

Congress of the United States
Washington, DC 20515

May 1, 2024

The Honorable Robert Aderholt
Chairman
Subcommittee on Labor, HHS,
Education, and Related Agencies
House Committee on Appropriations
Washington, DC 20515

The Honorable Rosa DeLauro
Ranking Member
Subcommittee on Labor, HHS,
Education, and Related Agencies
House Committee on Appropriations
Washington, DC 20515

Dear Chairman Aderholt and Ranking Member DeLauro:

Thank you for your longstanding leadership in advancing funding for research, training, and data activities in the Autism CARES Act. The demonstrated results of these activities have greatly improved services and supports for children and adults with autism and their families across our country. Previous funding provided by this Subcommittee has made a tremendous difference in improving our understanding of autism, increasing awareness, and enhancing services.

Despite the progress that has been made, significant gaps remain. Therefore, for the FY2025 Labor, Health and Human Services, Education, and Related Agencies Appropriations (LHHS) bill, we urge the Subcommittee to increase investments in autism research in accordance with the recommendations of the Interagency Autism Coordinating Committee (IACC), which has recommended significant increases in funding for autism research to meet the needs of the 1 in 36 children and 1 in 45 adults on the autism spectrum. Specifically, we urge the Committee to ensure the National Institutes of Health (NIH) is budgeting to meet the recommendations of the IACC, and that increases are provided for programs including the Autism and Developmental Disability Monitoring Network and the Maternal and Child Health Bureau's Autism Research Program.

The IACC was created by Congress to assist in coordinating federal autism research and activities and to provide recommendations for strategic improvements across a myriad of research areas. Composed of representatives across numerous federal departments and agencies, autistic adults, family members, advocacy groups, and researchers, the IACC's expertise and insight is an invaluable tool for Congress. In its 2021-2023 [Strategic Plan](#), the IACC articulated 23 strategic objectives for autism research and recommended a substantial increase in funding levels to help achieve those objectives. Unfortunately, research spending continues to fall far short of the recommended levels despite the increased prevalence of autism and significant challenges facing autistic individuals throughout their lifespan.

As many of the agencies funded by the LHHS bill participated in developing and approving the IACC's budget recommendations, we urge the Committee to provide the resources

and direction necessary to carry out those objectives. The National Institutes of Health plays a key role in funding autism research. However, as the Committee acknowledged in FY2024, there are significant gaps in autism research that persist. For example, there continues to be a dearth of research devoted to issues across the lifespan of autistic individuals and significantly more research is needed to address health equity challenges and disparities experienced by autistic individuals and their families in underserved communities. We urge the Committee to not only continue to encourage the NIH to address gaps in research, but also to direct the NIH to proactively budget to invest in autism research in accordance with the recommendations of the IACC.

While we believe that the Committee should encourage additional investment and provide resources to all federal agencies involved in autism research, training and surveillance activities, we have several specific increases we are requesting for FY2025.

We would specifically like to request an overall funding level of \$61.344 million for HRS's Autism and Developmental Disabilities program. The FY2025 request for the Autism and Other Developmental Disabilities program will support training programs, research, and systems with a focus on improving access, quality, and systems of care for children, adolescents, and young adults with autism or other developmental disabilities from underserved backgrounds. The requested funding will allow the program to serve approximately 137,000 more children.

This will provide needed resources to support the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs, and the Developmental Behavioral Pediatrics (DBP) programs, and the Maternal and Child Health Bureau's (MCHB) Autism Research Program. Despite autism prevalence rates that have steadily increased, funding for MCHB autism research has declined over the past decade despite critical gaps that MCHB has identified that additional funding could help address. We believe that MCHB would be well positioned to help address key issues across the lifespan, services, and disparities.

For the LEND program, we would specifically request a funding level of at least \$40 million. The 60 LEND programs (located in 44 U.S. states with six additional states and three territories reached through program partnerships without additional federal or state aid) are an effective workforce program that operate within a university medical system and provide graduate-level, interdisciplinary training to the next generation of clinical, research, and community leaders. The training prepares trainees from diverse professional disciplines to assume leadership roles in their respective fields and enhances the clinical expertise of professionals to identify, assess, and provide care to children who have or are at increased likelihood of developing autism or other developmental disabilities.

In addition to professionals, the trainees and faculty include persons with disabilities and family members. Persons with disabilities and their families provide an invaluable perspective to enhance the trainee understanding of lived experiences. As trainees, persons with disabilities and family members also develop their leadership and advocacy skills as part of an interdisciplinary care team. In FY 2021, the LEND and Developmental-Behavioral Pediatrics (DBP) programs collectively provided diagnostic services to confirm or rule out autism and other developmental

disabilities to over 137,000 children; and trained over 22,000 trainees in over 40 professional disciplines.

The increased funding for the LEND programs will provide the LEND programs with funding to train additional professionals to address significant disparities in evaluation, diagnosis, and treatment of persons with autism and other developmental disabilities, including persons from underserved communities. The funding will also provide the LEND programs with additional funding to continue to recruit and support more autistic adults as faculty and trainees. The LEND programs will also continue to focus on expanding the LEND curriculum to include and address the needs of adults.

We also request a \$5 million increase for autism-related activities at the National Center for Birth Defects and Developmental Disabilities. This funding would enable the Autism and Developmental Disability Monitoring Network to expand beyond the existing sites and ensure that more sites can monitor outcomes for young adults transitioning from school-age to adult services.

We also encourage you to examine opportunities for further investment in research, education, and training within the Department of Education so that educators and students are given the tools needed to succeed. We specifically encourage increased investment at the Department of Education's Institute of Education Sciences (IES) and Office of Special Education and Rehabilitation Services (OSERS), to improve educational outcomes for students with autism and other developmental disabilities.

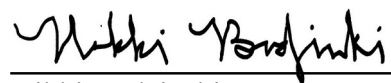
We appreciate the spending constraints that the Committee and our nation face and the difficult decisions involved in putting together the annual appropriations bills. However, there are tremendous opportunities to build off existing programs and shore up the gaps in research and services and follow through on the comprehensive recommendations of the Interagency Autism Coordinating Committee.

Thank you very much for your consideration and for your work on behalf of the millions of individuals on the autism spectrum and their families.

Sincerely,



Christopher H. Smith
Member of Congress



Nikki Budzinski
Member of Congress



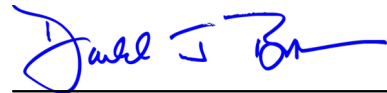
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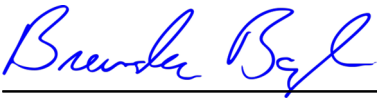
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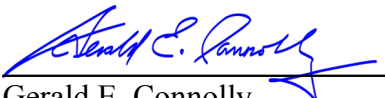
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Brendan F. Boyle
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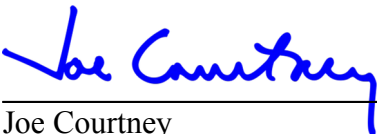
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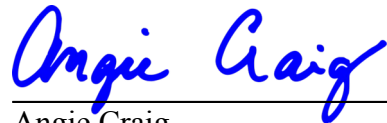
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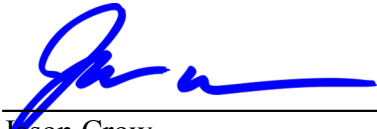
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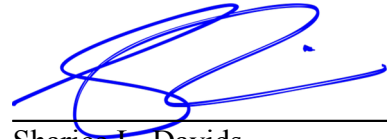
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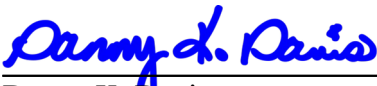
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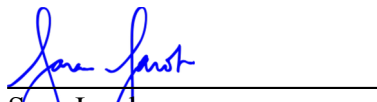
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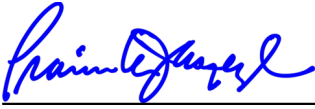
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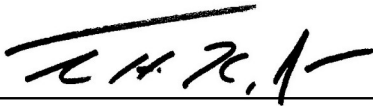
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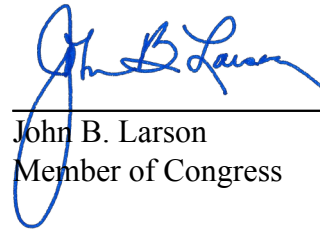
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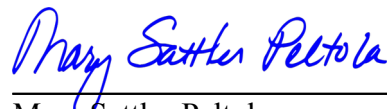
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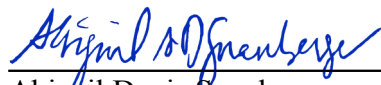
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