



## Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Programs

### FY 2014 Labor, HHS, and Education Appropriations Bill Health Resources and Services Administration Autism and Other Developmental Disorders

<i>In millions</i>	<b>FY 2013</b>	<b>FY 2014</b>	<b>President's FY 2015 Request</b>	<b>FY 2015 AUCD Request</b>
Autism and other DD	\$45,000,000	\$47,000,000	\$47,000,000	<b>\$47,000,000</b>
LENDs	\$26,451,215	\$28,042,255	\$28,042,255	<b>\$28,042,255</b>

**Recommendation:** Appropriate at least \$47,000,000 for Autism and other Developmental Disabilities. Of this amount, appropriate \$28 million for the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program. This will continue funding at the FY 2014 level so that the LEND programs can continue to increase the training of professionals in the interdisciplinary care and treatment of children and youth with autism spectrum disorders (ASD) and other developmental disabilities.

**Background:** Leadership Education in Neurodevelopmental and Related Disabilities (LEND) have been funded for over 20 years to provide leadership training to students and fellows from approximately 12 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 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.

In 2006 the Combating Autism Act (P.L. 109-416) amended the Public Health Service (PHS) Act to add an emphasis in the 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. 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 existing programs and to gradually increase the number of states that do not yet have a LEND program.

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. According to the report, in FY 2010, the 39 LENDs collectively screened more than 46,000 infants and children and provided diagnostic evaluation services 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 close to 56,000 infants and children in 2012. 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. Each LEND receives approximately \$600,000 each year. Trainees from LEND programs go on to serve in hospitals, clinics, schools and other community programs by providing exemplary services to children and youth and their families. LEND disciplines include: audiology, genetics, nursing, nutrition, occupational therapy, pediatrics, pediatric dentistry, physical therapy, psychology, social work, special education, speech-language pathology and all programs also include a family member. The law also 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 identification of exemplary practices.

**Justification:** Autism continues to pose a significant public health challenge. The prevalence of autism has risen dramatically over the past several decades (over 600 percent). According to the CDC, autism affects about 1 percent of the population, including 1 in 54 boys, making it more common than pediatric cancer, diabetes, and AIDS combined. It is increasingly 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 problem. 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. FY 2015 funding will allow LEND programs to continue to train professionals to diagnose and provide care for individuals with ASD and other DD. 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.

**Recommended Report Language:** The Committee has also provided \$28,042,255 for the LEND program within the HRSA Autism and Other Developmental Disabilities to allow the LEND programs to maintain their capacity to train professionals to diagnose, treat, and provide interventions to individuals with autism spectrum disorder authorized by the Combating Autism Act. This will allow these programs continue their work in the area of interdisciplinary leadership training to meet the needs of children with Autism Spectrum Disorders and other developmental disabilities.