Written Testimony of
the Autism Society of America
Submitted to the U.S. House Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education and Related Agencies

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Thank you for the opportunity to submit written testimony with recommendations for Fiscal Year 2022 (FY22) appropriations for the programs important to the Autism Society of America.

The Autism Society of America is the nation’s oldest and largest grassroots organization representing individuals on the autism spectrum and their families. The Autism Society envisions a world where individuals and families living with autism are able to maximize their quality of life, are treated with the highest level of dignity, and live in a society in which their talents and skills are appreciated and valued. Along with our 74 affiliates nationwide, we provide advocacy, education, information and referral, support, and community engagement opportunities at national, state and local levels.

In addition to this testimony, the Autism Society of America, helped to develop and signed on to the testimony submitted on behalf of the Consortium for Citizens with Disabilities (CCD) Autism, Developmental Disabilities, and Family Support Task Force as well as the Education Task Force. The Autism Society’s recommendations are consistent with CCD’s recommendations.

In general, most annual discretionary programs that support people with autism are authorized by the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act), Assistive Technology Act, Autism CARES Act, the Lifespan Respite Care Act, the National Family Caregiver Support Program and Parent Information Centers, and the Individuals with Disabilities Education Act administered by the Departments of Education and Health and Human Services (HHS).

The pandemic caused significant hardships for families caring for children and adults with autism and it exposed significant and, often deadly, gaps in the service system. Families of children and adults with autism struggled to work while caring for their family members without assistance. Some family members were unable to visit their loved ones in congregate settings. Some family members were lost due to COVID in group homes where it was difficult to follow the safety protocols. One study showed that having an intellectual disability was the strongest independent risk factor for presenting with a Covid-19 diagnosis and the strongest independent risk factor other than age for Covid-19 mortality.

Now is the time for Congress to provide urgently needed increased funding to federal programs designed to ensure people with autism are provided the services and support they need to live, work, go to school, and recreate in their communities safely.

**Autism CARES Act Programs**

The Autism Society recommends a $150 million increase in FY2022 for Autism and other Developmental Disabilities line funding the Autism Collaboration, Accountability, Research, Education and Support (CARES) Act of 2019. The law coordinates federal agencies engaged in autism research, surveillance and services through the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), and Health Resources and Services Administration (HRSA). Since the Autism CARES Act was first enacted in 2006, this funding has helped to expand research and coordination, increase public awareness and surveillance, and expand interdisciplinary health professional training to identify (or rule-out autism) and develop evidence-based services and support for people with autism spectrum disorders. In 2019,
Congress reauthorized and improved the Autism CARES Act, urging the programs to better serve people with autism across the lifespan. Additional funds would allow agencies to fill current extreme gaps in needed development of evidence-based services. The reauthorized law also expands the Interagency Autism Coordinating Committee (IACC), including requirements for additional community stakeholders to serve on the committee.

Within this request for the Autism CARES Act, we recommend at least $38 million for Leadership Education in Neurodevelopmental Disabilities and Related Services (LEND) programs within HRSA. The LEND programs are making significant strides toward improved screening, diagnosis, interdisciplinary training, and development of evidence-based interventions for individuals with ASD. Additional funding is needed to address critical shortages of professionals trained to meet the needs of people on the spectrum.

We recommend $50 million for CDC’s autism-related activities which is needed for CDC to conduct a prevalence study on adults with autism and expand the current network of 11 states that monitor autism prevalence in children. CDC funds one of the largest U.S. prevalence studies to date, called the Study to Explore Early Development (SEED), a multi-year study on risk factors in multiple sites (CA, CO, GA, MD, MO, NC, PA, WI) and a data coordinating center (MI).

**Developmental Disabilities Assistance and Bill of Rights Act Programs**

We respectfully request $85 million in FY 2022 for the State and Territorial Councils on Developmental Disabilities (DD Councils); $45 million for the Protection and Advocacy Systems (P&A); $45 million for the University Centers for Excellence in Developmental Disabilities (UCEDD); and $14 million for Projects of National Significance in Intellectual and Developmental Disabilities (PNS). The DD Act authorized these programs to improve the lives of people with IDD through research and training, capacity building, systems change, advocacy, and the enforcement and protection of civil rights. DD Act programs are mandated to work with marginalized communities including people with IDD from different racial and ethnic backgrounds, rural, tribal and immigrant communities. DD Act programs invest in programs tailored to the needs of the state and are flexible enough to respond rapidly to emergencies, such as the COVID-19 pandemic by providing immediate and continuing support.

We recommend $14 million for the DD Act Projects of National Significance (PNS). PNS allows ACL to respond to emerging needs of national significance such as demonstration projects as well as research and data collection to inform policy.

**Assistive Technology Act Programs**

We respectfully request $50 million in funding in FY2022 for Assistive Technology (AT) Act programs. The AT Act provides critical funding for programs that assure people with disabilities can access and acquire the technology they need to live, work, and attend school in their communities. People with autism, especially those that need technology to communicate, benefit from these state programs that support people at low or no costs.

**Family Caregiver Support Programs**

The Autism Society recommends $14.2 million in FY 2022 for Lifespan Respite Care Program and $205.5 million for the National Family Caregiver Support Program (NFCSP). The
COVID-19 pandemic has amplified the need for support to caregivers. Fifty-three million family caregivers provide most of our nation’s long-term services and supports. There are approximately 3 million family caregivers of persons with IDD, the majority of which provide more than 40 hours of care per week. Lifespan Respite grants help states build capacity to provide respite and improve quality by requiring states to focus on addressing training and recruitment, creating new respite services and help family caregivers afford respite services. The NFCSP, authorized under the Older Americans Act, funds respite, counseling, support groups, and caregiver training for family caregivers of adults, including those with IDD. Additional funding for NFCSP is needed due to increased demands on caregivers brought on by COVID-19 and the aging of our population.

Parent Training and Information Centers

We recommend $30 million for the Parent Training and Information Centers within the U.S. Department of Education. This program provides crucial assistance to families of infants, toddlers, children, and youth with disabilities ages birth to 26, helping parents and youth navigate the early intervention and special education process and improving academic, social, and postsecondary outcomes.

Department of Education

During the school closures due to the COVID-19 pandemic, many students with autism were unable to benefit from remote learning. Many students either had no access or limited access to the technology needed to benefit or they were unable to benefit without significant support. In addition, many students with autism went without important related services such as physical, speech, occupational, or behavioral therapies. Schools and districts will need additional resources to provide essential services to infants, toddlers, children, and youth with disabilities who may have struggled to access special education services over the last year. Schools and districts will also need sustained funding to reverse the special educator shortage crisis, which predates the pandemic but has been significantly exacerbated.

The Autism Society urges Congress to fulfill the commitment made in 1975, when IDEA became law, that it would provide up to forty percent of the excess costs of educating students with disabilities. Fiscal Year 2021 Federal funding for IDEA grants to states was $12.94 billion, which equates to approximately 13 percent of the authorized amount. State and local budgets must cover this Federal shortfall, estimated at more than $23 billion. Likewise, Congress must provide a meaningful investment in the full continuum of IDEA programs to ensure the law operates as intended.

We recommend no less than the following amounts for each program within IDEA in FY22:

- Part B Section 611 (Grants to States): $15.5 billion
- Part B Section 619 (Preschool Grants): $598 million
- Part C (Grants to serve infants and toddlers): $732 million
- Part D (National Activities):
○ State Personnel Development: $42 million
○ Technical Assistance and Development: $47 million
○ Personnel Preparation: $300 million
○ Parent Training and Information Centers: $33 million
○ Media and Technology: $33 million

For Transition to Postsecondary Programs for Students with Intellectual Disabilities Demonstrations (TPSID) we recommend: $14 million. **Investments in the Carl D. Perkins Act Career and Technical Education (CTE) Act (Perkins V)** should also be expanded to ensure students with disabilities are robustly included in secondary and post-secondary settings and educators are provided tools to assure accessible educational materials, assistive technology and more.

While districts and schools work to address anticipated instructional loss, mental health impacts, and other adverse pandemic-related impacts of COVID-19 for students with disabilities, the need for additional IDEA funding is critical. A significant increase in Federal funding for IDEA would ensure that funding is available for school programs that can benefit all students, including students with autism. These recommendations are consistent with the CCD Education Task Force for which the Autism Society provides leadership.

Many people with autism lost their jobs due to the pandemic. Some of these jobs will never come back. We urge the federal government to significantly increase funding for the State Supported Employment Services Program authorized by Title VI of the Rehabilitation Act of 1973, as amended by Title IV of the Workforce Innovation and Opportunity Act. This program provides grants to assist states in developing and implementing collaborative programs with appropriate entities to provide supported employment services for individuals with the most significant disabilities. This line item has not been increased for many years. It is time for the federal government to invest in this evidenced based practice that has been successful in assisting people with IDD to become employed in the community. We recommend doubling the supported employment program to $45 million.

Thank you for considering the recommendations of the Autism Society of America as you work toward reaching an agreement on the FY2022 appropriations bill for the Departments of Labor, HHS, Education, and Related Agencies. If you have any questions, please contact Christopher Banks, President and CEO at cbanks@autism-society.org or Kim Musheno, Vice President of Public Policy at kmusheno@autism-society.org.