



Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Programs

FY 2019 Labor, HHS, and Education Appropriations Bill

Health Resources and Services Administration

Autism and Other Developmental Disabilities

	FY 2016 Final	FY 2017	FY 2018 CR	FY 2019 AUCD Request
Autism and other DD	\$47,000,000	\$47,000,000	\$47,000,000	\$52,000,000
LENDs	\$29,042,255	\$31,317,485	\$31,317,485	\$35,245,159

Recommendation: Appropriate at least \$52,000,000 for Autism and other Developmental Disabilities. This amount is \$5 million more than the FY 2017 amount to address the need for ongoing research into evidence-based interventions for Autism Spectrum Disorders (ASD) and other developmental disabilities, 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 and other developmental disabilities. Of this amount, appropriate \$35,245,159 million, an increase of \$3.9 million, for the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program. This amount would restore funding to each LEND site that was cut to increase the number of sites from 43 to 52.

Background: Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs have been funded for over 30 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 autism spectrum disorders, 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 developmental disabilities, and 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 autism spectrum disorders because of the rising epidemic of children with ASD in the US. This law was reauthorized in 2011 as P.L. 112-32 and again in 2014 as the Autism CARES Act (P.L. 113-157). 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 programs to all states by gradually adding LEND programs in each of the thirteen states that currently did not have such a program.

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 (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. According to the report, in 2010 LEND programs provided interdisciplinary diagnostic evaluations for more than 35,000 infants and children. With the expanded number of LEND grantees and trainees, the LEND programs provided interdisciplinary diagnostic evaluations for more than 109,000 infants and children in 2016-2017. By continuing to meet the growing demand for these services, the LEND programs are reducing wait times for diagnostic evaluation and entry into intervention services. Moreover, because the LEND programs typically target underserved populations, their efforts are also helping to address disparities in early identification of ASD and other developmental disabilities. On average, each LEND receives approximately \$600,000 each year. Trainees from LEND programs 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 programs also include a family leader. 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 of exemplary practices.

Justification: Autism continues to pose a significant public health challenge. 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 68, including 1 in 42 boys; 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 treatment 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 programs include: interdisciplinary training; leadership skill development; culturally competent clinical training; community outreach and continuing education; translating research to practice; technical assistance; collaboration; and product development and dissemination. The increase in FY 2017 allowed additional programs to be developed in states that did not have them in order to address this shortage. FY 2019 funding will allow LEND programs to continue to build these new programs to train professionals to diagnose and provide care for individuals with ASD and other DD. This funding will also enable the LEND network to assist in ongoing developmental monitoring, especially for children exposed to lead and other environmental toxins and for infants exposed to the Zika virus with its resulting complications. The LENDs are a strong community link to services and supports for these newest members of the disability community and their families. In addition, the funding will allow these programs 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 \$35,245,159 for the LEND program within *HRSA Autism and Other Developmental Disabilities* to allow the LEND programs 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 as authorized by the Autism CARES Act. This funding will also enable the LEND network to assist in ongoing developmental monitoring, especially for children exposed to lead and other environmental toxins and for infants

exposed to the Zika virus with its 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 treatment. 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, communities and into practice; and promote life-course considerations, from developmental screening in early childhood to transition to adulthood issues.