

## Detailed Summary

### Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act of 2024 (HR 7213)

September 18, 2024

#### **SUMMARY:**

The House of Representatives passed the Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act of 2024 (HR 7213) on September 18, 2024, under suspension of the rules on a roll-call vote of 402-13. The bill then moved to the Senate where two Senators have anonymously lodged complaints resulting in the bill not being passed before recess. Fortunately, the law was included in the Continuing Resolution which extended it to December 20. We have high hopes that the bill will be passed when the Senate returns following the November elections. Below is a summary of the bill after the House and Senate resolved the differences between the two versions.

#### **BACKGROUND:**

First signed into law in 2006, this law continues to serve as the most comprehensive law supporting research, education, and training for individuals with Autism and their families. The law authorizes funding for surveillance, awareness, and early identification at the Centers for Disease and Prevention (CDC); Health Resources and Services Administration (HRSA) to provide interdisciplinary training of health professionals and the development of evidence-based interventions; and the National Institutes of Health (NIH) to conduct basic research to better understand the complexities of Autism. The law also authorizes the Interagency Autism Coordinating Committee to develop a strategic plan for research and to coordinate federal activities across agencies.

#### **SUMMARY OF HR 7213:**

HR 7213 reauthorizes the programs in the Autism CARES Act through 2029 (five years), improves many of the programs, and requires the U.S. Department of Health and Human Services (HHS) to submit various reports to Congress.

Specifically, it authorizes \$28 million a year for the CDC developmental disabilities surveillance and research program; \$56 million a year for the HRSA autism education, early detection and intervention programs; and \$306 million a year for the interagency autism coordinating committee and NIH research activities. This totals approximately \$2 billion over five years.

It also authorizes HHS to provide training and technical assistance to states, Native American tribes, tribal organizations, localities or territories regarding how federal funding may be used to provide individuals with autism spectrum disorder and other developmental disabilities access to



evidence-based services, tools and technologies that support communication needs. HHS must report annually to Congress on the technical assistance it provided in the preceding year.

#### *LEND*

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 bill increases 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.

#### ***NIH Requirements***

The bill expands activities the National Institutes of Health (NIH) conducted under the Autism CARES programs by including an examination of support for caregivers and research that reflects the **entire population of individuals with autism spectrum disorder, including those with co-occurring conditions and the full range of needs for supports and services, including to ensure safety and promote well-being.**

It expands the minimum number of **centers of excellence** established for research on autism spectrum disorder from five to seven and allows NIH to provide guidance to the centers on opportunities to promote engagement with and solicit input from individuals with autism spectrum disorder and their families to inform the activities of the center. With this increase, Congress intends for **the additional centers to focus on addressing the needs of those with complex medical and behavioral support needs and health equity issues** resulting in premature death such as Alzheimer's, diabetes, and higher rates of suicide.

The director of the centers may provide guidance on strategies to engage and solicit input from individuals with Autism and their families, **including those individuals with co-occurring conditions and the full range of needs for supports and services, including such supports and services to ensure the safety, and promote the well-being, of such individuals, to inform the activities of the center.**

It requires that NIH submit to the President of the U.S. for review and transmit to Congress a budget estimate for FY 2026 through FY 2029 pursuant to the strategic plan developed by the Interagency Autism Coordinating Committee (IACC). The IACC must be given the opportunity to comment upon — but not change — the budget estimate.

#### ***Reporting Requirements***

The bill requires HHS to report to Congress, within two years of enactment, on the need for and feasibility of expanding the **developmental-behavioral pediatrician (DBP) training programs**



located in rural or underserved areas. This is important because 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. This report would help inform future policies to increase the number of DBPs across the country.

It requires HHS, in consultation with other relevant federal departments and agencies and by Sept. 30, 2028, to report to Congress progress on activities related to Autism and other developmental disabilities. The report must be publicly available, including through the HHS website.

By Sept. 30, 2026, HHS must also provide an update on challenges related to transitioning from school-based services to services available during adulthood. HHS must also report to Congress on the **mental health needs** of individuals with Autism. The report must include an overview of relevant policies and programs, including an identification of existing federal laws, regulations, policies, research and programs; and must include recommendations to improve mental health outcomes and address related disparities for individuals with Autism, including prevention, care coordination, and community-based services.

### ***Communication Needs***

A significant portion of the autistic community is unable 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. 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.

The Autism CARES Act of 2024 authorizes a new **Autism intervention research network focused on communication needs (AIR-C)**, in particular, augmentative and alternative communication or AAC.

In addition to the AIR-C, the new law authorizes the Secretary of HHS to provide technical assistance to states to help individuals with Autism and other developmental disabilities with access to evidence-based services, tools, and technologies that support communication needs (Sec. 4). This new section is a very paired down component of the Augmentative and Alternative Communication Centers to Establish National Training Act (AACCENT Act), a bill to provide technical assistance to states. The Secretary must prepare a report to the House and Senate health committees summarizing the technical assistance provided.



**CONCLUSION and ACTION:**

The Autism Society supports HR 7213 and will continue to advocate for its passage when Congress returns from its election recess. Please continue to [thank Representatives](#) who supported the bill's passage in the House and educate Senators about the importance of finishing its work and passing the bill upon their return.

Please contact Kim Musheno, Vice President of Public Policy at the Autism Society of America ([kmusheno@autism-society.org](mailto:kmusheno@autism-society.org) or 800-328-8476, ext 9020) if you have any questions about this summary.