

Autism Speaks Support of the Autism CARES Act of 2024 (H.R. 7213)

House Committee on Energy and Commerce

June 12, 2024 at 10:00am - 2123 Rayburn

Autism Speaks is a national, non-profit organization dedicated to creating an inclusive world for all individuals with autism throughout their lifespan. We do this through advocacy, services, supports, research and innovation, and advances in care for autistic individuals and their families. We are grateful to Chair McMorris Rodgers and Ranking Member Pallone for convening this markup and for co-chairs of the Autism Caucus, Reps. Chris Smith and Henry Cuellar, for introducing the Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act of 2024 (H.R. 7213) to invest in autism research and training programs that ensure better care and well-being for autistic people.

As discussed in our statement submitted for subcommittee consideration, the Autism CARES Act exemplifies how bipartisan collaboration has fundamentally transformed our understanding of autism and shaped the landscape of services and support for the 1 in 36 children and 1 in 45 adults on the autism spectrum in the United States. 12 The Autism CARES Act has been the single most important driver of federal investment in autism research and training programs since first passing in 2006 and, because of the investments made over the past two decades under previous iterations of the law, we are poised to take the next steps to advancing support for autistic people and their families. We are grateful to the leadership and members of this Committee for their recognition of this progress and for their efforts to continue the Autism CARES Act, which must be renewed before September 30, 2024, when significant provisions of the current law sunset.

As far as we have come in terms of our understanding of autism and acceptance of autistic people, there is so much work to do to ensure that every autistic person can access the personalized health care, services, and supports that meet their needs. The Autism CARES Act of 2024 offers the opportunity to help close this gap and ensure that every autistic person can reach their full potential. In addition to continuing the vital programs that have led to key progress, the bill includes important enhancements that would encourage research focused on the daily life challenges of autistic people across the lifespan with a new emphasis on autism and aging. The bill would add an Autism Intervention Research Network for Communication Needs (AIR-C) to address how to best support autistic people who are non-speaking or may need additional communication support. And it would further efforts for greater inclusivity in research activities, so that people

¹ Maenner MJ, Warren Z, Williams AR, et al. Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2020. MMWR Surveill Summ 2023;72(No. SS-2):1–14. DOI: http://dx.doi.org/10.15585/mmwr.ss7202a1.

² Dietz PM, Rose CE, McArthur D, Maenner M. National and State Estimates of Adults with Autism Spectrum Disorder. J Autism Dev Disord. 2020;50(12):4258-4266. doi:10.1007/s10803-020-04494-4

across the spectrum are better represented as we move closer to meeting the entire autism community's outstanding needs.

Finally, the Autism CARES Act of 2024 will for the first time provide the autism community with a **comprehensive**, **forward-looking budget plan for autism research** through the addition of a Professional Judgment Budget for Autism Research. This will provide the autism community and Congress with a clearly articulated resource on the priority research areas and resources needed to accomplish important research goals for the autism community, as outlined in recommendations by the Interagency Autism Coordinating Committee's Strategic Plan. Autism Speaks applauds the Committee for providing the transparency and accountability that the autism community deserves through this bill enhancement.

We are grateful for the Energy and Commerce Committee's work to advance the Autism CARES Act of 2024 and look forward to working with the Committee and House leadership to ensure the bill is quickly passed before portions expire in September. The Committee's leadership continues to be key in drawing attention to the urgent priority for federal research, training and data programs to meet the current and future needs of the autism community.