communicate and function in our world.

The children of this nation need us to be responsible and to tend to their needs. My son who was not supposed to be able to ever speak a sentence, was the first student ever with ASD to graduate from a self-contained classroom at his elementary school. In middle school he had a lead in his school play and competed on the school’s forensics team in the field of public speaking. As a result of the numerous sacrifices my family made in covering all of the horrendous expenses to pay for biomedical treatments for my son, he no longer needs to be a burden on tax payers to care for him throughout his life. We were fortunate to have the means, as well as the help and support of family to accomplish this goal. Other families are not so fortunate. And so, their children continue to suffer greatly and the tax payers burden grows exponentially.

As members of the Interagency Autism Coordinating Committee appointed by the HHS, I am asking you on behalf of myself and all autism families in this country, to please include research for biomedical treatments for individuals with autism in the IACC’s recommendations for the Autism CARES Act. You have the power to change lives.

Sheryl Melling **July 19, 2016**

My name is Sheryl Melling and I am both a teacher in a Michigan public school district as well as a parent of a 13 year old son with an Autism Spectrum Disorder. I would like my comment to focus on the dire need for educating educators on how to appropriately meet the vast needs of individuals with ASD so that they can be mainstreamed with non-disabled peers instead of being pushed into more restrictive environments such as resource rooms and emotionally impaired schools.

My son is extremely high functioning so much that his autism might be missed by many. This often makes his disability invisible to others. hence, leading to misunderstandings in his behavior. Many children with Autism Spectrum Disorders have difficulty regulating their emotions, reading social cues, and communicating their needs appropriately. Their behavior is often viewed as being defiant, purposefully disobedient and even deliberate. They are often punished and alienated in a school environment due to this understanding and lack of appropriate education in regard to this disorder. Because many school staff are not trained on how to address these behaviors or better yet able to avoid such behaviors the children not only suffer but tend to worsen. They are then excluded from their education and recommended to be moved toward other programs such as emotionally impaired classrooms.

This happened with my own child once he reached middle school. He was placed on a punitive point system where he would get 6 tickets at the start of the day and lose 2 tickets at a time for any mess-ups. Certain mess-ups would count as a complete loss of all 6 tickets for something perceived as a big ?no-no? such as saying ?What the hell? or leaving the classroom without permission. Once he lost all 6 tickets, he was sent home. This created a pattern with our son which only worsened his behavior. He was sent home nearly every day within the first half hour of school. His middle school wanted him to go to an emotionally impaired school, which was 35-40 minutes from our home. Mind you, the 6 years he spent at his elementary school, the words ?Emotionally Impaired? or different placement were never brought up or mentioned. He was also rarely sent home at his elementary school. He never was violent are harmed anyone in any way. Due to the district excluding my son from school so many times and not providing him FAPE we ended up removing our son from his local district and placing him in private school at our cost of $24,000/school year. This should never have happened as our son was basically forced out of his school.

Proper training along with some compassion would have gone a long way in helping our son adapt to his new middle school and attain success. . In talking with more and more parents of special needs children, I have realized that our story is not unique but on the contrary quite common. Teachers and administrators need to learn from the experts in Autism strategies and techniques on how to help these children succeed. University education programs need to have entire classes relating to Autism Spectrum Disorders. Schools also need to be held more accountable when they are excluding these children from the education they are entitled to instead of pushing them out of the school or district. This is unacceptable, only further damages the child, and leaves parents stuck between a rock and a hard place. Parents often get nowhere when trying to hire attorneys because school districts use tax dollars to pay for their attorneys while parents have to dip into their own pockets to pay for their private attorneys.

Please help our country address this issue by requiring extensive training on Autism Spectrum Disorders as well as provide funding to schools specific toward helping students with ASD. School districts also need to be held more accountable when not meeting the needs of these students. A little flexibility, a positive behavior plan, and the proper supports set in place could have made a world of difference for our son?s short-lived public middle school experience.

Thank You!

Sheryl and Greg Melling

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

Dr. Eileen Nicole Simon **July 19, 2016**

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

An article in the October 1969 issue of the Scientific American reported damage of the inferior colliculus caused by asphyxia at birth. The inferior colliculus is a component of the brainstem auditory pathway. For me this provided a plausible explanation of why my first two sons were not learning to speak.

Language is the defining characteristic of the human species. Developmental language disorder is a disaster.

Aphasia following brain injury in an adult is likewise a disaster. Understanding the brain circuits between the temporal lobes and frontal cortex has been an important focus of research since the discoveries of Broca in 1861 and Wernicke in 1874. Why these circuits fail to develop in autistic children should be a primary goal of research.

The Combatting Autism Act and the IACC were intended to promote scientific investigation of what causes early childhood autism, and why the prevalence began to increase in the early 1990s.

I have proposed that:
(1) Injury to the inferior colliculus during prenatal life or early infancy could disrupt auditory signal processing, and also, maturation of the language areas in the cerebral cortex.
(2) Damage of the basal ganglia appears to underly the repetitive movement disorder of autistic children. The basal ganglia are also damaged by asphyxia at birth.
(3) Diminished environmental awareness is most likely (in neurological terms) part of a diminished level of consciousness (LOC). In my written comments, I discussed research on how this might also result from injury of the inferior colliculus.

"Social disorder" was a euphemism adopted to promote a sense of hope. I could be wrong, but "autism" diagnosed later should be considered a distinct and different affliction.

Brooke Potthast **July 19, 2016**

As the mother of 4 children, I was very surprised to have my 4th child, a typically developing 21 month old, begin to lose skills, stop answering to his name and slowly lose the ability to speak. His clear, pure baby voice; easy to understand and used with perfect affect and intonation disappeared into apraxic, groping sounds with unreliable and inconsistent speech production.

No doctor or evaluator ever answered the question as to why a typically developing child with normal speech lost the ability to speak and became non-verbal and apraxic. There is no doubt in my mind that our son?s ?autism? was a stroke like incident occurring in the brain as a result of the bolus doses of aluminum adjuvants in his childhood immunizations. Nine hundred mcg of aluminum injected into the bloodstream, which happened to our son at 21 months, is enough to produce a stroke in the brain with catastrophic results.

Having spent the last 12 years working with our son and with families whose children also lost speech it has become apparent that there is an egregious misdiagnosis going on with a large percentage of the children identified as being on the autism spectrum.

Our son and many individuals like him are not socially or cognitively disabled, as the diagnosis would lead you to believe but have severe sensory movement disturbances.
These individuals have significant problems with praxis and body control, all of it made worse by damaged and overwhelmed sensory systems.

The most important thing the IACC could do (other than insist on a safer vaccine schedule) is mandate early diagnosing of movement disorder and the degree the individual is dealing with and treat accordingly. Rather than addressing deficits with behavior modification programs the children need extensive sensory motor therapy focusing on praxis and body control. Children should be getting therapy that will improve the ability to execute chains of smooth motor movements. Children in this subset of autism need to receive physical, occupational and motor therapy that will help them with the gap they have between intention and action.

In addition to traditional speech therapy the children should be receiving from a young age motor therapy that targets shoulder, arm, elbow, wrist and finger control so they will be able to point to letters to spell their thoughts (eventually typing) rather than having to depend on unreliable and rote verbal expression.

Our son spent 12 years being trapped in a body that would not and still does not respond to his brain?s messages. If we had relied on the current medical and educational information available he would be locked in silence. Instead we sought methods and therapy that are not considered mainstream and he is a fully communicating, happy, thriving, son, brother, friend and student who hopes to have a fulfilling future. Despite the assaults on his infant system his intellect and cognition are intact. Unfortunately, he has to spell letter by letter and word by word what he wants to say but it is worth the sacrifice to be known and heard.

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Chiara King, Esq. **July 19, 2016**

I am here to discuss the study publicized by Johns Hopkins earlier this year, which showed increased risk of having a child with autism in women with excessive quantities of folate and vitamin B12 in their bloodstreams after birth (1). Women with excessive folate had 2 times greater risk; women with excessive B12 had 3 times greater risk; and women with excessive levels of both folate and B12 had over 17 times greater risk of having an autistic child.

The media's downplay of these results is shocking. Genetic mutations impairing folate and B12 metabolism in the methylation cycle are extremely common. Despite this, current obstetric practice in this country is to recommend folic acid supplementation throughout the entire pregnancy, well after the danger of neural tube defect has passed, without any regard whatsoever to maternal methylation impairment. This is important because women with these mutations cannot efficiently metabolize folic acid, which is of course a synthetic substance. This may allow folic acid to accumulate in pregnant women's bodies to an unprecedented extent.

Folic acid has been known since the 1950's to promote estrogen-sensitive growth (2). Estrogen impacts a number of cognitive functions that are commonly affected in autism, like motor coordination, movement disorders, epilepsy vulnerability, attentiveness, regulation of pain pathways and the serotonin system, memory, and spatial ability (3-4). Testosterone converts to an estrogen in the brain during fetal development, and then acts upon neuronal estrogen receptors, so simply being a male fetus may be a natural risk factor for excessive estrogen-sensitive brain development. There are many other drugs and chemicals that interact with estrogen receptors that might add to the cumulative effect. SSRI antidepressants and pyrethroid insecticides, for example, have recently been linked to autism (5-6). SSRIs are used to complement estrogen therapy, and pyrethroids are known to interact with estrogen receptors (7-8). Thus, infantile autism may be the result of excessive estrogen-sensitive brain growth during a specific period of fetal development (9).

Children born of methylation-impaired women would be expected to possess some of their mothers' metabolic mutations. Autism is indeed associated with various combinations of methylation mutations (10-11). Methylation cycle impairments have also been associated with developmental regression as well as increased incidence of adverse vaccine reactions (12-14).

I am here today to ask you what possible benefit there could be to 90% of American women taking folic acid for an entire nine months, when the neural tube closes by the 28th day after conception. Is this practice worth the risk?

Sincerely,
Chiara King, Esq.
Glen Arm, MD
[PII redacted]

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Lida M. Wiederlight, MPP **July 19, 2016**

Asking the Hard Questions About Federal Autism Policy and Research

Testimony Presented By
Lisa M. Wiederlight, MPP
Executive Director, SafeMinds
Before the
Interagency Autism Coordinating Committee
July 19, 2016
National Institutes of Mental Health
Bethesda, MD

Years ago, when I worked for the Office of National Drug Control Policy, I helped produce the National Drug Control Strategy. We had to accomplish two things:

A) Answer the “so what” question; and

B) Be accountable to Congress for making a difference with real outcome measures each year.

At every IACC meeting, I’m reminded of these principles. Stakeholders are providing the “so what”. Are the IACC's Federal agencies listening and being accountable to make a measurable difference?

Each meeting, passionate parents convey the struggles they face in addressing severe autism. The Committee hears letter after letter about the dangers from wandering, the toll of seizures and gastrointestinal disease, the harm of uncontrollable aggression and self-injury, the diminished quality of life from unremitting anxiety, depression and suicidal behaviors, the lack of respite from 24/7 care for those with diminished cognition. For three minutes, committee members discuss how important these so-what's are, but little is proposed that would make a measurable difference.

Over a million children have been diagnosed with autism since 2000. With rising prevalence, unmet demands on services, and grim reports from parents, it's obvious that the government response is inadequate.

What is being done to improve the epidemiology so that we have an accurate count of the number of affected individuals? Is the prevalence 1 in 68 and flat as just reported by the CDC, or is it 1 in 41 and still rising as reported by New Jersey? There is a big difference in projected costs and needs between 41 and 68.

What proportion are severely impacted by co-occurring conditions? What are the trends? The CDC's methodology cannot give the answers. Should Federal coordinating agencies allow this sloppy research to remain the foundation for autism policy?

Has severe autism always been around at the present rate, or have we witnessed a true epidemic due to modifiable environmental factors which are increasing risk? How can federal agencies charged with autism not demand a rigorous answer so that strategy aligns with reality?

The Senate HELP Committee, in report language for Fiscal Year 2017, urged the NIH to:

- “include research on environmental factors related to autism, especially regressive autism, in the upcoming revision to the Strategic Plan for Autism Research”,

- “ask the IACC to consider research on environmental factors related to autism, including onset patterns, in the upcoming revision to the IACC Strategic Plan for Autism Research”,
- “assure that research on environmental factors continues to be supported, ” and
- “study the relationship between GI diseases and Autism Spectrum Disorders”

How will the IACC be accountable to Congress for these directives?

The President proposed $1.9 billionto Congress to address Zika virus. As of July 6th, 1,133 Zika cases were reported. Over 1.5 million Americans are diagnosed with autism, which increases mortality and significant disability and costs $268 billion a year. How much have your individual agencies asked Congress for autism this year?

This Committee's work is to inform and promote effective public policy. Please take a moment now, on record, to tell Congress and those facing autism across the country – when and how you will do this.

Adrienne McBride **July 19, 2016**

On behalf of JaLynn Prince, President and Founder of Madison House Autism Foundation

This is not the first time I have presented comments at the IACC, and it will probably not be my last. My goal here is not to be redundant. My goal is to stand up for adults on the autism spectrum including my 26-year-old son - so their needs will be known and perhaps their life trajectories will change for the better. **It is not looking so good if things don't change and change dramatically.**

Through Madison House Autism Foundation, now ten-years old, and Madison Fields, our farm/housing project, we are addressing the many issues that adults on the autism spectrum face after they turn 21 and no longer receive federally-mandated services. **A large portion of society has never thought that children with autism grow up to be adults with autism.**

The outcomes are dismal; the funding on state and federal levels is most scarce for those most vulnerable among us. The services that do exist are inadequate. Job prospects are virtually nonexistent with researchers projecting 80% unemployment or underemployment. Many autistic adults live with their parents for decades. What is going to happen when these parents can no longer care for their adult children?

Let me share some background: Madison House Autism Foundation is a 501(c)(3) organization, headquartered in Rockville, Maryland. Madison House addresses quality of life issues for adults with autism and their families. Madison Fields, a local project provides a location for respite, recreation, riding and agricultural-based employment and job training for adults with autism, veterans groups, seniors, neurotypical, volunteers and all others who can benefit from our inclusive programs.

Recent initiatives include:

- A relaunch of our Autism Housing Network to great acclaim: this national initiative is sparking ideas to create innovative residential opportunities
- A new and exciting arts employment initiative a replicable program for those on the autism spectrum who may be considering a career in the arts.
- Declaring April 21 as Autism After 21 Day and we are asking colleagues, other organizations and you to observe this day accordingly
- The championing of universities to develop training for careers in the field of autism and, for greater accommodations for those on the autism spectrum who are candidates for education to have a higher level of success, and
- Working with the medical community to look closely at the uniqueness of autism when providing medical care.

More than awareness, we need evidenced-based studies and creative action on the federal level. Not all adults with autism will grow up to be self-advocates much like most neuro-typical individuals will not grow up to be politicians. In fact, self-advocates have very different support needs than many others on the spectrum.

Support needs are costly. Even supports delivered in a community-based setting - a family home - can bankrupt families both emotionally and financially. We are living in times that are rapidly changing and the way we deliver services must change as well. Our politics and leadership reflect the complexity.

These are frightening times for families - however: **Madison House is changing outcomes and we need people like you. I am honored to be part of a working group to change the future of adults with autism.**