

Congress of the United States
Washington, DC 20515

March 24, 2023

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, 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. Despite the progress that has been made, significant gaps remain. Therefore, for the FY2024 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 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 FY2023, 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 FY2024.

We would specifically like to request an overall funding level of \$61.344 million for HRSA autism-related activities. This will provide needed resources to support the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program and other important programs, including 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) operate within universities and collaborate with university hospitals and/or academic health centers. The LEND programs provide advanced interdisciplinary training to enhance the leadership skills and clinical expertise of professionals to identify, assess, and provide care to individuals who have or are at increased likelihood of developing autism and other neurodevelopmental or 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 LEND program is an effective workforce development program.

The FY2024 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 125,000 more children. The increased funding for the LEND programs will allow the programs to address significant disparities in evaluation, diagnosis, and treatment, including for individuals from underserved communities. The funding will also support the LENDs to recruit and support more autistic adults as faculty advocates and trainees, with an emphasis on expanding the LEND curriculum to include and address adult life needs. It will also fully restore the cuts to the LEND programs. In June 2021, the number of LEND programs was expanded from 52 to 60. At that time, the expansion included no increase in funding, and the programs received a 3.3 percent cut to accommodate the growth. While some cuts have been restored, the LENDs continue to expand the number of trainees they serve.

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,



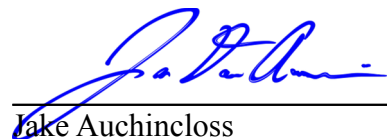
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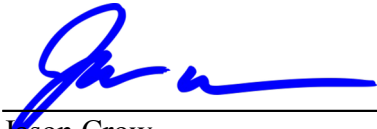
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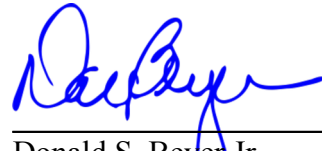
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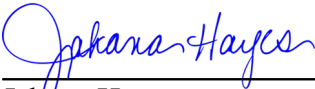
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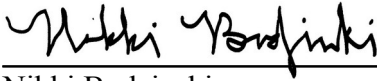
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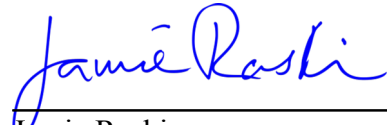
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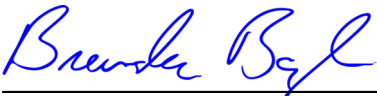
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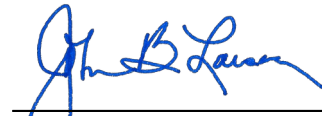
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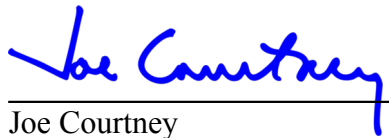
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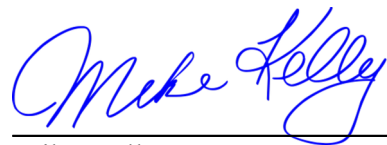
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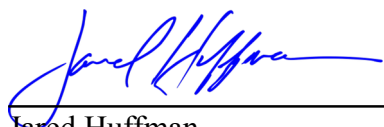
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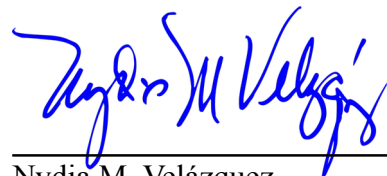
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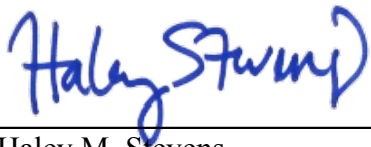
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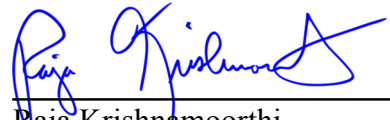
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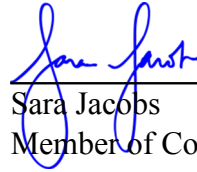
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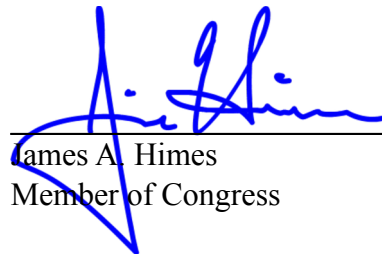
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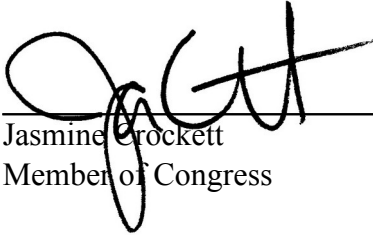
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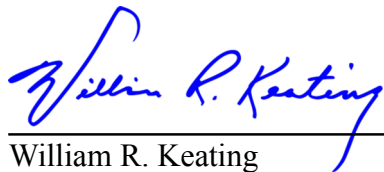
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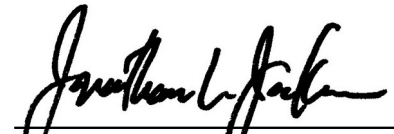
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