

Submission by the Association of University Centers on Disabilities
Point of Contact: Cindy Smith, Director of Public Policy
1100 Wayne Avenue, Suite 1000, Silver Spring, MD 20910
csmith@aucd.org or 240.821.9464

Prepared for the Subcommittee on Labor, Health and Human Services, Education and Related Agencies. This testimony primarily addresses three programs in the U.S. Department of Health and Human Services, including: (1) UCEDD: Administration on Community Living (ACL); (2) LEND: Health Resources and Services Administration (HRSA); and (3) IDDRC: National Institutes of Health, National Institute for Child Health and Human Development (NICHD).

The Association of University Centers on Disabilities

The Association of University Centers on Disabilities (AUCD) is a membership organization that supports and promotes a national network of university-based interdisciplinary programs. Network members consist of 143 centers, including 67 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 all people with developmental and other disabilities, their families, and their communities by supporting our members in research, education, health, and service activities that achieve our vision. AUCD's network of programs are located in every state and territory and are all part of universities or university medical centers. AUCD's programs excel in basic and applied research, training, information dissemination, creation of model demonstration programs, systemic reform, and policy analysis. Given that these programs work collaboratively, innovations from one program can be rapidly implemented in communities throughout the country. AUCD's programs serve as a bridge between the university and the community, bringing together the resources of both to achieve meaningful systemic change.

University Centers for Excellence in Developmental Disabilities

The University Centers for Excellence in Developmental Disabilities (UCEDD): UCEDDs are interdisciplinary centers authorized in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) (Section 156 of P.L. 106-402, Subtitle D). The UCEDDs are located in every state and territory, with some states having multiple UCEDDs to serve the unique needs of the state. The funding supports the basic infrastructure costs of operation for each UCEDD. Each center leverages the investment to secure additional funding to carry out the purpose of the DD Act. The 67 UCEDDs provide training, technical assistance, service, research, and information sharing to people with disabilities, their families, state and local government agencies, and providers with a focus

on building the capacity of communities and creating improvements in the service delivery system for people with Intellectual and Developmental Disabilities (I/DD) and other disabilities. The UCEDDs have directly improved services and supports in the states and territories in the areas of early intervention, healthcare, public health, community-based services, education, employment, housing, assistive technology, emergency response and transportation.

Leadership Education in Neurodevelopmental Disabilities (LEND) programs

The Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Programs are authorized in The Autism Collaboration, Accountability, Research, Education and Support Act (Autism CARES Act) (P.L. 116-60). The LEND programs are located in 44 states, with an additional six states and three territories reached through program partnerships, (without additional federal or state aid). LEND programs operate within universities and collaborate with university hospitals and/or academic health centers to provide advanced interdisciplinary training to enhance the clinical expertise and leadership skills of professionals in a broad array of professional disciplines in the identification, assessment, and intervention of children and youth with neurodevelopmental and other related disabilities. The training programs have an explicit focus on training professionals to provide culturally and linguistically relevant care and to recruit diverse students and professionals into the programs. In FY 2020, 24% of long-term trainees in the LEND programs were from underrepresented racial groups and 13% were Hispanic or Latino. LEND programs also include self-advocates and family members as trainees and faculty to ensure trainees interact with people with lived experiences and to increase the leadership skills of self-advocates and family members as part of an interdisciplinary care team. The LEND programs have pivoted in response to the COVID-19 emergency. Critical clinical services have transitioned to a mix of telehealth and in-person formats, providing access to assessment, support, and treatment. A real-time transition to the provision of training either remotely or in a hybrid model proved an added benefit of building maternal and child health leaders with experience in telehealth to support the population of people with neurodevelopmental disabilities.

Eunice Kennedy Shriver Intellectual and Developmental Disability Research Centers (IDDRC)

The Intellectual and Developmental Disabilities Research Centers (IDDRCs) were established in 1963. The IDDRC's represent the nation's first and foremost sustained effort to prevent and treat disabilities through biomedical and behavioral research. The network of IDDRCs with AUCD membership consists of 16 Centers with current P30 core grant funding from the Eunice Kennedy Shriver National Institute for Child Health and Human Development (NICHD). Each IDDRC supports 40-100 research projects on an annual basis that seek to advance the understanding of chromosomal conditions and biochemical processes as they relate to brain function and I/DD. IDDRCs contribute to the development and implementation of evidence-based practices by evaluating the effectiveness of biological, biochemical, and behavioral interventions; developing assistive technologies; and advancing prenatal

diagnosis and newborn screening. They also provide invaluable research training, mentoring, and support to emerging leaders in clinical and research science.

FY 2023 Appropriations Requests and Justification

AUCD requests that Congress appropriate \$47,173 million for the UCEDDs for FY 2023 within the Administration for Community Living (ACL) in the Labor-HHS-Education appropriations bill. The increased funding will ensure the UCEDDs meet the requirements of the DD Act and that people with disabilities are fully included and accounted for as states and territories respond to the significantly increased demand for assistance due to the pandemic. In FY 2020, the UCEDDs reached 13 million people through community training and technical assistance activities and trained 6,242 professionals that work with people with disabilities. In FY 2021, the number of requests for technical assistance to UCEDDs increased by 44% and the number of technical assistance products developed for the UCEDDs increased by 83%. These increases are a direct result of the impact of the pandemic on the systems supporting people with disabilities and are not sustainable without additional assistance. As regulatory and service systems continue to evolve once the public health emergency expires, the support needs of people with I/DD and their families will not decline. In addition, the increased funding will enable the UCEDDs to fund a new round of competitive grants focused on increasing diversity, equity and inclusion by partnering with minority-serving institutions and will also support other UCEDD activities and programs to promote opportunities for people with I/DD to exercise self-determination, be independent, and be included in all aspects of community life.

AUCD requests that Congress appropriate \$57,344,000 for Autism and other Developmental Disabilities for FY 2023 and of this amount appropriate \$40,000,000 for LENDs (in report language) within Health Resources and Services Administration (HRSA) in the Labor-HHS-Education appropriations bill. The increased funding will ensure the LEND programs can address the significant unmet needs and disparities in evaluation, diagnosis, and treatment as well as supporting LENDs to recruit and support more autistic adults as faculty advocates and as trainees, with an emphasis on expanding LEND curriculum to include and address adult life needs and healthcare. Furthermore, while we are grateful the number of LEND programs were expanded from 52 to 60 in June of 2021, this was done with no increase in funding. All funded programs were subject to a 3.3% cut in their allocated funds to accommodate the expansion. We are hopeful the LEND programs will see their funding restored in FY 2023.

AUCD requests that Congress appropriate \$1.816 billion for the NICHD within the National Institutes of Health (NIH) (a 7.9 percent increase from FY 2021). AUCD additionally requests a proportional increase of 7.9 percent for IDDRCs within the NICHD in the Labor-HHS-Education appropriations bill.

The increased funding for NICHD is essential to building upon the cutting-edge research and collaboration of the IDDRC network to better understand the neural and biomolecular underpinnings of I/DD to better inform treatments and interventions. Previous increases in NICHD funding have not resulted in increases to the IDDRCs. This research is more important given the reality that people with I/DD are experiencing more severe symptoms of COVID-19 and die at disproportionately higher rates than people without disabilities.

Other Programs that Support and Serve Children and Adults with Disabilities

AUCD supports the proposed increases in the President's budget for programs that support and serve people with disabilities, such as special education, post-secondary education, and vocational rehabilitation programs; programs that improve the health of children and adults with disabilities; and programs that generate new knowledge and promote its effective use to strengthen opportunities for an inclusive life in the community. We are specifically supportive of the President's proposed increases for the following programs:

- *Transition Programs for Students with Intellectual Disabilities (TPSID)* and related technical assistance centers (NCC and NDTAC) to promote college programs for students with intellectual disabilities;
- *Projects of National Significance (PNS)*, innovative demonstration projects to monitor progress on key policy priorities for people with I/DD;
- *The National Institute on Disability Independent Living and Rehabilitation Research (NIDILRR)*, the federal government's primary disability research organization, which funds programs that generate new knowledge and promote its effective use to strengthen individual and community capacity for inclusion; and
- *The National Center on Birth Defects and Developmental Disabilities (NCBDDD)* strives to advance the health and well-being of people with disabilities by preventing birth defects, promoting better understanding of developmental disabilities, and improving the health of people with disabilities.

AUCD and AUCD's member centers frequently secure grants from these programs. For example, the PNS fund three national long-term data collection projects that help policymakers, service providers, and people with I/DD and their families to make the most informed policy and individual decisions related to healthcare and employment. All three of the national longitudinal studies are

conducted by AUCD's members. The studies include a study of the evolution of integration and inclusion of people ID/DD in society and more than 20 years of studies about community integration and employment for people with I/DD.