

# United States Senate

WASHINGTON, DC 20510

May 25, 2022

The Honorable Patty Murray  
Chair, Subcommittee on Labor,  
Health and Human Services, Education,  
and Related Agencies  
United States Senate  
Washington, D.C. 20510

The Honorable Roy Blunt  
Ranking Member, Subcommittee on Labor,  
Health and Human Services, Education,  
and Related Agencies  
United States Senate  
Washington, D.C. 20510

Dear Chair Murray and Ranking Member Blunt:

As you and your colleagues work on the Fiscal Year (FY) 2023 appropriations bills, we respectfully request that you fund programs that focus on autism spectrum disorder (ASD) research, screening, and support at the highest level possible, including activities authorized by the Autism Collaboration, Accountability, Research, Education, and Support Act of 2019 (PL 116-60), which was passed unanimously by the House and Senate.

According to the most recent data from the Centers for Disease Control and Prevention (CDC), the number of children identified with ASD has increased over time. The identified prevalence of ASD increased from 1 in 150 among children in 2000, to 1 in 44 in 2018.<sup>1</sup> In 2020, the CDC released its first estimate of the number of adults on the autism spectrum: 5.4 million adults (2.21 percent of all adults).<sup>2</sup> 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 percent of those estimated costs.<sup>3</sup>

Continued federal investment is vital to support children and adults with ASD and help improve earlier diagnosis, personalized interventions, and greater access to services and supports. Programs at the CDC, National Institutes of Health (NIH), and Health Resources and Services Administration (HRSA) are essential to the children and families affected by ASD. As the nation's leading public health agency, the CDC works to better understand the epidemiology of ASD by researching risk factors and providing comprehensive estimates of the prevalence of ASD. The CDC's "Learn the Signs, Act Early" health program educates families with young children on the importance of identifying developmental concerns early. The campaign also promotes universal screenings that help ensure that children diagnosed with ASD can be connected with needed services and support early on.

---

<sup>1</sup> National Center for Birth Defects and Developmental Disabilities, (March 2022). "Data & Statistics on Autism Spectrum Disorder." Centers for Disease Control and Prevention. <https://www.cdc.gov/ncbddd/autism/data.html>.

<sup>2</sup> Dietz, Patricia M et al., (2020) "National and State Estimates of Adults with Autism Spectrum Disorder." *Journal of Autism and Developmental Disorders* 50, no.12 (2020): 4258-4266. Centers for Disease Control and Prevention. Retrieved from: <https://doi.org/10.1007/s10803-020-04494-4>.

<sup>3</sup> Interagency Autism Coordinating Committee, (October 2017). "2016-2017 Interagency Autism Coordinating Committee Strategic Plan For Autism Spectrum Disorder." U.S. Department of Health and Human Services. Retrieved from: <https://iacc.hhs.gov/publications/strategic-plan/2017>.

Research supported by the NIH has improved the ability to screen for and diagnose ASD, advanced our understanding of the biology of autism, and spurred innovative treatments for people with ASD. Strong funding for the NIH is instrumental in helping plan research initiatives to advance the understanding of autism. The NIH funds the Autism Centers of Excellence, a cross-NIH initiative that supports large-scale multidisciplinary studies with the goal of determining the causes and best treatments for ASD.

Importantly, there has been tremendous progress in the research to better understand autism. The number of research participants has doubled from 5,205 whole genomes analyzed in the landmark 2017 report published in *Nature Neuroscience* to 11,325 whole genomes from over 4,500 families affected by autism and wanting to support science.<sup>4</sup> As a result of studying these samples we now have a better understanding of the biology of autism, pointing towards important pathways and therapeutic targets. All of these pathways affect how brain cells develop and communicate with each other, meaning that they have clear potential as targets for developing personalized health care needed for people with ASD. Given the important progress in the field, it is vital that we sustain and improve our investment in autism research.

Complementing the focus on the biology of ASD, HRSA supports quality health care for people with ASD and the transition of youth with ASD to adult health care services, employment, and participation in community life. In addition, HRSA funds programs critical to educating health care professionals in best practices of care for children with ASD and other developmental disabilities.

We respectfully request that you include the following report language to accompany the FY 2023 appropriations bill:

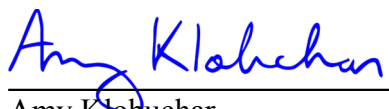
*Autism Spectrum Disorder (ASD).—The Committee supports the research budget recommendation included in the Interagency Autism Coordinating Committee’s (IACC) Strategic Plan for ASD and directs the NIH to include a spending plan in the fiscal year 2024 Congressional Budget Justification detailing how each NIH Institute that serves on the IACC will implement the IACC’s budget recommendation.*

We know that more funding is needed to build on the great progress that has been made. We urge you to support strong funding in FY 2023 for programs that help us better screen, diagnose, treat, and provide services and supports for people with ASD. These programs will make a real difference in the lives of millions of Americans. Thank you for considering this request.

Sincerely,

---

<sup>4</sup> Brett Trost et al., (2022). “Genomic architecture of Autism Spectrum Disorder from comprehensive whole-genome sequence annotation.” medRxiv. Retrieved from: <https://doi.org/10.1101/2022.05.05.22274031>.



Amy Klobuchar  
United States Senator



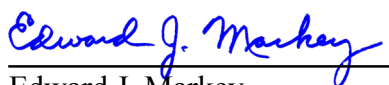
Thom Tillis  
United States Senator



Robert Menendez  
United States Senator



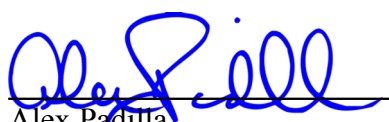
Cory A. Booker  
United States Senator



Edward J. Markey  
United States Senator



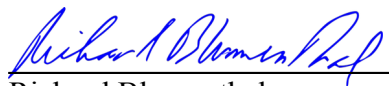
Kirsten Gillibrand  
United States Senator



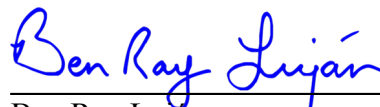
Alex Padilla  
United States Senator



Benjamin L. Cardin  
United States Senator



Richard Blumenthal  
United States Senator



Ben Ray Lujan  
United States Senator



Chris Van Hollen  
United States Senator



Debbie Stabenow  
United States Senator



Sherrod Brown  
United States Senator



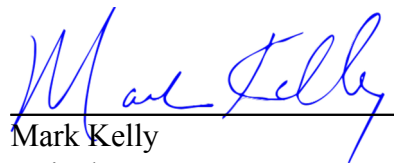
Jack Reed  
United States Senator



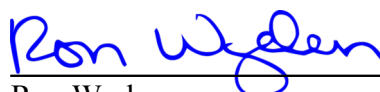
Susan M. Collins  
United States Senator



Roger W. Marshall  
Member of Congress



Mark Kelly  
United States Senator



Ron Wyden  
United States Senator



Kyrsten Sinema  
United States Senator