Oral Public Comments

IACC Full Committee Meeting

April 8, 2014

List of Oral Public Comments

Carolyn Gammicchia

April 8, 2014

A Consideration of Expectations: A Response to the IACC from the Autism Community

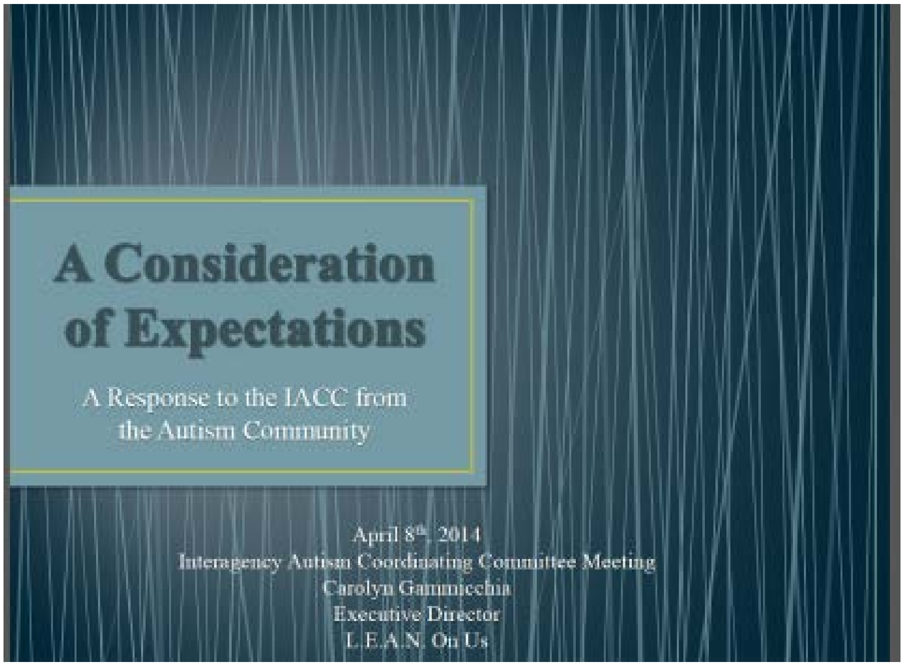
April 8th, 2014

Interagency Autism Coordinating Committee Meeting

Carolyn Gammicchia

Executive Director

L.E.A.N. On Us



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GAO Summary Report Findings in Reference to Federally Funded Autism Research

Four Years of Funding for Autism Research

1.18 billion dollars

84% Replication = What in transferrable application of viable research for those living with Autism?

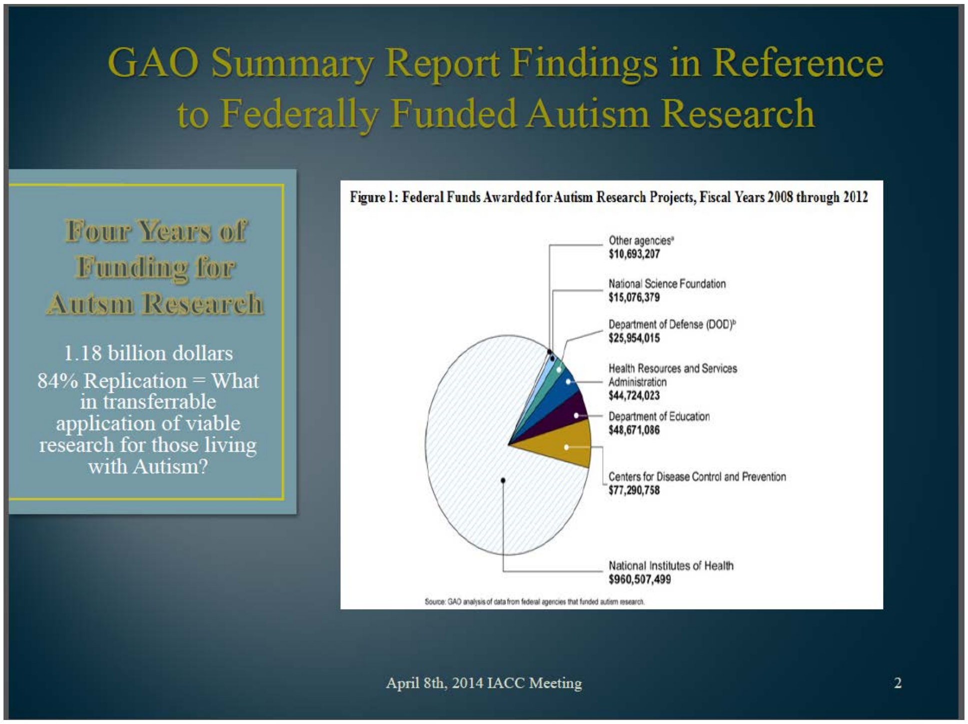

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Figure 1: Federal Funds Awarded for Autism Research Projects, Fiscal Years 2008 through 2012

Source: GAO analysis of data from federal agencies that funded autism research.

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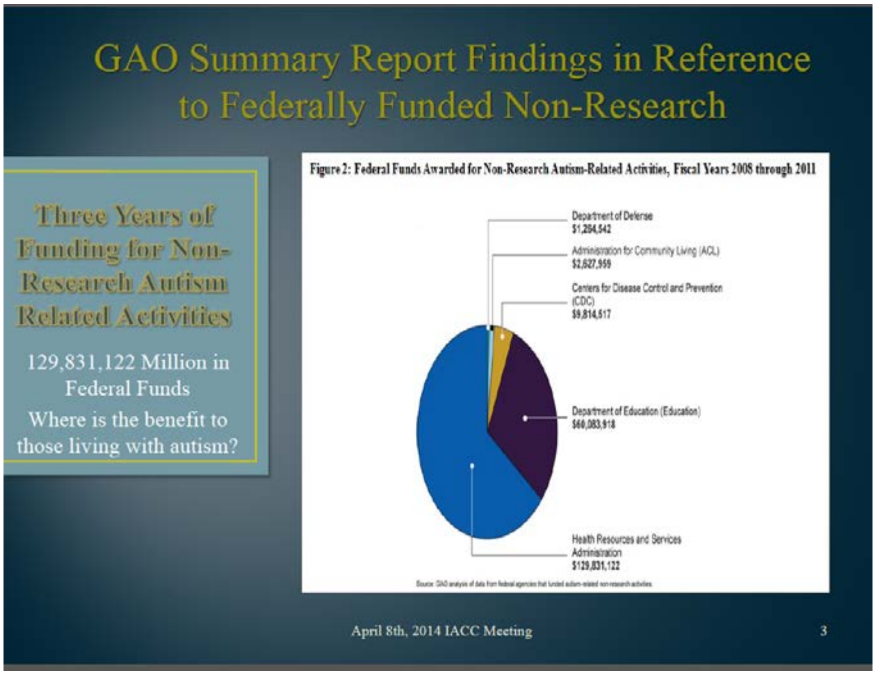
Three Years of Funding for Non-Research Autism Related Activities

129,831,122 Million in Federal Funds

Where is the benefit to those living with autism?



GAO Summary Report Findings in Reference to Federally Funded Non-Research

Three Years of Funding for Non-Research Autism Related Activities

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Figure 2: Federal Funds Awarded for Non-Research Autism-Related Activities, Fiscal Years 2008 through 2011

Source: GAO analysis of data from federal agencies that funded autism-related non-research activities.

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July 2012 Strategic Plan Research Areas

Does the IACC have it's own checks and balance system for coordinating their own activities? The GAO report stipulates that is not the case.

GAO Summary Report Findings in Reference to the IACC Strategic Plan in Research Areas

July 2012 Strategic Plan Research Areas

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Figure 3: Interagency Autism Coordinating Committee (IACC) Strategic Plan Research Areas, July 2012

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IACC

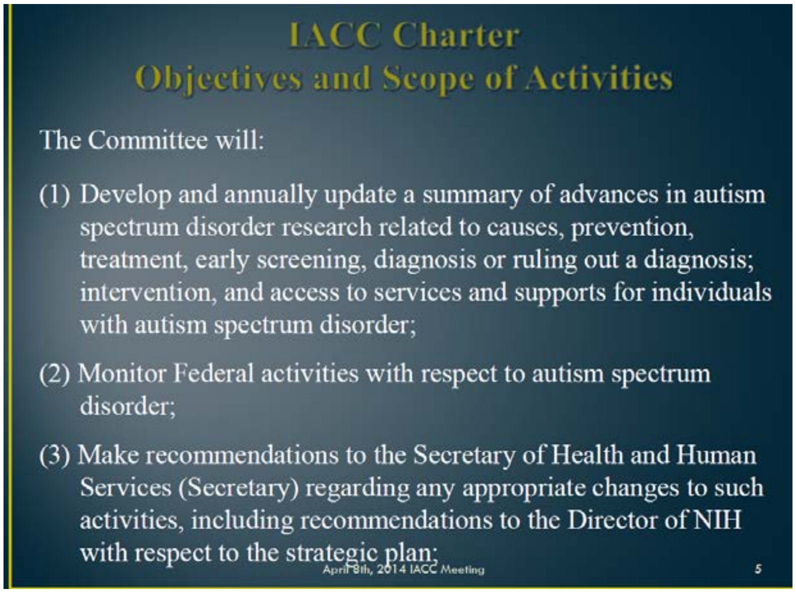
Charter Objectives and Scope of Activities

The Committee will:

1. Develop and annually update a summary of advances in autism spectrum disorder research related to causes, prevention, treatment, early screening, diagnosis or ruling out a diagnosis; intervention, and access to services and supports for individuals with autism spectrum disorder;

2. Monitor Federal activities with respect to autism spectrum disorder;

3. Make recommendations to the Secretary of Health and Human Services (Secretary) regarding any appropriate changes to such activities, including recommendations to the Director of NIH with respect to the strategic plan;



IACC Charter
Objectives and Scope of Activities

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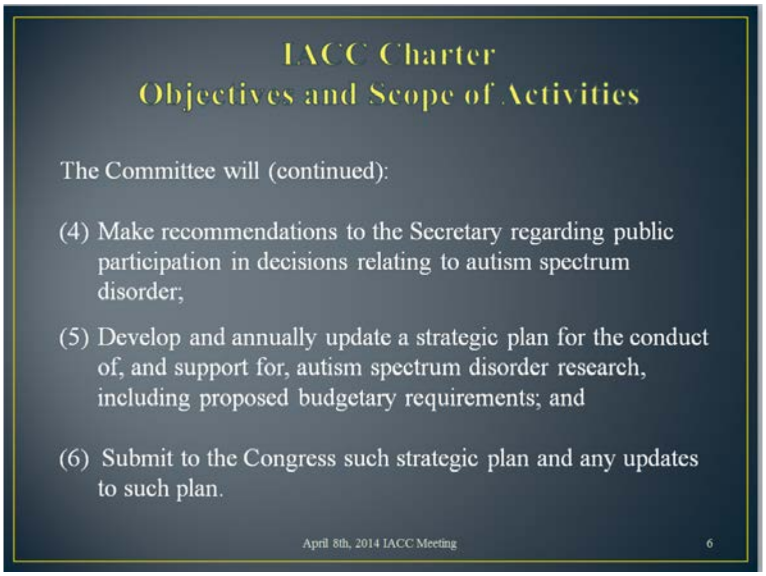
IACC Charter Objectives and Scope of Activities

The Committee will (continued):

4. Make recommendations to the Secretary regarding public participation in decisions relating to autism spectrum disorder;
5. Develop and annually update a strategic plan for the conduct of, and support for, autism spectrum disorder research, including proposed budgetary requirements; and
6. Submit to the Congress such strategic plan and any updates to such plan.



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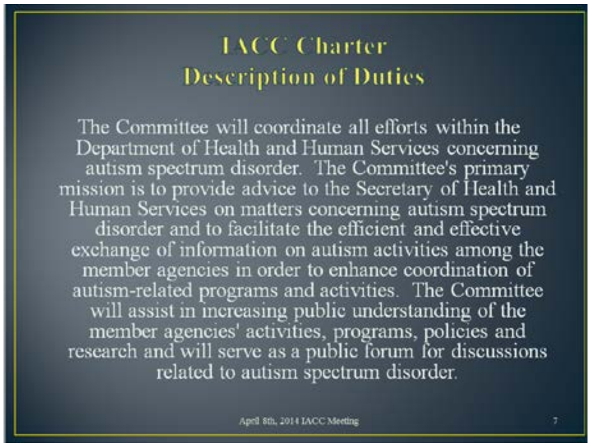
IACC Charter Description of Duties

The Committee will coordinate all efforts within the Department of Health and Human Services concerning autism spectrum disorder. The Committee's primary mission is to provide advice to the Secretary of Health and Human Services on matters concerning autism spectrum disorder and to facilitate the efficient and effective exchange of information on autism activities among the member agencies in order to enhance coordination of autism-related programs and activities. The Committee will assist in increasing public understanding of the member agencies' activities, programs, policies and research and will serve as a public forum for discussions related to autism spectrum disorder.



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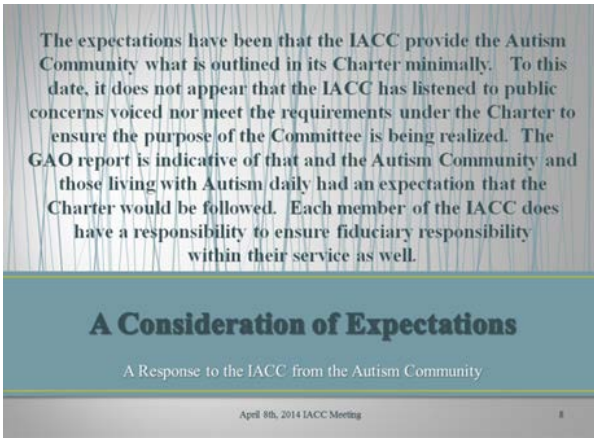
The expectations have been that the IACC provide the Autism Community what is outlined in its Charter minimally. To this date, it does not appear that the IACC has listened to public concerns voiced nor met the requirements under the Charter to ensure the purpose of the Committee is being realized. The GAO report is indicative of that and the Autism Community and those living with Autism daily had an expectation that the Charter would be followed. Each member of the IACC does have a responsibility to ensure fiduciary responsibility within their service as well.

A Consideration of Expectations

A Response to the IACC from the Autism Community



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A Consideration of Expectations

A Response to the IACC from the Autism Community

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Dawn Loughborough

April 8, 2014

One in sixty-eight children born in 2002 have been diagnosed with Autism. That is a 30% increase from last year. Part of the increase in prevalence estimates stems from greater recognition. However, it is absurd to argue that there were just as many, or even anywhere nearly so, severely affected children and adults with autism in earlier years as today. One would have to believe that large numbers of nonverbal, combative and often self-injurious children, unable to pass basic developmental milestones towards independence, including being able to toilet train, many enduring intense pain from GI disorders or seizures, were somehow just never noticed before in American society. One would have to believe that individuals with autism wandered and died in comparable numbers just 20 years ago but, again, they simply went unnoticed.

In fact, the numbers of such severely afflicted of our children has skyrocketed, and if there is consensus on anything in the field, it is that there are still far more questions than answers as to why this is happening, and still no meaningful advances in prevention for regressive autism, treatment and/or cure for those affected by co-occurring conditions, nor adequate services -- across a lifespan of needs -- for those living with autism.

We have a public health crisis and need urgent federal response. 1.2M individuals with Autism need to be considered a special patient population so that when they show up, non-verbal or combative, in a hospital emergency room, the staff knows how to investigate their pain and diagnose their health problems using evidence based medicine.

As medicine advances for Autism, we will find the underlying medical associations and the environmental toxin and disease ideology triggers. Here are some examples from the CDC Website:

"In the United States, about 1 in 6 children have a developmental disability… a diverse group of severe chronic conditions that are due to mental and/or physical impairments. People with developmental disabilities have problems with major life activities such as language, movement, learning, self-help, and living by themselves.

Sometimes we have something very simple that can offer a positive solution:

Dr. Rachel Avchen, a current CDC EIS officer who is assigned to investigate developmental disabilities in children is studying kernicterus in infants, a type of brain damage that is preventable and caused by severe and untreated jaundice "and that prompt light exposure reduces risk. (CDC website)

Asthma, which was originally viewed as a psychiatric diagnosis in the 1950s has become known as a disease that affects the lungs. However, this disease view has expanded further, and in 2013 the Johns Hopkins University Public Health magazine ran a cover story saying that they have found a new connection between Asthma and GI Disorders.

“The specific cause of most developmental disabilities is unknown. They may result from an interaction between genetic, environmental, and social factors… some can be prevented or lessened by … healthy pregnancy, by detecting and treating conditions early, and by preventing harmful exposures and injuries.” (CDC website)

This IACC has not fulfilled on the intent of congress to investigate all potential causes of Autism, in particular environmental causes, and a recent GAO Report states a concern for potentially duplicative research.

Society wants answers and real help for this national public health crisis akin to an epidemic. It’s a matter of national security and human rights.

- Dawn Loughborough

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

Albert Enayati

April 8, 2014

Subject: Human DNA in Childhood Vaccines

DO VACCINE CAUSE AUTISM
Human DNA in Childhood Vaccines

Testimony Presented By

Albert Enayati
Research Scientist in Medical Technology
Father of [PII redacted], who regressed into autism after a vaccination.
[PII redacted]

Before the
Interagency Autism Coordinating Committee (IACC)
April 8, 2014
Bethesda MD.

Human DNA in Childhood Vaccines

Many of the routinely recommended childhood vaccines are produced in media derived from human cell lines, including MMR (MMR II), chickenpox (Varivax)), Hepatitis A (Vaqta, Twinrix, Havrix), and a DTP-Polio-Hib combination (Pentacel).[1] The two particular fetal cell lines that are used in production of current vaccines are WI-38, developed at the Wistar Institute in Philadelphia, and MRC-5, developed for the Medical Research Council in England. Both were created in the 1960s. The shocking revelation of the cell line MRC-5 is that, the lung tissue taken from a 14 week fetus aborted for a **psychiatric** reason.

In the mid to late 1970s, pharmaceutical companies switched from using animal cell lines to using fetal human cell lines to produce some of their vaccines. It was assumed by the manufacturers that using fetal cells would result in a more efficient production system. The high volume of vaccine production means a large quantity of these cells. The final vaccine is never completely 'pure' and DNA and cellular debris from the production cells are in the final product. For example, the package insert for Varivax, a chickenpox vaccine, states that the vaccine contains "residual components of MRC-5 cells including DNA and protein." Merck, the manufacturer, documents that Varivax is contaminated with over 2 micrograms of human fetal DNA fragments.

The Human DNA in these vaccines has the potential to become incorporated in the host's genes by a process called illegitimate or homologous recombination. Human DNA in the vaccines may now be propagating in the human cells of those given the vaccines. Homologous recombination is an established biological phenomenon in which a segment of a cell's DNA is substituted by another segment of DNA that is from the same species. This can occur during cell division or DNA repair. Homologous recombination occurs naturally to create genetic diversity in our offspring, and is also conveniently harnessed by scientists to introduce experimental DNA into cells and animals. We do not know yet if this occurs with the contaminated human DNA found in childhood vaccines, and if so, to what extent. It is critical to find out, due to the potential consequences as vaccines are given multiple times starting as early as 2 months of age, and DNA may be incorporated into a child's developing brain and immune system.

It is possible that human DNA-contaminated vaccines contribute to some cases of autism. One hypothesis [10, 11] presented to us is that the homologous recombination of DNA from another human incorporated in a host's DNA may cause auto-immune reactions and/ or subsequent somatic mutations. [3,4] Our own immune system destroys altered self which, in this case, is the new DNA incorporated in the host's DNA, a target for altered-self destruction. The autoimmune reaction could result in neurological injury. Emerging research is showing continuous brain inflammation in those with autism.[8]

The epidemiology of autism is compatible with a human cell line vaccine link. Since 1983 or earlier, the MMR vaccine in the US has only been produced using aborted fetal cells. Coincidentally, severe autism began to rise in the US in the 1980s, increasing from less than 1 child per 10,000 to 16 to 17 children per 10,000 (or about 1 in 500) by 1990. The late 1980s witnessed a concerted effort by health authorities to increase the immunization compliance for infants, including both on-time immunization and coverage rates resulting in widespread earlier dose administration for birth cohorts from 1887 on. A 2010 report published in Environmental Science and Technology by scientists in the EPA identified 1988-1989 as the "change point" in ASD occurrence.[6] Like the CDC, they recognized the debate over "the nature of increasing autism," but affirm that "the potential for this increase to be real and involve exogenous environmental stressors exists." The MMR vaccine produced in fetal tissue was introduced to the UK about a decade later, and an immediate rise in autism levels were noted, which lead to the suspected link between Vaccines and Autism.[7] In 2013, the CDC's Autism and Developmental Disabilities Monitoring Network reported that approximately 1 in 50 children born in 2007 were diagnosed with an Autism Spectrum Disorder[5] **.** Since the 1990s, the Hepatitis A and varicella vaccines joined the ACIP recommended schedule and Pentacel was approved by the FDA for US use.

Autism is four times more prevalent in boys than girls. Seven hot spots for DNA insertion are found on the X chromosome in eight autism-associated genes involved in nerve cell synapse formation, central nervous system development, and mitochondrial function.[9] This could provide some explanation of why autism is predominantly a disease of boys.

We have found brief discussions about potential adverse health consequences of using human cell lines for vaccine production in minutes from FDA advisory meetings. We have used many search engines to investigate safety studies of human cell lines and vaccines. We were not able to find any study that actually measured the extent of those potential adverse consequences. As a scientist myself and the father of a severely autistic son, I find this omission regrettable given the deployment of these vaccines for all healthy children across our country.

On November 29, 1999, fourteen years ago, Peter Patriarca, MD, then the Division Director of FDA's CBER, Viral Products Division (The Pink Sheet, November 29, 1999)[12] wrote an article, "Vaccine Technology Outpacing Ability to Predict Adverse Events". Dr. Patriarca stated, "One of the important things is that the technology used to make these vaccines actually exceeds the science and technology to understand how these vaccines work and to predict how they will work, so this has the potential for ending up in a situation which I call a 'black box' Vaccine". The CBER official also stated, "While continuous cell lines are being used for many good reasons including their ability to propagate and grow viruses to a high titer, the worst thing we're concerned about is malignancy, because some of these continuous cell lines have the potential for growing tumors in laboratory animals".

Fourteen years later, on May 8, 2013, at the Vaccines and Related Biological Products Advisory Committee Meeting, [13] Keith Peden, PhD, Chief, Laboratory of DNA Viruses at CBER, questioned (slide#23) "Does Residual Cell-Substrate DNA in Vaccines Represent a Risk?" He answered, "Whether DNA from the cell substrate poses a risk to vaccine recipients has been debated for approximately fifty years." According to the CBER office, the agency still does not know whether or not extraneous DNA in vaccines is safe.

Based on this information I am requesting that the IACC investigate the merits of these concerns. Of particular importance in any review is requesting safety data on the effect of incorporated DNA in causing immune or neurological irregularities in children which may result in some instances in features of autism.

Sincerely,

____
Albert Enayati, MSME
Tel: [PII redacted] / Cell: [PII redacted]

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

Holly Bortfeld

April 8, 2014

Thank you for giving me the opportunity to read my testimony here today. My name is Holly Bortfeld. I am the mother of 2 children with Autism Spectrum Disorder. My son [PII redacted], who is here today, is 18 and my daughter is 20. Neither were born with autism but both regressed into it, at age 2 for my son and age 5 for my daughter.

It's taken a lot of time, effort, money, services, pain and supposedly 'alternative' treatment from some of the most prestigious hospitals in the country and also some nondescript medical offices to get my kids healthy. The medical establishment has fought us the entire way, never a partner in our health care needs. I would not have healthy children if I didn't fight the medical system and their status quo.

It took more than 2 years to find medical practitioners who tested and treated my son’s many co-occurring issues, and he can now do all the things the "best specialists" promised me he'd never do. And I have no doubt that had I listened to them and medically drugged him into submission rather than treat the underlying cause of his autism they would have been right. He would have rotted and like many of his peers, died from wandering or seizures, or spent the last 16 years in unnecessary pain.

Parents should not have to fight their doctors for medical care or travel all over the country to get help like we did, and still do.

I have calculated that it's cost me, insurance and the state $1.6 Million dollars to get my son to this point. He is not recovered from autism and will still need lifelong care, but he's not in pain anymore and that's priceless.

Our kids have treatable medical conditions that can turn them from sick children to healthy taxpayers when we can get proper medical care. All you need to do is look at the body and what's wrong with it, then fix those things, and you'll be amazed. Autism is treatable. Autism is recoverable. It really is.

Now, let’s have a reality check about what autism does to our country. With the recent CDC announcement of the rising numbers of ASD, now 1 in every 68 children in the US, what did we get from our government? Not much, as usual, “just better diagnosing, nothing to see here”. Well, guess what America? This is a NATIONAL EMERGENCY. Even if it doesn’t affect one of your family members, YET, it DOES affect your pocketbook. Who do you think is going to foot the bill for my son’s care? Or the other 1.2 million children, much less the uncounted adults? The taxpayers.

Between educational, medical and therapy costs, my son costs the state $100K a year for appropriate treatment. And he still lives at home. The residential placement costs are over $100K per year per person. Do the math: $200K per year for 1.2 million kids for the next 70 years. That’s 16.8 TRILLION DOLLARS just for these kids much less all the adults and all the children not yet included in the “prevalence estimates”.

Plus add in their loss of income and tax base since they won't have jobs as 90+% of people with ASD are unemployed or underemployed. When they turn 22, and the school bus stops coming, our kids have nothing but wait lists. Nothing to do, nowhere to go. That means that we have to quit our jobs to be able to care for them all day. So now you get two people on public assistance. Who will pay for your Social Security? No one. Scared yet?

180 children in America will be diagnosed today. 180 more will be diagnosed tomorrow. And EVERY SINGLE DAY. Where is the urgency? It certainly isn't coming from the federal government. What number will it take until the federal government gets it? What number will it take before members of this committee get it?

And we're NOT buying that there is no real increase anymore. If there is no real increase, where are the 1:68 adults with autism, more than 50% of whom should be nonverbal? They're not misdiagnosed, they're not wandering the streets. They don't exist. And neither do any adult services programs that WOULD exist if they did.

Almost 15 years ago, the CDC introduced the "Learn the Signs. Act Early." campaign which costs about $3 Million annually, but according to their own data, the median age for diagnosis is still 4.5 years old so the campaign has done absolutely nothing to reduce the age of diagnosis despite spouting the efficacy of early intervention on long term outlook. Being diagnosed at 4.5 years old is 1.5 years too late to get any Early Intervention at all! STOP WASTING OUR TIME AND MONEY.

So what does my family want?

We want the government to declare autism a crisis, the national emergency that it is. We want the CDC to actually count, and do it properly. New Jersey does it properly, follow their lead, and do it in a timely manner. With proper counts, we can accurately judge changes in autism over time and plan for the needs of individuals with autism throughout their lifespan.

Stop the duplicative research in areas that have been researched unendingly but produce no treatments and focus on the environmental impacts on our children's health. The federal government has spent $1.6 billion on autism since 2006, but the money is not helping those affected in meaningful ways. We need to improve medical treatment for the many co-occurring health concerns of individuals with autism and address the wave of students who are aging out and entering an adult world with no plan for them. Study our sick kids, find out why they are sick and what they have in common. Listen to parents and community stakeholders. Stop blowing us off. We were there, you weren't. We'll be here when you're gone.

NOTHING SHOULD BE OFF THE TABLE. NOTHING. Until you can definitively prove what does cause autism, or autisms, EVERYTHING, including vaccines, should be researched. Every time you cut that discussion off, you cut off your usefulness to our community. Make yourself irrelevant, and we will make sure you are replaced. The government hasn't prevented one case of autism, hasn't produced one treatment. Since the CDC started "watching autism", autism has increased 14,700%. In the public sector, this type of performance gets you fired. Get on the right side of this issue and do it now. The clock is ticking and we don't have any more time to waste.

Holly Bortfeld, Mom to 2 amazing kids

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Bobby Enayati

April 8, 2014

My name is Bobby Enayati, and I have a younger brother who suffers from autism. I am here today to draw attention to the Autism epidemic that is affecting millions of people in the country. In 2012, the Center for Disease Control reported that 1 in 55 children in the United States suffer from autism. This is a 1,000 percent increase over the past four decades combined.

So what does this mean? It means that we have a big crisis on our hands, but more so, it means that this problem is worsening. It's getting worse, not better, and whatever direction we are currently heading is not working. Whatever research has been implemented has failed, and has done nothing to find a cause or obtain a cure.

My brother [PII redacted], now 24 years old, healthily progressed after birth, and was functioning just like any other normal American toddler. Then suddenly, my brother lost his speech and cognitive abilities, and was then diagnosed with autism.

Many are quick to point to genetics. But if it was genetics, how do you explain the very recent spike in autism? If genetics was the culprit, then why did autism only become noticeable in the 20th Century? Did the genetics generational pass down decide to take a break all these past centuries, and suddenly decide to spring into action in the 1990s? Or is modern medicine's common introduction to vaccines the culprit?

Common knowledge tells us that human beings are at their most sensitive and vulnerable point in their lives when they are born. Vaccines are preparations of weakened or dead viruses, which are introduced to a person's body in the hopes that the body can fend them off. But what happens if the body can't fend them off? What happens if the subject's body is only a few minutes old, or if toxic chemicals such as mercury or Aluminum Hydroxide are included in that vaccine? Or what about aborted fetal cell lines? What happens if the mother of the aborted fetus had a psychiatric disorder? Is this practice really safe?

What you have is a recipe for disaster. A disaster where, children are abruptly vaccinated immediately after they are born, without positively knowing if or how the child's immune system can successfully respond to the injected vaccines. Worse, this hasteful decision to vaccinate can be a larger mistake when one does not take into consideration or even bother to investigate past family history, and its ability to respond successfully to vaccinations.

Vaccines are beneficial in preventing one to succumb to a disease in the future. The problem is that they also carry incredible risk, and can be detrimental to one's safety, and actually cause a new disorder in the present. Currently, this risk is being ignored, and not being given its needed attention, and vaccines are being given out in such a way, that no oversight is present. This free, unsupervised ability to administer vaccination, especially to newborns, infants, and children, must better be regulated, in addition to the implementation of badly needed research, more studies and testing being conducted by impartial groups and entities, to effectively obtain a better understanding of vaccines, and the links to autism and other neurological disorders.

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Casandra Oldham

April 8, 2014

Thank you for the opportunity to tell you about my family and our struggle with Autism.

Let's focus on some facts. I'm a mom of three boys who were born healthy. At my middle son's second birthday medical records have him normal, healthy and developing on target. Right after that he got sick and regressed over a number of months and developed autism.

During the time my son regressed he had physiological issues that I was told had nothing to do with him developing autism. I was told I had missed the signs.

Nine months later over a period of three weeks my youngest child lost all his words, clapping, pointing and responding to his name, eye contact, waving and the ability to chew. I called the experts; they tested him for things that they didn't test his brother for. He came up positive for mitochondrial disease. After we brought his brother in for testing and he was positive as well.

We did genetic testing. I don't have mitochondrial disease; I don't carry the trait for mitochondrial disease. My children acquired mitochondrial disease from and attack on their immune system from environmental toxins and the mito disease manifest itself in autistic tendencies. Now it is important to note that no one else in the house was sick from environmental toxins. This is how it was explained to me, is that if you get hit in the head hard enough anyone can develop epilepsy. Two people can get hit with the same force and only one might have a seizure. We all have different thresholds. It's not something that you can test for or screen. We just need to wear helmets when doing activities where our head might get hit. So for my children and children like them (and there are a lot) we need to scale down how much stress we put on the immune system. What we are doing right now, is too much for too many.

My reaction to the Doctor telling me it was toxins, was," Ok, let's test for what these toxins are". They said, "We can't" So I shipped my children's urine to France for testing.

My boys were so sick and their behavior was insane. No doctor that accepted insurance knew how to help them. I learnt of some doctors but you had to pay out of pocket. With two home ABA programs costing more than twice monthly mortgage, it took a long time for me to be able to afford access to these Doctors. I couldn't bear the thought of choosing one child over the other. No parent who's paying for insurance should have to make a decision about which child to treat!!! When we finally got them tested they had ulcers all up and down the GI track, in the stomach, large and small intestines. The youngest had some in his throat. They were in so much pain and had not been able to tell us. When we treated that, they slept for the first time in years. When we tested and treated for other conditions, all the self-injurious behavior went away. Head banging gone, in a few hours from treating!! They stopped beating me up and my little guy wore shoes for the first time in two years. When I put my middle son, [PII redacted] on antivirals he started to put words together. [PII redacted] had cognitive leaps. Anti-yeast and bacteria help them not stim.

I have medical evidence that my children were harmed by vaccines. I did not have that in the three year window that I needed to file in court because I could not afford the medical tests and could not find an attorney to help me with that process. It would be ridiculous to expect someone who had a burglary in their home or experienced any other crime to do their own forensic science. Why do we expect parents to?

In my opinion, we don't need more studies. What we need is for people to take action on what we already know. Treat the child. My brother got sick and his brain was inflamed they didn't suddenly enrol him in a study with other kids with that condition, a double blind placebo before drilling holes in his skull to relieve the pressure on his brain. They didn't say some of them are getting fake holes and some of you will get the real ones. They took action to save a little boy and reduce brain damage. Why won't anyone give these children the same care with the same urgency?

My children are gone. I am left with the shell of the body but who they are; who they could be is gone! They have also lost the very basic of human right. They lost speech! My children can't talk, they could but now they can't imagine! And imagine the people who can help them doing nothing.

A [PII redacted] was shot and when they were on the Today show her husband said that the worst part was when she couldn't talk. The worst part was when she couldn't talk!?

A beautiful little girl in my town died of a brain tumor. [PII redacted]. They just passed a bill in her name. Her mother said the worst part about when she was dying was when she couldn't talk.

I'm here today because of my children, not for them. Hope for my children is gone. Your inaction helped that. I 'm here to speak for the children diagnosed today that maybe you don't give them the same inaction you gave my children. This inaction speaks volumes. You can change that!

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

Deanna Mulvihill

April 8, 2014

I am a grandmother of two children who have the diagnosis of mitochondrial disease and regressive autism. I am however also a nurse with and PhD and extensive experience in general pediatrics and child and family psychiatry. When I first when into nursing autism was a rare disease but I did have experience with these children and although my grandchildren share some characteristics or symptoms with them, they are also very different. Those children did not have the physiological symptoms that my grandchildren and many others have today. They did not have the low blood counts and they did not have the ulcers throughout their GI tract. The fact is they did not have the autoimmune disease that my grandchildren and many others have.

Evidence is accumulating that these symptoms such as oxidative stress, mitochondrial dysfunction, and inflammation in the GI tract, exposure to environmental toxins, immunological abnormalities, and infections agents are related to developmental regression and seizures. These abnormalities when present may not only cause many of the symptoms of autism but can also cause severe pain. My daughter frequently says children should not be left in pain simply because they cannot tell us about it in words. Sometimes when these symptoms are addressed there is a great improvement in functionality.

The most devastating thing for me is that many physicians and other healthcare professionals are not recognizing the physical symptoms and even if they do are not treating them. They say, he just has autism this is to be accepted. Fortunately, other physicians have not accepted this and have opted out of the system and have begun caring and treating these children. For example one of my grandchildren was pulling his hair out, constantly banging his head, and bouncing so much on his buttocks that he had permanent bruising. All of these symptoms, these self-injurious behaviors, these symptoms of severe pain stopped after intravenous gammaglobin treatment (IVIg). This treatment is not a recognized treatment (by the insurance agencies) for children with autism but would be for an Aids patient with similar blood work. This is not fair. Neither is there any recognized treatment for the heavy metal levels in their bodies, yet there is research on the symptoms of neurotoxicity that these metals cause. I have even had a speech therapist tell me when I spoke to her about my grandson's pronunciation that I could not expect any more as after all he has autism, she said this even though in his records it was clear that two years ago he was nonverbal.

My grandsons were both born normal and became ill and regressed. I thank God for my daughter and son in law's determination to search everywhere for physicians and treatments that make them more comfortable in their bodies. These dedicated physicians are studying and working with each other to develop proper protocols. They can be found at Medical Academic of Pediatric Special Needs (MAPS) led by [PII redacted].

Autism needs champions, it needs persons who can wake up the scientists to stop spending money on looking for a genetic cause: to wake up the public and the government to stop this epidemic. I had a son with Reyes Syndrome, a son who survived with enough of his brain power intact that he is now a critical care paramedic. When he had it they already knew aspirin was involved and so was a viral infection, but they also knew that there was a third factor, we never found out what the third factor was because we stopped giving aspirin for a viral infection and we stopped giving aspirin to children. We may never know what all specific factors are involved in the development of autism but let's fund our scientist to do comparative research on numerous treatment protocols. Let's get the information of the symptoms and treatments possible to all physicians and let's stop this epidemic and the suffering.

Also, there are so many disagreements between the different professionals and organizations that say that they are there to service affected families unfortunately they disagree with each other and discuss these disagreements with their clients and leave parents confused and caught in the middle. Examples are ABA consultant who does not believe in diet restrictions and or other teaching methods. Speech therapist who will only work with your child if you use or don't use certain electronic speech aids. The pro and cons of different treatment and teaching techniques are for the classrooms, for conferences and for rounds. To share partial informed decisions or biases with parents is not professional. Many of these persons are not licensed and have no concept of confidentiality. They all should be educated, licensed, have background checks and routine drug testing should be mandatory. The icing on the cake is the public: for those of us who bring our children to parks, theatres and even family restaurants. It is not just the looks. When our children have been very excited and make strange noises we have been told not to bring our children out until they learn to behave, and worst, not to bring them out until we medicate them.

I introduced myself as a researcher, I am not the type of researcher that cranks out numbers and percentages, but one that uses an ethnographic approach and determines the type of impact policies and corporate decisions have on the culture of the organization, the people who work there and the care of those who they service. Many professionals in all fields are still labelling this disease autism, so they don't have to do anything about it. How many more children have to suffer before action is taken. Is it the Interagency Autism Coordinating Committee's mission to serve each other or to serve the families and children who are suffering with this autoimmune disease? I ask you now; can you be the champions we so desperately need?

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James Williams

April 8, 2014

First, I would like to thank the IACC for giving me the opportunity for me to present at this meeting. This is my first time presenting at an IACC committee meeting.

I am a young male with autism, aged 25. I was diagnosed with autism at the age of 3 in 1991. I currently live in Northbrook, Illinois, a northern suburb of Chicago.

For the past 14 years, I have written about and given presentations on autism all around America. My presenting career began in 1999, at the age of 11, when I was brought in to answer questions about my autism after a presentation made by Annabel Stehli, a parent of a person with autism, and the founder of the Georgiana Institute. The event was held at the Medical College of Wisconsin in Wauwatosa, Wisconsin. And I have presented on autism ever since.

There are many things that I could talk about today, but I have decided to talk about biomedical issues with autism from an insider's perspective. Not from the perspective of a parent of a child with autism or a MAPS doctor, but from the perspective of a person with autism who has endured many biomedical issues in their life.

One year after my presenting career, in 2000, I endured a major life-changing experience. I started enduring issues alongside my autism that are referred to as "biomedical." One week after I finished elementary school, I suffered a major chronic illness that almost took my life. I almost starved to death, and my immune system collapsed. At the height of my illness, I weighed only 95 pounds and was approximately 5 feet tall. I lived on liquid meal replacements for almost 6 months and was unable to digest solid food normally during that time. As I slowly became more emaciated, I started developing symptoms of schizophrenia and started hearing voices in my brain.

It took several months to diagnose the cause of this mysterious illness. Although the symptoms were quite apparent—loss of digestive abilities, followed by immune system impairments and other issues, etc.—countless doctors struggled to find a cause to my chronic illness. Many doctors sent me and my parents home, despite being openly ill, and told them there was nothing wrong with me. Finally, a holistic doctor accurately diagnosed my chronic illness as that of a combination between an autoimmune and a digestive system collapse. My white blood count was low and I was extremely malnourished.

I did finally recover after being ill for 10 months. My recovery was made possible by a combination of multiple remedies—including acupuncture, herbal teas, and mineral supplements, such as zinc—a remedy that was recommended to my parents by [PII redacted], a doctor who treats individuals with autism who endure biomedical issues.

To this day I take vitamin and mineral supplements—"biomedical supplements"—in order to function. I also am very strictly gluten-free, a diet I must maintain in order to function. If I eat even a small amount of gluten, I get very sick, and can suffer chills, hot flashes, a sore throat and stuffy nose, burning in my eyes, and sometimes, attacks of arthritis. And if it weren't for biomedical interventions during my autoimmune collapse, I would have starved to death many years ago and would not be here speaking to you today.

As the years passed, I have met countless individuals with autism of all ages who endure biomedical issues alongside their autism. And I have met adults much older than me who have endured such issues at a time when biomedical issues were not even discussed in the autism community. Some of the adults I have met that are biomedical survivors were often laughed at when they tried to share their issues to others. [PII redacted], a registered nurse with autism, in our co-presentation "Biomedical Issues from an Autistic Perspective," shared with me that when she was growing up, the biomedical issues she endured were often ignored and she was dismissed as being crazy and "mental."

The stories of adults like myself and [PII redacted] show that biomedical issues are not new, and are not just issues that children with autism face. Indeed, these issues might just as much be symptoms of autism as sensory issues and social deficits are.

More research needs to be done regarding the nature of the biomedical issues people with autism endure. Research needs to also be formally done on the effectiveness of the emerging treatments that are being used to help treat these issues. But more importantly, research for these issues needs to be supported rather than suppressed. The "vaccine" controversy" that has been going on for over a decade now has delayed much essential research regarding biomedical issues, even though not all biomedical research is "anti-vaccine." And when individual doctors who treat biomedical issues are disbarred or tainted by scandals, countless other biomedical doctors are shamed and criticized.

In my community, there was an orthodontist that engaged in dishonest practices and was considered a "quack" by most other orthodontists. Would we argue that because one orthodontist turned out to be dishonest that the entire field of orthodontics was flawed or dishonest? No. Yet we often try to discredit the field of biomedical treatments after individual doctors have been discredited and disbarred, such as [PII redacted], even when many of these doctors have never engaged in dishonest practices and have never openly spoken against vaccinations.

Today, I come to the IACC not to complain, but to ask: How can we support research on biomedical issues? How can we stop the vaccine controversy from getting in the way of conducting research on the symptoms that so many people with autism suffer from on a daily basis? And how can we give help and assistance to the countless people with autism and their families that are enduring such issues?

I hope that the IACC and other agencies start to take the biomedical issues of autism more seriously. In the end, anecdotal evidence and data regarding an issue or topic should not be used to totally discredit the issue or topic at hand, but should be used to trigger further research.

Thank you for listening.

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Desireé Kameka

April 8, 2014

Coalition for Community Choice (CCC) is a national grassroots collaboration of persons with disabilities, their families and friends, disability rights advocates, professionals, educators, and housing and services providers to advance the principle that community can be experienced in all residential settings. CCC was created to:

1) Promote and defend the rights of people with intellectual and developmental disabilities (I/DD) and autism to choose their residential settings from the broadest range of options;

2) Educate federal and state governments on innovative Olmstead-compliant housing alternatives to "one-size fits all" approaches; and 3) preserve access to essential, publicly-funded services and supports in these settings.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2013 (www.stateofthestates.org)

[PII redacted], a self-advocate and witness at the last Congressional Hearing on Autism, testified that our greatest need is in the present and that autism is a national "service crisis". In response, communities across the country are rolling up their sleeves to create local solutions. They know they cannot rely on government supports alone and there is no time to waste! We need more research into issues of adulthood; we need immediate housing and support service options; and we must eliminate barriers in policy and regulations for people trying to create public-private solutions.

Unfortunately, two barriers are making it difficult to proceed.

The first is:

Lack of research in autism specific supports for adults:

a. How do setting design, program structure, and/or sensory friendly environments influence quality of life? Are these unique supports protected in policy?

b. Those who have the most challenges are often the first denied opportunities. What are better supports for elopement? Self-injurious behavior? Or for those who become so frustrated that their only way to communicate is through physical expression? These individuals are most often isolated in their family home, being continuously excluded from their community. Where will they live when their parents can no longer be their primary caregiver?

c. What trainings, assessments, and retention strategies are most effective for direct service staffing?

The second barrier is:

Restrictive public policy. Policy *must not* limit the opportunities for autistic adults to live self-determined lives. New HCBS regulations stigmatize farmsteads as an example of an "isolating setting" despite the fact that no research has been done on the quality of life for those who live in agricultural or intentional communities. Yet, for neurotypicals, the New York Times reported Agri-hoods are the newest housing trend, a residential development where a working farm is the central feature, in the same way that other communities may cluster around a golf course, pool or fitness center. Why shouldn't autistic adults be able to use an HCBS waiver for a home and community of *their choice?*

Research is needed to answer the following questions:

a. The housing and support options available for autistic adults in every state must be quantitatively and qualitatively assessed. How do they plan to meet the demand? Who is being left out or falling through the cracks? Are they meeting the needs and preferences of their constituents?
b. What factors influence quality of life in private pay residential opportunities in comparison to publically funded options? Are they more financially sustainable?

c. What incentives can influence the immediate increase of direct support staff and affordable housing opportunities to meet the needs of 1 million adults with a developmental disability who live with caregivers over the age of 60?

The Coalition for Community Choice is not a special interest group. We are a coalition of families, advocates and organizations willing to work together on real, meaningful, and self- directed solutions to give adults on the spectrum the future they want! Please advance both research and policy that decreases barriers and increases person-centered options. Thank you.

JaLynn Prince

April 8, 2014

Subject: Serving and Supporting the Missing Millions – A Moral and Economic Imperative

MADISON
HOUSE
AUTISM
FOUNDATION

Madison House Autism Foundation *is a public 501 c 3 non-profit, national organization working to eliminate barriers and increase opportunities for the rapidly growing numbers of adults with autism. Its immediate priority is to address the near total lack of flexible housing options for adults with autism. Its programs and philosophy are based on the belief that sustainable, replicable solutions must engage all sectors including public and private sectors, non-profits, families and advocates. For more information, visit www.madisonhouseautism.org.*

IACC is making important and promising strides addressing issues in autism and adults. But a silent crisis still exists, and it is growing. I refer to the growing number of undiagnosed and underserved adults with autism. They are largely invisible and they and their families are in crisis. We have both a moral and an economic imperative to respond.

With our new prevalence rates looking at children age 8, we know for a certainty that most of those 8-year-olds will live the vast majority of their lives as adults and that they are likely to have little or no services.

We know that in 13 years, a blink of an eye, these beautiful children will disappear from view and will join an existing population of uncounted numbers, who are already adults.

We know that among these thousands, if not millions, of individuals, there are

- Those who have not been able to qualify for adult services,
- Those who have limited services,
- Those who are living with aging parents,
- Those who are on the streets, and
- Those who have taken up residency in our penal institutions.

This invisible group is called, "**Adults on the Autism Spectrum**."

We cannot afford to ignore these individuals, or families, either morally or for economic reasons.

Let me share three examples:

This past week, a mother sat across from me at Madison House Autism Foundation. She is in her mid-70's. Her son, now 30, was not diagnosed with autism until the age of 26. Because of a later diagnosis, he has been unable to secure any services. Unless he becomes violent and is a threat to his parents or has an altercation with the police, they will not be able to get much-needed help in the foreseeable future. His elderly mother *has just one* resource – a support group that meets *every other week* for an hour.

A second mother came in to talk about her son who is 28. The parents served our nation in the diplomatic core, transferring from country-to-country throughout their careers. Because they didn't live in a state, their son has no funded services. He is living at home and the mother is her son's 24/7 caregiver, teacher, health care provider, and advocate. She is without help and is exhausted. The father has retired from working in our embassies but is now taking jobs to enable them to fund their son's care and future.

My own son [PII redacted] represents a typical story of a young adult aging out of services. When he graduated 20 months ago, the student body gave him a standing ovation. He had a transition plan in place. He was to be in a placement in a yearlong program that would be the bridge to a longer-term program. But the interim program did not have in place staff that knew autism, though we were assured they did. Although he was promised a position for the following year, the ball was dropped, and then his first caseworker moved, the second one quit the agency. The next was fired. Another resigned. The next was reassigned. He now has finally has landed in the lap of the sixth caseworker - all since last May. The program he was to enter last fall denied him, I am sure largely, because of lack of follow through. My once happy, productive young man –- was in crisis for 20 months -- needing medical intervention, suffering from depression and low self-esteem, and experienced a complete lack of community with peers. With no remedy in sight, recently we put together a private program for him, and he is starting to come back to us. The system designed to help him has actually hurt him.

If this can happen to me, a professional in the autism arena, what happens when parents have no resources, are single parents, have other children, or which is often the case, and have multiple children on the spectrum? And what is happening in our own neighborhoods to families who are silently, with dignity, diligently trying to cope day-to-day with adult children in their homes who are becoming increasingly more depressed, agitated, aggressive, and overweight. And may I add lonely. The strongest among us would reach a breaking point.

With all of the progress with children, little is being done for the invisible millions of adults and families dealing with particular types of autism.

Many decisions that have been made on behalf of those with disabilities are placing large portions of *our* population at risk -- physically, emotionally, economically and socially.

All of us need to roll up our sleeves and take a look at the big picture: What is being done that needs correcting and what needs to be done that is NOT being done? We need a more comprehensive approach looking at things between each of your agencies, with none of us placing ourselves in a position of defending policies that don't work in harmony with creating better, person-entered, positive futures. We need to innovate to have public-private partnerships to address the issues before us. Madison House Autism Foundation and thousands of parents, and individuals stand ready to help find comprehensive solutions. We need your unwavering leadership. And we need to work on behalf of those on the spectrum and beyond our own careers. We can retire from our jobs, but these individuals will be living with autism for the rest of their lives.

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

Eileen Nicole Simon

April 8, 2014

Subject: Comments on Language and Obstetrics

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

Two kinds of autism are in the news: (1) a non-disabling “difference”, and (2) a neurological disorder that prevents normal language development. Repetitive motor movements are also part of this neurological disability. The Combating Autism Act was clearly intended to address the neurological disability, and its increasing prevalence.

The increase in autism prevalence began in the mid-1980s. This is when an obstetric protocol was put in place to clamp the umbilical cord immediately after birth. There is no health benefit from clamping the cord. Clamping the cord before the first breath is dangerous. It can cause asphyxia, and the need for resuscitation. Could the IACC recommend that this procedure be stopped?

My son, [PII redacted], had to be resuscitated at birth. His older brother had suffered head trauma at birth, and at 20 months of age was diagnosed with cerebral palsy. We felt greatly relieved that [PII redacted] did not have delayed motor development like his brother. But before we had heard of autism we were worried about his language development, and his hearing.

An article on asphyxia at birth in the Scientific American appeared shortly after [PII redacted]’s diagnosis of autism, with pictures of damage in the brainstem auditory pathway. The auditory pathway? This seemed to explain [PII redacted]’s problems with language, and his hearing.

Development of the language areas in the cerebral cortex is just beginning in infancy. Maturation of the language areas over the child's next 5 to 10 years is guided by trophic neurotransmitters produced in brainstem auditory nuclei. Damage of these small nuclei cannot be considered minimal.

I would appreciate discussion of my comments by members of the IACC.
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Conrad Simon Memorial Research Initiative
To seek understanding of brain system impairments in autism.
http://conradsimon.org/

Linda Varsou

April 8, 2014

With this April 2014 Autism Awareness Month, I would like to present to the IACC Committee, for the 4th time, the widespread, serious and devastating issue of **chronic parental "denial"** (*non-acceptance or non-resolution*), of their child's autism, and/or denial of the extent of its severity. As the prevalence of autism is on the increase, chronic parental denial is on the increase as well, with detrimental consequences to the families, the child (or adult) with autism being the final and definite victim.

It is expected that members of the IACC Committee, as well as parents and advocates for the cause of autism, underestimate the deleterious effects of "denial", even its existence, because due to their active involvement in autism, by definition they are not in denial themselves.

The issue of chronic parental denial is increasingly mentioned in blogs, autism groups and societies; now we have a solid study from Israel reporting denial as high as 53%, an article which I have forwarded to all of you (*J Autism Dev Disord (2010) 40:89–99).* We cannot ignore anymore the prevalence of denial in the U.S., unofficially reported by professionals as high as 45%.

As I have mentioned previously at length, with fast, low-cost methods and meta-analysis, by including and investigating the factor of "denial" in every new, on-going, and past longitudinal research protocols, we could evaluate its prevalence, and have more reliable results out of most autism studies.

In conclusion, I would like to see IACC addressing the devastating issue of "denial", so as to improve the quality of research and to show its support and commitment to every family and person struggling with autism in the U.S.

By Linda (Angeliki) Papadimitriou-Varsou, PhD, MPH, DABCC, Asst. Professor, interested person representing myself. Mother of a 28-year-old college student with autism, advocate for the Rights and Strengths of People with Autism, and a fervent supporter of the concept: ***"An Autism Friendly Society will benefit us all"***.