

Oral Public Comments

**IACC Full Committee
Meeting**

April 9, 2013

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Jen Repella

April 9, 2013

AUT1SMSOCIETY

4340 East-West Highway, Suite 350
Bethesda, Maryland 20814
(p) 301.657.0881
(F) 301.657.0869
(e) info@autism-society.org
www.autism-society.org

The Autism Society is the nation's largest grassroots organization serving over a 1,000,000 people each year. Founded in 1965, the Autism Society national system involves a partnership of more than 100 local and state affiliates working in conjunction with the national office of the Autism Society.

The Autism Society has a simple goal: To assure that each person living with autism is able to maximize his or her dignity and independence, therefore obtaining the highest quality of life. While significant progress has occurred in our nation regarding services and supports to individuals with autism since 1965, so much more needs to be done to create a society where each person, regardless of where they fall on the autism spectrum (ASD), is provided equal opportunity to succeed. The manner in which we provide services must no longer place unnecessary obstacles in the path to that success.

In the year 2013, the Autism Society, its 107 affiliates and all who rely upon the important work of the Society are most interest in the following:

I Services

Today, over 800,000 people living with a developmental disability (including ASD) face very long (often as long as ten years) waiting lists to receive basic services to which they are entitled through Medicaid Community Services support. These individuals often don't have the resources to secure privately paid services and therefore, far too often, as a result of wait lists they simply experience lack of access to Medicaid funded services. This denial of services is particularly critical for individuals with ASD, because it is well documented that early and intensive intervention significantly improves the outcomes and can reduce lifetime costs by as much as 2/3. If the individual goes without services it is common for regression in behaviors and skills as well as lost opportunities to advance to their fullest potential through the public school years.

The reality of addressing the violation of the basic rights of individuals with Developmental Disabilities due to waiting lists is that there are several approaches that could decrease an individual's waiting time and reduce the waiting lists altogether. The following can occur right now and help individuals stuck on waiting lists.

- A. Portability of Medicaid Eligibility: Medicaid services receive significant funds from the federal government, yet are administered on a state by state basis. This can create unnecessary duplication of effort and result in wasted administrative costs. Each state has its own set of administrators and the rules for eligibility often times are the same from state to state. An individual goes through a state assessment process to determine eligibility for Medicaid services, but if that individual goes to another state due to a move, he or she has to begin the process again in the new state. In a nation that provides for low costs transfer of driver's license, car registration and voting registration, a much less expensive and arduous system can certainly be developed to allow limited dollars to be used for their intended purpose -direct service to individuals.
- B. Far too often, government funded services are highly categorized and a person must fit into criteria that often times does not allow for differences in need and ability. What results is that certain individuals might not have access to sufficient funds from one government funding source while another source may have available fund that go unused because the criteria definition doesn't meet the specifics of the situation of an individual. Government needs to examine ways to pool available funding sources for an individual and promote comprehensive planning and case management, based on outcome measures that enable the person to advance in his/her defined goals.
- C. Government funding for services to a person with a developmental disability often times assures maintenance of condition without really examining how best to achieve positive and measurable progress that results in improvement in that person's quality of life throughout their lifespan. Government funding needs to be allocated based on achievable and measurable positive outcomes that enhance a person's independence. We must move from funding services that assure only safety and maintenance to those that assure safety and enhancement of quality of life. In the end, this will save significant dollars for our nation by helping people reduce life-long reliance on services and allow other (who would continue to wait) to begin receiving services that help them progress.
- D. There needs to be a closer partnership among the private and public sector when it comes to addressing service needs. Private sector dollars should be allowed to be used by states to match Medicaid Funds provided by the federal government and even in some cases, money from an individual or his/he family should be made available to help have the state receive Medicaid funds, provided the process does not give advantages to the rich over the poor.
- E. Our nation must address the growing and now critical need for adult services, which if funded can help an individual advance his/her life skills, employability, and so much more. We also must support services to help transition the primary individual's caregiver; it is inevitable that parents will grow old and die or become too frail and can no longer adequately serve as an individual's caregiver. Medicaid portability must be examined so that eligible individuals can move to a new caregiver even when they live in another state and not be in danger of losing Medicaid and other federal support services.
- F. Jobs, job preparation and more jobs. Services have to be provided to help individuals obtain sufficient skills required for competitive employment, receive support to seek out meaningful employment and retain their employment without loss of government funds needed to live. Vocational Rehabilitation services must be changed to focus on outcomes that relate to lowering unemployment among the developmentally disabled cohort and assuring that the job obtained is one that matches the person's interests, skills and ability.

II Insurance and the Affordable Health Care Act

During the past few years, much progress related to health care coverage has enabled more people living with autism to obtain critical services and supports. The passage of the Affordable Health Care Act has increased the ability for individuals to get insurance coverage and eliminated circumstances when preexisting conditions resulted in denial of services. This has massive beneficial impact for individuals living with autism and their families, allowing them to be eligible for the same coverage and therefore access to medical services as the general population. But, we must be aware that these two important achievements are not a final solution. Adding Autism Coverage to requirements imposed by states is only beneficial if a person has the insurance covered by the state mandate. While such coverage is effective, it often times is not readily available in low-income areas due to the economy of scale needed to balance insurance paid and private paid individuals for services such as ABA therapy. If the insurance isn't available or affordable to populations that are typically underserved, then far too often, the result is that services remain inaccessible or unobtainable to lower income communities.

While the Affordable Health Care Act will provide access to insurance, it remains unclear how each state will define what is in its State's exchange program with respect to autism. The exchange program for each state will define the coverage for those unable to secure insurance through their employer or on their own through the private sector. Currently, most states are not including autism coverage in such exchange service availability and some of the exchange plans are being proposed with very high deductibles. Now that our nation is comprised of states that each have their own exchange plan, we can't assume that the collective plans will include autism coverage. And, finally, autism insurance coverage has to provide more than Applied Behavior Analysis. Covered services must be provided to address the unique lifespan needs of that individual as they access health care support.

III The "Haves" and "Have Nots"

Often times, the figure used to estimate the annual cost of supporting an individual with ASD is \$100,000. In today's economy, that means close to 99% of the working families in our nation can't afford the care for their child living with autism. Autism remains a disorder whose outcomes literally depend on the economic status of the family affected. Those with sufficient wealth can access the best services and supports; those without such funds go without or rely on limited services provided through the public school system or remain on waiting lists for government services. This is not something our nation should allow. Wealth should not be a key indicator of one's ability to access services and advance toward a higher quality of life than a person living in a family with very limited means.

IV Discrimination

Autism is a condition that remains unrecognized or, at best, not fully acknowledged as a condition that causes a person to experience significant and unlawful discrimination. From denial of basic rights to a quality public education, or access to employment, it is common for a person with autism to face regular discrimination throughout their life. With unemployment rates sometimes estimated to be as high as 70% for adults with ASD, there is no question that equal access to opportunities does not exist for many. Denial may come in the form of: educational systems that do not adequately prepare students for competitive employment after graduation, unwillingness of an employer to consider an individual with ASD as a qualified candidate for a position, or resistance to provide the necessary accommodations for employment of adults with autism. This kind of discrimination is pervasive throughout society and can be

witnessed in regard to housing, transportation, access to recreational activities and other components that make a person an integral part of their community. False stereotypes and other factors that lead to lack of understanding and result in diminished community acceptance must no longer be allowed. Our nation must immediately address this discrimination of people living with autism and other developmental disabilities. Our nation has done so much throughout history for disenfranchised groups and individuals with less visible disabilities should be no exception.

V Institutional Bias in Long-Term Care Policy

In 1999 the World Institute on Disability hosted a conference, Personal Assistance Services in the New Millennium, "focused on eliminating institutional bias. Delegates stated that" government policies and funding should not perpetuate the forced segregation, isolation, or institutionalization of people with disabilities of any age". Disability used to be regarded as a condition that prevented people from participating in most activities of daily life and living safely in our communities. Many with disabilities were segregated and isolated from society, housed in large institutions without consideration of appropriate, less restrictive, alternatives. Traditional Medicare and Medicaid funding streams provided strong financial incentives to long term care provided in aggregate settings (e.g. nursing homes, rehabilitation centers, hospitals, etc). Legislation from the late 1960s related to Medicare and Medicaid guaranteed payment for institutional services. This means that nursing home care in this country is an entitlement-- any person eligible for nursing home services cannot be denied provided there is space available. Medicaid waivers and 'Money Follows the Person' initiatives have provided substantial progress but community-based services do not have this entitlement status. There is still a strong institutional bias in federal and state policies and funding which provide finance group homes and agency-provided residential services and employment training in the form of sheltered workshops.

The financial eligibility criteria for receiving services in the community should not be more stringent than for comparable services provided in institutional settings. Medicaid and SSI asset and income limits for a person receiving services in the community should allow that individual the greatest opportunity to remain in the community and not be forced into an institution. Income limits should not encourage dependence on government support but rather allow an individual to have the financial stability to pursue independence, fulfillment and productivity. Social services should not force people to live in poverty, they should encourage work, family and savings (all common American values) and assist people to reach to their maximum potential and be empowered, self-sufficient citizens who contribute to their community.

VI Research

Research is a critical component to understanding the autism spectrum as well as gaining greater knowledge as to which treatment is most responsive to particular individuals. But, in these times of national fiscal strain, we must balance the need for research against the growing needs of those who are seeking services and most importantly those who are forced to wait due to limited funding or availability of appropriate services. Our country can engage in meaningful research endeavors while meeting the needs of those living with autism today, but only through a comprehensive review of allocation of funds that is based upon not only need but the delivery of measurable outcomes that improve people's lives.

VII Diagnosis

We all know that the earlier a diagnosis, the better it will be for the family and the individual diagnosed to achieve a higher quality of life. We also know that access to diagnosis is often dependent on income, race and ethnicity and where they live. We must make sure that all people have equal access to appropriate evaluation and are accurately diagnosed. We must realize that we live in a society where the cultural realities of a person often defines how they access help and we must make sure that our efforts are culturally sensitive and responsive. We must define areas of need for diagnosis and then work with the communities and individuals in that group to define the best approach to achieve higher rates of understanding of autism and diagnosis and the next steps that result in improved outcomes.

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

Eileen Nicole Simon

April 9, 2013

Comments for the IACC meeting on April 9, 2013

Eileen Nicole Simon, PhD, RN

[PII redacted]

I am here, in public view, to ask if the IACC could urge the obstetric profession to stop using a clamp on the umbilical cord? Use of a clamp to terminate placental respiration should be investigated as the cause of increasing numbers of children with autism.

There is no evidence of any health benefit from amputation of the placenta at birth. In written comments I listed several reasons why clamping the umbilical cord is dangerous. In brief: (1) clamping the cord prevents transfer of blood from the placenta to the baby's lungs. (2) The capillaries surrounding the alveoli must be filled with blood before they can receive oxygen. (3) The lungs take absolute priority, and blood will be drained from other organs, including the brain, to initiate breathing.

The Apgar score may be a perfect 10, but a well-known pattern of damage in the brainstem may occur.

Damage of brainstem centers prevents normal maturation of their target areas in the cerebral cortex. This should be investigated as a possible cause of the underconnectivity now visible in functional-MRI scans of people with autism.

After the discovery of anesthesia, surgeons took over from midwives the management of childbirth. (Midwifery was banned in my state, Massachusetts, and some midwives were even jailed for continuing to deliver babies).

Surgical clamps were adopted for ligating the umbilical cord at the beginning of the 20th century, but always with instruction to first wait for pulsations of the cord to cease. Pulsations are evidence of ongoing circulation to and from the placenta.

Until the mid 1980s, textbooks taught that pulsations of the cord should cease before clamping. This teaching more and more was not heeded. By the end of the 1980s, clamping immediately after birth became standard practice. This was the beginning of the dramatic increase in autism prevalence.

Why aren't we all autistic? It is like Russian Roulette, or sheer dumb luck, whether the clamp leaves more blood in the placenta or in the baby. Clamping the cord at birth is not healthy for any child.

Please consider the list in my written comments of problems caused by clamping the umbilical cord at birth.

Following is a partial list of problems caused by clamping the umbilical cord at birth:

1. There is no evidence of any health benefit from clamping the umbilical cord.

2. Clamping the cord prevents ongoing placental respiration after birth.
3. The newborn lungs should become fully functional before placental respiration is stopped.
4. The lungs become functional only after blood fills the capillaries surrounding the alveoli.
5. Hemoglobin in the blood receives oxygen from air that fills the alveoli.
6. Until all the alveoli have expanded, oxygen from the placenta is needed.
7. The anatomy of the heart must change at birth.
8. Fetal ducts in the heart must close, and blood flow redirected to the lungs.
9. How arrogant to think that clamping the cord will force the newborn lungs to open!
10. If the baby does not breathe right away, ventilation of the airways is begun.
11. Ventilation of the lungs, at best, inflates only the lobes near the airways.
12. Blood must fill the capillaries surrounding the alveoli to receive oxygen.
13. The lungs take absolute priority at birth.
14. Blood will be drained from other organs to jump-start the lungs.
15. If blood is drained from the brain, ischemic injury of the brain will occur.
16. Ischemic injury most severely affects brainstem nuclei in the auditory pathway.
17. Ischemic injury also affects the subcortical centers for motor control.
18. The pattern of ischemic injury is known from experiments with monkeys subjected to asphyxia at birth.
19. Experimental asphyxia was inflicted by obstructing the airways, and clamping the umbilical cord.
20. The brainstem damage caused by asphyxia was thought to be "minimal."
21. However, brain maturation was disrupted in monkeys subjected to asphyxia.
22. Postnatal development of the cerebral cortex depends upon integrity of underlying subcortical systems.
23. Damage in the brainstem auditory pathway prevents normal development of the language areas of the cortex.
24. Damage in the brainstem auditory pathway prevents normal processing of sounds, especially speech.
25. Much more can be said, much of which I have presented to the IACC in the past.

The IACC was established to investigate the cause of the increasing prevalence of autism. The purpose was not to preach acceptance, or to determine lifespan care needs, or recommend legislation for insurance coverage.

Please maintain the mission to promote scientific research on the brain impairment in autism, and its causes.

Dena Gassner

April 9, 2013



Center for Understanding

@ Athena Counseling

1720 West End Avenue Suite 240 Nashville, TN 37203

c4ucontact@gmail.com

denagassner.com

615-200-2091

March 29, 2013

My name is Dena Gassner and I am a licensed and UCEDD (University Center for Excellence in Developmental Disabilities) trained social worker that provides systems navigation support to individuals with autism spectrum conditions. Thank you for allowing me to address the lack of accessibility in three current service programs.

Instead of seeking new and creative programming I'd suggest IACC encourage reasonably expedited access to current programs such that employment and quality of life could be immediately enhanced.

Both Social Security and Vocational Rehabilitation offices are environmentally assaultive. "Interpreter services" provided to other disability communities are not provided for ours. Asking for a private place to wait is responded to with outrage.

In the four states in which I have served, adults wait anywhere from 2-4 years to obtain social security benefits. The automatic first denial protocol must end. We must exit a purely medical model for determination and incorporate inconsistent work history, relational issues, prior misdiagnoses and failed outcomes in determination protocols. The fact that treatment has not been used is not a proper measure of need. It's more often a reflection of diagnostic and management supports.

With Vocational Rehabilitation (VR), inconsistencies in state interpretations of federal regulations do considerable harm for our community. Eligibility determination based on observation is permitted—a bias against our community when many have more invisible expressions of their autism. Timelines and client

self-determination desires are ignored. Post-secondary programs are frequently denied despite federal regulations that mandate that no client on SSI can be asked to financially contribute to their post-secondary goal. For me personally, that was a \$13,000 expense for just last year despite a Free Application for Federal Student Aid (FASFA) score of 0.

Self-employment is a delay ridden, red tape burdened protocol complicated by difficulties with PASS plans. The executive function demands of these options result in the person's capacity being whether you can manage the systems—not do the work. So too, it is with Schedule A Hiring.

“Schedule A is a hiring authority for Federal agencies to use to tap into a diverse and vibrant talent pool without going through the often lengthy traditional hiring process. Schedule A allows individuals to apply for a Federal appointment through a noncompetitive hiring process.”

Except that, that hiring process is so complex and so language driven as to prohibit people with autism from even attempting the Federal Government's highly distinctive protocol. “It was hard for me and I'm not disabled” is not an effective response to a request for support.

Who is helping those who are forced into poverty not because they are disabled but because they are denied accessibility, the most seminal of our disability Civil Rights? Even those most likely to achieve long-term employment suffer delays, denials, mandated appeals and lower eligibility status.

REQUESTS:

1. Provide environmentally accessible offices
2. Enhance the training for case managers; train at least one staff member to “highly qualified” status such that enhanced communication support is available.
3. Create a cap on eligibility and appeal timelines to allow for a humane existence.
4. Terminate “hidden” automatic denial and appeal protocols.
5. Consider the “whole person” in factoring eligibility determination.

6. Provide full funding of post-secondary training when no others are available in state; fund the autism supports as well.
7. Build coaches and employment support vendors who understand how to work and communicate with individuals with ASD.
8. Provide technical assistance in utilizing all of these programs.

Sincerely,

Dena L Gassner, LMSW (signed electronically 3/29/13)

Dena L. Gassner, LMSW

Director

Center For Understanding

Dawn Loughborough

April 9, 2013

This comment is for the Interagency Autism Coordinating Council meeting scheduled for April 9, 2013. The current care paradigm for Autism Care is missing physiological care pathways. Currently the pathway for Autism diagnoses channels children into behavioral therapies, speech and occupational therapy, and psychiatric models. Autism parents want to have a special patient population defined for the medical needs of our children. We have 1 in 50 children with Autism. IACC needs to look at environmental causation and treating our children medically.

I write to the IACC members to follow up on the physiological needs of our children with Autism:

1. Include a strategic objective for the IACC 2013 Strategy focused on immune, neurological and digestive clinical concerns with autism. Create a special patient population for Autism.
2. Enable our existing health care delivery system to regard Autism as physiological. Currently, our children are identified by behaviors, but underlying those behaviors are medical concerns that need to be assessed and treated appropriately. Parents want the same medical investigation, lab tests, and referrals that any other special patient population is afforded.
3. Reduce overall long term costs of autism care by treating the underlying causes of Autism. Many of our medically treated children improve and/or recover.
4. Autism is treatable. Form focus groups with physicians and parents and interview families. Create new science models that think outside the box that enable research to get our children well again. Track clinical data and analyze trends to inform and perfect treatments over time.
5. Currently, medical treatment protocols for hospitalization, pediatrician's offices, and clinics is lacking for the autistic population. Parents want tracking for clinical care to inform best practices, standards of care, patient centered care, and continuous improvement for our children's managed care.
6. It is time to legitimize the existence of the vaccine injured child in society. The government has awarded vaccines injured autism via the National Vaccine Compensation Insurance Program. Address the health needs of our population. Encourage hospitals to do the medical investigations for these sick children. Open the door to run diagnostic tests and treat this population medically.
7. In 2009, Secretary Sebelius asked the media to stop covering vaccine concerns. It is time for a responsible conversation about the realities of cascading vaccine damage in the human body. Allow the media to cover our children with Autism and transform the way we manage infectious disease in this nation. The National Vaccine Program is at risk because families have lost trust in our government public health care policies. Vaccines save lives is only one side of the medical health story. Many families see the cascading effects of vaccines and our nation has the worst health outcomes of the wealthy nations.
8. Perform Generation Zero studies and Vaccinated v Unvaccinated studies. IACC has obfuscated this responsibility to autism families and instead should be driving the leadership to get this researched. The Centers for Disease Control (CDC) is not the correct agency to direct these health studies since they are the ones proposing vaccination. Take action for our children. Make 2013 the year to address the medical needs of our autism population.

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Linda Varsou

April 9, 2013

STATEMENT FOR ORAL COMMENTS at the NIH/NIMH IACC Full Committee Meeting of April 9, 2013

With this April 2013 Awareness Month, it is time to highlight and research the prevalence and dramatic consequences of the serious and devastating issue of a **parent's denial** of their child's autism and/or the extent of its severity.

Denial is part of a normal mechanism within the "grievance" process that follows the diagnosis of autism -a process whereby the parent's reaction can be one of shock, denial, anger, bargaining, sadness, shame, guilt, depression, fear, anxiety, a narcissistic trauma, eventually leading to adjustment, reparation, and acceptance.

Chronic denial from a substantial number of parents (usually from fathers, rarely from both) is the most devastating issue with the child (or adult) with autism being the ultimate victim.

Coping strategies by which parents adapt to the stress associated with autism are mainly: a) the *problem-focused coping*, aiming to solve the problem, and b) the *emotion-focused coping*, aiming to manage or reduce the feeling of distress. Denial, i.e. permanent resistance of acceptance, or the attitude of "*flight instead of fight*", is the negative side of the latter.

Unfortunately, advocates and autism professionals underestimate the significance, impact and deleterious effect of a parent's denial, which can be summarized as follows:

- Children miss out on the crucial early intervention therapies and decisive earliest positive professional help and advice.
- Collaboration among parents and professionals, educators, etc., which is of undeniable and utmost importance, fails.
- Any amount of effort, services and funding provided for children with autism cannot prevent a parent's denial.
- Denial has a detrimental effect on the entire family. The parent who recognizes all the implications of autism has the additional heavier burden of having to deal with the other parent's denial. The child with autism pays the ultimate price of the family's conflict. (Divorces, abandonment, lack of support, lack of collaboration between parents, etc.)
- Denial is widespread in many countries around the world (due to the disability's stigma, prejudice, lack of awareness, stereotyping, discrimination, etc.), but unfortunately it is also common in the US (not counting rare cases of filicide).

On November 29, 2012, the Congress Oversight and Government Reform Full Committee had a hearing on the issue of "**1 in 88 Children: A Look into the Federal Response to Rising Rates of Autism**". Could it be possible that the alarming recently reported autism prevalence of "**1 in 50**" from CDC is just the result of increased awareness and decreased denial?

An extensive literature search shows no data regarding the prevalence of denial in the US. Most articles and thesis deal with "*mother's stress*", family questionnaires filled out by "*mothers*", etc. As a consequence, it is impossible to assess the issue of denial as there is a substantial bias which masks the extent of the problem. The only "data" to emerge are found on the internet, from autism awareness groups and parents' blogs reporting their dramas and all desperately seeking help on the issue of denial.

I would propose low-cost fast research protocols and meta-analysis, to investigate the issue of denial, its extent and consequences, as well as measures to deal with the problem and prevent family dramas, as follows:

1. From now on, any type of research on autism must include and evaluate the factor of denial in each individual case.
2. For all ongoing research protocols, there is still time to incorporate the evaluation of the factor of denial.
3. For past, older or longitudinal autism studies, if access to data is still available, it is possible to go back and add the factor of denial, leading to a new updated publication. It is possible that denial could be a confounding factor that would alter the results.
4. A meta-analysis could give an accurate estimation of the prevalence and degree of parents' denial.
5. Based on solid scientific data, IACC and Autism Organizations could propose the much needed mandatory judiciary changes to Family Court legislation, considering "denial" as serious as the act of abandoning a child with autism.

I am willing and available to help anyone from the IACC Committee in many different ways due to my scientific background in epidemiology and autism, because relevant scientific literature is sadly wanting right now.

In conclusion, I would like to see this month of April 2013 addressing this particularly devastating question of "denial", so as to show its support and commitment to every family struggling with autism in the US.

By Linda (Angeliki) Papadimitriou-Varsou, PhD, MPH, DABCC, interested person representing herself.

Mother of a 27-year-old college student son 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"***. Contact: Baltimore, MD [PII redacted] -

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Alison Hoffman

April 9, 2013

IACC Public Comments for 4/9/13 Meeting

Good morning. I'd like to thank the committee for allowing public comments today. I appreciate the opportunity to share our story and drive change to help families like ours living with Autism.

My name is Ali Hoffman. I live here in Bethesda with my husband, Mike and our 8 year old son, [PII redacted] -. [PII redacted] was diagnosed with regressive autism and encephalopathy after a viral infection in 2006. [PII redacted] had a history of frequent viral, ear, skin, and strep infections. In late November of 2006, he was diagnosed with a double ear infection and herpetic eye infection. He cried all day, covered his eyes to shield them from the light, refused to go up and down the stairs, and had explosive diarrhea. He didn't know us, wouldn't smile, and stopped sleeping.

Our pediatricians were helpful and had us admitted to Childrens National Medical Center for testing. Our pediatrician ordered an electroencephalography (EEG), magnetic resonance imaging (MRI), Lumbar puncture, and blood panels to help determine how to best help [PII redacted]. I'm incredibly grateful for her help in getting us started down the right path. We received a 30 minute electroencephalography (EEG). We got a lumbar puncture and it did not show an active herpetic infection. We received consults from the many departments at CNMC but with all the same input. Kids with Autism have gastrointestinal issues, abnormal electroencephalography (EEGs), and get sick a lot but we don't know why. The doctors stopped looking at our son and only saw Autism. We left Childrens National Medical Center (CNMC) armed with test results but couldn't find doctors to work with us on [PII redacted] medical issues. We were fortunate to start occupational and speech therapy right away. Applied behavioral therapy (ABA) was \$100 an hour and not covered by insurance. We did not choose to pursue it at that time.

We started a journey to find practitioners who had the knowledge and desire to help kids like [PII redacted]. Here is what we learned:

In 2007, we learned [PII redacted] has MTHFR genetic mutation. This information was helpful in many areas of his life. We would warn doctors before anesthesia that he had this and avoided nitrous oxide. [PII redacted] wakes up from anesthesia beautifully now. We also started the gluten free casein free diet. After one month, [PII redacted] started to smile again. After one year, [PII redacted] started having normal stools again.

In 2008, we took [PII redacted] to an eyes nose and throat doctor (ENT) who removed his very enlarged adenoids and cauterized his nasal passage to aid his breathing. [PII redacted] runny nose stopped and he stopped snoring.

In 2009, we trialed three attention deficit hyperactivity disorder (ADHD) drugs to help improve his attention and reduce his hyperactivity. We were unsuccessful in finding a match to help [PII redacted].

In 2010, we enrolled in an autism and sleep study at the National Institutes of Health (NIH). We checked in for our two night sleep study and electroencephalography (EEG). After the electroencephalography (EEG), our Dr. told us that [PII redacted] was having petit mal seizures. After speaking with the National Institutes of Health (NIH) doctors, I sought out a local neurologist who would help us treat this condition. Treating [PII redacted] seizures has improved his life immensely. He has longer attention spans, follows directions, has better body control, and his school performance improved. His echolalia and self talk both decreased significantly.

In 2011, our neurologist ordered an annual magnetic resonance imaging (MRI). He discovered excess fluid in [PII redacted] brain. We are monitoring this fluid at this time. Because [PII redacted] primary diagnosis is Autism, there is no process or procedure for fluid for this condition.

In 2012, I sought out a gastroenterologist at the UMMC. [PII redacted] lost weight and was having very bad constipation and diarrhea. Our gastroenterologist scoped [PII redacted] and diagnosed inflammation and severe reflux. Treating these two conditions has led to growth and improvement in overall health.

Also in 2012, we realized [PII redacted] was still experiencing infections and tested his immune system with our MAPS physician. He was diagnosed with hypogammaglobulinemia and receives IVIG monthly. We are hopeful as his immune system heals that he will be able to fight off infections and enjoy better health.

The practice of medicine requires dialogue between doctors and patients. Diagnosis and care are driven by patient input. The non-verbal ASD population cannot participate in this process. As parents, we are doing our best to help identify medical issues but we need help. We need the medical community to help us rule out issues and see past the single diagnosis of Autism. With the right medical support, our kids with autism who have co-morbid conditions improve. The IACC should research and develop this standard of medical care.

Thank you.

Jake Crosby

April 9, 2013

Hello, my name is Jake Crosby – a Master of Public Health Candidate studying epidemiology at the George Washington (GW) School of Public Health and Health Services. I am diagnosed with Asperger Syndrome.

Just recently another study was released by Centers for Disease Control (CDC) attempting to whitewash away an autism association with vaccines based on what the paper defined as the quantity of “antigen” exposure from vaccines, not the quantity of vaccine exposure. Since the whole-cell pertussis vaccine contained the lion’s share of “antigens” among routinely-given vaccines, the study was basically comparing who received this vaccine as opposed to the acellular pertussis vaccine across groups of children with and without autism. However, the vaccine schedule and the autism prevalence both increased at the same time the whole-cell pertussis vaccine was being replaced by acellular pertussis vaccine. So whole-cell pertussis vaccination in lieu of acellular pertussis vaccination did not cause the autism epidemic; this so-called research was completely unnecessary and was produced for PR purposes.

To make matters even worse, Autism Speaks’ so-called Chief Science Officer Geraldine Dawson misrepresented this study as exonerating the number of vaccinations received as a cause of autism when this study did nothing of the sort. Obviously, she has not earned one red cent of her six-figure salary as an Autism Speaks Executive.

Coalition for SafeMinds’ Vice President Lyn Redwood is another such person tied to Autism Speaks who is deserving of contempt, having made a total of \$27,500 as a SafeMinds officer during the years of 2010 and 2011. She is supposed to serve on this committee as an advocate for those who contend that vaccinations – especially mercury in vaccinations – caused the autism epidemic. Rather than fulfilling her role, she has willingly chosen to be the token mercury mom in Tom Insel’s pocket. She has a unique opportunity to question some of the people most responsible for the cover-up of autism epidemic causation by the vaccine program – people like IACC Chair Tom Insel, CDC’s Coleen Boyle and former CDC insider Jose Cordero. But does Redwood? Not even close.

At the last IACC meeting, Lyn Redwood asked Jose Cordero about the breakdown of age for autism prevalence in Puerto Rico. What she should have asked him is how he can expect to be taken seriously when he has asked the journal Pediatrics to fast-track the notorious study by international fugitive [PII redacted]. Principal Investigator [PII redacted] and his colleagues used fudged autism statistics to make it look like autism was going up after thimerosal was removed in Denmark even though the opposite happened, as revealed in email correspondences uncovered by biochemical engineer and autism parent [PII redacted].

[PII redacted] would have spoken about this and other instances of malfeasance at Congress, but he was prevented from doing so by Lyn Redwood’s Coalition for SafeMinds. After SafeMinds’ Government Affairs Committee Chair Mark Blaxill got the scoop on the congressional autism hearing from someone working with [PII redacted] on getting the hearings going, SafeMinds hired scientology-tied lobbyist [PII redacted]. She misrepresented him to congressional staff and changed the hearing topic from autism causation and the vaccine program to the so-called “federal response,” opening the door for autism epidemic deniers to be invited and give testimony as representatives on the autism spectrum.

After I supported testifying about [PII redacted] to Congress and contacting [PII redacted]. [PII redacted] for more information about [PII redacted], SafeMinds' President and Lyn Redwood's boss [PII redacted] killed the idea of SafeMinds testifying about him before Congress - flat-out preventing such issues from even being addressed. She said the cover-up should be resolved "behind-the-scenes" – in-effect kept covered up - and that SafeMinds needs to make demands that are "much safer and easier for Issa," the congressional committee chair. [PII redacted] remains on the board of Autism Speaks even after it has endorsed the IOM's 2011 pre-empted whitewash of a vaccine-autism link and after Geraldine Dawson's recent misrepresentation of the CDC's latest PR to absolve vaccines of causing autism – tacitly endorsing these positions while pretending to be on the side that is critical of vaccine safety.

In January, Lyn Redwood claimed in email to me how "sad" she was that [PII redacted] got left out of SafeMinds' testimony when trying to talk me out of writing an article that exposed how SafeMinds gutted the hearing. I don't buy it; if she was so sad, she could have testified about [PII redacted] before Congress herself. Instead, she gave up her speaking slot to Mark Blaxill, who turned SafeMinds' testimony into his own personal self-promotion and book pitch – systematically avoiding vaccines throughout his entire speech. Her excuse was that she was picking up her son from his first quarter of college on the day of the hearing, but the hearing happened two weeks after her son's college quarter ended. Even if she had spoken, she would probably have been no more effective than she is as a token on IACC.

Meanwhile, SafeMinds' assault on vaccine safety scientists continues with its recent dissemination of a hit-piece against Dr. Andrew Wakefield to thousands of followers on Facebook and Twitter.

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

Lori McIlwain

April 9, 2013

[Lori McIlwain's presentation can be viewed here.](#) (PDF – 890 KB)

Karen Heffler

April 9, 2013

Presentation to the IACC 4/9/13

I am speaking as a physician, trained at the University of Pennsylvania, a parent of an autistic son, now 21 years old, and as an individual involved with the special needs community who has observed and spoken with many families with children in the autism spectrum.

I believe that the research community has overlooked a potential contributing cause of autism that needs urgent attention and I share this concern with several clinicians who independently have reached similar conclusions.

We urgently need to investigate the potential adverse role that television(tv)/video/electronic screen- time has on the developing infant mind and the neurodevelopment of autism.

The infant brain is exquisitely sensitive to visual stimuli. As an ophthalmologist, I know that there is a critical period for visual development in the first few months of life. For example, if a child has a severe cataract, or opacity of the eye, and this is not corrected in the first year of life, the brain loses the ability to develop vision from that eye. From this we know that the brain has a critical period of heightened response to visual stimuli during the first months and year of life.

Video/ television (tv)/other screen time exposure in an infant or toddler is an environmental dose-related exposure. According to studies, infants are exposed to 1 to 2 hours of television (tv) and/or video per day, and in some cases much more. We do not know what effect this visual exposure has on the developing brain that does not have the capacity to understand the lights and images and may be making neuronal connections to try to make sense out of the onslaught of images.

We do know that:

1. Brain changes in Autism are found as early as 6 month of age (1)
2. Some of these brain changes affect the pathways connected to the occipital cortex, which is the visual part of the brain. (2)
3. Videos and repetitive viewing of tv programs began to be available in the late 1980's and early 1990's when autism rates began to rise. Before the 1990's this type of environmental exposure was not available. The availability of screen image exposure (video/cable, digital video recorder (dvr), computer, car videocassette recorder (vcr), tablet, smartphone) has continued to increase during the time coinciding with increasing autism rates.
4. Positive effects of early intervention suggest that there may be an environmental exposure that is either negated or affected by the early intervention. Screen time electronic exposure fits this model.
5. A 2011 scientific article by researchers in Thailand found an association with autism and earlier television viewing and more time spent watching television than children without autism. Those

with autism on average started viewing at 6 months of age versus those without autism at 12 months of age. (3)

6. Research has shown that among infants aged 8 to 16 months, exposure to “baby DVDs/videos-such as Baby Einstein and Brainy Baby-was strongly associated with lower scores on a Communicative Development Inventory. (4)
7. The American Academy of Pediatrics recommends that pediatricians should urge parents to avoid television viewing in children younger than 2 years of age.
8. 90% of parents report that their children younger than 2 years old watch some form of electronic media (5)

These articles show evidence of an association with increased electronic screen image viewing and autism, as well as increased viewing and language delay and lower communicative development. Yet, the general public has not been made aware of these studies, nor has the autism research community in the United States included any parameters to evaluate this as a potential cause of autism.

Despite hundreds of millions of dollars in research, there has been no significant finding that by changing that factor, autism rates have fallen. Electronic screen time is an environmental factor that is easily observable and quantifiable and if found to be a contributing factor to autism, educating parents on this exposure could have a profound positive effect on future generations of children.

I am urging the IACC, as an agency that sets priorities for autism research, to look at this as an urgent need and to set the priority that electronic media viewing in infants is an environmental exposure that urgently needs to be assessed with research instruments and /or surveys in our National Children’s Study and the Autism Sibs Consortium Study and to bring this to the attention of the research community so that other studies can investigate this environmental exposure. As autism rates continue to rise from 1 in 10,000 in the 1980’s to 1 in 50 by the latest statistics, the IACC should not wait until the next Strategic Plan for ASD Research is undertaken, but, rather, take up discussion on this now and make recommendations to include parameters to study this potentially very significant environmental exposure in current ongoing national studies. Also, in view of the articles above associating television (tv)/video/electronic viewing in young children with adverse outcomes with regard to language development and autism, and no research to suggest otherwise, the American Academy of Pediatrics recommendation regarding media viewing in children younger than 2 should be more widely publicized and parents urged to exercise caution.

Thank you for your attention.

Karen F. Heffler, MD

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