

**Congress of the United States**  
**Washington, DC 20515**

April 27, 2022

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

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

Dear Chairwoman DeLauro and Ranking Member Cole,

Thank you for your longstanding leadership in advancing funding for research, services, and supports that benefit 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 across our nation. Despite the progress that has been made, significant gaps remain. Therefore, for the FY2023 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 44 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 2016-2017 Strategic Plan, the IACC articulated 23 strategic objectives for autism research and provided recommended a doubling of 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 FY2022, 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 and services, we have several specific increases we are requesting for FY2023.

We would specifically like to request an overall funding level of \$64.6 million for HRSA autism-related activities to account for the \$2.755 million increase for Leadership Education in Neurodevelopmental and Related Disabilities (LEND) and \$7.5 million increase for the Maternal and Child Health Bureau's (MCHB) Autism Research Program. Despite autism prevalence rates that have steadily increased, funding for MCHB autism research funding has declined over the past decade and there are critical gaps in research that MCHB has identified, that additional funding could help address. We believe that the MCHB is well-positioned, with additional funding to help fund research that would address key gaps like research to address issues across the lifespan, services, and disparities.

As part of this increase, we would specifically like to request a funding level of at least \$40 million for the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program at HRSA.

The 60 LEND programs (located in 44 U.S. states) operate within universities and collaborate with university hospitals and/or academic health centers to provide advanced interdisciplinary training to enhance the clinical expertise and leadership skills of professionals in a broad array of professional disciplines in the identification, assessment, and intervention of children and youth with neurodevelopmental and other related disabilities. The training programs focus on training professionals to provide culturally and linguistically relevant care and to recruit diverse students and professionals into the programs.

The number of LEND programs were expanded from 52 to 60 in 2021, resulting in all funded programs receiving a 3.3% cut to accommodate the expansion. The increased funding for the LEND programs will allow the LEND programs to address significant unmet needs and disparities in evaluation, diagnosis, and treatment as well as will support LENDs to recruit and support more autistic adults as faculty advocates and as trainees, with an emphasis on expanding LEND curriculum to include and address adult life needs and healthcare.

The FY2023 request for the Autism and Other Developmental Disabilities program will support training programs, research, and state systems with a focus on improving access, quality, and systems of care for underserved children, adolescents, and young adults with autism or other

developmental disabilities from underserved backgrounds. The requested funding will allow the program to serve approximately 125,000 more children. The increased funding for the LEND programs will allow the LEND programs to address significant unmet needs and disparities in evaluation, diagnosis, and treatment as well as will support LENDs to recruit and support more autistic adults as faculty advocates and as trainees, with an emphasis on expanding LEND curriculum to include and address adult life needs and healthcare.

We also request an increase to a total of at least \$33.1 million for autism-related activities at the National Center for Birth Defects and Developmental Disabilities. Providing an increase of \$10 million or more would enable the Autism and Developmental Disability Network to expand beyond the existing 11 sites and also 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 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,



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MIKE DOYLE  
Co-Chair, Autism Caucus



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CHRISTOPHER H. SMITH  
Co-Chair, Autism Caucus



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Member of Congress



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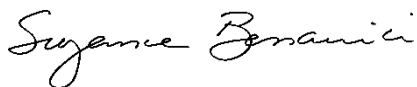
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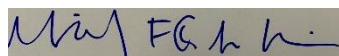
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