

A Look at IDD Funding in the U.S.

Twenty-five years ago, the U.S. Supreme Court's landmark decision in *Olmstead v. L.C.* found the unjustified segregation of people with disabilities violated the Americans with Disabilities Act. The decision ultimately influenced the amount and distribution of federal funds to support individuals with intellectual and developmental disabilities, which now totals \$80.6 billion.

In recognition of the anniversary of the 1999 decision, which was [celebrated June 20 by the U.S. Department of Health and Human Services](#), University of

Kansas researchers shared information about how federal funds are distributed to each state to help individuals, families and caretakers.

The figures are a part of the work conducted by the State of the States in Intellectual and Developmental Disabilities Ongoing Longitudinal Data Project of National Significance. [The project](#), now based at the KU Life Span Institute, has tracked federal spending in this area for more than 40 years and provides governments and the public with state-by-state data and comparisons.

Project director Shea Tanis, associate research professor at the KU Center on Developmental Disabilities, and research team members explored what the public receives with its investment and broke down the \$80.6 billion spent in fiscal year 2021, the latest year for complete figures.

Tanis is nationally recognized for her expertise in applied technology solutions, cognitive accessibility, and advancing the rights of people with cognitive disabilities to access information and technology.

“The investments in intellectual and developmental disabilities services and supports across the nation are a measure of our conscience and commitment to the disability community. It demonstrates our expectations of full-participation, equal opportunity, economic self-sufficiency and independent living outlined in the Americans with Disabilities Act.”

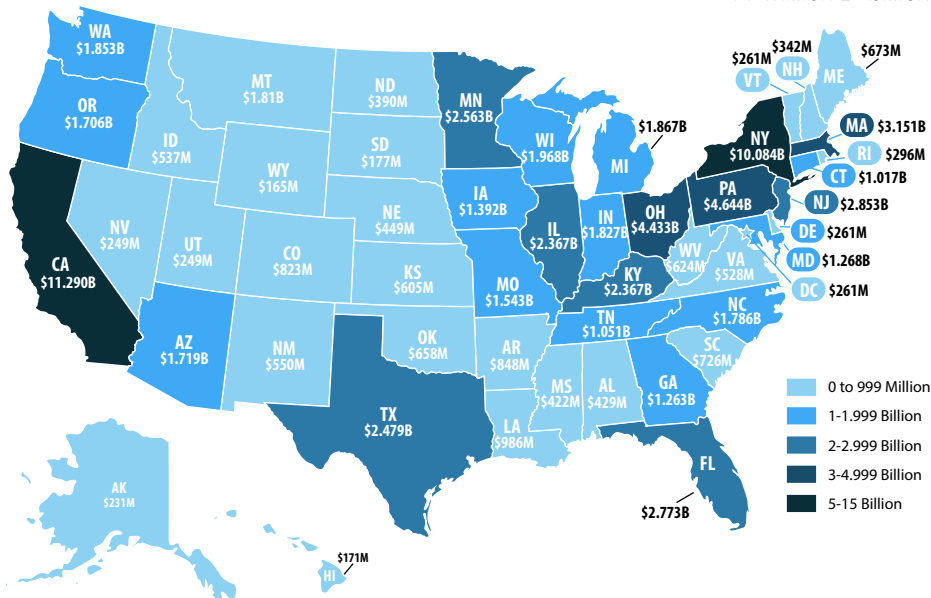


Shea Tanis

Associate research professor, Kansas University Center on Developmental Disabilities and director, State of the States in Intellectual and Developmental Disabilities project

AN OVERVIEW OF IDD FUNDING IN THE U.S.

Total Public Spending for IDD Supports and Services (FY 2021)
M=million B=billion



HOW MUCH DOES THE PUBLIC INVEST IN IDD?

An estimated 7.57 million people in the U.S. have intellectual and developmental disabilities (IDD). Many live in family homes and community-based settings.

The federal government invests in areas such as supported living, family supports, personal assistance, supported employment and other programs equal to about **0.1% of the \$6.8 trillion federal budget** for 2021 reported by the Congressional Budget Office, or about \$80.6 billion.

In 2021 87% of the total public funding for IDD services was distributed through Medicaid related services.

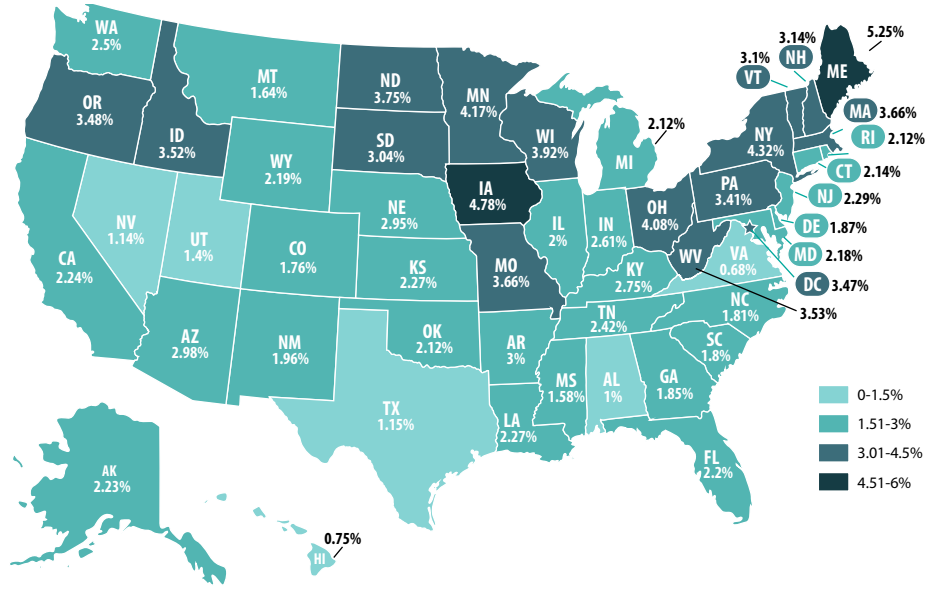
IDD = Intellectual and Developmental Disabilities

AN OVERVIEW OF IDD FUNDING IN THE U.S.

Percentage of Public Spending for IDD Supports and Services (FY 2021)

WHAT PORTION OF BUDGETS FUND IDD SERVICES?

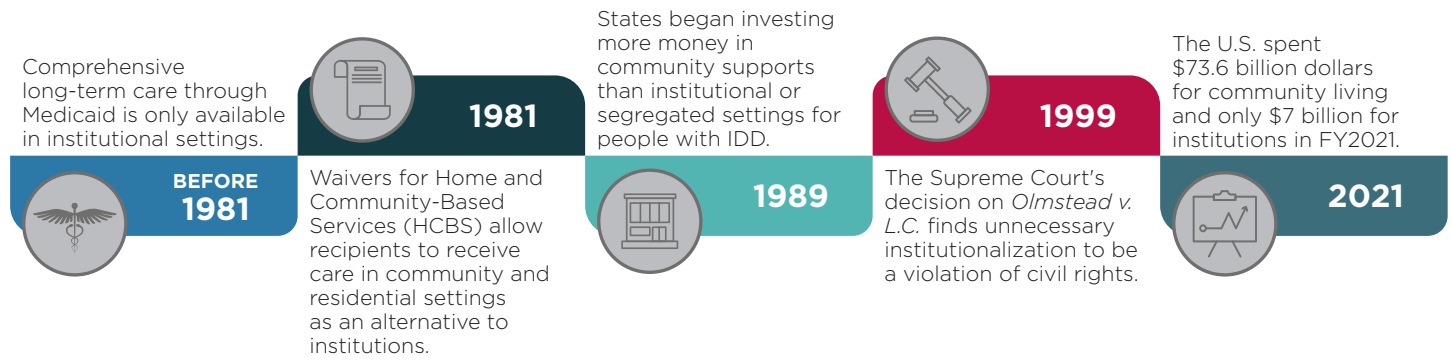
As a percentage of each state's budget, supports for intellectual and developmental disability services make up between <1% and 6% of any state's budget, or an average of 2.57%.



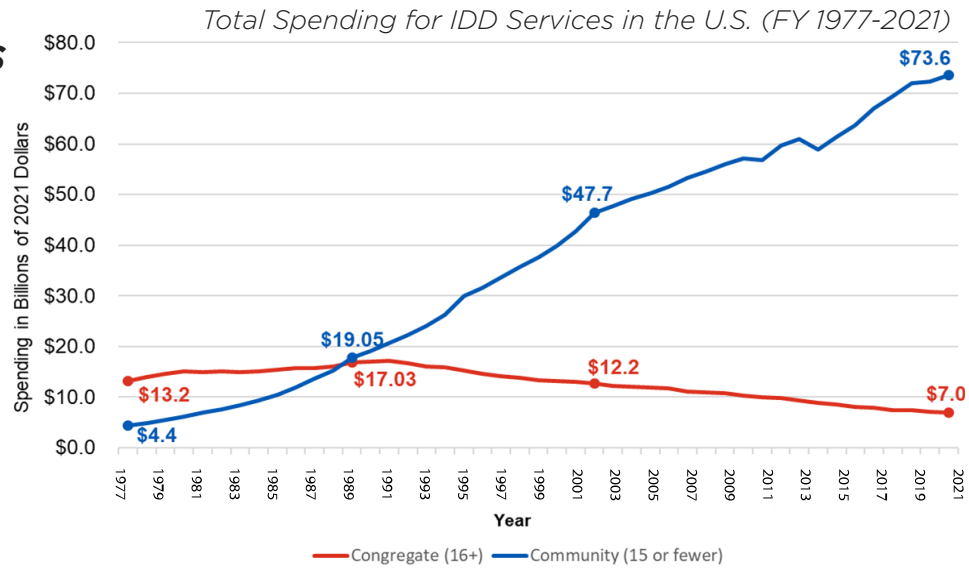
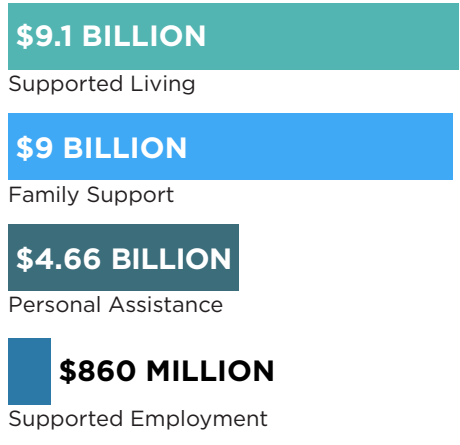
IDD = Intellectual and Developmental Disabilities

HOW HAS FUNDING FOR IDD SUPPORTS SHIFTED?

A Pivot Away from Congregate Settings to Home and Community-Based Care: Before 1981, the U.S. largely provided comprehensive long-term care in institutionalized or congregate settings. In the decades since, states have greatly increased investment in home and community-based services, or HBCS.



FY 2021 TOTAL SUPPORT FOR SELECTED PROGRAMS



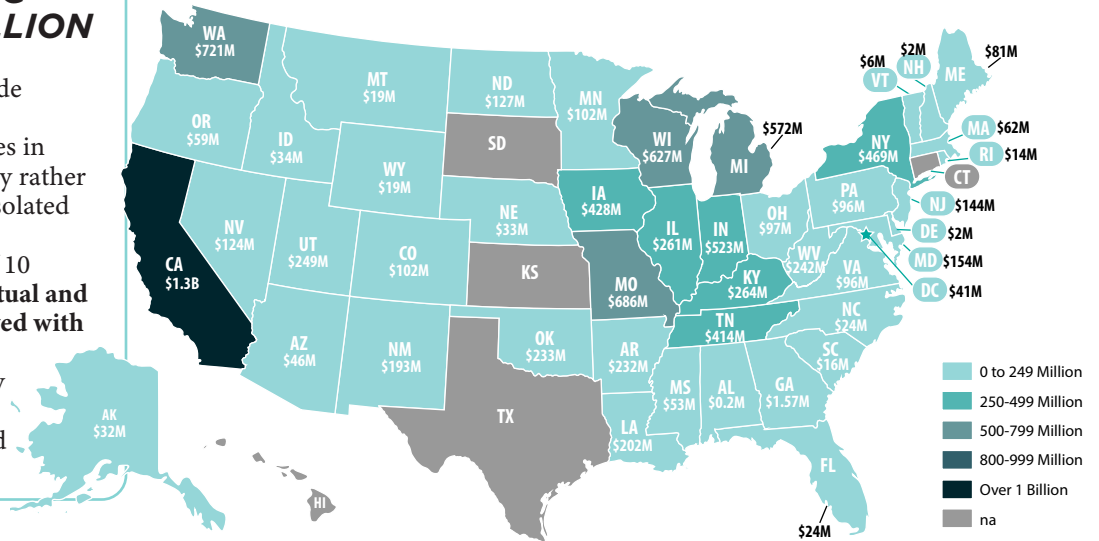
A BREAKDOWN OF SELECTED IDD SUPPORT & SERVICES

Spending on Supported Living Services
M=million B=billion

SUPPORTED LIVING SERVICES: \$9.1 BILLION

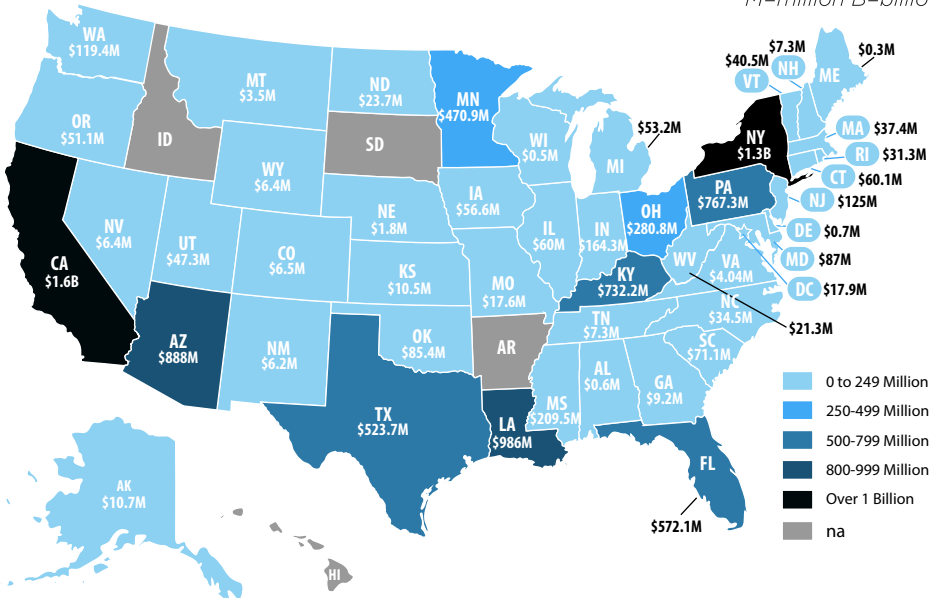
Home and Community Based Services (HCBS) provide opportunities for Medicaid beneficiaries to receive services in their own home or community rather than in institutions or other isolated settings.

In 2021, more than 7 out of 10 (72%) of people with intellectual and developmental disabilities lived with family members. The HCBS program has grown nationally to support 894,000 people and families across the United States.



72% of people with an IDD lived with family members in 2021

Spending on IDD Family Support Services
M=million B=billion



FAMILY SUPPORTS: \$9 BILLION

Family supports are community-based services provided to families of children or adults with an intellectual or developmental disability living in the family home, with the family as the primary beneficiary.

There are two categories of family support: **financial subsidy/cash payments** to families, and **general family support payments** including respite care, family counseling, equipment, architectural adaptation of the home, parent education and training, or other state-designated categories of family support. A state agency may provide vouchers, direct cash payments to families, reimbursement, or direct cash payments to serve providers.

In 2021, while 72% of people with intellectual and developmental disabilities lived with family members, only 10% of all caregiving families received supports from state intellectual and developmental disabilities state agencies.



10%

of caregiving families receive supports from state IDD agencies.



24%

of caregiving families are aged 60 and older.

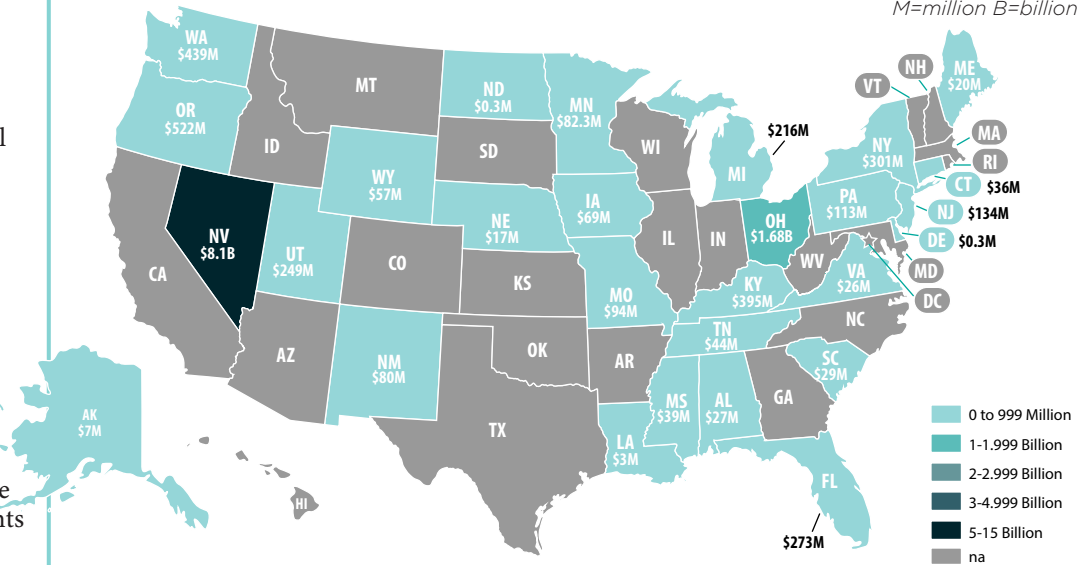


A BREAKDOWN OF SELECTED IDD SUPPORT & SERVICES

Spending on Personal Assistance
M=million B=billion

PERSONAL ASSISTANCE: \$4.66 BILLION

Personal assistance funds provide adults with intellectual and developmental disabilities the necessary level of support to remain in their homes. Some people use personal assistance to support daily activities such as getting up and ready for work, bathing, dressing, cooking, cleaning, or running errands, while for others it can be support in the workplace. Personal assistance includes guidance toward more independence and arrangements that offer the participant self-direction.

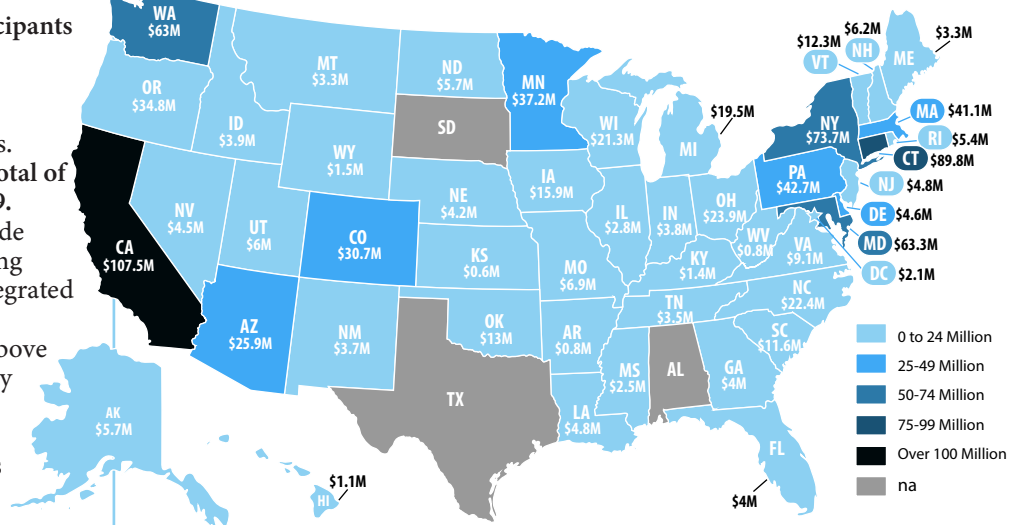


SUPPORTED EMPLOYMENT: \$860.80 MILLION

There were 536,771 work participants funded through federal or state employment support in FY2021. Of these, 22% were in supported employment programs or services. This is down nearly 14% from a total of 622,297 work participants in 2019.

Employment investments include support for obtaining and retaining what is known as competitive integrated employment, or CIE. In CIE, the individual is compensated at or above minimum wage comparable to pay to employees without disabilities performing similar duties, receives similar benefits, interacts with other individuals without disabilities and has similar opportunities for advancement.

Spending on Supported Employment (FY 2021)
M=million B=billion



TECHNOLOGY SOLUTIONS

Assistive technology can be used to facilitate:

- Communication
- Mobility
- Control of environment
- Daily activities
- Employment
- Recreation
- Education



Less than

1%

of IDD funding from states is for technology solutions.

Technology spending (FY 2021)

