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Statement of Congressman Chris Smith
Tenth Anniversary of the National Center on Birth Defects and Developmental Disabilities
PSE&G Children’s Specialized Hospital in New Brunswick
April 29, 2011

Good Morning. Thank you, Dr. Boyle for that introduction. I am pleased to join so many New Jersey and national leaders dedicated to improving the lives of individuals with autism and their families.

I would like to thank you Dr. Boyle and Dr. Yeargin-Allsopp and other staff at the National Center on Birth Defects and Developmental Disabilities for the important, foundational work which you do to provide researchers, service providers, and those who develop policy here in New Jersey and across the country with research results and data that guide us as we strive to improve the assistance provided to individuals with autism.

It has long been a truism of mine that you can’t effectively address a problem until you understand that problem well. Good data is an absolute prerequisite for good policy, so we are all indebted to the National Center for the breadth and depth of their autism programs.

I am gratified to be here to participate in the celebration of the ten year anniversary of the creation of the National Center on Birth Defects and Developmental Disabilities, and, in particular, the work the Center does to improve our understanding of autism.

I would also like to thank Amy Mansue for hosting this event here at Children’s Specialized Hospital, which is recognized as having one of the most comprehensive and coordinated autism programs in the State, providing not only multidisciplinary care and treatments, but also conducting cutting-edge research and clinical trials. Thankfully, for the residents, Children’s Specialized Hospital has three of its eight facilities located near or within my congressional district – in Toms River and Hamilton.

I also would like to thank Peter Bell, Vice President of Autism Speaks, and Jeff Sell, Vice President of the Autism Society, for inviting me to celebrate with you today. Both of these organizations are national and international leaders in serving the autism community. I have benefitted greatly over the years from their expertise.

I am honored to be here with NJ Commissioner of Health and Senior Services, Mary O'Dowd, and with Gary Weitzen, Executive Director of NJ Parents of Autistic Children, and Dr. Linda Meyer, Executive Director of Autism New Jersey. These are the organizations and people who make NJ a national leader in services for individuals with autism and their families. Gary and I actually go back 25 years when we worked on issues related to the GI Bill of Rights, then our paths converged again on the crisis of autism.

While it is good to pause and recognize the important work that is being done and the dedicated professionals and volunteers who are so committed to helping individuals with autism and their families, we are never far from the reality that we are neck deep in the midst of a serious and devastating public health crisis. The most recent data from 2006 are that 1 in 110 of our children or approximately 1 percent of the population suffers with an autism spectrum disorder.

As many of you know, Dr. Michael Ganz of the Harvard School of Public Health, calculated that it can cost $3.2 million to take care of one autistic person over his or her lifetime. Dr. Ganz estimated the total cost to society of autism at $35 billion annually. Other estimates put the total cost at $90 billion annually.

Looking at medical expenses alone, a CDC study of employer-based health insurance showed that individuals with an ASD had average medical expenditures that exceeded those without an ASD by $4,100 to $6,200 per year. Several multiples higher per capita costs, coupled with skyrocketing prevalence rates and earlier identification can be expected to greatly increase the costs of autism to the health care system. We must prepare ourselves so that the quality of care is not compromised.

The cost of caring for those with autism is staggering. Thankfully, New Jersey has been a national leader in autism services and research. We have some of the top schools in the nation and we have some of the most experienced and competent professionals in the field of autism in our non-profit organizations, in our medical institutions, and in our universities.

Yet we know we know that we also are on the precipice of a crisis within a crisis – and that is the growing population of individuals with autism who will age out of the school system and face life as adults with autism. As a nation, we are still seriously lagging in our care of children with autism, but we are even further unprepared to address the needs of adults with autism. I know many parents are scared to death and look toward the future with apprehension and fear.

The other day my office received a call from a parent of a child who has a severe form of autism. I know you all know this, but I would like to say that we need to have a special concern for those parents who have a child or children with a more severe form of autism, a child who exhibits more extreme anti-social behaviors, or a child who suffers from dual diagnoses of multiple, serious disabilities. They are the parents who frequently do not know how they will get through one more day, much less how they will prepare for the future.

In many ways, as a nation, we have only just begun to scratch the surface of meeting the needs of families with autistic individuals. However, New Jersey again was a leader in establishing a Task Force on Adults with Autism, which produced recommendations for a plan of action to address the needs of adults with an ASD, and that in creating an Office of Autism within Division of Developmental Disabilities to act as the lead ASD agency for the State. We must find ways to support these new initiatives as we move forward.

I would like to change gears somewhat and to speak for a few minutes regarding my experiences in Congress working to address autism.

Personally, I became deeply involved in autism in 1982, when I first visited Eden Institute in Princeton. Eden is one of the many outstanding autism schools that we are blessed to have in New Jersey.

Then, the magnitude of the autism crisis came into sharper focus for me in 1998, when I was visited by Bobbie and Billie Gallagher from Brick Township, the parents of three children, two with autism - a boy and a girl, who are now 19 and 20 years old. The Gallagher's told me of their concerns about a perceived explosion in the prevalence of autism cases in Brick Township.

After meeting with the Gallagher's and other families, I was convinced there was a serious and largely unrecognized problem and I convened a meeting in my office with the CDC that confirmed that we needed to take immediate action. I requested CDC and the Agency for Toxic Substances and Diseases Registry to conduct an investigation of the autism cases in Brick. As we know the investigation revealed that the prevalence of autism in Brick - at 6.7 per 1,000 or 1 in 149 - was indeed higher than what was generally believed to be the prevalence. To underline the lack of awareness of the scope of the problem, CDC noted in its report that there were no recent prevalence studies in the US with which to make a comparison. Common estimates at the time were that autism prevalence was 1 in 500, and that was considered a high-end estimate.

In follow-up to the launching of the federal study in Brick Township, I introduced in January 1999 the Autism Statistics, Surveillance, Research, and Epidemiology (ASSURE) Act to authorize grants and contracts for the collection, analysis and reporting of data on autism and pervasive developmental disabilities and to establish not less than three centers of excellence in autism and pervasive developmental disabilities epidemiology.

These provisions of the ASSURE Act were incorporated into Title I (the Autism Title) of the Children's Health Act of 2000, which authorized the Autism and Developmental Disabilities Monitoring (ADDM) Network and also the Centers for Autism Developmental and Disabilities Research and Epidemiology (CADDRE) Network. Other provisions of Title I of the Children's Health Act established the Centers of Excellence in Autism Research in NIH and created the Interagency Autism Coordinating Committee.

And very importantly, Title VI, Subtitle B of the Children's Health Act established the National Center on Birth Defects and Developmental Disabilities. While having a wider portfolio, including birth defects, developmental disorders, and blood disorders, the National Center has been an excellent partner in research and education on autism.

With the creation of the ADDM Network, New Jersey became one of six sites for the monitoring of the prevalence of ASDs among 8-year-olds in the year 2000. The principal investigator for New Jersey's ADDM surveillance was and continues to be Dr. Walter Zahorodny at the New Jersey Medical School, UMDNJ. Dr. Zahorodny is extremely committed to having absolutely the best possible data on autism prevalence and demographics, so that we can maximize what we are able to learn about the possible etiology of autism.

The ADDM Network was expanded for study year 2002 to include 14 sites. In February 2007, CDC published data for the 2002 study which showed an average prevalence of autism among the sites of 1 in 152, while New Jersey reported the highest prevalence at 1 in 94.

The most recent data published in December 2009 for results at 11 ADDM sites for study year 2006, showed as I noted earlier an average prevalence of autism of 1 in 110, which is a sharp increase from the 2002 data. New Jersey did not participate in the ADDM network for 2006, but the New Jersey Governor's Council provided funding and results for New Jersey are expected to be published soon. I think we know in which direction the data will trend.

I am pleased that New Jersey has been awarded a 4-year grant from CDC to participate in studies of 8 year olds for the years 2010 and 2012, and also was selected as one of six ADDM sites to conduct a pilot study of 4 year olds.

The ADDM Network has been a successful collaboration of federal, state, and local organizations. The combined data from the various ADDM sources promises to provide researchers with revealing information about possible causes of autism and factors contributing to increases in autism. Hopefully, we also will see valuable information coming from CDC's CADDRE Network and the Study to Explore Early Development, which will be the largest collaborative scientific study to date of the causes of autism.

It is only with this type of knowledge, combined with other research and studies, that we will be able to develop effective interventions to interrupt autism development pathways and to develop more effective treatments to help our children and our neighbors reach their potential fulfillment.

At the time that I asked for the Brick investigation, CDC was spending less than $300,000 per year on all of its autism activities - year after year. I believe that the $22 million that CDC spent last year on autism will be shown to be well spent. We should also remember that CDC accounts for only about 10 percent of the autism expenditures for the federal Department of Health and Human Services.

To provide a focus for autism efforts on Capitol Hill, in the immediate aftermath of passage of the Children's Health Act, I co-founded in 2001 the Congressional Coalition for Autism Research & Education or CARE, which currently has over 150 members.

CARE worked hard to get co-sponsors for the Combating Autism Act of 2006 and to have the bill brought to the floor of the House. As you may know, the Combating Autism Act or CAA reauthorized and strengthened the autism provisions of the Children's Health Act. Additionally, the CAA directed both CDC and NIH to investigate possible environmental causes of autism, and the law authorized a robust autism education, early detention, and intervention program at the Health Resources and Services Administration.

The CAA has resulted in significant improvements in autism surveillance, education, and research. Prior to the CAA, HRSA was not sure what it was spending on autism or even what it was doing. Under the CAA, HRSA's Maternal and Child Health Bureau has developed coordinated programs of education, early detection, and research on evidence-based interventions.

Under the Children's Health Act and the CAA, NIH also has significantly expanded its autism research portfolio – tripling ITS ITS investment in autism research, including development of a Strategic Plan for Collaborative Research on ASDs that recently came out in its third iteration. And, I believe that the release of CDC's surveillance reports in February 2007 and in December 2009 reinforced to NIH the urgency of finding the causes of autism and developing effective interventions.

The top autism-related priority in Congress this year is to reauthorize the CAA. Lacking reauthorization, CDC's autism surveillance and epidemiology programs, as well as HRSA's education, early detection and intervention programs and the Interagency Autism Coordinating Committee will all sunset after September 30, 2011.

I have been working with Autism Speaks, the Autism Society and others on strategizing how best to package reauthorization of the Combating Autism Act and possible enhancements. I plan to move forward with a reauthorization bill in the near future.

You may also be interested to know that as Chairman of the Subcommittee that includes Global Health and Global Human Rights, I intend to conduct a hearing on the global problem of autism within the next two months. I recently met with CDC Director Frieden to discuss CDC's expanding role in global health and the value of international collaborations on addressing global public health crises, including autism. We will use the hearing to bring the issue of autism to the forefront in Congress and to build support for our legislative agenda.

We have come a very long way from when the Gallagher's told me of their concerns regarding autism in Brick, but we can not kid ourselves, we have a very long and arduous road ahead of us. We must continue the public-private partnerships and collaborations at the federal, state and local levels that will be necessary to continue to make progress. And we must remain committed until we see the research come to fruition and until we are providing the services so that all families affected by an ASD or other developmental disability can live with dignity and a reasonable level of comfort.