



Leadership Education in Neurodevelopmental and Related Disabilities Programs

The Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Programs are authorized in The Autism Collaboration, Accountability, Research, Education and Support Act (Autism CARES Act) (P.L. 116-60). LEND programs operate within universities and collaborate with university hospitals and/or academic health centers to provide advanced interdisciplinary training to enhance the clinical expertise and leadership skills of professionals in a broad array of professional disciplines in the identification, assessment, and intervention of children and youth with neurodevelopmental and other related disabilities. The training programs have an explicit focus on training professionals to provide culturally and linguistically relevant care and to recruit diverse students and professionals into the programs. In FY 2020, 24% of long-term trainees in the LEND programs were from underrepresented racial groups and 13% were Hispanic or Latino. LEND programs also include self-advocates and family members as trainees and faculty to ensure trainees interact with people with lived experiences and to increase the leadership skills of self-advocates and family members as part of an interdisciplinary care team.

The 60 LEND programs, (located in 44 U.S. states, with an additional six states and three territories reached through program partnerships, without additional federal or state aid), have pivoted in response to the COVID-19 emergency. Critical clinical services have transitioned to a mix of telehealth and in-person formats, providing access to assessment, support, and treatment. A real-time transition to the provision of training either entirely remotely or in a hybrid model proved an added benefit of building maternal and child health leaders with experience in telehealth to support the population of people with neurodevelopmental disabilities.

While we are grateful the number of LEND programs were expanded from 52 to 60 in June of 2021, this was done with no increase in funding. All funded programs were subject to a 3.3% cut in their allocated funds to accommodate the expansion. We are hopeful the LEND programs will see their funding restored in FY 2023.

FY 2023 Funding Request:

AUCD requests that Congress appropriate \$57,344,000 for Autism and other Developmental Disabilities for FY 2023 and of this amount appropriate \$40,000,000 for LENDs (in report language) within Health Resources and Services Administration (HRSA) in the Labor-HHS-Education appropriations bill.

Funding History (in millions):

	FY 18	FY 19	FY 20	FY 21	FY 22	FY23 Request
Autism and other DD	\$49,000	\$50,000	\$52,344	\$53,844	\$54,344	\$57,344
LENDs	\$31,317	\$33,500	\$35,245	\$36,245	\$37,245	\$40,000

Justification:

The FY 2023 request for the Autism and Other Developmental Disabilities program will support training programs, research, and state systems with a focus on improving access, quality, and systems of care for underserved children, adolescents, and young adults with autism or other developmental disabilities from underserved backgrounds. The requested funding will allow the program to serve approximately 125,000 more children. The increased funding for the LEND programs will allow the LEND programs to address significant unmet needs and disparities in evaluation, diagnosis, and treatment as well as will support LENDs to recruit and support more autistic adults as faculty advocates and as trainees, with an emphasis on expanding LEND curriculum to include and address adult life needs and healthcare.

For more information on LEND work in your state, visit www.aucd.org or contact Cindy Smith, Director of Public Policy, at csmith@aucd.org



Recommended Report Language:

The Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Programs are uniquely positioned to provide 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 to promote life-course considerations – from developmental screening in early childhood to transition to adulthood issues.

The funding is critical to the LENDs' role in providing direct clinical assessment and evidence-based interventions. The increased funding will restore the 3.3 percent cut in individual LEND program funds, provide the LENDs with the funding needed to serve under-represented communities and fulfill its expanded statutory mandate to serve individuals across the lifespan and address a critical shortage of healthcare professionals for adults with autism and other developmental disabilities. In addition, the funding will allow these programs to contribute to the development of telehealth clinical services to support individuals with neurodevelopmental disabilities and their families.

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