



September 14, 2023

Dear Senator Menendez, Representative Smith and Representative Cuellar,

On behalf of the undersigned organizations of the Consortium for Constituents with Disabilities (CCD) Developmental Disabilities, Autism and Family Support Task Force (Task Force), we write to urge Congress to reauthorize the Autism Collaboration, Accountability, Research, Education and Support (CARES) Act as soon as possible this session.

The Task Force believes a swift passage to extend the current programs, with increased funding authorization levels to meet the critical need for research and training should be a priority. The Task Force also submits the following recommendations as examples of policy options for consideration as you work to draft and reauthorize the Autism CARES Act; individual Taskforce members may support additional recommendations.

The Task Force's recommendations include:

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 developmental 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 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 developmental 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 they serve.

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 P&A centers turn away 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.

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 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.

Due to a sunset provision set for September of 2024, this law must be reauthorized without delay. Please consider the above improvements and most importantly reauthorize this important law.

Sincerely,

Access Ready Inc
Allies for Independence
American Academy of Pediatrics
American Music Therapy Association
American Therapeutic Recreation Association
Association of University Centers on Disabilities
Autism Society of America
Autism Speaks
Autistic People of Color Fund (APOC)
Autistic Self Advocacy Network
Autistic Women and Nonbinary Network
CommunicationFIRST
Council of Parent Attorneys and Advocates
Family Voices
National Association of Councils on Developmental Disabilities
National Center for Parent Leadership, Advocacy, and Community Empowerment (National PLACE)
National Disability Rights Network (NDRN)
National Down Syndrome Congress
National PLAN Alliance
National Respite Coalition
The Arc of the United States

The Consortium for Constituents with Disabilities (CCD) is the largest coalition of national organizations working together to advocate for Federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society free from racism, ableism, sexism, and xenophobia, as well as LGBTQ+ based discrimination and religious intolerance.

cc: House Energy and Commerce Committee Members and Senate Health Education Labor and Pensions Committee

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