H.R. 7213, Autism CARES Act of 2024
Remarks of Rep. Chris Smith (R-NJ) during Floor debate
December 16, 2024

Mr. Speaker,

It all started in September 1997—27 years ago—with Brick Township New Jersey parents Bobbie and Billy Gallagher and their indomitable commitment to help their two children—Austin and Alanna—and everyone else with autism.

We met several times (and continue to plan and strategize to this day), invited the CDC to Brick only to realize that federal autism programs were woefully inadequate—almost nonexistent.

So, I introduced the Autism Statistics, Surveillance, Research and Epidemiology Act (ASSURE) in both 1998 and 1999—with 199 bipartisan cosponsors— that would have established 3 to 5 autism centers of excellence, authorize serious prevalence studies and establish an autism advisory committee—now called IAAC.

I am deeply grateful the ASSURE Act was incorporated in large part by Chairman Mike Bilirakis as Title 1 of the Children's Health Act of 2000.

In 2016, Bobbie Gallagher, now a Board Certified Behavior Analyst (BCBA) wrote an amazing book: A Brick Wall—How a Boy with No Words Spoke to the World.

Doctors told the Gallaghers not to worry about telltale early warning signs of autism…one doctor was so uninformed and said that her daughter Alanna just needed a "good swift kick in the ass".

She points out that all parents of children with autism face hardship, frequent tears, agony, as well as physical, emotional and spiritual exhaustion.

She recounts however the big moments that she treasures deep within her heart like when 11-year-old Austin called her mommy for the first time—"It was slow and deliberate—mmaameee, and it was beautiful," or when he asked for a cookie.

She writes of the moment when she realized why she is on this earth: "I am here to fight for children with autism."

And fight she and her husband Billy has—like so many other tenacious, brave and remarkable parents who deeply love their children. We wouldn't be here without them.

Mr. Speaker, the Autism Collaboration, Accountability, Research, Education and Support Act—or simply the Autism CARES Act of 2024—is a comprehensive reauthorization and strengthening of America's whole-of-government Autism Spectrum Disorder (ASD) initiative.

As the prime author of the Autism CARES Act of 2024—and previous iterations of the law in 2011, 2014, and 2019—let me extend special thanks to cosponsor Henry Cuellar for his leadership and partnership on this important issue; to the Chairman of the Health Subcommittee, Brett Guthrie for faithfully shepherding this legislation through the committee and for his critical assistance when we hit a snag in the Senate. Special thanks as well to Energy and Commerce Ranking Member Frank Pallone, and it is with the deepest respect and gratitude that I thank Chairwoman Cathy McMorris Rodgers—a tenacious, effective and brilliant advocate for the Autism community.

Let me extend my thanks to Senators Susan Collins and Ben Ray Lujan for their important support in the Senate.

I want to thank committee staff including Molly Brimmer, Kristin Fritsch, and Caitlin Wilson, among others, for their tremendous help and assistance. I'd also like to thank my staff, John McDonough and Scott Badesch, for their incredible dedication to advancing this legislation.

Mr. Speaker, HR 1732—the Autism Cares Act of 2024 pursues critical research goals, and focuses on responsive and effective interventions for an estimated 6.8 million individuals with autism—27% of whom or over 1.8 million are profoundly autistic. According to the CDC, 1 in 36 children in the United States, including 1 in 35 children in my home state of New Jersey, are on the autism spectrum.

H.R. 7213 authorizes more than $1.95 billion over five years for programs at the National Institutes of Health (NIH), Centers for Disease Control (CDC), and the Health Resources and Services Administration (HRSA).

At CDC, the funding will support ongoing developmental disability surveillance and research; at HRSA, the funding will cover education, early detection and intervention services; at NIH, the funding will drive research as well as the coordination of autism-related activities, including the Inter Agency Coordinating Committee (IACC).

Specifically, H.R. 7213:

- Directs the NIH to include in the scope of research issues encountered by individuals and caregivers as they age, mental health concerns, issues related to aging, as well as co-occurring conditions and needs for supports and services, such as care necessary for physical safety and the prevention of self-injurious behavior.

- Increases the number of NIH Centers of Excellence to seven and ensures research reflects the entire population of individuals with autism spectrum disorder and is designed to address the full range of needs faced by individuals, including to ensure the physical safety and to promote the well being of all Americans with autism.
- Includes, for the first time, a professional bypass budget to provide the autism community with a comprehensive budget highlighting priority research areas and resources needed to advance quality of life improvements for all individuals with autism.

- Promotes the adoption of assistive communication technologies to improve communications outcomes for those with communication assistance needs.

My bill also helps adults with autism who were and are today often misdiagnosed, underdiagnosed and overlooked.

Language throughout the bill continues to emphasize that causes, diagnosis, detection, prevention and treatment of autism spectrum disorder must be throughout the lifespan of a person. To this end, Congress has included the study of gerontology – the study of aging, including the physical, mental, and social changes that occur as people age, as an NIH research priority.

H.R. 7213 continues to emphasize the need for early detection and intervention – including the use of advanced technologies in early detection – to provide the highest quality of life possible for those with autism.

The earlier a child can be identified as having ASD, the earlier they can access interventions and services.

Researchers have developed technologies to identify signs of autism in children as young as eighteen months- this is an incredible development and there is more research being done now to determine if autism can be identified even earlier. However, the median age of diagnosis in the United States is not until after 4 years of age, and diagnosis often occurs even later among those without intellectual disabilities or delays in social communication.[1]

The delivery of services and interventions must keep up with a younger patient population, and services and interventions for autistic individuals must continue to improve across their lifespans.

Examples of services and interventions research include approaches to address conditions that affect the quality of life for individuals on the autism spectrum, such as behavior that puts individuals with significant support needs or their caregivers at risk (e.g., self-injurious, elopement, aggression, etc.), or mental health concerns (anxiety, depression, suicidality). The Autism CARES Act emphasizes the need to improve the quality of life for individuals with the full range of needs across the lifespan. Continued research by NIH to study how to improve interventions and the delivery of services is crucial.

H.R. 7213 calls for a report on youth aging out of school-aged services since the pandemic, and recommendations to improve mental health outcomes and address related disparities in mental health care for individuals with autism spectrum disorder, including prevention, care coordination, and community-based services.

Finally, this legislation is strongly supported by a broad range of community stakeholders, including

- Autism Speaks—which said "*The Autism CARES Act is the single most important driver of autism research, training and data collection programs at the National Institutes of Health (NIH), Health Resources and Service Administration (HRSA) and the Centers for Disease Control and Prevention (CDC).*"

- Autism Society said: "The Autism CARES Act is a pivotal law for individuals with Autism and their families to live fully… it is crucial to understand the immense impact this law has on the daily lives of the Autism community."

- the Association of University Centers on Disabilities said: "*This piece of legislation is crucial to maintaining and improving the monitoring, training and research programs… focused on children and adults with autism, and people with other neurodevelopment disabilities and their families.*"

- *Profound Autism Alliance has pushed hard for the Autism Cares Act of 2024 and its enhanced focus on individuals with profound autism which they define as people who "require lifetime, 24/7 care"*