

LTSS Recipients with IDD in the US 2014

National HCBS Data: In What Directions do the Data Point Us
AUCD 2016 Conference Washington DC
December 6, 2016

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Purpose

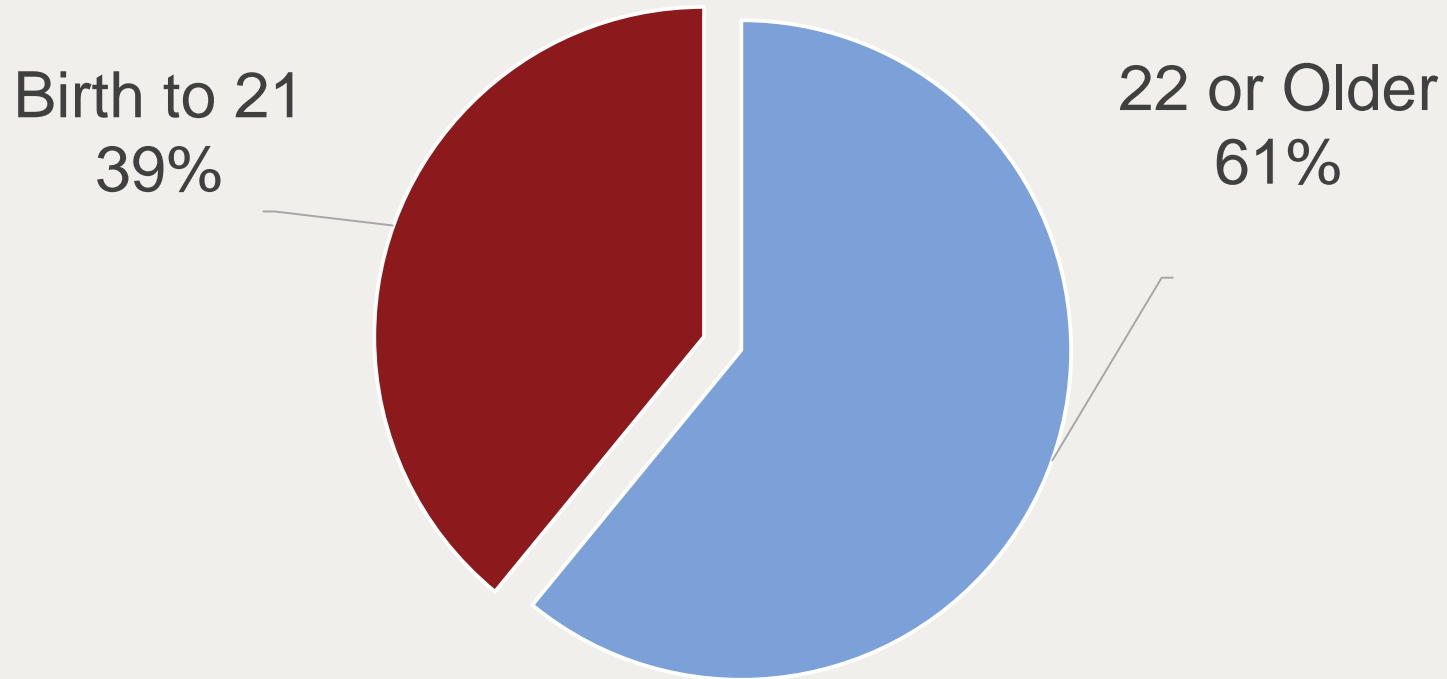
- Track status and trends in deinstitutionalization and community residential supports and services
 - Nationally
 - State-by-state
- Used by federal and state policy makers, and advocates to:
 - Present national and state trends in LTSS to Congress, State Legislatures, Courts and other stakeholders
 - 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

People with IDD in the US in 2014

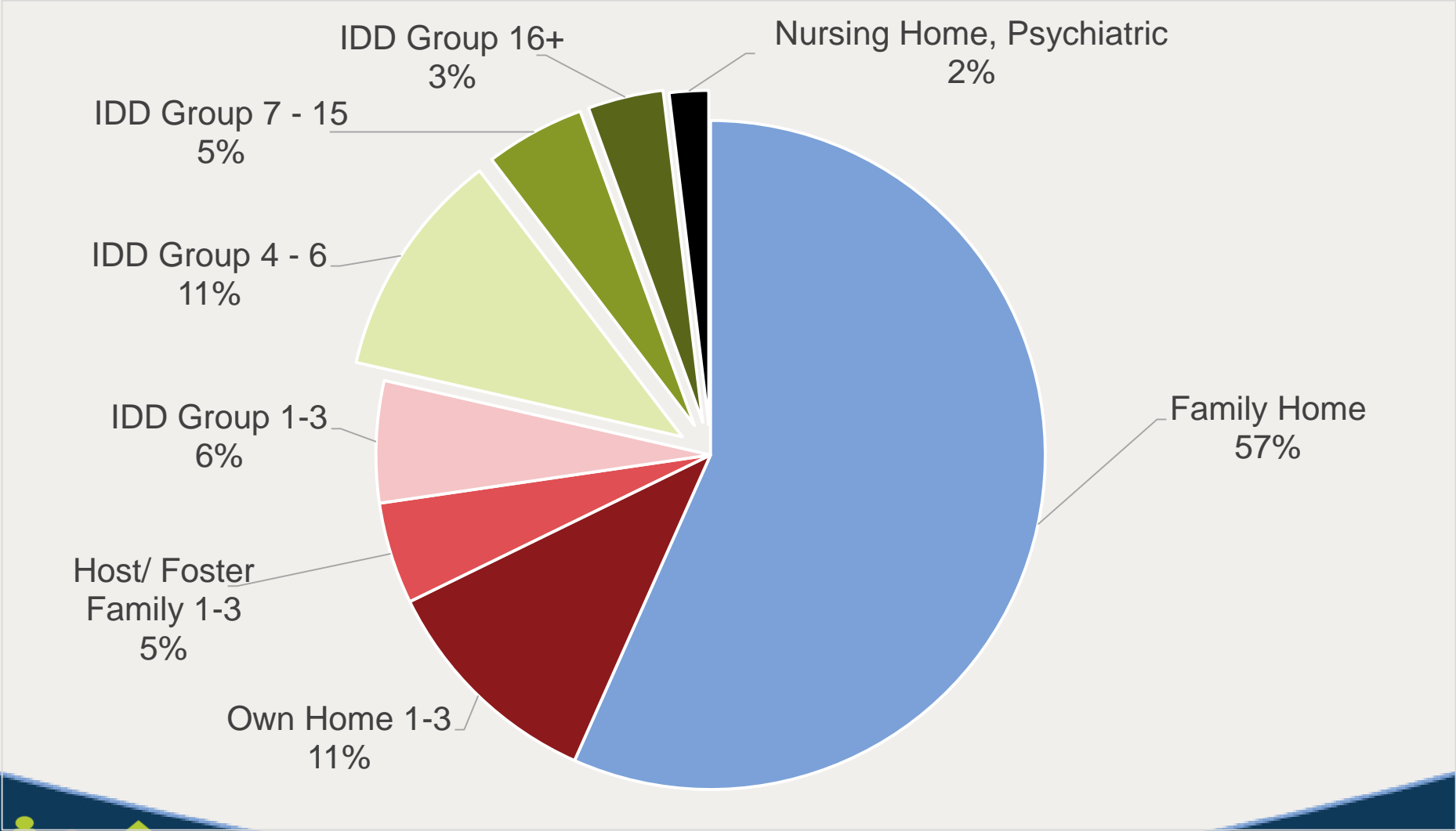


1,168,860 receive LTSS through State IDD agencies

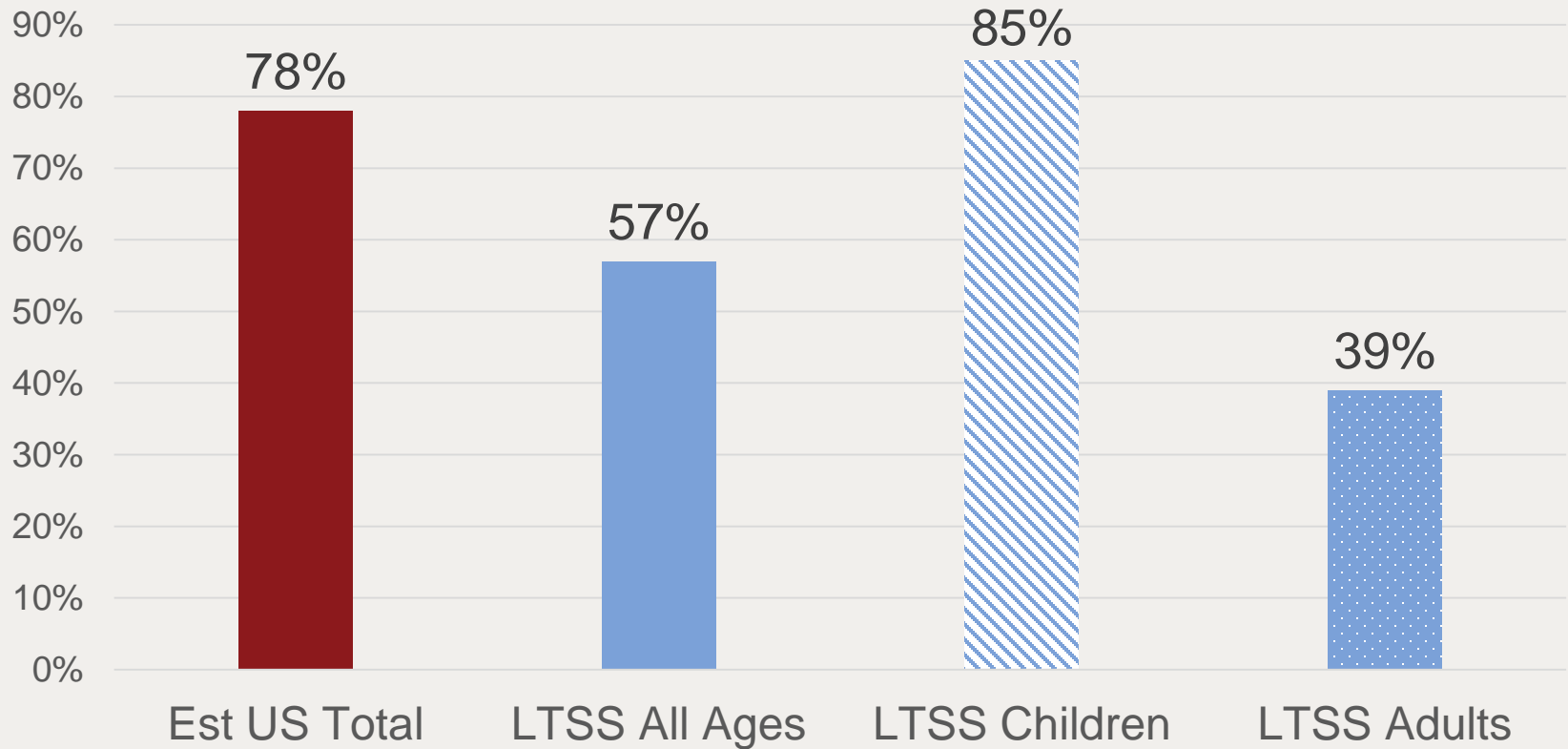
Age of People in State IDD Systems in 2014



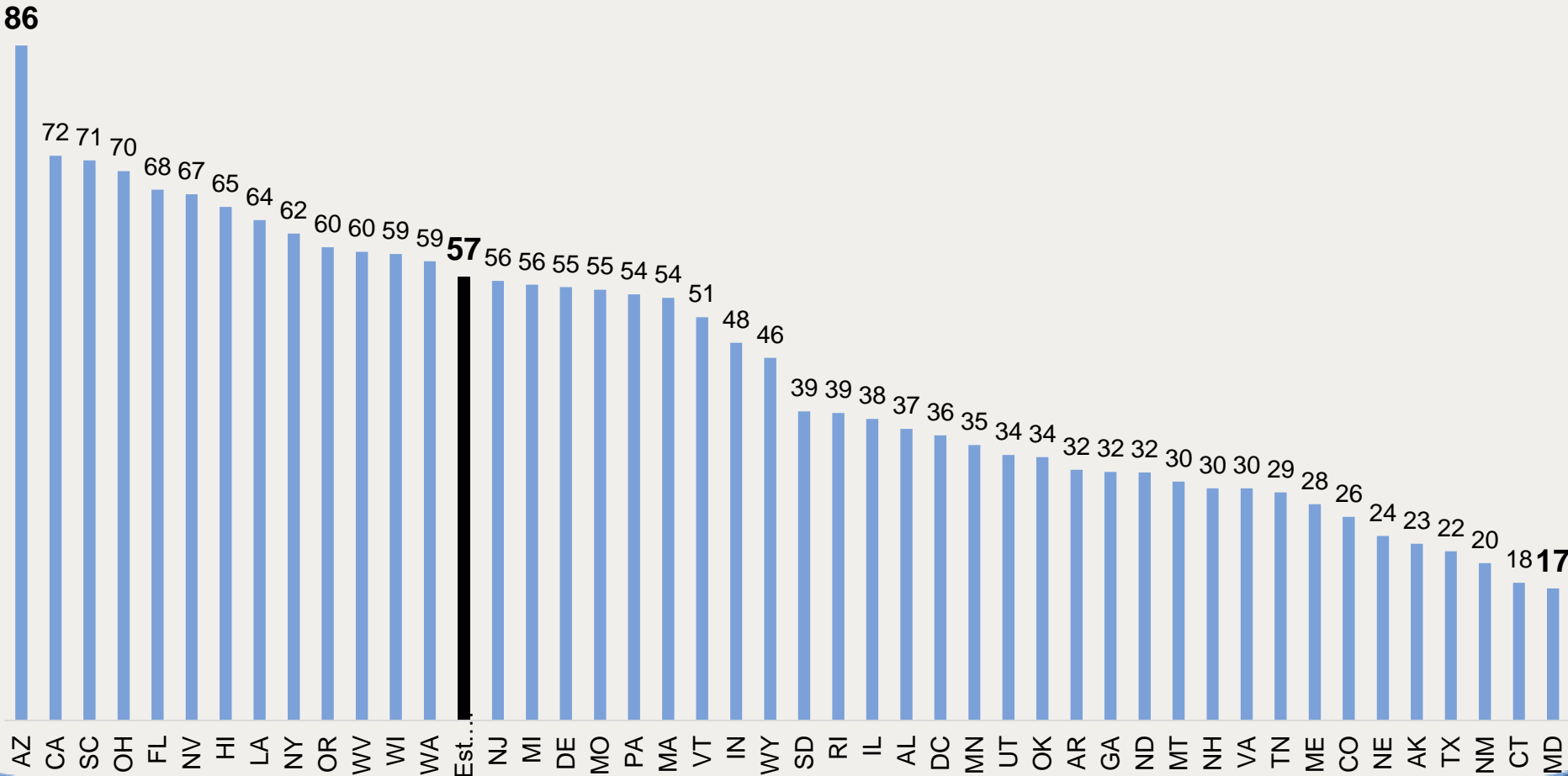
Living Arrangements of Service Recipients in 2014



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



Percent Living with a Family Member by State in 2014



RISP Dimensions

Operating Entity
(State vs Non-state)

Setting Type
(ICF/IID, group home, host home/foster, own home, family home, other)

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

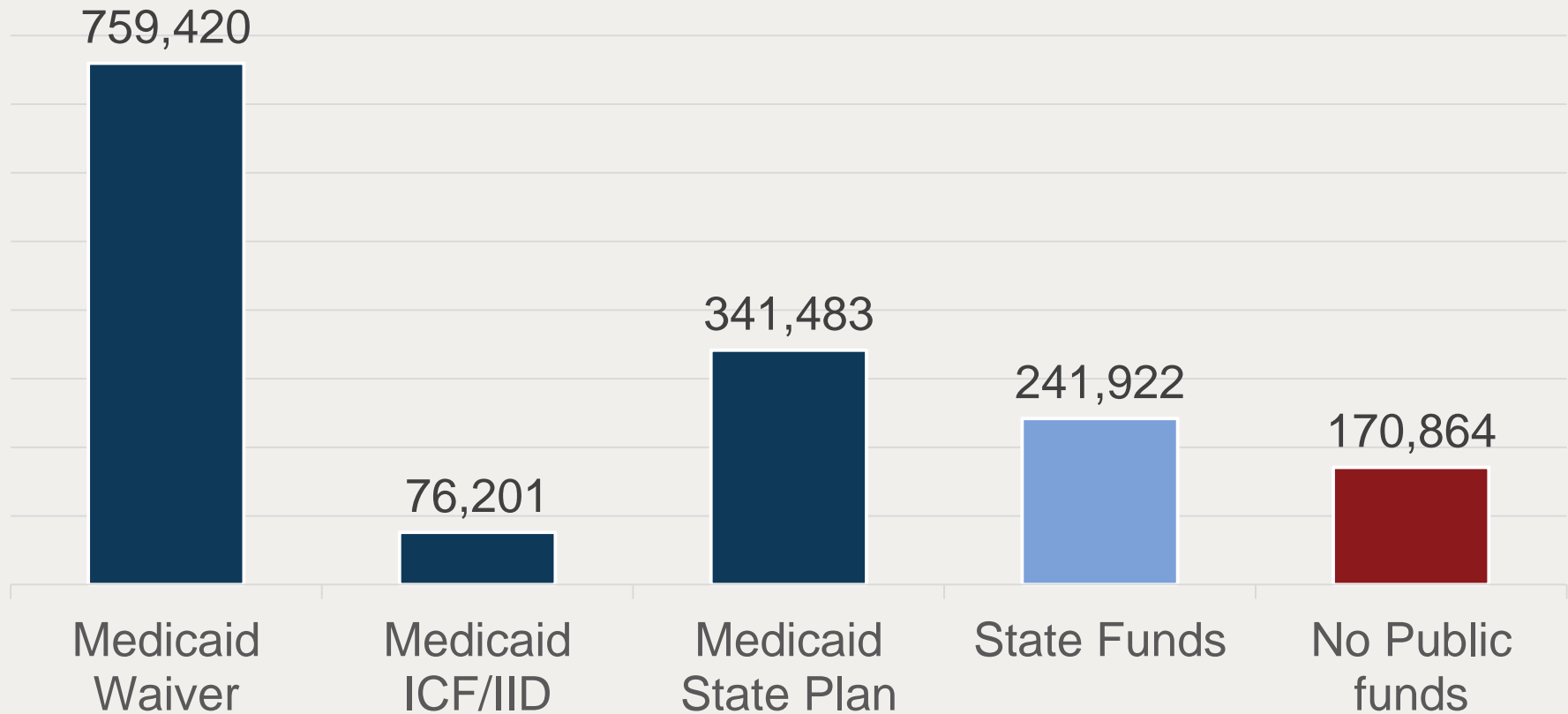
Medicaid State Plan

- 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

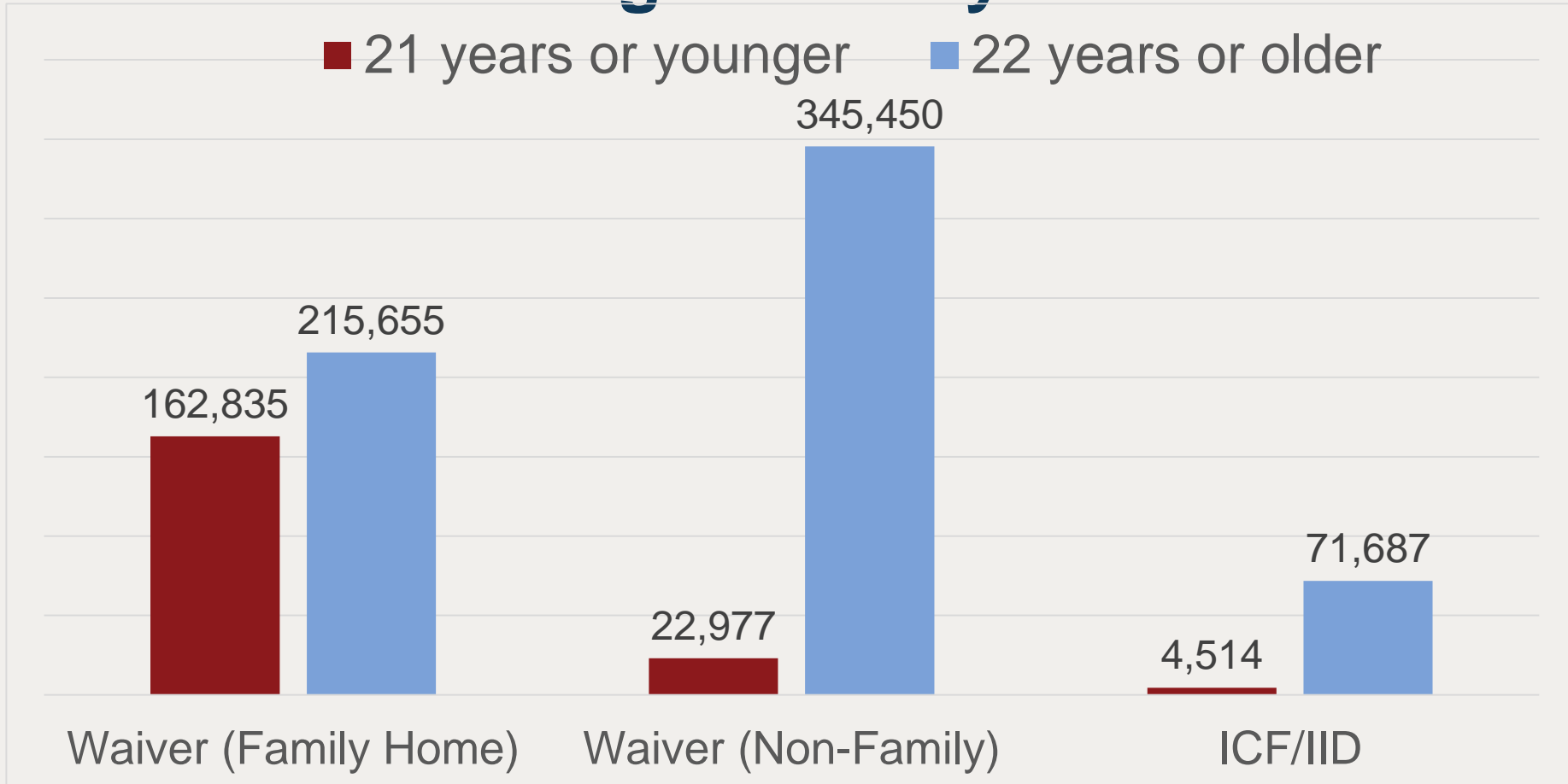
Number of People with IDD by Funding Authority 2014



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

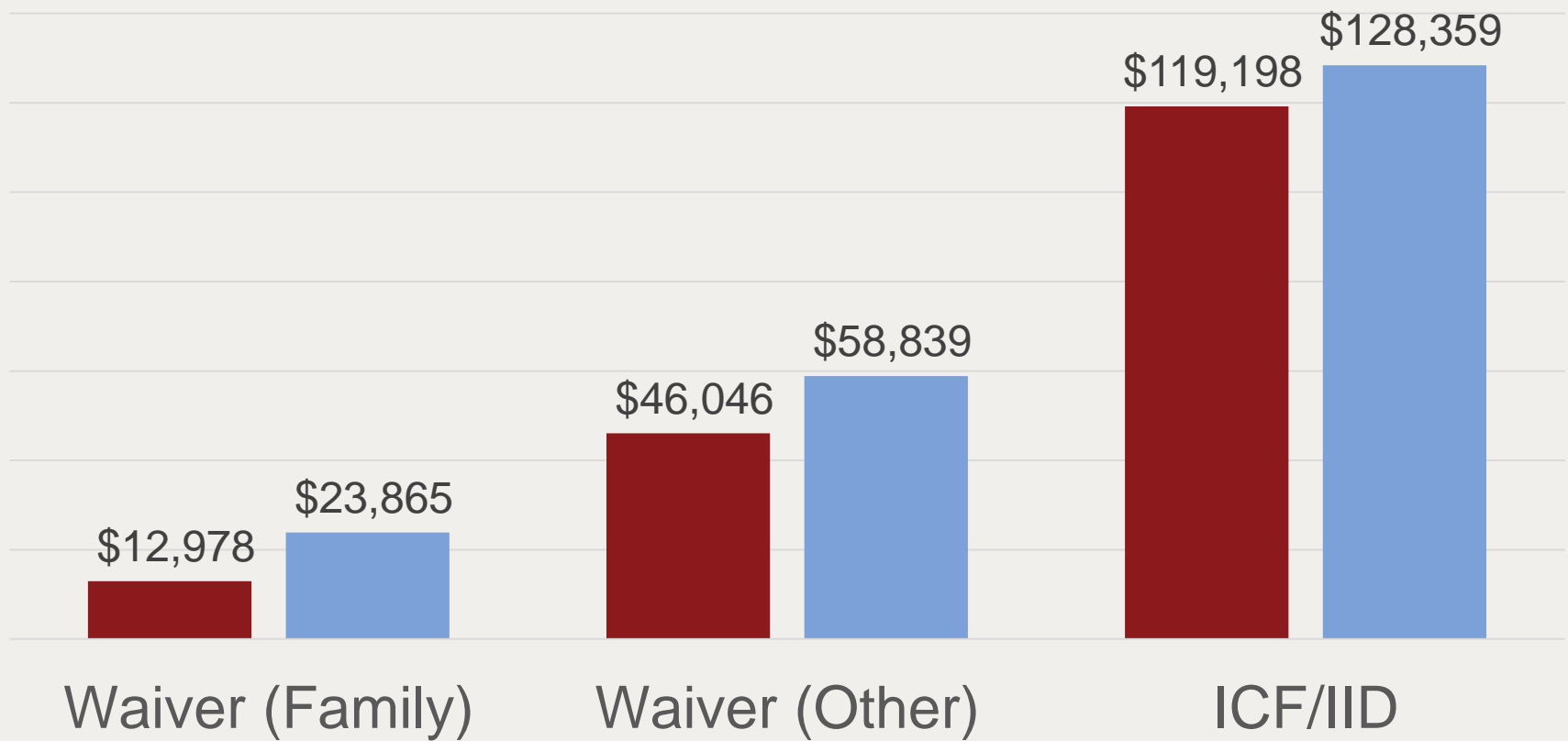
Medicaid Recipients by Age, Residence and Funding Authority 2014

■ 21 years or younger ■ 22 years or older

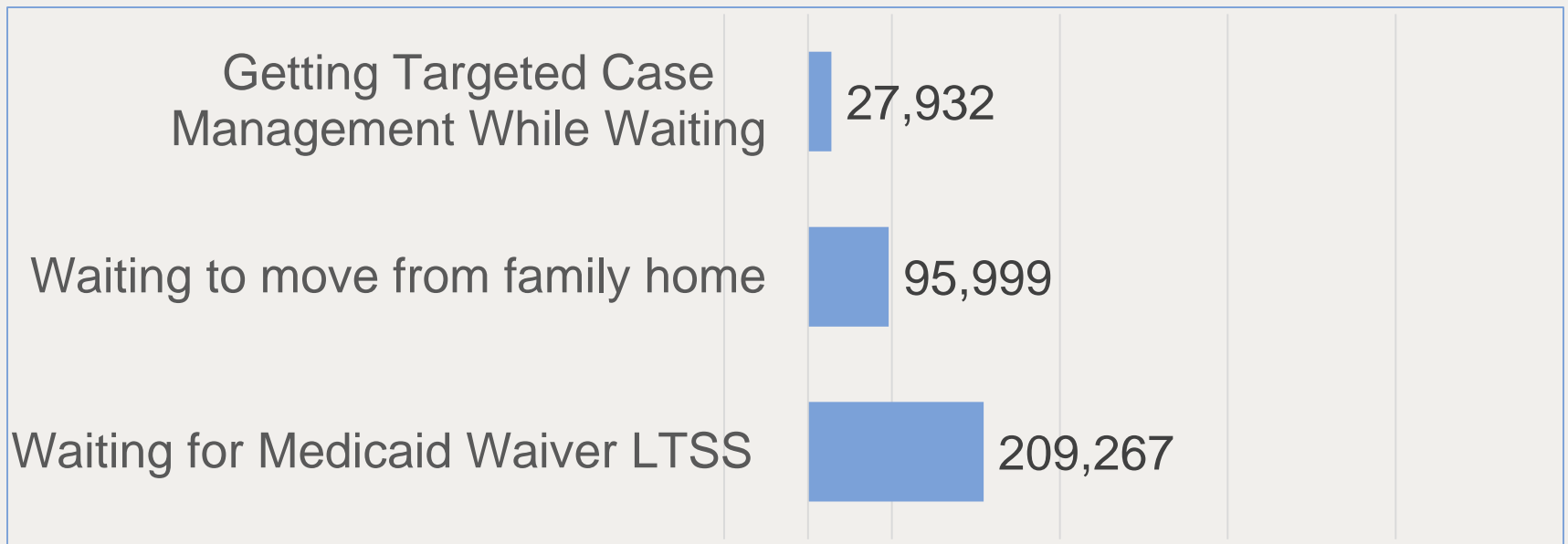


Average Annual Per Person Expenditures by Age, Residence, and Funding Authority FY 2014

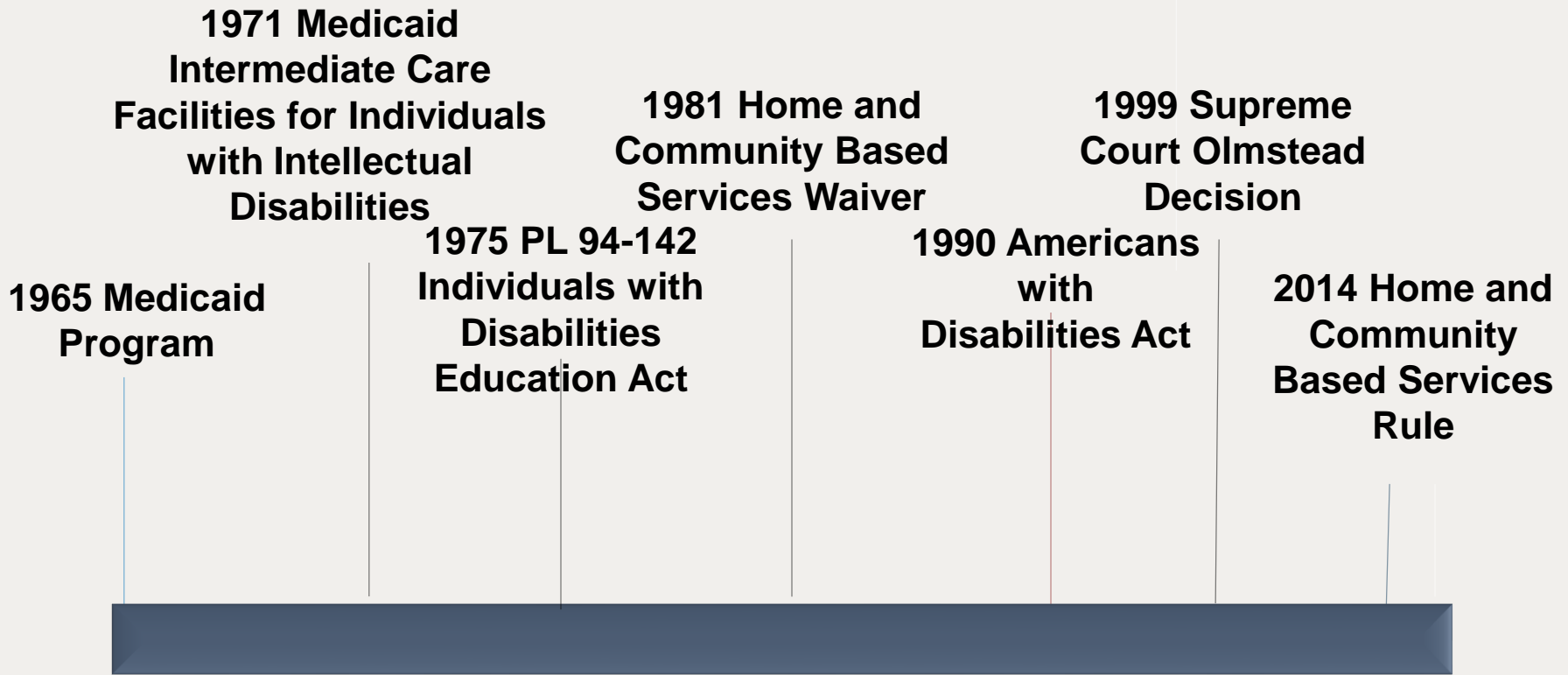
■ 21 years or younger ■ 22 years or older



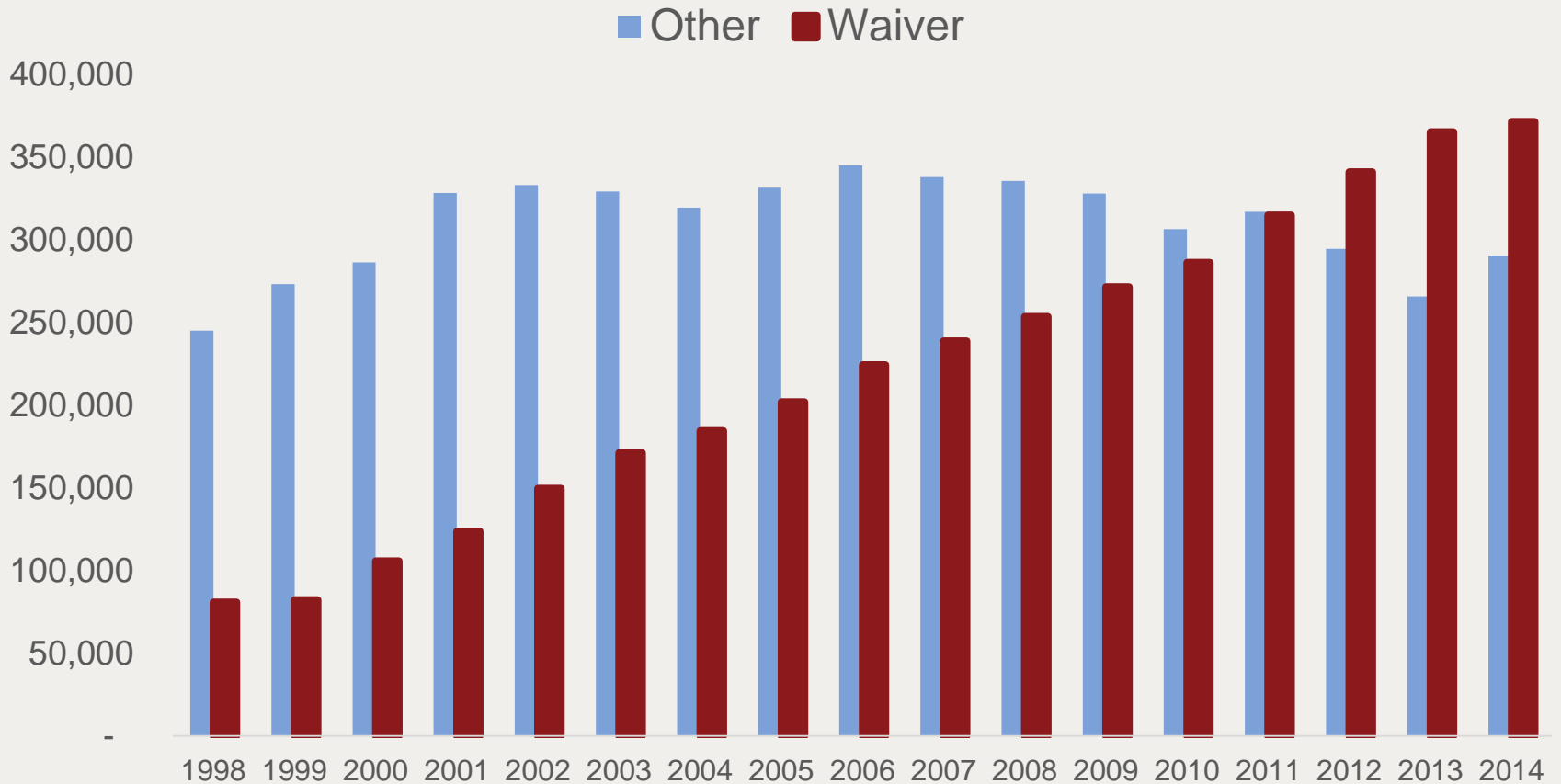
Medicaid Waiting Lists and Utilization FY 2014



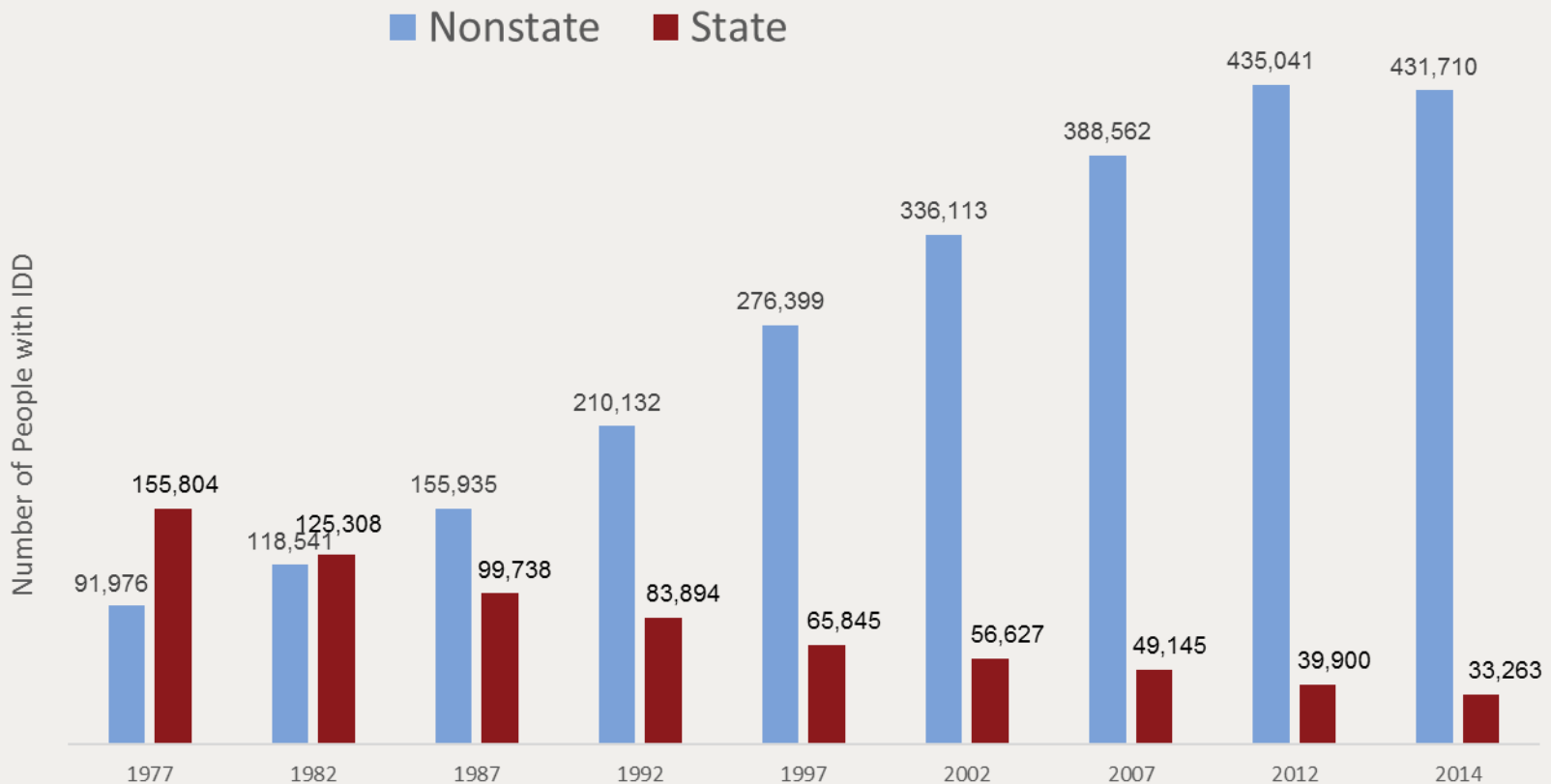
Milestones



Funding Source for LTSS Recipients Living with Family 1998 to 2014

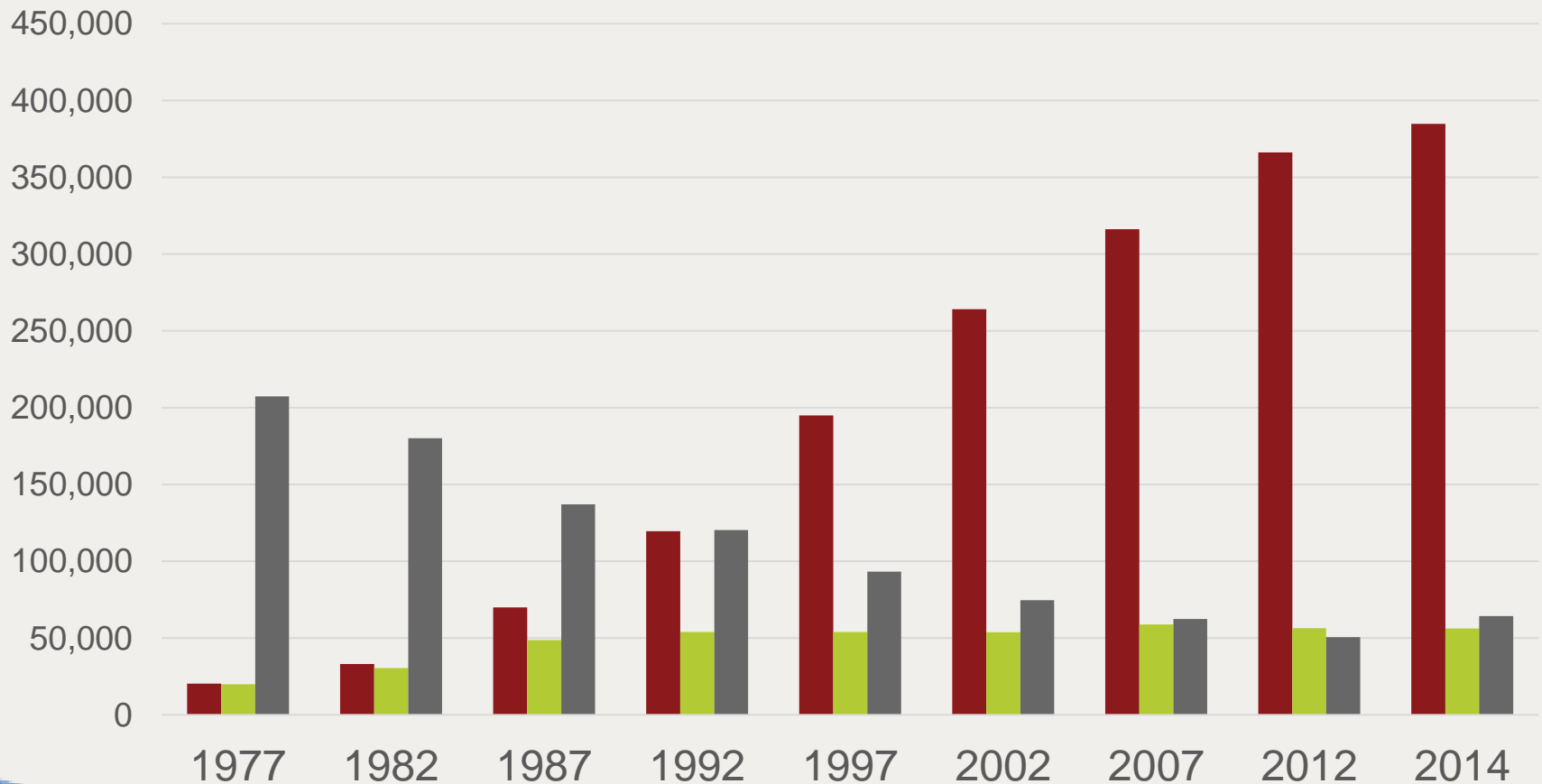


LTSS Recipients in Non-Family Settings by Operating Entity 1977 to 2014



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

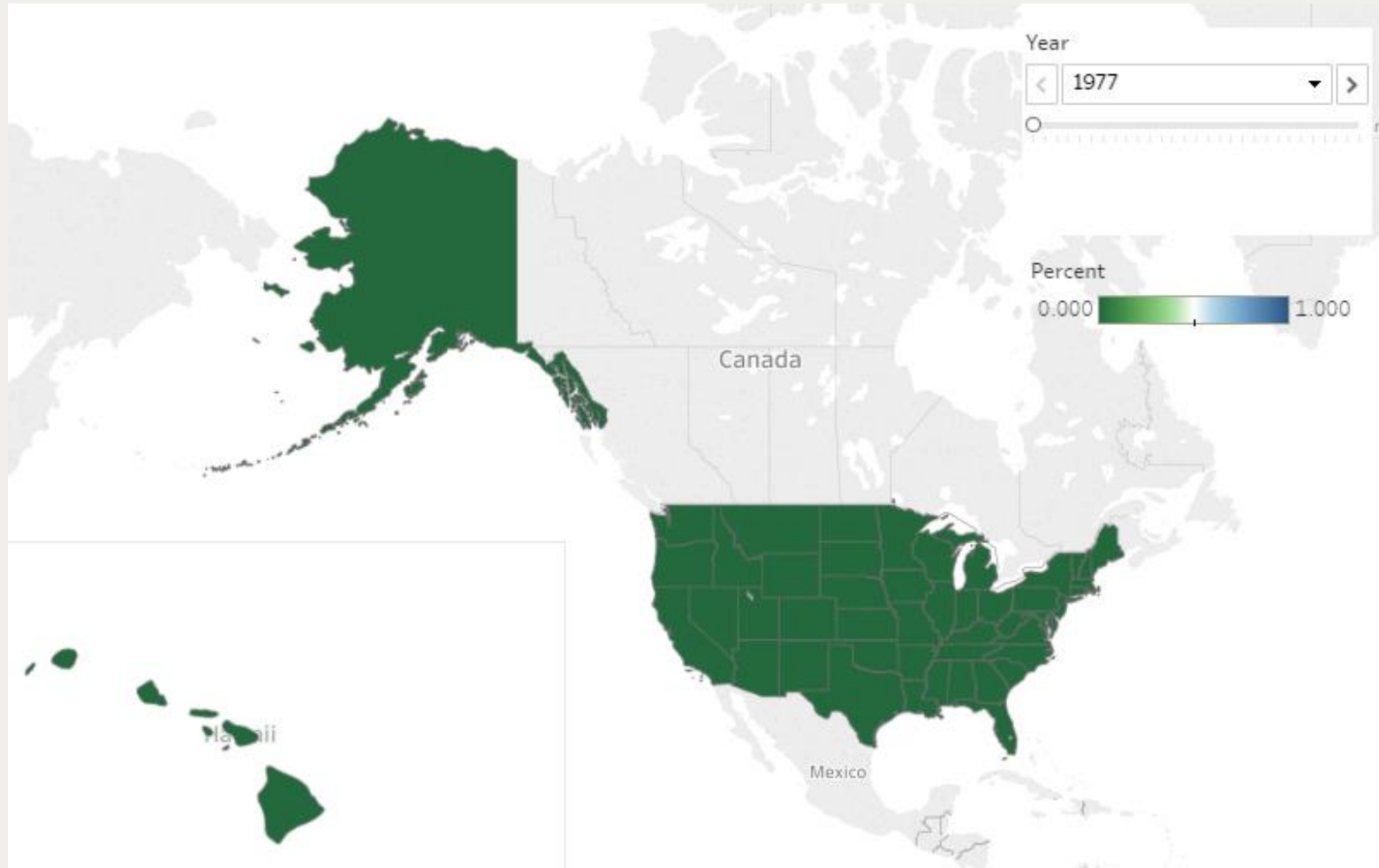
(Dark Green)

To

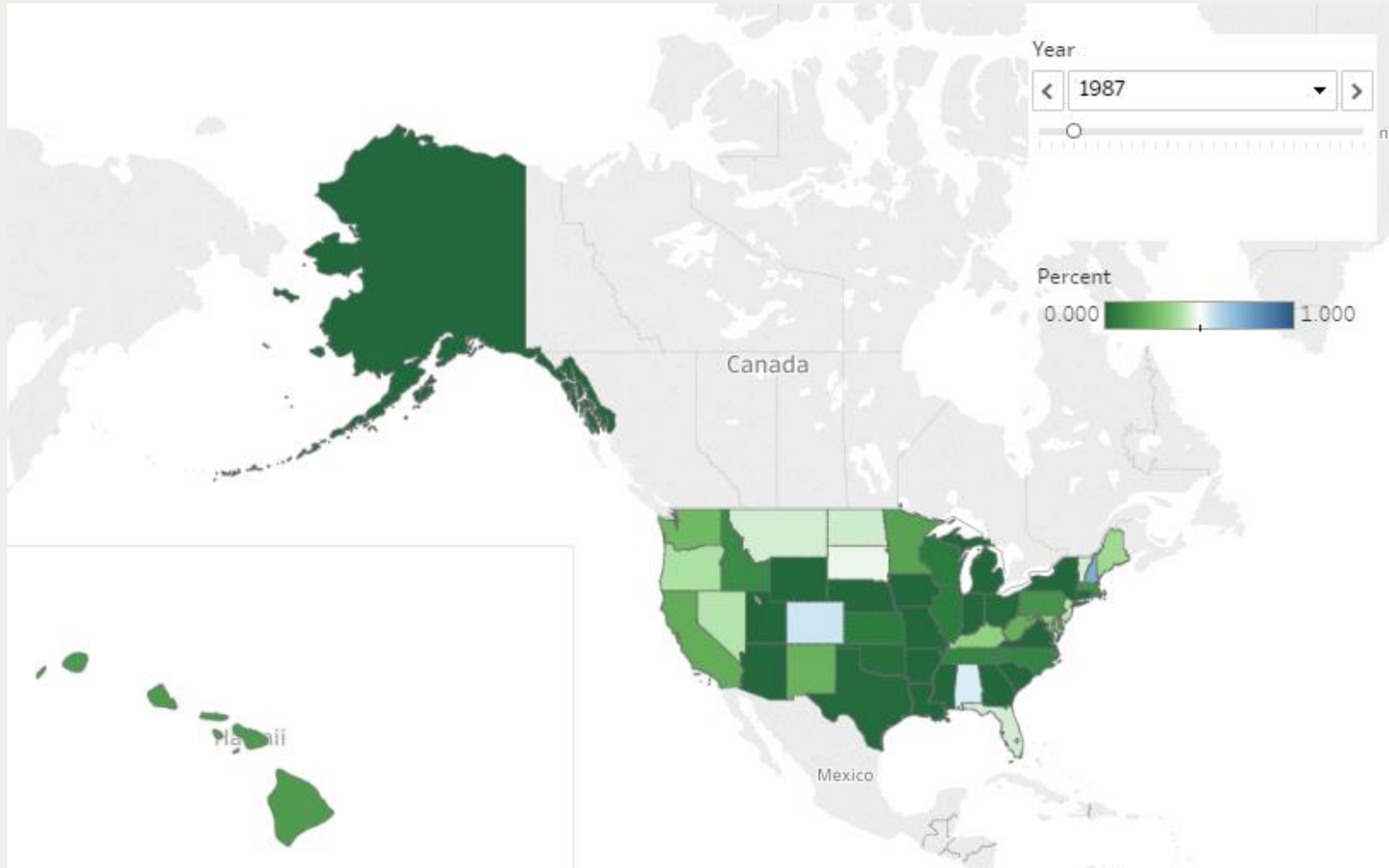
Home and Community
Based Waiver Services

(Dark Blue)

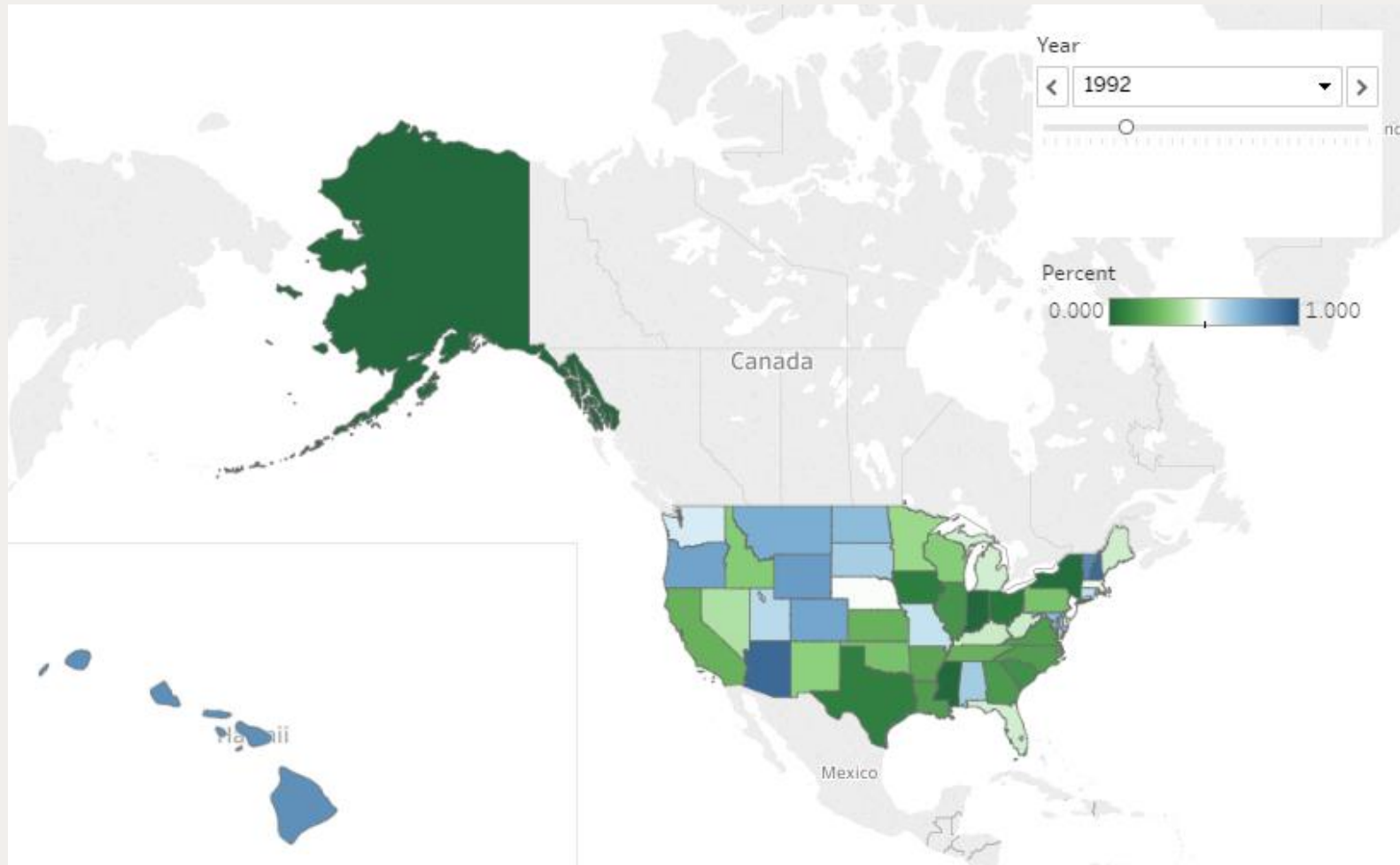
1977



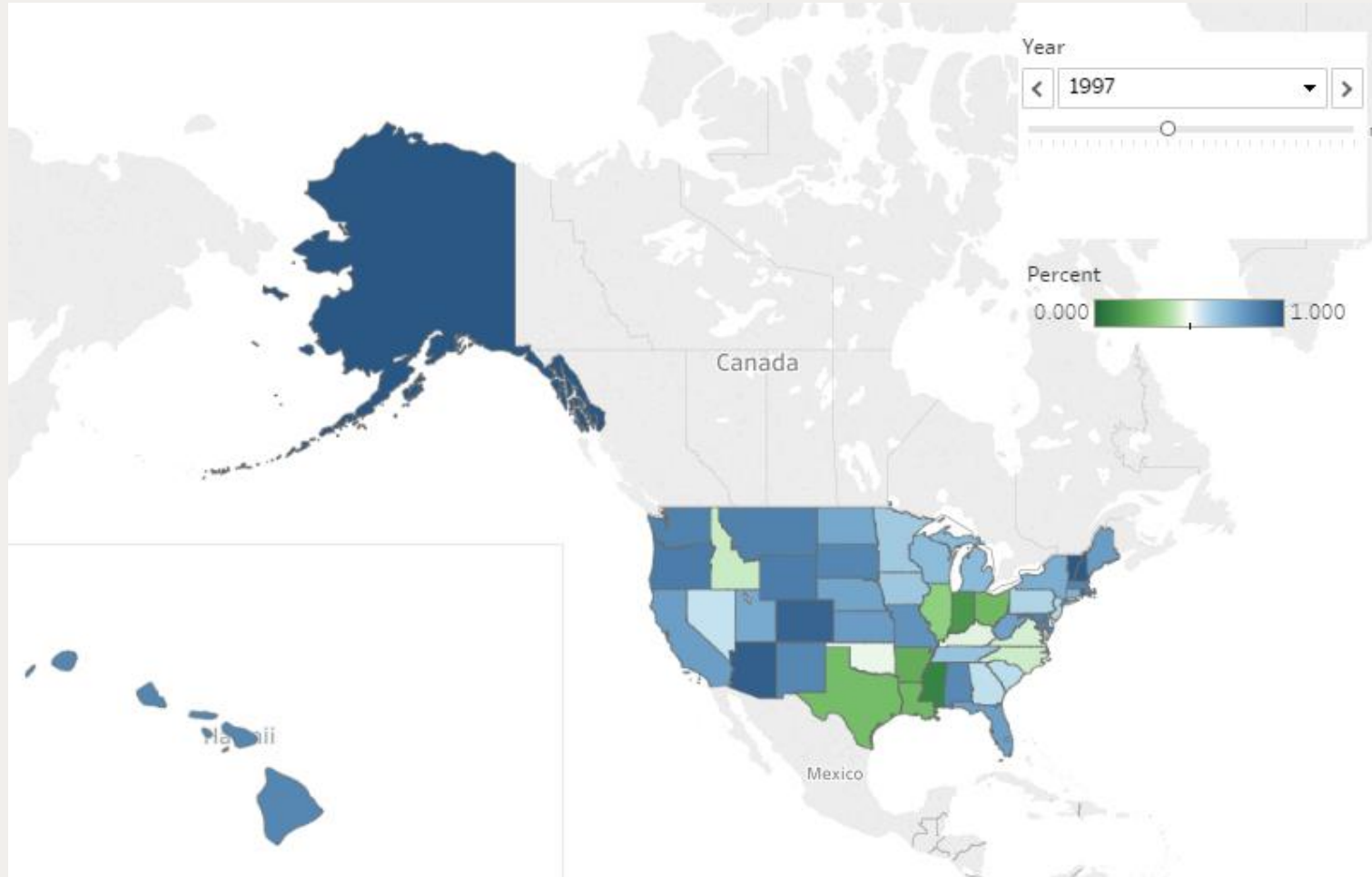
1987



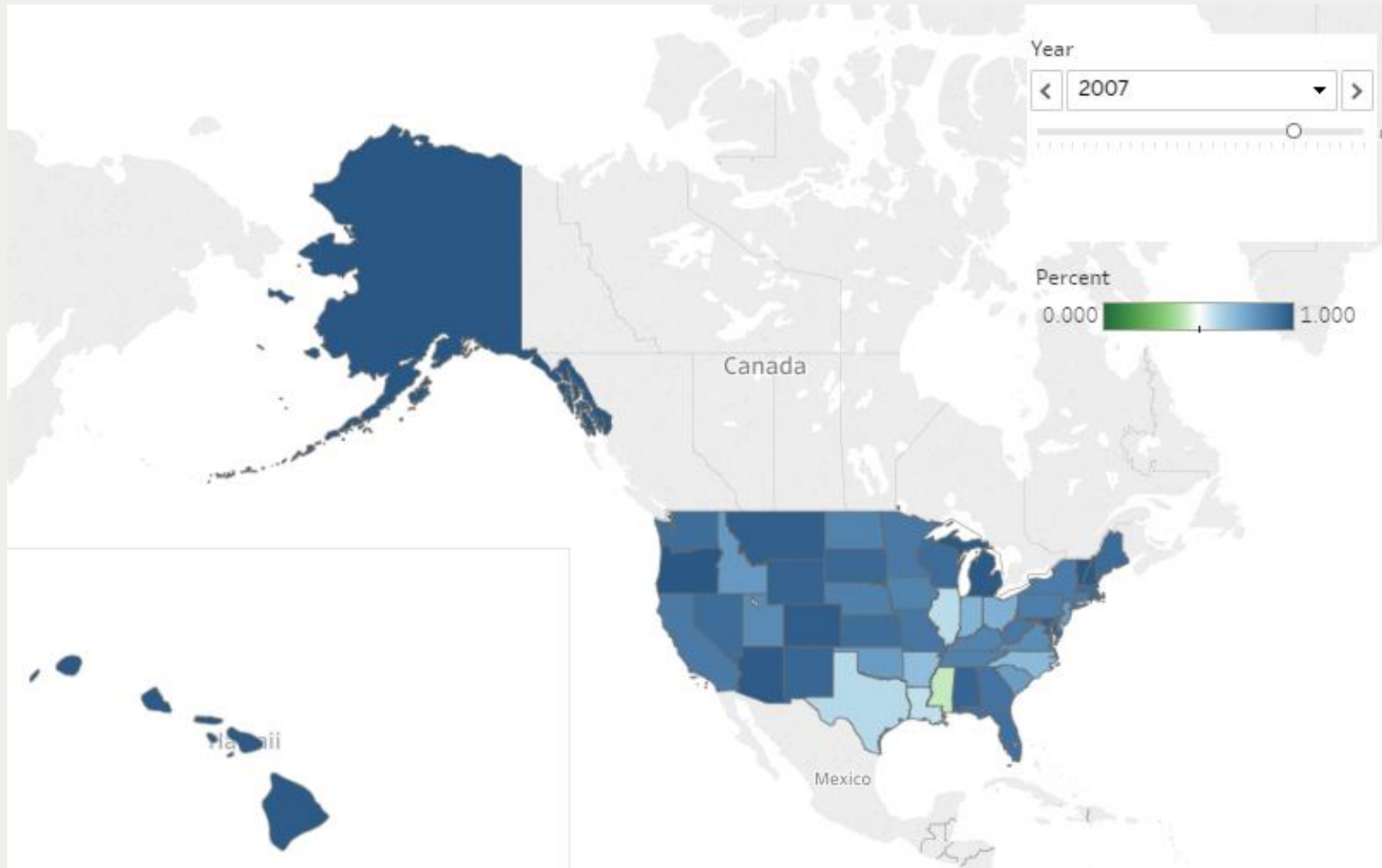
1992



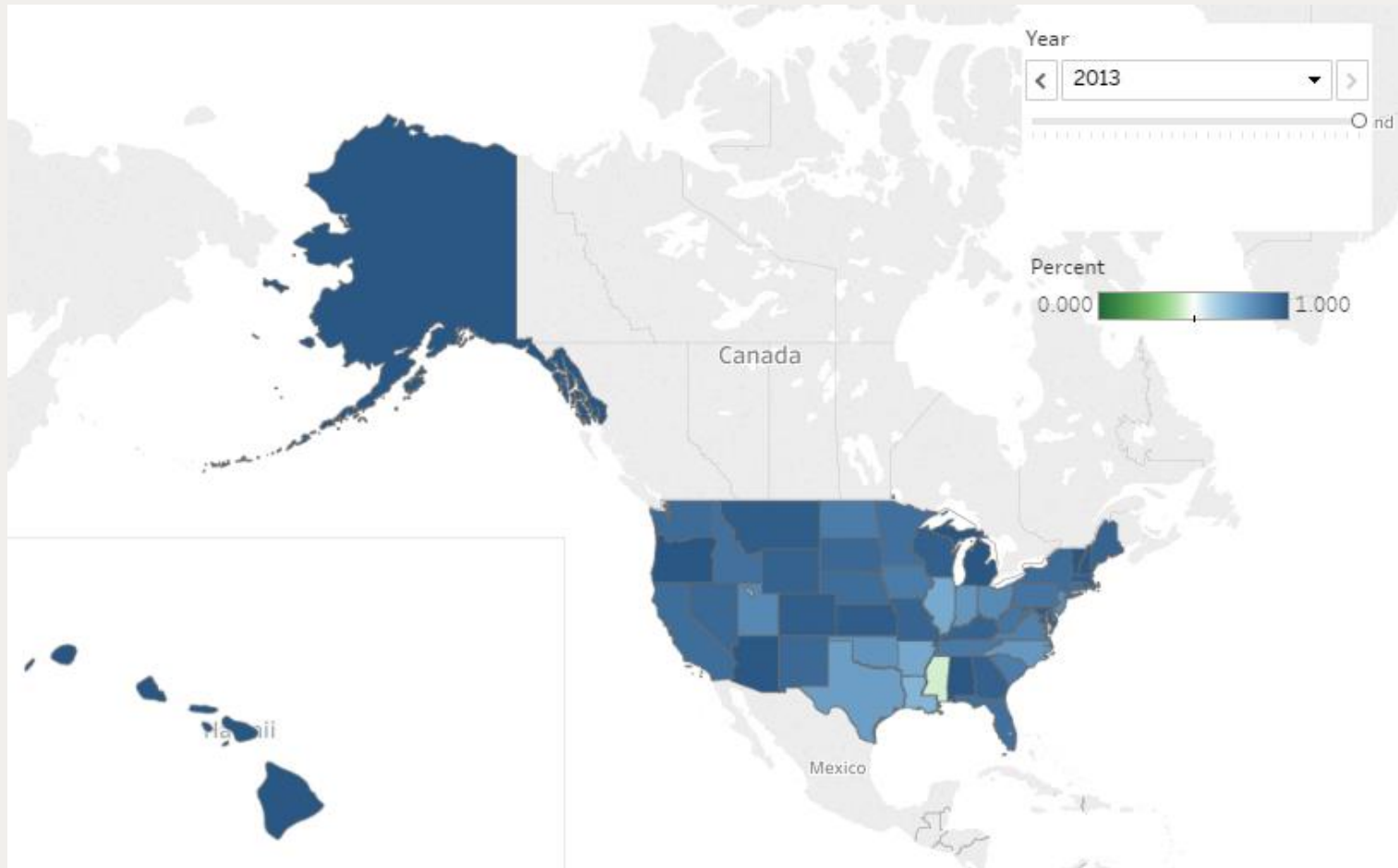
1997



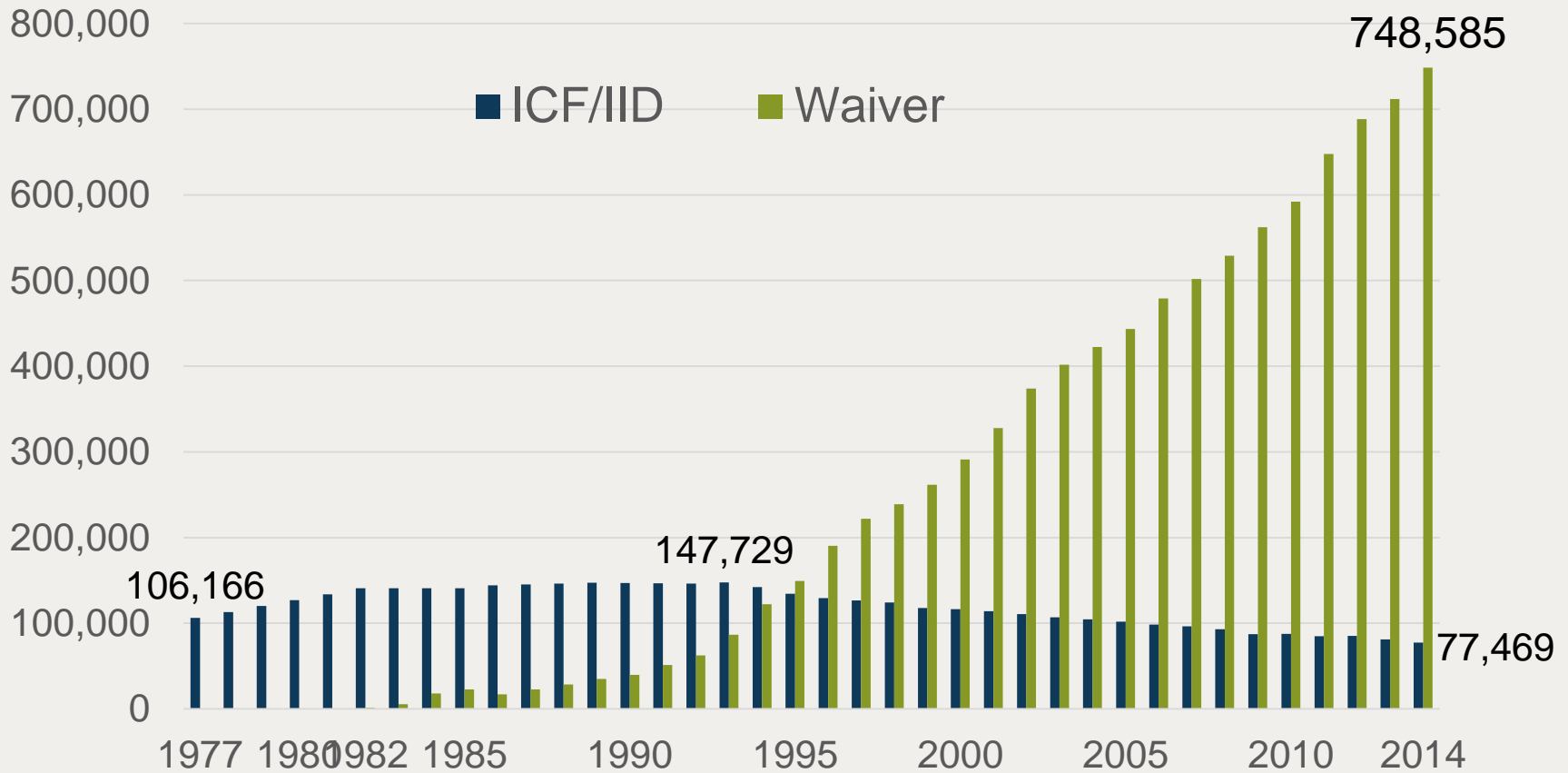
2007



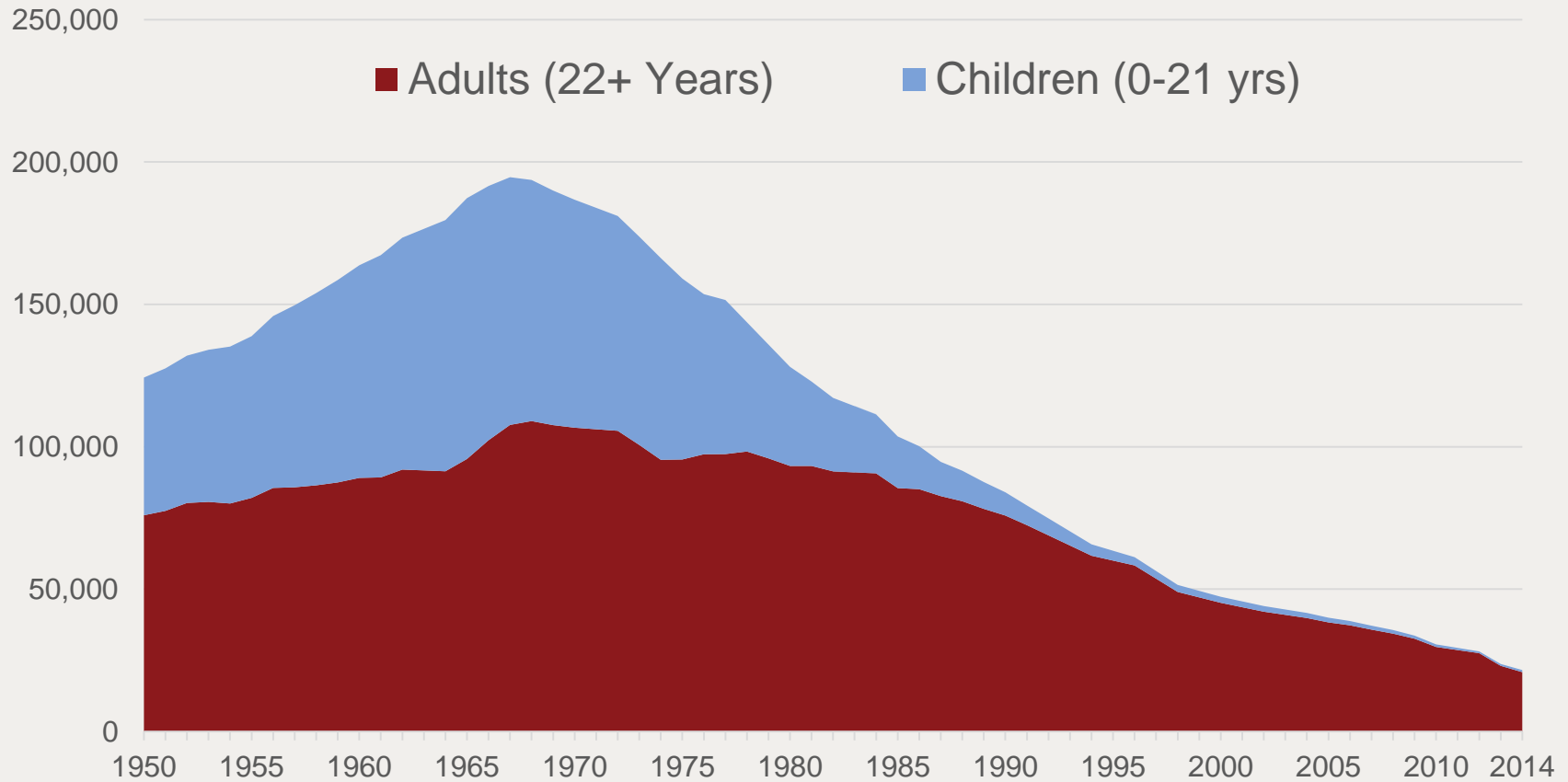
2013



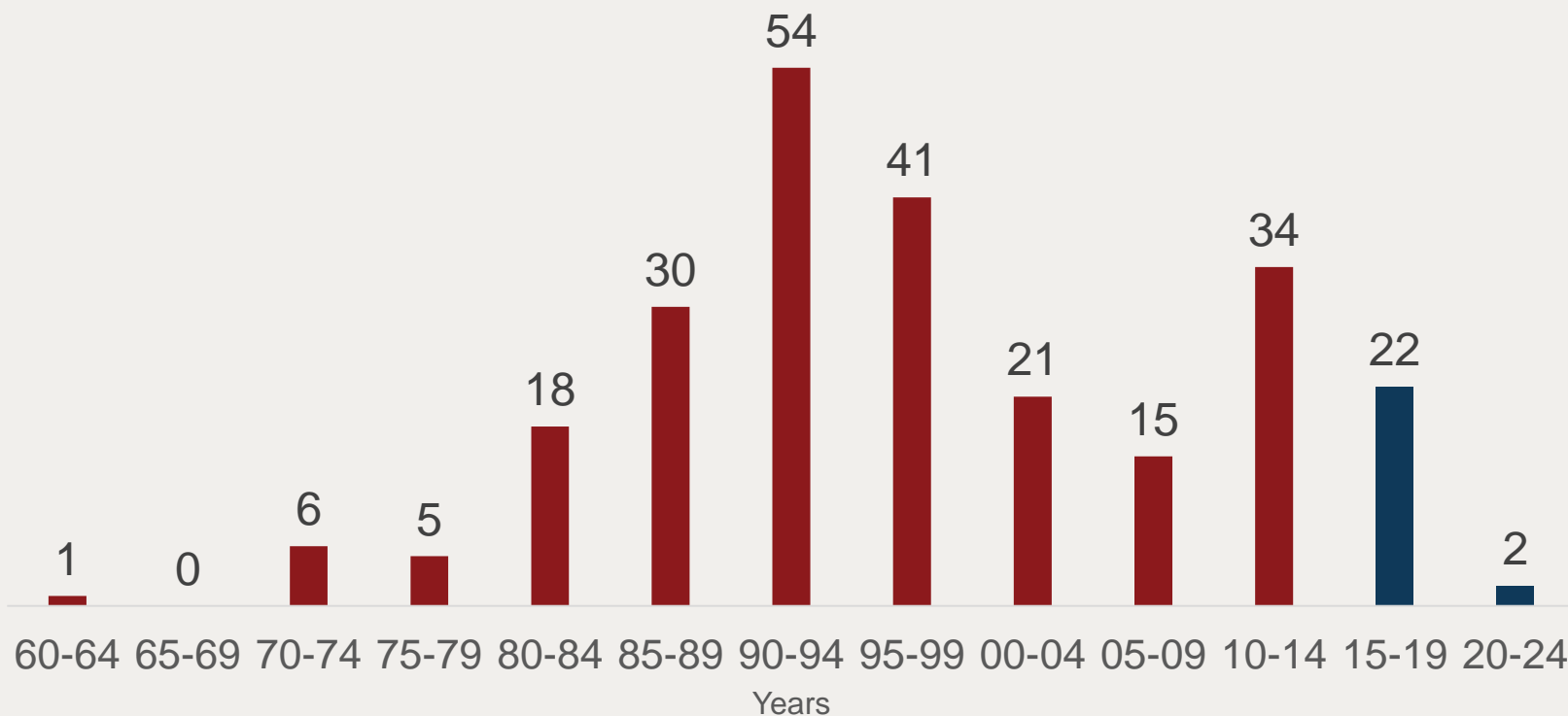
Medicaid LTSS Recipients with IDD 1977 to 2014



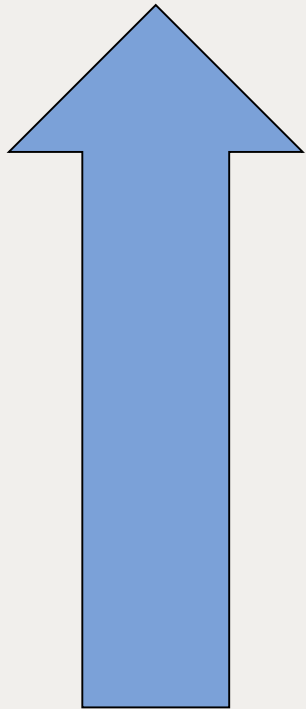
People with IDD in Large State Institutions 1950 to 2014



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

Status

- 22% of people w/IDD are supported in the IDD system (mostly adults)
- Most people w/IDD of ALL ages live with a family member
- 51% in non-family settings shared a home with 3 or less people with IDD
- 232,204 waiting for Medicaid LTSS
- IDEA funded supports

Trends

- Changing numbers and types of funding authorities
- Growth of Medicaid LTSS Managed Care
- Deinstitutionalization success
 - 14 states have no large state IDD facilities
 - 34 state-operated facilities closed between 2010 and 2014
 - 99% reduction in the number of children in large facilities since 1965

Challenges

- 112,000 people with IDD live in a facility of 7 or more people
 - 69,326 in nonstate IDD facilities
 - 28,002 in state IDD facilities
 - 21,011 in nursing homes
 - 2,613+ in state psychiatric facilities
- 2014 HCBS Waiver Rule (Settings)
- Changing diagnoses of those leaving school

2014 CMS HCBS Rule

Medicaid HCBS funded services must

- Be integrated in and provide **support for full access to the greater community**, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community, to the same degree as individuals not receiving Medicaid HCBS.
- **Be selected by the individual** from among setting options including non-disability specific settings and an option for a private unit in a residence. The setting options are identified and documented in the person-centered service plan and are based on the individual's needs, preferences, and, for residential settings, resources available for room and board.
- Ensure an individual's rights of **privacy, dignity and respect, and freedom from coercion and restraint**.
- Optimize individual **initiative, autonomy, and independence in making life choices**, including but not limited to, daily activities, physical environment, and with whom to interact.
- Facilitate individual **choice regarding services and supports**, and who provides them.

HCBS in Provider Owned or Controlled Residences

- The unit or dwelling must be a specific physical place that can be owned, rented, or occupied under a legally enforceable agreement by the individual receiving services, and the individual has, at a minimum, the same responsibilities and protections from eviction that tenants have under the landlord/tenant law of the State, county, city, or other designated entity.
- Each individual has privacy in their sleeping or living unit including:
 - Entrance doors can be locked by the individual, with only appropriate staff having keys.
 - Individuals sharing units have a choice of roommates within that setting.
 - Individuals have the freedom to furnish and decorate their sleeping or living units to the extent allowed by the lease or other agreement.
 - Ensure individuals have the freedom and support to control their own schedules and activities, and have access to food at any time.
 - Ensure individuals are able to have visitors of their choosing at any time.
 - Be physically accessible to the individual.

FY 2014 RISP State Profile

United States

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

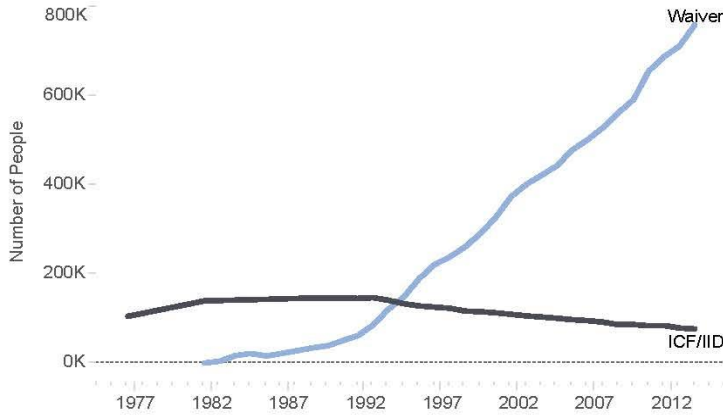


Figure 2: 2014 Medicaid Spending Per Person

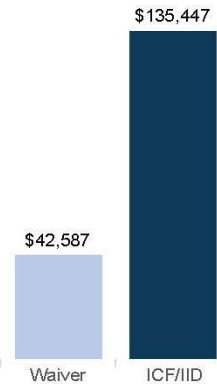


Figure 3: Residence Size and Type on June 30, 2014

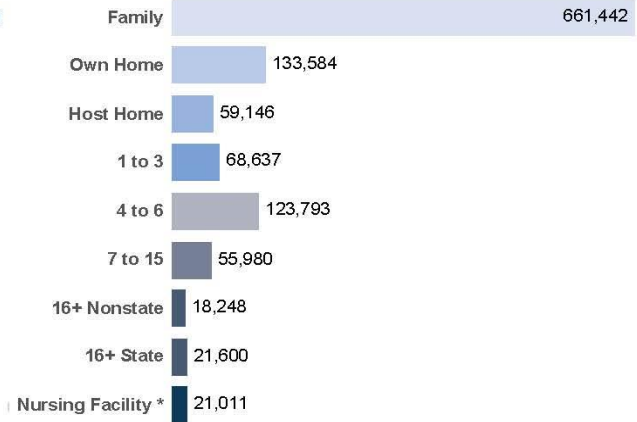


Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

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 Settin..	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).

For More Information

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