

# **Oral Public Comments**

**IACC Full Committee  
Meeting**

**April 19, 2016**

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**Nathan Olson**

**April 19, 2016**

*Subject: My Journey in Higher Education: A Firsthand Perspective*

**Nathan D. Olson**

Student and Advocate

Mr. Chair and Members of the Committee,

I am honored to appear before you today, especially as we commemorate Autism Awareness Month across our nation, and around the world. I am a junior undergraduate studying Cultural Anthropology, at Pacific Lutheran University. I was a late diagnosis of autism as an adult at the age of 22 years old in 2011, and that diagnosis changed the course of my life, and transformed my perception of self. I posed the question: "How could I ask you to accept me, if I didn't have the courage to first accept myself?" I am also diagnosed with ADHD and Nonverbal Learning Disability respectively as of last summer, yet the pride always remains the same because I view it as one more piece of the puzzle that further helps me understand how to succeed in the classroom and in life. I have made the cause of disability advocacy that deep sense calling which defines my life, and I promise you it is the most profoundly rewarding opportunity I've had. That is what inspires me to come share my experiences in higher education.

In my journey in higher education, I have experienced tremendous academic failure at prior schools attended prior to the diagnosis. When the diagnosis came it helped fuel a sense of academic vitality that I never knew I was capable of achieving. I owe my success academically to the Autism Spectrum Navigators Program at Bellevue College, (WA), which I was part of for my two years attending there. This is a program, designed and directed by our Autism Spectrum Navigators Program Director/Professor Sara Gardner, a person who I owe my success to greatly for creating a program that gave me the opportunity to fulfill that dream to graduate from college, overcoming tremendous failure to achieve it. What she has done with the ASN program profoundly inspires me, and her leadership led to a new partnership with our Central Washington University, Ellensburg (WA) to implement this program on their campus.

The program focuses on four areas: self-advocacy, self-regulation, executive functioning, and social interaction, and has quarterly classes required of students in these areas, and is one of the most unique programs serving students with autism in the United States. I am so proud to say I had the privilege of being part of it. The experience to take classes with those who were like me was a powerful opportunity. The program encouraged me to wake up believing that: "I am worthy of myself", and owe this renewed mindset to our Program Director/Professor Sara Gardner, who is a person that inspires me greatly for what she has achieved with the Autism Spectrum Navigators Program over the last five years since its inception. I am one of many students who graduated from Bellevue College because of the individualized academic support received. I am proud that my alma mater Bellevue College is an institution had the courage to understand who I was, take the notion of "learning differently", and turn it into something that transforms lives, and changes perceptions. Being part of the Autism Spectrum Navigators Program, helped me find that calling in life to advocate for all those with autism and disabilities all over the world.

The Bellevue College (ASN) Program, led to my current institution to reach out to them and seek to create our own version of this transformational program, molded for the PLU community here on

campus. Since January 2016, I have served as the new “SAND” Assistant in the Office of Disability Support Services at Pacific Lutheran University. The “Strategic Access Network Development” (SAND) program, is a new program which is in the process of being designed, and will be launched this September at the start of the 2016-2017 academic year. This new PLU program will focus on the same four focus areas (which the ASN Program has: self-regulation, executive functioning, self-advocacy, and social interaction (socialization)). I am honored to have been given the opportunity to utilize my personal experience as a student with autism, to help my campus community understand life in my shoes. Education and awareness are how we break down those barriers together.

I will conclude with this thought: **“All it takes is five minutes of your compassion to understand us, and that could transform your life.”**

**Thank you.**

**Background:** The continued increase in prevalence figures for ASD and value of early intervention services has increased pressure for accurate and early diagnosis. Several factors increase the complexity of this process, including variation of expressions in the severity and type of symptom and comorbidity. Studies document diagnostic disparities based on age, language, severity, ethnicity, sex, socioeconomic background, IQ, and location. Despite the complexity of the diagnosis many professionals receive little practicum experience for the confounding factors that complicate accurate diagnosis. Documented inconsistency in ASD diagnostic services results in late diagnosis, misdiagnosis and “diagnostic substitution” where a diagnosis may vary as the child ages or is diagnosed by different professionals.

**Presentation Material:** With generous support from NIH, we developed a tool that we hope will help with this critical diagnostic training need. It uses expert interpretations of ASD behaviors defined in 3,000 video clips to duplicate hands-on practicum experience. Individuals with ASD and typically developing from ages 6 months to 55 years displaying characteristics described in the DSM-5 are accessible through a web delivered video library and training courses. Video and print resources clinicians most request including parent feedback guidance and support, analysis of complex case examples and ready to use handouts and treatment aids are available. Courses and quizzes using videos from hundreds of children and adults allow clinicians to practice and improve their skills at their convenience from anywhere. Free secure access is available to any clinician or professional assessing or diagnosing ASD. For IRB subject protections the videos are not available to the general public.

The program is described in a short 1minute video at <https://www.youtube.com/watch?v=FmmFy2nplwE>

**Research Verification:** To measure the value of this video training support, 120 Psychology graduate students took one of two training courses on recognizing DSM-5 ASD behaviors in children ages two to ten years. Half of the students accessed a course that included short videos documenting the behaviors and half used a standard university ASD textbook. Both groups took Pre/Post training quizzes to document skills before and after training. While both video-based and textbook trained groups improved in diagnostic skills after training when compared using expert clinician weighted scoring, the improvement in identifying ASD behaviors was significantly better for the video-based group. The study indicates web delivered, video supported training can improve recognition of symptoms among students in training to diagnose ASD. The extensive video library provides a base for clinicians and educators to create easily accessible training programs to support and improve diagnostic services worldwide.

**Request for IACC Guidance:** ASD Experts who scored the pre/post quizzes showed significant agreement when identifying ASD behaviors using this new tool, indicating that despite variations in present diagnostic services, well trained experts are in general agreement on DSM-5 ASD behaviors. This argues for improved training using guidance from these expert clinicians and strong visual examples of their judgement criteria provided by this program. We seek IACC guidance on how to best disseminate this program within the community.

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

**Karen Heffler, M.D.**

[PII redacted]

**April 19, 2016**

*Is TV and other electronic screen media exposure in babies and young children a contributing cause of autism spectrum disorder (ASD)?*

I am a physician and parent of a 24-year-old with ASD. I recently reviewed the literature in autism, early brain development and neuroplasticity and with a co-author developed a model (1) which explains many of the findings in ASD. I am presenting today as I was asked to do so by some members of the NIH, as we have not adequately studied a significant risk factor for ASD. Television, video and other screen exposure early in life may serve as a trigger for developing ASD and alter brain development in those with a genetic predisposition.

People with ASD have superior abilities in visual (2-5) and auditory tasks (6-8). However, this atypical neuro-connectivity is correlated with the degree of autism symptoms (8-10) and seems to interfere with subsequent brain development (11-12). These brains are sensory overloaded (13).

Infants are attracted to the light and motion on screens (14). Infants do not yet have the brain processing pathways to understand any social relevancy in screen viewing. Actors on a screen do not respond to the coos, smiles or glances of the baby. Yet, research shows that an infant's brain develops according their experiences (15-17). Are they developing purely sensory brain connectivity or meaningful social brain connectivity? Their experiences matter.

Children with ASD pay attention to purely sensory stimuli called audiovisual synchrony instead of the people and social activity around them (18). This is an abnormal behavior not seen throughout the animal kingdom (19-23). What could these children be exposed to that would contribute to their brains developing this way? Could we be inadvertently exposing our children to harm that has not been adequately studied? Children's brains develop according to the environmental experiences of the infant or child and the brain determines behavior. These atypical behavioral responses, which distract the child from social engagement, may be a response to heightened audiovisual screen exposure (1). Research has shown that ASD is associated with younger age of television viewing and more hours of TV viewing (24). Increased TV viewing is also associated with language delay (25,26), behavioral problems (27), ADHD (28) and interferes with parent-child interaction (29-30) and toy play (30-31). Increased television viewing in childhood is associated with structural alterations in the brain that correlate with decreased IQ (32). The association between TV viewing and ASD was first found by Dr Waldman et al. in 2006 (33).

Screen viewing interferes with the face-to-face interaction which is necessary for a child to learn (34, 29-30). This model is consistent with extensive findings in autism including the larger brains (35,36), atypical sensory responses (2-8), repetitive behavior (8,11), time-course of emerging symptoms (35-39), varied spectrum of involvement, and positive effects of early intervention (1).

This model is also consistent with the findings:

- (1) Environmental factors contribute to at least 50% of ASD causation (40-41).
- (2) Increase in the availability of and exposure to screen based audiovisual materials in infancy and young children over the last 30 years parallels the rise in ASD prevalence (42-46).

There are many individuals advocating for their children and adults with ASD. Who is advocating for those at risk? You, the members of the IACC must advocate for children at risk of ASD and designate a research focus on screen viewing as a likely environmental trigger for developing autism. I am working on this research at Drexel and I would like to help the IACC direct attention, and coordinate research efforts to study this critical area of investigation. I am here with compassion for those with young children with ASD and for those at risk. Eliminating/minimizing screen exposure in infants and young children may have significant potential for both intervention and prevention in ASD.

The American Academy of Pediatrics urges parents to avoid screen viewing in children younger than 2 years, but this recommendation is rarely followed.

Please read the full text of the Model of Causation paper attached.

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**Lisa Wiederlight, M.P.P**

Executive Director, SafeMinds

**April 19, 2016**

*Addressing Foundational Issues of Federal Autism Policy and Research*

My name is Lisa Wiederlight. I am a mother to a 15 year old boy with autism, epilepsy, and gastrointestinal disorders. I am also the executive director of SafeMinds, a national, 501 (c)3 nonprofit organization whose mission is to end the autism epidemic by promoting environmental research and effective treatments for people with autism today.

Five months ago, SafeMinds implored this Committee to convene four work groups that will inform the work of the IACC Strategic Plan. I am told that those work groups, Autism and Wandering; Co-Occurring Conditions with Autism; Environmental Contributors; and Caregiver Support, are likely to be formed shortly. For this I am grateful. Today, SafeMinds asks for the inclusion of and consultation with diverse subject matter experts, including, but not limited to, people with autism who are not able to participate regularly in IACC meetings due to the characteristics and/or severity of their autism, caregivers across the country, environmental health experts, toxicology specialists, gastroenterologists, and public safety professionals.

In addition to having quality input into and feedback on its Strategic Plan, the IACC needs high-quality, dependable, and consistent data upon which to make policy and budget decisions. It does not.

On March 31st of this year, the Centers for Disease Control and Prevention announced that autism prevalence has stayed the same as it was in 2012, at 1 in 68 American children. This defies human observation, and befuddles educational and medical professionals. The data comes from the Autism and Developmental Disabilities Monitoring (ADDM) network, which is coordinated by the CDC's National Center for Birth Defects and Developmental Disabilities, and led by Dr. Collen Boyle.

The policy implications of using faulty data on autism prevalence at such a high level of prevalence and urgency cannot be overstated. I will go into more specifics, but the data, as collected, represents an underestimation of autism prevalence, which then results in unfunded mandates for such agencies as the departments of Education, Housing, and Labor, among others.

The ADDM's goal, according to Dr. Boyle's 2012 testimony in front of the House Committee on Oversight and Government Reform, is to "provide comparable, population-based estimates of the prevalence rates of autism and related disorders in different sites over time." In this 2012 testimony, Dr. Boyle herself sites the following reasons for the rise in autism prevalence from 1 in 110 in 2009 to 1 in 88 in a March 2012 report. These reasons, as you will hear, are likely not to have abated since the last prevalence estimate her office provided four years ago. They are, in part, from:

- Improved methods for identification and diagnosis
- Increased public awareness

However, these two factors alone are not responsible for all of the increased prevalence we have seen since the early 1990s.

The most current 1 in 68 figure released less than a month ago in 2016, represents children who were born in 2004, who were diagnosed with autism by age eight, in 2012. This data is therefore four years old. The Strategic Plan will guide the IACC for how many years, and it is based on four year old data? Where is the urgency that this crisis so obviously demands?

Notably, the state with the highest prevalence was New Jersey. New Jersey has kept the most rigorous and consistent case ascertainment practices since its inclusion in the ADDM network. The state continues to see an increase in prevalence—rising 12 percent in two years, from 1 in 45 in the 2010 report, to 1 in 412 in the latest report.

The ADDM report chronically underestimates the rate of autism by including sites that only collect medical records, rather than both medical and educational records. Medical records miss a high percentage of autism cases—17.1 per 1,000 are ascertained using both sources, while only 10.7 per 1,000 using medical records alone.

The variability in case ascertainment methodology among catchment areas also threatens the integrity of the data. This includes how sites access records, how medical records are kept, and the quality of the investigators assigned to a site.

We are equally concerned about the court case which will be held in Utah, brought by former principal investigator for the Utah ADDM site, [PII redacted]. [PII redacted] is alleging that the CDC's ADDM network allowed research misconduct and persistent data errors in their autism prevalence reports, and that she alerted the CDC to these allegations. This raises significant worry about the integrity of the CDC's ADDM reports.

Another study, the National Health Interview Study, puts autism prevalence at 1 in 45. This estimate is based on data from 2014, two years later than the ADDM compilation. This research is coordinated by the National Center for Health Statistics, which is run by Charles Rothwell. To quote the National Health Statistics Report from November 13, 2015, "Children diagnosed with developmental disabilities typically require a substantial number of services and treatments to address both behavioral and developmental challenges. Measuring the prevalence of these conditions in children aids in assessing the adequacy of available services and interventions that may improve long-term outcomes."

Improving long-term outcomes and getting the best return on the taxpayer's investment is what is really most important. Therefore, SafeMinds suggests moving the ADDM to the National Center for Health Statistics so that the research scientists there can compare and contrast the findings of the National Health Interview Study and the ADDM to ensure that estimate of autism prevalence is the most accurate and strongly-supported estimate available to the decision makers at the IACC and elsewhere in the federal government for appropriate resource allocation and better long term results.

Thank you.