

**CHRISTOPHER H. SMITH**  
4TH DISTRICT, NEW JERSEY

CONSTITUENT SERVICE CENTERS:

MONMOUTH  
112 Village Center Drive  
Freehold, NJ 07728-2510  
(732) 780-3035

OCEAN  
405 Route 539  
Plumsted, NJ 08514-2303  
(609) 286-2571; (732) 350-2300

MERCER  
4573 South Broad Street  
Hamilton, NJ 08620-2215  
(609) 585-7878

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

<http://chrissmith.house.gov>



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## H.R. 1058—Autism CARES Act of 2019

*excerpts of remarks by Rep. Chris Smith (R-NJ)  
during debate on H.R. 1058 in the  
House of Representatives—July 24, 2019*

Autism spectrum disorder (ASD), is “a neurodevelopmental condition characterized by persistent impairments in social communication and social interaction, as well as restricted and repetitive patterns of behavior, leading to difficulty in developing, maintaining and understanding relationships with others” ([Report](#) to Congress).

As [Autism Speaks](#) notes “it is often accompanied by sensory sensitivities and medical issues such as gastrointestinal (GI) disorders, seizures or sleep disorders, as well as mental health challenges such as anxiety, depression and attention issues.”

The Autism Collaboration, Accountability, Research, Education and Support Act—or simply the [Autism CARES Act of 2019](#) —is a comprehensive reauthorization and strengthening of America’s whole-of-government Autism Spectrum Disorder (ASD) initiative.

As prime author of the bill let me extend special thanks to cosponsor Mike Doyle of Pennsylvania for his extraordinary leadership, partnership and friendship and to the Chairwoman of the Health subcommittee Anna Eshoo for expertly shepherding this through the committee with ranking member Dr. Michael Burgess and my deep gratitude to full committee chair Frank Pallone and ranking member Greg Walden.

I also want to thank staff including Kelsey Griswold, Kate Werley, Rachel Fybel, Dr. Kristen Shatynski, and Stephen Holland for their tremendous help and assistance.

And frankly, we couldn’t have done this without so many autism advocates especially Stuart Spielman of Autism Speaks and Scott Badesch of Autism Society.

Mr. Speaker, this bipartisan, bicameral legislation powerfully supports and pursues durable remedies and effective interventions for the approximately [1.5 million children with ASD](#), —that is an estimated [1 in 59](#) children in the United States, [in my home State of New Jersey, 1 in 34 children, the highest rate in the CDC study](#) .

This bill also helps adults with autism who were and are today often misdiagnosed, underdiagnosed and overlooked. Language throughout the bill emphasizes that causes, diagnosis,

detection, prevention and treatment of autism spectrum disorder must be throughout the lifespan of a person.

According to Drexel University's AJ Drexel Autism Center, [about fifty to sixty thousand children “age out” to adulthood each year](#) creating challenges for education, housing, employment and access to health care. Autism CARES of 2019 continues the work on aging out begun under the [Autism CARES Act of 2014](#).

The Autism CARES Act of 2019 assists the parents, families and caregivers who deeply love and cherish children with ASD and want the brightest future possible for them. In addition to its groundbreaking prevalence studies and early intervention work, [CDC's Learn the Signs. Act Early](#) is an amazing tool for parents.

The legislation also robustly supports the dedicated physicians, scientists and support teams who daily strive to treat, research and provide meaningful answers.

The Autism CARES Act of 2019 authorizes a little over \$1.8 billion over five years for the [National Institutes of Health \(NIH\)](#), the [Centers for Disease Control and Prevention \(CDC\)](#) and the [Health Resources and Services Administration \(HRSA\)](#).

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

In September of 1997, Bobbie and Billy Gallagher of Brick, New Jersey— parents of two small autistic children—walked into my Ocean County 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 the CDC, [ATSDR](#) 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 prevalence, I introduced the [ASSURE Act](#), cosponsored by 199 members, which was incorporated as title I of the Children's Health Act of 2000.

Mr. Speaker, much progress has been made since. Today, the evidence suggests there is no single cause of autism or type. Genetic risk, coupled with environmental factors, including advanced parental age, low birth weight, and prematurity—among other factors—may be triggers. Other studies have identified ASD risk factors including pesticides, air pollutants, dietary factors.

Early intervention is making a major positive impact in the lives of children with ASD but parents need more support. In 2016, Bobbi Gallagher wrote a book: [A Brick Wall—How a Boy with No Words Spoke to the World](#). In this highly personal, extraordinarily moving must read account of raising two children with autism, Bobbi writes: “This mom thing is hard.”

Mr. Speaker, Autism CARES Act of 2019 ensures that the federal government continues to help hundreds of thousands of parents like the Gallaghers—funding research and support programs and sharing best practices. The bill reauthorizes and expands the [Interagency Autism Coordinating Committee \(IACC\)](#) managed so effectively and professionally by [Dr. Susan Daniels](#), Director of the Office of Autism Research Coordination (OARC).

Coordination is key to maximizing outcomes. The Director of the National Institutes of Mental Health (NIMH) [Dr. Joshua Gordon](#)—who also serves as IACC chair said yesterday:

“The National Institutes of Health is proud to work hand-in-hand with the Interagency Autism Coordinating Committee to ensure the coordination of research efforts focusing on critical topics related to autism, such as developing early detection and screening tools,

understanding the genetic and biological underpinnings of autism, and developing and testing the effectiveness of services and supports to improve functional and health outcomes of individuals with autism.”

New members of IACC added by our new bill are representatives from the Departments of Labor, Justice, Veterans Affairs and Housing and Urban Development as well as raising from two to three members who are self-advocates, parents or legal guardians and advocacy/service organizations.

IACC not only includes a cross section of knowledgeable stakeholders, but periodically develops the [IACC Strategic Plan for ASD](#) and most recently the [2018 update](#) .

The IACC strategic plan asks the seven most essential questions and helps steer research projects and resources to find answers including:

- How can I recognize the signs of ASD, and why is early detection so important?
- What is the biology underlying ASD?
- What causes ASD, and can disabling aspects of ASD be prevented or preempted?
- Which treatments and interventions will help?
- What kinds of services and supports are needed to maximize quality of life for people on the Autism spectrum?
- How can we meet the needs of people with ASD as they progress into and through adulthood?
- How do we continue to build, expand, and enhance the infrastructure system to meet the needs of the ASD community?

Also, each year since 2007, [IACC has published a Summary of Advances in Autism Spectrum Disorder Research](#).

[Dr. Ann Wagner](#) does an extraordinary job as National Autism Coordinator—created by Autism CARES Act of 2014—ensuring the implementation of national autism spectrum disorder (ASD) research, services, and support activities across federal agencies.

As my colleagues know, the Health Resources and Services Administration (HRSA) is the “primary federal agency for improving healthcare to people who are geographically isolated, economically or medically vulnerable.” The work begun under Autism CARES Act of 2014 continues and is expanded with this legislation including the training of health care professionals “to provide screening, diagnostic and early, evidence-based intervention services...”. This includes the 52 Leadership Education in Neurodevelopmental and other Related Disabilities (LEND) training programs like the one at Rutgers in my state and 10 Developmental-Behavior Pediatric (DBP) training programs.

The HHS Secretary is empowered by the new legislation to prioritize DBP grants to “rural and underserved areas.”

According to the April 2019 Report to Congress, most children who have autism are not diagnosed until after they reach age 4 years—or later—even though many children can be identified before age 2 years...Recent studies supported by NIH have uncovered distinct differences in the brain development of children with ASD, as early as 6 months. The earlier ASD is found, the earlier interventions can begin.

Finally, not later than 2 years after enactment, the Autism CARES Act requires a comprehensive report on the demographic factors associated with the health and well-being of individuals with ASD, recommendations on establishing best practices to ensure interdisciplinary coordination, improvements for health outcomes, community based behavioral support and interventions, nutrition and recreational and social activities, personal safety and more.

Mr. Speaker, more than three dozen major organizations have helped shape this legislation and strongly support passage including:

- Autism Society of America
- Autism Speaks
- Autism New Jersey
- American Academy of Neurology
- American Academy of Pediatrics
- American Association on Health and Disability
- American Psychological Association
- American Therapeutic Recreation Association
- Association of Maternal & Child Health Programs
- Association of Special Children and Families
- Association of University Centers on Disability
- Autism Science Foundation
- Children's Hospital Association
- Council on Exceptional Children
- Easterseals
- EveryLife Foundation
- Family Voices
- Family Voices New Jersey
- Family Voices North Dakota
- Lakeshore Foundation
- Madison House Autism Foundation
- Maine Parent Federation
- Marcus Autism Center
- National Alliance on Mental Illness
- National Association of Councils on Developmental Disabilities
- National Association of Pediatric Nurse Practitioners
- National Association of State Directors of Developmental Disabilities Services
- National Center for Learning Disabilities
- National Council on Severe Autism
- National Down Syndrome Congress
- National Down Syndrome Society
- National Fragile X Foundation
- Network of Jewish Human Service Agencies
- SPAN Parent Advocacy Network
- TASH
- The Independence Center
- The Jewish Federations of North America
- Thompson Center for Autism & Neurodevelopmental Disorders