



ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES

THE LEADERSHIP, EDUCATION, ADVOCACY & RESEARCH NETWORK

Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Programs

FY 2021 Labor, HHS, and Education Appropriations Bill Health Resources and Services Administration (HRSA) Autism and Other Developmental Disabilities

	FY18	FY19	FY20	AUCD FY21 Request
Autism and other DD	\$49,000,000	\$50,000,000	\$52,344,000	\$53,844,000
LENDs	\$31,317,485	\$33,500,000	\$35,245,000	\$36,245,000

Recommendation: Appropriate at least \$53,844,000 for Autism and other Developmental Disabilities. This amount increase is to address the need for ongoing research into evidence-based interventions for Autism Spectrum Disorders (ASD) and other developmental disabilities (DD), to develop and promote screening tools, and to disseminate the information and results. Each state and territory expresses significant needs for increased capacity to screen, diagnose and provide evidence-based interventions to individuals with ASD/DD. Of this amount, appropriate \$36,245,000, an increase of \$1 million, for the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program. This amount would restore funding to each LEND site for which funding was cut when the number of sites was increased from 43 to 52 – including sites in seven states that previously did not have a program presence.

Background: Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs have been funded for nearly 50 years to 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 ASD, 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; as a result, families often have to wait months to get a comprehensive diagnosis.

In 2006, the Combating Autism Act (P.L. 109-416) amended the Public Health Service (PHS) Act to add an emphasis in the early identification, diagnosis, and treatment of children with ASD because of the rising prevalence rates across the U.S. This law was reauthorized in 2011 as P.L. 112-32, in 2014 as the Autism CARES Act (P.L. 113-157), and again in 2019 as the Autism CARES Act (P. L. 116-60) The law recognizes the benefits of the LEND network in addressing this significant public health issue by authorizing the expansion of the network. The law expanded the LEND program to all states by gradually adding LEND host and/or partnership sites in each of the thirteen states that did not then have such a presence.

There are currently 52 LEND programs located in 44 U.S. states, with an additional six states and three territories reached through program partnerships. According to the Congressionally-mandated Report to Congress on the Combating Autism Act (2018), 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. Thanks to the expanded number of LEND grantees and trainees across health and other related disciplines, the national LEND network provided interdisciplinary diagnostic evaluations for an average of 113,623 infants and children annually between 2014 and 2017. By continuing to meet the growing demand for these services, LENDs are reducing wait times for diagnostic evaluation and entry into intervention services. Moreover, because LENDs typically target underserved populations, their efforts are also helping to address disparities in early identification of ASD/DD. On average, each LEND receives approximately \$640,000 per year. LEND graduates go on to serve in hospitals, clinics, schools and other community programs, providing exemplary services to children and youth and their families. LEND disciplines include: audiology, genetic counselling, 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; all sites also engage family leaders and many engage adults with ASD/DD. Additionally, the law authorized a technical assistance award for the interdisciplinary training network that helps to build connections across programs and provides a venue for collecting efficacy data, shared learning and curricula development, and identification/sharing of exemplary practices. Meeting the lifecourse needs as outlined in the legislation will require additional efforts to include the experiences and needs of adults via expanded training and increased faculty relationships.

Justification: The prevalence of autism diagnoses has risen dramatically over the past several decades (over 600 percent). According to the CDC, autism affects about 1 in 59 children, and boys are four times more likely than girls to be identified with ASD. Beyond autism, about 1 in 6 children has a developmental disability. It is difficult for these individuals to obtain an appropriate diagnosis, early intervention, and services because of the lack of trained health and allied health care providers, as well as the failure to update the education and training of health care professionals, educators, therapists, and other elements of the service system. LEND programs are exceptionally qualified to address the shortage of professionals needed to tackle this national challenge. The key components of LEND include: interdisciplinary training; leadership skill development; culturally competent clinical training; community outreach and continuing education; translating research to practice; provision of technical assistance; stakeholder collaboration; and product development and dissemination.

However, while great strides have been made in supporting children with autism and other developmental disabilities, that same progress has not been seen across the lifespan. Adults with autism in particular are frequently unable to access appropriate diagnosis, health care, and services. Research shows that autistic adults may experience shortened lifespans as a direct result of inadequate access to basic health care. The 2017 Report to Congress: Young Adults and Transition Youth with Autism Spectrum Disorder calls out the need to expand services, training and supports to autistic adults. Transition-age youth and young adults with ASD may experience barriers around issues such as: coordination of complex clinical care, access to health insurance and services, access to services and supports to facilitate individual and family management, development of meaningful relationship and social networks, and achievement and management of independent living. An increase in FY21 funding will support LENDS to recruit and support autistic adults as faculty advocates and as trainees, with particular emphasis on expanding LEND curriculum to include and address adult life needs and healthcare.

Increased FY 2021 funding will allow LENDs to expand their efforts, training more professionals to diagnose and provide high quality care for individuals of all ages with ASD/DD. This funding will also enable the LEND network to assist in ongoing developmental monitoring, especially for children impacted by pressing public health crises (opioids, lead and other environmental toxins, the Zika virus, and other new or emerging issues) with resulting complications. The LENDs are a strong community link to services and supports for addressing emerging issues within the disability community for individuals and their families. In addition, the funding will allow LENDs to develop innovative strategies to integrate and enhance existing investments, including translating into practice research findings on interventions, guidelines, tools, and systems management

approaches to training settings and communities, and to promote life-course considerations – from developmental screening in early childhood to transition to adulthood issues.

Recommended Report Language: The Committee has also provided \$36,245,000 for the LEND program within *HRSA Autism and Other Developmental Disabilities* to allow the existing 52 LEND sites to maintain their capacity to train professionals to screen, diagnose, and provide evidence-based interventions to individuals with autism spectrum disorder and other developmental disabilities (ASD/DD) as authorized by the Autism CARES Act. This funding will enable the LEND network to fulfill its expanded statutory mandate to serve individuals across the lifespan, addressing a critical shortage of health care professionals for adults with autism and other developmental disabilities. This funding will also enable the LEND network to assist in ongoing developmental monitoring, especially for children impacted by pressing public health crises (opioids, lead and other environmental toxins, the Zika virus, and other new or emerging issues) with resulting complications. The LENDs are a strong community link to services and supports for these newest members of the disability community and their families. This funding is critical to the LENDs' role in providing direct clinical assessment and evidence-based interventions. In addition, the funding will allow these programs to develop innovative strategies to integrate and enhance existing investments, including translating research findings on interventions, guidelines, tools, and systems management approaches to training settings, to communities, and into practice; and promote life-course considerations – from developmental screening in early childhood to transition to adulthood issues.