



# #WhyAutismCARES

## SCIENTIFIC ADVANCEMENTS THROUGH POLICY

[AUTISMSPEAKS.ORG](http://AUTISMSPEAKS.ORG)

**Since 2007, over \$3.1 billion has been dedicated to autism activities at the NIH, CDC and HRSA.**

Since the late 1990s, Autism Speaks and its predecessor organizations have focused on federal efforts related to autism, placing a special emphasis on research, surveillance and training.

The Children's Health Act of 2000 was the first autism-specific legislation ever enacted by Congress. Since then, the autism provisions of that omnibus legislation have been amended and carried forward, in the Combating Autism Act of 2006, the Combating Autism Reauthorization Act of 2011 and the Autism Collaboration, Accountability, Research, Education and Support Act of 2014.

**The Autism Collaboration, Accountability, Research, Education and Support (CARES) Act of 2019.** The Autism CARES Act of 2019 (H.R.1058/S.427) was introduced to continue activities authorized under the Autism CARES Act of 2014.

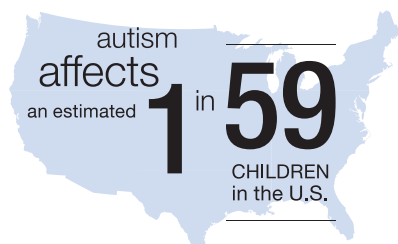
**Without enactment by September 30, 2019, portions of the current law will expire.**

It authorizes funding for autism research and services at the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA), reauthorizes the Inter-agency Autism Coordinating Committee (IACC) and places a new emphasis on improving lifespan services and reducing disparities.

Passing the Autism CARES Act of 2019 is a crucial step to ensuring the development of treatments and evidence-based services for individuals across the spectrum and through the life span.

### **The Impact of Autism CARES:**

**Surveillance and Research at the CDC.** CDC initiatives direct research into potential factors that might put children at risk for autism, help communities direct outreach efforts to those who need it most and provide resources for early-screening and life span services.



The CDC's **Autism and Developmental Disabilities Monitoring (ADDM) Network** estimates the number of children with autism spectrum disorder (ASD) living in different areas of the United States and identifies changes in ASD over time. Through these prevalence studies, we know 1 in 59 children in the U.S. is diagnosed with autism.

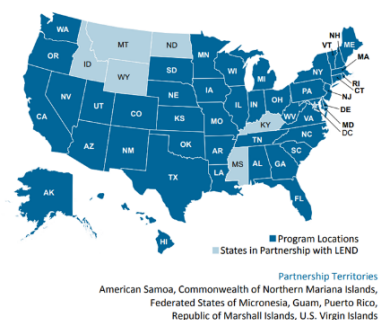


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**In its 2016-2017 Strategic Plan, the IACC recommended doubling the government and private autism research budget by 2020.**

**500,000 families served in the Autism Treatment Network since its founding with 400,00+ toolkits downloaded.**



**Research at NIH's Centers of Excellence.** Funding authorized by Autism CARES has supported NIH research, including center and network grants through the Autism Centers of Excellence program. The Autism Centers of Excellence Program is a NIH initiative **that studies ASD to determine its causes and potential treatments.** The program fosters collaboration between teams of specialists working at the same research center as well as researchers at facilities throughout the country through the ACE research network.

**Interagency Autism Coordinating Committee (IACC).** The IACC was established by the Autism CARES Act to **coordinate all federal efforts on autism** and advise the U.S. Department of Health and Human Services on issues related to autism. IACC meetings are open to the public and cover a variety of topics including recent advances in science, autism policy issues and IACC projects.

### **AIR-P Programs Carried Out by the Autism Treatment Network.**

The Autism Intervention Research Network on Physical Health (AIR-P) is a collaborative funded through the Autism CARES Act that **partners with families, clinicians and researchers to improve healthcare** for children and adolescences diagnosed with autism.

AIR-P's work is carried out by the 12 medical centers in the Autism Speaks Autism Treatment Network. Through network programs like the Autism Learning Health Network and ECHO, **research and clinical best practice findings are translated into improved care.**

### **Programs Supported by the Health Research and Services Administration (HRSA).**

HRSA initiatives increase awareness of autism, reduce barriers to screening and diagnosis, promote the use of evidence-based interventions and train professionals.

**Fifty-two Leadership Education in Neurodevelopmental and Other Related Disabilities (LEND) Programs** train future leaders to improve the health of children who have or are at risk of developing neurodevelopmental disabilities or other similar conditions such as autism. Their interdisciplinary training enhances clinical expertise and builds the capacity of providers to deliver high-quality services.

**Twelve Developmental Behavioral Pediatrics Training Programs** support fellows in developmental-behavioral pediatrics by providing practitioners, residents and medical students with essential clinical, research and leadership skills.