



U.S. House of Representatives
Committee on Oversight and Government Reform
"1 in 88 Children: A Look Into the Federal Response to the Rising Rates of Autism"
November 29, 2012 - 2:00 pm

STATEMENT FROM THE NATIONAL AUTISM ASSOCIATION

Chairman Issa, Ranking Member Cummings and members of the Committee;

We thank you for holding this hearing and bringing long overdue attention to the autism epidemic, which continues to explode under the current Administration. We are especially grateful to retiring Representative Dan Burton for his years of service and advocacy, and to Elizabeth Birt, one of our founding directors, who worked closely with Congressman Burton back in 2000 when he first called attention to the plight of families and desperate need of good science.

Founded in 2003, the National Autism Association (NAA) is one of two membership-based autism organizations that serve the national population. A parent-run advocacy organization, NAA represents the severe side of the autism spectrum, which includes nonverbal autism, regressive autism, and comorbid conditions of autism that include intellectual disabilities and underlying medical conditions. In addition to advocacy for medical treatment and environmental research, our key issues include autism safety, autism abuse, and crisis prevention. Our mission is to respond to the most urgent needs of the autism community, providing real help and hope so that all affected can reach their full potential.

Unlike those diagnosed with high-functioning Autism, those who are severely affected cannot be present at your hearing to advocate for themselves, nor can their parents or caregivers. They require around-the-clock care, assistance with basic daily living skills, supervision and protection. Some live

in a constant mode of crisis and physical pain accompanied by irritability, aggression, sleep disorders and horrific self-injurious behaviors. Many are unable to effectively communicate, putting them at staggering risk of becoming silent victims of maltreatment and brutal physical, mental and sexual abuse - without the ability to defend themselves. They often suffer from debilitating comorbid medical conditions that continue to go unacknowledged and untreated due to the blatant failure of our federal agencies to hear the cries for help from this community and direct research funding toward effective treatment.

As of four years ago, an estimated one out of 88 children born in 2000 carried a diagnosis of an Autism Spectrum Disorder (ASD), an increase of 78% from data released only six years prior. These rough data are sure to be an under-ascertainment of children with an ASD since they are largely based on medical records. In 2006, after the Government Accountability Office investigated "Federal Autism Activities," their findings showed that while autism research funding increased, surveillance challenges between agencies like Centers for Disease Control and Prevention (CDC) and Department of Education (DOE), needed to be resolved. An excerpt of note:

CDC's surveillance methodology has relied, in part, on information in student education records, but CDC officials believe that a 2003 change in the Department of Education's (Education) interpretation of relevant federal privacy law has hindered CDC's ability to use this methodology to determine the prevalence of autism. Education stated that the law does not allow CDC to access these records without written parental consent. A 2003 law required HHS and Education to submit a report to the Congress by June 2005 describing ways to overcome the challenges CDC faces in obtaining education records. As of June 2006, CDC and Education had not agreed on options for overcoming these challenges and could not estimate when the report would be completed.

As of 2012, these surveillance challenges have not been resolved. Further, the CDC reports that the prevalence of autism is much higher in sites that have access to education sources. And with the lack of qualitative data, we remain unclear on what percentage of our population will need ongoing care into their adult years and throughout their lives.

Although other countries share similar prevalence numbers, the ASD surge in the United States is still considered to be an illusion of a 20-year-old diagnostic-criteria change, along with better overall awareness and diagnosis. As a community focusing on the more severe effects of autism, we know these explanations to be invalid. The majority of new ASD cases are the result of a very real rise in autism, and, as stated by Centers for Disease Control in their most recent data report, “ASD prevalence continues to rise in most ADDM Network sites, indicating an expanded need for programs serving children with ASDs.” Yet there are no such programs.

The National Autism Association feels that this epidemic denial has prevented the development of critically-needed solutions and resources. The result of soft Federal response continues to come in the form of stalled progress among already affected children, and potential crippling of the entire nation’s future economic health.

In 2005, the average annual medical cost for Medicaid-enrolled children was six times higher than costs for children without an ASD. In addition to medical costs, intensive behavioral interventions for children with ASDs cost \$40,000 to \$60,000 per child per year.

It is for these reasons the National Autism Association cannot help but compare the Federal Response to the Rising Rates in Autism, to FEMA’s response to Hurricane Katrina. With more fatalities of children this year compared to the last two years combined, and abuse and sexual assault cases rapidly increasing, our families are left to face very serious and often dire challenges of autism alone. And with that, we respectfully submit seven (7) recommendations for your consideration:

1. **Declare autism as an epidemic.** We feel this declaration will necessitate actions to mobilize a crisis-level response. CDC has declared epidemics in everything from obesity to distracted driving. With a 78% increase in cases since 2002, Autism needs to be addressed as a true epidemic.
2. **Create a national plan with measurable goals.** Currently there is no formal 10-year, 20-year, or 30-year plan that maps out access to qualitative data, treatment strategies, housing, adult programs, abuse prevention, training for schools and first responders, family services, early

screening, safety initiatives, and access to critical resources on all fronts. Autism still remains an orphan among federal agencies despite its rapidly growing needs that cannot be met under the broader disability umbrella. Unfortunately, the Combatting Autism Act (CAA) is a drop in the bucket.

3. **Create environmental research initiatives.** Studies have shown that among identical twins, if one child has an ASD, the other will be affected about 36-95% of the time. In non-identical twins, if one child has an ASD, then the other is affected about 0-31% of the time. Both suggest environmental triggers play a significant role. In fact, it is a scientific consensus that most cases of autism are caused by environmental triggers in genetically susceptible children. Yet only a tiny percentage of research funds have been spent on determining these environmental triggers, while the majority of funding goes to relatively low-priority, low-impact studies. There has been very little Federal response to the environmental component of autism, thereby stalling targeted approaches in both prevention and treatment.
4. **Provide the autism community with Autism.Gov.** Similar to the AIDS and Alzheimer's communities, our families need easy access to multilingual and literacy-friendly information from federal, state, and local entities. Through the Administration on Developmental Disabilities, Secretary Sebelius awarded an \$8 million grant to the ARC to build the Autism NOW program and web site, a public-address government site specific to autism. While no doubt a fine organization within its area of expertise, ARC has no special expertise in autism. Further, the content of this central web site focuses primarily on the higher-functioning adult community and remains out of touch with the lower-functioning and severely affected population. Should families who are new to the autism diagnosis Google "autism," they will not find this government website that has cost taxpayers millions of dollars. With a 78% increase since 2002, we feel administrations should take autism seriously enough to award our community Autism.Gov as a central source of information covering a wide range of topics, starting from diagnosis and early intervention, to treatment, safety and housing options.
5. **Fund Studies that Compare Health Outcomes Between Vaccinated & Unvaccinated Populations.** Vaccines can cause immune and/or inflammatory injuries to the brain that

eventually manifest as an autism diagnosis. Bipartisan colloquia during passage of the CAA called on the new IACC to leave "no stone unturned" in resolving how many cases of autism are being caused by vaccines. Despite fierce demands from parent advocates on IACC, this vital research remains unfunded. Although the Vaccine Injury Compensation Program has paid hundreds of millions in judgments and settlements of cases resulting in a diagnosis of autism, the CDC continues to falsely claim there is "no evidence" that vaccines cause autism. What remains unknown is the true magnitude of vaccine-caused autism. This causation rate can most readily be determined by a comparative health outcomes study of vaccinated vs. unvaccinated children, even if based on historical data.

6. **Create A 24/7 National Autism Taskforce.** IACC's four-per-year meetings are insufficient. The Committee is also limited in what it can do, as pointed out in the still-valid 2006 GAO report,

"The primary vehicle for coordinating federal agencies' autism activities is the Interagency Autism Coordinating Committee (IACC), and although it has enhanced communication and coordination among federal agencies, coordination remains limited."

While the Committee's primary mission is to facilitate the efficient and effective exchange of information on autism activities among the member agencies, autism remains somewhat of an orphan among federal agencies, having no parent agency to take

"lead responsibility for addressing the service needs of adults with autism or services for children beyond education."

IACC also oftentimes falls prey to discussions and commentary that offer no transition into direct and meaningful application on the ground. The 2006 report noted,

"Federal agencies support services for people with autism primarily through broader programs that focus on disabilities, and some services may not always be available to meet the needs of this population."

In short, we need a lead agency, and a 24/7 taskforce that works on autism and only autism.

7. **Create Training Programs for Educators and First Responders.** NAA, a member of APRAIS is seeing more parents in the autism community – especially those caring for someone with high-anxiety, or high-aggression autism – opting for homeschooling. We’ve gone from segregation to inclusion to isolation, which goes against the very goal of peer interaction and inclusion. With mounting news headlines covering cases of children stuffed into a duffel bag, or force-fed hot sauce or vinegar-soaked cotton balls as a form of “therapy,” our trust has become broken. A 2009 Government Accountability Office investigation reported that thousands of students have been physically injured and emotionally traumatized as the result of restraint, seclusion, and aversive interventions, yet a common-sense federal law that would prohibit airflow restriction has become impossible to pass.

In closing, the National Autism Association believes these seven actions are critical in responding to the current autism crisis and epidemic.

Respectfully submitted,

A handwritten signature in black ink that reads "Lori McIlwain". The signature is written in a cursive, flowing style.

Lori McIlwain

Executive Director