

September 1, 2023

Dear Member of Congress,

On behalf of the Autism Society of America, we write to urge Congress to reauthorize the Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act as soon as possible. We also offer the following recommendations to strengthen the law and address the current critical needs of people with Autism.

The Autism Society of America is the nation's largest and oldest organization representing individuals with Autism and their families.

The Autism CARES Act is the most comprehensive federal law addressing the urgent needs of the Autism community. 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 U.S., the urgency to continue the work in research, surveillance, professional training, and the development of effective interventions and supports must continue and be increased.

Due to a sunset provision set for September 2024, this law must be reauthorized without delay. Please consider the following improvements as you work to reauthorize this important law:

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.

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 the capacity to evaluate, diagnose or rule out, develop, and provide evidence-based interventions to individuals with Autism spectrum disorders (ASD) and other developmental disabilities (DD). 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 and 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.

Increase the Capacity of Leadership Education in Neurodevelopmental and Related Disabilities programs

The Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program trains the next generation of future leaders in various fields to improve the health of infants, children, and adolescents with disabilities. Trainees include graduate students from allied health and other studies, self-advocates, and family members of people with disabilities. The law should increase the authorization to ensure that the existing 60 LEND programs across the country are improved and have sufficient resources to serve the diversity of their respective areas.

Communication Needs

Create a new Autism intervention research network focused on communication needs (in particular, augmentative and alternative communication or AAC) - AIR-C. 25-30% of individuals with Autism are non-speaking or minimally speaking. Individuals need access to communication assistants and/or devices at school and work. We need additional research to develop evidence-based alternative augmentative communication devices and methods. 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.

Include 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 Augmentative and Alternative Communication (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 CARES reauthorization. The AACCENT Act establishes comprehensive national training, technical assistance, and resource centers to support all individuals with communication disabilities, including Autistic individuals.

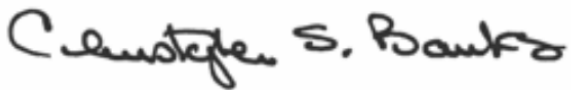
Authorize a Protection and Advocacy Program for Autism

Authorize a Protection and Advocacy program that protects the rights of and advocates for people with Autism. Individuals with Autism make up 38% of the cases in the Protection and Advocacy for Individuals with Developmental Disabilities (PADD) program. Unfortunately, many Protection and Advocacy centers turn away individuals with Autism and their families due to a lack of designated resources. Authorizing a new Protection and Advocacy 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.

Thank you for your leadership on this important law. We hope you will consider these modest recommendations for the reauthorization of the Autism CARES Act. We will do everything we can to help you move a bill to reauthorize this critical law as soon as possible.

Please reach out to [Kim Musheno](#), Vice President of Public Policy with any questions.

Sincerely,



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