

Congress of the United States

Washington, DC 20510

April 27, 2022

The Honorable Rosa DeLauro
Chairwoman
Subcommittee on Labor, Health and Human
Services, Education and Related Agencies
Committee on Appropriations
Washington, DC 20515

The Honorable Tom Cole
Ranking Member
Subcommittee on Labor, Health and Human
Services, Education and Related Agencies
Committee on Appropriations
Washington, DC 20515

Dear Chairwoman DeLauro and Ranking Member Cole:

As you prepare the Fiscal Year 2023 Labor, Health and Human Services, Education and Related Agencies Appropriations bill, we respectfully request a funding level of \$89,000,000 for the State and Territorial Councils on Developmental Disabilities (DD Councils), \$59,659,000 for the Protection and Advocacy for Individuals with Developmental Disabilities (PADD) program, which is utilized by Protection and Advocacy (P&A) Systems, \$47,173,000 for the University Centers for Excellence in Developmental Disabilities (UCEDD), and \$24,600,000 under the ACL/AIDD program for the Projects of National Significance in Intellectual and Developmental Disabilities (PNS). These programs are authorized under the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) and are located in every state and territory.

The current levels of funding for the DD Councils, P&As, and UCEDDs have not kept pace with the increased need. Persons with intellectual and developmental disabilities (I/DD) are living longer lives as a result of better diagnoses and treatment options, and new issues around aging and caregiving must be met by these programs. There is an increasing demand for services to address ongoing issues for the disability community, such as barriers to education and employment that prevent persons with developmental disabilities from becoming economically self-sufficient. Each program is actively working to educate policy makers, empower self-advocates, and provide innovative solutions to allow people with I/DD to live their fullest lives in the community. They are also helping states work towards implementation of Medicaid home and community-based services and ending waitlists for these services.

During the COVID-19 pandemic, states have become aware of the systemic barriers to health care, education, employment, housing, transportation, and other aspects of our society that have been made worse by the public health emergency. DD Councils, UCEDDs, P&As and PNS must have adequate funding to support the states' ongoing work to break down these barriers. The DD Act programs will build on this momentum to drive programs and policies that benefit individuals with I/DD and our society as a whole.

DD Councils invest in programs tailored to the needs of states that help people with developmental disabilities live in their communities. Appointed by governors – and with

memberships that are at least 60% people with DD and their families – DD Councils assess problems or gaps in state systems and design solutions accordingly. DD Councils often bring about public-private partnerships in transportation, education, healthcare, housing and more to increase the percentage of individuals with developmental disabilities who are independent, self-sufficient, and integrated into the community. Most recently, DD Councils have improved emergency services that support people with disabilities and their families, particularly in areas where health inequities exist, such as rural communities, racially and linguistically marginalized communities, tribal communities, and other spaces where the intersection of disability, race, and poverty exist. The DD Councils' success is the result of partnerships with local organizations to help individuals and families create their own innovative solutions to improve access to support, services and more. The request for \$89,000,000 for the Councils is based on increased demand for services, as well as language in the authorizing statute.

P&As utilize PADD funding to provide direct services to ensure that children and adults with I/DD are free from abuse, neglect, and financial exploitation. PADD programs also emphasize critical supports and services, including education, employment, housing, and transportation, that make community living a long-term reality. P&As advocate on behalf of persons with disabilities and are the largest provider of legally-based advocacy services for people with disabilities in the United States. With 57 locations, there is one in every state, the District of Columbia, and each U.S. territory. At the local and state level, PADDs have been fighting for the rights of people with disabilities, including equal access to testing, vaccination, and treatment during the COVID-19 pandemic, along with ending discriminatory medical rationing practices in several states. An increase in PADD funding to \$59.659 million is needed to address these new and arising issues while maintaining the other important work that P&As do through the PADD program for people with I/DD.

UCEDDs provide interdisciplinary pre-service preparation of students and fellows, continuing education, community training, research, model services, technical assistance, and information dissemination. UCEDDs exist to provide unique, expert state and community resources to facilitate the independence and full participation in the community of people living with developmental and other disabilities. Centers are housed in universities and translate the best scientifically validated practices into broad-based, high quality, community practices. The UCEDD network used its valuable expertise and resources to help federal, state, and local disability leaders advocate for disability inclusion in COVID-19 response and vaccine distribution plans.

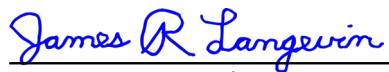
Congress has recognized the need for data collection about people with disabilities, their families, and their communities by its decades-long support for PNS. PNS gather longitudinal data to monitor progress on important policy priorities for people with I/DD, such as where they work and live, average wages earned, and the costs and outcomes of services and supports. PNS have contributed to the development of evidence-based practices and improved state-level policies that support people with I/DD to lead quality lives in the community, and avoid costly institutional services. PNS also fund short-term projects on emerging issues. For example, the Community Collaborations for Employment project – funded by PNS – is investing in


demonstration projects to increase and enhance collaborations across existing local systems. This is maximizing a seamless experience for and outcomes of youth with I/DD as they transition between school and working in the community.


Despite fiscal constraints over the past decade, DD Councils, P&As, UCEDDs, and PNS have engaged communities and created positive change. Ensuring adequate funding levels for FY 2023 will help to make certain that UCEDDs, P&As, DD Councils, and PNS continue to successfully promote equality of opportunity and inclusion for persons with I/DD across all aspects of community life.


Thank you for your consideration of this request and for your continued attention to these important national priorities.


Sincerely,


James R. Langevin
Member of Congress


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Member of Congress


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