

THE STATE OF THE STATES



In Intellectual and Developmental Disabilities Project of National Significance

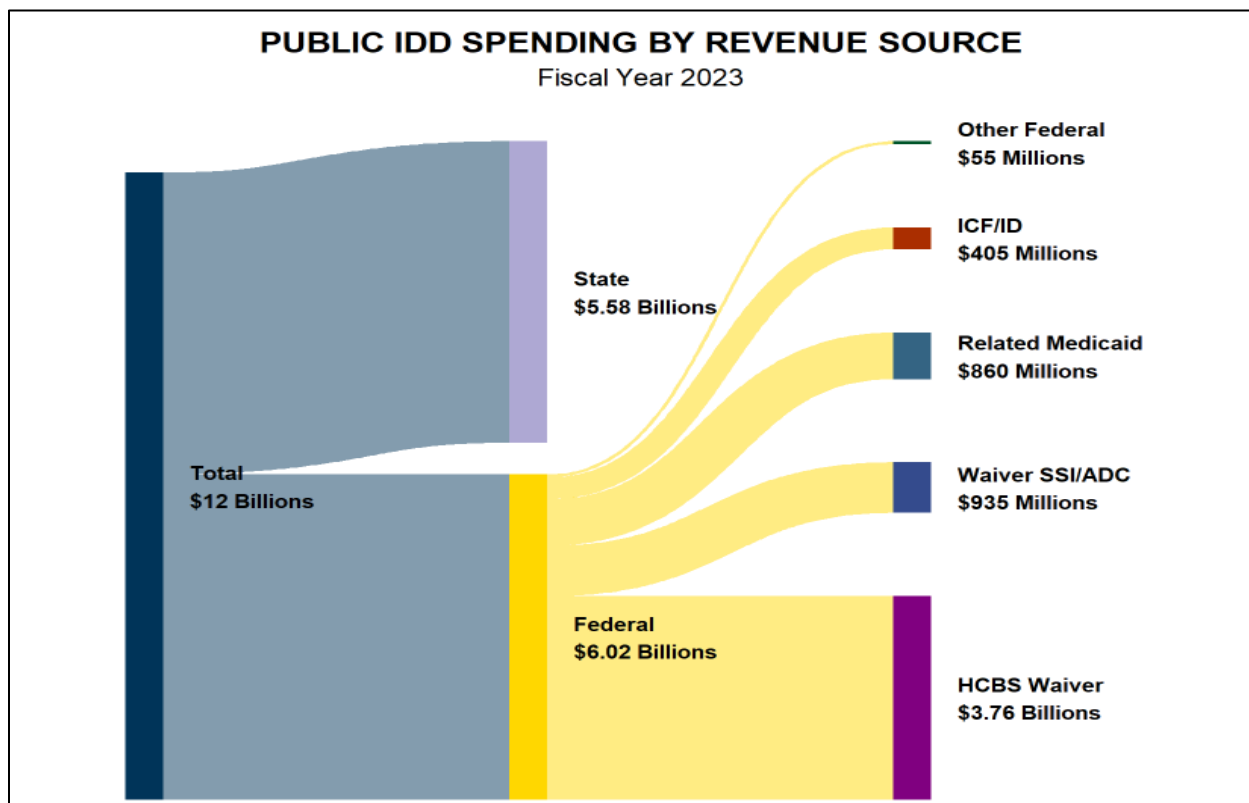
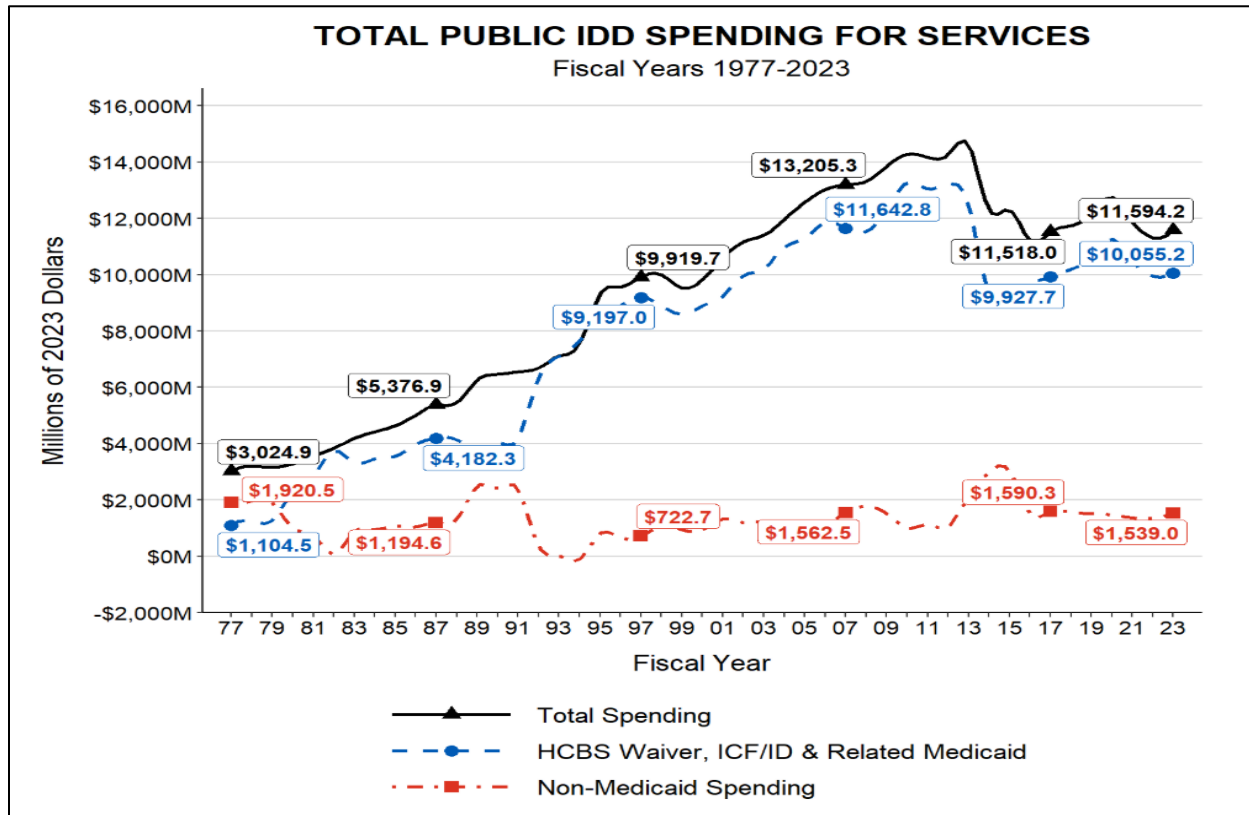
The State of the States in Intellectual and Developmental Disabilities project was initiated in 1982 to investigate the determinants of public spending for intellectual and developmental disabilities services in the United States. The Project has developed a 40-year record of revenue, spending, and programmatic 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.



This project is supported by the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS), Cooperative Agreement #90DNPA00005-01-00, as part of a financial assistance award totaling \$449,915 annually with 100% funding by ACL/HHS. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by ACL/HHS, or the U.S. Government. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions.

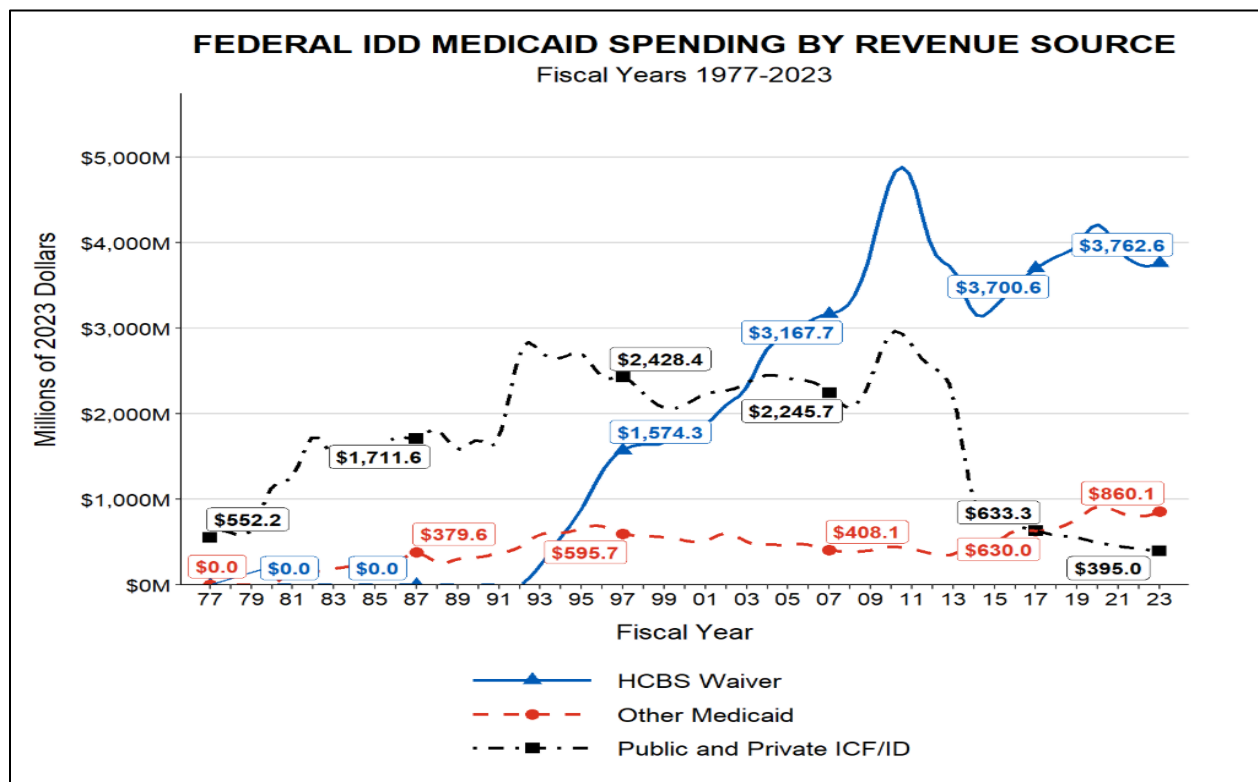
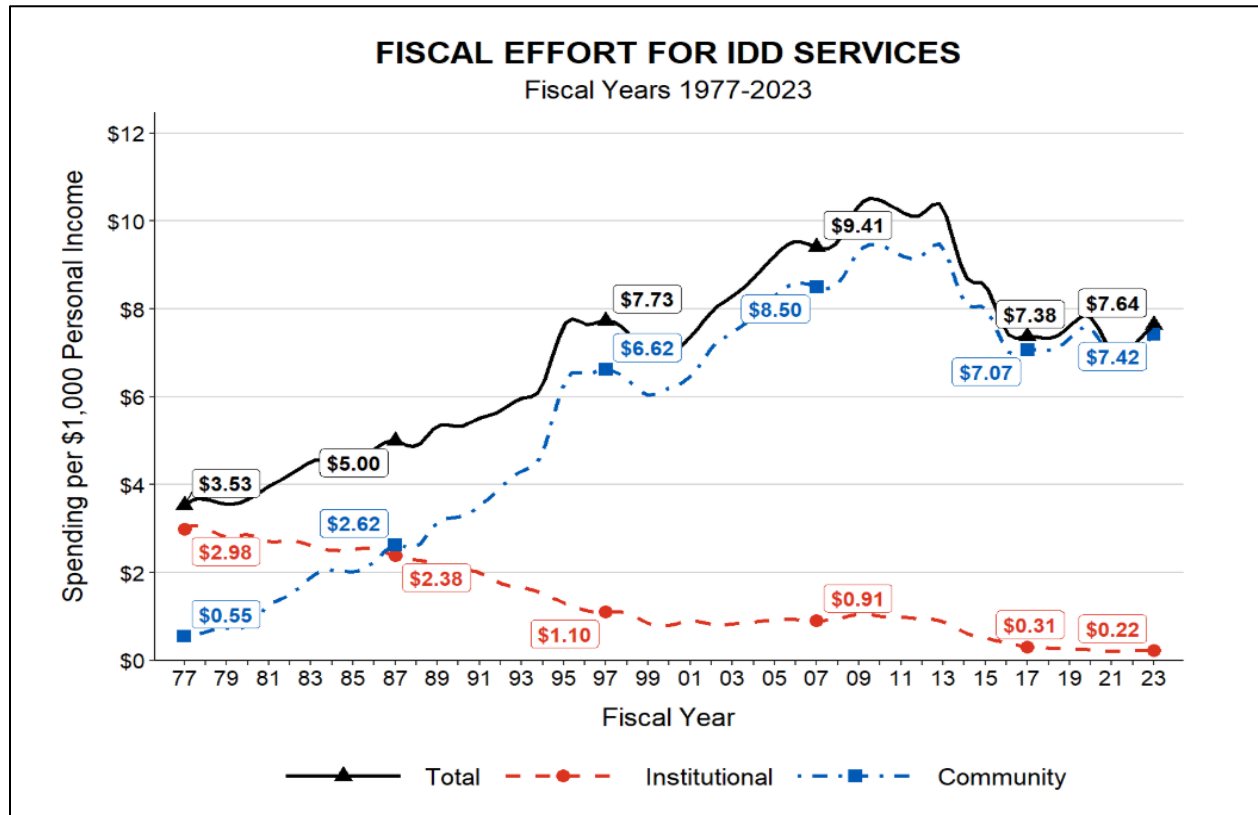
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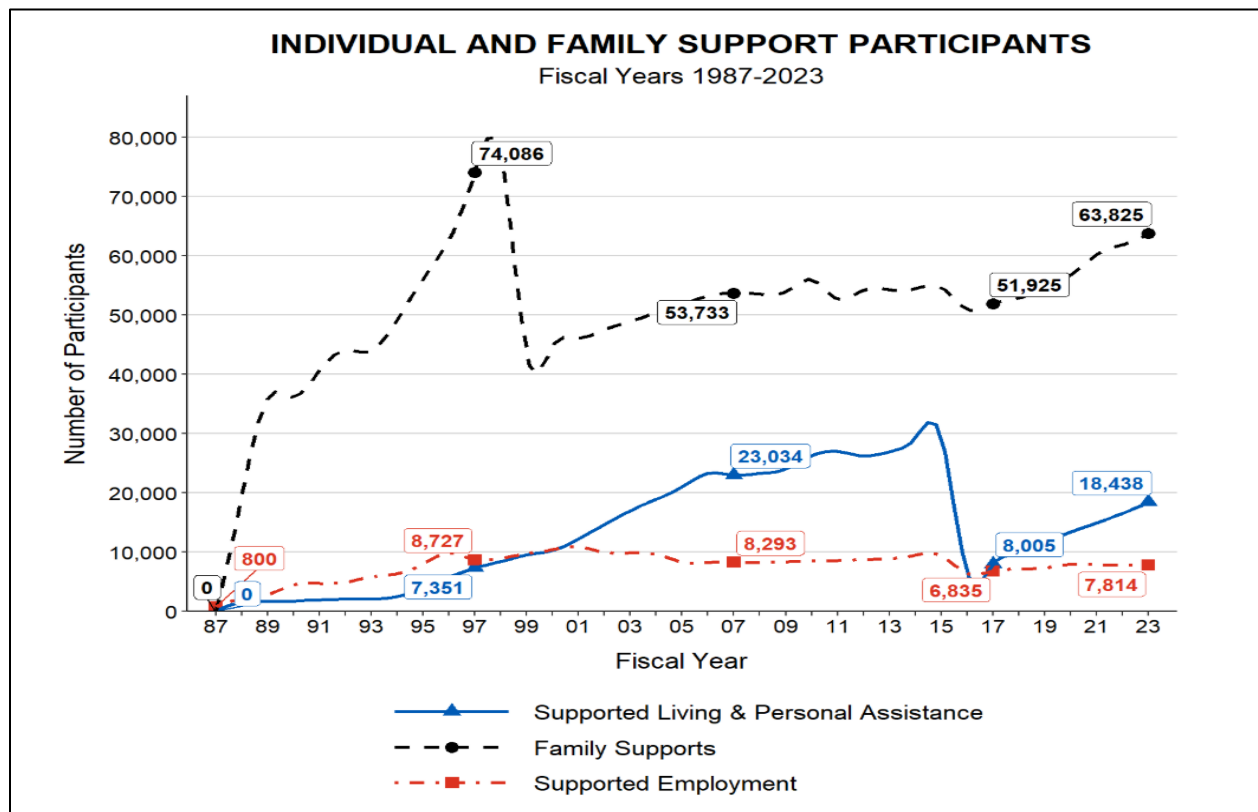
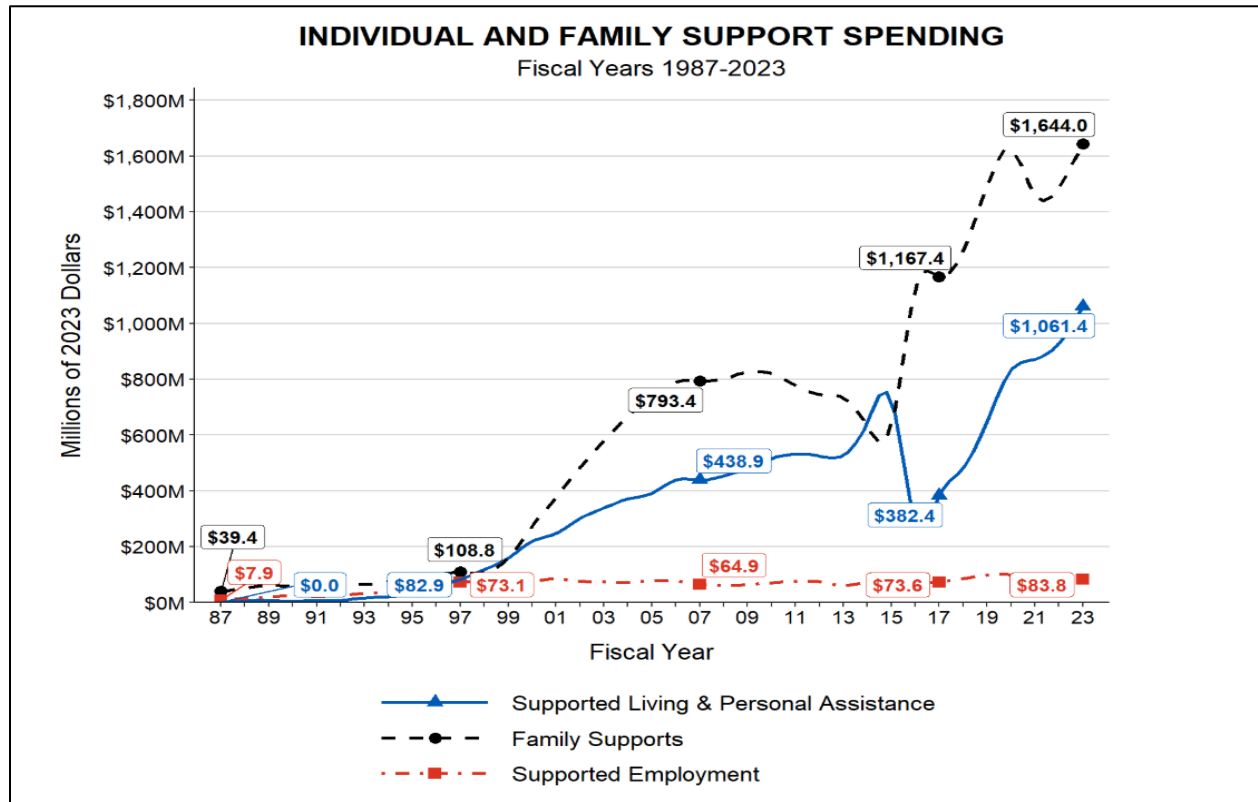
Source: Tanis, E.S., et al. (2025). The State of the States in Intellectual and Developmental Disabilities, Kansas University Center on Disabilities, The University of Kansas. <https://stateofthestates.ku.edu>

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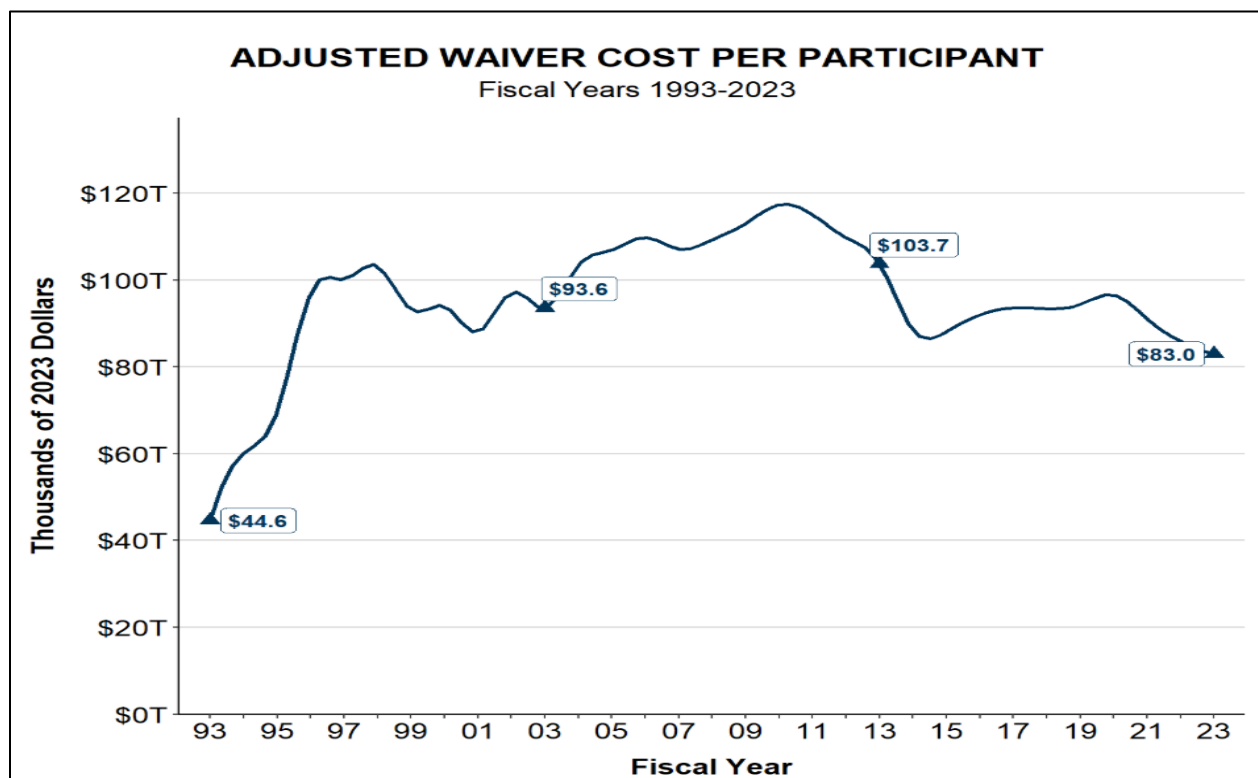
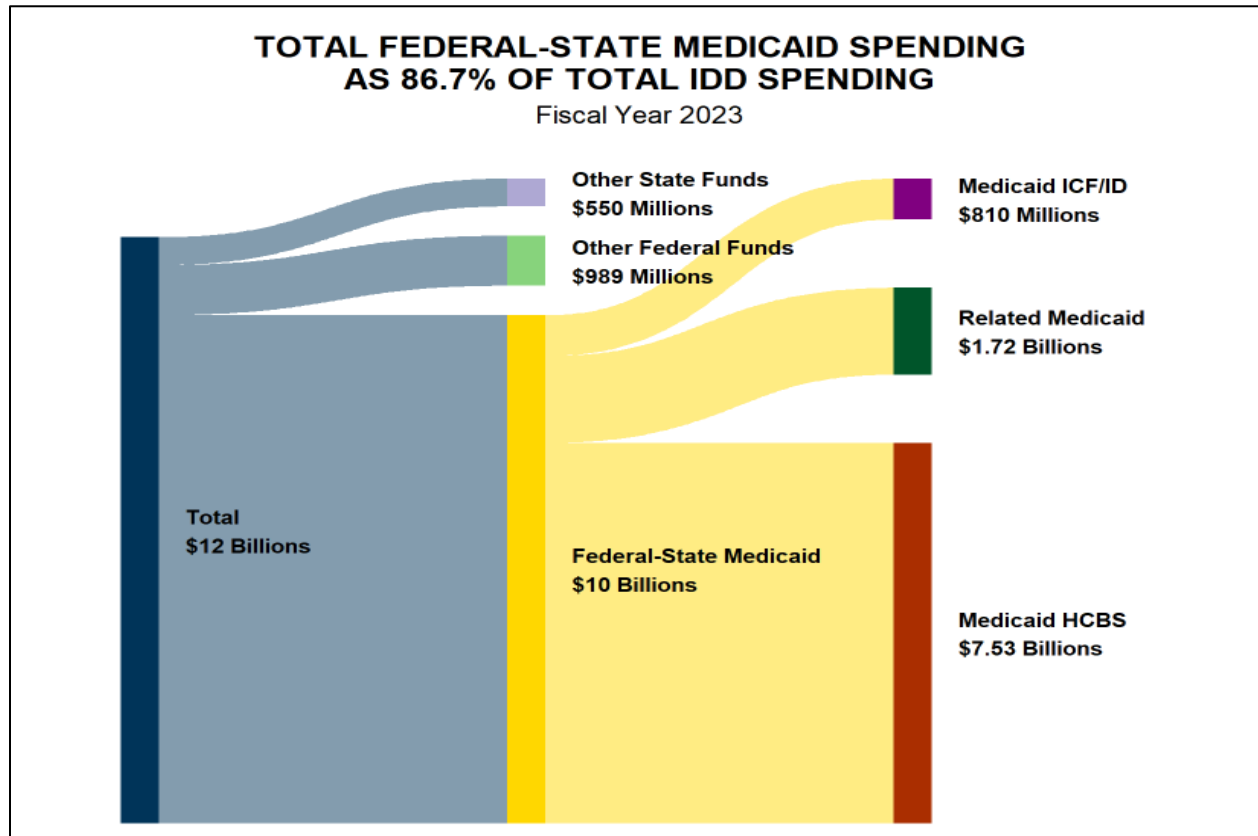
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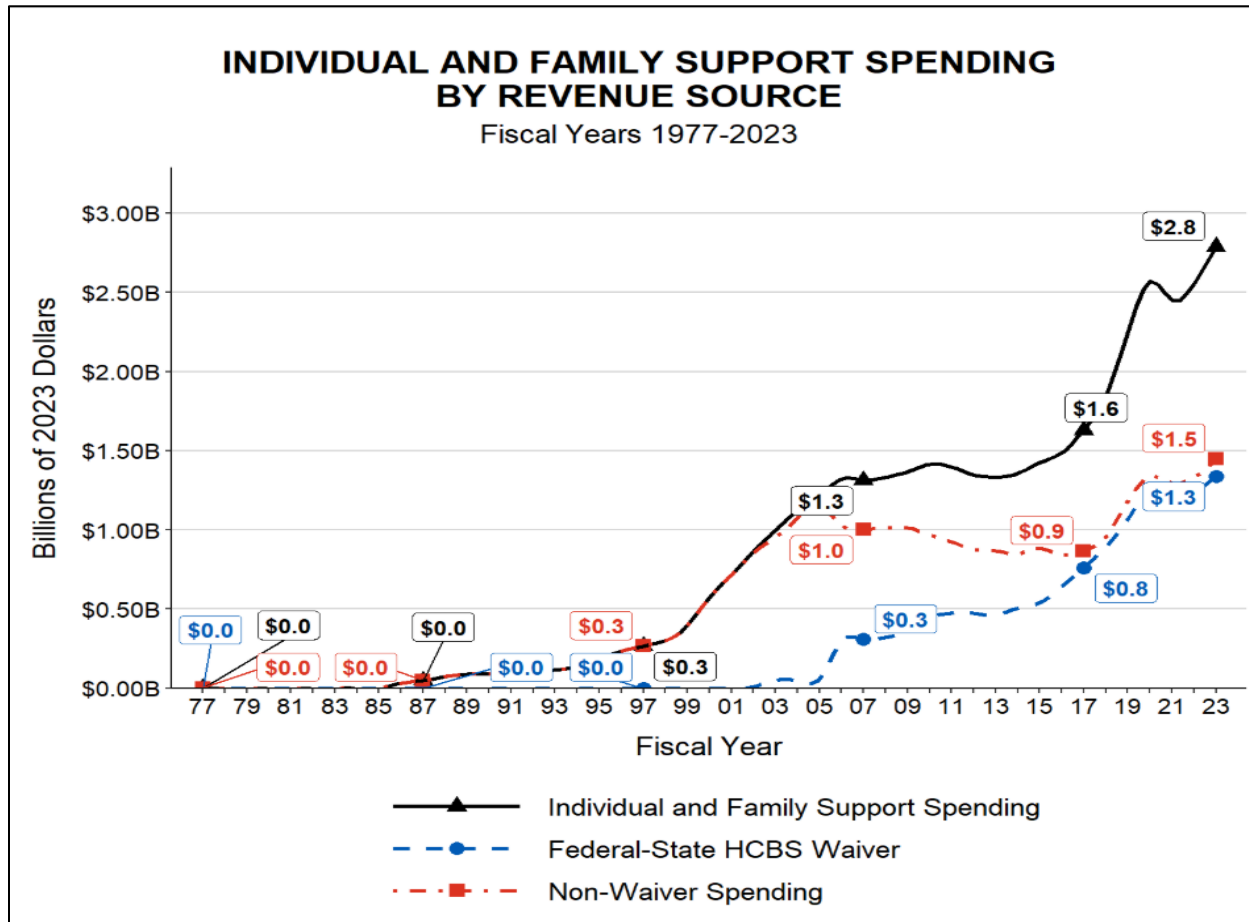
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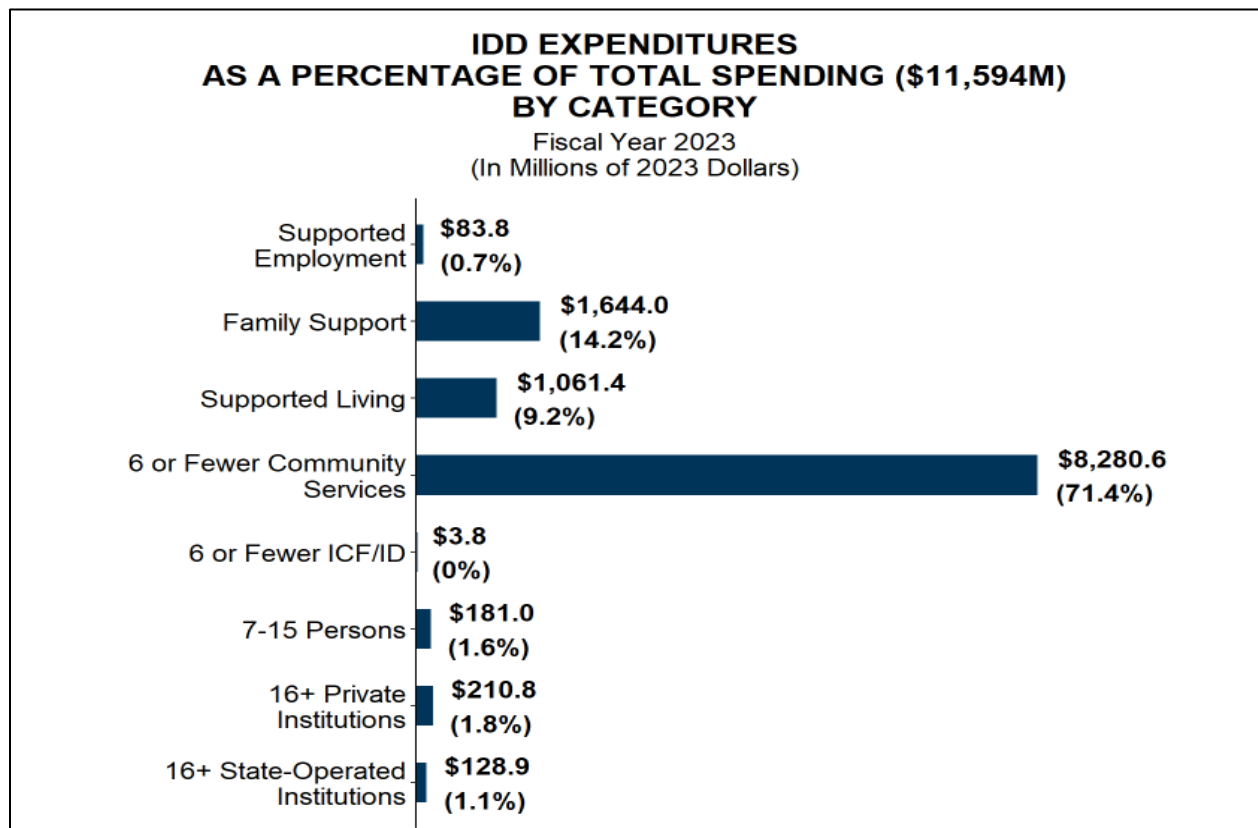
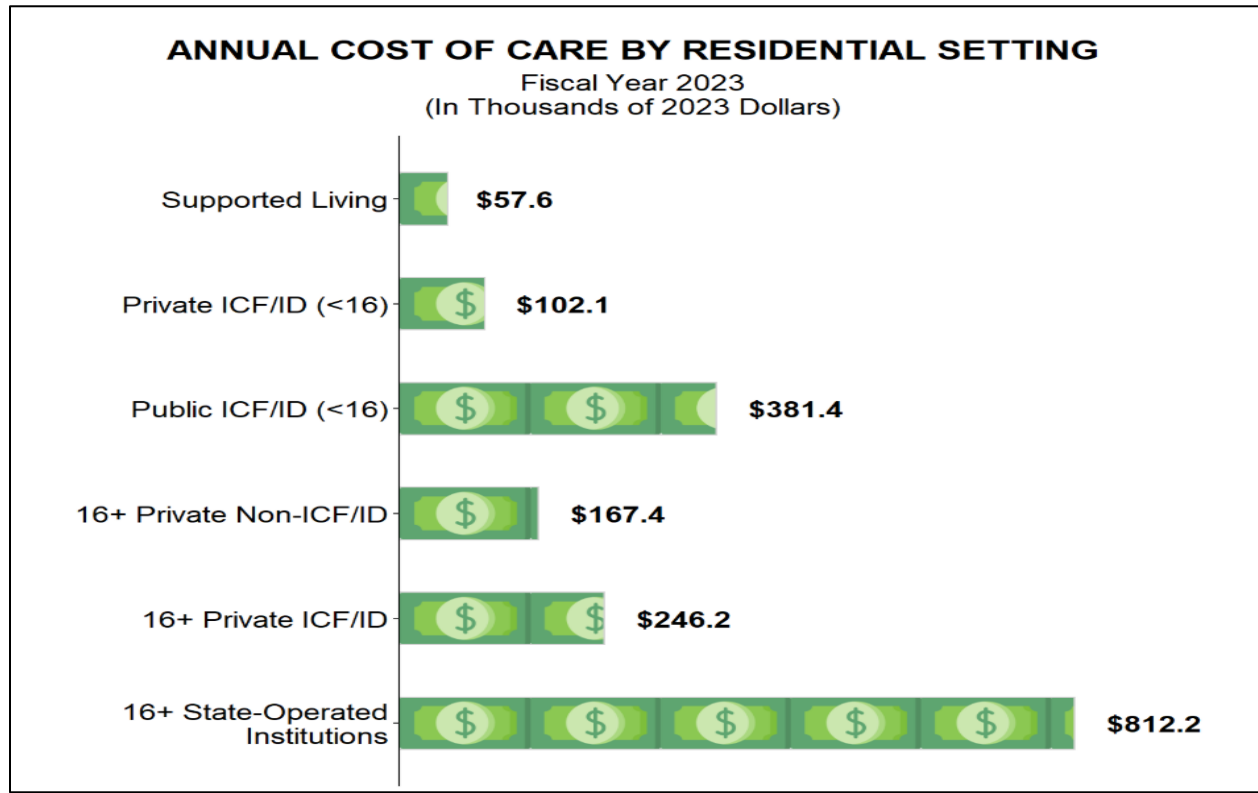
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PERSONS WITH IDD BY SIZE OF SETTING: Fiscal Years 2013–2023											
	2013	2014	2015	2016	2017	2018	2019	2020	2021	2022	2023
Total	69,822	72,388	72,673	47,831	48,468	48,462	50,030	51,906	52,642	53,673	54,974
16+ PERSONS	7,133	7,105	6,586	5,104	4,297	2,874	2,936	3,003	2,899	2,756	2,755
Nursing Facilities	4,117	4,169	3,981	3,308	2,825	1,704	1,792	1,887	1,858	1,700	1,722
State Institutions	1,015	890	581	375	262	199	182	178	163	168	159
Private ICFs (16+)	952	942	963	973	891	915	905	881	823	832	818
Other Residential (16+)	1,049	1,104	1,061	448	319	56	57	57	56	57	57
7-15 PERSONS	18,664	18,030	18,024	18,584	18,520	17,978	17,938	17,862	17,404	17,110	16,906
Public ICFs (7-15)	59	53	44	31	17	19	17	18	19	21	17
Private ICFs (7-15)	4,158	4,140	4,105	3,753	3,397	3,065	2,804	2,487	2,298	2,184	2,079
Other Residential (7-15)	14,447	13,837	13,875	14,800	15,106	14,894	15,117	15,358	15,087	14,905	14,810
6 or Less PERSONS	44,025	47,253	48,063	24,143	25,651	27,610	29,156	31,041	32,339	33,807	35,313
Public ICFs (<=6)	34	34	27	19	9	8	6	3	4	4	3
Private ICFs (<=6)	454	455	468	459	415	369	359	373	367	353	355
Supported Living (<=6)	26,955	29,242	29,546	6,405	8,005	9,579	11,417	13,402	14,915	16,563	18,438
Other Residential (<=6)	16,582	17,522	18,022	17,260	17,222	17,654	17,374	17,263	17,053	16,887	16,517

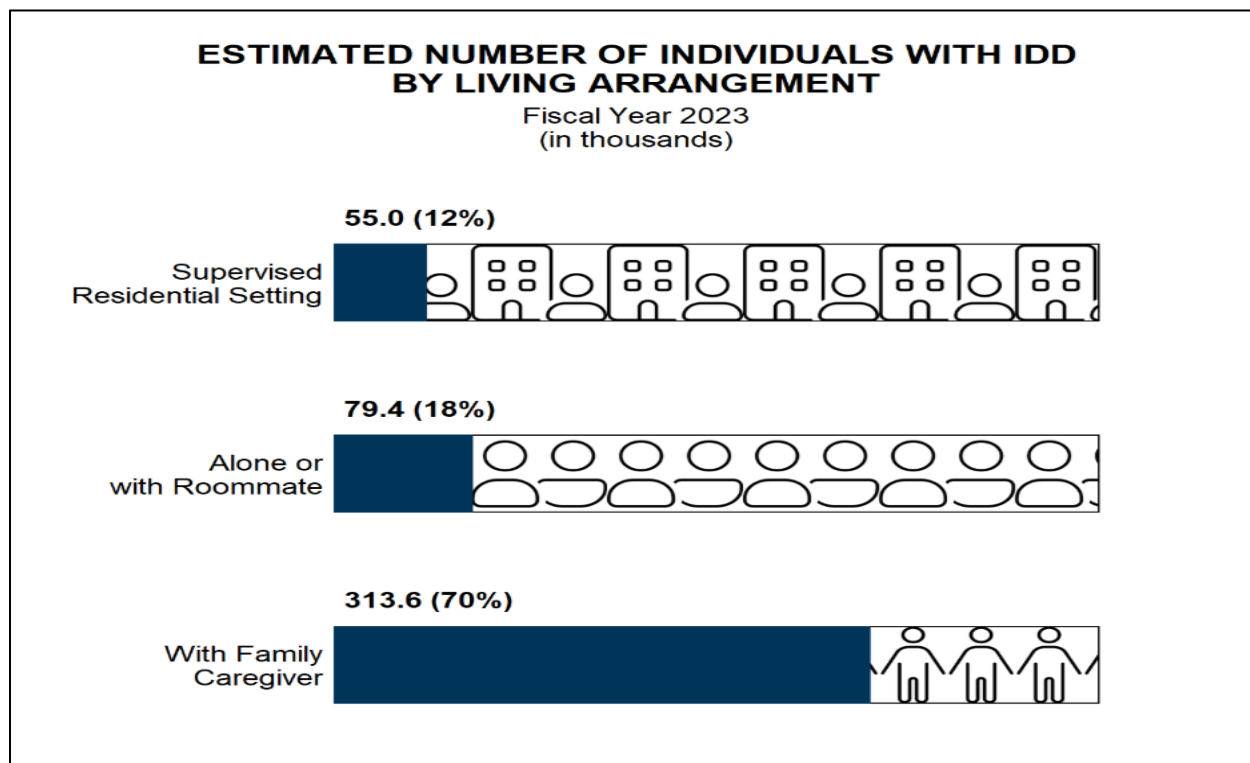
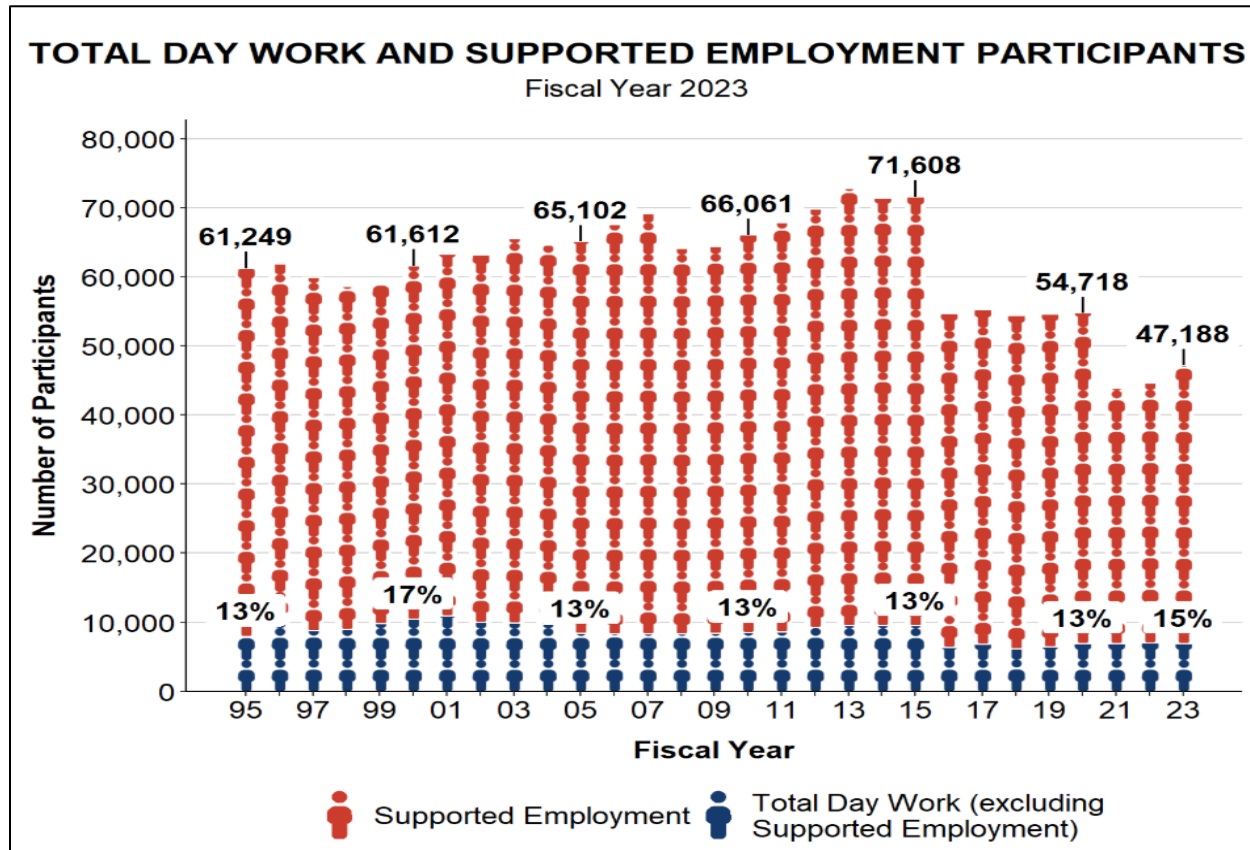
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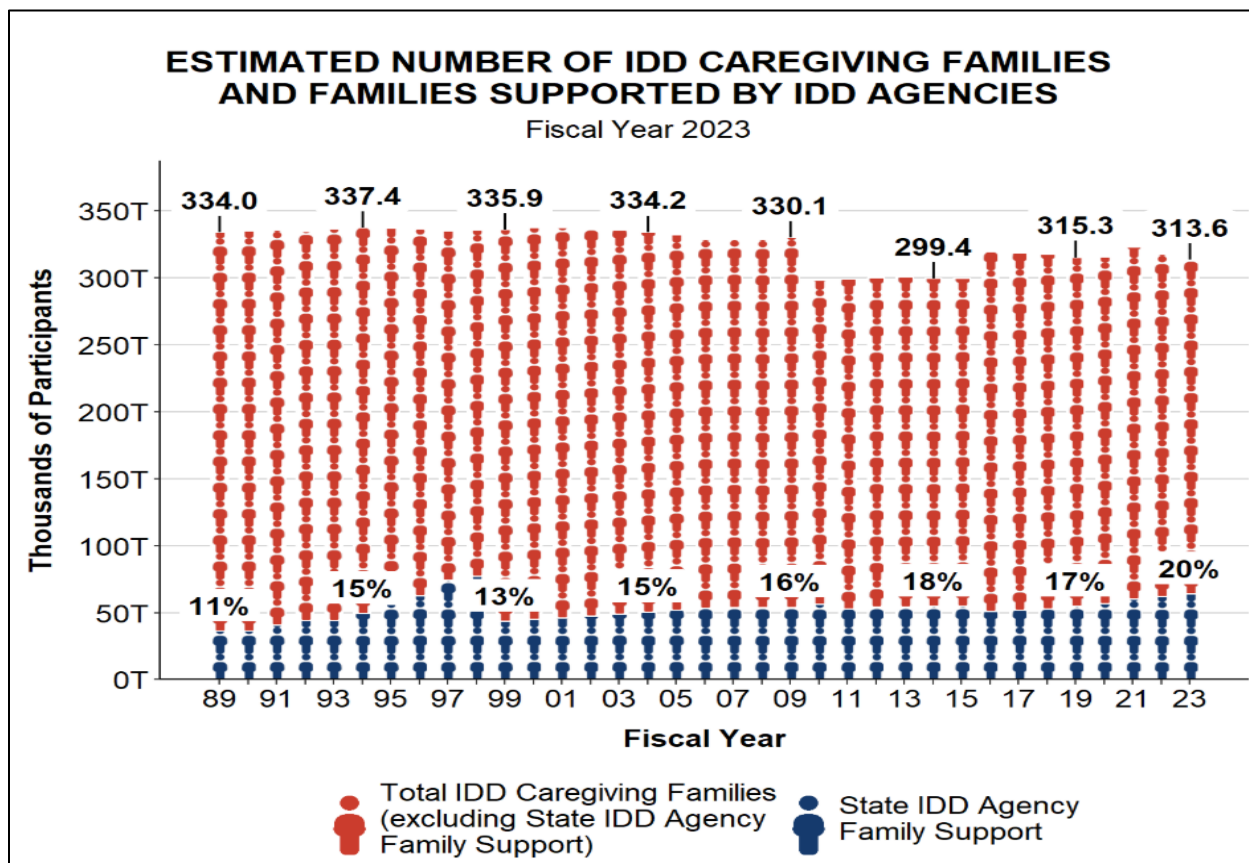
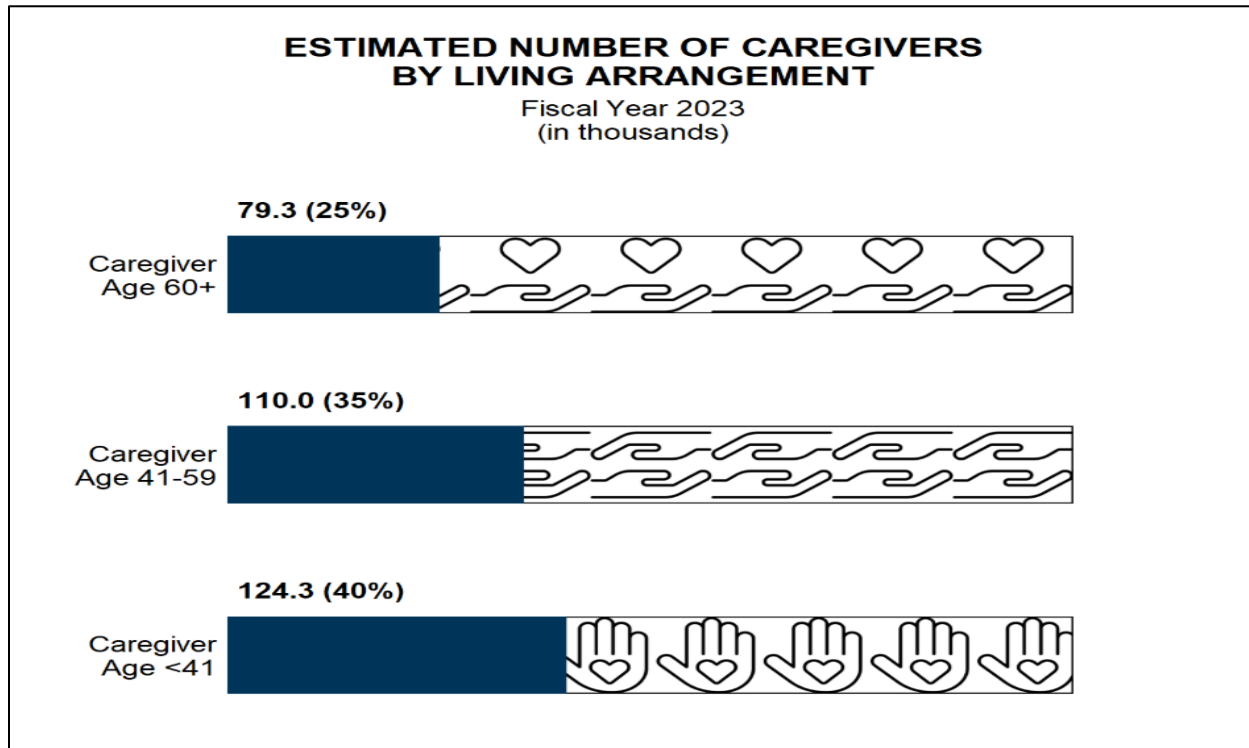
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New York (NY)

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. *Affected graphs: Persons with I/DD by Size of Setting, Individual and Family Support Participants*
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. *Affected graphs: Individual and Family Support Spending*

The State of the States in Intellectual and Developmental Disabilities Project is a national longitudinal comparative study of financial and programmatic trends in spending on supports and services for people with intellectual/developmental disabilities (IDD) in the United States. The project is funded by the U.S. Administration on Community Living as a Longitudinal Data Project of National Significance.

Source: Tanis, E.S., et al. (2025). The State of the States in Intellectual and Developmental Disabilities, Life Span Institute, University of Kansas. www.stateofthestates.ku.edu



Terms and Definitions

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

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 charts: Individual and Family Support Spending, 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 charts: Total Public IDD Spending for Services, Federal IDD Medicaid Spending by Revenue Source*
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 charts: Total Public IDD Spending for Services, Federal IDD Medicaid Spending by Revenue Source*
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 charts: Total Public IDD Spending for Services, Federal IDD Medicaid Spending by Revenue Source*
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 charts: Individual and Family Support Spending, 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 charts: Individual and Family Support Spending, Individual and Family Support Participants*

**State Profile Charts and Term Definitions:****Page 1****❖ Total Public IDD Spending for Services**

A line chart illustrating Total Public Intellectual and Developmental Disabilities (IDD) Spending for Services. The X axis represents fiscal years 1977-2023, while the Y axis represents millions of 2023 dollars. 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 Home and Community Based Services (HCBS) Waivers, Intermediate Care Facilities for Individuals with Intellectual Disabilities, & other related Medicaid spending compared to non-Medicaid spending over time.

❖ Public IDD Spending by Revenue Source

A Sankey chart illustrating Public IDD Spending by Revenue Source in FY 2023. The chart aims to show how much of the total public spending comes from federal, state, and/or local funds. It also aims to show a breakdown of what services were paid through federal spending. Total percentage values may be greater than or less than 100% by up to 1% due to rounding.

Page 2**❖ Fiscal Effort for IDD Services**

A line chart illustrating Fiscal Effort for IDD Services. Fiscal Effort is a State of the States measure for spending on IDD services per \$1,000 of aggregate statewide personal income. The X axis represents fiscal years 1977-2023. The Y axis represents spending per \$1,000 personal income. 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.

**❖ Federal IDD Medicaid Spending by Revenue Source**

A line chart illustrating Federal I/DD Medicaid Spending by Revenue Source. The X axis represents fiscal years 1977-2023. The Y axis represents spending per millions of 2023 dollars. The chart aims to show how spending from HCBS Waivers, spending from other Medicaid sources; and spending from public and private ICF/IDs have increased, decreased, or maintained over time. Total percentage values may be greater than or less than 100% by up to 1% due to rounding.

Page 3**❖ Total Federal-State Medicaid Spending as a Percentage of Total IDD Spending**

A Sankey chart illustrating Total Federal-State Medicaid Spending as a Percentage of Total IDD Spending in FY 2023. The chart aims to show how much of the total public spending comes from federal-state Medicaid, other federal funds, and/or other state funds. It also aims to show a breakdown of what services were paid through Medicaid spending.

❖ Adjusted Waiver Cost per Participant

A line chart illustrating the Adjusted Waiver Cost per Participant from FYs 1993-2023. The X axis represents fiscal years 1993-2023, and the Y axis represents cost in 2023 dollars (in \$1,000). The chart aims to show how the waiver costs per person has increased, decreased, or maintained overtime.

Page 4**❖ Individual and Family Support Spending**

A line chart illustrating Individual and Family Support Spending. The X axis represents fiscal years 1987-2023, and the Y axis represents spending per millions of 2023 dollars. The chart aims to show how spending for supported living and personal assistance, family supports, and supported employment have increased, decreased, or maintained overtime.

❖ Individual and Family Support Participants

A line chart illustrating Individual and Family Support Participants. The X axis represents fiscal years 1987-2023, and the Y axis number of people receiving the service. The chart aims to show how the number of people receiving supported living and personal assistance, family supports, and supported employment services have increased, decreased, or maintained overtime.

**Page 5****❖ Individual and Family Support Spending by Revenue Source**

A line chart illustrating Individual and Family Support Spending by Revenue Source. The X axis represents fiscal years 1997-2023, and the Y axis represents millions of 2023 dollars. Total spending is broken into Federal-State HCBS Waiver and Non-Waiver spending. The chart aims to show how total individual and family support spending has increased, decreased, or maintained overtime. The chart also aims to show what percentage of the total spending went to federal-state HCBS waivers compared to non-waiver spending.

❖ Persons with IDD by Size of Setting

A table illustrating Persons with IDD by Size of Setting for fiscal years 2013-2023. The left column represents the different type of residential settings, while the top row represents fiscal years 2013-2023. The table aims to compare how total persons with IDD in a variety of residential settings have increased, decreased, or maintained overtime. Residential settings are broken down by settings of 16+ persons, 7-15 persons, and 6 or less persons.

Page 6**❖ Annual Cost of Care by Residential Setting**

A horizontal bar chart illustrating the Annual Cost of Care by Residential Setting in FY 2023. X axis represents thousands of 2023 dollars and the Y axis represents type of residential setting. Chart aims to show the annual cost of care for supported living, private ICF/ID, public ICF/ID, 16+ non ICF/ID, 16+ private ICF/ID, and 16+ state operated institutional settings.

❖ IDD Expenditures as a Percentage of Total Spending by Category

A horizontal bar chart illustrating IDD Expenditures in 2023. The chart aims to show the total spending in 2023 and break down the total spending by service category as percentages of the total. Categories can include: 6 or fewer community services, ICF/IDs of 6 or fewer persons, settings 7-15 persons, public institutions, private institutions, supported employment; family supports; supported living.

**Page 7****❖ Total Day/Work and Supported Employment Participants**

A stacked column bar chart illustrating Total Day/Work and Supported Employment Participants. The X axis represents fiscal years 1987-2023, and the Y axis represents the number of participants. Total participants are broken into the total number of Day Work participants and the percentage of supported employment participants. The chart aims to show how the total number of day work participants has increased, decreased, or maintained overtime. The chart also aims to show what percentage of the total Day Work participants are utilizing Supported Employment services overtime.

❖ Estimated Number of Individuals With IDD by Living Arrangement

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.

Page 8**❖ Estimated Number of Caregivers by Age**

A horizontal bar chart illustrating the Estimated Number of Caregivers by Age in 2023. The chart aims to show what percentage of caregivers are caregivers aged 60 or older, caregivers aged 41-59; or caregivers aged 41 or younger.

❖ Estimated Number of IDD Caregiving Families and Families**Supported by IDD Agencies**

A stacked column bar chart illustrating the Estimated Number of IDD Caregiving Families and Families Supported by IDD Agencies. The X axis represents fiscal years 1989-2023, and the Y axis represents the number of families. The bars in the chart are broken into total number of IDD caregiving families and the percentage of families supported by state IDD agencies. The chart aims to show how the total number of IDD caregiving families has increased, decreased, or maintained overtime. The chart also aims to show what percentage of those caregiving families were supported by state IDD agencies overtime.