

LTSS Recipients with IDD in the US 2014

National HCBS Data: In What Directions do the Data Point Us

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Purpose

- Track status and trends in long term supports and services for people with IDD (especially residential and in home supports)
 - Nationally
 - State-by-state
- Used by federal and state policy makers, and advocates to:
 - Describe impact of policies on people with IDD to Congress, State Legislatures, Courts and other stakeholders
 - Compare a state's performance to the nation or other states
 - Inform decision making
 - Advocate for systems change
- Enhances ongoing programs of research:
 - Provides state level data to help explain variability in outcomes
 - Provide context for research findings

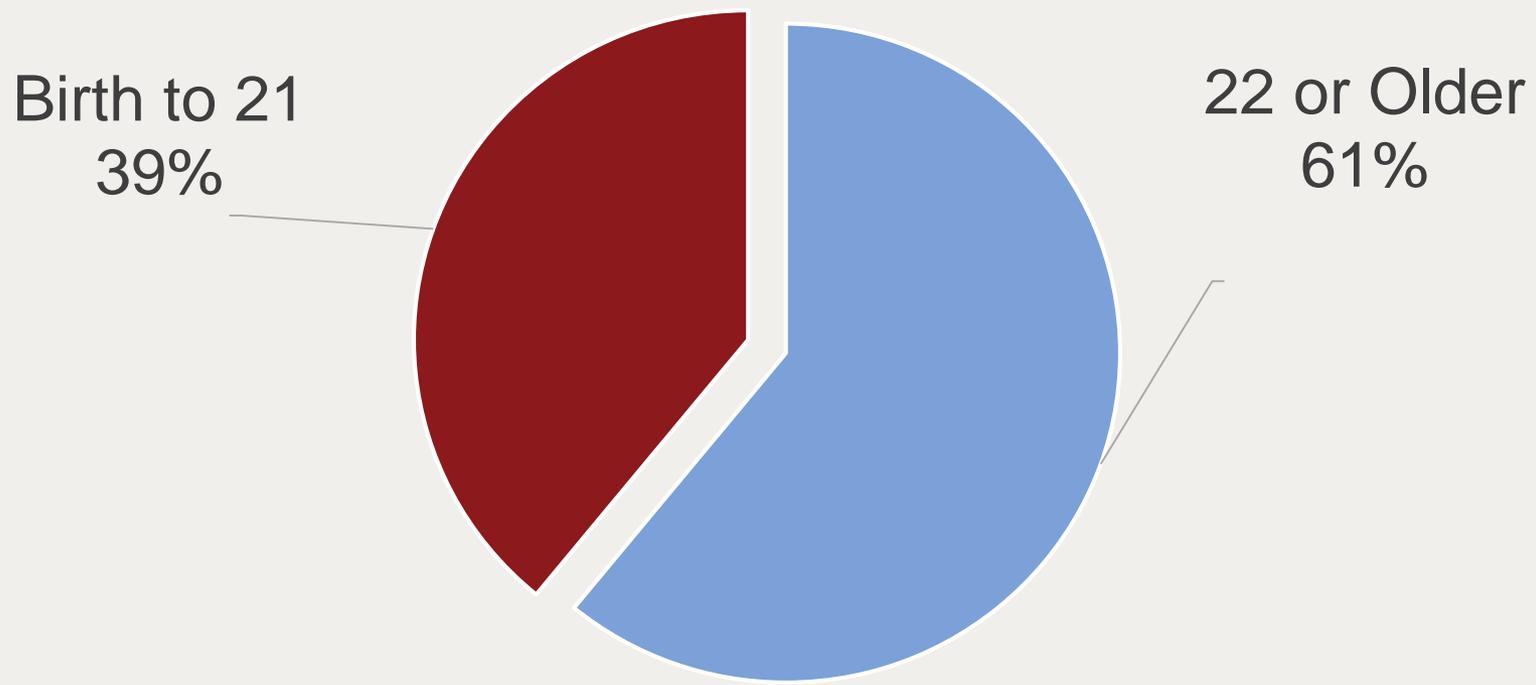
1.47% of people in the US had IDD in 2014



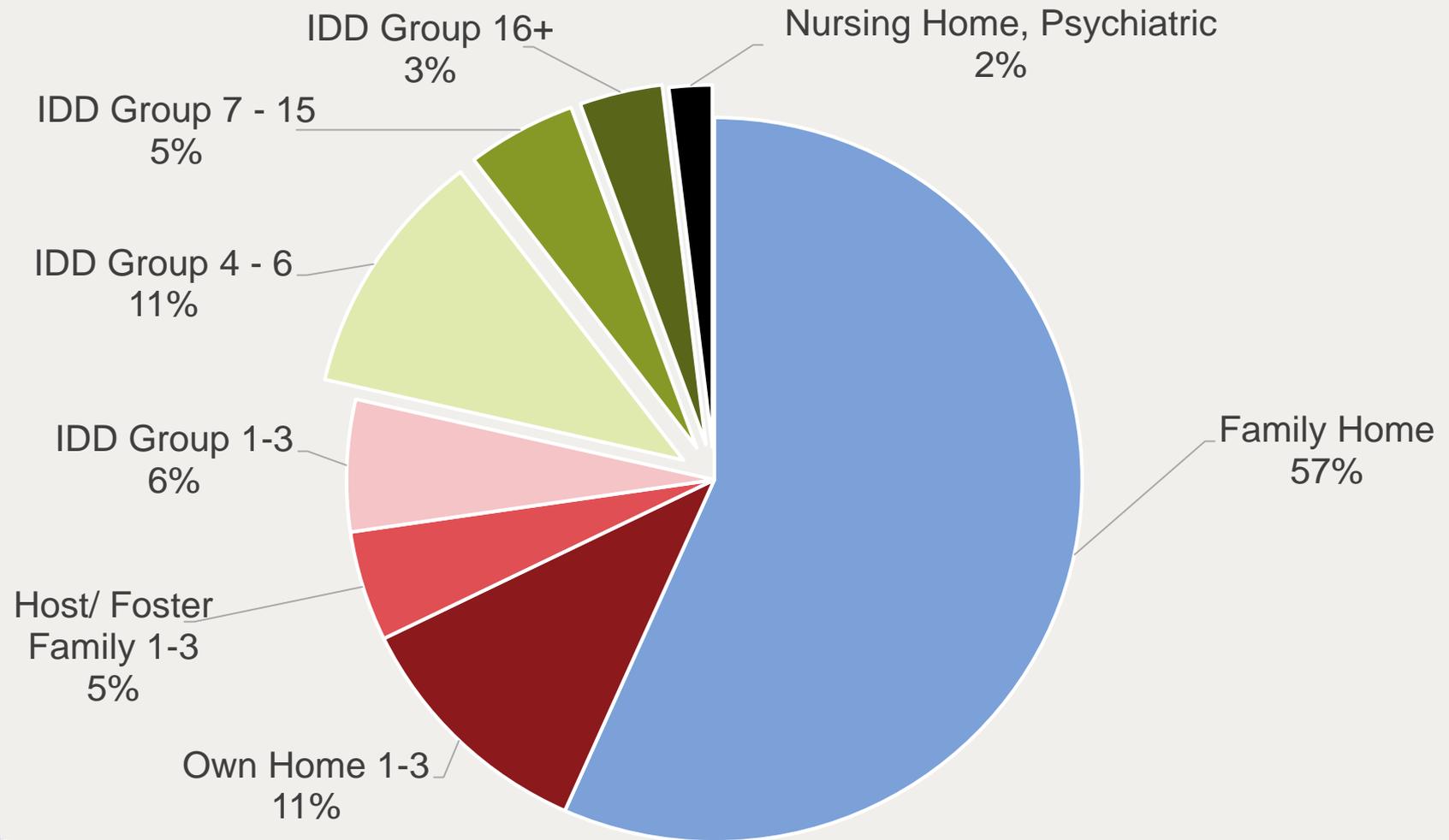
1.4 million (29%) are known to or served by State IDD agencies



Age of People in State IDD Systems 2014

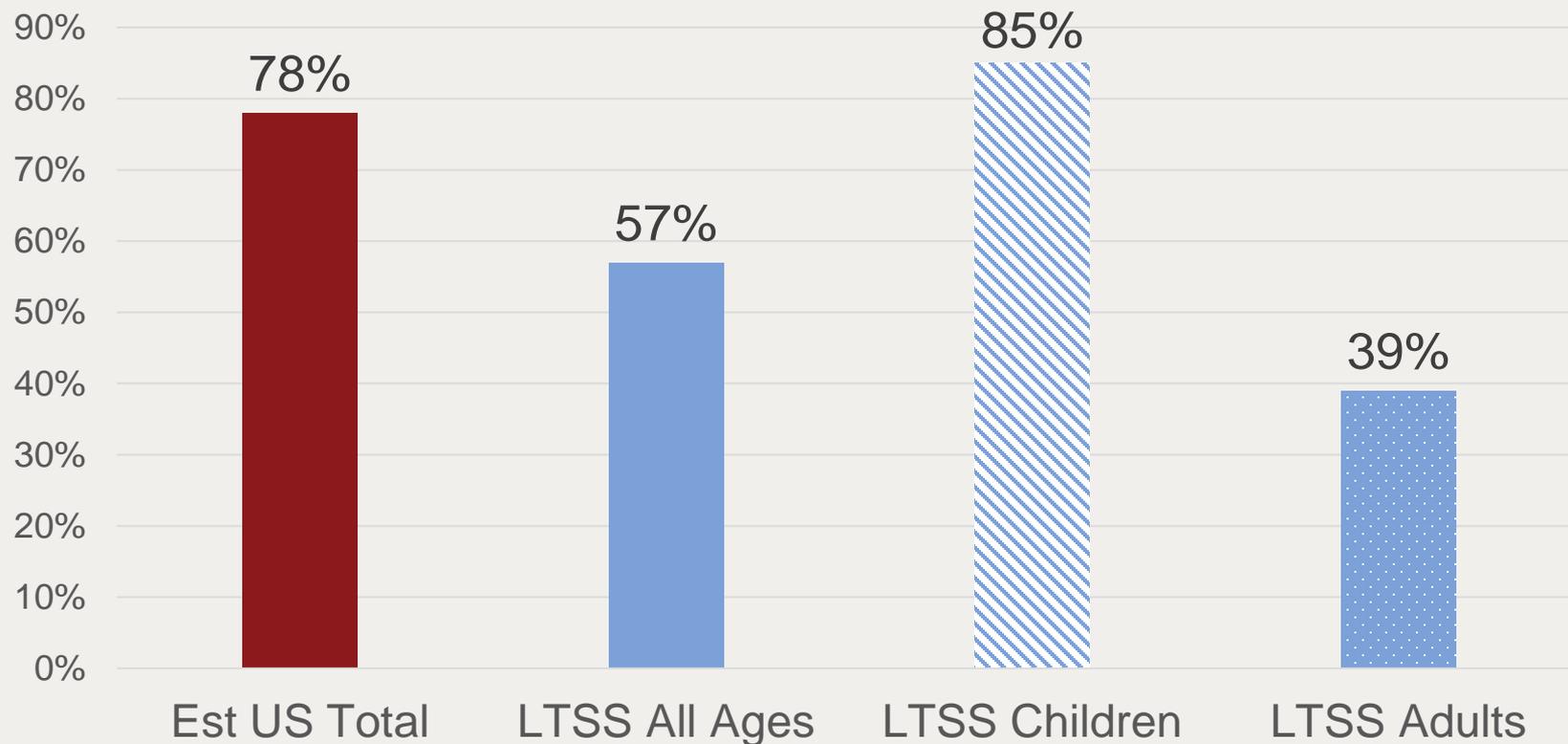


Living Arrangements of Service Recipients in 2014

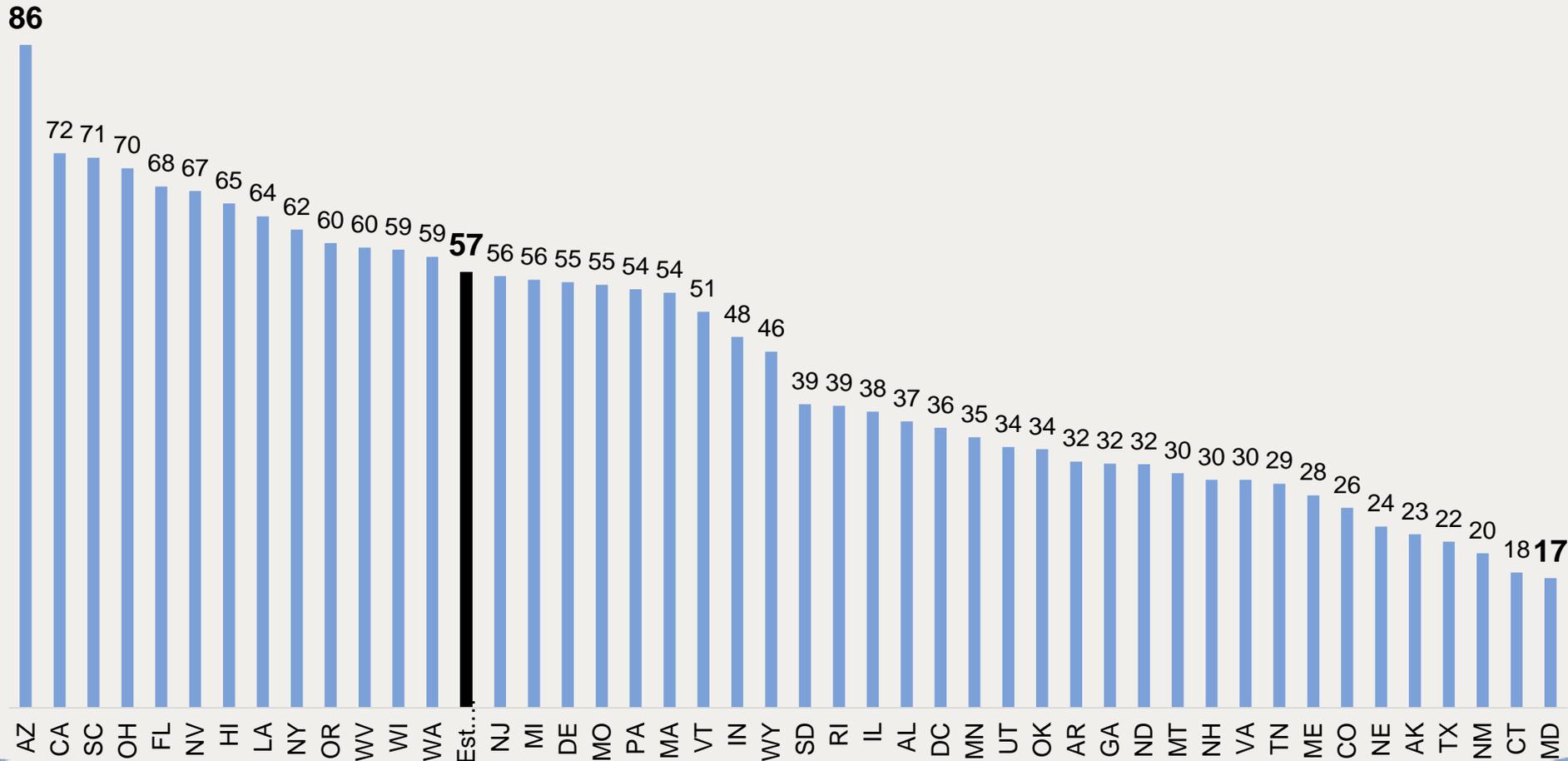




Percent of People with IDD Living With a Family Member in 2014



Percent Living with a Family Member by State in 2014



Differences that Matter

Operating Entity
(State vs Non-state)

Setting Type
(own home, family home host or family foster homes, group homes or institutions)

Age
0-21 vs 22+

Funding Authority
(Medicaid Waiver, Medicaid State Plan, Other)

Setting Size
(1-3, 4-6, 7-15, 16+)
How many people? How many settings?

Funding Authority (Flavors of Waivers)

Medicaid HCBS Waiver

- 1115 Demonstration waivers
- 1915(a) – Voluntary managed care
- 1915(b) – Managed care
- 1915(b/c) – Managed care
- 1915 (c) Waivers
 - Comprehensive Waivers
 - Capped Supports Waivers
 - Model Waivers (e.g., for people with special healthcare needs)
 - Autism waivers
- Other Medicaid Waiver Authorities

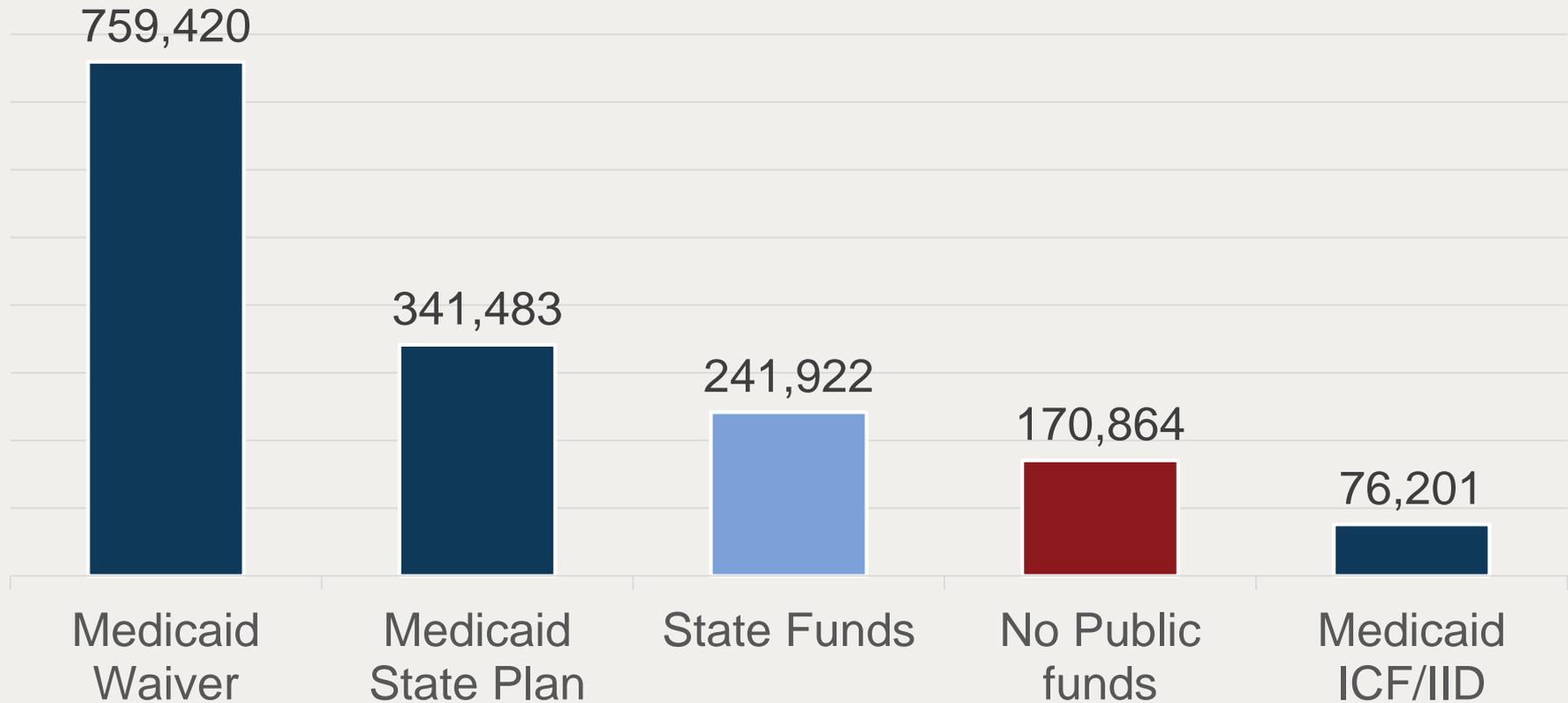
Medicaid State Plan

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

Non-Medicaid funded

- State IDD Agency
- Other State Agency
- Other

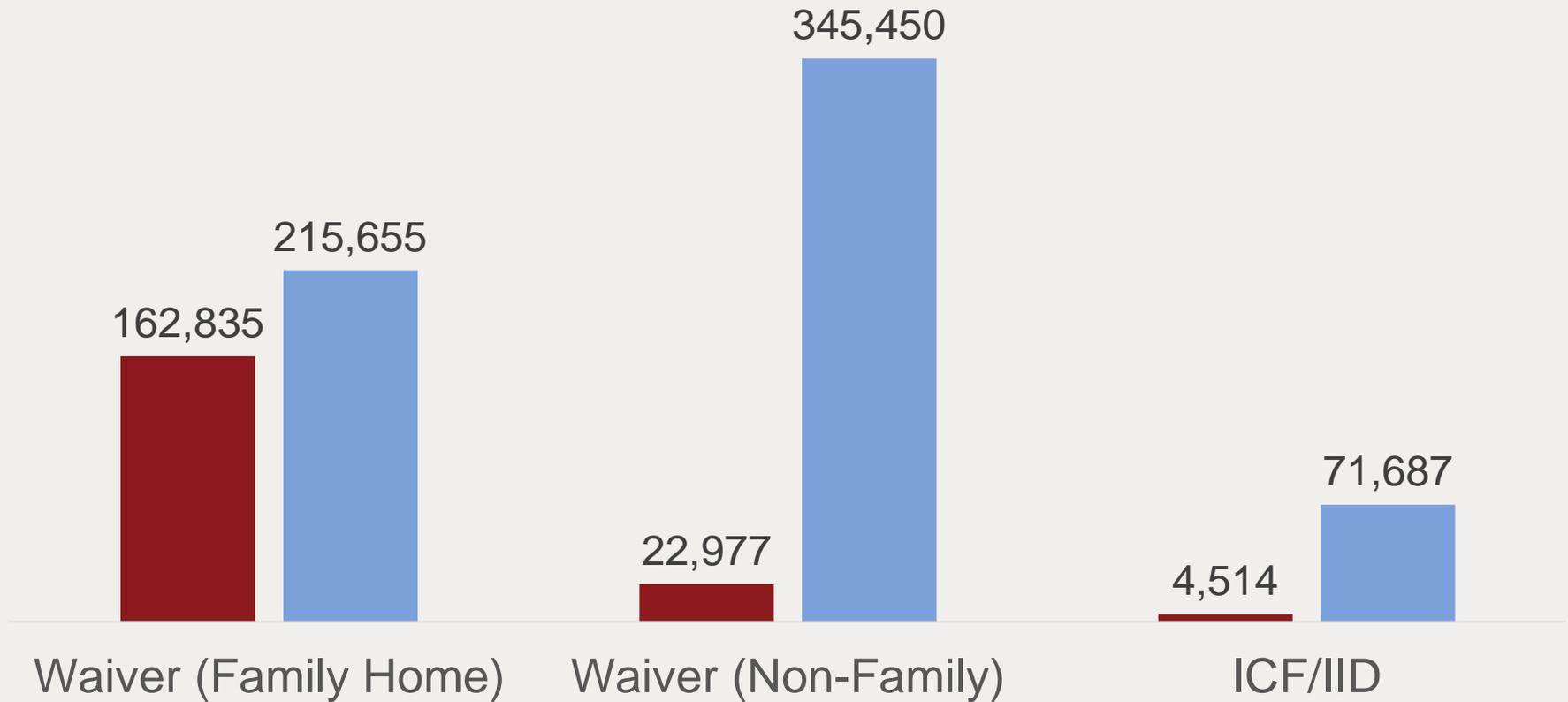
Number of People with IDD by Funding Authority 2014



Includes duplicate counts. State plan and state funds can be combined with other funding authorities

Medicaid Recipients by Age, Residence and Funding Authority 2014

■ 21 years or younger ■ 22 years or older



Average Annual Per Person Expenditures by Age, Residence, and Funding Authority FY 2014

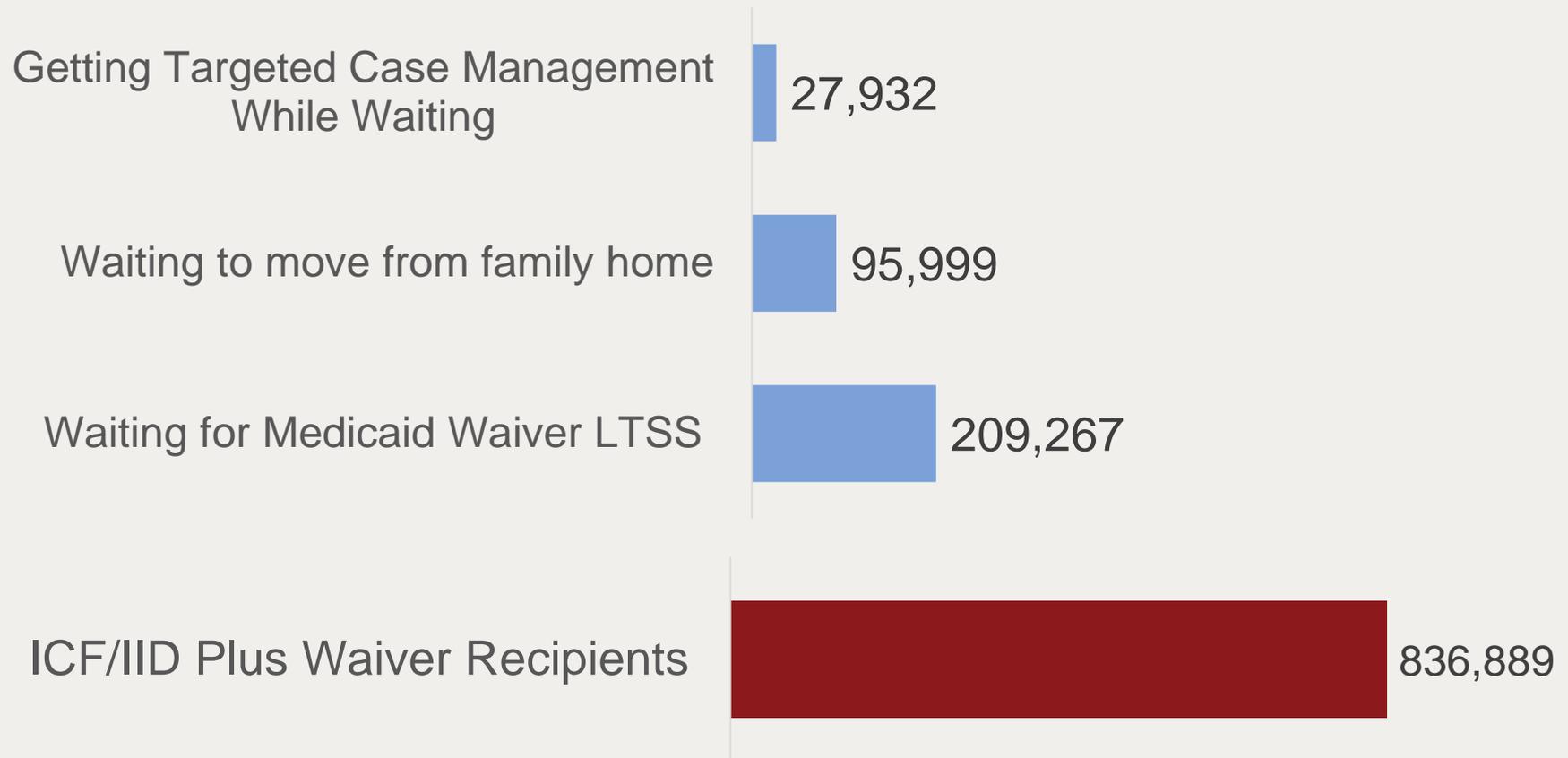
■ 21 years or younger ■ 22 years or older



Only states reporting expenditures for both children and adults are represented here (45 states for Waiver, and 25 states for ICF/IID).



Medicaid Waiting Lists and Utilization FY 2014



Longitudinal Trends and Associated Milestones

Milestones

1965

- Medicaid Program

1971

- Medicaid ICF/IID

1975

- PL 94-142 Individuals with Disabilities Education Act

1981

- Medicaid Home and Community Based Waiver

1990

- Americans with Disabilities Act

1999

- US Supreme Court Olmstead Decision

2010

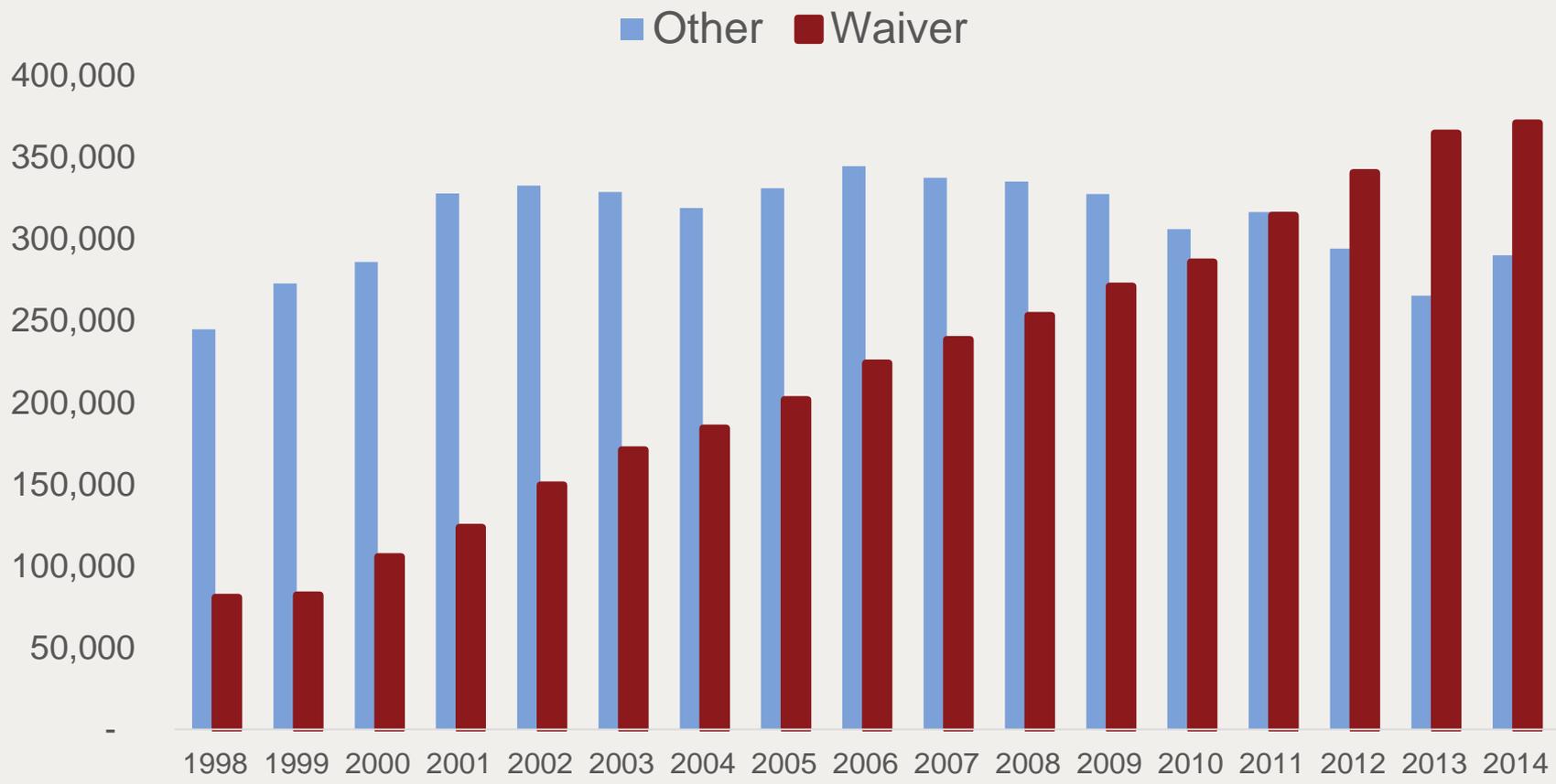
- Affordable Care Act (1915i, 1915j, 1915k)

2014

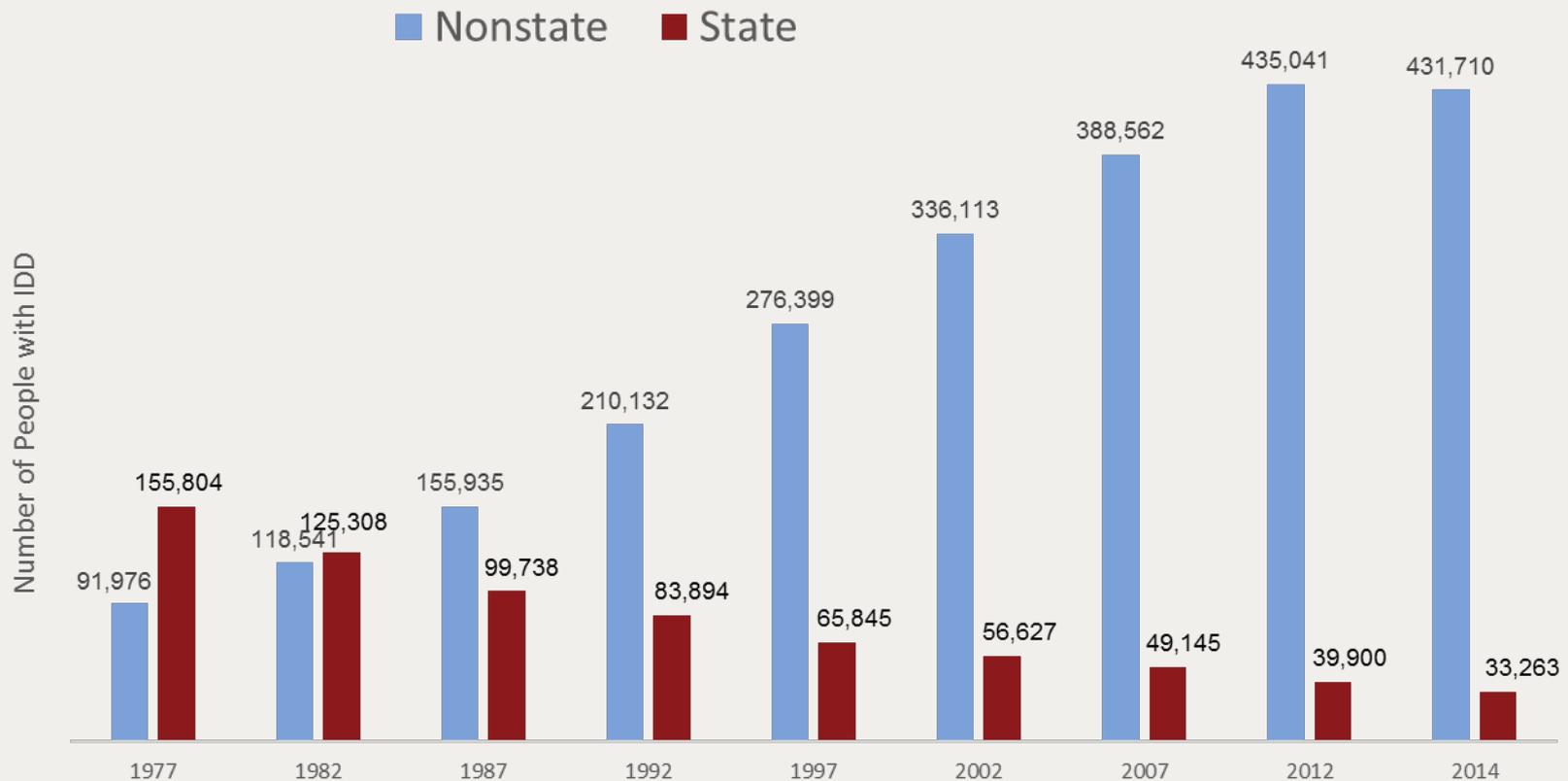
- Home and Community Based Waiver Rule



Funding Source for LTSS Recipients Living with Family 1998 to 2014



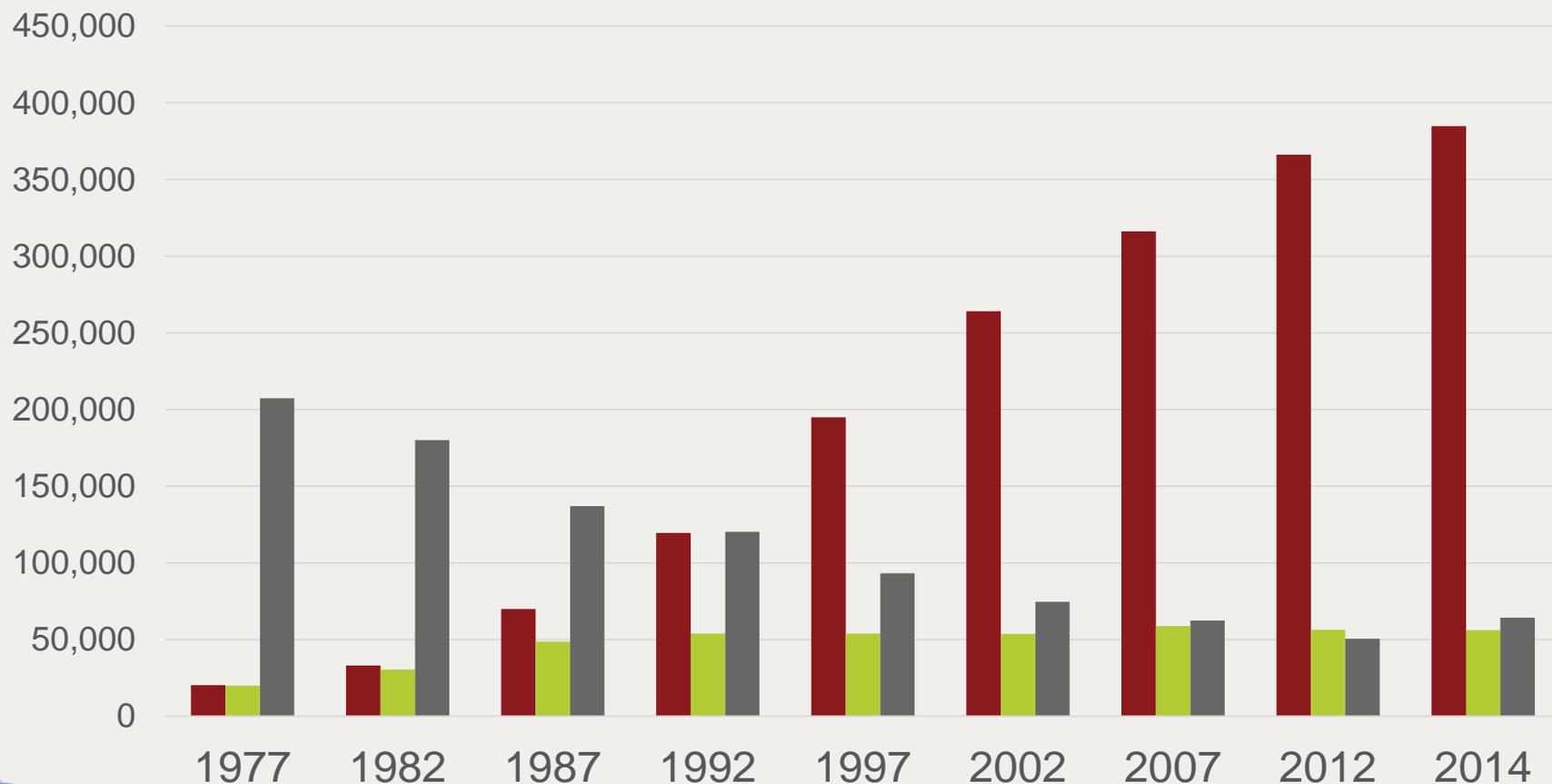
LTSS Recipients in Non-Family Settings by Operating Entity 1977 to 2014





People in Non-Family Residential Settings of Different Sizes 1977 to 2014

■ 1-6 ■ 7-15 ■ 16+



Medicaid Funded LTSS for People with IDD in the US States 1977 to 2013

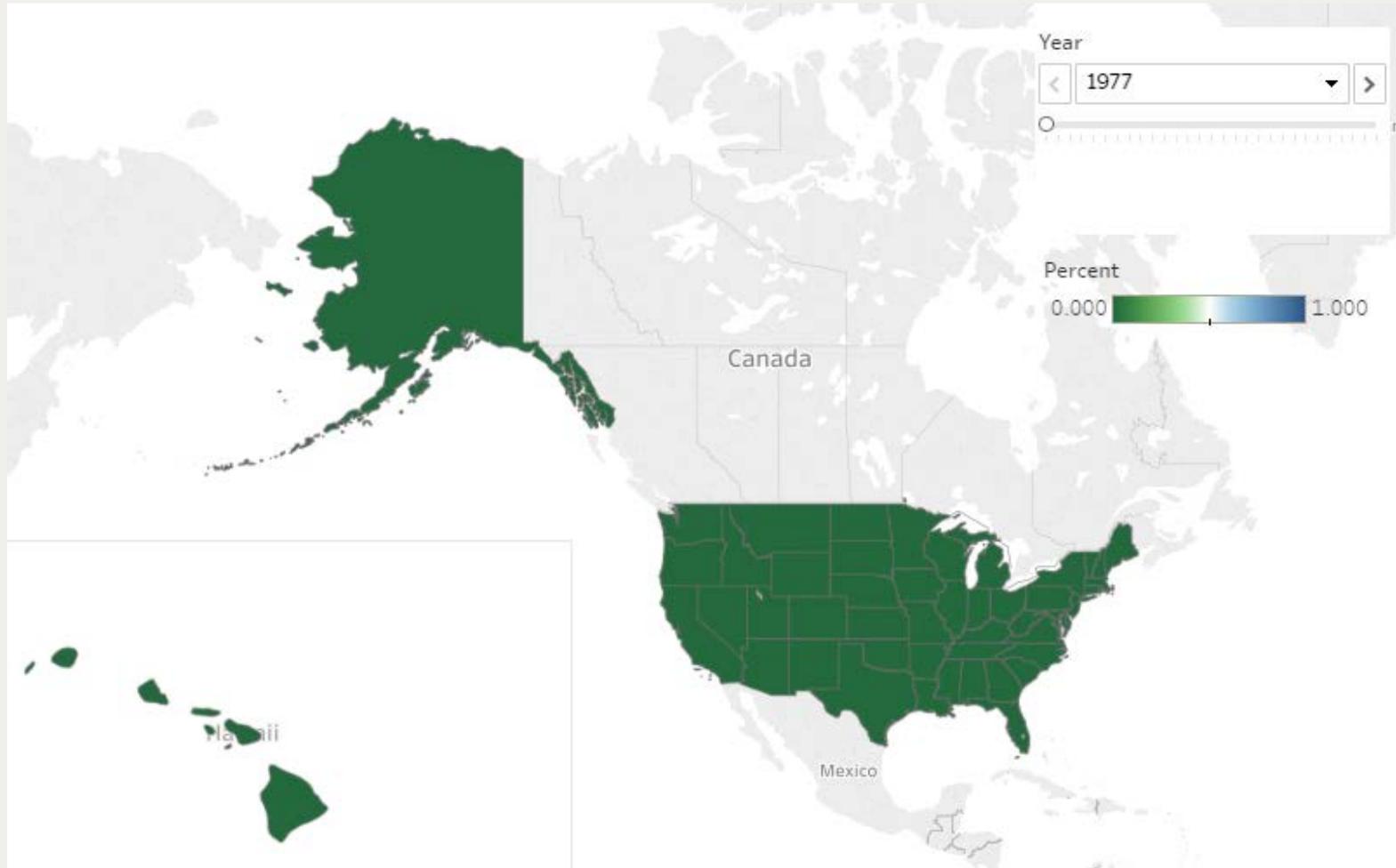
Moving From

Intermediate Care Facilities
for Individuals with
Intellectual Disabilities
(Dark Green)

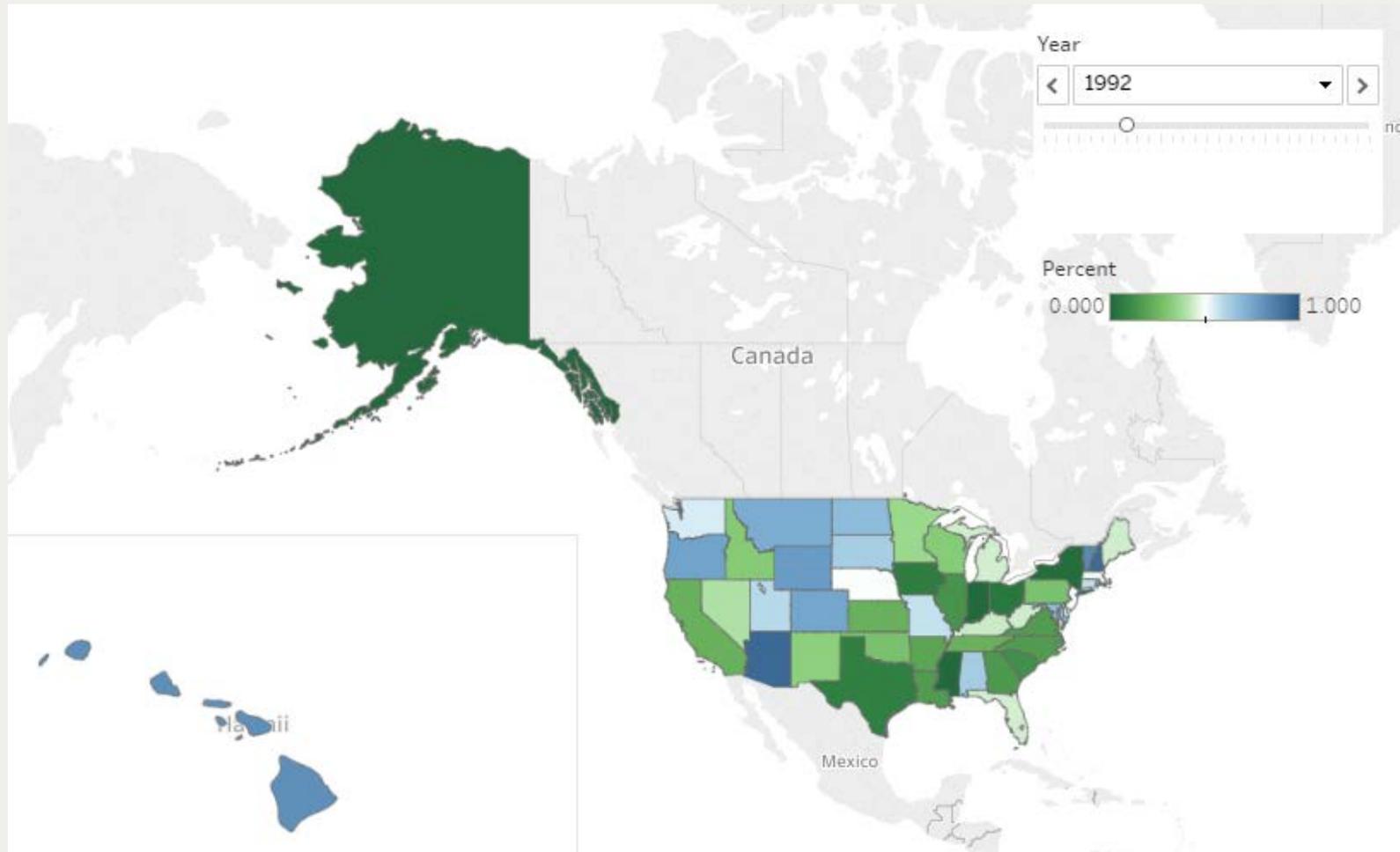
To

Home and Community
Based Waiver Services
(Dark Blue)

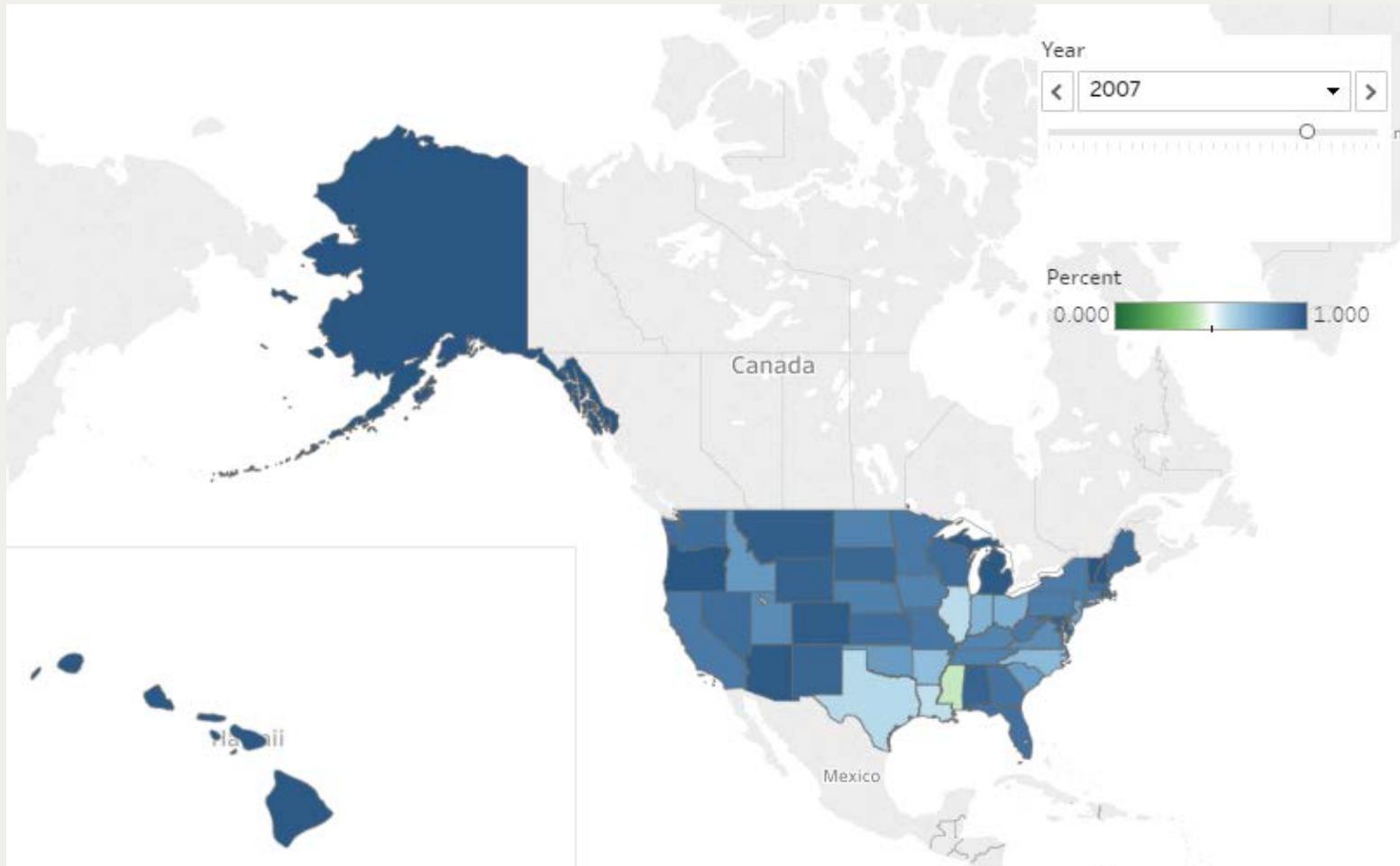
1977



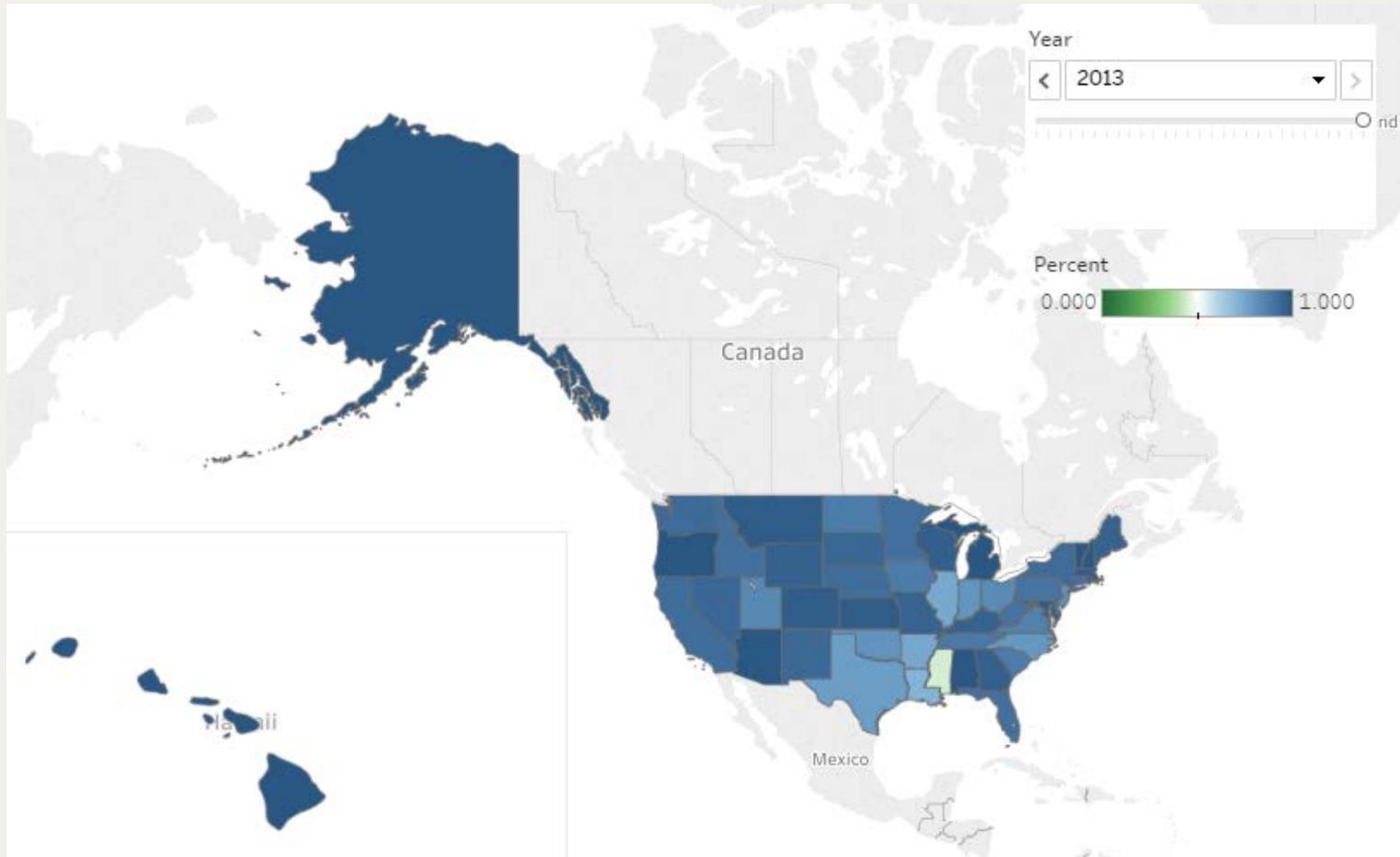
1992



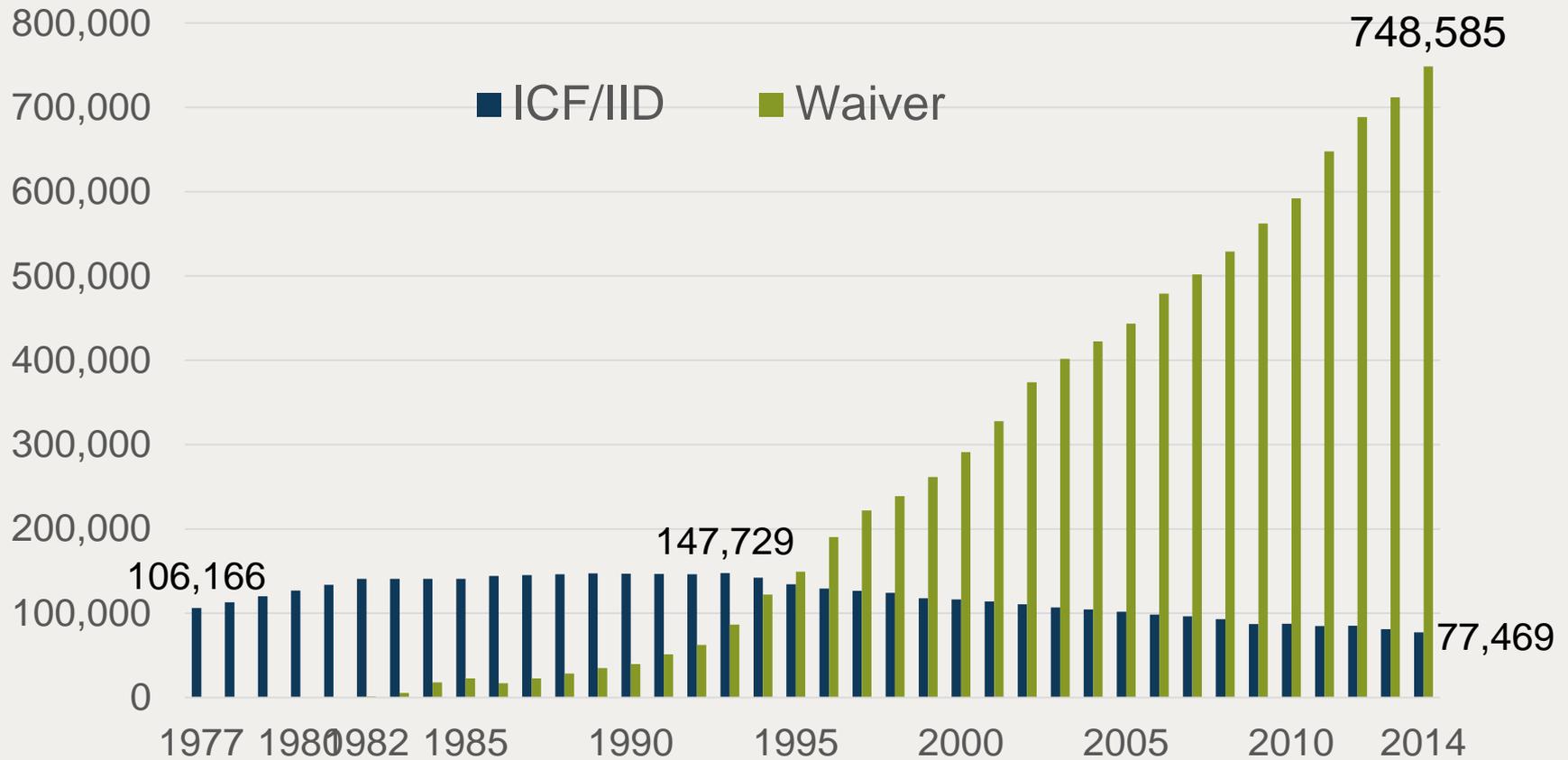
2007



2013

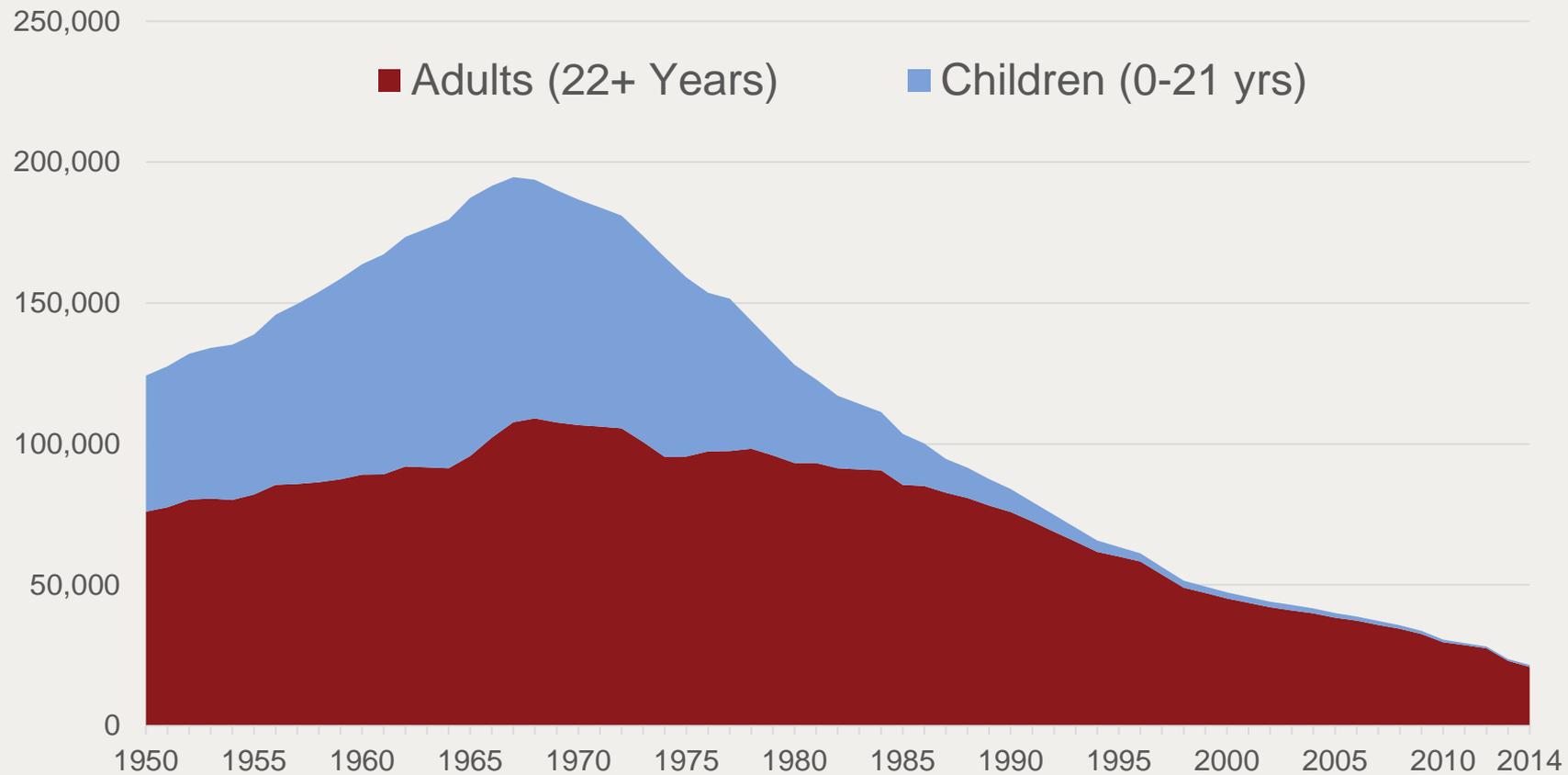


Medicaid LTSS Recipients with IDD 1977 to 2014

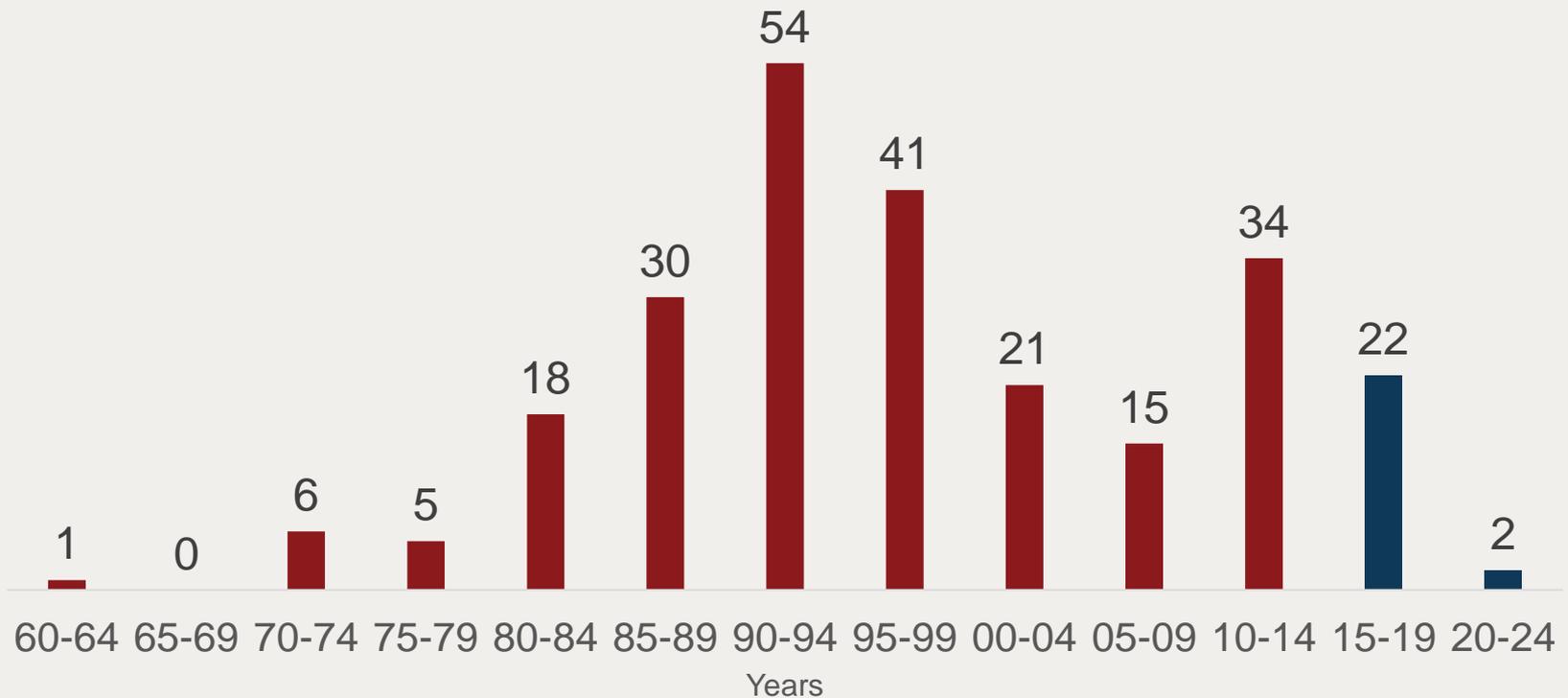




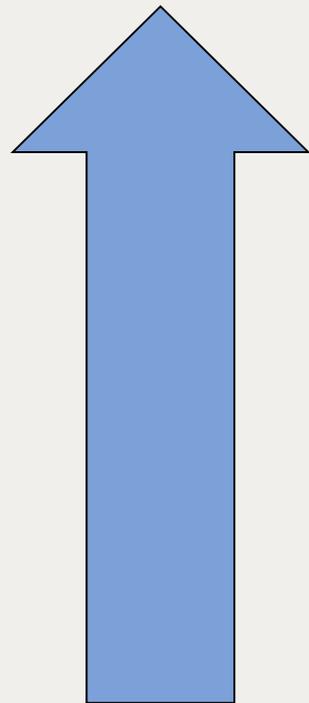
People with IDD in Large State Institutions 1950 to 2014



PRF Facility/ IDD Unit Closures and Projected Closures in 5-Year Intervals 1960 to 2024



People in Individualized Services Have Better Outcomes



- Family satisfaction
- Individual satisfaction
- Choice
- Skills
- Cost per person

FY 2014 RISP State Profile

United States

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

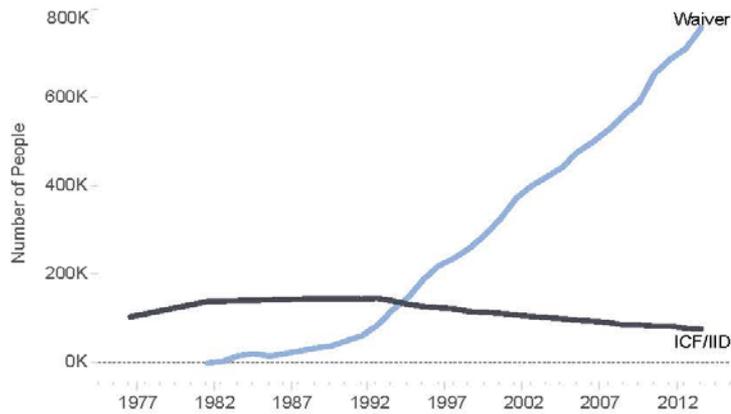


Figure 2: 2014 Medicaid Spending Per Person

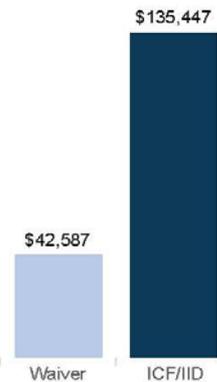


Figure 3: Residence Size and Type on June 30, 2014

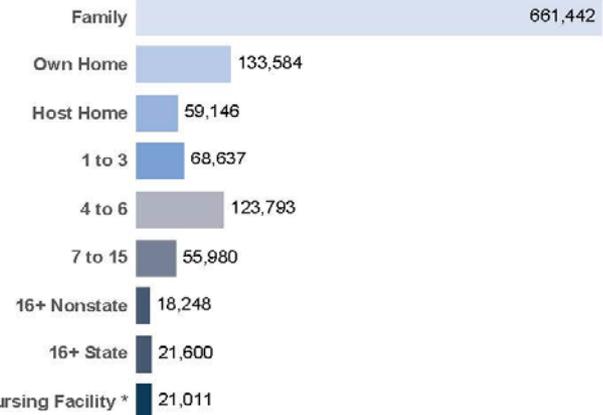


Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

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
	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 FY 2014 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).

What do the data tell us?

- LTSS for people with IDD are dramatically different today than they were 50 years ago and they continue to change.
- There are tremendous differences between states in how IDD services are designed and delivered. People in some states are much more likely to have access to home and community based services that are tailored specifically for them and that support choice and control over those services

What do the data tell us?

- Only about 25% of all people with IDD get IDD LTSS and most of those live in the home of a family member.
- Deinstitutionalization has reduced the total number of people living in institutions serving 7 or more people to just 112,000 in 2014 but
 - 69,328 people still live in nonstate IDD facilities
 - 28,002 still live in state IDD facilities
 - 21,011 still live in nursing homes and
 - At least 2,613 live in psychiatric facilities

What do the data tell us?

- State differ in how LTSS are provided along the dimensions of
 - Type of operation (state or nonstate)
 - Funding authority (Medicaid Waiver, State Plan, ICF/IID)
 - Setting size
 - Type of living arrangement, and
 - Age
- Fair comparisons across states require an understanding of those differences
- These differences likely account for much of the variability across states in quality outcomes.

For More Information

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