

Trends in HCBS Services for People with IDD: Policy Implications



August 30, 2017 RISP FY 2014 data

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.

The Residential Information Systems Project (RISP)



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Residential Information Systems Project (RISP)

An Administration on Community Living
Data Project of National Significance



Funded under the DD Act of 1988 and subsequent reauthorizations to inform Congressional decisions about funding supports and services for people with IDD.

RISP Purpose

- Track status and trends in long-term supports and services (LTSS) for people with intellectual or developmental disabilities (IDD)
 - Nationally
 - State-by-state
- Provide research evidence used by federal and state policy makers, advocates and other stakeholders to:
 - Describe national and state trends in LTSS for people with IDD
 - Compare a state's performance to the nation or other states
 - Inform legislation, litigation and policy decisions
 - Advocate for systems change
 - Evaluate impact of policy decisions
- Inform and provide a context for research and training
 - Describe state variations in service utilization and expenditures
 - Provide context for public discourse (in the media, by advocates)

RISP Topics

- Conduct annual surveys of IDD agencies in 50 states and the District of Columbia
- Collect longitudinal data on
 - Medicaid- and State-funded Long-Term Supports and Services (LTSS) for people with Intellectual or Developmental Disabilities (IDD) since 1977
 - Residential IDD Institutions since 1880
- Report Status and Trends in
 - Living arrangements (Own home, family home, congregate settings)
 - Supports for families
 - Congregate setting sizes
 - Medicaid rebalancing and deinstitutionalization
 - State-operated residential services
 - Medicaid utilization and expenditures
 - Age of LTSS recipients
- Monitor the impact of legislation, policy and litigation on services for people with IDD

Long-Term Supports and Services

- Supported or competitive employment
- Adult day care
- Environmental Modifications and Technology
- Supports for families
- Habilitation (skill development)
- Behavior Supports



Long-Term Supports and Services



- Personal Care: ADLs
- Residential and In-home Services: IADLs
- Respite
- In-Home Therapies and Medical Supports
- Participant Directed Supports
- Transportation

Long-Term Supports and Services Dimensions

Operating Entity

(State vs Nonstate)

The proportion of LTSS recipients living in non-state settings increased from 37% in 1977 to 93% in 2014

Setting Type

(Own home, family home, host/foster home, group residence, institution)

57% of LTSS recipients lived in the home of a family member

Age

61% of LTSS recipients were 22 years +
Range: 34% (AZ) to 95% (DC)

Funding Authority

(Medicaid State Plan, Waiver, ICF/IID; State only)

91% of 826,350 Medicaid ICF/IID plus waiver recipients received Medicaid Waiver funding.

Setting Size

(1-3, 4-6, 7-15, 16+)

Of 483,784 LTSS recipients not living with a family member

53% lived in settings of 1 to 3 people
26% lived in settings of 4 to 6 people

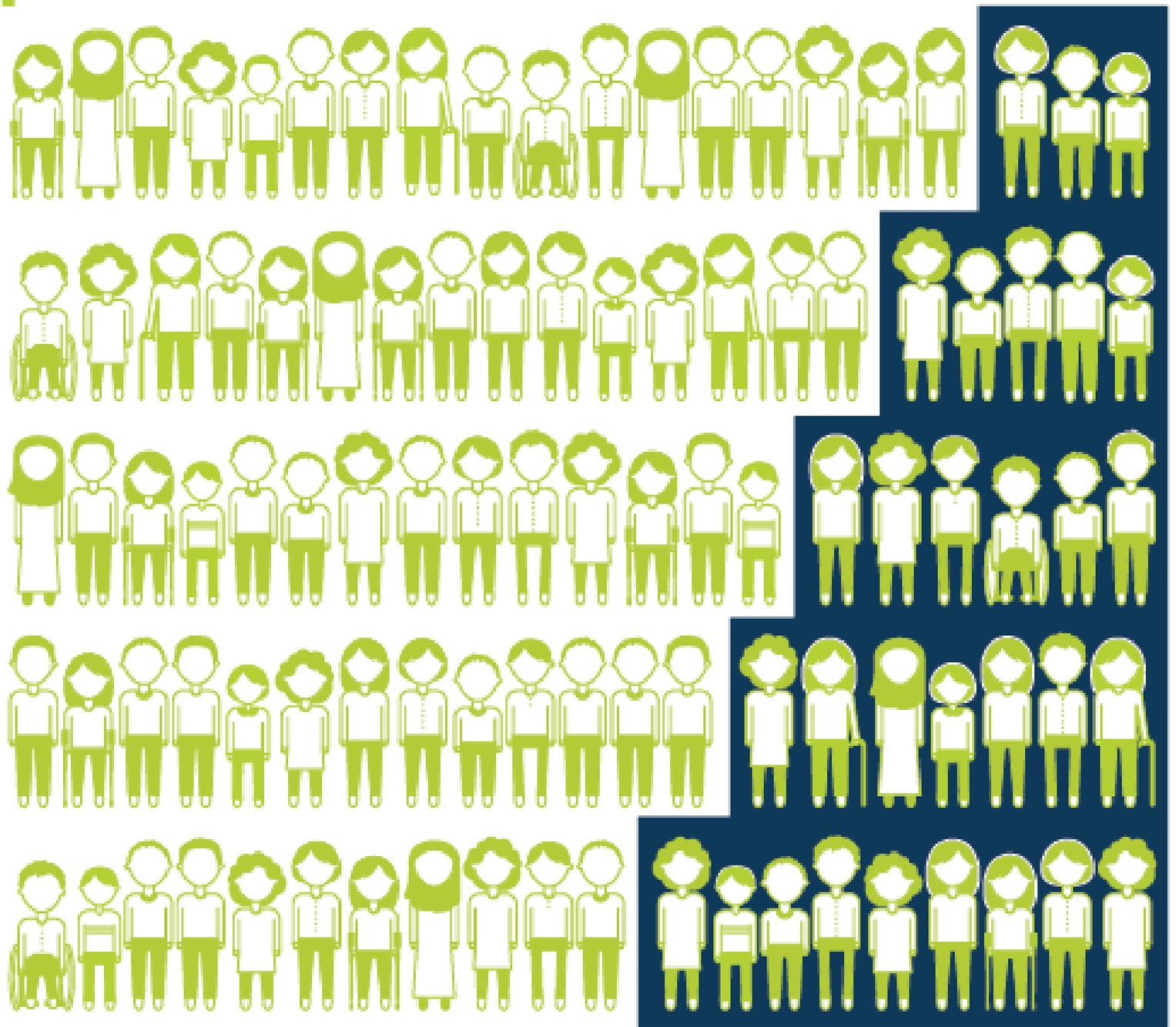
Prevalence of Intellectual and Developmental Disabilities

How many people in the U.S. have an IDD?
How many receive supports and services?





4.7 million people in the United States had Intellectual or Developmental Disabilities (IDD) in 2014

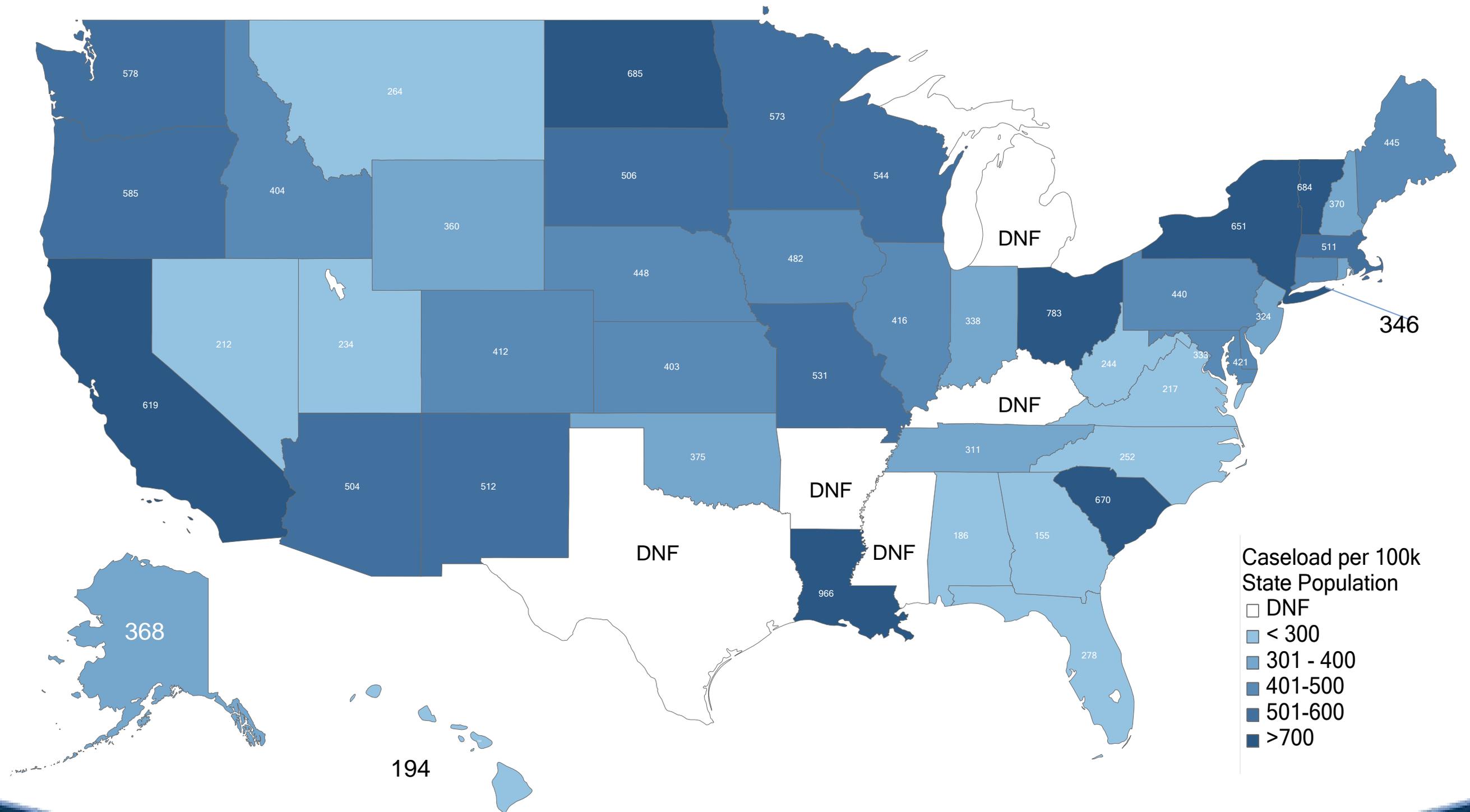


1.17 million received long-term supports or services through state IDD agencies

1,374,398 people with IDD were known to or served by state IDD agencies **30%**

State IDD Agency Caseloads per 100,000

431 per 100,000 people in the United States are known to state IDD agencies (on their caseload)



Caseload per 100k
State Population

- DNF
- < 300
- 301 - 400
- 401-500
- 501-600
- >700

LTSS Policy



Milestones

**1971 Medicaid
Intermediate Care
Facilities for Individuals
with Intellectual
Disabilities**

**1981 Home and
Community Based
Services Waiver**

**1999 Supreme
Court Olmstead
Decision**

**1965
Medicaid
Program**

**1975 PL 94-142
Individuals with
Disabilities
Education Act**

**1990 Americans
with
Disabilities Act**

**2014 Home and
Community
Based Services
Rule**

Federal and State Funding Authorities

Medicaid Waivers

- 1115 Demonstration waivers
- 1915(a) Voluntary managed care
- 1915(b) Managed care
- 1915(b/c) Managed care
- 1915 (c) HCBS Waivers
 - Comprehensive Waivers
 - Capped Supports Waivers
 - Model Waivers for people with
 - Special healthcare needs
 - Autism

Medicaid State Plan

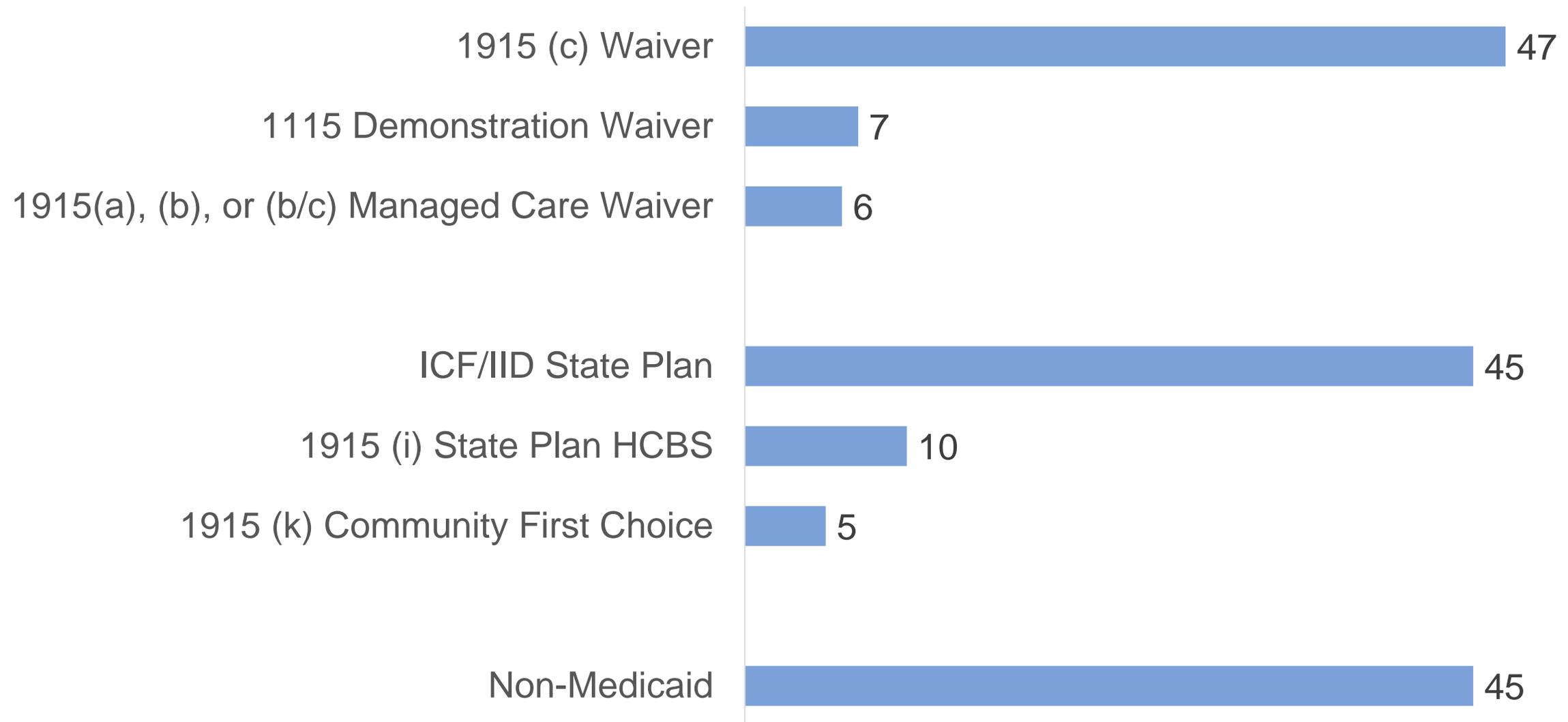
- Intermediate Care Facility for Persons with Intellectual Disabilities (ICF/IID)
- 1915(i) State plan HCBS
- 1915(j) Self-Directed Personal Assistance Services
- 1915(k) Community First Choice
- Other state plan
- Other Medicaid Authority

Non-Medicaid

- State IDD Agency
- Other state or local funding

Use of LTSS Funding Authorities for People with IDD

(Number of States Using in FY 2014)



Number of reporting states:

1915(c) – 51

1915(i) – 49

All other funding authorities - 50

2014 Medicaid Home and Community Based Services (HCBS) Rule

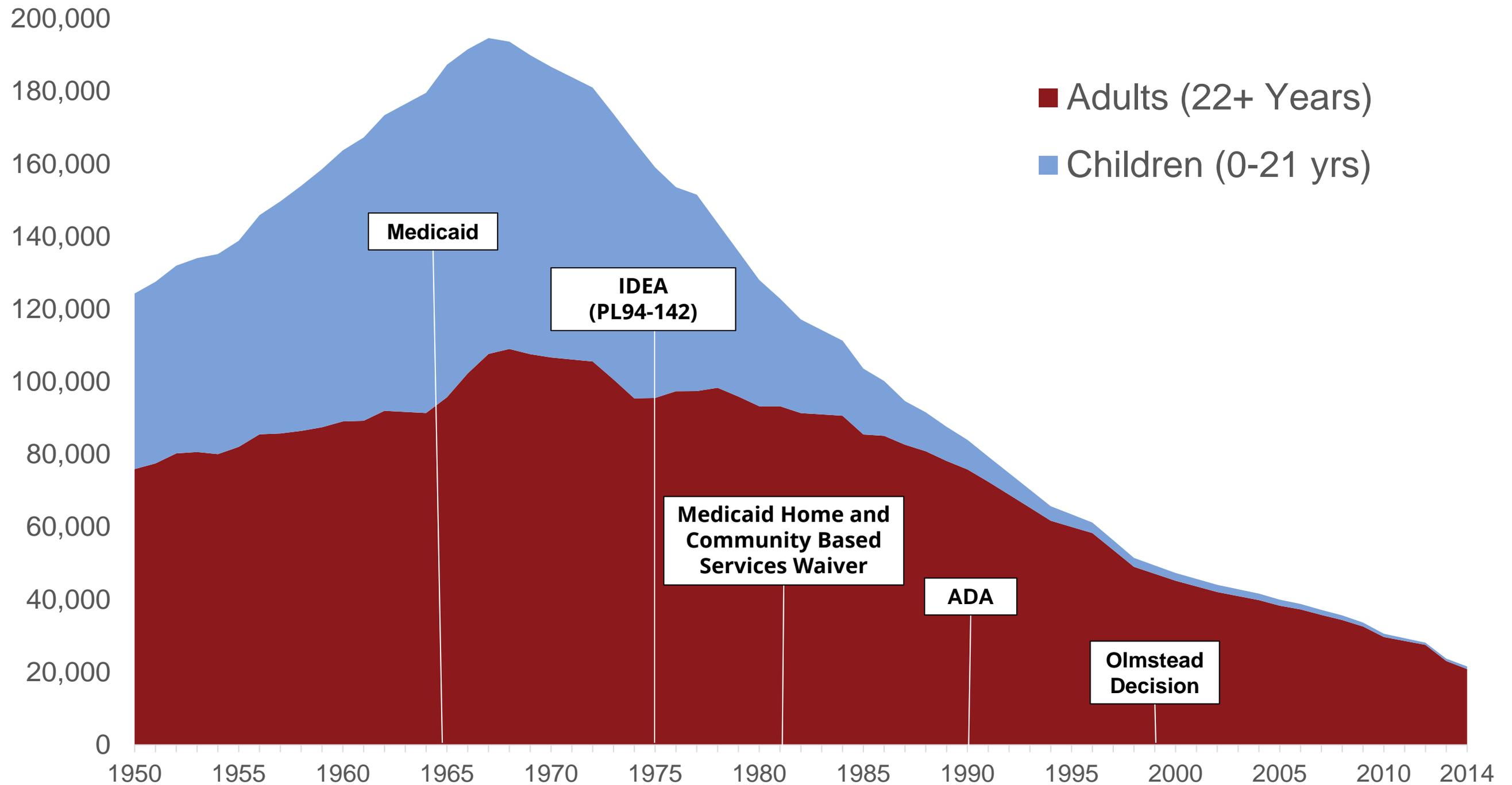
HCBS services must

- Support for full access to the greater community
- Be selected by the individual
- Privacy, dignity and respect, and freedom from coercion and restraint.
- Initiative, autonomy, and independence in making life choices
- Choice regarding services and supports

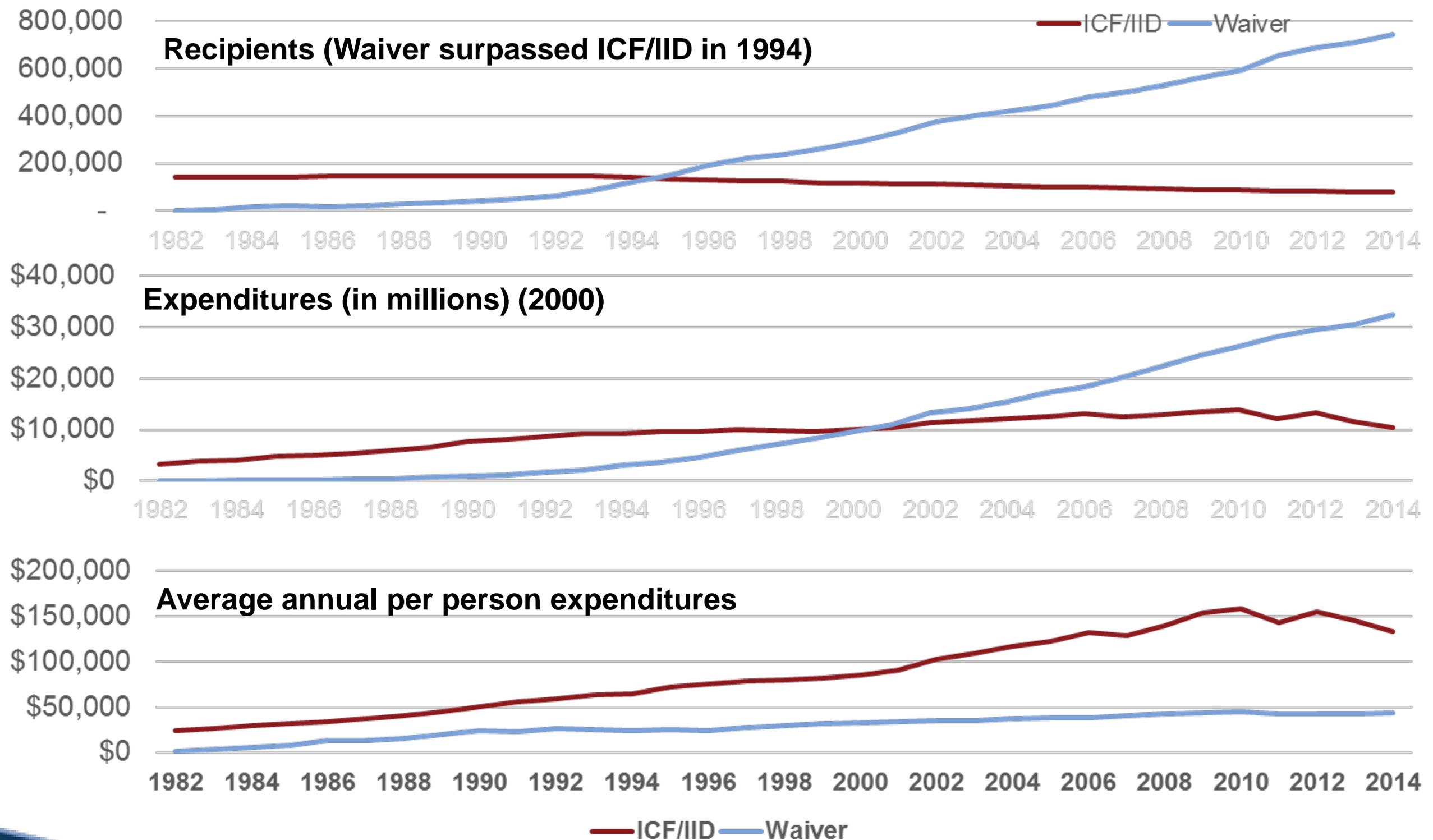
Key Provisions

- Conflict of interest provision
- Requires Person centered planning
- Settings rule
 - Rights of LTSS recipients living in provider-owned housing

People in Large State Operated IDD Facilities (16+ people) 1950 to 2014



Rebalancing Medicaid LTSS Settings for People with IDD

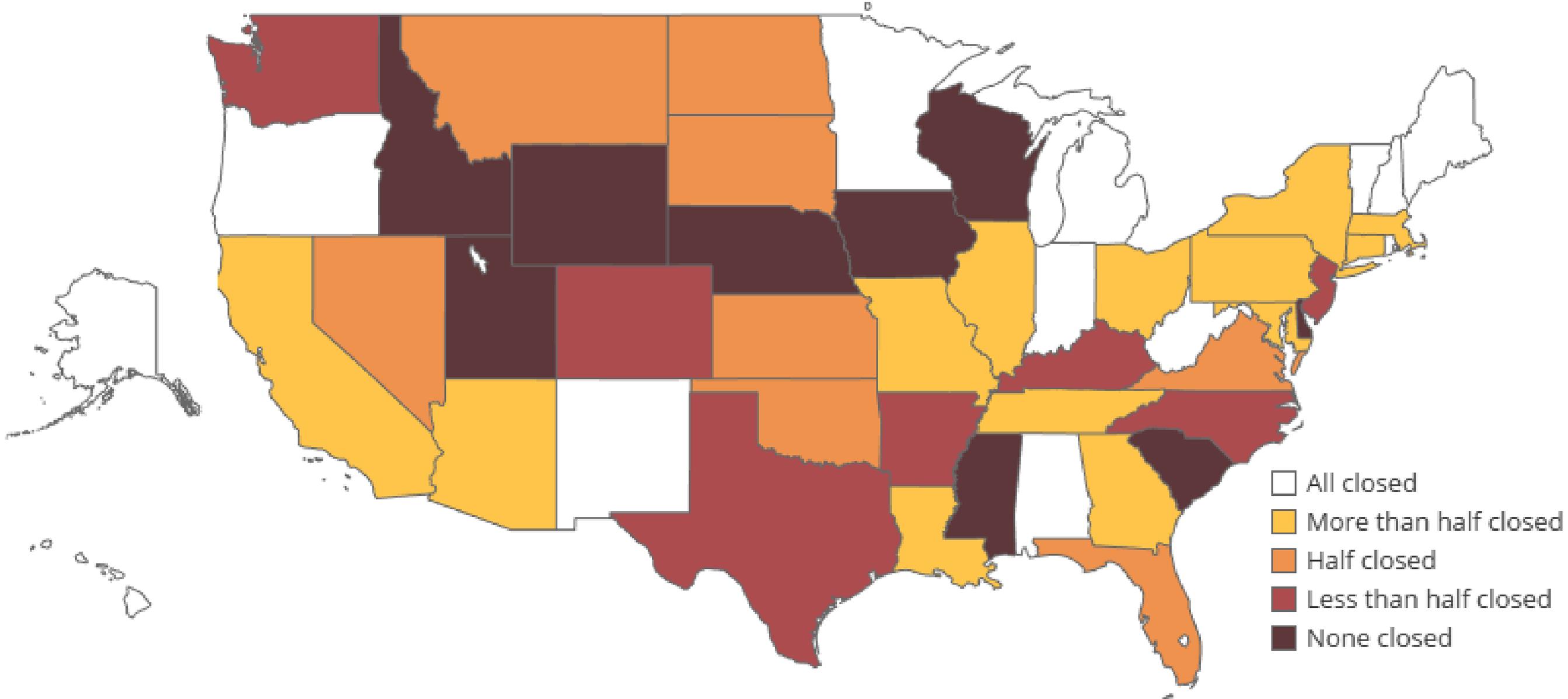


* Truven data used for 5 states, Eiken et al., (2016)



Closures of State IDD Facilities with 16+ People

327 Facilities in 1977; 151 in 2014



Trends

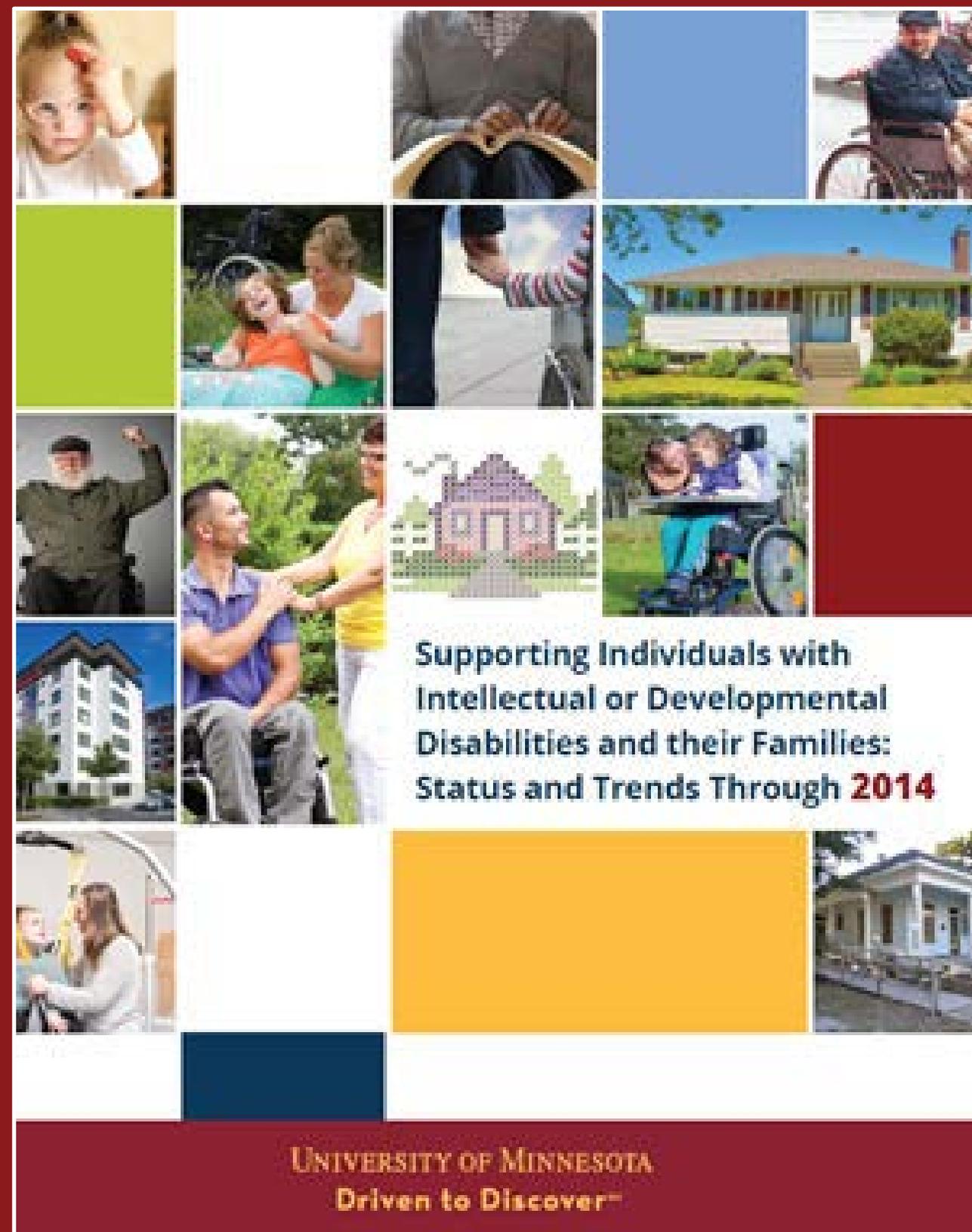
- Expansion of Medicaid funding authorities
- Growth of Medicaid LTSS Managed Care
- Availability of Medicaid-funded supports for people living in the home of a family member
- Continued deinstitutionalization as individualized HCBS services are developed

What's Next

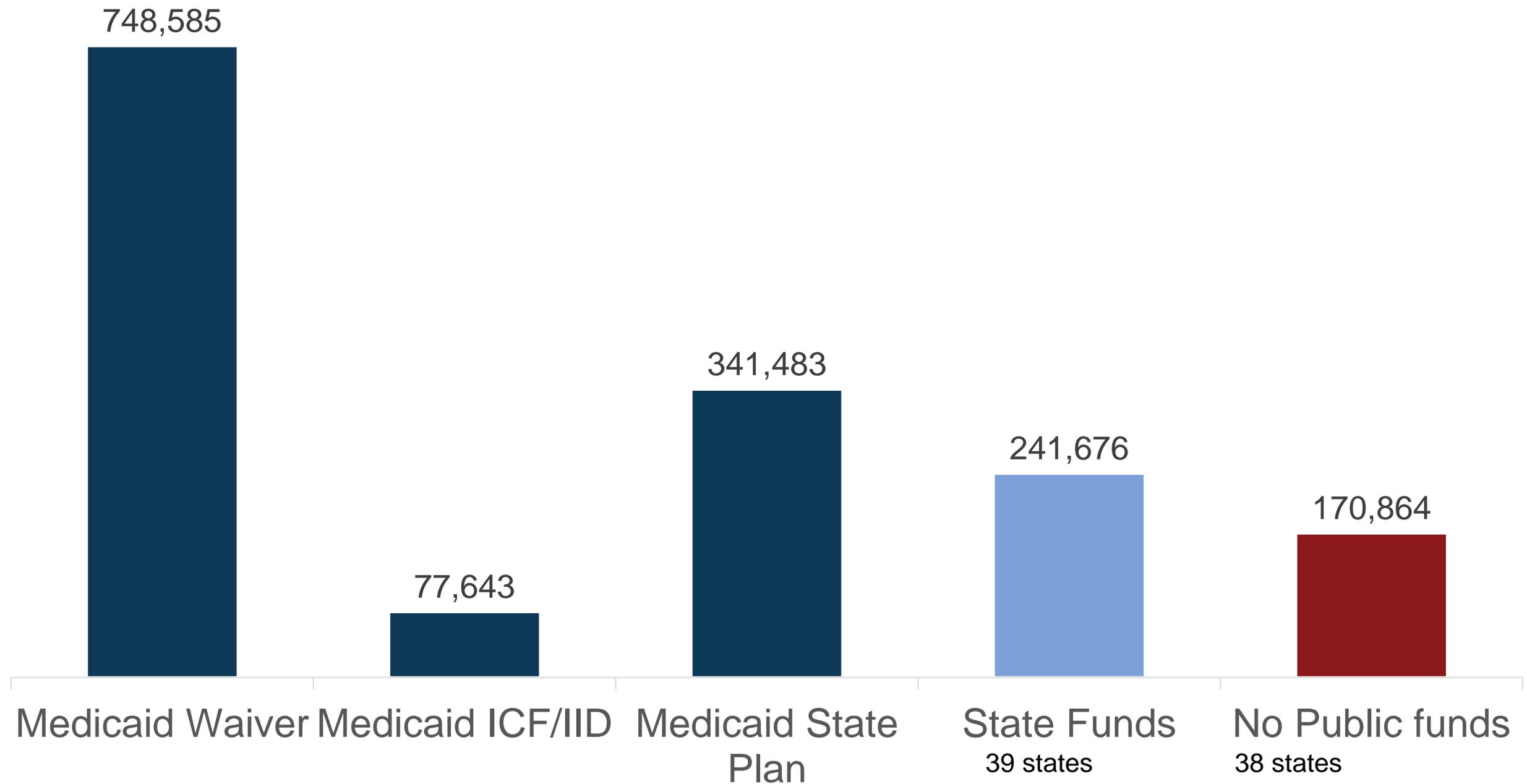
- Significant cuts to the Medicaid program, including LTSS, have been the focus of intense public debate in Congress.
- Future funding levels for Medicaid remain unknown, but demand for services continues to rise.
- States are still negotiating their transition plans with CMS for implementing the 2014 HCBS rules. Significant changes will be needed to comply with the new standards.

RISP Highlights

What is the status of the long-term supports and services states are providing to people with Intellectual and Developmental Disabilities?



LTSS Recipients with IDD by Funding Authority



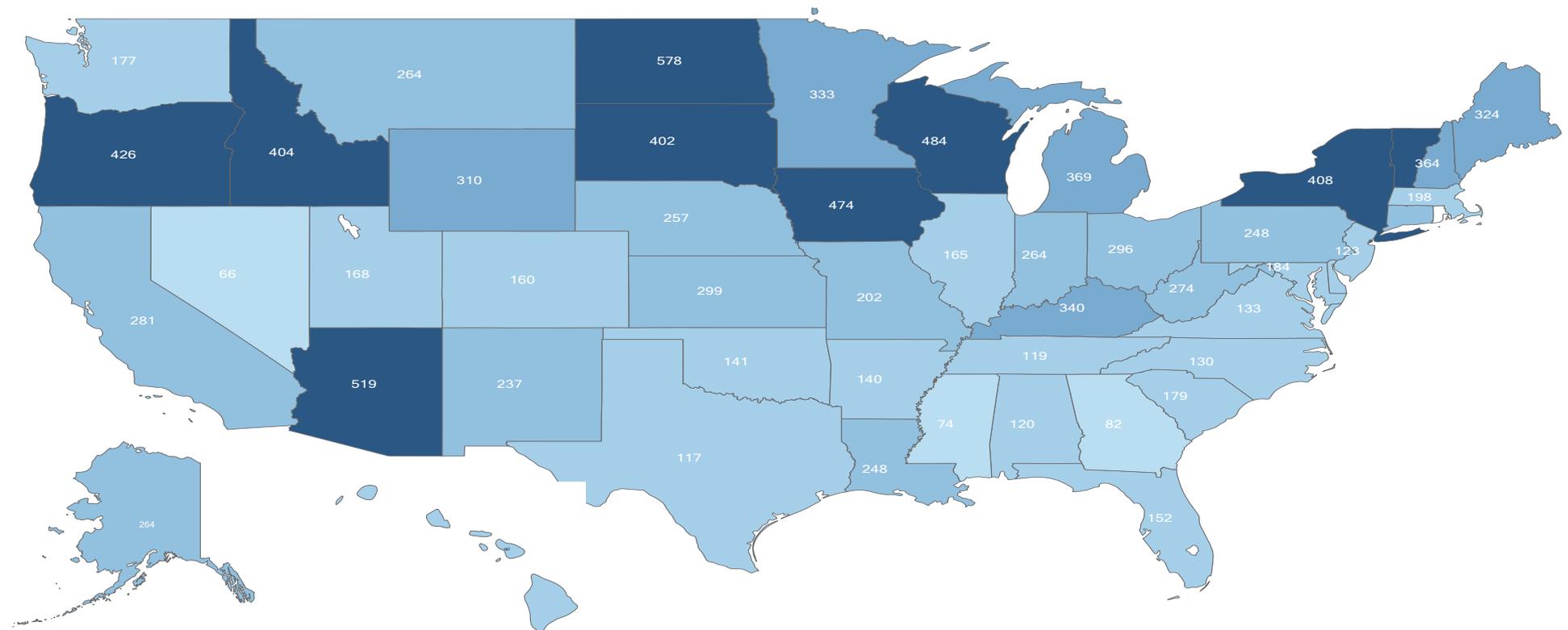
FY 2014

Includes duplicate counts. Medicaid state plan and Non-Medicaid state funds can be combined with other funding authorities

Medicaid LTSS Utilization per 100,000

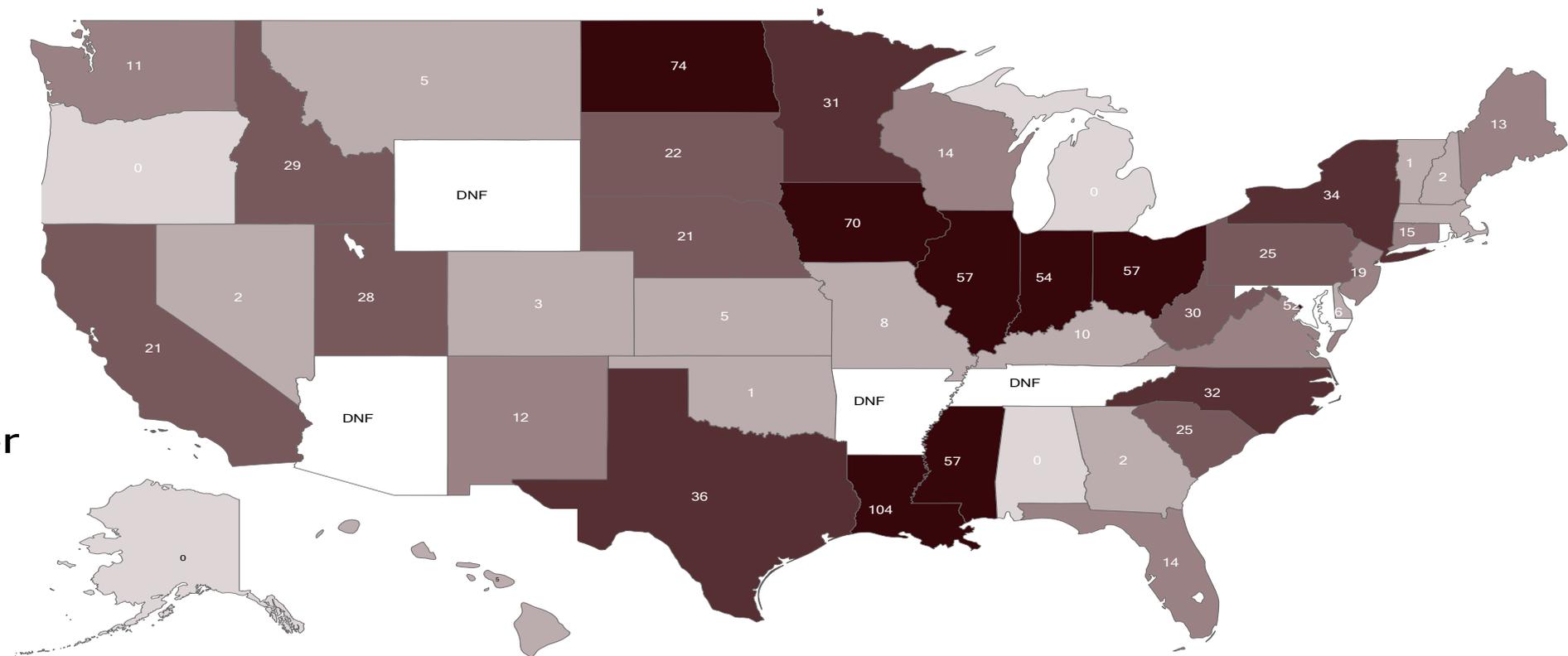
HCBS Waiver
235.0

- DNF
- <100
- 101-200
- 201-300
- 301-400
- >400



ICF/II
D
24.4

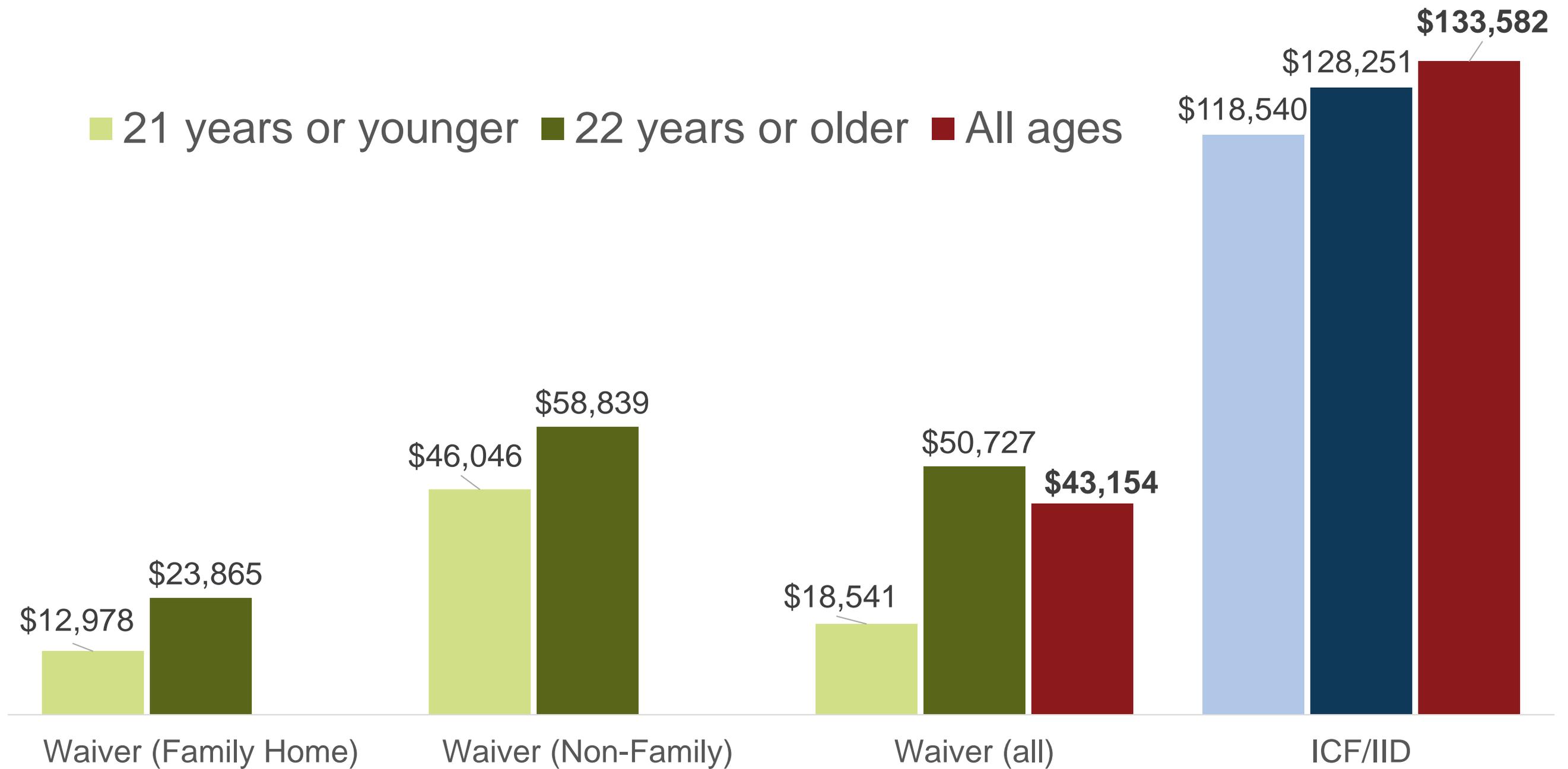
- DNF
- 0
- 10 or fewer
- 11-20
- 21-30
- 31-40
- 41 or greater



FY 2014

UNIVERSITY OF MINNESOTA

Annual Per Person Medicaid Waiver and ICF/IID Expenditures by Age and Living Arrangement

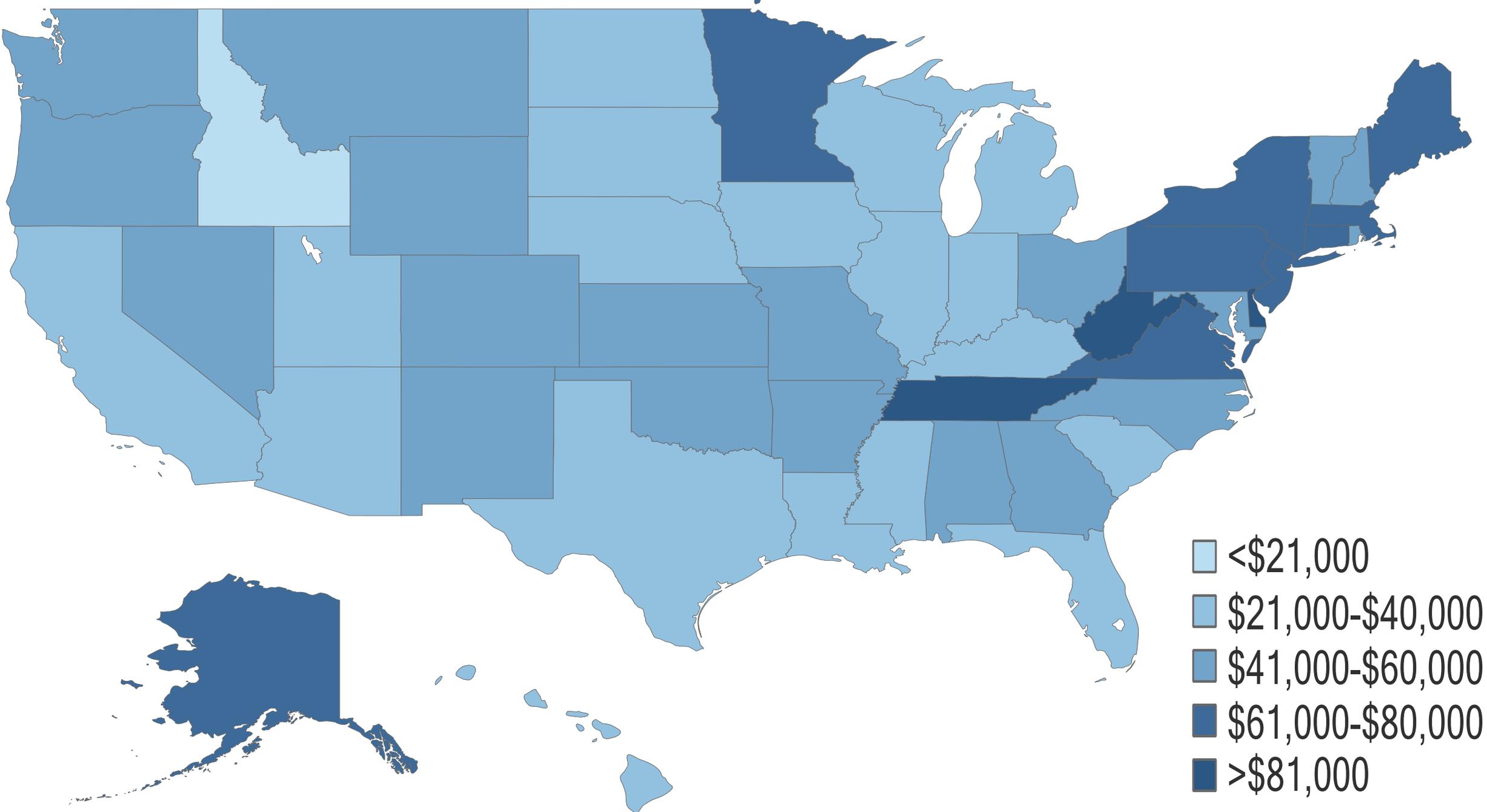


RISP FY 2014

UNIVERSITY OF MINNESOTA

Annual HCBS Expenditures per Recipient with IDD

National Average \$43,154



FY 2014

Age of Service Recipients with IDD

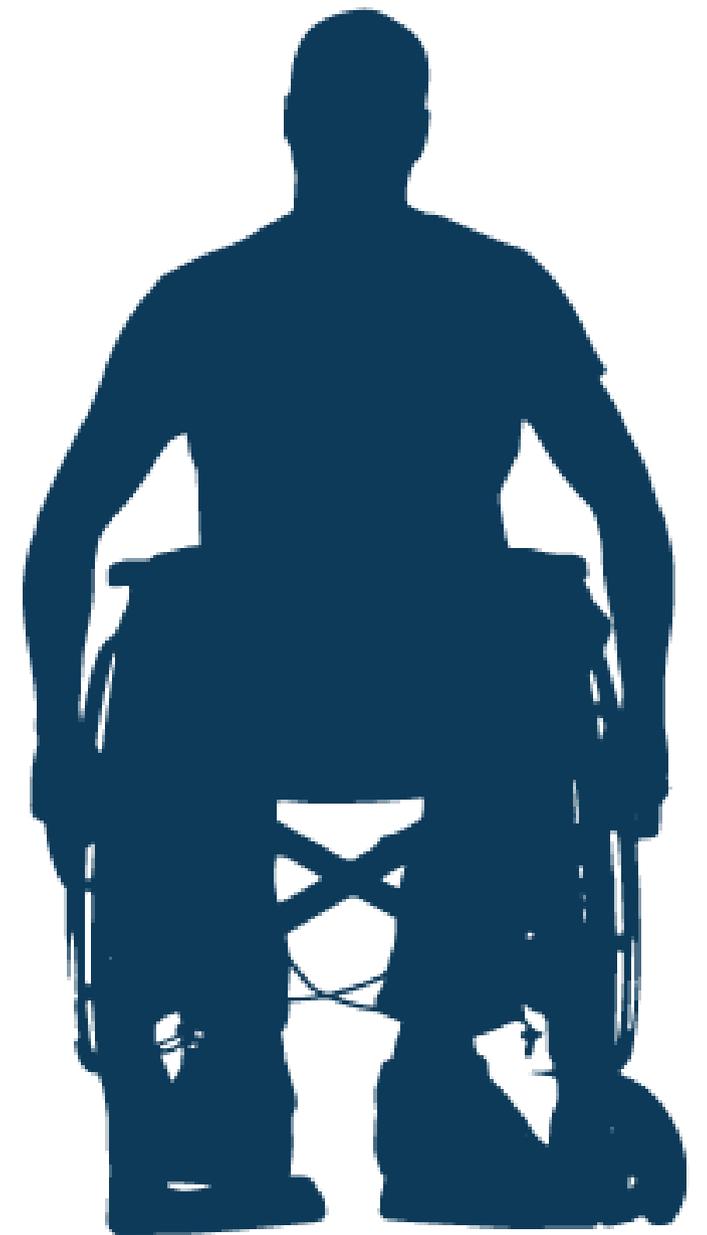
An estimated 1.4 million people with IDD were known to or served by state IDD agencies on June 30, 2014. Of these:

61%

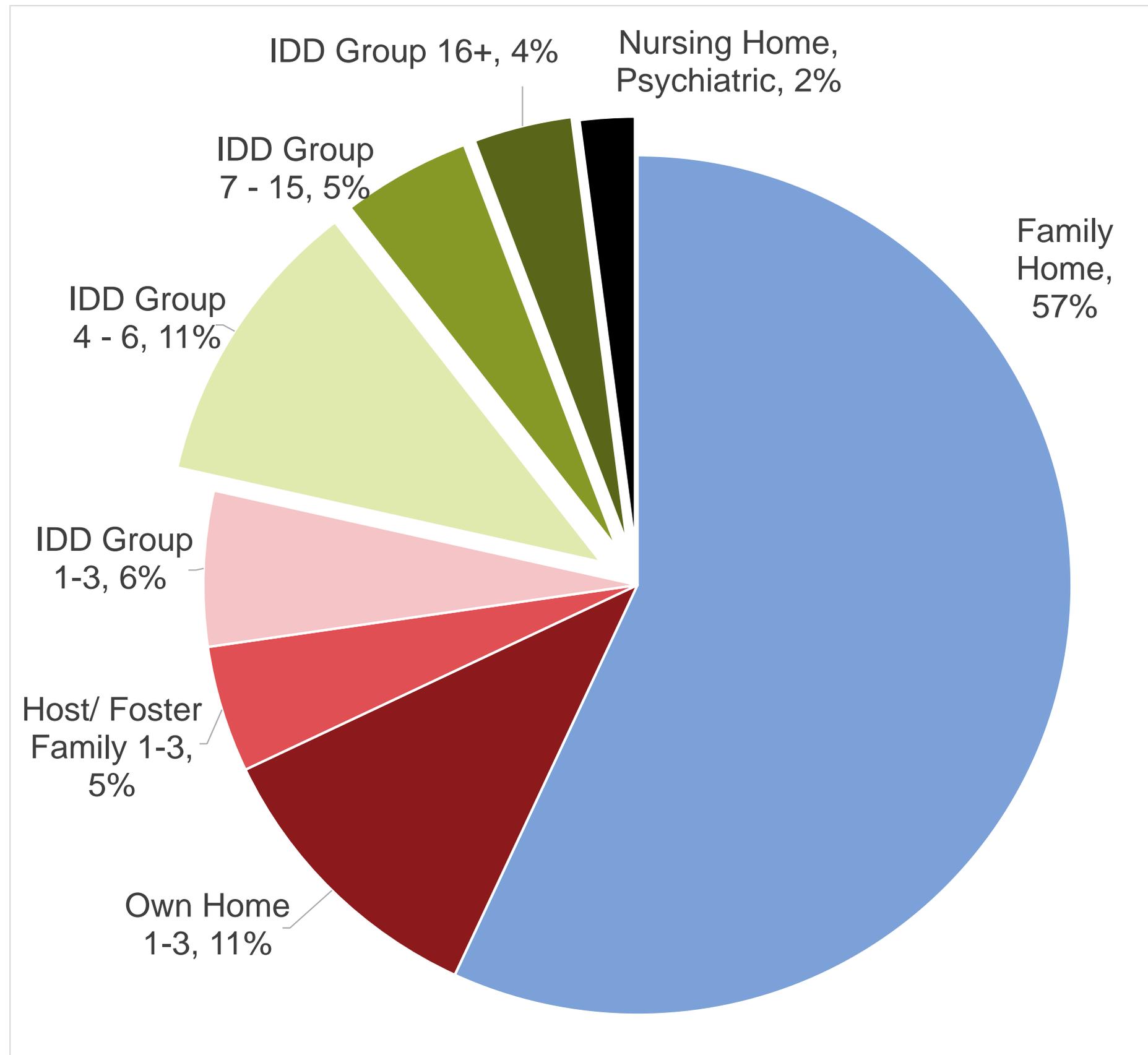
WERE 22 YEARS
OR OLDER

39%

WERE BIRTH
TO 21 YEARS OLD

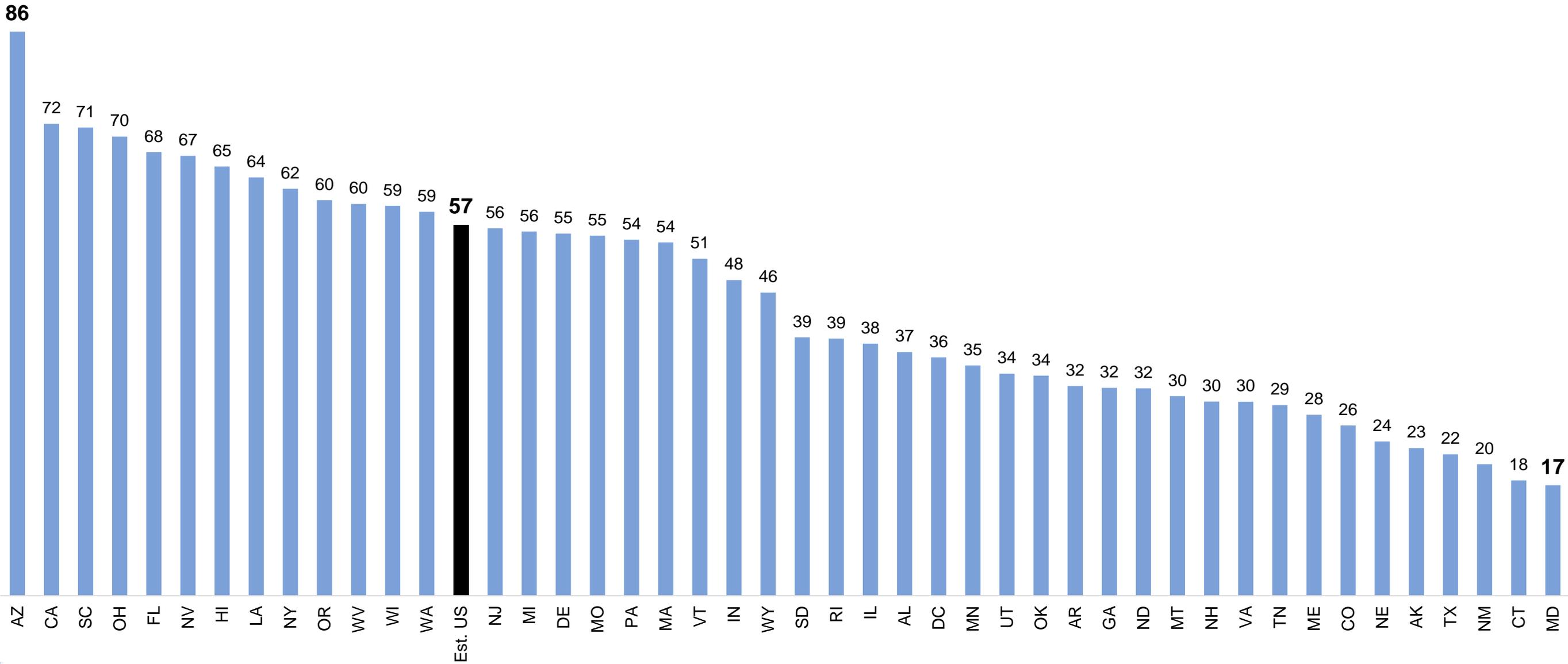


Where did LTSS Recipients with IDD Live?



FY 2014

Percent Living in Home of a Family Member by State



FY 2014

People With IDD Receiving or Waiting for Medicaid HCBS Funded Supports 1996 to 2014

% increase needed to serve people living with a family member or in a home of their own who are waiting for HCBS funded supports

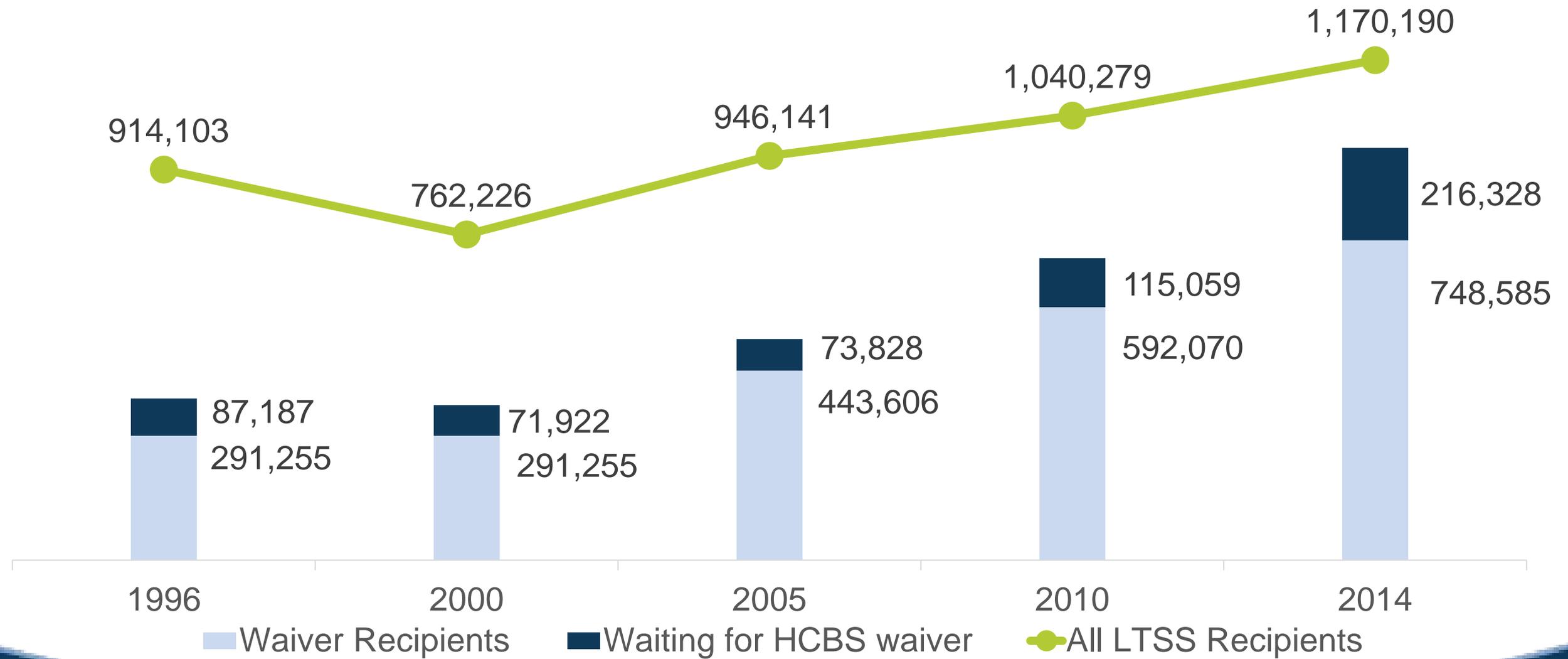
27%

19%

18%

25%

26%



Using RISP Data to Inform Policy and Practice



National Association of State Directors of Developmental Disabilities Services (NASDDDS)

- NASDDDS represents the nation's agencies in 50 states and the District of Columbia providing services to children and adults with IDD and their families
- We promote and assist state agencies in developing effective, efficient service delivery systems that furnish high-quality supports to people with IDD.

NASDDDS Continued...

- NASDDDS provides both broad-based membership resources as well as state-specific detailed technical assistance.
- RISP is an essential tool in all efforts.
- RISP data show state's longitudinal progress on settings and expenditures, as well as a national vantage point of emerging and effective supports and service models.

NASDDDS Continued...

- Our members use RISP data to illustrate key issues for state leadership and legislators, as well as other key partners and stakeholders.
- For example, several states have used the RISP data to support efforts to grow and expand more individualized service models, such as shared living and supports to families.

Human Services Research Institute (HSRI)

- As policy consultants for LTSS systems for people with I/DD, HSRI uses RISP data to observe trends in service populations and expenditures.
- Utilizing RISP data allows for quick comparison between states and a national average to use as a benchmark on a number of data points.
- RISP data allows us to show states comparable systems by finer grain-- such as by similar service populations by age, numbers served per 100,000, funding authority, or others.

HSRI Continued...

- We see huge variability in what states spend per person– from over \$100,000 per person in some states, to \$30,000 or less in many others.
- However, we don't find that support needs differ greatly between states– so why do costs?
 - How much is enough?
 - What are states that serve many but spend little doing differently than those that serve few but spend a lot?

University of Minnesota Research and Training

- Characteristics of state IDD programs are used to explain variability in National Core Indicators outcome findings over and above variability that can be explained by individual characteristics or types of service settings.
- Context for research proposals, journal articles and presentations on the LTSS system for people with IDD
- ICI core certificate program course for graduate students

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1 person, 1 home, millions of dollars

INVESTIGATORS: 1 person, 1 home, millions of dollars
7 minutes left



JEFF PASSOLT / AMY HOCKERT

FOX 9 9:14 12° **THE MONEY PIT**

By: Jeff Baillon

POSTED: FEB 02 2017 07:11PM CST
UPDATED: FEB 04 2017 07:13AM CST

f t G+ t p e

Using Research Data to Inform the Media

1 Person 1 Home

<http://www.fox9.com/news/investigators/233418548-story#.WTHoQOm27rs.email>

University of Minnesota Technical Assistance

- Media Inquiries: Deinstitutionalization stories
- State and Federal agencies – data to compare outcomes or policy impacts over time or across states (e.g., Medicaid HCBS)
- Protection and Advocacy and litigators – status and trends in a state or comparing one state to another
- Families and people with IDD – What state should I move to if I want xx type of services?

Resources

RISP.UMN.EDU

- RISP Annual Report (2000-Present)
- Build a Report: Compare States on Waiver and ICF/IID Recipients and Expenditures
- State Profiles
- Infographics
- Presentation Slides

FISP.UMN.EDU

- FISP Annual Report (2012-2014)
- Special Reports
- State Profiles
- Infographics
- Presentations
- Research Data Briefs
- Impact feature issue

Contact us at risp@umn.edu for technical assistance to interpret or customize reports

FY 2014 RISP State Profile

United States

Figure 1: Medicaid Recipients with IDD by Funding Authority 1977-2014

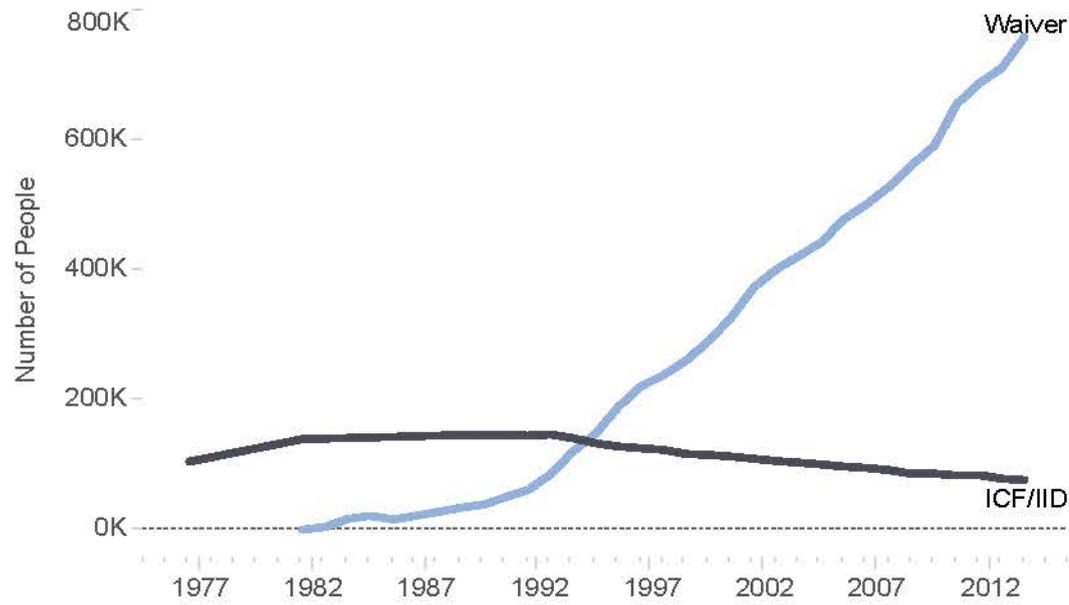


Figure 2: 2014 Medicaid Spending Per Person



Figure 3: Residence Size and Type on June 30, 2014

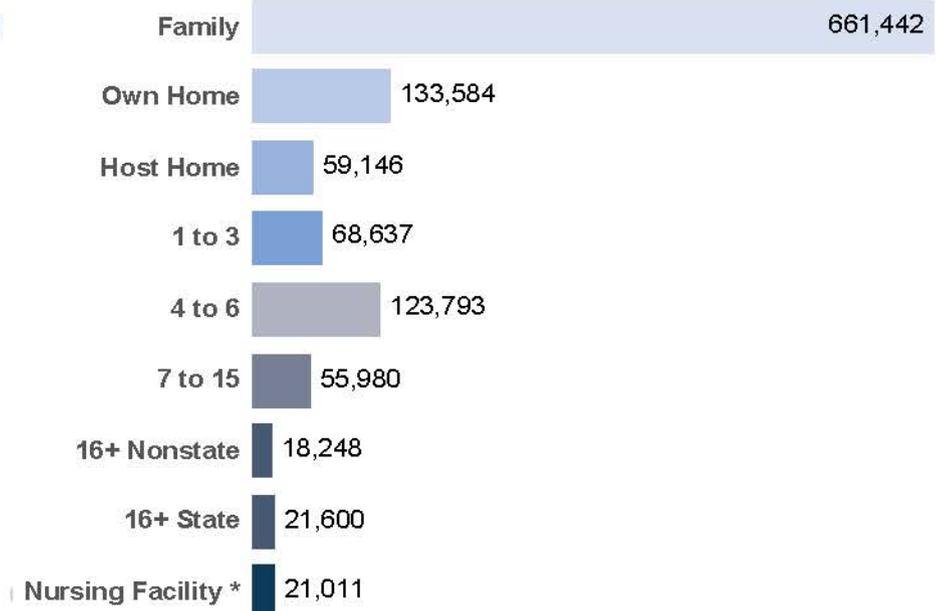


Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1987	1991	1996	2000	2005	2010	2014
Individualized Settings	Own Home					46,608	73,147	101,143	127,455	133,584
	Family					590,180	391,859	533,048	592,180	661,442
	Host Home					24,675	37,367	35,386	40,060	59,146
	1 to 3		15,702				33,360	49,037	62,584	68,637
Congregate Settings by size and type	4 to 6		17,486				67,146	107,573	105,290	123,793
	1 to 6	20,400	33,188	69,933	108,479	100,915	124,469	156,610	167,874	192,430
	7 to 15	20,024	30,515	48,637	53,475	56,389	52,802	52,888	55,682	55,980
	16+ Nonstate	51,638	55,786	42,081	48,001	37,016	35,253	27,005	25,927	18,248
	16+ State	155,716	124,180	95,052	79,407	58,320	47,329	40,061	31,101	21,600
	16+ Total	207,356	180,146	137,103	127,408	95,336	82,582	67,066	57,028	43,599
Non-DD Specific Sett...	Nursing Facility *	42,242	40,538	45,843	39,208	30,591	32,195	30,027	31,832	21,011
	State Psychiatric Facility	15,524	7,865	2,520	121	1,269	488	392	873	2,613
People with IDD in the Sys..	Waiting list					87,187	71,922	73,828	115,059	209,267
	Estimated Total	247,780	243,849	255,673	289,362	914,103	762,226	946,141	1,040,279	1,168,858
Medicaid Recipients and Expenditures	Waiver Expenditures per Person	0	901	12,955	22,319	24,783	33,142	38,679	44,396	43,183
	Waiver Recipients per 100,000	0	6	94	20	72	103	150	192	235
	ICF/IID Expenditures per Person *	5,798	14,886	24,826	55,636	73,926	85,040	119,162	146,999	135,447
	ICF/IID per 100,000 *	48	61	60	58	49	41	34	28	24

*Data for FY2014 may be from an outside source for these data elements. For ICF/IID expenditures and number of people, the source would be Eiken et al (2016). For Nursing Facilities, the source would be AHCA (2014a), (2014b), or (2014c).

Chart Gallery



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What are the ages of people who receive home and community-based services in their family homes?

State

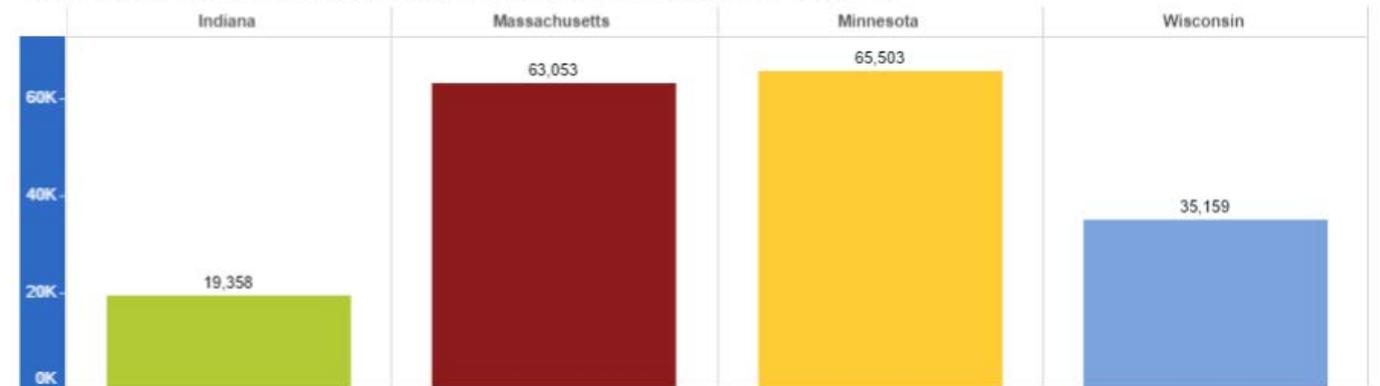


This data is for FY 2013.

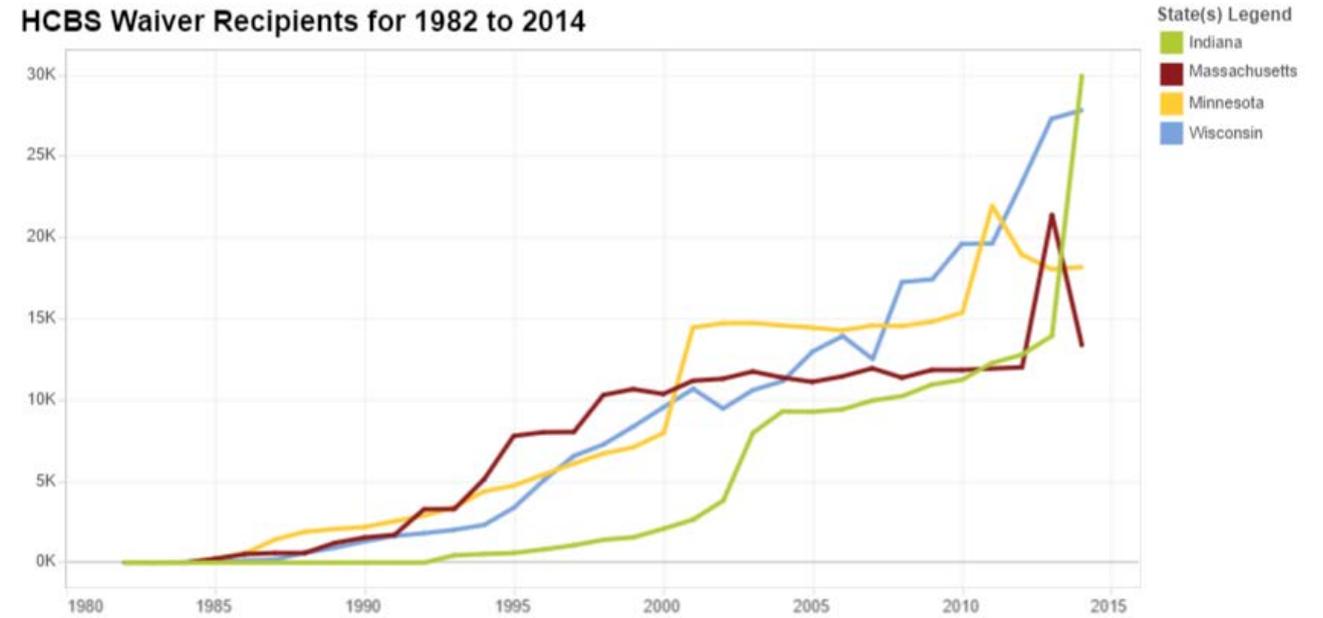
- In fiscal year 2013, about 55% of people with IDD known to state agencies receive HCBS-funded long-term supports and services. This is about 11% of all the people believed to have an intellectual or developmental disability living in the United States.
- More Medicaid dollars are now spent on Home and Community Based Services and supports than on institutional services (such as large group homes) for people with disabilities.
- Because children are in school and often receive supports through schools, there are age differences in both the proportion of children receiving Medicaid funded supports and in the cost of providing these supports.

Build a Report

HCBS Waiver Average Annual per Person Expenditures for 2014



HCBS Waiver Recipients for 1982 to 2014



Medicaid Long-Term Supports and Services for People with Intellectual or Developmental Disabilities <http://risp.umn.edu/viz>

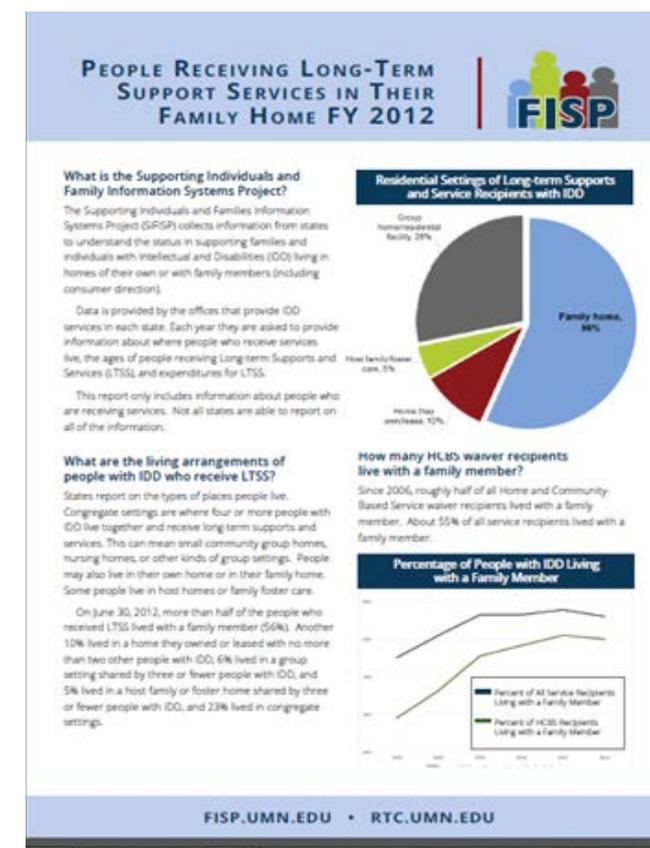
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HSRI: Val Bradley, John Agosta, Brittany Taylor, Yoshi Kardell, Alexandra Bonardi
NASDDDS: Mary Lee Fay, Mary Sowers, Mary Lou Bourne, Barbara Brent



Family Briefs

Discussion

- Your comments and questions
- How do the status and trends in LTSS for people with IDD compare with other HCBS populations?
 - Living arrangements
 - Rebalancing progress
- Why is it important to monitor trends in Medicaid LTSS utilization and expenditures?
- Why do states vary so widely?

Medicaid LTSS Utilization and Waiting Lists FY 2014

