



Leadership Education in Neurodevelopmental and Related Disabilities Programs



The Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Programs are an effective workforce development program that operate within a university medical system and provides graduate-level, interdisciplinary training to the next generation of clinical, research, and community leaders. The training prepares trainees from diverse professional disciplines to assume leadership roles in their respective fields. It also enhances the clinical expertise of professionals to identify, assess, and provide care to children who have or are at increased likelihood of developing autism or other developmental disabilities.

The LEND Programs are authorized in the Autism Collaboration, Accountability, Research, Education and Support (CARES) Act (P.L.116-60). The 60 LEND Programs are located in 44 states, with six additional states and three territories reached through program partnerships without additional federal or state aid.

In FY 2021, the LEND and Developmental-Behavioral Pediatrics (DBP) Programs (an interdisciplinary training program for specialized pediatricians) collectively provided diagnostic services to confirm or rule out autism and other developmental disabilities to over 137,000 children and trained over 22,000 trainees in over 40 professional disciplines. In addition to professionals, the trainees and faculty include persons with disabilities and family members. Persons with disabilities and their families provide an invaluable perspective to enhance the trainee understanding of lived experiences. As trainees, persons with disabilities and family members also develop their leadership and advocacy skills as part of an interdisciplinary care team.

“I want to use research to step into people’s shoes and see how they explore and how their brains might respond differently...That’s where the lessons from LEND come in – in not just assuming how someone with autism might see the world differently than you do. It’s been a great experience for me.”

Sanju Koirala, LEND Fellow at Institute on Community Integration

When there is respectful collaboration and shared decision-making, the health and well-being of people with disabilities improve. Additionally, partnerships with organizations led by people with lived experience honors the strengths, culture, traditions, and expertise when collectively engaged in program planning, implementation, evaluation, and policy activities. These partnerships help trainees to connect with people with lived experience from underrepresented and diverse groups to ensure their perspectives are considered in providing care. In FY 2023, over 38 percent of trainees in the LEND Programs were from underrepresented racial groups, and over 10 percent were Hispanic or Latino.

FY 2025 Funding Request:

AUCD requests that Congress appropriate \$58.344 million for the Autism and other Developmental Disabilities Program, and of this amount appropriate not less than \$40 million for the LEND Programs (in report language) within the Health Resources and Services Administration in the Labor-Health-Human Services-Education-Related Agencies appropriations bill.





Funding History (in millions):

	FY 19	FY20	FY 21	FY 22	FY 23	FY 24	FY 25 Request
Autism & other DD	\$50	\$52.3	\$53.8	\$54.3	\$56.3	\$56.3	\$58.3
LENDs	\$33.5	\$35.2	\$36.2	\$37.2	\$38.2	\$38.2	\$40

Justification:

The growing number of children, youth, and adults identified with autism and other developmental disabilities has increased the demand for services and the need for highly qualified health professionals. Approximately one in 36 children in the United States has been diagnosed with autism. On average, children with autism are typically not identified and diagnosed until after age four, even though diagnosis is possible as early as age two.

Children with autism and other developmental disabilities have complex health and developmental needs that require multiple service systems and interactions with professionals across disciplines. Despite the great need, there is a significant shortage of professionals and providers trained to care for and support persons with autism and developmental disabilities across the lifespan. The challenges around diagnosis and providing services across the lifespan are exacerbated by social determinants of health such as sex, race, ethnicity, socioeconomic status, and community factors. These challenges result in stark disparities in health and other life outcomes.

The FY 2025 request for the Autism and Other Developmental Disabilities program, including the LEND Programs, will support research, training programs, and state systems to improve access to quality systems of care and public awareness of issues affecting persons with autism and other developmental disabilities and their families. The increased funding for the LEND Programs will provide the Programs with funding to train additional professionals to address significant disparities in evaluation, diagnosis, and treatment of persons with autism and other developmental disabilities, including persons from underserved communities. The funding will also provide the LEND Programs with additional funding to continue to recruit and support more autistic adults as faculty and trainees. The LEND Programs will also continue to focus on expanding the LEND curriculum to include and address the needs of adults.

Recommended Report Language:

The Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Programs are funded at not less than \$40 million. This workforce development program is essential to increasing the number of professionals with advanced interdisciplinary training in a broad array of professional disciplines to train professionals to improve the evaluation, diagnosis, and treatment of people with autism and other developmental disabilities. The increased funding provides the LENDs with the funding needed to address the critical shortage of professionals, increase the number of trainees, serve under-represented communities, and fulfill the expanded statutory mandate to serve persons with autism and developmental disabilities across the lifespan.