

**The State of the States in
Intellectual and Developmental Disabilities:
Emerging from the Great Recession**

The State of the States in Intellectual and Developmental Disabilities: Emerging from the Great Recession

*David Braddock, Richard Hemp, Mary C. Rizzolo,
Emily Shea Tanis, Laura Haffer, Jiang Wu*

Department of Psychiatry and
Coleman Institute for Cognitive Disabilities
University of Colorado

IN COLLABORATION WITH THE
Department of Disability and Human Development
University of Illinois at Chicago

TENTH EDITION



**DISTRIBUTED BY
THE AMERICAN ASSOCIATION ON INTELLECTUAL AND
DEVELOPMENTAL DISABILITIES
Washington, DC**

**Copyright © 2014 by David L. Braddock
All rights reserved**

**State of the States in Intellectual and Developmental Disabilities website:
www.stateofthestates.org**

This publication was supported in part by a cooperative agreement between the U.S. Administration on Intellectual and Developmental Disabilities, United States Department of Health and Human Services and the University of Colorado School of Medicine, Department of Psychiatry. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration on Intellectual and Developmental Disabilities policy.

TABLE OF CONTENTS

TABLES AND FIGURES	ix
ACKNOWLEDGMENTS	xi
 PART I. THE STATE OF THE STATES IN INTELLECTUAL AND DEVELOPMENTAL DISABILITIES: EMERGING FROM THE GREAT RECESSION	
I. INTRODUCTION.....	3
II. APPROACH.....	4
Data Collection.....	4
State survey instruments.....	5
National data sources.....	6
Data Analysis	6
Financially-focused analysis.....	6
Participant-focused analysis.....	8
III. NATIONAL TRENDS IN IDD SPENDING	8
Trends in Spending by State: FY 2011–2013	10
Changes in Inflation-Adjusted Spending by Fiscal Year: 2011, 2012, and 2013	10
Comparative Analysis of Institutional and Community Services.....	13
Growth of community resources and institutional spending reductions.....	12
IV. FISCAL EFFORT FOR IDD SERVICES IN THE STATES	16
V. OUT-OF-HOME RESIDENTIAL PLACEMENTS FOR PERSONS WITH IDD	19
Costs by Residential Setting in 2013	23
VI. PUBLIC AND PRIVATE INSTITUTIONS	26
State-Operated Institutions.....	26
Closures of state-operated institutions	28
Thirty-seven states maintained state-operated institutions in 2013	31
Public spending for institutions in the states	32
Privately-Operated IDD Institutions.....	32
Nursing Facilities	33
Data sources	34
Census of persons with intellectual and developmental disabilities by state.....	34
VII. COMMUNITY SERVICES AND SUPPORTS	36
Significance of Medicaid in Community Living Services.....	36
Medicaid ICF/ID program	36
Medicaid HCBS Waiver program	37
Nationwide study of IDD Medicaid HCBS Waivers	37
Most IDD spending is Medicaid	42
Other sources of revenue for IDD community services and supports	42
<i>Federal funds</i>	42
<i>Local/county funds</i>	44

Individual and Family Supports	45
Self-advocacy, individual support, and family support.	45
Supported living and personal assistance	46
Supported employment	47
<i>Employment First and employment studies</i>	50
<i>Proportion of workers in supported employment plateaus</i>	51
Family Support Services	55
<i>Supporting family members with disabilities at home.</i>	56
<i>Family support receives a small fraction of total IDD spending.</i>	57
<i>HCBS Waiver's role in family support.</i>	59
<i>Unmet need for family support</i>	60
VIII. DEMAND FOR SERVICES AND SUPPORTS	62
Aging Caregivers	62
Increased Longevity of People with IDD	64
Waiting Lists in the States	65
Direct Support Professionals' Wage Issues	66
Recent Litigation Promoting Community Services.	67
Department of Justice statements of interest	70
Enforcing <i>Olmstead</i>	70
Recent Federal Government Initiatives.	71
Technology Initiatives in the States	72
Smart homes and remote supports	73
Technology pilot Survey and the HCBS Waiver	73
Coleman Institute for Cognitive Disabilities	74
University based centers on cognitive technology.	76
IX. SUMMARY OF THE STUDY	77
Intellectual and Developmental Disabilities Spending Growth Slows Down	77
U.S. Fiscal Effort for Services Declined in FY 2013.	78
Census of Public and Private Institutions Continues to Decline.	78
Growth Rate for Community Services and Supports Slows FY 2011–13.	78
Significance of Medicaid HCBS Waivers.	78
Supported living commitments vary across states.	79
Number of workers in supported employment declines	79
Family support declines.	79
Federal Efforts to Address State Budget Deficiencies	79
Living on the Fiscal Cliff	81
Unemployment Remains High in Most States	82
X. CONCLUSION: THE RIGHTS OF PEOPLE WITH COGNITIVE DISABILITIES TO TECHNOLOGY AND INFORMATION ACCESS.	83
Economic Inequality Rising	83
Effect on economic growth	84
Effect on economic security	84
Advancing the Rights of People with Cognitive Disabilities to Technology and Information Access	85
REFERENCES CITED	86
COLLABORATION WITH STATE IDD AGENCIES FOR DATA COLLECTION	93

PART II. PRESENTATION OF PROFILES FOR THE 50 STATES AND THE DISTRICT OF COLUMBIA . . .	97
ALABAMA	98
ALASKA	100
ARIZONA	102
ARKANSAS	104
CALIFORNIA	106
COLORADO	108
CONNECTICUT	110
DELAWARE	112
DISTRICT OF COLUMBIA	114
FLORIDA	116
GEORGIA	118
HAWAII	120
IDAHO	122
ILLINOIS	124
INDIANA	126
IOWA	128
KANSAS	130
KENTUCKY	132
LOUISIANA	134
MAINE	136
MARYLAND	138
MASSACHUSETTS	140
MICHIGAN	142
MINNESOTA	144
MISSISSIPPI	146
MISSOURI	148
MONTANA	150
NEBRASKA	152
NEVADA	154
NEW HAMPSHIRE	156
NEW JERSEY	158
NEW MEXICO	160
NEW YORK	162
NORTH CAROLINA	164
NORTH DAKOTA	166
OHIO	168
OKLAHOMA	170
OREGON	172
PENNSYLVANIA	174
RHODE ISLAND	176

SOUTH CAROLINA	178
SOUTH DAKOTA	180
TENNESSEE.....	182
TEXAS	184
UTAH.....	186
VERMONT.....	188
VIRGINIA	190
WASHINGTON	192
WEST VIRGINIA.....	194
WISCONSIN	196
WYOMING	298
UNITED STATES.....	200
STATE, COUNTY, AND LOCAL FUNDS POTENTIALLY AVAILABLE TO MATCH FEDERAL MEDICAID FUNDING, BY STATE	202
APPENDICES.....	203
I. <i>The Rights of People with Cognitive Disabilities to Technology and Information Access</i> (The Declaration).	205
II. 182 Representative Organizations in the U.S. and Canada Endorsing <i>The Declaration</i> <i>of the Rights of People with Cognitive Disabilities to Technology and Information Access</i>	206
III. AAIDD article reprint: Braddock, D., Hoehl, J., Tanis, E., Ablowitz, E., & Haffer, L., <i>The Rights of People with Cognitive Disabilities to Technology and Information Access</i>	210

TABLES AND FIGURES IN PART I

TABLES

Table 1.	Budget Categories/Variables for State Spending/Data Collection.	4
Table 2.	Key Program/Participant Variables for Data Collection	5
Table 3.	Public IDD Spending for Community Services in the States: FY 2011–13	10
Table 4.	Percentage Change in Spending by Setting: FY 2011, 2012 and 2013	12
Table 5.	Fiscal Effort for IDD Services: Percent Change FY 2011–13	17
Table 6.	State Fiscal Effort Rankings: FY 2011 and 2013.	18
Table 7.	Persons with IDD in Out-of-Home Residential Settings By Size of Setting and State: FY 2013	21
Table 8.	Utilization Rate by Individuals with IDD in Settings for Six or Fewer Persons and Seven or More Persons: FY 2013	23
Table 9.	Annual Cost of Care Per Person in Six Residential Settings: FY 2013	24
Table 10.	Average Daily Residents in State-Operated 16+ IDD Institutions: FY 2011–13	27
Table 11.	Completed and In-Progress Closures of IDD State-Operated 16+ Institutions in the U.S.: FY 1969–2020 (n=173)	29
Table 12.	Average Daily Spending Per Person in State-Operated Institutions: FY 2011–13	33
Table 13.	Residents with IDD in Nursing Facilities by State: FY 2011–13	35
Table 14.	The Home and Community Based Services (HCBS) Waiver: IDD Participants and Spending in FY 2013	39
Table 15.	Federal-State Medicaid Funds Constituted 78% of Total IDD Spending in the States in FY 2013.	43
Table 16.	Local Government IDD Spending: FY 2013	45
Table 17.	Supported Living/Personal Assistance Programs in the States: IDD Participants and Spending in FY 2013	48
Table 18.	State IDD Agency Supported Employment Programs in the States: Participants and Spending in FY 2013	54
Table 19.	Family Support in the States: Spending for Participants with IDD in FY 2013.	58
Table 20.	Estimated Number of IDD Caregiving Families Compared to Families Supported by State IDD Agency Federal, State and Local Funds: FY 2013	60
Table 21.	Estimated Number of Persons with IDD Living with Aging Caregivers in FY 2013	65
Table 22.	The Status of Selected Community IDD Services Litigation, 2014.	69

FIGURES

Figure 1.	Annual Percentage Change in Inflation-Adjusted State General Fund Spending in the U.S. FYs 1979–2014	3
Figure 2.	Annual Percentage Change in Total IDD Spending in the U.S.: FY 1978–2013	8
Figure 3.	Annual Percentage Change in IDD Community and Institutional Spending in the U.S.: FY 1978–2013.	9
Figure 4.	United States IDD Spending by Service Category: FY 2013	9
Figure 5.	Forty-Three States and DC Increased Inflation-Adjusted IDD Spending During FY 2011–13; 7 States Cut Spending.	11
Figure 6.	Trends in IDD Spending Using Six or Fewer Persons to Define Community Residential Services: FY 1977–2013	15
Figure 7.	Fiscal Effort for IDD Services in the United States: FY 1977–2013	16

Figure 8.	Out-of-Home Residential Placements in the U.S. by Setting: FY 2011 and FY 2013	20
Figure 9.	Number of Persons with IDD Residing in Settings for Six or Fewer Persons: FY 1960–2013	22
Figure 10.	Persons Served in Public and Private Institutions and Nursing Facilities in the United States: FY 1990–2013	26
Figure 11.	Cumulative Number of Completed and In-Progress Closures of State-Operated 16+ Institutions in the United States: 1969–2020	31
Figure 12.	Thirty-seven States Financed 151 State-Operated Institutions: FY 2013	32
Figure 13.	Daily Spending Per Person in State-Operated 16+ IDD Institutions in the U. S.: FY 1977–2013	34
Figure 14.	Federal-State IDD Spending for HCBS Waiver, ICF/ID, and Related Medicaid in the U.S.: FY 1977–2013	36
Figure 15.	Components of Federal-State IDD Medicaid Spending in the U.S.: FY 1977–2013	38
Figure 16.	Federal-State Medicaid was the Majority of Total IDD Spending in FY 2013	40
Figure 17.	Federal Medicaid IDD Long-Term Care Spending as a Percentage of Total Federal Medicaid Spending in the U.S.: FY 1977–2013	41
Figure 18.	Community Services Revenue Sources: FY 2013	44
Figure 19.	Individuals with IDD in Day Programs, Workshops and Employment: FY 1988–2013	52
Figure 20.	Percentage of Total Day/Work Recipients with IDD in Supported Employment: FY 1988–2013	53
Figure 21.	Federal Medicaid Funding for Day Programs and Supported Employment: FY 1992–2013	55
Figure 22.	Family Support Spending and Number of Individuals Supported in the Family Home: FY 1990–2013	57
Figure 23.	Inflation-Adjusted Spending for Family Support Services, FY 1986–2013	59
Figure 24.	Estimated Number of IDD Caregiving Families and Families Supported by IDD Agencies: FY 1988–2013	61
Figure 25.	Growing Numbers of Americans Aged 65+ Years: 2000–2050	62
Figure 26.	U.S. Estimated Distribution of Individuals with IDD by Living Arrangement, FY 2013	63
Figure 27.	U.S. Estimated Number of Individuals with IDD by Age Group Living with Family Caregivers: FY 2013	64
Figure 28.	Hourly Wages in 2014	68
Figure 29.	Prevalence of Cognitive Disability in the U.S., FY 2013	74
Figure 30.	Average Annual Percentage Change in Inflation-Adjusted IDD Spending by Decade: U.S.	77
Figure 31.	State and Federal IDD Spending: FY 1977–2013 (Adjusted for Inflation)	80
Figure 32.	IDD Spending as a Percentage of the U.S. Gross Domestic Product: 1977–2013	81
Figure 33.	U.S. Unemployment Rate Peaked During the Great Recession: Remains Above 2007 Level	82
Figure 34.	U.S. Income Earners: Top 10% had 50% of the Nation’s Income in 2007 and in 1928	83

ACKNOWLEDGMENTS

This is the tenth published edition of *The State of the States in Intellectual and Developmental Disabilities*. In this new edition we analyze financial and programmatic data across fiscal years 1977–2013. Data collected for the study were obtained with the assistance of 175 intellectual and developmental disabilities (IDD) agency personnel in the 50 states and the District of Columbia. These individuals are acknowledged by name on pages 93–95.

Data collection for this study is a formidable endeavor. It is a particularly demanding task for state officials. It is not an overstatement to say that we cannot thank the states enough because their participation over many years has made this study possible. The continuing support of the National Association of State Directors of Developmental Disabilities Services, directed by Nancy Thaler, is also central to our data collection and dissemination process. Nancy, and her predecessor and founder of the organization Robert M. Gettings, have been steadfast supporters of our project for over three decades. The Arc of the United States, led by CEO Peter Berns, and the American Association on Intellectual and Developmental Disabilities (AAIDD), led by CEO and Executive Director Margaret Nygren, also have key roles in the nationwide dissemination of this publication through their extensive national, state, and local networks.

The State of the States Project has received a significant portion of its funding for over 30 years as a Project of National Significance from the Administration on Intellectual and Developmental Disabilities (AIDD), U.S. Department of Health and Human Services. We are grateful for AAIDD's long-term support. We acknowledge with appreciation AIDD Commissioner Aaron Bishop, Principal Deputy Administrator for ACL Sharon Lewis, and especially our AIDD Project Officer Katherine Cargill-Willis.

Substantial non-federal Project resources are also contributed to support the project from the Universities of Colorado and Illinois at Chicago. Specifically, financial and administrative support for the project is provided by the University of Colorado, Anschutz School of Medicine, Department of Psychiatry, the Coleman Institute for Cognitive Disabilities, and the University of Illinois at Chicago, Department of Disability and Human Development. Thus, our project is a collaborative effort among two universities (Colorado and Illinois), the 50 states and the District of Columbia, and the Administration on Intellectual and Developmental Disabilities in the U.S. Department of Health and Human Services.

Mary Kay Rizzolo, Glenn Fujiura, Vijay Vasudevan and Carli Friedman at the University of Illinois at Chicago, Department of Disability and Human Development, are key contributors to our project and an integral part of our core research team. Martha King at the Denver-based National Conference of State Legislatures (NCSL) contributes through a subcontract for the project's dissemination to 7,000 state legislators in the 50 states. Jennifer Kraft provides administrative support for project activities here in Boulder.

Prior to publication a draft of this monograph was distributed for review and comment by state I/DD agency directors and their staff. Their participation in this study was essential. The study is not possible without them; but, as is customary, the listed authors bear responsibility for any errors or omissions contained herein.

DAVID BRADDOCK, Ph.D., Coleman-Turner Chair and Professor of Psychiatry,
University of Colorado School of Medicine,
Executive Director, Coleman Institute for Cognitive Disabilities, and
Senior Associate Vice President, Office of the University of Colorado President
<http://stateofthestates.org>

PART I
The State of the States in
Intellectual and Developmental Disabilities:
Emerging from the Great Recession

I. INTRODUCTION

The primary purpose of this study is to measure the impact of the *Great Recession* and its aftermath on services and supports for people with Intellectual and Developmental Disabilities (IDD) and their families in the United States.

The monograph presents the results of our continuing study of trends in spending and services for people with IDD and their families. Our specific focus is long-term care services and supports in the United States. The study adds fiscal years (FYs) 2012 and 2013 to our ongoing study. Our data set now encompasses 37 years: FYs 1977–2013.

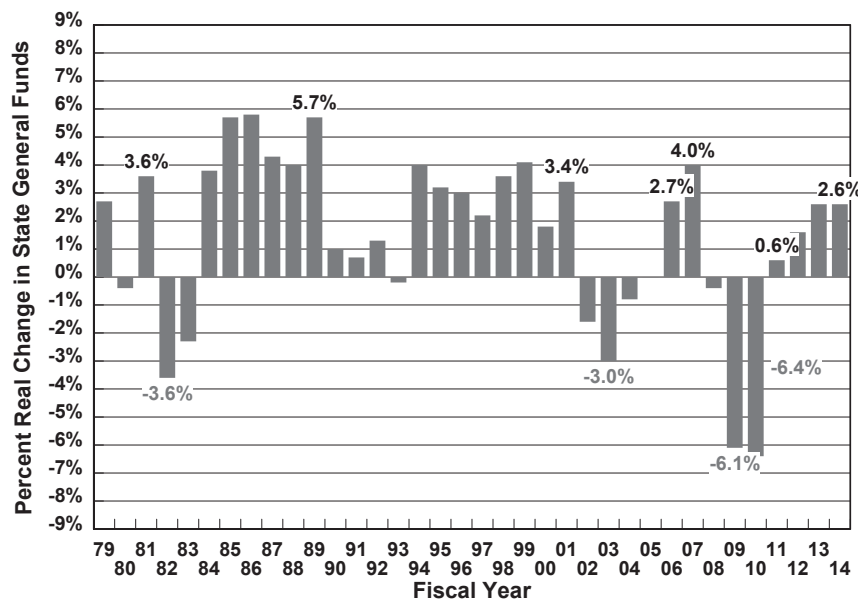
The Great Recession began in December 2007 and ended June 2009 (National Bureau of Economic Research, 2012). In summary, during the Great Recession, aggregate inflation-adjusted state general funds fell 6.1% in 2009 and 6.4% in 2010 before recovering to 0.6% growth in 2011 and 1.6% growth in 2012 (Figure 1 below) (National Governors Association, 2014). State general fund expenditures are critical to IDD long-term services

and supports. They match federal Medicaid reimbursement for Home and Community-Based Services (HCBS) Waivers and other community Medicaid programs.

The adjusted state general fund spending reductions in 2009 and 2010 were the largest in 35 years. However, state general fund spending rebounded 2.6% in FY 2013 and in FY 2014. But this growth was sluggish as compared to rebounds from previous recessions.

The Great Recession, in fact, was qualitatively and quantitatively different from the also substantial 1981–82 U.S. recession. The labor market decline was deeper and longer in the 2007–2009 event (Hoynes, Miller & Schaller, 2012; Katz, 2010). In the 1981–82 recession, aggregate state general fund expenditures declined by 3.6% in 1982 and 2.4% in 1983. This was significantly less than state general fund reductions in the Great Recession (as previously noted, 6.1% and 6.4% in 2009 and 2010, respectively). Moreover, the weak economic recovery in 2011 and 2012 fell far short of past recessions' recoveries.

Figure 1
ANNUAL PERCENT CHANGE IN INFLATION-ADJUSTED
STATE GENERAL FUND SPENDING IN THE U.S.: FYs 1979-2014



Source: National Governors Association and National Association of State Budget Officers (Spring 2014)
79-12 are "actual" state expenditures; 2013 is "preliminary actual"; and 2014 is "appropriated."

II. APPROACH

Data Collection

We collected new intellectual and developmental disabilities (IDD) financial and programmatic data from the states for FYs 2012 and 2013.¹ This extended our overall longitudinal analysis of trends in the United States across the entire 37-year period from 1977 to 2013.

Data collection procedures included: 1) acquisition and analysis of budget and program documents from each state and the District of Columbia (DC); 2) development of 51 specialized survey instruments reflecting the fiscal and programmatic idiosyncrasies of each state and DC; 3) implementation of these surveys in all states and DC; and 4) extensive collaboration with state agency officials to obtain, verify, and interpret the IDD financial and programmatic data collected.

Federal, state, and local program/budget categories employed in our analysis are outlined in Table 1. This taxonomy was the basis both for the survey instruments we constructed for each state, and for our comparative state-by-state statistical analyses. In addition to the federal, state, and local revenue and expenditure categories specified in Table 1, specialized data sets for spending, revenue, and participant data were collected for family support, supported living, and supported employment in each state, along with revenue and participant data for day and work programs. A specialized data set for participants in residential services by size of setting² was also collected to generate cost of care statistics specifically tied to the financial data we collected (Table 2 on page 5).

Numerous methodological problems are encountered in any comparative, longitudinal, nationwide study of public spending. In this study, four empirical problems were confronted in regard to budgets used in the states (Braddock, Hemp, & Fujiura, 1986; 1987): 1) the wide variety of budgeting systems (e.g., *program budgets* vs. *line-item budgets*); 2) several types of capital,

Table 1
BUDGET CATEGORIES/VARIABLES
FOR STATE SPENDING/DATA COLLECTION

I. COMMUNITY SERVICES FUNDS

A. COMMUNITY SERVICES (15 OR FEWER PERSONS)

1. STATE FUNDS
 - a. General Funds
 - b. Medicaid Match
 - c. Other State Funds
 - d. Local Funds
 - e. SSI State Supplement Funds
2. FEDERAL FUNDS
 - a. Public ICF/ID¹ (≤15 persons)
 - b. Private ICF/ID (≤15 persons)
 - c. HCBS Waiver
 - d. Other Medicaid Services
 1. Rehabilitative Services
 2. Clinic Services
 3. Targeted Case Management
 4. Personal Care Services
 5. Administrative, Other Community Services
 - e. Title XX/Social Services Block Grant
 - f. Other Federal Funds
 1. Temporary Assistance for Needy Families (TANF)
 2. Other Federal Funds
 - g. SSI and Adult Disabled Child (ADC) benefits for HCBS Waiver Participants

II. INSTITUTIONAL SERVICES FUNDS

A. PUBLIC INSTITUTIONS (16 OR MORE PERSONS)

1. STATE FUNDS
 - a. General Funds
 - b. ICF/ID Medicaid Match
 - c. Other State Funds
 - d. Local Funds
2. FEDERAL FUNDS
 - a. Federal ICF/ID
 - b. Title XX/Social Services Block Grant
 - c. Other Federal Funds

B. PRIVATE INSTITUTIONS (16 OR MORE PERSONS)

1. STATE FUNDS
 - a. General Funds
 - b. ICF/ID Medicaid Match
 - c. Other State Funds
2. FEDERAL FUNDS
 - a. Federal ICF/ID
 - b. Other Federal Funds

¹Formerly "ICF/MR," hereafter ICF/ID

Sources: Braddock (1981, 2002a); Braddock, Hemp, & Fujiura (1987).

1. Unless otherwise noted, all years refer to states' fiscal years that run July 1 through June 30. Exceptions are Alabama, the District of Columbia, and Michigan (October 1–September 30); New York (April 1–March 31); and Texas (September 1–August 31).

2. For additional information on IDD residential services and supports, see research by Sheryl Larson and colleagues at: www.ici.umn.edu/

equipment, and debt service budgeting methods and varied budgeting practices for fringe benefit costs; 3) the varied reliability of the spending figures reported in official state budget documents (i.e., whether the budget reported actual expenditures, preliminary or revised appropriations, governor's recommendations,

Table 2
KEY PROGRAM/PARTICIPANT
VARIABLES FOR DATA COLLECTION

- I. COMMUNITY RESIDENTIAL SETTINGS (1-6 PERSONS)
 - A. Public ICFs/ID
 - B. Private ICFs/ID
 - C. Supported Living
 - D. Personal Assistance
 - E. Other residential settings
(Group homes, apartments, foster homes, host homes)
- II. COMMUNITY RESIDENTIAL SETTINGS (7-15 PERSONS)
 - A. Public ICFs/ID
 - B. Private ICFs/ID
 - C. Other residential settings for 7-15 persons
- III. DAY/WORK PROGRAM PARTICIPANTS
 - A. Sheltered employment/work activity
 - B. Day habilitation ("day training")
 - C. Supported/competitive employment
- IV. HCBS WAIVER PARTICIPANTS
- V. PUBLIC & PRIVATE INSTITUTIONAL SETTINGS (16+ PERSONS)
 - A. State-operated institutions
 - B. Private ICFs/ID
 - C. Other private residential facilities
 - D. Nursing facility residents with I/DD

Sources: Braddock (1981, 2002a); Braddock, Hemp, & Fujiura (1987).

or special legislatively requested data); and, 4) the complex problem of disaggregating federal, state, and local funds reported in states' executive budget documents.

The first empirical challenge is related to the wide variety of budgeting systems across the states. Fiscal data available in program budgets are frequently unavailable or available only in part in line-item budgets. Comparative nationwide financial studies are thus constrained by the lowest common denominator; that is, by the amount of detail in the least detailed state budget. Thus, extensive personal interpretive contact was required with state agency officials in this study to supplement budget document analysis.

Several types of capital, equipment, and debt service budgeting methods are used in the 50 states and DC. A number of states integrate these expenditures into their regular operating budgets, and these amounts have to be carefully extracted from operating expenditures to ensure comparability across states. In addition, fringe benefit costs for state employees are often reported separately from IDD agency budgets. These nontrivial sums, which can exceed 20–25% of state agencies' personnel budgets, must be obtained directly from other state agencies, (e.g., personnel management agencies), and subsequently aggregated with IDD operating expenditures managed by the principal IDD state agency.

The third empirical problem stems from the different levels of reliability in the spending figures reported in official state budget documents. The stability of a reported spending figure depends upon the stage of the budget process in which it is captured. Gubernatorial recommended or requested figures are subject to substantial change because they are subsequently reviewed and often modified by legislative appropriation committees. Actual expenditures are not subject to change and represent fixed values after the official closing of the books. Actual expenditures are generally available within two years of the initial appropriation. Intermediate stage spending data include revised appropriations and obligations, the latter reflecting legally binding financial commitments incurred by an agency. Revised appropriations figures are adjusted periodically during and after the fiscal year in which the funds were originally appropriated.

Data used for the analysis of trends in IDD state spending should be based on actual expenditures and obligations, or, at a minimum, revised appropriations. As we completed different iterations of this study over the years, we worked closely with the states to continuously revise and improve the reliability of prior years' data.

State executive budget documents typically provide three years of data. Most governors' executive budgets for FY 2014 were published in early calendar year 2013. They typically presented actual expenditure data for FY 2012, revised appropriations for 2013, and the *governor's recommendation or legislative request* for 2014.

Some state budgets provide a level of detail on IDD institutional and community services spending and related performance measures including participant data. However, useful budget detail in gubernatorial executive budgets is the exception, not the rule. We must obtain fiscal and programmatic data via state-specific survey instruments, and through ongoing communication with state IDD, Medicaid, and social services agency officials.

As Caiden (1978) warned 36 years ago, the methodological problems noted above pose significant challenges to completing any comprehensive and accurate nationwide study of public spending.

State survey instruments. Initial contact with a given state is preceded by inspection of the state's published executive budget documents, and a review of acquired programmatic and financial documents including material from our data collection efforts in previous years. Interviews with state IDD agency

personnel helped guide development of a fiscal classification system sensitive to each state's budgeting terminology.

The project's survey instruments include electronic spreadsheets that are sufficiently detailed to reflect each state's unique budget structure, and that are consistent with the study's classification categories (Table 1 on page 4). Reliability of the classification of IDD revenue and spending data into the various classification categories by our project's data collection specialists has been demonstrated to be strong (Braddock & Fujiura, 1991). Winer's (1971) unbiased intraclass correlation coefficients were determined to be between .88 and 1.00 for our classification process.

At the outset of each data collection cycle, each state is provided with a guide containing definitions and instructions along with three data collection instruments. The first, for revenue and expenditure data, is structured according to the classification categories outlined in Table 1 (p. 4); a second is for data on the number of participants in residential programs as outlined in Table 2 (p. 5); and a third is for spending, revenue, and participant data on services to support individuals living in the family home (family support), supported living/personal assistance, and day/work programs including a minimum data set on supported employment spending activities.³ We have also been collecting data on an exploratory basis for smart homes and other personal support technologies.

The data we collect on *family support*, *supported living*, and *supported employment* are all subsets of the broader category of community services spending. The data we collect on supported living participants are a subset of residential services data.

National data sources. Some state-by-state data utilized in this study were obtained from national sources. For example, Supplemental Security Income (SSI) and SSI state supplement data were obtained from *Social Security Statistical Supplements* (Social Security Administration, 2014) and employed in our profiles of the states. Also, to augment and cross-check some of the Medicaid Intermediate Care Facility for Persons with Intellectual disability (ICF/ID) and Home and Community Based Services (HCBS) Waiver data we collected from state IDD agencies. We utilized "Medicaid Statistical Information System (MSIS)" beneficiary

data, CMS-64 expenditure, and CMS-372 Waiver data (Centers for Medicare and Medicaid Services, 2014; Eiken, Sredl, Gold, Kasten, Burwell, & Saucier 2014). Data for persons with IDD in nursing facilities in some states were from the Centers for Medicare and Medicaid Services (CMS) "Online Survey, Certification and Reporting (OSCAR)" data set (American Health Care Association, 2014).

In various analyses we employed census, demographic, income, and poverty data from the Assistant Secretary for Planning and Evaluation (2014) and the U.S. Census Bureau, (2014). Statewide aggregate personal income data came from the U.S. Department of Commerce, (2014c), and states' general fund expenditures were from the National Governors Association and National Association of State Budget Officers (2014).

In this 2015 edition, we made a special effort, when appropriate, to identify, evaluate, and revise missing or non-incremental budgetary and participant data across the 37-year span of the project's data collection efforts. This entailed collaboration with state IDD agencies to obtain, when possible, revised historical data of improved quality.

Data Analysis

We analyzed data collected to determine the presence or absence of financial and participant trends within each state and across the nation. The 42 key program/budget data collection categories presented in Table 1 (p. 4) and the 20 program/participant data categories in Table 2 (p. 5) enabled us to analyze the structure and financing of institutional and community services for the 50 states and DC as well as for the nation as a whole.

Financially focused analysis. Public spending for institutional and community services was summarized by level of government (federal, state, and local) and by revenue source. *Institutional* spending supported publicly and privately-operated ICF/ID-certified and non-ICF/ID facilities for 16 or more persons. (Nursing facility spending was not included in this analysis.)

Community services spending included residential and non-residential services for 1–15 persons. This included publicly and privately-operated ICFs/ID; Medicaid Home and Community Based Services (HCBS) Waiver funds; and, other federal, state, or local funding for a wide range of residential services and supports including group homes, apartments, foster

3. For more comprehensive data on employment services for persons with IDD, see research by John Butterworth and colleagues at: www.statedata.info

homes, supported living/personal assistance, as well as non-residential community supports. Analyses were also completed on spending in the states for *individual and family support* (i.e., supported living/personal assistance, supported employment, family support), as well as assistive technology initiatives. In addition, we determined community services spending that excluded settings for 7–15 persons; i.e., spending for six person or fewer settings and “individual and family support.” (see discussion on page 13).

A consistent method of estimating the impact of inflation on IDD spending in the states was utilized: “The State and Local Government Sub-Index of The Gross Domestic Product (GDP) Government Consumption Expenditure” (United States Department of Commerce, Bureau of Economic Analysis, 2014a). Gross Domestic Product (GSP) data were utilized as well (U.S. Department of Commerce, Bureau of Economic Analysis (2014b)).

U.S. inflation rates for 2005 and 2006 were the highest in over 20 years, at 5.6% and 5.2%, respectively. The inflation rate then dropped slightly to 4.7% in 2007 and 5.0% in 2008. During the *Great Recession*, inflation rates plummeted to 2.4% in 2009, 0.8% in 2010, 3.0% in 2011, and to 2.3% in 2012. The inflation rate dropped again to 0.9% in 2013, and increased slightly to 1.1% in 2014. The 2010 inflation rate was the lowest level in the 37-year history of our study.

Fiscal effort, defined as IDD spending as a share of aggregate statewide (and nation-wide) personal income (U.S. Department of Commerce, 2014c) was computed

for each state, DC, and the U.S. for: (a) community settings; (b) public and private 16+ institutional settings; and (c) total IDD spending in the states.

Participant-focused analysis. We collected participant data in terms of average daily participants on a fiscal year basis for and supported living. Also collected were full-time equivalent participants for day programs and supported employment, and unduplicated participants in the HCBS Waiver and family support programs. Compared to end-of-year or point-in-time data, these data produce more accurate daily cost-of-care statistics.

We computed the average cost of care by state in: (a) public and private institutions for 16+ persons; (b) public and private ICFs/ID for 15 or fewer persons; and (c) supported living settings. Participant utilization rates (per citizen of the state general population) were also computed for public institutions and non-specialized nursing facilities for residential settings for 7–15 persons, for residential settings for six or fewer persons, and for the HCBS Waiver program.

In other analyses we estimated the number of persons with IDD living with aging caregivers in each state and nationally, identified completed and in-progress state-operated institutional closures in the states, summarized recent developments in IDD-relevant litigation in the states through 2014, determined the proportion that Medicaid constituted of total IDD spending in each state, and estimated funds potentially available for matching additional federal Medicaid reimbursement.

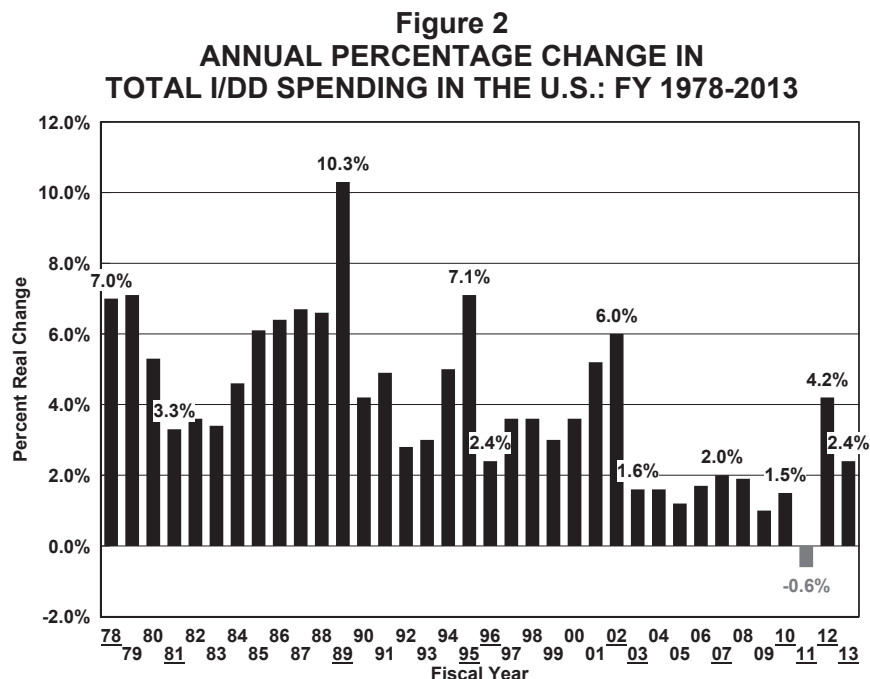
III. NATIONAL TRENDS IN IDD SPENDING

Annual growth rates for total IDD spending in the U.S. were 1.5% in FY 2010, negative 0.6% in FY 2011, 4.2% in 2012, and 2.4% in 2013 (Figure 2 below). The 2011 rate was the only annual decline in IDD spending in our 37 year span of data collection. Moreover, total public spending for IDD services in the U.S. increased by only 0.5% from 2009 to 2011. However, as noted, total IDD spending increased during 2012 and 2013.

Annual percentage change in IDD community and institutional spending is illustrated in Figure 3 (on the following page). Real spending for the community services component of total IDD spending was 0.0% in 2011—the first one-year period of no growth since our study began in 1977. Moreover, inflation-adjusted public and private institutional spending for persons in 16+ settings fell 3.4% in 2011, 0.5% in 2012, and 2.8% in 2013. The proportion of total U.S. public IDD spending allocated for 15 person or fewer community services versus 16+ institutional services increased marginally from 85% in 2011 to 87% in 2013.

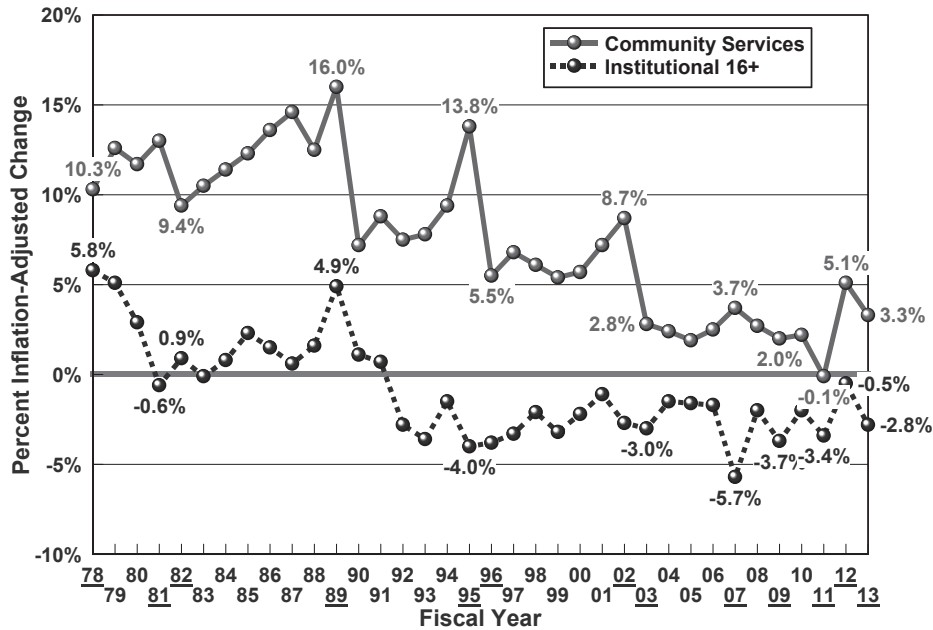
Spending for IDD service categories in 2013 is illustrated in Figure 4 on the following page. Percentages were rounded. Total IDD spending in the U.S. in 2013 was \$61.46 billion; \$50.0 billion of this amount was allocated for community residential and related services for six or fewer persons (81.3%). An additional \$3.3 billion (5%) was committed by states to residential services for 7–15 persons, including ICFs/ID. Spending totaled \$6.3 billion for state-operated 16+ institutional settings (10%), and \$1.9 billion funded privately-operated settings serving 16 or more persons per setting (3%).

Individual and family support services—consisting of family supports, supported living, and supported employment combined—constituted 20.9% of total IDD spending in 2013. By far the largest IFS component was supported living and personal assistance (\$7.9 billion), constituting 12.8% of total IDD spending. Family support funds (\$4.1 billion) comprised only 6.7% of total spending. Supported employment totaled \$868 million, 1.4% of total spending.



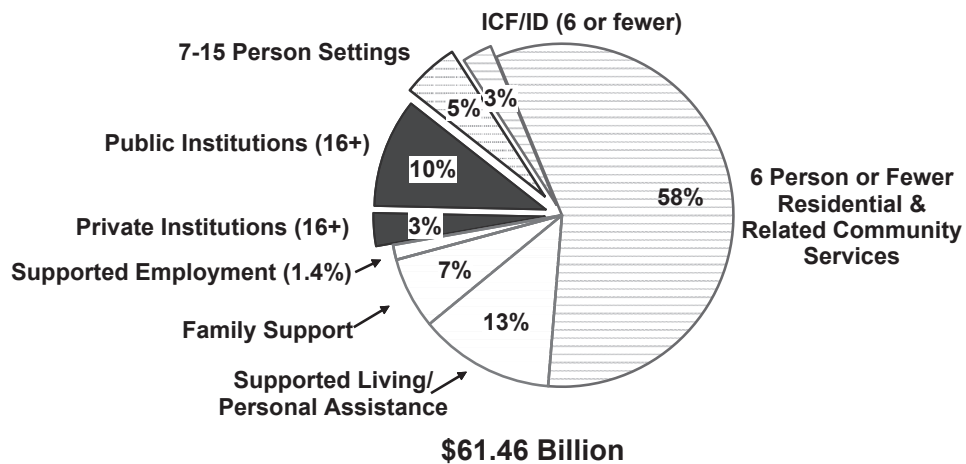
Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

Figure 3
ANNUAL PERCENTAGE CHANGE IN I/DD COMMUNITY AND INSTITUTIONAL SPENDING IN THE U.S.: FY 1978-2013



Source: Braddock, et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.
NOTE: Community services spending includes 15 or fewer person settings; Institutional services includes public and private 16+ person institutions; excludes nursing facility spending.

Figure 4
UNITED STATES
I/DD SPENDING BY SERVICE CATEGORY: FY 2013



Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

Trends in Spending by State: FY 2011–2013

During 2011–13, inflation-adjusted community spending in the U.S. advanced 8.5% (Table 3 below). Eight states reduced community services spending during 2011–13, ranging from a 0.2% reduction in New Mexico to a 9.6% reduction in Hawaii. Other large community spending reductions were in Florida (9.4%), and Rhode Island (5.2%).

The largest state increase in community spending during 2011–13 was in Kentucky (40.3%). Kentucky's community spending growth was heavily underwritten by the HCBS Waiver, the result of the *Michelle P* class action litigation (Ng, Wong, & Harrington, 2009). Other state leaders in the growth of community services spending during 2009–11 were Mississippi (39%); Louisiana, Missouri, and Virginia (35%); Alaska (30%); Pennsylvania (26%); West Virginia (23%); Montana (21%); and Georgia (20%).

Total IDD institutional and community spending during 2011–13 increased 20% or more in nine states: Mississippi (33%), Alaska (30%), Virginia (29%),

Missouri (28%), Kentucky (26%), Louisiana (24%), West Virginia (23%), Pennsylvania (22%), and Montana (20%). Thirty-three states and the District of Columbia increased spending between 0.05% and 15%.

Reductions in total inflation-adjusted intellectual and developmental disabilities spending occurred in seven states during 2011–13 (see Figure 5 on the following page). These included Hawaii (10%), Florida (9%), Illinois (7%), Rhode Island (6%), Alabama (5%), Arizona (1%), and New Mexico (0.2%).

Changes in Inflation-Adjusted Spending by Fiscal Year: 2011, 2012, and 2013

Recovery from the Great Recession was analyzed in terms of inflation-adjusted change in spending by state, service sector, and year (2011, 2012, and 2013) (Table 4 on page 12). The number of states with community spending reductions dropped from 27 states in 2011 to 12 states in 2013. States reducing total spending fell from 31 states in 2011 to 13 states in 2013. Only Florida had community and institutional spending reductions

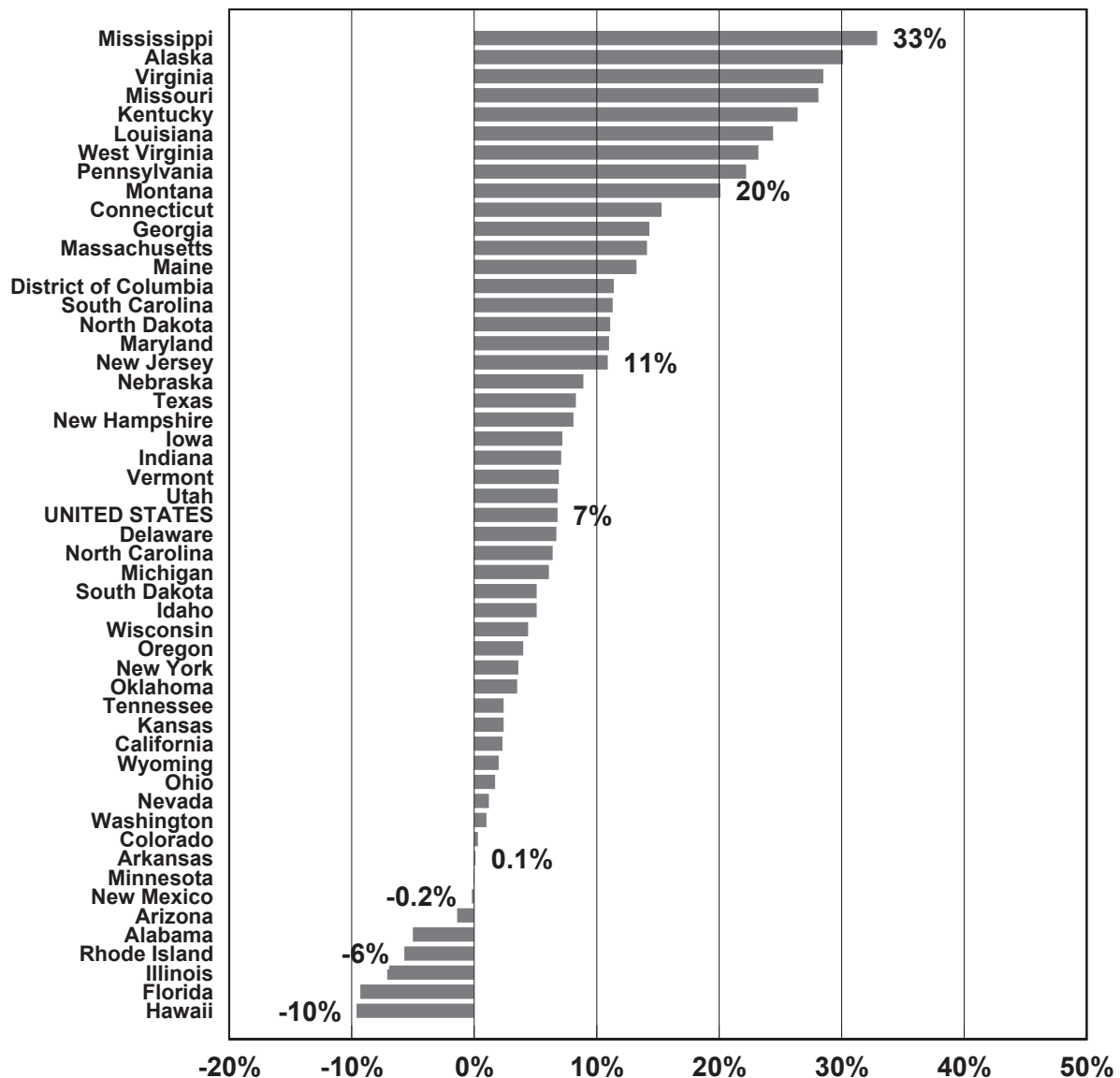
TABLE 3
PUBLIC I/DD SPENDING FOR COMMUNITY SERVICES IN THE STATES: FY 2011-13

State	Community Spending		% Real Change 2011-13 ¹	State	Community Spending		% Real Change 2011-13 ¹
	2013	2011			2013	2011	
Alabama	\$365,940,032	\$335,133,155	5.8%	Montana	\$157,188,442	\$126,331,727	20.6%
Alaska	\$201,532,918	\$150,136,938	30.1%	Nebraska	\$303,290,065	\$257,632,033	14.1%
Arizona	\$814,217,645	\$800,391,291	-1.4%	Nevada	\$150,226,860	\$143,232,796	1.6%
Arkansas	\$366,739,903	\$365,157,752	-2.7%	New Hampshire	\$277,181,929	\$248,652,647	8.0%
California	\$5,829,780,987	\$5,420,881,085	4.2%	New Jersey	\$1,233,843,626	\$1,069,375,545	11.8%
Colorado	\$485,138,119	\$477,983,086	-1.6%	New Mexico	\$361,742,908	\$351,276,212	-0.2%
Connecticut	\$990,379,182	\$838,600,414	14.4%	New York	\$9,760,945,439	\$9,043,498,300	4.6%
Delaware	\$133,358,929	\$121,190,479	6.6%	North Carolina	\$1,154,938,136	\$1,036,177,229	8.0%
District of Columbia	\$282,030,691	\$245,219,678	11.4%	North Dakota	\$241,835,860	\$208,298,958	12.5%
Florida	\$1,271,150,396	\$1,360,248,844	-9.4%	Ohio	\$2,786,453,131	\$2,590,553,534	4.2%
Georgia	\$810,848,458	\$655,346,776	19.9%	Oklahoma	\$432,124,497	\$404,499,262	3.5%
Hawaii	\$161,577,571	\$173,161,665	-9.6%	Oregon	\$801,630,481	\$747,094,612	4.0%
Idaho	\$184,025,096	\$179,571,122	-0.7%	Pennsylvania	\$3,007,010,916	\$2,317,542,892	25.7%
Illinois	\$1,201,616,397	\$1,120,981,935	3.9%	Rhode Island	\$251,949,523	\$257,524,408	-5.2%
Indiana	\$1,304,942,929	\$1,158,423,978	9.2%	South Carolina	\$494,096,042	\$423,610,612	13.0%
Iowa	\$647,046,377	\$559,042,334	12.2%	South Dakota	\$142,353,692	\$136,002,204	1.4%
Kansas	\$432,012,358	\$417,207,115	0.3%	Tennessee	\$839,053,133	\$751,907,116	8.1%
Kentucky	\$603,706,311	\$417,100,930	40.3%	Texas	\$1,844,431,103	\$1,613,805,131	10.8%
Louisiana	\$1,237,479,247	\$886,051,292	35.3%	Utah	\$213,014,638	\$189,915,884	8.7%
Maine	\$439,111,984	\$377,534,453	12.7%	Vermont	\$178,644,406	\$161,983,207	6.9%
Maryland	\$974,146,551	\$833,914,912	13.2%	Virginia	\$1,029,622,204	\$738,332,272	35.1%
Massachusetts	\$1,896,320,622	\$1,634,851,221	12.4%	Washington	\$877,718,743	\$839,649,029	1.3%
Michigan	\$1,456,707,667	\$1,328,070,686	6.3%	West Virginia	\$442,947,586	\$347,965,236	23.4%
Minnesota	\$1,682,313,990	\$1,619,492,116	0.7%	Wisconsin	\$1,234,424,509	\$1,137,462,282	5.2%
Mississippi	\$208,859,530	\$145,811,171	38.8%	Wyoming	\$125,023,297	\$118,384,129	2.3%
Missouri	\$913,115,019	\$656,360,936	34.8%	United States	\$53,235,790,070	\$47,538,572,618	8.5%

¹ Inflation-adjusted percentage change, 2011 to 2013.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

Figure 5
Forty-Three States and DC Increased Inflation-Adjusted I/DD Spending During FY 2011-13; 7 States Cut Spending



Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015

TABLE 4
PERCENT CHANGE IN SPENDING BY SETTING: FY 2011, 2012, and 2013¹

STATE	PUBLIC/PRIVATE 16+ INSTITUTIONS ²			COMMUNITY ³			TOTAL		
	2011	2012	2013	2011	2012	2013	2011	2012	2013
Alabama	-3.2%	-69.1%	-100.0%	5.9%	1.1%	4.7%	4.4%	-6.1%	1.2%
Alaska	No 16+ spending			4.7%	19.6%	8.8%	4.7%	19.6%	8.8%
Arizona	-3.2%	5.8%	-7.5%	0.4%	-1.2%	-0.2%	0.2%	-1.0%	-0.5%
Arkansas	0.0%	8.5%	-1.5%	4.6%	6.8%	-8.9%	3.3%	7.3%	-6.8%
California	-3.4%	-6.5%	-8.4%	-0.5%	-1.0%	5.3%	-0.8%	-1.6%	3.9%
Colorado	24.8%	22.9%	2.8%	-4.8%	2.2%	-3.7%	-3.2%	3.6%	-3.2%
Connecticut	-0.3%	19.9%	-0.5%	-1.8%	18.4%	-3.3%	-1.5%	18.6%	-2.8%
Delaware	6.7%	1.8%	5.0%	-4.9%	8.1%	-1.3%	-2.7%	6.7%	0.0%
District of Columbia	No 16+ spending			-19.7%	6.0%	5.1%	-19.7%	6.0%	5.1%
Florida	-6.2%	-6.0%	-2.7%	-3.2%	-5.9%	-3.8%	-3.7%	-5.9%	-3.6%
Georgia	-8.4%	-15.5%	-17.7%	0.9%	8.8%	10.2%	-0.2%	6.1%	7.7%
Hawaii	No 16+ spending			-1.2%	-6.6%	-3.2%	-1.2%	-6.6%	-3.2%
Idaho	-14.7%	52.9%	25.1%	-11.1%	7.0%	-7.2%	-11.4%	9.9%	-4.4%
Illinois	-0.6%	-24.6%	-5.6%	-2.5%	0.2%	3.7%	-1.9%	-8.2%	1.1%
Indiana	-19.5%	-30.8%	-15.8%	-5.4%	9.6%	-0.4%	-6.1%	8.0%	-0.8%
Iowa	-6.7%	1.3%	-5.5%	0.4%	5.8%	6.0%	-1.8%	4.5%	2.6%
Kansas	-4.7%	24.6%	-2.8%	2.8%	-0.9%	1.3%	2.0%	1.6%	0.8%
Kentucky	-3.6%	-5.3%	-5.2%	14.9%	22.1%	14.9%	9.2%	14.6%	10.4%
Louisiana	-0.6%	-4.9%	-13.3%	-2.3%	33.4%	1.4%	-2.0%	25.5%	-0.9%
Maine	-2.3%	51.0%	-2.6%	-5.3%	13.6%	-0.7%	-5.2%	14.1%	-0.8%
Maryland	-10.5%	-14.2%	-5.2%	-1.3%	10.0%	2.9%	-1.9%	8.4%	2.5%
Massachusetts	-22.4%	0.5%	33.0%	-1.3%	8.3%	3.8%	-3.4%	7.7%	6.0%
Michigan	24.9%	2.2%	-3.8%	-0.5%	3.2%	3.0%	-0.1%	3.1%	2.9%
Minnesota	-15.3%	-21.3%	-1.6%	-0.2%	3.3%	-2.5%	-0.7%	2.6%	-2.5%
Mississippi	-6.3%	21.3%	6.0%	-8.0%	23.2%	12.7%	-7.0%	22.1%	8.9%
Missouri	-9.4%	0.3%	-10.3%	3.6%	16.9%	15.4%	1.4%	14.4%	12.0%
Montana	-18.5%	1.6%	12.3%	2.0%	18.7%	1.6%	0.1%	17.3%	2.3%
Nebraska	-8.8%	-8.8%	-0.9%	3.9%	4.3%	9.4%	0.8%	1.4%	7.3%
Nevada	2.5%	3.9%	-6.5%	-1.7%	-1.7%	3.4%	-1.4%	-1.2%	2.5%
New Hampshire	-4.6%	7.6%	8.0%	3.3%	3.7%	4.2%	3.2%	3.7%	4.3%
New Jersey	7.3%	12.5%	-2.7%	3.9%	5.8%	5.7%	5.2%	8.4%	2.3%
New Mexico	No 16+ spending			-6.9%	-1.6%	1.4%	-6.9%	-1.6%	1.4%
New York	-1.4%	-1.2%	-5.6%	-0.2%	1.9%	2.7%	-0.3%	1.6%	1.9%
North Carolina	-3.4%	6.9%	-5.2%	-0.3%	7.7%	0.3%	-1.0%	7.5%	-1.0%
North Dakota	-0.8%	-3.9%	5.8%	5.2%	9.0%	3.2%	4.4%	7.4%	3.5%
Ohio	0.5%	-5.3%	-5.1%	0.8%	1.6%	2.5%	0.8%	0.4%	1.3%
Oklahoma	-21.4%	3.5%	0.0%	-0.3%	-0.5%	4.0%	-4.5%	0.2%	3.3%
Oregon	No 16+ spending			3.7%	3.6%	0.3%	2.9%	3.6%	0.3%
Pennsylvania	-3.1%	11.6%	-4.4%	-4.4%	16.3%	8.1%	-4.1%	15.4%	5.9%
Rhode Island	-9.4%	-25.2%	3.0%	-9.6%	-6.6%	1.5%	-9.6%	-7.1%	1.5%
South Carolina	0.8%	6.7%	-2.6%	2.6%	8.3%	4.4%	2.2%	8.0%	3.1%
South Dakota	-14.5%	35.8%	-5.8%	1.9%	-1.7%	3.2%	-0.8%	3.5%	1.6%
Tennessee	-28.1%	-25.3%	-8.0%	0.6%	2.4%	5.6%	-4.9%	-1.6%	4.1%
Texas	-0.5%	0.1%	3.1%	10.4%	8.3%	2.2%	6.6%	5.7%	2.5%
Utah	-9.3%	-0.2%	1.5%	-4.9%	3.6%	4.9%	-6.0%	2.6%	4.1%
Vermont	No 16+ spending			0.6%	1.5%	5.3%	0.6%	1.5%	5.3%
Virginia	-2.2%	4.5%	4.0%	4.2%	25.3%	7.8%	2.5%	20.1%	7.0%
Washington	-11.9%	-3.1%	2.8%	-0.6%	-1.3%	2.6%	-2.8%	-1.6%	2.7%
West Virginia	6.9%	0.1%	4.7%	-1.1%	14.7%	7.6%	-1.0%	14.6%	7.5%
Wisconsin	-5.1%	0.3%	-1.3%	8.7%	-1.5%	6.7%	6.7%	-1.3%	5.7%
Wyoming	0.8%	8.9%	-8.2%	2.4%	6.6%	-4.0%	2.1%	6.9%	-4.7%
United States	-3.4%	-0.5%	-2.8%	-0.1%	5.1%	3.3%	-0.6%	4.2%	2.4%
NO. OF STATES WITH REDUCTIONS	35	18	31	27	13	12	31	12	13

¹ Inflation-adjusted percentage change Fiscal Years 2010-11, 2011-12 and 2012-13.

² "Public/private 16+ institution" spending excludes nursing facility spending. AK, DC, HI, NM, OR, and VT had no 16+ setting spending during 2011-13; Alabama closed all 16+ settings in 2013.

³ "Community" was defined to include residential settings for 15 or fewer persons.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

all three years. However 18 states had these reductions in 2011, four in 2012, and eight in 2013.

The largest community services spending reductions from 2012 to 2013 were in Arkansas (9%) and Idaho (7%). In 2012, the largest reductions were in Hawaii and Rhode Island (7%) and in Florida (6%).

However, in fiscal year 2011, community spending dropped five percent or more in nine jurisdictions: District of Columbia (20%); Idaho (11%); Rhode Island (10%); Mississippi (8%); New Mexico (7%); and Colorado, Indiana, Maine, and Utah (5%). Twenty-four states did not reduce community spending in 2011.

Three successive years of IDD community services spending reductions in such a large number of states has no doubt harmed community services provider organizations, families, and individuals with IDD. For example, although inflation-adjusted family support spending dropped only 0.4% from 2011 to 2013, there were 2011–13 spending reductions in family support spending ranging from 0.2% to 57% in 22 states. Idaho provided no family support services in 2013; Virginia had no family support spending in 2012, but instituted a new cash subsidy for families in 2013.

The broad and deep annual reductions in public and private 16+ institutional spending continued in the U.S. in 2011–13. Inflation-adjusted institutional spending declined 3.3%. The annual inflation-adjusted institutional spending declines in the U.S. were 3.4% in 2011, 0.5% in 2012, and 2.8% in 2013. However, 31 states posted real spending increases for public/private institutional services in 2011, 2012, or 2013. Of these states, only three, Colorado, Delaware, and West Virginia increased institutional spending all three years.

The largest reductions in public and private institutional spending were in seven states. They are listed here with their 2011, 2012, and 2013 spending reductions: California (3%, 7%, 8%); Georgia (8%, 16% and 18%); Indiana (20%, 31%, 16%); Maryland (11%, 14%, 5%); Minnesota (15%, 21%, 2%), New York (1%, 1% and 6%); and Tennessee (28%, 25%, and 8%).

Institutional spending increased in 10 states in 2011, 27 states in 2012, and 14 states in 2013. States posting real growth in 2013 in public/private institutional spending were: Massachusetts (33%); Idaho (25%); Montana (12%); New Hampshire (8%); Mississippi and North Dakota (6%); Delaware and West Virginia (5%); Virginia (4%); Colorado, Rhode Island, Texas, and Washington (3%); and Utah (2%).

It should be noted that institutional spending in New Hampshire and West Virginia consisted exclusively of

16+ person privately operated settings. In Michigan, which closed its remaining state-operated institution in 2009, spending increases in 2011 and 2012 were for IDD facilities sponsored by the Michigan State Housing Development Authority. Indiana's spending reductions resulted from the closure of the remaining IDD units in the Evansville, Madison, and Richmond State Psychiatric Hospitals in 2012 and Logansport in 2013. (Table 4 on page 12).

Total institutional and community IDD spending declined in 31 states in 2011, 12 states in 2012, and in 13 states in 2013. In 2013, four states had reductions of 4% or more: Arkansas (7%), Wyoming (5%) and Florida and Idaho (4%). The other states, with reductions ranging from 3% to 0.4%, were: Colorado, Hawaii, Connecticut, Minnesota, North Carolina, Louisiana, Indiana, Maine, and Arizona. All states with reductions in total IDD spending in 2013, except Colorado and Idaho, also posted reductions in institutional services spending (Hawaii had no state institution spending during 2011–2013).

Comparative Analysis of Institutional and Community Services

Five empirical characteristics of states' patterns of financing institutions and community services were used to gauge resource allocation trends in the states over the past four decades. These include: (a) the year in which community spending first exceeded institutional spending (parity); (b) the rate at which community services resources have grown over time; (c) the rate at which institutional spending has declined; (d) the proportion of total IDD resources committed to community services versus institutional services; and, (e) the extent of resource commitments in the states to individual and family support activities.

Public spending for community services in the U.S. first exceeded institutional spending in 1989. In 2013, all states but Mississippi were spending more for community services than for institutional services. Mississippi, however, has also significantly increased public resources for community services over the past 17 years. However, their community spending share is still only 44%. Alaska, in 1981, and Colorado and Michigan, in 1982, were the first three states to allocate a majority of their total IDD funding base to community services. They were followed by Montana, New Hampshire, Rhode Island, and Vermont in 1983–84.

An additional 15 states and the District of Columbia began committing the majority of IDD resources to community services activities during 1985–88. Twenty-four states reached this benchmark during 1989–97. Georgia, New Jersey and Tennessee reached parity in 1998, followed by Arkansas in 1999.

Growth in community resources and institutional spending reductions. Inflation-adjusted community spending in the U.S. advanced 8.5% from 2011 to 2013. During this period, as noted, community services spending declined by 10% in Hawaii and 9% in Florida, while a 40% increase was reported in Kentucky following the *Michelle P* class action litigation. Other leaders and laggards in the expansion of community services resources during 2011–13 were identified previously in Table 3 (p. 10) and Table 4 (p. 12).

Another metric by which to gauge trends in public spending in the states is the rate of decline in state financing of institutional care. For example, the public and private institutional care sector spending peaked in 1991, at \$14.87 billion (adjusted for inflation), but it has declined each year, dropping to \$8.22 billion in 2013. During 2011–13, combined public/ private 16+ person institutional spending declined by 100% in Alabama and Oregon, and by 42% in Indiana as those states became the 12th, 13th, and 14th “institution-free” states. There were also institutional spending reductions of 31% in Tennessee, 30% in Georgia, 29% in Illinois, 23% in Rhode Island and Minnesota, 19% in Maryland, 18% in Louisiana, 14% in California, 10% in Kentucky, Ohio, Missouri, and Nebraska and between 9% to 0.4% in Florida, New York, Iowa, Nevada, Arizona, Michigan Wisconsin, and Washington State. Minnesota closed the “METO” unit at Cambridge State Hospital, but some individuals with intense support needs were still awaiting alternate placement in 2013.

Public and private institutional spending increased between 1% and 91% in 21 states during 2011–13. The largest increases were in Idaho (91%), Maine (47%), Massachusetts (34%), Mississippi (29%), South Dakota (28%), Colorado (26%), Kansas (21%), Connecticut (19%), New Hampshire (16%), and Montana (14%). Increases in public and private institutional spending ranged from 9% to 1% in New Jersey, Virginia, Arkansas, Delaware, Pennsylvania, West Virginia, South Carolina, Oklahoma, Texas, North Dakota, Utah, and North Carolina. The increases in Maine, New Hampshire, and West Virginia were for private 16+ settings.

The increasing proportion of total IDD resources dedicated to community services activities was a

significant aspect of state IDD financing in 2013. Eighty-seven percent of total IDD spending in the states was dedicated to 15–person or fewer community services and supports. Alabama, Alaska, DC, Hawaii, New Mexico, Oregon, and Vermont devoted 100% of IDD resources to community services.

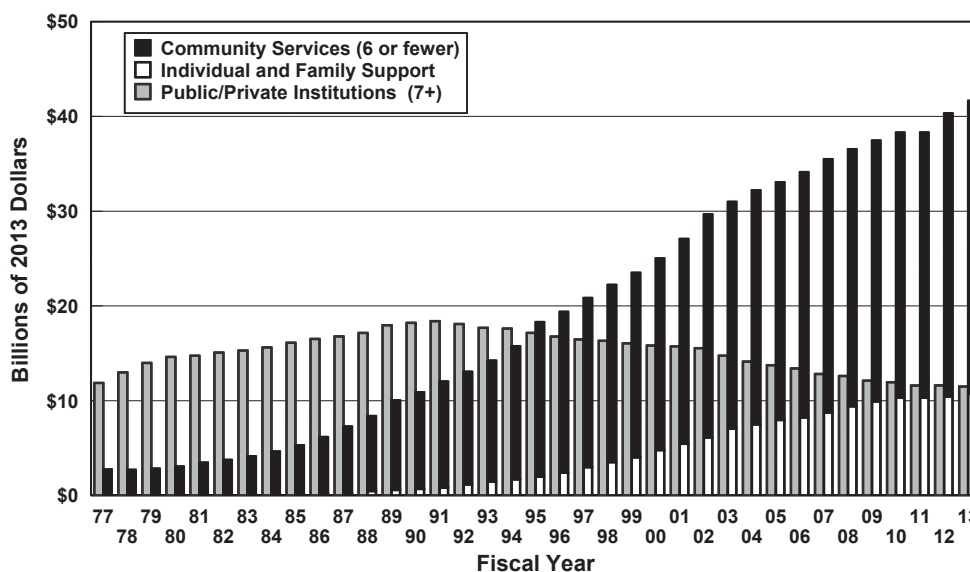
Eighteen additional states dedicated at least 90% of total resources to community services. These states included Arizona, California, Colorado, Georgia, Indiana, Maine, Maryland, Massachusetts, Michigan, Minnesota, Missouri, Montana, Nevada, New Hampshire, New York, Rhode Island, Tennessee, and West Virginia. At the other end of the spectrum, Mississippi (44%), New Jersey (62%), Arkansas and Texas (69%), Iowa (73%), and Illinois (74%) allocated a considerably smaller share of total IDD resources to community services.

When community services are redefined from 1–15 person settings to 1–6 person settings, an estimated 81% of total IDD spending in the U.S. was committed to six-person or fewer settings in 2013. As presented in Figure 6 on page 15, spending for public/private settings for seven or more persons has declined in inflation-adjusted terms for 22 consecutive years since 1991. The only exception was a 0.2% increase in 2012. A substantial portion of the increase in 2012 was due to spending for 7–15 person settings and for 16+ public and private institution spending increases in Mississippi, New Jersey, and Pennsylvania.

Public/private spending for settings for 7 or more persons fell an average annual 0.5% from 2011–13. This was slower than the 2.1% annual drop during 2009–11. The drop was due to an average annual increase of 4.3% in spending for 7–15 person settings during 2011–13 compared to a 1.5% increase during 2009–11. Spending for public and private institutions for 16 or more persons declined 0.5% from 2011–2012 and by 2.8% from 2012 to 2013. Thus, it appears that as states recovered from the Great Recession, they allocated somewhat more revenues to community supports as well as to institutional care.

There were adjusted spending increases for 7–15 person settings in 24 states during 2011–13. In 2013, spending for 7–15 person settings constituted 6% or more of total IDD spending in 20 states: Indiana (22%); Illinois (20%); Mississippi and North Dakota (16%); West Virginia (12%); Arkansas, Louisiana and South Dakota (11%); New York (10%); Florida and South Carolina (9%); Alabama, Iowa, Montana, and Tennessee (7%); and Idaho, Maine, Ohio Virginia, and Wisconsin

Figure 6
TRENDS IN I/DD SPENDING USING SIX OR FEWER PERSONS
TO DEFINE COMMUNITY RESIDENTIAL SERVICES: FY 1977-2013



(1) "Community Services" includes residential settings for 6 or fewer persons & day programs;
(2) "Individual and Family Support," a subcomponent of community services, includes family support, supported living, personal assistance, and supported employment; (3) "Public/Private Institutions" serve 7 or more persons. Nursing facility spending is excluded.

Source: Braddock, et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

(6%). In 2013 68% of the nation's spending for 7–15 person settings was accounted for by just six states: Florida, Illinois, Indiana, Louisiana, New York, and Ohio.

The proportion of public spending for individual and family support (consisting of supported living and personal assistance, supported employment, and family support), declined fractionally from 21.6% to 20.9% of total IDD spending from 2011 to 2013. This unusual decline was primarily due to family support spending reductions in the states. Family support spending dropped from 7.2% to 6.7% of total IDD spending, while the supported living share held at 12.8%. Supported employment dropped from 1.5% to 1.4% of total spending from 2011 to 2013. Individual and family support spending advanced from 14 to 18% of

total IDD spending during 2002–05, from 18 to 21.6% during 2006–11, before dropping to 20.9% in 2012 and in 2013. (See additional discussion of individual and family support beginning on p. 45.)

There is great variability among individual states, however. The proportion of individual and family support spending ranged from less than 4% of total IDD spending in Alabama to 40% or more in 10 states: Washington (61%), New Mexico (59%), Nevada (56%), West Virginia (52%), Oklahoma (50%), Arizona (48%), Tennessee (47%), Missouri (42%), and Hawaii and Louisiana (40%). The HCBS Waiver played a large role in financing community services and individual and family support. This trend will be discussed in detail later in this report (p. 37).

IV. FISCAL EFFORT FOR IDD SERVICES IN THE STATES

Fiscal effort was defined in this study as a state's commitment to IDD services after controlling for state wealth (Braddock & Fujiura, 1987). Fiscal effort is theoretically based on the competitive struggle for government funding described by Key (1949) and Wildavsky (1974) as the essence of politics. It is measured in terms of IDD spending for services per \$1,000 of statewide aggregate personal income (United States Department of Commerce, Bureau of Economic Analysis, 2014c). Fiscal effort was calculated for each of the states using total spending, public and private institutional spending, and 15 person or fewer community services spending. Nursing facilities were excluded in the calculation of institutional spending.

Figure 7 below illustrates changes in fiscal effort across the U.S. during 1977–2013. In 1977, \$2.24 per \$1,000 of aggregate U.S. personal income was expended for IDD services. Fiscal effort has increased by 97% to \$4.40 in 2013. This 37-year trend has two

major subcomponents: the continuing growth of community services and supports, and the steady decline and reallocation of spending for public and private institutions in the states

Total IDD fiscal effort increased by only 0.1% from 2011 to 2013 (Table 5 on page 17). This reduction reflects the impact of the Great Recession—a more pronounced example of recession-driven slow growth than that experienced in recessions in 1980–81 and March–November 2001. The recent peak in 2010 is attributable to reductions in personal income in many states that year. Inflation-adjusted personal income declined nationwide by 3% in 2009 and 2% in 2010. It rebounded with 2% growth in 2011, 2% in 2012, and 4% in 2013.

However, 32 states posted reductions in total IDD fiscal effort from 2011 to 2013 and two states' fiscal effort grew less than 0.5%. The largest fiscal effort reductions were in Hawaii (15%), Florida (13%), Illinois (11%) and North Dakota and Rhode Island (10%). States with

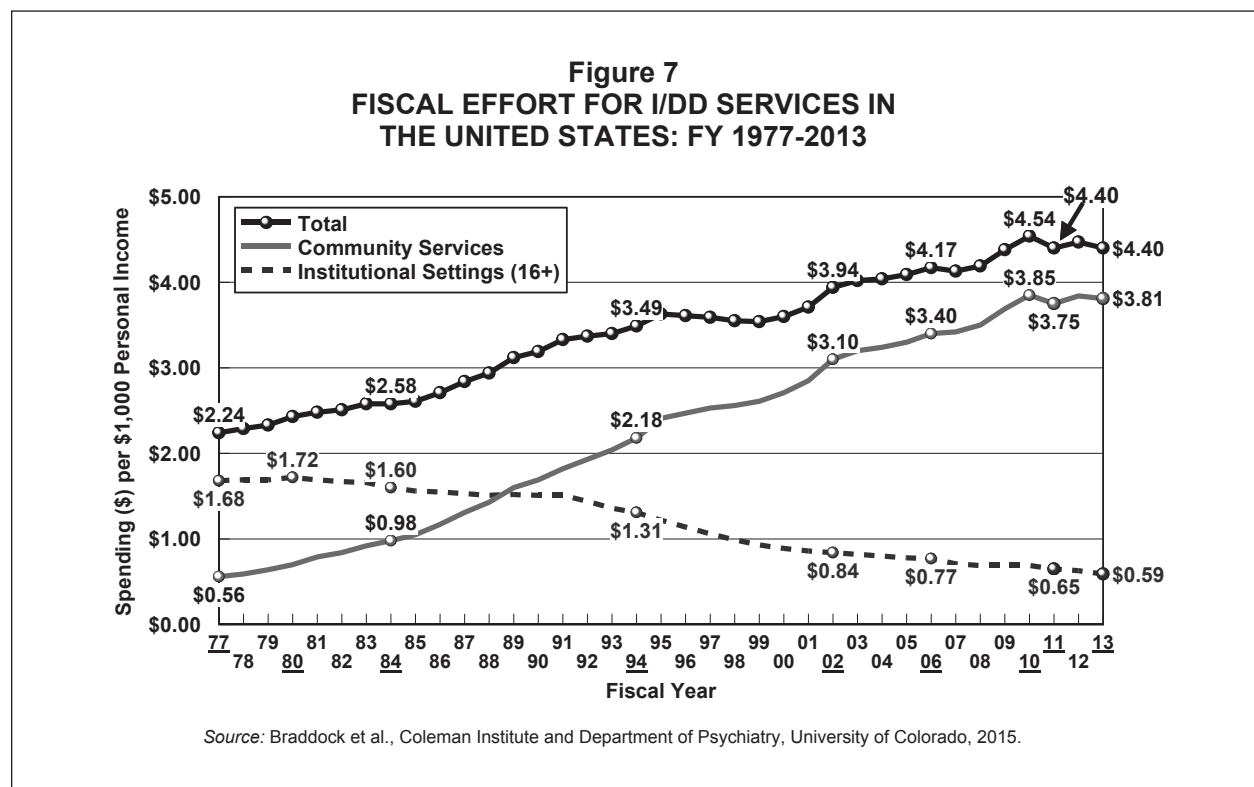


TABLE 5
FISCAL EFFORT FOR I/DD SERVICES:
PERCENT CHANGE FY 2011-13¹

State	2013	2011	% Change	Rank ²
Alabama	\$2.08	\$2.24	-7%	46
Alaska	\$5.51	\$4.68	18%	6
Arizona	\$3.49	\$3.72	-6%	41
Arkansas	\$4.94	\$5.26	-6%	39
California	\$3.52	\$3.76	-6%	42
Colorado	\$2.19	\$2.34	-6%	40
Connecticut	\$5.65	\$5.04	12%	9
Delaware	\$4.12	\$4.19	-1.5%	27
District of Columbia	\$5.82	\$5.45	7%	14
Florida	\$1.88	\$2.17	-13%	50
Georgia	\$2.32	\$2.14	8%	11
Hawaii	\$2.57	\$3.01	-15%	51
Idaho	\$3.67	\$3.76	-2%	29
Illinois	\$2.70	\$3.04	-11%	49
Indiana	\$5.28	\$5.32	-1%	21
Iowa	\$6.44	\$6.59	-2%	30
Kansas	\$3.89	\$4.07	-4%	35
Kentucky	\$4.75	\$3.96	20%	4
Louisiana	\$7.63	\$6.44	19%	5
Maine	\$8.33	\$7.71	8%	12
Maryland	\$3.22	\$3.10	4%	17
Massachusetts	\$5.55	\$5.15	8%	13
Michigan	\$3.86	\$3.84	0.5%	18
Minnesota	\$6.73	\$7.13	-6%	38
Mississippi	\$4.70	\$3.69	27%	1
Missouri	\$4.23	\$3.45	23%	2
Montana	\$4.31	\$3.91	10%	10
Nebraska	\$4.31	\$4.37	-1.4%	25
Nevada	\$1.52	\$1.58	-4%	34
New Hampshire	\$4.24	\$4.24	0%	19
New Jersey	\$4.07	\$3.85	6%	15
New Mexico	\$4.85	\$5.04	-4%	33
New York	\$10.11	\$10.25	-1%	24
North Carolina	\$3.98	\$4.01	-0.9%	22
North Dakota	\$7.06	\$7.83	-10%	48
Ohio	\$7.05	\$7.38	-4%	37
Oklahoma	\$3.27	\$3.50	-7%	43
Oregon	\$5.19	\$5.26	-1%	26
Pennsylvania	\$6.17	\$5.40	14%	8
Rhode Island	\$5.27	\$5.84	-10%	47
South Carolina	\$3.57	\$3.42	5%	16
South Dakota	\$4.48	\$4.57	-2%	28
Tennessee	\$3.66	\$3.83	-4%	36
Texas	\$2.33	\$2.36	-1%	23
Utah	\$2.70	\$2.76	-2%	32
Vermont	\$6.34	\$6.35	-0.2%	20
Virginia	\$3.26	\$2.71	21%	3
Washington	\$3.24	\$3.47	-7%	45
West Virginia	\$6.81	\$5.80	17%	7
Wisconsin	\$5.75	\$5.88	-2%	31
Wyoming	\$4.94	\$5.28	-7%	44
United States	\$4.40	\$4.40	0.1%	

¹ "Fiscal effort" is spending for I/DD services per \$1,000 of aggregate statewide personal income.

² States' ranking, highest to lowest, on percentage change in total fiscal effort from 2011 to 2013.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

very significant fiscal effort increases included Mississippi (27%), Missouri (23%), Virginia (21%), Kentucky (20%), Louisiana (19%), Alaska (18%), West Virginia (17%), Pennsylvania (14%), Connecticut (12%), and Montana (10%).

Two principal factors produced nine states' dramatic changes in fiscal effort during 2011–13: 1) enhanced (or reduced) HCBS Waiver spending, and 2) fiscal effort reductions in 2011 due to the Great Recession. Kentucky, Missouri, Virginia, and West Virginia allocated substantially more Waiver spending during 2011–13. However, dramatic Waiver reductions were implemented in Florida and Hawaii. The Recession produced fiscal effort reductions in 2011, which in turn led to significant percentage increases in fiscal effort from 2011–13 in Louisiana, Mississippi, and Pennsylvania.

There were wide variations in fiscal effort among the states in 2013 and several notable developments in the performance of individual states over the preceding two-year period. Louisiana, Maine, New York, North Dakota, and Ohio led the nation in 2013 in total fiscal effort, each allocating over \$7.00 for IDD services spending per \$1,000 of aggregate statewide personal income. At the other end of the spectrum, Alabama, Colorado, Florida, and Nevada committed \$2.19 or less per \$1,000 of state wealth to IDD services (Table 5).

Community services fiscal effort for 15 person or fewer settings has grown dramatically from \$.56 per \$1,000 of personal income in 1977 to \$3.81 in 2013. In contrast, institutional fiscal effort peaked in 1980 at \$1.72 per \$1,000 and declined each year to \$0.59 per \$1,000 in 2013. This was a 65% decline from 1977–2013.

Advances in community services fiscal effort during the 2011–13 period were posted by 23 states and DC, with the most significant increases, 10% or more, in Kentucky and Mississippi (33%), Missouri and Louisiana (29%), Virginia (27%), Alaska, Pennsylvania and West Virginia (18%), Georgia (14%), and Connecticut and Montana (11%).

Community services fiscal effort declined 0.1% to 15% in 27 states. The largest reductions (5% or more) were in Hawaii (15%); Florida (13%); Arkansas and Rhode Island (9%); Colorado and Idaho (8%); Oklahoma (7%); Arizona, Kansas, Washington, and Wyoming (6%); and Minnesota and South Dakota (5%).

The most significant increases in total IDD fiscal effort rankings during 2011–13 occurred in five states: Alaska, Connecticut, Kentucky, Mississippi, and Missouri. These states advanced 6 to 13 positions nationally (Table 6 on page 18). Between 2011 and 2013, Alaska's, Connecticut's,

TABLE 6
STATE FISCAL EFFORT RANKINGS: FY 2011 and 2013¹

State	Total Spending		Community		Institutional ²	
	2013	2011	2013	2011	2013	2011
Alabama	49	48	44	46	45	34
Alaska	15	21	10	16	45	47
Arizona	38	35	30	27	41	41
Arkansas	19	17	28	23	4	3
California	37	33	34	30	31	29
Colorado	48	47	48	42	33	38
Connecticut	13	19	19	21	6	13
Delaware	29	25	33	31	11	15
District of Columbia	11	12	9	9	45	47
Florida	50	49	50	48	32	30
Georgia	47	50	43	47	36	32
Hawaii	45	43	41	34	45	47
Idaho	34	34	32	28	28	33
Illinois	43	42	47	45	19	8
Indiana	16	14	12	13	39	35
Iowa	8	6	18	17	2	2
Kansas	32	26	29	25	26	28
Kentucky	22	28	23	39	9	7
Louisiana	3	7	5	12	7	5
Maine	2	3	2	2	34	42
Maryland	42	41	36	37	35	36
Massachusetts	14	18	16	15	25	27
Michigan	33	31	25	24	42	43
Minnesota	7	5	4	3	37	37
Mississippi	23	36	45	50	1	1
Missouri	28	39	24	35	27	26
Montana	26	29	22	26	30	31
Nebraska	25	23	27	29	14	12
Nevada	51	51	51	51	38	40
New Hampshire	27	24	20	20	43	45
New Jersey	30	30	42	41	3	4
New Mexico	21	20	17	14	45	47
New York	1	1	1	1	13	14
North Carolina	31	27	35	33	10	11
North Dakota	4	2	7	4	12	10
Ohio	5	4	8	6	5	6
Oklahoma	39	37	38	36	24	24
Oregon	18	16	11	10	51	46
Pennsylvania	10	13	13	19	8	9
Rhode Island	17	10	14	8	40	39
South Carolina	36	40	37	40	22	21
South Dakota	24	22	26	22	16	22
Tennessee	35	32	31	32	29	25
Texas	46	46	49	49	17	17
Utah	44	44	46	43	21	19
Vermont	9	8	6	5	45	47
Virginia	40	45	40	44	20	20
Washington	41	38	39	38	23	23
West Virginia	6	11	3	7	44	44
Wisconsin	12	9	15	11	18	18
Wyoming	20	15	21	18	15	16

¹ "Fiscal effort" is spending for I/DD services per \$1,000 of aggregate statewide personal income. See Part Two of this monograph for 1977- 2013 fiscal effort levels for each state.

² In 2013, AL, AK, DC, HI, NM, and VT had no institutional spending, and were tied for 45th.

Source : Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

and Kentucky's rankings increased by six positions, Missouri by 11, and Mississippi by 13 positions.

The increase in total fiscal effort ranking in these four states was primarily attributable to growth in spending for community services. Adjusted federal HCBS Waiver spending increases for these states were: Mississippi (104%), Missouri (46%), Alaska (35%), and Connecticut (31%).

Although 15 states and DC posted increases in total IDD fiscal effort rankings, reductions in total fiscal effort rankings occurred in 29 states during 2011–13 (six states had no change). The largest reductions in national rankings were in Rhode Island (7 positions); Kansas (6 positions); Wyoming (5 positions); and California, Delaware, and North Carolina (4 positions).

V. OUT OF HOME RESIDENTIAL PLACEMENTS FOR PERSONS WITH IDD

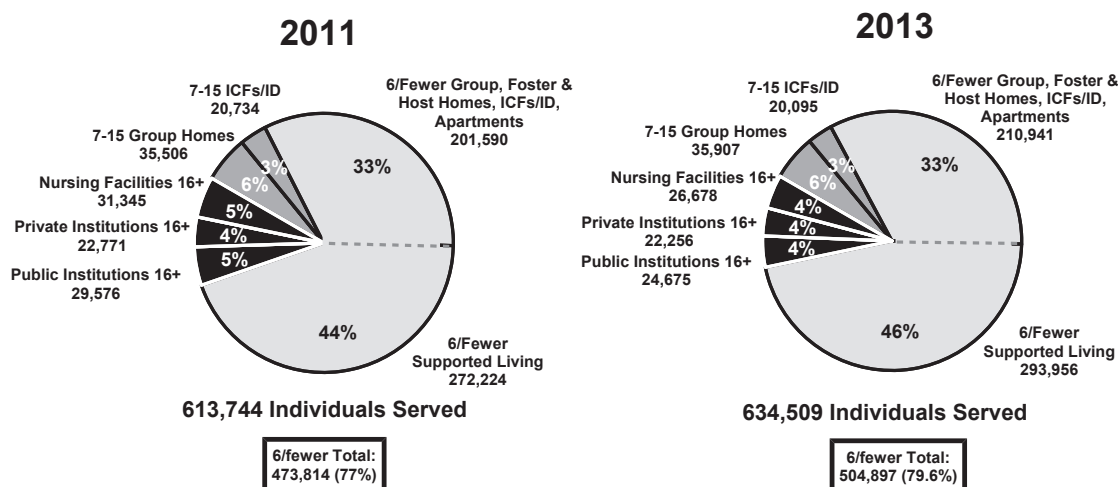
During 2011–13, total out-of-home residential placements advanced from 613,744 to 634,509 persons, an increase of 3.4% (Figure 8 below). On an average per year basis, placements advanced 1.7% during 2011–13. This was well below average annual growth rates of 2.9% during 2009–11 and 2.5% during 2006–09. The proportion of people with IDD served in all 1–6 person settings in the U.S. increased from 77% in 2011 to 80% in 2013; of that, the proportion in supported living increased from 44% to 46%. However, the proportion residing in 7–15 person ICFs/ID and group homes remained at 9% of the IDD out-of-home service delivery system.

Settings for 16 or more persons in nursing facilities, private institutional settings, and state-operated institutions fell from 14% to 12% of total U.S. out-of-home placements. The state-operated institutional census declined 17% nationwide, exceeding the 2009–11 rate of decline of 12%.

During 2011–13, utilization rates for community residences for 1–15 persons per 100,000 of the state general population grew 4%. This was well below the 2009–11 growth rate of 6%. Nationwide, there were 201 residential services participants per 100,000 persons in 2013 (Table 7 on page 21). Total out-of-home utilization rates increased in the U.S. by 2% from 2011 to 2013. However, there were reductions in utilization in 20 states: Alaska, and Georgia (14%); Idaho (12%); New Hampshire (11%); West Virginia (10%); Maine (9%); Iowa (6%); Mississippi, Montana, Rhode Island, and Washington (4%); Arkansas and Oklahoma (3%); and Colorado and Utah (2%). Alabama, Connecticut, Louisiana, New York, and North Dakota each declined 1%. Utilization rates increased in 25 states. The largest were in Wyoming (30%), District of Columbia (29%), Hawaii (21%), Illinois (14%), and Wisconsin (9%).

The number of individuals with IDD in six-person or fewer settings has grown rapidly from an estimated

Figure 8
OUT-OF-HOME RESIDENTIAL PLACEMENTS IN
THE U.S. BY SETTING: FY 2011 AND FY 2013



Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

TABLE 7
PERSONS WITH I/DD IN OUT-OF-HOME RESIDENTIAL SETTINGS
BY SIZE OF SETTING AND STATE: FY 2013¹

State	1-6 Persons ²			7-15 Persons		16+ Persons ⁴		Total	Rate ⁵
	Number	%	Rank ³	Number	%	Number	%		
Alabama	3,171	67%	43	798	17%	787	17%	4,756	98
Alaska	1,357	98%	2	18	1%	8	1%	1,383	189
Arizona	4,389	95%	8	31	1%	179	4%	4,599	70
Arkansas	4,056	60%	47	790	12%	1,900	28%	6,746	228
California	52,647	90%	16	1,572	3%	4,390	7%	58,609	154
Colorado	8,578	95%	9	149	2%	337	4%	9,064	173
Connecticut	7,119	84%	26	288	3%	1,044	12%	8,451	235
Delaware	979	86%	23	0	0%	157	14%	1,136	123
District of Columbia	1,788	98%	1	7	0%	25	1%	1,820	283
Florida	15,742	74%	35	2,087	10%	3,302	16%	21,131	109
Georgia	11,421	88%	19	0	0%	1,543	12%	12,964	130
Hawaii	2,602	97%	5	7	0%	62	2%	2,671	191
Idaho	2,769	84%	28	273	8%	272	8%	3,314	207
Illinois	14,834	50%	50	8,768	29%	6,207	21%	29,809	232
Indiana	8,692	66%	44	2,573	20%	1,824	14%	13,089	200
Iowa	5,550	66%	46	842	10%	2,079	25%	8,471	275
Kansas	5,246	93%	11	44	1%	321	6%	5,611	194
Kentucky	5,347	79%	33	166	2%	1,293	19%	6,806	155
Louisiana	4,176	55%	49	1,582	21%	1,868	24%	7,626	165
Maine	2,891	86%	25	309	9%	161	5%	3,361	253
Maryland	7,910	96%	7	0	0%	371	4%	8,281	140
Massachusetts	12,202	88%	18	775	6%	830	6%	13,807	207
Michigan	29,957	92%	14	1,338	4%	1,364	4%	32,659	330
Minnesota	18,164	93%	12	536	3%	784	4%	19,484	361
Mississippi	1,566	35%	51	670	15%	2,183	49%	4,419	148
Missouri	9,418	80%	32	867	7%	1,557	13%	11,842	196
Montana	1,487	72%	36	374	18%	210	10%	2,071	205
Nebraska	3,466	86%	24	9	0%	552	14%	4,027	216
Nevada	1,932	93%	13	0	0%	152	7%	2,084	75
New Hampshire	2,463	96%	6	27	1%	85	3%	2,575	195
New Jersey	9,590	68%	40	661	5%	3,888	27%	14,139	159
New Mexico	3,559	94%	10	120	3%	98	3%	3,777	181
New York	44,025	66%	45	18,664	28%	4,429	7%	67,118	343
North Carolina	16,333	83%	29	392	2%	2,932	15%	19,657	201
North Dakota	1,451	67%	42	484	22%	230	11%	2,165	304
Ohio	28,727	77%	34	2,590	7%	6,031	16%	37,348	323
Oklahoma	2,940	56%	48	587	11%	1,752	33%	5,279	138
Oregon	14,037	98%	4	218	2%	123	1%	14,378	367
Pennsylvania	23,253	84%	27	561	2%	3,814	14%	27,628	216
Rhode Island	2,017	89%	17	163	7%	95	4%	2,275	216
South Carolina	4,144	69%	39	914	15%	941	16%	5,999	126
South Dakota	1,916	67%	41	595	21%	338	12%	2,849	339
Tennessee	7,417	82%	30	670	7%	921	10%	9,008	139
Texas ⁶	46,754	87%	20	547	1%	6,265	12%	53,566	204
Utah	2,315	70%	38	54	2%	925	28%	3,294	114
Vermont	1,738	98%	3	0	0%	35	2%	1,773	283
Virginia	6,533	71%	37	627	7%	1,980	22%	9,140	111
Washington	14,199	91%	15	147	1%	1,273	8%	15,619	225
West Virginia	4,627	87%	21	392	7%	298	6%	5,317	287
Wisconsin	15,203	80%	31	2,624	14%	1,140	6%	18,967	331
Wyoming	2,200	86%	22	92	4%	257	10%	2,549	440
United States	504,897	80%		56,003	9%	73,609	15%	634,509	201

¹ The table reports average daily residents for FY 2013.

² Settings for 1-6 persons included 293,956 supported living/personal assistance participants.

³ States' ranking, highest to lowest, on percentage of total persons with I/DD in out-of-home settings who reside in 1-6 person settings.

⁴ 16+ settings include state-operated institutions, private ICFs/ID and non-ICFs/ID, and nursing facilities.

In Alaska, New Mexico, and Vermont, 16+ settings are exclusively persons with I/DD in nursing facilities.

⁵ Utilization rate, per 100,000 citizens of the general population, for all I/DD out-of-home placements in the state.

⁶ Texas reported out-of-home placements in the following categories: 8 or fewer, 9-13 and 14+ persons.

Source : Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

4,000 persons in 1960 to 504,897 persons in 2013 (Figure 9 below). However, the annual rate of growth in the number of persons receiving community residential services during 2011–13 (3.2%) was significantly below the rate during 2009–11 (4.8%). The rate of reduction in residents of state-operated institutions was 9% per year during 2011–13. This significantly exceeded the average rate of reduction of 6% during 2009–11.

The number of persons residing in one to six person settings per 100,000 of state general population is an important metric to compare states on their utilization of community residential services. These residences include group homes and ICFs/ID for four to six persons and HCBS Waiver supported residences including apartments, foster homes, host homes, supported living and personal assistance.

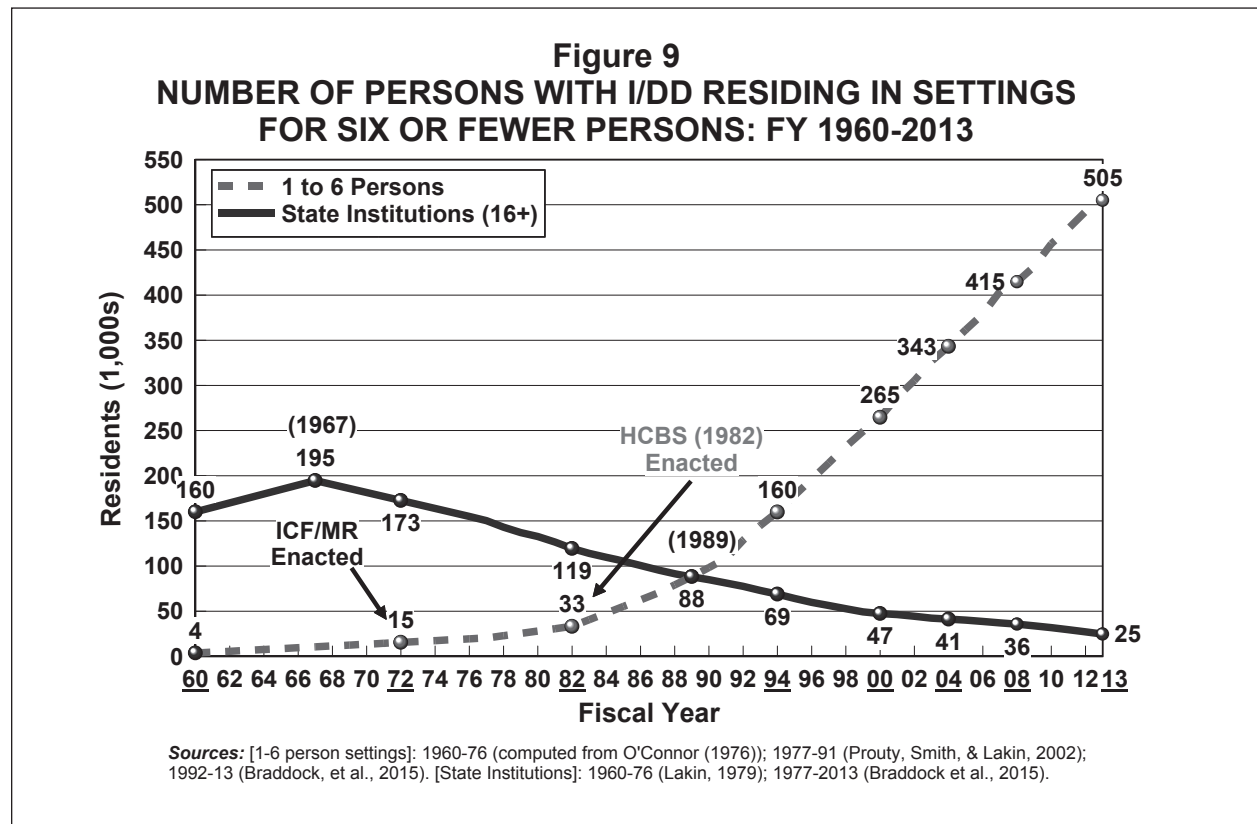
The nationwide six-person or fewer community residential services utilization rate in 2013 was 160 per 100,000 of the state general population. This was a 5% increase over the 2011 utilization rate of 153. Rates in the states ranged from 80 or less per 100,000 in Alabama, Arizona, Mississippi, Nevada, Oklahoma, Utah, and Virginia to 250 or more per 100,000 persons in DC, Michigan, Minnesota, Oregon, Vermont, Wisconsin,

and Wyoming. The states are ranked from highest to lowest in six-person or fewer residential utilization in Table 8 on page 23.

Also presented in Table 8 is the seven-person or more utilization rate by state, ranked from lowest to highest. This is an inverse complement to the six person or fewer utilization rates. Two states—Oregon and Vermont—have high rankings in both six or fewer and 7+ person utilization rates because they have few large facilities and comparatively large numbers of small community residences including supported living arrangements.

Arizona ranked at the top in fewest 7+ person utilization, but 49th in six person or fewer utilization rate. Arizona dedicated a high proportion—95%—of its out-of-home residential service system to settings for six or fewer persons, but utilization is low on a per capita basis. Moreover, as is presented below in the discussion of family support, Arizona also ranked 2nd highest in the number of families supported per capita in 2013 (Table 19 on page 58).

Larson, Hallas-Muchow, Aiken, Hewitt, Anderson, Pettingell, Moseley, et al. (2014) estimated that 217,421 individuals with IDD were living in settings for three or fewer persons in 2012. This was a dramatic increase



from only 8,700 persons in such settings in 1977 (Lakin, Prouty, & Coucouvanis, 2006). The number of individuals now living in three or fewer person settings declined from 228,421 in the year before, 2011 (Larson, Salmi, Smith, Anderson, & Hewitt, 2013).

TABLE 8
UTILIZATION RATE BY INDIVIDUALS WITH I/DD IN
SETTINGS FOR SIX OR FEWER PERSONS AND
SEVEN OR MORE PERSONS: FY 2013¹

State	SIX OR FEWER		SEVEN OR MORE	
	2013 Rate ²	State Rank ³	2013 Rate ²	State Rank ⁴
Alabama	66	50	33	26
Alaska	185	20	4	2
Arizona	67	49	3	1
Arkansas	137	33	91	45
California	138	32	16	14
Colorado	164	29	9	10
Connecticut	198	15	37	33
Delaware	106	41	17	15
District of Columbia	278	5	5	3
Florida	81	44	28	23
Georgia	115	38	15	13
Hawaii	186	17	5	4
Idaho	173	26	34	29
Illinois	115	37	116	50
Indiana	133	35	67	42
Iowa	180	24	95	46
Kansas	182	23	13	12
Kentucky	122	36	33	27
Louisiana	91	42	75	44
Maine	218	12	35	32
Maryland	134	34	6	7
Massachusetts	183	21	24	17
Michigan	303	4	27	22
Minnesota	336	3	24	18
Mississippi	52	51	95	47
Missouri	156	30	40	36
Montana	147	31	58	38
Nebraska	186	19	30	24
Nevada	70	48	5	5
New Hampshire	186	18	8	8
New Jersey	108	40	51	37
New Mexico	171	27	10	11
New York	225	11	118	51
North Carolina	167	28	34	28
North Dakota	204	14	100	48
Ohio	248	9	75	43
Oklahoma	77	47	61	40
Oregon	359	2	9	9
Pennsylvania	182	22	34	31
Rhode Island	192	16	25	19
South Carolina	87	43	39	35
South Dakota	228	10	111	49
Tennessee	115	39	25	20
Texas ⁵	178	25	26	21
Utah	80	45	34	30
Vermont	278	6	6	6
Virginia	79	46	32	25
Washington	205	13	20	16
West Virginia	249	8	37	34
Wisconsin	265	7	66	41
Wyoming	380	1	60	39
United States	160		46	

¹ "Seven or more settings" include public and private facilities for seven or more persons and nursing facilities; ² Rate per 100,000 citizens of the general population.

³ States ranked 1-51 on highest to lowest six or fewer utilization rate; excludes family support; ⁴ States ranked 1-51 on lowest to highest seven or more utilization rate.

⁵ Texas officials reported on settings for 8 or fewer persons.

Source: Braddock et al., Coleman Institute, Department of Psychiatry, CU, 2015.

Costs by Residential Setting in 2013

The average annual cost per person by setting in 2013 is presented in Table 9 on page 24. Costs ranged from \$26,708 in supported living to \$255,692 in state-operated institutions. The national average cost of care in *private ICF/ID settings serving 16 or more persons* was \$98,951. Costs per person ranged from less than \$50,000 in California, Illinois, Oklahoma, and Texas to more than \$150,000 in Arizona, Kentucky, Maine, Missouri, Nevada, New Jersey, New York, North Dakota, Rhode Island, Tennessee, and Virginia.

The U.S. average cost of care in *private non-ICF/ID settings for 16 or more persons* was considerably less—\$36,634. Costs per person ranged from \$1,330 in Washington to over \$100,000 in New Jersey and Wisconsin. Wisconsin's single setting was a county-funded child-care institution for 34 children with complex needs and the cost per person has steadily increased from \$102,000 in 2006 to \$420,471 in 2013. New Jersey funded 210 persons in 16+ person settings not licensed as ICFs/ID.

Michigan's 16+ person settings included Michigan State Housing Development Authority (MSHDA) residences in which 692 individuals with developmental disabilities were supported with Medicaid personal care funds and state general funds.

The U.S. average annual cost of care in 2013 for the 37 states that operated *state-operated 16+ institutions* was \$255,692. Costs ranged from \$129,374 in Arizona to more than \$300,000 in California, Colorado, Connecticut, Delaware, Kentucky, Maryland, Massachusetts, Nebraska, New York, Pennsylvania, Tennessee, and Virginia.

In addition to Alabama's closure of Partlow in 2011, Minnesota closed the Minnesota Extended Treatment Options (METO) unit in 2011 (10 remaining METO residents with high needs were still pending appropriate alternative placements in 2013). Thirteen states and the District of Columbia are IDD state institution-free today. Indiana closed its remaining ICF/ID units at the Evansville, Madison, and Richmond Mental Health Centers in 2012 and at Logansport Mental Health Center in 2013.

The U.S. average annual cost per person in 2013 for the 35 states funding *private ICFs/ID for 15 or fewer persons* was \$95,507. Costs ranged from below \$50,000 in Idaho and Oklahoma to more than \$200,000 in Colorado, DC, Maine, and Virginia.

Eleven states financed *publicly-operated ICFs/ID for 15 or fewer persons* in 2013. The average annual cost was \$133,003. Costs ranged from \$71,897 in South

TABLE 9
ANNUAL COST OF CARE PER PERSON
IN SIX RESIDENTIAL SETTINGS: FY 2013¹

State	Institutions for 16+ persons			ICFs/ID for 15 or fewer persons		Supported Living/ Personal Assistance
	Private ICF/ID	Non-ICF/ID	State-Operated	Private	Public	
Alabama	\$0	\$0	\$0	\$54,339	\$0	\$15,520
Alaska	\$0	\$0	\$0	\$160,737	\$0	\$46,148
Arizona	\$386,076	\$0	\$129,374	\$0	\$150,517	\$52,275
Arkansas	\$131,110	\$0	\$141,476	\$77,307	\$0	\$42,821
California	\$38,306	\$15,596	\$381,378	\$50,599	\$0	\$24,588
Colorado	\$0	\$0	\$308,886	\$261,757	\$0	\$12,416
Connecticut	\$0	\$54,113	\$413,615	\$190,733	\$0	\$39,249
Delaware	\$132,479	\$0	\$441,186	\$0	\$0	\$36,189
District of Columbia	\$0	\$0	\$0	\$238,707	\$0	\$34,702
Florida	\$99,039	DNF	\$134,016	\$174,744	\$0	\$11,135
Georgia	\$59,865	\$0	\$140,781	\$0	\$0	\$11,940
Hawaii	\$0	\$0	\$0	\$87,799	\$0	\$25,408
Idaho	\$91,697	\$0	\$278,334	\$47,302	\$0	\$19,208
Illinois	\$46,100	\$18,133	\$150,392	\$53,649	\$0	\$13,573
Indiana	\$103,959	\$0	\$0	\$114,469	\$0	\$49,330
Iowa	\$145,471	\$15,437	\$276,134	\$120,360	\$0	\$49,157
Kansas	\$0	\$0	\$181,189	\$105,049	\$0	\$8,284
Kentucky	\$185,565	\$0	\$393,350	\$0	\$143,291	\$18,668
Louisiana	\$91,814	\$0	\$252,445	\$98,658	\$603,979	\$73,224
Maine	\$155,649	\$0	\$0	\$203,082	\$0	\$44,518
Maryland	\$0	\$0	\$395,681	\$0	\$0	\$51,809
Massachusetts	\$0	\$0	\$372,058	\$0	\$0	\$13,432
Michigan	\$0	\$43,508	\$0	\$0	\$0	\$16,270
Minnesota	\$74,235	\$0	\$0	\$81,703	\$101,765	\$16,350
Mississippi	\$81,592	\$0	\$181,459	\$0	\$123,343	\$12,352
Missouri	\$240,874	\$27,344	\$207,195	\$55,922	\$0	\$50,095
Montana	\$0	\$0	\$228,775	\$0	\$0	\$14,634
Nebraska	\$79,254	\$0	\$397,352	\$167,935	\$0	\$26,653
Nevada	\$193,702	\$0	\$205,387	\$85,500	\$0	\$43,495
New Hampshire	\$146,438	\$0	\$0	\$0	\$0	\$7,657
New Jersey	\$185,539	\$334,648	\$291,743	\$0	\$0	\$33,862
New Mexico ²	\$0	\$0	\$0	\$107,725	\$770,826	\$53,981
New York	\$251,783	DNF	\$603,259	\$156,454	\$270,938	\$14,540
North Carolina	\$117,241	DNF	\$209,090	\$113,404	\$0	\$24,751
North Dakota	\$204,314	\$0	\$278,054	\$144,752	\$0	\$58,365
Ohio	\$99,987	DNF	\$187,528	\$95,723	\$0	\$32,859
Oklahoma ²	\$37,519	\$0	\$181,368	\$37,167	\$0	\$94,899
Oregon	\$0	\$0	\$0	\$0	\$0	\$22,157
Pennsylvania	\$134,303	\$73,266	\$378,016	\$101,281	\$0	\$10,615
Rhode Island	\$257,307	\$0	\$0	\$0	\$139,959	\$22,488
South Carolina	\$0	\$0	\$147,890	\$0	\$71,897	\$17,507
South Dakota	\$104,999	\$0	\$159,699	\$0	\$0	\$4,982
Tennessee	\$156,332	\$0	\$426,236	\$156,332	\$353,090	\$62,756
Texas	\$40,128	\$0	\$205,499	\$52,651	\$224,685	\$22,820
Utah	\$62,848	\$0	\$164,062	\$67,841	\$0	\$12,268
Vermont	\$0	\$0	\$0	\$191,744	\$0	\$12,511
Virginia	\$201,158	\$0	\$316,939	\$307,008	\$0	\$35,493
Washington	\$0	\$1,330	\$207,314	\$102,138	\$0	\$44,396
West Virginia	\$142,026	\$0	\$0	\$133,501	\$0	\$39,549
Wisconsin ²	\$82,153	\$420,471	\$295,205	\$78,168	\$0	\$11,396
Wyoming	\$0	\$0	\$292,616	\$0	\$0	\$13,665
United States	\$98,951	\$36,634	\$255,692	\$95,507	\$133,003	\$26,708

¹ Computed from average daily resident and financial data provided by the states; a "\$0" indicates the state did not provide the service and "DNF" indicates the state did not furnish financial data with which to calculate cost of care. The U.S. averages were computed from aggregated spending divided by aggregated participants, across all participating states.

² See text regarding the high cost of care rates in New Mexico, Oklahoma, and Wisconsin.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015

Carolina to over \$200,000 in Louisiana, New Mexico, New York, Tennessee, and Texas. High cost facilities supported small numbers of persons with IDD in Kentucky (24), Louisiana (16), Rhode Island (17) and Texas (19). In New Mexico a high-risk individual received a court-ordered placement that required 24-hour supervision as an alternative to prison. Connecticut and Nevada terminated use of publicly-operated ICFs/ID for 15 or fewer persons in 2001.

Residents of *private ICFs/ID for 15 or fewer persons* decreased 2% during 2011–13, a decrease of 738 persons. In 2013, 11 states did not fund public or private ICFs/ID that served 15 or fewer persons. These states are Delaware, Georgia, Maryland, Massachusetts, Michigan, Montana, New Hampshire, New Jersey, Oregon, South Dakota, and Wyoming.⁴ (Two additional states, Nebraska and Vermont, provided funding for only nine and six persons, respectively, in ICFs/ID for 15 or fewer persons). Five of these 11 states, in addition to funding no *public or private ICFs/ID settings for 15 or fewer persons*, did not fund congregate 16+ person private settings. The states are Delaware, Maryland, Massachusetts, Montana, Oregon, and Wyoming.

Supported living was defined for purposes of this study to include housing in which individuals choose

where and with whom they live, ownership is by someone other than the support provider, and the individual has a personalized support plan (PSP) that changes as needs and/or abilities of the individual change. Personal assistance services were a subset of the broader category of supported living. It includes support provided to people living in their own homes financed by either state funds or federal-state Medicaid funds. It also includes state plan personal care assistance funding or the personal care service available to states under the HCBS Waiver.

All states provided supported living or personal assistance services in 2013 (Table 9 on page 24). Spending levels reflected different levels of support across and within the states. The national average cost was \$26,708. Supported living/personal assistance costs ranged widely from below \$10 thousand in Kansas, Pennsylvania, and South Dakota to over \$60 thousand in Louisiana, Oklahoma, and Tennessee.

The majority of Oklahoma's 1,661 supported living and personal assistance participants were former members of a federal class action lawsuit. The judge had issued a permanent injunction that decreed continuous supported living services for class members in *Homeward Bound v. Hissom Memorial Center* (1990).

4. However, five of these states—Delaware, Georgia, New Jersey, and South Dakota—did fund ICFs/ID for 16 or more persons.

VI. PUBLIC AND PRIVATE INSTITUTIONS

The use of large residential settings for 16 or more persons continue to decline. The consolidated data in Figure 10 below depicts the trend since 1990 in reducing the census of state-operated and privately-operated institutions serving 16 or more people.

During 1990–2013, the number of residents in these settings, including nursing facilities, declined 57%, from 171,897 to 73,609 persons. Most of this reduction was associated with reductions in public institutions, which fell 71% from 84,818 to 24,675 persons during 1990–2013.

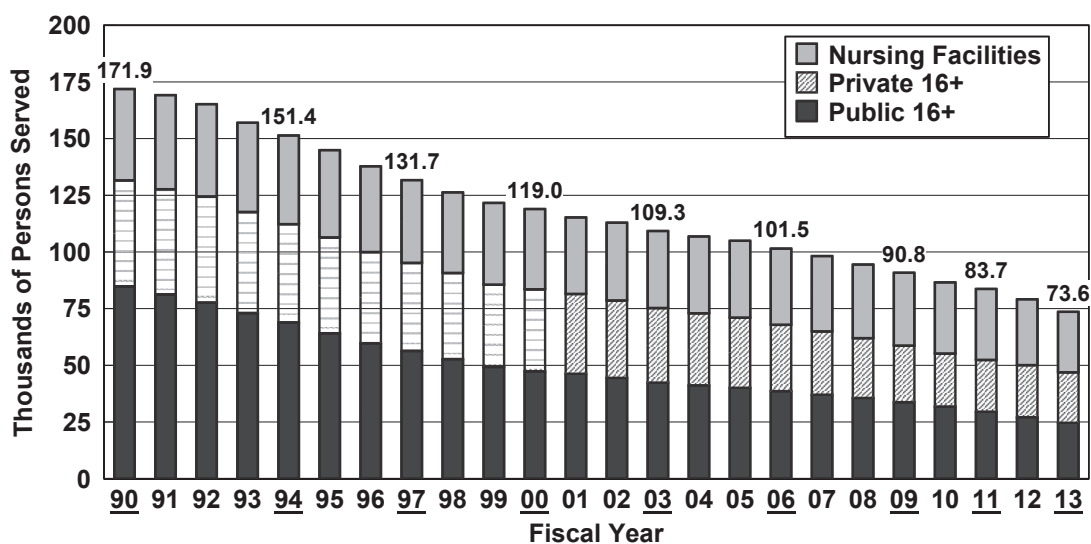
The number of residents in private facilities for 16 or more persons, including ICFs/ID and non-ICF/ID settings, declined 52% (from 46,777 to 22,256); and the number of nursing facility residents fell 34% (40,301 to 26,678) from 1990–2013. By comparison, the U.S. general population increased by 27%—from 248.2 to 315.1 million people—from 1990 to 2013.

State-Operated Institutions

For the purposes of this study, state-operated institutions included developmental centers, training centers, state schools, and designated IDD units in state psychiatric hospitals. In 1967, the nation's institutional census peaked at 194,650 individuals in 165 state IDD facilities (United States Department of Health, Education, and Welfare, 1972). Since 1968, the number of individuals with IDD served in these large state facilities declined by an average 4% each year for 45 consecutive years. During 2006–09 the average annual rate of decline was 4.4%.

The census declined by 6.4% per year during 2009–11. From 2011 to 2013, the population residing in these facilities dropped even more rapidly—an average of 8.7% per year from 29,576 to 24,675 persons (Table 10 on page 27). In 2013, 37 states continued to finance

Figure 10
PERSONS SERVED IN PUBLIC AND PRIVATE INSTITUTIONS
AND NURSING FACILITIES IN THE UNITED STATES: FY 1990-2013



Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

AVERAGE DAILY RESIDENTS IN STATE-OPERATED 16+ I/DD INSTITUTIONS FY 2011-13

State	2013	2011	% Change 2011-13	2013 Utilization ¹ Rate	Rank
Alabama	0	91		0.0	1
Alaska	0	0		0.0	1
Arizona	106	111	-5%	1.6	15
Arkansas	948	961	-1%	32.1	50
California	1,348	1,774	-24%	3.5	21
Colorado	149	160	-7%	2.8	20
Connecticut	552	656	-16%	15.4	47
Delaware	61	68	-10%	6.6	26
District of Columbia	0	0		0.0	1
Florida	852	874	-3%	4.4	23
Georgia	370	808	-54%	3.7	22
Hawaii	0	0		0.0	1
Idaho	36	49	-27%	2.2	18
Illinois	1,790	2,034	-12%	13.9	43
Indiana	0	82		0.0	1
Iowa	434	486	-11%	14.1	44
Kansas	321	339	-5%	11.1	38
Kentucky	297	345	-14%	6.8	28
Louisiana	446	917	-51%	9.7	37
Maine	0	0		0.0	1
Maryland	129	147	-12%	2.2	17
Massachusetts	540	716	-25%	8.1	33
Michigan	0	0		0.0	1
Minnesota	10	21	-52%	0.2	14
Mississippi	1,157	1,333	-13%	38.7	51
Missouri	465	553	-16%	7.7	32
Montana	55	51	8%	5.4	25
Nebraska	126	341	-63%	6.8	27
Nevada	47	48	-2%	1.7	16
New Hampshire	0	0		0.0	1
New Jersey	2,341	2,649	-12%	26.4	49
New Mexico	0	0		0.0	1
New York	1,015	1,313	-23%	5.2	24
North Carolina	1,300	1,572	-17%	13.3	41
North Dakota	92	107	-14%	12.9	40
Ohio	1,066	1,228	-13%	9.2	35
Oklahoma	274	292	-6%	7.1	29
Oregon	0	0		0.0	1
Pennsylvania	1,069	1,174	-9%	8.4	34
Rhode Island	0	0		0.0	1
South Carolina	721	763	-6%	15.2	46
South Dakota	140	139	1%	16.7	48
Tennessee	182	293	-38%	2.8	19
Texas	3,932	4,331	-9%	14.9	45
Utah	206	206	0%	7.2	30
Vermont	0	0		0.0	1
Virginia	779	1,105	-30%	9.5	36
Washington	826	914	-10%	11.9	39
West Virginia	0	0		0.0	1
Wisconsin	415	443	-6%	7.2	31
Wyoming	78	82	-5%	13.5	42
United States	24,675	29,576	-17%	7.8	

¹Utilization in 2013 per 100,000 citizens of the general population in the state and states' ranking, lowest to highest, on institutional utilization. Alabama's census of 91 in 2011 was for the months before Partlow closed; Indiana census in 2011 was for mental health center I/DD units no longer utilized.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

state-operated institutions. Thirteen states and DC did not support such facilities.

All but three states reduced their census during 2011–13. The greatest reductions on a percentage basis were: Nebraska (63%), Georgia (54%), Minnesota (52%),⁵ Louisiana (51%), Tennessee (38%), and Virginia (30%). However, two states—Montana and South Dakota—increased their institutional census by 8% and 1%, respectively, during 2011–13. Utah's census did not change.

In 2013, seven states served 106 or fewer individuals with IDD in their remaining state-operated institutions: Arizona, Delaware, Idaho, Montana, Nevada, North Dakota, and Wyoming.

Closures of state-operated institutions. The year 2014 marks the 15th anniversary of the landmark *Olmstead v. L.C.* decision requiring states to eliminate segregation of persons with disabilities and ensure services in the most integrated setting appropriate. In 1991, New Hampshire closed the Laconia State School, becoming the first state to provide IDD services exclusively in community settings. By 2013, as previously noted, 14 jurisdictions no longer operated state-operated IDD institutional facilities: Alabama, Alaska, the District of Columbia, Hawaii, Indiana, Maine, Michigan, Minnesota, New Hampshire, New Mexico, Oregon, Rhode Island, Vermont, and West Virginia.

Institutional closures listed in Table 11 on the following two pages, were defined as completed or in-progress terminations of state-operated facilities for people with intellectual and developmental disabilities. The list also includes closures of state-designated IDD units in psychiatric facilities. An in-progress closure implied that the state IDD agency was implementing a legislatively sanctioned phase-out of the facility. Institutional closures typically could be verified by examining published state budget documentation or by obtaining data from the states as they responded to our survey.

The 173 completed and projected institutional closures from 1960 to 2020 are illustrated in Figure 11 on page 31. The trend toward closing institutions gained momentum during the recession of the early 1980s and has continued. Braddock and Heller (1985) identified 24 closures in 12 states during 1970–84. The present study identified 173 completed and in-progress closures scheduled through 2020 in 43 states.

With the Partlow closure in 2011, Alabama became the first southern state to be institution-free. The Northwest Georgia Regional Hospital in Rome closed in 2011, and the remaining three Georgia facilities are scheduled to close as well. Included in the state's planned institutional closures is the Regional State Hospital in Atlanta, which has ceased admitting individuals with IDD. As previously noted, Georgia's institutional census declined 54% from 2011–13.

In addition to the institutional closures that rendered states “institution-free,” other closure activity included the 2012 closing of the Francis Haddon Morgan Center in Washington; the 2013 closures of the Nevada Habilitation Center and Northwest Habilitation Center in Missouri; and closure of Jacksonville Developmental Center in Illinois. There were scheduled closures of the Lanterman Center in California; closures of the Southern and Northern Resource Centers in Oklahoma in 2015 and 2016, respectively; and the closure of Fernald and the planned closure of Templeton in Massachusetts.

Virginia, in a settlement agreement with the U.S. Department of Justice on January 26, 2012, is scheduled to close four of the Commonwealth's five IDD state institutions. Scheduled closures include Southside Virginia Training Center in Petersburg (2014), Northern Virginia Training Center in Fairfax (2015), Southwestern Virginia Training Center in Hillsville (2018), and Central Virginia Training Center in Lynchburg (2020). The Southeastern Virginia Training Center in Chesapeake will remain open to support 75 individuals (Virginia Department of Behavioral Health and Developmental Services, 2012). Virginia's institutional census dropped 30% from 2011–13.

The eight states that have not closed any state-operated institutions are: Delaware, Idaho, Iowa, Mississippi, Nebraska, North Carolina,⁶ Utah, and Wyoming. Five of these eight states (Delaware, Idaho, Nebraska, Utah, and Wyoming) have only one state IDD facility currently operating.

As the nation's institutional census continues to decline and average daily costs increase, there will be continued pressure on states to close institutions. The national census of state-operated institutions declined by 16% from 2011 to 2013.

5. The Minnesota Extended Treatment Option (METO) at Cambridge Mental Health Center closed in 2011; ten individuals remained, and required alternative placement.

6. North Carolina had previously reported the closure of Black Mountain Center; this Center is in fact continuing to serve persons with IDD and persons with Alzheimer's.

TABLE 11
COMPLETED AND IN-PROGRESS CLOSURES OF I/DD
STATE-OPERATED 16+ PERSON INSTITUTIONS IN THE U.S. FY 1969-2020 (n=173)

State	Institution	Year Built/ Became ID Facility	Original Use	# Residents, Closure Announcement	Fiscal Year of Closure	Alternate Use
Alabama	Brewer-Bayside	1984	ID Facility	67	2003	Corrections
	Glenn Ireland	1986	ID Facility	20	1996	To be sold
	Partlow	1923	ID Facility	199	2011	To be determined
	Tarwater	1976	ID Facility	74	2003	Corrections
	Wallace	1970	ID Facility	80	2003	Corrections
Alaska	Harborview	1964	ID Facility	45	1997	Community Programs
Arizona	Phoenix	1974	ID Facility	46	1988	Commercial
	Tucson	1972	ID Facility	13	1997	Outreach Offices
Arkansas	Alexander Human Dev. Ctr.	1923/1968	TB Sanitarium	109	2011	Undetermined
California	Agnews	1885/1966	MI Facility	411	2009	Undetermined
	Camarillo	1935	ID Facility	497	1998	University
	DeWitt	1942/1947	Army Hospital	819	1972	Placer County Recreation
	Lanternman	1927	ID Facility	398	2013	Undetermined
	Modesto Unit	1943/1948	Army Hospital	1,394	1969	Modesto Co. Comm. College
	Napa	1875/1967	MH/ID Asylum	30	2001	MH Use Only
	Stockton	1852	MH Asylum	414	1996	University
Colorado	Pueblo	1935	MH/ID Facility	163	1989	Pueblo Regional Center
Connecticut	John Dempsey Center	1964	ID Facility	23	1998	Administrative Offices
	Mansfield	1906/1917	Epilepsy Colony	146	1993	Corrections/U. of Connecticut
	New Haven	1964	ID Facility	56	1994	Job Corps
	Seaside	1961	ID Facility	41	1996	Administrative/Storage
	Waterbury	1963/1972	Convent	40	1989	Administrative Offices
DC	Forest Haven	1925	ID Facility	1,000	1991	Private Rehab/PH Infirmiry
Florida	Community of Landmark	1965	ID Facility	256	2005	Revert to Dade County social programs
	Gulf Coast Center	1960	ID Facility	312	2010	Florida Gulf Coast University
	Orlando	1929/1959	TB Hospital	1,000	1984	Demolished, land to school, county
	Tallahassee	1928/1967	TB Hospital	350	1983	Demolished; private, multi-family housing
Georgia	Bainbridge	1967	WW II Air Force School	129	2001	Corrections
	Brook Run	1969	ID Facility	364	1997	Undetermined
	Central State Hospital	1842	MH Facility	150	2013	Forensic Unit
	Georgia Regional-Augusta	1969/	MH Facility	438	2003	East Central Regional Hospital (ECRH)
	Gracewood School/Hospital	1921	ID Facility	93	2003	East Central Regional Hospital (ECRH)
	NW Georgia Regional Hospital	1943/1974	Battley Veteran's Hospital	110	2011	Undetermined
	Rivers' Crossing	1969	ID Facility	37	1994	Undetermined
Hawaii	Kula Hospital	1910/1984	TB Hospital	8	1999	Private Hospital
	Waimano	1921	ID Facility	96	1999	Art Center for PWD
Illinois	Adler	1967	MH/ID Facility	16	1982	Water Survey Offices
	Bowen	1965	ID Facility	105	1982	Corrections
	Dixon	1918	ID Facility	820	1987	Corrections/New ID Facility
	Galesburg	1950/1969	Army Hospital	350	1985	Head Start/Community Programs
	Howe	1973	ID Facility	251	2010	Undetermined
	Jacksonville	1851/1974	MH Facility	200	2012	Undetermined
	Lincoln	1877	ID Facility	153	2004	Vacant
	Meyer	1966/1970	MH Facility	53	1993	Women's Prison
	Murray	1964	ID Children's Facility	275	2015	Undetermined
	Singer	1966	MH Facility	45	2003	Undetermined
Indiana	Central State	1848	MH/ID Facility	83	1994	Undetermined
	Ft. Wayne	1887	ID Facility	120	2007	To be demolished
	Muscatatuck	1920	ID Facility	287	2005	Natl Guard urban training center
	New Castle	1907	Epilepsy Village	200	1998	Corrections
	Northern Indiana	1943	ID Facility	53	1998	Undetermined
Kansas	Norton	1926/1963	TB Hospital	60	1988	Corrections
	Winfield	1888	ID Facility	250	1998	Undetermined
Kentucky	Frankfort	1860	ID Facility	650	1972	Demolition
	Outwood	1922/1962	TB Hospital	80	1983	Demolition/New Campus
Louisiana	Columbia	1967	ID Facility	14	2004	From DHH to office of juvenile justice (2009)
	Hammond/N. Services & Support	1964	ID Facility	213	2012	Privatized/Undetermined
	Leesville	1913/1964	High School	20	2004	CEA/Leased to the City of Leesville 2012
	Metropolitan	1967	ID Facility	242	2007	Leased & planned sale/Plaquemines Parish
	Northwest	1973	ID Facility	136	2012	Privatized/Undetermined, family donated land
	Peltier Lawless	1958/1982	Community Hospital	10	2010	Building currently not being utilized
	Ruston/Northeast	1942/1958	WAC Trng/POW/TB Hosp.	72	2010	Grambling State University Ag Dept
Maine	Aroostook	1972	ID Facility	12	2004	Opportunity Training Center
	Levinson	1971	ID Facility	13	1999	Privatized
	Pineland	1908	ID Facility	265	1996	Undetermined
Maryland	Brandenburg	1978	ID Facility	13	2011	Vacant
	Victor Cullen	1908/1974	TB Hospital	79	1991	Private Juvenile Facility
	Great Oaks	1970	ID Regional Center	273	1997	Private Senior Retire. Community
	Henlyton	1928/1962	TB Hospital	312	1985	Undetermined
	Highland Health	1870/1972	General Hospital	88	1989	Sold to Johns Hopkins University
	Rosewood	1888	ID Facility	153	2009	University (after toxic clean-up)
Massachusetts	Belchertown	1922	ID Facility	297	1992	Vacant
	Fernald	1848/1890	Experimental School/ID Facility	162	2015	Town of Waltham/State Capital Management
	Templeton	1900	ID Agriculture Training	122	2015	Templeton Visioning/State Capital Mgt.
	John T. Berry	1900/1963	TB Sanitarium	101	1995	Undetermined
	Paul A. Dever	1940/1946	P.O.W. Camp	294	2001	Undetermined
	Glavin	1975	ID Regional Center	28	2013	Undetermined
	Monson	1854/1866	State Almshouse	17	2013	Property Leased
Michigan	Alpine	1937/1959	TB Hospital	200	1981	Notsego County Offices
	Caro	1914	MH Facility	110	1998	Regional MH Center
	Coldwater	1874/1939	Orphanage	113	1987	Corrections
	Fort Custer	1942/1956	Army Hospital	1,000	1972	Back to U.S. Dept. of Defense
	Hillcrest	1905/1961	TB Hospital	350	1982	Demolition
	Macomb-Oakland	1967/1970	CDA	100	1989	Reverted to Community Dev.
	Muskegon	1969	ID Facility	157	1992	Vacant
	Mt. Pleasant	1893/1934	Indian Boarding School	88	2009	Undetermined

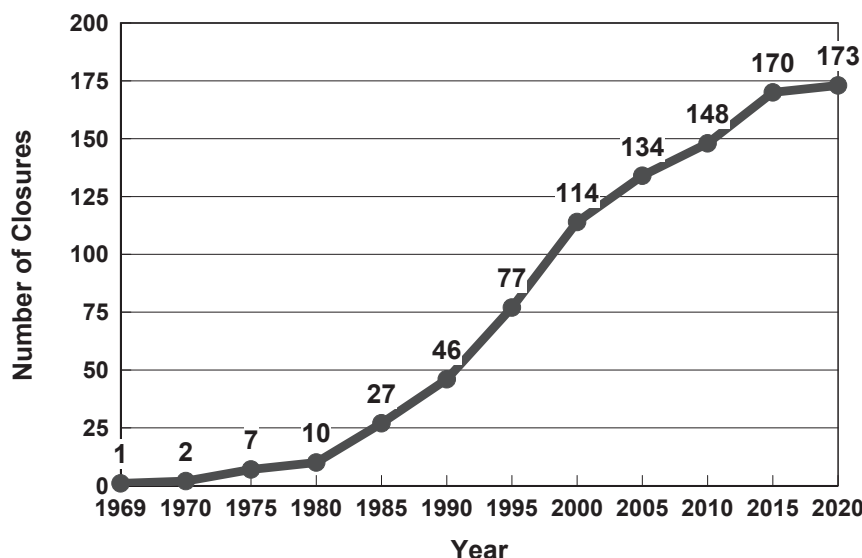
Source : Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

TABLE 11 CONTINUED

State	Institution	Became ID	Original Use	Closure	Year of	Alternate Use
Michigan (Cont.)	Newberry	1896/1941	MH Facility	39	1992	Vacant
	Northville	1952/1972	MH/ID Facility	180	1983	Revert to MH Use
	Oakdale	1895	ID Facility	100	1991	Vacant/County Negotiating
	Plymouth	1960	ID Facility	837	1984	County/State Offices
	Southgate	1977	ID Facility	55	2002	Undetermined
Minnesota	Brainerd	1958	ID Facility	33	1999	Unused
	Cambridge Reg. Ctr.	1923	Epilepsy Colony	37	2000	Housing, park
	Faribault	1879	ID Facility	501	1998	Portion used by Corrections
	METO	1995	MH Facility	48	2011	Cambridge Mental Health Center
	Fergus Falls	1888/1969	MH Asylum	38	2000	Regional MH Center
	Moose Lake	1938/1970	Psychiatric Hosp	34	1993	Corrections
	Owatonna	1895/1947	Orphanage	250	1970	County/City/Substance Abuse
	Rochester	1879/1972	MH Facility	150	1982	Federal Corrections
	St. Peter	1866/1968	MH Facility	47	1996	Vacant
Missouri	Willmar	1912/1973	MH Facility	20	1996	Min-West Technology
	Nevada Habilitation Center	1885/2000	State Mental Hospital	119	2013	Undetermined
Montana	St. Louis DDTC-Northwest Hab. Ctr.	1986	ID Facility	53	2013	Undetermined
	Eastmont	1969/1979	Residential School	29	2003	Nursing Facility
Nevada	Sierra	1882/1970	Mental hospital	15	2008	State I/DD Regional Center
New Hampshire	Laconia	1903	ID Facility	4	1991	Corrections
New Jersey	Edison	1975/1981	Corrections	70	1988	Sold at public auction
	Johnstone	1955	ID Facility	239	1992	Corrections
	North Princeton	1898/1975	Epileptic Colony	512	1998	Undetermined
New Mexico	Fort Stanton	1964	Army Apache Outpost/TB Hosp.	145	1995	Skilled Nursing/Respite
	Los Lunas	1929	ID Facility	252	1997	Community Based Program I/DD
	Villa Solano	1964/1967	Missile Base	82	1982	Demolition/Community Housing
New York	J.N. Adam	1912/1967	TB Hospital	180	1993	Undetermined
	Bronx	1977	ID Facility	217	1992	Plans Not Final
	Craig	1896/1935	Epilepsy Hospital	120	1988	Corrections
	Gouverneur	1962	ID Facility	N/A	1978	Leased site
	O.D. Heck	1972	ID Facility	274	1999	Administrative Offices; non-profit use
	Letchworth	1911	ID Facility	704	1996	Undetermined
	Long Island	1965	ID Facility	682	1993	Undetermined
	Manhattan	1919/1972	Warehouse	197	1991	OPDD Office
	Newark	1878	Custodial Asylum	325	1991	Community College
	Rome	1825/1894	County Poorhouse	638	1989	Corrections
	Sampson	1860/1961	Naval Base	695	1971	Office of Mental Health
	Staten Island/Willowbrook	1942/1952	Army Hospital	692	1987	OPDD & community college
	Sunmount	1922/1965	TB Hospital	503	2003	OPDD Specialty Units
	Syracuse	1851/1972	ID Facility	409	1997	Undetermined
	Valatie	1971	ID Facility	N/A	1974	Private Holdings and ICFs/ID
	West Seneca	1963	ID Facility	80	2012	Clinical services
	Westchester	1932/1979	MH Facility	195	1988	Office of MH
	Wilton	1960	ID Facility	370	1995	Sold to private industry
North Dakota	San Haven	1922/1973	TB Hospital	86	1987	Vacant
Ohio	Apple Creek	1931	ID Facility	178	2006	Undetermined
	Athens MH, Developmental Ctr.	1874/1981	Mental hospital	6	1993	Small psychiatric facility built
	Broadview	1930/1967	TB Hospital	178	1992	City Administration Building/Retirement
	Cleveland	1855/1963	MH Facility	149	1988	Vacant/Negot. with City of Cleveland
	Orient	1898	ID Facility	800	1984	Corrections
	Springview	1910/1975	TB Hospital	86	2004	Undetermined
Oklahoma	Hissom	1967	ID Facility	451	1994	Corrections/Educational
	Northern Oklahoma Resource Ctr.	1909	ID Facility	108	2016	Undetermined
	Southern Oklahoma Resource Ctr.	1907/1953	School for Wayward Boys	123	2015	Undetermined
Oregon	Columbia Park	1929/1963	TB Hospital	304	1977	College
	Eastern Oregon	1929/1963	TB Hospital	50	2009	Corrections/Opened New ID Facility
	Fairview	1907	ID Facility	327	2000	Light commercial/housing
Pennsylvania	Altoona	1975	ID Facility	90	2008	Undetermined
	Cresson	1912/1964	TB Hospital	155	1982	Corrections
	Embreeville	1880/1972	County Poorhouse	152	1998	Undetermined
	Holidaysburg	1974	ID Facility	60	1976	Revert to MH Use
	Laurelton	1920	ID Facility	192	1998	Undetermined
	Marcy Center	1915/1974	TB Hospital	152	1982	Vacant
	Pennhurst Center	1908	ID Facility	179	1988	Veterans' Medical Center
	Philadelphia	1983	MH/ID Facility	60	1989	Vacant
	Western	1962	ID Facility	133	1999	Vacant
	Woodhaven	1974	ID Facility	N/A	1985	Became private institution
Rhode Island	Dix Building	1945/1982	WPA	80	1989	Corrections
	Ladd Center	1907	ID Facility	292	1994	Undetermined
South Carolina	Clyde Street	1973	Home for unwed mothers	20	1995	Administrative Offices
	Live Oak	1987	Nursing home	50	1999	To be sold
South Dakota	Custer	1964	TB Hospital	76	1996	Boot camp for delinquent boys
Tennessee	Arlington	1969	ID Facility	128	2010	Undetermined
	Winston	1979		37	1998	
Texas	Forth Worth	1976	ID Facility	339	1995	Tarrant County Resources Connection
	Travis	1934	ID Facility	585	1997	Corrections/Private Non-Profit
Vermont	Brandon	1915	ID Facility	26	1993	For Sale, Local Realty
Virginia	Southside Virginia Training Ctr.	1971	ID Facility	246	2014	Undetermined
	Northern Virginia Training Ctr.	1973	ID Facility	157	2015	Undetermined
	SW Virginia Training Ctr.	1973	ID Facility	182	2018	Undetermined
	Central Virginia Training Ctr.	1910/1983	Epilepsy Hospital	394	2020	Undetermined
Washington	Interlake School	1946/1967	Geriatric MH Facility	123	1995	Other State Agency
	Frances Haddon Morgan Ctr.	1943/1988	Military Hospital	52	2012	State Office/School/Transition Housing
West Virginia	Colin Anderson	1920s	ID Facility	85	1998	Possible Juvenile Corrections
	Greenbrier	1801/1974	Women's College	56	1994	Community College
	Weston	1864/1985	MH/ID Facility	99	1988	Revert to MH Use
Wisconsin	Northern Wisconsin Ctr.	1897	ID Facility	173	2005	Intensive short-term dual Dx treatment

Source : Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

Figure 11
CUMULATIVE NUMBER OF COMPLETED AND
IN-PROGRESS CLOSURES OF STATE-OPERATED 16+
INSTITUTIONS IN THE UNITED STATES: FY 1969-2020



Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

The largest census reductions nationally were in Louisiana (471), Georgia (438), and California (426). There were also significant reductions in Texas (398), Virginia (326), New Jersey (308), New York (298), North Carolina (272), Illinois (244), and Nebraska (215). These 10 states accounted for 74% of the 4,849-person reduction in the U.S. institution census during 2011–13.

Thirty-seven states maintained state-operated institutions in 2013. In 1880, there were 10 “public institutions for the mentally retarded” in the states. The number of state-operated institutions expanded to 236 by 1978 (Lakin, 1979). In 2013, 37 states continued to finance 151 state-operated IDD institutions (Figure 12 on page 32). Since 1978, several states have opened new facilities, and other states (e.g., Oklahoma, Virginia) are planning the closure of facilities (Table 11 on pages 29–30). These facilities are also included in the figure.

The number of remaining institutions by state ranges from 24 in New York⁷ to a single remaining

institution in 10 states. Thirteen states operated five or more institutions in 2013: New York, Texas, Ohio, Illinois, New Jersey, Connecticut, Arkansas, California, Mississippi, North Carolina, Pennsylvania, South Carolina, and Virginia.⁸

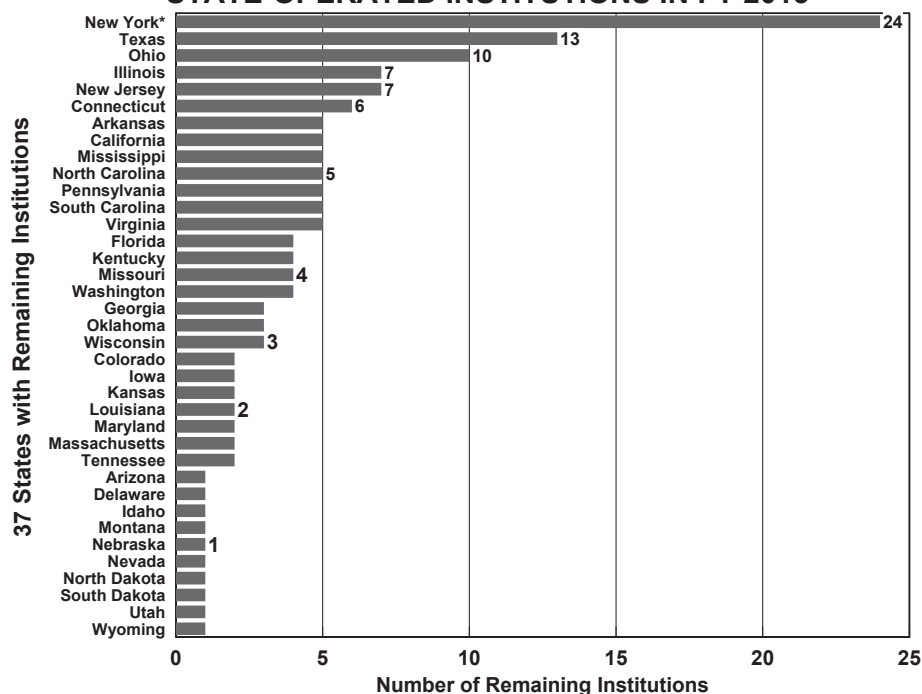
Institutional utilization rates in these states were nine or more persons per 100,000 of the general population. The highest utilization rates were in Mississippi (39), Arkansas (32), and New Jersey (26). The lowest utilization rates were in California (3.5 per 100,000) and Pennsylvania (8.4) among the 13 states with five or more remaining institutions.

The 10 states that financed only one remaining institution were Arizona, Delaware, Idaho, Montana, Nebraska, Nevada, North Dakota, South Dakota, Utah, and Wyoming. These states each supported 139 or fewer residents in their remaining state-operated facility. Institutional utilization rates ranged from 12 persons per 100,000 or more in South Dakota, Wyoming and North Dakota to two persons per 100,000 or less in Idaho, Nevada, and Arizona.

7. New York’s 24 “units” had an average size of 42 daily residents in 2013. The units ranged in size from 84 residents at the Broome Local Intensive Treatment (LIT) to eight residents at the Wassaic Multiple Disabilities Unit (MDU).

8. Virginia has planned the closures, through 2020, of four of the state’s remaining five institutions.

Figure 12
THIRTY-SEVEN STATES FINANCED 151 REMAINING
STATE-OPERATED INSTITUTIONS IN FY 2013



Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

The average cost of care in state institutions continued to increase by an inflation-adjusted 14.5% in the U.S. from 2011 to 2013. A number of states—including some operating multiple facilities—plan closures. Which states will be the next to join the 13 states and DC that are now institution-free?

Public spending for institutions in the states.

Total spending for the nation's public institutions has declined 42% in inflation-adjusted terms since 1977. Institutional spending decreased by 4.6% from 2011 to 2013, but the average daily cost of care per resident increased by 14.5% (Table 12 on page 33).

States varied greatly in terms of average daily spending per person for state-operated institutions in 2013. Spending ranged from under \$400 per day in Arizona, Arkansas, Florida, and Georgia to over \$1,000 per day in California, Connecticut, Delaware, Kentucky, Maryland, Massachusetts, Minnesota, Nebraska, New York, Pennsylvania, and Tennessee.

During 2011–13, inflation-adjusted growth rates in average spending per resident for state-operated

institutional care were 20% or more in: Colorado, Connecticut, Georgia, Kansas, Massachusetts, Mississippi, Nebraska, New Jersey, North Dakota, Pennsylvania, and Virginia. Inflation-adjusted spending per resident declined during 2011–13 in 11 states. The largest declines were in Illinois (26%), Minnesota (14%), and Maryland (7%).

As reported in our previous study, average adjusted daily spending per person declined slightly for the first time in 33 years of data collection, from \$562 in 2006 to \$551 in 2008 (Figure 13 on page 34). However, during 2011–13, institutional spending per person grew an adjusted 14.5%, thus continuing the steady annual growth in daily cost that preceded the Great Recession.

Privately-Operated IDD Institutions

Private institutional facilities provide 24-hour care for 16 or more persons in the same location. They include ICFs/IDs and other state-funded facilities such as child

TABLE 12
AVERAGE DAILY SPENDING PER PERSON IN
STATE-OPERATED INSTITUTIONS: FY 2011-13¹

State	FY 2013	FY 2011	Real Change 2011-2013 ²
Alabama		\$1,143	-100%
Alaska			
Arizona	\$354	\$345	-1%
Arkansas	\$388	\$352	7%
California	\$1,045	\$903	12%
Colorado	\$846	\$604	36%
Connecticut	\$1,133	\$769	43%
Delaware	\$1,209	\$991	18%
District of Columbia			
Florida	\$367	\$367	-3%
Georgia	\$386	\$257	45%
Hawaii			
Idaho	\$763	\$673	10%
Illinois	\$412	\$537	-26%
Indiana		\$861	-100%
Iowa	\$757	\$697	5%
Kansas	\$496	\$376	28%
Kentucky	\$1,078	\$1,046	0%
Louisiana	\$692	\$605	11%
Maine			
Maryland	\$1,084	\$1,132	-7%
Massachusetts	\$1,019	\$557	77%
Michigan			
Minnesota ¹	\$1,179	\$1,324	-14%
Mississippi	\$497	\$310	55%
Missouri	\$568	\$517	6%
Montana	\$627	\$574	6%
Nebraska	\$1,089	\$429	146%
Nevada	\$563	\$548	-0.5%
New Hampshire			
New Jersey	\$799	\$618	25%
New Mexico			
New York	\$1,653	\$1,430	12%
North Carolina	\$573	\$466	19%
North Dakota	\$762	\$611	21%
Ohio	\$514	\$501	-1%
Oklahoma	\$497	\$434	11%
Oregon			
Pennsylvania	\$1,036	\$748	34%
Rhode Island			
South Carolina	\$405	\$357	10%
South Dakota	\$438	\$421	1%
Tennessee	\$1,168	\$1,014	12%
Texas	\$563	\$474	15%
Utah	\$449	\$424	3%
Vermont			
Virginia	\$868	\$579	45%
Washington	\$568	\$498	10%
West Virginia			
Wisconsin	\$809	\$729	8%
Wyoming	\$802	\$739	5%
United States	\$701	\$593	14.5%

¹ States with no data reported did not operate 16+ state-operated institutions; Minnesota has closed the last institution, but there are still 10 persons pending alternative placements.

² Adjusted for inflation.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015

care institutions, residential schools, and sheltered care homes (i.e., non-ICF/ID settings).

The total population of these facilities, excluding nursing facilities, declined 2% during 2011–13, from 22,771 to 22,256 persons. There was a 1.5% increase in the number of persons residing in private ICFs/ID for 16 or more persons, an increase of 258 persons; and a 15% decline (772 fewer persons), in private settings not certified as ICFs/ID. Public financial support for all private institutions, excluding nursing facilities, increased by 1% in inflation-adjusted terms from 2011–13.

Thirteen states and DC did not operate private 16+ ICF/ID nor settings not certified as ICFs/ID: Alabama, Alaska, Colorado, DC, Hawaii, Kansas, Maryland, Massachusetts, Montana, New Mexico, Oregon, South Carolina, Vermont, and Wyoming.

Of the remaining 37 states, 18 states reduced the number of persons in private 16+ settings. The largest reductions were in seven states: Iowa (438), California (237), Pennsylvania (185), Texas (151), New York (95), Tennessee (69), and Ohio (63). There were reductions from 27 to one person in 11 states (Arizona, Connecticut, Indiana, Florida, Michigan, Minnesota, Nebraska, North Dakota, Oklahoma, Washington, and Utah).

Fourteen states *increased* populations in their private 16+ facilities. Those with the greatest increases included: Louisiana (358 persons), Wisconsin (187), Idaho⁹ (150), Illinois (87), and Virginia (40). There were increases of 25 persons or less in Arkansas, Delaware, Georgia, Indiana, Maine, Missouri, New Jersey, Rhode Island, and South Dakota.

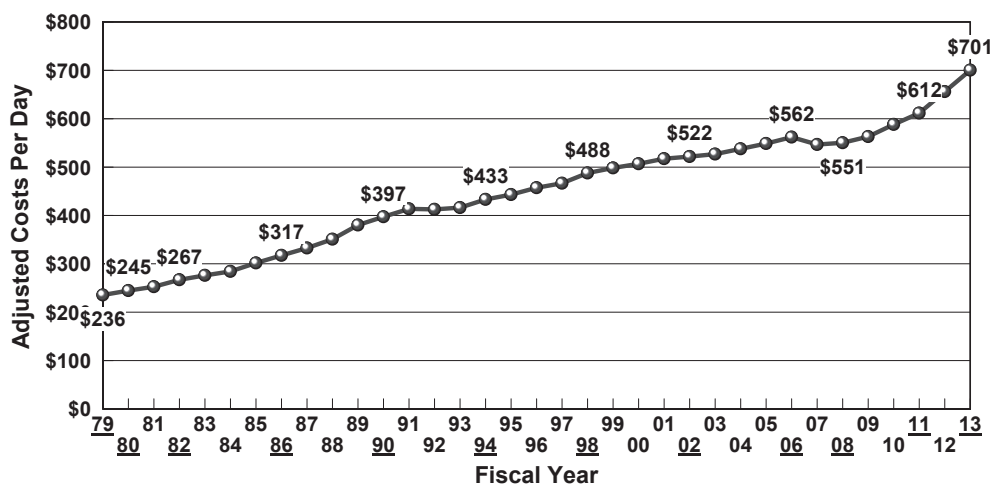
The five remaining states—Kentucky, Mississippi, Nevada, New Hampshire, and West Virginia—had no census change during 2011–13: For a discussion of costs of private 16+ settings, see “Cost by Setting” (pages 23–25).

Nursing Facilities

An additional objective of the study included the collection of data on the number of persons with intellectual and developmental disabilities residing in nursing facilities in the states. IDD nursing facility data for the present study originally was from the reporting

9. Idaho had reported a 16+ private facility census during 1988 to 2002; reported no census from 2003–11; and then reported 71 persons in 2012 and 150 persons in 2013.

Figure 13
**DAILY SPENDING PER PERSON IN STATE-OPERATED 16+
 I/DD INSTITUTIONS IN THE U.S.: FY 1977-2013**



Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

requirements of the *Nursing Home Reform Act*, *Omnibus Budget Reconciliation Act (OBRA) of 1987* (Pub. L. 100–203) (Mitchell & Braddock, 1990).

In May 2013, the landmark 1998 *Rolland v. Patrick* class action lawsuit in Massachusetts was dismissed after approximately 1,800 people with IDD were moved from inappropriate placement in nursing facilities to community-based homes. In Texas, an interim agreement was reached between the parties in the *Steward v. Perry* case that would expand community living for people with IDD currently living in, or at risk of being placed in, nursing facilities (United States Department of Justice Civil Rights Division, 2014).

With the downsizing of state-operated institutions increased waiting lists states and families have relied on nursing facilities as the “next generation” of institutions for persons with disabilities (Center for Public Representation, 2014). However, results of our study indicate reductions in utilization in most states.

Data sources. Nursing facility data were collected from two primary sources: a) direct contact with state officials in IDD agencies; and b) from the Online Survey, Certification and Reporting (OSCAR) System of the Federal Government’s Centers for Medicare and Medicaid Services (CMS). The OSCAR dataset is a compilation of data collected by CMS and state long-term care surveying agencies. During the Medicare and

Medicaid certification inspections of nursing facilities, state surveyors collect data on patient characteristics using CMS form 672. The data from each nursing facility in the U.S. are entered into the OSCAR database.

In our analysis of OSCAR IDD nursing facility data during 1993–2013, we utilized three data sources. First, data for 1993–2002 were obtained from online reports prepared by researchers at the University of California-San Francisco (Harrington, Carillo, & Mercado-Scott, 2005; Harrington, Carillo, Thollaug, Summers, & Wellin, 2000; Harrington, Carrillo, Wellin, & Shemirani, 2002). Second, we obtained OSCAR data for 2003–04 on CD ROMs from CMS (2005); and third, we obtained the OSCAR data for 2005–13 from the American Health Care Association (AHCA, 2014).

The nursing facility data we collected directly from state IDD agencies for 1993–2011 were compared state-by-state and year-by-year, to the OSCAR “mental retardation” data set for the same period. Discrepancies were discussed in consultation with the project’s data contacts in the states and revisions were made accordingly. For example, in 2013 we utilized OSCAR data in 19 states and the District of Columbia and state sources for the remaining 31 states.

Census of persons with IDD by state. The number of people with IDD residing in nursing facilities in the U.S. declined by 4,667 persons during 2011–13

(Table 13 below). There was considerable state variation in the utilization of nursing facilities. Nine states reported increases in the number of nursing facility residents with IDD during 2011–13. The highest utilization rates, 20–31 per 100,000, were reported by Arkansas, Indiana, Iowa, and Wyoming. The lowest per capita utilization rates for nursing facilities, at less than three per 100,000 of the state population, were reported by Alaska, Arizona, and Delaware.

Kansas reported no persons with IDD in nursing facilities during 2011–13. In 2013, the national utilization rate for nursing facilities for persons with IDD was 8.5 per 100,000 of the states' populations. This was significantly below the rate of 10.1 in 2011.

Nursing facility census reductions were reported by 39 states and DC while no change was reported by two states (Kansas and New Hampshire). The leading states in census reduction for persons with IDD during 2011–13 were: Texas (1,107 persons), Missouri (481), Illinois (470), Georgia (414), Ohio (309), Maryland (222), Mississippi (210), Florida (201), Massachusetts (189), Pennsylvania (185), Tennessee (181), Arkansas and Nebraska (168 each), West Virginia and Wisconsin (132 each), and Alabama (127). There were increases in nursing facility residents in New Jersey (270), New York (203), Louisiana (159), Washington State (21), Montana (12), Iowa (10) and Connecticut (7), and Vermont and Minnesota (1 each).

TABLE 13
RESIDENTS WITH I/DD IN NURSING FACILITIES BY STATE: FY 2011-13

State	2013	2011	% Change 2011-13	Utilization Rate, 2013 ¹	State	2013	2011	% Change 2011-13	Utilization Rate, 2013 ¹
Alabama ²	787	914	-14%	16.3	Montana	155	143	8%	15.3
Alaska	8	15	-47%	1.1	Nebraska	205	373	-45%	11.0
Arizona	38	52	-27%	0.6	Nevada	87	100	-13%	3.1
Arkansas ²	615	783	-21%	20.8	New Hampshire	60	60	0%	4.5
California	1,187	1,241	-4%	3.1	New Jersey	1,278	1,008	27%	14.4
Colorado	188	274	-31%	3.6	New Mexico	98	109	-10%	4.7
Connecticut	388	381	2%	10.8	New York	1,883	1,680	12%	9.6
Delaware	27	43	-37%	2.9	North Carolina	959	962	0%	9.8
District of Columbia ²	25	31	-19%	3.8	North Dakota	108	124	-13%	15.2
Florida ²	919	1,120	-18%	4.7	Ohio ²	1,801	2,110	-15%	15.6
Georgia ²	1,059	1,472	-28%	10.6	Oklahoma ²	529	616	-14%	13.8
Hawaii	62	105	-41%	4.4	Oregon ²	123	166	-26%	3.1
Idaho ²	86	117	-27%	5.4	Pennsylvania ²	1,353	1,538	-12%	10.6
Illinois ²	946	1,415	-33%	7.3	Rhode Island	73	98	-26%	6.9
Indiana	1,527	1,533	0%	23.3	South Carolina	220	258	-15%	4.6
Iowa	629	619	2%	20.4	South Dakota	134	153	-12%	16.0
Kansas	0	0		0.0	Tennessee ²	658	839	-22%	10.2
Kentucky ²	842	846	0%	19.2	Texas ²	1,831	2,938	-38%	7.0
Louisiana	551	392	41%	11.9	Utah	195	203	-4%	6.8
Maine ²	103	148	-30%	7.7	Vermont	35	34	3%	5.6
Maryland ²	242	464	-48%	4.1	Virginia	1,045	1,075	-3%	12.7
Massachusetts	290	479	-39%	4.3	Washington	289	268	8%	4.2
Michigan	672	692	-3%	6.8	West Virginia ²	274	406	-32%	14.8
Minnesota	359	358	0%	6.6	Wisconsin ²	252	384	-34%	4.4
Mississippi ²	347	557	-38%	11.6	Wyoming	179	209	-14%	30.9
Missouri ²	959	1,440	-33%	15.9	United States	26,678	31,345	-15%	8.5

¹ Rate: Nursing facility placements in 2013 per 100,000 of the state's general population.

² Data for these 20 states were based on the "Online Survey, Certification and Annual Reporting" data set (OSCAR) of the Centers for Medicare and Medicaid Services (CMS). (See text for additional detail on data sources.)

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

VII. COMMUNITY SERVICES AND SUPPORTS

Significance of Medicaid in Community Living Services

Medicaid ICF/ID program. For two decades after the Intermediate Care Facilities for Persons with Intellectual Disability (ICF/ID) statute was enacted in 1971 (Pub. L. 92-223), spending for ICFs/ID grew rapidly (Figure 14 below). Initially, the program exclusively financed state-operated institutions for 16+ persons, but states soon began to finance ICFs/ID for 15 or fewer persons in the mid-1970s. Adjusted federal-state ICF/ID spending peaked in 1993, at \$17.9 billion (adjusted). Three quarters of this funding was allocated to settings for 16 or more persons.

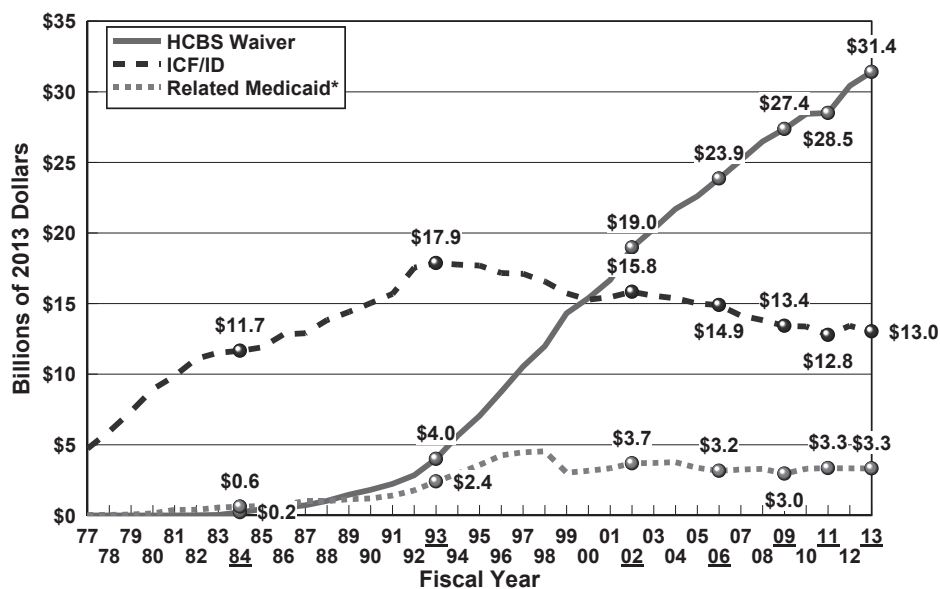
The institutional bias of ICF/ID funding to finance Medicaid long-term services and supports was identified beginning in the 1980s (The Arc, 1989; Braddock

& Hemp, 1996; Nelis & Ward, 1995; Taylor, Brown, McCord, Giambetti, Searl, Mlinarcik, Atkinson, et al., 1981). In 2013, 69% of federal ICF/ID funding was still associated with state and private institutional settings for 16 or more persons; 55% of funding was for state institutions alone.

As noted previously, 11 states do not finance ICF/ID settings for 15 or fewer persons. They use HCBS Waiver funding instead. The states are Delaware, Georgia, Maryland, Massachusetts, Michigan, Montana, New Hampshire, New Jersey, Oregon, South Dakota, and Wyoming.

Inflation-adjusted federal-state spending in the U.S. for public and private ICFs/ID supporting 15 or fewer persons increased 12.8% from 2011 to 2013. Public ICF/ID facilities' spending increased 16.1%; and private facilities' spending increased 12.7%. In 2013, 40,442 individuals were supported in public and

Figure 14
FEDERAL-STATE I/DD SPENDING FOR HCBS WAIVER, ICF/ID, AND RELATED MEDICAID IN THE U.S.: FY 1977-2013



*Related Medicaid includes Clinic and Rehabilitative Services, Targeted Case Management, Personal Assistance, State Plan Home and Community (e.g., 91-i, 91-j) and Administrative Services.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

private ICFs/ID for 15 or fewer persons. Federal-state spending was \$3.94 billion.

Medicaid HCBS Waiver. The Home and Community-Based Services (HCBS) Waiver is the principal Medicaid program underwriting IDD long-term services and supports. In 2000, Waiver spending surpassed Medicaid ICF/ID spending in the U.S. (Figure 14 on page 36). Authorized by Congress in 1981 (Pub. L. 97–35) as an alternative to the ICF/ID program, federal-state HCBS Waiver spending in the U.S. grew from \$6.5 million in 1982 to \$31.4 billion in 2013.

Included with the HCBS Waiver spending figure in 2013 was \$646.8 million for Arizona’s Section 1115 Research and Demonstration Waiver; \$959.2 million for Michigan’s 1915(b)(c) Waiver “B-3 Community-Living Services”; \$150.4 million for Vermont’s Global Commitment to Health managed care program; and \$871.5 million for Wisconsin’s “Family Care and Family Care Partnership/PACE” managed care.

The HCBS Waiver provides federal reimbursement for a wide array of community services and supports. These include residential habilitation, day habilitation, personal assistance, respite care and other family support, case management, transportation, supported employment, supported living, a range of professional therapies, assistive technology, and other types of assistance in home and community-based environments. Although no state financed all of these options, there was considerable variability in the services that states offered under the Waivers.

Federal, state and local HCBS Waiver spending increased 10.2% in inflation-adjusted terms from 2011 to 2013. There was an adjusted 0.6% decline in “related” IDD Medicaid spending that was comprised of declines in clinic services (0.5%), in rehabilitative services (7.1%) and in “other Medicaid” including early intervention and community services administration (14%).

There were “related Medicaid” increases of 7% in targeted case management spending and 14% in personal assistance. In summary, from 2011 to 2013 there was an adjusted federal-state Medicaid spending increase of \$250.5 million for ICF/ID spending, an \$18.9 million reduction in “related” Medicaid spending, and a \$2.90 billion increase in adjusted HCBS Waiver spending.

Total adjusted federal-state Waiver spending fell in seven states during 2011–13: Florida (7%), Rhode Island, (6%); New York, Colorado, and Arizona (3%); Hawaii (1%), and Delaware (0.1%). Between 2010 and 2011, adjusted federal-state Waiver spending declined in 20 states, with the largest reductions in New Mexico

(8%), Indiana (7%), and California, Florida, Maine, and Mississippi (6%).

During 2011–13, combined federal, state, and local IDD Medicaid spending increased an adjusted 7% to \$47.8 billion. (Figure 15 on page 38). The figure also illustrates a slight decline (–1.1%) in spending from 2010–11. This is attributable to two factors. First, enhanced federal medical assistance percentage (FMAP) rates were in effect during 2009–11, and states with budget constraints could opt to receive an increased amount of federal Medicaid reimbursement without increasing state matching funding.

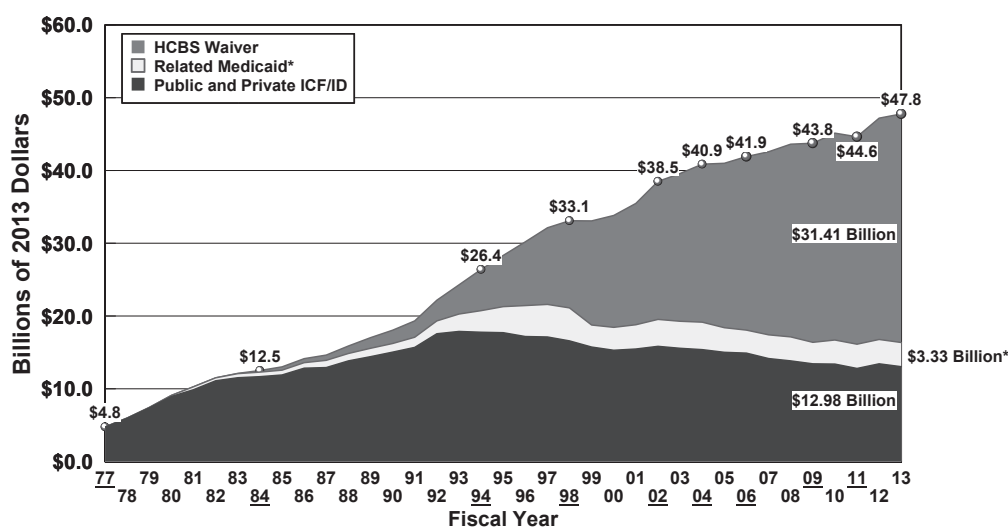
Second, total Recession-driven state General Fund spending declined by 6.1% in 2009 and by 6.4% in 2010 (Figure 1 on page 3). These were the largest General Fund reductions in over two decades. Since state general funds are used to match federal Medicaid funding, state matching funds captured less federal Medicaid for the states. Enhanced FMAP rates coupled with state overall financial constraints contributed to the reduction of 1.1% in Medicaid spending in 2011.

Appendix I on page 202 presents the estimated amount of currently unmatched state, county and local government IDD funding in each state potentially available for matching additional federal Medicaid funds. Such resources could be used to increase total spending for the HCBS Waiver and optional Medicaid services.

Nationwide study of IDD Medicaid HCBS Waivers. In 2013, an analysis was completed by the State of the States Project analyzing trends in spending allocations in the states for long-term care offered through the HCBS Waiver program (Rizzolo, Friedman, Lulinski-Norris, & Braddock, 2013). Eighty-eight 1915c Medicaid HCBS Waiver applications in 41 states and the District of Columbia were analyzed to gain insight into how states were providing long-term services and supports (LTSS) within the 1915c Program. Analysis of service definitions resulted in a taxonomy of 18 categories of support.

A new analysis of these data was initiated in 2014 to examine FY 2013 data (Friedman & Rizzolo, under review). Project staff obtained 99 Waivers from 44 states and DC, representing over \$28 billion of projected Waiver spending. In FY 2013, the primary service category funded was residential habilitation, which constituted 48% of the proposed spending across the 99 Waivers analyzed. The second and third largest categories were day habilitation—18% of total projected spending—and personal assistance/supported living, which also included homemaker and companion services (16% of projected spending).

Figure 15
COMPONENTS OF FEDERAL-STATE I/DD
MEDICAID SPENDING IN THE U.S.: FY 1977-2013



*In 2013, "Related Medicaid" consisted of \$1.241 billion for targeted case management, \$1.003 billion for administration/other; \$0.594 billion for personal assistance, \$0.487 billion for clinic/rehabilitative services, and \$4.2 million for state plan Home and Community Services.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

The remaining categories comprised relatively small percentages of total spending: prevocational services (3%); supported employment, family training and counseling, transportation, care coordination, health and professional services, and respite care (2% each); community transition supports, and assistive and medical technologies each comprised 1%.

Financial support services, adult day health, individual goods and services, self-advocacy training,¹⁰ education, and recreation and leisure each comprised less than 1% of total nationwide projected spending for the 99 waivers analyzed.

The 2013 analysis also included a comparison of average cost per person in traditional comprehensive waivers. These waivers included residential habilitation

in licensed settings outside the family home and support waivers, or waivers that included the same supports with the exception of residential habilitation. Sixteen states in the analysis offered both a comprehensive waiver and a support waiver with similar target groups. In these states, the cost of the support waivers was approximately one-fifth the average cost per person in comprehensive waivers (Friedman & Rizzolo, under review).

States have evolved toward offering multi-tiered system of supports to: 1) reduce the average per person cost by eliminating residential care in the support waiver; 2) utilize family caregivers; 3) reduce growing waiting lists for services; and, 4) leverage federal funds for services formerly paid for solely by state and local governments (Smith, Agosta, & Fortune, 2007).

Clearly, the HCBS Waiver is an essential part of community services funding in the states, especially for supported living and personal assistance, family support, and supported employment. In 2013, 685,828 participants were supported by the HCBS Waiver across the nation.

Table 14 on page 39 presents data for: 1) the number of years states' HCBS Waivers have been in effect, 2) the

10. Self advocacy and/or self determination were sub-components of other services in almost half the states analyzed (e.g., included in residential habilitation, individual goods and services, day habilitation, family and individual support services, and supported employment service definitions). The "self-advocacy training" category in the proposed taxonomy consisted of the four waivers across two states in which the entire service was devoted to self-advocacy training.

TABLE 14
THE HOME AND COMMUNITY BASED SERVICES (HCBS) WAIVER:
I/DD PARTICIPANTS AND SPENDING IN FY 2013

State	Years in Effect	Participants	Spending ¹	Waiver Cost Per Participant	Waiver Spending % of Total I/DD Spending	Waiver \$s Per Capita ²	Rank ³
Alabama	31	5,848	\$298,607,248	\$51,061	82%	\$62	39
Alaska	20	1,885	\$154,510,327	\$81,968	77%	\$211	7
Arizona ⁴	25	24,873	\$646,829,176	\$26,005	77%	\$98	29
Arkansas	24	4,147	\$180,303,847	\$43,478	34%	\$61	41
California	29	103,629	\$2,297,751,317	\$22,173	36%	\$60	42
Colorado	30	8,072	\$328,451,248	\$40,690	62%	\$63	38
Connecticut	26	9,346	\$761,400,745	\$81,468	62%	\$212	6
Delaware	29	954	\$91,636,647	\$96,055	54%	\$99	28
District of Columbia	13	1,635	\$149,512,826	\$91,445	53%	\$232	4
Florida	30	29,068	\$856,160,648	\$29,454	57%	\$44	46
Georgia	24	12,065	\$431,145,281	\$35,735	50%	\$43	47
Hawaii	30	2,695	\$103,289,526	\$38,326	64%	\$74	37
Idaho	30	2,775	\$63,758,930	\$22,976	31%	\$40	49
Illinois	30	18,545	\$627,419,738	\$33,832	39%	\$49	45
Indiana	24	13,727	\$765,285,208	\$55,750	57%	\$117	23
Iowa	21	12,157	\$400,718,303	\$32,962	45%	\$130	17
Kansas	30	8,424	\$327,623,634	\$38,892	67%	\$113	25
Kentucky	30	12,773	\$468,777,232	\$36,701	63%	\$107	26
Louisiana	27	11,661	\$723,655,977	\$62,058	50%	\$157	13
Maine	30	4,185	\$319,782,934	\$76,412	71%	\$241	2
Maryland	30	13,407	\$753,351,350	\$56,191	73%	\$128	18
Massachusetts	29	12,892	\$783,685,592	\$60,789	37%	\$118	22
Michigan ⁴	26	23,584	\$959,182,512	\$40,671	65%	\$97	30
Minnesota	29	19,738	\$1,247,493,417	\$63,203	73%	\$231	5
Mississippi	18	1,961	\$88,508,388	\$45,134	19%	\$30	50
Missouri	25	12,110	\$629,462,513	\$51,979	62%	\$104	27
Montana	32	2,306	\$91,755,154	\$39,790	54%	\$91	32
Nebraska	26	4,636	\$236,223,987	\$50,954	64%	\$127	19
Nevada	31	1,680	\$75,610,199	\$45,006	46%	\$27	51
New Hampshire	30	4,637	\$212,483,988	\$45,824	76%	\$161	12
New Jersey	30	10,740	\$785,138,342	\$73,104	39%	\$88	33
New Mexico	29	4,071	\$285,659,316	\$70,169	79%	\$137	16
New York	22	78,325	\$5,433,238,510	\$69,368	51%	\$277	1
North Carolina	30	10,985	\$598,167,693	\$54,453	40%	\$61	40
North Dakota	30	4,165	\$137,337,593	\$32,974	50%	\$193	9
Ohio	23	32,492	\$1,349,069,574	\$41,520	41%	\$117	24
Oklahoma	28	5,190	\$293,142,715	\$56,482	57%	\$76	36
Oregon	32	14,335	\$479,015,065	\$33,416	60%	\$122	21
Pennsylvania	30	26,589	\$1,781,635,919	\$67,007	50%	\$140	15
Rhode Island	30	3,254	\$208,572,619	\$64,097	81%	\$198	8
South Carolina	22	9,414	\$281,410,294	\$29,893	47%	\$59	43
South Dakota	31	3,306	\$105,329,118	\$31,863	61%	\$125	20
Tennessee	27	7,689	\$624,768,696	\$81,255	67%	\$96	31
Texas	28	29,620	\$1,102,895,602	\$37,235	41%	\$42	48
Utah	26	4,423	\$164,904,408	\$37,283	59%	\$57	44
Vermont ⁴	31	2,768	\$150,406,247	\$54,338	84%	\$240	3
Virginia	23	10,282	\$639,956,105	\$62,240	49%	\$78	35
Washington	30	12,056	\$600,333,914	\$49,795	57%	\$87	34
West Virginia	30	4,492	\$335,490,977	\$74,686	75%	\$181	11
Wisconsin ⁴	30	23,925	\$871,521,920	\$36,427	62%	\$152	14
Wyoming	23	2,292	\$105,229,377	\$45,912	71%	\$182	10
United States	32	685,828	\$31,407,601,899	\$45,795	51%	\$100	

¹ Federal, state and local government Waiver spending; ²Per citizen of the general population of the state.

³ States' ranking, highest to lowest, on federal-state Waiver spending per citizen of the general population.

⁴ Waiver spending in Arizona derived from a Section 1115 Research and Demonstration Waiver; in Michigan, \$959.2 million of spending consisted of the State's 1915b/c Waiver and "B-3 Community Living Services"; in Vermont, \$150.4 million derived from the Global Commitment to Health managed care program; and in Wisconsin \$877.5 consisted of the "Family Care and Family Care Partnership/PACE managed care program.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

number of individuals participating in HCBS Waiver funded services, 3) federal-state Waiver spending in the states, 4) Waiver cost per participant, 5) Waiver spending as a percentage of total IDD spending, 6) Waiver spending per capita of the general population, and 7) each state's ranking in Waiver spending per capita.

New York, Maine, Vermont, District of Columbia, Minnesota, Connecticut, Alaska, and Rhode Island had the largest Waiver programs in 2013 based on federal-state spending per person of the state general population. Spending ranged from \$198 to \$277 per capita in these seven states and the District of Columbia. In terms of the absolute number of participants served, the largest HCBS Waiver programs in 2013 were in the populous states of California, New York, Ohio, Texas, Florida, Pennsylvania, Florida, Wisconsin, and Michigan. These states served from 23,000 to 103,000 participants. In terms of total expenditure, the largest HCBS Waiver programs were in New York, California, Ohio, Pennsylvania, Minnesota, Texas, Michigan, Florida, Wisconsin, and Arizona.

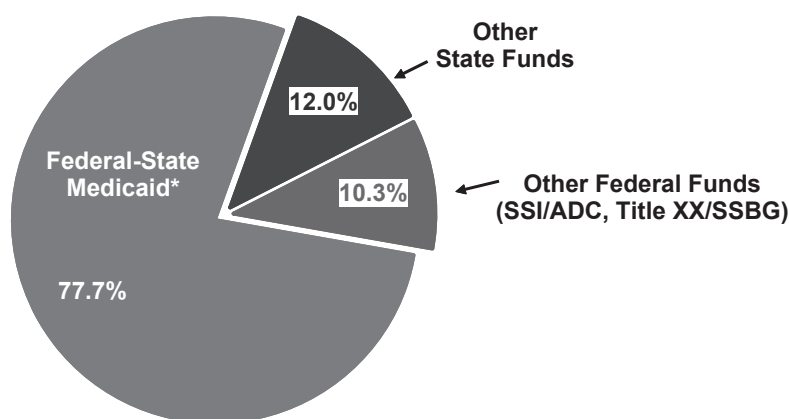
As previously noted, HCBS Waiver spending first surpassed ICF/ID spending in 2000. Inflation-adjusted

federal-state Waiver spending increased an average of 6% per year during 2011–13, This contrasted with 2% per year increases for adjusted ICF/ID spending.

In 2013, the average annual state institutional cost per ICF/ID resident was \$254,905, while the average annual cost per Waiver participant was \$45,795. Federal-state Waiver spending constituted more than 50% of total IDD long-term care spending in 33 states (Table 14 on page 39). The annual HCBS Waiver cost in each of these states did not exceed Delaware's per participant cost of \$96,055. In most states costs ranged from \$26,000 to \$70,000 per participant. This was substantially below the average nationwide institutional ICF/ID cost of \$255,692.

The Medicaid program is the single most important public sector program in the United States for people with IDD. Federal-state Medicaid spending in 2013 constituted 77.7% of the \$61.46 billion in IDD long-term care spending (Figure 16 below). Sixty-six percent of the \$47.77 billion in federal-state Medicaid funding in 2013 consisted of HCBS Waiver funds. Twenty-seven percent supported public and private ICF/ID facilities of all sizes. The balance, 7%, consisted of related Medicaid services.

Figure 16
FEDERAL-STATE MEDICAID WAS THE MAJORITY
OF TOTAL I/DD SPENDING IN FY 2013



Total I/DD Spending: \$61.46 Billion

*Total federal-state Medicaid: \$47.77 billion
a) HCBS Waiver (66%);
b) Public & Private ICFs/ID (27%); and
c) Related Medicaid (7%)

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

State Medicaid programs differ in terms of mandatory services that states must provide versus the elected or optional services that each state may provide, as specified in its state plan. For example, inpatient hospital, out-patient hospital, Early and Periodic Screening, Diagnosis, and Treatment (EPSDT), and some nursing facility services are mandatory services that are provided by all states.

The HCBS Waiver, ICF/ID, and four related Medicaid services constituted the six optional services that are extensively utilized for individuals with intellectual and developmental disabilities. Two are health care services (clinic and rehabilitative services), one is an institutional long-term care service (ICF/ID), and three are community-based long-term services and supports consisting of the HCBS Waiver, personal assistance, and targeted case management). Clinic services, rehabilitative services, personal assistance, and targeted case management services constitute the *Related Medicaid* category in Figures 14 (p. 36) and 15 (p. 38).

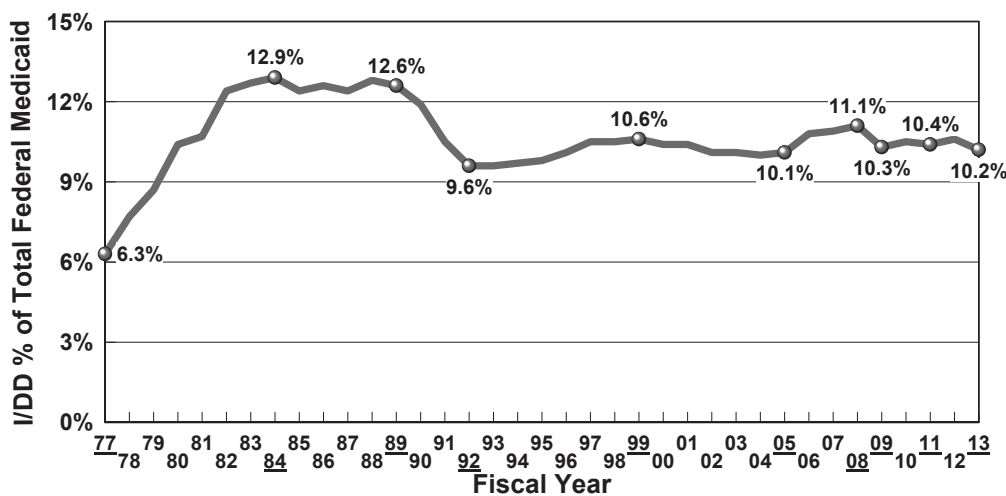
Each state has its own *Federal Medical Assistance Percentage (FMAP)* rate based on per capita personal income in the state, with a minimum rate of 50%. The FMAP rate determines the levels of federal and state matching funds. Mississippi receives the highest FMAP

rate because it has the lowest per capita personal income. If Mississippi provides one dollar in state Medicaid matching funds, it receives nearly four dollars in federal Medicaid reimbursement. In 2013, fourteen states had the minimum FMAP rate of 50%. These states included Alaska, California, Colorado, Connecticut, Illinois, Maryland, Massachusetts, Minnesota, New Hampshire, New Jersey, New York, Virginia, Washington, and Wyoming. Each dollar of state funds is matched by one dollar of federal Medicaid reimbursement.

In 2009, the *American Recovery and Reinvestment Act (ARRA)* temporarily enhanced FMAP rates in all states. Rates that usually ranged from 50% to 75% were increased in 2009 to range from 55% in Wyoming to 82% in Mississippi. In 2010, enhanced rates ranged from 61% in Wyoming to 85% in Mississippi, and in 2011, rates ranged from 60% in the nine wealthiest states to 83% in Mississippi. The FMAP rates dropped in 2012 and 2013 to range from 50% in the 10 wealthiest states to 74% in Mississippi.

The proportion of total Medicaid spending in the U.S. devoted to Medicaid long-term services and supports for persons with IDD declined from a peak of 13% in 1984 to between 10% and 11% during 1992–2013 (Figure 17 below). The increased IDD share from

Figure 17
FEDERAL MEDICAID I/DD LONG-TERM CARE SPENDING AS A PERCENTAGE OF TOTAL FEDERAL MEDICAID SPENDING IN THE U.S.: FY 1977-2013



Sources: Total medicaid spending was compiled from U.S. Government Printing Office data (2014).
I/DD spending is from Braddock et al. 2015.

2006 to 2008 was attributable in part to a decline in total federal Medicaid spending—from \$181.7 billion in 2005 to \$180.6 billion in 2006—and slower total Medicaid growth in 2007 and 2008. Total adjusted federal Medicaid dropped 2% in 2011 and 11% in 2012 (as the federal enhanced FMAP rates expired) before increasing 5% in 2013.

The IDD percentage drop in 2009 was attributable to the aforementioned leveling of total IDD Medicaid spending for long-term supports and services and to an increase in total federal Medicaid spending resulting from increased enrollment of the unemployed. The Great Recession stimulated a 25% increase during 2008–09 in total federal Medicaid spending (U.S. Government Printing Office, 2010).

Most IDD spending is Medicaid. The vast majority of federal, state and local government spending for IDD services in the states in 2013 (78%) derived from the federal-state Medicaid program (Table 15 on page 43).

The 10 highest ranked states in FY 2013 in Medicaid spending as a percentage of their total IDD spending were, in order: West Virginia, Tennessee, Arkansas, Indiana, Maine, Connecticut, Mississippi, Louisiana, Minnesota, and Idaho and Rhode Island (both 87%). The 10 lowest ranked states were Massachusetts, Georgia, California, Montana, Ohio, Nevada, Pennsylvania, Hawaii, New Jersey and Colorado and Wisconsin (both 76%).

Do states with a high FMAP¹¹ (i.e., “poorer states”) seek more federal Medicaid funding? Indeed, the comparatively poorer states Arkansas, Idaho, Mississippi, and West Virginia were among the highest ranked states on Medicaid percentage of total IDD spending. In contrast, three other high FMAP states ranked 30th or lower: Kentucky, Montana, and South Carolina.

It will be very important to carefully follow trends in the low ranking states in Table 15 in the years ahead. Will these states emulate the strong HCBS Waiver expansions in Alabama, Maine, Minnesota, and Rhode Island? Or, like Massachusetts, Georgia, California, Pennsylvania, and New Jersey, will they seek to continue to rely more on state funds for financing home and family-based services? It will also be important to gauge the economic and quality of life outcomes for those utilizing HCBS Waivers. For example, Cidav, Marcus & Mandell (2014) found state cost savings for

children enrolled in the HCBS Waiver (compared to those not enrolled) when the spending per child was under \$1,450 per month.

In summary, as a percentage of total IDD spending, Medicaid spending grew from 31% in 1977 to 78% in 2013. Our website (stateofthestates.org) provides greater detail on 1977–2013 Medicaid spending as a share of total IDD spending in each state. The State of the States website also provides 1977–2013 spending trends in Medicaid ICFs/ID, the HCBS Waiver, and related Medicaid programs.

Other sources of revenue for community services and supports. In 1977, federal funds constituted only 23% of the total allocation for IDD community services in the U.S. By 2013, that proportion had increased to 53% of total U.S. community services spending (\$53.23 billion) (Figure 18 on page 44). The state government general revenue component of total U.S. community services spending, including state Medicaid matching funds and state augmentation of federal Supplemental Security Income (SSI) payments, comprised 44% of community services revenues in 2013. Local funds from counties, municipalities, townships, parishes, and special districts made up the remaining 3%. The combined state and local proportion of community spending declined from 49% in 2008 to 40% in 2010. It increased to 47% in fiscal year 2013.

Federal funds. In 2013, federal HCBS Waiver funds—and income maintenance payments (SSI/ADC) for participants receiving Waiver funding—represented 83% of total federal spending for community services and 44% of all funding allocated for community services. The remaining federal funds supporting community services included funding for public and private ICFs/ID for 15 or fewer persons (8% of federal community services funding). *Related Medicaid* funding for targeted case management, clinic/rehabilitative services, personal care, and administration constituted 7%. The Social Services Block Grant (Title XX/SSBG) constituted only 1%; and the remaining 1% of federal funding consisted of various project funds from federal agencies such as the Office of Special Education and Rehabilitative Services and the Administration on Intellectual and Developmental Disabilities.

Social Services Block Grant funds (SSBG), formerly Title XX, constituted 18% of U.S. community IDD spending in 1977, but only 0.6% in 2013. The SSBG has rapidly declined in the states as revenue for IDD services since enactment of the HCBS Waiver and the conversion of Title XX to a block grant in the *Omnibus*

11. The Federal Medical Assistance Percentage (FMAP) is based on per capita personal income in each state. (See discussion above.)

TABLE 15
FEDERAL-STATE MEDICAID FUNDS CONSTITUTED 78% OF
TOTAL I/DD SPENDING IN THE STATES IN FY 2013

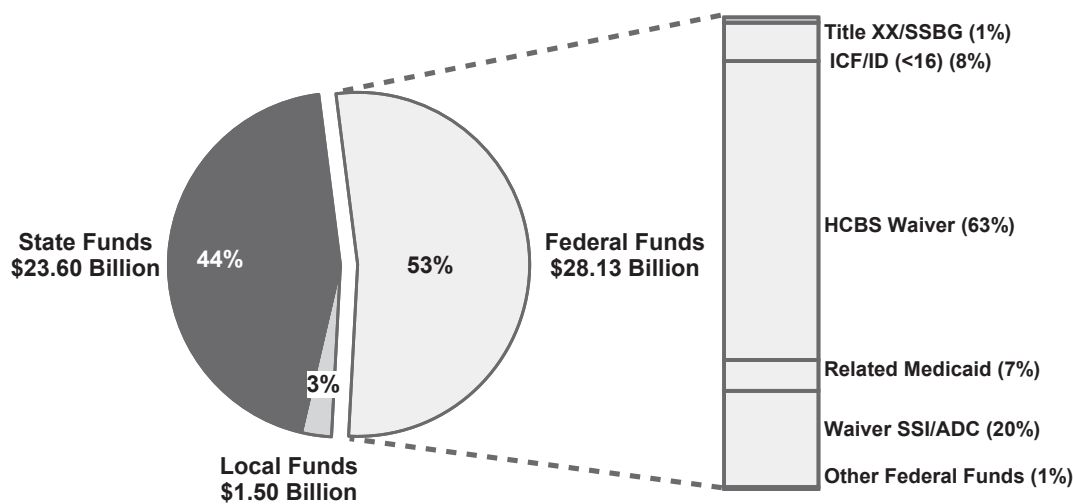
State	Total I/DD Spending	Medicaid Spending ¹	Medicaid Spending % of Total I/DD Spending	Rank ²
Alabama	\$365,940,032	\$315,281,117	86%	13
Alaska	\$201,532,918	\$165,649,615	82%	27
Arizona	\$841,563,743	\$683,924,779	81%	28
Arkansas	\$527,999,330	\$480,384,610	91%	3
California	\$6,390,317,836	\$3,922,346,520	61%	49
Colorado	\$531,162,109	\$401,319,431	76%	42
Connecticut	\$1,224,322,460	\$1,091,998,334	89%	6
Delaware	\$169,412,299	\$135,169,567	80%	31
Dist. of Columbia	\$282,030,691	\$239,388,017	85%	21
Florida	\$1,511,310,251	\$1,188,876,696	79%	36
Georgia	\$869,762,020	\$483,906,047	56%	50
Hawaii	\$161,577,571	\$111,360,630	69%	44
Idaho	\$207,799,707	\$181,358,477	87%	10
Illinois	\$1,617,099,416	\$1,280,033,937	79%	34
Indiana	\$1,334,739,878	\$1,208,973,882	91%	4
Iowa	\$882,275,768	\$764,053,989	87%	12
Kansas	\$490,174,045	\$413,779,795	84%	23
Kentucky	\$749,108,402	\$600,466,304	80%	30
Louisiana	\$1,433,045,715	\$1,272,664,595	89%	8
Maine	\$448,139,612	\$403,045,547	90%	5
Maryland	\$1,025,189,427	\$776,173,938	76%	41
Massachusetts	\$2,097,231,847	\$1,159,831,378	55%	51
Michigan	\$1,486,804,014	\$1,127,318,731	76%	39
Minnesota	\$1,717,424,059	\$1,503,313,912	88%	9
Mississippi	\$474,208,880	\$422,076,426	89%	7
Missouri	\$1,019,972,411	\$807,974,180	79%	33
Montana	\$169,771,070	\$109,988,486	65%	48
Nebraska	\$370,871,573	\$317,624,541	86%	16
Nevada	\$163,366,688	\$109,605,532	67%	46
New Hampshire	\$280,842,881	\$237,990,020	85%	22
New Jersey	\$1,999,346,983	\$1,459,259,973	73%	43
New Mexico	\$361,742,908	\$310,560,563	86%	15
New York	\$10,612,950,881	\$9,074,042,341	85%	18
North Carolina	\$1,496,279,728	\$1,186,712,260	79%	32
North Dakota	\$273,546,233	\$230,567,393	84%	24
Ohio	\$3,301,037,315	\$2,174,186,819	66%	47
Oklahoma	\$517,425,196	\$428,327,620	83%	26
Oregon	\$801,627,121	\$665,403,946	83%	25
Pennsylvania	\$3,596,533,856	\$2,467,739,374	69%	45
Rhode Island	\$257,610,278	\$223,642,915	87%	11
South Carolina	\$600,724,815	\$471,765,233	79%	38
South Dakota	\$171,431,472	\$134,781,469	79%	37
Tennessee	\$929,290,910	\$845,704,612	91%	2
Texas	\$2,672,609,039	\$2,301,721,929	86%	14
Utah	\$279,743,642	\$238,564,394	85%	20
Vermont	\$178,644,406	\$152,841,502	86%	17
Virginia	\$1,307,898,466	\$1,031,137,108	79%	35
Washington	\$1,053,779,340	\$852,899,656	81%	29
West Virginia	\$446,356,220	\$408,407,804	91%	1
Wisconsin	\$1,407,295,564	\$1,065,627,569	76%	40
Wyoming	\$147,847,342	\$126,311,183	85%	19
United States	\$61,458,718,366	\$47,766,084,694	78%	

¹ Federal, state and local government Medicaid spending.

² States' ranked from 1 (highest) to 51 (lowest), on Medicaid percentage of total spending.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

Figure 18
COMMUNITY SERVICES REVENUE SOURCES: FY 2013



Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

Budget Reconciliation Act of 1981 [Pub. L. 97–35] (Braddock, 1986; Braddock & Fujiura, 1987; Braddock & Hemp, 1996).

During 1982–2013, Social Services Block Grant spending for community IDD services in the U.S. declined by an average 2.3% per year in adjusted terms. In 2013, nationwide SSBG spending totaled \$309 million and 17 states allocated SSBG spending for persons with IDD services ranged from \$0.31 million in Vermont to \$219.4 million in California.

Local-county funds. Local government resources allocated for IDD services are derived primarily from counties. Modest levels of funds are also provided by municipalities and special districts. In 2013, 16 states reported local government spending (Table 16 on page 45). However, local IDD spending fell from \$1.62 billion in 2011 to \$1.53 billion in 2013. This was a reduction of 8% when adjusted for inflation. Although modest in scale, local funding is quite important as state matching funds.

Twenty-six percent of local-county government resources consisted of a portion of the required state matching funds for the Medicaid HCBS Waiver and ICF/ID programs. The remaining 74% of local

government funding supported county government operated IDD congregate care settings and small group homes, day programs, and other community services and supports.

Six states—Iowa, Minnesota, Ohio, Oregon, Texas and Washington State—utilized local government funds as a portion of their state Medicaid matching requirement. Iowa and Minnesota also used local funds as part of their federal Medicaid matching requirement for state-operated institutions, and North Carolina employed a local Medicaid match for private 16+ ICFs/ID. Iowa, Minnesota and North Carolina also provided county funding for private 16+ facilities.

Local resources as a share of states' total IDD spending in 2013 were notable IDD revenue components in five states: Ohio (33%), Missouri (8%), Virginia (7%), Colorado (6%) and Wisconsin (5%). Local governments in Nevada, Illinois, Minnesota, Texas, Washington State, Iowa,¹² North Carolina, Pennsylvania,

12. The negative \$675,891 in Iowa's Medicaid match in Table 16 represents a state government reimbursement to the counties in 2013.

TABLE 16
LOCAL GOVERNMENT I/DD SPENDING: FY 2013¹

STATE	TOTAL I/DD LOCAL GOVERNMENT SPENDING ²	LOCAL % of TOTAL I/DD SPENDING	LOCAL GOVERNMENT MEDICAID MATCH	ALL OTHER LOCAL GOVERNMENT I/DD SPENDING
Ohio	\$1,088,256,745	33.0%	\$315,718,960	\$772,537,785
Missouri	\$76,108,017	7.5%	\$0	\$76,108,017
Virginia	\$85,788,920	6.6%	\$0	\$85,788,920
Colorado	\$30,802,357	5.8%	\$0	\$30,802,357
Wisconsin	\$74,646,087	5.3%	\$74,646,087	\$0
Nevada	\$4,302,332	2.6%	\$0	\$4,302,332
Illinois	\$28,898,065	1.8%	\$0	\$28,898,065
Minnesota	\$29,206,051	1.7%	\$1,540,383	\$27,665,668
Texas	\$43,859,457	1.6%	\$7,554,784	\$36,304,673
Washington	\$11,499,153	1.1%	\$0	\$11,499,153
Iowa	\$9,544,813	1.1%	-\$675,891	\$10,220,704
North Carolina	\$12,744,499	0.9%	\$0	\$12,744,499
Pennsylvania	\$26,145,232	0.7%	\$0	\$26,145,232
Michigan	\$3,671,538	0.2%	\$0	\$3,671,538
Oregon	\$1,073,114	0.1%	\$1,073,114	\$0
Kentucky	\$200,041	0.03%	\$0	\$200,041
United States	\$1,526,746,421	2.5%	\$399,857,437	\$1,126,888,984

¹Local government includes counties, municipalities, townships, parishes, and special districts.

²Includes \$29.5 million in public and private congregate (16+ persons) local Medicaid match and other local spending.

Source : Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

Michigan, Oregon, and Kentucky contributed three percent or less of total IDD revenues in their states.

In 2013, 71% of total local/county IDD spending in the U.S. was attributable to a single state: Ohio. Ohio also led all states in the proportion of community services funded by local/county sources (39%); Missouri and Virginia (8%); Colorado and Wisconsin (6%); Nevada (3%) and Illinois, Minnesota and Texas (2%) followed Ohio's lead. Washington State, Iowa, North Carolina, Pennsylvania, Michigan, Oregon and Kentucky each funded less than 1% of community IDD services with local government funds.

Individual and Family Supports

Individual and Family Support (IFS) is a classification category that consists of supported living and personal assistance, supported employment, and family

support. Total individual and family support spending was \$12.9 billion in 2013. This constituted 21% of the \$61.46 billion in total IDD spending across the U.S. Individual and family support spending grew slowly (1.8% per year during 2011–13) compared to 2.0% per year during 2009–11, and 6.5% per year during 2006–09. During 2001–06, individual and family support spending grew 9% per year, adjusted for inflation.

In 2013, sixty-one percent of nationwide funding for individual and family support was allocated for supported living and personal assistance, 32% financed family support services, and 7% funded supported employment.

Self-advocacy, individual support, and family support. Self-Advocates Becoming Empowered (SABE), the national self-advocacy organization, estimates there are over 1,200 local self-advocacy chapters across the nation, with an estimated 2,200 members. In 2002, (Hayden & Nelis, 2002) estimated that state

level self-advocacy groups existed in 31 states, and an additional 9 states had state coordinators. The Autistic Self Advocacy Network and National Youth Leadership Network are two equally important self-advocacy organizations that support, among others, people with IDD. These self-advocacy organizations play a vital role in ensuring policies and practices embrace principles of self-determination, inclusion, and equal access. They also provide opportunities for people with IDD to develop self-advocacy and leadership skills to share their expertise with other individuals, organizations, and government agencies (The Arc, 2014).

During 2011 and 2012, the Administration on Intellectual and Developmental Disabilities (AIDD) sponsored a series of nine regional summits across the U.S. to better understand the self-advocacy movement. Teams were established in each state and charged with developing an overview of self-advocacy in their state-territory, developing team goals to promote self-advocacy, and presenting recommendations to AIDD on ways the AIDD and other federal agencies can further the self-advocacy movement. To view individual state-territory plans and federal recommendations for augmenting self-advocacy, see <http://alliesinselfadvocacy.org/>.

A research team from the Illinois University Center for Excellence in Developmental Disabilities (UCEDD) developed a report of findings from the summits. One area examined was the resources needed to support self-advocacy. While states varied in their commitment and support, there was universal consensus that very minimal financial resources are currently being provided to support self-advocacy organizations. Very few states have secured sufficient funding to hire full time executive directors to lead the organizations (Caldwell, Arnold, & Rizzolo, 2012).

One third of the states reported receiving some form of support, either direct funding or in-kind support, from their state IDD agency. Five states indicated that they received support through subcontracts on AIDD grants, and eight states reported funding from Centers for Independent Living in their area. The majority of states reported receiving support from their Developmental Disabilities Councils. It is a requirement in the *Developmental Disabilities Act* for councils “to support the establishment and strengthening of at least one statewide self-advocacy organization for individuals with IDD in each State and Territory.” UCEDDs and Protection and Advocacy organizations (P&As) also contributed in many states, often through indirect or

in-kind support such as meeting space, supplies, travel reimbursement, assistance with grant writing, and advising (Caldwell et al., 2012). The University of Illinois at Chicago UCEDD was instrumental in launching Illinois’ first self-advocacy chapter in 1998.

AIDD followed up its regional summits in 2013 by funding the establishment of three regional centers for self-advocacy technical assistance. The three projects are *Our Community Standing Strong* administered by SABE, *North East Advocates Together (NEAT)* administered by Vermont Protection and Advocacy Inc., and *The Pacific Alliance on Disability Self Advocacy* administered by the Autistic Self Advocacy Network.

In addition to the positive impact that self-advocacy has had on the growth of family support, supported living, and supported employment across the states, the HCBS Waiver has substantially underwritten the nation’s expansion of small community residences and for individual and family supports in the states. For example, federal-state Waiver funding constituted 86% of supported living and personal assistance spending for the 48 states and DC that provided such services in 2013. In fact, all states but Delaware reported using the Waiver for supported living and/or personal assistance.

The HCBS Waiver also provided 69% of all supported employment spending in the 49 participating states and DC. (Kansas reported no Waiver funding for supported employment.) Twelve states (Alabama, Arizona, Hawaii, Illinois, New Hampshire, New Jersey, Oregon, Pennsylvania, Tennessee, Utah, West Virginia, and Wyoming) relied solely on the Waiver to finance their supported employment initiatives.

Waiver spending constituted 82% of total spending for family support in the 48 participating states and DC that provided family support services. Idaho terminated family support spending in 2011 and Virginia did so in 2012. Virginia, however, began funding a cash subsidy for families in 2013. Of the 50 states providing family support services in 2013, 40 states and DC financed these services with the Waiver. Nine states (Alabama, Arkansas, Colorado, Delaware, Maine, Nevada, North Carolina, Tennessee, and Virginia) used other funding to finance family support services, principally state or county funds.

Supported living and personal assistance. Supported living was defined in this study to include housing in which individuals choose where and with whom they live; ownership is by someone other than the support provider (such as the individual, family, landlord or a housing cooperative); and the individual has a

personalized support plan (PSP) that changes as her or his needs and abilities change.

Personal assistance services, a subset of the broader category of supported living, was defined in the present study to include support provided to people living in their own home or in the family home. Funding for personal assistance services typically derives from Medicaid state plan “personal care assistance” or from HCBS Waiver personal care services.

As previously noted, growth in supported living values reflect the growing strength of the self-advocacy movement by people with developmental disabilities (Caldwell et al., 2012; Dybwad & Bersani, 1996; Hayden & Senese, 1996; Yuskas, 2005). Increasingly, self-advocates are articulating where they want to live and what kind of support they prefer (e.g., Durban-Westby, Neeman, & Topper, 2010; Nelis & Ward, 1995).

Supported living services were initiated in Colorado, Florida, Missouri, North Dakota, Ohio, Oregon, and Wisconsin in the mid-1980s (Smith, 1990). Subsequently, these supports expanded to all 50 states and DC (Table 17 on page 48) and grew internationally as well, including in Canada (Stainton et al., 2007) and England (Fryson, Tarleton, & Ward, 2007). At least 20 states operate Medicaid *Support Waivers*, which have smaller authorized caps per beneficiary than HCBS Waivers and flexibility in support is offered. They also encourage significant unpaid support from family caregivers and friends.

Smith, et al., (2007) identified 17 states that were operating Support Waivers: Alabama, Colorado, Connecticut, Florida, Indiana, Louisiana, Missouri, Montana, Nebraska, Ohio, Oklahoma, Oregon, Pennsylvania, South Dakota, Tennessee, Texas, and Washington. In an analysis of 2010 data for 88 HCBS Waivers, Rizzolo et al. (2013) identified six additional states operating *Support Waivers*: Georgia, Illinois, Massachusetts, North Carolina, South Carolina, and Virginia.

Supported living has been the fastest growing residential services option for persons with IDD in the U.S. since 1993 (Braddock et al., 2005, 2008, 2011, 2013). There were 293,956 participants with IDD receiving supported living or personal assistance services in 2013, constituting 46% of total out-of-home residential placements.

In 2013, all 50 states and DC reported that they provided supported living, personal assistance, or both services. Table 17 (p. 48) provides state-by-state data regarding the number of supported living and personal assistance participants and associated spending. The

table also provides data on combined supported living/personal assistance participants, utilization rates (participants per 100,000 of the general population in the state), combined total spending, and spending per capita of the general population.

Thirty-five states and DC increased supported living/personal assistance spending in adjusted terms during 2011–13; 15 states did not increase spending. Annual spending per participant varied greatly across the states—from \$4,982 in South Dakota to \$94,899 in Oklahoma (Table 9 on page 24). The national average was \$26,708 per person.

During 2011–13 inflation-adjusted supported living and personal assistance spending grew 55% in Delaware, an advance from \$420 to \$651 thousand. Adjusted spending increased in an additional 34 states and DC. Examples include: West Virginia (45%), Hawaii (42%), Pennsylvania (40%), Nebraska (36%), Alaska (35%), DC and Maine (32%), Missouri (31%), Illinois (29%), Vermont (27%), Oregon (21%), North Dakota (20%), Maryland and Virginia (17%), and Iowa and Georgia (15%).

Adjusted spending for supported living increased from 14% to 0.1% in the following states: Wyoming, Michigan, Connecticut, Arkansas, Minnesota, Tennessee, California, Wisconsin, North Carolina, Kansas, Ohio, Nevada, South Dakota, Washington, Alabama, New Mexico, South Carolina, Texas, New York, and Florida. However, seven states reported adjusted supported living spending reductions of 67% to 10%. The states were: Rhode Island (67%); Massachusetts (55%); Colorado and New Jersey (13%); Arizona and Idaho (11%); and Montana (10%). An additional seven states reducing spending from 8% to 0.4% included Indiana, Louisiana, Oklahoma, Kentucky, Utah, Mississippi, and New Hampshire.

Inflation-adjusted growth in supported living spending nationwide has dropped in recent years. Spending grew only 3% per year during 2011–13. This was below the growth rate of 4% per year during 2009–11 and well below the average annual growth rates of 10% during 2006–09 and 11% during 2004–06.

Supported employment. For purposes of our data collection effort in the states, we defined *supported employment* to include small business enterprise, work crews, enclaves within industry, and individualized job placements (Inge, Revell, & Brooke, 2014; Mank, Rhodes, & Bellamy, 1986; Wehman, Inge, Revell, & Brooke, 2007). Supported employment was further defined in our study to include IDD state agency-financed

TABLE 17
SUPPORTED LIVING/PERSONAL ASSISTANCE PROGRAMS IN THE STATES:
I/DD PARTICIPANTS AND SPENDING IN FY 2013

State	Supported Living		Personal Assistance		Total SL/PA Participants	State Population	Utilization Rate ¹	Total SL/PA Spending ²	Spending Per Capita ³
	Participants	Spending	Participants	Spending					
Alabama	72	\$1,024,600	605	\$9,482,314	677	4,829,674	14	\$10,506,914	\$2.18
Alaska	666	\$30,149,064	166	\$8,246,025	832	732,720	114	\$38,395,089	\$52.40
Arizona	462	\$24,151,045	0	\$0	462	6,588,887	7	\$24,151,045	\$3.67
Arkansas	4,056	\$173,680,927	0	\$0	4,056	2,954,601	137	\$173,680,927	\$58.78
California	23,547	\$578,976,770	0	\$0	23,547	38,166,200	62	\$578,976,770	\$15.17
Colorado	4,126	\$51,228,467	0	\$0	4,126	5,228,913	79	\$51,228,467	\$9.80
Connecticut	769	\$74,596,225	1,935	\$31,532,007	2,704	3,593,923	75	\$106,128,232	\$29.53
Delaware	18	\$651,409	0	\$0	18	921,401	2	\$651,409	\$0.71
District of Columbia	410	\$14,625,739	36	\$851,249	446	643,194	69	\$15,476,987	\$24.06
Florida	4,099	\$26,961,131	4,700	\$71,011,911	8,799	19,436,805	45	\$97,973,042	\$5.04
Georgia	8,735	\$104,297,639	0	\$0	8,735	9,953,907	88	\$104,297,639	\$10.48
Hawaii	123	\$9,439,988	1,451	\$30,552,062	1,574	1,397,072	113	\$39,992,050	\$28.63
Idaho	1,613	\$30,983,375	0	\$0	1,613	1,603,863	101	\$30,983,375	\$19.32
Illinois	9,197	\$124,835,290	0	\$0	9,197	12,875,164	71	\$124,835,290	\$9.70
Indiana	7,514	\$370,662,463	0	\$0	7,514	6,554,342	115	\$370,662,463	\$56.55
Iowa	4,621	\$249,689,871	583	\$6,125,312	5,204	3,082,728	169	\$255,815,183	\$82.98
Kansas	0	\$0	253	\$2,095,807	253	2,889,678	9	\$2,095,807	\$0.73
Kentucky	3,136	\$57,102,226	30	\$1,999,981	3,166	4,387,513	72	\$59,102,207	\$13.47
Louisiana	2,420	\$179,440,698	32	\$104,169	2,452	4,613,802	53	\$179,544,867	\$38.91
Maine	538	\$24,854,623	355	\$14,899,650	893	1,328,402	67	\$39,754,273	\$29.93
Maryland	2,182	\$113,047,350	0	\$0	2,182	5,906,841	37	\$113,047,350	\$19.14
Massachusetts	2,683	\$36,038,559	0	\$0	2,683	6,669,064	40	\$36,038,559	\$5.40
Michigan	5,782	\$172,345,961	18,214	\$218,078,648	23,996	9,892,346	243	\$390,424,609	\$39.47
Minnesota	3,046	\$35,392,743	2,185	\$50,136,175	5,231	5,400,013	97	\$85,528,918	\$15.84
Mississippi	0	\$0	1,226	\$15,143,106	1,226	2,988,829	41	\$15,143,106	\$5.07
Missouri	4,356	\$340,150,214	3,207	\$38,716,852	7,563	6,034,347	125	\$378,867,066	\$62.79
Montana	1,023	\$14,970,561	0	\$0	1,023	1,010,330	101	\$14,970,561	\$14.82
Nebraska	848	\$22,724,119	196	\$5,102,135	1,044	1,861,933	56	\$27,826,253	\$14.94
Nevada	1,794	\$76,659,605	102	\$5,806,339	1,896	2,772,245	68	\$82,465,944	\$29.75
New Hampshire	485	\$3,713,590	0	\$0	485	1,322,538	37	\$3,713,590	\$2.81
New Jersey	2,153	\$67,884,478	0	\$5,019,803	2,153	8,883,544	24	\$72,904,281	\$8.21
New Mexico	3,043	\$178,277,209	411	\$8,174,646	3,454	2,084,414	166	\$186,451,855	\$89.45
New York	21,776	\$206,677,063	5,179	\$185,243,908	26,955	19,594,876	138	\$391,920,971	\$20.00
North Carolina	6,402	\$256,852,012	7,250	\$81,075,586	13,653	9,798,212	139	\$337,927,599	\$34.49
North Dakota	999	\$59,337,507	31	\$778,173	1,030	712,369	145	\$60,115,680	\$84.39
Ohio	3,826	\$85,278,997	24,356	\$840,761,601	28,182	11,561,920	244	\$926,040,597	\$80.09
Oklahoma	1,661	\$157,627,072	0	\$0	1,661	3,833,174	43	\$157,627,072	\$41.12
Oregon	1,023	\$45,651,018	7,285	\$138,432,278	8,308	3,914,933	212	\$184,083,296	\$47.02
Pennsylvania	9,758	\$103,580,013	0	\$0	9,758	12,769,138	76	\$103,580,013	\$8.11
Rhode Island	491	\$11,041,494	0	\$0	491	1,050,908	47	\$11,041,494	\$10.51
South Carolina	694	\$12,869,646	732	\$12,095,807	1,426	4,749,128	30	\$24,965,453	\$5.26
South Dakota	716	\$3,566,915	0	\$0	716	839,462	85	\$3,566,915	\$4.25
Tennessee	3,974	\$366,942,728	2,622	\$46,998,295	6,596	6,475,446	102	\$413,941,023	\$63.92
Texas	21,463	\$477,602,069	2,455	\$68,198,069	23,918	26,319,061	91	\$545,800,137	\$20.74
Utah	431	\$6,175,392	169	\$1,185,694	600	2,877,872	21	\$7,361,086	\$2.56
Vermont	283	\$3,540,605	0	\$0	283	626,292	45	\$3,540,605	\$5.65
Virginia	1,746	\$46,822,209	1,367	\$63,667,482	3,113	8,223,517	38	\$110,489,691	\$13.44
Washington	4,129	\$340,031,628	8,204	\$207,504,521	12,333	6,933,362	178	\$547,536,149	\$78.97
West Virginia	4,534	\$179,315,246	0	\$0	4,534	1,855,492	244	\$179,315,246	\$96.64
Wisconsin	7,001	\$81,298,426	2,922	\$31,788,851	9,923	5,733,634	173	\$113,087,277	\$19.72
Wyoming	532	\$6,195,333	740	\$11,186,678	1,272	579,642	219	\$17,382,011	\$29.99
United States	194,957	\$5,638,961,311	98,999	\$2,211,995,133	293,956	315,057,657	93	\$7,850,956,443	\$24.92

¹ Participants in supported living and personal assistance per 100,000 citizens of the general population in the state.

² Supported Living/Personal Assistance cost per participant is presented in **Table 9, Annual Cost of Care Per Person**.

³ Spending for supported living and personal assistance per citizen of the general population in the state.

Source : Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

programs for long-term employment support with the goal of developing independent work skills leading to competitive wages for individuals with IDD.

Supported employment is an evidenced-based practice originally designed as an employment option for traditionally marginalized individuals, including those who would not otherwise be considered employable.

Through the provision of intense initial supports, and subsequently follow-along supports, people with IDD become more able to bridge the gap between their skills and the requirements of their job to maintain competitive integrated employment (Wehman, et al., 2007).

Funding for supported employment is provided through state IDD agencies, state vocational

rehabilitation services, special education, and HCBS Waivers (Hall, Freeze, Butterworth, & Hoff, 2011). Due to the wide array of funding mechanisms and programs available for employment supports and services and the specifications under which they can each be utilized, most *employment specialist professionals* (ESP) are now using *braided funding* strategies. These strategies are used to develop service plans to assist in the acquisition and retention of jobs for people with disabilities (Nicholas, Kauder, & Krepicio, 2011). The use of braided funding strategies increases the complexity of obtaining accurate data for supported employment expenditures.

Follow along work support for the 19 states that reported it is distinguished from supported employment in terms of the intensity of supports and the level of support funding. The primary purpose of follow-along work support is assisting with job retention and career advancement.

According to the *Current Population Survey* on labor force participation (October 2014), 20.0% of persons with a disability were in the labor force in contrast to 68.8% of persons without a disability (United States Census Bureau, 2014). The current unemployment rate for people identified as having a disability is 11.3%. This has been consistently higher than the 5.3% unemployment rate for people without a disability. The challenges of employment for people with disabilities before, during, and following the Great Recession were quite difficult and remain so (Fogg, Harrington, & McMahon, 2010).

Employment services were identified as a priority for individuals with IDD in the 1984 *Developmental Disabilities Act* Amendments (Rusch & Hughes, 1990). During 1983–89, national leadership from Madeleine Will, then Assistant Secretary of the Office of Special Education and Rehabilitation Services, promoted supported employment and school-to-work transition (Johnson, 2004; Test, 2004). State IDD agencies began providing long-term support for workers with IDD, supplementing the employment options available through states' vocational rehabilitation (VR) agencies.

Such advances in employment services in the states coupled with the enactment of the *Americans with Disabilities Act of 1990* (Pub. L. 101–336), and a growing body of research and demonstration activities, contributed to the growth of supported employment during the 1980s and 1990s (Blanck, 1998; National Council on Disability, 2007). Several longitudinal studies of people moving from sheltered to supported employment underscored the benefits for consumers and taxpayers

(Gilmore, Schuster, & Butterworth, 2001; Kregel, Wehman, & Banks, 1989; Thompson, Powers, & Houchard, 1992; Wehman, Inge, Revell, & Brooke, 2007).

However, even with empirically validated outcomes and strong advocacy in promoting supported employment, the participation of hundreds of thousands of people with IDD in sheltered workshops and non-work services continues (Butterworth, Hall, Smith, Migliore, Winsor, Domin, & Sulewski, 2013).

In April 2014, the U.S. Department of Justice entered into a statewide settlement in Rhode Island to address the ADA violations of placing approximately 3,250 people with IDD in segregated and sheltered work programs. The 10 year Agreement with the Department of Justice will allow over 2,000 people with IDD the opportunity to work in competitive employment and provide 1,250 students transition planning to enter into the workforce (Providence Journal, 2014).

In addition, people with cognitive disabilities continue to be denied vocational and rehabilitation services because their disabilities are inappropriately considered “too severe.” From 2011 to 2012 1.5% of vocational rehabilitation applicants were considered “too disabled” for services, and 91.5% percent of this group had either a cognitive or physical disability (Cimera, Burgess, Novak & Avellone, in press).

In July of 2014, *The Workforce Innovation and Opportunity Act* (WIOA) (Pub. L.113–128) was signed into law. Replacing the *Workforce Investment Act* of 1998, and amending the *Rehabilitation Act* of 1973, WIOA acknowledges the underrepresentation of people with disabilities in the workforce and reaffirms the nation's commitment to increasing employment opportunities. Changes to the *Rehabilitation Act* programs includes: increased services to youth with disabilities, increased emphasis on employer engagement, increased efforts and training of state vocational rehabilitation programs and services, and greater federal accountability (Office of Special Education and Rehabilitation Services, 2014). Along with WIOA, President Obama introduced the “Ready to Work: Job-Driven Training American Opportunity,” a federal effort to ensure more Americans are prepared to work through the attainment of marketable skills. Together, these initiatives should open-doors for all people with disabilities including people with IDD. The Centers for Medicare and Medicaid Services (CMS) Bulletin (2014) recently provided clarification of existing CMS guidance on development and implementation of §1915 (c) Waivers regarding employment and employment related services.

The Bulletin did not propose new policy, but rather highlighted opportunities available to use waiver supports to increase employment opportunities for individuals with disabilities within current policy. The Bulletin underscored CMS's commitment to the importance of work for waiver participants by providing CMS guidance on several core service definitions and promising practices.

The *Ticket to Work and Work Incentives Improvement Act* is one such program that enables workers with disabilities to have higher earnings and maintain their Medicaid Coverage through Medicaid Buy-In. Forty-six states currently have a Buy-In program and in 2011 over 400,000 people participated in the Medicaid Buy-In program. Research has demonstrated that through the Medicaid Buy-In, participants improved quality of life and lowered Medicaid costs (Shea, 2014).

Even with the support of the Medicaid Buy-in Program, people with disabilities face additional financial and societal barriers that prevent them from economic self-sufficiency. Out-of-pocket expenses for daily living make having a disability a financial burden. Additional medical expenses (e.g. uncovered medical supplies and equipment, uncovered medical treatments, and increased number of co-payments), housing requirements, necessary supports and services, and transportation add to their cost of living (Senate Committee on Health, Education, Labor & Pensions, 2014).

Despite a national emphasis on increasing employment rates and equality, people with disabilities continue to earn approximately \$10,500 less than their non-disabled counterparts, causing more people with disabilities to be unable to cover monthly expenses or to accrue assets and savings. Fifty-three percent of respondents with disabilities indicated they could not come up with \$2,000 in the case of an unexpected expense in the next month compared to 23% of other respondents (FINRA Investor Education Foundation, 2014).

On October 31, 2014 the National Council on Disability (NCD) released their latest report *National Disability Policy: A Progress Report*. In the report they identify three areas for advancement that would facilitate greater opportunities for meaningful employment: transportation, customized employment and assistive technology. Final recommendations of the NCD include guidance, collaboration, and universal design standards for the U.S. Department of Transportation to aid in utilization of public transit by people with disabilities; guidance for employers around flexible work arrangements and natural support provided by the U.S.

Department of Labor; and reducing cost and increasing availability of accessible technology for people with disabilities along with incentives to industry to provide affordable technologies for use by people with disabilities (National Council on Disability, 2014).

Employment First and employment studies. Cimera (2010a) analyzed Rehabilitative Services Administration data for the 231,204 clients for whom supported employment was the vocational goal. Wages earned, rates of employment, and number of hours worked were also examined for people with intellectual and developmental disabilities. For the 104,213 individuals with IDD who had supported employment as a goal, 64,692 were successfully employed and generated an average monthly net benefit of \$475.35 and a benefit-cost ratio of 4.20. Cost-efficiency of supported employment was manifest across all states and U.S. territories, with benefit-cost ratios ranging from 13.54 in Washington State to 1.86 in Wisconsin.

In another study, Cimera (2010b) also identified longitudinal trends in supported employment literature and cost-accounting studies. He concluded that, over time, supported employment has become more financially beneficial to people with disabilities as opposed to relying on government subsidies for financial support.

Cimera also recently completed a cost-benefit analysis of 227 supported employees to determine the best method for providing follow-along individual-provided support or agency-provided support services as gauged by the lowest cost to taxpayers and favorable vocational outcomes (Cimera, 2012). He found that in 90% of cases, individual-provided support for employees was more cost-effective, costing taxpayers over \$200 less on average per person per month. He also found that individually supported employees were almost twice as likely to obtain community-based jobs; whereas, those in agency-provided supported employment programs were more likely to be employed in segregated, facility-based settings. Thus, according to his preliminary research, one method for reducing taxpayers' costs and improving supported employment outcomes is to provide follow-along services from community agency resources, as opposed to the State.

Although cost-benefit analyses provide a strong argument for the employment of people with disabilities, it may not be the deciding factor for employers. According to the Office of Disability Employment Policy (ODEP) "exposure to people from diverse backgrounds has had a greater influence on the decline in

discrimination by employers than the economic argument” (p. 3). Emergent research from ODEP’s *Business Case for Hiring People with Disabilities* suggests that the decision to hire people with disabilities is influenced by culturally embedded stereotypes. To help combat such attitudinal barriers, ODEP introduced *The Employer Engagement Strategy* to rebrand the image of employees with disabilities through marketing and psychological approaches (Social Dynamics, 2014).

Employment First is a grassroots movement that supports:

. . . employment in the general workforce as the first and preferred outcome in the provision of publicly funded services for all working age citizens with disabilities, regardless of level of disability (Association of People Supporting Employment First, 2010, p. 1)

Employment First has manifested differently across states based on constituents, funding streams, and legislation. However, these initiatives preserve the common goal of community-based inclusive employment for all people with disabilities (Flippo & Garder, 2011; Niemiec, Lavin & Owens, 2009). Forty-seven states and Canada have an Employment First effort. Twelve states have passed *Employment First* legislation (Alaska, California, Delaware, Illinois, Kansas, Maine, Ohio, Oregon, Texas, Utah, Washington, and Wyoming) while 18 states (Arkansas, Colorado, Connecticut, District of Columbia, Florida, Louisiana, Maryland, Massachusetts, Minnesota, Mississippi, Missouri, New Jersey, Oklahoma, Pennsylvania, Rhode Island, South Carolina, Tennessee, and Virginia) have some official policy or Executive Order (State Employment Leadership Network, 2013).

An *Employment First* initiative has been embraced by the National Association of Councils on Developmental Disabilities (NACDD) and the National Association of State Directors of Developmental Disabilities Services (NASD-DDS). The NASDDDS has also developed an exceptional partnership with the University of Massachusetts’ Institute for Community Inclusion to improve integrated employment outcomes through a membership-based network of state IDD agencies. The purpose of the network is to share successful policies and practices across the states. To date, 28 states are members of the *State Employment Leadership Network* (State Employment Leadership Network, 2014). With raised expectations of Employment First, policies and new funding streams, some states today are supporting

more inclusive and competitive employment for their citizens with disabilities.

Consistent with the Employment First movement, several federal agencies and national organizations have also highlighted employment for people with disabilities as a major agenda item. For example, in 2010, President Obama signed Executive Order 13548 to increase the number of individuals with disabilities in the federal workforce by 100,000 by 2015. Each federal agency was directed to develop an agency-specific plan for recruitment, hiring, and retention of employees with disabilities. In September 2012, the Office of Disability Employment Policy within the U.S. Department of Labor produced a summary of “Promising and Emerging Practices” outlined by the agency-plans of 10 federal agencies (United States Department of Labor, 2012).

This initiative likely contributed to the increase in supported employment participants and funding for the District of Columbia presented in this current State of the States study.

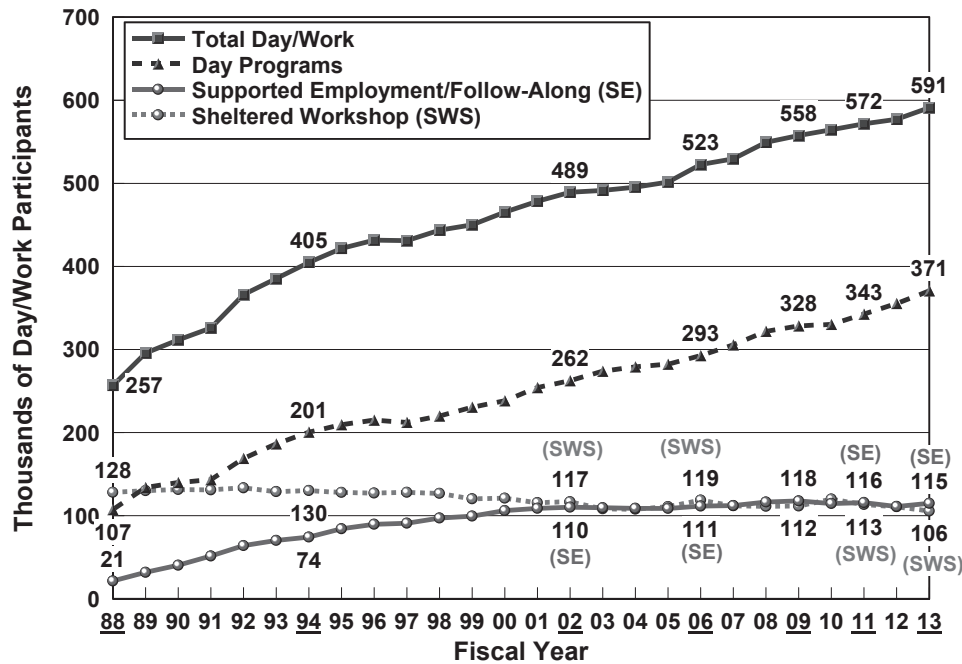
In honor of the 40th anniversary of IDEA and 25th of the ADA, Senator Harkin introduced the “Six by ’15 Campaign.” It included the goal of increasing the number of Americans with disabilities participating in the workforce to six million people by 2015 in the public and private sectors. To date the “Six by ’15” goals have been endorsed by over 140 disability organizations (Six-by-fifteen.org).

Proportion of workers in supported employment plateaus: 2002–13. Despite the obvious benefit of such federal and state integrated employment initiatives, most states continue to maintain their commitment to segregated sheltered work and day programs. The number of individuals in all day/work programs has grown from 256,656 individuals in 1988 to 590,832 individuals in 2013 (Figure 19 on page 52). Eighty-one percent of day/work recipients in 2013 received segregated services in day habilitation, clinic, rehabilitation or other segregated day programs.

There were 370,666 persons with IDD in non-work day programs (63%) and 105,531 persons in sheltered workshops and work activity centers (18%). Supported employment and workers receiving follow-along work supports totaled 114,635, constituting 19% of the total of 590,832. The number of supported employment and follow-along work support workers is greater than the number of sheltered workshop participants during 2007–13, with the exception of 2010.

From 2011 to 2013, sheltered workshop participants decreased by 7,952 but there were 24,132 additional

Figure 19
INDIVIDUALS WITH I/DD IN DAY PROGRAMS,
WORKSHOPS AND EMPLOYMENT: FY 1988-2013



Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

day program participants. Workers engaged in supported employment or receiving follow-along work supports decreased by 1,360 persons during the two-year period. With the slight decline in supported employment workers combined with substantial day program growth, the supported employment worker percentage of all day and work programs in 2013 (19.4%) increased slightly from 19.2% in 2012, but both 2012 and 2013 supported employment percentages were below the 20.2% employment rate in 2011. There has been a continuous 13-year decline from the peak of 22.8% in 2000 (Figure 20 on page 53).

In 2013, the percentage of workers in supported employment and follow-along work support ranged from 10% or less in Alabama, Illinois, Kentucky, Arkansas and Wisconsin to between 40% and 65% in Maryland, Vermont, New Hampshire, Connecticut, Louisiana, Oklahoma, and Washington.

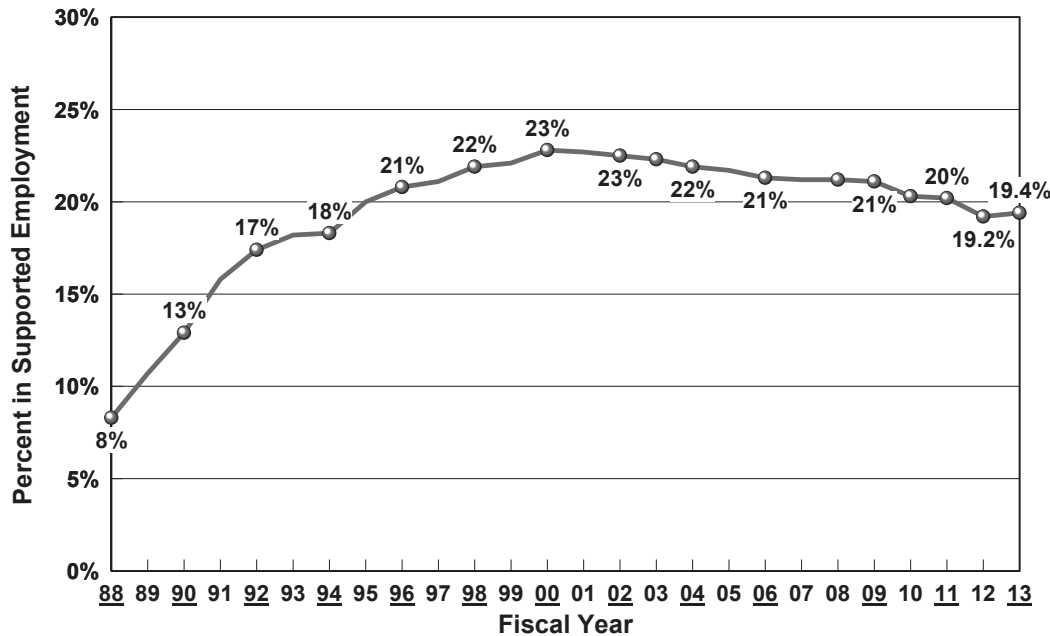
Supported employment spending by state IDD agencies, adjusted for inflation, peaked at \$0.91 billion in

2002, but then declined to \$0.84 billion in 2006 and was flat during 2007–2013. The figure for 2013 was \$0.86 billion. Supported employment spending increased by 0.6% in inflation-adjusted terms during 2011–13.

However, nine states posted spending increases of 25% or more: Missouri, Oregon, West Virginia, Washington State, Arizona, Colorado, Arkansas, Alaska, and South Dakota. Alternatively, 28 states and DC reduced supported employment spending during 2011–13. Reductions ranged from 0.2% in Oklahoma to over 50% in DC, Hawaii, and Delaware. In 2013, supported employment spending per capita of the general population ranged from \$0.10 in Texas¹³ to

13. Texas is the only state that reported state-operated facility supported employment workers in 2013. The 98 institutional workers with IDD in Texas in 2013 included 24 *supported employment*, 69 *enclave* and 5 *competitive employment* participants, ranging from 75 in 2005 to 92 in 2012. These participants are not included with Texas' supported employment workers in this publication.

Figure 20
PERCENTAGE OF TOTAL DAY/WORK RECIPIENTS WITH I/DD
IN SUPPORTED EMPLOYMENT: FY 1988-2013



Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

over \$10.00 in Alaska, Connecticut, Maryland, Oregon, and Vermont. The national average was \$2.76 (Table 18 on page 54).

For the first time since 1998 the State of Colorado provided data on supported employment spending for 2010 and 2011, and continued to report data in 2012 and 2013. Colorado's workers per capita and the percentage of total day work in supported employment were both above the national averages in 2013.

The percentage of supported employment funded by the HCBS Waiver in the U.S. has increased as more states have taken advantage of the provisions of the Balanced Budget Act of 1997 (P. L.105-33). The act expanded supported employment opportunities for HCBS Waiver participants. Prior to the enactment of this legislation, only those Waiver participants who had resided in nursing facilities or ICFs/ID were eligible for prevocational or supported employment services funded through the Waiver (West, Revell, Kregel, & Bricout, 1999).

The proportion that Medicaid reimbursement constituted of supported employment and day programs spending in the states is presented in Figure 21 on page 55.¹⁴ Waiver spending as share of total Medicaid funding for day and work programs more than doubled from 27% to 68% during 2002-2013. Despite this substantial expansion of Waiver funding for supported employment in the states, clinic and rehabilitative services still constitute a major share of federal Medicaid funding for all day and work programs (32% in 2013).

Clinic and rehabilitative services funding can be a disincentive for states to develop integrated work programs (Gilmore, Schuster, & Butterworth, 2001; Rusch & Braddock, 2004). Funding for these two programs

14. The total for 2013 in the figure, \$0.89 billion, which includes day program Medicaid spending, is coincidentally close to the total 2013 State IDD agency spending for supported employment noted above (\$0.86 billion).

TABLE 18
STATE I/DD AGENCY SUPPORTED EMPLOYMENT PROGRAMS IN THE
STATES: PARTICIPANTS AND SPENDING IN FY 2013

State	Participants ¹	Utilization Rate ²	Spending	Spending Per Capita ³	Supported Employment % ⁴
Alabama	222	5	\$2,557,191	\$0.53	5%
Alaska	540	74	\$7,833,820	\$10.69	22%
Arizona	2,080	32	\$17,244,175	\$2.62	19%
Arkansas	97	3	\$651,263	\$0.22	8%
California	9,927	26	\$87,713,652	\$2.30	12%
Colorado	2,038	39	\$10,227,289	\$1.96	33%
Connecticut	4,422	123	\$56,773,603	\$15.80	47%
Delaware	432	47	\$5,400,000	\$5.86	22%
District of Columbia	261	41	\$1,316,743	\$2.05	36%
Florida	2,019	10	\$6,246,357	\$0.32	15%
Georgia	2,407	24	\$10,202,717	\$1.02	23%
Hawaii	17	1	\$207,650	\$0.15	12%
Idaho	845	53	\$3,475,125	\$2.17	12%
Illinois	1,059	8	\$8,720,090	\$0.68	6%
Indiana	2,894	44	\$9,347,643	\$1.43	17%
Iowa	2,486	81	\$8,419,945	\$2.73	25%
Kansas	246	9	\$3,955,120	\$1.37	13%
Kentucky	942	21	\$3,497,041	\$0.80	8%
Louisiana	1,683	36	\$12,185,013	\$2.64	48%
Maine	994	75	\$3,915,616	\$2.95	23%
Maryland	4,765	81	\$80,419,975	\$13.61	40%
Massachusetts	2,312	35	\$34,969,180	\$5.24	14%
Michigan	4,015	41	\$26,818,518	\$2.71	31%
Minnesota	2,906	54	\$19,971,991	\$3.70	20%
Mississippi	476	16	\$2,509,818	\$0.84	23%
Missouri	688	11	\$6,816,562	\$1.13	26%
Montana	172	17	\$990,469	\$0.98	17%
Nebraska	1,430	77	\$10,309,682	\$5.54	45%
Nevada	458	17	\$3,614,543	\$1.30	21%
New Hampshire	346	26	\$5,100,300	\$3.86	45%
New Jersey	1,157	13	\$9,266,786	\$1.04	18%
New Mexico	1,106	53	\$9,804,561	\$4.70	32%
New York	8,896	45	\$45,657,142	\$2.33	12%
North Carolina	1,608	16	\$12,368,270	\$1.26	19%
North Dakota	299	42	\$2,781,762	\$3.90	16%
Ohio	7,039	61	\$95,373,875	\$8.25	23%
Oklahoma	2,525	66	\$25,212,400	\$6.58	67%
Oregon	1,149	29	\$51,868,233	\$13.25	15%
Pennsylvania	3,842	30	\$28,703,586	\$2.25	17%
Rhode Island	533	51	\$2,914,534	\$2.77	14%
South Carolina	1,479	31	\$8,218,206	\$1.73	25%
South Dakota	578	69	\$7,527,249	\$8.97	24%
Tennessee	1,202	19	\$11,163,540	\$1.72	25%
Texas	2,214	8	\$2,677,823	\$0.10	7%
Utah	608	21	\$4,561,824	\$1.59	22%
Vermont	1,088	174	\$10,989,831	\$17.55	44%
Virginia	1,357	17	\$25,639,959	\$3.12	31%
Washington	6,418	93	\$49,794,507	\$7.18	84%
West Virginia	462	25	\$2,503,735	\$1.35	25%
Wisconsin	1,624	28	\$8,622,601	\$1.50	10%
Wyoming	241	42	\$1,211,921	\$2.09	15%
United States	98,604	31	\$868,273,437	\$2.76	19%

¹ Table does not include 16,031 follow-along work support workers assisted by I/DD agencies in 19 states: AZ, CT, DC, GA, HI, IA, KS, LA, MI, MO, MT, NE, NH, NJ, NY, NC, OH, SC, and WA.

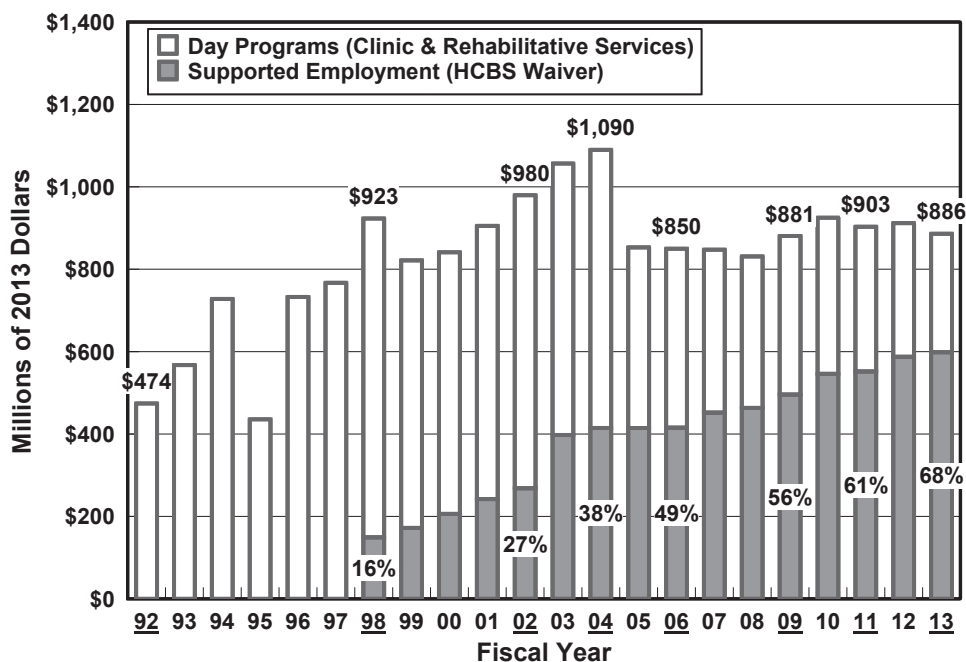
² Supported employment participants per 100,000 citizens of the general population of the state.

³ Spending per citizen of the general population.

⁴ Percentage in supported employment includes persons in follow-along work support (referenced in Note 1).

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

Figure 21
FEDERAL MEDICAID FUNDING FOR
DAY PROGRAMS AND SUPPORTED EMPLOYMENT FY 1992-2013



Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado (2015).

declined during 2005–08, but increased during 2009–10. Funding declined again in 2011–13.

The drop in Medicaid clinic and rehabilitative services spending for day habilitation programs during 2004–05 was primarily attributable to the reduction of optional Medicaid spending in Ohio (the state’s “community alternative funding source”) and Washington State in those years. The Medicaid clinic and rehabilitative services share of total Medicaid spending for day/work programs dropped from 44% in 2009 to 32% in 2013.

Family support services. Support for children and adults with IDD living in the family home, family support, varies greatly across the nation. In the present study, family support was defined as persons with IDD living in the family home receiving any community-based service administered or financed by the state IDD agency. States have great latitude in determining what services and supports will be included in their family support program, as well as in determining whether children, adults, or both children and adults, will be eligible to receive the supports.

States also vary in how they define family (Hewitt, Agosta, Heller, Williams, & Reinke, 2013; Turnbull, Stowe, Agosta, Turnbull, Schrandt, & Muller, 2007). Family members with IDD can receive instrumental support from siblings, aunts and uncles, grandparents and others in addition to parents. However, these other familial supports are not often recognized under state or federal policy. For example, siblings are not explicitly covered under the Family and Medical Leave Act (FMLA) as providers of essential supports to their brothers and sisters with disabilities (Johnson, 2014).

Regardless of the variation in state definitions, the goals of family support are largely agreed upon by advocates, family members, policymakers, and researchers. A principal goal is keeping the family intact and building upon the family’s existing strengths and resources so that the individual with a disability can continue to live in the family home. According to Swenson and Lakin (2014), “Caregiving by family members of individuals with disabilities is the single most important element to the sustainability of the system of long-term services and supports in the United

States” (p. 186). Another important goal is helping to assure that the individual with a disability supported in the family home has the best possible transition to adulthood (“Synthesis of discussion group perspectives,” 2006).

Services and supports that states offer to families with children or adults with IDD include respite services, financial services such as cash subsidies and vouchers, in-home supports such as personal assistance or homemaker services, assistive technology and environmental modification, adaptive medical equipment, health and professional services, therapies, family counseling, family training, parent support groups, transportation, recreation activities, and specialized clothing and dietary services. Even though family caregivers are the largest source of Long-Term Services and Supports (LTSS) for individuals with IDD, significant family support did not emerge as a priority for IDD state agencies until the early 1980s (Fujiura, Garza, & Braddock, 1990; Turnbull & Turnbull, 2000).

In 1986, the first year family support data was collected by our study, spending in the U.S. totaled \$77 million. That was only 0.8% of the \$9.7 billion in total IDD spending that year. By 2013, \$4.1 billion (7%) of the \$61.5 billion spent for IDD long-term services and supports was allocated for family support.

Supporting family members with disabilities at home. In the late 1980s, a new means of providing support to families emerged in the form of financial subsidies. Spending for cash subsidies peaked at \$97 million in 2008. In 2013, 17 states provided cash subsidies to families, down from 18 states in 2011, 22 states in 2009 and 24 states reporting cash subsidies in 2006.

A growing number of consumer-directed services are utilizing “individualized budgets.” Individuals with disabilities at times are also allowed to hire family members to provide support (Caldwell, 2007). The hiring of family members has been shown to be associated with increased community involvement for children and adults with developmental disabilities (Caldwell & Heller, 2007).

Increased family control over respite and personal care services can result in positive outcomes for families including reduced stress and reduced financial worries (Herman, 1991); increased self-efficacy (perceived ability to provide care) (Heller, Miller, & Hsieh, 1999; Zimmerman, 1984); increased satisfaction with services (Caldwell & Heller, 2007); decreased need for out-of-home placement (Heller et al., 1999); and fewer placements into nursing homes and institutions

(Caldwell, 2007; Caldwell & Heller, 2007). Increased maternal employment is another potentially important outcome as well (Caldwell & Heller, 2007).

Heller and Factor (2008) also contend that much of the family support research has been unidirectional, strictly focusing on the benefits to family caregivers. They note that in many instances, the family member with IDD is also providing support, to elderly parents with increasing needs as they age.

Literature from the aging field stresses the importance of assessing and addressing caregiver’s needs that may hinder their ability to provide care. Effectively assessing caregiver needs can postpone out of home placement and result in better outcomes for the person with a disability (Feinberg & Houser, 2012). Research with siblings of persons with IDD has shown a need for support groups as well as training on issues such as caregiving responsibilities and financial planning (Arnold, Heller & Kramer, 2012; Heller & Kramer, 2009).

Across the nation, however, very little public resources are being allocated for training, education, and counseling for family caregivers of persons with IDD (Rizzolo et al., 2013). Although studies have demonstrated the potential cost effectiveness of family support programs in the states, savings are in fact due to a shifting of costs from taxpayers to unpaid family caregivers (Lewis & Johnson, 2005). In 2009, family caregivers for disabled and elderly persons in the U.S. contributed an estimated \$450 billion in unpaid care (Feinberg, Reinhard, Houser, & Choula, 2011).

Families of individuals with IDD often experience higher rates of poverty than other families (Fujiura, 1998). Fujiura, Roccoforte, and Braddock (1994) estimated that families spent \$6,300 in 1990 (\$13,172 in 2013 inflation-adjusted dollars) on out-of-pocket expenses not reimbursed by formal programs. Parish, Thomas, Rose, Kilany, & Shattuck (2012) found that 34% of families with children with autism spent over 3% of their family income on out-of-pocket health care expenditures.

Caldwell (2006) concluded that families in an Illinois sample who were recipients of the Illinois Home Based Support Services Program had lower out-of-pocket expenses (\$3,462) than families on the state’s waiting list for the program (\$5,358). The largest out-of-pocket expenses for Illinois families were the costs of respite/personal assistance services, transportation, medications, and related supplies. Greater expenses for families contributed to lower access to healthcare for family caregivers (Caldwell, 2006). Unfortunately, Ho, Collins, Davis, and Doty (2005), in their review of

research, concluded that half of caregivers caring for individuals with disabilities and the elderly forego their own medical care due to financial constraints.

In light of the breadth of supports needed for family members to produce positive outcomes for their relatives with disabilities, a better way of describing the constellation of such supports is through the use a broader term than family support, such as *supports for families*. The availability of external supports has been shown to increase families' willingness and ability to keep their children with IDD at home (Cole & Meyer, 1989; Fujiura et al., 1994).

Effective supports empower families and also maximize self-determination by the individual with a disability. Dunst, Trivette, and Hamby (2007) assert that such programs should "honor and respect [families'] values and choices" (p. 370). Unfortunately, "Cultural caregiving norms and language barriers reflecting our increasingly diverse society are creating a hidden need for services that typically do not surface until families are in a crisis situation" (Heller & Factor, 2008, p. 132).

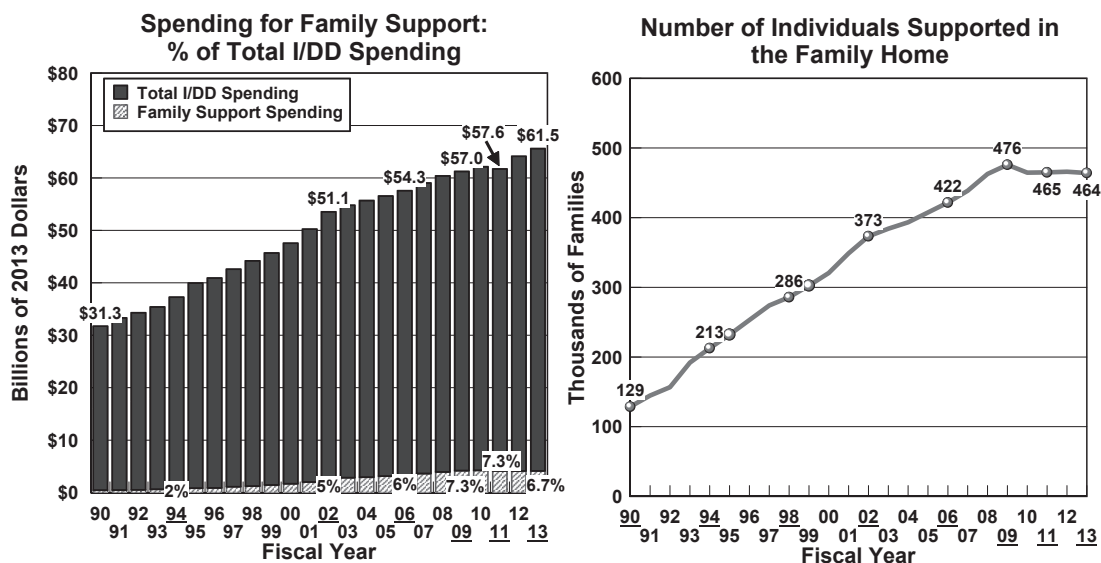
Family support receives a small fraction of total IDD spending. Figure 22 below depicts the number of families supported and the inflation-adjusted proportion

of total IDD spending allocated for family support services in the states from 1990–2013. The majority of long-term services and supports for persons with IDD is provided in family homes, yet only a fraction of public spending has been directed towards family support. Forty-nine states and the District of Columbia (all states except Idaho) reported a family support initiative in either cash subsidy or other family support activity such as respite and in-home supports. But in 2013 only 6.7% of total IDD spending was allocated to support individuals receiving IDD agency financed family support services in the family home. This was a decline in family support spending from 7.2% in 2011.

It is a matter of considerable concern that total adjusted family support spending and the number of families supported declined 2011 to 2013—from \$4.16 to \$4.14 billion and from 464,989 to 464,043 families. This represented a 0.4% inflation-adjusted reduction in spending and a 0.2% reduction in the number of families supported. The reduced number of families supported during 2011–13 follows a reduction in 2009–11 as well, by 2.3%.

Inflation-adjusted HCBS Waiver spending for family support advanced 12% from 2009–11, but only

Figure 22
FAMILY SUPPORT SPENDING AND NUMBER OF INDIVIDUALS SUPPORTED IN THE FAMILY HOME: FY 1990-2013



Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

2% from 2011–13. The Waiver was a principal factor in maintaining family support spending in the states. Federal-state Waiver funds constituted 82% of family support spending in 2013.

In 2013, the average family support spending per family (both subsidy and non-subsidy) in the U.S. was \$8,931. Table 19 below provides state-by-state data on the allocation of family support resources for cash

TABLE 19
FAMILY SUPPORT IN THE STATES:
SPENDING FOR PARTICIPANTS WITH I/DD IN FY 2013

State	Total Family Support ¹		Spending Per Family	Rank ²	Families Supported Per 100K	Rank ³	Cash Subsidy		Other Family Support	
	Families	Spending					Families	Spending	Families	Spending
Alabama	987	\$502,775	\$509	49	20	48	0	\$0	987	\$502,775
Alaska	1,377	\$10,429,966	\$7,574	22	188	17	0	\$0	1,377	\$10,429,966
Arizona	19,002	\$363,769,803	\$19,144	8	288	2	1	\$4,647	19,001	\$363,765,156
Arkansas	414	\$523,859	\$1,265	46	14	49	0	\$0	414	\$523,859
California	104,099	\$729,359,025	\$7,006	23	273	8	0	\$0	104,099	\$729,359,025
Colorado	2,183	\$2,348,496	\$1,076	47	42	43	0	\$0	2,183	\$2,348,496
Connecticut	3,069	\$54,980,964	\$17,915	10	85	34	1,738	\$2,955,493	1,331	\$52,025,471
Delaware ⁴	2,610	\$2,037,800	\$781	48	283	3	95	\$575,100	2,610	\$1,462,700
District of Columbia	753	\$15,610,362	\$20,731	7	117	27	0	\$0	753	\$15,610,362
Florida	15,617	\$327,858,454	\$20,994	5	80	35	39	\$117,735	15,578	\$327,740,720
Georgia	3,273	\$17,908,146	\$5,471	30	33	46	0	\$0	3,273	\$17,908,146
Hawaii	1,740	\$24,457,501	\$14,056	14	125	25	0	\$0	1,740	\$24,457,501
Idaho	0	\$0			0		0	\$0	0	\$0
Illinois	4,945	\$33,757,975	\$6,827	24	38	44	139	\$924,048	4,806	\$32,833,927
Indiana	6,661	\$44,076,198	\$6,617	26	102	31	0	\$0	6,661	\$44,076,198
Iowa	739	\$28,027,869	\$37,927	1	24	47	217	\$659,515	522	\$27,368,354
Kansas	2,811	\$50,180,281	\$17,851	11	97	32	0	\$0	2,811	\$50,180,281
Kentucky	2,771	\$11,592,149	\$4,183	35	63	39	0	\$0	2,771	\$11,592,149
Louisiana	12,558	\$374,835,470	\$29,848	2	272	9	1,647	\$4,475,278	10,911	\$370,360,192
Maine	480	\$8,447,527	\$17,599	12	36	45	480	\$600,000	0	\$7,847,527
Maryland	7,516	\$62,678,938	\$8,339	20	127	24	0	\$0	7,516	\$62,678,938
Massachusetts	11,759	\$37,855,140	\$3,219	40	176	18	0	\$0	11,759	\$37,855,140
Michigan	16,699	\$61,707,193	\$3,695	37	169	19	6,914	\$18,272,323	9,785	\$43,434,870
Minnesota	13,711	\$284,989,320	\$20,785	6	254	10	3,164	\$13,071,304	10,547	\$271,918,016
Mississippi	4,859	\$30,769,279	\$6,332	28	163	20	0	\$0	4,859	\$30,769,279
Missouri	4,621	\$43,138,430	\$9,335	18	77	37	0	\$0	4,621	\$43,138,430
Montana	2,856	\$12,892,812	\$4,514	33	283	5	0	\$0	2,856	\$12,892,812
Nebraska	2,569	\$20,619,859	\$8,026	21	138	22	0	\$0	2,569	\$20,619,859
Nevada	2,426	\$5,866,890	\$2,418	43	88	33	595	\$2,671,856	1,831	\$3,195,034
New Hampshire	3,142	\$6,392,547	\$2,035	44	238	13	0	\$0	3,142	\$6,392,547
New Jersey	4,564	\$39,868,869	\$8,736	19	51	42	0	\$0	4,564	\$39,868,869
New Mexico	5,725	\$16,710,745	\$2,919	42	275	7	0	\$0	5,725	\$16,710,745
New York	54,309	\$545,479,789	\$10,044	17	277	6	0	\$0	54,309	\$545,479,789
North Carolina	10,021	\$39,325,866	\$3,924	36	102	30	0	\$0	10,021	\$39,325,866
North Dakota	779	\$17,004,084	\$21,828	3	109	28	6	\$86,529	773	\$16,917,554
Ohio	21,882	\$98,410,606	\$4,497	34	189	16	0	\$0	21,882	\$98,410,606
Oklahoma	4,496	\$75,002,046	\$16,682	13	117	26	2,113	\$5,792,470	2,383	\$69,209,576
Oregon	2,030	\$970,552	\$478	50	52	41	0	\$0	2,030	\$970,552
Pennsylvania	25,429	\$81,087,979	\$3,189	41	199	15	0	\$0	25,429	\$81,087,979
Rhode Island	1,575	\$33,084,019	\$21,006	4	150	21	43	\$144,743	1,532	\$32,939,276
South Carolina	11,764	\$59,768,916	\$5,081	32	248	11	2,350	\$1,211,100	9,414	\$58,557,816
South Dakota	1,922	\$6,324,861	\$3,291	39	229	14	0	\$0	1,922	\$6,324,861
Tennessee	4,761	\$7,133,400	\$1,498	45	74	38	0	\$0	4,761	\$7,133,400
Texas	20,156	\$238,841,452	\$11,850	16	77	36	0	\$0	20,156	\$238,841,452
Utah	1,723	\$11,240,253	\$6,524	27	60	40	1	\$58	1,722	\$11,240,195
Vermont	1,774	\$21,184,286	\$11,942	15	283	4	0	\$0	1,774	\$21,184,286
Virginia	325	\$1,845,355	\$5,678	29	4	50	325	\$1,845,355	0	\$0
Washington ⁴	7,436	\$50,276,399	\$6,761	25	107	29	2,122	\$5,078,384	6,170	\$45,198,015
West Virginia	2,544	\$48,347,261	\$19,004	9	137	23	0	\$0	2,544	\$48,347,261
Wisconsin	23,192	\$77,504,036	\$3,342	38	404	1	0	\$0	23,192	\$77,504,036
Wyoming	1,389	\$7,329,504	\$5,277	31	240	12	0	\$0	1,389	\$7,329,504
United States	464,043	\$4,144,355,306	\$8,931		147		21,989	\$58,485,938	443,005	\$4,085,869,367

¹ Total family support consisted of cash subsidy and "other family support" that included respite care, family counseling, architectural adaptation of the home, in-home training, sibling support, education and behavior management services, and the purchase of specialized equipment.

² States' ranking, highest to lowest, on total family support spending per family supported.

³ States' ranking, highest to lowest, on total families supported per 100,000 citizens of the general population.

⁴ In Delaware each of the families receiving cash subsidies also received other family support; and in Washington, the majority of cash subsidy families also received other (i.e., non-subsidy) family support.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

subsidy and other family support. It also ranks the states on the basis of average spending per family and on families supported per 100,000 of the state general population, respectively. Annual per-family spending ranged from \$478 in Oregon to \$37,927 in Iowa. Thirty-two states spent more than \$5,000 per family in 2013, while three states spent less than \$1,000.

As noted, inflation-adjusted family support spending in the U.S. dropped 0.4% during 2011–13 (Figure 23 below), but growth rates exceeded 50% in West Virginia, District of Columbia, Rhode Island, and Kentucky. Conversely, 22 states reduced their family support funding between 2011 and 2013, with reductions of 10% or more in Alabama, Nevada, Florida, Washington State, New Jersey, New Hampshire, and Colorado. As noted, Idaho reported no family support spending beginning in 2011. In 2012, Virginia terminated family support spending, but in 2013 instituted a cash subsidy.

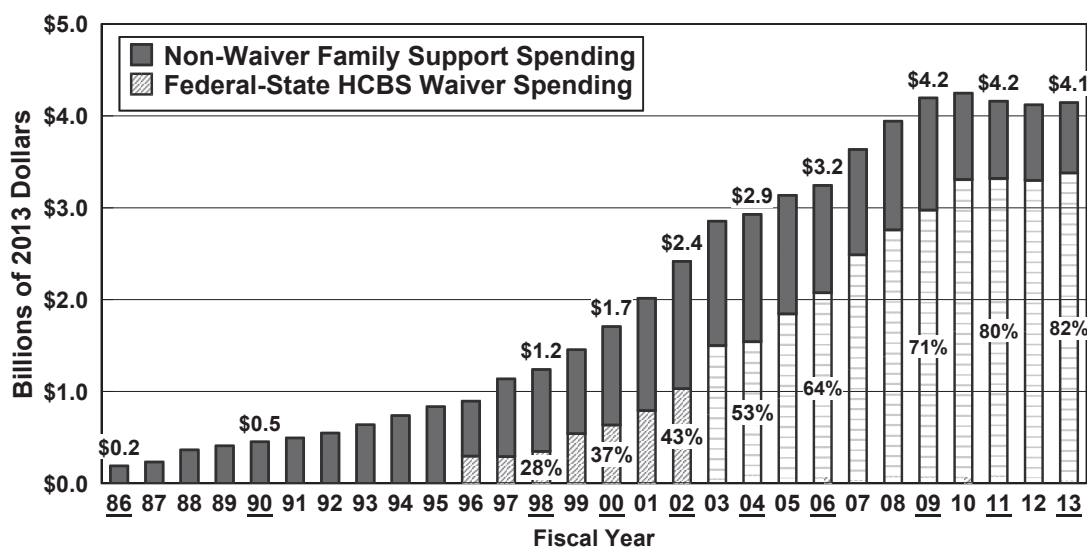
Seven states that had financed cash subsidies in 2008 no longer did so in 2013: Arkansas, Kansas, New Hampshire, New Jersey, New Mexico, Tennessee, and Texas. Total cash payments to families in the U.S. declined from \$96.8 million in 2008 to \$58.5 million in 2013 (a 45% inflation-adjusted decline).

The average annual subsidy payment to a family in the U.S. in 2013 was \$2,660, ranging from \$58 in Utah to \$14,422 in North Dakota. The combined cash subsidy programs in four states, Michigan, Minnesota, Oklahoma, and Washington accounted for 75% of all subsidy payments in the nation in 2013.

HCBS Waiver's role in family support. The Medicaid Home and Community Based Services (HCBS) Waiver has been instrumental in helping states reduce their reliance on institutional settings while developing community services including family supports (Figure 23). In fact, the HCBS Waiver has emerged as the principal funding source for services that support individuals living in the family home (Rizzolo, et al., 2006, 2009, 2013). Larson, et al. (2014) recently reported that over 55% of HCBS recipients in 2012 lived with their parents or other family member, an increase from 48% in 2011 (Larson et al., 2013).

In 2013, the HCBS Waiver financed 82% of all family support services spending in the United States. The states varied greatly in the extent to which they utilized HCBS Waiver funds to finance family support initiatives. Twenty-four states funded 90% or more of their family support services with the Medicaid HCBS

Figure 23
INFLATION- ADJUSTED SPENDING FOR
FAMILY SUPPORT SERVICES: FY 1986-2013



Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

Waiver. Conversely, nine states opted to finance their family support initiatives solely through state funding.

Unmet need for family support. National trends in family support spending and number of families supported demonstrate an effort to maintain support for family caregivers, despite the impact of the Great Recession. However, in nearly all states and in the nation as a whole, the number of families supported is a pitifully small portion of all families providing care for a child or adult with IDD.

The states varied greatly in the proportion of families with family members with IDD who received cash subsidies or other forms of state agency financed family support in 2013 (Table 20). Of the estimated 3.6 million families, over 3.0 million did not receive any IDD state agency family support services. The table presents estimates of total caregiving families with children with IDD based on *Survey of Income and Program Participation (SIPP)* data (Fujiura, 2012).

Fourteen states were estimated to be providing IDD family support services to 20% or more of total IDD caregiving families: Arizona, California, Delaware, Louisiana, Minnesota, Montana, New Hampshire, New Mexico, New York, South Carolina, South Dakota, Vermont, Wisconsin, and Wyoming. However, it is estimated that 13 other states provided family support services to only 5% or less of those in need. These states are Alabama, Arkansas, Colorado, Georgia, Idaho, Illinois, Iowa, Kentucky, Maine, New Jersey, Oregon, Utah, and Virginia.

There was an increase in the proportion of caregiving families receiving IDD state agency support between 1988 and 2009 (from 4% to 14%). Support declined to 13% during 2009–13, primarily due to family support cutbacks in multiple states resulting from the budget impact of the Great Recession (Figure 24 on page 61).

With the expanding role of the HCBS Waiver, general problems with Waiver financing of family support services have emerged. Issues include limited Waiver capacity, cost-per-participant caps, cost-neutrality requirements, and various cost-containment strategies such as spending ceilings, service limits, and hourly and geographic limits. Waiver utilization issues can seriously limit expansion and adequate financing of family support services (Harrington, Ng, Kaye, & Newcomer, 2009).

The hallmark of family support remains individualization and flexibility. However, data on “non-duplicated” families in some states include high proportions of families receiving minimal services such as episodic respite care or service coordination. Other states may

TABLE 20
ESTIMATED NUMBER OF I/DD CAREGIVING
FAMILIES COMPARED TO FAMILIES SUPPORTED BY
STATE I/DD AGENCY FEDERAL, STATE, AND LOCAL
FUNDS: FY 2013

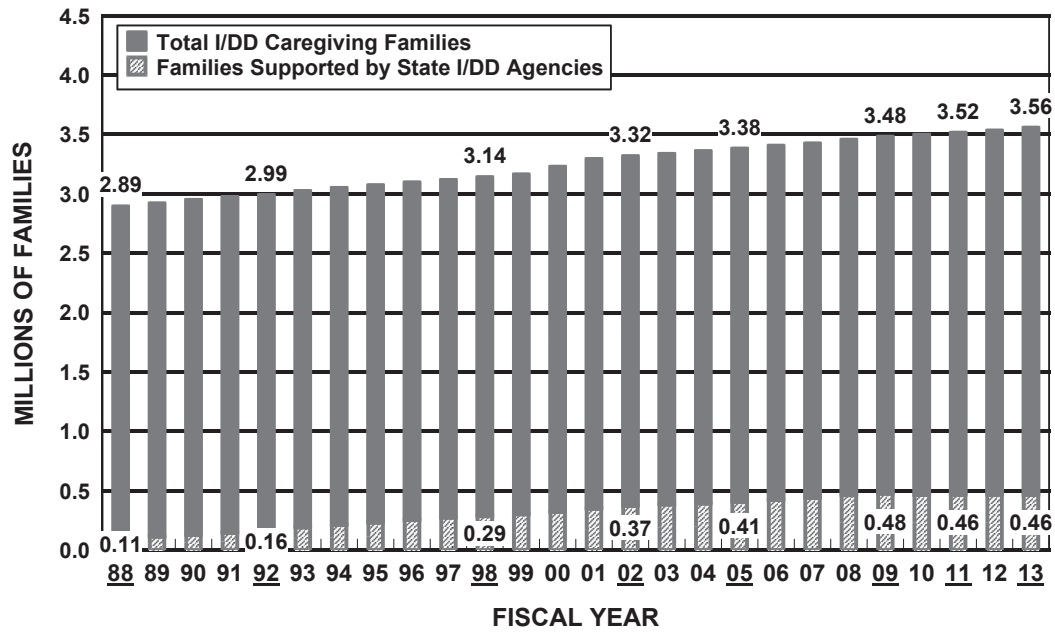
State	Total IDD Caregiving Families	Families Supported by I/DD Agencies	% of Families Supported	Rank ¹
Alabama	58,602	987	2%	48
Alaska	8,349	1,377	16%	17
Arizona	81,495	19,002	23%	11
Arkansas	32,708	414	1%	49
California	445,877	104,099	23%	10
Colorado	60,240	2,183	4%	43
Connecticut	39,585	3,069	8%	33
Delaware	10,993	2,610	24%	8
Dist. of Columbia	6,833	753	11%	24
Florida	234,210	15,617	7%	37
Georgia	118,188	3,273	3%	46
Hawaii	15,891	1,740	11%	25
Idaho	18,040	0	0%	51
Illinois	142,194	4,945	3%	44
Indiana	74,095	6,661	9%	31
Iowa	32,953	739	2%	47
Kansas	32,798	2,811	9%	32
Kentucky	51,201	2,771	5%	39
Louisiana	53,458	12,558	23%	9
Maine	14,437	480	3%	45
Maryland	69,653	7,516	11%	26
Massachusetts	74,991	11,759	16%	19
Michigan	101,261	16,699	16%	18
Minnesota	53,920	13,711	25%	5
Mississippi	35,057	4,859	14%	20
Missouri	68,387	4,621	7%	36
Montana	11,378	2,856	25%	6
Nebraska	20,796	2,569	12%	23
Nevada	34,167	2,426	7%	34
New Hampshire	15,005	3,142	21%	13
New Jersey	103,375	4,564	4%	42
New Mexico	23,879	5,725	24%	7
New York	198,592	54,309	27%	2
North Carolina	110,692	10,021	9%	30
North Dakota	7,445	779	10%	27
Ohio	119,026	21,882	18%	15
Oklahoma	45,279	4,496	10%	28
Oregon	38,885	2,030	5%	40
Pennsylvania	142,608	25,429	18%	16
Rhode Island	11,736	1,575	13%	21
South Carolina	56,541	11,764	21%	14
South Dakota	8,529	1,922	23%	12
Tennessee	76,416	4,761	6%	38
Texas	296,704	20,156	7%	35
Utah	34,542	1,723	5%	41
Vermont	6,652	1,774	27%	3
Virginia	98,928	325	0.3%	50
Washington	76,927	7,436	10%	29
West Virginia	19,656	2,544	13%	22
Wisconsin	58,660	23,192	40%	1
Wyoming	5,413	1,389	26%	4
UNITED STATES	3,557,246	464,043	13%	

States ranked, highest to lowest, on percent of family caregivers receiving I/DD state agency support.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

provide higher proportions of intensive in-home supports of longer duration. Our data confirm a very high level of unmet needs in the states for substantial expansion of IDD supports for families and their relatives with intellectual and developmental disabilities.

Figure 24
ESTIMATED NUMBER OF I/DD CAREGIVING FAMILIES
AND FAMILIES SUPPORTED BY I/DD AGENCIES: FY 1988-2013



Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

VIII. DEMAND FOR SERVICES AND SUPPORTS

Formal out-of-home residential services were being provided to 634,509 persons in the

states in 2013. The vast majority of these settings are operated by private, non-profit service providers. The structure of the residential care system has changed markedly over the past 25 years as state-operated residential institutions have increasingly been supplanted by community residential services.

The nation's overall residential system capacity increased by 48% from 1999–2013, with an average annual growth rate of 3% per year. Growth was 1% per year in the U.S. general population.

Aging Caregivers

The longevity revolution directly influences demand for IDD services because of the number of people with IDD residing with family caregivers. As these caregivers age beyond their caregiving capacities, formal living

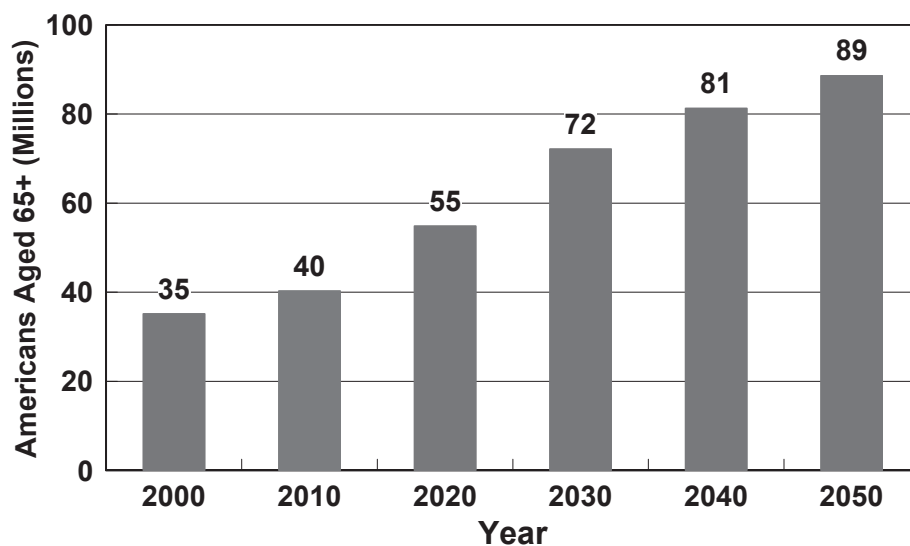
arrangements must be established to support their relatives with disabilities.

The aging of our society is the product of several forces, including the size of the baby boom generation (persons born during 1946–1964), declining fertility rates, and increased longevity. Baby boomers began to reach age 65 in 2011.

The number of persons in our society aged 65+ years is projected by the U.S. Census Bureau (2014) to reach 55 million in 2020 and 89 million in 2050 (Figure 25 below). Currently, 13.3% of the U.S. general population is aged 65+ years. In the U.S., 37% of persons 65 years of age and over have one or more physical disabilities as opposed to 11% of the population under age 65 (Schiller, Lucas, Ward, & Peregoy, 2012).

Americans 80 years or older are expected to be the fastest growing age group. Many countries will be affected by this demographic trend, particularly Brazil, China, India, Indonesia, and Japan. The UN estimates that, by 2050, the percentage of Japan's citizens over the

Figure 25
GROWING NUMBERS OF AMERICANS
AGED 65+ YEARS: 2000-2050



Source: U.S. Census Bureau (2012).

age of 60 will have increased from 30% to 44%. At least 16% of their population will be over age 80 (United Nations, 2009). Europe now has the oldest population, with a median age of nearly 40 years that is projected to reach 47 years in 2050. On a global basis, life expectancy at birth was 68 years in 2005–10. It is projected to be 76 years in 2045–50 (United Nations, 2009).

Estimating the impact of aging on the increased demand for intellectual and developmental disabilities services in the states requires data on the prevalence of developmental disabilities in our society. Based on data from the National Health Interview Survey-Disability Supplement (NHIS-D), Larson, Lakin, Anderson, Kwak, Lee, & Anderson (2001) recommended using a rate of 1.58% to estimate prevalence for persons with intellectual disability, cerebral palsy, autism, epilepsy, and other childhood disabilities originating prior to 22 years of age.

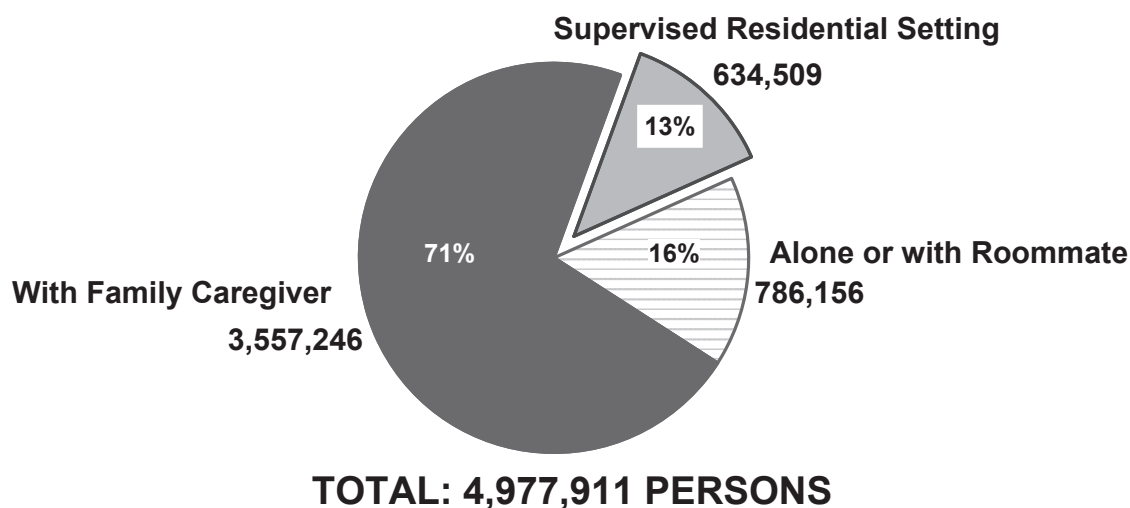
Fujiura (1998, 2012) determined that in 2010, 71% of persons with developmental disabilities in the U.S. resided with family caregivers, and 29% lived on their own or within the formal out-of-home residential care system in the states. We updated Fujiura's analysis using

data pertaining to the 2013 IDD out-of-home residential system, and the U.S. general population in 2013.

The results are presented in Figure 26 below, which indicates that 3.56 million of the 4.98 million persons with intellectual and developmental disabilities in the U.S. population in 2013 were receiving residential care from family caregivers. This "informal" system of residential care served nearly six times the number of persons served by the formal out-of-home residential care system (634,509 persons). Moreover, Fujiura (1998, 2012) determined that 25% of individuals with developmental disabilities in the U.S. lived with family caregivers aged 60+ years, and an additional 35% were in "households of middle-aged caretakers for whom transition issues are near-term considerations" (Fujiura, 1998, p. 232). Without proper supports and coping strategies, long-term caregiving places family members at risk for physical and psychological issues as they age (Seltzer, Floyd, Song, Greenberg & Hong, 2011).

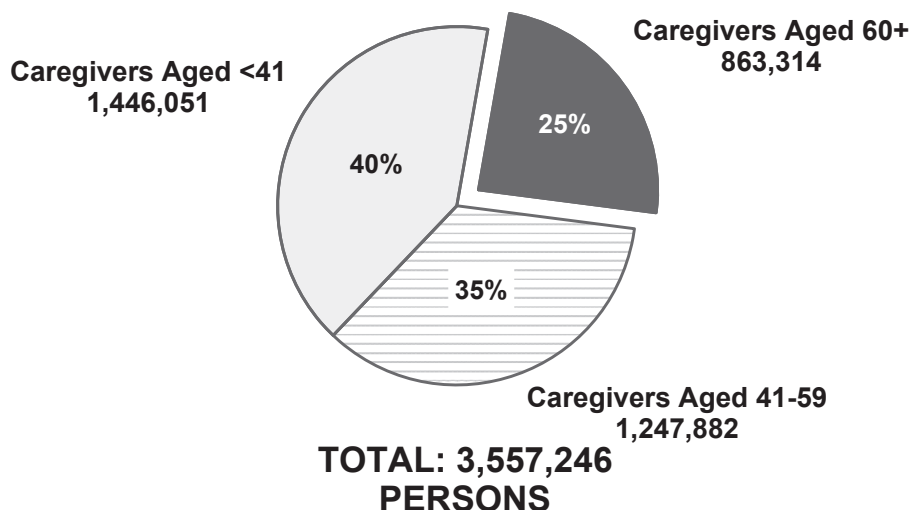
We further examined the data in Figure 26 to draw specific attention to the size of the aging family caregiver cohort in the states. It is 863,314 persons in 2013 (Figure 27 on page 64).

Figure 26
UNITED STATES
ESTIMATED DISTRIBUTION OF INDIVIDUALS
WITH I/DD BY LIVING ARRANGEMENT, FY 2013



Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015, based on Fujiura (2012).

Figure 27
UNITED STATES
ESTIMATED NUMBER OF INDIVIDUALS WITH I/DD
BY AGE GROUP LIVING WITH FAMILY CAREGIVERS, FY 2013



Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015, based on Fujiura (2012).

How large is the aging caregiver cohort in each of the states? State-by-state estimates can be generated by taking into account differences in states' utilization of out-of-home placements and the number of the states' caregivers who are over age 60. For example, an estimated 5% of persons with IDD in Arizona and Nevada live in out-of-home settings while the figure is 23% in Oregon. The percentage of individuals over age 65 in the oldest state, Florida (17.6%), is over two times the percentage of older individuals in the youngest state, Alaska (8.1%) (United States Census Bureau, 2014).

State-by-state estimates of the number of individuals with intellectual and developmental disabilities living with aging caregivers appear in Table 21 on the following page.

Increased Longevity of People with Intellectual Disability

A second factor contributing to the growing demand for IDD services is the increase in the lifespan of individuals with intellectual and developmental disabilities. The mean age of death for persons with developmental

disabilities was 66 years in 1993, compared to 59 years in the 1970s and 33 years in the 1930s. The average longevity of people with Down syndrome increased from nine years in the 1920s to 31 years in the 1960s and 56 years in 1993 (Janicki, Dalton, Henderson, & Davidson, 1999.)

The mean age at death for the general population in 1993 was 70 years (Janicki, et al., 1999). In 2009, the life expectancy at age 65 for all Americans was 84.1 years (Centers for Disease Control and Prevention, 2013). An Australian study reported that the average age of death for people with mild and moderate intellectual impairment who do not have any chronic health conditions is 71 years (Bittles, Petterson, Sullivan, Hussain, Glasson, & Montgomery, 2002).

Information has emerged on genetic and nonspecific neurodevelopmental conditions linked to intellectual disability, which are affected differently by maturation and aging. For example, Down syndrome has been linked to premature aging, Alzheimer's disease, and certain organ dysfunctions (Nakamura & Tanaka, 1998; Prasher, 2006; Pueschel, 2006).

In addition to genetic disorders, specific health problems related to the older age trajectories of several common neurodevelopmental conditions include

TABLE 21
ESTIMATED NUMBER OF PERSONS
WITH I/DD LIVING WITH AGING
CAREGIVERS IN FY 2013¹

State	Persons with I/DD
Alabama	15,455
Alaska	1,298
Arizona	21,210
Arkansas	8,730
California	96,375
Colorado	12,118
Connecticut	10,645
Delaware	2,911
DC	1,450
Florida	77,467
Georgia	22,627
Hawaii	4,256
Idaho	4,031
Illinois	32,732
Indiana	17,460
Iowa	9,137
Kansas	8,150
Kentucky	12,479
Louisiana	12,603
Maine	4,230
Maryland	15,794
Massachusetts	19,092
Michigan	24,123
Minnesota	12,401
Mississippi	8,355
Missouri	17,633
Montana	3,198
Nebraska	5,311
Nevada	7,843
New Hampshire	3,631
New Jersey	26,301
New Mexico	6,361
New York	50,487
North Carolina	25,635
North Dakota	2,116
Ohio	30,310
Oklahoma	11,613
Oregon	9,470
Pennsylvania	41,085
Rhode Island	3,071
South Carolina	14,481
South Dakota	2,306
Tennessee	18,991
Texas	58,158
Utah	5,825
Vermont	1,794
Virginia	23,019
Washington	17,536
West Virginia	5,860
Wisconsin	14,721
Wyoming	1,429
United States	863,314

¹ Caregivers aged 60 years and older.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

cerebral palsy (e.g., osteoporosis, degenerative joint disease), autism (e.g., digestive system disorders and neuropsychiatric factors) and spina bifida (e.g., neuro-motor and other organ system consequences) (Janicki, Henderson, & Rubin, 2008).

In an international review, Katz (2003) summarized research on life expectancy for persons with intellectual disability from several countries including the U.S. He concluded that life expectancy for the vast majority of persons with mild and moderate degrees of intellectual disability did not differ significantly from the general population. Patja, Iivanainen, Vesala, et al. (2000) noted, however, a 19 to 35% diminishment of life expectancy in the much smaller cohort of persons with “severe and profound” degrees of intellectual disability (cited in Katz, 2003, p. 268). The Patja et al. (2000) study was carried out in Finland.

As persons with intellectual and developmental disabilities live longer, they require services and support for longer periods of time, different types of supports, as well as supports for their aging caregivers. This directly impacts the finite capacities of state service delivery systems. The increased life expectancy of persons with IDD since 1970 accounts for a significant percentage of the increased demand for residential services in the states today. That demand will only grow in the future.

The likelihood of older persons with IDD living into their own retirement and outliving their family caregivers has increased substantially. This has stimulated growing demand for additional services and supports. The need to provide these services is frequently unanticipated by federal, state, and local agencies. This often results in a crisis situation for families. It is an unfortunate reality that many family caregivers must become incapacitated or die before their relative with a disability for whom they are caring can receive support from publicly financed state service system.

Waiting Lists in the States

In 2012, 31 states reported that 77,353 persons with IDD were on formal state waiting lists for residential services and not receiving services (Larson, et al., 2014). Based on this figure, Larson et al. (2014) estimated that 110,039 persons with IDD nationally were awaiting residential services.

Some states maintain detailed waiting lists of service needs for persons with IDD while others do not

officially collect waiting list data.¹⁵ Ten states (Indiana, Kansas, Louisiana, Massachusetts, Michigan, Mississippi, New Jersey, Ohio, Texas, and Washington State) did not furnish waiting list data in the Larson et al. (2014) study and another 10 states indicated that their waiting lists were at zero (California, District of Columbia, Hawaii, Idaho, Iowa, North Dakota, Oregon, Rhode Island, South Dakota, and Vermont).

California maintained no waiting list because services are considered an entitlement under the state's *Lanterman Act*. Hawaii eliminated its waiting list in 2000 as part of the settlement agreement in the *Makin et al. v. State of Hawaii* waiting list lawsuit. (Hawaii's IDD spending increased 107% in inflation-adjusted terms from 1999 to 2013). In 1999, Idaho eliminated its waiting list when the legislature removed the "cap" on the projected number of waiver participants. The number of waiver participants increased from 474 in 1999 to 2,775 in 2013.

Lakin (1998) has stated that waiting list initiatives in the states have generally involved expanding family support to prevent or delay the need for placement, and obtaining new or reallocated resources from the following sources: closure of state-operated institutions, ICF/ID conversion to HCBS Waiver programs, capping reimbursement for existing programs, and seeking additional Medicaid funding.

Several states have begun to address the need for services in response to waiting lists. As we reported previously, New York's *NYS-CARES* waiting list initiative was originally established in 1998 for five years and was subsequently made a permanent part of the Office for People with Developmental Disabilities (OPWDD) budget in 2003 (Braddock et al., 2011). Then Governor Pataki had recommended a \$154 million ten-year additional commitment to the *NYS-CARES II* program (through 2013) and the program's first five years established 5,078 additional community residential options and exceeded the original 4,900-bed goal. The 10% growth from 2009–11 in New York's settings for six or fewer persons ranked 17th among the states, but barely above the U.S. average state's increment of 9%.

Other recent waiting list initiatives were authorized in legislation in Kentucky and New Jersey, and in response to the settlement in the *Boulet* class action litigation in Massachusetts (Braddock et al., 2013).

Direct Support Professionals' Wage Issues

Given that demand for IDD services is being stimulated by aging caregivers, increasing longevity of people with IDD, and class action litigation, the recruitment and retention of qualified direct support professionals (DSPs) is a critical issue. Turnover of DSPs and the inability to recruit staff are detrimental to the quality of developmental disabilities long-term care programs (Mitchell & Braddock, 1994) and to individual quality of life (Larson, Hewitt, & Lakin, 2004). If there is excessive staff turnover, persons with disabilities can experience a steady withdrawal of the support staff upon whom they depend for nurturing, consistency, understanding, and appropriate habilitation programs (Lakin, 1988). Employee turnover affects all organizations, but the problem is often magnified in human service organizations.

Adequate wages are a major factor in recruiting and retaining qualified staff. In a large nationwide sample of providers, Braddock and Mitchell (1992) found that date of employment and average wages (adjusted for states' differing costs of living) were inversely correlated with turnover in community residential programs. Lower wages led to higher turnover. Similar results on the relationship of low wages and turnover were also reported in other studies by the Minnesota Department of Employee Relations (1989); and Larson and Lakin (1999).

Powers and Powers (2010) estimated that a 24–31% increase in annual wages for caregivers would cut turnover rate by one-third. The Paraprofessional Healthcare Institute (2011) found that 45% of direct-care workers (e.g., nursing assistants/aides, home health aides, personal care aides) lived below the federal poverty level and as many as 46% lived in households that received public assistance (e.g., Medicaid, food stamps). In addition to low wages, 48% of the direct-care workforce is employed part-time or for only part of the year, thus decreasing wages and the likelihood of healthcare coverage. "In 2009, an estimated 900,000 direct-care workers did not have any health coverage" (Paraprofessional Healthcare Institute, 2011, p. 2).

In collaboration with the American Network of Community Options and Resources (ANCOR), the consulting firm BDO Seidman (2002) found three general economic constraints in the recruitment and retention of IDD direct support staff: 1) rapidly increasing health insurance costs; 2) growing demand in competing service industries; and 3) the advantage that private

15. State DD Councils beginning in 2014 are required to provide their states' waiting list data in their annual reports to AIDD.

sector “supply and demand” employers have over publicly-funded human service systems, which, unlike the private sector, are restricted by fixed appropriations. None of these problems have been resolved over the past decade.

Fixed appropriations can be used as a means of legislative control over total costs, thereby suppressing staff wages and benefits, which constitute 60–70% of IDD community services program budgets. In contrast, for state-operated services like IDD state institutions, salary increases are typically tied to a cost of living increase annually and to employee length of time on the job. Greater purchasing power of states also enables state employee fringe benefits to be more generous than benefits for DSPs in community settings.

Powers and Powers (2011) examined the effect of caretaker turnover rates on long-term care operating costs in Illinois and found increases in turnover were related to workers compensation costs, increased state-reimbursed training expenditures, and the share of workers engaged in training. On the other hand, high rates of turnover had no effect on residential vacancies or training expenditures incurred by the state. As a result the authors suggest wage subsidies as a viable option to combat employee turnover.

Direct support professional wages in privately-operated community-based residences are well below the wages of all workers covered by unemployment insurance (United States Bureau of Labor Statistics, 2014). They also fall well below wages for state-operated institutional employees and are below nursing aides (United States Bureau of Labor Statistics, 2014). In fact, direct support professional’s wages are only four cents above the 2014 poverty level for a family of four (Assistant Secretary for Planning and Evaluation, 2014) (Figure 28 on the following page).

In Minnesota, direct support professionals in community provider organizations reportedly receive an average \$11.25 per hour while front-line supervisors received an average of \$15.45 per hour (Bogenschutz, Hewitt, Nord, and Hepperlen, 2014).

Thirteen years ago the U.S. Bureau of Labor Statistics (2001) had projected a 63% increase in demand for disability-related direct support staff through the year 2010. This was more than twice the projected increase in job demand for nursing aides and fast food workers. Medicaid funding for community services, including HCBS Waiver funds, is the primary financial resource available to the states to address the growing problem of recruiting and retaining qualified DSPs.

Direct-care occupations are projected to be the second largest occupational group in the U.S. by 2018 reaching 4,322,000 employees and exceeding the number of teachers, nurses, and law enforcement professionals (Paraprofessional HealthCare Institute, 2011).

In 2009, Representative Lois Capps (D-CA) introduced H.R. 868, the Direct Support Professionals Fairness and Security Act of 2009, to the 111th Congress. This bill was introduced first in the 107th Congress as H.R. 1279, and also in subsequent years, to no avail. The bills all died, referred to Committee.¹⁶ H.R. 868 sought to “amend title XIX of the *Social Security Act* to provide funds to States to enable them to increase the wages paid to targeted direct support professionals in providing services to individuals with disabilities under the Medicaid Program.” Perhaps now that the U.S. economy is stronger, it is time to reintroduce Rep. Capps’ 2009 legislation.

In August 2014 President Obama reported on a year’s progress to raise the minimum wage (Executive Office of the President, 2014). State regulations vary widely as to whether they provide minimum wage and/or overtime protection. In 2014 President Obama moved to increase the minimum wage in federal contracts.¹⁷ Legislation in the House and Senate is stalled, and still lacking bipartisan support as of September 2014.

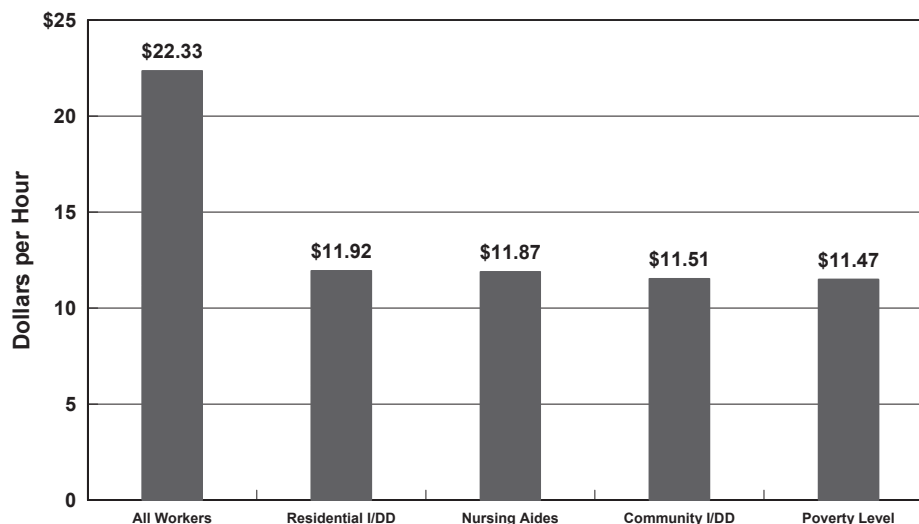
Recent Litigation Promoting Community Services

As in our past studies, this section will focus on *Olmstead* deinstitutionalization, waiting list, and access to benefit cases for people with intellectual and developmental disabilities. *Olmstead* cases compel states to meet the requirements of the 1999 *Olmstead* decision that established that people with disabilities have a right to be served in the most integrated setting appropriate to their needs and wishes. *Olmstead* cases include basic cases involving deinstitutionalization such as waiting list cases which have been filed to compel states to expand services to people on waiting lists. Also included are access to Medicaid benefit cases which include lawsuits filed on behalf of individuals eligible for Medicaid services but who failed to receive benefits.

16. <http://www.govtrack.us/congress/bills/111/hr868>.

17. <http://www.dol.gov/whd/flsa/nprm-eo13658/fs-EO13658.pdf>.

Figure 28
HOURLY WAGES IN 2014



Sources: Mean hourly wage for "All Workers," for "Nursing, Psychiatric and Home Health Aides, Aides" and for "Residential I/DD" for May 2013 (Bureau of Labor Statistics, April 2014); "Community I/DD" (BLS, 2014 [Under BLS31.103 Psychiatric Aides/Individual and Family Services]); and "Poverty Level" for 2014 for family of four (Assistant Secretary for Planning and Evaluation, 2014).

Table 22 on the following page presents examples of ongoing *Olmstead* litigation, and litigation that has been settled since our last published study. The table presents the primary type of the case (*Olmstead*, waiting list, or access to benefits), the state involved, the name of the case, the date the lawsuit was originally filed, the disposition, and whether the judgment or settlement appeared to favor the plaintiff(s) or defendants.

We begin with updates to some of the cases that are still active since our last study (Braddock et al., 2013). But first an update on a case that we previously reported as settled. Although a case may have been reported to be settled, it can be revisited, even if a fairness hearing has been held to ascertain that the agreement was reasonable. This was the case in *Benjamin v. Dept. Pub. Welfare* in a Pennsylvania case reported as settled in 2011 and favoring the plaintiffs. According to Priaulx in her 2014 update of *Docket of Cases Related to Enforcement of the ADA Title II Integration Regulation* (p. 30), on December 12, 2012, "the Third Circuit ruled that the district court abused its discretion in denying the intervention and held that the family members were allowed to challenge the settlement agreement

and seek decertification of the class." Thus, although the plaintiffs and defendants reached a settlement, the case appears to be ongoing.¹⁸

New Jersey Disability Rights New Jersey, Inc., v. Velez is a case that could be considered both a deinstitutionalization and a waiting list case. It was settled in 2013. The case began as *New Jersey Protection and Advocacy et al. v. Velez* in 2008. (The P & A changed its name to Disability Rights New Jersey later that year). The case alleged that hundreds of people with developmental disabilities not only were being segregated in large state-owned New Jersey institutions, but also there was a long waiting list for in-home supports and services. On February 26, 2013, Governor Chris Christie announced the state had agreed to settle. It agreed to increase funding for HCBS Waivers. The 2013 state budget included \$83 million in new funds for community based services.

In Pennsylvania, *Mumford et al. v. Pennsylvania* was filed in 2011. The case remains open. It alleges

18. <http://www.clearinghouse.net/>

TABLE 22
The Status of Selected Community I/DD Services Litigation, 2014

State	Lawsuit	Date Filed	Disposition	Favored
Waiting List Cases				
New Jersey	<i>New Jersey Protect. & Advocacy et al. v. Velez</i>	2008	Settled 2013	Plaintiffs
Florida	<i>Dykes v. Dudek</i>	2011	Open	Open
Olmstead Cases				
Florida	<i>U.S. v. Florida</i>	2013	DOJ filed statement of interest 2014	Ongoing
Illinois	<i>IL. League of Advoc. for the Dev. Disabled v. DHS</i>	2013	Judge ordered parties to file more infor.	Open
New Jersey	<i>Sciarrillo ex rel. St. Aman v. Christie</i>		Dismissed 2013	Defendants
New Jersey	<i>Carey et al. v. Christie</i>	2013	Ongoing	Ongoing
New Jersey	<i>Disability Rights New Jersey, Inc. v. Velez</i>	2008	Settled 2013	Plaintiffs
Pennsylvania	<i>Mumford et al. v. Pennsylvania</i>	2011	Ongoing	Ongoing
Pennsylvania	<i>Benjamin v. Dept. of Public Welfare</i>	2009	Despite settlement, Court ruled family allowed to intervene	Ongoing
Texas	<i>Steward et al. v. Perry et al.</i>	2010	Interim agreement. 2013	Plaintiffs
Access to Benefit Cases				
Arkansas	<i>Pediatric Spec. Care, Inc. et al. v. AR Dept. of HS et al.</i>	2001	Trial scheduled at district court level	Ongoing
Kansas	<i>Interhab, Inc. et al. v. Schalansky et al.</i>	2002	Court rejected state's motion to dismiss	Ongoing
Washington	<i>Boyle v. Braddock</i>	2001	Settled, 2010, but under appeal	Court Dismissed May 2013

Data Sources:

Ng. et al. (2013). www.pascenter.org/olmstead/olmstead
The ADA website: www.ada.gov/olmstead-cases-list2.htm#ri-state
The Disability Rights Docket (2014), by Elizabeth Prialux: www.ndrn.org/issues/community-integration
The Kaiser Commission on Medicaid and the Uninsured: www.kaiserfamilyfoundation.files.wordpress.com/
Separate and Unequal: States Fail to Fulfill the Community Living Promise of the Americans with Disabilities Act, US Senate's Health, Education, Labor, and Pensions Committee: <http://www.harkin.senate.gov/documents/pdg/OlmsteadReport.pdf>
The Civil Rights Litigation Clearinghouse of the University of Michigan Law School: www.clearinghouse.net/detail.php?id=12653
www.justice.gov/crt/about/spl/disability.php

Compiled from the above sources by: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015

that plaintiffs with developmental disabilities are inappropriately institutionalized in psychiatric hospitals.¹⁹ From the Information and Technical Assistance on the Americans with Disabilities Act page of the United States Department of Justice, Civil Rights Division (www.ada.gov), we learned that the Texas case of *Steward et al. v. Perry et al.*, filed in 2010, entered into an interim two year agreement in 2013, awaiting court approval. Under the terms of the agreement, the state will begin to expand community services so that people with developmental disabilities in Texas will no longer need to be inappropriately housed in nursing facilities. The state agreed to continue to expand community-based services through HCBS waivers. In this case, the DOJ filed a statement of interest on behalf of the plaintiffs. (www.kaiserfamilyfoundation.files.wordpress.com/).

In Florida, the *Dykes V. Dudek* lawsuit, filed originally in 2011, remains open. Primarily a waiting list case, this class action case was filed on behalf of approximately 19,000 people with developmental disabilities who are still on waiting lists for community services.

Three access to benefit cases we previously reported remain open:

1. *Arkansas Pediatric specialty Care Inc et al v. AR Dept of Human Services et al* involves a trial at the district court level. In this case, the plaintiffs, children and service providers, are challenging plans to reduce Medicaid services for children with developmental disabilities by ending same-day treatment and therapy.
2. In Kansas, the District Court rejected the state's motion to dismiss *Interhab, Inc. et al. v. Schalansky et al.* Interhab, an association of providers, claims that the State is underfunding the HCBS waiver.

19. http://www.americanbar.org/content/dam/aba/events/homelessness_poverty/2013_Annual_Meeting_Medicaid/intro_to_olmstead_lawsuits_and_plans.authcheckdam.pdf

3. Finally, in Washington State, although the *Boyle v. Braddock* case was settled in 2010, plaintiffs appealed and it is ongoing. The case is about the failure of the State to make the full range of services available through the HCBS waiver to people with developmental disabilities.²⁰

Department of Justice statements of interest. During 2014, the mandate of the Department of Health and Human Services to the Civil Rights Division of the United States Department of Justice to enforce the Supreme Court's decision in *Olmstead v. L.C.* (1999) was apparently still a priority. The United States Department of Justice (DOJ) intervened in several cases in 2013–14 to enforce the *Olmstead* decision as it relates to deinstitutionalization, waiting list, and access to benefit cases for people with intellectual and developmental disabilities.

For example, the DOJ filed a statement of interest on March 31, 2014 in a case involving children with disabilities with significant medical needs who were being inappropriately placed in nursing facilities rather than in community settings. The DOJ had filed the original lawsuit against the state, *U.S. v. Florida* on July 22, 2013. When the State of Florida moved to dismiss the plaintiff's complaints, the DOJ filed its statement of interest (United States Department of Justice, 2014).

There have been three recent cases that the DOJ intervened in that involved plaintiffs opposing deinstitutionalization. In *Sciarrillo ex rel. St. Amand v. Christie*, a New Jersey case, the DOJ filed a statement of interest in support of the defendants. Private plaintiffs who opposed the deinstitutionalization plan for people with developmental disabilities sought to stop the state from closing two developmental centers as part of the State's *Olmstead* plan. The case was dismissed in 2013.²¹

In the New Jersey case, *Carey et al. v. Christie*, the DOJ filed a Notice of Interest in March of 2013. Plaintiffs "creatively" argued that the ADA should allow them to stay in a state-operated institution. The United States responded that if this case goes to court it would file a Statement of Interest.

And in the Illinois case, *ILADD (Illinois League of Advocates for the Developmentally Disabled) v. DHS*, the United States filed a Statement of Interest in April, 2013. It stated that the plaintiffs claims that the ADA gives

them the right to stop the closure of state-run institutions was not supported. This class action case remains open. According to Priaulx, 2014, p. 23, "A hearing injunction was held in January 2014, after which the Judge ordered both parties to file further information with the Court on issues that arose during the hearing."

The most recent case developments have not been related to deinstitutionalization, access to benefits, or waiting list cases for people with intellectual and developmental disabilities. However, there is evidence that the DOJ is still actively pursuing the mandate. An important example occurred on April 8, 2014, when a settlement agreement was entered involving the State of Rhode Island. It upheld the rights of individuals who have been segregated in sheltered workshops and day programs to access alternative employment options. This agreement affects 3,250 individuals with intellectual and developmental disabilities in the State over a ten year period. The State will provide supported and integrated employment opportunities, and also transition services for youth as they enter the workforce.

Enforcing *Olmstead*. Although the Department of Justice has made *Olmstead* enforcement a priority, more needs to be done according to the United States Senate's Health, Education, Labor, and Pensions Committee. In 2013, the Committee issued a report "Separate and Unequal: States Fail to Fulfill the Community Living Promise of the Americans with Disabilities Act. The report states that: "Congress should amend the ADA to clarify and strengthen the law's integration mandate in a manner that accelerates *Olmstead* implementation (p. 4)."

To prepare this report, then Chairman of the Committee Senator Tom Harkin requested information on the HCBS Waiver use from the Governors of all 50 states. His purpose was to learn if states were actually providing opportunities for individuals with disabilities to live independently, among other data relevant to the implementation of the ADA. Harkin received responses from only 33 states, two of which declined to provide information due to pending *Olmstead* litigation. Seventeen states did not respond at all.

As a result of this investigation, the Committee made many recommendations, among them to create a high-level interagency task force, to make it clear to the states that they are obliged to comply with the Supreme Court's 1999 *Olmstead v. L.C.* decision.²²

20. <http://www.ndrn.org/issues/communityintegration/304-olmstead-progress-report.html>

21. <http://www.justice.gov/crt/about/spl/findsettle.php>

22. http://www.harkin.senate.gov/documents/pdf/Olmstead_Report.pdf

Recent Federal Government Initiatives

The Deficit Reduction Act (DRA) of 2005 (P.L.109–171) authorized \$11.5 billion in Medicaid spending reductions during 2006–10 and \$43.2 billion by 2015. However, Section 6071 of the DRA also contained provisions for persons with disabilities that included grants for Money Follows the Person (MFP) rebalancing services demonstration projects.

The MFP's intent was four-fold: 1) increase the utilization of home and community-based services (HCBS) in the states while reducing reliance on institutional services; 2) enable Medicaid-eligible individuals to receive long-term services and supports (LTSS) in the setting of their choice; 3) strengthen HCBS provisions for those who choose to transition out of institutional settings; and 4) make available quality assurance and improvement procedures. In turn, states benefitted from provisions that included an enhanced Federal Medical Assistance Percentage (FMAP), reimbursement for additional administrative costs, and technical assistance (Centers for Medicare and Medicaid Services, 2012a).

By June 2013, over 35,000 people with chronic conditions and disabilities transitioned from institutions into the community through MFP programs. The Affordable Care Act (ACA) of 2010 strengthened and expanded the MFP program by allowing more states to apply. Currently, only six states are *not* participating in the MFP demonstration: Alaska, Arizona, Florida, New Mexico, Utah, and Wyoming. In addition to extending the MFP through 2016, the ACA included three additional system rebalancing initiatives: 1) the Community Living Assistance Services and Supports Act, 2) State Balancing Incentive Payments Program, and 3) the Community First Choice Option.

The Community Living Assistance Services and Supports Act (CLASS) (Sen. Edward Kennedy, D-MA, S. 1758; Rep. Frank Pallone, D-NJ, H.R., 3001) would have created a national voluntary insurance program. However, the proposed CLASS Act was repealed in the “fiscal cliff” negotiations and legislation of January 2, 2013 (H.R. 8).

The State *Balancing Incentive Payments* program (BIP), effective October 1, 2011, was a non-competitive grant program intended to provide states a temporary financial stimulus to increase the use of HCBS through enhanced FMAP rates. Required reforms included a single point of services entry, conflict-free case management, and utilization of core standardized assessment instruments.

Eligible states must have spent more than 50% of Medicaid long-term services and supports (LTSS) funds on institutions in federal fiscal year 2009. States could have applied through August 1, 2014, or until total BIP funding reached its limit of \$3 billion in federal matching payments, whichever occurred first. States in which 25–50% of Medicaid spending was for non-institutional LTSS were eligible for a 2% FMAP increase. States in which less than 25% of total Medicaid spending was for non-institutional LTSS were eligible for a 5% FMAP increase (Centers for Medicare and Medicaid Services, 2012b). States that received a 2% enhanced FMAP had to achieve a 50% benchmark of total expenditures on non-institutional LTSS, while states receiving a 5% enhanced FMAP must achieve a 25% non-institutional LTSS by the BIP expiration date of September 30, 2015 (Centers for Medicare and Medicaid Services, 2012c).

By September 2014, 20 states had been approved by CMS for Balancing Incentive Payments: Arkansas, Connecticut, Georgia, Illinois, Indiana, Iowa, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Mississippi, Missouri, Nevada, New Hampshire, New Jersey, New York, Ohio, Pennsylvania, Texas. Among these states, all but Massachusetts, Nevada and Pennsylvania also had “structural change work plans,” i.e., revised BIP plans.

Twelve states and the District of Columbia were determined to be ineligible for BIP participation because their spending on HCBS exceeded 50%: Alaska, Arizona, California, Colorado, District of Columbia, Kansas, Minnesota, New Mexico, Oregon, Vermont, Washington, Wisconsin, and Wyoming.

The Community First Choice option, (CFC), initially introduced in both the House and Senate in 2007 and again in 2009 as a stand-alone piece of legislation, was also included in the ACA. This new state plan option was intended to expand community-based Medicaid coverage by providing person-centered attendant services and supports for individuals determined to need an institutional level of care.

Services are required to be delivered in the most integrated setting appropriate to the individual's needs. Originally scheduled to begin October 2011, final rules were not released until April 26, 2012 (Centers for Medicare and Medicaid Services, 2012d) with an implementation date of July 6, 2012, and an end date of May 31, 2015 (Community First Choice Option, 2012). States electing participation in CFC are eligible for a 6% FMAP increase conditioned on eligibility requirements

that include: stakeholder input, a quality assurance system, and maintenance of comparable expenditures from the previous 12 months, commonly referred to as maintenance of effort, or MOE (Sebelius, 2014).

The definition of a “home and community setting” has been discussed extensively. There are now final rules and guides.²³ The Centers for Medicare and Medicaid Services, National Association of State Units on Aging and Disability (NASUAD), National Senior Citizens Law Center (NSCLC.org), and other organizations have produced technical assistance guidelines for implementation of the CMS “community settings” rules.

In addition to legislative efforts to increase community-based services and supports, there were recent structural changes within DHHS. In April 2012, Secretary Kathleen Sebelius announced the creation of the Administration for Community Living (ACL) a single agency overseeing the Administration on Aging, the Office on Disability, and the Administration on Intellectual and Developmental Disabilities. The ACL was mandated to “enhance and improve the broad range of supports that individuals may need to live with respect and dignity as full members of their communities” (United States Department of Health and Human Services, 2012). ACL’s chief administrator is Principal Deputy Assistant Secretary Sharon Lewis.

Technology Initiatives in the States

In the findings section of the Assistive Technology Act as Amended in 2004 (AT Act), Congress stated that access to assistive technology, “. . . increase[s] involvement in, and reduce[s] expenditures associated with programs and activities that facilitate communication, ensure independent functioning, enable early childhood development, support educational achievement, provide and enhance employment options, and enable full participation in community living for individuals with disabilities.”

The AT Act provides federal funds to states and territories for 56 statewide comprehensive assistive technology resource programs that support persons of all ages with disabilities with their assistive technology needs.

The majority of program funds must support four areas of activities: 1) state finance systems, 2) device reutilization programs, 3) device loan programs, and 4) device demonstrations. States and territories are also required to develop leadership activities that include public awareness and information dissemination, technical assistance and coordination, and collaboration.

The Center for Assistive Technology Act Data Assistance (CATADA) collects data related to state AT programs’ activities. CATADA analyzed state AT program data for fiscal year 2013 and found that all of the 57 state and territories now have AT programs. The programs collectively provided 49,325 assistive technology devices for short-term loans. The average length of a loan was 34 days. Forty-seven percent of the loans were directly to individuals with disabilities, followed by family members, guardians, and authorized individuals. Communication aids constituted the most commonly loaned AT devices (18%), followed by daily living and learning and cognition devices (16%).

All states also reported on data related to reutilization of AT device programs. A reported 38,258 individuals received reutilized AT devices at an estimated \$21.6 million in savings to consumers. In addition, over \$9.2 million in financial loans were reported for 40 state programs (Center for Assistive Technology Act Data Assistance, 2014).

Medicaid is an important source of financing for assistive technology (AT). There are several means by which Medicaid can finance technology support. First, Medicaid’s category of “durable medical equipment” funds medically necessary devices including aids for daily living, prosthetics and orthotics, aids for vision and hearing impairments, wheelchairs and other mobility aids. Second, other “mandatory” Medicaid services, such as Early and Periodic Screening, Diagnosis and Treatment (EPSDT), finances assistive technology and home health. Third, Medicaid “optional” programs, including rehabilitative services and physical therapy, finance technology such as augmentative and alternative communication (AAC), mobility aids, and AT devices.

The HCBS Waiver also has a specific “assistive technology” Waiver service available in most states. Virtually all states finance technology to some degree through the Waiver or the Medicaid State Plan. However, states have different terminology and authorization requirements. Some states also have annual or lifetime limits on technology payments (Moore & O’Connell, 2006).

23. <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Downloads/HCBS-setting-fact-sheet.pdf>

In 2010, President Obama signed into law The Twenty-First Century Communications and Video Accessibility Act of 2010 (Pub. L. 111–206). The act requires new technologies such as smart phones and other emerging digital communication technologies to be accessible to individuals with hearing impairments, or who are deaf, blind or have low-vision. The act provides \$10 million in funding each year for assistive technologies for people with sensory disorders.

The law does not specifically promote cognitive accessibility guidelines or specifically include people with IDD, but its safeguards and requirements benefit people with IDD through adaptations and modifications to meet the needs of all people with disabilities (Twenty-First Century Communications and Video Accessibility Act, 2010).

Smart homes and remote supports. One particularly notable assistive technology initiative for persons with IDD is increased research, development and utilization of “smart homes.” A smart home is “one where smart technologies are installed to facilitate automatic or user-initiated communication involving a range of appliances, sensors, actuators and switches. In smart homes, communication takes place between devices to serve and empower people and, in so doing, improve their quality of life” (Fisk, 2001, p. 10).

Smart homes also may be structured to enhance activities of daily living and promote health and wellness, employment, and community integration (Rizzolo, Bell, Braddock, Hewitt, & Brown, 2005). Smart homes typically combine human tracking technology, environmental automation, and ubiquitous computing to promote independence and monitor health status in real time (Dewsbury, Clarke, Rouncefield, Somerville, Taylor, & Edge, 2003; Storey, 2010). Such technologies can be useful in complementing the activities of direct support staff in long-term care facilities and in family support settings as well (Braddock, Rizzolo, Thompson, & Bell, 2004; Dawe, Fischer, Gorman, Kintsch, Konomi, Sullivan, Taylor, & Wellems, 2005). The State of Indiana’s Medicaid agency has authorized a special reimbursement rate structure for providers utilizing smart home technology. The rate structure recognizes reductions in staff levels made possible by such utilization.

An innovative Colorado community services agency, *Imagine!*, has opened three smart homes for people with IDD in Boulder and Longmont, Colorado. Construction of the homes was supported by Housing and Urban Development (HUD) funds, local

government, the Colorado state IDD agency, and private donations. The homes began serving consumers in 2008 and 2010 (*Imagine!*, 2014).

Rest Assured, a venture of ResCare, Inc., utilized extensive remote monitoring technologies for people with IDD. In 2014, it supported 200 consumers at 125 sites, an increase from 107 consumers in 49 homes in 2011 (personal communication, D. Wright, General Manager, Rest Assured, LLC, September 10, 2014). Rest Assured reports increased consumer independence since caregivers are not a constant presence in the home.

Sound Response/Night Owl, Inc., in Dane County, Wisconsin supports 425 people, in 260 residences in Indiana, Vermont and Wisconsin (personal communication, Chris Patterson, Sound Response, September 10, 2014). This is an increase from 197 persons and 130 residences in 2008.

Although the emergence of smart home technologies and remote supports, including innovations such as telecare, can provide people with IDD greater opportunity for self-direction and improve quality of life, there are some caveats. Great care must be taken by providers to ensure that such technologies do not impede self-determination by limiting choice and control through over-reliance on automation. In addition, lifestyle monitoring by third parties without informed consent is not appropriate (Fisk, 2001; Perry, Beyer & Holm, 2009).

Technology pilot survey and the HCBS Waiver.

As a part of this year’s State of the States study, we completed a pilot survey in several states and District of Columbia on participants and spending levels for consumers with IDD utilizing smart homes, remote supports, and personal support technologies. Five states reported spending for smart homes and remote supports: Colorado, Missouri, Montana, Ohio and South Carolina. An additional three states (Arizona, New Mexico, and Pennsylvania) reported spending for personal support technologies. The five states reporting smart homes/remote support spent \$925,000 for 328 participants in 2013. The three states that reported utilizing personal support technology spent \$5.5 million for 1,461 participants. The HCBS Waiver was the primary funding source in these states for these technologies.

There is, however, quite a bit more activity in the states in technology. Rizzolo, Friedman, Lulinski-Norris, & Braddock (2013), in a comprehensive nationwide analysis of HCBS Waiver services and spending in 2010, reported that Waiver spending across states

totaled \$287.0 million for “assistive and medical technologies” and totaled an additional \$126.2 million for “assistive technology and environmental modifications.” Forty of the 42 reporting states utilized “assistive and medical technologies” as a service in one or more of their Waivers.

Due to diverse expenditure tracking methodologies and variations among Waiver definitions across states, specific categories of technology spending are difficult to determine. Friedman (in press) has focused on electronic monitoring in HCBs Waivers across the states. In a subsequent study, we propose to utilize state-by-state Waiver data to assist data collection on smart home/remote supports and personal support technology data in the states.

According to Rodney Bell, a leading technology consultant:

Despite the advantages of emerging technology, usage remains low (less than 1% of residents with IDD) due to rigid reimbursement rates, rules that favor in-person services, inertia against change, and uncertainty about efficacy or impact. At lower prices, families can implement

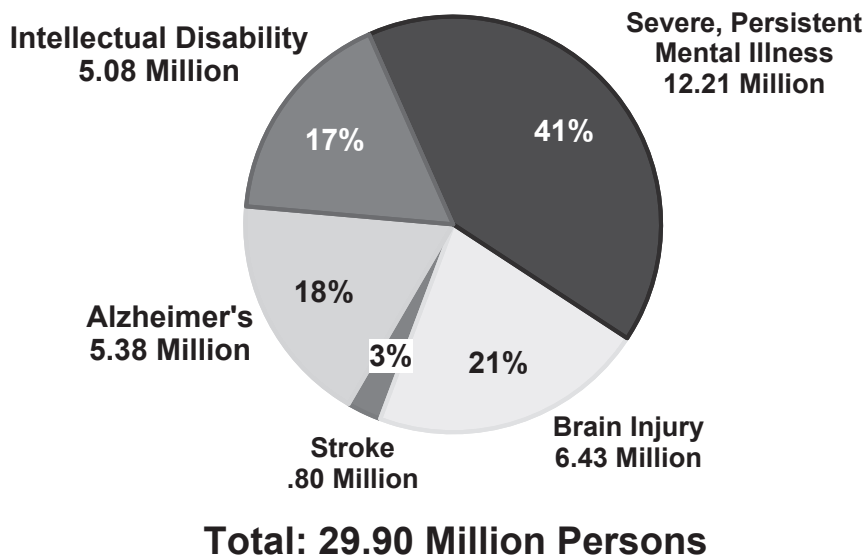
do-it-yourself remote supports, such as those widely available in senior care. To better support governance of this emerging technology there is a need for more data on technology uptake by people with cognitive disabilities and their families. (personal communication, Rodney Bell, ASSET Consulting, LLC, Portland, Oregon, November 6, 2014).

Coleman Institute for Cognitive Disabilities

The Coleman Institute for Cognitive Disabilities is a resource in cognitive support technology for people with intellectual and developmental disabilities. The Institute’s mission is to catalyze and integrate advances in science, engineering, and technology to promote quality of life and independent living for people with cognitive disabilities. It’s a big market. There are an estimated 30 million citizens with cognitive disabilities in the U.S., as illustrated in Figure 29 below.

The Institute is actively engaged in supporting research, development, dissemination, and education in

Figure 29
PREVALENCE OF COGNITIVE
DISABILITY IN THE U.S., FY 2013



Source: D. Braddock. (2015). Boulder, CO: University of Colorado, Coleman Institute for Cognitive Disabilities.

cognitive disabilities on the four campuses of the University of Colorado (in Boulder, Colorado Springs, Denver, and at the Anschutz Medical Campus in Aurora).

A hallmark of the Institute is its annual conference held in the fall, bringing together over 600 leaders nationwide in the fields of technology and intellectual disability. The use of computer-related technologies for communication, education, health and work has become ubiquitous in developed countries; but the inaccessibility of such technologies to people with IDD has created a new meaning for the term *digital divide* (Rizzolo & Braddock, 2008).

At the 13th Annual Coleman Institute National Conference on Cognitive Disability and Technology in 2013, a coalition of disability organizations and individuals articulated the concept of a “right to technology and information access” by people with cognitive disabilities (Braddock, Hoehl, Tanis, Ablowitz, & Haffer, 2013). A formal Declaration was produced, entitled: *The Rights of People with Cognitive Disabilities to Technology and Information Access*. This article and *The Declaration* appear in the Appendix.

As of November 2014, The Declaration had been signed by 200 national, state, and local organizations including American Network of Community Options and Resources (ANC-OR), The Arc/United States, and the American Association on Intellectual and Developmental Disabilities (AAIDD).²⁴ Individual signatories include self-advocates, family members, professionals, and community service providers including technology providers. The Declaration has become a rallying point for advancing the legal right to technology inclusion for people with cognitive disabilities. The Colorado Legislature recently unanimously voted to adopt a resolution in support of The Declaration. Other states are now considering adoption of the resolution as well.

At the 14th Annual Coleman Institute Conference in October 2014, noted attorney and Professor Peter Blanck of Syracuse University presented his new book, *e-Quality: The Struggle for Web Accessibility by People with Cognitive Disabilities*. The book was commissioned by the Coleman Institute and distributed to all conference participants. It provides a comprehensive

overview of the current state of the field and appeals to a worldwide audience.

Market forces, of course, will primarily drive advances in cognitive technologies as our nation ages. However, regulatory policies and standards have not kept pace with the growing need for more broadly inclusive accessibility standards for people with cognitive disabilities such as intellectual disability. Organizations such as the U.S. Access Board and the World-Wide-Web Consortium have begun to address web accessibility, but the principles of the ADA are still unrealized with respect to technology access for people with cognitive disabilities—as the need for The Declaration suggests (Karreman, van der Geest, & Buursink, 2007).

Cognitive support technologies take many forms (LoPresti, Bodine, & Lewis, 2008). Personal digital assistants are being used as prompting or memory aids and can enhance the ability of a person with an intellectual disability to perform job tasks, remember the steps to prepare a meal, and promote a healthy lifestyle. PDA-based software systems with Global Positioning System (GPS) technology enable people with IDD to navigate a bus route independently (Davies, Stock, Holloway, & Wehmeyer, 2010). Technology programs using pictures and voice-driven messaging can facilitate social communication, employment activities, and promote healthy behaviors (Braddock et al., 2004; Bryen, Carey, & Friedman, 2007; Davies, Stock, & Wehmeyer, 2001).

As noted technology consultant Rodney Bell has pointed out, the future is promising:

Rapid changes in technology offer many new options that have outpaced policies and rules for public funding. People with cognitive disabilities and their families are increasingly turning to general-purpose smart mobile devices, rather than to limited-purpose reimbursable devices such as Augmentative and Alternative Communication (AAC) which can cost 10 times more than smart mobile devices. The increased use of small, personal devices is supported by the diversity and number of applications, the popularity of conference sessions about these apps, support from educational and public organizations for buying and using smart mobiles, and anecdotal success stories. And, individuals and families are increasingly using the Internet for social engagement, news, and entertainment—without public funding, but with some support from service providers. (Bell, personal communication, November 6, 2014).

24. See the Appendix and/or the Institute's website (<http://colemaninstitute.org/declaration>) for information about the Declaration and to read the AAIDD *Inclusion* article on the rights of people with cognitive disabilities to technology and information access (Braddock, et al., 2013).

University-based centers on cognitive technologies. In addition to spearheading the development and dissemination of *The Declaration of the Rights of People with Cognitive Disabilities to Technology and Information Access*, the Coleman Institute has developed and disseminated recommendations pertaining to the advancement and diffusion of applied cognitive support technologies for people with IDD in the United States (Braddock, 2013, 2002; Rizzolo et al., 2005). One key recommendation is developing several university-based centers on cognitive technology research, development and dissemination. The centers could be based in the existing national network of University Centers for Excellence in Developmental Disabilities (UCEDDs), and link with computer science departments and engineering colleges.

The proposed centers would advance the field of applied cognitive technology and “provide research and development to provide technology supports that enable people with cognitive disabilities to successfully

function in inclusive environments, and to promote social inclusion, self-determination, and quality of life” (Wehmeyer & Shogren, p. 92, 2013). Such centers would not only include trainees from the traditional disability related areas such as medicine, psychology, physical therapy, occupational therapy, special education, and social work. They would also include trainees from computer science, business, marketing, electrical and computer engineering, natural science and mathematics.

Core funding for a UCEDD-based applied cognitive technology initiative should include resources from federal agencies such as the U.S. Administration on Intellectual and Developmental Disabilities, the National Institute on Disability and Rehabilitation Research, and the U.S. Department of Commerce. Corporate and foundation partners, persons with IDD and their families, and community service providers must play an important role in this collaborative effort as well.

IX. SUMMARY OF THE STUDY

Intellectual and Developmental Disabilities Spending Growth Slows Down

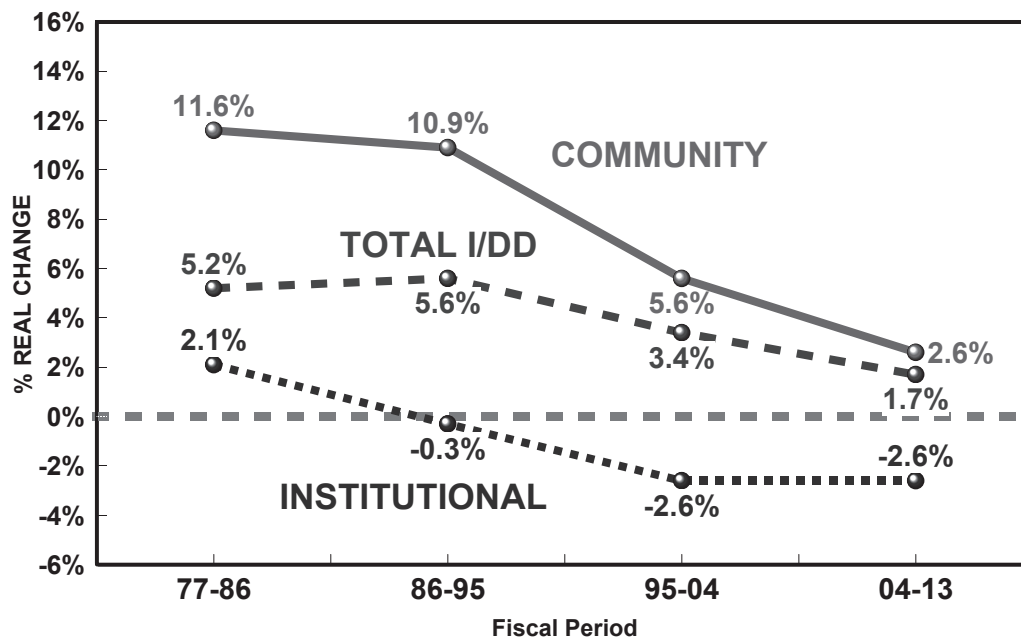
Total average annual IDD inflation-adjusted spending by decade continues to grow, but that growth has slowed down significantly. Institutional spending dropped rapidly during 1977–1995 and leveled off to a negative 2.6% from 1995–2013. The community services component of IDD spending exhibited positive growth continuously; but the average rate of that growth to 2.6% above the rate of inflation (Figure 30 below).

Four major factors influence growing demand for IDD community services: a) aging family caregivers struggling to support their adult children with IDD; b) litigation promoting access to funding for community services; c) increasing longevity of persons with IDD; and d) downsizing and closure of public and private IDD institutions.

The 2011–13 growth rate for community services spending slowed down in eight states, by 0.2% to 9.6%. Twelve states reduced community services spending on an inflation-adjusted basis in 2013. This followed reductions in 13 states in 2012 and 27 states in 2011 as the recession's impact moderated.

During fiscal years 2011–13, total nationwide adjusted IDD spending grew by an average 3.3% per year. Spending fell 0.6% in 2011. This was the slowest growth rate in total IDD spending in our 37 years of data collection. The growth rate recovered significantly in 2012 (4.2%); and, to a lesser degree, in 2013 (2.4%). The 2011–13 average annual growth rate (3.3%) was well above the annual growth of 0.5% during 2009–11. Spending growth for IDD services in 2013 (2.4%) was roughly equivalent to the growth rate for the overall United States economy (2.2%), as measured by Gross Domestic Product (GDP).

Figure 30
AVERAGE ANNUAL PERCENTAGE CHANGE IN
INFLATION-ADJUSTED I/DD SPENDING BY DECADE: U.S.



Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

Local funding was another important funding stream for IDD services impacted by the *Great Recession* in a number of states. Local government IDD spending declined 4% per year in real economic terms during 2009–11. Local spending was also negative 4% during 2011–13. However, local governments including counties, municipalities, and special districts, accounted for only 2.5% of total IDD spending in 2013. In 13 states with significant county funding, these resources were critical to the solvency of community services organizations and family support.

U.S. Fiscal Effort for IDD Services Declined in FY 2013

Fiscal effort is defined as federal, state and local government spending for IDD community and institutional services per \$1,000 of statewide personal income. This analysis adjusts for the wealth (capacity) of a given state. Total IDD fiscal effort increased 4% in 2010 but dropped by 3% in 2011. It grew 2% in 2012 and dropped again in 2013 by 2%.

Total fiscal effort for consolidated IDD services fell during the 1995–97 and 1997–99 periods by 0.6% and 0.8%, respectively. These were the only other periods in which total IDD services fiscal effort levels declined during the 37 years of our Project. Average IDD fiscal effort growth was only 0.3% per year in 2009–11. It was even less, 0.04% per year, during 2011–13.

Community services fiscal effort increased nationally by only 0.9% per year during both 2009–11 and 2011–13. In contrast, fiscal effort for public/private 16+ institutions (excluding nursing facilities) declined 3% per year during 2009–11, and an additional 5% during 2011–13. Institutional fiscal effort declined in 29 states during 2011–13.

Census of Public and Private Institutions Continues to Decline

The census of state-operated IDD institutions for 16 or more persons declined 17% in 2011–13, falling from 29,576 to 24,675. This was an average annual percentage reduction of 9%, which significantly exceeded the annual reduction rate during 2009–11 (6%). Thirty-five of the 37 states financing state institutions reduced their censuses. Only Montana and South Dakota increased their institutional census: by four and one person, respectively. Utah had no institutional census change during 2011–2013.

The national census of privately-operated 16+ institutions fell 2% to 22,256 persons during 2011–13. However, this percentage decline was significantly less than the 17% census reduction in state-operated facilities. In total, the combined census of publicly and privately-operated 16+ person institutions in the U.S., excluding nursing facilities, declined by 5,465 persons during 2011–13, a reduction of 10%. The nursing home census of persons with intellectual and developmental disabilities fell by 4,666 persons to 26,678, a 15% reduction. Eight states, however, reported an increase in nursing home census. Five states reported no change.

Thirty-four states and DC operated ICFs/ID for 7–15 persons. The nationwide census in these facilities declined by 639 persons during 2011–13 (3%). In contrast, the census of 7–15 person group homes not certified as ICFs/ID increased by 402 persons to 35,907 residents in 2013 (1%).

Growth Rate for Community Services and Supports Slows FY 2011–13

During 2011–13, total out-of-home IDD residential placements nationally increased by 20,765 persons to 634,509. This was an average annual increment of 1.7%, well below the 2.9% average growth rate in this sector during 2009–11. Eighty percent of the 634,509 persons with IDD in out-of-home placements in 2013 are now living in settings for six or fewer persons.

Fifty-eight percent of the individuals in six or fewer settings were in supported living. The remaining 42% lived in group homes for six persons or less including ICFs/ID, foster and host homes, and apartments. The number of individuals living in settings for six or fewer persons increased by 7% during 2011–13. This is an average growth rate of 3.2% per year, but it is well below the 4.8% annual increase seen during 2009–11.

Significance of Medicaid HCBS Waivers

The Medicaid program continued to provide a large and growing proportion of total nation-wide public IDD spending in the U.S. It reached 78% of total IDD spending in 2013. Spending for the HCBS Waiver is the largest component of Medicaid IDD spending. It alone constituted 51% of total IDD spending in 2013. This compared to 21% for ICFs/ID.

Total HCBS Waiver inflation-adjusted spending grew from \$28.5 billion in federal, state, and local

dollars in 2011 to \$31.4 billion in 2013, a growth of 10%. The HCBS Waiver supported 685,828 participants. Federal-state Waiver spending adjusted for inflation increased 9% in 2012 and 4% in 2013. The average annual adjusted growth rate during 2011–13 (7%) significantly exceeded the annual growth rate during 2009–11 (4%). However, during 2006–08 the average annual Waiver spending growth rate was greater (11%).

In contrast to the continuing growth of HCBS spending nationally, total adjusted ICF/ID program spending increased marginally from \$12.8 billion in 2011 to \$13.0 billion in 2013. However, this 2.0% increase in real ICF/ID spending contrasts with a 4.8% decline during 2009–11.

Supported living commitments vary across states. The average cost of care for persons in supported living varied greatly across states and within states. Supported living spending per person ranged from a high of \$94,899 in Oklahoma to a low of \$4,982 in South Dakota. The fifty states and DC all reported that they provided supported living and/or personal assistance services to 293,956 persons with IDD in 2013. Adjusted spending grew by an average of 3% per year on a national basis during 2011–13, compared to a 4% annual growth rate during 2009–11.

The HCBS Waiver financed 86% of supported living and personal assistance spending in 2013. Waiver funding constituted 100% of supported living/personal assistance spending in 23 states.

Number of workers in supported employment declines. States spent \$868 million in FY 2013 to support 98,604 workers with IDD—not including 16,031 follow-along work support participants in 19 states. States are increasingly reliant on Medicaid HCBS Waiver dollars to fund supported employment initiatives. In 2013, the HCBS waiver program funded 69% of supported employment spending in the U.S. This was more than double the 27% rate 12 years earlier.

The proportion of supported employment workers in combined day and work programs managed by state IDD agencies was 20.2% in 2011, 19.2% in 2012, and 19.4% in 2013. These were the lowest rates since the peak of 22.8% in 2000.²⁵

Family support declines. Inflation-adjusted total family support spending stabilized at \$4.1 billion during 2011–13, but the number of families supported

declined slightly from 464,989 families in 2011 to 464,043 families in 2013. Cash subsidy payments to families were being provided in only 18 states in 2013, an increase from 17 states in 2012, but less than the 24 states with subsidies in 2008.

The average annual subsidy payment nationally was \$2,660 per family and it ranged from \$58 to \$14,442. Arkansas (in 2009); Kansas and New Jersey (2010); Tennessee (2011); and New Hampshire, New Mexico, and Texas (2012) have ceased providing cash subsidies. In 2012, Virginia joined Utah in not providing family support services; however, Virginia established a new cash subsidy in 2013.

In 2013, the HCBS Waiver financed 82% of family support services spending nationally. Family support spending, however, remains a small component of total spending for IDD services: only 6.7% in 2013, down from 7.2% in 2011. State IDD agency family support funding reached only 13.0% of the estimated 3.6 million IDD family caregivers in the U.S. in 2013, down from 13.2% in 2011.

Federal Efforts to Address State Budget Deficiencies

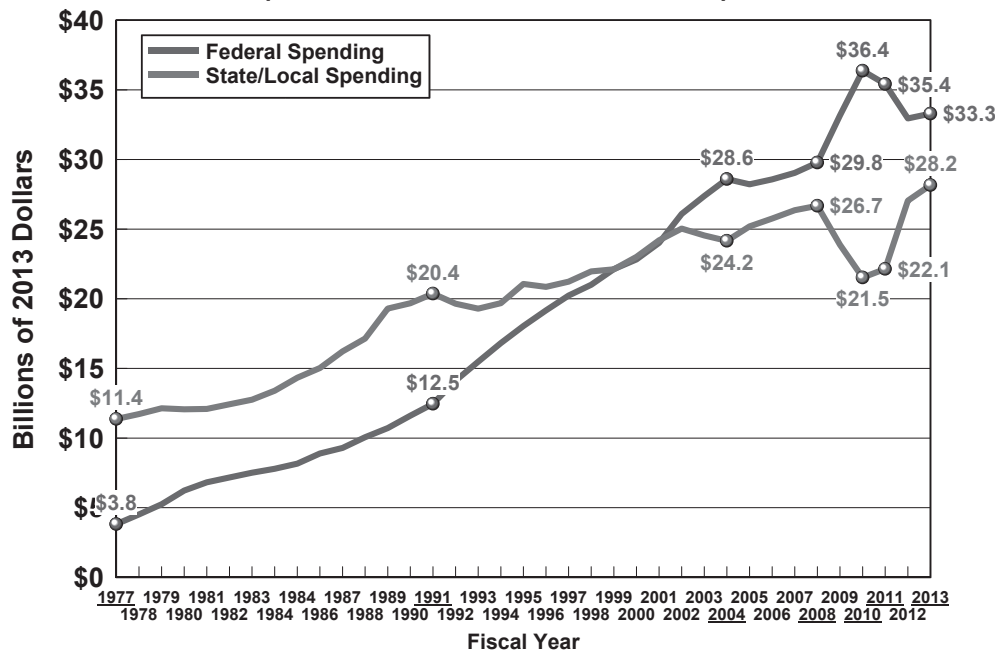
During fiscal years 2006–08, most states had reasonably strong economic and fiscal conditions. However, fiscal years 2009–11 proved to be the most difficult state budget period in the 37 years of the State of the States Project's data collection efforts. Figure 31 on page 80 compares inflation-adjusted federal and state spending in the states from 1977 through 2013. Note the countercyclical federal spending versus state spending from 2010–12. The influence of the Great Recession is evident in the divergence during 2009 to 2011 of state and federal spending for IDD services. The Federal government utilized enhanced Federal Medical Assistance Percentage (FMAP) to mitigate the effects of the Recession.

From 2008 to 2010, adjusted federal spending increased 22%, state spending dropped 19%, and total IDD adjusted spending increased 3%. From 2010 to 2012, as state FMAP rates returned to pre-Recession levels, state spending jumped 26% in adjusted terms, federal spending dropped 9%, and total spending grew 4%. Total IDD spending, and the relative federal and state share of spending, was back on the course established in 2008 before the Great Recession.

The enhanced FMAP rates provided essential assistance to state IDD agencies' reimbursements for HCBS

25. For more comprehensive data on employment services for persons with IDD, see: www.statedata.info

Figure 31
STATE AND FEDERAL I/DD SPENDING: FY 1977-2013
(ADJUSTED FOR INFLATION)



Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

Waivers, ICF/ID facilities, and Medicaid optional services such as targeted case management, personal care, and clinic and rehabilitative services. Enhanced FMAP rates also benefitted states' other Medicaid-funded services including reimbursements for physicians, other health care providers, hospitals, and nursing facilities.

As previously noted, total IDD spending grew only an average 0.5% per year during 2009–11. Spending then rebounded to an average growth rate of 3.3% per year during 2011–13. The lack of federal stimulus would have very adversely affected IDD services in the states.

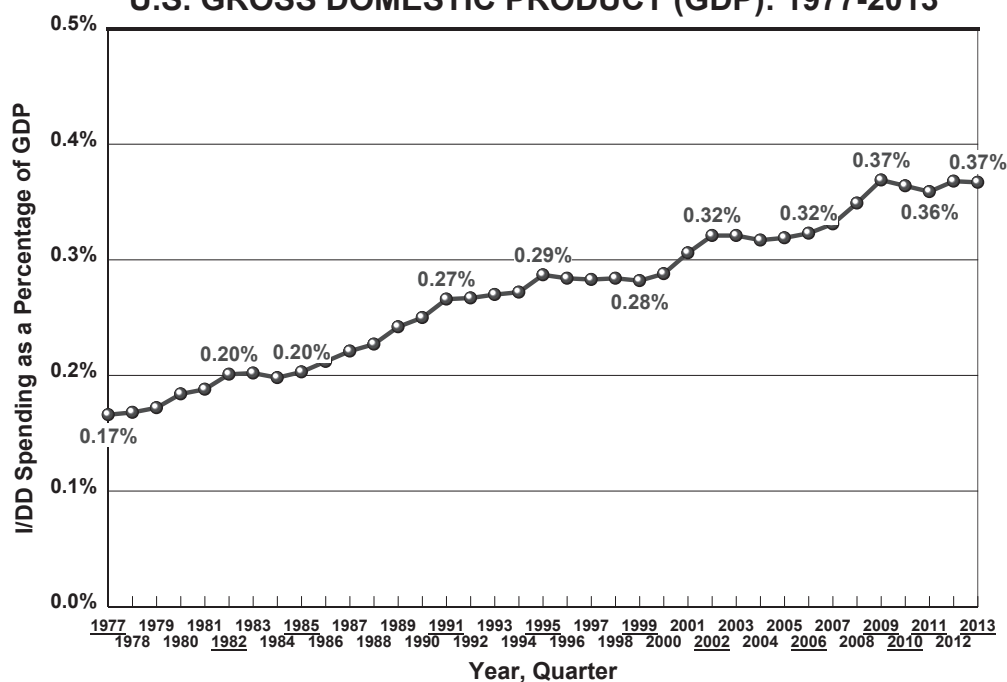
Beginning with the onset of the Great Recession in December 2007, the Federal Government, including the Federal Reserve, employed a number of conventional and unconventional efforts to improve economic conditions across the states. These included, in addition to enhanced FMAP rates, near-zero interest rates and the purchase of Treasury Bonds and other assets, a procedure known as “quantitative easing.” Four Congressional fiscal stimulus programs were implemented: a) the 2008 Troubled Asset Relief Program (TARP) to

recapitalize the banks; b) the 2008 Economic Stimulus Act; c) the 2009 American Recovery and Reinvestment Act; and d) the 2010 Tax Relief, Unemployment Insurance Reauthorization, and Job Creation Act (Alpert, Hockett, & Roubini, 2011).

The American Recovery and Reinvestment Act (ARRA) stimulus funding authorized in 2009 compensated states with \$135–\$140 billion over a two and one-half year period, addressing between 30% and 40% of projected state budget gaps during 2009–11. However, ARRA contributions to address state budget problems dropped to only \$7 billion in 2012 and to \$200 million in 2013 (Oliff, Mai, & Palacios, 2012).

Total IDD spending as a percentage of the U.S. Gross Domestic Product more than doubled between 1977 and 2009. This remarkable growth was driven in part by class action litigation in the states or the threat thereof, and it was driven by the advocacy efforts of The Arc and ANCOR organizations and by individuals with intellectual and developmental disabilities and family advocates. However, as a percentage of GDP, IDD spending

Figure 32
I/DD SPENDING AS A PERCENTAGE OF THE
U.S. GROSS DOMESTIC PRODUCT (GDP): 1977-2013



Source: U.S. Department of Commerce (2014); Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

plateaued during 2009–13, replicating previous plateaus in 2002–06, 1996–00, and 1982–84 (Figure 32 above).

Living on the Fiscal Cliff

On January 2, 2013, enactment of the American Taxpayer Relief Act (H.R. 8) averted the “fiscal cliff” of sequestration, or automatic spending cuts, scheduled to go into effect on January 1, 2013 (American Network of Community Options and Resources, 2013). This was a comprehensive, but temporary, Act. It postponed by two months the sequestration of fiscal year 2013 spending, blocked a scheduled reduction in Medicare physician reimbursement rates, made several Bush-era tax cuts permanent, and did not approve the extension of the temporary payroll tax cut benefiting lower and middle income workers. Contentious issues that emerged during sequestration negotiations included Social Security allocations, Medicare and Medicaid reform, and Affordable Care Act implementation.

Spending policy in H.R. 8 included extending the sequestration to March 27, 2013, and extending long-term unemployment insurance benefits for one year. There was also a change from mandatory to discretionary funding for two programs under the Supplemental Nutrition Assistance Program (SNAP), the food stamp program.

Health care provisions included blocking the scheduled 27% reduction in physicians’ Medicare reimbursement rate through December 31, 2013; extending Disproportionate Share Hospital (DSH) adjustment payments through fiscal year 2022; and repealing the Community Living Assistance Services and Supports (CLASS) Program, a key priority of the late Senator Ted Kennedy that would have established a long-term care insurance option for people with disabilities.

In December 2013, House Budget committee Chairman Paul Ryan (R-WI) and Senate Budget committee Chairwoman Patty Murray (D-WA) reached another temporary, two-year budget deal; but it was not as

comprehensive as H.R. 8 had been. It provided \$63 billion in sequestration relief over the next two fiscal years, but since the sequestration was set to cut about \$180 billion, this deal only provided modest relief. In March 2014, the Senate also approved a one-year delay in the 24% cut in payments to physicians who accept Medicare patients.

On December 13, 2014, by a 56–40 vote, the Senate passed the \$1.1 trillion “cromnibus” (continuing resolution omnibus) legislation, funding most government operations through the remainder of FFY 2015. Virtually all ACL programs were level funded in 2015, including IDD programs.

The bill adheres to the Ryan-Murray spending caps negotiated during last year’s government shutdown, funding most programs to September 30, 2015. The Department of Homeland Security was funded only through February 27 when Congress intends to return to President Obama’s executive order on immigration.

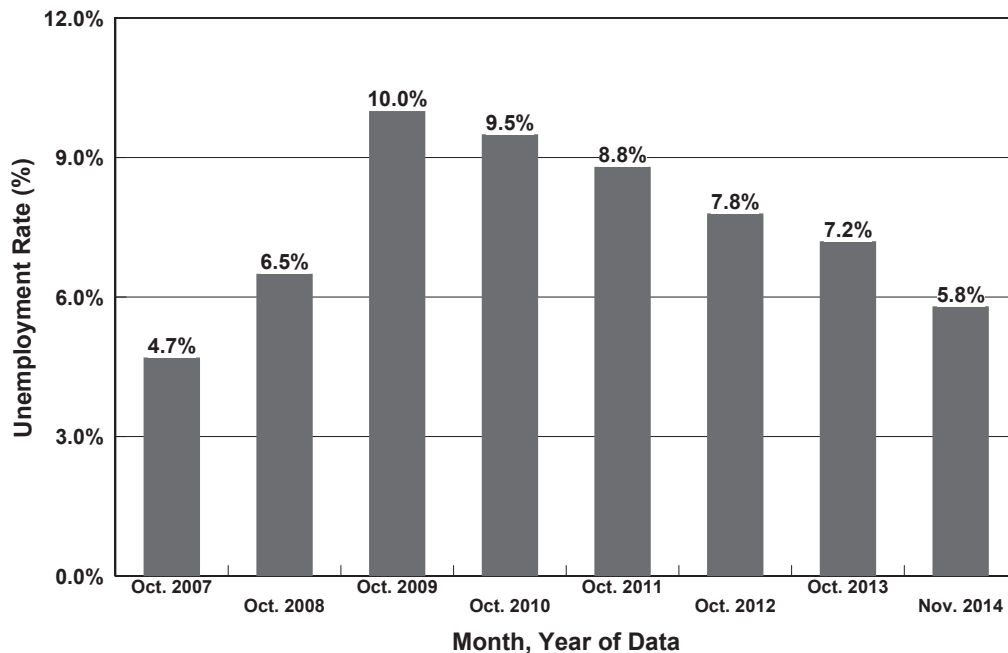
Unemployment Remains High in Most States

Two of the greatest drags on the U.S. economic recovery were plunging home equity values for middle class families coupled with high unemployment rates. Before the Recession, nationwide unemployment was 4.7%.

Unemployment climbed steadily and peaked at 10.0% in October 2009 (Figure 33 below). Despite a steady improvement in the unemployment rate through September 2014, quite troubling is the fact that the nation has not yet returned to the pre-recession unemployment rate of 4.7%.

Moreover, in April 2014 only 12 states had unemployment rates better than the pre-Recession rate of 4.7%. These states were Minnesota, Oklahoma, Louisiana, Hawaii, New Hampshire, Iowa, South Dakota, Utah, Wyoming, Nebraska, Vermont, and North Dakota. The remaining 38 states and DC have unemployment rates ranging from 8.3% in Rhode Island to 4.8% in Montana.

Figure 33
U.S. UNEMPLOYMENT RATE PEAKED DURING THE GREAT RECESSION: REMAINS ABOVE 2007 LEVEL



Source: United States Bureau of Labor Statistics (2014). *Unemployment Rate by Month, January 2004 through November 2014; Seasonally Adjusted; (November 2014 is "preliminary")*

X. CONCLUSION

Economic Inequality Rising

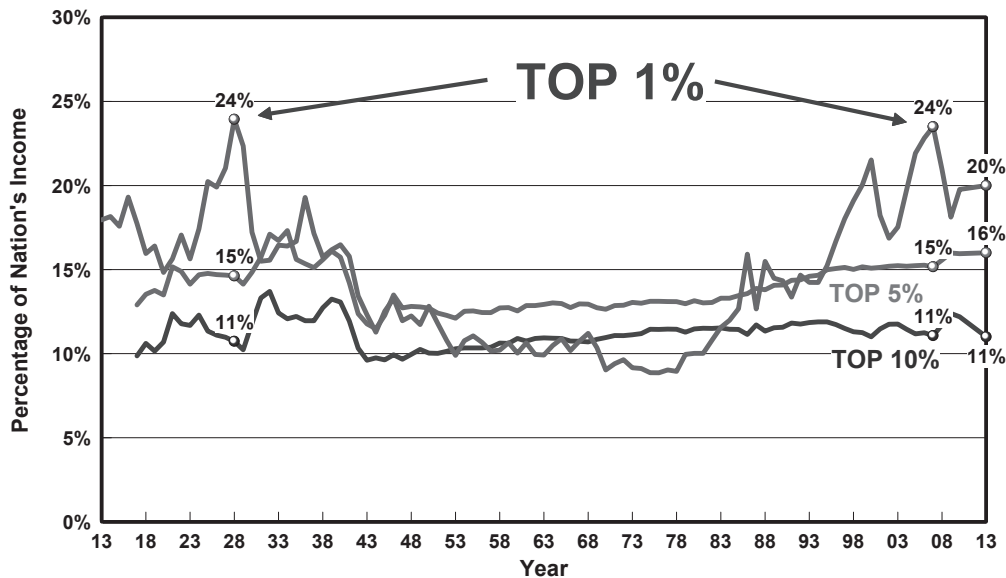
President Obama last year described income equality as “. . . the defining challenge of our time.” Federal Reserve Bank chairwoman, Janet L. Yellen also stated that income equality was “. . . one of the most important issues and one of the most disturbing trends facing the nation” (Appelbaum, 2014).

The concentration of wealth in the United States in 2007–13 was equal to the 1920’s just prior to the Great Depression. The top 1% of U.S. income earners captured 24% of all income earned in the U.S. in 2007—precisely the same as in 1928 (Figure 34 below). Moreover, 50% of the nation’s wealth was received by the top 10% of U.S. income earners in 2007. This also matched the pre-Depression 1928 statistics.

The proportion of income captured by the top 10% of earners was virtually the same in 2013: 47.5%. This is despite the fact that business and asset income declined sharply in the Great Recession and financial crisis. Rising income for the top earning three percent in 2013 contrasts with declining income received by the bottom 90% of the income distribution, which fell to 52.7% of total income in 2013 (Board of Governors of the Federal Reserve System, 2014).

For the most affluent 10% of American families, average incomes rose by 10% from 2011–13. The least affluent families had the largest reductions. Average incomes dropped by 8% for the bottom 20% of families. The Federal Reserve report is broadly consistent with other data on the aftermath of the Great Recession. It confirms why so many Americans think the economy is

Figure 34
U.S. INCOME EARNERS: TOP 10% HAD 50% OF THE NATION'S INCOME--IN 2007 AND IN 1928



Sources: Board of Governors of the Federal Reserve System (2014); adapted from: E. Saez & T. Piketty, Cal-Berkeley and Paris School of Economics, *NY Times*, April 17, 2012.

not improving sufficiently (Board of Governors of the Federal Reserve System, 2014). While the financial pie has grown, most people are getting smaller slices. For the top 10% of families ranked by income, estimated average wealth increased 2% to \$3.3 million, while for the bottom 20% of families, average wealth dropped sharply by 21% to \$65,000 (Applebaum, 2014).

Although young families are better educated than ever before, they are earning smaller real incomes. The median family headed by someone under 35 years of age earned \$35,509. Adjusted for inflation, that income was six percent less than reported for that median family in the first Federal Reserve survey of consumer finances in 1989 (Norris, 2014). Twenty-four years after the 1989 Federal Reserve consumer survey, adjusted incomes of families with heads over 55 years increased, but incomes of families under the age of 55 years declined.

In 1989, the median income of families headed by college graduates was nearly 100% above the median income of families headed by high school graduates. Now the difference is only 52%. The age group with the greatest real income growth over the last quarter century is families with heads aged 65–74 years. Previously, this group's median income was lower than younger families, but now it is higher (Norris, 2014).

Effect on economic growth. Are wealth and income inequalities restricting economic growth in the U.S.? Although French economist Thomas Piketty (2014) argues that wealth concentration is a natural tendency in all market economies, there is growing evidence that inequality is weighing on economic growth by keeping a disproportionate amount of money in the hands of those who already have so much and are less inclined to spend it. Christine Lagarde, the International Monetary Fund (IMF) Managing Director—along with some of the Fund's most powerful shareholders—has stated that inequality threatens longer-run economic prospects. Lagarde said the income gap risked creating “an economy of exclusion, and a wasteland of discarded potential.” The IMF has highlighted a problem that Pope Francis as well as President Obama have called a defining issue of our time. The Fund's potential prescriptions—raising taxes and redistributing wealth—will be a lightning rod for debate in the future (Talley, 2014).

Consider the perspective of one of America's most admired business leaders, Mohammed El-Erian, former head of bond giant PIMCO. El-Erian recently

addressed inequality in an interview with *Bloomberg Business Week*:

The inability [of the U.S.] to bounce back from the global financial crisis, long-term unemployment, youth unemployment, the extent to which we haven't been able to invest in the educational system, lack of labor mobility, and social mobility—all that speaks to inequality of opportunity, which is a major concern, not just for this generation but the next generation. That's new for the U.S. The U.S. always prided itself on being one of the most equal societies in terms of opportunity. . . We control our destiny, but we're talking about [only] 2.5% to 3% growth. If we want more, and certainly need more, then we need the rest of the world to go from providing headwinds to providing some tailwinds. (El-Erian, 2014, p. 54).

Effect on economic security. A significant effect of the Recession on families in the U.S. has been measured by an Economic Security Index (ESI) (Hacker, Huber, Nichols, Rehm, & Craig, 2012). The ESI measures the share of state residents who lost at least one quarter of their available income from one year to the next—whether from income reductions or out-of-pocket medical costs. The ESI is based on the Survey of Income and Program Participation (SIPP) and the Current Population Survey of the U.S. Census Bureau.

Citizens of nearly every state experienced record insecurity during the Great Recession. All states had a substantial rise in economic insecurity from 1986 to 2010. In fact, ESI differences between states were smaller than other indicators such as the poverty and unemployment rates. Hacker et al. (2012) maintain that this indicated that Americans at nearly all income levels and all geographic areas have broad vulnerability to significant income losses.

Economic insecurity affected 14.3% of Americans in 1986. It rose to 18.8% during the recession of March to November, 2001 (National Bureau of Economic Research, 2012). In the aftermath of the Great Recession, it peaked in 2010 at a record 20.4% of American citizens. Roughly 62 million Americans experienced this economic insecurity. The Great Recession's impact on economic insecurity was higher in the South and West and lower in the Northeast and North Central regions (Hacker et al., 2012). As Stiglitz (2012) stated, the Great Recession was devastating for the poorest people in our country. People with cognitive disabilities

and their families were no doubt substantially affected, although we do not have data to confirm this. This area is ripe for future study.

Advancing the Rights of People with Cognitive Disabilities to Technology and Information Access

People with cognitive disabilities in the United States comprise a significant proportion of those individuals most negatively affected by economic uncertainty and growing income inequality. Even though we have made significant strides as a nation in disability rights and progress in service provision in recent decades, growing concentrations of wealth in the United States risks putting millions of people with cognitive disabilities and their families in economic jeopardy.

Compounding this problem and based on FY 2013 data presented in this study, our nation is only increasing financial and services commitments for people with intellectual and developmental disabilities at roughly the rate of the average annual increase of our gross domestic product (2.2% per year). This modest level of resource expansion does not adequately address unmet need for IDD services across the nation; nor does it invest appropriately for the aging of people with intellectual and developmental disabilities and their

families in our society. The modest share of GDP currently being allocated for IDD services and supports in the United States, 0.37% or less during 2009–13, is patently inadequate to address the formidable challenges we face as the nation's baby boom generation becomes increasingly limited in its capacity to provide caregiving at home for their relatives with intellectual and developmental disabilities.

Litigation to address the challenges posed by long waiting lists and other *Olmstead*-related civil rights infractions in the states is poised to become more pervasive and problematic in the future. But it is also becoming very clear that technology supports will need to be utilized increasingly in our service delivery systems in the future as well. It is clear too that the quality and reliability of technology services and supports is not negotiable. Technology must be consistent with high standards of reliability, and be exceptionally person-centered and adaptive to context.

When the *Declaration of the Rights of People with Cognitive Disabilities to Technology and Information Access* is universally accepted by the United States Government and its citizenry as a civil right, and when it is also fully embraced as a valid frontier by technology companies, IDD service providers, and families with relatives with disabilities as well, together we will all have moved one giant step closer to a just and inclusive future for all.

REFERENCES

- Alpert, A., Hockett, R., & Roubini, N. (2011, October). *The way forward: Moving from the post-bubble, post-bust economy to renewed growth and competitiveness* (Research Report). Retrieved from New America Foundation website: http://growth.newamerica.net/sites/newamerica.net/files/policydocs/NAF—The_Way_Forward—Alpert_Hockett_Roubini.pdf
- American Health Care Association. (2014). *OSCAR data reports: Patient characteristics*. [Data file]. Retrieved from www.ahca.org/research/oscarpatient.htm
- American Network of Community Options and Resources (ANCOR). (2013). *Final fiscal cliff deal leaves much uncertain*. Retrieved from: <http://www.ancor.org/-newsroom/news/final-fiscal-cliff-deal-leaves-much-uncertain>
- Applebaum, B. (2014, September 5). 'Least affluent families' incomes are declining, Fed survey shows. *NY Times*, pp. B-2
- Association of People Supporting Employment First (2010). *APSE Statement on Employment First*. Retrieved from <http://www.apse.org/docs/APSE-%20Employment%20First%20Statement%20-%20FINAL-1.pdf>
- Arnold, C. K., Heller, T., and Kramer, J. (2012) Support Needs of Siblings of People with Developmental Disabilities. *Intellectual and Developmental Disabilities*, 50(5), 373–382.
- Assistant Secretary for Planning and Evaluation. (2014). *The 2014 HHS poverty guidelines*. Washington, DC: Office of the Assistant Secretary, U.S. Department of Health and Human Services. Retrieved from www.aspe.hhs.gov/poverty
- Bittles, A. H., Petterson, B. A., Sullivan, S. G., Hussain, R., Glas-son, E. J. & Montgomery, P. D. (2002). The influence of intel-lectual disability on life expectancy. *Journal of Gerontology: Medical Sciences*, (57A)7, M470–M472.
- Blanck, P. (1998). *The emerging workforce: Employment integra-tion, economic opportunity, and the Americans with Disabil-ities Act; Empirical study from 1990–1996*. Washington, DC: American Association on Mental Retardation.
- Blanck, P. (2014). *e-Quality: The Struggle for Web Accessibility by People with Cognitive Disabilities*. Cambridge, UK: Cam-bridge University Press.
- Board of Governors of the Federal Reserve System. (2014, Sep-tember 5). Changes in U.S. Family Finances from 2010 to 2013: Evidence from the Survey of Consumer Finances. *Fed-eral Reserve Bulletin*, 100(4)
- Bogenschutz, M. D., Hewitt, A., Nord, D., & Hepperlen, R. (2014). Direct support workforce supporting individuals with IDD: Current wages, benefits, and stability. *Intellectual and Developmental Disabilities*, 52(5), 317–329.
- Braddock, D. (2013, July 17). *Testimony for the Congress Long Term Care Commission, Dirksen Federal Building, United States Capital Complex*. Washington, DC.
- Braddock, D. (Ed.). (2002). *Disability at the dawn of the 21st Century and the state of the states*. Washington, DC: Ameri-can Association on Mental Retardation.
- Braddock, D. (1986). Federal assistance for mental retardation and developmental disabilities II: The modern era. *Mental Retardation*, 24, 175–182.
- Braddock, D. (1981). Deinstitutionalization of the retarded: Trends in public policy. *Hospital & Community Psychiatry*, 32(9), 607–615.
- Braddock, D., & Fujiura, G. (1991). Politics, public policy, and the development of community mental retardation services in the US. *American Journal on Mental Retardation*, 95, 369–387.
- Braddock, D., & Fujiura, G. T. (1987). State government finan-cial effort in mental retardation. *American Journal of Mental Deficiency*, 91(5), 450–459.
- Braddock, D., & Heller, T. (1985). The closure of mental retarda-tion institutions I: Trends in the United States. *Mental Retar-dation*, 23, 168–176.
- Braddock, D., & Hemp, R. (1996). Medicaid spending reductions and developmental disabilities. *Journal of Disability Policy Studies*, 7(1), 1–32. doi: 10.1177/104420739600700101.
- Braddock, D., Hemp, R., & Fujiura, G. (1987). National study of public spending for mental retardation and developmen-tal disabilities. *American Journal of Mental Deficiency*, 92, 121–133.
- Braddock, D., Hemp, R., & Fujiura, G.T. (1986). *Public expen-ditures for mental retardation and developmental disabilities in the United States: State profiles* (2nd ed.). Chicago: Uni-versity of Illinois at Chicago, Evaluation and Public Policy Analysis Program, Institute for the Study of Developmental Disabilities.
- Braddock, D., Hemp, R., Rizzolo, M., Coulter, D., Haffer, L., & Thompson, M. (2005). *The state of the states in develop-mental disabilities, 2005*. Boulder, CO and Washington, DC: University of Colorado School of Medicine, Department of Psychiatry and American Association on Intellectual and Developmental Disabilities.
- Braddock, D., Hemp, R., Rizzolo, M.C., Haffer, L., Tanis, E.S., & Wu, J. (2011). *The state of the states in developmental dis-abilities: 2011*. Boulder CO: University of Colorado, Depart-ment of Psychiatry and Coleman Institute for Cognitive Disabilities.
- Braddock, D., Hoehl, J., Tanis, S., Ablowitz, E., & Haffer, L. (2013). The rights of people with cognitive disabilities to technology and information access. *Inclusion*, 1(2), 95–102.
- Braddock, D., & Mitchell, D. (1992). *Residential services and developmental disabilities in the United States: A national sur-vey of staff compensation, turnover and related issues*. Washing-ton, DC: American Association on Mental Retardation.

- Braddock, D., Rizzolo, M. C., Thompson, M., & Bell, R. (2004, Fall). Emerging technologies and cognitive disability. *Journal of Special Education Technology*, 19(4), 49–56. Retrieved January 26, 2011, from ProQuest Nursing & Allied Health Source. (Document ID: 807446581).
- Butterworth, J., Hall, A. C., Smith, F. A., Migliore, A., Winsor, J., Domin, D., & Sulewski, J. (2013, Winter). *StateData: The national report on employment services and outcomes*. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.
- Bryen, D. N., Carey, A., & Friedman, M. F. (2007). Cell phone use by adults with intellectual disability. *Intellectual and Developmental Disabilities*, 45(1), 1–9. doi: 10.1352/1934-9556(2007)45[1:CPUB-AW]2.0.CO;2
- Caiden, N. (1978). *Collection of data on public expenditures for care of the mentally disabled*. (Memorandum prepared for Commission on the Mentally Disabled). Washington, DC: American Bar Association, Public Service Activities.
- Caldwell, J. (2007). Experiences of families with relatives with intellectual and developmental disabilities in a consumer-directed support program. *Disability & Society*, 22(6), 549–562. doi:10.1080/09687590701560139.
- Caldwell, J. (2006). Consumer-directed supports: Economic, health, and social outcomes for families. *Mental Retardation*, 44(6), 405–417. doi: 10.1352/0047-6765(2006)44[405:CSEHAS-]2.0.CO;2
- Caldwell, J., Arnold, K., & Rizzolo, M. (2012). *Envisioning the future: Allies in self-advocacy report*. Silver Spring, MD: Association of University Centers on Disabilities.
- Caldwell, J., & Heller, T. (2007). Longitudinal outcomes of a consumer-directed program. *Intellectual and Developmental Disabilities*, 45(3), 161–173. doi: 10.1352/1934-9556(2007)45[161:LOOACP]2.0.CO;2.
- Centers for Disease Control and Prevention (CDC). (2013, July 18). State-specific healthy life expectancy at Age 65 Years—United States, 2007–2009. Vol. 62(28). Washington, DC.
- Center for Assistive Technology Act Data Assistance. (2014). *A national data summary of state assistive technology programs: Fiscal year 2013 (Issue Brief No. 6)*. Retrieved 10/01/2014 from <http://www.catada.info>.
- Centers for Medicare and Medicaid Services (2012a). *Invitation to apply for GY2012 Planning Grant The Money Follows the Person Rebalancing Demonstration Program*. Baltimore, MD: U.S. Department of Health and Human Services.
- Centers for Medicare and Medicaid Services (2012b). *State Balancing Incentive Payments Program initial announcement*. Baltimore, MD: U.S. Department of Health and Human Services.
- Centers for Medicare and Medicaid Services (2012c). *Balancing incentive program*. Baltimore, MD: U.S. Department of Health and Human Services. Retrieved from: <http://www.medicare.gov/Medicare-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Balancing/Balancing-Incentive-Program.html>
- Centers for Medicare and Medicaid Services (2012d). *Community First Choice Option* Section 1915(k), [Fact sheet]. Baltimore, MD: U.S. Department of Health and Human Services.
- Centers for Medicare and Medicaid Services. (2014). *State Waiver programs and demonstrations*. Baltimore, MD: U.S. Department of Health and Human Services. Retrieved from <http://cms.hhs.gov/medicaid/waivers/-waivermap.asp>
- Centers for Medicare and Medicaid Services. (2005, November). *Online Survey, Certification and Annual Review (OSCAR) data set* (CD Rom purchased by the project). Baltimore: Author.
- Center for Public Representation (2014). *Nursing Facility Cases*. [Data file] Retrieved from <http://www.centerforpublicrep.org/litigation-and-major-cases/ada/40-litigation/nursing-facility-cases>
- Cidav, Z., Marcus, S. C., & Mandell, D. S. (2014). Home and community-based waivers for children with autism: Effects on service use and cost. *Intellectual and Developmental Disabilities*, 52(4), 239–248
- Cimera, R. E. (2012a, September). Follow-up services: Agency vs. individual—which is better? *Job Training and Placement Report*, 36(9).
- Cimera, R. E. (2010a). The national cost-efficiency of supported employees with intellectual disability: The worker's perspective. *Journal of Vocational Rehabilitation*, 33, 123–131. doi: 10.3233/JVR-2010-0521.
- Cimera, R. E. (2010b). The national cost-efficiency of supported employees with intellectual disability: 2002 to 2007. *American Journal on Intellectual and Developmental Disabilities*, 115, 19–29.
- Cimera, R. E., Burgess, S., Novak, J. & Avellone, L. (in press). *Too Disabled to Work: A Crossroad Once Thought Past*.
- Cole, D. A., & Meyer, L. H. (1989). Impact of needs and resources on family plans to seek out-of-home placement. *American Journal on Mental Retardation*, 93, 380–387.
- Community First Choice Option*, 77 Fed. Reg. 26827 (2012) (to be codified at 42 CFR pt. 441).
- Davies, D. K., Stock, S. E., Holloway, S., & Wehmeyer, M. L. (2010). Evaluating a GPS-based transportation device to support independent bus travel by people with intellectual disability. *Intellectual and Developmental Disabilities*, 48(6), 454–463. doi: 10.1352/1934-9556-48.6.454
- Davies, D. K., Stock, S. E., & Wehmeyer, M. L. (2001). Enhancing independent time-management skills of individuals with mental retardation using a Palmtop personal computer. *Education & Training in Mental Retardation and Developmental Disabilities*, 36(1), 107–113. doi: 10.1352/0047-765(2002)040<0358: EITMSO>2.0.CO;2
- Dawe, M., Fischer, G., Gorman, A., Kintsch, A., Konomi, S., Sullivan, J., Taylor, J., & Wellems, G. (2005). *Smart care: The importance and challenges of creating life histories for people with cognitive disabilities*. Proceedings of the HCI International Conference. Retrieved from <http://l3d.cs.colorado.edu/~agorman/pdf/smartcare-hcii-005.pdf>

- Dewsbury, G., Clarke, K., Rouncefield, M., Sommerville, I., Taylor, B., & Edge, M. (2003). Designing acceptable “smart” home technology to support people in the home. *Technology and Disability*, 15(3), 191–199.
- Dunst, C. J., Trivette, C. M. & Hamby, D. W. (2007). Meta-analysis of family-centered help-giving practices research. *Mental Retardation and Developmental Disabilities Research Reviews*, 13, 370–378. doi: 10.1002/mrdd.20176
- Durban-Westby, P. C., Neëman, A., & Topper, K. (Eds.). (2010). *Keeping the promise: Self-advocates defining the meaning of community living*. Kansas City, MO: National Community Living Summit of Self-Advocates with Developmental and Intellectual Disability.
- Dybwad, G. & Bersani, H. (Eds.) (1996). *New Voices: Self-advocacy by people with disabilities*. Cambridge, MA: Brookline Books.
- El Erian, M. (2014, November 12). Liberty, fraternity, inequality. *Bloomberg News*.
- Eiken, S., Sredl, K., Gold, L., Kasten, J., Burwell, B., & Saucier, P. (2014). *Medicaid expenditures for long term services and supports in FFY 2012*. Cambridge, MA: Truven Health Analytics and Mathematica Policy Research, Inc.
- Executive Office of the President. (2014, August). *A year of action: Progress report on raising the minimum wage*. Washington, DC: Author.
- Feinberg, L. & Houser, A. (June, 2012). *Assessing family caregiver needs: Policy and practice considerations*. Fact Sheet 258. Washington, DC: The AARP Public Policy Institute.
- Feinberg, L., Reinhard, S. C., Houser, A., & Choula, R. (July, 2011). Valuing the invaluable: 2011 update—the growing contributions and costs of family caregiving. Washington, DC: The AARP Public Policy Institute.
- FINRA Investor Education Foundation. (2014). *Financial Capability of Adults with Disabilities*. http://www.real-economic-impact.org/data/files/reports/NDI_financial_capability_report_july_2014.pdf
- Fisk, M (2001) The Implications of Smart Home Technologies. In S. Peace, C. Holland (Eds.), *Inclusive Housing in an Ageing Society: Innovative Approaches* (101–125), Bristol, UK: Policy Press, Bristol.
- Flippo, K. F., & Garder, J. F. (2011). Employment: It is everybody’s business. *Intellectual and Developmental Disabilities*, 49(4), 305–309.
- Fogg, N., Harrington, P., & McMahon, B. T., (2010). The impact of the Great Recession upon the unemployment of Americans with disabilities. *Journal of Vocational Rehabilitation*, 33(3), 193–202.
- Friedman, C. (under review). Electronic monitoring in Medicaid Home and Community Based Services Waivers for people with intellectual and developmental disabilities. *Journal of Telemedicine and Telecare*.
- Friedman, C. & Rizzolo, M.C. (in preparation). 99 Waivers: An analysis of state-by-state HCBS Waivers for persons with intellectual disability. Chicago: University of Illinois at Chicago.
- Fryson, R., Tarleton, B., & Ward, L. (2007). *Support for living? The impact of the Supporting People programme on housing and support for adults with learning disabilities*. Bristol, UK: The Policy Press and Joseph Rowntree Foundation.
- Fujiura, G. T. (2012, June). *Structure of Intellectual and Developmental Disabilities Households in the United States: Demographics of the Family in 2010*. Presented at AAIDD 136th Annual Meeting, Charlotte, NC.
- Fujiura, G. T. (1998). Demography of family households. *American Journal on Mental Retardation*, 103, 225–235.
- Fujiura, G. T., Garza, J., & Braddock, D. (1990). *National survey of family support services in developmental disabilities*. Chicago, IL: University of Illinois at Chicago, University Affiliated Program in Developmental Disabilities.
- Fujiura, G. T., Roccoforte, J. A., & Braddock, D. (1994). Costs of family care for adults with mental retardation and related developmental disabilities. *American Journal on Mental Retardation*, 99(3), 250–261.
- Gilmore, D., Schuster, J., & Butterworth, J. (2001). *Vocational rehabilitation outcomes for people with mental retardation, cerebral palsy, and epilepsy: An analysis of trends from 1985 to 1998*. Boston, MA: Institute for Community Inclusion, Children’s Hospital.
- Hacker, J. S., Huber, G. A., Nichols, A., Rehm, P., & Craig, S. (2012, June). *Economic insecurity across the American states: New state estimates from the Economic Security Index*. Albany, NY: The Rockefeller Foundation.
- Hall, A. C., Freeze, S., Butterworth, J. & Hoff, D. (2011). Employment funding for intellectual/developmental disability systems. *Journal of Vocational Rehabilitation*, 34, 1–15. doi: 10.3233/JVR-2010-0529
- Harrington, C., Carillo, H., & Mercado-Scott, C. (2005). *Nursing facilities, staffing, residents, and facility deficiencies, 1998 through 2004*. San Francisco, CA: University of California, Department of Social and Behavioral Sciences.
- Harrington, C., Carillo, H., Thollaug, S.C., Summers, P.R., & Wellin, V. (2000, January). *Nursing facilities, staffing, residents, and facility deficiencies, 1992 through 1998*. San Francisco, CA: University of California, Department of Social and Behavioral Sciences.
- Harrington, C., Carrillo, H., Wellin, V., & Shemirani, B. B. (2002). *Nursing facilities, staffing, residents, and facility deficiencies, 1995 through 2001*. San Francisco, CA: University of California, Department of Social and Behavioral Sciences.
- Harrington, C., Ng, T., Kaye, H. S., & Newcomer, R. J. (2009). Medicaid Home and Community Based Services: Proposed policies to improve access, cost and quality. *Public Policy and Aging Report*, 19(2), 13–18. Retrieved from http://www.pas-center.org/documents/Harrington_Ng_Kaye_Newcomer.pdf
- Hayden M., & Nelis, T. (2002). Self-Advocacy. In R.L. Schalock, P.C. Baker, & M.D. Croser (Eds.), *Embarking on a new century: Mental retardation at the end of the 20th Century* (pp. 221–233). Washington, CD: American Association on Mental retardation.

- Hayden, M.F., & Senese, D. (1996). *Self-advocacy groups: 1996 Directory for North America*. Minneapolis, MN: University of Minnesota, RRTC on Community Living.
- Heller, T., & Factor, A. (2008). Family support and intergenerational caregiving: Report from the State of the Science in Aging with Developmental Disabilities Conference. *Disability and Health Journal*, 1, 131–135. doi:10.1016/j.dhjo.2008.04.004
- Heller, T., & Kramer, J. (2009) Involvement of adult siblings of persons with developmental disabilities in future planning. *Intellectual and Developmental Disabilities*, 47(3), 208–219.
- Heller T., Miller A. B., & Hsieh K. (1999). Impact of a consumer-directed family support program on adults with disabilities. *Family Relations*, 48, 419–427.
- Herman, S. E. (1991). Use and impact of a cash subsidy program. *Mental retardation*, 29, 253–258.
- Hewitt, A., Agosta, J., Heller, T., Williams, A. C. & Reinke, J. (2013). Families of individuals with intellectual and developmental disabilities: Policy, funding, services, and experiences. *Intellectual and Developmental Disabilities*, 51(5), 349–359.
- Ho, A., Collins, S., Davis, K., & Doty, M. (2005). *A look at working-age caregivers' roles, health concerns, and need for support*. New York, NY: The Commonwealth Fund.
- Homeward Bound v. Hissom Memorial Center. No. 85–C-437–E (N.D. Okla. Jan. 12, 1990), 14 MPDLR 133.
- Hoynes, H. W., Miller, D. L., & Schaller, J. (2012, March). Who Suffers During Recessions? *NBER Working Paper No. 17951*.
- Imagine! (2014). *Smart Homes*. Retrieved from <http://www.imaginecolorado.org/smarthomes>
- Janicki, M. P., Dalton, A. J., Henderson, C. M., & Davidson, P. W. (1999). Mortality and morbidity among older adults with intellectual disability: Health service considerations. *Disability and Rehabilitation*, 21(5/6), 284–294.
- Janicki, M. P., Henderson, M. C., & Rubin, I.L. (2008). Neurodevelopmental conditions and aging: Report on the Atlanta Study Group Charrette on Neurodevelopmental Conditions and Aging. *Disability and Health Journal*, 1(2), 116–124.
- Johnson, D. R. (2004). Supported employment trends: Implications for transition-age youth (Commentary on Rusch & Braddock, 2004). *Research & Practice for Persons with Severe Disabilities*, 29(4), 243–247.
- Johnson, L. C. (2014). Am I not my brother's keeper? *The Atlantic*. Retrieved from <http://www.theatlantic.com/business/archive/2014/11/am-i-not-my-brothers-keeper/382354/>
- Karreman, J., Van Der Geest, T., & Buursink, E. (2007). Accessible website content guidelines for users with intellectual disability. *Journal of Applied Research in Intellectual Disability*, 20, 510–518.
- Katz, L. F. (2010). *Long term unemployment in the Great Recession*. Testimony for the Joint Economic Committee, U.S. Congress (April 29, 2010).
- Katz, R. T. (2003). Life expectancy for children with cerebral palsy and mental retardation: Implications for life care planning. *NeuroRehabilitation*, 18, 261–270.
- Key, V. O., Jr. (1949) *Southern politics in state and nation*. New York, NY: Knopf.
- Kregel, J., Wehman, P., & Banks, P. D. (1989). The effects of consumer characteristics and type of employment model on individual outcomes in supported employment. *Journal of Applied Behavior Analysis*, 22, 407–415. doi:10.190-/jaba.1989.22–407
- Lakin, K. C. (1979). *Demographic studies of residential facilities for the mentally retarded: an historical review of methodologies and findings*. Minneapolis: University of Minnesota, Department of Educational Psychology.
- Lakin, K. C. (1998). Perspectives. On the outside looking in: Attending to waiting lists in systems of services for people with developmental disabilities. *Mental Retardation*, 36, 157–162. doi:10.135–2/00476765(1998)036<0157:2.0.CO;2
- Lakin, K. C. (1988). Strategies for promoting the stability of direct care staff. In M. Janicki, M. Krauss, & M. Seltzer (Eds.), *Community residences for persons with developmental disabilities: Here to stay* (pp. 231–238). Baltimore, MD: Paul H. Brookes Publishing Company.
- Lakin, K. C., Prouty, R., & Coucouvanis, K. (2006). Trends & Milestones: Changing patterns in size of residential settings for persons with intellectual and developmental disability, 1977–2005. *Mental Retardation*, 44(4), 306–309.
- Larson, S. A., Hewitt, A. S., & Lakin, K. C. (2004). A multi-perspective analysis of the effects of recruitment and retention challenges on outcomes for persons with intellectual and developmental disabilities and their families. *American Journal on Mental Retardation*, 109, 481–500
- Larson, S. A., & Lakin, K. C. (1999). A longitudinal study of recruitment and retention in small community homes supporting persons with developmental disabilities. *Mental Retardation*, 37, 178–191.
- Larson, S. A., Lakin, K. C., Anderson, L., Kwak, N., Lee, J., & Anderson, D. (2001). Prevalence of Mental Retardation and Developmental Disabilities: Estimates From the 1994/1995 National Health Interview Survey Disability Supplements. *American Journal of Mental Retardation*, 106(3), 231–252.
- Larson, S. A., Hallas-Muchow, L., Aiken, F., Hewitt, A., Anderson, L. L., Pettingell, S., Moseley, C., Sowers, M., Fay, M. L., Smith, D., Kardell, Y., & Agosta, J. (2014). *Supporting Individuals with Intellectual or Developmental Disabilities and their Families: Status and Trends Through 2012*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
- Larson, S., Salmi, P., Smith, D., Anderson, L. & Hewitt, A. (2013). *Residential services for persons with developmental disabilities: Status and trends through 2011*. Minneapolis, MN: University of Minnesota, Institute on Community Integration, Research and Training Center on Community Living.
- Lewis, D. R. & Johnson, D.R. (2005). Costs of family care for individuals with developmental disabilities. In R.J. Stancliffe & K. C. Lakin (Eds.) *Costs and outcomes of community*

- services for people with intellectual and developmental disabilities. (pp. 63–89). Baltimore, MD: Brookes.
- LoPresti, E. F., Bodine, C., & Lewis, C. (2008). Assistive technology for cognition. *IEEE Engineering in Medicine and Biology Magazine*, 27(2), 29–39.
- Mank, D. M., Rhodes, L. E., & Bellamy, G. T. (1986). Four supported employment alternatives. In W. E. Kiernan and J. A. Stark (Eds.) *Pathways to Employment for Adults with Developmental Disabilities*, (139–153). Baltimore, MD: Paul H. Brookes Publishing Co.
- Minnesota Department of Employee Relations. (1989). *Study of employee wages, benefits, and turnover in Minnesota direct care facilities serving persons with developmental disabilities*. St. Paul, MN: Author.
- Mitchell, D., & Braddock, D. (1994). Compensation and turnover of direct care staff in developmental disabilities residential facilities in the United States II: Turnover. *Mental Retardation*, 32, 34–42.
- Mitchell & Braddock (1990). Issues in the the implementation of nursing home reform. *Mental Retardation*, 28, 201–210.
- Moore, T., & O'Connell, B. (2006, October 27). *Compendium of home modification and assistive technology policy and practice across the states. Volume I: Final report*. Washington DC: Abt Associates.
- Nakamura, E., & Tanaka, S. (1998). Biological ages of adult men and women with Down's syndrome and its changes with aging. *Mechanisms of Ageing and Development* 105 (1–2):89–103.
- National Bureau of Economic Research (NBER). (2012). *United States business cycles and contractions*. Retrieved from <http://www.nber.org/cycles/cyclesmain.html>
- National Council on Disability (2014). *National disability policy: A progress report*. Retrieved from http://www.ncd.gov/progress_reports10312014
- National Council on Disability. (2007, October). *Empowerment for Americans with disabilities: Breaking barriers to careers and full employment*. Washington, DC: Author.
- National Governors Association and National Association of State Budget Officers. (2014, June). *The fiscal survey of states*. Washington, DC: Authors.
- Nelis, T., & Ward, N. (1995). Operation Close the Doors: Working for freedom. *Impact*, 9, 12. Minneapolis, MN: University of Minnesota, Institute on Community Integration.
- Ng, T., Wong, A., & Harrington, C. (2009). *HCBS services: Community integrated-Olmstead and Olmstead-related lawsuits*. (www.pascenter.org/olmstead/olmsteadcases.php).
- Nicholas, R., Kauder, R., & Krepicio, K. (2011). *Using braided funding strategies to advance employer hiring initiatives that include people with disabilities*. (Research Report) Retrieved from <http://www.dol.gov/odep/pdf/BraidedFSReport.pdf>.
- Niemiec, B., Lavin, D. & Owens, L. A. (2009). Establishing a national Employment First agenda. *Journal of Vocational Rehabilitation*, 31, 139–144. doi: as10.3233/JVR-2009-0483.
- Norris, F. (2014, September 12). Young households, even educated ones, lose ground in income. *NY Times* Retrieved from http://www.nytimes.com/2014/09/13/business/economy/young-households-are-losing-ground-in-income-despite-education.html?_r=0
- O'Conner (1976). *Home is a good place: A national perspective of community residential facilities for developmentally disabled persons*. Washington, DC and Eugene, Oregon. American Association on Mental Retardation and the University of Oregon.
- Office of Special Education and Rehabilitation Services. (2014). *U.S. Department of Education The Workforce Innovation and Opportunity Act Overview of Title IV: Amendments to the Rehabilitation Act of 1973*. <http://www2.ed.gov/about/offices/list/osers/rsa/publications/wioa-changes-to-rehab-act.pdf>
- Oliff, P., Mai, C., & Palacios, V. (2012, June 27). States continue to feel recession's impact. Washington, DC: *Center on Budget and Policy Priorities*.
- Olmstead v. L.C., 119 S. Ct. 2176 (1999).
- Pajta, K., Iivanainen, M., Vesala, H., et. al. (2000). Life expectancy of people with intellectual disability: A 35-year follow-up study. *Journal of Intellectual Disability Research*, 44, 591–599
- Paraprofessional Healthcare Institute. (2011, February). *Who are direct-care workers?* (Issue brief) Bronx, NY: Author.
- Parish, S. L., Thomas, K. C., Rose, R., Kilany, M., & Shattuck, P. T. (2012). State Medicaid spending and financial burden of families raising children with autism. *Intellectual and Developmental Disabilities*, 50(6), 441–451. doi: 10.1352/1934-9556-50.06.441
- Perry, J., Beyer, S. and Holm, S. (2008). Assistive technology, telecare and people with intellectual disability: ethical considerations. *Journal of Medical Ethics*, 35, 81–86.
- Picketty, T. (2014). *Capital in the Twenty-First Century*. Cambridge, MA: Harvard University Press.
- Powers, E. T., & Powers, N. J. (2011). Should government subsidize caregiver wages? Some evidence on worker turnover and the cost of long-term care in group homes for persons with developmental disabilities. *Journal of Disability Policy Studies*, 21(4), 195–209. doi: 10.1177/104-4207310389176
- Providence Journal (2014, October 27). *Chafee order aims to increase jobs for R.I.'s disabled*. Retrieved from <http://www.providencejournal.com/-breaking-news/content/20141027-chafee-order-aims-to-increase-jobs-for-r.i.-s-disabled.ece>
- Prasher, V. P. (2006). *Down Syndrome and Alzheimer's Disease: Biological Correlates*. Oxon, UK: Radcliffe.
- Priault, E. (2014, September). *Docket of significant protection and advocacy cases related to community integration*. Washington, DC: Administration on Developmental Disabilities. Private correspondence.
- Pueschel, S. M. (2006). *Adults with Down syndrome*. Baltimore, MD: Paul Brookes.

- Rizzolo, M. C., Bell, R., Braddock, D., Hewitt, A., & Brown, C. (2005). Emerging technologies for persons with intellectual and developmental disabilities. In K. C. Lakin and A. Turnbull (Eds.), *Keeping the promises: Findings and recommendations. National goals, state of knowledge and research agenda for persons with intellectual and developmental disabilities*, 289–310. Washington, D.C.: American Association on Mental Retardation.
- Rizzolo, M. C. & Braddock, D. (2008). People with Cognitive Disabilities. In S. Helal, M. Mokhtari, and B. Abdulrazak (Eds.), *The engineering handbook of smart technology for aging, disability, and independence*, pp. 203–216. Hoboken, NJ: John Wiley & Sons.
- Rizzolo, M. C., Hemp, R., & Braddock, D. (2006, February). Family support services in the United States. *Policy Research Brief*, 17(1), 1–11. Minneapolis, MN: University of Minnesota, Center on Residential Services and Community Living.
- Rizzolo, M. C., Friedman, C., Lulinski-Norris, A., & Braddock, D. (2013). Home and Community Based Services (HCBS) Waivers: A nationwide study of the states. *Intellectual and Developmental Disabilities*, 51(1), 1–21.
- Rotman, D. (2014, October 21). Technology and inequality. *MIT Technology Review*. Retrieved from <http://www.technologyreview.com/featuredstory/531726/technology-and-inequality/>
- Rusch, F. R., & Braddock, D. (2004). Adult day programs versus supported employment (1988–2002): Spending and service practices of mental retardation and developmental disabilities state agencies. *Research and Practice for Persons with Severe Disabilities*, 29(4), 237–242.
- Rusch, F. R., & Hughes, C. (1990). Historical overview of supported employment. In F.R. Rusch (Ed.), *Supported employment: Models, methods and issues* (pp. 5–14). Sycamore, IL: Sycamore.
- Saez, E. & Piketty, T. (2014) Inequality in the long-run. *Science* 344, 838–843.
- Schiller, J. S., Lucas, J. W., Ward, B. W., & Peregoy, J. A. (2012). Summary health statistics for U.S. adults: National Health Interview Survey, 2010. National Center of Health Statistics. *Vital Health Stat.* 10,252.
- Sebelius, K. G. (2014). *Report to Congress, Community First Choice: Interim Report to Congress as Required by the Patient Protection and Affordable Care Act of 2010 (P.L. 111–148)*. Baltimore: U.S. Department of Health and Human Services, Office of the Secretary.
- Seltzer, M. M., Floyd, F. J., Song, J., Greenberg, J. S. & Hong, J. (2011). Midlife and aging parents of adults with intellectual and developmental disabilities: Impacts of life-long parenting. *American Journal on Intellectual and Developmental Disabilities*, 116, 479–499.
- Shea, A. (2014). Medicaid Buy-In opens doors to employment for people with disabilities. [ACL Blog]. Retrieved from http://acl.gov/News-Room/blog/2014/2014_10_27.aspx
- Smith, G. A. (1990). *Supported living: New directions in services to people with developmental disabilities*. Alexandria, VA: National Association of State Mental Retardation Program Directors.
- Smith, G. A., Agosta, J., & Fortune, J. (2007, April). *Gauging the use of HCBS Support Waivers for people with intellectual and developmental disabilities. Final Project Report*. Portland, OR: Human Services Research Institute.
- Social Security Administration. (2014). *SSI annual statistical report, 2013*. Baltimore: Office of Policy, Office of Research, Evaluation, and Statistics. [Accessed September 2014: http://www.social-security.gov/policy/docs/statcomps/ssi_asr/].
- Stainton, T., Hole, R., Charles, G., Yodanis, C., Powell, S., Crawford, C., Wilson, L., Halcrow, S., & Goode, B. (2007, March). *Residential options for adults with developmental disabilities: Quality and cost outcomes, a plain language summary*. Vancouver, B.C.: The Univ. of British Columbia, School of Social Work and Family Studies.
- State Employment Leadership Network (2014). *Employment First Resource List Revised October 2014*. Retrieved from <http://www.apse.org/wp-content/uploads/2014/10/Employment-First-List-10-14-APSE-version.pdf>
- The State Employment Leadership Network. (2014). *About the SELN*. http://selnmembers.org/components/content/wpcontent/uploads/2014/08/seln_about_fact_sheet2014_7252014.pdf
- Stiglitz, J. E. (2012). *The price of inequality*. New York: W.W. Norton & Company.
- Storey, K. (2010) Smart Houses and Smart Technology: Overview and Implications for Independent Living and Supported Living Services. *Intellectual and Developmental Disabilities: December*, 48(6), pp. 464–469.
- Swenson, S. & Lakin, C. (2014) A wicked problem: Can governments be fair to families living with disabilities? *Family Relations*, 63, 185–191. doi:10.1111/fare.12056
- “Synthesis of discussion group perspectives: Family support and self-determination.” (2006, December 3–5). Lawrence, KS: Summit on Family Support for Enhancing Quality of Life.
- Talley, I. (2014, March 13). IMF warns inequality is a drag on growth. *Wall Street Journal*.
- Taylor, S. J., Brown, K., McCord, W., Giambetti, A., Searl, S., Mlinarcik, S., Atkinson, T., & Lichter, S. (1981). *Title XIX and deinstitutionalization: The issue for the 80s*. Syracuse, NY: Syracuse University, Center on Human Policy.
- Test, D. W. (2004). Invited commentary on Rusch and Braddock (2004): One person at a time. *Research & Practice for Persons with Severe Disabilities*, 29(4), 248–252.
- Thompson, L., Powers, G., & Houchard, B. (1992). The wage effects of supported employment. *Journal of the Association for Persons with Severe Handicaps*, 17, 87–94.
- Turnbull, H. R., Stowe, M. J., Agosta, J., Turnbull, A. P., Schrandt, M. S., & Muller, J. F. (2007). Federal family and disability policy: Special relevance for developmental disabilities. *Mental*

- Retardation and Developmental Disabilities*, 13, 114–120. doi:10.1002/mrdd.20145
- Turnbull, H. R., & Turnbull, A. P. (2000). Family support: Retrospective and prospective. In M. L. Wehmeyer & J. R. Patton (Eds.), *Mental retardation in the 21st century* (pp. 3–17). Austin, TX: Pro-Ed.
- Twenty-first Century Communications and Video Accessibility Act of 2010, Pub. L. No. 111–260 (2010).
- United Nations, Department of Economic and Social Affairs, Population Division (2009). World Population Prospects: The 2008 Revision, Highlights, Working Paper No. ESA/P/WP.210
- United States Bureau of Labor Statistics. (2014). *State average annual pay for 2014*. Washington, DC: U.S. Department of Labor. Retrieved from www.bls.gov/oes/current/oes_nat.htm#b00-0000.
- United States Census Bureau. (2014). *U.S. interim projections by age, sex, race, and Hispanic origin*. Retrieved from www.census.gov/ipc/www/usinterimproj.
- United States Department of Commerce, Bureau of Economic Analysis. (2014a). *National income and product accounts, Table 1.1.4 Implicit price deflators for gross domestic product [index numbers 2009=100], last revised May 15, 2014*.
- United States Department of Commerce, Bureau of Economic Analysis. (2014b). *Percent change (chained 2009 dollars and current dollars) from preceding period in real gross domestic product, Table 1.1.1, last revised November 16, 2014*.
- United States Department of Commerce, Bureau of Economic Analysis. (2014c). *Quarterly personal income, by state, last revised November 11, 2014*.
- United States Department of Health and Human Services Assistant Secretary for Planning and Evaluation Office of Disability, Aging and Long-Term Care Policy (2006). *Compendium of home modification and assistive technology policy and practice across the states: Volume I: Final report*. Retrieved from: <http://aspe.dhhs.gov/daltcp/reports/2006/HM-ATI.pdf>
- United States Department of Health and Human Services (2012, April 16). *A statement from Secretary Sebelius on the Administration for Community Living*. Washington, DC: U.S. Department of Health and Human Services. Retrieved from: <http://www.hhs.gov/news/press/>.
- United States Department of Health, Education, and Welfare. (1972, September). *Mental retardation source book of the DHEW*. Washington, DC: U.S. DHEW, Office of the Secretary, Office of Mental Retardation Coordination.
- United States Department of Justice Civil Rights Division. (November 19, 2014). *Olmstead: Community Integration for Everyone*. Retrieved from http://www.ada.gov/olmstead/olmstead_cases_list2.htm
- United States Department of Labor, Office of Disability Employment Policy, Social Dynamics, LLC (2014). *Employer Engagement Strategy: Workforce Inclusion*. (DOL Publication No. DOLU1294 33926). Retrieved from <http://www.dol.gov/odep/pdf/20140604BusinessCaseEngagementWhitePaper.pdf>
- United States Senate Committee on Health, Education, Labor & Pensions (2014). *Fulfilling the Promise: Overcoming persistent barriers to economic self-sufficiency for people with disabilities*. Washington, DC: Author. http://www.autismspeaks.org/sites/default/files/docs/gr/help_committee_disability_and_poverty_report.pdf
- Virginia Department of Behavioral Health and Developmental Services. (2012). *Virginia's settlement agreement with the U.S. Department of Justice and proposed plan to implement the terms of the agreement*. Richmond: Author.
- Wehman, P., Inge, J., Revell, G., & Brooke, V. (2007). *Real work for real pay: Inclusive employment for people with disabilities*. Baltimore, MD: Paul H. Brookes Publishing Company.
- Wehmeyer, M. L., & Shogren, K. A. (2013). Establishing the field of applied cognitive technology. *Inclusion*, 1(2), 91–94.
- West, M., Revell, G., Kregel, J., & Bricout, J. (1999). The Medicaid Home and Community-Based Waiver and supported employment. *American Journal on Mental Retardation*, 104, 78–87.
- The White House. (2014). *Ready to Work: Job-Driven Training and American Opportunity*. Retrieved from http://www.whitehouse.gov/sites/default/files/skills_report_072014_2.pdf
- Wildavsky, A. (1974). *The politics of the budgetary process* (2nd ed.). Boston: Little, Brown.
- Winer, B. J. (1971). *Statistical principles in experimental design*. New York: McGraw-Hill.
- Winsor, J. E. (2014). State intellectual disability and developmental disabilities agencies, service trends. *DataNote Series, Data Note 49*. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.
- Yuskauskas, A. (2005). Medicaid program innovations that support individual autonomy. *TASH Connections*, March/April, 6–13.
- Zimmerman, S. L. (1984). The mental retardation family subsidy program: Its effect on families with a mentally handicapped child. *Family Relations*, 33, 105–118.

COLLABORATION WITH STATE IDD AGENCIES FOR DATA COLLECTION

State agency officials listed below were essential in the collection of FY 2012–2013 data. The data they provided, reviewed and confirmed are the foundation of this report.

Alabama. Andy Slate, Fiscal Officer and Daphne Rosalis, Director of Systems Management, Division of Developmental Disabilities, Department of Mental Health.

Alaska. Anastasiya S. Podunovich, Research and Analysis Unit, and Duane Mayes, Director, Senior & Disabilities Services, Department of Health & Social Services.

Arizona. Anna M. Mendoza, Sherry M. Klein, Laura Love, Ph.D., Elisabeth Ek-Mcherron, Rebecca Lynch, Sherri Wince, Linda Tasco, and, Larry L. Latham, Ph.D., FAAIDD, Assistant Director, Division of Developmental Disabilities, Department of Economic Security.

Arkansas. Shelley Lee, Assistant Director for Quality Assurance, Regina Davenport, Program Administrator; QA Outreach; Jerry Hodge, Waiver Policy Administrator; Stephen Sullivan, Contracts; Kim Goh Walker, DDS Fiscal Manager, and James C. Green, Ph.D., Director, Division of Developmental Disabilities Services, Department of Human Services.

California. Yasir Ali, Federal Programs Operations Section, Carie Powell, Federal Programs Operations Section, Greg Nabong, Program Operations Branch, Jim Knight, Office of Federal Programs & Fiscal Support, Department of Developmental Services.

Colorado. Emily Blanford, Budget and Finance Director, and Barbara D. Ramsey, Director, Division for Developmental Disabilities, Department of Human Services.

Connecticut. Tim Deschenes-Desmond, Planning Specialist, Office of the Deputy Commissioner, Joseph Drexler and Shawn Boisclair, Department of Developmental Services.

Delaware. Lennie Warren, Program Evaluator, Marie Nonnenmacher, and Jane Gallivan, Director, Division of Developmental Disabilities Services, Department of Health and Social Services.

District of Columbia. Erin Leveton and Adam Mingal, State Office of Disability Administration, Darlene Richardson,

Administrative Officer, Srinivas Bheemreddy, Chief Information Officer, Laura L. Nuss, Director, Department on Disability Services.

Florida. Duncan Hoehn, Jenny Hart, Tina Weber, Denise Arnold, Lorena Fulcher, David Dobbs, Tom Rice, Cheryl Smith, Tim Graves, Tom Rankin and Denzil Weimorts, Agency for Persons with Disabilities.

Georgia. Eddie Towson, Director of Quality Assurance, and Dan Howell, Assistant Commissioner, Division of Developmental Disabilities, Department of Behavior Health and Developmental Disabilities.

Hawaii. Jenny Gong, Research Statistician, and David Fray, DDS, Chief, Developmental Disabilities Division, Department of Health.

Idaho. Rebecca Fadness, DD Policy Program Manager, and Cameron Gilliland, Bureau Chief, Family and Community Services; Arthur Evans, Chief, Division of Medicaid; and Tom Rosenthal, Division of Finance, Department of Health and Welfare.

Illinois. Connie Sims, Dan Blair, and Kevin Casey, Director, Division of Developmental Disabilities, Department of Human Services.

Indiana. Nicole Norvell, Director and Thomas G. Williams, Data Manager, Division of Disability and Rehabilitative Services, Family and Social Services Administration.

Iowa. Ben Cleveland, Suzanne Fross, and Theresa Armstrong, Community Services and Planning, and Rick Shults, Division Administrator, Division of Mental Health and Disability Services, Department of Human Services.

Kansas. George Van Hoozer, Program Oversight Manager, Community Services and Programs Commission, Kansas Department for Aging and Disability Services, Carla Campbell, Brad Ridley KS Department for Aging and Disability Services.

Kentucky. Ericka Jenkins, Claudia Johnson, and Mary Reinle Begley, Commissioner, Department for Behavioral Health and Developmental and Intellectual Disability, Cabinet for Health and Family Services.

Louisiana. Beth Jordan, Program Manager, Kin Hodge, Pam Sund, Julia Kenny, and Laura Brackin, Ph.D., Director, Office for Citizens with Developmental Disabilities, Department of Health and Hospitals.

Maine. Jim Martin, Director, Bridget Bagley, HCBS Waiver Program Manager, Terry Sandusky, Information Services Manager, Deb Gellatly, Resource Development Manager, Joy Swift, Senior Staff Accountant, Office of Aging and Disability Services, Department of Health and Human Services.

Maryland. Peter deFries, Assistant Director, and Bernard A. Simons, Executive Director, Developmental Disabilities Administration, Department of Health and Mental Hygiene.

Massachusetts. Janet George, Assistant Commissioner for Policy Planning and Children's Services, Jeanette Maillet, Division of Policy, Planning and Children's Services and Elin Howe, Commissioner, Department of Developmental Services.

Michigan. Kathleen Haines, Division for Quality Management and Planning, Debra Tsutsui, Managed Care Specialist, William Harrison, DCH Consultant, and Judy Webb, Director, Division of Quality Management and Planning, Behavioral Health and Developmental Disabilities Administration, Department of Community Health.

Minnesota. Melanie Fry, Lead Policy Consultant, Mahesh Gorregattu, and Alex Bartolic, Director, Disability Services Division, Department of Human Services.

Mississippi. Ashley Lacoste and Kenneth Leggett, Bureau of Intellectual and Developmental Disabilities, Department of Mental Health.

Missouri. Gary Schanzmeyer, Fiscal Manager, and Valerie Huhn, Director, Division of Developmental Disabilities, Department of Mental Health.

Montana. Jennifer Finnegan, Budget Analyst, and Jeff Sturm, Director, Developmental Disabilities Program, Department of Public Health and Human Services.

Nebraska. Kathie Lueke, Deputy Administrator of Quality Improvement, Scott Hartz, Data/Financial Analyst, Mike Kaczmarczyk, Program Analyst, DHHH Financial and Program Analysis (FAPA), and Jodi M. Fenner, Director, Division of Developmental Disabilities, Nebraska Department of Health and Human Services.

Nevada. Jim Cribari, Program Evaluator, Rosie Melarkey, Clinical Program Planner, and Jane Gruner, Administrator, Division

of Aging and Disability Services Division, Department of Health and Human Services.

New Hampshire. Ken Lindberg, Bureau Liaison, Karen Kimball, Medicaid and Finance Administrator, Bureau of Developmental Services, Division of Community Based Care Services, Department of Health and Human Services.

New Jersey. Elizabeth Shea, Assistant Commissioner, Thomas Papa, Chief of Staff, NJ Division of Developmental Disabilities, Department of Human Services.

New Mexico. Cathy Stevenson, Division Director, Developmental Disabilities Supports Division, New Mexico Department of Health; Wendy Corry, Director of Systems Improvement, Developmental Disabilities Supports Division, New Mexico Department of Health; Roberta Duran, Bureau Chief of the Community Programs Bureau, Developmental Disabilities Supports Division, New Mexico Department of Health; Gene Lujan, Business Analyst, Information Technology Services Division, New Mexico Department of Health.

New York. Laura Rosenthal, Christine Muller, Becki Lifford, Christine Carey, Martha Dalton, Kim Thayer, and Kerry Delaney, Acting Commissioner, Office for People with Developmental Disabilities.

North Carolina. Shealy Thompson, Ph.D., Lead, Quality Management, Terrie Qadura, and Steve Jordan, Director, Division of Mental Health, Developmental Disabilities, and Substance Abuse Services, Department of Health and Human Services.

North Dakota. Brianne Skachenko, Residential and Day Services Administrator, and Tina Bay, Director, Developmental Disabilities Services Division, Department of Human Services.

Ohio. Clay Weidner, Fiscal Administration; Hope McGonigle; and John Martin, Director, Department of Developmental Disabilities.

Oklahoma. Marie Moore, Chief Fiscal Officer, and Jim Nicholson, Division Director, Developmental Disabilities Services Division, Department of Human Services.

Oregon. Laura Bastien, Budget Analyst, DHS Budget Division, Vera Krainick, Research Analyst, Office of Business Intelligence, and Lilia Teninty, Director, Developmental Disability Services, Oregon Department of Human Services.

Pennsylvania. Theresa Boucher, Budget Analyst III and Timothy O'Leary, Chief, Division of Financial Management; Suzanne Puzak and Connie Meeker, Director, Bureau of Policy

and Program Support; and Stephen Suroviec, Deputy Secretary, Office of Developmental Programs, Department of Public Welfare.

Rhode Island. Deb Mazzone, Principal Rate Analyst, Amy Vincenzi, Administrator and Craig Stenning, Director, Department of Behavioral Healthcare, Developmental Disabilities, and Hospitals, Department of Human Services.

South Carolina. Nancy Rumbaugh, Trina Smalley, Lisa Weeks, SC DDSN Budget Division; Tom Waring, Associate State Director, Administration and Beverly Buscemi, Ph.D., State Director, Department of Disabilities and Special Needs.

South Dakota. Tammie Herrlein, Laura Ellenbecker, Dan Lusk, Director, Darryl Millner, and Nicholas Cotton, Office of Budget & Finance, Division of Developmental Disabilities, Department of Human Services.

Tennessee. Melinda Lanza, Budget Director; Lance Iverson, Deputy Commissioner, Fiscal and Administrative Services; Debra K. Payne, Commissioner, Department of Intellectual and Developmental Disabilities.

Texas. Janie Eubanks, Quality Reporting, Michelle Martin, and Chris Adams, Director, Center for Policy and Innovation, and Jon Weizenbaum, Director, Texas Department of Aging and Disability Services (DADS).

Utah. Mel Castillo, Tyler D. Black, Administration, and Paul Smith, Director, Division of Services for People with Disabilities, Department of Human Services.

Vermont. June Bascom, M.A., Program Development and Policy Analyst and Camille George, Director, Developmental Disabilities Services Division, Department of Disabilities, Aging and Independent Living.

Virginia. Rupinder Kaur, Cheri Stierer, Ph.D., Community Resource Manager, and Lee Price, Director, Office of Developmental Services, Department of Behavioral Health and Developmental Services.

Washington. Lisa Weber and Chris Shelley, Developmental Disabilities Administration with Steve Kuehn, Jennifer Usrey-Scott, and Dave Cook, Management Services Division; Aging and Disability Services; Department of Social and Health Services.

West Virginia. Cassandra Toliver, Patricia Nisbet, Deborah Reed, and Jim Cremeans, Community Supports, and Beth Morrison, Director, Division of Intellectual and Developmental Disabilities, Bureau for Behavioral Health and Health Facilities, Department of Health and Human Resources.

Wisconsin. Michelle Prost, Budget and Policy Analyst, Michael Pancook, Senior Rate Analyst, Curtis Cunningham, Bureau of Financial Management Director, and Beth Wroblewski, Division of Long-Term Care Administrator, Department of Health and Family Services.

Wyoming. Colleen Noon, Data Analyst/Epidemiologist, Aaron Wales, Accounting Analyst-Medicaid, Kevin Kulow, Business Office Manager-WLRC and Chris Newman, Administrator, Developmental Disabilities Division, Wyoming Department of Health.

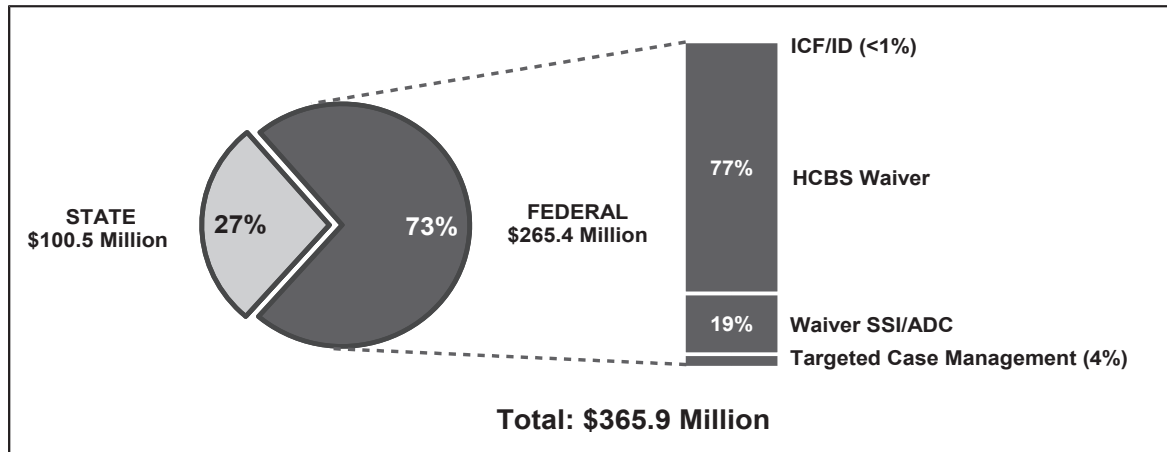
PART II

Presentation of Profiles for the 50 States and the District of Columbia

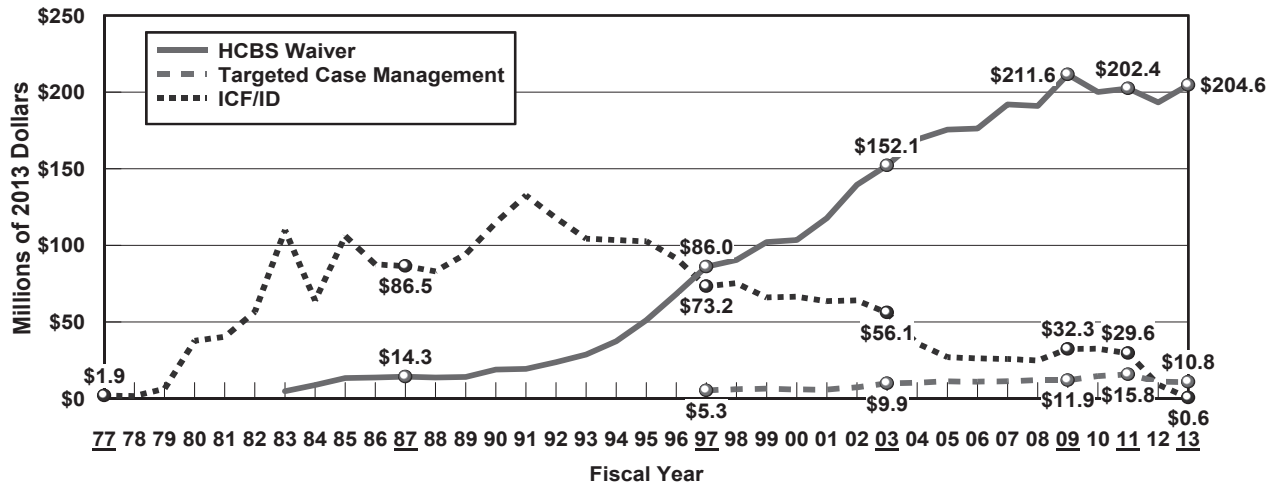
To Create Your Own Charts, Go To <http://www.stateofthestates.org/>

ALABAMA

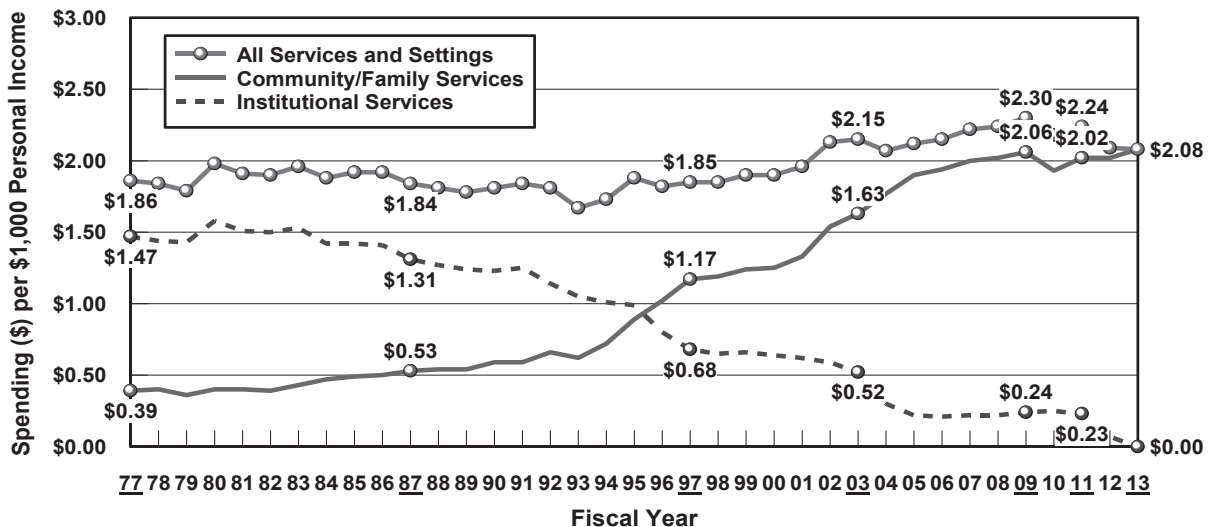
PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013



FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



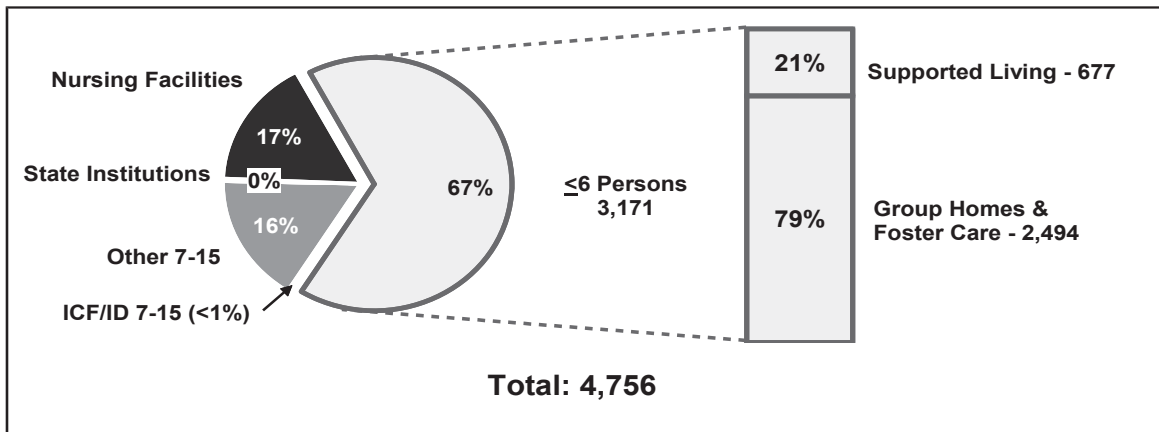
FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013



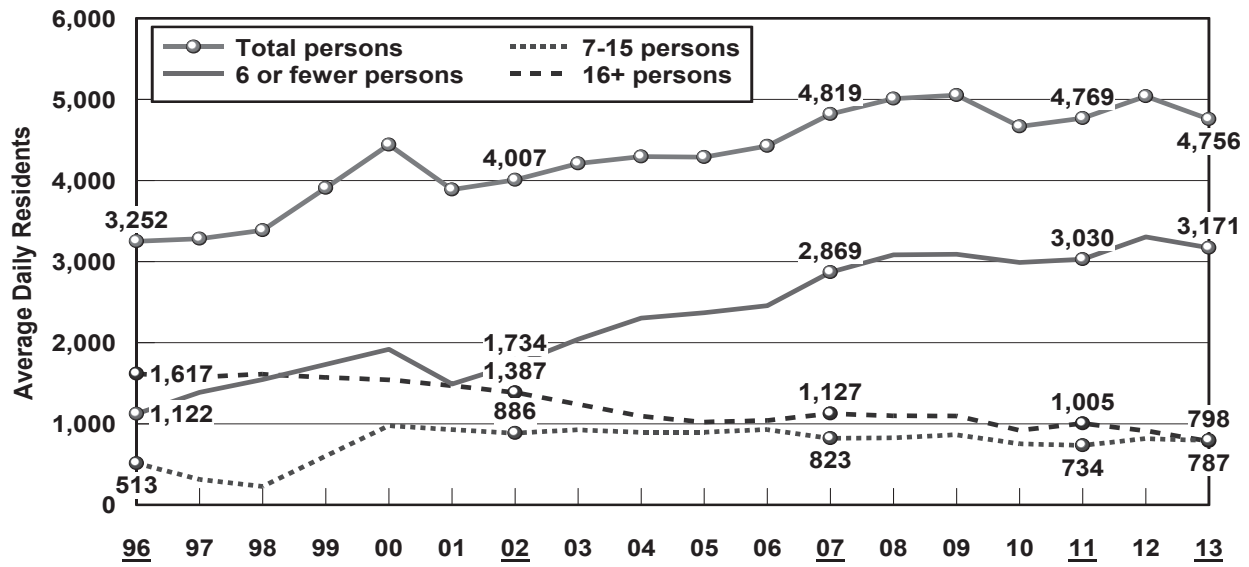
Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.
<http://stateofthestates.org>

ALABAMA

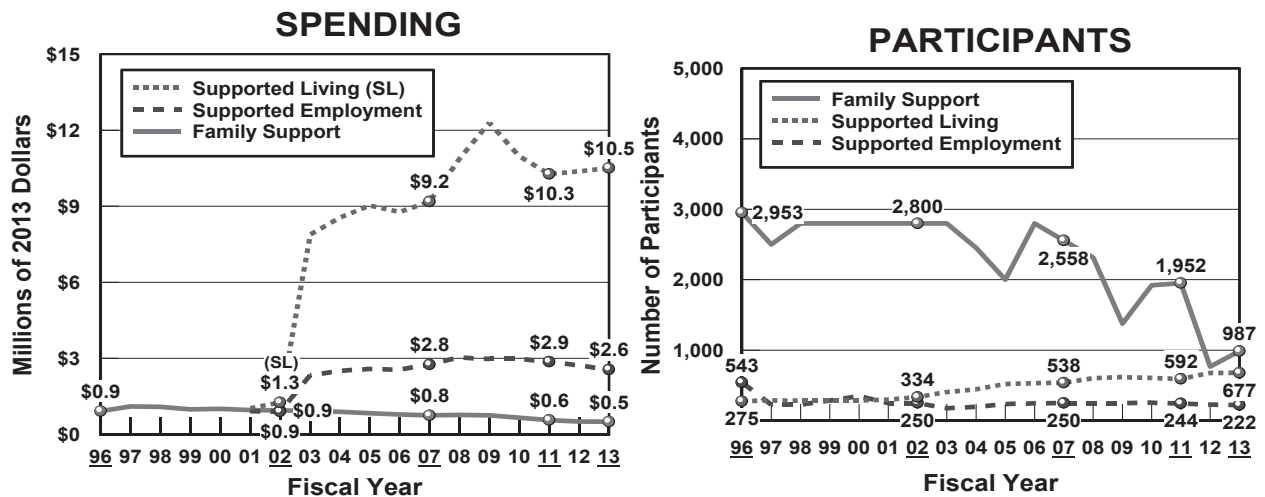
PERSONS BY SETTING IN FISCAL YEAR 2013



PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013



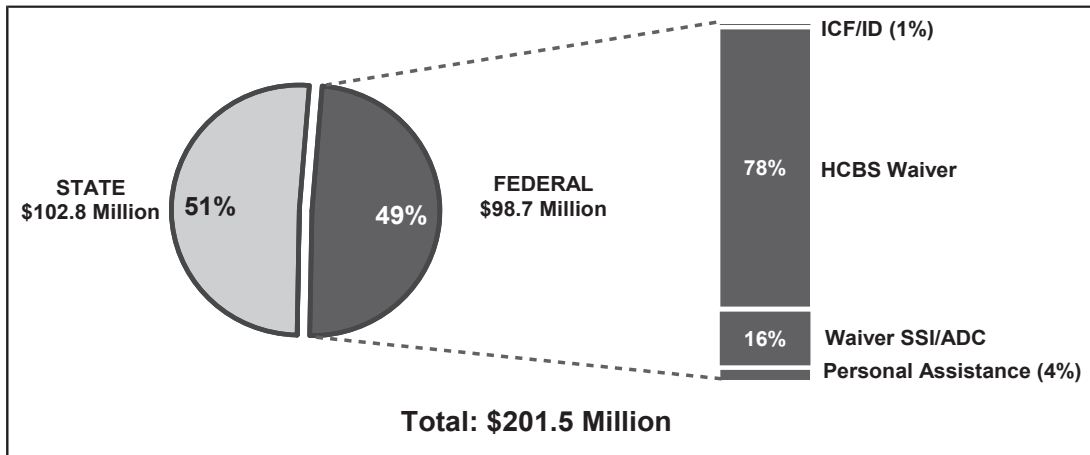
INDIVIDUAL AND FAMILY SUPPORT



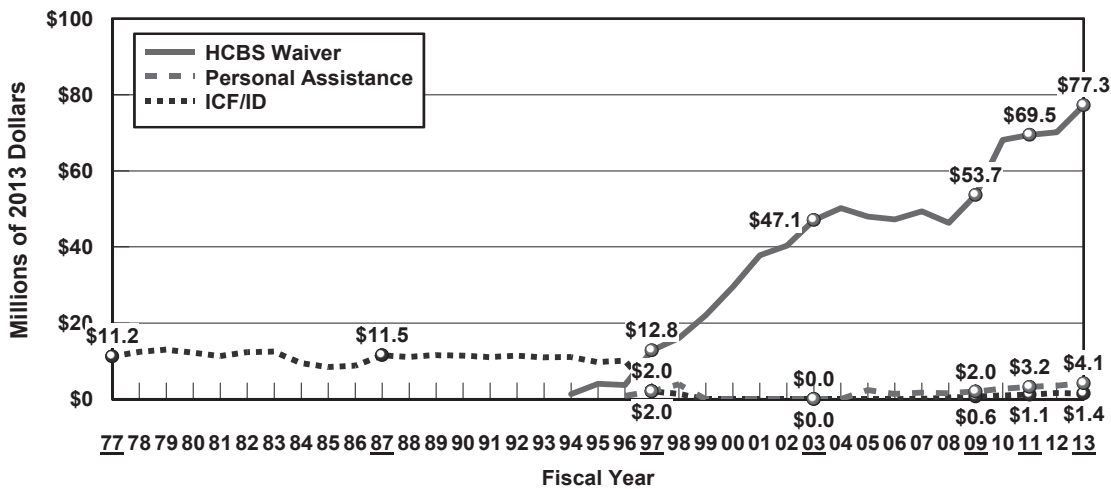
Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.
<http://stateofthestates.org>

ALASKA

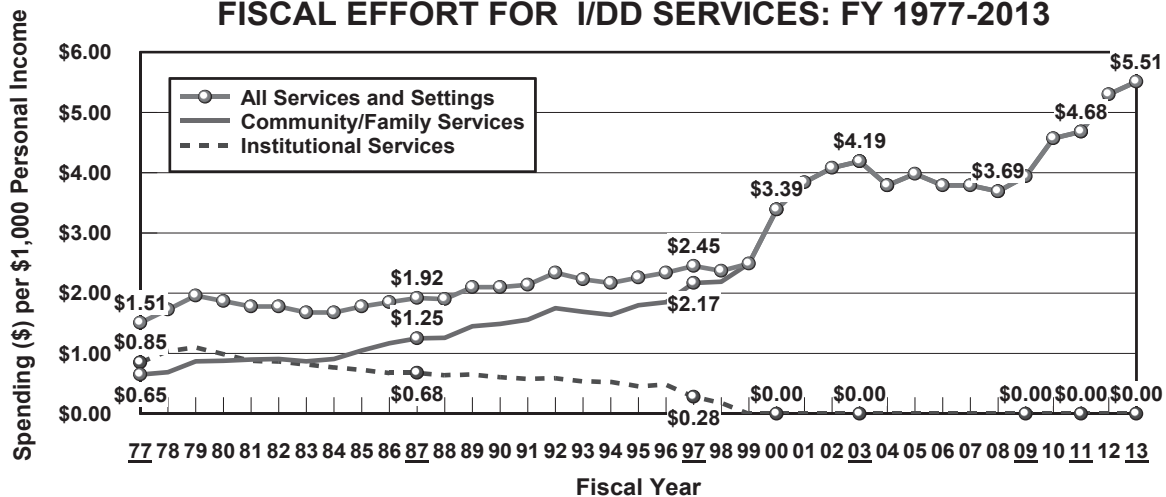
PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013



FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013

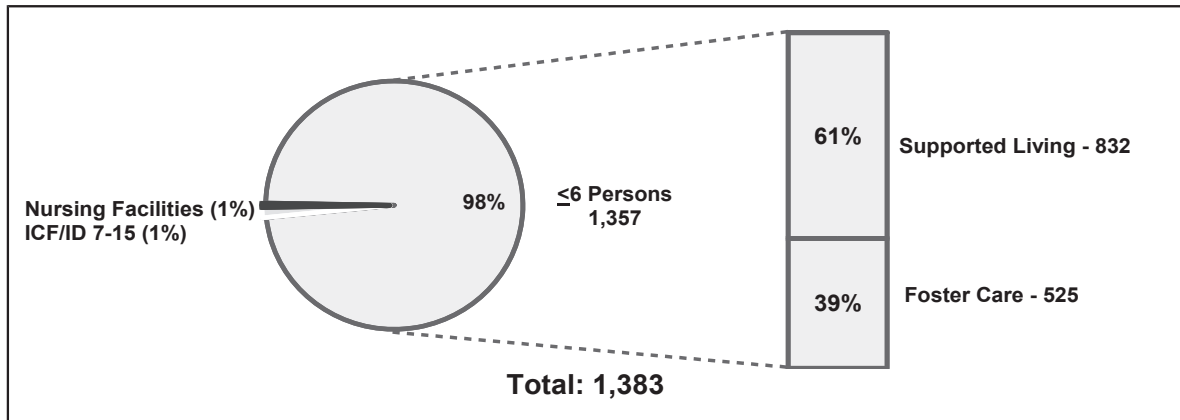


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

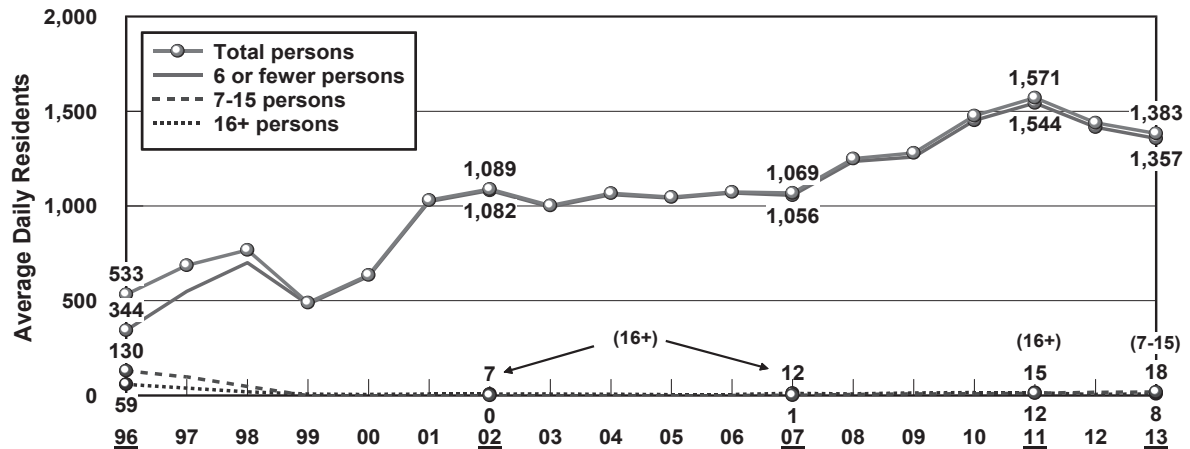
<http://stateofthstates.org>

ALASKA

PERSONS BY SETTING IN FISCAL YEAR 2013

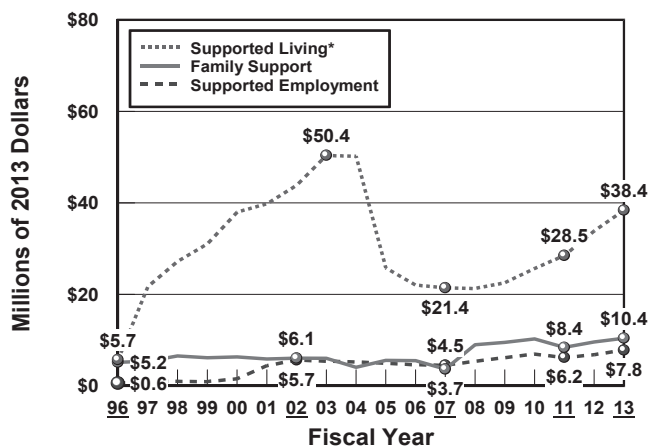


PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013

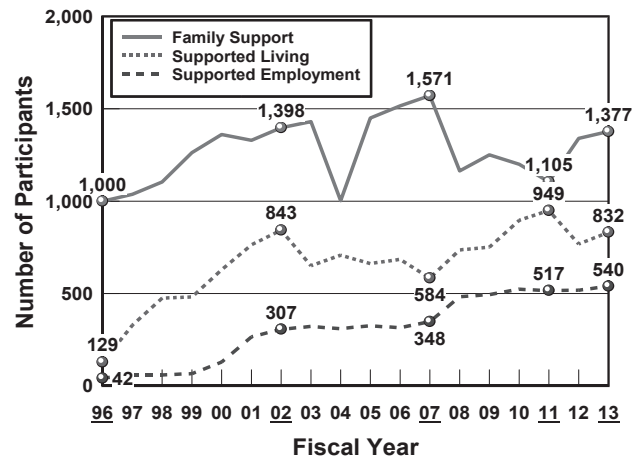


INDIVIDUAL AND FAMILY SUPPORT

SPENDING



PARTICIPANTS



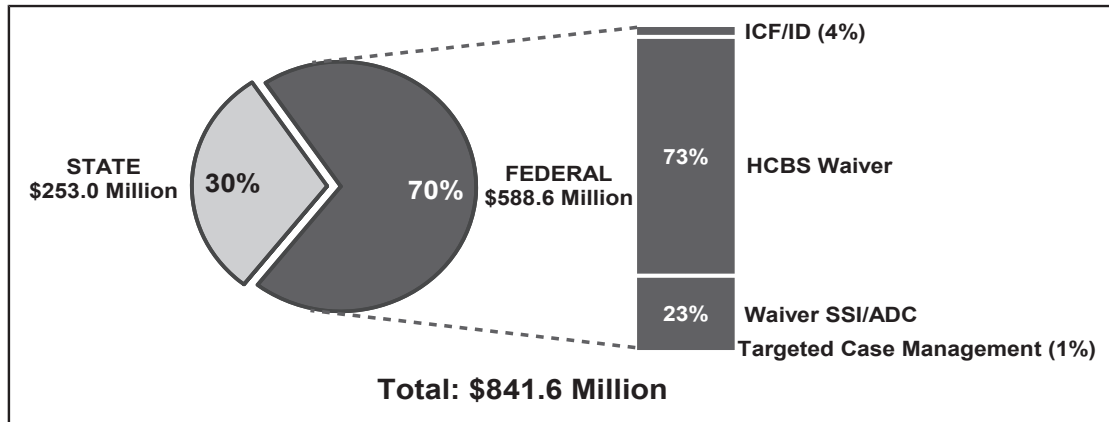
*State revised supported living spending for 2005-2011.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

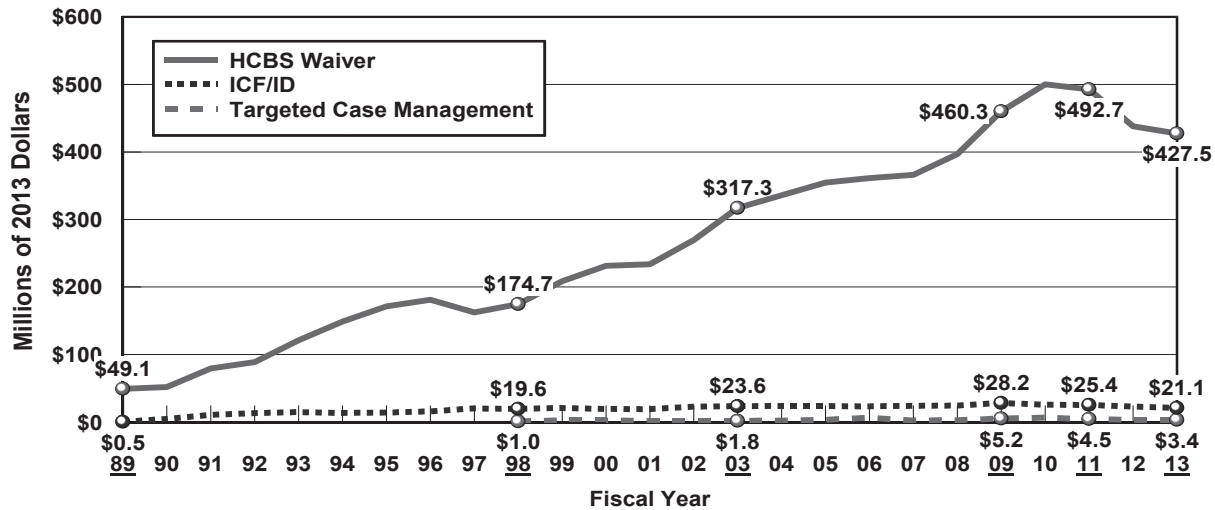
<http://stateofthestates.org>

ARIZONA

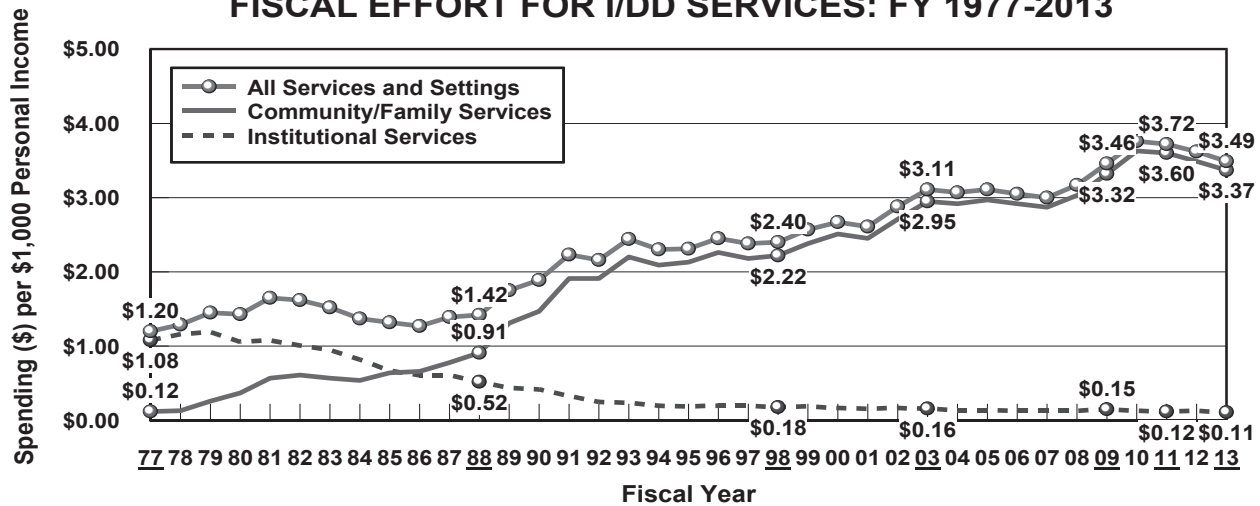
PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013



FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013

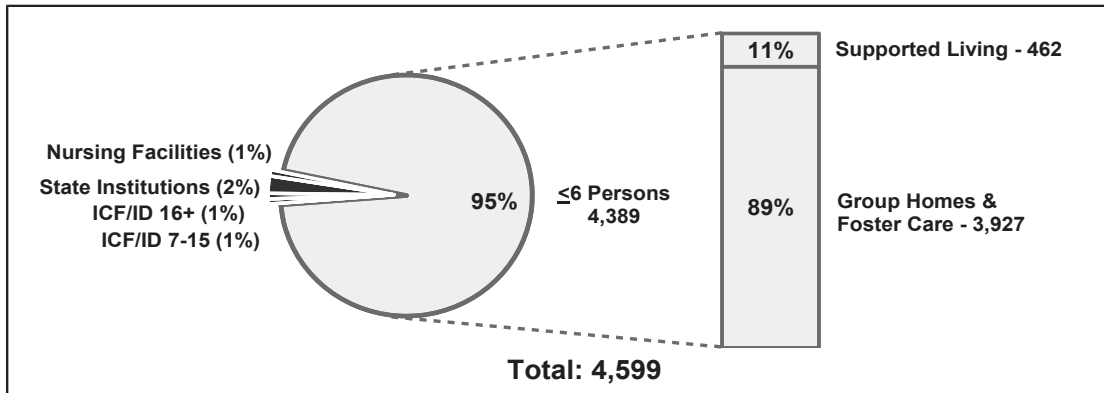


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

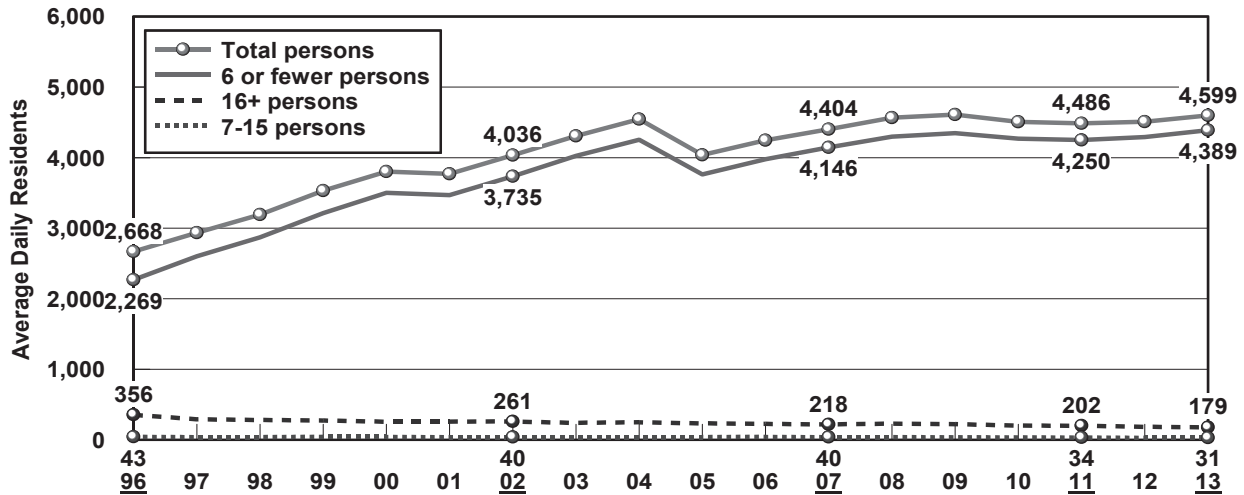
<http://stateofthestates.org>

ARIZONA

PERSONS SERVED BY SETTING IN 2013

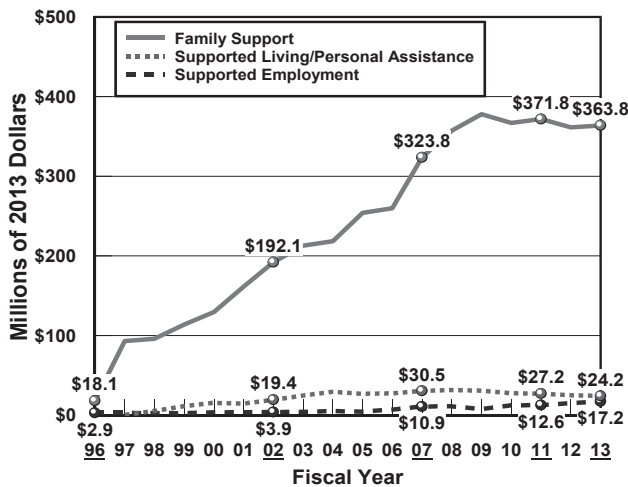


PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013

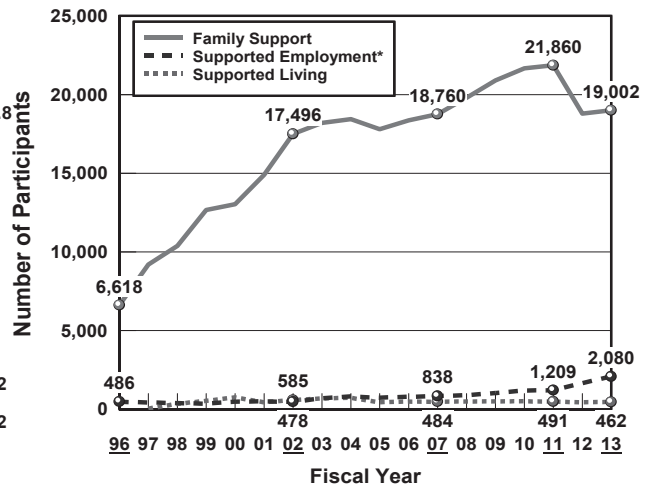


INDIVIDUAL AND FAMILY SUPPORT

SPENDING



PARTICIPANTS



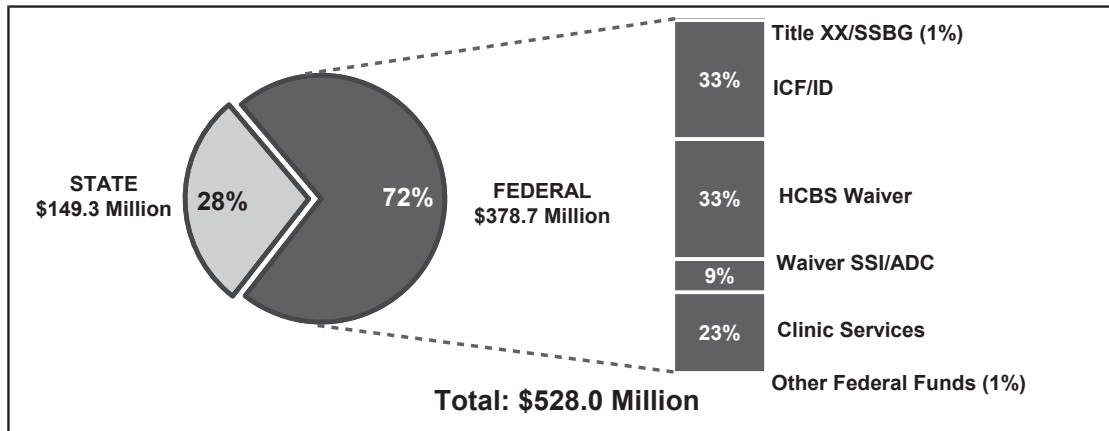
*Does not include follow-along work support workers: 151 in 2012 and 170 in 2013.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

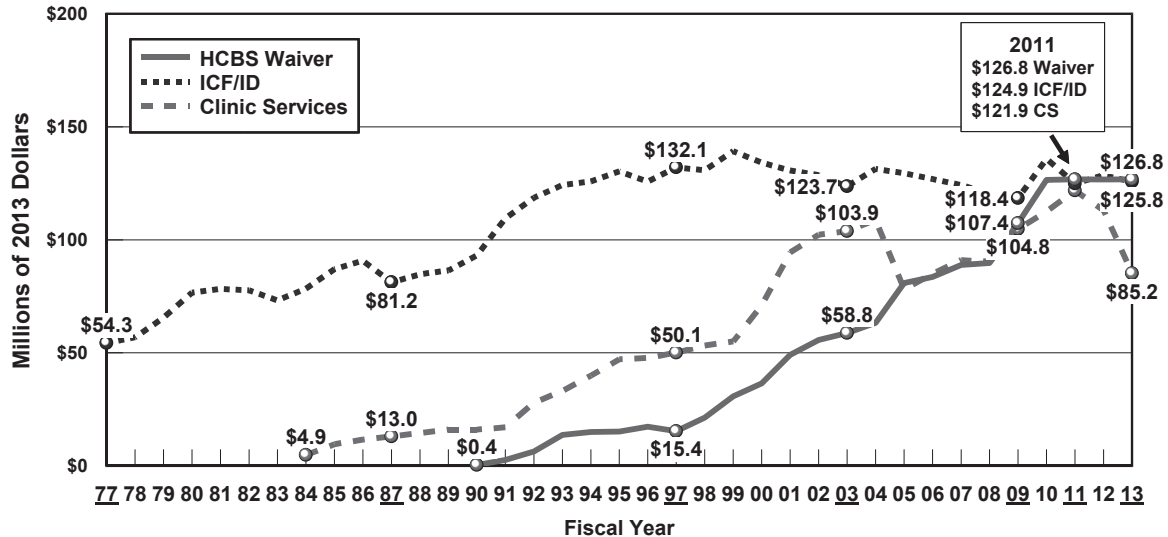
<http://stateofthestates.org>

ARKANSAS

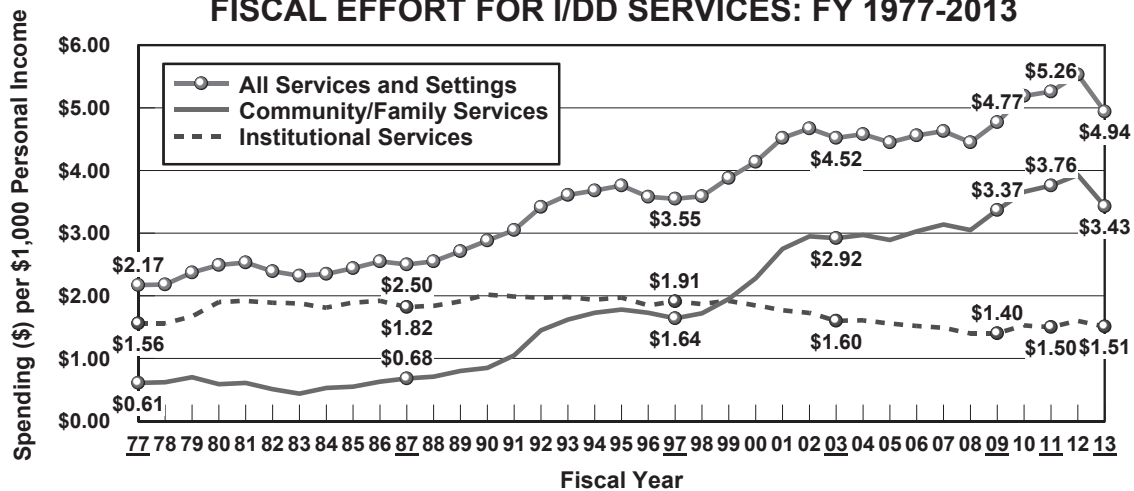
PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013



FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



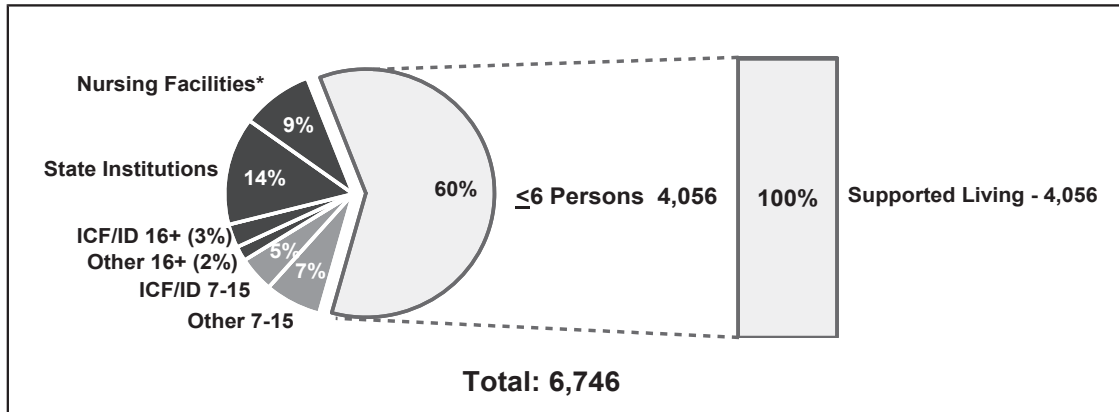
FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013



Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.
stateofthestates.org

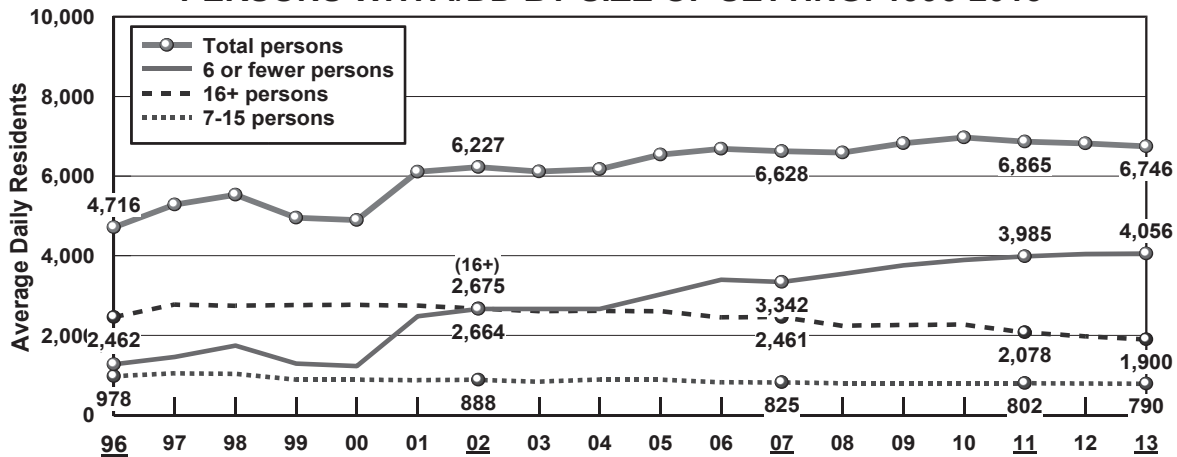
ARKANSAS

PERSONS BY SETTING IN FISCAL YEAR 2013

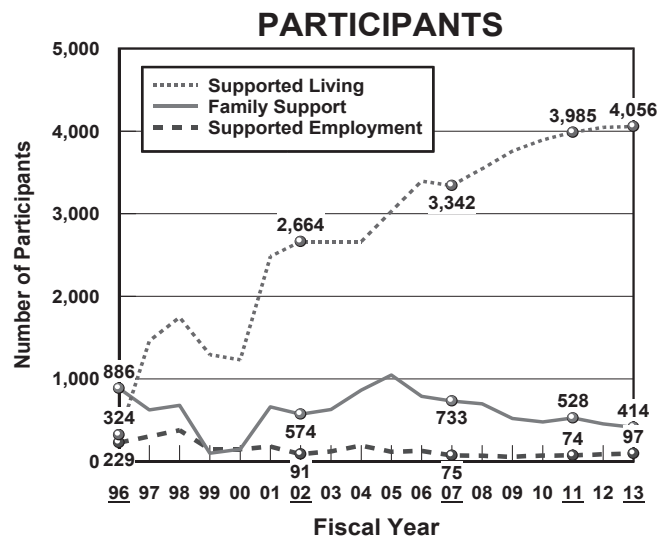
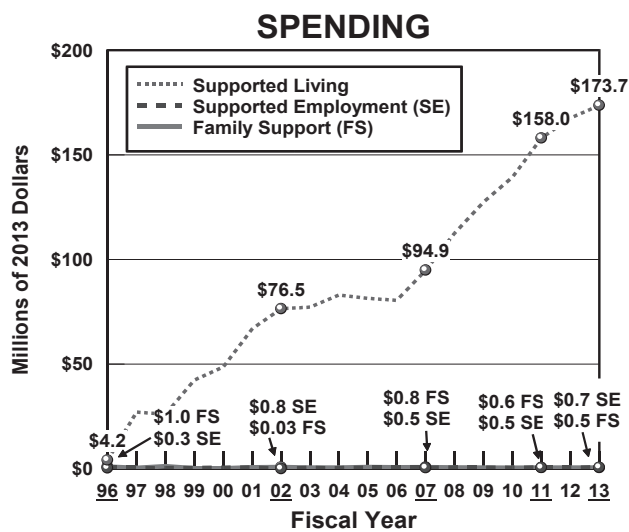


*2006-13 nursing facility data revised to incorporate CMS OSCAR data.

PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013



INDIVIDUAL AND FAMILY SUPPORT

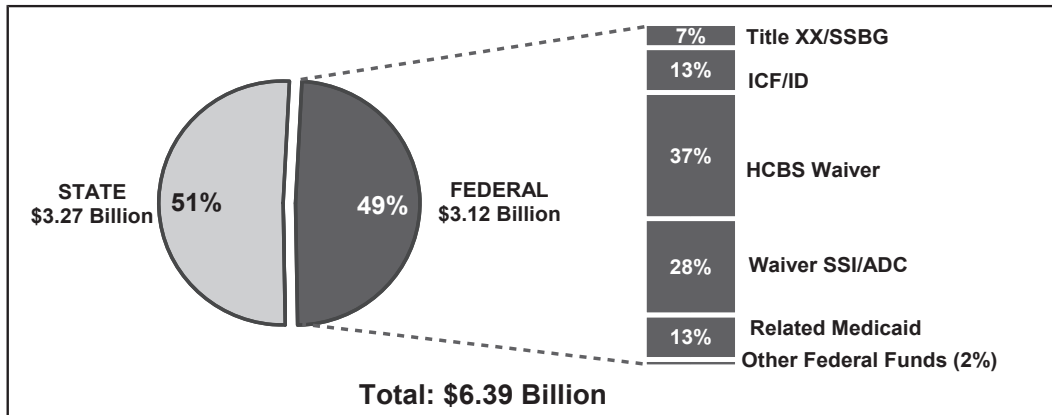


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

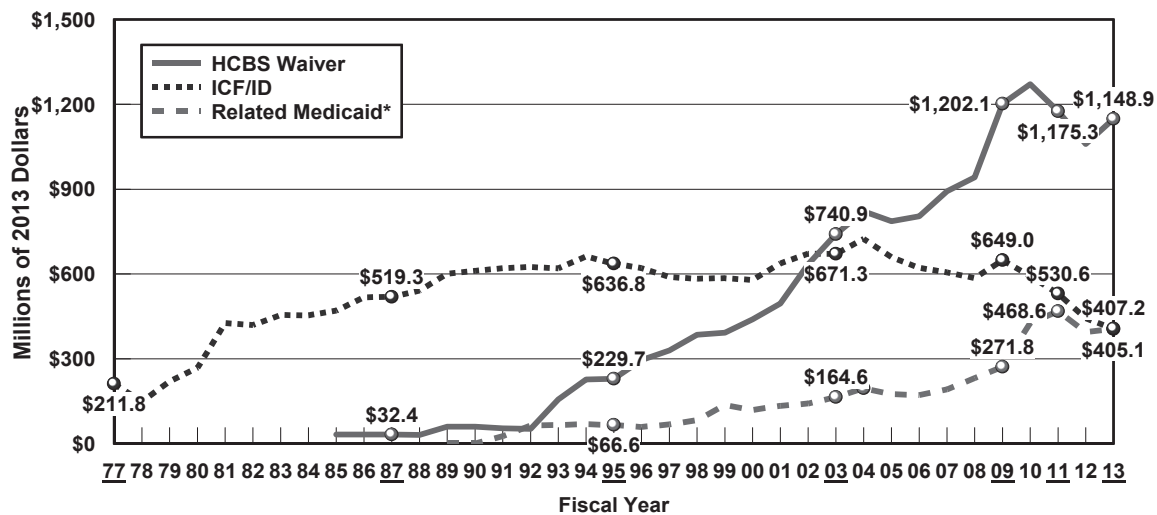
<http://stateofthestates.org>

CALIFORNIA

PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013

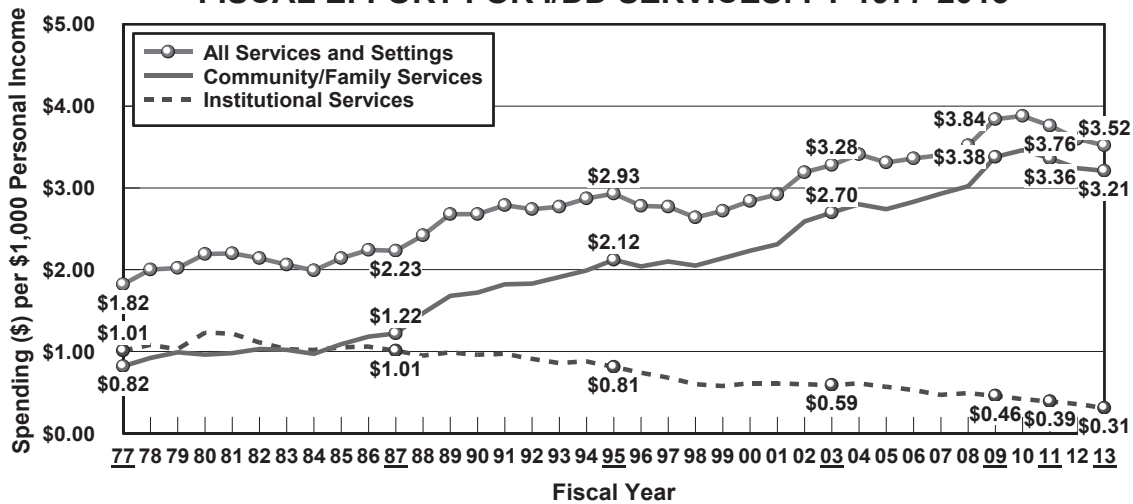


FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



*In 2013, "Related Medicaid" was administration (\$259.1 million) and targeted case management (\$146.0 million).

FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013

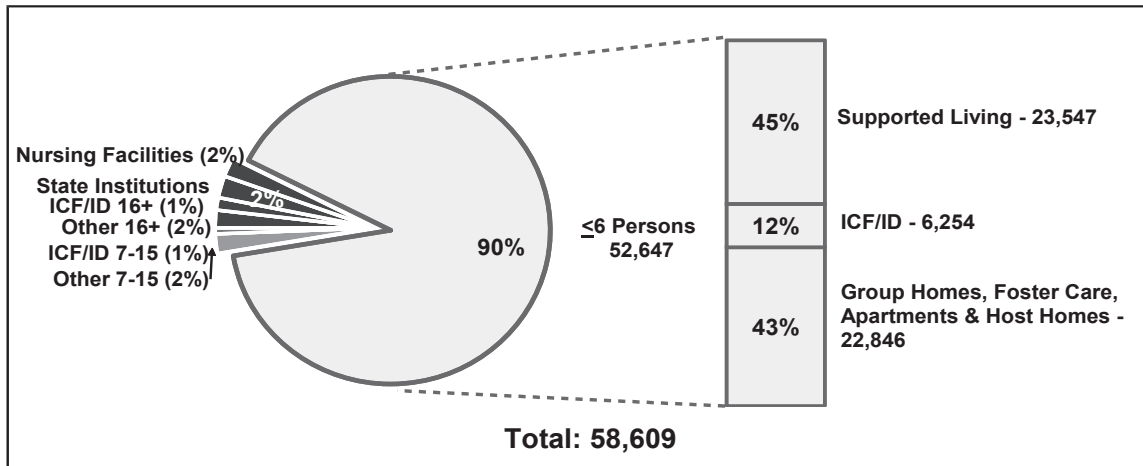


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

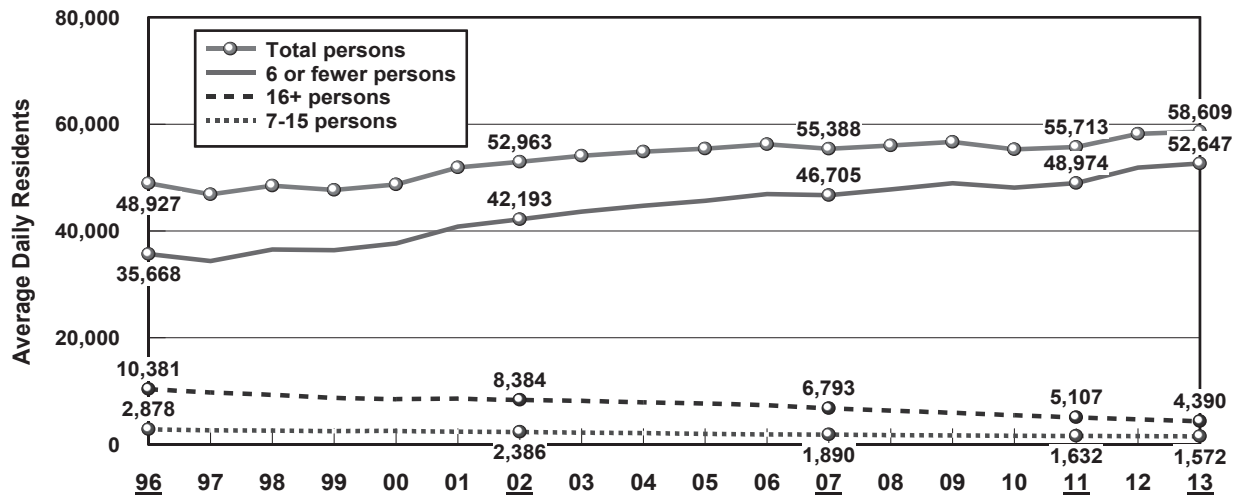
<http://stateofthestates.org>

CALIFORNIA

PERSONS SERVED BY SETTING IN FISCAL YEAR 2013

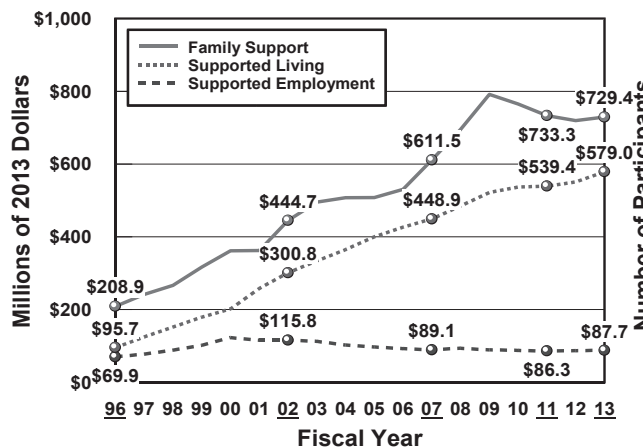


PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013

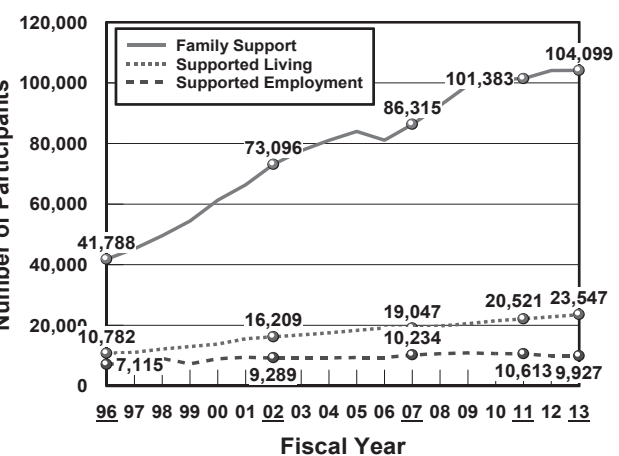


INDIVIDUAL AND FAMILY SUPPORT

SPENDING



PARTICIPANTS

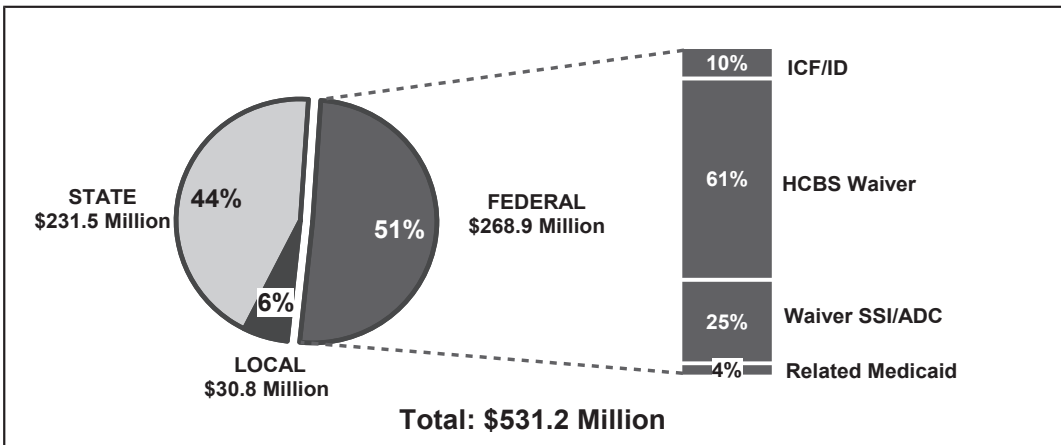


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

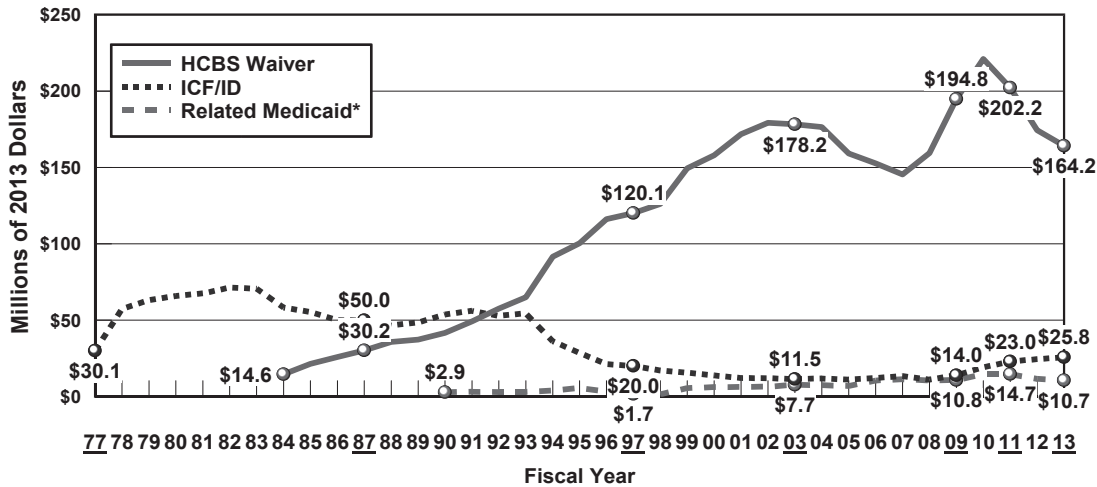
<http://stateofthestates.org>

COLORADO

PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013

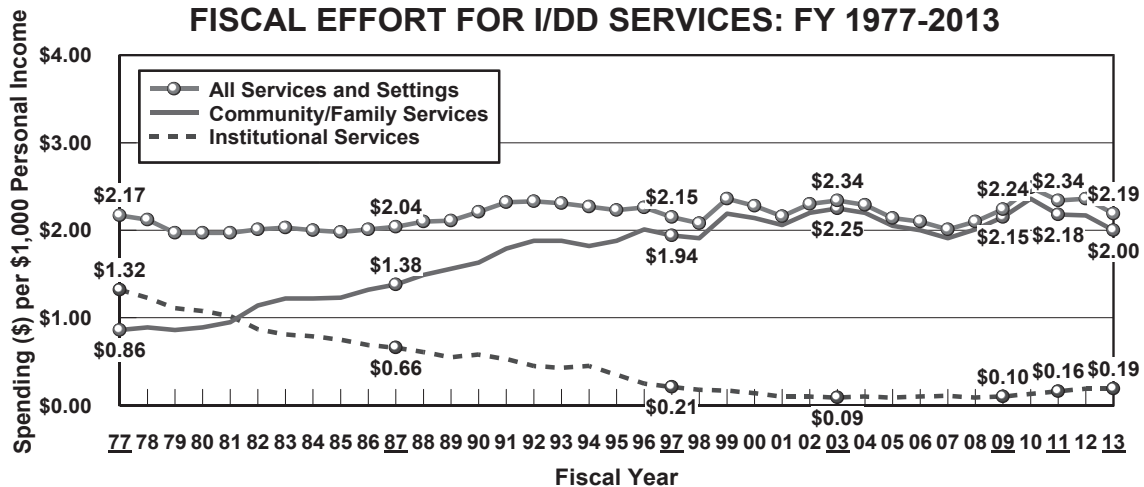


FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



*In 2013, "Related Medicaid" was targeted case management (\$9.4 million) and administration (\$1.3 million).

FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013

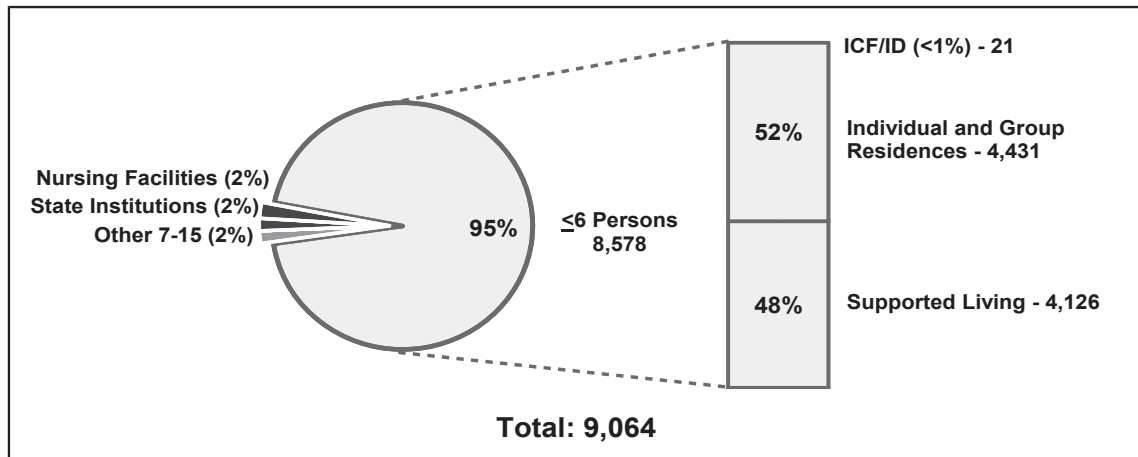


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

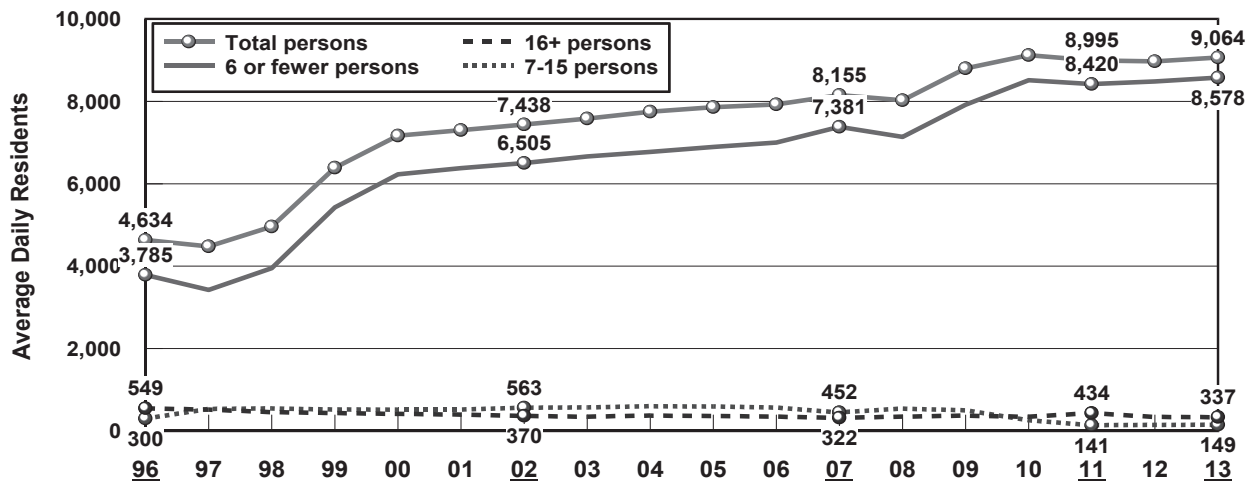
<http://stateofthestates.org>

COLORADO

PERSONS BY SETTING IN FISCAL YEAR 2013

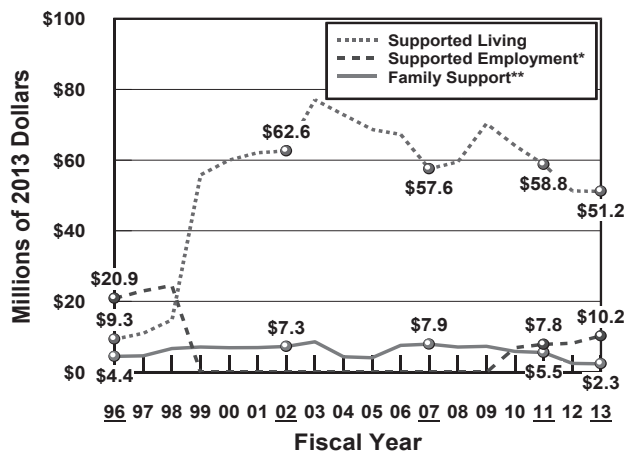


PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013

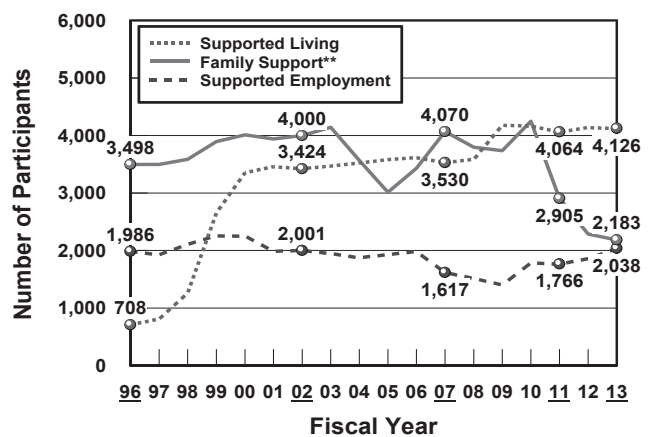


INDIVIDUAL AND FAMILY SUPPORT

SPENDING



PARTICIPANTS



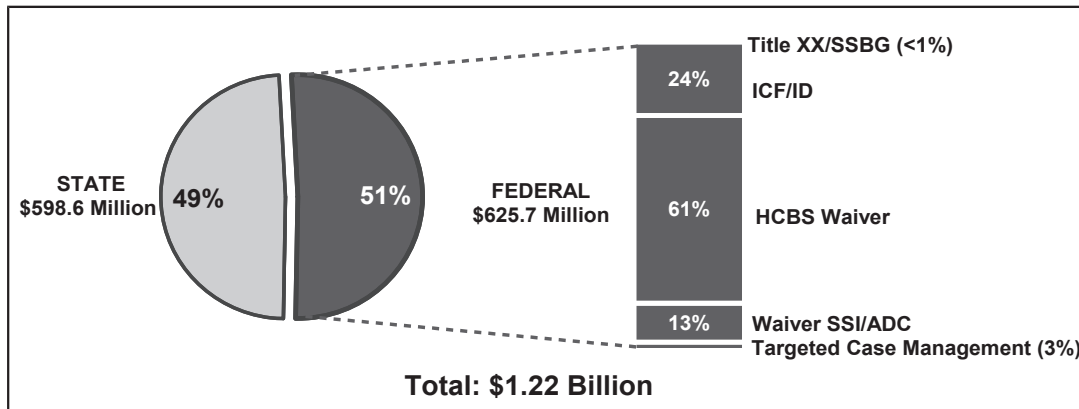
*State reported no data for Supported Employment spending during 1999-2009. and 2010-13 due to state general fund reductions.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

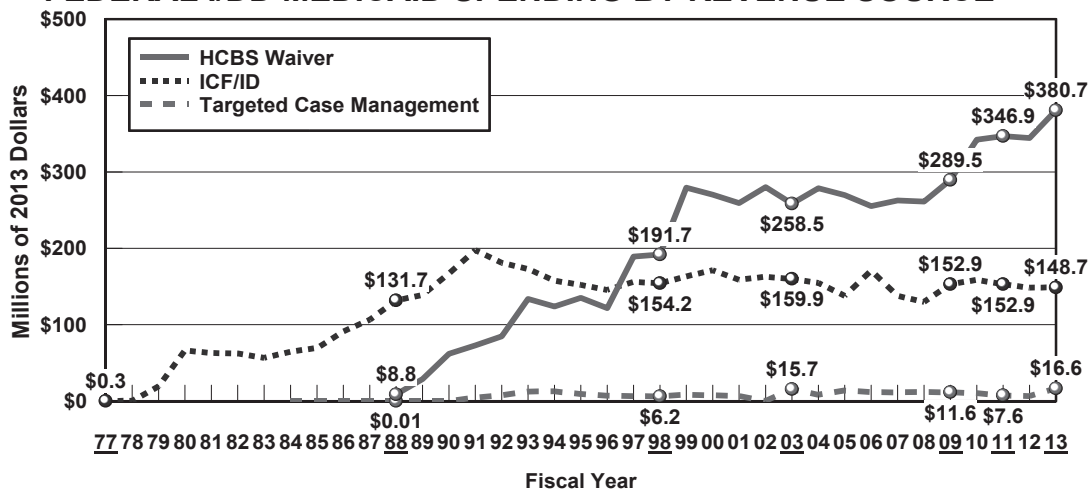
<http://stateofthestates.org>

CONNECTICUT

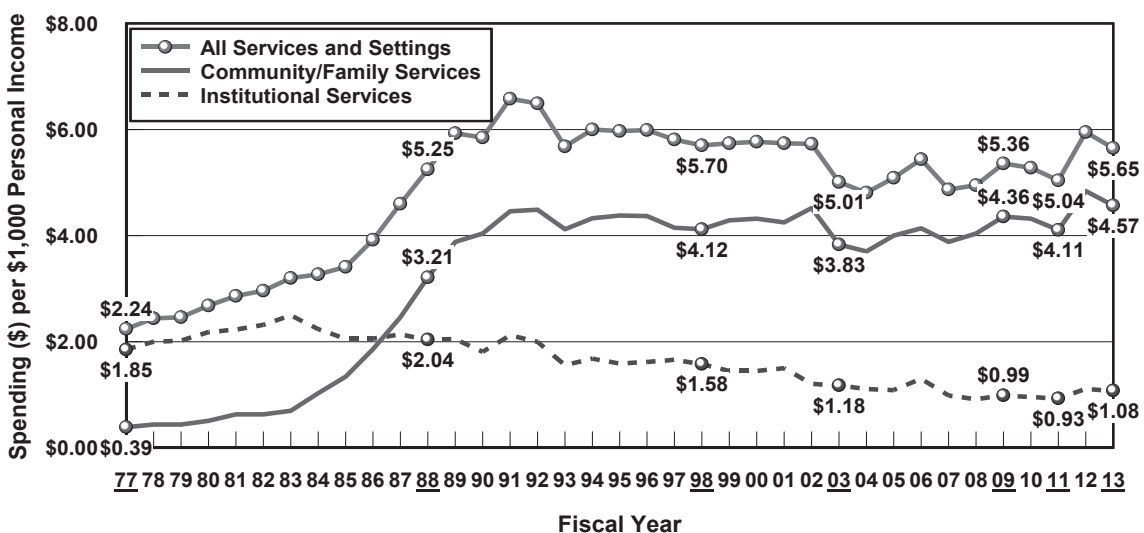
PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013



FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013

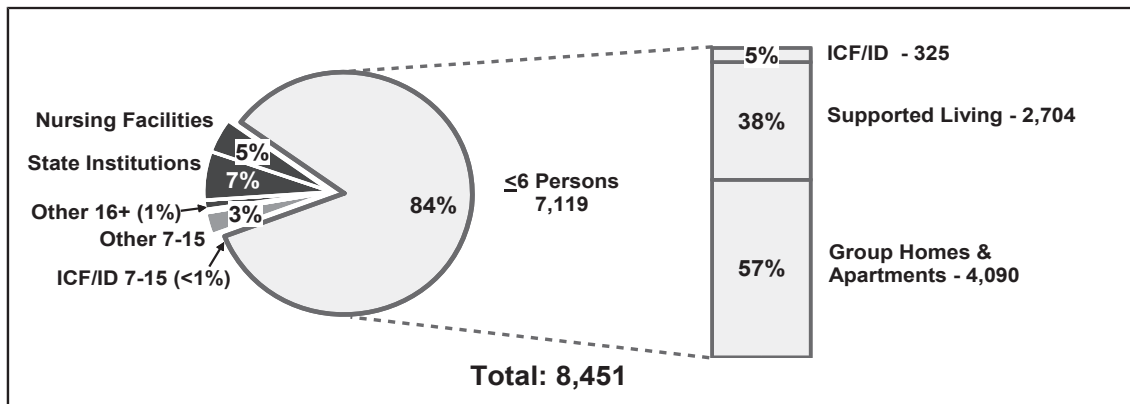


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

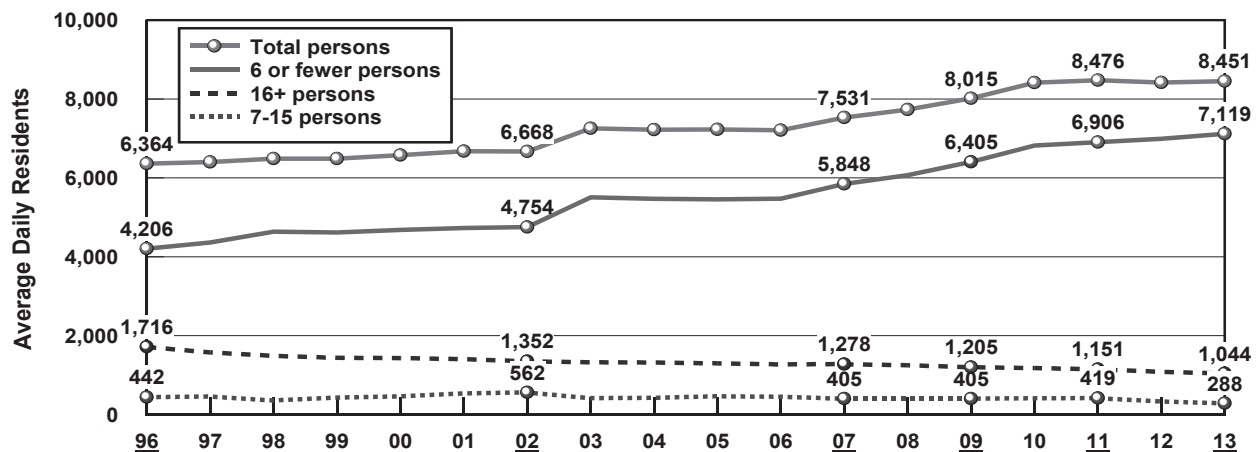
<http://stateofthestates.org>

CONNECTICUT

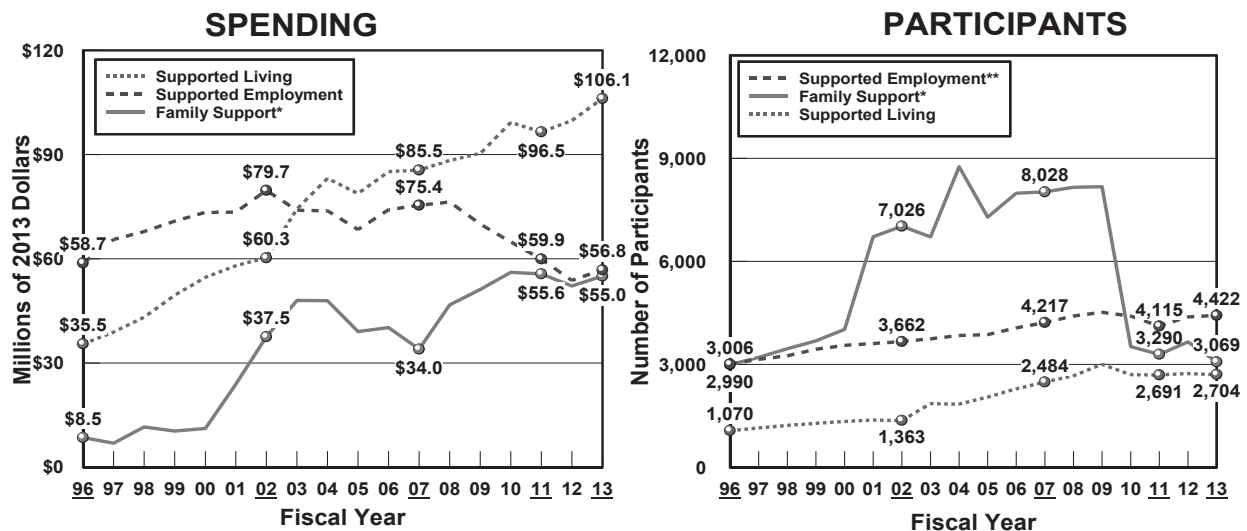
PERSONS BY SETTING IN FISCAL YEAR 2013



PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013



INDIVIDUAL AND FAMILY SUPPORT



*In 2010-11 nearly 4,000 families no longer received respite grants (\$200-\$500 per family).

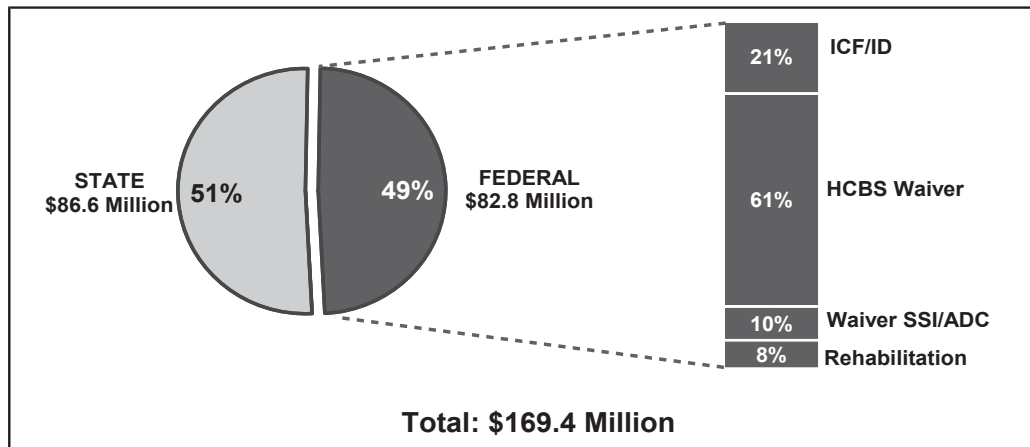
**Does not include 345 follow-along work support workers in 2012 and 326 workers in 2013.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

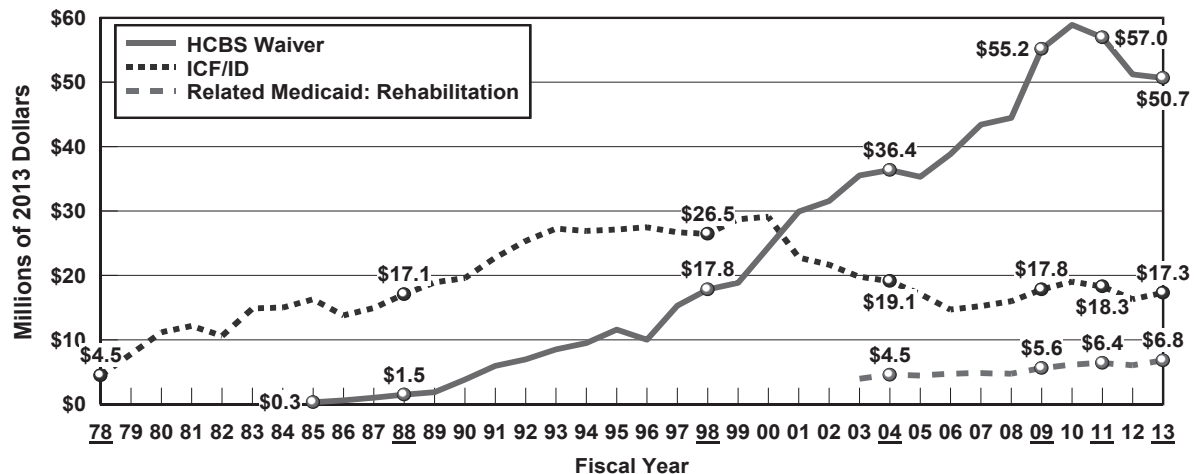
<http://stateofthestates.org>

DELAWARE

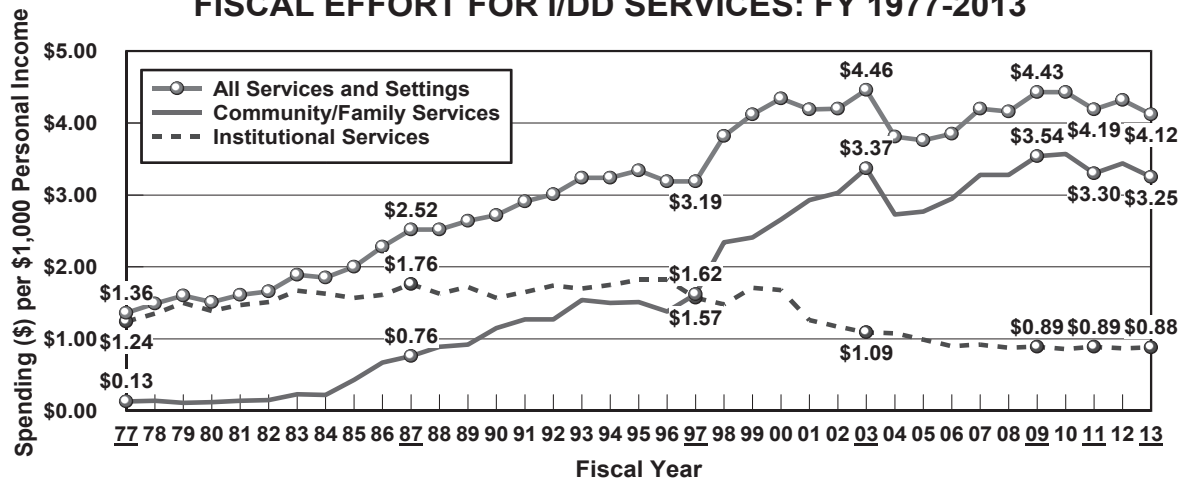
PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013



FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



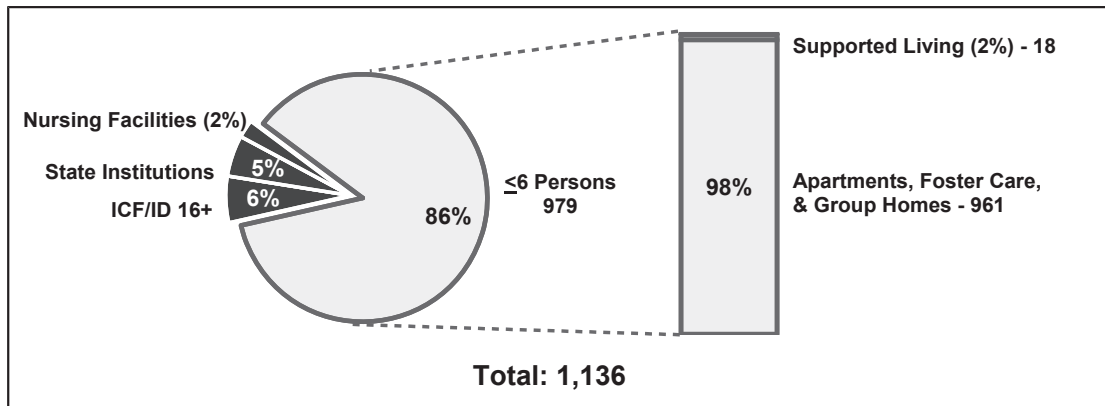
FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013



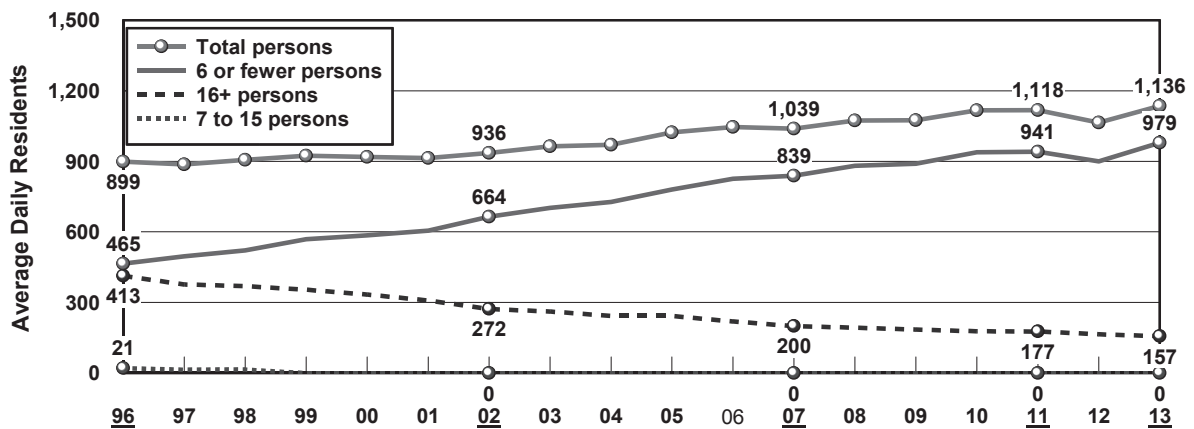
Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.
<http://stateofthestates.org>

DELAWARE

PERSONS BY SETTING IN FISCAL YEAR 2013

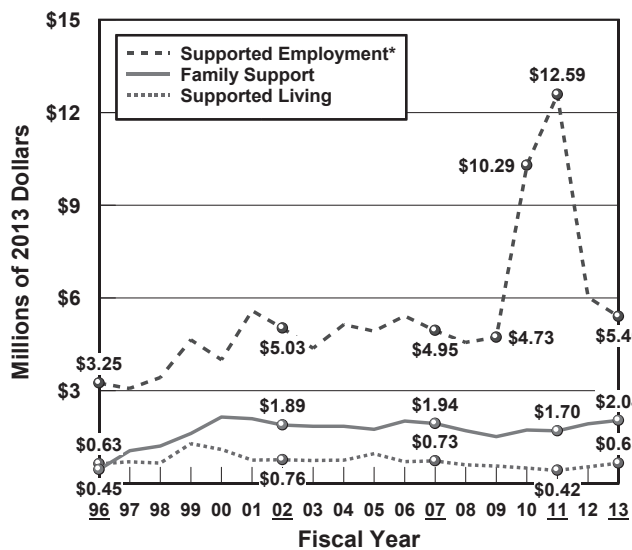


PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013

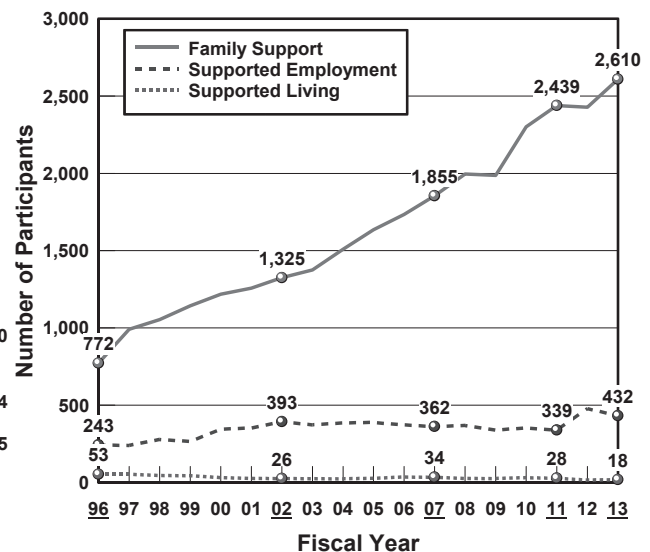


INDIVIDUAL AND FAMILY SUPPORT

SPENDING



PARTICIPANTS

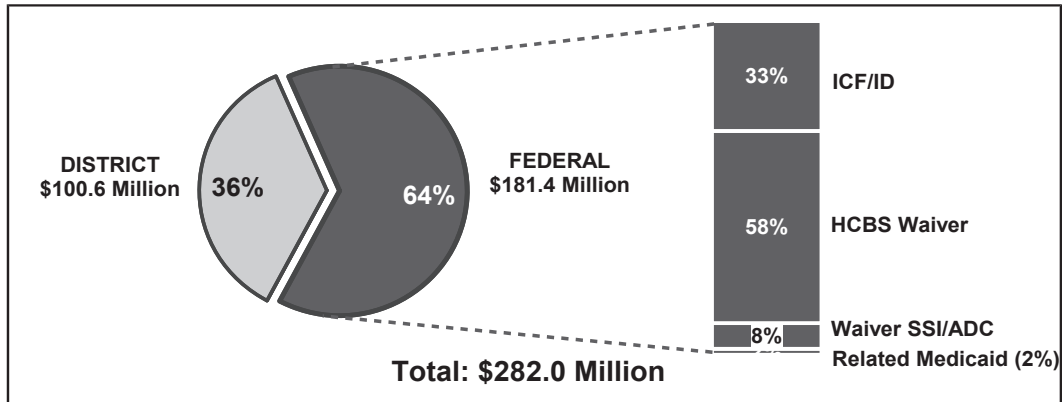


*The state in 2011 paid an enhanced per worker, which declined to previous levels in 2012-13.

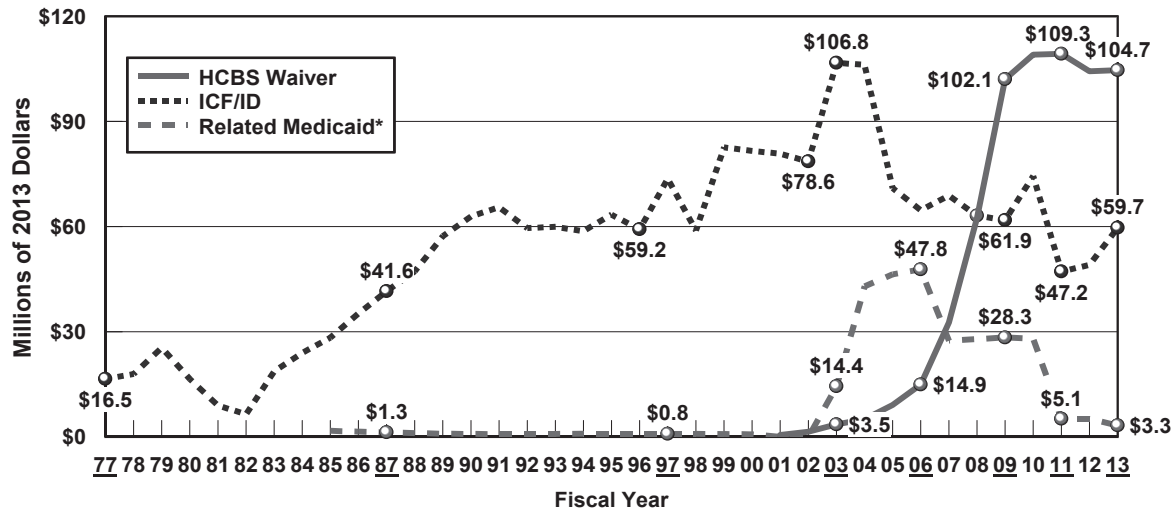
Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

<http://stateofthestates.org>

DISTRICT OF COLUMBIA PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013

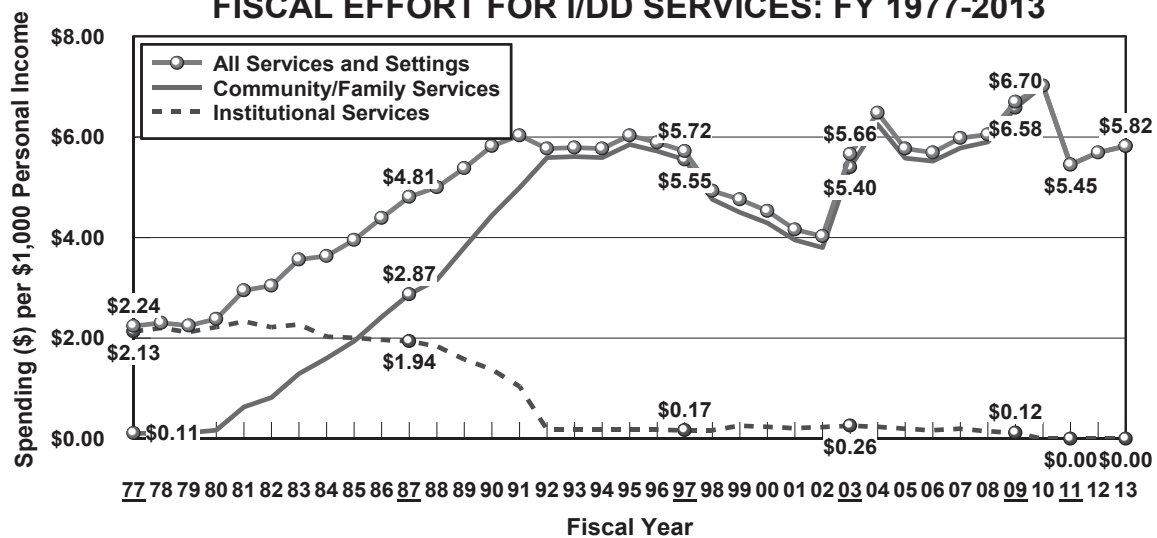


FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



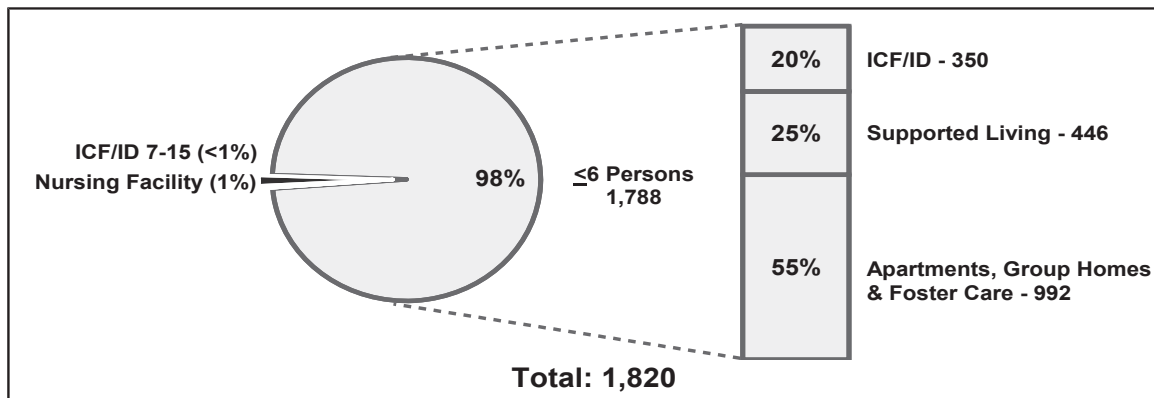
*Related Medicaid in 2013 included clinic rehabilitation (\$2.7 M.) and personal assistance (\$0.6 M.).

FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013

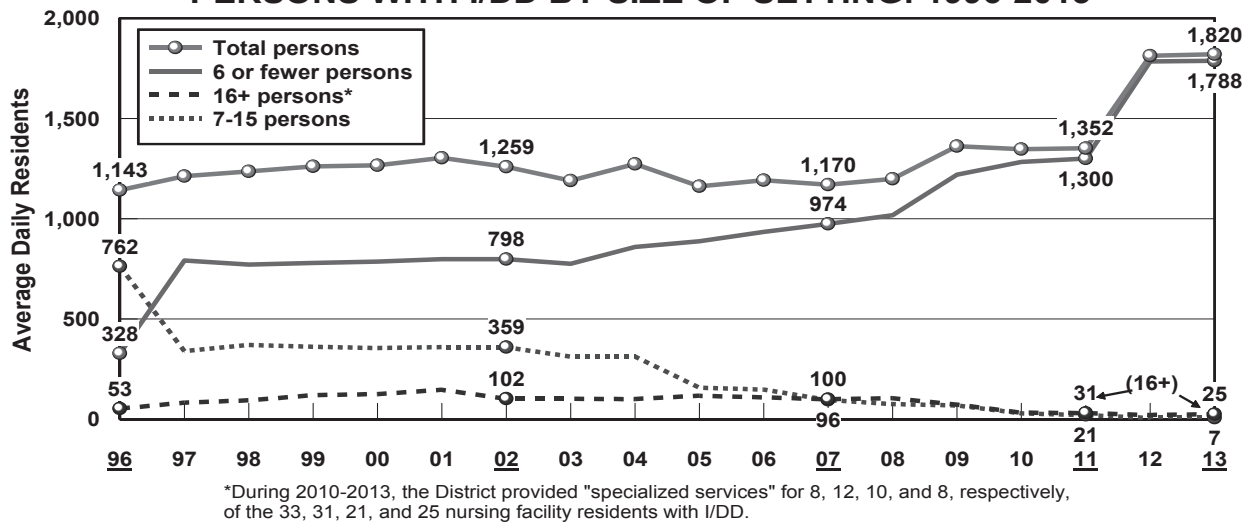


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.
<http://stateofthestates.org>

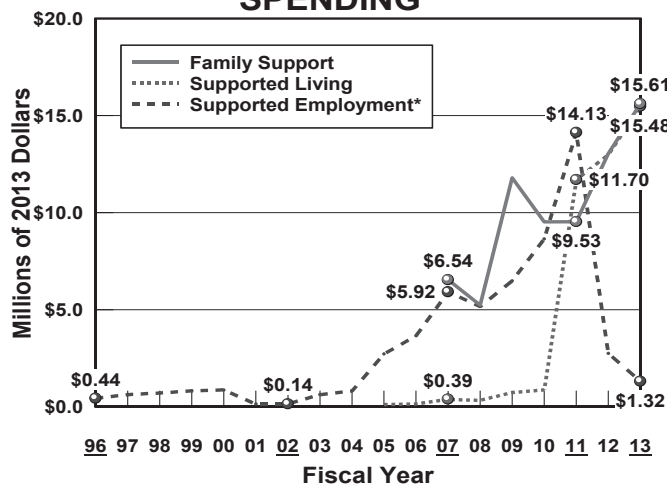
DISTRICT OF COLUMBIA PERSONS BY SETTING IN FISCAL YEAR 2013



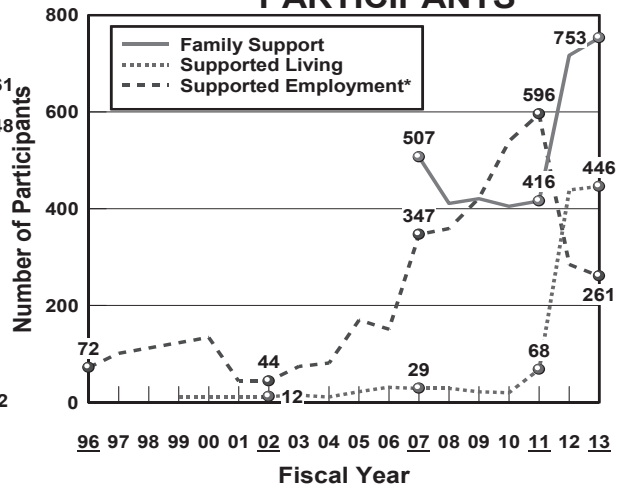
PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013



INDIVIDUAL AND FAMILY SUPPORT SPENDING



PARTICIPANTS

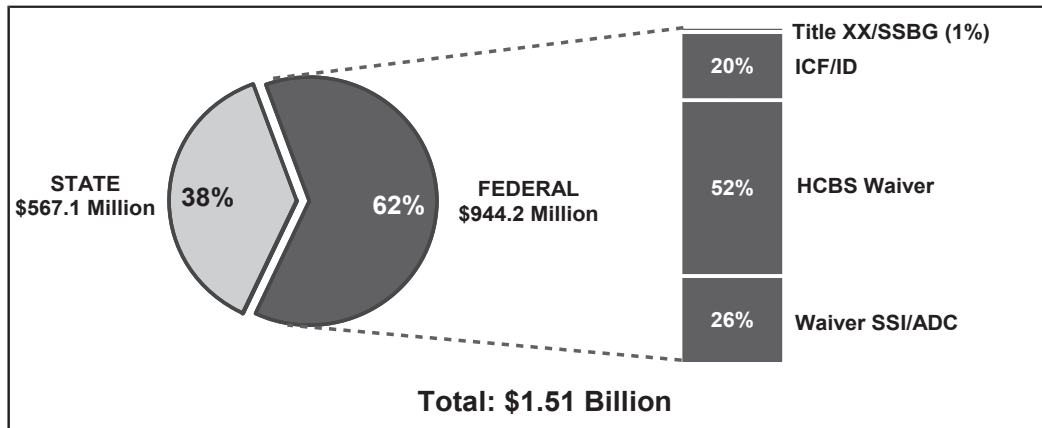


*State policy increased employment outreach for people with I/DD including a doubling of Medicaid Waiver funding from 2010 to 2011, but employment spending and workers then declined 2012 & 2013. Workers do not include 190 and 367 follow-along work support workers in 2012 and 2013.

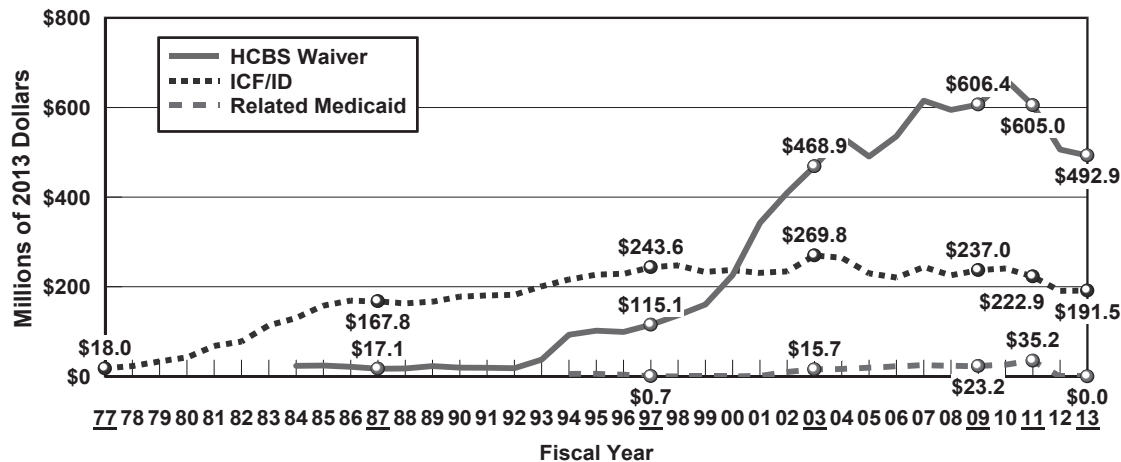
Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.
<http://stateofthestates.org>

FLORIDA

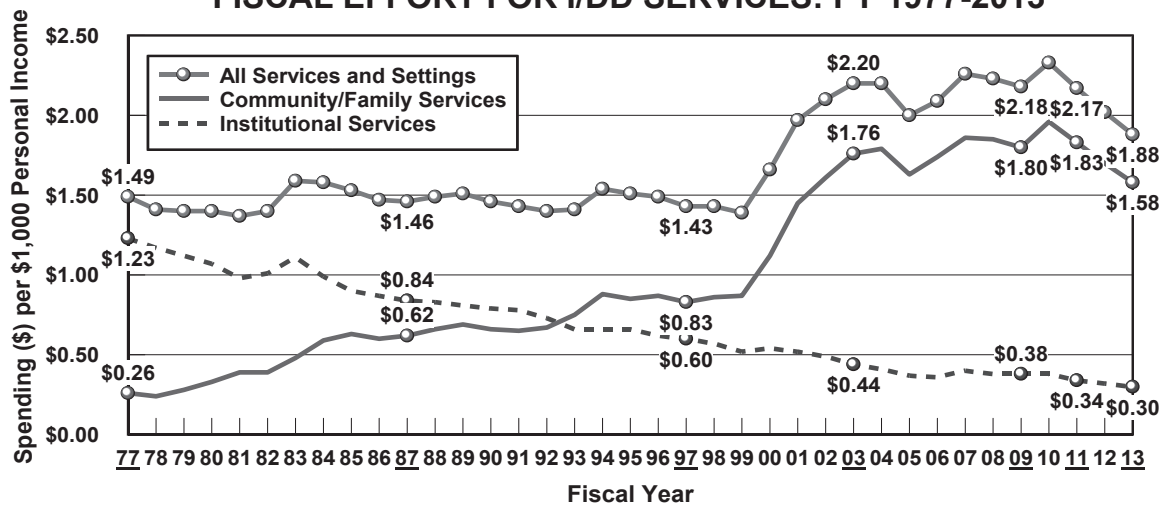
PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013



FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013

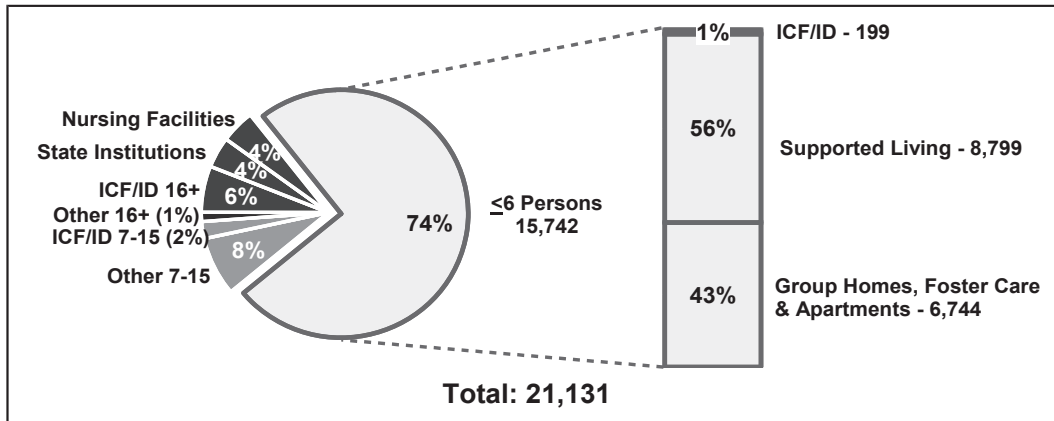


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

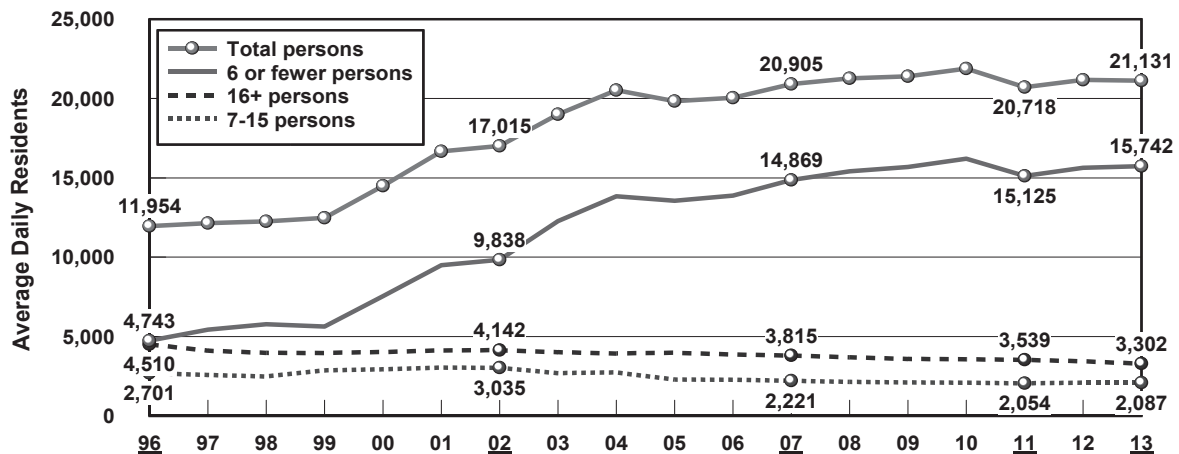
<http://stateofthestates.org>

FLORIDA

PERSONS BY SETTING IN FISCAL YEAR 2013

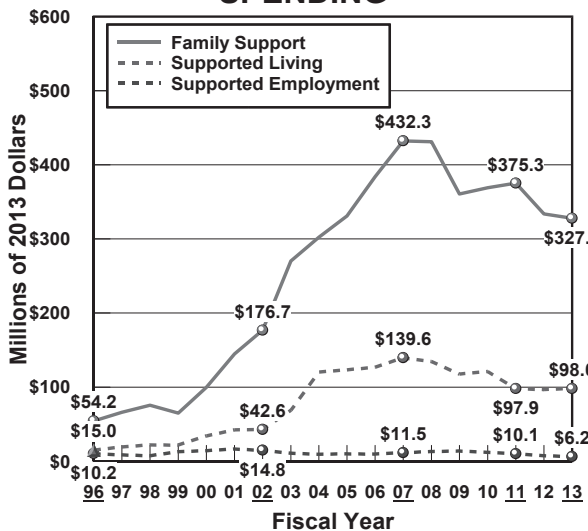


PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013

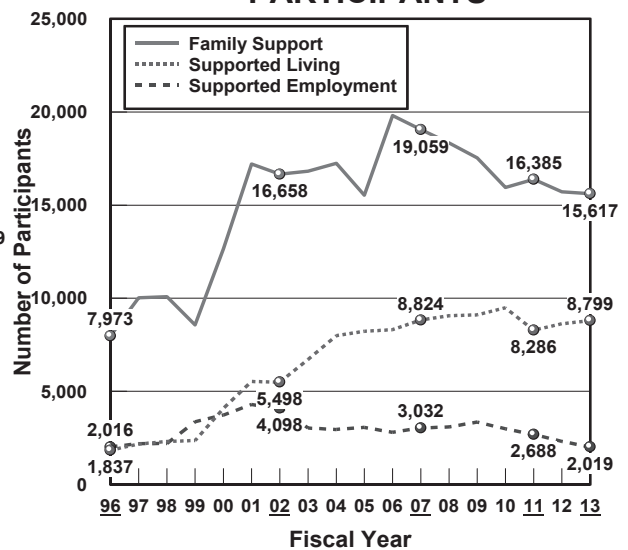


INDIVIDUAL AND FAMILY SUPPORT

SPENDING



PARTICIPANTS

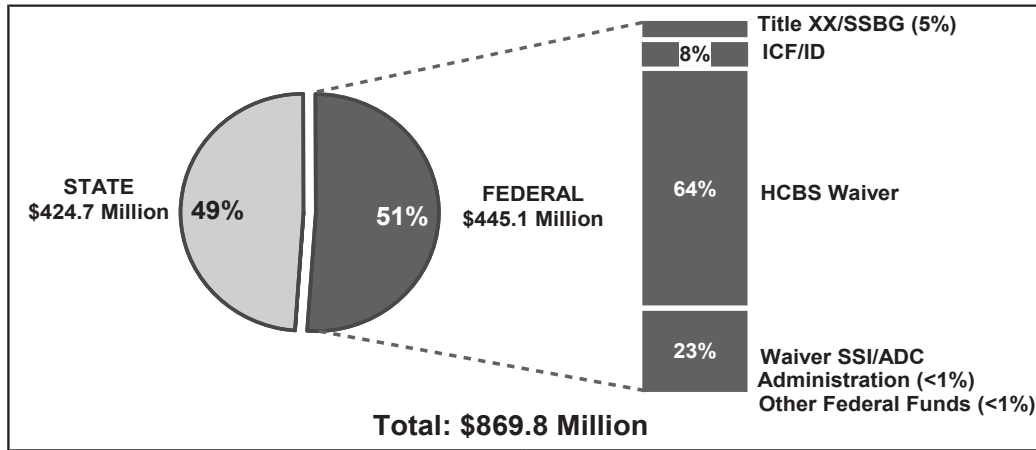


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

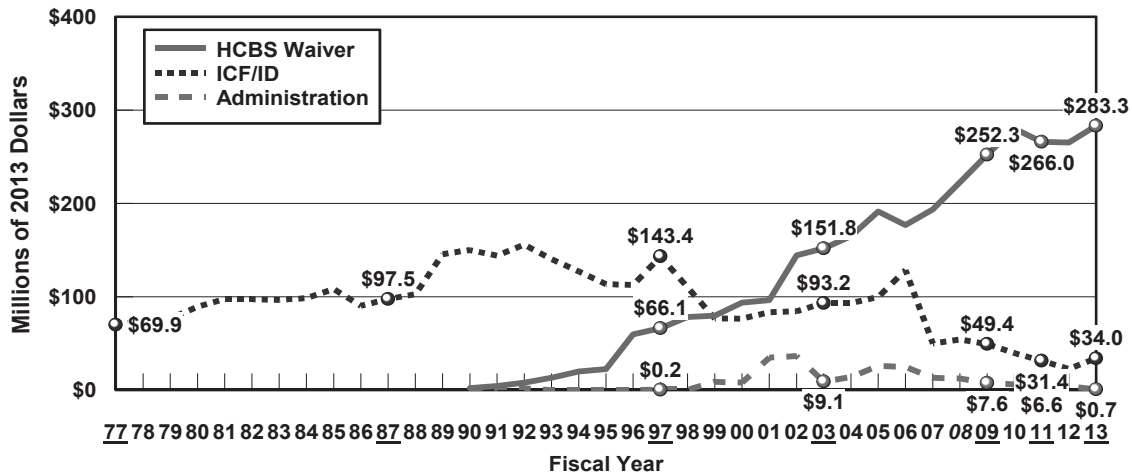
<http://stateofthestates.org>

GEORGIA

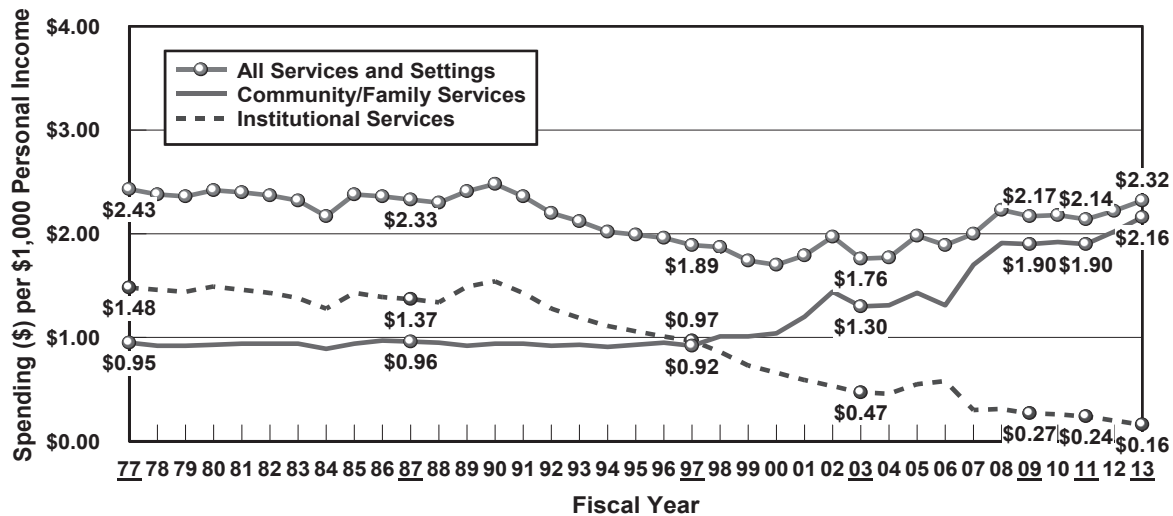
PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013



FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



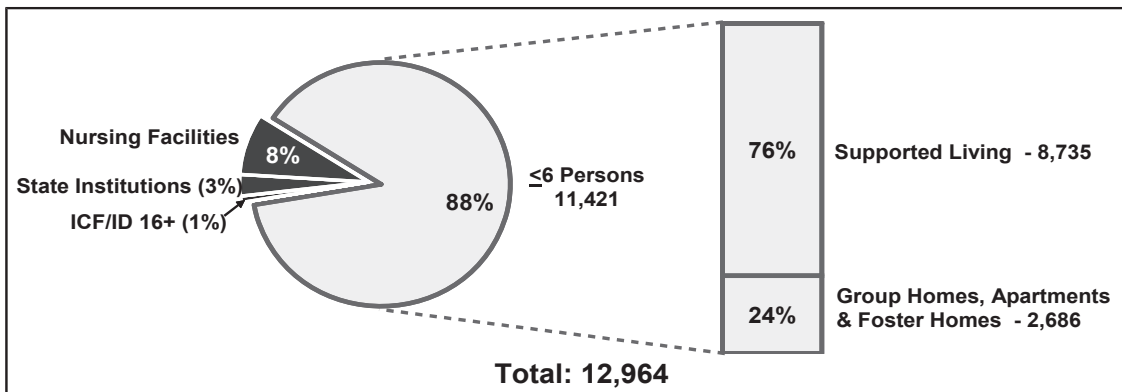
FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013



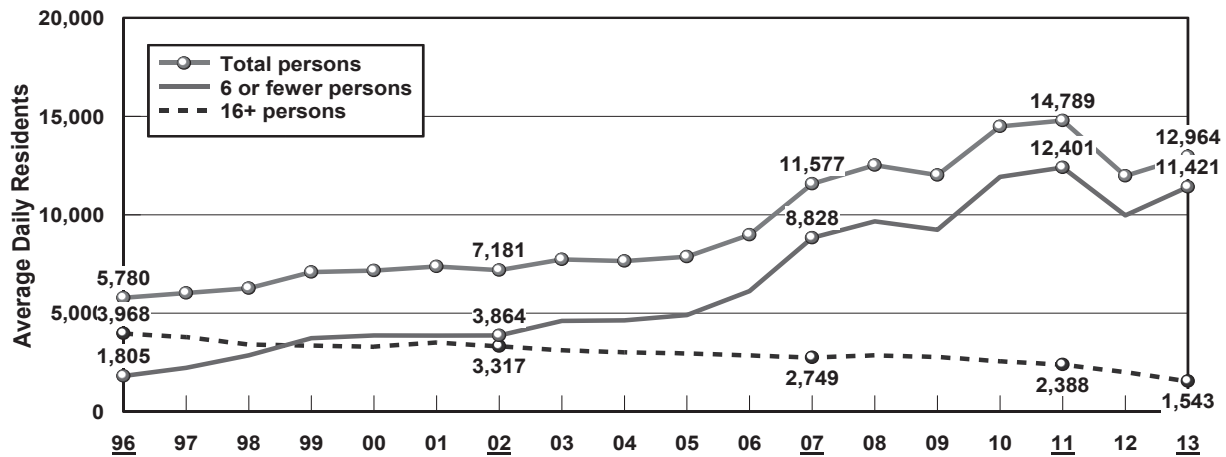
Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.
<http://stateofthestates.org>

GEORGIA

PERSONS BY SETTING IN FISCAL YEAR 2013

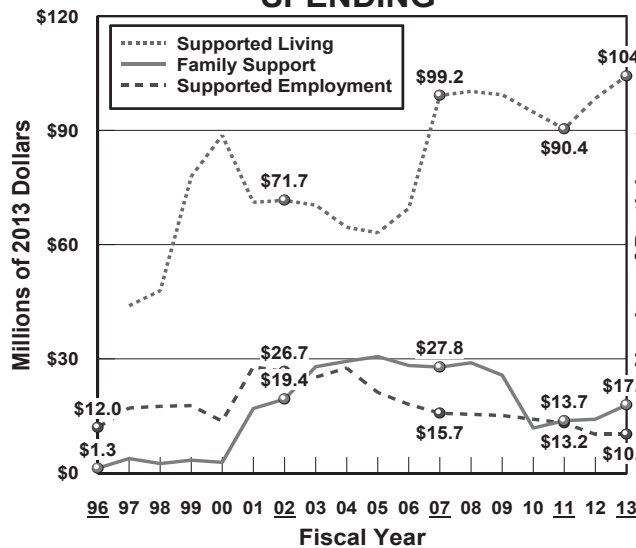


PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013

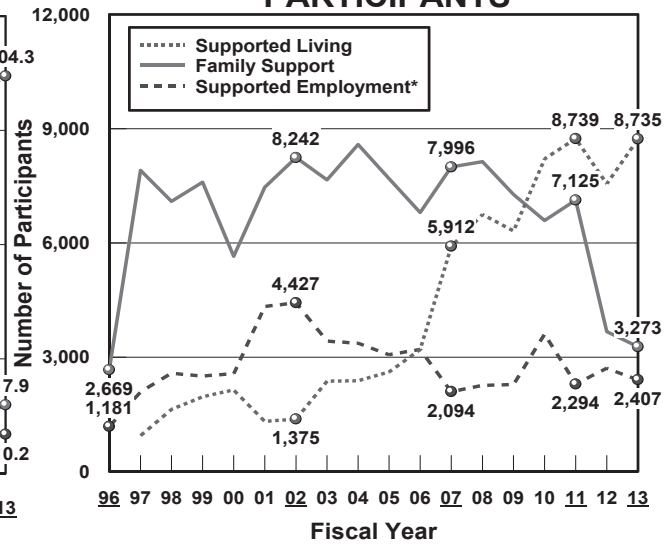


INDIVIDUAL AND FAMILY SUPPORT

SPENDING



PARTICIPANTS



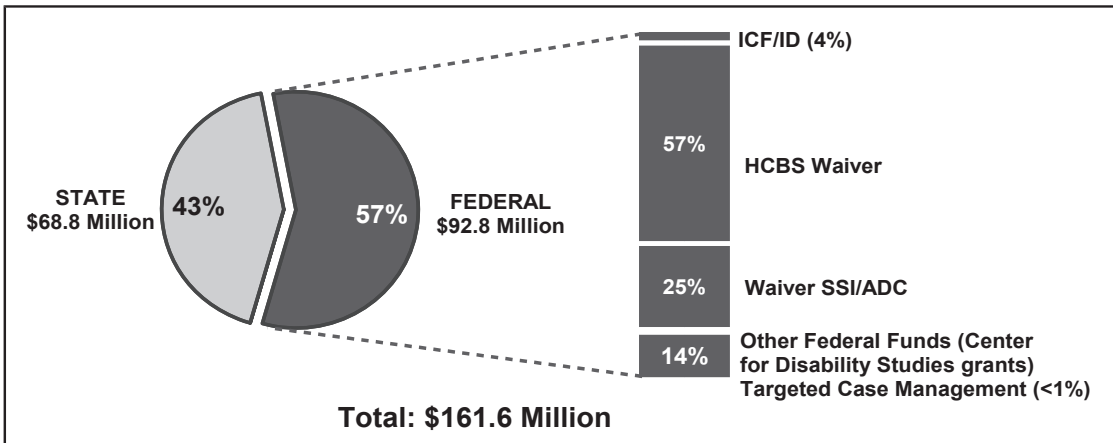
*Does not include 1,493 follow-along work support workers in 2013 (data not available for prior years).

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

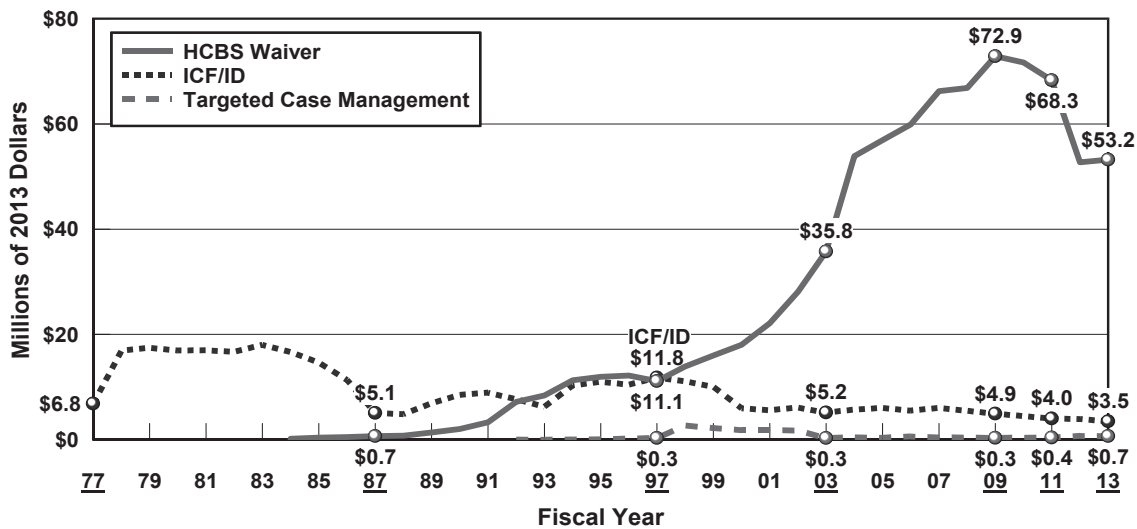
<http://stateofthestates.org>

HAWAII

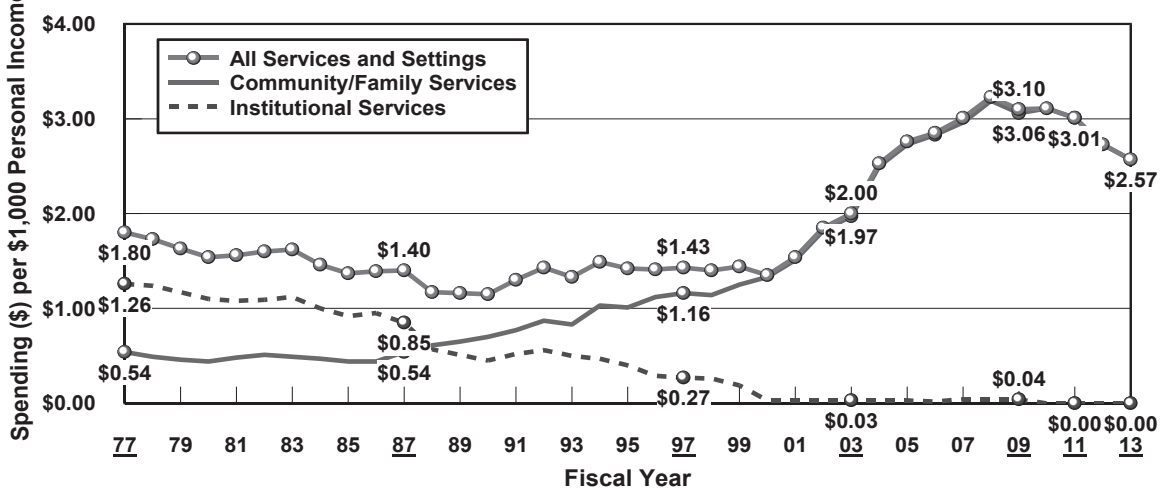
PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013



FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013

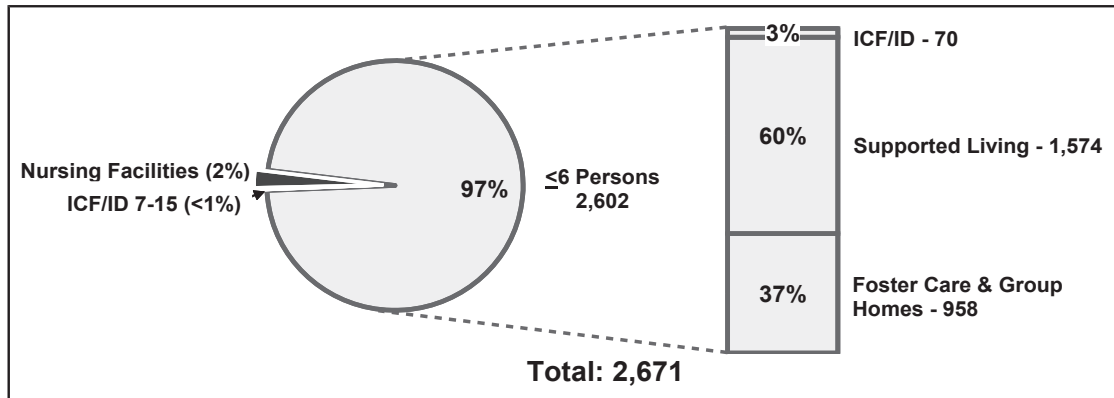


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

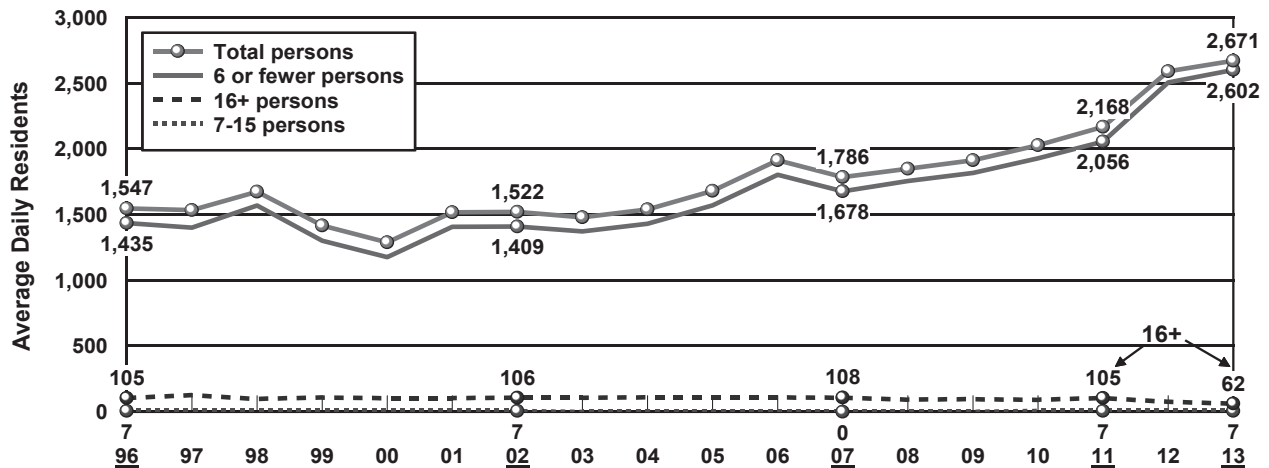
<http://stateofthestates.org>

HAWAII

PERSONS BY SETTING IN FISCAL YEAR 2013

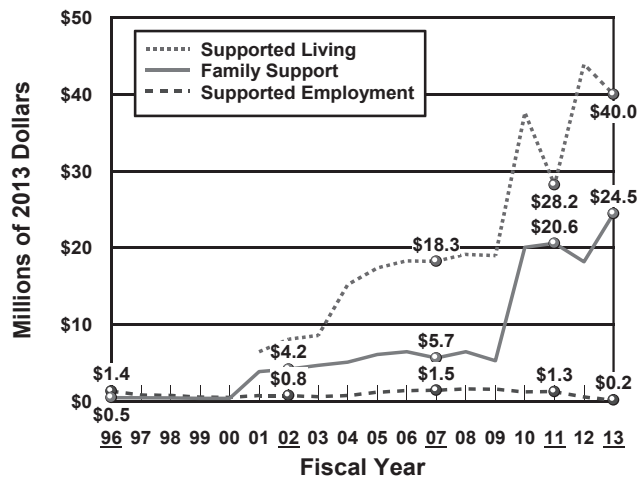


PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013

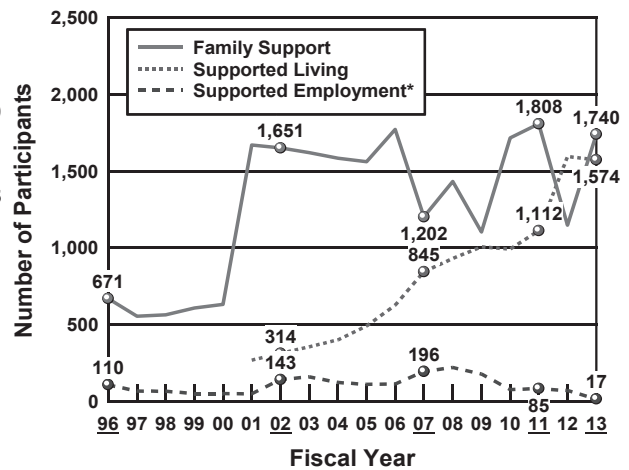


INDIVIDUAL AND FAMILY SUPPORT

SPENDING



PARTICIPANTS



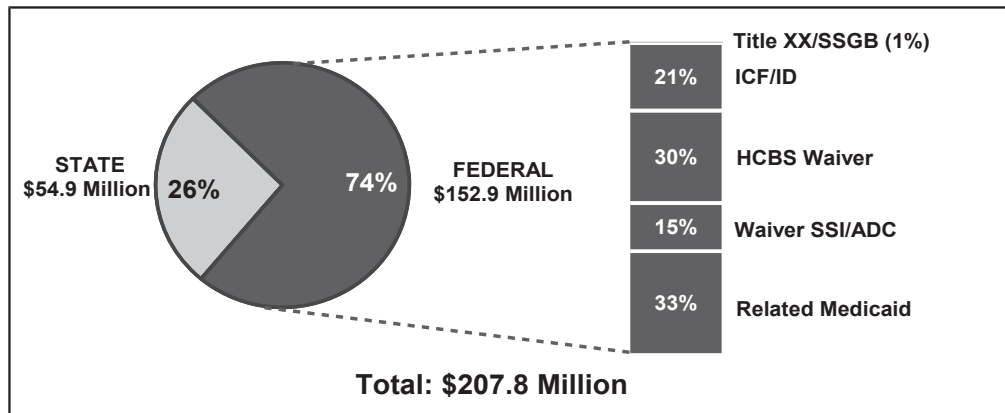
*Does not include 181 follow-along work support workers in 2012 and in 2013.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

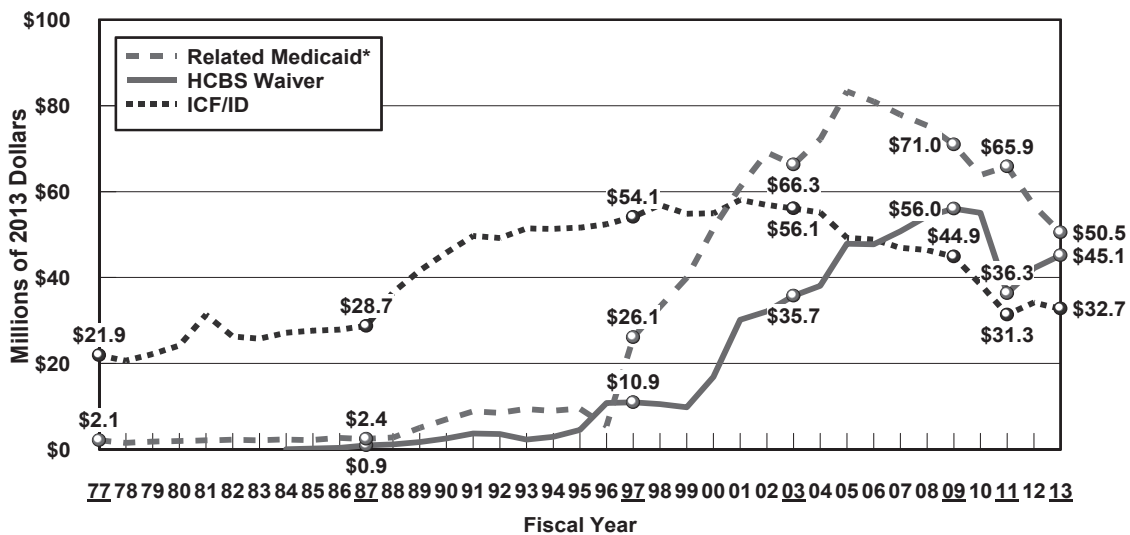
<http://stateofthestates.org>

IDAHO

PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013

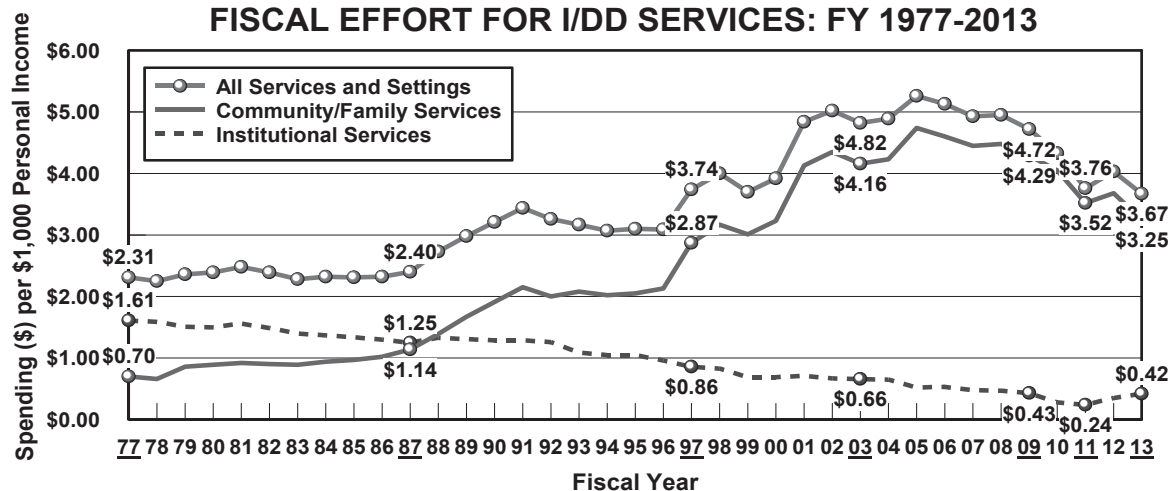


FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



*In 2013, "Related Medicaid" consisted of rehabilitative services (\$31.3 M), personal assistance (\$15.9 M), and targeted case management (\$3.3 million).

FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013

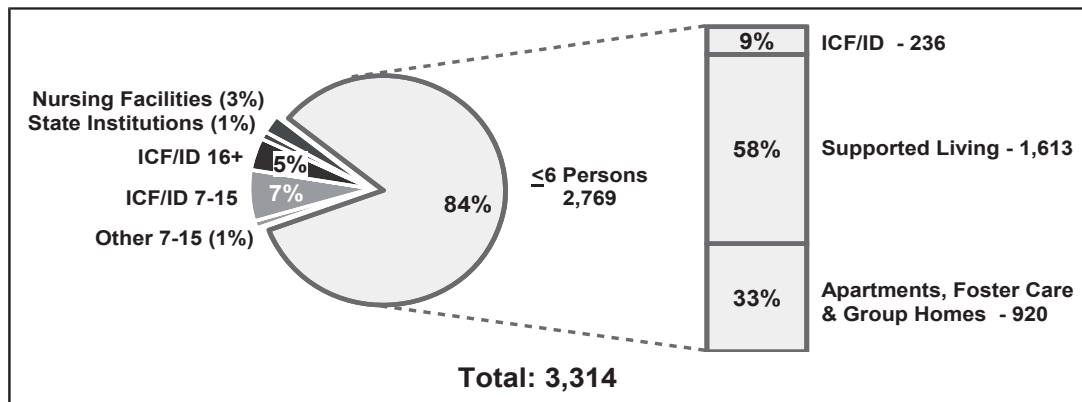


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

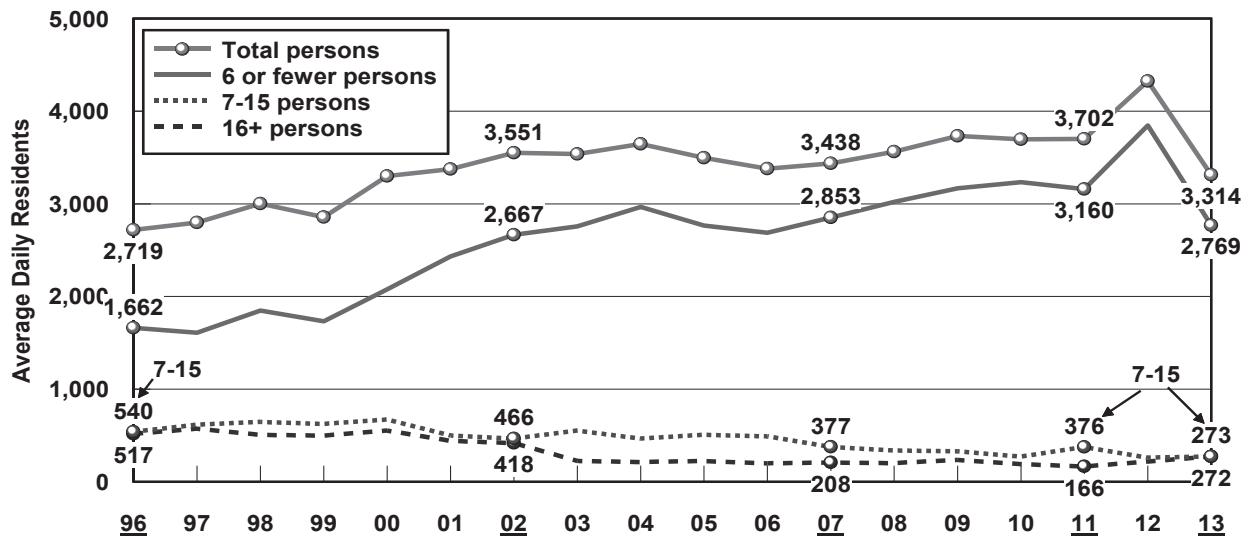
<http://stateofthestates.org>

IDAHO

PERSONS BY SETTING IN FISCAL YEAR 2013

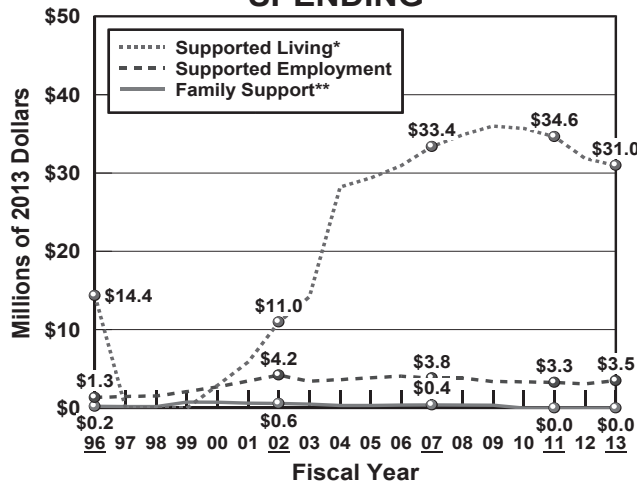


PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013

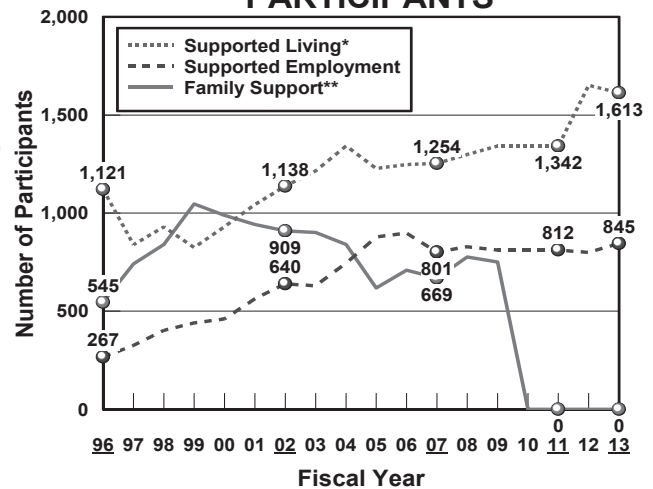


INDIVIDUAL AND FAMILY SUPPORT

SPENDING



PARTICIPANTS



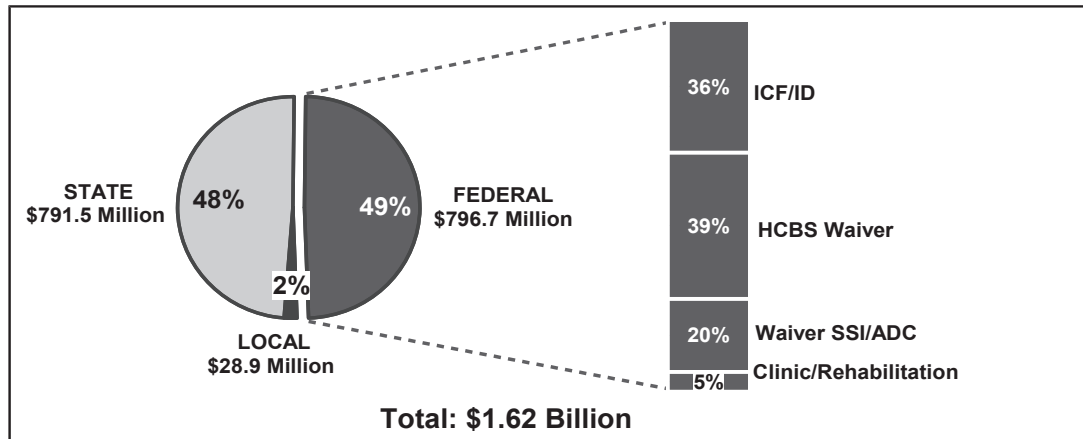
*State did not provide data for Supported Living spending during 1997-99. **Family Support program terminated in 2010.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

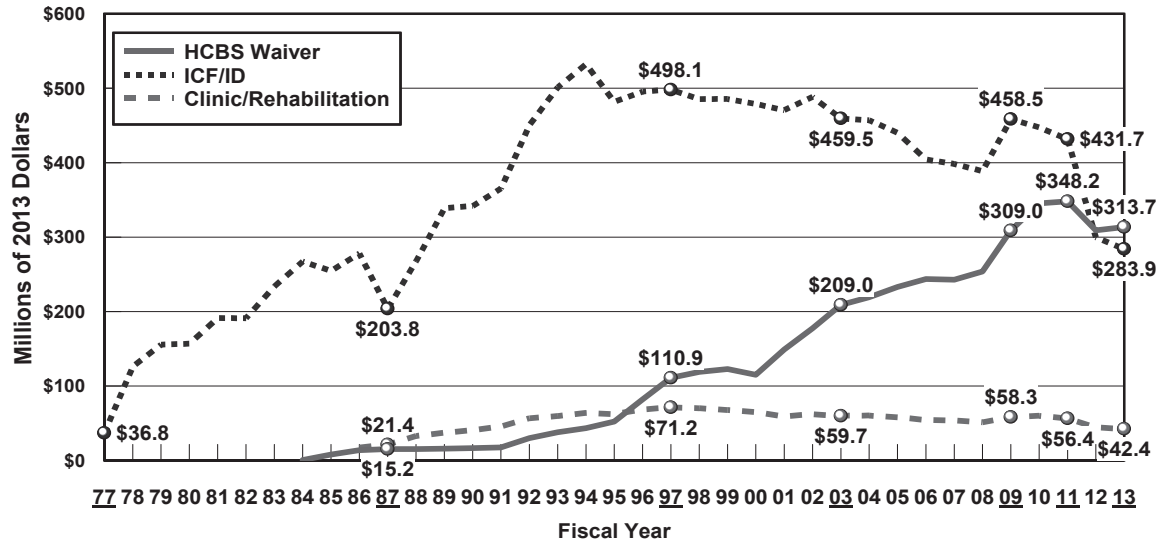
<http://stateofthestates.org>

ILLINOIS

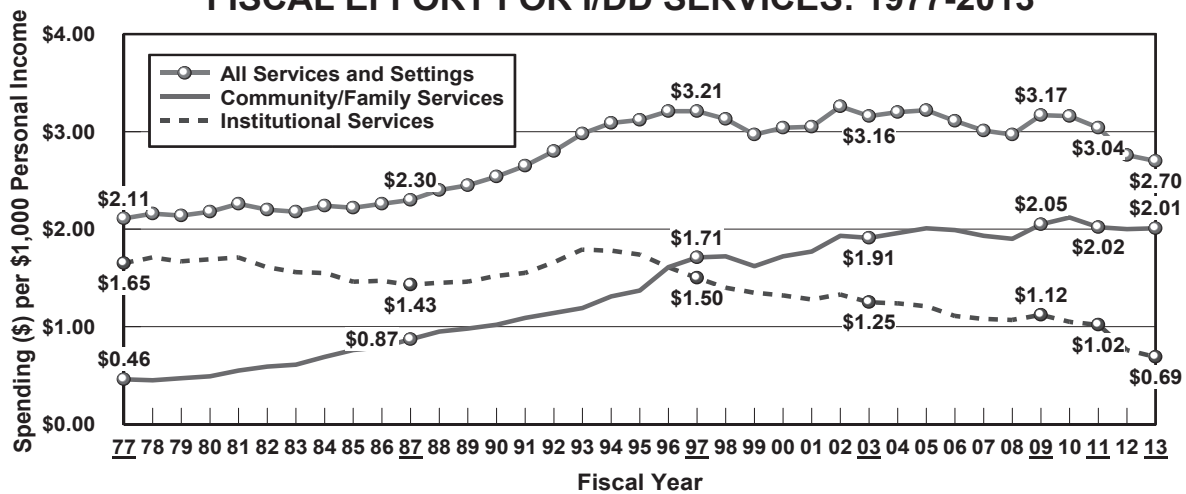
PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013



FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



FISCAL EFFORT FOR I/DD SERVICES: 1977-2013

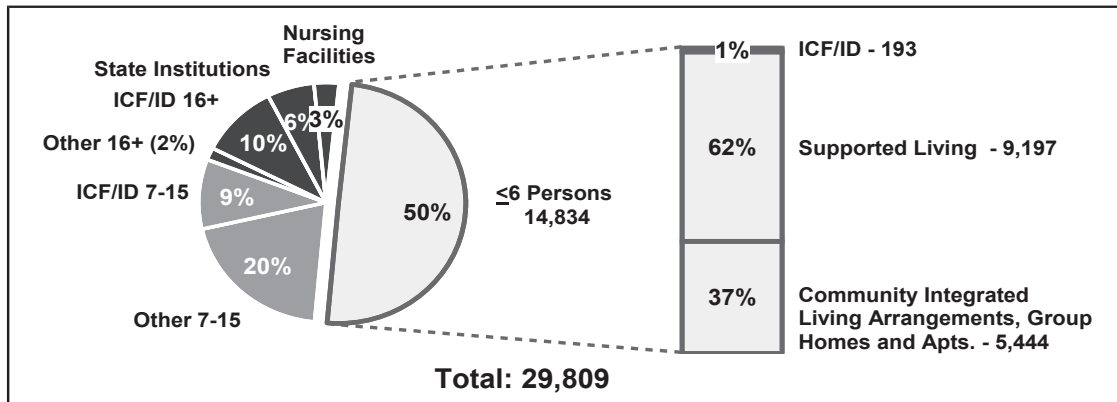


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

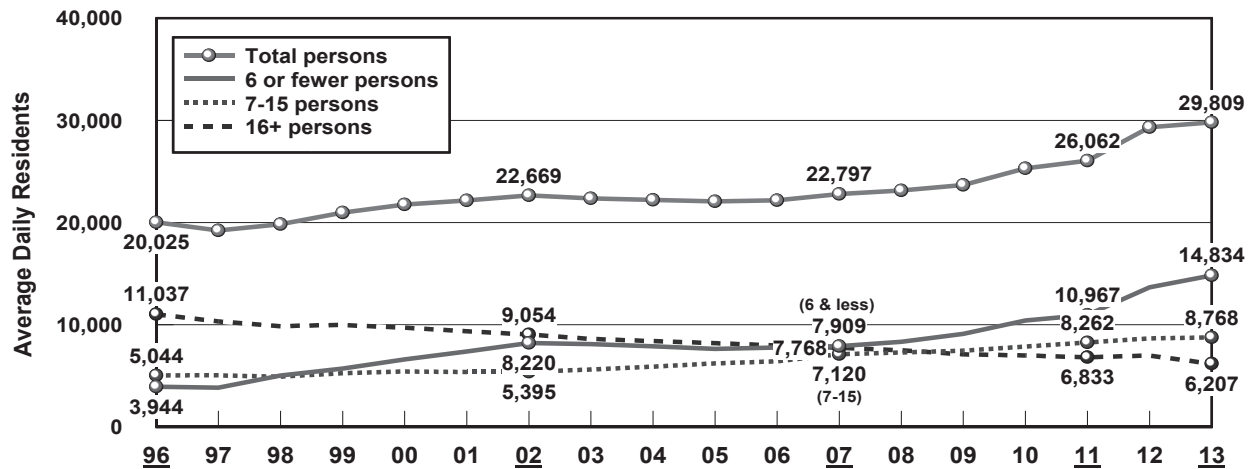
<http://stateofthestates.org>

ILLINOIS

PERSONS BY SETTING IN FISCAL YEAR 2013

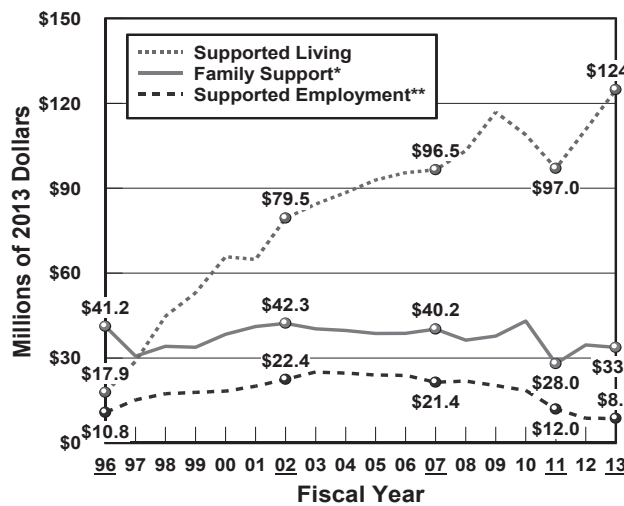


PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013

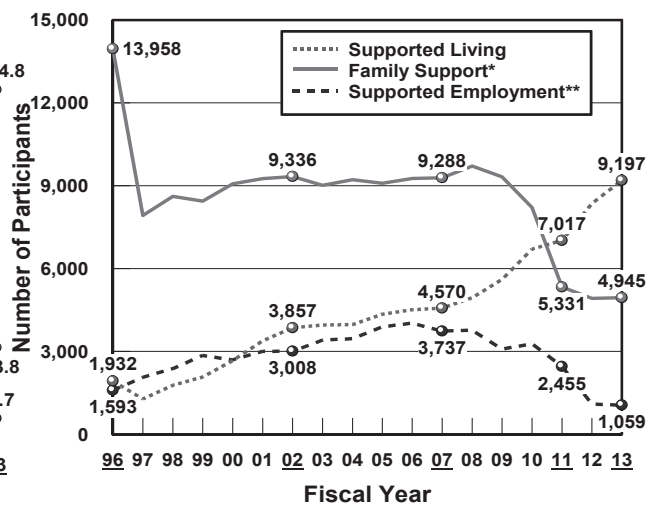


INDIVIDUAL AND FAMILY SUPPORT

SPENDING



PARTICIPANTS



*Family Support spending and families supported dropped in 2010-13 due to reductions in general fund and HCBS Waiver funding.

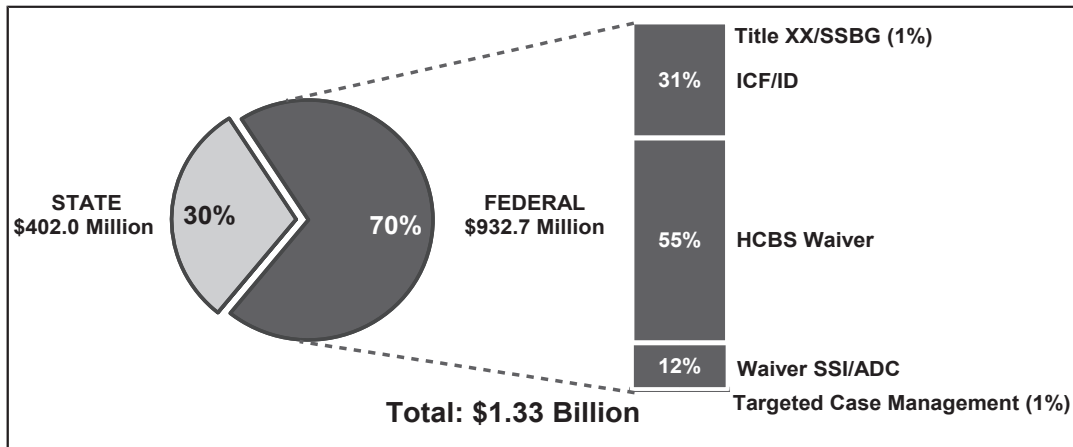
**Grant funded Supported Employment, that served more workers, converted to fee-for-services and HCBS funding in 2012.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

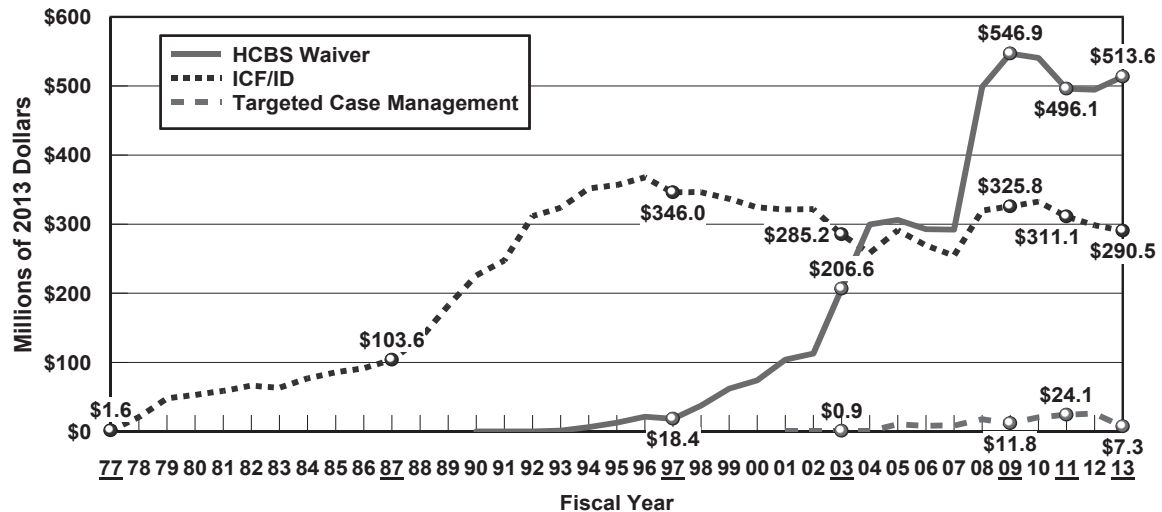
<http://stateofthstates.org>

INDIANA

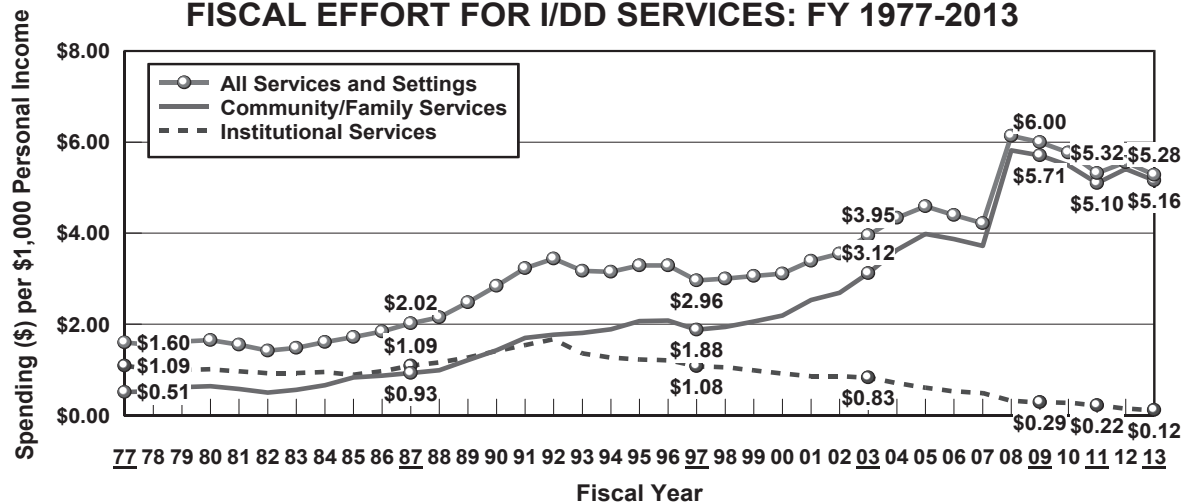
PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013



FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013

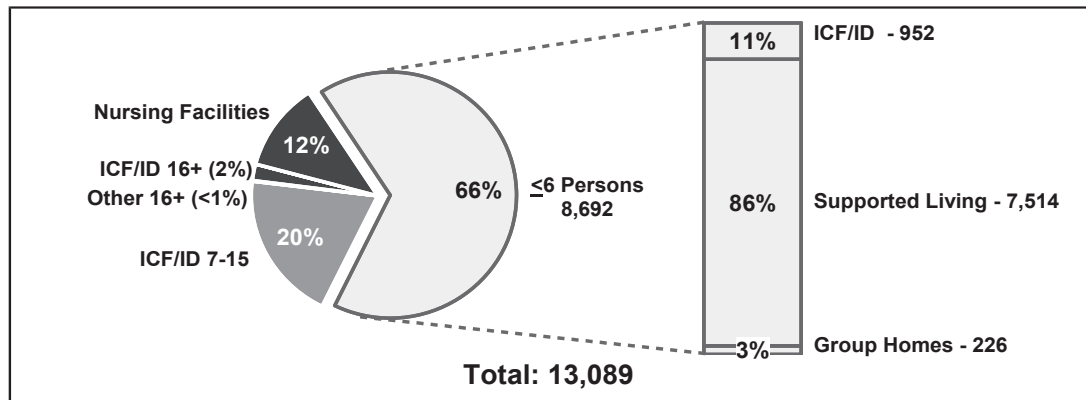


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

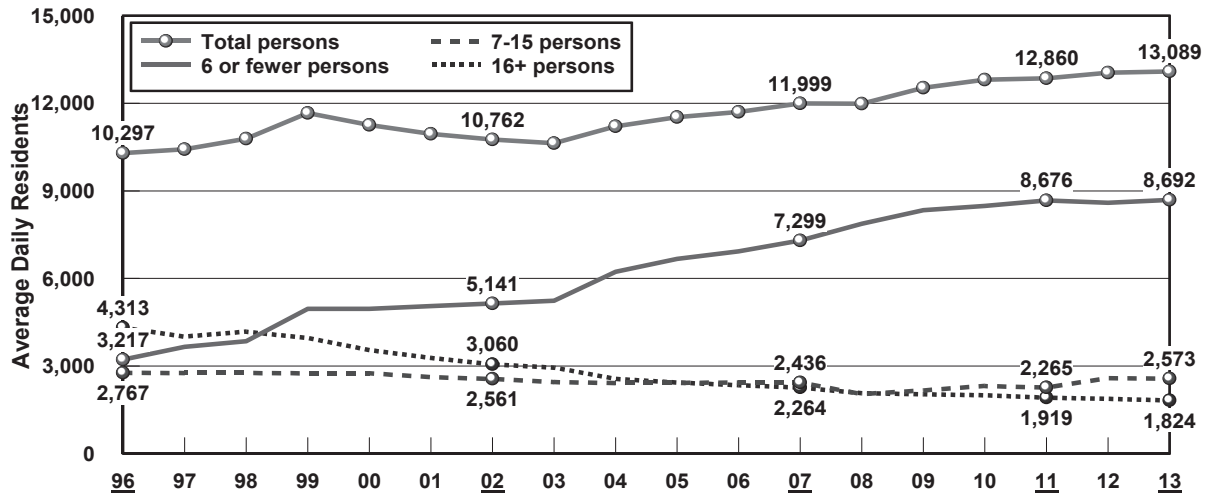
<http://stateofthestates.org>

INDIANA

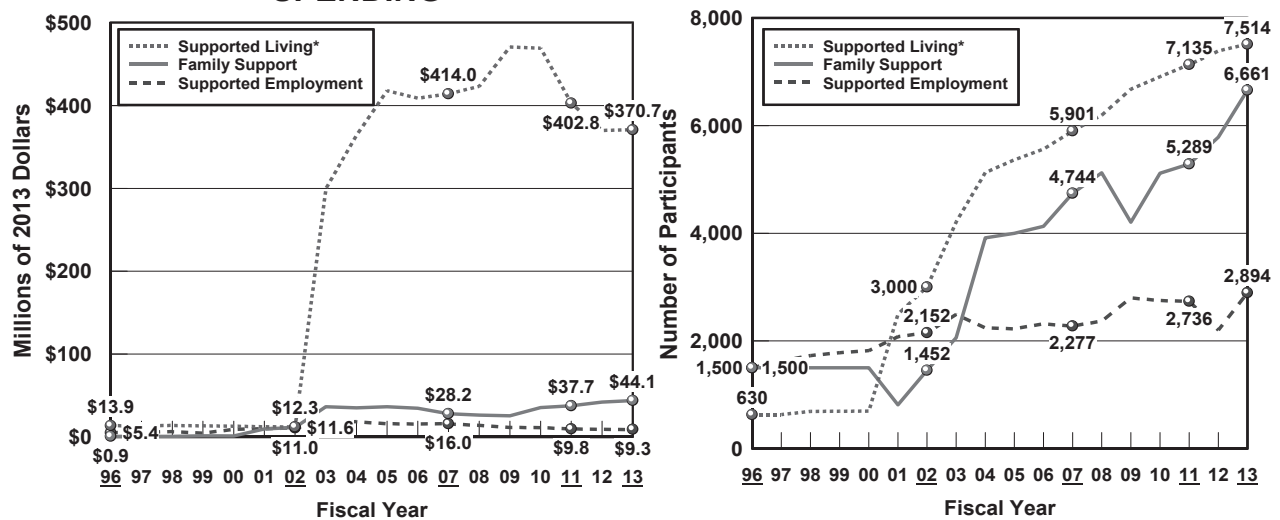
PERSONS BY SETTING IN FISCAL YEAR 2013



PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013



INDIVIDUAL AND FAMILY SUPPORT PARTICIPANTS



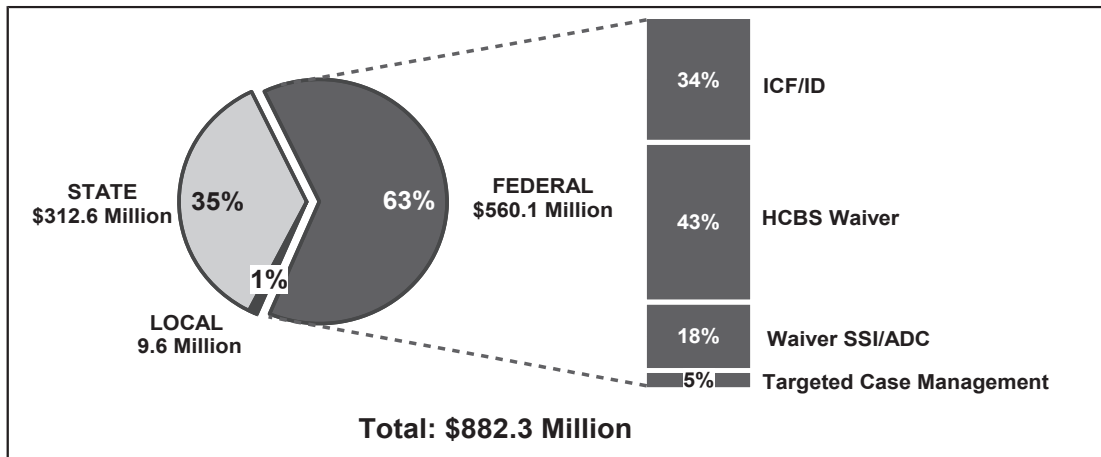
*Supported Living growth in 2003-2004 reflected a statewide priority, accompanied by extensive staff recruitment and training; the HCBS Waiver financed 88% of supported living spending in 2003 (Braddock & Hemp, 2004, Developmental Disabilities Services in Indiana: 2004 Progress Report).

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

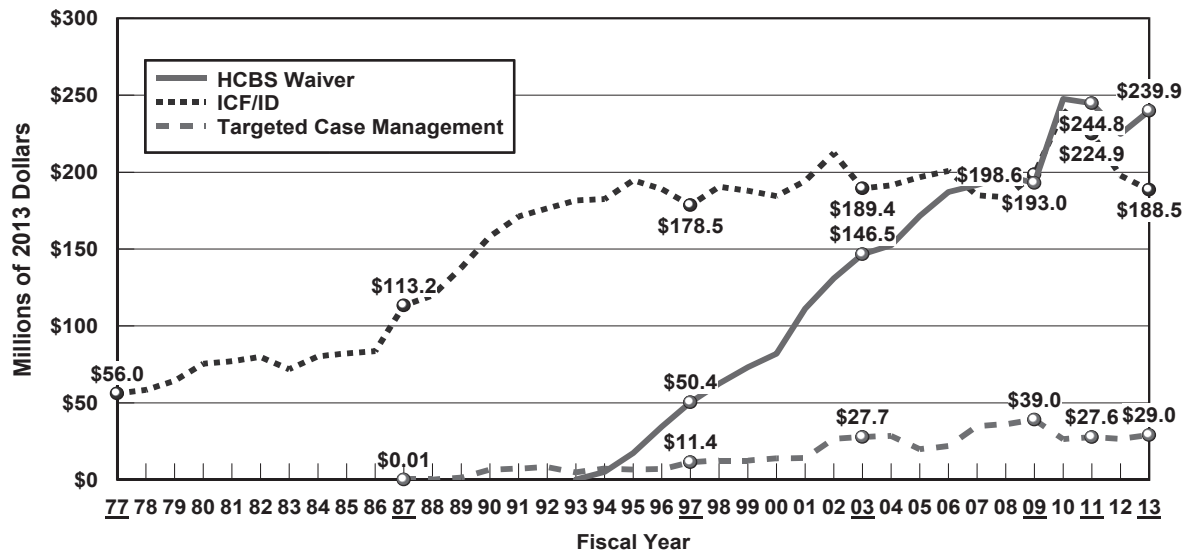
<http://stateofthestates.org>

IOWA

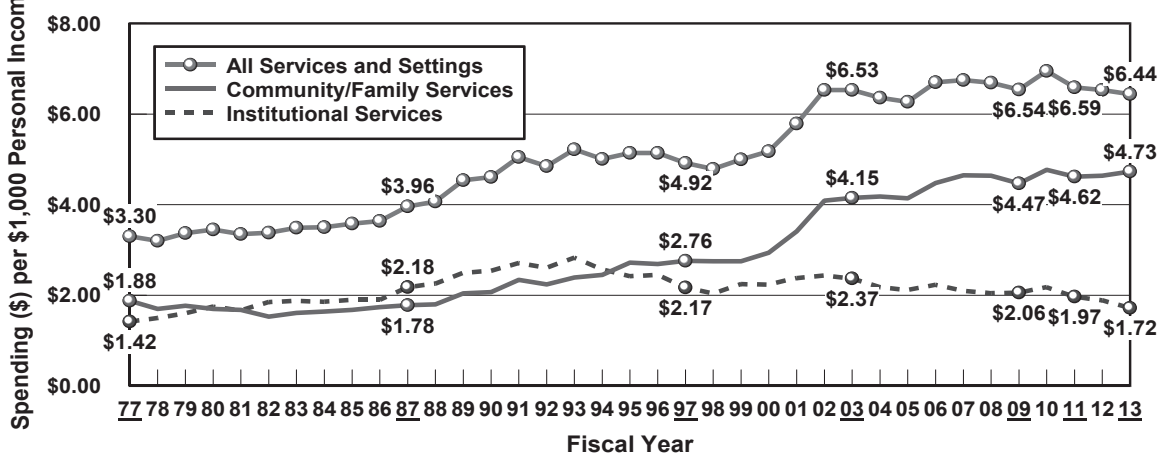
PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013



FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013

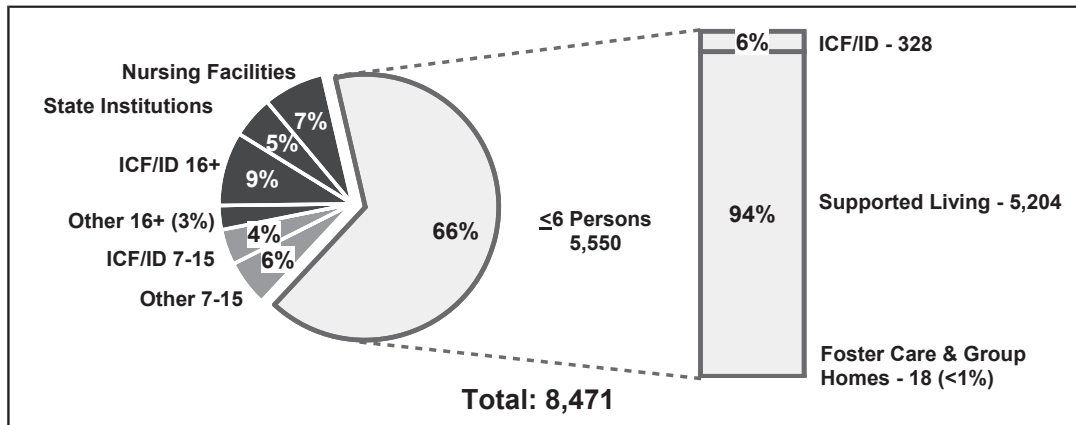


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

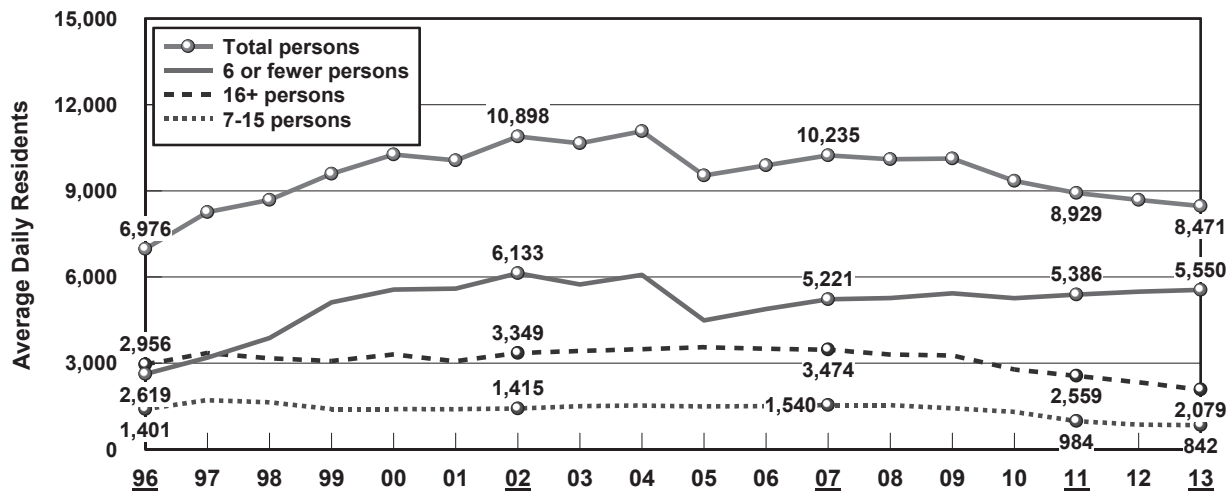
<http://stateofthestates.org>

IOWA

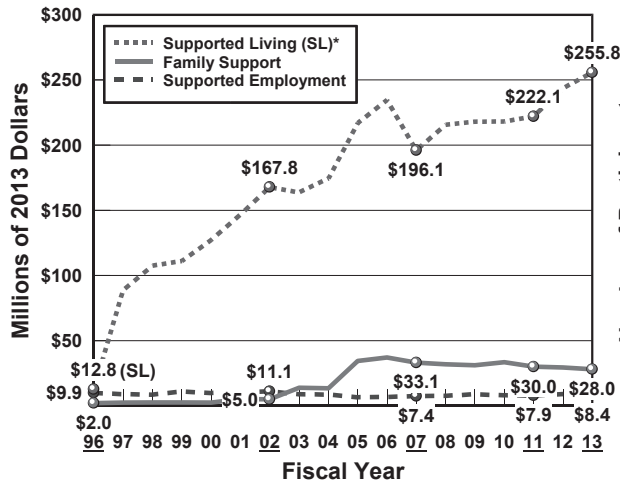
PERSONS BY SETTING IN FISCAL YEAR 2013



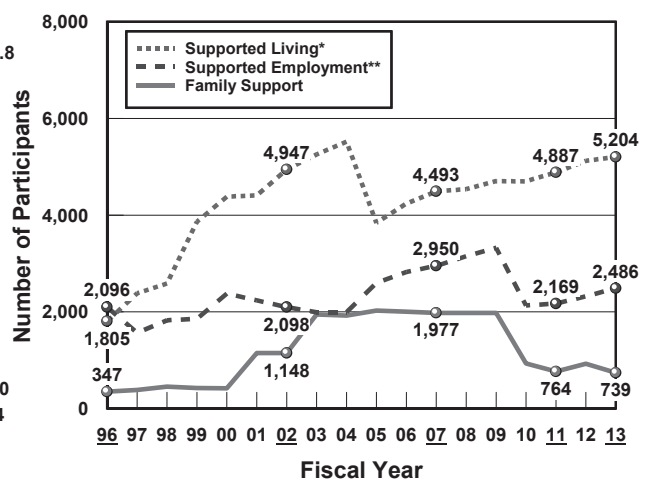
PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013



INDIVIDUAL AND FAMILY SUPPORT SPENDING



PARTICIPANTS



*State revised supported living data during 2007-09 for spending and 2005-09 for participants.

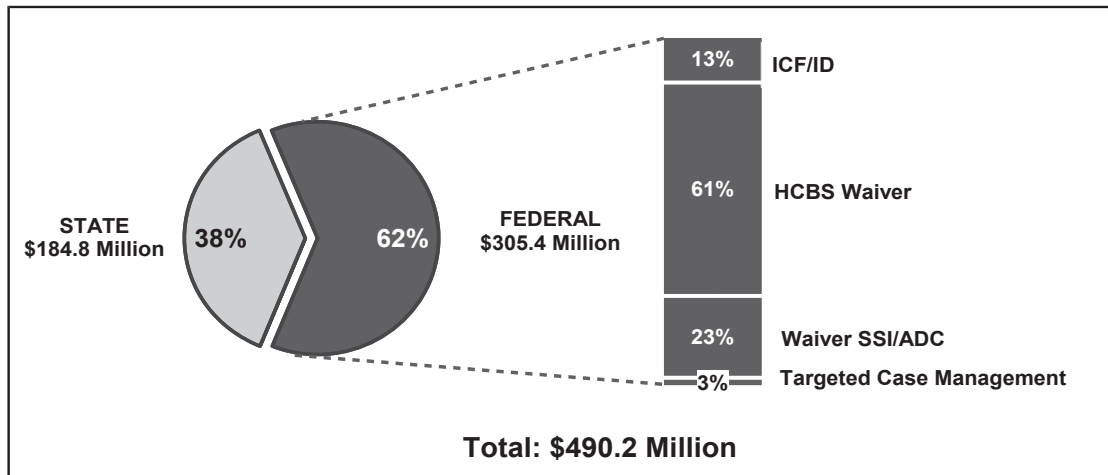
**Supported Employment does not include 138 and 112 follow-along work support workers in 2012 and 2013.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

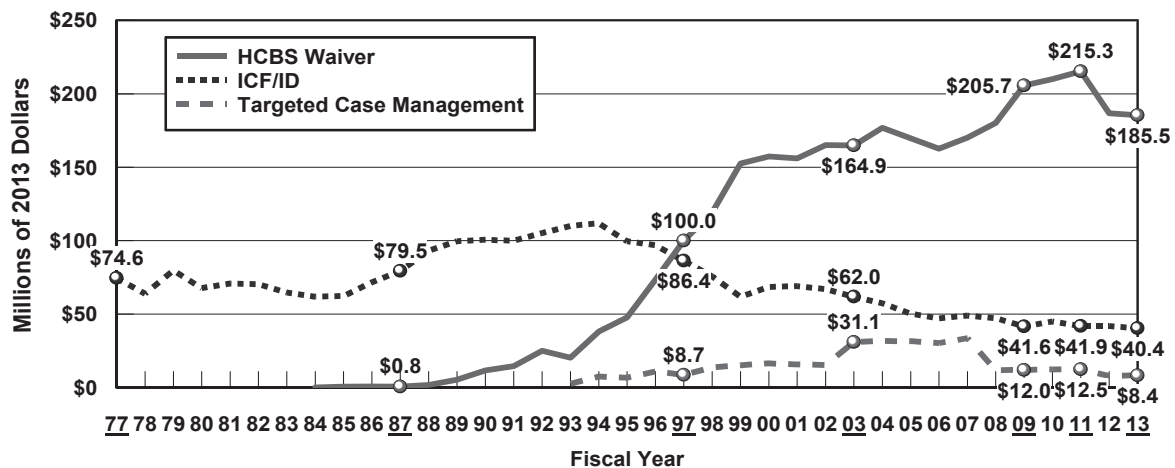
<http://stateofthestates.org>

KANSAS

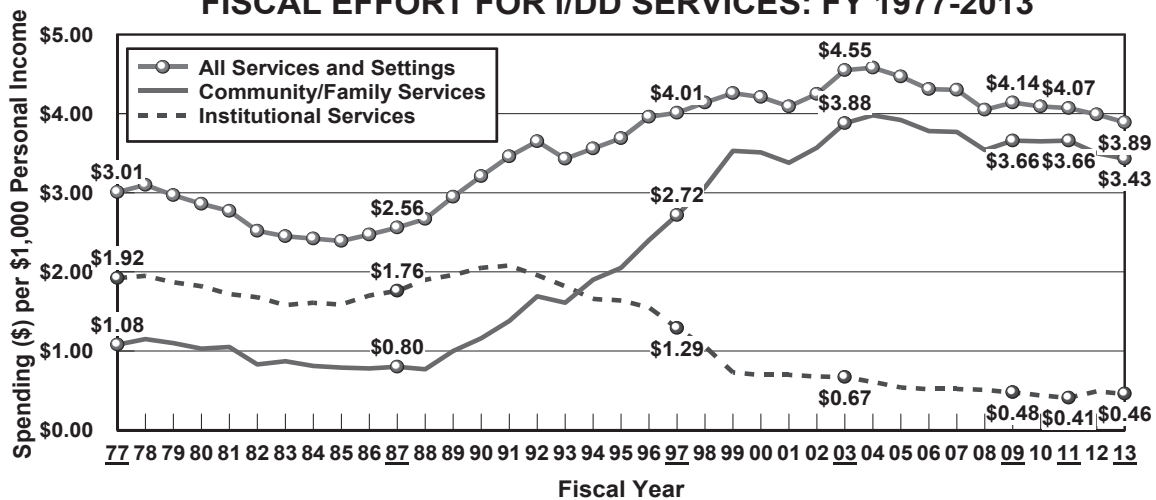
PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013



FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013

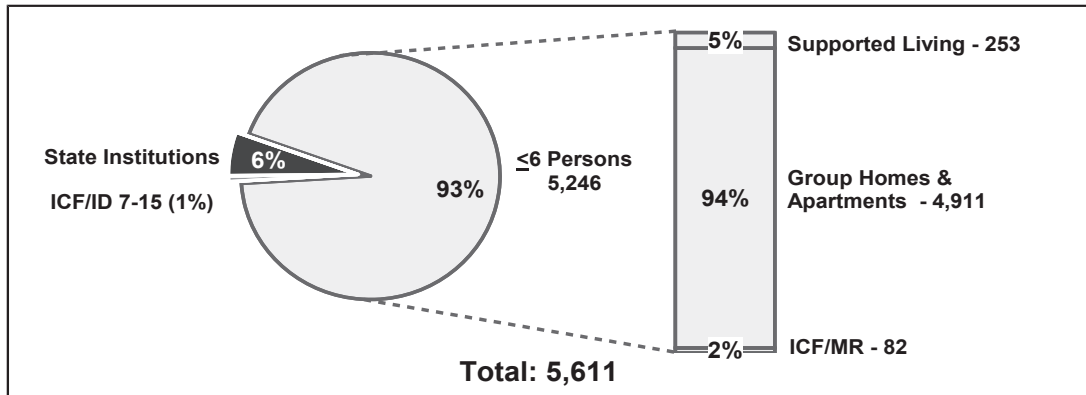


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

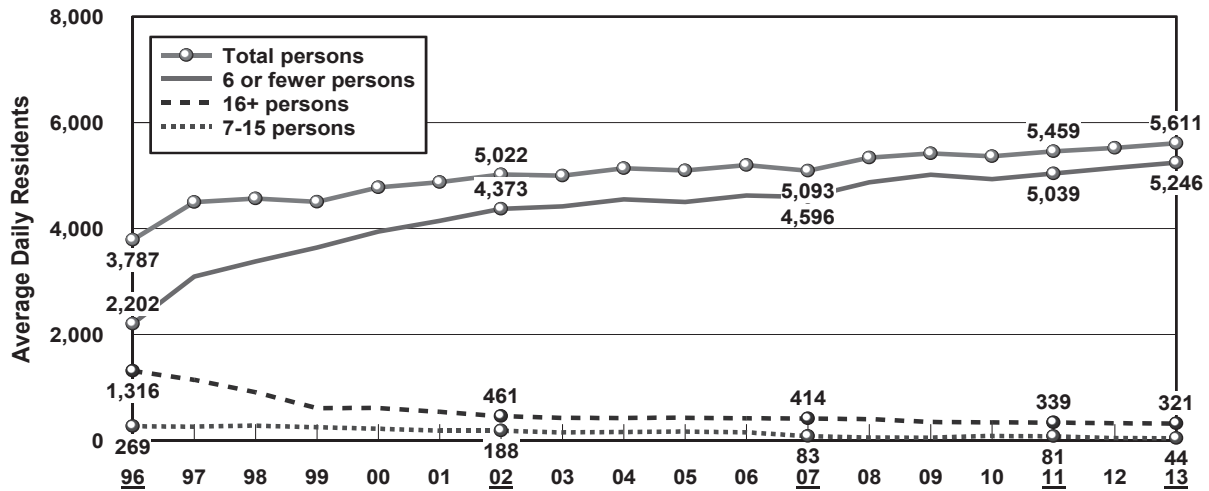
<http://stateofthestates.org>

KANSAS

PERSONS BY SETTING IN FISCAL YEAR 2013

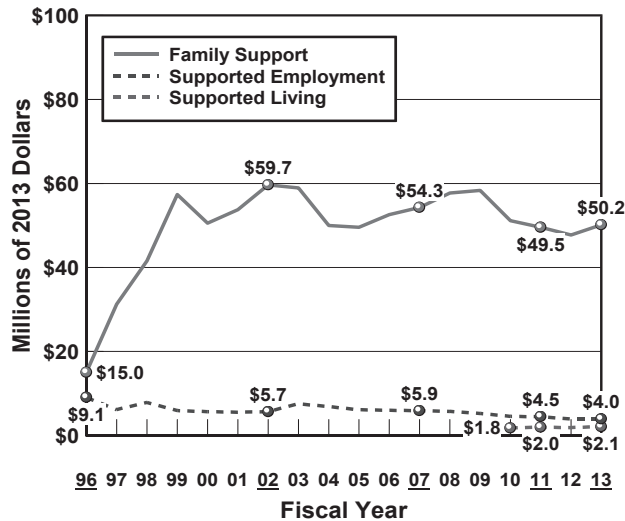


PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013

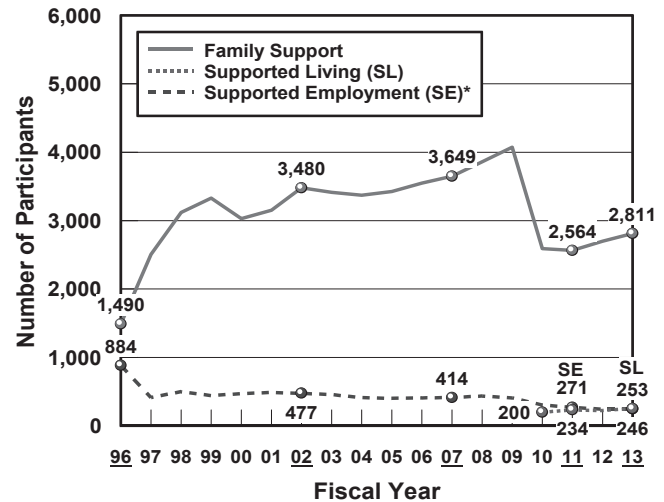


INDIVIDUAL AND FAMILY SUPPORT

SPENDING



PARTICIPANTS



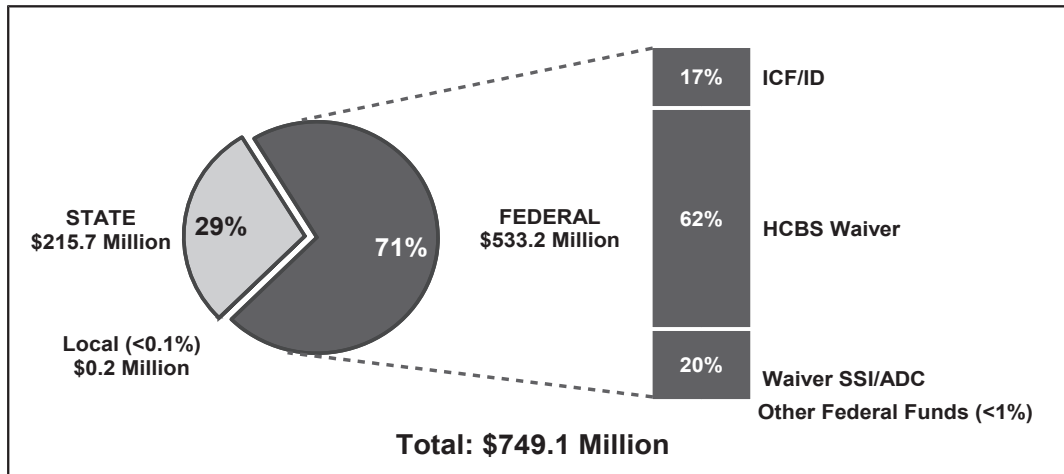
**Does not include 890 follow-along work workers in 2012 and 895 in 2013.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

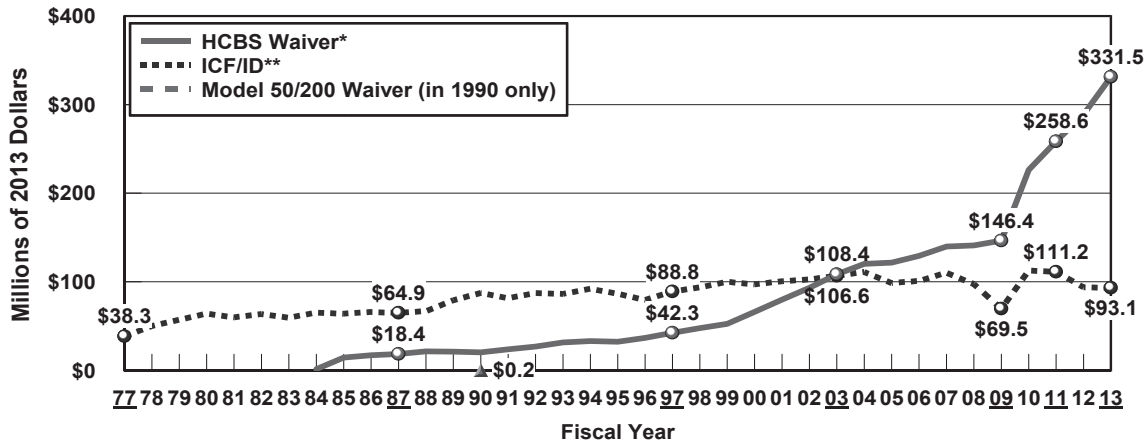
<http://stateofthestates.org>

KENTUCKY

PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013



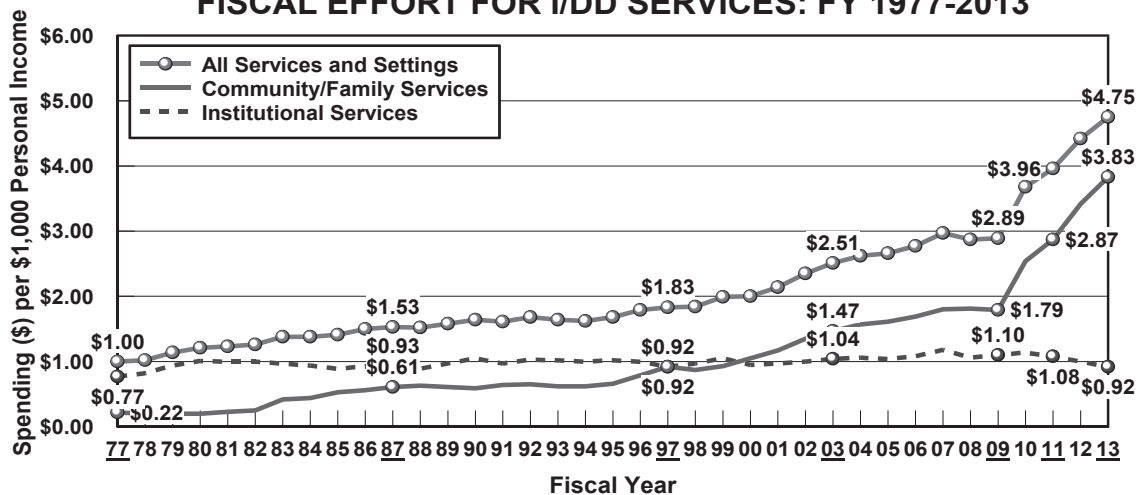
FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



*Waiver growth 2010-11 from new Michelle P. Waiver (Michelle P. et al. v. Morgan et al., 2002, amended 2008).

**Oakwood lost federal ICF/ID funding in May 2008, which was restored in March 2009.

FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013

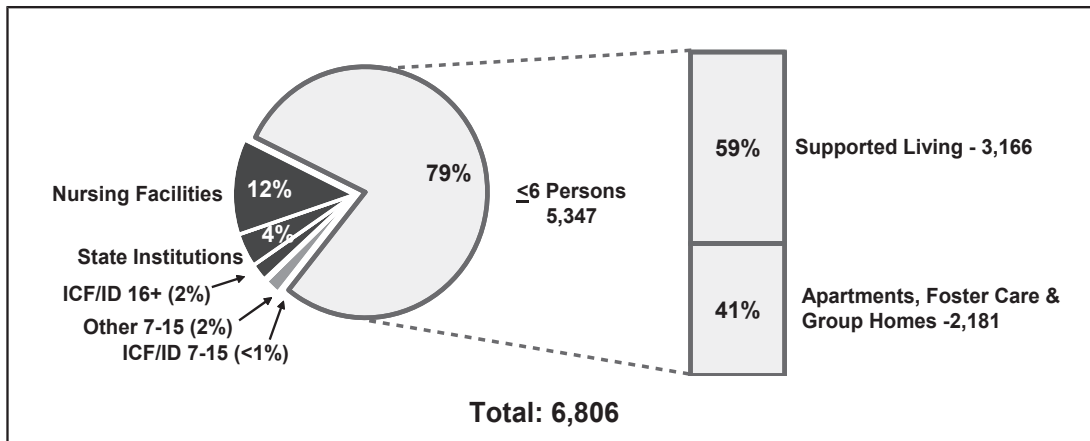


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

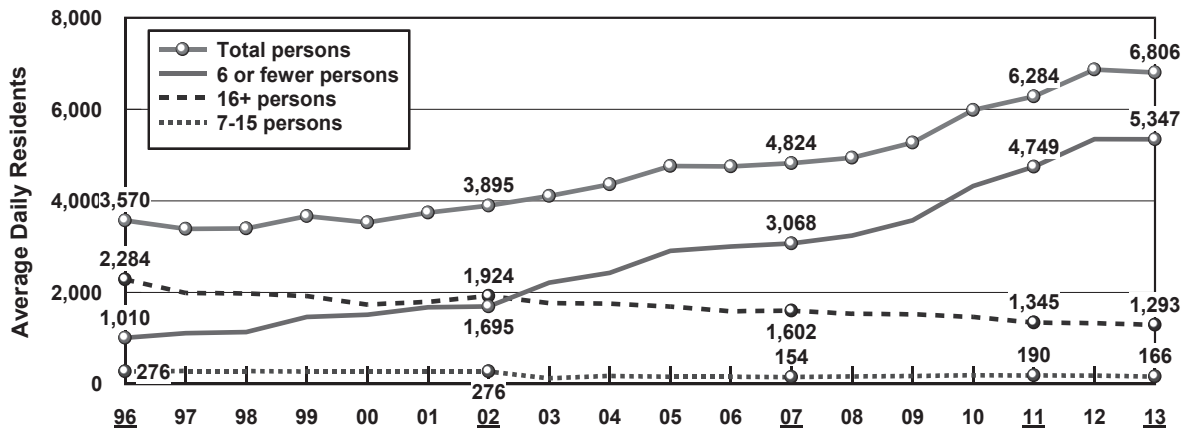
<http://stateofthestates.org>

KENTUCKY

PERSONS BY SETTING IN FISCAL YEAR 2013

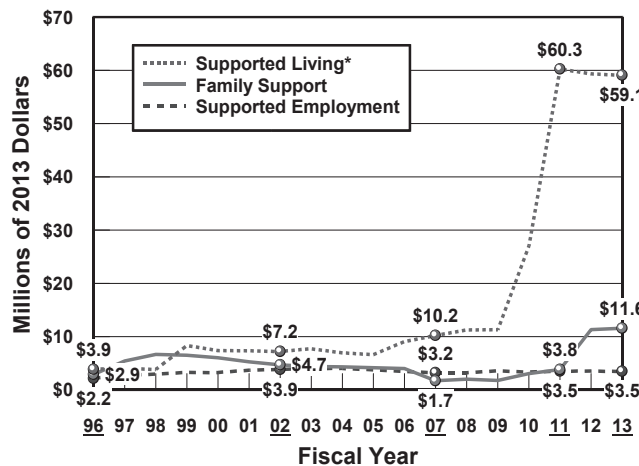


PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013

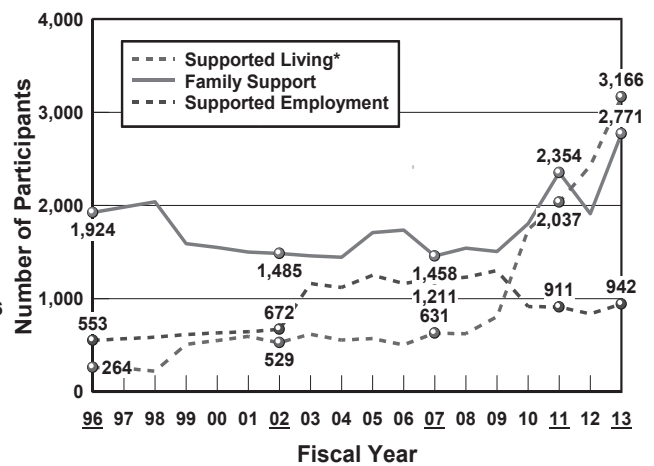


INDIVIDUAL AND FAMILY SUPPORT

SPENDING



PARTICIPANTS



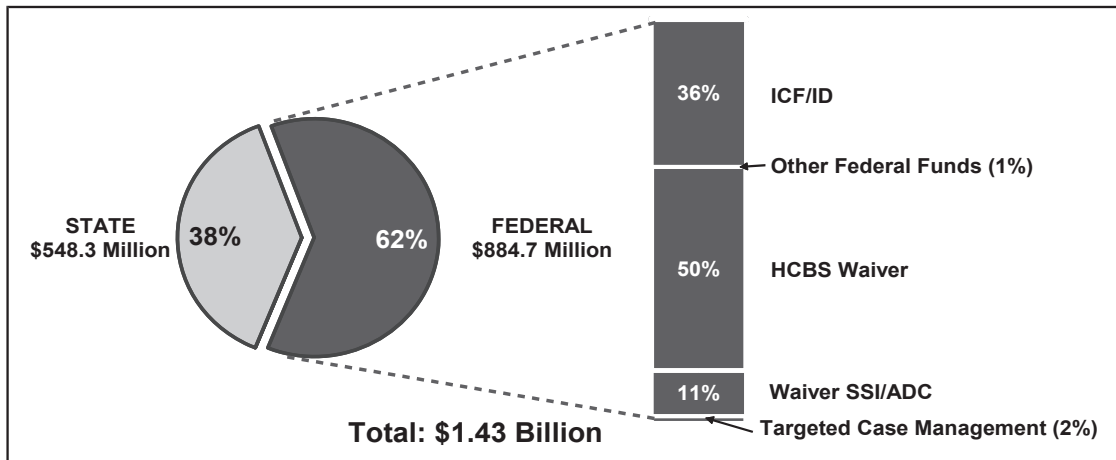
*Supported Living growth in 2010-11 primarily from new Michelle P. Waiver implemented in fiscal year 2009.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

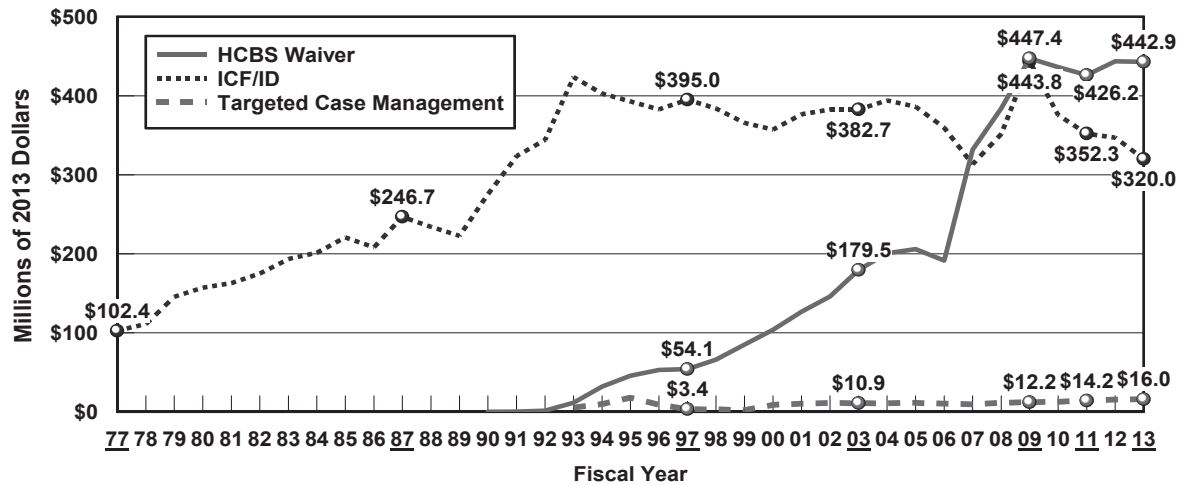
<http://stateofthstates.org>

LOUISIANA

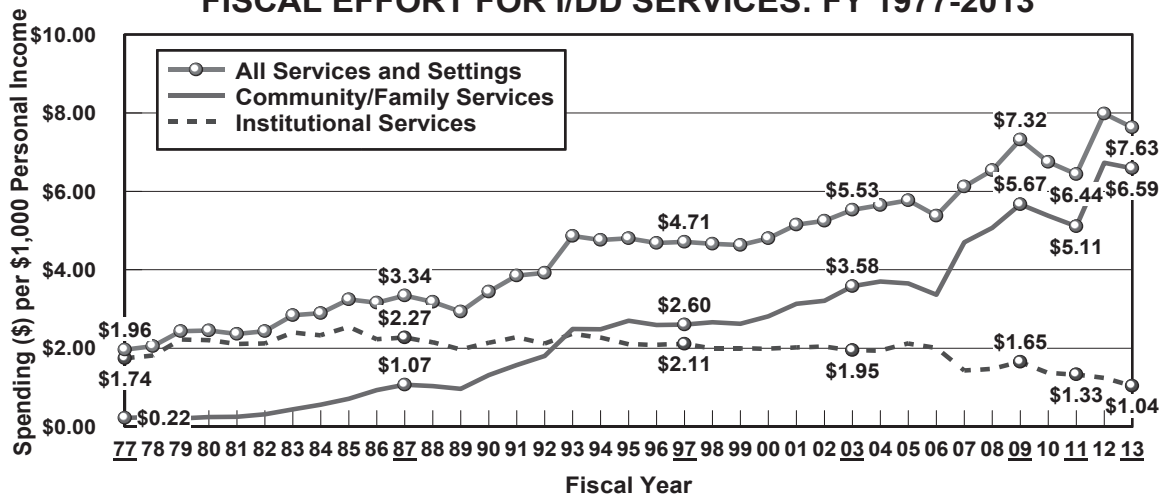
PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013



FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013

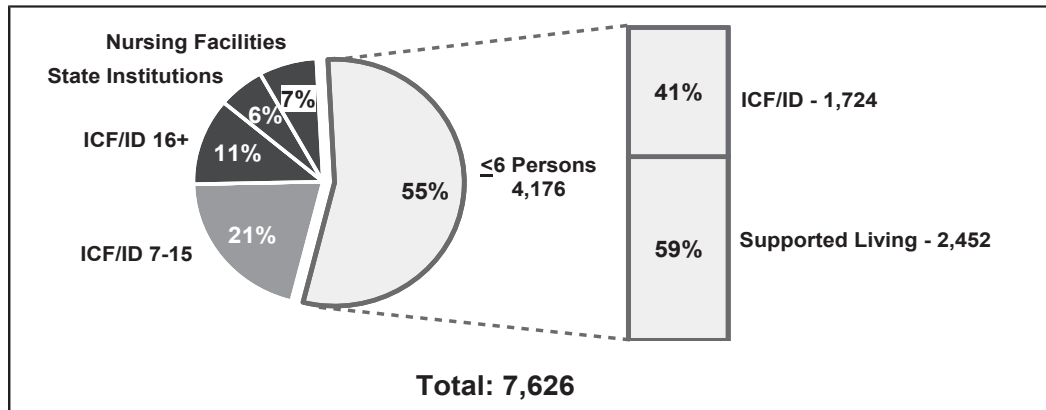


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

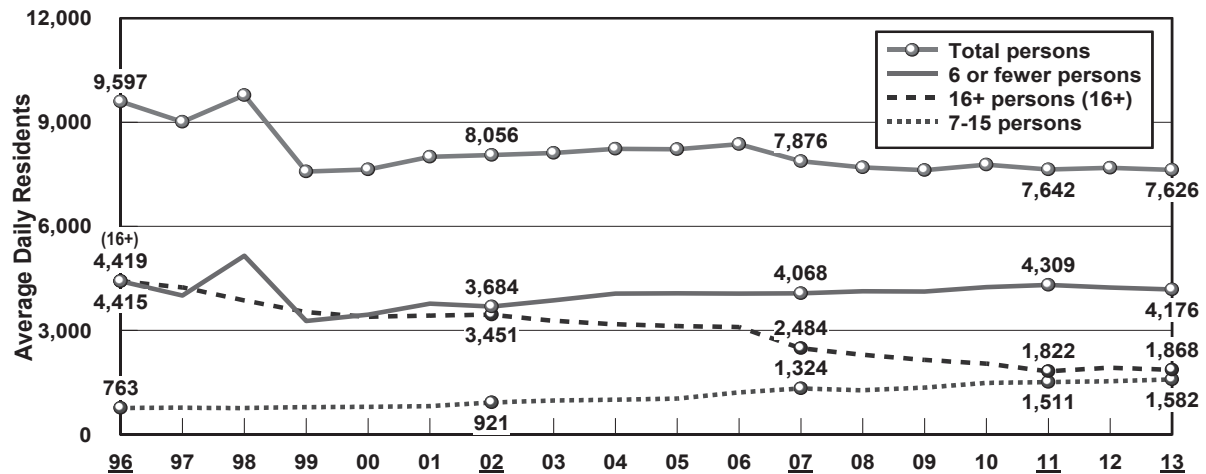
<http://stateofthestates.org>

LOUISIANA

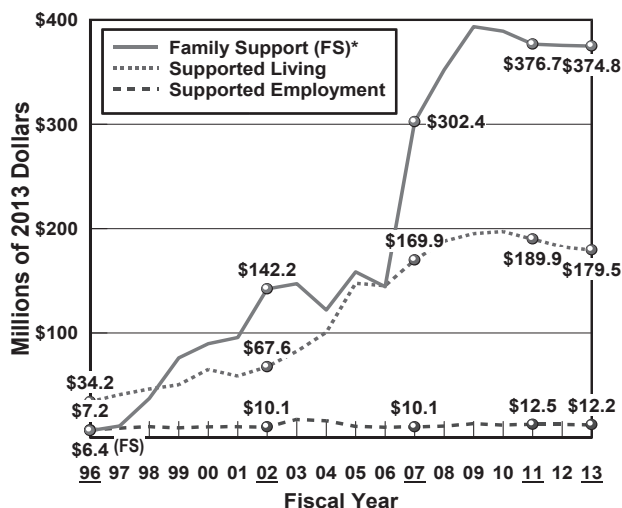
PERSONS BY SETTING IN FISCAL YEAR 2013



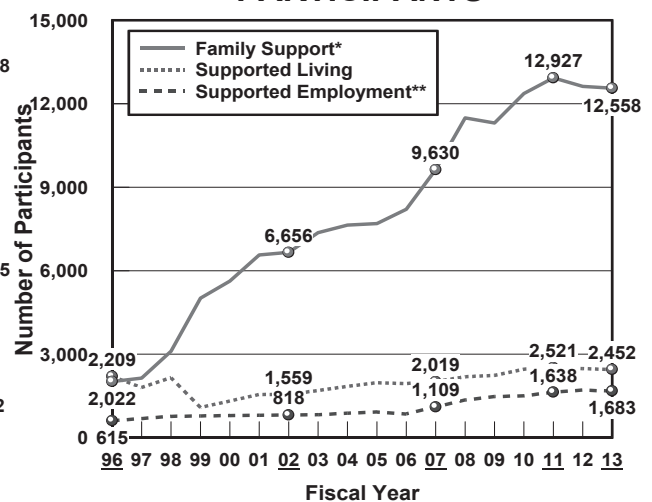
PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013



INDIVIDUAL AND FAMILY SUPPORT SPENDING



PARTICIPANTS



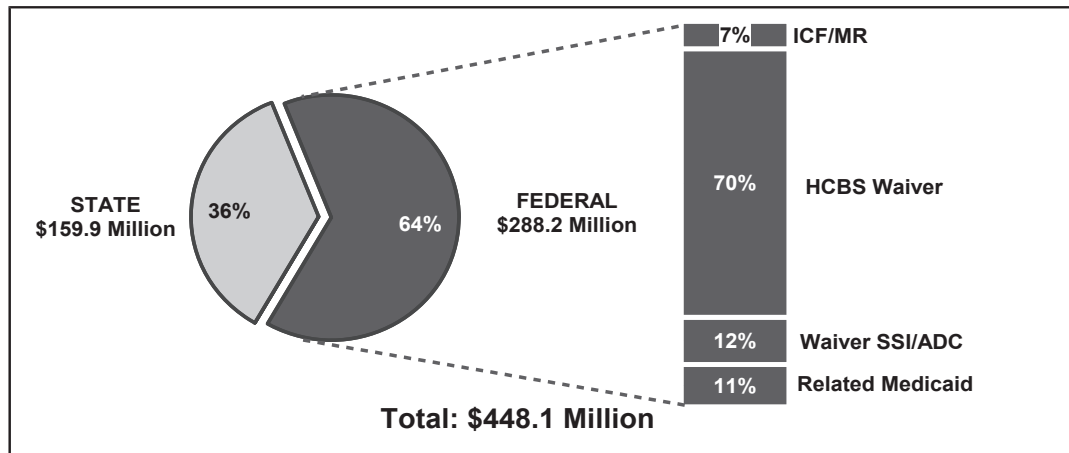
*The Family Support increase in 2007 followed the State's recovery from Katrina (September 2005) and paralleled the large HCBS waiver increase; Waiver funding constituted 95% of FS spending in 2007. **Does not include 1,654 follow-along work support workers in 2012 and 1,641 in 2013.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

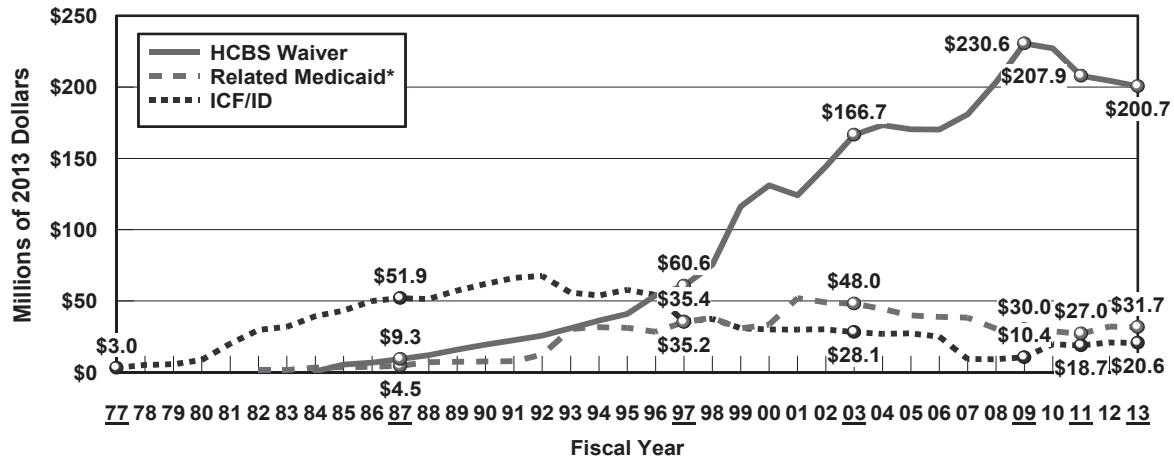
<http://stateofthestates.org>

MAINE

PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013

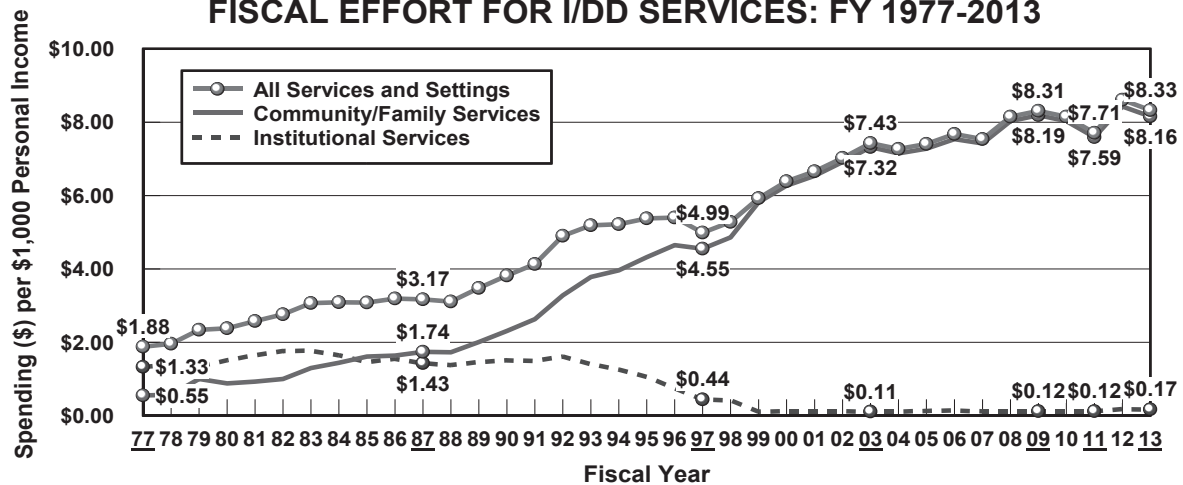


FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



*In 2013, "Related Medicaid" targeted case management (\$13.0 million), rehabilitation (\$13.0 million) and administration (\$5.7 million).

FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013

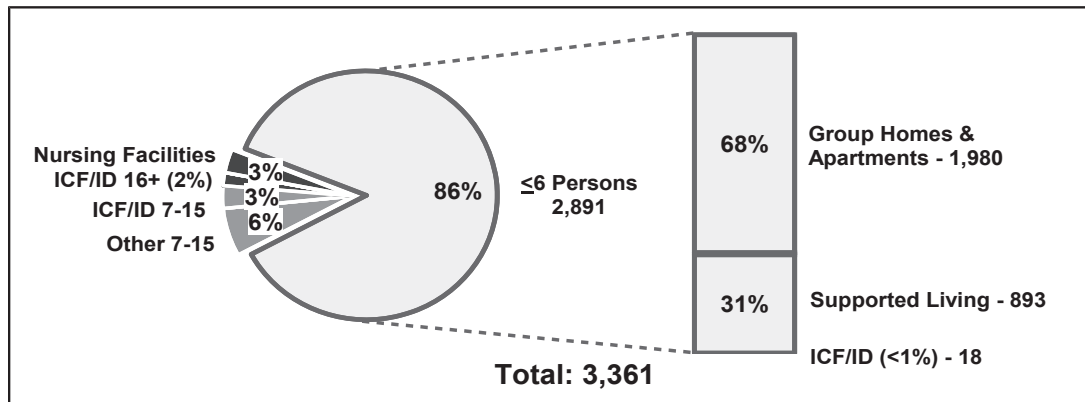


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

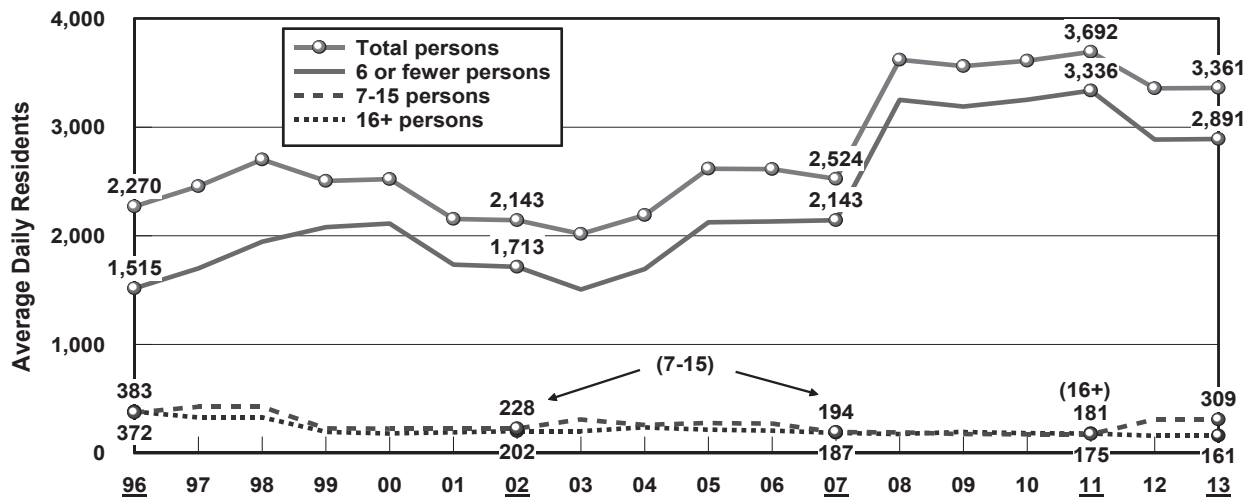
<http://stateofthestates.org>

MAINE

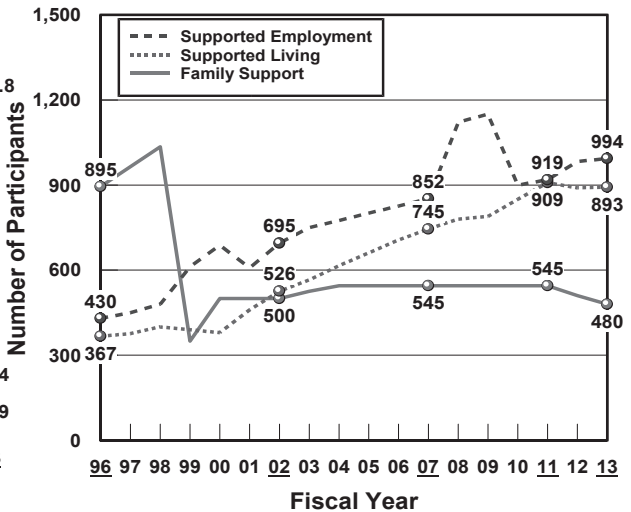
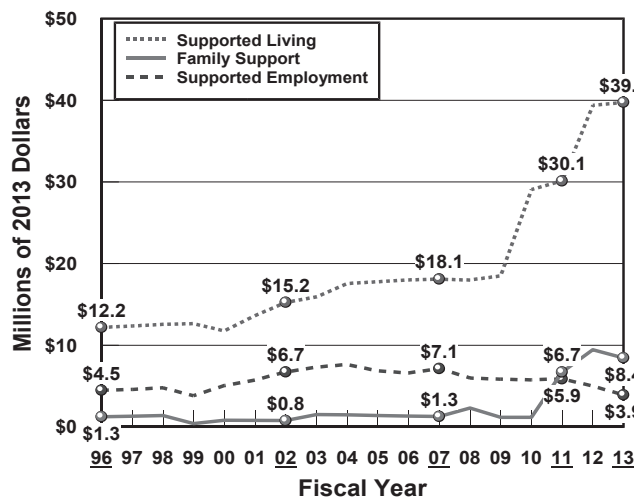
PERSONS BY SETTING IN FISCAL YEAR 2013



PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013



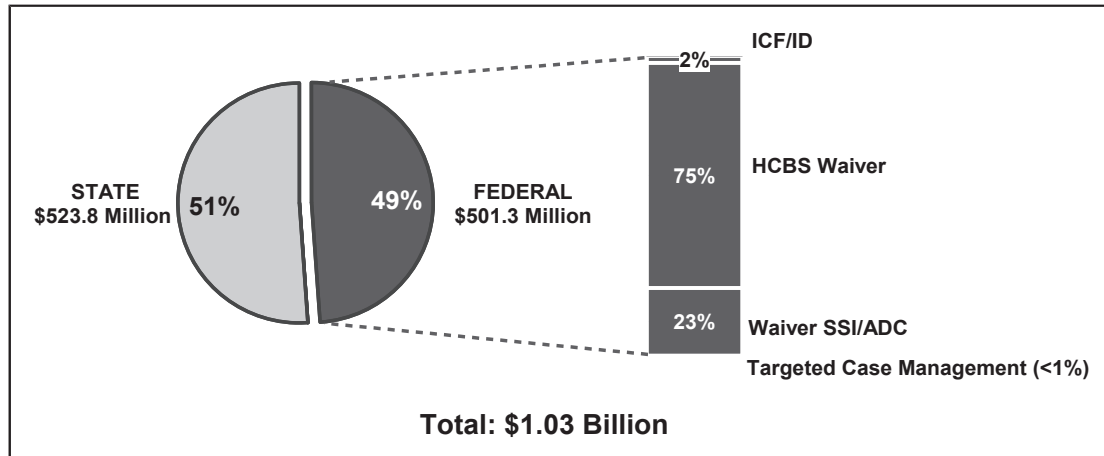
INDIVIDUAL AND FAMILY SUPPORT



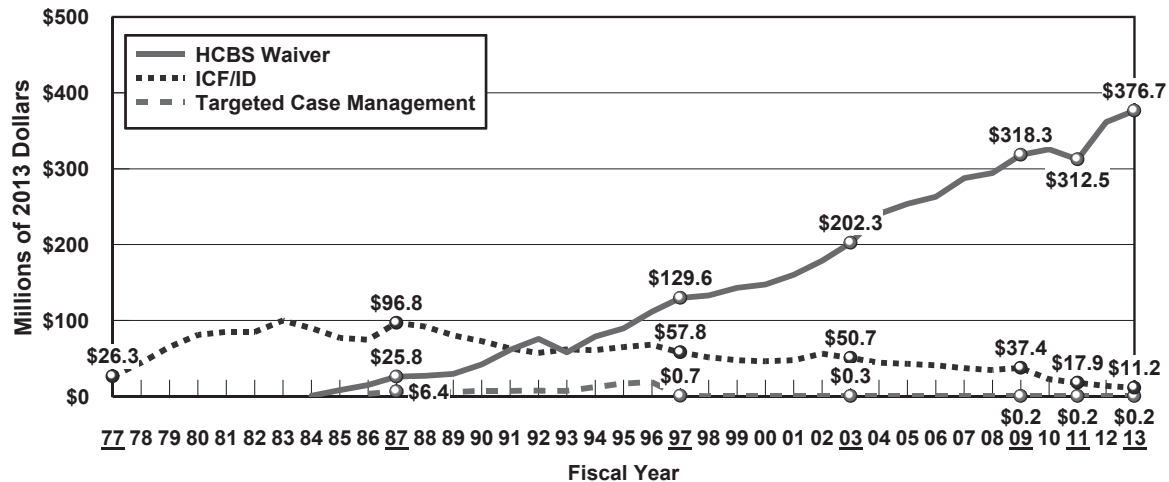
Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.
<http://stateofthestates.org>

MARYLAND

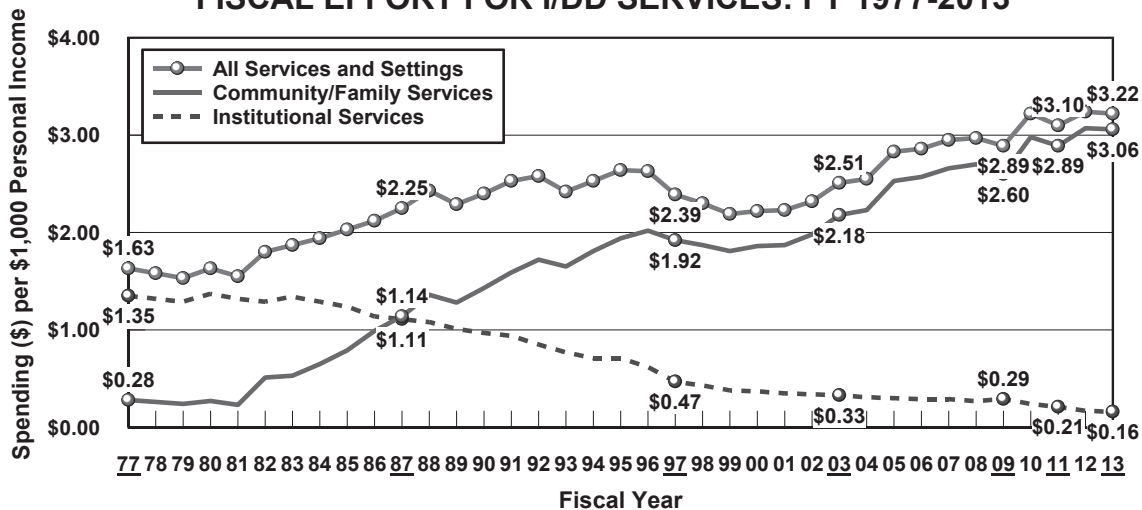
PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013



FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013

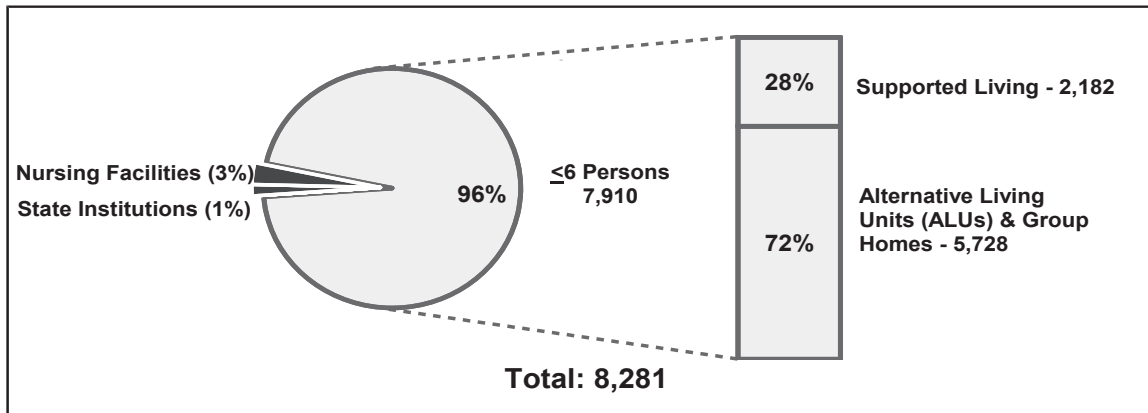


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

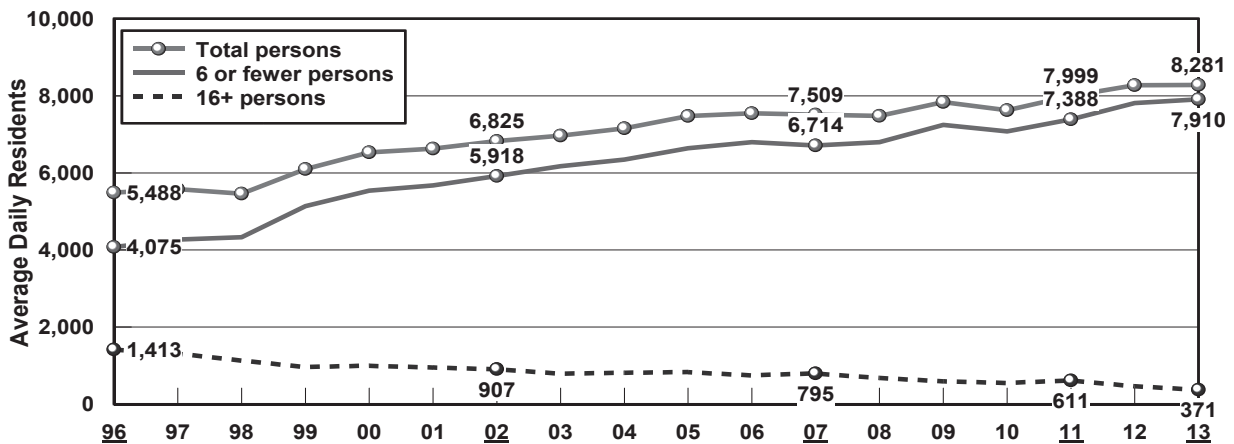
<http://stateofthestates.org>

MARYLAND

PERSONS BY SETTING IN FISCAL YEAR 2013

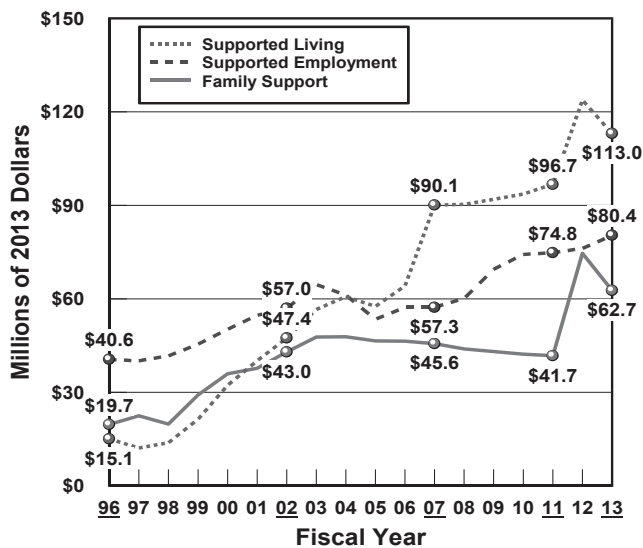


PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013

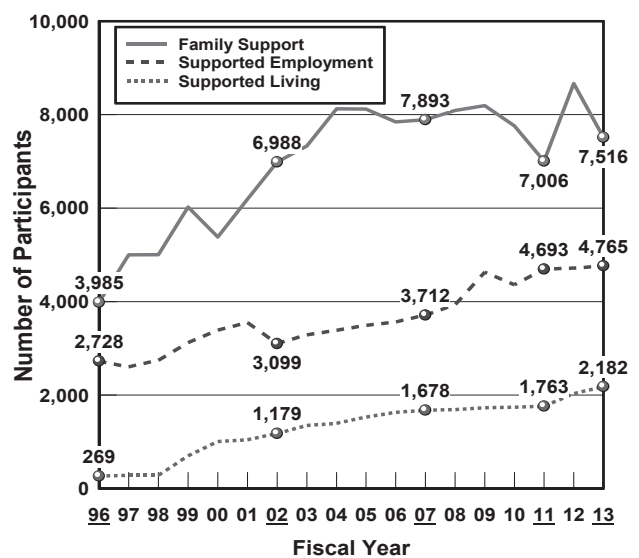


INDIVIDUAL AND FAMILY SUPPORT

SPENDING



PARTICIPANTS

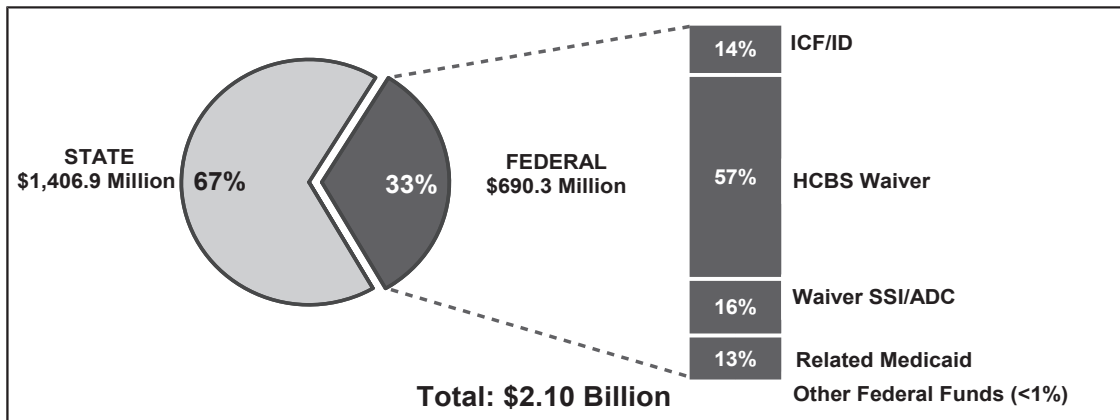


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

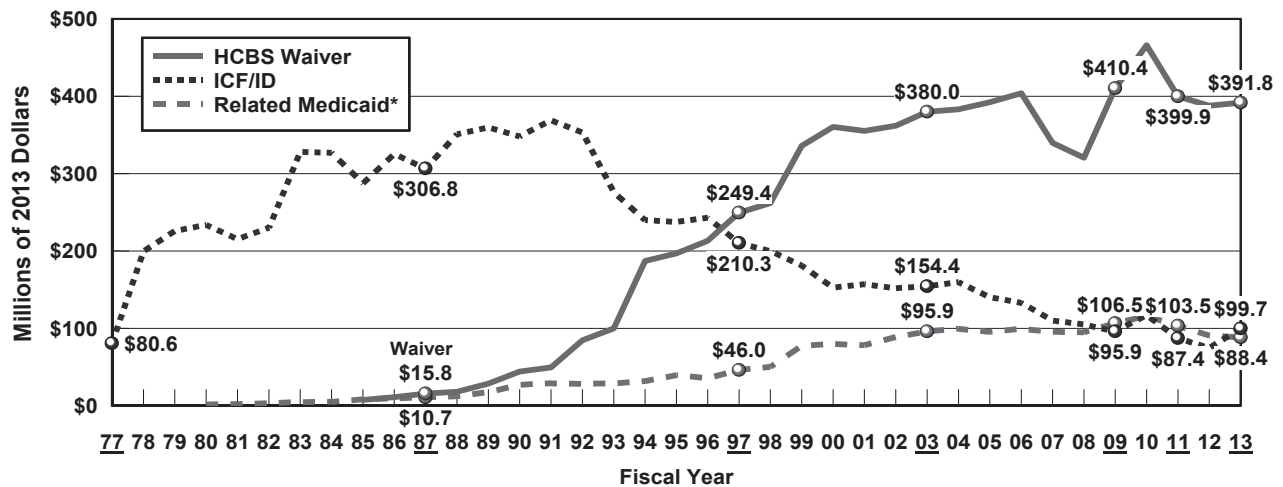
<http://stateofthestates.org>

MASSACHUSETTS

PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013

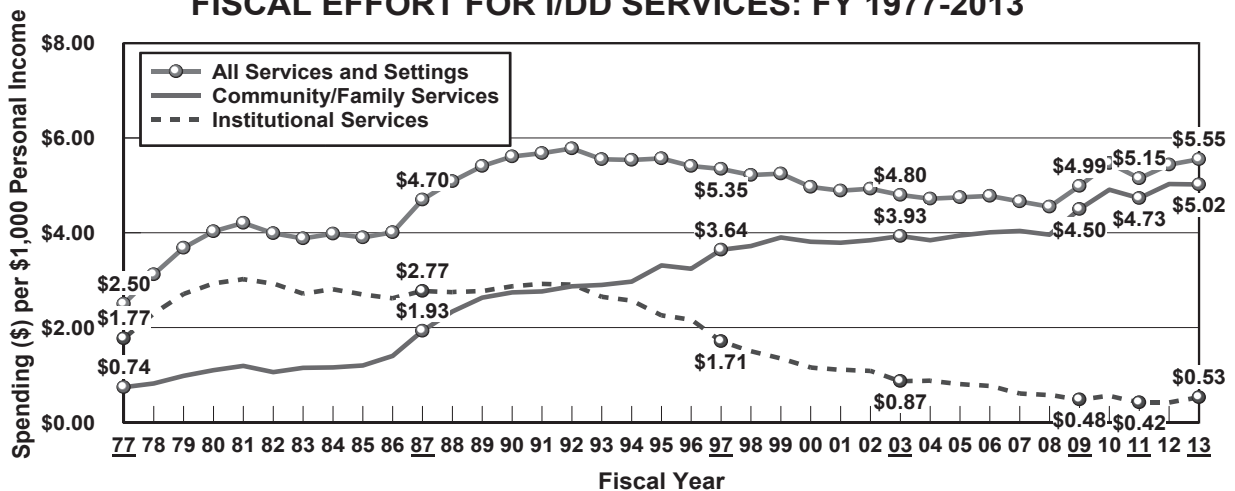


FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



*In 2013, "Related Medicaid" was clinic rehabilitation (\$72.8 million), clinic services for early intervention (\$14.7 million), and targeted case management (\$0.9 million).

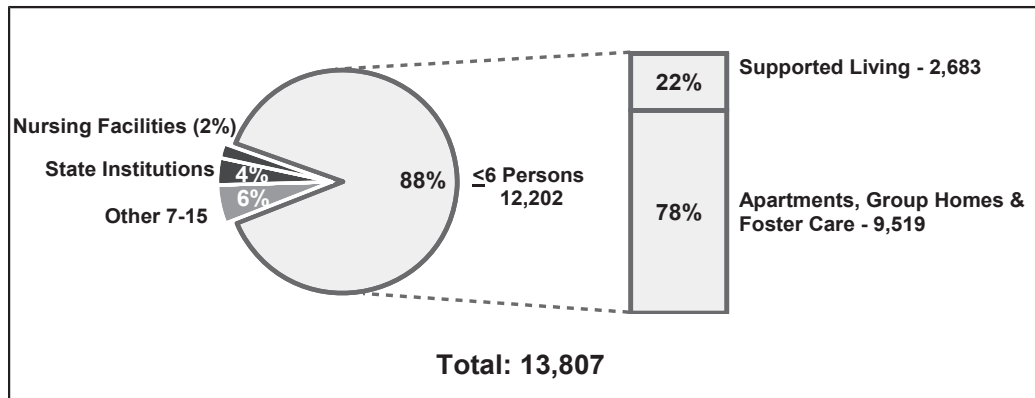
FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013



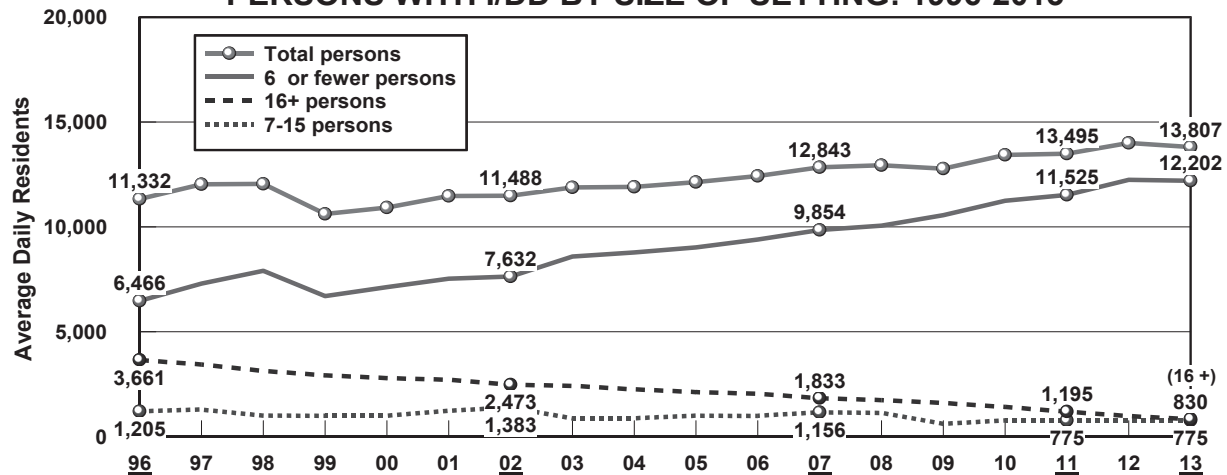
Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.
<http://stateofthestates.org>

MASSACHUSETTS

PERSONS BY SETTING IN FISCAL YEAR 2013

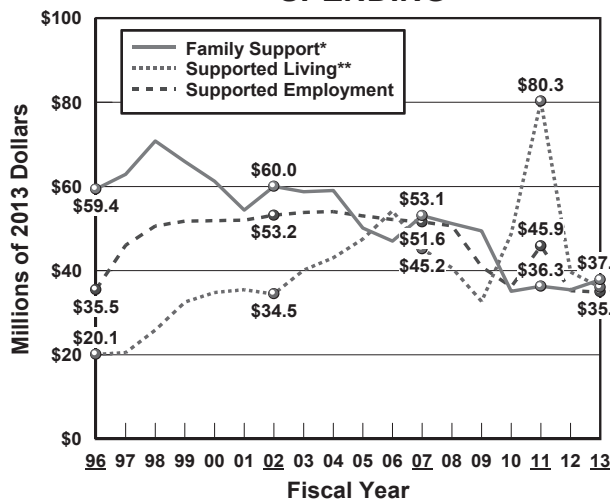


PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013

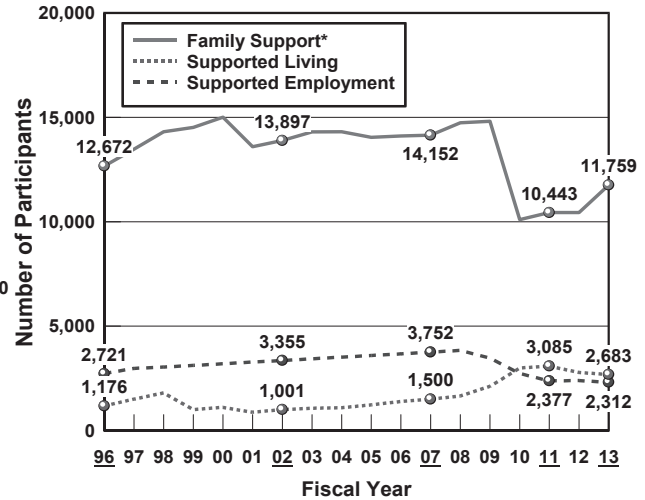


INDIVIDUAL AND FAMILY SUPPORT

SPENDING



PARTICIPANTS



*Reductions 2010-11 reflected major State budget reductions resulting in nearly 4,000 families losing services.

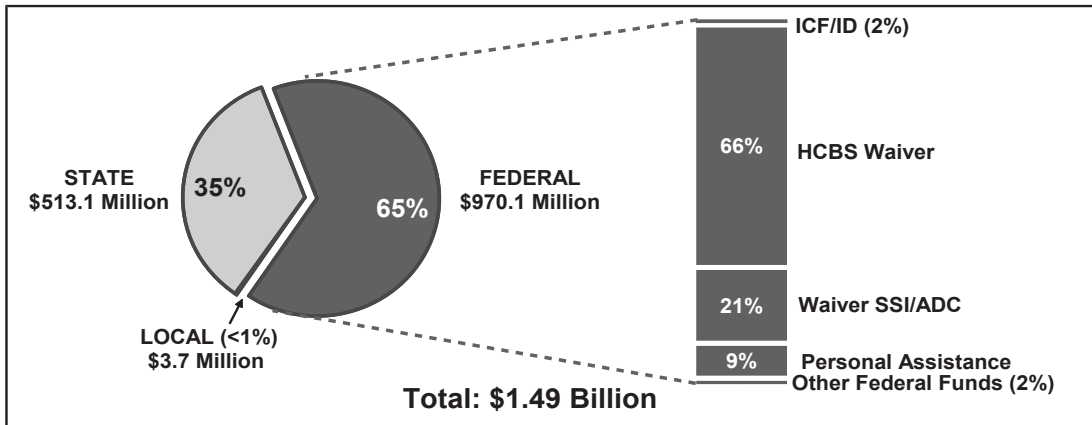
**Supported Living spending declined 2011 to 2013 due to support Waiver funding with reduced cost per participant.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

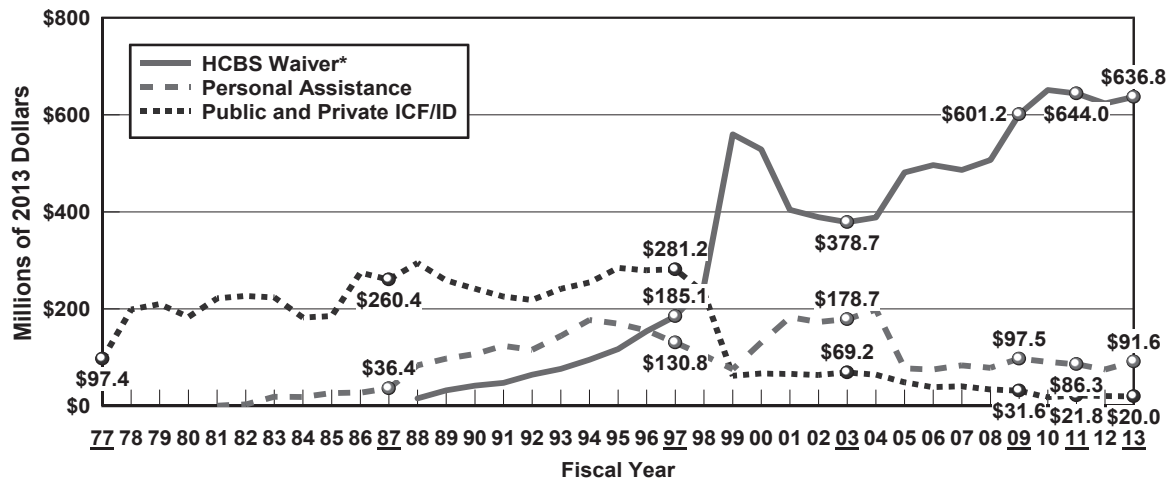
<http://stateofthestates.org>

MICHIGAN

PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013

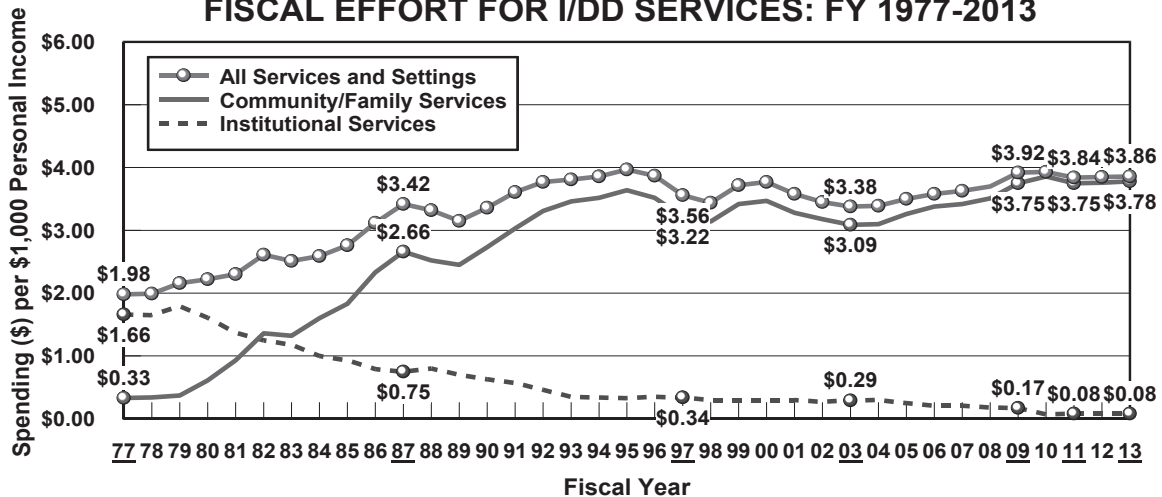


FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



*Medicaid funding for Michigan's 1915b/c Waiver & for "B-3 Community Living Services" (CLS) is included with the HCBS Waiver spending. Funding for these two programs ranged from \$14.1 M in 1988 to \$636.8 M in 2013. The marked changes in Waiver spending and in "related Medicaid" (personal assistance) during 1998-2004 were due in part to growth in person-centered planning and the B-3 Waiver, and in part to poor data quality during the transfer from fee for service to managed care in 1998.

FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013

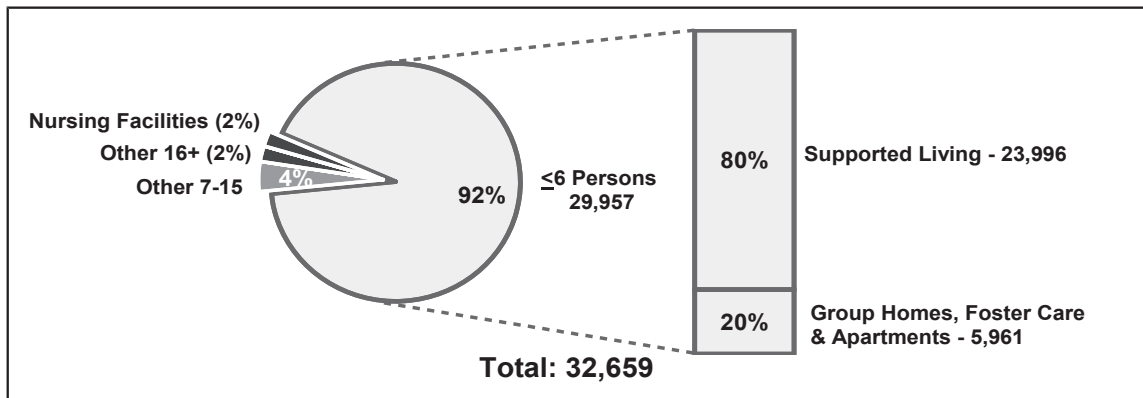


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

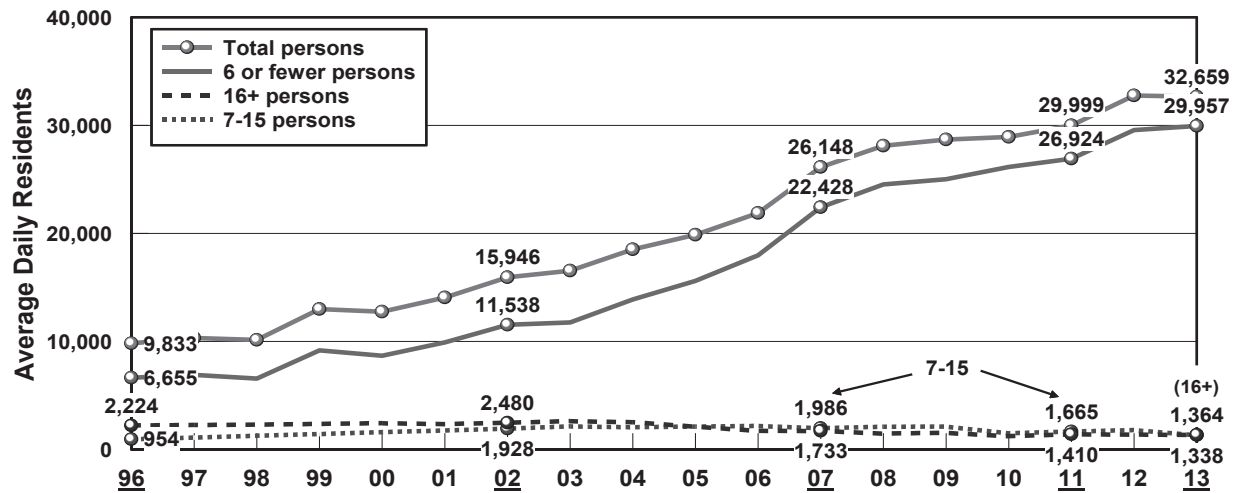
<http://stateofthestates.org>

MICHIGAN

PERSONS BY SETTING IN FISCAL YEAR 2013

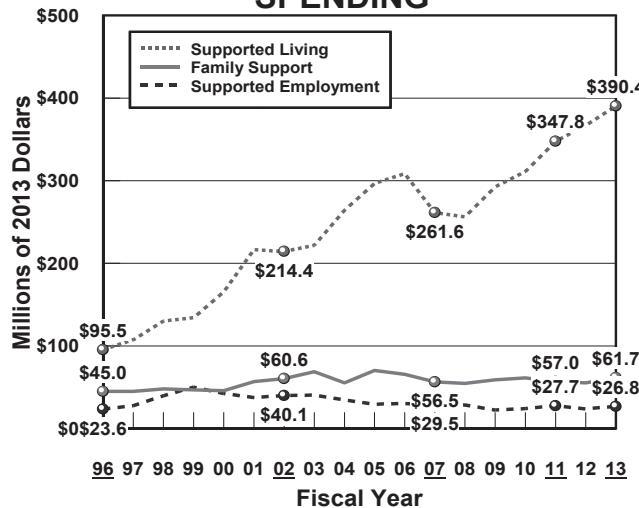


PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013

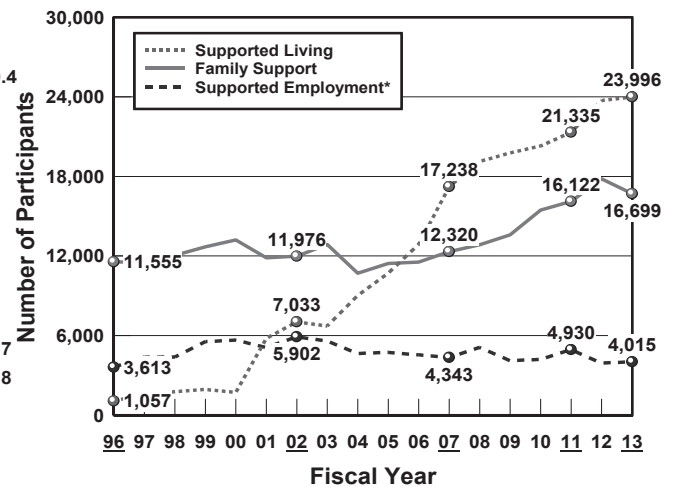


INDIVIDUAL AND FAMILY SUPPORT

SPENDING



PARTICIPANTS



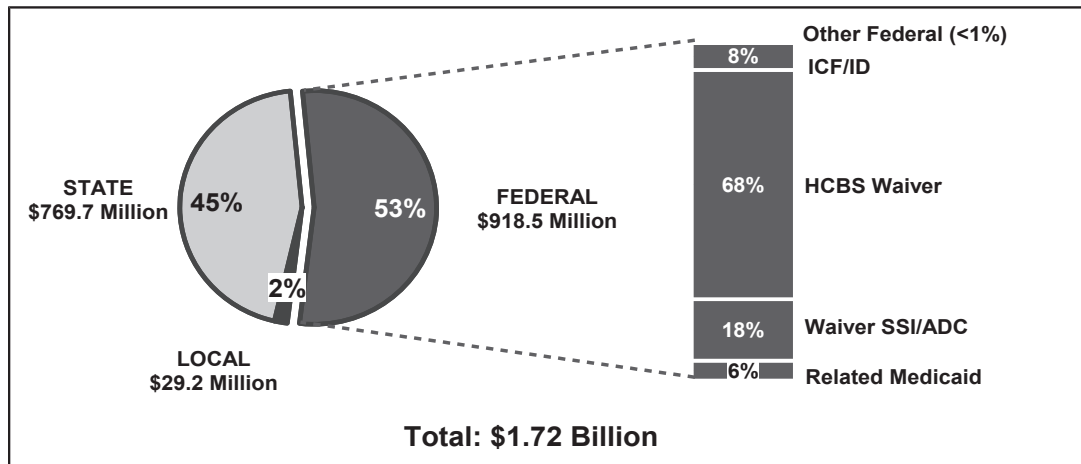
*Does not include follow-along work support workers: 2,518 in 2012, and 2,511 workers in 2013.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

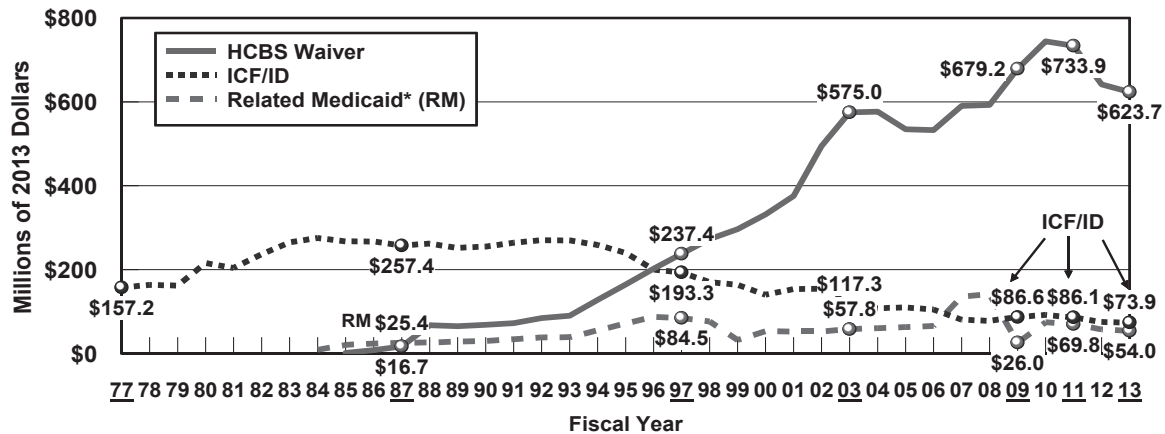
<http://stateofthestates.org>

MINNESOTA

PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013

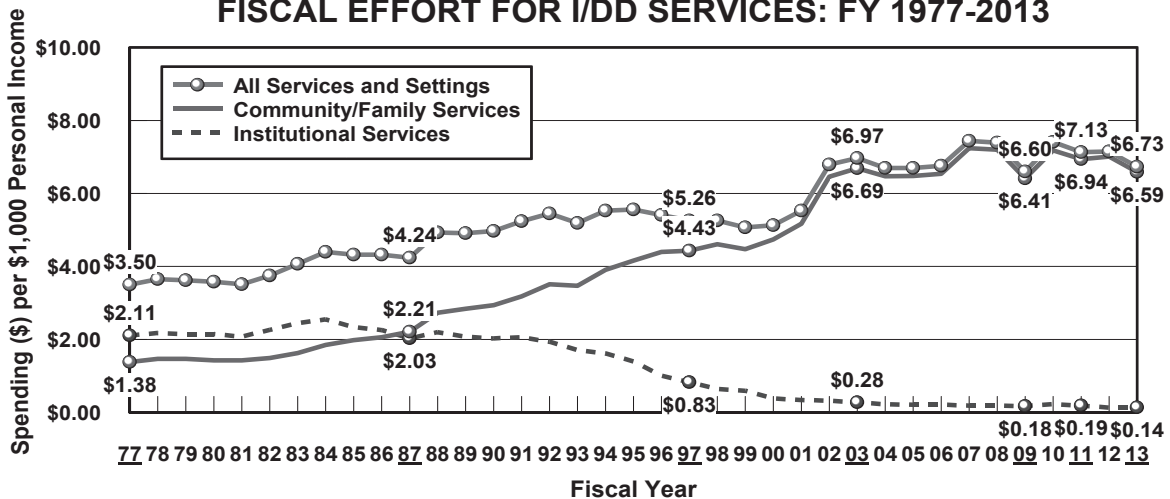


FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



*In 2013, "Related Medicaid" was targeted case management (\$10.3 million), personal assistance (\$26.3 million) and administration (\$17.4 million).

FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013

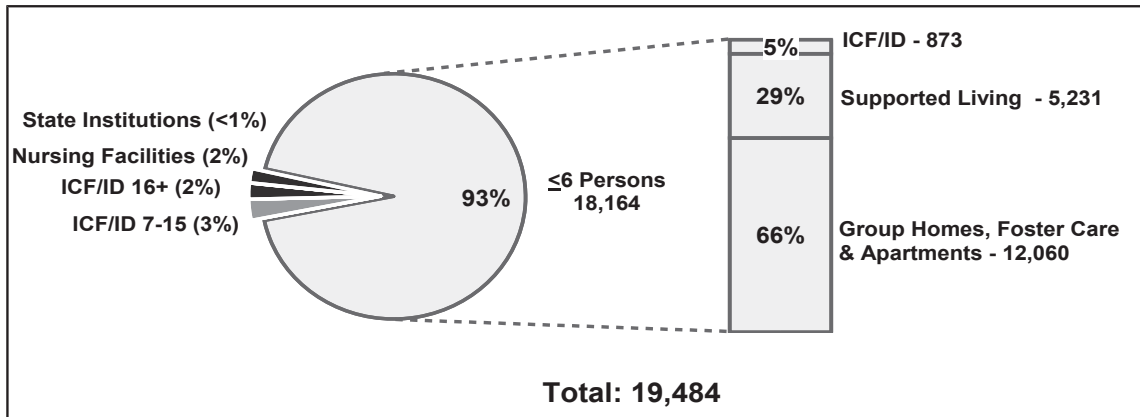


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

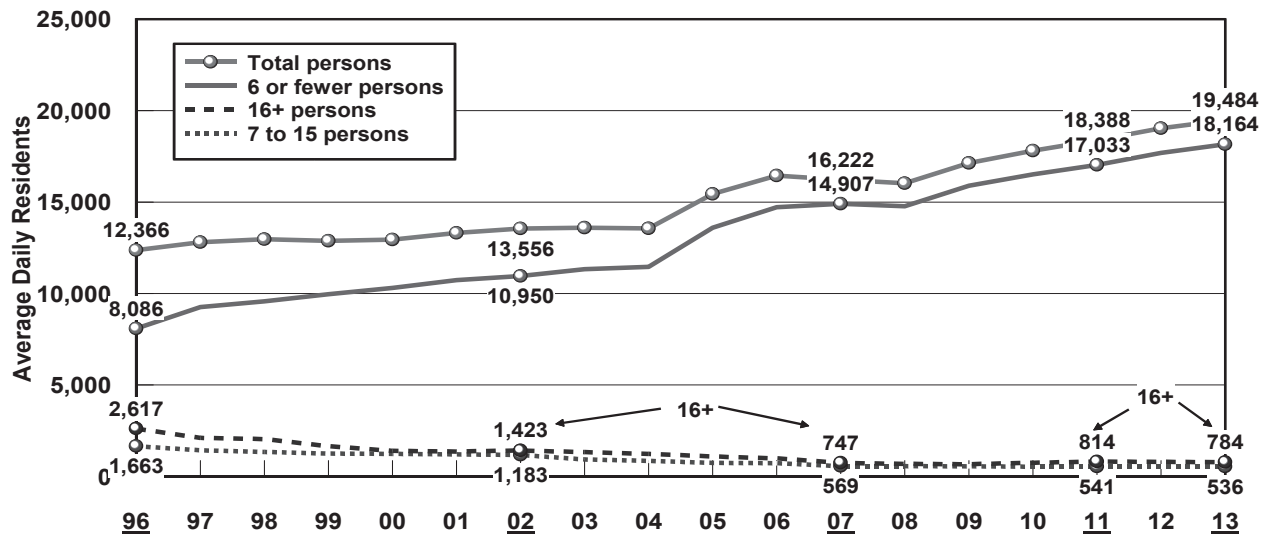
<http://stateofthstates.org>

MINNESOTA

PERSONS BY SETTING IN FISCAL YEAR 2013

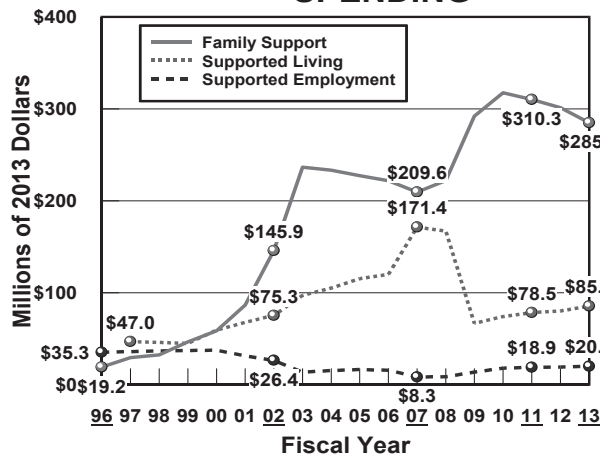


PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013

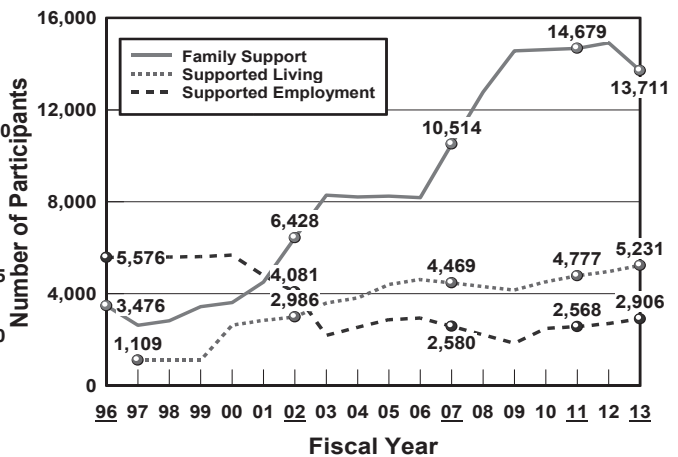


INDIVIDUAL AND FAMILY SUPPORT

SPENDING



PARTICIPANTS

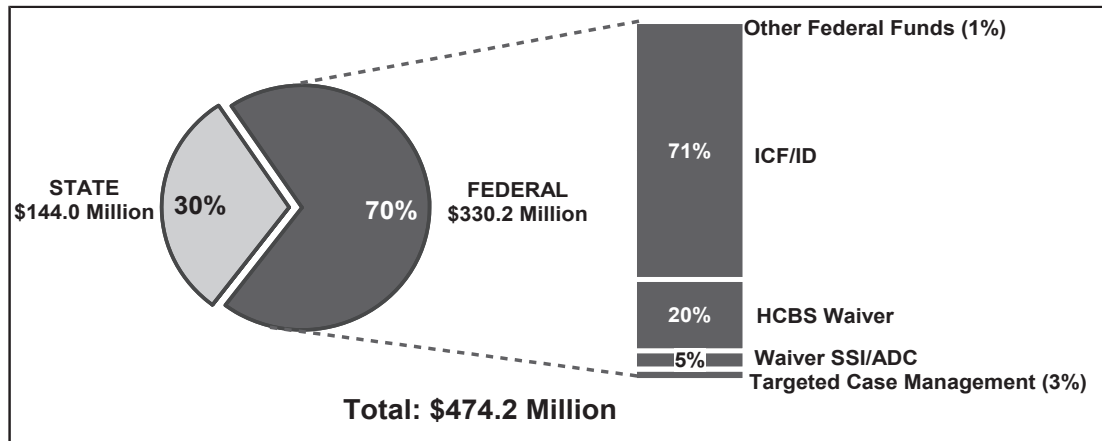


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

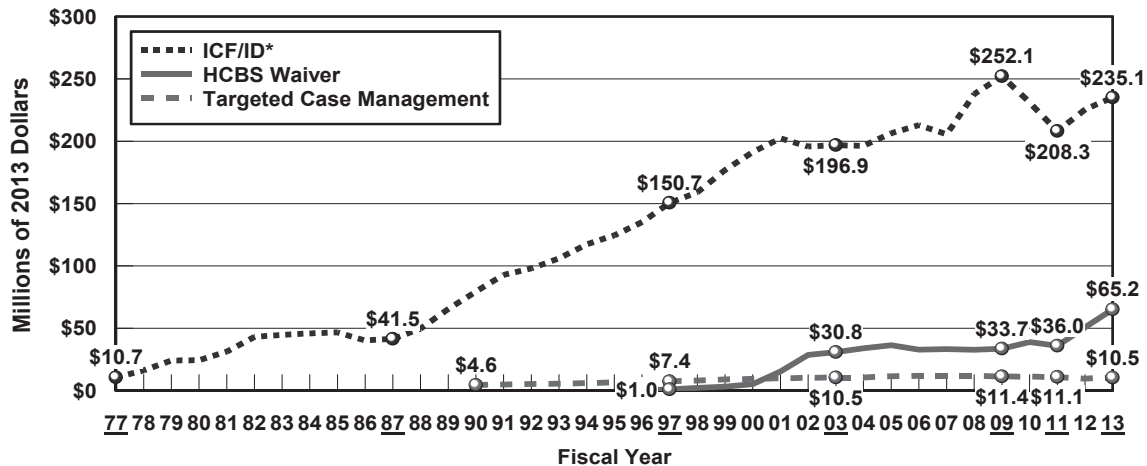
<http://stateofthestates.org>

MISSISSIPPI

PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013

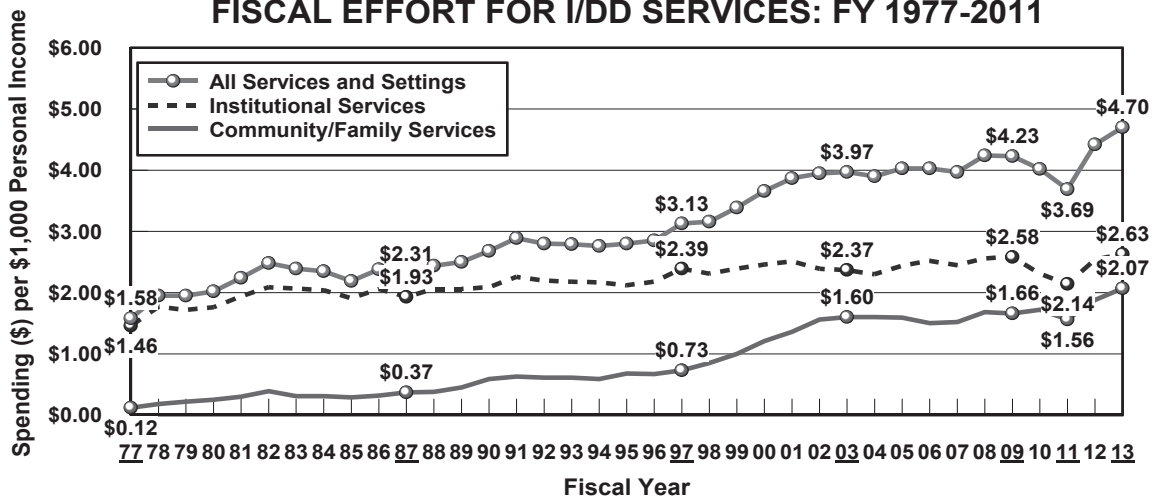


FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



*ICF/ID spending decline in 2010-11 due to reduction in state institution census and limited state match funding.

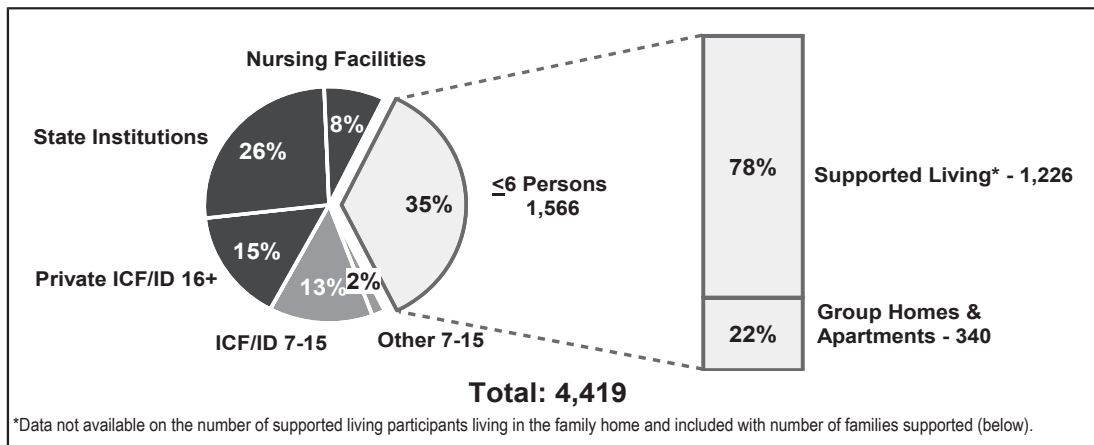
FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2011



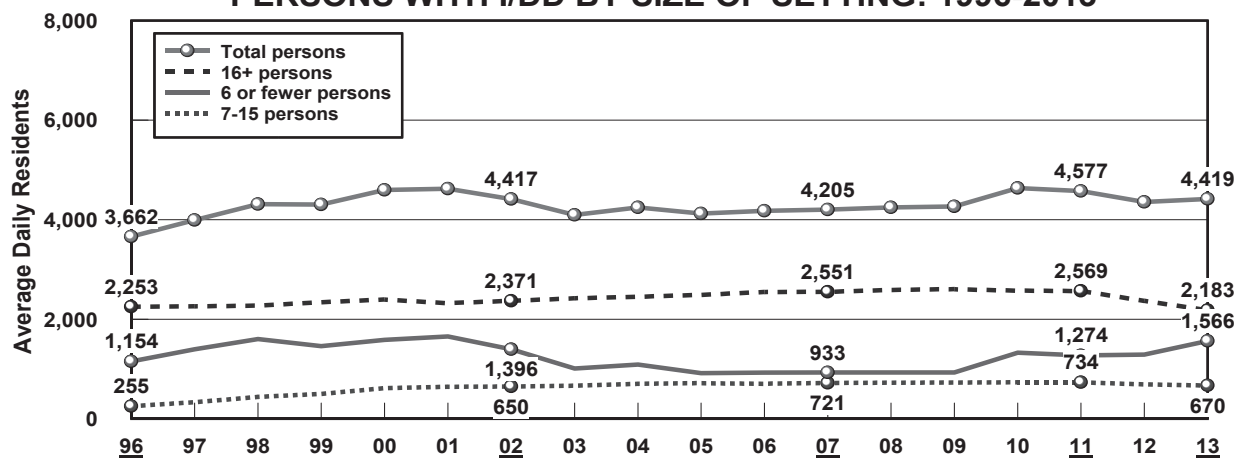
Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.
<http://stateofthestates.org>

MISSISSIPPI

PERSONS BY SETTING IN FISCAL YEAR 2013

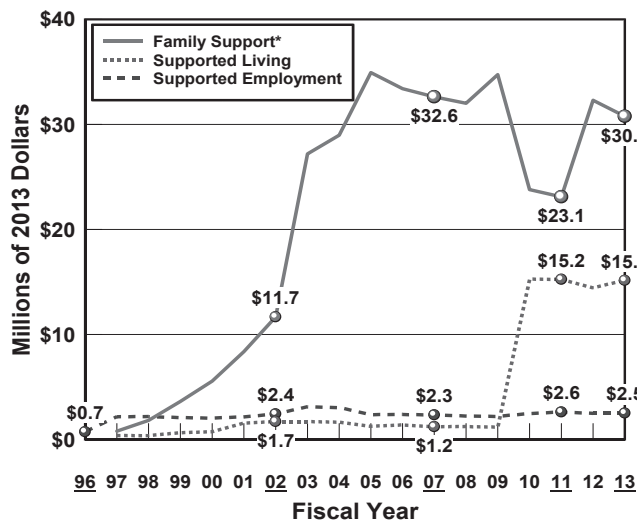


PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013

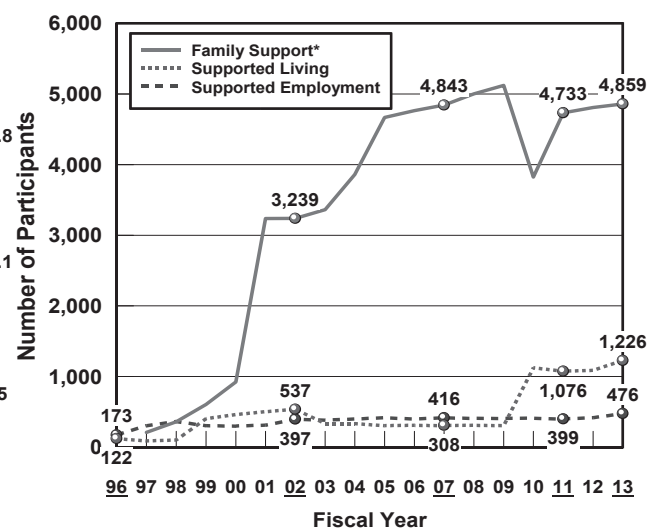


INDIVIDUAL AND FAMILY SUPPORT

SPENDING



PARTICIPANTS



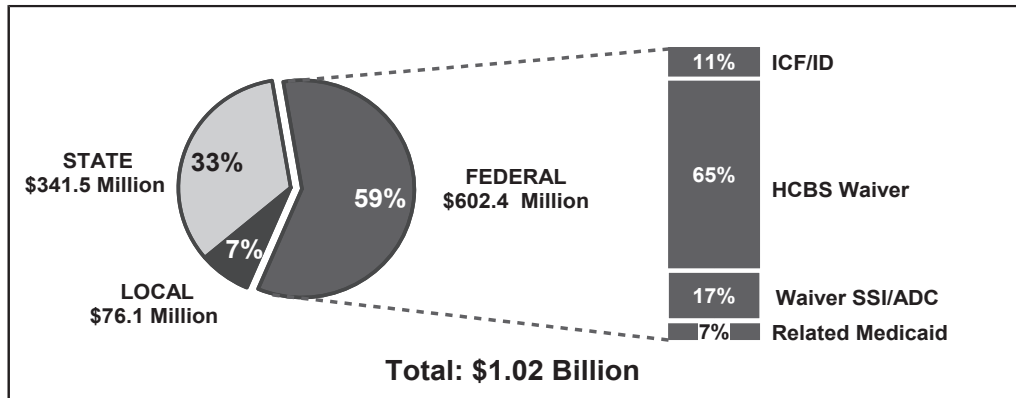
*The 2006-11 reduction in family support spending, and plateau in families supported, were due to reductions in state funding.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

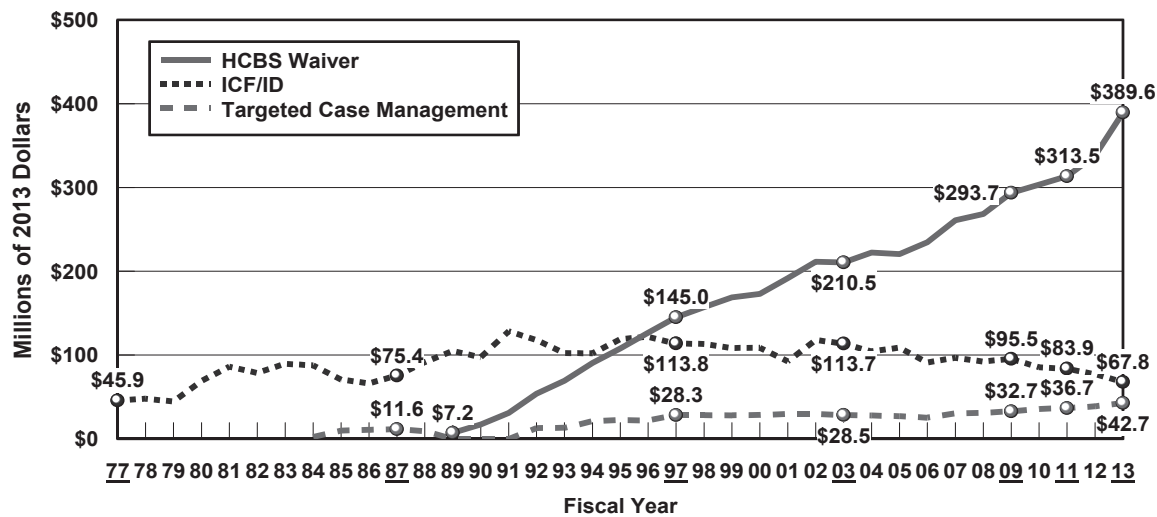
<http://stateofthstates.org>

MISSOURI

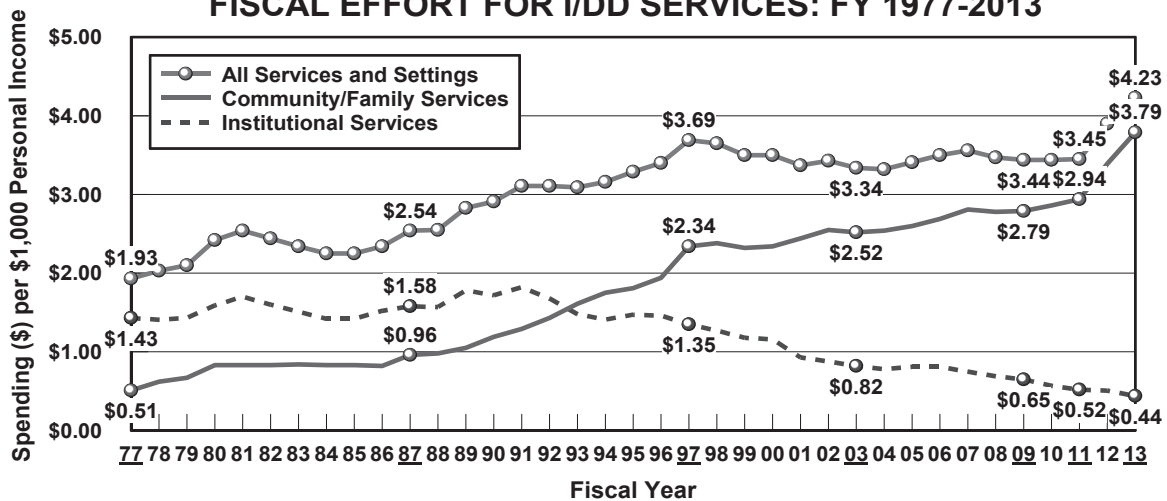
PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013



FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013

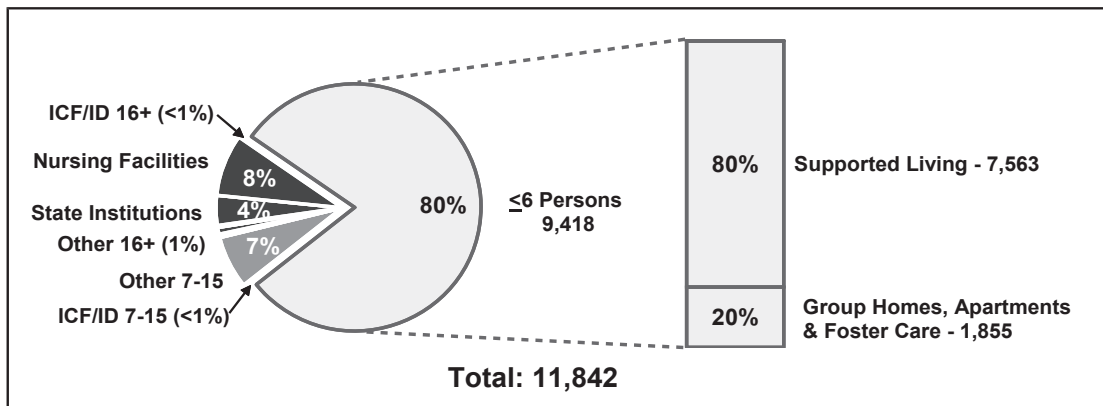


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

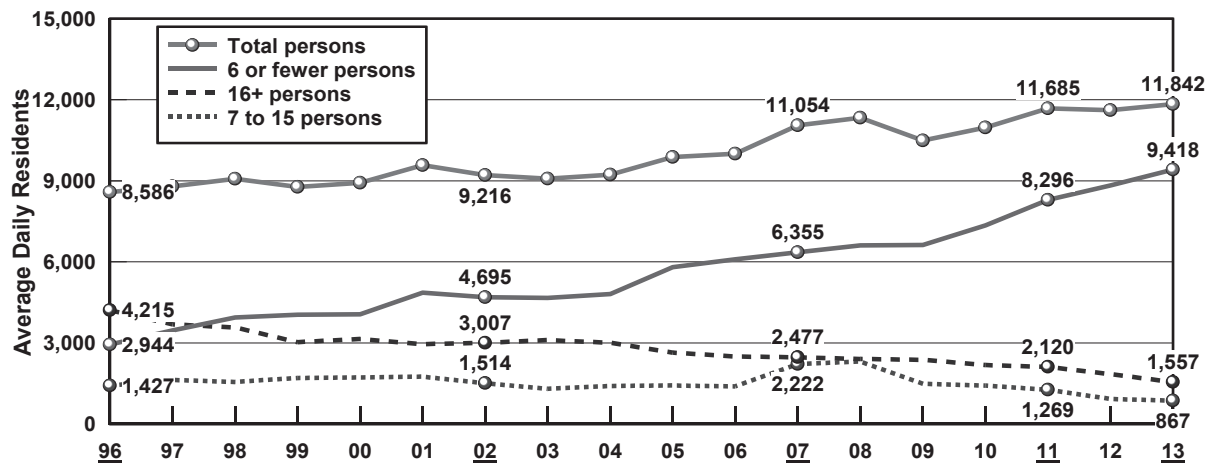
<http://stateofthestates.org>

MISSOURI

PERSONS BY SETTING IN FISCAL YEAR 2013

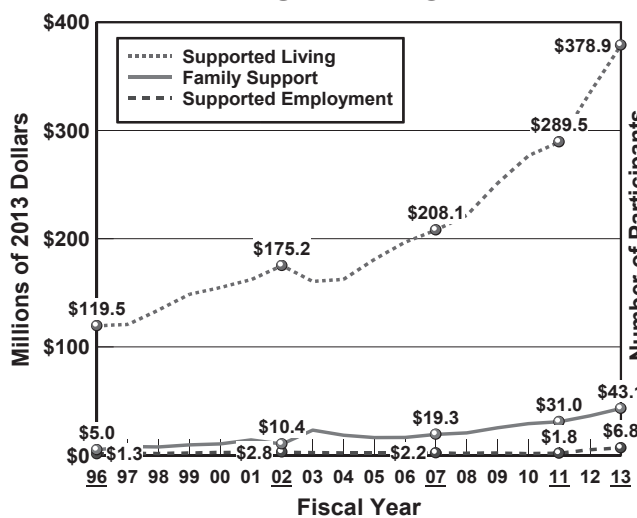


PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013

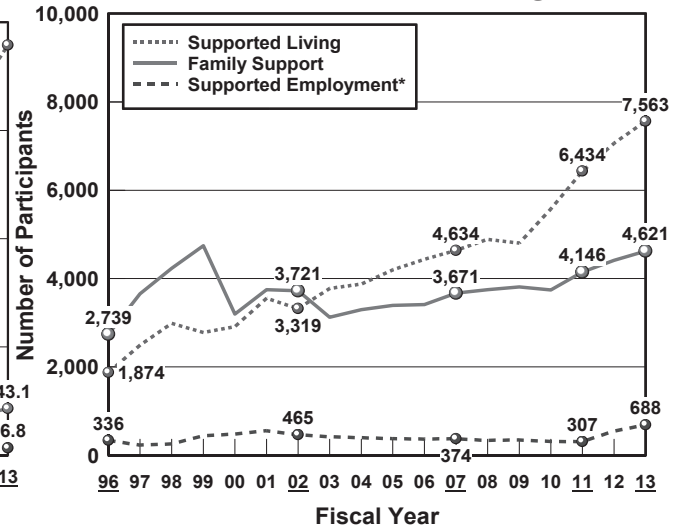


INDIVIDUAL AND FAMILY SUPPORT

SPENDING



PARTICIPANTS



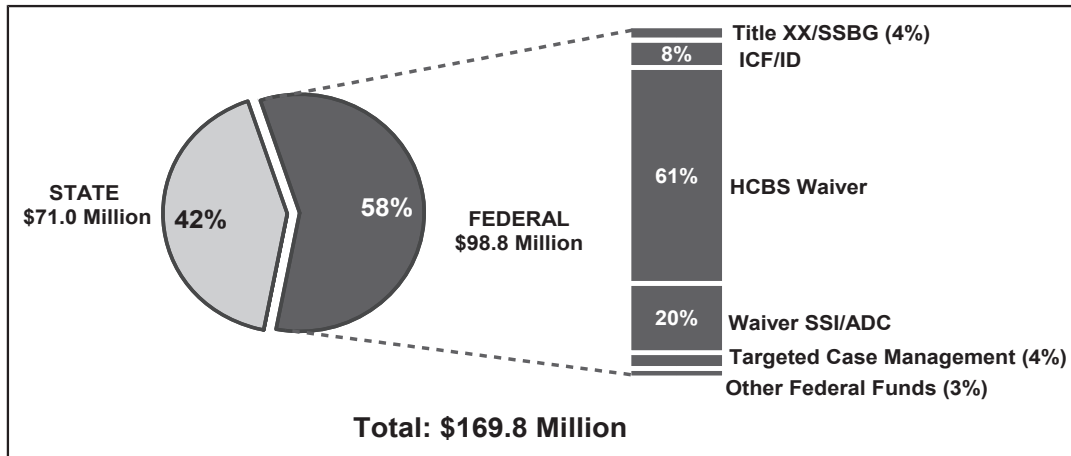
*Not included were 842 and 974 follow-along work support workers in 2012 and 2013.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

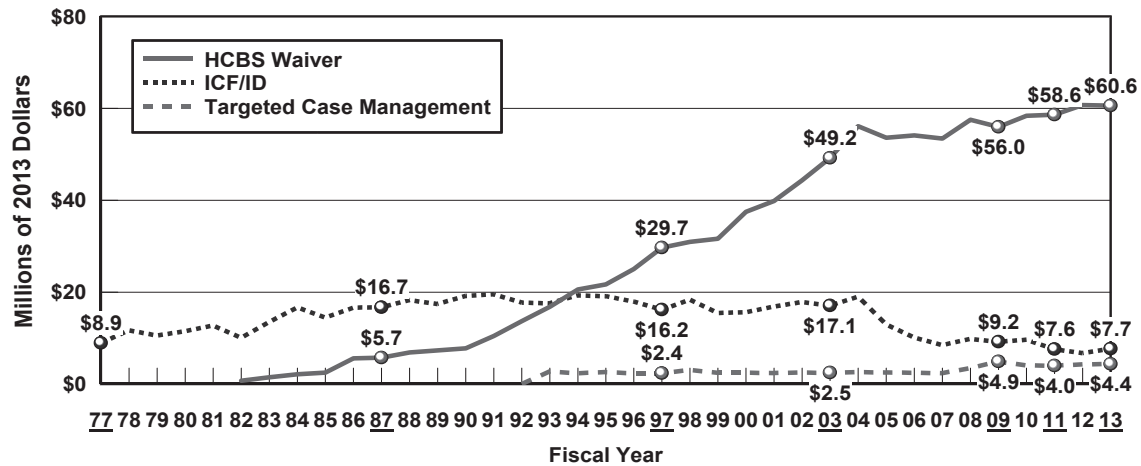
<https://stateofthestates.org>

MONTANA

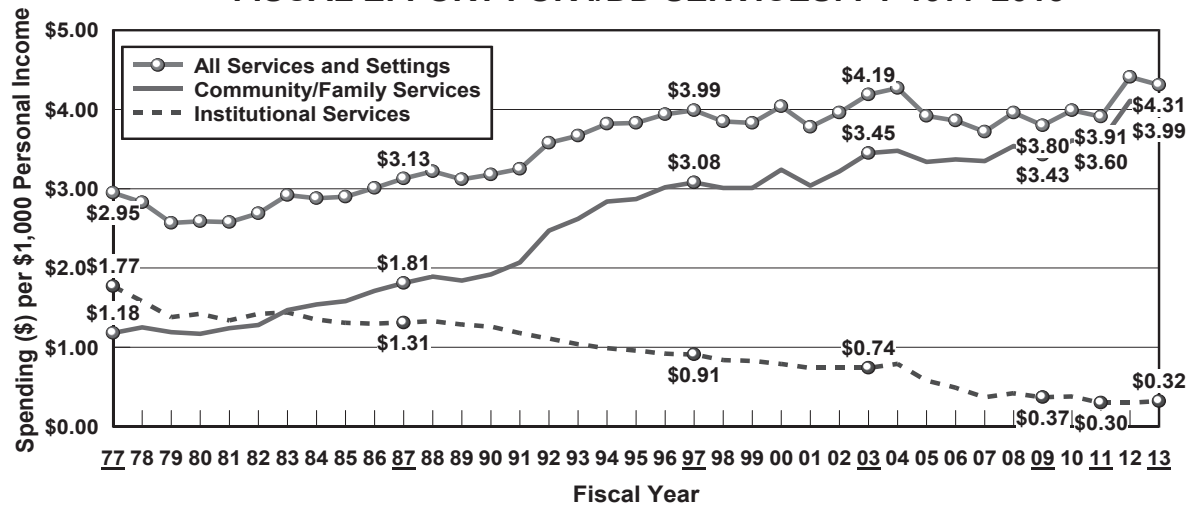
PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013



FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013

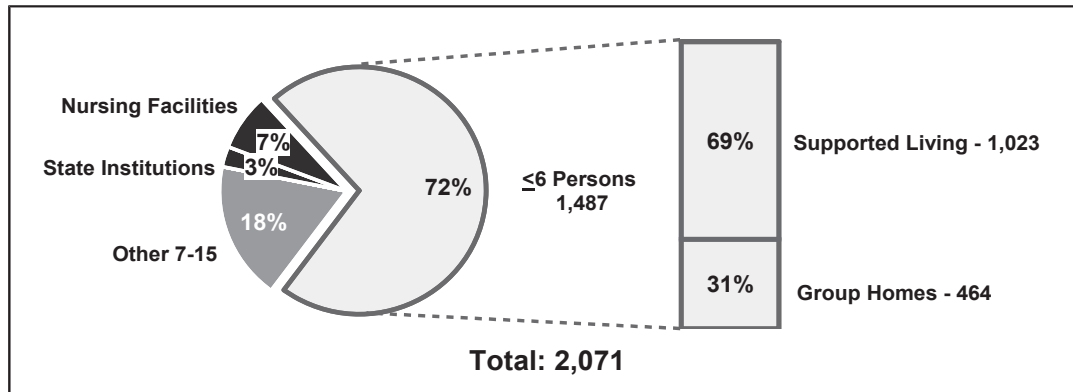


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

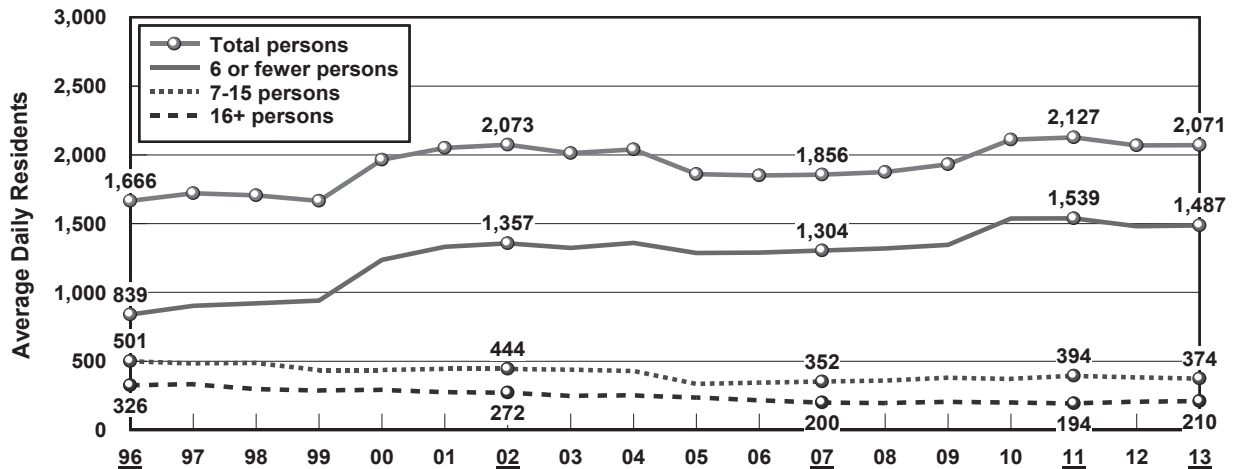
<http://stateofthestates.org>

MONTANA

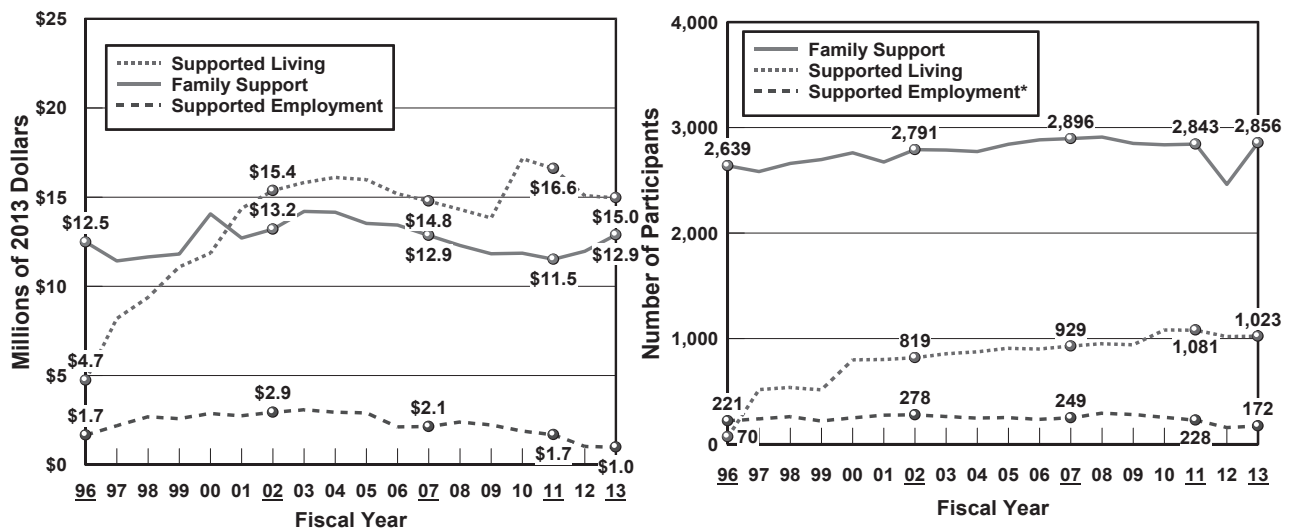
PERSONS BY SETTING IN FISCAL YEAR 2013



PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013



INDIVIDUAL AND FAMILY SUPPORT SPENDING PARTICIPANTS



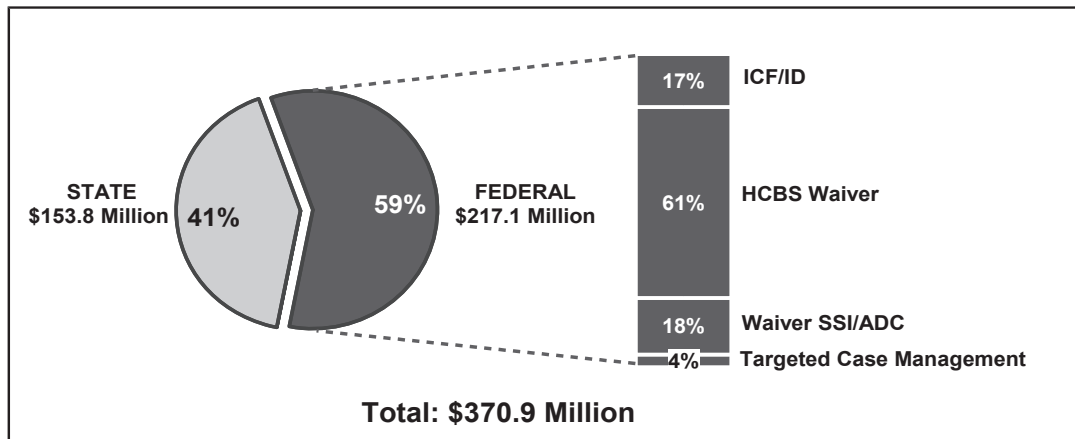
*Does not include 94 and 106 follow-along work support workers in 2012 and 2013.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

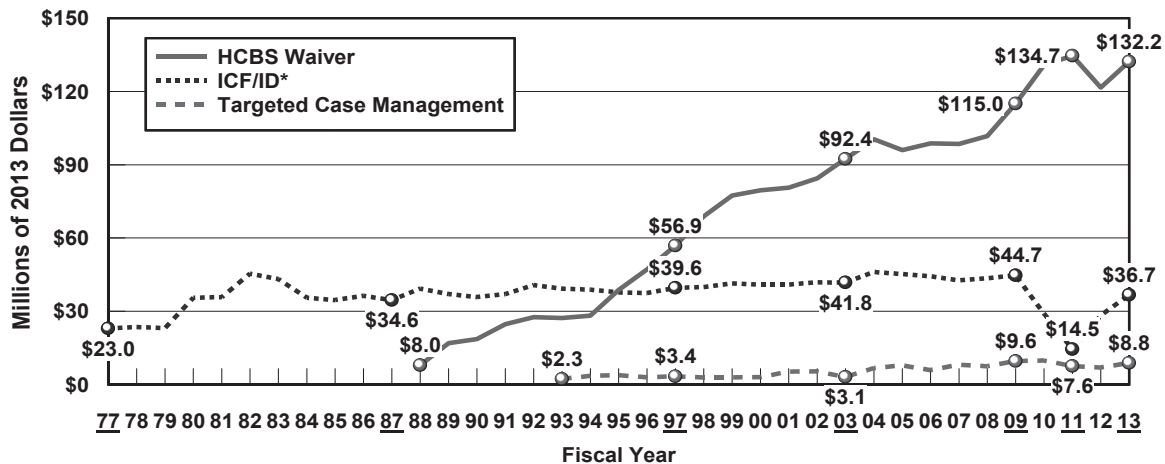
<http://stateofthestates.org>

NEBRASKA

PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013

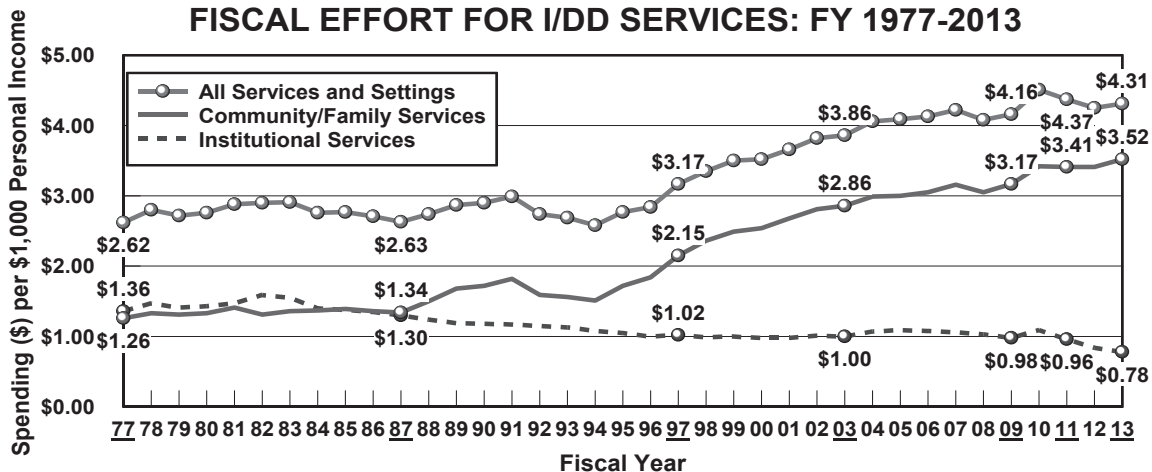


FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



*Beatrice State Center's ICF/ID reimbursement was limited due to de-certification during Fiscal Years 2010-11.

FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013

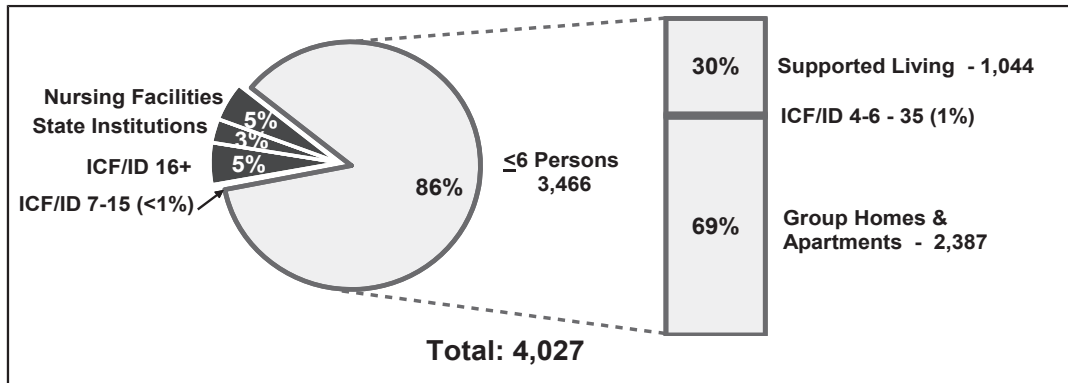


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

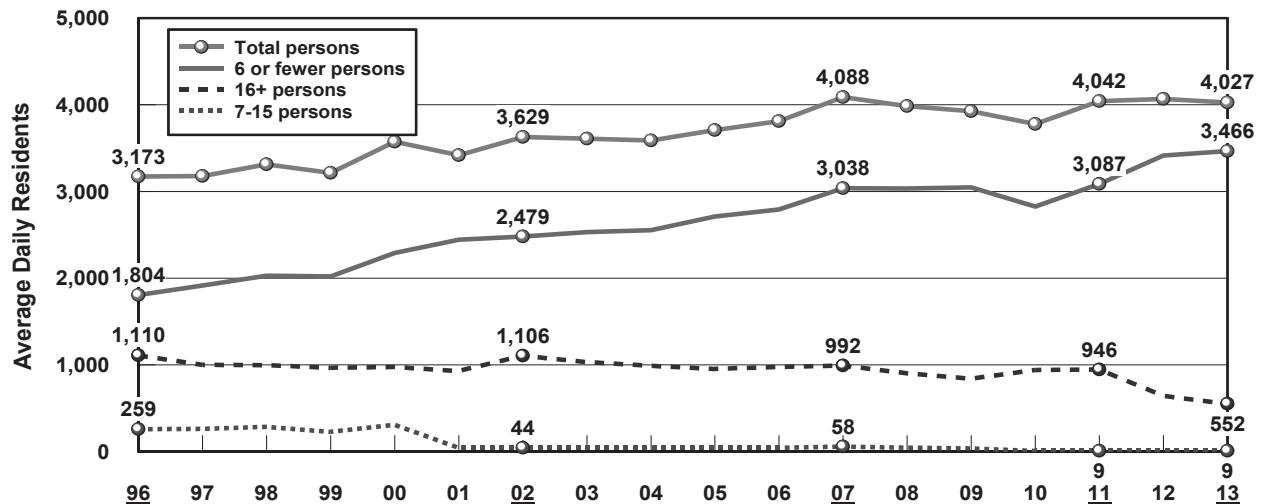
<http://stateofthestates.org>

NEBRASKA

PERSONS BY SETTING IN FISCAL YEAR 2013

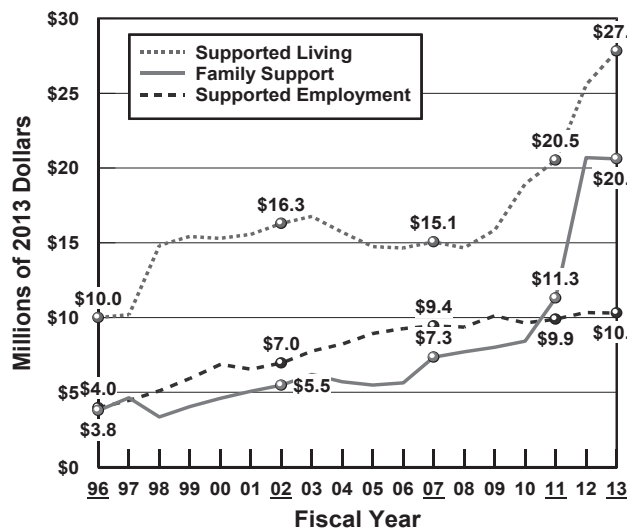


PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013

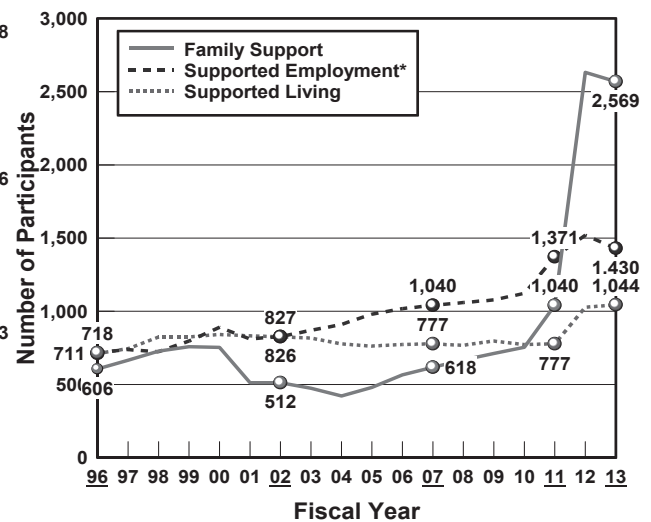


INDIVIDUAL AND FAMILY SUPPORT

SPENDING



PARTICIPANTS



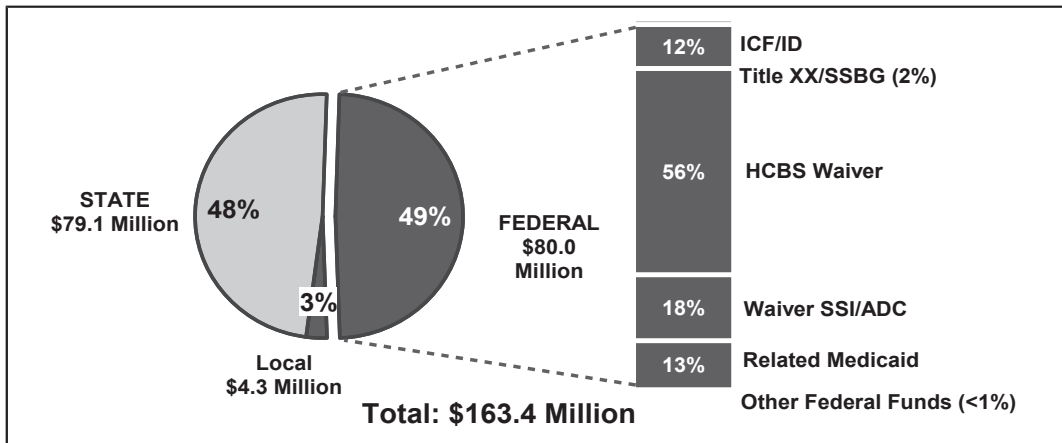
*Does not include 19 follow-along workers in 2012 and 1,007 in 2013.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

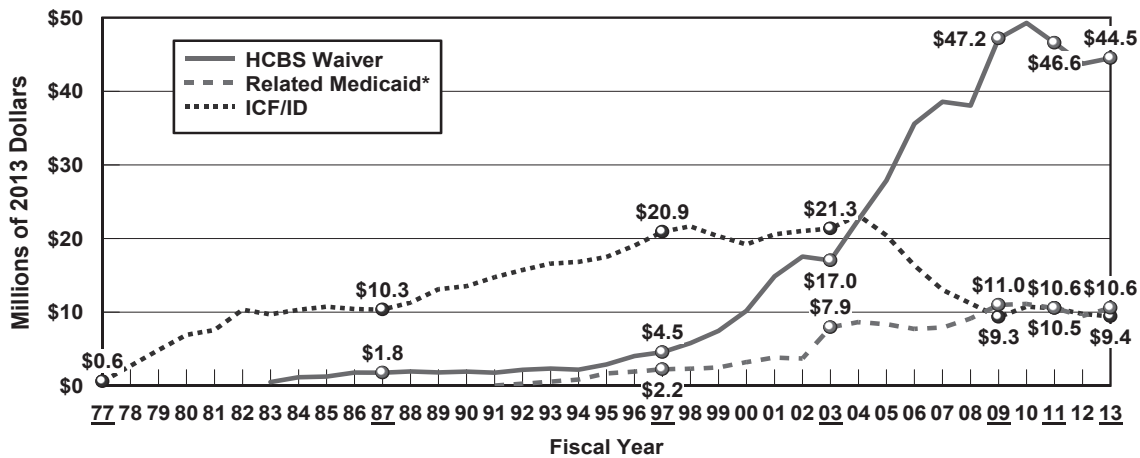
<http://stateofthestates.org>

NEVADA

PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013

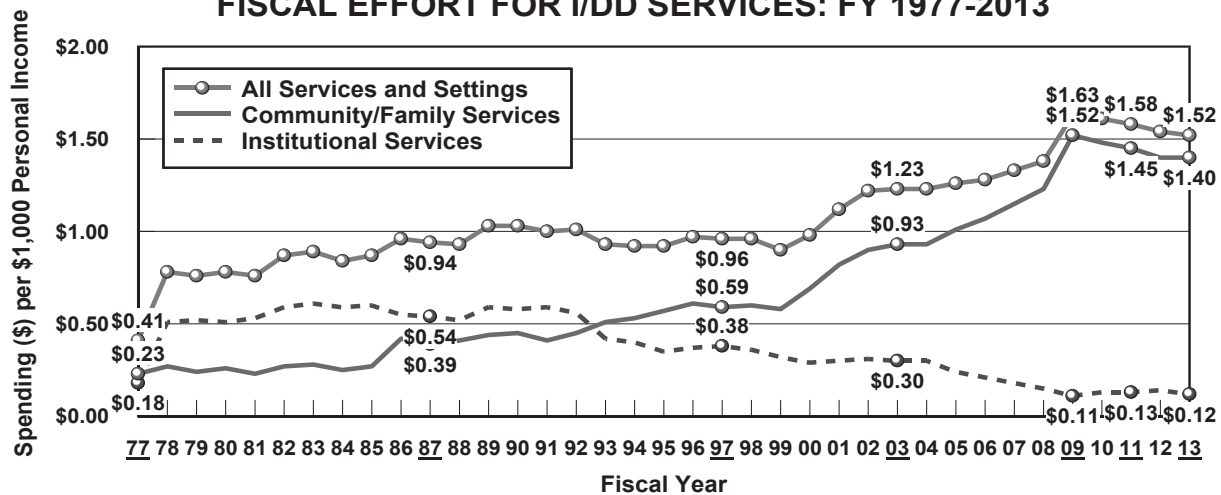


FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



*In 2013, "Related Medicaid" was targeted case management (\$7.2 million) and personal care services (\$3.4 million).

FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013

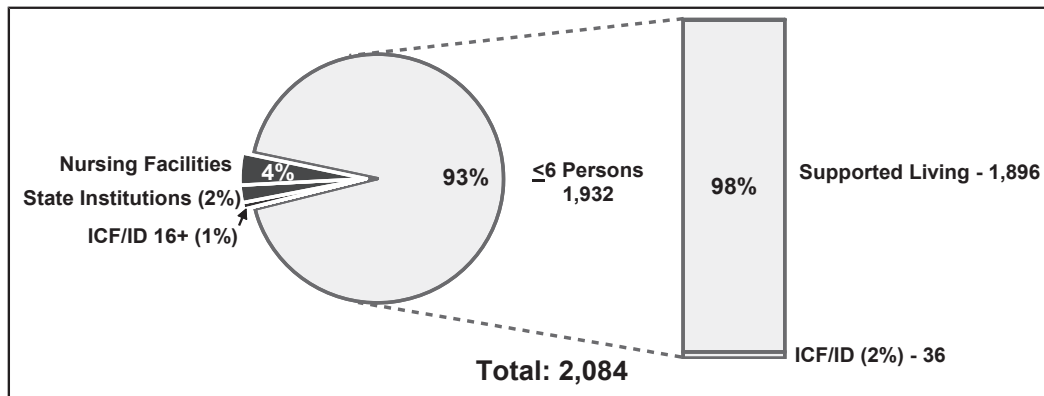


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

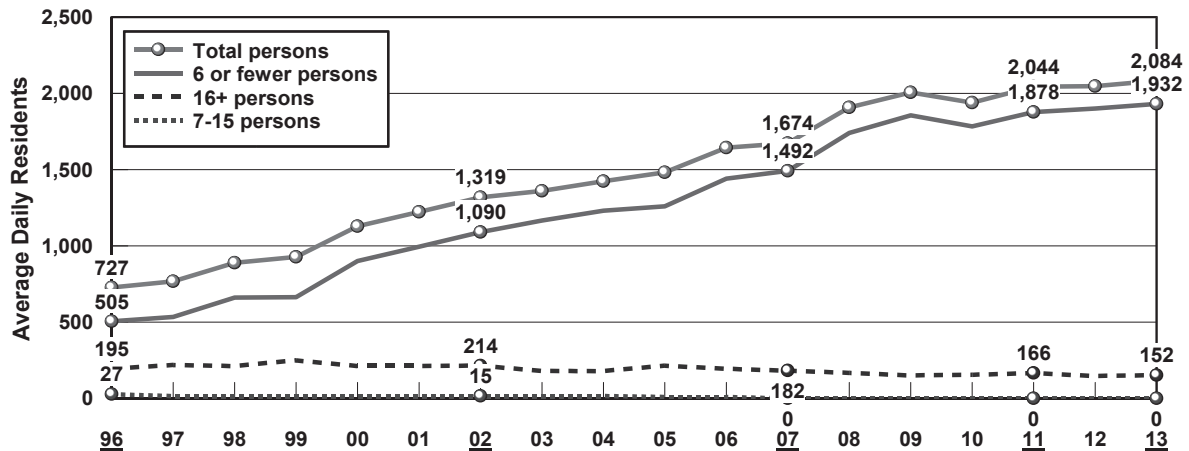
<http://stateofthestates.org>

NEVADA

PERSONS BY SETTING IN FISCAL YEAR 2013

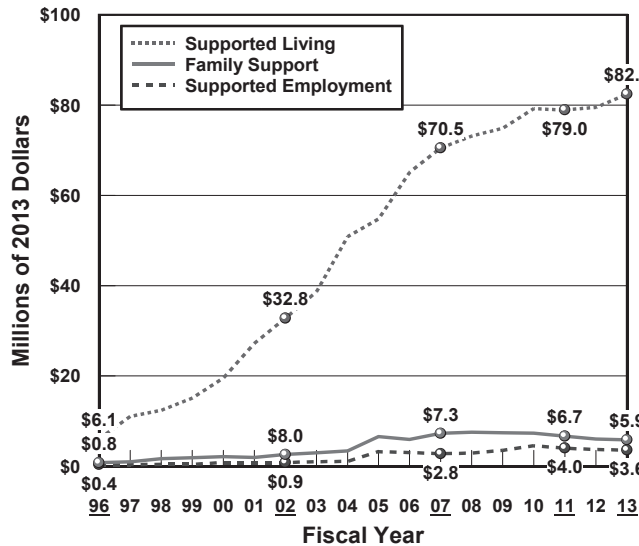


PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013

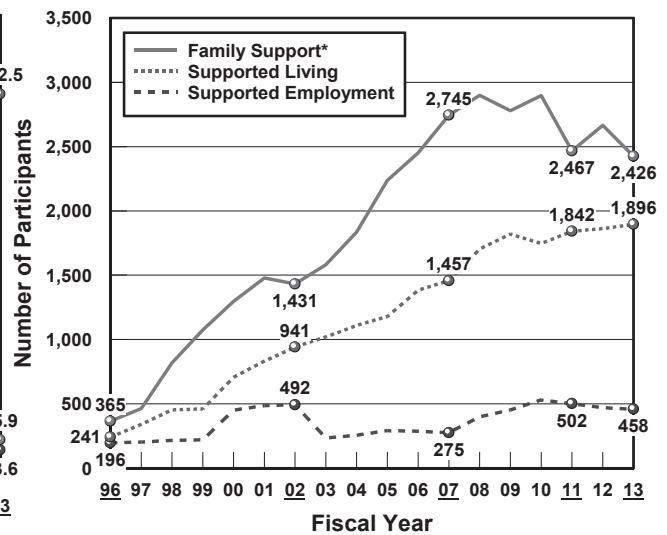


INDIVIDUAL AND FAMILY SUPPORT

SPENDING



PARTICIPANTS



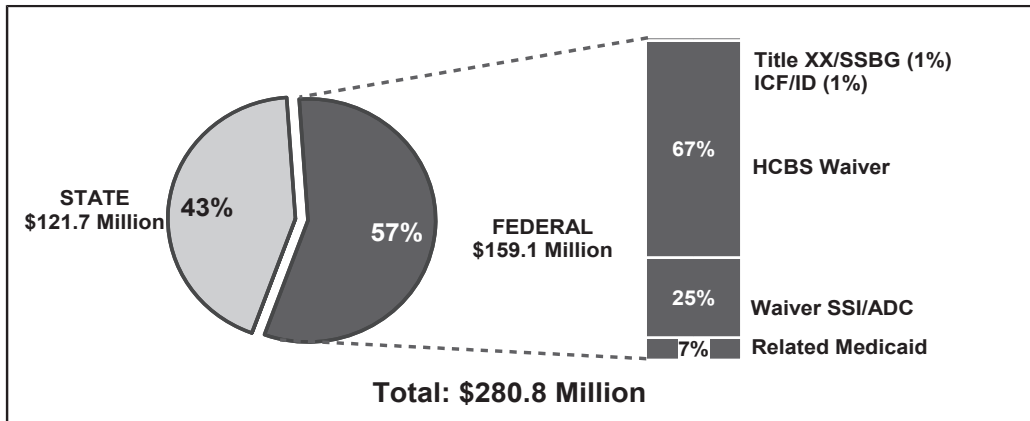
*State budget issues and a drop in poverty eligibility led to the 2011 drop in families supported; in addition, media reports on state budget problems may have deterred some families from applying.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

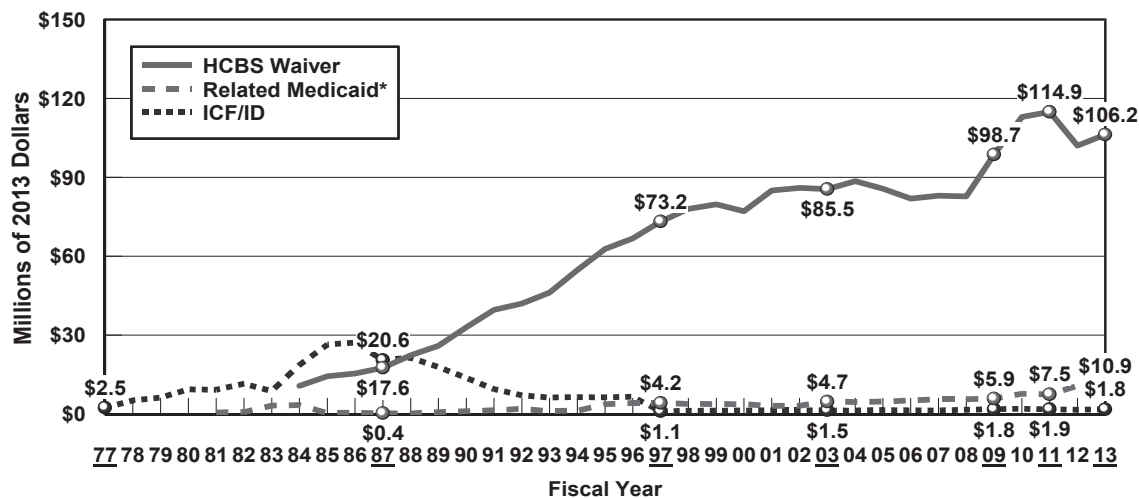
<http://stateofthestates.org>

NEW HAMPSHIRE

PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013

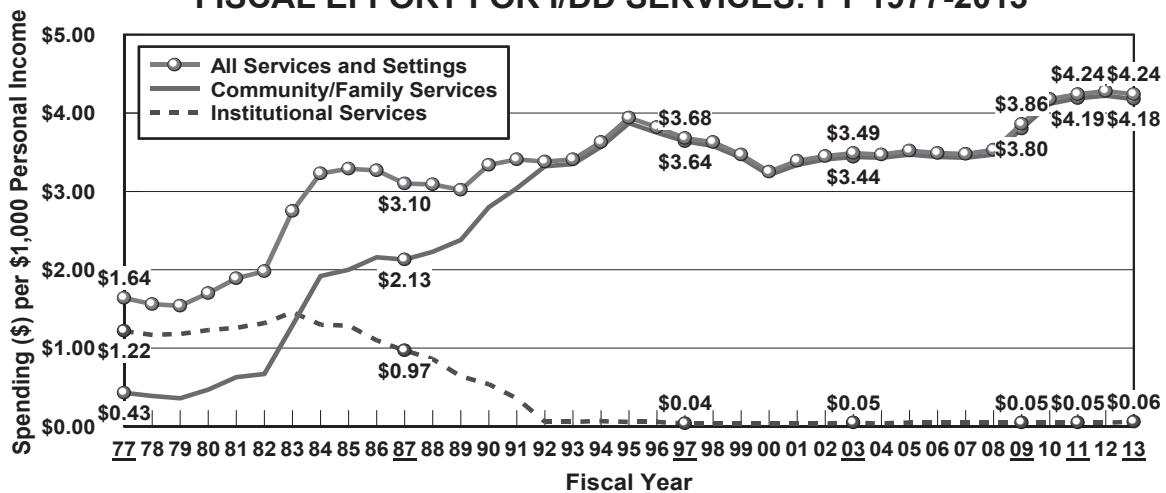


FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



* In 2013, "Related Medicaid" was rehabilitative services (\$8.9 million) and targeted case management (\$2.0 million).

FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013

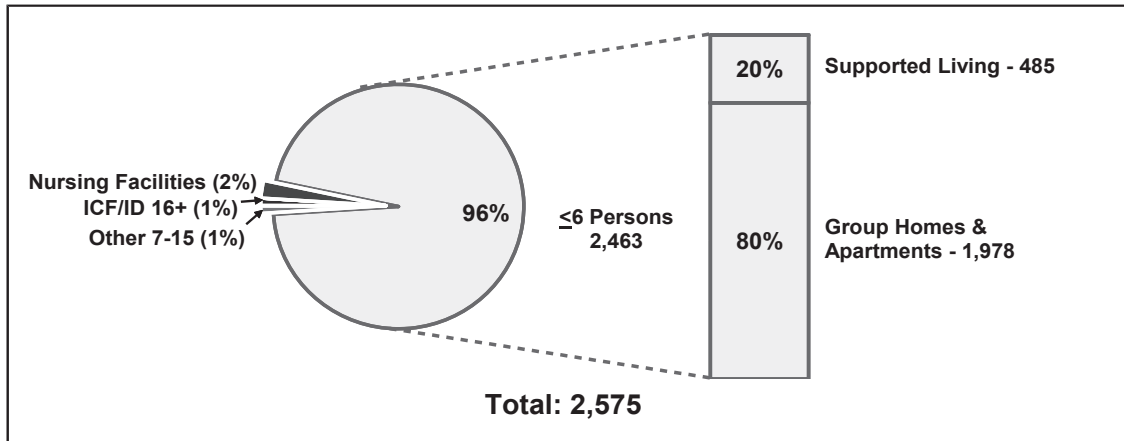


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

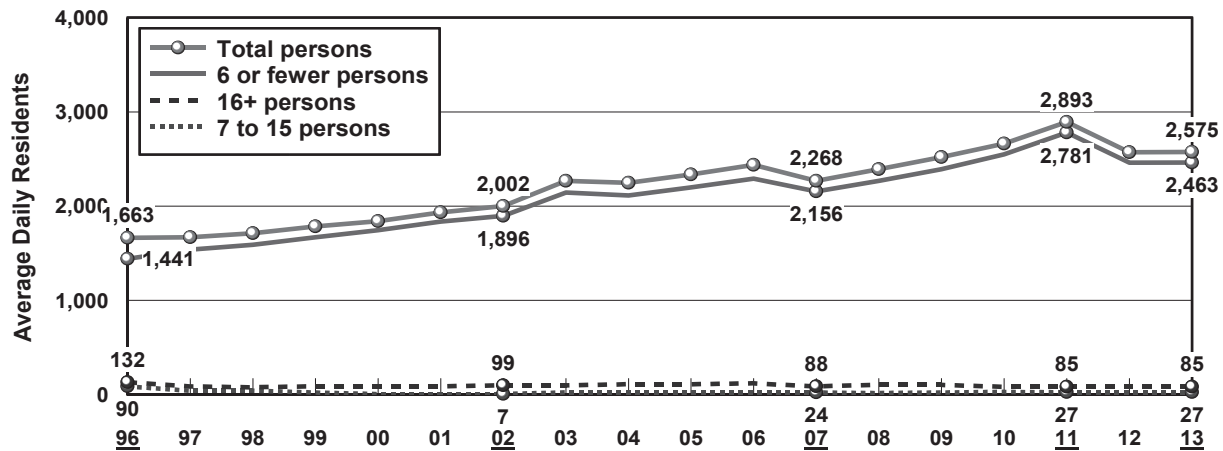
<http://stateofthestates.org>

NEW HAMPSHIRE

PERSONS BY SETTING IN FISCAL YEAR 2013

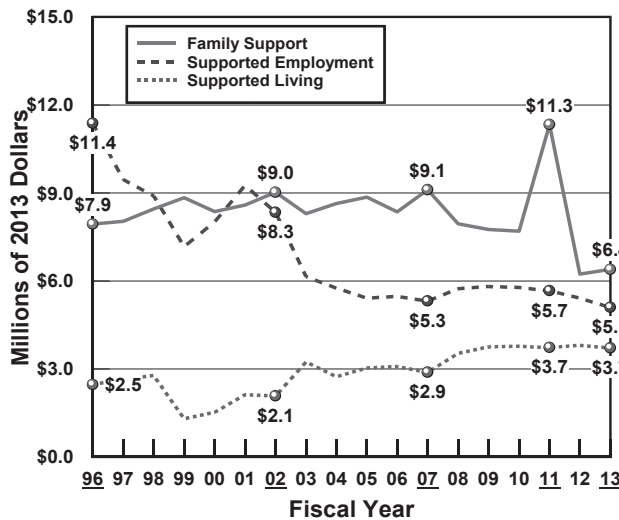


PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013

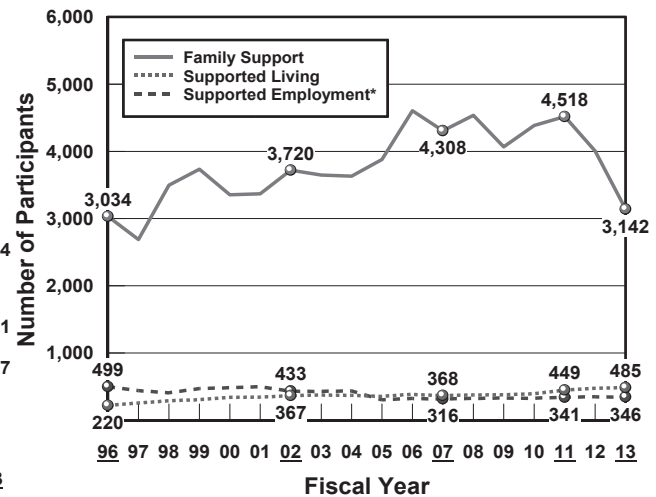


INDIVIDUAL AND FAMILY SUPPORT

SPENDING



PARTICIPANTS



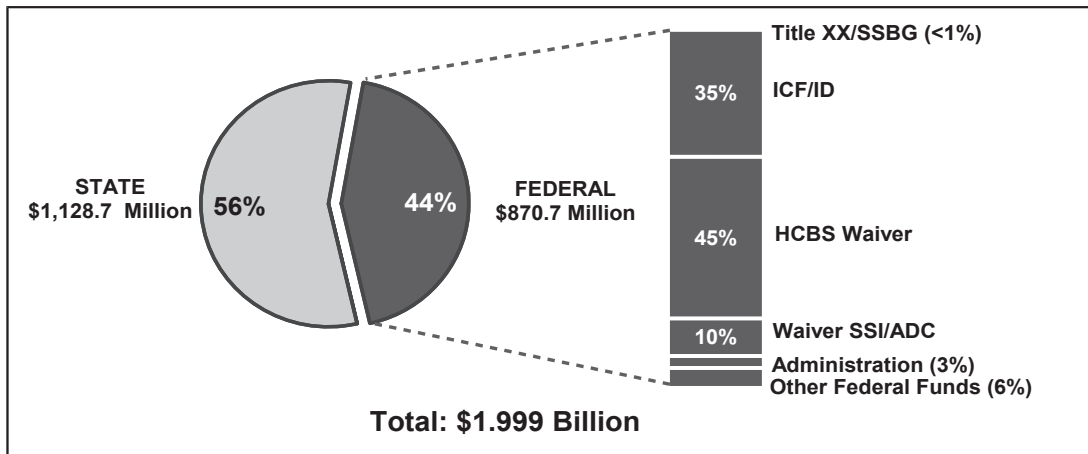
*Does not include 1,195 competitive employment workers in 2012 and 2013.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

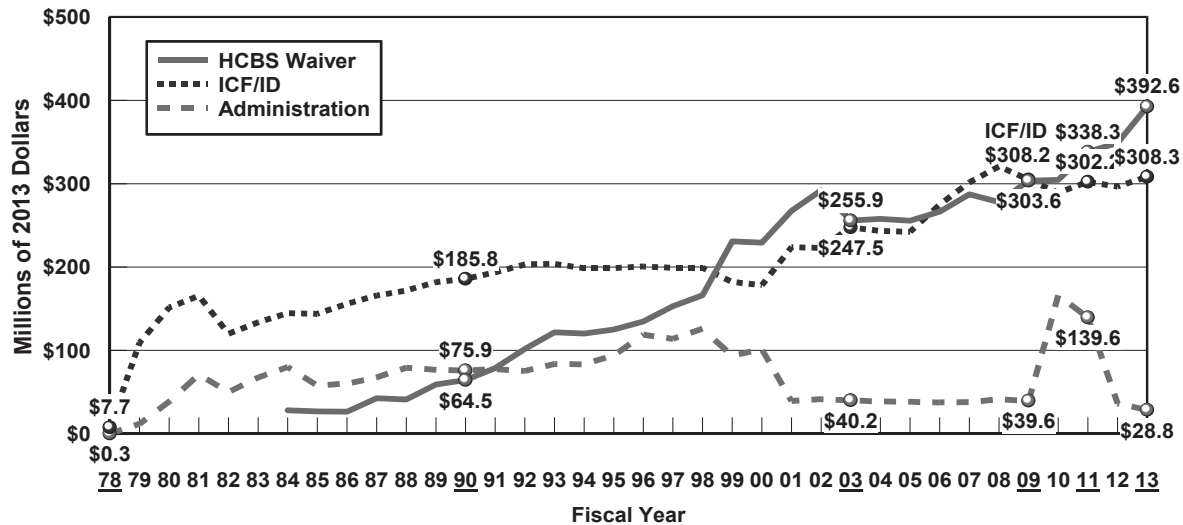
<http://stateofthestates.org>

NEW JERSEY

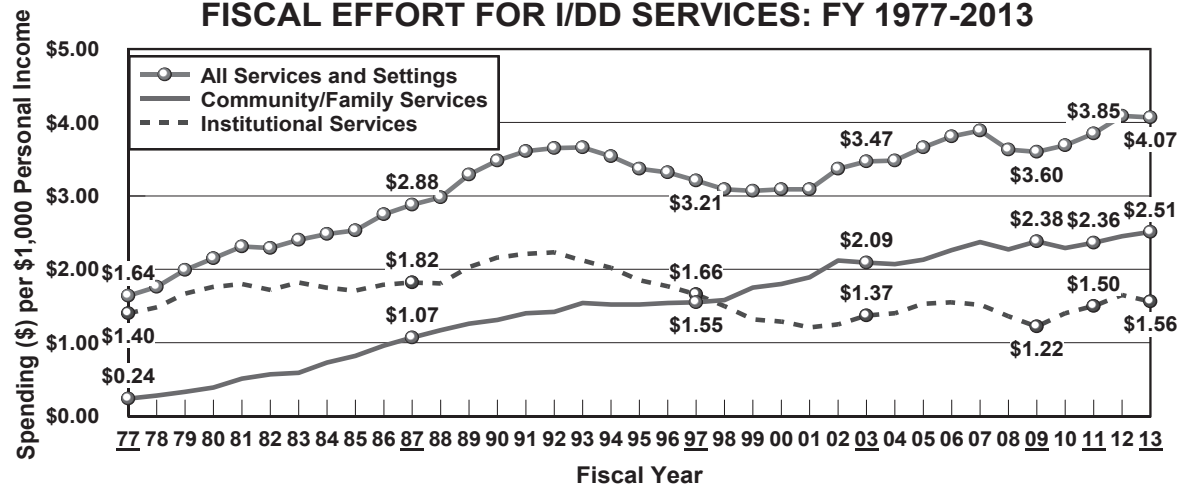
PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013



FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013

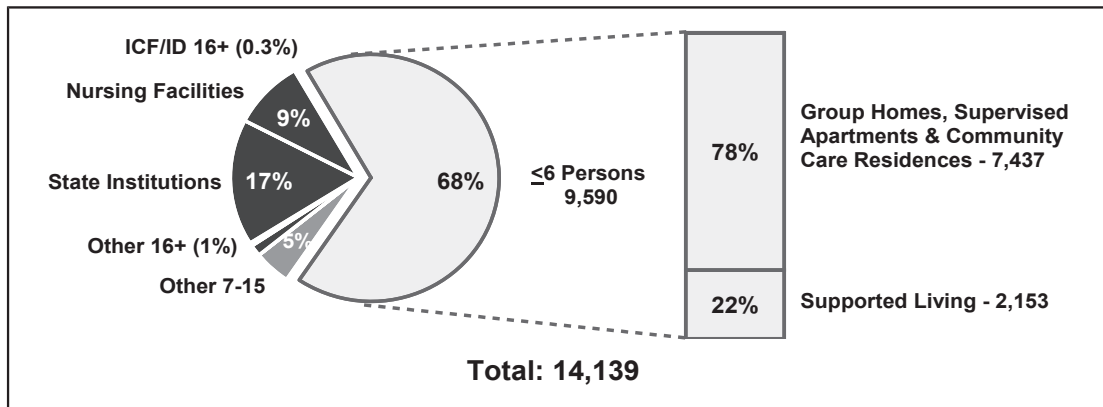


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

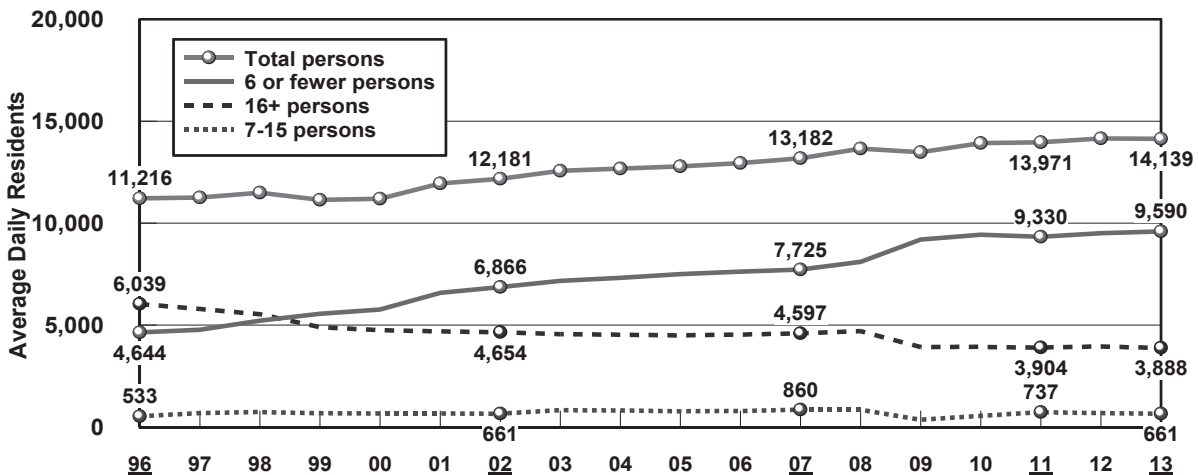
<http://stateofthestates.org>

NEW JERSEY

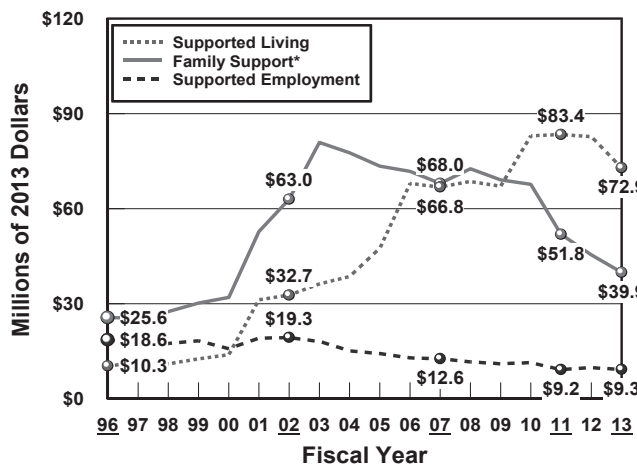
PERSONS BY SETTING IN FISCAL YEAR 2013



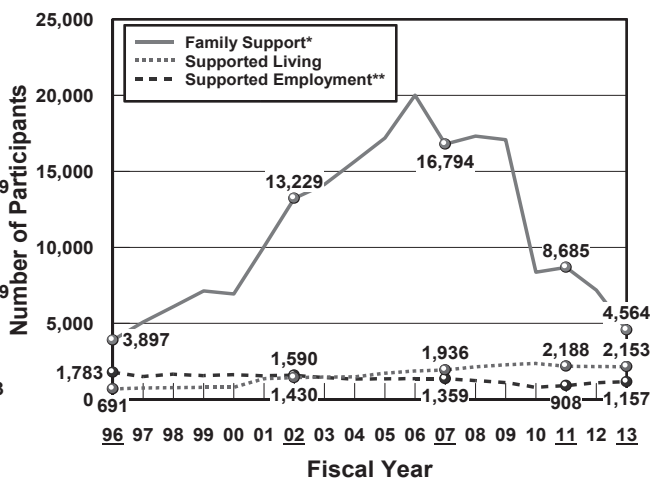
PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013



INDIVIDUAL AND FAMILY SUPPORT SPENDING PARTICIPANTS



*In 2009, cash subsidies were terminated, and many families began receiving Division of Disability Services Information & Referral Services (non-I/DD agency supports) to meet their needs.



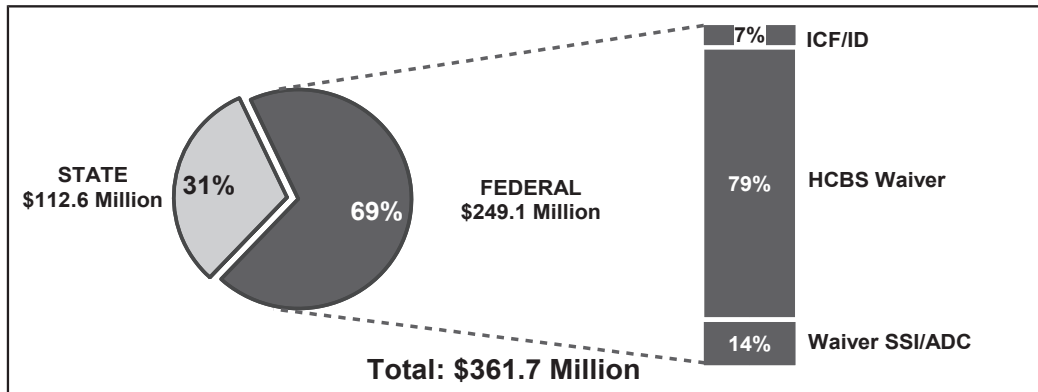
**Does not include 1,237 follow-along work support workers in 2012 and 1,101 workers in 2013.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

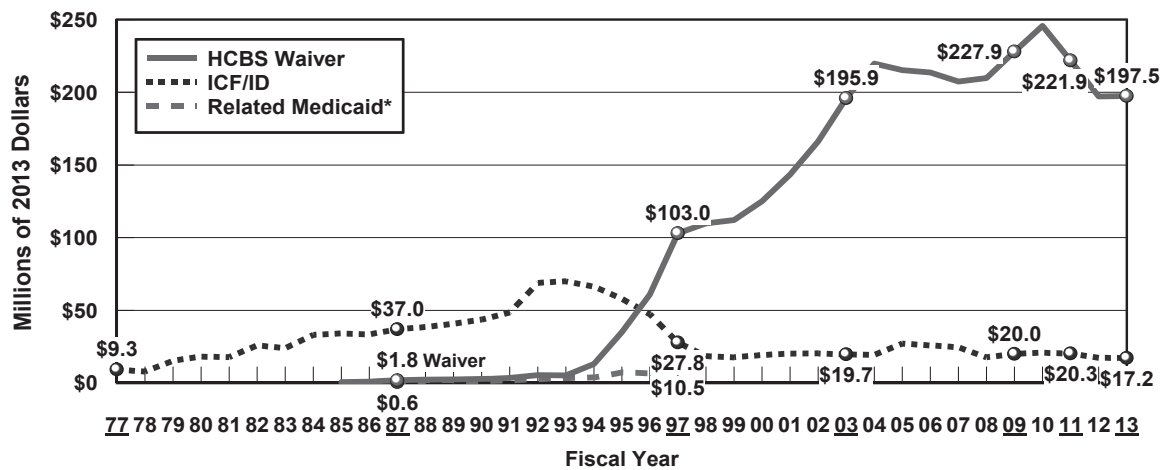
<http://stateofthestates.org>

NEW MEXICO

PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013

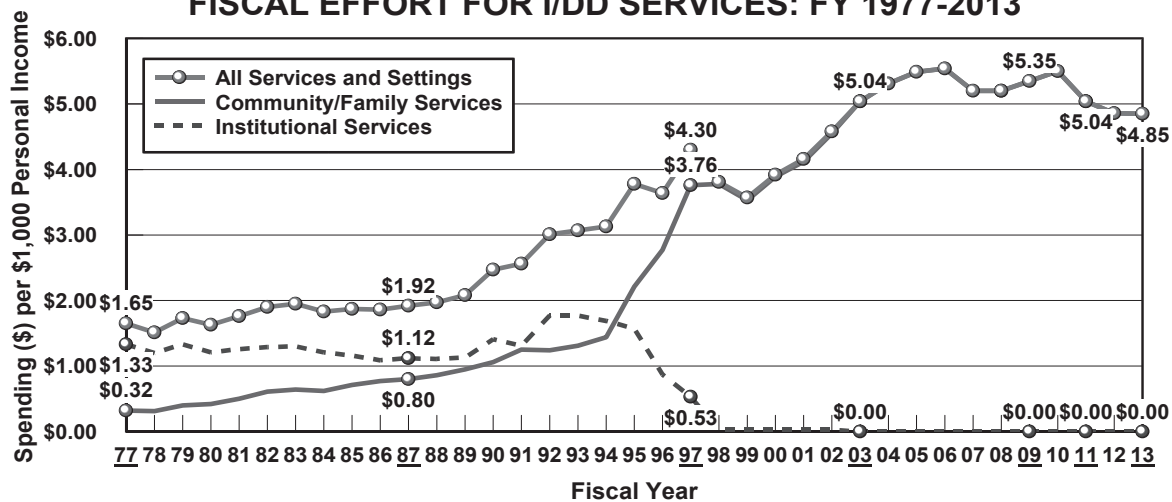


FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



*In 1997, "Related Medicaid" was Model 50/200 Waiver (\$4.6 million), administration (\$4.6 million) and targeted case management (\$1.3 million). No related Medicaid spending reported 1999-2013.

FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013

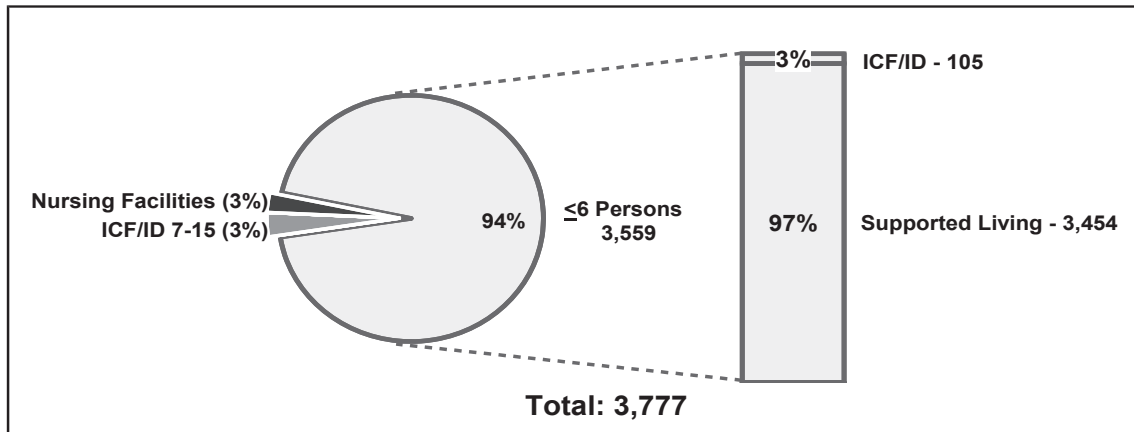


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

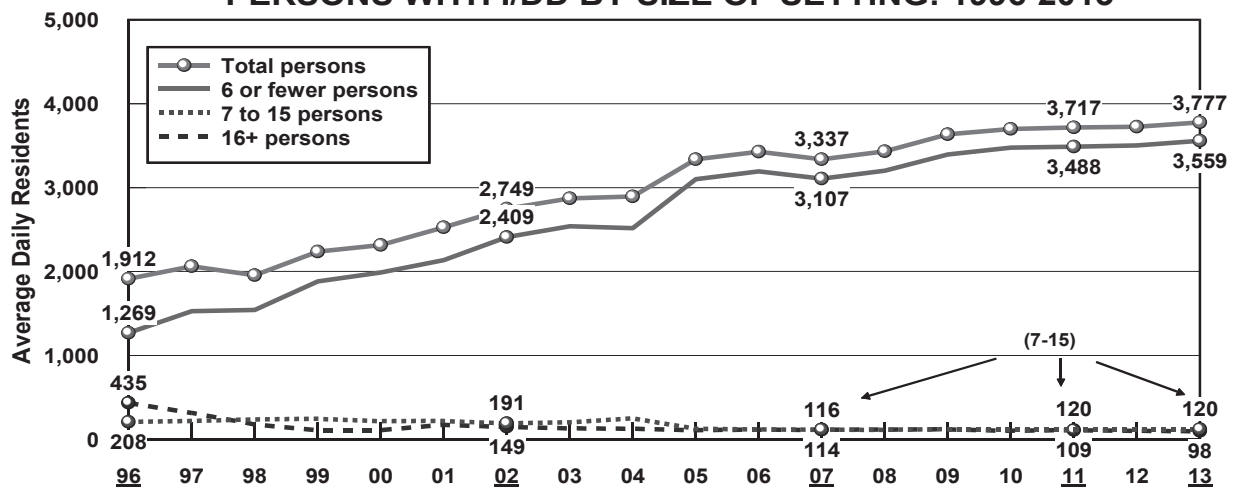
<http://stateofthestates.org>

NEW MEXICO

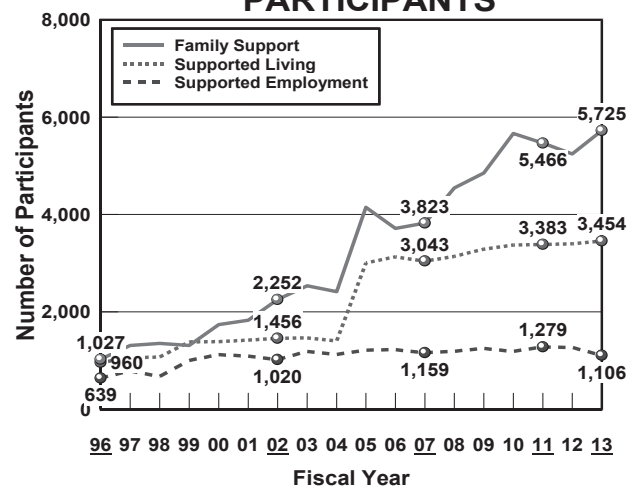
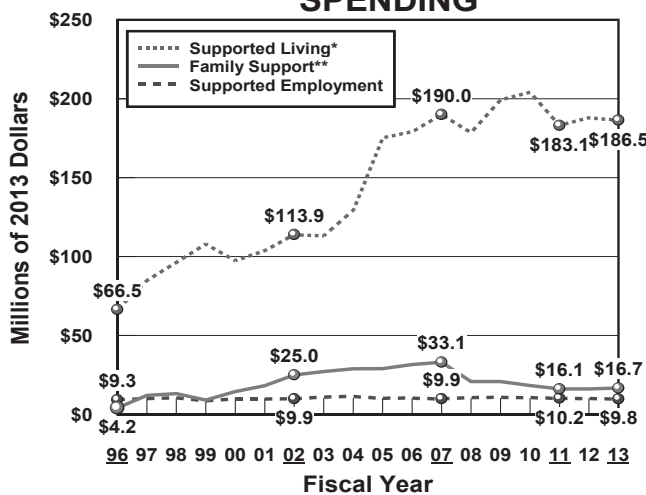
PERSONS BY SETTING IN FISCAL YEAR 2013



PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013



INDIVIDUAL AND FAMILY SUPPORT PARTICIPANTS



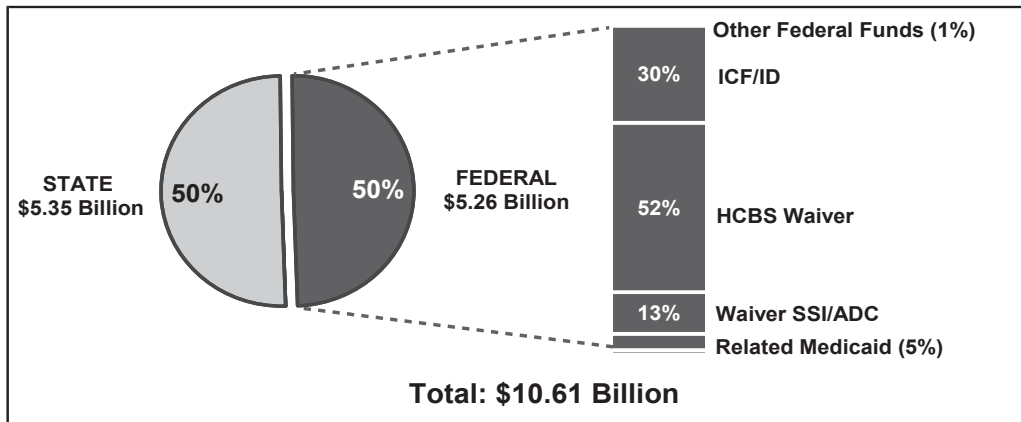
*In 2011 the State reduced Supported Living provider rates.

**State reduced General Funds for cash subsidies in 2010-11.

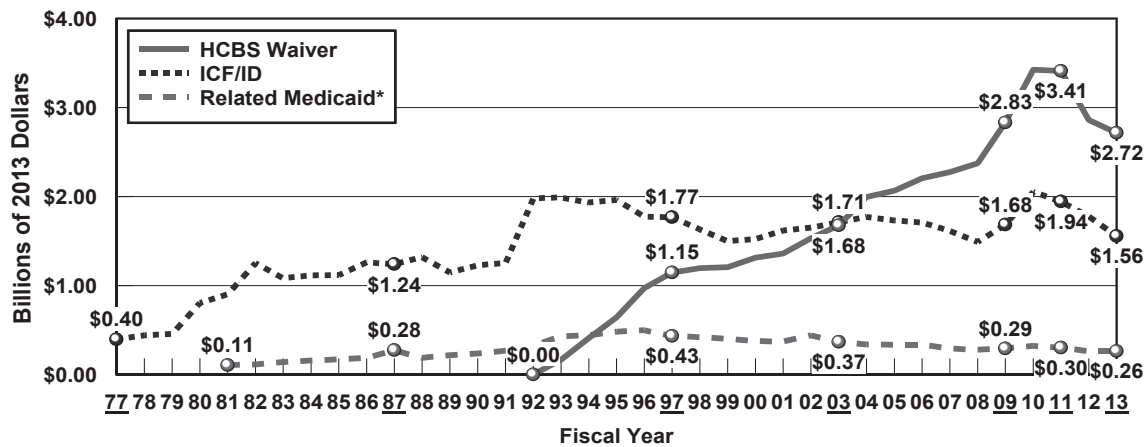
Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.
<http://stateofthestates.org>

NEW YORK

PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013

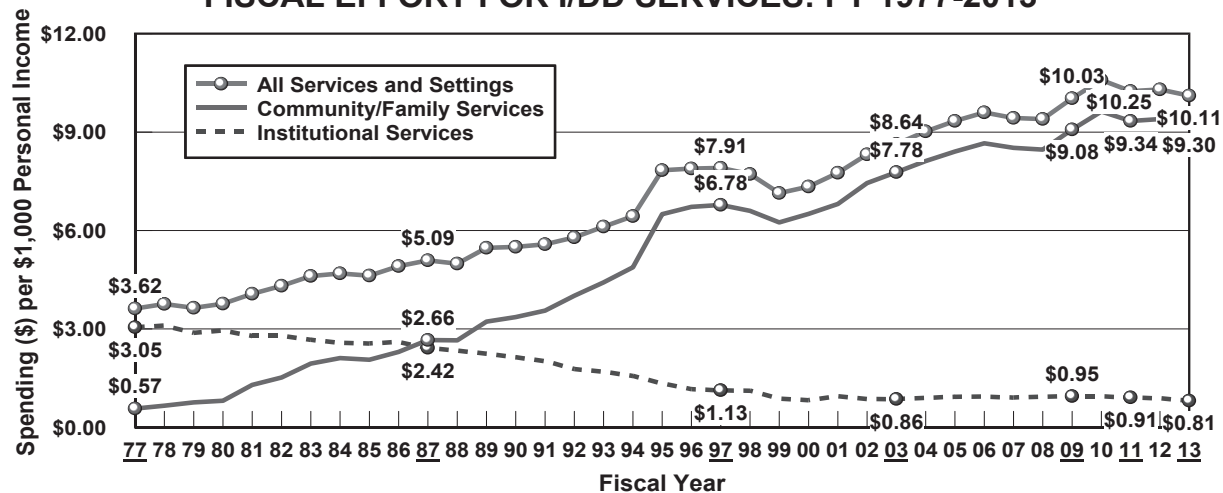


FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



*In 2013, "Related Medicaid" included targeted case management (\$106.5 million), personal assistant (\$92.6 million), administration (\$64.1 million) and clinic rehabilitation (\$0.11 million).

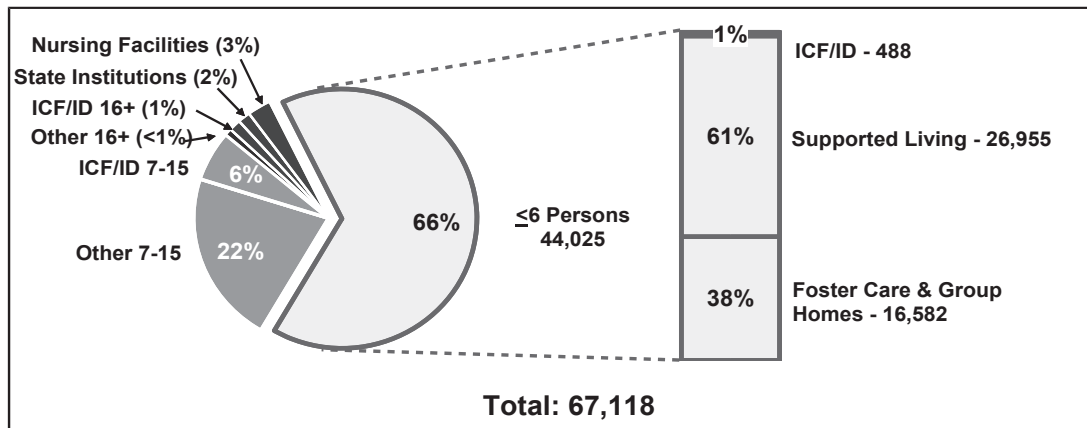
FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013



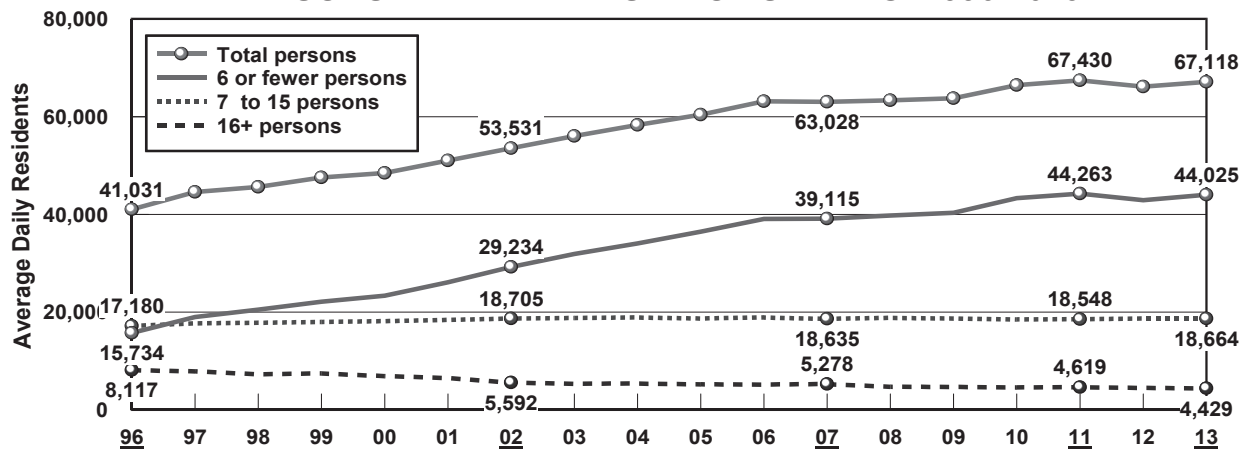
Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.
<http://stateofthestates.org>

NEW YORK

PERSONS BY SETTING IN FISCAL YEAR 2013

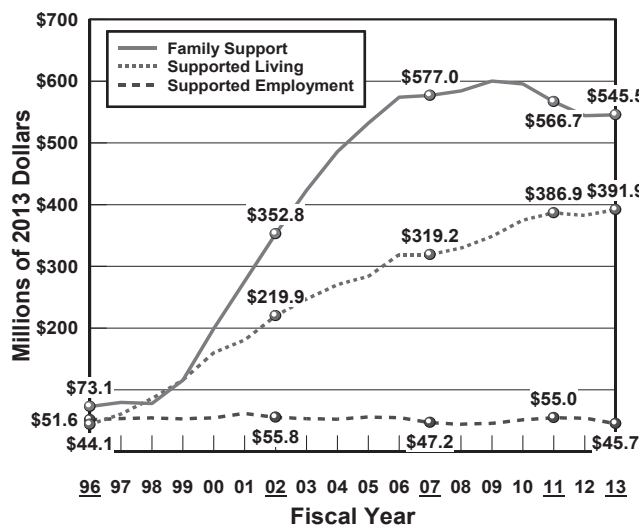


PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013

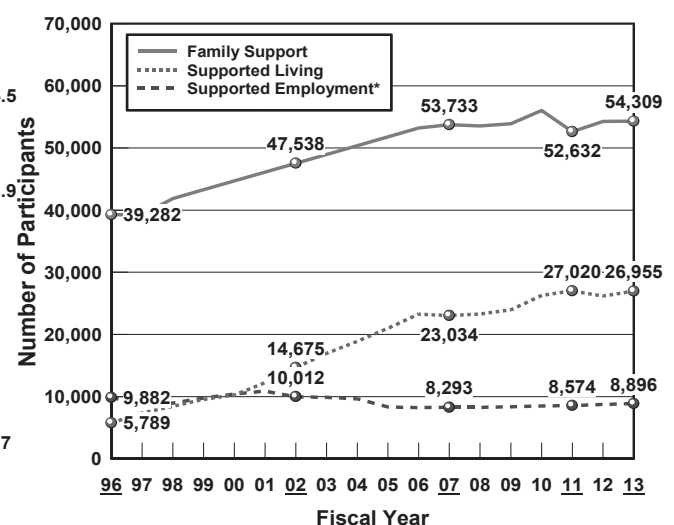


INDIVIDUAL AND FAMILY SUPPORT

SPENDING



PARTICIPANTS



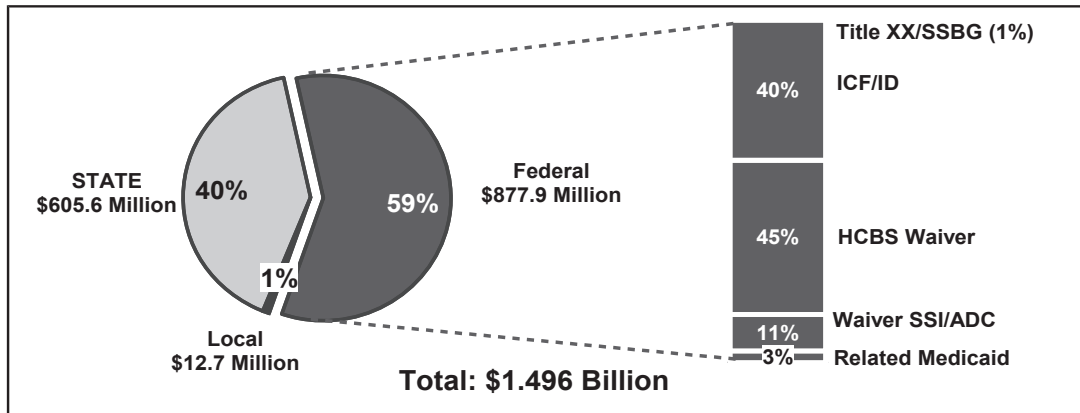
*Does not include 495 follow-along work support workers in 2012 and 566 in 2013.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

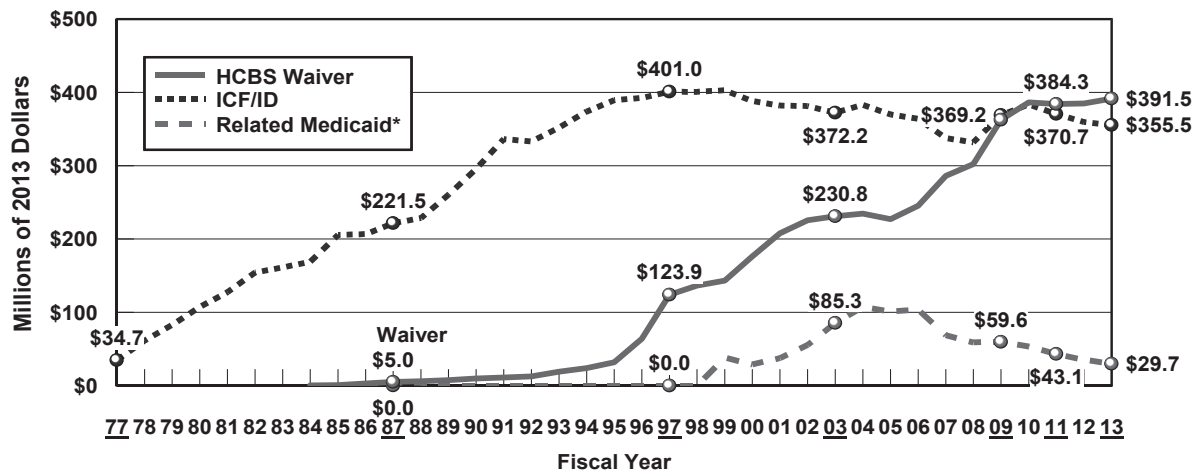
<http://stateofthestates.org>

NORTH CAROLINA

PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013

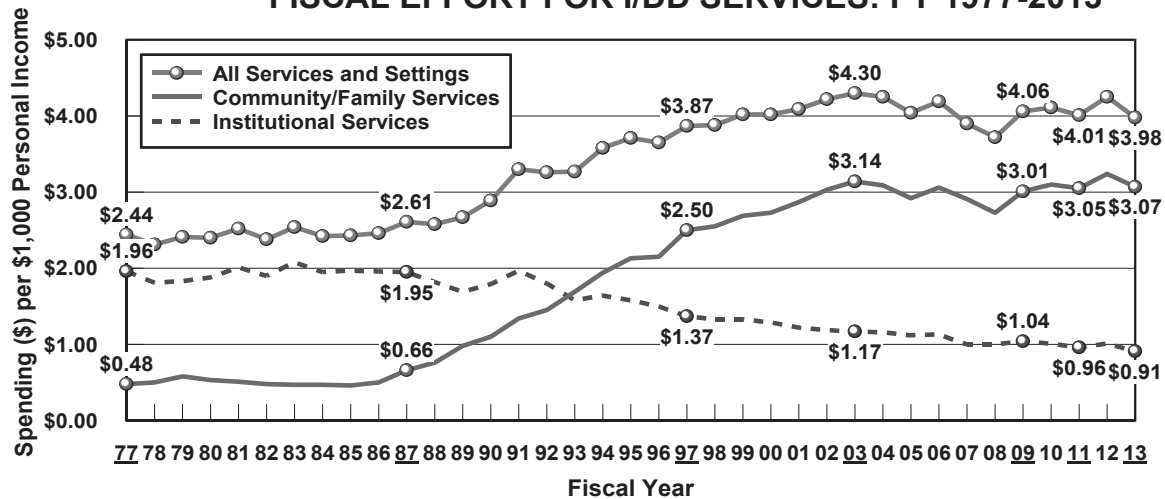


FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



* In 2013, "Related Medicaid" was rehabilitative services (\$7.0 million), targeted case management (\$22.2 million), and administration (\$0.5 million).

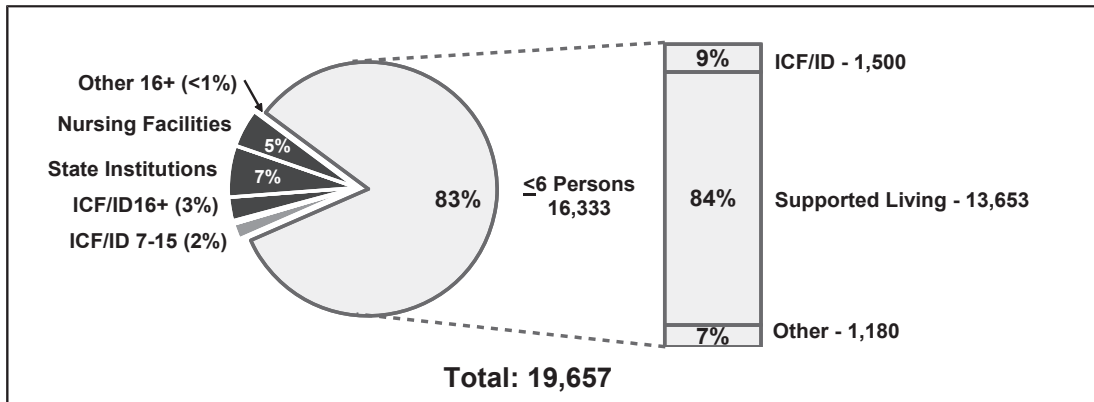
FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013



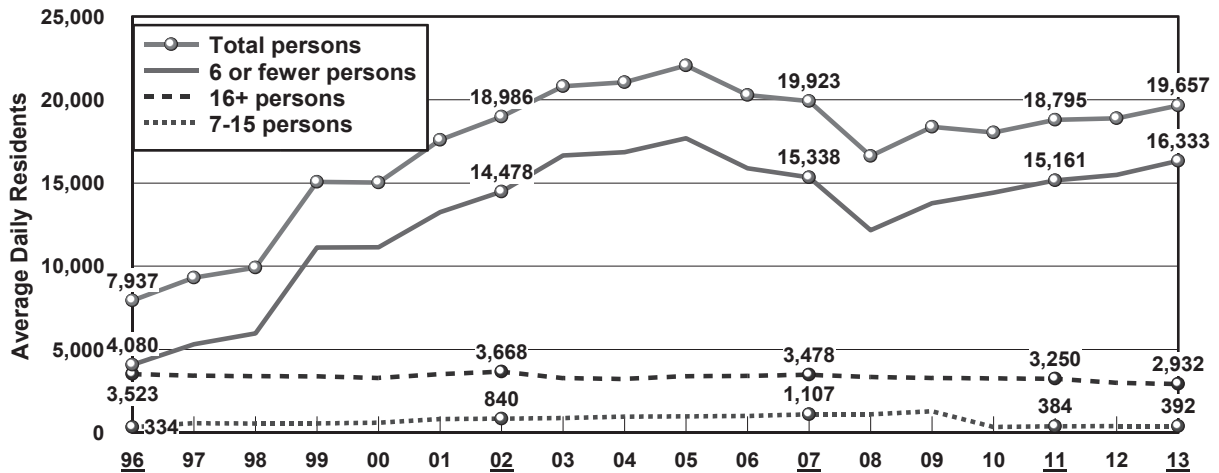
Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.
<http://stateofthestates.org>

NORTH CAROLINA

PERSONS BY SETTING IN FISCAL YEAR 2013

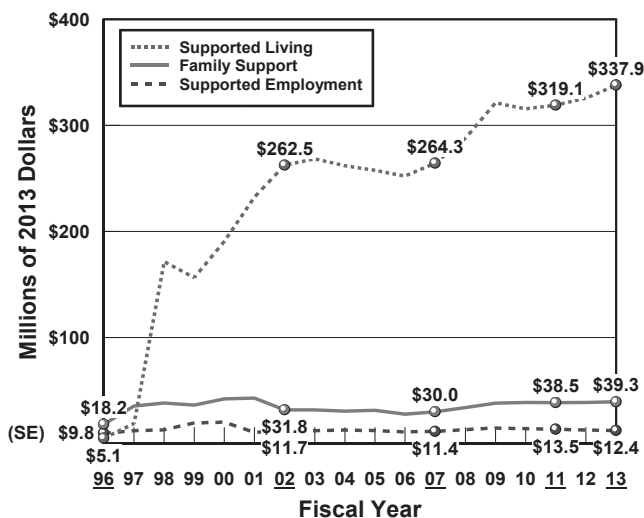


PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013

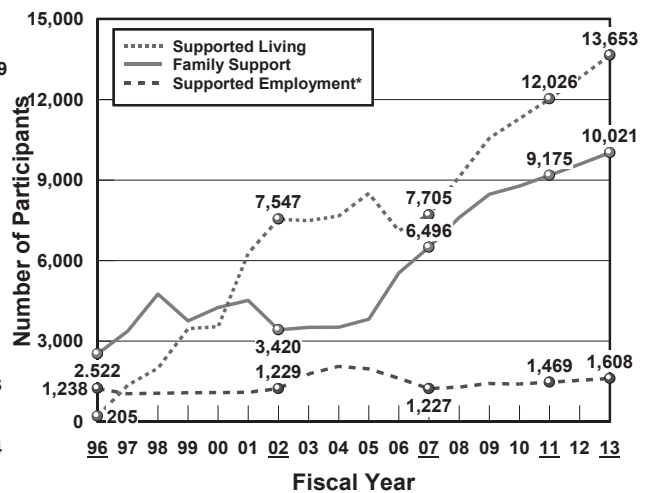


INDIVIDUAL AND FAMILY SUPPORT

SPENDING



PARTICIPANTS



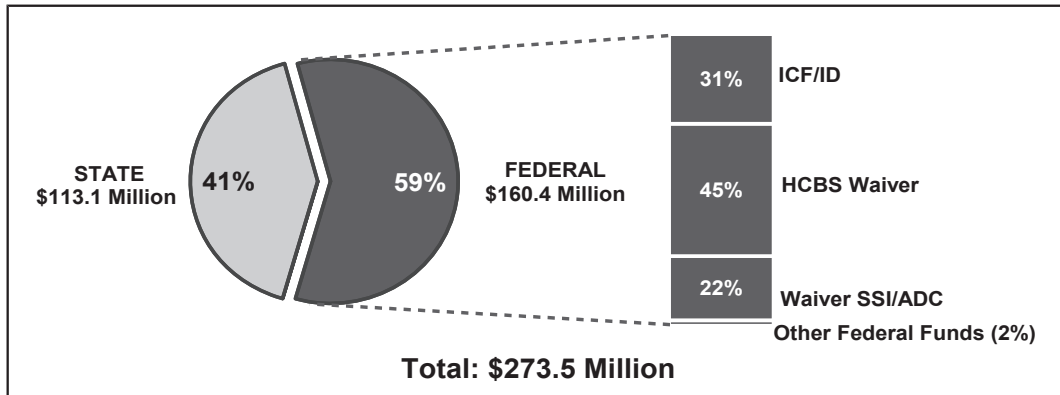
*Does not include 1,663 follow-along work support workers in 2012 and 1,686 workers in 2013.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

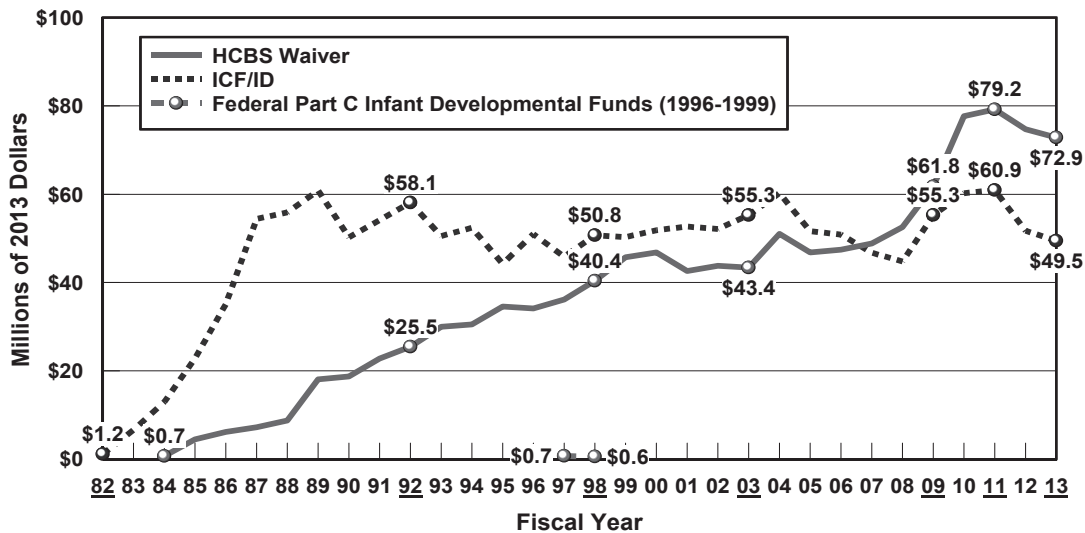
<http://stateofthestates.org>

NORTH DAKOTA

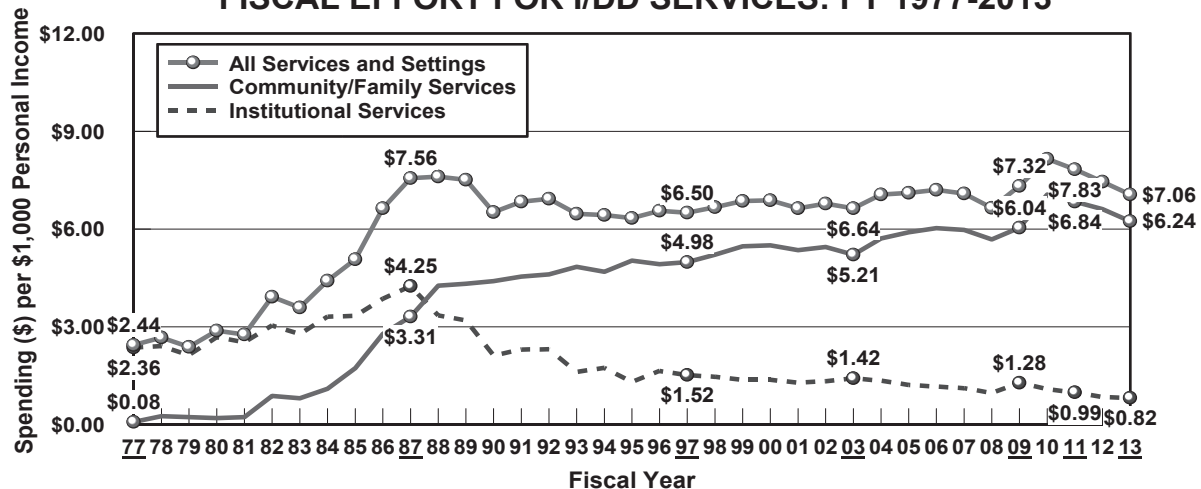
PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013



FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013

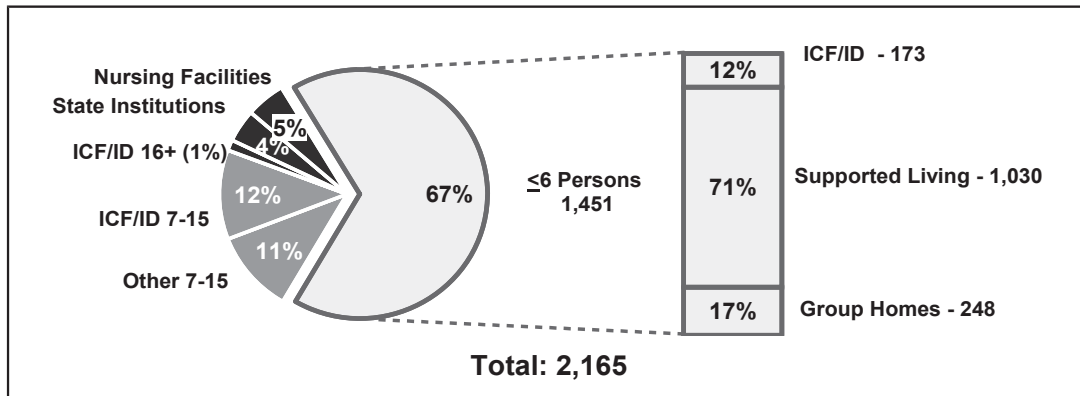


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

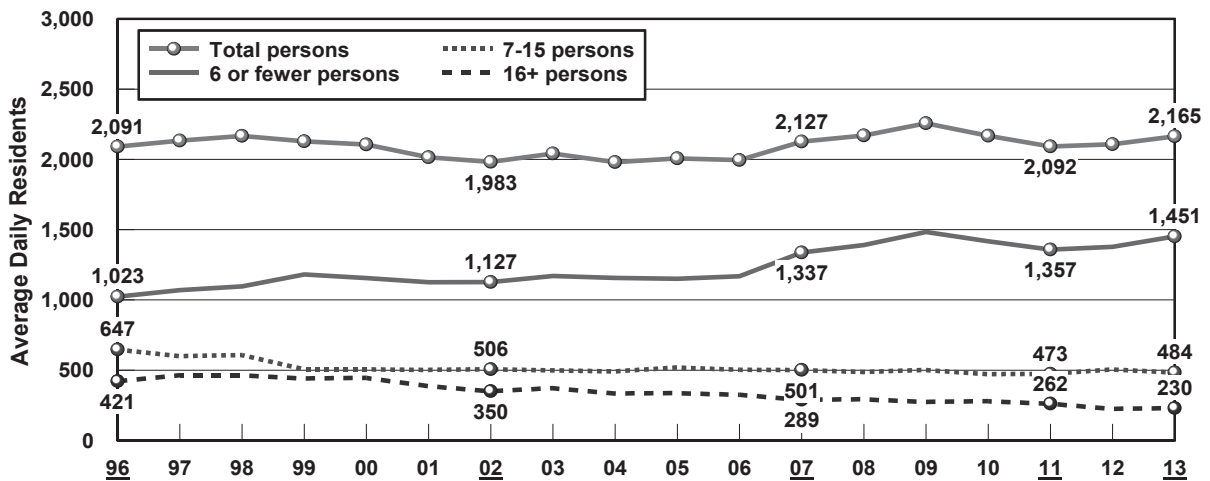
<http://stateofthestates.org>

NORTH DAKOTA

PERSONS BY SETTING IN FISCAL YEAR 2013

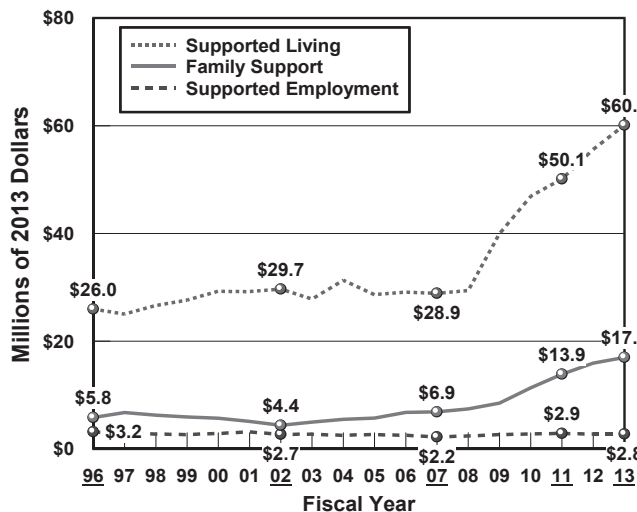


PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013

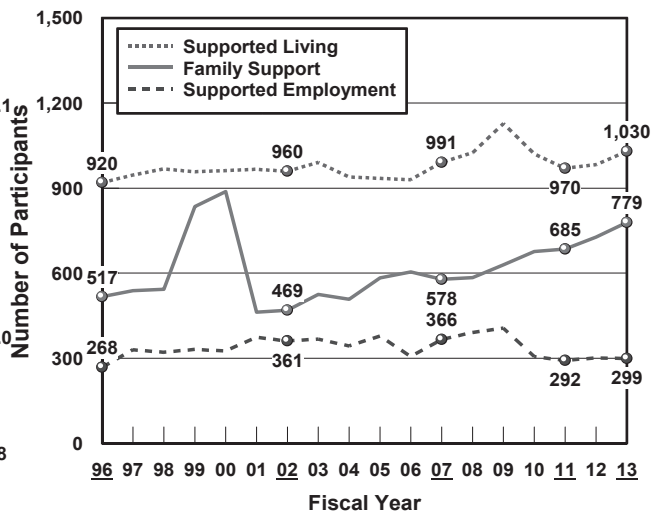


INDIVIDUAL AND FAMILY SUPPORT

SPENDING



PARTICIPANTS

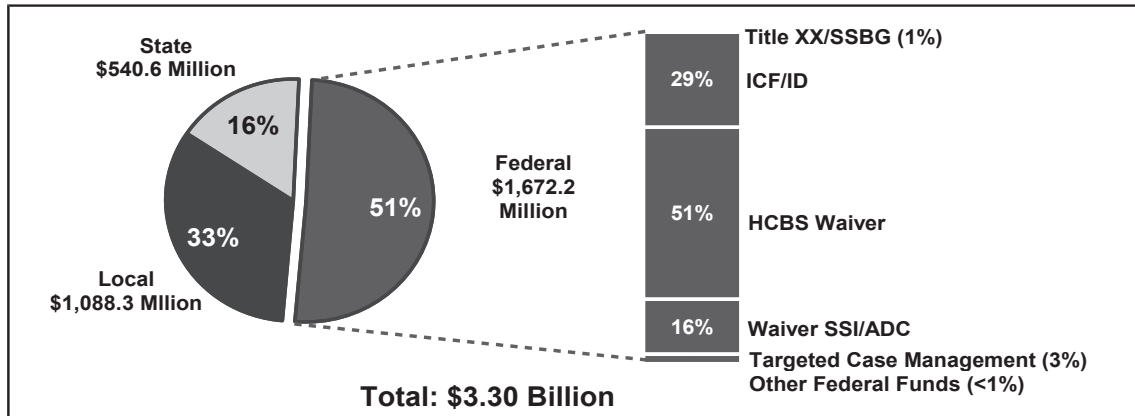


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

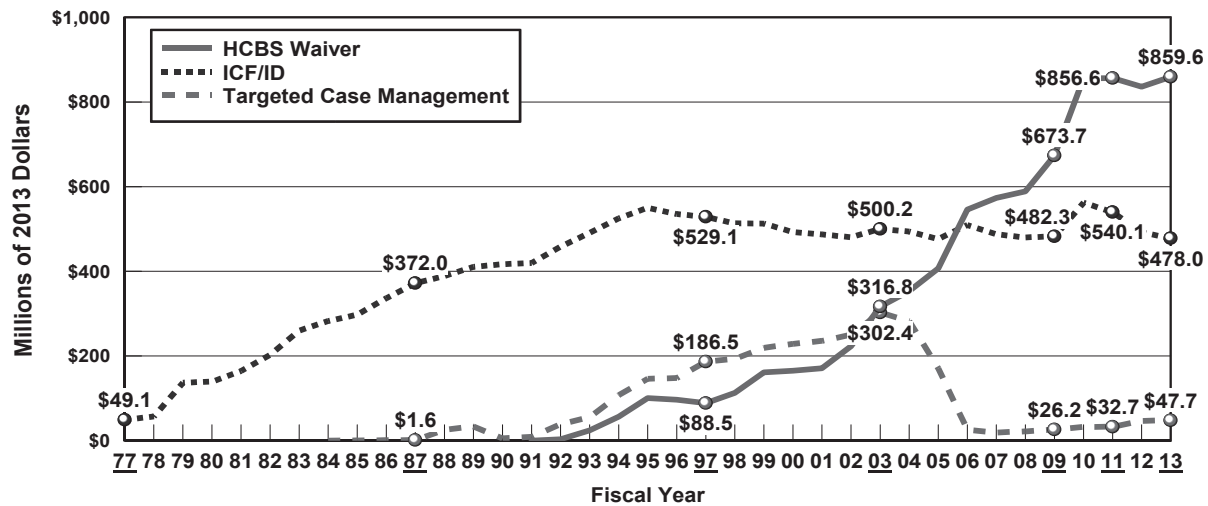
<http://stateofthestates.org>

OHIO

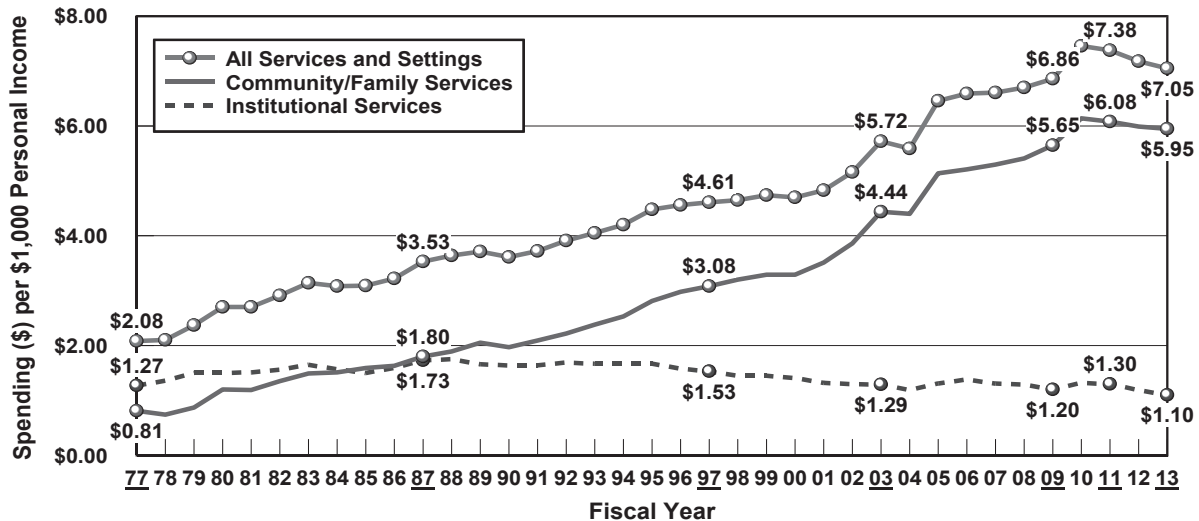
PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013



FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013

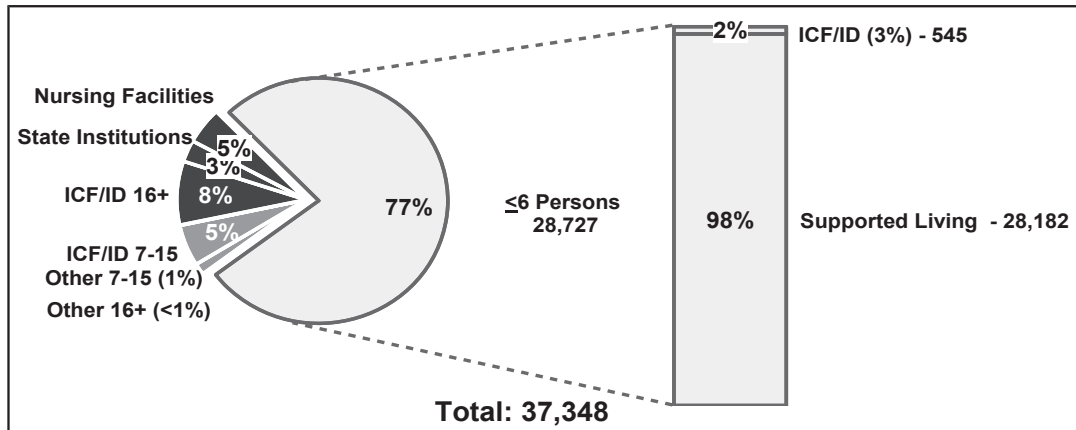


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

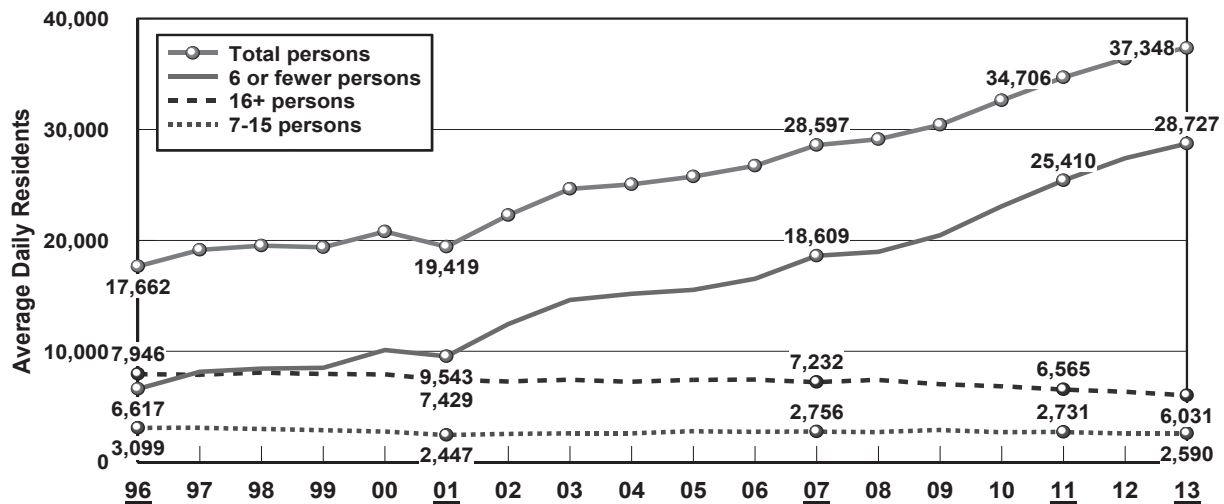
<http://stateofthestates.org>

OHIO

PERSONS BY SETTING IN FISCAL YEAR 2013

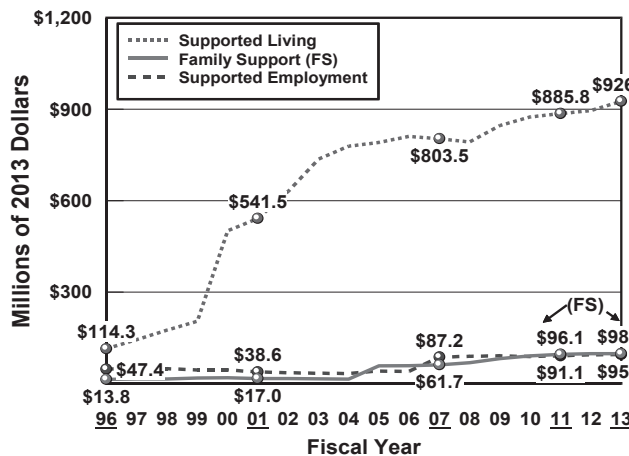


PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013

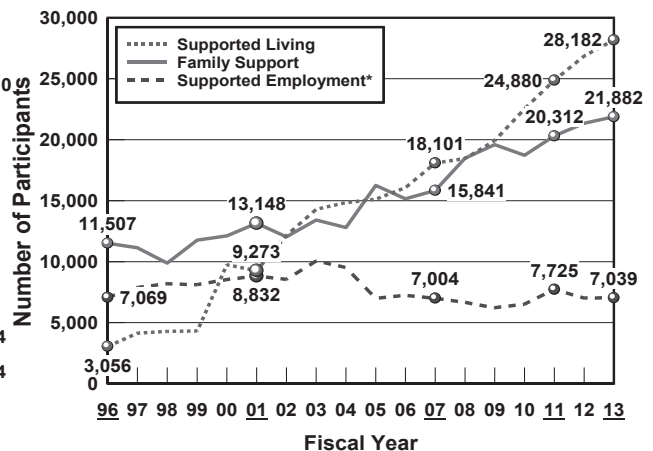


INDIVIDUAL AND FAMILY SUPPORT

SPENDING



PARTICIPANTS



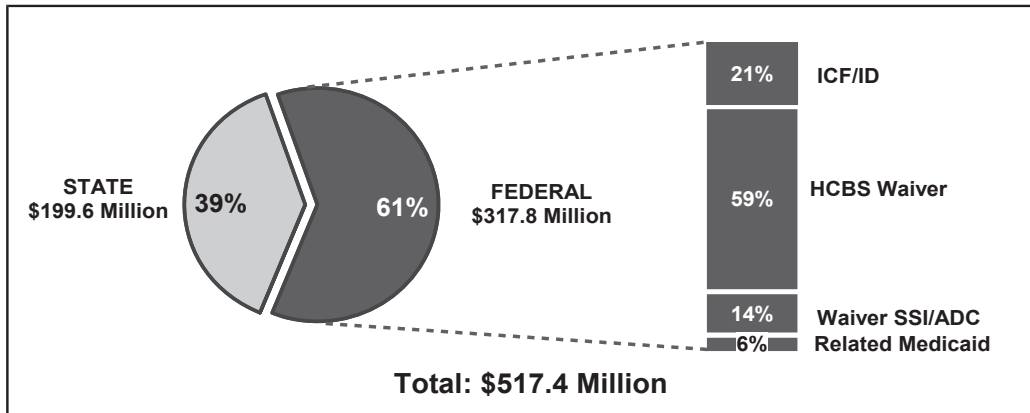
*Does not include 279 follow-along work support workers in 2012 and 412 workers in 2013.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

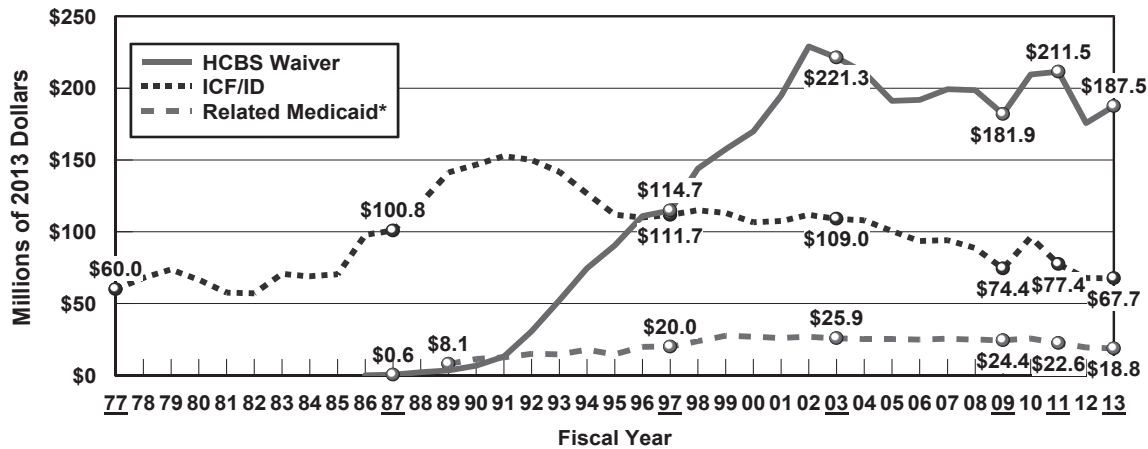
<http://stateofthestates.org>

OKLAHOMA

PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013

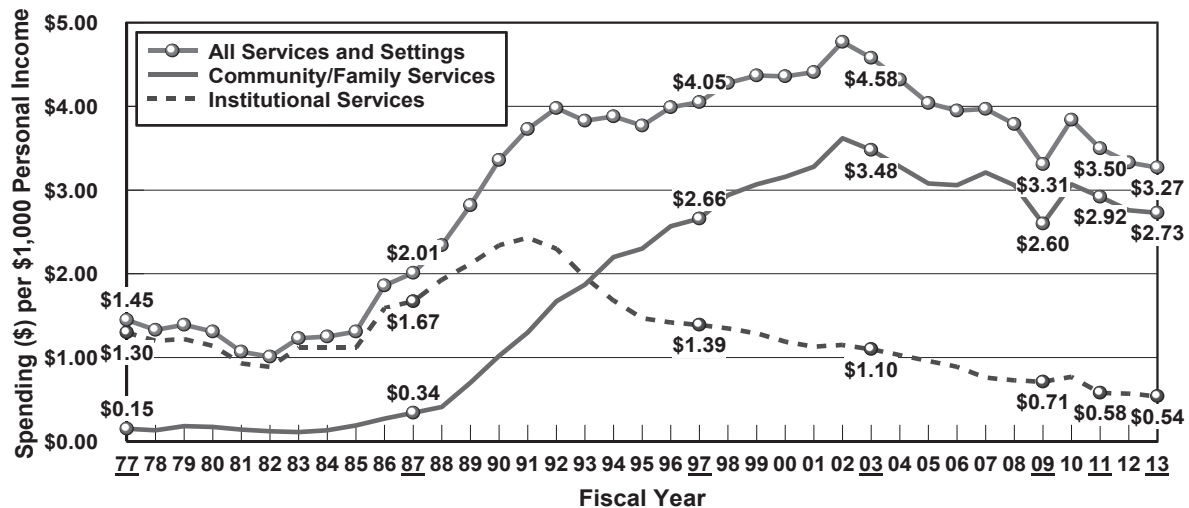


FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



*In 2013, "Related Medicaid" was targeted case management (\$11.3 million) and administration (\$7.5 million).

FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013

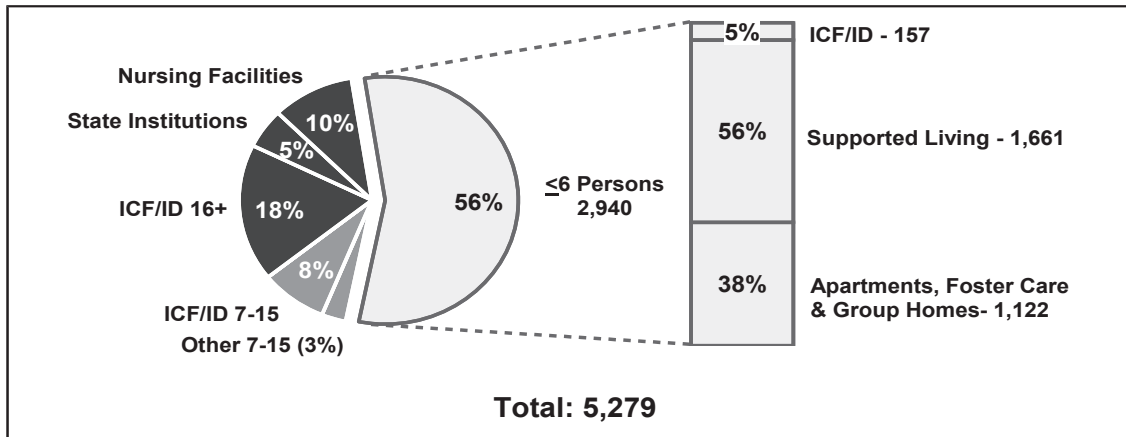


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

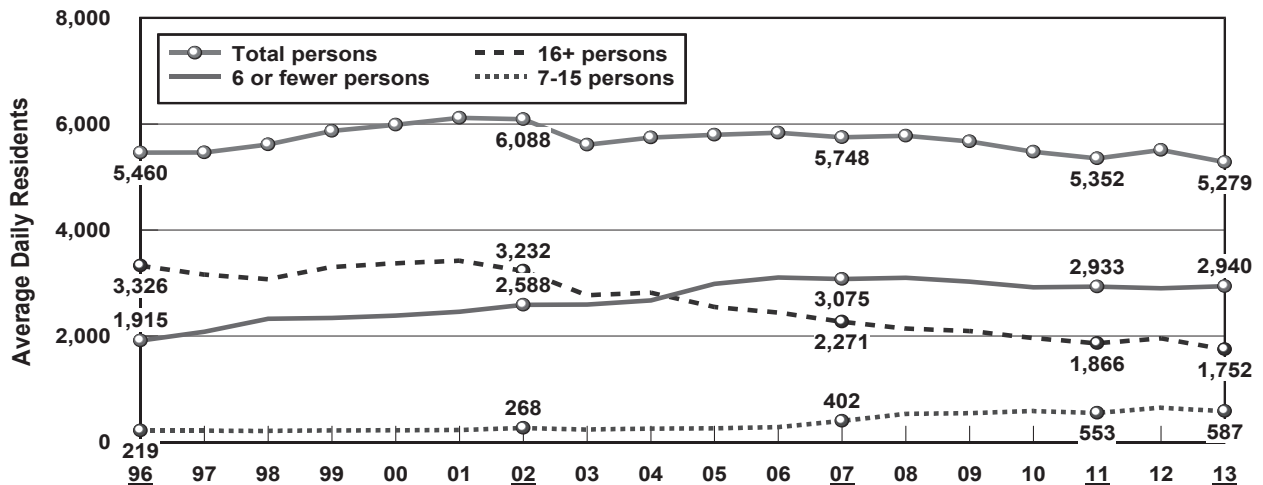
<http://stateofthestates.org>

OKLAHOMA

PERSONS BY SETTING IN FISCAL YEAR 2013

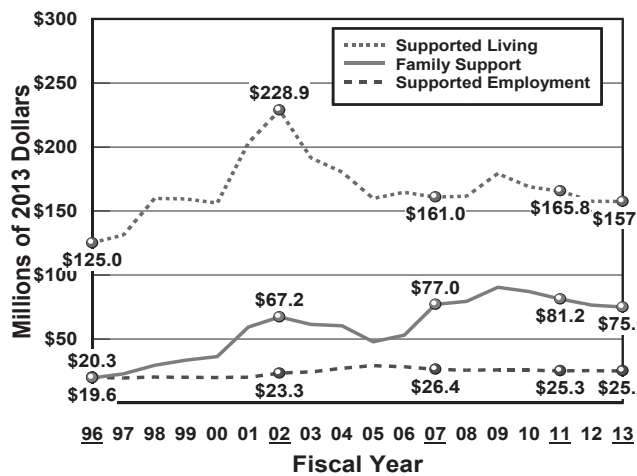


PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013

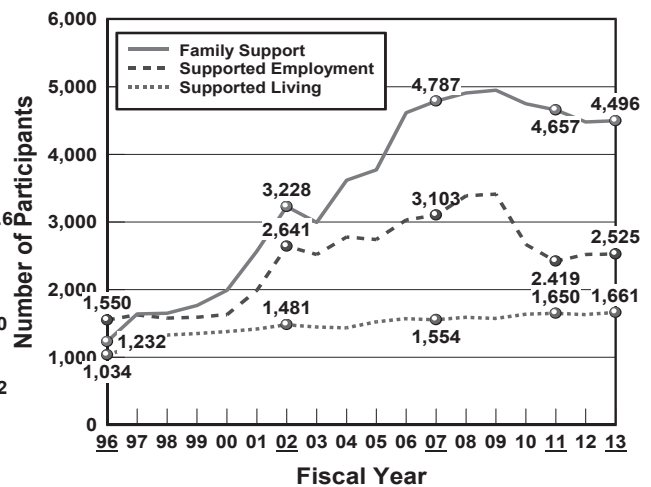


INDIVIDUAL AND FAMILY SUPPORT

SPENDING



PARTICIPANTS

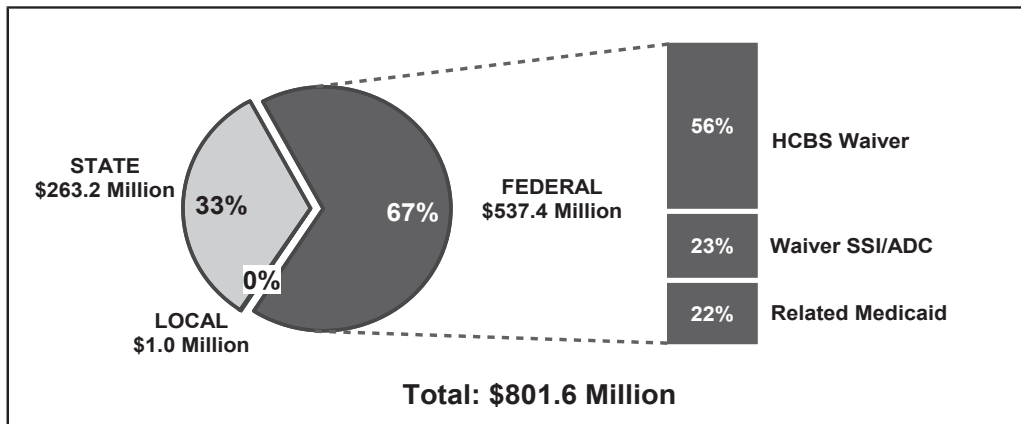


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

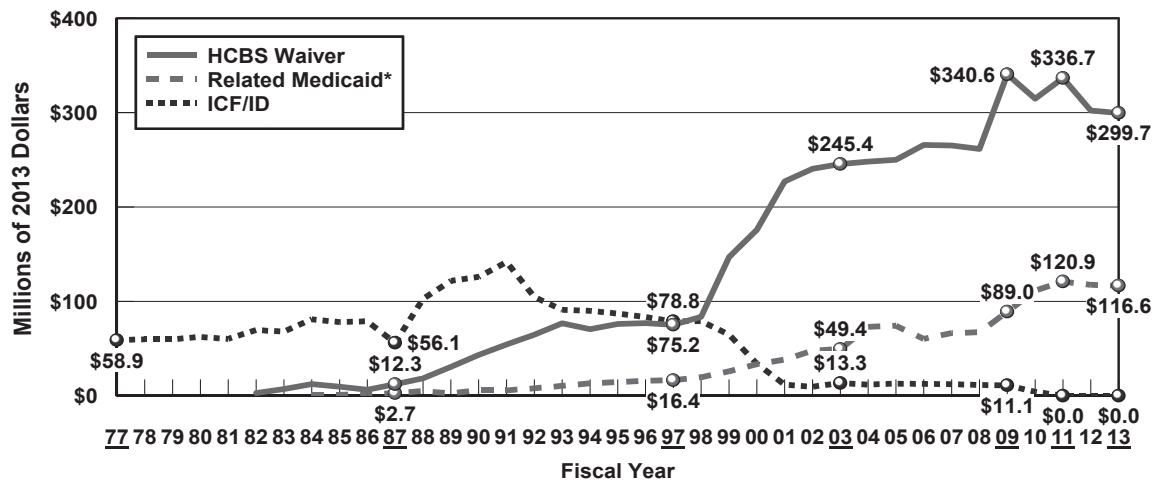
<http://stateofthestates.org>

OREGON

PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013

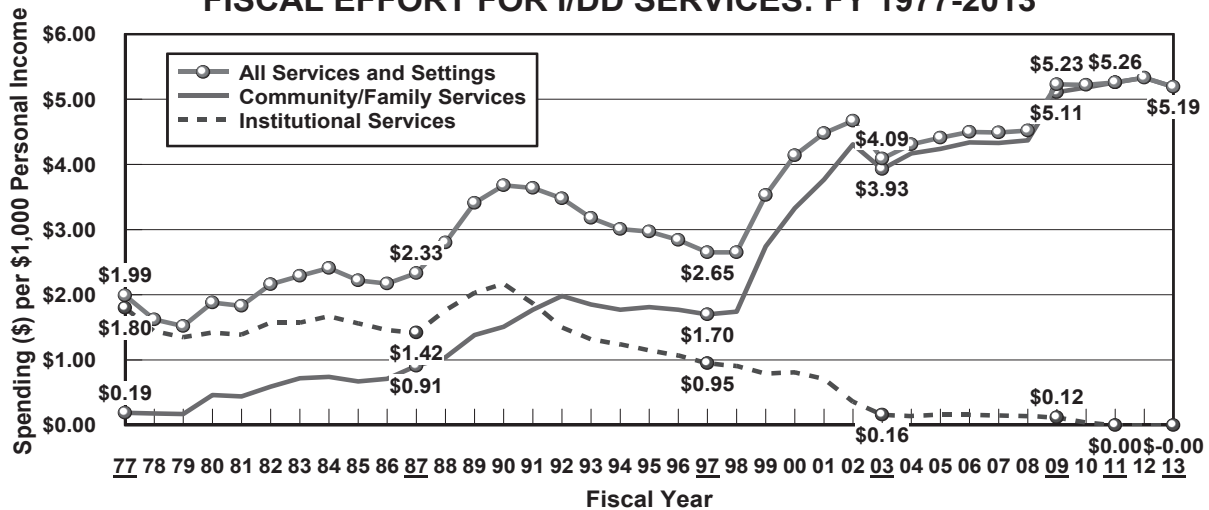


FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



*In 2013, "Related Medicaid" was targeted case management (\$17.3 million), administration (\$10.2 million) and personal assistance (\$89.1 million).

FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013

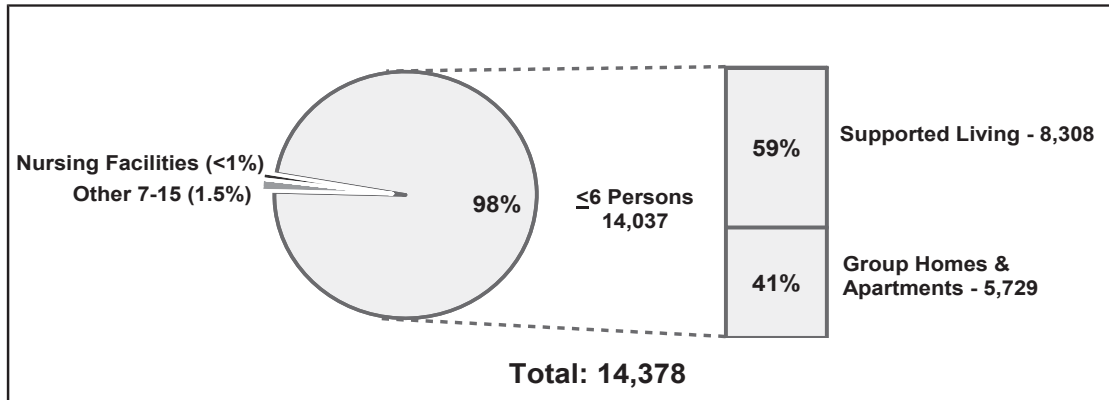


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

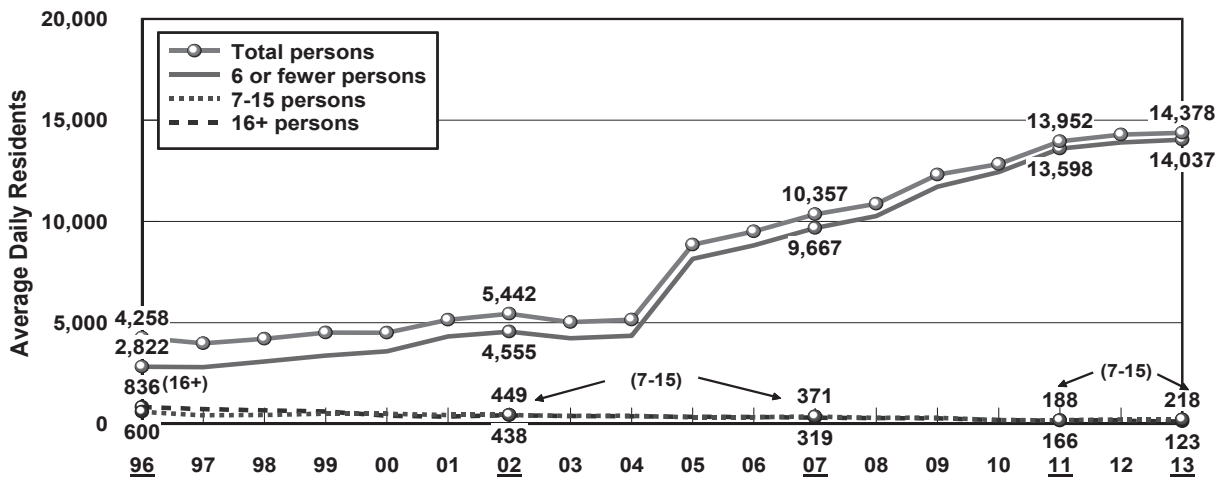
<http://stateofthestates.org>

OREGON

PERSONS BY SETTING IN FISCAL YEAR 2013

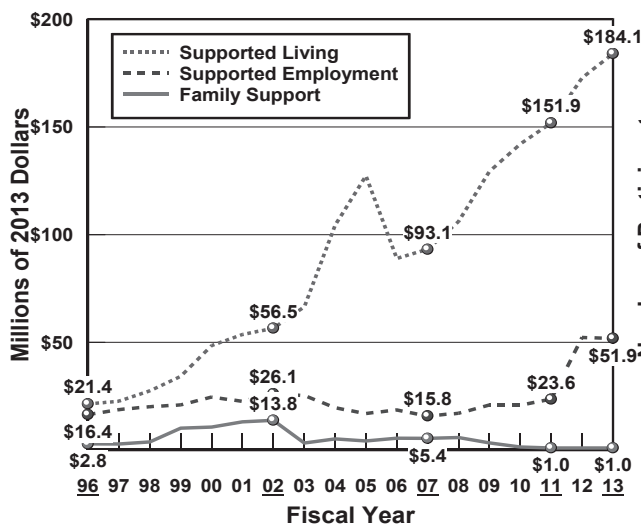


PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013

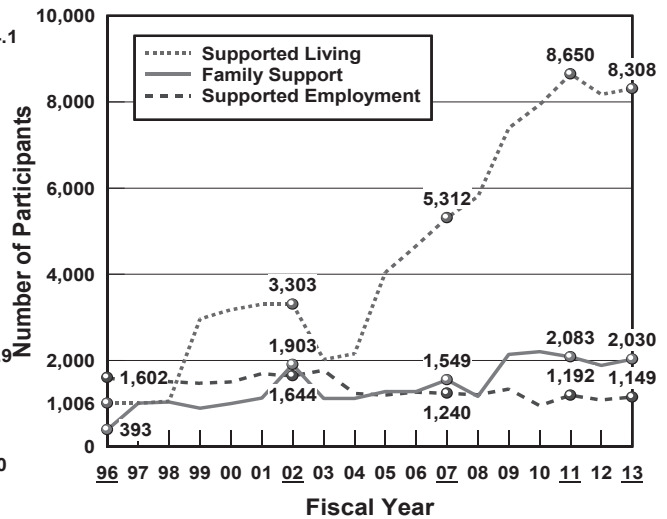


INDIVIDUAL AND FAMILY SUPPORT

SPENDING



PARTICIPANTS

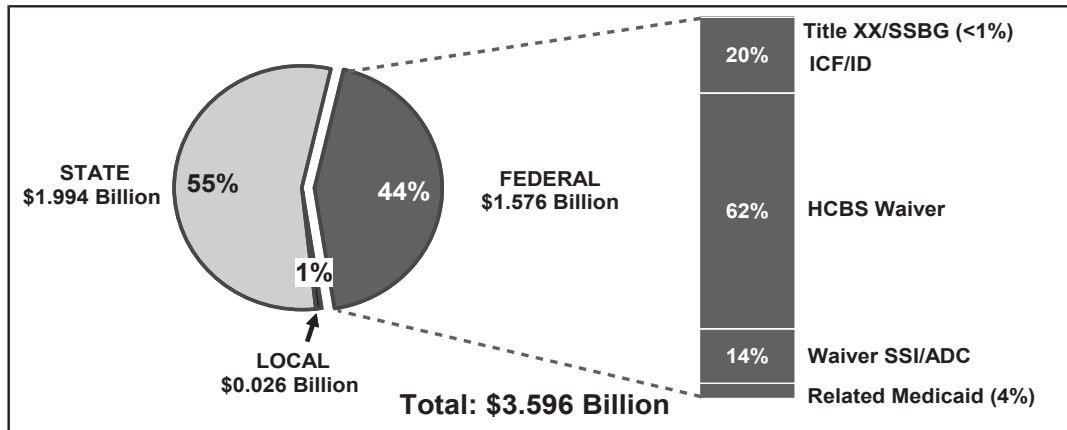


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

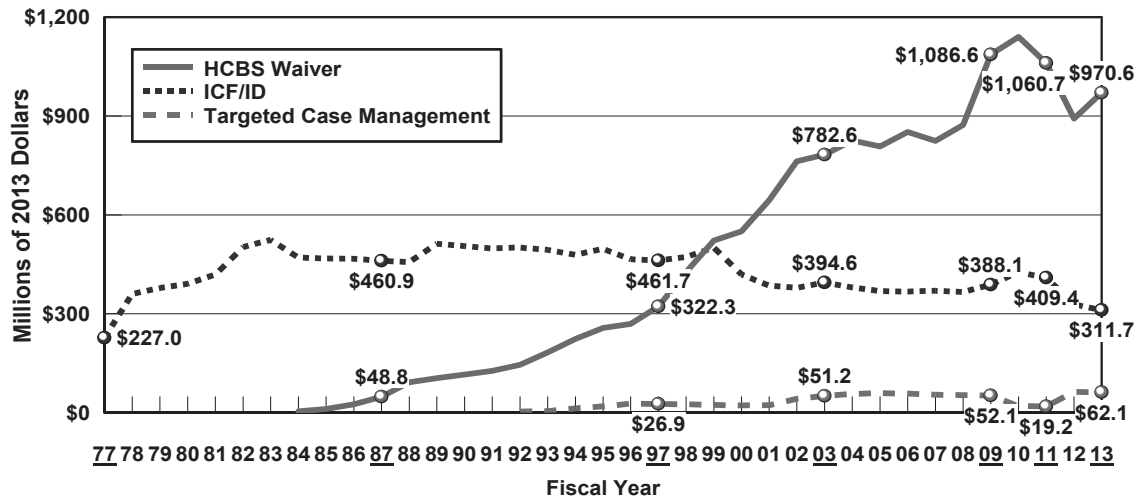
<http://stateofthestates.org>

PENNSYLVANIA

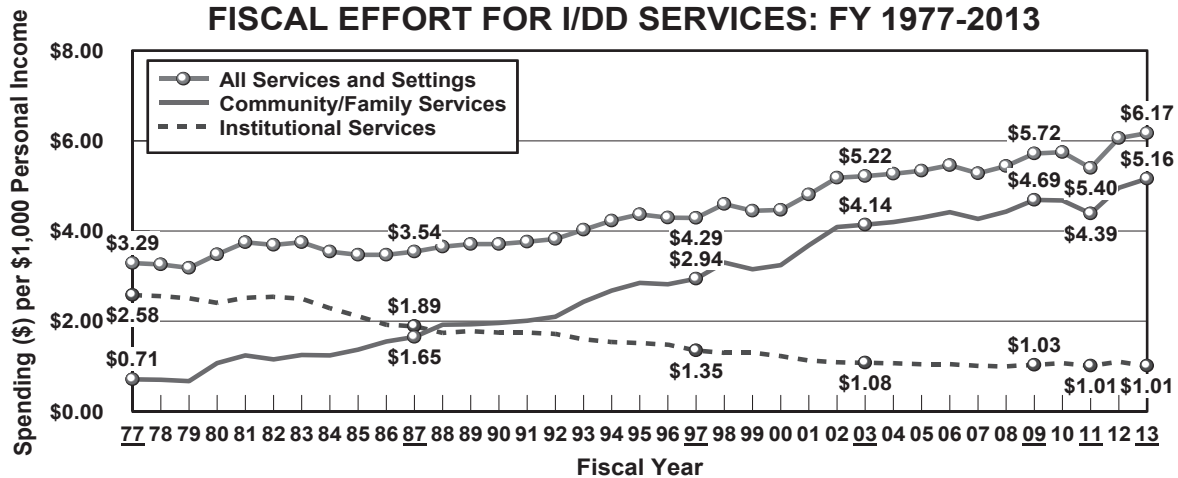
PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013



FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



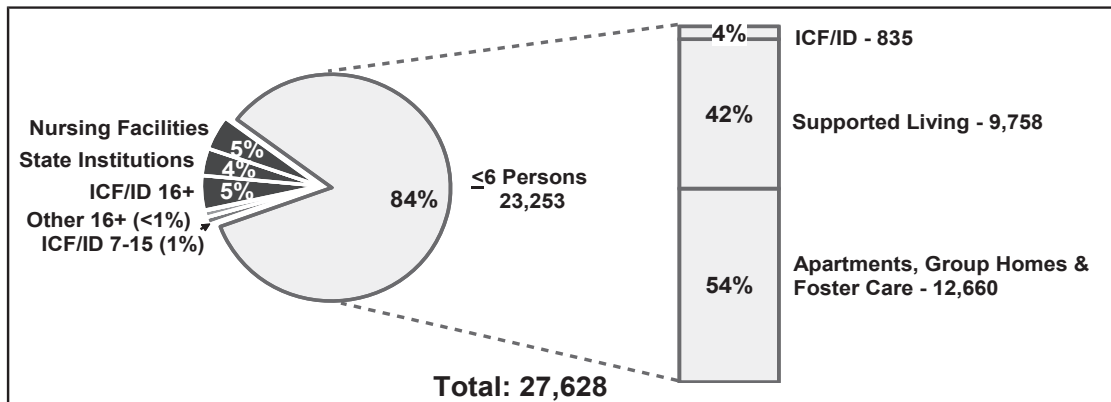
FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013



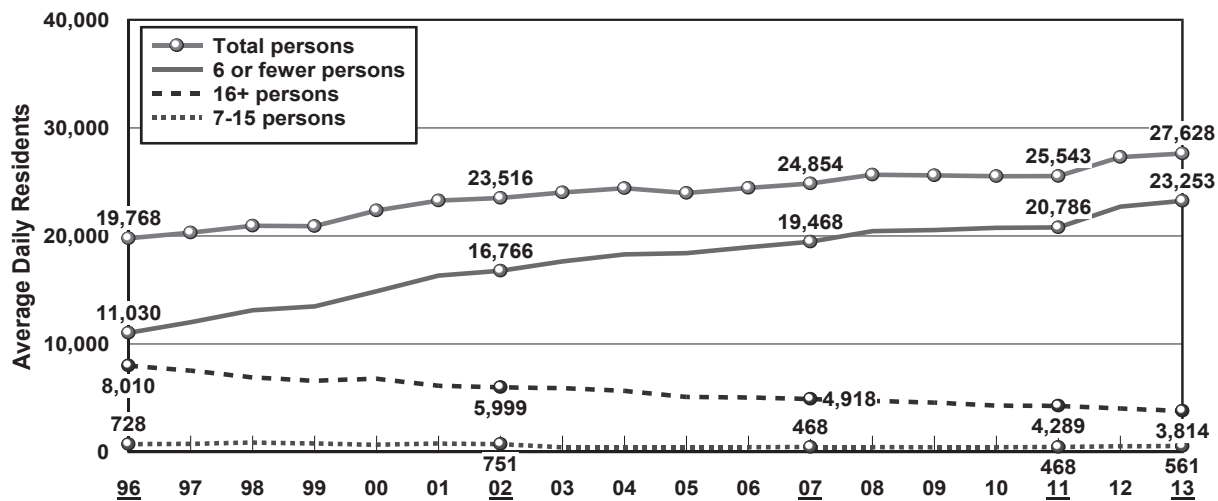
Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.
<http://stateofthestates.org>

PENNSYLVANIA

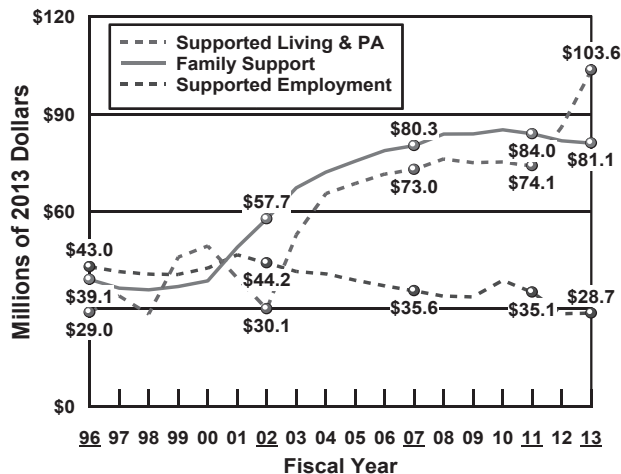
PERSONS BY SETTING IN FISCAL YEAR 2013



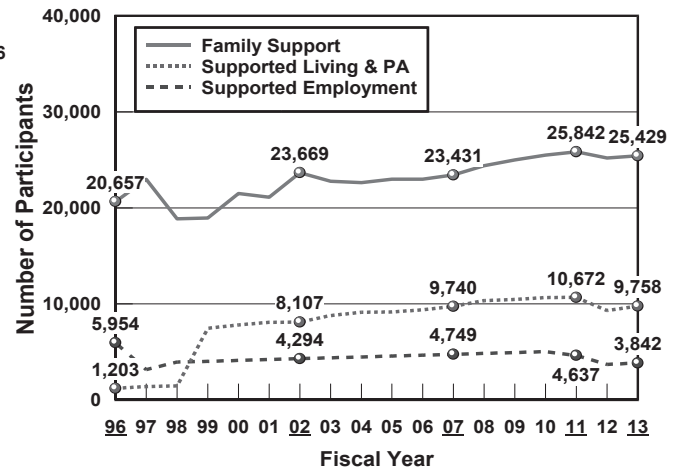
PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013



INDIVIDUAL AND FAMILY SUPPORT SPENDING



PARTICIPANTS

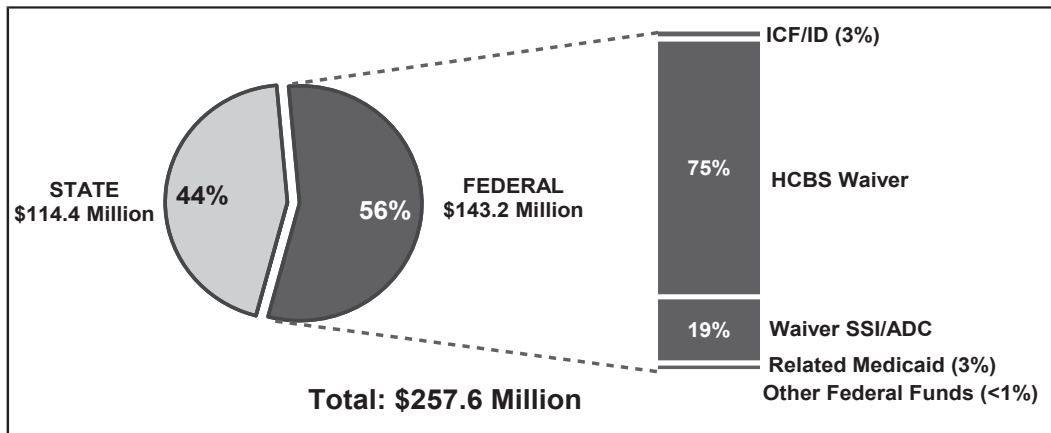


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

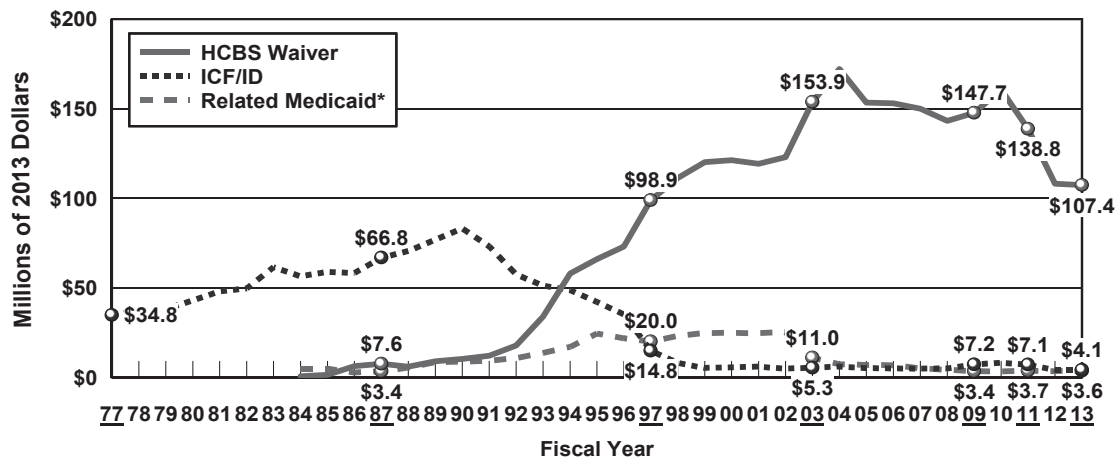
<http://stateofthestates.org>

RHODE ISLAND

PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013

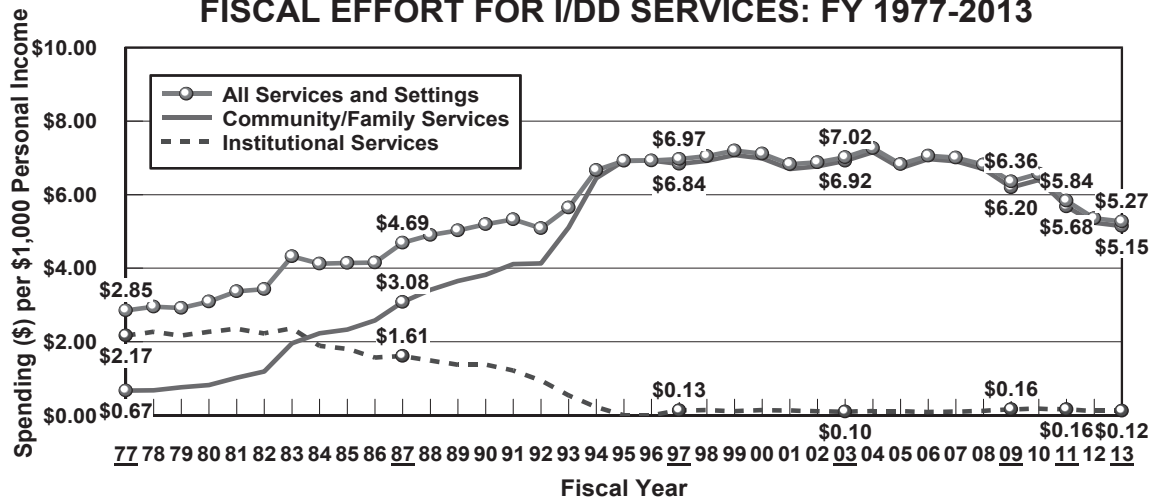


FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



*In 2013, "Related Medicaid" was rehabilitative services (\$0.6 million) and other medicaid services (\$3.0 million).

FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013

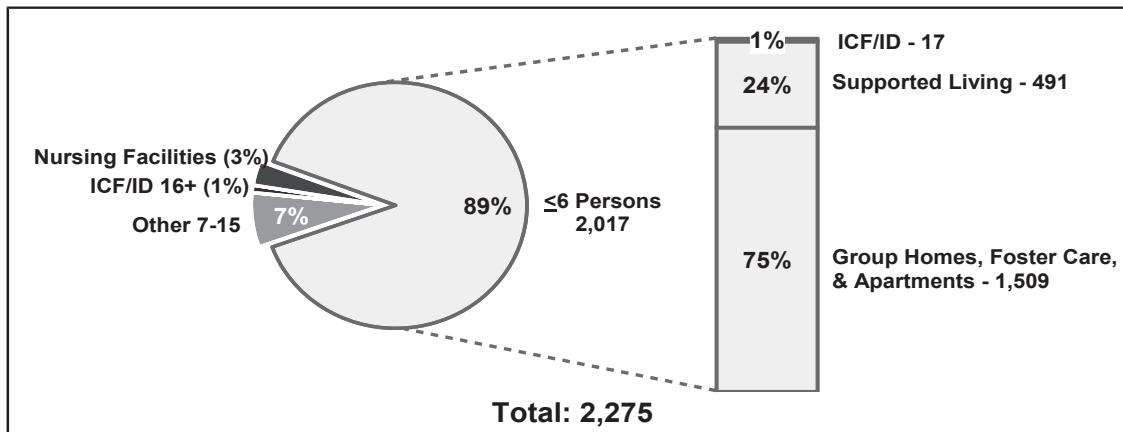


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

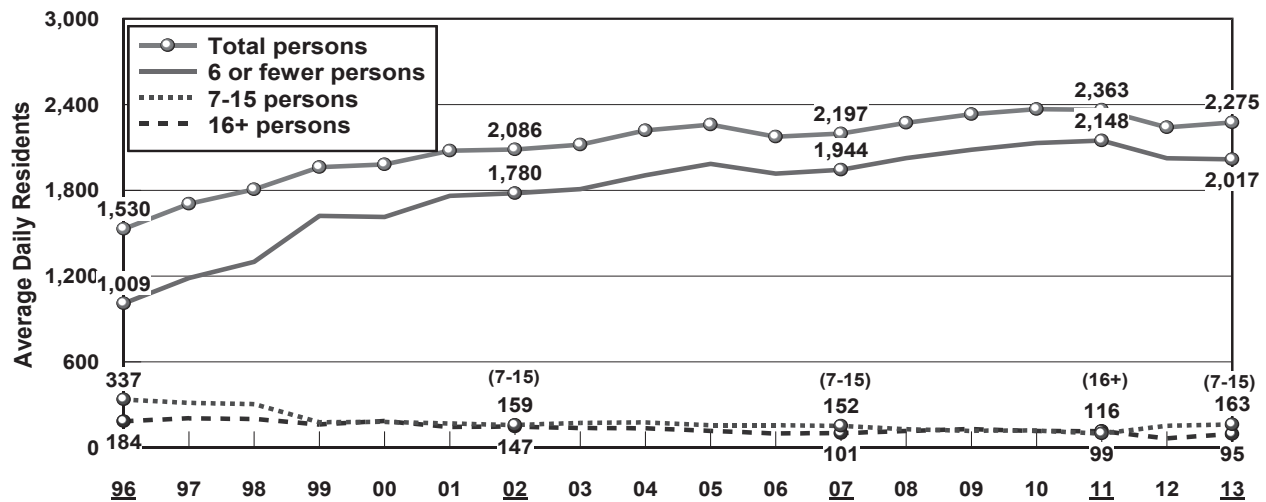
<http://stateofthestates.org>

RHODE ISLAND

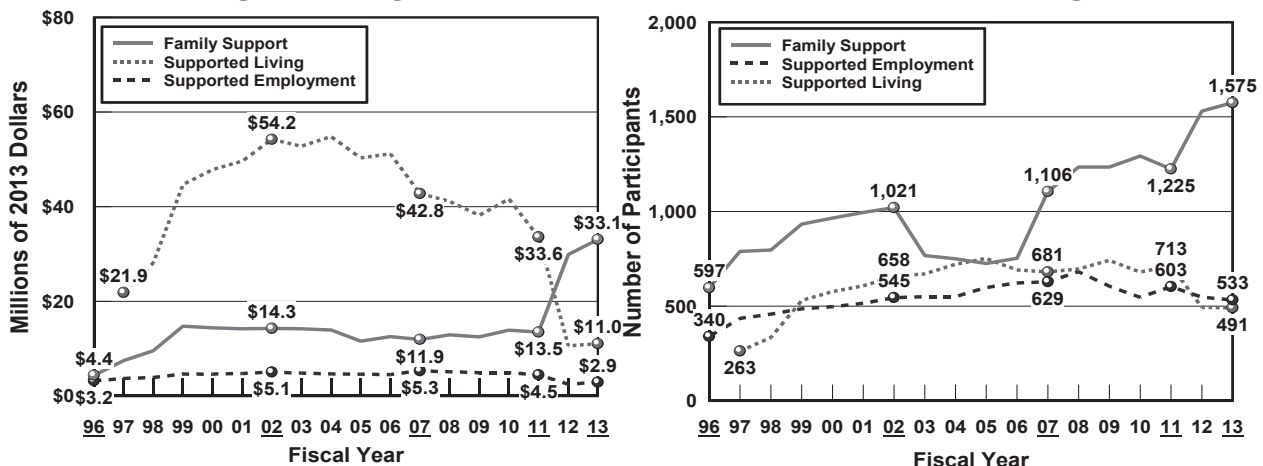
PERSONS BY SETTING IN FISCAL YEAR 2013



PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013



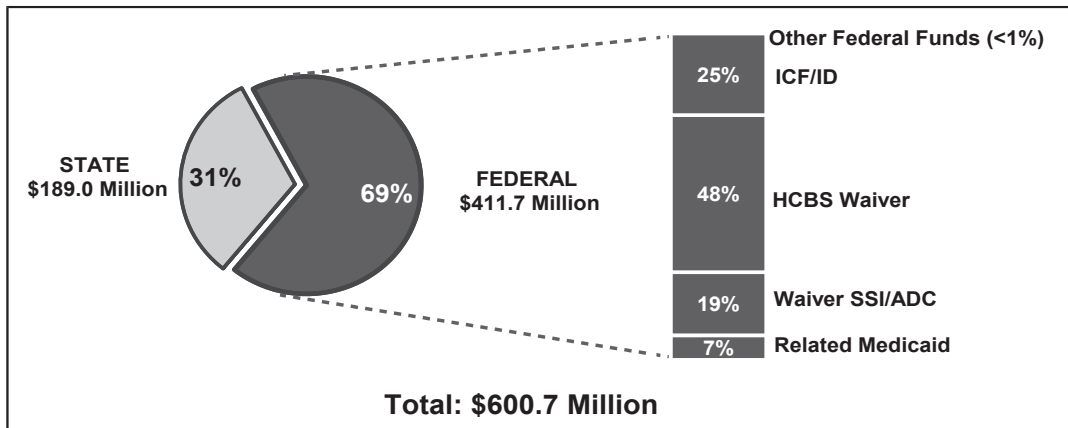
INDIVIDUAL AND FAMILY SUPPORT SPENDING PARTICIPANTS



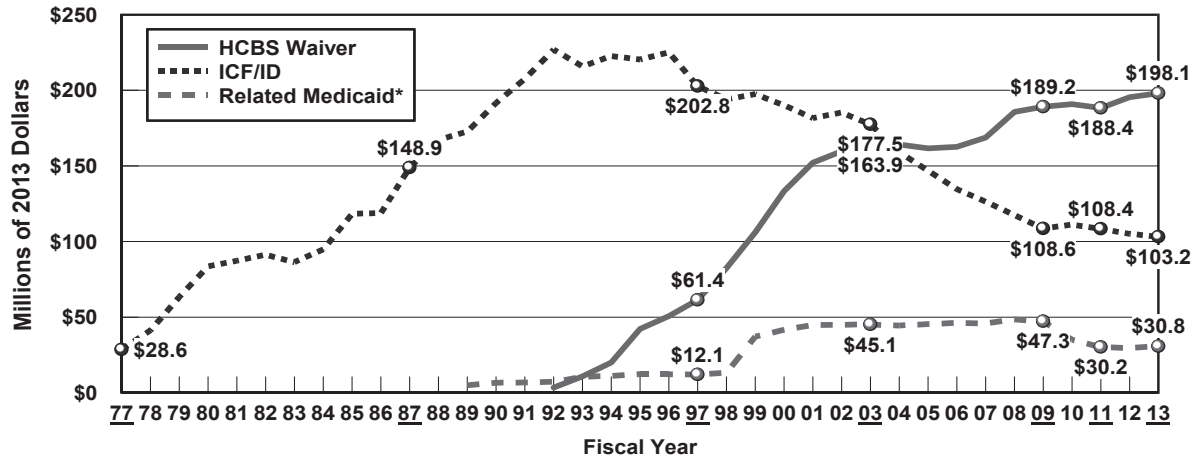
Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.
<http://stateofthestates.org>

SOUTH CAROLINA

PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013

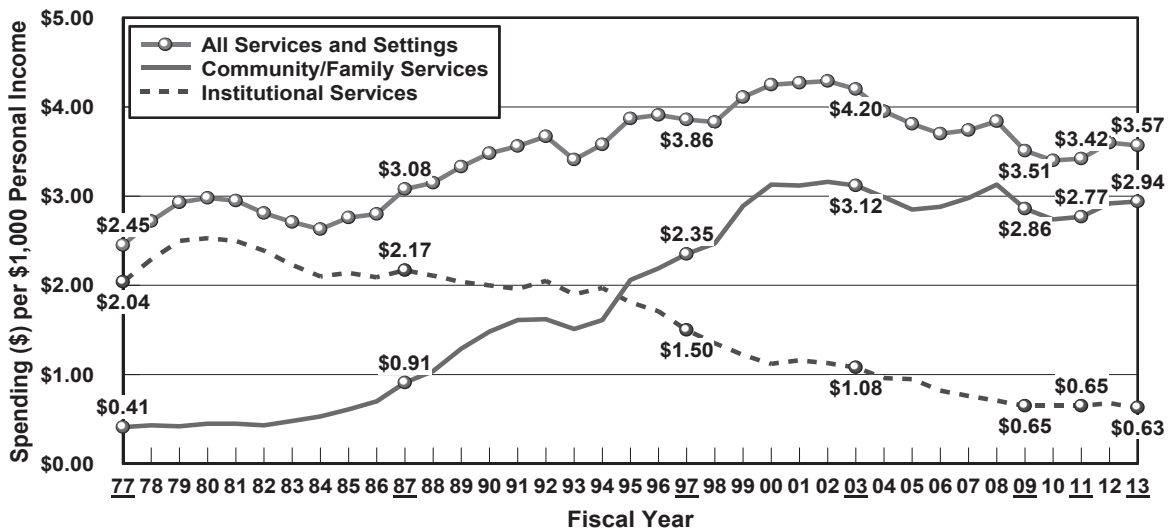


FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



*In 2013, "Related Medicaid" was rehabilitative services (\$15.0 million) and targeted case management (\$15.8 million).

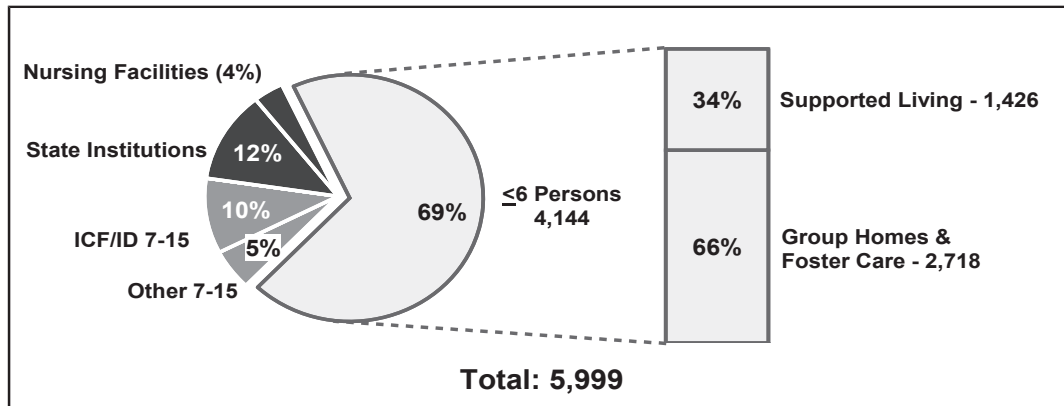
FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013



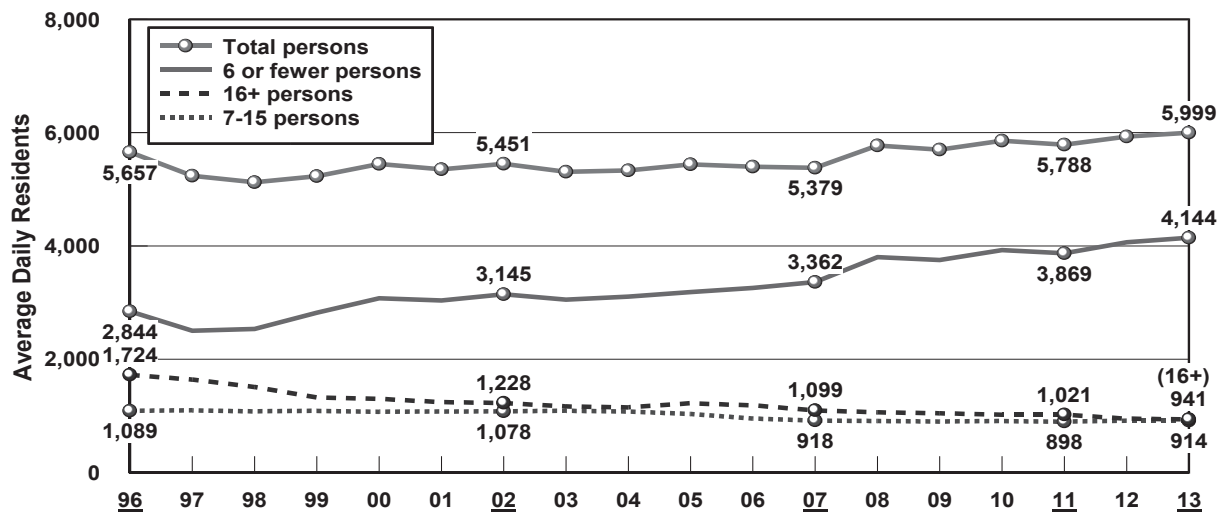
178 Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.
<http://stateofthestates.org>

SOUTH CAROLINA

PERSONS BY SETTING IN FISCAL YEAR 2013

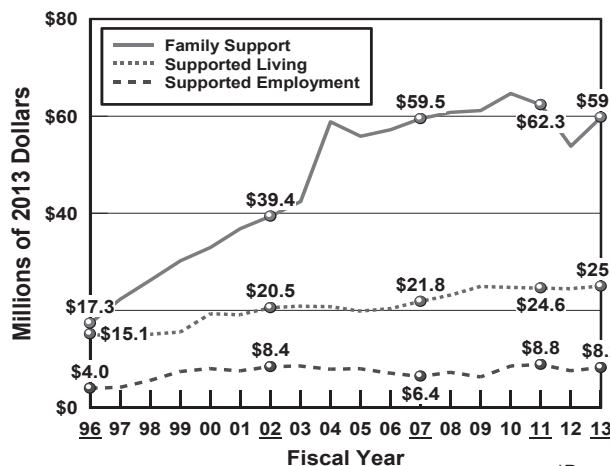


PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013

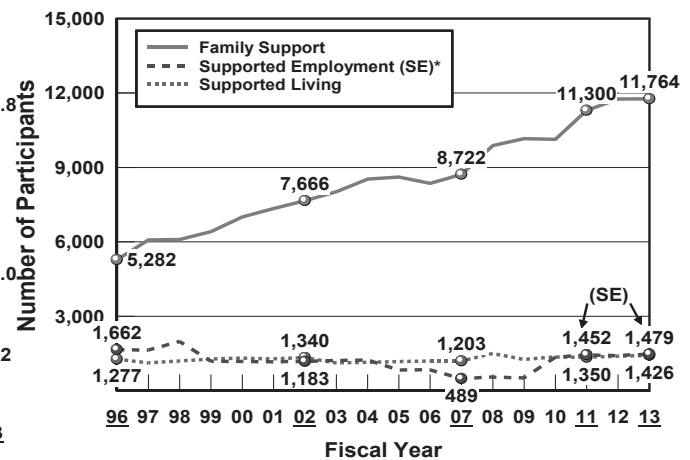


INDIVIDUAL AND FAMILY SUPPORT

SPENDING



PARTICIPANTS



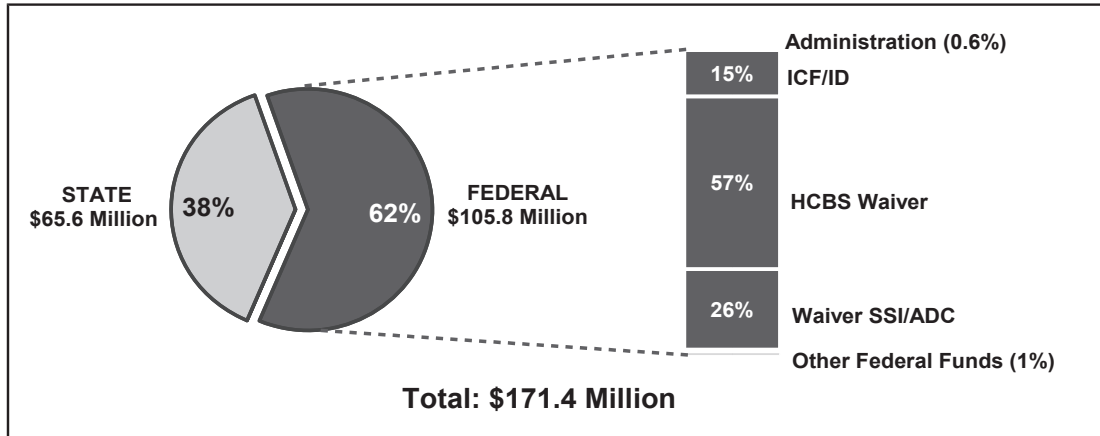
*Does not include 510 follow-along work support workers in 2012, and 511 in 2013.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

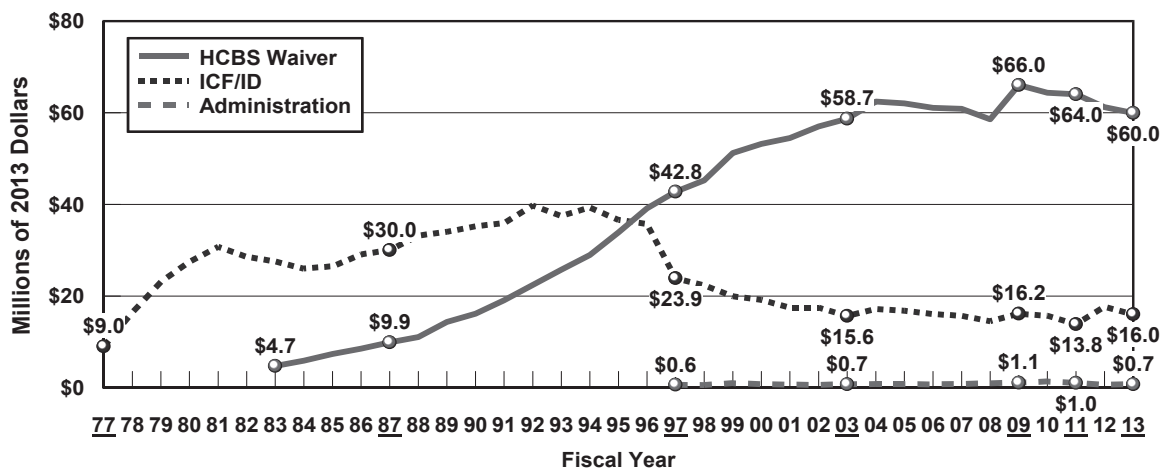
<http://stateofthstates.org>

SOUTH DAKOTA

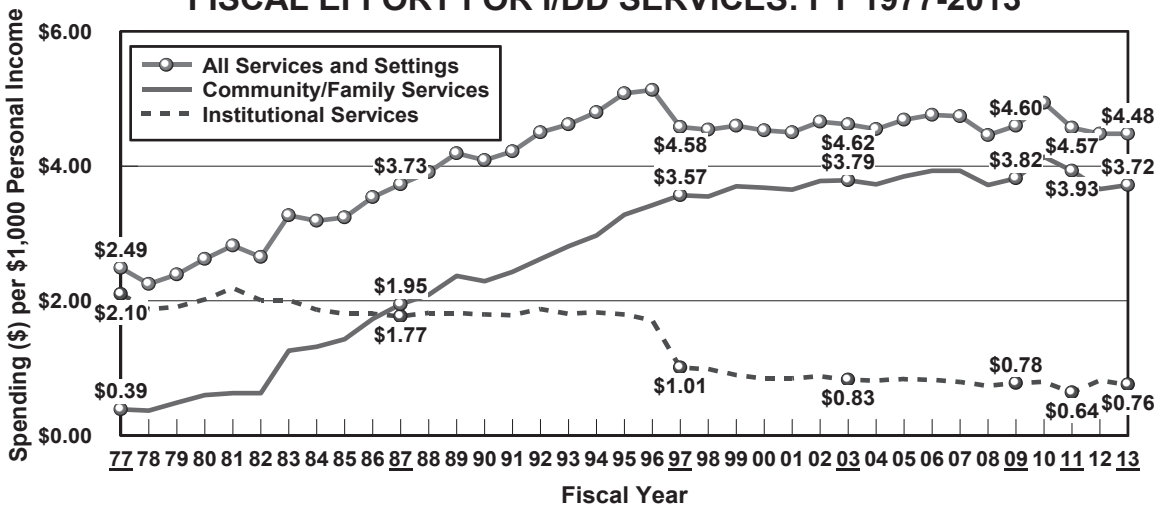
PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013



FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013

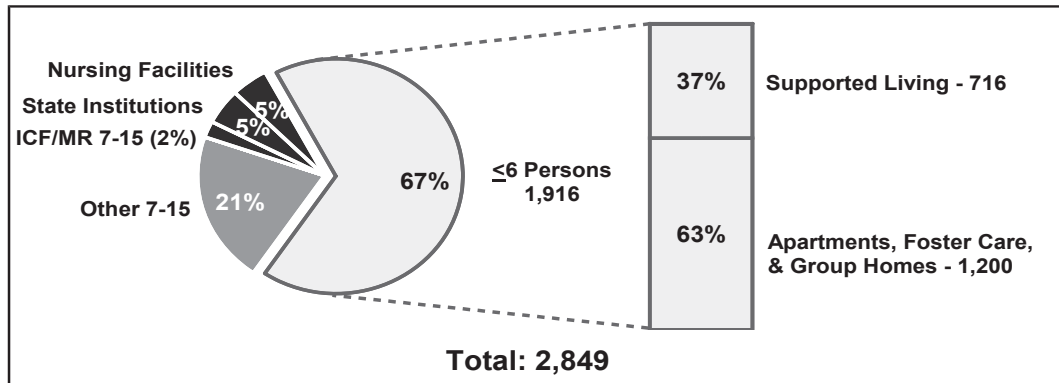


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

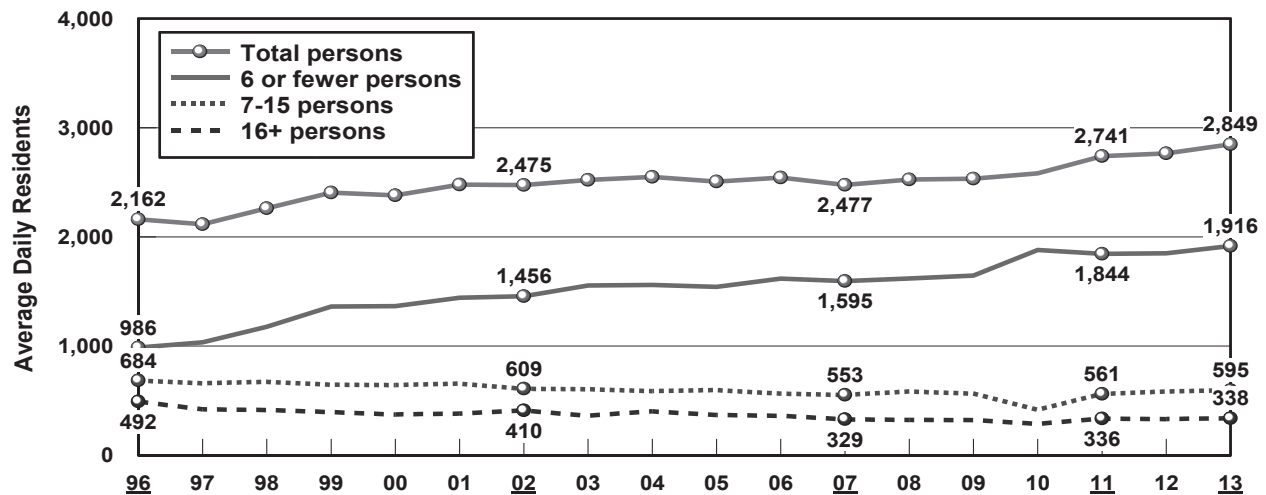
<http://stateofthestates.org>

SOUTH DAKOTA

PERSONS BY SETTING IN FISCAL YEAR 2013

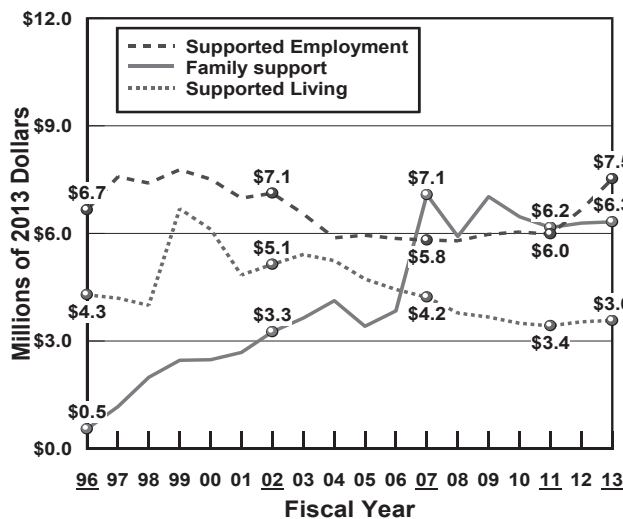


PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013

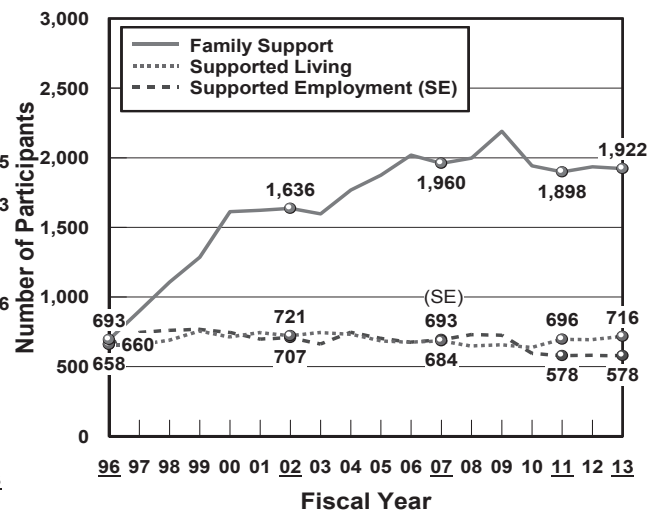


INDIVIDUAL AND FAMILY SUPPORT

SPENDING



PARTICIPANTS

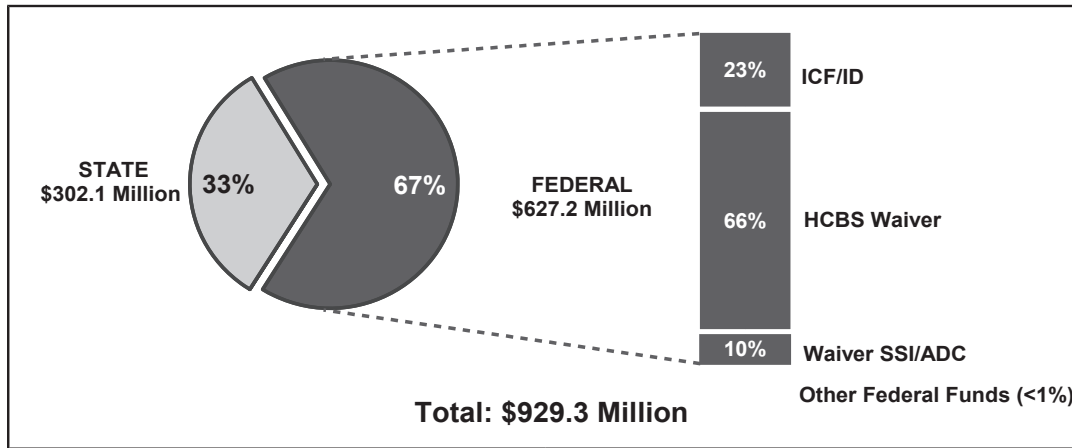


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

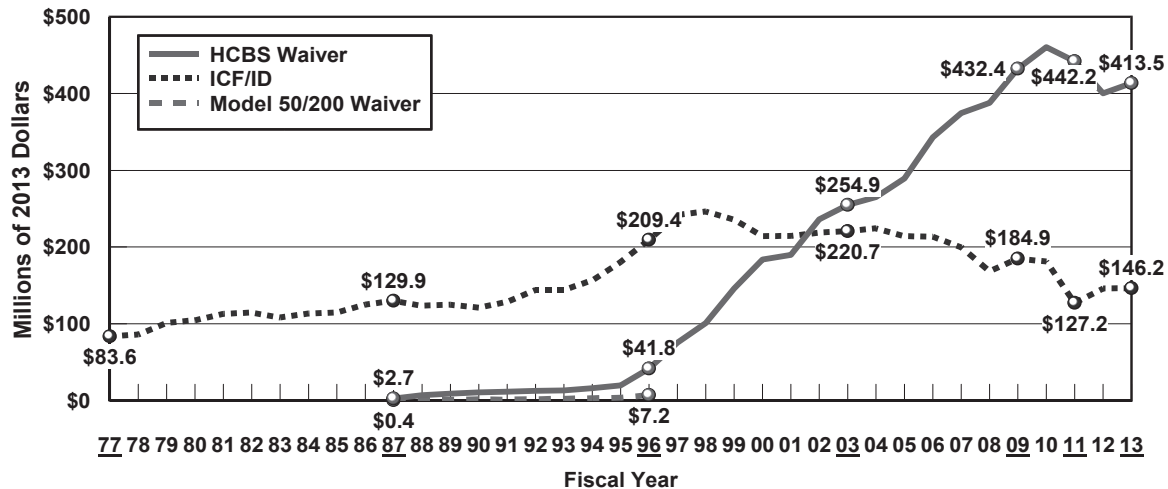
<http://stateofthestates.org>

TENNESSEE

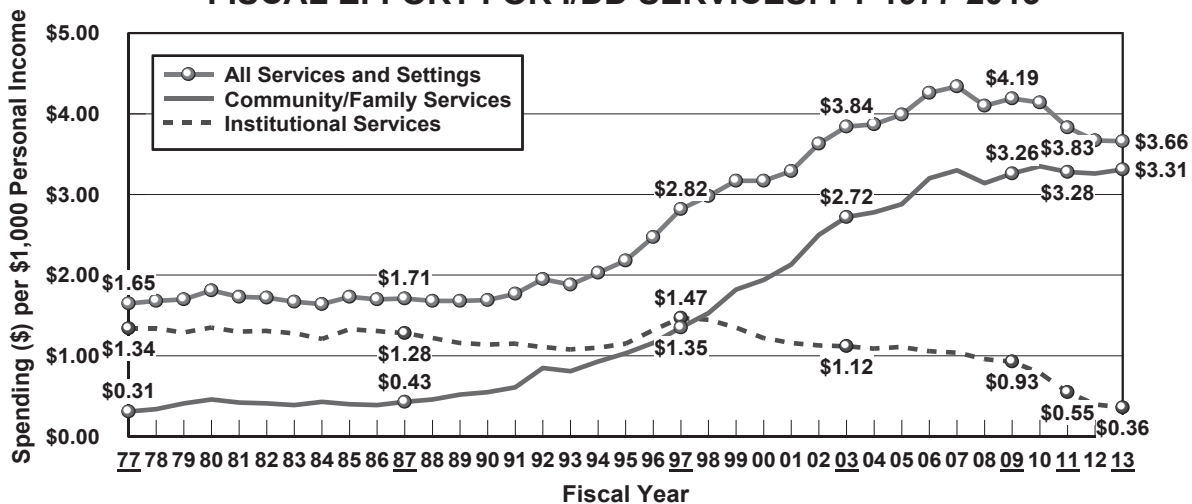
PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013



FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013

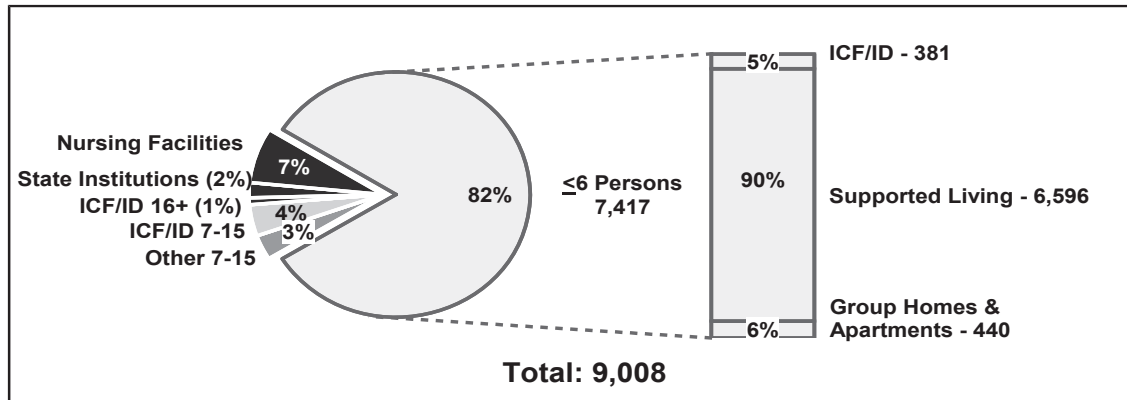


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

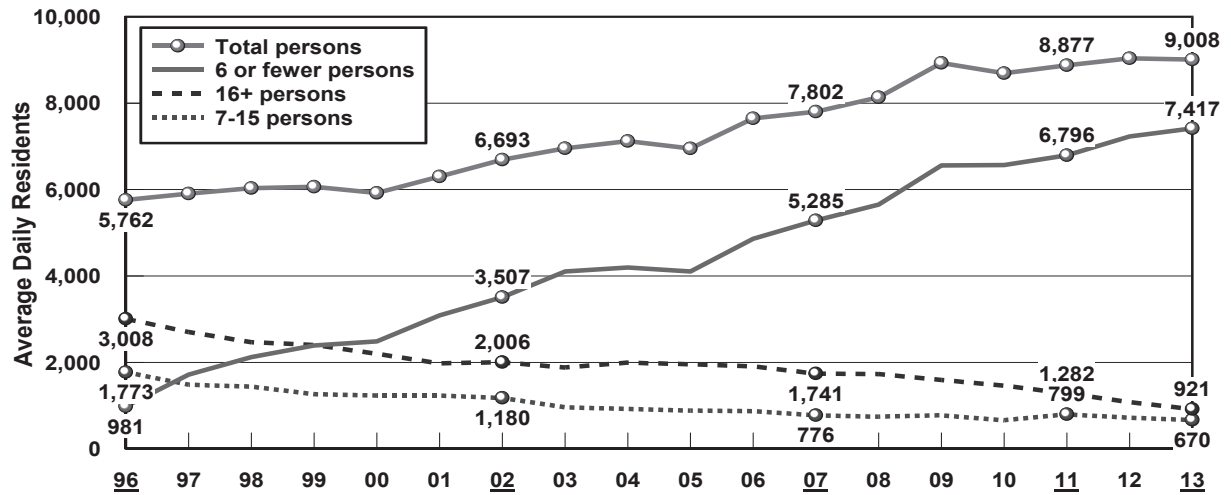
<http://stateofthestates.org>

TENNESSEE

PERSONS BY SETTING IN FISCAL YEAR 2013

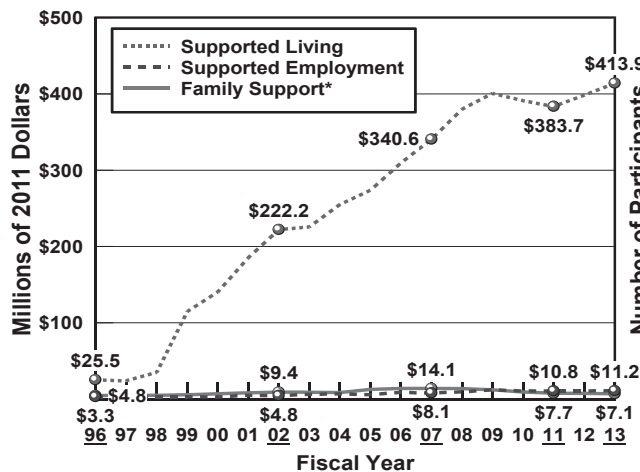


PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013

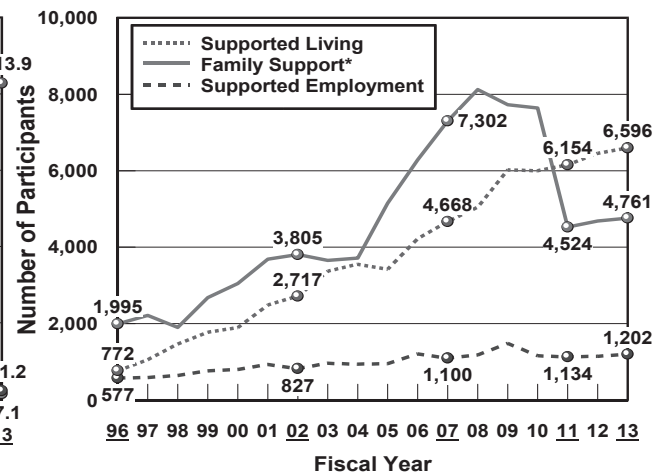


INDIVIDUAL AND FAMILY SUPPORT

SPENDING*



PARTICIPANTS*



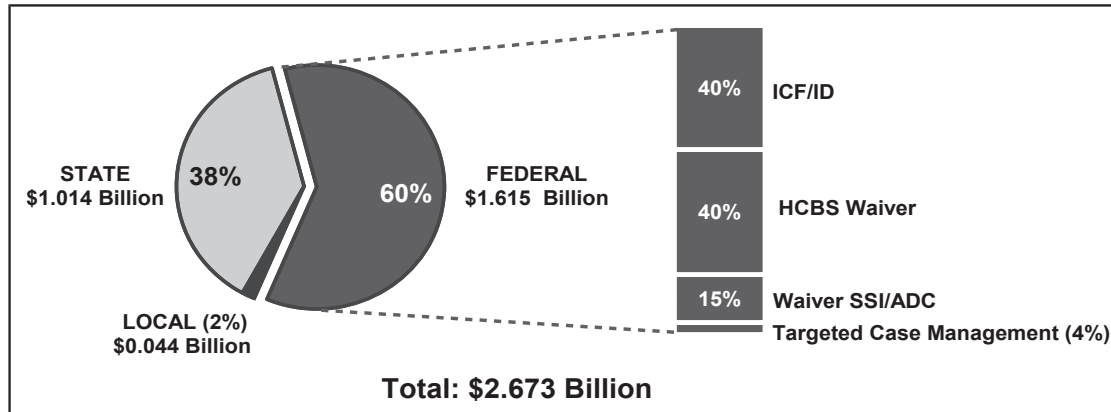
*The Brown/People First settlement 2005-09 established cash subsidies ranging from \$2.4 to \$4.9 million for 1,120 to 3,403 families. The subsidy dropped to \$3.5 million in 2010 and terminated in 2011.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

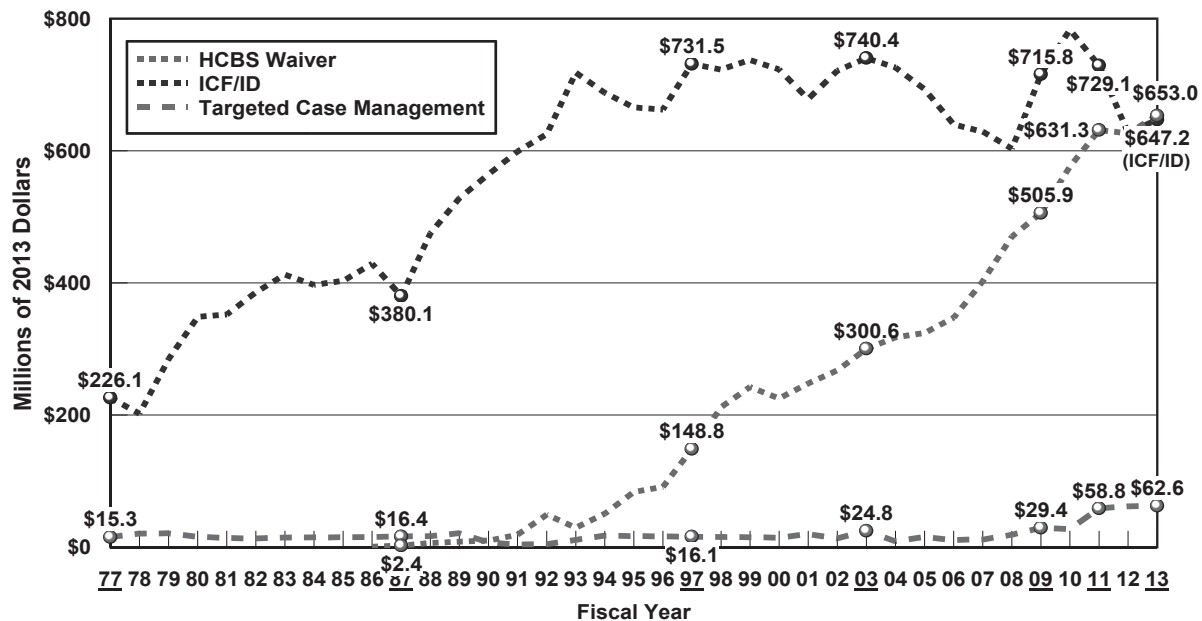
<http://stateofthestates.org>

TEXAS

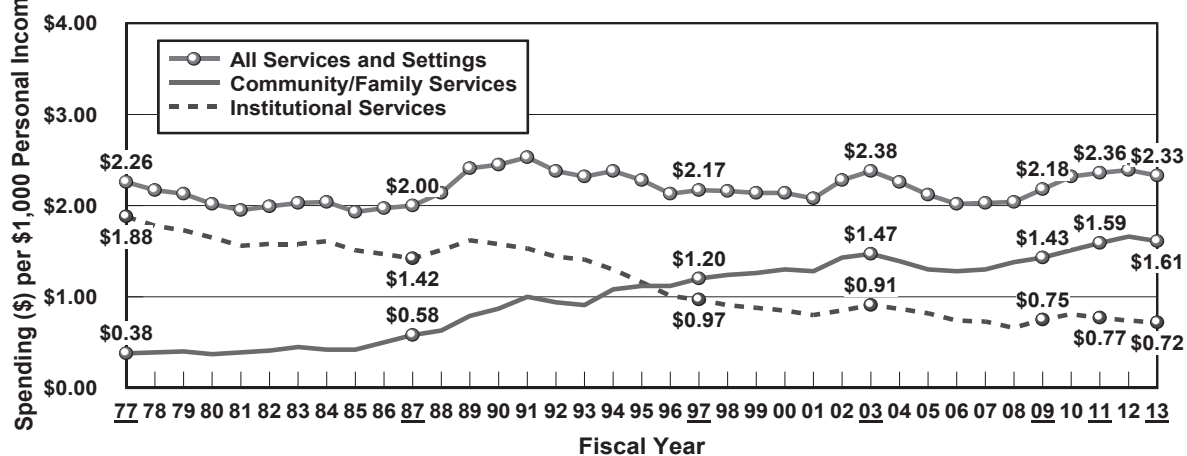
PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013



FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



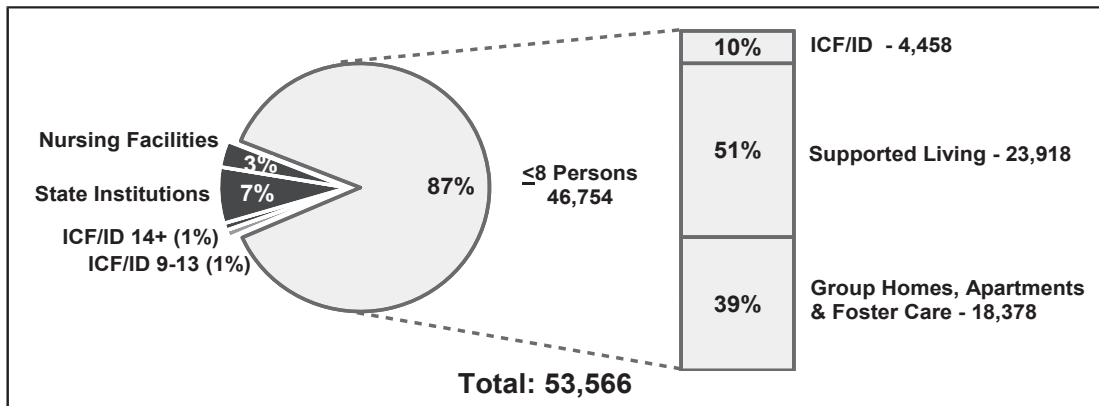
FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013



Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.
<http://stateofthestates.org>

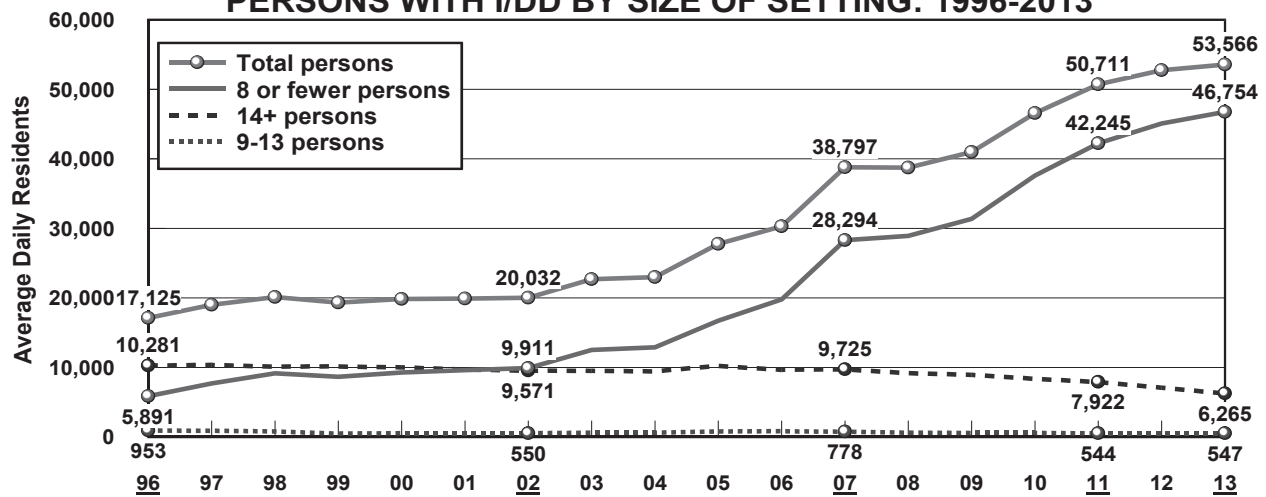
TEXAS

PERSONS BY SETTING IN FISCAL YEAR 2013*

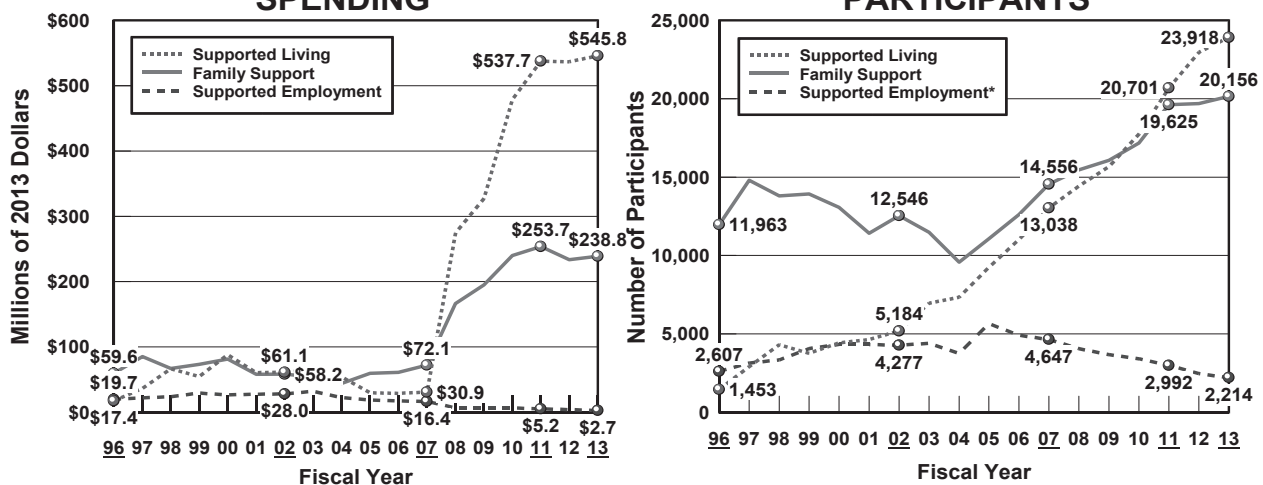


*Texas reported out-of-home placements in the following categories: 8 or fewer, 9-13 and 14+ persons.

PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013



INDIVIDUAL AND FAMILY SUPPORT SPENDING PARTICIPANTS



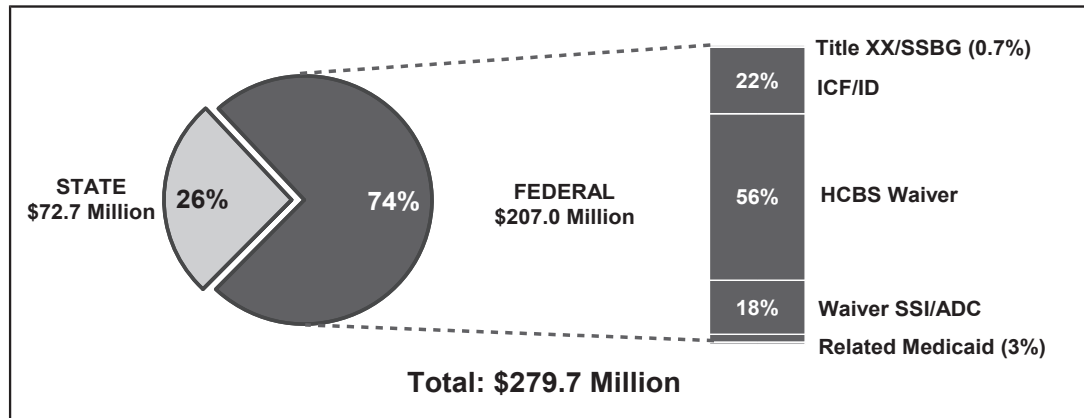
*Not included are State Supported Living Center (SSLC) workers, ranging from 75 in 2005 to 98 in 2013.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

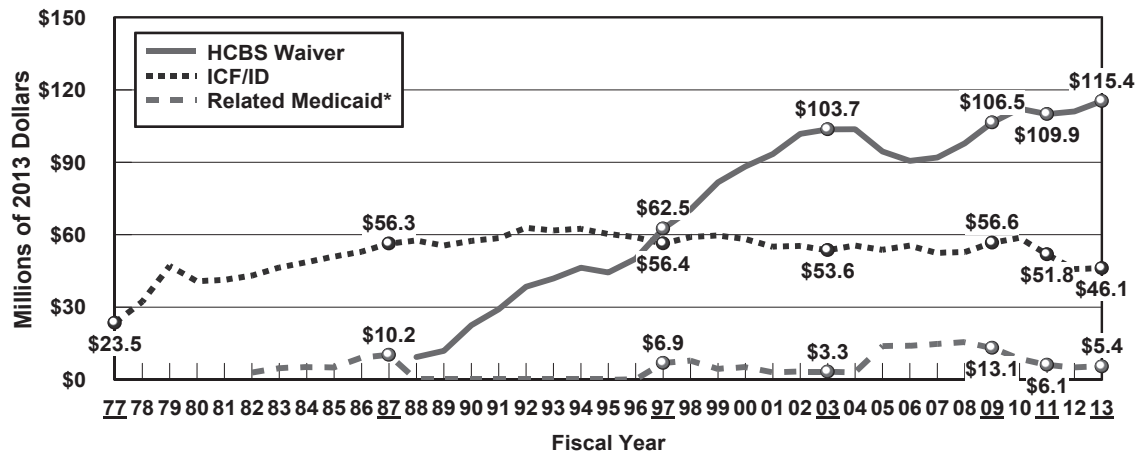
<http://stateofthstates.org>

UTAH

PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013

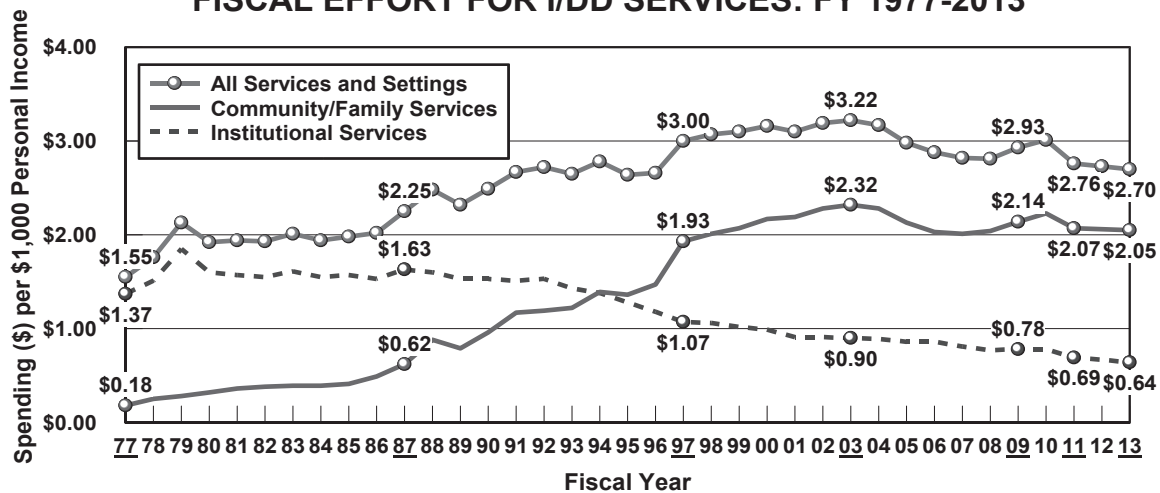


FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



* In 2013, "Related Medicaid" was administration (\$3.9 million) and personal assistance (\$1.5 million).

FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013

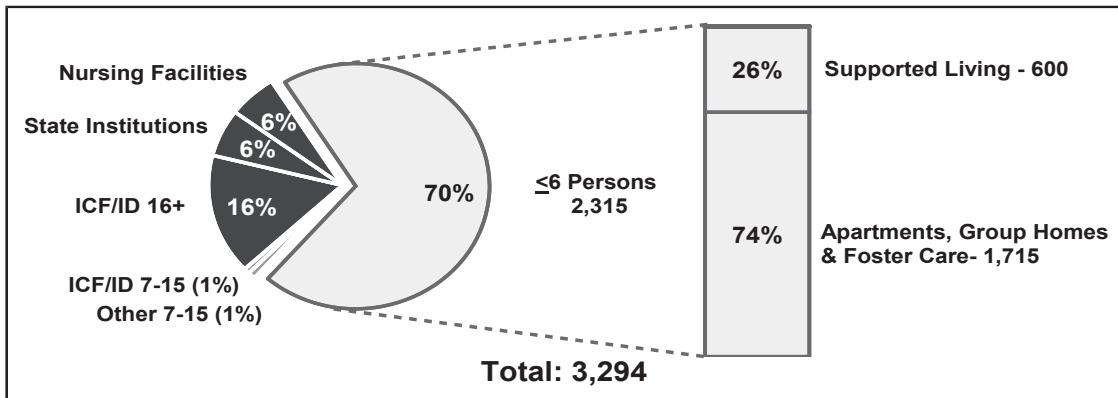


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

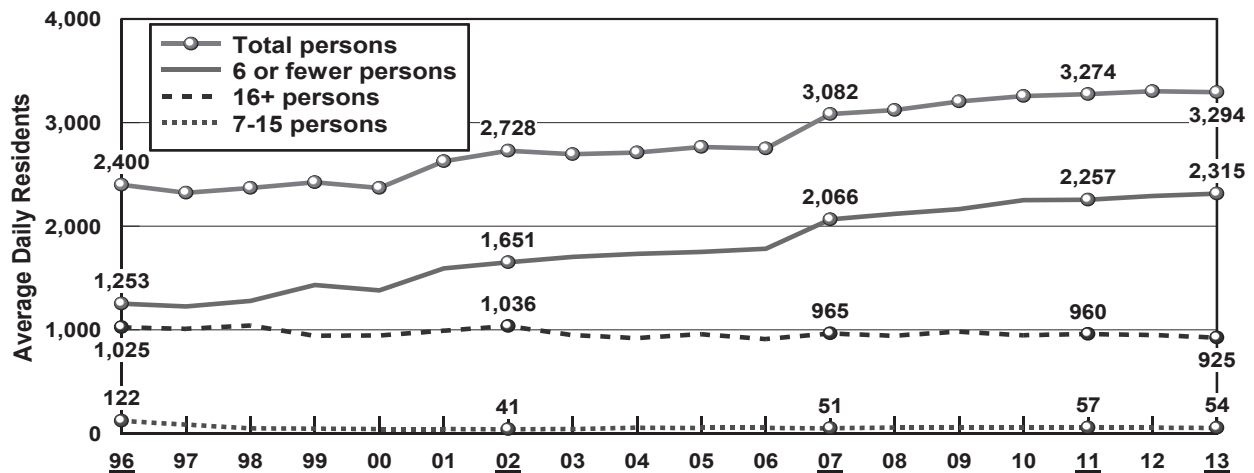
<http://stateofthestates.org>

UTAH

PERSONS BY SETTING IN FISCAL YEAR 2013

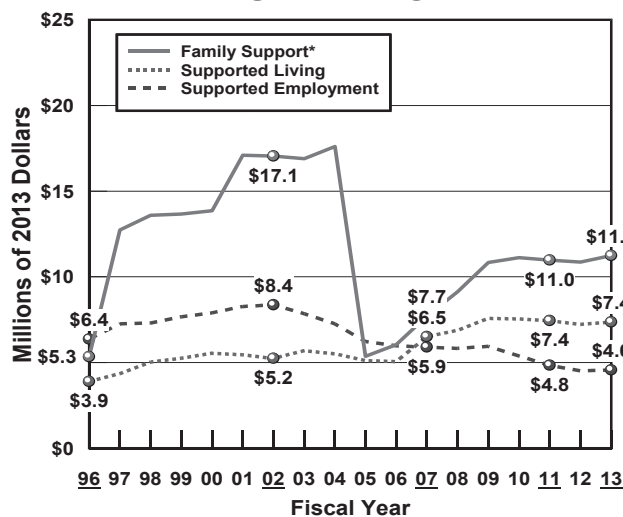


PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013

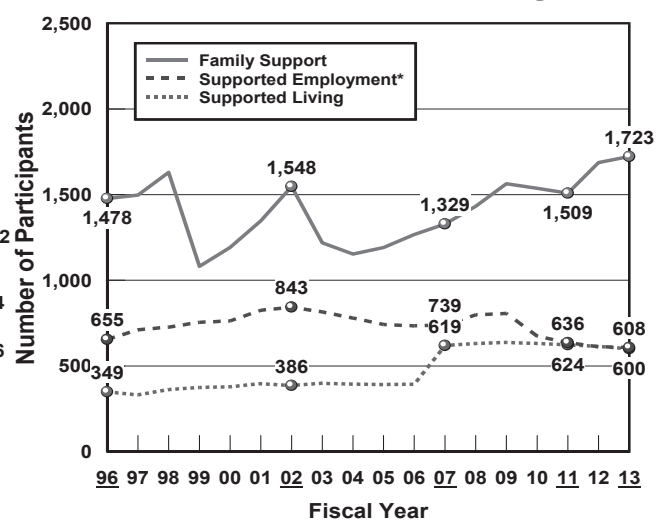


INDIVIDUAL AND FAMILY SUPPORT

SPENDING



PARTICIPANTS



*In 2005, state re-defined portion of family support services as supported living.

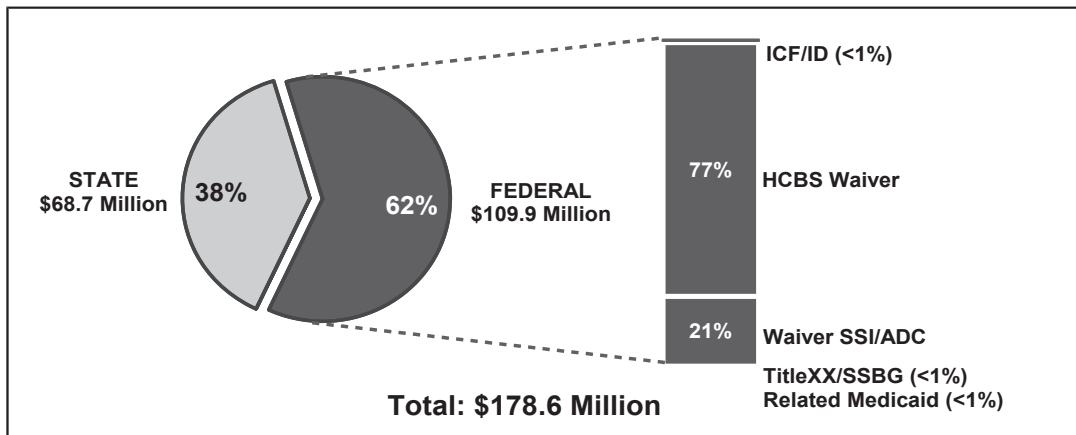
*100 follow-along work support workers in 2011; none reported in 2012-13.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

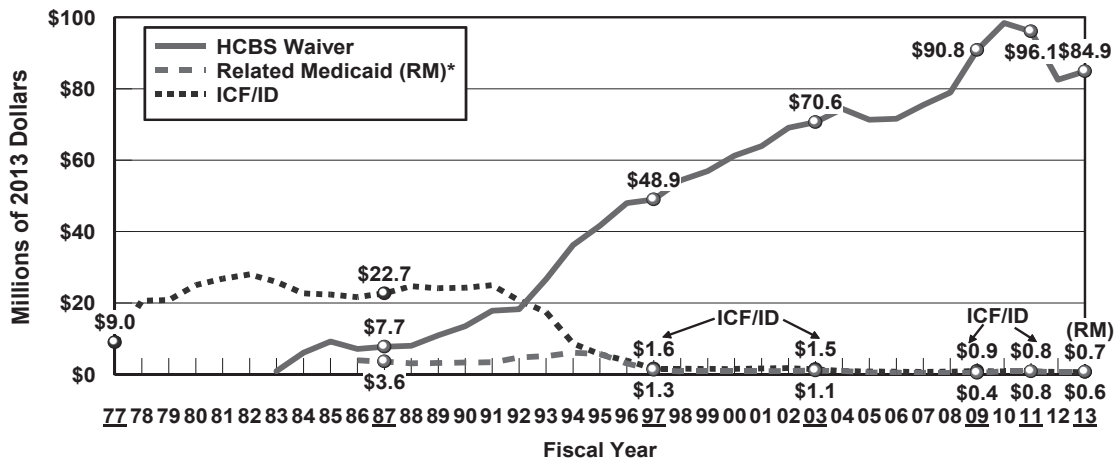
<http://stateofthestates.org>

VERMONT

PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013

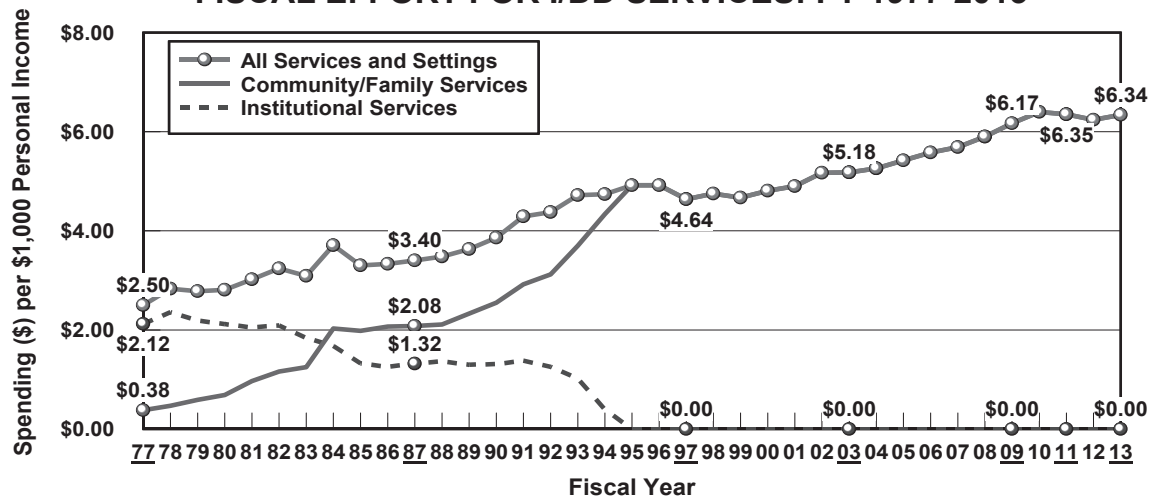


FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



*In 2013, "Related Medicaid" was rehabilitative services (\$0.06 million), and targeted case management (\$0.66 million).

FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013

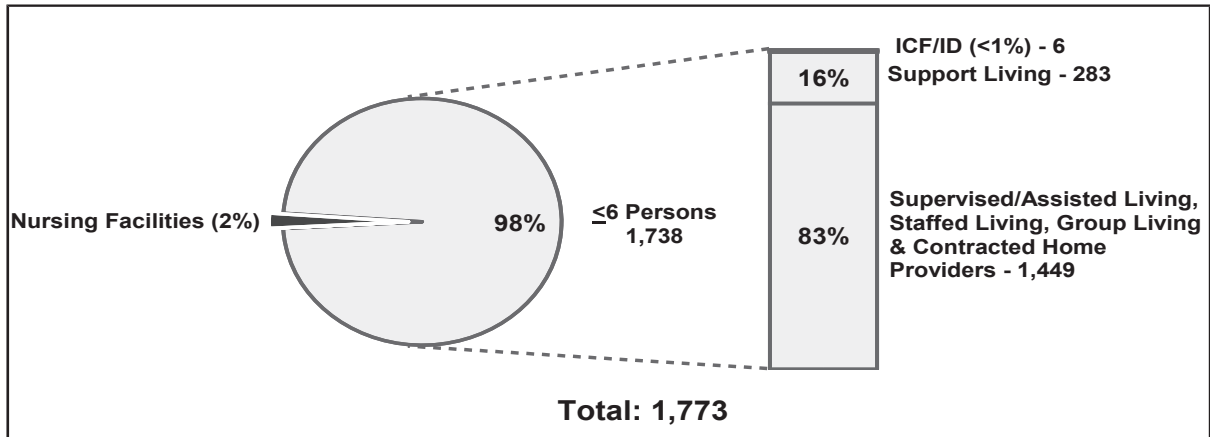


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

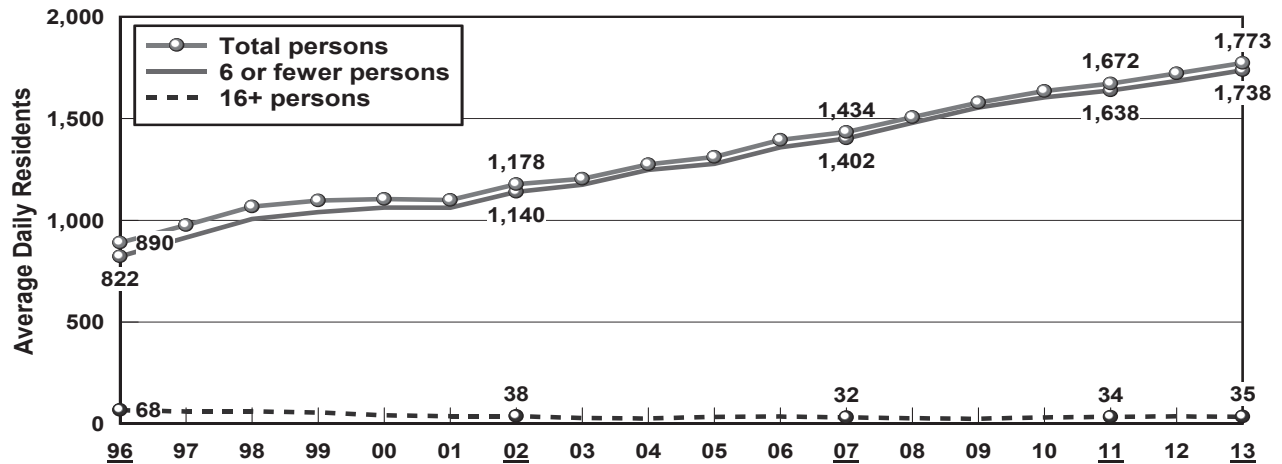
<http://stateofthestates.org>

VERMONT

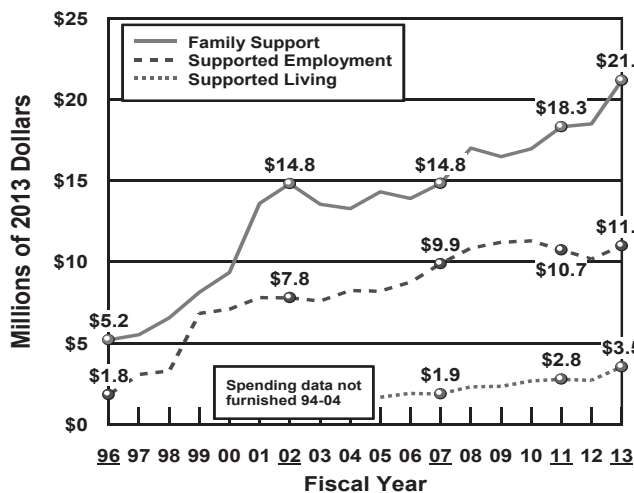
PERSONS BY SETTING IN FISCAL YEAR 2013



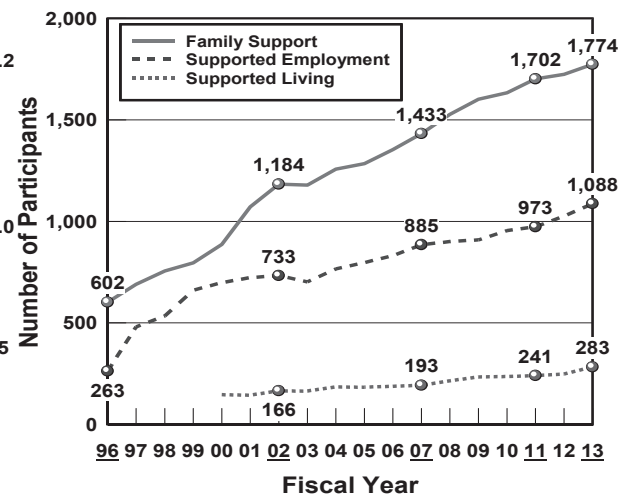
PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013



INDIVIDUAL AND FAMILY SUPPORT SPENDING



PARTICIPANTS

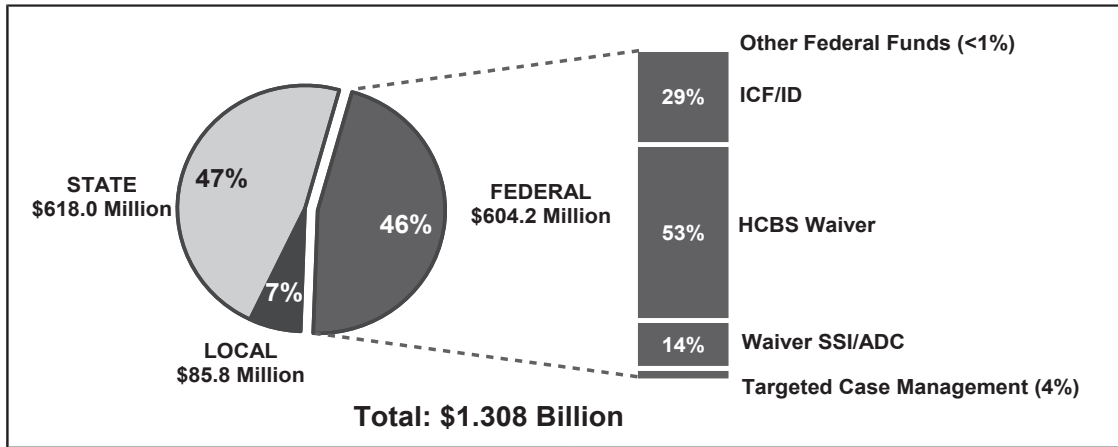


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

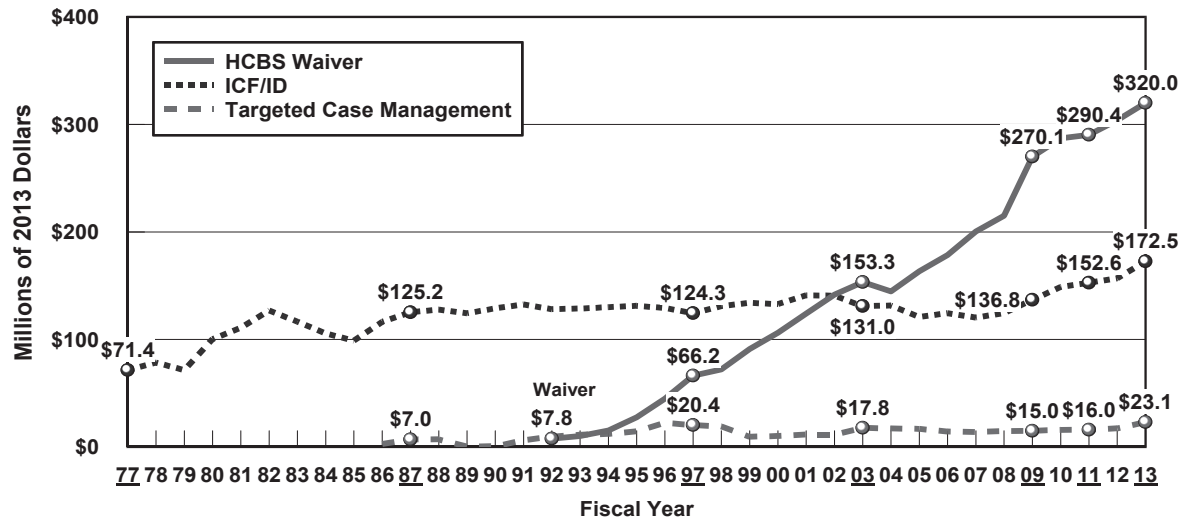
<http://stateofthestates.org>

VIRGINIA

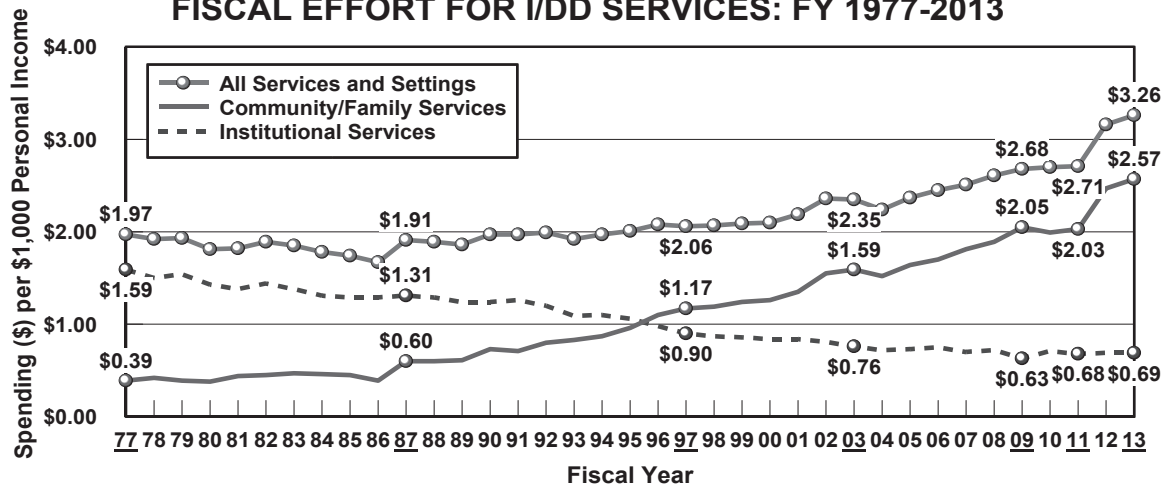
PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013



FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013

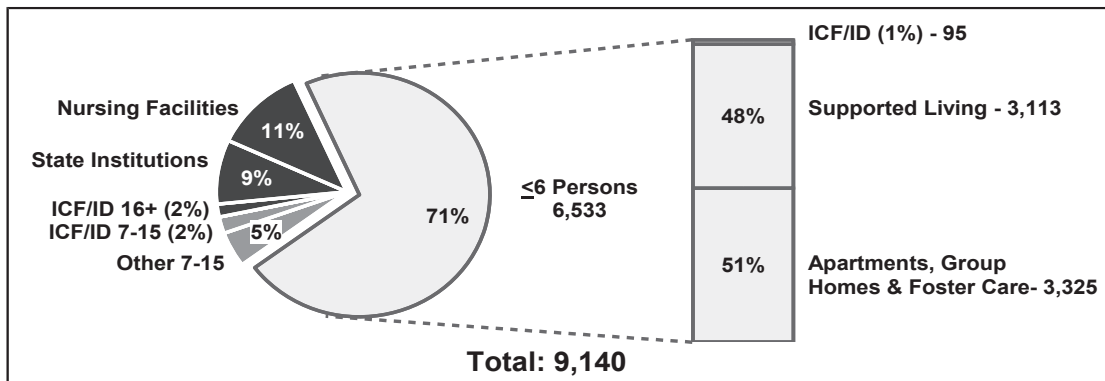


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

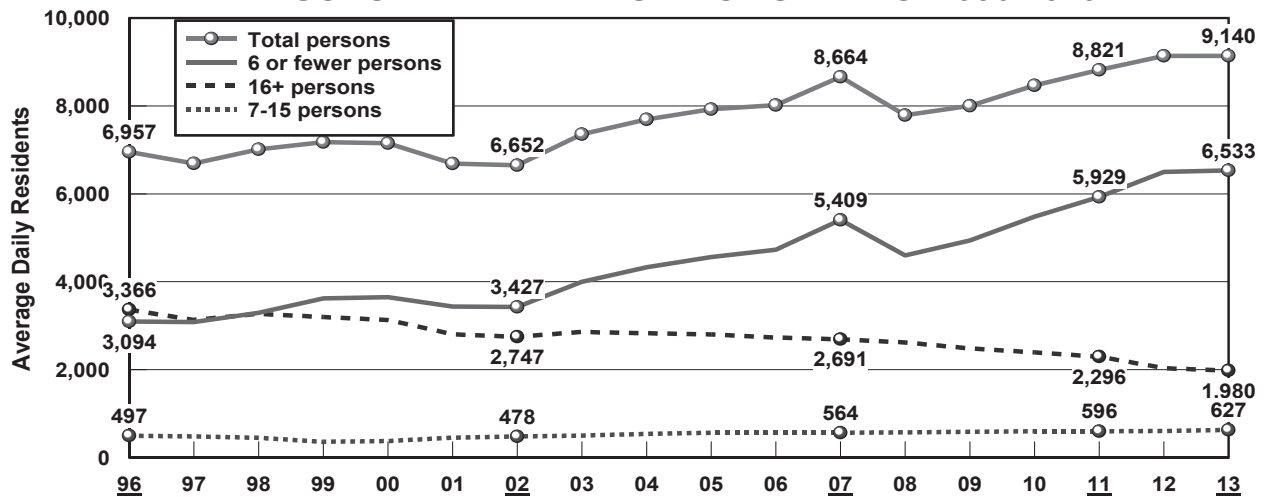
<http://stateofthestates.org>

VIRGINIA

PERSONS BY SETTING IN FISCAL YEAR 2013

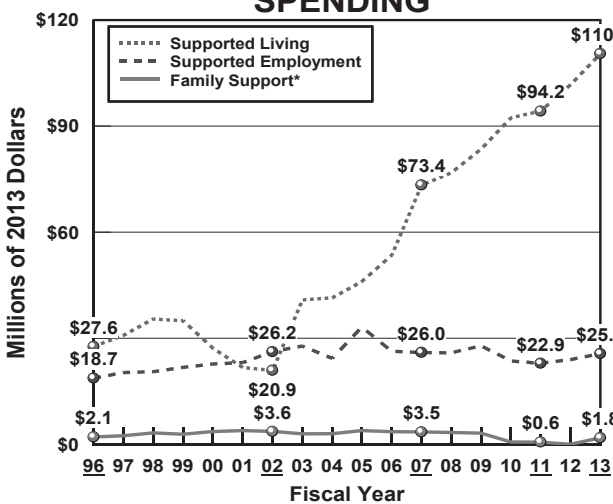


PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013

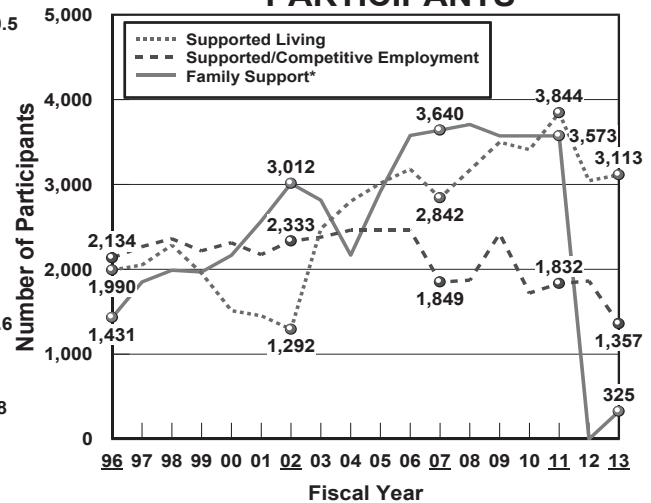


INDIVIDUAL AND FAMILY SUPPORT

SPENDING



PARTICIPANTS



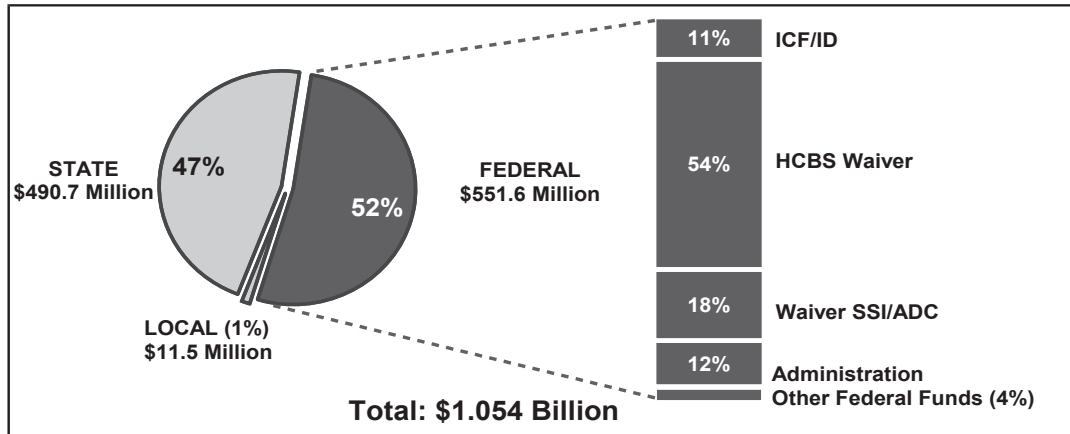
*Reductions in family support spending and families supported, and supported employment spending and workers in 2010-11 due to state general fund reductions. Family support spending was terminated in 2012, but a new cash subsidy was implemented in 2013.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

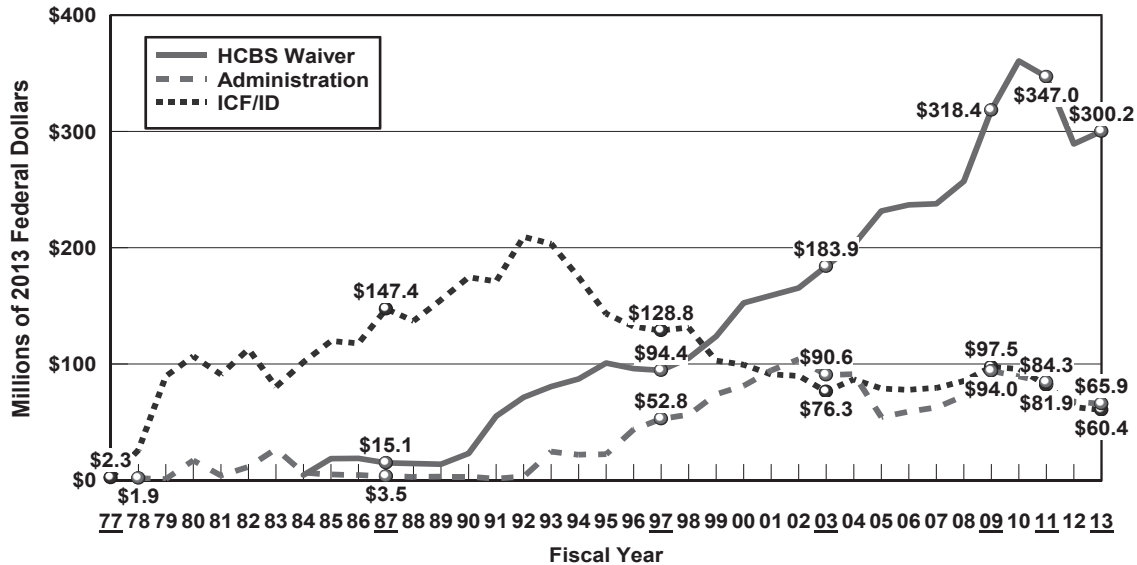
<http://stateofthestates.org>

WASHINGTON

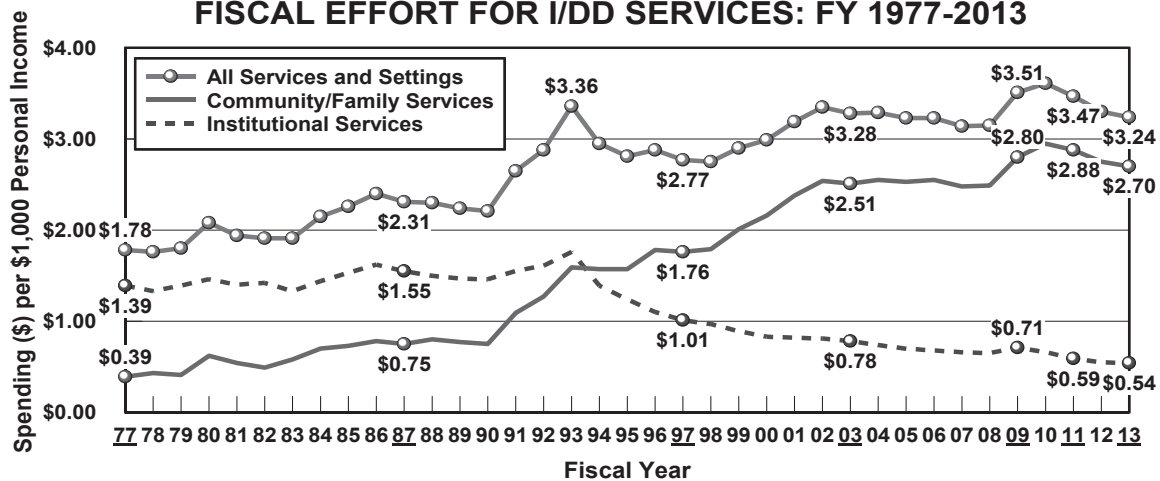
PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013



FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013

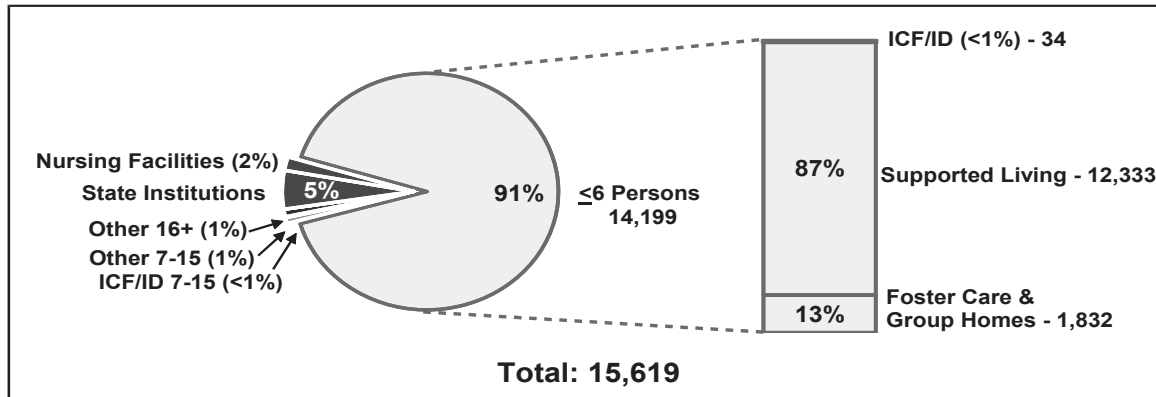


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

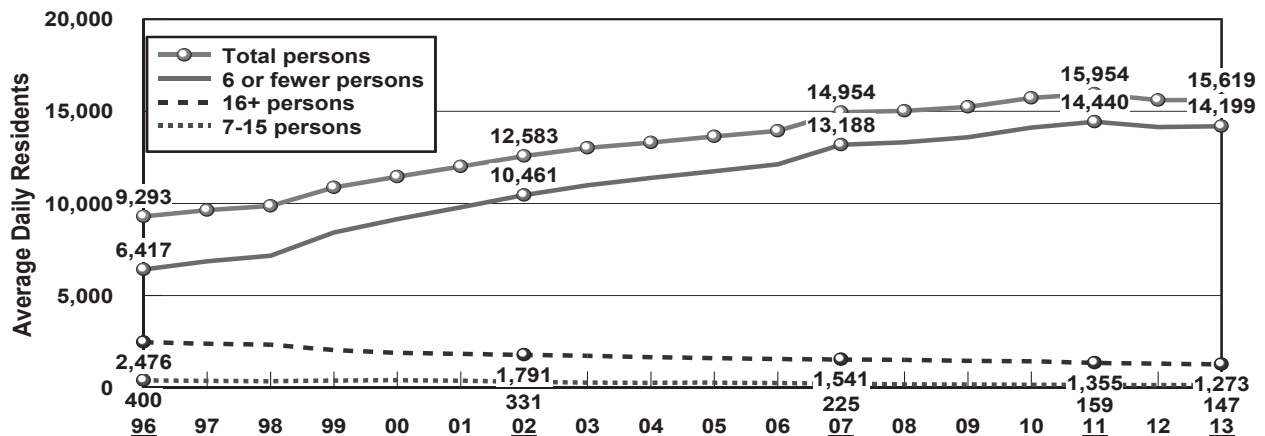
<http://stateofthestates.org>

WASHINGTON

PERSONS BY SETTING IN FISCAL YEAR 2013

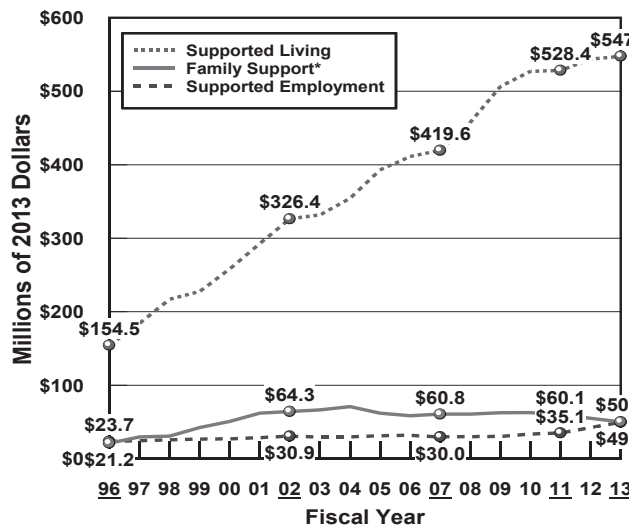


PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013

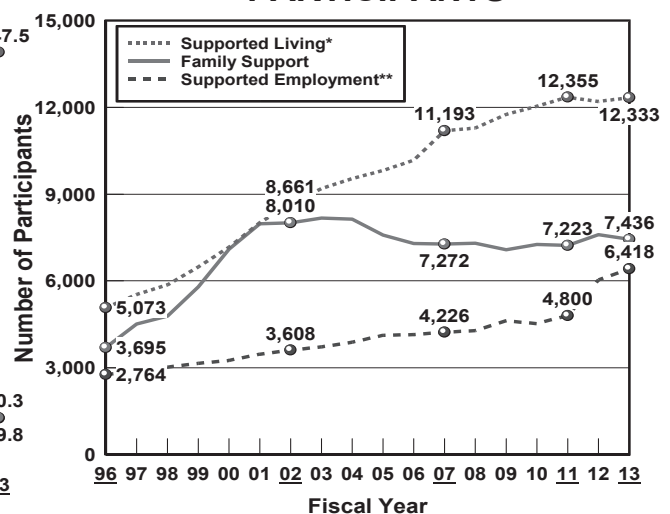


INDIVIDUAL AND FAMILY SUPPORT

SPENDING



PARTICIPANTS



*Family support also includes in-home personal care for children, voluntary placement programs for persons in the family home, SSI state supplements, and HCBS Waiver services.

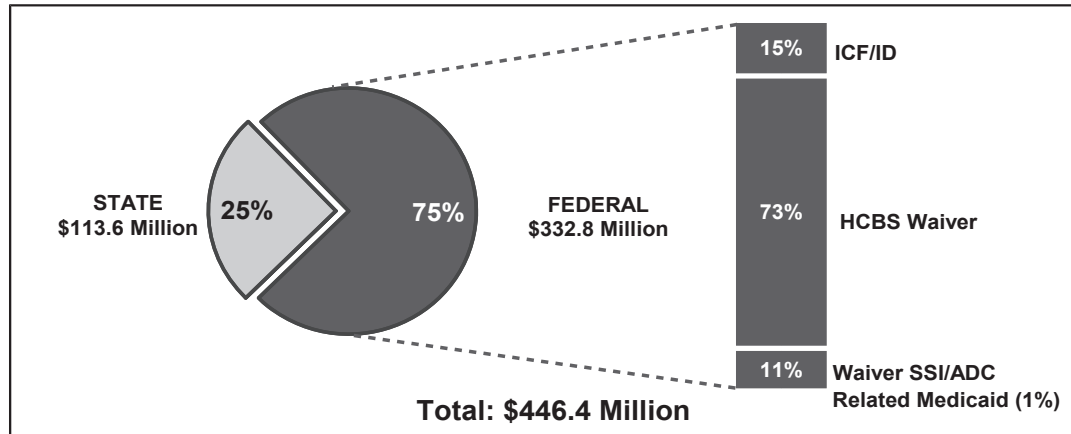
*Includes the State's "supported living" program and other supports that include personal assistance to adults in the family home.

**Includes 762 follow-along work support workers in 2012 and 777 workers in 2013.

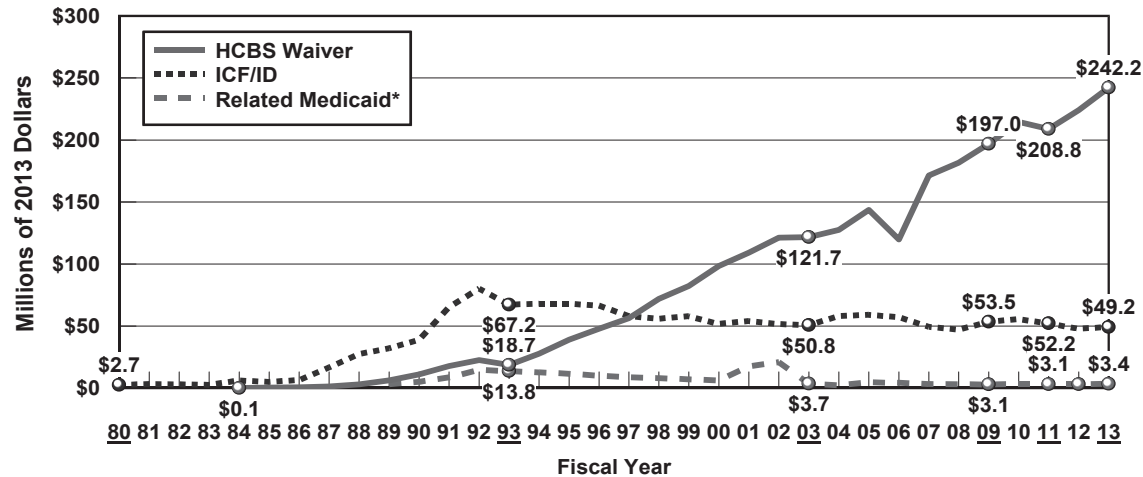
Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.
<http://stateofthestates.org>

WEST VIRGINIA

PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013

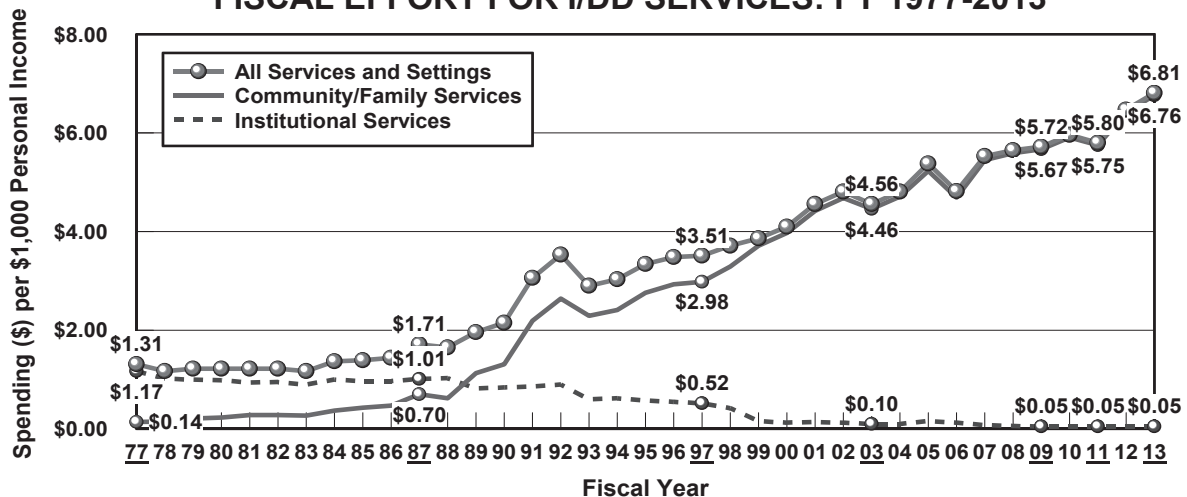


FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



*In 2013, "Related Medicaid" was personal assistance (\$2.96 million), rehabilitative services (\$0.44 million), clinic services (\$0.06 million), and targeted case management (\$0.006 million).

FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013

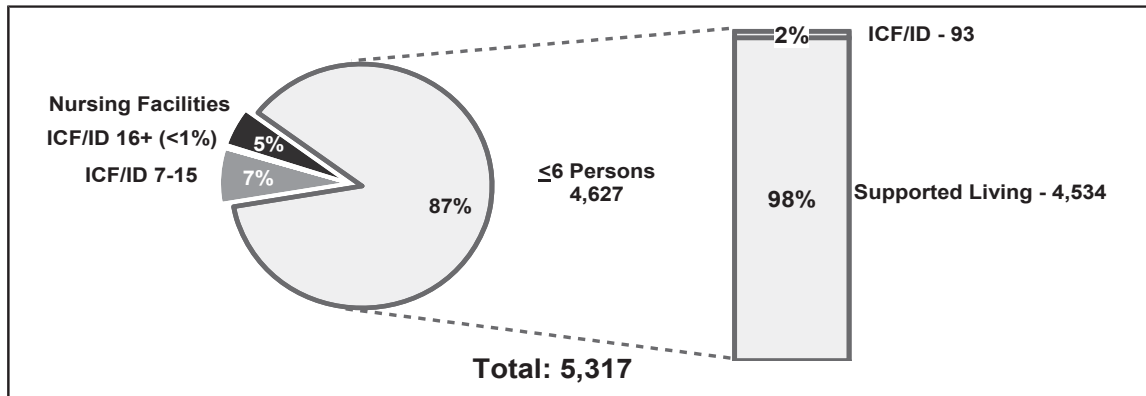


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2013.

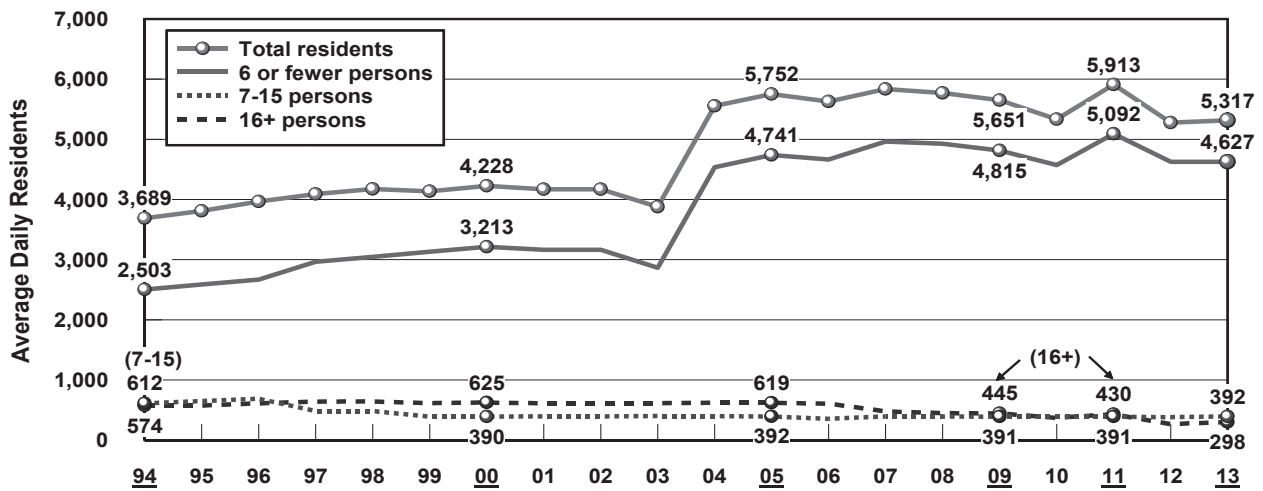
<http://stateofthestates.org>

WEST VIRGINIA

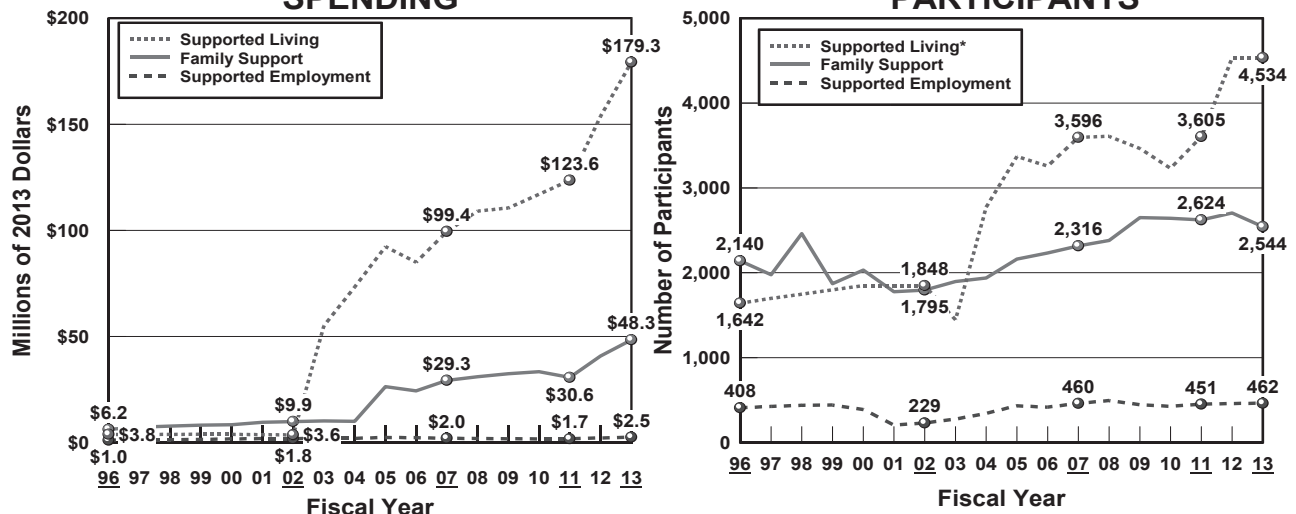
PERSONS BY SETTING IN FISCAL YEAR 2013



PERSONS WITH I/DD BY SIZE OF SETTING: 1994-2013



INDIVIDUAL AND FAMILY SUPPORT SPENDING PARTICIPANTS



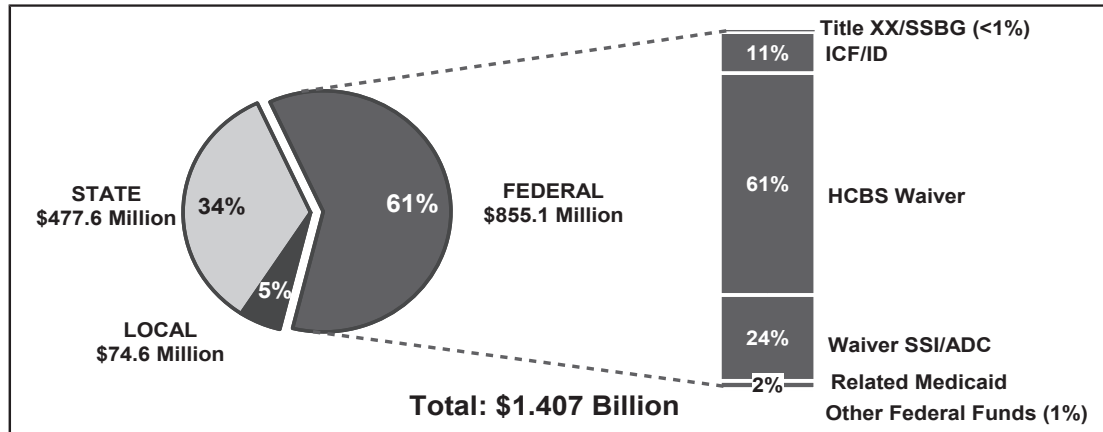
*Supported Living participants in 2012 and 2013 estimated based on capacity of the service.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

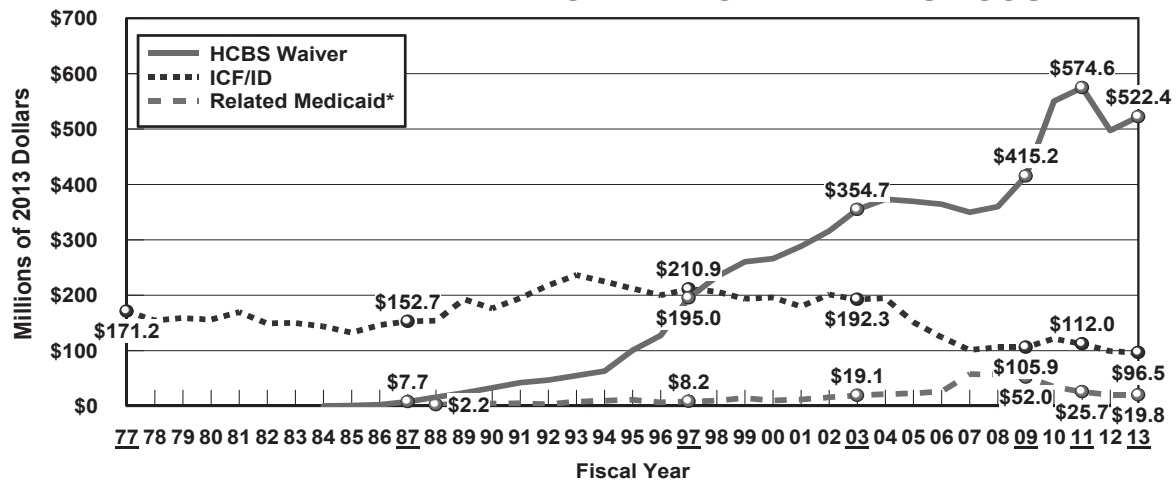
<http://stateofthestates.org>

WISCONSIN

PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013

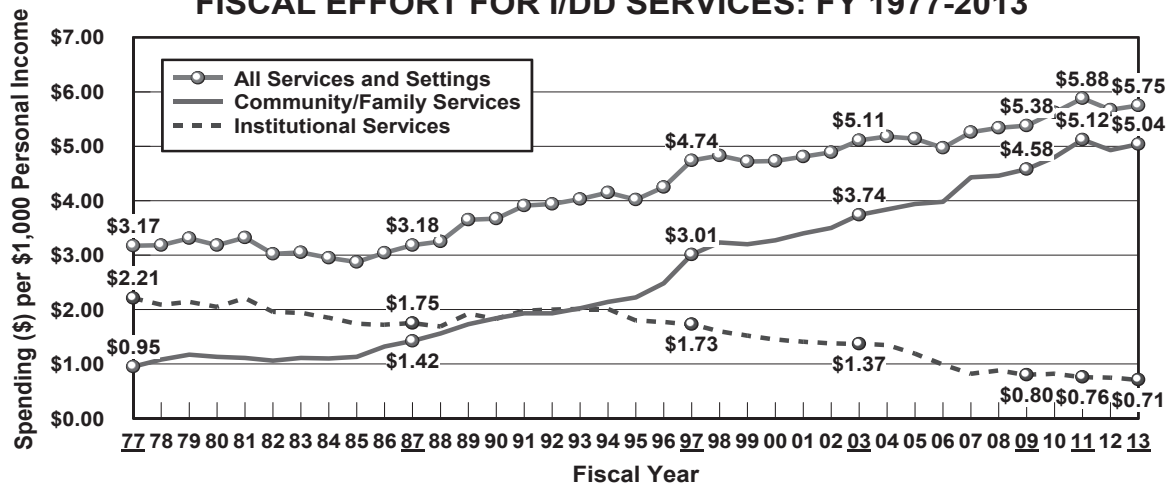


FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



*In 2013, "Related Medicaid" was targeted case management (\$0.8 million) and personal assistance (\$19.0 million).

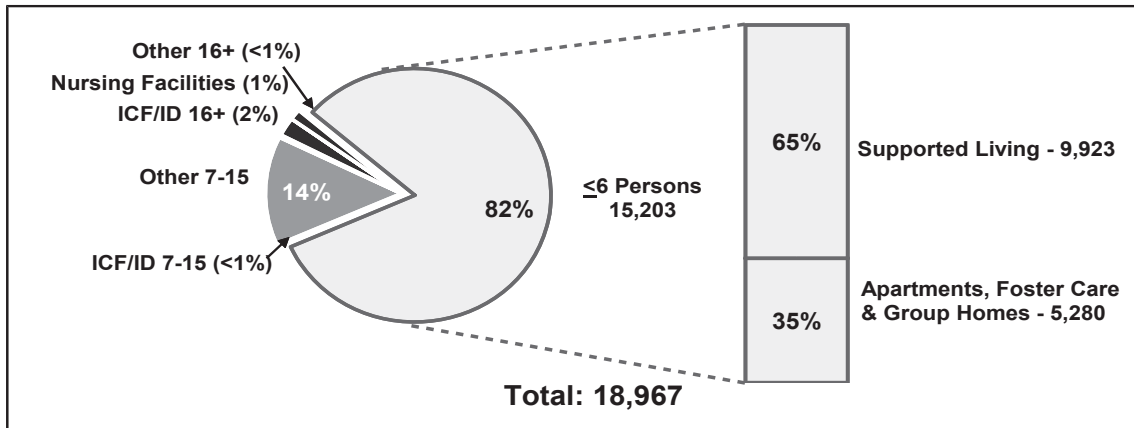
FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013



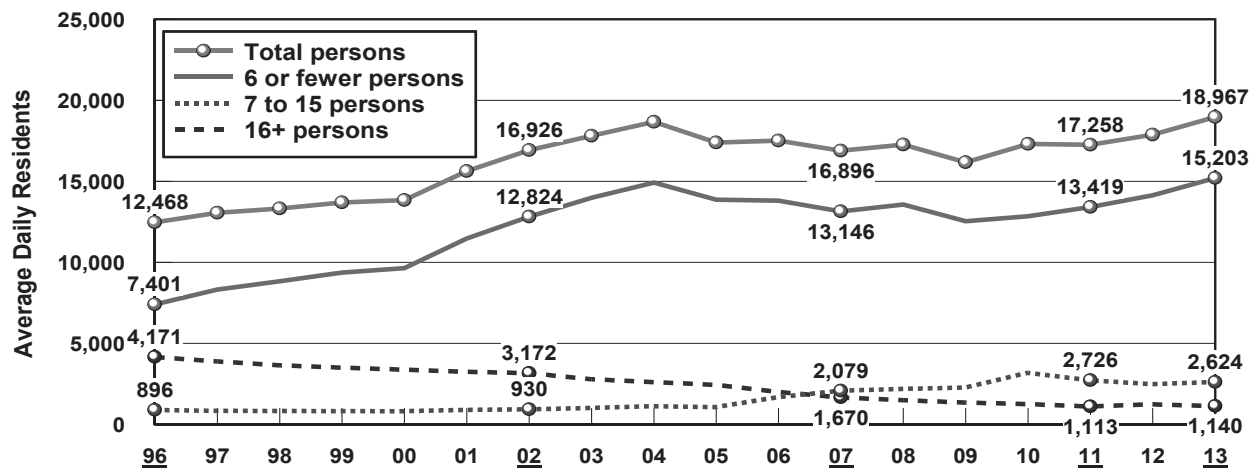
Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.
<http://stateofthestates.org>

WISCONSIN

PERSONS BY SETTING IN FISCAL YEAR 2013

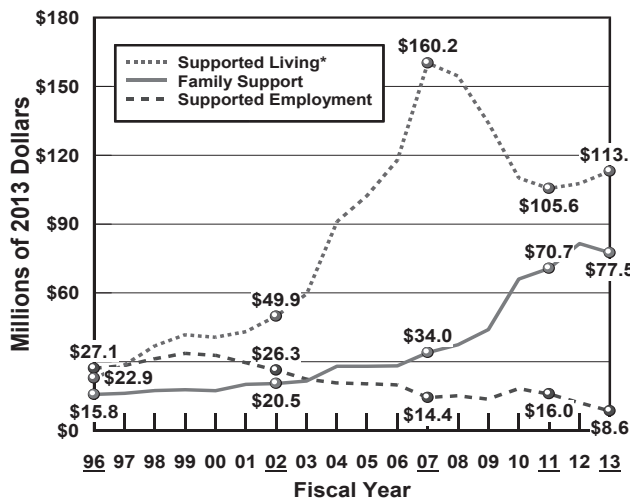


PERSONS WITH I/DD BY SIZE OF SETTING: 1996-2013

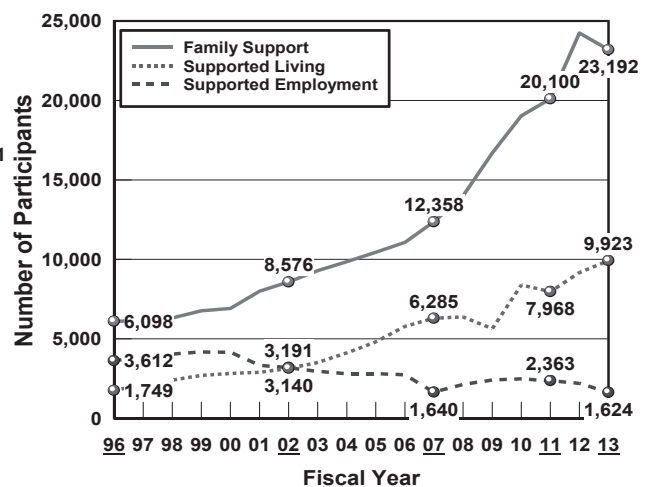


INDIVIDUAL AND FAMILY SUPPORT

SPENDING



PARTICIPANTS



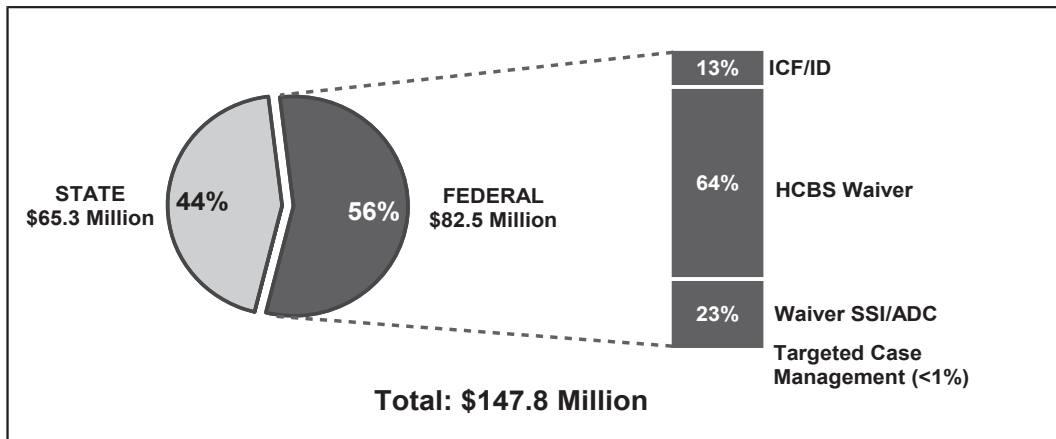
*In shift to Family Care, Family Care partnership & PACE, funding for individuals (Supported Living) re-classified by state as Family Support.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

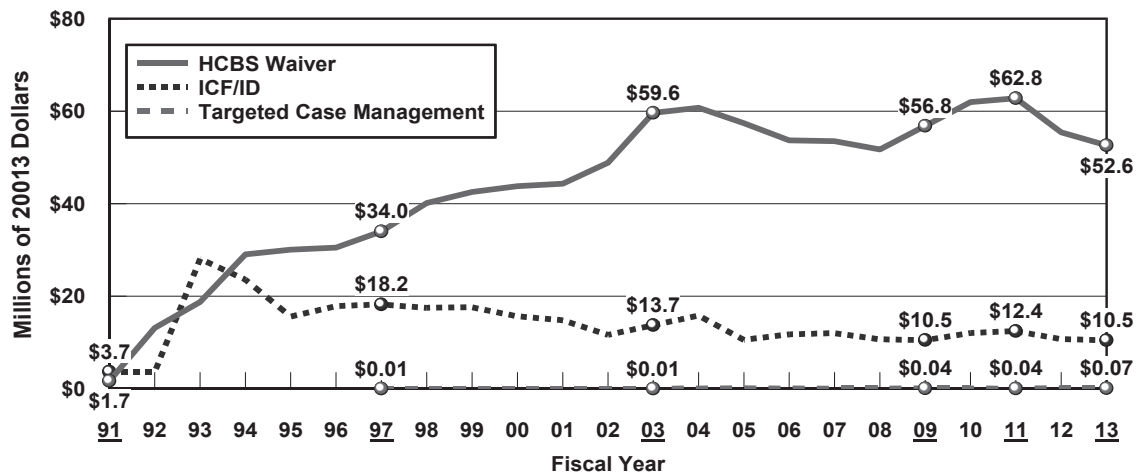
<http://stateofthestates.org>

WYOMING

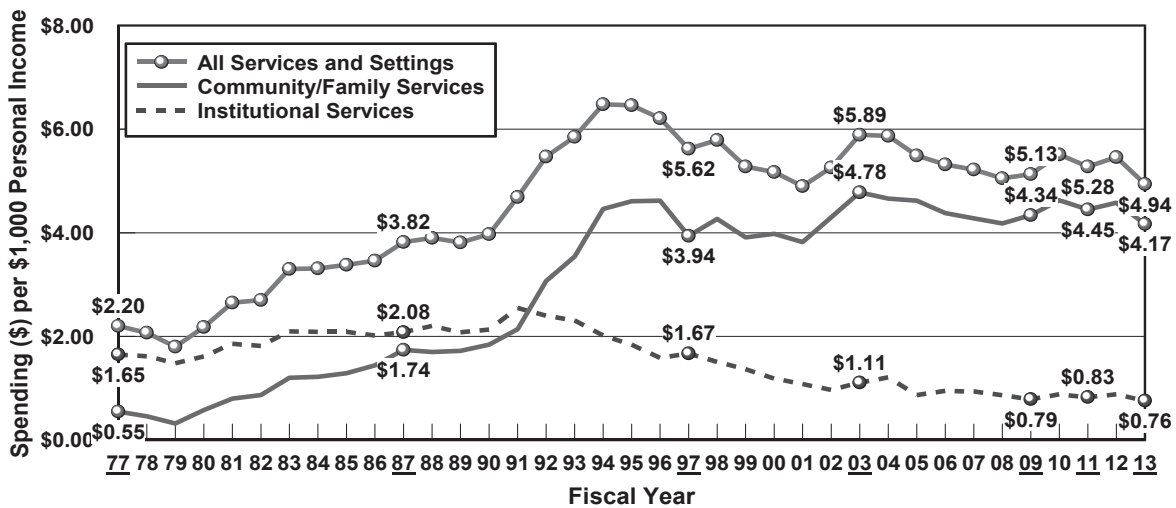
PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2013



FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013

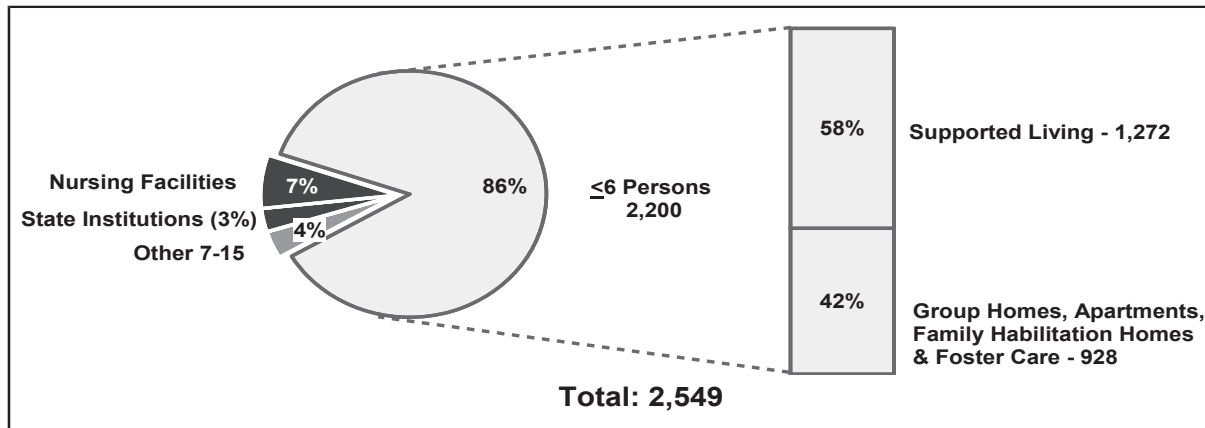


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

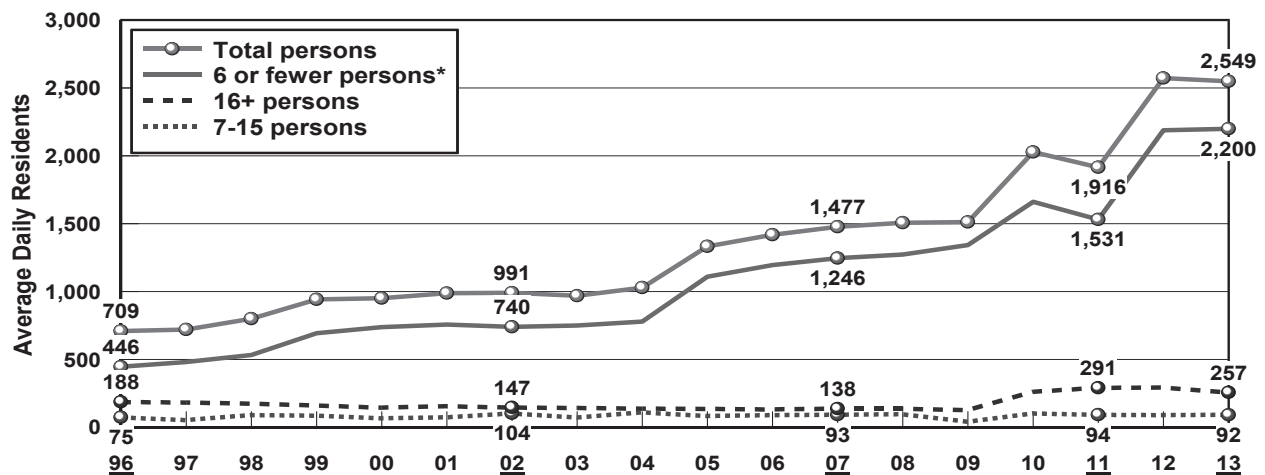
<http://stateofthestates.org>

WYOMING

PERSONS BY SETTING IN FISCAL YEAR 2013



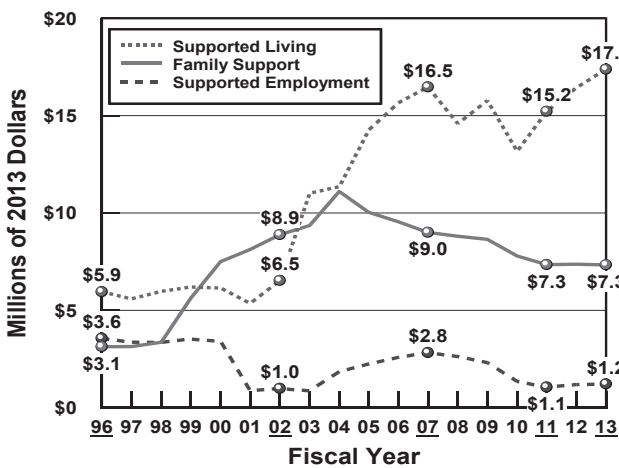
PERSONS WITH I/DD BY SIZE OF SETTING: 1994-2013



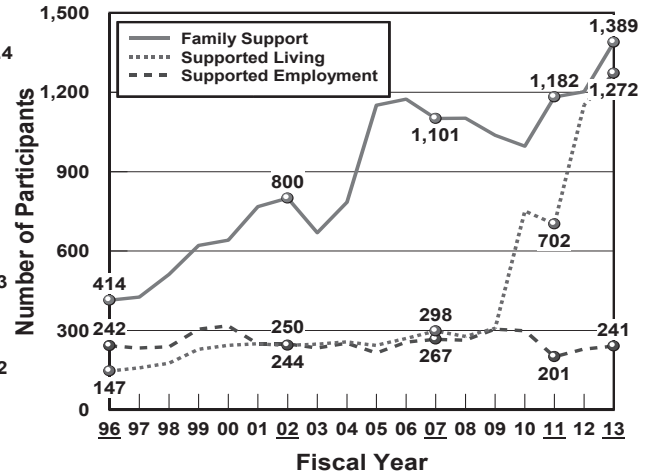
*Increase in 6 or fewer persons settings 2010-13 due to increase in personal assistance participants.

INDIVIDUAL AND FAMILY SUPPORT

SPENDING



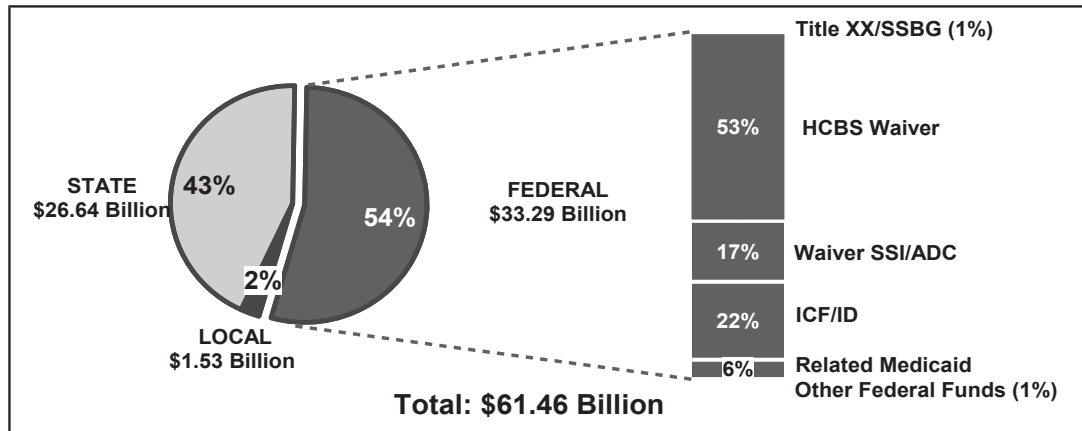
PARTICIPANTS



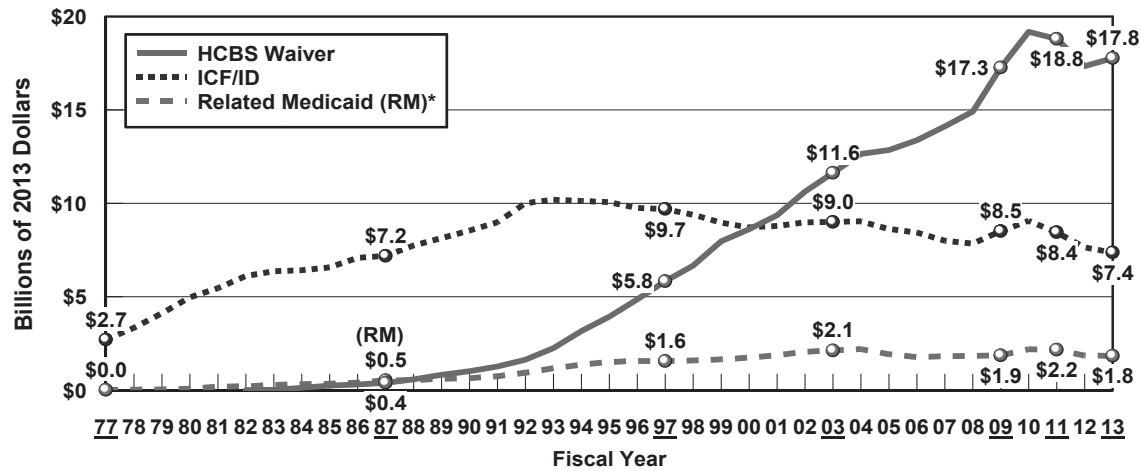
Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.
<http://stateofthestates.org>

UNITED STATES

PUBLIC I/DD SPENDING BY REVENUE SOURCE: FY 2011

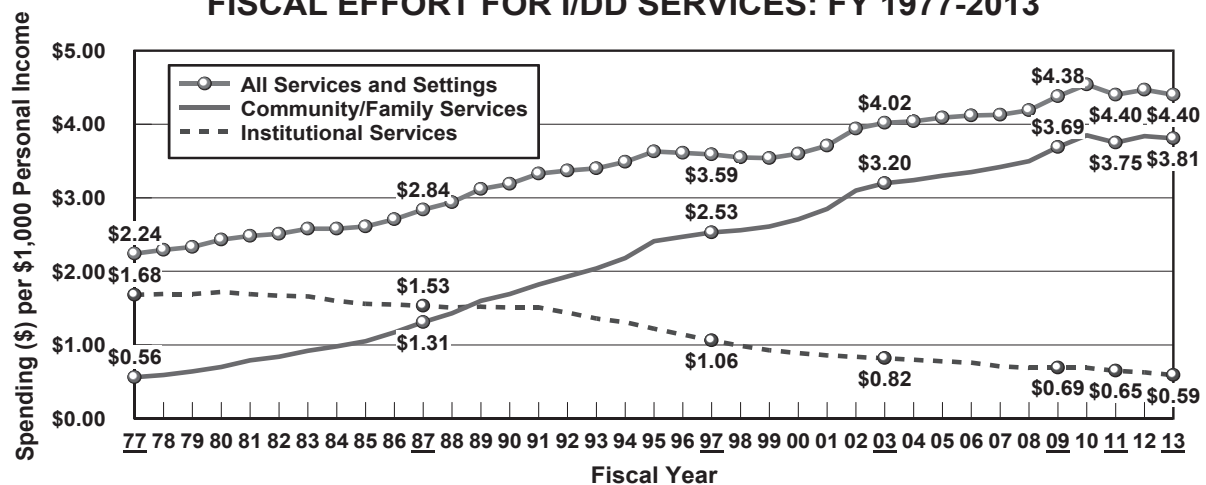


FEDERAL I/DD MEDICAID SPENDING BY REVENUE SOURCE



*In 2013, "Related Medicaid" was administration (\$0.52 billion), clinic/rehabilitative services (\$0.29 billion), targeted case management (\$0.69 billion), and personal assistance (\$0.35 billion).

FISCAL EFFORT FOR I/DD SERVICES: FY 1977-2013

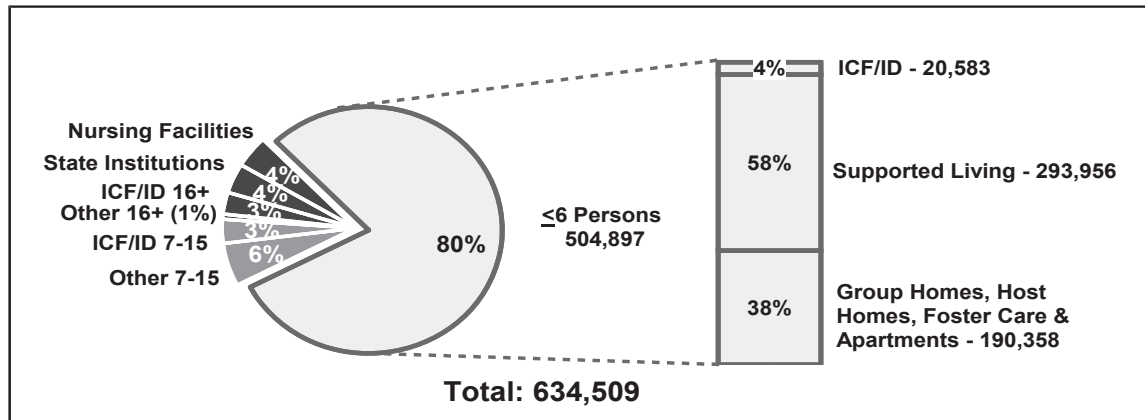


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

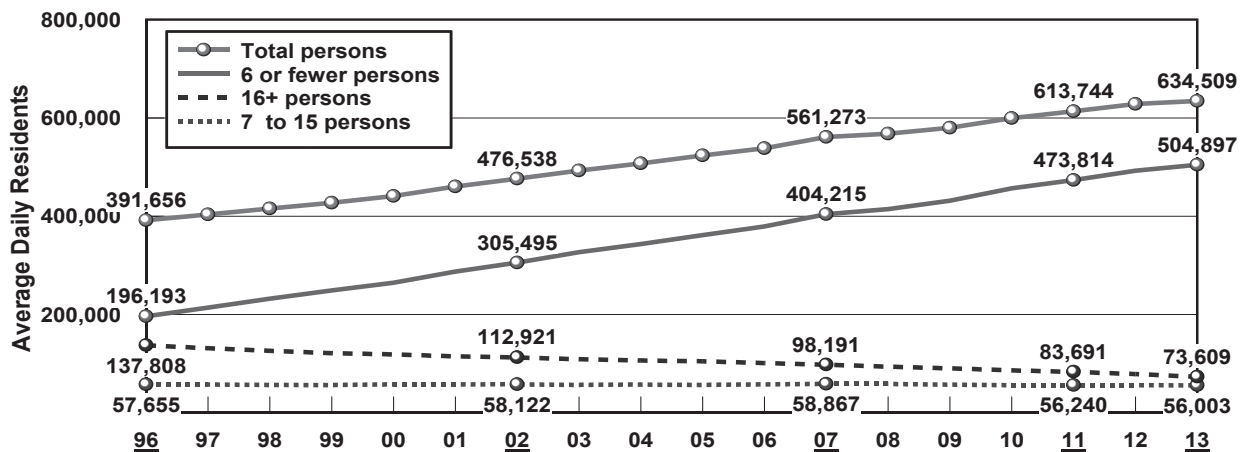
<http://stateofthestates.org>

United States

PERSONS BY SETTING IN FISCAL YEAR 2013

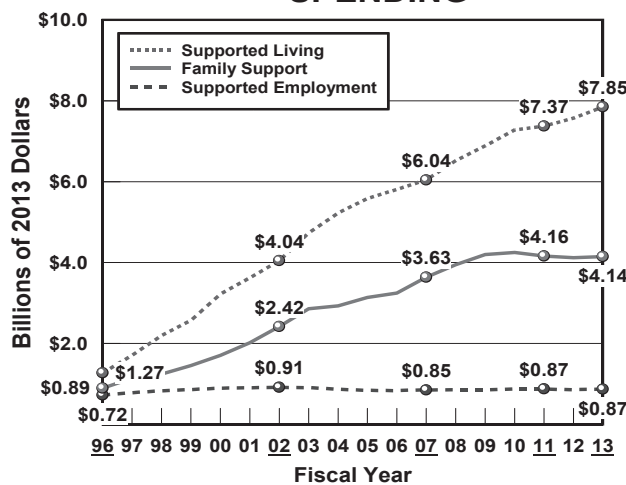


RESIDENTS WITH I/DD BY SIZE OF SETTING: 1996-2013

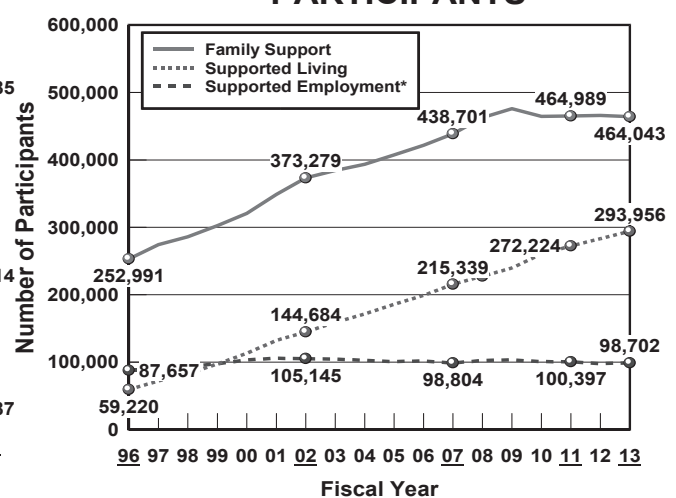


INDIVIDUAL AND FAMILY SUPPORT

SPENDING



PARTICIPANTS



*Does not include 16,031 follow-along work support workers in 2013 in 19 states: AZ, CT, DC, GA, HI, IA, KS, LA, MI, MO, MT, NE, NH, NJ, NC, NY, OH, SC & WA.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

<http://stateofthestates.org>

**STATE, COUNTY AND LOCAL FUNDS POTENTIALLY AVAILABLE TO MATCH
ADDITIONAL FEDERAL MEDICAID FUNDING, BY STATE: FY 2013^{1,2}**

Rank	State	Total Federal, State, County & Local I/DD Spending	Total Unmatched State, County & Local Funds	Unmatched % of Total Spending
47	Alabama	\$365,940,032	\$1,233,224	0.3%
24	Alaska	\$201,532,918	\$12,615,481	6%
34	Arizona	\$841,563,743	\$21,056,347	3%
42	Arkansas	\$527,999,330	\$6,685,604	1%
9	California	\$6,390,317,836	\$938,445,563	15%
13	Colorado	\$531,162,109	\$60,671,568	11%
32	Connecticut	\$1,224,322,460	\$45,189,483	4%
8	Delaware	\$169,412,299	\$25,949,293	15%
16	District of Columbia	\$282,030,691	\$27,698,821	10%
30	Florida	\$1,511,310,251	\$61,494,394	4%
2	Georgia	\$869,762,020	\$258,625,392	30%
18	Hawaii	\$161,577,571	\$12,889,415	8%
51	Idaho	\$207,799,707	\$0	0%
15	Illinois	\$1,617,099,416	\$173,303,127	11%
48	Indiana	\$1,334,739,878	\$2,373,039	0.2%
40	Iowa	\$882,275,768	\$14,079,961	2%
43	Kansas	\$490,174,045	\$5,163,175	1%
26	Kentucky	\$749,108,402	\$36,629,931	5%
31	Louisiana	\$1,433,045,715	\$54,440,240	4%
36	Maine	\$448,139,612	\$8,447,527	2%
12	Maryland	\$1,025,189,427	\$134,025,953	13%
1	Massachusetts	\$2,097,231,847	\$800,538,841	38%
17	Michigan	\$1,486,804,014	\$127,267,109	9%
35	Minnesota	\$1,717,424,059	\$35,369,566	2%
21	Mississippi	\$474,208,880	\$32,692,056	7%
14	Missouri	\$1,019,972,411	\$109,692,952	11%
6	Montana	\$169,771,070	\$33,407,081	20%
33	Nebraska	\$370,871,573	\$12,651,309	3%
5	Nevada	\$163,366,688	\$38,250,024	23%
44	New Hampshire	\$280,842,881	\$2,729,485	1%
7	New Jersey	\$1,999,346,983	\$383,683,363	19%
27	New Mexico	\$361,742,908	\$16,773,966	5%
22	New York	\$10,612,950,881	\$680,595,859	6%
11	North Carolina	\$1,496,279,728	\$195,685,611	13%
38	North Dakota	\$273,546,233	\$4,896,419	2%
3	Ohio	\$3,301,037,315	\$838,412,487	25%
25	Oklahoma	\$517,425,196	\$26,425,108	5%
37	Oregon	\$801,627,121	\$14,664,905	2%
4	Pennsylvania	\$3,596,533,856	\$865,235,035	24%
45	Rhode Island	\$257,610,278	\$1,327,616	1%
19	South Carolina	\$600,724,815	\$46,208,380	8%
29	South Dakota	\$171,431,472	\$7,222,231	4%
39	Tennessee	\$929,290,910	\$16,143,425	2%
28	Texas	\$2,672,609,039	\$118,638,738	4%
46	Utah	\$279,743,642	\$1,032,109	0%
49	Vermont	\$178,644,406	\$42,778	0%
10	Virginia	\$1,307,898,466	\$183,293,641	14%
20	Washington	\$1,053,779,340	\$72,692,088	7%
50	West Virginia	\$446,356,220	\$0	0%
23	Wisconsin	\$1,407,295,564	\$88,942,086	6%
41	Wyoming	\$147,847,342	\$1,941,779	1%
United States		\$61,458,718,366	\$6,657,473,585	10.8%

¹States ranked lowest have the highest percentage of Unmatched Funds as a percentage of total I/DD Spending. Unmatched funds consisted of total I/DD spending, minus federal-state Medicaid, federal SSI/ADC for HCBS Waiver participants, SSI state supplementation, and social services and other federal funds.

²County governments provided 20% of Ohio's unmatched state and local funds; unmatched funds in Iowa & Wisconsin also included county and other local government funding (see **Table 16**, p. 41).

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

APPENDICES

I.	<i>The Rights of People with Cognitive Disabilities to Technology and Information Access</i> (The Declaration).....	205
II.	182 Representative Organizations in the U.S. and Canada Endorsing <i>The Declaration of the</i> <i>Rights of People with Cognitive Disabilities to Technology and Information Access</i>	206
III.	AAIDD article reprint: Braddock, D., Hoehl, J., Tanis, E., Ablowitz, E., & Haffer, L., <i>The Rights of People with Cognitive Disabilities to Technology and Information Access</i>	210

I. The Rights of People with Cognitive Disabilities to Technology and Information Access (The Declaration)

The Rights of People with Cognitive Disabilities to Technology and Information Access

Whereas

- Twenty-eight million United States citizens have cognitive disabilities such as intellectual disability; severe, persistent mental illness; brain injury; stroke; and neurodegenerative disorders such as Alzheimer's disease;
- People with cognitive disabilities are entitled to inclusion in our democratic society under federal laws such as the Americans with Disabilities Act (ADA), the Developmental Disabilities Assistance and Bill of Rights Act (DD Act), the Individuals with Disabilities Education Act (IDEA), Section 504 of the Rehabilitation Act, and under state and local laws;
- The disruptive convergence of computing and communication technologies has substantially altered how people acquire, utilize, and disseminate knowledge and information;
- Access to comprehensible information and usable communication technologies is necessary for all people in our society, particularly for people with cognitive disabilities, to promote self-determination and to engage meaningfully in major aspects of life such as education, health promotion, employment, recreation, and civic participation;
- The vast majority of people with cognitive disabilities have limited or no access to comprehensible information and usable communication technologies;
- People with cognitive disabilities must have access to commercially available devices and software that incorporate principles of universal design such as flexibility and ease of use for all;
- Technology and information access by people with cognitive disabilities must be guided by standards and best-practices, such as personalization and compatibility across devices and platforms, and through the application of innovations including automated and predictive technologies;
- Security and privacy must be assured and managed to protect civil rights and personal dignity of people with cognitive disabilities;
- Enhanced public and private funding is urgently required to allow people with cognitive disabilities to utilize technology and access information as a natural consequence of their rights to inclusion in our society;
- Ensuring access to technology and information for the 28 million people with cognitive disabilities in the United States will create new markets and employment opportunities; decrease dependency on public services; reduce healthcare costs; and improve the independence, productivity, and quality of life of people with cognitive disabilities.

Therefore

We hereby affirm our commitment to equal rights of people with cognitive disabilities to technology and information access and we call for implementation of these rights with deliberate speed.

View endorsers of this document and join us at: colemaninstitute.org/declaration

© 2013 Coleman Institute for Cognitive Disabilities

II. 182 Representative Organizations in the U.S. and Canada Endorsing *The Declaration of the Rights of People with Cognitive Disabilities to Technology and Information Access*

Ability Beyond	Bethel, CT
AbleLink Technologies, Inc.	Colorado Springs, Colorado
Access Services	Fort Washington, PA
ACT - Alternative Community Training	Columbia, MO
Additional Kare for Kids	Allen, Texas
ADEC	Elkhart, IN
AdvocacyDenver	Denver, CO
All About You, LLC	Ada, OK
Alliance	Denver, Colorado
American Association on Intellectual and Developmental Disabilities	Washington, D.C.
American Network of Community Options and Resources	Alexandria, Virginia
APSE	Rockville, MD
ARRM	South St. Paul, Minnesota
Asset Consulting, LLC	Portland, Oregon
Assistive Technology Partners	Denver, Colorado
Association of Assistive Technology Act Programs (ATAP)	Washington, DC
Association of University Centers on Disabilities	Silver Spring, MD
Autism Society of America	Bethesda, Maryland
Autistic Self Advocacy Network	Washington, DC
Avenues to independence	Park ridge, Illinois
Beach Center on Disability, University of Kansas	Lawrence, Kansas
Bethesda Institute	Watertown, Wisconsin
Bethesda Lutheran Communities	Castle Rock, Colorado
Bethesda Lutheran Communities	Cortland, IL
Bethesda Voices Public Policy Advocates	Watertown, Wisconsin
Black Hills Works	Rapid City, SD
Bost, Inc.	Fort Smith, Arkansas
Bright Star Learning bv	Brussels, Belgium
Burton Blatt Institute, Syracuse University	Syracuse, New York
CaraSolva Inc	Boulder, Co
Center for Accessible Information	West Bloomfield, MI
Center for Disabilities	Sioux Falls, South Dakota
Center for Enriched Living	Riverwoods, IL
Center on Human Policy	Syracuse, New York
Cheyenne village	Colorado springs, Co
Coast Rehabilitation Services	Warrenton, Oregon
CanDo Technology Solutions	Glenwood Springs,
Cognitopia	Eugene, OR
Coleman Colorado Foundation	Boulder, Colorado
Coleman Institute for Cognitive Disabilities, University of Colorado	Boulder, Colorado
Colorado Bluesky Enterprises	Pueblo, Colorado
Colorado Cross Disability Coalition	Denver, Colorado
Colorado Developmental Disabilities Council	Denver, Colorado
Colorado Respite Coalition	Denver, CO
Commonwealth Case Management	Monticello, Kentucky
Community Drive	Brighton, Michigan

TO ADD YOUR ORGANIZATION AS AN ENDORSER, GO TO:

ColemanInstitute.org/declaration-endorse

Community Link	Boulder, Colorado
Community Partners, Inc.	Biddeford, Maine
Community Support Services, Inc	Salem, Oregon
Community Support Services, Inc	Biddeford, Maine
Consortium for Citizens with Disabilities Technology Task Force	Washington, DC
Continuum of Colorado	Englewood, Colorado
CQLVThe Council on Quality and Leadership	Towson, Maryland
Danville Services of Oregon, LLC	Portland, OR
DDSME	Belleville, Illinois
Delaware Creative housing, inc.	Delaware, Ohio
Delta Alpha Pi Honor Society- Beta Zeta Chapter @ IU of	Indiana, PA
Delta Community Supports, Inc	Blue Bell, Pennsylvania
Developmental Disabilities	Richmond, BC, Canada
Developmental Disabilities Association	Vancouver, British
Developmental Pathways	Aurora, Colorado
Developmental Pathways	Englewood, CO
Developmental Services of Northwest Kansas, Inc.	Hays, Kansas
Devereux	Devon, PA
Disability Law Center of Utah	Salt Lake City, Utah
Disability Services	Boulder, CO
Discover Goodwill of Southern and Western Colorado	Colorado Springs, CO
Doglet Captioning	North Vancouver, BC,
Dungarvin	Mendota Heights, MN
DylanListed LLC	Dallas, TX
East Tennessee Technology Access Center, Inc.	Knoxville, East Tennessee
Eastern Colorado Services	Sterling, Colorado
Exceptional Persons Inc.	Waterloo, IA
Extreme Sports Camp	Aspen, Colorado
Family Residences and Essential Enterprises	east meadow, NY
FAYCO Enterprises, Inc.	Vandalia, IL
Garvin County Community Living Center, Inc	Pauls Valley, OK
GMS	Westbrook, Maine
Goldie B. Floberg Center	Rockton, IL
Good Shepherd Center for Exceptional Children	Hazelcrest, Illinois
Guam System for Assisstive Technology	Mangilao, Guam
Hammer Residences Inc.	Wayzata , MN
Harvard Law School Project on Disability	Cambridge, MA
Havar	Athens, Ohio
Hills & Dales	Dubuque, IA
Hope Association	Rumford, Maine
Hope Association	Mexico, Maine
Horizons Specialized Services	Steamboat Springs, CO
Hybrid Pedagogy, Inc.	Madison, WI
IAC	New York, New York
IHS Services, Inc	Worthington, Ohio
Illinois Valley Industries, Inc.	Morris, IL
Imagine!	Lafayette, Colorado
Imagine!	Longmont , CO
Imagine!	Boulder, CO
Imagine! Innovations	Boulder, Colorado
Institute for Matching Person and Technology	Webster, New York
Institute on Disability and Human Development, Uofll at Chicago	Chicago, Illinois
International Friends for the Developmentally Disabled	Winfield, Illinois
Iowa Association of Community Providers	Urbandale, Iowa
Iowa Developmental Disabilities Council	Des Moines, Iowa
Kansas University Center on Developmental Disabilities	Lawrence, Kansas
Kids Together, Inc	Coopersburg, Pennsylvania
KIFDD	seoul, koera
Know Me, LLC	Chapel Hill, North Carolina

Lehman Disability Planning	Denver, CO
Liberty	Niskayuna, NY
Liberty Enterprises, Montgomery County ARC.	Amsterdam, NY
Lifeworks, Inc.	Norwood, MA
Little City Foundation	Palatine, IL
Living Resources Corporation	Albany, New York
Lutheran Services in America Disability Network	Washington, DC
Maine Association for Community Service Providers	Hallowell, Maine
McComb Consulting and Government Relations	Chester, Maryland
Michigan Assisted Living Association	Livonia, Michigan
Michigan Disability Rights Coalition	East Lansing, MI
Missouri Assistive Technology	Blue Springs, Missouri
Missouri Developmental Disabilities Council	Jefferson City, Missouri
Monarch	Albemarle, NC
Mondo Mediaworks	Brattleboro, Vermont
Mountain Valley Developmental Services	Glenwood Springs, CO
NADD	Kingston, NY
National Association of Qualified Developmental Disability	Joliet, IL
Natl Jt. Comm. for the Communication Needs of Persons with Severe	Sylva, North Carolina
Disabilities	
New Day Enterprises, Inc	La Grande, Oregon
NHS Human Services	Pittsburgh, Pa.
No Boundaries Case Management	Lexington, Kentucky
None	Galway, NY
Ocss -NC	Statesville, , Nc
OHI	Hermon, Maine
OHI	Brewer, Maine
Ohio Developmental Disabilities Council	Columbus, Ohio
Oklahoma ABLE Tech	Stillwater, Oklahoma
Oklahoma Community-based Providers, Inc.	Oklahoma City, OK
PAR	Harrisburg, PA
PEAK Parent Center	Colorado Springs, Colorado
People First of Marshall Mo.	Marshall, Mo.
Project Janus, Inc.	San Angelo, Texas
Puerto Rico Assistive Technology Program	San Juan, Puerto Rico
Quality Trust for Individuals with Disabilities	Washington, DC
RESNA	Arlington, VA
RHD	Philadelphia, pa
Rocky Mountain Human Services	Denver, Colorado
Rouses Group Home Inc	Stoneville, NC
Rush University Medical Center	Chicago, Illinois
Ryan Law Firm, LLC	Denver, CO
Sanford School of Medicine Center for Disabilities	Sioux Falls, South Dakota
Security Partners, LLC	Lancaster, Pennsylvania
SEEC	Silver Spring, MD
Self Advocates Becoming Empowered	Mansas City, Missouri
Self-Advocacy Association of New York State	Schenectady, NY
Sengistix	Mendota Heights, MN
Sertoma Centre, Inc.	Alsip, Illinois
Shore Community Services, Inc.	Skokie, IL
Sibling Leadership Network	Boulder, Colorado
SimplyHome, Ilc	Asheville, North Carolina
Solace Healthcare	Denver, Colorado
Southern Illinois Community Support Services	New Baden, IL
Southern Illinois Living Centers, Inc.	New Baden, IL
Southwest Community Services	Tinley Park, Illinois
Space2Create	Loveland, Colorado
Spectrum Foundation of Colorado	Lafayette, CO

SRVS	Memphis, TN
super host hotels inc	Albany, N.Y.
Supportive Living, Inc.	Woburn, MA
Tarjan Center at UCLA	Los Angeles, CA
Texas Technology Access Program	Austin, Texas
The Arc Arapahoe & Douglas	Centennial, Colorado
The Arc Jackson County	Medford, OR
The Arc- Jefferson, Clear Creek, & Gilpin Counties	Lakewood, Co
The Arc of Arlington, TX	Arlington, TX
The Arc of Greater Cleveland	Cleveland, Ohio
The Arc of the Pikes Peak Region	Colorado Springs, CO
The Arc of the U.S.	Washington, D.C.
The Arc: Greater Houston Chapter	Houston, Texas
The Brain Injury Alliance of Colorado	Denver, Colorado
The Lawrence B. Taishoff Center for Inclusive Higher Education	Syracuse, NY
The Legal Center for People with Disabilities and Older People	Denver, CO
The National Center on Disability and Access to Education	Logan, Utah
The Resource Center	Jamestown, New York
The Resource Exchange	Colorado Springs, Colorado
Trinity Services, Inc	New Lenox, Illinois
United Cerebral Palsy Association of San Diego County	San Diego, California
University of Colorado	Boulder, Colorado
University of Colorado - Parking & Transportation Services	Boulder, Colorado
Unlimited Possibilities of Colorado	Greeley, CO
Uplift, Inc.	Gardiner, Maine
Values Into Action	Media, Pennsylvania
Westchester Institute for Human Development	Valhalla, New York
YAI	NYC, NY

The Rights of People With Cognitive Disabilities to Technology and Information Access

David Braddock, Jeffery Hoehl, Shea Tanis, Enid Ablowitz, and Laura Haffer

Abstract

Information and communication technologies are ubiquitous and valuable tools for billions of people worldwide today. Yet people with cognitive disabilities, particularly individuals with intellectual and developmental disabilities, have quite limited access to such technologies. This article presents the case for mounting significant efforts to advance the rights of millions of people with cognitive disabilities to technology and information access. A formal statement of these rights is presented, formulated by professionals and consumers representing a variety of disciplines and perspectives. The statement is currently endorsed by numerous national, state and local organizations in the developmental disabilities field in the United States. Your comments and participation are invited and appreciated.

The Rights of People With Cognitive Disabilities to Technology and Information Access

Cognitive disabilities include intellectual and developmental disabilities; autism spectrum disorders; severe, persistent mental illness; brain injury; stroke; Alzheimer's disease; and other dementias. An estimated 28.5 million Americans, more than nine percent of the U.S. population, had a cognitive disability in 2012. People with cognitive disabilities worldwide are believed to exceed 630 million individuals, according to recent World Health Organization estimates (2011).

The prevalence of people with cognitive disabilities living in developing nations substantially exceeds their presence in developed nations. This is primarily because the vast majority of the world's population resides in poor countries with limited access to medical care and educational opportunities. However, there is considerable cause for optimism.

Advances in technology and information science have positively impacted the potential for learning and information access for all people, including people with cognitive disabilities. As Eric Schmidt and Jared Cohen (2013) observed in their book, *The New Digital Age*:

Soon everyone on earth will be connected. With five billion more people set to join the virtual world, the boom in digital connectivity will bring gains in productivity, health, education, quality of life and myriad other avenues in the physical world—and this will be true for everyone, from the most elite users to those at the base of the economic pyramid (p.13).

People with cognitive disabilities comprise a very significant component of “the base of the economic pyramid” in all countries, not just in the developing world. Reducing barriers for people with cognitive disabilities who cannot readily access or utilize information and communication technologies without significant support therefore becomes an extremely important objective in the context of Schmidt and Cohen's prediction.

The pace of the digital age is expected to accelerate rapidly through new innovations in cloud computing, which lends itself exceedingly well to the development of customized, personal platforms to fit varied interests and competencies (Coleman, 2013). Highly individualized cloud computing platforms are expected to become formidable tools analogous to “utilities” fostering inclusion and promoting quality of life of people with cognitive disabilities. Areas of potential positive impact of cloud-based initiatives include not only improved personal communications, but

also health promotion, disease prevention, enhanced social interaction, and individualized supported employment opportunities such as remote job coaching.

A particularly provocative question must also be addressed about the future of over one billion people with disabilities worldwide, including those 630 million individuals with cognitive disabilities. How effectively, and how soon, can human-centered computational support technologies be adapted or uniquely developed and properly disseminated to match the unique needs and preferences of individuals with cognitive disabilities? People with cognitive disabilities, in fact, comprise over 60% of the world's total estimated population of people with disabilities. They also often present quite unique challenges for technologists developing personalized human-computer interfaces.

People with sensory disabilities and their advocates have promoted the benefits and adoption of technology and information access for their constituencies much more intensely and effectively than cognitive disability advocates and consumers. The diffusion of captioning online video content and screen readers are two recent examples of effective advocacy by sensory disability constituencies and subsequent responsiveness by industry. People with cognitive disabilities and their parents, friends, and professional support personnel, have not been nearly as effective as sensory disability constituencies in promoting access to personalized technologies and information to meet their unique access needs.

Writing in the inaugural issue of the journal, *Inclusion*, Gomez (2013), immediate past president of the American Association on Intellectual and Developmental Disabilities (AAIDD), drew attention to this point in stating that "focusing on friendship networks for people with (intellectual) disabilities represents a paradigm shift from skills development to social inclusion" (p.1). Thus, the key related question becomes how can greater attention to cognitive disability and technology be generated to promote diffusion of innovation in inclusion to enhance friendship networks, general social participation, employment, education, health and general communications?

One obvious objective is to stimulate greater attention nationally and worldwide to the possibilities now at hand for people with cognitive disabilities through technology while simultaneously championing their rights as citizens to

access such technologies in home, school and workplace. On October 21, 2010 at the University of Colorado's Coleman Institute for Cognitive Disabilities Tenth Annual National Conference on Cognitive Disability and Technology, the following question was posed by the lead author of this article and conference chair to one of the most respected civil rights attorneys in the history of our field, Thomas Gilhool. As Gilhool was introduced to a national audience from over 40 states, he was asked: "Forty years after *Pennsylvania Association of Retarded Children [PARC] v. Commonwealth of Pennsylvania*, is there an emerging right to technology and information access for people with cognitive disabilities, including intellectual and developmental disabilities?"

Gilhool, formerly chief counsel of the Public Interest Law Center of Philadelphia, Secretary of Education of the Commonwealth of Pennsylvania, and University of Southern California law professor, argued the seminal case in a Philadelphia Federal Court in 1971 that led to establishing the right to a public education for children with disabilities (*Pennsylvania Association for Retarded Children V. Commonwealth of Pennsylvania*, 1971), and ultimately led to the enactment by the federal government of the Education for All Handicapped Children's Act in 1975 and its successor legislation, The Individuals With Disabilities Education Act (IDEA) in 2004.

In a poignant response to the question about access to technology, Gilhool stated that he believed a right to technology access by people with cognitive disabilities was ascendant in the United States today—potentially enabling a future with far better access to appropriate education, community living and employment opportunities. He encouraged the 500 participants at our conference in Colorado that day to advance this issue with further thought and action.

The Coleman Institute subsequently engaged Gilhool and Syracuse University law professor Peter Blanck, head of the Burton Blatt Institute. We asked them both to explore the implications of existing legal precedents to the rights to education, habilitation and community living as those established rights might inform, and possibly encompass, evolving law and policy pertaining to inclusive technology and web access rights for individuals with cognitive disabilities. This research was commissioned by the Coleman Institute and will be published in book form by Cambridge University Press in 2014. British law

instructor Eliza Varney recently authored an important, complimentary international treatise published by Cambridge University Press as well. *Disability and Information Technology: A Comparative Study in Media Regulation* (2013) comparatively and meticulously examined information and communications technology (ICT) regulation across four international domains: Canada, European Union, United Kingdom, and the United States). In addressing the rationale for access to information and technology by people with disabilities, she stated that:

The regulatory approach for the ICT (Information and Technology) sector should perceive persons with disabilities not only as consumers but also as citizens with democratic expectations of effective access to information. Furthermore, the regulatory framework should be based on a clearly defined framework of principles such as equality of citizenship and the protection of human dignity (p.38).

We concur, and Ms. Varney will deliver a keynote address at the Coleman Institute Conference on Cognitive Disability and Technology on October 2, 2013 in Colorado.

To build on the groundwork already done towards documenting the rights of people with cognitive disabilities to technology and information access, in the fall of 2012, the Coleman Institute convened a group of leaders in the United States representing numerous national disability associations and disciplines in cognitive disability, computer science, technology, engineering, special education, disability studies, rehabilitation, psychology, philosophy, philanthropy, and law and public policy. Together we crafted and collectively endorsed *The Rights of People with Cognitive Disabilities to Technology and Information Access*, which appears at the end of this article along with a list of its authors and the initial organizational endorsers of that document*. This document is being officially released internationally through the new AAIDD journal, *Inclusion*, and at the Coleman Institute's October 2, 2013 conference in Colorado where approximately 500 attendees from over 40 states and abroad will have the opportunity to endorse it. Additional supporters may endorse the document online at the Coleman Institute's website (<http://www.colemaninstitute.org>)

The Rights of People with Cognitive Disabilities to Technology and Information Access is a statement of principles. It builds on the history of community

integration rights for people with intellectual and developmental disabilities established in law, policy and practice through decades of advocacy by parents, people with disabilities themselves, and conscientious professionals in the field (Syracuse University, 1979). Centuries of abuse, social isolation, prejudice and incomprehensible discrimination toward people with cognitive disabilities and their families are being addressed in our nation today, albeit at a painstakingly slow pace and unevenly across individual states, cities, communities and neighborhoods. In fact, advocacy by people with cognitive disabilities themselves and their siblings and parents, through organizations like *Self Advocates Becoming Empowered* and the *Sibling Leadership Network*, are playing larger roles in advancing the rights of people with cognitive disabilities today. And *The Arc of the United States*, sixty-one years after its initial formation, retains significant vitality and nationwide influence across virtually all states and in many local communities.

To date, these three advocacy organizations are among those who have officially endorsed our Statement. Other boards of directors of national organizations endorsing *The Rights of People with Cognitive Disabilities to Technology and Information Access* include those from the American Association on Intellectual and Developmental Disabilities (AAIDD), The American Network of Community Options and Resources, The Arc (United States), Beach Center on Disability at the University of Kansas, the Burton Blatt Institute at Syracuse University, the Coleman Colorado Foundation and Coleman Institute for Cognitive Disabilities at the University of Colorado, the Institute on Disability and Human Development at the University of Illinois at Chicago, the Kansas University Center on Developmental Disabilities, Self Advocates Becoming Empowered, and the Westchester Institute for Human Development, New York. AAIDD, it is noted, had the foresight to establish a Technology Special Interest Group (SIG) 15 years ago and continues today to define and lead key aspects of the field by creating and disseminating new knowledge about services and supports.

As signatories of the document presented herein, we are honored and grateful that leading organizations in the intellectual and developmental disabilities field are charter signatories of *The Rights of People with Cognitive Disabilities to Technology and Information Access*. Their collective

endorsements signal substantial momentum to advance the right to technology and information access and to act forthwith to implement those rights.

Inclusion and *choice* are indeed cornerstones of the disabilities field today. Their implementation in the United States, incomplete it may be, spans several decades of commitments to deinstitutionalization and community integration, implementation of the right to education nationally, promulgation and implementation of the Syracuse University Community Imperative (1979), and enactment and implementation of the Americans with Disabilities Act of 1990 and the Developmental Disabilities and Bill Of Rights Act of 1975. Inclusion and choice have also driven the self-

determination movement by people with developmental disabilities to new heights of independence and productivity (Wehmeyer, Agran, Hughes, Martin, Mithaug, & Palmer, 2007).

Advancing the rights of people with cognitive disabilities to technology and information access is an extremely important next step in the worldwide implementation of inclusion and choice. Modern and developing societies are capable of moving more rapidly toward an inclusive future through the diffusion and application of information and communication technology supports. In this spirit, we present our statement of *The Rights of People with Cognitive Disabilities to Technology and Information Access*.

Figure 1

The Rights of People With Cognitive Disabilities to Technology and Information Access

WHEREAS:

Twenty-eight million United States citizens have cognitive disabilities such as intellectual disability; severe, persistent mental illness; brain injury; stroke; and neurodegenerative disorders such as Alzheimer's disease;

People with cognitive disabilities are entitled to inclusion in our democratic society under federal laws such as the Americans with Disabilities Act (ADA), the Developmental Disabilities Assistance and Bill of Rights Act (DD Act), the Individuals with Disabilities Education Act (IDEA), Section 504 of the Rehabilitation Act, and under state and local laws;

The disruptive convergence of computing and communication technologies has substantially altered how people acquire, utilize, and disseminate knowledge and information;

Access to comprehensible information and usable communication technologies is necessary for all people in our society, particularly for people with cognitive disabilities, to promote self-determination and to engage meaningfully in major aspects of life such as education, health promotion, employment, recreation, and civic participation;

The vast majority of people with cognitive disabilities have limited or no access to comprehensible information and usable communication technologies; People with cognitive disabilities must have access to commercially available devices and software that incorporate principles of universal design such as flexibility and ease of use for all;

Technology and information access by people with cognitive disabilities must be guided by standards and best-practices, such as personalization and compatibility across devices and platforms, and through the application of innovations including automated and predictive technologies; Security and privacy must be assured and managed to protect civil rights and personal dignity of people with cognitive disabilities;

Enhanced public and private funding is urgently required to allow people with cognitive disabilities to utilize technology and access information as a natural consequence of their rights to inclusion in our society;

Ensuring access to technology and information for the 28.5 million people with cognitive disabilities in the United States will create new markets and employment opportunities; decrease dependency on public services; reduce healthcare costs; and improve the independence, productivity, and quality of life of people with cognitive disabilities.

THEREFORE, BE IT RESOLVED THAT:

We the undersigned hereby affirm our commitment to equal rights of people with cognitive disabilities to technology and information access and we call for implementation of these rights with deliberate speed.

INITIAL ENDORSING ORGANIZATIONS

AbleLink Technologies

AbleLink Technologies was founded in 1997 specifically to address the significant need for research-based cognitive support technologies for individuals with cognitive disabilities and those experiencing cognitive decline. The team has been built purposefully with individuals representing relevant fields of expertise including human services, human factors, rehabilitation technology, software engineering, occupational therapy, and clinical and experimental psychology.

American Association on Intellectual and Developmental Disabilities

Since 1876, the American Association on Intellectual and Developmental Disabilities (AAIDD) has been providing worldwide leadership in the field of intellectual and developmental disabilities. AAIDD is the oldest and largest interdisciplinary organization of professionals and citizens concerned about intellectual and developmental disabilities in the world.

American Network of Community Options and Resources

The American Network of Community Options and Resources (ANCOR) is a national, nonprofit trade association representing more than 800 private community providers of services to people with disabilities. Combined, they serve over 400,000 individuals with disabilities and work to shape policy, share solutions, and strengthen community.

The Arc

The Arc is the largest national community-based organization advocating for and serving people with intellectual and developmental disabilities and their families. They encompass all ages and all spectrums from autism, Down syndrome, Fragile X and various other developmental disabilities. With more than 140,000 members and more than 700 state and local chapters nationwide, they are on the front lines to ensure that people with intellectual and developmental disabilities and their families have the support they need to be members of the community. Founded in 1950, The Arc was comprised of a small group of concerned and passionate parents and community members who would be a catalyst for changing the public perception of children with disabilities. For the past 60 years, The Arc has continued to grow and evolve along with the changing needs and issues people with disabilities and their families face.

ASSET Consulting

ASSET Consulting (Applying Systems, Software, and Engineering Technology) helps organizations adopt, market, or develop emerging technologies. For over 20 years, ASSET Consulting has specialized in applications for long-term care and people with cognitive disabilities. Clientele include service providers, technology vendors, academic institutions, trade associations, and government agencies. The mission of ASSET Consulting is to advance the effective use of emerging technology in service of social needs.

Assistive Technology Partners, University of Colorado

Assistive Technology Partners was established in 1989 and is part of the Department of Physical Medicine and Rehabilitation, School of Medicine, University of Colorado. It encompasses programs in four major areas: clinical services, outreach and information services, research and engineering, education and professional development. Assistive Technology Partners provides a unique integration of capabilities and services for persons with disabilities and associated professional affiliations.

Beach Center on Disability, University of Kansas

The Beach Center on Disability is a multi-disciplinary research and training center committed to making a significant and sustainable positive difference in the quality of life of individuals and families affected by disability and the professionals who support them. Its staff of approximately 40 professors, researchers, educators, doctoral students, and support personnel carry out research, technical assistance, and undergraduate, masters, and doctoral training. Its staff focuses on families, family quality of life, and family support; public policy in special education and disability services; school reform, with emphasis on inclusion of students with and without disabilities in general education; conceptualizing self-determination and its application to people with disabilities; conceptualizing and defining intellectual disability; defining

and measuring supports and support needs; technology use by people with cognitive disability; and positive behavioral supports and services.

Burton Blatt Institute, Syracuse University

The Burton Blatt Institute (BBI) at Syracuse University reaches around the globe in its efforts to advance the civic, economic, and social participation of people with disabilities. BBI builds on the legacy of Burton Blatt, former dean of Syracuse University's School of Education and a pioneering disability rights scholar, to better the lives of people with disabilities. BBI has offices in Syracuse, Washington, D.C., and Atlanta. Given the strong ties between one's ability to earn income and fully participate in their communities, BBI's work focuses on two interconnected Innovation Areas: Economic Participation and Community Participation. Through program development, research, and public policy guidance in these Innovation Areas, BBI advances the full inclusion of people with disabilities.

Coleman Colorado Foundation

The Coleman Colorado Foundation (CCF) supports the Coleman Institute for Cognitive Disabilities' activities through a private endowment and sustained annual contributions by the founding donors, William T. and Claudia L. Coleman. The CCF is a 501 (c) (3) public charity classified as a 509 (a) (3) supporting organization to the University of Colorado.

Coleman Institute for Cognitive Disabilities, University of Colorado

The Coleman Institute for Cognitive Disabilities' mission is to catalyze and integrate advances in science, engineering, and technology to promote the quality of life and independent living of people with cognitive disabilities. The Coleman Institute for Cognitive Disabilities was established in 2001 by the Regents of the University of Colorado. A private endowment and sustained annual contributions by their founding donors, William T. and Claudia L. Coleman, support the Institute's activities through the Coleman Colorado Foundation (CCF).

Imagine!

Imagine! was established in 1963 as a private, not-for-profit organization and as the first community-centered board (CCB) in Colorado. In addition to serving as a state CCB, Imagine! provides services designed to incorporate people with developmental, cognitive and physical challenges into the fabric of their communities. Services include educational and therapeutic services, job training and placement, recreation and leisure activities, opportunities for community living, behavioral health services, technology solutions and support for families.

Institute for Matching Person and Technology

The Institute for Matching Person and Technology was formed to better match users of technologies with the most appropriate devices for their use. The Institute works to enhance the situation of technology users through research, assessment, training and consultation. The Matching Person and Technology (MPT) assessment process is one means for providing a more personal approach to matching person and technology.

Institute on Disability and Human Development, University of Illinois at Chicago

The Institute on Disability and Human Development (IDHD), a University Center for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD) is dedicated to promoting the independence, productivity and inclusion of people with disabilities into all aspects of society. The mission is addressed by conducting research and disseminating information about disability to academicians, policymakers, businesses, government agencies, service providers and the general public. The IDHD also provides an extensive array of clinical and community service activities and, through the Department of Disability and Human Development and other academic departments, offers interdisciplinary pre-service training. The values of cultural diversity, consumer choice and self-determination are emphasized across the life span in all training, public service, and research activities of the IDHD.

Kansas University Center on Developmental Disabilities

The Kansas University Center on Developmental Disabilities (KUCDD), established in 1969, is a component of the Life Span Institute at the University of Kansas. The KUCDD maintains facilities on the University's main campus in Lawrence, at the KU Medical Center in Kansas City, and in Parsons. In addition to these primary sites, the KUCDD supports affiliated projects in many Kansas communities and provides training and other types of support to all regions of the state. As a University Center for Excellence in Developmental Disabilities (UCEDD) funded by the Administration on Developmental Disabilities, the

core functions of the KUCDD are: pre-service training, research, information dissemination, and community services.

The National Center on Disability and Access to Education

The National Center on Disability and Access to Education (NCDAE) exists to address issues of technology and disability in education policies and practices to enhance the lives of people with disabilities and their families. NCDAE works on policy, research, training and technical assistance, and dissemination of information. NCDAE accomplishes its purpose through an affiliate network of over 500 national and international partners in education, business and industry, and government.

Self Advocates Becoming Empowered

Self Advocates Becoming Empowered (SABE) is the self-advocacy organization for people with developmental disabilities in the United States. It consists of local, state, and national components. Founded in 1990, the organization promotes the full inclusion of people with developmental disabilities in the community throughout the 50 states. Their non-profit advocacy organization is run by a board of self-advocates representing 9 regions of the country.

Sibling Leadership Network

The Sibling Leadership Network's (SLN) mission is to provide siblings of individuals with disabilities the information, support, and tools to advocate with their brothers and sisters and to promote the issues important to them and their entire families. The Network promotes a broad network of siblings nationally who share the experience of disability and people concerned with sibling issues by connecting them to social, emotional, governmental, and provisional supports across the lifespan. This enables them to be effective advocates with their brothers and sisters, and to serve as change agents for themselves and their families.

Westchester Institute for Human Development

Westchester Institute for Human Development is a leader in addressing major social and health issues affecting people with disabilities and vulnerable children. WIHD addresses major social and health issues by developing and delivering medical, clinical and support services to individuals, their families and caregivers. As one of only 67 University Centers for Excellence in Developmental Disabilities, WIHD creates better futures for these individuals through the creation and dissemination of innovative research, professional leadership education and best practices trainings.

***Acknowledgement of co-authors of the Statement on The Rights of People With Cognitive Disabilities to Technology and Information Access:**

Twenty-four people participated in the Coleman Institute Preconference Workshop on Cognitive Disability and Technology. The event was held in Broomfield, Colorado on November 16, 2012. Discussion at that event centered on the merit, content and dissemination strategy of a formal statement to advance the development, access and utilization of technology by people with cognitive disabilities in the United States. A formal statement was collectively drafted and revised over the course of the following year. That Statement appears as Figure 1 of this article as *The Rights of People With Cognitive Disabilities to Technology and Information Access*.

Enid Ablowitz, Coleman Institute for Cognitive Disabilities, University of Colorado

Rodney Bell, ASSET Consulting, LLC, Portland OR

Peter Blanck, Burton Blatt Institute, Syracuse University

Cathy Bodine, Department of Rehabilitation Medicine, CU-Denver School of Medicine

David Braddock, Coleman Institute for Cognitive Disabilities, Office of the President and Department of Psychiatry, University of Colorado

Claudia Coleman, Coleman Colorado Foundation
William T. Coleman, Coleman Colorado Foundation

Daniel K. Davies, AbleLink Technologies, Inc., Colorado Springs

Mark Emery, Imagine! Colorado

Cathy Enfield, Self-Advocates Becoming Empowered

Laura Haffer, Coleman Institute for Cognitive Disabilities, Boulder, CO

Richard Hemp, Coleman Institute for Cognitive Disabilities and CU Department of Psychiatry

Jeffery Hoehl, Coleman Institute for Cognitive Disabilities and CU-Boulder Department of Computer Science
Clayton Lewis, Coleman Institute for Cognitive Disabilities and CU-Boulder Department of Computer Science
Margaret A. Nygren, American Association on Intellectual and Developmental Disabilities, Washington, DC
David O'Hara, Westchester Institute for Human Development, Westchester, NY
Renee Pietrangelo, American Network of Community Options and Resources, Alexandria, Virginia
Mary Kay Rizzolo, Institute on Disability & Human Development, University of Illinois-Chicago
Cyndi Rowland, Center for Persons with Disabilities, Utah State University, Provo
Marcia Scherer, University of Rochester and Institute for Matching Person and Technology
Emily Shea Tanis, Coleman Institute for Cognitive Disabilities and Department of Psychiatry, University of Colorado
Michael L. Wehmeyer, Department of Special Education, Kansas University Center on Developmental Disabilities, and Beach Center on Disability, University of Kansas
Greg Wellems, Imagine! Colorado
Ann Cameron Williams, The Arc, Washington, DC

References

- Braddock, D. (2013). Testimony on Long Term Care and Developmental Disabilities in the United States. Washington, DC: Hearings Before the United States Congress Bipartisan Long Term Care Commission, Dirksen Federal Building, July 17, 2013.
- Coleman, III., W.T. "The Greatest Inflection Point: The Cloud and People with Cognitive Disabilities" Presentation at the National Institute on Standards and Technology, Washington DC, 2013.
- Gomez, S. C. (2013). The vision for inclusion. *Inclusion*, 1(1). 1-4.
- Schmidt, E. & Cohen, J. (2013). *The New Digital Age: Reshaping the Future of People, Nations and Business*. New York: Knopf.
- Syracuse University Center on Human Policy (1979). *The Community Imperative: A refutation in support of institutionalizing anybody because of mental retardation*. Syracuse: Author.
- Varney, E. (2013). *Disability and Information Technology*. Cambridge: Cambridge University Press.
- Wehmeyer, M., Agran, M., Hughes, C., Martin, J. Mithaug, D.E., & Palmer, S. (2007). *Promoting self-determination in students with developmental disabilities*. New York: Guilford.
- World Health Organization (2011). *World Report on Disability*. Geneva: Health Organization Press.

Author:

David Braddock, david.braddock@cu.edu, Coleman Institute for Cognitive Disabilities University of Colorado, Boulder, 3825 Iris Ave., Suite 200, Boulder, CO 80301; **Jeffery Hoehl** Coleman Institute for Cognitive Disabilities, University of Colorado, Boulder; **Shea Tanis**, Coleman Institute for Cognitive Disabilities, University of Colorado, Boulder; **Enid Ablowitz** Coleman Institute for Cognitive Disabilities, University of Colorado, Boulder; **Laura Haffer** Coleman Institute for Cognitive Disabilities, University of Colorado, Boulder

