Oral Public Comments

IACC Full Committee Meeting

April 30, 2010

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

Eileen Nicole Simon

April 30, 2010

The Strategic Plan needs to include something on birth injury, and how trauma and anoxia affect the brain. How safe are obstetric and neonatal procedures?

Vaccinations are highly visible treatments, and rightfully questioned as a cause of harm, but what about less visible interventions, or interventions we have been taught to take for granted?

It has been pointed out to me that clamping the umbilical cord at birth may be very dangerous. Effects of clamping the cord are unpredictable. The newborn lungs cannot function until blood supply to the alveoli is established. This blood should come from the placenta, but if transfer of blood from the placenta is blocked, blood for the lungs will be drained from other organs.

If blood is drained from the brain, a well-defined pattern of ischemic injury will occur in nuclei of the auditory pathway. The Apgar score may be a perfect 10, but the baby left with auditory system impairment severe enough to prevent normal language development.

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Developmental language disorder also needs a higher priority in the Strategic Plan. The unusual hypo- and hyper-sensitive signs of auditory system dysfunction likewise need to be made a higher priority for research.

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I have cited the evidence for auditory system vulnerability (to all of autism's many causes) in my written comments – and online at www.conradsimon.org.

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Also in my written comments and online, I have urged that mandatory long-term care insurance be required for all citizens, form birth, to cover the huge cost of life-span care. Requiring long-term care insurance would also involve actuarial scientists in research on why the prevalence of autism has been increasing.

Eileen Nicole Simon
[PII redacted]

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Jim Moody

April 30, 2010

Subject: Statement From The National Autism Association

EXTERNAL CAUSES OF DEATH AMONG CHILDREN & ADULTS WITH AUTISM SPECTRUM DISORDERS

Previous requests from the National Autism Association have primarily focused on an increase of environmental-based research and the overwhelming need for biomedical-treatment funding, the acknowledgement of underlying pathologies, and the long overdue study of vaccinated versus unvaccinated populations. We've voiced our concerns over political agendas overshadowing the real needs of those with autism, and how our children's stories deserve to be heard by the medical mainstream without bias. Our position on these issues remains the same. Today, however, we wish to address a different area, which is the external causes of death among children with autism…and the lack of resources, support, and research to help counter these very preventable deaths.

Last week [PII redacted], a three-year-old boy with autism from Caroll County Arkansas, drowned in a nearby creek. Two weeks prior, [PII redacted], a six-year-old boy with autism, was found dead in a pond in Atlanta. Before that, [PII redacted], a seven-year-old boy with autism, wandered from his home in the frigid temperatures and was found two days later with a faint pulse. He died shortly thereafter. [PII redacted], age nine, died in a neighbor's pool. [PII redacted], age 11, was struck and killed by a truck. This is just a sampling of the children with autism who have recently died following a wandering-related incident.

In 2008, Danish researchers found that the mortality rate among the autism population is twice as high as the general population. Seven years earlier in 2001, a California research team found that elevated death rates were due to seizures and accidents, respiratory problems, and gastrointestinal bleeding. Deaths were also attributed in large part to suffocation and drowning. The National Autism Association is working to address the external factors in particular, most notably suffocation due to improper restraint procedures and drowning. Drownings, prolonged exposure, and other wandering-related factors remain among the top causes of death within the autism population.

Please note that we are unable to provide you with data that shows just how many adults and children have died in the last decade due to wandering, and although we can assure you that the death count increases each year based on our own observations, we have no research to back our claims, nor can we guarantee any sort of percentage of increase. This is the reason we are here today. Without any kind of hard data on wandering-related incidents and deaths, it has been difficult to gain the attention of lawmakers, government health agencies, the media and law enforcement agencies.

Our children and adults with autism are dying unimaginable deaths, many times without even a voice to call for help. They die alone, and they die terrified. Their loved ones are faced with having a child still missing after the sun goes down. Because of a lack of research, preventative measures, mass awareness, resources and emergency interventions are grossly lacking. If we're all here to support science that increases progress, prevention, services and quality of life among those with autism, we ask for your help in countering these deaths. Prevention and safety materials distributed by pediatricians to caregivers are imperative. Assigning a subclassification ICD-9 code for autism elopement – or at the very least a DSM code – could help families pay for safety devices, raise the seriousness level of the condition, and open up critical dialogue between physicians and caregivers. Our children are not covered under the AMBER Alert system, nor are they covered under most Silver Alert systems, although this particular alert system does cover adults with autism. Because AMBER Alert criteria only includes abducted children, it is our goal to revise the guidelines to include "any child who is endangered," which by definition would be those with a mental disability or life-threatening medical condition. We also need funding for Project Lifesaver tracking equipment, law enforcement training, access to swimming lessons and home security items. Statistics would help justify this. Lastly, we need awareness, because in this case, greater awareness will promote better understanding. We need to understand how these deaths are happening, why they are happening, how many times they've happened, and how much they may be increasing. We need to understand that children like Aiden were in the care of his grandparents that other children were in the care of their parents, my child in particular has gone missing seven different times from three different schools. These children are not wandering because of neglect or bad parenting, they are wandering because they have a medical condition. With one in 110 children now diagnosed with autism, the potential for more tragedies is tremendous. The National Autism Association respectfully requests your thoughtful review of this matter, and for your help in gaining answers that could help save lives.

ABOUT THE NATIONAL AUTISM ASSOCIATION:

The mission of the National Autism Association (NAA) is to educate and empower families affected by autism and other neurological disorders, while advocating on behalf of those who cannot fight for their own rights. We educate society that autism is not a lifelong incurable genetic disorder but one that is biomedically definable and treatable. NAA raises public and professional awareness of environmental toxins as causative factors in neurological damage that often results in an autism or related diagnosis. We encourage those in the autism community to never give up in their search to help their loved ones reach their full potential, funding efforts toward this end through appropriate research for finding a cure for the neurological damage from which so many affected by autism suffer.

The National Autism Association helps those with autism by:

- funding important scientific research to determine the cause of autism to prevent it in the future and treat those with autism now

- providing a Helping Hand grant program that gives money to families of autistic individuals in need – helping them pay for treatments and other critical services

- funding the FOUND program, which provides lifesaving equipment and wristbands to individuals with autism who are at risk of wandering

- funding the Family First program that provides counseling services to families who are threatened by divorce thus disrupting very vulnerable children's treatments and services

- leading national and statewide advocacy efforts that cover all areas of need within the autism community

CONTACT:
Lori McIlwain, Board Chair
National Autism Association
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Caroline Rodgers

April 30, 2010

Subject: Why the IACC Should Investigate Prenatal Ultrasound Without Delay

Good morning, and thank you for this opportunity to speak to you today as you launch the updated IACC Strategic Plan. Many hours were dedicated to meetings and a great deal of research went into updating this plan to end autism – a goal I know is close to all of your hearts. I am here to invite you to take the bold step of modifying the plan even further to include research that could lead to preventing autism. Delaying this investigation another year could contribute to an unprecedented increase in this disorder.

In January when I addressed the IACC, I shared what I had discovered when I integrated the findings of three Centers for Disease Control (CDC) reports[1 2 3]. To recap briefly, the three CDC reports, taken together, painted a troubling picture: as more women across all ethnic groups received prenatal care, the autism rate among their children increased, with greater increases among the groups that had more early prenatal care. This was a big surprise.

The CDC's latest autism prevalence report showed that while the over-all autism rate grew 57 percent, Alabama Hispanics had a 68 percent decrease in autism[4]. The two states with the lowest increase in autism, Alabama and Florida, were the only two states among those monitored that had cutbacks in Medicaid funding for prenatal care[5] during the critical period when the children assessed had been in gestation[6].

Today I am bringing to your attention a study that could explain these numbers. The study, "Trends in Prenatal Ultrasound Use in the United States,"[7] found that the average number of prenatal ultrasound scans nearly doubled over the 10-year period ending in 2005-2006. It also found that women in the South were 40 percent less likely to receive an ultrasound during a prenatal visit than women in the Northeast. Further, Hispanic women – the one group of women consistently found to have fewer autistic children – were 20 percent less likely to have an ultrasound than White women. If ultrasound is causing autism, the facts regarding reduced Southern and Hispanic ultrasound exposure start to explain the 68 percent autism decrease among Alabama Hispanics.

Most people believe that prenatal ultrasound is perfectly safe, and to a large extent, they may be right. If prenatal ultrasound is causing autism and 99 out of 100 children do not have autism, clearly the overwhelming majority of children exposed to ultrasound are not harmed by it. Another point to consider is that if prenatal ultrasound is causing autism then neither the OB-GYN nor the pediatrician would have all of the necessary information to make a correlation. The OB-GYN, after delivering the baby and perhaps one post-partum check-up, usually sees the mother only once a year; meanwhile, the care of the baby is immediately transferred to a pediatrician, who does not collect information regarding prenatal ultrasound exposure. Finally, since an autism diagnosis is not usually made until the child is 18 months old, the amount of time that has elapsed between ultrasound scans and an autism diagnosis is such that it would not be likely to occur to the most diligent diagnostician to consider ultrasound a factor in causing autism.

Was there any warning that ultrasound could cause anything like autism? Yes. Besides a handful of studies that found an increased incidence of left-handedness, speech delay and dyslexia, which are considered neurological markers, a 1982 World Health Organization (WHO) report on ultrasound, in its summary of section 6.5 Human Fetal Studies, concluded, "There are many gaps in the data from human studies that prevent a meaningful risk assessment of ultrasonic exposure. It is therefore necessary to use the result of animal studies to test the hypothesis that similar effects may also occur in human subjects. Animal studies suggest that neurological, behavioral, [and] developmental changes . . . can result from exposure to ultrasound." [8]

Doctors at that time were not overly concerned, and perhaps had little reason to be, as ultrasound was used sparingly. However, since then prenatal ultrasound has changed rapidly in every possible respect, whether it be the technology and acoustic output, the gestational window of exposure, the number of scans per pregnancy or the percentage of women scanned. What was once an imaging technology used only in high-risk situations became routine[9]. These changes, no doubt sincerely believed to be improvements that would benefit mother and child, quickly overtook scientific studies that could verify their safety.

Geneticists who are actively involved in searching for the cause of autism can be a great help in the investigation into prenatal ultrasound's possible role. The very fact that the search for definitive "autism genes" has not yielded much in the way of results is highly valuable in guiding future efforts, such as discovering the source of copy variations that appear to be involved in autism, yet cannot be traced to either parent. These copy variations, since they are not inherited, must occur early on in the womb. Could some copy variations be caused by ultrasound during the critical time when a female embryo is forming all of the eggs that will be released during her fertile years? Geneticists can pave the way to understanding this and other questions regarding genetic tendencies and ultrasound.

If prenatal ultrasound is a leading causing of autism, then the increase in scans that has occurred in the 10-year period ending in 2005-06 means that we might start seeing an autism rate approaching 2 percent by 2014 – a trend that typically would not be reported until 2016, as it takes about two years to crunch the numbers and produce such an extensive report. Can we afford to wait another six years to start investigating prenatal ultrasound?

Studying whether prenatal ultrasound causes autism is not easy. Only one study has attempted to discover if there is an association. The retrospective study, "Antenatal Ultrasound and the Risk of Autism Spectrum Disorders," did not find a correlation, yet by its own admission, was lacking pertinent data in one-quarter of both the autistic and control cases[10]. One prominent ultrasound safety expert who read the study said, ". . . without knowing exposure data (output power, type and length of examination), no conclusion can be drawn."

I am asking the IACC to aggressively call for and fund relevant studies, starting now. Wherever possible in existing, ongoing field studies, the IACC should make every effort to provide additional funding for researchers to collect and analyze ultrasound data. The IACC should ask the FDA to develop a uniform way of recording ultrasound sessions and require that all ultrasound sessions be recorded in that manner, to build a database for further study.

Taking such bold, proactive steps may take you outside the bounds of current procedure, but you gave yourselves the authority to take such action when you created the IACC's top core value, which calls for a "sense of urgency" to respond rapidly and efficiently when challenges arise.

You are here because you care about the one-in-100 child who has autism and you want to discover how to prevent it. If there is even a chance that prenatal ultrasound is causing autism, due diligence requires that you take whatever measures are necessary to investigate it promptly.

Thank you.

References

[1] Prevalence of Autism Spectrum Disorders – Autism and Development Disabilities Monitoring Network, United States, 2006. MMWR, Dec. 18, 2009.
http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5810a1.htm

[2] 2002 PRAMS Surveillance Report: Multistate Exhibits Medicaid Coverage for Prenatal Care. http://www.cdc.gov/PRAMS/2002PRAMSSurvReport/MultiStateExhibits/Multistates9.htm (IACC Note: URL is not valid.)

[3] Entry Into Prenatal Care – United States, 1989-1997. MMWR, May 12, 2000
http://www.cdc.gov/mmwr/preview/mmwrhtml/mm4918a1.htm

[4] Prevalence of Autism Spectrum Disorders – Autism and Development Disabilities Monitoring Network, United States, Table 5. 2006. MMWR, Dec. 18, 2009.
http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5810a1.htm

[5] 2002 PRAMS Surveillance Report: Multistate Exhibits Medicaid Coverage for Prenatal Care. http://www.cdc.gov/PRAMS/2002PRAMSSurvReport/MultiStateExhibits/Multistates9.htm (IACC Note: URL is not valid.)

[6] After my presentation, some people suggested that the low autism numbers found in Alabama and Florida might be due to the fact that researchers only had access to health records and not school records in those states, because when researchers had access to both health records and school records, they tended to find a higher incidence of autism. However, Missouri, which along with Arizona had the highest autism prevalence among those states monitored, also did not provide school records, proving that the lack of such records does not guarantee a low autism prevalence rate. Conversely, in Colorado where researchers had access to both sets of records, the autism rate was lower than three of the five states where researchers only had access to health records.

[7] Lantos JD, et al. Trends in prenatal ultrasound use in the United States: 1995 to 2006. Med Care 2009 Nov;47(11):1129-35.

[8] "International Programme on Chemical Safety. Environmental Health Criteria 22. Ultrasound." 1982. United Nations Environment Programme, International Labour Organisation and International Radiation Protection Association. www.inchem.org/documents/ehc/ehc/ehc22.htm. Accessed 22 May 2006.

[9] Lantos JD, et al. Trends in prenatal ultrasound use in the United States: 1995 to 2006. Med Care 2009 Nov;47(11):1129-35.

[10] Croen LA, et al. Antenatal Ultrasound and Risk of Autism Spectrum Disorders. J Autism Dev Discord 2010 Feb;40(2):238-45. Epub 2009 Sep 1.

Lindsey Nebeker

April 30, 2010

I want to thank you for giving me the opportunity to speak to you today.

My name is Lindsey Nebeker, and I am personally representing myself as an individual with autism. I also have one younger brother, also diagnosed with autism.

Even though we share the same diagnosis, the way that autism has manifested set us far apart. I am verbal, while my brother does not speak. My education was generally mainstream, while my brother responded more effectively in a special education setting. Even though I have faced many challenges growing up, I have been fortunate enough to learn how to speak, receive a college degree, and live independently without additional supports.

For [PII redacted], it was more complicated. We tried speech therapy, sign language, PECS, and AAC devices, and sadly, the results have been extremely limited. From his frustrations, his aggression, and his cries, I know he wants to communicate and be understood. I have met parents who go through similar struggles of trying to teach their non-verbal autistic sons and daughters, children and adults, to communicate and be understood. Some do thrive on the methods I have mentioned, and I applaud this. But some do not, and I believe with continued research on communication, we can sum up with additional ways to give non-verbal autistic individuals the greatest gift of all: an opportunity to communicate and be understood.

Even though [PII redacted] situation and outcome was different, he still benefitted from what he was able to receive. His achievements may be small and insignificant to most people's standards, but to those of us who raised and worked with those who have severe challenges like [PII redacted], these little achievements are not overlooked.

I am very open to new ideas and possibilities that research can do for behavioral, educational, and other treatment methods which are deemed safe and ethical. I also support genetic research which is deemed ethical; however, because of the current need of providing effective services for families, I would focus the majority of funding towards assessing early intervention, transitional services, and other effective intervention methods. I would discourage funding for treatment which pose a health risk, or have not yet had enough evidence to support the safety in conducting such treatment. We need to focus on the current need, because today we as Americans are living in the current need.

I know very well how vast the autism spectrum is. [PII redacted] has given me the opportunity to see this, and after years of meeting and working with kids, adolescents, and adults like him, I understand how real the situation can be. [PII redacted] is now 26, and for the past 10 years has been enrolled in a community housing program with 24/7 rotating experienced staff.

Growing up in the 80’s and 90’s, the early intervention that my brother and I were directed to was easy to locate; however, my parents were at a loss of where to direct us afterward. The options laid in front of us was either a path towards living in full independence (with no supports), or living in complete dependency (with full supports). We weren't aware of the options in between. I was fortunate enough to take that path to independence, but my brother had to take the path of full dependence.

Over the past 2 decades, I have witnessed gradual improvement in support groups, transitional programs, and housing programs. I have barely begun to hear the adolescents and adults being brought up in the conversation. I strongly encourage that we include adults in the conversation, because they are our greatest teachers in the autism community. There are many autistic adults in our country who are seeking help, and don’t feel like they have a voice. We need to give them a voice.

As a female with autism, I felt even more alone during my school years -- no support group, no programs tailored to girls on the spectrum. I felt alone, and I felt silenced. It wasn't until after college that I gained the confidence and courage to disclose my autism, and my hope is that no other woman with autism have to grow up like that, where they feel afraid to speak up because they are not being brought up as much in the conversation of autism, especially teen girls and adult women on the autism spectrum.

As a female with autism, I feel there is a need to increase the focus on research for females on the autism spectrum. The signs were profound enough that I was able to receive a diagnosis at a young age. However, the majority of girls with autism are diagnosed later in life than in boys, because the indicators are often undetected and often mistaken as a state of extreme shyness. When you hear that girls with autism tend to suffer in silence, it is true. Women with autism need to be included in the conversation.

Regardless of where we stand on personal views, we can all accept that autism is presently a lifelong condition. These children will someday become adolescents, and these adolescents will someday become adults. Parents may vary in their personal beliefs and views on autism, but they all do agree on one thing: providing the best for their children. There are many parents I have met who are still left in the dark as to where to direct these children after early intervention is completed. And from my personal experience as well as my brother's experience, I can assure you that services cannot end in early childhood. Services will be needed throughout the lifespan.

I can testify to you that every child, adolescent, and adult with an Autism Spectrum Disorder, no matter where they are the spectrum, deserves to receive care, live to his or her full potential, and are entitled to have a voice like every other American citizen, and nations elsewhere.

Paula Durbin-Westby

April 30, 2010

ASAN
The Autistic Self Advocacy Network

Thank you for the opportunity to comment. I am Paula Durbin-Westby. I am on the Board of Directors of the Autistic Self Advocacy Network. On behalf of ASAN, I would like to welcome the new members of the Interagency Autism Coordinating Committee.

The Autistic Self Advocacy Network is the largest organization run exclusively by individuals who are on the autism spectrum. We count among our supporters people on the autism spectrum, parents of children, teens and adults on the spectrum, educators, and practicing professionals.

For those new IACC members who are not aware of ASAN’s priorities for the Interagency Autism Coordinating Committee, they are these:

Focus funding toward research and practices that will have practical benefit for people on the autism spectrum, our families, friends and communities.

Focus on services for people on the spectrum throughout the lifespan, including adults, underserved populations such as ethnic minorities, women on the spectrum, people who do not use language-based forms of communication, and others.

Redirect research attention toward developing functional communication systems, through developing and making accessible Alternative and Augmentative Communication systems and individualizing communication systems so that each autistic person can have the most accessible means of communicating. As an adjunct to this, make IACC meetings and materials accessible to people with a wide range of disabilities, both physical needs, communication differences, intellectual, cognitive, and developmental needs.

Focus away from a fixation on “causes” and “cures,” especially when these research focuses, on a variety of genetic/genomic differences, and various biomarkers for autism, have the potential to bring about eugenics, or the selection out of the “gene pool”, of a certain subset of the American population. Keep eugenics out of autism research.

Ethical concerns must be kept foremost and the ethical concerns need not stop with the concern about how to transmit notions of “risk” during pregnancy. Ethical issues should also be addressed when researching pharmaceutical treatments, behavioral interventions that, without careful consideration of unintended consequences, may be physically, psychologically, or emotionally harmful to the individuals receiving these treatments. All such research and subsequent practice must be rigorously monitored so that the health and well-being of the individual person on the autism spectrum is the first priority.

Those researchers who work in close consultation with, and call on the expertise of, those of us living on the autism spectrum, in areas of development, interpretation, implementation, and evaluation, are the researchers who will be most likely to make advances that will directly impact the lives of autistic people in a positive way.

In closing, I am going to quote from Ari Ne'eman's testimony at the November 30, 2007 IACC meeting. "We encourage this Committee to take the first steps towards shifting the main buzzword about autism from "cure" to "communication" and ultimately, to moving the dialogue about the autism spectrum to one of acceptance, inclusion and, above all, respect."