

National Association of Councils on Developmental Disabilities Subcommittee on Labor, Health, Human Services, and Education, and Related Agencies Administration for Community Living

Chairman Blunt, Ranking Member Murray and members of the committee, the National Association of Councils on Developmental Disabilities (NACDD), a national membership organization for the State Councils on Developmental Disabilities (DD Councils), appreciates the opportunity to present this testimony. NACDD respectfully requests that Congress appropriate \$80 million for the DD Councils within the Administration for Community Living (ACL) in the Labor-HHS-Education appropriations bill for Fiscal Year (FY) 2020 and clarify in report language that not less than \$700,000 of that amount be provided for technical assistance and training for the DD Councils.

Authorized by the bipartisan Developmental Disabilities Assistance and Bill of Rights Act (DD Act), DD Councils work collaboratively with the University Centers for Excellence in Developmental Disabilities (UCEDDs) and Protection and Advocacy program for Developmental Disabilities (P&As), to "assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life, through culturally competent programs."¹ The DD Act design threads these three distinctly different programs together to ensure a well-trained cadre of experts provide services to individuals with DD and their families, protect the rights of individuals with DD, and ensure that people with DD are fully included in the work to improve services and systems to make them fully inclusive. Working within this federal framework, the role of the DD Councils is to promote personcentered and family-centered system improvements with and for people with developmental disabilities.

Since 1970, Congress has recognized that DD Councils are in a strategic position in each state and territory to invest in dynamic and innovative programs that improve services and systems that help people with developmental disabilities live in the community. Appointed by Governors, and consisting of at least 60% people with DD and their families, DD Councils assess problems or gaps in the system and design solutions. Innovative solutions from the DD Councils often bring about public-private partnerships that make real changes to systems such as transportation, education, healthcare, housing and more.

This FY 2020 funding request reflects the need for DD Councils to direct resources through partnerships with local non-profits, businesses and state and local governments, to overcome obstacles to community living for people with DD. Community living provides supports and services that empower children and adults with DD to live their lives to the fullest. People with DD are living longer and contributing to the social and economic growth of our country at

¹ 42 U.S.C. 15001(b).

historic levels. States and territories rely on DD Councils to turn fragmented approaches into innovative and cost-effective strategies to increase the percentage of individuals with DD who become independent, self-sufficient and integrated into the community. DD Council work helps people with DD realize competitive and integrated employment, access to qualified direct support workers, successfully transition to independent living, access affordable housing, build leadership and advocacy skills, and more. DD Council members also provide a critical and unique role in educating state and local policymakers by directly participating in the design of state and local government-funded supports and services affecting their lives.

DD Councils promote community living in the states through narrowly tailored, state specific initiatives. For example, even though persons with developmental disabilities want to go to work and continue to be contributing members to the workforce, national statistics indicate that persons with developmental disabilities experience significantly higher unemployment rates than their peers without disabilities. The Missouri DD Council invests funds towards statewide efforts that contribute to expanding opportunities for persons with developmental disabilities to get and keep competitive jobs in integrated work settings. The DD Council supported a project called Show-Me-Careers, which scaled up evidence-based practices in eight pilot communities. The project adopted a variety of approaches, including skill-building of youth, career planning, and development of partnerships with the local business community. Furthermore, recognizing lack of transportation was a significant obstacle to employment, the DD Council partnered with three Regional Planning Commissions and leveraged funding with the Missouri Department of Transportation (MODOT) to launch MO-RIDES, a referral service that connects riders to transportation providers. MO-RIDES works with existing transportation providers to find affordable, accessible and flexible transportation for people with DD who need a ride to work, appointments or shopping, thus improving their quality of life, by giving them greater access to their community.

Another example of local solutions stemming from DD Council efforts comes from Washington. The popular understanding of Autism spectrum disorder focuses primarily on children and the importance of early detection and intervention. However, Autism is a lifelong condition and supports and treatments change as people grow older. The Washington State DD Council is leading a five-year Community of Practice to explore different ways of supporting families with individuals with Autism across his or her lifespan. Some of their work includes developing strategies to address the needs of aging caregivers, establishing an adult sibling support network, educating parents with intellectual and developmental disabilities about parenting support services, and more.

The Georgia DD Council is another great example of Councils applying state-based solutions to obstacles to community living. Individuals with disabilities should have the opportunity to live full, self-determined lives in the community. That is why the Georgia Council on DD is the lead supporter of the UNLOCK! Coalition. UNLOCK! works to rebalance the state system of long-term services and supports, so that fewer dollars are spent on institutional care and more dollars are invested into home and community-based supports. Because of UNLOCK!, self-advocates, their families, providers, and other allies successfully advocated to bring additional resources for long term supports and services for people with disabilities to their state.

The 56 DD Councils require continuous support in order meet the requirements of the DD Act. The DD Act provides funding for technical assistance to DD Councils on how to implement the DD Act.² Previously funded through Projects of National Significance within the Administration for Community Living, starting in FY 2018, Congress authorized the same technical assistance within the appropriation for DD Councils. Unlike previous years, the FY 2018 and FY 2019 legislation did not contain report language to protect technical assistance funding at levels that reflect the need for these services. Unfortunately, for both FY 2018 and 2019, the Secretary of Health and Human Services reduced funding both through a departmental transfer as well as for other administrative needs in the department. For that reason, NACDD respectfully requests that the committee include report language reflecting minimum levels of funding of not less than \$700,000 for technical assistance and training.

Thank you for consideration of this request.

² The Information and Technical Assistance for Councils on Developmental Disabilities is a federally funded technical assistance project authorized by Section 129(b) of PL 106–402.