

**Andy Imparato, Executive Director**  
**Association of University Centers on Disabilities -Testimony for the record**

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:

- 67 University Centers for Excellence in Developmental Disabilities (UCEDD), funded by the Administration on Intellectual and Developmental Disabilities (AIDD)
- 52 Leadership Education in Neurodevelopmental Disabilities (LEND) Programs funded by the Maternal and Child Health Bureau (MCHB)
- 14 Intellectual and Developmental Disability Research Centers (IDDRC), most of which are funded by the Eunice Kennedy Shriver National Institute for Child Health and Development

All of AUCD's member programs have unique strengths that they share with each other and with the greater disability community. Some are exemplary educators: they train professional leaders, health care specialists, individuals with disabilities, and family members in areas such as early care and education, primary health care, special education, and innovative housing and employment programs. Others excel in basic and applied research, model demonstration programs, systemic reform, and policy analysis. Because these programs work collaboratively, innovations from one program can be rapidly implemented in communities throughout the country—thus affecting more lives than any one program could touch.

By working together, UCEDDs, LENDs, and IDDRCs engage in significant research that informs national policy and best practices. The network emphasizes national and international implementation of innovations in disability-related education, health care, and supports and services. It offers leadership on major social problems affecting all people with disabilities or special health needs. Below is a summary of each of these programs.

## **University Centers for Excellence in Developmental Disabilities (UCEDD)**

AUCD requests **\$40 million in FY 2018 within the Administration for Community Living (ACL)** to provide continued support to maintain the existing 67 UCEDDs. The Developmental Disabilities Assistance and Bill of Rights Act of 2000 (P.L. 106-402, Subtitle D) authorizes this network to 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 a unique, expert state and community resource to facilitate the independence and full participation in the community of people of all ages living with developmental and other disabilities.

Due to the funding formula in the Developmental Disabilities Act that requires appropriated funds to provide cost of living adjustments to Centers before funding National Training Initiatives (NTI) and technical assistance to Centers, this level of funding is necessary to support the core functions of the Centers in addition to being able to fund emerging national issues.

Developmental disabilities are disabilities that significantly affect three or more activities of daily living, occur prior to the age of 22, and include such disabilities as autism, behavioral disorders, cerebral palsy, brain injury, fragile X, Down syndrome and other genetic syndromes, fetal alcohol syndrome, intellectual disabilities, and spina bifida.

The national network of UCEDDs is well situated to facilitate communication across agencies, schools, and other providers as they are accustomed to blending resources and have had extensive experience working with multiple state and local agencies, interdisciplinary academic departments and community partners. Continued funding will be used to address obstacles to improve outcomes for youth in ways that can save money and lead to greater independence. Youth with intellectual and developmental disabilities want to graduate from school, find a job that pays a living wage, and be able to fully participate in our society as contributing citizens. What often stands in the way of this goal are poorly

coordinated and poorly supported transitions from school to postsecondary education and/or work, including needed services in the housing, transportation, health and direct supports sectors.

Continued funding will also be used to leverage the UCEDD's existing relationship with state agencies, disability organizations and youth with disabilities to help implement provisions under the recently passed Workforce Innovations and Opportunities Act and the Every Student Achieves Act, such as training educational professionals regarding the use of evidence-based practices in educating students with disabilities and improving comprehensive transition outcomes from adolescence to adulthood in ways that lead to successful postsecondary education and meaningful employment.

This funding will also help the UCEDD network to address other critical national and emerging needs such as ongoing developmental monitoring, especially for children exposed to lead and other environmental teratogens and for infants exposed to the Zika virus with its resulting complications.

#### **Leadership Education in Neurodevelopmental Disabilities (LEND)**

**AUCD recommends \$31.3 million for the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program within the Maternal and Child Health under the Health Care Resources and Services Agency.** This is the amount that was provided in FY 2017 that resulted in an increased number of sites available to screen, diagnose and provide evidence-based interventions to individuals with ASD/DD as authorized under the **Autism CARES Act**.

LEND programs provide advanced training to students and fellows from a broad array of professional disciplines in the identification, assessment, and treatment of children and youth with a wide range of developmental disabilities, including autism, intellectual disability, fragile X syndrome, cerebral palsy, spina bifida, Down syndrome, epilepsy and many other genetic and metabolic disorders. Nationally, there are tremendous shortages of personnel trained to screen, diagnose and treat individuals with DD,

and as a result, families often have to wait months to get a comprehensive diagnosis and begin to receive supports and services.

In 2006, the Combating Autism Act (P.L. 109-416) amended the Public Health Service (PHS) Act to add an emphasis on the early identification, diagnosis and treatment of children with ASD because of the rising epidemic of children in the US with an ASD diagnosis. This law was reauthorized in 2014 as the Autism CARES Act (P.L. 113-157). The law recognizes the benefits of the LEND network to address this significant public health issue by authorizing the expansion of the network.

The LEND network is currently made up of 52 programs in 44 states, with an additional six states and five territories reached through program partnerships. With the expanded number of LEND grant recipients and trainees, the LEND programs provided interdisciplinary diagnostic evaluations for over 94,000 infants and children in 2014-15. By continuing to meet the growing demand for these services, the LEND programs and its graduates are reducing wait times for diagnostic evaluation and entry into intervention services. Moreover, because the LEND programs typically targets underserved populations, their efforts are also helping to address disparities in early identification of ASD/DD.

Each LEND receives approximately \$600,000 each year; that number varies based on number of trainees and faculty disciplines represented. Trainees from LEND programs go on to serve in hospitals, clinics, schools and other community settings; they not only provide exemplary services to children and their families, but display leadership in local, state, and national efforts to develop more effective systems of care. LEND disciplines include: audiology, genetic counseling, health administration, nursing, nutrition, occupational therapy, pediatrics, neurology, pediatric dentistry, physical therapy, psychology, psychiatry, public health, social work, rehabilitation counseling, special education, and speech-language pathology.

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

**AUCD supports an additional \$2 billion for the National Institutes of Health over FY2017, including a proportionate amount for NICHD in FY2018.** NICHD provides funds for the national network of IDDRCs. Since their inception in the late 1960's, IDDRCs have been the national resource for basic research into the genetic and biological basis of human brain development, greatly improving our understanding of the causes of developmental disabilities and promoting the development of effective treatments consistent with their translational science mission.

For example, exciting research results from our IDDRC network were recently announced by the Carolina Institute for Developmental Disabilities (IDDRC) at the University of North Carolina in collaboration with the Centers in Washington state, Missouri, and Pennsylvania. The study is the first to show it is possible to identify which infants – among those with older siblings with autism – will be diagnosed with autism at 24 months of age. Using magnetic resonance imaging (MRI), researchers from around the country were able to correctly predict 80 percent of those infants who would later meet criteria for autism at two years of age. Prior to this research, it has been impossible to identify those at ultra-high risk for autism prior to 24 months of age. Diagnosis prior to 24 months will allow the introduction of new therapies early in the course of autistic progression, potentially improving the neurodevelopmental outcome of the child by treating before permanent signs and symptoms are established.

**AUCD urges NICHD to provide additional resources to the IDDRCs** for research infrastructure and expansion of cores so that they can conduct basic and translational research to develop effective prevention, treatment, and intervention strategies for children and adults with developmental disabilities.