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 (P.L. 116-60). The LEND programs operate within universities and collaborate with university hospitals and/or academic health centers. The LEND programs provide advanced interdisciplinary training to enhance the leadership skills and clinical expertise of professionals to identify, assess, and provide care to individuals who have or are at increased likelihood of developing autism and other neurodevelopmental or related disabilities. The LEND program is an effective workforce development program.

The 60 LEND programs (located in 44 states, with six additional states and three territories reached through program partnerships without additional federal or state aid) explicitly focus on recruiting diverse students and professionals and training professionals in a broad array of professional disciplines. These professionals provide culturally and linguistically relevant and family-centered care. The LEND programs are committed to improving health equity in underserved populations. In Fiscal Year (FY) 2022, 29.8 percent of trainees in the LEND programs were from underrepresented racial groups, and 9.4 percent were Hispanic or Latino. LEND programs also include self-advocates with disabilities and family members as trainees and faculty to further enhance their leadership and advocacy skills as part of an interdisciplinary care team. They also offer an invaluable perspective based on their lived experience.

In June 2021, the number of LEND programs was expanded from 52 to 60. At that time, the expansion included no increase in funding, and the programs received a 3.3 percent cut to accommodate the growth. While some cuts have been restored, the LENDs continue to expand the number of trainees they serve.

FY 2024 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 LENDs (in report language) within the Health Resources and Services Administration (HRSA) in the Labor-HHS-Education appropriations bill.

Funding History (in millions):

<table>
<thead>
<tr>
<th></th>
<th>FY 18</th>
<th>FY 19</th>
<th>FY 20</th>
<th>FY 21</th>
<th>FY 22</th>
<th>FY 23</th>
<th>FY 24 Request</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism and other DD</td>
<td>$49,000</td>
<td>$50,000</td>
<td>$52,344</td>
<td>$53,844</td>
<td>$54,344</td>
<td>$56,344</td>
<td>$58,344</td>
</tr>
<tr>
<td>LENDs</td>
<td>$31,317</td>
<td>$33,500</td>
<td>$35,245</td>
<td>$36,245</td>
<td>$37,245</td>
<td>$38,245</td>
<td>$40,000</td>
</tr>
</tbody>
</table>

Justification:
Approximately one in 68 children in the United States has been identified with autism. Diagnosis can be difficult and needs to be made by well-trained professionals. On average, most children are not identified and diagnosed until after age four, even though diagnosis as early as age two is possible. It is well-established that the public health and healthcare systems lack sufficient providers trained in systems thinking and interdisciplinary practices to meet the needs of children with autism, who often have multiple co-occurring conditions. Furthermore, significant racial and ethnic disparities exist in the diagnosis and recognition of autism as well as in access to care. The LEND training program seeks to meet these documented needs.

For more information on LEND work in your state or territory, visit www.aucd.org or contact Cindy Smith, Director of Public Policy, at csmith@aucd.org
The FY 24 request for the Autism and Other Developmental Disabilities programs, including the LEND program, will support research, training programs, and state systems to improve access to and the quality of systems of care for individuals with autism and other neurodevelopmental and related disabilities. The increased funding for the LEND programs will allow the programs to address significant disparities in evaluation, diagnosis, and treatment, including for individuals from underserved communities. The funding will also support the LENDs to recruit and support more autistic adults as faculty advocates and trainees, with an emphasis on expanding the LEND curriculum to include and address adult life needs.

**Recommended Report Language:**
The Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Programs are funded at not less than $40 million. The LEND programs play a critical role in providing direct clinical assessment and evidence-based care to individuals with autism and other neurodevelopmental and related disabilities. This workforce development funding is essential to increasing the number of providers with advanced interdisciplinary training in a broad array of professional disciplines to improve the identification, assessment, and care for individuals with autism and other neurodevelopmental and related disabilities. The increased funding will provide the LENDs with the funding needed to address a critical shortage of healthcare professionals, serve under-represented communities, and fulfill the expanded statutory mandate to serve individuals across the lifespan.