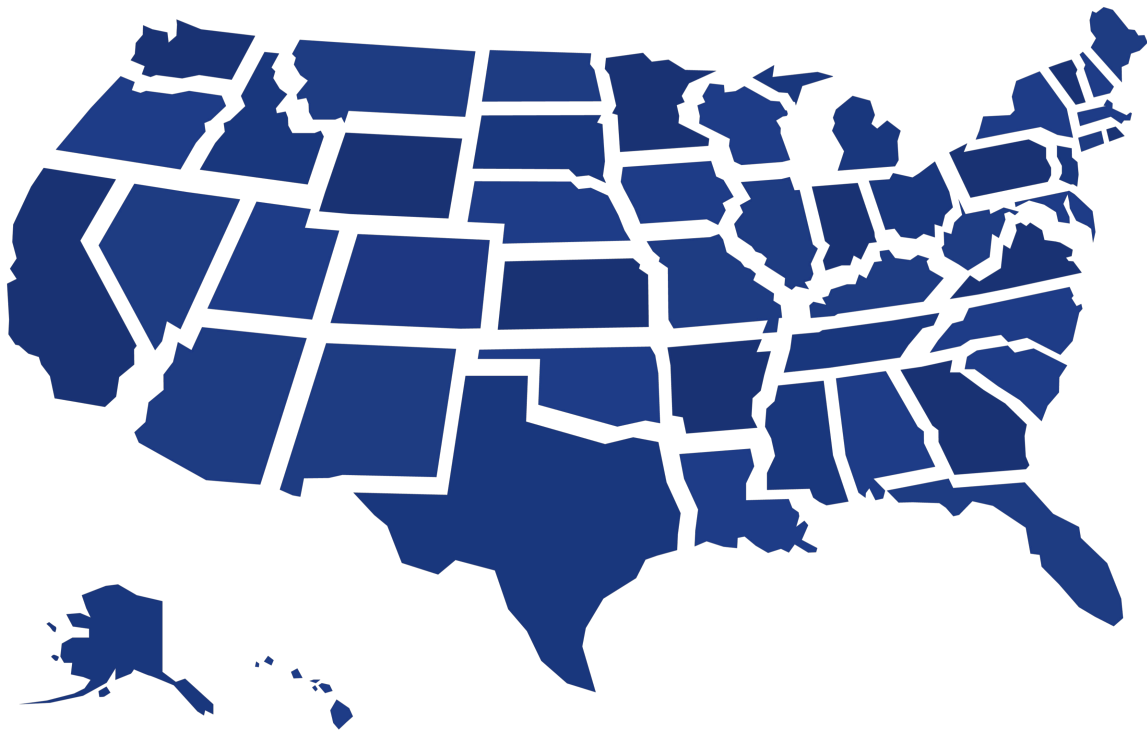


State Data Trends- 2025

Special Edition

NEW YORK



NATIONAL CONFERENCE OF STATE LEGISLATURES



State of the States

In Intellectual and Developmental Disabilities

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The State of the States



In Intellectual and Developmental Disabilities Ongoing Longitudinal Data Project of National Significance

The State of the States in Intellectual and Developmental Disabilities project was initiated in 1982 to investigate the determinants of public spending for intellectual and developmental disabilities services in the United States. The Project has developed a 40-year record of revenue, spending, and programmatic trends in the 50 states, the District of Columbia, and the United States as a whole. The data demonstrates the impact over time of federal, state, and local government fiscal policy. The data also reveals important service delivery trends in the states for community living, public and private residential institutions, family supports, employment, supported living, technology solutions, and Medicaid waivers.

As a Project of National Significance, the State of the States is a program authorized by the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) to empower individuals with developmental disabilities and their families to help shape policies that impact them. DD Act programs conduct important research and test innovative new service delivery models to bring the latest knowledge and resources to those who can put them to the best use, including self-advocates, families, service providers, and policymakers.



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CHART GLOSSARY

Terms and Definitions

All terms, definitions, and their sources can be found at stateofthestates.ku.edu/data-dictionary



State of the States
In Intellectual and Developmental Disabilities

- 1. Family Supports-** Community-based services provided to families of children or adults with IDD living in the family home with the family as the primary beneficiary. The state IDD agency may provide vouchers, direct cash payments to families, reimbursement, or direct cash payments to serve providers. There are two categories of family support, 1) financial subsidy/cash payments to families; and 2) 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. *Used in chart: Individual and Family Support Participants*
- 2. Fiscal Effort (FE)-** Spending for IDD services per \$1,000 of aggregate statewide personal income. *Used in chart: Fiscal Effort for IDD Services*
- 3. Home and Community Based Services (HCBS)-** 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. *Used in chart: Total Public IDD Spending for Services*
- 4. Intellectual and Developmental Disabilities (IDD)-** A term used to describe a group that includes either people with both intellectual disability and another developmental disability or a group that includes people with intellectual disability or another developmental disability. *Used in all charts.*
- 5. Intermediate Care Facility for Individuals with Intellectual Disability (ICF/ID)-** An optional Medicaid benefit that enables states to provide comprehensive and individualized health care and rehabilitation services to individuals to promote their functional status and independence. *Used in chart: Total Public IDD Spending for Services*
- 6. Medicaid-** Medicaid provides health coverage administered by the states, according to federal requirements. It provides health coverage to millions of Americans, including low-income adults, children, elderly adults, pregnant women and people with disabilities. It covers many long-term services and supports. *Used in chart: Total Public IDD Spending for Services*
- 7. Personal Assistance-** Services that provide adults with IDD the necessary level of support to remain in their homes. This includes guidance toward more independence and arrangements that exercise a measure of participant-direction. *Used in chart: Individual and Family Support Participants*
- 8. Supported Living -** Supports funded by the state IDD agency for adults in housing arrangements that guarantee: a) choice of where participants live and choice of house-mates; b) control of the living arrangement by the individual, the individual's family or an organization not providing services to the individual with a disability; and c) supported living planning that recognizes the individual's changing needs for effective support in their living arrangement and daily life. *Used in chart: Individual and Family Support Participants*

STATE DATA

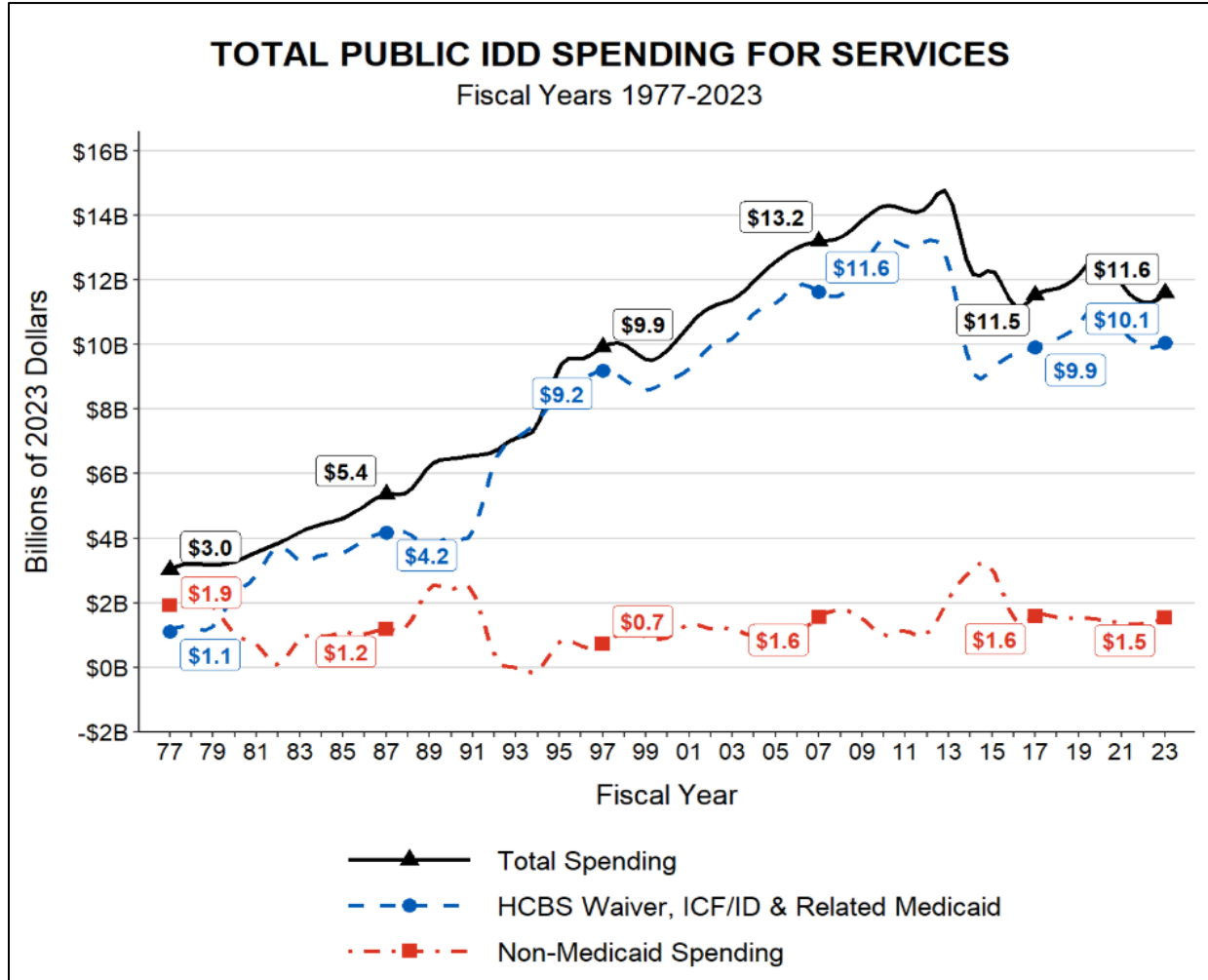


CHART DESCRIPTION

The chart aims to show how total spending has increased, decreased, or maintained over time. It also aims to show how much of the total spending on IDD services has come from Medicaid spending. Specifically, it shows spending for HCBS Waivers, ICF/IDs, & other related Medicaid spending compared to non-Medicaid spending over time.

COMPARISON-NATIONAL DATA

When comparing to the United States, the U.S.’s total spending has increased from \$20.9 billion in 1977 to \$104.6 billion in 2023. HCBS Waiver, ICF-ID, & Related Medicaid spending has increased from \$6.6 billion in 1977 to \$86.9 billion in 2023, and Non-Medicaid spending has increased from \$14.4 billion in 1977 to \$17.6 billion in 2023.

STATE DATA

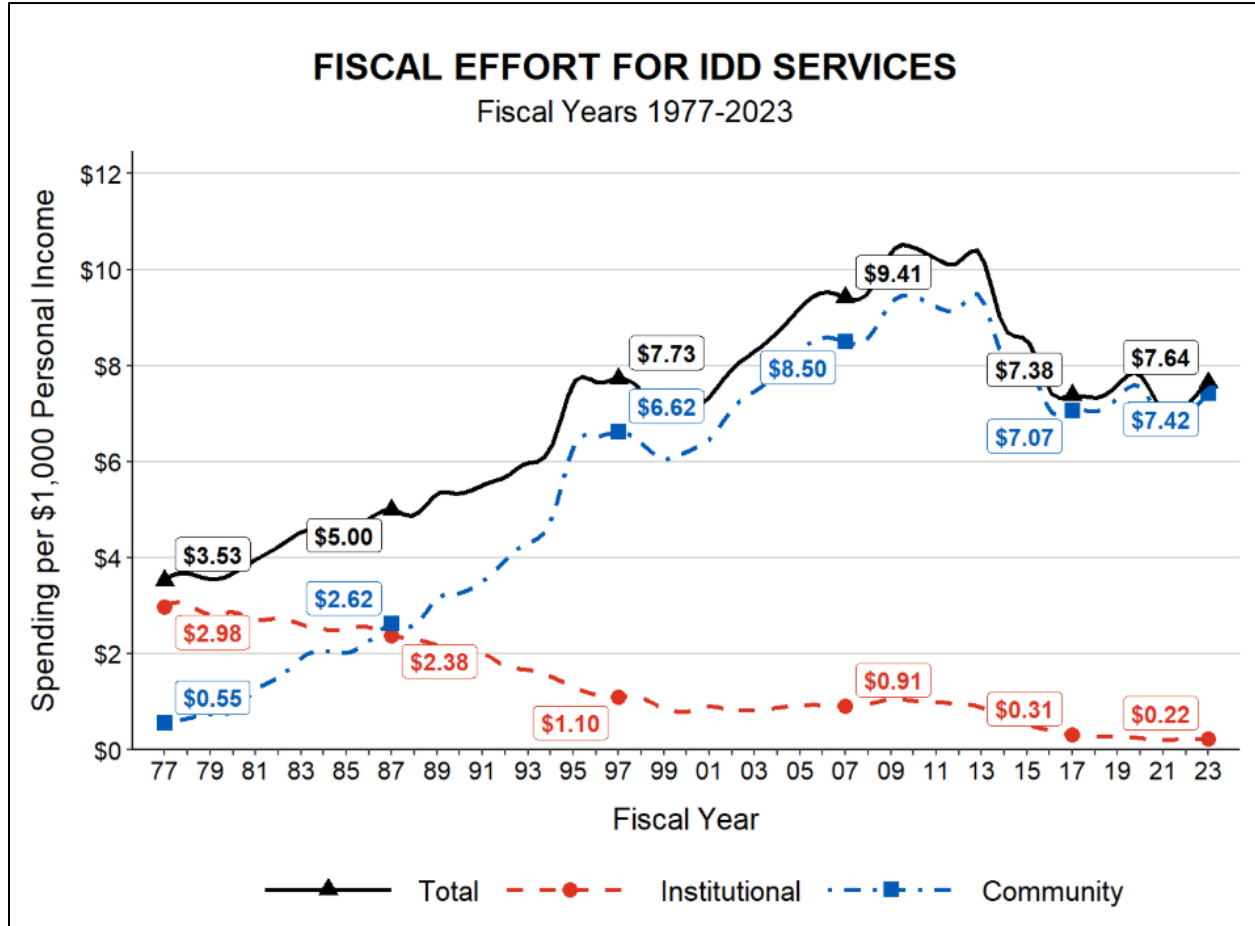


CHART DESCRIPTION

The chart aims to show how the total fiscal effort for IDD services have increased, decreased, or maintained over time. Specifically, it aims to show how community fiscal effort has increased, decreased, or maintained compared to institutional fiscal effort. Community fiscal effort is spending on services serving 15 persons or less with IDD, while institutional fiscal effort is spending on settings of 16 or more persons with IDD.

COMPARISON-NATIONAL DATA

Total fiscal effort for IDD services in the United States has increased from \$2.20 in 1977 to \$4.66 in 2023. Community fiscal effort has increased from \$0.55 in 1977 to \$4.30 in 2023, while institutional fiscal effort has decreased from \$1.65 in 1977 to \$0.35 in 2023.

STATE DATA

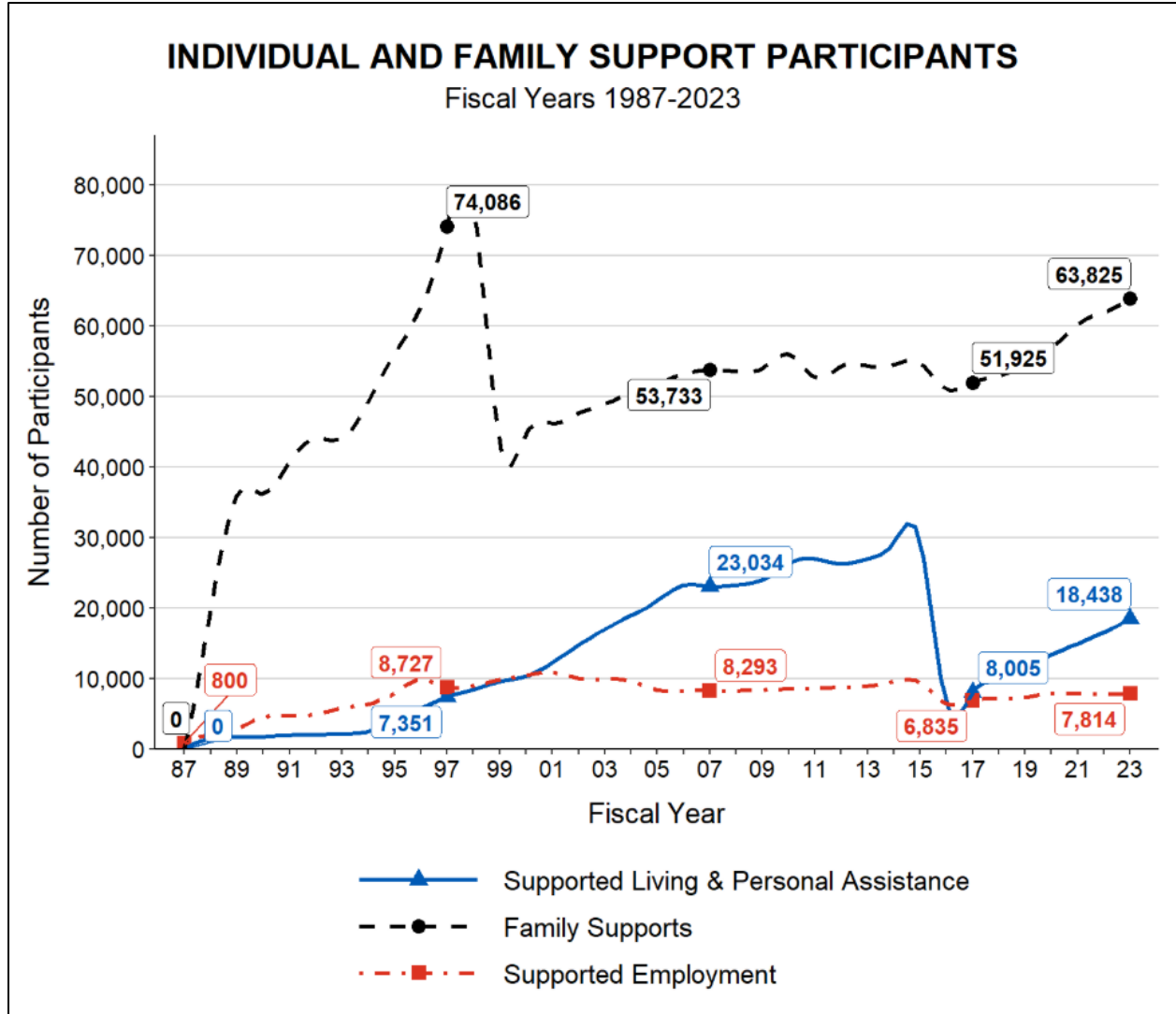


CHART DESCRIPTION

The chart aims to show how the number of people receiving supported living and personal assistance, family supports, and supported employment services has increased, decreased, or maintained over time.

COMPARISON-NATIONAL DATA

In the United States, supported living and personal assistance spending increased from \$0.0 billion in 1987 to \$18.1 in 2023, while family supports spending increased from \$0.3 billion in 1987 to \$11.1 in 2023, and supported employment spending increased from \$0.1 billion in 1987 to \$1.1 billion in 2023.

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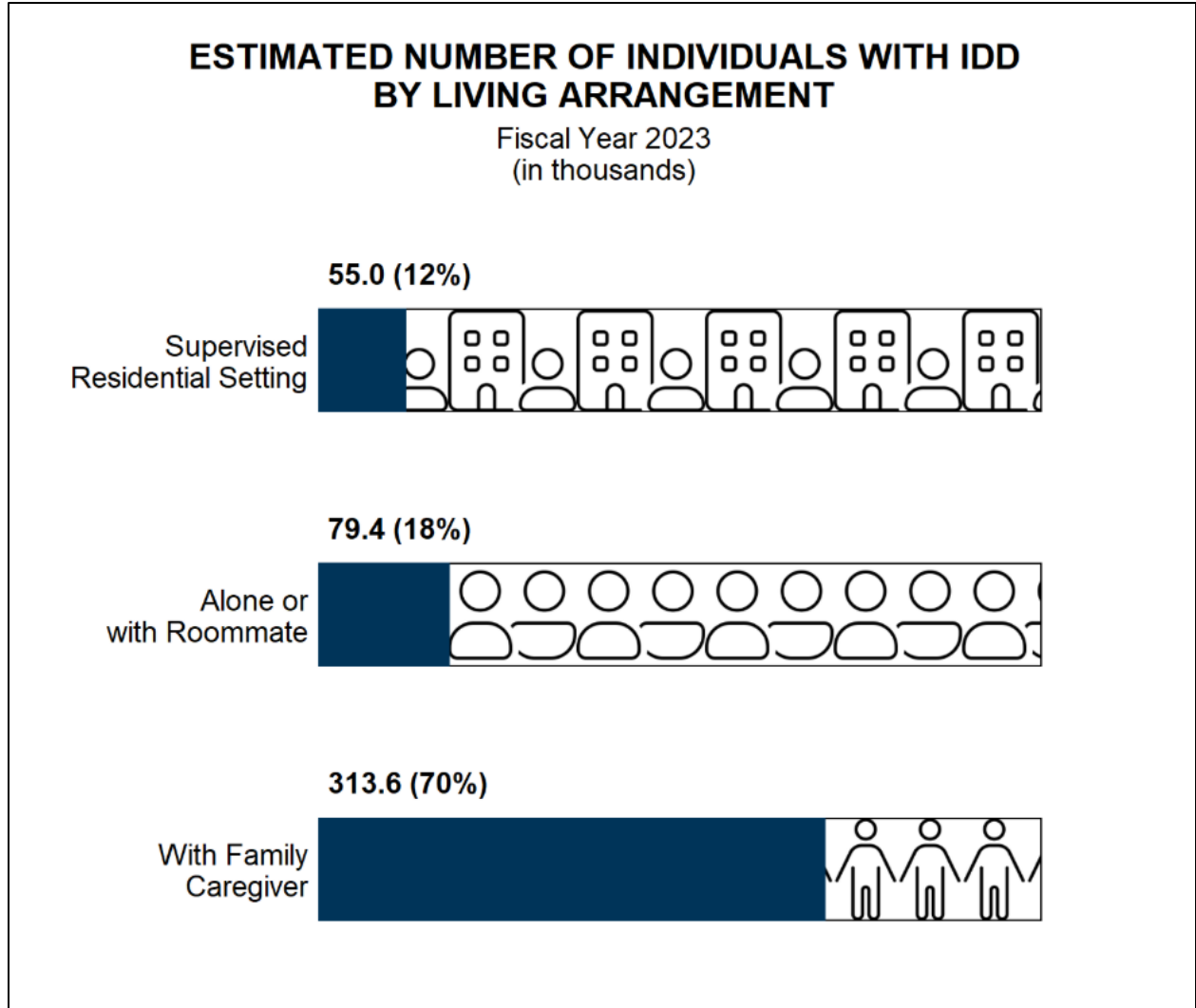


CHART DESCRIPTION

A horizontal bar chart illustrating the Estimated Number of Individuals with IDD by Living Arrangement in FY 2023. The chart aims to show what percentage of individuals with IDD live in a supervised residential setting, live alone or with a roommate, or live with a family caregiver.

COMPARISON-NATIONAL DATA

For FY 2023 in the United States, the percentage of individuals in a supervised residential setting was at 10% (729,100 people), while individuals living alone or with roommate was at 18% (1,392,000 people), and individuals living with a family caregiver was at 72% (5,498,900 people).

New York (NY)

1. Beginning fiscal year 2016, New York shifted from aggregate-level to claim-level data sources for its State of the States submission. This permitted reliable counts of distinct (unduplicated) individuals participating in multiple current support programs for the first time. It also permitted the State to better distinguish service recipients by age. Participant counts for supported living/personal assistance arrangements were particularly impacted because those living in such arrangements often rely on packages of multiple services and supports. Hence, there was a steep drop in supported living/personal assistance participants in 2016. Because individuals participating in supported living/personal assistance arrangements are also a component of the “Community Residential – 1 to 6 Persons” category, there is a similar drop for those counts.
2. The data source change also led to a reallocation of service dollars between the supported living and family support expenditure categories, though the total combined expenditures for these categories did not change.