Oral Public Comments

IACC Full Committee Meeting

July 8, 2014

List of Oral Public Comments

Wendy Fournier

July 8, 2014

Subject: Statement from the National Autism Association

I'm here today representing the National Autism Association to update you on the issue of autism---related wandering, which has tragically taken the lives of another 27 of our loved ones since last year. We are aware of at least 67 deaths since we first brought this issue to IACC in 2010.

NAA is focused on, and dedicated to the safety of individuals with autism. We have been tracking wandering cases through media reports since 2011, and are beginning to see some trends that I will share with you today in our PowerPoint slides.

Most notably, the average age of individuals who elope and become lost appears to be increasing along with our children. Our anecdotal interpretation of what we're seeing and hearing in the community is that the most frequent and dangerous wandering incidents are involving individuals born during a particular time frame – perhaps this represents a sub---group of individuals whose safety is at increased risk because they are more severely affected by autism. Further data collection and analysis is needed.

We are also documenting more cases that we would classify as "bolting" – when an individual suddenly becomes frustrated or overwhelmed and quickly leaves his or her immediate environment. We believe that in many cases, this is due to a specific trigger than causes a fight or flight response for the individual. Based on our own experience and observations, and backed by the Interactive Autism Network (IAN) data on wandering that was published in Pediatrics in 2012, we are currently developing and funding a follow---up study looking at auditory sensitivities as a safety risk. Unfortunately, unlike other hearing disorders which have specifically---designed technology to assist individuals affected – our children's symptoms are commonly dismissed as "part of autism," and no options for relief of this co---occurring medical condition are offered. While people without autism have nearly invisible hearing aids or white noise devices available to them, you will most likely see a child with autism wearing a pair of bulky construction worker headphones from Home Depot. Our children deserve better.

I will share with you in our slides a timeline of what's been done to date to address wandering and the things that we still desperately need that your committee can help to coordinate, specifically:

- Research on the root causes of wandering/elopement incidents
- Development of, and access to technology to help individuals who are at risk
- An effective means of communication is vital to physical safety, AAC devices should be considered medically necessary and covered by insurance
- The majority of deaths due to a wandering incident are by drowning, adaptive swimming lessons should be available to all individuals with Autism under ADA Title III
- Policy guidance from the Department of Education for all schools
- FDA pre---market notification regulations for retailer GPS personal locating devices
- First responder training through the Department of Justice, and an alert system that applies to all who have a disability, regardless of their age

Please feel free to email me if you would like additional information, or have any questions regarding our

statement and presentation.
Wendy Fournier | wendy@nationalautism.org

Wendy Fournier’s presentation can be viewed here. (PDF – 416 KB)

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

Eileen Nicole Simon

July 8, 2014

My comments have only to do with brain damage that impairs language development.

Language is the distinguishing feature of the human species. Failure to acquire language is a neurological disability, not just a difference. A name other than “autism” should be used to describe children who have trouble learning to speak, perhaps “developmental aphasia?” The cause must be looked for in the brain.

Complications at birth are documented in the medical records of many children who have trouble with language development. My son, [PII redacted], had to be resuscitated at birth. 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.

[PII redacted] died at age 31 in a group home, from a prescribed overdose of Thorazine (500 milligrams, 3 times per day).

I put up a website in [PII redacted]’s memory, 14 years ago, and immediately received many email messages asking how soon after birth his umbilical cord was clamped. Clearly it was clamped before he was breathing, and resuscitation efforts seemed interminable before I heard his first weak cry.

Since the mid 1980s clamping the cord immediately after birth has become a standard protocol, whether or not breathing has begun. This is dangerous and now rightfully controversial.

Thank you Drs. Batra, Crandy, and Guttmacher for your discussion of my comments in April. Can we discuss this further?

There are no health benefits from clamping the umbilical cord.
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Conrad Simon Memorial Research Initiative
To seek understanding of brain system impairments in autism.
http://conradsimon.org/

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James Williams

July 8, 2014

Good afternoon, IACC. Thank you once again for welcoming me to give another public comment.

Today I come before you to talk about another pertinent issue relating to people with autism. And that refers to the struggles that adults with autism have in finding employment.

I shall speak to you today excerpting a paper I co-wrote regarding this issue one year ago with fellow self-advocate with autism [PII redacted]. In this excerpt, the names of all individuals mentioned have been changed to protect their privacy.

Based on my own personal experiences, and the experiences of the individuals with autism I have met, I have concluded that there are multiple barriers to employment with autism, and that these barriers need to be addressed in order for individuals with autism to succeed in the work world.

First, people need to understand that although people attend school in order to get a job and join the workforce, to many people with autism, school and work are two different environments with very different expectations. Many individuals with autism, such as my co-author, thrived in school but did not thrive in the work world. When I left high school, I discovered that although my high school education gave me knowledge that helped me in my work, very few of the social rules and expectations that I needed to survive in school transferred into the adult and work world. Yet ironically, teachers would often judge my social skills in high school to predict my ability to function in the work world and adult world. And students with autism often find that even with the proper credentials for certain jobs, they still lack the social skills necessary to survive in that workplace.

Second, many indirect workplace requirements or indirect working conditions exist in any given workplace or career field that are not always discussed when people with autism pursue a job or career, such as social expectations in a work setting. All workplaces have social rules, social expectations, and a social culture that people have to negotiate when holding down a job, yet people rarely mention that social culture when a person pursues a specific career and applies for a job. At the same time, academic programs and job training programs may teach the skills or lead to a degree required for a job, but often do not cover the social requirements expected on the job that a person is receiving training for completing a degree for. Instead, for most people, that culture is something they learn instinctively without instruction, or when they start their career and pursue it.

However, many individuals with autism are not able to learn that culture due to their social deficits, and as a result, they have had to leave jobs or have been fired from jobs because they lacked the social skills to function in the social culture of their workplace, even if they were qualified academically and had the skills to perform the job. Some individuals with autism with advanced degrees find themselves working high school level work because of these limitations. Researcher Brenda Smith Myles, in several of her presentations, tells a story of a person with Asperger syndrome who has a doctoral degree in biology but currently shelves books at a library, unable to succeed as a biologist due to his social limitations.

Workplaces also have sensory inputs, and sometimes a person's sensory issues can make them unable to function in a workplace. The sounds may be too loud in a workplace or the lights may be too bright. And many individuals with autism do not always learn about those sensory inputs until after they have been hired for a job. Many job applications, after all, usually don't tell you the sensory requirements for the job you are applying for.

Third, health barriers to employment exist that people are not always aware of. It is believed that autism strictly refers to a mental disorder, but new research has shown that people with autism have health issues that are distinct to their condition, sometimes referred to as co-morbidities. Dr. Jeff Bradstreet, founder of the Bradstreet Wellness Center, has done extensive research that suggests that autism has just as many physical symptoms as mental symptoms, and that autism is just as much a physical disorder as it is a mental disorder. He has attributed many behavioral issues of autism to health issues that he has sometimes found to be more common in individuals with autism. And this is a barrier to employment since people with autism are sometimes frequently ill, sometimes resulting in them missing work.

I know an individual with autism in her thirties who has routinely had to miss work because of psychological treatments (due to her autism) that would often result in chronic stays in rehabilitation centers, requiring absences from work. In college, she sometimes would be unable to attend class due to bouts of nausea related to her digestive issues.

In addition, the issues of a person with autism, whether they are health-related, sensory-related, or socially-related, sometimes limits the hours they are able to work. Some individuals with autism are only able to work part time because a full time job would be too demanding for them. This can also hinder the efforts of a person attempting to find a living wage job.

Fourth, more awareness needs to occur regarding the distinction between employment and independence. Employment is often discussed in transition plans and is often seen as a stepping stone to independence. But one thing I have observed on my travels is that employment and independence are actually quite different, and in many cases, employment does not lead to independence.

One of the realities that I have seen when traveling is that most young adults I have met who live independently do so with support via an SSI or disability check, not by employment. Meanwhile, the majority of the jobs that my autistic friends and the people I meet are not in "living-wage jobs"—that is, jobs that make enough income to enable them to be independent. My friend [PII redacted] is a person with autism in her twenties and has worked a variety of jobs yet is still living at home because none of those jobs pay enough to support themselves independently. Yet my friend [PII redacted], also in his twenties, lives independently quite well, and does so by receiving an SSI check, which gives him enough money to pay for his needs, along with guaranteed coverage for health issues thru Medicaid.

Like [PII redacted], I dream of a world where people with autism who desire employment and choose to work can be accommodated in workplaces and that their dream of independence can be fulfilled. I hope that someday the reality I have seen in the world today can be changed.

Employment barriers are complex and there are many issues that autistic people face when they pursue employment. My life experiences and the stories I have heard in my travels from others with autism have led me to conclude that the following questions need to be asked if we are going to help individuals with autism find meaningful employment:

If individuals with autism are often employed in non-living wage jobs, is it worth it for them to pursue higher education and advanced degrees before they pursue employment?
How do we find employment that enables a person with autism to live independently, even with the additional expenses that a person with autism might have due to their autism?

If an individual with autism is pursuing a specific career, what are the social requirements and sensory requirements necessary to function in the workplace environment specific to that career, some of which may be unrelated to the work skills themselves?

Likewise, if welfare provides superior support to adults with autism than conventional employment, how do we challenge this perverse incentive that is an economic reality to these adults?

The answers are probably different in different parts of the United States and the rest of the world, and the right path is probably different for each individual with ASD based on their specific issues, skills, and situation. But I believe that these are the questions we need to ask ourselves to help people with ASD find employment in society.

I shall also close by quoting [PII redacted] from her portion of the paper that we wrote: *"I am perfectly healthy, educated, qualified, and capable of working. My language skills include full fluency in Spanish and intermediate reading proficiency in Russian. I have a masters degree in taxation. My work experience includes publishing a newsletter on the Latin American Internet industry and finding successful stock and real estate investments. I want to work and earn a living with dignity like the rest of my Ivy League peers. I don't need or want a six-figure income, particularly since I am childless and not interested in motherhood. But I know that I don't belong on welfare and that I deserve to be financially self-sufficient."*

Tara McMillan

July 8, 2014

Good day, my name is Tara McMillan. The reason I am here is because my son has Autism.

More specifically he developed encephalitis thru the set of vaccinations he received as a baby.

How do I know this?

Because my son's medical records tell me that he was injured after every vaccine he received.

It was only after I read a book about one moms account of mercury poisoning , did I think to actually investigate for myself exactly what happened to my son, and how he lost all verbal communication skills.

I went back thru my sons records, and noticed what no doctors had even cared to look at—the pattern of illness after every injection.

This shows me that indeed correlation does mean causation. If you are going to inject your body with heavy metals, animal DNA, and unidentified virus's something bad will happen. This is not rocket science, or anything that requires a PHD. It's plain and simple common sense.

The rise of autism continues to skyrocket. Why is this? It doesn't take a meta-analysis to figure it out. Nothing has been done about the use of dangerous vaccines on our perfectly healthy children. Our babies are born with Apgar scores that are normal, and above average, yet when they receive their vaccinations soon after they regress and get sick.

By now I would think someone would come after you with handcuffs for all that you have ignored, Mr. Insel.

As a parent I feel that you need some time locked away in a jail cell. Why? Because you have not done what you have the power to do. You have not heeded the concerns of pleas of parents. You have not seen vaccines for what they really are. They are a train wreck, and our kids are on that train.

More kids are being injured every day, because people who have power like you fail to do anything about vaccines about their paths of destruction.

There is no path for recourse, no plan for compensation for our injured, because vaccine makers are not liable for any injury or death. They are free to kill and maim as many as they want without oversight. Doctors ignore parents when children get sick, and we are left dealing with brain injury on our own. There is little if any help from doctors. They simply tell us, it couldn't be the vaccines. Vaccines don't cause injury, or a fever and screaming for hours is normal.

You may think you are free to do anything you want but one day you will have to answer for what you have failed to do. If you don't get time in jail, I know that it would be a hard thing to live with having the injured children with autism on your conscience. Thank You.

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

[Name of minor redacted]

July 8, 2014

Subject: How Autism changed my life

My name is [name of minor redacted]. My brother [PII redacted] has autism. I really don't remember [PII redacted] having autism. I remember him being the cutest little baby ever. I remember asking myself "why can't [PII redacted] talk?" now that I am older I understand why. When I finally got that picture in my head. It changed my entire perspective on life. I was only 3 when [PII redacted] was born. So as I grew older it was difficult. I remember him bagging his head on the wall. Hanging of the stairway ledge. Pulling our hair. Biting us. In a way it made us stronger. But sometimes it tore us down in ways I can't explain. I would cry at night begging someone to make him better. But every day I would wake up and find that nothing had changed. My dad is in the army. So we moved around a lot. I remember telling my new friends that my brother having a condition called autism. They would call me lucky when I told them I was homeschooled. But I told them over and over again that I would do anything to get away from home. And the chaos that went with it. As I grew older I started going to conferences with my mom. The doctors there would say stuff about vaccines. And my Mom would talk about them at home. So I was snooping through my mom's closet and I found my brothers medical files. And I found that when my brother was only 17 months old he had 10 vaccines at once! That I believe caused [PII redacted]'s autism. If you don't believe me Mr. Tom . You can look for yourself. I don't know how you sleep at night. Knowing that those kids out there not just the autistic but there siblings need your help. And you are just sitting there saying no. we need you to look into vaccines. If vaccines are harmless why not. Do you have something to hide. Or are you just scared. Mister Tom why? Why are you holding back when we need your help? When I need your help. You have no idea how hard it is just having to make sure that [PII redacted] is in the same room as me. Cleaning up every mess he makes. You have no idea how grateful I would be if you just said yes. Please just say yes. If you won't do it for us do it for yourself. Thank you.

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[Name of minor redacted]

July 8, 2014

Hello, my name is [name of minor redacted] and my brother had a vaccine reaction when he was only 17 months old, I was six when it happened so I don’t remember it that well, but it affected my family tremendously.

About 7 months after [PII redacted]’s vaccine reaction, my little sister [PII redacted] was born and if my mom hadn't stopped the shots after his newborn shots, she would probably been worse off than [PII redacted] is.

I know after this you will just continue on to the next person, and you won't even think twice about what I'm saying now,

And you're going to ignore more and more people as they talk about their REAL lives, because sir, these are real lives, the things me, and countless others are telling you about are our REAL lives, there not made up stories you can just pass along!

You need to think about someone other than yourself you can make a difference by saying a sentence.

You could CHANGE LIVES by doing this.

Before my brothers vaccine reaction, he was a normal kid, afterwards, he lost the ability to nurse, he couldn’t even crawl or sit up until he was 2, now he still can't talk, but he can ask for things by pointing, he taught himself to READ.

Before my mom found out about the vaccine reaction, we were constantly eating junk food, and I had psoriasis all over my body from wheat allergies, now, we eat a box of mac N' cheese about once a month, we eat salads for lunch, I no longer have an allergic reaction to wheat, and we are a mostly gluten free, organic family.

If my brother never had Autism I wouldn't know half the people I do today, so in a way, I'm thankful for my brothers Autism,

But is it NOT a gift and I will be glad when I can hear my little brother talk to me like a normal kid.

So please don't just ignore the people talking to you today and do something about it.

My brother is now 8 years old and still cannot talk, Thank you.