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Autism CARES Act on House Floor

Congressman Chris Smith (NJ-04)
Floor Debate of H.R. 4631
Excerpts of Remarks
June 24, 2014

Mr. Speaker, I rise today to urge passage of HR 4631, the Autism Collaboration, Accountability, Research, Education and Support Act of 2014—Autism CARES ACT of 2014.

Mr. Speaker, previous autism law including the Combatting Autism Act of 2011 made critical investments—continued by this bill—that are working to determine the causes of autism spectrum disorder (ASD), identify autistic children as early as possible to begin treatment, raise critical awareness and develop new therapies and effective services.

According to the National Institutes of Health (NIH), ASD is a range of complex neurodevelopment disorders, characterized by social impairments, communication difficulties, and restricted, repetitive, and stereotyped patterns of behavior. Autistic disorder, sometimes called autism or classical ASD, is the most severe form of ASD, while other conditions along the spectrum include a milder form known as Asperger syndrome...”

The latest prevalence data from the Centers for Disease Control and Prevention (CDC) is shocking: 1 in every 68 American children are on the autism spectrum—a tenfold increase over the last 40 years. Boys on the autism spectrum outnumber girls 5 to 1.

In my home state of New Jersey, 1 in every 45 children has ASD, the highest rate in the CDC study.

I’ve chaired two congressional hearings on global autism—and this developmental disability is everywhere. One conservative estimate: 67 million worldwide.

Looking back, it was two dedicated parents from New Jersey who helped launch the comprehensive federal policy we seek to reauthorize today.

Almost 17 years ago—September 13, 1997—Bobbie and Billy Gallagher of Brick, New Jersey and parents of two small children with autism, walked into my Ocean County district office looking for help. They believed Brick had a disproportionate number of students with autism and wanted action especially for their son Austin and daughter Alana. So I invited CDC and other federal agencies to Brick for an investigation only to learn that prevalence rates were high not only in Brick but in nearby communities as well. Believing we had a serious spike in the prevalence of autism, I introduced HR 274—the Autism Statistics, Surveillance, Research and Epidemiology Act (ASSURE) which was enacted as Title 1 of the Children Health Act of 2000.

Much progress has been made since. Today, the evidence suggests that there is no single cause or type of autism. Genetic risk coupled with environmental factors including advanced parental age, low birth weight and prematurity among other factors may be triggers. Signs of autism in a child usually manifest between 12-18 months—some as early as 6 months—while some “regress” after 2.

Yet, transformative early intervention continues to lag. According to the Interagency Autism Coordinating Committee (IACC): “The clinical reality is that currently only about 20 percent of children with ASD are being identified early (by 3 years of age)” and that members of the House is not good and has got to change. Early diagnosis means early intervention and better outcomes. IACC says “More needs to be done to raise awareness in the practitioner community of the current capabilities and benefits of early, repeated screenings, early diagnosis, and early intervention.”

Research on autism is showing tremendous promise. The most recent IACC strategic plan—which is reauthorized for five years by Section 5—is filled with insight and actionable information:

- “During the past few years there has been a major revolution in ASD genetics research. Using the newest molecular and epidemiological methods, recent data continues to strongly support the role of genes in ASD, and the understanding of this role has been greatly refined.”
- “In infants at high genetic risk for ASD due to having an older sibling with autism, symptoms of autism begin to emerge as young as 6 months of age in those who later develop ASD. These new findings suggest that it may someday be possible to screen for children at risk for ASD before the emergence of the full symptoms of autism and early enough to facilitate even more effective intervention.”
- “Research on the potential relationship between the immune system and ASD has grown considerably over the past 2 years, resulting in several major breakthroughs. In the realm of basic developmental research, immune cells and immune signaling molecules have been identified as essential for establishing stable connections between neurons during early brain development.”
- “Much progress has been made in understanding the prevalence and biology of conditions that commonly co-occur with ASD, including epilepsy, sleep disorders, gastrointestinal (GI) disturbances, attention deficit hyperactivity disorder, and other psychiatric comorbidities.”
- “The time around conception and during pregnancy are likely the most important time windows of heightened vulnerability for the development of the brain with supporting evidence from early reports linking autism symptoms to maternal ingestion of drugs.”

- “Particularly intriguing are the results of prenatal vitamin intake through supplements and diet, showing a 40 percent reduction in risk of ASD with prenatal vitamin supplements taken in the 3 months before or during the first month of pregnancy.”
- “A trend of decreasing ASD risk as mothers consumed greater daily folic acid intake from foods, vitamins, and supplements in the first month of pregnancy was also reported.”

Over the past 5 years, progress has been made toward developing tools and practices for more effective screening and early diagnosis—and I am pleased that the Committee reports includes language that will ensure federal agencies pay particular attention to the need to focus on early diagnosis and intervention in children.

While biological differences in individuals with ASD were hypothesized earlier, there is now *“data demonstrating specific changes in the genome and epigenome, gene expression, cell structure and function, brain connectivity, and behavior that have been linked to the causes and underlying biology of ASD.”*

I mentioned Bobbie and Billy Gallagher’s children earlier because they represent a generation of young men and women who are aging-out—both are now over 21 years old, which means far too much of their support system no longer exists.

Mr. Speaker, every year 50,000 young people on the autism spectrum matriculate to adulthood.

Jonathan Kratchman, a 16-year-old with Asperger’s from New Jersey, was the keynote speaker at a “Dare To Dream Conference” at Mercer County Community College last year, where he stated: “I know I can be a great contributor to society when I graduate. However, I need continuing support to get there... Here is a fast fact. If you take your high school diploma at age 18, you automatically lose services from your school district.”

Both individuals with autism, like Jonathan, and their parents find themselves confronted with almost unimaginable challenges including loss of school instruction, housing and job needs. We are in the midst of huge yet largely invisible crisis that begs serious focus and remedies.

The Autism CARES Act tasks multiple federal agencies to comprehensively study and report back to Congress on the special needs of autistic young adults and transitioning youth.

While studies show that young adults with autism appear to fare worse in employment outcomes—including when compared to young adults with other types of disabilities—there is evidence that with specialized support programs employment is feasible even among individuals with higher support needs.

I’m planning a congressional hearing next month in my global health committee on employers like software giant SAP which has actively recruited and hired over 700 young adults on the autism spectrum and recently told me these diligent young employees are extraordinarily effective workers.

Well planned transition programs will not only assist families and help shape a brighter future for individuals with ASD, they are also a smart investment that will reduce government spending in the long-term. The University Centers for Excellence in Developmental Disabilities recently estimated that: *“Diverting just one young person into living-wage employment could save an average of \$150,000 in SSI benefits over their lifetime. According to the Social Security Administration, transitioning just one half of*

one percent of current SSDI and SSI beneficiaries from benefits to self-sustaining employment would save \$3.5 billion in cash benefits over the work-life of those individuals."

IACC recently concluded that since 2009, the adult services research field has made some important advances, including gathering of new data on the services available across the states, information about how adults are interacting with the service system, and data on the service needs of adults on the autism spectrum.

But in light of the severity of the aging out crisis, we must do more and do it fast and ensure we are providing a comprehensive and thorough review of available services—and those that need to be established. Additionally, Chairman Upton and Chairman Pitts are in the process of requesting a comprehensive autism aging-out GAO report that will include key stakeholder involvement.

We are making real progress, but we still don't have all the answers.

Specifically, the Autism Cares Act of 2014 authorizes funding for each of fiscal years 2015 through 2019 at \$22 million for the CDC, \$48 million for the Health Resources and Services Administration (HRSA) and \$190 million for the National Institutes of Health (NIH) and IACC activities—for a total of \$1.3 billion.

I especially want to thank Majority Leader Eric Cantor, Chairman Fred Upton and former Chairman Henry Waxman as well as Chairman Joe Pitts—all strong and committed friends of persons with autism—for their critical support of this legislation.

Special thanks to my friend Mike Doyle. Since 2000, Mike and I have co-chaired the 91 member congressional autism caucus—the Coalition on Autism Research and Education (CARE).

I am very grateful to the many excellent, professional staff who played key roles in helping move the bill and negotiate text including Gary Andres, Cheryl Jaeger, Brenda Destro, Jean Roehrenbeck, Katie Novaria, Cate Benedetti and of course Neil Bradley.

I also want to express my deep appreciation for the extraordinary contributions made by Autism Speaks, the Autism Society, the Association of University Centers on Disabilities and the American Academy of Pediatrics—all of whom strongly endorse HR 4631.

Mr. Speaker, passage of this bill today is an investment in a very important group of people who, along with their families, caregivers and friends, face seemingly endless challenges and struggles. I urge support.