



April 26, 2021

The Honorable Patrick Leahy, Chairman
Committee on Appropriations
Room S-128, The Capitol
Washington, D.C. 20510

The Honorable Rosa DeLauro, Chairwoman
House Committee on Appropriations
H-307, The Capitol
Washington, DC 20515

The Honorable Richard Shelby, Vice
Chairman
Committee on Appropriations
Room S-128, The Capitol
Washington, D.C. 20510

The Honorable Kay Granger, Ranking
Member
House Committee on Appropriations
H-307, The Capitol
Washington, DC 20515

Dear Sens. Leahy and Shelby and Reps. DeLauro and Granger:

On behalf of the Consortium for Citizens with Disabilities Developmental Disabilities, Autism and Family Supports Task Force (Task Force) and undersigned organizations, we write to urge adequate Fiscal Year 2022 funding for programs 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, and Kevin and Avonte's Law, as well as the National Family Caregiver Support Program and Parent Information Centers.

The Consortium for Citizens with Disabilities (CCD) is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration, and inclusion of children and adults with disabilities in all aspects of society. The Task Force advocates for federal public policies that directly relate to individuals with developmental disabilities (I/DD), including autism spectrum disorders; family supports; and the prevention of child abuse and neglect.

The upcoming year presents unique challenges for people with I/DD. The COVID-19 pandemic has altered the lives of Americans with I/DD on many levels. In every state and territory, developmental disability systems including federal agencies, state developmental disability agencies, and an array of non-profit disability membership and advocacy organizations have pivoted to meet crisis-related needs of people with disabilities and their families in all parts of their lives. Within these systems, the programs listed in this letter addressed emergency threats to health, education, employment, and community living for people with I/DD. Next year we will continue to be dealing with the fallout from the crisis and use the opportunity to take what we have learned and improve and make permanent supports and services for people with I/DD by fully funding the programs below.

CCD Taskforce on Developmental Disabilities, Autism and Family Supports Fiscal Year 2022 Appropriations Recommendations		
Program	Subcommittee	FY2022 Recommendation
State and Territorial Councils on Developmental Disabilities (DD Councils)	Labor, Health and Human Services, Education	\$85 million
Protection and Advocacy for Individuals with Developmental Disabilities (PADD)	Labor, Health and Human Services, Education	\$45 million
University Centers for Excellence in Developmental Disabilities (UCEDD)	Labor, Health and Human Services, Education	\$45 million
ACL/AIDD Projects of National Significance in Intellectual and Developmental Disabilities (PNS).	Labor, Health and Human Services, Education	\$14 million
Assistive Technology (AT) Act Programs	Labor, Health and Human Services, Education	\$50 million
Autism CARES Act Programs	Labor, Health and Human Services, Education	\$56.5 million (at least \$38 million of which for LENDs within Health Resources and Services Administration (HRSA))
Lifespan Respite Care Program	Labor, Health and Human Services, Education	\$14.2 million
National Family Caregiver Support Program (NFCSP)	Labor, Health and Human Services, Education	\$205.5 million
Parent Training and Information Centers	Labor, Health and Human Services, Education	\$30 million
Kevin and Avonte's Law Programs	Commerce, Justice, Science and Related Agencies	\$3 million

Developmental Disabilities Assistance and Bill of Rights Act Programs

We respectfully request that the House and Senate Subcommittees on Labor, Health and Human Services, Education, and Related Agencies and House and Senate Appropriations Committees, provide FY2022 funding of \$85 million for the State and Territorial Councils on Developmental Disabilities (DD Councils); \$45 million for the Protection and Advocacy for Individuals with Developmental Disabilities (PADD) program; \$45 million for the University Centers for Excellence in Developmental Disabilities (UCEDD); and \$14 million under the ACL/AIDD program for the Projects of National Significance in Intellectual and Developmental Disabilities (PNS).

The DD Act established DD Councils, Protection and Advocacy agencies, and UCEDDs (DD Act programs) to improve the lives of people with I/DD through capacity building, systems change, advocacy, and the enforcement and protection of civil rights. DD Act programs strive for intersectionality by working with marginalized communities including people with I/DD from different racial and ethnic backgrounds nationwide, including rural, tribal and immigrant communities. The DD Act programs have been integral to the growth and development of service systems across the nation that states alone would not have the capacity to do. For example, the DD Act programs work with state governments, advocates, and other stakeholders to:

1. Invest in programs tailored to the needs of the state that help people with developmental disabilities live in the community;
2. Conduct extensive interdisciplinary training on cutting-edge service strategies and evidenced-based practices, continuing education, community training, research, model services, technical assistance, and information dissemination to promote community living;
3. Provide advocacy, and legal and direct services to ensure that children and adults with intellectual and developmental disabilities are free from abuse, neglect, and financial exploitation;
4. Respond rapidly to COVID-19 pandemic by providing immediate support including: creating “plain language” public health information; advocating for non-discrimination in COVID testing, treatment and immunization; providing personal protective equipment (PPE) to people with I/DD and caregivers; providing subgrants for internet connection and devices to access telehealth; and more.

We also request continued support for the Administration for Community Living's Administration on Intellectual and Developmental Disabilities' Projects of National Significance (PNS). PNS fill critical research gaps and invest in demonstration projects targeting emerging needs. For example, PNS gather and report longitudinal data on the costs of, status of, and trends in residential, in-home, individual, family, and employment services for people with intellectual and developmental disabilities. PNS also provide technical assistance to strengthen and support service networks and disseminate research and best practices and fund demonstration projects in emerging areas such as cost-effective family supports, increasing employment opportunities, and ensuring an adequate supply of qualified caregivers. PNS also inform policymakers and stakeholders about critical emerging needs.

Assistive Technology Act Programs

We respectfully request that the House and Senate Subcommittees on Labor, Health and Human Services, Education, and Related Agencies and House and Senate Appropriations Committees provide \$50 million in funding for FY2022 Assistive Technology (AT) Act programs. The AT Act provides critical funding for programs that assure people with disabilities can access and acquire the assistive technology devices and services they need to live, work, and attend school in their communities.

Statewide AT programs provide information and assistance, training, technical assistance, and coordination and collaboration of programs that are available for persons with all types of disabilities, all ages, in all environments (education, employment, community living and information technology). Programs include state financing activities (such as financial loans,

cooperative buy, funds of last resort, etc.), device reutilization (including recycling, repair, refurbishment and device exchange), device loan/borrowing, and device demonstration services. While individuals with disabilities, their families, and guardians are the primary beneficiaries of services, the AT Act requires states AT programs to provide a wide range of services and supports to other stakeholders such as educators; employers; health care providers; rehabilitation providers; and technology experts including web designers, procurement officials, and AT manufacturers and vendors.

Autism CARES Act Programs

We respectfully request that the House and Senate Subcommittees on Labor, Health and Human Services, Education, and Related Agencies and House and Senate Appropriations Committees provide at least \$56.5 million for Autism and other Developmental Disabilities for FY 2022 and, of this amount, appropriate \$38 million for LENDs within Health Resources and Services Administration (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 professionals for adults with autism and other developmental disabilities.

Since the law 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 and support people with Autism Spectrum Disorders (ASD) and their families. Last year, Congress overwhelmingly reauthorized this successful program. However, we must follow through with sufficient funding to provide interdisciplinary diagnostic services for hundreds of thousands of children, training for tens of thousands of graduate students, and important research being conducted around the nation via Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs. The LEND network program recruits and supports autistic adults as faculty advocates and as trainees, and expands 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 request the increase for the LEND program as part of a \$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 ACL, and the Agency for Healthcare Research and Quality (AHRQ).

Congress should encourage agencies to use this funding to fill current gaps in research and services, such as developing and disseminating new clinical standards can be developed and disseminated, helping support autistic individuals transitioning into adulthood, improving our understanding of autism across the lifespan and our understanding of effective supports and services, and creating two new Centers for Excellence - one on autism across the lifespan, and one on adult services. In addition, prevalence monitoring at the CDC should be expanded beyond the current 11 states that monitor autism prevalence in children and should include a new prevalence study on adults with autism. 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).

Family Caregiver Support Programs

To address the growing need to support family caregivers who are the linchpin of the nation's long-term services and supports system, we are requesting \$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, which has left an estimated tens of thousands of Americans with long-term debilitating symptoms, has amplified the need for supporting caregivers. President Biden recently asked for Congress to meet this need. Fifty-three million family caregivers provide the vast majority of our nation's long term services and supports, permitting individuals of all ages to remain in their communities and avoid or delay more costly out-of-home placements. For caregivers of people with I/DD, the levels of responsibility are not only greater than many other caregivers, but frequently lifelong. There are approximately 3 million family caregivers of persons with I/DD in the U.S. According to The Arc's Family and Individual Needs for Disability Supports (FINDS) survey, the majority of respondents provide more than 40 hours of care per week.

Lifespan Respite grants help states build respite capacity and improve quality by requiring states to focus on addressing respite provider/volunteer training and recruitment and start-up of new respite services. The program also helps family caregivers who struggle financially to pay for respite, but are not eligible for any publicly funded respite services.

The NFCSP funds respite, counseling, support groups, and caregiver training for family caregivers. The recent Older Americans Act reauthorization removes the state requirement for a 10% funding cap on serving older parents and relative caregivers of adults with disabilities. Despite recent positive outcomes for family caregivers reported in the NFCSP Outcome Evaluation from the Administration for Community Living, including the positive impact of respite and caregiver education on reducing caregiver burden, funding for NFCSP has not kept up with the increasing need due to COVID-19 and the aging population.

Kevin and Avonte's Law Program

We respectfully request that the House and Senate Subcommittees on Commerce, Justice, Science and Related Agencies, and House and Senate Appropriations Committees, provide \$3 million to fund Kevin and Avonte's Law Programs for FY 2022. Also, we request report language directing the Attorney General to use these funds to supplement, not supplant, any discretionary funds at his disposal currently used for other training programs to ensure spending is consistent with congressional intent to prevent injuries and deaths due to wandering.

Kevin and Avonte's Law authorizes grants to local law enforcement and nonprofit agencies to address the life-threatening problem of wandering among people with disabilities, especially autism and dementia. These funds can be used for education, training, notification systems, and resources to better address the needs of those at risk for wandering.

Parent Training and Information Centers

We respectfully request that the House and Senate Subcommittees on Labor, Health and Human Services, Education, and Related Agencies and House and Senate Appropriations Committees provide \$30 million for the Parent Training and Information Centers program at 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 to navigate the early intervention and special education process and improving academic, social,

and postsecondary outcomes.

In conclusion, these funding increases are necessary to meet the needs of people with I/DD and their families who have been under fiscal constraints over the past decade and continue to face considerable challenges due to the impact of the COVID-19 pandemic. Assuring the levels of funding we request for FY 2022 recognizes the critical role for research, program development, education, advocacy, and training that protects the civil rights and enhances the lives of individuals with developmental disabilities, their families, and communities.

Thank you for your consideration of this request and your continued attention to these important national priorities. For more information please contact Erin Prangley, Co-Chair, CCD Task Force on Developmental Disabilities, Autism and Family Supports at eprangley@nacdd.org.

Sincerely,

American Academy of Pediatrics
American Association on Intellectual and Developmental Disabilities (AAIDD)
American Music Therapy Association
American Network of Community Options & Resources (ANCOR)
American Occupational Therapy Association
American Speech-Language-Hearing Association (ASHA)
American Therapeutic Recreation Association
Association of Assistive Technology Act Program
Association of Assistive Technology Act Programs
Association of University Centers on Disabilities (AUCD)
Autism Society of America
Autistic Women & Nonbinary Network
Brain Injury Association of America
Delaware Developmental Disabilities Council (DDac)
Division for Early Childhood of the Council for Exceptional Children (DEC)
Easterseals
IDEA Infant and Toddler Coordinators Association (ITCA)
National Association of Councils on Developmental Disabilities
National Association of State Directors of Developmental Disabilities Services
National Association of State Directors of Special Education (NASDSE)
National Center for Parent Leadership, Advocacy and Community Empowerment (National PLACE)
National Disability Rights Network (NDRN)
National Down Syndrome Congress
National Respite Coalition
RespectAbility
TASH
The Arc of the United States

cc:

The Honorable Patty Murray, Chairwoman
Subcommittee on Labor, HHS, Education, and Related Agencies
Senate Appropriations Committee

The Honorable Roy Blunt, Vice Chairman
Subcommittee on Labor, HHS, Education, and Related Agencies
Senate Appropriations Committee

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

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

The Honorable Jeanne Shaheen, Chairwoman
Subcommittee on Commerce, Justice, Science, & Related Agencies
Senate Committee on Appropriations

The Honorable Jerry Moran, Vice Chairman
Subcommittee on Commerce, Justice, Science, & Related Agencies
Senate Committee on Appropriations

The Honorable José Serrano, Chairman
Subcommittee on Commerce, Justice, Science, & Related Agencies
House Committee on Appropriations

The Honorable Robert Aderholt, Ranking Member
Subcommittee on Commerce, Justice, Science, & Related Agencies
House Committee on Appropriations

The Consortium for Citizens with Disabilities (CCD) is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society. The Education Task Force of CCD monitors federal legislation and regulations that address the educational needs of children and youth with disabilities and their families, including regulatory efforts under federal law such as the Individuals with Disabilities Education Act (IDEA), the Every Student Succeeds Act (ESSA), Section 504 of the Rehabilitation Act of 1973, and the Americans with Disabilities Act (ADA). The Education Task Force advocates for high expectations for children with disabilities under these and other laws.

www.c-c-d.org