

**ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES**

**TESTIMONY**

**BEFORE THE**

**HOUSE SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN  
SERVICES, EDUCATION AND RELATED AGENCIES**

**APPROPRIATIONS**

**PREPARED BY**

**Andrew Imparato  
Executive Director, Association of University Centers on Disabilities (AUCD)  
1000 Wayne Ave.  
Suite 1000  
Silver Spring, MD 20910**

**April 29, 2015**

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 Developmental Disabilities (AIDD)
- 43 Leadership Education in Neurodevelopmental Disabilities (LEND) Programs funded by the Maternal and Child Health Bureau (MCHB)
- 15 Intellectual and Developmental Disability Research Centers (IDDRC), most of which are funded by the National Institute for Child Health and Development (NICHD)

To frame the need for the AUCD network in “people terms,” approximately 19% or almost 1 in 5 Americans have a disability. This translates to 57 million citizens.<sup>1</sup> 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. Disabilities place individuals at risk living in poverty<sup>1</sup>, having significant secondary health risks, and for being un- and under-employed. Compared to other populations in the United States who suffer from health disparities, individuals with disabilities have the highest percentage of self-rated poor or fair health and, the highest proportion of sedentary lifestyle, smoking, obesity, and diabetes.<sup>2</sup> Only 41% of individuals with disabilities, ages 21-64 years, are employed and subgroups of people with disabilities, such as those with intellectual disabilities have a workforce participation rate of less than 20%.

Underserved racial and ethnic populations with disabilities, i.e., African American, Hispanic/Latino and Native Americans have even higher percentages of delayed diagnosis, poor health, lack of access to health and education services, and unemployment.<sup>2</sup> Without increased funding, the population of individuals with disabilities, especially those from underserved populations, will continue to demonstrate disparities in receiving early identification, optimum education, and treatment, thereby increasing the lifetime cost of services.<sup>2,3</sup> Through the clinical care, teaching, training, research, and advocacy efforts of the AUCD network, the number of individuals with disabilities who are living in poverty, have unmet health needs, and/or are unemployed can be reduced.

All of AUCD’s member Centers have unique strengths in research, education, and training that they share through partnerships with the programs and individuals whom they serve. AUCD’s member centers exist in all 50 US states and territories provide a wealth of resources to the nation. These resources include exemplary educators who train the next generation of professionals; clinical, education, and research leaders who work in partnership with individuals with disabilities to advocate for and promote inclusion and optimal functioning, and the ability

to address the needs of family members in areas such as early care and education, primary health care, special education, and innovative housing and employment programs. AUCD centers excel in basic and translational research, developing assays for early detection of and treatment for neurodevelopmental diseases, creating demonstration programs, advocating for systemic reform to optimize functioning, and analyzing the impact of policies. AUCD members serve as professional resources for local, state, and federal agencies. The synergy created by the AUCD network members, supported by the AUCD infrastructure, allows innovative interdisciplinary collaboration, promoting rapid dissemination of advances in identification, prevention, and treatment to the population and communities most in need—thus affecting more lives than any one program could touch. I'd like to summarize for you the scope of each program

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

Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs provide advanced training to students from multiple disciplines including neurology, audiology, genetics, nursing, nutrition, occupational therapy, pediatrics, pediatric dentistry, physical therapy, psychology, psychiatry, social work, rehabilitation counseling, special education, and speech-language pathology. With the guidance of expert professional faculty these trainees learn how to identify and treat a wide range of developmental disabilities, including autism spectrum disorders, speech-language disorders, hearing and vision impairments, cerebral palsy, epilepsy, spina bifida, fragile X syndrome, Down syndrome and other intellectual disabilities, and a wide range of genetic and metabolic disorders. Nationally, there are tremendous shortages of personnel trained to screen, diagnose and treat individuals with developmental disabilities, and as a result, families often have to wait months to get a comprehensive diagnosis and evidence-based interventions.

The LEND network is currently made up of 43 programs in 37 states. According to the Congressionally mandated Report to Congress on the Combating Autism Act (2014), the LEND programs have collectively made significant strides toward improved screening and diagnosis of autism among younger children and helped train a variety of healthcare professionals who treat a number of different developmental and intellectual disabilities.

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 autism spectrum disorders because of the significantly rising prevalence of children with ASD in the US. This law was reauthorized in 2011 and again 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 law intends to expand the LEND

programs to all states by gradually adding LEND programs in each of the thirteen states that currently do not have such a program.

For Fiscal Year 2016, AUCD is requesting \$30 million, a \$2 million increase for the LEND program. This is the amount that was authorized (but never reached) for FY 2011 under the original Combating Autism Act. This additional funding would provide resources for up to two new LEND programs in states that do not have one and increase funding for existing LEND programs. The increase would expand the number of sites and professionals to screen, diagnose, and provide interventions to individuals with autism spectrum disorder and other developmental disabilities as intended by the law and will increase the capacity to address the racial and ethnic delays in diagnosing these disabilities.

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

Authorized under the DD Act, the Administration for Community Living (ACL) supports a network of 67 University Centers for Excellence in Developmental Disabilities (UCEDD) that provide interdisciplinary pre-service preparation of students and fellows, continuing education, community training, research, model services, technical assistance, and information dissemination. The national network of UCEDDs are well situated in all 50 states and territories 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.

For Fiscal Year 2016, AUCD has requested \$39 million to provide continued support to maintain the existing 67 UCEDDs. Due to the funding formula in the Developmental Disabilities Act that requires appropriated funds to provide cost of living adjustments (COLA) 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, such as transition from school to postsecondary education, service, and/or integrated employment, and others identified by the DD network. 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, such as improving comprehensive transition outcomes from adolescence to adulthood in ways that lead to post-secondary education and meaningful employment.

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

For over 40 years, the Eunice Kennedy Shriver Intellectual and Developmental Disabilities Research Centers (IDDRC) have been at the forefront of basic and translational research on human brain development. In the early years of the IDDRC network, investigators identified

the basic processes by which the brain is formed. In the years since, the genes and cellular mechanisms that promote normal development have been discovered and the genetic and environmental causes of disrupted development causing intellectual and developmental disorders revealed. Based on this work, we are now at the dawn of an era when we can treat the basic mechanisms that cause intellectual and developmental disorders and not just the symptoms. As an example, about 15 years ago IDDRC investigators discovered that mutations of the MeCP2 gene cause Rett syndrome, a neurodegenerative disorder that afflicts young girls causing autism, epilepsy, altered breathing, intellectual disability and impaired motor function. An initial clinical trial was just completed shows improved breathing and behavior through treatment with IGF-1, a molecule whose function was discovered to be altered by the MeCP2 mutation. Similar approaches are emerging to treat other neurodevelopmental disorders, often manifest with autism and/or intellectual disability, with a goal to reverse the process, to enable the child to grow and develop to achieve with the absolute highest quality of life. New insights have also been gained into the causes of intellectual and developmental disabilities in children exposed to harmful environmental exposures, with approaches implemented to lessen these exposures and their impact on the developing brain. For newborn infants, neuroprotective strategies have been developed and implemented to lessen the effects of brain injury, enhancing the developmental potential of these highly vulnerable children.

### **Collaboration**

By working together, UCEDDs, LENDs, and IDDRCs engage in research that informs best treatment practices and national policy. The network emphasizes national implementation of innovations in disability-related education, health care, and supports and services.

One family's partnership with Tennessee's Vanderbilt Kennedy Center, which houses an IDDRC, UCEDD, and LEND, illustrates a lifelong relationship of engagement in the areas of training, research, and service. The mother began interactions with the Center when she was a graduate student training at Vanderbilt Peabody College. After embarking upon a career in teaching, she and her husband adopted a son, who would later be diagnosed at Vanderbilt with autism and bi-polar disorder. The child grew older and entered an inclusive pre-school on campus. During his school years, he was involved with research projects, and summer camps. His parents enrolled in a Center research project on mindfulness-based stress reduction offered to parents who have sons or daughters with disabilities. Their son would go on to perform and learn valuable social skills through the Center's SENSE Theatre project. This year, he will graduate from Next Steps at Vanderbilt, the Center's postsecondary education program for students with intellectual and developmental disabilities. While a Next Steps student, he completed an internship with the preschool he attended as a child. Several of his Next Steps classes were taught by current Center trainees, who like his mother, will go on to support individuals with

disabilities and work to improve their quality of life in a variety of settings. With the Center's lifespan approach, this partnership is sure to continue as needs and opportunities arise. This mother said, "I do not know what my husband and I would have done without the practical and researched-based wisdom of the Vanderbilt Kennedy Center."

In conclusion, the collaborative network of AUCD member organizations provide comprehensive services with the goal of optimizing health, education, functioning, inclusion, and well-being for individuals with disabilities and their families. With increased funding the AUCD member organizations have the potential to expand comprehensive services to address the health, education, housing, and employment needs of this severely underserved and vulnerable population of United States citizens. There is more to be done to allow AUCD to become the model proactive system of comprehensive care that it has the potential to be. Investments in these activities now will result in significantly decreased costs for future generations.

1. Nearly 1 in 5 People Have a Disability in the U.S., Census Bureau Reports: Report Released to Coincide with 22nd Anniversary of the ADA [press release]. Washington DC: United States Census Bureau, July 25, 2012 2012.
2. Drum C, McClain MR, Horner-Johnson W, Taitano G. *Health disparities chart book on disability and racial and ethnic status in the United States*. Durham, NH 2011 2011.
3. Belcher HM, Hairston-Fuller TC, McFadden J. How do we assess family supports and fairness in early intervention? *Developmental disabilities research reviews*. 2011;17(1):36-43.