

In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends **2018**



Residential Information Systems Project

INSTITUTE *on* COMMUNITY INTEGRATION | **rtc** *on* community living | UNIVERSITY OF MINNESOTA
A UNIVERSITY CENTER *for* EXCELLENCE *in* DEVELOPMENTAL DISABILITIES



LONG-TERM SUPPORTS AND SERVICES FOR INDIVIDUALS WITH INTELLECTUAL OR DEVELOPMENTAL DISABILITIES: STATUS AND TRENDS THROUGH 2018

RESIDENTIAL INFORMATION SYSTEMS PROJECT (RISP)

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2018

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PREFACE

The Residential Information Systems Project (RISP) at the University of Minnesota maintains data on long-term supports and services (LTSS) recipients with intellectual and developmental disabilities (IDD). This report describes the status and trends in publicly funded LTSS for the year ending June 30, 2018 (Fiscal Year 2018).

The FY 2018 report, state profiles and interactive chart builder are available online at www.risp.umn.edu. Most historical RISP reports can also be downloaded from the RISP website.

We hope you enjoy this RISP report. As always, if you have questions about the report, or need help customizing a report to meet your needs, please contact us at risp@umn.edu. We continue to refine and expand our product offerings based on the requests and feedback we receive from readers.

Sheryl Larson, RISP Principal Investigator

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The RISP project is guided by a group of national advisors who meet quarterly with whom project staff can consult on an as needed basis. For 2019/2020 our National Advisors include:

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TECHNICAL USER'S GROUP

NASDDDS Research Committee

The NASDDDS Research Committee serves as the RISP project's Technical Users Group (TUG). Its membership includes state IDD directors, and researchers from projects of national significance and other key researchers or partners within NASDDDS projects as non-voting members. The TUG provides feedback on survey processes, data elements, and the project evaluation. They also consult with project staff on strategies to ensure that the information collected is relevant and responsive to changes in Federal Medicaid policies. From time to time, the Research Committee will pull together an ad-hoc group of state staff for the sole purpose of RISP-related items.

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ACRONYMS

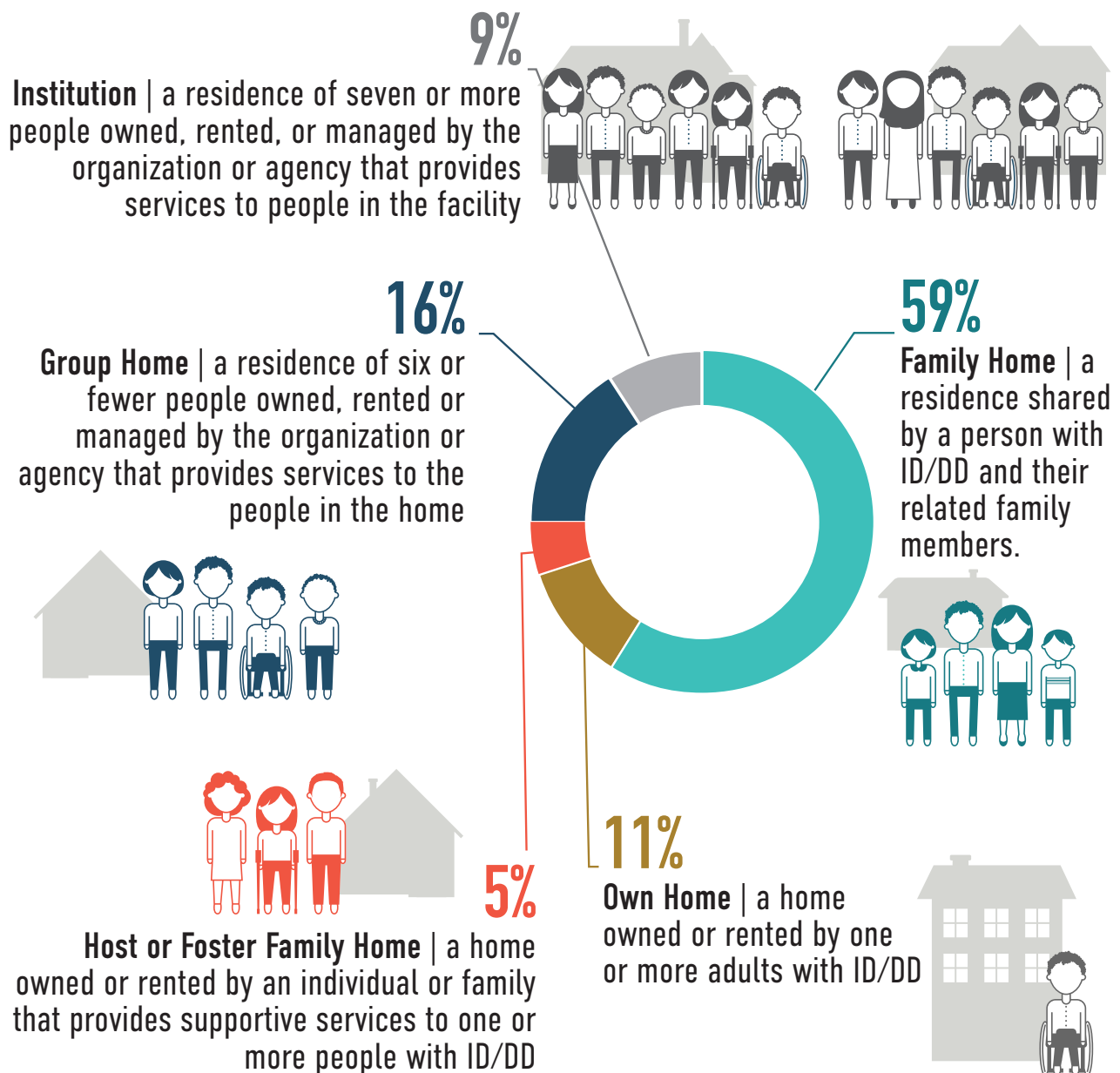
ACL	Administration on Community Living
ADA	Americans with Disabilities Act
AHCA	American Health Care Association
AIDD	Administration on Intellectual and Developmental Disabilities (formerly ADD)
APDDA	Association of Professional Developmental Disabilities Administrators
ASD	Autism Spectrum Disorder
CASPER	Certification and Survey Provider Enhanced Reporting (CMS)
CEHD	College of Education and Human Development (University of Minnesota)
CMS 64	Centers for Medicare & Medicaid Services Quarterly Expense Report CMS, Centers for Medicare & Medicaid Services
DD	Developmental Disabilities
DNF	Did Not Furnish
FFP	Federal Financial Participation
FMAP	Federal Medical Assistance Percentage
FY	Fiscal Year (FY 2018 is July 1, 2017 to June 30, 2018 unless otherwise specified)
HCBS	Home and Community-Based Services (Medicaid)
HSRI	Human Services Research Institute
ICF/IID	Intermediate Care Facility for Individuals with Intellectual Disabilities
ICI	Institute on Community Integration (University of MN's UCEDD)
ID	Intellectual Disabilities
IDD	Intellectual and Developmental Disabilities
IDEA	Individuals with Disabilities Education Act
LTSS	Long-term supports and services
MCO	Managed Care Organization
MFP	Money Follows the Person
NASDDDS	National Association of State Directors of Developmental Disabilities Services
NASUAD	National Association of States United for Aging and Disabilities
NHIS	National Health Interview Survey
NHIS-D	National Health Interview Survey-Disability Supplement
NIDILRR	National Institute on Disability, Independent Living, and Rehabilitation Research
OBRA-87	Omnibus Budget Reconciliation Act of 1987
OSCAR	Online Survey, Certification and Reporting System (Medicaid)
PASRR	Preadmission Screening and Resident Review
PD	Partial data reported by state
PRF	Public residential facility (a state-operated IDD facility serving 16 or more individuals)
QIDP	Qualified Intellectual Disability Professional
RISP	Residential Information Systems Project (University of MN)
RTC/CL	Research and Training Center on Community Living for persons with Intellectual and Developmental Disabilities (University of MN)
SNF	Skilled Nursing Facility
SSA	Social Security Administration
UCEDD	University Centers of Excellence in Developmental Disabilities

EXECUTIVE SUMMARY

People with intellectual or developmental disabilities (IDD) in the United States live in many different types of settings including homes of their own, with a family member, with a host or foster family, or in a provider- owned or -operated setting. An estimated

17% of people with IDD in the United States were receiving Medicaid- or State-funded long-term supports and services (LTSS) through state IDD agencies on June 30, 2018.

Living arrangements for long-term services and supports recipients with IDD on June 30, 2018



SECTION 1 SUMMARY: IN-HOME AND RESIDENTIAL SUPPORTS

Section 1 reports the prevalence of IDD, the number of people with IDD known to state IDD agencies, and the living arrangements of long-term supports and services recipients with IDD as of June 30, 2018.

Of the people in the U.S. with IDD how many were known to state IDD agencies?

An estimated 7.43 million people with IDD (22.8 per 1,000 of the population) lived in the United States on June 30, 2018. An estimated 72% of those people were 21 years or younger. An estimated 1,546,869 people with IDD were known to or served by state IDD agencies (21%; 4.6 people per 1,000). Of the people served by state IDD agencies, 37% (572,521 people) were 21 years or younger and 63% (972,521 people) were 22 years or older.

Where did people with IDD receiving LTSS live?

An estimated 18% of people with IDD (1,308,659 people) in the United States received LTSS provided by or under the auspices of state IDD agencies (85% of the people known to state IDD agencies) on June 30. Of those,

- 61% (792,030 people) lived in the home of a family member
- 23% (299,848 people) lived in a group home, ICF/IID or other group setting
- 12% (153,092 people) lived in a home they owned or leased
- 5% (63,689 people) lived in a host or foster family home

At least 26,400 more people with IDD lived in nursing homes and at least 1,766 more people lived in a psychiatric facility (the exact numbers of people with IDD in psychiatric facilities are unknown due to incomplete data). State IDD agencies managed services for some but not all individuals with IDD in psychiatric facilities or nursing homes.

How many LTSS recipients shared non-family settings in which people with IDD lived?

People with IDD who received LTSS and did not live with a family member resided in a variety of settings including: own home, host/foster family homes, group homes, Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID), and other group or institutional settings. The size of the estimated 229,246 non-family residences in which LTSS recipients with IDD lived varied. Of those settings,

- 83% (190,948 settings) were home to three or fewer people
- 13% (29,958 settings) were home to 4 to 6 people
- 3% (7,405 settings) were home to 7 to 15 people
- 0.4% (935 settings) were home to 16 or more people

An estimated 516,629 people with IDD lived in non-family settings. Of those,

- 55% (285,233 people) lived in a setting shared by three or fewer people
- 27% (138,897 people) lived in a setting shared by 4 to 6 people
- 11% (56,196 people) lived in a setting shared by 7 to 15 people
- 7% (36,825 people) lived in a setting shared by 16 or more people

What was the average size of non-family settings?

The average non-family residence was shared by 2.3 people with IDD.

In non-state settings, there were an average of

- 1.7 people per own home setting,
- 1.4 people per host/foster family home,
- 3.6 people per non-state group home (other than ICF/IID), and
- 7.6 people per non-state ICF/IID.

In state-operated IDD settings, there were an average of

- 5.4 people per group home (other than ICF/IID),
- 8.9 people per “other” group setting, and
- 75.2 people per ICF/IID

What proportion of people with IDD living in settings other than the home of a family member lived in congregate settings of seven or more people? (A Healthy People 2030 indicator)

An estimated 120,622 people with IDD (22% of those living in places other than the home of a family member) lived in IDD group settings shared by seven or more people, nursing homes or psychiatric facilities on June 30, 2018. This is a slight increase from 116,933 (21%) on June 30, 2017.

SECTION 2 SUMMARY: MEDICAID LTSS RECIPIENTS AND EXPENDITURES

Section 2 describes the Medicaid and state authorities through which LTSS for people with IDD are funded. It describes the number of recipients, total expenditures, and expenditures per recipient for Medicaid Waiver and ICF/IID. For Waiver recipients, it also describes recipients, expenditures and expenditures per recipient by age and living arrangement.

What Medicaid and State funding authorities were used to finance LTSS for people with IDD?

In 2018,

- All 50 states and the District of Columbia provided service funded by one or more Medicaid Home and Community-Based Services Waivers
- 47 states used Medicaid 1915(c) Home and Community-based Waivers
- 11 states used Medicaid 1115 Demonstration Waivers
- 8 states used Medicaid managed care waivers (1915a, b, or b/c)
- 49 states used the Medicaid Intermediate Care Facilities for Individuals with Intellectual Disabilities funding authority
- 7 states used Medicaid State Plan 1915(k) Community First Choice
- 7 states used Medicaid State Plan 1915(i) Home and Community-based Services

In this report, “Medicaid Waiver” refers to services funded through Medicaid Waivers authorized under Sections 1115, or 1915 (a), (b), (b/c) or (c) of the Social Security Act. “Medicaid Home and Community-based Services (HCBS)” refers to services funded through Medicaid 1115, or 1915 (a), (b), (b/c) or (c) Waivers as well as Medicaid State Plan 1915(i) and 1915 (k) funding authorities.

How many people with IDD received LTSS through Medicaid or state funding authorities on June 30?

Of the 1,308,659 LTSS recipients with IDD,

- 67% (879,062 people) received LTSS through a Medicaid Waiver funding authority
- 17% (216,431 people) received LTSS through a Medicaid State Plan HCBS funding under the 1915(i) or 1915(k) authorities

- 15% (192,486 people) received state-funded LTSS
- 5% (70,046 people) received supports in a Medicaid ICF/IID

Of the 1,546,869 people with IDD known to or served by state IDD agencies

- 13% (206,941 people) received no Medicaid or state-funded LTSS
- 14% (208,889 people) were waiting for Medicaid HCBS Waiver funded supports

Some people received services funded through more than one funding authority.

Medicaid Waiver

How many people with IDD were waiting for Medicaid Waiver funded supports?

An estimated 208,889 people with IDD were living with a family member and waiting for Medicaid Waiver funded LTSS. Of those,

- 33% (69,701 people) were waiting to move to a different setting
- 19% (38,682 people) received Medicaid State Plan-funded Targeted Case Management services while waiting.

Fourteen states reported no people with IDD waiting for Medicaid Waiver funded LTSS. Eight states did not report the number of people who were waiting for HCBS Waiver funded services.

The number of Medicaid Waiver plus ICF/IID recipients with IDD would have to increase by 22% to serve every person with IDD on the Medicaid Waiver waiting list.

Where did Medicaid Waiver recipients with IDD live?

Of the 879,062 Medicaid Waiver recipients with IDD

- 55% (483,367 people) lived with a family member
- 25% (218,393 people) lived in a group setting
- 14% (120,288 people) lived in a home they owned or leased
- 6% (57,014 people) lived with a host or foster family

How old were Medicaid Waiver recipients with IDD? What proportion of each age group lived in the home of a family member?

- Of the 879,062 Medicaid Waiver Recipients with IDD
- 25% (222,623 recipients) were 21 years or younger, of whom
 - 90% (199,440 people) lived in the home of a family member
 - 10% (23,183 people) lived in own home, host or foster family home, or a group setting
 - 75% (656,439 recipients) were 22 years or older, of whom
 - 44% (287,539 people) lived in the home of a family member
 - 56% (368,900 people) lived in own home, host or foster family home or a group setting

There were 270 Medicaid Waiver recipients with IDD per 100,000 of the United States' population.

- 247 Medicaid Waiver recipients with IDD per 100,000 of the population were 21 years or younger
- 279 Medicaid Waiver recipients with IDD per 100,000 of the population were 22 years or older

What proportion of LTSS recipients with IDD living in their own home or with a family member received Medicaid Waiver funded supports?

- 79% (120,288 LTSS recipients) living in their own home received Medicaid Waiver funded supports
- 61% (483,367 LTSS recipients) living in the home of a family member received Medicaid Waiver funded supports

What were total FY 2018 Medicaid Waiver expenditures for recipients with IDD? What proportion of Medicaid Waiver expenditures for people with IDD were for people 22 years or older?

- Estimated Medicaid Waiver expenditures for people with IDD were \$42.29 billion (\$130 per U.S. resident) of which
- 10% (\$4.10 billion) was for people 21 years or younger
 - 90% (\$38.19 billion) was for people 22 years or older

What were the average annual per recipient Medicaid Waiver expenditures for people with IDD in FY 2018? How did the average differ by age and living arrangement?

- Average annual Medicaid Waiver expenditures were \$47,835 per year-end recipient with IDD. Average expenditures were
- \$18,301 per recipient 21 years or younger overall
 - \$14,813 for people 21 years or younger living in the home of a family member
 - \$49,496 for people 21 years or younger living in other settings
 - \$57,894 per recipient 22 years or older overall
 - \$28,313 for people 22 years or older living in the home of a family member
 - \$73,487 for people 22 years or older living in other settings

Medicaid Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID)

How many ICF/IIDs were operating on June 30, 2018? How many people with IDD received services in ICF/IID of different sizes?

- There were 6,069 ICF/IID settings in the United States on June 30, 2018. Of those,
- 4% (243 ICF/IID) were state-operated including
 - 25% (61) serving 6 or fewer people
 - 28% (68) serving 7 to 15 people
 - 47% (114) serving 16 or more people
 - 96% (5,826 ICF/IID) were non-state including
 - 64% (3,714) serving 6 or fewer people
 - 30% (1,765) serving 7 to 15 people
 - 6% (347) serving 16 or more people

There were no ICF/IID facilities of any size reported in Alaska, Michigan, and Oregon; and no ICF/IID facilities of 16 or more people in Alabama, the District of Columbia, Hawaii, Montana, Rhode Island, Vermont, and West Virginia.

How many people lived in state or non-state ICF/IID of various sizes on June 30, 2018?

An estimated 70,046 people lived in an ICF/IID on June 30, 2018. Of those,

- 26% (18,271 people) lived in a state-operated ICF/IID including
 - 1% (259) in a setting of 6 or fewer people
 - 5% (859) in a setting of 7 to 15 people
 - 94% (17,153) in a setting 16 or more people
- 74% (51,775 people) lived in a non-state ICF/IID including
 - 38% (19,680) in a setting of 6 or fewer people
 - 33% (16,929) in a setting of 7 to 15 people
 - 29% (15,166) in a setting of 16 or more people

- 79% (15,166 of 19,268 people) in non-state IDD facilities

What were FY 2018 Medicaid ICF/IID expenditures?

Total ICF/IID expenditures in FY 2018 were \$9.61 billion (\$29.60 per United States resident). Average annual ICF/IID expenditures were \$137,560 per year-end recipient. The average was

- \$119,752 for recipients 21 years or younger
- \$142,381 for recipients 22 years or older

What proportion of combined Medicaid ICF/IID and Waiver recipients and expenditures were for people in ICF/IID settings in FY 2018?

An estimated 949,108 Medicaid LTSS recipients with IDD lived in an ICF/IID or received Medicaid Waiver funded LTSS. Of those,

- 93% received Medicaid Waiver funded LTSS
- 7% lived in an ICF/IID

Total Medicaid ICF/IID plus Waiver expenditures for people with IDD were \$51.93 billion in FY 2018. Of the total,

- 81% (\$42.29 billion) was for Medicaid Waiver recipients
- 19% (\$9.64 billion) was for people in ICF/IID

How old were people living in an ICF/IID?

Of the 70,046 people living in an ICF/IID (21.5 people per 100,000 of the population)

- 7% (4,916 people) were 21 years or younger (5.5 people per 100,000 of the population)
- 93% (65,130 people) were 22 years or older (27.7 people per 100,000 of the population)

What proportion of people living in IDD settings of 16 people or more lived in an ICF/IID?

Of the 36,825 people living in IDD settings of 16 or more people, 90% (32,319 people) lived in an ICF/IID including

- 98% (17,153 of 17,557 people) in state-operated IDD facilities



SECTION 3 SUMMARY: TRENDS IN LONG-TERM SUPPORTS AND SERVICES

Section 3 describes trends in LTSS recipients and expenditures by funding authority, setting type and setting size.

How have the type and sizes of the places in which LTSS recipients with IDD live changed?

Between 1998 and 2018, the total number of LTSS recipients with IDD more than doubled increasing from 639,691 to 1,336,131. The number of LTSS recipients with IDD living in

- The home of a family member increased 143% from 325,650 to 792,030 people. The proportion living with a family member who received Medicaid Waiver funded supports increased from 25% to 61%.
- A home of their own increased 144% from 62,669 to 153,092 people
- A host/foster home or IDD group setting of three or fewer people increased 129% from 63,279 to 145,066 people
- An IDD group setting of 4 to 6 people increased 71% from 73,658 to 126,010 people
- An IDD group setting of 7 to 15 people increased 3% from 53,940 to 55,758 people
- An IDD facility, Nursing Home or Psychiatric Facility of 16 or more people decreased 44% from 114,495 to 64,175 people

How have the number, size and type of operation of settings other than the home of a family member in which LTSS recipients with IDD lived changed?

Between 1977 and 2018, the number non-family IDD settings increased from 11,008 to 229,246 settings.

- The proportion of non-family IDD settings serving six or fewer people increased from 63% (6,898 facilities) to 96% (229,246 facilities).
- The proportion of non-state IDD settings serving six or fewer people increased from 65% (6,855 facilities) to 97% (227,249 facilities).
- The proportion of state-operated IDD settings serving six or fewer people increased from 9% (43 facilities) to 68% (1,348 facilities).

How has the number of people with IDD living in settings other than the home of a family member of different sizes and types of operation changed between 1977 and 2018?

The proportion (and number) of LTSS recipients in non-family IDD settings of

- 6 or fewer people increased from 8% (20,400 people) in 1977 to 82% (423,608 people) in 2018
- 7 to 15 people increased from 8% (20,024 people) in 1977 to 11% (56,196 people) in 2018
- 16 or more people decreased from 84% (207,356 people) in 1977 to 7% (36,825 people) in 2018

Of the people living in non-family IDD settings, the proportion living in state-operated settings declined from 63% (155,804 people) in 1977 to 5% (27,960 people) in 2018.

- Of the people in settings of 1 to 6 people, the proportion in a state-operated facility increased from 0.1% (216 people) in 1977 to 18% (5,385 people) in 2018.
- Of the people in settings of 7 to 15 people, the proportion in a state-operated facility increased from 1% (950 people) in 1977 to 18% (5,018 people) in 2018.
- Of the people in settings of 16 or more people, the proportion in a state-operated facility decreased from 99% (154,638 people) in 1977 to 63% (17,557) in 2018.

Between 1977 and 2018, the average size of all non-family IDD settings declined from 22.5 to 2.3 people per setting. The average size of

- State-operated IDD settings declined from 335.1 to 14.0 people per setting.
- Non-state IDD settings declined from 8.7 to 2.2 people per setting.

How have Medicaid Waiver and ICF/IID recipients, expenditures, and expenditures per person changed?

Between 1980 and 2018 the proportion of Medicaid expenditures for ICF/IID and Waiver funded services for people with IDD decreased from 11.9% to 8.4%.

Between 1982 and 2018,

The number of people with IDD

- Receiving Medicaid Waiver funded supports increased from 1,381 to 879,062 people.

- In a Medicaid ICF/IID setting declined from 140,752 to 70,046 people.

Total expenditures for people with IDD

- Receiving Medicaid Waiver funded services increased from \$5.8 million to \$42.3 billion in 2018 inflation adjusted dollars.
- In ICF/IID settings increased from \$8.7 billion to \$9.6 billion in 2018 inflation adjusted dollars.

Average annual per person Medicaid expenditures for

- Waiver funded services for people with IDD increased from \$4,224 to \$47,835 in 2018 inflation adjusted dollars.
- ICF/IID services for people with IDD increased from \$61,895 to \$137,560 in 2018 inflation adjusted dollars.

In 1984, annual per person ICF/IID expenditures (\$68,471 in 2018 inflation adjusted dollars) were 5.12 times higher than annual per person Waiver expenditures (\$13,378 in 2018 inflation adjusted dollars). By 2018, annual per person ICF/IID expenditures (\$137,560) were 2.87 times

higher than annual per person Waiver expenditures (\$47,835). Expenditures for Medicaid ICF/IID and Waiver funded services differ in important ways. For example, Medicaid Waiver expenditures exclude room and board costs while those expenditures are included for ICF/IID.

How has the number of people with IDD living with family members who were waiting for Medicaid Waiver funded LTSS changed?

The number of people with IDD living with a family member waiting for Medicaid Waiver funded LTSS declined 10% from 232,204 people in 2013 to 208,889 people in 2018. The number waiting to move to a residence other than the home of a family member declined 35% from 107,204 in 2013 to 69,701 in 2018.



SECTION 4 SUMMARY: STATUS AND TRENDS IN STATE-OPERATED IDD FACILITIES SERVING 16 OR MORE PEOPLE

Section 4 examines the status of and national trends in the number of people with IDD living in state-operated IDD facilities serving 16 or more people (Public Residential Facilities, or PRF) or in state-operated psychiatric facilities.

How many people lived in PRFs on June 30, 2018? How did the number of people living in PRFs change during FY 2018?

An estimated 17,557 people with IDD lived in a PRF on June 30, 2018 (down 4% from 18,239 on June 30, 2017). The average daily population for FY 2018 was 17,596. The number of people per facility ranged from 19 to 471 and averaged 170 (87 facilities reporting).

During 2018, PRFs had an estimated

- 1,059 admissions or readmissions
- 1,453 discharges
- 632 deaths
- 576 short-term admissions (less than 90 days)

People ages 21 years or younger were only 4% of the PRF population on June 30, 2018, but they were

- 32% of all admissions or readmissions
- 17% of all discharges

People 63 years or older were 25% of the PRF population on June 30, 2018, but were

- 4% of new admissions or readmissions
- 17% of discharges

Of the people newly admitted or readmitted to PRFs in FY 2018

- 22% came from a correctional facility
- 18% came from the home of a family member
- 18% came from a psychiatric facility
- 18% came from a group IDD setting of 6 or fewer people
- 12% came from another (Nursing home, Hospital or Assisted Living) or unknown setting
- 3% came from their own home or a host or foster family home
- 3% came from a group IDD setting of 7 or more people

Of the people who moved from a PRF to another setting in FY 2018

- 57% went to a group IDD setting of six or fewer people
- 9% went to a correctional facility
- 7% went to a group IDD setting of 7 or more people
- 6% went to the home of a family member
- 5% went to their own home or a host or foster family home
- 4% went to a mental health facility
- 10% went to another (Nursing home, Hospital or Assisted Living) or unknown setting

What were the characteristics of people with IDD living in PRFs in 2018?

On June 30, 2018, of the people living in PRFs, an estimated

- 4% were 21 years or younger, 21% were 22 to 39 years, 50% were 40 to 62 years and 25% were 63 years or older.
- 14% had mild or no intellectual disabilities (ID), 15% had moderate ID, 17% had severe ID, and 54% had profound ID.
- 7% were of Hispanic origin.
- 71% were white, 19% were black or African American, and 3% were another race, two or more races. Race was not specified for the 7% who were Hispanic.
- 37% had epilepsy, 20% had autism, and 16% had cerebral palsy
- 58% received medications for mood, anxiety or behavior, had a psychiatric disorder, or had a behavior disorder.

What were the vacancy and turnover rates of staff in PRFs?

Vacancy rates on June 30, 2018 were

- 14.5% for direct support professionals (up from 6% in 2006)
- 10% for frontline supervisors (up from 5% in 2006)

Crude separation rates (turnover) for FY 2018

- 40.7% for direct support professionals (up from 29% in 2006)
- 16.1% for frontline supervisors (up from 13% in 2006)

How has the number of PRFs changed?

Of the 376 PRFs operating between 1960 and 2018,

- 260 closed before July 1, 2017
- 1 closed between July 1, 2017 and June 30, 2018
- 115 were open on June 30, 2018, 8 of which anticipated closing by June 30, 2022.

On June 30, 2018, there were no PRFs serving people with IDD in 17 states: Alabama, Alaska, the District of Columbia, Hawaii, Indiana, Maine, Michigan, Minnesota, Montana, New Hampshire, New Mexico, Oklahoma, Oregon, Rhode Island, Tennessee, Vermont, and West Virginia.

How has the census of PRFs changed?

The average daily PRF population declined from a peak of 194,650 in 1967 to 17,596 in 2018. The average daily number of people with IDD in state-operated psychiatric facilities declined from 41,823 in 1961 to 1,660 people on June 30, 2018.

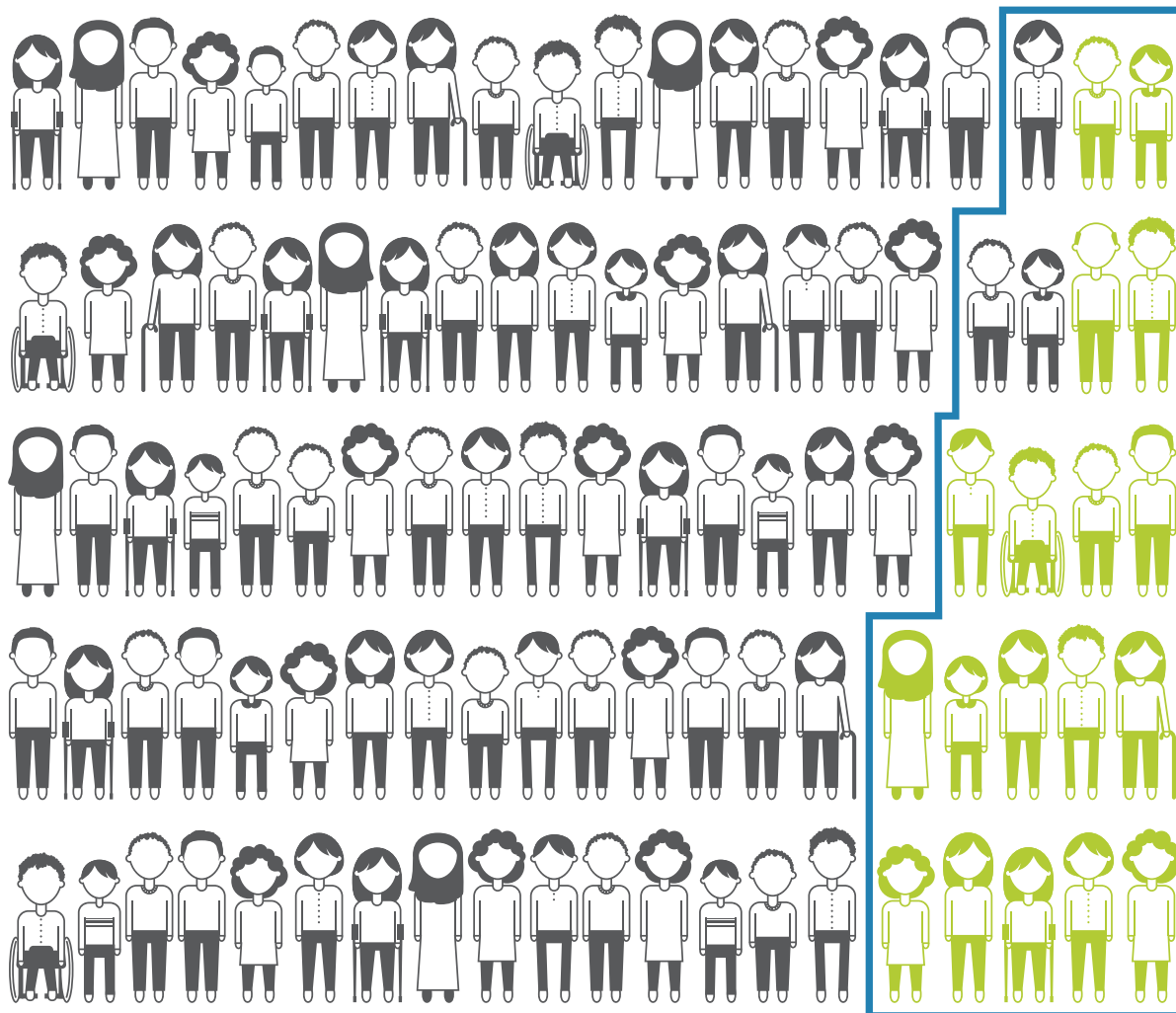
2018



Introduction

FY 2018

7.43 million people in the United States had Intellectual or Developmental Disabilities (IDD) in 2018



21% 1.55 million people with IDD were known to or served by state IDD agencies

18% 1.31 million people with IDD received long-term supports or services through state IDD agencies

Note: U.S. IDD prevalence estimates from 1994/5 and 2017 National Health Interview Surveys

INTRODUCTION

People with IDD and their families expect to have the same opportunities as people who do not receive formal supports to participate fully in community activities, events, and organizations; interact with family and friends; and for working age people, work in a job earning at least minimum wage alongside people without disabilities. For many people who receive publicly funded long-term supports and services (LTSS), however, opportunities to participate in preferred ways may be limited by their living arrangement, by the type or amount of support needed, or the way needed supports are delivered.

Long-term supports and services assist people to participate fully in all aspects of community life including:

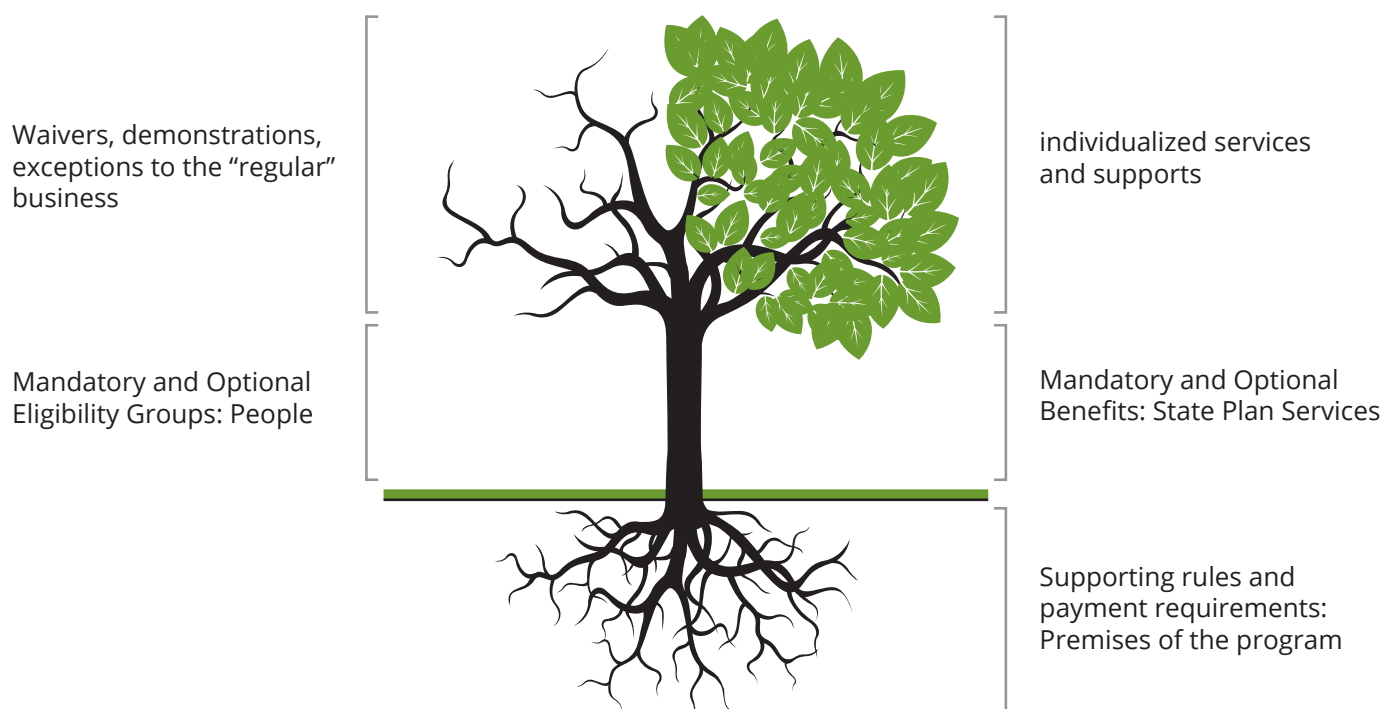
- Activities of daily living such as dressing, bathing and eating
- Household activities such as shopping, cooking, cleaning, and money management
- Developing and maintaining relationships

- Identifying and pursuing personal interests such as hobbies, sports, clubs or worship
- Health and Wellness (physical, emotional and spiritual)
- Employment
- Formal and informal learning opportunities
- Making decisions about where and with whom to live; schedules and activities; and about how to spend earnings and other resources
- Civic participation such as voting and paying taxes
- Traveling to and from work, school, or other places

Full participation in all aspects of life may require a different combination of informal and formal supports for each person. **Table A** describes some of the more common types of LTSS that may be provided to support full participation, and provides selected examples of services in each category.

Full participation is affected by the availability and competence of paid and non-paid support providers,

Figure A.1 Key Elements of the Medicaid Program



Adapted from NASDDDS 2019

Table A: Long-Term Supports and Services Used by People with IDD

Service	Brief description	Examples
Behavior Supports	Supports to prevent or reduce behavior-related issues or mitigate crisis needs. Includes services provided by professional staff, as well as preemptive solutions	Mental health assessment, crisis intervention, behavioral support, counseling, assertive community treatment
Employment and Day Services	Services provided to support participation in community-based employment, activities, and education	Job development, supported employment (individual, group, competitive), prevocational services, day habilitation
Environmental Modifications and Technology	Adaptive equipment, home modifications, modification or repair to a vehicle, adaptive equipment, augmentative communication devices,	Personal emergency response systems, ramps, grab bars, bathroom modifications, home and vehicle modifications, adaptive equipment
Family Caregiver Support	Services to help the caregiver or family provide supports to the individual	Home delivered meals, homemaker/chore services, caregiver counseling, caregiver training
Habilitation	Support for skill development for activities of daily living such as dressing and eating, instrumental activities of daily living such as cooking, cleaning, shopping, and money management, and developing and maintaining relationships	Home-based habilitation, recreation and leisure
Housing Supports	Services to assist the person to obtain and maintain housing	Housing coordination, Community Transition Services
Medical and Health Supports	Supports to improve or maintain health, and to gain or maintain physical functioning. Includes clinical services, such as occupational therapy (OT), physical therapy (PT), and speech therapies as well as in home nursing services	Home health aide, OT, PT, speech and language therapies, skilled and private nursing, clinic services
Participant Directed Supports	Assistance to individuals/families who self-direct services. Includes the development of a person centered plan, managing individual budgets, recruiting workers and accessing services and supports	Financial management services, participant training, goods and services, interpreter, other
Personal Care Supports	Hands-on assistance, or direct supervision for activities of daily living such as dressing, eating, changing positions (getting in and out of bed/chair), using the toilet, and bathing.	Companion services, personal care/assistance
Residential Services	Housing and habilitation supports provided in a place other than the home of a family member or a home owned or leased by the person	Group home, Shared Living, Board and Care
Respite	Temporary relief from caregiving duties for the family caregiver	Respite (in home, out of home), individual support (day or night)
Transportation	Supports to transport an individual from their residence to community settings including day services, employment settings, and community-based activities	Community transportation services, non-medical transportation

This adaptation of the Medicaid HCBS taxonomy originally appeared in Anderson, L.L., Larson, S.A., Kardell, Y., Taylor, B., Hallas-Muchow, L., Eschenbacher, H.J., Hewitt, A.S., Sowers, M., & Bourne, M.L. (2016). Supporting Individuals with Intellectual or Developmental Disabilities and their Families: Status and Trends through 2014. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. The Centers for Medicare and Medicaid Services detailed taxonomy for home and community-based services is available at https://www.cms.gov/mmrr/Briefs/B2014/MMRR2014_004_03_b01.html

the type and amount of supports provided, federal and state policies regarding LTSS oversight, operation, and funding, and the extent to which services are individualized to each person's family, community, and culture. LTSS in the United States

for people with IDD may be funded by Medicaid, state or local governments without Medicaid matching dollars or the individual or family privately.

THE POLICY CONTEXT

LTSS in the United States are influenced by Medicaid statute and regulations, as well as federal laws such as the Rehabilitation Act of 1973, the Americans with Disabilities Act, the Workforce Innovation and Opportunity Act of 2014, the Supreme Court's 1999 Olmstead decision, and other federal and state legislative actions, judicial decisions and policies. A few of these influences are briefly described here. A more detailed description of the Medicaid program can be found at the end of Section 2 of this report.

The 2014 Medicaid Home and Community-Based Services (HCBS) Rule

On March 17, 2014, the Centers for Medicare and Medicaid Services (CMS) issued new guidelines for Medicaid funded supports provided in Home and Community-Based Service (HCBS) settings (CMS, 2014; Final Regulation CMS-2249-F/ CMS-2296-F). The 2014 HCBS Rule requires person-centered planning and service delivery and prohibit conflicts-of-interest for those who develop plans of care. HCBS services must support full access to the community through competitive integrated employment; choice of service providers and settings, meaningful daily activities, and accessible physical environments; choice of where and with whom to interact; freedom to exercise individual rights of privacy, dignity, respect; and freedom from restraint and coercion.

The 2014 HCBS rule describes characteristics of settings that qualify for Medicaid HCBS funding, and describes additional requirements for services provided in provider-owned or controlled settings. For example, recipients living in provider-owned or controlled residences must have the same responsibilities and protections from eviction that tenants have under the landlord/tenant law of the state, county, city or other jurisdiction. They must also have privacy in their sleeping or living units, control over their schedules and activities, and access to food and visitors at any time.

Most provisions of the regulation became effective on March 17, 2014. However, states have until 2023 to implement the settings portion of the rule. By then, each state must have a transition plan approved by CMS describing how services and settings currently funded through a Medicaid

Waiver authority that are not fully compliant with the 2014 rule will be modified or how recipients in non-compliant settings will transition to a compliant service setting. Most states have had their plans initial plans approved. As of summer 2021, 21 states had their final plans approved.

The Americans with Disabilities Act and The Supreme Court's Olmstead Decision Enforcement

The Americans with Disabilities Act of 1990 (PL 101-336) spelled out the right of people with disabilities to be free of discrimination in employment, housing, and other key areas. It requires businesses and local governments to make reasonable accommodations to allow all people including those with disabilities to access and use their settings and services.

The Supreme Court in their 1999 Olmstead Decision established a right to "placement in the most integrated setting" under its interpretation of Title II of the Americans with Disabilities Act. The Court held that public entities must provide community-based rather than institutional services to people with disabilities when:

- such services are appropriate;
- the affected persons do not oppose community-based treatment; and
- community-based services can be reasonably accommodated, taking into account the resources available to the public entity and the needs of others who are receiving disability services from the entity (www.ada.gov/olmstead/olmstead_cases_by_issue.htm).

The United States Department of Justice's (DOJ) enforcement of the Olmstead Decision has produced pivotal settlement agreements in several states that continue to shape the availability and delivery of HCBS. Notably, the Rhode Island, Virginia, and Oregon agreements contain very specific requirements related to the nature and settings of services. See the Department of Justice Olmstead website for more information (<https://www.ada.gov/olmstead/>).

State Litigation and Policy Initiatives

Many states have been subject to individual or class action lawsuits related to reimbursement rates for Medicaid services, availability of Medicaid or state funded services and supports, or other elements of their LTSS systems. These cases influence state decisions regarding resources management, as well as the nature of services provided. State legislation and policy initiatives also influence service delivery options spurred through legislative activities, grassroots advocacy efforts, or executive branch efforts to address identified needs within the state. These efforts can sometimes change the landscape of service delivery and supports within the state.

Using long-term supports and services data to inform public policy

Policymakers are charged with creating systems to respond to the support needs of current and future generations of individuals with IDD. As the settings in which services are delivered continue to shift from institutional to home and community-based settings, families, advocates, policymakers, and other stakeholders need accurate and timely information on publicly-funded supports to assess system performance, implement appropriate policies and practices, evaluate state service systems against national trends, and to track effective practices. Decision makers need information about the numbers and ages of people served, the sizes and types of settings in which services are delivered, total and per-person expenditures, the types of Medicaid, state, and local funding authorities used, the characteristics and needs of service recipients, and of those waiting for services, and about individual and systems level performance outcomes. Information is needed about the extent to which funded programs support valued personal outcomes such as opportunities to build authentic relationships and to participate in and contribute to communities.

Data from the RISP project can help answer key questions about service delivery systems at the state and national levels such as:

- How many people have IDD?
- Of those people, how many are known to or served by the state IDD agencies?

- How many children versus adults are served by State IDD agencies?
- Where do people with IDD who receive LTSS live?
- How many people with IDD are waiting for Medicaid Waiver funded LTSS?
- How do service settings types and sizes differ by state, over time, and by funding authority?
- How do expenditures for services differ by funding authority, setting type, and recipient age?

Medicaid Basics

Medicaid LTSS programs are complex, with an array of statutory authorities requiring states to adhere a variety of different program rules. To participate in Medicaid, states must offer a specific set of services (mandatory benefits), and may choose to offer additional services (optional benefits). Similarly, states must cover some populations within the state (mandatory eligibility categories), and may choose to offer eligibility to additional groups of individuals (optional eligibility categories). All Medicaid programs generally must operate within a standard set of requirements, though Congress has enacted authority to waive some of those rules under certain circumstances.

The tree below illustrates key components of the Medicaid program. The roots represent the rules and statutes that apply to all Medicaid programs (largely but not exclusively contained at Section 1902 and Section 1903 of the Social Security Act). The tree's trunk represents the Medicaid State Plan services and eligibility groups (mandatory and optional) which serve as the backbone for state's Medicaid programs. The branches of the tree represent waivers or deviations from standard practice that states may choose to request to address the needs of specific groups of recipients. Finally, the leaves on the tree represent the individually tailored supports and services available to individuals receiving services through the array of Medicaid funding authorities selected by the state.

The roots and trunk of the Medicaid "tree" support and guide all state Medicaid programs, but each state uses a unique combination of branches and leaves to meet the local needs of its citizens. All states must offer eligible recipients a set of mandatory benefits such as inpatient and outpatient

hospital services, physician services, nursing facility services, Early and Periodic Screening, Diagnostic and Treatment Services, home health services, and laboratory and x-ray services (see <https://www.medicaid.gov/medicaid/benefits/mandatory-optional-medicaid-benefits/index.html> for a list of state plan benefits). States can choose whether to offer optional State Plan benefits such as occupational, physical, or speech therapy, dental care, case management, prescription drugs, personal care services, services in an Intermediate Care Facility for Individuals with Intellectual Disabilities and State Plan home and community-based services. State Plan services (whether mandatory or optional) must be available to all state Medicaid beneficiaries who need the service in sufficient amount, duration and scope to achieve their purpose (O’Keeffe, et al., 2010). States are not allowed to maintain waiting lists for State Plan benefits and State Plan benefits must be uniformly available statewide.

States may apply for waivers from certain Medicaid rules to offer services that do not conform to all of the rules that apply to State Plan services. Services funded through Medicaid funding authorities differ by state on many dimensions including but not limited to the following:

- **Eligibility criteria.** States are required to cover individuals within specific financial parameters (mandatory eligibility groups). States may elect to cover additional groups and/or income and/or resource levels (optional eligibility groups). In an HCBS 1915(c) waiver, a Special Income Level (SIL) group (further at 42 CFR 435.217) can be identified for whom income and resources differently are counted differently for eligibility purposes. In addition to being financially eligible, Medicaid HCBS waiver participants must meet clinical “institutional level of care” requirements. States also may choose to apply additional diagnostic or age-related eligibility restrictions.
- **Services offered and service definitions.** Service and program definitions vary from state to state. For example, many states offer a service called “Family Support.” What is included under that label, however, can be very different (ranging a single service such as respite, to an intensive array of 24-hour in-home support). Some Waiver funded services include annual or life-time caps on expenditures for participants.

- **Populations served.** States designate the populations to be served in their Medicaid Waiver program(s). Some waivers target only people with I/DD 18 years and older while others serve only children or serve people of any age. The age break between supports for children and for adults ranges from 18 years to 22 years. Some waivers target people with a specific diagnosis such as autism spectrum disorder or intellectual disabilities while others define eligibility in terms of functional support needs. While 1915(c) waivers originally were limited to a single population, states now have the option to include individuals with IDD, people with physical disabilities, older adults, and people with mental health diagnoses in a single waiver.
- **Medicaid authority options.** Medicaid authorities include state plan services, demonstration waivers, managed care waivers, and other waiver options. States may elect to offer Medicaid funded services through various service delivery models such as fee-for-services or managed care.
- These options result in very different Medicaid programs and LTSS offerings from state to state. Because each state’s program is different, it is important understand the state specific landscape in order to understand the full array of supports and services available to individuals with I/DD.

The RISP project collects a common core set of data from all state IDD agencies. However, interpreting the data properly requires an understanding of the state variations in eligibility criteria, service definitions, populations served and funding options. For example, the proportion of service recipients with IDD who live with a family member may differ depending on whether the IDD system serves both children and adults or only adults, because children are more likely than adults to live with a family member. Throughout this report, the narrative includes key considerations for interpreting specific tables and figures. Additional details about the survey questions and their operational definitions can be found in the appendix. Also in the appendix are state notes describing state-specific factors for interpreting the tables and charts. RISP project staff members are available to assist you to understand the findings (email: risp@umn.edu). As you examine specific findings, you may also want to check state IDD agency website, or with the IDD Agency

director for clarification. State-specific information is available on the following websites:

- The National Association of State Directors of Developmental Disabilities Services website (www.nasddds.org) lists state IDD agencies.
- The National Association of Councils on Developmental Disabilities website (<https://www.nacdd.org/>) lists state DD councils.
- The National Disability Rights Network website (<https://www.ndrn.org/>) lists member Protection and Advocacy (P&A) and Client Assistance Program (CAP) organizations.
- The Advancing States website (<http://www.advancingstates.org/>) hosts the home and community-based services clearinghouse.
- The RISP project website (<https://risp.umn.edu/>) publishes fact sheets, data visualizations, state profiles, and other resources.

THE RESIDENTIAL INFORMATION SYSTEMS PROJECT (RISP)

RISP is an Administration on Community Living (ACL) Longitudinal Data Project of National Significance (PNS) that maintains longitudinal records on residential and in-home supports for people with IDD. RISP reports chronicle the history of institutionalization, deinstitutionalization, and the development of community-based LTSS for people with IDD in the 50 U.S. states and the District of Columbia.

The RISP project is housed at the University of Minnesota's Institute on Community Integration in the Research and Training Center on Community Living. RISP staff members are employed by the University of Minnesota, the Human Services Research Institute (HSRI), and the National Association of State Directors of Developmental Disabilities Services (NASDDDS).

The RISP project, operating under a variety of names and funding sources, has collected and reported data on LTSS for people with IDD since 1977 and references historical records dating back to the 1880 U.S. Census (U.S. Census, 1893). Over the course of the project, state- and federally-funded LTSS for people with IDD shifted from being primarily provided in large segregated public IDD residential

facilities to supporting people to participate fully in home and community settings.

In 1977 and 1982, the University of Minnesota conducted national censuses of all state and non-state residential facilities for people with IDD (Bruininks, Hill & Thorsheim, 1982; Hauber, et. al., 1984). The use of public (state-operated) residential facilities serving 16 or more people was monitored by the Association of Professional Developmental Disabilities Administrators under the leadership of R.C. Scheerenberger from 1965 through 1991. Data were jointly published with the RISP annual report from 1983 to 1991, and have been published in the RISP annual report since 1991. Individual state profiles summarizing the status and trends in residential and community supports were added in 1995.

The RISP project has described LTSS for people with IDD receiving supports funded through the Medicaid ICF/IID and HCBS Waiver funding authorities annually since 1982. As Medicaid added new LTSS funding authorities, the project adjusted survey items to differentiate funding authorities in finer detail. At the request of AIDD and in consultation with state IDD agency directors, in 2013 we began collecting and reporting more details about the age of LTSS recipients with IDD, and about services provided to people living in their own homes or the home of a family member. We also developed new products translating RISP research findings into formats individuals with IDD, families and advocates can use. In 2015, to respond to the CMS Healthy People 2020 monitoring needs, we incorporated questions on children living in institutional settings into our annual data collection protocol. Finally, to respond to technical assistance requests from AIDD and other Federal and State agencies we added a table showing the estimated U.S. population with IDD by state.

In 2021, the RISP project published a joint report with the University of Massachusetts – Boston ThinkWork! Project and the University of Colorado, Boulder's State of the State project called *30 years of Community Living* in collaboration with a team of individual advocates with IDD. That book, available on the ACL website (www.ACL.gov/30years) translates key research findings from RISP and the

other projects into an easy to use report for the general public.

This Annual RISP report describes Medicaid and state-funded LTSS managed by, or under the auspices of, state IDD agencies in Fiscal Year (FY) 2018 (July 1, 2017 through June 30, 2018) and examines trends across time. The RISP report describes six dimensions of LTSS:

1. Type of entity managing or operating services (state or non-state)
2. Living arrangement (own home, family home, host or foster family home or group setting)
3. Setting size (number of service recipients sharing a home)
4. Recipient age (21 years or younger, or 22 years or older)
5. Funding authority (Medicaid ICF/IID, Waiver, State Plan; State only funding; or other)
6. Time (State Fiscal Year)

Study Methodology

RISP surveys are distributed electronically to state IDD Directors and designated data staff annually. RISP project staff review prior year study findings and provide instructions for completing the survey for respondents via an annual webinar. The staff team provides individual assistance to state respondents, reviews incoming surveys to identify missing data and inconsistencies, and works with states to ensure the published data are as accurate as possible.

Prior to 2007, the annual RISP survey of state IDD Directors were collected via a paper survey. The first online survey was used from 2007-2012. The online data collection system was redesigned and new features were added in 2013. State data providers and project staff can view previous year's data for each data element, and can assign special codes to indicate estimates, external data sources used, data imputed by project staff, and alternative dates if data were not available for the requested date. State data providers may enter notes to help research staff and readers of the report to interpret the data

correctly, or to record reasons for changes. Data proofing tools were added for the 2015 survey to assist states to identify possible arithmetic errors, inconsistencies within or across survey sections, and large year-to-year changes requiring explanation. Additional refinements were made as the online database moved to its current platform for the FY 2017 survey.

A separate survey of administrators of state-operated IDD facilities serving 16 or more people (PRF) was fielded in even numbered years from 1991 to 2016 in cooperation with the Association of Professional Developmental Disabilities Administrators (APDDA) and its predecessors. The survey was shortened and has been fielded annually since 2017. The sample frame was based on the 1977 census of PRFs. State-operated IDD facilities not in the 1977 sample are not surveyed. PRFs open on June 30 of the fiscal year are surveyed. The final disposition of facilities that close, no longer serve people with IDD, merge, or downsize to fewer than 16 people with IDD prior to June 30 are recorded. In some states, a designee from the state IDD agency completes the PRF surveys for all facilities in a state.

The PRF survey includes questions about characteristics such as age, gender, race, ethnicity and types of disabilities of people in residence on June 30, admissions, readmissions, discharges, and deaths during year, facility closures and planned closures, and average daily per person expenditures. Survey data are analyzed using Microsoft Excel and SPSS 23.0 software. Missing or inconsistent responses are confirmed in follow-up communications with the survey respondents.

Definitions

Caseload is the number of people known to the state office who are receiving services, waiting for services, or known to the state IDD agency but not receiving services. In some states, people in psychiatric or nursing home facilities are included in the IDD agency caseload. In other states, an office other than the state IDD agency manages their care. The caseload does not include people for whom eligibility for services has not yet been established.

Estimated Values are individual data elements whose value is estimated by the survey respondent.

2018

An “e” designates a value estimated by the state respondent.

Footnotes. Table and figure footnotes describe annotations and identify secondary data sources used.

Imputed Values are state specific estimates computed by RISP staff when incomplete information has been provided. An “i” designates values imputed by RISP project staff.

LTSS Recipients are people with IDD who receive one or more long-term support or service in addition to case management provided by, or under the auspices of, state IDD agencies.

Missing Data. Substantial state effort is required to compile data for the RISP survey. Occasionally, data reporting or collection activities exceed the state’s capacity, resulting in partial data. Footnotes identify instances where a value is based on incomplete information.

- If a state did not provide data for an item on the current year survey, but a value was provided for a prior or subsequent year, data from the adjacent year is used and flagged “d” other date.
- If a state does not furnish data for two or more years in a row, missing data are flagged “Data Not Furnished” (DNF)
- “Partial Data” (PD) signifies instances when some, but not all, of the data required for a computation were furnished by the state. Partial totals are reported for psychiatric facilities.
- Additional codes specify whether data were missing for state-operated settings, non-state settings or both.
- Not Applicable. N/A is used only in reference to expenditures when a state did not use a particular program, setting, or funding source.

Other Sources. The reference section lists other data sources referenced in this report. Data from

other sources is identified by the “s” footnote and the data source is specified.

Other Date. The footnote “d” indicates that the state provided data from a date other than June 30, 2018. Data flagged with the “d” footnote are from the immediately preceding or subsequent data year or in a few cases from a data other than June 30.

The **Reported Total** row shows the sum of the values provided by all reporting states without imputations for missing data.

United States Estimated Totals include imputations by project staff to replace missing data based on historical trends, national distributions of setting sizes, secondary data sources, and other questions on the survey. Rows or columns of tables are labeled as estimated totals when they contain imputed data to replace missing responses.

Setting Types. The RISP survey uses standard operational definitions for setting type and setting size. The categories were designed to be congruent with state administrative data sets. However, state service categories are not always completely consistent with the RISP definition. When a state uses a setting type or size definition that differs from the RISP operational definition, the variation is described in the state notes.

State Notes. States have considerable flexibility in how they provide services and administer Medicaid HCBS-funded services. This creates gaps, variations, or unique explanations for the data reported in the RISP report. State notes describe caveats or provide context to assist in interpreting state data.

The FY 2018 RISP survey and operational definitions are available at the end of the report.



SECTION ONE

**In-Home and
Residential Supports**

FY 2018

Where do people served by state IDD agencies live?

An estimated 1,308,659 people received long-term supports and services (LTSS) from state IDD agencies as of June 30, 2018

lived in a host home or with a foster family **5%** **23%** lived in a group IDD setting

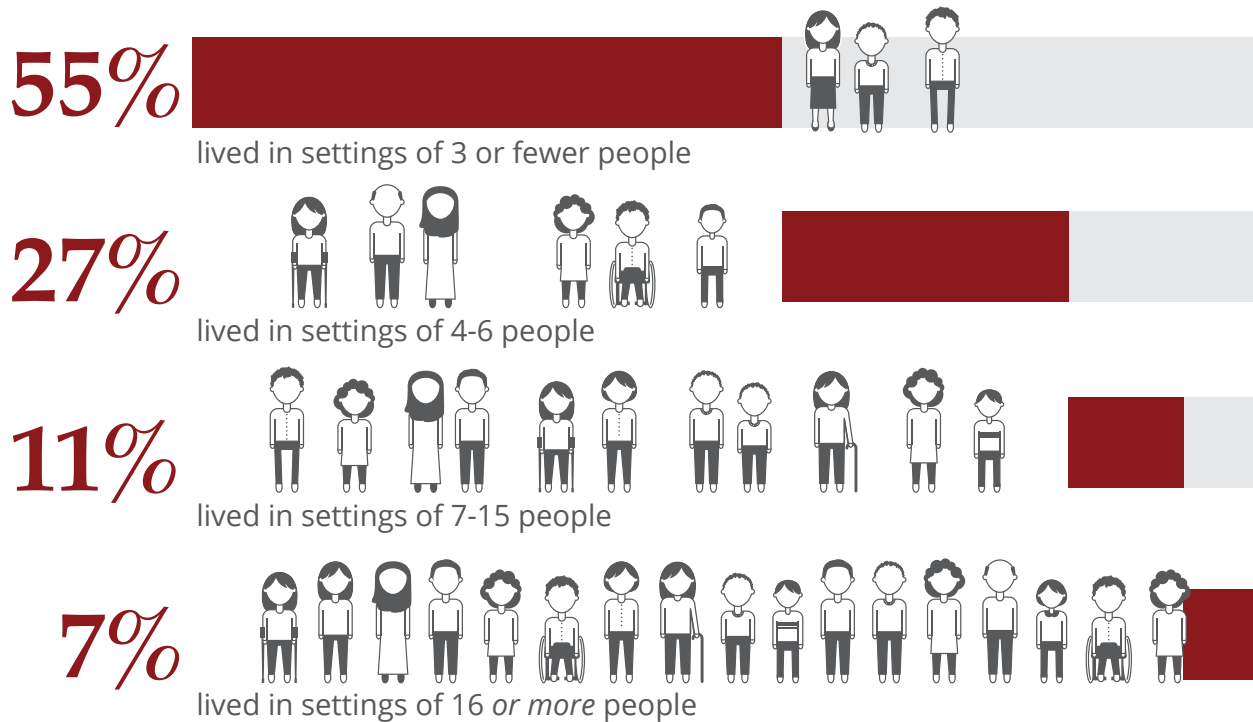


61% lived in the home of a family member

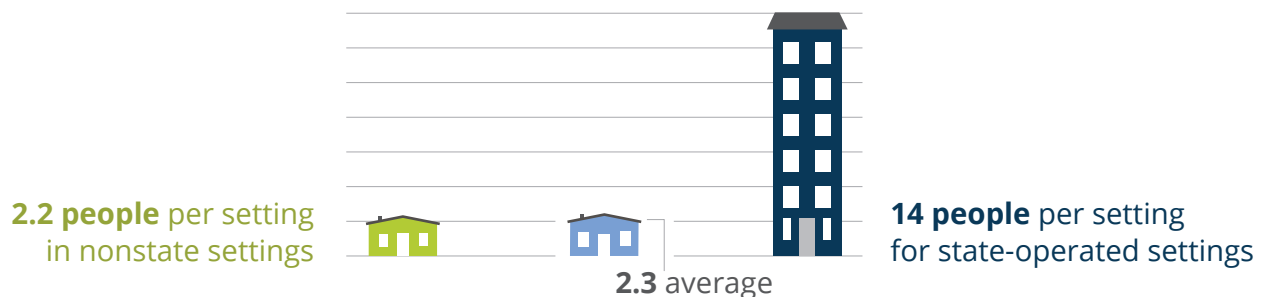
12% lived in a home they owned or leased

Note: These percentages exclude nursing home and psychiatric facilities

Of the estimated 516,629 LTSS recipients not living with a family member:



An average of 2.3 people lived in each non-family IDD setting



SECTION 1: IN-HOME AND RESIDENTIAL LONG-TERM SERVICES AND SUPPORTS (LTSS)

ESTIMATING PREVALENCE OF IDD IN THE UNITED STATES

Public health surveillance, administrative records and nationally representative surveys can be used to estimate the total number of people with IDD in the United States.

Public Health Surveillance

The CDC's Autism and Developmental Disabilities Monitoring Network (ADDM) network reviews educational and health records to estimate prevalence rates for autism spectrum disorder (ASD) for 8-year-old children in eleven states. For 2014, they reported that 16.8 per 1,000 children had ASD (Baio, et al., 2018). Using 2014 data, they estimated the prevalence of intellectual disabilities for 8-year-old children in nine geographic regions to be 11.8 per 1,000 children (Patrick et al., 2021).

Administrative Prevalence

The number of people with IDD in the United States can be estimated from records from agencies providing or administering services to people with disabilities. For example, an estimated 50.7 million students were enrolled in pre-K to grade 12 in US schools in 2018 (National Center for Education Statistics, 2019). Of those, 1.78 million students had intellectual disabilities (ID), ASD, developmental delay, or multiple disabilities. Amongst students 3 to 17 years, for every 1,000 students, 32.6 had IDD (13.8 had ASD, 7.3 had ID, 9.3 had a developmental delay, and 2.2 had multiple disabilities; Office of Special Education and Rehabilitative Services, 2020).

The Office of Special Education and Rehabilitative Services (2021) also reports the number of students ages 6 to 21 years educated in correctional facilities, homebound or hospitals, or residential facilities by disability type. In 2018, 10,375 students with disabilities were living in correctional facilities including 774 students with ASD, ID, or multiple disabilities; 23,812 were homebound or in hospitals, including 8,635 students with ASD, ID or multiple disabilities, and 14,081 were educated in

other residential facilities including 4,918 students with ASD, ID or multiple disabilities. In all, an estimated 14,327 (0.8%) of the 1.78 million students with ID, ASD or multiple disabilities ages 6 to 21 years received educational services while living in a residential school, a hospital, a correctional facility or while homebound.

Administrative data sets maintained by other federal and state agencies can also be used to estimate the administrative prevalence of various disabilities. For example, a study using Adoption and Foster Care Reporting System data for 46 states, DC and Puerto Rico estimated 2.6% of the children in the child welfare system in 1999 had ID (Slayter & Springer, 2011). In that study, of the 17,714 children in the child welfare system with IDD, 4,789 (27.1%) lived in a group home or institution. Another study using the 2014 data from the same data base reported that 3.7% of 7,117 youth ages 18 to 21 years in the foster care system had a diagnosis of ID (Cheatham, Randolph & Boltz, 2020).

In an analysis of the 31 million adults receiving care through Medicaid fee-for-service arrangements in 2016, an estimated 483,595 (1.56%) had IDD or related conditions (Reichard, Haile & Morris, 2019). An analysis of responses from the Social Security Administration's National Beneficiary Survey from 2004, 2006, 2006, and 2010 revealed that an estimated 1,326,794 Supplemental Security Income or Social Security Disability Insurance recipients ages 18 to 64 had intellectual disabilities (Livermore, Bardos & Katz, 2017).

The RISP project uses administrative data from state IDD agencies to estimate the number of people with IDD who receive publicly-funded LTSS through or under the auspices of those agencies.

U.S. Population-Based Surveys

Several U.S. population-based surveys managed by the National Center for Health Statistics include questions that might be used to identify and describe people with disabilities. The U.S. Department of Justice used the National Inmate

Survey to describe the prevalence of disabilities among prison and jail inmates. That survey asks three of the six disability questions from the American Community Survey (hearing, vision, and cognitive impairments). It also asks about difficulties walking or climbing stairs, dressing or bathing, or living independently. In 2011, 2.9% of state and federal prisoners and 5.8% of jail inmates had three or more of the listed disabilities (Bronson et al., 2015). However, it is unknown how many of those people had IDD.

The National Health Interview Survey (NHIS) is an annual nationally representative survey of the Civilian non-institutionalized U.S. population. In 1994 and 1995, the National Center on Health Statistics (NCHS) fielded a disability supplement to the annual NHIS survey (NHIS-D) that allowed researchers to identify sample members with ID, a closely related condition such as ASD, or DD based on having three or more substantial functional limitations as defined in the Developmental Disabilities Act of 1997. Researchers using the 1994/1995 NHIS-D estimated that the prevalence of IDD was 38.4 per 1,000 (3.8%) for children ages 5 years or younger, 31.7 per 1,000 (3.2%) for children 5 to 17 years, and 7.9 per 1,000 (0.79%) for adults 18 years or older (Larson, et al., 2001). Prevalence estimates for IDD in adults have not been updated using nationally representative data since 1995. The rate for children have been updated. Prevalence rates from the 2015 through 2018 NHIS were 2.5% for ASD, 1.2% for ID, and 4.1% for developmental delays amongst children ages 3 to 17 years (Zablotsky & Black, 2020). The combined prevalence rate of ASD, ID or other developmental delays was estimated to be 69.9 per 1,000 for 2016 (Zablotsky et al., 2017).

The estimated prevalence of ID, DD or ASD for children increased from 31.7 per 1,000 for children ages 5 to 17 years based on the 1995 NHIS-D to 69.9 per 1,000 for ID, ASD, or developmental delays in children ages 3 to 17 based on the 2016 NHIS. This increase is likely related to several factors. Most notably, the three or more substantial functional limitations definition of developmental disabilities used by Larson et al. (2001) was much more restrictive than the operational definition of developmental delays used by Zablotsky, et al. (2017). The dramatic increase in the estimated

prevalence of ASD between 1995 and 2016 is also a contributing factor.

The impact of differences in the operational definition of disability is illustrated in a 2019 Social Security Administration report that found that only 53% of youth deemed eligible for Supplemental Security Income at age 17 based on the childhood definition of disability continued to be eligible for benefits when the adult criteria focusing on impairments in substantial gainful employment was imposed at age 18 (Social Security Administration, 2019). Given these important differences in prevalence estimates based on how disability is defined, readers are cautioned not to project the number of 18-year-olds who might be eligible for IDD services using the 2016 prevalence estimates for children. The 1995 prevalence estimate for IDD in adults of 7.9 people per 1,000 of the population provides a more conservative, and likely more accurate rate to use to project the number of people who might be eligible for IDD services at age 18.

We applied the 1994/1995 NHIS-D prevalence rate of 7.9 per 1,000 for IDD in adults (Larson et al., 2001) and the 2016 NHIS prevalence of 69.9 per 1,000 for IDD in children (Zablotsky et al., 2017) to U.S. Census reports of the 2018 U.S. population by age (U.S. Census Bureau, Population Division, 2019) to estimate the number of people with IDD in the United States. In 2018, there were an estimated 5.1 million children ages birth to 17 years, 133,347 million young adults ages 18 to 21 years, and 1.86 million adults 22 years or older with ID in the noninstitutionalized US population. Since the NHIS sample frame excludes people living in congregate settings, we added 313,562 people with IDD who lived congregate settings of 4 or more people in FY 2018 resulting in a total estimate of 7,430,728 people with IDD (22.8 per 1,000) in 2018 (See **Table 1.1**). Including people living in congregate settings we estimate that there were 5,315,522 children and youth ages 21 years or younger and 2,117,727 adults ages 22 years or older in the U.S. on June 30, 2018.

IDD AGENCY CASELOADS

A state IDD agency caseload includes all people with IDD who receive publicly-funded LTSS through or under the auspices of the state IDD agency. The agency caseload also includes people with IDD who



Table 1.1 United States Population and People with IDD by Age and State on June 30, 2018

State	2018 US Population by age ⁵			Estimated Population with IDD					
	Age 0-17	Age 18-21	Age 22 +	Not in Congregate Settings (NHIS) ¹			Total	In Congregate Settings ²	Estimated Total All Ages
				Age 0-17	Age 18-21	Age 22+			
AL	1,091,834	253,847	3,528,162	76,319	2,005	27,872	106,197	2,455	108,652
AK	182,696	33,384	499,628	12,770	264	3,947	16,981	253	17,234
AZ	1,637,590	383,892	5,116,915	114,468	3,033	40,424	157,924	1,669	159,593
AR	702,704	159,104	2,142,663	49,119	1,257	16,927	67,303	3,594	70,897
CA	8,971,556	2,022,216	28,311,718	627,112	15,976	223,663	866,750	30,394	897,144
CO	1,263,753	283,456	4,108,137	88,336	2,239	32,454	123,030	1,171	124,201
CT	735,668	204,692	2,624,251	51,423	1,617	20,732	73,772	4,114	77,886
DE	203,712	47,828	710,521	14,239	378	5,613	20,230	640	20,870
DC	126,648	40,549	530,171	8,853	320	4,188	13,361	710	14,071
FL	4,221,995	961,457	15,992,965	295,117	7,596	126,344	429,057	14,206	443,263
GA	2,506,660	558,135	7,383,322	175,216	4,409	58,328	237,953	2,601	240,554
HI	302,741	57,237	1,015,338	21,162	452	8,021	29,635	495	30,130
ID	444,839	91,071	1,211,090	31,094	719	9,568	41,381	2,228	43,609
IL	2,854,914	645,187	9,195,256	199,558	5,097	72,643	277,298	21,546	298,844
IN	1,570,622	379,349	4,742,687	109,786	2,997	37,467	150,251	8,780	159,031
IA	729,325	183,567	2,233,925	50,980	1,450	17,648	70,078	4,288	74,366
KS	705,496	164,244	2,018,882	49,314	1,298	15,949	66,561	2,219	68,780
KY	1,007,203	231,209	3,205,957	70,403	1,827	25,327	97,557	2,081	99,638
LA	1,096,754	232,271	3,314,739	76,663	1,835	26,186	104,684	9,635	114,319
ME	250,303	63,139	1,024,248	17,496	499	8,092	26,087	969	27,056
MD	1,339,438	300,031	4,361,282	93,627	2,370	34,454	130,451	3,604	134,055
MA	1,364,784	408,686	5,104,231	95,398	3,229	40,323	138,950	7,640	146,590
MI	2,162,182	539,035	7,279,146	151,137	4,258	57,505	212,900	10,106	223,006
MN	1,302,437	282,849	4,018,825	91,040	2,235	31,749	125,024	8,330	133,354
MS	706,660	160,265	2,100,037	49,396	1,266	16,590	67,252	4,020	71,272
MO	1,376,605	312,215	4,413,931	96,225	2,466	34,870	133,561	3,686	137,247
MT	228,749	53,187	775,167	15,990	420	6,124	22,534	987	23,521
NE	476,237	108,096	1,334,676	33,289	854	10,544	44,687	1,489	46,176
NV	688,242	131,852	2,196,420	48,108	1,042	17,352	66,501	1,086	67,587
NH	257,787	73,421	1,020,951	18,019	580	8,066	26,665	533	27,198
NJ	1,951,181	426,118	6,499,333	136,388	3,366	51,345	191,099	9,646	200,745
NM	481,824	109,973	1,489,292	33,679	869	11,765	46,314	1,366	47,680
NY	4,070,683	994,841	14,439,884	284,541	7,859	114,075	406,475	39,438	445,913
NC	2,301,788	544,665	7,437,674	160,895	4,303	58,758	223,955	11,465	235,420
ND	178,054	44,261	528,592	12,446	350	4,176	16,972	1,417	18,389
OH	2,593,542	607,847	8,466,195	181,289	4,802	66,883	252,974	14,901	267,875
OK	954,512	209,972	2,756,308	66,720	1,659	21,775	90,154	4,233	94,387
OR	869,075	200,345	3,109,907	60,748	1,583	24,568	86,899	4,231	91,130
PA	2,650,621	673,682	9,470,317	185,278	5,322	74,816	265,416	10,484	275,900
RI	205,971	67,043	780,842	14,397	530	6,169	21,096	1,170	22,266
SC	1,106,758	254,060	3,681,850	77,362	2,007	29,087	108,456	4,666	113,122
SD	216,422	47,362	611,451	15,128	374	4,830	20,333	1,452	21,785
TN	1,508,345	335,130	4,907,557	105,433	2,648	38,770	146,851	2,738	149,589
TX	7,375,845	1,547,911	19,590,247	515,572	12,228	154,763	682,563	22,866	705,429
UT	929,678	190,738	2,028,297	64,984	1,507	16,024	82,515	2,079	84,594
VT	115,394	41,579	466,813	8,066	328	3,688	12,082	122	12,204
VA	1,865,959	439,392	6,080,693	130,431	3,471	48,037	181,939	9,240	191,179
WA	1,658,122	347,989	5,465,567	115,903	2,749	43,178	161,830	11,532	173,362
WV	364,436	87,933	1,350,951	25,474	695	10,673	36,841	1,360	38,201
WI	1,275,039	313,810	4,215,555	89,125	2,479	33,303	124,907	5,628	130,535
WY	134,539	29,191	410,779	9,404	231	3,245	12,880	520	13,400
US Total	73,317,922	16,879,313	235,303,345	5,124,923	133,347	1,858,896	7,117,166	316,083	7,433,249

⁵ U.S. Census Bureau, Population Division (2019). ¹ IDD prevalence rates for people 17 years or younger from 2016 National Health Interview Survey (NHIS) were 6.99% in 2016 (Zablotsky et al., 2017). IDD prevalence rates for people 18 years or older from the 1994/1995 NHIS-Disability Supplement were 0.79% (Larson, et al., 2001). The sample for the NHIS excludes people living in congregate or institutional settings. ² Congregate settings are residences in which 4 or more people with IDD live and include nursing homes and psychiatric facilities. Estimates for congregate settings use the most recent data available for each state which was not always 2018. The estimated totals do not account for state to state differences in prevalence rates.

Table 1.2 People Known to or Served by State IDD Agencies by Age on June 30, 2018

State	Number of People ¹			% of People	
	Birth-21	22+ years	All Ages	Birth-21	22+ years
N States	46	46	49	46	46
AL	292 ²	7,709 ¹	8,001 ¹	4	96
AK	508	1,532	2,040	25	75
AZ	28,784	14,262	43,046	67	33
AR	921 ^{6,1}	4,894 ^{6,1}	5,815 ^{6,1}	16	84
CA	145,023	136,705	281,728	51	49
CO	7,489	11,968	19,457	38	62
CT	4,243	12,795	17,038	25	75
DE	1,317	3,535	4,852	27	73
DC	71	2,265	2,336	3	97
FL	16,513	43,222	59,735	28	72
GA	DNF	DNF	DNF	DNF	DNF
HI	797	2,521	3,318	24	76
ID	4,294	3,940	8,234	52	48
IL	9,429	31,658	41,087	23	77
IN	10,843	21,837	32,680	33	67
IA	12,260	11,853	24,113	51	49
KS	4,296	8,931	13,227	32	68
KY	6,218 ⁶	9,418	15,636 ⁶	40	60
LA	13,168	26,518	39,686	33	67
ME	634	4,715	5,349	12	88
MD	6,004	19,833	25,837	23	77
MA	12,478	25,381	37,859	33	67
MI	17,771 ¹	32,471 ¹	50,242 ¹	35	65
MN	11,473	22,511	33,984	34	66
MS	DNF	DNF	6,871	DNF	DNF
MO	15,571	21,585	37,156	42	58
MT	1,827	2,730	4,557	40	60
NE	934	6,027	6,961	13	87
NV	2,705	4,344	7,049	38	62
NH	DNF	DNF	DNF	DNF	DNF
NJ	0	28,144	28,144	0	100
NM	3,043	6,413	9,456	32	68
NY	45,961	92,598	138,559	33	67
NC	11,836	21,224	33,060	36	64
ND	3,150	2,923	6,073	52	48
OH	53,007	54,198	107,205	49	51
OK	5,404	8,875	14,279	38	62
OR	11,001	15,725	26,726	41	59
PA	14,905	43,769	58,674	25	75
RI	325	4,018	4,343	7	93
SC	20,856	20,161	41,017	51	49
SD	1,591	3,013	4,604	35	65
TN	3,485	11,232	14,717	24	76
TX	DNF	DNF	46,246 ^{6,1}	DNF	DNF
UT	2,945	5,369	8,314	35	65
VT	1,454	3,158	4,612	32	68
VA	11,345 ¹	15,596 ¹	26,941 ¹	42	58
WA	17,967	36,613	54,580	33	67
WV	DNF	DNF	6,493	DNF	DNF
WI	11,963 ¹	36,013	47,976	25	75
WY	919	1,734	2,653	35	65
Reported Total	557,020	905,936	1,522,566	37	60
Estimated Total	572,521	974,348	1,546,869	37	63

² Other date (data from previous or next year). DNF Did not furnish. ⁶ Estimate. ¹ One or more component value imputed by RISP staff. ³ Source U.S. Census Bureau, Population Division (2018). * See state notes in Appendix. ¹ The caseload total includes people with IDD who receive services, are waiting for services or are known to but not receiving services under the auspices of the state IDD agency.

had requested and were waiting for services, as well as people known to state IDD agencies, but not receiving publicly funded LTSS on June 30, 2018. It does not include people with IDD served by other state agencies such as a department of education, child welfare, vocational rehabilitation, corrections, or a state Medicaid office operating separately from the IDD agency unless those individuals were also served by or known to the state IDD agency or residents of an ICF/IID.

On June 30, 2018, an estimated 1,546,869 people with IDD (21% of the estimated total people with IDD in the United States) were served by or known to their state IDD agency (See **Table 1.2**). The majority (63%, 972,814 people) were 22 years or older. State IDD agencies served an estimated 10.7% of children and youth ages 21 years or younger and 46.0% of adults 22 years or older with IDD.

The proportion of the state IDD caseload who were adults varied widely by state. States in which adults comprised 90% or more of the IDD agency caseload were New Jersey (100% were 22 years or older), the District of Columbia (97%), Alabama (96%), and Rhode Island (93%). States that served more children or youth than adults were Arizona (67% were 21 years or younger), Idaho and North Dakota (52%) and California, South Carolina, and Iowa (51%).

State differences in the age distribution of people on the IDD agency caseload reflect differences in state policy and practice with regard to which state agency administers services for various Medicaid funding authorities, whether the state IDD agency or another state agency manage services for children with IDD, and the menu of services offered.

LONG-TERM SERVICES AND SUPPORT SETTINGS

LTSS may be provided where a person lives, works, or participates as a community member. The RISP project tracks LTSS funded through Medicaid or state funding authorities that are state-operated (staffed by employees of a state agency) or non-state (staffed by employees of a private organization, local governmental agency and managed care entity).

We track the places LTSS recipients live regardless of which LTSS they receive or where the services

are delivered (some LTSS recipients with IDD receive employment, day habilitation, or community supports but do not receive funded residential or in-home supports). LTSS recipients with IDD live in many different settings including:

Family Home: A residence shared by a person with IDD, and his or her related family members in which the person receives long-term supports or services (e.g., respite care, homemaker services, personal assistance).

Own home: A home owned or rented by one or more persons with IDD in which the person receives LTSS. The own home category excludes residences owned, rented, or managed by a residential services provider or the provider’s agent.

Host/Foster Family Home: A home owned or rented by an individual or family in which they live and provide LTSS to one or more unrelated persons with IDD.

IDD Group Home: A residence owned, rented, or managed by the service provider, or the provider’s agent, to provide housing for persons with IDD in which staff provide care, instruction, supervision, and other support. This category does not include ICF/IID certified facilities.

Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID): Medicaid-certified institutions housing four or more people with IDD that provide comprehensive and individualized health care and rehabilitation services to promote their functional status and independence 24 hours per day/365 days per year.

Other non-state settings: Residential settings other than own home, family home, host/foster family home, IDD group home or ICF/IID operated by a non-state entity in which a person served by or under the auspices of the state IDD agency lives and receives LTSS. Examples of “other” settings include board care facilities, and assisted living facilities.

Non-state setting, type unknown: Some states are not able to identify the residential setting type for all LTSS recipients with IDD. Those states are asked to indicate the total number of people for whom setting type is not known. In some instances, states can identify people living in family home or own home settings combined, but are not able to specify how many are in each setting type. A set of imputation rules are used to estimate the number in own home versus family home settings for U.S. Estimated totals.

Other state settings: State-operated residences not certified as a Medicaid ICF/IID or funded by a Medicaid Waiver authority in which people with IDD served by or under the auspices of the state IDD agency live.

In addition to describing recipients living in family home, own home or host/foster family homes, we describe the following clusters of settings (See **Table B**):

- IDD Group (Group home, ICF/IID and other group settings),
- IDD Nonfamily (Own Home, Host/Foster Family, ICF/IID, Group home, and Other), and

Table B: Living Arrangements for LTSS Recipients with IDD

Residence Type	Service Operator		Setting Clusters			
	State Entity	Non-state Entity	IDD Group Home	IDD Nonfamily Setting	Any IDD Residence	All Settings
Family Home		X			X	X
Own Home		X		X	X	X
Host/Foster Family Home		X		X	X	X
Group Home (Not ICF/IID)	X	X	X	X	X	X
ICF/IID	X	X	X	X	X	X
Other	X	X	X	X	X	X
Nursing Home	X	X				X
Psychiatric Facility	X	X				X
Unknown		X				X

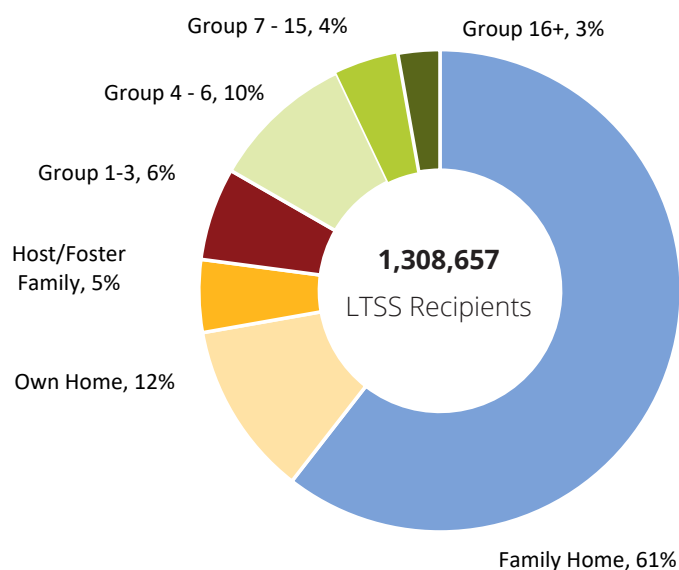
Table 1.3 LTSS Recipients with IDD by Setting Type, Type of Operation, and State on June 30, 2018

Setting Type	Non-State Settings							State-Operated Settings			Estimated Total Recipients ^f
	Family home	Own home	Host /Foster Family Home	Group not ICF/IID	ICF/IID	Other	Unknown	Group Waiver	ICF/IID	Group Other	
N States	41	46	48	48	51	49	49	51	51	51	51
AL	2,640 ⁱ	55	0	3,420 ⁱ	25	0	0	0	0	0	6,140
AK	178	575	108	654 ^e	14	0	525	0	0	0	2,054 ^e
AZ	36,439	276	1,543	3,134	38	5	0	133	0	0	41,568
AR	1,973	639	575	1,106	518	0	0	0	917	0	5,728
CA	192,592	26,265	6,224	20,193	6,567	0	0	0	534 ^e	0	252,375 ^e
CO	8,730	0	3,180	774	25	1,368	0	122	125	0	14,377
CT	4,649	1,441	380	3,883	358	213 ⁱ	0 ⁱ	213	349	0	11,486
DE	3,413	55	100	966	70	0	0	0	50	0	4,654
DC	859	8	93	1,052	309	18	0	0	0	0	2,339
FL	40,916	5,957	301	8,762	2,073	1,021	0	0	563	135	59,792
GA	DNF	DNF	DNF	DNF	0 ^s	0	0	0	116	59	8,781 ^{si}
HI	2,172	92	543	332	73	0	0	0	0	0	3,212
ID	DNF	DNF	552	217	421 ^e	0 ⁱ	DNF	0	23	0	8,680 ⁱ
IL	12,627	1,969	302	9,302	4,884	0	0	0	1,664	0	30,748
IN	19,297	2,514 ^e	300	5,006 ^e	3,159	0	0	0	0	0	30,276
IA	7,860 ^{ej}	7,185 ⁱ	0	1,649	1,095	387	0	0	346	0	18,522
KS	DNF	DNF	DNF	DNF	135	0	9,124	0	305	0	9,564 ^e
KY	DNF	DNF	1,844	2,815	472	0	10,664 ^e	0	263 ^{si}	0	16,058 ^{ss}
LA	DNF	2,264	10	0	4,134	0	0 ⁱ	0	519	0	16,520
ME	DNF	822	991	1,783	187	DNF	1,566 ^e	0	0	4	5,362
MD	124	4,571	244	6,268	0	0	5,330	0	95	0	16,631 ⁱ
MA	9,420	2,677	959	9,013	0	0	0	1,062	385	48	23,564
MI	29,603 ⁱ	10,077 ⁱ	464 ⁱ	9,194 ^{ej}	0 ^s	457 ⁱ	0 ⁱ	0 ⁱ	0 ⁱ	0 ⁱ	49,795 ⁱ
MN	13,475 ^e	3,471 ^e	873 ^e	8,318 ^e	1,170	6,224 ^e	0	359	13	0	34,161 ⁱ
MS	2,512 ^e	174	0	602	686 ^s	0	0	189	1,439	3	5,605
MO	12,115	4,956	489	1,842	75	0	0	217	321	0	20,025
MT	DNF	DNF	46	855	0	11	0	0	1	11	2,758
NE	2,148	1,177	845	1,248	239	0	0	0	109	0	5,800 ^{si}
NV	4,852	1,841	170	0	43	102	0	0	41	0	7,049
NH	DNF	0	DNF	DNF	20 ⁱ	DNF	DNF	0 ⁱ	0 ⁱ	6 ⁱ	6,462
NJ	14,883	59	554	8,438	60	619	0	0	1,325	0	25,938 ^e
NM	3,456	344	0	1,152	278	0	0	71	4	0	5,306
NY	89,066 ⁱ	11,795	1,584	24,887	4,167	0	0	6,420	373	0	138,862
NC	DNF	274 ^e	2,307	4,073 ^e	2,880 ^e	167 ^e	0 ⁱ	0	1,099	181	29,729 ^{ej}
ND	2,928	1,338	14	349	460	0	0	0	68	0	5,157
OH	80,284	15,380	2,364	2,547	4,720	1,260	0	0	650	0	107,205
OK	1,895	2,451 ^e	325 ^e	844 ^e	1,367 ^s	0	0	0	0	0	6,931 ⁱ
OR	14,153	708	3,304	3,020	0	0	0	0	0	92	21,277
PA	22,712 ^e	3,368 ^e	1,476	11,669	1,912	2,270	48	0	779	0	44,295 ⁱ
RI	1,636	517	369	1,086	0	0	0	130	10	0	3,775
SC	16,062	696	179	3,035	499	0	0	0	672	0	21,143
SD	DNF	536	1	1,825	61 ^s	0	0	0	115	0	3,990 ⁱ
TN	6,991	3,986	476	569	883	6	0	0	149	0	13,062 ⁱ
TX	11,287	3,623	13,698	8,588	4,893	0	1,178	0	2,979	0	46,246
UT	1,787 ^e	1,262 ^e	445	1,847 ^e	593 ^e	0	0	0	185	0	6,119
VT	2,292	543	1,376	142	6	0	253 ^e	0	0	0	4,612 ^e
VA	4,296	807	2,176	6,963	538	0	0	0	155	0	14,935
WA	15,026	13,024	633	3,986	1	1,202	0	328	668	0	34,899
WV	2,218	857	214	1,344	517	0	0	0	0	0	5,150
WI	29,539	7,017	6,842	3,612	86	19	0	0	308	0	47,548
WY	1,120	476	52	618	0 ^s	7	54	0	59	8	2,394
Reported US Total	730,225	148,122	59,525	192,982	50,711	15,356	28,742	9,244	17,776	547	
Estimated US Total	792,030	153,092	63,689	203,700	51,775	16,413	0	9,142	18,271	547	1,308,659

DNF Did not furnish. PD Partial data. ^a Missing values (DNF) assumed to be zero. ^d Other date (data from previous or next year). ^e Estimate. ⁱ One or more component value imputed by RISP staff. ^s See state notes in Appendix. g A few states could not separate out people living in their own home versus a family home and reported those groups together in either the other or unknown category, those people were reallocated for the US estimated total.



Figure 1.1 LTSS Recipients with IDD by Residence Type and Size (Excluding people in Nursing Homes and Psychiatric Facilities) on June 30, 2018



The total includes people in settings of unspecified size or type. Percentages are based on settings of known type and size

- All IDD Settings (Family home, Own Home, Host/Foster Family Home, Group Home, ICF/IID and Other).
- All LTSS Settings (Family home, Own Home, Host/Foster Family Home, Group Home, ICF/IID, Other, nursing home, psychiatric facility, and LTSS recipients with IDD in an unknown type of residence).

Of the 1.54 million people served by state IDD agencies, an estimated 85% (1,307,800 people) received publicly funded LTSS. An estimated 18% of the people with IDD in the U.S. received LTSS as reported by state IDD agencies (See **Table 1.3**). Of those people, an estimated

- 98% (1,280,699 people) received LTSS from a non-state entity, including:
 - 792,030 who lived in the home of a family member,
 - 153,092 who lived in a home they owned or leased,
 - 63,689 who lived in a host/foster family home,

Table 1.4 LTSS Recipients with IDD Living with a Family Member by State on June 30, 2018

State	LTSS Recipients Served by State IDD Agencies		
	Estimated Total	Number Living with Family	% Living with Family
N States	51	41	41
AL	6,140 ^d	2,640	43
AK	2,054 ^e	178	9
AZ	41,568	36,439	88
AR	5,728	1,973	34
CA	252,375 ^c	192,592	76
CO	14,377	8,730	61
CT	11,486	4,649	40
DE	4,654 ^d	3,413 ^d	73
DC	2,339	859	37
FL	59,792	40,916	68
GA	8,781 ^g	DNF	DNF
HI	3,212	2,172	68
ID	8,680	DNF	DNF
IL	30,748	12,627	41
IN	30,276	19,297	64
IA	18,522	7,860 ^h	42
KS	9,564 ^e	DNF	DNF
KY	16,058 ^g	DNF	DNF
LA	16,520 ^d	DNF	DNF
ME	5,362	DNF	DNF
MD	16,631	124	1
MA	23,564	9,420	40
MI	49,795 ^c	29,603 ^c	59
MN	34,161 ⁱ	13,475 ^c	39
MS	5,605 ⁱ	2,512 ^e	45
MO	20,025	12,115	60
MT	2,758	DNF	DNF
NE	5,800 ^h	2,148	37
NV	7,049	4,852	69
NH	6,462	DNF	DNF
NJ	25,938 ^f	14,883	57
NM	5,306	3,456	65
NY	138,862 ^h	89,066 ⁱ	64
NC	29,729 ^h	DNF	DNF
ND	5,157	2,928	57
OH	107,205	80,284	75
OK	6,931	1,895	27
OR	21,277	14,153	67
PA	44,295 ^e	22,712 ^f	51
RI	3,775	1,636	43
SC	21,143	16,062	76
SD	3,990 ^h	DNF	DNF
TN	13,062	6,991	54
TX	46,246	11,287	24
UT	6,119	1,787 ^f	29
VT	4,612 ^f	2,292	50
VA	14,935	4,296	29
WA	34,899	15,026	43
WV	5,150	2,218	43
WI	47,548	29,539	62
WY	2,394	1,120	47
Reported US Total		730,225	
Estimated US Total	1,308,659	792,030	61

DNF Did not furnish. ^d Other date (data from previous or next year). ^e Estimate. ⁱ One or more component value imputed by RISP staff. * See state notes in Appendix.

- 203,700 who lived in a non-state IDD group home,
- 51,775 who lived in a non-state ICF/IID, and
- 16,412 who lived in another type of non-state setting, and
- 2% (27,960 people) received LTSS while living in a state-operated residential setting including:
 - 18,271 who lived in a state-operated Medicaid-certified ICF/IID, and
 - 9,142 who lived in a Medicaid Waiver funded state-operated IDD group settings, and
 - 547 who lived in a state-operated group residence funded by another funding authority

The most common living arrangements for LTSS recipients with IDD by state were:

- Family home in 32 states (Arizona, Arkansas, California, Colorado, Connecticut, Delaware, Florida, Hawaii, Illinois, Indiana, Iowa, Massachusetts, Minnesota, Mississippi, Missouri, Nebraska, Nevada, New Jersey, New Mexico, New York, North Dakota, Ohio, Oregon, Pennsylvania, Rhode Island, South Carolina, Tennessee, Vermont, Washington, West Virginia, Wisconsin, and Wyoming),
- Group homes in nine states (Alabama, Alaska, the District of Columbia, Maine, Maryland, Montana, South Dakota, Utah, and Virginia),
- Host/family foster home in two states (Idaho and Texas), and
- Own Home settings in one state (Oklahoma),
- Unknown due to missing data in seven states (Georgia, Kansas, Kentucky, Louisiana, Michigan, New Hampshire, and North Carolina).

Excluding people with IDD living in nursing homes or psychiatric facilities there were an estimated 1.3 million LTSS recipients with IDD (See **Figure 1.1**). Of those, an estimated:

- 61% lived in the home of a family member,
- 23% lived in a non-family setting of 3 or fewer people including
 - 12% in an “own home” setting,
 - 6% in an IDD group setting of 3 or fewer people,
 - 5% in a host/foster family home, and

- 17% lived in an IDD group setting of four or more people including:
 - 10% in an IDD group setting of 4 to 6 people,
 - 4% in an IDD group setting of 7 to 15 people, and
 - 3% in an IDD group setting of 16 or more people (See **Figure 1.1**).

Home of a Family Member

On June 30, 2018, an estimated 792,030 LTSS recipients with IDD lived in the home of a family member (See **Table 1.4**). The proportion of LTSS recipients living in the home of a family member ranged from 1% in Maryland to 88% in Arizona (See **Figure 1.2**). Ten states were not able to report the number of LTSS recipients living in the home of a family member.

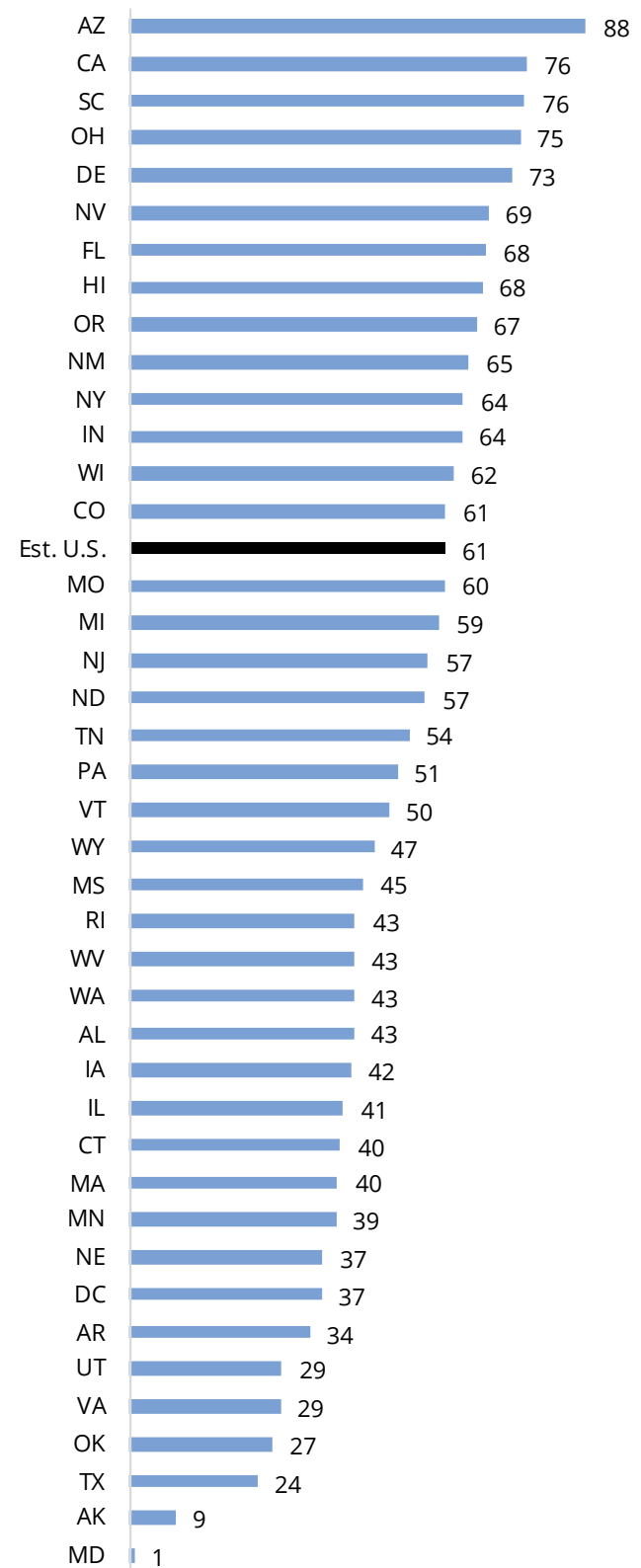
- States reporting three fourths or more LTSS recipients with IDD lived with family members were Arizona (87%), California (76%), South Carolina (76%), and Ohio (75%).
- States reporting one fourth or fewer LTSS recipients with IDD lived with family members were Maryland (1%), Alabama (9%), and Texas (24%).

Differences in the proportion of LTSS recipients living with family members are often related to whether the state IDD agency provides LTSS to children with IDD, and to the proportion of LTSS recipients who are 21 years or younger. For example, in Arizona where 88% of LTSS recipients lived with a family member, 67% of LTSS recipients served by the state IDD agency were 21 years or younger. Conversely, in Maryland, where 1% of recipients lived with a family member, only 23% of LTSS recipients served by the state IDD agency were 21 years or younger. Variations may also be related to the use of different eligibility criteria for LTSS or the availability of different service options.

Own Home

An estimated 30% of LTSS recipients with IDD (153,092 of 516,092 people) who did not live with a family member lived in a home they owned or leased (Own Home) on June 30, 2018 (See **Table 1.5**). Five states were not able to report the number of LTSS recipients who lived in an own home setting.

Figure 1.2 Percent of LTSS Recipients with IDD Living with a Family Member by State on June 30, 2018



Note: VY 2018 Family home data not available from GA, ID, KS, KY, LA, ME, MT, NH, NC, SD.

Table 1.5 LTSS Recipients with IDD in Own Home Settings by State and Setting Size on June 30, 2017

Setting Size	Own Home Settings				Non-Family Setting	
	1 to 3	4 to 6	Unknown	Total	Estimated Total ¹	In Own Home (%)
N States	35	35	41	44	51	44
AL	55	0	0	55	4,159	1
AK	705 ^d	0 ^d	0	705	1,627	43
AZ	265	0	0	265	5,066	5
AR	613	26	0	639	3,745	17
CA	25,968	0	0	25,968	59,627	44
CO	DNF	DNF	5,120	5,120	10,614	48
CT	1,455	0	0	1,455	6,921	21
DE	18	0	0	18	1,239	1
DC	15	0	0	15	1,448	1
FL	5,742 ^d	0 ^d	0	5,742	17,748	32
GA	1,107 ^d	38 ^d	0	1,145 ^d	5,575	21
HI	77	0	0	77	790	10
ID	DNF	DNF	0	2,464 ^d	5,278	47
IL	1,050	933	0	1,983	18,295	11
IN	6,147	302	0	6,449	10,542	61
IA	DNF	DNF	DNF	DNF	9,064	DNF
KS	DNF	DNF	DNF	DNF	3,478	DNF
KY	DNF	DNF	DNF	DNF	7,150	DNF
LA	DNF	DNF	DNF	DNF	19,223	DNF
ME	729 ^e	0	0	729	3,675	20
MD	3,838	9	0	3,847	13,973	28
MA	DNF	DNF	0	2,702	14,095	19
MI *	DNF	DNF	DNF	DNF	19,004	DNF
MN	3,471 ^d	0	0	3,471 ^d	20,686	17
MS	78	0	0	78	3,131	2
MO	4,748	0	0	4,748	7,845	61
MT	DNF	DNF	DNF	143 ^d	1,132	13
NE	1,172	5	0	1,177	3,644	32
NV	1,043	578	0	1,621	2,045	79
NH	DNF	DNF	DNF	DNF	2,114	DNF
NJ	79	0	0	79	11,161	1
NM	DNF	DNF	0	DNF	3,251	DNF
NY	11,734 ^d	0 ^d	0 ^d	11,734 ^d	50,098	23
NC	47 ^e	0 ^e	161 ^e	208	11,376	2
ND	1,293	0	0	1,293	2,151	60
OH	15,048	851	0	15,899	27,432	58
OK	2,451 ^d	0 ^d	0	2,451 ^d	5,006	49
OR	709	0	0	709	7,112	10
PA	3,485 ^e	0	0	3,485	21,725	16
RI	510	0	0	510	2,136	24
SC	704	0	0	704	5,099	14
SD	DNF	DNF	DNF	536 ^d	2,554	21
TN	4,084	0	0	4,084	6,220	66
TX	DNF	DNF	DNF	3,821 ^d	34,601	11
UT	1,229	0	0	1,229	4,335	28
VT	546 ^e	0	0	546	2,070	26
VA	DNF	DNF	DNF	230 ^d	9,322	2
WA	5,540	107	0	5,647	8,715	65
WV	857	0	0	857	1,722	50
WI	DNF	DNF	0	6,512 ^e	17,452	37
WY	DNF	DNF	0	456	1,229	37
Reported US Total	106,612	2,849	5,281	130,348		
Estimated US Total	148,831	3,928	0	152,759	516,505	30%

DNF Did not furnish. PD Partial data. ^d Other date (data from previous or next year). ^e Estimate. ¹ Total is larger than component parts due to unknown settings or sizes. ² One or more component value imputed by RISP staff. * See state notes in Appendix. ³ All non-family includes people in state and non-state IDD group homes or facilities, own home, host/foster family home and other non-state settings (estimates are used when states did not furnish complete information) but excludes people in family homes.

Fewer than 2% of people in non-family settings lived in Own Home settings in Alabama (0.9%), Arizona (0.7%), Colorado (0%), Delaware (1.2%), the District of Columbia (0.3%), New Jersey (0.2%), and North Carolina (0.9%). States with the highest percentages of LTSS recipients with IDD in own home settings were Iowa (38.8%), Oklahoma (35.9%), Tennessee (30.5%), and Washington (36.4%).

Overall, 94% of people with IDD in Own Home settings lived with two or fewer other LTSS recipients, while 6% shared their home with three or more other LTSS recipients. In 32 states, all of the people in Own Home settings shared their home with two or fewer other LTSS recipients. By contrast, 47% of people with IDD in Own Home settings in Illinois lived in own home settings shared by 4 or



more LTSS recipients, as did 40% in Washington, and 34% in Nevada.

Host/Family Foster Home

An estimated 12% of LTSS recipients with IDD (63,689 people) not living with a family member lived in an estimated 37,651 host or foster family homes (See **Table 1.6**) on June 30, 2018. Of those living with a Host or Foster Family, an estimated:

- 93.2% (59,328 people) lived in homes shared by three or fewer people with IDD,
- 6.6% (4,226 people) lived in homes of four to six people with IDD, and
- 0.2% (135 people) lived in homes of seven to fifteen people with IDD.

On average 1.7 people with IDD lived in each host or foster family home. The average number of LTSS recipients with IDD per home was 2.0 or more people in Colorado, Montana, New Jersey, Oregon, and Wisconsin.

Group IDD Settings

An estimated 58% of LTSS recipients with IDD (298,390 people) who did not live with a family member lived in an IDD group home, Medicaid ICF/IID, or another IDD group setting (See **Table 1.7**). Group IDD settings do not include Own Homes, Host or Foster Family Homes, or Family Homes, nor do they include Nursing Homes or Psychiatric Facilities.

There were an estimated 77,487 IDD group settings on June 30, 2018. Of those,

- 56% (43,189 settings) served three or fewer people
- 35% (26,919 settings) served four to six people,
- 8% (6,442 settings) served 7 to 15 people, and
- 1% (934 settings) served 16 or more people.

While 90% of IDD group settings housed six or fewer LTSS recipients, the proportion varied by state ranging from less than half in Arkansas (49%), Iowa (41%), and Nevada (11%) to more than 95% in 17 states.



Table 1.6 Host or Foster Family Homes and LTSS Recipients with IDD in Them by Setting Size and State on June 30, 2018

Setting Size	Host/Family Foster Settings by Size						People in Host/Family Home by Setting Size					
	1-3	4-6	1-6	7-15	Unknown	Total	1-3	4-6	1-6	7-15	Unknown	Total
N States	40	42	40	47	44	41	43	43	44	48	48	48
AL	0	0	0	0	0	0	0	0	0	0	0	0
AK	94	0	94	0	0	94	108	0	108	0	0	108
AZ	1,033	1	1,034	0	0	1,034	1,539	4	1,543	0	0	1,543
AR	575	0	575	0	0	575	575	0	575	0	0	575
CA	DNF	0	DNF	0	0	DNF	6,224	0	6,224	0	0	6,224
CO	1,590	0	1,590	0	0	1,590	3,180	0	3,180	0	0	3,180
CT	260	0	260	0	0	260	380	0	380	0	0	380
DE	86	0	86	0	0	86	100	0	100	0	0	100
DC	73	0	73	0	0	73	93	0	93	0	0	93
FL	DNF	DNF	DNF	DNF	0	DNF	66	139	205	96	0	301
GA	DNF	DNF	DNF	0	0	DNF	DNF	DNF	DNF	0	0	DNF
HI	295	0	295	0	0	295	543	0	543	0	0	543
ID	384	22	406	0	0	406	507	45	552	0	0	552
IL	227	0	227	0	0	227	302	0	302	0	0	302
IN	226	4	230	0	0	230	284	16	300	0	0	300
IA *	0	0	0	0	0	0	0	0	0	0	0	0
KS	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
KY	997 ^g	0	997 ^g	0	0	997 ^g	1,844	0	1,844	0	0	1,844
LA	10	0	10	0	0	10	10	0	10	0	0	10
ME	914	3	917	1	0	918	969	12	981	10	0	991
MD	217	0	217	0	0	217	244	0	244	0	0	244
MA	DNF	0	DNF	0	DNF	DNF	959	0	959	0	0	959
MI	DNF	DNF	DNF	0	DNF	DNF	DNF	DNF	DNF	0	DNF	464 ^f
MN	640 ^e	15 ^e	655 ^e	0	0	655 ^e	812 ^e	61 ^e	873 ^e	0	0	873 ^e
MS	0	0	0	0	0	0	0	0	0	0	0	0
MO	445	0	445	0	0	445	489	0	489	0	0	489
MT	DNF	DNF	DNF	0	16	16	DNF	DNF	DNF	0	46	46
NE	688	2	690	0	0	690	832	13	845	0	0	845
NV	142	0	142	0	0	142	170	0	170	0	0	170
NH	DNF	DNF	DNF	0	DNF	DNF	DNF	DNF	DNF	0	DNF	DNF
NJ	273	0	273	0	0	273	554	0	554	0	0	554
NM	0	0	0	0	0	0	0	0	0	0	0	0
NY	884	50	934	0	0	934	1,380	204	1,584	0	0	1,584
NC	739	0	739	0	701	1,440	755	0	755	0	1,552	2,307
ND	14	0	14	0	0	14	14	0	14	0	0	14
OH	2,089	0	2,089	0	0	2,089	2,364	0	2,364	0	0	2,364
OK	325 ^e	0	325 ^e	0	0	325 ^e	325	0	325	0	0	325 ^e
OR	669	671	1,340	14	0	1,354	1,034	2,241	3,275	29	0	3,304
PA	1,191	0	1,191	0	0	1,191	1,476	0	1,476	0	0	1,476
RI	369	0	369	0	0	369	369	0	369	0	0	369
SC	139	0	139	0	0	139	179	0	179	0	0	179
SD	1	0	1	0	0	1	1	0	1	0	0	1
TN	372	8	380	0	0	380	476	0	476	0	0	476
TX	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	13,698	13,698
UT	389 ^e	0	389 ^e	0	0	389 ^e	445	0	445	0	0	445
VT	1,236	0	1,236	0	0	1,236	1,376	0	1,376	0	0	1,376
VA	DNF	DNF	DNF	0	DNF	DNF	DNF	DNF	2,176	0	0	2,176
WA	387	8	395	0	0	395	593	40	633	0	0	633
WV	168	0	168	0	0	168	214	0	214	0	0	214
WI	1,753	0	1,753	0	0	1,753	6,842	0	6,842	0	0	6,842
WY	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	52	52
Reported US Total	19,894	784	20,678	15	717	21,410	38,627	2,775	43,578	135	15,348	59,525
Estimated US Total	36,378	1,244	37,622	29	0	37,651	59,328	4,226	63,554	135	0	63,689

DNF Did not furnish. PD Partial data. ^d Other date (data from previous or next year). ^e Estimate. * See state notes in Appendix.



Table 1.7 Group LTSS Settings and People with IDD Living in them by Setting Size and State on June 30, 2018

Setting Size	Number of Group Settings ¹						Number of People in Group IDD Settings						
	1-3	4-6	1-6	7-15	16+	All Sizes	1-3	4-6	1-6	7-15	16+	Size Unknown	All Sizes
N States	40	37	40	40	42	42	41	36	39	39	41	47	48
AL	961	111	1,072	78	0	1,150	2,201	454	2,655	790	0	0	3,445
AK	201	200	401	24	11	436	507 ^e	PD	PD	PD	PD	14	668 ^f
AZ	739	285	1,024	3	2	1,029	1,742	1,428	3,170	22	118	0	3,310
AR	99	20	119	99	25	243	106	56	162	925	1,454	0	2,541
CA	PD	PD	5,299	115	57	5,471	PD	PD	24,390	986	1,918 ^e	0	27,294 ^e
CO	746	214	960	15	2	977	1,371	889	2,260	105	49	0	2,414
CT	692	568	1,260	26	6	1,292	1,669	2,793	4,462	193	361	0	5,016
DE	278	89	367	0	2	369	587	379	966	0	120	0	1,086
DC	473	83 ^e	556	0 ^e	0 ^e	556	990	389 ^e	1,379	0 ^e	0 ^e	0 ^e	1,379
FL	PD	PD	PD	PD	PD	PD	253	7,176	7,429	1,658	2,446	1,021	12,554 ^f
GA	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD
HI	0	185	185	3	0	188	0	368	368	37	0	0	405
ID	0	PD	PD	PD	PD	143 ^f	0	PD	PD	PD	PD	421	661 ^f
IL	134	914	1,048	825	43	1,916	235	4,126	4,361	7,164	4,325	0	15,850
IN	1,570 ^e	398 ^e	1,968 ^e	324 ^e	2	2,294 ^e	4,002 ^e	1,744 ^e	5,746 ^e	2,369 ^e	50	0	8,165 ^e
IA	107	116	223	113	213	549	1,063	450	1,513	815	1,149	0	3,477
KS	PD	PD	PD	PD	2	PD	PD	PD	PD	PD	305	PD	PD
KY	1,146	42	1,188	11	7	1,206	2,643	198	2,841	176	533	0	3,550
LA	1	281	282	246	12	540	1	1,644	1,645	1,963	1,045	0	4,653
ME	670	106	776	13	3	792	1,326	465	1,791	135	48	0	1,974
MD	1,721	489	2,210	25	2	2,237	3,914	2,168	6,082	186	95	0	6,363
MA	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	10,123	10,508 ^f
MI	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	9,651 ^f
MN	PD	PD	9,677 ^e	36	10	9,723 ^e	PD	PD	15,511 ^e	323	250	0 ^e	16,084 ^e
MS	17	164	181	39	14	234	74	745	819	515	1,585	0	2,919
MO	131	194	325	111	8	444	329	881	1,210	872	373	0	2,455
MT	12	78	90	55	0	150 ^f	31	403	434	433	0	11	878 ^f
NE	425	103	528	26	3	557	727	421	1,148	140	308	0	1,596
NV*	2	4	6	0	51	57	2	25	27	0	159	0	186
NH	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD
NJ	1,125 ^e	1,395	2,520 ^e	78	8	2,606 ^e	2,249	5,484	7,733	689	2,020	0	10,442
NM	DNF	DNF	334	15	1	350	PD	PD	1,329 ^f	160	16	0	1,505
NY	2,153	2,582	4,735	1,942	34	6,711	3,945	13,088	17,033	17,619	1,195	0	35,847
NC	328	882	1,210	45	18	1,275 ^f	366	1,453 ^e	1,819 ^e	111 ^e	1,494 ^e	4,976 ^e	8,400 ^f
ND	1	68	69	50	2	121	3	361	364	415	98	0	877
OH	202	527	729	270	62	1,061	362	2,497	2,859	2,259	2,799	1,260	9,177 ^f
OK	0	PD	PD	PD	PD	224 ^f	0	PD	PD	PD	PD	1,367	2,211 ^f
OR	488	373	861	15	13	889	1,292	1,698	2,990	97	25	0	3,112
PA	4,432 ^e	726 ^e	5,158	53 ^e	23 ^e	5,234 ^e	8,992	3,085	12,077	414	1,869	2,270 ^e	16,630 ^f
RI	91	193	284	28	0	312	179	925	1,104	122	0	0	1,226
SC	177	560	737	102	5	844	447	2,251	2,698	836	672	0	4,206
SD	532	93	625	73	2	700	698	466	1,164	661	176	0	2,001
TN	117	147	264	73	1	338	285	646	931	600	76	0	1,607
TX	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	8,592	16,460 ^f
UT	815 ^e	95 ^e	910 ^e	7 ^e	17	934 ^e	1,312 ^e	PD	PD	PD	PD	593	2,625 ^f
VT	42	17	59	0	0	59	63	85	148	0	0	0	148
VA	0	PD	PD	PD	4	PD	0	PD	PD	PD	271	7,385	7,656 ^f
WA	707	313	1,020	161	7	1,510 ^f	1,250	1,548	2,798	1,468	717	1,202	6,185 ^f
WV	696 ^e	16	712	54	0	766	1,229	207	1,436	425	0	0	1,861
WI	0 ^e	570 ^e	570 ^e	1	21	592 ^e	0	3,612	3,612	8	386	19	4,025 ^f
WY	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	625	692 ^f
Reported US Total	22,059	15,492	51,458	5,266	821	58,084	46,495	77,083	157,824	46,585	32,677	39,879	286,616
Estimated US Total	43,189	26,919	70,108	6,442	935	77,485	81,377	126,010	207,392	55,758	36,698	0	299,848

DNF Did not furnish. PD Partial data. * Other date (data from previous or next year). ^e Estimate. ^f Total is larger than component parts because of incomplete data. ¹ One or more component value imputed by RISP staff to state reported people in unknown settings. * See state notes in Appendix. ¹ This table includes state and non-state ICF/IID, group homes, and "other" IDD settings. It excludes people living with family members, host family/family foster settings, own home settings, nursing homes and psychiatric facilities.

Table 1.8 Non-Family Residential Settings for LTSS recipients with IDD by Type of Operation and Setting Size on June 30, 2018

Size	Non-State Settings						State-Operated Settings						Total Settings ¹					
	1-3	4-6	1-6	7-15	16+	Total	1-3	4-6	1-6	7-15	16+	Total	1-3	4-6	1-6	7-15	16+	Total
N States	41	42	44	44	45	38	49	49	50	50	51	50	41	42	44	44	45	38
AL	1,016	111	1,127	78	0	1,205	0	0	0	0	0	0	1,016	111	1,127	78	0	1,205
AK	526	200	726	24	11	761	0	0	0	0	0	0	526	200	726	24	11	761
AZ	1,939	282	2,221	0	1	2,222	5	4	9	3	1	13	1,944	286	2,230	3	2	2,235
AR	1,287	26	1,313	99	20	1,432	0	0	0	0	5	5	1,287	26	1,313	99	25	1,437
CA	DNF	DNF	5,299	115	53	DNF	0	0	0	0	4	4	PD	PD	5,299	115	57	PD
CO	2,335	199	2,534	0	0	2,534	1	15	16	15	2	33	2,336	214	2,550	15	2	2,567
CT	2,387	537	2,924	21	2	2,947	6	31	37	5	4	46	2,393	568	2,961	26	6	2,993
DE	419	89	508	0	1	509	0	0	0	0	1	1	419	89	508	0	2	510
DC	554	83	637	0	0	637	0	0	0	0	0	0	554	83	637	0	0	637
FL	0	38	38	20	51	DNF	0	0	0	0	3	3	0	38	38	20	54	PD
GA	DNF	DNF	DNF	DNF	DNF	DNF	0	0	0	0	3	3	PD	PD	PD	PD	PD	PD
HI	387	185	572	3	0	575	0	0	0	0	0	0	387	185	572	3	0	575
ID	384	22	406	29	49	548 ^f	0	0	0	0	1	1	384	22	406	29	50	549 ^f
IL	957	1,120	2,077	825	36	2,938	0	0	0	0	7	7	957	1,120	2,077	825	43	2,945
IN	4,074	402	4,476	324	2	4,802	0	0	0	0	0	0	4,074	402	4,476	324	2	4,802
IA	7,292	116	7,408	113	211	7,732	0	0	0	0	2	2	7,292	116	7,408	113	213	7,734
KS	1	17	18	6	0	DNF	0	0	0	0	2	2	1	17	18	6	2	PD
KY	2,143	42	2,185	3	5	2,193	0	0	0	8	2	10	2,143	42	2,185	11	7	2,203
LA	2,275	281	2,556	246	9	2,811	0	0	0	0	3	3	2,275	281	2,556	246	12	2,814
ME	1,581	109	1,690	14	3	DNF	3	0	3	0	0	3	1,584	109	1,693	14	3	PD
MD	5,875	492	6,367	25	0	6,392	0	0	0	0	2	2	5,875	492	6,367	25	2	6,394
MA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	2	DNF	PD	PD	PD	PD	PD	PD
MI	DNF	DNF	DNF	DNF	DNF	DNF	0	0	0	0	0	0	PD	PD	PD	PD	PD	PD
MN	3,939	135	13,515	36	10	13,561	27	89	116	0	0	116	3,966	224	13,631	36	10	13,677
MS	72	137	209	0	8	217	17	27	44	39	6	89	89	164	253	39	14	306
MO	2,481	190	2,671	111	2	2,784	79	4	83	0	6	89	2,560	194	2,754	111	8	2,873
MT	11	78	89	54	0	164 ^f	1	0	1	1	0	2	12	78	90	55	0	166 ^f
NE	2,157	106	2,263	26	2	2,291	0	0	0	0	1	1	2,157	106	2,263	26	3	2,292
NV	996	160	1,156	0	50	1,206	0	0	0	0	0	1	996	160	1,156	0	51	1,207
NH	DNF	DNF	DNF	DNF	DNF	DNF	0	1	1	0	0	1	PD	PD	PD	PD	PD	PD
NJ	1,457	1,395	2,852	78	3	2,933	0	0	0	0	5	5	1,457	1,395	2,852	78	8	2,938
NM	DNF	DNF	315	15	1	DNF	DNF	DNF	19	0	0	19	PD	PD	334	15	1	PD
NY	2,918	2,182	5,100	1,507	29	6,636	119	450	569	435	5	1,009	3,037	2,632	5,669	1,942	34	7,645
NC	1,210	882	2,092	45	13	2,925 ^f	0	0	0	0	5	5	1,210	882	2,092	45	18	2,930 ^f
ND	1,353	68	1,421	50	1	1,472	0	0	0	0	1	1	1,353	68	1,421	50	2	1,473
OH	14,012	780	14,792	270	54	15,116	0	0	0	0	8	8	14,012	780	14,792	270	62	15,124
OK	DNF	DNF	DNF	DNF	DNF	DNF	0	0	0	0	0	0	PD	PD	PD	PD	PD	PD
OR	1,865	1,024	2,889	29	13	2,931	0	20	20	0	0	20	1,865	1,044	2,909	29	13	2,951
PA	8,991	726	9,717	53	18	9,788	0	0	0	0	5	5	8,991	726	9,717	53	23	9,793
RI	977	168	1,145	27	0	1,172	0	25	25	1	0	26	977	193	1,170	28	0	1,198
SC	404	560	964	102	0	1,066	0	0	0	0	5	5	404	560	964	102	5	1,071
SD	1,069	93	1,162	73	1	1,236	0	0	0	0	1	1	1,069	93	1,162	73	2	1,237
TN	2,567	121	2,688	73	1	2,762	4	34	38	0	0	38	2,571	155	2,726	73	1	2,800
TX	DNF	736	736	41	3	DNF	0	2	2	0	13	15	PD	738	738	41	16	PD
UT	2,354	95	2,449	7	16	2,472	0	0	0	0	1	1	2,354	95	2,449	7	17	2,473
VT	1,821	17	1,838	0	0	1,838	0	0	0	0	0	0	1,821	17	1,838	0	0	1,838
VA	DNF	DNF	DNF	DNF	2	DNF	0	0	0	0	2	2	PD	PD	PD	PD	4	PD
WA	5,068	1,290	6,358	161	3	6,844 ^f	42	43	85	0	4	89	5,110	1,333	6,443	161	7	6,933 ^f
WV	1,721	16	1,737	54	0	1,791	0	0	0	0	0	0	1,721	16	1,737	54	0	1,791
WI	1,753	570	2,323	1	18	2,342	0	0	0	0	3	3	1,753	570	2,323	1	21	2,345
WY	DNF	DNF	DNF	DNF	DNF	DNF	0	0	0	0	2	2	PD	PD	PD	PD	PD	PD
Reported US Total	94,628	15,880	125,563	4,758	702	123,785	304	745	1,068	507	118	1,691	94,932	16,625	126,631	5,265	820	125,476
Estimated US Total	190,463	29,095	219,558	6,875	816	227,249	485	863	1,348	530	119	1,997	190,948	29,958	220,906	7,405	935	229,246

DNF Did not furnish. PD Partial data. ^g Other date (data from previous or next year). ^e Estimate. ^f Total is larger than component parts due to unknown settings or sizes. ^h One or more component value imputed by RISP staff. * See state notes in Appendix. ¹ This table includes group homes, ICF/IIDs, host and foster family homes, own home, and "other" settings. It excludes family homes, nursing homes and psychiatric facilities. The number Nonstate "other" settings is assumed to be 0 unless otherwise specified by the state.

Of the 298,439 LTSS recipients with IDD living in group settings on June 30, 2018,

- 27% (81,387 people) lived in settings of three or fewer people,
- 42% (125,760 people) lived in settings of 4 to 6 people,
- 19% (55,289 people) lived in settings of 7 to 15 people, and
- 12% (36,016 people) lived in facilities with 16 or more residents.

Non-Family IDD Residential Settings

Tables 1.8 through **1.10** combine data on own home settings, host or foster family homes, IDD group homes, ICF/IID certified facilities and other IDD congregate settings. They do not include family home settings, nursing homes or psychiatric facilities (see state notes for exceptions). **Table 1.8** shows state-operated and nonstate-operated IDD settings in operation on June 30, 2018. Of the 229,246 non-family residences, an estimated:

- 84% (190,948 settings) served 1 to 3 people,
- 13% (29,958 settings) served 4 to 6 LTSS people,
- 3% (7,405 settings) served 7 to 15 LTSS people, and
- 0.4% (935 settings) served 16 or more LTSS people.

Of the estimated 227,249 non-state IDD settings,

- 84% (190,463 settings) served 1 to 3 people,
- 13% (29,095 settings) served 4 to 6 people,
- 3% (6,867 settings) served 7 to 15 people, and
- 0.4% (816 settings) served 16 or more people.

States reporting no non-state IDD facilities serving 16 or more people included Alabama, Colorado, the District of Columbia, Hawaii, Kansas, Maryland, Montana, Rhode Island, South Carolina, Vermont, and West Virginia.

Of the estimated 1,997 state-operated IDD settings:

- 24% (485 settings) served 1 to 3 people,
- 43% (863 settings) served 4 to 6 people,
- 27% (530 settings) served 7 to 15 people, and
- 6% (119 settings) served 16 or more people.

There were no state-operated IDD facilities of any size in Alabama, Alaska, the District of Columbia,

Table 1.9 Residence Size and Type of Operation for LTSS Recipients with IDD not Living with a Family Member by State on June 30, 2018

Size	People in Non-State Settings						People in State-Operated Settings						Total People						Unknown Size	Reported Total
	1-3	4-6	1-6	7-15	16+	Total	1-3	4-6	1-6	7-15	16+	Total	1-3	4-6	1-6	7-15	16+	Total		
N States	46	44	48	44	45	44	50	50	50	50	51	51	45	44	47	44	45	48	44	
AL	2,256	454	2,710	790	0	3,500	0	0	0	0	0	0	2,256	454	2,710	790	0	0	3,500	
AK	1,190	100	1,290	47	0	1,337	0	0	0	0	0	0	1,190	100	1,290	47	0	14	1,351	
AZ	3,544	1,414	4,958	0	38	4,996	13	18	31	22	80	133	3,557	1,432	4,989	22	118	0	5,129	
AR	1,294	82	1,376	925	537	2,838	0	0	0	0	917	917	1,294	82	1,376	925	1,454	0	3,755	
CA	32,489	5,909	56,879	986	1,384	59,249	0	0	0	0	534	534	32,489	5,909	56,879	986	1,918	0	59,783	
CO	4,548	799	5,347	0	0	5,347	3	90	93	105	49	247	4,551	889	5,440	105	49	0	5,594	
CT	3,475	2,629	6,104	157	14	6,275	15	164	179	36	347	562	3,490	2,793	6,283	193	361	0	6,837	
DE	742	379	1,121	0	70	1,191	0	0	0	0	50	50	742	379	1,121	0	120	0	1,241	
DC	1,091	389	1,480	0	0	1,480	0	0	0	0	0	0	1,091	389	1,480	0	0	0	1,480	
FL	6,276	7,315	13,591	1,754	1,748	17,093	0	0	0	0	698	698	6,276	7,315	13,591	1,754	2,446	1,021	18,812	
GA	DNF	DNF	DNF	DNF	DNF	DNF	0	0	0	0	175	175	PD	PD	PD	PD	PD	DNF	PD	
HI	635	368	1,003	37	0	1,040	0	0	0	0	0	0	635	368	1,003	37	0	0	1,040	
ID	507	45	552	99	118	769	0	0	0	0	23	23	507	45	552	99	141	421	1,213	
IL	1,579	5,053	6,632	7,164	2,661	16,457	0	0	0	0	1,664	1,664	1,579	5,053	6,632	7,164	4,325	0	18,121	
IN	6,800	1,760	8,560	2,369	50	10,979	0	0	0	0	0	0	6,800	1,760	8,560	2,369	50	0	10,979	
IA	8,248	450	8,698	815	803	10,316	0	0	0	0	346	346	8,248	450	8,698	815	1,149	0	10,662	

Hawaii, Indiana, Michigan, Oklahoma, Vermont and West Virginia. Other states with no state-operated IDD facilities with 16 or more people included Maine, Minnesota, Montana, New Hampshire, New Mexico, Oregon, Rhode Island, and Tennessee.

IDD Group and Individualized Settings Other than the Home of a Family Member

An estimated 516,629 LTSS recipients lived in non-family IDD settings on June 30, 2018 (See **Table 1.9**). Of those, an estimated

- 55% (285,233 people) lived in settings of 3 or fewer people,
- 27% (138,897 people) lived in settings of 4 to 6 people,
- 11% (56,196 people) lived in settings of 7 to 15 people, and
- 7% (36,825 people) lived in settings of 16 or more people.

Alabama, Alaska, the District of Columbia, Hawaii, Montana, Rhode Island, Vermont, and West Virginia reported no people with IDD living in settings of 16 or more people. States reporting that 20% or more of people in non-family settings lived in a setting of 16 or more people were Arkansas (39%, 1,454 people), Illinois (24%, 4,325 people), Kansas (69%, 305 people), and Mississippi (51%, 1,585 people).

Of the people who did not live with a family member, an estimated 95% (488,669 people) lived in non-state settings, and 5% (27,960 people) lived in state-operated settings. States with the lowest proportion of people living in non-state settings were Texas (14%), North Carolina (27%), Kansas (31%), and Mississippi (47%).

Of the 488,669 people in non-state IDD settings, an estimated

- 58% (283,992 people) lived with three or fewer people,
- 28% (134,758 people) lived with 4 to 6 people,
- 10% (51,178 people) lived with 7 to 15 people, and
- 4% (19,268 people) lived with 16 or more people.

Of the 27,960 people in state-operated IDD settings, an estimated

- 4% (1,241 people) lived in settings of 3 or fewer people,
- 15% (4,139 people) lived in settings of 4 to 6 people,
- 18% (5,018 people) lived in settings of 7 to 15 people, and
- 63% (17,557 people) lived in settings of 16 or more people with IDD.

The proportions of people in non-state settings by setting size were

- 99.6% of people in settings of 1 to 3 people,
- 97% of people in settings of 4 to 6 people,
- 91% of people in settings of 7 to 15 people, and
- 52% of people in settings of 16 or more people.

An estimated 516,629 people with IDD lived in 229,246 non-family settings on June 30, 2018 (an average of 2.3 people per setting; See **Table 1.10** and **Figure 1.3**). States reporting the fewest people per setting were Vermont (1.1), Iowa (1.4), Minnesota (1.5), and North Dakota (1.5). States averaging more than 3 people per residence included Mississippi (10.1), Illinois (6.2), South Carolina (4.7), and Montana (4.5), Louisiana (3.7), New Jersey (3.7), North Carolina (3.4), and Virginia (3.3).

Overall, there were an estimated 2.0 LTSS recipients per non-state setting, and 10.2 LTSS recipients per state-operated setting. The average number of people per setting by setting type and type of operation was:

- Non-state other group settings (1.3 people per home)
- Own home (1.4 people)
- Host or Foster Family home (1.7 people)
- Non-state IDD group home (3.6 people)
- State-Operated IDD group home (5.4 people)
- State-Operated, other group setting (7.6 people)
- Non-state ICF/IID (8.9 people)
- State-Operated ICF/IID (75.2 people)

On June 30, 2018, 82% of people living in a setting other than the home of a family member lived in a home shared by six or fewer LTSS recipients with IDD. The proportion living in settings of six or fewer people ranged from 32% in Mississippi to

Table 1.10 LTSS Settings and Recipients with IDD Not Living with a Family Member by Setting Size and Per 100,000 of the Population by State on June 30, 2018

State	Estimated Settings	Estimated Recipients ¹	People Per Setting	% in Settings of		State Population in 100,000's	People in LTSS Settings Per 100,000
				3 or Fewer People	6 or Fewer People		
AL	1,205	3,500 ⁱ	2.9	64	77	49	72
AK	859 ^j	1,563 ^e	1.8	85	95	7	218
AZ	2,235	5,129	2.3	69	97	71	72
AR	1,437	3,755	2.6	34	37	30	125
CA	29,355 ⁱ	59,783 ^e	2.0	62	95	393	152
CO	2,567	5,647 ⁱ	2.2	81	96	57	100
CT	2,993	6,837	2.3	51	92	36	192
DE	510	1,241 ⁱ	2.4	60	90	10	129
DC	637	1,480	2.3	74	100	7	212
FL	7,578 ⁱ	18,876 ⁱ	2.5	38	77	212	89
GA	3,111 ⁱ	5,507 ^{e,i}	1.8	74	94	104	53
HI	575	1,040	1.8	61	96	14	76
ID	1,592 ^{e,i}	3,773 ⁱ	2.4	55	86	17	216
IL	2,945	18,121	6.2	9	37	127	143
IN	4,802 ^e	10,979	2.3	62	78	67	164
IA	7,734 ⁱ	10,662	1.4	77	82 ⁱ	31	339
KS	1,733 ⁱ	4,126 ^e	2.4	57	83	29	143
KY	2,203 ^{e,i}	5,394 ^{e,s}	2.4	83	87	44	121
LA	1,854 ⁱ	6,927 ⁱ	3.7	33	57 ⁱ	46	149
ME	2,352 ⁱ	3,796 ⁱ	1.6	82	95	13	284
MD	6,884 ⁱ	13,330 ⁱ	1.9	76	96	60	222
MA	4,814 ⁱ	14,144	2.9	52	86 ⁱ	69	206
MI	10,235 ⁱ	20,192 ⁱ	2.0	54	90	100	202
MN	13,677 ^e	20,686 ⁱ	1.5	68	97	56	369
MS *	306	3,093 ⁱ	10.1	8	32	30	104
MO	2,873	7,910 ⁱ	2.8	73	84	61	130
MT	218 ⁱ	996 ⁱ	4.6	15	57	11	94
NE	2,292	3,652 ^{e,i}	1.6	75	87	19	190
NV	1,207	2,197	1.8	63	93	30	73
NH	2,542 ^{e,i}	5,283 ⁱ	2.1	94	97	14	391
NJ	2,976 ⁱ	11,055 ^e	3.7	26	75	89	125
NM	619 ⁱ	1,850 ⁱ	3.0	47	90	21	89
NY	17,794 ⁱ	49,796 ⁱ	2.8	34	61	195	255
NC	3,573 ⁱ	12,145 ^{e,i}	3.4	39	70 ⁱ	103	118
ND	1,473	2,229	1.5	61	77	8	297
OH	16,211 ⁱ	26,921	1.7	68	81	117	231
OK	2,403 ⁱ	5,036 ⁱ	2.1	54	71	39	128
OR	2,951	7,124	2.4	43	98	42	170
PA	11,753 ⁱ	21,554 ⁱ	1.8	74	88	128	168
RI	1,199 ⁱ	2,139 ⁱ	1.8	50	93	11	203
SC	1,071	5,081	4.7	26	70	50	101
SD	1,237	2,538 ⁱ	2.1	49	67	9	290
TN	2,800	6,071 ⁱ	2.2	78	89	68	90
TX	13,340 ⁱ	34,257	2.6	57	85 ⁱ	285	120
UT	2,473 ⁱ	4,332	1.8	70	81	31	138
VT	1,950 ⁱ	2,187 ^e	1.1	96	100	6	351
VA	3,254 ⁱ	10,639	3.3	26	85	84	127
WA	6,941 ⁱ	19,873	2.9	50	87	75	266
WV	1,791	2,932	1.6	78	86 ⁱ	18	163
WI	9,528 ⁱ	18,009	1.9	76	97 ⁱ	58	310
WY	584 ⁱ	1,242	2.1	61	86	6	216
Estimated US Total	229,246	516,629	2.3	55	82	3,255	159

^d Other date (data from previous or next year). ^e Estimate. ⁱ One or more component value imputed by RISP staff. This table uses estimated totals for settings and people.* See state notes in Appendix. ¹ Includes people in group homes, host/foster family homes, own homes, and other IDD settings. Excludes people in family homes, nursing homes, psychiatric settings.

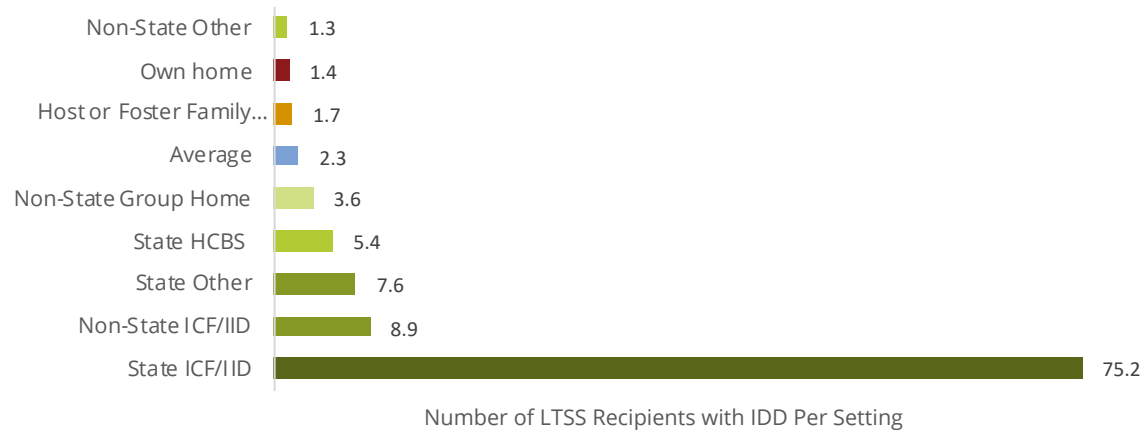
100% in the District of Columbia and Vermont. The proportion was 90% or greater in 20 states. The proportion was less than 50% in Arkansas (37%), Mississippi (32%), and Illinois (37%).

New Hampshire (94%). The proportion of LTSS recipients in settings of three or fewer was lowest in Mississippi (8%), Illinois (9%), Montana (15%), South Carolina (26%), New Jersey (26%), and Virginia (26%).

More than half (55%) of people with IDD not living with a family member lived alone or shared their home with one or two other LTSS recipients (See **Figure 1.4**). The proportion living in settings of 3 or fewer people was highest in Vermont (96%) and

The 2014 Medicaid HCBS rule does not require provider-operated Waiver funded residences and vocational programs to be of a specific size, but it does require them to be community-based, inclusive (not segregated by disability)

Figure 1.3 LTSS Recipients with IDD per Setting by Setting Type on June 30, 2018



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

Figure 1.4 Percent of People not Living with Family Members who lived in Settings of 1 to 3 or 1 to 6 People by State on June 30, 2018

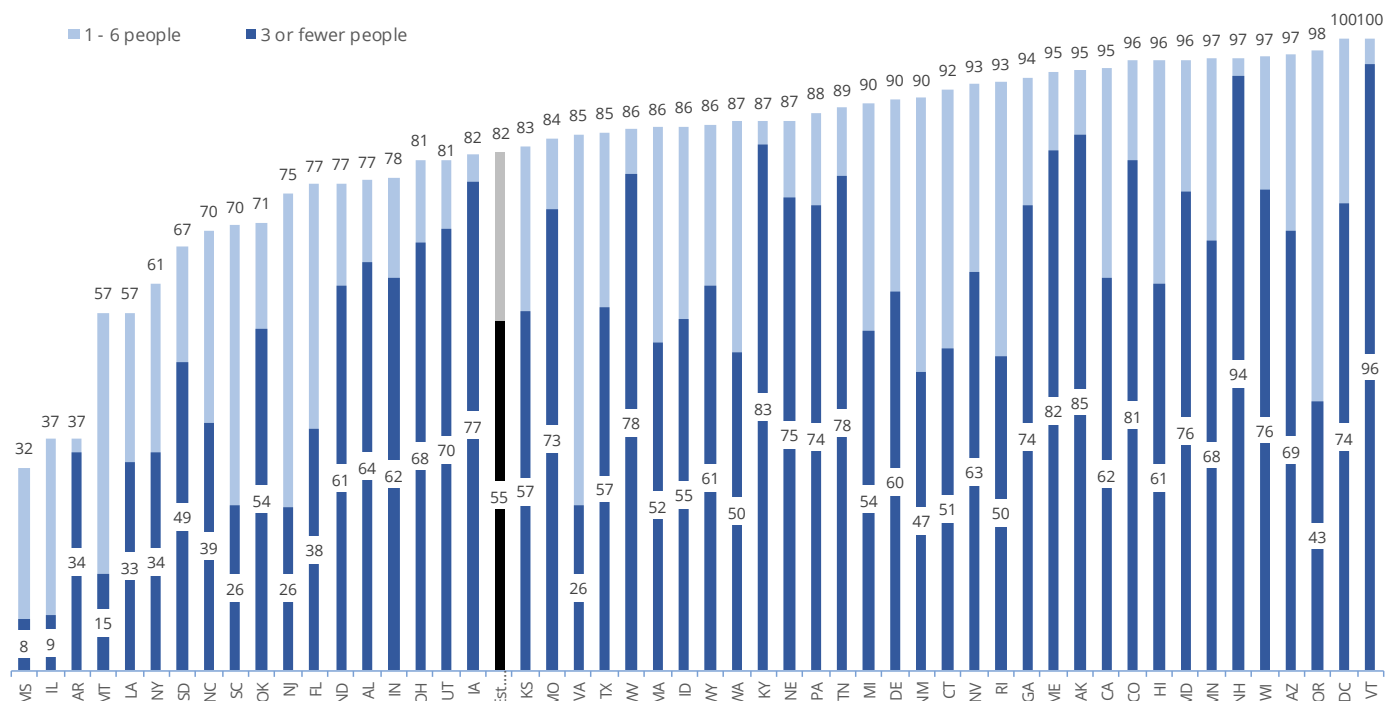
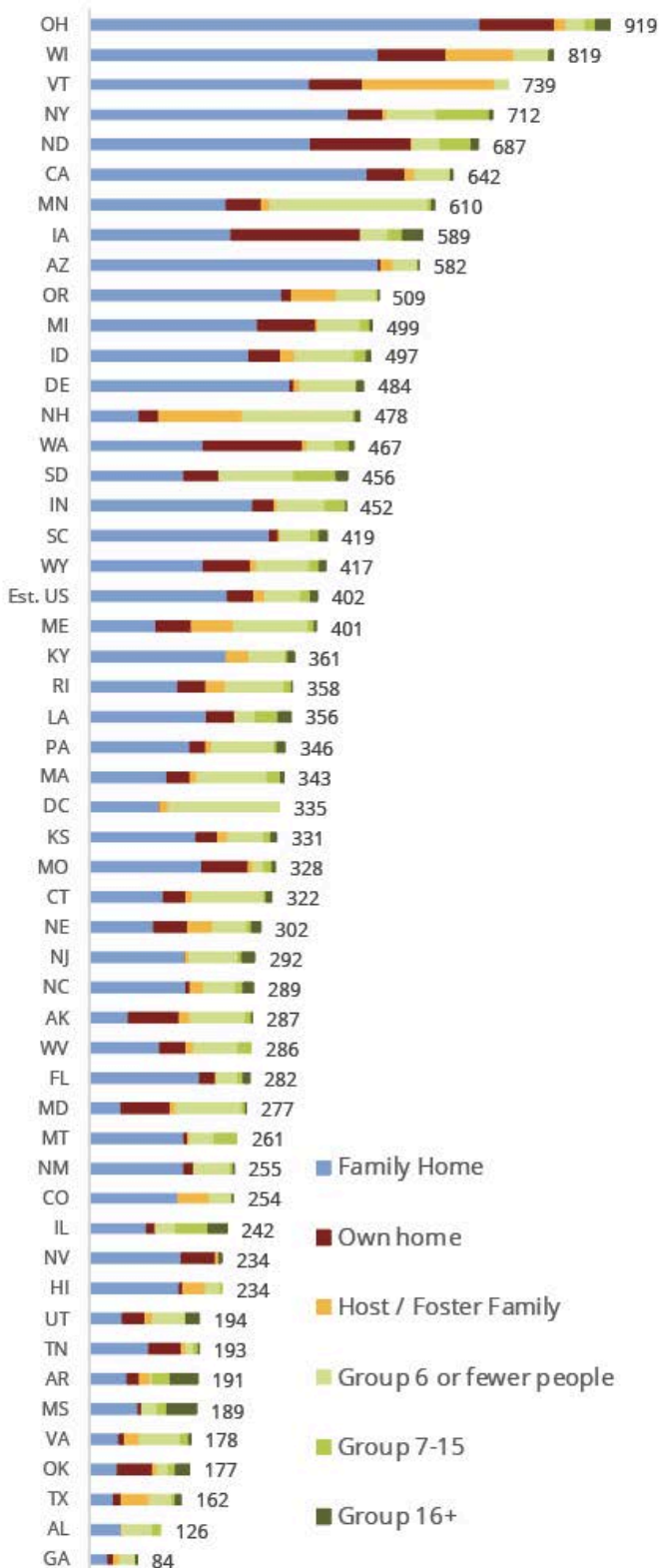


Figure 1.5 Estimated LTSS Recipients with IDD in Family or LTSS Settings per 100,000 of the Population by Setting Type and State on June 30, 2018



and to use individualized, person-centered planning and practices. In a review of 30 years of deinstitutionalization research, 37 of 43 studies of people with IDD who moved from institutions to homes shared by 6 or fewer people showed improved adaptive behavior (daily living skills) for people who moved improved while less or no change was observed for people who remained in institutions (Larson, Lakin, & Hill, 2012). Setting size is a significant predictor of better outcomes in areas such as everyday choice and expenditures (e.g., Bershadsky, et. al., 2012; Lakin et al., 2008; Ticha, et. al., 2012). People in settings of three or fewer people had better outcomes than those living in larger settings in many areas.

Utilization of IDD LTSS Services per 100,000 of the Population by Setting Type

On June 30, 2018, counting people in both family and non-family settings, state IDD agencies provided LTSS to an average of 402 people with IDD per 100,000 of the population (See **Figure 1.5**). However, access to publicly-funded LTSS for people with IDD varied widely across states. States providing LTSS to the most people with IDD per 100,000 included Ohio (919 people per 100,000), Wisconsin (819), Vermont (739), New York (712), North Dakota (687), California (642), and Minnesota (610). States providing LTSS to the fewest people with IDD per 100,000 were Georgia (83 per 100,000), Alabama (126), Texas (162), Oklahoma (177), Virginia (178), Mississippi (189), Arkansas (191), Tennessee (193), and Utah (194).

State variations were also evident in utilization rates for each type of LTSS setting. The average number of LTSS recipients with IDD per 100,000 of the population (and range across states) by setting type and state were as follows:

- Family home (average 243 per 100,000; range 31 per 100,000 in Georgia to 688 in Ohio)
- Own home (47 per 100,000; range 0 in Colorado to 228 in Iowa)
- Host/foster family home (20 per 100,000; range less than 1 in five states to 233 in Vermont)
- Group setting 1 to 6 people (64 per 100,000; range 1 in Nevada to 279 in Minnesota)

- Group setting 7 to 15 people (17 per 100,000; range less than 1 in seven states to 92 in New York) and
- Group setting 16 or more people (11 per 100,000; range less than 1 in six states to 53 in Mississippi)

LTSS utilization rates reflect differences in whether the state IDD agency administers LTSS for people ages 21 years or younger, historical patterns of institutional use and deinstitutionalization, lawsuits and consent decrees, and other factors such as the Federal Medicaid Matching percentage (see **Table 2.14a**).

People with IDD in Psychiatric Facilities, Nursing Homes or Other Congregate Settings

This section estimates of the number of people with IDD receiving LTSS in state-operated or non-state psychiatric facilities or nursing homes on June 30, 2018. Some states were not able to report on people receiving LTSS through a managed care organization

or in settings licensed by an entity other than the state IDD agency.

Psychiatric Facilities

While Medicaid funds are available for LTSS provided in most settings, they may not be used to fund services in “Institutes for Mental Disease” for individuals 18 to 64 years old. Those services must be funded by state, local or private funds. Of states that reported this statistic (N=32), roughly 34% (11 states) reported no people with IDD living psychiatric facilities. In the other 20 states a total of 1,766 people with IDD lived in state or non-state psychiatric facilities on June 30, 2018 (See **Table 1.11**). Totals reflect partial data for states reporting people with IDD only for state-operated or only for non-state psychiatric facilities. These figures are very likely an undercount because the majority of states were unable to furnish complete information about both state and non-state psychiatric facilities. Lack of alternative data sources on this topic prevent us from estimating the total number of people with IDD in psychiatric facilities.

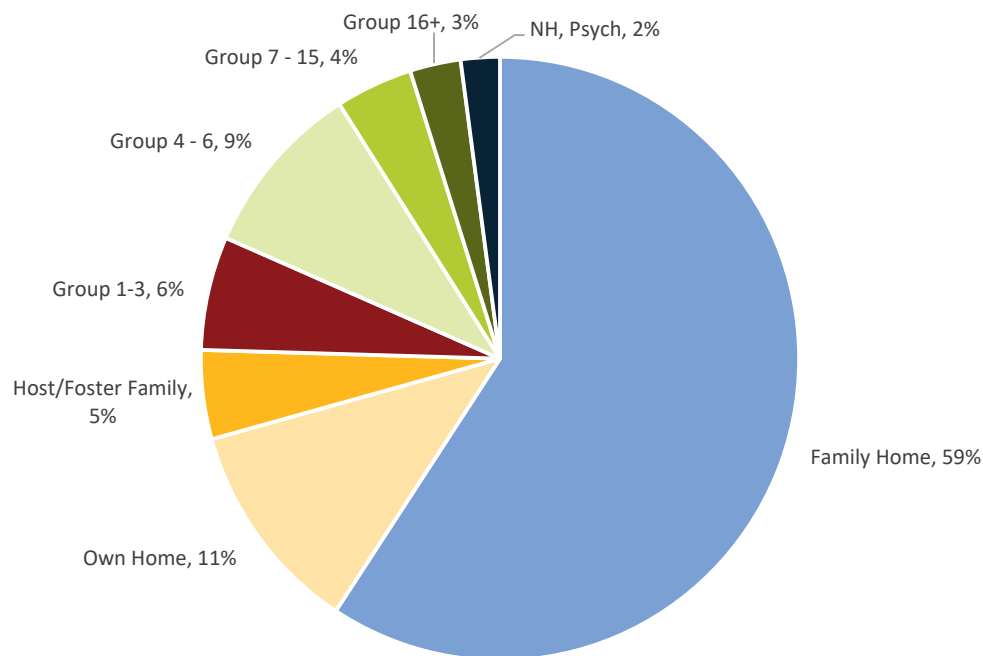


Table 1.11 People with IDD in State-Operated and Non-State Nursing Homes or Psychiatric Facilities by State on June 30, 2018

	People in Psychiatric Facilities			People in Nursing Homes			
	State	NonState	Reported Total	State	Non-State	Estimated Total	People per 100,000
N States	33	27	32	34	33	51	51
AL	63	0	63	0	1,123 ^s	1,123 ^s	23
AK	0	0	0	0	0	0	0
AZ	0	0	0	0	46	46	1
AR	0	0	0	DNF	DNF	615 ^s	21
CA	0	29	29	0	1,055	1,055	3
CO	0	0	0	0	47	47	1
CT	0	1	1	0	311	311	9
DE	3	0	3	9	59	68	7
DC	6	0	6	0	6	6	1
FL	1	5	6	0	254	254	1
GA	DNF	DNF	DNF	DNF	1,150 ⁱ	1,150 ^s	11
HI	7	0	7	0	10	10	1
ID	DNF	DNF	DNF	DNF	DNF	127 ^s	8
IL	0	0	0	0	120	120	1
IN	51	0	51	0	1,391	1,391	21
IA	4	108	112	0	280	280	9
KS	187	0	187	0	114	114	4
KY	DNF	DNF	DNF	DNF	DNF	702 ^s	16
LA	0	0	0	10	805	815	17
ME	DNF	DNF	DNF	0	90	90	7
MD	12	0	12	7	342	349	6
MA	DNF	DNF	DNF	0	414 ⁱ	414 ^s	6
MI	DNF	DNF	DNF	DNF	DNF	727 ^s	7
MN	DNF	DNF	DNF	0	147	147	3
MS	DNF	DNF	DNF	DNF	DNF	415 ^s	14
MO	150	0	150	DNF	DNF	1,114 ^s	18
MT	DNF	DNF	DNF	DNF	DNF	141	14
NE	0	13	13	0	DNF ^f	282 ^{is}	15
NV	0	0	0	0	127	127	4
NH	DNF	DNF	DNF	DNF	DNF	72 ^s	5
NJ	31	DNF	31 ⁱ	0	774	774	9
NM	DNF	DNF	DNF	DNF	DNF	81 ^s	4
NY	DNF	DNF	DNF	DNF	DNF	1,718	9
NC	293	1	294	180	8	881 ^s	9
ND	3	DNF	3 ⁱ	0	83	83	11
OH	DNF	DNF	DNF	0	DNF	1,315 ^s	11
OK	DNF	DNF	DNF	0	544	544 ^s	14
OR	0	0	0	0	141	141	3
PA	67	171 ^e	238 ^f	0	2,334 ^e	2,334 ^e	18
RI	DNF	DNF	DNF	DNF	DNF	69 ^s	7
SC	DNF	DNF	DNF	119 ^j	289	408 ^s	8
SD	0	0	0	0	88	88 ^s	10
TN	54	DNF	54 ⁱ	0	513 ⁱ	513 ^s	8
TX	442	DNF	442 ^{pd}	DNF	DNF	2,964 ^s	11
UT	0	DNF	DNF	DNF	DNF	173 ^s	6
VT	0	0	0	0	27	27	4
VA	DNF	DNF	DNF	DNF	DNF	652 ^s	8
WA	40	16	56	320	259	579	8
WV	DNF	DNF	DNF	DNF	DNF	211 ^s	12
WI	0	0	0	0	698	698	12
WY	8	DNF	8 ⁱ	DNF	DNF	35 ^s	6
Reported US Total	1,422	344	1,766	645	13,649		
Estimated US Total						26,400	8

DNF Did not furnish. PD Partial data. ^a Missing values (DNF) assumed to be zero. ^d Other date (data from previous or next year). ^e Estimate. ^f Total is larger than component parts due to unknown settings or sizes. ^s Source APHA 2018c. * See state notes in Appendix.

Figure 1.6 Percent of LTSS Recipients with IDD in Family Home, LTSS Settings, Psychiatric Facilities or Nursing Homes by Residence Type and Size on June 30, 2018



Nursing Homes

For 2018, 34 states provided data on people in state-operated nursing homes and 33 states provided data on non-state nursing homes (either from 2017 or in 2018). Estimated totals are the sum of people in state plus non-state nursing home for states furnishing both values. For states that provided no or partial data, estimated totals were pulled from CMS CASPER data for nursing homes on June 30, 2018 (AHCA, 2018c). On June 30, 2018, there were an estimated 26,400 people with IDD living in nursing homes (See **Table 1.11**). National estimates are not available for the breakdown of people in state-operated versus nonstate-operated nursing homes.

States serving the greatest numbers of people with IDD in nursing homes included Indiana (1,391), New York (1,718), Ohio (1,315), Pennsylvania (2,334) and Texas (2,964). Arizona, Arkansas, Colorado, the District of Columbia, Hawaii, Vermont and Wyoming reported fewer than 50 people with IDD living in nursing homes on June 30, 2018. When indexed by state population, states with the highest utilization rates for nursing homes with rates of more than 15 people with IDD per 100,000 of the population included Alabama, Arkansas, Indiana, Kentucky,

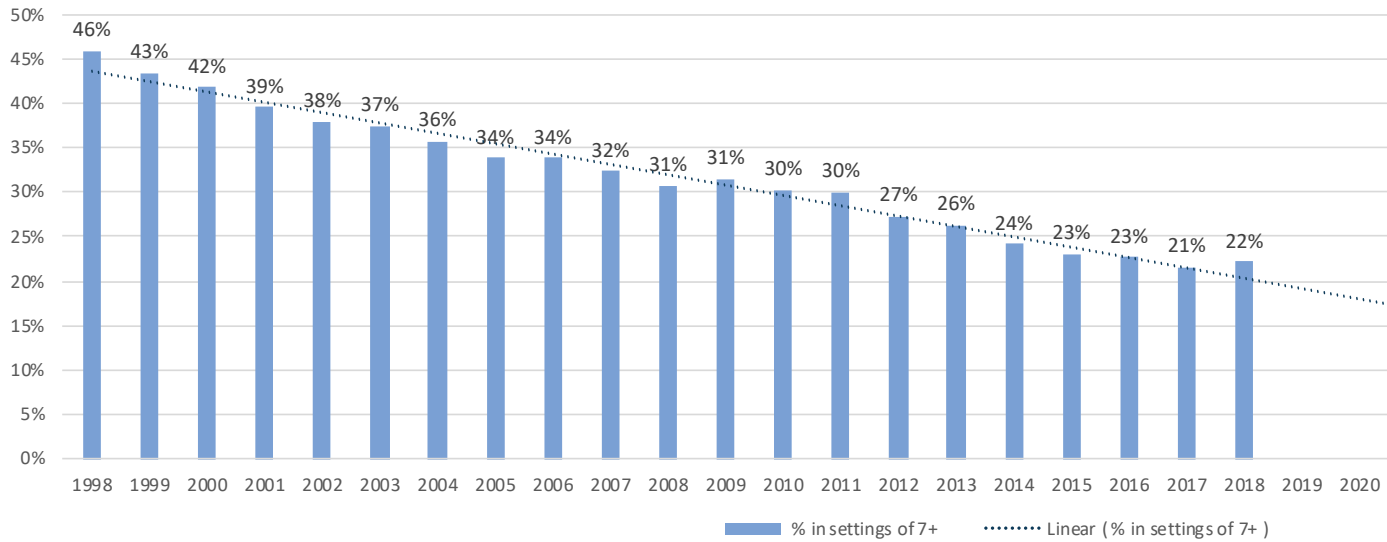
Louisiana, Missouri, and Pennsylvania. States with fewer than two people with IDD per 100,000 living in nursing homes included Alaska, Arizona, Colorado, the District of Columbia, Florida, Hawaii, Illinois, and North Carolina.

Including people in nursing homes and psychiatric facilities, an estimated 1,336,136 people with IDD received LTSS on June 30, 2018. Of those, 2% lived in a nursing home or psychiatric facility, 23% lived in a group IDD setting of any size, 11% lived in their own home, 5% lived in a host or foster family home, and 59% lived with a family member (See **Figure 1.6**). The number of people with IDD living in IDD facilities of 16 or more people (36,698) has declined steadily and is now approaching the number known to be living in nursing homes or psychiatric facilities (28,166).

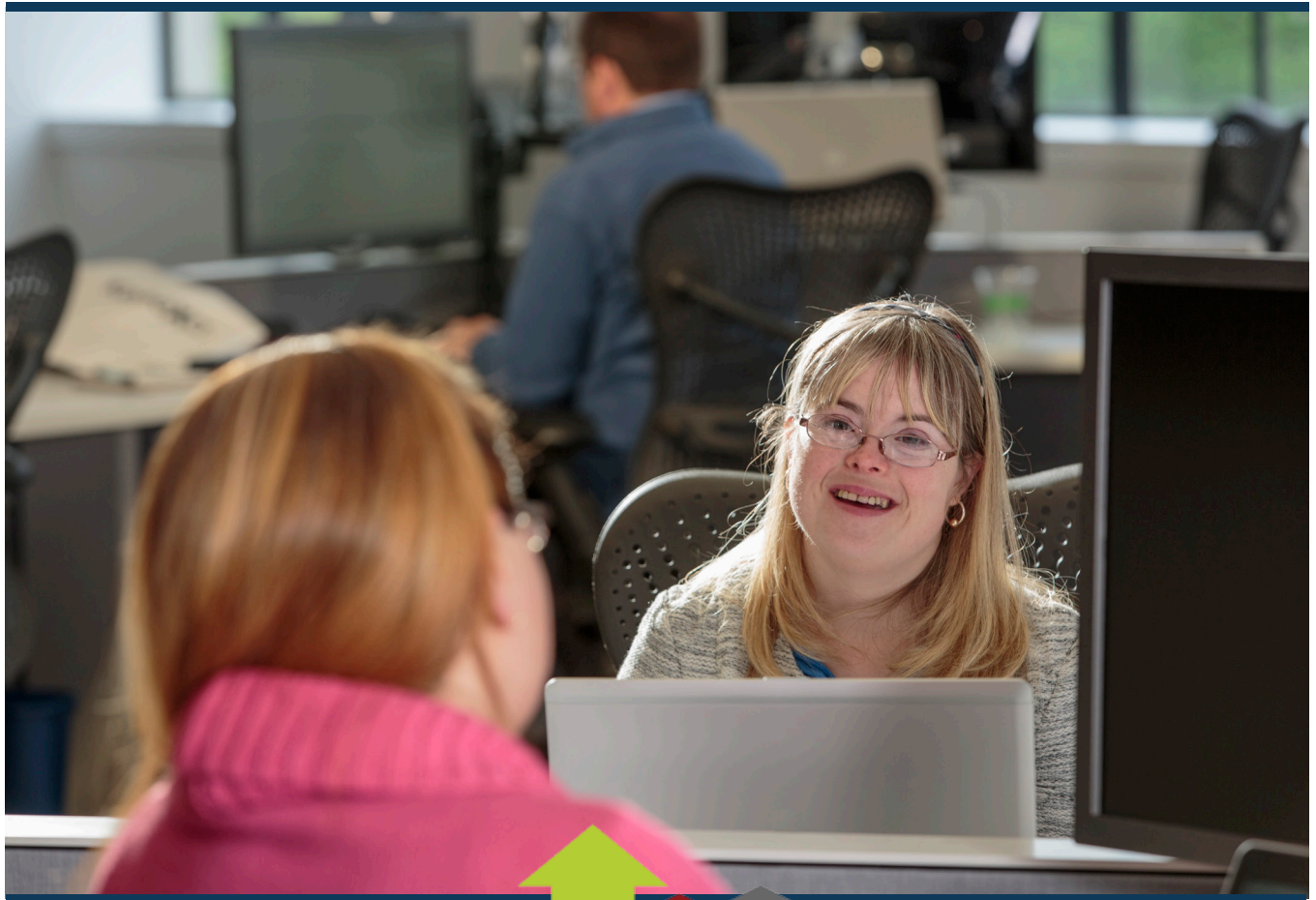
PROGRESS ON HEALTHY PEOPLE 2030 OBJECTIVE DH-03

The Centers for Disease Control and Prevention Healthy People initiative establishes a set of objectives updated every 10 years to monitor progress toward improving the health of all Americans. RISP survey data are used to monitor

Figure 1.7 Percent of people in nonfamily settings who live in congregate settings of 7 + people 1998 to 2018 with linear projections to 2030



progress on one Healthy People 2030 objective (see the objectives on the Healthy People website at www.healthypeople.gov). Objective DH-03 for HP 2030 is to reduce the proportion of LTSS recipients with IDD who live in congregate care residences with 7 or more people from 22.7% in 2016 to 11.5% by 2030. On June 30, 2018, an estimated 21.9% of LTSS recipients with IDD lived in IDD facilities of seven or more people, nursing homes, or psychiatric facilities (See **Figure 1.7**). This was a slight increase from 21.5% in 2017. Between 1998 and 2018 the proportion living in settings of seven or more people declined from 46% to 22%.



SECTION TWO

**Long-Term Supports and Services
Funding Authorities**

FY 2018

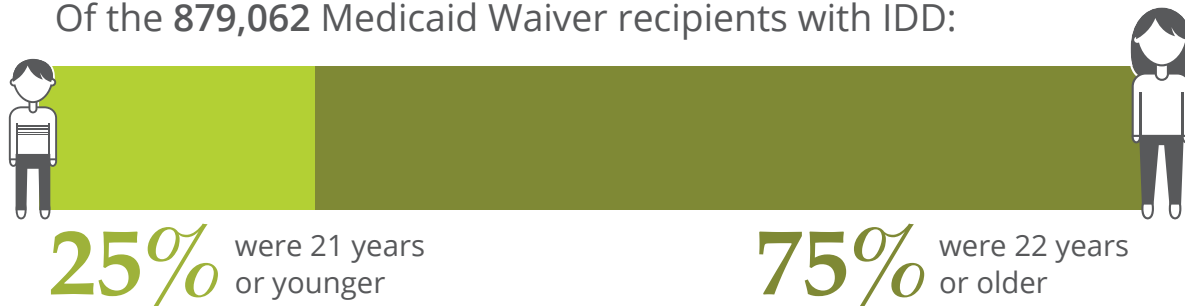
Medicaid HCBS Waiver funded services

\$42.3 billion was expended to provide Medicaid Waiver funded supports to 879,062 people with IDD (\$47,835 per person)

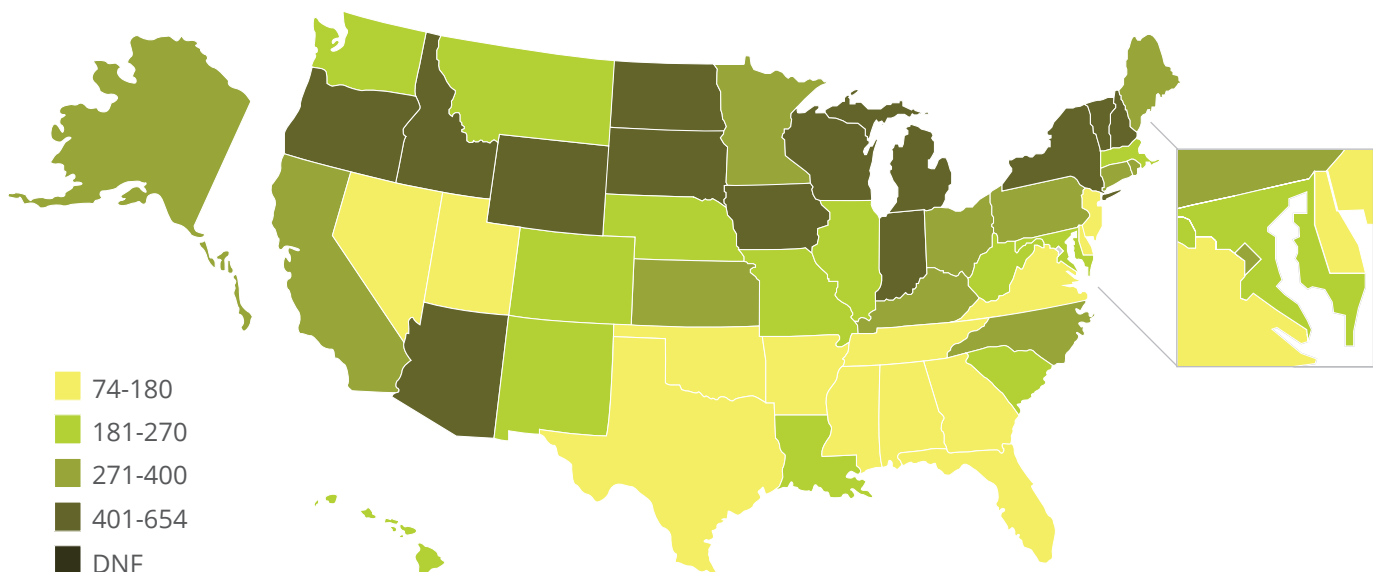
Annual per person Medicaid Waiver expenditures



Of the 879,062 Medicaid Waiver recipients with IDD:



270 people with IDD per 100,000 of the population had Medicaid Waivers



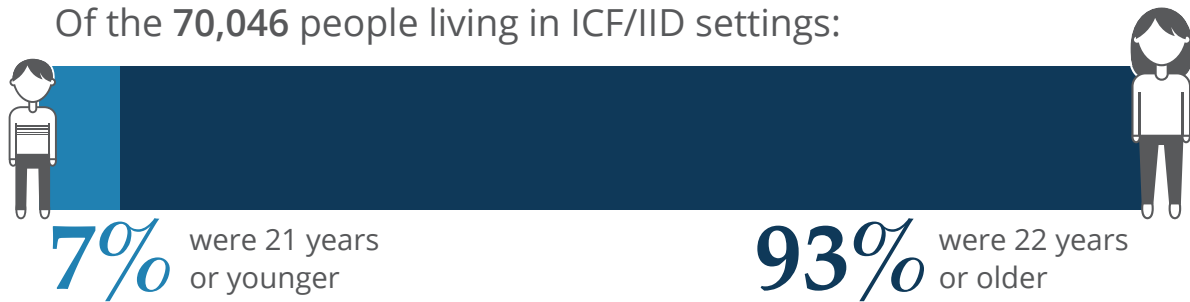
Medicaid Intermediate Care Facility for Individuals with Intellectual and Developmental Disabilities (ICF/IID)

\$9.6 billion was expended to provide Medicaid ICF/IID services to 70,046 people with IDD (\$137,560 per person)

Annual per person ICF/IID expenditures



Of the 70,046 people living in ICF/IID settings:



21.5 people with ID per 100,000 of the population lived in an ICF/IID

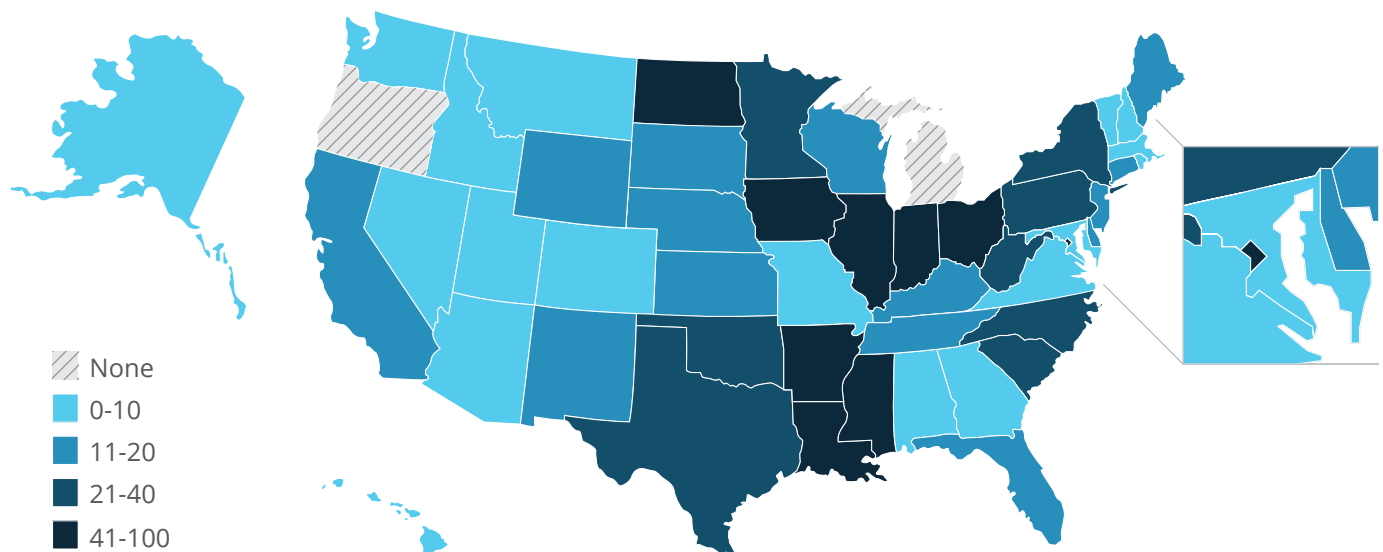


Table C: Medicaid Funding Authorities

Funding Authority	Description
Medicaid Waiver Authorities	Waivers allow states to test or continue to deliver and pay for LTSS provided in home and community-based settings. Medicaid rules requiring statewide access to all eligible people can be waived. As a result, many states have waiting lists of people who qualify for this funding but do not receive it. Key Medicaid Waiver authorities include:
Section 1115	Research and Demonstration Projects. States may design programs that expand Medicaid eligibility to individuals who are not otherwise eligible, provide services not typically covered by Medicaid, or that use innovative service delivery systems that improve care, increase efficiency, and reduce costs.
1915(a)	Voluntary managed care. A managed care option in which individuals may (but are not required to) enroll.
1915(a)/(c)	Voluntary managed care program. A managed care option that incorporates home and community-based services in which individuals may (but are not required to) enroll.
1915(b)	Renewable waiver authority for managed care. Managed care with options to limit providers as well as to mandate enrollment of certain groups.
1915(b)/(c)	Voluntary, or mandatory, managed care program with home and community-based services. Allows targeted eligibility and permits states to mandate enrollment. States must apply for both the (b) and the (c) waiver concurrently and comply with the individual requirements of each.
1915(c)	Home and Community-Based Services (HCBS) Waivers. The most widely used waiver. States may provide community-based LTSS in home and community-based settings to specified populations. States can provide comprehensive supports or can limit the amount or types of services for eligible recipients.
Medicaid State Plan Services	To receive Federal Financial Participation for Medicaid expenditures states are required to provide a certain benefits such as inpatient hospital, physician services, Early and Periodic Screening, Diagnostic and Treatment services (EPSDT) for children, and nursing facility services to all eligible recipients. States can choose to provide optional benefits such as targeted case management, physical and occupational therapy, preventative health care, and dental services to eligible individuals. Key optional Medicaid State Plan funding authorities include:
1915(i) HCBS	HCBS State Plan Option. Provides Home and Community-based LTSS to one or more specific populations and allows any or all of those services to be self-directed. Authorized under the Deficit Reduction Act of 2005, and amended in the 2010 Affordable Care Act.
1915(j) HCBS	Self-Directed Personal Assistance Services. Eligible recipients can set provider qualifications and train self-directed personal assistance services providers. Given a set budget, participants determine how much they will pay for a service, support, or item. Recipients may hire legally liable relatives, such as parents or spouses, to provide supports. States can limit the number of participants and can choose to target only parts of the state. Authorized under the Deficit Reduction Act of 2005.
1915(k) HCBS	Community First Choice (CFC). States may provide statewide HCBS attendant care services and supports to individuals who need the level of supports once offered only in institutions. This program can fund assistance with Activities of Daily Living (ADLs) or Instrumental ADLs (IADLs) and health-related tasks; ensure continuity of services, and provide voluntary training on how to select, manage, and dismiss staff. Recipients may use an agency provider or self-direct services. Authorized by the Affordable Care Act in 2010.
Home health	State plan home health services include skilled nursing services, therapy services, home health aide services, and in 15 states, assistance with instrumental activities of daily living.
1932(a)	State plan amendment authority for mandatory and voluntary managed care.
1905(a)	State plan personal care. Assistance with instrumental activities of daily living, transportation services, and case management.
1905(a)	Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID). ICFs/IID offer comprehensive health care and rehabilitation services to individuals with IDD who need and receive daily active treatment services. ICF/IID services have prescriptive Federal regulations. Facilities are institutions regardless of size. Access to ICF/IID services for eligible individuals may not be limited, and cannot be subject to waiting lists, though the program is optional for states.
1905(a)	Inpatient psychiatric services for people younger than 21 or older than 65 years in an Institution for Mental Disease.

SECTION 2: MEDICAID AND STATE LTSS FUNDING AUTHORITIES

Medicaid offers an array of different mechanisms (or “authorities”) through which states can request matching federal funds to provide LTSS (see **Table C**). States can request flexibility in administration and in determining the type, amount, duration, and scope of services, as well as the design and delivery of services to be covered, consistent with federal regulations. The federal financial portion (called the Federal Medicaid Assistance Percentage, or FMAP) varies by state, based on per capita income and the size of the state. For FY 2018, state FMAP ranged from 50% in 14 states to 75.7% in Mississippi. In states with a 50% FMAP, every dollar the state spends on Medicaid funded supports is matched by a dollar from the federal government.

States use unique blends of these funding authorities to support LTSS for people with IDD. Meaningful comparisons of Medicaid programs across states requires consideration of the funding authorities, eligibility criteria, and the menu of services covered under each authority by each state.

STATE UTILIZATION OF LTSS FUNDING AUTHORITIES

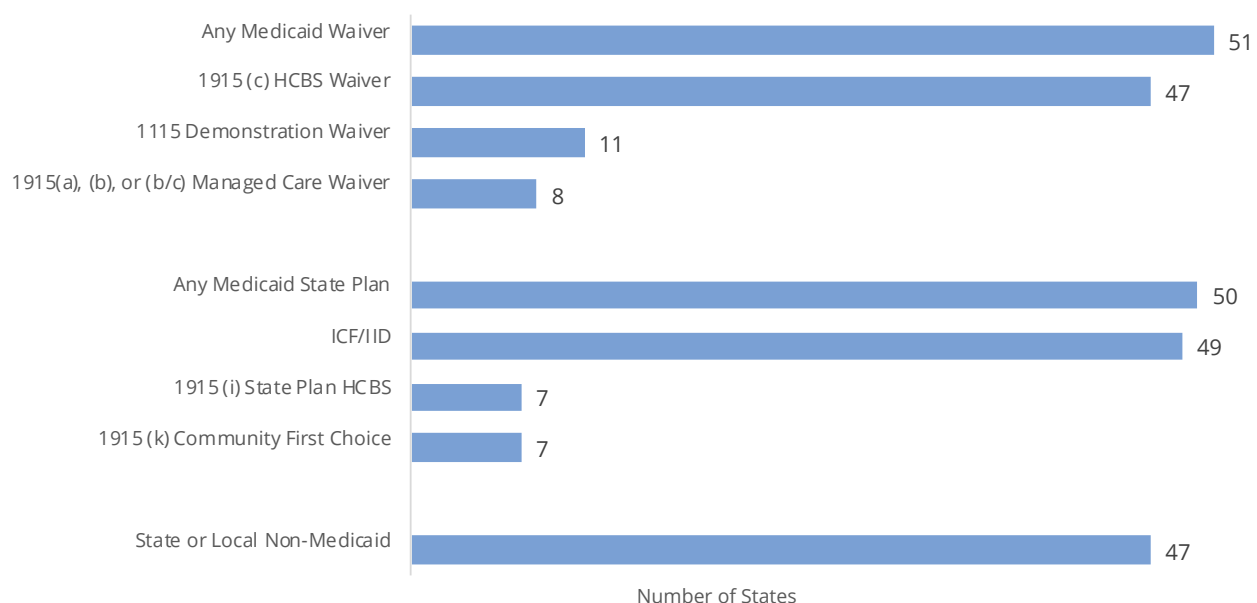
In 2018, all 50 states and the District of Columbia funded LTSS for people with IDD through one or more Medicaid Waiver funding authority (See **Figure 2.1**). The number of states using Medicaid Waiver authorities included: 1915(c) Home and Community-based Waiver (47 states), 1115 Demonstration Waiver (11 states), and Medicaid Managed Care Waivers 1915(a), (b), or (b/c) (8 states).

In 2018, 50 states reported using one or more Medicaid State Plan funding authority to support LTSS for people with IDD. The number of states using State Plan funding authorities to support people with IDD included: Medicaid ICF/IID (49 states), Medicaid State Plan 1915(i) HCBS (7 states), and State Plan 1915(k) Community First Choice (7 states). 47 states also reported funding LTSS for people with IDD through non-Medicaid, state funding authorities.

LTSS RECIPIENTS WITH IDD BY FUNDING AUTHORITY

Of the 1.55 million people with IDD known to, or served under the auspices of state IDD agencies

Figure 2.1 Funding Authorities Used by States to Provide LTSS for People with IDD on June 30, 2018



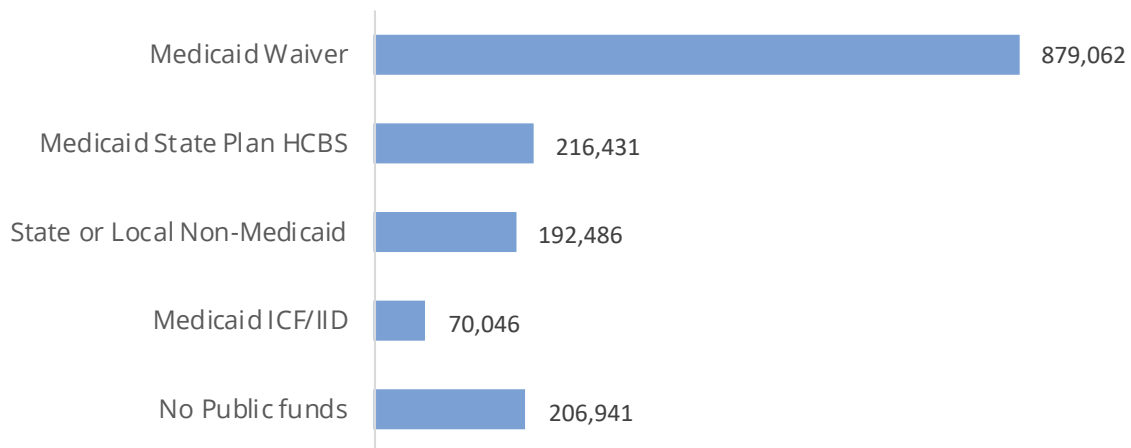


in FY 2018, an estimated 879,062 people received Medicaid Waiver funded LTSS, 70,046 lived in a Medicaid ICF/IID, 216,431 received supports through Medicaid State Plan 1915(i) or 1915 (k) funding authorities, 192,486 received non-Medicaid state-funded LTSS, and 206,941 did not receive LTSS funding. Some people received supports through more than one funding authority.

PEOPLE WITH IDD WAITING FOR MEDICAID WAIVER-FUNDED SUPPORTS

43 states reported the number of people with IDD living with a family member or their own home who had requested Medicaid Waiver-funded services but were waiting for those supports as of June 30, 2018 (See **Table 2.1**). People who already received

Figure 2.2 Estimated LTSS Recipients with IDD by Funding Authority on June 30, 2018



Some people receive services from more than one funding authority. Medicaid Waiver authorities include 1115, 1915 (a), 1915 (a/c), 1915 (b), 1915 (b/c) and 1915 (c) For FY '18 Medicaid State Plan Home and Community Based Services authorities included 1915(i) and 1915(k) but did not include Targeted Case Management.



Table 2.1 People with IDD Living with Family Members Waiting for Medicaid Waiver-Funded LTSS, Total ICF/ID and Medicaid Waiver Recipients and Growth Needed to Serve those Waiting by State on June 30, 2018

State	People Waiting for Medicaid Waiver Funded LTSS			Estimated Medicaid Waiver + ICF/ID Recipients	Increase Needed to Serve All Waiting (%)
	Number Waiting	Gets Targeted Case Management	Waiting to Move from Family Home		
N States	43	35	24	51	43
AL	2,281	0	DNF	3,920	58
AK	904	0	198	2,181	41
AZ	136	0	0	33,294	0
AR	2,802	DNF	DNF	5,800	48
CA	0	0	0	124,115	0
CO	3,212	0	3,212	12,860	25
CT	388	326	130	10,592	4
DE	0	0	0	1,331	0
DC	0	0	0	2,336	0
FL	21,470	DNF	1,585	37,256	58
GA	DNF	DNF	DNF	8,854	DNF
HI	0	0	0	2,905	0
ID	0	0	0	8,678	0
IL	10,339	0	3,322	29,686	35
IN	1,868	0	DNF	30,276	6
IA	DNF	DNF	DNF	14,655	DNF
KS	3,673	1,766	DNF	9,564	38
KY	DNF	DNF	DNF	15,869	DNF
LA	DNF	DNF	DNF	17,193	DNF
ME	396 ^e	396 ^e	DNF	5,425	7
MD	5,656	5,384	DNF	15,319	37
MA	0	0	0	16,766	0
MI	DNF	DNF	DNF	49,589	DNF
MN	29 ^e	29	DNF	23,233	0
MS	1,794	DNF	DNF	4,763	38
MO	0	0	0	15,129	0
MT	DNF	DNF	DNF	2,746	DNF
NE	1,184	328	DNF	5,048	23
NV	466	466	DNF	2,303	20
NH	DNF	DNF	DNF	6,462	DNF
NJ	997	DNF	DNF	17,021	6
NM	4,834	400 ^e	DNF	4,907	99
NY	0	0	6,205	90,165	0
NC	10,459	51	258	37,220	28
ND	0	0	0	5,436	0
OH	33,279	6,933	DNF	45,572	73
OK	7,050	0	0	7,041	100
OR	0	0	0	24,140	0
PA	8,555 ^e	7,573 ^e	2,807 ^e	38,625	22
RI	0	0	0	3,775	0
SC	8,986	DNF	223	11,930	75
SD	0	0	0	3,801	0
TN	0	0	DNF	8,869	0
TX	DNF	DNF	DNF	47,157	DNF
UT	2,857	0	1,494	6,063	47
VT	0	0	0	3,172	0
VA	12,774	DNF	DNF	13,793	93
WA	14,448	DNF	DNF	18,371	79
WV	1,229	DNF	DNF	5,151	24
WI	861	208	DNF	36,298	2
WY	259	259	DNF	2,453	11
Reported US Total	163,186	24,119	19,434		
Estimated US Total	208,889	38,682	69,701	949,108	22

DNF Did not furnish. ^d Other date (data from previous or next year). ^e Estimate. * See state notes in Appendix. HCBS: Home and Community Based Services. ICF/ID: Intermediate Care Facilities for Individuals with Intellectual Disabilities.

2018

Medicaid Waiver-funded supports who were asking for different supports, people living in an ICF/IID and people not living with a family member or in their own home were not counted.

Number of People with IDD Waiting

An estimated 208,889 people with IDD living with a family member or in their own home were not already receiving but were waiting for Medicaid Waiver-Funded LTSS on June 30, 2018. 14 states (California, Delaware, the District of Columbia, Hawaii, Idaho, Massachusetts, Missouri, New York, North Dakota, Oregon, Rhode Island, South Dakota, Tennessee, and Vermont) reported not having a waiting list or reported no people waiting for Medicaid Waiver-funded supports. States reporting more than 10,000 people with IDD waiting for Medicaid Waiver-funded supports included Florida (21,470), Illinois (10,339), North Carolina (10,459), Ohio (33,279 people), Virginia (12,774), and Washington (14,448). Some states have shifted to offering Medicaid state-plan funded home and community-based supports for which waiting lists are not permitted for eligible individuals.

People Receiving Targeted Case Management Services While Waiting

Of the people with IDD waiting for Medicaid Waiver-funded supports, an estimated 19% (38,682 people)

in 12 states received Medicaid State Plan-funded Targeted Case Management (TCM) services while waiting. 22 states reported not providing TCM to people who were waiting. More than 90% of people waiting received TCM services in Maine, Maryland, Minnesota, Nevada, and Wyoming. People waiting may have received LTSS funded by a Medicaid State Plan, or by a non-Medicaid state funding authority during their wait.

People Waiting to Move to a Non-family Setting

An estimated 69,701 people (33%) of people waiting were waiting for Medicaid Waiver funding to enable them to move from the home of a family member to their own home, a host or foster family home, a group home, or another non-family setting. States reporting that more than half of people waiting wanted to move to a non-family setting were Colorado (100%) and Utah (56%).

Growth in Medicaid Funded LTSS Required to Serve All People Waiting

An estimated 949,108 people with IDD received Medicaid Waiver funded supports or lived in an ICF/IID on June 30, 2018 (See **Figure 2.3**). To serve all of the people waiting for Waiver funded supports in states with waiting lists, the number of Waiver funded plus ICF/IID LTSS recipients would have to

Figure 2.3 Total Medicaid ICF/IID and Waiver Recipients and People in Own or Family Home Waiting for Waiver Funding as of June 30, 2016, 2017 and 2018

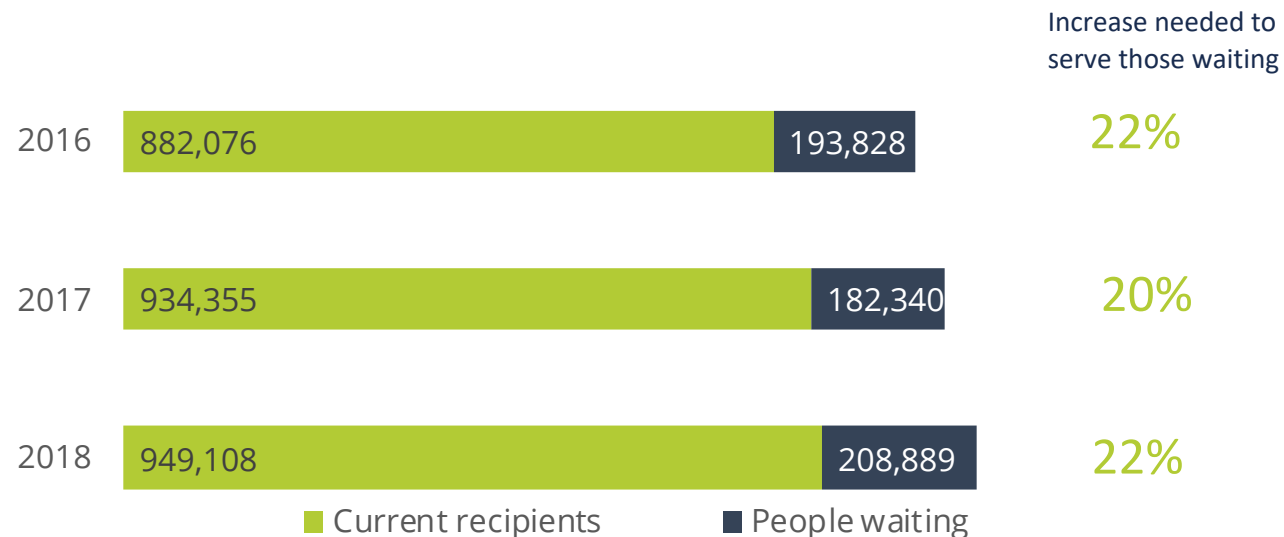
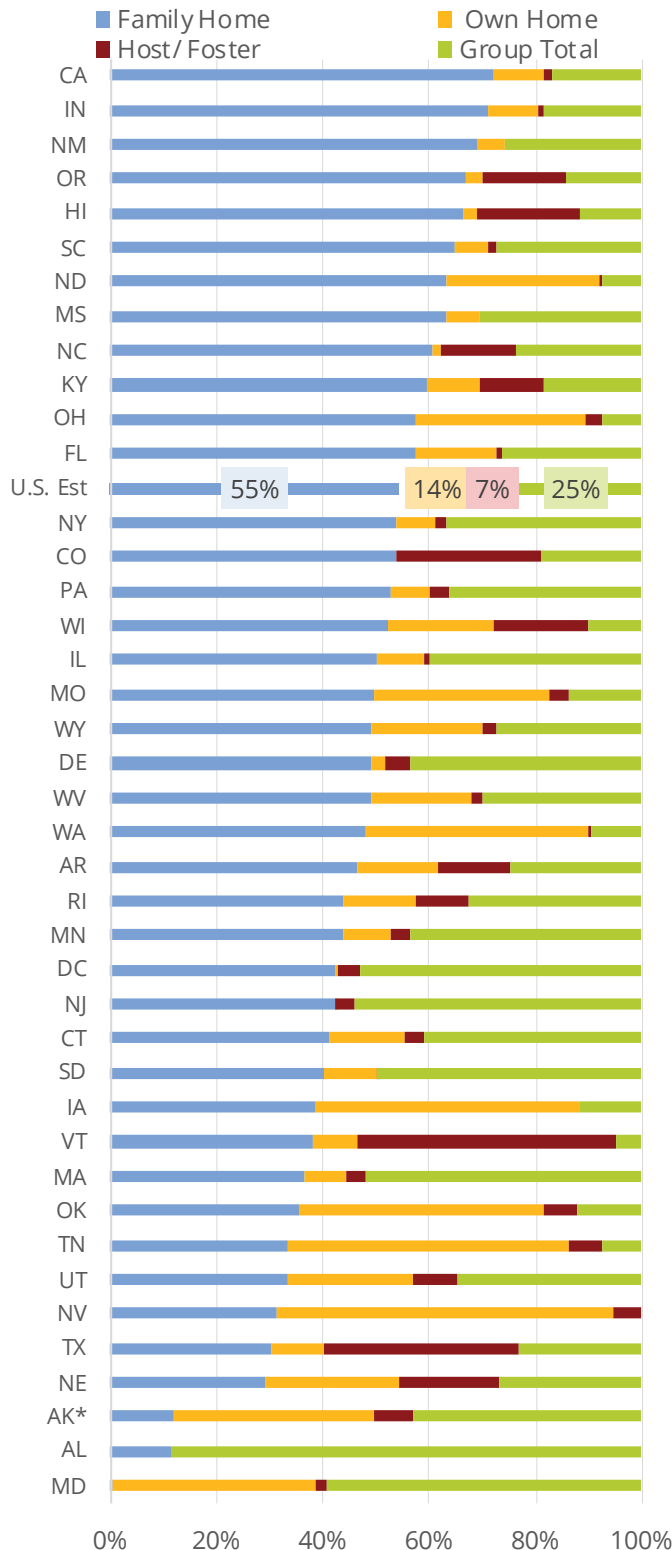


Figure 2.4 Percent of Medicaid Waiver Recipients with IDD in Family Home, Own Home, Host or Foster Family Home, or Group Settings by State June 30, 2018



*States with incomplete setting type data for Waiver recipients were AK, CT, GA, ID, KS, LA, ME, MD, MI, NH, NC, PA, and VA

increase by 22% overall, with the proportion ranging from 0% in 16 states to 100% in Oklahoma.

LIVING ARRANGEMENTS FOR PEOPLE RECEIVING MEDICAID WAIVER FUNDED LTSS

The RISP survey asks about Medicaid Waiver recipients by age, living arrangement, and operating entity (state or non-state). It also asks for the number of people for whom Medicaid Waiver expenditures are reported. In many states, the number of people for whom expenditure data are provided differs from the number of recipients by setting type because recipient characteristics and living arrangements are reported for people as of June 30 while expenditures are reported for the whole fiscal year.

Residential setting type was reported for 744,446 of the estimated 879,062 Medicaid Waiver recipients (See **Table 2.2** and **Figure 2.4**). Setting type was not reported for 134,616 waiver recipients in 13 states (Alaska, Connecticut, Georgia, Idaho, Kansas, Louisiana, Maine, Maryland, Michigan, New Hampshire, North Carolina, Pennsylvania, and Virginia).

Home of a Family Member

An estimated 483,367 Medicaid Waiver recipients (55%) lived in the home of a family member. The proportion of Waiver recipients living with a family member ranged from less than 1% in Maryland to 85% in Arizona and exceeded 50% in 19 states.

Own Home

An estimated 120,288 Waiver recipients with IDD (14%) lived in a home they owned or leased on June 30, 2018. The proportion of Waiver recipients who lived in a home of their own ranged from zero in Alabama, Colorado, the District of Columbia, and New Jersey, to 63% in Nevada. In 23 states, fewer than 10% of Medicaid Waiver recipients with IDD lived in a home of their own, whereas in Iowa, Tennessee and Nevada more than 50% of recipients lived in a home of their own.

Table 2.2 Medicaid Waiver Recipients with IDD by Reported Residence Type and State on June 30, 2018

	Family Home	Own Home	Host/ Foster Family	Group Settings			Group Total	Setting Type Unknown
				Non-State IDD	Non-State Other	State IDD		
N States	43	44	46	45	46	51	44	13
AL	444	0	0	3,451	0	0	3,451	0
AK	178	575	108	654	0	0	654	525
AZ	27,646	276	1,521	3,077	5	133	3,215	0
AR	1,925	639	570	1,027	0	0	1,027	0
CA	84,134	11,366	1,539	19,975	0	0	19,975	0
CO	6,380	0	3,180	774	1,368	122	2,264	0
CT	4,084	1,379	369	3,747	84	213	4,044	11
DE	1,086	55	98	966	0	0	966	0
DC	859	5	93	1,052	18	0	1,070	0
FL	19,612	5,356	373	8,739	212	0	8,951	0
GA	DNF	DNF	DNF	DNF	DNF	0	PD	DNF
HI	1,870	79	543	332	0	0	332	0
ID	1,689	DNF	552	DNF	0 ⁱ	0	PD	DNF
IL	11,656	1,969	302	9,211	0	0	9,211	0
IN	19,297	2,514 ^e	300	5,006 ^e	0	0	5,006 ^e	0
IA	5,295	6,776	0	1,462	116	0	1,578	0
KS	DNF	DNF	DNF	DNF	DNF	0	PD	9,124
KY	8,883 ⁱ	1,509 ⁱ	1,794	2,720	0	0	2,720	0 ^f
LA	DNF	2,264	10	0	0	0	0	9,593
ME	DNF	822	991	1,783	DNF	0	PD	DNF
MD	36	3,810	230	5,934	0	0	5,934	5,303
MA	6,344 ^{e,i}	1,366	628	8,043	0	1,062	9,105	0
MI	DNF	DNF	DNF	DNF	DNF	0 ⁱ	PD	DNF
MN	9,555 ^e	1,946 ^e	873 ^e	8,318 ^e	806 ^e	359	9,483 ^e	0
MS	1,640 ^e	174	0	602	0	189	791	0
MO	7,031	4,755	483	1,753	0	217	1,970	0
MT	DNF	DNF	46	854	11	0	865	0
NE	1,338	1,165	844	1,245	0	0	1,245	0
NV	693	1,404	122	0	0	0	0	0
NH	DNF	DNF	DNF	DNF	DNF	0 ⁱ	PD	DNF
NJ	6,585	59	554	8,438	0	0	8,438	0
NM	3,181	240	0	1,131	0	71	1,202	0
NY	45,592 ^e	6,027 ^e	1,572	24,826	0 ⁱ	6,420	31,246	0 ⁱ
NC	8,794 ^e	193 ^e	2,083	3,187	256 ^e	0	3,443	377
ND	2,928	1,338	14	349	0	0	349	0
OH	22,712	12,797	1,215	2,547	356 ^e	0	2,903	0
OK	1,895	2,445	325	645	0	0	645	0
OR	14,134	704	3,282	3,011	0	0	3,011	0
PA	18,693 ^e	2,529	1,395	11,468	1,351 ^e	0	12,819	17
RI	1,636	517	369	1,086	0	130	1,216	0
SC	6,976	644	175	2,964	0	0	2,964	0
SD	1,453	365	1	1,809	0	0	1,809	0
TN	2,518	3,986	476	569	6	0	575	0
TX	11,287	3,623	13,698	8,588	0	0	8,588	0
UT	1,759	1,242	445	1,839	0	0	1,839	0
VT	1,088	241	1,376	142	0	0	142	0
VA	DNF	DNF	DNF	DNF	0 ⁱ	0	PD	13,100
WA	10,775	9,347	134	1,633	224	328	2,185	0
WV	2,218	857	96	1,344	0	0	1,344	0
WI	18,741	6,994	6,473	3,568	3	0	3,571	0
WY	1,120	476	52	618	7	0	625	0
Reported US Total	405,760	104,828	49,304	170,487	4,823	9,244	184,554	38,050
Estimated US Total	483,367	120,288	57,014	201,926	7,325	9,142	218,393	0

DNF Did not furnish. ^d Other date (data from previous or next year). ^e Estimate. * See state notes in Appendix. Many states were unable to report residence type for all Waiver recipients. Please refer to Table 2.3 for an estimate of the total number of Waiver recipients. Medicaid Waiver authorities include 1115, 1915 (a), 1915 (a/c), 1915 (b), 1915 (b/c) and 1915 (c). 14,678 Waiver recipients are not accounted for on this table.

Host or Family Foster Home

An estimated 57,014 Waiver recipients with IDD (7%) lived with a host or foster family on June 30, 2018. The proportion of Waiver recipients with IDD who lived with a host or foster family ranged from less than 1% in Alabama, New Mexico, Mississippi, Iowa, North Dakota, and South Dakota to 55% in Maine. In 34 states, fewer than 10% of Medicaid Waiver recipients with IDD lived with a host or foster family.

Group Settings

An estimated 218,393 Waiver recipients with IDD (25%) lived in group settings including an estimated 201,926 who lived in a non-state group home, 9,142 who lived in a state-operated group home, and 7,325 who lived in a non-state group setting of another type. The proportion of Waiver recipients living in group homes ranged from none in Nevada to 95% in Montana. Besides Montana, states in which 50% or more of Medicaid Waiver recipients lived in a group setting included Alabama (89%) Maryland (59%), New Jersey (54%), the District of Columbia (53%), Massachusetts (52%) and South Dakota (50%). Fewer than 10% of Medicaid Waiver recipients with IDD lived in a group setting Nevada (0%), Vermont (5%), Ohio (7%), North Dakota (8%), Tennessee (8%), Arizona and Washington (just under 10%).

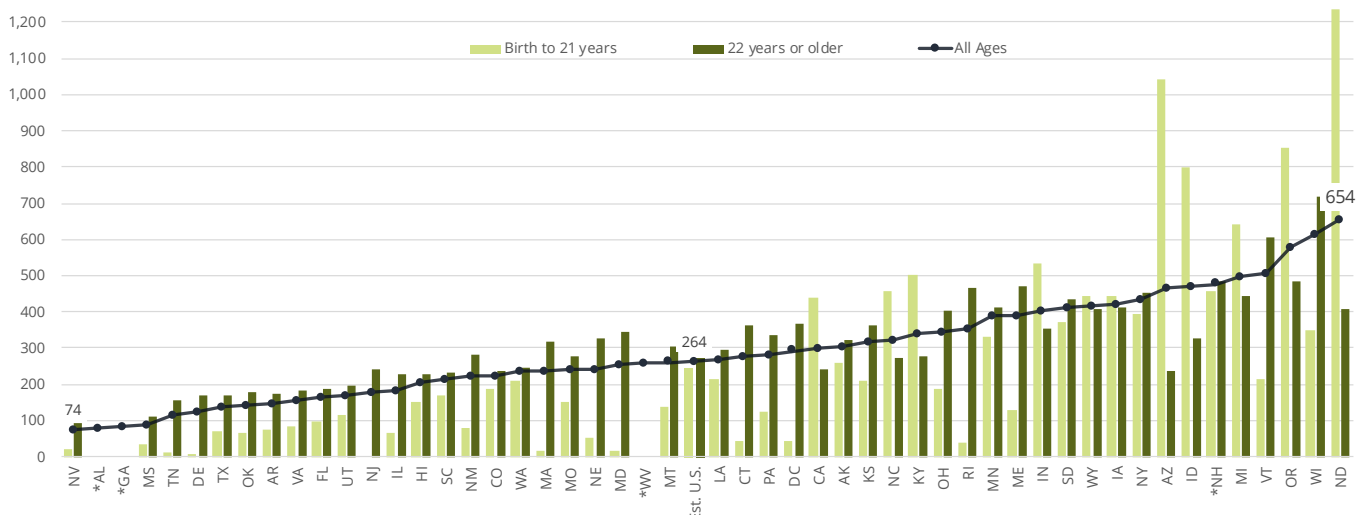
MEDICAID WAIVER UTILIZATION RATES BY AGE AND STATE

Of the estimated 879,062 Medicaid Waiver recipients with IDD, an estimated 222,540 (22%) were 21 years old or younger and 656,522 (75%) were 22 years or older (See **Table 2.3** and **Figure 2.5**). Thirteen states (Connecticut, Delaware, the District of Columbia, Illinois, Maine, Maryland, Massachusetts, Nebraska, New Jersey, New Mexico, Rhode Island, Tennessee) reported that 90% or more of Waiver recipients were 22 years or older. Three states reported that fewer than 50% of Waiver recipients were 22 years or older: Arizona (37%), Idaho (48%) and North Dakota (44%).

Nationally, there were an estimated 270 Medicaid Waiver recipients with IDD per 100,000 of the population. Medicaid Waiver utilization rates ranged from 74 per 100,000 in Nevada to 654 per 100,000 in North Dakota. In addition to Nevada, Alabama (80), Georgia (82) and Mississippi (89) had utilization rates of less than 100 per 100,000. In addition to North Dakota, Vermont (508), Oregon (578) and Wisconsin (616) reported Medicaid Waiver utilization rates of more than 500 to per 100,000.

Waiver utilization rates for children and youth with IDD 21 years or younger averaged 247 per 100,000 of the population and ranged from 0 in New Jersey to 1,234 per 100,000 in North Dakota. In addition

Figure 2.5 Medicaid Waiver Recipients with IDD per 100,000 of the Population by Age and State on June 30, 2018



*Age breakdowns not available for AL, GA, NH, WV

Table 2.3 Medicaid Waiver Recipients with IDD total and per 100,000 by Age and State on June 30, 2018

Age	Waiver Recipients			Percent 22 years or older	State Population in 100,000's		Recipients per 100,000 by Age		
	Birth to 21 years	22 years or older	All Ages		Birth to 21 years	22 years or older	Birth to 21 years	22 years or older	All Ages
N states	48	48	51	48	51	51	48	48	51
AL	DNF	DNF	3,895	DNF	13	35	DNF	DNF	80
AK	559	1,608	2,167	74	2	5	259	322	303
AZ	21,038	12,116	33,154	37	20	51	1,041	237	464
AR	628	3,737	4,365	86	9	21	73	174	145
CA	48,428	68,586	117,014	59	110	283	441	242	298
CO	2,907	9,750	12,657	77	15	41	188	237	224
CT	416	9,469	9,885	96	9	26	44	361	277
DE	20	1,191	1,211	98	3	7	8	168	126
DC	71	1,956	2,027	96	2	5	42	369	291
FL	4,978	29,578	34,556	86	52	160	96	185	163
GA	DNF	DNF	8,579	DNF	31	74	DNF	DNF	82
HI	543	2,289	2,832	81	4	10	151	225	206
ID	4,294	3,940	8,234	48	5	12	801	325	471
IL	2,276	20,862	23,138	90	35	92	65	227	182
IN	10,444	16,673	27,117	61	19	47	536	352	405
IA	4,047	9,167	13,214	69	9	22	443	410	420
KS	1,814	7,310	9,124	80	9	20	209	362	316
KY	6,194	8,940	15,134	59	12	32	500	279	341
LA	2,834	9,706	12,540	77	13	33	213	293	270
ME	406	4,823	5,229	92	3	10	130	471	391
MD	264	14,960	15,224	98	16	44	16	343	254
MA	267	16,114	16,381	98	18	51	15	316	238
MI	17,353 ⁱ	32,236 ^j	49,589 ^j	65	27	73	642	443	497
MN	5,268	16,524	21,792	76	16	40	332	411	389
MS	308	2,330	2,638	88	9	21	36	111	89
MO	2,576	12,147	14,723	83	17	44	153	275	241
MT	393	2,347	2,740	86	3	8	139	303	259
NE	300	4,366	4,666	94	6	13	51	327	243
NV	160	2,059	2,219	93	8	22	20	94	74
NH	1,507 ^j	4,935 ^j	6,442 ^j	77	3	10	455	483	476
NJ	0	15,636	15,636	100	24	65	0	241	176
NM	464	4,160	4,624	90	6	15	78	279	222
NY	19,988 ^d	65,067 ^e	85,055 ^f	76	51	144	395	451	436
NC	13,052	20,189	33,241	61	28	74	459	271	323
ND	2,744	2,164	4,908	44	2	5	1,234	409	654
OH	6,052	34,150	40,202	85	32	85	189	403	345
OK	742	4,883	5,625	87	12	28	64	177	143
OR	9,104	15,036	24,140	62	11	31	851	483	578
PA	4,174	31,700	35,874	88	33	95	126	335	280
RI	105	3,633	3,738	97	3	8	38	465	355
SC	2,281	8,478	10,759	79	14	37	168	230	213
SD	981	2,644	3,625	73	3	6	372	432	414
TN	192	7,643	7,835	98	18	49	10	156	116
TX	6,202	33,083	39,285	84	89	196	69	169	138
UT	1,290	3,995	5,285	76	11	20	115	197	168
VT	338	2,828	3,166	89	2	5	215	606	508
VA	1,892 ^{g,i}	11,208 ^j	13,100	86	23	61	82	184	156
WA	4,200	13,471	17,671	76	20	55	209	246	237
WV	DNF	DNF	4,634	DNF	5	14	DNF	DNF	257
WI	5,534	30,245	35,779	85	16	42	348	717	616
WY	726	1,668	2,394	70	2	4	443	406	417
Reported US Total	220,354	641,600	879,062	73	902	2,353	244	273	270
Estimated US Total	222,623	656,439	879,062	75	902	2,353	247	279	270

DNF Did not furnish. ^d Other date (data from previous or next year). ^e Estimate. ^f Source U.S. Census Bureau, Population Division (2017). ^g See state notes in Appendix. Medicaid Waiver authorities include 1115, 1915 (a), 1915 (a/c), 1915 (b), 1915 (b/c) and 1915 (c). Does not include 1915(i) or 1915(k).

to New Jersey, Delaware (8), Tennessee (10), Massachusetts (15), and Maryland (16) provided Medicaid Waiver funded supports to fewer than 20 children or youth per 100,000. Several states provide Medicaid Waiver funded LTSS to young adults 18 to 21 years old but do not serve children younger than age 18.

Medicaid Waiver utilization rates for people 22 years or older averaged 279 per 100,000 of the population and ranged from 94 per 100,000 in Nevada to 717 per 100,000 in Wisconsin. 10 states provided Medicaid Waiver funded supports to fewer than 200 adults with IDD ages 22 years or older per 100,000 of the state population (Arkansas, Delaware, Florida, Mississippi, Nevada, Oklahoma, Tennessee, Texas, Utah, and Virginia). Fourteen states provided Medicaid Waiver funded supports to more than 400 adults ages 22 years or older with IDD per 100,000 of the state population (Iowa, Maine, Michigan, Minnesota, New Hampshire, New York, North Dakota, Ohio, Oregon, Rhode Island, South Dakota, Vermont, Wyoming, and Wisconsin).

For people with IDD, access to Medicaid Waiver funded LTSS differs by age and one's state of residence. In 37 states, adults 22 years or older are more likely than children and youth 21 years or younger to receive Medicaid Waiver funded LTSS. Utilization rates are more than 10 times higher for children in some states than in others, and for adults are 7 times higher in some states than in other states.

Factors associated with differences in overall Waiver utilization rates or utilization rates for children versus adults may include state wealth, state policies regarding funding for Medicaid LTSS, historical use of ICF/IID versus Medicaid Waiver funding, and, whether the state offers Medicaid State Plan-funded HCBS to Medicaid recipients who are eligible for LTSS.

Access to Medicaid Waiver funding is one of several factors to weigh when evaluating which states provide the most generous LTSS for people with IDD. Other factors include but are not limited to:

- the extent to which people with IDD continue to live in congregate settings of 7 or more people,





- the type of settings in which LTSS recipients live (family home, own home, host/foster family home, or group setting),
- for children and youth, the extent to which the schools in the state provide inclusive educational and transition services to students with IDD and the maximum age for receipt of those services,
- for adults, the proportion of adults with IDD who get day or vocational supports who work in integrated community jobs at least part-time (Winsor, et al., 2019; <https://www.thinkwork.org/statedatainfo/>),
- and the amount of state and Medicaid dollars allocated per person to LTSS, and the extent to which the state supports purchase of assistive devices and technology supports for Medicaid recipients (Tanis, Lulinski, Braddock, & Hemp, 2020; <https://stateofthestates.org/>).

Medicaid Waiver Recipients by Age and Living Arrangement

The living arrangements for Medicaid Waiver recipients differ by age. Of the Medicaid Waiver recipients who were 21 years or younger, an estimated 199,440 (90%) lived in the home of a family member and 23,183 (10%) lived in another type of residence. Of the Medicaid Waiver recipients who were ages 22 years or older, an estimated 287,539 (44%) lived with a family member, and 368,900 (56%) lived in another type of residence. (See **Table 2.4** and **Figure 2.6**).

The proportion of child Medicaid Waiver recipients who lived with a family member ranged from 0 in New Jersey and Massachusetts to 99% in North Dakota. Fewer than half of Medicaid Waiver recipients ages 21 years or younger lived with a family member in Alaska (48%), Delaware (35%), the District of Columbia (46%), Iowa (45%), Maryland (8%), Massachusetts (0%), Nevada (23%), New Jersey (0%), Tennessee (35%) and Utah (49%).

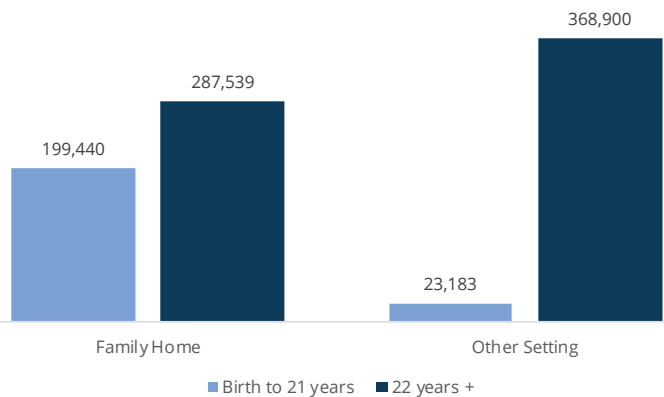


Table 2.4 Medicaid Waiver Recipients with IDD Living in Family Homes or Other LTSS Settings by Age and State and Percent by Age Living in Family Home on June 30, 2018

Age	Family Home		Other Settings ¹		% in Family Home	
	Birth to 21 years	22 years or older	Birth to 21 years	22 years or older	Birth to 21 years	22 years or older
N States	38	38	37	37	36	36
AL	DNF	DNF	DNF	DNF	DNF	DNF
AK	271	0	288	1,608	48	0
AZ	17,141	10,505	910	3,969	95	73
AR	DNF	DNF	DNF	DNF	DNF	DNF
CA	46,975	37,159	1,453	31,427	97	54
CO	2,588	4,626	414	5,253	86	47
CT	363	3,722	53	5,747	87	39
DE	7	107	13	1,084	35	9
DC	27	832	32	1,168	46	42
FL	4,062	15,134	916	14,444	82	51
GA	DNF	DNF	DNF	DNF	DNF	DNF
HI	454	1,416	21	769	96	65
ID	DNF	DNF	DNF	DNF	DNF	DNF
IL	1,822	9,834	454	11,028	80	47
IN	10,195	9,102	249	7,571	98	55
IA	1,832	3,310	2,215	5,857	45	36
KS	DNF	DNF	DNF	DNF	DNF	DNF
KY	6,032 ^d	4,901 ^e	DNF	DNF	DNF	DNF
LA	DNF	DNF	DNF	DNF	DNF	DNF
ME	DNF	DNF	DNF	DNF	DNF	DNF
MD	20	19	244	14,721	8	0
MA	267	6,070	0	10,044	0	38
MI	DNF	DNF	DNF	DNF	DNF	DNF
MN	4,657 ^e	4,898 ^e	611 ^e	11,626 ^e	88	30
MS	DNF ^f	DNF	DNF	DNF	DNF	DNF
MO	2,113	5,045	405	7,008	84	42
MT	DNF	DNF	38	940	DNF	DNF
NE	207	2,735	DNF	DNF	DNF	DNF
NV	37	656	123	1,403	23	32
NH	DNF	DNF	DNF	DNF	DNF	DNF
NJ	0	6,585	0	9,051	0	42
NM	452	3,257	12	903	97	78
NY	19,303 ^g	26,880 ^e	685 ^e	38,187 ^h	97	41
NC	7,604	9,980	2,137	6,942	78	59
ND	2,692	236	40	1,643	99	13
OH	5,383	16,694	669	17,456	89	49
OK	436	1,459	304	3,418	59	30
OR	8,053	8,993	1,051	6,043	88	60
PA	3,660	15,203	514	16,497	88	48
RI	79	1,526	26	2,107	75	42
SC	2,198	4,778	83	3,700	96	56
SD	892	560	91	2,084	91	21
TN	68	2,038	124	5,605	35	27
TX	3,860	8,153	2,374	24,312	62	25
UT	626	1,133	664	2,862	49	28
VT	195	893	143	1,935	58	32
VA	DNF	DNF	DNF	DNF	DNF	DNF
WA	3,874	6,239	326	7,232	92	46
WV	DNF	DNF	DNF	DNF	DNF	DNF
WI	5,432	13,309	102	16,936	98	44
WY	628	492	59	1,094	91	31
Reported US Total	164,505	248,479	17,843	303,674	90	45
Estimated US Total¹	199,440	287,539	23,183	368,900	90	44

DNF Did not furnish. ^d Other date (data from previous or next year). ^e Estimate. * See state notes in Appendix. This table shows the number of people by age and setting for whom Waiver expenditures were reported. ¹ Other settings include own home, host or foster family home, and all group settings. Medicaid Waiver authorities include 1115, 1915 (a), 1915 (a/c), 1915 (b), 1915 (b/c) and 1915 (c). An estimated 8,731 people are not accounted for in the Estimated totals on this table.

Figure 2.6 Estimated Number of Waiver Recipients by Age and Residence Type on June 30, 2018



The proportion of Medicaid Waiver recipients 22 years or older who lived with a family member averaged 44%. More than half of all adult Medicaid Waiver recipients lived with a family member in nine states: Arizona (73%), California (54%), Florida (51%), Hawaii (65%), Indiana (55%), New Mexico (78%), North Carolina (59%), Oregon (60%), and South Carolina (56%). No Medicaid Waiver recipients who were adults lived in the home of a family member in Alaska or Maryland.

People in Own Home or Family Home Settings Receiving Medicaid Waiver funded Supports

On June 30, 2018, of the estimated 153,092 LTSS recipients who lived in a home of their own, 120,288 (79%) received supports funded by a Medicaid Waiver. All recipients living in their own home received Medicaid Waiver funded supports in 16 states. In another eight states, 90% or more received Waiver funded supports. Fewer than half of recipients living in their own home received Medicaid Waiver funded supports in Alabama (0%), California (43%), Colorado (0%), and Vermont (44%).

Of 792,030 LTSS recipients living with a family member, 483,367 (61%) received Medicaid Waiver funded supports (See **Table 2.5**). All recipients living with a family member received Medicaid Waiver funded supports in 9 states as did more than 90% of recipients in an additional four states. In 11 states, fewer than half of LTSS recipients living with a family member received Medicaid Waiver funded supports.

Table 2.5 Medicaid Waiver and LTSS Recipients with IDD in Own Home or Family Settings by State on June 20, 2018

State	All LTSS Recipients		Waiver Recipients		% with Waiver Funding ¹	
	Own Home	Family Home	Own Home	Family Home	Own Home	Family Home
N States	46	41	44	43	43	39
AL	55	2,640	0	444	0	17
AK	575	178	575	178	100	100
AZ	276	36,439	276	27,646	100	76
AR	639	1,973	639	1,925	100	98
CA	26,265	192,592	11,366	84,134	43	44
CO	0	8,730	0	6,380	0	73
CT	1,441	4,649	1,379	4,084	96	88
DE	55	3,413	55	1,086	100	32
DC	8	859	5	859	63	100
FL	5,957	40,916	5,356	19,612	90	48
GA	DNF	DNF	DNF	DNF	DNF	DNF
HI	92	2,172	79	1,870	86	86
ID	DNF	DNF	DNF	1,689	DNF	DNF
IL	1,969	12,627	1,969	11,656	100	92
IN	2,514 ^e	19,297	2,514 ^e	19,297	100	100
IA	7,185 ⁱ	7,860 ^h	6,776	5,295	94	67
KS	DNF	DNF	DNF	DNF	DNF	DNF
KY	DNF	DNF	1,509 ^j	8,883 ^j	DNF	DNF
LA	2,264	DNF	2,264	DNF	100	DNF
ME	822	DNF	822	DNF	100	DNF
MD	4,571	124	3,810	36	83	29
MA	2,677	9,420	1,366	6,344 ^{ei}	51	67
MI	10,077 ^j	29,603 ^j	DNF	DNF	DNF	DNF
MN	3,471 ^e	13,475 ^e	1,946 ^e	9,555 ^e	56	71
MS	174	2,512 ^e	174	1,640 ^e	100	65
MO	4,956	12,115	4,755	7,031	96	58
MT	DNF	DNF	DNF	DNF	DNF	DNF
NE	1,177	2,148	1,165	1,338	99	62
NV	1,841	4,852	1,404	693	76	14
NH	0	DNF	DNF	DNF	DNF	DNF
NJ	59	14,883	59	6,585	100	44
NM	344	3,456	240	3,181	70	92
NY	11,795	89,066	6,027 ^f	45,592 ^e	51	51
NC	274 ^e	DNF	193 ^e	8,794 ^e	70	DNF
ND	1,338	2,928	1,338	2,928	100	100
OH	15,380	80,284	12,797	22,712	83	28
OK	2,451 ^e	1,895	2,445	1,895	100	100
OR	708	14,153	704	14,134	99	100
PA	3,368 ^e	22,712 ^e	2,529	18,693 ^e	75	82
RI	517	1,636	517	1,636	100	100
SC	696	16,062	644	6,976	93	43
SD	536	DNF	365	1,453	68	DNF
TN	3,986	6,991	3,986	2,518	100	36
TX	3,623	11,287	3,623	11,287	100	100
UT	1,262 ^e	1,787 ^e	1,242	1,759	98	98
VT	543	2,292	241	1,088	44	47
VA	807	4,296	DNF	DNF	DNF	DNF
WA	13,024	15,026	9,347	10,775	72	72
WV	857	2,218	857	2,218	100	100
WI	7,017	29,539	6,994	18,741	100	63
WY	476	1,120	476	1,120	100	100
Reported US Total	148,122	730,225	104,828	405,760	71	56
Estimated US Total	153,092	792,030	120,288	483,367	79	61

DNF Did not furnish. ^d Other date (data from previous or next year). ^e Estimate. ⁱ One or more component value imputed by RISP staff. Unknown values distributed according to national proportions. * See state notes in Appendix. ¹ Proportion of recipients who received services funded by a Waiver. Medicaid Waiver authorities include 1115, 1915 (a), 1915 (a/c), 1915 (b), 1915 (b/c) and 1915 (c).



Table 2.6 Medicaid Waiver Expenditures for Recipients with IDD, Per Recipient and Per State Resident by Age and State in FY 2018

State	Waiver Expenditures (\$)			FY 2018 Waiver Recipients	Expenditures per Recipient (\$)			State Population ⁵ (100,000)	Expenditures per State Resident (\$)
	Birth to 21	22 Years +	Total		Birth to 21	22 years +	Total		
N States	43	43	49	51	42	43	49	51	49
AL	DNF	DNF	362,745,747	3,895	DNF	DNF	93,131	49	74
AK	23,249,925	163,749,814	186,999,739	2,167	41,592	101,834	86,294	7	261
AZ	382,793,523	718,239,101	1,101,032,624	33,154	18,195	59,280	33,210	71	154
AR	21,847,426	215,665,149	237,512,575	4,365	34,789	57,711	54,413	30	79
CA	426,589,482	2,965,287,761	3,391,877,243	117,014	8,809	43,235	28,987	393	86
CO	54,421,780	428,147,271	482,569,051	12,657	18,721	43,913	38,127	57	85
CT	20,065,279	939,274,276	959,339,555	9,885	48,234	99,195	97,050	36	269
DE	2,006,582	140,543,797	142,550,378	1,211	100,329	118,005	117,713	10	148
DC	1,858,682	236,759,078	238,617,760	2,027	26,179	121,042	117,720	7	342
FL	76,744,118	992,119,344	1,068,863,462	34,556	15,417	33,542	30,931	212	50
GA	DNF	DNF	647,324,952 ^c	8,579 ^j	DNF	DNF	75,455	104	62
HI	11,777,112	110,057,772	121,834,883	2,832	21,689	48,081	43,021	14	89
ID	58,122,316	195,791,863	253,914,178	8,234	13,536	49,693	30,837	17	145
IL	75,712,840	879,443,454	955,156,294	23,138	33,266	42,155	41,281	127	75
IN	81,493,675	563,780,121	645,273,796	27,117	7,803	33,814	23,796	67	96
IA	99,824,483	473,935,463	573,759,945	13,214	24,666	51,700	43,421	31	182
KS	65,372,092	457,023,254	522,395,346	9,124	36,038	62,520	57,255	29	181
KY	209,518,627	456,063,103	665,581,730	15,134	33,826	51,014	43,979	44	150
LA	45,622,315	426,410,284	472,032,599	12,540	16,098	43,933	37,642	46	102
ME	11,470,060	370,083,159	381,553,219	5,229	28,251	76,733	72,969	13	285
MD	12,900,495	1,048,612,382	1,061,512,877	15,224	48,866	70,094	69,726	60	177
MA	5,112,195	1,510,768,927	1,515,881,122	16,381	19,147	93,755	92,539	69	220
MI	DNF	DNF	DNF	49,589 ^j	DNF	DNF	DNF	100	DNF
MN	247,727,300	1,306,582,380	1,554,309,680	21,792	47,025	79,072	71,325	56	277
MS	DNF	DNF	114,590,471	2,638	DNF	DNF	43,438	30	39
MO	77,083,945	846,791,637	923,875,582	14,723	29,924	69,712	62,751	61	151
MT	8,505,229	105,114,472	113,619,700	2,740	21,642	44,787	41,467	11	107
NE	16,240,061	282,058,072	298,298,133	4,666	54,134	64,603	63,930	19	155
NV	10,229,438	104,113,679	114,343,117	2,219	63,934	50,565	51,529	30	38
NH	DNF	DNF	DNF	6,442 ^j	DNF	DNF	DNF	14	DNF
NJ	0	1,206,523,878	1,206,523,878	15,636	N/A	77,163	77,163	89	136
NM	20,520,527	352,243,352	372,763,879	4,624	44,225	84,674	80,615	21	179
NY	359,615,000	5,583,657,638	5,943,272,638	85,055 ^e	17,992	85,814	69,876	195	305
NC	182,874,336	1,080,078,501	1,262,952,837	33,241	14,011	53,498	37,994	103	123
ND	DNF	DNF	194,814,542 ^e	4,908	DNF	DNF	39,693	8	259
OH	111,614,828	1,638,483,300	1,750,098,128	40,202	18,443	47,979	43,533	117	150
OK	19,001,930	291,645,170	310,647,099	5,625	25,609	59,727	55,226	39	79
OR	33,017,913	110,179,885	143,197,798	24,140	3,627	7,328	5,932	42	34
PA	105,070,389	3,024,170,066	3,129,240,455	35,874	25,173	95,400	87,229	128	245
RI	2,562,107	240,242,613	242,804,720	3,738	24,401	66,128	64,956	11	230
SC	73,454,832	273,016,252	346,471,084	10,759	32,203	32,203	32,203	50	69
SD	8,369,671	107,598,396	115,968,067	3,625	8,532	40,695	31,991	9	132
TN	14,296,291	670,148,669	684,444,960	7,835	74,460	87,681	87,357	68	101
TX	218,474,877	1,325,861,254	1,544,336,131	39,285	35,227	40,077	39,311	285	54
UT	41,030,356	222,667,996	263,698,352	5,285	31,806	55,737	49,896	31	84
VT	22,689,111	191,468,761	214,157,872	3,166	67,128	67,705	67,643	6	343
VA	DNF	DNF	911,721,026 ^c	13,100	DNF	DNF	69,597	84	109
WA	19,035,266	541,762,960	560,798,226	17,671	4,532	40,217	31,736	75	75
WV	DNF	DNF	149,187,009 ^e	4,634	DNF	DNF	32,194	18	83
WI	53,870,061	1,284,303,021	1,338,173,082	35,779	9,734	42,463	37,401	58	231
WY	10,300,975	87,526,324	97,827,299	2,394	14,189	52,474	40,864	6	170
Estimated US Total	4,101,574,529	38,191,112,136	42,292,676,687	879,062	18,301	57,894	47,835	3,255	130

DNF Did not furnish. ^a Other date (data from previous or next year). ^b Estimate. ^c U.S. Census Bureau, Population Division (2019); Murray, et al., (2021) (Total Waiver expenditures). * See state notes in Appendix. Medicaid Waiver authorities include 1115, 1915 (a), 1915 (a/c), 1915 (b), 1915 (b/c) and 1915 (c). US estimated expenditures per person calculated based only on states providing data for all elements by age.

LTSS recipients in own home or family home settings whose services were not funded by a Medicaid HBS Waiver usually received Medicaid Home and Community-based Supports through a State Plan option, and/or received state-funded LTSS.

MEDICAID WAIVER EXPENDITURES

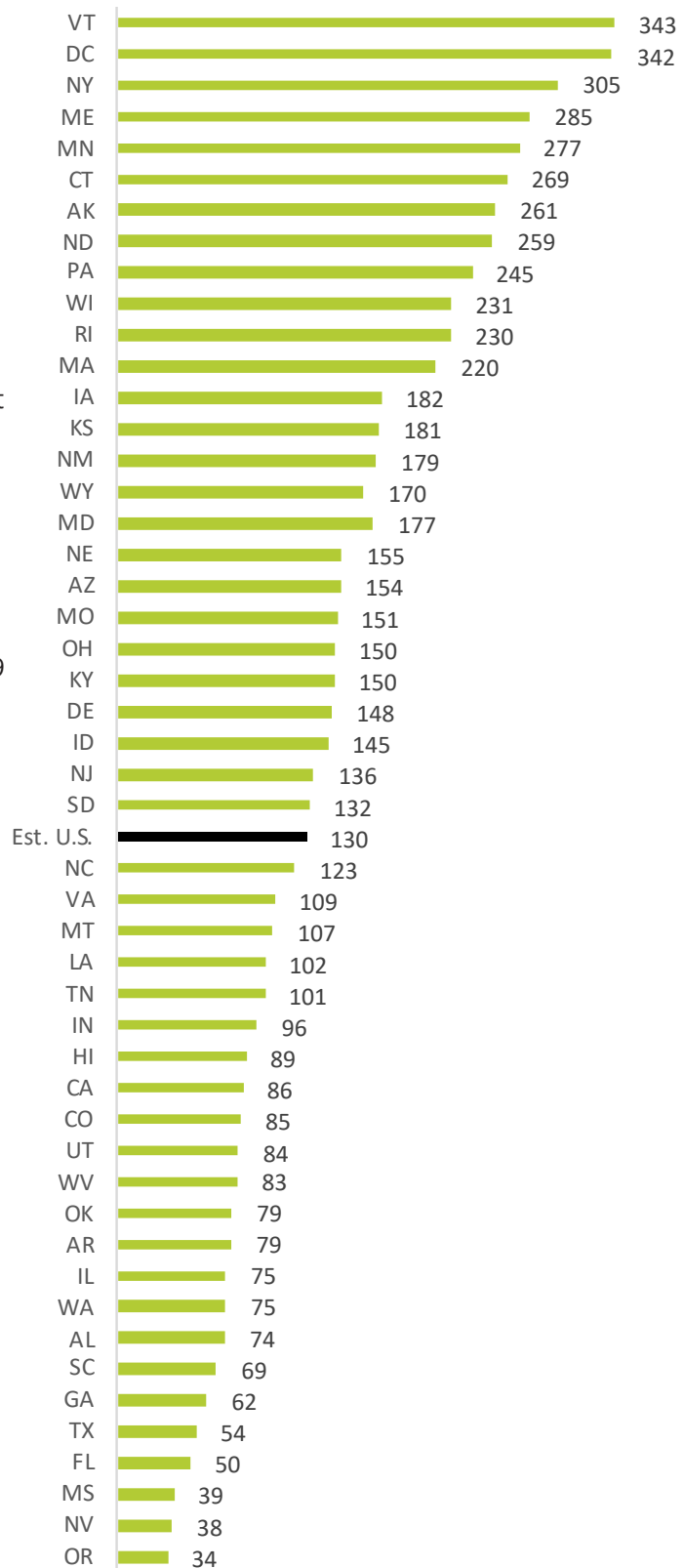
In FY 2018, annual Medicaid Waiver expenditures for 879,062 recipients with IDD were \$42.1 billion, an average of \$47,657 per person per year (See **Table 2.6**). Annual per person Medicaid Waiver expenditures ranged from \$5,932 in Oregon to \$117,713 in Delaware and \$117,720 in the District of Columbia. Massachusetts, Alabama, and Connecticut also spent more than \$90,000 per person per year.

Annual Medicaid Waiver expenditures for recipients with IDD ages 21 years or younger were \$3.91 billion (\$18,090 per person per year). Average per recipient expenditures for recipients 21 years or younger ranged from zero in New Jersey and \$3,627 in Oregon (see state note regarding 1915(k) funding) to \$100,329 in Delaware. Other states reporting averages of more than \$50,000 per year for recipients 21 years or younger included Tennessee (\$74,460), Vermont (\$67,128), and Nebraska (\$54,134). In addition to New Jersey and Oregon, California, Indiana, South Dakota, Washington and Wisconsin reported averages of less than \$10,000 per year.

Annual Medicaid Waiver expenditures for recipients with IDD ages 22 years or older were \$35.85 billion, (\$57,176 per recipient per year). Average per recipient expenditures for recipients 22 years or older ranged from \$7,328 in Oregon (see state note) to \$121,042 in the District of Columbia, and \$118,005 in Delaware. Other states with averages of more than \$90,000 per person included Alaska, Connecticut, Massachusetts, and Pennsylvania.

Total FY 2018 Medicaid Waiver expenditures for people with IDD averaged \$129 per United States resident (See **Figure 2.7**). Highest expenditures per state resident were reported for Vermont (\$343), the District of Columbia (\$342), New York (\$305), Maine (\$285), and Minnesota (\$277). Lowest per capita expenditures were reported for Florida (\$50), Mississippi (\$39), Nevada (\$38), and Oregon (\$34). While differences in average per person expenditures can be explained by recent shifts

Figure 2.7 Annual Medicaid Waiver Expenditures for People with IDD per State Resident by State FY 2018



Note: MI, NH, NM, and WV are not shown due to incomplete data.



Table 2.7 Medicaid Waiver Expenditures and Average per Recipient by Age, Living Arrangement, and State in FY 2018

Setting	Annual Waiver Expenditures (\$)				Average Per Person Expenditures (\$)			
	Family Home		Other Settings		Family Home		Other Settings	
	Birth to 21	22 years +	Birth to 21	22 years +	Birth to 21	22 years +	Birth to 21	22 years +
N States	35	33	34	32	34	32	32	32
AL	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
AK	11,571,731	0	11,678,195	163,749,814	42,700	N/A	40,549	101,834
AZ	310,978,516	287,650,209	71,849,888	430,637,394	18,142	27,382	78,956	108,500
AR	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
CA	331,617,352	790,649,627	94,972,130	2,174,638,133	7,059	21,277	65,363	69,196
CO	29,685,209	56,845,274	24,797,125	371,794,881	11,470	12,288	59,896	70,778
CT	11,116,973	140,140,095	8,948,306	799,134,181	30,625	37,652	168,836	139,052
DE	218,144	538,702	1,788,437	140,005,095	31,163	5,035	137,572	129,156
DC	1,216,975	43,770,693	1,929,105	191,933,456	45,073	52,609	60,285	164,327
FL	29,398,806	283,772,190	47,345,312	708,347,154	7,238	18,751	51,687	49,041
GA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
HI	9,791,881	60,968,165	1,870,957	49,019,061	21,568	43,057	89,093	63,744
ID	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
IL	37,757,056	233,498,883	37,955,784	645,944,571	20,723	23,744	83,603	58,573
IN	73,746,487	167,488,279	7,747,188	396,291,842	7,234	18,401	31,113	52,343
IA	44,964,321	82,081,873	54,860,162	391,853,590	24,544	24,798	24,768	66,903
KS	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
KY	201,421,609 ^g	158,669,492 ^g	DNF	DNF	33,392 ^g	32,375 ^g	DNF	DNF
LA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
ME	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MD	363,412	478,098	10,562,827	995,741,641	18,171	25,163	43,290	67,641
MA	5,112,195	569,106,654	0	941,662,272	19,147	93,757	N/A	93,754
MI	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MN	173,465,141	238,972,026	74,262,159	1,067,610,354	37,248 ^g	48,790 ^g	121,542 ^g	91,830 ^g
MS	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MO	27,704,683	111,761,295	49,590,836	735,941,259	13,112	22,153	122,447	105,014
MT	DNF	DNF	2,443,897	51,671,214	DNF	DNF	64,313	54,969
NE	7,869,211	117,153,136	DNF	DNF	38,016	42,835	DNF	DNF
NV	944,530	10,581,188	9,284,908	93,532,491	25,528	16,130	75,487	66,666
NH	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NJ	0	DNF	0	DNF	N/A	DNF	N/A	DNF
NM	18,852,627	221,354,736	1,667,900	130,888,616	41,709	67,963	138,992	144,949
NY	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NC*	95,492,713	290,613,473	48,534,604	359,117,775	12,558	29,120	22,712	51,731
ND	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
OH	75,550,024	437,377,975	36,064,804	1,201,105,325	14,035	26,200	53,909	68,808
OK	5,091,702	33,534,120	13,910,226	258,189,876	11,678	22,984	45,757	75,538
OR	27,313,477	60,889,027	5,704,436	49,290,858	3,392	6,771	5,428	8,157
PA	42,306,790	646,973,474	62,763,599	2,377,196,592	11,559	42,556	122,108	144,099
RI	1,024,488	45,901,238	1,537,619	194,341,375	12,968	30,079	59,139	92,236
SC	70,781,991	153,865,493	2,672,841	119,150,759	32,203	32,203	32,203	32,203
SD	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
TN	1,712,797	56,065,343	12,583,493	614,083,327	25,188	27,510	101,480	109,560
TX	123,684,994	286,443,071	92,802,825	1,024,166,698	32,043	35,133	39,091	42,126
UT	11,215,615	31,388,347	31,839,151	197,140,444	17,916	27,704	47,951	68,882
VT	9,882,160	43,060,102	12,806,952	148,408,658	50,678	48,220	89,559	76,697
VA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
WA	6,885,736	48,339,806	12,149,529	493,363,159	1,777	7,748	37,268	68,219
WV	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
WI	48,640,494	DNF	5,229,567	DNF	8,954	DNF	51,270	DNF
WY	8,910,692 ^g	25,817,208 ^g	837,151 ^g	57,406,556 ^g	14,189 ^g	52,474 ^g	14,189 ^g	52,474 ^g
Reported total	1,856,290,532	5,735,749,290	852,991,913	17,573,358,421				
Estimated US Total					14,813	28,313	49,496	73,487

DNF Did not furnish. N/A Not applicable. PD Partial data. ^a Missing values (DNF) assumed to be zero. ^b Other date (data from previous or next year). ^c Estimate. ^d Total is larger than component parts due to unknown settings or sizes. ^e One or more component value imputed by RISP staff. ^f See state notes in Appendix. Average spending per person is estimated based on states providing complete data by age and setting. Medicaid Waiver authorities include 1115, 1915 (a), 1915 (a/c), 1915 (b), 1915 (b/c) and 1915 (c).

2018

from Medicaid Waiver to Medicaid State Plan HCBS funding streams in some states, some states spent 10 times more per state resident on Medicaid Waiver HCBS for people with IDD than others.

Waiver Expenditures by Age and Residence Type

For FY 2018, 32 states provided complete information about recipients and expenditures for Medicaid HCBS Waiver funded supports by age and residence type (See **Table 2.7**). Per person Medicaid Waiver expenditures for people of different ages living in different residential settings varied dramatically. U.S. estimated totals have been adjusted to maintain the national proportion of recipients by age as reported on **Table 2.3**. Of the \$42.1 billion in Medicaid Waiver expenditures for FY 2018, expenditures by age and residence type information was provided for \$26.0 billion (62% of the total). The reported national averages may not represent expenditure patterns by age and living arrangement in non-reporting states. Estimated average per person expenditures are based only on states providing complete information.

Estimated average annual per person Medicaid Waiver expenditures for recipients living with a family member were \$14,813 for children and youth through age 21 and \$28,313 for adults. Estimated averages for recipients living in other settings were \$49,496 for children and youth through age 21 and \$73,487 for adults (See **Figure 2.8**). Medicaid Waiver expenditures are higher for adults than for children in part because children with disabilities are entitled free and appropriate educational services authorized under the Individuals with Disabilities Education Act while there are no comparable entitlement programs for adults. Average per person expenditures were lower for recipients living with a family member than for recipients living in other settings in part because of unreimbursed hours of support provided by family caregivers to family members with IDD living with them would be financed with public dollars if those individuals lived in other settings.

State Differences

Estimated annual average per recipient Medicaid HCBS Waiver expenditures for children and youth through age 21 living with a family member ranged

from \$1,777 in Washington to \$50,678 in Vermont. Expenditures for recipients 21 years or younger living in other settings ranged from \$5,428 in Oregon to \$168,836 in Connecticut. For adults 22 years or older living with a family member the averages ranged from \$5,035 in Delaware to \$93,757 in Massachusetts. Finally, for adults living in other settings average expenditures ranged from \$8,157 in Oregon to \$164,327 in the District of Columbia.

INTERMEDIATE CARE FACILITIES FOR INDIVIDUALS WITH INTELLECTUAL DISABILITIES (ICF/IID)

While most LTSS recipients with IDD receive Medicaid Waiver funded supports, Medicaid continues to offer an institutional option for people with IDD through the Medicaid ICF/IID program. All ICF/IID facilities are considered institutions under the 2014 Medicaid Waiver rule. However, unlike Medicaid Waiver funded services, access to ICF/IID services is an entitlement for people with IDD who meet level of care eligibility criteria in the 49 participating states (all states except Michigan and Oregon) that opt to include ICF/IID services in their Medicaid State Plan. Alaska does not operate any ICF/IID facilities in the state but they do send people with IDD to ICF/IID settings in other states.

Figure 2.8 Estimated Average Annual per Person Medicaid Waiver Expenditures by Age and Living Arrangement in FY 2018

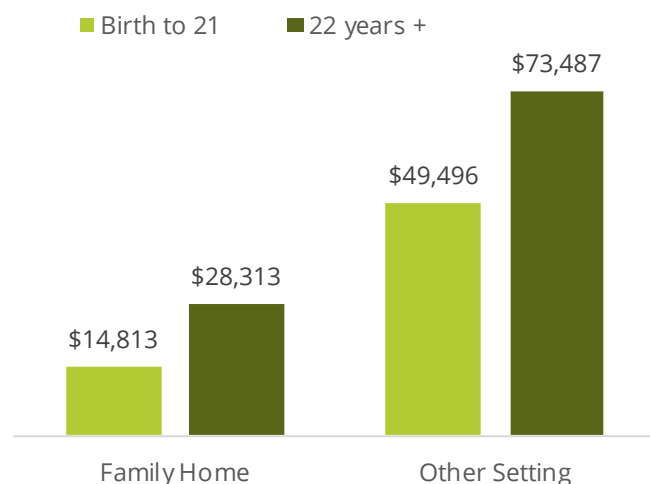




Table 2.8 Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) by Size, Type of Operation and State on June 30, 2018

Size	State-Operated				Nonstate-Operated				All Facilities			
	1-6	7-15	16+	Total	1-6	7-15	16+	Total	1-6	7-15	16+	Total
N States	51	51	51	51	48	48	49	51	48	48	49	51
AL	0	0	0	0	0	2	0	2	0	2	0	2
AK	0	0	0	0	0 ⁱ	0 ⁱ	0 ⁱ	0 ⁱ	0	0	0	0
AZ	0	0	0	0	0	0	1	1	0	0	1	1
AR	0	0	5	5	0	33	4	37	0	33	9	42
CA	0	0	4	4	1,167	0	10	1,177	1,167	0	14	1,181
CO	4	10	1	15	5	0	0	5	9	10	1	20
CT	1	0	4	5	64	4	0	68	65	4	4	73
DE	0	0	1	1	0	0	1	1	0	0	2	2
DC	0	0	0	0	67	0	0	67	67	0	0	67
FL	0	0	2	2	38	20	51	109	38	20	53	111
GA	0	0	2	2	0 ⁱ	0 ⁱ	0 ⁱ	0 ^s	0	0	2	2
HI	0	0	0	0	16	1	0	17	16	1	0	17
ID	0	0	1	1	DNF	DNF	DNF	64 ^o	DNF	DNF	DNF	65
IL	0	0	7	7	36	153	30	219	36	153	37	226
IN	0	0	0	0	158	314	2	474	158	314	2	474
IA	0	0	2	2	58	42	20	120	58	42	22	122
KS	0	0	2	2	18	6	0	24	18	6	2	26
KY	0	8 ^j	2 ^j	10 ^s	4	3	5	12	4	11	7	22
LA	0	0	3	3	282	246	9	537	282	246	12	540
ME	0	0	0	0	7	11	3	21	7	11	3	21
MD	0	0	2	2	0	0	0	0	0	0	2	2
MA	0	0	2	2	0	0	0	0	0	0	2	2
MI	0 ⁱ	0 ⁱ	0 ⁱ	0 ⁱ	0 ⁱ	0 ⁱ	0 ⁱ	0 ⁱ	0	0	0	0
MN	3	0	0	3	120	36	10	166	123	36	10	169
MS	5	39	6	50	0	0	8	8	5	39	14	58
MO	0	0	6	6	0	6	1	7	0	6	7	13
MT	1	0	0	1	0	0	0	0	1	0	0	1
NE	0	0	1	1	6	1	2	9	6	1	3	10
NV	0	0	1	1	4	0	1	5	4	0	2	6
NH	0 ⁱ	0 ⁱ	0 ⁱ	0 ⁱ	0 ⁱ	0 ⁱ	1 ⁱ	1 ^s	0	0	1	1
NJ	0	0	5	5	0	0	2	2	0	0	7	7
NM	1 ⁱ	0	0	1 ⁱ	27	15	1	43	28	15	1	44
NY	4	8	5	17	80	279	28	387	84	287	33	404
NC	0	0	4	4	299	28	13	340	299	28	17	344
ND	0	0	1	1	46	23	1	70	46	23	2	71
OH	0	0	8	8	161	210	53	424	161	210	61	432
OK	0	0	0	0	DNF	DNF	DNF	87 ^o	DNF	DNF	DNF	87
OR	0	0	0	0	0	0	0	0	0	0	0	0
PA	0	0	5	5	126	28	18	172	126	28	23	177
RI	2	0	0	2	0	0	0	0	2	0	0	2
SC	0	0	5	5	0	61	0	61	0	61	5	66
SD	0	0	1	1 ^s	0	0	1	1 ^s	0	0	2	2
TN	38	0	0	38	80	54	1	135	118	54	1	173
TX	2	0	13	15	736	41	3	781	738	41	16	796
UT	0	0	1	1	0 ⁱ	2	16 ⁱ	18 ^s	0	2	17	19
VT	0	0	0	0	1	0	0	1	1	0	0	1
VA	0	0	2	2	DNF	DNF	2	62	DNF	DNF	4	64
WA	0	0	4	4	1	0	0	1	1	0	4	5
WV	0	0	0	0	16	54	0	70	16	54	0	70
WI	0	0	3	3	0	1	18	19	0	1	21	22
WY	0	0	1	1	0 ⁱ	0 ⁱ	0 ⁱ	0 ^s	0	0	1	1
Reported US Total	61	65	112	238	3,623	1,674	316	5,825	3,684	1,739	428	6,063
Estimated US Total	61	68	114	243	3,714	1,765	347	5,826	3,775	1,833	461	6,069

DNF Did not furnish, d Other date (data from previous or next year), e Estimate, o Other Source (AHCAa CASPER data, 2018). Totals for 16+ state operated may differ those reported on Table 4.10 because Table 4.10 includes state operated facilities not certified as ICF/IID. See State Notes for more information.

ICF/IID Facilities by Size and Type of Operation

There were an estimated 6,069 ICF/IIDs on June 30, 2018 (See **Table 2.8**). Alaska, Michigan, and Oregon reported no ICF/IID facilities. 12 states reported having only one or two ICF/IID facilities. States with the most ICF/IID facilities were California (1,181), Texas (796), and Louisiana (540).

Of the 6,069 ICF/IID facilities, 243 (4%) were state-operated, and 5,826 (96%) were operated by a non-state entity. There were no non-state ICF/IID facilities in Alaska, Georgia, Maryland, Massachusetts, Michigan, Montana, Oregon, Rhode Island, or Wyoming. All ICF/IID facilities in Alabama, Arizona, the District of Columbia, Hawaii, Indiana, Maine, New Hampshire, Oklahoma, Vermont and West Virginia were operated by a non-state entity. There were no state-operated ICF/IID in Alabama, Alaska, Arizona, the District of Columbia, Hawaii, Indiana, Maine, Michigan, New Hampshire, Oklahoma, Oregon, Vermont, or West Virginia. All ICF/IIDs were state-operated in Georgia, Maryland, Massachusetts, Montana, Rhode Island, and Wyoming.

Overall, 62% of the ICF/IIDs served six or fewer people, 30% served 7 to 15 people, and 8% served 16 or more people. Of the state-operated ICF/IIDs, 25% served six or fewer people, 28% served 7 to 15 people, and 47% served 16 or more people. Of the nonstate-operated ICF/IIDs, 64% served six or fewer people, 30% served 7 to 15 people and 6% served 16 or more people.

There were no ICF/IIDs serving 16 or more recipients in Alabama, Alaska, the District of Columbia, Hawaii, Michigan, Montana, Oregon, Rhode Island, Vermont, or West Virginia. All ICF/IIDs in Arizona, Delaware, Georgia, Maryland, Massachusetts, New Hampshire, New Jersey, South Dakota, and Wyoming served 16 or more people.

LTSS Recipients with IDD in ICF/IID Facilities by Size and Type of Operation

On June 30, 2018, an estimated 70,046 people lived in an ICF/IID (3,809 fewer than on June 30, 2017; See **Table 2.9**). Fewer than 100 people lived in an ICF/IID in 13 states (Alabama, Alaska, Arizona, Hawaii, Maryland, Michigan, Montana, Nevada, New Hampshire, Oregon,





Table 2.9 People Living in an ICF/IID by Type of Operation, Setting Size and State on June 30, 2018

Size	State-Operated				Non-State				Total			
	1-6	7-15	16+	Total	1-6	7-15	16+	Total	1-6	7-15	16+	Total
N States	51	51	51	51	46	46	47	51	46	46	47	51
AL	0	0	0	0	0	25	0	25	0	25	0	25
AK	0	0	0	0	DNF	DNF	DNF	14	DNF	DNF	DNF	14
AZ	0	0	0	0	0	0	38	38	0	0	38	38
AR	0	0	917	917	0	317	201	518	0	317	1,118	1,435
CA	0	0	534 ^e	534 ⁱ	5,909	0	658	6,567	5,909	0	1,192	7,101
CO	22	75	28	125	25	0	0	25	47	75	28	150
CT	2	0	347	349	322	36	0	358	324	36	347	707
DE	0	0	50	50	0	0	70	70	0	0	120	120
DC	0	0	0	0	309	0	0	309	309	0	0	309
FL	0	0	563	563	205	258	1,610	2,073	205	258	2,173	2,636
GA	0	0	116	116	0 ⁱ	0 ⁱ	0 ⁱ	0 ^s	0	0	116	116
HI	0	0	0	0	64	9	0	73	64	9	0	73
ID	0	0	23	23 ^s	DNF	DNF	DNF	421 ^s	DNF	DNF	DNF	444
IL	0	0	1,664	1,664	175	2,139	2,570	4,884	175	2,139	4,234	6,548
IN	0	0	0	0	780	2,329	50	3,159	780	2,329	50	3,159
IA	0	0	346	346	232	455	408	1,095	232	455	754	1,441
KS	0	0	305	305	75	60	0	135	75	60	305	440
KY	0	151 ⁱ	112 ^{s,j}	263 ^s	26	25	421	472	26	176	533	735
LA	0	0	519	519	1,645	1,963	526	4,134	1,645	1,963	1,045	4,653
ME	0	0	0	0	18	121	48	187	18	121	48	187
MD	0	0	95	95	0	0	0	0	0	0	95	95
MA	0	0	385	385	0	0	0	0	0	0	385	385
MI	0 ⁱ	0 ⁱ	0 ⁱ	0 ⁱ	0 ⁱ	0 ⁱ	0 ⁱ	0 ^s	0	0	0	0
MN	13	0	0	13	597	323	250	1,170	610	323	250	1,183
MS	25	515	899	1,439	0 ⁱ	0 ⁱ	686 ⁱ	686 ^s	25	515	1,585	2,125
MO	0	0	321	321	0	45	30	75	0	45	351	396
MT	1	0	0	1	0	0	0	0	1	0	0	1
NE	0	0	109	109	33	7	199	239	33	7	308	348
NV	0	0	41	41	25	0	18	43	25	0	59	84
NH	0 ⁱ	0 ⁱ	0 ⁱ	0 ⁱ	0 ⁱ	0 ⁱ	20 ⁱ	20 ⁱ	0	0	20	20
NJ	0	0	1,325	1,325	0	0	60	60	0	0	1,385	1,385
NM	4	0	0	4	102	160	16	278	106	160	16	282
NY	16	96	261	373	429	2,824	914	4,167	445	2,920	1,175	4,540
NC	0	0	1,099	1,099	647	111	214 ^e	2,880 ^e	647	111	1,313	3,979
ND	0	0	68	68	249	181	30	460	249	181	98	528
OH	0	0	650	650	833	1,754	2,133	4,720	833	1,754	2,783	5,370
OK	0	0	0	0	DNF	DNF	DNF	1,367 ^s	DNF	DNF	DNF	1,367
OR	0	0	0	0	0	0	0	0	0	0	0	0
PA	0	0	779	779	607	215	1,090	1,912	607	215	1,869	2,691
RI	10	0	0	10	0	0	0	0	10	0	0	10
SC	0	0	672	672	0	499	0	499	0	499	672	1,171
SD	0	0	115	115 ^s	0	0	61	61 ^s	0	0	176	176
TN	149	0	0	149	358	449	76	883	507	449	76	1,032
TX	10	0	2,969	2,979	4,190	469	230	4,893	4,200	469	3,199	7,872
UT	0	0	185	185	DNF	DNF	DNF	593 ^s	DNF	DNF	DNF	778
VT	0	0	0	0	6	0	0	6	6	0	0	6
VA	0	0	155	155	DNF	DNF	116	538	DNF	DNF	271	693
WA	0	0	668	668	1	0	0	1	1	0	668	669
WV	0	0	0	0	92	425	0	517	92	425	0	517
WI	0	0	308	308	0	8	78	86	0	8	386	394
WY	0	0	59	59	0 ⁱ	0 ⁱ	0 ⁱ	0 ⁱ	0	0	59	59
Reported US Total	252	837	16,687	17,776	17,954	15,207	12,821	50,711	18,206	16,044	29,508	68,487
Estimated US Total	259	859	17,153	18,271	19,680	16,929	15,166	51,775	19,939	17,788	32,319	70,046

DNF Did not furnish. ^d Other date (data from previous or next year). ^e Estimate. ^s Source (ACHA CASPER data, 2018) * See state notes in Appendix. The number of people in ICF/IID settings of an unknown size are not shown but they are included in the totals.

Rhode Island, Vermont, and Wyoming). By contrast, more than 2,000 people lived in an ICF/IID in California (7,101), Florida (2,636), Illinois (6,548), Indiana (3,159), Louisiana (4,653), Mississippi (2,125) New York (4,540), North Carolina (3,979), Ohio (5,370), Pennsylvania (2,691), and Texas (7,872).

An estimated 18,271 (26%) people in ICF/IIDs lived in state-operated facilities while 51,775 (74%) lived in non-state facilities. An estimated 28% of people in ICF/IID's lived in settings of 1 to 6 people, 25% lived in facilities of 7 to 15 people and 46% lived in settings of 16 or more people. However, 94% of those in state-operated settings were in settings of 16 or more people compared with 29% of those in nonstate-operated settings. Nearly all of the people living in ICF/IIDs of 1 to 6 people (99%) or 7 to 15 people (95%) were in nonstate-operated facilities.

All of the people in ICF/IID facilities were in settings of 16 or more people in Arizona, Delaware, Georgia, Maryland, Massachusetts, New Hampshire, New Jersey, South Dakota, and Wyoming. Between 75% and 99% of people in ICF/IID facilities were in settings of 16 or more people in Arkansas, Florida, Missouri, and Wisconsin.

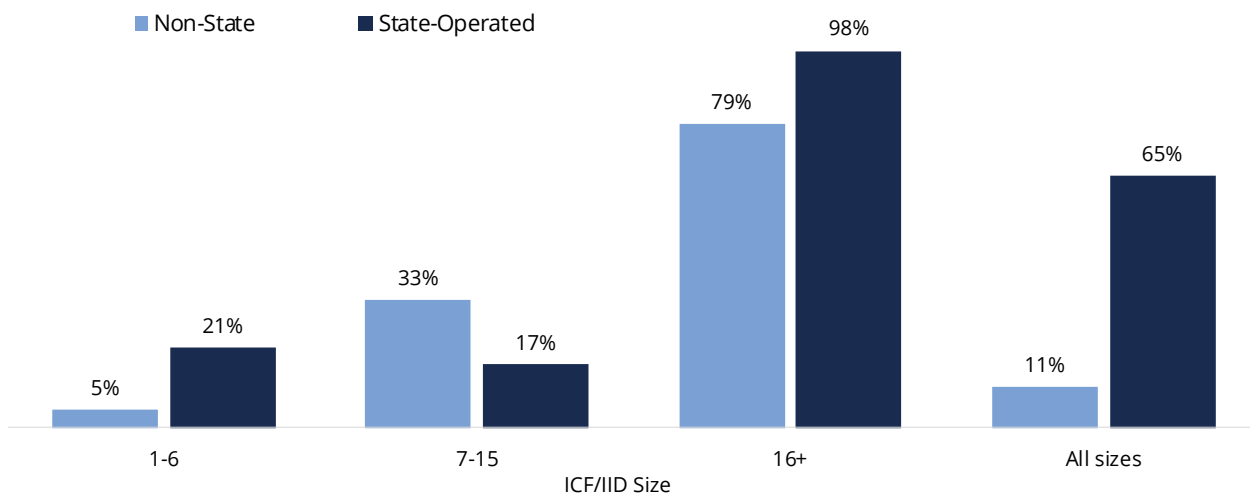
ICF/IID Residents as a Proportion of All People in IDD Group Settings

Until 1981, the ICF/IID was the only Medicaid-funded residential option specifically for people with IDD. Once Medicaid began funding home and community-based services in 1981, the use of ICF/IID facilities began to decline. By June 30, 2018 only 14% of LTSS recipients with IDD who did not live with a family member lived in an ICF/IID (11% of people in non-state settings, and 65% of people in state-operated settings; See **Figure 2.9**). Among people living in non-family settings of six or fewer people, 5% of those in a non-state setting and 21% of those in a state-operated setting lived in an ICF/IID. Among people living in facilities serving 7 to 15 people, 32% of those in non-state settings and 17% of those in state-operated settings lived in an ICF/IID. Among people with IDD in facilities of 16 or more people, 78% of those in non-state settings and 97% of those in state-operated settings lived in an ICF/IID.

ICF/IID Recipients by Age

Of the people living in an ICF/IID on June 30, 2018, an estimated 4,916 (7%) were 21 years or younger and 65,130 (93%) were 22 years or older (See **Table 2.10**). There were no people 21 years or younger in ICF/IID facilities in Alabama, Connecticut, the District of Columbia, Hawaii, Maryland, Massachusetts, Michigan, Missouri, Montana, New Jersey, Oregon, Rhode Island, Washington, or Wisconsin. Three

Figure 2.9 Proportion of LTSS Recipients in an ICF/IID Certified Facility by Type of Operation and Setting Size on June 30, 2018



This figure includes people in group homes, ICF/IIDs, host and foster family homes, own home, and IDD "other" settings. It excludes people living with a family member, in a nursing home or psychiatric setting.

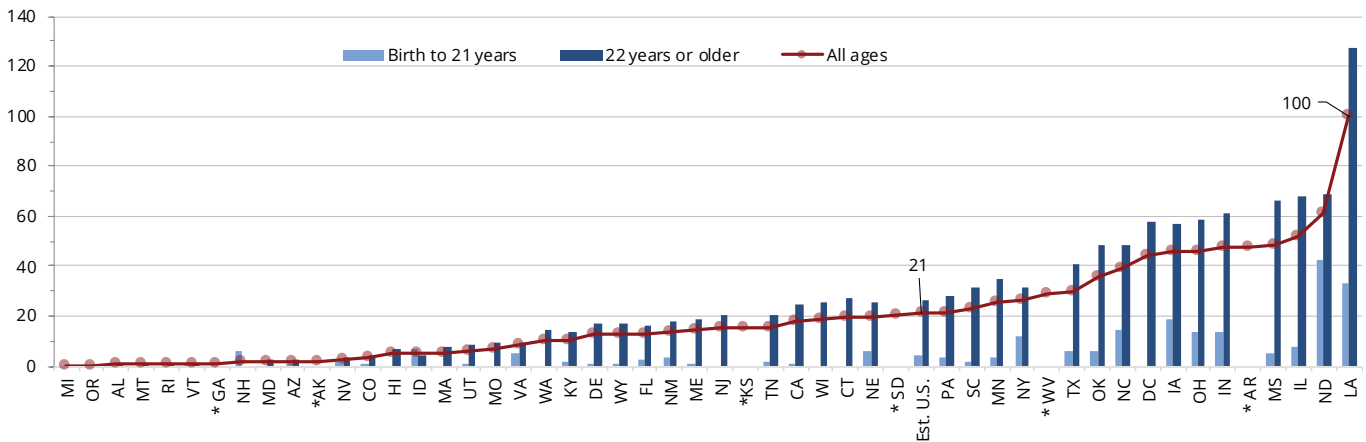


Table 2.10 People Living in an ICF/IID Per 100,000 of the Population by Age and State on June 30, 2018

Age	Population in 100,000s ⁵			ICF/IID Residents			ICF/IID Residents per 100k			
	Birth to 21 years	22+ years	All Ages	Birth to 21 years	22+ years	All Ages	Birth to 21 years	22+ years	All Ages	
N States	51	51	51	45	45	51	45	45	51	
AL	13	35	49	0	25	25	0	1	1	
AK*	2	5	7	DNF	DNF	14	DNF	DNF	2	
AZ	20	51	71	3	124	127	0	2	2	
AR	9	21	30	DNF	DNF	1,435	DNF	DNF	48	
CA	110	283	393	106	6,970	7,076	1	25	18	
CO	15	41	57	20	183	203	1	4	4	
CT	9	26	36	0	707	707	0	27	20	
DE	3	7	10	1	119	120	0	17	12	
DC	2	5	7	0	307	307	0	58	44	
FL	52	160	212	121	2,579	2,700	2	16	13	
GA	31	74	104	DNF	DNF	116	DNF	DNF	1	
HI	4	10	14	0	73	73	0	7	5	
ID	5	12	17	37	56	93	7	5	5	
IL	35	92	127	280	6,268	6,548	8	68	52	
IN	19	47	67	268	2,891	3,159	14	61	47	
IA	9	22	31	167	1,273	1,440	18	57	46	
KS	9	20	29	DNF	DNF	440	DNF	DNF	15	
KY	12	32	44	22	450	472	2	14	11	
LA	13	33	46	436	4,217 ⁷	4,653	33	127	100	
ME	3	10	13	1	195	196	0	19	15	
MD	16	44	60	0	95	95	0	2	2	
MA	18	51	69	0	373	373	0	7	5	
MI	27	73	100	0	0	0	0	0	0	
MN	16	40	56	54	1,387	1,441	3	35	26	
MS	9	21	30	43 ⁷	1,396 ⁷	1,439 ⁷	5	66	49	
MO	17	44	61	0	406	406	0	9	7	
MT	3	8	11	0 ¹	6 ¹	6 ¹	0	1	1	
NE	6	13	19	36	346	382	6	26	20	
NV	8	22	30	12	72	84	1	3	3	
NH	3	10	14	20 ¹	0 ¹	20 ¹	6	0	1	
NJ	24	65	89	0	1,325	1,325	0	20	15	
NM	6	15	21	22	261	283	4	18	14	
NY	51	144	195	604	4,506	5,110	12	31	26	
NC	28	74	103	406	3,573	3,979	14	48	39	
ND	2	5	8	94	366	460	42	69	61	
OH	32	85	117	430	4,940	5,370	13	58	46	
OK	12	28	39	72 ⁷	1,344 ⁷	1,416	6	49	36	
OR	11	31	42	0	0	0	0	0	0	
PA	33	95	128	113	2,638	2,751	3	28	22	
RI	3	8	11	0	10	10	0	1	1	
SC	14	37	50	25	1,146	1,171	2	31	23	
SD	3	6	9	DNF	DNF	176 ¹	DNF	DNF	20	
TN	18	49	68	32	1,002	1,034	2	20	15	
TX	89	196	285	501	7,909	8,410	6	40	29	
UT	11	20	31	13	172	185	1	8	6	
VT	2	5	6	1	5	6	1	1	1	
VA	23	61	84	126 ^{5,1}	567 ^{5,1}	693 ^{5,1}	5	9	8	
WA	20	55	75	0	769	769	0	14	10	
WV	5	14	18	DNF	DNF	517	DNF	DNF	29	
WI	16	42	58	0	1,092	1,092	0	26	19	
WY	2	4	6	2	70	72 ⁰	1	17	13	
Reported US Total	902	2,353	3,255	4,068	62,213	68,979	0	5	26	21
Estimated US Total	902	2,353	3,255	4,916	65,130	70,046	0	5	28	22

DNF Did not furnish. ¹ Nonstate only. ² State only. ³ Other date (data from previous or next year). ⁴ Estimate. ⁵ Sum of setting size data substituted for reported value. ⁶ Source U.S. Census Bureau, Population Division (2018) for population data; ACHA (2018a) CASPER data for ICF/IID residents. * See state notes in Appendix. ⁷ The reported number of ICF/IID recipients by age when imputed uses AHCA (2018a) CASPER data for proportions.

Figure 2.10 People Living in an ICF/IID per 100,000 of the Population by State and Age on June 30, 2018



ICF/IID Intermediate Care Facility for Individuals with Intellectual Disabilities; * Age breakdowns not reported

percent or fewer ICF/IID recipients were 21 years or younger in California, Delaware, Maine, Mississippi, South Carolina, and Wyoming. By contrast, 40% of ICF/IID residents in Idaho and 100% in New Hampshire were 21 years or younger.

An estimated 21 people with IDD per 100,000 of the U.S. population lived in an ICF/IID on June 30, 2018 (See **Figure 2.10**). ICF/IID utilization rates ranged from zero in Michigan and Oregon to 54 per 100,000 in Illinois, 61 per 100,000 in North Dakota and 100 per 100,000 in Louisiana. ICF/IID utilization rates averaged 5 per 100,000 for children and youth 21 years or younger and 27 per 100,000 for adults 22 years or older.

ICF/IID EXPENDITURES

Estimated FY 2018 ICF/IID expenditures were \$9.64 billion nationally. Amongst states reporting expenditures, expenditures ranged from \$883,803 in West Virginia to \$1.19 billion in Texas (See **Table 2.11**). Rhode Island and Utah only reported expenditures for people in their state-operated ICF/IID. North Dakota only reported ICF/IID expenditures for people in non-state ICF/IID settings.

Per Person ICF/IID Expenditures

Estimated FY 2018 per person ICF/IID expenditures averaged \$137,560 and ranged from \$50,938 in Oklahoma to \$338,704 in New Jersey. Eleven states reported per person annual ICF/IID expenditures of

less than \$100,000. Five states (Kentucky, Maryland, New Jersey, Washington, and Wyoming) reported per person annual ICF/IID expenditures of more than \$300,000. Per person expenditures for West Virginia and Arizona were less than \$10,000 per year suggesting that those were partial numbers.



Table 2.11 ICF/IID Expenditures, Recipients, Expenditure Per Person, and Expenditures Per State Resident by State in Fiscal Year 2018

State	ICF/IID Recipients	ICF/IID Expenditures	Expenditures per ICF/IID Recipient	State Population (100,000)	Expenditures per State Resident (\$)
N States	51	49	48	51	49
AL	25	2,033,302 ⁵	92,423	49	0
AK*	14	2,616,721	186,909	7	4
AZ	127	1,221,000	9,614	71	0
AR	1,435	171,344,670 ⁵	119,404 ⁴	30	57
CA	7,076	654,498,652	92,496	393	17
CO	203	44,761,565	220,500	57	8
CT	707	200,960,676	284,244	36	56
DE	120	33,174,352	276,453	10	34
DC	307	89,215,875	290,605	7	128
FL	2,700	331,590,954	122,811	212	16
GA	116	33,587,180 ⁵	289,545 ³	104	3
HI	73	8,323,705	114,023	14	6
ID	93	8,375,870	90,063	17	5
IL	6,548	613,172,414	93,643	127	48
IN	3,159	270,721,188	85,698	67	40
IA	1,440	231,887,228	161,033	31	74
KS	440	41,086,372	93,378	29	14
KY	472	142,186,626	301,243	44	32
LA	4,653	342,021,630	73,506	46	74
ME	196	41,484,333	211,655	13	31
MD	95	31,087,411	327,236	60	5
MA	373	97,483,726	261,350	69	14
MI	0	0	N/A	100	0
MN	1,441	114,405,788	79,393	56	20
MS	1,439 ⁵	189,902,209	131,968 ⁵	30	64
MO	406	84,553,890	208,261	61	14
MT	6 ¹	DNF	DNF	11	DNF
NE	382	68,761,423	180,004	19	36
NV	84	15,965,645	190,067	30	5
NH	20 ¹	DNF	DNF	14	DNF
NJ	1,325	448,782,356	338,704	89	51
NM	283	28,813,241	101,814	21	14
NY	5,110	965,311,448	188,906	195	49
NC	3,979 ⁵	377,779,911	138,182	103	37
ND	460	80,522,599	175,049	8	107
OH	5,370	671,976,796	125,135	117	58
OK	1,416 ⁵	72,127,501 ⁵	50,938 ⁵	39	18
OR	0	0	0	42	0
PA	2,751	602,231,860	218,914	128	47
RI	10	2,966,035	296,604	11	3
SC	1,171	140,057,004	119,605	50	28
SD	176 ¹	31,807,132 ⁵	180,722 ¹	9	36
TN	1,034	185,901,182	179,788	68	28
TX	8,410	1,185,871,467	141,007	285	42
UT	185	39,603,213	214,071	31	13
VT	6	1,367,478	227,913	6	2
VA	693 ⁵	205,733,421 ⁵	296,874 ⁵	84	25
WA	769	237,685,309	309,084	75	32
WV	517	833,803 ⁵	1,613 ⁵	18	0
WI	1,092	146,976,721	134,594	58	25
WY	72	23,217,862	322,470	6	40
Reported US Total	68,979	9,315,990,745	135,055	3,255	29
Estimated US Total	70,046	9,641,149,741	137,560	3,255	30

¹ Includes non-state operated ICF/IIDs only ² Includes only state operated ICF/IIDs. ³ Other date (data from previous or next year). ⁴ Estimate. ⁵ One or more component value imputed by RISP staff. DNF Did not furnish. ⁶ Other Source: U.S. Census Bureau, Population Division (2018); ACHA (2018a) ICF/IID recipients; Murray et al, (2021) ICF/IID expenditures. *See state notes in Appendix.



Expenditures per State Resident

Annual ICF/IID expenditures averaged \$30 per state resident nationally and ranged from less than \$1 per state resident in Alabama, Arizona and West Virginia to \$128 per state resident in the District of Columbia. Seventeen states reported average expenditures of less than \$10 per state resident including Alaska, Colorado, Georgia, Hawaii, Idaho, Maryland, Nevada, Rhode Island, and Vermont. Besides the District of Columbia, only North Dakota (\$107) reported expenditures exceeding \$100 per state resident.

Expenditures by Age

For FY 2018, 29 states reported ICF/IID recipient and expenditure data for people 21 years or younger, and 39 states provided ICF/IID recipient and expenditure data for people 22 years or older. Average per person expenditures in reporting states were \$119,752 for people 21 years or younger and \$142,381 for people 22 years or older (See **Table 2.12**). Among states

with 10 or more ICF/IID recipients 21 years or younger average per person expenditures ranged from \$48,774 in Delaware to \$263,970 in Kentucky. Amongst state reporting 10 or more ICF/IID recipients 22 years or older, annual per person expenditures ranged from \$73,445 in Louisiana to \$338,704 in New Jersey.

MEDICAID WAIVER AND ICF/IID RECIPIENTS AND EXPENDITURES

Total combined Medicaid Waiver and ICF/IID expenditures for 949,108 recipients were \$51.8 billion in FY 2018 (See **Table 2.13**). An estimated 93% of combined recipients received Medicaid Waiver funded Home and Community-based Supports while 7% received supports while living in an ICF/IID (See **Table 2.13** and **Figure 2.11**). In 39 of the 51 states, Medicaid HCBS Waiver recipients were 90% or more of the combined recipients. Exceptions were Arkansas (75% were HCBS Waiver recipients), the District of Columbia (87%), Illinois (78%), Indiana (90%), Louisiana (73%), Mississippi



Table 2.12 Annual ICF/IID Recipients, Expenditures and Expenditures Per Person by Age and State in Fiscal Year 2018

State	ICF/IID Recipients		Annual Expenditures \$		Expenditures Per Person \$	
	Birth to 21 years	22 years +	Birth to 21 years	22 years +	Birth to 21 years	22 years +
N States	45	45	40	39	29	39
AL	0	25	0	DNF	N/A	DNF
AK	DNF	DNF	DNF	DNF	DNF	DNF
AZ	3	124	78,100	1,142,900	26,033	9,217
AR	DNF	DNF	DNF	DNF	DNF	DNF
CA	106	6,970	8,997,298	645,501,354	84,880	92,611
CO	20	183	3,860,721	40,900,844	193,036	223,502
CT	0	707	0	200,960,676	N/A	284,244
DE	1	119	5,480	33,168,872	5,480	278,730
DC	0	307	0	89,215,875	N/A	290,605
FL	121	2,579	13,527,778	318,063,176	111,800	123,328
GA	DNF	DNF	DNF	DNF	DNF	DNF
HI	0	73	0	8,323,705	N/A	114,023
ID	37	56	1,804,632	6,571,238	48,774	117,344
IL	280	6,268	19,733,204	593,439,210	70,476	94,678
IN	268	2,891	24,908,456	245,812,732	92,942	85,027
IA	167	1,273	25,079,797	206,807,431	150,178	162,457
KS	DNF	DNF	DNF	DNF	DNF	DNF
KY	22	450	5,805,134	136,381,491	263,870	303,070
LA	436 ^c	4,217 ^e	32,304,388	309,717,242	74,093	73,445 ^e
ME	1	195	279,703	41,204,630	279,703	211,306
MD	0	95	0	31,087,411 ^e	N/A	327,236 ^e
MA	0	373	0	97,483,726	N/A	261,350
MI	0	0	0	0	N/A	N/A
MN	54	1,387	4,719,082	109,686,706	87,390	79,082
MS	43 ^c	1,396 ^e	5,674,632 ^c	184,227,577 ^c	131,968 ^c	131,968 ^c
MO	0	406	0	84,553,890	N/A	208,261
MT	0 ^c	6 ^c	DNF	DNF	DNF	DNF
NE	36	346	4,368,190	64,393,233	121,339	186,108
NV	12	72	2,008,704	13,956,941	167,392	193,846
NH	20 ^c	0 ^c	DNF	DNF	DNF	DNF
NJ	0	1,325	0	448,782,356	N/A	338,704
NM	22	261	2,246,682	26,566,559	102,122	101,788
NY	604	4,506	102,565,939	862,745,509	169,811	191,466
NC	406 ^c	3,573 ^c	38,160,327	339,619,585	106,152	141,818 ^{c1}
ND	94	366	DNF	DNF	DNF	DNF
OH	430	4,940	54,009,346	617,967,450	125,603	125,095
OK	72 ^c	1,344 ^c	DNF	DNF	0	0
OR	0	0	0	0	0	0
PA	113	2,638	21,707,339	580,524,521	192,100	220,062
RI	0	10	0	2,966,035	N/A	296,604
SC	25	1,146	2,990,115	137,066,889	119,605	119,605
SD	DNF	DNF	DNF	DNF	DNF	DNF
TN	32	1,002	5,406,389	180,494,793	168,950	180,135
TX	501	7,909	61,497,357	1,124,374,110	122,749	142,164
UT	13	172	2,782,743	36,820,470	214,057	214,073
VT	1	5	227,913	1,139,565	227,913	227,913
VA	126 ^{e1}	567 ^{e1}	DNF	DNF	DNF	DNF
WA	0	769	0	237,685,309	N/A	309,084
WV	DNF	DNF	DNF	DNF	DNF	DNF
WI	0	1,092	5,418	146,971,303	DNF	134,589
WY	2	70	644,941	22,572,921	322,471	322,470
Reported US Total	4,068	62,213	445,399,809	8,228,898,236		
Estimated US Total	4,916	65,130			119,752	142,381

Note: US estimates for expenditures per person are calculated based on states reporting complete age by expenditure data. ^c State only. ^d Other date (data from previous or next year). ^e Estimate. ¹ One or more component value imputed by RISP staff. ^{*} Source, ACHA (2018) ICF/IID residents; Murray, et al, 2021 ICF/IID expenditures. DNF Did not furnish. N/A Not Applicable - no ICF/IID settings. ^{*} See state notes in Appendix.

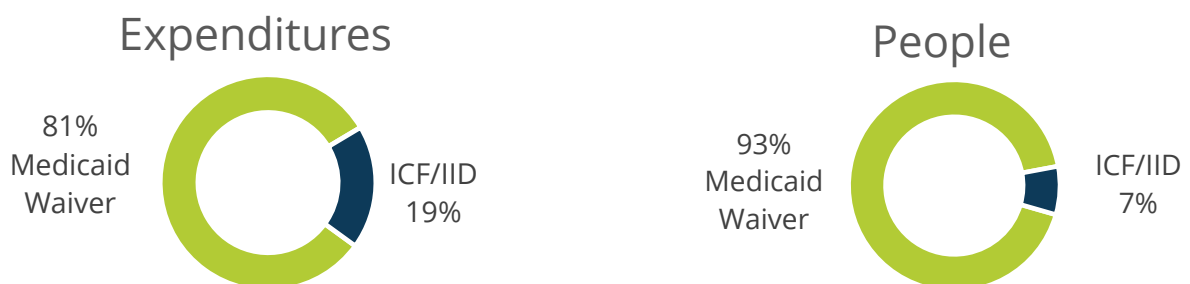
Table 2.13 ICF/IID and Medicaid Waiver Recipients and Expenditures Total and Percent by Funding Authority and State on June 30, 2018

State	Total ICF/IID + Waiver		% of Recipients		% of Expenditures	
	Recipients	Expenditures (\$)	Waiver	ICF/IID	Waiver	ICF/IID
N States	51	48	51	51	48	48
AL	3,920	364,779,049	99%	1%	99%	1%
AK	2,181	189,616,460	99%	1%	99%	1%
AZ	33,281	1,102,253,624	100%	0%	100%	0%
AR	5,800	408,857,245	75%	25%	58%	42%
CA	124,090	4,046,375,895	94%	6%	84%	16%
CO	12,860	527,330,616	98%	2%	92%	8%
CT	10,592	1,160,300,231	93%	7%	83%	17%
DE	1,331	175,724,730	91%	9%	81%	19%
DC	2,334	327,833,635	87%	13%	73%	27%
FL	37,256	1,400,454,416	93%	7%	76%	24%
GA	8,695	680,912,132	99%	1%	95%	5%
HI	2,905	130,158,588	97%	3%	94%	6%
ID	8,327	262,290,048	99%	1%	97%	3%
IL	29,686	1,568,328,708	78%	22%	61%	39%
IN	30,276	915,994,984	90%	10%	70%	30%
IA	14,654	805,647,174	90%	10%	71%	29%
KS	9,564	563,481,718	95%	5%	93%	7%
KY	15,606	807,768,356	97%	3%	82%	18%
LA	17,193	814,054,229	73%	27%	58%	42%
ME	5,425	423,037,552	96%	4%	90%	10%
MD	15,319	1,092,600,288	99%	1%	97%	3%
MA	16,754	1,613,364,848	98%	2%	94%	6%
MI	49,589	DNF	100%	0%	DNF	DNF
MN	23,233	1,668,715,468	94%	6%	93%	7%
MS	4,077	304,492,680	65%	35%	38%	62%
MO	15,129	1,008,429,473	97%	3%	92%	8%
MT	2,746	DNF	100%	0%	DNF	DNF
NE	5,048	367,059,556	92%	8%	81%	19%
NV	2,303	130,308,762	96%	4%	88%	12%
NH	6,462	DNF	100%	0%	DNF	DNF
NJ	16,961	1,655,306,234	92%	8%	73%	27%
NM	4,907	401,577,120	94%	6%	93%	7%
NY	90,165	6,908,584,086	94%	6%	86%	14%
NC	37,220	1,640,732,749	89%	11%	77%	23%
ND	5,368	275,337,141	91%	9%	71%	29%
OH	45,572	2,422,074,924	88%	12%	72%	28%
OK	7,041	382,774,600	80%	20%	81%	19%
OR	24,140	143,197,798	100%	0%	100%	0%
PA	38,625	3,731,472,315	93%	7%	84%	16%
RI	3,748	245,770,755	100%	0%	99%	1%
SC	11,930	486,528,088	90%	10%	71%	29%
SD	3,801	147,775,199	95%	5%	78%	22%
TN	8,869	870,346,142	88%	12%	79%	21%
TX	47,695	2,730,207,598	82%	18%	57%	43%
UT	5,470	303,301,565	97%	3%	87%	13%
VT	3,172	215,525,350	100%	0%	99%	1%
VA	13,793	1,117,454,447	95%	5%	82%	18%
WA	18,440	798,483,535	96%	4%	70%	30%
WV	5,151	150,020,812	90%	10%	99%	1%
WI	36,871	1,485,149,803	97%	3%	90%	10%
WY	2,466	121,045,161	97%	3%	81%	19%
Reported US Total	948,041	49,206,455,588	93%	7%	81%	19%
Estimated US Total	949,108	51,933,826,428	93%	7%	81%	19%

^d Other date (data from previous or next year). ^e Estimate. ^f Sum of setting size data substituted for reported value. ^g Source ACHA (2018) * See state notes in Appendix. Medicaid Waiver authorities include 1115, 1915 (a), 1915 (a/c), 1915 (b), 1915 (b/c) and 1915 (c).



Figure 2.11 Proportion Expenditures and Recipients of Medicaid Waivers and ICF/IID in FY 2018



(65%), North Carolina (89%), Ohio (88%), Oklahoma (80%), Tennessee (88%), Texas (82%), and West Virginia (90%).

An estimated 81% of the combined expenditures for FY 2018 were for Medicaid HCBS Waiver recipients while 19% were for ICF/IID recipients. Only 19 states reported that 90% or more of their combined expenditures were for HCBS Waiver recipients.

Those states were Alabama, Alaska, Arizona, Colorado, Georgia, Hawaii, Idaho, Kansas, Maine, Maryland, Massachusetts, Minnesota, Missouri, New Mexico, Oregon, Rhode Island, Vermont, West Virginia and Wisconsin.

Medicaid Waiver and ICF/IID Recipients by Age and Type of Residence

Living arrangements varied depending on age and Medicaid funding authority (See **Figure 2.12**). Across all funding authorities and setting types adults outnumbered children. Overall, 25% of all HCBS Waiver recipients and 7% of ICF/IID recipients were children. Amongst HCBS Waiver recipients, however, children were 42% of those living with a family

member compared to just 6% of those living in any other type of setting.

Medicaid Waiver and ICF/IID Expenditures by Age and Living Arrangement

Average annual per person expenditures also varied by both age and living arrangement (See **Figure 2.13**). Across all setting types, average expenditures

Figure 2.12 Medicaid LTSS Recipients with IDD by Age, Funding Authority and Living Arrangement (Estimated) on June 30, 2018

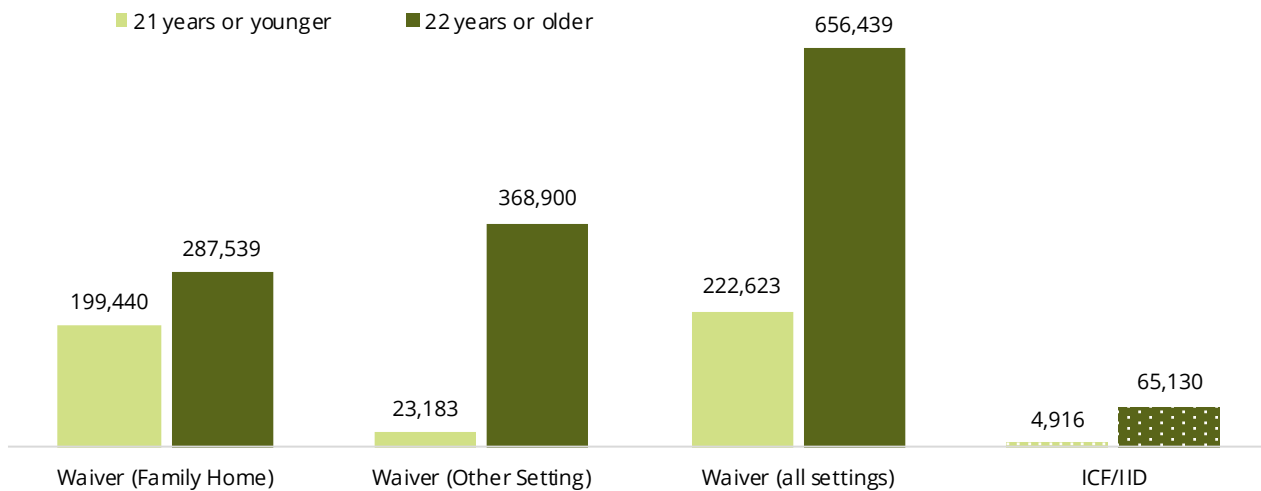
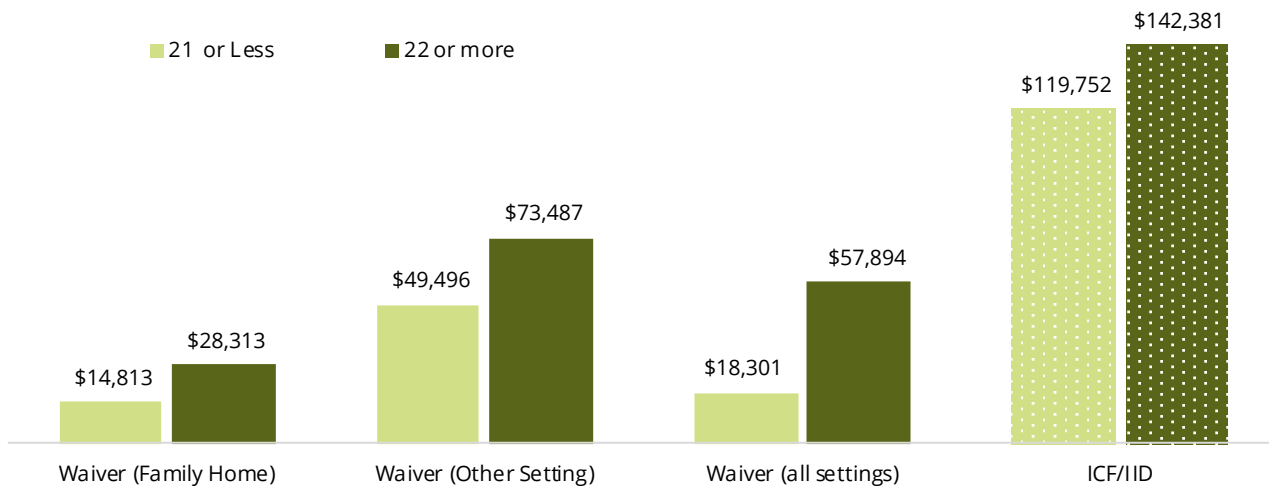


Figure 2.13 Average Annual per Person Medicaid Expenditures by Age, Funding Authority and Living Arrangement (Estimated) in FY 2018



Settings other than the family home (Other settings) include Foster Family, Own Home, Group Home and Other IDD group settings. Only states providing all data elements are included in the computation of expenditures per person.

were lower for children than for adults. Average annual per person expenditures for ICF/IID settings were \$119,752 for children compared with \$142,381 for adults. Across settings average HCBS Waiver per person expenditures were \$18,090 for children and \$57,176 for adults. Average annual HCBS Waiver expenditures for people living with a family member (\$14,813 for children and \$28,313 for adults) were lower than those for people living in any other setting (\$49,496 for children and \$73,487 for adults).

Annual per person expenditures for ICF/IID residents are likely higher than for Medicaid Waiver recipients at least in part because ICF/IID expenditures include room and board costs and several types of medical services that are not bundled into the cost for Medicaid Waiver funded LTSS. Average annual expenditures for children were lower than for adults in part because children are entitled to a free appropriate public education which is paid for by other sources.

Medicaid Expenditures and Benefits by State

Tables 2.14a and **2.14b** compare the Federal dollars invested in each state's Medicaid LTSS program for people with IDD to the state's payments to the Federal government in the form of Business and individual income taxes.

Federal Medicaid Expenditures

Federal Medicaid reimbursement rates vary by states based on factors such as state wealth. The FMAP is the proportion of total Medicaid expenditures reimbursed by the Federal government. The average FMAP for FY 2018 was 55% (ranging from 50% in 13 states to 76% in Mississippi).

The Federal share of Medicaid ICF/IID and Waiver expenditures for people with IDD were estimated by multiplying the state's FMAP by the total Medicaid ICF/IID and Waiver expenditures. Combined Medicaid ICF/IID and Waiver expenditures for people with IDD in FY 2018 were an estimated \$51.9 billion, of which an estimated \$28.6 billion was reimbursed by the Federal government. Federal Medicaid reimbursements were an estimated \$23.3 billion in FY 2018 for Medicaid Waiver funded supports and an estimated \$5.3 billion for services in an ICF/IID.

Proportion of Federal Expenditures by State

The first set of columns on **Table 2.14b** show the relative proportion of Medicaid HCBS Waiver and ICF/IID expenditures provided to each state by the Federal Medicaid program. The Federal Medicaid program contributed a total of \$23.2 billion of the \$42.3 billion total HCBS Waiver expenditures for people with IDD in FY 2018. It contributed \$5.3 billion of the \$9.6 billion in Medicaid ICF/IID expenditures in FY 2018.

The Federal contribution toward expenditures for Medicaid HCBS Waiver recipients with IDD differed by state. Of the \$23.2 billion in federal Medicaid Waiver expenditures, the proportion going to each state ranged from 0.2% for Wyoming to 12.8% for New York. Other states receiving high proportions of total Federal HCBS Waiver expenditures were Pennsylvania (7.0%) and California (7.3%). Other states receiving low proportions of Federal HCBS Waiver expenditures were Alaska (0.4%), Delaware (0.3%), Missouri (0.4%), Montana (0.3%), Nevada (0.3%), North Dakota (0.4%), Oregon (0.4%), South Dakota (0.3%), and Wyoming (0.2%). Of the \$5.3 billion in Federal Medicaid ICF/IID reimbursements paid in FY 2018, less than 0.2% went to Arizona, Vermont, and West Virginia while more than 5% went to California (6.2%), Illinois (5.9%), New York (9.1%), Ohio (8.0%), Pennsylvania (5.9%), and Texas (12.7%). Combined proportions of Medicaid HCBS and ICF/IID expenditures by state ranged from 0.2% in Wyoming to 12.1% in New York.

Not surprisingly, the proportion of Federal Medicaid Expenditures allocated to each state varied by state population with the more populous states getting higher proportions of the expenditures than sparsely populated states.

Federal Income Tax Paid

The second set of columns on **Table 2.14b** show total business and individual income tax paid by each state and the proportion of total Federal business and individual income taxes paid by each state. The totals shown do not include unemployment insurance, railroad retirement tax, estate and trust income tax, estate tax, gift tax, or excise tax. Totals also exclude taxes paid by U.S Armed Service members overseas, in Puerto Rico, people in other nations and undistributed

Table 2.14a FY 2018 Medicaid Expenditures for People with IDD, Federal Matching Percentage, and Federal Share by Funding Authority and State

State	Total FY 2018 Expenditures			Federal Matching Percentage (%) ¹	Federal Share of Total Expenditures (\$)		
	Waiver (\$)	ICF/IID (\$)	Combined		Waiver	ICF/IID	Combined
N States	49	49	48	51	49	49	48
AL	362,745,747	2,033,302 ^s	364,779,049	71%	259,145,562	1,452,591	260,598,153
AK	186,999,739	2,616,721	189,616,460	50%	93,499,870	1,308,360	94,808,230
AZ	1,101,032,624	1,221,000	1,102,253,624	70%	769,511,701	853,357	770,365,058
AR	237,512,575	171,344,670 ^s	408,857,245	71%	168,325,162	121,431,968	289,757,130
CA	3,391,877,243	654,498,652	4,046,375,895	50%	1,695,938,622	327,249,326	2,023,187,948
CO	482,569,051	44,761,565	527,330,616	50%	241,284,525	22,380,782	263,665,308
CT	959,339,555	200,960,676	1,160,300,231	50%	479,669,778	100,480,338	580,150,116
DE	142,550,378	33,174,352	175,724,730	56%	80,441,179	18,720,287	99,161,465
DC	238,617,760	89,215,875	327,833,635	70%	167,032,432	62,451,113	229,483,545
FL	1,068,863,462	331,590,954	1,400,454,416	62%	660,450,733	204,890,050	865,340,784
GA	647,324,952 ^s	33,587,180 ^s	680,912,132	69%	443,417,592	23,007,218	466,424,810
HI	121,834,883	8,323,705	130,158,588	55%	66,741,149	4,559,726	71,300,875
ID	253,914,178	8,375,870	262,290,048	71%	180,710,721	5,961,107	186,671,827
IL	955,156,294	613,172,414	1,568,328,708	51%	484,646,304	311,123,683	795,769,986
IN	645,273,796	270,721,188	915,994,984	66%	423,235,083	177,566,027	600,801,110
IA	573,759,945	231,887,228	805,647,174	58%	335,534,816	135,607,651	471,142,467
KS	522,395,346	41,086,372	563,481,718	55%	285,959,212	22,490,680	308,449,892
KY	665,581,730	142,186,626	807,768,356	71%	473,694,517	101,194,221	574,888,739
LA	472,032,599	342,021,630	814,054,229	64%	300,637,562	217,833,576	518,471,138
ME	381,553,219	41,484,333	423,037,552	64%	245,491,341	26,691,020	272,182,361
MD	1,061,512,877	31,087,411	1,092,600,288	50%	530,756,439	15,543,706	546,300,144
MA	1,515,881,122	97,483,726	1,613,364,848	50%	757,940,561	48,741,863	806,682,424
MI	DNF	0	DNF	65%	DNF	0	DNF
MN	1,554,309,680	114,405,788	1,668,715,468	50%	777,154,840	57,202,894	834,357,734
MS	114,590,471	189,902,209	304,492,680	76%	86,687,691	143,661,021	230,348,712
MO	923,875,582	84,553,890	1,008,429,473	65%	596,916,014	54,630,269	651,546,282
MT	113,619,700	DNF	DNF	65%	74,284,560	DNF	DNF
NE	298,298,133	68,761,423	367,059,556	53%	156,755,669	36,134,128	192,889,797
NV	114,343,117	15,965,645	130,308,762	66%	75,180,599	10,497,412	85,678,011
NH	DNF	DNF	DNF	50%	DNF	DNF	DNF
NJ	1,206,523,878	448,782,356	1,655,306,234	50%	603,261,939	224,391,178	827,653,117
NM	372,763,879	28,813,241	401,577,120	72%	268,986,415	20,791,635	289,778,050
NY	5,943,272,638	965,311,448	6,908,584,086	50%	2,971,636,319	482,655,724	3,454,292,043
NC	1,262,952,837	377,779,911	1,640,732,749	68%	853,882,413	255,416,998	1,109,299,411
ND	194,814,542 ^s	80,522,599	275,337,141	50%	97,407,271	40,261,300	137,668,571
OH	1,750,098,128	671,976,796	2,422,074,924	63%	1,098,711,605	421,867,033	1,520,578,637
OK	310,647,099	72,127,501 ^s	382,774,600	59%	181,946,006	42,245,077	224,191,083
OR	143,197,798	0	143,197,798	64%	91,102,439	0	91,102,439
PA	3,129,240,455	602,231,860	3,731,472,315	52%	1,621,572,404	312,076,550	1,933,648,954
RI	242,804,720	2,966,035	245,770,755	51%	124,923,028	1,526,025	126,449,053
SC	346,471,084	140,057,004	486,528,088	72%	248,004,002	100,252,803	348,256,805
SD	115,968,067	31,807,132 ^s	147,775,199	55%	64,176,728	17,602,067	81,778,795
TN	684,444,960	185,901,182	870,346,142	66%	450,501,673	122,360,158	572,861,831
TX	1,544,336,131	1,185,871,467	2,730,207,598	57%	878,418,391	674,523,690	1,552,942,082
UT	263,698,352	39,603,213	303,301,565	70%	185,274,462	27,825,217	213,099,680
VT	214,157,872	1,367,478	215,525,350	53%	114,510,214	731,190	115,241,405
VA	911,721,026 ^s	205,733,421 ^s	1,117,454,447	50%	455,860,513	102,866,711	558,727,224
WA	560,798,226	237,685,309	798,483,535	50%	280,399,113	118,842,655	399,241,768
WV	149,187,009 ^s	833,803 ^s	150,020,812	73%	109,264,565	610,677	109,875,243
WI	1,338,173,082	146,976,721	1,485,149,803	59%	786,444,320	86,378,219	872,822,539
WY	97,827,299	23,217,862	121,045,161	50%	48,913,650	11,608,931	60,522,581
Estimated US Total/Average	42,292,676,687	9,641,149,741	51,933,826,428	55%	23,260,972,178	5,302,632,357	28,563,604,536

^s Other date (data from previous or next year). * Estimate. DNF Did not furnish. * See state notes in the Appendix. ¹ Source: FY 2018: [Federal Register, November 15, 2016 (Vol 81, No. 220), pp 80078-80080](https://www.gpo.gov/fdsys/pkg/FR-2016-11-15/pdf/2016-27424.pdf). Medicaid Waiver authorities include 1115, 1915 (a), 1915 (a/c), 1915 (b), 1915 (b/c) and 1915 (c)

Table 2.14b FY 2018 State Medicaid Expenditures, Federal Income Taxes, and State Medicaid Benefit Ratios by Funding Authority and State

State	State Proportion of Total Federal Expenditures			Federal Business and Individual Income Tax Paid		State Medicaid Benefit Ratio ²
	Medicaid Waiver	ICF/IID	Combined	Billions (\$)	Percent (%)	
N states	49	49	48	51	51	48
AL	1.1	0.0	0.9	0.8	1.15	1.2
AK	0.4	0.0	0.3	0.2	2.14	2.1
AZ	3.3	0.0	2.7	1.3	2.02	2.0
AR	0.7	2.3	1.0	0.9	1.09	1.1
CA	7.3	6.2	7.1	13.4	0.53	0.5
CO	1.0	0.4	0.9	1.7	0.53	0.5
CT	2.1	1.9	2.0	1.6	1.28	1.3
DE	0.3	0.4	0.3	0.5	0.67	0.7
DC	0.7	1.2	0.8	0.8	0.95	1.0
FL	2.8	3.9	3.0	6.0	0.51	0.5
GA	1.9	0.4	1.6	2.7	0.61	0.6
HI	0.3	0.1	0.2	0.3	0.90	0.9
ID	0.8	0.1	0.7	0.3	2.02	2.0
IL	2.1	5.9	2.8	4.6	0.61	0.6
IN	1.8	3.3	2.1	1.8	1.20	1.2
IA	1.4	2.6	1.6	0.7	2.22	2.2
KS	1.2	0.4	1.1	0.7	1.50	1.5
KY	2.0	1.9	2.0	1.0	1.94	1.9
LA	1.3	4.1	1.8	1.3	1.45	1.5
ME	1.1	0.5	1.0	0.2	4.03	4.0
MD	2.3	0.3	1.9	2.2	0.88	0.9
MA	3.3	0.9	2.8	3.5	0.81	0.8
MI	DNF	0.0	DNF	2.5	DNF	DNF
MN	3.3	1.1	2.9	3.0	0.99	1.0
MS	0.4	2.7	0.8	0.3	2.38	2.4
MO	2.6	1.0	2.3	1.8	1.24	1.2
MT	0.3	DNF	DNF	0.2	DNF	DNF
NE	0.7	0.7	0.7	0.7	0.94	0.9
NV	0.3	0.2	0.3	0.6	0.49	0.5
NH	DNF	DNF	DNF	0.4	DNF	DNF
NJ	2.6	4.2	2.9	4.1	0.71	0.7
NM	1.2	0.4	1.0	0.3	3.82	3.8
NY	12.8	9.1	12.1	8.3	1.46	1.5
NC	3.7	4.8	3.9	2.5	1.58	1.6
ND	0.4	0.8	0.5	0.2	2.47	2.5
OH	4.7	8.0	5.3	4.1	1.30	1.3
OK	0.8	0.8	0.8	0.7	1.10	1.1
OR	0.4	0.0	0.3	1.0	0.32	0.3
PA	7.0	5.9	6.8	4.0	1.70	1.7
RI	0.5	0.0	0.4	0.4	1.02	1.0
SC	1.1	1.9	1.2	0.8	1.44	1.4
SD	0.3	0.3	0.3	0.2	1.45	1.5
TN	1.9	2.3	2.0	2.0	1.00	1.0
TX	3.8	12.7	5.4	7.6	0.72	0.7
UT	0.8	0.5	0.7	0.7	1.10	1.1
VT	0.5	0.0	0.4	0.1	3.08	3.1
VA	2.0	1.9	2.0	2.5	0.78	0.8
WA	1.2	2.2	1.4	2.7	0.52	0.5
WV	0.5	0.0	0.4	0.2	1.87	1.9
WI	3.4	1.6	3.1	1.5	2.01	2.0
WY	0.2	0.2	0.2	0.1	1.64	1.6
Estimated US Total/Average	100	100	100	3,291	100	1.0

² The State Medicaid Benefit Ratio compares the proportion of the total federal income tax paid by the state to the proportion of total ICF/IID plus Medicaid Waiver federal expenditures for the state. A value greater than 1 indicates that the state receives a higher proportion of Federal Medicaid ICF/IID and Waiver expenditures than the proportion of Federal Income taxes paid by the state. A value of less than 1 indicates that the state receives a lower proportion of Federal expenditures than the proportion of federal income taxes paid.

taxes. In FY 2018, states paid a total of \$3.3 trillion in federal business and individual income taxes. The proportion paid varied by state ranging from 13.4% by California, to less than 0.2% paid by Alaska (0.16%), Montana (0.18%), Vermont (0.13%), and Wyoming (0.13%).

State Medicaid Benefit Ratios

The State Medicaid Benefit Ratio compares the proportion of Federal Medicaid ICF/IID and Waiver reimbursements received with the proportion of federal income taxes paid by each state. A state Medicaid Benefit Ratio of 1.0 indicates that the proportion of Federal Medicaid ICF/IID plus Waiver reimbursements for a state is equal to the proportion of federal income taxes paid by the state. A ratio higher than 1.0 indicates that the state received a higher proportion of Federal Medicaid ICF/IID and Waiver reimbursements for recipients with IDD than the proportion it paid of total federal income taxes. A ratio of less than 1.0 indicates that the state received a lower proportion of all Federal Medicaid ICF/IID and Waiver reimbursements for people with IDD than the proportion it paid of total federal income taxes. Benefit Ratios could not be computed for states that provided incomplete Medicaid ICF/IID and Waiver expenditures information.

For FY 2018, state Medicaid Benefit Ratios ranged from 0.32 for Oregon to 4.03 for Maine. Across the 48 reporting states, 30 had Medicaid Benefit ratios of 1.0 or higher and 18 states had ratios of less than 1.0. The relative benefit states got from the Federal Medicaid program was associated with FMAP ($r = .26$). That is, states for whom the Federal government paid a higher share of Medicaid expenditures got proportionately more out of Medicaid than they paid in Federal Business and Income taxes. For example, of the 18 states with a benefit ratio of less than 1, 8 had an FMAP of 50% (California, Colorado, Massachusetts, Maryland, Minnesota, New Jersey, Virginia, and Washington), and 5 had an FMAP of 51% to 57% (Delaware, Hawaii, Illinois, Nebraska and Texas). These generally wealthier states got less back in Federal Medicaid reimbursements than they paid in business and personal income taxes.

However, another factor was more strongly predictive of whether a state got a positive fiscal

benefit. States that provided HCBS Waiver plus ICF/IID services to more recipients per 100,000 of the state's population were more likely to have a positive Medicaid Benefit Ratio ($r = .42$). An estimated 17% of state to state variation in the Medicaid Benefit Ratio could be explained or accounted for by the number of service recipients per 100,000. To illustrate, the three states serving the fewest people with IDD per 100,000 benefited least (Nevada served 76 people per 100,000 and had a benefit ratio of 0.49; Georgia served 83 people per 100,000 and had a benefit ratio of 0.61; and Alabama served 80 people per 100,000 and had a benefit ratio of 1.13). Conversely, North Dakota served 715 people per 100,000 and had a benefit ratio of 2.47; Wisconsin served 635 people per 100,000 and had a benefit ratio of 2.01, Vermont served 509 people per 100,000 and had a benefit ratio of 3.09, and Maine served 404 people per 100,000 had had a benefit ratio of 4.04. There were exceptions to this. States such as Oregon and Nevada that used other Medicaid funding mechanisms to finance LTSS for people with IDD had low benefit ratios for ICF/IID and HCBS Waiver expenditures but would likely have had much higher benefit ratios had those other funding mechanisms been included in the analyses.

A SHORT HISTORY OF LTSS FOR PEOPLE WITH IDD: ROLE OF THE MEDICAID PROGRAM

Most people with IDD in the United States live with family members throughout their lives and get needed supports from family, friends or neighbors. A minority live in non-family settings of different types and sizes. For more than 100 years, most people with IDD in the United States who received publicly funded long-term supports and services lived in state-operated facilities shared by 16 or more people with IDD. However, in recent decades LTSS for people with IDD (both those living with family members and those receiving supports in other settings) have been radically transformed. This section summarizes key milestones driving that transformation.

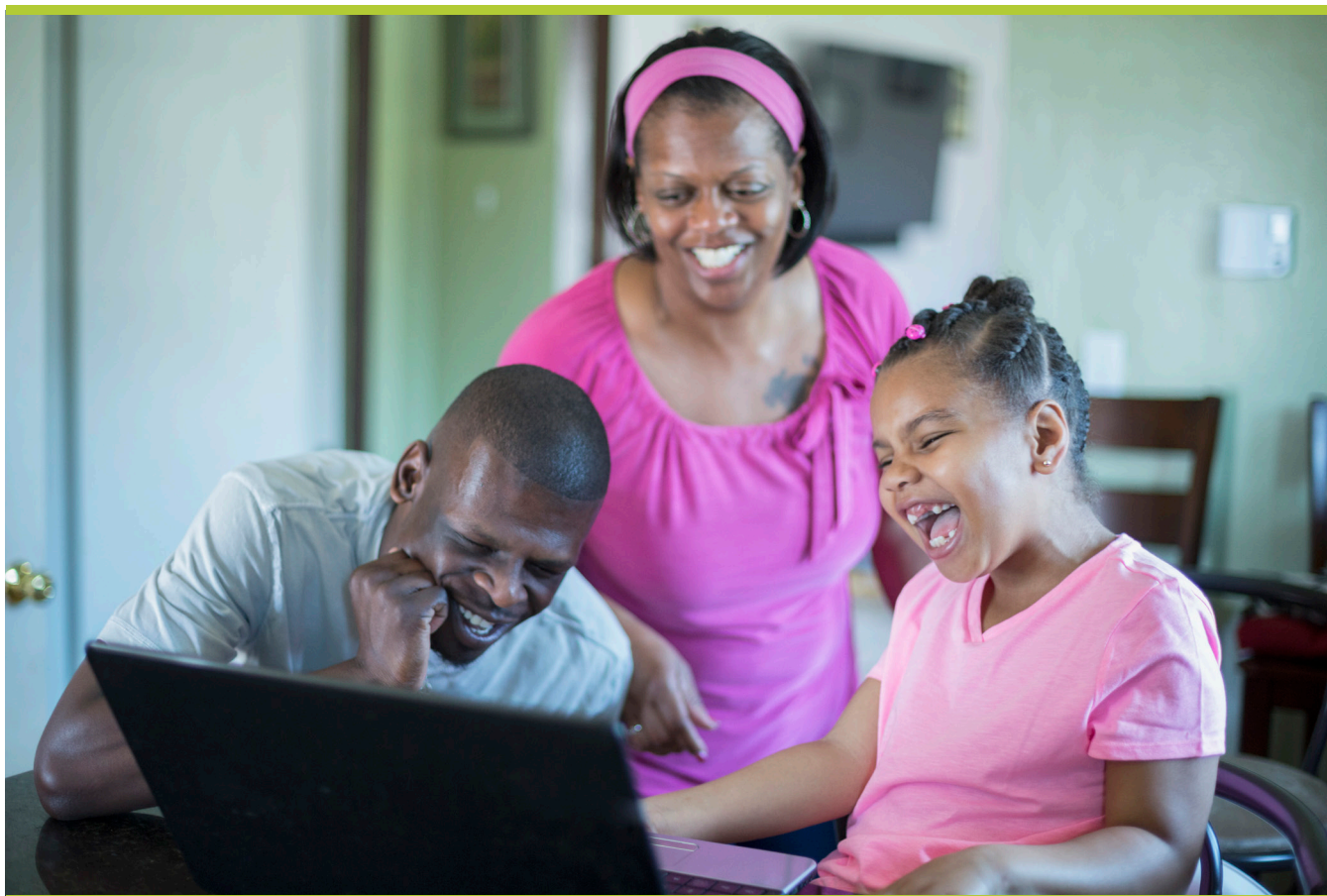
Institutionalization and Deinstitutionalization

The 1880 U.S. Census enumerated 76,895 people with IDD in the United States of whom 9,725 (13%) lived in institutions, almshouses, or prisons (Lakin, 1979). The number of people with IDD living in institutional settings in the United States grew for the first six decades of the 20th Century, and most of those institutions were state-operated. In 1903, 15,511 people with IDD lived in institutions 98.6% of whom lived in a state-operated facility. By 1946, the average daily population of state-operated IDD facilities had grown to 115,927. The average daily population nearly doubled during the baby boom years from 1946 and 1964, reaching an all-time high of 194,650 people in 1967. In 1967, an estimated 33,850 additional people with IDD lived in state-operated psychiatric facilities (the combined average daily population of state-operated IDD or psychiatric facilities was 228,500 in 1967).

Despite their widespread use, by the 1950s families, parent associations, professionals, and

policy makers protested that large state-operated IDD institutions were overcrowded, understaffed, and sometimes unfit for human habitation. President John F. Kennedy, whose sister Rosemary had ID, urged Congress in 1963 to move away from providing services to people with IDD in custodial institutions to providing services in community settings (John F Kennedy Library). In 1965, after visiting the Willowbrook State School in New York, Senator Robert Kennedy reported that the children at the facility lived in filth and called the facility a “snake pit” (Minnesota Developmental Disabilities Council, 2016).

Burton Blatt and F. Kaplan’s 1966 *Christmas in Purgatory* photo essay showed institutionalized children and adults at the Fernald State School in Massachusetts, wandering (some with no clothing) in sparsely furnished day rooms, doing nothing. Geraldo Rivera’s 1972 documentary *Willowbrook: The Last Great Disgrace* profiled a crowded New York institutional ward housing 50 people with IDD, mostly children, living under similar circumstances.



Against this backdrop, professionals argued that segregating and institutionalizing people based on disability enhanced negative stereotypes and was dehumanizing. Wolf Wolfensberger, Bengt Nirje, and others articulated a Normalization Principle, which argued that people with IDD should not be segregated in institutions (e.g., Kugel & Wolfensberger, 1969). Instead, they should be supported to live, play, work, and learn in culturally normative physically and socially inclusive settings regardless of the type or severity of a person's disability. This meant:

- having daily schedules defined by individual preferences and needs rather than by the needs of staff or a facility
- spending time in a variety of different settings each week for work, learning, and leisure rather than remaining in the institution all day every day
- taking breaks from normal routines to vacation, celebrate holidays, and enjoy seasonal activities
- participating in inclusive activities in settings typical for people of similar age
- being treated with respect and dignity with the right to make choices about both the little things (like what to wear or what to eat), and big things (like where to live and with whom)
- living, working, and playing in settings that included both men and women
- working for a decent wage during adulthood and having sufficient resources to care for basic human needs (such as food, clothing, personal hygiene, shelter, and transportation) and
- living, working and playing in physically accessible environments, with modifications or accommodations supporting full participation.

Lawsuits and subsequent settlement agreements challenging the quality of care in institutions, seeking improved conditions as well as access to community alternatives, were filed in the 1970s in several states including Pennsylvania (PARC v. Commonwealth of Pennsylvania, 1972); New York (ARC v. Rockefeller, 1972); Alabama (Wyatt v. Stickney, 1971) and Minnesota (Welsch v. Likins, 1972). Legislative action during the 1960's and 1970's propelled a movement to deinstitutionalize services for people with IDD.

Introduction of Medicaid Funding

Before 1965, there was no federal funding for LTSS for persons with IDD. In 1965, Medicaid was enacted as Medical Assistance, Title XIX of the Social Security Act. Medicaid is a state-federal partnership in which the federal government covers at least half of the service costs for eligible recipients. Initially, Medicaid funded long-term supports for people living in Skilled Nursing Facilities (SNF). Many state-operated IDD facilities were converted to Medicaid SNFs once the Medicaid program was in place, and the number of people with IDD in Medicaid certified facilities increased rapidly. However, federal officials grew concerned that some people in SNFs were receiving more and more costly medical care than they needed. They were also concerned that the services offered in SNFs did not meet the developmental needs of children and adults with IDD (General Accounting Office, 1970).

Intermediate Care Facilities for Individuals with Intellectual Disabilities

In 1967, a less medically oriented and less expensive form of long-term supports, the "Intermediate Care Facility" (ICF) program was authorized under Title XI of the Social Security Act. In 1971, the SNF and ICF programs were combined under Title XIX of the Social Security Act. Within the legislation, was a hardly noticed, scarcely debated amendment that authorized Federal Financial Participation (FFP) for "intermediate care" provided in public and private facilities geared specifically to meet the needs of people with IDD. Medicaid facilities for people with IDD were initially called Intermediate Care Facilities/Mental Retardation [sic] (ICF/MR) but because of Rosa's Law in 2010 are now referred to as Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID; Centers for Medicare and Medicaid Services, 2013b).

The ICF/IID legislation provided substantial federal incentives to states for upgrading the physical environment and the quality of care and habilitation in certified IDD facilities. It also neutralized incentives for states to place persons with IDD in SNFs by creating a federally subsidized alternative offering care that was more appropriate and habilitation in the form of active treatment. In the ensuing years, most state IDD facilities were certified as ICF/IIDs with two notable results: 1) nearly every

state secured federal funding for large public IDD facilities, and 2) to maintain federal participation, states were compelled to invest substantial state dollars to bring their IDD facilities into conformity with ICF/IID standards. Forty states had at least one ICF/IID certified facility by June 30, 1977 (Krantz, Bruininks, & Clumper, 1979). Between 1978 and 1980, nearly a billion state dollars were invested in facility improvements to meet ICF/IID standards (Gettings & Mitchell, 1980).

In 1975, PL 94-142 (Education of all Handicapped Children Act; now the Individuals with Disabilities Education Act) passed, mandating access to a free, appropriate public education for all children regardless of the type or severity of disability. As the law was implemented, families were able to enroll their children in a public school instead of placing them in an IDD facility or paying privately for educational services. The law also required a free and appropriate publicly-funded education for children with disabilities living in SNF, ICF/IID, and other institutions.

Beginning in the 1960s, states began to reduce the number of children living in state IDD facilities to reduce overcrowding as required by the ICF/IID standards, and to respond to the educational requirements of PL 94-142. The proportion of state IDD facility residents ages 21 years or younger peaked in 1965 at 49% (91,592 of 187,305 the people with IDD living in state facilities were children; NIMH, 1966). By 1977, the proportion of children in state IDD facilities with 16 or more residents with IDD had dropped to 36% (54,098 of 151,532 total residents), and by 1987 the proportion was 13% (12,310 of 94,695). The proportion declined to 5% in 1998 and was 4% in FY 2018 (694 of the average daily population of 17,596).

In the 1970s as ICF/IID expenditures grew, critics charged that the ICF/IID program had

- a. created direct incentives for maintaining people in large state facilities by financing more than half of the costs of those services;
- b. diverted funds that could otherwise have been spent on community program development into facility renovations required to maintain eligibility for federal financial participation;

- c. promoted the development of large private ICF/IID facilities; and,
- d. promoted organizational inefficiency and individual dependency by promoting a single uniform standard for care and oversight for all people in ICF/IID settings irrespective of the nature and degree of their disabilities and/or their relative capacity for independence

These criticisms and the growing desire to increase access to federal matching funds stimulated the development of ICF/IID settings serving 4 to 15 people.

Downsizing ICF/IID Settings

Although Congressional debate about the ICF/IID program focused on large state facilities, the statute did not specifically limit ICF/IID coverage to only state facilities or to only large institutions. They simply restricted ICF/IID facilities to “four or more people in single or multiple units” (42 CRF 435.1010(b) (2)). The focus of the legislation was on improving the general quality of care in residential facilities rather than on the size of those facilities. The ICF/IID regulations published in January 1974 delineated two categories of ICF/IID, those housing 16 or more people and those housing four to fifteen people. Smaller facilities were given greater flexibility in meeting ICF/IID standards.

States varied in the rate at which they developed ICF/IID facilities serving four to 15 people. Some states developed hundreds, while others had none. In 1982, nearly two-thirds (65%) of the 1,202 ICF/IIDs serving 4 to 15 people were located in Minnesota, New York, Michigan, and Texas. Some states and national organizations argued that the uneven distribution of the smaller ICF/IID facilities reflected a lack of clear and consistent policy guidelines for certifying ICF/IID participation and/or a lack of support for those facilities in some regions.

In 1981, the Health Care Financing Administration (HCFA), now the Centers for Medicare and Medicaid Services (CMS), issued “Interpretive Guidelines” for certifying ICF/IIDs of four to fifteen people. Following the publication of the guidelines, substantially more states began to develop smaller ICF/IIDs. In the same year, Congress enacted legislation giving greater opportunity and flexibility to states to use Medicaid funding for community services through the HCBS waiver funding authority.

2018

Medicaid Home and Community-Based Services

Section 2176 of the Omnibus Budget Reconciliation Act of 1981 (PL 97-35) created Section 1915(c) of the Social Security Act, granting the Secretary of Health and Human Services the authority to waive certain Medicaid requirements and allow states to finance “non-institutional” services for Medicaid-eligible individuals. The change was intended to reduce the institutional bias of the Medicaid program. The Medicaid 1915(c) HCBS Waiver offered home and community-based services to people with disabilities who otherwise would remain in, or be at a risk of placement in a Medicaid funded institution.

Regulations for the 1915(c) HCBS Waiver program were first published in March 1985. Initially, states were required to demonstrate reductions in the number of recipients of, and total expenditures for, Medicaid-funded institutional settings such as an ICF/IID roughly equal to the increases in HCBS participants and expenditures. As the number of

people in ICF/IID settings declined, those restrictions were relaxed and then dropped in 1994.

States specify in their 1915(c) Medicaid Waiver applications which Medicaid eligible population(s) will be served and which services will be available (e.g., homemaker, home health aide, personal care, day and residential habilitation, respite care or other services as approved by the Secretary of the U.S. Department of Health and Human Services; www.Medicaid.gov, 2016). Although not allowed to use HCBS reimbursements to pay for room and board, all states provide residential support services under categories such as personal care, residential habilitation, and in-home supports. HCBS recipients with IDD live with family members or use their own resources, usually cash assistance from other Social Security Act programs and state supplements to cover room and board costs.

While some Medicaid Waiver recipients live in host/foster family homes or group homes, most recipients live with family members or in a home they own or lease. With their flexibility and potential



for promoting individualized services, Medicaid HCBS Waiver authorities have been the primary source of funding for home and community-based LTSS for more than three decades.

Balancing Medicaid Home and Community-Based and Institutional LTSS

Several Medicaid reforms and initiatives have supported the shift from institutional to community-based LTSS. Medicaid LTSS expenditures for people with IDD living in home and community-based settings first exceeded expenditures for institutional services in 2001. By 1995, more than half of all LTSS recipients with IDD in Medicaid-funded settings were in home and community-based settings. It wasn't until 2013, however, that more than half of all Medicaid LTSS expenditures across all population groups were for services provided in home and community-based settings (Eiken et. al., 2015).

Nursing Facility Reform

In the Omnibus Budget Reconciliation Act (OBRA) of 1987, (PL 100-203) Congress restricted admission to Medicaid-reimbursed nursing facilities to persons requiring specific levels of medical/nursing services. People who did not need nursing services were required to move to other appropriate residential settings, except that people living in a specific nursing home for longer than 30 months could choose not to move. Nursing facilities were required to assure to meet each person's needs for "active treatment" (later termed "specialized services").

Despite state alternative disposition plans for moving persons with IDD out of nursing facilities, and preadmission screening and resident review (PASRR), class action court cases established that the requirements of OBRA-87 were not always achieved (See Roland, et. al., v Cellucci, et. al., 1999, in Massachusetts, and Olesky et. al. v. Haveman et. al., 1999, in Michigan, Gettings, 1990).

Expansion of Medicaid Waiver Funding Authorities

Since 1999, Congress has added several additional Medicaid HCBS funding authorities allowing states to expand Medicaid-funded community services and reduce demand for institutional services. Many states operate HCBS programs for two or

more different eligible populations. In February 2020, the Medicaid website (<https://www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/index.html>) listed 291 approved Section 1915(c) Home and Community-based Waivers, 53 approved 1115 Waivers, and 78 1915 (b) Waiver Authorities. Many states also offer HCBS under State Plan 1915(i), 1915(j) or 1915(k) funding authorities, though people with IDD are sometimes excluded from participating in those programs.

Supports for Families

While the Medicaid program initially funded LTSS in only institutional settings, funding options for people with IDD living with family members have expanded. Medicaid Waiver funded supports for people living with a family member include, but are not limited to:

- a. caregiver support and training;
- b. respite from caregiving responsibilities;
- c. personal care supports provided to the individual;
- d. habilitation (teaching people new skills);
- e. employment or day services (supports for working or participating in activities in a setting other than the home of a family member);
- f. behavior supports;
- g. medical supports and therapies such as physical or speech therapy;
- h. participant-directed supports (assistance to help the individual or family manage aspects of the publicly funded services they receive);
- i. transportation; and
- j. environmental modifications and technology (such as home and vehicle modifications)

CMS has also expanded other Medicaid funding authorities through which LTSS may be paid for people living with family members or in their own homes.

Money Follows the Person

The Money Follows the Person (MFP) initiative authorized in the Deficit Reduction Act of 2005 is a federal demonstration program designed to help states reduce their use of institutional care while expanding options for people to receive care in the community. The legislation provided

a system of flexible and augmented financing to assist states in moving people to smaller, more integrated, appropriate, and preferred settings. The program was amended by Section 2403 of Patient Protection and Affordable Care Act (P.L. 111-148), the Medicaid Extenders Act of 2019 (P.L. 116-3), the Medicaid Services Investment and Accountability Act of 2019 (P.L. 116-16), and was last expanded through the Sustaining Excellence in Medicaid Act of 2019 (P.L. 116-39).

MFP is the largest demonstration program in the history of Medicaid designed to transform LTSS. MFP grants enabled states to develop systems and services to help long-term residents of nursing facilities, ICF/IIDs, and Institutions for Mental Disease (i.e., psychiatric hospitals) to move to home or community-based settings. The program began in 2007, and by December 2016, it had supported more than 75,151 people with disabilities to move from institutions to community residences. As of February 2020, 43 states and the District of Columbia were participating. Between January 2017 and December 31, 2018 an additional 18,640 people had moved from institutions to community settings (<https://www.medicaid.gov/medicaid/long-term-services-supports/money-follows-person/index.html>).

Medicaid Managed LTSS

Many states have opted to use a capitated managed care model as an alternative to fee-for-service financing to manage some or all of their Medicaid LTSS. Section 1115 Research and Demonstration Projects allow states the flexibility to test new or existing approaches for financing and delivering Medicaid services, including the option to provide home and community-based services through a managed care entity. Similarly, states can amend their Medicaid State Plan under the 1932(a) federal authority to implement a managed care delivery system. Section 1915(a) and (b) Managed Care authorities also allow states to use managed care delivery systems. A hybrid program (concurrent 1915(b) and 1915(c) waivers – also referred to as 1915(b)/(c) concurrent waivers) allows states to implement two types of waivers at the same time as long as all federal requirements were met for both programs.

Developed in the private healthcare sector, managed care models and operational strategies are designed to reduce the costs of care while simultaneously improving accessibility, quality, and outcomes at both the individual and systems-levels by shifting risk away from state agencies to private managed care companies. While states must administer publicly financed services in the most cost-effective manner possible, some people are concerned.

Managed care contracting and operational strategies for LTSS furnished to people with IDD and other disabilities could decrease access to care, narrow the scope of services, and divert funds that could be used to address waiting lists and unmet service needs to cover expanded administrative activities.

As states increasingly are using managed care to deliver long-term services and supports (MLTSS) to seniors and people with disabilities enrolled in Medicaid, CMS sought to provide additional requirements related to MLTSS programs and beneficiary protections, while allowing states flexibility in program design and administration. They issued a final rule on April 25, 2016.

Many states see managed care as a way to gain additional control over the costs of LTSS delivery. The number of states offering Medicaid MLTSS programs increased from 16 in 2012 to 24 in 2017, with 11 states offering more than one MLTSS program (Lewis, Eiken, Amos & Saucier, 2018). Most MLTSS programs exclude certain populations or categories of services. In 2017, 30 MLTSS programs excluded institutional care and 28 excluded HCBS programs for people with IDD.

Self-Directed Medicaid HCBS

Self-directed Medicaid options allow participants, or their legal representatives, to exercise decision-making authority and management responsibility over services. States can offer self-directed services through several funding authorities including 1915(c) HCBS waiver, the 1915(i) HCBS State Plan Option; 1915(k) Community First Choice; and the 1915(j) Self-Directed Personal Assistance Services State Plan Option.

In self-directed services, Medicaid recipients can choose their service provider and direct supports



and services. Recipients may directly manage budgeted Medicaid funds under some self-directed services options. Medicaid funded self-directed services must use a person-centered planning process and specify services and supports to be offered in a service plan. Many self-directed options, in addition to offering the individual “employer authority” where they may hire their own staff, use an individualized budget, and allow individuals decision-making opportunities on the management of that budget.

All self-direction programs must offer information and assistance to people receiving self-directed services (<https://www.medicaid.gov/medicaid/ltss/self-directed/index.html>). In addition, a supports broker/consultant/counselor and financial management services must be available to participants, use an individualized budget, and offer information and assistance to people receiving self-directed services (<https://www.medicaid.gov/medicaid/ltss/self-directed/index.html>).

Milestones in LTSS Policy

- **1965 Medicaid Program.** An anti-poverty program establishes Medicaid as an LTSS funder.
- **1971 Medicaid Intermediate Care Facilities for Individuals with Intellectual Disabilities.** This was the beginning of federal involvement in funding services for people with IDD although still with an institutional focus. While many of the early ICF/IID certified facilities were large state-operated institutions, funding was available to settings of four or more people who complied with the certification standards. During the 1970s, a large number of smaller institutional settings were opened, with those that housed six people being the most common.
- **Rehabilitation Act of 1973** prohibited discrimination based on disability in federally funded programs.
- **1975 PL 94-142 (Now the Individuals with Disabilities Education Act).** PL 94-142 required school districts to provide an appropriate education to children with disabilities. This was

the first time children with IDD could go to school in their communities instead of in residential institutions. Many states began to reduce the number of children living in state IDD facilities to reduce overcrowding as required by the ICF/IID standards, and to respond to the new educational requirements of PL 94-142.

- **1981 Medicaid Home and Community-based Services Waiver.** The Medicaid HCBS Waiver started in 1981. It was an option states could use to fund LTSS in community settings other than ICF/IID certified institutions. Initially, the program was a cost saving measure more than a tool to support people with disabilities to live lives of their choosing in their communities. Participating states were required to demonstrate that their total Medicaid Waiver expenditures and the total number of people served grew no more than would be expected without the Waiver.
- **1987 Nursing Facility Reform.** With the Omnibus Budget Reconciliation Act (OBRA) of 1987, (PL 100-203) Congress restricted admission to Medicaid-reimbursed nursing facilities to persons requiring specific levels of medical/nursing services. People who did not need nursing services were required to move to other appropriate residential settings, except that individuals living in a specific nursing home for longer than 30 months could choose not to move.
- **1990 Americans with Disabilities Act.** The ADA is the landmark Civil Rights legislation for people with disabilities that prohibits discrimination based on disability with the goal of making sure that people with disabilities have access to the same opportunities as their fellow citizens. It required businesses and other organizations to make reasonable accommodations to allow all people including those with disabilities to access and use their settings and services.
- **1999 Supreme Court Olmstead Decision.** The Supreme Court in their 1999 Olmstead Decision established a right to “placement in the most integrated setting” under its interpretation of Title II of the Americans with Disabilities Act. The decision holds that people should not be required to live in institutions to have their medical needs met unless there are no integrated options available. The ADA coupled with the Olmstead decision pushed the service system to focus more on individualized supports and services that offer people greater choice and control over their lives.
- **2005 Deficit Reduction Act.** This legislation contained several provisions affecting LTSS. Among those provisions was creation of the 1915(i) funding authority and initial authorization of the Money Follows the Person program.
- **2010 Affordable Care Act.** This Federal legislation authorized the State Balancing Incentive Payments program, made modifications to the Medicaid 1915 State Plan LTSS option, and the Medicaid Waiver 1915(k) Community First Choice option, and extended funding for the Money Follows the Person program. It allows states to fund HCBS services through Medicaid State Plan and prohibits discrimination based on disability in federally funded health care.
- **2014 Medicaid Home and Community-based Services Rule.** In 2014, CMS promulgated new rules that strengthen the requirements for integration, autonomy, choice and control, and person-centered services for Waiver recipients. All provisions of the rule became effective upon promulgation except those provisions related to HCBS settings. States have until 2023 to implement transition plans to bring all HCBS funded service settings into compliance with the rule.



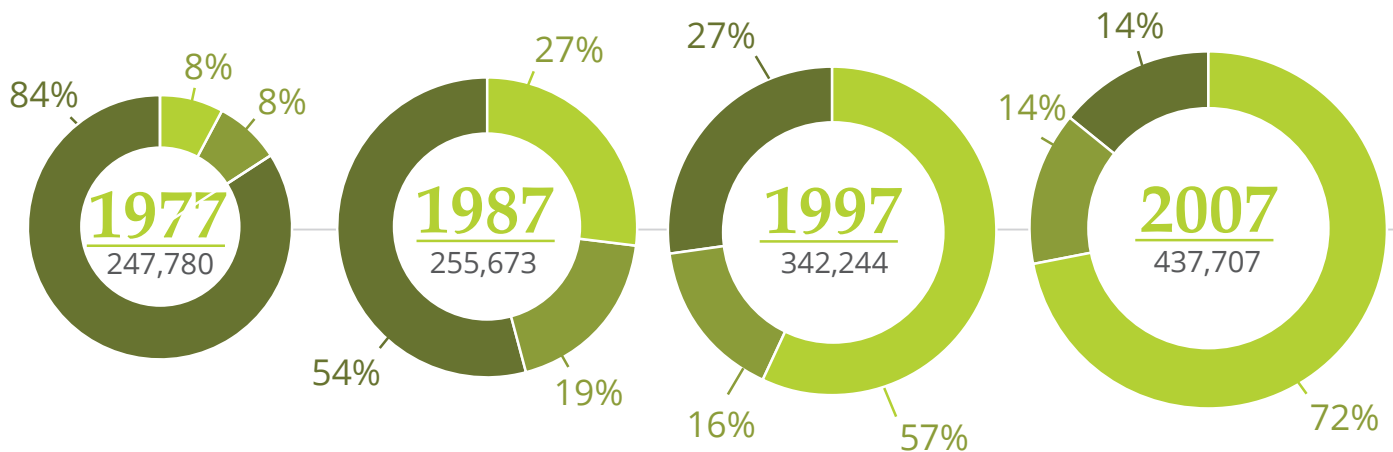
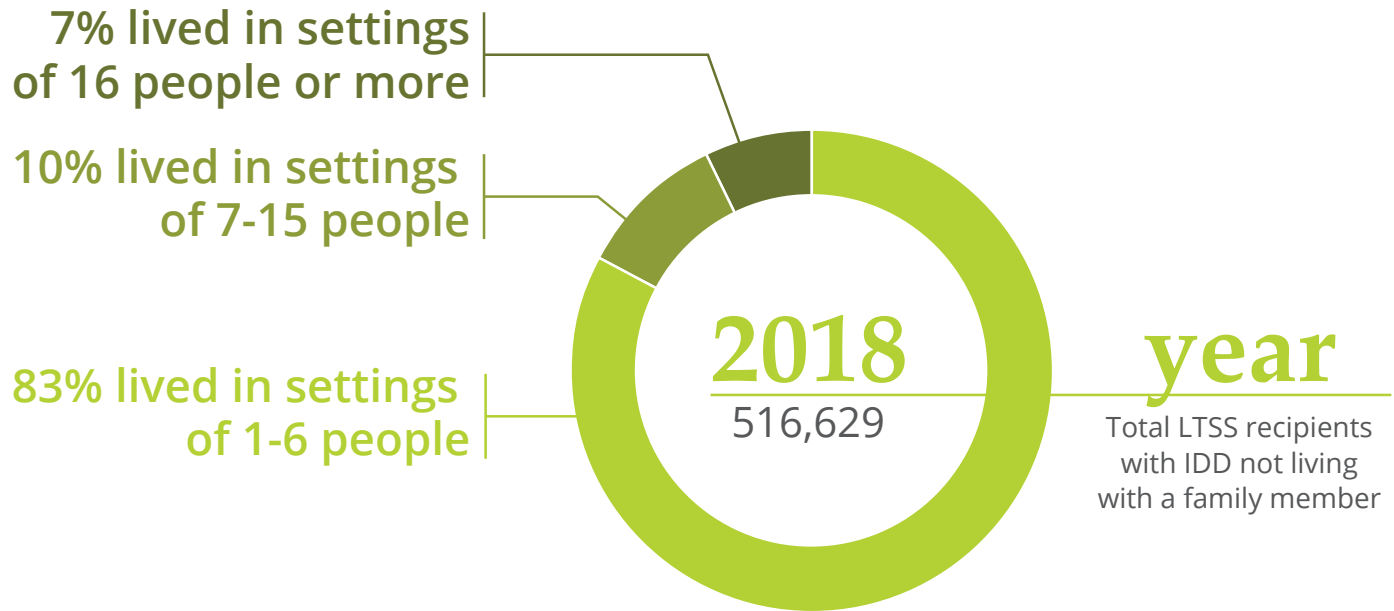
SECTION THREE

Historical Perspectives and Trends through 2015 in Long-Term Supports and Services

FY 2018

Change in the Total Number of People in Non-Family IDD Settings and Proportion in Settings of Different Sizes Between 1977 and 2018

Proportion non-family that are nonstate operated



SECTION 3: HISTORICAL PERSPECTIVES AND TRENDS IN LTSS

Section 3 describes trends in the number LTSS recipients with IDD, Medicaid Waiver and ICF/IID expenditures and recipients, size and type of places LTSS recipients with IDD live, and the use of state-operated residential services.

homes or psychiatric facilities, between 1998 and 2018 the total number of LTSS recipients with IDD increased 93% from 693,691 to 1,336,131 people (See **Figure 3.1**).

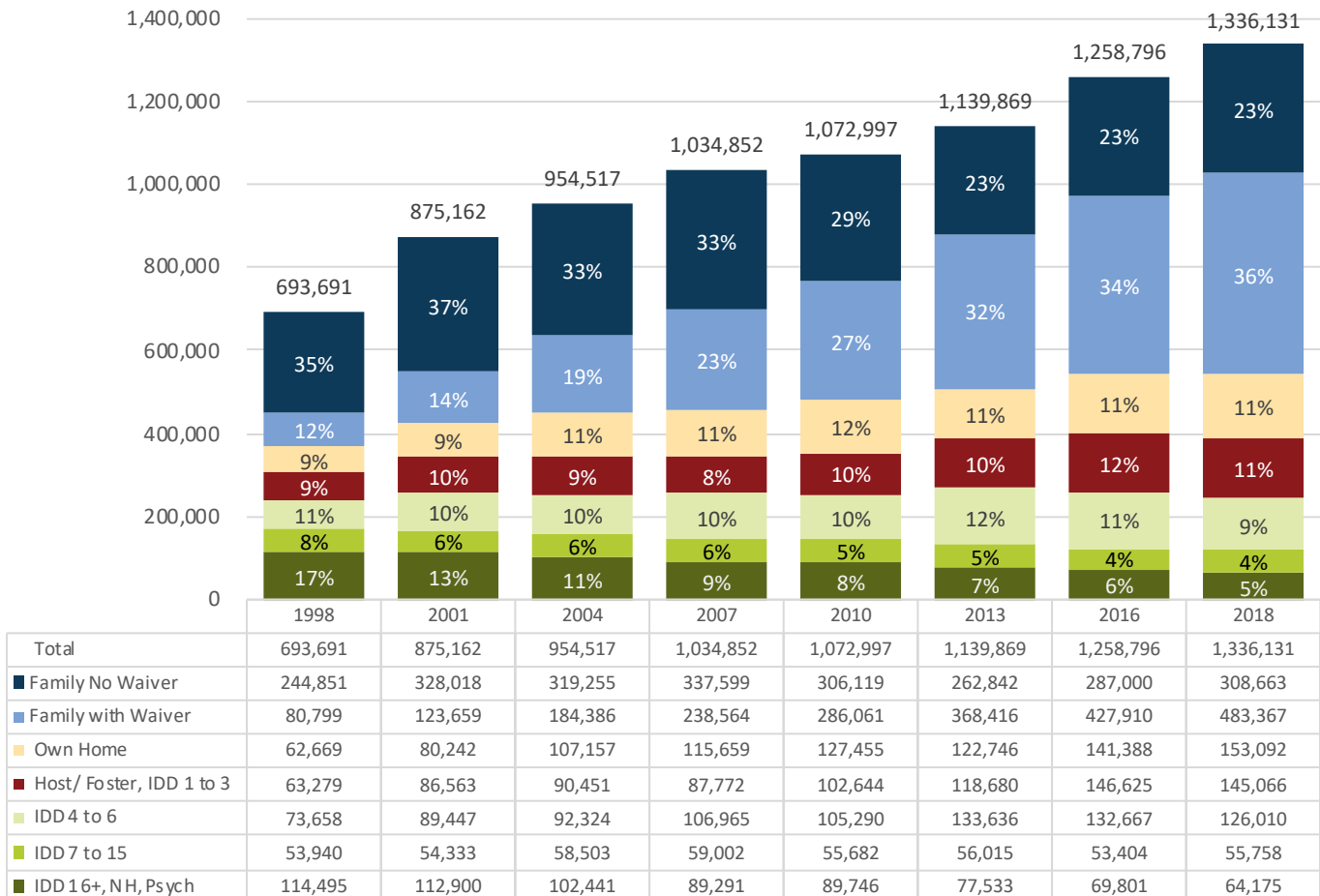
TRENDS IN TYPES OF LIVING ARRANGEMENTS

Data on the size of non-family residential settings for people with IDD have been collected since 1977 but annual data on people living in the home of a family member, in their own home or in a host/foster family home has only been collected since 1998. Including people with IDD living in nursing

Family Home

The number of LTSS recipients with IDD who lived in the home of a family member increased by 143% from 325,650 in 1998 to 792,030 in 2018. The proportion of LTSS recipients who lived with a family member increased from 47% to 59%. The proportion LTSS recipients living with a family member who received Medicaid Waiver funded supports increased from 25% in 1998 to 61% in 2018.

Figure 3.1 Number and Percent of LTSS Recipients with IDD by Living Arrangement Type and Size: Select Years 1998 to 2018



IDD Intellectual or Developmental Disabilities, LTSS Long-term supports and services, NH Nursing home; Psych Psychiatric facility

Non-Family Settings

Between 1998 and 2018, the number of LTSS recipients with IDD living in settings other than the home of a family member increased 48% from 368,041 to 544,101 people. The number of LTSS recipients with IDD living in their own home increased by 144% from 62,669 (9% of recipients) in 1998 to 153,092 (11%) in 2018. Amongst those living in group homes, host or foster family homes, IDD institutions, nursing homes, or psychiatric facilities, the proportion who lived in settings of:

- 3 or fewer people increased 129% from 63,279 to 145,066 people,
- 4 to 6 people increased 71% from 73,658 to 126,010 people,
- 7 to 15 people increased 3% from 53,940 to 55,758 people, and
- 16 or more people declined 44% from 114,495 to 64,175 people.

The proportion of LTSS recipients living in settings of 7 or more people, including nursing homes or psychiatric settings declined from 23% in 1998 to just 9% in 2018.

TRENDS IN RESIDENCE SIZE AND TYPE OF OPERATION

The remainder of Section 3 focuses on trends in setting size, type of operation and funding authorities for LTSS recipients with IDD from 1977 or the first year a service was tracked through 2018. Trends related to people living in state-operated psychiatric facilities are covered in Section 4.

Tables 3.1 and **3.2** and **Figures 3.2** through **3.4** show changes in the size and type of operation of settings other than the home of a family member, nursing homes or psychiatric facilities in which LTSS recipients with IDD lived, and in the number of LTSS recipients in those settings.

Number of Facilities by Size and Type of Operation

Between 1977 and 2018, the number of non-family settings serving LTSS recipients with IDD increased more than 20-fold from 11,008 to 229,380 (See

Table 3.1). The number of non-family settings serving:

- 1 to 6 LTSS recipients increased 31-fold from 6,898 to 220,906,
- 7 to 15 LTSS recipients increased by 165% from 2,405 to 7,405, and
- 16 or more LTSS recipients decreased by 57% from 1,705 to 935.

Between 1977 and 2018, the proportion of non-family settings serving

- 1 to 6 LTSS recipients increased from 63% to 96%
- 7 to 15 LTSS recipients decreased from 22% to 3%
- 16+ LTSS recipients decreased from 15% to 0.4%

LTSS Recipients with IDD by Residence Size and Type of Operation

Between 1977 and 2018, the number of LTSS recipients living in settings other than the home of a family member more than doubled, increasing from 247,780 to 516,629 (See **Table 3.2**). The number of LTSS recipients with IDD living in settings serving

- 1 to 6 LTSS recipients increased 20.7-fold from 20,400 to 423,608
- 7 to 15 LTSS recipients increased 181% from 20,024 to 56,196
- 16 or more LTSS recipients decreased 4.7-fold from 207,356 to 36,825

Between 1977 and 2018, the proportion of LTSS recipients in non-family settings serving

- 1 to 6 LTSS recipients increased from 8% to 82%
- 7 to 15 LTSS recipients increased from 8% to 11%
- 16 or more LTSS recipients decreased from 84% to 7%

Between 1977 and 2018, the number of LTSS recipients with IDD living in state-operated IDD settings declined from 155,804 to 27,960 (See **Figure 3.2**). The number of LTSS recipients with IDD living in non-state settings increased from 91,976 to 488,669.

Between 1977 and 2018, the proportion of LTSS recipients living in non-state settings increased from 37% to 94%. The proportion in non-state settings serving

2018

- 1 to 6 LTSS recipients remained at 99%
- 7 to 15 LTSS recipients decreased from 95% to 91%
- 16 or more LTSS recipients doubled from 25% to 52% (See **Figure 3.3**).

Average Setting Size

The average number of LTSS recipients with IDD per setting declined from 22.5 people in 1977 to 2.3 people in 2018. The average number of people per non-state setting declined from 8.7 in 1977 to 2.2 in 2018. The average number of people per

state-operated setting declined from 335.1 in 1977 to 14.0 in 2018.

Trends in Type of Operation for IDD Settings of 16 or More People

Figure 3.4 highlights trends in the number of people with IDD living in state-operated and non-state IDD facilities serving 16 or more LTSS recipients with IDD and projects the number of people who will be living in those settings through 2037. The number of LTSS recipients with ID living in non-state settings of

Figure 3.2 People with IDD in Non-family LTSS Settings by Type of Operation on June 30 Selected Years

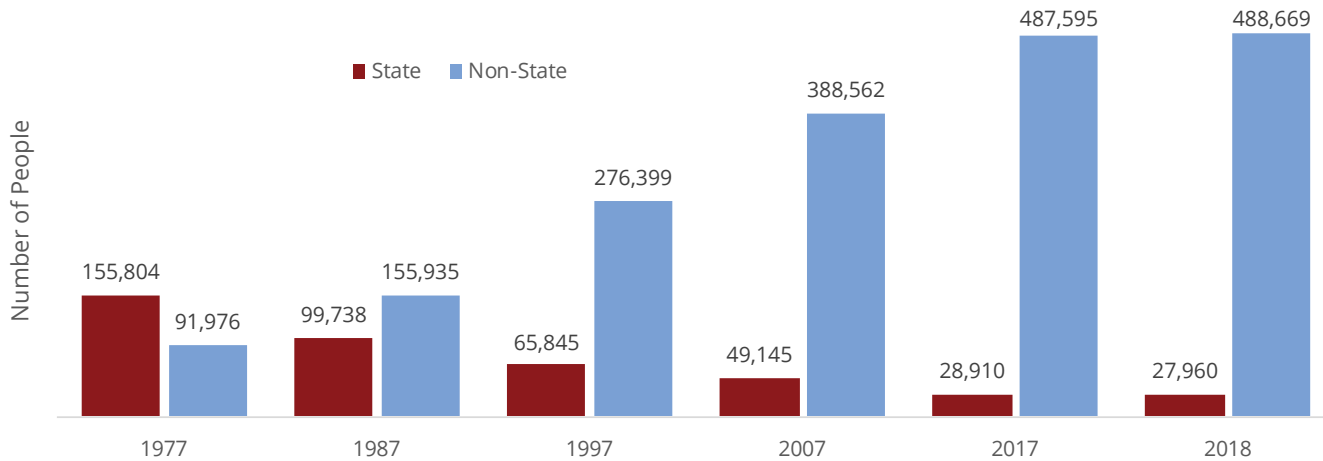


Figure 3.3 Proportion of People with IDD Living in IDD Settings of 16 or more people who live in Non-State Settings Selected Years 1977 to 2018

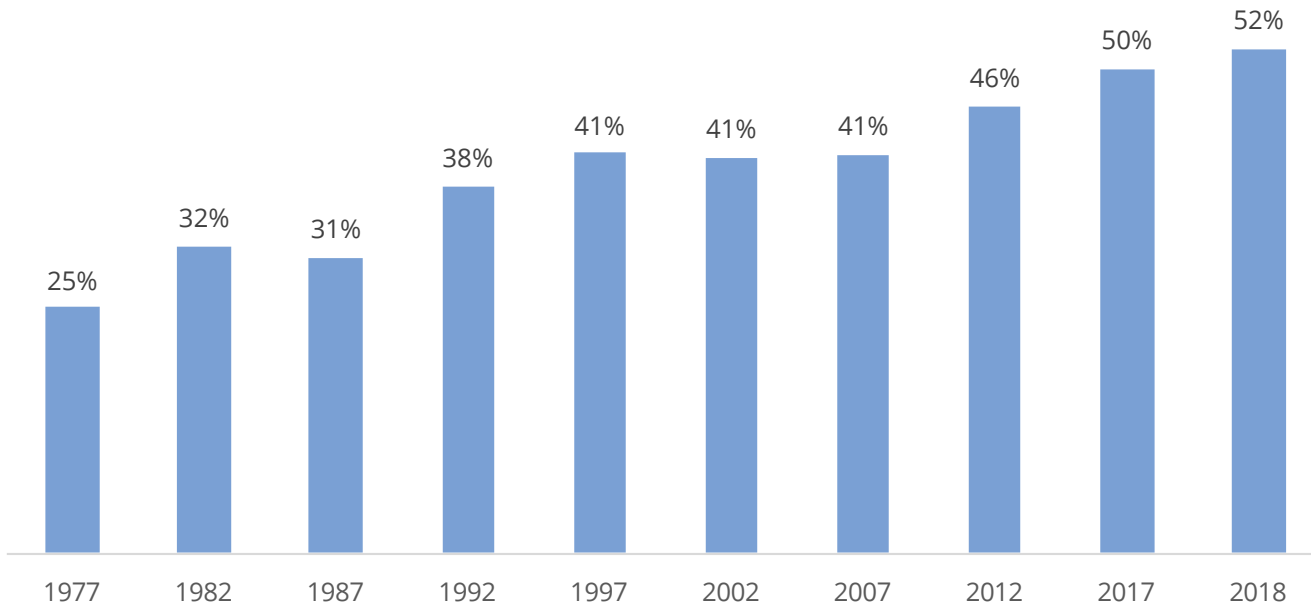
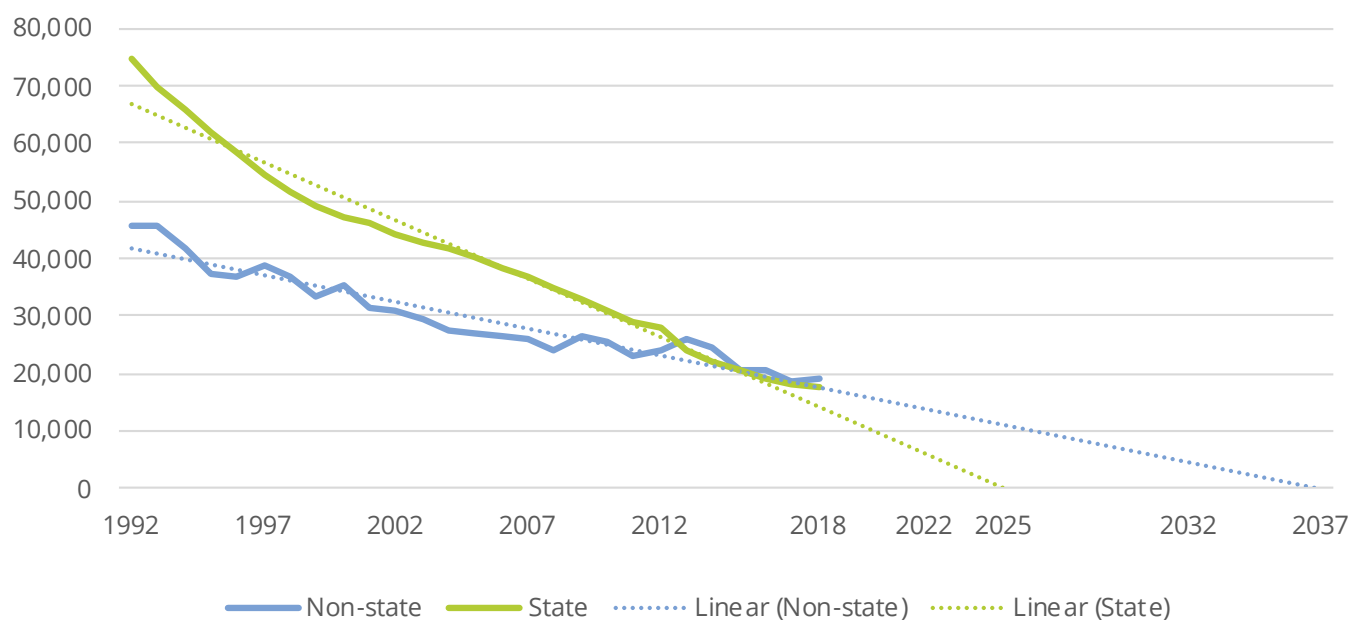




Figure 3.4 Number of LTSS Recipients with IDD in State-Operated and Non-State Settings of 16+ People 1992 to 2018 with Linear Projections to 2020



16 or more people dropped from 45,805 in 1992 to 18,268 in 2018 (a decrease of 26,537 people or 60%). The number of LTSS recipients with IDD in state-operated settings of 16 or more people dropped from 74,538 in 1992 to 17,557 in 2018 (a decrease of 56,981 people or 76%). At these rates of decline, there would no longer be any LTSS recipients with IDD in state-operated settings of 16 or more people by 2025, but it wouldn't be until 2037 that there would no longer be any people with IDD in non-state-operated IDD settings of 16 or more people, if current trends continue.

TRENDS IN MEDICAID RECIPIENTS AND EXPENDITURES

Total Medicaid expenditures for all populations grew from \$14.55 billion in 1980 to \$585.60 billion in 2018 (See **Table 3.3**). Medicaid ICF/IID and Waiver funding for people with IDD increased from \$1.74 billion in 1980 to \$49.47 billion in 2018. The proportion of Medicaid expenditures allocated to LTSS for people with IDD declined from 11.9% in 1980 to 8.4% in 2018.

Recipients

The number of people in ICF/IID settings peaked at 147,729 in 1993, but declined by 52% to 70,046 by 2018 (See **Figure 3.5a**). In 1982, there were 1,381 Medicaid Waiver recipients (1% of Medicaid Waiver plus ICF/IID LTSS recipients) and 140,752 people (99%) in an ICF/ IID. By June 30, 2018, the number of Medicaid Waiver recipients had grown to 879,062 (92% of Medicaid Waiver plus ICF/IID recipients) compared with 70,046 people in ICF/IID settings.

Expenditures

In 1982, Medicaid ICF/IID expenditures were \$3.35 billion (99.9% of combined expenditures) while Medicaid Waiver expenditures for people with IDD were \$2.24 million (See **Figure 3.5b**). By 2001, annual Medicaid Waiver expenditures exceeded annual ICF/IID expenditures (\$11.0 billion compared with \$10.35 billion). In 2018, annual Medicaid Waiver expenditures were \$42.14 billion (80% of combined expenditures) compared to \$9.64 billion for ICF/IID.

Annual per Recipient Costs

The average annual per person costs have always been higher for people in ICF/IID settings than for Medicaid Waiver recipients with IDD (See **Figure 3.5c**). In 1982, average annual per recipient expenditures were \$1,624 for Medicaid Waiver recipients (\$4,224 in 2018 inflation adjusted dollars) and \$23,806 for people in ICF/IID settings (\$61,895 in 2018 inflation adjusted dollars). In 2018, average annual per-recipient expenditures had increased to \$47,657 for Medicaid Waiver recipients and to \$137,560 for people in ICF/IID settings. In both real and inflation adjusted dollars the average annual per person expenditures for people in ICF/IID has declined since it peaked in 2010. This is likely heavily influenced by the continued closure of high cost state-operated ICF/IID facilities (The number of state operated facilities with 16 or more people declined from 203 in 2010 to 121 in 2018).

Table 3.3 Medicaid Expenditures for ICF/IID and Waiver Recipients with IDD as a Proportion of All Medicaid Expenditures Select Years 1980 to 2018

Fiscal Year	Total Medicaid Expenditures (Billions)	Medicaid ICF/IID and Waiver Expenditures for Persons with IDD (Billions)*	Proportion of Total Expenditures for People with IDD (%)
1980	\$14.55	\$1.74	11.9%
1988	\$30.46	\$3.65	12.0%
1992	\$64.00	\$5.78	9.0%
1994	\$136.64	\$12.19	8.9%
1996	\$154.16	\$14.45	9.3%
1998	\$167.67	\$16.97	10.2%
2000	\$194.35	\$19.57	9.5%
2002	\$243.50	\$23.85	9.9%
2004	\$285.71	\$27.44	9.7%
2006	\$299.02	\$30.89	10.3%
2008	\$337.08	\$34.27	10.3%
2010	\$391.72	\$41.85	10.7%
2011	\$414.50	\$40.68	9.8%
2012 ¹	\$419.83	\$42.62	10.2%
2013 ²	\$437.67	\$42.21	9.6%
2014 ²	\$480.04	\$41.71	8.7%
2015 ²	\$527.08	\$44.37	8.4%
2016 ²	\$549.31	\$45.98	8.4%
2017 ³	\$576.64	\$48.46	8.4%
2018 ⁴	\$585.60	\$51.93	8.9%

* RISP data 1 Source: Eiken et al (2017). 2 Source: Eiken et al. (2018), www.medicaid.gov/medicaid/tss/reports-and-evaluations/ 3 Source: <https://www.kff.org/medicaid/state-indicator/total-medicaid-spending/> Medicaid Waiver authorities include 1115, 1915 (a), 1915 (a/c), 1915 (b), 1915 (b/c) and 1915 (c). 4 Source: MACPAC (2019), MACStats: Medicaid and CHIP Data Book

Figure 3.5a Medicaid ICF/IID and HCBS Waiver Recipients with IDD from 1982 to 2018

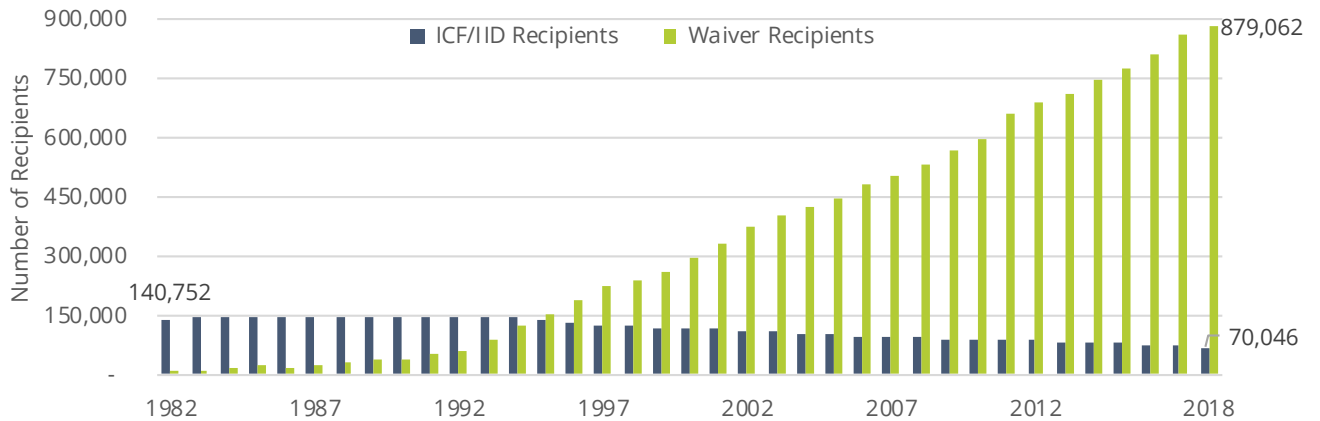


Figure 3.5b Medicaid ICF/IID and HCBS Waiver Expenditures in Billions for People with IDD from 1982 to 2018

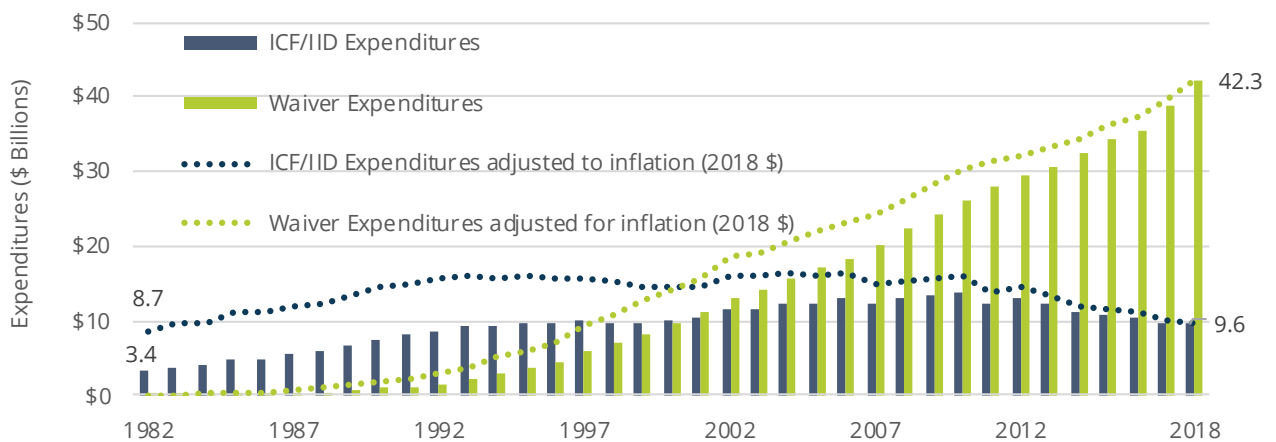
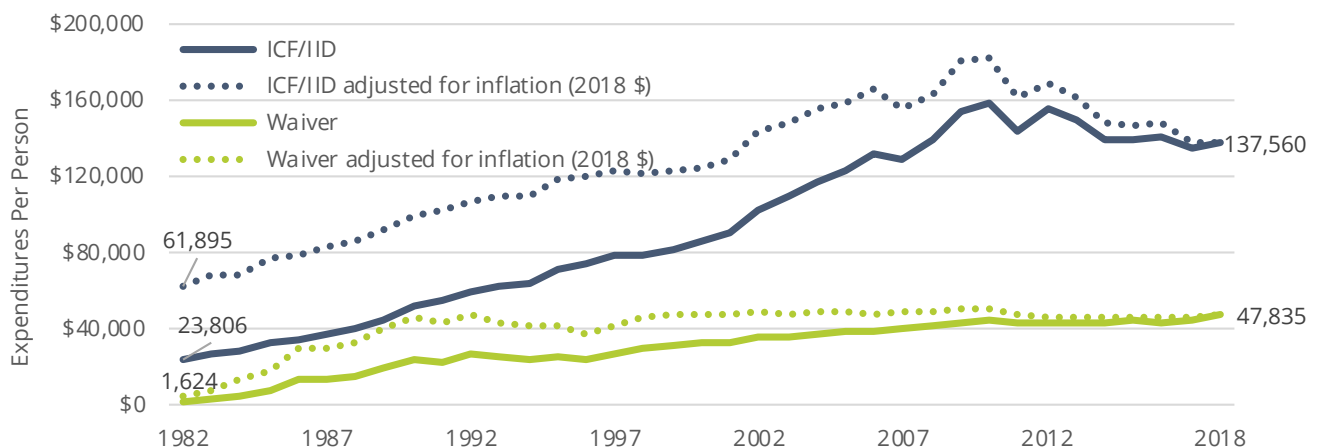


Figure 3.5c Average Annual per Person ICF/IID and Waiver Expenditures for People with IDD from 1982 to 2018



Medicaid Participants and Expenditures by State

Tables 3.4 through **3.7** show trends in Medicaid Waiver and ICF/IID participants and expenditures by state for selected years 1982 to 2018. Data from each state for all available years can be viewed at the RISP website in the Chart Gallery.

Medicaid HCBS Waiver

In 1982, two states offered supports to people with IDD funded by a Medicaid Waiver authority. By 2018, all 51 states offered supports funded by a Medicaid Waiver authority. The number of recipients grew from 1,381 in 1982 to 850,211 in 2012. Between 2012 and 2018, the total number of Medicaid Waiver recipients with IDD increased from 688,410 to 879,062, an increase of 28% (See **Table 3.4**). Between those years the number of Medicaid Waiver recipients grew in every state except Alabama (which reported a decrease from 5,604 to 3,895; -31%), and Georgia (which reported a decrease from 11,621 to 8,579; -26%). States reporting the greatest percentage growth in Medicaid Waiver recipients were Idaho (growing by 210% from 2,660 to 8,234 recipients), Indiana (growing by 112% from 12,786 to 27,117 recipients), and North Carolina (growing by 160% from 12,800 to 33,241).

Between 2012 and 2018, total Medicaid Waiver expenditures increased from \$29.54 billion to \$42.14 billion, an increase of 43% (See **Table 3.5**). Four states posted increases of 100% or more in Medicaid Waiver Expenditures between 2012 and 2018. Those states were Idaho (increasing 294% from \$64.4 million to \$254 million), Michigan (increasing 345% from \$446 million to \$1.98 billion) Mississippi (increasing 161% from \$44.0 million to \$115 million), and North Carolina (increasing 104% from \$620 million to \$1.26 billion).

Medicaid Waiver expenditures declined between 2012 and 2018 in Oregon (declining from \$598 million to \$143 million as the state shifted from HCBS Waiver to state plan HCBS funding), and West Virginia (declining from \$303 million to \$149 million).

Medicaid ICF/IID

Overall, between 2012 and 2018 the number of people with IDD living in ICF/IID facilities declined 18% from 85,384 to 70,046 people with 41 states reporting declines (See **Table 3.6**). States reporting the largest declines were Montana (declining from 89% from 55 to 6 people), New Jersey (declining 43% from 2,426 to 1,385), Virginia (declining 48% from 1,326 to 693), and Wisconsin (declining 42% from 895 to 519).

Nine states reported increases in the total number of ICF/IID recipients between 2012 and 2018. The largest increases were reported in Kentucky (increasing 41% from 523 to 735 people), Maryland (increasing 76% from 54 to 95), New Mexico (increasing 21% from 234 to 283), and Washington (increasing 11% from 629 to 700).

Total Medicaid ICF/IID expenditures declined 28% overall between 2012 and 2018 from \$12.9 billion to \$9.3 billion (See **Table 3.7**). ICF/IID expenditures decreased in 31 states with the largest decreases in Alabama (decreasing 81% from \$10.6 million to \$2.0 million), Arizona (decreasing 96% from \$32.6 million to \$1.2 million), New York (decreasing 71% from \$3.38 billion to \$965 million), and West Virginia (decreasing 99% from \$64.4 million to \$834,000).

Eighteen states reported increases in ICF/IID expenditures between 2012 and 2018. States reporting the largest increases were Delaware (increasing 90% from \$17 million to \$33 million), the District of Columbia (increasing 28% from \$69 million to \$89 million), and Washington (increasing 124% from \$106 million to \$238 million). Maryland also appeared to have a very large increase in ICF/IID expenditures but their 2012 total may have not included all claims.

Other historical trends for states can be viewed in the state profiles at the end of this report (See Section 5). Interactive visualizations on the RISP project website show Medicaid Waiver and ICF/IID recipients, expenditures and expenditures per person for each state for all available years (See <https://risp.umn.edu/viz>).

Table 3.4 Estimated Medicaid Waiver Recipients with IDD by State on June 30th Selected Years, 1982 to 2018

State	1982	1987	1992	1997	2002	2007	2012	2017	2018	% Change 2012 vs 2018
AL	0	1,570	2,184	3,713	4,764	5,230	5,604	5,622	3,895	-30%
AK	0	0	0	353	884	1,011	1,703	2,093	2,167	27%
AZ	0	0	4,832	8,508	13,471	19,066	24,617	30,982	33,154	35%
AR	0	0	415	496	2,494	3,342	4,037	4,138	4,365	8%
CA	0	3,027	3,360	37,478	44,205	73,024	97,868	124,081	117,014	20%
CO	0	1,389	2,204	4,276	6,516	7,148	8,147	12,184	12,657	55%
CT	0	0	1,693	3,371	5,972	7,692	8,638	9,979	9,885	14%
DE	0	81	290	379	547	788	855	4,364	1,211	42%
DC	0	0	0	0	225	1,090	1,479	1,796	2,027	37%
FL	0	2,631	2,637	11,399	25,921	31,425	29,353	33,812	34,556	18%
GA	0	0	359	2,332	8,190	9,194	11,621	8,579	8,579	-26%
HI	0	56	452	560	1,560	2,481	2,544	2,367	2,832	11%
ID	0	55	225	434	1,139	2,015	2,660	8,113	8,234	210%
IL	0	664	2,006	5,400	6,787	12,800	18,355	22,810	23,138	26%
IN	0	0	0	1,067	3,802	9,976	12,786	25,099	27,117	112%
IA	0	4	137	3,932	6,228	12,751	11,359	12,716	13,214	16%
KS	0	135	555	3,872	6,239	7,195	8,274	8,891	9,124	10%
KY	0	609	819	1,040	1,807	3,033	11,046	17,392	15,134	37%
LA	0	0	939	2,048	4,232	6,915	9,957	12,085	12,540	26%
ME	0	400	509	1,078	2,440	2,781	4,101	4,948	5,229	28%
MD	0	685	1,972	3,392	6,768	10,294	12,489	15,283	15,224	22%
MA	0	593	3,288	8,027	11,315	11,962	11,987	15,354	16,381	37%
MI	0	3	2,741	6,199	8,550	8,089	39,838	45,115	49,589	24%
MN	0	1,423	2,890	6,097	14,735	14,593	18,963	21,792	21,792	15%
MS	0	0	0	231	1,673	1,978	1,831	2,690	2,638	44%
MO	0	0	2,241	6,282	8,143	8,396	11,041	14,152	14,723	33%
MT	21	210	444	891	1,452	2,242	2,668	2,796	2,740	3%
NE	0	0	710	2,010	2,419	3,304	4,531	4,592	4,666	3%
NV	0	129	136	374	1,083	1,372	1,652	2,152	2,219	34%
NH	0	541	1,059	2,063	2,779	3,339	4,519	5,387	6,442	43%
NJ	0	2,596	3,971	5,705	7,486	9,923	11,297	11,874	15,636	38%
NM	0	220	334	1,603	2,794	3,711	4,115	4,616	4,624	12%
NY	0	0	379	29,019	48,165	56,401	77,047	82,656	85,055	10%
NC	0	328	939	3,726	6,013	9,309	12,800	21,786	33,241	160%
ND	0	724	1,334	1,792	2,011	3,535	4,059	4,956	4,908	21%
OH	0	100	397	2,646	7,858	16,362	30,872	39,180	40,202	30%
OK	0	70	949	2,497	4,100	5,308	5,223	5,625	5,625	8%
OR	1,360	832	1,458	2,586	8,017	10,287	14,865	21,200	24,140	62%
PA	0	1,203	2,705	8,931	24,969	26,558	29,963	34,911	35,874	20%
RI	0	136	993	2,178	2,674	3,126	3,316	4,354	3,738	13%
SC	0	0	471	3,412	4,410	5,186	8,394	10,929	10,759	28%
SD	0	596	852	1,457	2,295	2,609	3,215	3,625	3,625	13%
TN	0	213	704	3,293	4,340	7,244	7,680	8,137	7,835	2%
TX	0	70	968	4,753	7,873	16,301	29,193	37,582	39,285	35%
UT	0	0	1,367	2,315	3,589	4,003	4,319	4,960	5,285	22%
VT	0	196	413	1,372	1,844	2,200	2,649	3,070	3,166	20%
VA	0	0	537	1,764	5,491	7,523	9,754	12,511	13,100	34%
WA	0	886	1,918	6,643	9,900	9,317	11,898	16,900	17,671	49%
WV	0	124	513	1,441	2,796	3,852	4,447	4,514	4,634	4%
WI	0	190	1,812	6,558	9,474	12,504	23,396	33,060	35,779	53%
WY	0	0	318	916	1,507	2,079	2,150	2,401	2,394	11%
Estimated US Total	1,381	22,689	62,429	221,909	373,946	501,864	688,410	850,211	879,062	28%
N States	2	35	47	50	51	51	51	51	51	51

Data for all years since 1982 can be viewed in the Chart Gallery Section of the RISP.umn.edu website. Medicaid Waiver authorities include 1115, 1915 (a), 1915 (a/c), 1915 (b), 1915 (b/c) and 1915 (c).

Table 3.5 Estimated Medicaid Waiver Expenditures (in \$1,000s) for People with IDD by State Selected Years 1982 to 2018

State	1982	1987	1992	1997	2002	2007	2012	2017	2018	% change 2012-2018
AL	0	\$8,326	\$12,400	\$72,327	\$120,395	\$253,259	\$288,701	\$380,161	\$362,746	26%
AK	0	0	0	17,668	51,866	70,955	134,516	176,258	187,000	39%
AZ	0	0	98,716	203,898	386,529	556,450	640,785	982,473	1,101,033	72%
AR	0	0	11,250	12,063	53,077	91,380	173,135	225,030	237,513	37%
CA	0	30,400	54,049	355,246	853,788	1,532,880	2,107,489	3,383,876	3,391,877	61%
CO	0	25,455	60,192	133,282	205,028	268,080	331,010	453,993	482,569	46%
CT	0	7	83,575	222,364	386,547	454,125	720,878	929,152	959,340	33%
DE	0	846	5,105	16,279	34,181	75,090	94,329	135,182	142,550	51%
DC	0	0	0	0	1,648	19,678	147,196	218,864	238,618	62%
FL	0	12,850	20,246	131,805	496,921	908,572	879,855	1,004,430	1,068,863	21%
GA	0	0	10,250	63,130	286,390	263,542	407,212	356,495	647,325 [†]	59%
HI	0	565	4,385	11,721	34,728	97,000	102,910	102,074 [‡]	121,835	18%
ID	0	568	1,188	9,996	27,804	60,937	64,425	249,874	253,914	294%
IL	0	12,840	79,600	116,000	140,200	416,200	591,460	923,395	955,156	61%
IN	0	0	0	33,301	198,630	402,597	489,971	741,069	645,274	32%
IA	0	0	774	48,271	127,081	275,728	387,580	565,174	573,760	48%
KS	0	638	13,737	93,519	189,358	247,334	330,269	489,936	522,395	58%
KY	0	10,974	19,821	29,430	91,756	163,060	406,429	655,991	665,582	64%
LA	0	0	1,785	44,291	129,015	258,220	407,248	473,862	472,033	16%
ME	0	5,674	13,250	60,067	136,461	230,661	291,071	346,241	381,553	31%
MD	0	21,708	72,327	140,673	251,357	495,386	686,894	1,003,268	1,061,513	55%
MA	0	13,278	90,000	280,000	483,391	587,453	876,814	1,483,297	1,515,881	73%
MI	0	80	81,039	162,809	538,109	316,274	445,712	DNF	1,983,102 [‡]	345%
MN	0	13,170	95,381	260,223	699,687	889,902	1,215,081	1,554,310	1,554,310	28%
MS	0	0	0	631	20,699	39,461	43,976	94,711	114,590	161%
MO	0	0	65,792	154,768	235,897	379,435	533,967	889,123	923,876	73%
MT	375	3,596	10,827	22,500	42,005	68,412	90,871	114,648	113,620	25%
NE	0	0	25,522	58,901	108,402	140,172	239,921	291,120	298,298	24%
NV	0	1,489	2,400	4,877	24,367	61,585	78,767	104,967	114,343	45%
NH	0	13,518	44,400	89,427	117,922	143,209	192,025	DNF	264,074 [‡]	38%
NJ	0	35,888	108,601	180,006	402,988	496,612	737,871	1,047,873	1,206,524	64%
NM	0	1,410	8,829	46,295	157,256	247,597	285,949	356,141	372,764	30%
NY	0	712	34,496	1,114,423	2,125,806	3,449,069	5,468,225	5,615,944	5,943,273	9%
NC	0	3,059	13,833	106,199	254,337	377,747	619,805	1,063,758	1,262,953	104%
ND	0	5,438	18,975	30,176	47,531	71,823	129,617	199,935	194,815 [‡]	50%
OH	0	1,131	12,824	90,058	245,009	660,978	1,240,863	1,635,258	1,750,098	41%
OK	0	392	39,375	93,593	222,356	253,401	273,952	310,647	310,647	13%
OR	1,869	8,306	58,604	105,178	361,705	385,762	597,868	90,153	143,198	-76%
PA	0	35,975	133,681	415,399	977,487	1,199,739	1,816,306	2,705,916	3,129,240	72%
RI	0	5,648	14,367	107,962	160,859	245,521	203,663	209,184	242,805	19%
SC	0	0	4,961	51,300	142,500	185,700	291,243	329,786	346,471	19%
SD	0	6,153	16,257	38,739	58,935	81,945	101,739	115,968	115,968	14%
TN	0	1,853	14,431	72,738	205,314	525,964	604,098	682,075	684,445	13%
TX	0	1,828	39,755	159,896	321,671	566,475	1,058,827	1,515,458	1,544,336	46%
UT	0	0	23,000	50,794	88,991	113,867	155,515	244,217	263,698	70%
VT	0	4,840	14,154	47,980	74,856	109,071	141,617	198,042	214,158	51%
VA	0	0	15,975	67,430	198,911	394,326	602,412	821,443	911,721 [‡]	51%
WA	0	12,068	39,974	105,006	214,490	315,624	550,896	56,035	560,798	2%
WV	0	777	13,200	43,660	120,218	203,371	303,862	DNF	304,222 [‡]	0%
WI	0	3,503	39,078	155,238	312,785	439,299	855,374	1,222,445	1,338,173	56%
WY	0	0	12,508	33,428	56,957	87,041	98,497	92,449	97,827	-1%
Estimated US Total	2,243	304,961	1,654,887	5,964,966	13,224,202	20,177,966	29,538,694	36,841,697	42,292,677	43%
N States	2	36	47	50	51	51	51	51	51	51

Data for all years 1982 to 2016 can be viewed in the Chart Gallery of the RISP.umn.edu website. [‡] Other date (data from previous or next year). [†] Estimate. [‡] One or more component value imputed by RISP staff. DNF Did not furnish. [§] Source: (Eiken et al., 2018). Medicaid Waiver authorities include 1115, 1915 (a), 1915 (a/c), 1915 (b), 1915 (b/c) and 1915 (c).



Table 3.6 Estimated ICF/IID Recipients by State, Selected Years 1982 to 2018

State	1977	1982	1987	1992	1997	2002	2007	2012	2017	2018	% change 2012-2018
AL	0	1,470	1,364	1,304	745	472	244	41	22	25	-39%
AK	135	118	107	86	10	0	0	0	7	14	N/A
AZ	0	0	0	214	214	207	185	148	139	140 ⁱ	-5%
AR	1,385	1,420	1,453	1,737	1,558	1,684	1,616	1,467	1,425	1,435	-2%
CA	0	10,374	10,871	10,923	10,681	10,839	9,598	8,726	7,602	7,101 ⁱ	-19%
CO	4,537	2,017	1,149	754	229	111	125	343	189	203	-41%
CT	687	1,598	1,414	1,378	1,377	1,192	1,148	993	741	707	-29%
DE	477	513	439	325	292	241	141	135	118	120	-11%
DC	0	436	666	761	754	734	640	363	332	309 ⁱ	-15%
FL	370	2,128	3,180	3,118	3,476	3,338	3,205	2,806	2,774 ^s	2,700	-4%
GA	2,369	2,491	1,913	1,935	1,770	1,475	1,034	300	275 ^s	275 ⁱ	-8%
HI	524	387	296	154	122	94	78	79	79	73	-8%
ID	583	482	461	519	579	576	543	487	455 ^s	444 ⁱ	-9%
IL	5,353	8,144	10,346	12,311	10,500	9,923	9,213	8,344	6,653	6,548	-22%
IN	1,026	2,798	4,690	6,234	5,938	4,981	4,012	3,839	3,179	3,159	-18%
IA	1,432	1,673	1,840	2,088	2,268	2,157	2,123	2,002	1,708	1,441 ⁱ	-28%
KS	1,810	2,078	2,081	1,921	1,395	688	599	509	433	440	-14%
KY	999	1,250	1,187	1,200	1,180	876	637	523	422	735 ⁱ	41%
LA	3,682	4,849	6,016	5,645	6,014	5,539	5,320	4,604	4,443 ^{si}	4,653	1%
ME	310	630	677	630	548	246	222	202	200	196	-3%
MD	1,367	1,851	1,429	954	624	502	336	54	92	95	76%
MA	4,242	4,041	3,698	3,304	1,598	1,125	952	594	396	385 ⁱ	-35%
MI	5,760	4,002	3,683	3,180	2,899	173	151	0	0 ^s	0	N/A
MN	5,303	6,899	6,339	5,202	3,604	2,756	2,513	1,719	1,441 ⁱ	1,441	-16%
MS	491	1,614	1,678	1,825	2,256	2,534	2,601	2,765	1,486	2,125 ⁱ	-23%
MO	2,051	1,878	1,868	1,751	1,466	1,398	1,020	590	424	406	-31%
MT	0	290	253	170	148	119	54	55	14	6 ⁱ	-89%
NE	1,356	980	808	739	643	642	582	433	374	382	-12%
NV	0	175	188	146	275	242	118	104	91	84	-19%
NH	288	339	204	81	23	25	25	25	23 ⁱ	20 ⁱ	-20%
NJ	525	4,366	3,815	3,942	3,948	3,370	2,963	2,426	1,402	1,385 ⁱ	-43%
NM	426	553	709	730	348	284	182	234	254 ^s	283	21%
NY	18,601	15,577	17,567	18,497	11,472	9,815	7,995	7,288	5,742	5,110	-30%
NC	2,073	2,762	3,445	4,502	4,777	4,645	4,124	3,930	3,510	3,979 ⁱ	1%
ND	0	219	888	476	609	629	593	559	470	528 ⁱ	-6%
OH	2,488	6,040	7,535	8,384	7,615	7,240	6,667	6,926	5,814	5,370	-22%
OK	1,978	1,803	3,242	2,776	2,292	2,243	1,630	1,549	1,386 ^s	1,416 ⁱ	-9%
OR	1,989	1,918	1,284	668	373	51	41	0	0	0	N/A
PA	7,355	8,598	7,364	7,282	6,192	4,280	3,833	3,419	2,851	2,751	-20%
RI	763	881	1,093	602	21	40	41	42	8	37 ⁱ	-12%
SC	1,017	2,665	3,300	3,261	2,555	1,992	1,615	1,313	1,158	1,171	-11%
SD	540	721	650	552	328	189	158	199	192	176 ⁱ	-12%
TN	2,149	2,377	2,198	2,399	1,900	1,460	1,223	1,108	1,051	1,034	-7%
TX	10,486	13,959	12,211	11,187	12,985	12,684	11,447	9,467	8,590	7,872 ⁱ	-17%
UT	1,193	1,199	945	930	833	783	794	801	190	778 ⁱ	-3%
VT	352	385	238	146	12	12	6	6	6	6	0%
VA	3,558	3,616	3,018	2,743	2,225	1,885	1,684	1,326	801 ^s	693 ^e	-48%
WA	440	2,464	2,539	1,695	1,126	880	767	629	750	700 ⁱ	11%
WV	0	176	417	699	574	515	477	562	514 ^d	517	-8%
WI	3,696	3,548	3,378	4,110	3,187	2,580	1,059	895	923	519 ⁱ	-42%
WY	0	0	0	90	139	106	93	79	73	59 ⁱ	-25%
Estimated US Total	106,166	140,752	146,134	146,260	126,697	110,572	96,427	85,384	71,222	70,046	-18%
N States	42	49	49	51	51	50	50	48	49	49	50

Data for all available years available in the Chart Gallery Section of the RISP.umn.edu website. ^b Non-State only. ^c State only. ^d Other date (data from previous or next year). ^e Estimate. ^s Sum of setting data substituted for reported value. ⁱ One or more component value imputed by RISP staff. ^{si} Source: ACHA (2018a); Eiken, et al (2018). DNF Did not furnish. PD Partial Data. *See state notes in Appendix.

Table 3.7 Estimated Medicaid ICF/IID Expenditures (in \$1,000s) by State, Selected Years 1982 to 2018

State	1982	1988	1992	1997	2002	2007	2012	2017	2018	% change 2012-2018
AL	\$31,076	\$54,014	\$80,701	\$58,306	\$60,516	\$31,522	\$10,586	\$1,990 ^e	\$2,033 ^s	-81%
AK	6,830	9,038	10,384	2,032	0	161	3,051	2,736	2,617	-14%
AZ	0	0	0	0	0	0	32,593	1,336 ⁱ	1,221	-96%
AR	34,603	51,087	88,047	105,950	28,958	146,960	168,540	DNF	171,345 ^s	2%
CA	87,544	269,638	316,072	380,655	663,954	824,990	821,840	696,318	654,499	-20%
CO	-1,194	43,403	55,495	23,575	19,202	22,647	39,533	43,853	44,762	13%
CT	41,722	109,464	192,888	188,190	213,455	240,165	284,642	194,535	200,961	-29%
DE	8,281	15,246	26,543	31,233	31,219	26,647	17,462	32,392	33,174	90%
DC	7,350	40,108	51,774	74,258	79,480	85,051	69,494	92,289	89,216	28%
FL	48,048	130,435	181,802	248,208	310,393	319,288	328,460	331,591	331,591	1%
GA	48,271	84,730	115,391	127,303	110,659	105,885	67,117	DNF	33,587 ^s	-50%
HI	10,962	14,290	6,571	11,628	8,572	8,683	7,715	4,437	8,324	8%
ID	12,490	23,130	35,545	43,454	57,714	59,702	23,064	DNF	8,376	-64%
IL	120,855	243,824	499,573	580,152	720,932	696,183	688,115	586,802	613,172	-11%
IN	37,326	86,777	272,735	304,187	338,947	318,531	294,064	269,363	270,721	-8%
IA	52,267	88,710	150,456	178,213	192,996	276,651	301,739	206,347	231,887	-23%
KS	40,647	69,568	102,523	94,468	65,863	65,288	64,412	40,556	41,086	-36%
KY	39,053	47,597	59,843	75,691	97,888	151,886	130,481	147,232	142,187	9%
LA	97,076	165,291	260,925	422,009	362,343	442,023	467,517	352,396	342,022	-27%
ME	15,699	30,613	62,854	45,548	50,370	71,664	74,915	40,200	41,484	-45%
MD	53,170	83,621	65,023	63,699	61,628	68,466	123	25,780	31,087	25167%
MA	125,500	198,722	385,149	254,062	198,023	206,612	165,995	97,514	97,484	-41%
MI	152,838	213,105	180,561	519,144	27,648	28,824	0	0 ⁱ	0	N/A
MN	155,020	238,700	283,108	238,628	207,841	175,376	164,145	114,406 ⁱ	114,406	-30%
MS	20,579	32,524	62,156	119,386	178,043	255,287	270,287	196,141	189,902	-30%
MO	35,207	71,080	106,866	155,768	230,169	105,836	108,468	89,799	84,554	-22%
MT	0	10,179	13,124	15,809	14,061	10,632	11,320	5,759	DNF	DNF
NE	21,336	25,477	32,910	36,896	47,671	66,940	57,654	62,084	68,761	19%
NV	5,661	9,523	16,670	22,845	30,309	21,390	17,955	18,627	15,966	-11%
NH	6,339	14,142	6,127	1,299	1,953	2,522	3,154	DNF	DNF	DNF
NJ	122,552	237,997	276,342	373,077	462,969	628,421	650,873	461,199	448,782	-31%
NM	12,078	23,587	39,164	21,729	18,993	21,263	24,809	26,785	28,813	16%
NY	797,385	1,158,161	1,715,103	2,010,006	2,472,622	3,057,177	3,382,395	1,060,094	965,311	-71%
NC	79,192	158,440	278,485	363,153	416,623	466,789	444,383	398,948	377,780	-15%
ND	498	40,216	39,980	43,653	54,683	61,655	92,146	71,114	80,523	-13%
OH	36,634	278,624	468,322	391,631	962,507	697,689	757,788	716,348	671,977	-11%
OK	32,395	83,725	111,773	100,900	112,292	127,291	113,228	DNF	72,128 ^s	-36%
OR	5,287	73,727	83,138	75,273	11,346	22,407	0	0	0	N/A
PA	326,340	384,252	502,755	527,594	506,212	584,411	580,876	603,230	602,232	4%
RI	28,759	60,548	90,368	10,401	7,244	7,810	9,160	2,708	2,966	-68%
SC	36,020	94,198	165,299	174,750	174,843	157,180	150,914	140,018	140,057	-7%
SD	14,890	22,005	29,221	20,194	18,448	20,149	29,594	31,198	31,807 ^s	7%
TN	56,831	77,504	111,715	212,774	252,512	243,129	216,276	203,300	185,901	-14%
TX	233,539	357,823	468,605	640,849	811,722	906,152	1,047,598	1,113,101	1,185,871	13%
UT	23,711	27,666	39,659	45,047	54,883	58,134	63,278	40,106	39,603	-37%
VT	13,421	11,335	17,841	1,479	1,631	0	1,212	1,151	1,367	13%
VA	78,609	106,785	153,992	159,667	216,052	231,030	288,116	243,550	205,733 ^s	-29%
WA	72,202	119,320	182,045	128,968	127,817	114,854	106,120	192,150	237,685	124%
WV	1,982	8,662	15,031	52,705	47,513	57,354	65,414	DNF	834 ^e	-99%
WI	63,845	89,337	193,185	201,998	226,014	131,158	197,496	132,954	146,977	-26%
WY	0	0	2,556	17,778	15,543	20,007	20,745	18,713	23,218	12%
Estimated US Total	3,350,726	5,887,947	8,706,396	9,996,224	11,383,282	12,449,872	12,936,860	9,111,148	9,315,991	-28%
N States	48		49	50	51	50	51	50	50	50

^b Nonstate only. ^d Other date (data from previous or next year). ^e Estimate. DNF Did not furnish. PD Partial data. ^s Other Source (Eiken et al., 2017) Data for all states and available years can be viewed in the Chart Gallery at the RISP.umn.edu website.



SECTION FOUR

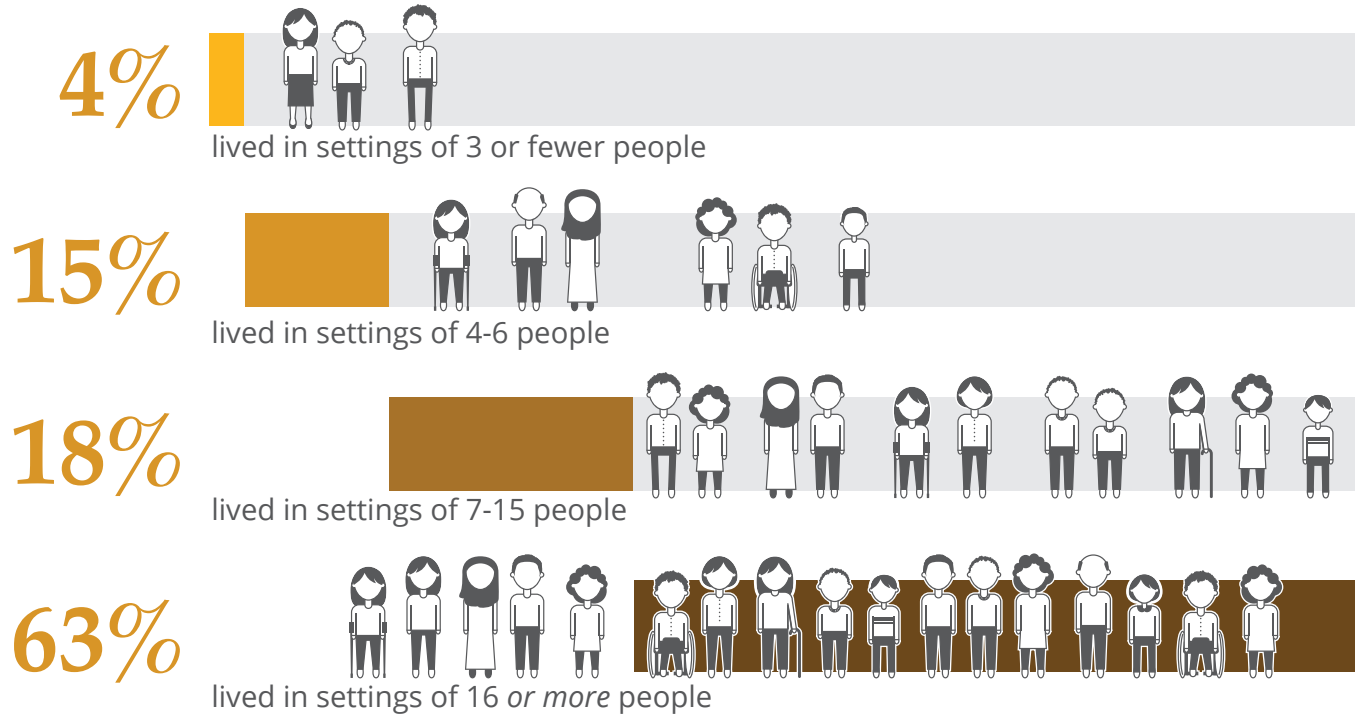
**STATUS AND TRENDS IN STATE-
OPERATED IDD FACILITIES SERVING 16
OR MORE PEOPLE**

FY 2018

2018

State-Operated Facilities Serving People with Intellectual or Developmental Disabilities on June 30, 2018

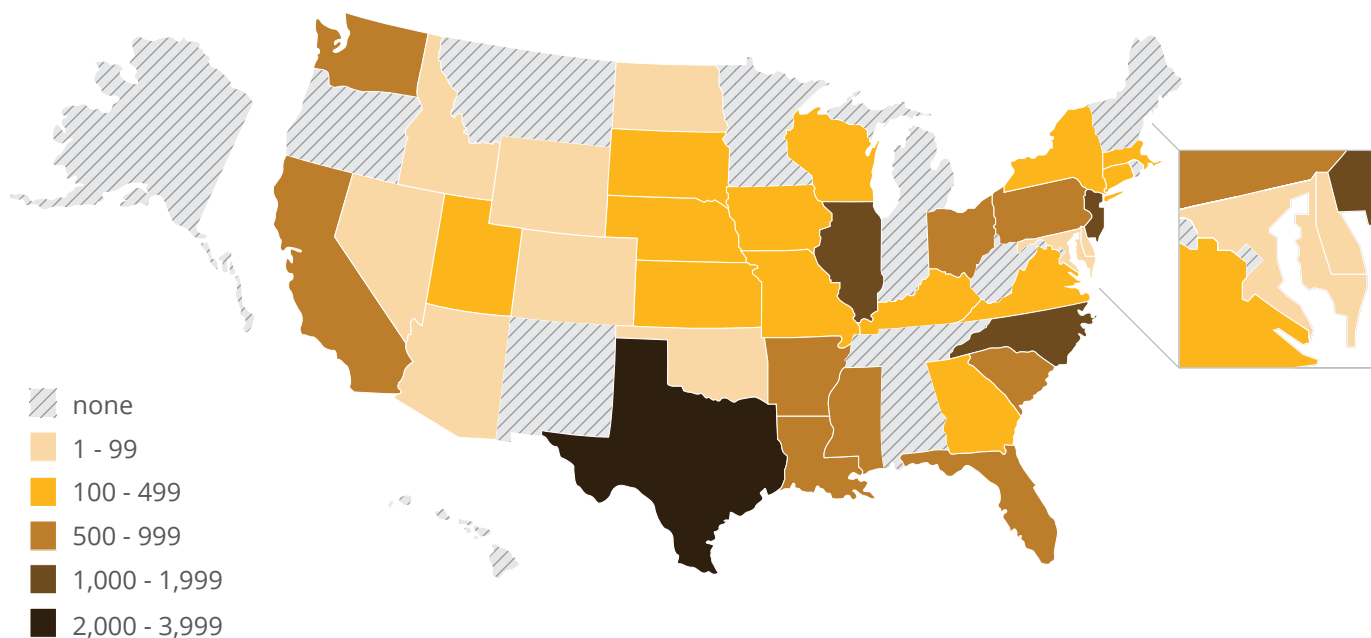
Of the 28,910 people with IDD living in state-operated settings,



Number of people in large public residential IDD facilities (PRFs)

In 1977, there were 154,638 people with IDD living in 327 large PRFs in every US state.

By 2018, there were 17,557 people with IDD living in 115 PRFs in 34 states.



SECTION 4: STATUS AND TRENDS IN LARGE STATE-OPERATED IDD FACILITIES

Section 4 describes the status of state-operated IDD facilities serving 16 or more people (Public Residential Facilities or PRFs) on June 30, 2018 and trends in utilization of PRFs. It describes trends in average daily and year-end populations, movement patterns (admissions, discharges, deaths and short-term admissions), resident characteristics, previous residence of PRF current residents, staff characteristics, and services provided to community residents.

This section also lists PRFs open on June 30, 2018, and PRFs that had closed, downsized to fewer than 15 residents, privatized or converted to a different purpose by June 30, 2018. By June 30, 2018, 17 states had closed, downsized, privatized or converted all of the PRFs that previously served people with IDD including: Alabama, Alaska, the District of Columbia, Hawaii, Indiana, Maine, Michigan, Minnesota, Montana, New Hampshire, New Mexico, Oklahoma, Oregon, Rhode Island, Tennessee, Vermont and West Virginia.

Tables 4.1, 4.10, 4.11, 4.12, 4.13, and 4.14, and Figures 4.6, 4.7, 4.8, 4.9, and 4.10 use data from the annual RISP survey of State IDD Agency Directors. The remaining tables and figures in Section 4 use data from the annual survey of administrators of large state-operated IDD facilities (PRF survey) fielded in with the cooperation of with the Association of Public and Private Developmental Disabilities Administrators (APDDA). 2018 PRF surveys were returned by one or more facility in all states except Arizona, Kansas, and South Carolina.

STATUS OF PUBLIC RESIDENTIAL FACILITIES (PRFS) SERVING 16 OR MORE PEOPLE WITH IDD

The average daily PRF population declined from 18,516 in 2017 to 17,596 people in FY 2018 (See **Table 4.1**). The June 30 population decreased from 18,239 to 17,557 between 2017 and 2018. The number of people living in PRFs increased between June 30, 2017 and June 30, 2018 in eight states: Arkansas (1%), Colorado (14%), Delaware (4%), Illinois (less than 1%), Kansas (1%), Louisiana (2%), Maryland (3%) and South Carolina (2%). Six states reported a decline of more than 10% in the number of residents including California (-33%),

Georgia (-17%), Kentucky (-54%), Nevada (-15%), South Dakota (-13%), and Virginia (-54%). Of the states with open PRFs, eight had fewer than 100 residents on June 30, 2018: Arizona (80), Colorado (49), Delaware (50), Idaho (23), Maryland (95), Nevada (41), North Dakota (68), and Wyoming (67).

Admissions

During FY 2018, an estimated 1,059 people were admitted or readmitted to PRFs for stays of more than 90 days (6% of the year's average daily population). More than 100 people were admitted or readmitted to PRFs in California (102), Florida (110), and Texas (154). Six states admitted more than 10% of their June 30, 2018 population including California (19%), Colorado (27%), Idaho (30%), Maryland (82%), Florida (16%), and Nevada (107%). Admissions do not include transfers from one PRF to another.

Discharges

An estimated 1,453 people were discharged from a PRF in 2018 (8% of the average daily population). More than 100 people were discharged from PRFs in California (360), Florida (101), Ohio (189), and Texas (117).

Deaths

An estimated 632 people with IDD (4% of the June 30 population) died while residing in a PRF in 2018. Three states reported more than 50 deaths in FY 2018 including: New Jersey (52), North Carolina (68), and Texas (87). Three states reported no deaths in FY 2018 (Delaware, Nevada, and South Dakota). Three states reported deaths of more than 6% of their June 30, 2018 population: Kentucky (10%), Colorado (8%), and Arizona (11%).

Short-Term Admissions

There were an estimated 576 short-term admissions (lasting fewer than 90 days) in FY 2018 (3% of the June 30 population). Fourteen states reported no short-term admissions in FY 2018. Two states reported more than 100 short-term admissions: Washington (131), Ohio (151).

Table 4.1 PRF Daily Population, Admissions, Discharges, Deaths and per Person Expenditures by State for Fiscal Year 2018

State	Average Daily Population	Admissions	Discharges	Deaths	June 30 Residents			Short -term Admissions	Average Daily Per Person ICF/IID Cost ¹
					2017	2018	1-Year % Change		
N States	49	49	47	48	50	51	51	47	30
AL	0	0	0	0	0	0	0%	0	N/A
AK	0	0	0	0	0	0	0%	0	N/A
AZ	83	5	0	9	84	80	-5%	0	N/A
AR	905	36	64	24	907	917	1%	52	404
CA	660	102	360	32	793	534 ^e	-33%	0	1,236
CO	24	13	8	4	43	49	14%	0	1,018
CT	361	0	15	16	375	347	-7%	1	1,327
DE	49	2	7	0	48	50	4%	7	1,306
DC	0	0	0	0	0	0	0%	0	N/A
FL	698	110	101	14	724	698	-4%	0	416
GA	DNF	DNF	DNF	DNF	210	175	-17%	0	DNF
HI	0	0	0	0	0	0	0%	0	N/A
ID	21	7	10	1	24	23	-4%	1	1,219
IL	1,662	97	62	31	1,660	1,664	0%	0	443
IN	0	0	0	0	0	0	0%	0	N/A
IA	346	14	8	11	351	346	-1%	0	911
KS	301	24	10	12	302 ^e	305	1%	0	444
KY	266 ⁱ	9 ^{ej}	5 ^{ej}	11 ^{ej}	245	112 ^{ej}	-54%	8	DNF
LA	509 ⁱ	41	42	16	510	519	2%	3	691
ME	0	0	0	0	0	0	0%	0	N/A
MD	94	78	76	5	92	95	3%	0	896 ^e
MA	379	5	18	18	396	385 ^{pd}	-3%	15	880
MI	0 ⁱ	0 ⁱ	0 ⁱ	0 ⁱ	0	0	0%	0	N/A
MN	0	0	0	0	0	0	0%	0	N/A
MS	964	34	46	26	938	899	-4%	23	343
MO	317	0	5	14	341	321	-6%	10	658
MT	0	0	0	0	0	0	0%	0	N/A
NE	109	7	1	4	109	109	0%	1	998
NV	45	44	51	0	48	41	-15%	0	694
NH	0	0	0	0	DNF	0	0%	0	N/A
NJ	1,362	0	25	52	1,402	1,325	-5%	DNF	965
NM	0	0	0	0	0	0	0%	0	N/A
NY	DNF	DNF	DNF	DNF	289	261	-10%	DNF	DNF
NC	1,205	47	27	68	1,323	1,280	-3%	84	692
ND	68	32	30	3	69	68	-1%	20	1,045
OH	660	41	189	30	675	650	-4%	151	662
OK	0	0	0	0	0	0	0%	0	N/A
OR	0	0	0	0	0	0	0%	0	N/A
PA	825	14	54	39	858	779	-9%	0	1,071
RI	0	0	0	0	0	0	0%	0	N/A
SC	672	36	26	26	657	672	2%	0	456
SD	117	22	DNF	0	132	115	-13%	DNF	537
TN	0	0	0	0	0	0	0%	0	N/A
TX	2,964	154	117	87	3,019	2,969	-2%	0	924
UT	188	22	18	9	190	185	-3%	0	586
VT	0	0	0	0	0	0	0%	0	N/A
VA	187	8 ^e	DNF	DNF	340 ^e	155	-54%	DNF	1,048 ^e
WA	681	3	8	25	695	668	-4%	131	780
WV	0	0	0	0	0	0	0%	0	N/A
WI	314	0	0	13	321	308	-4%	65	903
WY	61	21	17	7	69	67	-3%	3	701
Reported US Total	17,097	1,028	1,400	607	18,239	17,171	-6%	575	751
Estimated US Total	17,596	1,059	1,453	632	18,239	17,557	-4%	576	751

Source: RISP 2018 survey ¹Arizona reported average costs of \$694 per person for people in Medicaid Waiver funded state operated settings of 16+ people, Florida reported average daily costs of \$550 for people in other funded 16+ person state-operated settings and North Carolina reported average daily costs of \$40 per person in other funded state operated settings of 16+ people.

Daily per Person Expenditures

Average daily per-person ICF/IID certified PRF expenditures for FY 2018 were \$751 (\$253,310 per year). The average ranged from \$343 per day (\$125,195) in Mississippi to \$1,327 per day (\$540,565) in Connecticut. States with average daily per person PRF expenditures of more than \$1,000 included: California (\$1,236), Colorado (\$1,018), Connecticut (\$1,327), Delaware (\$1,306), Idaho (\$1,219), North Dakota (\$1,045), Pennsylvania (\$1,071), and Virginia (\$1,048). States with average daily per person PRF expenditures of less than \$500 included: Arkansas (\$404), Florida (\$416), Illinois (\$443), Kansas (\$444), Mississippi (\$343), and South Carolina (\$456). Three states reported average daily expenditures in PRF's that were not certified as ICF/IIDs: Arizona, Florida and North Carolina.

CHARACTERISTICS OF PEOPLE LIVING IN PRFS

FY 2018 PRF surveys were returned by 89 of the 109 PRFs in the 2018 sample frame (an 82% response rate, See **Table 4.2**). Responding facilities served 14,924 people with IDD (85% of the 17,557 estimated

total residents on June 30, 2018). Response rates varied by survey item.

Of the people living in PRFs on June 30, 2018, 60% were male (an estimated 9,240 people), 4% were 21 years or younger (664 people), 21% were 22 to 39 years (3,676), 50% were 40 to 62 years (8,858), and 25% were 63 years or older (4,359). Of the residents, 67% were white, 18% were black or African American, and 3% were another race, two or more races or unknown race; and 6% were of Hispanic origin. More than half (54%) of PRF residents had profound ID while 17% had severe ID, 15% had moderate ID, 14% had mild or no ID, and the level of ID was unknown for 1%.

Other conditions reported for people living in PRFs included epilepsy (37%), ASD (20%), cerebral palsy (16%), and behavior disorders requiring planned interventions (58%). An estimated 846 (5%) of the people living in a PRF had been involved with the criminal justice system.

Table 4.2 Characteristics of People with IDD Living in PRFs on June 30, 2018

Characteristic		Reported Total	Percent of People	Estimated Total	Reporting facilities
Residents on June 30, 2018		14,924	85%	17,557	89
Gender	Male	9,240	60%	10,468	85
Age	0-21 Years	553	4%	664	84
	22-39 Years	3,060	21%	3,676	
	40-62 Years	7,374	50%	8,858	
	63+ Years	3,629	25%	4,359	
Race	White	10,334	71%	12,424	84
	Black/African American	2,751	19%	3,307	
	Hispanic/Latino	995	7%	1,196	
	Other Race or Multiple Races	444	3%	534	
Level of Intellectual Disability	Mild/No ID	2,055	14%	2,459	85
	Moderate	2,170	15%	2,597	
	Severe	2,421	17%	2,897	
	Profound	7,860	54%	9,407	
	Unknown	164	1%	196	
Other Conditions	Epilepsy	5,100	37%	6,441	78
	Autism	2,825	20%	3,518	79
	Cerebral Palsy	2,209	16%	2,822	77
	Behavior Disorder	7,958	58%	10,100	78
Involved with criminal justice system		667	5%	846	79

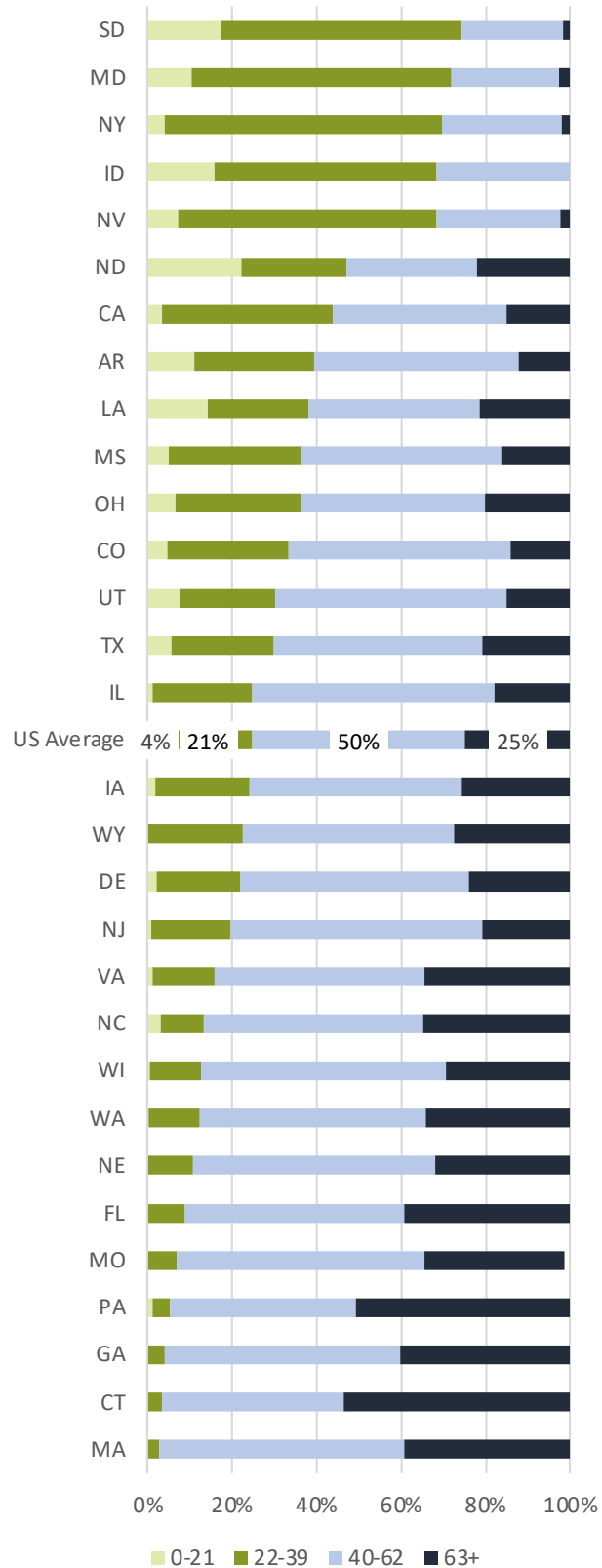
Source: PRF FY 2018 Survey

Table 4.3 Number of People with IDD in PRF's by Age and State on June 30, 2018

State	Age in Years						Total People
	0-18	19-21	0-21	22-39	40-62	63+	
AZ	DNF	DNF	DNF	DNF	DNF	DNF	DNF
AR	53	38	91	233	397	99	820
CA ¹	0	17	17	200	205	74	497
CO	0	1	1	6	11	3	21
CT	0	0	0	10	134	166	310
DE	0	1	1	10	27	12	50
FL	0	0	0	52	310	235	597
GA	0	0	0	6	82	59	147
ID	1	2	3	10	6	0	19
IL	1	17	18	394	952	296	1,660
IA	1	3	4	47	106	55	212
KS	DNF	DNF	DNF	DNF	DNF	DNF	DNF
LA	34	22	56	94	159	84	393
MD	1	3	4	24	10	1	39
MA	0	0	0	3	62	42	107
MS	26	16	42	270	406	142	860
MO ¹	0	0	0	19	162	91	276
NE	0	0	0	11	59	33	103
NV	0	3	3	25	12	1	41
NJ	0	12	12	248	786	275	1,321
NY	1	7	8	129	56	4	197
NC	25	14	39	129	659	441	1,268
ND	11	4	15	17	21	15	68
OH	13	12	25	112	165	76	378
PA	0	9	9	31	334	388	762
SC	DNF	DNF	DNF	DNF	DNF	DNF	DNF
SD	7	13	20	66	28	2	116
TX	85	80	165	717	1,473	614	2,969
UT	8	6	14	42	101	28	185
VA	1	1	2	23	79	55	159
WA	0	2	2	81	357	228	668
WI	1	1	2	38	186	94	320
WY	0	0	0	13	29	16	58
Reported US Total	269	284	553	3,060	7,374	3,629	14,621
Estimated US Total	323	341	664	3,676	8,858	4,359	17,557

Data Source: PRF Survey, N = 84 facilities,

Figure 4.1 Age Distribution of People Living in PRF's (in Percent) by State on June 30, 2018



Data Source: FY 2018 PRF Survey, Age data were not reported for AZ, KY, and NE.



Age

There were substantial state-to-state differences in the ages of PRF residents (See **Table 4.3** and **Figure 4.1**). The proportion of PRF residents who were 18 years or younger averaged 2% and ranged from 0% in fourteen states to 16% in North Dakota. States reporting 20 or more people 18 years or younger in PRFs included Texas (85), Arkansas (53), Louisiana (34), Mississippi (26), and North Carolina (25).

The proportion of PRF residents who were 19 to 21 years old averaged 2% and ranged from 0% in seven states to 11% in Idaho and South Dakota. States reporting 20 or more people ages 19 to 21 years in PRFs included Arkansas (38), Louisiana (22), and Texas (80).

The proportion of PRF residents who were 22 to 39 years averaged 21% and ranged from 3% in Connecticut to 65% in New York. States reporting that 50% or more of PRF residents were ages 22 to 39 years included Idaho (53%), Maryland (62%), Nevada (61%), New York (65%), and South Dakota (57%).

States serving the largest number of people ages 22 to 39 were Illinois (394), Mississippi (270) and Texas (717).

The proportion of PRF residents who were 40 to 62 years averaged 50% and ranged from 23% in South Dakota to 60% in New Jersey and Missouri. Other States reporting that more than 50% of PRF residents were 40 to 62 years old including Colorado (52%), Delaware (54%), Florida (52%), Georgia (56%), Illinois (57%), Massachusetts (58%), Nebraska (57%), North Carolina (52%), Washington (53%), and Wisconsin (58%). States serving the largest number of people ages 40 to 62 years were Illinois (952), New Jersey (786), North Carolina (659) and Texas (1,473).

Finally, the proportion of PRF residents who were 63 years or older averaged 25% with a range from 0% in Idaho to 51% in Pennsylvania and 54% in Connecticut. States serving the largest number of people ages 63 years or older were North Carolina (441), Pennsylvania (388) and Texas (614).

Table 4.4 Level of Intellectual Disability of People Living in Large State IDD Facilities by State (In Percent) on June 30, 2018

State	Level of Intellectual Disability (Percent)					Number of People
	Mild+	Moderate	Severe	Profound	Unknown	
AZ	DNF	DNF	DNF	DNF	DNF	DNF
AR	108	111	144	457	0	820
CA	204	69	44	135	45	497
CO	9	5	0	7	0	21
CT	23	37	71	173	6	310
DE	0	5	5	40	0	50
FL	102	97	75	323	0	597
GA	6	6	19	116	0	147
ID	5	8	6	0	0	19
IL	251	333	296	761	19	1,660
IA	30	27	38	117	0	212
KS	DNF	DNF	DNF	DNF	DNF	DNF
LA	92	83	45	171	2	393
MD	25	9	2	3	0	39
MA	16	9	2	3	0	107
MS	22	53	145	639	1	860
MO	43	59	99	119	4	324
NE	17	16	23	47	0	103
NV	10	11	12	8	0	41
NJ	136	100	166	919	0	1,321
NY	162	25	0	0	10	197
NC	66	143	225	827	7	1,268
ND	21	14	8	16	9	68
OH	66	116	71	126	0	379
PA	49	69	110	534	0	762
SC	DNF	DNF	DNF	DNF	DNF	DNF
SD	54	41	10	3	8	116
TX	430	551	522	1,418	48	2,969
UT	26	26	26	106	1	185
VA	8	13	42	96	0	159
WA	51	121	131	361	4	668
WI	14	9	49	248	0	320
WY	9	4	10	35	0	58
Reported US Total	2,055	2,170	2,421	7,860	164	14,670
Estimated US Total	2,459	2,597	2,897	9,407	196	17,557

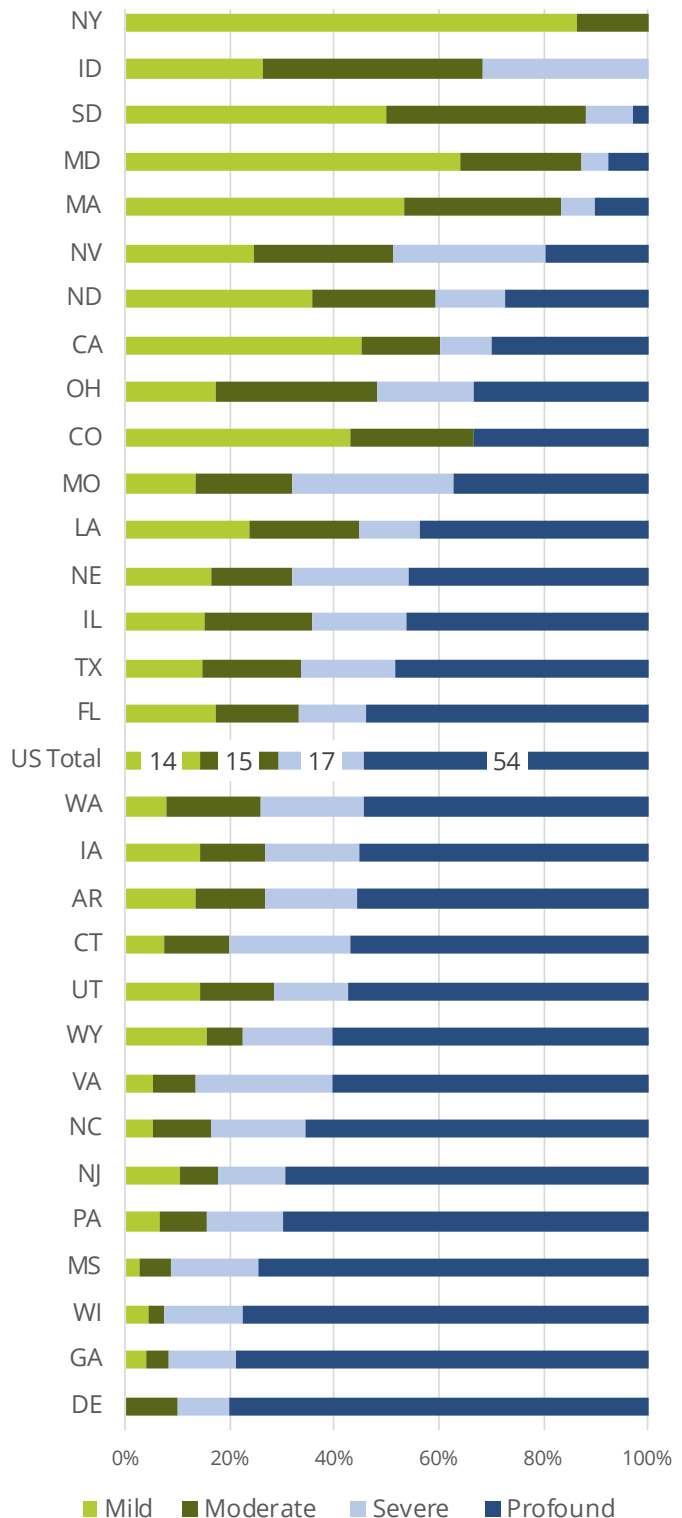
Data Source: PRF FY 2018 Survey. N = 85 facilities

Level of Intellectual Disability

States varied widely in the number and proportion of people in PRFs with different levels of ID (See **Table 4.4** and **Figure 4.2**). **Figure 4.2** excludes people whose level of ID was unknown or not reported.

The proportion of people in PRFs with no or mild ID averaged 14% and ranged from 0% in Delaware to 87% in New York. Other states in which fewer than 5% of people in PRFs had mild ID included Georgia (4%), Mississippi (3%), North Carolina (5%), Virginia (5%), and Wisconsin (4%). Other states in which 50%

Figure 4.2 Percent of People with IDD Living in PRFs by Level of Intellectual Disability and State on June 30, 2018



Data Source: FY 2018 PRF Survey, Data not available for AZ, KY, and NE.

or more of the people had mild or no ID included Maryland (64%), Massachusetts (53%) and South Dakota (50%). States serving the greatest number of people who had no or mild ID included California (204,) Illinois (251) and Texas (430).

The proportion of people in PRFs with moderate ID averaged 15% and ranged from 3% in Wisconsin and 4% in Georgia to 38% in South Dakota and 42% in Idaho. States serving the greatest number of people with moderate ID were Illinois (333) and Texas (551).

The proportion of people in PRFs with severe ID averaged 17% and ranged from 0% in Colorado and New York to 32% in Idaho. States serving the greatest number of people with severe ID were Illinois (296), and North Carolina (225), and Texas (522).

The proportion of people in PRFs with profound ID averaged 54% and ranged from 0% in Idaho and New York to 80% in Delaware. Fifteen additional states reported that 50% or more of people in PRFs had profound ID including Arkansas (56%), Connecticut (57%), Florida (54%), Georgia (79%), Iowa (55%), Mississippi (74%), North Carolina (66%), New Jersey (70%), Pennsylvania (70%), Utah (58%), Virginia (60%), Washington (54%), Wisconsin (78%) and Wyoming (60%). States serving the greatest number of people with profound ID included Illinois (761), Mississippi (639), New Jersey (919), North Carolina (827) and Texas (1,418).

Patterns of Age and Level of Disability

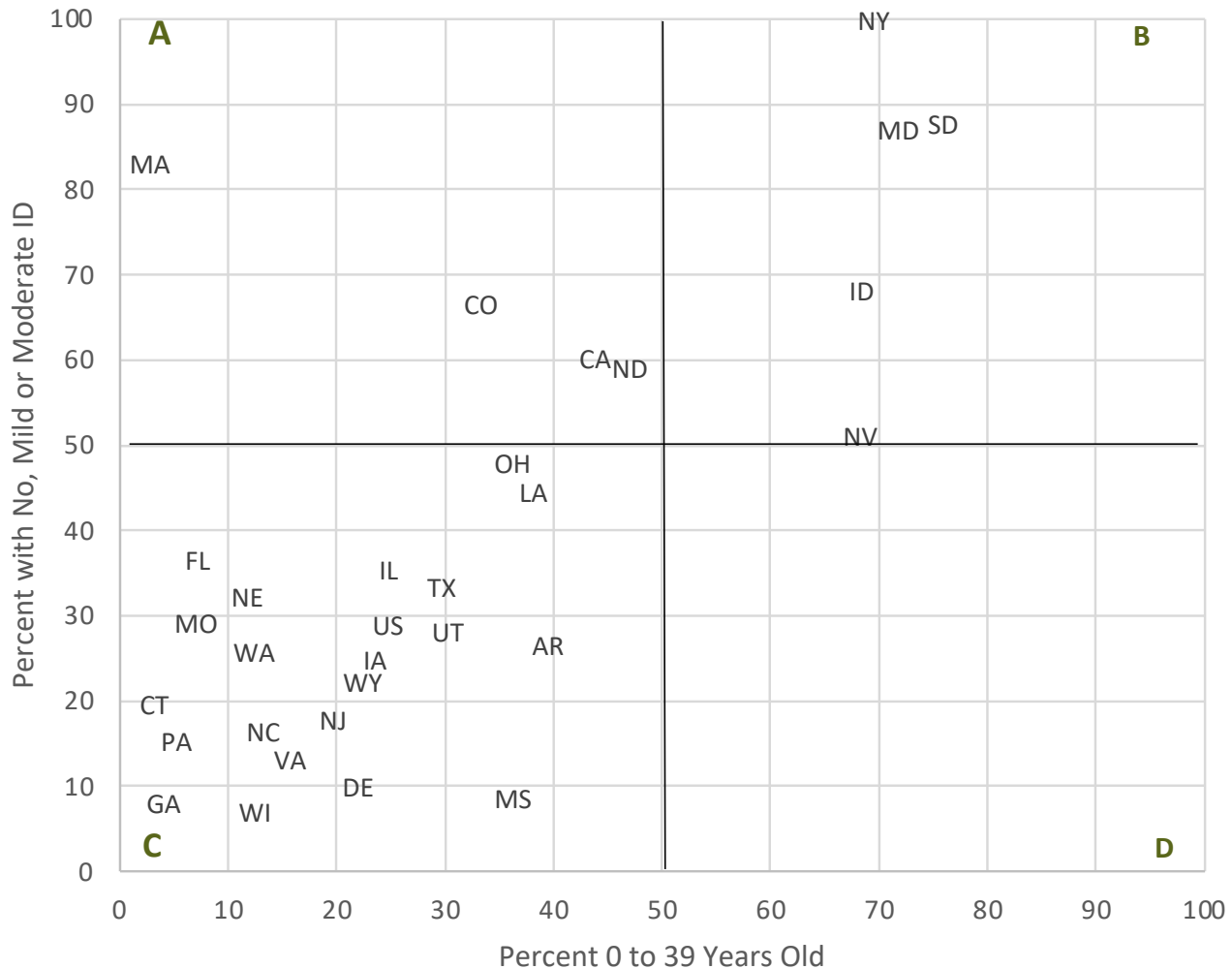
One way to further examine the characteristics of people in PRFs is to look at age and level of ID at the same time. To do this we created a scatterplot showing the percent of PRF residents who had no, mild or moderate ID and the percent who were 39 years or younger (See **Figure 4.2b**). We then divided the graph into quadrants separating the states who reported more or fewer than 50% of residents having no, mild or moderate ID, and who reported more or fewer than 50% of residents being 39 years or younger. In the next few paragraphs we describe states in quadrants A, B and C (no states were in quadrant D).

Twenty-two states were in quadrant C. In those states, the majority of people in PRFs were 40 years or older and had severe or profound ID. For example, in Georgia 94% of residents were 40 years or older and 92% had severe or profound ID. In Wisconsin 87% of residents were 40 years or older and 93% had severe or profound ID. At the other end but still in quadrant C, Ohio and Louisiana reported 62% and 64% respectively of residents ages 40 years or older and 55% and 52% respectively of residents having severe or profound ID.

Five states were in quadrant B (NY, MD, SD, ID and NV). In those states, most people in PRFs were 39 years or younger and had no, mild or moderate ID. For example, in New York, 70% of residents were 0 to 39 years and 100% had no, mild or moderate ID. In Maryland 72% were 39 years or younger and



Figure 4.2b Age and Level of ID of People with IDD Living in PRFs on June 30, 2018 by State



Data Source: PRF Survey, Data not available for AZ, KY and NE

87% had no, mild or moderate ID. In South Dakota, 72% were 39 years or younger and 87% had no, mild or moderate ID. Idaho and Nevada are also in Quadrant B.

Four states were in quadrant A (MA, CO, CA and ND). In those states the majority of residents were 40 years or older and the majority had no, mild or moderate ID. For example, Massachusetts reported that 3% of PRF residents were 39 years or younger, and 83% had no, mild or moderate ID. Colorado reported that 33% of PRF residents were 39 years or younger and 67% had no, mild or moderate ID.

There were no states in quadrant D (more than 50% of residents ages 39 years or younger and less than 50% of residents having no, mild or moderate ID)/.

Differences in the profiles of states may reflect intentional policy decisions, difference in states in the groups most effectively served in community residential settings, or the use of PRFs only for specific subgroups of LTSS recipients with IDD (such as younger people no, mild or moderate ID).

PRF ADMISSIONS AND DISCHARGES

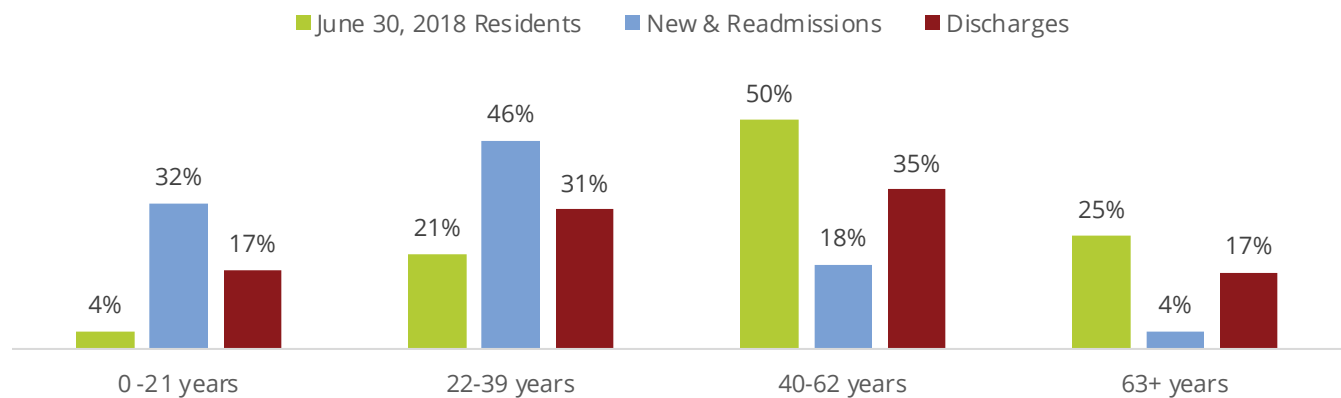
This section compares the age and level of intellectual disability for current residents on June 30, new admissions/readmissions in FY 2018 and discharges in FY 2018. Age was reported for 14,621 of the estimated 17,557 PRF residents on June 30, 2018. Age information was available for 884 of the 1,059 people admitted to PRFs in 2018,

Table 4.5 Age and Level of Intellectual Disabilities for Current, Newly or Readmitted, and Discharged Residents of PRFs in 2018

Characteristic	June 30, 2018 Residents		New & Readmissions		Discharges	
	Number	Percent	Number	Percent	Number	Percent
Reporting Facilities	84		60		74	
Age						
0-18 years	269	2%	156	18%	117	10%
19-21 years	284	2%	127	14%	91	8%
0 -21 years	553	4%	283	32%	208	17%
22-39 years	3,060	21%	405	46%	369	31%
40-62 years	7,374	50%	163	18%	423	35%
63+ years	3,629	25%	33	4%	201	17%
Age Unknown	5	0%	0	0%	2	0%
Level of ID						
Mild or None	2,055	14%	464	53%	428	36%
Moderate	2,170	15%	209	24%	223	19%
Severe	2,421	17%	77	9%	144	12%
Profound	7,860	54%	87	10%	383	32%
IDD Level Unknown	164	1%	39	4%	19	2%

Data Source: PRF Survey

Figure 4.3 Age Distribution for June 30, Newly Admitted, Readmitted and Discharged PRF Residents in FY 2018



and 1,203 of the 1,453 people discharged from 74 PRFs.

Admissions and Discharges by Age and Level of ID

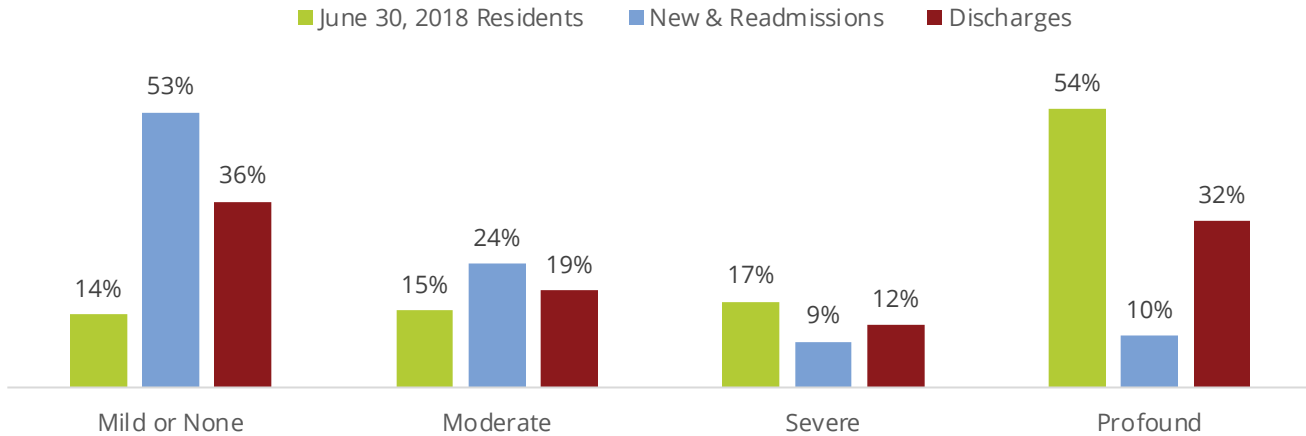
People who were admitted or discharged from PRFs in 2018 differed in age and level of disability from the people in residence on June 30, 2018 (See **Table 4.5**). Of the people in residence on June 30, 2018, 75% were 40 years or older, 21% were 22 to 39 years, and 4% were 21 years or younger. Of the people admitted or readmitted 22% were 40 years or older, 46% were 22 to 39 years, and 32% were 21 years or younger. Of the people discharged, 52%

were 40 years or older, 31% were 22 to 39 years, and 17% were 21 years or younger.

People 21 years or younger were 32% of admissions or readmissions but only 17% of discharges. People 22 to 39 years were 46% of admissions but only 31% of discharges (See **Figure 4.3**). Half of all residents (50%) of PRFs on June 30, 2018 were 40 to 62 years, but only 18% of those admitted and 35% of those discharged were in that age group. Finally, people 63 years or older were 25% of all residents on June 30, 2018, but only 4% of those admitted and 17% of those discharged.

Most (75%) of the people living in PRF's on June 30 were 40 years or older, while the people admitted

Figure 4.4 Level of Intellectual Disabilities for June 30, Newly Admitted, Readmitted and Discharged PRF Residents in FY 2018



were mostly 21 years or younger (32%) or 22 to 39 years (46%). People who were discharged were more evenly distributed across the age groups with 17% being 21 years or younger and 17% being 65 years or older.

The differences in level of intellectual disability were even more pronounced (See **Figure 4.4**). Of the people in residence on June 30, 54% had profound ID compared with 10% of those admitted and 32% of those discharged. By contrast, of the people in residence on June 30, only 14% had mild or no ID compared with 57% of those admitted and 36% of those discharged. PRFs that are still admitting or readmitting people with IDD are admitting a group that is younger and that is less likely to have severe or profound ID than the general population of those facilities. The majority of people being discharged (66%) were between 22 and 62 years old.

Previous and Subsequent Residence of People Admitted to or Discharged from PRFs

For FY 2018, 57 facilities reported previous residence for 800 of the estimated 1,059 people admitted to PRFs, and 71 facilities reported subsequent residence for 1,125 of the estimated 1,453 people leaving PRFs in 2018 (See **Table 4.6** and **Figure 4.5**).

Of the people admitted to PRFs in 2018, 21% previously lived in individualized settings (18% with a family member, 3% in their own home or a host or foster family home). A quarter (26%) previously

Table 4.6 Previous Residence for People Admitted or Readmitted to PRFs and Subsequent Residence Type for People Discharged from PRFs 2018 (in Percent)

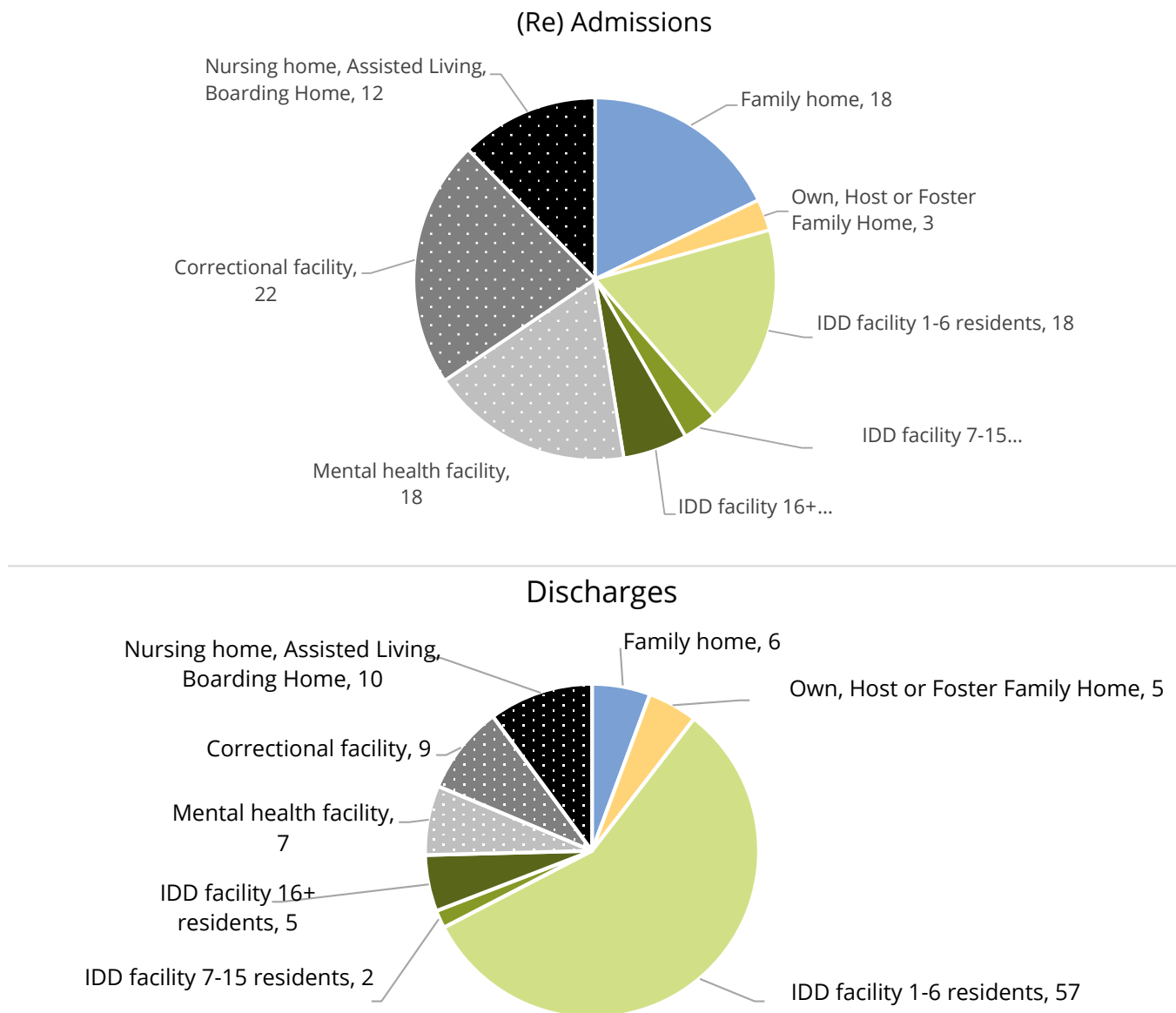
Setting Type	(Re) Admissions	Discharges
Number of reporting facilities	57	71
Total Reported (Re)Admissions/Discharges	800	1,125
Family home	18	6
Own, Host or Foster Family Home	3	5
IDD facility 1-6 residents	18	57
IDD facility 7-15 residents	3	2
IDD facility 16+ residents	6	5
Mental health facility	18	7
Correctional facility	22	9
Nursing home, Assisted Living, Boarding Home	12	10

Data Source: PRF survey. Previous residence was unknown for 55 (re)admissions (7%). Subsequent residence was unknown for 27 discharges (2%).

lived in a group home (17% in a home with six or fewer people; 3% in a home with 7 to 15 people, and 6% in a facility of 16 or more residents). But the majority (52%) previously lived in an institution not specifically designed to serve people with IDD including 18% who had been in a psychiatric hospital or facility, 22% who had been in a correctional facility, and 12% who had been in a nursing home, assisted living facility or boarding home.

In FY 2018, 11% of the people discharged from PRFs moved to an individualized setting (6% to the home of a family member and 5% to their own home or the home of a host or foster family). Almost two-

Figure 4.5 Known Previous Residence for People Admitted or Readmitted to PRFs and Subsequent Residence of People Discharged from PRFs in 2018 (in percent)



Data Source: PRF Survey

thirds (64%) moved to an IDD group setting including 57% who moved to a setting serving 6 or fewer LTSS recipients, 2% who moved to a setting serving 7 to 15 LTSS recipients with IDD, and 5% who moved to a setting serving 16 or more LTSS recipients with IDD. The remaining 26% moved to a facility not specifically designed to serve people with IDD including 7% who moved to a mental health facility or hospital, 9% who moved to a correctional facility, and 10% moved to a nursing home, assisted living facility, or boarding home.

PRF STAFFING CHARACTERISTICS AND OUTCOMES

Staffing characteristics and outcomes were reported for between 77 and 80 PRFs (See **Table 4.7**). Those PRFs employed 26,720 full-time equivalent (FTE) direct support professionals (DSPs) and 2,873 front line supervisors (FLS) on June 30, 2018. One FTE is 40 staff hours worked per week whether those hours are worked by one employee or shared by two or more employees. PRFs employed 1.79 FTE

2018

DSPs and 0.19 front line supervisors per June 30, 2018 resident. Applying these FTE ratios to the estimated 17,557 total recipients in PRFs produces an estimated total of 31,434 FTE DSPs and 3,380 FTE FLS working in PRFs on June 30, 2018.

Staff turnover rates were computed as the total number of staff who left during the year divided

Table 4.7 Staff Characteristics and Outcomes in PRFs in FY 2018

Type of Staff	N Facilities	N FTE staff	FTE staff per resident
Direct Support Professionals (DSP)	80	26,720	1.79
Front Line Supervisors (FLS)	80	2,873	0.19
Turnover and Vacancy Rate		Rate	
DSP Vacancy Rate (%)	78	14.5	
DSP Turnover Rate (%)	78	40.7	
FLS Vacancy Rate (%)	77	9.6	
FLS Turnover Rate (%)	77	16.1	
Wages or Salary		Average	
DSP Starting Hourly Wage	80	\$14.78	
DSP Average Hourly Wage	80	\$16.93	
FLS Starting Salary	78	\$41,604	
FLS Average Salary	78	\$48,127	

Data Source: FY 2018 PRF Survey, FTE Full time equivalent. (One FTE is 1 person working 40 hours per week or a combination of two more more people working a combined 40 hours per week).

by the total staff complement (including vacant positions) on June 30, 2018. Average turnover rates were 40.7% for DSPs and 16.1% for FLSs for FY 2018.

Vacancy rates were computed as the total number of vacant positions on June 30, 2018 divided by the number of current staff plus the number of vacancies to be filled. An estimated 14.5% of DSP positions and 9.6% of FLS positions were vacant on June 30, 2018.

In FY 2018, starting wages for DSPs were \$14.78 (\$30,742 annually) and average wages for DSPs were \$16.93 (\$35,214). The average FLS starting annual salary was \$41,604 and the average annual salary was \$48,127.

PRF STATUS BY FACILITY AS OF JUNE 30, 2018

Table 4.1 showed the characteristics of all PRFs in each state as reported by state IDD agencies on the RISP survey. **Table 4.8** shows the characteristics of individual PRFs that responded to the PRF survey. The June 30, 2018 population for the responding PRFs averaged 170 people and ranged from 19 people in Southwest Idaho Treatment Center to 471 people in Conway HDC (Arkansas). Daily per person expenditures averaged \$847 (\$309,155 per year)



Table 4.8 PRFs Open on June 30, 2018: Projected Closure Date, Population, Per Person Expenditures, Admissions, Discharges and Deaths By State and Facility Name

State	Facility Name (City)	Year Opened	(Projected) Closure Date	Residents With IDD June 2018	All Residents June 2018	Average Daily IDD Population 2018	Residents With IDD June 2017	% Change 2017-18	Average Daily Per Person Expenditures (\$)	Admissions/Readmissions	Discharges	Transfers	Deaths
AR	Arkadelphia Human Dev. Ctr. (Arkadelphia)	1968		116	116	113	110	5	425	13	2	7	1
AR	Booneville HDC (Booneville)	1972		124	124	124	128	-3	420	8	0	6	2
AR	Conway HDC (Conway)	1959		471	471	469	473	-0	420	27	6	15	20
AR	Jonesboro HDC (Jonesboro)	1970		109	109	106	107	2	400	15	2	8	3
AR	Southeast Arkansas HDC (Warren)	1978		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
AZ	Arizona Trng. Program (Coolidge)	1952		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
CA	Canyon Springs (Cathedral City)	2001		49	49	47	48	2	1,089	10	DNF	9	DNF
CA	Fairview Dev. Ctr. (Costa Mesa)	1959	2021	104	108	193	162	-36	2,071	2	DNF	47	13
CA	Porterville Dev. Ctr. (Porterville)	1953	Dec 2021	269	269	291	321	-16	1,590	91	10	131	2
CA	Sonoma Dev. Ctr. (Eldridge)	1891	Dec 2018	75	68	183	26	188	1,771	DNF	DNF	165	16
CO	Grand Junction Regional Ctr. (Grand Junction)	1919		21	21	22	22	-5	1,124	DNF	DNF	1	DNF
CO	Wheat Ridge Regional Ctr. (Wheatridge)	1912		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
CT	Northwest Ctr. (Torrington)	1984		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
CT	Hartford Regional Center (Newington)	1965		45	46	45	48	-6	1,514	1	DNF	2	2
CT	Lower Fairfield County Ctr. (Norwalk)	1976		67	67	67	68	-1	400	DNF	DNF	DNF	1
CT	Southbury Trng. School (Southbury)	1940		198	198	210	224	-12	1,325	0	0	12	14
DE	MAC Ctr. at Stockley (Georgetown)	1921		50	50	49	48	4	1,325	2	DNF	DNF	DNF
FL	Developmental Disabilities Defendant Program (DDDP, Chattahoochee)	1977		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
FL	Sunland Ctr. (Marianna)	1961		260	260	263	275	-5	400	15	DNF	21	9
FL	Tacachale Ctr. / Sequin Unit (Gainesville)	1921		337	337	345	350	-4	439	2	DNF	d	10
GA	East Central Regional Hospital (Gracewood & Augusta)	1921		147	147	159	178	-17	626	DNF	DNF	31	8
GA	Georgia Regional Hospital of Atlanta (Decatur)	1968		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
IA	Glenwood Resource Ctr. (Glenwood)	1876		212	212	212	219	-3	925	1	0	2	6
IA	Woodward Resource Ctr. (Woodward)	1917		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
ID	Southwest Idaho Treatment Center (Nampa)	1918		19	19	21	23	-17	1,219	7	DNF	10	1
IL	Choate Dev. Ctr. (Anna)	1873		190	190	184	177	7	746	30	9	26	0
IL	Fox Dev. Ctr. (Dwight)	1965		92	92	92	99	-7	775	5	DNF	2	10
IL	Kiley Dev. Ctr. (Waukegan)	1975		195	195	195	195	0	775	14	DNF	13	1
IL	Ludeman Dev. Ctr. (Park Forest)	1972		382	382	386	388	-2	775	11	5	6	3
IL	Mabley Dev. Ctr. (Dixon)	1987		107	107	109	109	-2	775	3	0	2	3
IL	Murray Dev. Ctr. (Centralia)	1964		225	225	224	213	6	858	19	1	4	3
IL	Shapiro Dev. Ctr. (Kankakee)	1879		469	470	476	477	-2	762	27	3	30	8
KS	Kansas Neurological Institute (Topeka)	1960		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF

Table 4.8 PRFs Open on June 30, 2018: Projected Closure Date, Population, Per Person Expenditures, Admissions, Discharges and Deaths By State and Facility Name

State	Facility Name (City)	Year Opened	(Projected) Closure Date	Residents With IDD June 2018	All Residents June 2018	Average Daily IDD Population 2018	Residents With IDD June 2017	% Change 2017-18	Average Daily Per Person Expenditures (\$)	Admissions/Readmissions	Discharges	Transfers	Deaths
KS	Parsons State Hospital (Parsons)	1952		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
KY	Bingham Gardens (Louisville)	1873		20	20	22	24	-17	DNF	2	5	1	0
KY	Hazelwood Ctr. (Louisville)	1971	July 2018	92	92	96	100	-8	DNF	7	0	4	11
LA	Louisiana Special Education Center (Alexandria)	1952		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
LA	Pinecrest Supports and Services Center (Pineville)	1918		393	393	407	415	-5	722	18	0	43	16
MA	Hogan Regional Ctr. (Hawthorne)	1967		107	123	107	119	-10	918	DNF	DNF	DNF	12
MA	Wrentham Dev. Ctr. (Wrentham)	1907		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MD	Holly Ctr. (Salisbury)	1975		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MD	Potomac Ctr. (Hagerstown)	1978		39	41	42	38	3	996	24	DNF	23	DNF
MS	Boswell Regional Ctr. (Sanatorium)	1976		95	95	96	93	2	380	12	0	8	2
MS	Ellisville State School (Ellisville)	1920		237	245	253	252	-6	385	7	0	12	10
MS	Hudspeth Regional Ctr. (Whitfield)	1974		217	217	213	225	-4	296	4	DNF	5	3
MS	Mississippi Adolescent Center (Brookhaven)	2011		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MS	North Mississippi Regional Ctr. (Oxford)	1973		207	207	212	214	-3	316	0	20	3	4
MS	South Mississippi Regional Ctr. (Long Beach)	1978		104	104	107	110	-5	355	DNF	DNF	2	4
MO	Bellefontaine Habilitation Ctr. (St. Louis)	1924		112	117	115	117	-4	761	0	0	0	5
MO	Higginsville Habilitation Ctr. (Higginsville)	1956		48	48	48	49	-2	920	1	DNF	0	2
MO	Southeast Missouri Residential Services (Poplar Bluff and Sikeston)	1992		60	60	60	61	-2	572	0	1	DNF	DNF
MO	Southwest Community Services (Nevada)	1973		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MO	St. Louis Dev. Disabilities Treatment Ctrs. (3: South County, St. Louis, and St. Charles Hab. Ctr.)*	2002		104	104	104	110	-5	814	DNF	DNF	DNF	2
NE	Sheridan Cottages ICF (Beatrice)	1875		103	109	109	108	-5	998	0	19	1	4
NV	Desert Regional Ctr. (Las Vegas)	1975		41	41	45	48	-15	DNF	44	0	51	0
NJ	Green Brook Regional Ctr. (Green Brook)	1981		95	95	100	102	-7	1,135	DNF	DNF	DNF	7
NJ	Hunterdon Dev. Ctr. (Clinton)	1969		457	457	467	475	-4	825	DNF	DNF	1	17
NJ	Vineland Dev. Ctr. (Vineland)	1888		196	196	196	207	-5	1,084	0	0	5	6
NJ	New Lisbon Dev. Ctr. (New Lisbon)	1914		313	313	325	340	-8	931	DNF	DNF	15	12
NJ	Woodbine Dev. Ctr. (Woodbine)	1921		260	260	268	277	-6	1,099	DNF	DNF	9	8
NY	Sunmount DDSO (Tupper Lake)	1965		152	152	154	155	DNF	DNF	41	DNF	41	DNF
NY	Valley Ridge (Norwich)	2000		45	45	45	45	0	DNF	11	DNF	7	1
NC	Black Mountain Ctr. (Black Mountain)	1982		84	152	87	86	-2	528	6	DNF	1	7

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NC	Caswell Ctr. (Kinston)	1914		314	314	317	328	-4	751	6	DNF	3	17
NC	J. Iverson Riddle Dev. Ctr. (Morganton)	1963		277	278	274	280	-1	649	9	DNF	3	9
NC	Murdoch Ctr. (Butner)	1957		405	409	411	423	-4	707	23	DNF	21	20
NC	O'Berry Ctr. (Goldsboro)	1957		188	188	193	201	-6	805	2	DNF	DNF	15
ND	Life Skills and Transition Center (Grafton)	1904		68	68	68	69	-1	1,045	32	0	30	3
OH	Cambridge Dev. Ctr. (Cambridge)	1965		67	67	68	70	-4	625	31	DNF	30	4
OH	Columbus Dev. Ctr. (Columbus)	1857		115	115	113	109	6	658	28	0	20	2
OH	Gallipolis Dev. Ctr. (Gallipolis)	1893		51	54	52	57	-11	761	14	DNF	17	3
OH	Mount Vernon Dev. Ctr. (Mount Vernon)	1948		70	70	76	80	-13	655	15	DNF	19	6
OH	Northwest Ohio Dev. Ctr. (Toledo)	1977		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
OH	Southwest Ohio Dev. Ctr. (Batavia)	1981		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
OH	Tiffin Dev. Ctr. (Tiffin)	1975		76	76	83	89	-15	560	16	0	23	4
OH	Warrensville Dev. Ctr. (Warrensville)	1975		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
PA	Ebensburg Ctr. (Ebensburg)	1957		211	211	195	220	-4	1,070	5	0	4	10
PA	Hamburg Ctr. (Hamburg)	1960	Aug 2018	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
PA	Polk Ctr. (Polk)	1897	2022	208	208	209	220	-5	1,026	0	2	2	12
PA	Selinsgrove Ctr. (Selinsgrove)	1929		222	222	217	224	-1	1,013	12	0	8	7
PA	White Haven Ctr. (White Haven)	1956	2022	121	121	115	117	3	1,025	11	0	1	DNF
SC	Coastal Ctr. (Ladson)	1968		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
SC	Midlands Ctr. (Columbia)	1956		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
SC	Pee Dee Regional Ctr. (Florence) and Thad E. Saleeby Ctr. (Hartsville)	1971		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
SC	Whitten Ctr. (Clinton)	1920		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
SD	South Dakota Dev. Ctr. (Redfield)	1902		116	116	117	121	-4	537	22	DNF	27	0
TX	Abilene State School (Abilene)	1957		269	269	275	282	-5	935	4	1	4	13
TX	Austin State School (Austin)	1917		177	177	178	180	-2	935	10	1	3	10
TX	Brenham State School (Brenham)	1974		254	254	253	259	-2	935	10	1	3	10
TX	Corpus Christi State School (Corpus Christi)	1970		205	205	206	208	-1	935	6	DNF	5	4
TX	Denton State School (Denton)	1960		449	449	448	447	0	935	11	6	3	12
TX	El Paso State Ctr. (El Paso)	1973		94	94	94	95	-1	935	3	DNF	4	DNF
TX	Lubbock State School (Lubbock)	1969		184	184	181	185	-1	935	12	2	8	5
TX	Lufkin State School (Lufkin)	1962		289	289	294	298	-3	935	5	1	6	6
TX	Mexia State School (Mexia)	1946		240	240	226	246	-2	935	57	3	56	6
TX	Richmond State School (Richmond)	1968		321	321	321	319	1	935	16	3	5	9

Table 4.8 PRFs Open on June 30, 2018: Projected Closure Date, Population, Per Person Expenditures, Admissions, Discharges and Deaths By State and Facility Name

State	Facility Name (City)	Year Opened	(Projected) Closure Date	Residents With IDD June 2018	All Residents June 2018	Average Daily Population 2018	Residents With IDD June 2017	% Change 2017-18	Average Daily Per Person Expenditures (\$)	Admissions/Readmissions	Discharges	Transfers	Deaths
TX	Rio Grande State Ctr. (Harlingen)	1973		62	62	63	60	3	935	9	DNF	1	5
TX	San Angelo State School (Carlsbad)	1969		202	202	200	213	-5	935	12	1	19	2
TX	San Antonio State School (San Antonio)	1978		223	223	225	227	-2	935	5	1	2	6
UT	Utah State Dev. Ctr. (American Fork)	1931		185	182	188	185	0	587	22	46	18	9
VA	Central Virginia Trng. Ctr. (Lynchburg)	1911	June 2022	86	86	115	144	-40	1,140	0	0	50	8
VA	Southeastern Virginia Trng. Ctr. (Chesapeake)	1975		73	73	72	72	1	940	8	DNF	7	DNF
WA	Fircrest (Seattle)	1959		176	176	180	185	-5	710	DNF	DNF	4	5
WA	Lakeland Village School (Medical Lake)	1915		160	160	164	169	-5	910	3	DNF	1	11
WA	DSHS Rainier School (Buckley)	1939		276	276	280	285	-3	726	DNF	DNF	3	6
WA	Yakima Valley School (Selah)	1958		56	56	57	59	-5	901	DNF	DNF	DNF	3
WI	Central Wisconsin Ctr. (Madison)	1959		189	201	192	196	-4	881	0	0	1	6
WI	Southern Wisconsin Ctr. (Union Grove)	1919		131	131	132	132	-1	929	16	DNF	12	6
WY	Wyoming Life Resource Ctr. (Lander)	1912		58	64	69	65	-11	705	2	DNF	2	7

Data Source: FY 2018 PRF Survey

and ranged from \$296 (\$108,770) for Hudspeth Regional Center in Mississippi to \$2,071 (\$755,915) for Fairview Developmental Center in California.

The net change in PRF populations between June 30, 2017 and June 30, 2018 averaged a reduction of 7 people (-2%) and ranged from an increase of 49 people for Sonoma Developmental Center in California (+188%) to a reduction of 58 people for Central Virginia Training School (-40%), and Fairview Developmental Center in California (-36%).

The number of admissions or readmissions for FY 2018 averaged 13 and ranged from 0 in 9 facilities to 91 for Porterville Developmental Center in California. The number of discharges per PRF averaged 4 and ranged from 0 in 19 facilities to 46 for Utah State Developmental Center. The number of transfers (in or out) averaged 15 per PRF and ranged from 0 in two facilities to 165 for Sonoma Developmental Center in California. Finally, the number of deaths during FY 2018 averaged 7 per PRF with a range from 0 in four facilities to 20 in Conway HDC in Arkansas and Murdoch Center in North Carolina.

Projected PRF Closures

The following facilities have projected closing dates between July 1, 2018 and June 30, 2022.

FY 2019 (July 1, 2018 – June 30, 2019)

- Sonoma Developmental Center (Eldridge, CA)
- Hamburg Center (Hamburg, PA)
- Hazelwood Center (Louisville, KY)

FY 2021 (July 1, 2020 – June 30, 2021)

- Fairview Development Center (Costa Mesa, CA)

FY 2022 (July 1, 2021 – June 30, 2022)

- Central Virginia Training School (Lynchburg, VA)
- Porterville Development Center (General population only. The Secure Treatment Area will remain open; Porterville, CA)
- Polk Center (Polk, PA)
- White Haven Center (White Haven, PA)

PRFs Closures and Projected Closures

Table 4.9 lists the names and disposition of 245 PRFs that closed, converted to serving a different population, converted from state-operation to

Table 4.9 Final Status of PRFs Closed, Privatized, Converted for Use by Another Population, Downsized to Less than 16 people, Merged or Otherwise No Longer in Operation as of June 30, 2018

State	Facility Name at Closure, Downsizing or Conversion	Year Opened	Final Status	
			Fiscal Year	Disposition ¹
AL	Albert P. Brewer Dev. Ctr. (Daphne)	1973	2004	
AL	Glen Ireland II Ctr. (Tarrant City)	1986	1996	
AL	J.S. Tarwater Dev. Ctr. (Wetumpka)	1976	2004	
AL	Lurleen B. Wallace Dev. Ctr. (Decatur)	1971	2003	
AL	Wm. D. Partlow Dev. Ctr. (Tuscaloosa)	1923	2011	
AK	Harborview Ctr. (Valdez)	1967	1997	
AZ	Arizona State Hospital (Phoenix)	1978	1994	
AZ	Arizona Trng. Program (Phoenix)	1973	1988	
AZ	Arizona Trng. Program (Tucson)	1970	1995	
AR	Alexander Human Dev. Ctr. (Alexander)	1968	2011	
CA	Agnews Dev. Ctr. (San Jose)	1966	2009	
CA	Camarillo Ctr. (Camarillo)	1968	1997	
CA	DeWitt State Hospital (Auburn)	1946	1972	
CA	Lanterman Dev. Ctr. (Pomona)	1927	2014	
CA	Modesto State Hospital (Modesto)	1947	1962	
CA	Napa State Hospital Forensic Unit (Napa)	1995	2000	
CA	Patton State Hospital (Patton)	1963	1982	
CA	Sierra Vista (Yuba City)	2000	2009	
CA	Stockton Ctr. (Stockton)	1972	1996	
CO	Pueblo State Regional Ctr. (Pueblo)	1935	1988	
CT	Bridgeport Ctr. (Bridgeport)	1965	1981	
CT	Clifford Street Group Home (Hartford)	1982	1995	
CT	Ella Grasso Ctr. (Stratford)	1981	2017	Closed
CT	John Dempsey Ctr. (Putnam)	1964	1997	
CT	Mansfield Trng. School (Mansfield)	1917	1993	
CT	Martin House Group Home (Norwalk)	1971	2000	
CT	Meridan Ctr. (Wallingford)	1979	2016	Downsized
CT	Mystic Ctr. (Groton)	1979	2010	
CT	New Haven Ctr. (New Haven)	1962	1994	
CT	Seaside Ctr. (Waterford)	1961	1996	
CT	Waterbury Ctr. (Cheshire)	1971	1989	
DC	Bureau of Forest Haven (Laurel, MD)	1925	1990	
DC	D.C. Village (Washington, DC)	1975	1994	
DC	St. Elizabeth's Hopital (Washington, DC)	1987	1994	
FL	Community of Landmark (Miami)	1966	2005	
FL	Florida State Hospital Unit 27 now with DDDP (Chattahoochee)	1976	2015	Merged
FL	Gulf Coast Ctr. (Fort Meyers)	1960	2010	
FL	N.E. Florida State Hospital (MacClenny)	1981	2000	
FL	Seguin Unit now with DDDP (Gainesville)	1989	2015	Merged
FL	Sunland Trng. Ctr. (Orlando)	1960	1984	
FL	Sunland Trng. Ctr. (Tallahassee)	1968	1983	
GA	Brook Run (Atlanta)	1969	1997	
GA	Central State Hospital (Milledgeville)	1842	2012	Converted
GA	Georgia Regional Hospital (Savannah)	2000	2005	
GA	Gracewood State School and Hospital, now East Central (Gracewood)	1921	2015	Merged
GA	Northwest Regional Hospital (Rome)	1971	2011	
GA	River's Crossing (Athens)		1996	
GA	Rose Haven (Thomasville)	1968	2000	
GA	Southwestern Development Center (Bainbridge)	1967	2000	
GA	Southwestern State Hospital (Thomasville)	1967	2013	

Table 4.9 Final Status of PRFs Closed, Privatized, Converted for Use by Another Population, Downsized to Less than 16 people, Merged or Otherwise No Longer in Operation as of June 30, 2018

State	Facility Name at Closure, Downsizing or Conversion	Year Opened	Final Status	
			Fiscal Year	Disposition ¹
GA	West Central Georgia Regional Hospital (Columbus)	2000	2004	
HI	Kula Hospital (Kula)	1984	1994	
HI	Waimano Trng. School and Hospital (Pearl City)	1921	1999	
IL	Alton Mental Health & Dev. Ctr. (Alton)	1914	1994	
IL	Bowen Ctr. (Harrisburg)	1966	1982	
IL	Dixon Ctr. (Dixon)	1918	1987	
IL	Elgin Mental Health & Dev. Ctr. (Elgin)	1872	1994	
IL	Galesburg Ctr. (Galesburg)	1959	1985	
IL	Howe Dev. Ctr. (Tinley Park)	1973	2010	
IL	Jacksonville Dev. Ctr. (Jacksonville)	1851	2012	
IL	Lincoln Dev. Ctr. (Lincoln)	1866	2002	
IL	Meyer Mental Health Ctr. (Decatur)	1967	1993	
IL	Singer Mental Health & Dev. Ctr. (Rockford)	1966	2002	
IN	Central State Hospital (Indianapolis)	1848	1995	
IN	Evansville State Hospital (Evansville)	1890	2011	
IN	Fort Wayne Dev. Ctr. (Fort Wayne)	1890	2007	
IN	Logansport State Hospital (Logansport)	1888	2012	Converted
IN	Madison State Hospital (Madison)	1910	2012	Converted
IN	Muscatatuck Dev. Ctr. (Butlerville)	1920	2005	
IN	New Castle Ctr. (New Castle)	1907	1998	
IN	Norman Beatty Memorial Hospital (Westville)	1951	1979	
IN	Northern Indiana Ctr. (South Bend)	1961	1998	
IN	Richmond State Hospital (Richmond)	1890	2010	
IN	Silvercrest State Hospital (New Albany)	1974	1995	
KS	Norton State Hospital (Norton)	1963	1988	
KS	Winfield State Hospital (Winfield)	1884	1998	
KY	Frankfort State Hospital and School (Frankfort)	1860	1973	
KY	Bluegrass Oakwood ICF/IID (Somerset)	1972	2006	Privatized
KY	Outwood ICF/IID (Dawson Springs)	1962	1994	Privatized
LA	Acadiana Region Supports and Services Center (Iota)	1972	2011	Privatized
LA	Bayou Region Supports and Services Center (Thibodaux)	1982	2010	Closed
LA	Columbia Dev. Ctr. (Columbia)	1970	2009	Downsized
LA	Leesville Dev. Ctr. (Leesville)	1964	2012	Downsized
LA	Metropolitan Development Center	1967	2007	
LA	North Lake Supports and Services Center (Hammond)		2012	Privatized
LA	Northeast Supports and Services Center (Ruston)	1959	2010	
LA	Northwest Louisiana Dev. Ctr. (Bossier City)	1973	2012	
ME	Aroostook Residential Ctr. (Presque Isle)	1972	1995	
ME	Elizabeth Levinson Ctr. (Bangor)	1971	1998	
ME	Pineland Ctr. (Pownal)	1908	1995	
MD	Great Oaks Ctr. (Silver Springs)	1970	1996	
MD	Henryton Ctr. (Henryton)	1962	1985	
MD	Highland Health Facility (Baltimore)	1972	1989	
MD	Joseph Brandenburg Ctr. (Cumberland)	1978	2011	
MD	Rosewood Ctr. (Owings Mills)	1887	2009	
MD	Victor Cullen Ctr. (Sabillasville)	1974	1992	
MD	Walter P. Carter Ctr. (Baltimore)	1978	1990	
MA	Belchertown State School (Belchertown)	1922	1992	
MA	Berry Regional Ctr. (Hawthorne)	1967	1994	
MA	Glavin Regional Ctr. (Shrewsbury)	1974	2013	Closed

Table 4.9 Final Status of PRFs Closed, Privatized, Converted for Use by Another Population, Downsized to Less than 16 people, Merged or Otherwise No Longer in Operation as of June 30, 2018

State	Facility Name at Closure, Downsizing or Conversion	Year Opened	Final Status	
			Fiscal Year	Disposition ¹
MA	Medfield State Hospital (Medfield)	1898	1994	
MA	Monson Dev. Ctr. (Palmer)	1898	2012	
MA	Paul A. Dever Dev. Ctr. (Taunton)	1946	2001	
MA	Templeton Dev Ctr (Baldwinsville)	1967	2015	Closed
MA	The Fernald Ctr. (Waltham)	1848	2014	Downsized
MA	Worcester State Hospital (Worcester)	1833	1994	
MI	Alpine Regional Ctr. for DD (Gaylord)	1960	1981	
MI	Caro Regional Mental Health Ctr. (Caro)	1914	1997	
MI	Coldwater Regional Ctr. for DD (Coldwater)	1935	1987	
MI	Fort Custer State Home (Augusta)	1956	1972	
MI	Hillcrest Regional Ctr. for DD (Howell)	1959	1982	
MI	Macomb-Oakland Regional Ctr. for DD (Mt. Clemens)	1967	1989	
MI	Mount Pleasant Ctr. (Mount Pleasant)	1937	2009	
MI	Muskegon Regional Ctr. for DD (Muskegon)	1969	1992	
MI	Newberry Regional Mental Health Ctr. (Newberry)	1895	1992	
MI	Northville Residential Trng. Ctr. (Northville)	1972	1983	
MI	Oakdale Regional Ctr. for DD (Lapeer)	1895	1992	
MI	Plymouth Ctr. for Human Development (Northville)	1960	1984	
MI	Southgate Regional Ctr. (Southgate)	1977	2002	
MN	Brainerd Regional Human Services Ctr. (Brainerd)	1958	1999	
MN	Faribault Regional Ctr. (Faribault)	1879	1998	
MN	Fergus Falls Regional Treatment Ctr. (Fergus Falls)	1969	2000	
MN	MN Ext. Treatment Options Program (Cambridge)	1997	2011	Converted
MN	Moose Lake Regional Treatment Ctr. (Moose Lake)	1970	1994	
MN	Owatonna State Hospital (Owatonna)	1945	1972	
MN	Rochester State Hospital (Rochester)	1968	1982	
MN	St. Peter Regional Treatment Ctr. (St. Peter)	1968	1996	
MN	Willmar Regional Treatment Ctr. (Willmar)	1973	1996	
MO	Albany Regional Ctr. (Albany)	1967	1989	
MO	Hannibal Regional Ctr. (Hannibal)	1967	1991	
MO	Joplin Regional Ctr. (Joplin)	1967	1992	
MO	Kansas City Regional Ctr. (Kansas City)	1970	1993	
MO	Kirksville Regional Ctr. (Kirksville)	1968	1988	
MO	Marshall Habilitation Ctr. (Marshall)	1901	2015	
MO	Midtown Habilitation Ctr. (St. Louis)		2004	
MO	Northwest Habilitation Ctr. (St. Louis)	2002	2012	
MO	Poplar Bluff Regional Ctr. (Poplar Bluff)	1968	1992	
MO	Rolla Regional Ctr. (Rolla)	1968	1984	
MO	Sikeston Regional Ctr. (Sikeston)	1969	1992	
MO	Southwest Community Services (Nevada)	1973	2017	Converted
MO	Springfield Regional Ctr. (Springfield)	1967	1990	
MT	Eastmont Human Services Ctr. (Glendive)	1969	2003	
MT	Montana Developmental Ctr. (Boulder)	1905	2017	Downsized
NV	Sierra Regional Ctr. (Sparks)	1977	2008	
NH	Laconia State School and Trng. Ctr. (Laconia)	1903	1991	
NH	New Hampshire Hospital, Brown Building (Concord)	1842	1990	
NJ	Ctr. at Ancora (Hammonton)		1992	
NJ	E.R. Johnstone Trng. & Research Ctr. (Bordentown)	1955	1992	
NJ	Edison Habilitation Ctr. (Princeton)	1975	1988	
NJ	North Jersey Dev Ctr (Totowa)	1928	2014	Closed

Table 4.9 Final Status of PRFs Closed, Privatized, Converted for Use by Another Population, Downsized to Less than 16 people, Merged or Otherwise No Longer in Operation as of June 30, 2018

State	Facility Name at Closure, Downsizing or Conversion	Year Opened	Final Status	
			Fiscal Year	Disposition ¹
NJ	North Princeton Ctr. (Princeton)	1975	1998	
NJ	Woodbridge Dev Ctr (Woodbridge)	1965	2015	Closed
NM	Fort Stanton Hospital and Trng. Ctr. (Fort Stanton)	1964	1995	
NM	Los Lunas Hospital and Trng. Ctr. (Los Lunas)	1929	1997	
NM	Villa Solano-Hagerman Residential School (Roswell)	1964	1982	
NY	Bernard M. Fineson Dev. Ctr. (Hillside; Howard Park)	1970	2017	Closed
NY	Bronx DDSO (Bronx)	1971	1992	
NY	Brooklyn DDSO (Brooklyn)	1972	2015	
NY	Broome DDSO (Binghamton)	1970	2016	
NY	Capital District DDSO (Schenectady)	1973	2015	Closed
NY	Central New York DDSO (Syracuse)	1851	1998	
NY	Craig DDSO (Sonyea)	1935	1988	
NY	Finger Lakes DDSO (Rochester)	1969	2013	Closed
NY	Gouverneur (New York)	1962	1978	
NY	Hudson Valley DDSO (Thiells)	1911	2000	
NY	J.N. Adams (Perrysburg)	1960	1993	
NY	Long Island DDSO (Commack)	1965	1993	
NY	Long Island Suffolk DDSO (Melville)	1965	1992	
NY	Manhattan Ctr. (New York)	1972	1992	
NY	Newark Ctr. (Newark)	1878	1991	
NY	Rome Ctr. (Rome)	1894	1989	
NY	Sampson State School (Willard)	1961	1971	
NY	Staten Island (Staten Island)	1987	2012	
NY	Taconic DDSO (Wassaic)	1930	2013	Closed
NY	Valatie (Valatie)	1971	1974	
NY	Westchester NY DDSO (Tarrytown)	1979	1988	
NY	Western NY DDSO (West Seneca)	1962	2011	
NY	Willowbrook State School (Staten Island)	1947	1988	
NY	Wilton DDSO (Wilton)	1960	1995	
NC	Broughton Ctr. (Morganton)	1883	1994	
ND	San Haven State Hospital (Dunseith)	1973	1987	
OH	Apple Creek Dev. Ctr. (Apple Creek)	1931	2006	
OH	Athens Mental Health & Dev. Ctr. (Athens)	1975	1994	
OH	Broadview Ctr. (Broadview Hgts.)	1967	1992	
OH	Cambridge Mental Health Ctr. (Cambridge)	1978	1990	
OH	Central Ohio Psychiatric Hospital (Cleveland)	1978	1994	
OH	Cleveland Ctr. (Cleveland)	1976	1988	
OH	Dayton Ctr. (Dayton)	1979	1983	
OH	Dayton Mental Health Ctr. (Dayton)	1978	1994	
OH	Massillon State Hospital (Massillon)	1978	1994	
OH	Montgomery Dev. Ctr. (Huber Heights)	1981	2017	
OH	Orient Ctr. (Orient)	1898	1984	
OH	Springview Developmental Ctr. (Springfield)	1975	2005	
OH	Western Reserve Psychiatric Hab. Ctr. (Northfield)	1978	1990	
OH	Youngstown Ctr. (Mineral Ridge)	1980	2017	
OK	Hisson Memorial Ctr. (Sand Springs)	1964	1994	
OK	Northern Oklahoma Resource Center (Enid)	1909	2014	Closed
OK	Robert M. Greer Memorial Ctr. (Enid)	1992	2000	Privatized
OK	Southern Oklahoma Resource Center (Pauls valley)	1952	2016	Closed
OR	Columbia Park Hospital & Trng. Ctr. (The Dalles)	1963	1977	

Table 4.9 Final Status of PRFs Closed, Privatized, Converted for Use by Another Population, Downsized to Less than 16 people, Merged or Otherwise No Longer in Operation as of June 30, 2018

State	Facility Name at Closure, Downsizing or Conversion	Year Opened	Final Status	
			Fiscal Year	Disposition ¹
OR	Eastern Oregon Trng. Ctr. (Pendleton)	1964	2009	
OR	Fairview Trng. Ctr. (Salem)	1908	2000	
PA	Allentown Mental Retardation Unit (Allentown)	1974	1988	
PA	Altoona Ctr. (Altoona)	1982	2006	
PA	Clarks Summit Mental Retardation Unit (Clarks Summit)	1974	1992	
PA	Cresson Ctr. (Cresson)	1964	1982	
PA	Embreeville Ctr. (Coatesville)	1972	1997	
PA	Harrisburg Mental Retardation Unit (Harrisburg)	1972	1982	
PA	Hollidaysburg Mental Retardation Ctr. (Hollidaysburg)	1974	1976	
PA	Laurelton Ctr. (Laurelton)	1920	1998	
PA	Marcy Ctr. (Pittsburgh)	1975	1982	
PA	Mayview Mental Retardation Unit (Mayview)	1974	2001	
PA	Pennhurst Ctr. (Pennhurst)	1908	1988	
PA	Philadelphia Mental Retardation Unit (Philadelphia)	1983	1989	
PA	Somerset Mental Retardation Unit (Somerset)	1974	1996	
PA	Torrance Mental Retardation Unit (Torrance)	1974	1998	
PA	Warren Mental Retardation Unit (Warren)	1975	1976	
PA	Wernersville Mental Retardation Unit (Wernersville)	1974	1987	
PA	Western Ctr. (Cannonsburg)	1962	2000	
PA	Woodhaven Ctr. (Philadelphia)	1974	1995	Privatized
RI	Dorothea Dix Unit (Cranston)	1982	1989	
RI	Dr. Joseph H. Ladd Ctr. (N. Kingstown)	1908	1994	
RI	Zambrano Memorial Hospital (Wallum Lake)	1967	1989	
SD	Custer State Ctr. (Custer)	1964	1996	
TN	Arlington Dev. Ctr. (Arlington)	1969	2010	
TN	Clover Bottom Dev. Ctr. (Nashville)	1923	2016	Closed
TN	Greene Valley Dev. Ctr. (Greeneville)	1960	2017	Closed
TN	Harold Jordan Habilitation Ctr. (Nashville)	1979	2003	
TN	Winston Ctr. (Bolivar)	1979	1998	
TX	Ft. Worth State School (Ft. Worth)	1976	1996	
TX	Travis State School (Austin)	1961	1996	
VT	Brandon Trng. School (Brandon)	1915	1993	
VA	Eastern State Hospital (Williamsburg)	1773	1990	
VA	Northern Virginia Trng. Ctr. (Fairfax)	1973	2016	Closed
VA	Southside Virginia Trng. Ctr. (Petersburg)	1939	2014	
VA	Southwestern State Hospital (Marion)	1887	1988	
VA	Southwestern Virginia Trng. Ctr. (Hillsville)	1976	2018	Closed
VA	Western State Hospital (Stanton)	1828	1990	
WA	Frances Haddon Morgan Ctr. (Bremerton)	1972	2011	
WA	Interlake School (Medical Lake)	1967	1994	
WV	Colin Anderson Ctr. (St. Mary's)	1932	1998	
WV	Greenbrier Ctr. (Lewisburg)	1974	1994	Closed
WV	Spencer State Hospital (Spencer)	1893	1989	
WV	Weston State Hospital (Weston)	1985	1988	
WI	Northern Wisconsin Ctr. (Chippewa Falls)	1897	2005	Converted

¹ Disposition is closed unless otherwise noted. Downsized - Serving 15 or Fewer People with IDD; Converted - Stopped serving people with IDD, Privatized- Converted from a state operated to a nonstate facility. Merged - combined with another PRF.

2018

private operation or downsized to fewer than 16 people with IDD on or before June 30, 2018. Some facilities on the list merged, split off, or changed names during the years they were in operation. Southwestern Virginia Training Center (Hillsville) which closed June 1, 2018 was the only PRF closure for FY 2018.

Methodology Note

Some facilities reported to be open on the survey of state IDD directors were not included in the PRF survey because they were not in the sample frame when the PRF longitudinal study began. Multiple units co-located on a single campus were sometimes counted differently by the IDD agency than by the PRF respondents. For example,

- Colorado operates 23 ICF/IID units on two campuses: Grand Junction Regional Center (Grand Junction, CO) and Wheat Ridge Regional Center (Wheat Ridge, CO).
- Wisconsin reports three PRFs with 16 or more residents with IDD including the Northern

Wisconsin Center in Chippewa Falls, which was converted to a short-term facility in 2005 but may have people who stay for more than 90 days.

- Other facilities counted separately by state IDD agencies submit a combined PRF survey. For example,
 - The Seguin Unit was combined with the Tacachale Community of Excellence (Gainesville, FL).
 - The two campuses of East Central Regional Hospital (Gracewood & Augusta, GA) were combined.
 - Thad E. Saleeby Ctr. (Hartsville, SC) was combined with the Pee Dee Regional Ctr. (Florence, SC).

TRENDS IN PUBLIC RESIDENTIAL FACILITY UTILIZATION

PRF Status by State

Of the 376 PRFs operating between 1960 and 2018, 260 (69%) closed, converted to a non-state facility or



downsized to 15 or fewer people before July 1, 2017 (See Table 10). One facility closed between July 1, 2017 and June 30, 2018, and 115 remained open on June 30, 2018. Eight PRFs were scheduled to close between July 2018 and June 2022.

As of June 30, 2018, seventeen states had closed all large PRFs serving people with IDD (Alabama, Alaska, the District of Columbia, Hawaii, Indiana, Maine, Michigan, Minnesota, Montana, New Hampshire, New Mexico, Oklahoma, Oregon, Rhode Island, Tennessee, Vermont and West Virginia).

Eight states had closed none of their PRFs, 3 states had closed 1 to 25%, 7 states had closed 26 to 50%, 11 states had closed 51 to 75% and 5 states had closed 76 to 99%.

PRF Closures and Projected Closures 1960 through 2024

The rate of PRF closures in the United States has varied over time (See **Figure 4.6**). One PRF closed between 1960 and 1969. The number of closures increased to 11 between 1970 and 1979, and 45 between 1980 and 1989. The number of PRF closures peaked at 93 during the decade of the 1990's with 53 closures between 1990 and 1994 and 40 closures between 1995 and 1999. There were only 39 closures between 2000 and 2009. However, the number of closures increased to 74 between 2010 and 2019. Five PRFs have anticipated closure dates between 2020 and 2024.

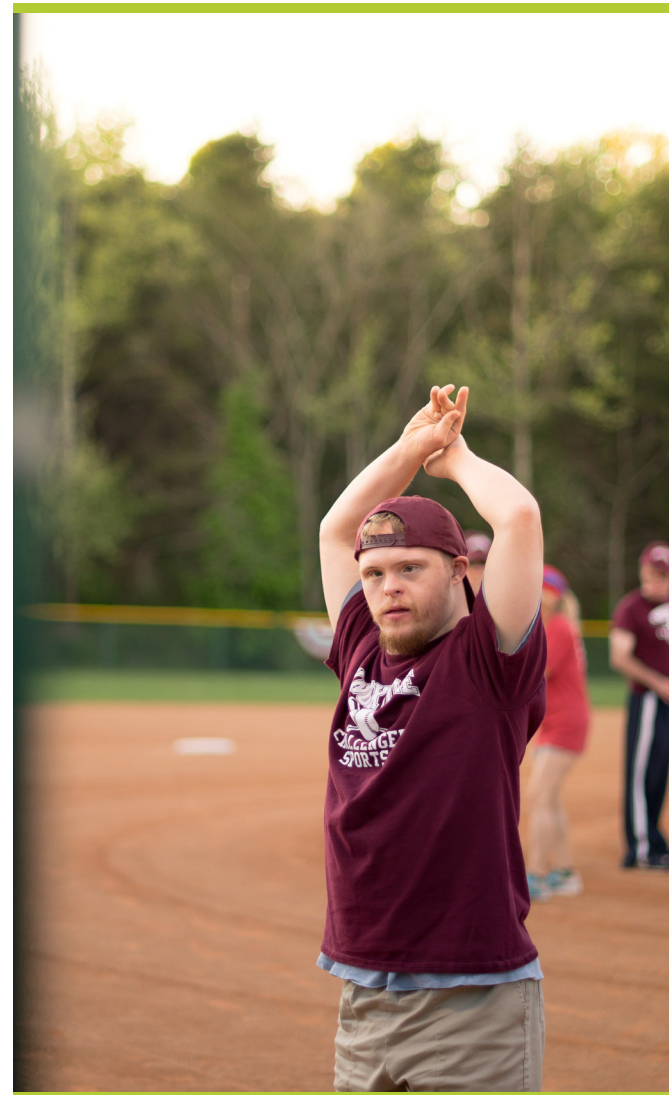
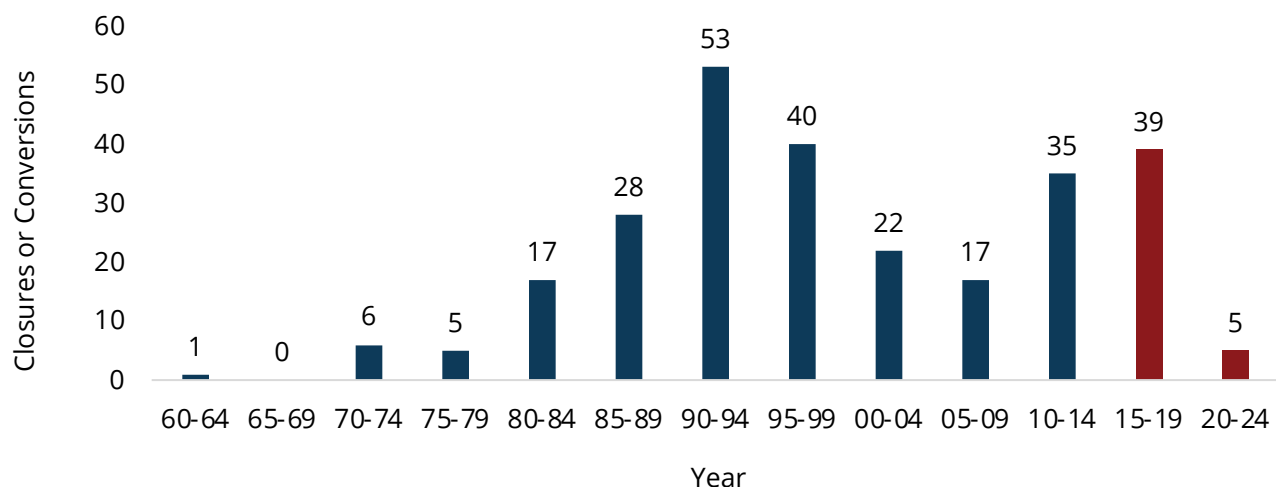


Figure 4.6 PRFs Closed or Converted to Non-IDD Use or Non-state Operation between 1960 and 2018 and Projected Closures for 2019 to 2024 in 5-Year Intervals



Average Daily Population of PRFs

The RISP project has historical data on the average daily population of state-operated IDD facilities of 16 or more people for selected years since 1880, and annually since 1927 (Lakin, 1979). The average daily population of PRFs increased from 2,429 in 1880 to 106,944 in 1940 (See **Table 4.11** and **Figure 4.7a**). The average daily population of PRFs peaked at 194,650 people in 1967. Average daily population of PRFs dropped to 151,532 in 1977,

95,886 in 1987, 56,161 in 1997, 37,172 in 2007, and 17,596 for FY 2018.

Utilization of PRFs per 100,000 of the Population

The utilization of PRFs for LTSS for people with IDD per 100,000 of the population mirrored the trends in the average daily population of those facilities (See Table 4.11). In 1890, there were an estimated 8.1 people with IDD living in PRFs per 100,000 of the population. Utilization rates increased ten-fold to

Figure 4.7a Average Daily Population of PRFs from 1880 to 2018

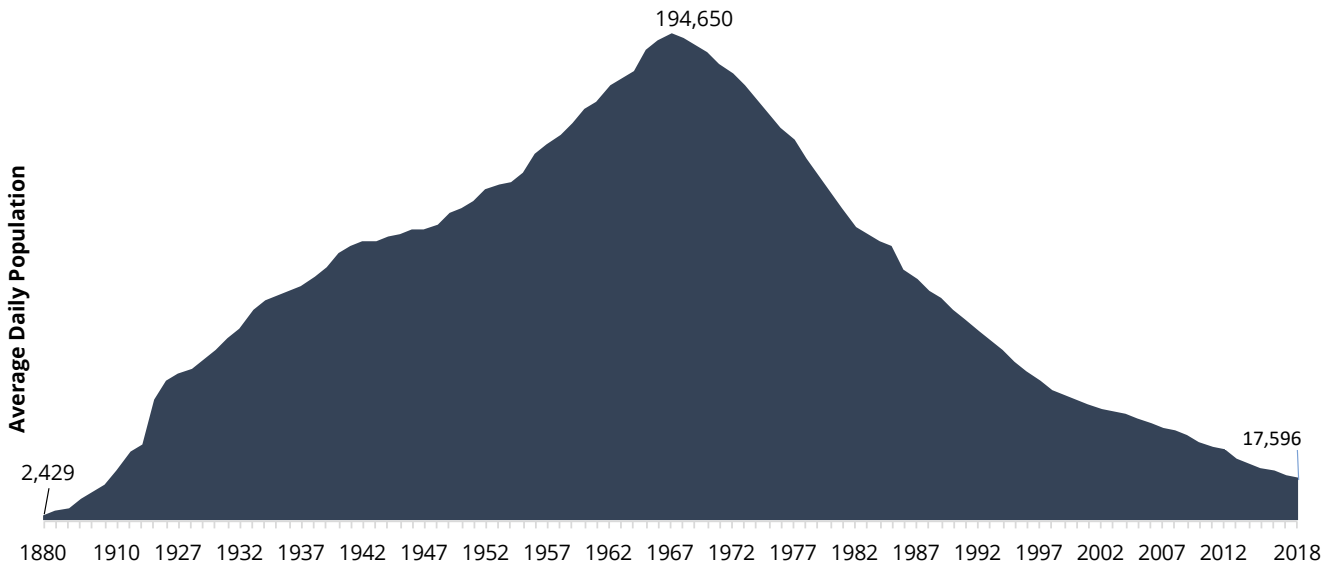
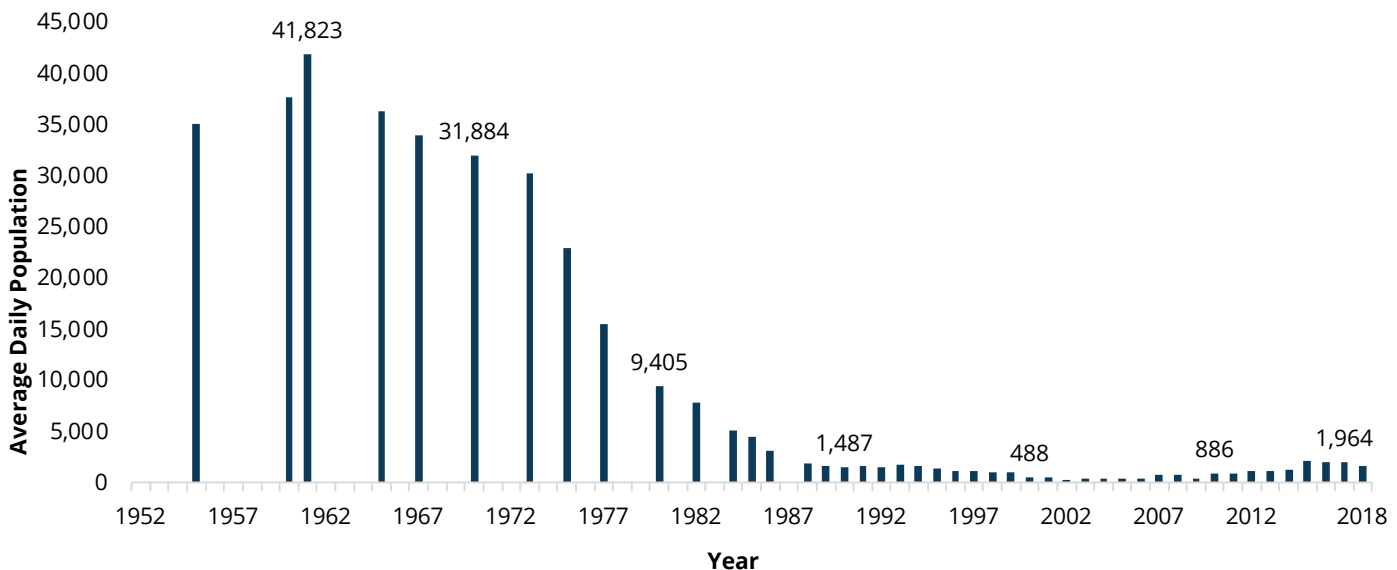


Figure 4.7b People with IDD in State-operated Psychiatric Facilities Selected Years 1950 to 2018



80.9 people with IDD per 100,000 of the population by 1940. Utilization rates of PRFs for people with IDD peaked in 1965 at 113.6 people with IDD in PRFs per 100,000 of the population. It took 25 years, to 1980 to decrease the utilization rates for PRFs in half to 57.7 people per 100,000 of the population. The rate dropped in half again in 15 years to 24.2 per 100,000 by 1995. Twelve years later, in 2007 the utilization rate had dropped in half again to 12.3 people per 100,000. The rate was halved again to 6.0 by 2016, and was 5.4 people per 100,000 in 2018.

State-Operated Psychiatric Facilities

States have reported the number of people with IDD living in state-operated psychiatric facilities since 1950 when there were 23,905 people with IDD living in those facilities (See **Figure 4.7b**). As with PRFs, the number of people with IDD in state psychiatric facilities rose in the 1950s reaching a peak of 41,823 people in 1961. The number of people with IDD in psychiatric facilities dropped to 33,850 in 1977, 2,520 in 1987, and 1,075 in 1997, reaching an all-time low of 267 people in 2002. By 2007 the number of people in state-operated psychiatric facilities had rebounded to 782, and was 1,660 in 2018. Reporting by states on the number of people with ID in state psychiatric facilities has declined since 2000 when 50 of 51 states reported. By 2018, only 34 state IDD agencies were able to report the number of people with IDD living in state operated psychiatric facilities.

Legislation in the late 1960s and early 1970s allowed states to obtain federal Medicaid cost sharing for institutional services provided in ICF/IIDs and in nursing homes, but prohibited use of Medicaid funding people for ages 18 to 64 years in facilities for “mental disease.” This provided a significant incentive for states to move people with IDD from psychiatric facilities to IDD units or separate IDD facilities and likely contributed to the reduction of people with IDD in psychiatric facilities since 1967.

Between 2011 and 2015 the number of people with IDD in state psychiatric facilities increased from 854 to 2,094. It then declined each of the last three years to 1,660 by 2018. The reason for the increased use of psychiatric facilities between 2015 and 2018 compared to the previous decade is unknown, though some variation is likely due to differences in which states report this information each year.

Table 4.10 Operational Status of PRFs by State on June 30, 2018 with Projected Closures to June 2022

State	Operating Between 1960 and 2017	Closed, Converted or Downsized ¹		Open June 30, 2018	Projected to Close July 2018 - June 2022
		1960 to 2017	FY 2018		
AL	5	5	0	0	0
AK	1	1	0	0	0
AZ	4	3	0	1	0
AR	6	1	0	5	0
CA	13	9	0	4	3
CO	3	1	0	2	0
CT	15	11	0	4	0
DE	1	0	0	1	0
DC	3	3	0	0	0
FL	10	7	0	3	0
GA	13	10	0	3	0
HI	2	2	0	0	0
ID	1	0	0	1	0
IL	17	10	0	7	0
IN	11	11	0	0	0
IA	2	0	0	2	0
KS	4	2	0	2	0
KY	5	3	0	2	1
LA	11	8	0	3	0
ME	3	3	0	0	0
MD	9	7	0	2	0
MA	11	9	0	2	0
MI	13	13	0	0	0
MN	9	9	0	0	0
MS	6	0	0	6	0
MO	18	13	0	5	0
MT	2	2	0	0	0
NE	1	0	0	1	0
NV	2	1	0	1	0
NH	2	2	0	0	0
NJ	11	6	0	5	0
NM	3	3	0	0	0
NY	45	40	0	5	0
NC	6	1	0	5	0
ND	2	1	0	1	0
OH	22	14	0	8	0
OK	4	4	0	0	0
OR	3	3	0	0	0
PA	23	18	0	5	3
RI	3	3	0	0	0
SC	5	0	0	5	0
SD	2	1	0	1	0
TN	5	5	0	0	0
TX	15	2	0	13	0
UT	1	0	0	1	0
VT	1	1	0	0	0
VA	8	5	1	2	1
WA	6	2	0	4	0
WV	4	4	0	0	0
WI	3	1	0	2	0
WY	1	0	0	1	0
Reported US Total	376	260	1	115	8
% of Total	100%	69%	0%	31%	2%

¹ Downsized - 15 or fewer people with IDD, Converted - no people with IDD. KY Two facilities of 16+ reported by the state to be state-operated on Table 1.8 have historically been counted as non-state facilities. NY 13 open facilities are not named on Table 4.8.

Table 4.11 Average Daily Population and People Per 100,000 of the US Population of PRFs and People with IDD in State-Operated Psychiatric Facilities, Selected Years 1890-2018

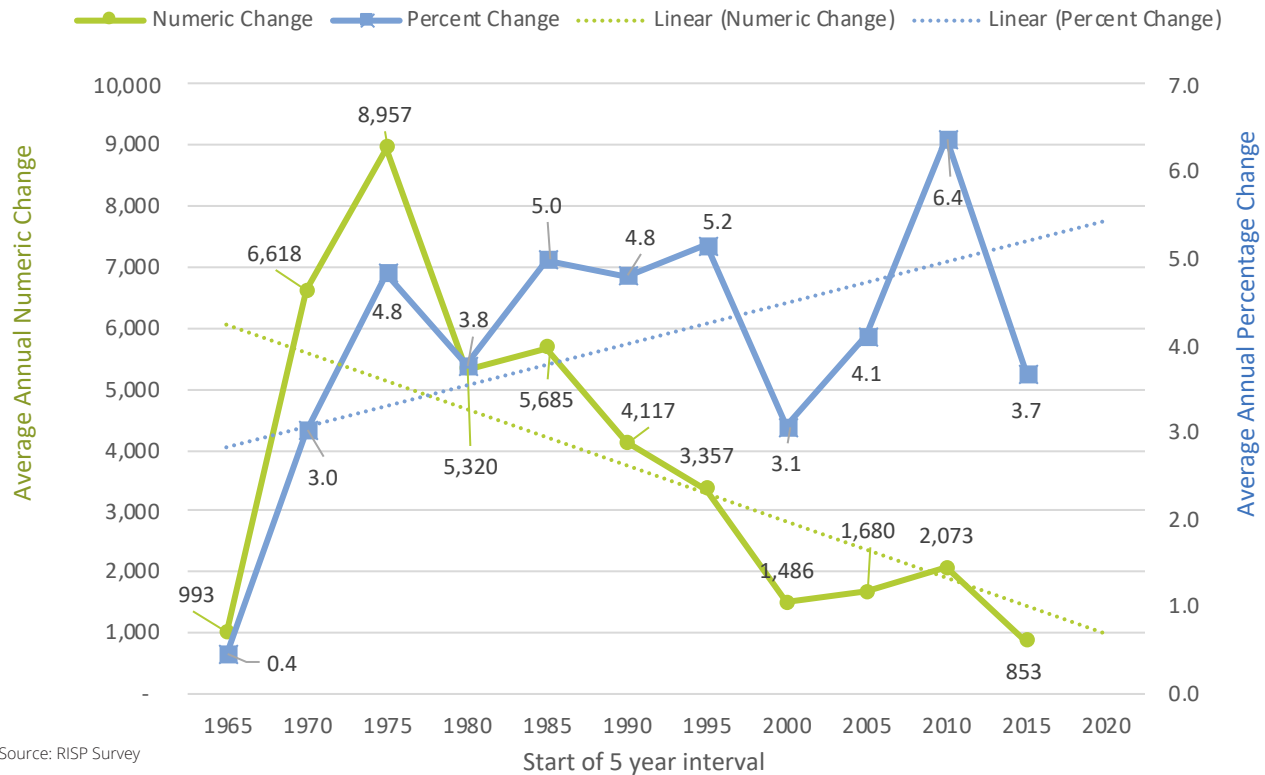
Year	Average Daily Population			Percent in Psychiatric Settings	US Population (100,000)	People Per 100k of the Population		
	State IDD	State Psychiatric ¹	Total			State IDD	State Psychiatric	Total
1890	5,103				630	8.1		
1910	19,499				922	21.1		
1923	47,963				1,119	42.8		
1930	68,035				1,232	55.2		
1935	89,760				1,273	70.5		
1940	106,944				1,322	80.9		
1945	114,018				1,399	81.5		
1950	124,304	23,905	148,209	16%	1,513	82.1	15.8	97.9
1955	138,831	34,999	173,830	20%	1,651	84.1	21.2	105.3
1960	163,730	37,641	201,371	19%	1,807	90.6	20.8	111.5
1965	187,305	36,285	223,590	16%	1,651	113.5	22.0	135.5
1967	194,650	33,850	228,500	15%	1,987	98.0	17.0	115.0
1970	186,743	31,884	218,627	15%	2,051	91.1	15.5	106.6
1975	162,654	22,881	185,535	12%	2,160	75.3	10.6	85.9
1977	151,532	15,524	167,056	9%	2,202	68.8	7.0	75.9
1980	131,345	9,405	140,750	7%	2,277	57.7	4.1	61.8
1985	109,614	4,536	114,150	4%	2,385	46.0	1.9	47.9
1987	95,886	2,520	98,406	3%	2,428	39.5	1.0	40.5
1990	84,239	1,487	85,726	2%	2,500	33.7	0.6	34.3
1995	63,762	1,381	65,143	2%	2,631	24.2	0.5	24.8
1997	56,161	1,075	57,236	2%	2,680	21.0	0.4	21.4
2000	47,872	488	48,360	1%	2,824	17.0	0.2	17.1
2005	40,532	396	40,928	1%	2,962	13.7	0.1	13.8
2006	38,810	361	39,171	1%	2,990	13.0	0.1	13.1
2007	37,172	782	37,954	2%	3,020	12.3	0.3	12.6
2008	35,651	300	35,951	1%	3,018	11.8	0.1	11.9
2009	33,682	417	34,099	1%	3,074	11.0	0.1	11.1
2010	31,654	873	32,527	3%	3,087	10.3	0.3	10.5
2011	29,809	864	30,673	3%	3,116	9.6	0.3	9.8
2012	28,146	1,075	29,221	4%	3,139	9.0	0.3	9.3
2013	23,724	1,151	24,875	5%	3,161	7.5	0.4	7.9
2014	22,262	1,295	23,557	5%	3,189	7.0	0.4	7.4
2015	21,084	2,094	23,178	9%	3,214	6.6	0.7	7.2
2016	19,502	2,044	21,546	9%	3,231	6.0	0.6	6.7
2017	18,807	1,964	20,771	9%	3,257	5.8	0.6	6.4
2018	17,596	1,660	19,256	9%	3,255	5.4	0.5	5.9

Data Source: RISP survey, ¹Number of states not reporting on psychiatric settings by year: 2000 (1); 2001 (3); 2002 (3); 2003 (3); 2004 (2); 2005 (3); 2006, 2007 and 2008 (4); 2009 (3); 2010 (5); 2011 (6) 2012 (0); 2013 (21); 2014 (16); 2015 (10); 2016 (9); 2017 (14); 2018 (17) ²Data imputed based on adjacent years

However, as we saw on **Figure 4.5**, in 2018 18% of all admissions to PRFs were from mental health facilities, and 7% of people discharged were sent to mental health facilities. It will be important to continue to monitor the movement of people with IDD between PRFs and other types of institutions

such as nursing homes, correctional facilities and mental health facilities.

Figure 4.8 Average Annual Change in the Number of People with IDD in PRFs and State Psychiatric Facilities in Five-Year Intervals 1965 to 2018 with Linear Trend Lines



Data Source: RISP Survey

Rates of Population Change in State-Operated IDD and Psychiatric Facilities

Another way to look changes in the populations of PRFs and state-operated psychiatric facilities is to compare average annual numeric change to average annual percentage change (See **Figure 4.8**). The numeric decline in people with IDD in PRFs or state-operated psychiatric facilities was highest between 1975 and 1979 with an average decline of 8,957 people per year. The average annual numeric decline decreased steadily after 1975 to 926 people per year between 2015 and 2018. Expressed as the percentage change in the population of PRFs and state psychiatric facilities, the annual rate increased from 0.4% per year between 1965 and 1969 to a peak of 6.4% per year between 2010 and 2014. The annual change slowed to 4.0% per year between 2015 and 2018.

population of PRFs dropped 87% from 131,345 to 17,596. In addition to the 17 states that closed all PRFs during this period, ten states reduced their total PRF populations by 90% to 99%, 15 states reduced their average daily populations by 75 to 89%, seven states reduced their average daily populations by 50% to 74%, and two reduced their populations by less than 50%.

Between 2010 and 2018, one additional state (Tennessee) closed its last PRF. The population decline in PRFs between 2010 and 2018 averaged 44% and ranged from 4% in Nevada to 100% in Tennessee. States that reduced their PRF populations by more than 50% between 2010 and 2018 were California (69%), Georgia (70%), Idaho (69%), Louisiana (56%), Massachusetts (50%), Missouri (53%), New York (87%), Ohio (52%), and Virginia (84%).

State Trends in Average Daily Populations

State trends in the average daily population of PRFs from 1980 to 2018 are shown on **Table 4.12**. Between 1980 and 2018, the average daily

Annual Number of Admissions, Discharges and Deaths

Table 4.13 shows annual admissions, discharges, and deaths for PRFs for selected years between 1950 and 2018. Transfers between PRFs are not

Table 4.12 Average Daily PRF Population by State Selected Years 1980 to 2018

State	Average Daily Population									% change	
	1980	1985	1990	1995	2000	2005	2010	2015	2018	1980-2018	2010-2018
N States	51	51	51	47	42	42	40	37	34	51	34
AL	1,651	1,422	1,305	985	642	212	178	0	0	-100	N/A
AK	86	76	58	33	0	0	0	0	0	-100	N/A
AZ	672	538	360	183	166	138	119	95	83	-88	-30
AR	1,550	1,254	1,260	1,262	1,229	1,079	1,067	913	905	-42	-15
CA	8,812	7,524	6,768	5,494	3,879	3,307	2,149	1,077	660	-93	-69
CO	1,353	1,125	466	241	129	110	DNF	28	24	-98	DNF
CT	2,944	2,905	1,799	1,316	992	847	705	493	361	-88	-49
DE	518	433	345	308	256	123	71	54	49	-91	-31
DC	775	351	309	0	0	0	0	0	0	-100	N/A
FL	3,750	2,268	1,992	1,502	1,508	1,341	963	848	698	-81	-28
GA	2,535	2,097	2,069	1,979	1,510	1,202	802	259	238	-91	-70
HI	432	354	162	83	0	0	0	0	0	-100	N/A
ID	379	317	210	139	110	94	68	24	21	-94	-69
IL	6,067	4,763	4,493	3,775	3,237	2,833	2,183	1,723	1,662	-73	-24
IN	2,592	2,248	1,940	1,389	854	456	205	0	0	-100	N/A
IA	1,225	1,227	986	719	674	646	525	400	346	-72	-34
KS	1,327	1,309	1,017	756	379	360	340	311	301	-77	-11
KY	907	671	709	679	628	489	170	263	266	-71	56
LA	3,171	3,375	2,622	2,167	1,749	1,571	1,144	453	509	-84	-56
ME	460	340	283	150	0	0	0	0	0	-100	N/A
MD	2,527	1,925	1,289	817	548	380	138	135	94	-96	-32
MA	4,531	3,580	3,000	2,110	1,306	1,089	759	478	379	-92	-50
MI	4,888	2,191	1,137	392	271	173	0	0	0	-100	N/A
MN	2,692	2,065	1,392	610	42	29	25	0	0	-100	N/A
MS	1,660	1,828	1,498	1,439	1,383	1,359	1,324	1,100	964	-42	-27
MO	2,257	1,856	1,860	1,492	1,286	1,152	671	410	317	-86	-53
MT	316	258	235	163	131	84	52	52	0	-100	N/A
NE	707	488	466	414	401	372	182	114	109	-85	-40
NV	148	172	170	160	157	93	47	47	45	-70	-4
NH	578	267	87	0	0	0	0	0	0	-100	N/A
NJ	7,262	5,705	5,069	4,325	3,555	3,096	2,711	1,701	1,362	-81	-50
NM	500	471	350	221	0	0	0	0	0	-100	N/A
NY	15,140	13,932	7,694	4,552	2,466	2,233	2,019	648	261	-98	-87
NC	3,102	2,947	2,654	2,288	1,939	1,736	1,515	1,328	1,205	-61	-20
ND	1,056	763	232	156	144	140	120	82	68	-94	-43
OH	5,045	3,198	2,665	2,150	1,996	1,728	1,376	923	660	-87	-52
OK	1,818	1,505	935	618	391	368	270	16	0	-100	N/A
OR	1,724	1,488	838	462	62	43	22	0	0	-100	N/A
PA	7,290	5,980	3,986	3,460	2,127	1,452	1,189	973	825	-89	-31
RI	681	415	201	0	0	0	0	0	0	-100	N/A
SC	3,043	2,893	2,286	1,788	1,129	953	786	681	672	-78	-15
SD	678	557	391	345	196	172	149	139	117	-83	-21
TN	2,074	2,107	1,932	1,669	948	680	416	127	0	-100	-100
TX	10,320	9,638	7,320	5,459	5,431	4,977	4,337	3,241	2,964	-71	-32
UT	778	706	462	357	240	230	215	208	188	-76	-13
VT	331	200	180	0	0	0	0	0	0	-100	N/A
VA	3,575	3,069	2,650	2,249	1,625	1,524	1,197	534	187	-95	-84
WA	2,231	1,844	1,758	1,320	1,143	973	914	777	681	-69	-25
WV	563	498	304	94	0	0	0	0	0	-100	N/A
WI	2,151	2,058	1,678	1,341	900	590	448	357	314	-85	-30
WY	473	413	367	151	113	98	83	72	61	-87	-26
Estimated US Total	131,345	109,614	84,239	63,762	47,872	40,532	31,654	21,084	17,596	-87	-44

Data Source: RISP Survey, ^d Other date (Usually a different fiscal year or the previous year). ^e Estimate. ^{DNF} Did not furnish. ^{N/A} No people in large state facilities in 2010, 2015, or both. * See state notes in the Appendix.

Table 4.13 Change in Estimated Average Daily Population and Annual Admissions, Discharges and Deaths in PRFs Selected Years 1950-2018

Year	Average Daily Population	Annual Number of			Net 1 year Change
		Admissions	Discharges	Deaths	
1950	124,304	12,197	6,672	2,761	
1955	138,831	13,906	5,845	2,698	5,363
1960	163,730	14,182	6,451	3,133	4,598
1965	187,305	17,225	9,358	3,585	4,282
1967	194,650	14,904	11,665	3,635	(396)
1970	186,743	14,979	14,702	3,496	(3,219)
1975	168,214	18,075	16,807	2,913	(1,645)
1980	128,058	11,141	13,622	2,019	(4,500)
1985	109,614	6,276	8,619	1,508	(3,851)
1990	84,732	5,034	6,877	1,207	(3,050)
1995	63,697	2,338	5,337	1,068	(4,067)
2000	47,872	1,936	2,425	915	(1,404)
2005	40,532	2,106	2,561	909	(1,364)
2010	30,602	1,833	2,690	820	(1,677)
2011	29,809	1,593	2,690	810	(1,907)
2012	27,665	1,141	2,436	747	(2,042)
2013	24,779	1,184	2,453	630	(1,899)
2014	22,437	1,235	1,997	643	(1,406)
2015	21,084	1,248	1,921	661	(1,334)
2016	19,502	1,014	1,897	635	(1,518)
2017	18,807	1,095	1,642	591	(1,138)
2018	17,596	1,059	1,453	632	(1,026)

Data Source: RISP Survey

included. In 1950, PRFs reported an average daily population of 124,304 with 12,197 admissions (10% of the average daily population), 6,672 discharges (5%), and 2,761 deaths (2.2%). In 2018, the average daily population was 17,596 with 1,059 admissions (6%), 1,453 discharges (8%), and 632 deaths (4%).

The number of annual admissions to PRFs grew from 12,197 in 1950 to a peak of 18,075 in 1975. However, by 1986, the number of annual admissions had dropped to 6,535 and by 2000 had dropped to 1,936. Between 2000 and 2010 the annual number of admissions held steady at between 1,800 and 2,200 people. The number of annual admissions declined from 1,593 in 2011, to 1,059 by 2018.

The number of discharges per year grew from 6,672 in 1950 to a peak of 16,807 in 1975 before dropping below 10,000 by the early 1980's, to 5,034 by 1990 and to 2,425 by 2000. Annual discharges remained above 2,000 until 2014 when 1,997

people were discharged. Total discharges in 2018 were 1,453.

Annual deaths in PRFs, peaked in 1967 at 3,635, dropped below 2,000 in in the early 1980's, and below 1,000 by 2000. The number of deaths per year in PRFs declined from 915 in 2000 to 591 in 2017 but increased slightly in 2018 to 632.

Annual Admissions, Discharges and Deaths as a Proportion of the Average Daily Population

Admissions as a proportion of the average daily population ranged from 8% to 11% between 1967 and 1975. As the average daily population of PRFs declined, admissions as a proportion of the average daily population dropped from 11% in 1975 to 6% in 1990 and was between 4% and 6% of the average daily PRF population between 1990 and 2018 (See **Figure 4.9**).

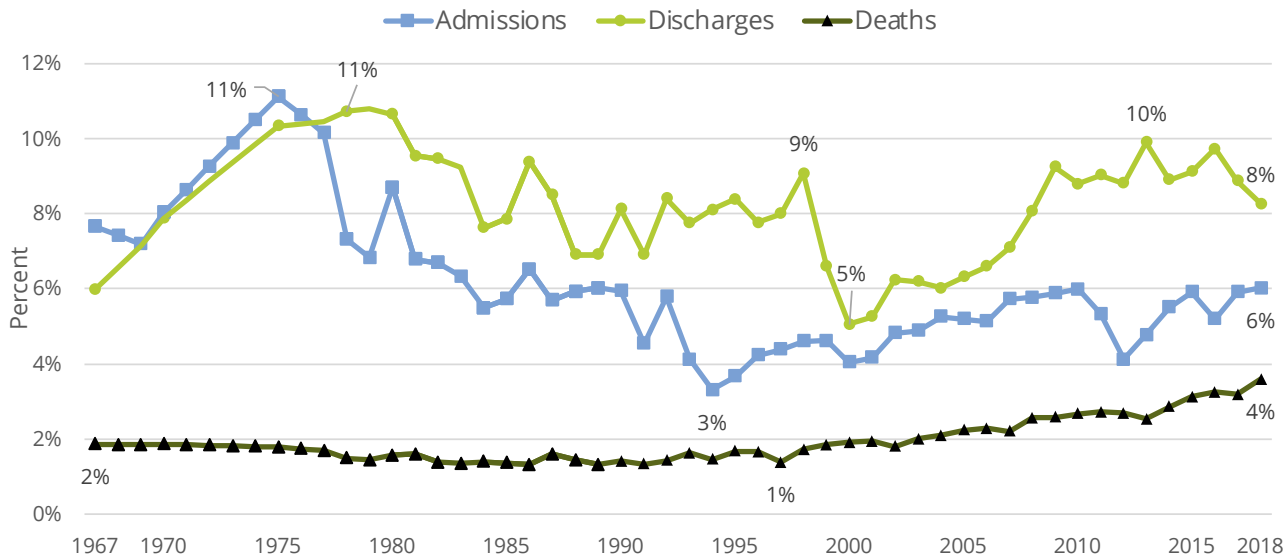
Annual discharges as a proportion of the average daily population increased from 3.9% in 1960 to 11% by 1978. The proportion declined from 11% in 1980 to 7% by 1989. The proportion remained 7% and 9% between 1990 and 1998 but dropped to 5% in 2000. The proportion rose to 10% in 2013 and 2016 before declining to 8% by 2018.

Deaths as a proportion of the daily population averaged 2% from 1950 through 1981. It was between 1 and 2% between 1981 and 1997. It averaged 1% from 1982 through 1997, 2% from 1998 through 2007, 3% from 2008 through 2017, and was 4% in 2018. The gradual increase in deaths as a proportion of the average daily population is a reflection of the overall increase in age amongst people living in PRFs.

TRENDS IN AVERAGE ANNUAL PER PERSON EXPENDITURES

Average annual per person expenditures for people living in PRFs were \$746 in 1950 (\$7,898 in 2018 inflation adjusted dollars, See **Table 4.14**). In inflation adjusted dollars annual per person expenditures were \$30,102 in 1970, one year before enactment of the ICF/IID program, average annual per person expenditures. By 1980, inflation adjusted expenditures had increased to \$76,005 ad

Figure 4.9 Annual PRF Admissions, Discharges and Deaths as a Proportion of the Average Daily Population 1967 to 2018



Data Source: RISP Survey

ICF/IID regulations, court decisions and settlement agreements drove increases in expenditures with their requirements to reduce overcrowding, upgrade staffing levels, increase participation in meaningful daily activities and improve physical environments. As the populations of PRFs declined, per person costs increased as fixed costs (e.g., grounds, utilities, food service, laundry, physical plant and so forth) were shared by fewer people and inflation adjusted expenditures increased from \$100,938 in 1985, to \$291,551 in 2016. The trend toward increased average daily expenditures ended in 2017 and in 2018 was \$274,173.

TRENDS IN CHARACTERISTICS OF PEOPLE WITH IDD LIVING IN PRFS

The proportion of PRF residents who were ages 22 to 39 years declined from 41% in 1977 to 23% in 2008, has been between 21% and 19% since 2008. The proportion ages 40 to 62 years increased from 19% in 1977 to 49% in 1998, and 61% in 2008 but then gradually declined to 50% by 2018. Finally, the proportion of residents who were 63 years or older has grown steadily, increasing from 4% in 1977 to 8% in 1998, 12% in 2008, and to 25% in 2018.

Table 4.14 Annual Per Person Expenditures for People with IDD in PRFs Selected Years 1950-2018

Year	Cost (\$)	Cost (\$1=2018)
1950	746	7,898
1955	1,286	12,137
1960	1,868	15,903
1965	2,361	18,827
1970	4,635	30,102
1975	10,155	47,742
1980	24,944	76,005
1985	44,271	103,678
1990	71,660	139,011
1995	85,760	141,709
2000	113,863	166,428
2005	148,811	192,796
2010	195,197	225,667
2011	226,106	252,418
2012	237,149	260,412
2013	246,063	265,542
2014	235,856	249,360
2015	263,196	277,921
2016	278,858	291,551
2017	253,187	260,457
2018	274,173	274,173

Data Sources: RISP Survey, ⁵; Inflation <https://data.bls.gov/cgi-bin/cpi/calc.pl>

Between 1977 and 2018, the number of people in PRFs

- Ages 21 years or younger declined from 54,400 to 664
- Ages 22 to 39 years declined from 61,956 to 3,676
- Ages 40 to 62 years declined from 28,711 to 8,858
- Ages 63 years or older declined from 6,044 to 4,359

Level of Intellectual Disability

Between 1964 and 2018, the proportion of people in PRFs with no or mild ID declined from 18% in 1964 to a low of 7% in 1987 but steadily increased to 14% in 2014 where it remains in 2018. The proportion of people in PRFs with moderate ID declined from 22% in 1964 to 9% in 1998 before increased to 12% in 2008, 13% in 2012, 14% in 2014, and 15% in 2018. The proportion of people in PRFs with severe ID decreased from 33% in 1964 to 16% in 2008, and was 17% in 2018. Finally, the proportion of people with profound ID increased from 27% in 1964 to 46% in 1977 and 65% in 1998. Between 2008 and 2018 the proportion declined from 58% to 54%.

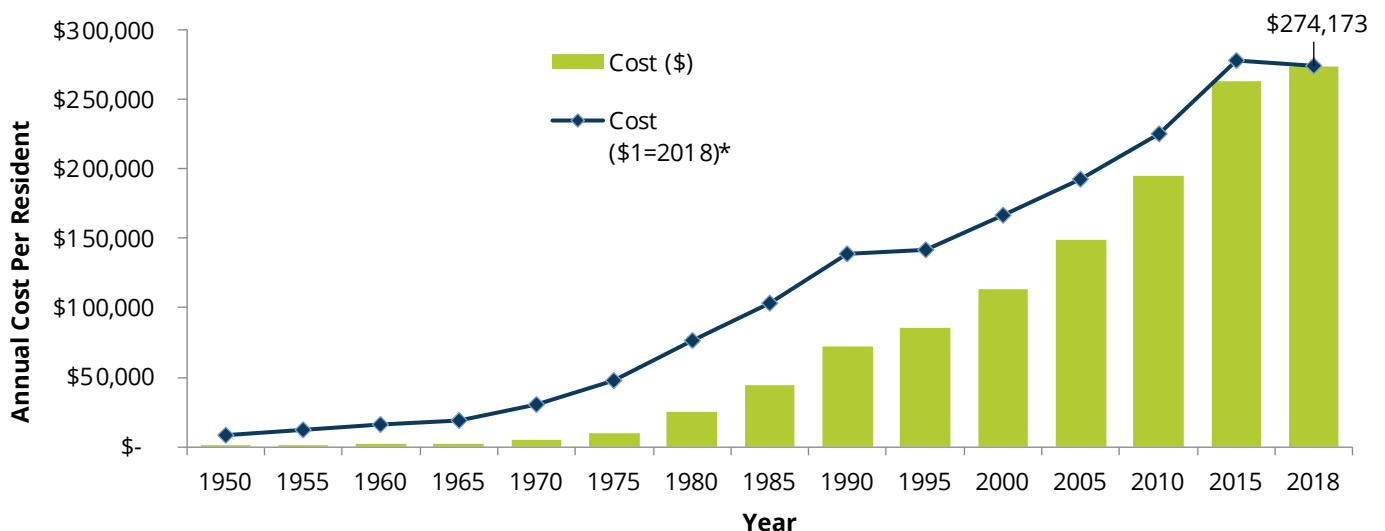
Between 1964 and 2018, the number of people living in PRFs with

- Mild or no ID decreased from 32,328 to 2,055
- Moderate ID decreased from 39,512 to 2,170
- Severe ID decreased from 59,297 to 2,421
- Profound ID decreased from 48,492 to 7,860

Other Conditions and Characteristics

The proportion of people living in PRFs who had epilepsy declined from 46% in 1998 to 37% in 2018. The proportion who had ASD was 19% in 2017 and 20% in 2018. The proportion with cerebral palsy increased from 19% in 1977 to 24% in 1998 but then declined to 16% by 2018. The proportion of people in PRFs who had a behavior disorder that required a planned intervention increased from 25% in 1977 to 58% in 2018. The proportion of people in PRFs who had prior involvement with the criminal justice system was 5% in both 2017 and 2018. Short-term admissions as a proportion of the average daily population decreased from 6% in 2017 to 3% in 2018.

Figure 4.10 Average Annual per Person Expenditures for State-Operated IDD Facilities Serving 16 or More People 1967 to 2018



Data Sources: FY 2018 RISP Survey, s Inflation <https://data.bls.gov/cgi-bin/cpicalc.pl>

Table 4.15 PRF Population Characteristics June 30th of Selected Years 1977 to 2018 (in percent)

Characteristic (Percent)		Year					
		1977	1987	1998	2008	2017	2018
Estimated total residents		151,112	94,695	51,485	35,035	18,239	17,557
Gender	Male	57%	57%	60%	63%	64%	63%
Age	0-21 Years	36	13	5	5	4	4
	22-39 Years	41	54	38	23	20	21
	40-62 Years	19	27	49	61	52	50
	63+ Years	4	6	8	12	24	25
Level of Intellectual Disability	Mild/No ID	10	7	8	14	14	14
	Moderate	16	10	10	12	14	15
	Severe	28	20	18	16	16	17
	Profound	46	63	65	58	55	54
Other Conditions	Epilepsy			46	44	39	37
	Autism					19	20
	Cerebral Palsy	19	21	24	23	17	16
	Behavior Disorder	25	41	44	52	56	58
	Prior Criminal Justice Involvement					5	5
Short Term Stays						6	3

Data Source: PRF Survey

Figure 4.11 Average Daily Population of PRFs and Percent 21 Years or Younger, 1950 to 2018

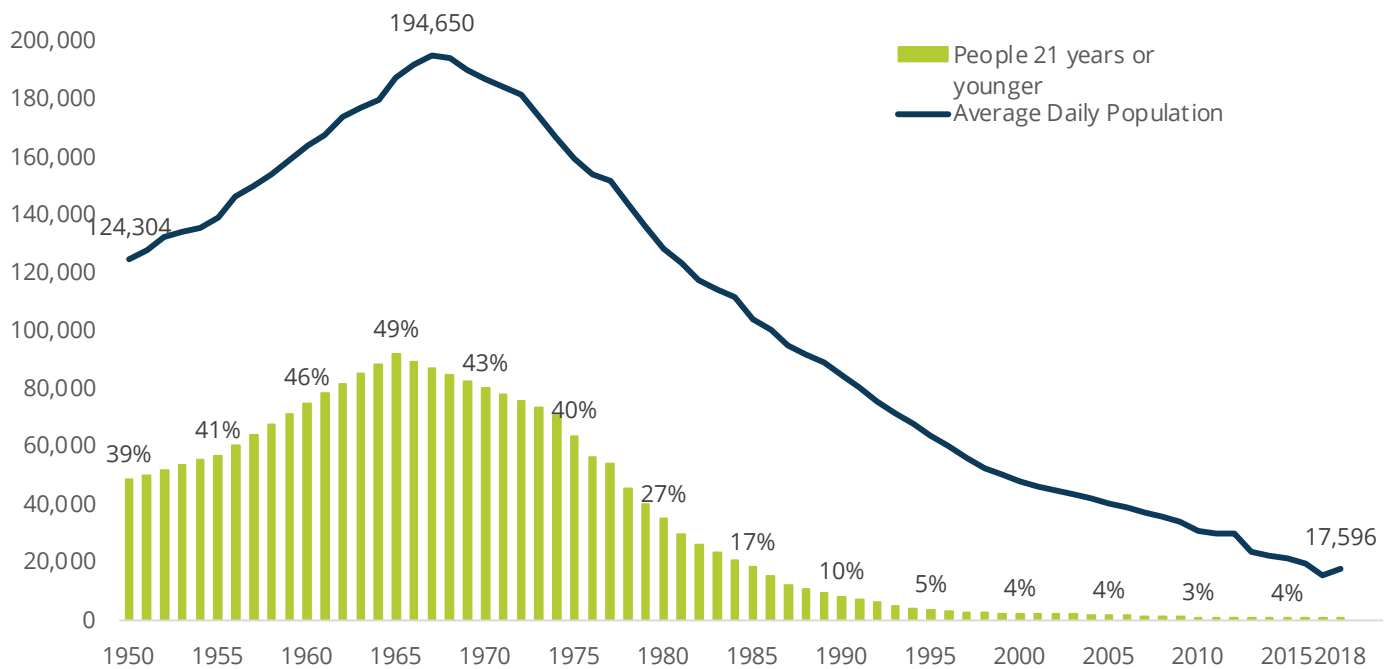
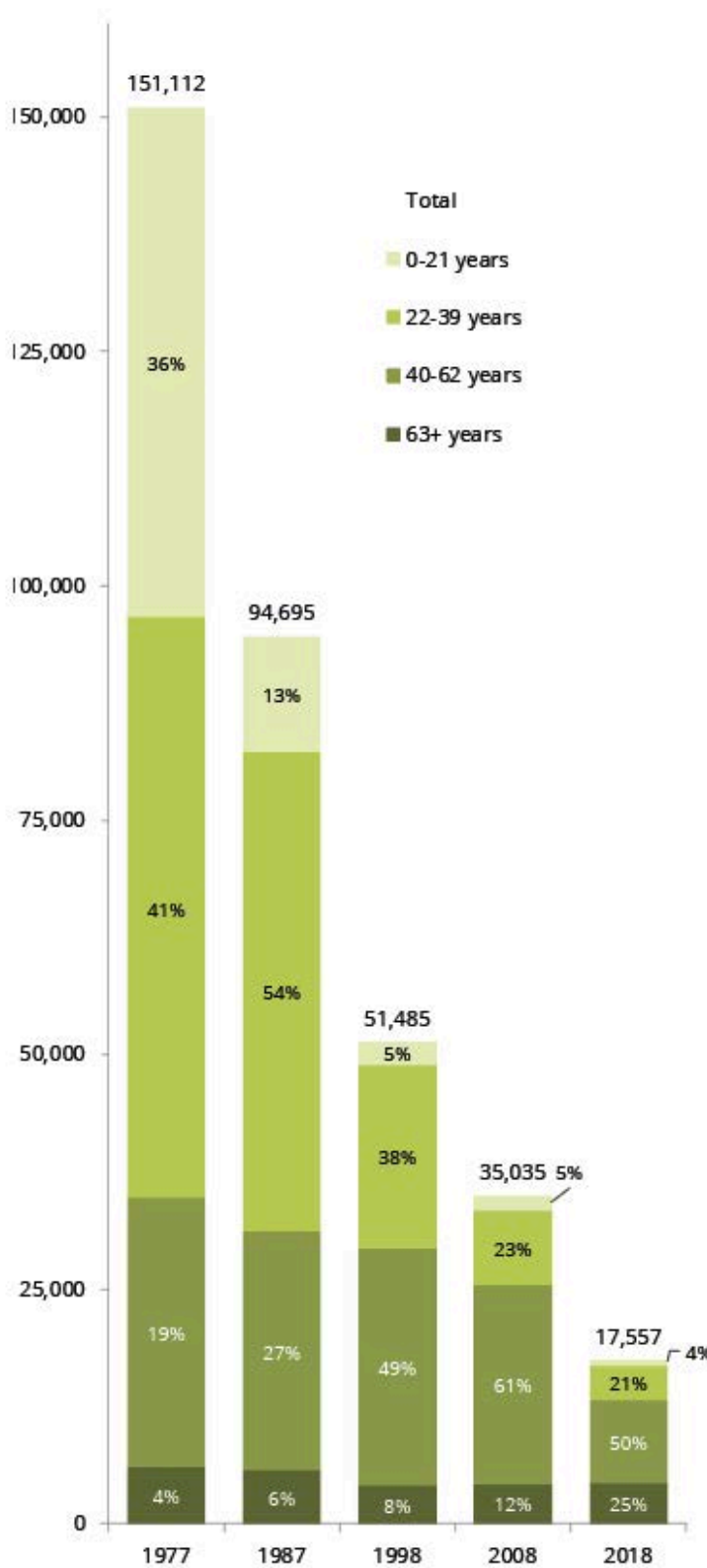
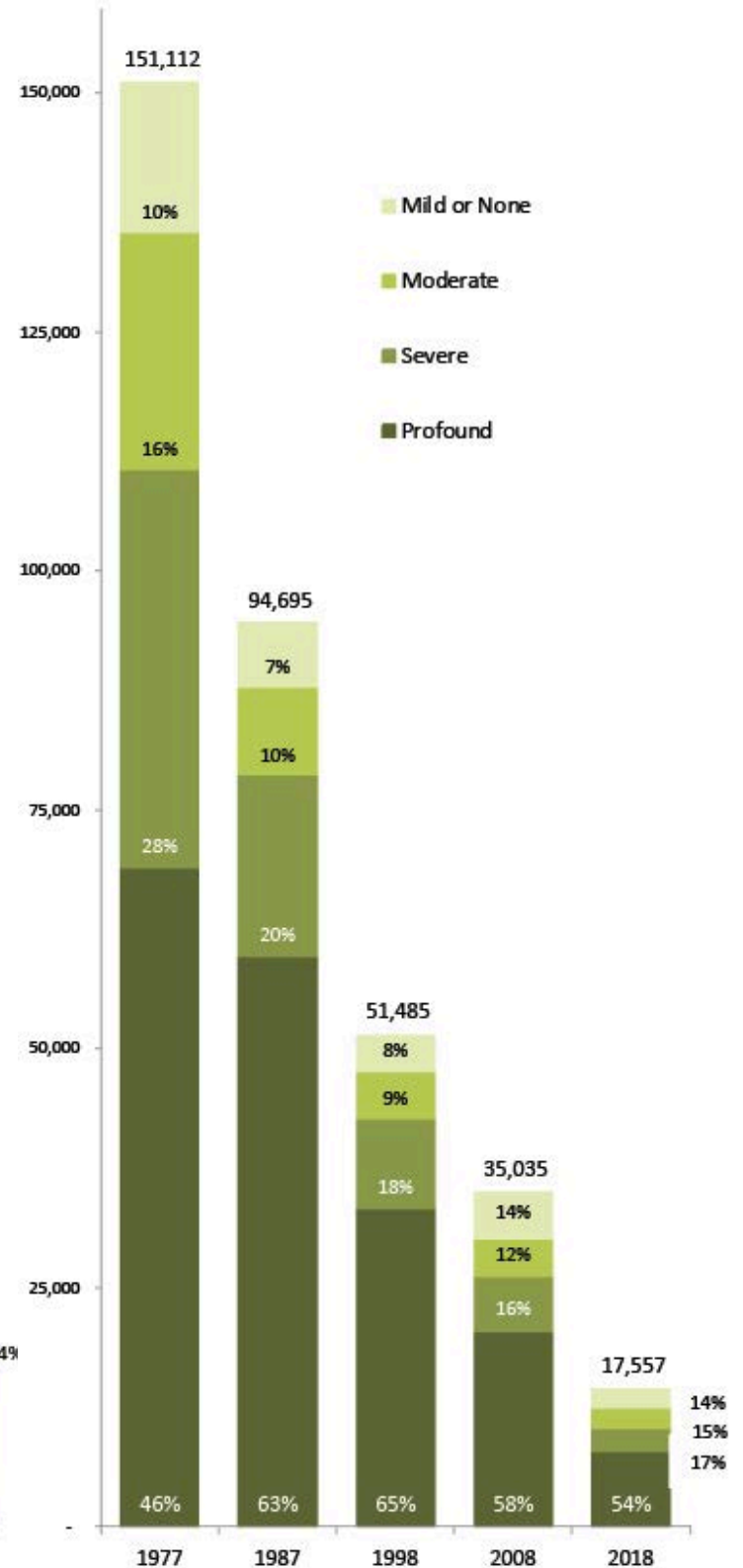


Figure 4.12 Estimated Number and Proportion of People in PRFs by Age Group on June 30 of Selected Years 1977 to 2018



Data Source: PRF Survey. Some surveys had incomplete data on age.

Figure 4.13 Estimated Number and Proportion of People with IDD Living in PRFs by Level of Intellectual Disability on June 30 of Selected Years 1977 to 2018



Data Source: PRF survey. This figure excludes people whose level of ID was unknown. Percentages for 2018 were mild or no 14%, moderate 15%, severe 17% and profound 54%.

TRENDS IN PRF ADMISSIONS, READMISSIONS AND DISCHARGES

Previous and Subsequent Residence

Tables 4.16 and 4.17 and Figures 4.14 and 4.15 show changes in the former residence of people admitted or readmitted to a PRF, and in the subsequent residence of people discharged from PRFs from 1985 to 2018. For the figures, we excluded unknown and other settings and combined the remaining setting types into four categories:

- Individualized settings (home of a family member, a host or foster family home, or own home)
- Group IDD settings of 15 or fewer people

- Group IDD settings of 16 or more people
- Non-IDD facilities (mental health facilities, correctional facilities, nursing homes, assisted living facilities)

Admissions

The proportion of PRF residents admitted or readmitted from an individualized setting such as the home of a family member, a host or foster family home or their own home decreased from 35% in 1989 to 21% in 2018. The proportion admitted from a group IDD setting serving 15 or fewer LTSS recipients increased from 8% to 21%. The proportion admitted from an IDD facility serving 16 or more LTSS recipients declined from 23% to 6%. Finally, the

Table 4.16 Previous Place of Residence of Persons (Re) Admitted to Large State IDD Facilities (in Percent) for Selected Years 1985 to 2018

Previous Place of Residence	Year									
	1985	1989	1994	1998	2002	2008	2012	2017	2018	
Home of parents or relative	39	29	19	21	19	21	24	21	18	
Own, Host or Foster Family Home	5	7	2	4	5	7	8	6	3	
Group home (1-6 res.)							6	20	18	
Group home (7-15 res.)							5	6	3	
Group home (15 or fewer res.)	6	8	14	14	16	22	11	25	21	
State or Nonstate IDD Facility (16+ res.)	26	23	32	31	22	20	14	13	6	
Mental health facility	14	16	16	12	16	13	14	13	18	
Correctional facility	2	3	4	10	13	8	13	17	22	
Nursing home, Assisted Living, Boarding Home	9	15	10	8	9	8	16	6	12	

Source: PRF Survey

Table 4.17 Subsequent Residence of People with IDD Discharged From a Public IDD Facility: Selected Years 1985 to 2018

New Place of Residence	Year												
	1985	1989	1994	1998	2002	2008	2010	2012	2014	2016	2017	2018	
Home of parents or relative	17	12	9	11	14	7	8	10	8	11	8	6	
Own, Host/Foster family home	9	9	13	16	11	10	12	15	13	3	6	5	
Group home (1-6 res.)								35	47	22	50	57	
Group home (7-15 res.)								9	6	4	6	2	
Group home (15 or fewer res.)	40	49	56	51	46	47	51	44	54	26	55	59	
Group IDD facility (16+ res.)	21	18	16	11	10	15	15	18	12	35	9	5	
Mental health facility	1	1	1	2	2	4	2	2	2	3	4	7	
Correctional facility	0	1	0	0	3	2	2	1	7	3	8	9	
Nursing home, Assisted Living, Boarding Home	11	9	10	11	14	17	11	10	5	19	10	10	
Total (may not add to 100 due to rounding)	100	100	105	100	99	100	100	100	100	100	100	100	

Data Source: PRF Survey, Percentages exclude unknown.

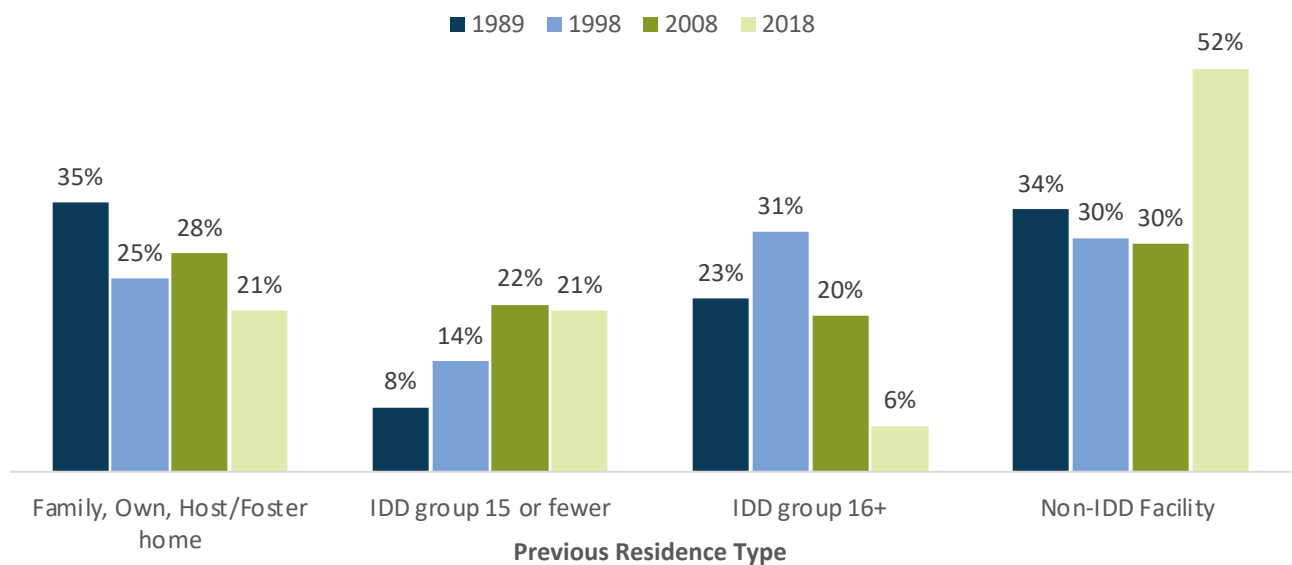
proportion admitted from a non-IDD facility such as a mental health facility, correctional facility, nursing home, or assisted living facility increased from 34% to 52% (21% were admitted from a mental health facility, 25% were admitted from a correctional facility, and 12% were admitted from a nursing home, or assisted living facility. Admissions from mental health facilities were level between 1985 and 2017 at between 12% and 16% but jumped to 21%

for 2018. Admissions from correctional facilities rose dramatically from 8% in 2008 to 25% in 2018.

Discharges

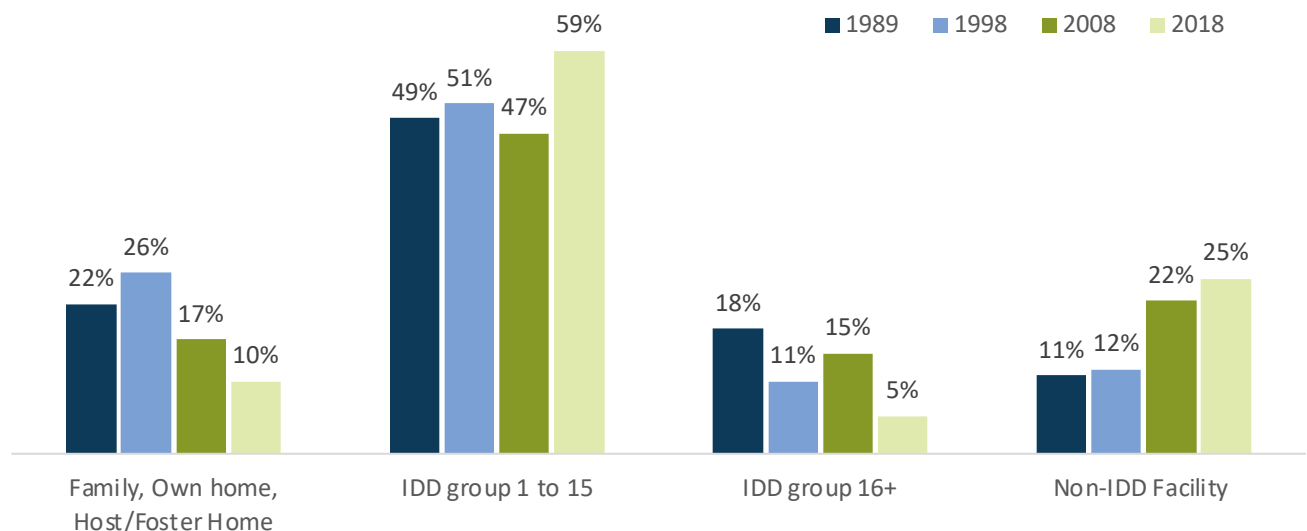
The proportion of PRF residents discharged to the home of a family member, their own home, or a host or foster family home declined from 22% in 1989 to 10% in 2018. The proportion who moved to an IDD group setting serving 15 or fewer LTSS

Figure 4.14 Previous Place of Residence for People (Re) Admitted to a Large State IDD Facilities in Percent Selected Years: 1989 to 2018



Source PRF Survey, Non-IDD Facilities include mental health facilities, correctional facilities, nursing homes, assisted living facilities, and boarding homes

Figure 4.15 Subsequent Residence of People with IDD Discharged From a Public IDD Facility Selected Years 1989 to 2018



Source PRF Survey, Non-IDD Facilities include mental health facilities, correctional facilities, nursing homes, assisted living facilities, and boarding homes



recipients increased from 49% to 59%. By 2018, 57% moved to settings serving 6 or fewer LTSS recipients while only 2% moved to settings serving 7 to 15 LTSS recipients. The proportion who moved to another large IDD setting declined from 18% to 5%. Finally, the proportion who moved to an institution not

specifically designed for people with IDD increased from 11% to 25%. Of those who moved to a non IDD setting 7% went to a mental health hospital or facility, 9% moved to a correctional facility, and 10% moved to a nursing home, assisted living setting or a boarding home.

Table 4.18 Percent of PRFs Providing Services to People Not Living On-Campus by Type of Service 2000 to 2018

Type of Service	Year										
	2000	2002	2004	2006	2008	2010	2012	2014	2016	2017	2018
Behavioral assessment and intervention	51	48	40	53	51	52	33	29	26	21	16
Respite	56	50	38	17	46	38	23	21	14	14	13
Crisis support	44	41	30	40	42	37	26	22	19	12	12
Dental	41	39	34	43	32	38	32	24	26	24	8
Consultant health services	29	28	25	32	25	22	14	22	7	10	8
Vocational training	25	31	26	9	29	24	21	20	9	15	4
Other	15	11	10	10	7	9	12	5	7	8	8
Average number of services provided	6	5	4	5	5	4	3	3	2	1	1

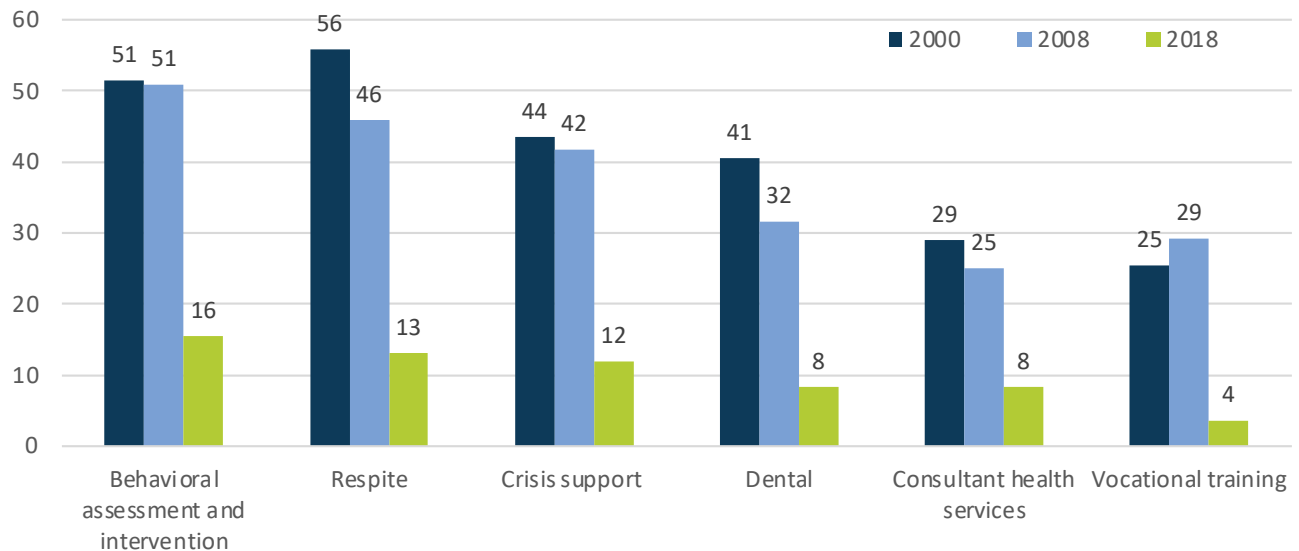
Data Source: PRF Survey, N = 84 facilities reporting in 2018. Each facility could report offering multiple types of services.

Training and Technical Assistance Provided to People Outside of PRFs

Historically, PRFs provided services both to people living in them and to community members with

IDD (See **Table 4.18** and **Figure 4.16**). However, this changed dramatically between 2000 and 2018. In both 2000 and 2008 more than half of reporting PRFs provided behavioral assessment and intervention services to community members.

Figure 4.16 Percent of PRFs Offering Behavioral Assessment, Dental, Crisis Support, or Respite Services to People with IDD not Living On-Campus 2000 to 2018



2018

More than 40% provided respite and crisis support services, slightly fewer provided dental services (44% in 2000 and 32% in 2008), other consultant health services (29% and 25%), or vocational training (25% and 29%). The proportion of facilities reporting providing these services decline to between 4% for vocational training and 16% for behavioral assessment and intervention services in 2018. Possible factors influencing these changes include a change in locus for technical assistance and services from PRFs to community settings, and increased enforcement of funding rules requiring

money paid to PRFs to be spent on the behalf of people residing in the PRF only.

Staffing Characteristics

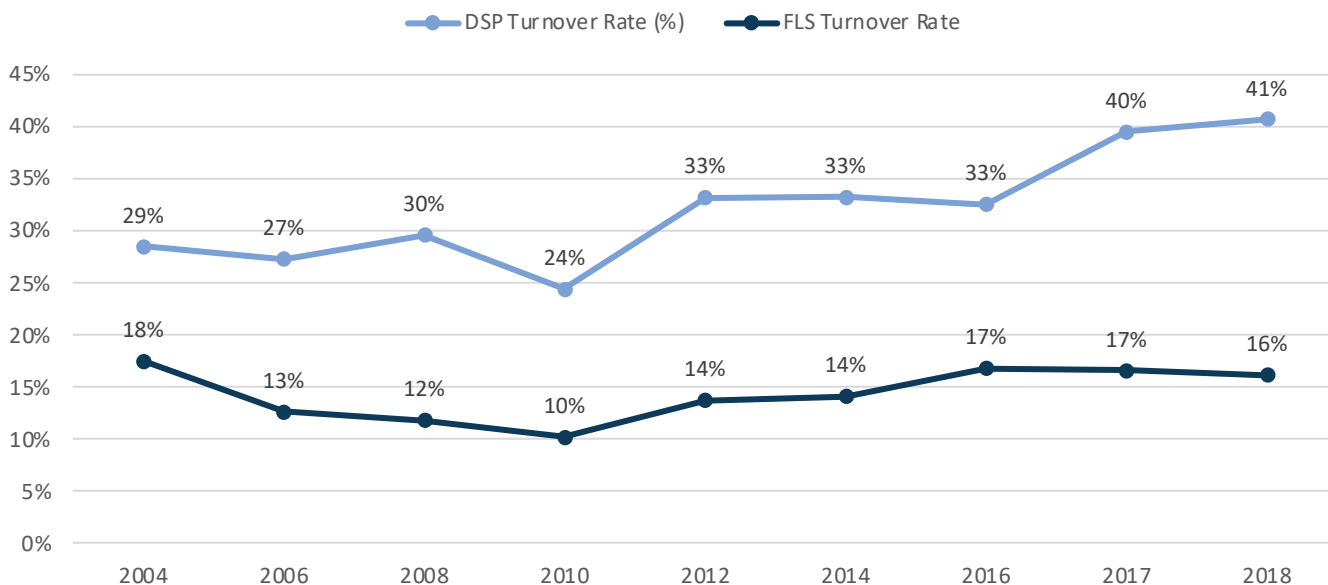
As the number and size of PRFs declined between 2004 and 2018, staffing outcomes also changed (See **Table 4.19** and **Figure 4.17**). Finding and keeping qualified DSPs and FLSs is one of the most commonly mentioned challenges for LTSS providers. DSP starting and average hourly wages kept pace with inflation between 2004 and 2018 with starting wages increasing from \$10.12 in 2004

Table 4.19 Staff Characteristics in Large State-Operated IDD Facilities Selected Years 2004 to 2018

Staffing Characteristics	Year									
	2004	2006	2008	2010	2012	2014	2016	2017	2018	
DSP Vacancy Rate (%)	6%	7%	7%	6%	8%	8%	11%	12%	14%	
DSP Turnover Rate (%)	29%	27%	30%	24%	33%	33%	33%	40%	41%	
DSP Starting Hourly Wage	\$10	\$11	\$11	\$12	\$12	\$12	\$13	\$14	\$15	
DSP Average Hourly Wage	\$13	\$13	\$14	\$15	\$15	\$15	\$16	\$16	\$17	
FLS Vacancy Rate	7%	5%	6%	6%	7%	8%	10%	10%	10%	
FLS Turnover Rate	18%	13%	12%	10%	14%	14%	17%	17%	16%	
FLS Starting Salary	\$27,397	\$29,914	\$30,979	\$35,228	\$33,118	\$34,732	\$36,396	\$38,123	\$41,604	
FLS Average Salary	\$33,299	\$35,783	\$36,924	\$42,590	\$38,062	\$41,132	\$43,374	\$47,678	\$48,127	

Data Source: PRF Survey, DSP Direct Support Professional; FLS Frontline Supervisor

Figure 4.17 DSP and FLS Turnover Rates in PRFs 2004 - 2018



(the equivalent of \$13.07 in 2018 dollars when adjusted to inflation) to \$14.78 in 2018. Average DSP wages increased from \$12.53 in 2004 (\$16.18 in inflation adjusted dollars) to \$16.93 in 2018. Between 2004 and 2018 vacancy rates for DSPs more than doubled from 6% to 14% and DSP turnover rates increased from 29% to 41%. At 41% the turnover rates in PRFs are similar to those reported for community-based LTSS providers.

Historically, turnover and vacancy rates for DSPs in PRFs have been lower than rates for DSPs providing home and community-based supports, but those gaps have narrowed considerably. A survey of 4,400 providers in 26 states for 2018 reported that the national average turnover rate for DSPs was 51%, the average vacancy rates were 12% for full-time positions and 18% for part-time positions. The median DSP hourly wage for providers of residential supports was \$12.57 (National Core Indicators, 2019).

Similar trends were seen for FLSs. Between 2004 and 2018, starting salaries for FLSs increased from \$27,397 to \$41,604, and average salaries increased from \$33,299 to \$48,127. During those years, vacancy rates for frontline supervisors increased from 7% to 10%. Turnover rates for supervisors remained between 10% and 18% between 2004 and 2018.

2018



SECTION FIVE

STATE NOTES AND PROFILES

FY 2018

SECTION 5: STATE NOTES AND PROFILES

STATE NOTES

State Notes describe variations from the survey definitions, alternative data sources used, reasons for large year-to-year changes, and other factors affecting data interpretation.

Alabama

Individuals who were waiting for but not yet getting LTSS were included in the count of service recipients living with a family member in 2014 and 2016, but they were not included in the 2018 count.

Alaska

IDD Group Home settings are licensed to provide services to people with IDD, mental health support needs, and seniors. Though they are licensed to provide services to these populations, they do not necessarily exclusively serve HCBS recipients.

A decrease in IDD grant program funding likely contributed to an increase in the number of people waiting for services in FY 2018.

Arizona

Arizona manages ICF/IID settings within their 1115 Managed Care Demonstration Waiver and reports ICF/IID and Waiver group settings together.

Alabama

Arkansas

Nursing home data are from AHCA (2018c).

California

Colorado

Colorado's two state-operated ICF/IID facilities (Grand Junction Regional Center and Wheat Ridge Regional Center) operate units both on a campus and in the community.

Non-State operated "other" settings are community-based group homes, host homes, or individualized environments where the person lives alone, with family, or with 1-2 other service recipients in their own home, family home, or agency supported home. In FY 2018, people getting Supported Living

Services were counted as living with a family member; in previous years they were counted as living in their Own Home.

Connecticut

The waiting list is not limited to people requesting Medicaid Waiver funded supports. However, most people on Connecticut's waiting list eventually move to a Waiver funded residential setting. Some people on the waiting list are not eligible for Targeted Case Management services.

ICF/IID recipients and expenditures by age included only state-operated ICF/IID settings from FY 2013 through FY 2016.

Delaware

Beginning in FY 2013, people receiving Family Support Specialist services were reported to be living in the home of a family member. In FY 2017, Delaware revised how it reported living arrangements for Waiver recipients. Waiver recipients living in settings other than the home of a family member were not counted.

In FY 2018, people with IDD participating in Delaware's 1115 demonstration were not counted as LTSS recipients.

District of Columbia

Due to updated Waiver rules, residential habilitation (group homes) provided in a home shared by at least four, but no more than six, persons were amended to decrease the setting size, and settings cannot exceed four people. Therefore, settings that had previously been 4-6 may now be group under settings of 3 or less due to vacancies and the rule change.

State-funded non-Medicaid expenditures pay for non-Waiver out-of-state residential facilities, certain adaptive equipment, and meals at day habilitation programs for adults who live with family members.

Florida

Georgia

The Gracewood and Augusta campuses of the East Central Regional Hospital have both SNF and

ICF/IID services. The Georgia Regional Hospital at Atlanta (in Decatur) has SNF services. Data elements for FY 2018 are from external sources or from previous year reporting. Nursing home data are from AHCA (2018c).

Hawaii

Hawaii implemented a new data system in FY 2018, which resulted in some shifts in reporting due to more accurate data. Some Waiver participants were active in the Waiver system but did not have a billed service in FY 2018, which is why there are more participants reported in expenditures than total Waiver participants in the system.

Idaho

The total number of people reported to be on the state IDD caseload for FY 2018 did not include people living in an ICF/IID.

Settings are reported by license or certification size. Some settings were not operating at capacity, or had no residents at all on June 30, 2018.

The significant decrease in expenditures for children on the Medicaid waiver is the result of several factors. First, in FY 2018, DDA terminated the Children's waiver and "redesign", and implemented the Children's DD enhancement program, putting all intervention services into the state plan rather than waiver. This means that children no longer have to meet ICF/ID level of care to qualify for intervention services. Additionally, many schools have implemented intervention plans and programs and a significant number of children aged out of children's services and into adult services in FY 2018.

The significant increase in expenditures for adults on the Medicaid waiver in FY 2018 is in part explained by the increase in children aging into adult services, but was also driven by a settlement agreement that permits adults on the Waiver to utilize the greatest annual DD budget they have been given since 2011 for services while DDA works to determine a court-approved budget allocation process for DD services. ICF/IID expenditures are reported only for a subtotal of all recipients.

Illinois

Prior to FY 2016, the number of people with IDD reported to be waiting for services included some people who were already receiving Medicaid Waiver

funded supports. Beginning in FY 2016, only people living with a family member or in their own home who requested Medicaid Waiver funded supports to begin within the next 12 months are counted.

Indiana

Information about people living in Nonstate Group Home and Own Home settings was not reported until FY 2018.

Iowa

Variation between previous reporting years and SFY 2018 is due to a change in reporting methods that include a more detailed data source. The number of non-state group home settings by size is based on the number of provider agencies and may, therefore, underestimate the total number of homes.

Kansas

Data in Kansas's state profile was updated after the FY 2018 RISP report tables were finalized. The state profile reflects the updated data but the tables in this report do not.

Kentucky

The state reports the total number of providers for Type II (Group Home) and Type III (Host/Family Foster Home); the number of settings by size was imputed based on the total number of recipients living in settings of each size.

In FY 2018, an estimated 10,664 Waiver recipients on the Michelle P Waiver lived in family homes or homes of their own, but Kentucky could not differentiate the number in family homes versus own home settings—these 10,664 are therefore reported in Unknown Setting Type. Nursing home data are from AHCA (2018c). ICF/IID recipients by age includes only people in nonstate ICF/IID.

Louisiana

Louisiana had three state-operated facilities serving 16 or more people with ICF/IID licenses: Pinecrest Supports and Services Center (Pineville), Central Louisiana Supports and Services Center (Alexandria) previously known as the Louisiana Special Education and Transition Center, and East Louisiana State Mental Hospital (a psychiatric facility with 3 ICF/IID-certified units).

2018

Maine

Four short-term state-operated IDD facilities are not counted since stays are limited to 90 days or less. A rise in nonstate-operated host/foster settings in FY 2018 was driven by a new shared living option.

Maryland

People with IDD living in “non-state other” settings receive Community Coordination Services, Behavior Support Services (BSS), Residential, Individual Family Care (IFC), or self-directed supports. The number of people served in FY 2018 increased because individuals receiving services through the state's 1915(i) and (k) programs were included and because Maryland added a Community Supports Waiver and a Family Supports program for people with IDD. Maryland has three state-operated facilities with 16 or more people. One of those, the Secure Evaluation and Therapeutic Treatment Program (SETT Unit), was not described in this report. A description of Maryland's facilities can be found online (<https://dda.health.maryland.gov/Pages/Facilities.aspx>).

Massachusetts

The number of LTSS recipients ages 21 and younger living with a family member have not been reported since 2015. Nursing home data are from AHCA (2018c).

Michigan

Michigan began reporting the number of 1915(b/c) waiver recipients in FY 2011 accounting for the jump in waiver recipients for that year. Data for FY 2018 are from external sources or from 2017. Nursing home data are from AHCA (2018c).

Minnesota

Non-state “Other” settings include Customized Living (Assisted Living) and Board and Lodging. Most Customized Living arrangements are Medicaid Waiver funded. In Minnesota, Waiver funded group homes are typically limited to four or fewer people (with certain exceptions allowing for five people). Claims data do not distinguish between settings of 1-3 and 4-6 people. Minnesota offers HCBS services under state plan authorities 1905(a) and 1915(g) which were not specifically covered on the FY 2018 RISP survey. The total number of LTSS recipients is therefore an undercount.

Mississippi

In FY 2018, MS stopped providing state-operated services other than case management funded by Medicaid 1915(c) and 1915(i) funding authorities. To ensure Conflict Free Case Management, people previously receiving state-operated IDD Waiver-funded residential services were transferred to Certified Private Providers except for those living in one state-operated facility. Four of the 5 large state-operated ICF/IID facilities also provide IDD Waiver Support Coordination (case management) and 1915(i) Targeted Case Management.

The total number of LTSS recipients living with a family member increased as more people began using supports funded by the Medicaid 1915(j) funding authority. For 2018, the number reported included only services in state-operated ICF/IIDs. Nursing home data and nonstate ICF/IID data are from AHCA (2018c).

Missouri

Waiting lists for Waiver funded supports in Missouri were eliminated in FY 2015. Beginning in FY 2015, all of the people reported to be waiting were actually moving through the assessment and provider selection process.

Montana

Since FY 2015, children ages 1-3 receiving Part C and/or Social Services Block Grant (Title XX) funding have been counted in the IDD agency caseload. People 16 years or older served by the state IDD agency are entitled to Medicaid State Plan-funded case management services.

As of June 30th, 2018, the final state-operated ICF/IID was closed by the Montana legislature. There is still, however, one person residing in this setting. This facility was reported in the FY 2017 RISP report as having downsized to fewer than 15 residents. The nonstate “Other” setting was an assisted living facility. Beginning in 2018, MT began using new data reports that provided more accurate data than was previously available. This explains changes in values between FY 2017 and FY 2018.

Nebraska

Beatrice State Development Center campus houses four separately licensed ICF/IID buildings. From FY

2011 to FY 2016, each building was reported as a separate facility.

Nevada

The non-state “other” category includes hospitals, correctional/ incarceration facilities, and similar facilities of 16 or more people. In FY 2018, 102 people on the IDD agency caseload lived in those settings. The number of people waiting for HCBS Waiver services declined in 2018 when additional waiver slots were made available.

New Hampshire

Data for FY 2018 are from external sources or from 2017. Nursing home data are from AHCA (2018c).

New Jersey

The New Jersey IDD agency only serves adults. In FY 2018, 3 people with IDD housed in a separate building of a state operated ICF/IDD had been convicted of crimes and court ordered to a disability rehabilitation setting. The number own home settings is not known and is estimated to be one setting per recipient. Since FY 2013, ICF/IID expenditures and ICF/IID recipients by age have been reported only for state-operated ICF/IID settings. In FY 2018, those numbers exclude 60 people in nonstate ICF/IID facilities. Significantly more people in family homes received waiver services in FY 2018 due to ramp up of the “Supports Program” Waiver, which was implemented in FY 2017.

New Mexico

Non-state IDD group homes and supported living facilities in New Mexico serve a maximum of four people. It is not possible to differentiate between homes with 1 to 3 people and homes with 4 to 6 people. Claims data for supported living services were used to identify FY 2018 recipients and expenditures for LTSS recipients living in nonfamily settings. Beginning in FY 2018, people who had previously been reported as living in host or foster homes are reported to be living with a family member or in an “Unknown” setting type.

New York

The 6,205 people waiting to move to a setting other than the home of a family member in

FY 2018 are people who expressed interest in Office for People with Developmental Disabilities supported housing. They may or may not currently live in family home or own home setting.

North Carolina

People in Black Mountain and O’Berry Centers were included in counts of people in state-operated facilities in FY 2018 but not in previous recent years. Data on residence size for nonstate settings is provided by LME-Managed Care Organizations that may not have access to accurate information on facility size. As a result the reported number of facilities may be an undercount.

North Dakota

In prior years, individuals receiving Infant Development were mistakenly excluded from counts of people in Family Home on the Medicaid Waiver. They are included this year. ICF/IID expenditures are only reported for recipients in non-state settings.

Ohio

People on the agency caseload but not receiving funded LTSS may be on the waitlist, in school, receiving early intervention, or other locally funded services. The waiting list includes people waiting for Medicaid Waiver funded supports who are not already Medicaid Waiver or ICF/IID recipients. It includes some people living in non-family settings. State funded expenditures do not include funds allocated through county boards, which provide many services through local dollars. Nursing home data are from AHCA (2018c).

Oklahoma

Data elements for FY 2018 are from external sources or from previous year reporting.

Oregon

Oregon began offering HCBS through the Medicaid State Plan 1915(k) funding authority in FY 2015. Total Medicaid Waiver recipients and expenditures declined shortly thereafter as recipients moved from Waiver to State Plan 1915(k) funding. However, FY 2018 was the first full year that case management was funded based on an individual’s Medicaid eligibility rather than a procedure code entered by field staff. This, along with regular caseload

2018

growth, greatly increased the number of individuals receiving a Waivered service, as case management remains a service offered on the Waiver.

Pennsylvania

Rhode Island

Rhode Island's DD agency does not utilize a waiting list. Reported ICF/IID expenditures include only the state-operated ICF/IID.

South Carolina

Own home settings could only be reported by the number of contracts held. There is no way to determine through the data the number of people served through each contract. Nursing home data are from AHCA (2018c).

Tennessee

Tennessee stopped accepting applications its 1915(c) Waiver on June 30, 2016 and no longer maintains a waiting list for 1915(c) Waiver funded services. People on the referral list for services under the 1115 Waiver have not been screened for eligibility. The Harold Jordan Center had 12 people on June 30, 2018. Of these 12 people, 5 were Medicaid ICF/IID funded and 7 were state funded. Data for 2018 are undergoing further review and may change from what is reported in this report. 2018 data has been removed from the TN state profile at the state's request.

Texas

The Texas fiscal year ends on August 31 (rather than June 30). All ICF/IID settings in the 1-6 people size category are licensed for six people. Nursing home data are from AHCA (2018c).

Utah

Increased expenditures for people on the Waiver and living at home with family were due to rate increases, and for people ages birth to 21 the addition of roughly 100 individuals to the waiver. ICF/IID recipients and expenditures, and age breakdowns are reported only for state-operated settings. Nursing home data are from AHCA (2018c).

Vermont

The date of birth cut off was incorrect for FY 2015 - FY 2017. This caused an undercount for those three

years, resulting in apparent increase in the number of children served and associated expenditures in FY 2018. Cost per person for people ages birth to 21 receiving state funded services increased in FY 2018 due to un-duplicating previously duplicated cases and no longer including "Employment Program Base" numbers, which lowered the overall recipient count. Vermont reported people receiving Medicaid State Plan funded HCBS but not 1915(i) or 1915(k) in the State Plan category.

Virginia

Data on nonstate Medicaid Waiver funded settings and Waiver expenditures are from a Kaiser Family Foundation Report (O'Malley Watts et al., 2020).

Washington

Washington implemented Medicaid Community First Choice State Plan Services in FY 2016. Personal care services previously funded through a Medicaid Waiver are now funded through the Community First Choice State Plan option. Medicaid State Plan expenditures increased and Medicaid Waiver expenditures decreased when the change was made. The number of people with IDD in Own Home settings varies from year to year because in some years, data were not available for all funding authorities.

West Virginia

Nursing home data are from AHCA (2018c).

Wisconsin

Setting size information was not available for LTSS recipients living in their own home or in a non-state other setting. Until FY 2014, Wisconsin reported only Waiver recipients living in own home, family home and nonstate "Other" settings. Since then, all LTSS recipients living in nonstate settings (including group homes and host or foster family homes) have been reported. Some children with IDD in state-operated settings receive Medicaid State Plan funded services who are not on the DD agency caseload are included as LTSS recipients. Large state-operated IDD facilities in Wisconsin include Central Wisconsin Center in Madison and Southern Wisconsin Center in Union Grove. Though Northern Wisconsin Center was converted into a short-term stay facility in 2005, some residents may stay more than 90 days.

Wyoming

Nonstate “Other” settings include an educational cooperative that provides both day and residential services to children with IDD ages 5 to 21 years. Nursing home data are from AHCA (2018c).

Public Residential Facility Survey Notes

Arkansas

- Boonville Human Development Center: Data on discharges by level of IDD and age breakdowns are estimated. Four people transferred to other facilities in FY 2018.

California

- Canyon Springs Community Facility: The only new admissions were for people who transferred in from FDC or PDC. For direct services provided to the community, 2017 data were used.
- Fairview Developmental Center: For direct services provided to the community, 2017 data were used.
- Sonoma Developmental Center: For direct services provided to the community, 2017 data were used.
- Porterville Developmental Center: The facility has 2 areas: the General Treatment Area (GTA) and the Secured Treatment Area (STA). Only GTA is closing in June 2021. STA will stay open.

Connecticut

- Hartford Regional Center: An estimated 18 DSPs left employment in FY 2018.

Illinois

- Elisabeth Ludeman Center: Five people transferred out from the facility: 1 went to another state-operated IDD facility and 4 to a state-operated MI facility.
- Choate Mental Health and Developmental Center: For current residents, unspecified ID was listed under ‘unknown’.
- Ann Kiley Center: Other direct services provided to the community included behavioral assessment and technical assistance services.

Massachusetts

- Charles V. Hogan Regional Center: Did not discharge any residents other than those there for short-term evaluation and treatment in the

“ESU” – Evaluation and Stabilization Unit. In FY 2018, six people from that unit returned to a group home or family home within 90 days. Other direct services provided to the community included recreational areas are available to community groups. These include their auditorium, gym, adapted gym, and pool.

Mississippi

- Ellisville State School: Some individuals who were discharged went to hospice settings
- Boswell Regional Center: Boswell Regional Center operates several community-based non-ICF/IID homes not located on the campus. People living in those programs have access to the Regional Center amenities.
- North Mississippi Regional Center: Some individuals who were discharged went to in-patient hospice (hospital/institution).

Missouri

- Southeast Missouri Residential Services: Average costs per person per day were \$529 for Popular Bluff, \$615 for Sikeston.

North Dakota

- Life Skills and Transition Center: Twenty of the 32 reported admissions were for short term stays. 20 of the 30 reported discharges were people who were admitted for a short-term stay.

Nevada

- Desert Regional Center: One person with unknown level of ID had Prader-Willi Syndrome. One person with unknown level of ID who was discharged had Fetal Alcohol Syndrome. Other direct services provided to the community included dietary consultations.

New York

- Sunmount Development Center: Other race/ethnicities included Asian or Pacific Islander (1 person), and American Indian/Alaskan (1 person). Race/ethnicity data were missing for 14 people. ID level was not available for 6 people who were new/readmitted and 6 people who were discharged.
- Valley Ridge: Data were missing for level of ID for 2 people, race/ethnicity for 5 people, and level of ID for 2 people who were admitted.

North Carolina

- Murdoch Developmental Center: Levels of ID were unknown for one current resident with ASD, two people with ASD who were admitted or readmitted, and for six people who were discharged (one had borderline ID and 5 had ASD).
- O'Berry Neuro-Medical Treatment Center: The person listed as having no ID has traumatic brain injury which occurred prior to 21st birthday. The current census includes both ICF and SNF beds. The ICF/IID is not admitting new people. Average daily per person expenditures were \$805.26 for the ICF/IID, \$564 for the SNF.

Ohio

- Mount Vernon Developmental Center: One individual was court ordered to the facility. Several others have been involved previously with the criminal justice system or came from jail.

South Dakota

- South Dakota Developmental Center: There are a total of 135 DSP positions. The number of vacancies is not known.

Texas

- Brenham State Supported Living Center: Twenty-three people who live in off-campus group homes receive services at Brenham Production Service (off-campus).
- Denton State Supported Living Center: The only service that they provide individuals living in the community is post-move monitoring for the first year after discharge. This is monitoring services and recommendation from the interdisciplinary team that is included in the community living discharge plan (CLDP). If within the first 90

days there is a potentially disruptive event that happens such as: police involvement, hospital/psych hospital admission, elopement, etc., the interdisciplinary team from the facility would meet and discuss with the provider if additional training would be needed and to share information to prevent the event from happening again. All other services are completed pre-move.

- San Angelo State Supported Living Center: Other direct services provided to the community included sex offender treatment.

Virginia

- Southeastern Virginia Training Center: Other direct services provided to the community included dental services for 281 people.

Wisconsin

- Southern Wisconsin Center: SWC no longer admits long-term residents, any new admits would be short-term only. In FY 2018, 15 short-term residents stayed longer than 90 days.
- Central Wisconsin Center for the Developmentally Disabled: There are 57 individuals who are on psych medications. One individual was discharged to hospice. Other direct services provided to the community included Outpatient Rehabilitation Technology Services. Average daily per person costs were \$1,198 for Short-term behavior units, and \$881 for Long-term care units and Medical short-term care units.

Wyoming

- Wyoming Life Resource Center: Other direct services provided to the community included assistive technology assessment and intervention.

STATE PROFILES

The state and United States profiles show longitudinal changes in residential settings for LTSS recipients with IDD, state IDD agency caseloads, Medicaid Waiver waiting lists and Medicaid recipients by funding authority. They also show expenditures per person by funding authority, setting type, and age. Blank spaces or breaks in a trend line indicate years in which a data element was not collected or for which a state provided incomplete or no data. Large year-to-year changes often reflect changes in state data sources or methodology, the addition or termination of a funding authority, or inclusion of a narrower or broader set of recipients. State Notes describe variations from the survey definitions, alternative data sources used, reasons for large year-to-year changes, and other factors affecting data interpretation. Additional national and state data can be viewed in the RISP project's Chart Gallery at <https://risp.umn.edu/viz>. Survey questions and operational definitions can be found in the Publications section of the RISP website.

IDD Agency Long Term Supports and Services Recipients by Residence Type

The first chart shows the number of long-term supports and services (LTSS) recipients by residence type (family home, own home, host or foster family home, and group homes) by year. Group settings such as ICFs/IID or Medicaid Waiver-funded group homes are broken down according to the number of people with IDD sharing the home (1 to 3, 4 to 6, 7 to 15 or 16 or more).

Caseload, LTSS and Medicaid Recipients and Waiting for Waivers

The second chart shows changes over time in the number people served by state IDD agencies, the number of people with IDD receiving one or more LTSS in addition to case management, and the number of people with IDD waiting for Medicaid Waiver funded services while living with a family member or in their own home. The waiting list numbers do not include people who already live in a group home or another LTSS setting or who already receive some Medicaid Waiver funded supports. The chart also shows changes in the number of LTSS recipients whose services are funded under the Medicaid ICF/IID program, or under one of several Medicaid Waiver funding authorities (1115, 1915 (a) (b) or (b/c), 1915(c)).

Average Annual Medicaid per Person Expenditures for FY 2018

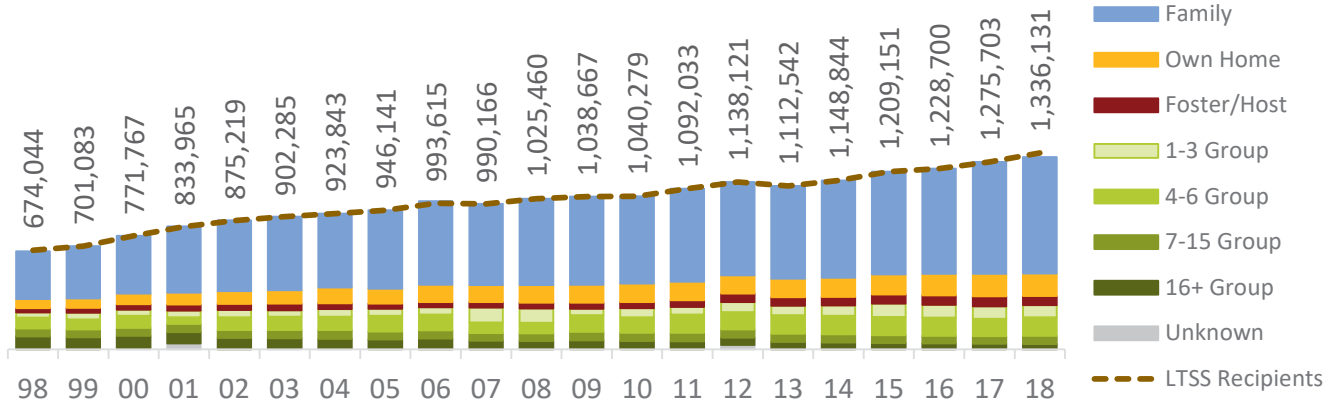
The third chart shows average annual per person expenditures for people with IDD living in an ICF/IID, or who receive LTSS funded by specific Medicaid Waiver funding authorities (1115, 1915 (a)(b) or (b/c), 1915(c)). When available, for Medicaid Waiver recipients, annual per person expenditures are also broken down by recipient age as of June 30 (birth to 21 years or 22 years or older) and by living arrangement (family home or any other setting).

United States

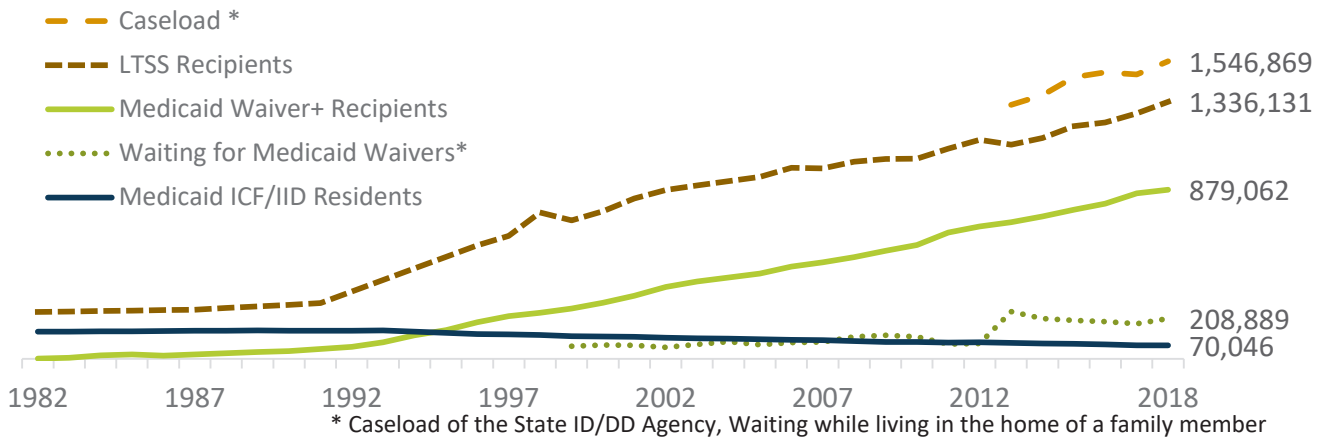
Fiscal year 2018

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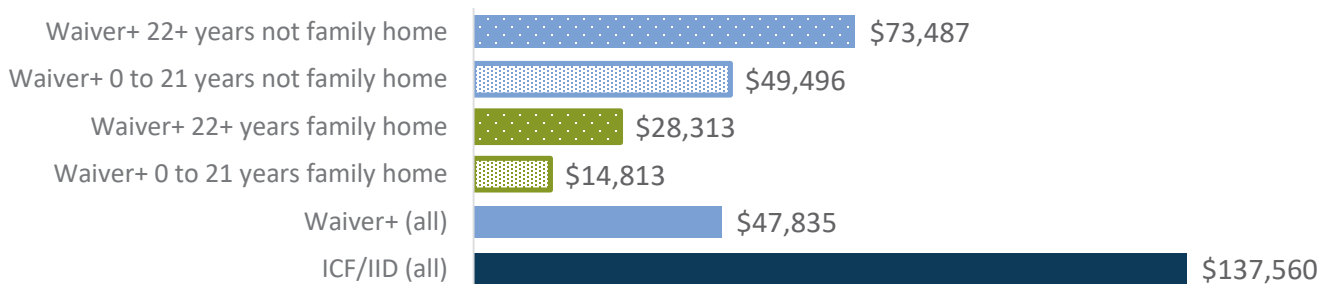
IDD Agency Long Term Supports and Services Recipients by Residence Type



Caseload, LTSS and Medicaid Recipients and Waiting for Waivers* 1982-2018



Average Spending Per Person by Medicaid Authority in Fiscal Year 2018



Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

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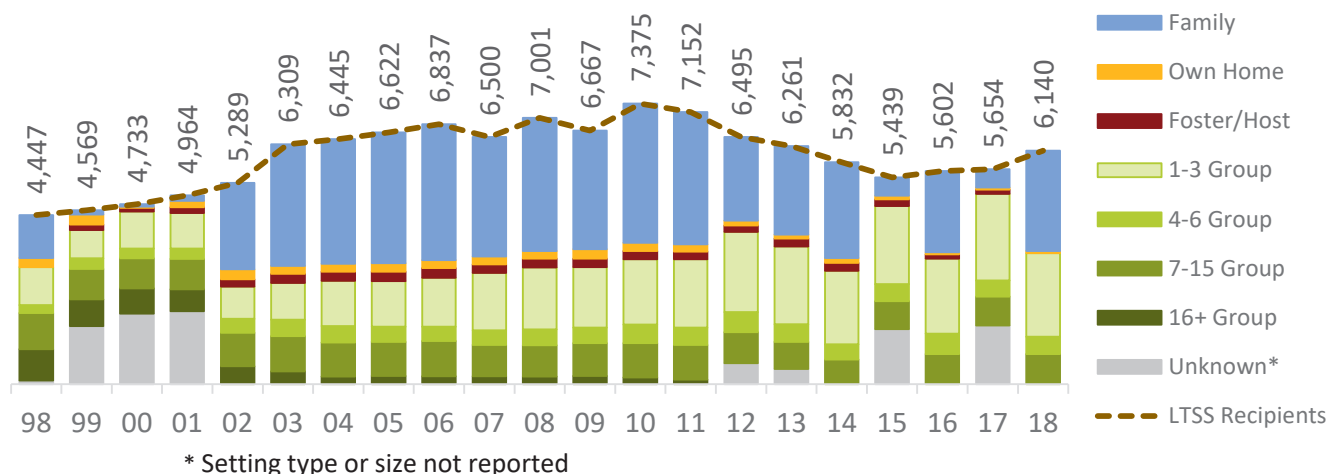
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Alabama

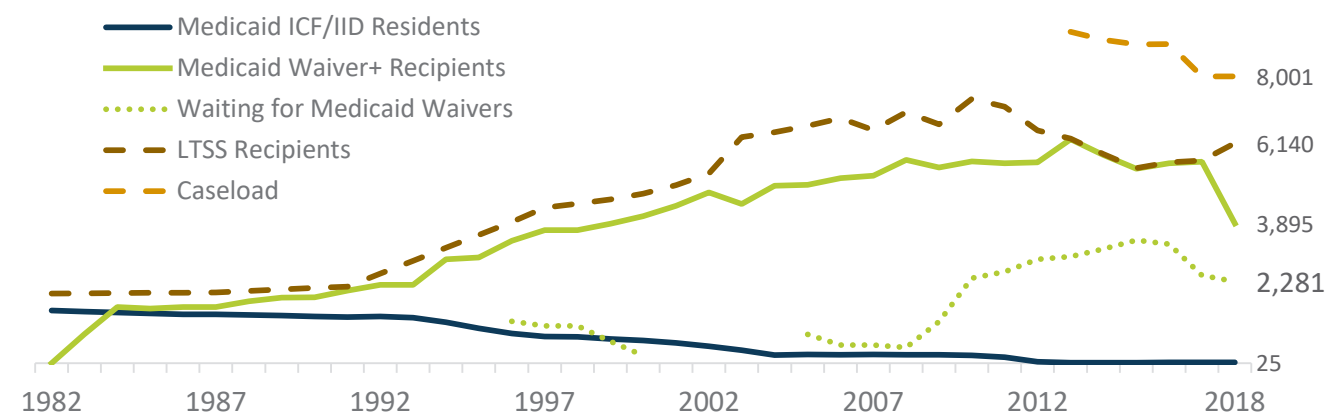
Fiscal year 2018

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IDD Agency Long Term Supports and Services Recipients by Residence Type



Caseload, LTSS and Medicaid Recipients and Waiting for Waivers* 1982-2018



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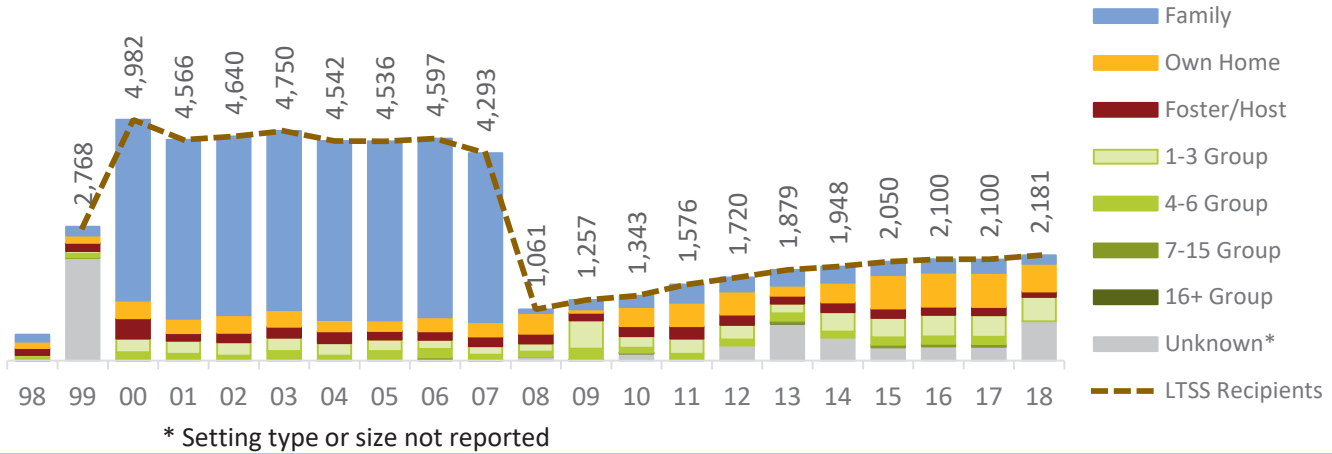
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Alaska

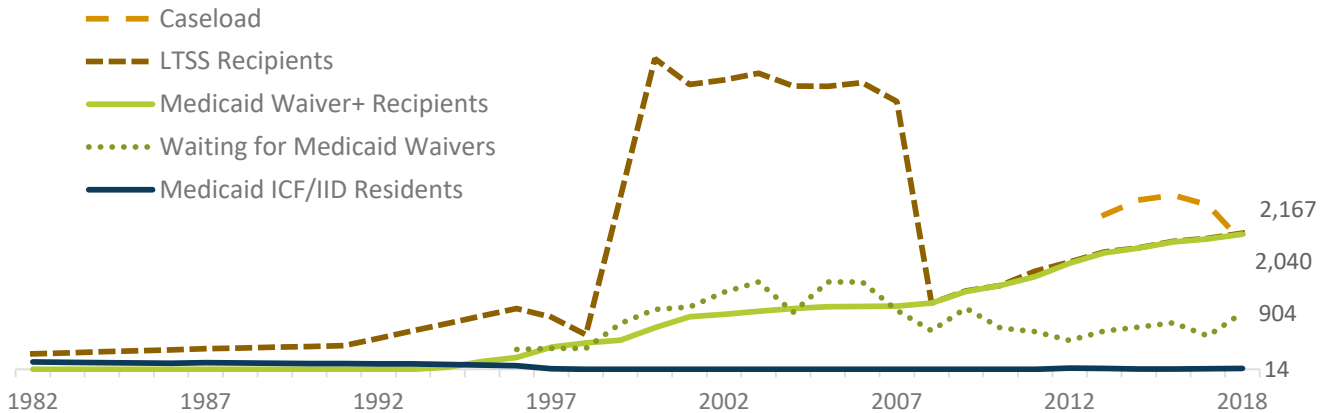
Fiscal year 2018

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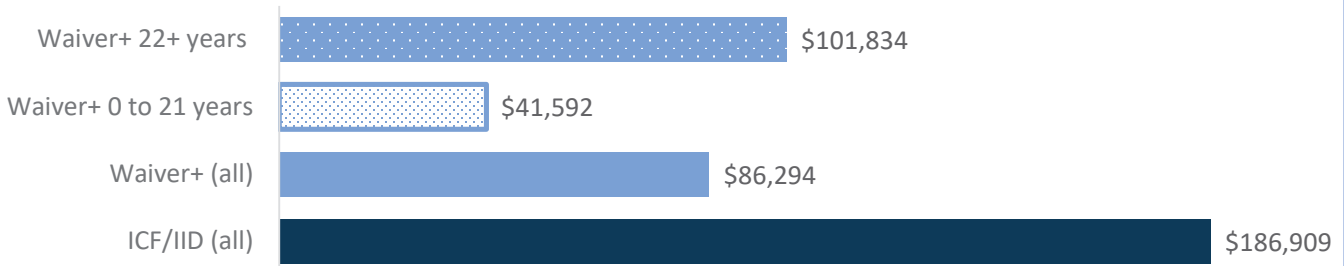
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Caseload, LTSS and Medicaid Recipients and Waiting for Waivers* 1982-2018



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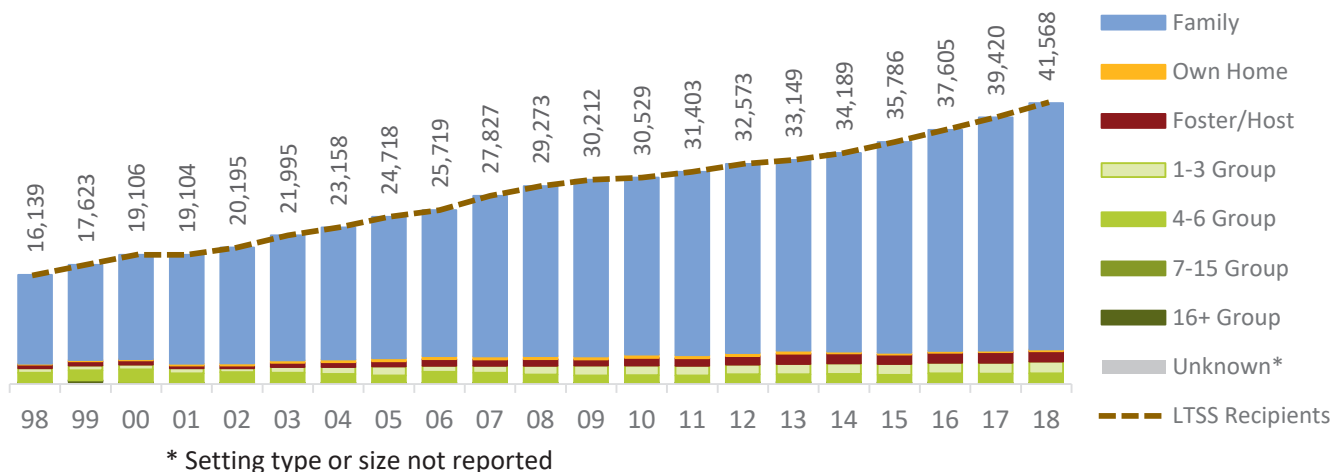
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Arizona

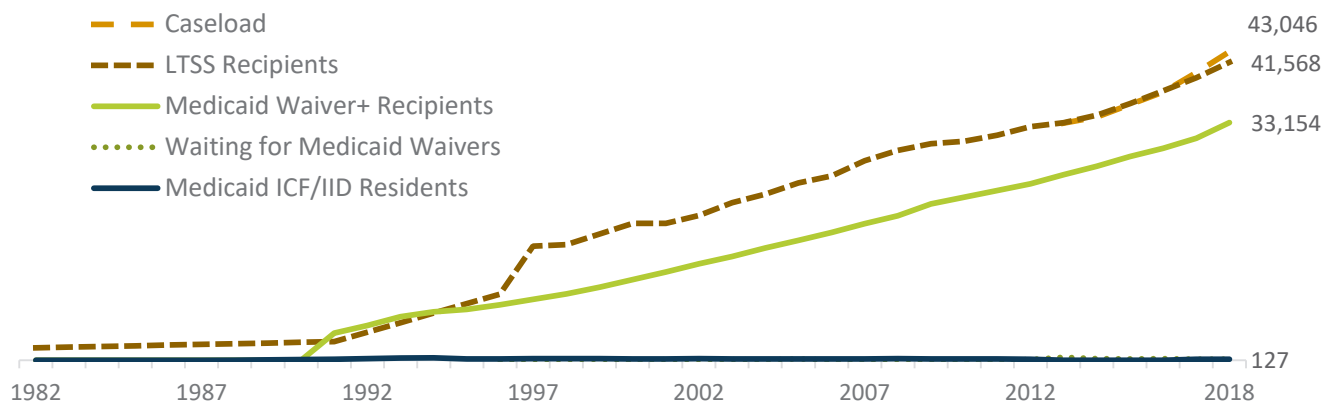
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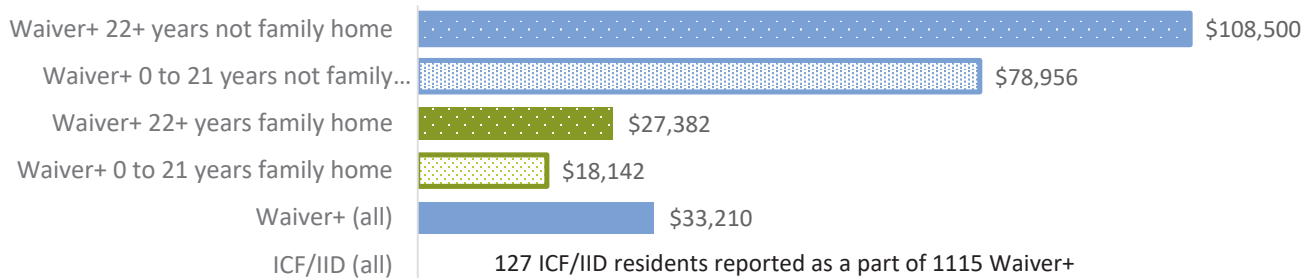
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Caseload, LTSS and Medicaid Recipients and Waiting for Waivers* 1982-2018



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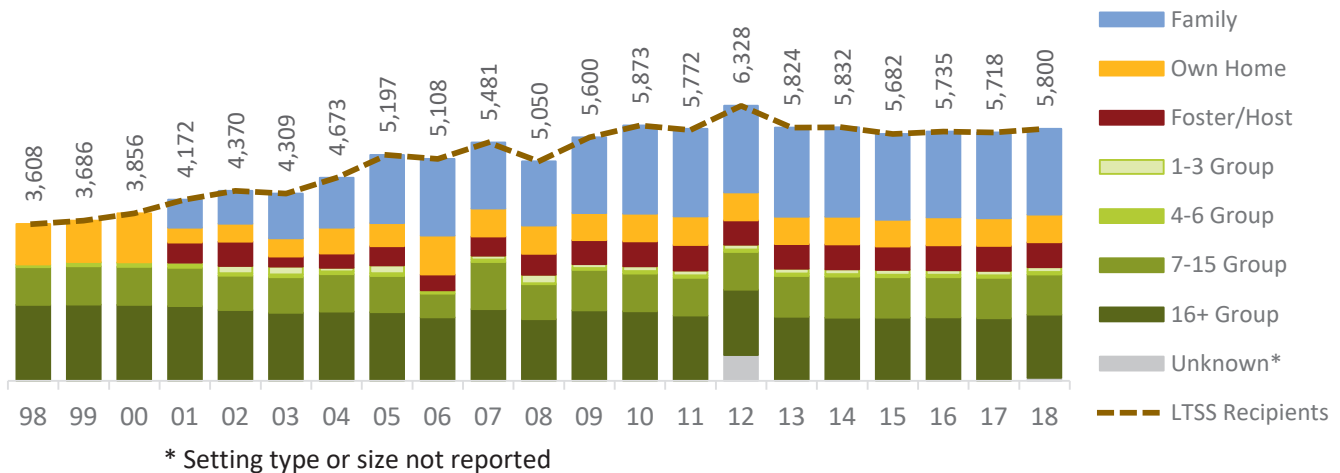
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Arkansas

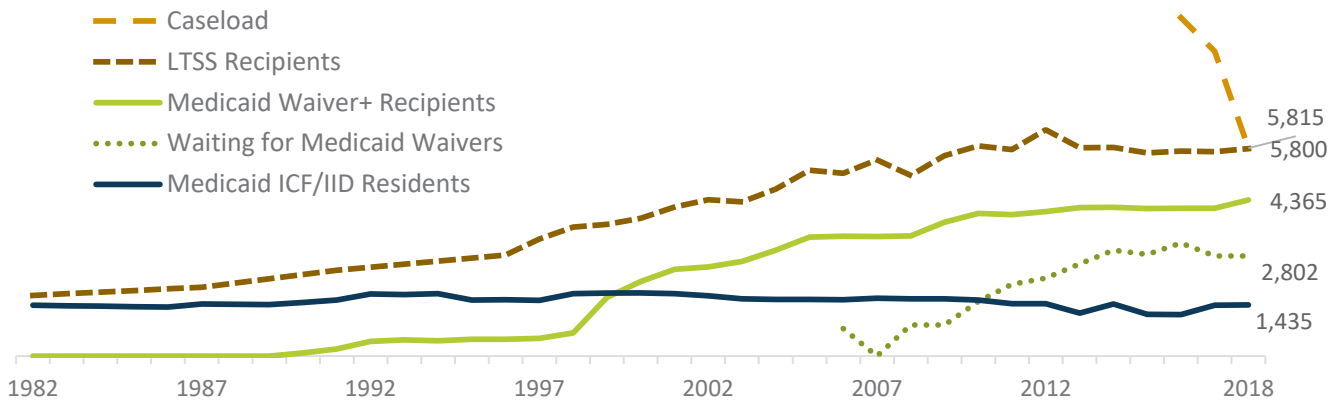
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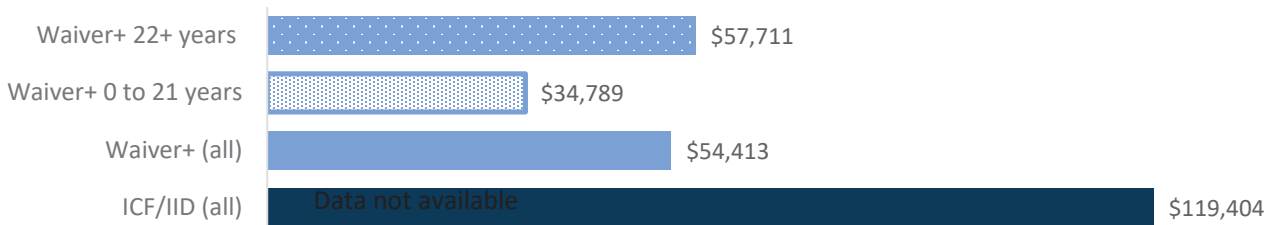
IDD Agency Long Term Supports and Services Recipients by Residence Type



Caseload, LTSS and Medicaid Recipients and Waiting for Waivers* 1982-2018



Average Spending Per Person by Medicaid Authority in Fiscal Year 2018



Waiver by age in family home or not family home spending per person not available.

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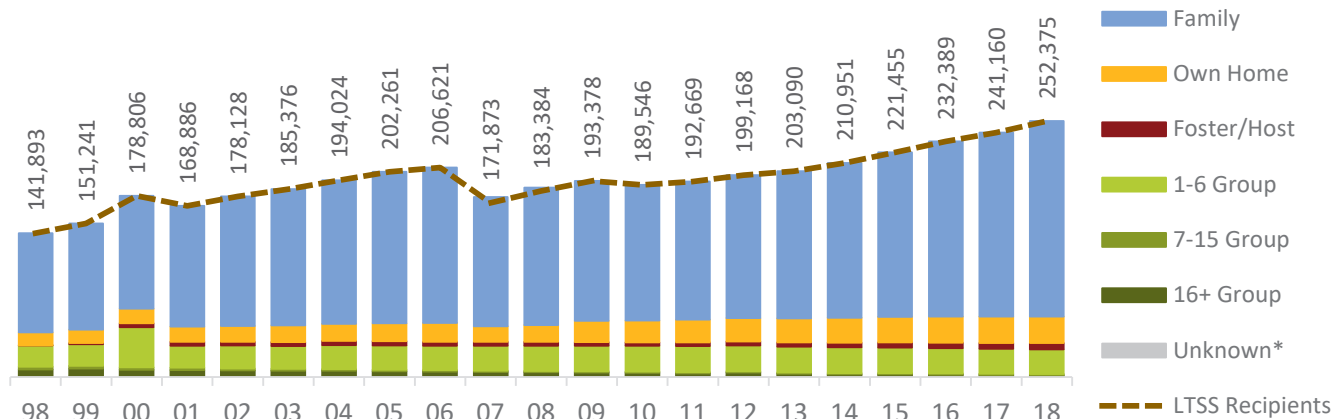
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California

Fiscal Year 2018

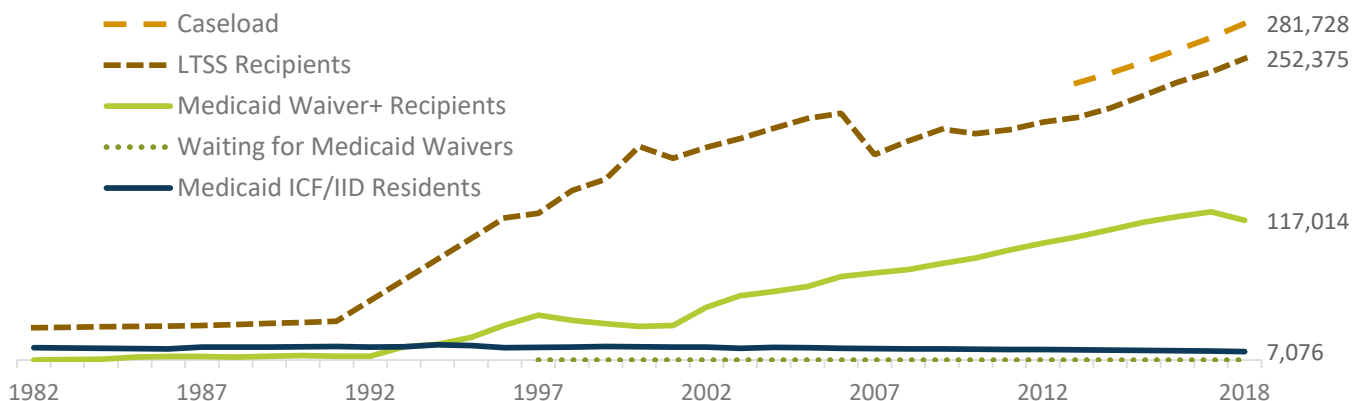
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IDD Agency Long Term Supports and Services Recipients by Residence Type

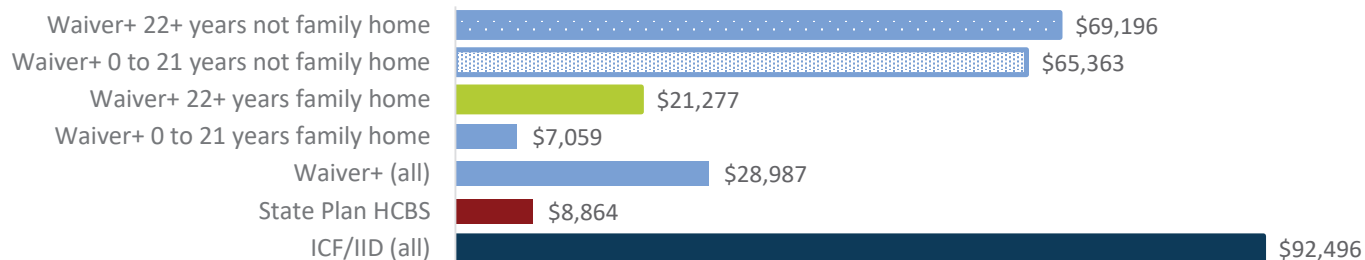


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Caseload, LTSS and Medicaid Recipients and Waiting for Waivers* 1982-2018



Average Spending Per Person by Medicaid Authority in Fiscal Year 2018



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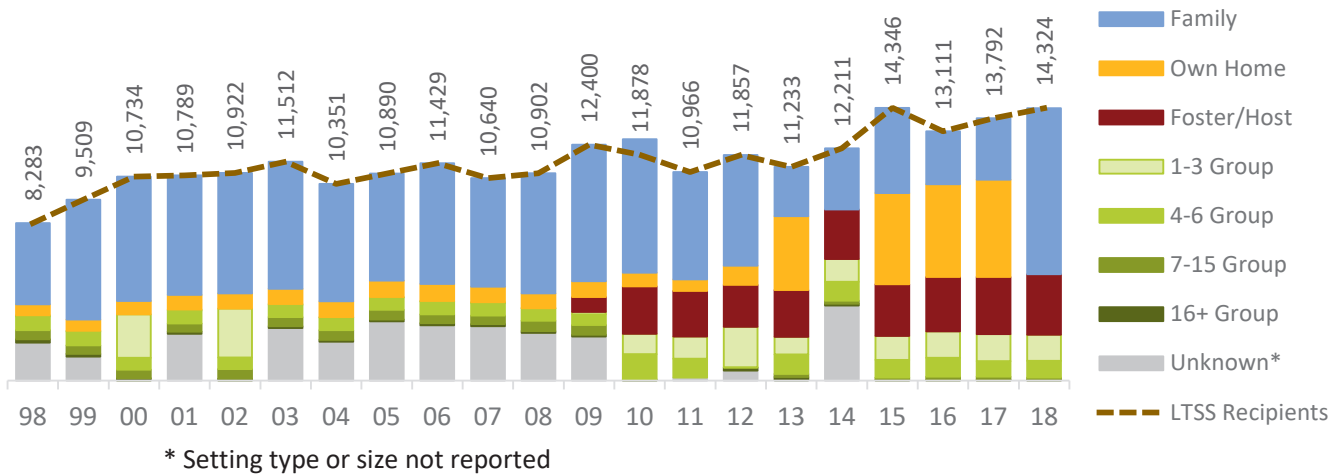
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Colorado

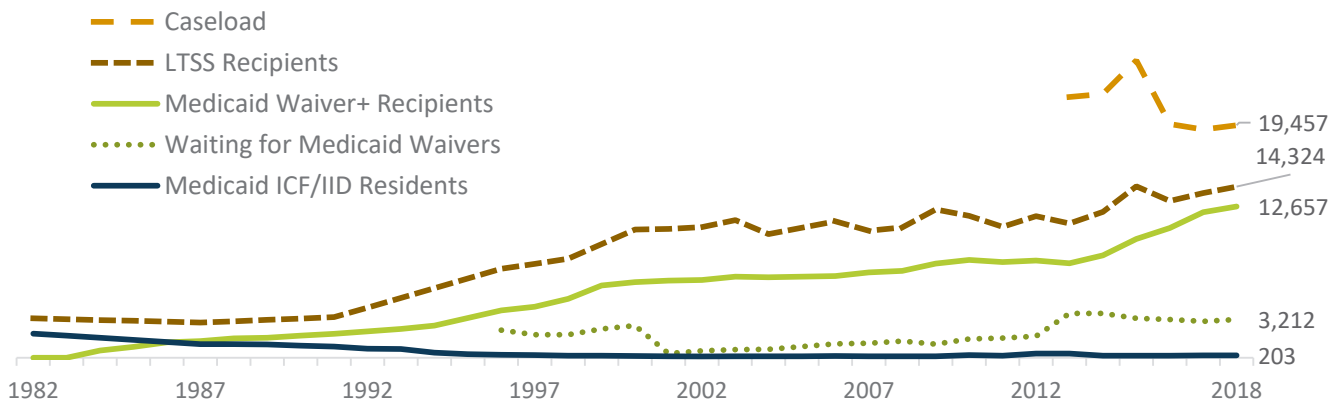
Fiscal Year 2018

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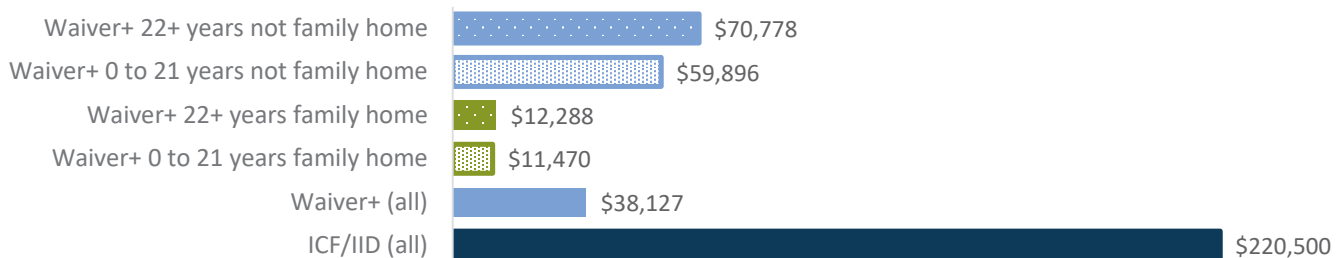
IDD Agency Long Term Supports and Services Recipients by Residence Type



Caseload, LTSS and Medicaid Recipients and Waiting for Waivers* 1982-2018



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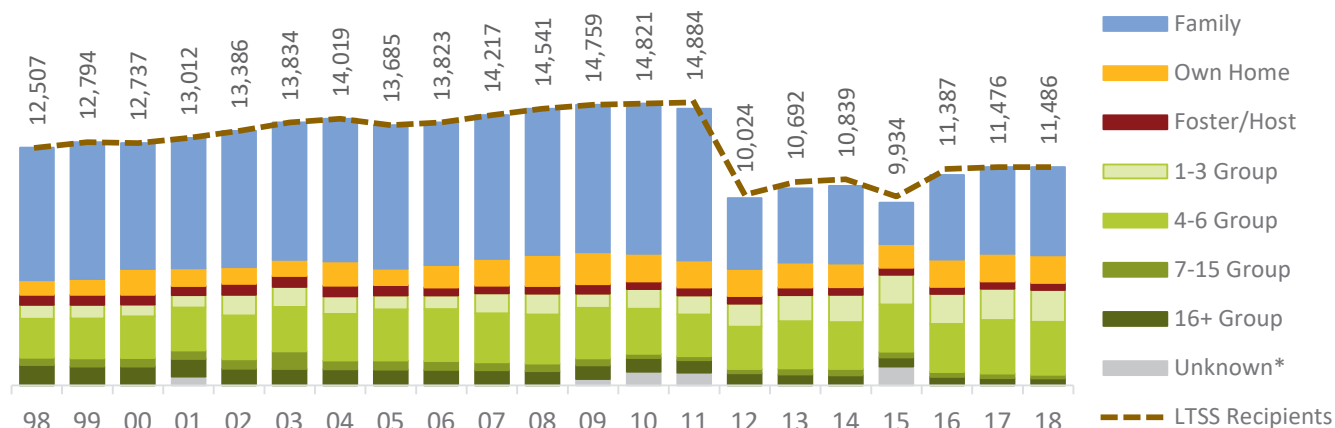
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Connecticut

Fiscal Year 2018

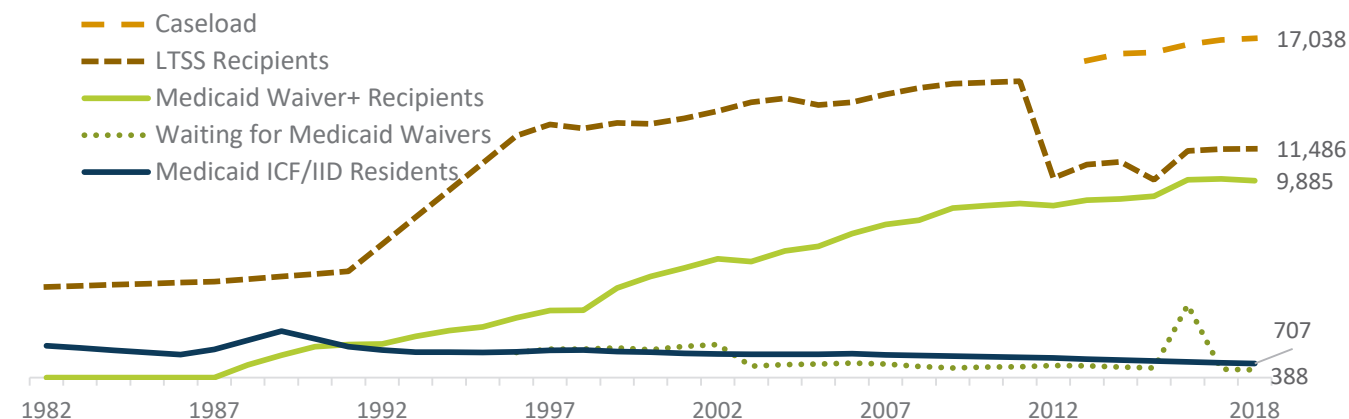
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IDD Agency Long Term Supports and Services Recipients by Residence Type

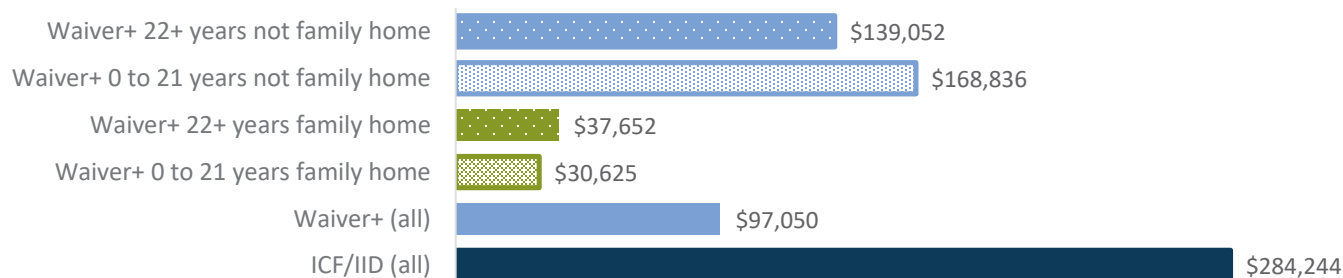


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Caseload, LTSS and Medicaid Recipients and Waiting for Waivers* 1982-2018



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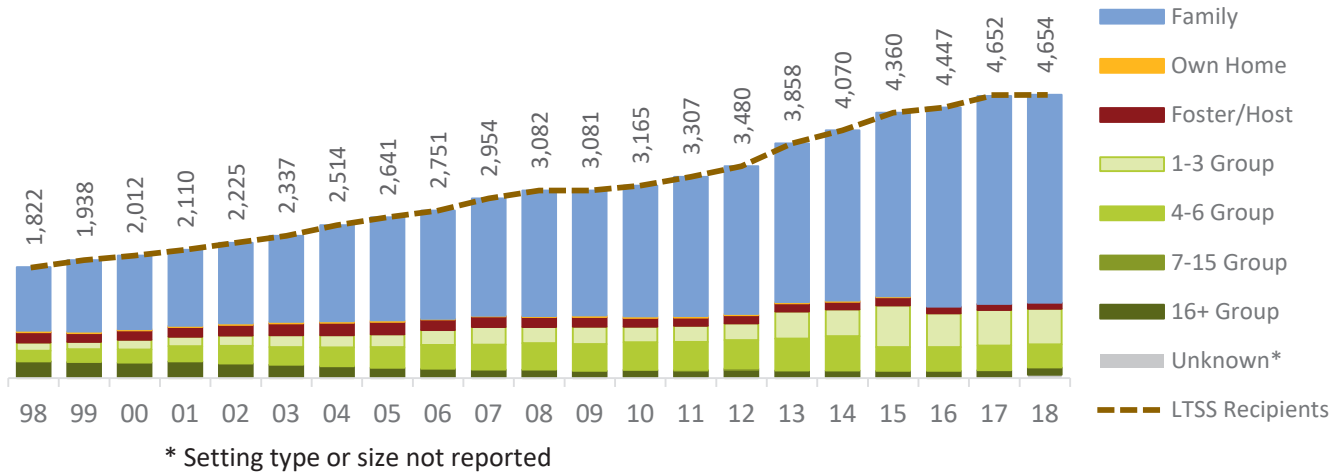
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Delaware

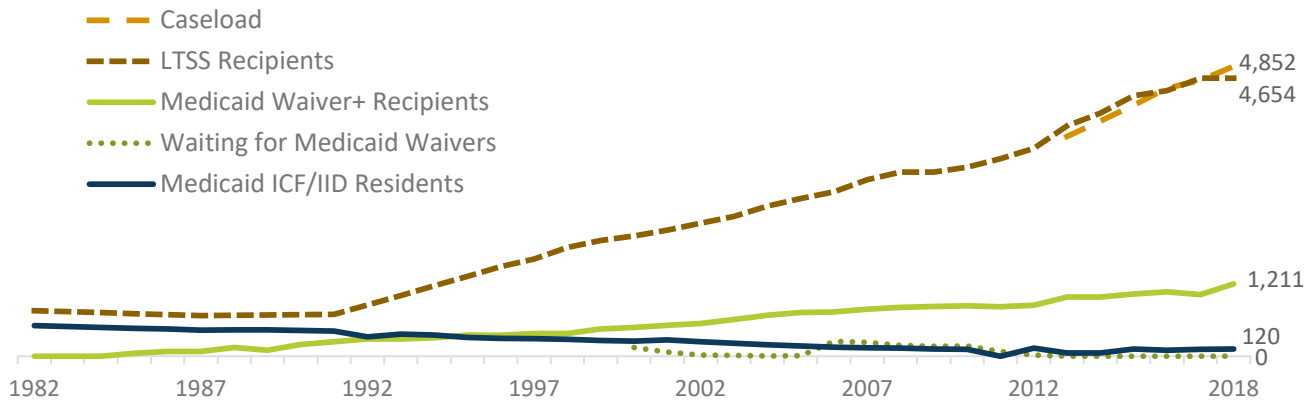
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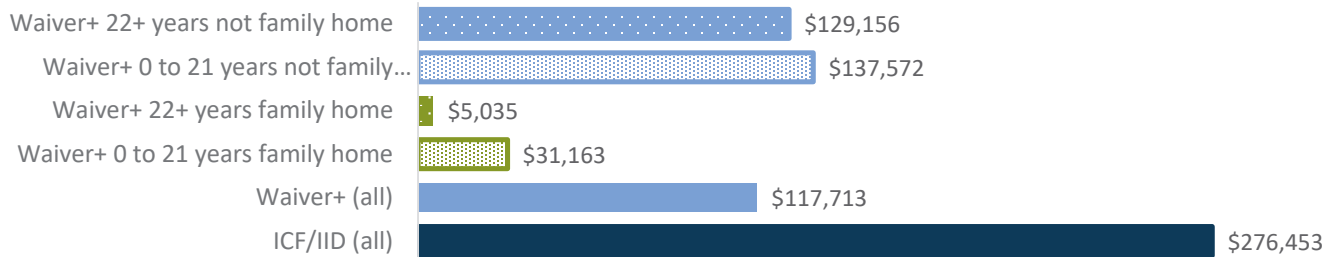
IDD Agency Long Term Supports and Services Recipients by Residence Type



Caseload, LTSS and Medicaid Recipients and Waiting for Waivers* 1982-2018



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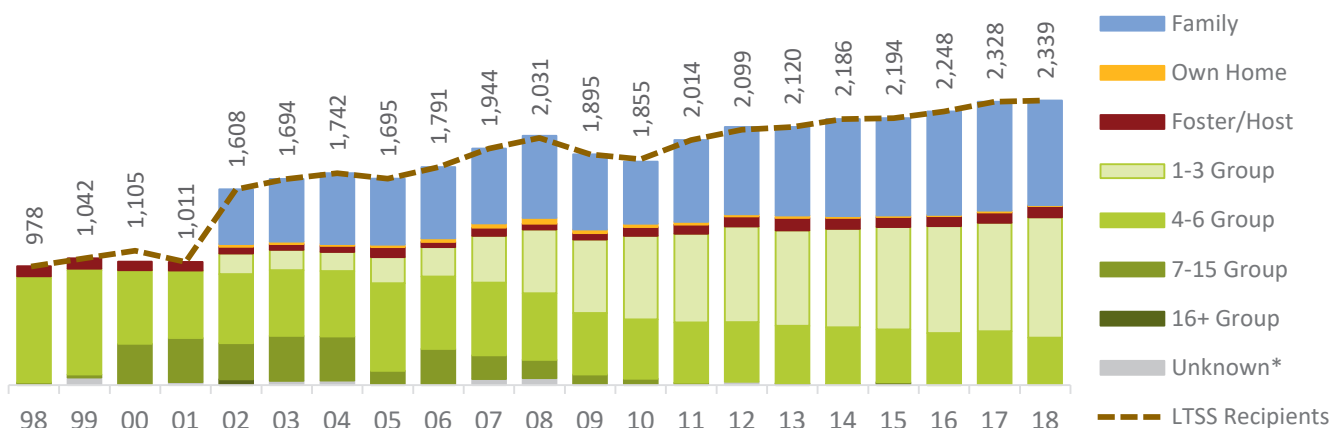
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District of Columbia

Fiscal Year 2018

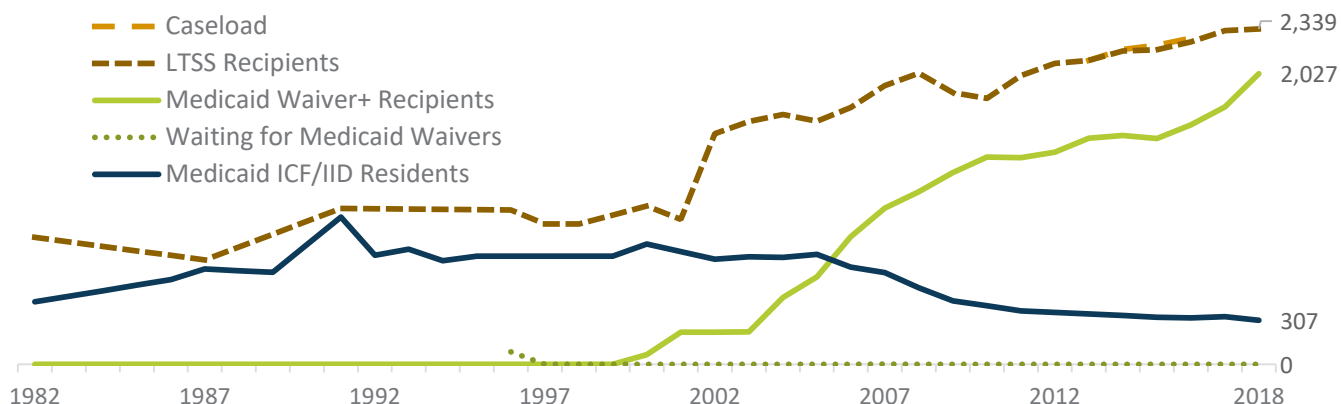
Residential Information Systems Project

IDD Agency Long Term Supports and Services Recipients by Residence Type

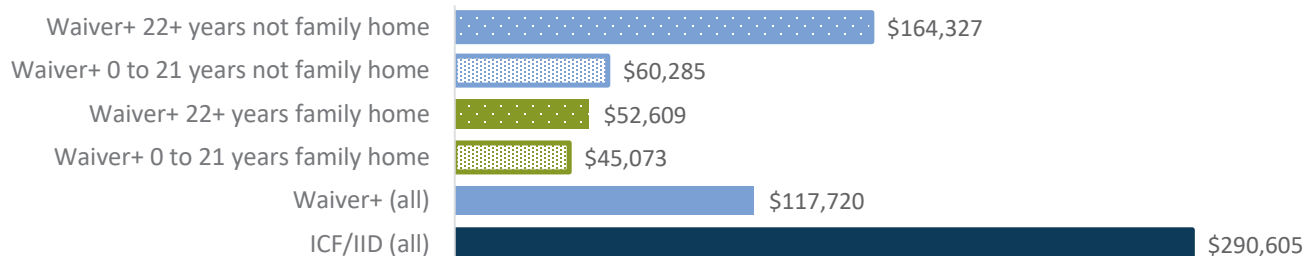


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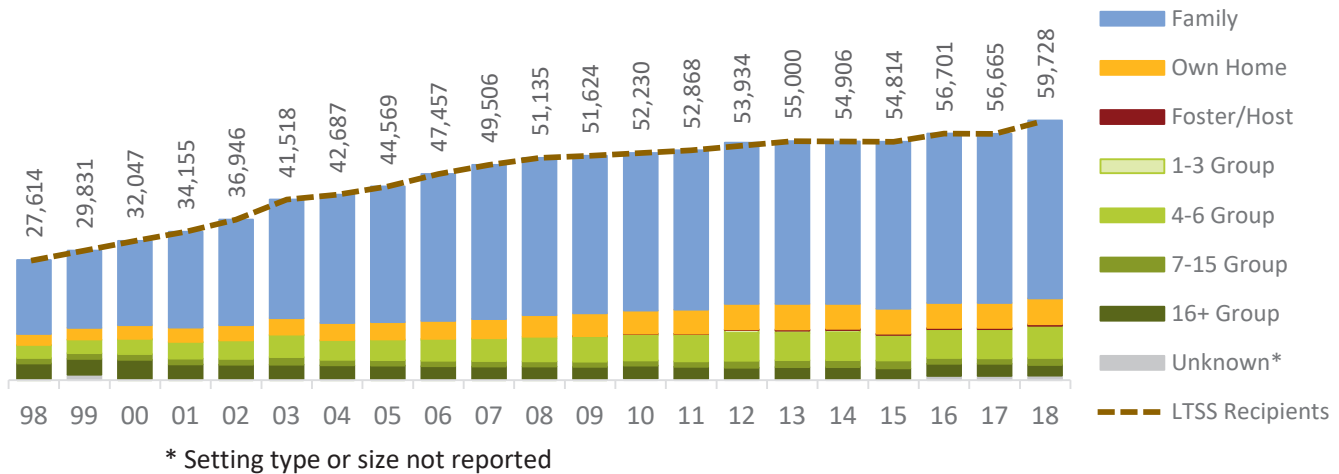
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Florida

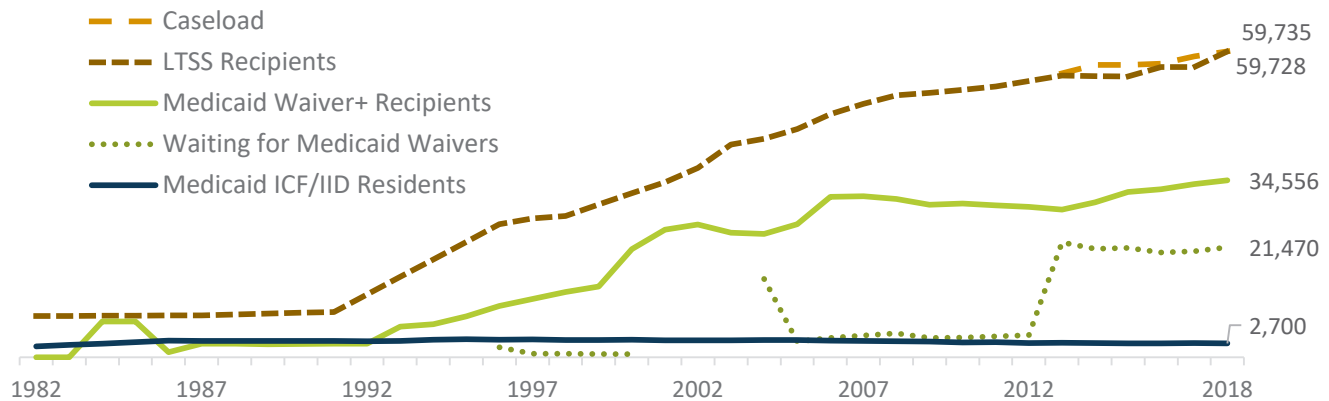
Fiscal Year 2018

Residential Information Systems Project

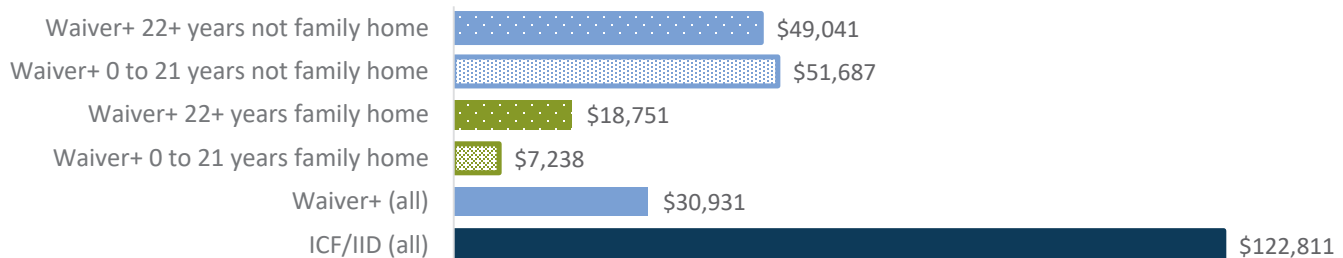
IDD Agency Long Term Supports and Services Recipients by Residence Type



Caseload, LTSS and Medicaid Recipients and Waiting for Waivers* 1982-2018



Average Spending Per Person by Funding Authority in Fiscal Year 2018



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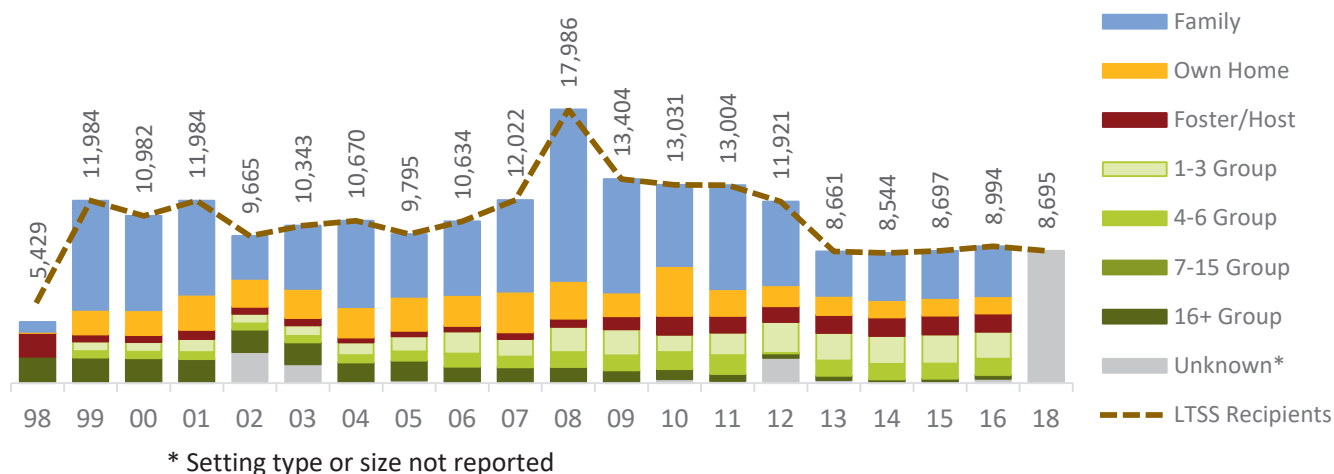
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Georgia

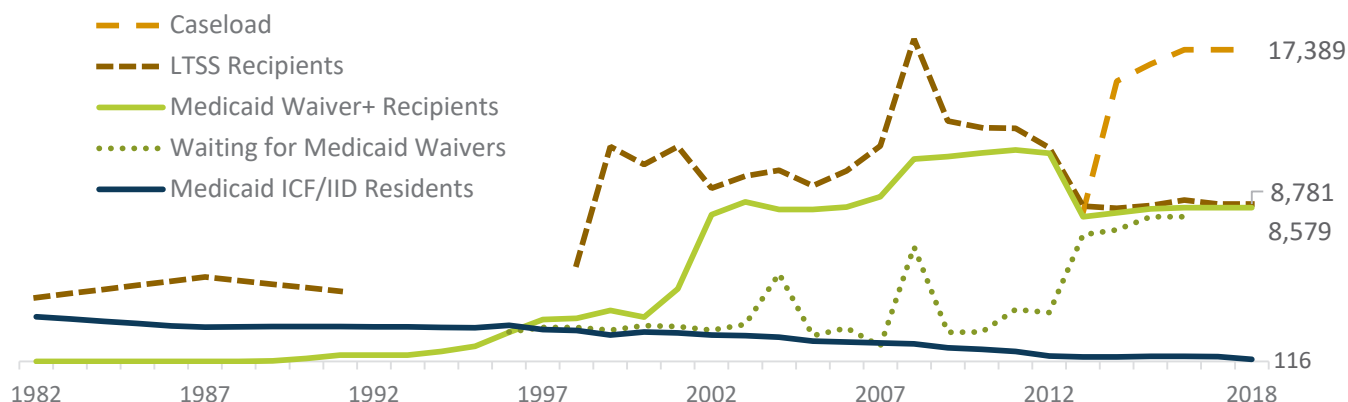
Fiscal year 2018

Residential Information Systems Project

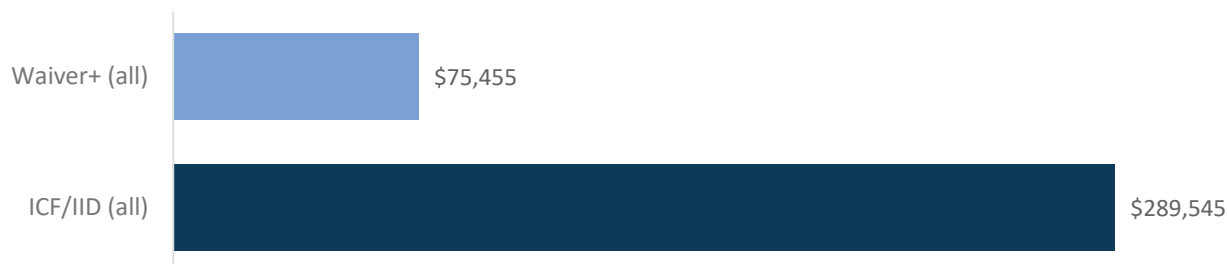
IDD Agency Long Term Supports and Services Recipients by Residence Type



Caseload, LTSS and Medicaid Recipients and Waiting for Waivers* 1982-2018



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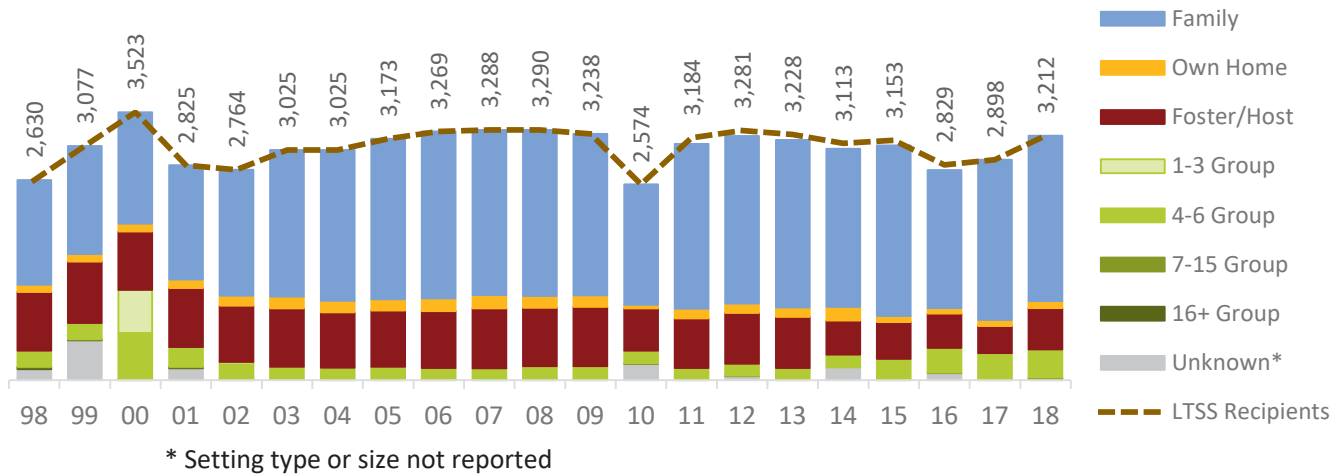
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Hawaii

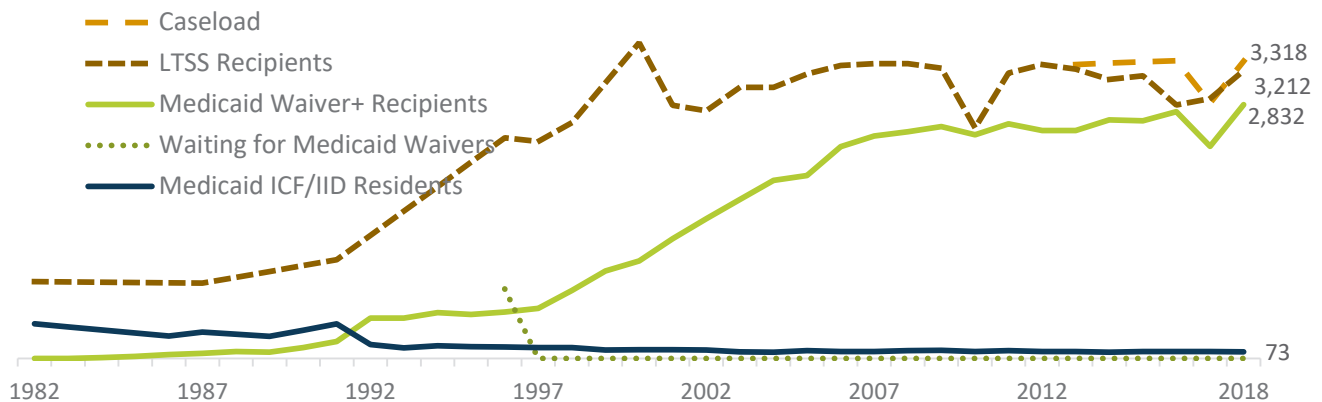
Fiscal Year 2018

Residential Information Systems Project

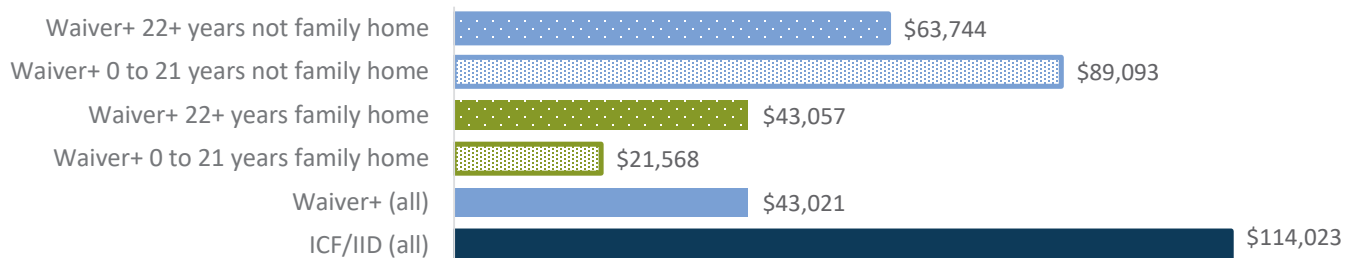
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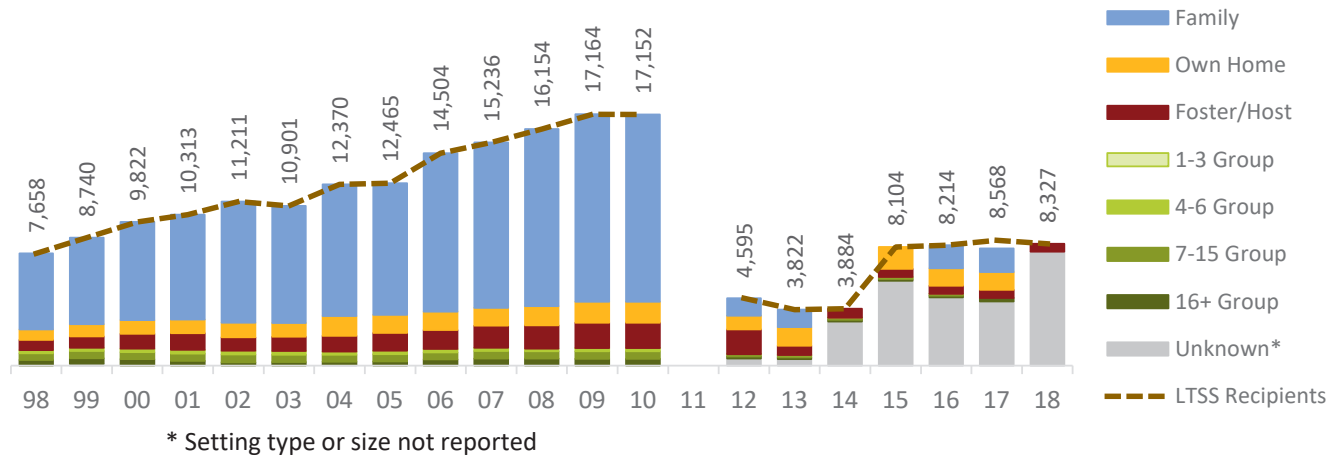
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Idaho

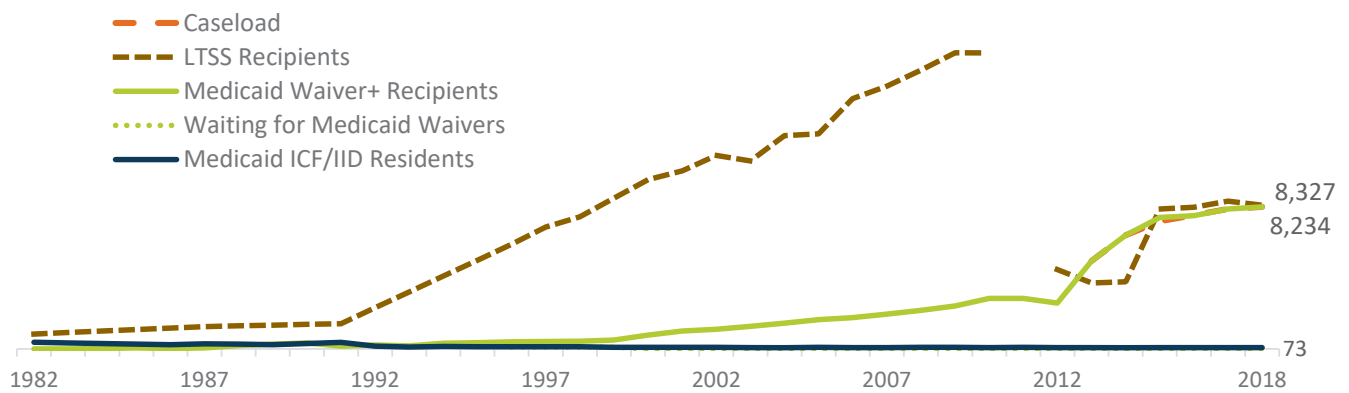
Fiscal Year 2018

Residential Information Systems Project

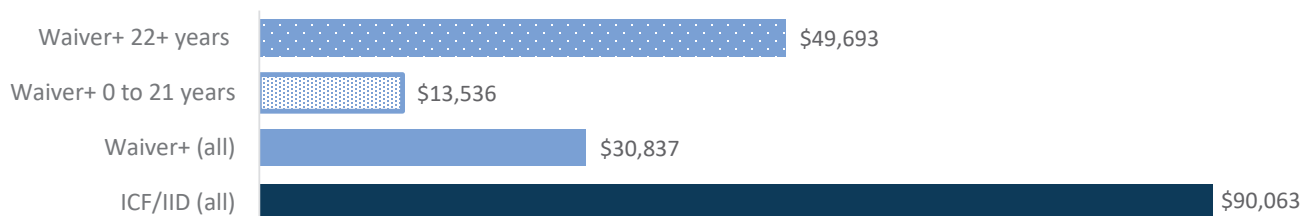
IDD Agency Long Term Supports and Services Recipients by Residence Type



Caseload, LTSS and Medicaid Recipients and Waiting for Waivers* 1982-2018



Average Spending Per Person by Medicaid Authority in Fiscal Year 2018



Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

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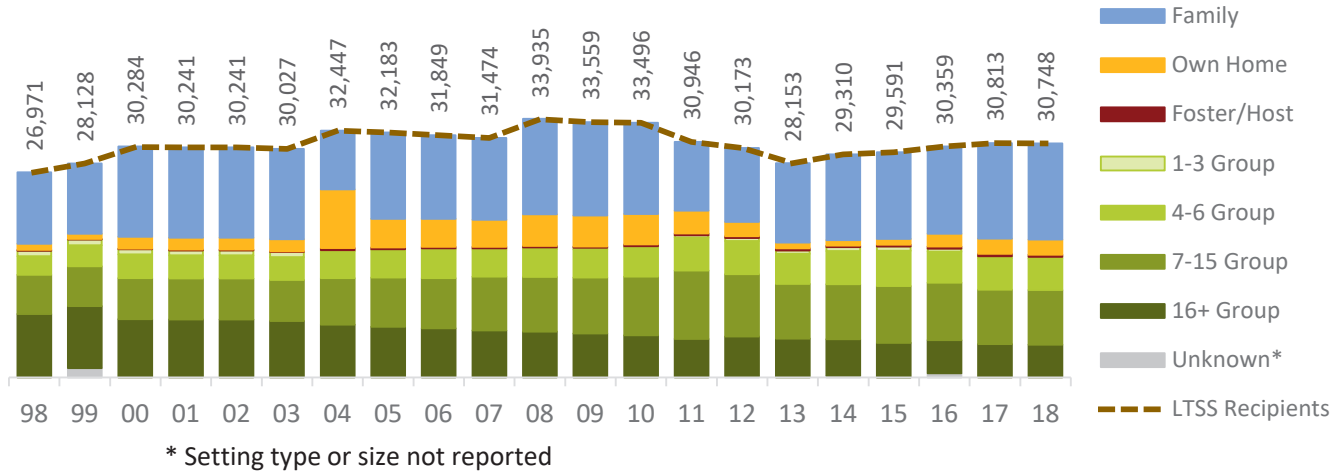
For more see risp.umn.edu

Illinois

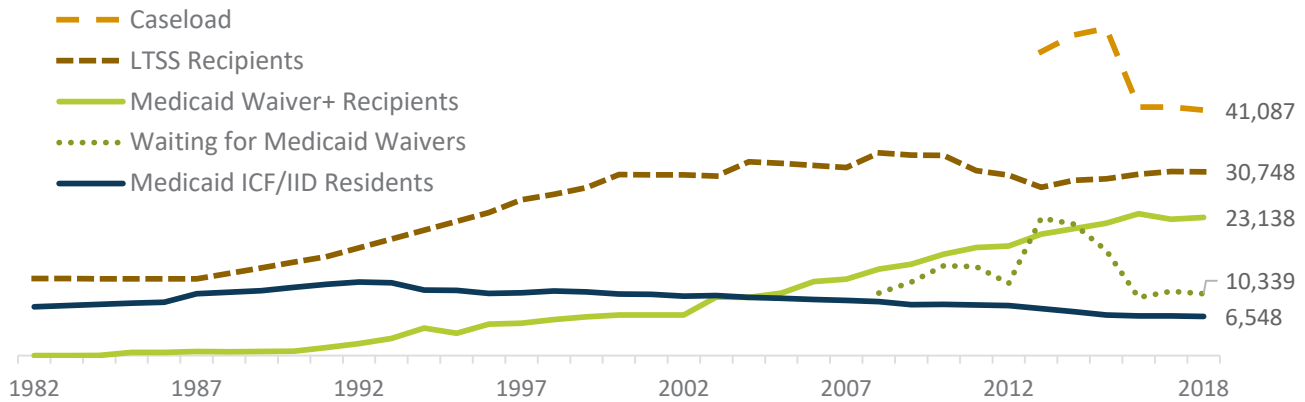
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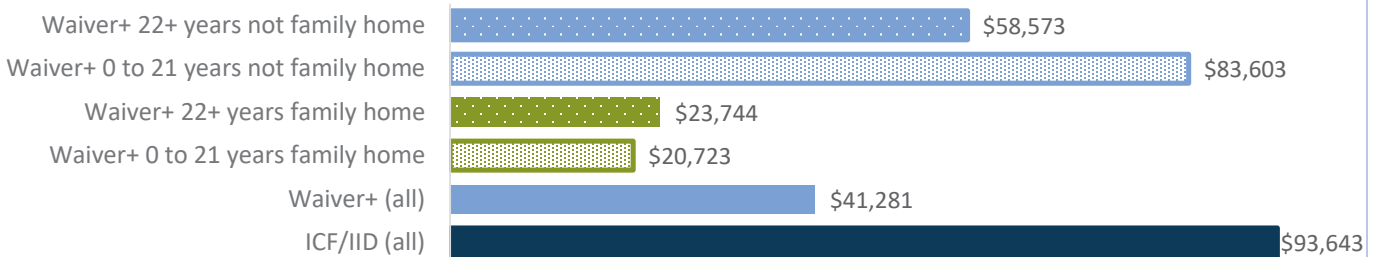
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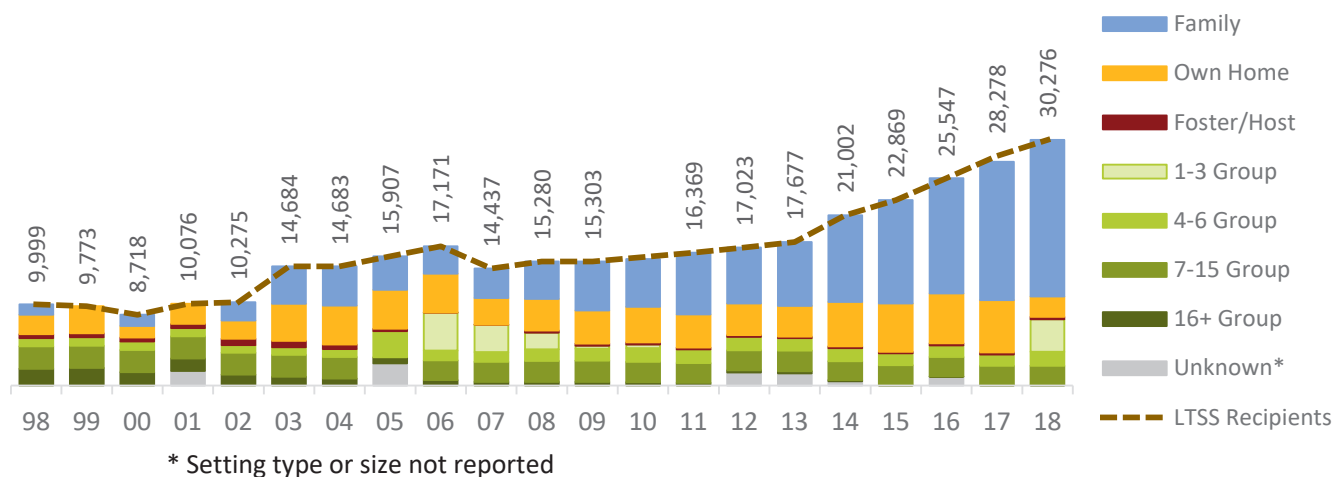
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Indiana

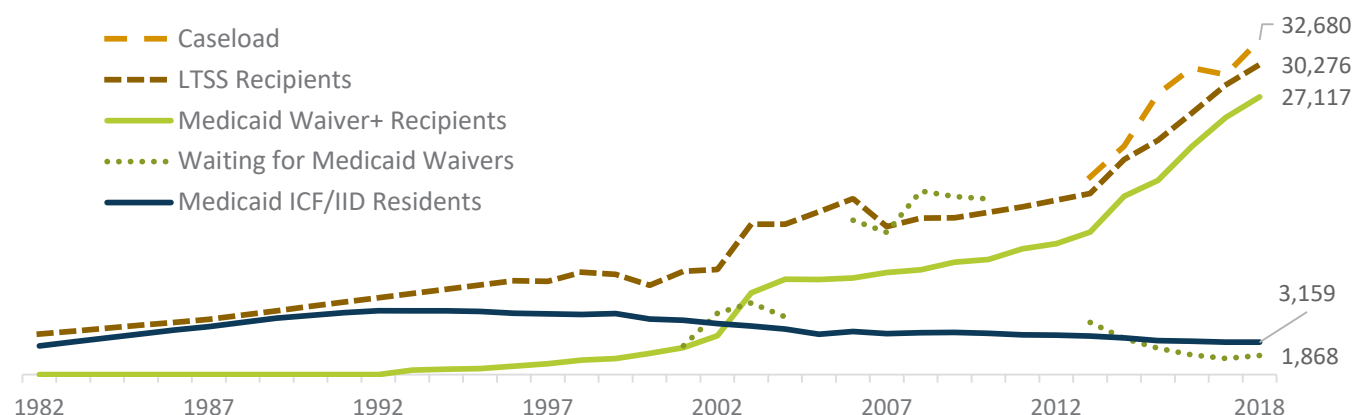
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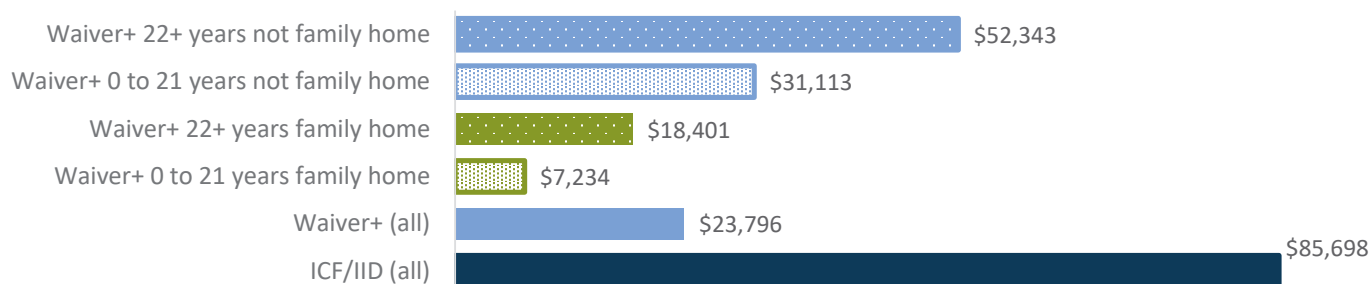
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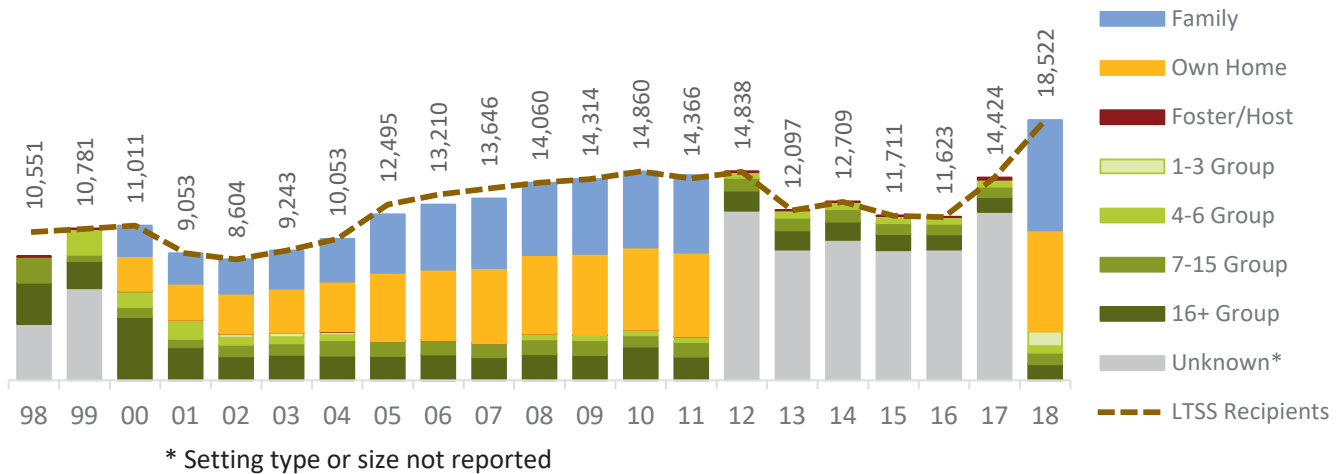
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Iowa

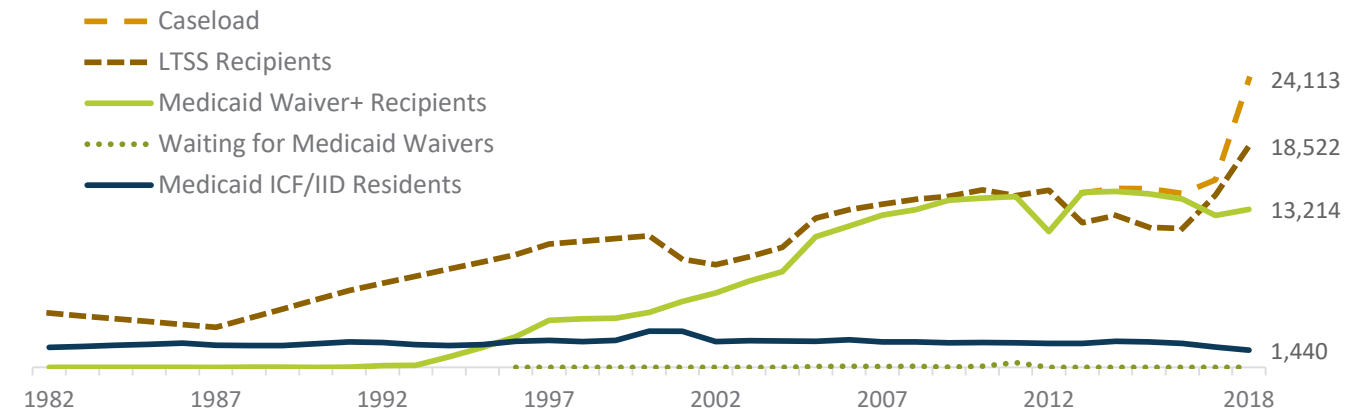
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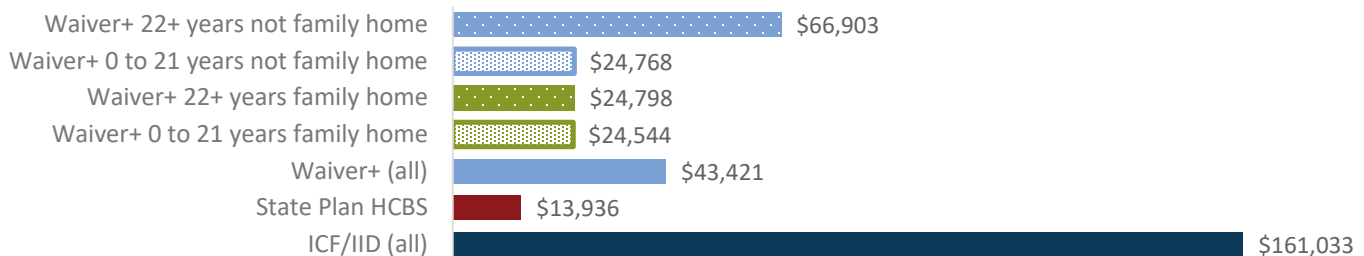
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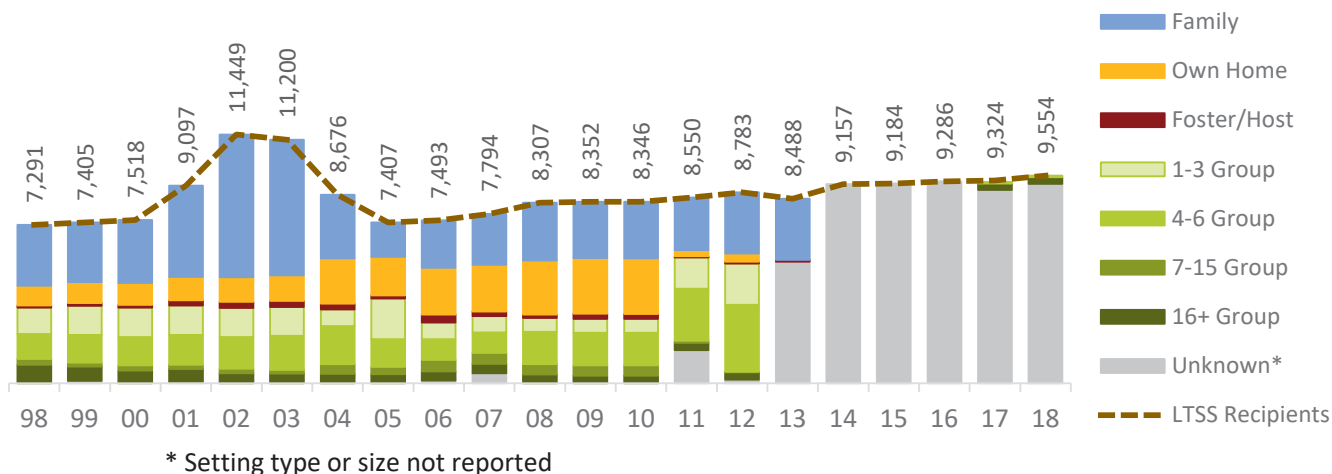
For more see risp.umn.edu

Kansas

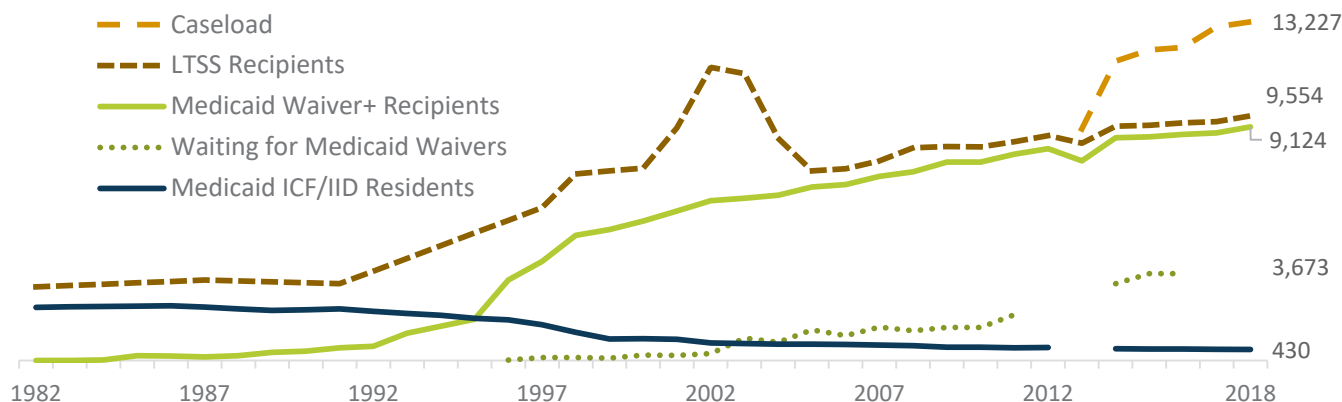
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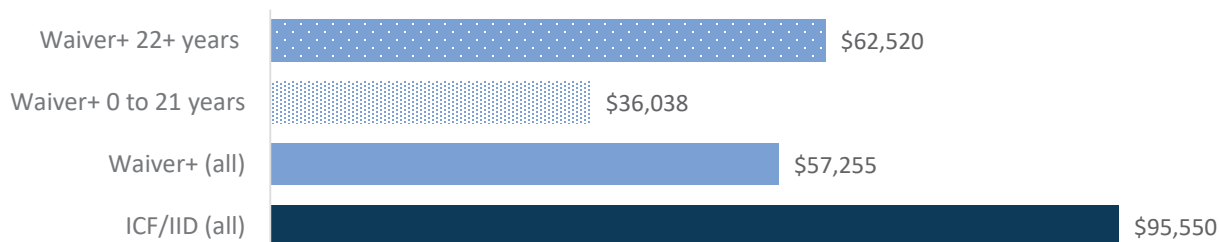
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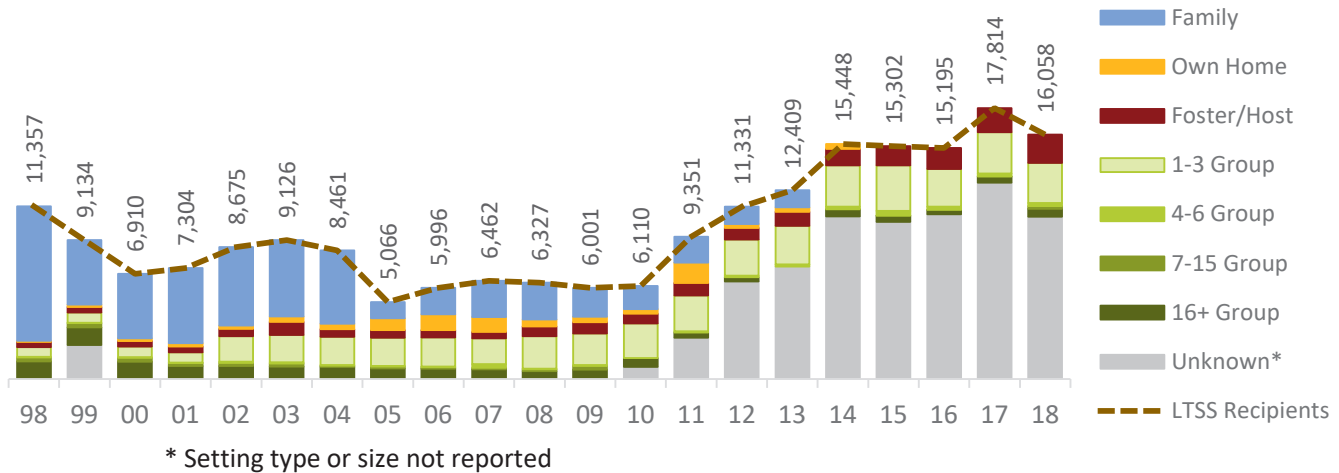
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Kentucky

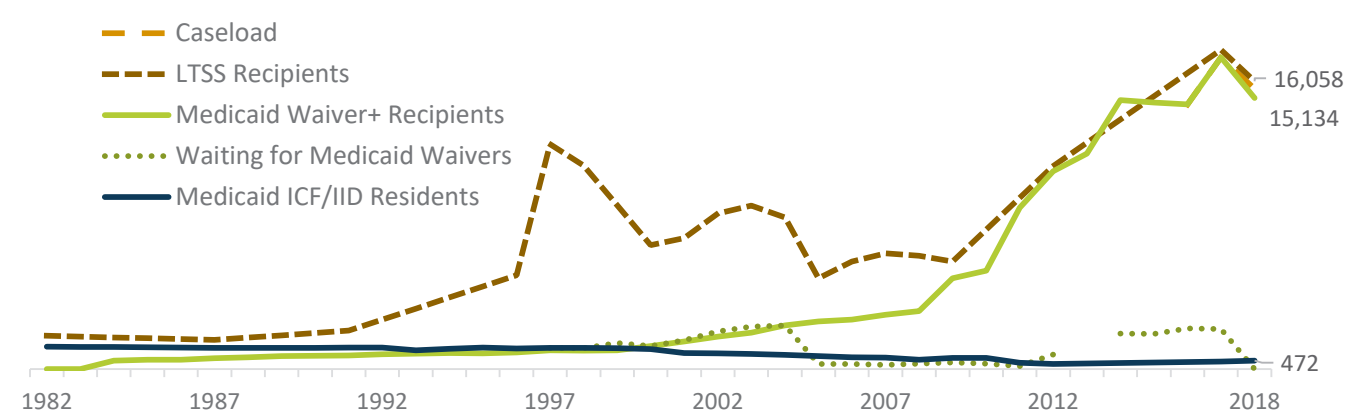
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Residential Information Systems Project

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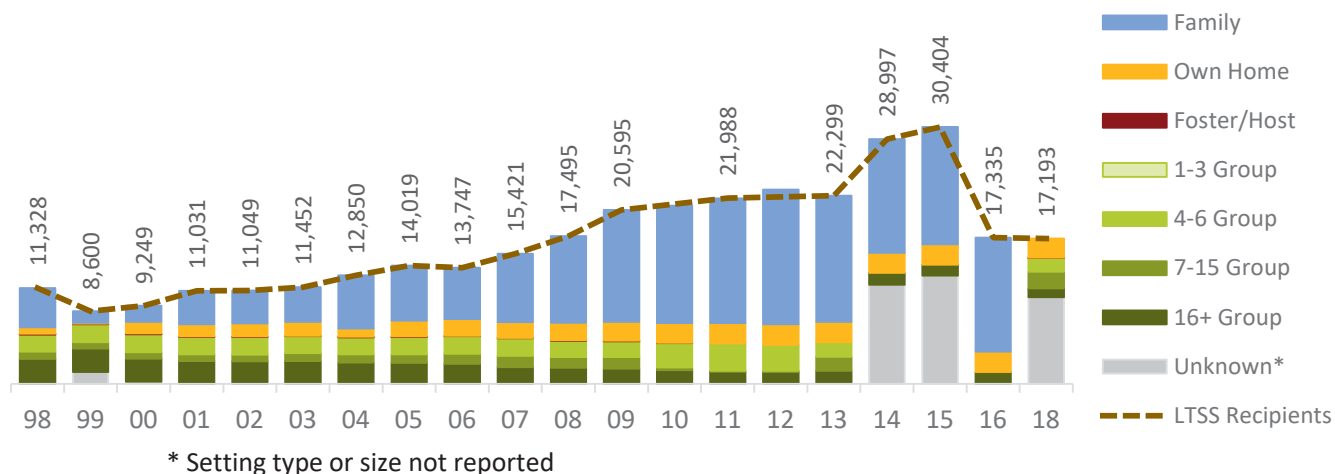
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Louisiana

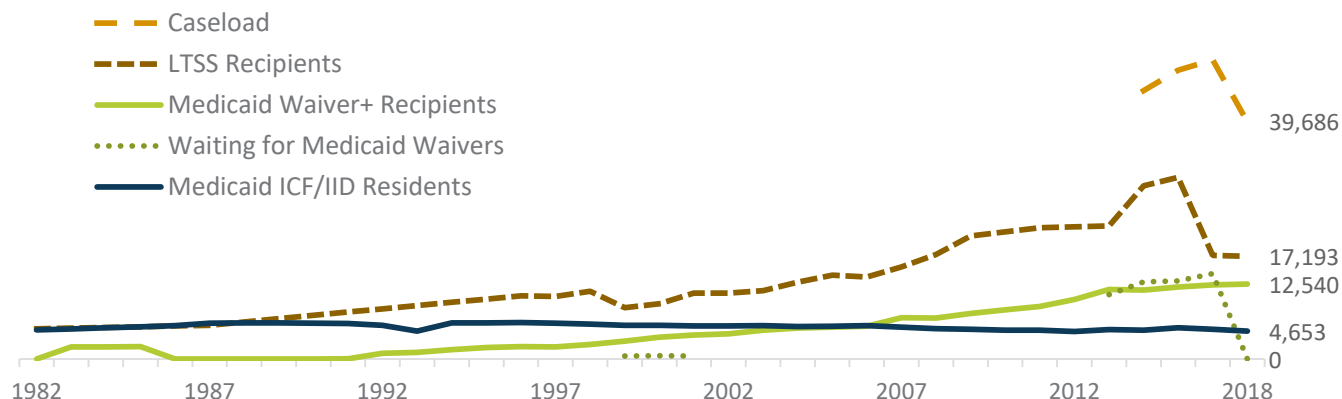
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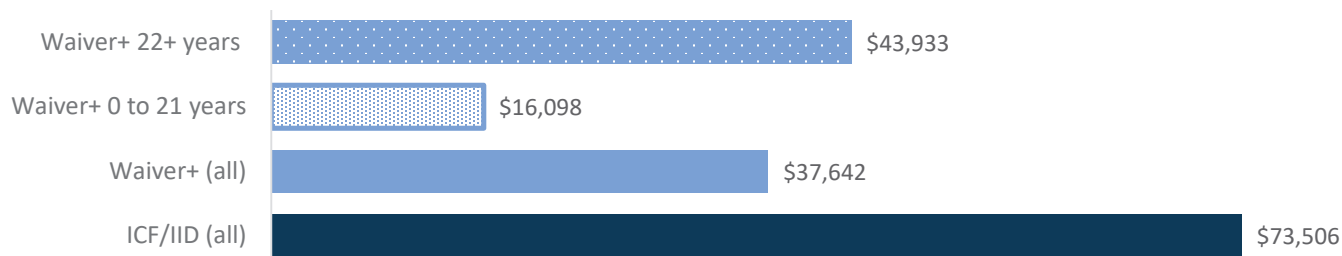
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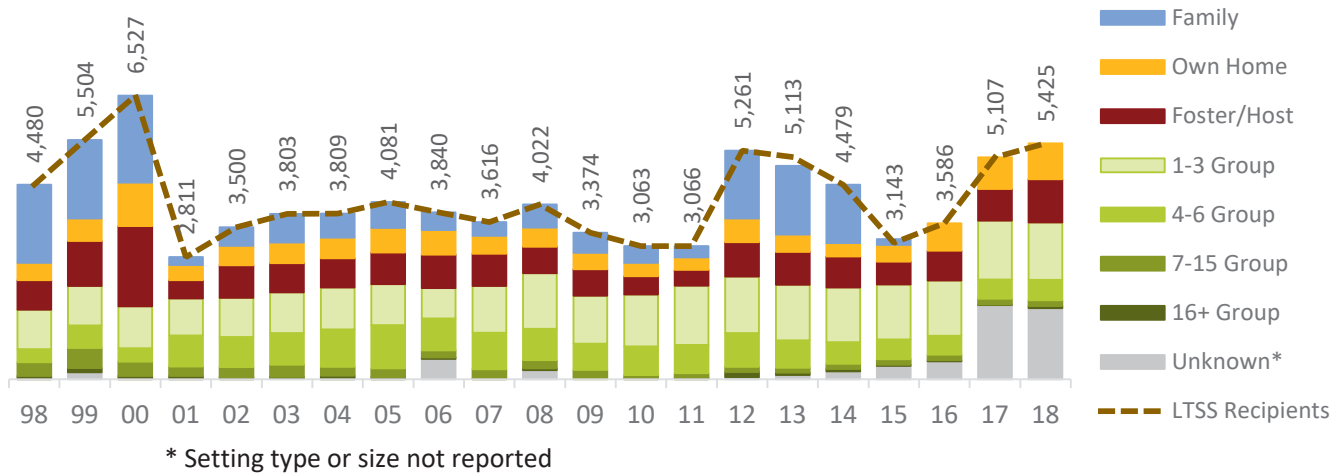
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Maine

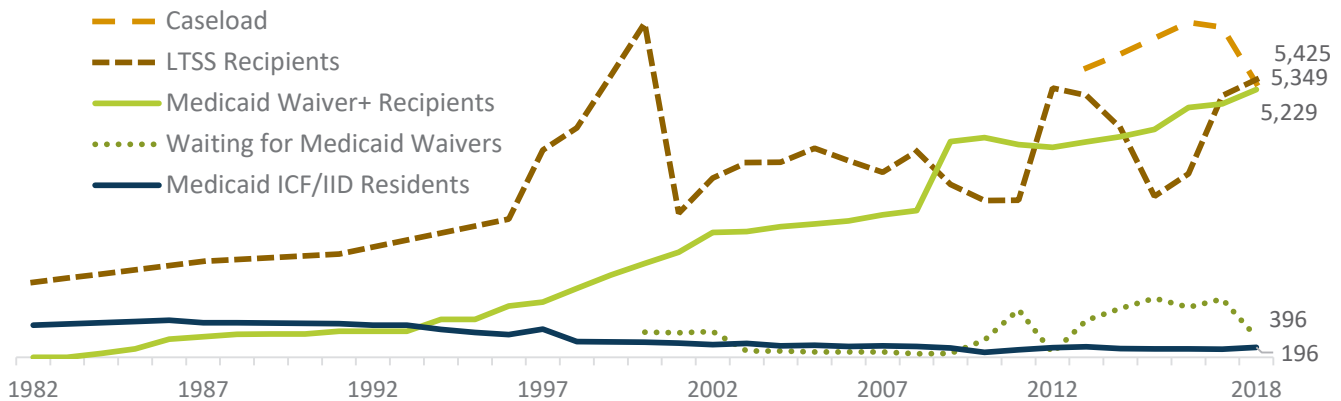
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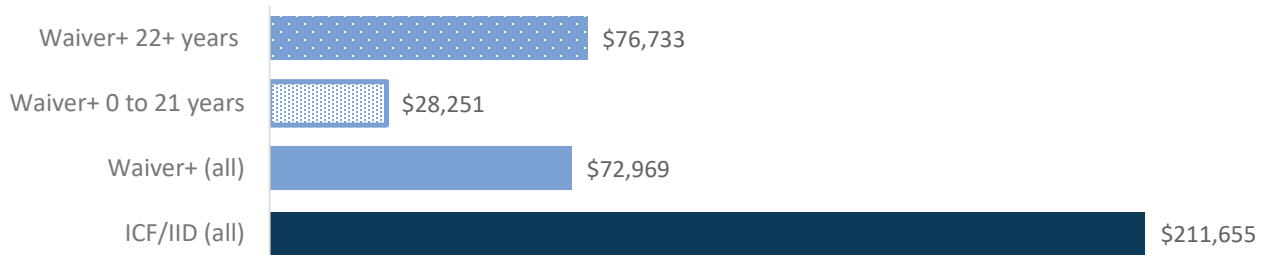
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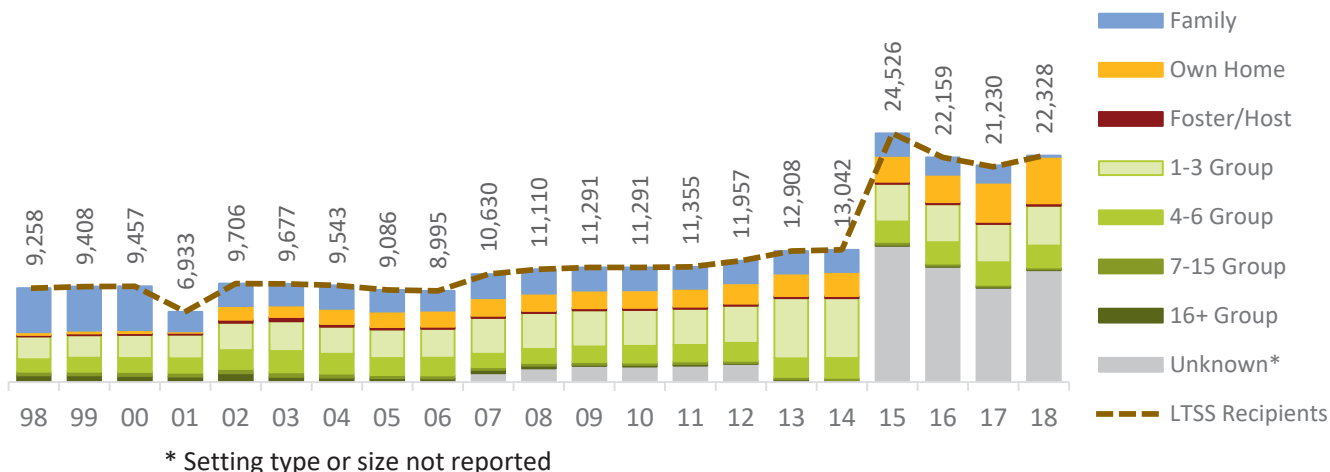
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Maryland

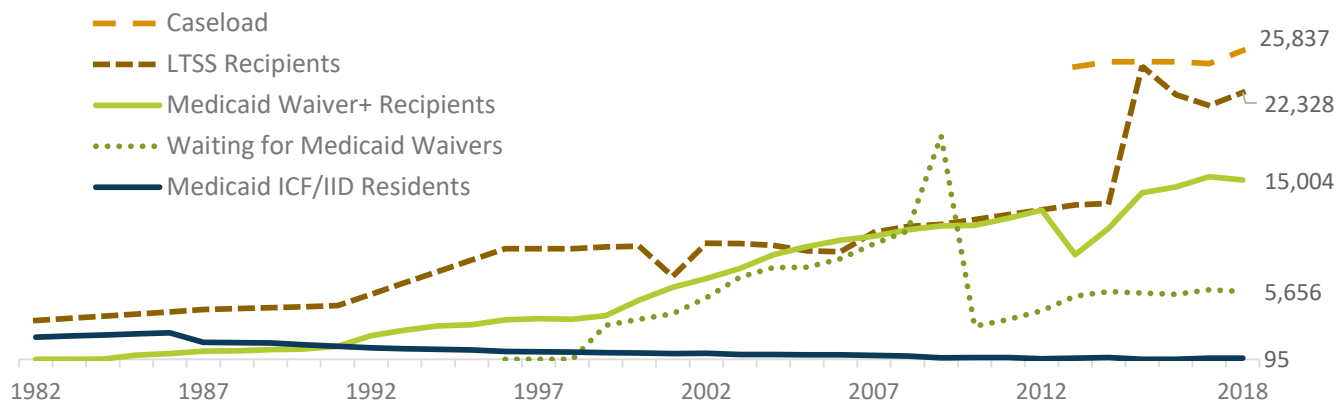
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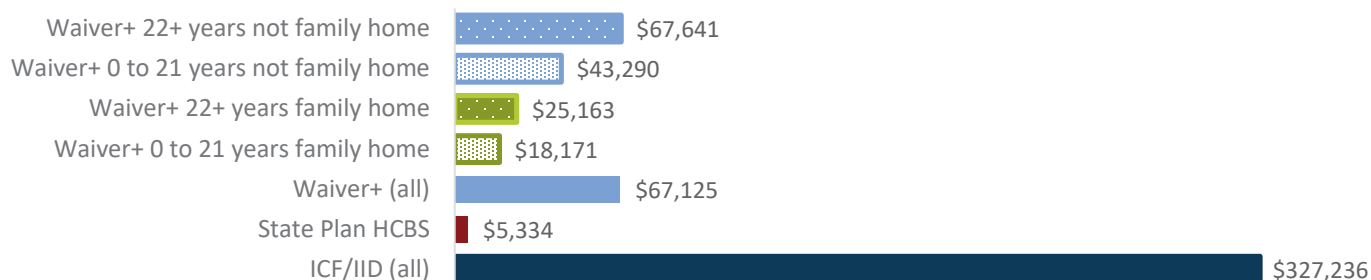
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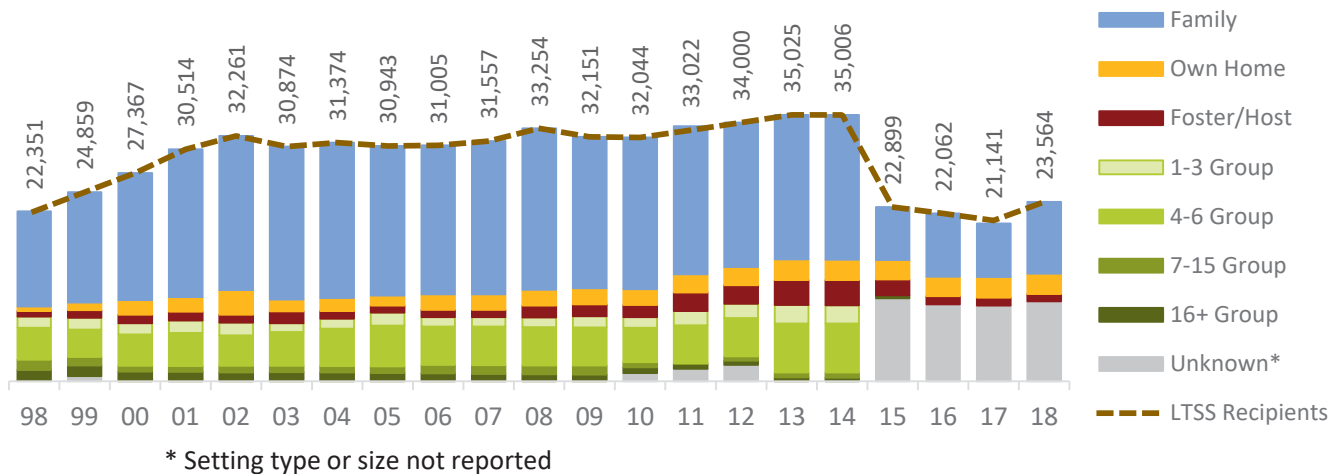
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Massachusetts

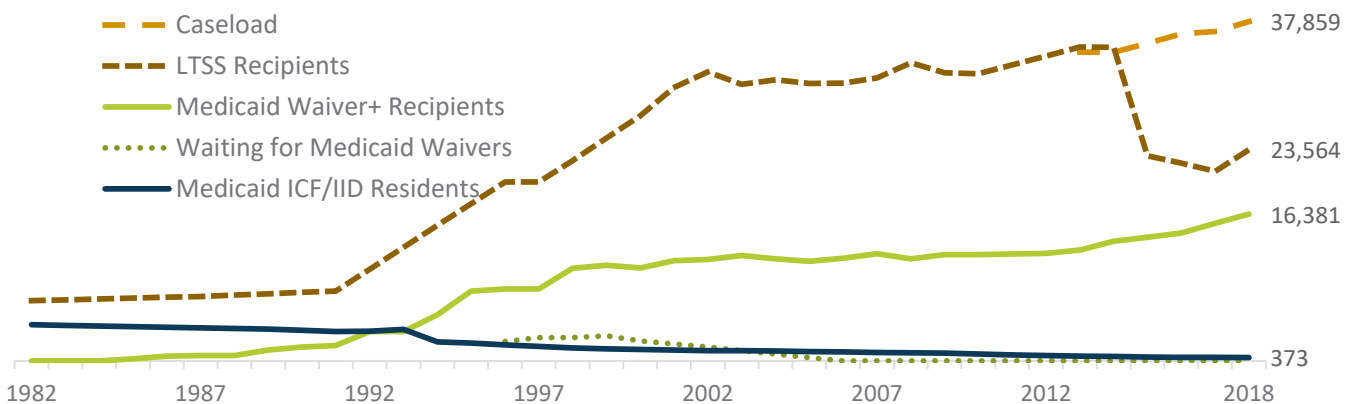
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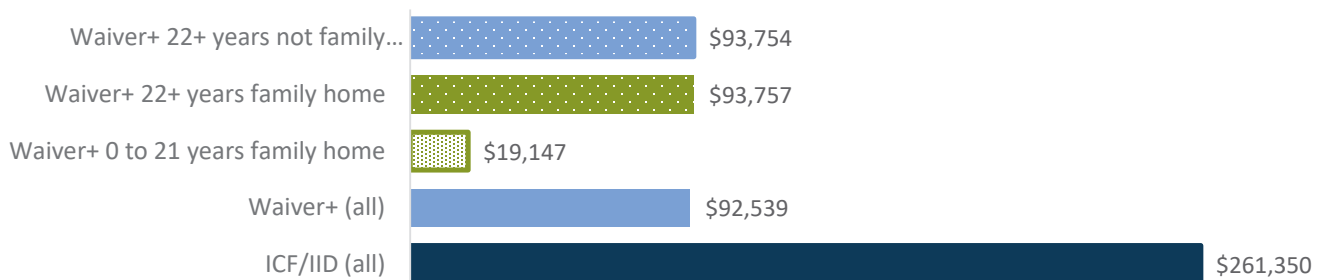
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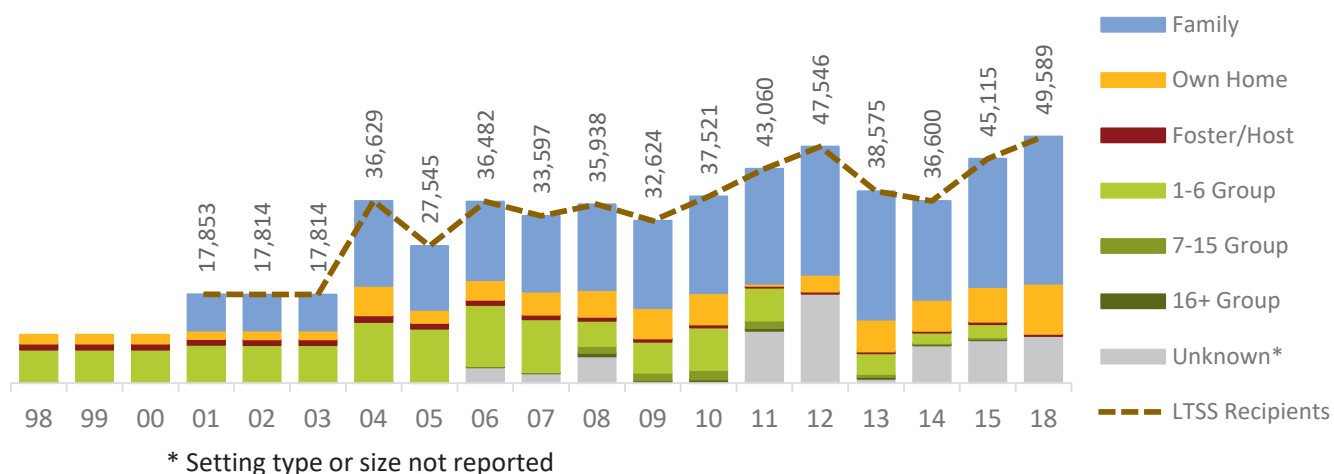
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Michigan

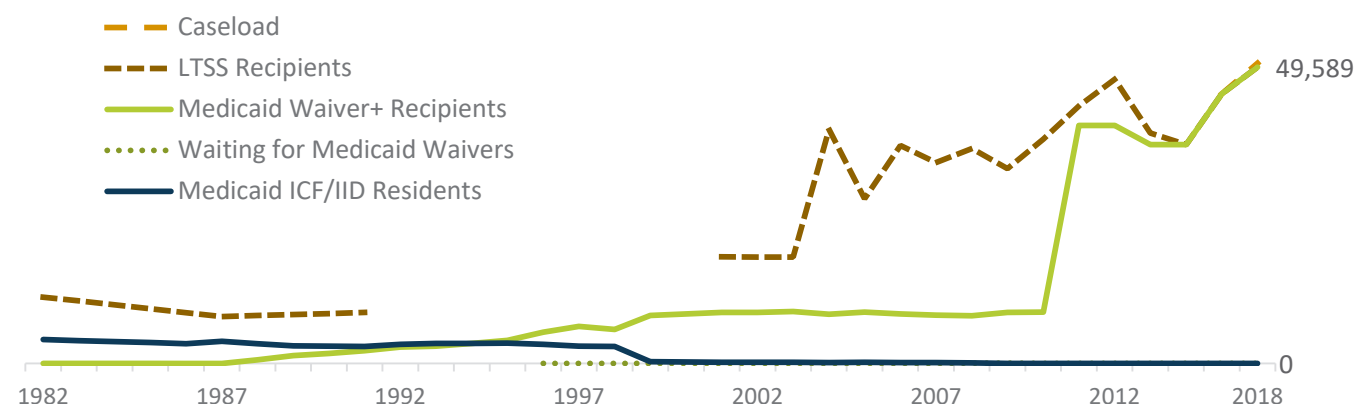
Fiscal year 2018

Residential Information Systems Project

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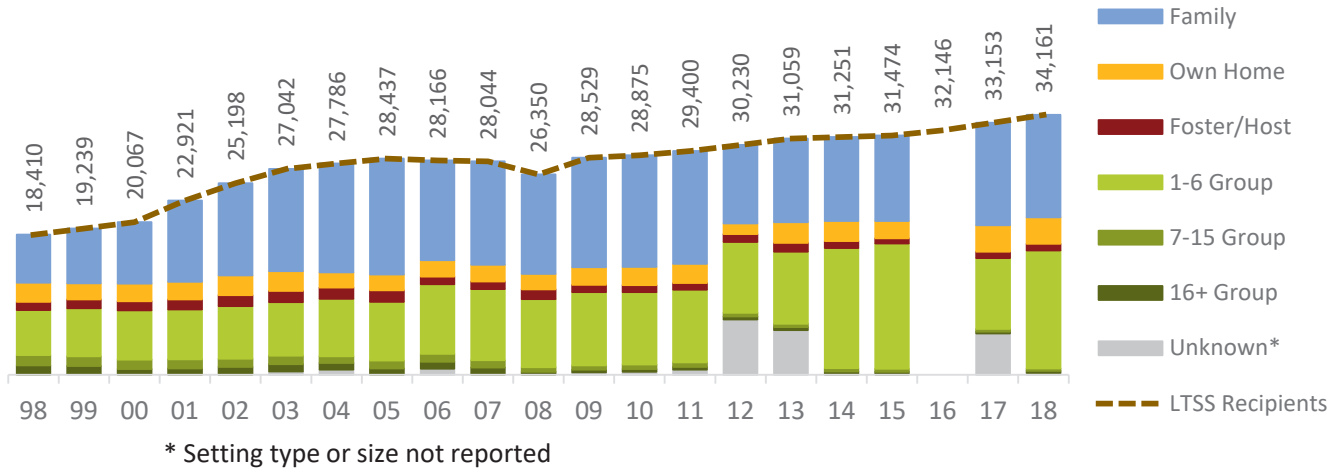
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Minnesota

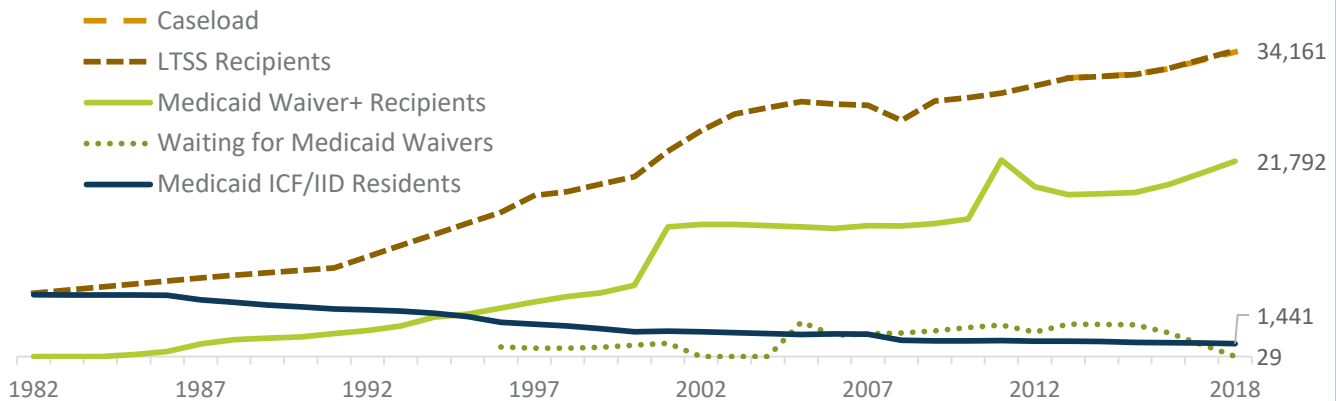
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Residential Information Systems Project

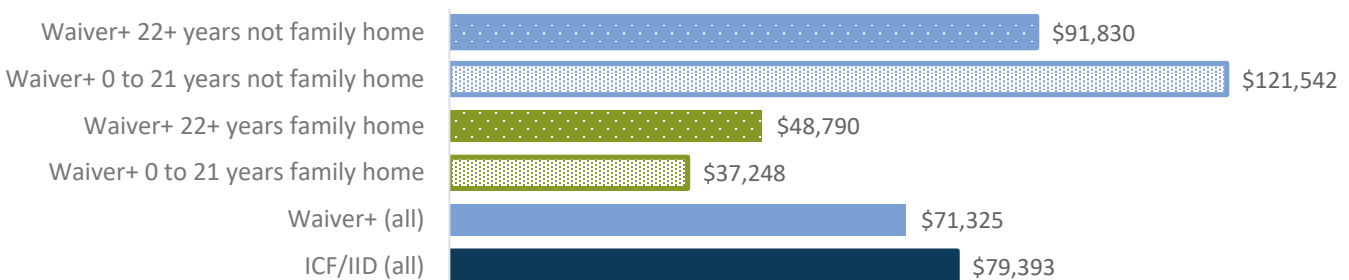
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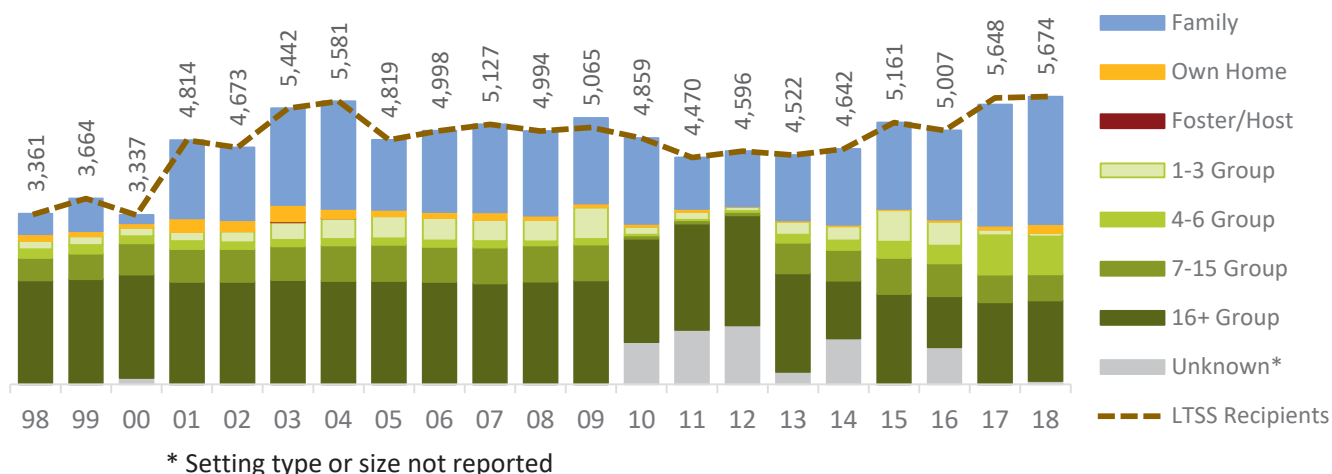
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Mississippi

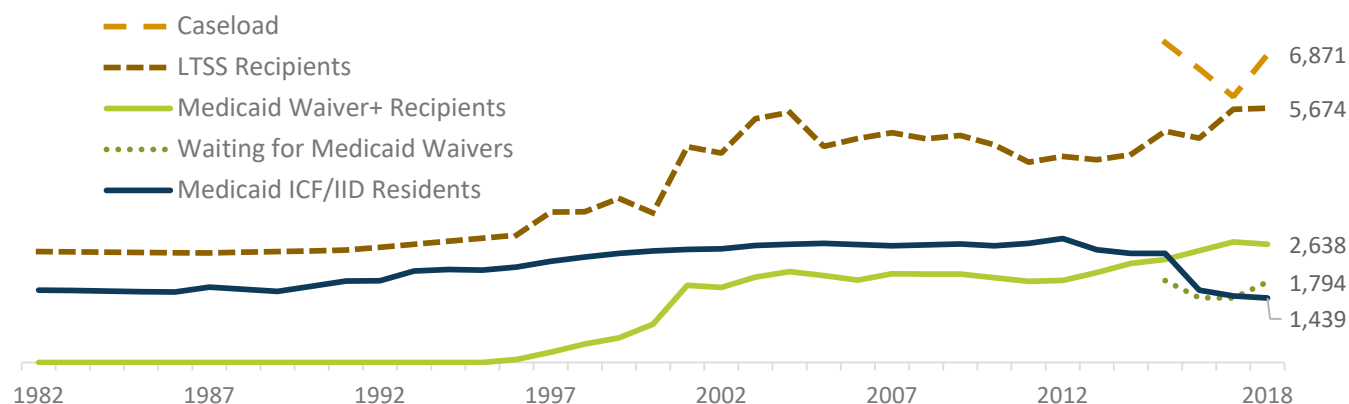
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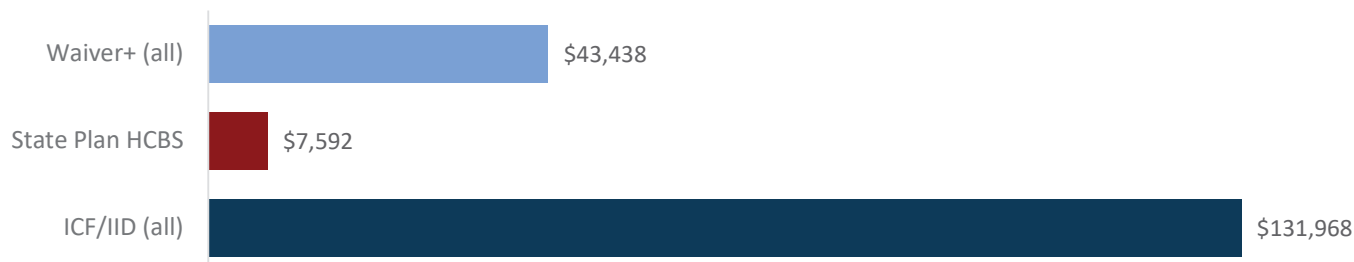
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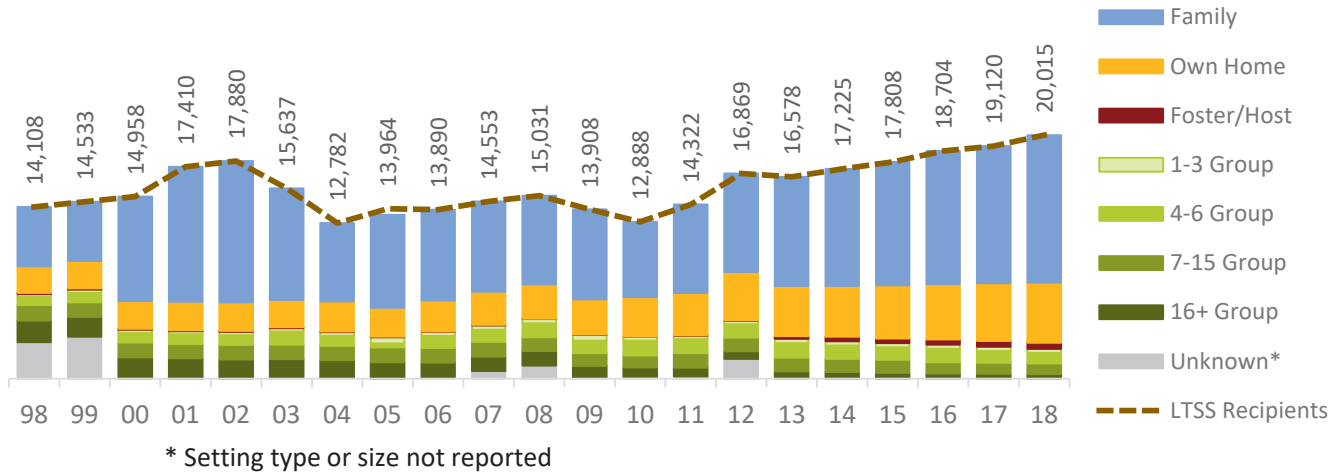
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Missouri

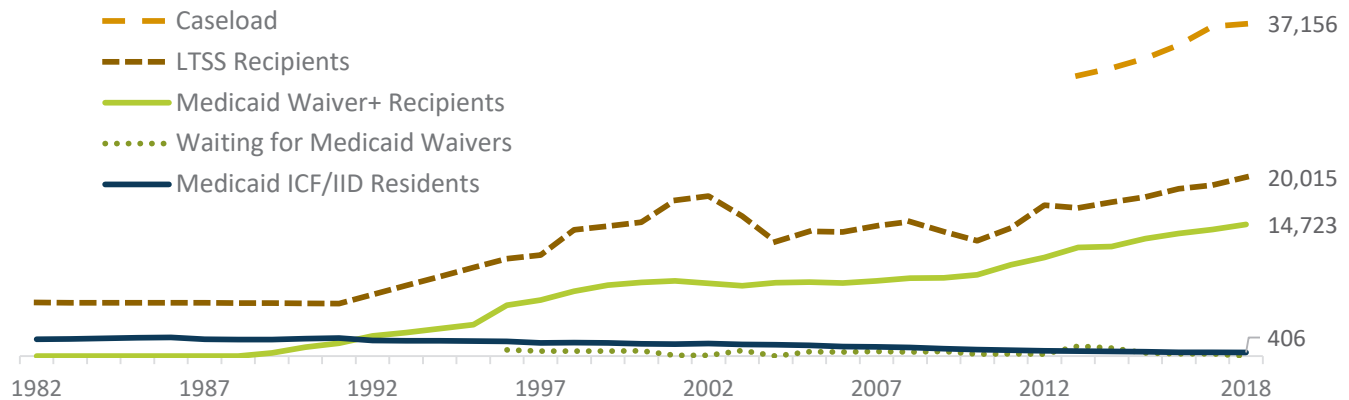
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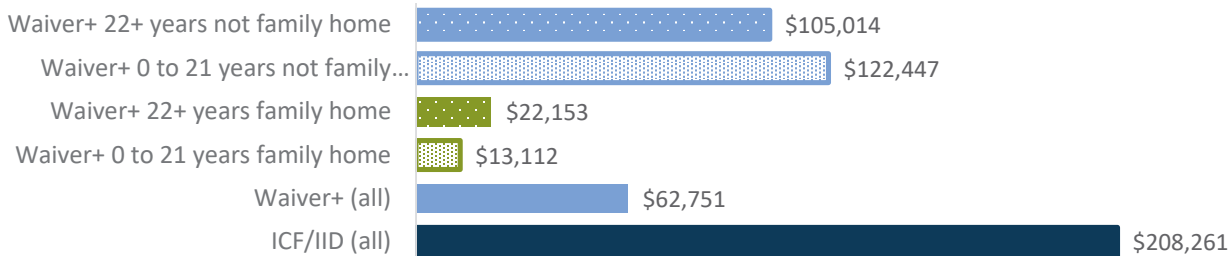
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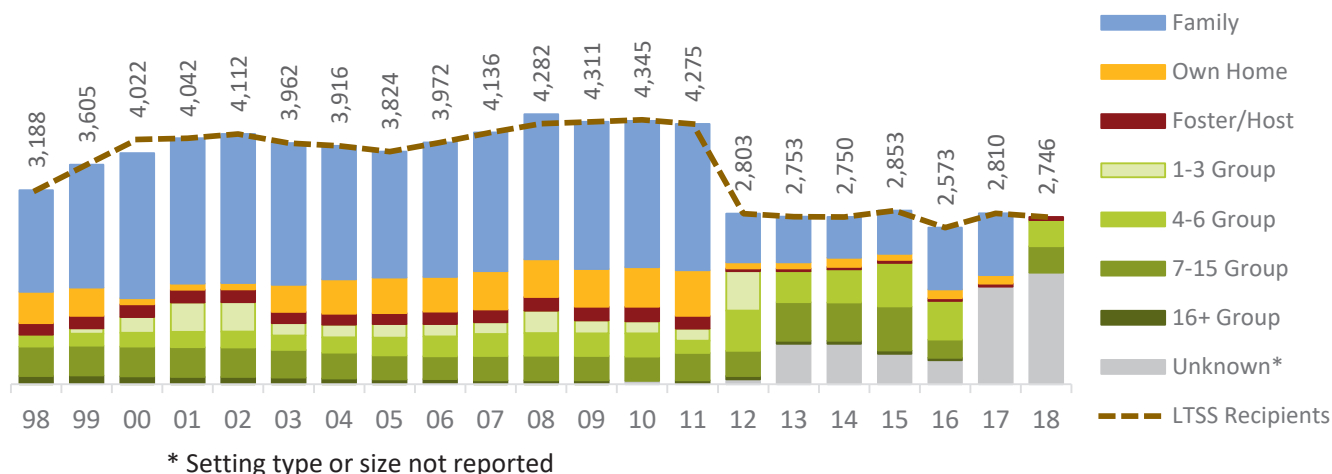
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Montana

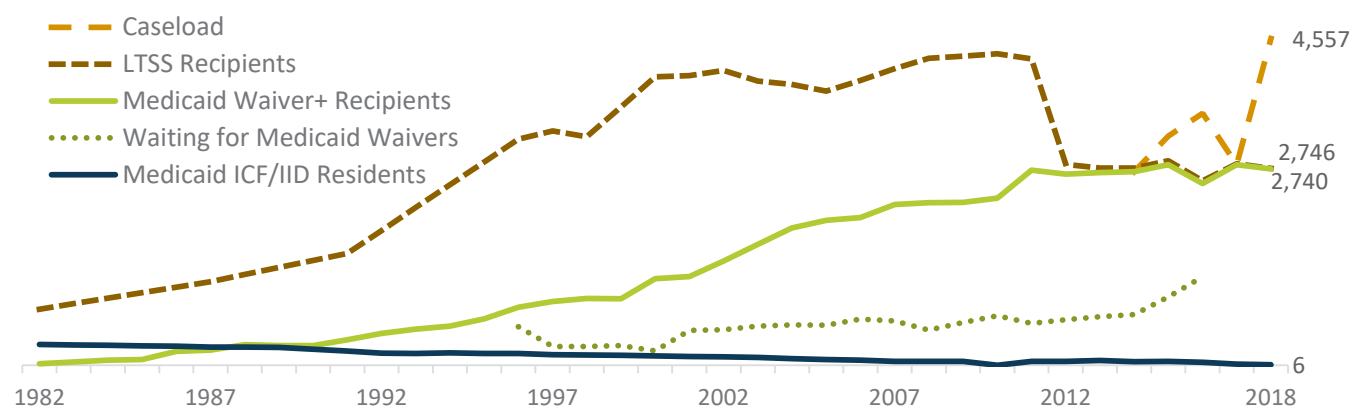
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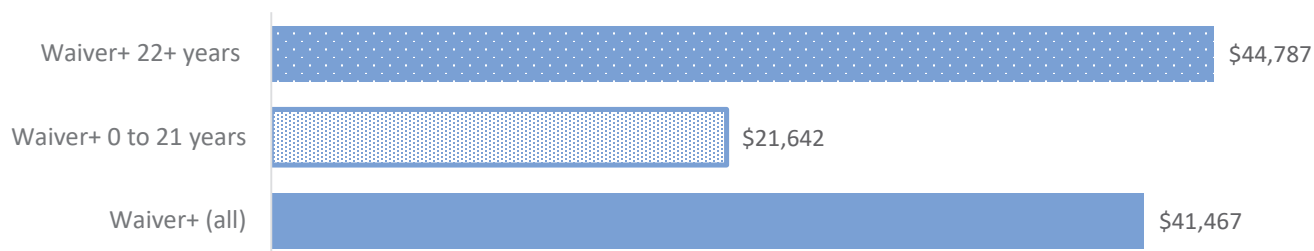
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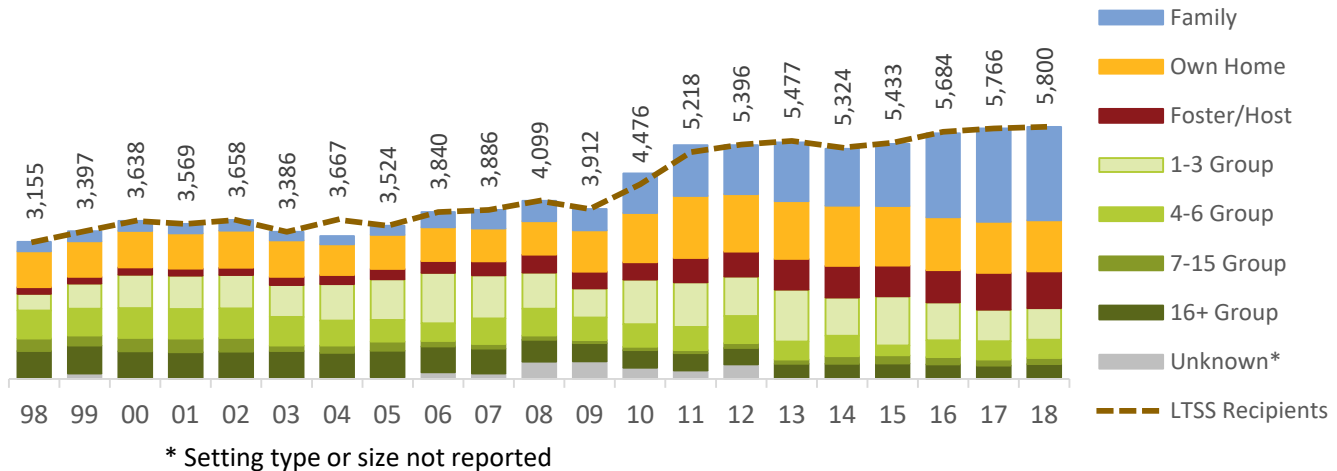
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Nebraska

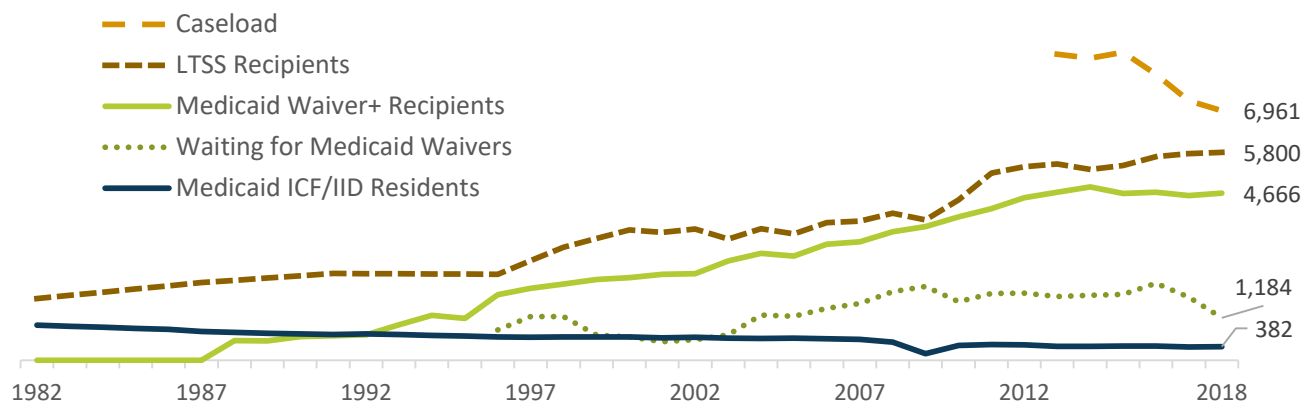
Fiscal Year 2018

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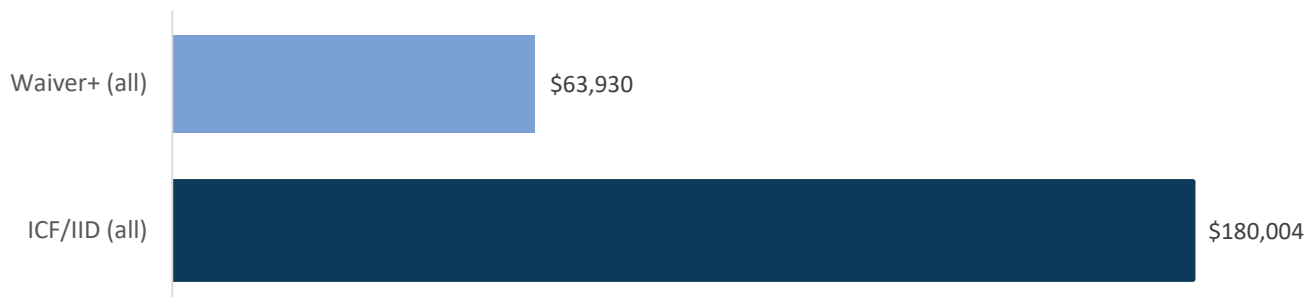
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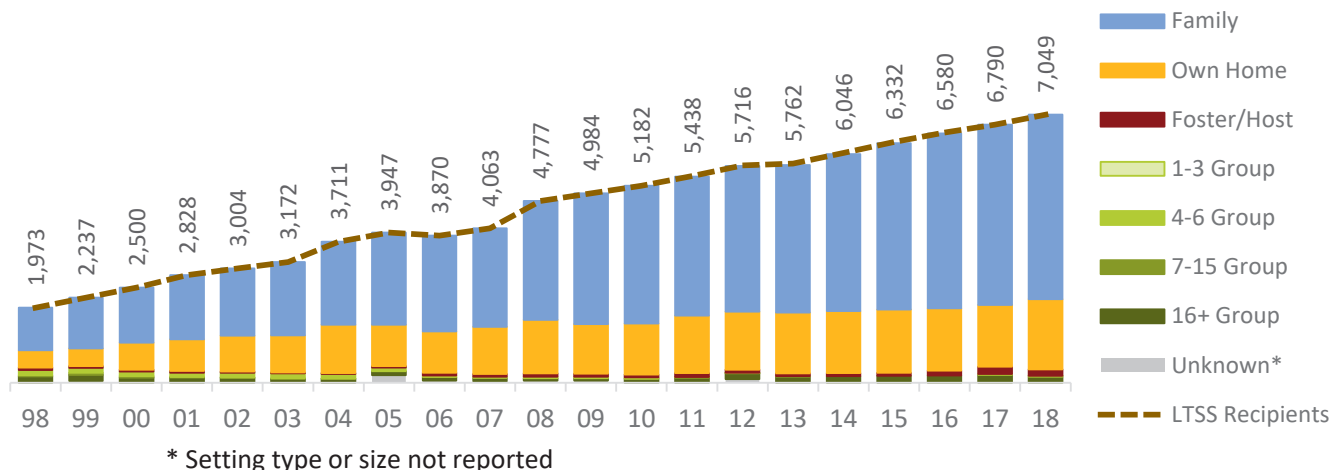
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Nevada

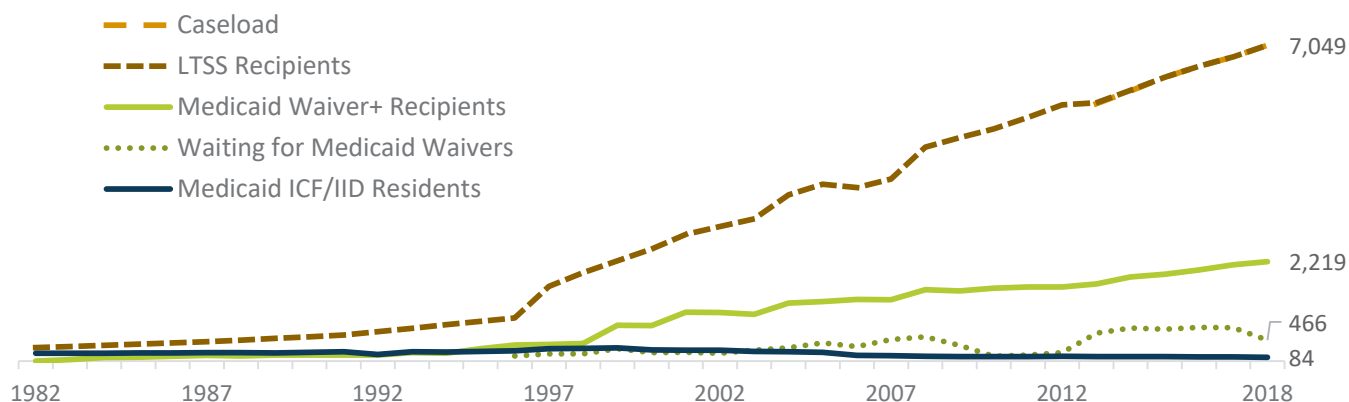
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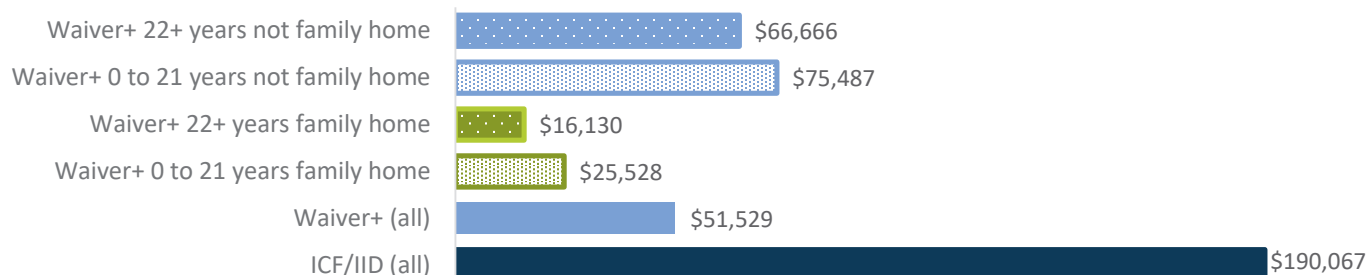
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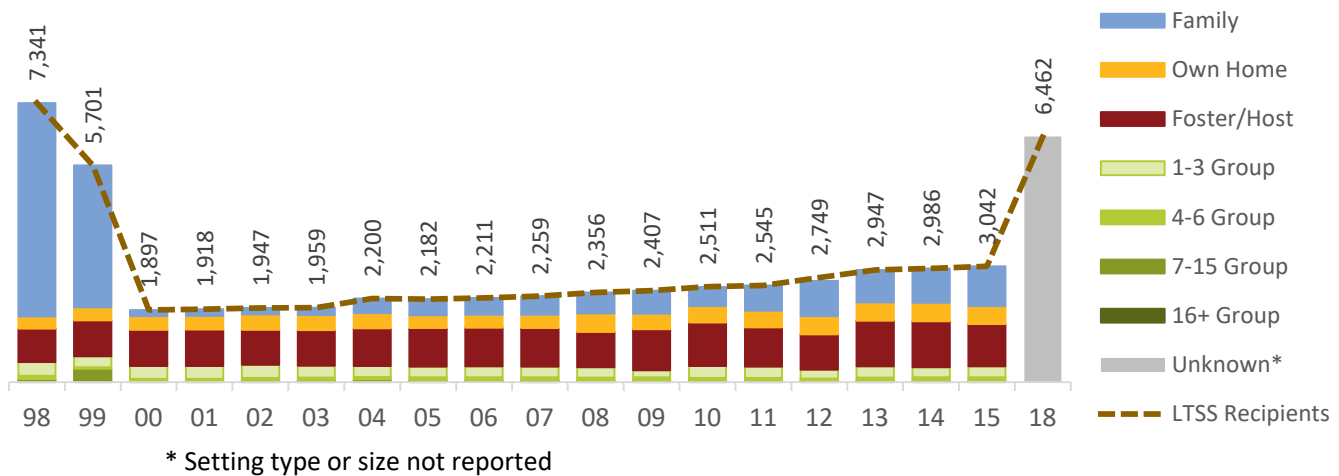
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New Hampshire

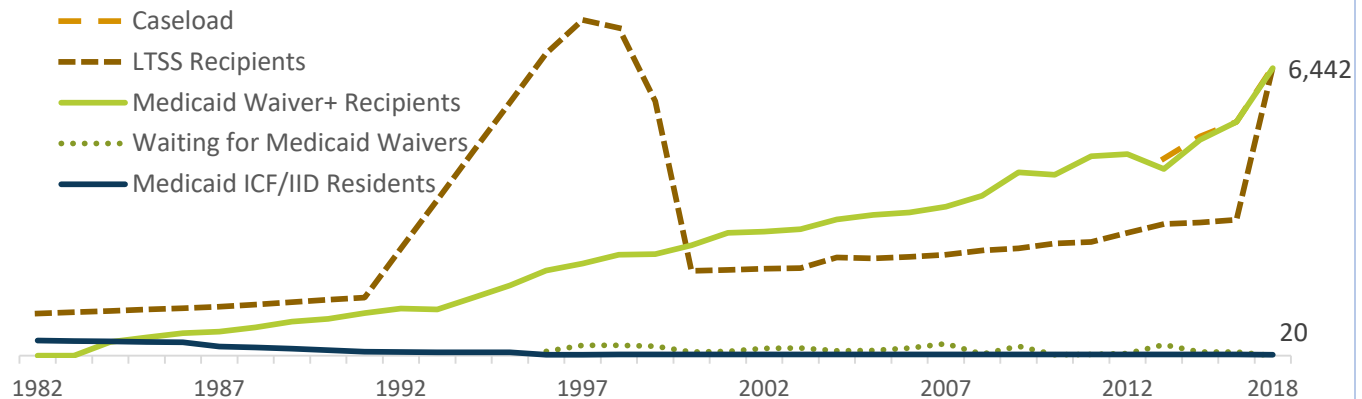
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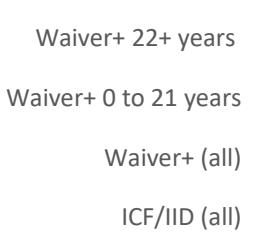
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No expenditure data available for FY 2018

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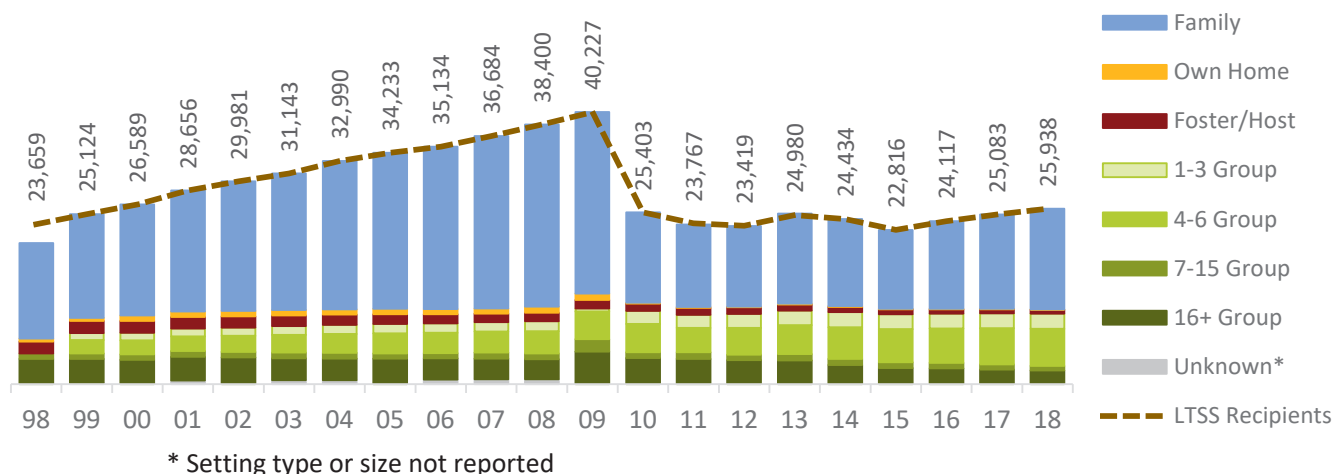
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New Jersey

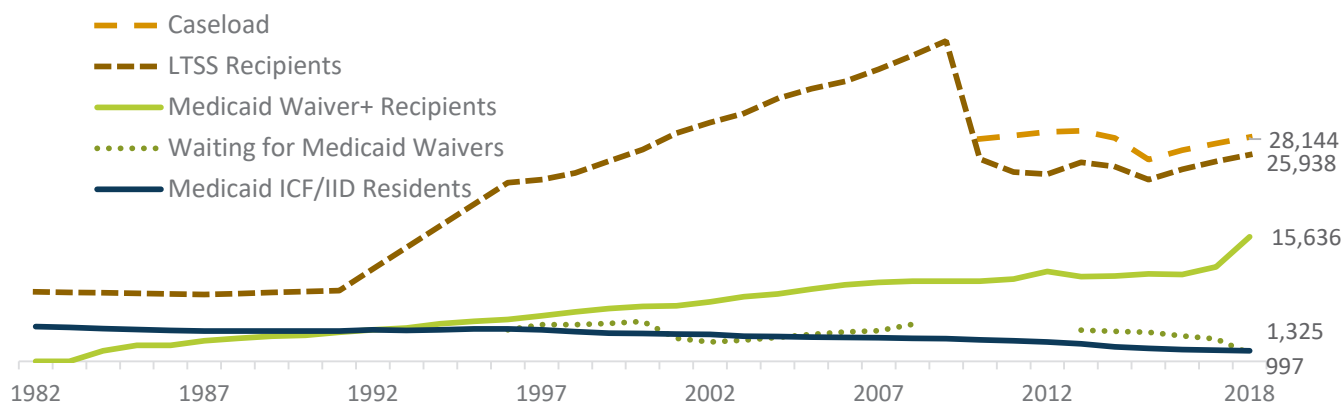
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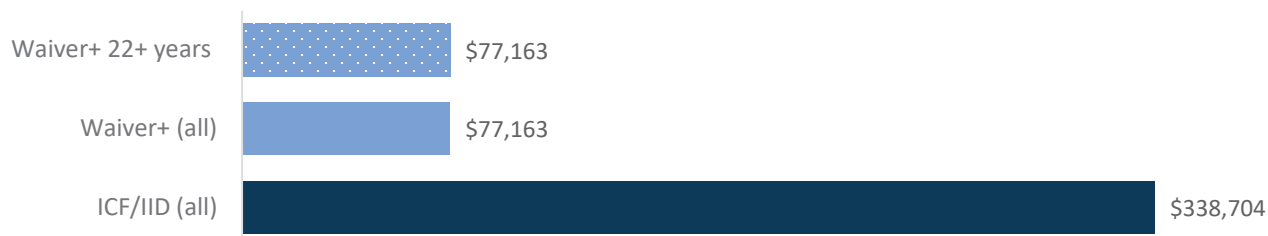
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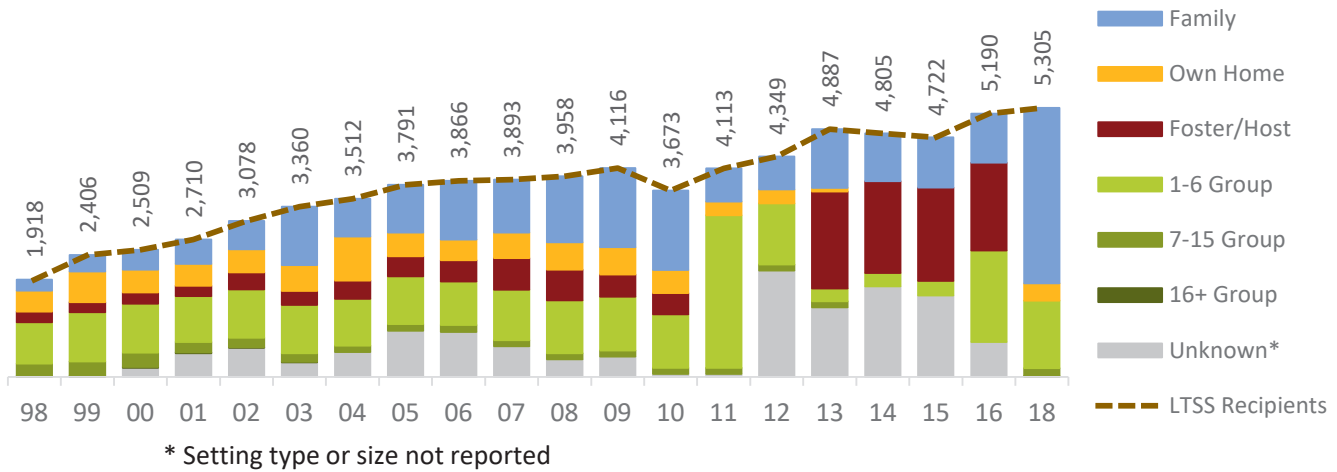
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New Mexico

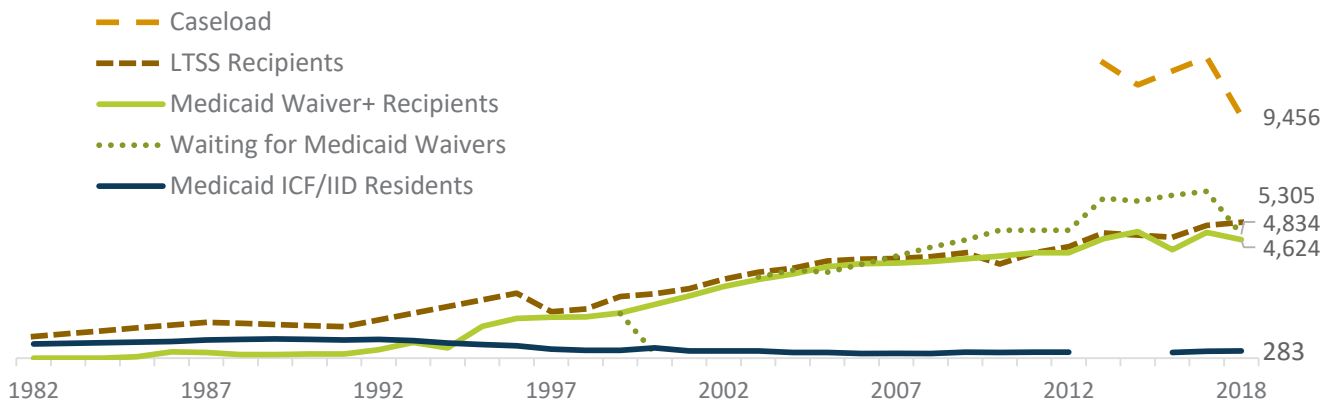
Fiscal year 2018

Residential Information Systems Project

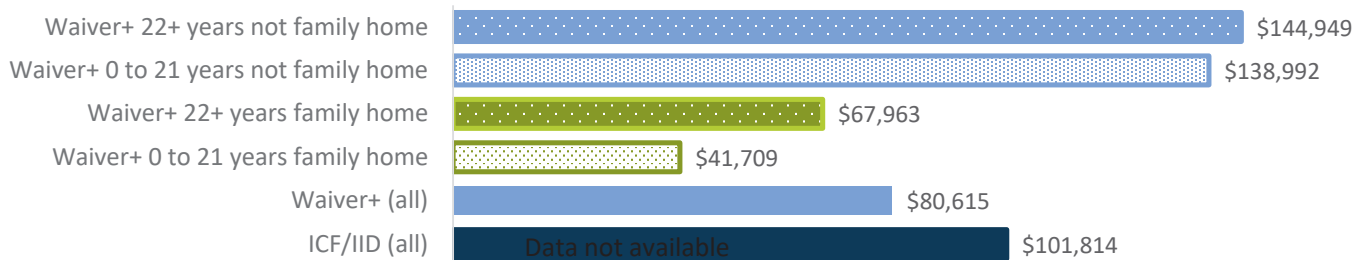
IDD Agency Long Term Supports and Services Recipients by Residence Type



Caseload, LTSS and Medicaid Recipients and Waiting for Waivers* 1982-2018



Average Spending Per Person by Medicaid Authority in Fiscal Year 2018



Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

ICF/IID: Intermediate Care Facilities for Individuals with Intellectual Disabilities

Group: Number of people with IDD in a setting (ICF/IID, group home or other)

Waiver+: Medicaid Authorities 1115, 1915 (a)(b) or (b)(c), 1915(c)

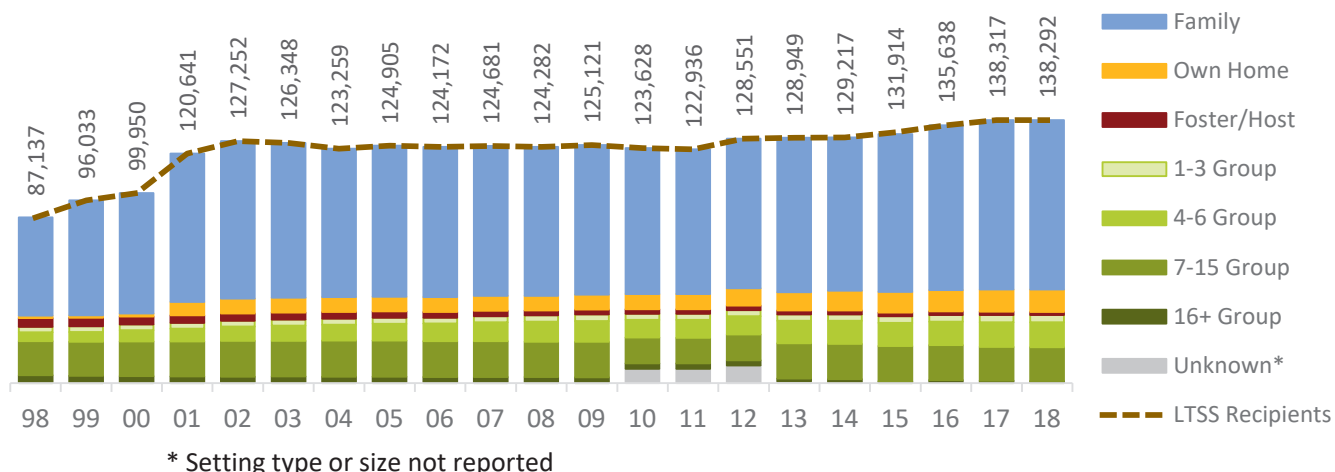
For more see risp.umn.edu

New York

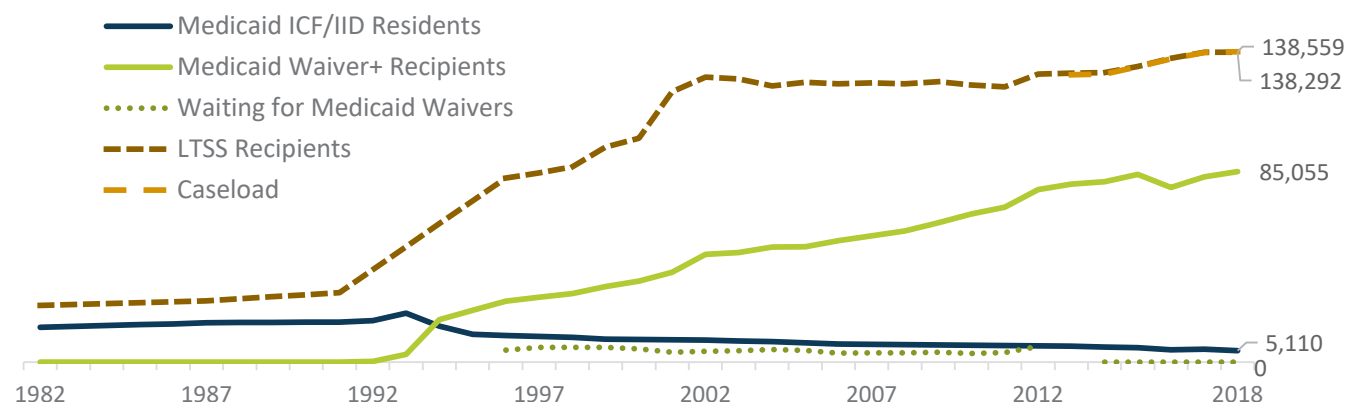
Fiscal Year 2018

Residential Information Systems Project

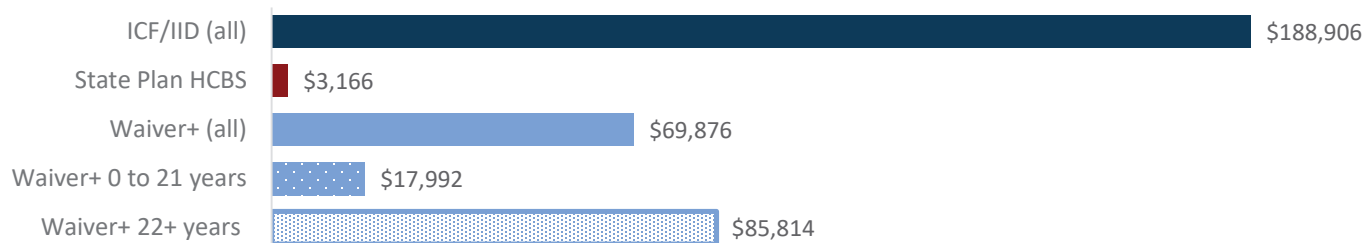
IDD Agency Long Term Supports and Services Recipients by Residence Type



Caseload, LTSS and Medicaid Recipients and Waiting for Waivers* 1982-2018



Average Spending Per Person by Medicaid Authority in Fiscal Year 2018



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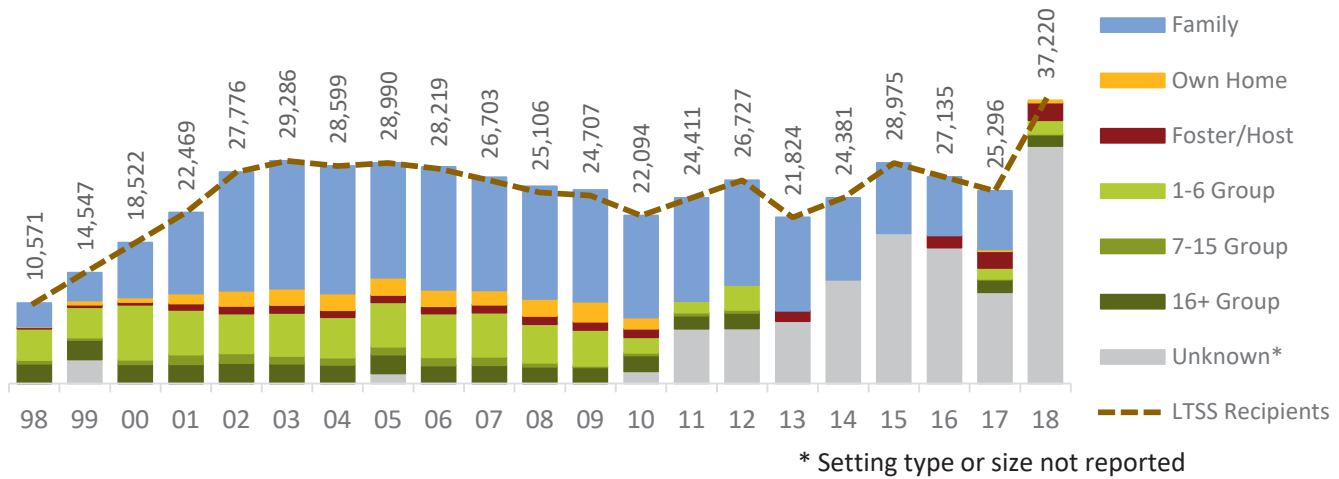
For more see risp.umn.edu

North Carolina

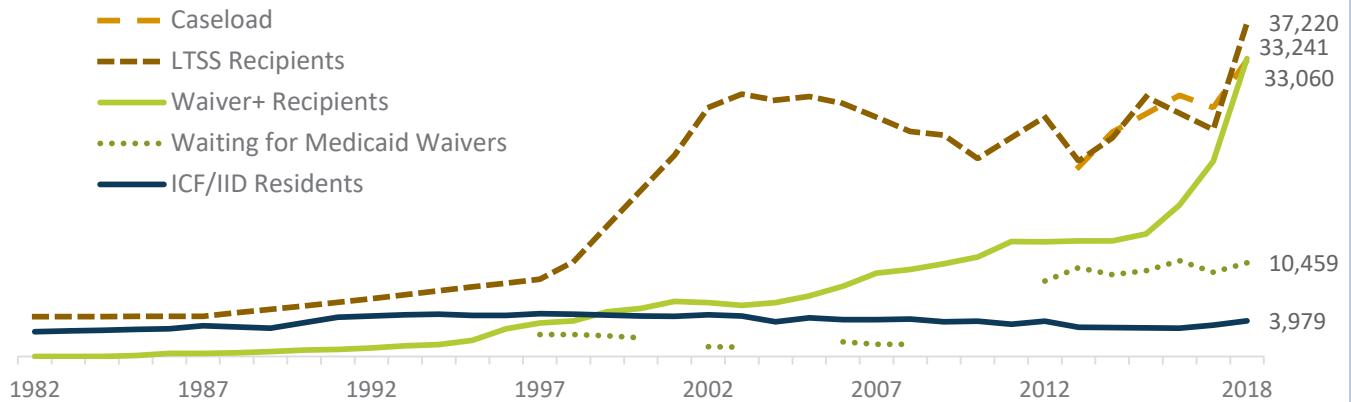
Fiscal Year 2018

Residential Information Systems Project

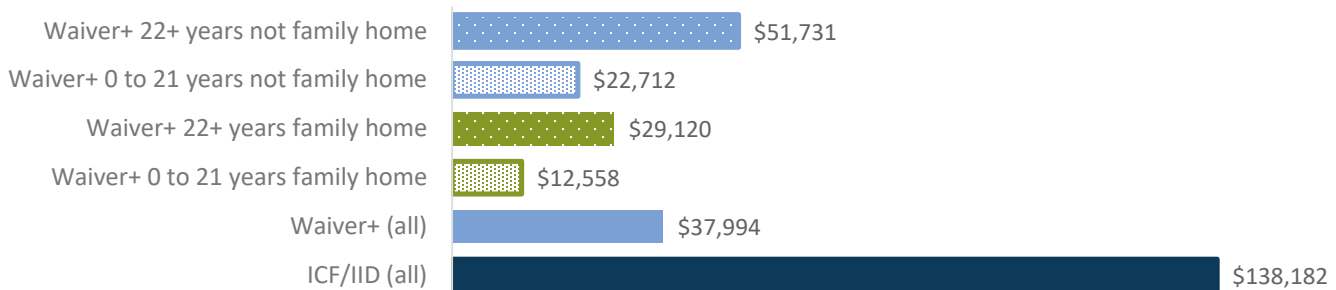
IDD Agency Long Term Supports and Services Recipients by Residence Type



Caseload, LTSS and Medicaid Recipients and Waiting for Waivers* 1982-2018



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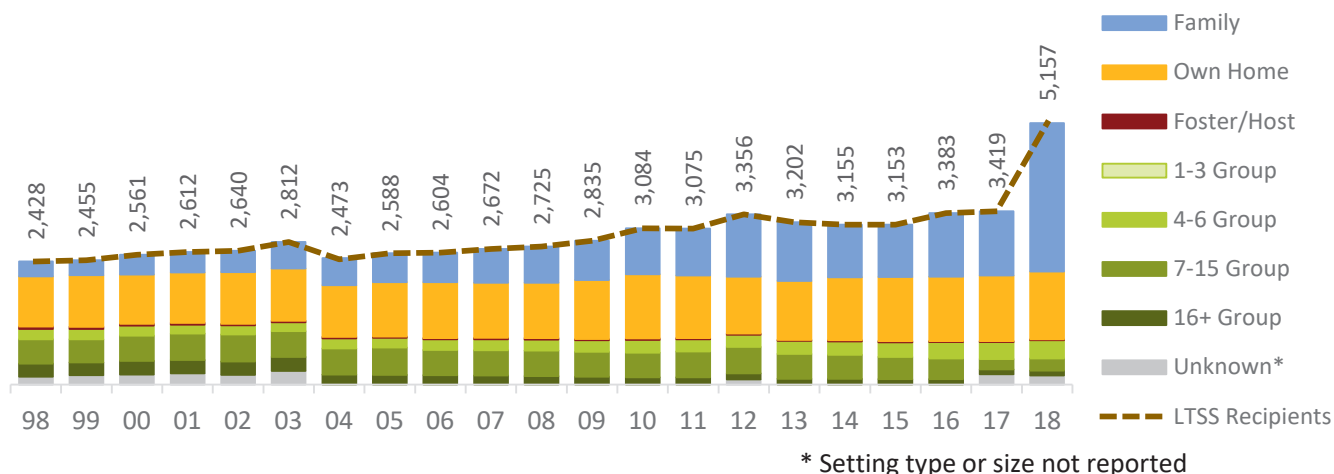
For more see risp.umn.edu

North Dakota

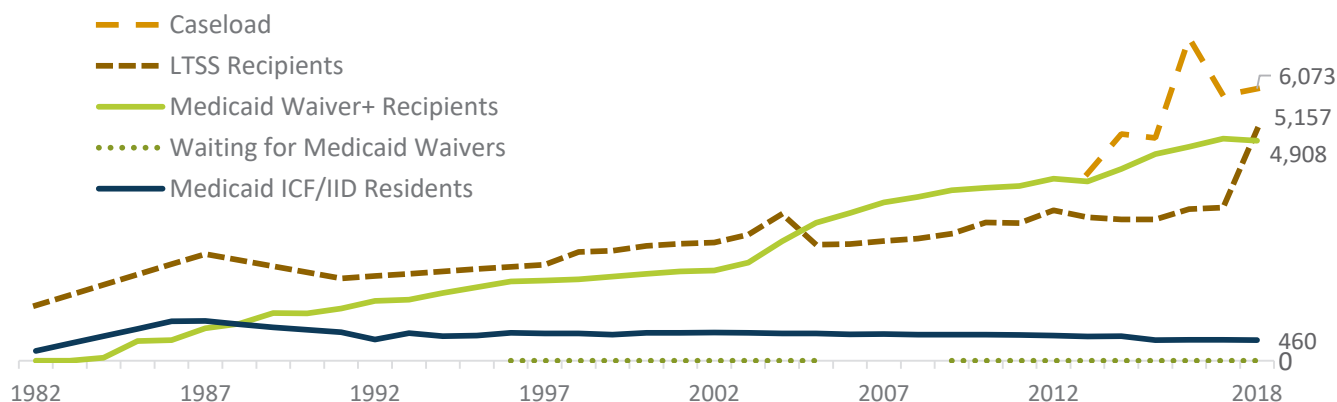
Fiscal Year 2018

Residential Information Systems Project

IDD Agency Long Term Supports and Services Recipients by Residence Type



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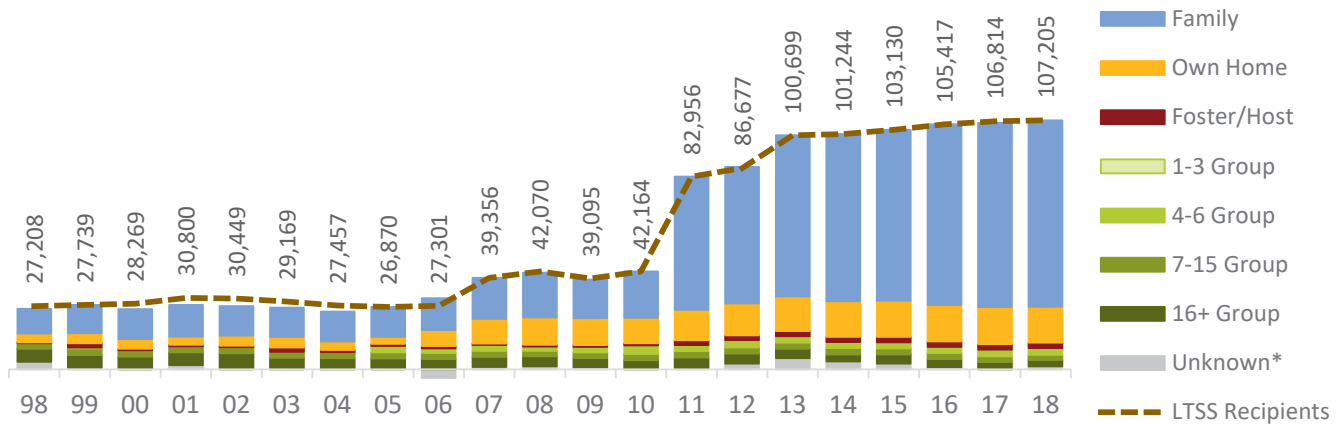
For more see risp.umn.edu

Ohio

Fiscal Year 2018

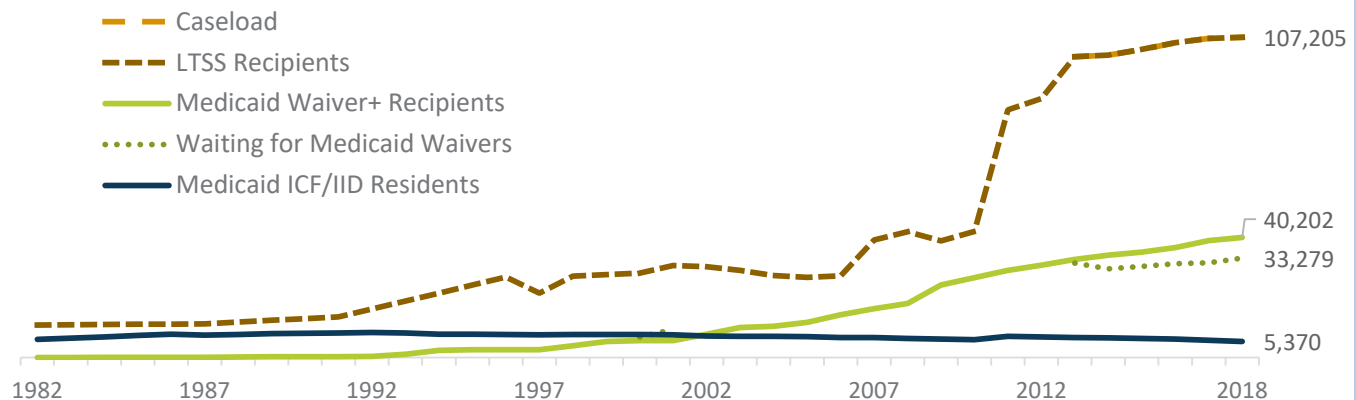
Residential Information Systems Project

IDD Agency Long Term Supports and Services Recipients by Residence Type

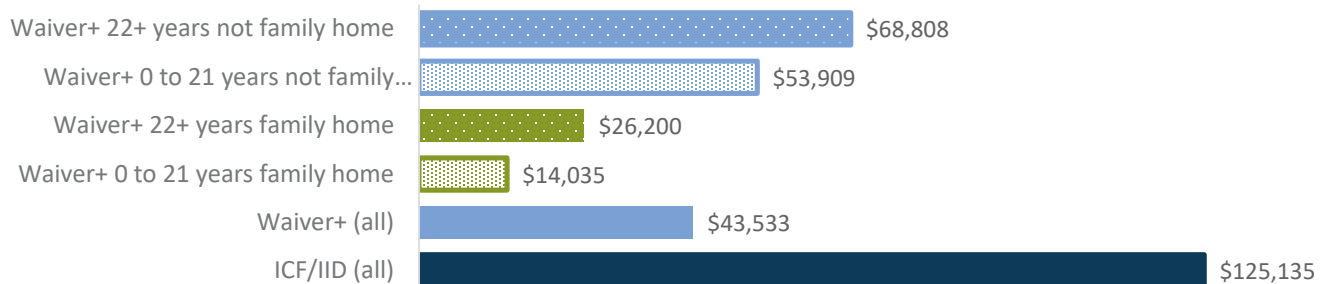


* Setting type or size not reported

Caseload, LTSS and Medicaid Recipients and Waiting for Waivers* 1982-2018



Average Spending Per Person by Medicaid Authority in Fiscal Year 2018



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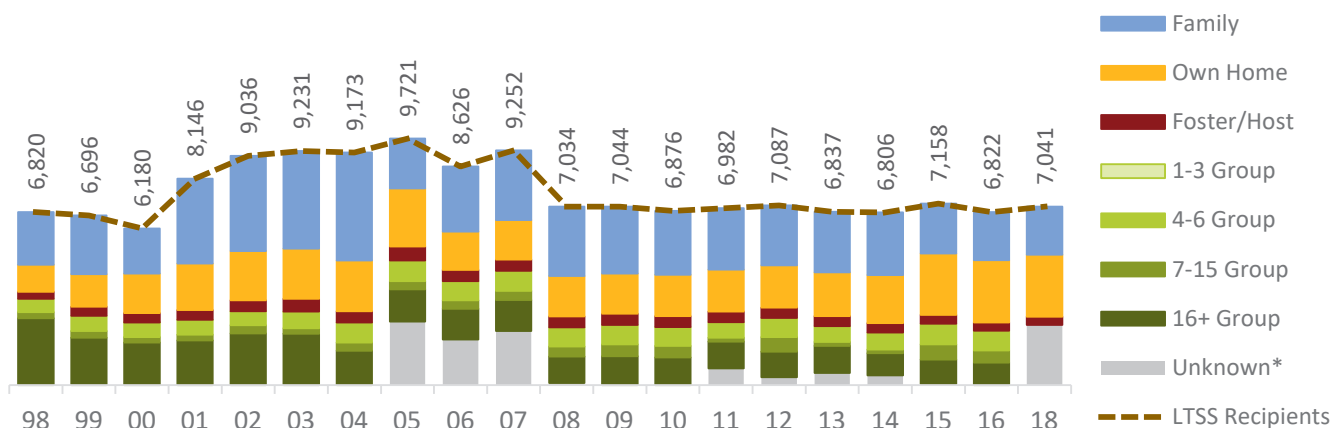
For more see risp.umn.edu

Oklahoma

Fiscal year 2018

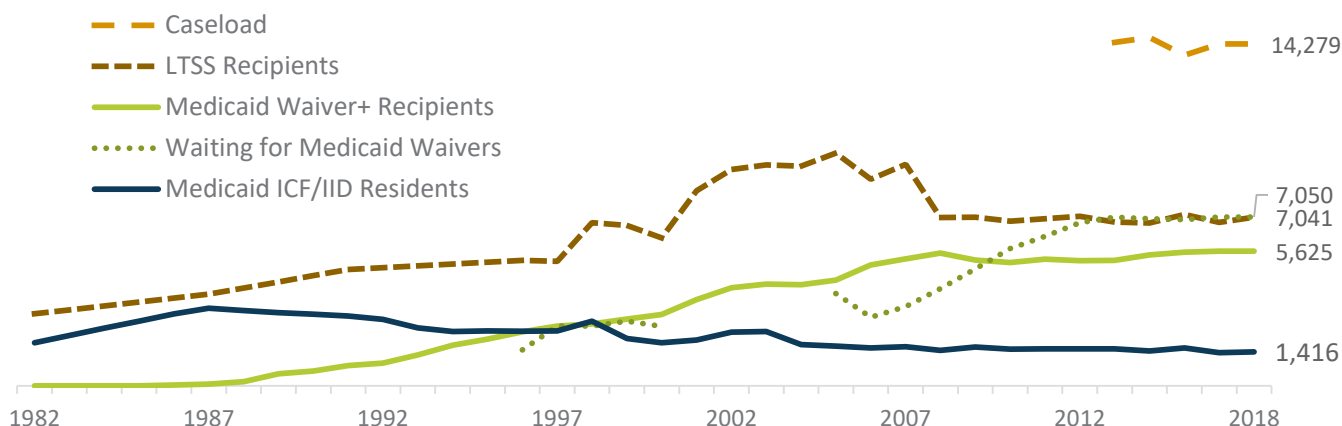
Residential Information Systems Project

IDD Agency Long Term Supports and Services Recipients by Residence Type

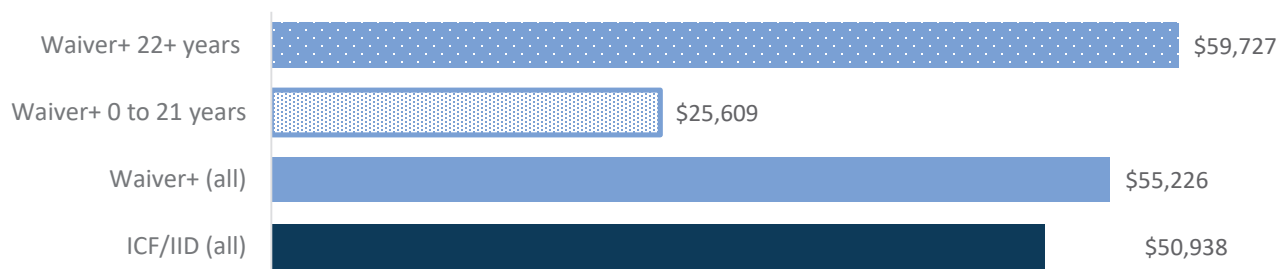


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Caseload, LTSS and Medicaid Recipients and Waiting for Waivers* 1982-2018



Average Spending Per Person by Medicaid Authority in Fiscal Year 2018



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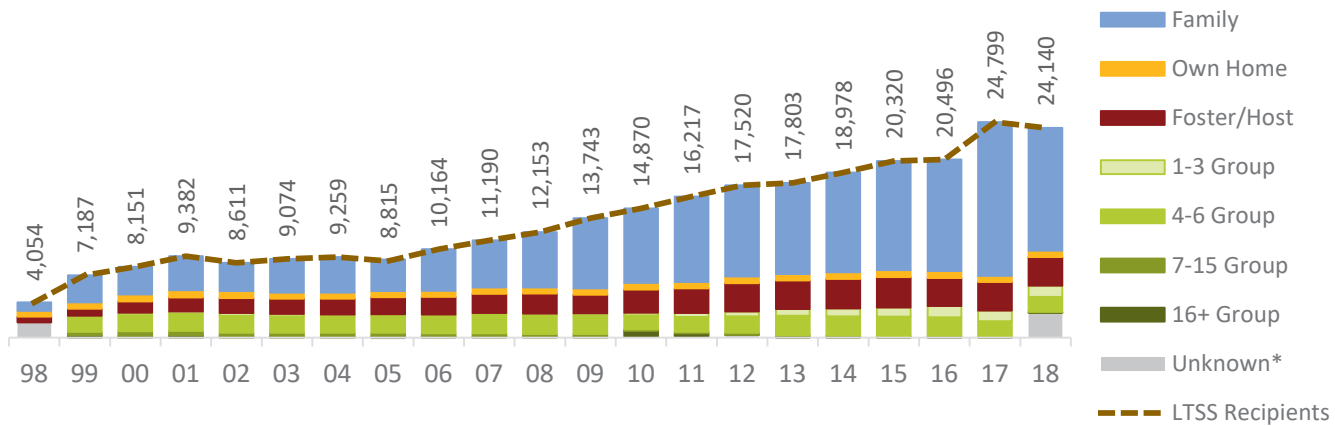
For more see risp.umn.edu

Oregon

Fiscal Year 2018

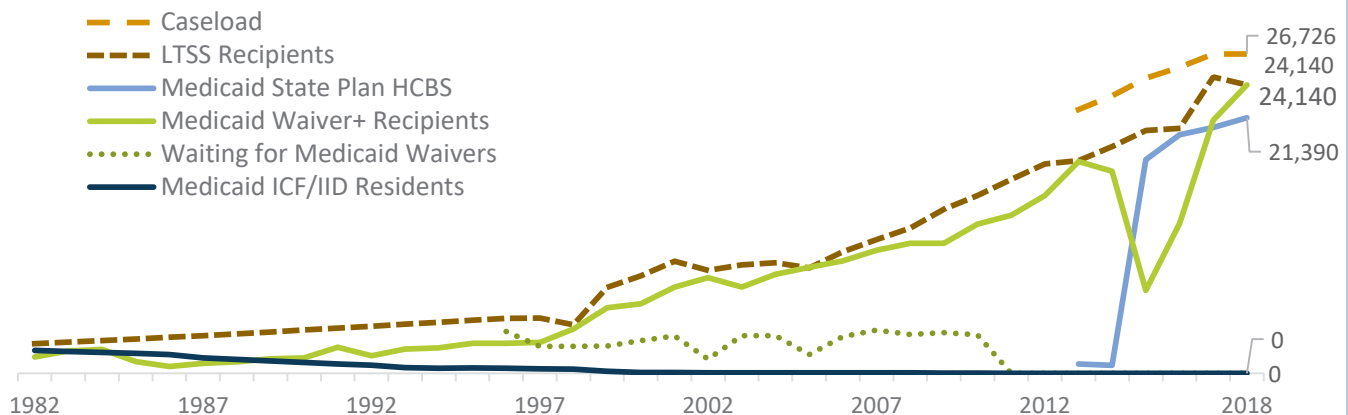
Residential Information Systems Project

IDD Agency Long Term Supports and Services Recipients by Residence Type

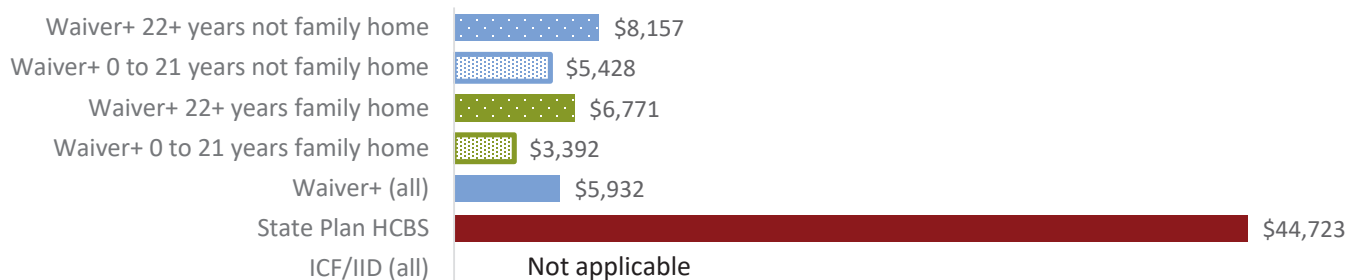


* Setting type or size not reported

Caseload, LTSS and Medicaid Recipients and Waiting for Waivers* 1982-2018



Average Spending Per Person by Medicaid Authority in Fiscal Year 2018



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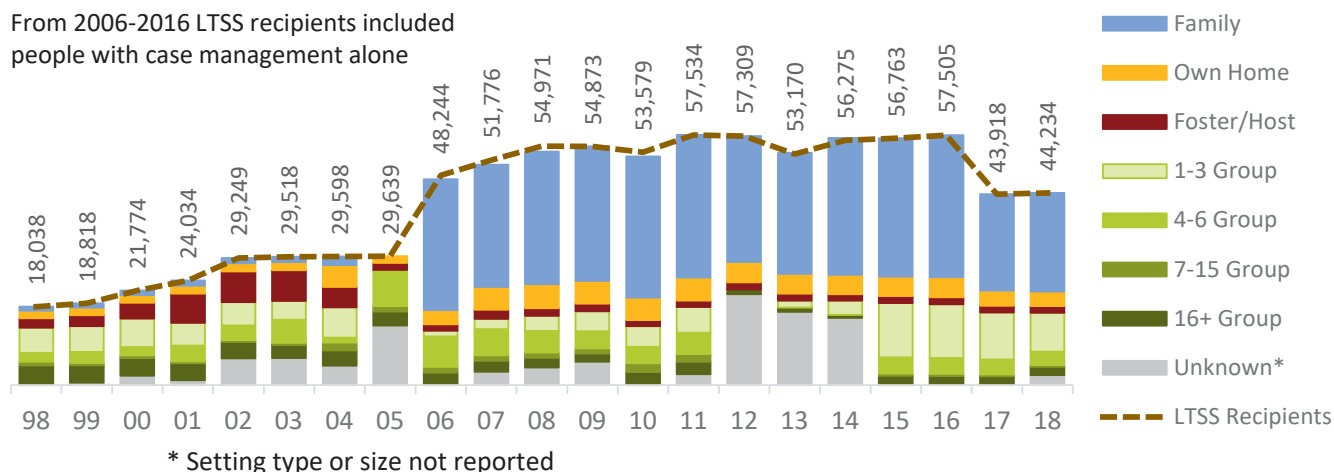
Pennsylvania

Fiscal Year 2018

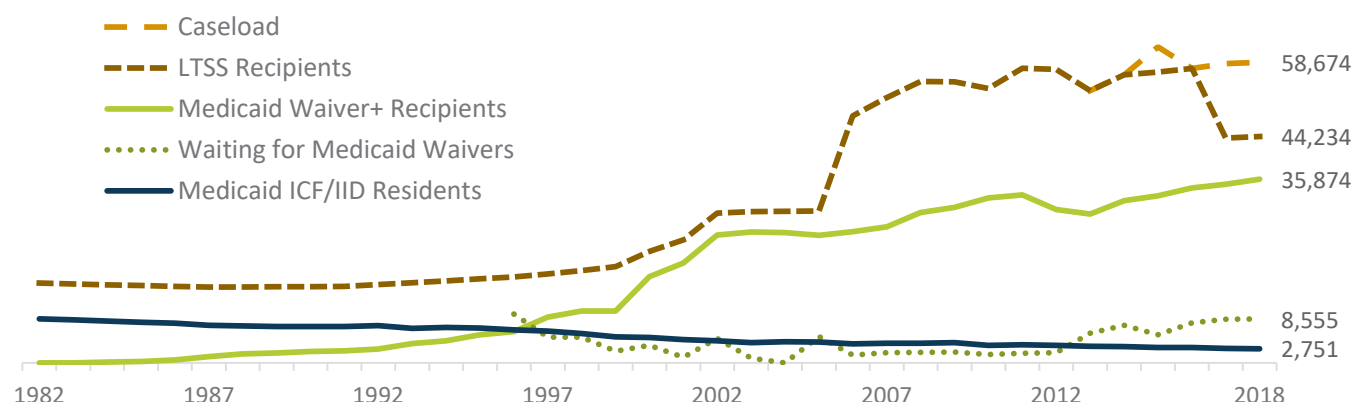
Residential Information Systems Project

IDD Agency Long Term Supports and Services Recipients by Residence Type

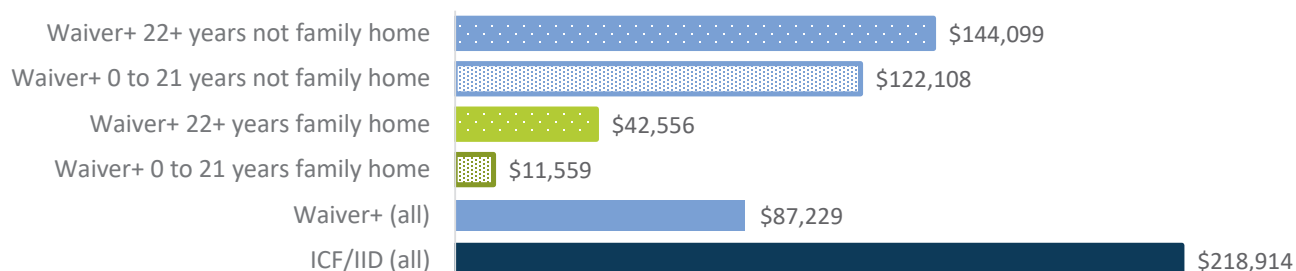
From 2006-2016 LTSS recipients included people with case management alone



Caseload, LTSS and Medicaid Recipients and Waiting for Waivers* 1982-2018



Average Spending Per Person by Medicaid Authority in Fiscal Year 2018



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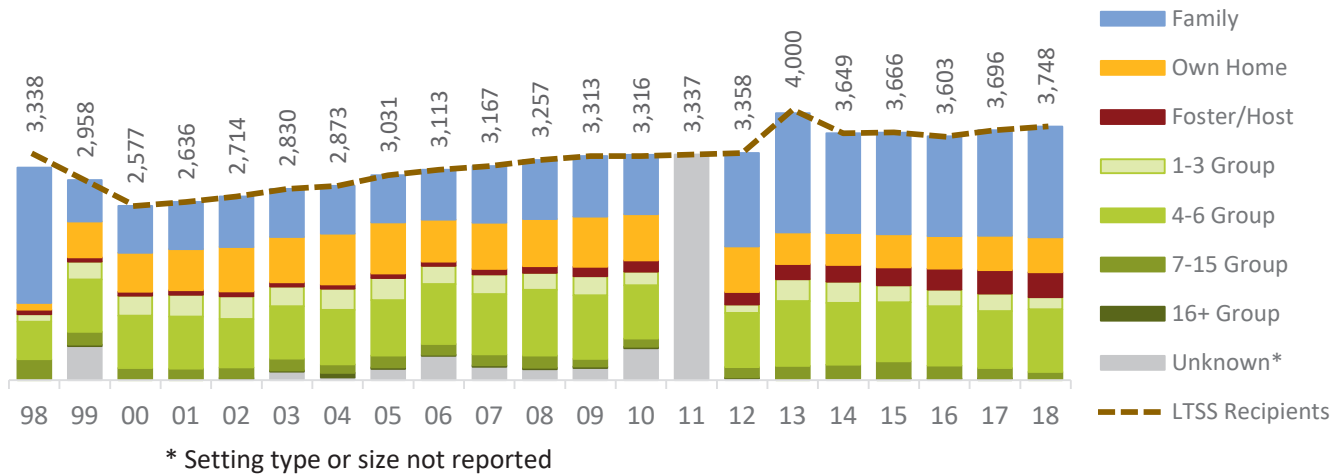
For more see risp.umn.edu

Rhode Island

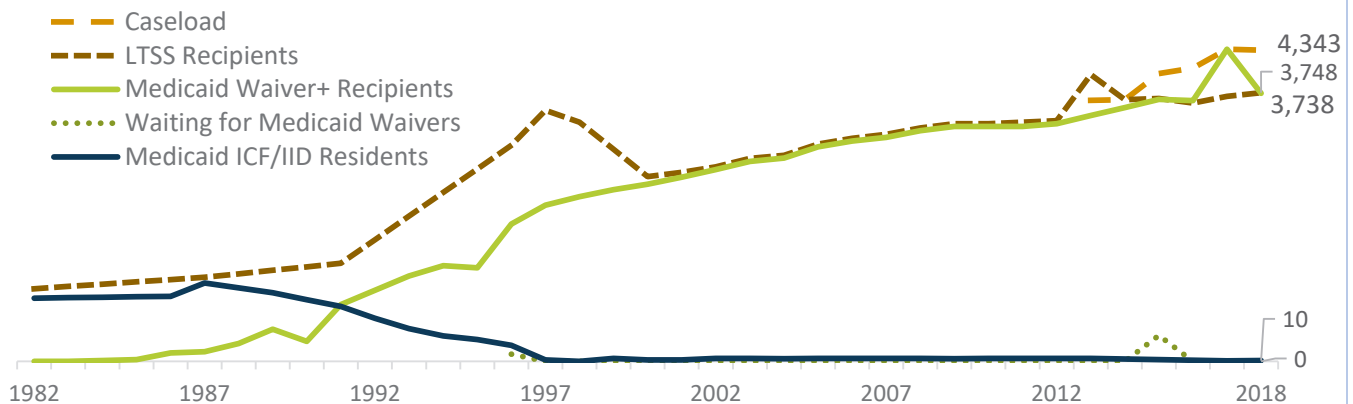
Fiscal Year 2018

Residential Information Systems Project

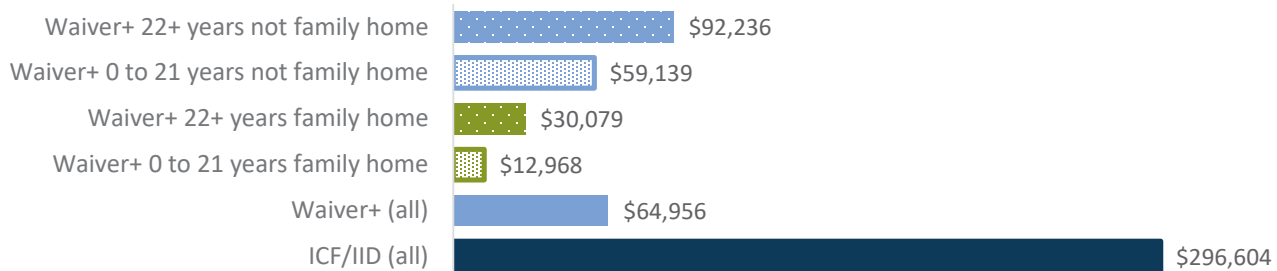
IDD Agency Long Term Supports and Services Recipients by Residence Type



Caseload, LTSS and Medicaid Recipients and Waiting for Waivers* 1982-2018



Average Spending Per Person by Medicaid Authority in Fiscal Year 2018



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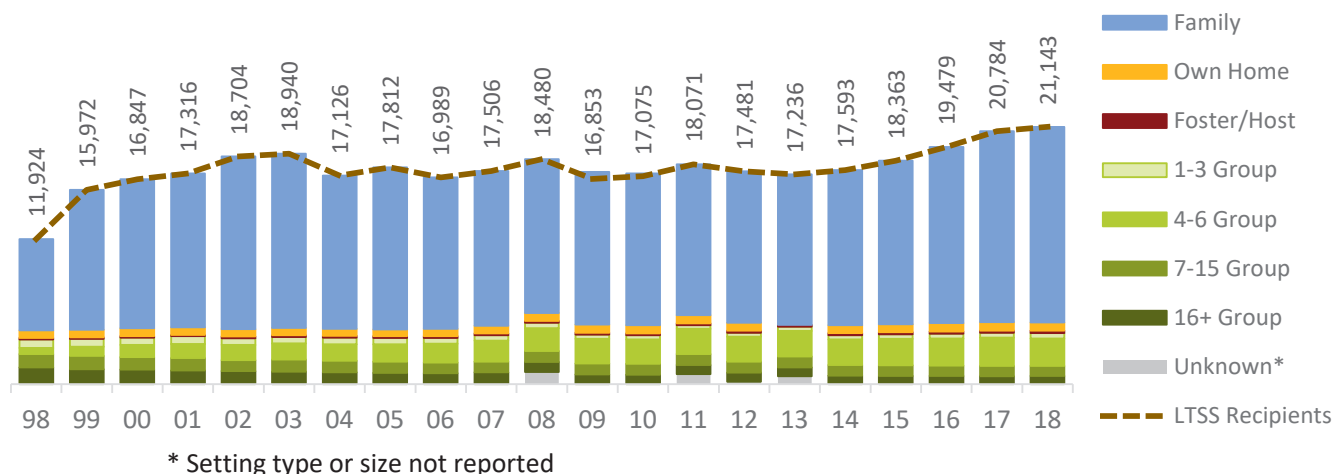
For more see risp.umn.edu

South Carolina

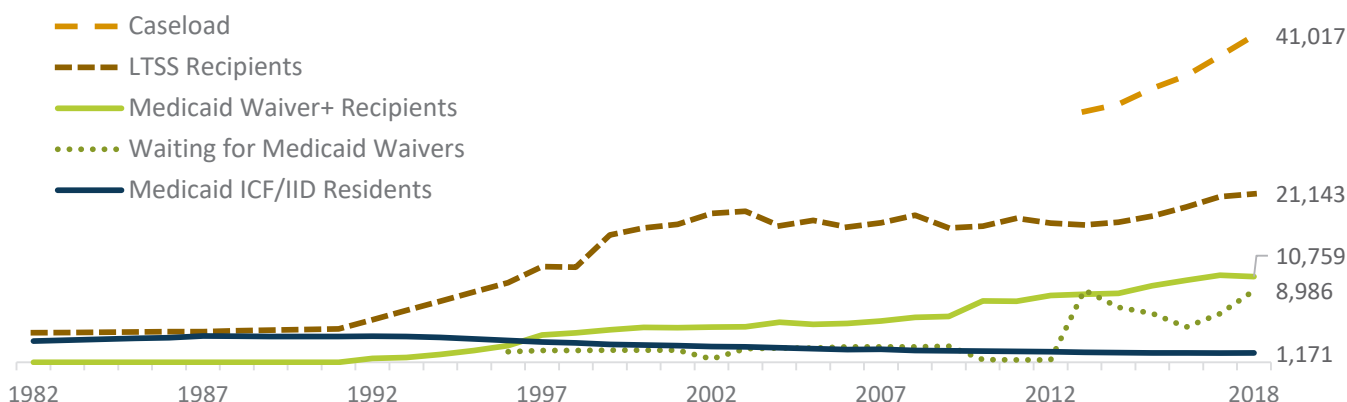
Fiscal Year 2018

Residential Information Systems Project

IDD Agency Long Term Supports and Services Recipients by Residence Type



Caseload, LTSS and Medicaid Recipients and Waiting for Waivers* 1982-2018



Average Spending Per Person by Medicaid Authority in Fiscal Year 2018



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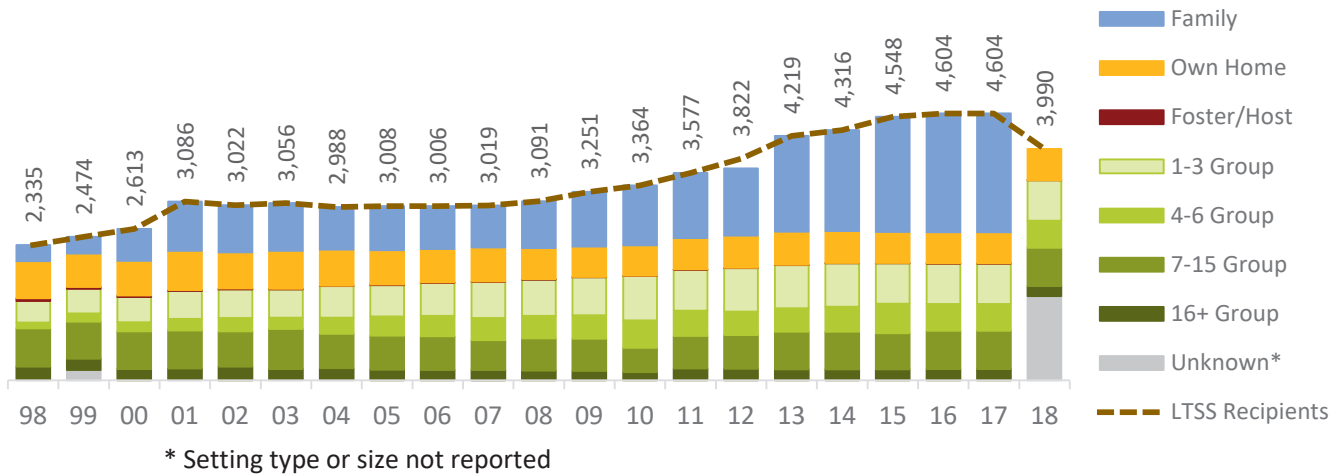
For more see risp.umn.edu

South Dakota

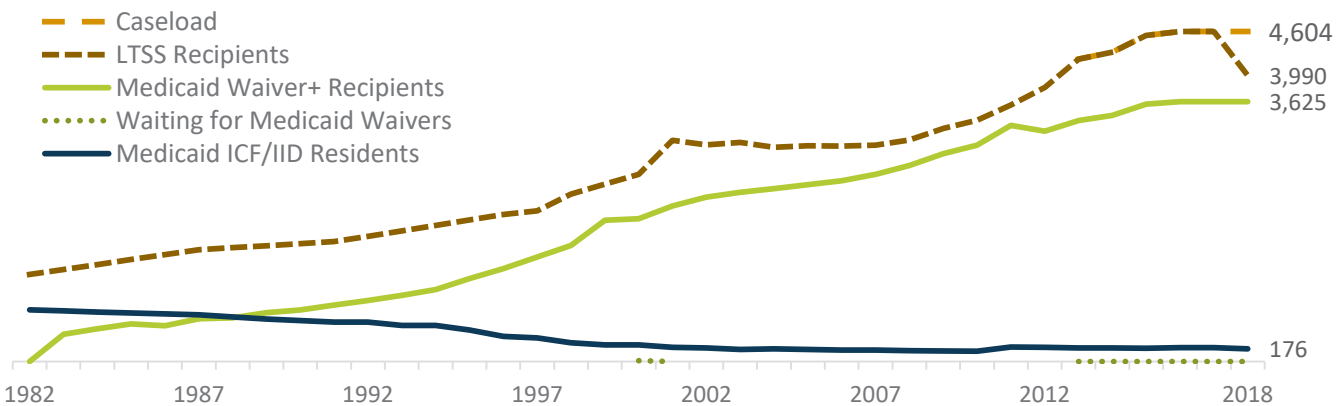
Fiscal Year 2018

Residential Information Systems Project

IDD Agency Long Term Supports and Services Recipients by Residence Type



Caseload, LTSS and Medicaid Recipients and Waiting for Waivers* 1982-2018



Average Spending Per Person by Medicaid Authority in Fiscal Year 2018



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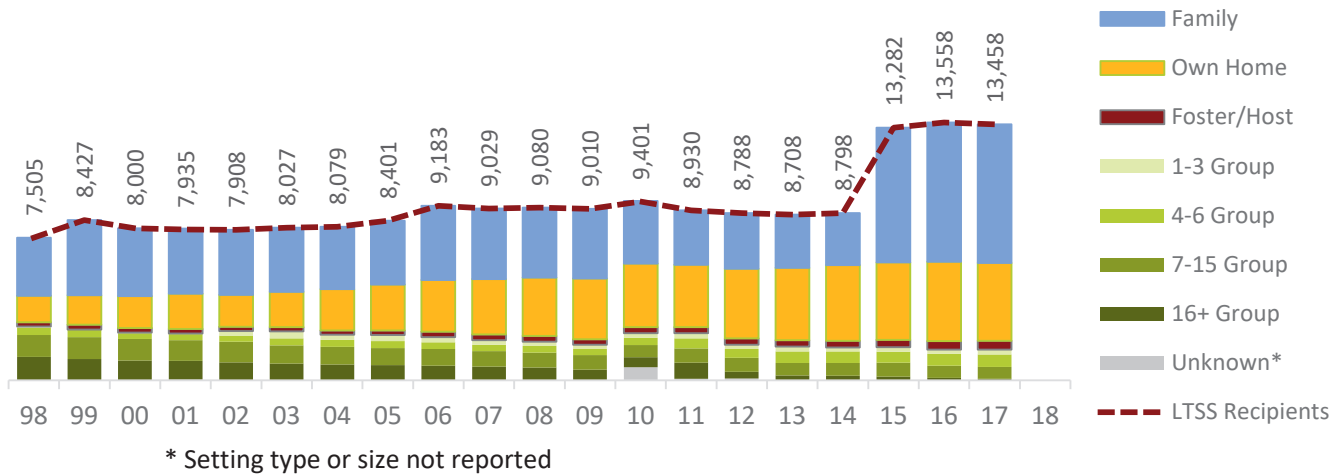
For more see risp.umn.edu

Tennessee

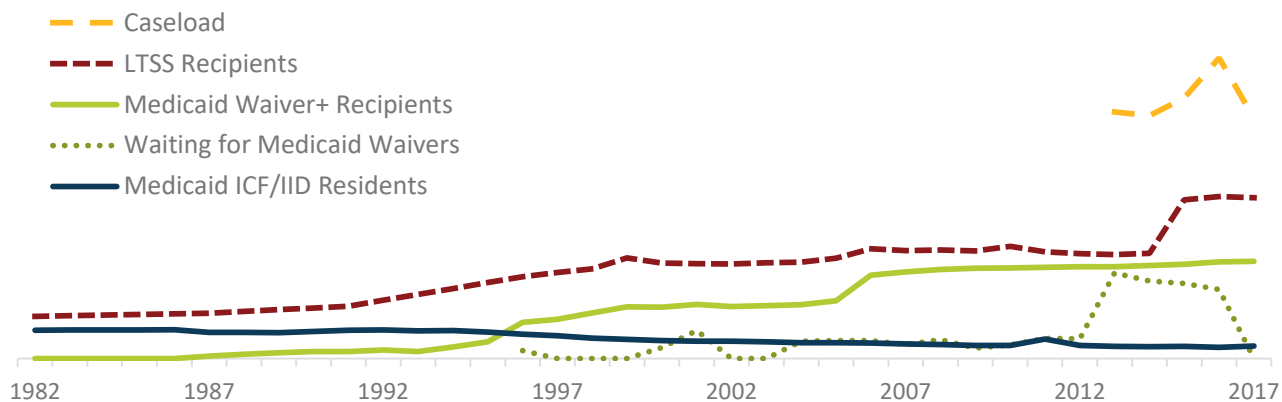
Fiscal Year 2018

Residential Information Systems Project

IDD Agency Long Term Supports and Services Recipients by Residence Type



Caseload, LTSS and Medicaid Recipients and Waiting for Waivers* 1982-2017



Average Spending Per Person by Medicaid Authority in Fiscal Year 2018

- Waiver+ 22+ years not family home
- Waiver+ 0 to 21 years not family home
- Waiver+ 22+ years family home
- Waiver+ 0 to 21 years family home
- Waiver+ (all)
- ICF/IID (all)

Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

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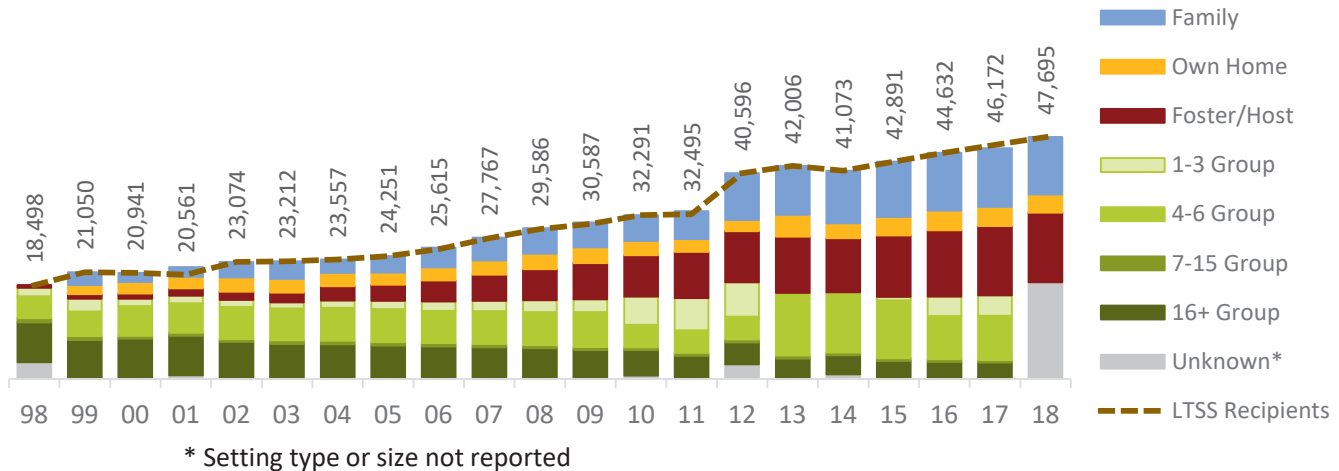
For more see risp.umn.edu

Texas

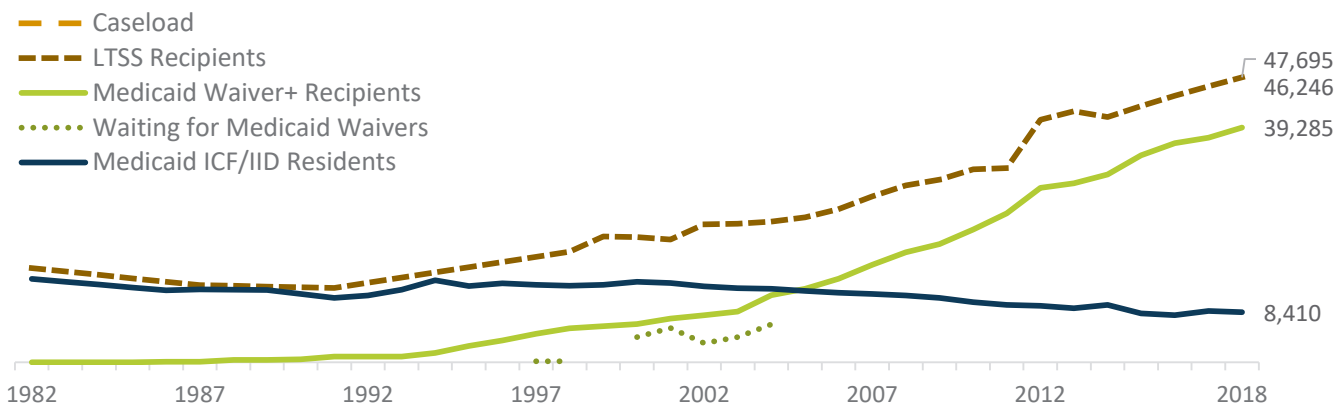
Fiscal Year 2018

Residential Information Systems Project

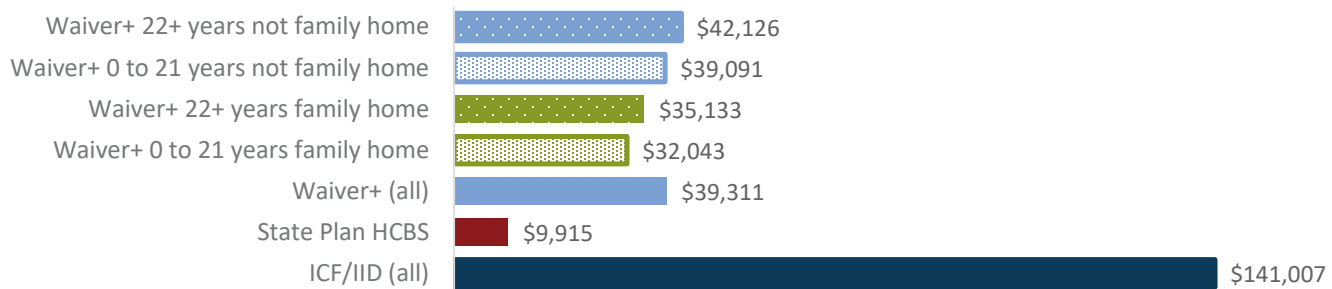
IDD Agency Long Term Supports and Services Recipients by Residence Type



LTSS and Medicaid Recipients and Waiting for Waivers* 1982-2018



Average Spending Per Person by Medicaid Authority in Fiscal Year 2018



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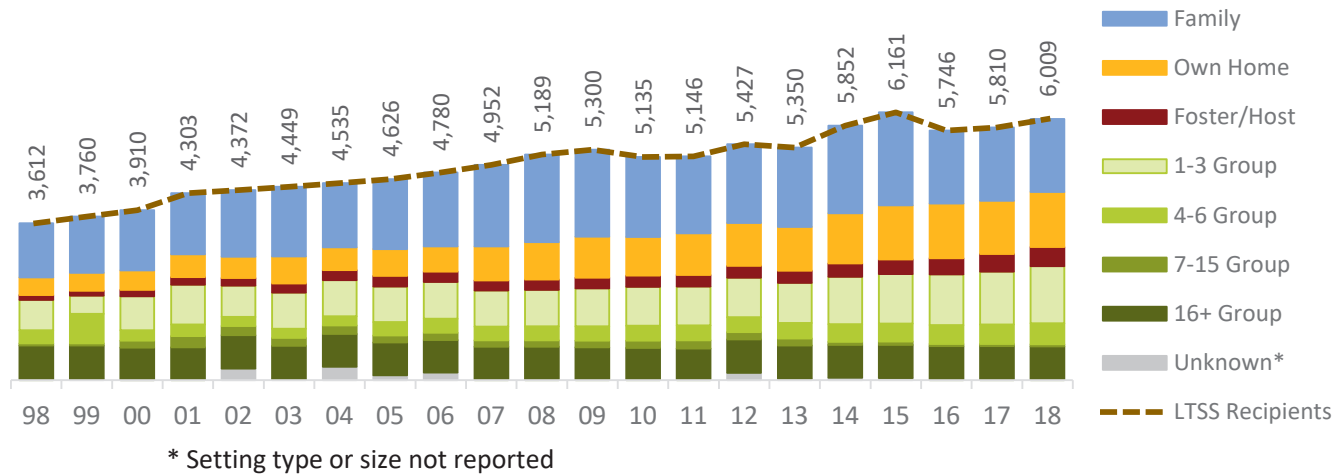
For more see risp.umn.edu

Utah

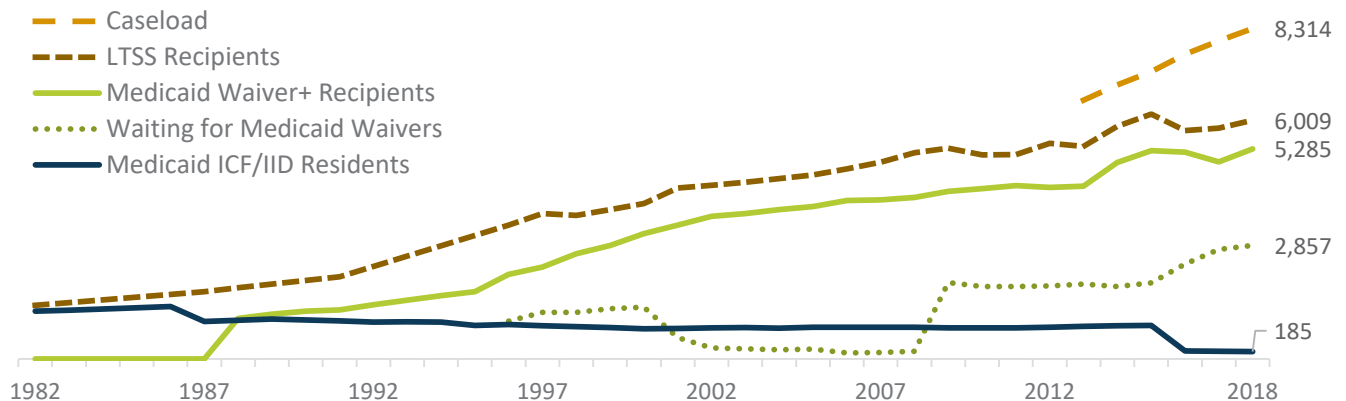
Fiscal Year 2018

Residential Information Systems Project

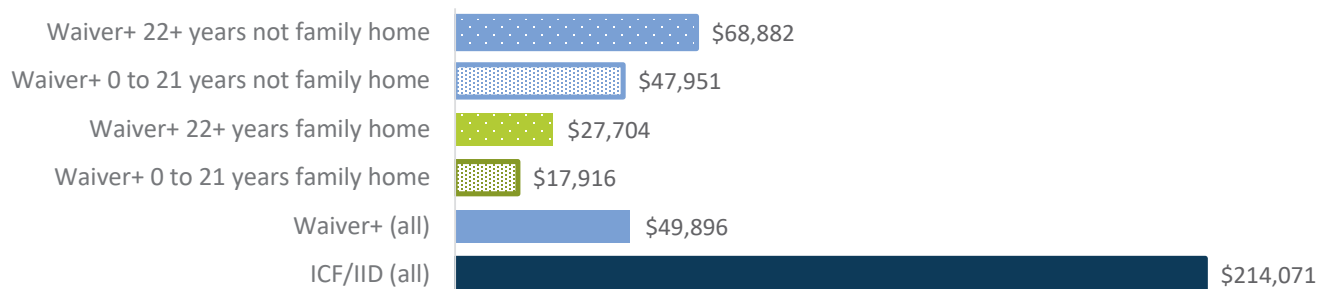
IDD Agency Long Term Supports and Services Recipients by Residence Type



Caseload, LTSS and Medicaid Recipients and Waiting for Waivers* 1982-2018



Average Spending Per Person by Medicaid Authority in Fiscal Year 2018



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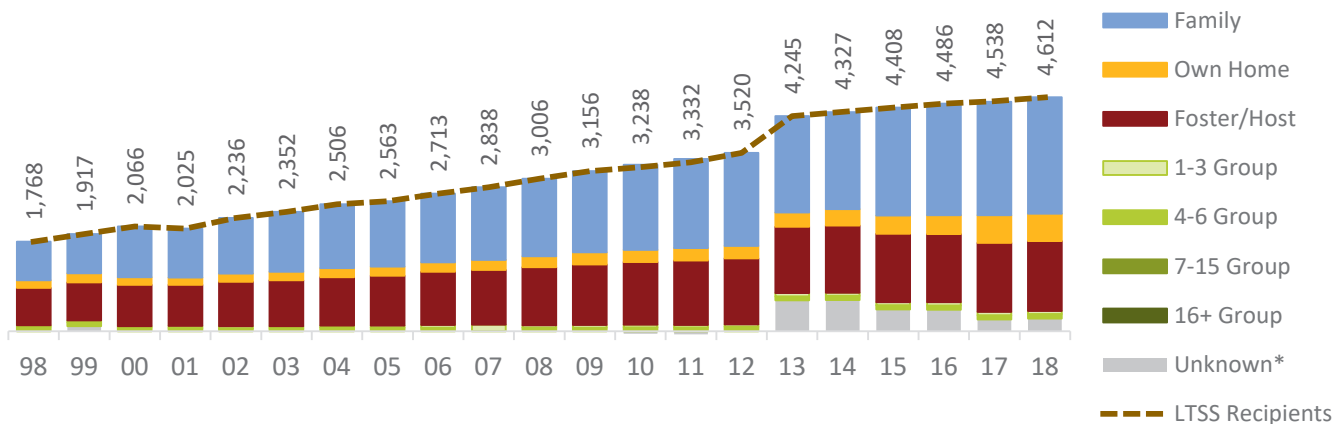
For more see risp.umn.edu

Vermont

Fiscal Year 2018

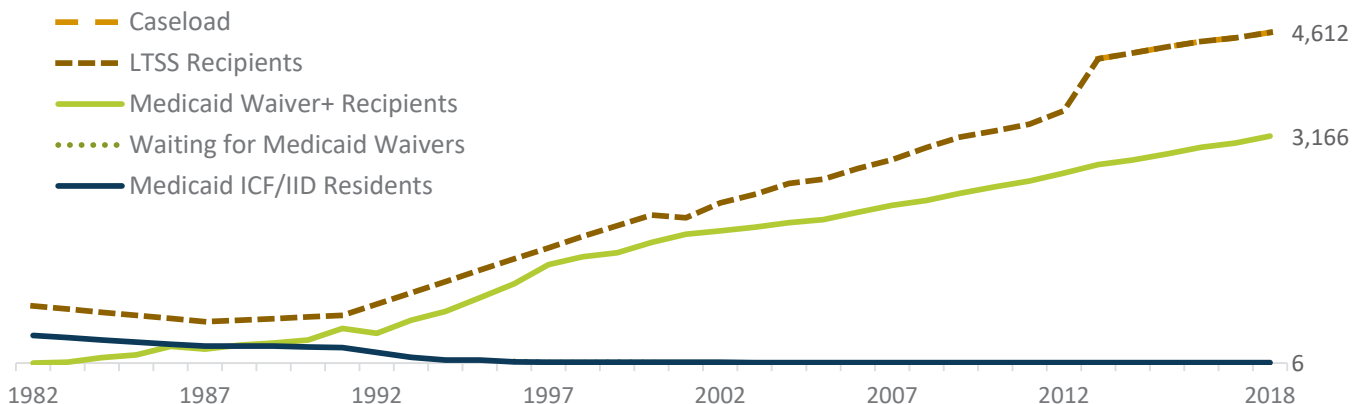
Residential Information Systems Project

IDD Agency Long Term Supports and Services Recipients by Residence Type

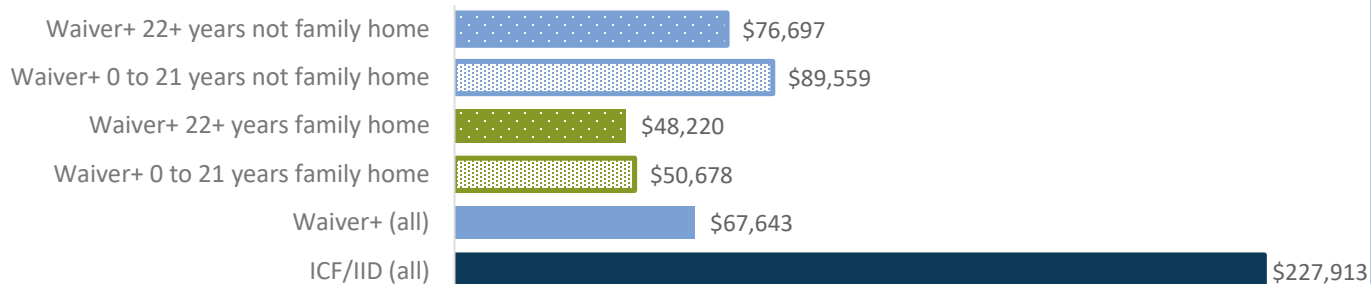


* Setting type or size not reported

Caseload, LTSS and Medicaid Recipients and Waiting for Waivers* 1982-2018



Average Spending Per Person by Medicaid Authority in Fiscal Year 2018



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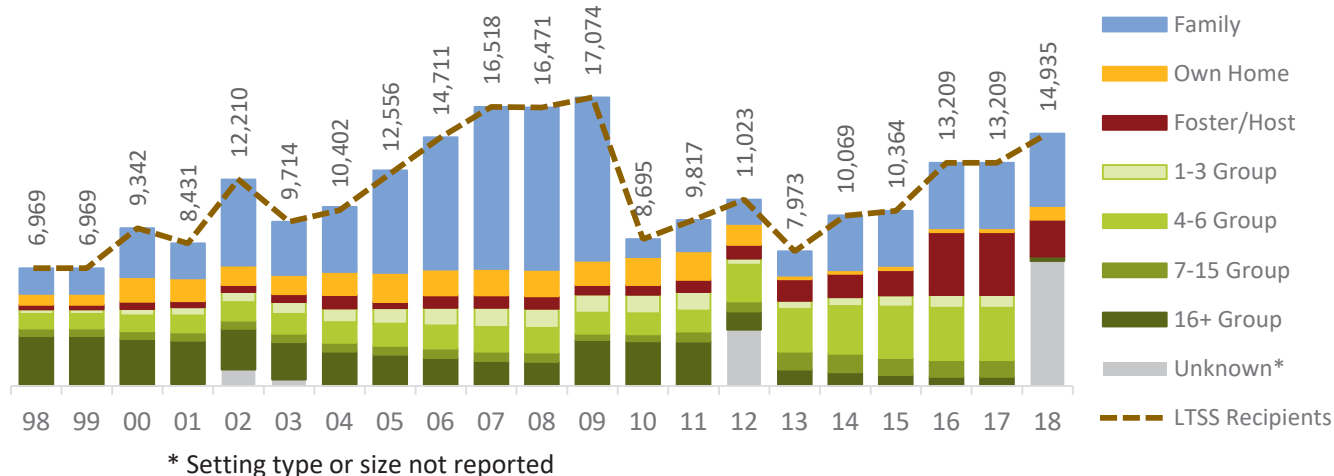
For more see risp.umn.edu

Virginia

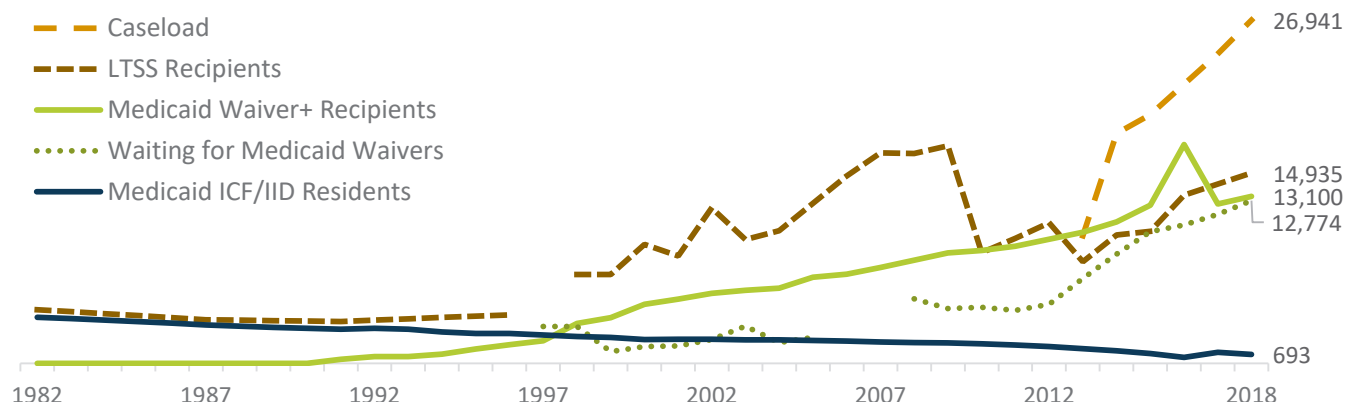
Fiscal Year 2018

Residential Information Systems Project

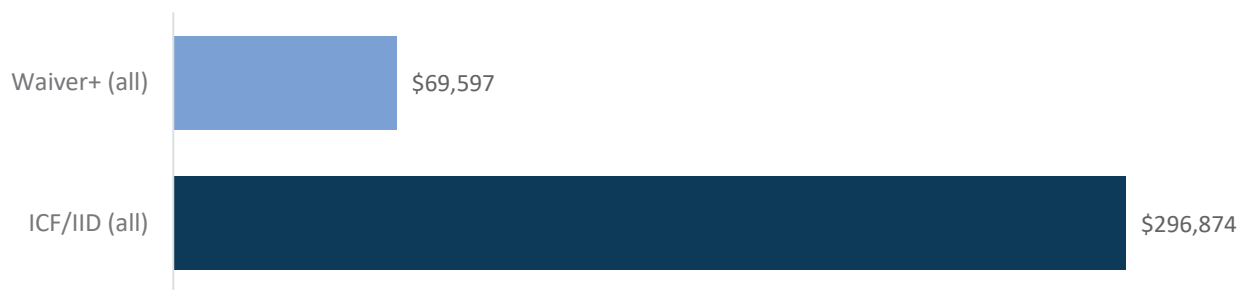
IDD Agency Long Term Supports and Services Recipients by Residence Type



Caseload, LTSS and Medicaid Recipients and Waiting for Waivers* 1982-2018



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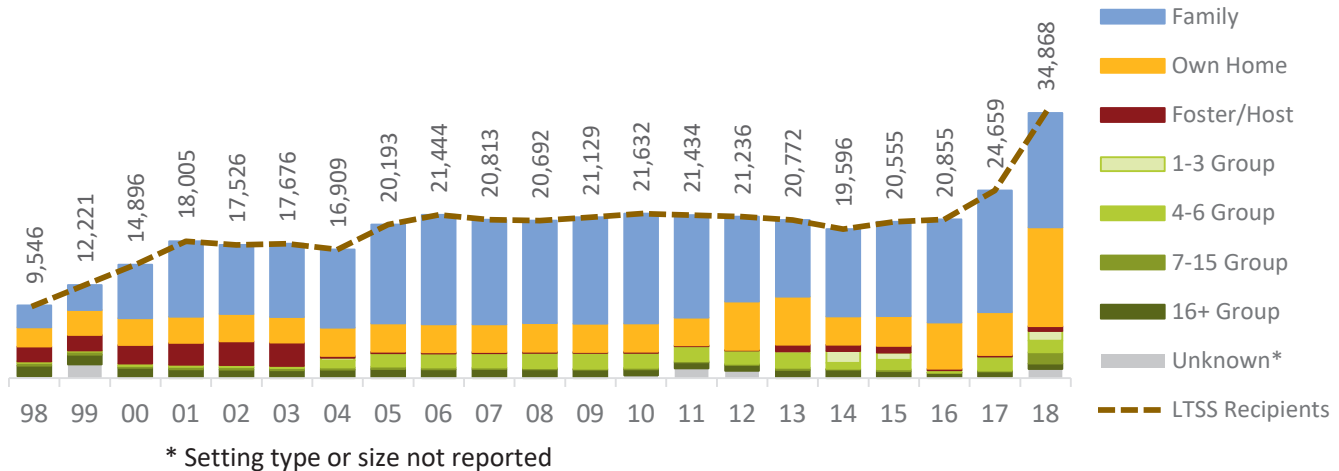
For more see risp.umn.edu

Washington

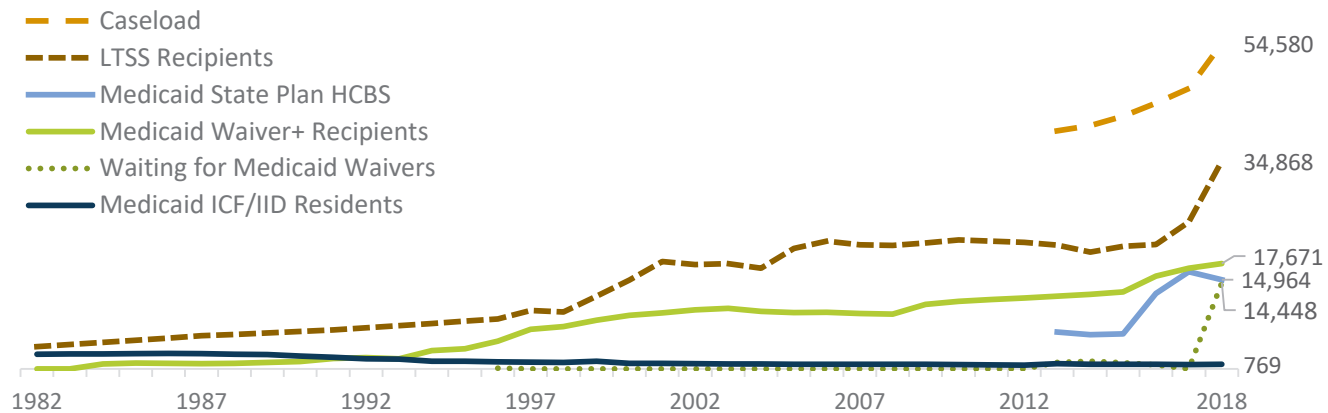
Fiscal Year 2018

Residential Information Systems Project

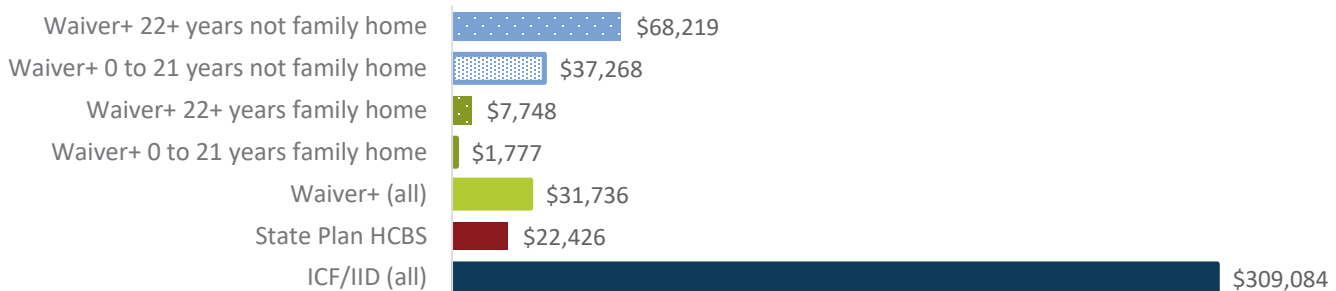
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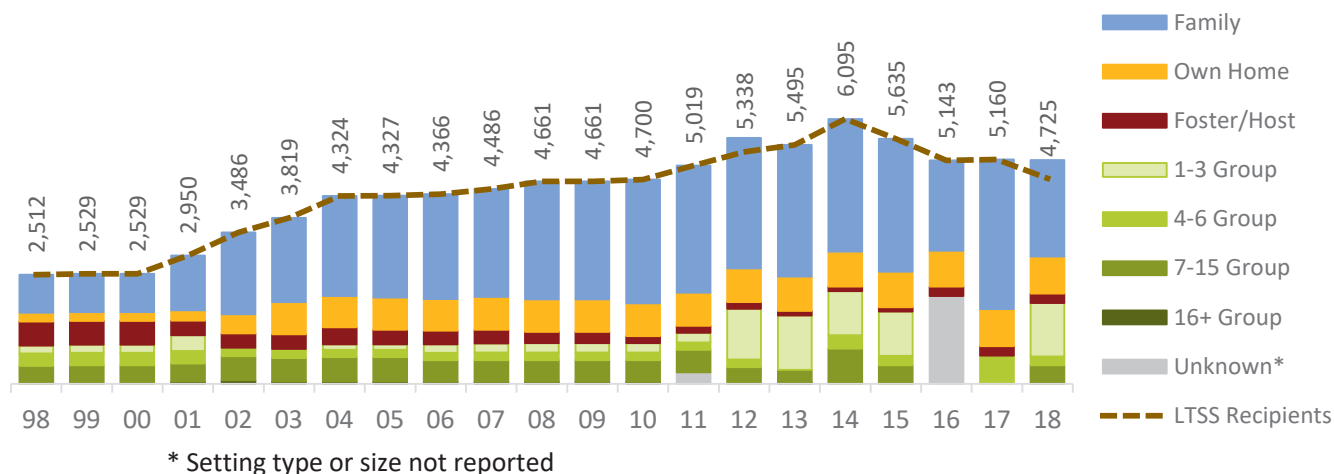
For more see risp.umn.edu

West Virginia

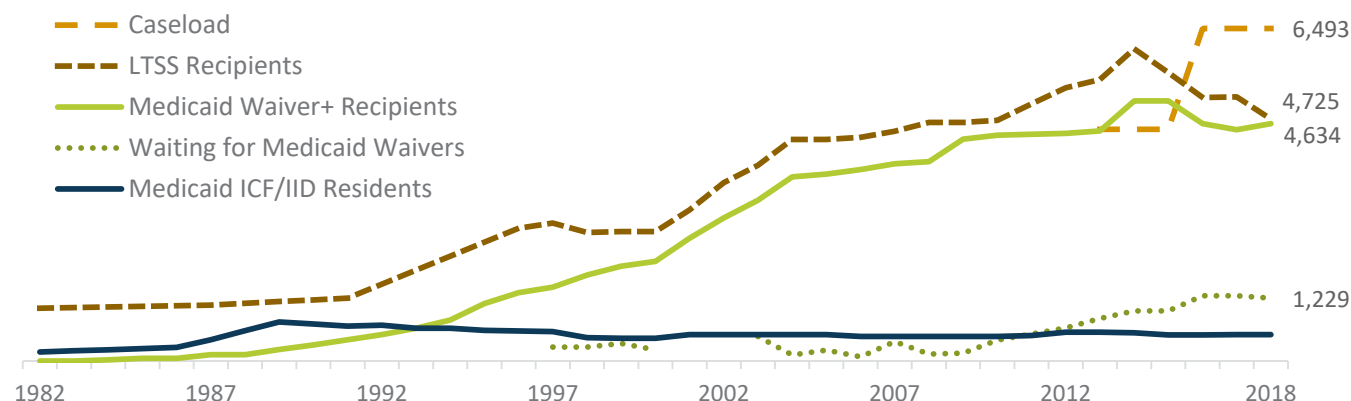
Fiscal Year 2018

Residential Information Systems Project

IDD Agency Long Term Supports and Services Recipients by Residence Type



Caseload, LTSS and Medicaid Recipients and Waiting for Waivers* 1982-2018



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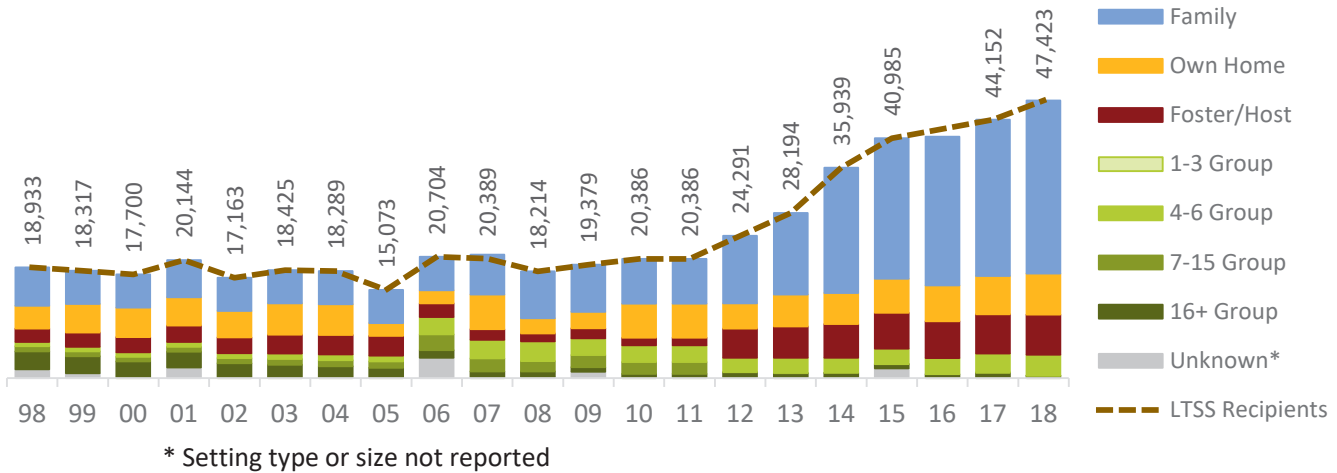
For more see risp.umn.edu

Wisconsin

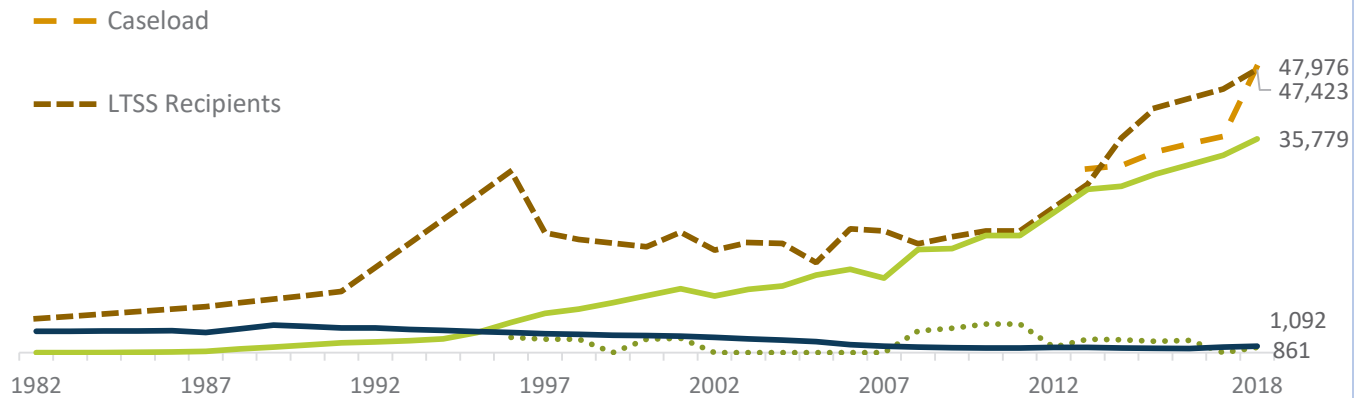
Fiscal Year 2018

Residential Information Systems Project

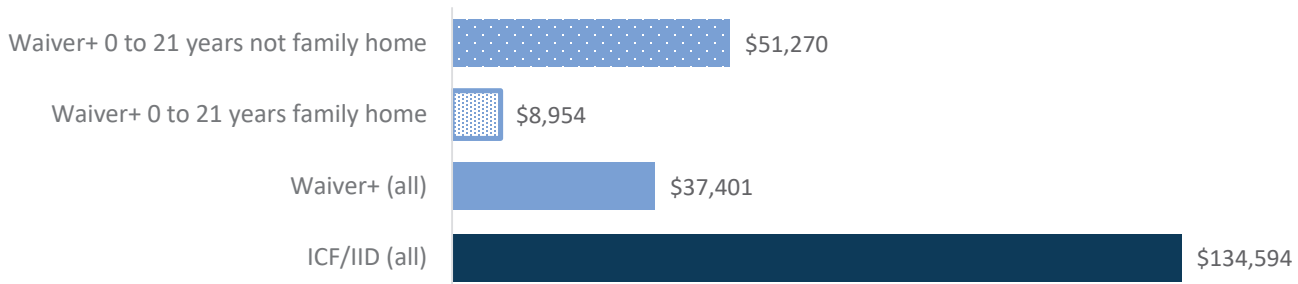
IDD Agency Long Term Supports and Services Recipients by Residence Type



Caseload, LTSS and Medicaid Recipients and Waiting for Waivers* 1982-2018



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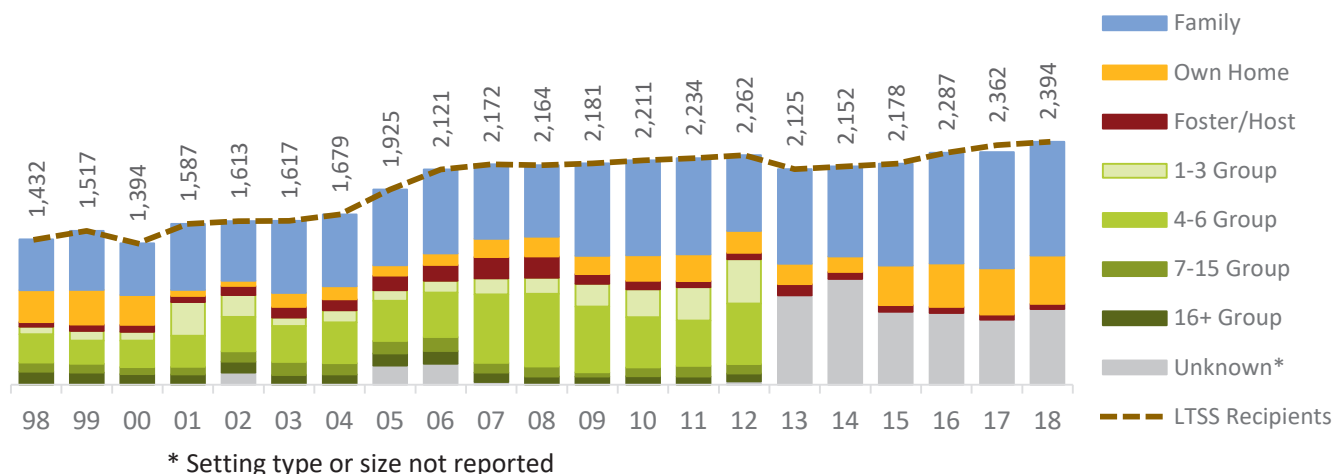
For more see risp.umn.edu

Wyoming

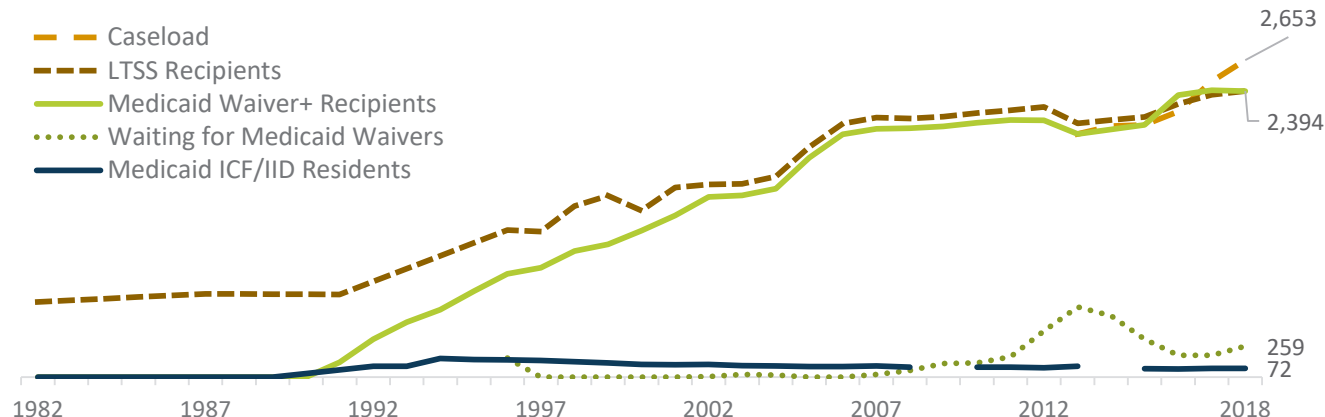
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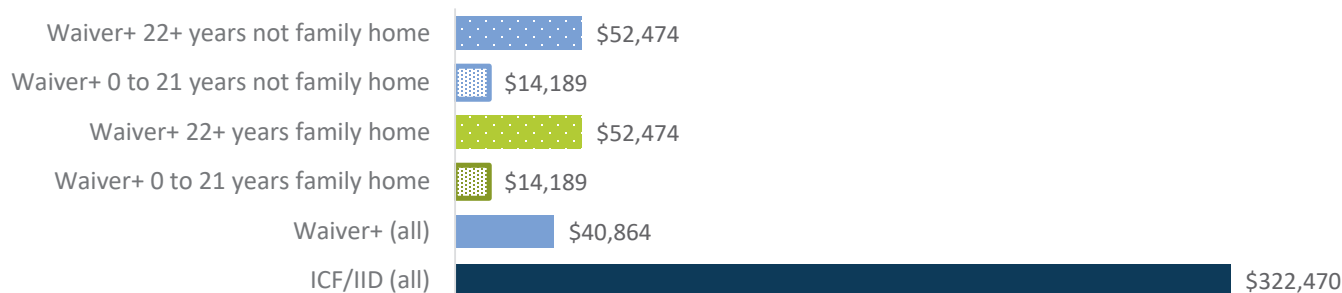
IDD Agency Long Term Supports and Services Recipients by Residence Type



Caseload, LTSS and Medicaid Recipients and Waiting for Waivers* 1982-2018



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Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

ICF/IID: Intermediate Care Facilities for Individuals with Intellectual Disabilities

Group: Number of people with IDD in a setting (ICF/IID, group home or other)

Waiver+: Medicaid Authorities 1115, 1915 (a)(b) or (b)(c), 1915(c)

For more see risp.umn.edu



SECTION SIX

APPENDICES

FY 2018

SECTION 6: REFERENCES, RESOURCES AND DATA SOURCES

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HISTORICAL DATA: OTHER SOURCES

Data on the history of LTSS and services for people with IDD prior to 1977 came from the following sources:

- Data on state IDD and psychiatric facilities for 1950 to 1968 from the National Institute of Mental Health's surveys of "Patients in Institutions;"
- Data on state IDD facilities for FYs 1969 and 1970 from surveys conducted by the Office on Mental Retardation Coordination, now AIDD;
- Data on large state IDD facilities for 1971 through 1977 from surveys of the National Association of Superintendents of Public Residential Facilities for People with Mental Retardation, now the APDDA; and
- Data on psychiatric facilities for 1969 to 1977 come from the National Institute of Mental Health's surveys of "Patients in State and County Mental Hospitals."

Medicaid Waiver Expenditures

1982-1991	Smith, G., & Gettings, R. (1991). <i>The Waiver Program and Services for People with Developmental Disabilities: An Update</i> . Alexandria, VA: National Association of State Mental Retardation Program Directors, Inc.
1992	Burwell, B. (1993). Personal Communication with K. Charlie Lakin.
2010	Eiken, S., Burwell, B., Gold, L. & Sredl, K. (2011). <i>Medicaid 1915(c) Waiver Expenditures: 2011 Update Period</i> . Cambridge, MA: Thomson Reuters.
2012	Eiken, S., Sredl, K., Gold, L., Kasten, J., Burwell, B., and Saucier, P. (2015). <i>Medicaid Expenditures for long-term services and supports in FFY 2012</i> . Cambridge, MA: Thomson Reuters; Washington, DC: Centers for Medicaid and Medicare Services.
2013-2016	Eiken, S., Sredl, K., Burwell, B., & Saucier, P. (2016). <i>Medicaid expenditures for long-term services and supports (LTSS) in FY 2016</i> . Downloaded from https://www.medicaid.gov/medicaid/long-term-services-supports/reports-evaluations/index.html
2017-2018	Murray, Caitlin, Alena Tourtellotte, Debra Lipson, and Andrea Wysocki. "Medicaid Long Term Services and Supports Annual Expenditures Report: Federal Fiscal Years 2017 and 2018." Chicago, IL: Mathematica, January 7, 2021.

ICF/IID Expenditures

1980-1989	Eiken, S. (personal communication, April 15, 2015).
1990-1991	Burwell, B. (1992, January). <i>Medicaid Long Term Expenditures for FY 1991</i> . Lexington, MA: Systemetrics/McGraw-Hill.
1992	Burwell, B. (1994, February). <i>Medicaid Long Term Expenditures in FY 1993</i> . Cambridge, MA: Systemetrics A MEDSTAT Division.
1993	Burwell, B. (1999, April). <i>Medicaid Long Term Expenditures in FY 1998</i> . Cambridge, MA: The MEDSTAT Group.

1994-1999 Burwell, B. (1999, April). Medicaid Long Term Expenditures in FY 1999. Cambridge, MA: The MEDSTAT Group. Medicaid ICF-MR expenditures by state FY 1995 to FY 2000: Data from the HCFA 64 report. The Medstat Group.

2000 Burwell, B. (2001). Table B Medicaid ICF-MR expenditures by state FY 1995 to FY 2000: Data from the HCFA 64 report. The Medstat Group.

2001-2003 Burwell, B., Sredl, K., Eiken, S. (2007). Medicaid Long-Term Care Expenditures in FY 2006. Cambridge, MA: Thomson Reuters.

2004 Eiken, S., Sredl, K., Burwell, B., and Gold, L. (2010, August). Medicaid Long-Term Care Expenditures in FY 2009. Cambridge, MA: Thomson Reuters.

2005 Eiken, S., Sredl, K., Burwell, B., and Gold, L. (2011, October). Medicaid Expenditures for Long-Term Services and Supports: 2011 Update. Cambridge, MA: Thomson Reuters.

2006 Eiken, S., Sredl, K., Gold, L., Kasten, J., Burwell, B., & Saucier, P. (2013, October). Medicaid Expenditures for Long Term Services and Supports in 2011. Truven.

2007-2011 Eiken, S., Sredl, K., Gold, L., Kasten, J., Burwell, B., & Saucier, P. (2015, April). Medicaid Expenditures for Long-Term Services and Supports in FFY 2012. Truven.

2011 Braddock, D., Hemp, R., Rizzolo, M.C., Tanis, E.S., Haffer, L., & Wu, J. (2015). The State of the States in Intellectual and Developmental Disabilities: Emerging from the Great Recession. Washington, DC: American Association on Intellectual and Developmental Disabilities (AAIDD).

2012-2014 Eiken, S., Sredl, K., Burwell, B., Saucier, P. (2016). Medicaid expenditures for long-term supports and services (LTSS) in FY 2014. Washington, DC: Truven Analytics. Retrieved from: www.medicaid.gov/Medicaid/ltss/downloads/ltss-expenditures-2014.pdf

2015 Eiken, S., Sredl, K., Burwell, B., Woodward, R. (2017). Medicaid expenditures for long-term supports and services (LTSS) in FY 2015. Washington, DC: Truven Analytics. Retrieved from: www.medicaid.gov/medicaid/ltss/downloads/reports-and-evaluations/ltssexpendituresffy2015final.pdf

2016-2018 Murray, Caitlin, Alena Tourtellotte, Debra Lipson, and Andrea Wysocki. "Medicaid Long Term Services and Supports Annual Expenditures Report: Federal Fiscal Years 2017 and 2018." Chicago, IL: Mathematica, January 7, 2021.

RISP FY 2018 SURVEY



**FY 2018 (July 1, 2017 – June 30, 2018)
Residential Information Systems Projects (RISP) Survey**

Background

About: This is a survey of the University of Minnesota's Residential Information Systems Project (RISP). It is part of a 40-year longitudinal study tracking Medicaid and state-funded long-term supports and services (LTSS) provided under the auspices of State Intellectual and Developmental Disability (IDD) Agencies. The survey is fielded annually in conjunction with the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and Human Services Research Institute (HSRI). It is used to create state and national profiles of LTSS recipients, settings, and expenditures.

Timeline: FY 2018 surveys are due March 30, 2019. Late responses may not be included in our FY 2018 annual report. Questions reference June 30, 2018, or the period from July 1, 2017 through June 30, 2018.

Target Populations: Parts 1 and 2 of the survey ask about people, served by **State IDD Agencies**, who receive one or more Medicaid or state-funded long-term support or service (LTSS) in addition to case management or service coordination (LTSS Recipients with IDD). This group includes people receiving in-home or residential supports, as well as people receiving other types of LTSS such as day habilitation or vocational services even if the person does not receive services in their home or in a residential facility. It also includes people served by the **State IDD Agency** who live in Nursing Homes or **Psychiatric Facilities**.

Parts 3 through 5 include a broader target population.

- People on the **State IDD Agency Caseload** (Parts 3 and 4). This group includes **LTSS Recipients** with IDD plus people with IDD receiving only case management or services coordination services, people waiting for services, and people known to the **State IDD Agency** but not currently receiving LTSS. It does not include people whose eligibility for services has not been determined.
- All people with IDD (Part 5), whether on the **State IDD Agency Caseload** or not, who live in **Nursing Homes**, **Psychiatric Facilities**, or other **Congregate Settings** housing four or more LTSS recipients (for people birth through age 21 years), or housing 16 or more LTSS recipients (for people ages 22 years and older).

Survey Changes for FY 2017 to 2018 – None.

Clarifications for FY 2018

1. Caseload should be for any individual who is known to the state agency to have either applied for services or is currently receiving services related to IDD. It is not about IDD prevalence or eligibility, but more about who is access the state agency (or agencies) for services and supports. This has always been the intention for caseload, but a question arose during FY 2017 that led to this clarification.
2. Age 21 and under is for anyone birth up to their 22nd birthday. The cut off date for FY 2018 is June 30, 1996 for age 21 and under. Likewise, age 22 and older would be anyone born after June 30, 1996 (i.e. on or after July 1, 1996).
3. In this document, the table borders that are black indicate editable, requested information for the online survey.

FY 2018 (July 1, 2017 – June 30, 2018) Residential Information Systems Projects (RISP) Survey

Instructions

This survey should be completed by the state director of IDD services, or his or her designee. Please consult your state's Medicaid office, or other relevant state agencies, as needed to provide accurate responses.

Complete responses are important to ensure that your state's system is accurately portrayed. We estimate values not provided when we compute estimated United States totals. We prefer to use estimates provided by states whenever possible. If you do not furnish complete information, the charts and graphs for your state may be incomplete or inaccurate.

The RISP survey is designed for online use. The online survey offers many tools, such as access to responses to previous year surveys, notes about data sources and explanations about specific values, interactive and context based instructions, and automated validation checks to confirm the accuracy of the reported data.

General Instructions

- Do not leave questions blank.
- Enter "0" when there are no people/settings/expenditures in a particular category or Funding Authority.
- Provide totals, even if you are unable to provide breakdowns by type of operation, age, setting type, or setting size.
- Use a "DNF" (Data Not Furnished) to indicate that you are unable to furnish a value, and you do not have a reasonable estimate that you could use.
- Use an "e" to designate estimated numbers.
- If the data are from a date other than June 30, 2018, please specify the date.
- Leave notes to explain anything the reader of the technical report needs to know to interpret the data correctly.
- Shaded boxes show values that are automatically computed in the online version of the survey.
- Definitions for words can be found in the end of the Word version of the survey, or by a dotted underline in the online version.

Online Survey Instructions

The web-based survey has been reorganized to mirror the Word version more closely to make data entry easier.

Expand

In the **Expand** menu, you can designate a value as an estimate (**e**), add notes, change the data date, or specify that you are unable to furnish a value (**DNF**). You can also see previous year data, validation warnings about possible data errors, and calculations used in the report.

- Use **Notes**
 - If a value has changed substantially from the previous year, or from the trend in recent years
 - If you used a definition different from the operational definition provided
 - If you used a different methodology, or categorized people differently, than in the past
 - To help readers correctly interpret your response
 - To explain why you were only able to answer part of a question
 - To help the person completing the survey in subsequent years know how you arrived at the value
- As notes are entered, they are added to a notes menu. Once a note is added, it can be selected from the list to apply it to other survey items.
- Previous year data can be found in the **Expand** menu. If you notice inaccuracies in data from previous years, please let your RISP staff team member know (You can find the name of the staff assigned to your state at the end of the survey). We will update the database, and use the revised data for subsequent reports and products.

FY 2018 (July 1, 2017 – June 30, 2018) Residential Information Systems Projects (RISP) Survey

- **Validation Warnings** about possible errors have been added. Details about each warning can be viewed by clicking the expand button in the section titled “Validation checks that need your attention.”

Notes can be designated as private or public.

- **Private detail** – not for publication, but helpful for RISP staff or state staff who enter data, or
- **Public detail** – for publication in the state notes section of RISP reports and other products so that readers can correctly interpret your data

Tips for using the Online Survey

- **Login.** The system automatically tracks all entries by login ID. Each person should have his or her own user name and password. If someone forgets their password or needs to initiate a new account password, please go to “Reset your password” at <https://risp.umn.edu/user/password> and enter your email address. An email will be sent to you to regenerate a password as long as your email is in the system. Please do not use another person's ID to log in. Contact a RISP team member to get a new person added for your state.
- **Definition of Terms.** Definitions for selected terms can be viewed by moving your cursor over the term with a dotted underline. Additional instructions about specific survey items can be found in the “Operational Definitions” document.
- **Save.** The save button is on the top of each screen. You will receive a message if there are changes before you move to another screen to remind you to save the data. It is best to save data frequently. If you do not wish to save changes to the data that are active, refresh or reload your browser to cancel all active changes. Active changes are outlined by a green box.
- **Expand button.** Codes, explanatory notes, historic data, and warnings about potentially incorrect data are all found under the “Expand” button. You can also specify the following for each response: “e” for estimates; “DNF” for did not or unable to furnish.
- **Alternate Date.** By default, we assume that the data you provide is correct as of June 30, 2018. If you are reporting data from a different date (such as data from a previous year), please note that date in the Expand section.
- **Computed values** have a shaded background. Some computed totals could only be changed by returning to the screen where the component value(s) were first entered. Entering a zero in the total of a row or column will often make the remaining cells zero.

Your assigned RISP project staff member is available by phone or email, and will contact you during the editing process if we find missing or possibly incorrect information, or notice a change from previous years that has not been explained in your comments. Thank you for your ongoing support of this Administration on Intellectual and Developmental Disabilities (US Health and Human Services) Data Project of National Significance.

Sherri Larson
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FY 2018 (July 1, 2017 – June 30, 2018) Residential Information Systems Projects (RISP) Survey

Funding Authorities

This section asks about federal and state **Funding Authorities** used to finance **long-term supports and services** for people with IDD as of June 30, 2018.

- Please respond “yes” to indicate any **Funding Authorities** for which you had expenditures in FY 2018 for people with IDD.
- Saying “no” will trigger the survey software to fill in 0’s for subsequent questions about the **Funding Authority**. You will not be able to enter recipients, settings, or expenditures for a **Funding Authority** if you say “no.”
- If you selected “no” by mistake, return to this section and change your “no” to a “yes” to enable data entry in other parts of the survey.
- If you are unsure, please verify your responses with your **State IDD Agency Director** or Medicaid office.

Which of these Funding Authorities were used to finance long-term supports and services for people with IDD on the State IDD Agency Caseload as of June 30, 2018?		Yes/No
Medicaid Waiver	1115 Demonstration Waiver	
	1915 (a) (b) or (b/c) Managed Care Waiver with LTSS	
	1915 (c) Home and Community Based Services Waiver	
Medicaid State Plan HCBS	1915(i) State plan Home and Community Based Services	
	1915(k) Community First Choice	
Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID)		
State Non-Medicaid	State funding for LTSS for people with IDD not matched with Federal Medicaid funds	

Part 1: State-Operated IDD Recipients and Settings on June 30, 2018

State-Operated IDD Settings are residential settings staffed by state employees that serve people with IDD.

- Include state-operated IDD facilities and IDD units of facilities serving multiple populations such as Nursing Homes or Psychiatric Facilities.
- Multiple units, cottages, or homes located on a single campus should be counted as a single setting. Units, cottages, or homes located on different campuses should be counted separately.
- **Setting size** is based on number service recipients living in the facility/on the campus as of June 30. Do not count “empty beds” in determining setting size (for example, a campus licensed to serve up to 20 people that has 12 people in residence on June 30 should be listed in the 7-15 people category).

1A. How many State-Operated IDD Settings served people on the IDD Agency Caseload on June 30, 2018 (by Facility Size and Funding Authority)?

State-Operated IDD Settings	Settings by Size						
	1-3	4-6	1-6 Total	7-15	16+	Size Unknown	All Sizes
Medicaid Waiver 1115; 1915 (a) (b) (b/c); and 1915 (c)							
Medicaid ICF/IID							
Other							
Total							

FY 2018 (July 1, 2017 – June 30, 2018) Residential Information Systems Projects (RISP) Survey

1B. How many people with IDD lived in State-Operated IDD Settings on June 30, 2018 (by Setting Size and Funding Authority)?

State-Operated IDD Settings People by Funding Authority	People by Setting Size						Total People
	1-3	4-6	1-6 Total	7-15	16+	Size Unknown	
Medicaid Waiver 1115; 1915 (a) (b) (b/c); and 1915 (c)							
Medicaid ICF/IID							
Other							
Total							

1C. Describe people with IDD and daily costs in State-Operated IDD Settings serving 16 or more people for the Year ending June 30, 2018 by Funding Authority

State Operated IDD Settings serving 16 or more people with IDD are also known as **Public Residential Facilities (PRF)**

	Medicaid Waiver	Medicaid ICF/IID	Other Funding Authority	Total
ADMISSIONS/READMISSIONS between July 1, 2017 and June 30, 2018 (Do not include short-term respite or crisis admissions of 90 days or less or transfers between PRFs)				
SHORT-TERM respite or crisis ADMISSIONS to PRFs (for stays of 90 days or less)				
DISCHARGES number of people who moved out of the facility between July 1, 2017 and June 30, 2018 (excluding short-term respite or crisis stays and transfers between PRFs)				
DEATHS People who died between July 1, 2017 and June 30, 2018 while living in a PRF.				
AVERAGE DAILY RESIDENTS between July 1, 2017 and June 30, 2018.				
PER DIEM (average daily per person cost of care). Enter N/A if there were no PRFs in a Funding Authority category on June 30, 2018.				

Part 1 Data date if not June 30, 2018:

Respondent Name: _____ Phone: _____ Email: _____

FY 2018 (July 1, 2017 – June 30, 2018) Residential Information Systems Projects (RISP) Survey

Part 2. Nonstate-Operated LTSS Recipients and Settings on June 30, 2018

Section Instructions

Nonstate-Operated settings LTSS settings staffed by employees of an entity other than the state.

Setting Size Number of service recipients living in the setting as of June 30, 2018. Do not count empty beds (for example, a campus licensed to serve 20 people with 12 people in residence on June 30 should be listed in the 7-15 people category).

Nonstate-Operated Living Arrangement Types

Type I: **ICF/IID**. Medicaid Intermediate Care Facilities for Individuals with Intellectual Disabilities.

Type II: **IDD Group Home**. A residence owned, rented, or managed by the residential services provider, or the provider's agent, to provide housing for persons with IDD in which staff provide care, instruction, supervision, and other support for residents with IDD. Include corporate foster care settings and provider-owned or controlled housing.

Type III: **Host/ Foster Family Home**. A home owned or rented by an individual or family in which they live and provide care for one or more unrelated persons with IDD.

Type IV: **Own Home**. A home owned or leased by one or more persons with IDD as the person(s)' own home, in which they receive personal assistance, instruction, supervision, and other supports. Do not include provider-owned or controlled housing. Include people sharing a home with a spouse/partner or other unrelated individuals. Do not include people living with a related family member.

Type V: **Family Home**. A residence of a person(s) with IDD who receives one or more long-term support or service such as respite care, personal assistance, day habilitation, or in-home supports in addition to case management services while living with a related family member.

Type VI: **Other Setting Type**. Other residential settings in which LTSS recipients with IDD on the caseload of the state IDD agency live. Other settings may include settings such as nonstate-operated hospitals, Nursing Homes, Psychiatric Facilities, assisted living facilities, board and care facilities, farmsteads, intentional, or gated communities. Do not include Type I ICF/IID settings or Type II IDD Group Homes in this category.

Type VII: **Unknown Setting Type**. The type of setting in which a LTSS recipient with IDD lives is not known (for questions 2B and 2C).

2A. In how many different Nonstate-Operated settings did LTSS Recipients with IDD live on June 30, 2018 (By Setting Size and Setting Type)?

Nonstate-Operated Settings by Residence Type	Settings by Size						Total Settings
	1-3	4-6	1-6 Total	7-15	16+	Size Unknown	
I. ICF/IID							
II. IDD Group Home							
III. Host/ Foster Family Home							
IV. Own Home							
V. Family Home	Not requested						
VI. Other Settings (specify)							
Total							
Other Setting type(s) description: (General Note in the online survey)							

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2B. How many LTSS recipients with IDD were served by nonstate entities on June 30, 2018 (By Setting Size and Residence Type)?

Nonstate-Operated Settings People by Residence Type	People by Setting Size						Total People
	1-3	4-6	1-6 Total	7-15	16+	Size Unknown	
I. ICF/IID							
II. IDD Group Home							
III. Host/ Foster Family Home							
IV. Own Home							
V. Family Home	Not requested						
VI. Other Setting Types (specify)							
VII. Unknown Setting Type	Not requested						
Total							
Other Setting type(s) description: (General Note in the online survey)							

2C. Of the LTSS Recipients with IDD living in each setting type, how many received services funded by a Medicaid Waiver (1115, 1915 (a), (b) or (b/c), 1915 (c)) or State Plan Home and Community Based Services (1915 (i) or 1915 (k)) Funding Authority? For each setting type, note the unduplicated total number of people with IDD who receive Medicaid Waiver and/or Medicaid State Plan funded LTSS.

Number of people in Nonstate Settings who receive Medicaid Waiver and/or Medicaid State Plan funded LTSS	In development: Not required		
	Medicaid Waiver 1115; 1915 (a) (b) (b/c); 1915 (c)	Medicaid State Plan 1915(i) or 1915(k)	Unduplicated Total
I. ICF/IID	Not applicable		
II. IDD Group Home			
III. Host/ Foster Family Home			
IV. Own Home			
V. Family Home			
VI. Other Setting Types (specify)			
VII. Unknown Setting Type			
Total in Nonstate settings			

Part 2 Data date if not June 30, 2018:

Respondent Name: _____ Phone: _____ Email: _____

Part 3: IDD Agency Caseload, LTSS Recipients, and Expenditures

This section asks about Medicaid and State LTSS expenditures for people on the State IDD Agency Caseload, by Funding Authority, age, and living arrangement (family home or other).

This is what you reported in Parts 1 and 2 (for those using the online survey)

LTSS Recipients Living in State-Operated Settings (Part 1B)	Total Part 1
LTSS Recipients in Nonstate Settings (Part 2B)	Total Part 2
Total LTSS Recipients	LTSS recipients

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State IDD Agency Caseload includes any individual who is known to the state agency to have either applied for services or is currently receiving services related to IDD.

- **Include**
 - People with IDD known to the **State IDD Agency** who receive one or more **long-term support or service** in addition to case management
 - People receiving only case management or service coordination services
 - People waiting for services, and
 - People known to the **State IDD Agency** but not receiving **LTSS**
- **Do not include** people whose eligibility for services has not been determined or people in the general population who have accessed the IDD service system.

3. How many people with IDD were on the State IDD Agency Caseload on June 30, 2018 (By Age)?

Provide an unduplicated total.

State IDD Agency Caseload	21 years or younger	22 years or older	Total All Ages
Number of People			

LTSS Recipients with IDD and Expenditures by Recipient Age and Living Arrangement

Report recipients and expenditures for FY 2018 (July 1, 2017 through June 30, 2018) for each **Funding Authority**. Medicaid expenditures include the Federal and the State/Local share. Annual per person expenditures are automatically computed in the on-line version of the survey.

3A: Medicaid Waiver Recipients and Expenditures by Age for FY 2018

Medicaid Waiver 1115, 1915 (a)(b)or (b/c), 1915 (c)	21 years and younger	22 years and older	Total All Ages	Recipients Parts 1 & 2
Recipients				
Expenditures				
Expenditures per person				

3B. Medicaid Waiver Recipients and Expenditures by Living Arrangement and Age for FY 2018

Medicaid Waiver 1115, 1915 (a)(b)or (b/c), 1915 (c)		21 years and younger	22 years and older	Total All Ages
Home of a Family Member	Recipients			
	Expenditures			
	Expenditures per person			
Other (non-family) Setting	Recipients			
	Expenditures			
	Expenditures per person			
Total Recipients by Living Arrangement				
Total Recipients by Age in 3A				

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3C: Medicaid State Plan Home and Community Based Services Recipients and Expenditures by Age

Medicaid State Plan HCBS 1915(i) or 1915(k)	21 years and younger	22 years and older	Total All Ages	Recipients (Part 2)
Recipients				
Expenditures				
Expenditures per person				

3D: Medicaid Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) Recipients and Expenditures by Age

Medicaid ICF/IID	21 years and younger	22 years and older	Total All Ages	Recipients (Parts 1 and 2)
Recipients				
Expenditures				
Expenditures per person				

3E: State-Funded Non-Medicaid LTSS Recipients and Expenditures by Age

State-Funded Non-Medicaid	21 years and younger	22 years and older	Total All Ages
Recipients			
Expenditures			
Expenditures per person			

3F: People with IDD on the State IDD Agency Caseload but not receiving funded LTSS on June 30, 2018

No Medicaid or State-Funded LTSS	21 years and younger	22 years and older	Total All Ages
People with IDD			

Part 3 Data date if not June 30, 2018:

Respondent Name: _____ Phone: _____ Email: _____

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Part 4: Medicaid Waiver Waiting List

4. How many people with IDD living with a Family Member, or in Own Home settings, were waiting for Medicaid Waiver-funded services on June 30, 2018?

- **Include people waiting for Medicaid Waiver-funded LTSS who**
 - Lived with a family member, or in their own home, as of June 30, 2018 and who
 - Did not receive Medicaid-funded LTSS other than case management/service coordination
- **Do not include people**
 - Living in an ICF/IDD, or in another non-family setting (such as a Skilled Nursing Facility) or
 - Already receiving Medicaid Waiver-funded services in addition to case management/service coordination

People Waiting for Medicaid Waiver 1115, 1915 (a)(b)or (b/c), 1915 (c) funding	Number of People
How many people with IDD living in their own home or the home of family member were waiting for (but not receiving) Medicaid Waiver-funded LTSS on June 30, 2018?	
a. Of the people waiting, how many were receiving case management (including Targeted Case Management) services?	
b. Of the people waiting, how many were waiting to move to a setting other than the home of a family member?	

Part 5 Psychiatric, Nursing Facilities and Other Congregate Settings

This section includes all people with IDD living in your state whether they are served by the State IDD Agency or not.

5A. How many people with IDD lived in state or nonstate operated Nursing Homes or Psychiatric Facilities on June 30, 2018? Note: Include people with IDD on the State IDD Agency Caseload who live in Nursing Homes or Psychiatric Facilities.

Number of People with IDD	State-Operated	Nonstate-Operated	Total People
In Nursing Homes			
In Psychiatric Facilities			

About this Section: The Centers for Disease Control (CDC) uses the data you report here to monitor national progress toward the Healthy People 2020 goals of reducing the number of children and adults with IDD living in congregate settings. It is very important that we receive data from all of the states on these questions.

Congregate Settings are

- State- or nonstate-operated non-family residential settings, such as PRFs, ICF/IID, IDD Group Homes, Nursing Homes, Psychiatric Facilities, Other Group Settings or similar facilities.
- In which rotating (or shift) staff members provide supports and services

For people ages 21 years or younger, report the number of LTSS recipients with IDD in Congregate Settings of four or more people.

For people ages 22 years or older, report the number of LTSS recipients with IDD in Congregate Settings of 16 or more people.

Congregate Settings do not include Own Home settings.

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People in Congregate Settings do not include people with IDD who:

- Live with birth or adoptive parents, or other family members (**Family Home**)
- Live in **Host/Foster Family Settings** in which no shift staff work
- Live only part of the year in a residential PreK-12 school
- Live in correctional or juvenile justice facilities
- Receive only respite services from a **Congregate Setting**
- Live in other states (do count people who live in your state whose services are paid by another state)

5B: How many people with IDD 21 years or younger lived in Congregate Settings of four or more people on June 30, 2018?

People with IDD ages 21 years or younger in congregate settings of four or more people	People
Nursing homes	
Other Congregate Settings	
Total	

5C: How many people with IDD 22 years or older lived in Nursing homes or other Congregate Settings of 16 or more people on June 30, 2018?

People with IDD ages 22 years or older in congregate settings of 16 or more people	People
In Nursing homes	
In Other Congregate Settings	
Total	

Part 5: Data date if not June 30, 2018:

Respondent Name: _____ Phone: _____ Email: _____

Thank you for completing the RISP survey. Please inform your RISP contact that you have completed the survey. The project team will review your data and your responses to any **validation warnings**. You can view **validation warnings** online by clicking “Expand,” or by viewing the Validation Summary. We will contact you if we have any questions about your responses. Contact your assigned RISP staff member listed at the end of the survey or contact the RISP project team at (RISP@umn.edu) if you have questions.

Final Question: Who should receive a print copy of the RISP report in your state?

We want to send copies of the RISP report to those who will use them. Each time we send hardcopies of the report, we send copies to each IDD Director ([listed on NASDDDS website](#)).

1) Who should receive a print copy of the RISP report in your state other than the IDD Director?

Name	Mailing Address

2) Who should be notified when an electronic copy (PDF) of the RISP report is available?

FY 2018 (July 1, 2017 – June 30, 2018) Residential Information Systems Projects (RISP) Survey

Name	Email

RISP Project Staff Members

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Abbreviations

"d"	The data are correct as of a date other than June 30, 2018
"e"	Estimate
DNF	Data not furnished
HCBS	Home and Community Based Services
HSRI	Human Services Research Institute
ICF/IID	Intermediate Care Facility for Individuals with Intellectual Disabilities
IDD	Intellectual or Developmental Disabilities
LTSS	Long-term supports and services
NASDDDS	National Association of State Directors of Developmental Disabilities Services
PD	Partial Data reported
PRF	Public residential facility (a state-operated IDD facility serving 16 or more individuals)
RISP	Residential Information Systems Project

Glossary

FY 2018 (July 1, 2017 – June 30, 2018) Residential Information Systems Projects (RISP) Survey

Alternate Date By default, we assume that the data you provide is correct as of June 30, 2018. If you are reporting data from a different date (such as data from a previous year), please note that date in the Expand section.

Annotate Data Designate a value as an estimate, from a different date, or to record that a value cannot be furnished.

Average Daily Residents Computed as either the average of people in a setting on June 30, 2017 and June 30, 2018, or the running average number of residents between those dates.

Computed values have a shaded background. Some computed totals could only be changed by returning to the screen where the component value(s) were first entered. The computed values will appear when all component elements have been reported.

Congregate Settings

- State or nonstate non-family residential settings (any Funding Authority), such as group homes, ICF/IID, Nursing Homes, Psychiatric Facilities, or any other similar facility) in which rotating (or shift) staff members provide supports and services.
- **People in Congregate Settings does not include people who:**
 - Live with birth or adoptive parents, or other family members
 - Live in **Host/Foster Family Settings** in which no shift staff work
 - Live only part of the year in a residential PreK-12 school
 - Live in correctional or juvenile justice facilities
 - Receive only respite services from a **Congregate Setting**
 - Live in other states (do count people who live in your state whose services are paid by another state)

Expand In the **Expand** menu, you can designate a value as an **estimate**, add notes, change the data date, or specify that you are unable to furnish a value (**DNF**). You can also see previous year data, **validation warnings** about possible data errors, and calculations used in the report

Funding Authorities Federal, state, or local statutes that authorize funding for long-term supports and services. The RISP survey asks about the following **Funding Authorities**

- **Medicaid Waiver** Funding authorized in Sections 1115; 1915 (a) (b) (b/c); or 1915 (c) of the Social Security Act
- **Medicaid State Plan Home and Community Based Services** Funding authorized in Sections 1915(i) or 1915(k) of the Social Security Act
- **Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID)**
- **State Funded-Non-Medicaid** Funding authorized by state or local jurisdictions that are not matched with Federal Medicaid funds

Home and Community-Based Services (HCBS) Long-Term Supports and Services provided in community settings designed to prevent the need for institutional placement, or to support a person to move out of an institution.

IDD Intellectual or developmental disabilities as defined in your state for service eligibility purposes. Some states require service recipients to have a condition such as an intellectual disability, autism, cerebral palsy, epilepsy, spina bifida, or a closely related condition. Other states define eligibility for IDD services based on the **Developmental Disabilities Assistance and Bill of Rights Act of 2000** definition, or based on the presence of specific functional limitations present before a specific age.

IDD Agency Caseload Caseload should be for any individual who is known to the state agency to have either applied for services or is currently receiving services related to IDD.

- **Include**
 - People with IDD known to the **State IDD Agency** who receive one or more long-term supports and services in addition to case management
 - People receiving only case management or service coordination
 - People waiting for services, and
 - People known to the **State IDD Agency** but not receiving **LTSS**

FY 2018 (July 1, 2017 – June 30, 2018) Residential Information Systems Projects (RISP) Survey

- **Do not include**

- People whose eligibility for services has not been determined
- People who receive services from another government agency, such as education or child welfare, unless they also are served by the State IDD Agency.

In development: Not required Items marked “In development” are optional. We will use annotations on tables to reflect when data from “In development” items are reported, but will not designate totals as DNF based on whether these items are completed or not.

Long-Term Supports and Services (LTSS) can be provided in an institution such as an **ICF/IID**, Nursing Home or Psychiatric facility or can be provided in **Home and Community-Based Settings**. 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.

LTSS Recipients People with **IDD** served by **State IDD Agencies** who receive one or more Medicaid or state-funded **LTSS** in addition to case management or service coordination.

- **Include** people receiving **LTSS** such as day habilitation, vocational services, or transportation even if they do not also receive in-home or residential services and people served by or under the auspices of the **State IDD Agency**.
- **Include** people with **IDD** living in **Nursing Homes** or **Psychiatric Facilities** in parts 1 and 2 if they are on the **IDD Agency caseload**, and in Part 5 whether or not they are on the **IDD Agency caseload**.

Did Not Furnish A value that is not available, and for which a reasonable estimate cannot be made.

Estimate An exact value is unavailable. The state’s best approximation of what the value would be if it had been available. Estimates can be the value for the item in the previous or subsequent fiscal year, but an estimate can be carried forward for only one year.

Expand A section of the online survey where users can add annotations, notes, and different dates. The menu also allows users to see previous year data, validations related to warnings about possible data errors, and calculations used in the report.

- **Private Detail** A note that is not for publication, but is helpful for RISP staff or other people from your state who enter data.
- **Public Detail** A note for publication in the state notes section of the RISP technical report, and with state profiles, to help readers correctly interpret your data.

Nonstate-Operated Settings LTSS settings in which services are provided by people who are not employees of the state government.

Other Date A date other than June 30, 2018, or a Fiscal Year ending on a date other than June 30, 2018.

Other Funding Authority (Part 1) State-Operated **LTSS** funded by a source other than Medicaid Waiver or ICF/IID.

Other Setting Type (Part 2) Settings in which **LTSS recipients** with **IDD** live other than an **ICF/IID**, group home, own home, host/foster family home, or family home. Other settings include, but are not limited to, **Nursing Homes** and **Psychiatric Facilities**.

Partial Data Used in the RISP technical report to indicate that a state furnished some, but not all, of the data needed to compute a value.

Psychiatric Facilities Residential facilities providing **LTSS** to persons with a primary diagnosis of a **Psychiatric disorder** (for example a mental health facility). Report only the number of people with **IDD** living in those settings.

Public Residential Facilities (PRF) State-Operated **IDD Facilities** with 16 or more residents (includes **IDD units** in state-operated facilities serving other populations).

Setting size Number of long-term services and supports recipients living in the same home, facility, or campus as of June 30, 2018 (Categories include 1 to 3 people, 4 to 6 people, 7 to 15 people, or 16 or more people). Do not count “empty beds” in determining setting size.

FY 2018 (July 1, 2017 – June 30, 2018) Residential Information Systems Projects (RISP) Survey

State IDD Agency the state entity responsible for overseeing Medicaid or State-funded long-term supports and services for people with IDD.

State-Operated IDD settings residential facilities staffed by employees of the state government.

State-Operated Settings, “Other” Funding Authority – LTSS settings staffed by employees of the state-government that are funded by a source other than Medicaid **ICF/IID** or a **Medicaid Waiver**.

Unknown Setting Size (Part 2, Questions 2A) Number of LTSS settings of each type for which the setting size is unknown. (Part 2, Question 2B) Number of people with IDD living in a setting type of an unknown size.

Unknown Setting Type (Part 2, Type 7, Questions 2B and 2C) Number of LTSS recipients on the caseload of the State IDD Agency living in a nonstate-operated setting, for whom residential setting type is unknown. If one or more people are reported to live in an unknown setting type, totals for all setting types will be coded as estimates.

Warnings Validations and computation checks have been built into the RISP online survey. They alert users about values that are inconsistent with previous values or other survey responses, and about possible arithmetic or data entry errors.

RESIDENTIAL INFORMATION SYSTEMS PROJECT OPERATIONAL DEFINITIONS | FY 2018 SURVEY

Survey Overview and Definitions

The RISP project is directed by Sheryl Larson at the University of Minnesota. The data collection team for FY 2018 includes Lynda Anderson and Heidi Eschenbacher from the University of Minnesota, and Brittany Taylor from the Human Services Research Institute. Each state is assigned a specific staff member for ongoing project communication. You can see who is assigned to your state in the survey introduction at <https://risp.umn.edu/survey-dashboard>.

RISP technical assistance is available to state staff and the public. See the RISP website for contact information: <https://risp.umn.edu/contactus>. General RISP questions can be emailed to risp@umn.edu. Someone from the RISP project team will get back to you as soon as possible.

Technical Assistance is available about:

- How to interpret a specific finding in the annual technical report
- Comparisons between two or more states, or comparing a state to the nation as a whole
- How RISP findings relate to a story being developed by the press or media
- How to use RISP findings in policy development, strategic planning, and policy advocacy
- Other topics

Abbreviations and Acronyms

CMS 64	Centers for Medicare & Medicaid Services Quarterly Expense Report
FY	State Fiscal Year July 1 to June 30, or as specified by states with different fiscal years
HCBS	Home and Community-Based Services
HSRI	Human Services Research Institute
IDD	Intellectual and Developmental Disabilities
ICF/IID	Intermediate Care Facility for Individuals with Intellectual Disabilities
LTSS	Long-term supports and services
NASDDDS	National Association of State Directors of Developmental Disabilities Services
NHIS-D	National Health Interview Survey-Disability Supplement
PD	Partial data reported
PRF	Public residential facility (a state-operated IDD facility serving 16 or more individuals)
RISP	Residential Information Systems Project (University of MN)
RTC	Research and Training Center on Community Living (University of MN)



Special designators for the RISP survey and annual technical report

“d” Other date.

If the provided data was not from June 30, please specify the alternate date used.

“e” Estimate.

The reported value is the closest available approximation when the exact value is not known. A value reported in FY 2017 can be used as an estimate for FY 2018 by designating the date as June 30, 2017. Do not use values originally reported in FY 2015 or earlier as estimates.

“DNF” Data not furnished

Use the DNF code **only** if a value is not known or not available, and it cannot be estimated. Please limit the use of the DNF code. If the state does not provide a value or an estimate, project staff must impute the value to generate the US estimated totals. Do not use zero “0” to reflect unknown values.

“i” imputed. For use by the RISP team only.

No value, or incomplete data were provided. RISP project staff estimated the value so that a US estimated total could be computed. Imputed values are based on previously reported data, and/or proportional estimates based on states with complete data.

“N/A” Not applicable.

This code is only used in reference to per-person expenditures for services provided in state-operated IDD facilities of 16 or more people for states that do not operate any facilities of that type. On all of the other questions, indicate that you do not use the service with a “0,” meaning no participants/facilities/expenditures etc.

“PD” – Partial Data. For use by the RISP team only in data analysis.

PD is noted on tables that include values computed using two or more survey items when some, but not all, of the components were reported by the state.

“s” Other source. For use by the RISP team only.

- Publicly available data from a federal data source are used for values such as the total state population by age, total income taxes paid by the state, and Federal Medical Assistance Percentages.
- Reports published quarterly by the American Health Care Association based on the Centers for Medicare and Medicaid Services CASPER reports are used as estimates if the state does not furnish complete data on the number of ICF/IID recipients, and number of people with IDD in Nursing Homes.
- IBM Watson (formerly Truven) has a contract with the Centers for Medicare and Medicaid Services to publish an analysis Medicaid long-term supports and services program expenditures as reported by states in their quarterly CMS 64 forms for each Federal Fiscal Year. However, those reports generally are based on date of payment rather than date of service, and are subject to revision for up to 2 years after the fiscal year ends. CMS no longer allows preliminary data to be released. The IBM Watson reports are usually not released until after the RISP technical report is published.

Key Definitions

Intellectual Disability

According to the American Association on Intellectual and Developmental Disabilities (AAIDD), intellectual disability is characterized by significant limitations both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior, which covers a range of everyday social and practical skills. This disability originates before the age of 18. The term intellectual disability covers the same population of individuals who were diagnosed previously with mental retardation in number, kind, level, type, duration of disability, and the need of people with this disability for individualized services and supports. Every individual who is, or was, eligible for a diagnosis of mental retardation is eligible for a diagnosis of intellectual disability. Alternative definitions are offered by the American Psychological Association (APA) in the DSM V, and by the World Health Organization (WHO) in the International Classification of Diseases and Related Health Problems.

The International Statistical Classification of Diseases in Related Problems (ICD) version 10 (<http://www.icd10data.com/>) defines codes used in health care settings. States may use one of these definitions, or may use another definition in rule and statute.

Developmental Disability (DD)

According to Congress, under the Developmental Disabilities Assistance and Bill of Rights Act of 2000 “developmental disability” is a severe, chronic disability of an individual that:

1. is attributable to a mental or physical impairment or combination of mental and physical impairments;
2. is manifested before the individual attains age 22;
3. is likely to continue indefinitely;
4. results in substantial functional limitations in 3 or more of the following areas of major life activity:
 - a. Self-care
 - b. Receptive and expressive language
 - c. Learning
 - d. Mobility
 - e. Self-direction
 - f. Capacity for independent living, or
 - g. Economic self-sufficiency; and
5. reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.” http://www.acl.gov/Programs/AIDD/DD_History/index.aspx

Related Conditions

States vary in which related conditions qualify an individual for IDD agency services. In some states people with a condition closely related to intellectual disabilities that results in the need for the same type, intensity, and duration of support as needed by a person with intellectual disabilities are eligible for IDD services. Common related conditions include autism spectrum disorder, cerebral palsy, down

syndrome, spina bifida, hydrocephalus, epilepsy, and fragile X syndrome.

Age

RISP defines children and youth as people ages birth to 21 years, and adults as people 22 years or older on June 30, 2018. These age groups were selected in cooperation with the NASDDDS Research Committee knowing that the age cutoff for children and youth varies by state. For the RISP survey, please use the 0-21 year age group if possible to permit meaningful comparisons across states. If your state uses a different age cutoff, or for some other reason you are unable to report using the 0-21 year group, please specify the age cutoff you used.

People born on or before June 30, 1996 should be reported in the ages birth to 21 years (21 years includes up to a person’s 22nd birthday). People born after June 30, 1996 (i.e. born on or after July 1, 1996) should be reported for the 22 years or older.

Long-Term Supports and Services

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.

- **Behavior Supports:** Supports to prevent or reduce behavior-related issues or mitigate crisis needs. Includes services provided by professional staff, as well as preemptive solutions.
 - Examples: Mental health assessment, crisis intervention, behavioral support, counseling, assertive community treatment

- **Case Management:** Services to assist an individual or family to identify the supports they need, establish eligibility for funded supports, access needed supports, and monitor the extent to which available supports meet the needs of the individual.
 - Examples: Case management, service coordination
- **Day Habilitation & Employment:** Services provided to support the individual in community-based activities (i.e., supported employment, day programs, education)
 - Examples: Job development, supported employment (individual, group, competitive), prevocational services, day habilitation, and early start programs
- **Environmental Modifications and Technology:** Services to accommodate physical disabilities
 - Examples: Personal emergency response systems, home modifications (such as ramps, bathroom modifications), vehicle modifications or repairs, other adaptive equipment, augmentative communication devices, and similar services
- **Family Caregiver Support:** Services provided to help the family caring for an individual with IDD
 - Examples: Home-delivered meals, home health aide, homemaker/chore, caregiver counseling, caregiver training
- **In-home Services:** Services to direct skills development and training to the individual living in the home of a family member, or the person's own home.
 - Examples: Home-based habilitation and training
- **LTSS Medical Supports:** Medical care needed to help individuals with disabilities to remain in their home, the home of a family member, or another home or community residential setting.
 - Examples: OT, PT, speech and language therapies, skilled and private-duty nursing
- **Participant-Directed Supports:** Assistance to individuals/families who self-direct services. Such assistance may include the development of the person-centered plan, managing individual budgets, recruiting workers, and accessing generic services and supports.
 - Examples: Financial management services, participant training, goods and services, other, interpreter
- **Personal Care Supports:** Direct one-to-one services to the individual provided in, or out of, home to provide instrumental support, community integration or skill training
 - Examples: Companion services, personal care/assistance
- **Residential Services:** Services provided to a person with IDD who lives in a setting other than the home of a family member while receiving funded supports.
 - Examples: Residential habilitation, group home, semi-independent living services, supported living services, shared living, corporate foster care, host home, family foster care
- **Respite:** Temporary relief from caregiving responsibilities for family caregivers
 - Examples: Respite (in home, out of home), individual support (day or night)
- **Transportation:** Supports to transport an individual to a community-based activity, including day services, employment services, or other community-based activities.
 - Examples: Community transportation services, non-medical transportation

Funding Authorities

The survey asks about the **funding authorities** used in your state to finance **long-term supports and services** for people with IDD as of June 30, 2018. We cluster funding authorities into four broad categories: Medicaid Waiver, Medicaid State Plan Home and Community Based Services (HCBS), Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID), and non-Medicaid state funding sources.

Medicaid Waivers. Under the Social Security Act, certain provisions give the Secretary of Health and Human Services the authority to waive otherwise applicable provisions of the Medicaid statute. The RISP survey asks about people with IDD who receive LTSS funded by one or more of the following authorities:

1115 Demonstration Waivers

Section 1115 Waivers allow states to test experimental, pilot, or demonstration projects that

promote the objectives of the Medicaid and CHIP programs. They give states additional flexibility to design and improve their programs to demonstrate and evaluate policy approaches such as expanding Medicaid eligibility criterion, providing services not typically covered by Medicaid, and using innovative service delivery systems that improve care, increase efficiency, and reduce costs.

Managed Care Waivers

Several Medicaid authorities allow states to contract with Managed Care Organizations (MCOs) to manage Medicaid-funded services and supports, rather than using a fee-for-service financing structure. The authorities monitored by the RISP project include:

- **1915(a) Managed Care Waiver.** This authority allows states to enroll Medicaid recipients voluntarily into a managed care program as an alternative to offering those services using a fee-for-service model.
- **1915(b) Managed Care Waiver.** This authority allows states to mandate certain groups of Medicaid recipients to receive services through enrollment in a managed care program.
- **1915(b)/(c) Managed Care with Home and Community Based services.** This authority allows states to operate a 1915(c) Home and Community Based Services Waiver concurrently with a managed care waiver authority.

1915(c) Home and Community Based Services Waivers

This funding authority allows states to provide Medicaid-funded long-term supports and services to eligible recipients in a home or community-based setting rather than in a Medicaid-funded institution. 1915(c) waivers can target specific populations, and each waiver includes a specified menu of covered services that assist in diverting people from entering institutional settings and/or transitioning individuals from institutional settings into their homes and community. States may operate several different 1915(c) waiver programs targeting different populations or service menus.

Medicaid State Plan. Medicaid State Plan services include acute care, institutional long-term supports and services, and home and community based

LTSS. Do not report on State Plan Targeted Case Management except in the waiting list question.

- **1915(i) State Plan Home and Community-Based Services.** The 1915(i) State Plan option allows states to target HCBS benefits to one or more Medicaid eligible population, define needs-based eligibility criteria, and provide a combination of acute care medical services such as dental services, and skilled nursing services, as well as LTSS, such as respite, case management, supported employment, or environmental modifications. This authority allows states to offer self-directed LTSS services. However, states must ensure that the benefit is available to all eligible individuals in the state.
- **1915(k) Community First Choice.** The 1915(k) funding authority is a State Plan Option that permits states to provide home and community-based attendant services and supports to eligible Medicaid enrollees. Participants must require institutional levels of care to qualify. It provides increased federal matching dollars for expenditures. States must ensure that the benefit is available to all eligible individuals statewide.
- **Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID)** is an optional institutional State Plan Medicaid benefit that funds comprehensive and individualized health care and rehabilitation services to individuals to promote their functional status and independence.

Other Funding Authorities

- **State Non-Medicaid.** State funded LTSS not eligible for federal Medical matching funds.
- **“Other” funding (Used in Part 1).** Any funding source other than Medicaid Waiver or Medicaid ICF/IID that funds state operated residential services for people with IDD.

Time Frame

- Each survey covers one Fiscal Year. For most states, FY 2018 is July 1, 2017 to June 30, 2018.
- Most questions reference people or settings as of June 30, 2018, or the last day of the fiscal year.
- Contact your RISP staff if you want to have a different fiscal year assigned as the default date for the online RISP survey.
- Report expenditures for services delivered between July 1, 2017 and June 30, 2018.

Populations of Interest

Parts 1 and 2 of the survey ask about people, served by State IDD Agencies, who receive one or more Medicaid or state-funded long-term support or service (LTSS) in addition to case management or service coordination (LTSS Recipients with IDD). This group includes people receiving in-home or residential supports, as well as people receiving other types of LTSS such as day habilitation or vocational services even if the person does not receive services in their home or in a residential facility. It also includes people served by the State IDD Agency who live in Nursing Homes or Psychiatric Facilities.

Parts 3 through 5 include a broader target population.

- People on the **State IDD Agency Caseload** (Parts 3 and 4). This group includes **LTSS Recipients** with IDD plus people with IDD receiving only case management or services coordination services, people waiting for services, and people known to the **State IDD Agency** but not currently receiving LTSS. It does not include people whose eligibility for services has not been determined. Caseload should be for any individual who is known to the state agency to have either applied for services or is currently receiving services. Caseload is about people accessing the supports and services related to IDD in the state.
- All people with IDD (Part 5), whether on the **State IDD Agency Caseload** or not, who live in **Nursing Homes, Psychiatric Facilities**, or other **Congregate Settings** housing four or more LTSS recipients (for people birth through age 21 years), or housing 16 or more LTSS recipients (for people ages 22 years and older).

Operating Entity

Operating entity refers to the organization that directly employs staff providing long-term supports and services. The organization may be **State-operated or Nonstate-operated**.

PART 1: STATE-OPERATED SERVICES

Part 1 Population of Interest: LTSS recipients with IDD living in state-operated IDD residential facilities of all sizes or in IDD units of state-operated Nursing Homes or Psychiatric Facilities. Include IDD

facilities or units managed by state agencies other than the State IDD Agency.

Setting size is based on number service recipients living in the facility/on the campus as of June 30. Do not count “empty beds” in determining setting size (for example, a campus licensed to serve up to 20 people that has 12 people in residence on June 30 should be listed in the 7-15 people category).

Public Residential Facilities (PRF): State-operated IDD residential facilities serving 16 or more people with IDD on one campus, or at one address. Multiple units located on a single institution campus are considered one facility regardless of the number of licensed units on the campus.

Admissions or Readmissions - The number of people with IDD admitted during FY 2018 (7/1/2017 to 6/30/2018) for stays of more than 90 days.

- Exclude transfers between large, state-operated IDD facilities with 16 or more people
- Exclude short-term admissions of 90 days or less for respite, crisis assessment or services or short-term emergency housing.

Short-term Admissions in FY 2018

- Report the total number of admissions for respite, crisis assessment or services, or short-term emergency housing for stays of 90 days or less
- Count each **admission** of less 90 days or less (some individuals may have multiple short-term admission in a single year).

Discharges - the number of people with IDD who moved out of a PRF between July 1, 2017 and June 30, 2018.

- Include people released or discharged to a hospital, Nursing Home or other long-term care setting
- Exclude transfers to other large state operated IDD facilities
- Exclude people admitted for respite, crisis assessment or services or short-term emergency housing stays of 90 days or less

Deaths - the number of people who died while a resident of a PRF between July 1, 2017 and June 30, 2018

- Include any people who died prior to discharge, even if their death occurred during a temporary stay in a hospice, hospital, Nursing Home or other facility

Average Daily Residents

- Average number of people living in any PRF in your state during the year.
- If not provided, average daily residents will be computed as the total number of PRF residents on June 30, 2017 plus the number of PRF residents on June 30, 2018 divided by 2.

Per Diem (average daily per person expenditures) in FY 2018

If a facility has more than one per diem rate, provide the average per diem paid across all residents with IDD.

Provide a single average for all facilities of the same type.

Include both state and federal Medicaid expenditures when computing the average.

PART 2. NONSTATE-OPERATED LIVING ARRANGEMENTS

Part 2 Population of Interest: **LTSS recipients** on the State **IDD Agency Caseload** receiving LTSS from an employee of an entity other than the state.

Include all LTSS recipients with IDD who

- Receive one or more Medicaid or state-funded long-term support or service (LTSS) in addition to case management or service coordination
- Receive in-home or residential services,
- Receive day habilitation, vocational services or other LTSS even if they do not receive in-home or residential services,
- Live in an ICF/IID (even if it is licensed or monitored by an agency other than the State IDD Agency),
- Live in a nonstate-operated Nursing Home or Psychiatric Facility

All LTSS recipients with IDD on the State IDD Agency Caseload should be counted either in the state-

operated residence or the nonstate-operated setting in which they live. Count LTSS recipients with IDD whose residence type is unknown in the Type VII Unknown Setting Type category.

Nonstate-Operated Residences

Type I: ICF/IID. Medicaid Intermediate Care Facilities for Individuals with Intellectual Disabilities.

Type II: IDD Group Home. A residence owned, rented, or managed by the residential services provider, or the provider's agent, to provide housing for persons with IDD in which staff provide care, instruction, supervision, and other support for residents with IDD.

- Include corporate foster care settings in which services are provided by staff, none of whom consider the home their permanent residence.
- Excludes ICF/IID certified facilities.

Type III: Host/ Foster Family Home. A home owned or rented by an individual or family in which they live and provide care for one or more unrelated persons with IDD.

Type IV. Own Home. A home owned or leased by one or more persons with IDD as the person(s)' own home, in which they receive personal assistance, instruction, supervision, and other supports.

- Include settings in which people with IDD
 - live alone or share a home with a spouse/partner or other unrelated individuals.
 - hold the title or lease in his or her own name; or is named on the lease,
 - can continue to live after discontinuing services from a particular provider, and
 - can substitute services from an alternative provider at any time.
- Do not include provider-owned or controlled housing (count those in Type II group homes).
- Do not include people living with a related family member (count those as Type V family home).

Type V. Family Home. A residence of a person(s) with IDD who receives one or more long-term support or service such as respite care, personal assistance, day habilitation, or in-home supports in

addition to case management services while living with a related family member.

Type VI. Other Setting. Other residential settings in which LTSS recipients with IDD on the caseload of the state IDD agency live. Other settings may include settings such as nonstate-operated hospitals, Nursing Homes, Psychiatric Facilities, assisted living facilities, board and care facilities, farmsteads, intentional, or gated communities. Do not include Type I ICF/IID settings or Type II IDD Group Homes in this category. If you report people with IDD living in other residential settings, please describe the “other” settings.

Type VII. Unknown Setting. The type of setting in which a LTSS recipient with IDD lives is not known.

- People known to be homeless should be counted as living in an unknown setting.
- All people on the IDD Agency caseload who receive one or more LTSS, and who live in a nonstate setting, should be accounted for either in Types 1 through VI or in Type VII.
- If left blank, this question will be recoded to 0.

Setting Size

Setting size is computed based on the total number of service recipients residing in the home/facility on June 30, 2018. Setting size categories include 1 to 3 people, 4 to 6 people, 7 to 15 people, and 16 or more people. Do not count empty beds (for example, a campus licensed to serve 20 people with 12 people in residence on June 30 should be listed in the 7-15 people category).

2A. Number of facilities by setting size. Homes or facilities that are clustered on a single campus or at a single address count as one facility. A facility or campus with multiple structures or licenses counts as one setting. For a facility in which 100 service recipients live, 10 of whom have IDD, report 1 facility of 16+ people and report 10 people living in a setting of 16+ people.

Assumptions:

1. There are no ICF/IID settings serving fewer than four people.

2. There are no host/foster family homes serving sixteen or more service recipients.
3. There are no own home settings in which seven or more service recipients live.

An override function is available for the online survey if any of these assumptions are untrue in your state.

We do not count the number of family homes in which people live.

We report the total number of facilities by size across all types of state-operated settings, and across all non-family nonstate-operated settings.

- A total will be automatically computed if you provide a value of 0 or larger for all relevant setting types and sizes
- If complete setting type and size information are not provided, a DNF (did not furnish) or PD (Partial data) will appear in the report and on your state profile.
- Please enter a note explaining all DNF values.
- If you account for all LTSS recipients with IDD in state-operated and non-state operated settings by using the size unknown, and/or setting type unknown fields we will report the totals rather than showing DNF or PD.

2B. Number of LTSS recipients by setting size.

Report the number of people with IDD living in settings of each size. If all service recipients in each setting have IDD, the number of people in a size category should be consistent with the number of settings in that size category. For example, if 100 people with IDD live in settings of 4 to 6 people, the total number of facilities serving 4 to 6 people should be between 17 (100 divided by 6) and 25 (100 divided by 4).

2C. Total Recipients by Funding Authority and Nonstate-Operated Residence Type

For each nonstate residential setting type, report the number of people with IDD whose services are funded by Medicaid Waiver (1115, 1915 a, b, b/c and c) and/or Medicaid State Plan HCBS (1915 i and k) funding authorities. Also, provide an unduplicated

total number of Medicaid Waiver or Medicaid State Plan HCBS recipients for each residence type.

PART 3 CASELOAD, LTSS RECIPIENTS, AND EXPENDITURES

3. Caseload is about people accessing the supports and services related to IDD in the state. The **IDD Agency Caseload** includes people with IDD known to or served by the auspices of the state IDD agency who:

- receive one or more LTSS in addition to case management or service coordination (LTSS Recipients)
- receive only case management or service coordination services
- are waiting for LTSS, and
- are known to the state IDD agency but not receiving LTSS as of June 30, 2018

Do not include people

- whose eligibility IDD services through the IDD agency has yet to be determined or
- who receive services through another state entity (such as child welfare, education, or income supports) unless they also meet the inclusion criteria above

If you provided complete data, total LTSS recipients reported in state-operated or nonstate-operated settings in Parts 1 and 2 are shown for your reference. The number of people on the IDD Agency Caseload should be equal to or greater than the total number of LTSS recipients reported in Parts 1 and 2.

3A through 3F People on the State IDD Agency Caseload Receiving Services, and Expenditures by Funding Authority.

Report people on the caseload of your state IDD agency not receiving LTSS as of June 30, 2018 by age in question 3F.

Report the number of LTSS recipients and total LTSS expenditures by age and funding authority in questions 3A through 3E. Duplicate counts are allowed in questions 3A through 3E.

Questions 3A and 3B both ask about LTSS recipients whose services are funded by a Medicaid Waiver funding authority. Question 3A requests the number of Medicaid Waiver recipients and total Medicaid Waiver expenditures between July 1, 2017 and June 30, 2018 by age. Question 3B requests the number of Medicaid Waiver recipients and total Medicaid expenditures by living arrangement (family home or other) and age (21 years and younger or 22 years and older).

Medicaid Expenditures include both the state/local and federal match expenditures

Per Recipient Expenditures. The online survey automatically computes average per person annual expenditures for all categories in which complete information was provided. It is not necessary to compute these totals when completing the Word version of the survey. Please be sure that the expenditures you report are for the number of recipients you report in each category (even if you report expenditures for only a subgroup of recipients). Please verify that the computed average expenditures per recipient are plausible for each category.

PART 4 MEDICAID WAIVER WAITING LIST

Part 4 population of interest: People on the **IDD Agency Caseload** waiting for **Medicaid Waiver-funded LTSS** while living in a **Family Home** or **Own Home** Setting as of June 30, 2018.

Include people waiting for Medicaid Waiver-funded LTSS who:

- Lived with a family member or in their own home as of June 30, 2018, and
- Did not receive Medicaid-funded LTSS, other than case management/service coordination as of June 30, 2018

Do not include people with IDD who:

- Lived in a setting other than a Family Home or Own Home or who
- Received Medicaid Waiver-funded LTSS as of June 30, 2018

2018

Report the number of people waiting who received case management service/service coordination (including through State Plan Targeted Case Management) on June 30, 2018.

Also, report the number of people living with a family member who were waiting for Medicaid Waiver funding to move to another setting type (such as **Own Home, Host/Foster Family Home, IDD Group Home** or **Other**) as of June 30, 2018.

PART 5 PSYCHIATRIC, NURSING FACILITIES, AND CDC HEALTHY PEOPLE 2020 MONITORING

Part 5 Population of Interest: All people with IDD living in congregate settings (whether on the **IDD Agency Caseload** or not).

Nursing Home

A state or nonstate institution offering skilled nursing or medical care and related services; rehabilitation supports needed due to injury, disability, or illness; and/or long-term care including health-related care and services (above the level of room and board) not available in the community, needed regularly due to a mental or physical condition. Admission to Medicaid Certified Nursing Homes requires a Preadmission Screening and Resident Review (PASSAR).

Psychiatric Facility

Residential facilities designed for persons with a psychiatric disorder, (for example a mental health facility or institute for mental disease).

People living in an ICF/IID certified unit of a Nursing Home or Psychiatric Facility should be counted in the ICF/IID facility category.

About this Section: The Centers for Disease Control (CDC) uses the data you report here to monitor national progress toward the Healthy People 2020 goals of reducing the number of children and adults with IDD living in congregate settings.

It is very important that we receive data from all of the states on these questions.

If you are unable to furnish separate data for nursing homes and other congregate settings, enter the combined total and add a note saying that separate data are not available by type of congregate setting.

Congregate Settings are

- State- or nonstate-operated non-family residential settings, such as **PRFs, ICF/IID, Group Homes, Nursing Homes, Psychiatric Facilities, Other Group Settings** or similar facilities.
- In which rotating (or shift) staff members provide supports and services

For people ages 21 years or younger, report the number of LTSS recipients with IDD in **Congregate Settings** of four or more people.

For people ages 22 years or older, report the number of LTSS recipients with IDD in **Congregate Settings** of 16 or more people.

Congregate Settings do not include **Own Home** settings.

People in Congregate Settings do not include people who:

- Live with birth or adoptive parents, or other family members
- Live in **Host/Foster Family Settings** in which no shift staff work
- Live only part of the year in a residential PreK-12 school
- Live in correctional or juvenile justice facilities
- Receive only respite services from a **Congregate Setting**
- Live in other states (do count people who live in your state whose services are paid by another state)

FREQUENTLY ASKED QUESTIONS

Where do I go to complete the RISP survey online?

- The URL for the RISP survey is <https://risp.umn.edu/survey-dashboard>.
- If you have not previously done so, you will need to contact your state's assigned RISP team

member for login information to access the survey. Please do not use someone else's login information.

What if fewer people live in a facility on June 30 than the licensed capacity?

- Report only number of individuals with IDD residing in the facilities on June 30. Do not report the licensed capacity.

What should we do when we cannot report a certain data element because it is not available?

- Report DNF to indicate that a data element is not available.
- Report totals whenever possible, even if you cannot provide subtotals. Examples:
 - If you know the number of people in settings of 1 to 6 people, but do not know how many are in settings of 1 to 3 and 4 to 6, report the 1-6 total, and enter DNF for 1 to 3 and 4 to 6.
 - If you know the total number of Medicaid Waiver recipients by age, but do not know how many people in each age group live in the home of a family member, report the totals by age, and enter DNF for the living arrangement component of the question.
- In reports using RISP data:
 - For individual survey items, DNF indicates that a particular value was not provided.
 - For tables that combine data from two or more separate elements, Partial Data (PD) indicates that at least one of the component values was reported, or DNF, if none of the component parts was reported.

What should we do if an entity other than the State IDD Agency manages some or all LTSS for people with IDD?

- Please request the data from the other entity (e.g., the managed care organization, the State Medicaid Agency).
- If you report data from another entity, and would like readers of the report to know the source, please identify the source in the public notes.

What if the State IDD Agency does not collect or report certain data (ever, or for a specific year)?

- Use the notes to explain why a data element is not available.
- Report data from the immediately prior year (if available). Do not repeat an estimate that is more than one year old.

Where do the Medicaid long-term care expenditure data used in the RISP report come from?

- The annual RISP state survey has been the primary source for expenditures since these dates:
 - FY 1982 for 1915(c) Waivers (referred to as "Home and Community Based Waivers," "regular ID/DD Waivers," or Medicaid Section 2176 HCBS Waiver" in earlier years of the survey).
 - FY 1982 Medicaid 1115, 1915 (a/c), (b), or (b/c), and "other Waivers" serving people with IDD. This category also included OBRA (Nursing Home) ID/DD Waivers and Model Waivers for people with ID/DD from FY 1994 to FY 2008.
 - FY 1990 to FY 1995 Medicaid Community Supported Living Arrangement option (used by 8 states)
 - FY 2012 ICF/IID
 - FY 2013 Medicaid State Plan 1915(i) and 1915(k)
- Other sources for Medicaid Expenditures (used only when states are unable to furnish the data)
 - Until FY 2010, a CMS contractor published a report summarizing Medicaid Waiver and ICF/IID expenditures based on CMS 64 reports in time to supplement data from non-reporting states for the annual RISP technical report. CMS no longer allows preliminary data to be released. This report is now released 21 to 24 months after the end of a fiscal year. As a result, the RISP technical report does not include data from the CMS 64 reports for the current year. Once they are released, those reports (currently produced by IBM Watson) are used to update our online database for states that furnished partial or no expenditure data.
 - ICF/IID expenditures for FY 2011 are from the State of the States survey
- Expenditure data are updated as follows

- States can provide updated expenditure data as it becomes available. Data provided by states is preferred.
- Historical data that came from Truven or IBM Watson reports are updated in the RISP database for all applicable years when the IBM Watson reports are released.

What other data sources are used for the RISP technical report?

- State populations by age are from US Census Data.
- Income taxes paid by state, and Medicaid federal match rates, are from the relevant federal databases.
- A summary of data from the Medicaid Certification and Survey Provider Enhanced Reporting (CASPER) reports for public and private ICF/IID and Nursing Homes is compiled quarterly by the American Health Care Association. Information from CASPER is used when a state is unable to furnish the number of people with IDD in ICF/IID or Nursing Home settings.
- The annual Public Residential Facility (PRF) survey is fielded by RISP staff to gather data about state-operated IDD facilities and IDD units in state-operated Nursing Homes or Psychiatric Facilities. The sample frame for this survey was developed in 1977, and includes most, but not all, state-operated IDD facilities serving 16 or more people still in operation. Facilities are removed from the sample frame when they close, downsize to 15 or fewer people, are converted for use by a different population, or merge before June 30. The survey asks about the demographics of people served, and of those who enter or leave a facility during a fiscal year. It also asks about facility characteristics such as the number of full-time equivalent staff.

Are duplicate counts ok?

- Unduplicated counts should be used throughout the report, except that
 - Duplicated counts are acceptable in the expenditure section (Part 3), when service recipients receive LTSS services through more than one Medicaid or state funding authority (e.g., 1915(c) Waiver and State Plan HCBS).
- We compute the average per-person expenditure overall, and for subgroups of recipients, so it is

important that the number of recipients reported matches the expenditures in each category.

Why do some totals differ from one table to the next in the annual RISP technical report?

- Some totals could be calculated using items from more than one section of the survey. For example, the total number of Medicaid Waiver Recipients on June 30 is computed by summing the number of Waiver recipients in state-operated residences from Part 1 and the number served by non-state providers from Part 2. The number of recipients for whom expenditures were reported comes from Part 3. Totals for states that reported different numbers of people in Parts 1 and 2 than in Part 3 will not match.
- The survey asks for year-end recipients, but some states report recipients with expenditures in a fiscal year, regardless of whether they were recipients on June 30.
- By default, we report the data as it was reported on the survey. However, if the number of Waiver and ICF/IID recipients as of June 30 reported in Parts 1 and 2 are greater than the values in are reported in Part 3, Expenditures, then we use the number of people in Parts 1 and 2 as the total number of Waiver or ICF/IID recipients. The values from the expenditure section are used in conjunction with the expenditures, and for the total number of recipients so long as the number in Part 3 is greater than or equal to the number of people reported in Parts 1 and 2.

What is a validation check? What should I use it for?

- Validation checks are used in the online survey. They warn the user of discrepancies such as values that may have a misplaced decimal or a missing digit, large year-to-year changes, or inconsistencies between responses for questions in different sections of the survey.
- If you see a validation warning, look at the “Expand” menu to see “Validation checks that need attention.” Please correct data entry errors, or explain the reason for the discrepancy or notable change from previously reported values.