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## *House of Representatives*

*Enact Smith-Doyle*

### **Urgent Need to Continue Research and Develop Services to Combat Autism**

HON. CHRIS SMITH OF NEW JERSEY  
(*Excerpts*)

Mr. Speaker, I rise today in support of H.R. 2005, the Combating Autism Reauthorization Act of 2011. This legislation is critically important to continue without interruption the progress we have made in understanding autism and in developing interventions that will have the greatest impact in helping individuals affected by autism or another developmental disability.

When I first got elected to Congress in 1980, the community accepted that autism prevalence rates in the United States were 3 in 10,000. Today, it is estimated to be 1 in 110, and in some places like New Jersey, 1 in 94 – for a total of 1.5 million individuals in the United States and autism is on the rise everywhere. On May 31 of this year, I chaired a hearing entitled, “Global Autism: ‘A developmental Disability Pandemic,’”

and my committee received testimony that some 67 million people suffer from ASD worldwide.

In 1998, the wonderful parents of two autistic children in my district, Bobbie and Billy Gallagher, asked me to look into what appeared to be an autism prevalence spike in Brick, New Jersey. I asked CDC and the Agency for Toxic Substances and Disease Registry and others to investigate, and not only did their probe show what appeared to be elevated numbers of children with the disorder in Brick, but the data strongly suggested a much wider problem than anticipated in other parts of the state.

In 1999, I introduced the Autism Statistics, Surveillance, Research and Epidemiology (ASSURE) Act to establish centers of excellence and create a federal

advisory committee, which became Title I of the Children's Health Act of 2000.

Five years later, the initiative was reauthorized and expanded in the Combating Autism Act – the law we respectfully ask members to renew today.

According to the National Institutes of Health, Autism Spectrum Disorder (ASD) is “Characterized by impaired verbal and nonverbal communication skills and social interactions and restricted, repetitive and stereotyped patterns of behavior, ranging in impact from mild to significantly disabling.”

The total cost to society of ASD is has been estimated from 35 to 90 billion dollars annually. 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. Looking at medical expenses alone, a CD 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.

A decade of research, surveillance, treatment and education has had a significant positive impact on the ASD affected person, as well as his or her family – who, as we all know, face huge financial and emotional challenges of their own.

The Combating Autism Reauthorization Act of 2011 will continue the success of the CAA of 2006 by authorizing funding for programs at NIH, CDC, and HRSA for three

additional years. Total funding for the legislation will be at the fiscal year 2011 appropriated level of \$231 million for each of fiscal years 2012, 2013, and 2014. The Reauthorization Act will authorize appropriations of \$22 million for the Developmental Disabilities Surveillance and Research Program; \$48 million for Autism Education, Early Detection, and Intervention; and \$161 million for NIH research and the Interagency Autism Coordinating Committee.

This is not considered “new” money, but rather a straight-line reauthorization of total funds for the legislation, in compliance with the “cut-go” requirements of the 112<sup>th</sup> Congress. The Combating Autism Reauthorization Act also retains sunset and reporting provisions that ensure appropriate review and accountability.

H.R. 2005 reauthorizes the Interagency Autism Coordinating Committee (IACC) – a panel of government and public members, tasked with coordinating all ASD-related activities within HHS, as well as developing and annually updating a strategic plan for ASD research. In order to enhance the quality, efficacy and applicability of research grants – and to avoid waste and duplication, the IACC has crafted 3 strategic research plans in 2009, 2010, and 2011.

For example, in 2009, the strategic plan included 40 research objectives, including the development of new diagnostic tools, identification of genetic and environmental risk factors, and

assessments of services for people with ASD of all ages in a community setting.

The 2010 IACC strategic plan 32 new objectives, including health disparities in early diagnosis and treatment of co-occurring conditions, such as epilepsy and sleep and gastrointestinal disorders.

And the 2011 strategic plan added another 16 objectives, including studies on the use and accessibility of alternative and augmentative communication (AAC) tools for nonverbal individuals.

The IACC also summarizes advances in ASD research identified as having the greatest impact on the field of autism, which has included the association between family history of autoimmune disease and ASD, genetic risk factors, racial disparities, and novel ways to diagnose ASD using speech patterns. Just for fiscal year 2010, NIH awarded 528 grants from baseline funding to pursue promising research related to autism.

This reauthorization bill also continues support of the critical surveillance and epidemiology programs that were established by the Children's Health Act and strengthened by the Combating Autism Act.

The Autism and Developmental Disabilities Network (ADDN) has published the most comprehensive and highest quality estimates to date of the prevalence of ASD in multiple areas of the US.

The Centers for Autism Developmental Disabilities Research and

Epidemiology has implemented the Study to Explore Early Development (SEED), which is the largest study planned to date of the causes of autism, including genetic and environmental risk factors. The study has enrolled 2700 families and initial findings are due next year.

The CAA also focuses on programs in education, early detection and interventions that have already impacted the lives of hundreds of thousands of individuals with autism and other developmental disabilities and their families.

CDC's health communication campaign, "Learn the Signs. Act Early," educates parents, health care professionals, and early childhood educators about the importance of monitoring a child's developmental milestones, seeking further evaluation where there is a concern, and seeking early intervention services as soon as possible.

The Maternal and Child Health Bureau of the Health Resources and Services Administration developed and implemented the Combating Autism Act Initiative, which is conducting research on and providing training to health professionals in the use of valid, reliable screening and diagnostic tools and in the provision of evidence-based interventions for children with ASD or another developmental disability.

As a result of increased awareness of the public, of educators, and of health care professionals, the median age for diagnosis

of autism – which currently is about 4.5 years - appears to be on the decline. However, it is important to continue our efforts, as there is still on average a 2 year time gap from developmental concerns to actual diagnosis, research has demonstrated the positive impact of implementing behavioral intervention before age 3, and Applied Behavioral Analysis has shown significant improvement for children as young as 18 months.

In summary, under the Children’s Health Act and the Combating Autism Act, our scientific infrastructure for addressing autism and other developmental disorders has developed and we have made major advances in our understanding of ASD. For the first time, we have high quality data on prevalence and data to support analysis of causes of autism, and a clearer picture of

promising paths and gaps in research. Health professionals have a level of knowledge for greatly improved diagnostics and interventions to provide meaningful medical and behavioral benefits. There is optimism that a sustained focus on genetic and environmental triggers will lead to efficacious treatments and prevention strategies. Importantly, the infrastructure and programs are in place to continue our progress.

I want to thank our Speaker Boehner and Majority Leader Cantor, as well as Energy and Commerce Chairman Upton, Health Subcommittee Chairman Pitts for the leadership that have shown in moving this legislation forward. I also would like to thank my friend and autism caucus co-chair, Congressman Mike Doyle, for his work in developing and supporting this legislation.