



ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES  
THE LEADERSHIP, EDUCATION, ADVOCACY & RESEARCH NETWORK

## Projects of National Significance

FY 2021 Labor, HHS, and Education Appropriations Bill  
HHS Administration for Community Living (ACL)  
Administration on Disabilities (AoD)  
Office of Intellectual and Developmental Disability Programs

FY17 <i>(in millions)</i>	FY18	FY19	FY20	AUCD FY21 Request
\$10.0	\$12.0	\$12.0	\$12.25	<b>\$14.0</b>

**Recommendation:** Appropriate at least \$14 million under the ACL/AoD program for the Projects of National Significance (PNS), a \$2 million increase over the FY 2019 level. This amount would restore the funding cut to this program made amid the recession during the 2012 fiscal year.

**Background:** Authorized under Section 162 of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (P.L. 106-402, Title I, Subtitle E), the HHS/ACL PNS gather longitudinal data to monitor progress on important policy priorities for people with intellectual and developmental disabilities (IDD) such as where they work and live, average wages earned, and the costs and outcomes of services and supports. The Administration on Disabilities is able to leverage PNS to provide technical assistance, disseminate research, and share best practices on how to serve those with disabilities. These projects help policymakers improve policies and services for people with IDD and inform policymakers of critical emerging needs, such as serving babies born with Zika and the continued impacts of the opioid crisis.

Developmental disabilities are disabilities that significantly affect three or more activities of daily living, occur prior to the age of 22, and include such disabilities as autism spectrum disorders, behavior disorders, brain injury, cerebral palsy, Down syndrome and other genetic syndromes, epilepsy, fetal alcohol syndrome, fragile X, intellectual disabilities and spina bifida.

The HHS/ACL PNS have contributed to the development of evidence-based practices and improved policies to support people with IDD to have quality lives in the community and avoid costlier institutional services by developing and demonstrating promising practices and strategies for state-level systems change that support transition from school to employment, family support and self-determination. PNS dollars have been used to develop an on-line training for direct support professionals who support people with IDD, fellowship opportunities to increase the number of trained disability professionals from diverse communities, positive behavior support practices and many more.

Projects of National Significance historically have also funded flexible and highly needed state family support programs. However, in FY 2012, significant cuts to the Projects of National Significance resulted in the elimination of programs designed to provide low-cost, highly efficient support to assist families to keep their family member with IDD in the family home.

**Justification:** The requested funds will support continuation of Projects of National Significance that (1) inform national and state policymakers about the status and trends in long-term supports and services for people with IDD through ongoing programs of data collection, analysis, information dissemination, and technical assistance to support emerging

and evidenced-based policy and practice; (2) support the development and demonstration of models for promising practices that support high quality personal outcomes and systems change; funds may also support a Project of National Significance focused on direct support workforce development and restore funds eliminated in FY 2012 for state-level family support programs.

The Projects of National Significance inform policy and practices at the national, state, and local levels. Continued funding of the projects will support informed policymaking and effective program monitoring, and will help support efforts to identify issues, find solutions, and advance effective practices related to the needs of individuals with IDD and their families.

Continued funding will track the impact of policy changes and identify better and more efficient strategies to improve outcomes for people with IDD. For example, through existing PNS projects, we know:

- The U.S. spent over \$65.21 billion on formal long-term services and supports (LTSS) for people with IDD, with most funding (85%) allocated for residential supports in settings for six or less, and for non-residential community supports (Braddock, et al., 2017).
- While 807,462 people with IDD received Medicaid Home and Community Based Services (HCBS)-funded supports in 2016, an additional 193,828 people with IDD living with a family member were waiting for Medicaid Waiver-funded supports (Larson, et al., 2018).
- Average per person Medicaid HCBS annual expenditures for recipients living with a family member were \$13,831 for people 21 years or younger and \$26,486 for people 22 years or older. For people living in any other setting, the averages were \$37,360 for those 21 years or younger, and \$72,609 for those 22 years or older (Larson et al., 2018).
- Between 1967 and 2016, the number of people living in large state IDD institutions (ICFs) declined from 194,650 to 19,091, and the number of facilities declined from 374 to 138. The average size of IDD group settings declined from 22.5 people per setting in 1977 to 2.2 people per setting in 2016 (Larson et al., 2018).

Youth with IDD want to graduate from school, find a living wage job, and participate fully as contributing citizens. What often stand in the way of this goal are poorly coordinated and poorly supported transitions from school to postsecondary education and/or work, and a significant lack of affordable housing, transportation, health and direct support services. The Projects of National Significance inform policymakers about innovative, evidence-based practices to support people with IDD to live and participate fully in their communities.

**Recommended Report Language:** Projects of National Significance — the Committee recommends \$14 million for Projects of National Significance in Intellectual and Developmental Disabilities. Those projects gather and report longitudinal data on the costs of, status of and trends in residential, in-home, individual, family and employment services for people with intellectual and developmental disabilities. They assist policy makers at the state and national levels to understand and improve policies and practices for people with intellectual and developmental disabilities by monitoring progress, measuring outcomes and identifying or developing new evidence-based practices. They demonstrate promising practices or improve existing practices in areas of national importance such as cost-effective family supports, increasing employment opportunities, and ensuring an adequate supply of qualified people to provide supports. They also inform policymakers and stakeholders about critical emerging needs (e.g., babies born with Zika infection, strategies for supporting the rising numbers of children and adults with autism spectrum disorders, and cost-effective supports and services for an aging population). Finally, they provide technical assistance to strengthen and support service networks and to disseminate research and best practices nationwide.