

## **Background and Recommendations for Reauthorization of the CARES Act in 2024**

The **Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act** ([P.L. 116-60](#)) was first signed into law by President George W. Bush in 2006 ([P.L. 109-416](#)). The purpose of the law is to create a coordinated response and increase investments across the U.S. Department of Health and Human Services (HHS) to address the dramatically rising numbers of children and adults diagnosed with autism.

According to the Centers for Disease Control and Prevention (CDC), approximately 1 in 36 children have been diagnosed with autism – an increase of approximately 300 percent since 2006.<sup>1</sup> Autism Spectrum Disorder (ASD), hereafter referred to as autism, is [defined by a certain set of behaviors](#) and is often referred to as a “spectrum condition”. The cause of autism is unknown and is a complex, lifelong developmental condition that typically appears during early childhood and can impact a person’s social skills, communication, relationships, and behavior. Autism impacts each person differently and to varying degrees.

The law was reauthorized in 2019 (P.L. 116-60). The bipartisan bill was passed unanimously in the House of Representatives and in the Senate. The law must be reauthorized by September 30, 2024. Following is a summary of authorized activities under the CARES Act.

### ***Interagency Committee in the U.S. Department of Health and Human Services***

The Interagency Autism Coordinating Committee (IACC) is a Federal advisory committee that coordinates Federal efforts and provides advice to the Secretary of HHS. The IACC is required to (1) develop and annually update a strategic plan for autism research, (2) develop and annually update a summary of advances in autism research, and (3) monitor Federal activities related to autism. Through its inclusion of both Federal and public members, the IACC helps to ensure that a wide range of ideas and perspectives are represented and discussed in a public forum.

### ***Programs in the National Institutes of Health***

The National Institutes of Health (NIH) is the largest biomedical research agency in the world and houses the Office of Autism Research Coordination (OARC), which assists the IACC by communicating information about autism/developmental disability research activities to Congress, government agencies and the public.

The Autism CARES Act supports NIH-funded research including Centers for Excellence that conduct basic and clinical research into autism. This research includes investigations into the causes, diagnosis, early and ongoing detection, prevention, and treatment of autism across the lifespan in the fields of developmental neurobiology, genetics, genomics, psychopharmacology, developmental psychology, behavioral psychology, and clinical psychology.

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<sup>1</sup> “Data and Statistics on Autism Spectrum Disorder”. Centers for Disease Control and Prevention. April 4, 2023.  
<https://www.cdc.gov/ncbddd/autism/data.html>

The Eunice Kennedy Shriver National Institute of Child Health and Human Development supports research on the individual and combined effects of evidence-based interventions in real world settings. The National Institute of Mental Health supports research aimed at developing and testing service system interventions that can be broadly implemented and rapidly engage young children with autism in evidence-based treatment and services early in life.

### ***Programs in the Centers for Disease Control and Prevention***

The Centers for Disease Control and Prevention (CDC) support the Autism and Developmental Disabilities Monitoring Network, a group of programs that estimate the number of children with autism and other developmental disabilities living in different areas of the United States. The CDC has also established the Centers for Autism and Developmental Disabilities Research and Epidemiology Network. These regional centers of excellence are working, in part to, help identify factors that may put children at risk for autism and other developmental disabilities. Learn The Signs. Act Early encourages parents of children ages birth to 5 years and providers who care for them to learn the signs of healthy development (developmental milestones), monitor every child's early development, and act early on possible developmental concerns. A dedicated cohort of 63 Act Early Ambassadors, spanning 49 states and Washington DC, as well as 4 territories and 3 American Indian and Alaskan Native tribal organizations, diligently deliver these resources to their communities through training, community meetings, and widespread resource distribution.

### ***Programs in the Health Resources and Services Administration***

There is a tremendous national shortage of personnel trained to screen, diagnose, and treat individuals with autism and other developmental disabilities. On average, most children are not identified and diagnosed until after age four, even though diagnosis as early as age two is possible.<sup>2</sup> The Maternal and Child Health Bureau of the Health Resources and Services Administration works to increase efforts to provide training to health and other professionals to screen for and diagnose (or rule out) autism and other neurodevelopmental disabilities, and to increase evidence-based interventions for children and adults with autism and other neurodevelopmental disabilities.

The Leadership Education in Neurodevelopmental and Related Disabilities programs and the Developmental Behavioral Pediatrics (DBP) Training programs provide interdisciplinary training to address the needs of children and adults with autism and other neurodevelopmental disabilities. In Fiscal Year 2021, LEND and DBP programs provided diagnostic services to over 137,000 children; provided training to over 22,000 trainees in pediatrics, other health professions and people with lived experience.

Research programs support four research networks to develop an interdisciplinary, multicenter research forum for scientific collaboration and infrastructure building, and provides leadership in research to advance the evidence base on effective interventions for children, adolescents, and adults with autism and other neurodevelopmental disabilities across the lifespan including two Single Investigator Innovation Programs to support focused research on priority, emerging and underdeveloped research areas in autism and other developmental disabilities; one Autism Field-Initiated Research Studies program to support innovative intervention studies; and one Autism Secondary Data Analysis Research Study to conduct secondary analysis of existing databases to determine evidence-based practices for interventions.

In Fiscal Year 2021, research programs conducted 95 studies on physical and behavioral health issues, screening and diagnostic measures, early intervention, and transition to adulthood. The

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<sup>2</sup> "Report to Congress on Activities Related to Autism Spectrum Disorder and Other Developmental Disabilities". Interagency Autism Coordinating Committee. March 2019. <https://iacc.hhs.gov/publications/report-to-congress/2018/diagnosis.shtml>

Autism Intervention Research Network on Physical Health conducts research on effective interventions for children and adolescents with autism and neurodevelopmental disabilities with a focus on addressing the physical health and well-being across the lifespan.

### ***Conclusion and Recommendations for the Reauthorization of the Autism CARES Act***

The Autism CARES Act is the most comprehensive federal law addressing the urgent needs of children, adolescents and adults with autism. Over its 17-year history, this law has resulted in a significant increase in our understanding of autism and related neurodevelopmental disabilities.

However, with one in 36 individuals diagnosed with autism in the United States, the urgency to continue the work in research, surveillance, professional training, and the development of effective interventions and supports must continue and be increased. There is still much more work to be done to improve the quality of lives of individuals with autism across the lifespan and to support their families.