

## **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 Services and Resources 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.

The State Public Health Autism Resource Center is a web-based resource that provides technical assistance to states. It provides resource development, screening tools, and publications, along with a peer learning component that includes site visits and peer-to-peer exchanges.

### ***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.

The Association of University Centers on Disabilities and the Autism Society of America urge Congress to reauthorize this important law before its expiration in September 2024. Please consider the following improvements as you work to reauthorize this important law:

**Increase the Capacity of the authorized Leadership Education in Neurodevelopmental and Related Disabilities programs.** The Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs train the next generation of future leaders in various fields to improve the health and wellbeing of infants, children, adolescents and adults with autism and other neurodevelopmental disabilities. Trainees include graduate students from allied health and other studies, self-advocates, and family members of people with disabilities. We want to ensure that the 60 LEND programs across the country are strengthened and have sufficient resources to train the next generation of leaders across the diverse areas and populations.

**Expand the number of authorized Developmental-Behavioral Pediatric Training Program sites.** The Developmental-Behavioral Pediatrics (DBP) Training Program trains the next generation of leaders in developmental-behavioral pediatrics and builds capacity to evaluate, diagnose or rule out, develop, and provide evidence-based interventions to individuals with autism and other neurodevelopmental disabilities. There is an extreme shortage of providers—with only 700+ board certified developmental-behavioral pediatricians in the United States—trained to diagnose and provide care for children with autism and other developmental disabilities. Expanding the number of sites by two, with a particular focus on areas of the country that do not currently have a DBP Training Program, could help expand the number of trained DBPs and help place DBPs in underserved locations.

**Conduct an Environmental Scan of How to Increase the Number of Developmental-Behavioral Pediatricians.** The Government Accountability Office should conduct a study to examine the factors impacting medical students, residents, and fellows from pursuing training to specialize in becoming DBPs.

**Increase the Number of Centers of Excellence.** There are too many families struggling to care for family members with complex and significant support needs. We recommend adding additional Centers of Excellence. Using report language, direct one new center to increase research into the

most effective evidence-based services that can help individuals and families with Autistic individuals with co-occurring complex medical and mental health needs, intellectual disabilities, and unaddressed communication needs, to live fully and become as independent and productive as possible. A second Center should address premature mortality among autistic individuals.

**Improve Communication Needs.** Twenty-five to thirty percent of individuals with autism are non-speaking or minimally-speaking. Individuals need access to communication assistants and/or devices at school and work. There are currently autism intervention networks focused on physical and behavioral health, but not yet on communication needs, despite the communication disparities between autistic and non-autistic individuals. A new autism intervention research network focused on communication needs (in particular, augmentative and alternative communication, or AAC) should be created. Additional research is also needed to develop evidence-based AAC devices and methods.

**Include the AACCENT Act.** A significant portion of the autistic community is not able to use speech to communicate everything they are thinking and feeling. Nonspeaking autistic people are often not given access to robust AAC devices, or adequate support in learning how to use them. Access to effective communication is a human right. Congress should incorporate the Augmentative and Alternative Communication Centers to Establish National Training Act (AACCENT Act) into the reauthorization. The AACCENT Act establishes comprehensive national training, technical assistance, and resource centers to support all individuals with communication disabilities, including autistic individuals.

**Authorize a Protection and Advocacy Program for Autism.** Individuals with autism make up 38 percent of the cases in the Protection and Advocacy (P&A) for Individuals with Developmental Disabilities (PADD) program. Congress should authorize a P&A program which protects the rights of and advocates for people with autism. Unfortunately, many agencies designated by the governor decline services to individuals with autism and their families due to a lack of designated resources. Authorizing a new P&A program for individuals with autism will increase the capacity of current P&As and allow for the needs of people with autism to be met.