



Association of University Centers on Disabilities Testimony for the Subcommittee on Labor, Health and Human Services, Education and Related Agencies

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The Association of University Centers on Disabilities (AUCD) is pleased to provide this testimony on behalf of three programs in the U.S. Department of Health and Human Services: Administration on Community Living (ACL), UCEDD (\$47 million requested); (2) Health Resources and Services Administration (HRSA) LEND (\$58,344 million requested for Autism and other Developmental Disabilities, and of this amount \$40 million for LENDs in report language); and (3) National Institutes of Health, National Institute for Child Health and Human Development (NICHD) IDDRC (\$1.891 billion requested including a proportional increase for IDDRCs within the NICHD).

The Association of University Centers on Disabilities (AUCD)

AUCD is a membership organization that supports and promotes a national network of 144 university-based interdisciplinary programs, includes 68 University Centers for Excellence in Developmental Disabilities (UCEDD), 60 Leadership Education in Neurodevelopmental Disabilities (LEND) programs, and 16 Eunice Kennedy Shriver Intellectual and Developmental Disability Research Centers (IDDRC). AUCD's mission is to advance policies and practices that improve the health, education, social, and economic well-being of people with developmental and other disabilities, their families, and communities by supporting our members' research, education, health, and service activities that achieve our vision. Network members, located in every state and territory, are all part of universities or university medical centers and serve as a bridge between the university and the community, bringing together the resources of both to achieve meaningful change. AUCD's programs excel in basic and applied research, training, information dissemination, creation of model demonstration programs, systemic reform, and policy analysis. Strong network collaboration enables one program's innovations to rapidly spread throughout the country.

University Centers for Excellence in Developmental Disabilities

Since 1963, Congress has recognized that the University Centers for Excellence in Developmental Disabilities (UCEDD): Education, Research, and Service located in every state and territory are a critical and expansive resource for building the capacity of communities and creating improvements in the service delivery system for people with intellectual and developmental disabilities (I/DD) and their families. The UCEDDs are interdisciplinary centers authorized by the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) (Section 156 of P.L. 106-402, Subtitle D) and are located in every state and territory, with some states having multiple UCEDDs. The UCEDDs provide training and technical assistance; conduct research, evaluation, and the analysis of public policy; and share information and resources with people with developmental disabilities, their families, government agencies, and

providers. Federal funding supports each UCEDD's basic costs of operation. Each UCEDD leverages that funding to secure additional funding to carry out the purpose of the DD Act. In Fiscal Year 2023, the UCEDD's and Leadership Education in Neurodevelopmental and Related Disabilities programs (frequently located in UCEDDs) leveraged over \$716 million dollars from additional local, state, federal and private funding to meet the needs of local communities.

The UCEDDs have directly improved services and supports in the states and territories related to early intervention, healthcare, public health, community-based services, education, employment, housing, assistive technology, emergency response and transportation.

The increased funding will ensure that the UCEDDs continue to implement the purpose and requirements of the DD Act and can respond to the increased demand for training and technical assistance. In FY 2023, the UCEDDs and Leadership Education in Neurodevelopmental and Related Disabilities programs (LEND) (frequently located in UCEDDs) reached 1.4 million people through community training and technical assistance activities and the UCEDDs and LENDs provided long-term training to over 5,000 professionals.

Leadership Education in Neurodevelopmental Disabilities (LEND) Programs

The LEND programs are an effective workforce development program that operate within a university medical system and provides graduate-level, interdisciplinary training to the next generation of clinical, research, and community leaders. The training prepares trainees from diverse professional disciplines to assume leadership roles in their respective fields and enhances the clinical expertise of professionals to identify, assess, and provide care to children who have or are at increased likelihood of developing autism or other developmental disabilities. The LEND programs are authorized in The Autism Collaboration, Accountability, Research, Education and Support Act (P.L.116-60). The 60 LEND programs are located in 44 states, with six additional states and three territories reached through program partnerships without additional federal or state aid. In FY 2021, the LEND and Developmental-Behavioral Pediatrics (DBP) programs (an interdisciplinary training program for specialized pediatricians) collectively provided diagnostic services to confirm or rule out autism and other developmental disabilities to over 137,000 children; and trained over 22,000 trainees in over 40 professional disciplines. In addition to professionals, the trainees and faculty include persons with disabilities and family members. Persons with disabilities and their families provide an invaluable perspective to enhance the trainee understanding of lived experiences. As trainees, persons with disabilities and family members also develop their leadership and advocacy skills as part of an interdisciplinary care team. In FY 2023, over 38 percent of trainees in the LEND programs were from underrepresented racial groups, and over 10 percent were Hispanic or Latino.

The FY 2025 request for the Autism and Other Developmental Disabilities program, including the LEND programs, will support research, training programs, and state systems to improve access to quality systems of care and public awareness of issues affecting persons with autism and other developmental disabilities and their families. The increased funding for the LEND programs will provide the LEND programs with funding to train additional professionals to address significant disparities in evaluation, diagnosis, and treatment of persons with autism and other developmental disabilities, including persons from underserved communities. The funding will also provide the LEND programs with additional funding to continue to recruit and support more autistic adults as faculty and trainees. The LEND programs will also continue to

focus on expanding the LEND curriculum to include and address the needs of adults.

E.K. Shriver Intellectual and Developmental Disability Research Centers (IDDRC) Other Programs that Support and Serve Children and Adults with Disabilities

The Intellectual and Developmental Disabilities Research Centers (IDDRCs) were established in 1963 as "centers of excellence" as the country's first national research opportunity to address intellectual and/or developmental disabilities. The IDDRC's remain the nation's foremost sustained effort to prevent and treat disabilities through biomedical and behavioral research. The IDDRC Network with AUCD membership consists of 15 Centers with current P50 core grant funding from the Eunice Kennedy Shriver National Institute for Child Health and Human Development (NICHD) at the National Institutes of Health (NIH). The IDDRCs support approximately 300 research projects on an annual basis that seek to advance the understanding and treatment of chromosomal conditions and biochemical processes as they relate to brain function and intellectual and/or developmental disabilities. IDDRCs' scientific and clinical findings are key drivers to developing cutting-edge tests for detecting and diagnosing brain health conditions, creating new behavioral, biological and biochemical therapies to be used in the clinic, and improving assistive technologies. These contributions aim to find solutions that will ensure people with disabilities can live independently and fully participate in their communities. The IDDRCs provide invaluable training, mentoring, and support opportunities for the current and next generation of emerging leaders in clinical and biomedical sectors. The increased level of funding for NICHD and the IDDRCs is essential to building upon the cutting-edge research and successful collaboration of the IDDRCs to better understand and treat chromosomal conditions and biochemical processes as they relate to brain function and intellectual and/or developmental disabilities.

While NICHD has seen annual funding increases, the funding for the IDDRCs has remained flat for several years. The research by the IDDRCs that is identifying specific genes causing life-threatening conditions and are developing interventions to preserve health and function in the earliest stages of life is critical to improving the lives of people with intellectual and/or developmental disabilities.

AUCD supports increases for other programs that support and serve people with disabilities. We specifically support the: (1) *Transition Programs for Students with Intellectual Disabilities (TPSID)*; (2) *Projects of National Significance (PNS)*; (3) *The National Institute on Disability Independent Living and Rehabilitation Research (NIDILRR)*, and (4) *The National Center on Birth Defects and Developmental Disabilities (NCBDDD)*. AUCD and its members frequently secure grants from these programs. For example, the PNS fund three national long-term data collection projects conducted by AUCD members. These projects help policymakers, service providers, and people with disabilities and their families to make the most informed policy and individual decisions related to healthcare and employment.