Testimony of

Erin Prangley, Co-Chair, Developmental Disabilities, Autism and Family Supports Task Force

Consortium for Citizens with Disabilities

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 testimony concerning Fiscal Year 2022 (FY22) appropriations for the 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 the National Family Caregiver Support Program and Parent Information Centers. The Consortium for Citizens with Disabilities (CCD) is the largest coalition of national disability advocacy organizations. The CCD Developmental Disabilities, Autism and Family Supports Task Force is co-chaired by myself and staff from Autism Speaks, the Autism Society of America, the Autistic Self Advocacy Network, the Autistic Women and Nonbinary Network and the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program. Our task force focuses on federal programs that directly relate to individuals with intellectual and developmental disabilities (I/DD), including autism spectrum disorders; family supports; and the prevention of child abuse and neglect. My testimony focuses on these programs and many task force priorities, however for a more detailed description of our appropriations requests as well as full list of task force organization signatories and funding table, you may refer to our letter submitted to Committee leaders on April 26th.

The pandemic exposed deadly gaps to services for people with I/DD and Congress now has the opportunity to fill those gaps by sufficiently funding existing programs designed to ensure people with I/DD can live fully and safely in the community.

Developmental Disabilities Assistance and Bill of Rights Act Programs

We respectfully request 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 Administration for Community Living (ACL) 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. For example, the DD Act programs: invest in programs tailored to the needs of the state; conduct extensive interdisciplinary training; provide advocacy, and legal and direct services; respond rapidly to COVID-19 pandemic by providing immediate and continuing support.

We also request continued support for the ACL Projects of National Significance (PNS). PNS fill critical research gaps and invest in demonstration projects targeting emerging needs and provide technical assistance to strengthen and support service networks and disseminate research and best practices.

Assistive Technology Act Programs

We respectfully request $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. Programs include state financing activities, device reutilization, device loan/borrowing, and device demonstration services. While individuals with disabilities are the primary beneficiaries of services, AT programs provide a wide range of services and supports to other stakeholders.

Autism CARES Act Programs

We respectfully request a $150 million increase in FY2022 for Autism and other Developmental Disabilities 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, the Agency for Healthcare Research and Quality, the Department of Education, and the Department of Labor. 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 and support people with autism spectrum disorders and their families. In 2019, Congress overwhelmingly reauthorized these successful programs and these additional funds could allow agencies to fill current gaps in research and services.

Of this, we request at least $38 million for LEND programs within 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 serve individuals across the lifespan and address critical shortages of health care professionals. This funding is critical to the LENDs' role in developing innovative strategies to translate research on interventions, guidelines, tools, and systems management approaches into practice.

Of this, we request $50 million for CDC's autism-related activities which could enable CDC to conduct a much-needed 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).

Family Caregiver Support Programs

We respectfully request $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 supporting caregivers. Fifty-three million family caregivers provide most 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. There are approximately 3 million family caregivers of persons with I/DD, the majority of which 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 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. 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 respectfully request $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 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 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.