

# AUTISM CARES

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## BACKGROUND

The Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act was first passed in 2006 and was signed into law by President George W. Bush. This law provides a coordinated response and increased investments across the Department of Health and Human Services (HHS) to address the rising numbers of children and adults being diagnosed with autism.

According to the Centers for Disease Control and Prevention (CDC), approximately one in 36 children have been diagnosed with autism – an increase of approximately 300 percent since 2006. Autism 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 Autism CARES Act established the Interagency Autism Coordinating Committee (IACC), a Federal advisory committee coordinating efforts and advising the Secretary of HHS. The Act increased efforts within federal agencies to address the increase and the needs. The National Institutes of Health (NIH) Office of Autism Research Coordination conducts basic and clinical research to better understand autism. The Centers for Disease Control and Prevention increased its surveillance and efforts to identify factors that may put children at risk for autism and other developmental disabilities. The Health Resources and Services Administration (HRSA) is home to the Leadership Education in Neurodevelopmental Disabilities (LEND) and Developmental-Behavioral Pediatric (DBP) Programs, which provide interdisciplinary training to future professionals to ensure that service providers are equipped with the knowledge to diagnose and address the increasing prevalence of autism.

## ISSUES

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.

## WHAT SHOULD CONGRESS DO?

Due to a sunset provision, the **Autism CARES Act must be reauthorized by September 30<sup>th</sup>, 2024**. We urge Congress to reauthorize the Autism CARES Act with the following improvements:

- Increase the capacity for the authorized Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs
- Expand the number of Developmental-Behavioral Pediatric (DBP) Training Programs
- Conduct an Environmental Scan on how to increase the number of Developmental-Behavioral Pediatricians
- Increase the number of Centers of Excellence: one focused on complex medical and behavioral support needs; and one focused on premature mortality
- Establish an autism intervention research network focused on addressing communication needs for youth with autism (AIR-C)
- Authorize a Protection and Advocacy Program for individuals with autism

APRIL 2024

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### FOR MORE INFORMATION PLEASE CONTACT

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National Association of Councils on Developmental Disabilities at (202) 506-5813  
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