

Congress of the United States
Washington, DC 20515

April 28, 2021

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. The funding provided by this Subcommittee over the past decade 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 FY2022 Labor, Health and Human Services, Education, and Related Agencies Appropriations (LHHS) bill, we urge the Subcommittee to align with the recommendations of the Interagency Autism Coordinating Committee (IACC) by providing an additional \$150 million for autism related activities.** The coronavirus pandemic has only exacerbated the challenges faced by autistic individuals and their families, making this investment that much more vital.

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 most recent [Strategic Plan](#), the IACC articulated 23 strategic objectives for autism research and provided recommended funding levels to help achieve those objectives. The Plan points out that the total annual cost of ASD in the United States – including medical, non-medical, economic, and lifetime costs – has been estimated to be at least \$236 billion, yet combined autism research funding among Federal and private sources totaled only 0.09-0.21% of those estimated costs.

Specifically, we recommend this **\$150 million increase at agencies engaged in autism research and services including at the National Institutes of Health (NIH), the Centers for Disease Control (CDC), Health Resources and Services Administration (HRSA), the**

Administration for Community Living (ACL), and the Department of Labor. This funding could help to fill current gaps in research and services. For example, prevalence monitoring may be expanded beyond the current 11 states, new clinical standards can be developed and disseminated, supports can be put in place to help autistic individuals transition into adulthood, and research on issues facing autistic individuals across the lifespan may be conducted. In addition, it is essential that across Departments, and in particular, at institutes like the National Institute of Minority Health and Health Disparities, that increased investments are made in research and services to address disparities experienced by autistic individuals and their families in underserved communities.

In addition, also in keeping with these increases, we would **specifically like to request an overall funding level of \$62.6 million for HRSA autism-related activities** to account for the \$1.755 million increase for LEND and a \$7.5 million increase in HRSA autism-related research. Despite steadily increasing autism prevalence rates, funding for HRSA autism research funding has declined over the past decade, and critical gaps in research have been identified which may be addressed with additional funding.

Within HRSA, we would specifically like to request a funding level of at least \$38,000,000 for the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program at HRSA. This amount is needed to fund the 52 LEND network programs in 44 states that are making significant strides toward improved screening, diagnosis, and care for individuals with ASD. This funding will enable the LEND network to fulfill its expanded statutory mandate to serve individuals across the lifespan, addressing a critical shortage of health care professional for adults with autism and other developmental disabilities. It will support LEND network programs to recruit and support autistic adults as faculty advocates and as trainees, and will expand efforts to train more professionals to diagnose and provide high quality care for individuals of all ages with ASD and other developmental disabilities. This funding is critical to the LENDs' role in developing innovative strategies to translate research on interventions, guidelines, tools, and systems management approaches to training settings, to communities and into practice.

We also request in keeping with these increases, an **overall funding level of \$50 million for CDC autism-related activities.** This funding could enable CDC to expand the number of Autism Developmental Disability Monitoring (ADDM) network, enhance the Learn the Signs, Act Early program, and study the prevalence of autism spectrum disorder among adults.

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,



MIKE DOYLE
Co-Chair, Autism Caucus



CHRISTOPHER H. SMITH
Co-Chair, Autism Caucus

Member of Congress

/s/
Jake Auchincloss
Member of Congress

/s/
Earl Blumenauer
Member of Congress

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G. K. Butterfield
Member of Congress

/s/
Cindy Axne
Member of Congress

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Lisa Blunt Rochester
Member of Congress

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André Carson
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