

CHRISTOPHER H. SMITH
4TH DISTRICT, NEW JERSEY

CONSTITUENT SERVICE CENTERS:
1540 Kuser Road, Suite A9
Hamilton, NJ 08619-3828
(609) 585-7878
TTY (609) 585-3650

108 Lacey Road, Suite 38A
Whiting, NJ 08759-1331
(732) 350-2300

2373 Rayburn House Office Building
Washington, DC 20515-3004
(202) 225-3765

<http://chrissmith.house.gov>



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Global Autism: ‘A Developmental Disability Pandemic’

67 Million People Affected According to Autism Speaks

Opening Statement by Chairman Christopher Smith
Africa, Global Health and Human Rights Subcommittee
May 31, 2011

Good afternoon, and welcome to our witnesses and to everyone who is joining us for this first ever congressional hearing examining the magnitude and severity of the global public health crisis of autism.

Autism is a complex neurodevelopmental disorder that impairs a person’s ability to communicate and to relate to others; the condition is often associated with rigid routines or repetitive behaviors. Autism is a spectrum disorder that affects each individual differently. The types and severity of symptoms vary from case to case and range from mild to extremely profound.

According to the Centers for Disease Control and Prevention, forty percent of children with an autism spectrum disorder (or ASD) do not talk at all, and another 25-30% speak some words at 12 – 18 months, but then lose that speech. Autism occurs in all racial, ethnic, and socioeconomic groups, but on average affects 4 to 5 times more boys than girls.

I became involved in, and immediately concerned with, autism in 1982, when I visited Dr. David Holmes, founder of Eden Institute, now Eden Autism Services, in Princeton, New Jersey. I am very pleased that Dr. Tom McCool, Eden’s current CEO, will tell us today how Eden is using its 36 years of experience to improve autism service programs around the globe. I became more deeply involved in 1998, when a family in my congressional district, Bobbie and Billie Gallagher, told me of their concerns about a perceived explosion in the prevalence of autism cases in Brick Township. After that meeting, I requested CDC and the Agency for Toxic

Substances and Diseases Registry to conduct an investigation, which revealed that the prevalence of autism in Brick - 1 in 149 - was indeed much higher than what was generally believed to be the prevalence.

As a consequence of the Brick study and CDC's admission that there were no recent prevalence studies in the US with which to make a comparison, I introduced legislation to authorize grants for autism and pervasive developmental disabilities surveillance and to establish centers of excellence in autism and pervasive developmental disabilities epidemiology. This legislation, the Autism Statistics, Surveillance, Research, and Epidemiology (ASSURE) Act of 1999, was incorporated into Title I of the Children's Health Act of 2000, which also established the Centers of Excellence in Autism Research in NIH and created the Interagency Autism Coordinating Committee. To continue to monitor implementation of these new federal autism programs, I established in 2001, along with my colleague Mike Doyle, the congressional autism caucus to raise awareness of autism and provide a forum for advocacy within Congress.

The Combating Autism Act of 2006 reauthorized the autism programs created by the Children's Health Act and also expanded the Act, calling for research into possible environmental causes of autism and creating an "Autism Education, Early Detection, and Intervention" program to improve early screening, diagnosis, interventions, and treatments for ASDs.

Just last week, I introduced a package of three comprehensive autism bills:

- The Combating Autism Reauthorization Act (HR 2005) will ensure continuation of the important federal autism programs for education, early detection, surveillance, and research.
- The National ASD Initiatives Act (HR 2006) makes the HHS Secretary the head of the national autism effort and ties budget authority to the Strategic Plan for Autism Research.
- The ASD Services Act (HR 2007) establishes grant programs to provide important services for children, transitional youth, and adults and establish training programs for service providers.

On a trip to Lagos, Nigeria, in 2007, I met with Mr. Chidi Izuwah, the parent of an autistic child. Mr. Izuwah is the Executive Director of the Public Private Partnership Resource Center in Abuja and his wife, Dr. Doris Izuwah is the Executive Director of the Olg Health Foundation & Autism Center in Port Harcourt. They told me of the large numbers of Nigerian children suffering with autism and of the lack of government or other supports. As a result of my discussions with the Izuwah's, I introduced in February 2008, the Global Autism Assistance Act (HR 5446), which directs the Administrator for the United States Agency for International Development to establish and administer a health and education grant program to support activities by nongovernmental organizations and other service providers focused on autism in developing countries and also establishes a "teach the teachers" program to train health and education professionals working with autistic children in developing countries. I will be reintroducing this legislation later this week.

While this is the first of its kind hearing, I plan on scheduling additional hearings on this escalating health crisis and on the “Global Autism Assistance Act.”

Clearly, progress has been made in recent years in increasing awareness and, particularly in some of the more developed nations, in improving services and treatments for autism. However, at the same time, we must take seriously the World Autism Organization’s assessment that in every part of the world the situation for dealing with autism remains inadequate, even in those countries with considerable experience and understanding of autism, because the systems that have been established are being completely swamped by the number of people in desperate need of support.

There are a wide range of autism prevalence figures between countries and individuals studies. Here in the US, CDC estimates that close to 1% of the population is affected by an ASD. Autism Speaks, the nation’s largest autism science and advocacy organization, describes a scientific consensus that 1% of the world’s population, or 67 million people, are affected with some form of an ASD. According to the World Health Organization, “tens of millions in Africa” are affected by autism.

In that context, autism is a “developmental disability pandemic.” It is largely under recognized, under appreciated in its impact, and under resourced.

Caring for individuals with autism often takes a high physical, emotional and economic toll on families and other caregivers. More severe forms of autism may multiply many times over the level and intensity of required care.

In developed nations, Autism can overwhelm families, as their lives become consumed with the considerable challenges of identifying appropriate biomedical and psychosocial treatments, schooling and other needed support systems for their autistic child – and eventually for an autistic adult.

In less developed countries, the situation is more desperate because very often there are no resources outside of the family to help. And, rather than a diagnosis of a developmental disorder, the child and the family may face cultural stigma and discrimination pushing the family and the child further into isolation and desperation.

We know that early interventions are effective in improving the functionality of the child and that the positive outcomes from early interventions can last throughout the life of the individual, but very few children in Africa and in developing countries in other parts of the world have access to such interventions. Even in more economically developed nations, there are large disparities in the quality of care.

Concerted actions are required to overcome the global challenges to effectively address autism and other developmental disabilities. We need to continue to help increase awareness of autism at all levels and in all countries, to advocate for the inclusion of developmental disabilities in national and state health policies, to increase the availability of quality services

across a continuum of care and across the lifespan, and to continue to support scientific research that will lead to more effective treatments, and one day, to effective strategies for prevention.

The benefits of international collaborations and cooperation are multidirectional. In fact, I am looking forward to learn about Northern Ireland's Autism Act of 2011 from Arlene Cassidy, CEO of Autism Northern Ireland. I am pleased we will have Ms. Cassidy join us today by videoconference, as I and congressional Autism caucus co-chair, Mike Doyle, signed a Memorandum of Understanding with The Northern Ireland Assembly to share information and to support common interests regarding autism.

In addition to Tom McCool and Arlene Cassidy, testifying today will be Ms. Brigitte Kobenan, founder of the Autism Community of Africa, and Andy Shih, PhD, Vice President of Scientific Affairs for Autism Speaks. I am looking forward to hearing the valuable perspectives that each of our witnesses brings to this discussion. Although they are not here today, I also would like to recognize the Autism Society for their invaluable work in advocating on behalf of individuals with autism both in the US and within the international community.