

Building Your Advocacy Case with Data

Disability Policy Seminar
April 24, 2018
Washington, DC

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STATE OF THE STATES
IN INTELLECTUAL AND
DEVELOPMENTAL DISABILITIES



A University Center for Excellence
in Developmental Disabilities
University of Oklahoma Health Sciences Center



Coleman Institute for Cognitive Disabilities
UNIVERSITY OF COLORADO

Boulder | Colorado Springs | Denver | Anschutz Medical Campus

“Don’t tell me what you value, show me your budget, and I’ll tell you what you value.”

~Joe Biden, 47th Vice President of the United States

11th Edition

Financial and Programmatic Trends Through FY 2015

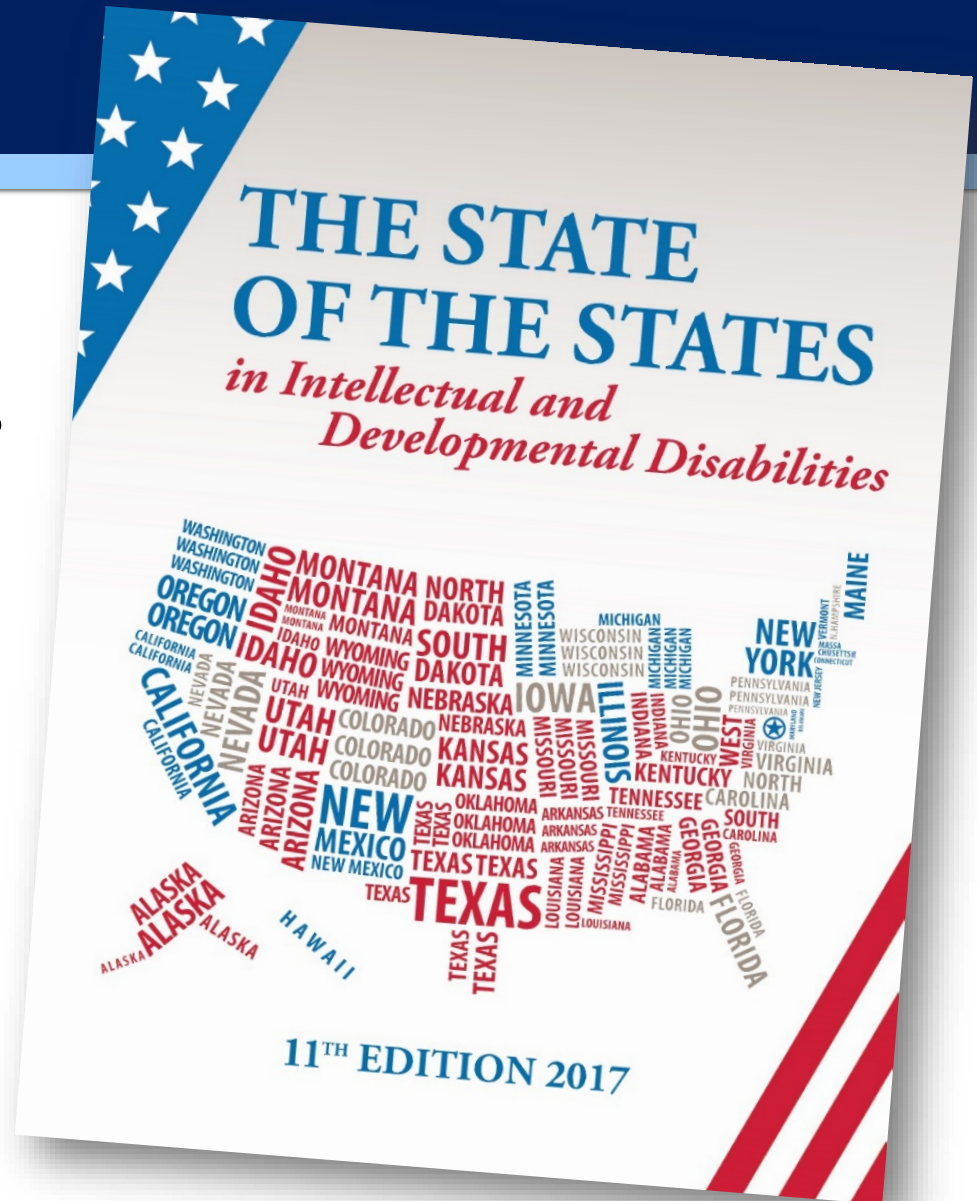
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American Association
on Intellectual and
Developmental Disabilities



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Key Federal and State Financial Supports Utilized in Data Collection

I. INSTITUTIONAL SERVICES FINANCIAL DATA

(16 or more persons)

A. PUBLIC 16+ INSTITUTIONAL SERVICES FUNDS

1. State Funds

- a. ICF/ID Medicaid Match
- b. General Funds (not including state ICF/MR match)
- c. Other State Funds (not including state ICF/MR match)
- d. Local Funds in Excess of Match

2. Federal Funds

- a. Federal ICF/ID
- b. Title XX/Social Services Block Grant
- c. Other Federal Funds

B. PRIVATE 16+ INSTITUTIONAL SERVICES FUNDS

1. State Funds

- a. ICF/ID Medicaid Match
- b. General Funds (not including state ICF/ID match)
- c. Other State Funds (not including state ICF/ID match)
- d. Local Funds in Excess of Match

2. Federal Funds

- a. Federal ICF/ID
- b. Other Federal Funds



Key Federal and State Financial Supports Utilized in Data Collection (continued)

II. COMMUNITY SERVICES FINANCIAL DATA

(15 or fewer persons)

A. COMMUNITY SERVICES FUNDS FOR 15 OR FEWER PERSONS

1. State Funds

- a. ICF/ID Medicaid Match
- b. General Funds (not including state ICF/ID match)
- c. Other State Funds (not including state ICF/ID match)
- d. Local/County Funds in Excess of Match
- e. SSI State Supplement Funds

2. Federal Funds

- a. Public ICF/ID (<16)
- b. Private ICF/ID (<16)
- c. HCBS Waiver
- d. Other Medicaid Services
 - 1. Rehabilitation Services
 - 2. Clinic Services
 - 3. Targeted Case Management
 - 4. Personal Care Services
 - 5. Other Medicaid Services
- e. Title XX/Social Services Block Grant
- f. Other Federal Funds
- g. SSI and Adults Disabled in Childhood (ADC) benefits –
HCBS Waiver participants



Key Program and Participant Categories

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, 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)

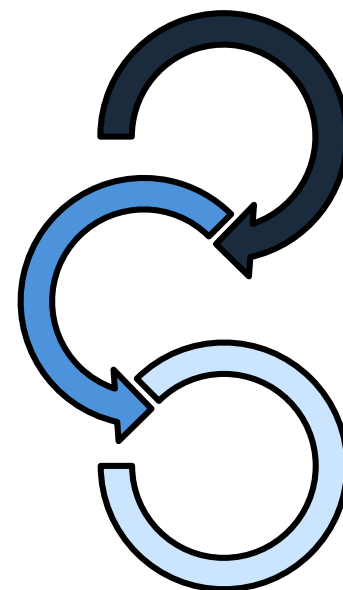
- A. State-operated institutions
- B. Private ICFs/ID
- C. Other private residential facilities
- D. Nursing facility residents with I/DD



State protocol

i Selected examples

- Review of:
 - Published budget documents
 - Conversations with state IDD agency personnel
- Data collection tool
 - Excel spreadsheets
 - Revenue and expenditure data
 - Number of participants
 - Spending, revenue, and participant data on specific support categories
 - Accompanied by an instruction guide and definitions



National data sources



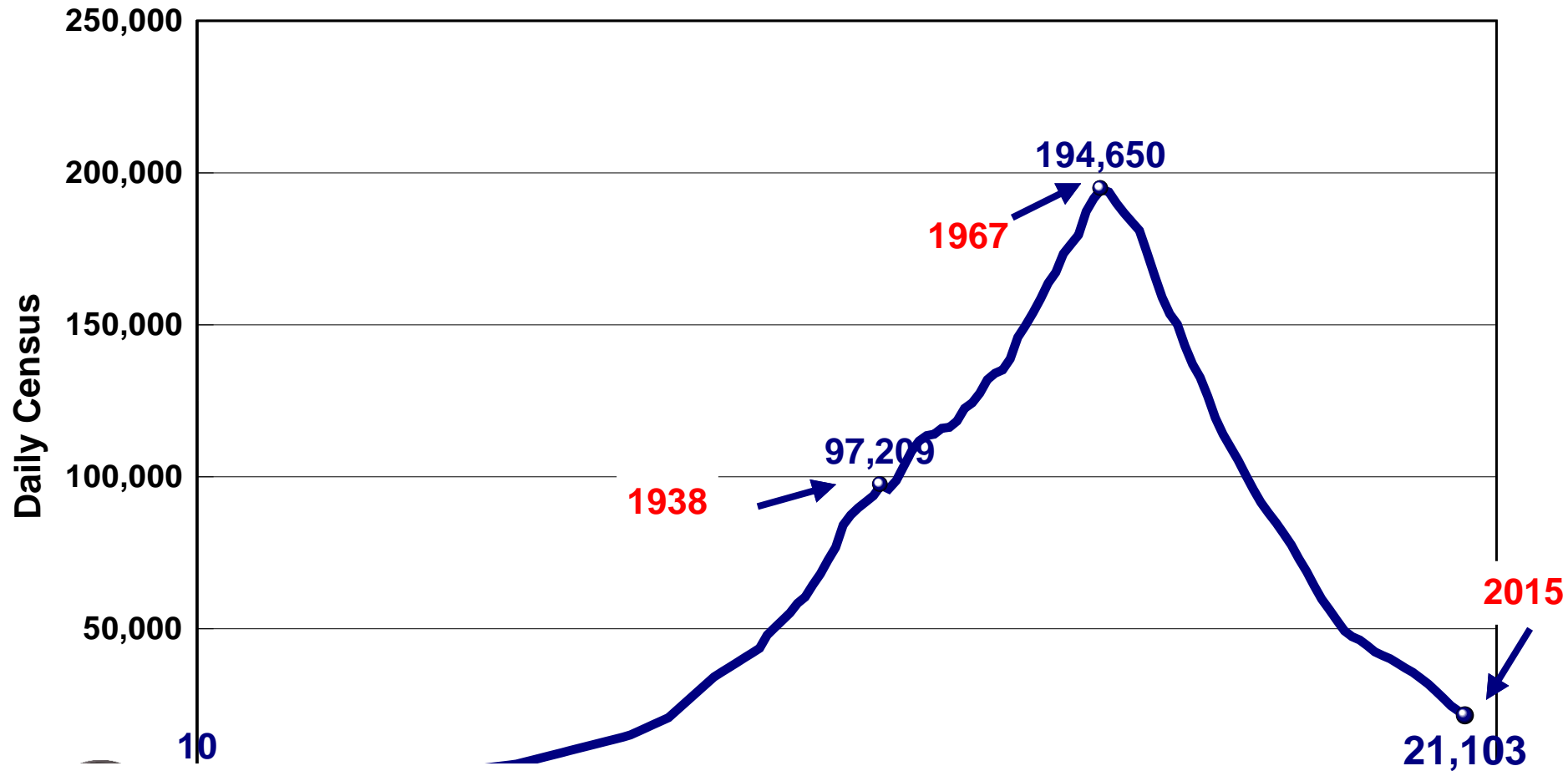
CMS

CENTERS for MEDICARE & MEDICAID SERVICES



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US IDD institutional census (1848-2015)



Public IDD institutional closures through 2015

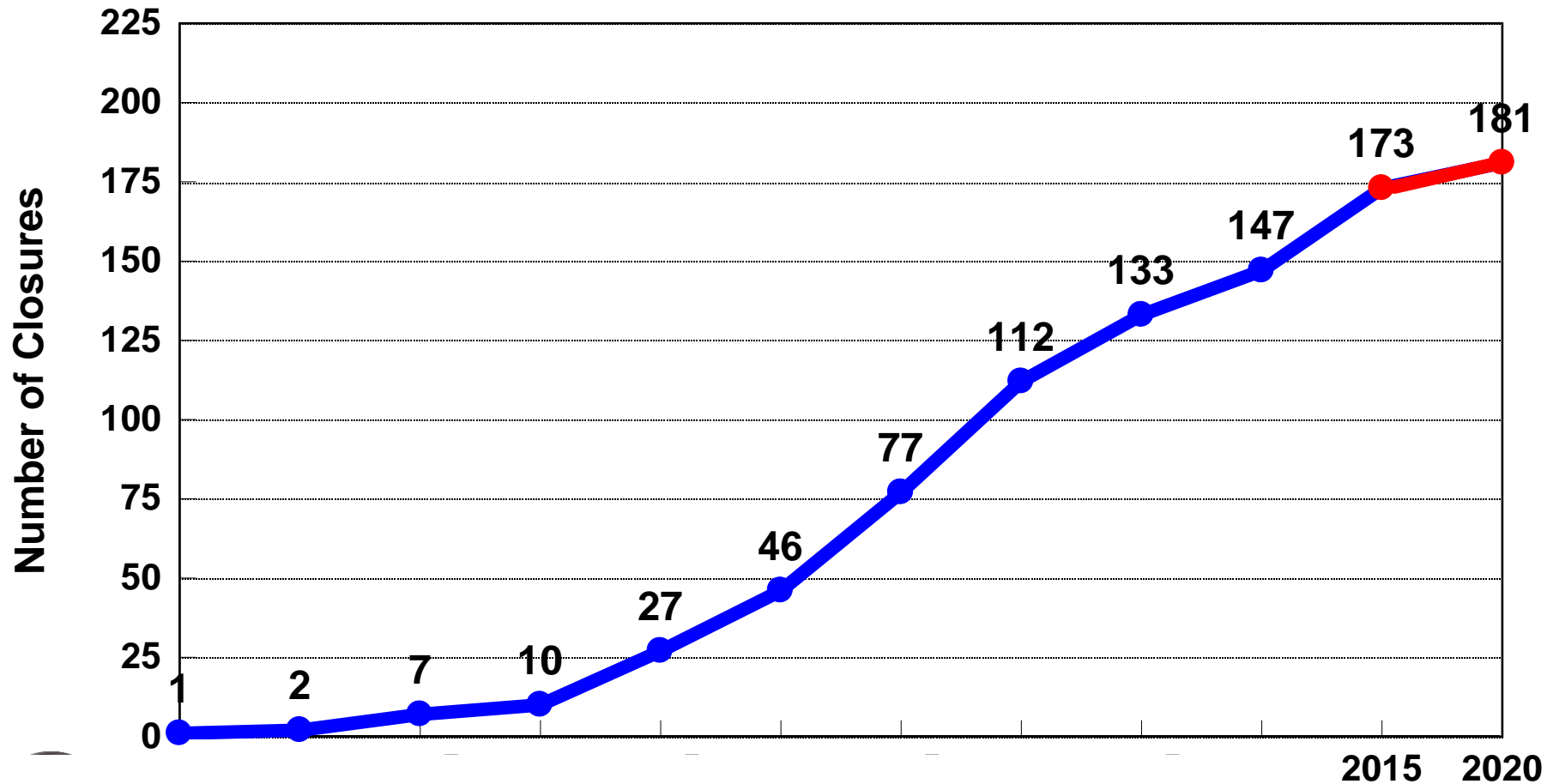
District of Columbia (1991)
New Hampshire (1991)
Rhode Island (1994)
Vermont (1995)
Alaska (1997)
New Mexico (1997)
West Virginia (1998)

Hawaii (1999)
Maine (1999)
Minnesota (2000)
Indiana (2007)
Michigan (2009)
Oregon (2009)
Alabama (2012)

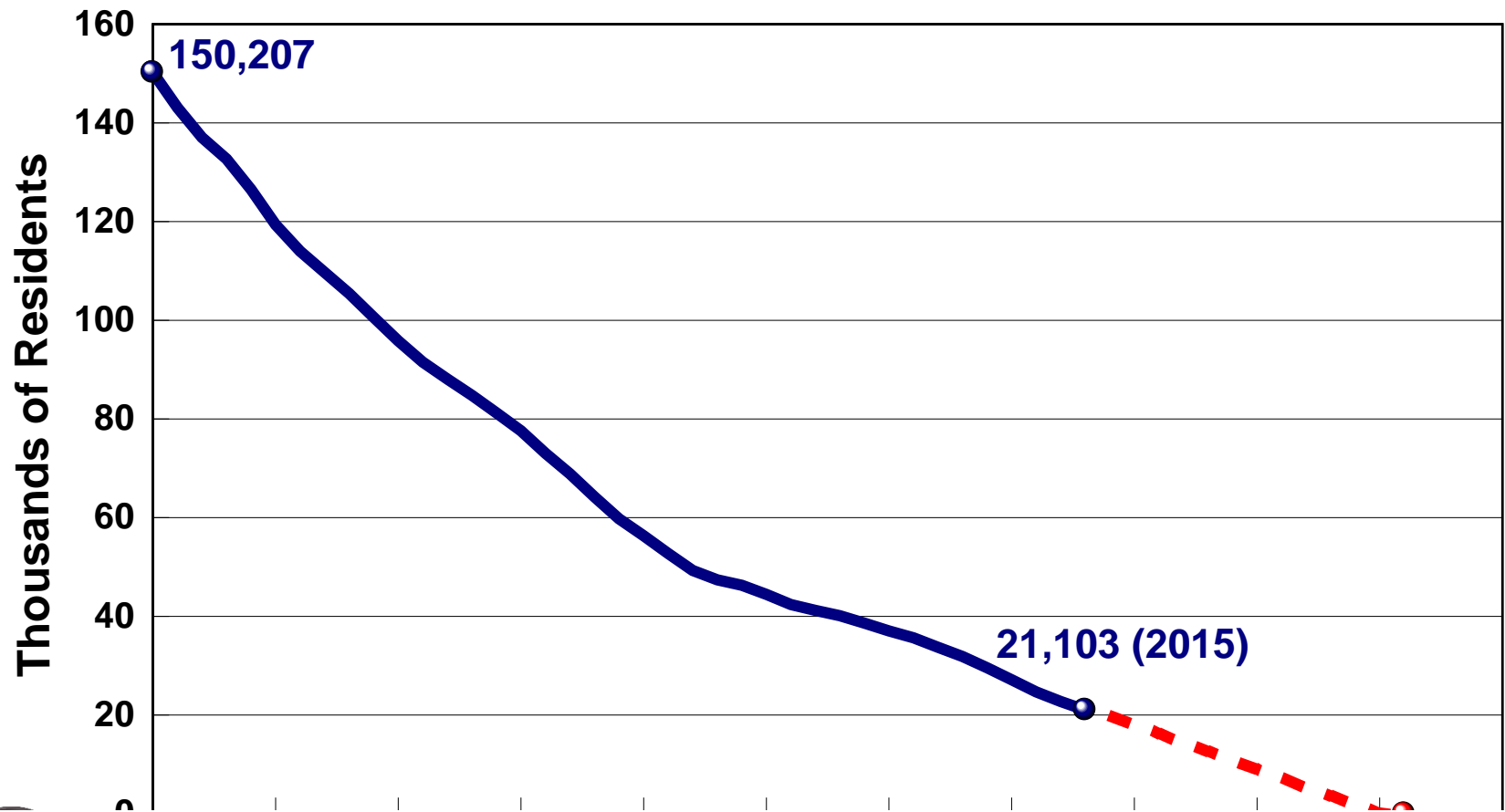
Source: Braddock, et al.(2017). *The State of the States in Intellectual and Developmental Disabilities:2017*



Projected institutional closures through 2020



Projected Trend in Public Institutional Census: 1977 - 2030



Who's next?

Smallest IDD institutional censuses

State	FY2015 census	FY2017 census	% change
1. Idaho	23	25	9%
2. Nevada	47	48	2%
3. Delaware	54	48	-11%
4. Montana	55	21	-62%
5. Oklahoma	66	50	-24%
6. Wyoming	70	64	-9%
7. North Dakota	82	74	-10%
8. Arizona	93	83	-11%
9. Nebraska	116	111	-5%
10. Maryland	122	92	-25%
Source: Braddock, et al.(2018). <i>Preliminary Data from The State of the States in Intellectual and Developmental Disabilities</i>			



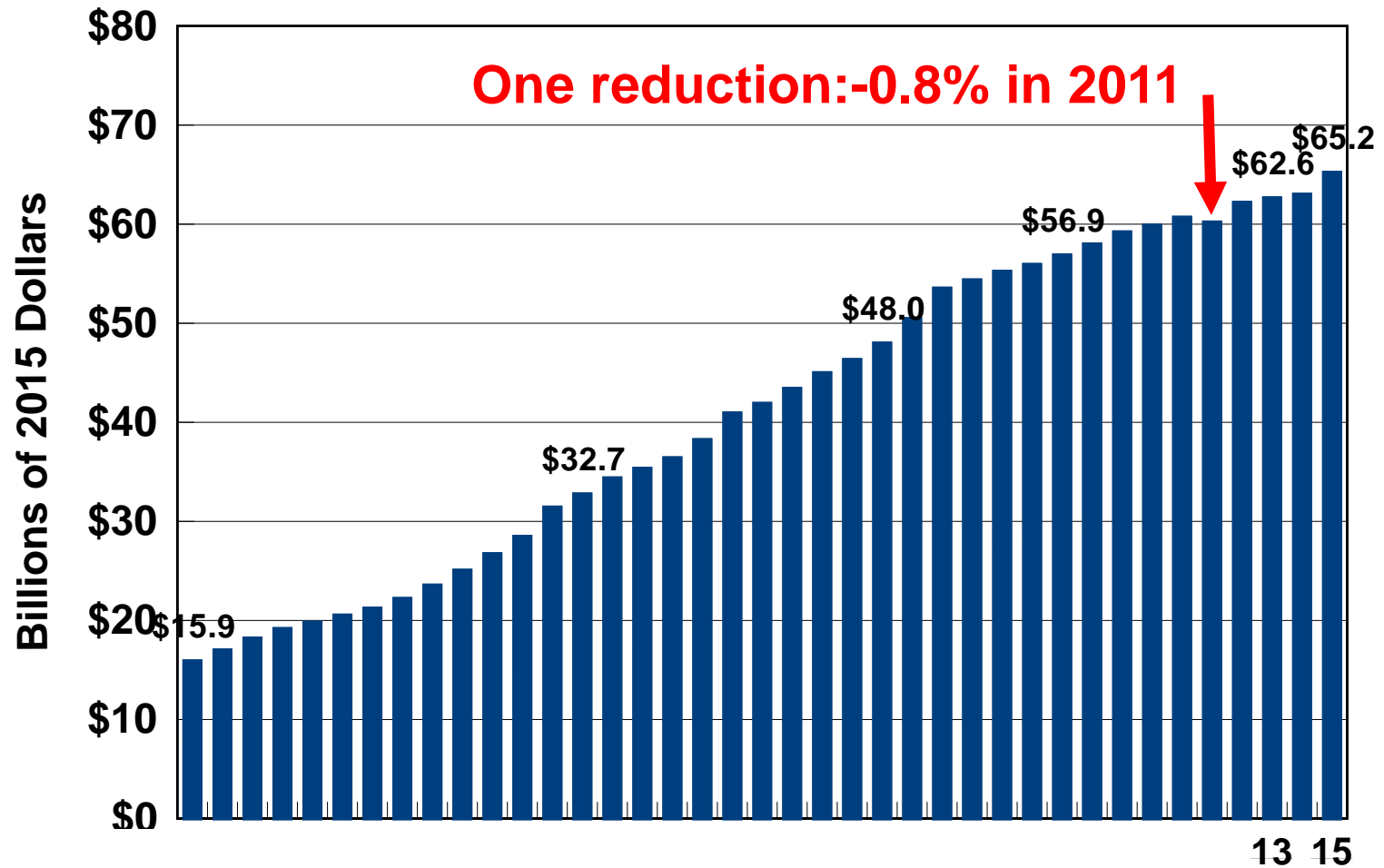
Ten largest IDD institutional censuses

State	FY2015 census	FY2017 census*	% change
1. Texas	3,541	Not yet reported	n/a
2. Illinois	1,724	1,656	-4%
3. New Jersey	1,701	1,437	-15%
4. North Carolina	1,194	1,125	-6%
5. Mississippi	1,063	938	-12%
6. California	1,011	787	-22%
7. Pennsylvania	971	880	-9%
8. Ohio	923	702	-24%
9. Arkansas	918	907	-1%
10. Florida	774	774	0

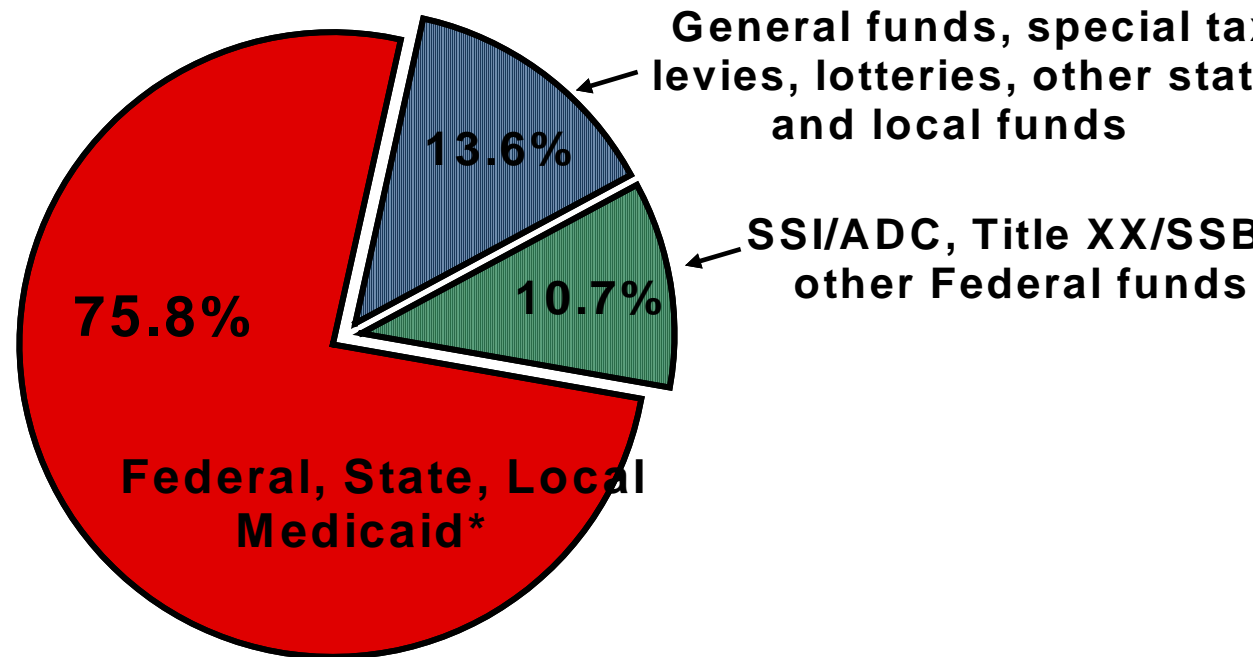
Source: Braddock, et al.(2018).Preliminary Data from *The State of the States in Intellectual and Developmental Disabilities*



Sustained growth of IDD service spending: 1977- 2015



Federal, state, and local Medicaid spending in FY 2015



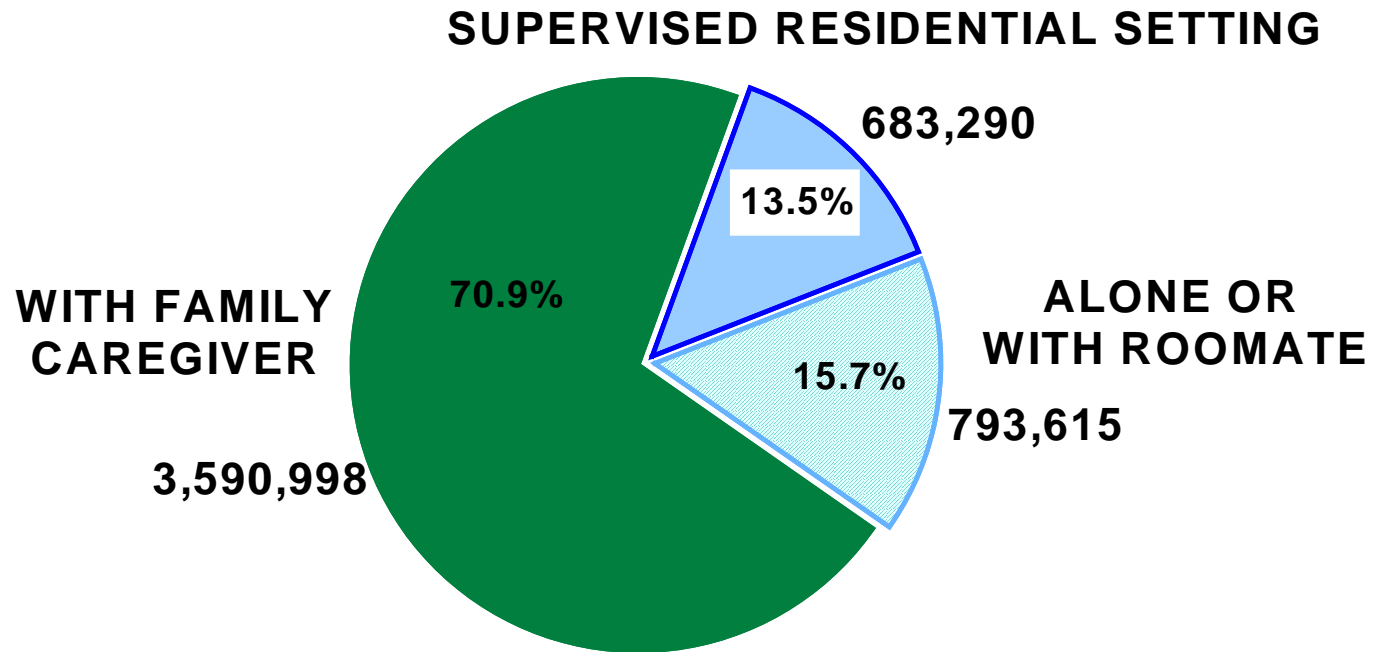
TOTAL IDD SPENDING: \$65.21 BILLION

***TOTAL FEDERAL-STATE MEDICAID: \$49.4 BILLION**

- a) HCBS WAIVER (70%)
- b) PUBLIC & PRIVATE ICFs/ID (22%)
- c) STATE PLAN MEDICAID (8%)



Estimated distribution of people with IDD by living arrangement (FY 2015)

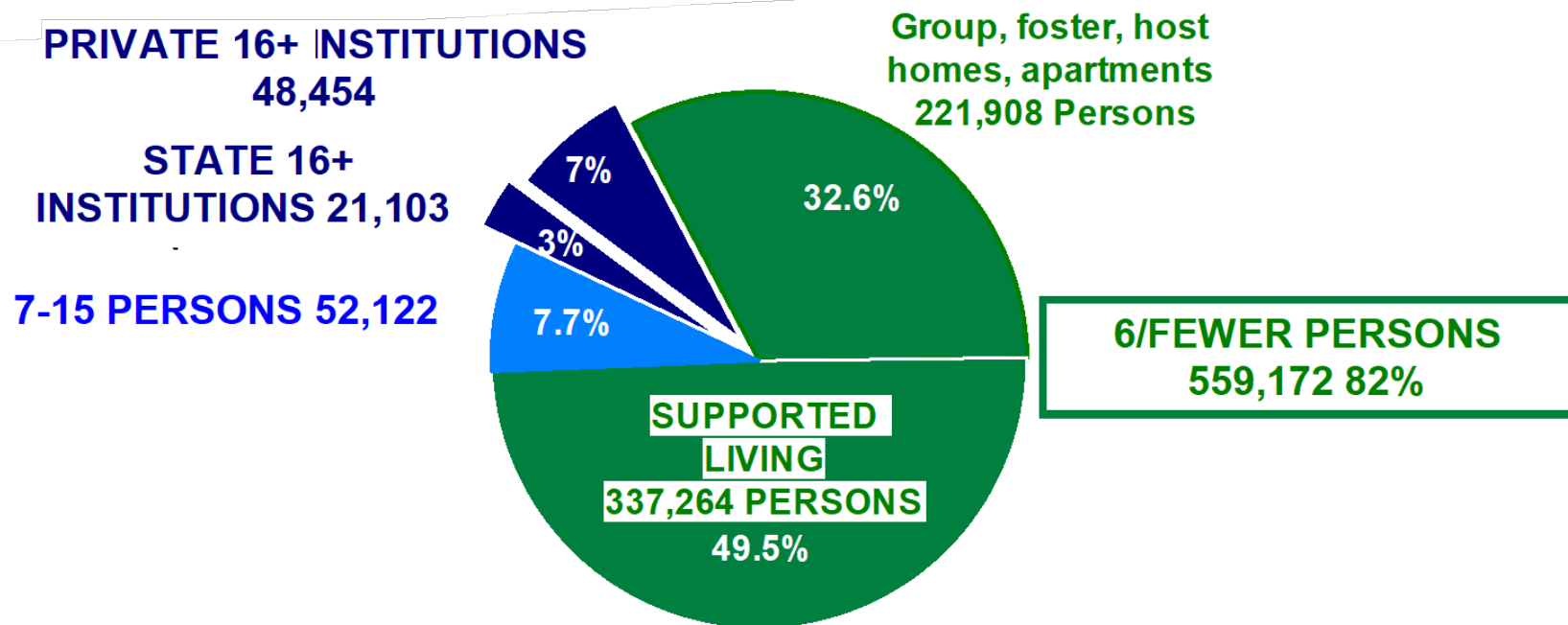


TOTAL: 5,067,903 PERSONS

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2016, based on Fujiura (2015).



Out-of-home placements

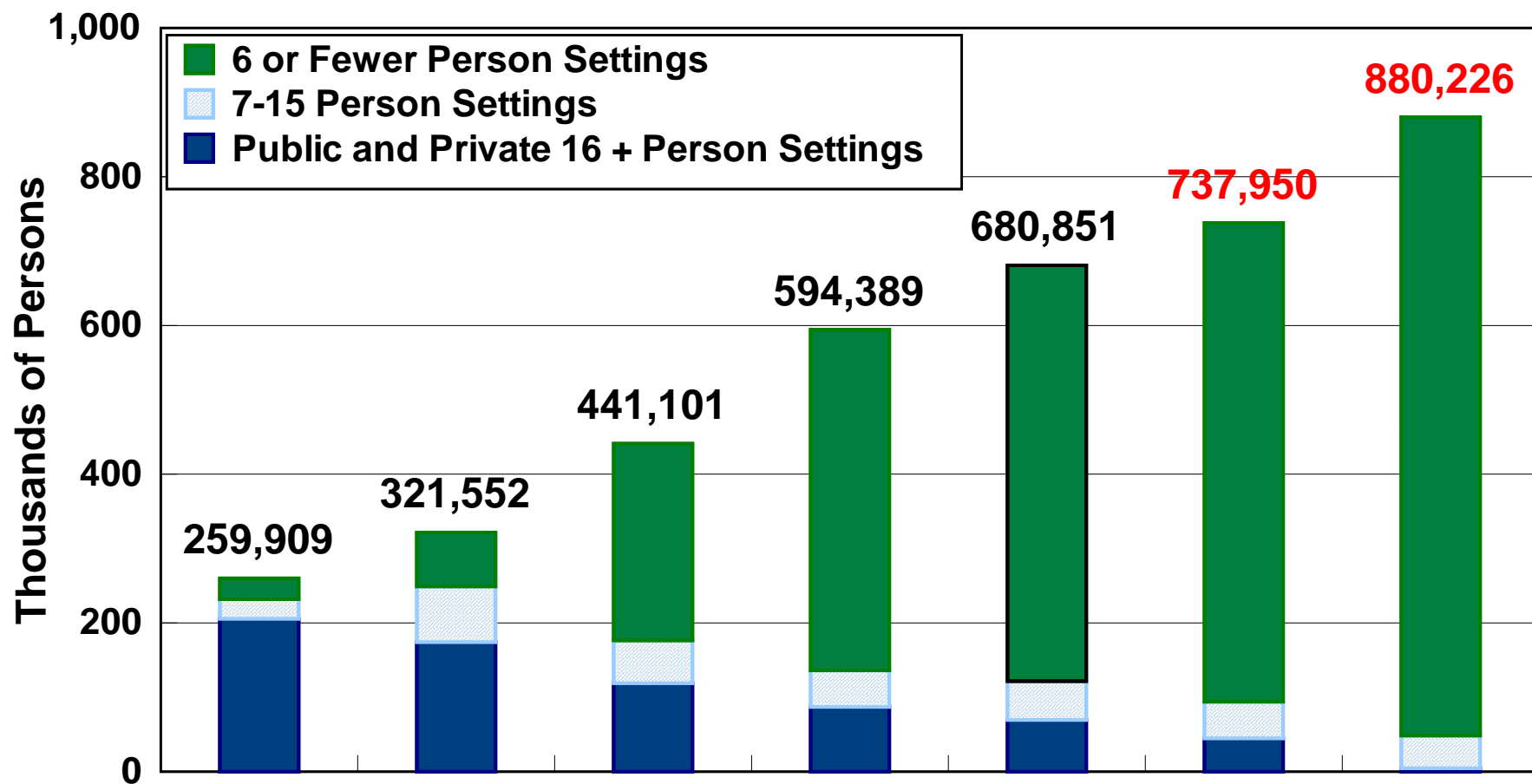


TOTAL: 680,851 PERSONS

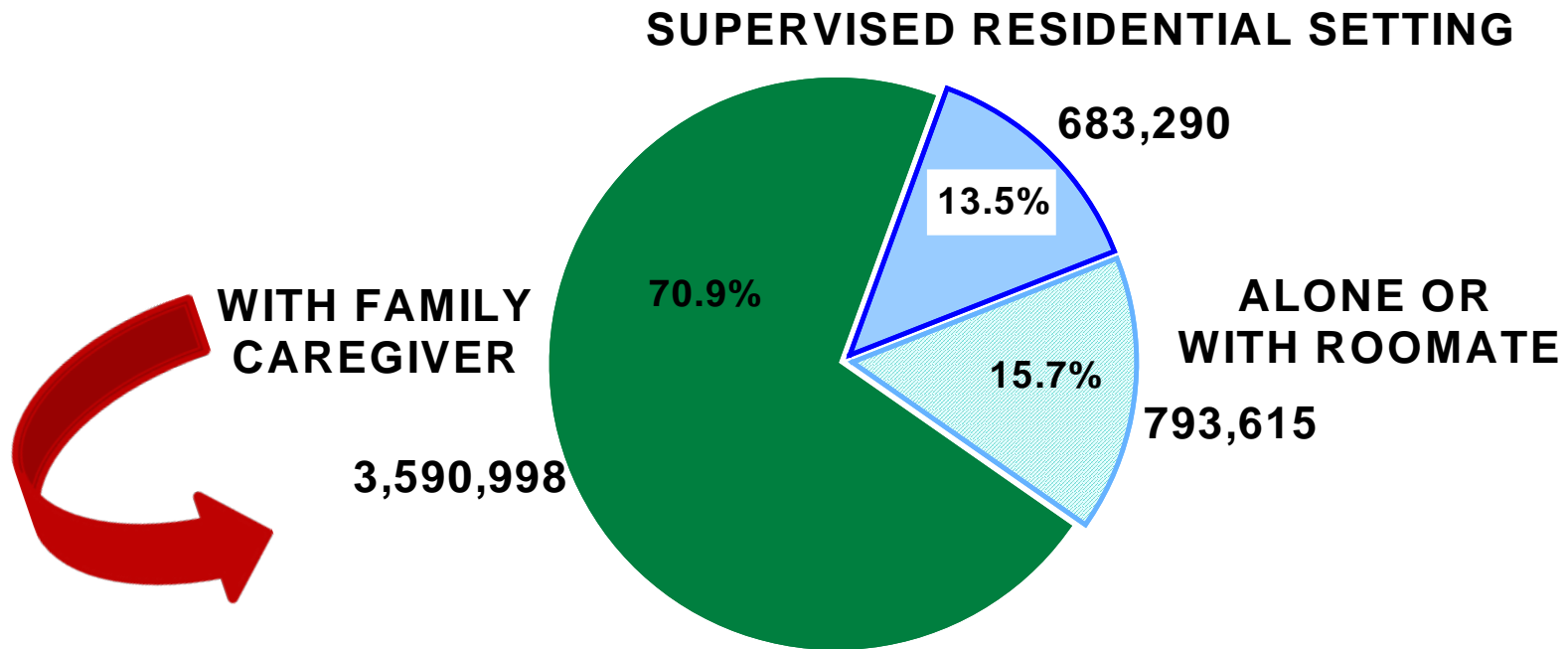
82% ARE IN 6/FEWER SETTINGS



Use of IDD residential settings for six or fewer are growing



Estimated distribution of people with IDD by living arrangement, FY 2015

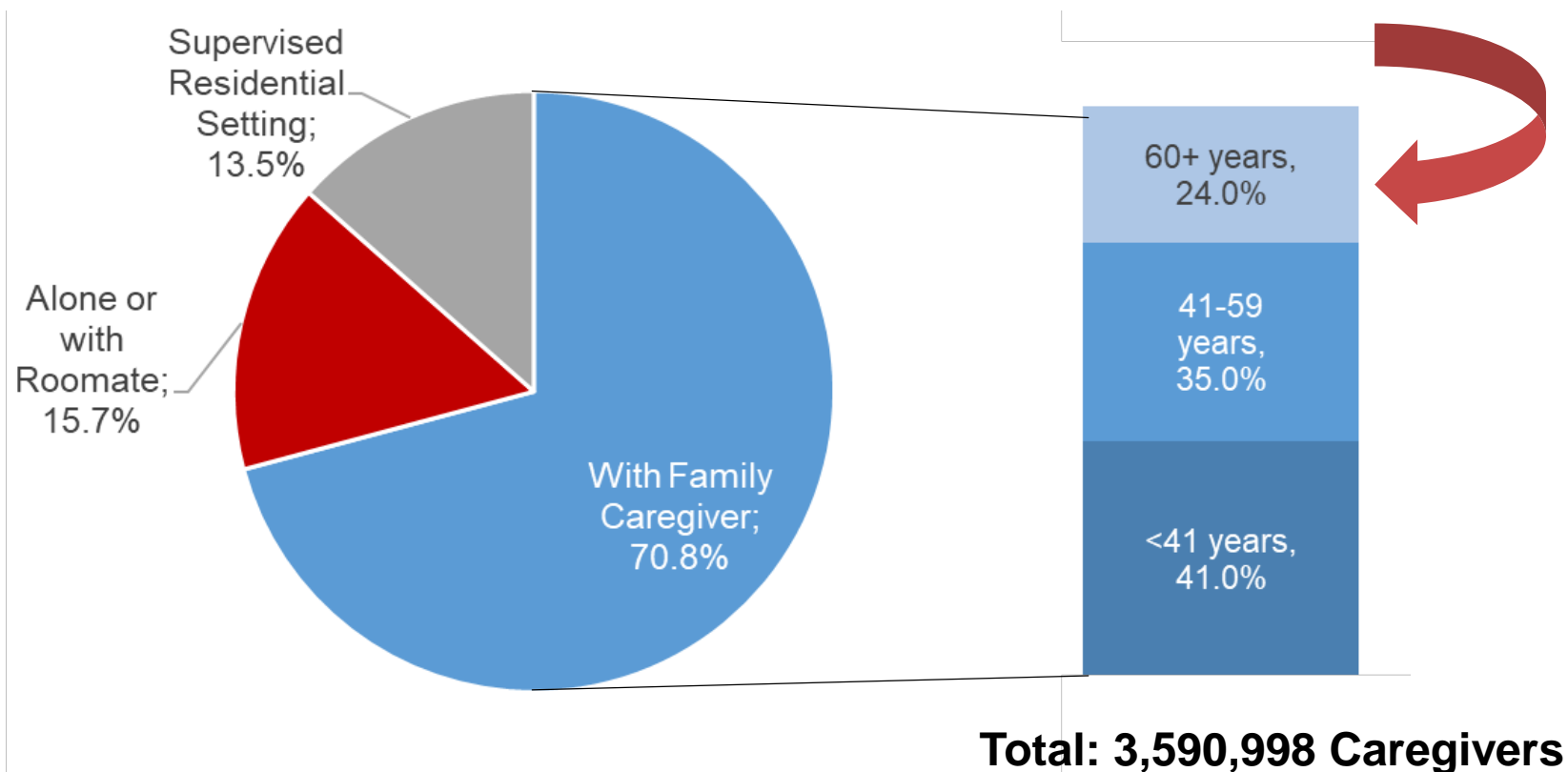


TOTAL: 5,067,903 PERSONS

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2016, based on Fujiura (2015).



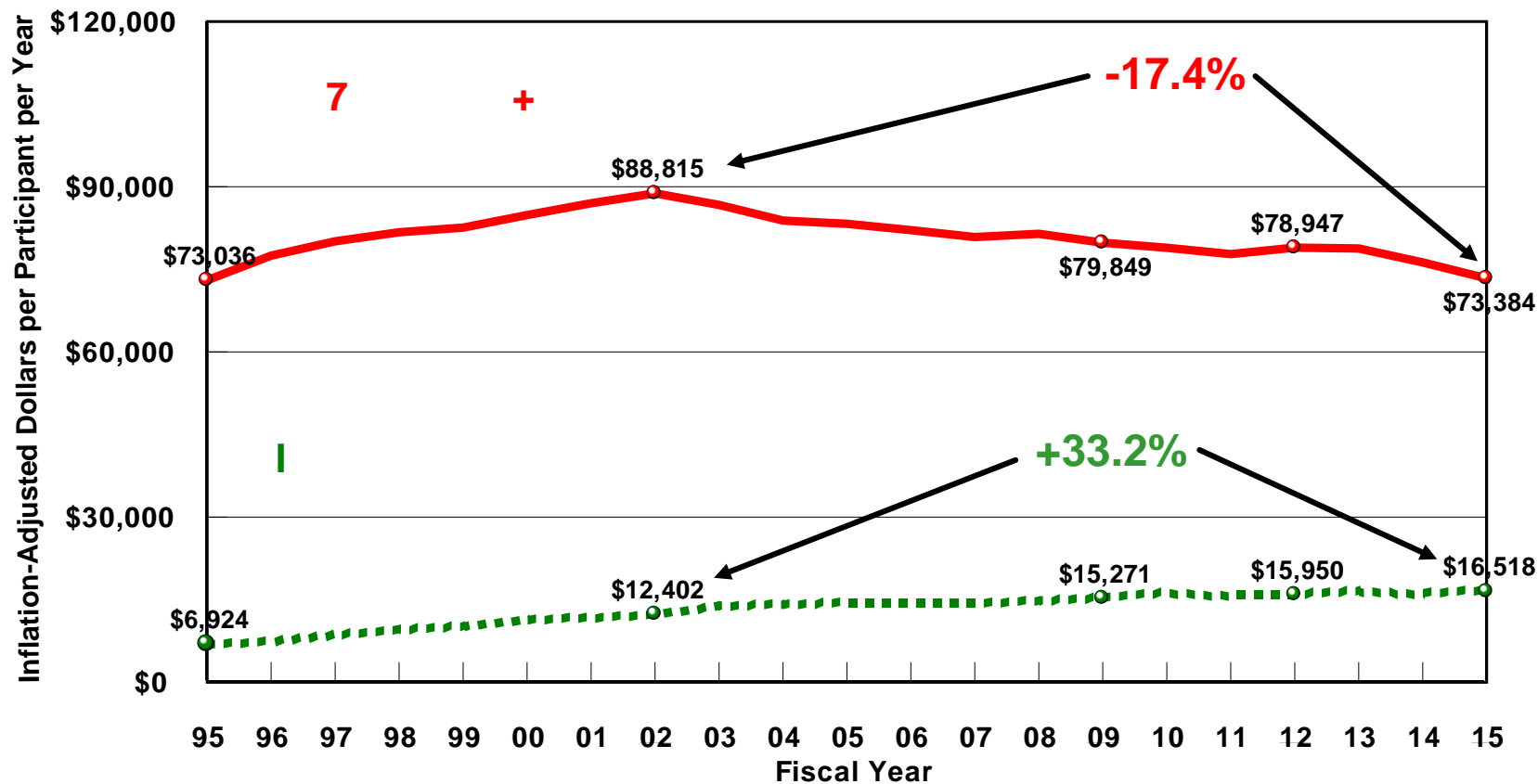
Estimated number of individuals with IDD living with family caregiver by age group, FY 2015



Source: Braddock, et al.(2017). *The State of the States in Intellectual and Developmental Disabilities:2017*



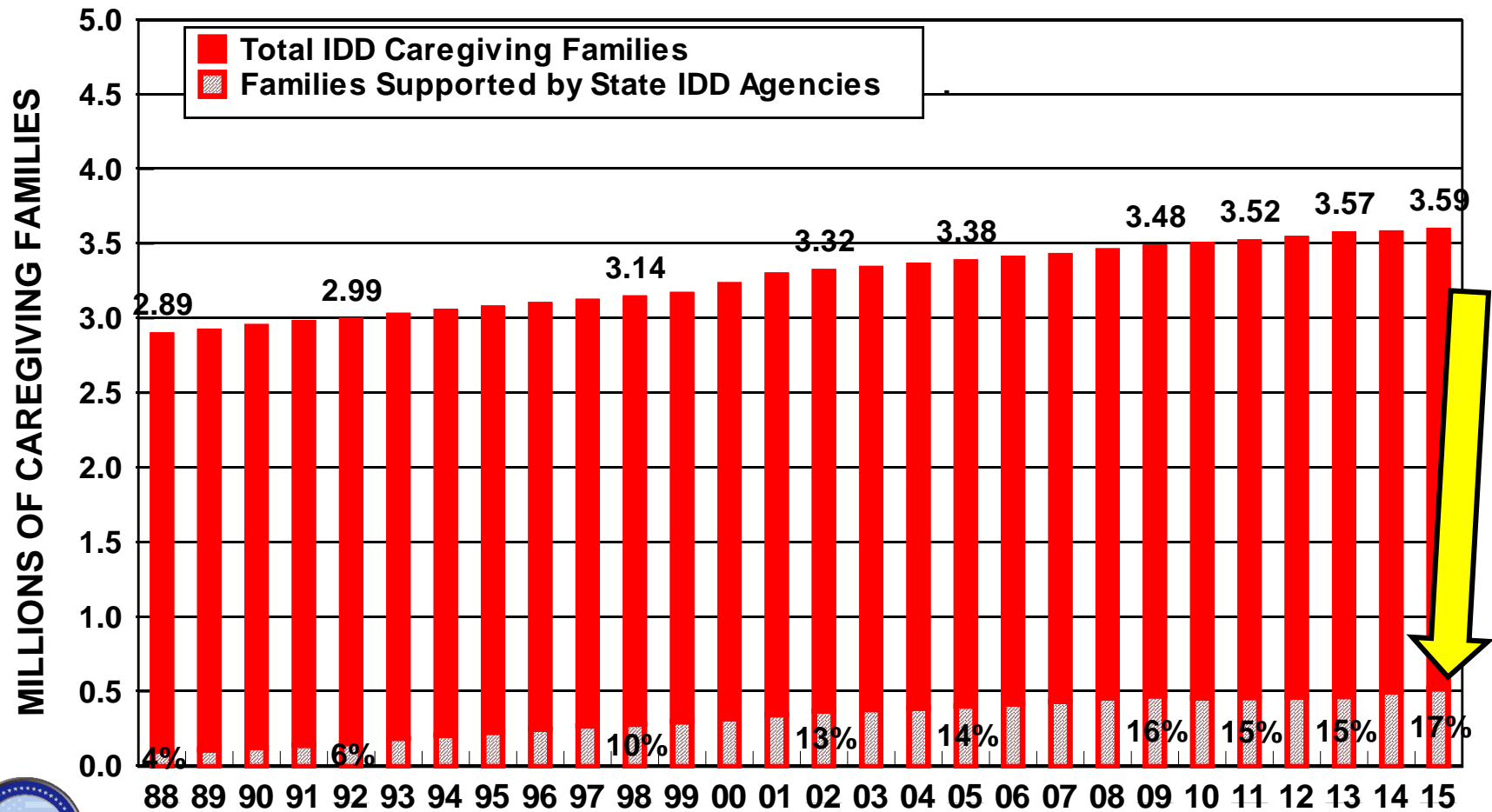
Largest Growth is in Individual and Family Support



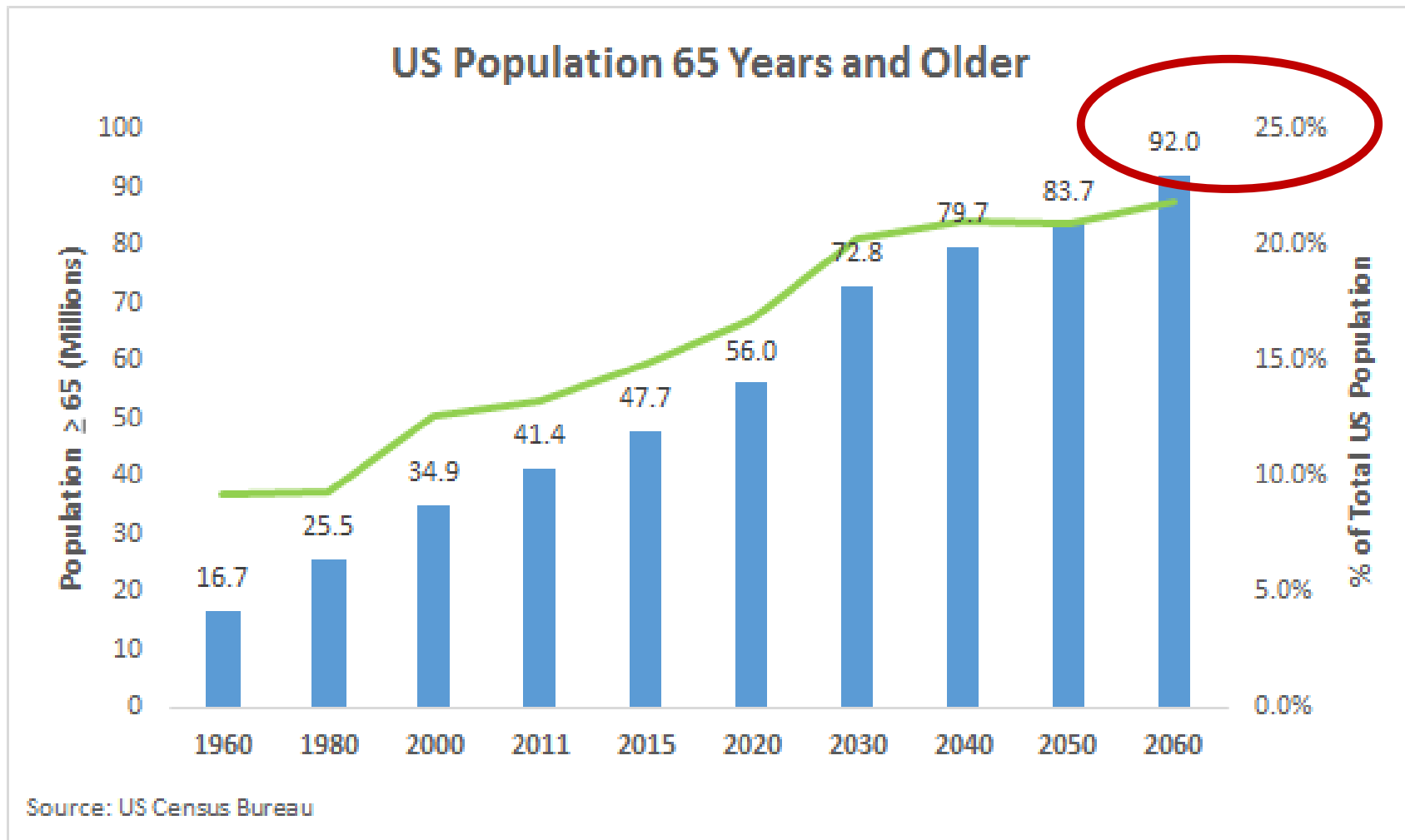
Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2017



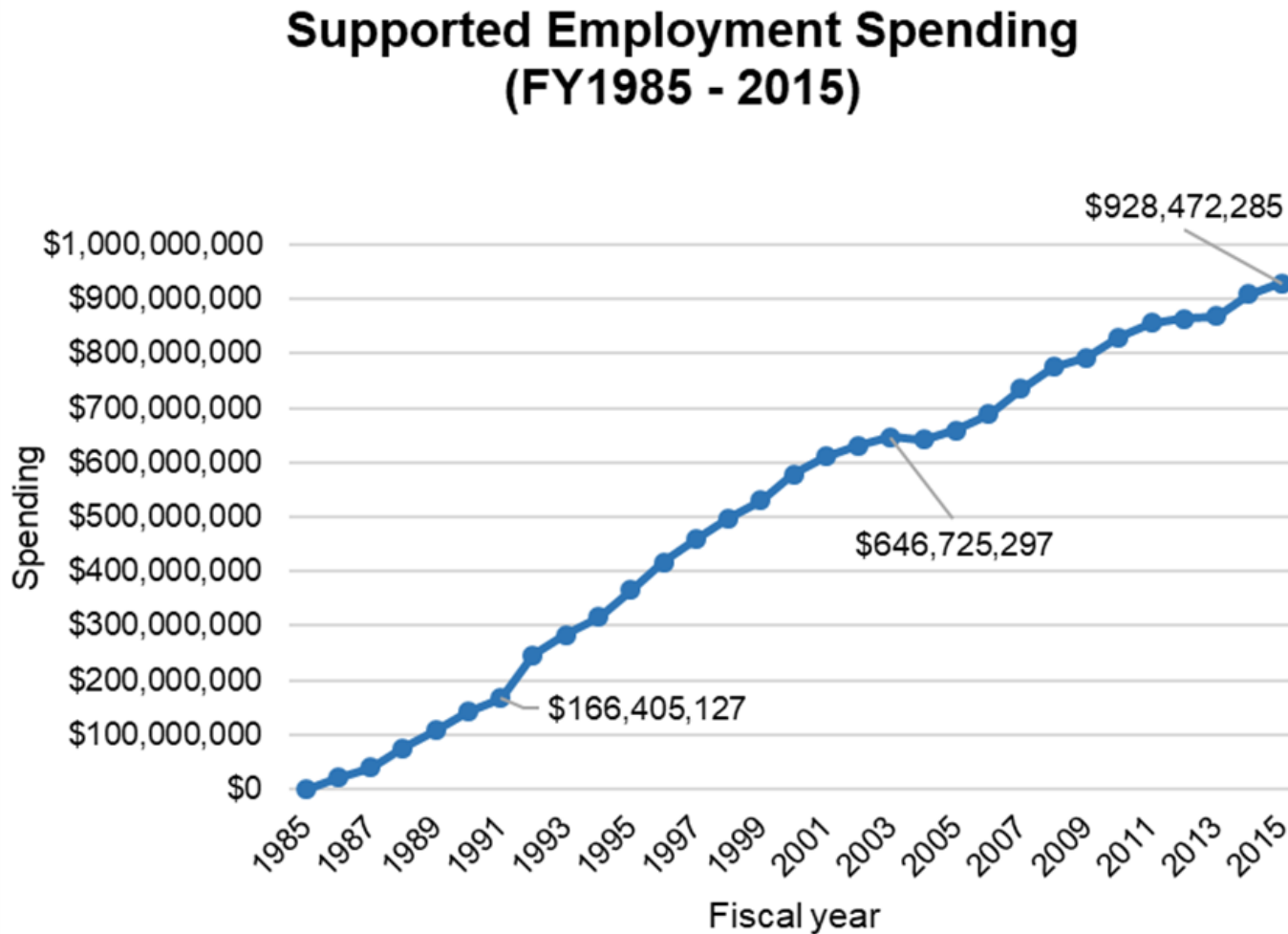
17% of caregiving families received formal IDD agency supports



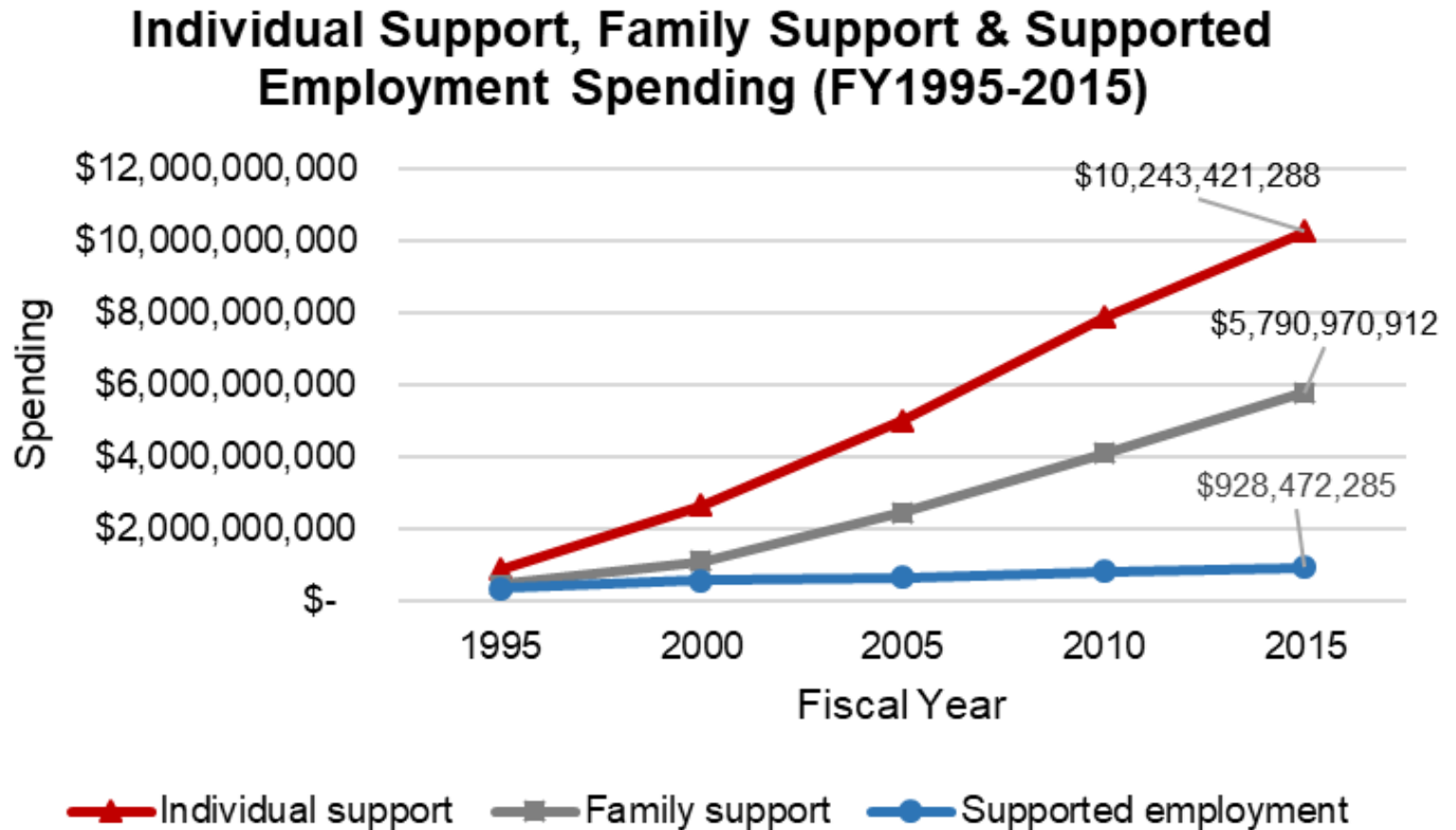
Projected aging of America



Supported employment

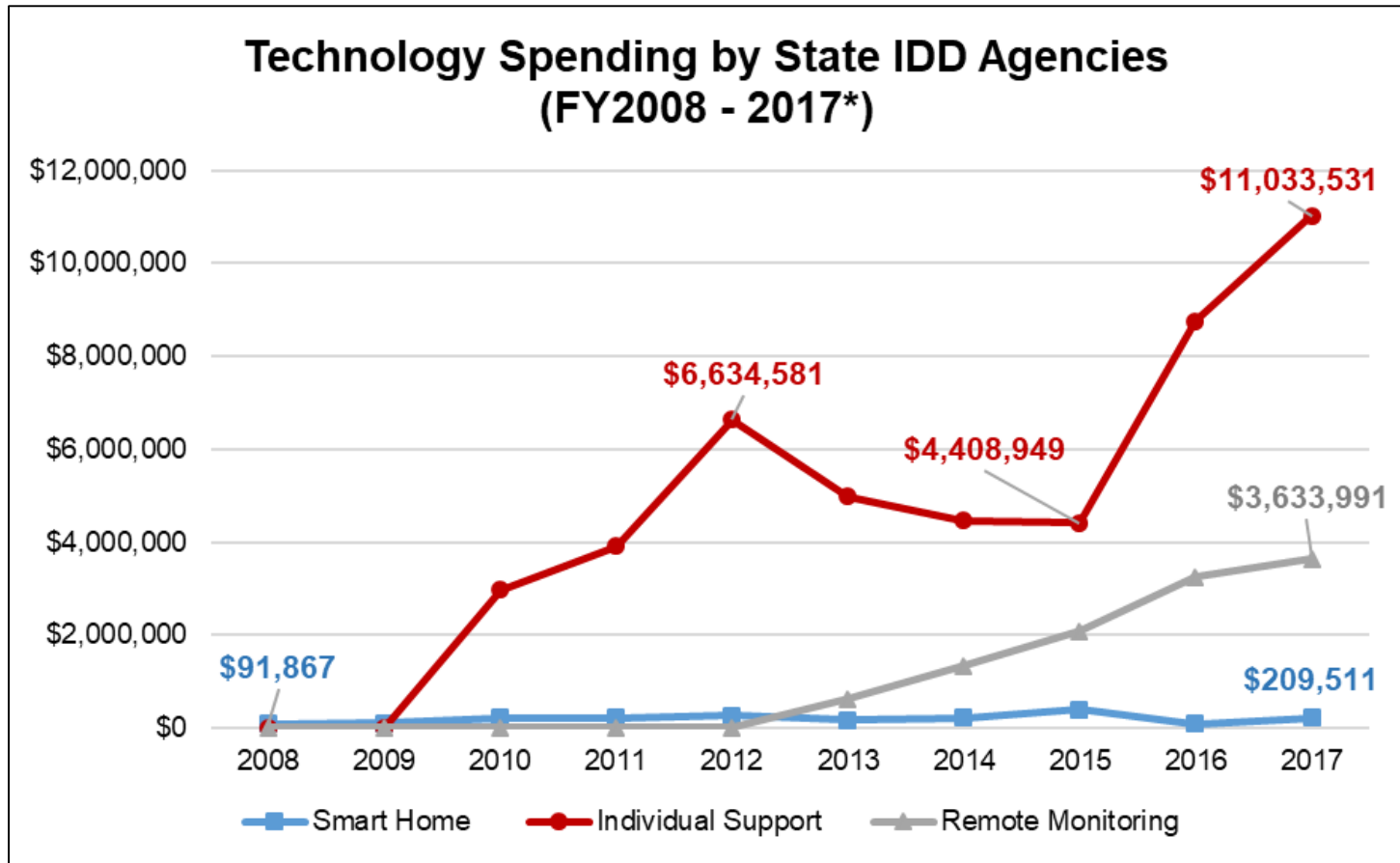


IFS & SEP spending



Source: Braddock, et al.(2017). *The State of the States in Intellectual and Developmental Disabilities:2017*

Technology spending



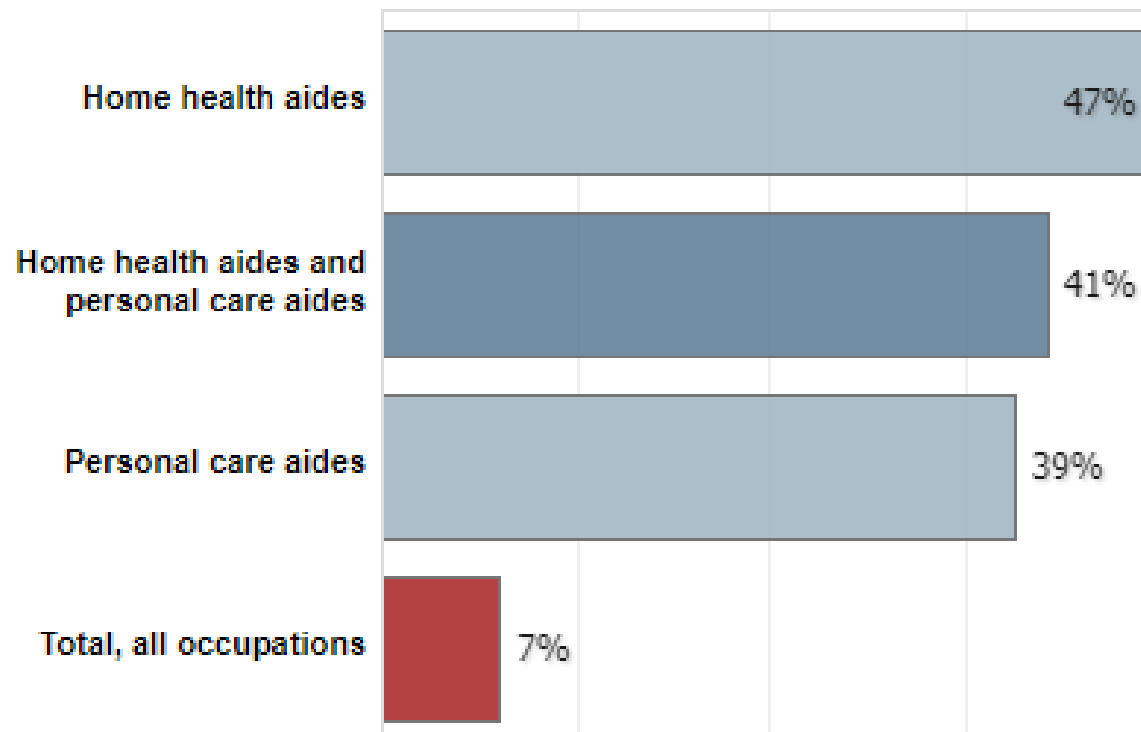
*FY 2016 – 2017 data is preliminary with 40 states obtained; 15 reporting technology spending
Source: Braddock, et al.(2018). *Preliminary Data from The State of the States in Intellectual and Developmental Disabilities*



DSP Workforce – Projected demand

Home Health Aides and Personal Care Aides

Percent change in employment, projected 2016-26



Note: All Occupations includes all occupations in the U.S. Economy.

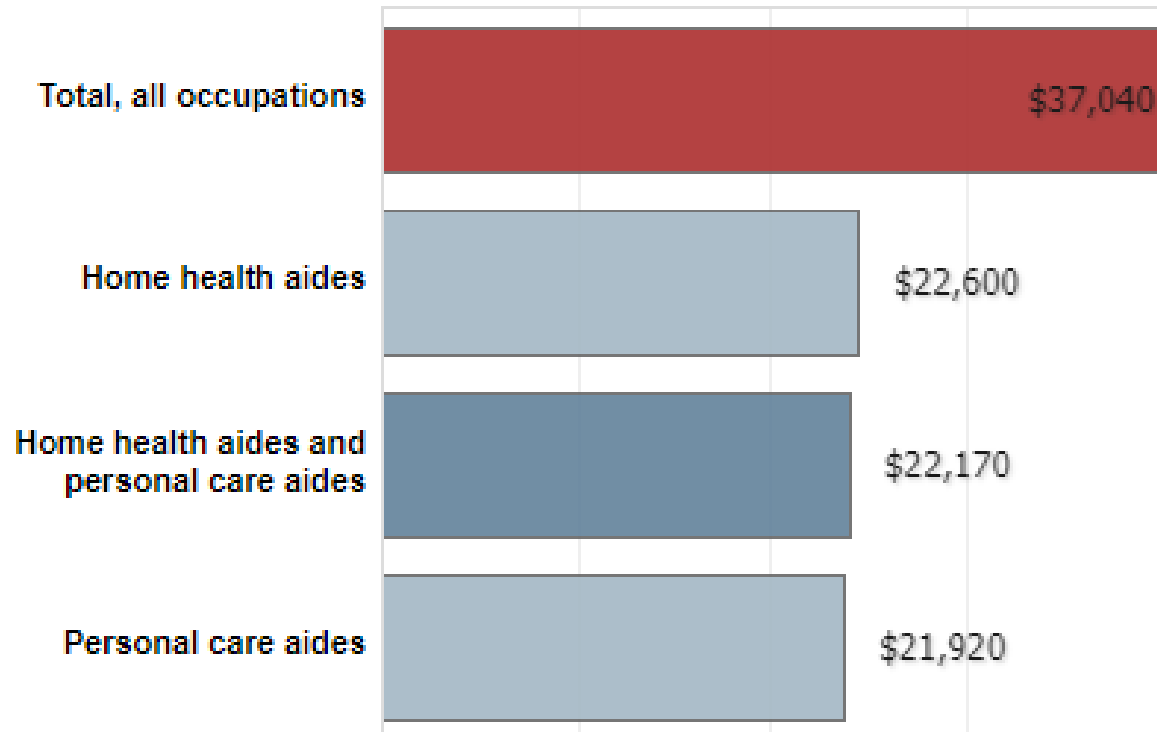
Source: U.S. Bureau of Labor Statistics, Employment Projections program



DSP Workforce – comparative pay

Home Health Aides and Personal Care Aides

Median annual wages, May 2016



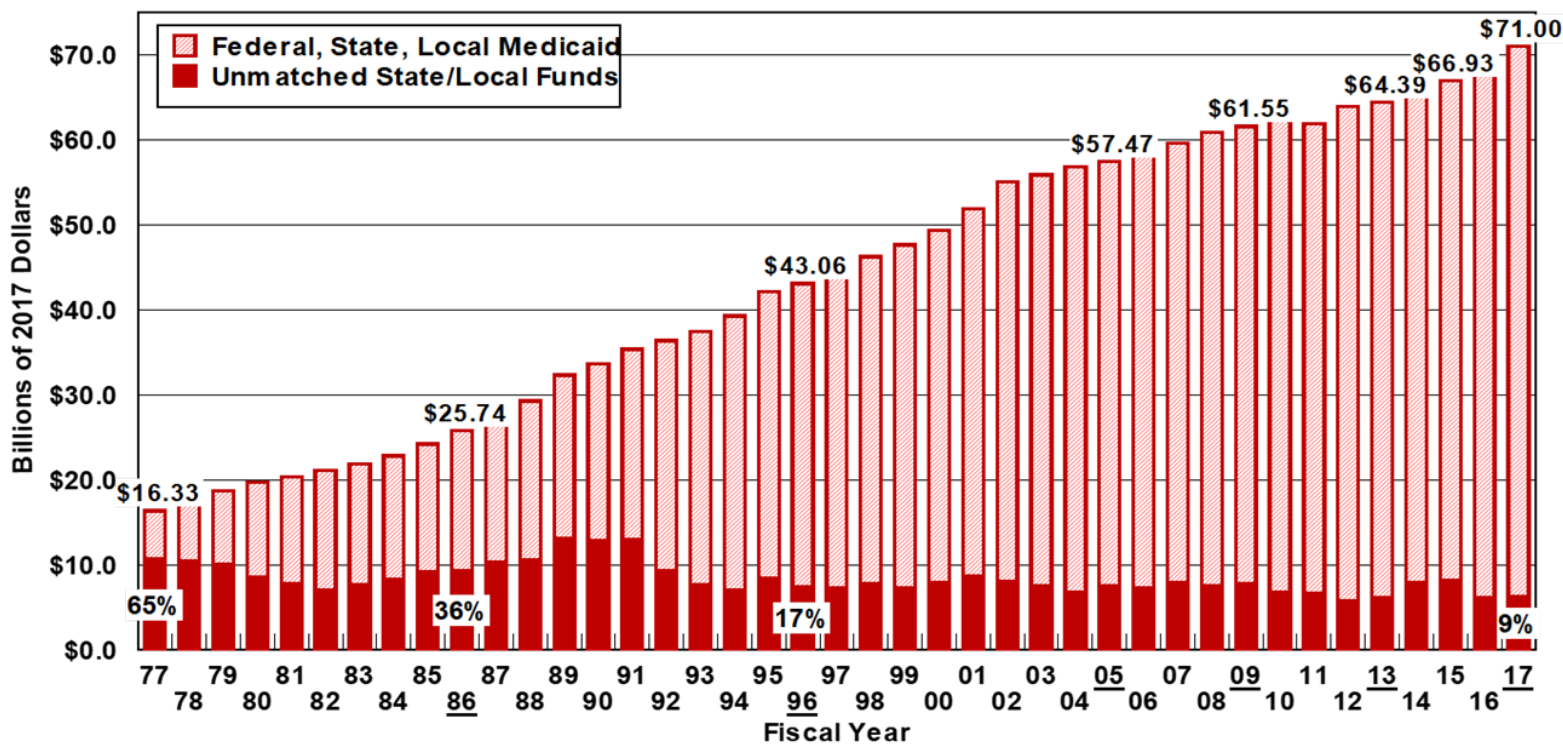
Note: All Occupations includes all occupations in the U.S. Economy.

Source: U.S. Bureau of Labor Statistics, Occupational Employment Statistics



Untapped resources

TOTAL IDD SPENDING: MATCHED AND UNMATCHED FUNDS*



Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2017.
 Note: Total Spending in 2016 and 2017 based on 3% adjusted annual growth FY 2009-15;



Personalize a Chart for your State or Region

<http://www.StateoftheStates.org/>



The State of the States in Developmental Disabilities

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Creating Charts for Fiscal Year 2015

You can create two types of charts:

A) to compare all or some subset of states or regions; or B) to quickly compare up to four states or regions.

For a chart of multiple states or regions:

1. First select the type of data to compare,
2. Then choose whether to sort alphabetically, from low to high, or from high to low.
3. Complete the selection by choosing all states and all regions or other selected groups of states/regions.

Create Chart

For the second type of chart, first select the type of data to display. Then select up to **four** states or regions.

Create Chart

Right click on the chart to print.

NOTE: Seven states that no longer finance 16+ person state-operated institutions do, however, finance 16+ private facilities (IN, ME, MI, MN, NH, RI, and WV).

If you need any assistance, contact us at stateofthestates@cu.edu.

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 - AIDD Projects of National Significance: Longitudinal Data Collection
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IN INTELLECTUAL AND
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State profile www.stateofthestates.org



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STATE OF THE STATES IN INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

Welcome to the website for the *State of the States* administered by the University of Colorado. The *State of the States* is a longitudinal study of intellectual and developmental disabilities, U.S. De and by the University of Colorado School of Medicine

You can access nationwide longitudinal financial and developmental disabilities services by going to [State](#)



STATE OF THE STATES
IN INTELLECTUAL AND
DEVELOPMENTAL DISABILITIES



The State of the States in Developmental Disabilities

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View State Profiles

State Profiles for IDD Spending During Fiscal Years 1977-2015

Select a state from the map to download a graphic profile in pdf format, or visit [Create a Chart](#) to make charts on-line.



Select a State

[View the United States profile](#)

[Chart Definitions](#)

NOTE: Seven states that no longer finance state-operated 16+ person institutions do, however, finance 16+ private facilities (IN, ME, MI, MN, NH, RI, and WV)

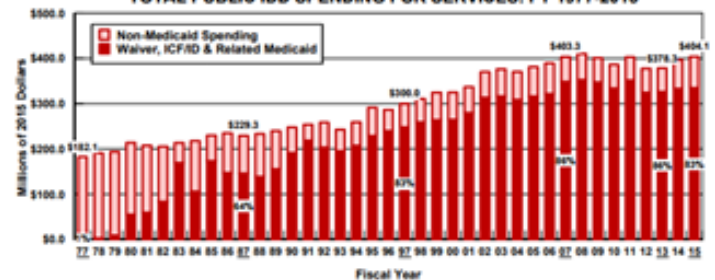
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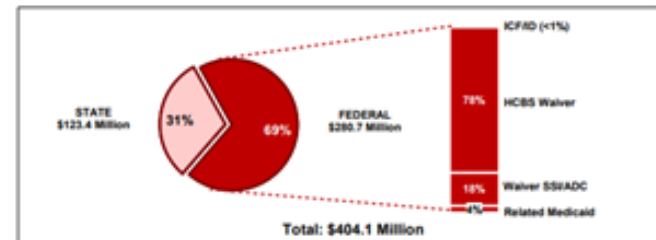
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Boulder, CO 80301

ALABAMA

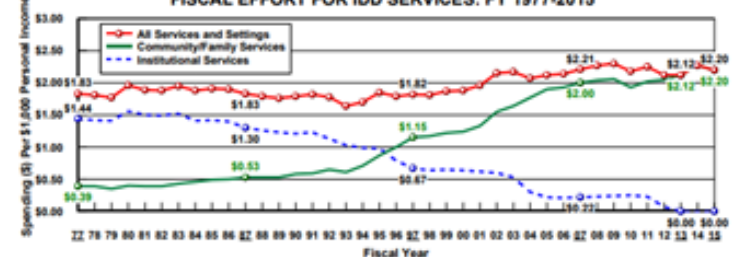
TOTAL PUBLIC IDD SPENDING FOR SERVICES: FY 1977-2015



PUBLIC IDD SPENDING BY REVENUE SOURCE: FY 2015



FISCAL EFFORT FOR IDD SERVICES: FY 1977-2015



Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2017.

<http://stateofthestates.org>

Create-a-chart

www.StateoftheStates.org

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**STATE OF THE STATES
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Welcome to the website for the *State of the States in Developmental Disabilities Project*, administered by the University of Colorado. The Project is funded by the [Administration on Intellectual and Developmental Disabilities](#), U.S. Department of Health and Human Services, and by the University of Colorado School of Medicine, Department of Psychiatry.

You can access nationwide longitudinal financial and programmatic trends in intellectual and developmental disabilities services by going to [State Profiles](#) and [Create a Chart](#).

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Creating Charts for Fiscal Year 2015

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[Create Chart](#)

Right click on the chart to print.

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Create-a-chart (state)

www.stateofthestates.org

Choose your variables

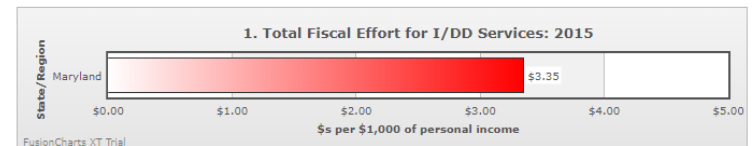
Choose your state(s)

Click next

Click table or chart

Print to PDF & paste into documents and presentations (don't forget to cite!)

Use Ctrl-P or Cmd-P to print.



Total community and institutional spending for I/DD services, per \$1,000 of personal income.

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To print, [click here](#).

1. Total Fiscal Effort for I/DD Services: 2015

State/Region	\$s per \$1,000 of personal income
Maryland	\$3.35

Total community and institutional spending for I/DD services, per \$1,000 of personal income.

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Create-a-chart (region)

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De-Select all states

Choose your variables

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CREATE CHARTS FOR FISCAL YEAR 2015

low to high, or from high to low;
from the list.

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Please select which data you would like to see charted from the list below.



- ☐ 1. Total Fiscal Effort for IDD Services
- ☐ 2. Community Fiscal Effort for IDD Services
- ☐ 3. Institutional (16+ Person) Fiscal Effort for IDD Services
- ☐ 4. Percent of Total Out-of-Home Placements in Settings for 6 or Fewer Persons
- ☐ 5. Percent of Total Statewide IDD Caregiving Families Supported by State IDD Agencies
- ☐ 6. Aging IDD Caregivers as Percent of Total Persons with IDD
- ☐ 7. Individual and Family Support Spending per Capita of General Population
- ☐ 8. Home and Community Based Services (HCBS) Waiver Federal/State Spending per Capita
- ☐ 9. Average Daily Cost of Care in State-Operated 16+ Person IDD Institutions
- ☐ 10. Average Annual Cost of Care for Supported Living
- ☐ 11. Annual Cost of Care for 7+ ICF/IID, Other Group Settings
- ☐ 12. Annual Cost of Care for 6 or Fewer Person ICF, Group, Host, Foster Homes
- ☐ 13. Average Annual Cost of Care for Supported Living
- ☐ 14. Nursing Facility Residents with IDD, Per 100,000 of the State Population
- ☐ 15. Six-on-Fewer Person Community Spending as a Percent of Total IDD Spending
- ☐ 16. Unmatched State Funds Potentially Available to Match Additional Federal Medicaid Funding
- ☐ 17. Medicaid Percent of Total IDD Spending
- ☐ 18. Public Spending for Family Support and Supported Living as a Percentage of Total IDD Spending

Select how you would like the data sorted. Default is alphabetical by state.

- ☒ Alphabetical
- ☐ Ascending
- ☐ Descending

[Next](#)

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Click next

Compare as many states or regions as you would like. A longer chart, however, may print on two pages.

Select All States De-Select All States

Select All Regions De-Select All Regions

- | | | | |
|--|---|--|---|
| <input type="checkbox"/> Alabama | <input checked="" type="checkbox"/> Illinois | <input type="checkbox"/> Montana | <input type="checkbox"/> Rhode Island |
| <input type="checkbox"/> Alaska | <input checked="" type="checkbox"/> Indiana | <input type="checkbox"/> Nebraska | <input type="checkbox"/> South Carolina |
| <input type="checkbox"/> Arizona | <input type="checkbox"/> Iowa | <input type="checkbox"/> Nevada | <input type="checkbox"/> South Dakota |
| <input type="checkbox"/> Arkansas | <input type="checkbox"/> Kansas | <input type="checkbox"/> New Hampshire | <input type="checkbox"/> Tennessee |
| <input type="checkbox"/> California | <input type="checkbox"/> Kentucky | <input type="checkbox"/> New Jersey | <input type="checkbox"/> Texas |
| <input type="checkbox"/> Colorado | <input type="checkbox"/> Louisiana | <input type="checkbox"/> New Mexico | <input type="checkbox"/> Utah |
| <input type="checkbox"/> Connecticut | <input type="checkbox"/> Maine | <input type="checkbox"/> New York | <input type="checkbox"/> Vermont |
| <input type="checkbox"/> Delaware | <input type="checkbox"/> Maryland | <input type="checkbox"/> North Carolina | <input type="checkbox"/> Virginia |
| <input type="checkbox"/> District of Columbia | <input type="checkbox"/> Massachusetts | <input type="checkbox"/> North Dakota | <input type="checkbox"/> Washington |
| <input type="checkbox"/> Florida | <input checked="" type="checkbox"/> Michigan | <input checked="" type="checkbox"/> Ohio | <input type="checkbox"/> West Virginia |
| <input type="checkbox"/> Georgia | <input checked="" type="checkbox"/> Minnesota | <input type="checkbox"/> Oklahoma | <input checked="" type="checkbox"/> Wisconsin |
| <input type="checkbox"/> Hawaii | <input type="checkbox"/> Mississippi | <input type="checkbox"/> Oregon | <input type="checkbox"/> Wyoming |
| <input type="checkbox"/> Idaho | <input type="checkbox"/> Missouri | <input type="checkbox"/> Pennsylvania | <input type="checkbox"/> UNITED STATES |
| <input type="checkbox"/> NEW ENGLAND (CT, ME, MA, NH, RI, VT) | | | |
| <input type="checkbox"/> NORTHEAST (NJ, NY) | | | |
| <input type="checkbox"/> MID-ATLANTIC (DE, DC, MD, PA, VA, WV) | | | |
| <input type="checkbox"/> SOUTHEAST (AL, FL, GA, KY, MS, NC, SC, TN) | | | |
| <input checked="" type="checkbox"/> GREAT LAKES (IL, IN, MI, MN, OH, WI) | | | |
| <input type="checkbox"/> SOUTHWEST (AR, LA, NM, OK, TX) | | | |
| <input type="checkbox"/> GREAT PLAINS (IA, KS, MO, NE) | | | |
| <input type="checkbox"/> ROCKY MOUNTAIN (CO, MT, ND, SD, UT, WY) | | | |
| <input type="checkbox"/> PACIFIC (AZ, CA, HI, NV) | | | |
| <input type="checkbox"/> NORTHWEST (AK, ID, OR, WA) | | | |

When you have selected your states/regions, click "Show Chart." Your chart will be produced. To view the data in tabular (table) form, click "Show Table."

[Show Chart](#)

[Show Table](#)

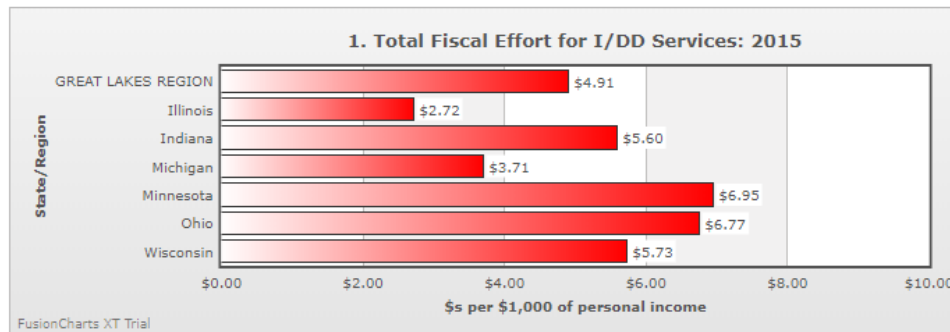
Choose your region & then your states



Create-a-chart (region, continued)

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Use Ctrl-P or Cmnd-P to print.



Total community and institutional spending for I/DD services, per \$1,000 of personal income.

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Chose table or chart. Print to PDF & paste into documents and presentations (don't forget to cite!)

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1. Total Fiscal Effort for I/DD Services: 2015

State/Region	\$s per \$1,000 of personal income
GREAT LAKES REGION	\$4.91
Illinois	\$2.72
Indiana	\$5.60
Michigan	\$3.71
Minnesota	\$6.95
Ohio	\$6.77
Wisconsin	\$5.73

Total community and institutional spending for I/DD services, per \$1,000 of personal income.

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Using SOS data for advocacy

i Advocacy organizations

- State budget hearings
- Advocacy efforts
- Strategic planning

i DD Councils

- Five year plan
- Advocacy
- Make the case for services/supports



“Don’t tell me what you value, show me your budget, and I’ll tell you what you value.”

~Joe Biden, 47th Vice President of the United States

Keep in Touch!



STATE OF THE STATES
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