

# Status and Trends in Indicators of Community Inclusion: Data Projects of National Significance

Amie Lulinski, University of Colorado

Heidi Eschenbacher, University of Minnesota

John Butterworth, University of Massachusetts - Boston



STATE OF THE STATES  
IN INTELLECTUAL AND  
DEVELOPMENTAL DISABILITIES



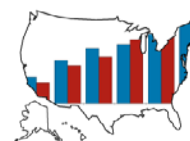
Coleman Institute for Cognitive Disabilities  
UNIVERSITY OF COLORADO

1610 1610 | 1610 1610 | 1610 1610



UNIVERSITY OF MINNESOTA

Driven to Discover<sup>SM</sup>



StateData.info

# Data Projects of National Significance

## Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act)



# Status and Trends in Financing Supports and Services for People with IDD

National Home & Community Based Services Conference  
August 28, 2018  
Baltimore, MD

Amie Lulinski, PhD, FAAIDD  
David Braddock, PhD  
Emily Shea Tanis, PhD, FAAIDD  
Richard Hemp, MA



**STATE OF THE STATES**  
IN INTELLECTUAL AND  
DEVELOPMENTAL DISABILITIES



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, 47<sup>th</sup> Vice President of the  
United States*

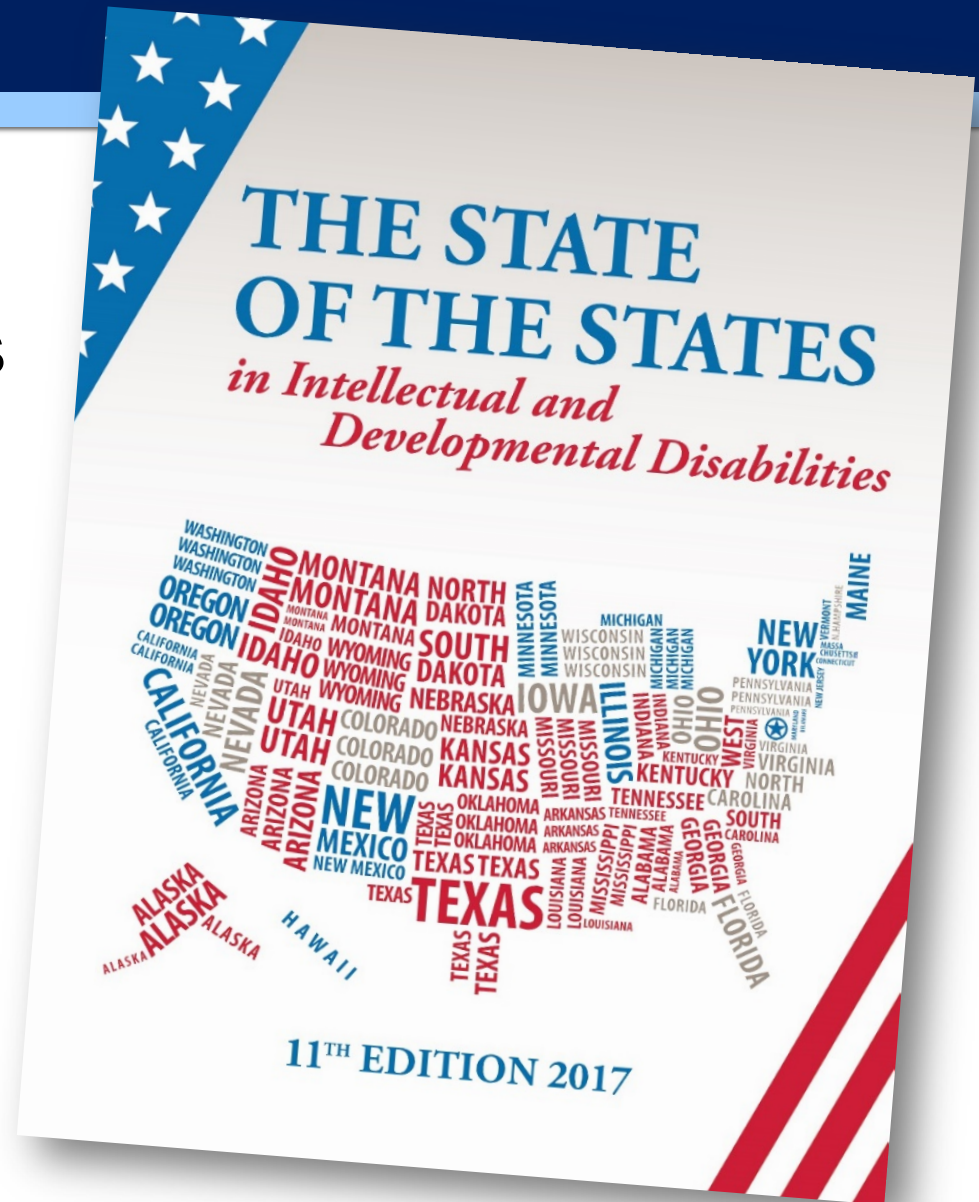
# 11<sup>th</sup> Edition

Financial and  
Programmatic Trends  
Through FY 2015

Published by



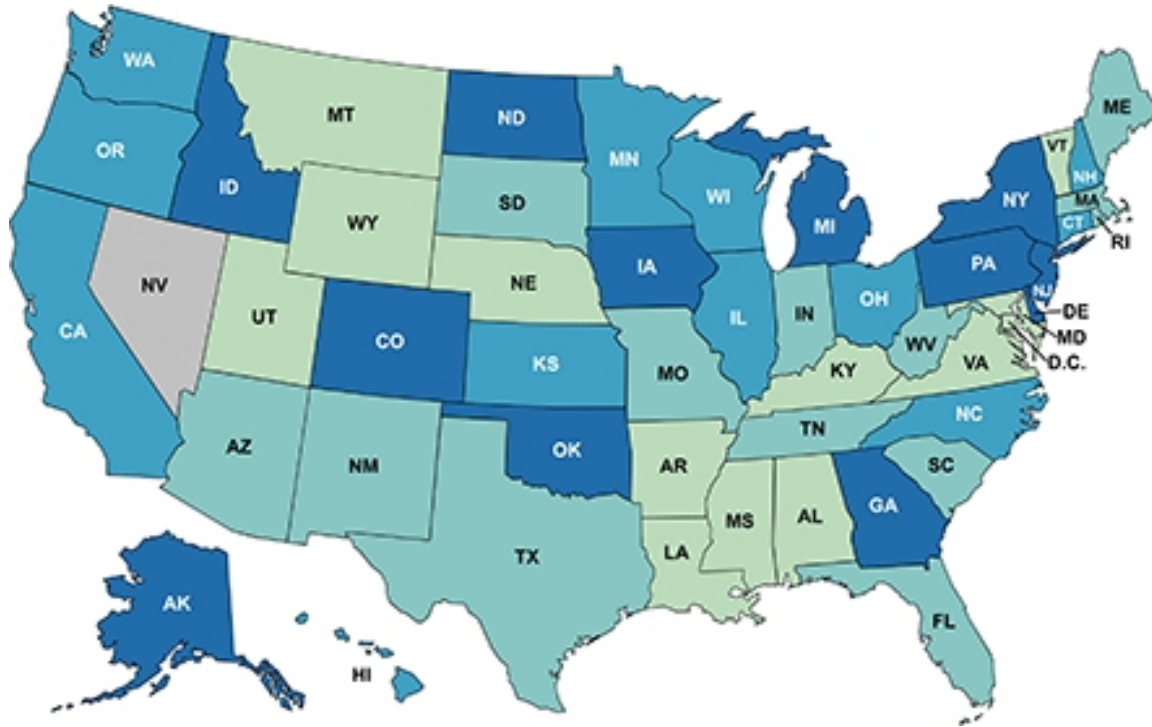
American Association  
on Intellectual and  
Developmental Disabilities



# Follow the money



# Data sources



United States™  
**Census**  
Bureau

***CMS***

*CENTERS for MEDICARE & MEDICAID SERVICES*

# What data do we collect?

## **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/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. 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





# What data do we collect? (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



# What data do we collect? (continued)

## 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

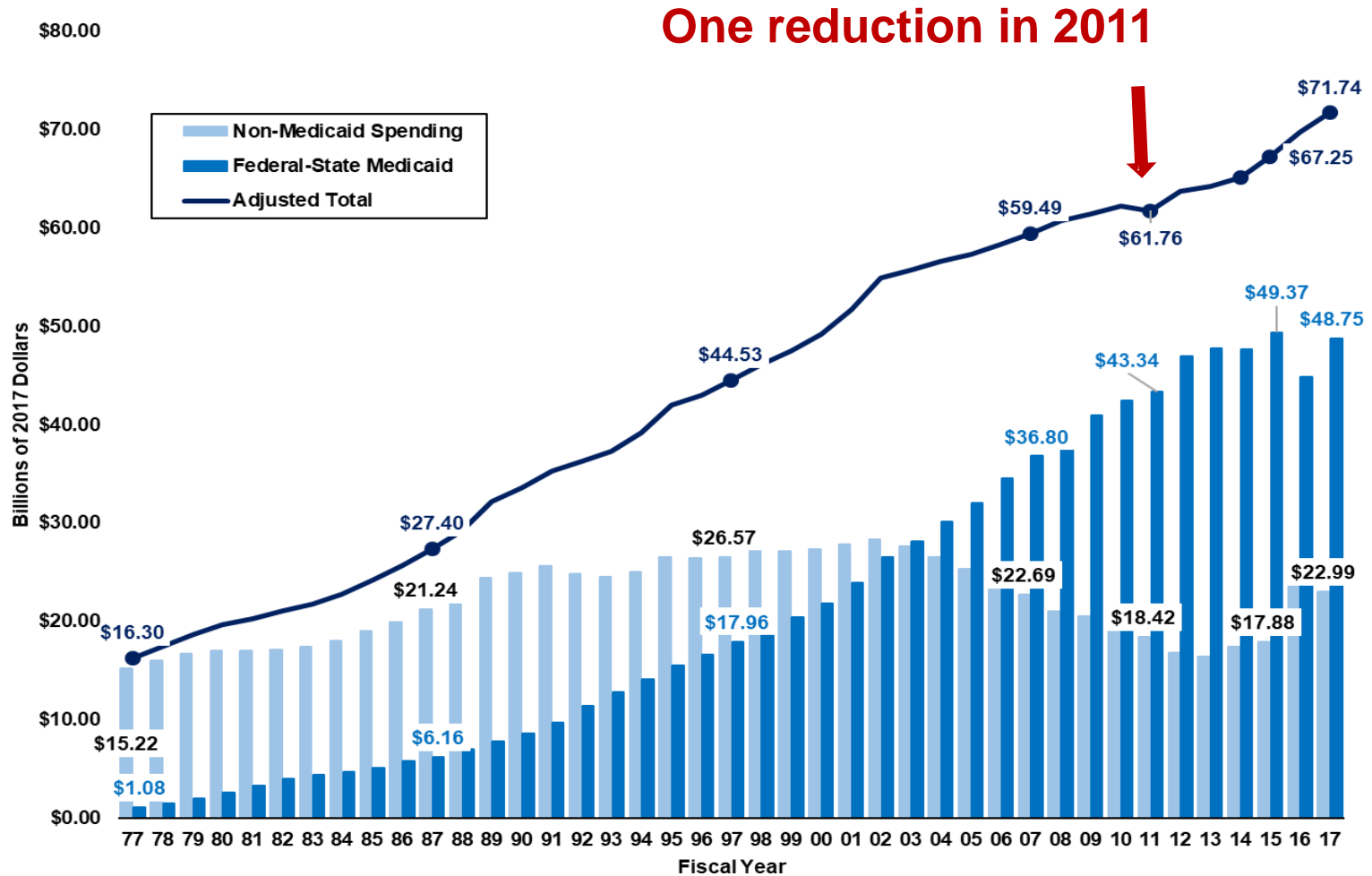


# Data Note

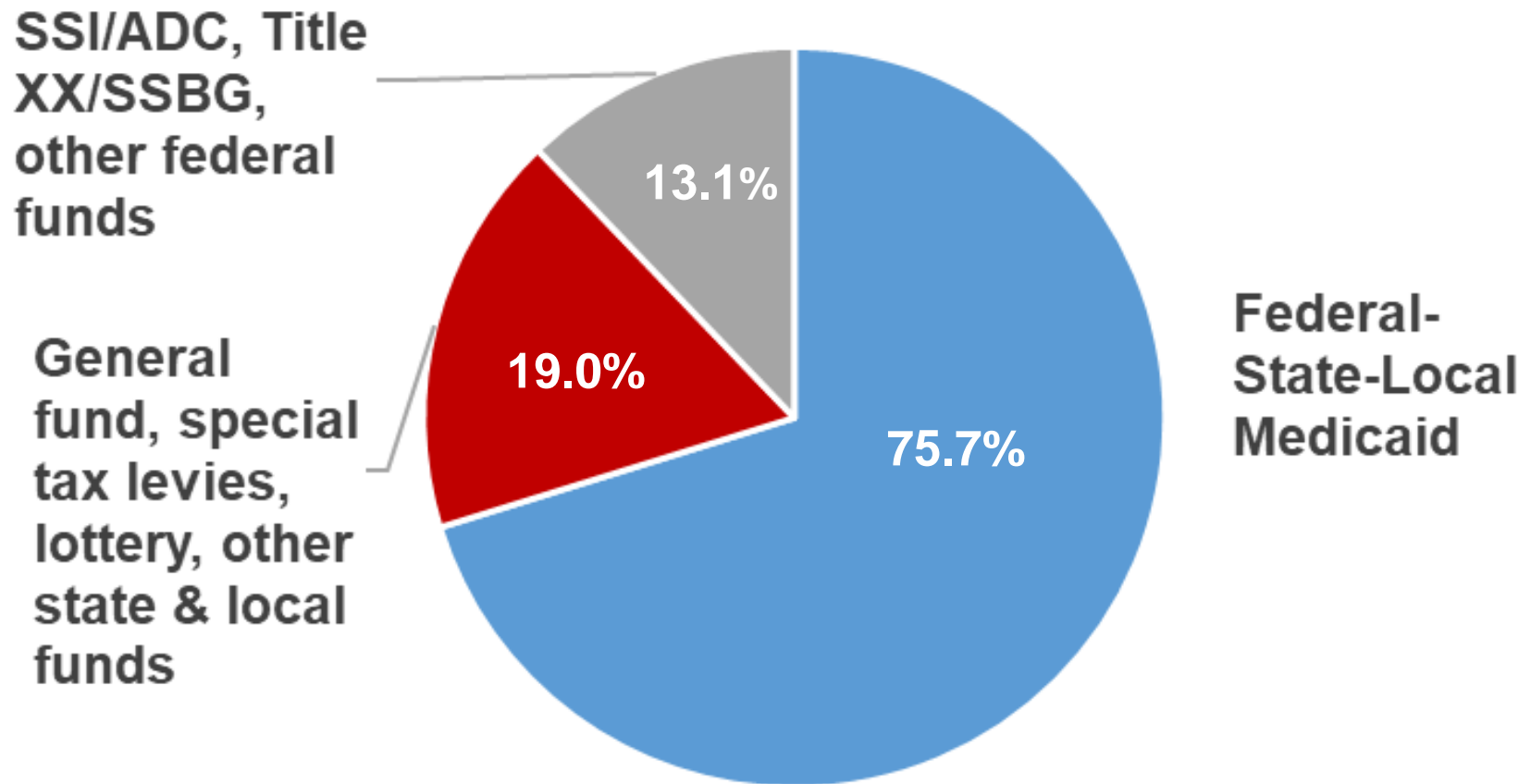
- Preliminary FY 2016-17 data
  - Subject to additional analysis



# Sustained growth of IDD services spending: FYs 1977 – 2017

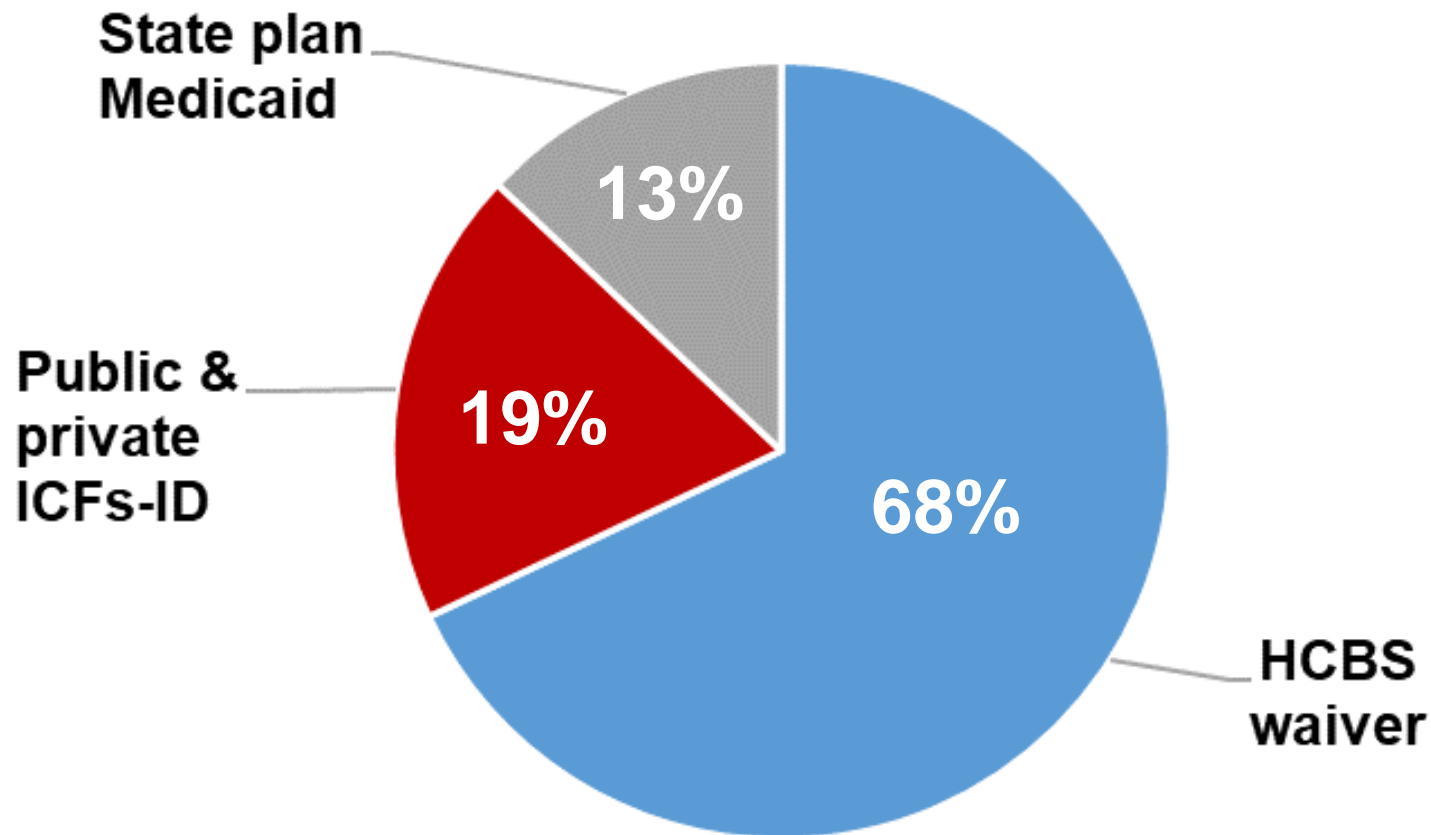


# Federal, State, and Local Medicaid Spending in FY 2017



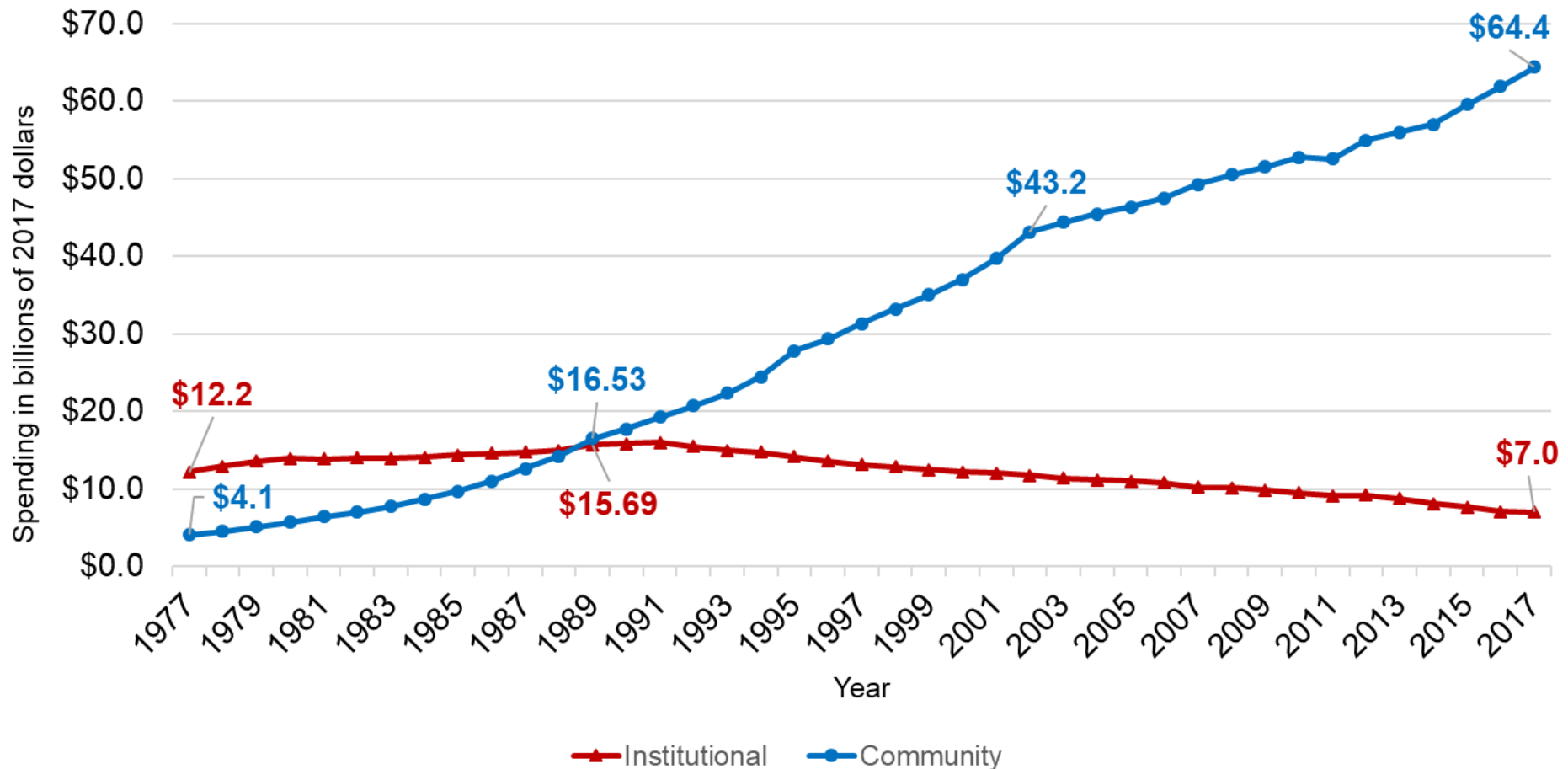
**Total spending: \$71.4 billion**

# Medicaid Spending FY2017



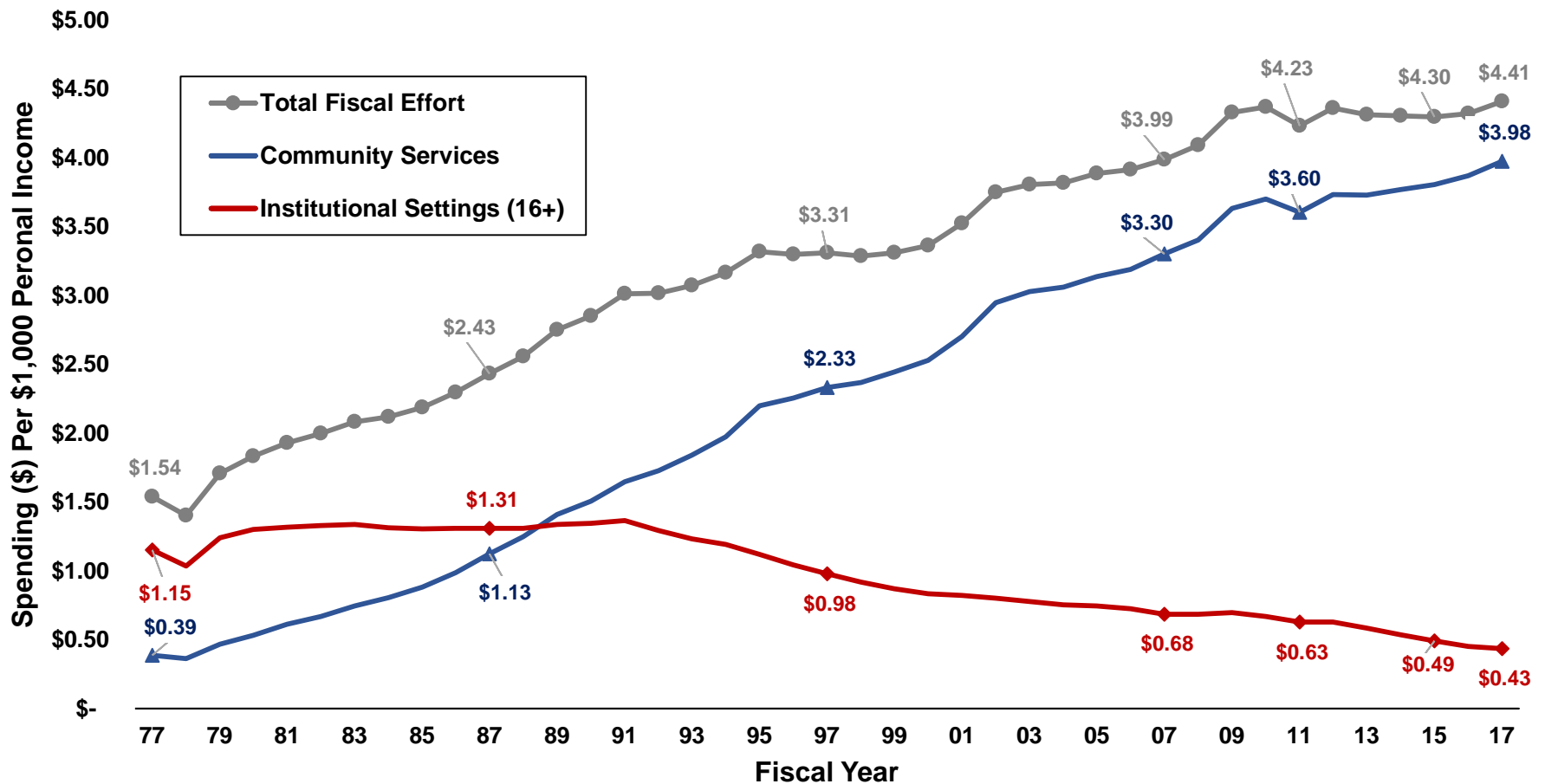
**Total federal-state Medicaid: \$48.5 billion**

# Institutional and community spending



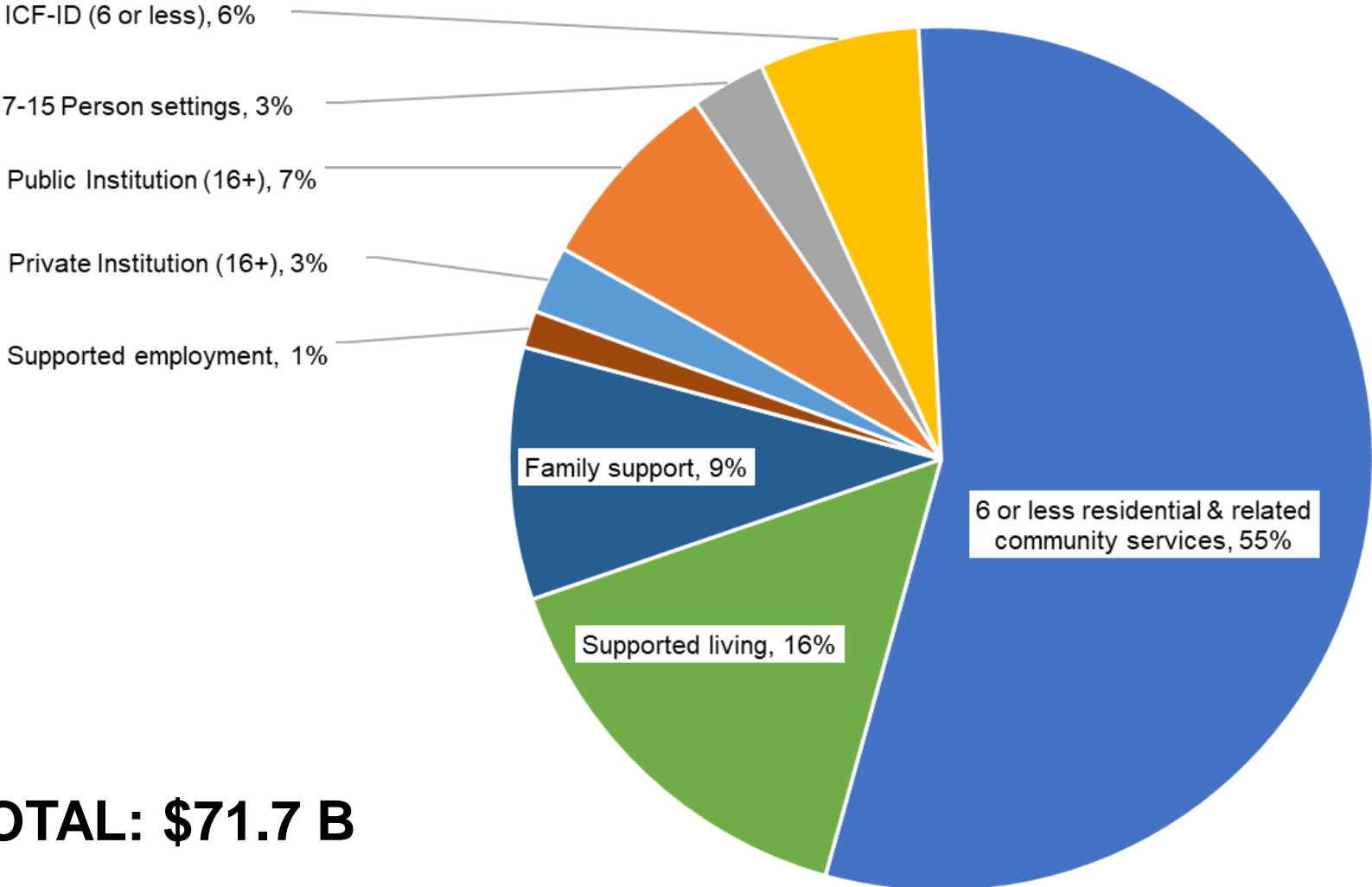
# Fiscal effort

## Fiscal effort for IDD services in the US: FYs 1977-2017



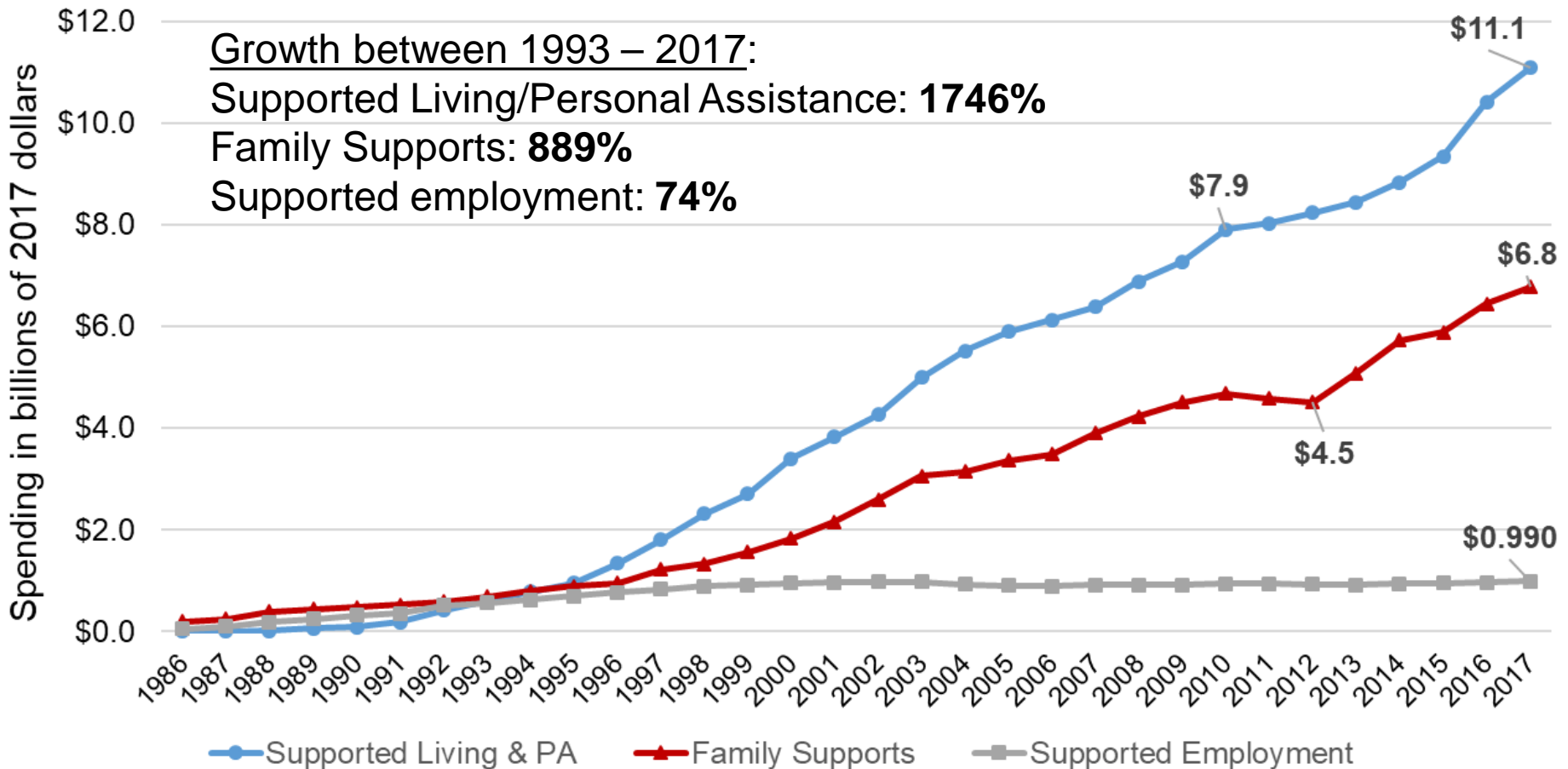


# Total IDD spending by category in US (FY 2017)



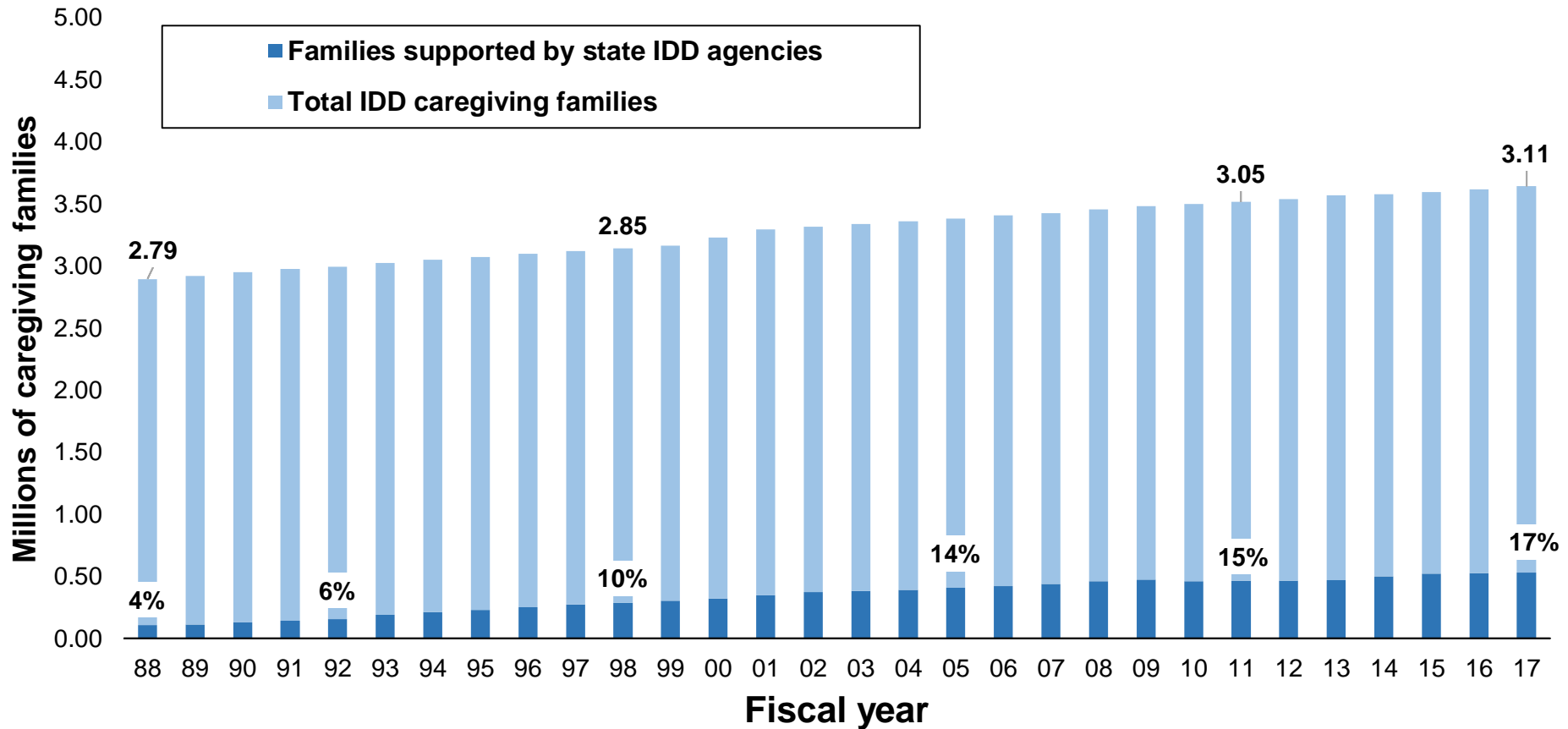
**TOTAL: \$71.7 B**

# Individual & family support and supported employment spending

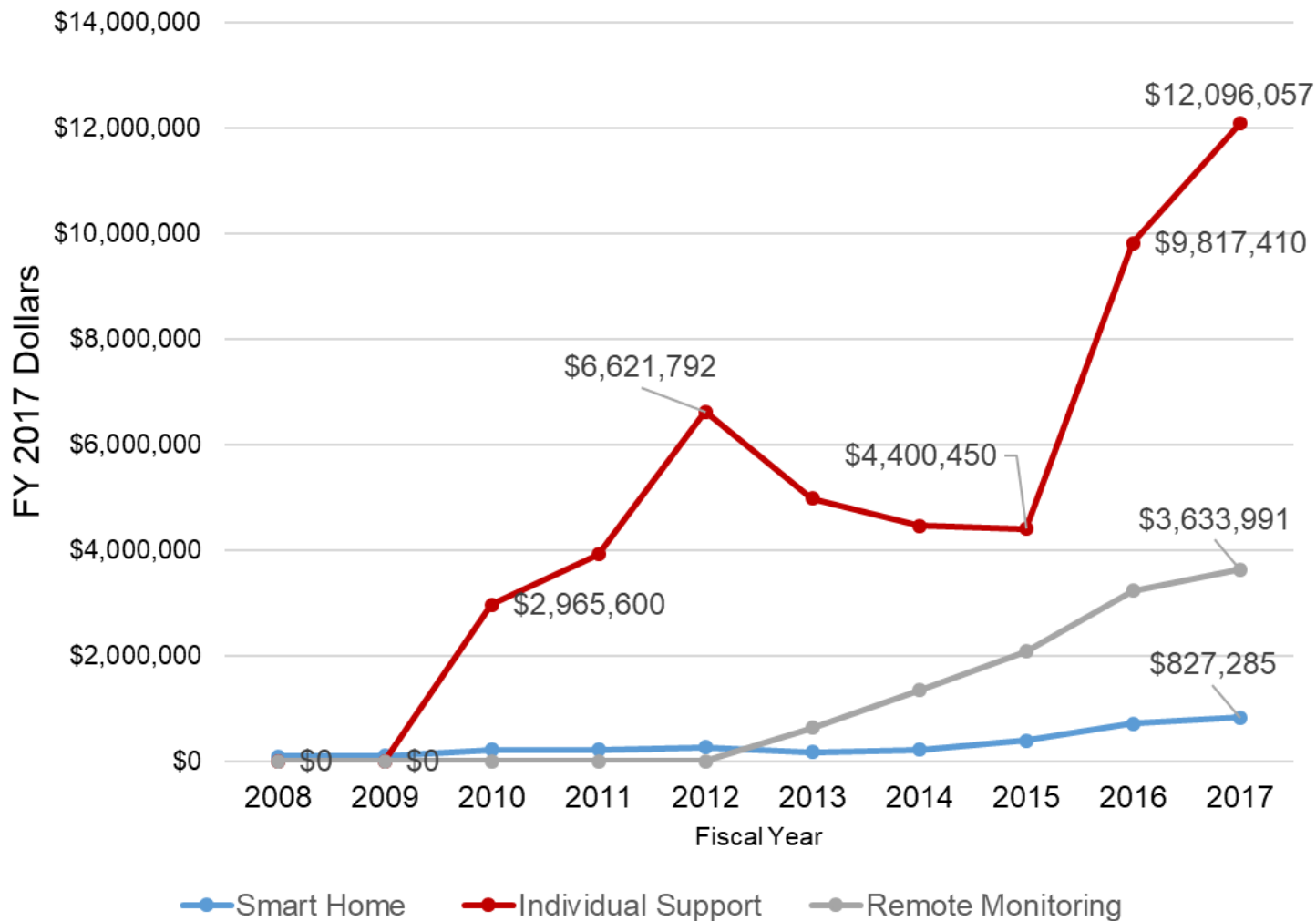


# Caregiving families

IDD caregiving families and families supported by state IDD agencies:  
FY 1988-2017



# State IDD Agency Technology Spending



Source: Braddock, D. et al. (2018). *The State of the States in Intellectual Disabilities*

# Personalize a Chart for your State or Region

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



## The State of the States in Developmental Disabilities

University of Colorado

BOULDER | COLORADO SPRINGS | DENVER | ANSCHUTZ MEDICAL CAMPUS

### 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](mailto:stateofthestates@cu.edu).

- What's New!
- State of the States
- Intellectual/Developmental Disabilities
  - Create a Chart
  - State Profiles
  - AIDD Projects of National Significance: Longitudinal Data Collection
- Cross Disability
  - Overview
  - Create a Chart
- About Us
- Publications
- Coleman Institute for Cognitive Disabilities
- Links
- Contact Us
- Search



# State profile [www.stateofthestates.org](http://www.stateofthestates.org)



The State of the States in Developmental Disabilities  
University of Colorado  
BOULDER | COLORADO SPRINGS | DENVER | ANSCHUTZ MEDICAL CAMPUS

- What's New!
- State of the States
- Intellectual/Developmental Disabilities
- **State Profiles**
- AIDD Projects of National Significance: Longitudinal Data Collection
- Cross-Disability



STATE OF THE STATES  
IN INTELLECTUAL  
DEVELOPMENTAL

Welcome to the website for the *State of the States* administered by the University of Colorado. The *State of the States* is a project of the University of Colorado Department of Psychiatry and the University of Colorado School of Medicine.

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



The State of the States in Developmental Disabilities  
University of Colorado  
BOULDER | COLORADO SPRINGS | DENVER | ANSCHUTZ MEDICAL CAMPUS

## 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)

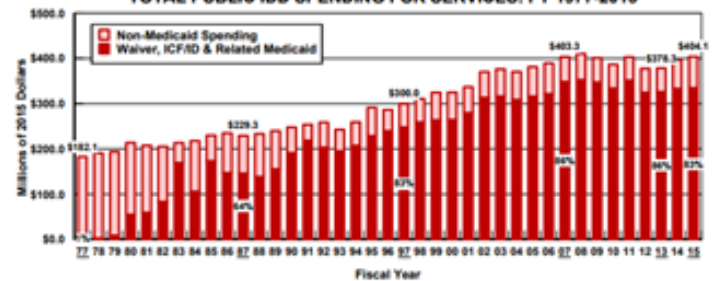
- What's New!
- State of the States
- Intellectual/Developmental Disabilities
- Create a Chart
- State Profiles
- AIDD Projects of National Significance: Longitudinal Data Collection
- Cross-Disability
- Overview
- Create a Chart
- About Us
- Publications
- Coleman Institute for Cognitive Disabilities
- Links
- Contact Us
- Search



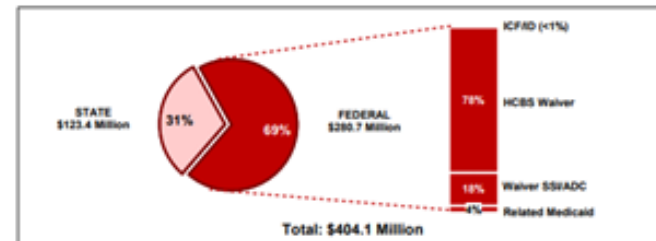
The State of the States  
in Developmental Disabilities  
University of Colorado Department of Psychiatry  
3225 1/2 Avenue, Suite 200  
Boulder, CO 80301

## ALABAMA

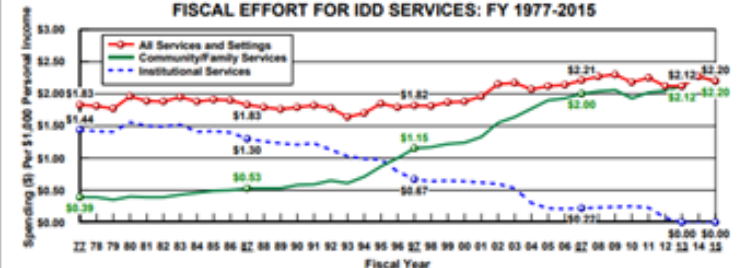
### TOTAL PUBLIC IDD SPENDING FOR SERVICES: FY 1977-2015



### 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



The State of the States in Developmental Disabilities  
University of Colorado  
BOULDER | COLORADO SPRINGS | DENVER | ANSCHUTZ MEDICAL CAMPUS

- What's New!
- State of the States
- Intellectual/Developmental Disabilities
  - **Create a Chart**
  - State Profiles
  - AIDD Projects of National Significance: Longitudinal Data Collection
- Cross Disability
  - Overview
  - Create a Chart
- About Us
- Publications
- Coleman Institute for Cognitive Disabilities
- Links
- Contact Us
- Search

**STATE OF THE STATES  
IN INTELLECTUAL AND  
DEVELOPMENTAL DISABILITIES**

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](#).



The State of the States in Developmental Disabilities  
University of Colorado  
BOULDER | COLORADO SPRINGS | DENVER | ANSCHUTZ MEDICAL CAMPUS

### Creating Charts for Fiscal Year 2015

You can create two types of charts:

**A) to compare all or some subset of states or regions up to four states or regions.** **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.

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

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](mailto:stateofthestates@cu.edu).

The State of the States  
in Developmental Disabilities  
University of Colorado Department of Psychiatry  
3825 Iris Avenue, Suite 200  
Boulder, CO 80301

# Create-a-chart (state or region)

www.stateofthestates.org

The State of the States in Developmental Disabilities  
University of Colorado  
BOULDER | COLORADO SPRINGS | DENVER | ANSCHUTZ MEDICAL CAMPUS

## CREATE CHARTS FOR FISCAL YEAR 2015

Begin creating a chart by following these three steps:

- 1) Select the type of data to compare;
- 2) Select whether to sort the data alphabetically, from highest to lowest, or from lowest to highest;
- 3) To compare as many states or regions as you would like, select them from the list.

Right click on the chart to print.

If you need any assistance, contact us at [stateofthestates@cu.edu](mailto:stateofthestates@cu.edu).

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

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

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

- Alphabetical
- Ascending
- Descending

[Next](#)

- What's New!
- State of the States
- Intellectual/Developmental Disabilities
  - Create a Chart
  - State Profiles
  - AIDD Projects of National Significance: Longitudinal Data Collection
- Cross Disability
  - Overview
  - Create a Chart
- About Us
- Publications
- Coleman Institute for Cognitive Disabilities
- Links
- Contact Us
- Search

[Facebook](#) [Twitter](#)

Click next

The State of the States in Developmental Disabilities  
University of Colorado Department of Psychiatry  
3825 Iris Avenue, Suite 200  
Boulder, CO 80301

The State of the States in Developmental Disabilities  
University of Colorado  
BOULDER | COLORADO SPRINGS | DENVER | ANSCHUTZ MEDICAL CAMPUS

## CREATE CHARTS FOR FISCAL YEAR 2015

Begin creating a chart by following these three steps:

- 1) Select the type of data to compare;
- 2) Select whether to sort the data alphabetically, from highest to lowest, or from lowest to highest;
- 3) To compare as many states or regions as you would like, select them from the list.

Right click on the chart to print.

If you need any assistance, contact us at [stateofthestates@cu.edu](mailto:stateofthestates@cu.edu).

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 checked="" type="checkbox"/> Alabama	<input checked="" type="checkbox"/> Illinois	<input checked="" type="checkbox"/> Montana	<input checked="" type="checkbox"/> Rhode Island
<input checked="" type="checkbox"/> Alaska	<input checked="" type="checkbox"/> Indiana	<input checked="" type="checkbox"/> Nebraska	<input checked="" type="checkbox"/> South Carolina
<input checked="" type="checkbox"/> Arizona	<input checked="" type="checkbox"/> Iowa	<input checked="" type="checkbox"/> Nevada	<input checked="" type="checkbox"/> South Dakota
<input checked="" type="checkbox"/> Arkansas	<input checked="" type="checkbox"/> Kansas	<input checked="" type="checkbox"/> New Hampshire	<input checked="" type="checkbox"/> Tennessee
<input checked="" type="checkbox"/> California	<input checked="" type="checkbox"/> Kentucky	<input checked="" type="checkbox"/> New Jersey	<input checked="" type="checkbox"/> Texas
<input checked="" type="checkbox"/> Colorado	<input checked="" type="checkbox"/> Louisiana	<input checked="" type="checkbox"/> New Mexico	<input checked="" type="checkbox"/> Utah
<input checked="" type="checkbox"/> Connecticut	<input checked="" type="checkbox"/> Maine	<input checked="" type="checkbox"/> New York	<input checked="" type="checkbox"/> Vermont
<input checked="" type="checkbox"/> Delaware	<input checked="" type="checkbox"/> Maryland	<input checked="" type="checkbox"/> North Carolina	<input checked="" type="checkbox"/> Virginia
<input checked="" type="checkbox"/> District of Columbia	<input checked="" type="checkbox"/> Massachusetts	<input checked="" type="checkbox"/> North Dakota	<input checked="" type="checkbox"/> Washington
<input checked="" type="checkbox"/> Florida	<input checked="" type="checkbox"/> Michigan	<input checked="" type="checkbox"/> Ohio	<input checked="" type="checkbox"/> West Virginia
<input checked="" type="checkbox"/> Georgia	<input checked="" type="checkbox"/> Minnesota	<input checked="" type="checkbox"/> Oklahoma	<input checked="" type="checkbox"/> Wisconsin
<input checked="" type="checkbox"/> Hawaii	<input checked="" type="checkbox"/> Mississippi	<input checked="" type="checkbox"/> Oregon	<input checked="" type="checkbox"/> Wyoming
<input checked="" type="checkbox"/> Idaho	<input checked="" type="checkbox"/> Missouri	<input checked="" type="checkbox"/> Pennsylvania	<input type="checkbox"/> UNITED STATES

NEW ENGLAND (CT, ME, MA, NH, RI, VT)

NORTHEAST (NJ, NY)

MID-ATLANTIC (DE, DC, MD, PA, VA, WV)

SOUTHEAST (AL, FL, GA, KY, MS, NC, SC, TN)

GREAT LAKES (IL, IN, MI, MN, OH, WI)

SOUTHWEST (AR, LA, NM, OK, TX)

GREAT PLAINS (IA, KS, MO, NE)

ROCKY MOUNTAIN (CO, MT, ND, SD, UT, WY)

PACIFIC (AZ, CA, HI, NV)

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](#)

- What's New!
- State of the States
- Intellectual/Developmental Disabilities
  - Create a Chart
  - State Profiles
  - AIDD Projects of National Significance: Longitudinal Data Collection
- Cross Disability
  - Overview
  - Create a Chart
- About Us
- Publications
- Coleman Institute for Cognitive Disabilities
- Links
- Contact Us
- Search

[Facebook](#) [Twitter](#)

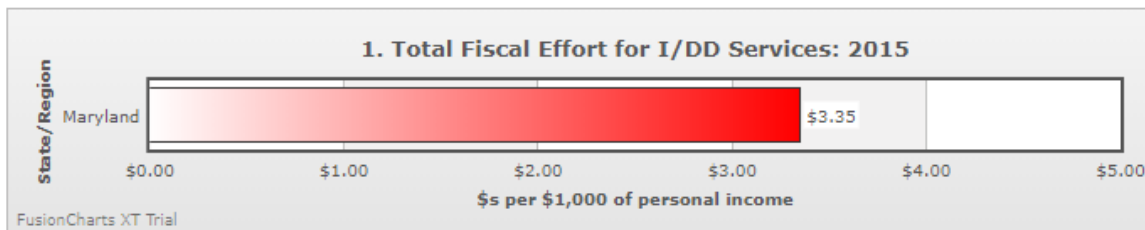
The State of the States in Developmental Disabilities  
University of Colorado Department of Psychiatry  
3825 Iris Avenue, Suite 200  
Boulder, CO 80301



# Create-a-chart, continued

[\[Close Window\]](#)

Use Ctrl-P or Cmnd-P to print.



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

Copyright © 2017, The State of the States in Developmental Disabilities Project

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

[\[Close Window\]](#)

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.

Copyright © 2017, The State of the States in Developmental Disabilities Project

# THANK YOU!

To learn more about the Coleman Institute visit [www.ColemanInstitute.org](http://www.ColemanInstitute.org)



Coleman Institute for Cognitive Disabilities

UNIVERSITY OF COLORADO

Boulder | Colorado Springs | Denver | Anschutz Medical Campus

For more information about State of the States visit:

<http://www.StateoftheStates.org>



STATE OF THE STATES  
IN INTELLECTUAL AND  
DEVELOPMENTAL DISABILITIES

Financial support was obtained from the U.S. Administration on Intellectual and Developmental Disabilities and the Coleman Institute for Cognitive Disabilities, University of Colorado.

# Keep in Touch!

Like us on FaceBook



Follow us on Twitter @SOS\_in\_DD



Email us:

[Shea.Tanis@cu.edu](mailto:Shea.Tanis@cu.edu)

[Amie.Lulinski@cu.edu](mailto:Amie.Lulinski@cu.edu)



# One4One

OCTOBER 3, 2018

2018 ANNUAL  
COLEMAN  
INSTITUTE  
CONFERENCE  
ON COGNITIVE  
DISABILITY  
AND TECHNOLOGY



Register at: [www.colemaninstitute.org](http://www.colemaninstitute.org)



Coleman Institute for Cognitive Disabilities  
UNIVERSITY OF COLORADO

Boulder | Colorado Springs | Denver | Anschutz Medical Campus



# Community Inclusion and the Residential Information Systems Project (RISP)

**risp.umn.edu**      **risp@umn.edu**

**HCBS Conference 2018**

**Heidi Eschenbacher** [hje@umn.edu](mailto:hje@umn.edu)

Larson, S.A., Eschenbacher, H.J., Anderson, L.L., Taylor, B., Pettingell, S., Hewitt, A., Sowers, M., & Bourne, M.L. (2018). In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends through 2016 . Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. Retrieved from:  
<https://risp.umn.edu>

Preparation of this presentation was supported, in part, by cooperative agreements (90DN0297, 90DN0291, and 90RT5019-01-00) from the US Health and Human Services, Administration on Community Living. 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 AIDD policy.



# Why is the RISP data important?

- Track status and trends in LTSS for people with IDD (e.g., deinstitutionalization)
  - Nationally
  - State-by-state
- Used by federal and state policy makers, advocates and other stakeholders to:
  - Review national and state progress toward LTSS goals
  - Compare a state's performance to the nation or other states
  - Prepare reports
  - Advocate for systems change
- Enhances ongoing programs of research:
  - Provides state level data to help explain variability in outcomes
  - Provides a local context for proposed changes

# System Information

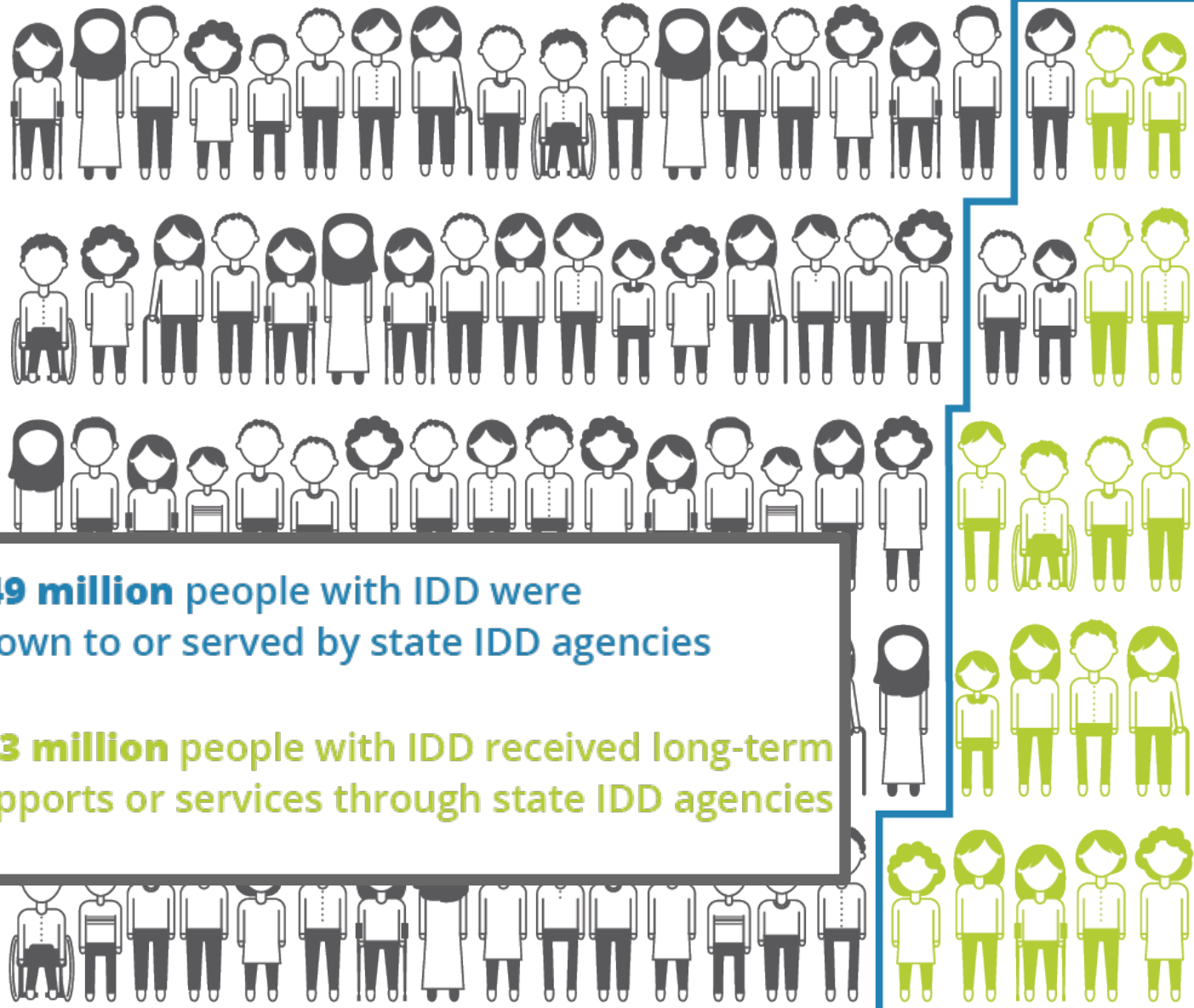
*How many people are there with IDD?  
What supports to people with IDD access?*



**7.37** million people in the United States had Intellectual or Developmental Disabilities (IDD) in 2016

# People with IDD in the US in 2016

2% of the U.S. population

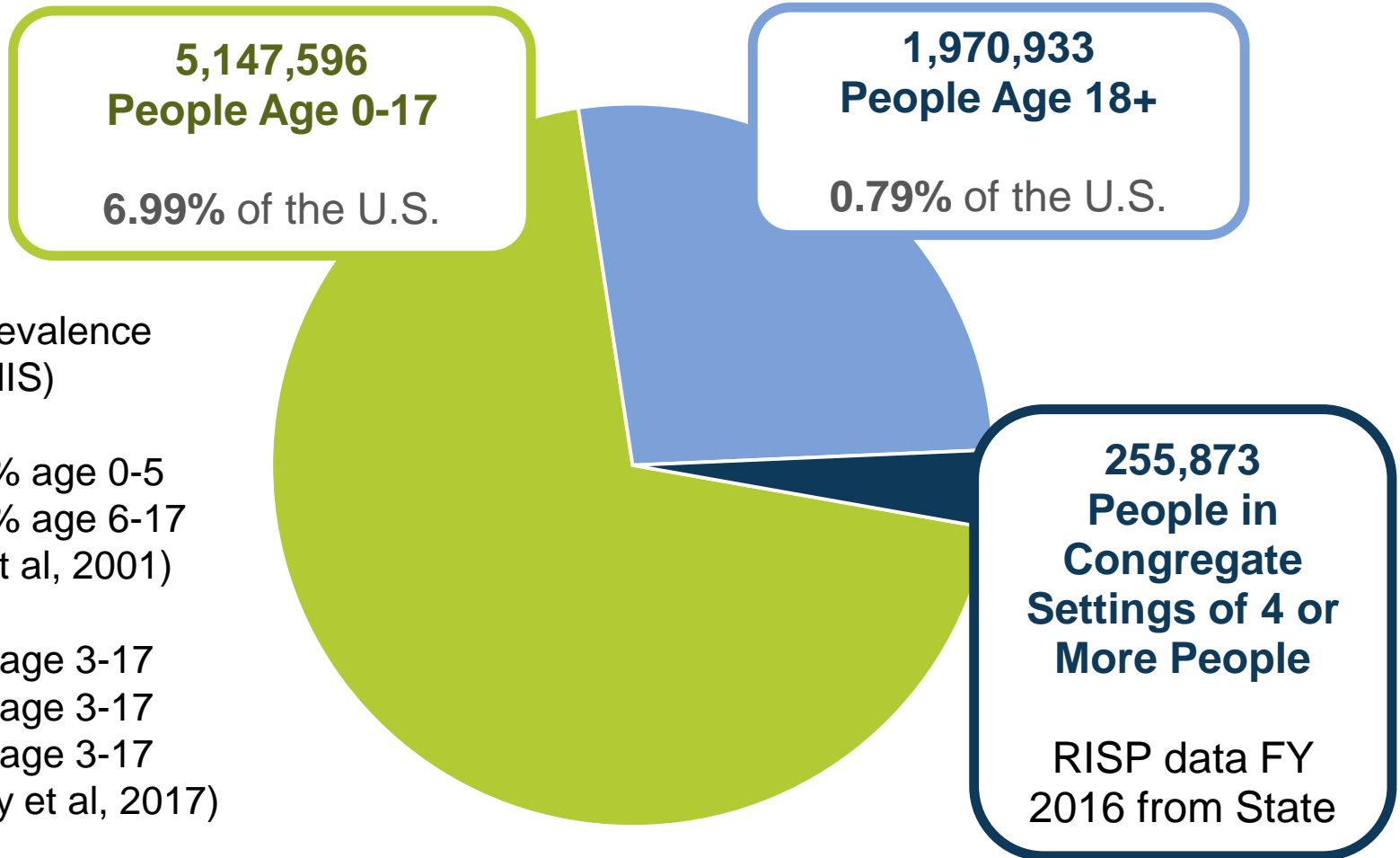


**20%** 1.49 million people with IDD were known to or served by state IDD agencies

**17%** 1.23 million people with IDD received long-term supports or services through state IDD agencies



# How RISP calculated Prevalence in FY2016



Children's' prevalence estimates(NHIS)

1994/5: 3.84% age 0-5  
1994/5: 3.17% age 6-17  
(Larson et al, 2001)

2014: 5.76% age 3-17  
2015: 6.04% age 3-17  
2016: 6.99% age 3-17  
(Zablotsky et al, 2017)



# Long-Term Supports and Services (LTSS)

**Long-Term Supports and Services (LTSS)** assist people experiencing ongoing difficulties as a result of aging, chronic illness, or disability to perform activities of daily living (such as eating, bathing, and dressing), instrumental activities of daily living (such as cooking, housekeeping, and managing money or medications), and to participate in employment, educational, recreation, and community activities of their choice.

LTSS include, but are not limited to,

- residential supports,
- in-home supports,
- personal care assistance,
- family supports,
- day or employment supports,
- case management,
- behavioral supports,
- support for participant direction,
- therapeutic services,
- non-medical transportation,
- equipment,
- technology and modifications,
- home delivered meals,
- community transition services,
- family and caregiver training,
- respite, and
- financial management services.

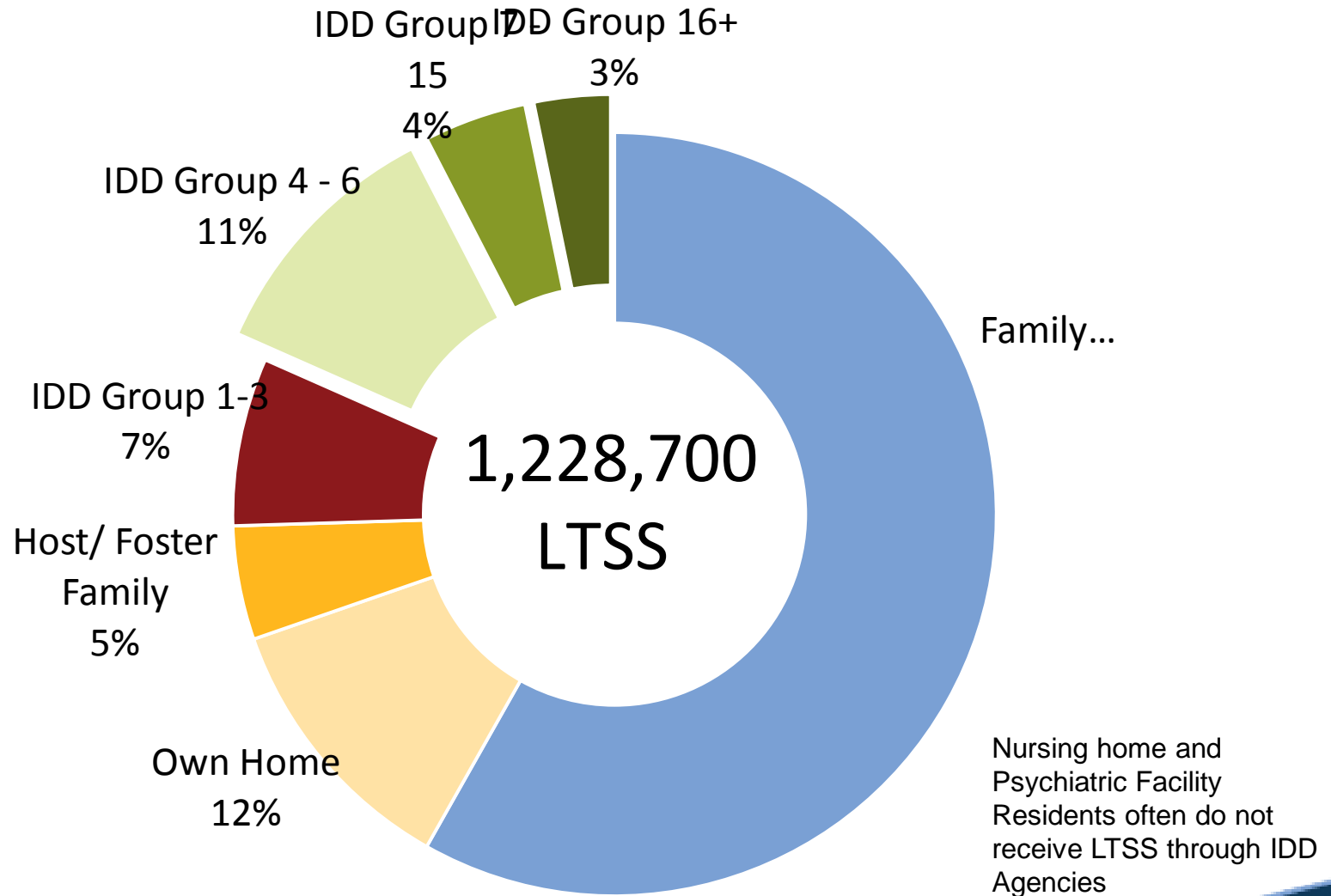
*Case management alone is not LTSS, but with one service it is LTSS.*



# FY 2016 Highlights

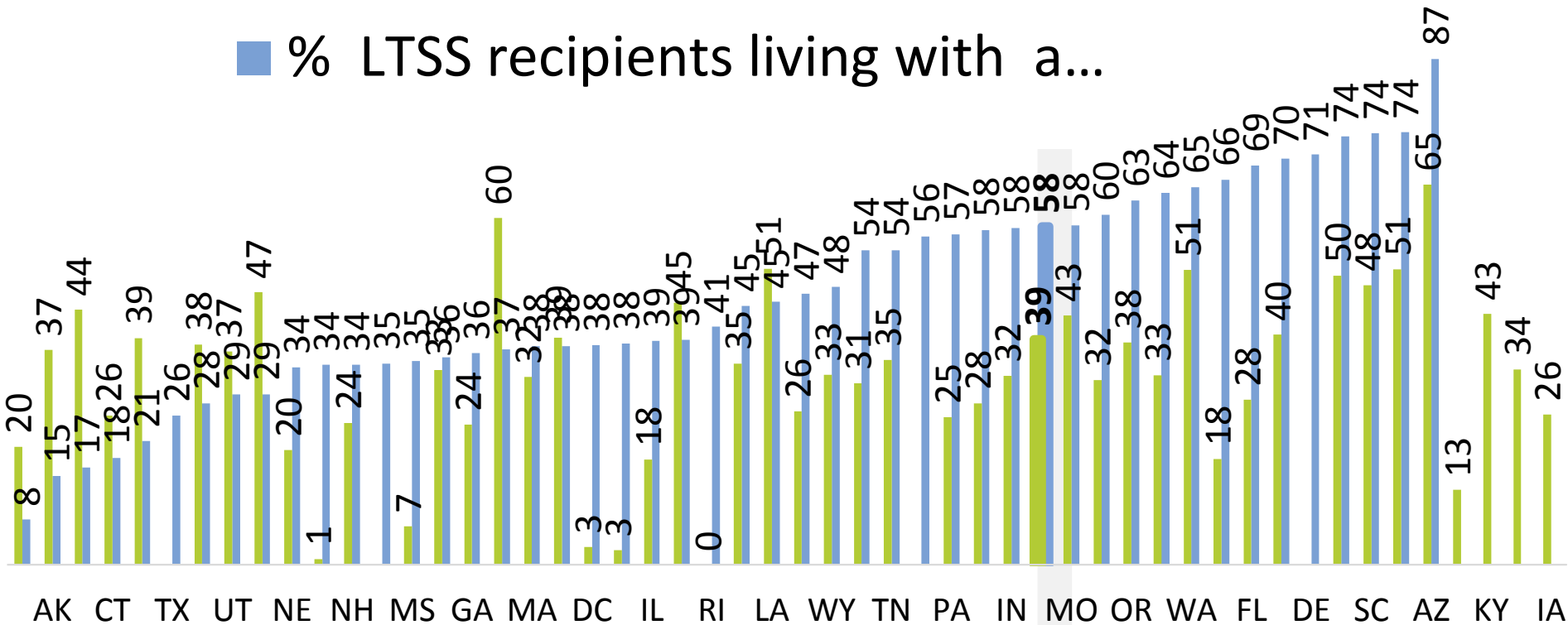


# Where did LTSS Recipients with IDD live?

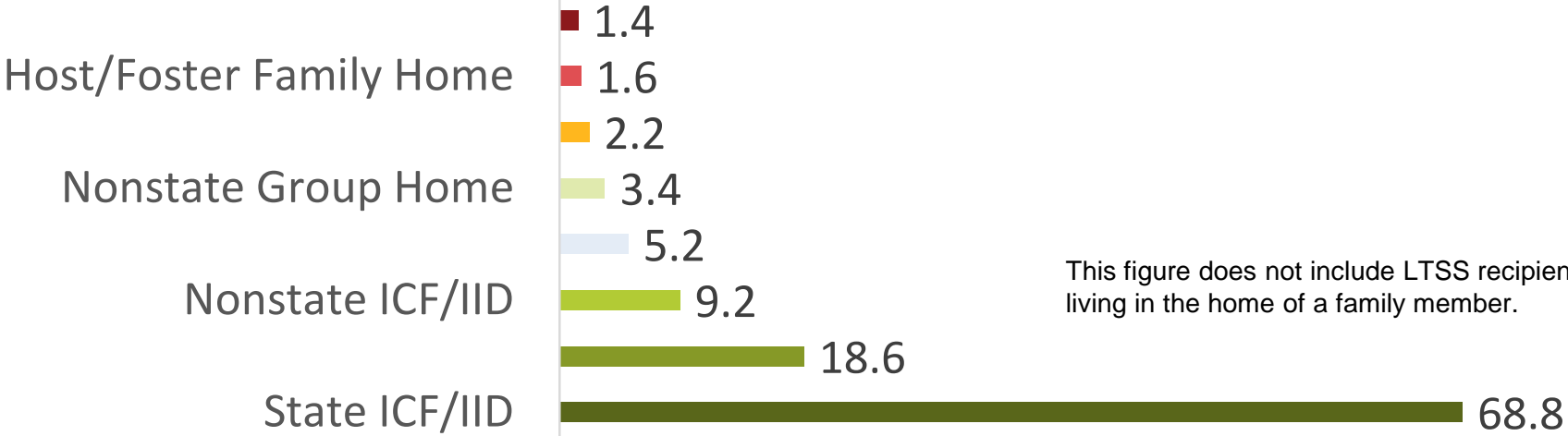


# Percent of LTSS Recipients with IDD Living with a Family Member Compared to the Proportion of People Served by the State IDD Agencies Age 21 and Under by State on June 30, 2016

■ % LTSS recipients living with a...



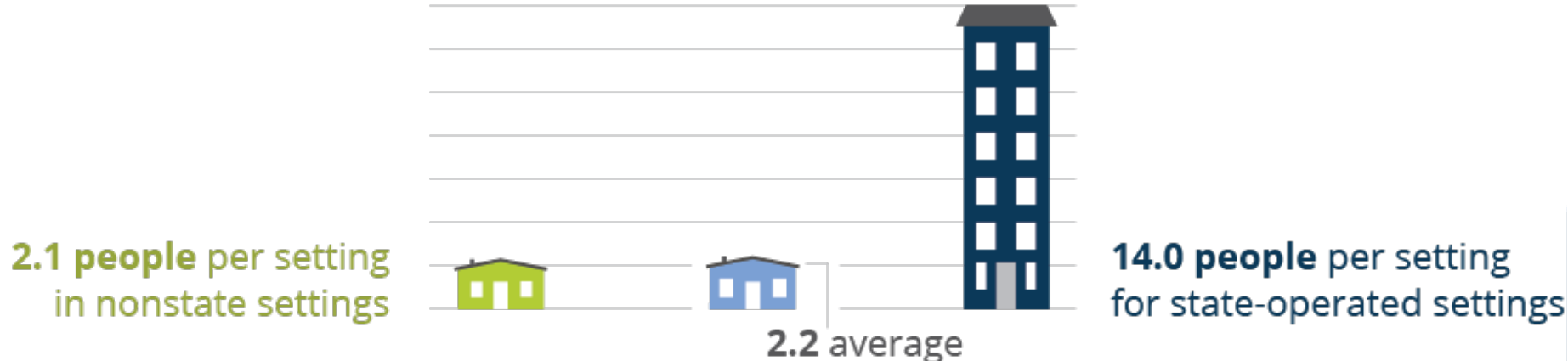
# Average Number of LTSS Recipients with IDD Per Setting as of June 30, 2016



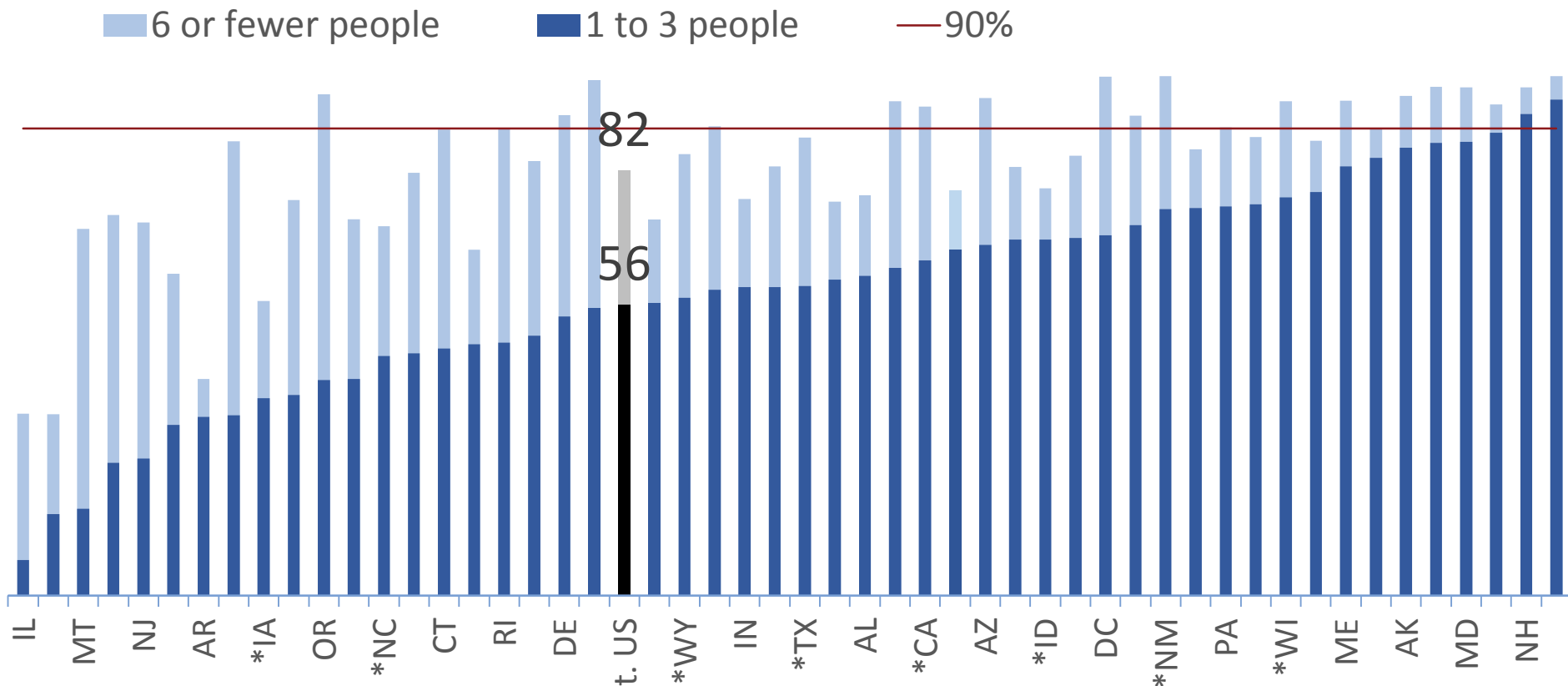
This figure does not include LTSS recipients living in the home of a family member.

Average Number of LTSS Recipients with IDD Per Setting

An average of 2.2 people lived in each non-family IDD setting



# Percent of LTSS Recipients who lived with 3 or fewer and 6 or fewer people with IDD on June 30, 2016



\* Imputed values for 1-3 and 4-6 proportions based on national estimates.

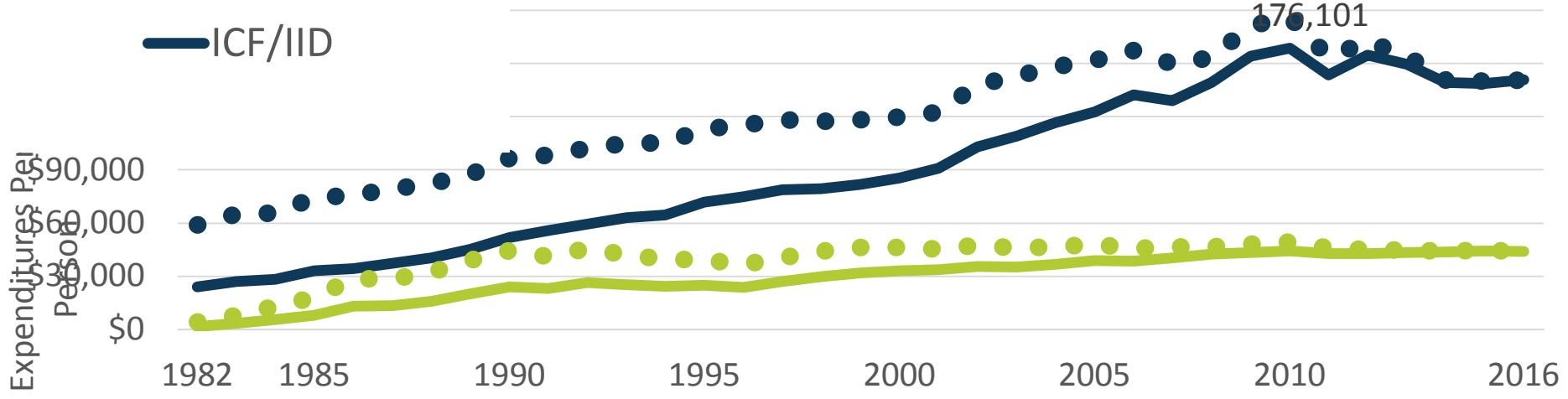
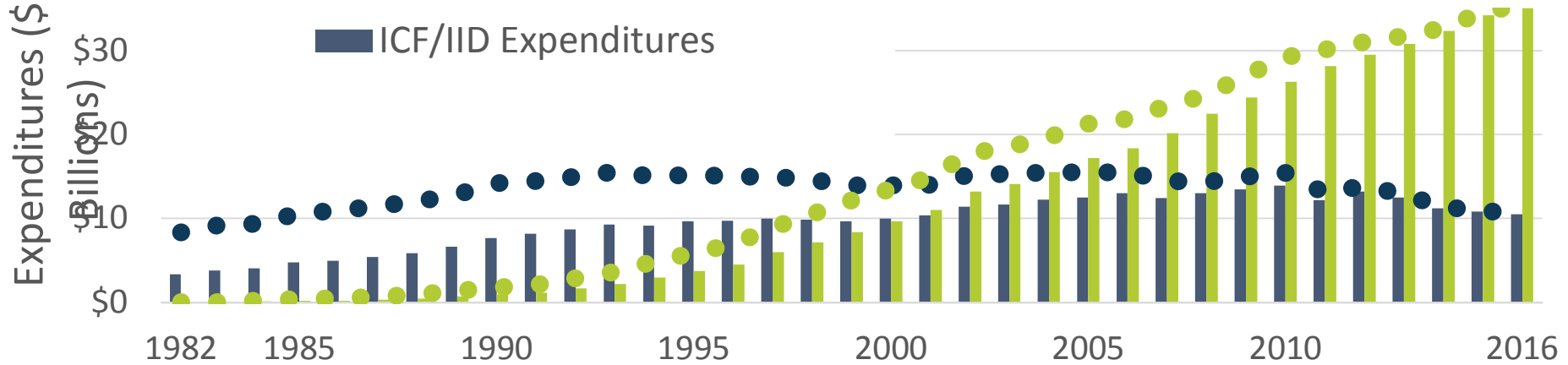
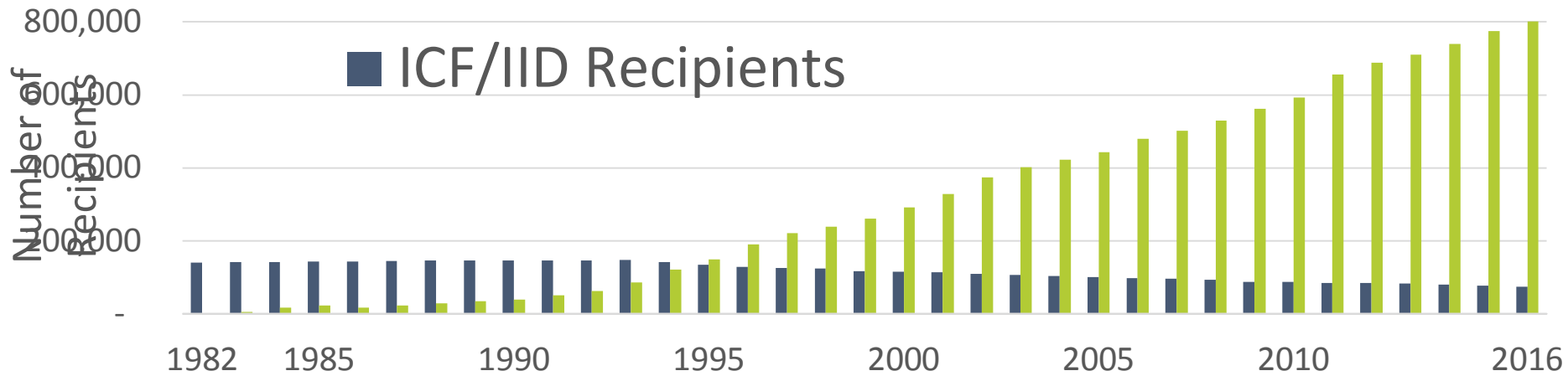
Percentages among people who receive LTSS who do not live with family members.



# Medicaid



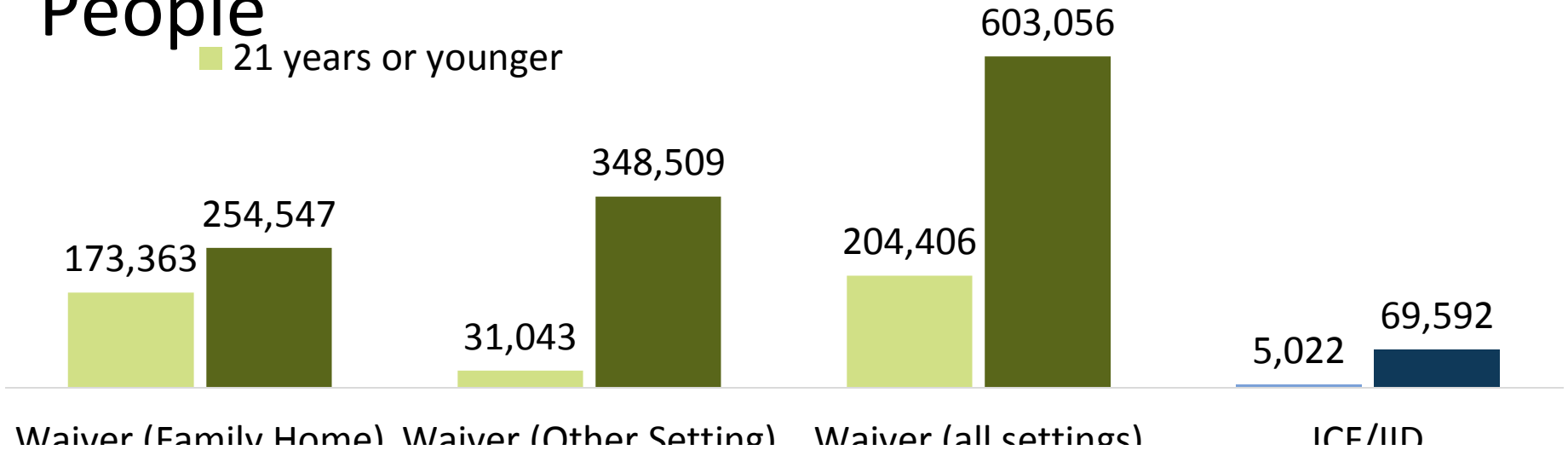




# Number of Individuals by Medicaid Funding Authority and Residence Type

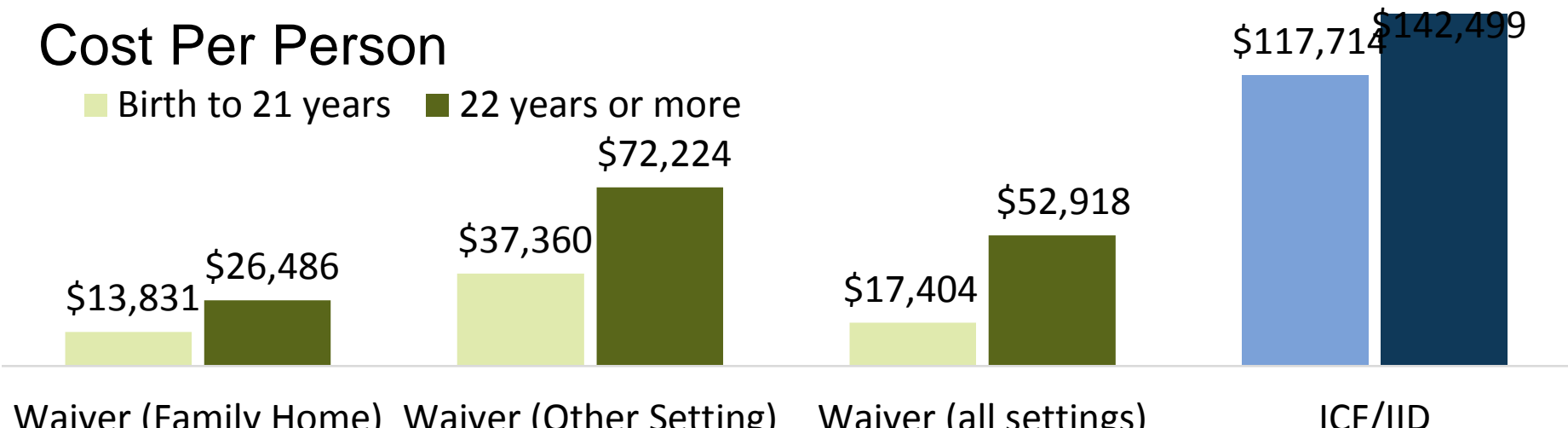
## People

■ 21 years or younger



## Cost Per Person

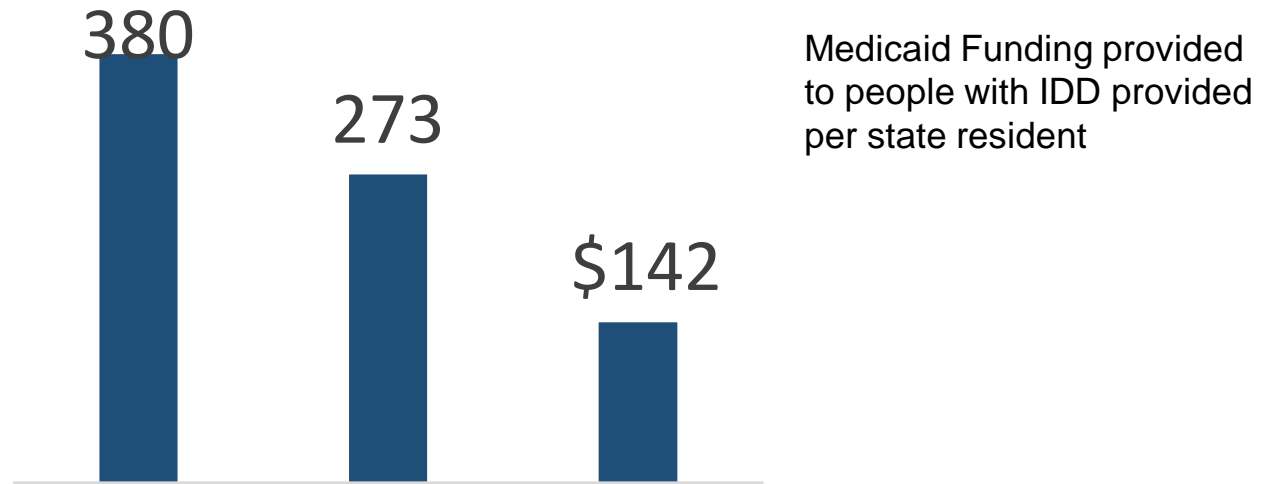
■ Birth to 21 years ■ 22 years or more



# Per Capita Investment in People with IDD

## FY 2016

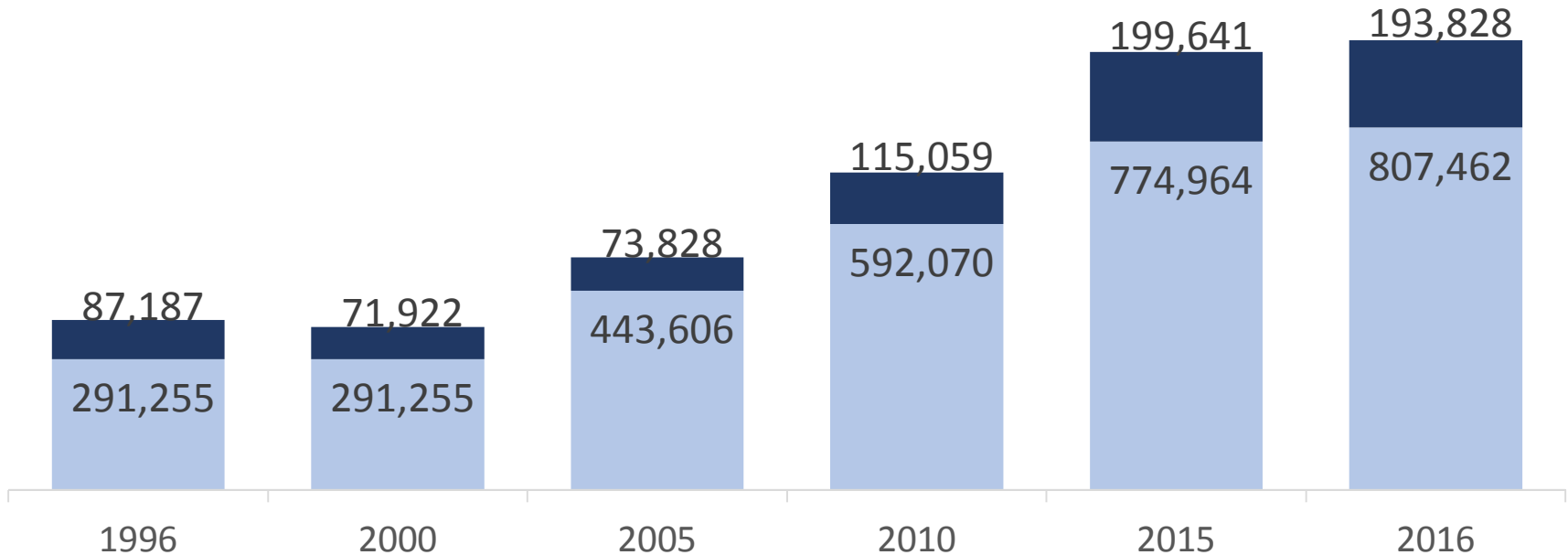
People with IDD Receiving Funded Supports and Services



Term Medicaid Recipients 380 People Receiving Funded Supports and Services 273 Medicaid Funding provided per state resident \$142

# People With IDD Waiting for Services in the United States...

■ Waiver Recipients ■ People Waiting



% is the amount of growth needed to serve those waiting.

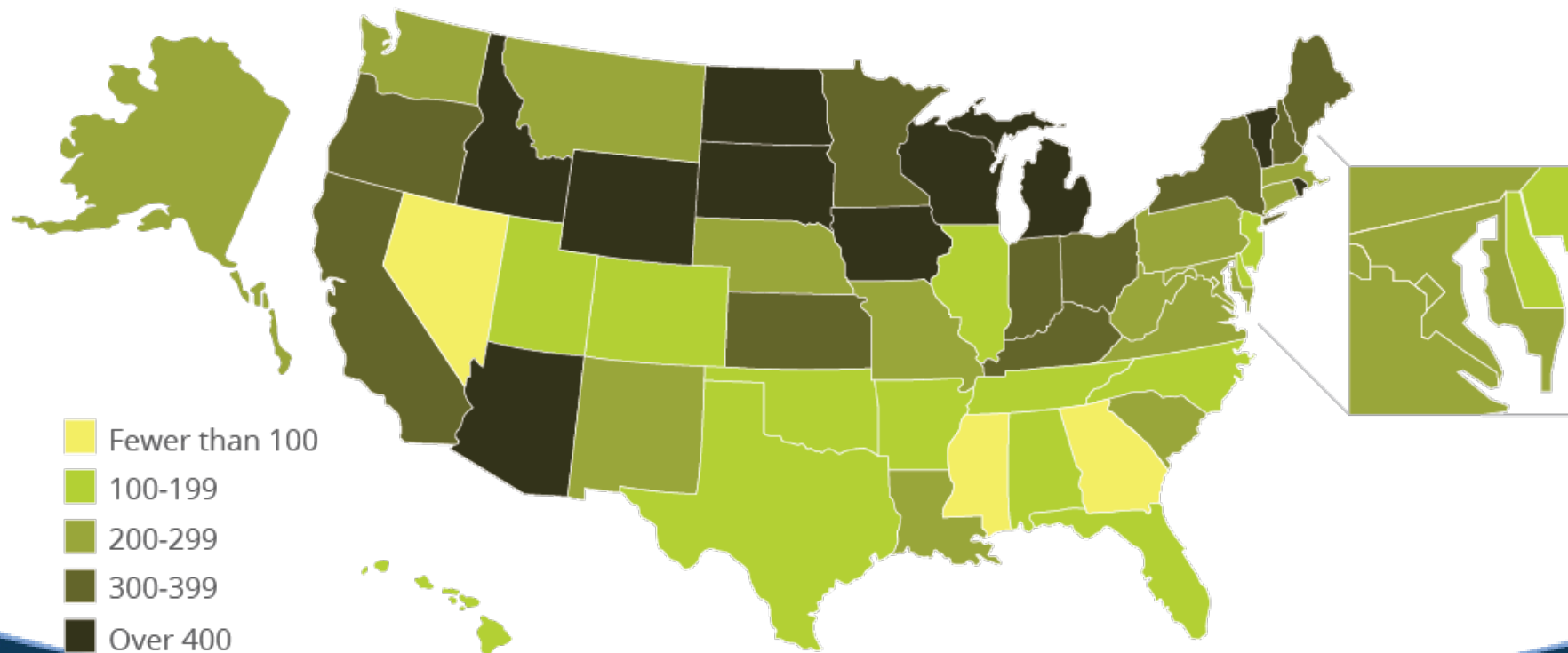
From 2010 on, people waiting may include people waiting for residential services in addition to the Medicaid Waiver. In 2015-16 people waiting were those waiting in the family home for Waiver Services.

# Medicaid Waiver



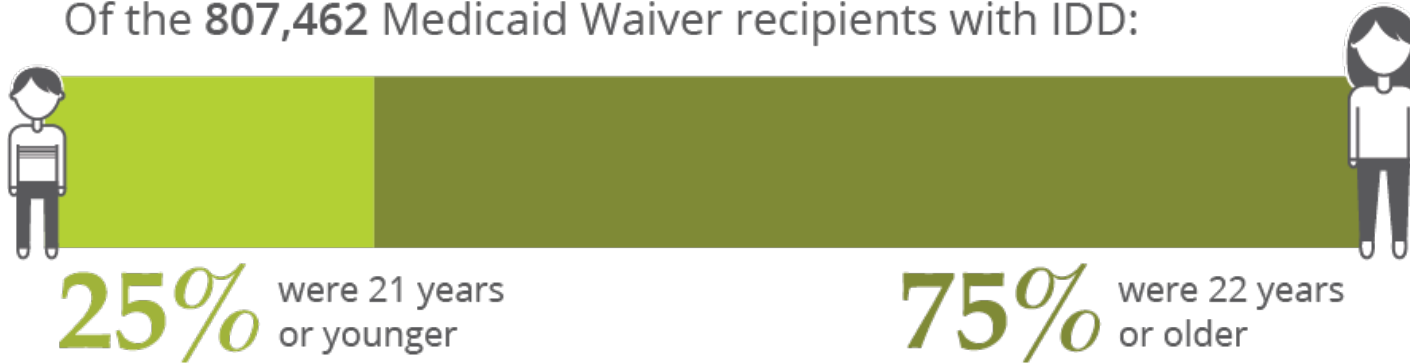
# Number of People Receiving Waiver-Funded Supports per 100,000 of the Population

250 people with IDD per 100,000 of the population received Medicaid Waiver-funded supports



# Age and Spending for Waiver Recipients Settings in 2016

Of the 807,462 Medicaid Waiver recipients with IDD:



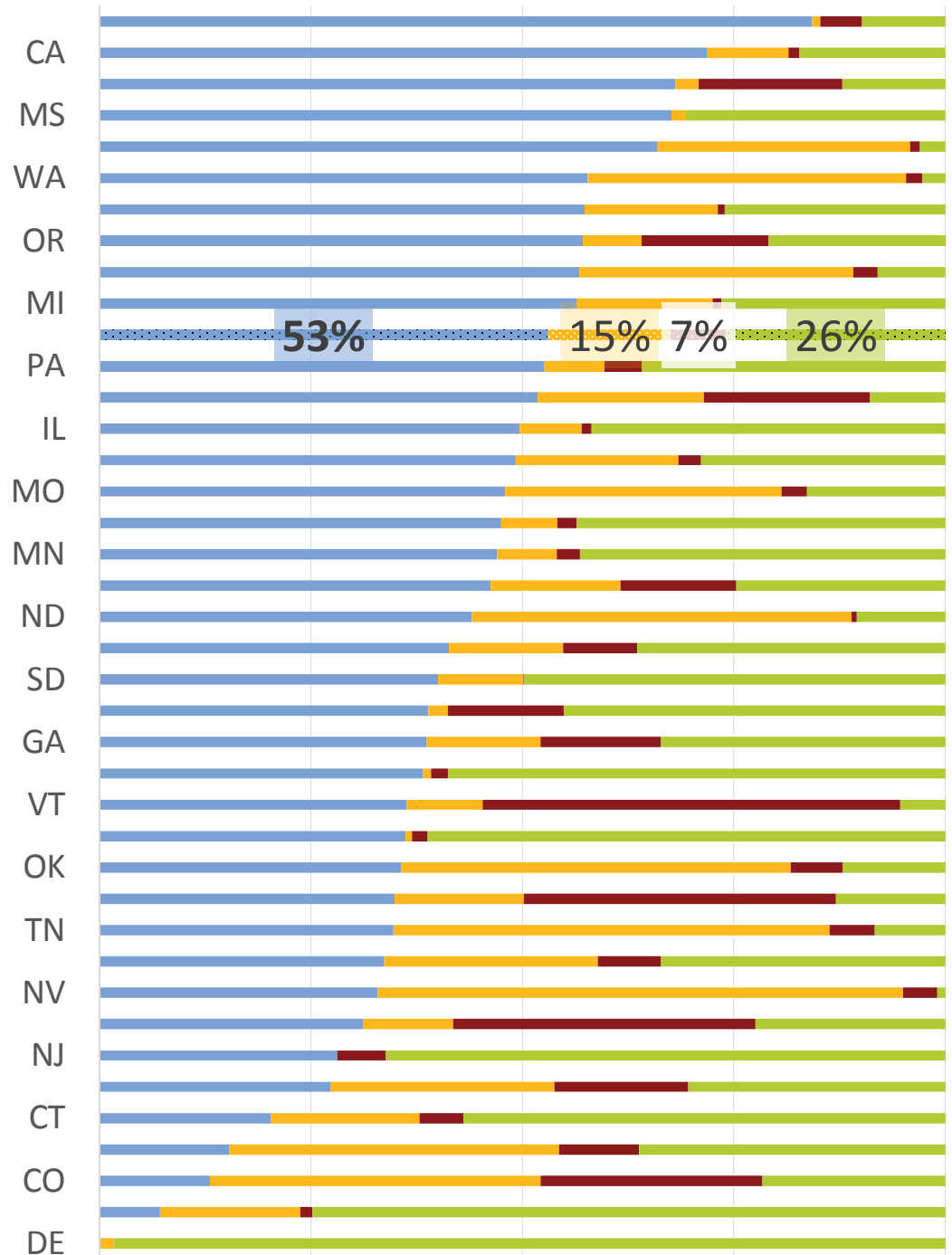
**\$35.5 billion** expended to provide Medicaid Waiver funded supports to 807,462 people with IDD (\$43,928 per person)

Annual per person Medicaid Waiver expenditures



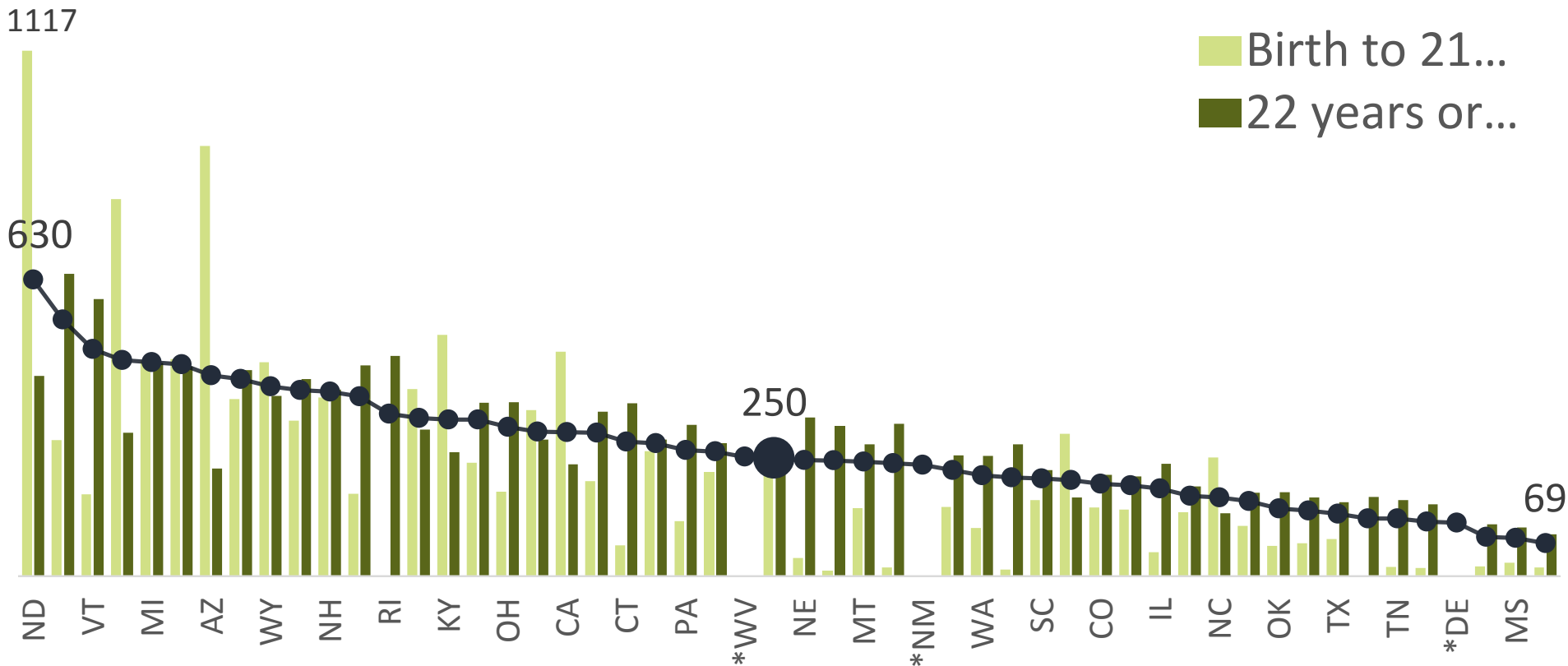
# Percent of Medicaid Waiver Recipients with IDD in Family Home, Own Home, Host or Foster Family Home, or Group Settings by State June 30, 2016

■ Family %

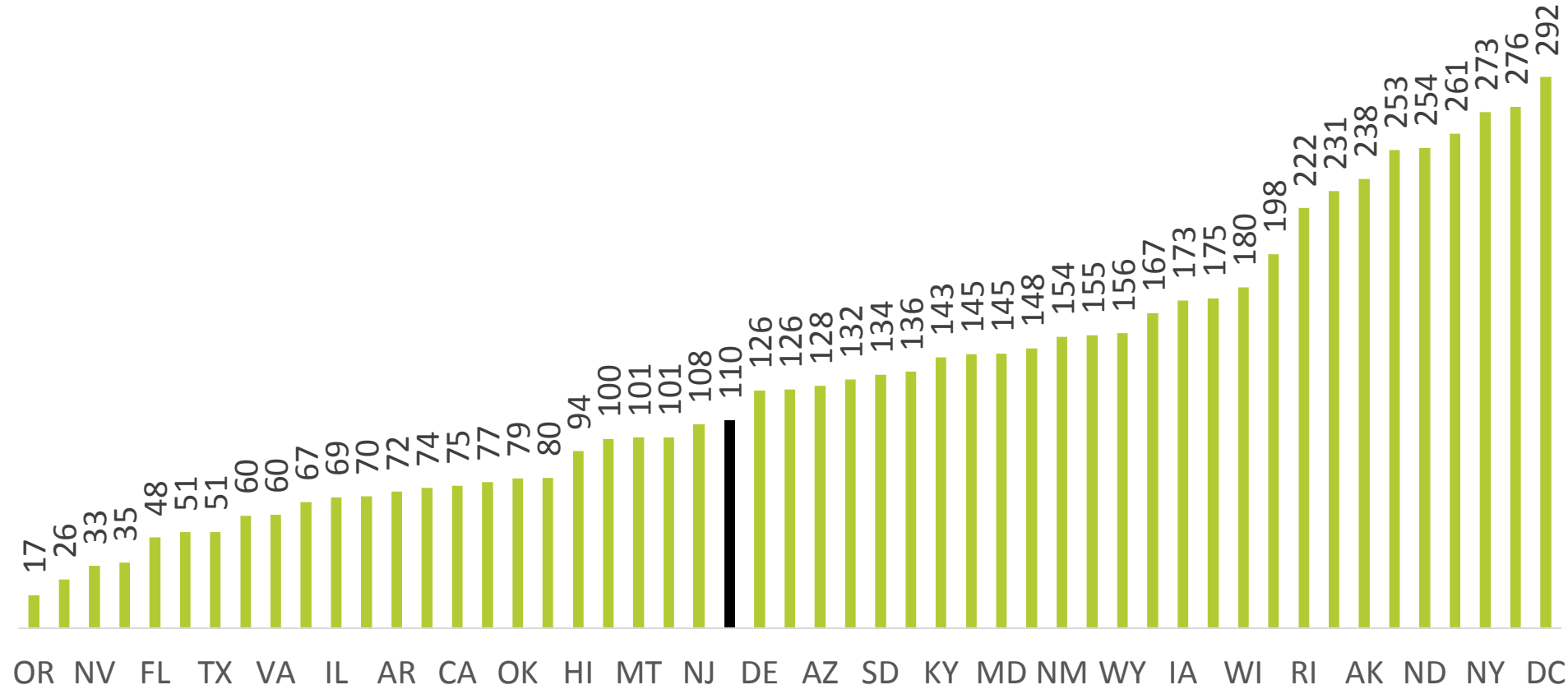




# Medicaid Waiver Recipients with IDD per 100,000 of the Population by Age and State on June 30, 2016



# Annual Medicaid Waiver Expenditures for People with IDD per State Resident by State FY 2016

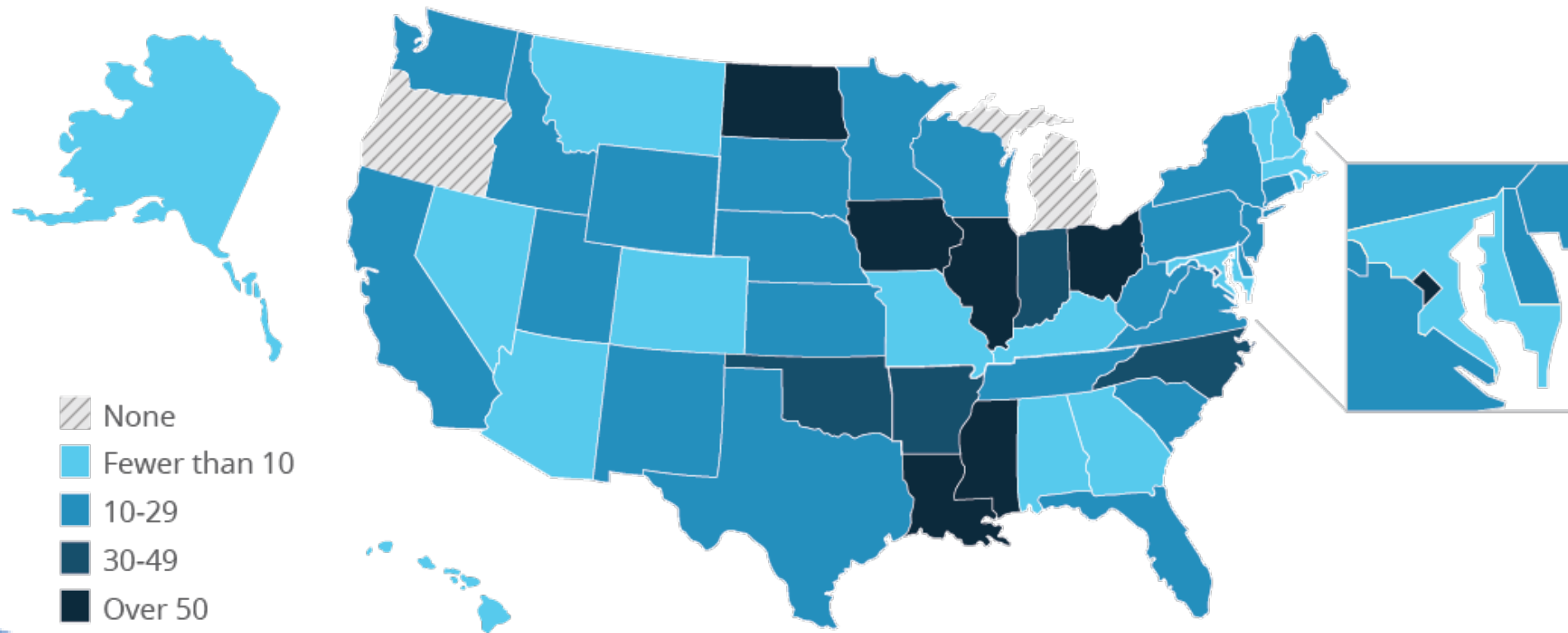


**ICF/IID**



# Number of People in ICF/IID Settings per 100,000 of the Population

23.2 people with IDD per 100,000 of the population lived in an ICF/IID



# Age and Spending for People Living in ICF/IID Settings in 2016

Of the 74,614 people living in ICF/IID settings:



**7%** were 21 years or younger



**93%** were 22 years or older

**\$10.8 billion** expended to provide Medicaid ICF/IID services to 74,614 people with IDD (140,831 per person)

Annual per person ICF/IID expenditures

21 years and younger

**\$117,714**

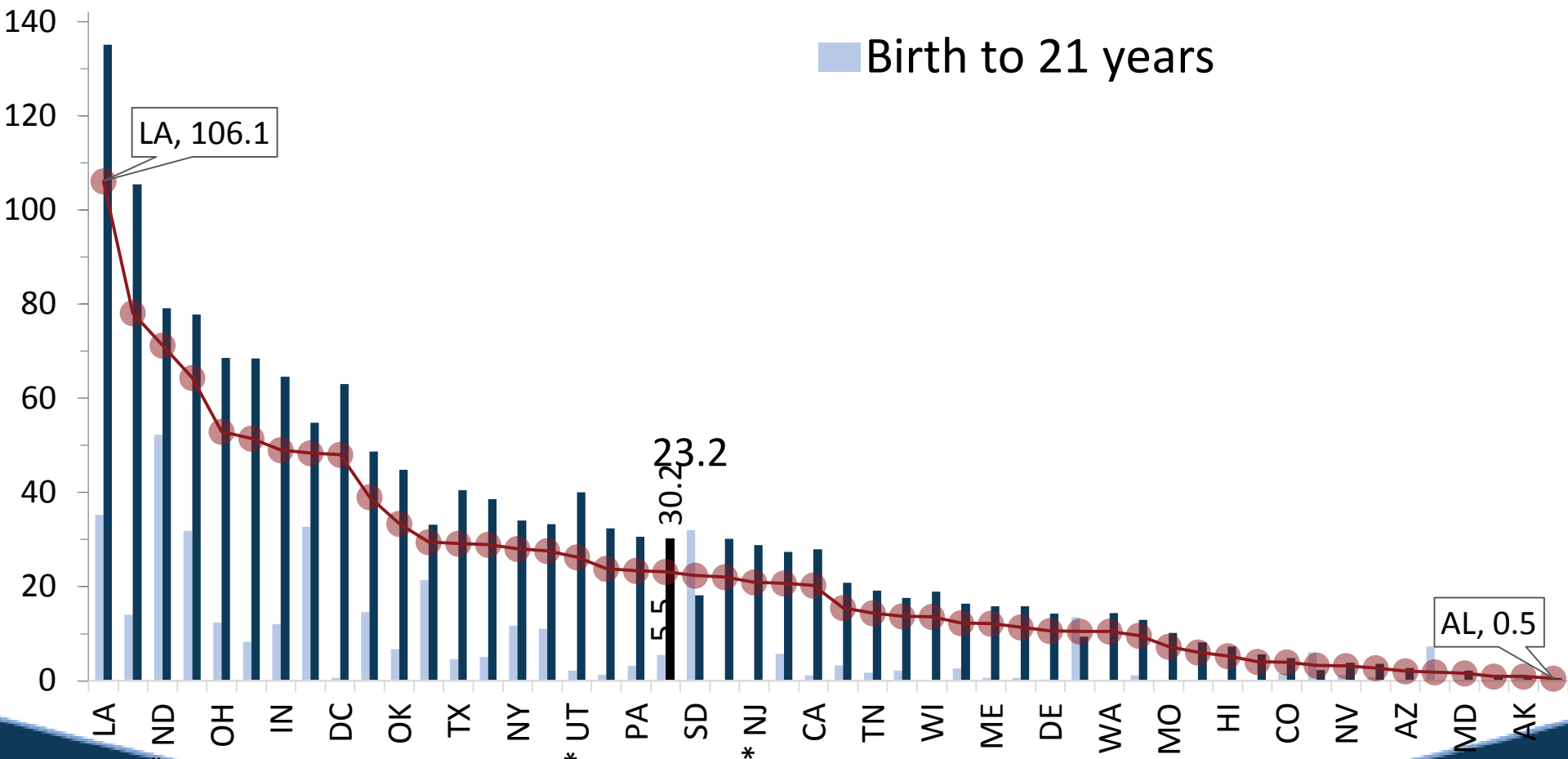


22 years and older

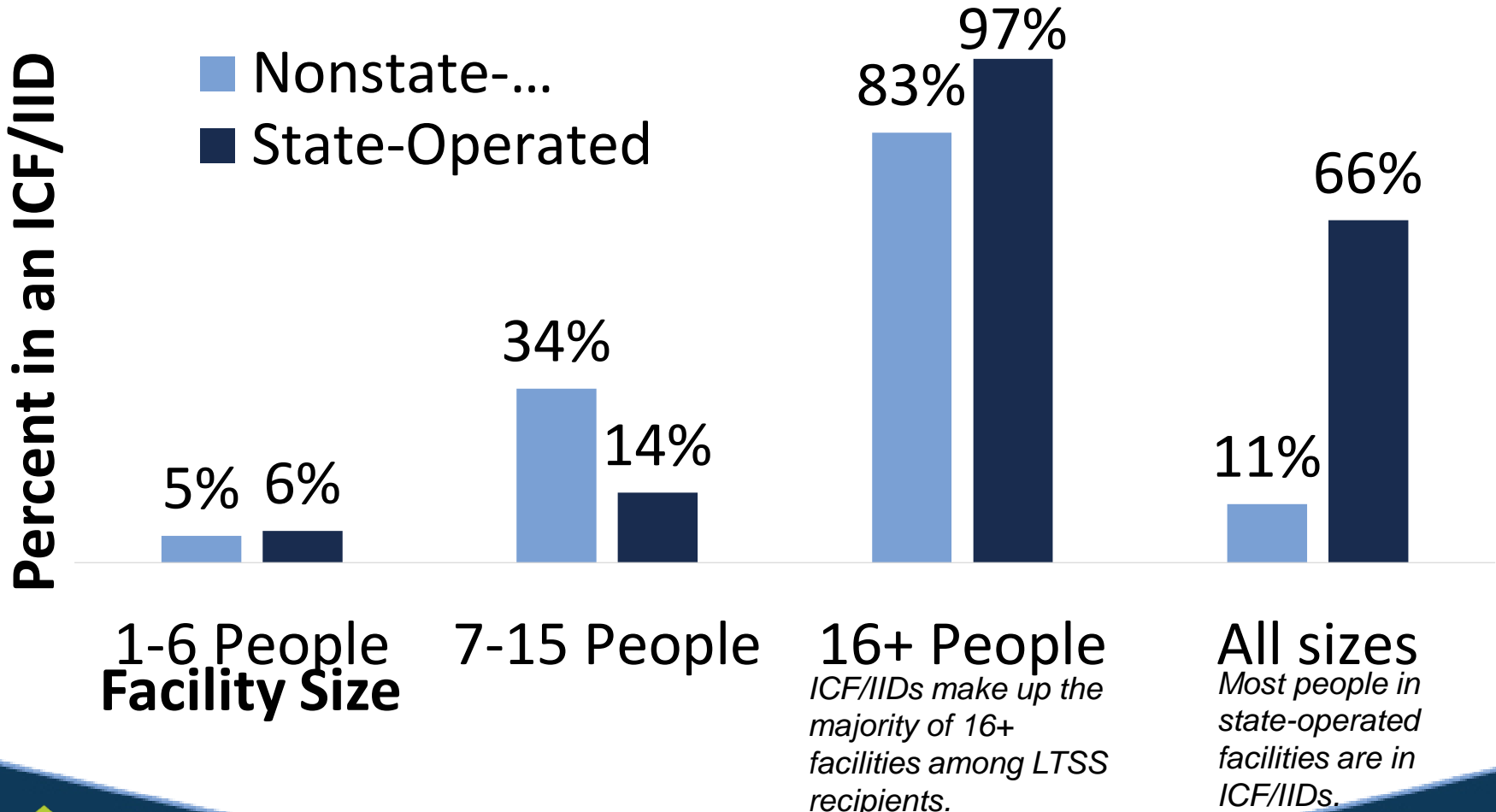
**\$142,499**



# People Living in an ICF/IID per 100,000 of the Population by State and Age on June 30, 2016



# Proportion of LTSS Recipients in an ICF/IID Certified Facility by Type of Operation and Setting Size on June 30, 2016



Excludes LTSS recipients with IDD living with a family member.



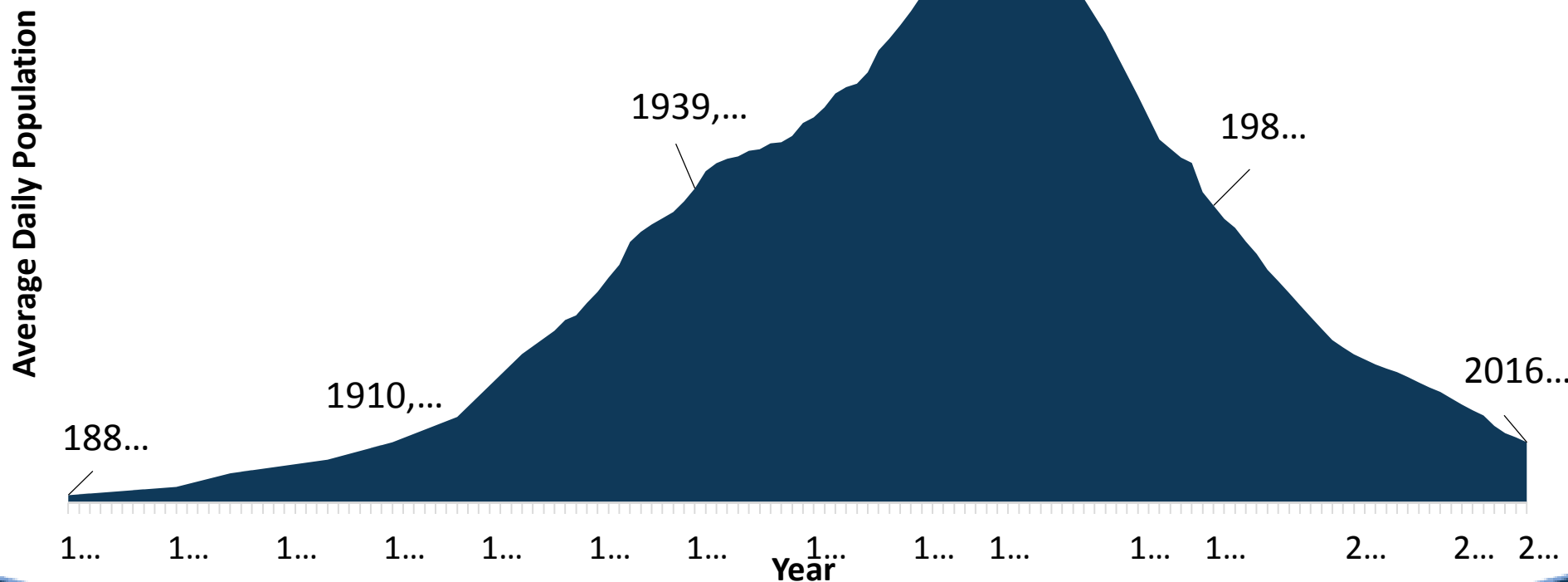
# Historical Trends



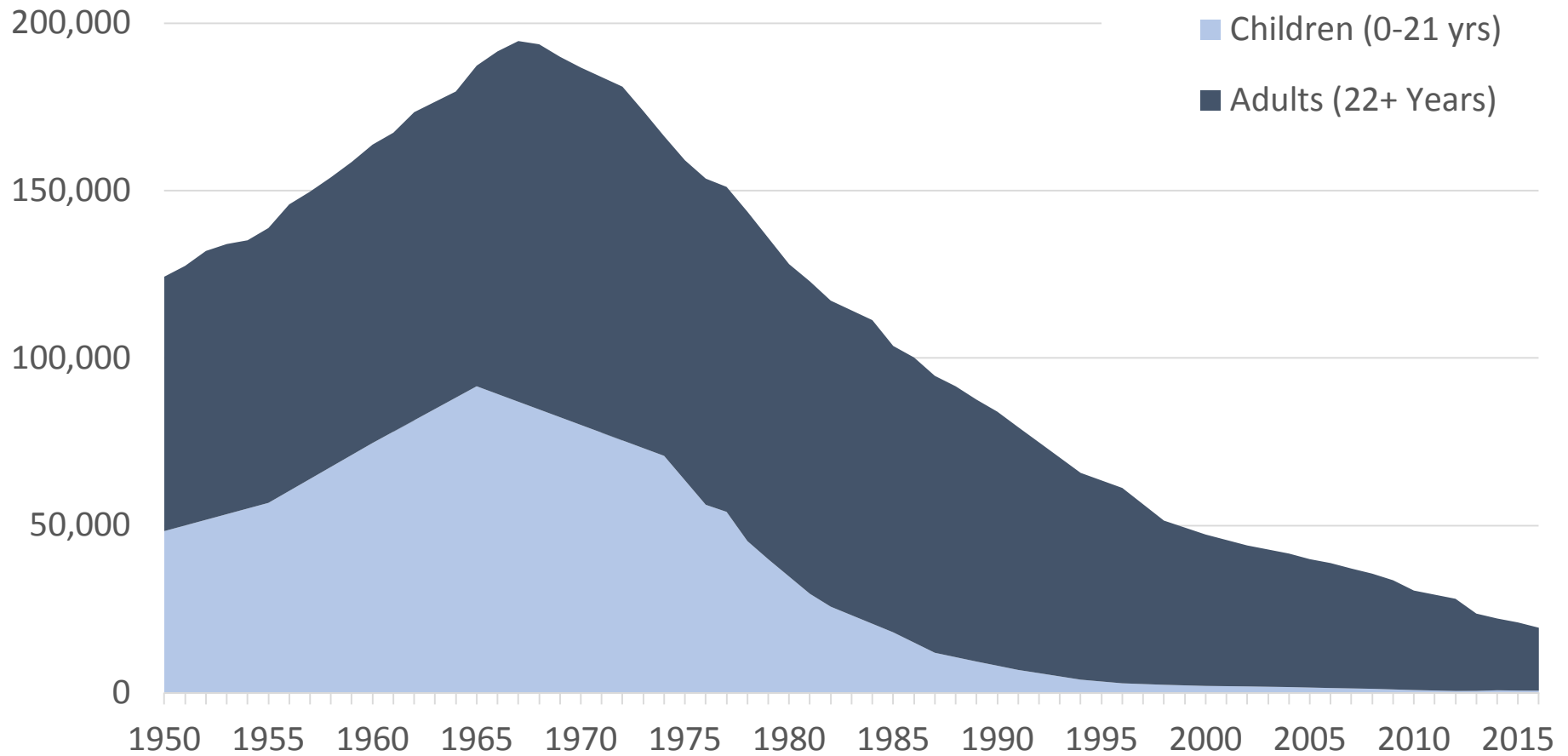


# Historic Trends: RISP tracks LTSS for people with IDD (e.g., deinstitutionalization)

## Number of people in State-Operated Facilities with 16 or more people with IDD

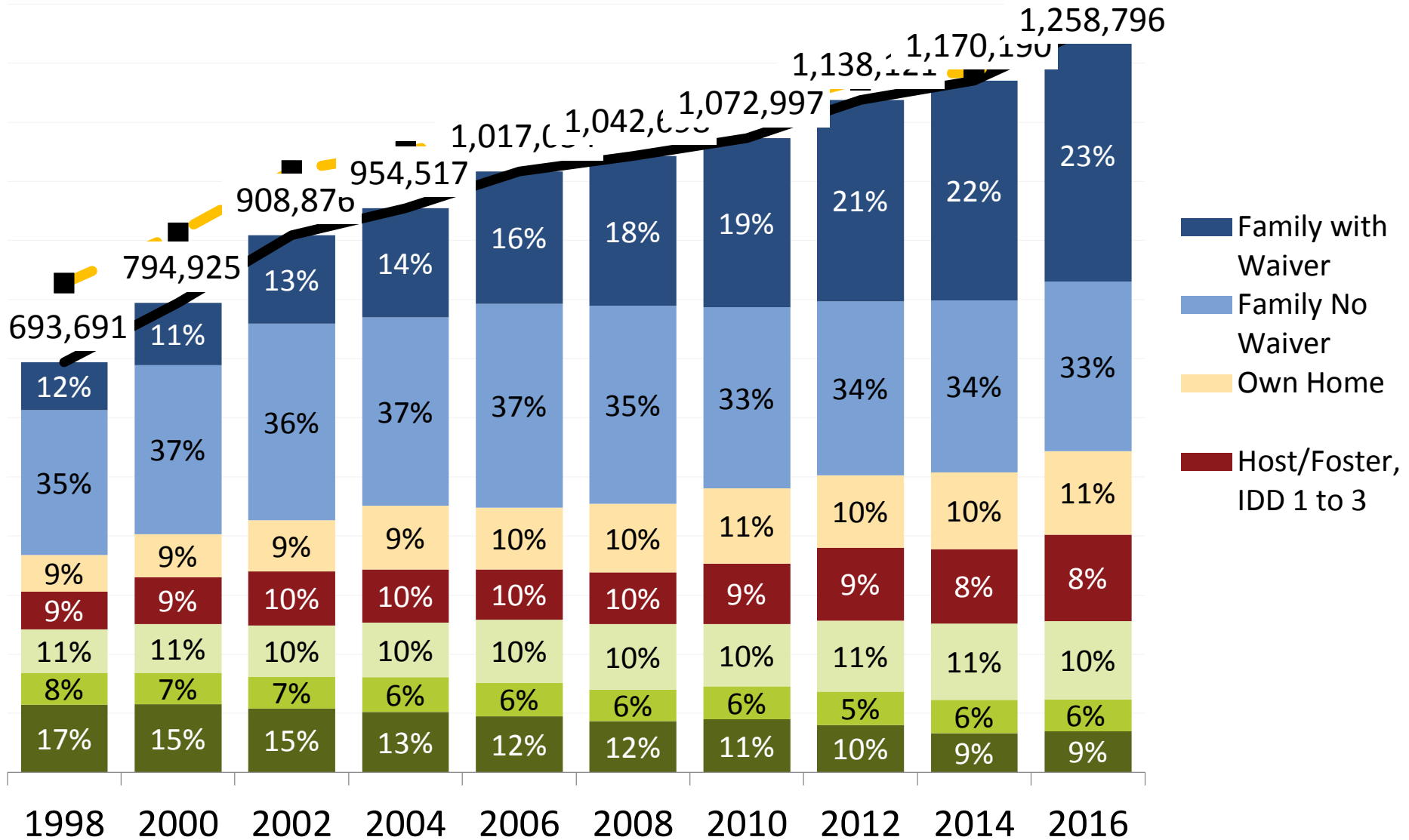


# Children and adults in large state IDD facilities of 16 or more people 1950-2016

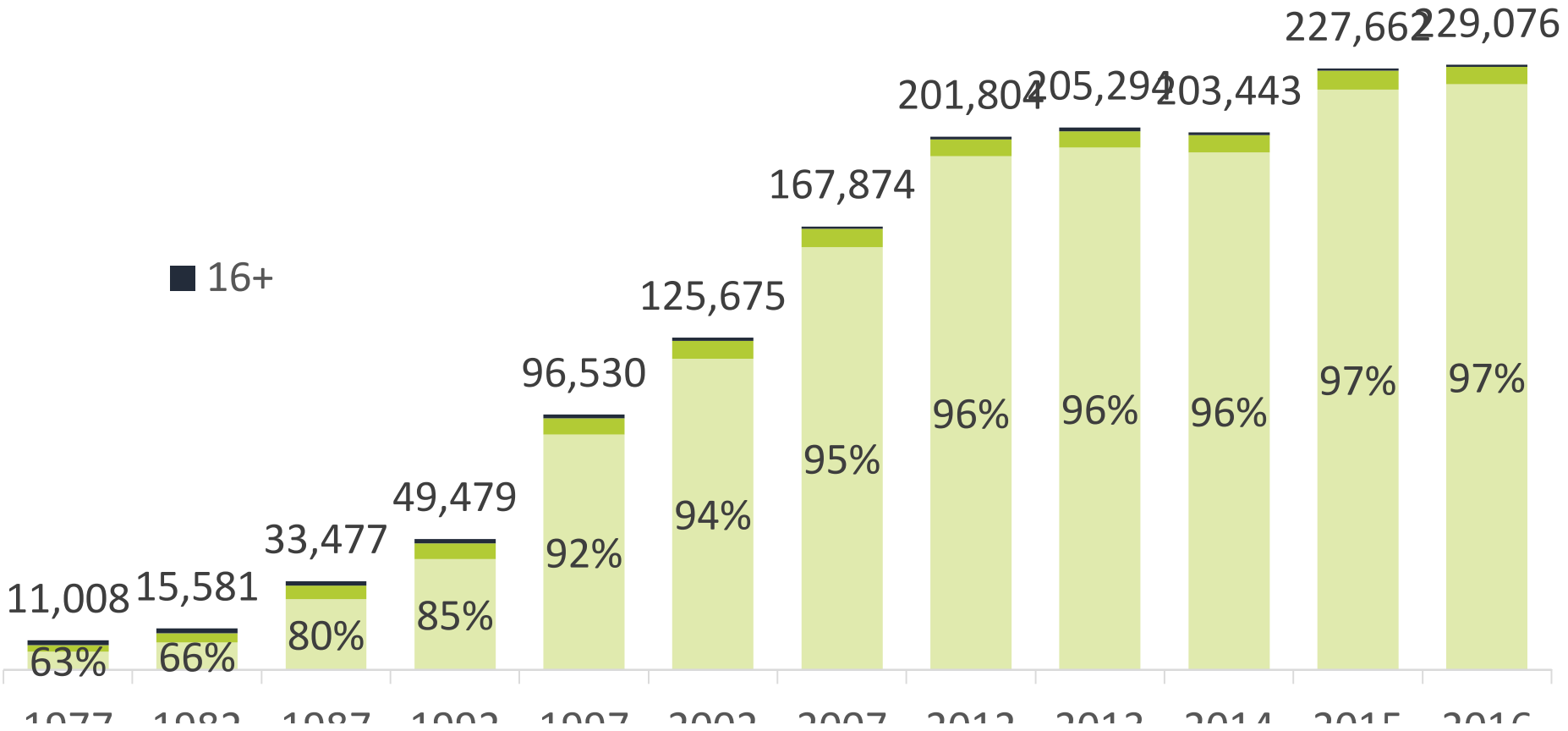


Source: RISP - Larson et al, 2018

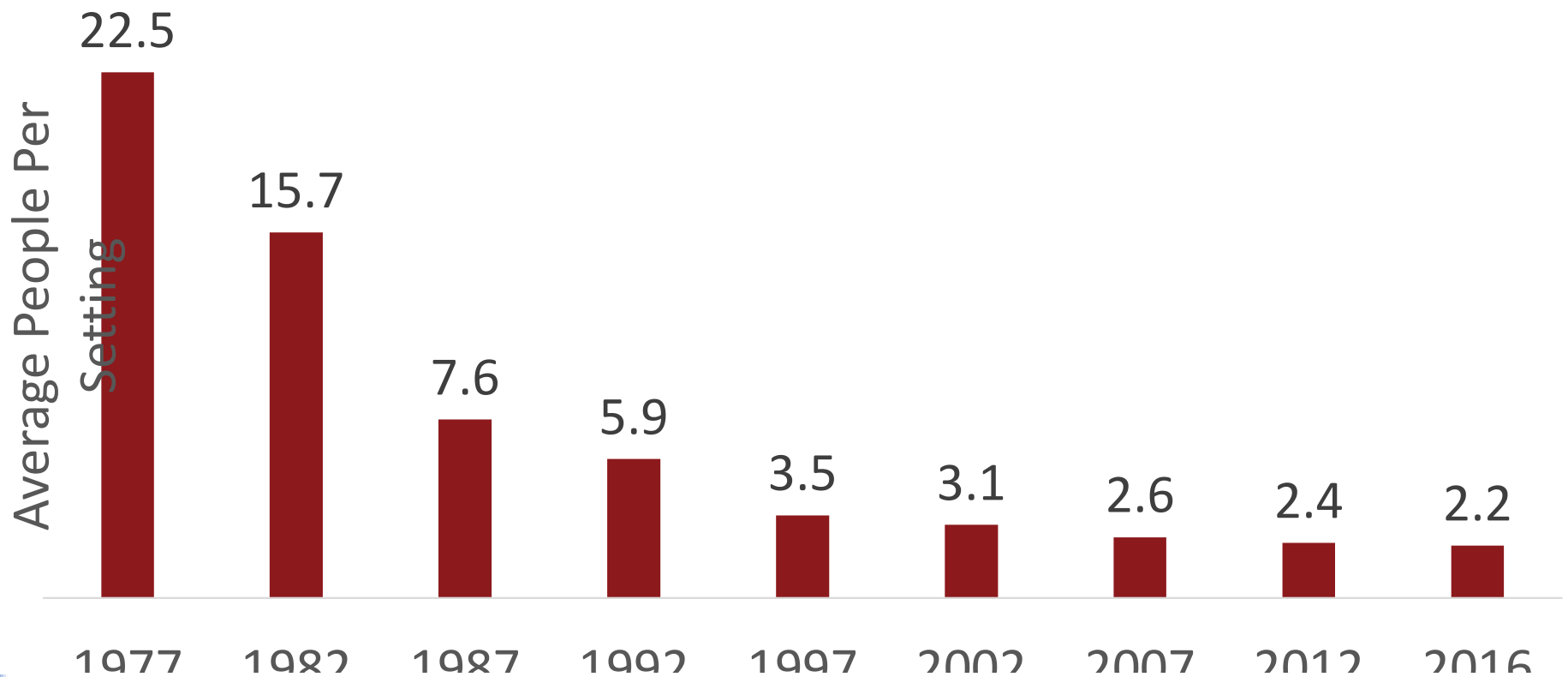
# Historic Trends: State IDD Agencies are serving more people, particularly in community settings



# Non-family IDD Settings by Setting Size, and Proportion with 1 to 6 People on June 30 of Selected Years, 1977 to 2016



# Recipients with IDD Per Non-family Setting on June 30 of Selected Years 1977 to 2016



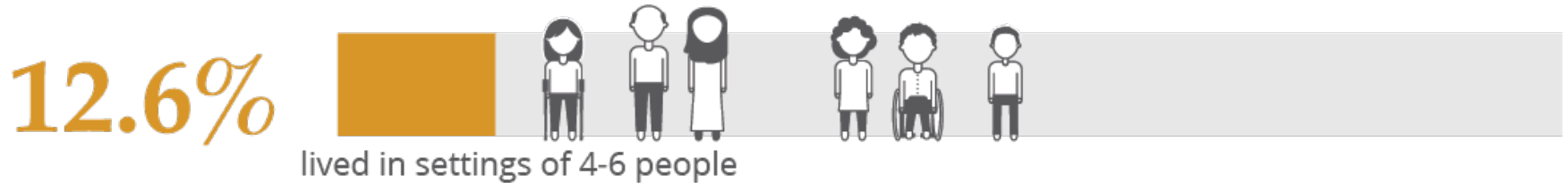
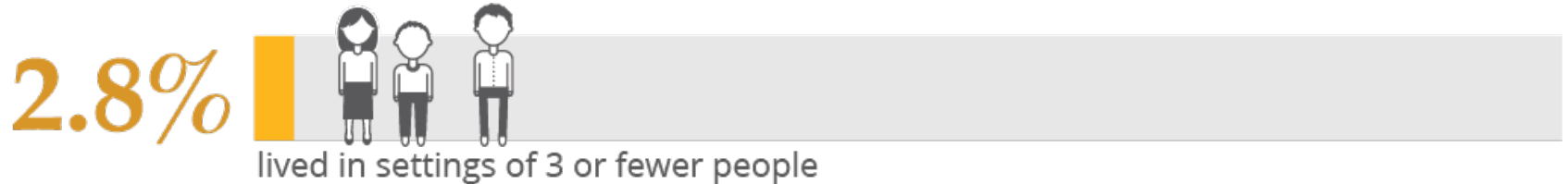
# Public Residential Facilities

State-Operated Facilities  
with 16 or more people



# State Operated Settings, by Size

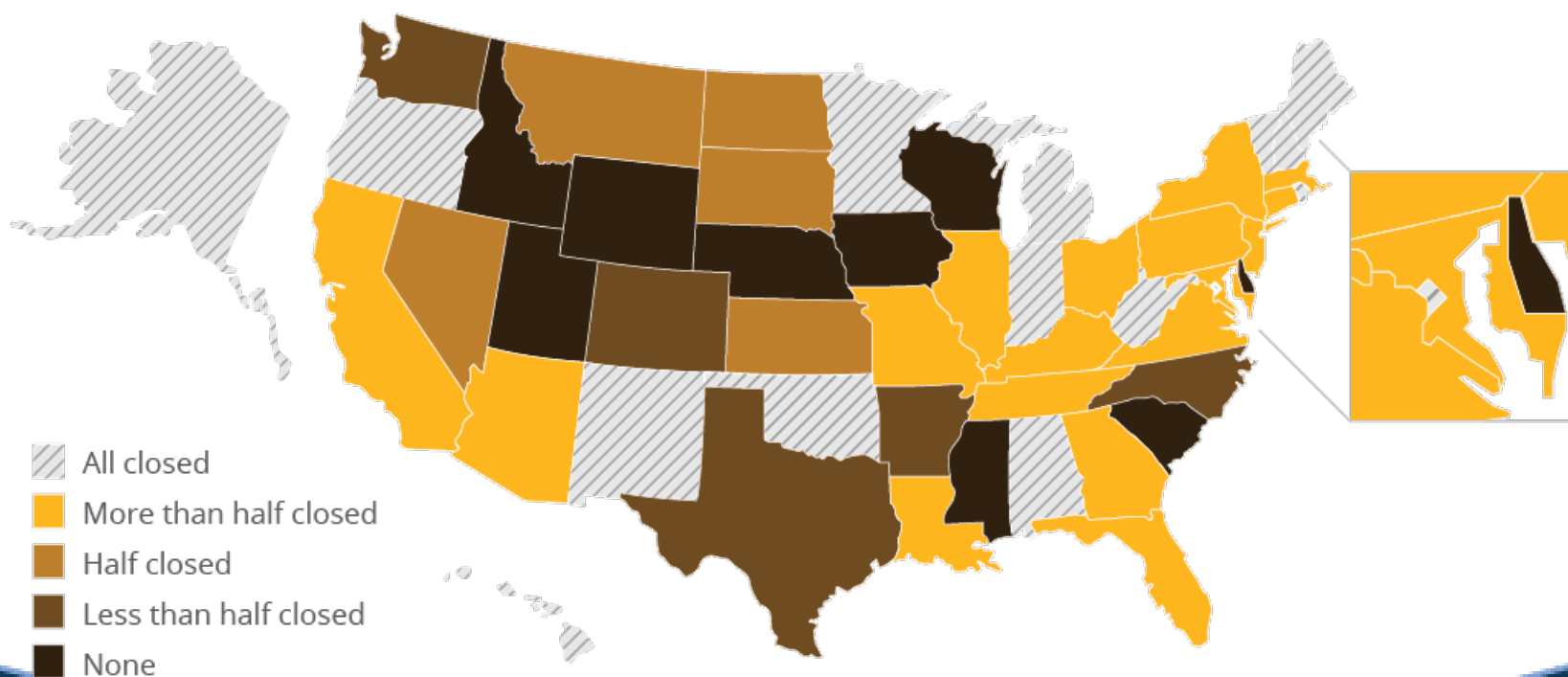
Of the 29,768 people with IDD living in state-operated settings,



# Closures of State-Operated Facilities with 16 or more People as of June 30, 2016

Closures by state as of June 30, 2016

In 1977 there were 327 state-operated IDD facilities serving 16 or more people, by 2016 the total had dropped to 140.

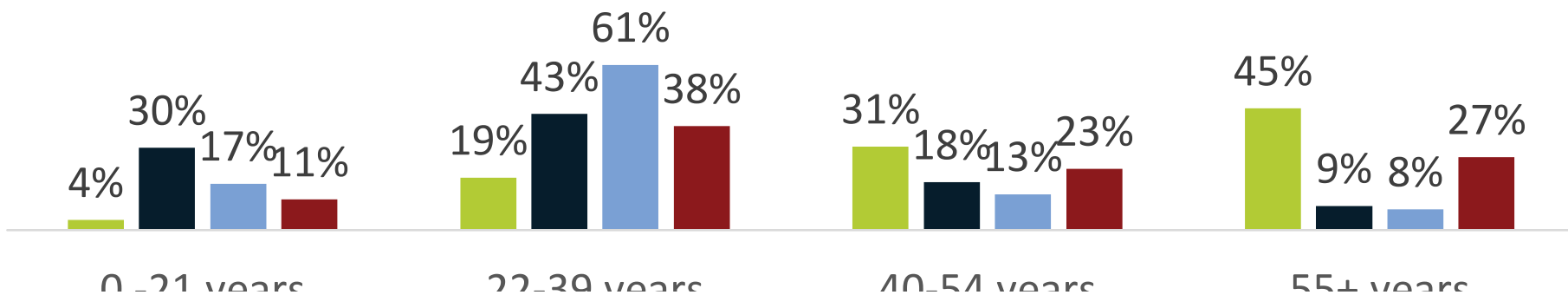




# Demographics of Newly Admitted, Readmitted, and Discharged PRF Residents in FY 2016

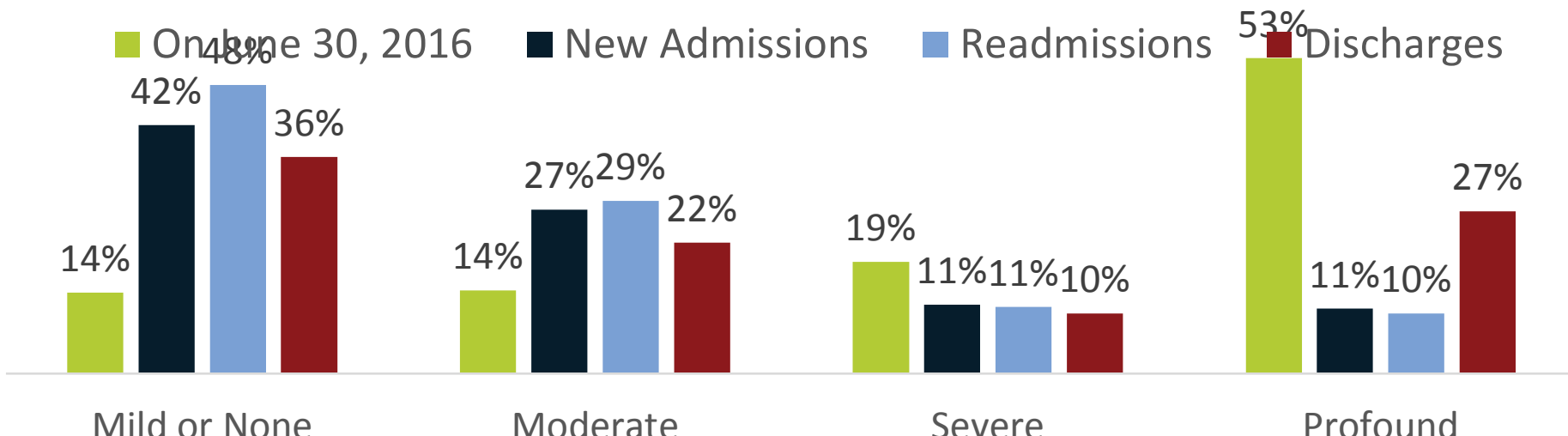
## Age Distribution

■ On June 30, 2016 
 ■ New Admissions 
 ■ Readmissions 
 ■ Discharges

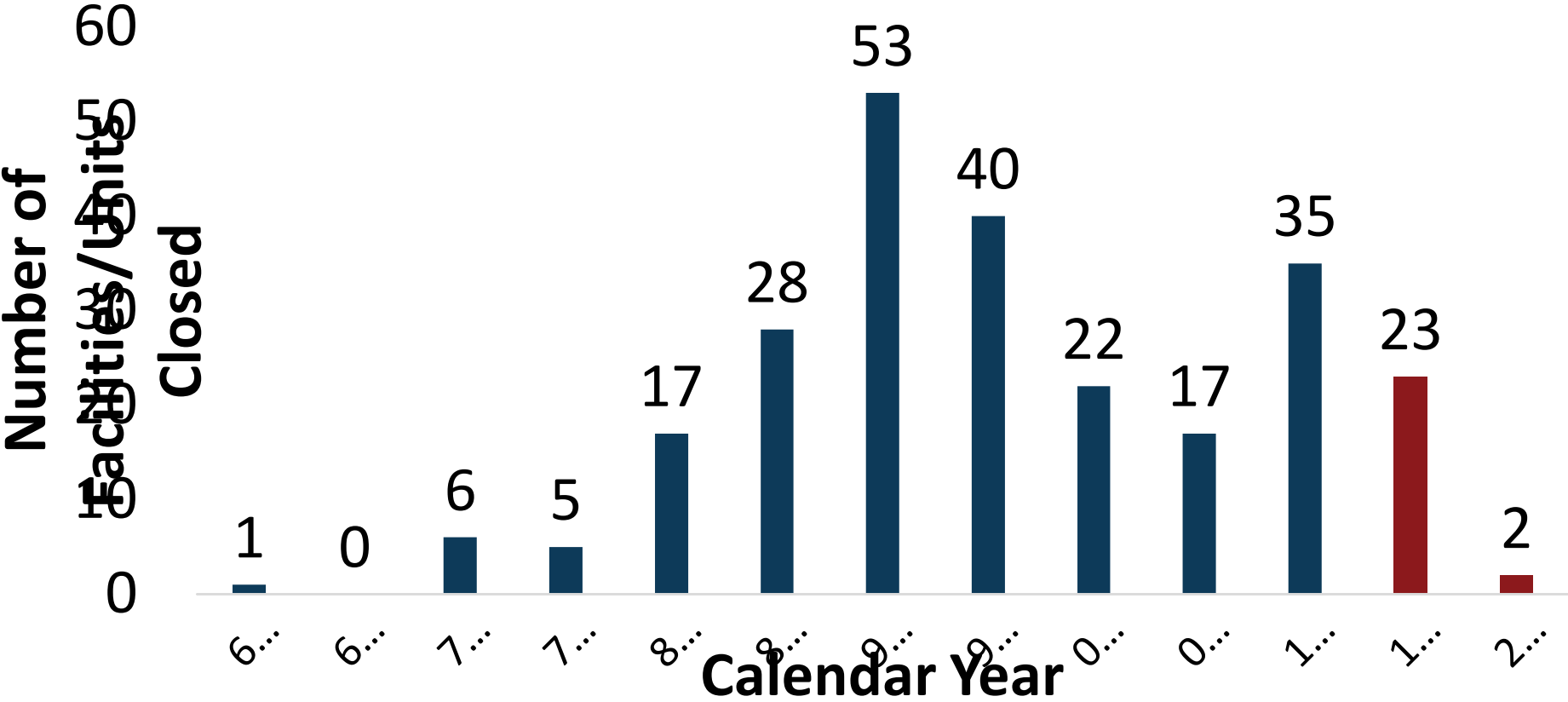


## Level of Intellectual Disabilities

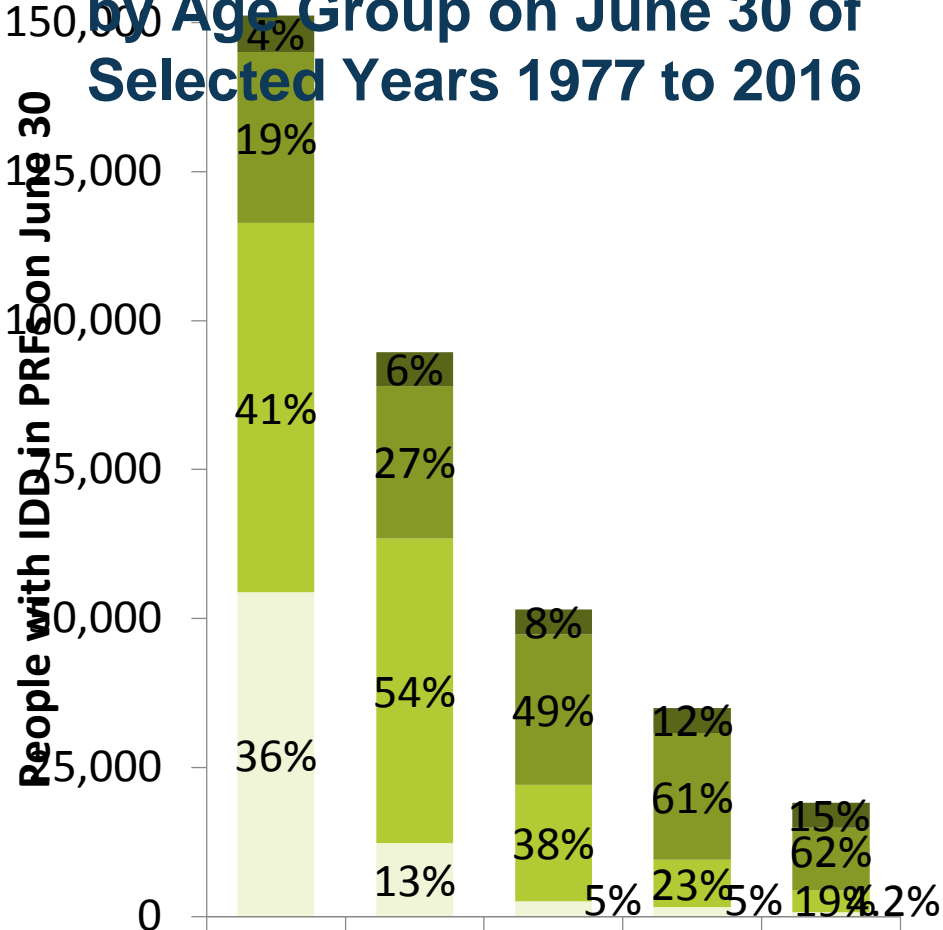
■ On June 30, 2016 
 ■ New Admissions 
 ■ Readmissions 
 ■ Discharges



# PRFs Closed, Downsized, or Converted to Non-IDD Use or Nonstate Operation Between 1960 and 2016 with Projected Closures for 2016 to 2024 in 5-Year Interval

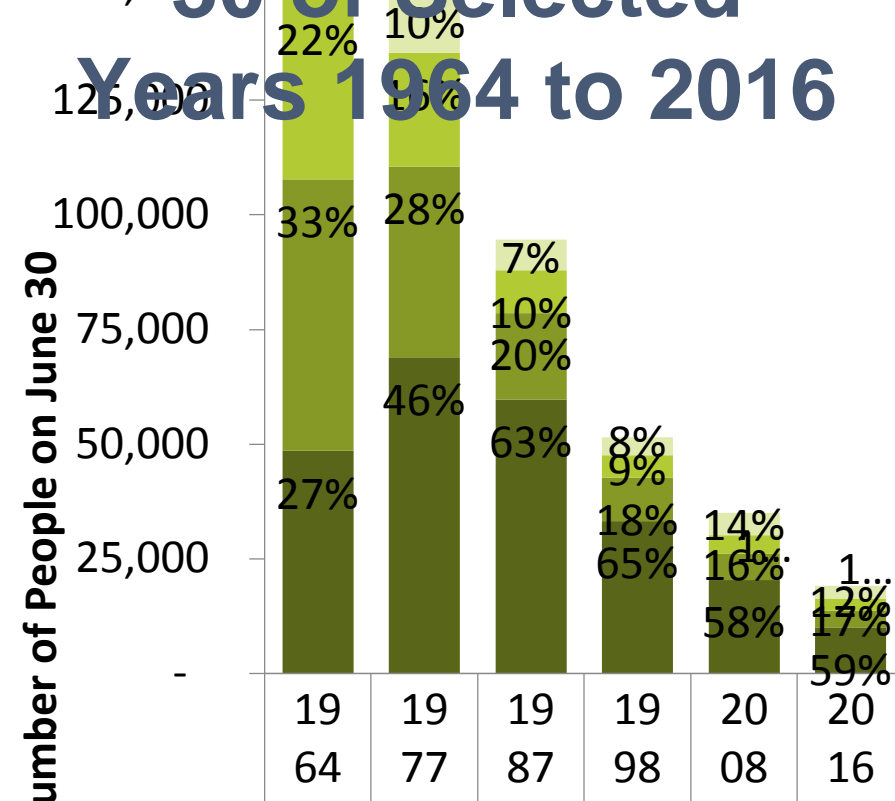


# Estimated Number and Proportion of People in PRFs by Age Group on June 30 of Selected Years 1977 to 2016



63+	6,044	5,682	4,119	4,204	4,130
40-62	28,711	25,560	25,220	21,300	10,570
22-39	61,950	51,130	19,560	7,918	3,662
0-21	54,400	12,310	2,574	1,612	714

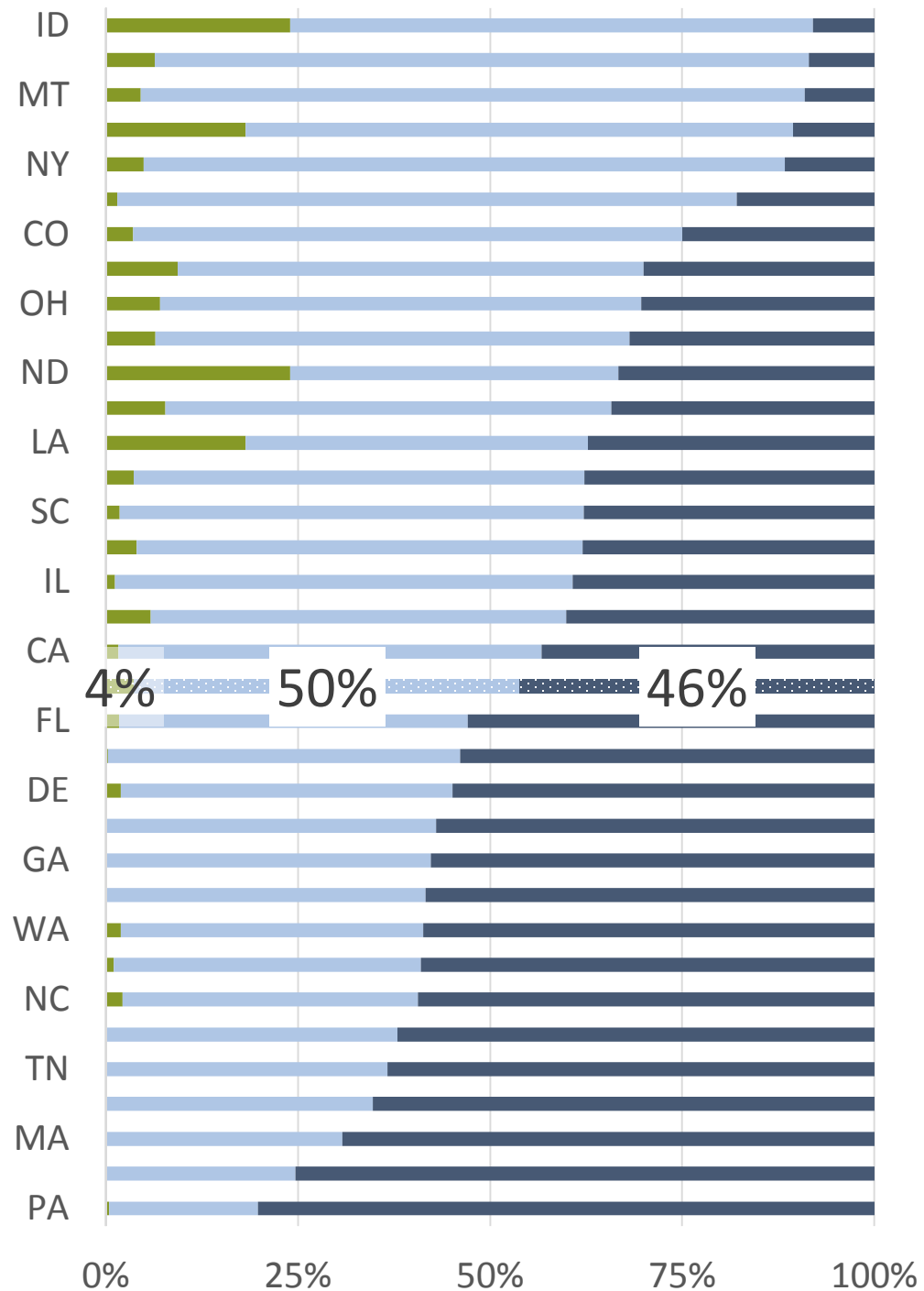
# Disability on June 30 of Selected Years 1964 to 2016



Disability Level	1964	1977	1987	1998	2008	2016
Mild or None	32,000	15,000	6,800	3,900	4,800	2,760
Moderate	39,000	24,000	9,200	4,800	4,000	2,660
Severe	59,000	41,000	18,000	9,400	5,700	3,600
Profound	48,000	68,000	59,000	33,000	20,000	10,000

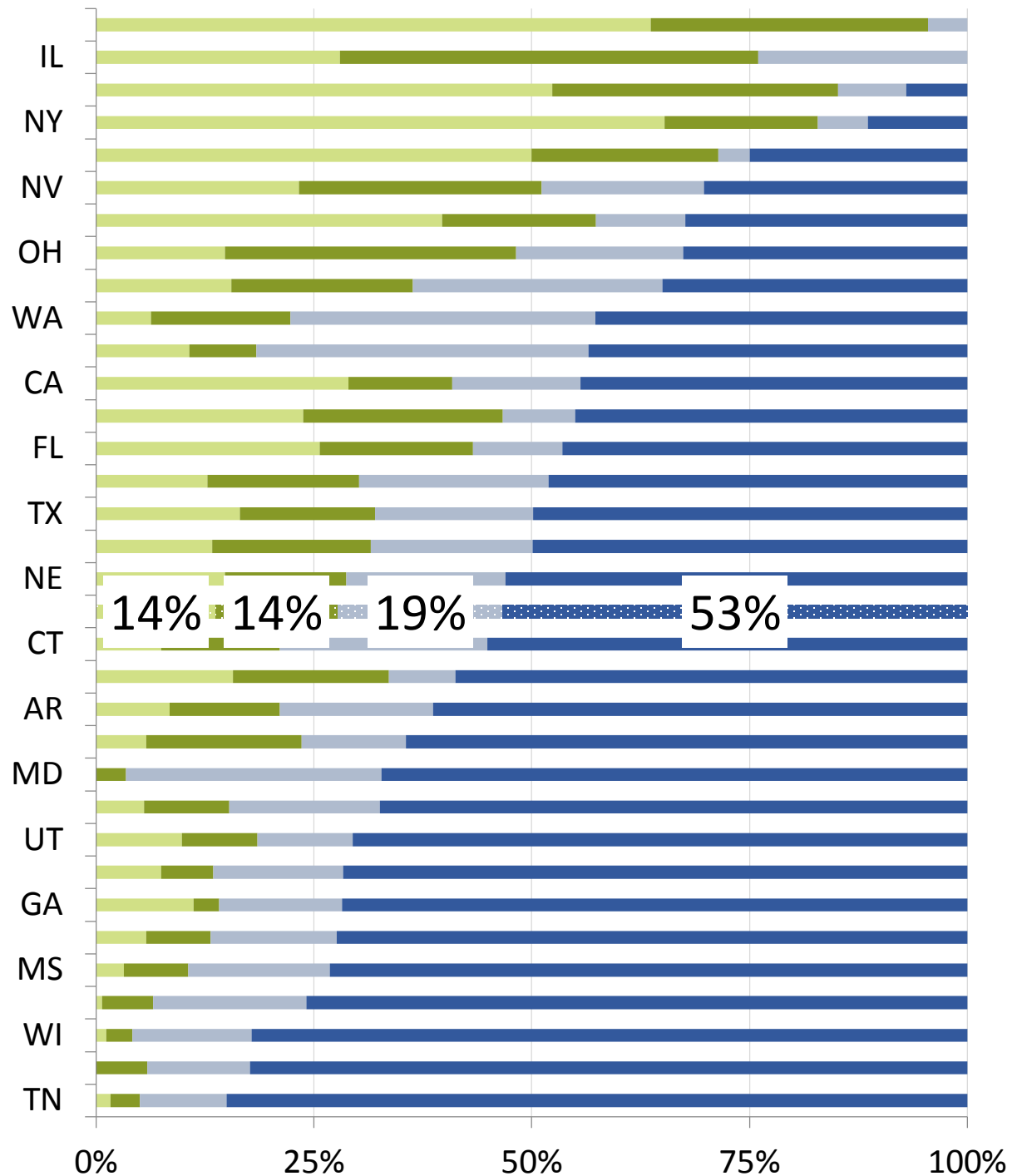
# Age Distribution of People Living in PRF's (in Percent) by State on June 30, 2016

■ % < 22 years



# Percent of People with IDD Living in PRFs by Level of Intellectual Disability and State on June 30, 2016

■ Mild/N one



# Contact Us, and What's Available Online



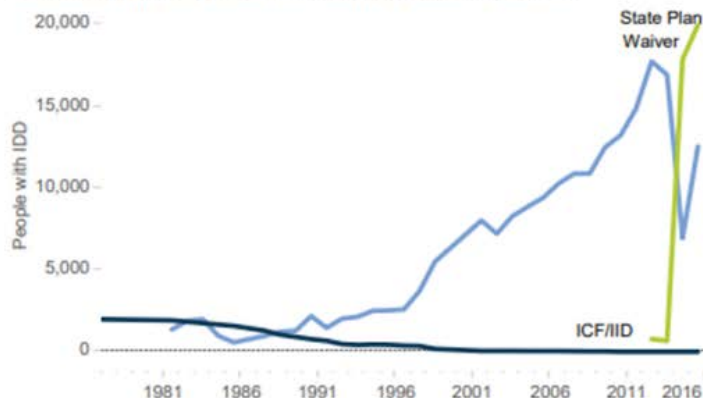
# Trends over time & current year data: State Profiles

## RISP Profile FY 2016

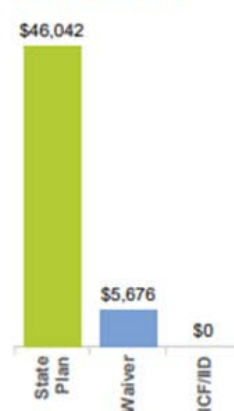
## Oregon

**Figure 1: Medicaid Waiver, State Plan, and ICF/IID Recipients 1977-2016**

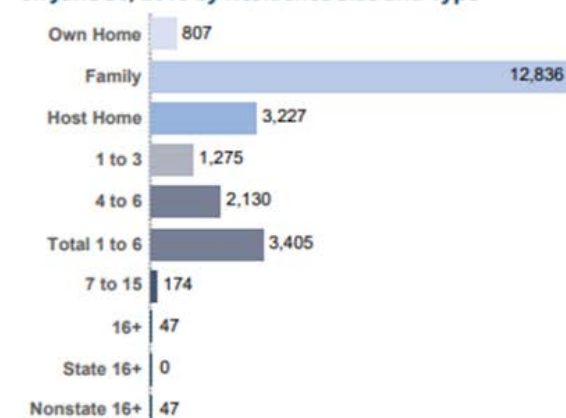
Note: Some people may receive both Waiver and State Plan services.



**Figure 2: Medicaid Spending Per Person Fiscal Year 2016**



**Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type**



**Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities**

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016	
People in Individualized Settings	Own Home				697	764	764	757	780	807	807	
	Family				3,468	8,589	10,479	10,483	11,448	12,551	12,836	
	Host Home				1,967	2,655	3,273	3,272	3,401	3,494	3,227	
	1 to 3				182	300	546	765	900	1,053	1,275	
People in Congregate Settings	4 to 6				1,924	1,720	2,018	2,259	2,216	2,230	2,130	
	Total 1 to 6	49	11	2,344	2,106	2,020	2,564	3,024	3,116	3,283	3,405	
	7 to 15	325	490	555	434	216	218	231	195	161	174	
	16+	2,233	1,979	879	143	626	27	36	38	24	47	
People Served by the DD Agency *	Caseload (known to the DD agency)							22,074	23,212	24,701	25,612	
	LTSS Recipients (1)	2,607	2,480	3,778	8,815	14,870	17,520	17,803	18,978	20,320	20,496	
	Waiting for Medicaid Waiver				1,570	3,219	0	0	0	0	0	
People in Non-DD Settings *	Nursing Facility (s)			452	168	9	195	0	0	161	161	
	Psychiatric Facility (2)			0	0	0	0	0	0	0	0	
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person				\$18,825	\$37,526	\$41,230	\$40,220	\$31,646	\$40,417	\$7,474	\$5,676
	ICF/IID Expenditures per Person				\$127,146	\$251,996	\$99,678	\$0	\$0	\$0	\$0	\$0
	Waiver Recipients per 100,000				74.5	243.4	326.1	381.2	451.3	426.2	172.1	306.5
	ICF/IID Residents per 100,000				26.4	1.2	0.6	0.0	0.0	0.0	0.0	0.0

(1) Long Term Supports and Service (LTSS) recipients may include imputed values; Until 2012 LTSS recipients may include people in nursing homes or psychiatric facilities who were not on the IDD agency caseload.

(2) Includes state operated facilities until 2013.

(s) Data may be from an outside source.

Settings by size includes ICF/IID, group homes, and nonstate other.

DNF = Did Not Furnished.

PD = Partial Data.

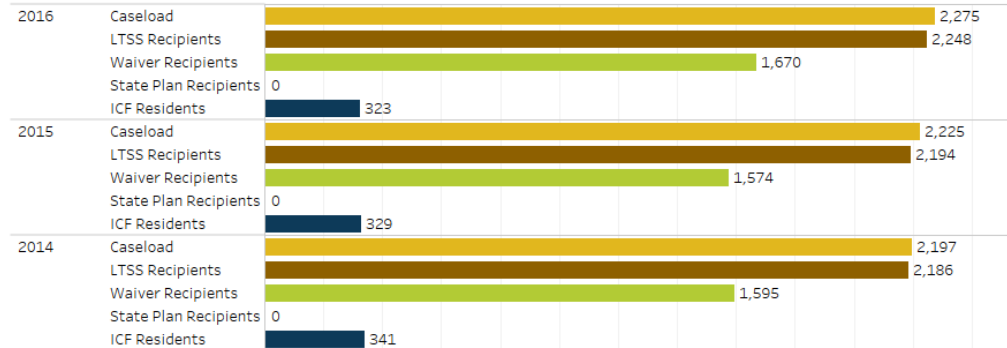
\* See state notes and the RISP report for further explanation.

Updated  
2/14/2018

# What's available online

- State Profiles
- Interactive Visualizations
- Reports
- Infographic pages

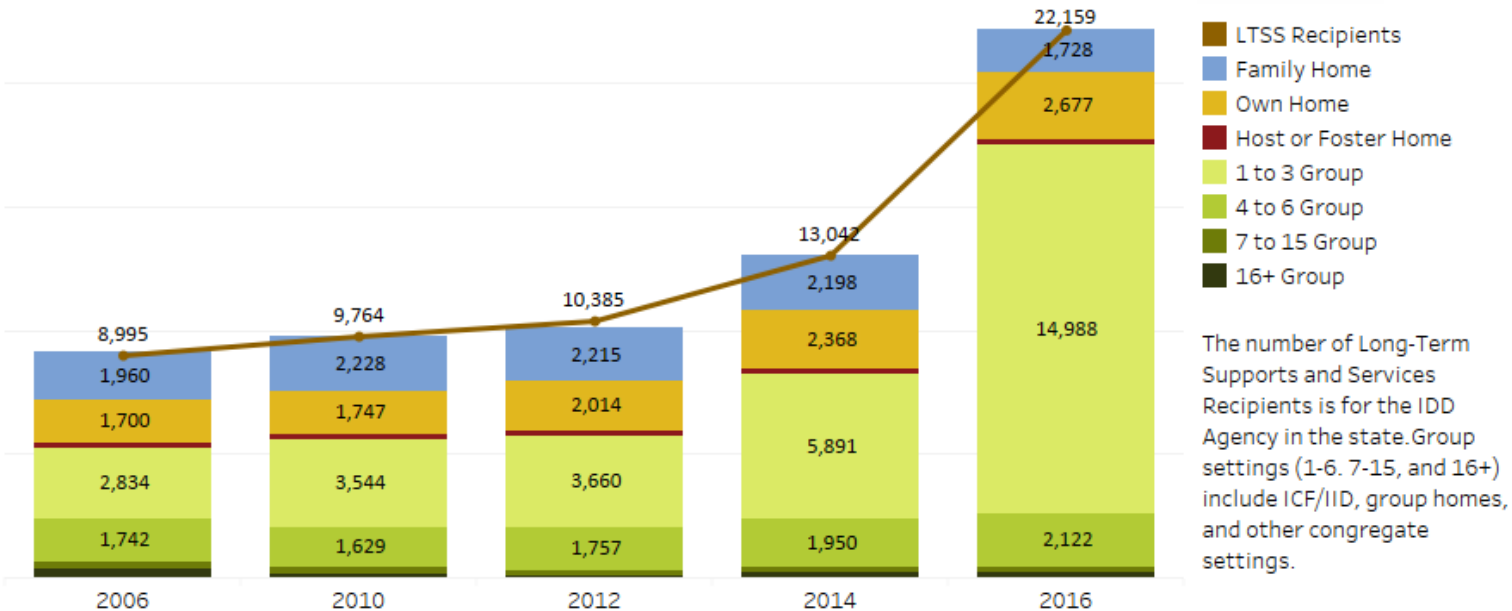
D.C. People Served by IDD Agencies by Fiscal Year



Caseload is the number of people known to or served by the State IDD Agency (available from 2013 onward). Long-Term Supports and Services include people with IDD who receive Medicaid or State-funded supports and services.

## Maryland

Living Arrangements of LTSS Recipients by Fiscal Year over Time



- LTSS Recipients
- Family Home
- Own Home
- Host or Foster Home
- 1 to 3 Group
- 4 to 6 Group
- 7 to 15 Group
- 16+ Group

The number of Long-Term Supports and Services Recipients is for the IDD Agency in the state. Group settings (1-6, 7-15, and 16+) include ICF/IID, group homes, and other congregate settings.





# Contact Us with questions or for technical assistance

Heidi Eschenbacher [hje@umn.edu](mailto:hje@umn.edu)

Sheryl Larson, Ph.D. Principal Investigator

*For general questions:*

**[risp@umn.edu](mailto:risp@umn.edu)**

RISP MN: Amy Hewitt (ICI Director), Sheryl Larson (Principal Investigator), Heidi Eschenbacher, Lynda Anderson, Sandy Pettingell, Kristin Dean, Jonathan Walz, Shawn Lawler, John Westerman, Sarah Hollerich

HSRI: Brittany Taylor, Yoshi Kardell, John Agosta

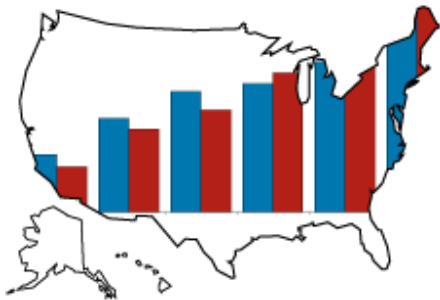
NASDDDS: Mary Lee Fay, Mary Sowers, Mary Lou Bourne

Research and Training Center on Community Living  
Institute on Community Integration (UCEDD)  
University of Minnesota, Twin Cities  
214 Pattee Hall, 150 Pillsbury Drive SE  
Minneapolis, MN 55455



# Access to Integrated Employment

## Employment Outcomes & Services

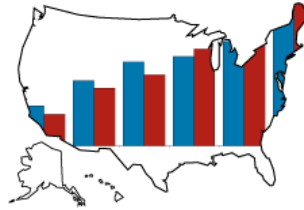


**StateData.info**

**ThinkWork!**



# Core Activities



StateData.info

- ❖ **National Survey on Day and Employment Services**  
State IDD Agencies
- ❖ **VR services and outcomes**  
RSA 911
- ❖ **National Core Indicators**
- ❖ **American Community Survey**  
Employment participation and outcomes
- ❖ **Social Security Administration**  
Work incentive use, work participation
- ❖ **Workforce development**  
Number of customers, entry into employment



# Core Activities **ThinkWork!**

## ❖ **Promising Practices**

IDD Agency, Community Providers,  
Community Life Engagement

## ❖ **National Survey of Community Rehabilitation Providers**

1987, 1992, 2002-2003, 2010

## ❖ **Employment first case studies**

## ❖ **Young Adult Outcomes and Services Report**

## ❖ **Real People Real Jobs**

[www.realworkstories.org](http://www.realworkstories.org)

# How many people are employed?

## WORK



No disability



Any disability



Cognitive disability

## POVERTY



No disability

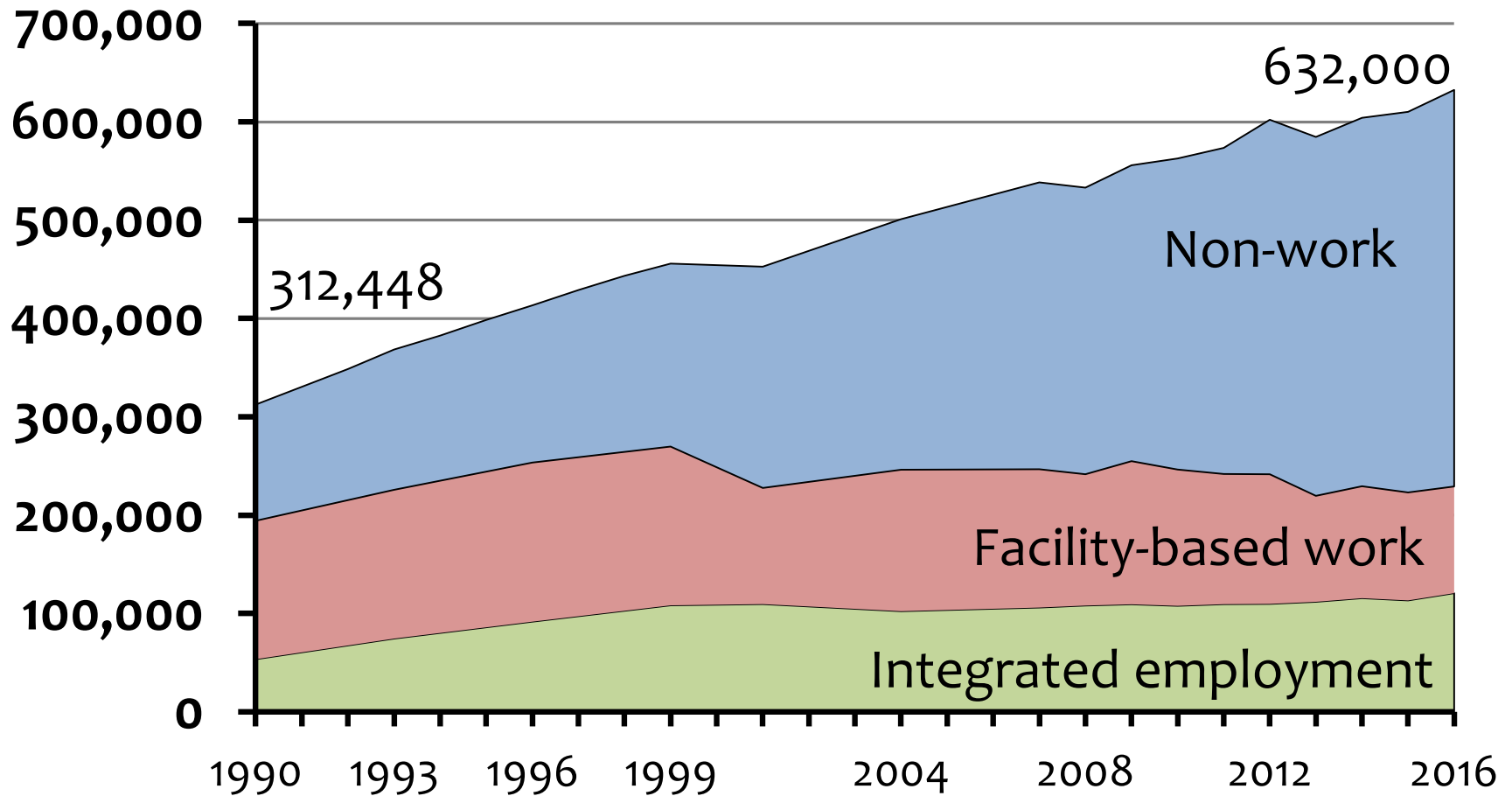


Any disability

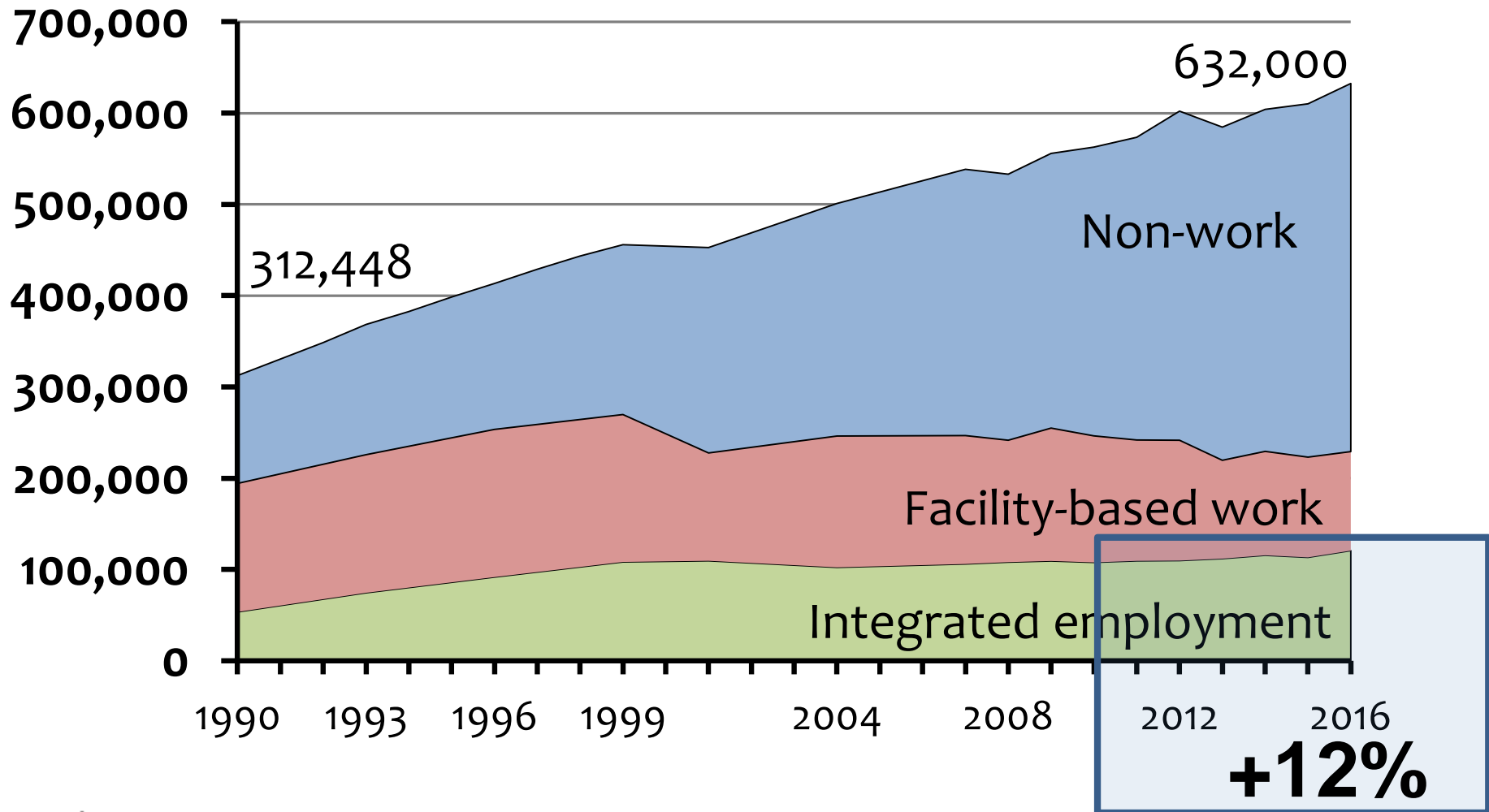


Cognitive disability

# Number in Employment and Day Services



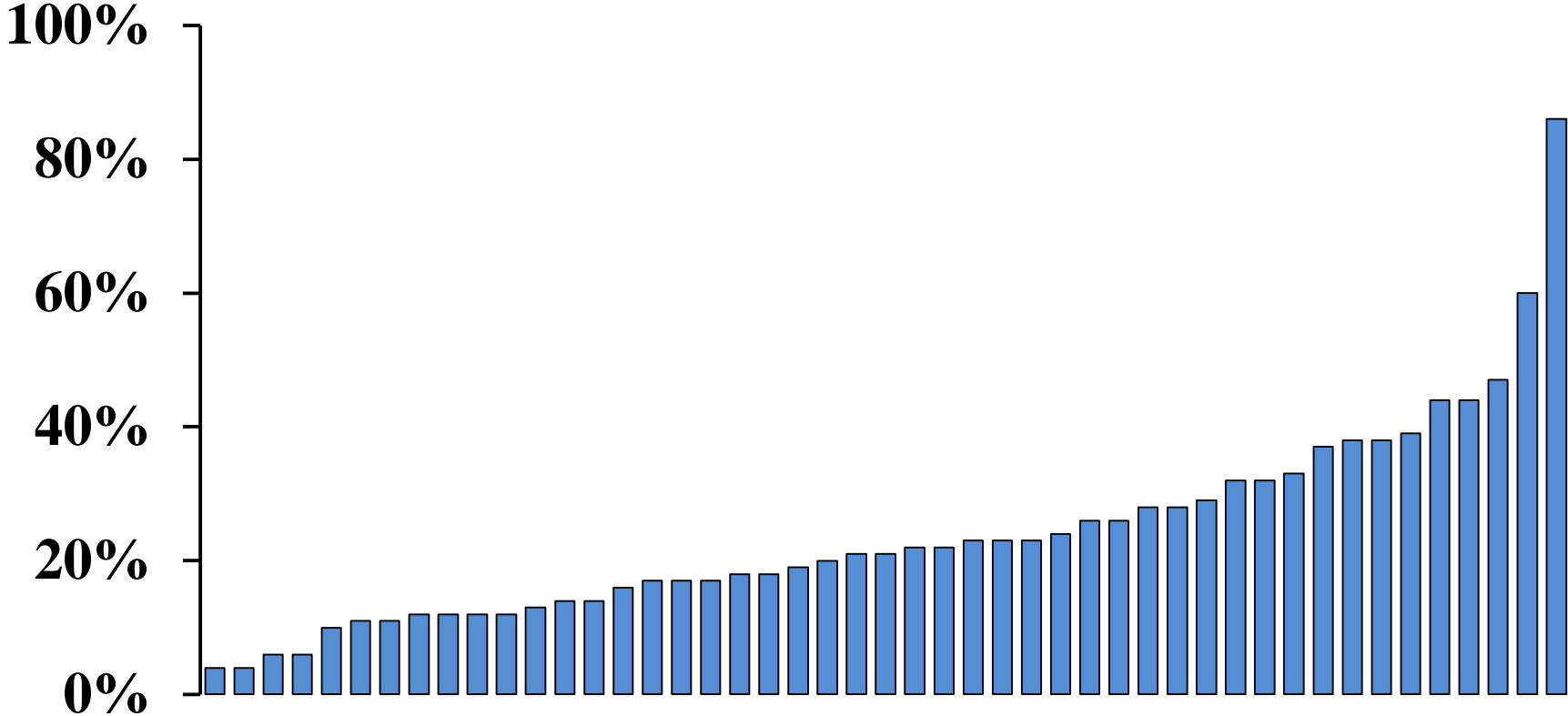
# Number in Employment and Day Services



Source: ICI National Survey of State IDD Agencies

**ThinkWork!**

# Participation in integrated employment services varies widely



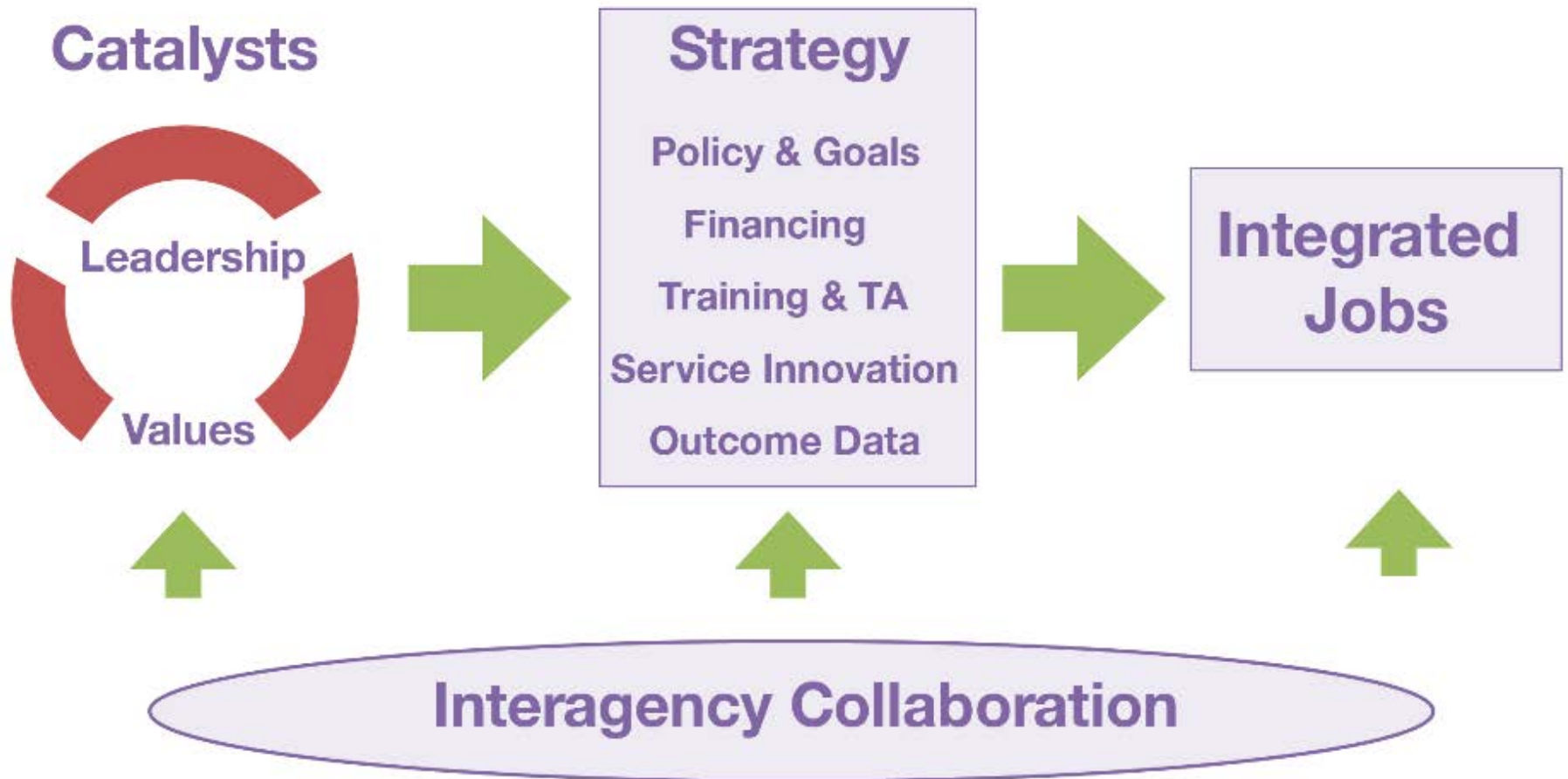
Source: ICI National Survey of State IDD Agencies 2015



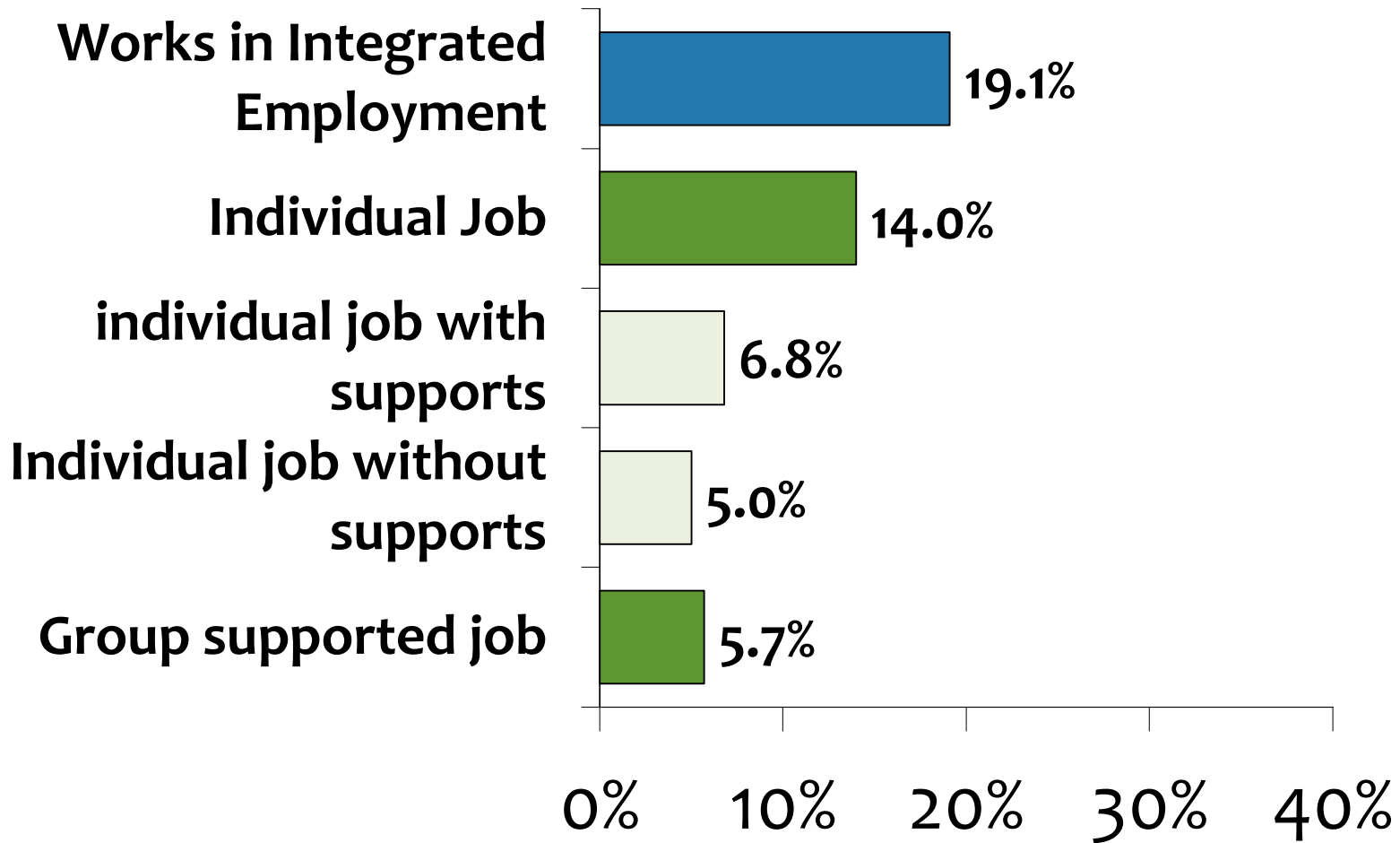


# Context matters

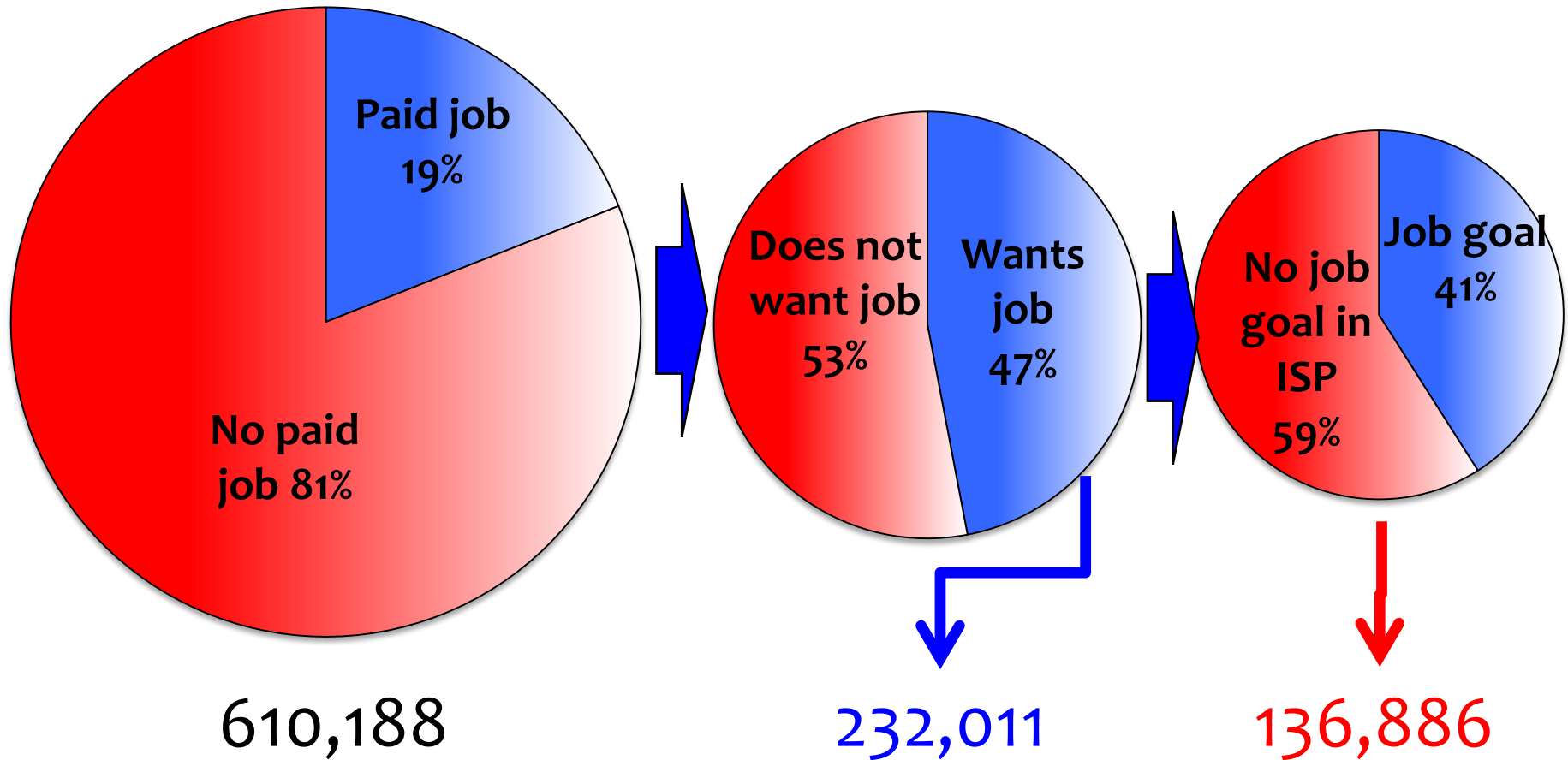
## Higher-Performing States Model



# Works In Integrated Employment Nation



# Supporting Choice



610,188

232,011

136,886

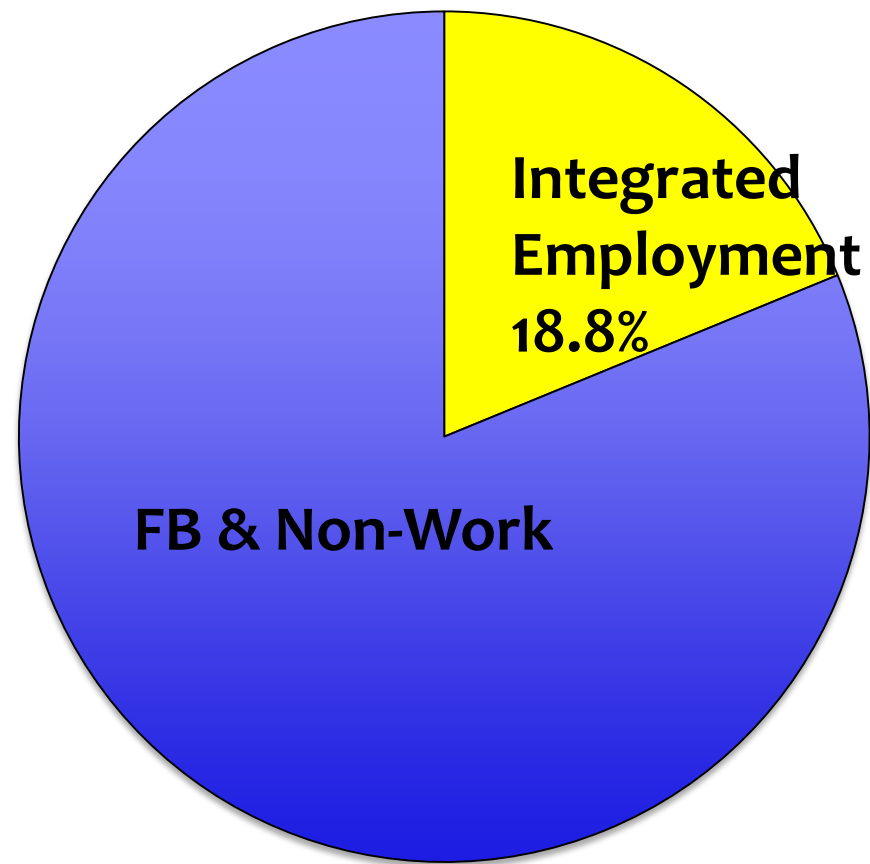


StateData.info

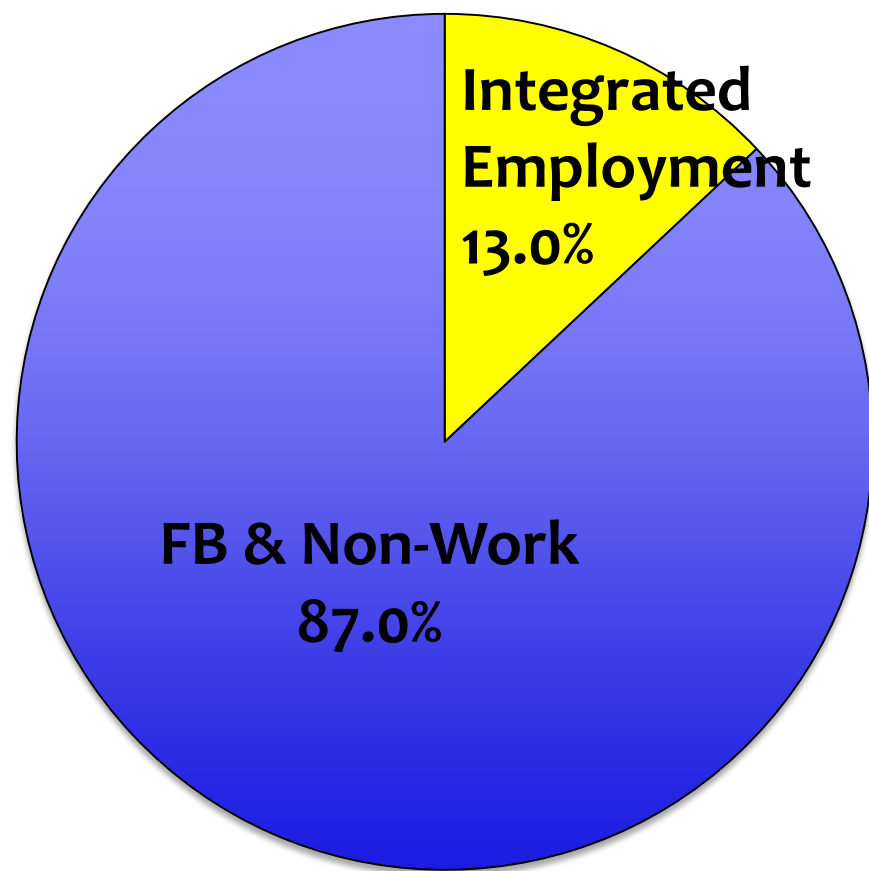
Source: National Core Indicators  
2015-2016

ThinkWork!

# Changing Investments



**Services**



**Funding**

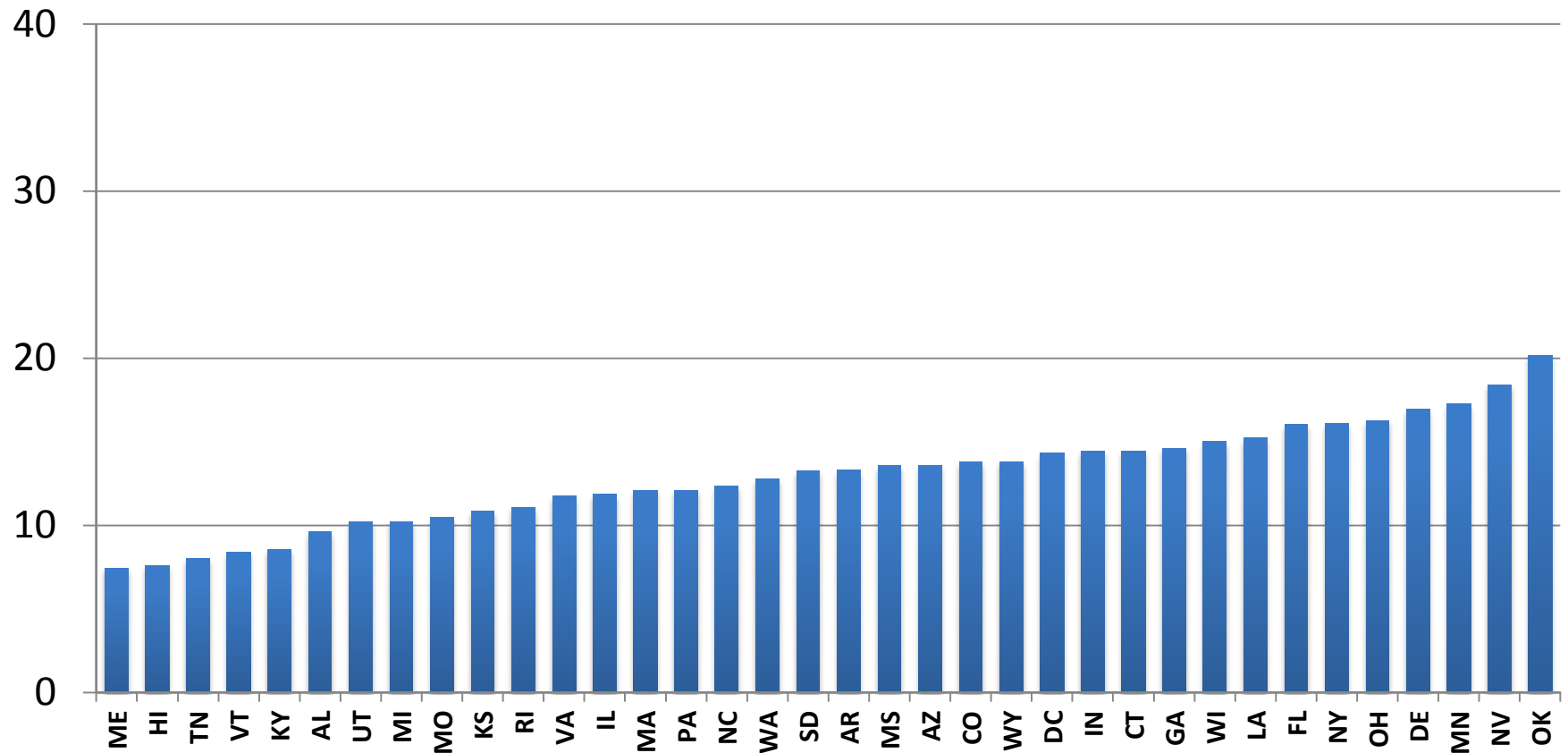
# Self Sufficiency & Meaningful Day

## Mean Hours and Wages per week

	Hours worked	Gross Wages
Individual job with supports	13	\$111
Individual job without supports	14	\$119
Group supported job	13	\$84

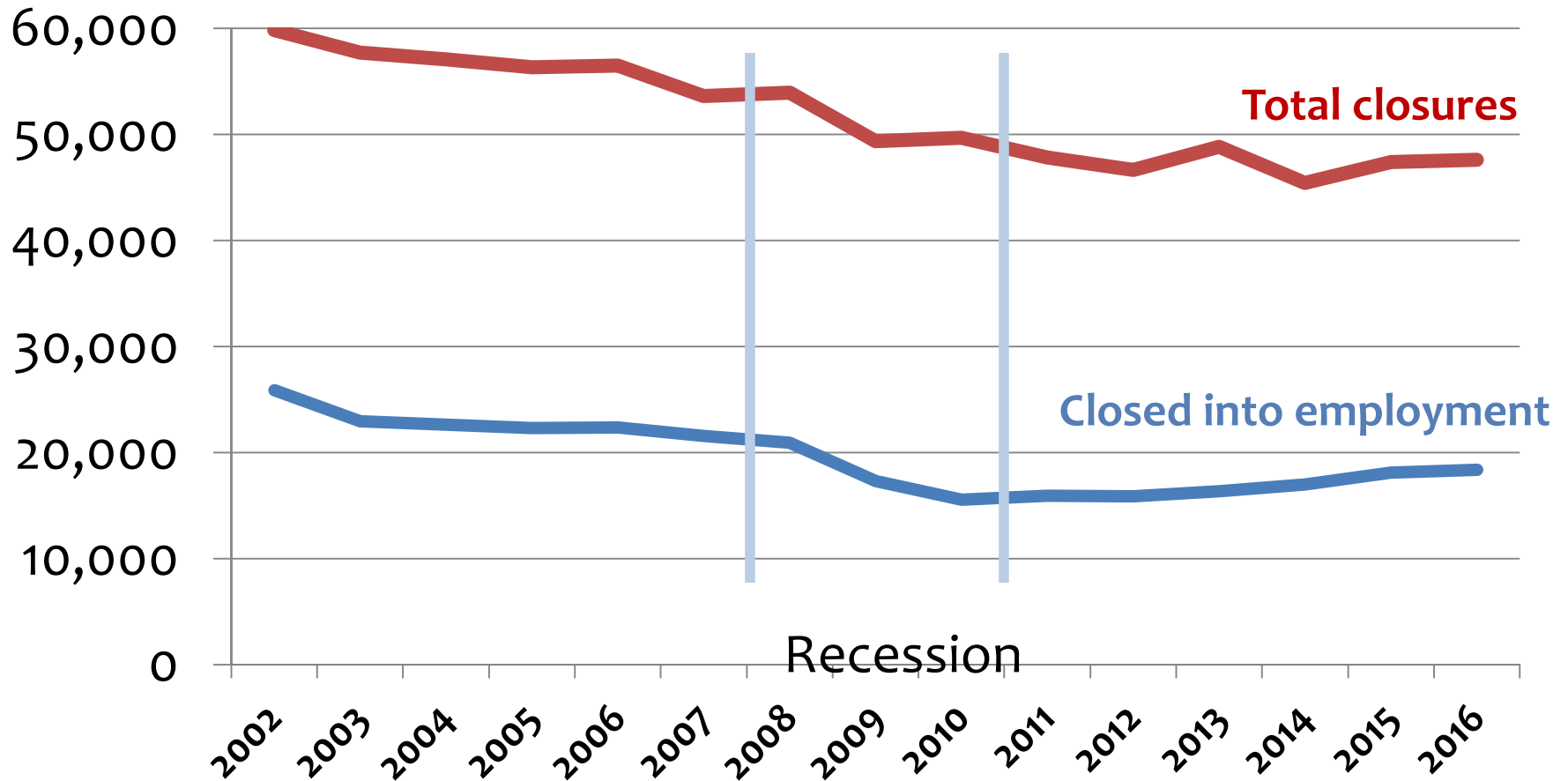
# Self Sufficiency & Meaningful Day

Average hours worked per week: Individual job

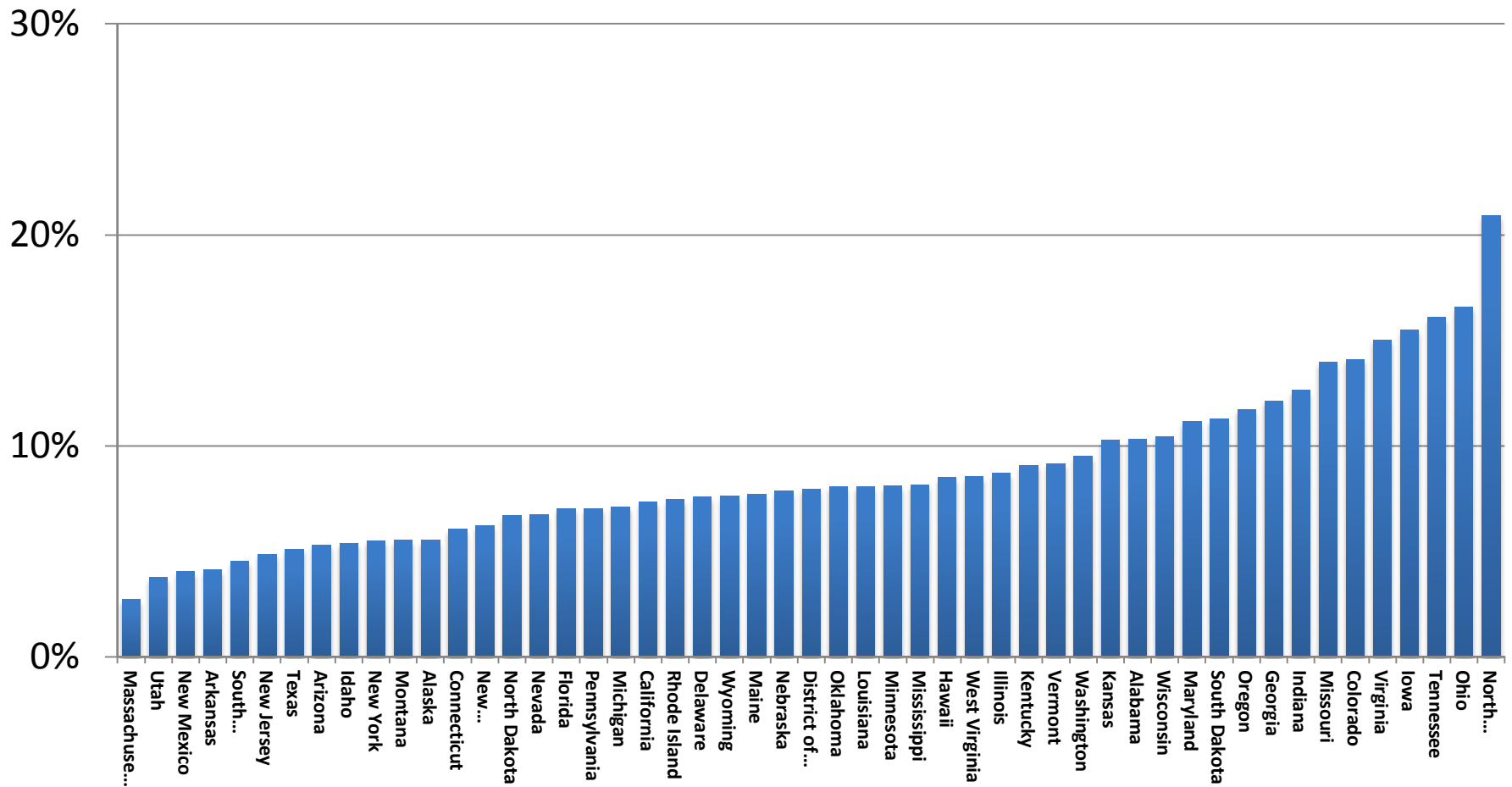


# VR trends: Nation

## Number of closures: Persons with ID

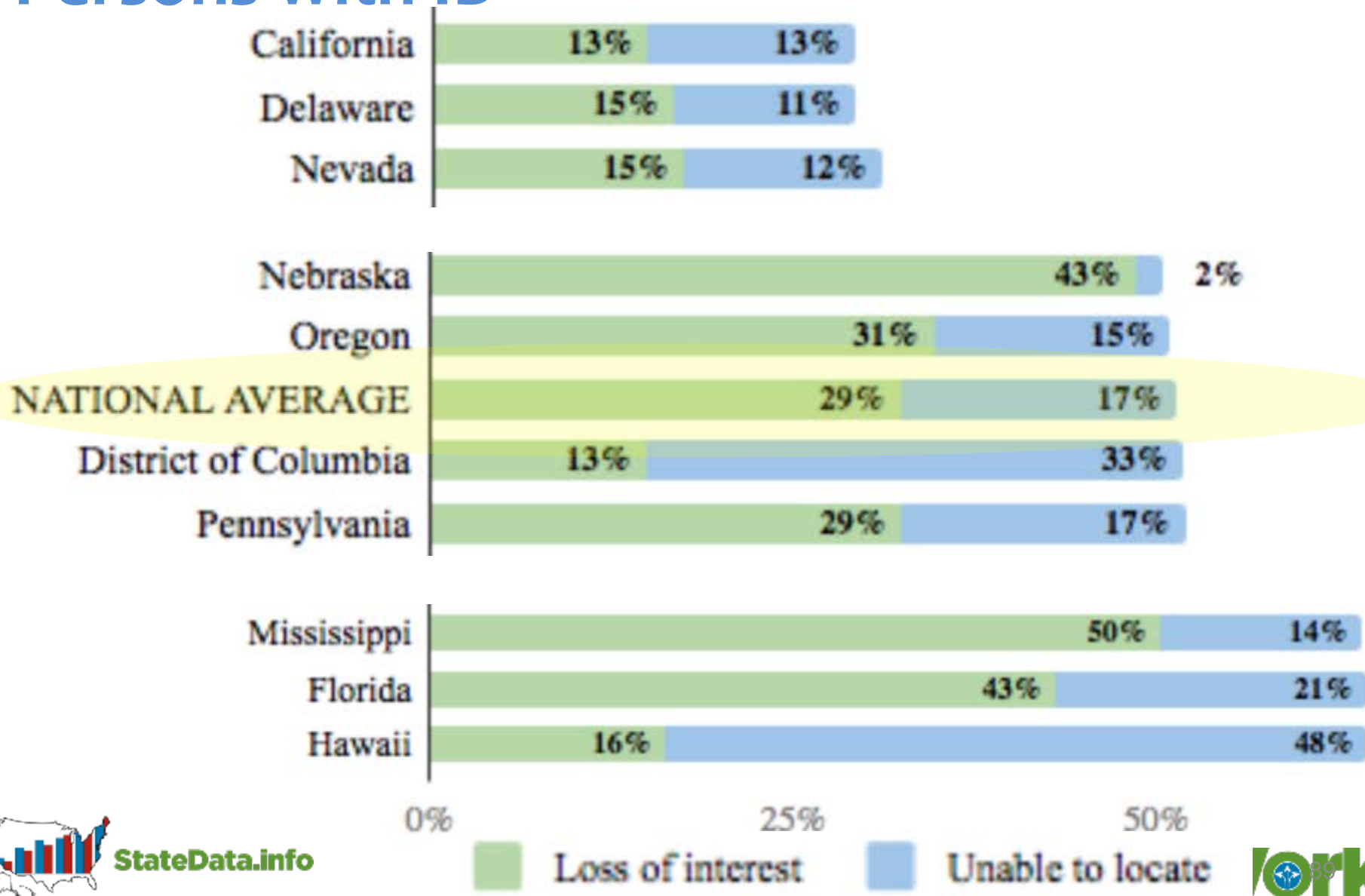


# VR: Engagement with individuals with an ID

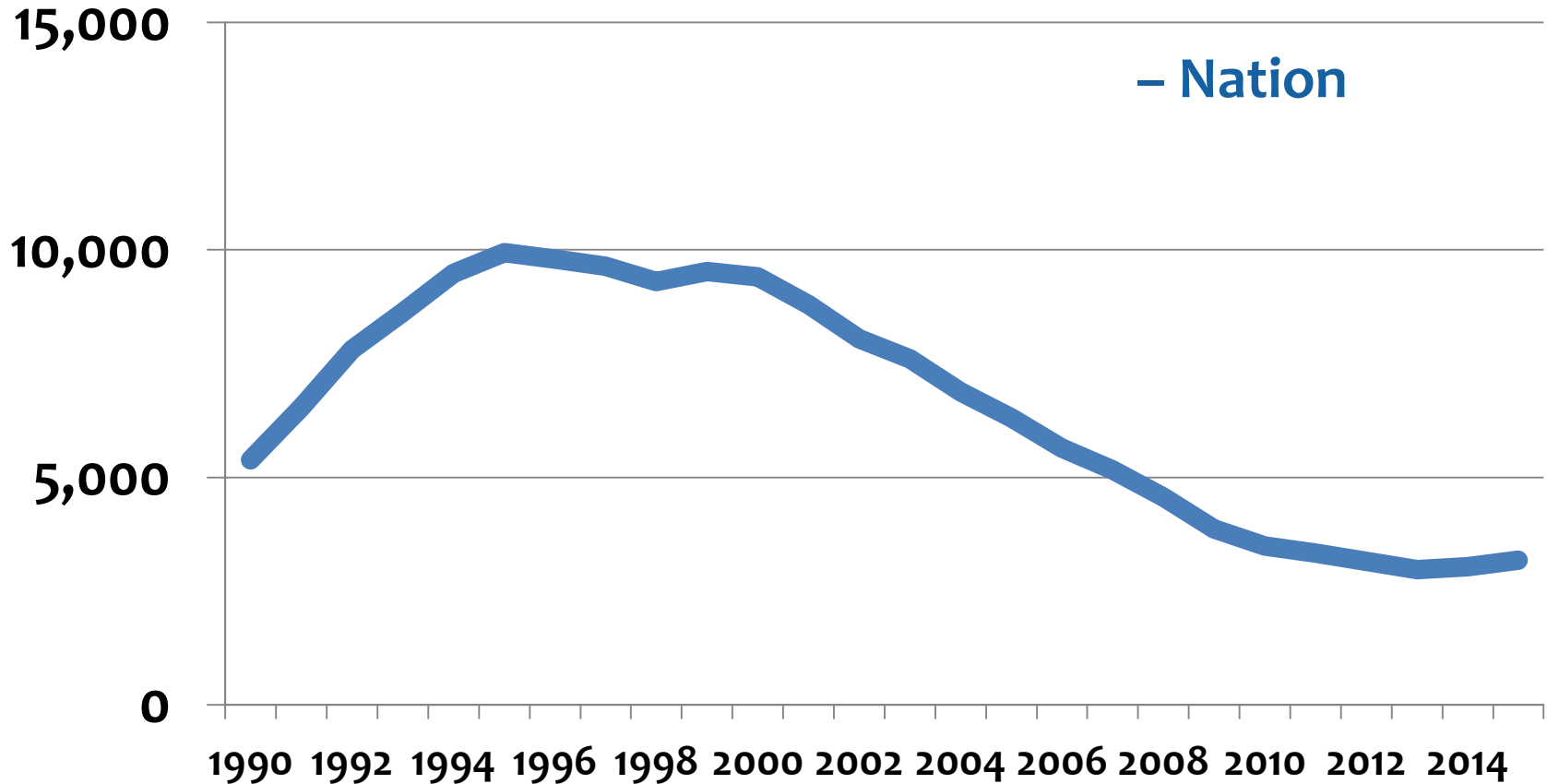




# Reasons for exiting VR without a job: Persons with ID



# Use of work incentives: Impairment Related Work Expenses



# Policy Influences

*CMS Employment Guidance*

*CMS Settings Rule*

*Department of Justice*

*WIOA*

*State Employment First*

# Focus Areas

WIOA Implementation

Pre-employment Transition Services

Section 511: Subminimum wage

Interagency collaboration

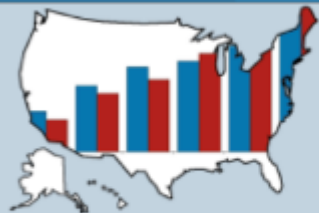
Community Life Engagement

Provider capacity

Case Management

Service definition redesign

Funding



Sign up for our Email Newsletter

Check the "Employment Data" box on the next page

GO

## PUBLICATIONS AND ANALYSIS

2016 Edition is here



### StateData: The National Report on Employment Services and Outcomes

StateData: The National Report on Employment Services and Outcomes. 2016 Edition. Access the latest information about employment and economic self-sufficiency for people with intellectual and developmental

disabilities. Both national and state-level statistics are included.

[Download the PDF here\\*](#)

[Download the report narrative, no tables \(Accessible PDF\)](#)

Download Your State:

Alabama



Go

## MAKE OUR DATA WORK FOR YOU

### State Snapshots

See the latest trends in state performance in work and participation for people with intellectual and developmental disabilities.

- Choose -

[View state summary](#)

### Build a Chart

[Our chart-building tool](#) offers descriptive information on state characteristics and services drawn from several national databases. View a single state trend, or compare several states and national data.



### Data Updates

According to WIOA data, there has been a



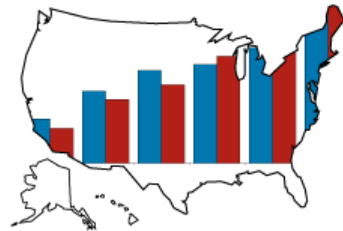
**John Butterworth**

(617) 287-4357

john.butterworth@umb.edu

**www.ThinkWork.org**

**www.RealWorkStories.org**



**StateData.info**



**ThinkWork!**