



In-Home and Residential
Long-Term Supports and Services
for Persons with Intellectual or
Developmental Disabilities:
Status and Trends Through **2016**

Residential Information Systems Project



IN-HOME & RESIDENTIAL SUPPORTS FOR PERSONS WITH INTELLECTUAL OR DEVELOPMENTAL DISABILITIES: STATUS AND TRENDS THROUGH 2016 RESIDENTIAL INFORMATION SYSTEMS PROJECT REPORT (RISP)

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PREFACE

NOTE TO OUR READERS

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, 2016.

Key changes for FY 2016 include:

- We updated the prevalence rate used to estimate the number of children ages 17 years or younger with IDD in the noninstitutionalized civilian U.S. population. The estimated prevalence for this age group increased from 33.8 per 1,000 based on prevalence estimates from the 1994/1995 National Health Interview Survey Disability Supplement (Larson, et al., 2001) to 69.9 per 1,000 based on prevalence estimates for the 2016 NHIS (Zablotsky, et al., 2017).
- We refined our methodology for computing average per person expenditures by funding authority, recipient age and living arrangement to reduce variability due to year-to-year differences in which states provide complete data.
- We added information about race and ethnicity of people in state-operated IDD facilities of 16 or more people (Public Residential Facilities or PRFs; See **Table 4.3**).
- We updated our methodology for estimating the number of people 21 years and younger with IDD in nursing homes (**Table 1.11**), ICF/IID settings (**Table 2.10**), and other IDD settings of four or more people (**Table 1.12**). We used values reported by states when available. Missing values for ICF/IID and nursing homes were estimated from analyses of Centers for Medicare and Medicaid Services CASPER data for June 2016 (American Health Care Association, 2017). Missing values for children in other IDD settings of four or more people were estimated using the proportion of people in ICF/IID settings who were 17 years or younger.
- FY 2016 surveys and operational definitions are posted with the online version of the FY 2016 report at risp.umn.edu. A complete list of past and current RISP products can be found under the publications section.

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.

Sherri Larson, RISP Principal Investigator

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The RISP project conducts annual surveys of state IDD agencies and state-operated IDD facilities serving 16 or more people. We are indebted to the many people who completed FY 2016 surveys and responded to questions to clarify their responses. The RISP project would not be possible without their knowledge, expertise, and generous assistance.

The National Association of State Directors of Developmental Disabilities Services (NASDDDS) research committee assists with identifying state contacts, reviewing survey instruments, conducting a periodic project evaluation, and reviewing and providing feedback on drafts of this report.

The Association of Professional Developmental Disabilities Administrators (APDDA) assists in identifying and contacting respondents for the survey of large state-operated residential facilities, presents survey results to its membership, and provides input regarding changes to the PRF survey.

Lisa Sinclair is the liaison between the RISP project and the Centers for Disease Control's Healthy People 2020 project.

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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, NASDDDS staff, and consultants who are 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.

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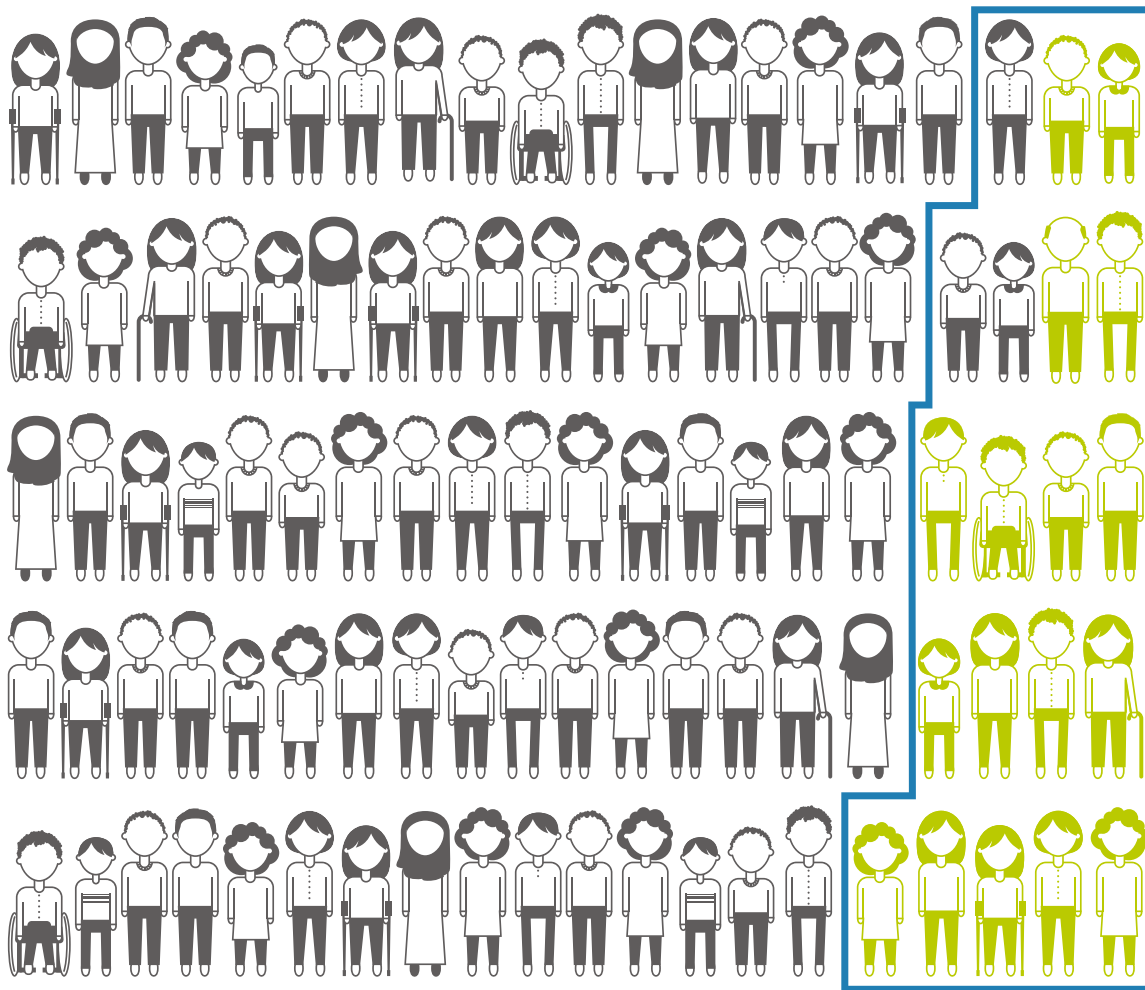
ACL	Administration on Community Living
AHCA	American Health Care Association
AIDD	Administration on Intellectual and Developmental Disabilities (formerly ADD)
APDDA	Association of Professional Developmental Disabilities Administrators
ASD	Autism Spectrum Disorder
CASPER	Certification and Survey Provider 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
FISP	Supporting Individuals and Families Information Systems Project (University of MN)
FMAP	Federal Medical Assistance Percentage
FY	State Fiscal Year (e.g., FY 2016 is July 1, 2015 to June 30, 2016)
HCBS	Home and Community-Based Services (Medicaid)
HSRI	Human Services Research Institute
ICF/IID	Intermediate Care Facility for Individuals with Intellectual Disabilities (formerly ICF/MR)
ICI	Institute on Community Integration (University of MN)
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, 2016. This report describes LTSS recipients with IDD and public LTSS expenditures by recipient age (birth to 21 years or 22 years and older), residence type and size, funding source, and provider type (state or nonstate).

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



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

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

Sources: Prevalence rates for children with ID, ASD, or DD from the 2016 National Health Interview Survey (NHIS; Zablotzky et al, 2017), prevalence rates for adults with ID, DD, or both from the 1994/1995 NHIS (Larson et al, 2001), estimated U.S. service recipients with IDD from the FY 2016 RISP report (see below).

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, 2016.

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

An estimated 7.37 million people with IDD (22.8 per 1,000 of the population) lived in the United States on June 30, 2016. An estimated 70% of those people were 21 years or younger.

An estimated 20% (1,488,732 people) of those with IDD were known to or served by state IDD agencies (4.6 people per 1,000). Of those served by state IDD agencies

- 39% (576,506 people) were 21 years or younger
- 61% (912,226 people) were 22 years or older

Where did people with IDD receiving LTSS live?

An estimated 17% (1,228,770 people) of people with IDD in the United States received LTSS provided by or under the auspices of state IDD agencies (83% of the people known to state IDD agencies) on June 30, 2016. Of those,

- 58% (714,910 people) lived in the home of a family member
- 25% (303,075 people) lived in a group home, ICF/IID or other group setting
- 12% (146,974 people) lived in a home they owned or leased
- 5% (63,750 people) lived in a host or foster family home

An additional 26,381 people with IDD lived in nursing homes and an estimated 3,715 lived in a psychiatric facility. State IDD agencies served 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?

Residential settings other than the home of a family member included own home, host/foster family homes, group homes, Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID), and other group settings.

LTSS recipients with IDD lived in an estimated 229,076 non-family settings, of which

- 84% (192,803 settings) were home to three or fewer people
- 13% (28,886 settings) were home to 4 to 6 people
- 3% (6,632 settings) were home to 7 to 15 people
- 0.3% (755 settings) were home to 16 or more people

An estimated 513,790 people with IDD lived in non-family settings. Of those,

- 56% (288,013 people) lived in a setting shared by three or fewer people
- 26% (132,667 people) lived in a setting shared by 4 to 6 people
- 10% (53,404 people) lived in a setting shared by 7 to 15 people
- 8% (39,705 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 2.2 people with IDD.

In nonstate-operated settings, there was an average of

- 1.4 people per own home setting
- 1.6 people per host/foster family home
- 3.4 people per group home (other than ICF/IID)
- 9.2 people per ICF/IID

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

- 5.2 people per group home (other than ICF/IID)
- 18.6 people per “other” group setting
- 68.8 people per ICF/IID

How many people with IDD 21 years or younger lived in congregate settings in which supports were provided by shift staff to four or more LTSS recipients? (A Healthy People 2020 indicator)

An estimated 15,712 people with IDD 21 years or younger lived in settings shared by four or more LTSS recipients. Of those,

- 8% (1,198 children and youth) lived in nursing homes and
- 92% (14,514 children and youth) lived in other congregate settings

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 as of June 30, 2016. It describes the number of recipients, total expenditures, and expenditures per recipient for Medicaid Waiver and Intermediate Care Facilities for Individuals with Intellectual Disabilities. 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?

- 48 states used Medicaid 1915(c) Home and Community Based Waiver
- 46 states used Medicaid Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID)
- 46 states used non-Medicaid state funds
- 9 states used Medicaid State Plan 1915(i) Home and Community Based Services
- 9 states used Medicaid 1115 Demonstration Waiver
- 8 states used Medicaid State Plan 1915(k) Community First Choice
- 5 states used Medicaid managed care waivers (1915a, b, or b/c)

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 in FY 2016?

Of the 1,228,700 LTSS recipients with IDD,

- 54% (807,462 people) received LTSS through a Medicaid Waiver funding authority
- 29% (438,160 people) received LTSS through a Medicaid State Plan HCBS funding authority
- 15% (216,969 people) received state-funded LTSS
- 5% (74,614 people) received supports in a Medicaid ICF/IID
- 13% (191,210 people) received no Medicaid or state-funded LTSS

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 on June 30, 2016?

An estimated 193,828 people with IDD were living with a family member and waiting for Medicaid Waiver-funded LTSS. Of those,

- 36% (69,279 people) were waiting to move to a different setting
- 23% (43,884 people) received Medicaid State Plan-funded Targeted Case Management services while waiting

Thirteen states reported no people with IDD waiting for Medicaid Waiver-funded LTSS.

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

Where did Medicaid Waiver recipients with IDD live on June 30, 2016?

Of the 807,462 Medicaid Waiver recipients with IDD

- 53% (427,910 people) lived with a family member
- 26% (209,133 people) lived in a group setting
- 15% (117,508 people) lived in a home they owned or leased
- 7% (52,911 people) lived in a host or foster family home

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

- 25% (204,406 Medicaid Waiver recipients) were 21 years or younger
 - 85% (173,363 people) lived in the home of a family member
 - 15% (31,043 people) lived in own home, host or foster family home, or a group setting
- 75% (603,056 Medicaid Waiver recipients) were 22 years or older
 - 42% (254,547 people) lived in the home of a family member
 - 58% (348,509 people) lived in own home, host or foster family home or a group setting

There were 250 Medicaid Waiver recipients with IDD per 100,000 of the United States' population.

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

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

- 80% (117,508 LTSS recipients) living in their own home received Medicaid Waiver-funded supports
- 60% (427,910 LTSS recipients) living in the home of a family member received Medicaid Waiver-funded supports

What were total FY 2016 Medicaid Waiver expenditures for recipients with IDD? What proportion of FY 2016 Medicaid Waiver expenditures for recipients with IDD were for people 22 years or older?

Estimated Medicaid Waiver expenditures for people with IDD in FY 2016 were \$35.47 billion (\$110 per U.S. resident).

- 10% (\$3.56 billion) was for people 21 years or younger
- 90% (\$31.91 billion) was for people 22 years or older

What were the average annual per recipient Medicaid Waiver expenditures for people with IDD in FY 2016? How did the average differ by age and living arrangement?

Average annual Medicaid Waiver expenditures were \$43,928 per year-end recipient with IDD in FY 2016. Average expenditures were

- \$17,404 per recipient 21 years or younger overall
 - \$13,831 for people 21 years or younger living in the home of a family member
 - \$37,360 for people 21 years or younger living in other settings
- \$52,918 per recipient 22 years or older overall
 - \$26,486 for people 22 years or older living in the home of a family member
 - \$72,224 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, 2016? How many people with IDD received services in ICF/IID of different sizes?

There were 6,271 ICF/IID settings operating on June 30, 2016. Of those,

- 5% (286 ICF/IID) were state-operated including
 - 23% (67) serving 6 or fewer people
 - 29% (84) serving 7 to 15 people
 - 47% (135) serving 16 or more people
- 95% (5,985 ICF/IID) were nonstate-operated including
 - 63% (3,777) serving 6 or fewer people
 - 31% (1,855) serving 7 to 15 people
 - 6% (353) serving 16 or more people

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

How many people lived in state or nonstate ICF/IID of various sizes on June 30, 2016?

An estimated 74,614 people lived in an ICF/IID on June 30, 2016. Of those,

- 26% (19,677 people) lived in a state-operated ICF/IID including
 - 1% (284) in a setting of 6 or fewer people
 - 4% (829) in a setting of 7 to 15 people
 - 94% (18,564) in a setting 16 or more people
- 74% (54,937 people) lived in a nonstate-operated ICF/IID including
 - 40% (21,881) in a setting of 6 or fewer people
 - 29% (15,920) in a setting of 7 to 15 people
 - 31% (17,136) in a setting of 16 or more people

How old were people living in an ICF/IID?

Of the 74,614 people of all ages living in an ICF/IID (23.2 people per 100,000 of the population)

- 7% (5,022 people) were 21 years or younger (5.5 people per 100,000 of the population)
- 93% (69,592 people) were 22 years or older (30.2 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 39,705 people living in IDD settings of 16 or more people, 90% (35,700 people) lived in an ICF/IID. The proportions in ICF/IID settings were

- 97% (18,564 of 20,624 people) in state-operated IDD facilities
- 83% (17,136 of 19,081 people) in nonstate-operated IDD facilities

What were FY 2016 Medicaid ICF/IID expenditures?

Total ICF/IID expenditures in FY 2016 were \$10.51 billion (\$33 per United States resident).

Average annual ICF/IID expenditures were \$140,831 per year-end recipient. The average was

- \$117,714 for recipients 21 years or younger
- \$142,499 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 2016?

An estimated 882,076 Medicaid LTSS recipients with IDD lived in an ICF/IID or received Medicaid Waiver-funded LTSS. Of those,

- 92% received Medicaid Waiver-funded LTSS
- 8% lived in an ICF/IID

Total Medicaid ICF/IID plus Waiver expenditures for people with IDD were \$46 billion in FY 2016. Of the total,

- 77% (\$35.47 billion) was for Medicaid Waiver recipients
- 23% (\$10.51 billion) was for people in ICF/IID

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 2016, the number of LTSS recipients with IDD living in

- The home of a family member increased 120% from 325,650 to 714,910 people.
 - The proportion living with a family member who received Medicaid Waiver-funded supports increased from 25% to 60%.
- A home of their own increased 126% from 62,669 to 141,388 people
- A host/foster home or IDD group setting of three or fewer people increased 132% from 63,279 to 146,625 people
- An IDD group setting of 4 to 6 people increased 80% from 73,658 to 132,667 people
- An IDD group setting of 7 to 15 people decreased 1% from 53,940 to 53,404 people
- An IDD facility, Nursing Home or Psychiatric Facility of 16 or more people decreased 39% from 114,495 to 69,801 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 2016, the number non-family IDD settings increased from 11,008 to 229,076 settings.

- The proportion of non-family IDD settings serving six or fewer people increased from 63% (6,898 facilities) to 97% (221,689 facilities).
- The proportion of nonstate-operated IDD settings serving six or fewer people increased from 65% (6,855 facilities) to 97% (220,405 facilities).
- The proportion of state-operated IDD settings serving six or fewer people increased from 9% (43 facilities) to 60% (1,284 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?

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% (420,681 people) in 2016
- 7 to 15 people increased from 8% (20,024 people) in 1977 to 10% (53,404 people) in 2016
- 16 or more people decreased from 84% (207,356 people) in 1977 to 8% (39,705 people) in 2016

Of the people living in non-family IDD settings, the proportion living in state-operated settings of any size declined from 63% (155,804 people) in 1977 to 6% (29,768 people) in 2016.

- Of the people in settings of 1 to 6 people, the proportion in a state-operated facility was 0.1% (216 people) in 1977 and 15% (4,580 people) in 2016.
- 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 21% (6,107 people) in 2016.
- 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 64% (19,081) in 2016.

Between 1977 and 2016, the average size of all non-family IDD settings declined from 22.5 to 2.2 people per setting. The average size of

- State-operated IDD settings declined from 335.1 to 14.0 people per setting.
- Nonstate-operated IDD settings declined from 8.7 to 2.1 people per setting.

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

Between 1982 and 2016, the number of people with IDD

- Receiving Medicaid Waiver-funded supports increased from 1,381 to 807,462 people.
- In a Medicaid ICF/IID setting declined from 140,752 to 74,614 people.

Between 1982 and 2016 total expenditures for people with IDD

- Receiving Medicaid Waiver-funded services increased from \$2.2 million to \$35.5 billion.
- In ICF/IID settings increased from \$3.4 billion to \$10.5 billion.

Between 1982 and 2016, average annual per person Medicaid expenditures for

- Waiver-funded services for people with IDD increased from \$1,624 to \$43,928.
- ICF/IID services for people with IDD increased from \$23,806 to \$140,831.

In 1984, annual per person ICF/IID expenditures (\$65,642 in 2016 inflation adjusted dollars) were 5.12 times higher than annual per person Waiver expenditures (\$12,825 in 2016 inflation adjusted dollars). By 2016, annual per person ICF/IID expenditures (\$140,831) were 3.21 times higher than annual per person Waiver expenditures (\$43,928).

Expenditures for ICF/IID and Medicaid 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 17% from 232,204 people in 2013 to 193,828 people in 2016. The number waiting to move to a residence other than the home of a family member declined 35% from 107,204 in 2013 to 69,279 in 2016.

How has the number of people with IDD 21 years old or younger living in IDD group settings of four or more people or nursing homes changed?

Between 1995 and 2016, the estimated number of people with IDD 21 years or younger living in IDD group settings of four or more people or in nursing homes declined 31% from 22,875 to 15,712 people.

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

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 for short) or in state-operated psychiatric facilities.

How many people lived in PRFs on June 30, 2016? How did the number of people living in PRFs change during FY 2016

An estimated 19,081 people with IDD lived in a PRF on June 30, 2016 (down from 20,709 on July 1, 2015). The average daily population for FY 2016 was 19,502.

The number of people per facility ranged from 22 to 495 and averaged 177 (100 facilities reporting).

During 2016, PRFs had an estimated

- 1,014 admissions or readmissions
- 1,897 discharges
- 635 deaths
- 932 short-term admissions (less than 90 days) of which
 - 56% (523 admissions) were for respite
 - 44% (406 admissions) were for evaluation
 - Less than 1% (3 admissions) were for crisis housing

People ages 21 years or younger were only 4% of the PRF population on June 30, 2016, but they were

- 30% of all admissions
- 17% of all readmissions
- 11% of all discharges

People 55 years or older were 46% of the PRF population on June 30, 2016 but were

- 9% of new admissions
- 8% of readmissions
- 27% of discharges

Of the people newly admitted to PRFs in FY 2016

- 17% came from the home of a family member, their own home or a host or foster family home
- 11% came from a group IDD setting of 6 or fewer people
- 13% came from a group IDD setting of 7 or more people
- 32% came from a nursing home, correctional facility, or mental health facility
- 25% came from another or unknown setting

Of the people who moved from a PRF to another setting in FY 2016

- 22% went to the home of a family member, their own home or host or foster family home
- 22% went to a group IDD setting of six or fewer people
- 39% went to a group IDD setting of 7 or more people
- 7% went to a nursing home, correctional facility or mental health facility
- 20% went to another or unknown setting

What were the characteristics of people with IDD living in PRFs in 2016?

On June 30, 2016, of the people living in PRFs, an estimated

- 4% were 21 years or younger, 19% were 22 to 39 years, 55% were 40 to 62 years and 21% were 63 years or older.
- 14% had mild or no intellectual disabilities (ID), 14% had moderate ID, 19% had severe ID, and 53% had profound ID.
- 7% were of Hispanic Origin.
- 74% were white, 20% were black or African American, and 6% were another race, two or more races or of an unknown racial background
- 40% had epilepsy, 19% had autism, 15% had cerebral palsy, and 15% were blind
- 54% received medications for mood, anxiety or behavior, 50% had a psychiatric disorder, and 42% had a behavior disorder.

The proportion requiring assistance or supervision was 64% for dressing, 58% for transferring, 58% for toileting, 56% for eating, and 41% for walking.

The proportion who could not express their needs verbally was 52% and the proportion who could not understand verbal requests was 29%.

What were the characteristics of the staff employed in PRFs?

PRFs employed an estimated 54,710 full-time equivalent staff, 59% of whom were direct support professionals.

Vacancy rates on June 30, 2016 were

- 11% for direct support professionals (up from 6% in 2006)
- 10% for frontline supervisors (up from 5% in 2006)

Crude separation rates (turnover) for FY 2016 were

- 33% for direct support professionals (up from 29% in 2006)
- 17% for frontline supervisors (up from 13% in 2006)

How has the number of PRFs changed?

Of the 374 PRFs operating between 1960 and 2016,

- 230 closed before July 1, 2015
- 6 closed, merged, downsized to less than 16 people or converted to a nonstate facility between July 1, 2015 and June 30, 2016
- 139 were open on June 30, 2016, 12 of which anticipated closing by June 30, 2021.

On June 30, 2016, there were no PRFs serving people with IDD in 15 states: Alabama, Alaska, the District of Columbia, Hawaii, Indiana, Maine, Michigan, Minnesota, New Hampshire, New Mexico, Oklahoma, Oregon, Rhode Island, 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 19,502 in 2016.

The average daily number of people with IDD in state-operated psychiatric facilities declined from 41,823 in 1961 to 267 in 2002 but increased to 2,044 people on June 30, 2016.

The number of people in PRFs or state-operated psychiatric facilities declined at a rate of 2,073 people year between 2010 and 2014, a 6% reduction. It declined by 1,093 people between 2015 and 2016, a reduction of 5%.



Introduction

FY 2016

Table A: Long-Term Supports and Services Categories

Service Category	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	<i>Mental health assessment, crisis intervention, behavioral support, counseling, assertive community treatment</i>
Employment and Day Services	Services provided to support participation in community-based activities, education, and employment	<i>Job development, supported employment (individual, group, competitive), prevocational services, day habilitation, early start programs</i>
Environmental Modifications and Technology	Adaptive equipment, home modifications (e.g., ramps, bathroom modifications, etc.), modification or repair to a vehicle, adaptive equipment, augmentative communication devices, personal emergency response systems	<i>Personal emergency response systems, home and vehicle modifications, adaptive equipment</i>
Family Caregiver Support	Services to help the caregiver, or family, provide supports to the individual	<i>Home delivered meals, homemaker/chore services, caregiver counseling, caregiver training</i>
Habilitation	Support for skill development for the individual 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	<i>Home-based habilitation, recreation and leisure</i>
Housing Supports	Services to assist the person to obtain and maintain housing	<i>Housing coordination, Community Transition Services</i>
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 for people who have ongoing support needs	<i>Home health aide, OT, PT, speech and language therapies, skilled and private nursing, clinic services</i>
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	<i>Financial management services, participant training, goods and services, interpreter, other</i>
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.	<i>Companion services, personal care/assistance</i>
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	<i>Group home, Shared Living, Board and Care</i>
Respite	Temporary relief from caregiving duties for the family caregiver	<i>Respite (in home, out of home), individual support (day or night)</i>
Transportation	Supports to transport an individual from their residence to community settings including day services, employment services, or other community-based activities	<i>Community transportation services, non-medical transportation</i>

This table 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.

INTRODUCTION

People with IDD, like those without IDD, live and participate in preferred communities in unique ways. 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 or by the type and amount of supports they receive.

The goal of LTSS is to 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, chores, and money management
- Developing and maintaining relationships
- Identifying and pursuing personal interests such as hobbies, sports, clubs or worship
- Health (physical and emotional)
- Employment
- Formal and informal learning opportunities
- Making decisions about where and with whom to live and about their schedules and activities
- Engaging in civic responsibilities such as voting and paying taxes

There are many different types of LTSS. **Table A** lists service categories with a brief description and selected examples of services in each category.

Full participation is affected by the availability and competence of paid and non-paid support providers, 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, by state or local governments without Medicaid matching dollars, or purchased by the individual or family privately.

THE POLICY CONTEXT

LTSS in the United States are influenced by Medicaid statute and rule, as well as federal laws such as the Rehabilitation Act of 1973, the Americans with Disabilities Act, the Supreme Court's Olmstead decision, and other federal and state legislative actions, judicial decisions and other 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 Home and Community-Based Services (HCBS) Rules establishing new guidelines for services and supports financed through several Medicaid LTSS funding authorities CMS, 2014; Final Regulation CMS-2249-F/ CMS-2296-F. The HCBS rules require person-centered planning and service delivery and prohibit conflicts-of-interest for those who develop plans of care. They require that recipients have full access to the greater community including competitive integrated employment; choice of services and service settings, daily activities, physical environments, and with whom to interact; freedom to exercise individual rights of privacy, dignity, respect; and freedom from restraint and coercion.

The 2014 HCBS rule defines settings that qualify for Medicaid HCBS funding, and describes 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. Services must be provided in settings that are physically accessible for the recipient.

Most provisions of the regulation became effective on March 17, 2014. However, states have until 2022 to implement the settings portion of the rule. Between now and then, each state must develop a transition plan approved by the Centers for Medicare & Medicaid Services (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. As of April 2018, Arkansas, Delaware, the District of Columbia, Kentucky, Oklahoma, Tennessee, and Washington, had received final approval from the CMS for their statewide transition plan. (CMS, n.d.; Statewide Transition Plans).

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 other organizations 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 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 (See the [ADA Olmstead webpage](#) for details).

The United States Department of Justice's (DOJ) enforcement of the 2009 Supreme Court's 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.

State Litigation and Legislative 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.

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?
- 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 and types differ for recipients of different ages (i.e., children versus adults)?
- How do expenditures for services differ by funding authority, setting type, and recipient age?

Medicaid LTSS programs have become more complex, offering new and different funding authorities requiring states who offer Medicaid-funded services to adhere to new program rules. Those complexities are important to consider when comparing states or interpreting data on service utilization or expenditures. When comparing states it is important to be aware of similarities and differences across states in:

- **Eligibility criteria.** Medicaid eligibility is complex. States are required to cover certain groups of individuals in specific income brackets, but may elect to cover additional groups and/or income levels. For Medicaid Waiver programs, federal guidelines establish minimum eligibility criteria (e.g., institutional level of care requirements). However, states have the authority to apply additional requirements such as diagnostic, or age-related, eligibility criteria. For example, some states consider family income when determining whether a child with a disability who resides in the family home is eligible for services while other states do not.

- **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 from small family stipends, or limited respite, to intensive 24-hour in-home support). Adding to the complexity, states offering similar services may refer to them using different names.
- **Populations served.** States designate the populations to be served in their Medicaid Waiver program(s). Some waivers target only people 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.
- **Data systems.** States differ in how they collect and maintain data about service recipients. Depending on the age and sophistication of the data management system, it may be difficult to identify people with IDD within Waivers serving multiple populations, or to report age and living arrangement sizes and types across funding authorities. In states using managed LTSS, some of the needed data is maintained by the managed care entities. Budget or staffing limitations can make it difficult to extract the information for the RISP report.
- **Funding options.** Many Medicaid funding authorities are available to states to finance services for individuals with IDD and their families, including state plan services, demonstration waivers, managed care waivers, and other waiver options. Information about Federal Medicaid funding authorities is available on the [Medicaid website for Institutional Long Term Care](#) or [Home and Community Based Funding Authorities](#). States may administer services and programs in cooperation with local governments and with the contribution of state and county dollars.

We encourage readers to review RISP report data in light of these complexities. Detailed information

about the surveys and operational definitions used for RISP can be found on the project website risp.umn.edu. These documents are used to provide guidance to states specifying the operational definitions for each data element. The state notes section of this report provides key background information needed to interpret data for specific states accurately. RISP project staff members are available to assist you to understand the findings (email risp@umn.edu). It may also be helpful to check your state's DD agency website, or with the DD Agency director if you need further clarification of a specific finding. Links to state-specific information are 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 (nacdd.org) lists [state DD councils](#).
- The National Disability Rights Network website (www.ndrn.org) lists [member Protection and Advocacy \(P&A\) and Client Assistance Program \(CAP\) organizations](#).
- The (risp.umn.edu) website publishes fact sheets, data visualizations, state profiles, and other resources.

THE RESIDENTIAL INFORMATION SYSTEMS PROJECT (RISP)

RISP is an Administration on Intellectual and Developmental Disabilities (AIDD) Project of National Significance (PNS) that maintains longitudinal records of LTSS 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 plus 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), or the National Association of State Directors of Developmental Disabilities Services (NASDDDS).

The NASDDDS Research Committee, comprised of state IDD Directors and key partners, advises the RISP project and its activities. The Association of Professional Developmental Disabilities Administrators (APDDA) assists with the ongoing longitudinal study of large state-operated IDD facilities.

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. During the forty-year history 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 participated in a census of all state and nonstate residential facilities for people with IDD (Bruininks, Hill & Thorsheim, 1982; Hauber, et. al., 1984). Trends in the use of public (state-operated) residential facilities serving 16 or more people have been included in annual RISP reports since 1983. Individual state profiles summarizing the status and trends in residential and community supports have been part of the report since 1995.

The annual RISP report has described LTSS for people with IDD receiving supports funded through the Medicaid Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) and Home and Community Based (HCBS) Waiver funding authorities since 1982. As Medicaid added new LTSS funding authorities, the project adjusted survey items to differentiate them 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 Centers for Medicare and Medicaid 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 Federal and State agencies we added

a table to the report showing the estimated U.S. population with IDD by state.

This RISP report describes Medicaid and state-funded LTSS managed by, or under the auspices of, state intellectual and developmental disabilities (IDD) agencies in State Fiscal Year (FY) 2016 (July 1, 2015 through June 30, 2016) and examines trends across time. The RISP report describes six dimensions of LTSS:

1. Type of entity providing services (state or nonstate)
2. Living arrangement (own home, family home, foster or host family home or group settings)
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, State, or other)
6. Time (state fiscal year – July 1 to June 30)

Study Methodology

State Directors of IDD Services (RISP Survey)

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 also 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, RISP data 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. The new version automatically tracks edits or changes by date and the person who made or requested the change. 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 FY 2015 and FY 2016 to assist states to identify possible arithmetic errors, inconsistencies within or across survey sections, and large year-to-year changes requiring explanation.

NASDDDS hosted a webinar for state IDD directors and designated data providers to launch the FY 2016 survey in January 2017. Most states submitted their surveys by September 2017. Preliminary state profiles were sent to states for review in December 2017. Requested changes were made and the final profiles were reviewed in February 2018. This report incorporates changes submitted by states through February 5, 2018. Corrections received after this date will be reflected in the online database and in subsequent reports.

Survey of Administrators of State-Operated Residential IDD Facilities (PRF Survey) Annual surveys of state-operated IDD facilities serving 16 or more people have been fielded since 1977 in cooperation with the Association of Professional Developmental Disabilities Administrators (APDDA) and its predecessors. The sample frame was based on the 1977 census of Public Residential Facilities (PRFs). A few state-operated IDD facilities not in the original sample frame are not surveyed. PRFs in the sample frame that were 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.

The PRF survey includes questions about characteristics such as age, gender, race, ethnicity and types of disabilities of people in residence on June 30, 2016, admissions, readmissions, discharges, and deaths during FY 2016, facility closures and planned closures, and average daily per person expenditures. Survey data were analyzed using Microsoft Excel and SPSS 21.0 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.

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 information provided on other questions on the survey. Rows or columns of tables are labeled as estimated totals when they contain imputed data.

Estimated Values are individual data elements whose value is estimated by the survey respondent. 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 annual IDD agency surveys. 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 will be flagged “Did Not Furnish” (DNF)

- “Partial Data” (PD) signifies instances when some, but not all, of the data elements required for a computation were furnished by the state.
- On the nursing home and psychiatric facility table, partial totals are reported. Additional codes specify whether data were missing for state-operated settings, nonstate-operated settings or both.

Not Applicable. N/A indicates a state did not use a particular program, setting, or funding source.

Other Sources. Appendix A lists other sources of data used in this report. Data from other sources is identified by the “s” footnote.

Other Date. The footnote “d” indicates that the state provided data from a date other than June 30, 2016. States with fiscal years ending on dates other than June 30 are indicated in the state notes section.

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

Setting Types. Setting type and setting size categories were designed to permit comprehensive annual data collection congruent with state administrative data sets. However, states have hundreds of different names for services, sometimes with subtle differences from similarly named programs in other states. When a state uses a definition that differs from the RISP operational definition, the variation is described in the state notes section of this report.

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 2016 RISP survey and operational definitions documents are available online on the RISP website at (risp.umn.edu) ■





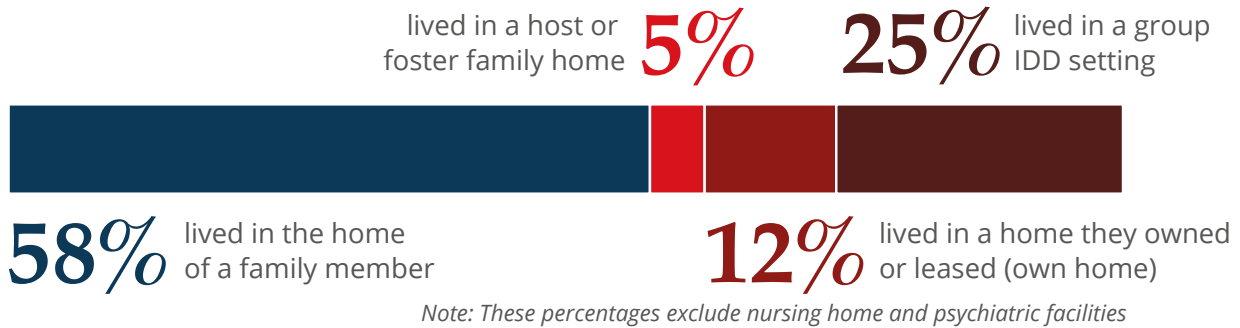
SECTION ONE

In-Home and Residential Supports

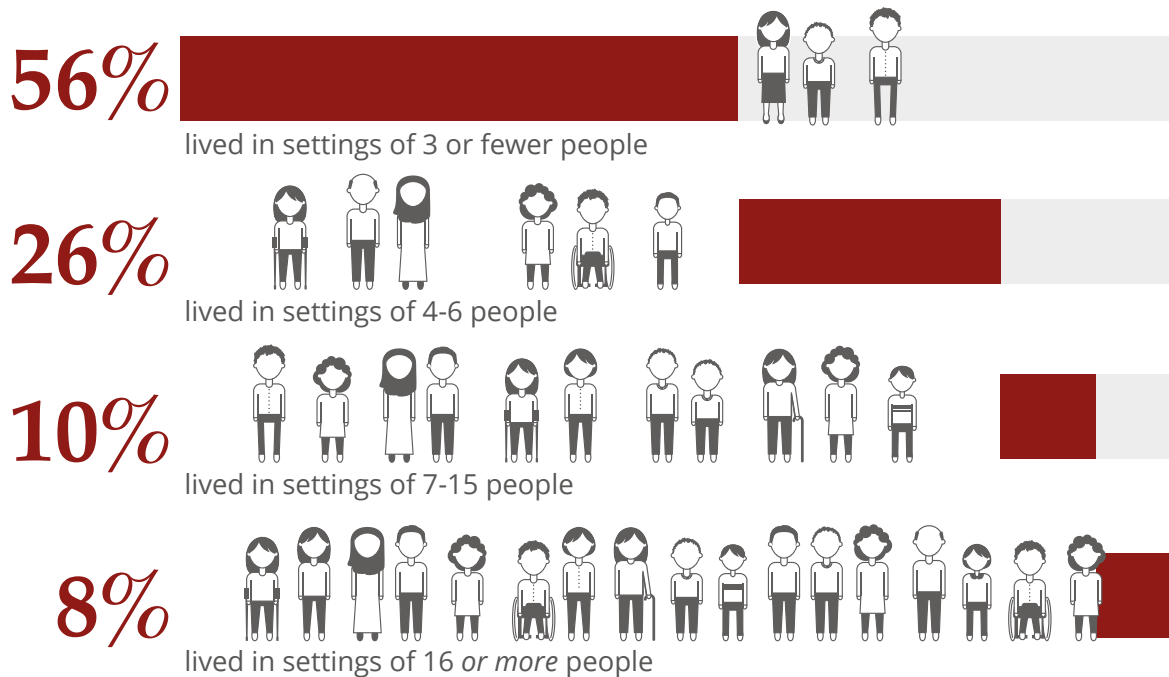
FY 2016

Where People Served by State IDD Agencies Lived on June 30, 2016

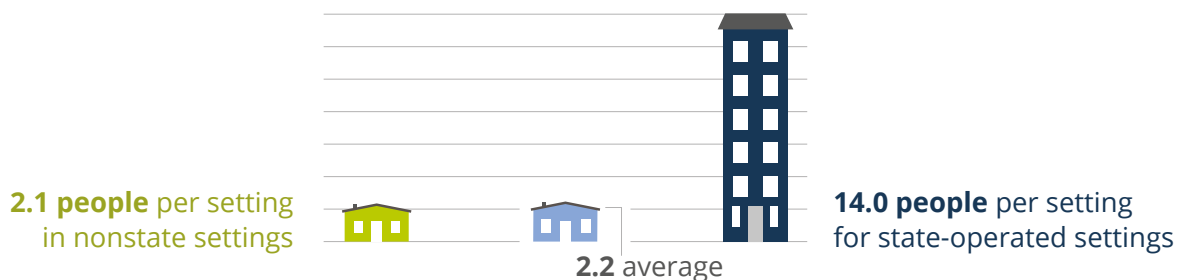
An estimated 1,228,700 people received long-term supports and services (LTSS) from state IDD agencies:



Of the estimated 513,790 LTSS recipients not living with a family member:



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



SECTION 1: IN-HOME AND RESIDENTIAL SUPPORTS

NUMBER OF PEOPLE WITH IDD IN THE UNITED STATES

Public health surveillance, administrative prevalence 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 reviewed educational and health records to estimate prevalence rates for Autism Spectrum Disorder (ASD) for 8-year-old children in 16 states and for 4-year-old children in six states in 2016 (CDC Fact Sheet, 2016; available from www.cdc.gov/addm). It estimated prevalence rates for intellectual disabilities for 8-year old children in nine states. The prevalence of ASD was 14.6 per 1,000 (1.46%) in ADDM sites in 2012 (Christianson, et al., 2016).

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, the U.S. Department of Education reports annually the number children and youth ages 3 to 21 years who receive special education services by disability category. In the 2015/2016 school year, 1.61 million students with intellectual disabilities (ID), autism spectrum disorder (ASD), developmental delay, or multiple disabilities were educated in U.S. schools. For every 1,000 students, 31.9 (3.19%) had intellectual or developmental disabilities (12.2 had ASD, 8.6 had ID, 8.4 had a developmental delay, and 2.6 had multiple disabilities; National Center for Educational Statistics, 2017). An estimated 6,150 of the 1.61 million students with ID, ASD or multiple disabilities ages 6 to 21 years (0.38% of students with IDD) received educational services while living in a residential school or correctional facility.

Administrative data sets are also maintained by other federal and state agencies such as the Social Security Administration, and state Child Welfare

agencies. 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 with IDD, 4,789 (27.1%) lived in a group home or institution as did 125,633 of the 655,536 children identified as not having ID (19.2%). The Centers for Medicare and Medicaid Services maintains data about people with intellectual or developmental disabilities living in nursing homes and other institutions but has not released yet comparable information about recipients living in home or community-based settings.

The RISP project uses administrative data from state developmental disabilities agencies to estimate the number of people with intellectual or developmental disabilities who receive publicly funded long-term supports and services 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. For example, the American Community Survey (ACS) asks if, because of a physical, mental, or emotional condition, a person has serious difficulty concentrating, remembering, or making decisions. While people with IDD would likely be among those reporting a cognitive limitation, in the ACS they are indistinguishable from the larger group of people who experience those difficulties due to dementia, mental illness, other disabilities or physical illness. Difficulty learning, one of the defining characteristics of intellectual disabilities, is assessed for children but not for adults in the ACS.

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 about three of the six types of disabilities measured in 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,

Table 1.1 United States Population and People with IDD by Age and State on June 30, 2016

State	US Population by age		People with IDD			
	0-17 years	18+ years	Not in Congregate Settings (NHIS) ¹		In congregate settings ²	Estimated Total
			0-17 years	18+ years		
AL	1,096,823	3,766,477	76,668	29,755	2,341	108,764
AK	187,327	554,567	13,094	4,381	222	17,697
AZ	1,631,492	5,299,579	114,041	41,867	1,642	157,550
AR	705,053	2,283,195	49,283	18,037	3,106	70,426
CA	9,092,863	30,157,154	635,591	238,242	22,226	896,058
CO	1,261,372	4,279,173	88,170	33,805	1,389	123,364
CT	753,294	2,823,158	52,655	22,303	3,785	78,743
DE	204,274	747,791	14,279	5,908	684	20,870
DC	120,893	560,277	8,450	4,426	438	13,315
FL	4,146,712	16,465,727	289,855	130,079	11,231	431,166
GA	2,511,544	7,798,827	175,557	61,611	2,853	240,021
HI	308,016	1,120,541	21,530	8,852	486	30,869
ID	437,173	1,245,967	30,558	9,843	887	41,288
IL	2,926,109	9,875,430	204,535	78,016	17,249	299,800
IN	1,575,452	5,057,601	110,124	39,955	5,813	155,892
IA	730,731	2,403,962	51,078	18,991	4,676	74,745
KS	714,951	2,192,338	49,975	17,319	1,761	69,056
KY	1,010,629	3,426,345	70,643	27,068	1,760	99,471
LA	1,113,949	3,567,717	77,865	28,185	10,209	116,259
ME	254,714	1,076,765	17,805	8,506	609	26,920
MD	1,348,728	4,667,719	94,276	36,875	2,844	133,995
MA	1,378,102	5,433,677	96,329	42,926	7,616	146,871
MI	2,191,057	7,737,243	153,155	61,124	12,821	227,100
MN	1,288,333	4,231,619	90,054	33,430	7,616	131,101
MS	721,288	2,267,438	50,418	17,913	3,123	71,454
MO	1,386,863	4,706,137	96,942	37,178	3,803	137,923
MT	227,611	814,909	15,910	6,438	1,089	23,437
NE	473,325	1,433,791	33,085	11,327	1,105	45,517
NV	677,427	2,262,631	47,352	17,875	927	66,154
NH	260,588	1,074,207	18,215	8,486	252	26,953
NJ	1,984,752	6,959,717	138,734	54,982	9,119	202,835
NM	490,663	1,590,352	34,297	12,564	1,303	48,164
NY	4,180,559	15,564,730	292,221	122,961	34,393	449,575
NC	2,298,720	7,848,068	160,681	62,000	7,978	230,659
ND	176,311	581,641	12,324	4,595	957	17,876
OH	2,612,172	9,002,201	182,591	71,117	10,680	264,389
OK	961,628	2,961,933	67,218	23,399	3,509	94,126
OR	868,727	3,224,738	60,724	25,475	4,640	90,839
PA	2,674,805	10,109,422	186,969	79,864	8,798	275,631
RI	208,381	848,045	14,566	6,700	1,096	22,361
SC	1,097,621	3,863,498	76,724	30,522	4,004	111,249
SD	213,287	652,167	14,909	5,152	1,406	21,467
TN	1,501,795	5,149,399	104,975	40,680	1,989	147,645
TX	7,294,587	20,568,009	509,892	162,487	16,325	688,704
UT	921,773	2,129,444	64,432	16,823	1,299	82,554
VT	118,528	506,066	8,285	3,998	111	12,394
VA	1,870,123	6,541,685	130,722	51,679	6,336	188,737
WA	1,629,498	5,658,502	113,902	44,702	1,771	160,375
WV	375,068	1,456,034	26,217	11,503	1,233	38,953
WI	1,287,693	4,491,015	90,010	35,479	3,817	129,305
WY	138,901	446,600	9,709	3,528	545	13,783
US Total	73,642,285	249,485,228	5,147,596	1,970,933	255,873	7,374,402

¹ U.S. Census Bureau, Population Division (2017). ² Estimated prevalence rates use most recent National Health Interview Survey (NHIS) data ages 0-17: 6.99% from the 2016 NHIS (Zablotsky et al, 2017) and 0.79% for people 18+ years from the 1994/1995 NHIS-D (Larson, et al., 2001). ³ Settings of 4 or more people, including nursing homes or psychiatric facilities. State estimates assume no state to state differences in prevalence of IDD.

2.9% of state and federal prisoners and 5.8% of jail inmates had three or more of the listed disabilities (Bronson et al., 2016). While people with IDD often have cognitive impairments, and many have self-care or independent living limitations, the National Inmate Survey is not specific enough to support estimates of the proportion of inmates or prisoners who have intellectual or developmental disabilities.

The National Health Interview Survey (NHIS) is set of annual nationally representative surveys of the civilian non-institutionalized U.S. population. In 1994 and 1995, the National Center on Health Statistics (NCHS) fielded a supplement to the annual NHIS survey that allowed researchers to identify sample members with an intellectual disability or closely related condition, or with developmental disabilities as defined by the Developmental Disabilities Act. The NHIS Disability Supplement (NHIS-D) included questions about functional limitations, the severity and age at onset of those limitations, expected duration of the limitations, and the condition causing the limitation. Researchers using the 1994/1995 NHIS-D estimated that the prevalence of intellectual disabilities, developmental disabilities or both 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).

In FY 2014 and FY 2015, we used the 1994/1995 NHIS-D prevalence rates with the U.S. Census reports of the U.S. population by state and age to estimate the total number of people with IDD in U.S. and in each state. Since the NHIS sample frame excludes people living in congregate settings, we added people with IDD in congregate settings of 4 or more people to the total. Including people in congregate settings, the number of people with IDD in the United States was estimated to be 4,705,856 in FY 2015 (up slightly from 4,680,606 people for FY 2014).

The current NHIS sample child survey asks whether a doctor or other health professional had ever diagnosed the child as having intellectual disabilities (ID), autism spectrum disorder (ASD), or other developmental delays (DD). Researchers used the 2016 NHIS child surveys to estimate that for every 1,000 children 3 to 17 years old, there were 11.4 children with ID, 27.6 with ASD, and 45.5 with a developmental delay (69.9 per 1,000 or 6.99% had one or more of these conditions; Zablotsky et al., 2017).

Number of People with IDD in the United States in 2016

The U.S. Census Bureau reported that there were 73.6 million children 17 years or younger and 249.5 million adults ages 18 years or older in the United States in 2016 (See **Table 1.1**). Applying the prevalence rate of 69.9 per 1,000 for children from the 2016 NHIS (Zablotsky, et. al., 2017) and 7.9 per 1,000 for adults from the 1994/1995 NHIS-D (Larson, et al., 2001) we estimate there were 5,147,596 children, and 1,970,933 adults with IDD in the 2016 U.S. civilian noninstitutionalized population. An additional 255,873 people with IDD of all ages lived in congregate settings of four or more people, nursing homes, or psychiatric facilities on June 30, 2016. In total, we estimate that there were 7,374,402 people with IDD in the U.S. in 2016 (22.8 per 1,000).

State IDD Agency Caseload

The state IDD agency caseload includes all people with IDD who receive publicly funded long-term supports and services (LTSS) through or under the auspices of the state IDD agency. The agency caseload also includes people with IDD who had requested and were waiting for services, or who were known to state IDD agencies, but not receiving publicly funded LTSS on June 30, 2016. 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.

On June 30, 2016, an estimated 1,488,732 people with IDD (20% of the people with IDD in the United States) were served by or known to their state IDD agency (See **Table 1.2**). The majority were ages 22 years or older (61%, 912,226 people). The proportion of adults with IDD varied widely by state. States in which adults comprised 90% or more of the IDD agency caseload included Rhode Island (100%), Arkansas (99%), Alabama (97%), the District of Columbia (97%), and Mississippi (93%). States that served more young people than adults on their caseload included California (49%), Washington (49%), Louisiana (49%), North Dakota (40%), and Arizona (35%).

Table 1.2 People Known to or Served by State IDD Agencies by Age on June 30, 2016

State	Number of People Served ¹			% of People Served	
	Birth-21	22+ years	All Ages	Birth-21	22+ years
N States	47	47	49	47	47
AL	224	8,680	8,904	3	97
AK	973	1,663	2,636	37	63
AZ	24,451	12,982	37,433	65	35
AR	94	9,369	9,463	1	99
CA	131,778	127,685	259,463	51	49
CO	7,628	11,939	19,567	39	61
CT	4,285	12,439	16,724	26	74
DE	DNF	DNF	4,657	DNF	DNF
DC	69	2,206	2,275	3	97
FL	16,249	41,068	57,317	28	72
GA	4,187 ^e	13,202 ^e	17,389 ^e	24	76
HI	605 ^d	2,717 ^d	3,322	18	82
ID	4,571	5,580	10,151	45	55
IL	7,521	34,050	41,571	18	82
IN	9,725	20,223	29,948	32	68
IA	3,761	10,796	14,557	26	74
KS	4,109	8,114	12,223	34	66
KY	6,369 ^e	8,399 ^e	14,768 ^e	43	57
LA	25,459	24,612	50,071	51	49
ME	841	5,700	6,541	13	87
MD	5,052	19,860	24,912	20	80
MA	11,779	24,712	36,491	32	68
MI	12,504 ^d	32,611 ^d	45,115 ^d	28	72
MN	10,536 ^d	20,950 ^d	31,486 ^d	33	67
MS	435	6,119	6,554	7	93
MO	14,907	19,895	34,802	43	57
MT	927	2,587	3,514	26	74
NE	1,571 ^e	6,408 ^e	7,979 ^e	20	80
NV	2,607	3,973	6,580	40	60
NH	1,275 ^d	3,960 ^d	5,235 ^d	24	76
NJ	DNF	DNF	26,523	DNF	DNF
NM	5,152 ^e	6,599	11,751	44	56
NY	44,113	91,315	135,428	33	67
NC	11,371 ^e	17,771 ^e	29,142 ^e	39	61
ND	4,294	2,910	7,204	60	40
OH	52,362	53,055	105,417	50	50
OK	5,404	8,875	14,279	38	62
OR	9,787	15,825	25,612	38	62
PA	14,614	42,903	57,517	25	75
RI	0	4,089	4,089	0	100
SC	17,299	18,684	35,983	48	52
SD	1,591	3,013	4,604	35	65
TN	8,857	16,302	25,159	35	65
TX	DNF	DNF	DNF	DNF	DNF
UT	2,812	4,857	7,669	37	63
VT	1,402	3,084	4,486	31	69
VA	12,004	13,616	25,620	47	53
WA	22,617	21,977	44,594	51	49
WV	DNF	DNF	DNF	DNF	DNF
WI	13,029 ^d	27,978 ^d	41,007 ^d	32	68
WY	725	1,497	2,222	33	67
Reported Total	541,925	856,849	1,429,954	38	60
Estimated Total	576,506	912,226	1,488,732	39	61

^d Other date (Usually a different fiscal year or June 30, 2015). ^e Estimate
 DNF Did not furnish (missing value). ^s Source U.S. Census Bureau, Population
 Division (2017). * 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.

State differences in the age distribution of people on the IDD agency caseload typically 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 service children, whether children are eligible for the services managed by the DD agency, and the menu of services offered.

Long-Term Supports and Services Recipients

Of the 1,488,732 people served by state IDD agencies on June 30, 2016, an estimated 83% (1,228,700 people) received publicly funded long-term supports or services (17% of the estimated total number of people with IDD in the U.S.; See **Table 1.3**). Long-term supports and services (LTSS) include many different types of supports. Those supports could be provided where the person lives, at school or at work, or in another community location. The RISP project tracks LTSS funded through a variety of Medicaid and State funding authorities whether those services are administered by the state, a local governmental agency or a managed care entity. We track the places LTSS recipients with IDD live regardless which publicly funded LTSS those recipients receive and regardless of where those services are delivered.

We gather information about the following types of living arrangements:

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 long-term supports or services. 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 supportive services 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

Table 1.3 LTSS Recipients with IDD Setting Type, Type of Operation, and State on June 30, 2016

	Nonstate-Operated IDD Settings						State-Operated IDD Settings			Estimated Total Recipients
	Family home	Own home	Host /Foster Family Home	Group not ICF/IID	ICF/IID	Other	Group Waiver	ICF/IID	Group Other	
N States	47	46	49	48	51	44	50	51	50	51
AL	2,131	55	111	3,283	22	0	0	0	0	5,602
AK	277	705	170	654 ^e	0	0	0	0	0	1,813
AZ	32,706	267	1,497	2,843	37	7	148	0	0	37,605
AR	1,973 ^{ed}	639	575	1,106 ^e	518	0	0	907	0	5,735
CA	172,850	25,569	5,335	20,624	6,955	0	0	963	0	232,389
CO	2,785	4,867	2,874	865	20	1,393	112	195	0	13,111
CT	1,477	1,274	410	3,788	361	0	308	429	0	8,047
DE	3,231	18	153	1,077	49	0	0	51	0	4,579
DC	848	11	83	969	323	14	0	0	0	2,248
FL	38,917	5,742	260 ^e	7,886	2,180	956	0	611	149	56,701
GA	3,274	1,145	1,203	2,825	0	23	0	0	240	8,994
HI	1,811	72	452	324	76	0	0	0	0	2,735
ID	1,554 ^d	1,206	559 ^d	213	431 ^s	DNF	0	26	0	4,020
IL	11,477	1,681	273	9,759	4,962	0	0	1,653	0	29,805
IN	14,175	6,180	234	629	3,249	0	0	0	0	24,467
IA	DNF	DNF	2	463	1,423	0	58	374	0	11,623 ^s
KS	DNF	DNF	DNF	DNF	136 ^s	DNF	0	314	2	10,287
KY	DNF	DNF	1,387	2,677	146	0	0	156	0	13,712 ^s
LA	13,526	2,413	DNF	DNF	4,324	0	0	536	0	29,921 ¹
ME	DNF	629 ^e	684 ^s	1,700 ^e	162	275 ^s	0	0	0	3,586
MD	1,728	2,677	213	6,066	0	11,353 [*]	0	96	26 ^d	22,159
MA *	8,294 [*]	2,593	1,058	8,579	0	0	1,078	409	51	22,062
MI	25,780 ^d	6,980 ^d	474 ^d	10,334 ^d	0	1,216 ^d	0	0	0	44,784
MN	11,232 ^d	2,294 ^d	664 ^d	9,191 ^d	1,462 ^d	6,152 ^d	350	74	0	31,474
MS	1,755	45	0	487	733 ^s	DNF	383	1,604	0	5,007
MO	10,922	4,558	414	2,140	82	0	228	360	0	18,704
MT	1,014 ^e	143 ^e	47	932 ^e	0	0	0	42	0	2,178
NE	1,928	1,220	741	1,402	266	0	0	126	0	5,684
NV	4,595	1,642	125	0	44	127	0	47	0	6,580
NH	1,047 ^d	470 ^d	1,106 ^d	388 ^d	25	0	0	0	6	3,042
NJ	14,466	87	662	8,209	414	307 ^e	0	1,467	12	25,624
NM	963 ^e	DNF	1,730 ^e	1,473 ^e	253 ^s	0	PD	4 ^s	PD	5,744 ^s
NY	86,722 ^e	11,233 ^e	1,820	23,670	4,940	DNF	6,638	462	0	135,638
NC *	7,674 ^e	DNF	1,591	4,070 ^e	2,666 ^{ed}	DNF	1	1,259	1	20,394 ^s
ND	1,252	1,276	18	298	464	0	0	75	0	3,383
OH	77,666	15,709	2,319	2,626	5,426	950 ^e	0	721	0	105,417
OK	1,895	2,451	325	844 ^e	1,307	DNF	0	0	0	6,822
OR	12,836 ^e	807 ^d	3,227	3,540	0	0	0	0	86	20,496
PA	32,654 ^e	4,645 ^e	1,589	11,691	2,037	3,935 ^e	0	904	0	57,505
RI	1,476	480	312	1,149	25 ^d	0	151	10 ^s	0	3,603
SC	14,457	690	172	2,995	497	DNF	0	666	0	19,479
SD	2,050	536	1	1,825	60	0	0	132	0	4,604
TN	7,329	4,173	435	674	725	0	0	222	9	13,558
TX	11,436 ^d	3,894 ^d	13,070 ^d	8,235 ^d	4,886 ^d	0 ^d	0 ^d	3,111 ^d	0 ^d	44,632
UT	1,681	1,261	367	1,651 ^e	595 ^s	0	0	191	0	5,746
VT	2,195	376	1,340	144	6	0	0	0	0	4,061
VA	3,871	230 ^e	3,734 ^s	4,491	518	0	0	363	0	13,209
WA	13,532 ^e	6,089	203	265 ^e	51	0	4	700 ^e	0	20,855
WV	2,077	2,461	214	DNF	509	14	0	0	0	6,004 ^s
WI	24,666 ^d	6,193 ^d	6,467 ^d	2,838 ^d	437 ^d	34 ^d	0	350 ^d	0	40,985
WY	1,092	428	58	636	0	6	0	67	0	2,287
Reported US Total	693,297	138,114	60,758	182,528	53,802	26,762	9,459	19,677	582	
Estimated US Total	714,910	146,974	63,750	191,599	54,937	26,762^a	9,514	19,677	577	1,228,700

^a Missing values (DNF) assumed to be zero. ^b Nonstate settings reported, but not state settings. ^c State settings reported, but not nonstate settings. ^d Other date (Usually a different fiscal year or June 30, 2015). ^{DNF} Did not furnish (missing data). ^e Estimate. ¹ One or more component value imputed by RISP staff. * See state notes in Appendix. This table does not include people with IDD living in nursing homes or psychiatric facilities.

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 nonstate settings: Residential settings other than own home, family home, host/foster family home, IDD group home or ICF/IID operated by a nonstate entity in which a person served by or under the auspices of the state IDD agency lives and receives LTSS. Examples of nonstate “other” settings include board care facilities, group facilities that do not exclusively serve people with IDD, provider-owned housing with supports, and assisted living facilities.

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.

We cluster the living arrangements of LTSS recipients with IDD into the following categories (also See **Table B**):

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

- LTSS Settings (IDD Group, Own Home, Host/Foster Family Home, and Family Home).

People with IDD may also live in a nursing home, or a psychiatric facility. We report on those setting types at the end of this Section.

LIVING ARRANGEMENT FOR LTSS RECIPIENTS

Residence Type

Of the 1.2 million LTSS recipients, an estimated

- 98% (1,198,923 people) received LTSS from a nonstate entity. Their living arrangements included:
 - 58% (714,910) in the home of a family member,
 - 16% (191,599) in an IDD group home,
 - 12% (146,974) in a home they owned or leased,
 - 5% (63,750) in a host/foster family home,
 - 4% (54,937) in a nonstate ICF/IID, and
 - 2% (26,762) in an “other” nonstate IDD setting.
- 2% (29,768 people) received LTSS in a setting operated by state employees. Of those people,
 - 0.8% (9,514) receive services funded through a Medicaid Waiver authority,
 - 1.6% (19,677) lived in a Medicaid-certified ICF/IID, and
 - 0.05% (577) received services funded by another funding authority.

The most common living arrangement for LTSS recipients with IDD varied by state. The setting type in which the largest number LTSS recipients with IDD lived was:

- Family home in 33 states (Arizona, Arkansas, California, Delaware, Florida, Georgia, Hawaii, Idaho, Illinois, Indiana, Louisiana, Michigan, Minnesota, Mississippi, Missouri, Montana,

Table B: Setting Clusters Used in this Report

Type of Setting	Type of Operation		Clusters		
	State	Nonstate	IDD Group	IDD Non-family	All IDD LTSS Settings
Own Home		X		X	X
Family Home		X			X
Host/Foster Family Home		X		X	X
Group Home (Except ICF/IID)	X	X	X	X	X
ICF/IID	X	X	X	X	X
Other	X	X	X	X	X

Nebraska, Nevada, New Jersey, New York, North Carolina, Ohio, Oregon, Pennsylvania, Rhode Island, South Carolina, South Dakota, Tennessee, Utah, Vermont, Washington, Wisconsin, and Wyoming),

- Nonstate group home (except ICF/IID) in 7 states (Alabama, Connecticut, the District of Columbia, Kentucky, Maine, Massachusetts, and Virginia),
- Own Home settings in 5 states (Alaska, Colorado, North Dakota, Oklahoma, and West Virginia),
- Host/family foster home in 3 states (New Hampshire, New Mexico, and Texas), and
- “Other” Nonstate IDD setting in one state (Maryland).

Iowa and Kansas did not provide enough information to identify the most common living arrangement for LTSS recipients with IDD in their states.

Residence Size

Figure 1.1 shows living arrangements for people with IDD served by or under the auspices of the state IDD agency. The proportion of LTSS recipients IDD who lived with a family member is shown in blue, the proportion of people in IDD settings of four or more people are shown in shades of green, and people in non-family settings shared by three or fewer LTSS are shown in shades of yellow and red. On June 30, 2016 of the 1,228,700 LTSS recipients with IDD:

- 58% lived in the home of a family member,
- 24% lived in a non-family setting of 3 or fewer people including
 - 12% in an “own home” setting,
 - 7% in an IDD group setting of 3 or fewer people, and
 - 5% in a host/foster family home.
- 18% lived in an IDD group setting of four or more people including:
 - 11% 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.

Figure 1.1 LTSS Recipients with IDD by Residence Type and Size on June 30, 2016

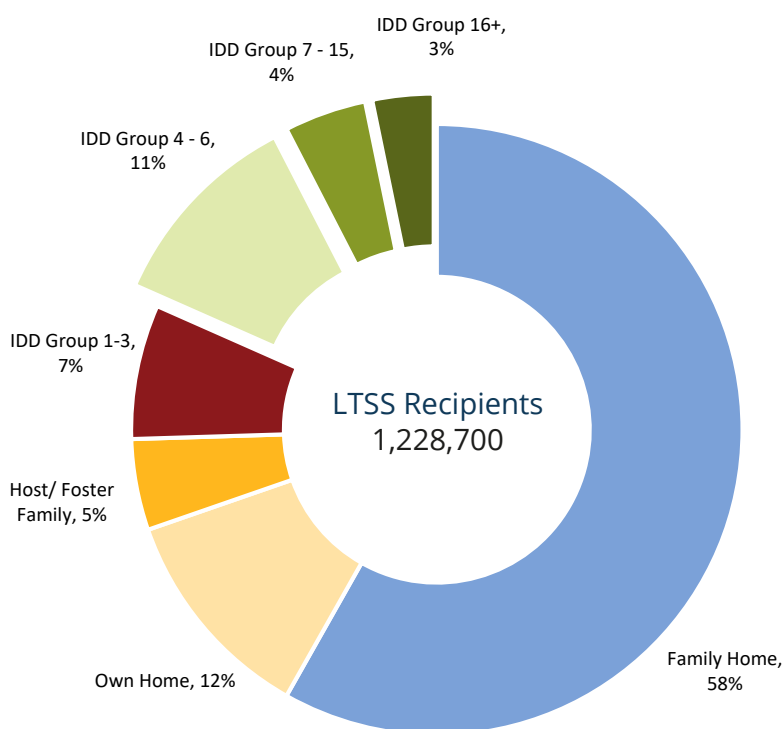
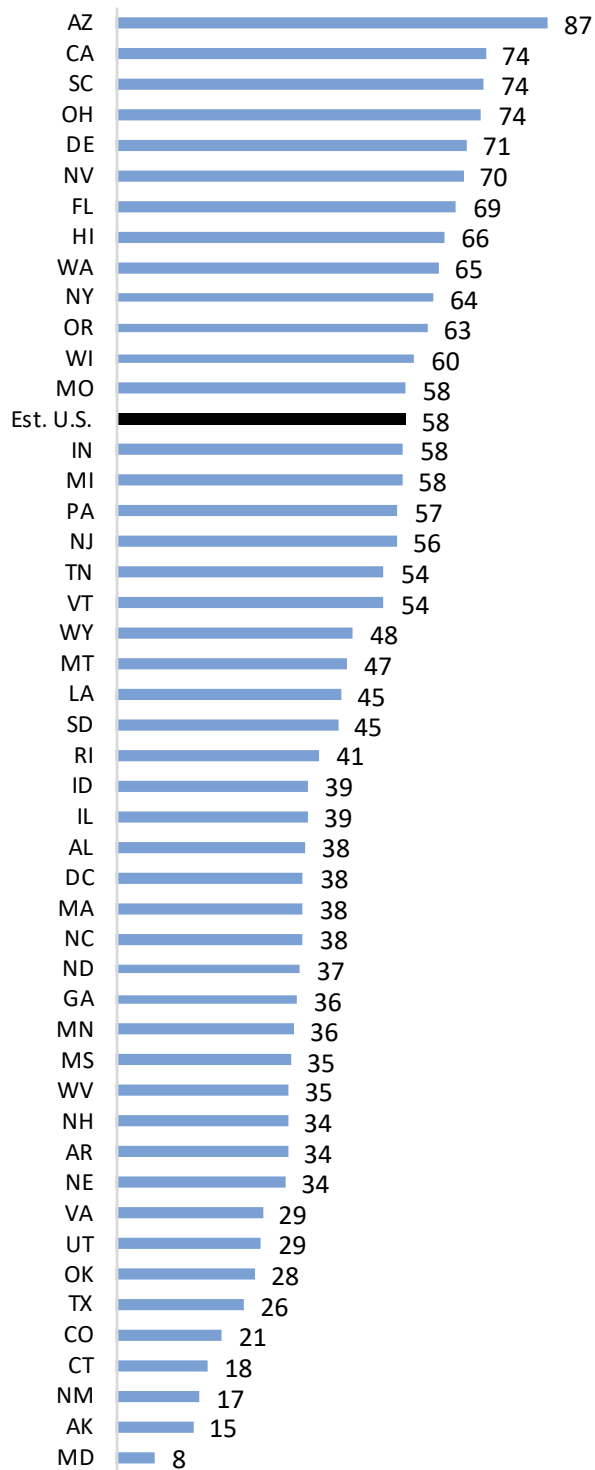


Table 1.4 LTSS Recipients with IDD Living with a Family Member by State on June 30, 2016

State	LTSS Recipients Served by State IDD Agencies		
	Estimated Total	Number Living with Family	% Living with Family
N States	51	47	47
AL	5,602	2,131	38
AK	1,813	277	15
AZ	37,605	32,706	87
AR	5,735	1,973 ^{ed}	34
CA	232,389	172,850	74
CO	13,111	2,785	21
CT	8,047	1,477	18
DE	4,579	3,231	71
DC	2,248	848	38
FL	56,701	38,917	69
GA	8,994	3,274	36
HI	2,735	1,811	66
ID	4,020 ⁱ	1,554 ^d	39
IL	29,805	11,477	39
IN	24,467	14,175	58
IA	11,623 ^j	DNF	DNF
KS	10,287 ^j	DNF	DNF
KY	13,712 ^j	DNF	DNF
LA	29,921 ⁱ	13,526	45
ME	3,586 ^j	DNF	DNF
MD	22,159	1,728	8
MA	22,062	8,294	38
MI	44,784	25,780 ^d	58
MN	31,474	11,232 ^d	36
MS	5,007 ^j	1,755	35
MO	18,704	10,922	58
MT	2,178	1,014 ^e	47
NE	5,684	1,928	34
NV	6,580	4,595	70
NH	3,042	1,047 ^d	34
NJ	25,624	14,466	56
NM	5,744 ⁱ	963 ^e	17
NY	135,638 ⁱ	86,722 ^e	64
NC	20,394 ⁱ	7,674 ^e	38
ND	3,383	1,252	37
OH	105,417	77,666	74
OK	6,822 ^j	1,895	28
OR	20,496	12,836 ^e	63
PA	57,505	32,654 ^e	57
RI	3,603	1,476	41
SC	19,479 ^j	14,457	74
SD	4,604	2,050	45
TN	13,558	7,329	54
TX	44,632	11,436 ^d	26
UT	5,746	1,681	29
VT	4,061	2,195	54
VA	13,209	3,871	29
WA	20,855	13,532 ^e	65
WV	6,004 ⁱ	2,077	35
WI	40,985	24,666 ^d	60
WY	2,287	1,092	48
Estimated US Total	1,228,700	714,910	58

^d Other date (Usually a different fiscal year or June 30, 2015). ^e Estimate. ^{DNF} Did not furnish. * See state notes in Appendix. ⁱ One or more component value imputed by RISP staff.

Figure 1.2 Percent of LTSS Recipients with IDD Living with a Family Member by State on June 30, 2016



Note: Family home data not available from IA, KS, KY and ME.

Home of a Family Member

On June 30, 2016, an estimated 714,910 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 8% in Maryland to 87% in Arizona (See **Figure 1.2**).

- States reporting the greatest proportion of LTSS recipients with IDD living with family members were Arizona (87%), California (74%), South Carolina (74%), Ohio (74%), Delaware (71%), and Nevada (70%).
- States reporting the smallest proportion of LTSS recipients with IDD living with family members were Colorado (21%), Connecticut (18%), New Mexico (17%), Alaska (15%), and Maryland (8%).

Differences in the proportion of LTSS recipients living with family members is related to whether or not the state IDD agency serves both children and adults, and to the proportion of LTSS recipients who are 21 years or younger. For example, in Arizona where 87% of LTSS recipients lived with a family member, 65% of all LTSS recipients were 21 years or younger. Conversely, in Maryland, where 8% of recipients lived with a family member, only 20% were 21 years or younger. Variations across states may also be related to the use of different eligibility criteria or different service menus.

Own Home

An estimated 29% of LTSS recipients with IDD (146,974 of 513,790 people) who did not live with a family member lived in a home they owned or leased (Own Home) on June 30, 2016 (See **Table 1.5**). Fewer than 2% of people in non-family settings lived in Own Home settings in Alabama (1.6%), Mississippi (1.4%), Delaware (1.3%), the District of Columbia (0.8%), and New Jersey (0.8%). More than two-thirds of LTSS recipients with IDD in non-family settings lived in Own Home settings in Nevada (83%), Washington (83%), and Tennessee (67%).

Overall 96% of people with IDD in Own Home settings lived with two or fewer other LTSS recipients, while 4% shared their home with 3 or more other LTSS recipients. In 28 states, all of the people in Own Home settings shared their home with two or fewer other LTSS recipients. Overall, 64% of people with IDD in Own Home

Table 1.5 LTSS Recipients with IDD in Own Home Settings by State and Setting Size on June 30, 2016

Setting Size	LTSS Recipients			People in Nonfamily Settings	
	1 to 3	4 to 6	Total	Estimated Total ¹	In Own Home (%)
N States	40	40	46	51	46
AL	55	0	55	3,471	2
AK	705	0	705	1,536	46
AZ	267	0	267	4,899	5
AR	613	26	639	3,762	17
CA	25,569	0	25,569	59,539	43
CO	DNF	DNF	4,867	10,326	47
CT	1,274	0	1,274	6,570	19
DE	18	0	18	1,348	1
DC	11	0	11	1,400	1
FL	5,742	0	5,742	17,784	32
GA	1,107	38	1,145	5,720	20
HI	72	0	72	924	8
ID	DNF	DNF	1,206	2,466	49
IL	603	1,078	1,681	18,328	9
IN	5,884	296	6,180	10,292	60
IA	DNF	DNF	DNF	4,098	DNF
KS	DNF	DNF	DNF	3,969	DNF
KY	DNF	DNF	DNF	6,078	DNF
LA	2,413	0	2,413	16,395	15
ME	629 ^e	0	629 ^e	3,450	18
MD	2,665	12	2,677	20,431	13
MA	DNF	DNF	2,593	13,768	19
MI *	226 ^d	81 ^d	6,980 ^d	19,004	37
MN	2,294 ^d	0 ^d	2,294 ^d	20,242	11
MS	39	6 ^e	45	3,252	1
MO	4,558	0	4,558	7,782	59
MT	143 ^e	0 ^e	143 ^e	1,164	12
NE	1,216	4	1,220	3,756	32
NV	1,045	597	1,642	1,985	83
NH	470 ^d	0 ^d	470 ^d	1,995	24
NJ	87	0	87	11,158	1
NM	DNF	DNF	DNF	4,781	DNF
NY	11,233 ^e	0	11,233 ^e	48,916	23
NC	DNF	DNF	DNF	12,720	DNF
ND	1,276	0	1,276	2,131	60
OH	14,919	790	15,709	27,751	57
OK	2,451	0	2,451	4,927	50
OR	807 ^d	0 ^d	807 ^d	7,660	11
PA	4,645 ^e	0 ^e	4,645 ^e	24,851	19
RI	480	0	480	2,127	23
SC	690	0	690	5,022	14
SD	536	0	536	2,554	21
TN	4,173	0	4,173	6,229	67
TX	DNF	DNF	3,894 ^d	33,196	12
UT	1,261	0	1,261	4,065	31
VT	376	0	376	1,866	20
VA	217 ^e	13 ^e	230 ^e	9,338	2
WA	5,969	120	6,089	7,323	83
WV	2,461	0	2,461	3,927	63
WI	DNF ^d	DNF ^d	6,193 ^d	16,319	38
WY	DNF	DNF	428	1,195	36
Reported US Total	109,199	3,061	138,114		
Estimated US Total	141,388	5,586	146,974	513,790	29%

^d Other date (Different fiscal year or June 30, 2015). ^e Estimate. ^{DNF} Did not furnish (missing value). * See state notes in Appendix. ¹ The total includes people in state and nonstate IDD group, own home, host/foster family home and other nonstate settings (estimates are used when states did not furnish complete information) but excludes people in family homes. People in nursing homes and psychiatric facilities are included only if the people are on the state IDD agency caseload.

Table 1.6 Host or Foster Family Homes and LTSS Recipients with IDD in Them by Setting Size and State on June 30, 2016

Setting Size	Host/Family Foster Settings by Size					People with IDD by Setting Size				
	1-3	4-6	1-6	7-15	Total	1-3	4-6	1-6	7-15	Total
N States	41	42	42	43	42	45	45	45	45	49
AL	57	0	57	1	58	104	0	104	7	111
AK	170	0	170	0	170	170	0	170	0	170
AZ	997	0	997	0	997	1,497	0	1,497	0	1,497
AR	575	0	575	0	575	575	0	575	0	575
CA	DNF	0	DNF	0	DNF	5,335	0	5,335	0	5,335
CO	1,437 ^e	0	1,437 ^e	0	1,437 ^e	2,874	0	2,874	0	2,874
CT	287	0	287	0	287	410	0	410	0	410
DE	117 ^d	0	117	0	117	153	0	153	0	153
DC	62	0	62	0	62	83	0	83	0	83
FL	50	39	89	7	96	52	141	193	67	260 ^e
GA	927	0	927	0	927	1,203	0	1,203	0	1,203
HI	275	3	278	0	278	440	12	452	0	452
ID	383 ^d	16 ^d	399 ^d	0 ^d	399 ^d	519 ^d	40 ^d	559	0 ^d	559 ^d
IL	235	0	235	0	235	273	0	273	0	273
IN	171	2	173	0	173	226	8	234	0	234
IA	2	0	2	0	2	2	0	2	0	2
KS	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
KY	816 ^e	0	816 ^e	0	816 ^e	1,387	0	1,387	0	1,387
LA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
ME	DNF	DNF	640 ^e	0	640 ^e	684 ^e	0	684 ^e	0	684 ^e
MD	200	0	200	0	200	213	0	213	0	213
MA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	1,058
MI	DNF	DNF	DNF	DNF	DNF	50 ^d	57 ^d	107	6 ^d	474 ^d
MN	593 ^d	5 ^d	598 ^d	0 ^d	598 ^d	644 ^d	20 ^d	664 ^d	0 ^d	664 ^d
MS	0	0	0	0	0	0	0	0	0	0
MO	388	0	388	0	388	414	0	414	0	414
MT	47	0	47	0	47	47	0	47	0	47
NE	651	0	651	0	651	741	0	741	0	741
NV	112	0	112	0	112	125	0	125	0	125
NH	853 ^d	1 ^d	854 ^d	1 ^d	855 ^d	1,093 ^d	6 ^d	1,099 ^d	7 ^d	1,106 ^d
NJ	309	0	309	0	309	662	0	662	0	662
NM	1,018 ^e	0 ^e	1,018 ^e	0	1,018 ^e	1,730 ^e	0	1,730 ^e	0	1,730 ^e
NY	895	143	1,038	0	1,038	1,364	456	1,820	0	1,820
NC	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	1,591
ND	18	0	18	0	18	18	0	18	0	18
OH	2,038	8	2,046	2	2,048	2,259	35	2,294	25	2,319
OK	325 ^e	0	325 ^e	0	325 ^e	325	0	325	0	325
OR	732	648	1,380	17	1,397	1,099	2,087	3,186	41	3,227
PA	1,239	0	1,239	0	1,239	1,589	0	1,589	0	1,589
RI	312	0	312	0	312	312	0	312	0	312
SC	135	0	135	0	135	172	0	172	0	172
SD	1	0	1	0	1	1	0	1	0	1
TN	333	0	333	0	333	435	0	435	0	435
TX	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	13,070 ^d
UT	321 ^e	0	321 ^e	0	321 ^e	367	0	367	0	367
VT	1,170	0	1,170	0	1,170	1,340	0	1,340	0	1,340
VA	DNF	DNF	DNF	DNF	DNF	3,704 ^e	29 ^e	3,733 ^e	1 ^e	3,734 ^e
WA	107	0	107	0	107	203	0	203	0	203
WV	166	0	166	0	166	214	0	214	0	214
WI	1,743 ^d	0 ^d	1,743 ^d	0 ^d	1,743 ^d	6,467 ^d	0 ^d	6,467 ^d	0 ^d	6,467 ^d
WY	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	58
Reported US Total	20,267	865	21,772	28	21,800	41,575	2,891	44,466	154	60,758
Estimated US Total	37,723	1,443	39,166	50	39,216	59,222	4,289	63,512	238	63,750

^d Other date (Different fiscal year or June 30, 2015). ^e Estimate. ^{DNF} Did not furnish. * See state notes in Appendix.

settings in Illinois shared their home with 3 or more other LTSS recipients as did 35% in Nevada and 13% in Mississippi.

Host/Family Foster Home

An estimated 12% of LTSS recipients with IDD (63,750 people) in non-family settings lived in a host or foster family home (See **Table 1.6**) on June 30, 2016. Of the 49 states reporting the number of people with IDD living in Host/Family Foster Homes, 45 reported the size of those settings and 42 reported the total number of those settings.

Of the LTSS recipients with IDD living in Host or Family Foster Homes

- 93% (59,222 people) lived in homes shared by 3 or fewer people with IDD,
- 6.7% (4,289 people) lived in homes of four to six people with IDD, and
- 0.4% (238 people) lived in homes of seven to fifteen people with IDD.

LTSS recipients with IDD lived in an estimated 39,2016 Host or Family Foster Homes on June 30, 2016. Of those settings, 96% were home to three or fewer LTSS recipients with IDD, 4% were home to four to six LTSS recipients, and less than 0.1% were home to more than six people with IDD. The average Host or Family Foster Home served 1.6 people with IDD. The average number of LTSS recipients with IDD per home was less than 1.5 people in 30 states but was 2.0 or more people in Colorado, Florida, New Jersey, Oregon, and Wisconsin.

Group LTSS Settings

IDD group settings include settings certified as Medicaid Intermediate Care Facilities for Individuals with Intellectual Disabilities, Medicaid Waiver-funded settings, and other group settings. It does not include Own Homes, Host or Family Foster Homes, Nursing Homes or Psychiatric Facilities. An estimated 59% of LTSS recipients with IDD (303,066 people) living somewhere other



Table 1.7 Group LTSS Settings and Recipients with IDD Living in Them by Setting Size and State on June 30, 2016

Size	Number of Group Settings ¹						Number of People with IDD in Group Settings					
	1-3	4-6	1-6	7-15	16+	All Sizes	1-3	4-6	1-6	7-15	16+	All Sizes
N States	42	41	45	44	44	46	42	40	43	42	43	48
AL	936	118	1,054	93	0	1,147	1,979	538	2,517	788	0	3,305
AK	193	192	385	19	10	414	450 ^e	150 ^e	600 ^e	54 ^e	0 ^e	654 ^a
AZ	653	290	943	4	2	949	1,543	1,336	2,879	33	123	3,035
AR	99	20	119	99	25	243	106 ^e	56 ^e	162 ^e	925 ^e	1,444 ^e	2,531 ^e
CA	PD	PD	5,334	131	59	5,524	PD	PD	25,079	1,099	2,364	28,542
CO	696 ^e	237 ^e	933 ^e	16	2	951 ^e	1,393	982	2,375	161	49	2,585
CT	567	552	1,119	32	6	1,157	1,445	2,770	4,215	242	429	4,886
DE	254 ^d	122 ^d	376 ^d	0	2	378	553	524	1,077	0	100	1,177
DC	500	90	590	1	0	591	878	427	1,305	1	0	1,306
FL	124 ^a	1,124 ^a	1,248 ^a	319 ^a	60 ^a	1,627 ^a	135 ^a	6,547 ^a	6,682 ^a	1,291 ^a	2,853 ^a	11,782 ^f
GA	964 ^e	259	1,223 ^e	1	2	1,226 ^e	1,769	1,068 ^e	2,837 ^e	11 ^e	240 ^e	3,088 ^e
HI	0 ^d	64 ^d	64 ^d	1 ^d	0	65	0	393 ^d	393 ^d	7 ^d	0	400
ID	0 ^a	23 ^a	23 ^a	71 ^a	46 ^a	140 ^a	0 ^a	PD	PD	PD	117 ^a	670 ^a
IL	168	860	1,028	843	48	1,919	374	4,093	4,467	7,543	4,364	16,374
IN	0	317	317	470	2	789	0	1,443	1,443	2,390	45	3,878
IA	11	95	106	80	23	209	33	442	475	753	1,090	2,318
KS	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD ^a
KY	829 ^e	32 ^e	861 ^e	3	4	868 ^e	2,485	192	2,677	24	278	2,979
LA	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD
ME	PD	PD	751 ^a	13 ^a	2 ^a	872 ^e	1,270 ^a	436 ^a	1,706 ^a	124 ^d	32 ^a	2,137 ^f
MD	12,617	496	13,113	30	5	13,148	14,988	2,122	17,110	234	197	17,541
MA	DNF	PD	PD	PD	PD	PD	DNF	PD	PD	PD	PD	10,117
MI *	PD	PD	PD	PD	PD	PD	334 ^d	2,317 ^d	2,651 ^d	387 ^d	209 ^d	11,550 ^f
MN	PD	PD	12,745 ^d	43 ^d	14 ^d	12,802 ^d	PD	PD	16,477 ^d	422 ^d	330 ^d	17,229 ^d
MS	381	PD	PD	PD	PD	643 ^{es}	471 ^e	PD ^e	PD	PD	PD ^e	3,207 ^a
MO	137	232	369	124	8	501	364	1,086	1,450	940	420	2,810
MT	2 ^e	90 ^e	92 ^e	90 ^e	1	183 ^e	5 ^e	627 ^e	632 ^e	300 ^e	42 ^e	974 ^e
NE	621	96	717	30	6	753	875	418	1,293	163	338	1,794
NV	0	5	5	0	69	74	0	26	26	0	192	218
NH	174 ^d	27 ^d	201 ^d	2 ^d	1	204 ^d	288 ^d	96 ^d	384 ^d	10 ^d	25 ^d	419 ^d
NJ	1,080 ^a	1,250 ^a	2,330 ^a	94 ^a	11 ^a	2,435 ^a	2,191	5,077 ^d	7,268 ^d	812 ^d	2,329	10,409 ^e
NM	PD	PD	511 ^e	0	0	511 ^e	PD	PD ^e	1,788 ^e	0	0 ^e	1,788 ^e
NY	1,979 ^a	2,493 ^a	4,472 ^a	2,071 ^a	52 ^a	6,595 ^a	3,507 ^a	12,351 ^a	15,858 ^a	18,463 ^a	1,389 ^a	35,710 ^a
NC	570 ^a	876 ^a	1,446 ^a	58 ^a	21 ^a	1,525 ^a	PD	PD	PD	PD	PD	7,997 ^a
ND	1	59	60	50	2	112	3	319	322	409	106	837
OH	205 ^a	490 ^a	695 ^a	303 ^a	88 ^a	1,086 ^a	372 ^a	2,330 ^a	2,702 ^a	2,546 ^a	3,525 ^a	9,723 ^f
OK	0 ^a	140 ^a	140 ^a	51 ^a	30 ^a	221 ^a	0 ^a	788 ^a	788 ^a	481 ^a	882 ^a	2,151 ^a
OR	454 ^d	497	951	28	19	998	1,275	2,130	3,405	174	47	3,626
PA	7,895 ^e	849 ^e	8,744 ^e	63 ^e	24 ^e	8,831 ^e	12,389	3,630	16,019	485	2,063	18,567 ^e
RI	109	184 ^d	293 ^d	24 ^d	1 ^d	318 ^d	245	877 ^{sd}	1,122 ^{sd}	188 ^d	25 ^d	1,335 ^{sd}
SC	162 ^a	552 ^a	714 ^a	104 ^a	5 ^a	823 ^{se}	421 ^a	2,216 ^a	2,637 ^a	855 ^a	666 ^a	4,158 ^a
SD	532	93	625	73	2	700	698	466	1,164	661	192	2,017
TN	95	147	242	81	2	325	235	614	849	641	131	1,621
TX	1,513 ^d	1,942 ^d	3,455 ^d	45 ^d	16 ^d	3,517 ^d	3,832 ^d	8,535 ^d	12,367 ^d	502 ^d	3,368 ^d	16,232 ^d
UT	728 ^e	85 ^e	813 ^e	PD	PD	836 ^{se}	1,172 ^e	429 ^e	1,601 ^e	PD	PD	2,437 ^{se}
VT	47	17	64	0	0	64	66	84	150	0	0	150
VA	250 ^e	522 ^a	772 ^a	75 ^a	8	855 ^e	748	3,100	3,848	990	534	5,372
WA	2	52	54	2	4 ^e	60 ^e	5	289 ^e	294 ^e	27	700	1,021 ^e
WV	44	26	70	54 ^d	1 ^d	125	PD	PD ^d	PD ^d	PD ^d	PD ^d	PD
WI	0 ^a	579 ^a	579 ^a	2 ^a	22 ^a	603 ^d	0 ^a	2,838 ^a	2,838 ^a	13 ^a	774 ^a	3,659 ^d
WY	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	709
Reported US Total	35,592	16,194	70,746	5,693	705	77,917	65,680	84,817	178,603	48,113	36,650	292,860
Estimated US Total	52,382	25,869	78,251	6,582	755	85,587	87,403	122,792	210,195	53,166	39,705	303,066

^a Missing values in Nonstate other settings assumed to be zero. ^d Other date (Usually a different fiscal year or June 30, 2015). ^e Estimate. ^f Total is larger than component parts due to unknown setting size. ^{DNF} Did not furnish all component elements. ¹ One or more component value imputed by RISP staff. ^{PD} Partial data, calculation incomplete and not included in reported totals. * See state notes in Appendix. ¹ This table includes state and nonstate 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 or psychiatric facilities.

than the home of a family member lived in an IDD group setting (See **Table 1.7**).

Number of Settings

There were an estimated 85,587 IDD group settings on June 30, 2016. Of those,

- 61% (52,382 settings) served three or fewer people
- 30% (25,869 settings) served four to six people,
- 8% (6,582 settings) served 7 to 15 people, and
- 1% (755 settings) served 16 or more people.

While 91% of IDD group settings housed six or fewer LTSS recipients, the proportion varied by state ranging from less than 50% in Arkansas, Indiana, Idaho, and Nevada to more than 95% in 21 states.

Number of People

An estimated 25% of LTSS recipients with IDD (303,066 people) lived in IDD group settings on June 30, 2016. Of those,

- 29% (87,403 people) lived in settings of three or fewer people,
- 41% (122,792 people) lived in settings of 4 to 6 people,
- 18% (53,166 people) lived in settings of 7 to 15 people, and
- 13% (39,705 people) lived in facilities with 16 or more residents.

More than 95% of all people in IDD group settings lived in settings of six or fewer people in New Mexico (100%), Vermont (100%), the District of Columbia (100%), Hawaii (98%), Maryland (98%), and Minnesota (96%). Fewer than 25% of people in IDD group settings lived in settings of six or fewer people in Michigan (23%), Iowa (20%), Nevada (12%), and Arkansas (6%).

LTSS Settings

Tables 1.8 through **1.10** report the number of LTSS recipients sharing a home (setting size) and type of operation (State-Operated or Nonstate-Operated) for settings other than the home of a family member in which LTSS recipients with IDD lived on June 30, 2016. They combine Own Home, Host or Foster Family Home, and Group Settings serving Medicaid Waiver recipients, ICF/IID settings, and group

settings funded by another source. Those tables do not include people living with a family member, in a nursing home or in a psychiatric facility, unless the people living in a nursing home or psychiatric facility receive services from the state IDD agency.

For FY 2016, 51 states reported the number of state-operated residences and 30 states reported the number nonstate-operated residences. The number of states providing complete information about the size of nonstate-operated settings varied by setting size. Complete size information was furnished by 28 states for settings of 1 to 3 or 4 to 6 people, 41 states for settings of 7 to 15 people, and 44 states for settings of 16 or more people. "Partial data" (PD) indicates that complete size information was reported for some but not all setting sizes and types.

Number of Settings

On June 30, 2016, LTSS recipients with IDD lived in an estimated 229,076 non-family IDD settings (See **Table 1.8**). Of those,

- 1% (2,130 settings) were state-operated,
- 99% (226,946 settings) were nonstate-operated.

Of the estimated 2,130 state-operated IDD settings,

- 21% (439 settings) in 12 states served 1 to 3 people,
- 40% (845 settings) in 18 states served 4 to 6 people,
- 33% (706 settings) in 11 states served 7 to 15 people, and
- 7% (140 settings) in 36 states served 16 or more people.

There were no state-operated IDD facilities in Alabama, Alaska, the District of Columbia, Hawaii, Indiana, Michigan, and Vermont.

Of the estimated 226,946 nonstate-operated IDD settings,

- 85% (192,364 settings) served 1 to 3 people,
- 12% (28,041 settings) served 4 to 6 people,
- 2.6% (5,926 settings) served 7 to 15 people, and
- 0.3% (615 settings) served 16 or more people.

Overall, of the 229,076 non-family settings, an estimated

Table 1.8 Living Arrangements for LTSS recipients not Living with a Family Member by Type of Operation and Setting Size on June 30, 2016

Size	Nonstate-Operated Settings ¹						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	28	28	30	41	44	30	49	49	50	51	51	28	28	28	30	41	44	30
AL	1,048	118	1,166	94	0	1,260	0	0	0	0	0	1,048	118	1,166	94	0	1,260	
AK	716	192	908	19	10	937	0	0	0	0	0	716	192	908	19	10	937	
AZ	1,814	287	2,101	0	1	2,102	6	3	9	4	14	1,820	290	2,110	4	2	2,116	
AR	1,287	26	1,313	99	20	1,432	0	0	0	0	5	1,287	26	1,313	99	25	1,437	
CA	DNF	PD	PD	131	55	PD	0	0	0	0	4	PD	PD	PD	131	59	PD	
CO	PD	PD	PD	0	0	PD	0	17	17	16	2	35	PD	PD	PD	16	2	PD
CT	2,087	512	2,599	24	0	2,623	12	40	52	8	6	66	2,099	552	2,651	32	6	2,689
DE	389	122	511	0	1	512	0	0	0	0	1	1	389	122	511	0	2	513
DC	573	90	663	1	0	664	0	0	0	0	0	0	573	90	663	1	0	664
FL	PD	PD	PD	326	57	PD	0	0	0	0	3	3	PD	PD	PD	326	60	PD
GA	2,839	268	3,107	1	0	3,108	0	0	0	0	2	2	2,839	268	3,107	1	2	3,110
HI	347	67	414	1	0	415	0	0	0	0	0	0	347	67	414	1	0	415
ID	PD	PD	PD	71	45	PD	0	1	1	0	1	2	PD	PD	PD	71	46	PD
IL	852	1,080	1,932	843	41	2,816	0	0	0	0	7	7	852	1,080	1,932	843	48	2,823
IN	3,567	393	3,960	470	2	4,432	0	0	0	0	0	0	3,567	393	3,960	470	2	4,432
IA	PD	PD	PD	80	21	PD	10	7	17	0	2	19	PD	PD	PD	80	23	PD
KS	DNF	DNF	DNF	DNF	DNF	PD	0	0	0	0	2	2	PD	PD	PD	PD	PD	PD
KY	PD	PD	PD	0	2	PD	0	0	0	3	2	5	PD	PD	PD	3	4	PD
LA	DNF	PD	PD	PD	PD	PD	0	1	1	3	2	6	PD	PD	PD	PD	PD	PD
ME	PD	PD	1,459	13	2	1,580	4	0	4	0	0	4	PD	PD	1,463	13	2	1,584
MD	15,308	499	15,807	30	2	15,839	0	0	0	0	3	3	15,308	499	15,807	30	5	15,842
MA	DNF	PD	PD	PD	PD	PD	DNF	DNF	DNF	DNF	2	262	DNF	PD	PD	PD	PD	PD
MI	DNF	PD	PD	PD	PD	PD	0	0	0	0	0	0	PD	PD	PD	PD	PD	PD
MN	PD	PD	15,483	43	14	15,540	14	102	116	0	0	116	PD	PD	15,599	43	14	15,656
MS	PD	PD	PD	PD	PD	PD	183	28	211	61	6	278	PD	PD	PD	PD	PD	PD
MO	2,273	224	2,497	124	2	2,623	75	8	83	0	6	89	2,348	232	2,580	124	8	2,712
MT	PD	PD	PD	90	0	PD	0	0	0	0	1	1	PD	PD	PD	90	1	PD
NE	2,377	97	2,474	29	2	2,505	0	0	0	1	4	5	2,377	97	2,474	30	6	2,510
NV	890	151	1,041	0	68	1,109	0	0	0	0	1	1	890	151	1,041	0	69	1,110
NH	1,497	27	1,524	3	1	1,528	0	1	1	0	0	1	1,497	28	1,525	3	1	1,529
NJ	1,476	1,250	2,726	94	6	2,826	0	0	0	0	5	5	1,476	1,250	2,726	94	11	2,831
NM	PD	PD	PD	0	0	PD	DNF	DNF	25	0	0	25	PD	PD	PD	0	0	PD
NY	PD	PD	PD	1,557	32	PD	66	423	489	514	20	1,023	PD	PD	PD	2,071	52	PD
NC	PD	PD	PD	PD	17	PD	0	2	2	0	4	6	PD	PD	PD	PD	21	PD
ND	1,295	59	1,354	50	1	1,405	0	0	0	0	1	1	1,295	59	1,354	50	2	1,406
OH	14,828	694	15,522	305	78	15,905	0	0	0	0	10	10	14,828	694	15,522	305	88	15,915
OK	PD	PD	PD	51	30	PD	0	0	0	0	0	0	PD	PD	PD	51	30	PD
OR	PD	PD	PD	45	19	PD	0	22	22	0	0	22	PD	PD	PD	45	19	PD
PA	13,779	849	14,628	63	19	14,710	0	0	0	0	5	5	13,779	849	14,628	63	24	14,715
RI	900	160	1,060	21	1	1,082	1	24	25	3	0	28	901	184	1,085	24	1	1,110
SC	386	552	938	104	0	1,042	0	0	0	0	5	5	386	552	938	104	5	1,047
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	2,558	110	2,668	80	1	2,749	0	37	37	1	1	39	2,558	147	2,705	81	2	2,788
TX	PD	PD	PD	PD	3	PD	0	2	2	0	13	15	PD	PD	PD	PD	16	PD
UT	2,198	85	2,283	PD	PD	2,305	0	0	0	0	1	1	2,198	85	2,283	PD	PD	2,306
VT	1,577	17	1,594	0	0	1,594	0	0	0	0	0	0	1,577	17	1,594	0	0	1,594
VA	PD	PD	PD	PD	5	PD	0	0	0	0	3	3	PD	PD	PD	PD	8	PD
WA	3,446	75	3,521	2	0	3,523	2	0	2	0	4	6	3,448	75	3,523	2	4	3,529
WV	1,454	26	1,480	54	1	1,535	0	0	0	0	0	0	1,454	26	1,480	54	1	1,535
WI	PD	PD	PD	2	19	PD	0	0	0	0	3	3	PD	PD	PD	2	22	PD
WY	DNF	PD	PD	PD	PD	PD	0	0	0	0	1	1	PD	PD	PD	PD	PD	PD
Reported US Total	82,830	8,123	107,895	4,993	579	110,937	373	718	1,116	614	140	2,130	82,926	8,236	108,224	5,543	705	111,352
Estimated US Total	192,364	28,041	220,405	5,926	615	226,946	439	845	1,284	706	140	2,130	192,803	28,886	221,689	6,632	755	229,076

DNF Did not furnish. PD Partial data, calculation incomplete and not included in reported totals. ¹ This table includes group homes or facilities, ICF/IIDs, host homes and family foster homes, own home, and "other" settings. It excludes family homes. Nursing homes and psychiatric settings are only included when reported in state or nonstate other. Nonstate other settings are assumed to be zero when not reported.

- 84% (192,803 settings) served 1 to 3 people,
- 13% (28,886 settings) served 4 to 6 people,
- 3% (6,632 settings) served 7 to 15 people, and
- 0.3% (755 settings) served 16 or more people.

People by Setting Size

An estimated 513,790 people lived in non-family IDD settings on June 30, 2016 (See **Table 1.9**). Of those,

- 56% (288,013 people) lived in settings of 3 or fewer people,
- 26% (132,667 people) lived in settings of 4 to 6 people,
- 10% (53,404 people) lived in settings of 7 to 15 people, and
- 8% (39,705 people) lived in settings of 16 or more people.

Alabama, Alaska, the District of Columbia, Hawaii, and Vermont reported no people with IDD living in settings of 16 or more people. States reporting the highest proportion of people in settings of 16 or more people were Arkansas (39%, 1,444 people), Florida (16%, 2,853 people), Illinois (24%, 4,364 people), New Jersey (21%, 2,329 people), and Oklahoma (18%, 882 people). States with more than 3,000 people in settings of 16 or more people included Illinois (4,364). Ohio (3,525 people) and Texas (3,368 people).

People by Type of Operation

Of the 513,790 people in non-family settings, 6% (29,768 people) lived in state-operated settings, and 94% (484,022 people) lived in nonstate settings.

The proportion living in nonstate settings varied by state. In nine states, all LTSS recipients with IDD who did not live with a family member were served by nonstate entities (Alabama, Alaska, the District of Columbia, Hawaii, Indiana, Maine, Michigan, Vermont, and Oklahoma). Only Mississippi (39% of the people), reported that less than 50% of people in non-family settings receiving services through a nonstate entity.

Of the 484,022 people in nonstate non-family settings, an estimated

- 59% (287,186 people) lived with three or fewer people,
- 27% (128,915 people) lived with 4 to 6 people,

- 10% (47,297 people) lived with 7 to 15 people, and
- 4% (20,624 people) lived with 16 or more people.

Of the 29,768 people in state-operated non-family settings, an estimated

- 3% (828 people) lived in settings of 3 or fewer people,
- 13% (3,752 people) lived in settings of 4 to 6 people,
- 21% (6,107 people) lived in settings of 7 to 15 people, and
- 64% (19,081 people) lived in settings of 16 or more people with IDD.

The proportion of people living in nonstate settings varied by setting size. Of the 288,013 people in settings of three or fewer people, 99.7% lived in nonstate settings. Of the 132,667 people in settings of 4 to 6 people, 97% lived in nonstate settings. Of the 53,404 people in settings of 7 to 15 people, 89% lived in nonstate settings. Of the 39,705 people in IDD settings of 16 or more people, 52% lived in nonstate settings.

Average Number of LTSS Recipients per Setting

An estimated 513,790 people with IDD lived in 229,076 non-family settings on June 30, 2016 (an average of 2.2 people per setting; See **Table 1.10** and **Figure 1.3**). The average number of LTSS recipients per setting ranged from 1.2 in Vermont to 6.5 in Illinois. Other states averaging less than 1.5 people per setting included Maryland (1.3 people per setting), Minnesota (1.3), and New Hampshire (1.3). Other states averaging more than 3.5 people per setting included Mississippi (4.8), South Carolina (4.8), New Jersey (3.9), Louisiana (3.9), and Montana (3.5).

The average number of people per non-family setting varied by setting type. The number of LTSS recipients per home averaged 1.4 for own home settings and 1.6 for host/foster family homes. Nonstate-operated group homes averaged 3.4 LTSS recipients per home for non-ICF/IID settings, and 9.2 LTSS recipients per home for ICF/IID certified settings. State-operated group homes varied in size by funding source. State-operated Medicaid Waiver-funded homes averaged 5.2 people, other-funded homes averaged 18.9 people, and ICF/IID settings averaged 68.8 people per setting.

Table 1.9 People with IDD in LTSS Settings by Type of Operation, Setting Size, and State on June 30, 2016

Size	People in Nonstate-Operated Settings						People in State-Operated Settings						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	36	35	38	41	43	44	49	49	50	50	51	51	36	35	38	41	43	44
AL	2,138	538	2,676	795	0	3,471	0	0	0	0	0	0	2,138	538	2,676	795	0	3,471
AK	1,325	150	1,475	54	0	1,529	0	0	0	0	0	0	1,325	150	1,475	54	0	1,529
AZ	3,291	1,323	4,614	0	37	4,651	16	13	29	33	86	148	3,307	1,336	4,643	33	123	4,799
AR	1,294	82	1,376	925	537	2,838	0	0	0	0	907	907	1,294	82	1,376	925	1,444	3,745
CA	PD	PD	55,983	1,099	1,401	58,483	0	0	0	0	963	963	PD	PD	55,983	1,099	2,364	59,446
CO	PD	PD	10,019	0	0	10,019	0	97	97	161	49	307	PD	PD	10,116	161	49	10,326
CT	3,098	2,554	5,652	181	0	5,833	31	216	247	61	429	737	3,129	2,770	5,899	242	429	6,570
DE	724	524	1,248	0	49	1,297	0	0	0	0	51	51	724	524	1,248	0	100	1,348
DC	972	427	1,399	1	0	1,400	0	0	0	0	0	0	972	427	1,399	1	0	1,400
FL	5,929	6,688	12,617	1,358	2,093	17,024 ^f	0	0	0	0	760	760	5,929	6,688	12,617	1,358	2,853	17,784
GA	4,079	1,106	5,185	11	0	5,196	0	0	0	0	240	240	4,079	1,106	5,185	11	240	5,436
HI	512	405	917	7	0	924	0	0	0	0	0	0	512	405	917	7	0	924
ID	PD	PD	PD	PD	92	2,409	0	1	1	0	25	26	PD	PD	PD	PD	117	2,435
IL	1,250	5,171	6,421	7,543	2,711	16,675	0	0	0	0	1,653	1,653	1,250	5,171	6,421	7,543	4,364	18,328
IN	6,110	1,747	7,857	2,390	45	10,292	0	0	0	0	0	0	6,110	1,747	7,857	2,390	45	10,292
IA	PD	PD	PD	753	716	PD	30	28	58	0	374	432	PD	PD	PD	753	1,090	PD
KS	DNF	DNF	DNF	DNF	DNF	PD	0	0	0	0	316	316	PD	PD	PD	PD	PD	PD
KY	PD	PD	PD	0	146	PD	0	0	0	24	132	156	PD	PD	PD	24	278	PD
LA	PD	PD	PD	PD	PD	PD	0	5	5	37	494	536	PD	PD	PD	PD	PD	PD
ME	2,583	436	3,019	124	32	3,450 ^f	0	0	0	0	0	0	2,583	436	3,019	124	32	3,450
MD	17,866	2,134	20,000	234	75	20,309	0	0	0	0	122	122	17,866	2,134	20,000	234	197	20,431
MA	DNF	PD	PD	PD	PD	12,230	DNF	DNF	DNF	DNF	409	1,538	DNF	PD	PD	PD	PD	13,768
MI	610	2,455	9,738	393	209	19,004 ^f	0	0	0	0	0	0	610	2,455	9,738	393	209	19,004
MN	PD	PD	19,011	422	330	19,763	28	396	424	0	0	424	PD	PD	19,435	422	330	20,187
MS	253	PD	PD	PD	PD	1,265	257	146	403	579	1,005	1,987	510	PD	PD	PD	PD	3,252
MO	5,140	1,054	6,194	940	60	7,194	196	32	228	0	360	588	5,336	1,086	6,422	940	420	7,782
MT	195	627	822	300	0	1,122	0	0	0	0	42	42	195	627	822	300	42	1,164
NE	2,832	422	3,254	152	223	3,629	0	0	0	11	115	126	2,832	422	3,254	163	338	3,755
NV	1,170	623	1,793	0	145	1,938	0	0	0	0	47	47	1,170	623	1,793	0	192	1,985
NH	1,851	96	1,947	17	25	1,989	0	6	6	0	0	6	1,851	102	1,953	17	25	1,995
NJ	2,940	5,077	8,017	812	850	9,679	0	0	0	0	1,479	1,479	2,940	5,077	8,017	812	2,329	11,158
NM	PD	PD	PD	0	0	PD	DNF	DNF	62	0	0	62	PD	PD	PD	0	0	PD
NY	15,941	10,817	26,758	13,952	953	41,663	163	1,990	2,153	4,511	436	7,100	16,104	12,807	28,911	18,463	1,389	48,763
NC	DNF	DNF	DNF	DNF	DNF	PD	0	6	6	0	1,255	1,261	PD	PD	PD	PD	PD	PD
ND	1,297	319	1,616	409	31	2,056	0	0	0	0	75	75	1,297	319	1,616	409	106	2,131
OH	17,550	3,155	20,705	2,571	2,804	27,030 ^f	0	0	0	0	721	721	17,550	3,155	20,705	2,571	3,525	27,751
OK	2,776	788	3,564	481	882	4,927	0	0	0	0	0	0	2,776	788	3,564	481	882	4,927
OR	3,181	4,131	7,312	215	47	7,574	0	86	86	0	0	86	3,181	4,217	7,398	215	47	7,660
PA	18,623	3,630	22,253	485	1,159	23,897	0	0	0	0	904	904	18,623	3,630	22,253	485	2,063	24,801
RI	1,034	749	1,783	158	25	1,966	3	128	131	30	0	161	1,037	877	1,914	188	25	2,127
SC	1,283	2,216	3,499	855	0	4,354	0	0	0	0	666	666	1,283	2,216	3,499	855	666	5,020
SD	1,235	466	1,701	661	60	2,422	0	0	0	0	132	132	1,235	466	1,701	661	192	2,554
TN	4,843	467	5,310	626	71	6,007	0	147	147	15	60	222	4,843	614	5,457	641	131	6,229
TX	PD	PD	PD	PD	265	30,085	0	8	8	0	3,103	3,111	PD	PD	PD	PD	3,368	33,196
UT	2,800	429	3,229	PD	PD	3,874	0	0	0	0	191	191	2,800	429	3,229	PD	PD	4,065
VT	1,782	84	1,866	0	0	1,866	0	0	0	0	0	0	1,782	84	1,866	0	0	1,866
VA	4,669	3,142	7,811	991	171	8,973	0	0	0	0	363	363	4,669	3,142	7,811	991	534	9,336
WA	6,172	409	6,581	27	0	6,608	5	0	5	0	700	705	6,177	409	6,586	27	700	7,313
WV	PD	PD	PD	PD	PD	PD	0	0	0	0	0	0	PD	PD	PD	PD	PD	PD
WI	PD	PD	PD	13	424	15,969	0	0	0	0	350	350	PD	PD	PD	13	774	16,319
WY	DNF	PD	PD	PD	PD	1,128	0	0	0	0	67	67	PD	PD	PD	PD	PD	1,195
Reported US Total	149,348	64,441	305,222	39,955	16,668	434,012	729	3,305	4,096	5,462	19,081	29,768	150,019	67,059	308,775	44,801	32,012	461,017
Estimated US Total	287,186	128,915	416,101	47,297	20,624	484,022	828	3,752	4,580	6,107	19,081	29,768	288,013	132,667	420,681	53,404	39,705	513,790

DNF Did not furnish. PD Partial data, calculation incomplete and not included in reported totals. * See state notes in Appendix. ¹ This table includes group homes or facilities, ICF/IIDs, host homes and family foster homes, own home, and "other" settings. It excludes family homes. People in nursing homes and psychiatric settings are included only if they are on the state IDD agency caseload. The number of Nonstate "other" settings is assumed to be 0 unless otherwise specified by the state. ^f The total does not include people reported to be living in settings of an unknown size.

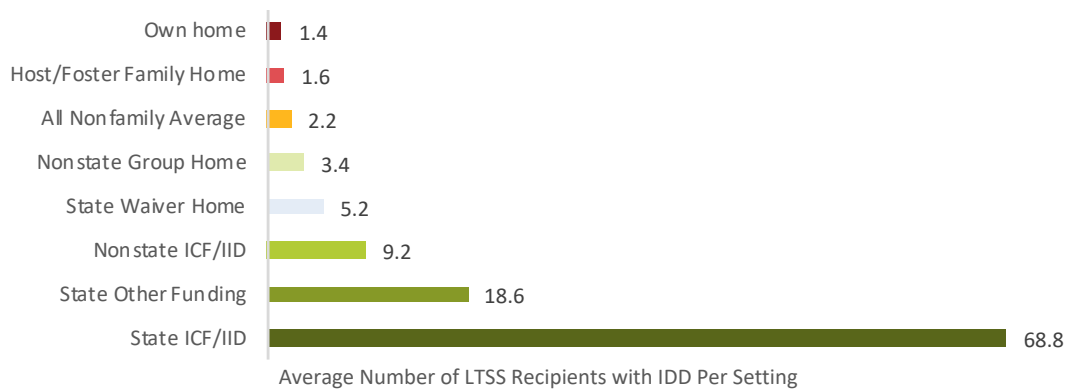
Proportion in Settings of Three or Fewer People

On June 20, 2016, about half (56%) of people with IDD not living with a family member lived alone or shared their home with one or two other LTSS recipients (See **Table 1.10** and **Figure 1.4**). More than 90% of those people lived alone or with one or two others in Vermont (95%) and in New Hampshire (93%). By contrast, fewer than 20% lived alone or with one or two others in Montana (17%), Mississippi (17%) and Illinois (7%).

Proportion in Settings of Six or Fewer People

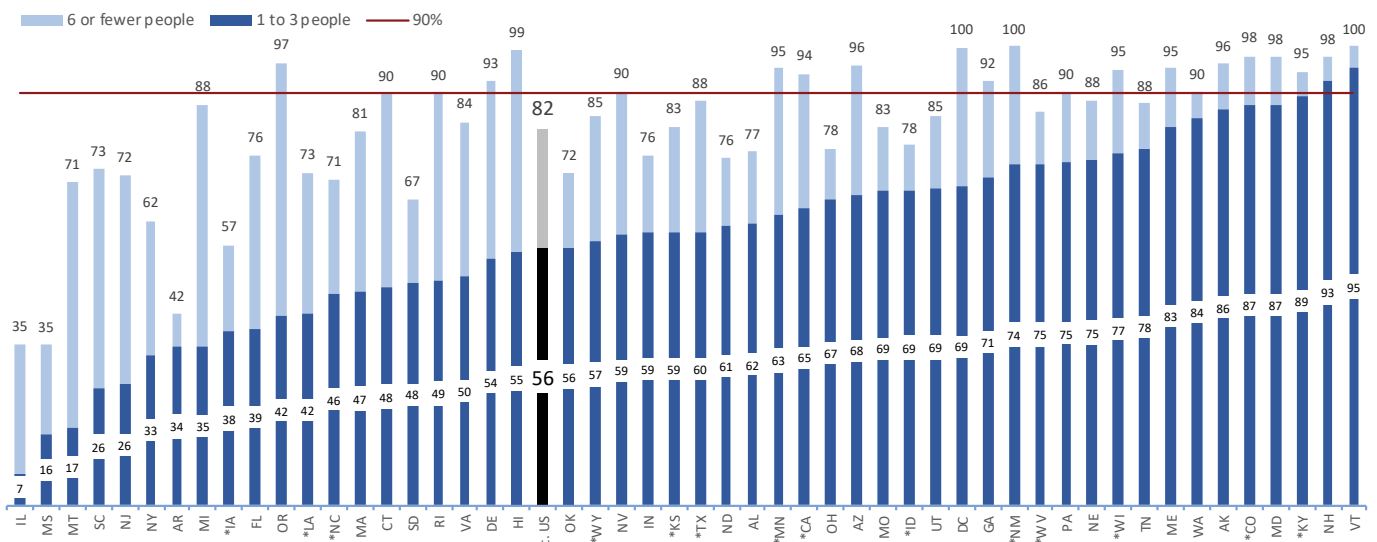
Nationally 82% of people with IDD not living with a family member shared their home with five or fewer other LTSS recipients. All of the people with IDD not living with a family member in the District of Columbia, New Mexico and Vermont lived in settings of six or fewer people. Other states in which 90% or more people lived in settings of six or fewer people included Hawaii (99%), Colorado (98%), Maryland (98%), New Hampshire (98%), Oregon (97%), Alaska (96%), Arizona (96%), Kentucky (95%), Maine (95%), Minnesota (95%), Wisconsin (95%), California (94%), Delaware (93%),

Figure 1.3 LTSS Recipients with IDD per Setting by Setting Type on June 30, 2016



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

Figure 1.4 Percent of People with IDD in LTSS Settings of 1 to 3, 4 to 6, or 1 to 6 LTSS Recipients by State on June 30, 2016



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

Table 1.10 LTSS Settings and Recipients with IDD by Setting Size and Per 100,000 of the Population by State on June 30, 2016

State	Estimated Nonfamily LTSS Settings	Estimated Recipients in Nonfamily Settings 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	1,260	3,471	2.8	62	77	49	71
AK	937	1,536 ⁱ	1.6	86	96	7	208
AZ	2,116	4,899 ⁱ	2.3	68	96	69	72
AR	1,437	3,762 ⁱ	2.6	34	42	30	126
CA	26,946 ⁱ	59,539 ⁱ	2.2	65 ⁱ	94	393	152
CO	5,841 ⁱ	10,326	1.8	87 ⁱ	98	55	189
CT	2,689	6,570	2.4	48	90	36	183
DE	513	1,348	2.6	54	93	10	143
DC	664	1,400	2.1	69	100	7	208
FL	5,797 ⁱ	17,784	3.1	39	76	206	88
GA	3,110	5,720 ⁱ	1.8	71	92	103	56
HI	415	924	2.2	55	99	14	65
ID	1,395 ⁱ	2,466 ⁱ	1.8	69 ⁱ	78 ⁱ	17	149
IL	2,823	18,328	6.5	7	35	128	143
IN	4,432	10,292	2.3	59	76	66	155
IA	1,321 ⁱ	4,098 ⁱ	3.1	38 ⁱ	57 ⁱ	31	131
KS	1,802 ⁱ	3,969 ⁱ	2.2	59 ⁱ	83 ⁱ	29	136
KY	2,810 ⁱ	6,078 ⁱ	2.2	89 ⁱ	95 ⁱ	44	137
LA	4,241 ⁱ	16,395 ⁱ	3.9	42 ⁱ	73 ⁱ	47	351
ME	1,584	3,450	2.2	83	95	13	260
MD	15,842	20,431	1.3	87	98	60	340
MA	5,313 ⁱ	13,768	2.6	47 ⁱ	81 ⁱ	68	203
MI	8,328 ⁱ	19,004	2.3	35	88	99	192
MN	15,656	20,242 ⁱ	1.3	63 ⁱ	95	55	369
MS	675 ⁱ	3,252	4.8	16	35 ⁱ	30	109
MO	2,712	7,782	2.9	69	83	61	128
MT	331 ⁱ	1,164	3.5	17	71	10	113
NE	2,510	3,756 ⁱ	1.5	75	88	19	198
NV	1,110	1,985	1.8	59	90	29	69
NH	1,529	1,995	1.3	93	98	13	150
NJ	2,844 ⁱ	11,158	3.9	26	72	89	125
NM	2,425 ⁱ	4,781 ⁱ	2.0	74 ⁱ	100 ⁱ	21	229
NY	15,602 ⁱ	48,916 ⁱ	3.1	33	62	197	247
NC	4,726 ⁱ	12,720 ⁱ	2.7	46 ⁱ	71 ⁱ	101	127
ND	1,406	2,131	1.5	61	76	8	282
OH	15,915	27,751	1.7	67	78	116	239
OK	2,285 ⁱ	4,927	2.2	56	72	39	126
OR	2,968 ⁱ	7,660	2.6	42	97	41	190
PA	14,715	24,851 ⁱ	1.7	75	90	128	194
RI	1,110	2,127	1.9	49	90	11	201
SC	1,047	5,022 ⁱ	4.8	26	73	50	103
SD	1,237	2,554	2.1	48	67	9	298
TN	2,788	6,229	2.2	78	88	67	94
TX	14,320 ⁱ	33,196	2.3	60 ⁱ	88 ⁱ	279	121
UT	2,306	4,065	1.8	69	85	31	136
VT	1,594	1,866	1.2	95	100	6	298
VA	3,315 ⁱ	9,338 ⁱ	2.8	50	84	84	111
WA	3,529	7,323 ⁱ	2.1	84	90	73	102
WV	1,535	3,927 ⁱ	2.6	75 ⁱ	86 ⁱ	18	213
WI	6,740 ⁱ	16,319	2.4	77 ⁱ	95 ⁱ	58	283
WY	530 ⁱ	1,195	2.3	57 ⁱ	85 ⁱ	6	204
Estimated US Total	229,076	513,790	2.2	56	82	3,231	160

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. ⁱ One or more component value imputed by RISP staff. This table uses estimated totals for settings and people.

Georgia (92%), Nevada (90%), Pennsylvania (90%), and Washington (90%). Fewer than 70% of LTSS recipients in non-family settings lived in settings of 6 or fewer people in South Dakota (67%), New York (62%), Iowa (57%), Arkansas (42%), Mississippi (35%), and Illinois (35%).

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) and to use individualized, person-centered planning and practices. In 37 of 43 studies of people with IDD who moved from institutional settings to community homes shared by 6 or fewer people, adaptive behavior (daily living skills) of 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.

Total LTSS Recipients with IDD per 100,000 of the U.S. Population

Since the number of LTSS recipients with IDD and total state populations vary dramatically, in this

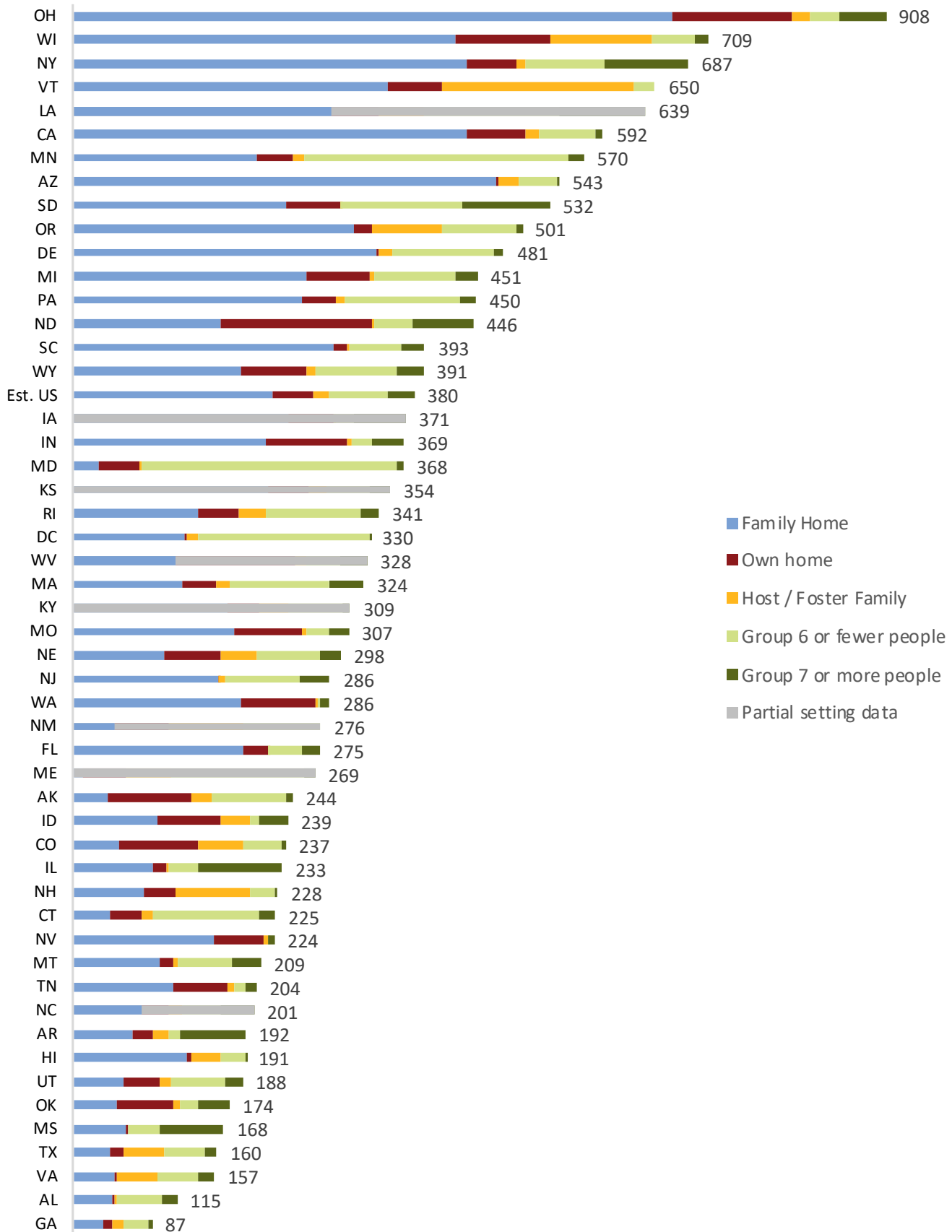
section we compare states based on utilization per 100,000 of a state's population.

There were 160 LTSS recipients with IDD per 100,000 of the population living in non-family IDD settings on June 30, 2016 (See **Table 1.10**). The number ranged from 55 per 100,000 in Georgia to 367 per 100,000 in Minnesota. States serving the fewest people per 100,000 in nonfamily settings were Tennessee (94 per 100,000), Florida (88), Arizona (72), Alabama (71), Nevada (6), Hawaii (65), and Georgia (56). States serving the most people per 100,000 in nonfamily settings were Minnesota (367), Louisiana (351), Maryland (340), Vermont (298), South Dakota (298), Wisconsin (283), North Dakota (282), and Maine (260).

The total LTSS utilization rates averaged of 380 people with IDD per 100,000 of the population nationally, which includes LTSS recipients living with a family member (See **Figure 1.5**). Substantial differences were evident across states. Ohio served more than twice as many people per 100,000 of the population as the national average (908 people per 100,000) while Georgia served less than a third of the national average (87 people per 100,000). A person with IDD living in Ohio is more than 10 times more likely to receive LTSS through a state IDD agency than a person in Georgia, without regard to the type of setting in which those services are provided.



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, 2016



States with the highest overall LTSS utilization rates for people with IDD were Ohio (908 people per 100,000), Wisconsin (709), New York (687), Vermont (650), and Louisiana (639). These states also served at least half of all LTSS recipients in the home of a family member. The most common non-family setting in which LTSS recipients lived differed for these states with Ohio using own home settings most, Wisconsin and Vermont using host or foster family settings most, Louisiana using group homes of 6 or fewer people most, and New York using group home settings of 7 or more people most. All of these states except Vermont continue to operate two or more large state operated IDD facilities.

States with the lowest overall LTSS utilization rates were Georgia (87 LTSS recipients with IDD per 100,000 of the population), Alabama (115), Virginia (157), Texas (160), and Mississippi (168). Fewer than half of LTSS recipients in these states lived in the home of a family member. The most common non-family setting was a host or foster family home in Texas (47 people per 100,000), a group home with 6 or fewer people in Georgia (29), Alabama (52), and Virginia (46), and a group home with seven or more people in Mississippi (71). All of these states except Alabama continue to operate two or more large state-operated IDD facilities.

State differences in LTSS utilization rates reflect differences in which state IDD agency administers LTSS for people ages 21 years or younger, historical patterns of institutional use and deinstitutionalization, lawsuits and consent decrees, or other factors not measured through the RISP survey.

PEOPLE WITH IDD IN PSYCHIATRIC FACILITIES OR NURSING HOMES

This section estimates of the number of people with IDD receiving LTSS in state- or nonstate-operated psychiatric facilities or nursing homes on June 30, 2016. 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 are not available for services

provided to people ages 18 to 64 years in “Institutes for Mental Disease.” Services in those settings must be funded by state, local or private funds. Forty-two states reported serving 2,044 people with IDD in state-operated psychiatric facilities, and 29 states reported 1,671 people with IDD living in nonstate-operated psychiatric facilities on June 30, 2016 (See **Table 1.11**). An estimated 45% of people with IDD living in a psychiatric facility lived in a nonstate facility while 55% lived in a state facility. The state totals are partial estimates if the state was unable to report on both state-operated and nonstate-operated psychiatric facilities. A United States estimated total cannot be computed until more of the states are able to furnish information on people with IDD in psychiatric facilities. We can say that at least 3,715 people with IDD lived in psychiatric facilities on June 30, 2016.

Nursing Homes

An estimated 26,381 people with IDD lived in a nursing home on June 30, 2016. Of those, an estimated 1% (358 people) lived in state operated nursing home and 99% (26,023 people) lived in nonstate facilities. For FY 2016, 38 states reported the number of people with IDD in state-operated nursing homes and 35 states reported on the number of people in nonstate nursing homes. All but two states (Alaska and Washington) reported people with IDD living in a nursing home. Missing values were estimated based on data reported by the state for FY 2015 (when available) or on data from the Centers for Medicare and Medicaid Services CASPER data for nursing homes on June 30, 2016 (AHCA, 2017c).

Proportion of LTSS Recipients with IDD in Nursing Homes or Psychiatric Facilities

Adding people with IDD living in nursing homes or psychiatric facilities to those in non-family IDD settings increases the estimated number of LTSS recipients with IDD in nonfamily settings from 513,790 to 543,886. Including people with IDD living in nursing homes and psychiatric facilities, there were an estimated 1,239,296 LTSS recipients with IDD in the United States on June 30, 2016 (See **Figure 1.6**). Of those, 57% lived in the home of a family member, 11% lived in an own home setting, 5% lived with a host or foster family, 25% lived in a group IDD setting, and 2% lived in a nursing home or psychiatric facility.

Table 1.11 People with IDD in State- and Nonstate-Operated Nursing Homes or Psychiatric Facilities by State on June 30, 2016

	Psychiatric Facilities (Psych)			Nursing Homes (NH)		
	State	Nonstate	Reported Total	State	Nonstate	Estimated Total
N States	42	29	43	38	35	51
AL	73	DNF	73	0	935	935
AK	0	0	0	0	0	0
AZ	0	0	0	0	50	50
AR	0	0	0	DNF	DNF	638 ^s
CA	0	34	34	0	1,112	1,112
CO	0	0	0	0	64	64
CT	5	0	5	0	339	339
DE	2	0	2	DNF	DNF	58
DC	4	0	4	0	6	6
FL	18	6	24	0	285	285
GA	240	DNF	240 ^c	0	DNF	972 ^s
HI	4	2	6	0	68	68
ID	DNF	DNF	DNF	DNF	DNF	113 ^d
IL	0	0	0	0	171	171
IN	63	0	63	0	1,568	1,568
IA	10	1,454	1,464	DNF	644	670 ^s
KS	28	DNF	28 ^c	0	121	121
KY	362	0	362	DNF	DNF	736 ^s
LA	49	DNF	49 ^c	18 ^e	580 ^e	598 ^e
ME	0	0	0	0	10	10
MD	0	0	0	0	279	279
MA	DNF	DNF	DNF	23	244	267
MI	0 ^d	0 ^d	0	0 ^d	411 ^d	411 ^d
MN	4 ^d	DNF ^d	4 ^c	0	155	155 ^d
MS	DNF	DNF	DNF	DNF	DNF	381 ^s
MO	209	DNF	209 ^c	DNF	DNF	1,148 ^s
MT	DNF	DNF	DNF	DNF	DNF	120 ^s
NE	0	4	4	0	177 ^d	177 ^d
NV	0	0	0	0	112	112
NH	DNF	DNF	DNF	5 ^d	103 ^d	108 ^d
NJ	45	DNF	45 ^c	0	856	856
NM	DNF	DNF	DNF	11	70	81
NY	DNF	DNF	DNF	DNF	DNF	1,581
NC	288	34 ^e	322 ^c	209	DNF	805 ^s
ND	1	DNF	1	0	122	122
OH	DNF	DNF	DNF	0	DNF	1,406 ^s
OK	DNF	DNF	DNF	0	1,358	1,358
OR	0	0	0	0	161	161
PA	89	137 ^e	226 ^e	0	2,344 ^e	2,344 ^e
RI	0 ^d	0 ^d	0 ^d	0 ^d	6 ^d	6 ^d
SC	0	0	0	0	265	265
SD	0	0	0	0	87	87
TN	36	DNF	36 ^c	0	567 ^d	567
TX	435 ^d	DNF	435 ^c	DNF	DNF	2,492 ^s
UT	0	0	0	0	DNF	34 ^d
VT	0	0	0	27	0	27
VA	10	DNF	10 ^c	DNF	DNF	1,657
WA	38	0	38	0	0	0
WV	22	DNF	22 ^c	DNF	DNF	213 ^s
WI	0 ^d	0 ^d	0 ^d	0 ^d	22 ^d	22 ^d
WY	9	DNF	9 ^c	DNF	DNF	27 ^s
Reported US Total	2,044	1,671	3,715	293	13,292	25,783
Estimated US Total				358	26,023	26,381

^b Excludes state-operated facilities. ^c Excludes nonstate-operated facilities. ^d Other date (Usually a different fiscal year or June 30, 2015) ^e Estimate. ^s Source AHCA (2017c). [†] One or more component value imputed by RISP staff.* See notes in Appendix.
The reported and estimated totals for nursing homes differ because the estimated total replace zeros with ACHA data for two states.

REDUCING THE NUMBER OF PEOPLE WITH IDD CONGREGATE SETTINGS

The Centers for Disease Control Health People establishes a set of objectives updated every 10 years to monitor progress toward improving the health of all Americans. Current objectives are listed on the Healthy People 2020 website at www.healthypeople.gov. The following objectives from the Disability and Health section specifically address living arrangements for people with IDD:

- DH-12 Reduce the number of people with disabilities living in congregate care residences.
- DH-12.1 Reduce the number of adults with disabilities aged 22 years and older living in congregate care residences that serve 16 or more persons.

- DH-12.2 Reduce the number of children and youth with disabilities aged 21 years and under living in congregate care residences.

Children and Youth 21 Years or Younger on Congregate Care Settings

Reducing the number of people with IDD 21 years or younger who live in congregate setting is an important HP 2020 goal. Updated estimates are 18,145 for 2013, 17,417 for 2014, 16,523 for 2015, and 15,712 in 2016 (an average decline of 4-5% per year). The number of people 21 years or younger in settings of serving four or more LTSS recipients was 23,870 in 1997, 22,875 in 2005, and 20,762 in 2009 (Larson, Lakin, Salmi, Scott, and Webster, 2011).

Congregate settings were defined as

- Non-family residential settings (state or nonstate settings of any size, type or funding authority)

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, 2016

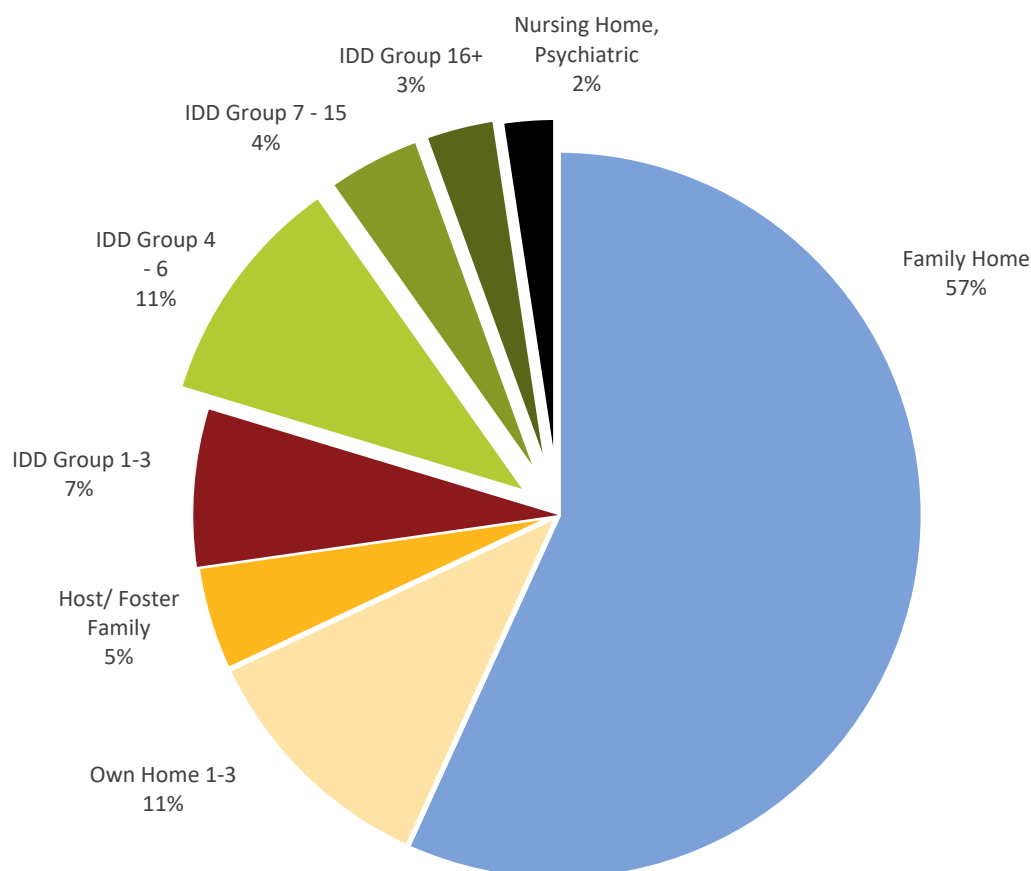


Table 1.12 People with IDD 21 Years or Younger Living in Congregate Settings of 4 or More People or Nursing Homes by State on June 30, 2016

	Setting Type		Total
	Other	Nursing Home	
N States	44	28	27
AL	211	DNF	PD
AK	58	0	58
AZ	456	0	456
AR	201	DNF	PD
CA	754	DNF	PD
CO	154	0	154
CT	124	0	124
DE	19 ^d	25 ^d	44
DC	1	1	2
FL	1,046	16	1,062
GA	108 ^{ed}	DNF	PD
HI	2	0	2
ID	DNF	DNF	DNF
IL	189	1	190
IN	402	110	512
IA	250	28	278
KS	DNF	0	PD
KY	DNF	DNF	DNF
LA	482	4 ^e	486
ME	94	0	94
MD	20	0	20
MA	DNF	DNF	DNF
MI	255 ^d	2 ^d	257
MN	DNF	DNF ^d	DNF
MS	87	DNF	PD
MO	506	DNF	PD
MT	191	DNF	PD
NE	234	DNF	PD
NV	51	15	66
NH	25 ^{ed}	DNF	PD
NJ	0	0	0
NM	DNF	DNF	DNF
NY	1,158	DNF	PD
NC	365 ^s	DNF	PD
ND	116	0	116
OH	138	DNF	PD
OK	DNF	DNF	DNF
OR	967	62	1,029
PA	383	5 ^e	388
RI	17 ^s	0 ^d	17
SC	49	0	49
SD	138	0	138
TN	450	DNF	PD
TX	1,269 ^d	DNF	PD
UT	137	DNF	PD
VT	0	0	0
VA	202	127	329
WA	96	0	96
WV	52 ^s	DNF	PD
WI	124 ^d	0 ^d	124
WY	17	DNF	PD
Reported US Total	11,598	396	11,994
Estimated US Total	14,514	1,198	15,712

^d Other date (Usually a different fiscal year or June 30, 2015) ^e Estimate. ^s Source AHCA (2017c). * See notes in Appendix.

- In which two or more individuals with IDD live
- In which rotating (or shift) staff members provide supports and services.

People with IDD 21 years or younger were excluded from this count if they:

- Lived with birth or adoptive parents or other family members
- Lived in family “foster care” settings in which no shift staff work
- Lived only part of the year in a residential PreK-12 school
- Lived in a correctional facilities
- Received only respite services from a congregate care facility
- Lived in another state

For states unable to furnish complete data, the number of people 21 years and younger in nursing homes was estimated from reports using the June 30, 2016 Medicaid CASPER data (AHCA, 2017c) and the number in other congregate settings was imputed based on other survey RISP survey items. We did not have a source from which to impute the number of people with IDD 21 years or younger in psychiatric facilities.

An estimated 15,712 people with IDD ages 21 years or younger lived in congregate settings on June 30, 2016 (See **Table 1.12**). Of those, an 8% (1,198 people) lived in nursing homes, and 92% (14,514 people) lived in other types of congregate settings. This was 5% (810 people) fewer than on June 30, 2015.

Between 1995 and 2016, the estimated number of people with IDD 21 years or younger living in IDD group settings of four or more people or in nursing homes declined 31% from 22,875 to 15,712 people. ■



SECTION TWO

Long-Term Supports and Services Funding Authorities

FY 2016

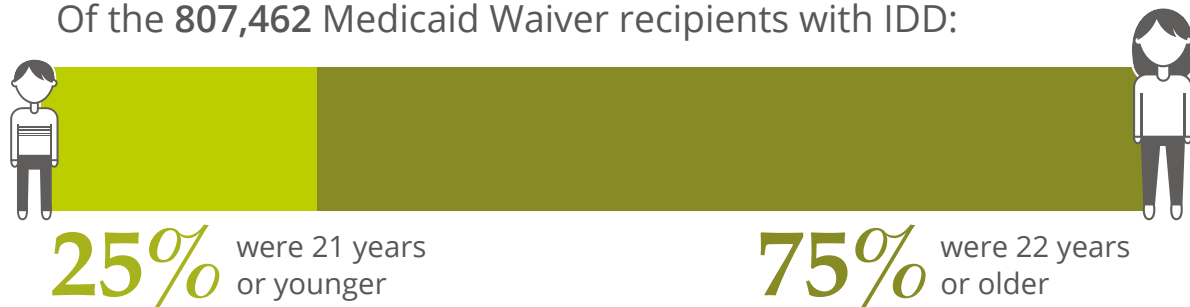
Medicaid Waiver Recipients and Expenditures 2016

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

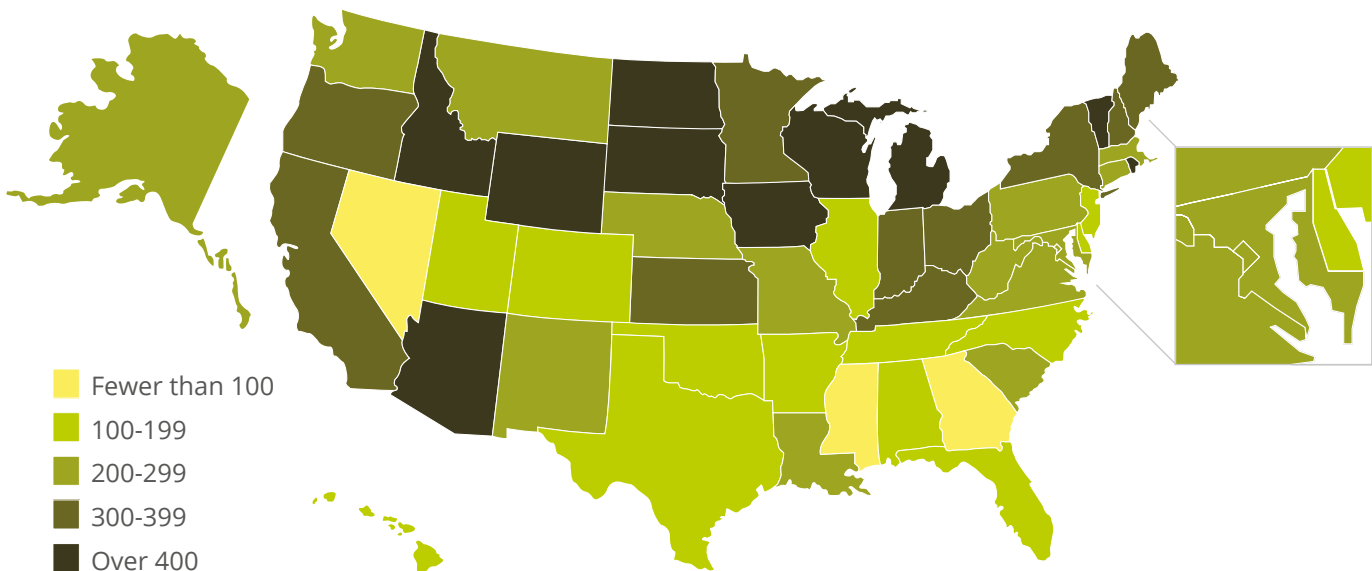
Annual per person Medicaid Waiver expenditures



Of the 807,462 Medicaid Waiver recipients with IDD:



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



Medicaid Intermediate Care Facilities for Individuals with Intellectual Disabilities ICF/IID 2016

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

Annual per person ICF/IID expenditures



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



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

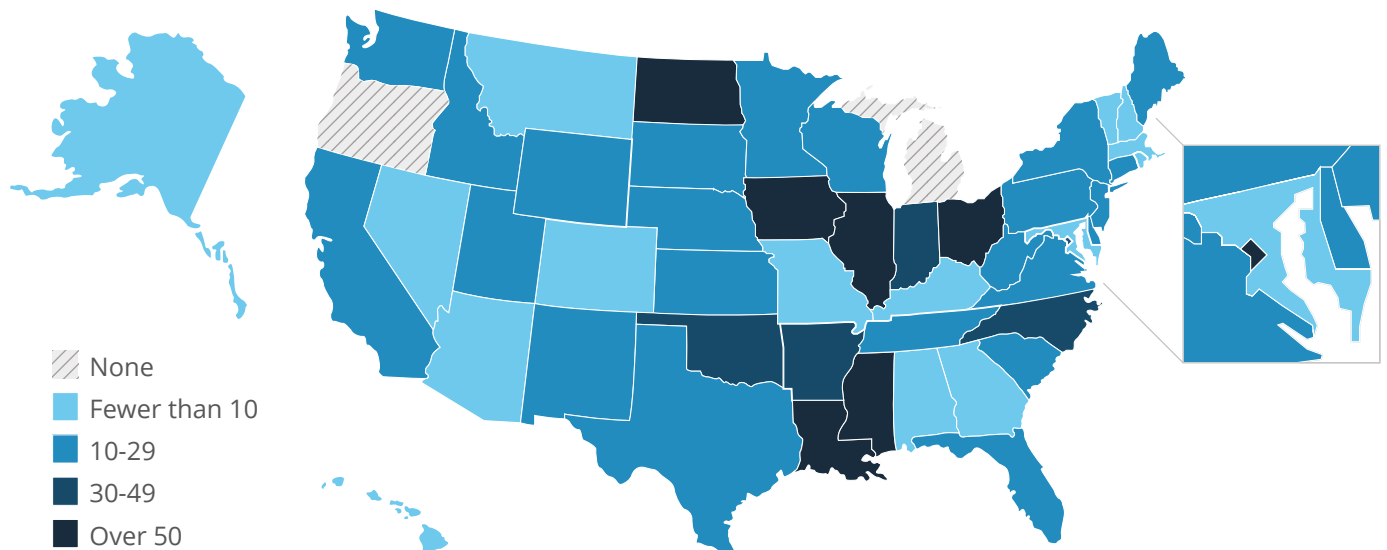


Table C: Medicaid Funding Authorities

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	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.
State plan home health services	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). ICF/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 can not 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

OVERVIEW OF PUBLIC LTSS FUNDING AUTHORITIES

Medicaid offers an array of different mechanisms (or “authorities”) through which states can request matching federal funds to provide LTSS¹(see **Table C**). States are permitted flexibility in administration and in determining the type, amount, duration, and scope of services, as well as the design and delivery of covered services, consistent with federal regulations. The federal financial portion (called the Federal Medicaid Assistance Percentage - FMAP) varies by state, based on per capita income and the size of the state. For FY 2016, state FMAP² ranged from 50% in 13 states to 74% 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.

State Utilization of LTSS Funding Authorities

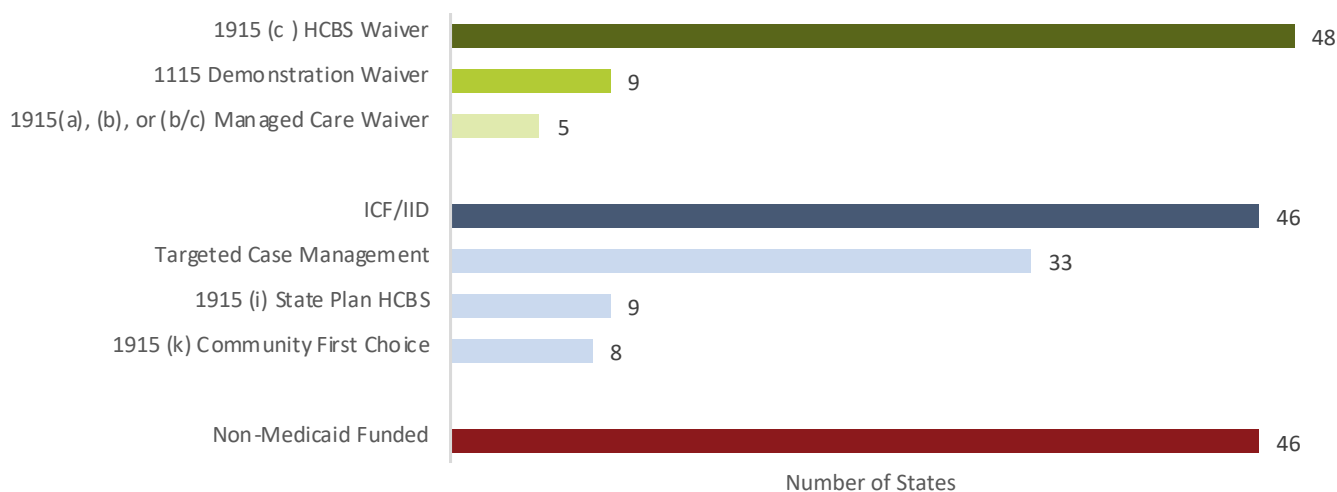
States funded LTSS for people with ID through the following Medicaid Waiver funding authorities in 2016: Medicaid 1915(c) HCBS (48 states), 1115 Demonstration Waiver (9 states), and Medicaid Managed Care Waivers (1915(a), (b), or (1915(a), (b), or (b/c) in 5 states, See **Figure 2.1**).

States funded LTSS for people with IDD through these Medicaid State Plan options: Medicaid ICF/IID (used by 46 states), Medicaid State Plan Targeted Case Management (33 states), Medicaid State Plan 1915(i) (9 states), and Medicaid State Plan 1915(k) Community First Choice (8 states). Forty-six states reported funding LTSS for people with IDD through non-Medicaid, state funding authorities.

LTSS Recipients with IDD by Funding Authority

Of the 1.49 million people with IDD known to, or served under the auspices of, state IDD agencies in FY 2016, an estimated 807,462 people with IDD received Medicaid Waiver-funded LTSS (See **Figure 2.2**). An estimated 74,614 lived in a Medicaid ICF/IID, 438,160 people received other Medicaid State Plan funded LTSS, and 216,969 received non-Medicaid state-funded LTSS. Some people received supports through more than one funding authority (e.g., through Medicaid Waiver and through a state-funded non-Medicaid program). An estimated 191,210 people with IDD known to state IDD agencies were not receiving funded LTSS on June 30, 2016. Some of those people were waiting for Medicaid Waiver or state-funded services.

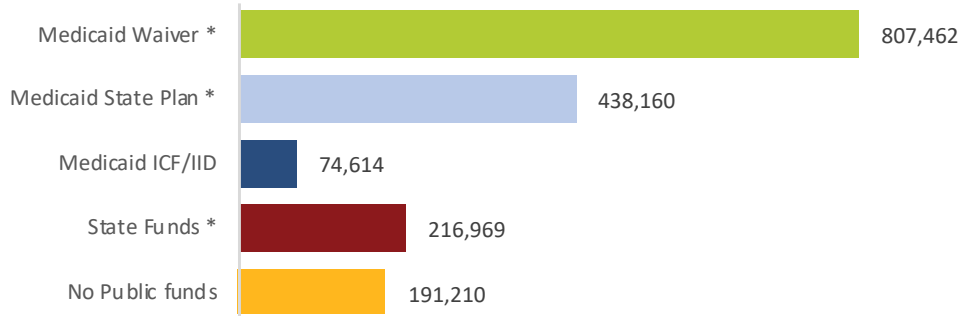
Figure 2.1 Funding Authorities Used by States to Provide LTSS for People with IDD on June 30, 2016



¹ Unless otherwise specified, the description of Federal Medicaid Authorities is from the Guide to Federal Medicaid Authorities Used in Restructuring Medicaid Health Care Delivery or Payment <http://www.medicaid.gov>.

² <https://aspe.hhs.gov/federal-medical-assistance-percentages-or-federal-financial-participation-state-assistance-expenditures>

Figure 2.2 Estimated LTSS Recipients with IDD by Funding Authority on June 30, 2016



* Some people may be counted in more than one of these three categories. Medicaid State Plan includes Targeted Case Management, 1915(i) and 1915(k).

People Waiting for Medicaid Waiver

Medicaid ICF/IID and Waiver recipients

882,076

People waiting for Waiver funding while living with a family member

193,828

22% increase needed to serve those waiting

PEOPLE LIVING WITH A FAMILY MEMBER WAITING FOR MEDICAID WAIVER-FUNDED SUPPORTS

Forty-nine states reported the number of people with IDD living with a family member who had requested Medicaid Waiver-funded services but who were not Medicaid Waiver recipients as of June 30, 2016. The number of people waiting excludes people already receiving Medicaid Waiver-funded supports, people living in an ICF/IID and people not living with a family member.

Number of People Waiting

An estimated 193,828 people with IDD living with a family member were waiting for Medicaid Waiver-Funded LTSS on June 30, 2016 (See **Table 2.1**). Thirteen states reported not having a waiting list or reported no people waiting. Those states were California, Delaware, the District of Columbia, Hawaii, Idaho, Massachusetts, Michigan,

New York, North Dakota, Oregon, Rhode Island, South Dakota, and Vermont. States reporting more than 10,000 people waiting included Ohio (31,467 people), Florida (20,486), Louisiana (14,289), Virginia (10,877), and North Carolina (10,687).

The number of people with IDD living with a family member waiting for Medicaid Waiver-funded LTSS declined 17% from 232,204 people in 2013 to 193,828 people in 2016. The number waiting to move to a residence other than the home of a family member declined 35% from 107,204 in 2013 to 69,279 in 2016.

In previous years, the number of people waiting for services included people living in an ICF/IID, living in a setting other than the home of a family member, or who were already Waiver recipients, but were requesting more funds or different services. For FY 2016, states were reminded to only include people living with a family member who were not already receiving Medicaid Waiver-funded services in this number.

Table 2.1 People with IDD Living with Family Members Waiting for Medicaid Waiver-Funded LTSS, Total ICF/IID and Medicaid Waiver Recipients and Growth Needed to Serve those Waiting by State on June 30, 2016

State	People Waiting for Medicaid Waiver Funded LTSS			Estimated Medicaid Waiver + ICF/IID Recipients	Increase Needed to Serve All Waiting (%)
	Number Waiting	Getting Targeted Case Management	Waiting to Move from Family Home		
N States	49	43	31	51	49
AL	3,324	0	2,060	5,602	59
AK	537	0	292	2,100	26
AZ	211	DNF	6	29,717	1
AR	3,161	0	0	5,577	57
CA	0	0	0	128,002	0
CO	3,199	0	3,173	11,061	29
CT	650	594	DNF	11,011	6
DE	0	0	0	1,177	0
DC	0	0	0	1,993	0
FL	20,486	DNF	1,511	35,621	58
GA	8,070 ^d	0 ^d	DNF	8,863	91
HI	0	0	0	2,829	0
ID	0	0	0	8,214	0
IL	9,725	0	3,404	30,359	32
IN	1,934	0	DNF	25,547	8
IA	DNF	DNF	DNF	16,102	DNF
KS	3,387	1,487 ^e	DNF	9,286	36
KY	2,276	DNF	DNF	15,195	15
LA	14,289	1,142	DNF	17,335	82
ME	1,264	1,264	DNF	5,249	24
MD	5,441	5,063	4,971	14,520	37
MA	0	0	0	14,683	0
MI	0 ^d	0 ^d	DNF	45,115	0
MN	3,564 ^d	1,412 ^d	DNF ^d	19,907	18
MS	1,441	198	44	4,745	30
MO	262	245	125	14,164	2
MT	1,233	1,233 ^e	DNF	2,575	48
NE	2,149	931	DNF	5,079	42
NV	752	752	607	2,124	35
NH	79 ^d	DNF	DNF	5,260	2
NJ	3,201	DNF	DNF	12,803	25
NM	6,516	DNF	DNF	5,173	126
NY	0	0	6,058	83,510	0
NC	10,687 ^e	0 ^e	DNF	20,817	51
ND	0	0	0	5,315	0
OH	31,467	5,054	DNF	42,964	73
OK	7,050	0	0	6,932	102
OR	0	0	0	12,548	0
PA	7,812 ^e	4,783 ^e	3,209 ^e	37,138	21
RI	0	0	0	3,673	0
SC	4,426	0	230	11,453	39
SD	0	0	0	3,817	0
TN	5,769	0	417 ^e	9,037	64
TX	DNF	DNF	DNF	44,668	DNF
UT	2,387	0	1,335	5,989	40
VT	0	0	0	3,016	0
VA	10,877	8,012 ^d	4,222	18,057	60
WA	671	0	17	16,337	4
WV	1,274	1,274	60 ^e	5,143	25
WI	1,890 ^d	80 ^d	DNF ^d	32,247	6
WY	182	182 ^e	DNF	2,427	7
Reported US Total	181,643	33,706	31,741	882,076	
Estimated US Total	193,828	43,884	69,279	882,076	22%

^d Other date (Usually a different fiscal year or June 30, 2015). ^e Estimate. ^{DNF} Did not furnish. * See state notes in Appendix. TCM: Medicaid funded Targeted Case Management Services. HCBS: Home and Community Based Services. ICF/IID: Intermediate Care Facilities for Individuals with Intellectual Disabilities.

Number of People Receiving Targeted Case Management Services While Waiting

Of the people waiting for Medicaid Waiver-funded supports, an estimated 23% (43,884 people) received Medicaid State Plan-funded Targeted Case Management Services (TCM) while waiting. Thirteen states did not provide TCM to people who were waiting. States providing TCM services to more than 90% of the people waiting included Maine (100%), Montana (100%), Nevada (100%), West Virginia (100%), Wyoming (100%), Missouri (94%), Maryland (93%), and Connecticut (91%).

Number of People Waiting to Move to a Non-family Setting

An estimated 69,279 people (36% of those waiting) were waiting for Medicaid Waiver funding to enable them to move from the home of a family member to a non-family setting. States reporting the highest proportion of people waiting to move to a non-family setting were Colorado (99%), Maryland (91%), Nevada (81%), Alabama (62%), Utah (56%), Alaska (54%), and Missouri (48%).

Growth Required to Serve All People Waiting

There were an estimated 882,076 people with IDD receiving Medicaid Waiver-funded supports or living in an ICF/IID on June 30, 2016. That number would have to increase by 22% to serve all of the people waiting for Medicaid Waiver-funded services as of June 20, 2016. The growth needed to serve people waiting ranged from none to 126% by state. States that would need to expand their Medicaid Waiver and/or ICF/IID programs by more than 50% to meet the needs of the people waiting were New Mexico (126%), Oklahoma (102%), Georgia (91%), Louisiana (82%), Ohio (73%), Tennessee (64%), Virginia (60%), Alabama (59%), Florida (58%), Arkansas (57%), and North Carolina (51%).

MEDICAID WAIVER RECIPIENTS

The RISP survey asks about Medicaid Waiver recipients by age, by living arrangement, and by whether services are provided by a state or a nonstate entity. It asks separately about the number

of people for whom Medicaid Waiver expenditures are reported. In some states, the number of people for whom expenditures data are provided differs from the number of recipients reported by age because recipient characteristics and expenditure data are tracked in different systems. Except in the expenditures section, this chapter refers to the total recipients reported by age.

Living Arrangements

There were an estimated 807,462 Medicaid Waiver recipients with IDD on June 30, 2016. Of those, 53% (427,910) lived with a family member, 15% (115,508) lived in an own home setting, 7% (52,911) lived in a host or foster family home, and 26% (209,133) lived in a group IDD setting (See **Table 2.2** and **Figure 2.3**).

Home of a Family Member

All states provided Medicaid Waivers to people living in the home of a family member. States serving the greatest number of Waiver recipients in family homes were California (86,298 recipients), New York (40,870 recipients), Arizona (25,050 recipients), Michigan (24,653 recipients), and Ohio (20,784 recipients). More than half of all Medicaid Waiver recipients lived in the home of a family member in Arizona (84%), California (72%), Hawaii (68%), Mississippi (68%), Indiana (66%), Washington (58%), Florida (57%), Ohio (57%), Oregon (57%), Michigan (56%), Pennsylvania (53%), and Wisconsin (52%). Fewer than 10% of all Waiver recipients lived in the home of a family member in Delaware (less than 1%), and Maryland (7%).

The proportion of Waiver recipients living in the home of a family member often varies with the proportion of Waiver recipients who are 21 years old or younger. For example, in Arizona 62% of all Medicaid Waiver recipients with IDD were 21 years or younger, 84% of Waiver recipients lived with a family member. By contrast, in Maryland, fewer than 2% of Waiver recipients were 21 years or younger and only 7% lived in the home of a family member.

Own Home

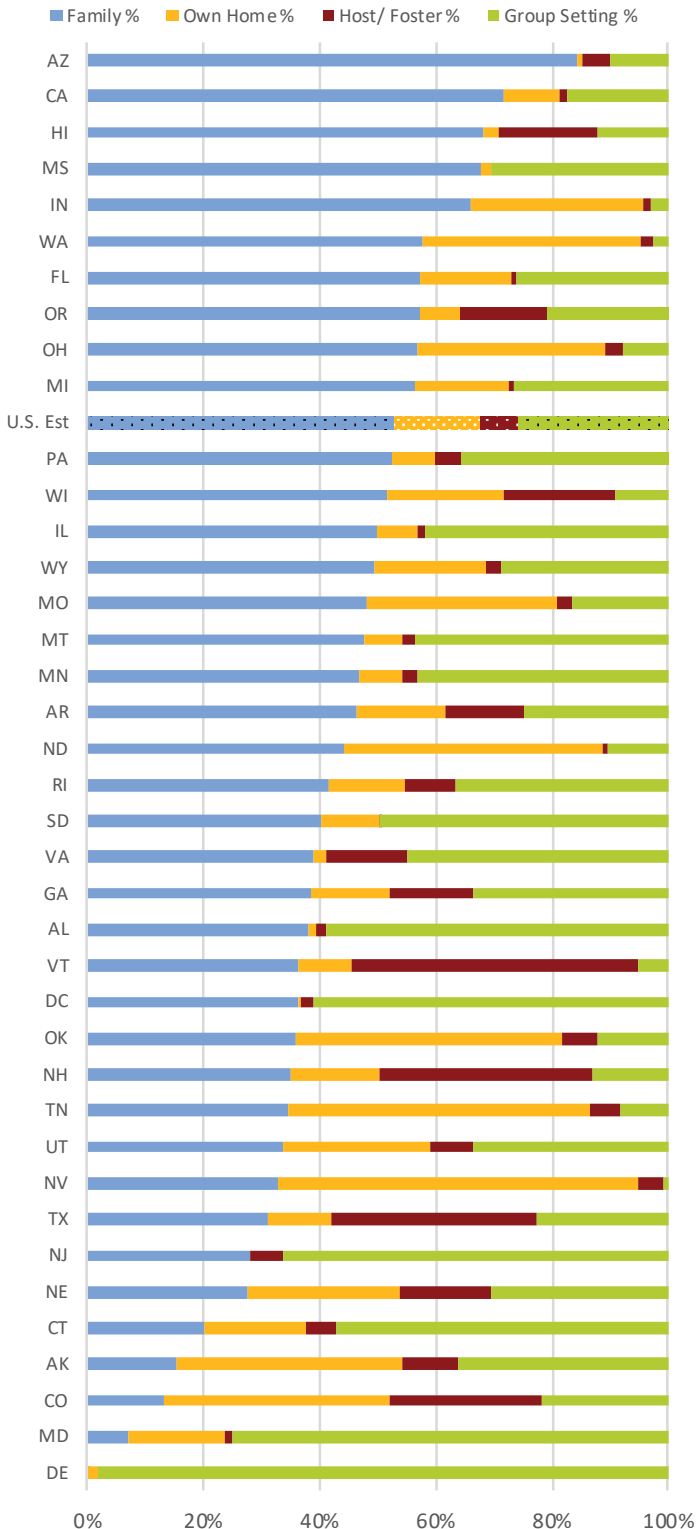
An estimated 117,508 Waiver recipients with IDD lived in a home they owned or leased on June 30, 2016. States serving more than half of all Waiver

Table 2.2 Medicaid Waiver Recipients with IDD by Residence Type and State on June 30, 2016

	Family Home	Own Home	Host/ Foster Family	IDD Group Settings			Group Total
				Nonstate IDD	Nonstate Other	State IDD	
N States	44	45	46	44	45	50	41
AL	2,131	55	111	3,277	0	0	3,277
AK	277	705	170	654	0	0	654
AZ	25,050	267	1,478	2,769	7	148	2,924
AR	1,925 ^{ed}	639	570	1,027 ^e	0	0	1,027
CA	86,298	11,540	1,529	20,717	0	0	20,717
CO	1,437	4,287	2,874	865	1,393	112	2,370
CT	1,428	1,241	369	3,708	0	308	4,016
DE	1 ^d	18 ^d	0 ^d	1,041 ^d	0	0	1,041
DC	574	11	30	969	0	0	969
FL	18,735	5,152	260 ^e	7,882	643	0	8,525
GA	3,274	1,145	1,203	2,825	23	0	2,848
HI	1,811	72	452	324 ^d	0	0	324
ID	DNF	1,206	559 ^d	DNF	DNF	0	PD
IL	11,477	1,681	273	9,651	0	0	9,651
IN	13,661	6,180	234	629	0	0	629
IA	DNF	DNF	DNF	DNF	DNF	58	PD
KS	DNF	DNF	DNF	DNF	DNF	0	PD
KY	DNF	DNF	1,387	2,485	0	0	2,485
LA	10,017	2,362	DNF	DNF	0	0	PD
ME	DNF	629 ^e	684 ^e	1,700 ^e	275 ^e	0	1,975
MD	1,037	2,389	206	5,838	4,965	0	10,803
MA	DNF	DNF	DNF	DNF	0	1,078	PD
MI	24,653 ^d	6,980 ^d	474 ^d	10,334 ^d	1,216 ^d	0	11,550
MN	11,232 ^d	1,683 ^d	664 ^d	9,191 ^d	775 ^d	350	10,316
MS	1,755	45	0	413	0	383	796
MO	6,695	4,557	414	2,056	0	228	2,284
MT	1,014 ^e	143 ^e	47	932	0	0	932
NE	1,248	1,202	720	1,386	0	0	1,386
NV	669	1,262	82	0	20	0	20
NH	1,047 ^d	459 ^d	1,106 ^d	388 ^d	0	0	388
NJ	3,072	0	628	7,222	0	0	7,222
NM	DNF	DNF	DNF	DNF	0	PD	PD
NY	40,870 ^e	5,449 ^e	1,812	23,545	DNF	6,638	PD
NC	7,227 ^e	DNF	1,377	2,759 ^e	DNF	1	PD
ND	1,252	1,276	18	298	0	0	298
OH	20,784	11,853	1,052	2,626	299	0	2,925
OK	1,895	2,445	325	645	0	0	645
OR	6,668	807 ^d	1,754	2,439	0	0	2,439
PA	18,337 ^e	2,500 ^e	1,522	11,348	1,197 ^e	0	12,545
RI	1,476	480	312	1,149 ⁱ	0	151	1,300
SC	6,570	637	165	2,917	DNF	0	PD
SD	1,453	365	1	1,809	0	0	1,809
TN	2,814	4,169	434	673	0	0	673
TX	11,436 ^d	3,894 ^d	13,070 ^d	8,235 ^d	0 ^d	0 ^d	8,235
UT	1,652	1,241	366	1,649	0	0	1,649
VT	986	242	1,340	144	0	0	144
VA	3,871	230	1,360 ^e	4,493	0	0	4,493
WA	5,902 ^e	3,857 ^e	197	275	0	4	279
WV	2,077	2,461	96	DNF	0	0	PD
WI	16,295 ^d	6,181 ^d	6,177 ^d	2,804 ^d	3 ^d	0	2,807
WY	1,092	428	58	636	6	0	642
Reported US Total	383,175	104,425	47,960	166,727	10,822	9,459	187,008
Estimated US Total ¹	427,910	117,508	52,911	188,797	10,822	9,514	209,133

^d Other date (Usually a different fiscal year or June 30, 2015). ^e Estimate. ^{DNF} Did not furnish. ^{PD} Partial data, calculation incomplete and not included in reported totals. * See state notes in Appendix. ¹ US estimated totals include Waiver recipients for whom setting type was not known. Some states did not furnish type of residence for all LTSS recipients.

Figure 2.3 Percent of Medicaid Waiver Recipients with IDD in Family Home, Own Home, Host or Foster Family Home, or Group Settings by State June 30, 2016



Fourteen states did not report setting type for all Waiver recipients (ID, IA, KS, KT, LA, MA, ME, MT, NM, NY, NC, OR, SC, and WV)

recipients in own home settings were Nevada (62%), Tennessee (52%), Oklahoma (46%), and North Dakota (45%). States in which very few or no Medicaid Waiver recipients with IDD lived in an own home setting included New Jersey (0%), Alabama, Arizona and the District of Columbia (1%), and Delaware, Mississippi, and Virginia (2%).

Host or Family Foster Home

An estimated 52,911 Waiver recipients with IDD lived with a host or foster family on June 30, 2016. All states except Delaware and Mississippi served Medicaid Waiver recipients in host or foster family settings. States serving the highest proportion of Medicaid Waiver recipients in host or foster family settings were Vermont (49%), New Hampshire (37%), Texas (36%), Colorado (26%), and Wisconsin (20%).

Group Settings

An estimated 209,133 Waiver recipients with IDD lived in LTSS group settings. States in which more than half of all Medicaid Waiver recipients with IDD lived in LTSS group settings included Delaware (98%), Maryland (75%), New Jersey (66%), the District of Columbia (61%), Alabama (59%), and Connecticut (57%). States in which fewer than 5% of Medicaid Waiver recipients with IDD lived in a group setting included Washington and Indiana (3%), and Nevada (1%).

Medicaid Waiver Utilization and Recipients by Age

Waiver Recipients by Age

On June 30, 2016, an estimated 25% (204,406 people) of Medicaid Waiver recipients with IDD were 21 years old or younger, and 75% (603,056 people) were 22 years or older (See **Table 2.3** and **Figure 2.4**). States in which more than 95% of Medicaid Waiver recipients were 22 years or older were New Jersey (100%), Rhode Island (100%), the District of Columbia (99%), Massachusetts (98%), Maryland (98%), Alabama (96%), Tennessee (96%), and Nebraska (95%). States in which more than 40% of Medicaid Waiver recipients with IDD were 21 years or younger were Arizona (62%), Idaho (54%), North Dakota (53%), California (44%), and Kentucky (43%).

Table 2.3 Medicaid Waiver Recipients with IDD total and per 100,000 by Age and State on June 30, 2016

Age	Number Waiver Recipients			Percent 22 years or older	State Population in 100,000's ⁵		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	224	5,356	5,580	96	13.5	35.1	17	153	115
AK	601	1,492	2,093	71	2.3	5.2	266	289	282
AZ	18,342	11,238	29,580	38	20.1	49.2	914	228	427
AR	600	3,535	4,135	85	8.6	21.2	69	166	138
CA	53,430	66,654	120,084	56	112.0	280.5	477	238	306
CO	2,249	8,597	10,846	79	15.5	39.9	145	215	196
CT	621	9,600	10,221	94	9.6	26.1	65	367	286
DE	DNF	DNF	1,077	DNF	2.5	7.0	DNF	DNF	113
DC	19	1,651	1,670	99	1.6	5.2	12	319	245
FL	5,417	27,413	32,830	83	51.0	155.2	106	177	159
GA	610	7,969	8,579	93	30.7	72.4	20	110	83
HI	531	2,222	2,753	81	3.8	10.5	141	211	193
ID	4,203	3,523	7,726	46	5.2	11.6	801	304	459
IL	1,800	21,944	23,744	92	36.0	92.0	50	238	185
IN	7,750	14,548	22,298	65	19.5	46.8	397	311	336
IA	4,228	9,863	14,091	70	9.2	22.2	461	445	450
KS	1,777	7,059	8,836	80	8.8	20.2	201	349	304
KY	6,369	8,399	14,768	57	12.4	31.9	512	263	333
LA	2,985	9,394	12,379	76	13.5	33.3	221	282	264
ME	558 ^e	4,529 ^e	5,087 ^e	89	3.2	10.1	175	447	382
MD	297	14,127	14,424	98	16.6	43.6	18	324	240
MA	246	14,028	14,274	98	17.9	50.2	14	279	210
MI	12,504 ^d	32,611 ^d	45,115 ^d	72	27.4	71.9	457	454	454
MN	3,784 ^d	14,532 ^d	18,316 ^d	79	15.7	39.5	241	368	332
MS	252	2,156	2,408	90	8.9	21.0	28	103	81
MO	2,505	11,217	13,722	82	17.1	43.8	147	256	225
MT	403	2,130	2,533	84	2.8	7.6	143	280	243
NE	224	4,462	4,686	95	5.8	13.2	38	337	246
NV	146	1,887	2,033	93	8.1	21.3	18	89	69
NH	1,275 ^d	3,960 ^d	5,235 ^d	76	3.4	10.0	379	396	392
NJ	0	10,922	10,922	100	24.2	65.2	0	167	122
NM	DNF	DNF	4,916	DNF	6.0	14.8	DNF	DNF	236
NY	17,250 ^e	60,705 ^e	77,955 ^e	78	52.3	145.2	330	418	395
NC	7,168 ^e	9,724 ^e	16,892 ^e	58	28.4	73.0	252	133	166
ND	2,512	2,264	4,776	47	2.2	5.3	1,117	425	630
OH	5,772	31,045	36,817	84	32.2	83.9	179	370	317
OK	742	4,883	5,625	87	11.7	27.5	63	178	143
OR	3,766	8,782	12,548	70	10.7	30.3	353	290	307
PA	3,924	30,223	34,147	89	33.6	94.2	117	321	267
RI	0	3,638	3,638	100	2.8	7.8	0	467	344
SC	2,187	8,101	10,288	79	13.6	36.0	161	225	207
SD	981	2,644	3,625	73	2.6	6.0	376	437	419
TN	344	7,746	8,090	96	18.4	48.2	19	161	122
TX	6,891 ^d	29,780 ^d	36,671 ^d	81	88.2	190.4	78	156	132
UT	1,499	3,704	5,203	71	11.1	19.5	136	190	171
VT	278	2,732	3,010	91	1.6	4.6	173	588	482
VA	7,026	10,150	17,176	59	23.2	60.9	302	167	204
WA	2,027	13,559	15,586	87	19.8	53.1	102	256	214
WV	DNF	DNF	4,634	DNF	4.7	13.7	DNF	DNF	253
WI	4,631 ^d	26,829 ^d	31,460 ^d	85	16.0	41.7	289	643	544
WY	768	1,592	2,360	67	1.7	4.2	454	382	403
Reported US Total	201,716	595,119	807,462	75	907.8	2,323.5	222	256	247
Estimated US Total	204,406	603,056	807,462	75	907.8	2,323.5	225	260	250

^d Other date (Usually a different fiscal year or June 30, 2015). ^e Estimate. ^{DNF} Did not furnish. ⁵ Source U.S. Census Bureau, Population Division (2017). * See state notes in Appendix.

Waiver Utilization Rates

On June 30, 2016, there were an estimated 250 Medicaid Waiver recipients with IDD per 100,000 of the U.S. population. Medicaid Waiver utilization rates per 100,000 of the population ranged from 69 per 100,000 in Nevada to 630 per 100,000 in North Dakota. States with the highest utilization rates were North Dakota (630 per 100,000), Wisconsin (544), Vermont (482), Idaho (459), Michigan (454), and Iowa (450). States with the lowest Medicaid Waiver utilization rates were Georgia (83 per 100,000), Mississippi (81), and Nevada (69).

Waiver Utilization Rates by Age

Medicaid Waiver utilization rates for people with IDD 21 years or younger averaged 225 recipients per 100,000 of the population. Rates for recipients 22 years or older averaged 260 per 100,000.

Waiver utilization rates for people 21 years or younger with IDD were highest in North Dakota (1,117 per 100,000), Arizona (914), Idaho (801), and Kentucky (512). They were lowest New Jersey and Rhode Island (less than 1 per 100,000), the District of Columbia (12) and Massachusetts (14).

Medicaid Waiver utilization rates for people 22 years or older with IDD were highest in Wisconsin (643 people with IDD per 100,000), Vermont (588), Rhode Island (467), and Michigan (454). They were lowest in Nevada (89 people with IDD per 100,000), Mississippi (103), Georgia (110), and North Carolina (133).

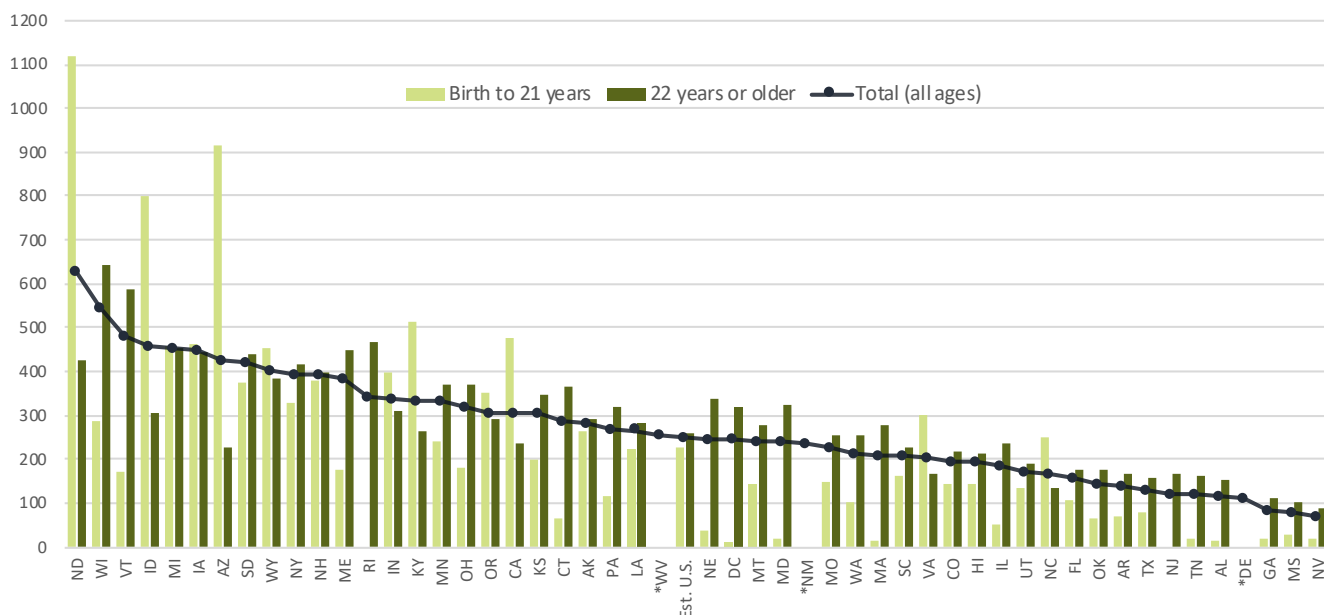
States with the biggest differences in Medicaid Waiver utilization rates in favor of people 21 years or younger with IDD included Arizona (914 recipients 21 years or younger versus 228 recipients 22 years or older), a four-fold difference; and Idaho (804 versus 304) and North Dakota (1,117 versus 425) both with utilization rates 2.6 times higher for people 21 years or younger.

States with the biggest differences in Medicaid Waiver utilization rates in favor of people 22 years or older with IDD included the District of Columbia (12 people per 100,000 versus 319, a 27 fold difference) Massachusetts (14 versus 279, a 20 fold difference), Maryland (18 versus 324, an 18 fold difference), and Alabama (17 versus 153, a 9 fold difference).

Medicaid Waiver Recipients by Age and Living Arrangement

Of the estimated 204,406 Medicaid Waiver recipients 21 years or younger, 85% (173,363

Figure 2.4 Medicaid Waiver Recipients with IDD per 100,000 of the Population by Age and State on June 30, 2016



* Age breakdowns were not available for Delaware, New Mexico or West Virginia

Table 2.4 Medicaid Waiver Recipients with IDD Living in Family Homes or Other LTSS Settings by Age and State on June 30, 2016

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	37	40	38	41	37	40
AL	13	2,118	211	3,238	6	40
AK	277	0	325	1,442	46	0.0
AZ	16,122	9,878	2,220	1,360	88	88
AR	DNF	DNF	DNF	DNF	DNF	DNF
CA	51,591	34,707	1,839	31,547	97	52
CO	1,437	0	812	8,597	64	0
CT	504	3,721	117	5,864	81	39
DE	0 ^d	1 ^d	27 ^d	1,013 ^d	0	0
DC	7	578	6	993	54	37
FL	4,393	13,974	856	13,164	84	51
GA	558 ^d	2,647 ^d	101 ^d	5,200 ^d	85	34
HI	420	1,391	39 ^d	711	92	66
ID	DNF	DNF	DNF	DNF	DNF	DNF
IL	1,345	6,476	455	15,468	75	30
IN	7,436	7,426	314	7,122	96	51
IA	DNF	DNF	DNF	DNF	DNF	DNF
KS	DNF	DNF	DNF	DNF	DNF	DNF
KY	DNF	DNF	120	3,916	DNF	DNF
LA	DNF	DNF	DNF	DNF	DNF	DNF
ME	DNF	DNF	DNF	DNF	DNF	DNF
MD	51	1,002	246	13,125	17	7
MA	DNF	2,588	DNF	11,440	DNF	18
MI	11,178 ^{ed}	13,530 ^d	1,283 ^{ed}	17,666 ^d	90	43
MN	3,138 ^d	3,595 ^d	646 ^d	10,937 ^d	83	25
MS	252	1,376	0	780	100	64
MO	1,999	4,500	506	6,721	80	40
MT	DNF	DNF	DNF	DNF	DNF	DNF
NE	178	1,162	154	3,205	54	27
NV	34	635	112	1,252	23	34
NH	DNF	1,047 ^d	DNF	1,494 ^d	DNF	41
NJ	DNF	3,072	DNF	7,850	DNF	28
NM	DNF	DNF	DNF	DNF	DNF	DNF
NY	16,515 ^e	23,808 ^e	735 ^e	36,897 ^e	96	39
NC	7,292 ^e	7,952 ^e	1,156 ^e	4,893 ^e	86	62
ND	1,056	196	33	1,562	97	11
OH	5,275	15,150	497	15,895	91	49
OK	436	1,459	304	3,418	59	30
OR	391	2,595	105	4,318	79	38
PA	4,360	13,977	567	16,000	88	47
RI	0	1,476	0	2,162	0	41
SC	2,117	4,453	70	3,648	97	55
SD	892	560	91	2,084	91	21
TN	143	2,671	201	5,075	42	34
TX	4,307 ^d	7,124 ^d	2,571 ^d	22,625 ^d	63	24
UT	836	1,074	663	2,630	56	29
VT	122	864	156	1,868	44	32
VA	DNF	DNF	DNF	DNF	DNF	DNF
WA	1,239 ^e	4,091 ^e	373 ^e	6,695 ^e	77	38
WV	DNF	DNF	DNF	DNF	DNF	DNF
WI	4,531 ^d	11,764 ^d	100 ^d	15,065 ^d	98	44
WY	662	430	63	1,067	91	29
Reported US Total	151,107	215,068	18,074	320,007	89	40
Estimated US Total¹	173,363	254,547	31,043	348,509	85	42

^d Other date (Usually a different fiscal year or June 30, 2015). ^e Estimate. ^{DNF} Did not furnish. ^{PD} Partial data, calculation incomplete and not included in reported totals. * See state notes in the Appendix. This table reports 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.

people) lived in the home of a family member on June 30, 2016 (See **Table 2.4**). All Medicaid Waiver recipients 21 years or younger in Mississippi lived in the home of a family member as did between 95% and 100% of Waiver recipients 21 years or younger in California, Indiana, New York, North Dakota, South Carolina, and Wisconsin. Fewer than half of all Waiver recipients 21 years or younger lived in the home of a family member in Alabama, Alaska, Delaware, Maryland, Nevada, Rhode Island, Tennessee and Vermont.

Of the 603,056 Medicaid Waiver recipients 22 years or older, 42% (254,547 people) lived in the home of a family member. The only states serving more than half of Waiver recipients with IDD ages 22 years or older in the home of a family member were Arizona (88%), Hawaii (66%), Mississippi (64%), and North Carolina (62%). Fewer than 20% of Waiver recipients 22 years or older lived in the home of a family member in Delaware (7%), Massachusetts (18%), and North Dakota (11%).

Living Arrangements by Funding Authority

Nationally, 66% (807,462 people) of the 1,228,700 people with IDD receiving LTSS on June 30, 2016 were Medicaid Waiver recipients. Of the estimated 146,974 LTSS recipients with IDD living in their own home, 80% (117,508 people) were Medicaid Waiver recipients. Of the 714,910 LTSS recipients living with a family member, 60% (427,910 people) were Medicaid Waiver recipients (See **Table 2.5**).

In 16 states, all LTSS recipients with IDD who lived with a family member received Medicaid Waiver-funded supports. In an additional five states, more than 95% of LTSS recipients living in the home of a family member received Medicaid Waiver-funded supports. Fewer than half of the LTSS recipients with IDD living in the home of a family member received Medicaid Waiver-funded supports in Florida (48%), New York (47%), South Carolina (45%), Vermont (45%), Washington (44%), Tennessee (38%), Ohio (27%), New Jersey (21%), Nevada (15%), and Delaware (less than 1%).

All of the LTSS recipients with IDD living in their own home received Medicaid Waiver-funded supports in 22 states. In nine additional states, more 95% of

Table 2.5 Medicaid Waiver and LTSS Recipients with IDD in Own Home or Family Settings by State on June 20, 2016

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	47	45	44	45	44
AL	55	2,131	55	2,131	100	100
AK	705	277	705	277	100	100
AZ	267	32,706	267	25,050	100	77
AR	639	1,973 ^{ed}	639	1,925 ^{ed}	100	98 ^{ed}
CA	25,569	172,850	11,540	86,298	45	50
CO	4,867	2,785	4,287	1,437	88	52
CT	1,274	1,477	1,241	1,428	97	97
DE	18	3,231	18 ^d	1 ^d	100	0
DC	11	848	11	574	100	68
FL	5,742	38,917	5,152	18,735	90	48
GA	1,145	3,274	1,145	3,274	100	100
HI	72	1,811	72	1,811	100	100
ID	1,206	1,554 ^d	1,206	DNF	100	PD
IL	1,681	11,477	1,681	11,477	100	100
IN	6,180	14,175	6,180	13,661	100	96
IA	DNF	DNF	DNF	DNF	DNF	DNF
KS	DNF	DNF	DNF	DNF	DNF	DNF
KY	DNF	DNF	DNF	DNF	DNF	DNF
LA	2,413	13,526	2,362	10,017	98	74
ME	629 ^e	DNF	629 ^e	DNF	100 ^e	DNF
MD	2,677	1,728	2,389	1,037	89	60
MA	2,593	8,294	DNF	DNF	PD	PD
MI	6,980 ^d	25,780 ^d	6,980 ^d	24,653 ^d	100 ^d	96 ^d
MN	2,294 ^d	11,232 ^d	1,683 ^d	11,232 ^d	73 ^d	100 ^d
MS	45	1,755	45	1,755	100	100
MO	4,558	10,922	4,557	6,695	100	61
MT	143 ^e	1,014 ^e	143 ^e	1,014 ^e	100 ^e	100 ^e
NE	1,220	1,928	1,202	1,248	99	65
NV	1,642	4,595	1,262	669	77	15
NH	470 ^d	1,047 ^d	459 ^d	1,047 ^d	98 ^d	100 ^d
NJ	87	14,466	0	3,072	0	21
NM	DNF	963 ^e	DNF	DNF	DNF	PD
NY	11,233 ^e	86,722 ^e	5,449 ^e	40,870 ^e	49 ^e	47 ^e
NC	DNF	7,674 ^e	DNF	7,227 ^e	DNF	94 ^e
ND	1,276	1,252	1,276	1,252	100	100
OH	15,709	77,666	11,853	20,784	75	27
OK	2,451	1,895	2,445	1,895	100	100
OR	807 ^d	12,836 ^e	807 ^d	6,668	100 ^d	52 ^e
PA	4,645 ^e	32,654 ^e	2,500 ^e	18,337 ^e	54 ^e	56 ^e
RI	480	1,476	480	1,476	100	100
SC	690	14,457	637	6,570	92	45
SD	536	2,050	365	1,453	68	71
TN	4,173	7,329	4,169	2,814	100	38
TX	3,894 ^d	11,436 ^d	3,894 ^d	11,436 ^d	100	100 ^d
UT	1,261	1,681	1,241	1,652	98	98
VT	376	2,195	242	986	64	45
VA	230 ^e	3,871	230	3,871	100 ^e	100
WA	6,089	13,532 ^e	3,857 ^e	5,902 ^e	63	44 ^e
WV	2,461	2,077	2,461	2,077	100	100
WI	6,193 ^d	24,666 ^d	6,181 ^d	16,295 ^d	100 ^d	66 ^d
WY	428	1,092	428	1,092	100	100
Reported US Total	138,114	693,297	104,425	383,175	77	56
Estimated US Total	146,974	714,910	117,508	427,910	80	60

^d Other date (Usually a different fiscal year or June 30, 2015). ^e Estimate. ^{DNF} Did not furnish. * See state notes in Appendix. ¹ Proportion of recipients whose services were funded by a Medicaid HCBS Waiver.

Figure 2.5 Annual Medicaid Waiver Expenditures for People with IDD per State Resident by State FY 2016



Note: WV is not shown due to incomplete data.

LTSS recipients living in their own home received Medicaid Waiver-funded supports. Three states reported fewer than half of the LTSS recipients living in their own home received Medicaid Waiver-funded supports in New York (49%), California (45%), and New Jersey (none).

MEDICAID WAIVER EXPENDITURES

Total Medicaid Waiver expenditures¹ for the 807,462 recipients with IDD in FY 2016 were \$35.47 billion (See **Table 2.6**). Medicaid Waiver expenditures were reported by 50 states. Expenditures for the missing state were estimated using Centers for Medicare and Medicaid Services quarterly expense report (CMS 64 data) for Federal Fiscal Year 2015 (Eiken, Sredl, Burwell, and Woodward, 2017). The CMS summary of FFY 2016 Medicaid LTSS expenditures was not released in time to be used for this report.

FY 2016 annual Medicaid Waiver expenditures for recipients with IDD averaged \$43,928 per recipient and ranged from \$5,676 to \$118,910 per recipient. The highest annual per recipient expenditures were reported in the District of Columbia (\$118,910), Delaware (\$111,093), Connecticut (\$91,495), New Jersey (\$88,230), Alaska (\$84,213), and Tennessee (\$82,986). The lowest annual per recipient expenditures were reported in Idaho (\$29,545), Virginia (\$29,352), California (\$24,579), Washington (\$23,737), Indiana (\$23,669) and Oregon² (\$5,676).

Total FY 2016 Medicaid Waiver expenditures were \$110 per United States resident (See **Figure 2.5**). Highest per capita Medicaid Waiver expenditures were reported for the District of Columbia (\$292), Vermont (\$276), New York (\$273), Connecticut (\$261), North Dakota (\$254), Maine (\$253), Alaska (\$238), and Minnesota (\$231). Lowest per capita Medicaid Waiver expenditures were for Texas (\$51), Washington (\$51), Florida (\$48), Georgia (\$35), Nevada (\$33), Mississippi (\$26), and Oregon (\$17).

¹ Unlike the Medicaid Intermediate Care Facilities for Individuals with Intellectual Disabilities funding authority, Medicaid Waiver funds may not be used to pay room and board costs (those expenses must be covered through non-Medicaid pro-grams).

² Oregon and Washington both introduced the Medicaid 1915(k) State Plan funding authority as an alternative to Medicaid Waiver funding reducing annual per person Waiver expenditures as a result (See their state profiles for more detail).

Table 2.6 Medicaid Waiver Expenditures for Recipients with IDD, Per Recipient and Per State Resident by Age and State in FY 2016

State	Waiver Expenditures (\$)			FY 2016 Waiver Recipients	Expenditures per Recipient (\$)			State Population ^s (100,000)	Expenditures per State Resident (\$)
	Birth to 21	22 Years +	Total		Birth to 21	22 years +	Total		
N States	47	47	50	51	47	47	50	51	50
AL	18,152,236	342,980,770	361,133,006	5,580	81,037	64,037	64,719	48.6	74
AK	25,701,813	150,555,938	176,257,752	2,093	42,765	100,909	84,213	7.4	238
AZ	311,167,944	576,991,819	888,159,763	29,580	16,965	51,343	30,026	69.3	128
AR	23,808,695	191,586,385	215,395,080	4,135	39,681	54,197	52,091	29.9	72
CA	544,645,716	2,406,940,809	2,951,586,525	120,084	10,194	36,111	24,579	392.5	75
CO	41,474,269	386,770,181	428,244,451	10,846	18,441	44,989	39,484	55.4	77
CT	25,455,275	909,716,621	935,171,896	10,221	40,991	94,762	91,495	35.8	261
DE	DNF	DNF	119,647,068	1,077	DNF	DNF	111,093	9.5	126
DC	1,350,290	197,228,879	198,579,169	1,670	71,068	119,460	118,910	6.8	292
FL	83,424,686	905,731,023	989,155,709	32,830	15,401	33,040	30,130	206.1	48
GA	16,063,804	340,430,926	356,494,730	8,579	26,334	42,719	41,554	103.1	35
HI	18,902,371	114,762,031	133,664,402	2,753	35,598	51,648	48,552	14.3	94
ID	72,820,635	155,442,300	228,262,935	7,726	17,326	44,122	29,545	16.8	136
IL	58,112,890	827,633,900	885,746,790	23,744	32,285	37,716	37,304	128.0	69
IN	56,173,890	471,608,591	527,782,481	22,298	7,248	32,417	23,669	66.3	80
IA	77,821,693	465,541,104	543,362,797	14,091	18,406	47,201	38,561	31.3	173
KS	79,017,858	405,155,493	484,173,351	8,836	44,467	57,396	54,796	29.1	167
KY	203,591,834	432,461,663	636,053,497	14,768	31,966	51,490	43,070	44.4	143
LA	54,407,572	413,754,452	468,162,024 ^e	12,379	18,227	44,045	37,819	46.8	100
ME	13,341,648 ^e	323,534,092 ^e	336,875,740 ^e	5,087	23,910	71,436	66,223	13.3	253
MD	7,719,193	866,115,979	873,835,172	14,424	25,991	61,309	60,582	60.2	145
MA	5,719,057	1,003,036,720	1,008,755,777	14,274	23,248	71,502	70,671	68.1	148
MI	242,962,540 ^d	1,194,686,390 ^d	1,437,648,930 ^d	45,115	19,431	36,634	31,866	99.3	145
MN	177,128,774 ^d	1,099,761,663 ^d	1,276,890,437 ^d	18,316	46,810	75,679	69,714	55.2	231
MS	7,982,322	68,704,972	76,687,294	2,408	31,676	31,867	31,847	29.9	26
MO	78,242,883	691,062,589	769,305,472	13,722	31,235	61,609	56,064	60.9	126
MT	10,389,185	94,693,142	105,082,327	2,533	25,780	44,457	41,485	10.4	101
NE	15,032,769	280,401,929	295,434,698	4,686	67,111	62,842	63,046	19.1	155
NV	7,767,584	88,699,143	96,466,727	2,033	53,203	47,005	47,450	29.4	33
NH	12,362,582 ^d	220,569,232 ^d	232,931,814 ^d	5,235	9,696	55,699	44,495	13.3	175
NJ	0	963,648,060	963,648,060	10,922	0	88,230	88,230	89.4	108
NM	DNF	DNF	320,915,462	4,916	DNF	DNF	65,280	20.8	154
NY	273,504,095	5,118,327,791	5,391,831,886	77,955	15,855	84,315	69,166	197.5	273
NC	110,671,666 ^e	493,137,931 ^e	603,809,596 ^e	16,892	15,440	50,713	35,745	101.5	60
ND	DNF	DNF	192,609,419	4,776	PD	PD	40,329	7.6	254
OH	110,727,451	1,418,432,042	1,529,159,493	36,817	19,184	45,690	41,534	116.1	132
OK	19,001,930	291,645,170	310,647,099	5,625	25,609	59,727	55,226	39.2	79
OR	9,964,131	61,263,409	71,227,540	12,548	2,646	6,976	5,676	40.9	17
PA	89,206,981	2,438,432,194	2,527,639,175	34,147	22,734	80,681	74,022	127.8	198
RI	0	234,726,062	234,726,062	3,638	0	64,521	64,521	10.6	222
SC	70,362,375	260,633,564	330,995,939	10,288	32,173	32,173	32,173	49.6	67
SD	8,369,671	107,598,396	115,968,067	3,625	8,532	40,695	31,991	8.7	134
TN	23,733,788	647,624,944	671,358,732	8,090	68,994	83,608	82,986	66.5	101
TX	219,212,969 ^d	1,198,794,073 ^d	1,418,007,042 ^d	36,671	31,811	40,255	38,668	278.6	51
UT	31,919,179	180,873,867	212,793,046	5,203	21,294	48,832	40,898	30.5	70
VT	13,722,693	158,504,434	172,227,127	3,010	49,362	58,018	57,218	6.2	276
VA	73,559,476	430,590,916	504,150,392	17,176	10,470	42,423	29,352	84.1	60
WA	48,094,694	321,864,490	369,959,184	15,586	23,727	23,738	23,737	72.9	51
WV	DNF	DNF	DNF	4,634	DNF	DNF	DNF	18.3	DNF
WI	55,030,605 ^d	986,236,882 ^d	1,041,267,487 ^d	31,460	11,883	36,760	33,098	57.8	180
WY	10,191,053	81,142,147	91,333,200	2,360	13,270	50,969	38,701	5.9	156
Estimated US Total	3,557,512,880	31,912,580,467	35,470,093,347	807,462	17,404	52,918	43,928	3,231.3	110

^d Other date (Usually a different fiscal year or June 30, 2015). ^e Estimate. ^{DNF} Did not furnish. ⁱ Missing value imputed (RISP estimated). ^s U.S. Census Bureau, Population Division (2017). * See state notes in Appendix.

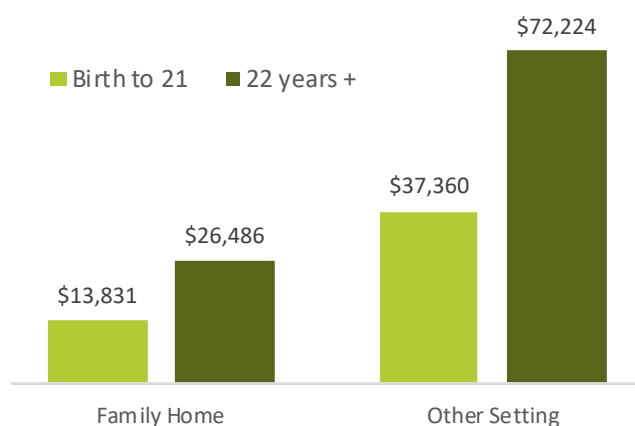
Waiver Expenditures by Age

Total FY 2016 Medicaid Waiver expenditures were \$3.56 billion for recipients with IDD ages 21 years or younger, and \$31.91 billion for recipients with IDD ages 22 years or older. While 90% of Medicaid Waiver expenditures were for people ages 22 years or older only 75% of Medicaid Waiver recipients with IDD were in that age group.

Average annual per person Medicaid Waiver expenditures in FY 2016 were \$17,404 for people ages birth to 21 years (See **Table 2.6**). States with the highest average per person expenditures for people ages birth to 21 years were Alabama (\$81,037), the District of Columbia (\$71,068), Tennessee (\$68,994) and Nebraska (\$67,111). States with the lowest average per person Waiver expenditures for people ages birth to 21 years were New Hampshire (\$9,696), South Dakota (\$8,532), Indiana (\$7,248), Oregon (\$2,646), New Jersey (none), and Rhode Island (none).

Average annual per person Medicaid Waiver expenditures in FY 2016 were \$52,918 for people ages 22 years or older. States with the highest average annual per person Waiver expenditures for people ages 22 years or older were the District of Columbia (\$119,460), Alaska (\$100,909), and Connecticut (\$94,762). States with the lowest per person expenditures for people 22 years or older were Florida (\$33,040), Indiana (\$32,417), South Carolina (\$32,173), Mississippi (\$31,867), Washington (\$23,738) and Oregon (\$6,976).

Figure 2.6 Estimated Average Annual Per Person Medicaid Waiver Expenditures by Age and Living Arrangement in FY 2016



Waiver Expenditures by Age and Residence Type

Thirty states reported annual Medicaid Waiver expenditures by age and living arrangement for FY 2016 (See **Table 2.7** and **Figure 2.6**). Thirty-seven states reported the number of Medicaid recipients by both age and living arrangement (See **Table 2.4**).

Prior to FY 2016, national estimates of average annual per person Medicaid Waiver expenditures by age and residence type were based only on the states that reported recipients and expenditures for people 21 years or younger and people 22 years or older, and for recipients living with a family member and recipients living in another setting. Beginning with this FY 2016 report, the U.S. estimated totals have been adjusted to maintain the national proportion of recipients by age as reported on **Table 2.3**.

Waiver Recipients 21 Years or Younger Living in the Home of a Family Member

In FY 2016, there were an estimated 173,363 Medicaid Waiver recipients with IDD ages 21 years or younger who lived in the home of a family member. Average annual per person Medicaid Waiver expenditures for this group were estimated to be \$13,841 per person nationally with state averages ranging from \$1,214 to \$45,948. States reporting the highest per person averages for this group were Vermont (\$45,948), Alaska (\$38,928), Minnesota (\$37,121), Hawaii (\$37,021), Alabama (\$36,672), and Mississippi (\$35,066). States reporting the lowest per person averages for this group were (\$9,720), Connecticut (\$9,539), California (\$8,637), Pennsylvania (\$8,629), Florida (\$8,329), and Indiana (\$6,136), and Oregon (\$1,214).

Waiver Recipients 22 Years or Older Living in the Home of a Family Member

In FY 2016, there were an estimated 254,547 Medicaid Waiver recipients ages 22 years or older living with a family member. Average annual per person Medicaid Waiver expenditures for this group were estimated to be \$26,486 per person nationally with state averages ranging from \$6,696 to \$71,502. States reporting the highest per person averages for this group were Massachusetts (\$71,502), Delaware (\$67,045), and the District of Columbia (\$54,438). States reporting the lowest per person averages for this group were Utah (\$19,139), California (\$17,199),

Table 2.7 Medicaid Waiver Expenditures and Average Per Recipient by Age, Living Arrangement, and State in FY 2016

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	33	32	34	33	31	30	32	33
AL	476,742 ¹	74,000,000 ¹	17,675,494 ¹	268,980,770 ¹	36,672 ¹	34,939 ¹	83,770 ¹	83,070 ¹
AK	10,783,135	0	14,918,679	150,555,938	38,928	N/A	45,904	104,408
AZ	253,376,912	205,917,522	57,791,033	371,074,297	15,716	20,846	26,032	272,849
AR	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
CA	445,589,517	596,930,722	99,056,199	1,810,010,087	8,637	17,199	53,864	57,375
CO	21,732,338	0	19,741,931	386,770,181	15,123	N/A	24,313	44,989
CT	4,807,785	122,810,759	20,647,489	786,905,862	9,539	33,005	176,474	134,193
DE	0 ^d	67,045 ^d	213,287 ^d	118,290,027 ^d	N/A ^d	67,045 ^d	7,900 ^d	116,772 ^d
DC	234,422	31,465,350	1,027,703	160,045,632	33,489	54,438	171,284	161,174
FL	36,588,897	283,927,596	46,835,789	621,803,427	8,329	20,318	54,715	47,235
GA	11,935,550 ^d	59,328,524 ^d	5,311,588 ^d	279,430,161 ^d	21,390 ^d	22,413 ^d	52,590 ^d	53,737 ^d
HI	15,549,029	65,008,432	866,924	45,426,161	37,021	46,735	22,229 ^d	63,891
ID	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
IL	23,725,800	171,354,960	34,387,090	656,278,940	17,640	26,460	75,576	42,428
IN	45,628,954	101,423,104	10,544,936	370,185,487	6,136	13,658	33,583	51,978
IA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
KS	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
KY	DNF	DNF	5,402,979	211,360,370	DNF	DNF	45,025	53,974
LA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
ME	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MD	1,104,396	33,030,806	6,614,797	833,085,173	21,655	32,965	26,889	63,473
MA	DNF	185,048,405	DNF	817,988,315 ^e	DNF	71,502	DNF	71,502 ^e
MI	185,290,949 ^d	273,684,749 ^d	57,671,591 ^d	921,001,643 ^d	16,576 ^{de}	20,228 ^d	44,951 ^{de}	52,134 ^d
MN	116,484,187 ^d	165,459,990 ^d	60,644,587 ^d	934,301,673 ^d	37,121 ^d	46,025 ^d	93,877 ^d	85,426 ^d
MS	8,836,568	48,071,431	0	27,249,793	35,066	34,936	N/A	34,936
MO	20,129,278	76,576,274	53,903,586	604,442,876	10,070	17,017	106,529	89,933
MT	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NE	3,037,243	29,706,477	12,950,025	244,710,237	17,063	25,565	84,091	76,353
NV	563,987	9,849,709	7,203,597	78,849,434	16,588	15,511	64,318	62,979
NH	DNF	DNF	DNF	DNF	DNF	PD	DNF	PD
NJ	DNF	DNF	DNF	DNF	DNF	PD	DNF	PD
NM	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NY	DNF	DNF	DNF	DNF	PD	PD	PD	PD
NC	106,346,967 ^e	260,250,670 ^e	34,288,643 ^e	343,332,554 ^e	14,584 ^e	32,728 ^e	29,661 ^e	70,168 ^e
ND	DNF	DNF	DNF	DNF	PD	PD	PD	PD
OH	83,665,193	367,188,092	27,062,258	1,051,243,950	15,861	24,237	54,451	66,137
OK	5,091,702	33,534,120	13,910,226	258,189,876	11,678	22,984	45,757	75,538
OR	474,505	17,375,465	440,024	46,367,894	1,214	6,696	4,191	10,738
PA	37,623,713	499,633,163	50,529,876	1,927,910,057	8,629	35,747	89,118	120,494
RI	0	DNF	0	DNF	N/A	PD	N/A	PD
SC	68,110,264	143,266,625	2,252,111	117,367,314	32,173	32,173	32,173	32,173
SD	DNF	DNF	DNF	DNF	PD	PD	PD	PD
TN	3,769,525	80,737,044	19,964,263	566,887,900	26,360	30,227	99,325	111,702
TX	120,855,917 ^d	237,923,195 ^d	95,295,308 ^d	946,861,382 ^d	28,060 ^d	33,397 ^d	37,065 ^d	41,850 ^d
UT	8,125,873	20,555,819	23,793,306	160,318,048	9,720	19,139	35,887	60,957
VT	5,605,698	38,323,331	8,116,995	120,181,103	45,948	44,356	52,032	64,337
VA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
WA	36,036,518 ^e	118,920,511 ^e	10,810,956 ^e	194,597,200 ^e	29,085 ^e	29,069 ^e	28,984 ^e	29,066 ^e
WV	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
WI	51,336,284 ^d	DNF ^d	3,694,320 ^d	DNF ^d	11,330 ^d	PD	36,943 ^d	PD
WY	DNF	DNF	DNF	DNF	PD	PD	PD	PD
Reported US Total	1,732,917,848	4,351,369,888	823,567,588	16,432,003,762				
Estimated US Total	2,397,747,719	6,741,831,479	1,159,765,161	25,170,748,988	13,831	26,486	37,360	72,224

^d Other date (Usually a different fiscal year or June 30, 2015). ^e Estimate. ^{DNF} Did not furnish. ^{N/A} Not applicable. ^{PD} Partial data, calculation incomplete and not included in reported totals. ¹ One or more component value imputed by RISP staff. * See state notes in the Appendix.

Missouri (\$17,017), Nevada (\$15,511), Indiana (\$13,658), and Oregon (\$6,696).

Waiver Recipients 21 Years or Younger Living in Other Settings

In FY 2016, there were an estimated 31,043 Medicaid Waiver recipients with IDD ages 21 and younger living in a non-family setting such as a host or foster family setting or a group home. Average annual per person Medicaid Waiver expenditures for this group were estimated to be \$37,360 per person nationally with state averages ranging from \$4,191 to \$176,474. States reporting the highest per person averages for this group were Connecticut (\$176,474), the District of Columbia (\$171,284), and Missouri (\$106,529). States reporting the lowest per person averages for this group were Colorado (\$24,313), Hawaii (\$22,229), Delaware (\$7,900) and Oregon (\$4,191).

Waiver Recipients 22 Years or Older Living in Other Settings

In FY 2016, there were an estimated 348,509 Medicaid Waiver recipients 22 years or older living in a non-family setting. Average annual per person Medicaid Waiver expenditures for this group were estimated to be \$72,224 per person nationally with state averages ranging from \$10,738 to \$272,849. States reporting the highest per person averages for this group were Arizona (\$272,849), the District of Columbia (\$161,174), Connecticut (\$134,193), Pennsylvania (\$120,494), Delaware (\$116,772), Tennessee (\$111,702), and Alaska (\$104,408). States reporting the lowest per person averages for this group were Mississippi (\$34,936), South Carolina (\$32,173), Washington (\$29,066), and Oregon (\$10,738).

Average annual per person expenditures were 2.7 times higher for recipients living in a non-family setting than for those living with a family member. The higher costs associated with Medicaid Waiver services provided in a setting other than the home of a family member can, in part, be explained by the unreimbursed time family members spend providing supports that would otherwise have to be provided by a paid caregiver.

Among Medicaid Waiver recipients living in the home of a family member, average annual expenditures were 35% higher for people 22 years or older than for people 21 years or younger. Among Waiver recipients living in other settings, average annual



expenditures for people 22 years or older were 34% higher than for people 21 years or younger.

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

While most people with IDD who receive LTSS under the auspices of state IDD agencies receive Medicaid Waiver-funded supports, a substantial minority resided in an ICF/IID. This section describes ICF/IID settings, recipients and expenditures as of June 30, 2016.

Table 2.8 State and Nonstate Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) by Size and State on June 30, 2016

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	49	48	48	51	49	48	48	51
AL	0	0	0	0	0	2	0	2	0	2	0	2
AK	0	0	0	0	0	0	0	0	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	1,195	0	10	1,205	1,195	0	14	1,209
CO	0	14	2	16	4	0	0	4	4	14	2	20
CT	0	0	6	6	63	5	0	68	63	5	6	74
DE	0	0	1	1	0	0	1	1	0	0	2	2
DC	0	0	0	0	67	1	0	68	67	1	0	68
FL	0	0	2	2	39	3	48	90	39	3	50	92
GA	0	0	0	0	0	0	0	0	0	0	0	0
HI	0	0	0	0	16 ^d	1 ^d	0	17	16	1	0	17
ID	1	0	1	2	22	41	0	63	23	41	1	65
IL	0	0	7	7	39	157	30	226	39	157	37	233
IN	0	0	0	0	164	321	2	487	164	321	2	487
IA	0	0	2	2	71	45	21	137	71	45	23	139
KS	0	0	2	2	DNF	DNF	DNF	24	DNF	DNF	DNF	26
KY	0	3	2	5	0	0	2	2	0	3	4	7
LA	1	3	2	6	305	212	9	526	306	215	11	532
ME	0	0	0	0	2	13	2	17	2	13	2	17
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 ^d	0 ^d	0 ^d	0	0 ^d	0 ^d	0 ^d	0	0	0	0	0
MN	15 ^d	0 ^d	0 ^d	15	136 ^d	43 ^d	14 ^d	193	151	43	14	208
MS	4	59	6	69	DNF	DNF	DNF	7	DNF	DNF	DNF	76
MO	0	0	6	6	0	6	1	7	0	6	7	13
MT	0	0	1	1	0	0	0	0	0	0	1	1
NE	0	1	4	5	6	1	2	9	6	2	6	14
NV	0	0	1	1	5	0	1	6	5	0	2	7
NH	0	0	0	0	0	0	1	1	0	0	1	1
NJ	0	0	5	5	0 ^d	0 ^d	1 ^s	1	0	0	6	6
NM	1	0	0	1	68 ^e	0	0	68	69	0	0	69
NY	2	3	20	25	79	363	31	473	81	366	51	498
NC	2	0	4	6	297 ^d	28 ^d	13 ^d	338	299	28	17	344
ND	0	0	1	1	41	26	1	68	41	26	2	69
OH	0	0	10	10	123	238	77	438	123	238	87	448
OK	0	0	0	0	19	35	30	84	19	35	30	84
OR	0	0	0	0	0	0	0	0	0	0	0	0
PA	0	0	5	5	123	34	19	176	123	34	24	181
RI	2 ^s	0 ^s	0	2	0 ^d	0 ^d	1 ^d	1	2	0	1	3
SC	0	0	5	5	0	61	0	61	0	61	5	66
SD	0	0	1	1	0	0	1	1	0	0	2	2
TN	37	1	1	39	68	47	1	116	105	48	2	155
TX	2 ^d	0 ^d	13 ^d	15	745 ^d	45 ^d	3 ^d	794	747	45	16	809
UT	0	0	1	1	0	DNF	DNF	17	0	DNF	DNF	18
VT	0	0	0	0	1	0	0	1	1	0	0	1
VA	0	0	3	3	25	24	4	53	25	24	7	56
WA	0	0	4	4	7	1	0	8	7	1	4	12
WV	0	0	0	0	16	52	0	68	16	52	0	68
WI	0 ^d	0 ^d	3 ^d	3	0 ^d	2 ^d	19 ^d	21	0	2	22	24
WY	0	0	1	1	0	0	0	0	0	0	1	1
Reported US Total	67	84	135	286	3,746	1,840	350	5,985	3,809	1,865	476	6,271
Estimated US Total	67	84	135	286	3,777	1,855	353	5,985	3,844	1,939	488	6,271

^d Other date (Usually a different fiscal year or June 30, 2015). ^e Estimate. ^{DNF} Did not furnish. ^s Other Source (AHCAa CASPER data, 2017). * See state notes in Appendix.

ICF/IID Facilities

State versus Nonstate Facilities

There were an estimated 6,271 ICF/IIDs on June 30, 2016 (See **Table 2.8**). Of those, 5% (286) were state-operated, and 95% (5,985) were operated by a nonstate entity. There were no state- or nonstate-operated ICF/IID facilities reported in Alaska, Georgia, Michigan, and Oregon, though those states may have paid for ICF/IID services provided to a state resident in an out of state facility.

There were no state-operated ICF/IIDs in Alabama, Alaska, Arizona, the District of Columbia, Hawaii, Indiana, Maine, Michigan, New Hampshire, Oklahoma, Oregon, Vermont, or West Virginia. There were more than ten state-operated ICF/IIDs in Mississippi (69 facilities), Tennessee (39), New York (25), Colorado (16), Minnesota (15), and Texas (15).

There were no nonstate-operated ICF/IIDs reported in Alaska, Georgia, Maryland, Massachusetts, Michigan, Montana, Oregon, or Wyoming. There were more than 500 nonstate ICF/IIDs in California (1,205 facilities), Texas (794), and Louisiana (526).

Facilities by Size

Of the ICF/IID settings on June 30, 2016, 61% (3,844 facilities) served six or fewer people, 31% (1,939 facilities) served 7-15 people and 8% (488 facilities) served 16 or more people. In New Mexico, and Vermont all ICF/IID settings served six or fewer people. The only ICF/IID in Alabama served 7 to 15 people. There were more than 20 ICF/IIDs serving 16 or more people in Ohio (87 facilities), New York (51), Florida (50), Illinois (37), Oklahoma (30), Pennsylvania (24), Iowa (23), and Wisconsin (22).

Of the 286 state-operated ICF/IIDs, 23% (67 facilities) had six or fewer residents, 29% (84 facilities) had 7 to 15 residents, and 47% (135 facilities) had 16 or more residents. Of the 37 states with a state-operated ICF/IID, 10 states had at least one facility serving six or fewer people, seven states had at least one facility serving 7 to 15 people, and 34 states had at least one facility of 16 or more people. All of the state-operated ICF/IID facilities in Minnesota, New Mexico, and Rhode Island served six or fewer people. In 24 states, all of the state-operated ICF/IID served 16 or more people.

Of the 5,985 nonstate ICF/IIDs, 63% (3,777 facilities) had six or fewer residents, 31% (1,855 facilities) had 7 to 15 residents, and 6% (353 facilities) had 16 or more residents. Of the 43 states that reported one or more nonstate ICF/IID, 28 states had at least one nonstate ICF/IID of 6 or fewer people, 28 states had at least one nonstate ICF/IID with 7 to 15 people, and 29 had one or more nonstate ICF/IID with 16 or more people. All nonstate ICF/IID in Colorado, New Mexico, and Vermont served six or fewer people. All nonstate ICF/IID in Arizona, Delaware, Kentucky, New Hampshire, New Jersey, Rhode Island, and South Dakota served sixteen or more people. States with 15 or more nonstate ICF/IIDs of 16 or more people were Ohio (77 facilities), Florida (48), New York (31), Illinois (30), Oklahoma (30), Iowa (21), Pennsylvania (19), and Wisconsin (19).

People in ICF/IID Settings

On June 30, 2016, an estimated 74,614 people lived in an ICF/IID (See **Table 2.9**). Over half (52%) of all ICF/IID recipients lived in six states (California, Illinois, Louisiana, New York, Ohio or Texas).



Table 2.9 People Living in an ICF/IID by Type of Operation, Setting Size and State on June 30, 2016

Size	State-Operated				Nonstate-Operated				All ICF/IID Settings			
	1-6	7-15	16+	Total	1-6	7-15	16+	Total	1-6	7-15	16+	Total
N States	51	51	51	51	51	51	51	51	51	51	51	51
AL	0	0	0	0	0	22	0	22	0	22	0	22
AK	0	0	0	0	0	0	0	0	0	0	0	0
AZ	0	0	0	0	0	0	37	37	0	0	37	37
AR	0	0	907	907	0	317	201	518	0	317	1,108	1,425
CA	0	0	963	963	6,226	0	729	6,955	6,226	0	1,692	7,918
CO	0	146	49	195	20	0	0	20	20	146	49	215
CT	0	0	429	429	318	43	0	361	318	43	429	790
DE	0	0	51	51	0	0	49	49	0	0	100	100
DC	0	0	0	0	322	1	0	323	322	1	0	323
FL	0	0	611	611	215	65	1,900	2,180	215	65	2,511	2,791
GA	0	0	0	0	0	0	0	0	0	0	0	0
HI	0	0	0	0	69 ^d	7 ^d	0	76	69	7	0	76
ID	1	0	25	26	DNF	DNF	0	431 ^s	DNF	DNF	25	457
IL	0	0	1,653	1,653	181	2,178	2,603	4,962	181	2,178	4,256	6,615
IN	0	0	0	0	829	2,375	45	3,249	829	2,375	45	3,249
IA	0	0	374	374	312	395	716	1,423	312	395	1,090	1,797
KS	0	0	314	314	DNF	DNF	DNF	136 ^s	DNF	DNF	DNF	450
KY	0	24	132	156	0	0	146	146	0	24	278	302
LA	5	37	494	536	1,738	1,685	901	4,324	1,743	1,722	1,395	4,860
ME	0	0	0	0	6	124	32	162	6	124	32	162
MD	0	0	96	96	0	0	0	0	0	0	96	96
MA	0	0	409	409	0	0	0	0	0	0	409	409
MI	0	0	0	0	0 ^d	0 ^d	0 ^d	0	0	0	0	0
MN	74 ^d	0	0	74	710 ^d	422 ^d	330 ^d	1,462 ^d	784	422	330	1,536
MS	20	579	1,005	1,604	DNF	DNF	DNF	733 ^s	DNF	DNF	DNF	2,337
MO	0	0	360	360	0	50	32	82	0	50	392	442
MT	0	0	42	42	0	0	0	0	0	0	42	42
NE	0	11	115	126	34	9	223	266	34	20	338	392
NV	0	0	47	47	26	0	18	44	26	0	65	91
NH	0	0	0	0	0	0	25 ^d	25	0	0	25	25
NJ	0	0	1,467	1,467	0 ^d	0 ^d	414	414	0	0	1,881	1,881
NM	4 ^s	0	0	4 ^s	253 ^s	0	0	253 ^s	257	0	0	257
NY	9	17	436	462	429	3,575	936	4,940	438	3,592	1,372	5,402
NC	6	0	1,253	1,259	DNF	DNF	DNF	2,666 ^{ed}	DNF	DNF	DNF	3,925
ND	0	0	75	75	228	205	31	464	228	205	106	539
OH	0	0	721	721	649	1,989	2,788	5,426	649	1,989	3,509	6,147
OK	0	0	0	0	108	317	882	1,307	108	317	882	1,307
OR	0	0	0	0	0	0	0	0	0	0	0	0
PA	0	0	904	904	617	261	1,159	2,037	617	261	2,063	2,941
RI	10 ^s	0	0	10 ^s	0 ^d	0 ^d	25 ^d	25 ^d	10	0	25	35
SC	0	0	666	666	0	497	0	497	0	497	666	1,163
SD	0	0	132	132	0	0	60	60	0	0	192	192
TN	147	15	60	222	283	371	71	725	430	386	131	947
TX	8 ^d	0	3,103 ^d	3,111 ^d	4,124 ^d	502 ^d	265 ^d	4,886 ^d	4,132	502	3,368	7,997
UT	0	0	191	191	0	DNF	DNF	595 ^s	0	DNF	DNF	786
VT	0	0	0	0	6	0	0	6	6	0	0	6
VA	0	0	363	363	123	239	156	518	123	239	519	881
WA	0	0	700 ^e	700 ^e	36	15	0	51	36	15	700	751
WV	0	0	0	0	84	425	0	509	84	425	0	509
WI	0	0	350 ^d	350 ^d	0 ^d	13 ^d	424 ^d	437 ^d	0	13	774	787
WY	0	0	67	67	0	0	0	0	0	0	67	67
Reported US Total	284	829	18,564	19,677	17,946	16,102	15,198	53,802	18,203	16,352	30,999	73,479
Estimated US Total	284	829	18,564	19,677	21,881	15,920	17,136	54,937	22,165	16,749	35,700	74,614

^d Other date (Usually a different fiscal year or June 30, 2015). ^e Estimate. ^{DNF} Did not furnish. ⁱ One or more component value imputed by RISP staff. ^s Other Source (ACHA CASPER data, 2017). * See state notes in Appendix.

State versus Nonstate

In 2016, 26% of all ICF/IID residents (19,677 people) lived in a state-operated facility and 74% (54,937 people) lived in a nonstate-operated facility. In four states, all ICF/IID residents lived in a state-operated setting (Maryland, Massachusetts, Montana, and Wyoming). In ten states, all ICF/IID residents lived in a nonstate setting (Alabama, Arizona, the District of Columbia, Hawaii, Indiana, Maine, New Hampshire, Oklahoma, Vermont and West Virginia).

Setting Size

On June 30, 2016, an estimated 30% of all ICF/IID residents (22,165 people) lived settings of six or fewer people, 22% (16,749 people) lived in settings of 7 to 15 people, and 48% (35,700 people) lived in settings of 16 or more people. States with the largest proportions of people living in ICF/IID settings of 1 to 6 people were New Mexico (100%), Vermont (100%), the District of Columbia (99.7%), Hawaii (91%), and California (79%). All ICF/IID recipients lived in settings of 16 or more people in Arizona (37 people), Delaware (100 people), Maryland (96 people), Massachusetts (409 people), Montana (42 people), New Hampshire (25 people), New Jersey (1,881 people), and South Dakota (192 people). States with

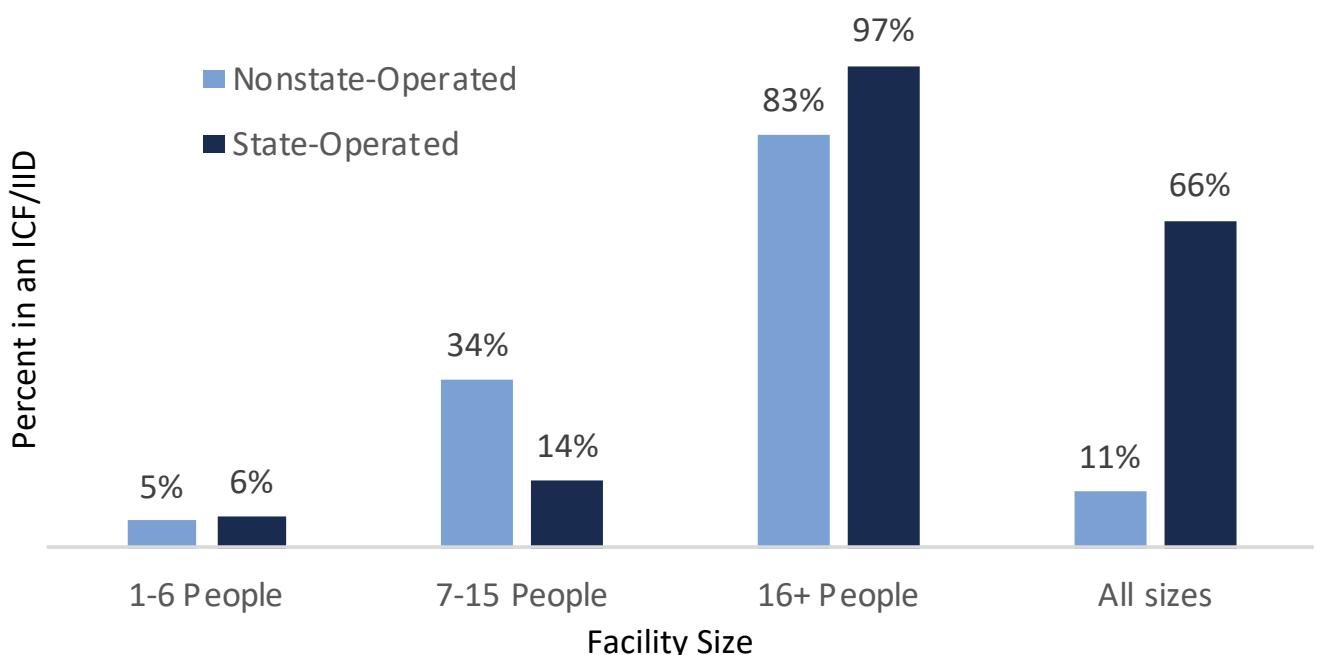
90% or more of people living in ICF/IID settings of 16 or more people included Wisconsin (98%, 774 people), Utah (97%), Washington (93%, 700 people), Kentucky (92%, 278 people), and Florida (90%, 2,511 people).

More than half (54%, 19,280 people) of all ICF/IID residents in settings of 16 or more people lived in California (1,692 people), Florida (2,511 people), Illinois (4,256 people), New Jersey (1,881 people), Ohio (3,509 people), Pennsylvania (2,063 people), or Texas (3,368 people).

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

Overall, 11% of people in nonstate-operated IDD group settings, and 66% of all people in state-operated IDD group settings lived in an ICF/IID (See **Figure 2.7**). Among people living in settings of 16 or more people, 97% of those in state-operated settings and 83% of those in nonstate-operated settings lived in an ICF/IID. Among people living in settings of 7 to 15 people, 14% of those in state-operated settings, and 34% of those in nonstate-operated settings lived in an ICF/IID. Among people living in LTSS group homes of one to six people, the

Figure 2.7 Proportion of LTSS Recipients in an ICF/IID Certified Facility by Type of Operation and Setting Size on June 30, 2016



Excludes LTSS recipients with IDD living with a family member.

Table 2.10 People Living in an ICF/IID Total and Per 100,000 of the Population by Age and State on June 30, 2016

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 ¹	Birth to 21 years	22+ years	All Ages ¹
N States	51	51	51	48	48	51	48	48	51
AL	13.6	35.0	48.6	0	22	22	0	0.6	0.5
AK	2.3	5.1	7.4	3	4	7	1.3	0.8	0.9
AZ	20.0	48.3	68.3	3 ^s	134 ^s	137	0	3	2
AR	8.6	21.1	29.8	282 ^s	1,160 ^s	1,442	32.7	54.8	48.4
CA	112.6	278.8	391.4	133	7,691	7,918 ^g	1.2	27.6	20.2
CO	15.4	39.1	54.6	19	148	215 ^g	1.2	3.8	3.9
CT	9.8	26.1	35.9	0 ^c	429 ^c	790 ^g	0.0	16.4	22.0
DE	2.5	6.9	9.5	DNF	DNF	100	DNF	DNF	10.6
DC	1.6	5.1	6.7	1	322	323	0.6	63.1	48.0
FL	50.5	152.2	202.7	109	2,605	2,791 ^g	2.2	17.1	13.8
GA	30.7	71.4	102.1	22 ^s	262 ^s	284	1	4	3
HI	3.8	10.5	14.3	0	76	76	0.0	7.2	5.3
ID	5.2	11.3	16.5	111 ^d	377 ^d	488	21.3	33.2	29.5
IL	36.5	92.1	128.6	303	6,312	6,615	8.3	68.5	51.4
IN	19.6	46.6	66.2	237	3,012	3,249	12.1	64.6	49.1
IA	9.2	22.1	31.2	292	1,719	2,011	31.9	77.9	64.4
KS	8.9	20.2	29.1	29	416	450 ^g	3.3	20.6	15.5
KY	12.4	31.8	44.3	15 ^s	412 ^s	427	1.2	13.0	9.6
LA	13.6	33.1	46.7	478	4,478	4,956	35.3	135.1	106.1
ME	3.2	10.1	13.3	2	160	162	0.6	15.9	12.2
MD	16.6	43.5	60.1	DNF	DNF	96 ^g	DNF	DNF	1.6
MA	18.0	50.0	67.9	0	409	409	0	8.2	6.0
MI	27.6	71.6	99.2	0 ^d	0 ^d	0	0	0	0
MN	15.7	39.2	54.9	79 ^d	1,512 ^d	1,591	5.0	38.6	29.0
MS	9.0	21.0	29.9	87 ^c	1,527 ^c	2,337 ^g	9.7	72.8	78.1
MO	17.2	43.7	60.8	0	436	442 ^g	0	10.0	7.3
MT	2.8	7.5	10.3	0	40	42 ^g	0	5.3	4.1
NE	5.8	13.2	19.0	33	360	393	5.7	27.4	20.7
NV	8.0	20.9	28.9	10	81	91	1.2	3.9	3.1
NH	3.4	9.9	13.3	25	0	25	7	0	2
NJ	24.4	65.1	89.6	0 ^c	1,477 ^c	1,881 ^g	0	22.7	21.0
NM	6.1	14.8	20.9	16 ^s	241 ^s	257	2.6	16.3	12.3
NY	52.8	145.1	198.0	619	4,936	5,555	11.7	34.0	28.1
NC	28.4	72.0	100.4	335	2,825	3,925 ^g	11.8	39.2	39.1
ND	2.2	5.3	7.6	101 ^b	363 ^b	539 ^g	45.0	68.2	71.2
OH	32.4	83.7	116.1	400	5,747	6,147	12.3	68.6	52.9
OK	11.7	27.4	39.1	DNF	DNF	1,307 ^g	DNF	DNF	33.4
OR	10.6	29.7	40.3	0	0	0	0	0	0
PA	33.9	94.1	128.0	107	2,884	2,991	3.2	30.6	23.4
RI	2.8	7.8	10.6	17 ^s	18 ^s	35	6.0	2.3	3.3
SC	13.6	35.4	49.0	17	1,148	1,165	1.3	32.4	23.8
SD	2.6	6.0	8.6	83	109	192	32.0	18.2	22.4
TN	18.4	47.6	66.0	32	905	947 ^g	1.7	19.0	14.3
TX	87.4	187.3	274.7	396 ^d	7,490 ^d	7,997 ^g	4.5	40.0	29.1
UT	10.9	19.0	30.0	6 ^c	195 ^c	786 ^g	0.5	10.2	26.2
VT	1.6	4.6	6.3	0	6	6	0	1.3	1.0
VA	23.3	60.5	83.8	168	302	881 ^g	7.2	5.0	10.5
WA	19.6	52.1	71.7	0	751	751	0.0	14.4	10.5
WV	4.7	13.7	18.4	52 ^s	454 ^s	509	11.0	33.1	27.6
WI	16.2	41.6	57.7	0 ^d	787 ^d	787	0.0	18.9	13.6
WY	1.7	4.2	5.9	1	66	67	0.6	15.8	11.4
Reported US Total	909.5	2,304.7	3,214.2	4,623	64,808	74,614	5.1	28.1	23.2
Estimated US Total	909.5	2,304.7	3,214.2	5,022	69,592	74,614	5.5	30.2	23.2

^b Nonstate settings reported, but not state settings. ^c State settings reported, but not nonstate settings. ^d Other date (Usually a different fiscal year or June 30, 2015). ^e Estimate. ^{DNF} Did not furnish. ^g Sum of setting size data substituted for reported value. ^s Other Source U.S. Census Bureau, Population Division (2017); (ACHAa, 2017 CASPER data). * See state notes in Appendix. ¹ The reported number of ICF/IID recipients by age may differ from the overall reported total recipients because information about age was not available for all recipients.

proportion living in an ICF/IID was 5% for nonstate settings and 6% for state-operated settings.

Mississippi (72.8), Ohio (68.6), Illinois (68.5), North Dakota (68.2), Indiana (64.6), and the District of Columbia (63.1).

ICF/IID Recipients by Age

Of the 74,614 people living in an ICF/IID on June 30, 2016, an estimated 7% (5,022 people) were 21 years old or younger and 93% (69,592 people) were 22 years or older (See **Table 2.10**). States with the highest proportion of ICF/IID residents age 21 and younger were New Hampshire (100%), Rhode Island (49%), South Dakota (43%), Idaho (23%), Arkansas (20%), Virginia (19%), and North Dakota (19%). All ICF/IID recipients were 22 years or older in Alabama, Hawaii, Massachusetts, Missouri, Montana, New Jersey, Vermont, Washington, and Wisconsin.

An estimated 23.2 people per 100,000 of the U.S. population lived in an ICF/IID on June 30, 2016 (See **Figure 2.8**). ICF/IID utilization rates ranged from zero in Michigan and Oregon to 106.1 per 100,000 in Louisiana. An estimated 5.5 people 21 years or younger per 100,000 of the population lived in an ICF/IID. The rates were highest in North Dakota (45.0 per 100,000), Louisiana (35.3), Arkansas (32.7), South Dakota (32.0), Iowa (31.9), and Idaho (21.3). An estimated 30.2 people 22 years or older per 100,000 of the population lived in an ICF/IID. Those rates were highest in Louisiana (135.1), Iowa (77.9),

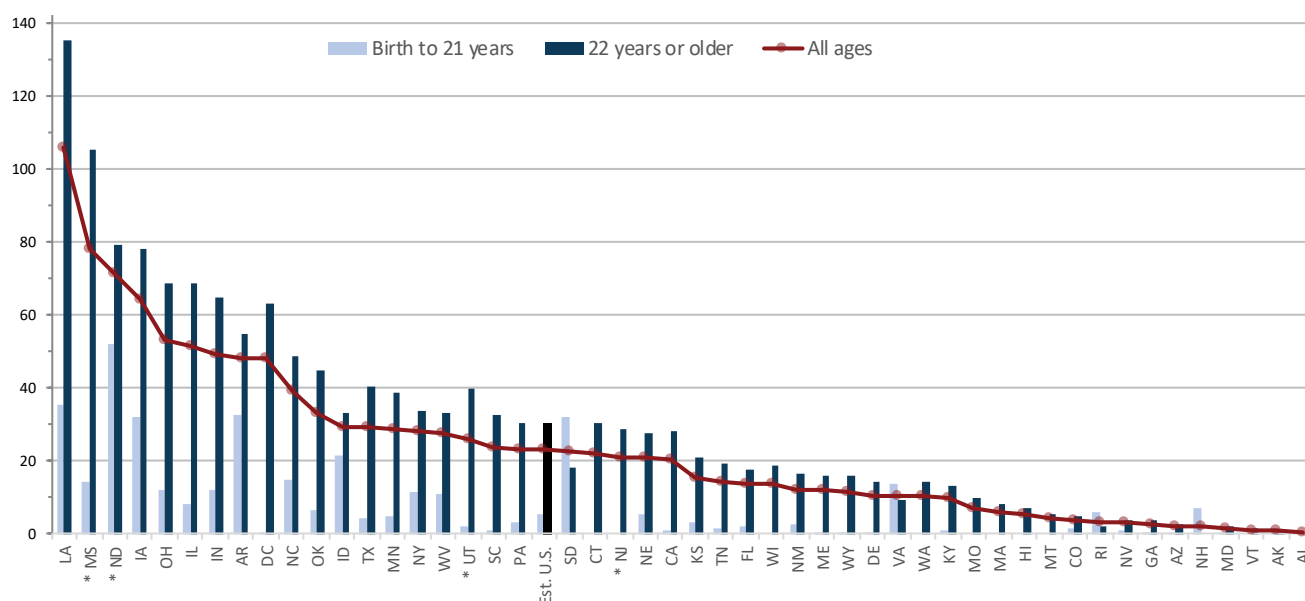
ICF/IID EXPENDITURES

Total FY 2016 ICF/IID expenditures were \$10.51 billion nationally and ranged from \$1.1 million in Vermont to \$1.19 billion in New York (See **Table 2.11**). Michigan and Oregon reported no ICF/IID expenditures for FY 2016. Six states with ICF/IID expenditures reported spending less than \$10 million (Alabama, Alaska, Hawaii, New Hampshire, Rhode Island, and Vermont). Seven states reported more than \$500 million in ICF/IID expenditures (California, Illinois, New Jersey, New York, Ohio, Pennsylvania, and Texas). Most states report expenditures based on paid claims data, but some reported budgeted expenditures. Some states reported ICF/IID expenditures for state-operated settings only (See the c superscript) or nonstate-operated settings only (See the b superscript).

Per Person Expenditures

Estimated FY 2016 per person ICF/IID expenditures averaged \$140,831 and ranged from \$77,398 to \$390,833. States with the highest average per person ICF/IID expenditures were Alaska (\$390,883

Figure 2.8 People Living in an ICF/IID per 100,000 of the Population by State and Age on June 30, 2016



ICF/IID Intermediate Care Facility for Individuals with Intellectual Disabilities; * State reported partial data by age, AHCA ICF/IID data used for age proportions. Michigan and Oregon have no ICF/IID.

Table 2.11 ICF/IID Recipients, Expenditures, Expenditure Per Person, and Expenditures Per State Resident by State in Fiscal Year 2016

State	ICF/IID Expenditures	FY 2016 Recipients	Expenditures per FY 2016 Recipient (\$)	State Population (100,000) ⁵	Expenditures per State Resident (\$)
N States	41	49	41	51	41
AL	1,996,769	22	90,762	48.6	0.4
AK	2,736,179	7	390,883	7.4	3.7
AZ	DNF	137 ^s	DNF	68.3	DNF
AR	DNF	1,442 ^s	DNF	29.8	DNF
CA	712,849,420	7,824	91,111	391.4	18.2
CO	40,223,818	167	240,861	54.6	7.4
CT	150,495,669 ^c	429 ^c	350,806 ^c	35.9	41.9 ^c
DE	30,480,708	100	304,807	9.5	32.2
DC	89,667,945	323	277,610	6.7	133.4
FL	DNF	2,714	DNF	202.7	DNF
GA	DNF	284 ^s	DNF	102.1	DNF
HI	9,241,744	76	121,602	14.3	6.5
ID	42,634,014	488	87,365	16.5	25.8
IL	602,641,683	6,615	91,102	128.6	46.9
IN	271,366,346	3,249	83,523	66.2	41.0
IA	283,081,201	2,011	140,766	31.2	90.6
KS	13,161,657 ^b	445	96,777 ^b	29.1	4.5 ^b
KY	DNF	427 ^s	DNF	44.3	DNF
LA	384,154,193	4,956	77,513	46.7	82.2
ME	31,452,291	162	194,150	13.3	23.7
MD	DNF	DNF	DNF	60.1	DNF
MA	107,491,155	409	262,815	67.9	15.8
MI	0 ^d	0 ^d	0 ^d	99.2	0.0 ^d
MN	124,444,235	1,591 ^d	78,218 ^d	54.9	22.7
MS	202,215,801 ^c	1,614 ^c	125,289 ^c	29.9	67.6 ^c
MO	88,947,639	436	204,008	60.8	14.6
MT	12,278,736	40	306,968	10.3	11.9
NE	62,816,481	393	159,838	19.0	33.1
NV	17,750,887	91	195,065	28.9	6.1
NH	1,934,950	25	77,398	13.3	1.5
NJ	508,433,602 ^c	1,881 ^c	270,300 ^c	89.6	56.8 ^c
NM	DNF	257	DNF	20.9	DNF
NY	1,185,815,292	5,555	213,468	198.0	59.9
NC	398,984,819	3,160	126,261	100.4	39.7
ND	77,031,130	464 ^b	166,015 ^b	7.6	101.8
OH	726,662,287	6,147	118,214	116.1	62.6
OK	DNF	DNF	DNF	39.1	DNF
OR	0	0	0	40.3	0.0
PA	598,380,954	2,991	200,060	128.0	46.7
RI	DNF	35 ^s	DNF	10.6	DNF
SC	139,364,034	1,165	119,626	49.0	28.5
SD	31,198,086	192	162,490	8.6	36.3
TN	201,882,848	937	215,457	66.0	30.6
TX	1,153,752,148 ^d	7,886 ^d	146,304 ^d	274.7	42.0 ^d
UT	37,489,515 ^c	201 ^c	186,515 ^c	30.0	12.5 ^c
VT	1,091,946	6	181,991	6.3	1.7
VA	82,724,325	470	176,009	83.8	9.9
WA	202,613,298	751	269,791	71.7	28.3
WV	DNF	509	DNF	18.4	DNF
WI	141,479,951 ^d	787 ^d	179,771 ^d	57.7	24.5 ^d
WY	18,935,011	67	282,612	5.9	32.3
Reported US Total	8,789,902,768	69,938	125,681	3,214.2	27.3
Estimated US Total	10,507,954,694	74,614	140,831	3,214.2	32.7

^b Nonstate settings reported, but not state settings. ^c State settings reported, but not nonstate settings. ^d Other date (Usually a different fiscal year or June 30, 2015). ^e Estimate. ^f One or more component value imputed by RISP staff. ^{DNF} Did not furnish. ⁵ U.S. Census Bureau, Population Division (2016); ACHA (2017a); Eiken, et al (2017). *See state notes in Appendix.

Table 2.12 Annual ICF/IID Expenditures Total and Per Person by Age and State in Fiscal Year 2016

Age	Total Expenditures \$		Annual Per Person \$	
	Birth to 21 years	22 years +	Birth to 21 years	22 years +
N States	39	39	25	35
AL	0	1,996,769	N/A	90,762
AK	1,143,086	1,593,093	381,029	398,273
AZ	DNF	DNF	PD	PD
AR	DNF	DNF	PD	PD
CA	5,660,208	707,189,212	42,558	91,950
CO	3,489,808	36,734,010	183,674	248,203
CT	0 ^c	150,495,669 ^c	N/A ^c	350,806 ^c
DE	DNF	DNF	DNF	DNF
DC	222,020	89,445,925	222,020	277,782
FL	DNF	DNF	PD	PD
GA	DNF	DNF	PD	PD
HI	0	9,241,744	N/A	121,602
ID	9,043,232 ^d	33,590,782 ^d	81,471 ^d	89,100 ^d
IL	19,897,489	582,744,194	65,668	92,323
IN	22,027,677	249,338,669	92,944	82,782
IA	33,834,788	249,246,413	115,873	144,995
KS	610,866 ^b	12,550,791 ^b	122,173 ^b	95,808 ^b
KY	DNF	DNF	PD	PD
LA	46,410,566	337,743,627	97,093	75,423
ME	447,577	31,004,714	223,789	193,779
MD	DNF	DNF	DNF	DNF
MA	0	107,491,155	N/A	262,815
MI	0 ^d	0 ^d	N/A ^d	N/A ^d
MN	5,837,347 ^d	118,606,888 ^d	73,890 ^d	78,444 ^d
MS	12,226,745 ^c	189,989,056 ^c	140,537 ^c	124,420 ^c
MO	0	88,947,639	N/A	204,008
MT	0	12,278,736	N/A	306,968
NE	3,659,323	59,157,157	110,889	164,325
NV	1,715,841	16,035,046	171,584	197,964
NH	1,934,950 ^d	0 ^d	77,398 ^d	N/A ^d
NJ	0 ^c	225,479,000 ^c	N/A ^c	152,660 ^c
NM	DNF	DNF	PD	PD
NY	113,178,587	1,072,636,705	182,841	217,309
NC	34,609,291	364,375,528	103,311	128,982
ND	DNF	DNF	PD	PD
OH	47,052,019	679,610,268	117,630	118,255
OK	DNF	DNF	DNF	DNF
OR	0	0	N/A	N/A
PA	19,471,254	578,909,700	181,974	200,732
RI	DNF	DNF	PD	PD
SC	2,033,638	137,330,396	119,626	119,626
SD	11,267,784	19,930,302	135,756	182,847
TN	5,171,035	196,711,813	161,595	217,361
TX	60,963,685 ^d	1,092,788,463 ^d	153,949 ^d	145,900 ^d
UT	1,119,090 ^c	36,370,425 ^c	186,515 ^c	186,515 ^c
VT	0	1,091,946	N/A	181,991
VA	29,378,684	53,345,641	174,873	176,641
WA	0	202,613,298	N/A	269,791
WV	DNF	DNF	PD	PD
WI	0 ^d	141,479,951 ^{ed}	N/A ^d	179,771 ^{ed}
WY	0	18,935,011	N/A	286,894
US Estimate	591,108,925	9,916,845,770	117,714	142,499

Note: This table only includes values if the state reported participants and expenditures by age. The US Averages are based only on states that provided complete information for birth to 21 and 22+ years. ^c State settings reported, but not nonstate settings. ^d Other date (Usually August 31, 2015 or June 30, 2014). ^e Estimate. ^f Missing value imputed (RISP estimated). ^g Source, AHCA (2017a). ^h DNF Did not furnish. ⁱ N/A Not Applicable - no ICF/IID settings. ^j PD Partial data, calculation incomplete and not included in reported totals. * See state notes in Appendix.

where all ICF/IID residents lived out of state), Connecticut (\$350,806 in state-operated ICF/IID), Montana (\$306,968), Delaware (\$304,807), Wyoming (\$282,612), District of Columbia (\$277,610), New Jersey (\$270,300), Washington (\$269,79), and Massachusetts (\$262,815). States with the lowest average per person expenditures were Minnesota (\$78,218), Louisiana (\$77,513), New Hampshire (\$77,398), and Kansas (\$29,577).

Expenditures per State Resident

Overall FY 2016 ICF/IID expenditures per state resident averaged \$32.7 and ranged from \$0.4 to \$133.4. Expenditures per state resident were highest in the District of Columbia (\$133.4), North Dakota (\$101.8), and Iowa (\$90.6). Expenditures per state resident were lowest in Kansas (\$4.5), Alaska (\$3.7), Vermont (\$1.7), New Hampshire (\$1.5), and Alabama (\$0.4). Neither Michigan nor Oregon reported ICF/IID expenditures for 2016.

Expenditures by Age

Total FY 2016 ICF/IID expenditures were \$591.1 million for people 21 years or younger and \$9.9 billion for people 22 years or older. Annual per person expenditures averaged \$117,714 for people 21 years or younger and \$142,499 for people 22 years or older (See **Table 2.12**). States with the highest average per person expenditures for people ages birth to 21 years were Alaska (\$381,029), Maine (\$223,789), and the District of Columbia (\$222,020). States with the highest average per person expenditures for people ages 22 years or older were Alaska (\$398,273), Montana (\$306,968), Wyoming (\$286,894), the District of Columbia (\$277,782), Washington (\$269,791), Massachusetts (\$262,815), and Colorado (\$248,203).

MEDICAID RECIPIENTS AND EXPENDITURES BY FUNDING AUTHORITY

Of the 882,076 Medicaid ICF/IID or Waiver recipients with IDD on June 30, 2016, 92% were Waiver recipients and 8% lived in an ICF/IID (See **Table 2.13**). The proportion of LTSS recipients with IDD who were Waiver recipients was 90% or higher in 38 of the 49 states. The proportion of recipients who received Medicaid Waiver-funded services was lowest in Mississippi (60%), Louisiana (71%), Arkansas (74%), and Illinois (78%).

Table 2.13 ICF/IID and Medicaid Waiver Recipients and Expenditures Total and Percent by Funding Authority and State on June 30, 2016

State	Total ICF/IID + Waiver		% of Recipients		% of Expenditures	
	Recipients ¹	Expenditures (\$)	Waiver	ICF/IID	Waiver	ICF/IID
N States	49	41	49	49	41	41
AL	5,602	363,129,775	100	0	99	1
AK	2,100	178,993,931	100	0	98	2
AZ	29,717 ^s	PD	100	0	PD	PD
AR	5,577 ^s	PD	74	26	PD	PD
CA	128,002 ^g	3,664,435,945	94	6	81	19
CO	11,061 ^g	468,468,269	98	2	91	9
CT	11,011 ^g	1,085,667,565 ^c	96	4	86	14
DE	1,177	150,127,776	92	8	80	20
DC	1,993	288,247,114	84	16	69	31
FL	35,621 ^g	PD	92	8	PD	PD
GA	8,863 ^s	PD	97	3	PD	PD
HI	2,829	142,906,146	97	3	94	6
ID	8,214	270,896,949	94	6	84	16
IL	30,359	1,488,388,473	78	22	60	40
IN	25,547	799,148,827	87	13	66	34
IA	16,102	826,443,998	88	12	66	34
KS	9,286 ^g	497,335,008 ^d	95	5	97	3
KY	15,195 ^s	PD	97	3	PD	PD
LA	17,335	852,316,217 ^e	71	29	55	45
ME	5,249 ^e	368,328,031 ^e	97	3	91	9
MD	PD	PD	PD	PD	PD	PD
MA	14,683	1,116,246,932	97	3	90	10
MI	45,115 ^{dd}	1,437,648,930 ^{dd}	100	0	100	0
MN	19,907 ^d	1,401,334,672 ^d	92	8	91	9
MS	4,745 ^g	278,903,095 ^c	60	40	27	73
MO	14,164 ^g	858,253,111	97	3	90	10
MT	2,575 ^g	117,361,063	98	2	90	10
NE	5,079	358,251,179	92	8	82	18
NV	2,124	114,217,614	96	4	84	16
NH	5,260 ^d	234,866,764 ^d	100	0	99	1
NJ	12,803 ^g	1,189,127,060 ^c	88	12	81	19
NM	5,173	PD	95	5	PD	PD
NY	83,510 ^e	6,577,647,178	93	7	82	18
NC	20,817 ^g	1,002,794,415 ^e	84	16	60	40
ND	5,315 ^g	269,640,549	91	9	71	29
OH	42,964	2,255,821,780	86	14	68	32
OK	PD	PD	PD	PD	PD	PD
OR	12,548	71,227,540	100	0	100	0
PA	37,138	3,126,020,129	92	8	81	19
RI	3,673 ^s	PD	99	1	PD	PD
SC	11,453	470,359,973	90	10	70	30
SD	3,817	147,166,153	95	5	79	21
TN	9,037 ^g	873,241,580	90	10	77	23
TX	44,668 ^g	2,571,759,190 ^d	82	18	55	45
UT	5,989 ^g	250,282,561 ^c	96	4	85	15
VT	3,016	173,319,073	100	0	99	1
VA	18,057 ^g	586,874,717	97	3	86	14
WA	16,337	572,572,482 ^e	95	5	65	35
WV	5,143	DNF ^d	90	10	DNF	DNF
WI	32,247 ^d	1,182,747,438 ^d	98	2	88	12
WY	2,427	110,268,211	97	3	83	17
Estimated US Total	882,076	45,978,048,041	92	8	77	23

^d Other date (Usually a different fiscal year or June 30, 2015). ^e Estimate. DNF Did not furnish. ^g Sum of setting size data substituted for reported value.

^s Source ACHA (2017a) * See state notes in Appendix.

Of the \$46.0 billion in Medicaid ICF/IID and Medicaid Waiver expenditures for people with IDD in FY 2016, 77% of the total was expended for Medicaid Waiver recipients and 23% was for ICF/IID recipients. The proportion of Medicaid LTSS expenditures for Waiver recipients ranged from 27% to 100%. Medicaid Waiver expenditures accounted for 95% or more of combined expenditures in Michigan (100%), Oregon (100%), Alabama (99%), New Hampshire (99%), Vermont (99%), Alaska (98%), and Kansas (97%). The proportion of expenditures for Medicaid Waiver recipients was lowest in Illinois (60%), Louisiana (55%), Mississippi (27%) and Texas (55%).

Kansas was the only state in which the proportion of expenditures for Medicaid Waiver services (97%) was higher than the proportion of recipients (95%). The biggest differentials between the proportion of Medicaid Waiver recipients and Medicaid Waiver expenditures were in Mississippi (60% of recipients and 27% of expenditures), North Carolina (84% and 60%), Texas (82% and 55%), and Washington (95% and 65%).

MEDICAID RECIPIENTS AND EXPENDITURES BY AGE, LIVING ARRANGEMENT AND FUNDING AUTHORITY

Recipients

The proportion Medicaid LTSS recipients who were 21 years or younger varied by funding authority and by living arrangement (See **Figure 2.9**). People 21 years or younger were 25% (204,406 people) of all Medicaid Waiver recipients. They were 41% (173,363 people) of Medicaid Waiver recipients living in the home of a family member, 8% (31,043 people) of Medicaid Waiver recipients living in any non-family setting, and 7% (5,022) of ICF/IID residents.

The most commonly used living arrangements differed by age and funding authority. Most of the people 21 years or younger (173,363 people) lived in the home of a family and received Medicaid Waiver-funded supports, 31,043 lived in a non-family setting while receiving Medicaid Waiver-funded supports, and 5,022 lived in an ICF/IID.

Most of the people 22 years or older (348,509 people) lived in a non-family setting and received

Medicaid Waiver-funded supports, 254,547 lived with a family member while receiving Medicaid Waiver-funded supports, and 69,592 lived in an ICF/IID.

Per Person Expenditures

Average annual per person Medicaid expenditures varied by age, funding authority and living arrangement (See **Figure 2.10**). Average annual per person Medicaid Waiver expenditures were lower for people 21 years or younger than for people 22 years or older overall (\$17,404 versus \$52,918). Medicaid Waiver expenditures were also lower for people 21 years or younger than for people 22 years or older whether they lived a family member (\$13,841 versus \$26,486) or in a non-family setting (\$37,360 versus \$72,224). Similarly, Medicaid ICF/IID expenditures were lower for people 21 years or younger than for people 22 years or older (\$117,714 versus \$142,499). Several factors probably contribute to explaining why per person expenditures are consistently lower for people ages 21 years or younger. For example, once a person with IDD reaches age 22 (or 18 in some states), they are no longer eligible for up to 30 hours per week of free educational services under the Individuals with Disabilities Education Act. Other expenses such as transportation to and from work or other day activities are also incurred for adults.

For both age groups the lowest annual per person expenditures were for Medicaid Waiver-funded services provided to people living with a family member followed by Medicaid Waiver-funded services provided to people living in a non-family setting. The highest annual per person expenditures were for ICF/IID services.

Average annual per person expenditures vary for several reasons. For example, people living with family members typically get ongoing unpaid supports from family members. In addition, Medicaid Waiver services are purchased ala cart with each person paying only for the amount and type of services they need. In an ICF/IID, everyone receives supports 24 hours a day, 365 days per year, the cost of specialist services such as nursing or therapies are often built into the rate, and the staff contingent often includes support staff to cook, clean, do the laundry and maintain the buildings and grounds.

Finally, room and board expenses, which are built into the rates for ICF/IID settings, cannot be paid from Medicaid Waiver funds. **Figure 2.11** shows the overall proportions of Medicaid Waiver and ICF/IID expenditures and recipients in FY2016.

Medicaid Benefit Ratios

Table 2.14a shows total Medicaid Waiver and ICF/IID expenditures, Federal Medicaid Assistance Percentages, and Federal Medicaid expenditures for ICF/IID and Waiver services in 2016. **Table 2.14b** shows the proportion of Federal Medicaid Waiver, ICF/IID, and combined expenditures for each

Figure 2.9 Medicaid LTSS Recipients with IDD by Age, Funding Authority and Living Arrangement (Estimated) on June 30, 2016

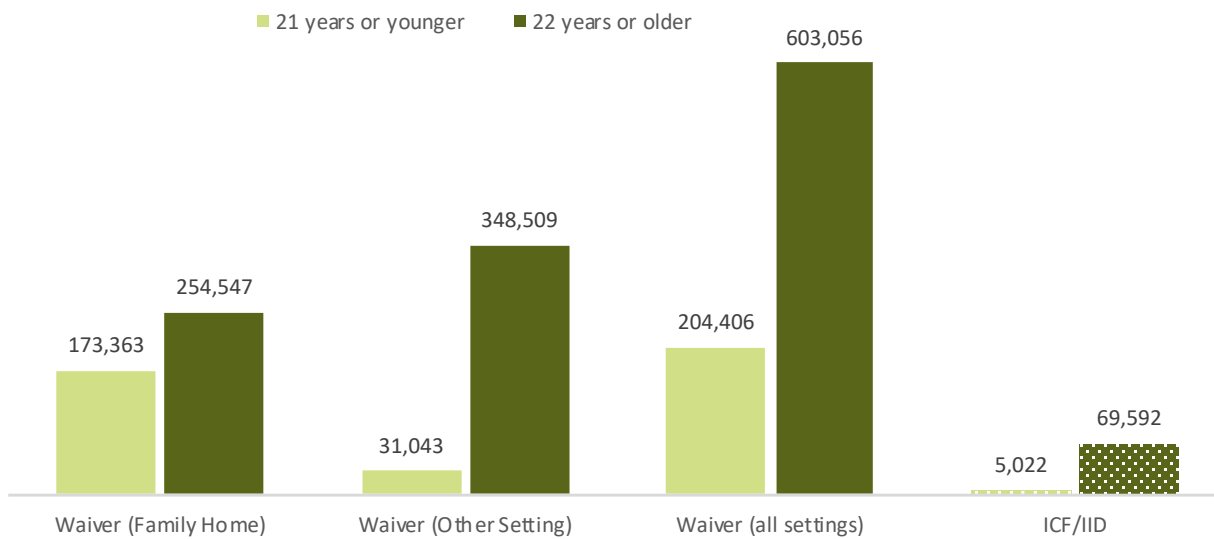
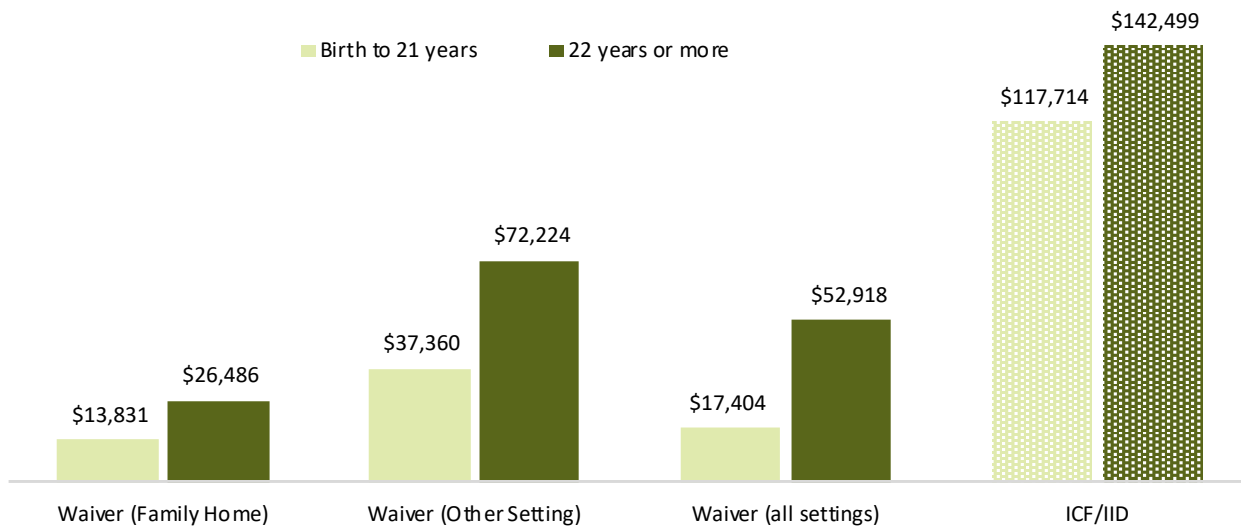
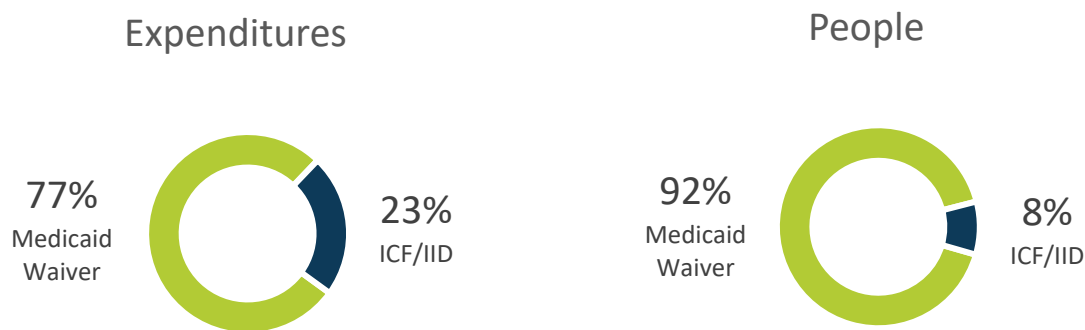


Figure 2.10 Average Annual Per Person Medicaid Expenditures by Age, Funding Authority and Living Arrangement (Estimated) in FY 2016



Settings other than the family home (Other settings) include Foster Family, Own Home, Group Home and Other. ICF/IID expenditures missing for AZ, AR, DE, FL, GA, KY, MD, NM, OK and WV. Partial data for ICF/IID expenditures in KS, MS, ND, NJ, UT. Values will be updated when CMS releases its ICF/IID Expenditure data.

Figure 2.11 Proportional Expenditures and Recipients of Medicaid Waivers and ICF/IID in FY 2016



state, total FY 2016 Federal Income taxes paid and the proportion of Federal Income taxes paid by each state. The state Medicaid Benefit ratio is the proportion of Federal Medicaid expenditures a state received divided by the proportion of Federal Income taxes it paid.

Federal Medicaid Expenditures

Federal Medicaid expenditures were estimated by multiplying total expenditures by the state's Federal Medicaid Assistance Percentage (FMAP). The average 2016 FMAP was 59% (ranging from 50% in 13 states to 74% in Mississippi). Combined Medicaid ICF/IID and Waiver expenditures for people with IDD in FY 2016 were an estimated \$45.9 billion, of which an estimated \$21.6 billion was federally funded. The federal government paid an estimated \$19.9 billion (56%) of the \$35.5 billion in Medicaid Waiver expenditures with the rest (\$15.5 billion) paid by states (See **Tables 2.14a** and **2.14b**). It also paid an estimated \$4.8 billion (46%) of the \$10.4 billion in ICF/IID expenditures with the rest (\$5.6 billion) paid by states.

Proportion of Federal Expenditures by State

FY 2016 Federal Medicaid expenditures for Waiver and ICF/IID recipients with IDD varied by state. States receiving the largest proportion of the \$19.98 billion in Federal Medicaid Waiver expenditures were New York (13.49%), California (7.38%), Pennsylvania (6.58%), Ohio (4.78%), and Michigan (4.72%). States receiving the largest proportion of the \$4.8 billion in Federal Medicaid ICF/IID expenditures were Texas (13.74%), New York (12.36%), Ohio (9.46%), California (7.43%), Pennsylvania (6.49%), and Illinois (6.39%).

States receiving the largest proportion of the \$45.86 billion in combined Federal Medicaid ICF/IID and

Waiver expenditures were New York (15.21%), California (8.47%), Pennsylvania (7.52%), Texas (6.80%) and Ohio (6.52%). The estimated proportions of people with IDD who lived in these states were California (12.15%), Texas (8.62%), Florida (6.38%), New York (6.11%), Illinois (3.96%), Pennsylvania (3.96%), Ohio (3.59%), and Michigan (3.07%).

Federal Income Tax Paid

State contributions to the federal budget through federal income taxes paid totaled \$3.3 trillion in FY 2016. States contributing the largest share of those taxes were California (12.75%), New York (8.02%), Texas (7.88%), Florida (5.68%), and Illinois (4.88%).

State Medicaid Benefit Ratios

"State Medicaid Benefit Ratios" compare the proportion of Federal Medicaid ICF/IID and Waiver expenditures for the state with the proportion of federal income taxes paid by the state. A state Medicaid Benefit Ratio of 1.0 indicates that the proportion of Federal Medicaid ICF/IID plus Waiver expenditures for recipients in 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 expenditures for people 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 expenditures for people with IDD than the proportion it paid of total federal income taxes.

For 2016, state Medicaid Benefit Ratios ranged from 0.22 to 4.51. Thirty-one states had ratios of 1.0 or higher, 11 states had ratios of less than 1.0 and 9 states did not report sufficient data to compute the ratio. States with lowest ratios were Nevada (0.57),

Table 2.14a FY 2016 Medicaid Waiver and ICF/IID Expenditures for People with IDD and Federal Share by State

State	Total FY 2016 Expenditures			Federal Cost Share (%) ¹	Federal Share of Total Expenditures (\$)		
	Waiver (\$)	ICF/IID (\$)	Combined		Waiver	ICF/IID	Combined
AL	361,133,006	1,996,769	363,129,775	70	252,323,631	1,395,143	253,718,774
AK	176,257,752	2,736,179	178,993,931	50	88,128,876	1,368,090	89,496,965
AZ	888,159,763	DNF	PD	69	612,119,709	DNF	PD
AR	215,395,080	DNF	PD	70	150,776,556	DNF	PD
CA	2,951,586,525	712,849,420	3,664,435,945	50	1,475,793,263	356,424,710	1,832,217,973
CO	428,244,451	40,223,818	468,468,269	51	217,205,585	20,401,521	237,607,106
CT	935,171,896	150,495,669 ^c	1,085,667,565	50	467,585,948	75,247,835	542,833,783
DE	119,647,068	30,480,708	150,127,776	55	65,602,487	16,712,572	82,315,060
DC	198,579,169	89,667,945	288,247,114	70	139,005,418	62,767,562	201,772,980
FL	989,155,709	DNF	PD	61	600,120,769	DNF	PD
GA	356,494,730	DNF	PD	68	240,812,190	DNF	PD
HI	133,664,402	9,241,744	142,906,146	54	72,152,044	4,988,693	77,140,738
ID	228,262,935	42,634,014	270,896,949	71	162,614,515	30,372,472	192,986,987
IL	885,746,790	602,641,683	1,488,388,473	51	450,756,541	306,684,352	757,440,894
IN	527,782,481	271,366,346	799,148,827	67	351,503,132	180,729,986	532,233,119
IA	543,362,797	283,081,201	826,443,998	55	298,360,512	155,439,887	453,800,399
KS	484,173,351	13,161,657 ^b	497,335,008	56	270,943,407	7,365,263	278,308,671
KY	636,053,497	DNF	PD	70	447,272,819	DNF	PD
LA	468,162,024 ^e	384,154,193	852,316,217	62	291,243,595	238,982,323	530,225,919
ME	336,875,740 ^e	31,452,291	368,328,031	63	211,120,026	19,711,151	230,831,177
MD	873,835,172	DNF	PD	50	436,917,586	DNF	PD
MA	1,008,755,777	107,491,155	1,116,246,932	50	504,377,889	53,745,578	558,123,466
MI	1,437,648,930 ^d	0 ^d	1,437,648,930	66	943,097,698	0	943,097,698
MN	1,276,890,437 ^d	124,444,235	1,401,334,672	50	638,445,219	62,222,118	700,667,336
MS	76,687,294	202,215,801 ^c	278,903,095	74	56,878,966	149,983,460	206,862,426
MO	769,305,472	88,947,639	858,253,111	63	486,816,503	56,286,066	543,102,569
MT	105,082,327	12,278,736	117,361,063	65	68,555,710	8,010,647	76,566,358
NE	295,434,698	62,816,481	358,251,179	51	151,144,392	32,136,912	183,281,303
NV	96,466,727	17,750,887	114,217,614	65	62,635,846	11,525,651	74,161,497
NH	232,931,814 ^d	1,934,950	234,866,764	50	116,465,907	967,475	117,433,382
NJ	963,648,060	225,479,000 ^c	1,189,127,060	50	481,824,030	112,739,500	594,563,530
NM	320,915,462	DNF	PD	70	225,828,211	DNF	PD
NY	5,391,831,886	1,185,815,292	6,577,647,178	50	2,695,915,943	592,907,646	3,288,823,589
NC	603,809,596 ^e	398,984,819	1,002,794,415	66	399,963,477	264,287,544	664,251,021
ND	192,609,419	77,031,130	269,640,549	50	96,304,710	38,515,565	134,820,275
OH	1,529,159,493	726,662,287	2,255,821,780	62	955,265,935	453,945,931	1,409,211,866
OK	310,647,099	DNF	PD	61	189,463,666	DNF	PD
OR	71,227,540	0	71,227,540	64	45,856,290	0	45,856,290
PA	2,527,639,175	598,380,954	3,126,020,129	52	1,314,625,135	311,217,934	1,625,843,069
RI	234,726,062	DNF	PD	50	118,348,880	DNF	PD
SC	330,995,939	139,364,034	470,359,973	71	235,271,913	99,059,955	334,331,869
SD	115,968,067	31,198,086	147,166,153	52	59,851,119	16,101,332	75,952,452
TN	671,358,732	201,882,848	873,241,580	65	436,718,855	131,324,793	568,043,648
TX	1,418,007,042 ^d	1,153,752,148 ^d	2,571,759,190	57	810,107,423	659,138,602	1,469,246,025
UT	212,793,046	37,489,515 ^c	250,282,561	70	149,465,836	26,332,635	175,798,471
VT	172,227,127	1,091,946	173,319,073	54	92,830,421	588,559	93,418,980
VA	504,150,392	82,724,325	586,874,717	50	252,075,196	41,362,163	293,437,359
WA	369,959,184	202,613,298	572,572,482	50	184,979,592	101,306,649	286,286,241
WV	358,871,525 ^d	DNF	DNF	71	256,306,043	DNF	DNF
WI	1,041,267,487 ^d	141,479,951 ^d	1,182,747,438	58	606,330,058	82,383,775	688,713,833
WY	91,333,200	18,935,011	110,268,211	50	45,666,600	9,467,506	55,134,106
Estimated US Total	35,470,093,347	10,507,954,694	45,978,048,041	59	19,983,776,072	4,794,149,555	21,499,959,199

^b Nonstate settings reported, but not state settings. ^c State settings reported, but not nonstate settings. ^d Other date (Usually a different fiscal year or June 30, 2015). ^e Estimate. ^{DNF} Did not furnish. ^{PD} Partial data, calculation incomplete and not included in reported totals. ^s Source: Internal Revenue Service (2016). * See state notes in the Appendix. ¹ Source: <http://kff.org/medicaid/state-indicator/federal-matching-rate-and-multiplier/>

Table 2.14b FY 2016 Federal Medicaid Waiver Expenditures, ICF/IID Expenditures, Income Taxes, and State Medicaid Benefit Ratios by State

State	Proportion of Total Federal Expenditures			Federal Income Tax Paid		State Medicaid Benefit Ratio ²
	Medicaid Waiver	ICF/IID	Combined	Billions (\$)	Percent (%)	
AL	1.3	0.0	1.2	25.8	0.8	1.52
AK	0.4	0.0	0.4	5.6	0.2	2.47
AZ	3.1	DNF	PD	42.0	1.3	PD
AR	0.8	DNF	PD	32.0	1.0	PD
CA	7.4	7.4	8.5	422.7	12.7	0.67
CO	1.1	0.4	1.1	54.8	1.7	0.67
CT	2.3	1.6	2.5	62.9	1.9	1.33
DE	0.3	0.3	0.4	20.0	0.6	0.64
DC	0.7	1.3	0.9	27.3	0.8	1.14
FL	3.0	DNF	PD	188.4	5.7	PD
GA	1.2	DNF	PD	90.8	2.7	PD
HI	0.4	0.1	0.4	8.8	0.3	1.35
ID	0.8	0.6	0.9	10.1	0.3	2.95
IL	2.3	6.4	3.5	161.9	4.9	0.72
IN	1.8	3.8	2.5	57.1	1.7	1.44
IA	1.5	3.2	2.1	23.9	0.7	2.92
KS	1.4	0.2	1.3	25.3	0.8	1.70
KY	2.2	DNF	PD	34.3	1.0	PD
LA	1.5	5.0	2.5	41.5	1.3	1.97
ME	1.1	0.4	1.1	7.9	0.2	4.53
MD	2.2	DNF	PD	67.7	2.0	PD
MA	2.5	1.1	2.6	108.8	3.3	0.79
MI	4.7	0.0	4.4	81.2	2.5	1.79
MN	3.2	1.3	3.3	103.7	3.1	1.04
MS	0.3	3.1	1.0	12.6	0.4	2.53
MO	2.4	1.2	2.5	66.5	2.0	1.26
MT	0.3	0.2	0.4	6.0	0.2	1.98
NE	0.8	0.7	0.9	25.2	0.8	1.12
NV	0.3	0.2	0.3	19.9	0.6	0.57
NH	0.6	0.0	0.5	11.5	0.3	1.58
NJ	2.4	2.4	2.8	143.0	4.3	0.64
NM	1.1	DNF	PD	8.7	0.3	PD
NY	13.5	12.4	15.3	266.0	8.0	1.91
NC	2.0	5.5	3.1	83.7	2.5	1.22
ND	0.5	0.8	0.6	6.9	0.2	3.00
OH	4.8	9.5	6.6	141.1	4.3	1.54
OK	0.9	DNF	PD	28.0	0.8	PD
OR	0.2	0.0	0.2	32.0	1.0	0.22
PA	6.6	6.5	7.6	135.9	4.1	1.84
RI	0.6	DNF	PD	14.6	0.4	PD
SC	1.2	2.1	1.6	25.5	0.8	2.02
SD	0.3	0.3	0.4	7.8	0.2	1.51
TN	2.2	2.7	2.6	65.0	2.0	1.35
TX	4.1	13.7	6.8	261.1	7.9	0.87
UT	0.7	0.5	0.8	21.1	0.6	1.28
VT	0.5	0.0	0.4	4.5	0.1	3.23
VA	1.3	0.9	1.4	83.6	2.5	0.54
WA	0.9	2.1	1.3	77.1	2.3	0.57
WV	1.3	DNF	DNF	6.9	0.2	DNF
WI	3.0	1.7	3.2	52.5	1.6	2.02
WY	0.2	0.2	0.3	4.5	0.1	1.90
Estimate US Total	100.0	100.0	100.0	3,315.6	100.0	1.00

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 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.

Washington (0.57), Virginia (0.54), and Oregon, (0.22). However, Washington and Oregon had Medicaid State Plan 1915(k) services that were not included in this calculation. States with the highest Medicaid Benefit Ratios were Maine (4.51), Vermont (3.21), North Dakota (2.99), Idaho (2.93), Iowa (2.91), Mississippi (2.52), Alaska (2.46), South Carolina (2.01), and Wisconsin (2.01).

State Medicaid Benefit Ratio Example

With a population of 39.25 million, California was the most populous state in the United States. Total 2016 Medicaid ICF/IID plus Waiver expenditures for its 128,002 recipients with IDD were \$3.66 billion (\$712 million for ICF/IID recipients and \$2.95 billion for Medicaid Waiver recipients). With a federal Medicaid cost share percentage of 50%, the federal Medicaid program paid half of total Medicaid expenditures (\$1.475 billion for Medicaid Waiver recipients and \$356 million for ICF/IID recipients). Total federal 2016 income taxes paid by California were \$422.7 billion.

In FY 2016 California

- Was home to 12.01% of the population of the United States and served 14.5% of total Medicaid ICF/IID plus Waiver recipients with IDD (14.9% of Medicaid Waiver recipients, 10.6% of ICF/IID residents)
- Paid 8.47% of total U.S. Medicaid ICF/IID plus Waiver expenditures for people with IDD (7.38% of Medicaid Waiver expenditures, 7.43% of ICF/IID expenditures)
- Paid 12.75% of all federal income taxes

California's State Medicaid Benefit Ratio was 0.66 (higher than only six other states). It paid a higher proportion of federal income taxes than the proportion of all Medicaid ICF/IID and Waiver expenditures for people with IDD the federal government paid for recipients in California.

A SHORT HISTORY OF LTSS FOR PEOPLE WITH IDD

This history section was originally authored by K. Charlie Lakin and published in earlier editions of the RISP report

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 of the 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. The world of LTSS for people with IDD (both those living with family members and those receiving supports in other settings) has been radically transformed over the last 140 years. This section summarizes some of the key milestones marking that transformation.

The 1880 U.S. Census enumerated 76,895 people with IDD of whom 9,725 (13%) lived in institutions, almshouses, or prisons. By 1903, 96.8% of the 15,511 people with IDD living in institutions lived in a state-operated facility. The average daily population of state-operated IDD facilities increased 10 fold between 1903 and 1946 to 115,928. The number nearly doubled again during the baby boom years of 1946 through 1964 reaching an all-time high of 194,650 in 1967. An additional 33,850 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 intellectual disabilities, urged Congress in 1963 to move away from providing services to people with IDD in custodial institutions to providing services in community settings (JFK Library). In 1965, Senator Robert Kennedy reported that the children at the Willowbrook State School in New York lived in filth and called the facility a “snake pit” (MN DD 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., Kugle & 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 an institution all day every day
- taking breaks from the normal routine 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.

THE MEDICAID PROGRAM

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 facilities were converted to Medicaid SNFs once the Medicaid program was in place, and the number of people 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. There were also concerns that the services offered in SNFs did not meet the developmental needs of children and adults with IDD (e.g., *The Arc of the United States* 1975).

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. Within the legislation, was a hardly noticed, scarcely debated amendment that authorized Federal Financial Participation (FFP) for "intermediate care" provided in public and private IDD facilities. 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; CMS, 2013b).

The ICF/IID legislation provided substantial federal incentives to states for upgrading the physical environment and the quality of care and habilitation in IDD facilities. It also neutralized incentives for

states to place persons with IDD in SNFs, creating an alternative that provided care that was more appropriate and habilitation in the form of active treatment. In the ensuing years, most state IDD facilities were certified as Intermediate Care Facilities 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. This allowed families to enroll their children in a public school instead of placing them in an IDD facility or paying for private educational services. The law also required a free and appropriate publicly funded education for children with disabilities living in SNF, ICF, and other 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 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 residents; 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 children 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 3.7% in 2016.

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 for community residential settings helped stimulate the development of smaller ICF/IID settings.

Community 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 CFR 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 regions developed hundreds, while other regions 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 Medicaid Home and Community Based Services (HCBS) waiver funding authority.

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 will be served and which services will be available (e.g., homemaker, home health aide, personal care, day and residential habilitation, or respite care; 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 in a home they own or lease or with family members. Given their flexibility and potential for promoting individualized services, the Medicaid Waiver authorities were the primary source of funding for community-based LTSS for more than three decades.

BALANCING MEDICAID HOME AND COMMUNITY-BASED SERVICES AND INSTITUTIONAL SERVICES

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 2013, 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, CMS has added several additional Medicaid Waiver authorities, regulations, and interpretive guidelines 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 October 2017, the Medicaid website www.medicaid.gov/medicaid/hcbs/authorities/index.html listed 294 approved Section 1915(c) Home and Community Based Waivers.

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 the 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, and expanded through the Affordable Care Act, 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.

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. The program was expanded through provisions of the Affordable Care Act, and as of August 2017, 43 states and the District of Columbia were participating (www.Medicaid.gov, March 2018). In 2013, 5 states received funding for MFP Tribal Initiatives to build community based support for American Indians and Alaska Natives.

Balancing Incentive Payment

The Medicaid State Balancing Incentive Payments Program was funded in the 2009 Affordable Care Act. It offered enhanced federal funding for states spending fewer than half of all Medicaid LTSS dollars in home or community based settings. In all, 21 states participated in the program between 2011 and 2015. Thirteen states continued participating after September 2015. Participating states had access to extensive technical assistance to support transition from institutional to community based service models.

MANAGED LONG-TERM SERVICES AND SUPPORTS

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 (MLTSS). 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(c) and 1915(b) waivers – also referred to as 1915(b)/(c) 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.

A report from the National Council on Disabilities (Gettings, Moseley, and Thaler, 2013) summarized the growth of managed care for both acute medical care and long-term supports and services and provided recommendations to state and federal authorities regarding the design and implementation of managed Medicaid long-term services and supports for people with disabilities. The report outlines key principles that managed care systems should address to ensure they are adequately meeting the needs of people with disabilities. The American Network of Community Options and Resources (ANCOR) also published guidelines on managed care for LTSS targeting people with IDD. These guidelines offer information on recommended approaches and parameters that policy makers need to embrace if they are recommending that LTSS for people with IDD move into managed care (ANCOR 2015).

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.

The number of states offering MLTSS programs for adults with IDD increased from eight in 2012 to 19 in 2017 (Lewis et al, 2018). Of those states, nine covered Medicaid HCBS funded services and six covered ICF/IID services. The number of states offering MLTSS programs for children with disabilities increased from eight in 2012 to 11 in 2017. Texas is the only state with an MLTSS program specifically for children.

SELF-DIRECTED SERVICES

In contrast to traditional or managed care service options, 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) Home and Community-Based Services waiver, the 1915(i) Home and Community-Based Services 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, specify services and supports to be offered in a service plan, 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>). In addition, a supports broker/consultant/counselor and financial management services must be available to participants.



KEY MILESTONES IN THE LONG-TERM SUPPORTS AND SERVICES POLICY

- **1965 Medicaid Program.** An anti-poverty program establishing Medicaid as a funder of long-term supports and services.
- **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 Home and Community Based Services 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 authorization of the Money Follows the Person program.
- **2009 Affordable Care Act.** This Federal legislation authorized the State Balancing Incentive Payments program, the Medicaid 1915 (i) State Plan LTSS option, and the Medicaid Waiver 1915(k) Community First Choice option, and extended funding for the Money Follows the Person program.
- **2014 Medicaid Home and Community Based Services (HCBS) Rule.** In 2014, the Centers for Medicare and Medicaid Services promulgated new rules that strengthen the requirements for integration, autonomy, choice and control, and person-centered services for Waiver recipients. States have until 2022 to implement transition plans to bring all HCBS funded service settings into compliance with the rule. ■



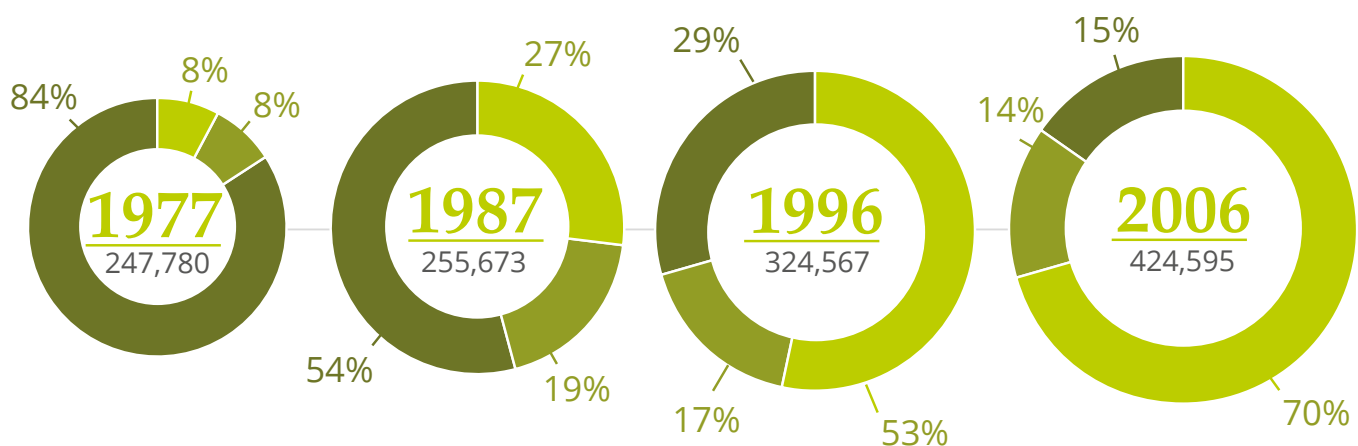
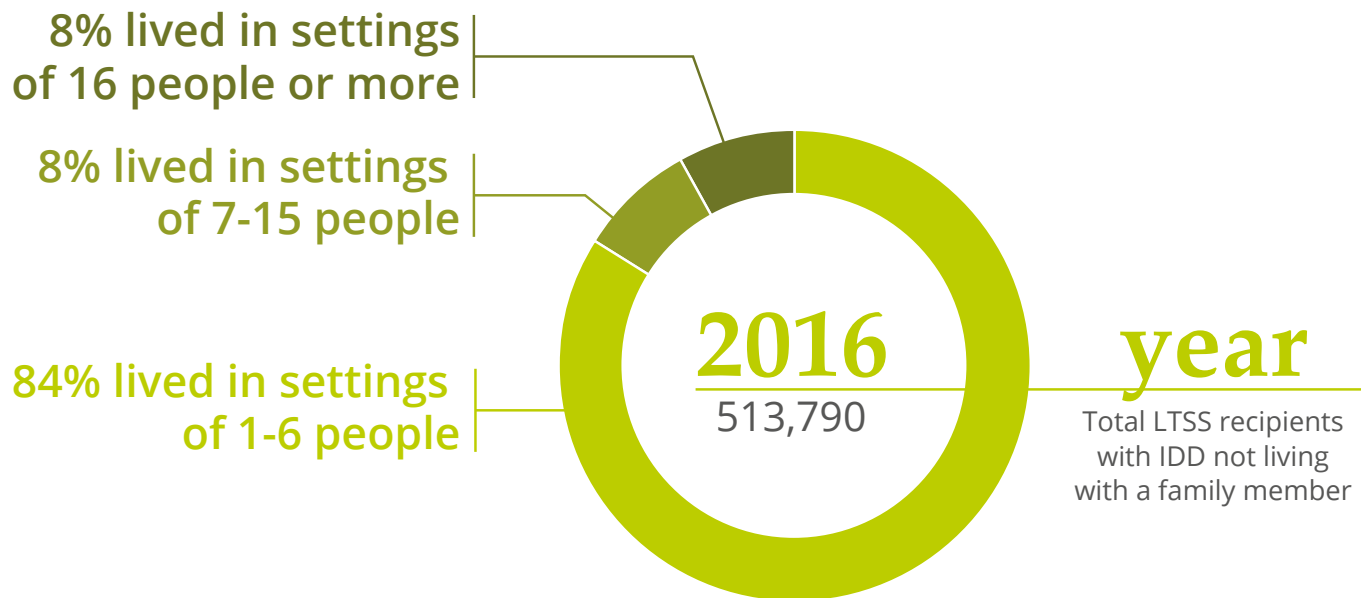
SECTION THREE

**Historical Perspectives and
Trends through 2016 in
Long-Term Supports and Services**

FY 2016

Change in the Total Number of People in Non-Family IDD Settings and Proportion in Settings of Different Sizes Between 1977 and 2016

Proportion of people living in non-family IDD settings



SECTION 3: HISTORICAL PERSPECTIVES AND TRENDS THROUGH 2016

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.

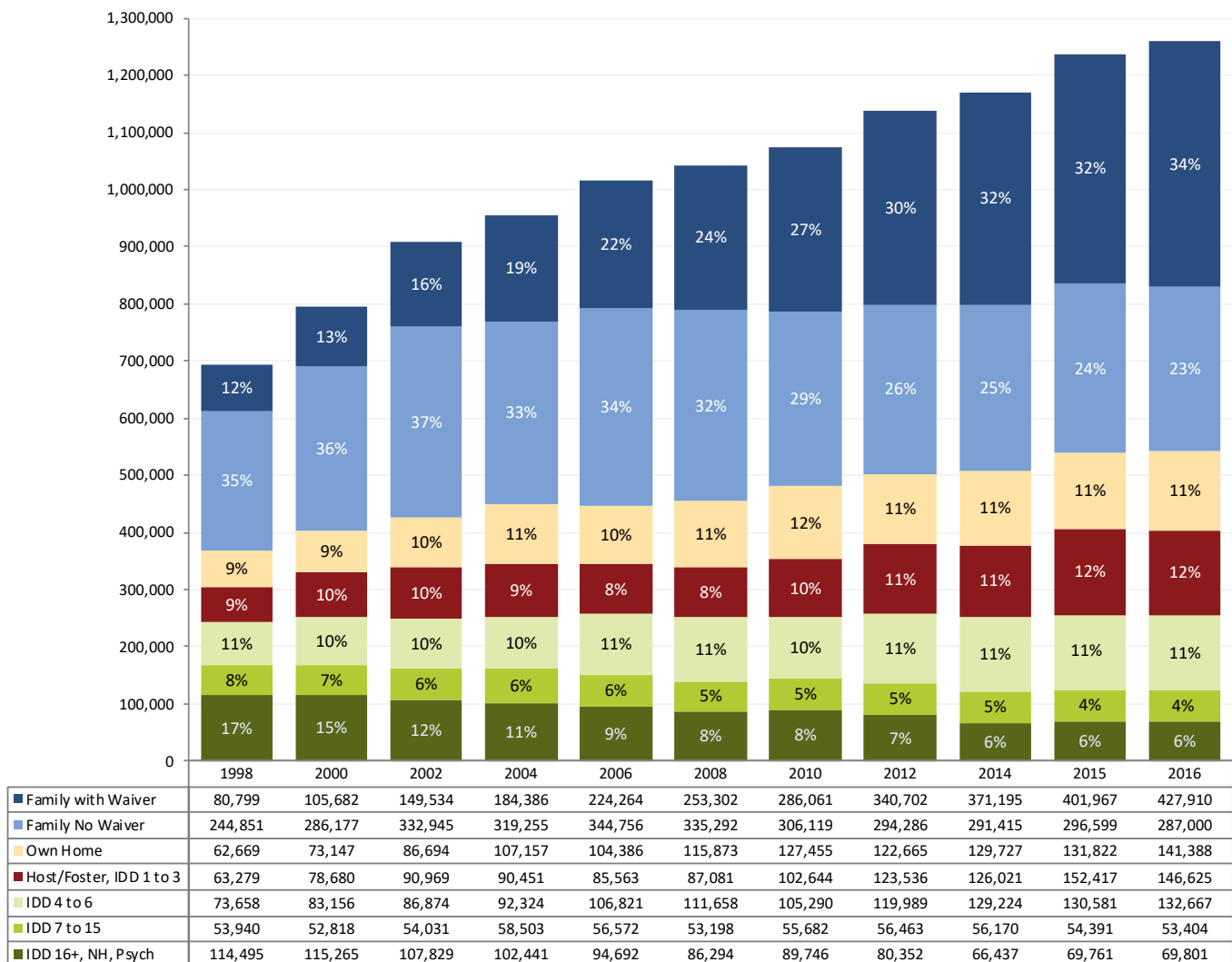
all settings including nursing homes and psychiatric facilities increased 81% from 693,691 to 1,258,796 people (See **Figure 3.1**). As the number of LTSS recipients increased, the types of settings in which they lived also changed.

TRENDS IN LIVING ARRANGEMENTS 1998 THROUGH 2016

The RISP longitudinal study has collected detailed information about people living in the home of a family member, in their own home or in a host/foster family home since 1998. Between 1998 and 2016, the total number of LTSS recipients with IDD in

The number of LTSS recipients with IDD living in their own home increased by 129% from 62,669 (9% of all recipients) in 1998 to 141,388 (12%) in 2016. The number of LTSS recipients with IDD living in the home of a family member increased by 120% from 325,650 (47% of all recipients) in 1998 to 714,910 (57%) in 2016. The funding source for LTSS recipients living with a family member also shifted. In 1998, of the 325,650 LTSS recipients with

Figure 3.1 LTSS Recipients with IDD by Living Arrangement Type and Size: Number and Percent, Select Years 1998 to 2016



IDD who lived with a family member 80,799 people (25%) received Medicaid Waiver funded supports. The proportion living with a family member who were Medicaid Waiver recipients increased to 50% in 2011, and was 60% in 2016.

Between 1998 and 2016, the number of LTSS recipients with IDD living in settings other than their own home or the home of a family member (host or foster family homes, group homes or facilities, nursing homes and psychiatric facilities) increased 33% from 305,372 to 405,473 people overall. The number of LTSS recipients with IDD in settings of:

- 3 or fewer people increased 132% from 63,279 to 141,388 people,
- 4 to 6 people increased 80% from 73,658 to 132,667 people,
- 7 to 15 people declined 1% from 53,940 to 53,404 people, and
- 16 or more people declined 39% from 114,495 to 69,801 people.

People with IDD living with family, in their own homes or in very small group settings are increasingly receiving LTSS funded by a Medicaid Waiver. The proportion of LTSS recipients living in facilities of 7 or more people, nursing homes or psychiatric settings declined from 23% in 1998 to just 10% in 2016. As the 2014 Medicaid HCBS rule which specifies the characteristics of settings in which home and community-based services may be provided is implemented, we expect this trend to continue.

NON-FAMILY IDD SETTINGS BETWEEN 1977 AND 2016

Table 3.1 and **Figure 3.2** show changes since 1977 in the size and type of non-family settings in which LTSS recipients with IDD lived. Non-family IDD settings include own home, host/foster family home, group homes (including ICF/IID), “other” group settings and state-operated IID units located in nursing homes or psychiatric facilities. **Table 3.1** and **Figure 3.2** do not include nursing homes or psychiatric facilities.

Between 1977 and 2016, the total number of non-family settings serving

- 1 to 6 LTSS recipients with IDD increased nearly 32 fold from 6,898 to 221,689 settings,

- 7 to 15 LTSS recipients increased 2.8 times from 2,405 to 6,632 settings, and
- 16 or more LTSS recipients decreased 56% from 1,705 to 755 settings.

Overall, the proportion of settings serving 6 or fewer LTSS recipients with IDD increased from 63% in 1977 to 97% in 2016. In 1977, 65% of 10,543 nonstate-operated settings, and 9% of 465 state-operated settings served six or fewer people. By 2016, 97% of 226,946 nonstate-operated settings, and 60% of 2,130 state-operated settings served 6 or fewer people.

There were 3.6 times more state-operated IDD settings in 2016 (2,130 settings) than in 1977 (465 settings). Between 1977 and 2016, the number of state IDD settings of

- 1 to 6 people increased 28.9 times from 43 to 1,284 settings,
- 7 to 15 people increased 6.4 times from 95 to 706 settings, and
- 16 or more people decreased 57% from 327 to 140 settings.

There were 20.5 times more nonstate IDD settings in 2016 (226,946) than in 1977 (10,543). Between 1977 and 2016, the number of nonstate IDD settings of

- 1 to 6 people increased 31.2 times from 6,855 to 220,405,
- 7 to 15 people increased 1.6 times from 2,310 to 5,926, and
- 16 or more people decreased 55% from 1,378 to 615.

Overall, the proportion settings that were nonstate-operated increased from 96% in 1977 to 99% in 2016. Of the settings with

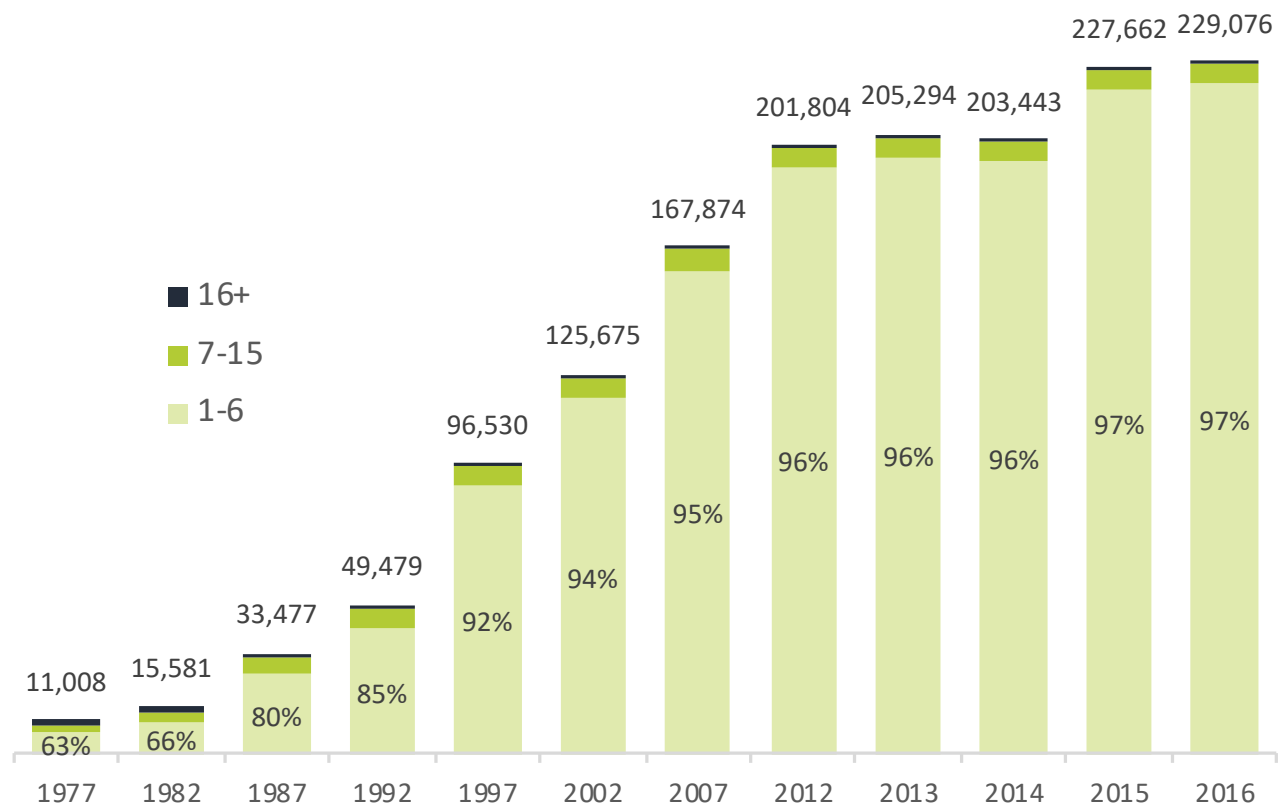
- 1 to 6 people almost all (99%) have been nonstate-operated since 1977,
- 7 to 15 people, the proportion that were operated by a nonstate entity declined from 96% in 1977 to 89% in 2016, and
- 16 or more people the proportion that were nonstate-operated ranged from 78% to 89% and was 81% in 2016.

Table 3.1 Non-Family IDD Residences by Type of Operation and Setting Size on June 30 of Selected Years, 1977 to 2016

Year	Number of Residential Settings														
	Nonstate					State					Total				
	1-6	7-15	16+	Total	%1-6	1-6	7-15	16+	Total	%1-6	1-6	7-15	16+	Total	%1-6
1977	6,855	2,310	1,378	10,543	65%	43	95	327	465	9%	6,898	2,405	1,705	11,008	63%
1982	10,073	3,181	1,370	14,624	69%	182	426	349	957	19%	10,255	3,607	1,719	15,581	66%
1987	26,475	4,713	1,370	32,558	81%	189	443	287	919	21%	26,664	5,156	1,657	33,477	80%
1992	41,444	5,158	1,320	47,922	86%	382	852	323	1,557	25%	41,826	6,010	1,643	49,479	85%
1997	87,917	5,578	1,040	94,535	93%	1,047	702	246	1,995	52%	88,964	6,280	1,286	96,530	92%
2002	116,189	5,880	1,026	123,095	94%	1,634	713	233	2,580	63%	117,823	6,593	1,259	125,675	94%
2003	135,700	6,320	849	142,869	95%	1,707	771	234	2,712	63%	137,407	7,091	1,083	145,581	94%
2004	139,963	5,173	831	145,967	96%	1,621	703	229	2,553	63%	141,584	5,876	1,060	148,520	95%
2005	144,084	4,987	782	149,853	96%	1,542	718	209	2,469	62%	145,626	5,705	991	152,322	96%
2006	149,114	6,436	849	156,399	95%	1,506	737	201	2,444	62%	150,620	7,173	1,050	158,843	95%
2007	158,365	6,092	784	165,241	96%	1,683	733	217	2,633	64%	160,048	6,825	1,001	167,874	95%
2008	161,830	6,214	791	168,835	96%	1,628	734	215	2,577	63%	163,458	6,948	1,006	171,412	95%
2009	164,379	5,659	764	170,802	96%	1,637	732	205	2,574	64%	165,682	6,391	969	173,042	96%
2010	176,596	7,086	833	184,516	96%	1,501	692	203	2,396	63%	178,097	7,778	1,036	186,912	95%
2011	191,457	5,259	885	197,601	97%	1,485	701	200	2,386	62%	192,942	5,960	1,085	199,987	96%
2012	193,008	5,518	879	199,213	97%	1,315	685	187	2,165	61%	194,323	6,203	1,066	201,378	96%
2013	196,416	5,555	1,176	203,146	97%	1,258	710	167	2,135	59%	197,674	6,265	1,343	205,281	96%
2014	194,505	5,931	808	201,244	97%	1,330	723	148	2,201	60%	195,835	6,654	956	203,445	96%
2015	218,487	6,311	774	225,573	97%	1,231	709	149	2,089	59%	219,718	7,020	923	227,662	97%
2016	220,405	5,926	615	226,946	97%	1,284	706	140	2,130	60%	221,689	6,632	755	229,076	97%

This table excludes family homes, nursing homes, and psychiatric settings. It includes ICF/IID, group homes, host homes and family foster homes, own home, and "other" settings.

Figure 3.2 Non-family IDD Settings by Setting Size, and Proportion with 1 to 6 People on June 30 of Selected Years, 1977 to 2016



PEOPLE IN STATE AND NONSTATE IDD SETTINGS BY SIZE AND TYPE OF OPERATION 1977 TO 2016

The number LTSS recipients living in settings other than the home of a family member doubled from 247,780 people in 1977 to 513,790 people in 2016 (See **Table 3.2**).

Between 1977 and 2016, the number of people living in settings of

- 6 or fewer people increased nearly 20 times from 20,400 to 420,681,
- 7 to 15 people increased 1.7 times from 20,024 to 53,404,
- 16 or more people decreased 81% from 207,356 to 39,705.

Of the people living in non-family IDD settings, the proportion living in settings of 6 or fewer people increased from 8% in 1977 to 82% in 2016. The proportion in

- nonstate-operated settings of six or fewer people increased from 22% in 1977 to 86% in 2016, and
- state-operated settings of six or fewer people increased from less than 0.5% in 1977 to 15% in 2016

Of the people living in non-family IDD settings, the proportion in settings of 16 or more people decreased overall from 84% in 1977 to 8% in 2016. The proportion

- In nonstate-operated settings of 16 or more people decreased from 57% (52,718 people) in 1977 to 4% (20,624 people) in 2016, and
- In state-operated settings of 16 or more people decreased from 99% (154,638 people) in 1977 to 64% (19,081 people) in 2016.

State Operated Settings

The number of people with IDD in state-operated settings decreased 81% from 155,804 to 29,768 people between 1977 and 2016 (See **Figure 3.3**). The number living in state-operated IDD serving

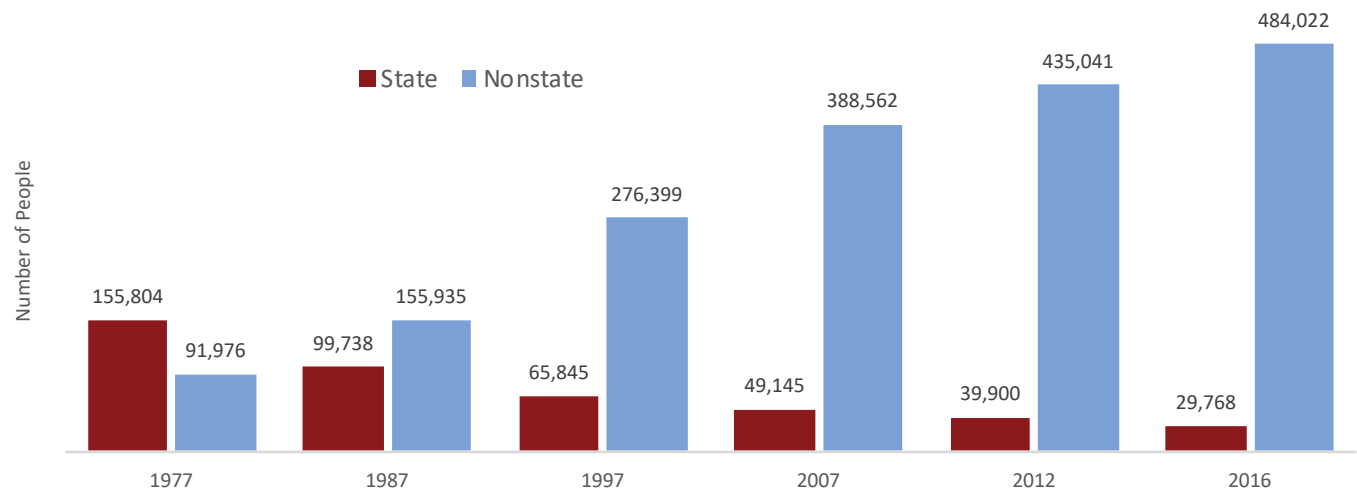
- 1 to 6 people increased 20.2 times from 216 to 4,580 people,
- 7 to 15 people increased 5.4 times from 950 to 6,107 people, and
- 16 or more people decreased 88% from 154,638 to 19,081 people.

Table 3.2 People with IDD in LTSS Settings by Setting Size, and Proportion with 1 to 6 People on June 30 of Selected Years, 1977 to 2016

Year	Number of People with IDD ¹														
	Nonstate					State					Total				
	1-6	7-15	16+	Total	%1-6	1-6	7-15	16+	Total	%1-6	1-6	7-15	16+	Total	%1-6
1977	20,184	19,074	52,718	91,976	22%	216	950	154,638	155,804	0%	20,400	20,024	207,356	247,780	8%
1982	32,335	28,810	57,396	118,541	27%	853	1,705	122,750	125,308	1%	33,188	30,515	180,146	243,849	14%
1987	68,631	45,223	42,081	155,935	44%	1,302	3,414	95,022	99,738	1%	69,933	48,637	137,103	255,673	27%
1992	118,304	46,023	45,805	210,132	56%	1,371	7,985	74,538	83,894	2%	119,675	54,008	120,343	294,026	41%
1997	190,715	46,988	38,696	276,399	69%	4,253	6,926	54,666	65,845	6%	194,968	53,914	93,362	342,244	57%
2002	258,709	46,728	30,676	336,113	77%	5,532	7,029	44,066	56,627	10%	264,241	53,757	74,742	392,740	67%
2003	269,907	46,961	29,639	346,507	78%	5,554	7,385	42,835	55,774	10%	275,461	54,346	72,474	402,281	68%
2004	289,456	49,248	27,495	366,199	79%	5,540	6,810	41,653	54,003	10%	294,996	56,058	69,148	420,202	70%
2005	285,671	46,027	27,005	358,703	80%	5,471	6,980	40,061	52,512	10%	291,142	53,007	67,066	411,215	71%
2006	293,755	53,458	26,559	373,772	79%	5,429	7,089	38,305	50,823	11%	299,184	60,547	64,864	424,595	70%
2007	310,874	51,842	25,846	388,562	80%	5,417	7,078	36,650	49,145	11%	316,291	58,920	62,496	437,707	72%
2008	320,065	45,039	23,818	388,922	82%	5,360	6,994	35,035	47,389	11%	325,425	53,424	57,462	436,866	74%
2009	316,036	51,400	26,695	394,131	80%	5,427	7,048	32,909	45,384	12%	321,463	58,448	59,604	439,515	73%
2010	348,039	49,711	25,712	423,677	82%	5,156	6,875	31,101	43,132	12%	353,195	56,586	56,813	466,809	76%
2011	342,339	51,273	22,796	419,783	82%	5,059	6,786	28,969	40,814	12%	347,398	58,059	51,765	460,597	75%
2012	360,804	50,069	24,168	435,041	83%	5,386	6,394	28,120	39,900	13%	366,190	56,463	52,288	474,941	77%
2013	369,826	49,404	26,163	445,393	83%	5,317	6,431	23,865	35,613	15%	375,143	55,835	50,028	481,006	78%
2014	379,184	50,280	24,679	454,142	83%	5,267	6,402	21,866	33,535	16%	384,451	56,682	46,545	487,677	79%
2015	410,224	48,109	20,665	478,998	86%	4,596	6,282	20,709	31,587	15%	414,820	54,391	41,374	510,585	81%
2016	416,101	47,297	20,624	484,022	86%	4,580	6,107	19,081	29,768	15%	420,681	53,404	39,705	513,790	82%

¹ This table excludes family homes. Nursing homes and psychiatric settings are only included when reported in state or nonstate other. It includes ICF/IID, group homes, host homes and family foster homes, own home, and "other" settings.

Figure 3.3 People with IDD in Non-family LTSS Settings by Type of Operation and Selected Years (Estimated) on June 30



Nonstate Operated Settings

The number of people in nonstate-operated settings increased 4-fold from 91,976 to 484,022 people between 1977 and 2016. The number living in nonstate IDD settings serving

- 1 to 6 people increased 19.6 times from 20,184 to 416,277 people,
- 7 to 15 people increased 1.5 times from 19,074 to 47,297 people, and
- 16 or more people decreased 61% from 52,718 to 20,624 people.

Between 2003 and 2016, the number of people with IDD living in nonstate-operated IDD facilities of 16 or more people declined by 8,974 people (an average of 748 people per year) while the number living in state-operated IDD facilities of 16 or more people declined by 23,754 (an average of 1,827 people per year). More people have lived in nonstate-operated facilities of 16 or more people than in state-operated facilities of the same size since 2013.

Differences in deinstitutionalization rates for state-operated versus nonstate facilities of 16 or more people in recent years prompts several questions. For example,

- Will deinstitutionalization continue for people with IDD in state-operated and nonstate IDD facilities, nursing homes, and psychiatric facilities who would like to move to a community home?

- How might deinstitutionalization strategies be different for nonstate settings?
- What are the similarities and differences between state and nonstate IDD facilities of 16 or more people? Why are the deinstitutionalization rates different?

Average People per Setting

The average size of non-family IDD settings declined from 22.5 people in 1977 to 2.2 people in 2016 (See **Figure 3.4**). The average in nonstate settings was 8.7 people in 1977, 4.8 in 1997, 2.4 in 2007, and 2.1 in 2016. The average number of people in state-operated settings was 335 people in 1977, 33 in 1997, 19 in 2007, and 14 in 2016.

MEDICAID EXPENDITURES FOR PEOPLE WITH IDD

Total Medicaid expenditures for all populations grew from \$14.55 billion in 1980 to \$553.45 billion in 2016 (See **Table 3.3**). Medicaid ICF/IID and Waiver funding for people with IDD increased from \$1.74 billion in 1980 to \$45.98 billion in 2016. The proportion of Medicaid expenditures allocated to LTSS for people with IDD declined from 11.9% in 1980 to 8.3% in 2016.

Figure 3.4 Recipients with IDD Per Non-family Setting on June 30 of Selected Years 1977 to 2016

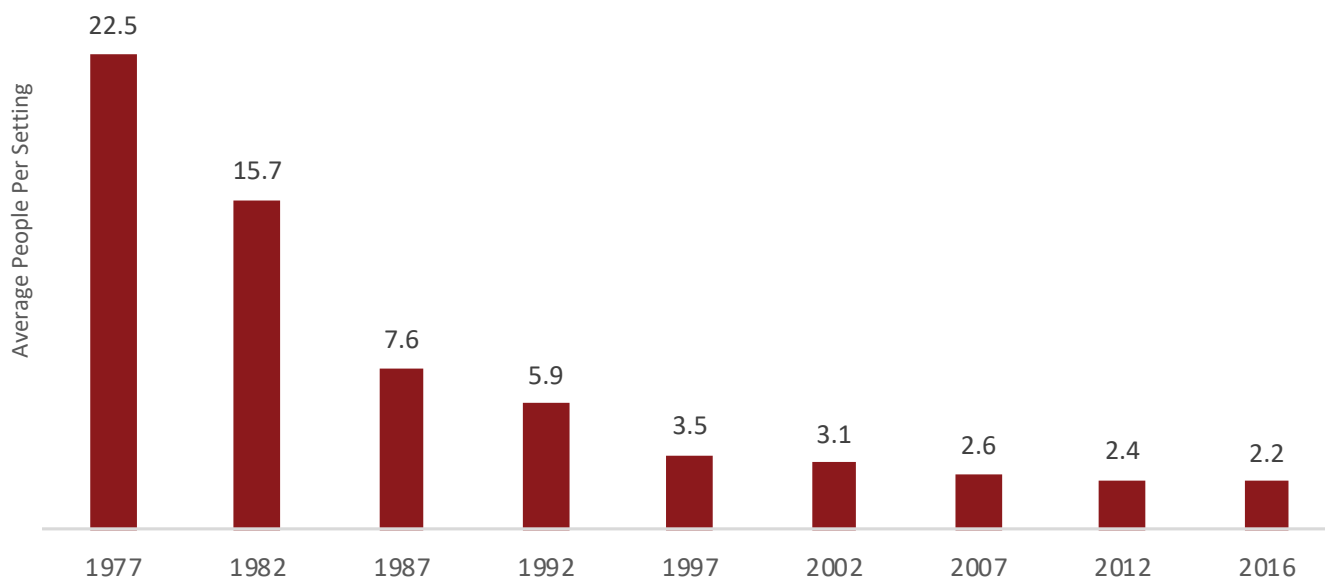


Table 3.3 Medicaid Expenditures for ICF/IID and Waiver Recipients with IDD as a Proportion of All Medicaid Expenditures Select Years, 1980 to 2016

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 ¹	\$391.72	\$41.85	10.7%
2011 ¹	\$414.50	\$40.68	9.8%
2012 ²	\$419.83	\$42.62	10.2%
2013 ²	\$437.86	\$42.21	9.6%
2014 ²	\$476.82	\$41.71	8.7%
2015 ²	\$524.29	\$44.37	8.5%
2016 ³	\$553.45	\$45.98	8.3%

¹ Source Eiken et al (2016). ² Source: Eiken et al. (2017). ³ Source: <https://www.kff.org/medicaid/state-indicator/total-medicaid-spending/>

TRENDS IN MEDICAID WAIVER AND ICF/IID RECIPIENTS, EXPENDITURES, AND PER RECIPIENT EXPENDITURES

Recipients

The number of people in ICF/IID peaked at 147,729 in 1993, but declined to 74,614 by 2016 (See **Figure 3.5a**). In 1982, there were 1,381 (1%) Medicaid Waiver recipients and 140,752 people (99%) in an ICF/IID. By June 30, 2016, the number of Medicaid Waiver recipients had grown to 807,462 (92%) compared with 74,614 people in ICF/IID settings (8%). The number of Medicaid Waiver recipients with IDD first exceeded the number of ICF/IID residents in 1995.

Expenditures

In 1982, Medicaid ICF/IID expenditures were \$3.35 billion (99.9% of total 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 2016, annual Medicaid Waiver expenditures were 77% of combined expenditures (\$35.5 billion) compared to \$10.5 billion for ICF/IID.

Figure 3.5a Medicaid ICF/IID and HCBS Waiver Recipients with IDD From 1982 to 2016

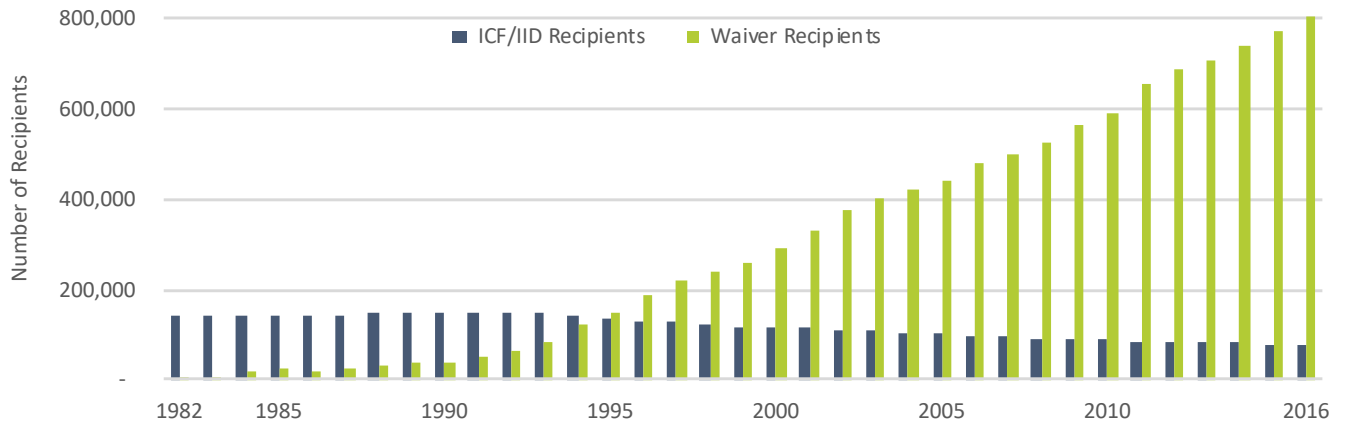


Figure 3.5b Medicaid ICF/IID and HCBS Waiver Expenditures for People with IDD From 1982 to 2016

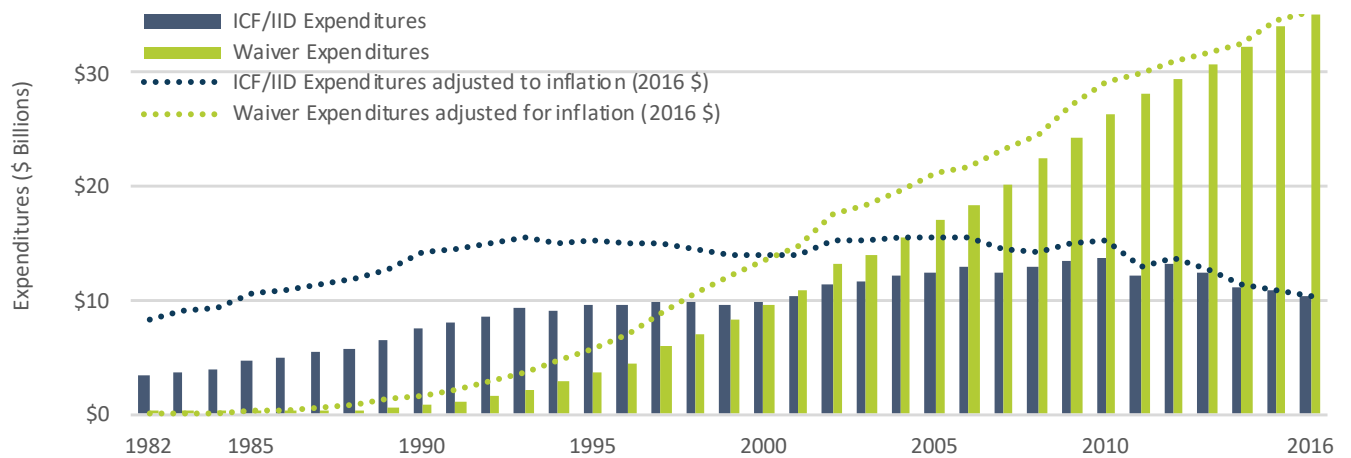
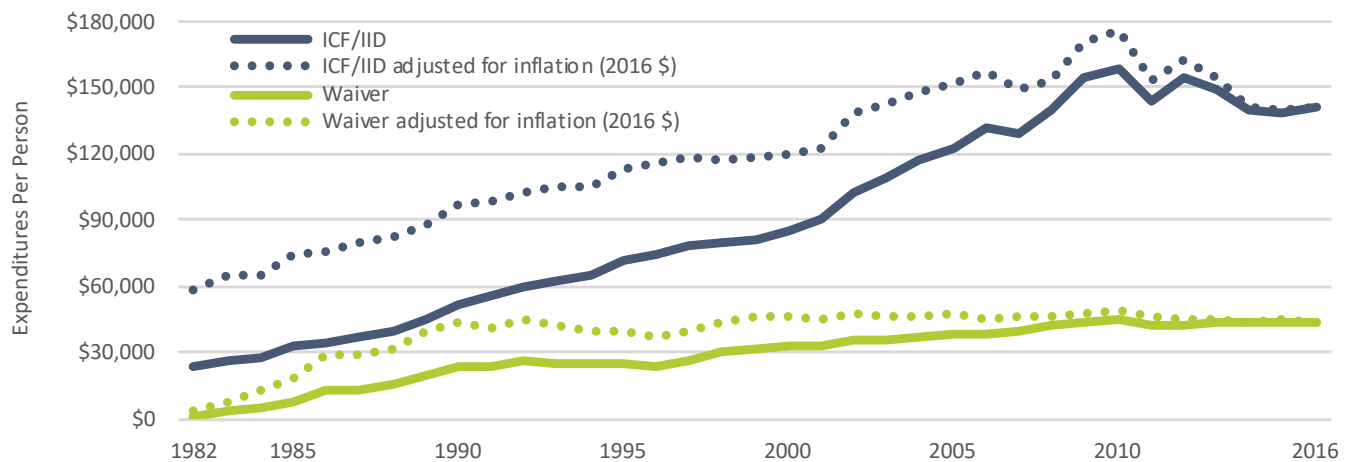


Figure 3.5c Average Annual Per Person ICF/IID and Waiver Expenditures For People with IDD From 1982 to 2016



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 (\$4,029 in 2016 inflation adjusted dollars) and \$23,806 for people in ICF/IID settings (\$59,039 in 2016 inflation adjusted dollars). In 2016, average annual per recipient expenditures had increased to \$43,928 for Medicaid Waiver recipients and to \$140,831 for people in ICF/IID settings.

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. The number of states with Medicaid Waiver recipients with IDD grew from two in 1982 to 51 in 2001. All states and the District of Columbia operated one or more ICF/IID in 1977 but by 2016, the number had declined to 49 states. 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 2016

State	1982	1987	1997	2007	2012	2014	2015	2016	% change 2012-2016
AL	0	1,570	3,713	5,230	5,604	5,807	5,425	5,580	0
AK	0	0	353	1,011	1,703	1,942	2,044	2,093	23
AZ	0	0	8,508	19,066	24,617	27,071	28,418	29,580	20
AR	0	0	496	3,342	4,037	4,160	4,122	4,135	2
CA	0	3,027	37,478	73,024	97,868	109,048	115,365	120,084	23
CO	0	1,389	4,276	7,148	8,147	8,569	9,932	10,846	33
CT	0	0	3,371	7,692	8,638	9,534	9,602	10,221	18
DE	0	81	379	788	855	989	1,041	1,077	26
DC	0	0	0	1,090	1,479	1,595	1,574	1,670	13
FL	0	2,631	11,399	31,425	29,353	30,281	32,277	32,830	12
GA	0	0	2,332	9,194	11,621	8,295	8,506	8,579	-26
HI	0	56	560	2,481	2,544	2,661	2,652	2,753	8
ID	0	55	434	2,015	2,660	6,598	7,616	7,726	190
IL	0	664	5,400	12,800	18,355	21,226	22,141	23,744	29
IN	0	0	1,067	9,976	12,786	17,407	18,950	22,298	74
IA	0	4	3,932	12,751	11,359	14,725	14,532	14,091	24
KS	0	135	3,872	7,195	8,274	8,695	8,734	8,836	7
KY	0	609	1,040	3,033	11,046	15,000	14,867	14,768	34
LA	0	0	2,048	6,915	9,957	11,539	12,042	12,379	24
ME	0	400	1,078	2,781	4,101	4,308	4,839	5,087	24
MD	0	685	3,392	10,294	12,489	10,970	13,935	14,424	15
MA	0	593	8,027	11,962	11,987	13,361	13,798	14,274	19
MI	0	3	6,199	8,089	39,838	36,600	45,115	45,115	13
MN	0	1,423	6,097	14,593	18,963	18,185	18,316	18,316	-3
MS	0	0	231	1,978	1,831	2,209	2,296	2,408	32
MO	0	0	6,282	8,396	11,041	12,242	13,133	13,722	24
MT	21	210	891	2,242	2,668	2,699	2,798	2,533	-5
NE	0	0	2,010	3,304	4,531	4,836	4,656	4,686	3
NV	0	129	374	1,372	1,652	1,877	1,941	2,033	23
NH	0	541	2,063	3,339	4,519	4,834	5,235	5,235	16
NJ	0	2,596	5,705	9,923	11,297	10,977	10,972	10,922	-3
NM	0	220	1,603	3,711	4,115	4,943	4,231	4,916	19
NY	0	0	29,019	56,401	77,047	80,574	83,739	77,955	1
NC	0	328	3,726	9,309	12,800	12,881	13,666	16,892	32
ND	0	724	1,792	3,535	4,059	4,277	4,613	4,776	18
OH	0	100	2,646	16,362	30,872	34,274	35,245	36,817	19
OK	0	70	2,497	5,308	5,223	5,463	5,577	5,625	8
OR	1,360	832	2,586	10,287	14,865	16,922	6,932	12,548	-16
PA	0	1,203	8,931	26,558	29,963	31,695	32,628	34,147	14
RI	0	136	2,178	3,126	3,316	DNF	3,654	3,638	10
SC	0	0	3,412	5,186	8,394	8,646	9,591	10,288	23
SD	0	596	1,457	2,609	3,215	3,433	3,592	3,625	13
TN	0	213	3,293	7,244	7,680	7,799	7,878	8,090	5
TX	0	70	4,753	16,301	29,193	31,447	34,623	36,671	26
UT	0	0	2,315	4,003	4,319	4,941	5,241	5,203	20
VT	0	196	1,372	2,200	2,649	2,833	2,917	3,010	14
VA	0	0	1,764	7,523	9,754	11,096	12,422	17,176	76
WA	0	886	6,643	9,317	11,898	12,483	12,892	15,586	31
WV	0	124	1,441	3,852	4,447	5,079	5,079	4,634	4
WI	0	190	6,558	12,504	23,396	27,838	31,460	31,460	34
WY	0	0	916	2,079	2,150	1,813	2,110	2,360	10
Estimated US Total	1,381	22,689	221,909	501,864	688,410	740,032	774,964	807,462	17
N States	2	35	50	51	50	51	51	51	

N/A Not applicable, means there were no people receiving Medicaid Waiver supports. Medicaid Waivers began in 1982. Data for years since 1982 can be viewed in the Chart Gallery Section of the RISP.umn.edu website.

Table 3.5 Estimated Medicaid Waiver Expenditures for People with IDD by State Selected Years, 1982 to 2016

State	1982	1987	1997	2007	2012	2014	2015	2016	% change 2012-2016
AL	0	8,325,700	72,327,370	253,259,493	288,701,202	318,480,978	324,101,031	361,133,006	25
AK	0	0	17,668,470	70,954,834	134,516,256	143,610,221	168,195,290	176,257,752	31
AZ	0	0	203,897,500	556,449,700	640,785,297	788,832,352	827,517,340	888,159,763	39
AR	0	0	12,063,322	91,379,808	173,134,527	190,226,399	204,761,648	215,395,080	24
CA	0	30,400,000	355,246,000	1,532,880,000	2,107,489,165	2,551,065,192	2,796,562,703	2,951,586,525	40
CO	0	25,454,800	133,282,479	268,080,321	331,009,675	355,864,334	395,467,924	428,244,451	29
CT	0	7,000	222,364,121	454,124,513	720,877,844	693,438,314	879,290,977	935,171,896	30
DE	0	845,500	16,279,225	75,089,815	94,328,870	103,491,162 ^e	118,357,072	119,647,068	27
DC	0	0	0	19,678,020	147,196,144	160,466,106	184,827,720	198,579,169	35
FL	0	12,849,800	131,804,756	908,572,039	879,855,035	857,528,282	889,313,799	989,155,709	12
GA	0	0	63,129,643	263,542,265	407,211,908	350,999,007	356,005,822	356,494,730	-12
HI	0	564,600	11,720,944	97,000,000	102,909,919	104,338,769	105,401,320	133,664,402	30
ID	0	568,200	9,996,472	60,937,200	64,424,617	103,036,140	196,902,851	228,262,935	254
IL	0	12,839,600	116,000,000	416,200,000	591,460,042	723,467,619	829,757,322	885,746,790	50
IN	0	0	33,300,620	402,596,549	489,970,561	578,990,198	606,865,582	527,782,481	8
IA	0	0	48,271,477	275,727,517	387,579,845	473,300,661	510,898,817	543,362,797	40
KS	0	637,700	93,518,741	247,333,699	330,269,359	400,136,206	413,799,134	484,173,351	47
KY	0	10,974,100	29,429,581	163,060,166	406,429,143	551,471,229	595,400,472	636,053,497	56
LA	0	0	44,291,400	258,219,940	407,247,885	446,673,888	463,018,241	468,162,024 ^e	15
ME	0	5,673,800	60,066,647	230,661,475	291,071,088	270,678,407	300,527,262 ^e	336,875,740 ^e	16
MD	0	21,708,000	140,673,425	495,385,519	686,893,892	557,424,779	816,424,318	873,835,172	27
MA	0	13,278,000	280,000,000	587,453,199	876,813,984	883,274,710 ^s	1,159,456,123 ^s	1,008,755,777	15
MI	0	79,800	162,808,522	316,274,000	445,712,073	1,184,470,148	1,437,648,930	1,437,648,930 ^d	223
MN	0	13,170,000	260,223,164	889,902,016	1,215,080,921	1,191,169,273	1,276,890,437	1,276,890,437 ^d	5
MS	0	0	631,007	39,460,620	43,976,251	69,586,843	71,373,275	76,687,294	74
MO	0	0	154,767,652	379,435,294	533,966,837	668,192,078	700,423,090	769,305,472	44
MT	374,900	3,595,900	22,500,000	68,411,681	90,871,419	120,729,711	120,621,602	105,082,327	16
NE	0	0	58,901,127	140,171,512	239,920,704	174,122,370	164,627,422	295,434,698	23
NV	0	1,489,400	4,877,293	61,584,554	78,766,702	93,448,000	95,273,457	96,466,727	22
NH	0	13,518,400	89,427,245	143,208,714	192,024,701	208,839,906	232,931,814	232,931,814 ^d	21
NJ	0	35,888,000	180,006,000	496,612,000	737,870,549	824,873,688 ^s	876,940,082	963,648,060	31
NM	0	1,409,600	46,295,349	247,597,401	285,948,508	277,066,357	189,878,752	320,915,462	12
NY	0	711,800	1,114,422,787	3,449,069,061	5,468,224,696	4,899,992,876	5,104,674,884	5,391,831,886	-1
NC	0	3,058,900	106,199,243	377,746,642	619,805,304	755,613,932 ^s	689,198,047 ^e	603,809,596 ^e	-3
ND	0	5,438,200	30,176,000	71,823,487	129,617,461	168,827,063 ^s	180,687,708	192,609,419	49
OH	0	1,130,500	90,058,170	660,978,417	1,240,862,952	1,375,523,420	1,434,162,087	1,529,159,493	23
OK	0	392,000	93,592,963	253,400,544	273,951,817	301,540,486 ^e	312,640,630	310,647,099	13
OR	1,868,500	8,305,800	105,178,092	385,761,698	597,868,202	683,931,909	51,810,862	71,227,540	-88
PA	0	35,974,800	415,398,542	1,199,738,817	1,816,306,161	2,175,066,007	2,308,611,230	2,527,639,175	39
RI	0	5,648,000	107,961,796	245,521,023	203,663,206	218,000,000 ^s	193,372,725	234,726,062	15
SC	0	0	51,300,000	185,700,000	291,243,055	258,611,956	281,265,947	330,995,939	14
SD	0	6,153,300	38,738,683	81,944,579	101,739,037	107,606,699	113,189,597	115,968,067	14
TN	0	1,853,100	72,738,465	525,963,523	604,098,205	642,522,366	669,248,000	671,358,732	11
TX	0	1,828,100	159,896,149	566,475,093	1,058,827,386	1,148,582,363 ^e	1,240,211,080 ^d	1,418,007,042 ^d	34
UT	0	0	50,793,746	113,867,000	155,514,728	178,260,955	192,118,347	212,793,046	37
VT	0	4,839,900	47,980,267	109,071,348	141,617,128	158,833,549	165,311,946	172,227,127	22
VA	0	0	67,429,885	394,326,044	602,412,138	737,955,990	727,153,068	504,150,392	-16
WA	0	12,068,200	105,005,621	315,623,788	550,895,554	603,214,931	722,125,854 ^e	369,959,184	-33
WV	0	777,200	43,659,534	203,371,121	303,861,581	422,183,821	358,871,525 ^s	DNF	DNF
WI	0	3,503,400	155,238,000	439,299,106	855,374,008	978,759,826	1,041,267,487	1,041,267,487 ^d	22
WY	0	0	33,428,015	87,040,867	98,496,506	95,006,103	89,473,522	91,333,200	-7
Estimated US Total	2,243,400	304,961,100	5,964,965,510	20,177,966,022	29,538,694,048	32,329,327,579	34,184,856,176	35,470,093,347	20
N States	2	36	50	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.

Table 3.6 Estimated Number of ICF/IID Recipients by State Selected Years, 1977 to 2016

State	1977	1988	1997	2007	2012	2014	2015	2016	% change 2012-2016
AL	0	1,364	745	244	41	14	14	22	-46
AK	135	107	10	0	0	6	6	7	N/A
AZ	0	0	214	185	148	137 ^s	131 ^s	137 ^s	-7
AR	1,385	1,453	1,558	1,616	1,467	1,455 ^s	1,444 ^s	1,442 ^s	-2
CA	0	10,871	10,681	9,598	8,726	8,230	8,109 ^g	7,918 ^g	-9
CO	4,537	1,149	229	125	343	175	175 ^g	215 ^g	-37
CT	687	1,414	1,377	1,148	993	871	845 ^s	790 ^g	-20
DE	477	439	292	141	135	125 ⁱ	120	100	-26
DC	0	666	754	640	363	341	329	323	-11
FL	370	3,180	3,476	3,205	2,806	2,788	2,742	2,791 ^g	-1
GA	2,369	1,913	1,770	1,034	300	249	291 ^s	284 ^s	-5
HI	524	296	122	78	79	70	76	76	-4
ID	583	461	579	543	487	469 ^s	488	488	0
IL	5,353	10,346	10,500	9,213	8,344	7,360 ^e	6,788	6,615	-21
IN	1,026	4,690	5,938	4,012	3,839	3,595	3,319	3,249	-15
IA	1,432	1,840	2,268	2,123	2,002	2,176	2,133	2,011	0
KS	1,810	2,081	1,395	599	509	462 ⁱ	450 ^s	450 ^g	-12
KY	999	1,187	1,180	637	523	476 ^g	435 ^s	427 ^s	-18
LA	3,682	6,016	6,014	5,320	4,604	4,825	5,247	4,956	8
ME	310	677	548	222	202	181 ^g	167	162	-20
MD	1,367	1,429	624	336	54	143 ⁱ	107 ^s	96 ^g	78
MA	4,242	3,698	1,598	952	594	499	433	409	-31
MI	5,760	3,683	2,899	151	0	0	0	0 ^d	N/A
MN	5,303	6,339	3,604	2,513	1,719	1,685	1,591	1,591 ^d	-7
MS	491	1,678	2,256	2,601	2,765	2,433	2,432	2,337 ^g	-15
MO	2,051	1,868	1,466	1,020	590	506	473	442 ^g	-25
MT	0	253	148	54	55	51	55	42 ^g	-24
NE	1,356	808	643	582	433	392	394	393	-9
NV	0	188	275	118	104	100	98	91	-13
NH	288	204	23	25	25	25 ⁱ	25	25	0
NJ	525	3,815	3,948	2,963	3,153	2,365 ⁱ	2,041 ⁱ	1,881 ^g	-40
NM	426	709	348	182	234	265 ⁱ	252 ^s	257	10
NY	18,601	17,567	11,472	7,995	7,288	6,782	6,502	5,555	-24
NC	2,073	3,445	4,777	4,124	3,930	3,359 ⁱ	3,965 ^s	3,925 ^g	0
ND	0	888	609	593	559	545 ^b	542 ^g	539 ^g	-4
OH	2,488	7,535	7,615	6,667	6,926	6,555	6,434 ^g	6,147	-11
OK	1,978	3,242	2,292	1,630	1,549	1,265 ⁱ	1,582 ^g	1,307 ^g	-16
OR	1,989	1,284	373	41	0	0	0	0	N/A
PA	7,355	7,364	6,192	3,833	3,419	3,164 ^g	3,039 ^g	2,991	-13
RI	763	1,093	21	41	42	42 ⁱ	32 ^s	35 ^s	-17
SC	1,017	3,300	2,555	1,615	1,313	1,207 ^g	1,184	1,165	-11
SD	540	650	328	158	199	190	190 ^g	192	-4
TN	2,149	2,198	1,900	1,223	1,108	999 ⁱ	1,020	947 ^g	-15
TX	10,486	12,211	12,985	11,447	9,467	9,626 ^d	8,304 ^g	7,997 ^g	-16
UT	1,193	945	833	794	801	839 ^g	841	786 ^g	-2
VT	352	238	12	6	6	6	6	6	0
VA	3,558	3,018	2,225	1,684	1,326	1,094 ^g	1,004 ^g	881 ^g	-34
WA	440	2,539	1,126	767	629	841 ⁱ	814 ^g	751	19
WV	0	417	574	477	562	553	509 ^g	509	-9
WI	3,696	3,378	3,187	1,059	895	791	787	787 ^d	-12
WY	0	0	139	93	79	75 ^s	70	67	-15
Estimated US Total	106,166	146,134	126,697	96,427	85,384	80,402	78,035^o	74,614	-13
N States	51	49	51	50	48	49	49 ^o	49	51

^{pd} Partial Data. Data for all available years available in the Chart Gallery Section of the RISP.umn.edu website. ^b Nonstate settings reported, but not state settings. ^d Other date (Usually a different fiscal year or June 30, 2015). ^e Estimate. ⁱ One or more component value imputed by RISP staff. ^g Sum of setting size data substituted for reported value. ^{DNF} Did not furnish. ^s ACHA (2017a); Eiken, et al (2017). *See state notes in Appendix.

Table 3.7 Estimated Medicaid ICF/IID Expenditures by State Selected Years, 1982 to 2016

State	1982	1988	1997	2007	2012	2014	2015	2016	% change 2012-2016
AL	31,075,591	54,013,748	58,305,599	31,522,229	10,586,376	1,092,487	945,886	1,996,769	-81
AK	6,830,128	9,037,943	2,032,452	161,277	3,050,708 ^s	3,055,280 ^s	2,525,936	2,736,179	-10
AZ	0	0	0	0	32,592,983 ^s	29,758,592 ^s	27,512,500 ^s	DNF	DNF
AR	34,603,287	51,086,511	105,949,531	146,959,897	168,540,154 ^s	177,477,436 ^s	178,580,760 ^s	DNF	DNF
CA	87,543,910	269,637,723	380,655,498	824,989,564	821,839,879	687,937,930	695,735,796	712,849,420	-13
CO	(1,194,225)	43,403,360	23,574,819	22,646,984	39,533,350	44,401,927	40,596,579	40,223,818	2
CT	41,722,212	109,463,764	188,190,274	240,164,975	284,641,964 ^s	257,577,351	264,688,024	150,495,669 ^c	PD
DE	8,280,692	15,246,191	31,232,628	26,647,205	17,461,859 ^s	29,913,432 ^s	42,611,779	30,480,708	75
DC	7,350,298	40,108,105	74,257,976	85,050,758	69,494,028	91,521,955	95,734,207	89,667,945	29
FL	48,047,516	130,435,326	248,207,991	319,288,105	328,459,559 ^s	326,678,953 ^s	334,092,690 ^s	DNF	DNF
GA	48,271,338	84,730,397	127,303,085	105,885,144	67,117,294 ^s	30,132,753 ^s	46,292,705 ^s	DNF	DNF
HI	10,961,878	14,290,183	11,627,954	8,682,856	7,714,574 ^s	8,801,232 ^s	9,241,744 ^s	9,241,744	20
ID	12,490,191	23,129,878	43,453,845	59,701,562	23,064,006 ^s	47,805,696 ^s	42,634,014	42,634,014	85
IL	120,855,066	243,824,403	580,152,170	696,182,835	688,114,511	627,855,900	636,318,364	602,641,683	-12
IN	37,325,581	86,776,690	304,187,079	318,530,548	294,063,947	280,518,255	273,327,092	271,366,346	-8
IA	52,266,560	88,710,333	178,213,310	276,650,630	301,738,929	281,400,871	284,676,738	283,081,201	-6
KS	40,646,701	69,567,908	94,467,990	65,288,398	64,412,398 ^s	61,238,528 ^s	65,228,609 ^s	13,161,657 ^b	PD
KY	39,052,684	47,597,483	75,690,587	151,886,094	130,480,686 ^s	142,907,257 ^s	140,520,784 ^s	DNF	DNF
LA	97,075,753	165,291,176	422,009,351	442,023,340	467,516,687	390,497,610	384,087,560	384,154,193	-18
ME	15,699,455	30,613,278	45,548,200	71,663,625	74,914,882	32,372,318	28,972,693	31,452,291	-58
MD	53,169,976	83,621,494	63,699,255	68,465,522	123,036 ^s	10,653,445 ^s	19,595,815 ^s	DNF	DNF
MA	125,500,190	198,722,295	254,061,832	206,611,974	165,995,204	122,672,000 ^d	DNF	107,491,155	-35
MI	152,838,152	213,104,699	519,144,242	28,824,017	0 ^s	0	0	0 ^d	N/A
MN	155,020,197	238,699,655	238,628,363	175,376,449	164,144,639	124,466,610	124,444,235	124,444,235	-24
MS	20,579,205	32,523,716	119,385,969	255,287,075	270,287,227	288,525,981	211,864,398 ^s	202,215,801 ^c	PD
MO	35,207,045	71,080,489	155,767,782	105,836,412	108,468,442	89,549,993	85,938,943	88,947,639	-18
MT	0	10,178,621	15,809,400	10,631,730	11,320,106 ^s	11,119,444 ^s	11,852,833	12,278,736	8
NE	21,336,101	25,477,085	36,895,824	66,940,338	57,653,500	32,043,236	31,511,391	62,816,481	9
NV	5,661,466	9,522,660	22,844,573	21,390,455	17,955,488 ^s	18,575,749 ^s	17,505,663	17,750,887	-1
NH	6,338,717	14,141,600	1,299,177	2,521,518	3,154,211 ^s	DNF	2,219,825	1,934,950	-39
NJ	122,552,250	237,997,341	373,077,452	628,420,857	650,873,269 ^s	664,348,972 ^s	508,433,602 ^s	225,479,000 ^c	PD
NM	12,077,857	23,586,513	21,728,673	21,263,002	24,809,317 ^s	25,888,375 ^s	26,285,597 ^s	DNF	DNF
NY	797,385,360	1,158,161,443	2,010,005,630	3,057,176,529	3,382,394,941	1,453,111,247	1,337,718,435	1,185,815,292	-65
NC	79,191,812	158,440,075	363,152,959	466,788,997	444,382,868 ^e	472,629,789 ^e	393,260,094 ^e	398,984,819	-10
ND	498,116	40,215,637	43,652,930	61,655,098	92,145,743 ^b	96,871,153 ^b	69,985,789 ^b	77,031,130	-16
OH	36,633,650	278,623,574	391,631,028	697,689,305	757,787,874	754,497,151	728,498,096	726,662,287	-4
OK	32,395,470	83,724,996	100,899,598	127,291,449	113,227,985 ^s	92,179,420 ^s	97,513,437 ^s	DNF	DNF
OR	5,286,751	73,726,772	75,273,311	22,407,372	0	0	0	0	N/A
PA	326,339,634	384,251,708	527,594,322	584,411,017	580,875,842	570,818,786	590,834,124	598,380,954	3
RI	28,759,032	60,547,566	10,401,463	7,810,448	9,159,578 ^s	9,004,728 ^s	7,927,749 ^s	DNF	DNF
SC	36,019,948	94,198,457	174,750,114	157,179,948	150,913,668 ^e	101,871,631	138,484,390	139,364,034	-8
SD	14,889,821	22,004,514	20,194,106	20,148,861	29,593,899	30,628,198	31,205,012	31,198,086	5
TN	56,831,429	77,504,336	212,774,040	243,129,310	216,276,177	211,207,200 ^s	214,552,400	201,882,848	-7
TX	233,538,852	357,822,572	640,849,004	906,152,352	1,047,598,095	1,083,265,241	1,097,795,812 ^d	1,153,752,148 ^d	10
UT	23,710,593	27,666,341	45,047,084	58,133,589	63,278,359	67,957,140	72,475,662	37,489,515 ^c	PD
VT	13,420,528	11,335,014	1,478,677	0	1,211,654	1,275,024	1,347,733	1,091,946	-10
VA	78,609,105	106,785,389	159,666,989	231,029,591	288,115,881 ^s	203,014,704	157,263,686	82,724,325	-71
WA	72,202,304	119,319,852	128,968,222	114,853,985	106,119,745 ^e	187,484,396	183,119,149 ^e	202,613,298	91
WV	1,982,377	8,661,642	52,705,244	57,353,867	65,414,249	67,189,026	67,561,689 ^s	DNF	DNF
WI	63,845,110	89,337,023	201,998,484	131,157,781	197,495,917	156,347,153	141,479,951	141,479,951 ^d	-28
WY	0	0	17,777,773	20,006,774	20,744,605 ^s	17,451,654 ^s	19,262,849	18,935,011	-9
Reported Total	3,350,725,663	5,887,947,479	9,996,223,859	12,449,871,648	12,936,860,293	11,221,488,897	10,835,874,672	10,507,954,694	-19
N States	48	49	51	50	49	47	48	39	51

^b Nonstate settings reported, but not state settings. ^c Other date (Usually a different fiscal year or June 30, 2015). ^e Estimate. ^{DNF} Did not furnish. ^{PD} Partial data. ^s Other Source (Eiken et al., 2016) Data for all states and available years can be viewed in the Chart Gallery at the RISP.umn.edu website.



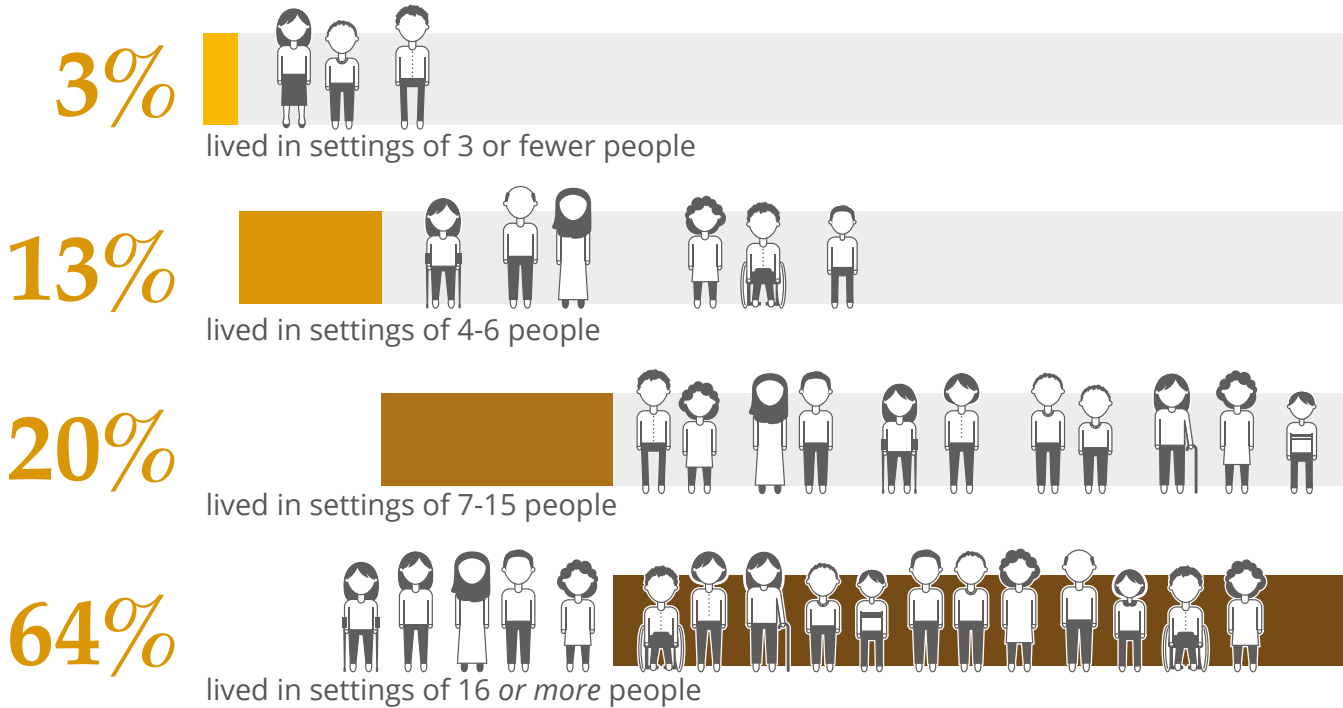
SECTION FOUR

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

FY 2016

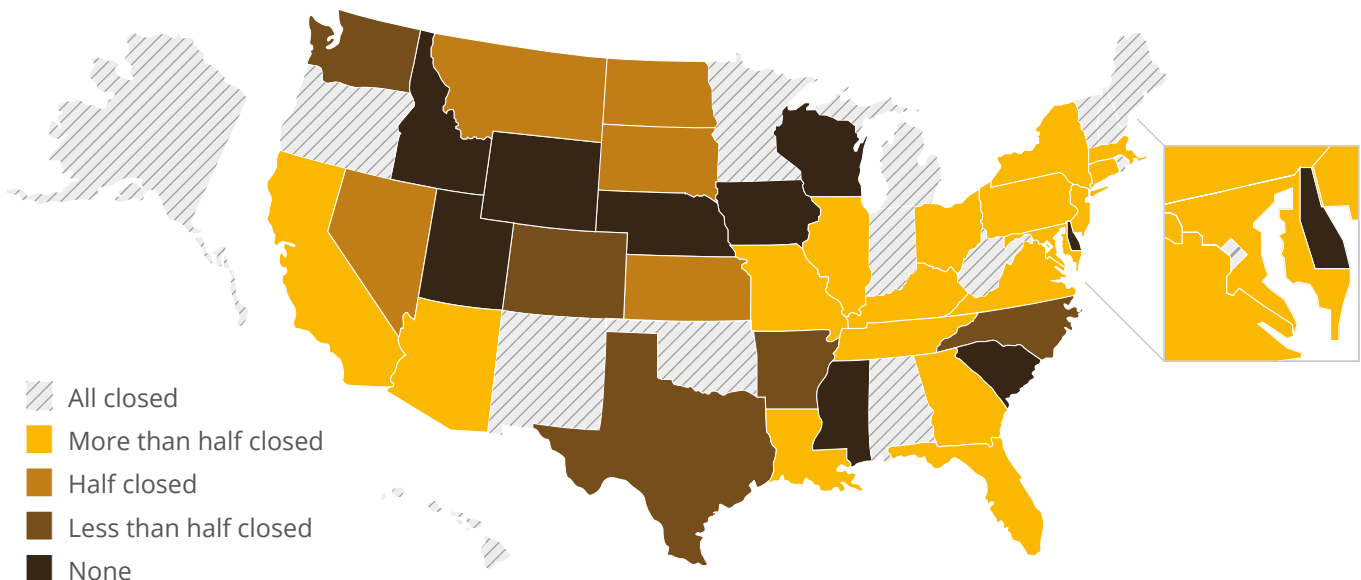
State-Operated Facilities Serving People with Intellectual or Developmental Disabilities 2016

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



Closures by state as of June 30, 2016

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



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

Section 4 describes the status as of June 30, 2016 of state-operated IDD facilities serving 16 or more people (Public Residential Facilities, or PRFs for short) and trends in utilization of PRFs. It describes 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. It also lists open PRFs as of June 30, 2016, and PRFs that had closed, downsized to fewer than 15 residents, privatized or converted to a different purpose by June 30, 2016. **Tables 4.1, 4.2, 4.10, 4.11, 4.12, and 4.13, and Figures 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 use data from the annual survey of administrators of state-operated IDD facilities (PRF survey) fielded in conjunction with the Association of Public and Private Developmental Disabilities Administrators (APDDA). All of the tables in this section providing state level data except for **Tables 4.10 and 4.11** show only states with one or more open PRF as of June 30, 2016.

AVERAGE POPULATION AND MOVEMENT PATTERNS IN FY 2016

The average daily PRF population was 19,502 people in FY 2016 (See **Table 4.1**). The PRF population declined 8% from 20,709 on June 30, 2015 to 19,081 on June 30, 2016. Nine states reported a decline of 10% or more in the number of residents between June 30, 2015 and June 30, 2016. Those states were:

- Kentucky (263 to 132 people, 50% fewer),
- Tennessee (109 to 60 people, 45% fewer),
- New York (648 to 436 people, 33% fewer),
- Virginia (483 to 363 people, 25% fewer),
- Montana (55 to 42 people, 24% fewer),
- North Carolina (1,436 to 1,255 people, 13% fewer),
- Ohio (815 to 721 people, 12% fewer),
- California (1,077 to 963 people, 11% fewer), and
- Georgia (267 to 240 people, 10% fewer).

Five states reported increases in PRF populations between June 30, 2015 and June 30, 2016. Those states were Colorado (increasing 69% from 29 in 2015 to 49 in 2016), Idaho (32%, from 19 to 25 people), Louisiana (5%, from 469 to 494 people), Nebraska (1%, from 114 to 115 people), and Kansas (1%, from 314 to 316 people).

Admissions

An estimated 1,014 people were admitted to PRFs during FY 2016 (5% of the year's average daily population). The number of people admitted to large state-operated IDD facilities was more than 20% of the 2016 average daily population in Nevada (25 people admitted, 53% of the average daily population), Idaho (13 people, 52%), and North Dakota (18 people, 24%). Admissions do not include people who transferred from one PRF to another. Short-term admissions of 90 days or less were tracked separately.

Discharges

An estimated 1,897 people were discharged from a PRF in 2016 (10% of the average daily population). More than 20% of the average daily population was discharged in FY 2016 in eleven states: Tennessee (39 people discharged, 65% of the average daily population), Nevada (24 people, 51%), Montana (20 people, 48%), Virginia (128 people, 35%), Colorado (16 people, 33%), Idaho (7 people, 28%), North Dakota (21 people, 28%), Ohio (182 people, 25%), South Dakota (28 people, 21%). Florida (154 people, 20%), and California (194 people, 20%).

Deaths

An estimated 635 people with IDD (3% of the average daily population) died while residing in a PRF in 2016. Three states with PRFs reported no deaths in FY 2016 (Idaho, Montana, and South Dakota). States with most deaths per person in the average daily population were Tennessee (12%), and Arizona (8%).

Table 4.1 PRF Population, Admissions, Discharges, Deaths and Average Annual Per Person Expenditures for Fiscal Year 2016

State	Average Daily Population	Admissions	Discharges	Deaths	Year End Residents			Short -term Admissions	Average Daily Per Person Cost ¹
					2015	2016	1-Year % Change		
N States	36	35	36	36	36	36	36	34	35
AZ	89	0	0	7	93	86	-8%	0	509
AR	900	54	50	36	913	907	-1%	41	404
CA	965	121	194	40	1,077	963	-11%	0	1,083
CO *	39	8	16	1	29	49	69%	0	688
CT	443	6	25	14	468	429	-8%	6	928
DE	52	1	0	1	52	51	-2%	0	1,085
FL	780	111	154	22	827	760	-8%	0	380/475 ²
GA	252	0	13	12	267	240	-10%	0	626
ID	23	13	7	0	19	25	32%	5	849
IL	1,670	80	81	32	1,686	1,653	-2%	0	425
IA	377	7	17	7	391	374	-4%	0	920
KS	316	17	10	6	314	316	1%	0	896
KY	132	DNF	DNF	DNF	263	132	-50%	21	1,063
LA	467	64	34	10	469	494	5%	1	689
MD	127	DNF	DNF	DNF	131	122	-7%	19	816 ^d
MA	422	1	20	26	433	409	-6%	17	764
MS	1,005	59	111	26	1,082	1,005	-7%	62	343
MO	345	0	23	9	393	360	-8%	20	642
MT	40 ^e	7	20	0	55	42	-24%	0	853
NE	115	0	0	1	114	115	1%	0	954 ^e
NV	47	25	24	1	47	47	0%	0	618
NJ	1,537	0	75	60	1,612	1,479	-8%	0	875
NY	542	DNF	DNF	DNF	648	436	-33%	DNF	DNF
NC	1,311	40	34	34	1,436	1,255	-13%	81	659
ND	80	18	21	1	79	75	-5%	11	867
OH	806	42	182	21	882	721	-18%	134	560
PA	926	7	14	37	950	904	-5%	0	988
SC	670	53	35	25	673	666	-1%	73	443
SD	136	20	28	0	140	132	-6%	0	482
TN	54	0	39	7	109	60	-45%	0	1,481
TX	3,124 ^d	170 ^d	154 ^d	99 ^d	3,186 ^d	3,103 ^d	-3%	0 ^d	837 ^d
UT	201	16	18	9	202	191	-5%	1	511
VA	412	31	128	23	483	363	-25%	DNF	943
WA *	673	5	3	26	765	700 ^e	-8%	238	767 ^e
WI	357 ^d	0 ^d	1 ^d	15 ^d	350	350 ^d	0%	179 ^d	870 ^d
WY	68	1	0	4	70	67	-4%	0	802
Reported US Total	19,502	977	1,531	612	20,708	19,081	-8%	909	706
Estimated US Total	19,502	1,014	1,897	635	20,709	19,081	-8%	932	

Data Source: RISP Survey ^d Other date (Usually August 31, 2016 or June 30, 2015). ^e Estimate. ^{DNF} Did not furnish. * See state notes in the Appendix. ^{N/A} Not applicable. ¹ Per person costs are ICF/IID expenditures except in Arizona which funds all 1115 Waiver services together and Georgia reported their facilities under other. ² Florida reported average daily costs of \$380 for people in ICF/IID certified PRF's, and \$475 for people in other funded facilities.

Short-Term Admissions

There were an estimated 932 short-term admissions of less than 90 days in PRFs in FY 2016. The number of people admitted was less than that because some people had multiple short-term stays. Eighteen states reported no short-term admissions in FY 2016. States reporting the most short-term admissions were Washington (238), Wisconsin (179), and Ohio (134).

Reason for Short-Term Admissions

Ninety-five PRFs reported the reasons for short-term admissions (See **Table 4.2**). Of the 909 short-term admissions reported, 56% were for respite and 44% were for evaluation purposes. Less than 1% of the short-term stays were for crisis housing.

Table 4.2 Short-Term Admissions to PRFs in FY 2016 by Admission Type

Type	Reported Total	Percent	Estimated Total
Respite	510	56%	523
Evaluation	396	44%	406
Crisis Housing	3	0.3%	3
Total	909	100%	932

Source: PRF survey, 95 facilities reported

Daily per Person Expenditures

Average daily per-person PRF expenditures in FY 2016 were \$706 per day (\$257,690 per year). The average ranged from \$343 per day (\$125,250) to \$1,085 per day (\$395,948). Five states (Arkansas, Illinois, Mississippi, South Carolina, and South Dakota) had average daily per person expenditures below \$500. Four states (California, Delaware, Kentucky, and Tennessee) had average daily per person expenditures above \$1,000.

CHARACTERISTICS OF PEOPLE LIVING IN PRFs IN FY 2016

Among the people living in PRFs on June 30, 2016, 63% were male, only 4% were 21 years or younger, 50% were 22 to 54 years, and 45% were 55 years or older (See **Table 4.3**). Of the residents, 74% were white, 20% were black or African American, and 6% were another race, two or more races or unknown race. Seven percent of PRF residents were of Hispanic origin. More than half (53%) of all PRF residents had profound intellectual disabilities while 19% had severe intellectual disabilities, 14% had moderate intellectual disabilities and 14% had mild or no intellectual disabilities.

In addition to IDD, people living in PRF had the following other conditions, were epilepsy (40% of the total on June 30, 2016), autism (19%), cerebral palsy (15%), and blindness (15%). Fewer than 10% were deaf (6%) or had Alzheimer's (2%). The majority of residents required assistance with dressing (64%),



transferring (58%), toileting (58%), or eating (56%). Fewer than half of the residents required assistance or supervision with walking (41%). While 71% of residents could understand verbal requests, only 46% expressed their needs verbally.

An estimated 54% of PRF residents took medication for mood, anxiety, or behavior, 50% had a diagnosed psychiatric disorder, and 42% had a behavior disorder requiring planned interventions.

Fewer than 10% of PRF residents were involved with the criminal justice system. An estimated 6% (865 people) had been found incompetent to stand trial, 5% (859 people) had engaged in a behavior that led to involvement of the criminal justice system, 3% (471 people) were under criminal court jurisdiction as of June 30, 2016, and 2% (305 people) had been charged with a crime and were receiving court-ordered competency training. Twenty-six PRF residents were under parole supervision on June 30, 2016.

Table 4.3 Characteristics of People with IDD Living in PRFs on June 30, 2016

		Reported Total	Percent	Estimated Total	N Reporting facilities
Estimated total				19,081	
Gender	Male	11,019	63	11,954	100
Age	0-21 Years	666	4	724	100
	22-39 Years	3,407	19	3,703	
	40-54 Years	5,427	31	5,898	
	55-62 Years	4,278	24	4,650	
	63+ Years	3,770	21	4,097	
Race	White	12,885	74	14,145	97
	Black/African American	3,465	20	3,804	
	Other Race	581	3	638	
	2 or more Races	361	2	396	
	Unknown	89	1	98	
Hispanic Origin	Yes	1,109	7	1,339	87
	No	14,628	93	17,659	
	Unknown	69	0	83	
Level of Intellectual Disability	Mild/No ID	2,390	14	2,583	100
	Moderate	2,460	14	2,659	
	Severe	3,308	19	3,576	
	Profound	9,328	53	10,083	
	Unknown	166	1	179	
Other Conditions	Epilepsy	6,836	40	7,663	95
	Autism	3,181	19	3,665	92
	Cerebral Palsy	2,536	15	2,922	92
	Blind	2,496	15	2,785	96
	Deaf	1,073	6	1,199	95
	Alzheimers	372	2	465	86
	2 or More Other Conditions	7,794	48	9,223	90
Needs assistance or supervision with...	Dressing	8,398	64	12,165	78
	Transferring	1,278	58	11,067	78
	Toileting	7,678	58	11,064	78
	Eating	7,794	56	10,777	80
	Walking	6,935	41	7,856	94
Communication, Cannot ...	Express needs verbally	8,548	52	9,865	91
	Understand verbal requests	3,621	29	5,606	72
Psychiatric and Behavior	Receives Mood, Anxiety or Behavior Medication	8,897	54	10,382	90
	Psychiatric Disorder	8,186	50	9,564	89
	Behavior Disorder	6,861	42	7,953	91
Involvement with the Criminal Justice System	Found incompetent to stand trial	865	6	1,050	90
	Behavior led to criminal justice involvement	859	5	1,043	
	Under criminal court jurisdiction - other	471	3	572	
	Charged and court ordered for competency training	305	2	370	
	Under parole supervision	26	0	32	

Data Source: PRF survey

Characteristics of People in PRFs by State

Age

There were dramatic state-to-state differences in the ages of PRF residents (See **Table 4.4** and **Figure 4.1**). States serving the highest proportion of people 21 years or younger were North Dakota (24%, 18 people), Idaho (24%, six people), South Dakota

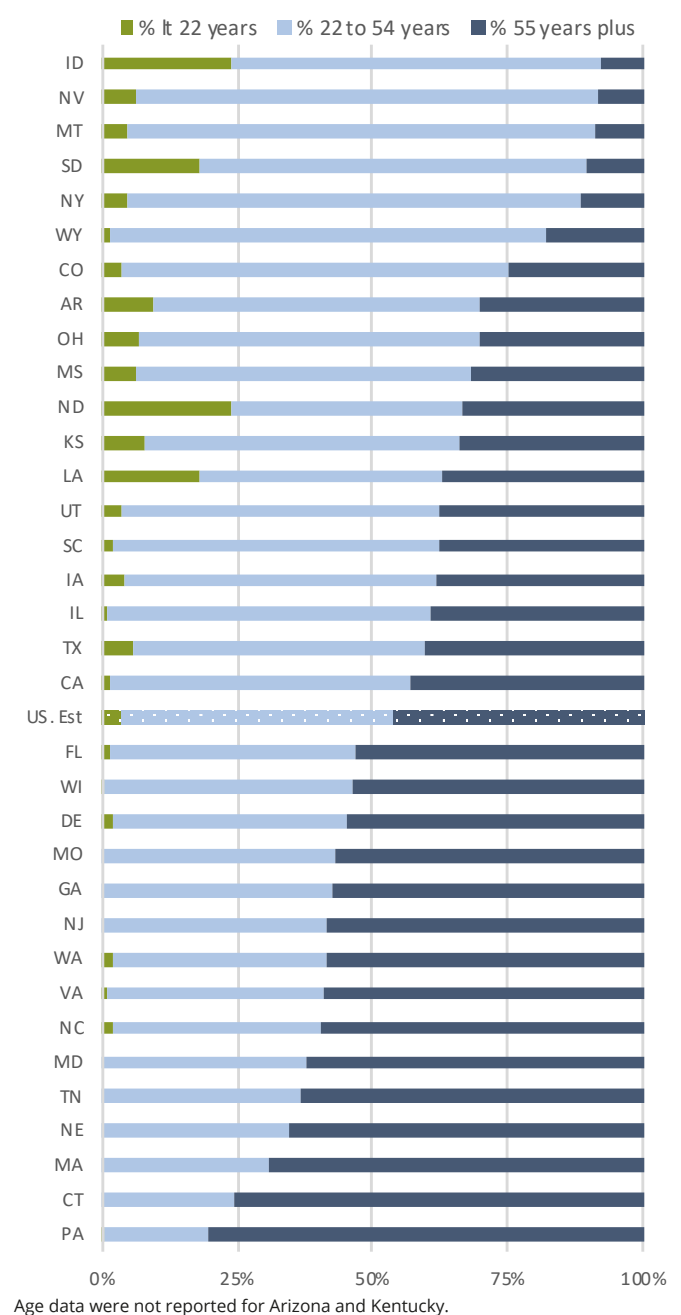
(18%, 24 people), and Louisiana (18%, 79 people). States in which 80% or more of the 2016 population were between 22 and 54 years were Montana (86%, 19 people), North Dakota (85%, 40 people), New Jersey (83%, 236 people), and Wyoming (91%, 54 people). States with the most people ages 55 years or older in 2016 were Pennsylvania (80%, 726 people), Connecticut (75%, 272 people), Maryland (69%, 81 people), and North Carolina (65%, 75 people).

Table 4.4 Ages of People Living in Large State IDD Facilities by State on June 30, 2016

State	Age in Years							Total People
	0-14	15-18	19-21	22-39	40-54	55-62	63+	
AZ	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
AR	15	34	27	218	276	174	71	815
CA	0	1	15	253	279	232	186	966
CO	0	0	1	13	7	5	2	28
CT	0	0	0	12	77	87	185	361
DE	0	0	1	7	15	14	14	51
FL	0	2	11	133	211	201	200	758
GA	0	0	0	18	84	52	87	241
ID	1	3	2	16	1	2	0	25
IL	0	0	20	337	645	447	201	1,650
IA	0	6	9	90	127	78	64	374
KS	1	11	12	77	103	76	30	310
KY	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
LA	13	44	22	89	105	75	87	435
MD	0	0	0	4	18	23	13	58
MA	0	0	0	5	31	42	39	117
MS	6	24	33	305	295	158	152	973
MO	0	0	0	38	115	109	94	356
MT	0	0	1	16	3	2	0	22
NE	0	0	0	12	28	42	33	115
NV	0	0	3	32	8	3	1	47
NJ	0	0	0	100	514	479	384	1,477
NY	0	3	11	161	75	27	6	283
NC	4	16	9	128	384	366	425	1,332
ND	4	6	8	16	16	12	13	75
OH	0	12	33	186	214	102	92	639
PA	0	0	4	27	148	346	380	905
SC	2	5	5	168	234	142	110	666
SD	4	9	11	78	16	10	4	132
TN	0	0	0	3	19	22	16	60
TX ¹	22	82	75	663	992	675	553	3,070
UT	2	2	3	45	67	46	26	191
VA	0	1	2	35	81	76	95	290
WA	0	3	8	69	155	143	191	569
WI	0	0	1	38	116	97	84	336
WY	0	0	1	21	33	0	12	67
Reported US Total	74	264	328	3,413	5,492	4,365	3,850	17,794
Estimated US Total	79	283	352	3,660	5,889	4,681	4,128	19,081

Data Source: PRF Survey. N = 113 facilities DNF Data not furnished.
¹ Eight people with unknown ages in Texas are not shown.

Figure 4.1 Age Distribution of People Living in PRF's (in Percent) by State on June 30, 2016



Level of Intellectual Disability

There were also notable state-to-state differences in the distribution of PRF residents by level of intellectual disability (See **Table 4.5** and **Figure 4.2**). The proportion of residents with no, mild or moderate ID ranged from 3% to 95%. States reporting that more than half of all PRF residents had no, mild or moderate ID included Montana

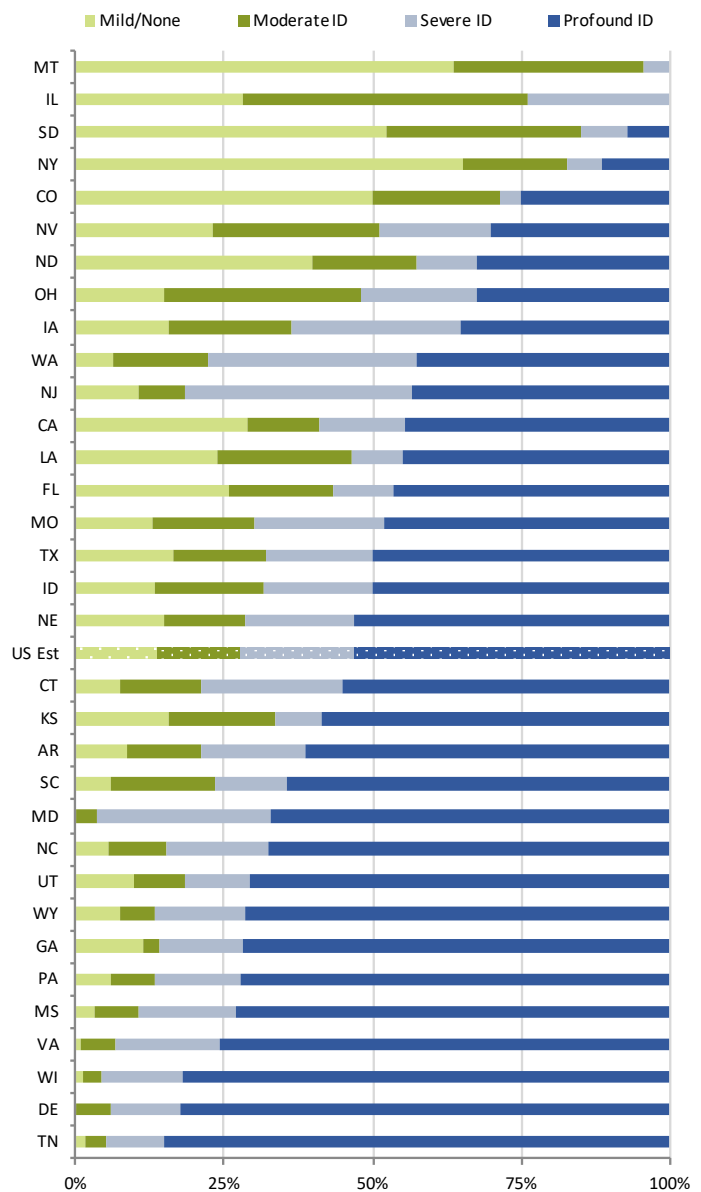
Table 4.5 Level of Intellectual Disability of People Living in Large State IDD Facilities by State on June 30, 2016

State	Level of Intellectual Disability (Percent)					Number of People
	Mild +	Moderate	Severe	Profound	Unknown	
AZ	DNF	DNF	DNF	DNF	DNF	DNF
AR	8	13	18	61	0	815
CA	28	12	14	43	3	929
CO	50	21	4	25	0	28
CT	7	14	24	55	0	361
DE	0	6	12	82	0	51
FL	25	17	10	46	1	758
GA	11	3	14	72	0	241
ID	28	48	24	0	0	25
IL	13	18	19	50	0	1,650
IA	16	21	29	35	0	374
KS	14	16	7	52	0	310
KY	DNF	DNF	DNF	DNF	DNF	DNF
LA	24	23	8	45	0	435
MD	0	3	29	67	0	58
MA	DNF	DNF	DNF	DNF	DNF	DNF
MS	3	7	16	73	0	973
MO	13	17	22	48	0	235
MT	64	32	5	0	0	22
NE	15	14	18	53	0	115
NV	21	26	17	28	9	47
NJ	11	8	38	43	0	1,477
NY	60	16	5	11	7	283
NC	5	10	17	67	0	1,332
ND	36	16	9	29	9	75
OH	15	33	19	32	1	639
PA	6	7	14	72	0	905
SC	6	17	12	62	4	666
SD	51	32	8	7	3	132
TN	2	3	10	85	0	60
TX	16	15	18	49	1	3,203
UT	9	8	10	64	9	191
VA	1	6	18	76	0	290
WA	6	16	35	43	0	569
WI	1	3	14	82	0	336
WY	7	6	15	72	0	67
Reported US Total	14	14	19	53	1	17,652
Estimated US Total	2,583	2,659	3,576	10,083	179	19,081

N = 106 facilities reporting. States with no PRFs are not shown

(95%), South Dakota (83%), New York (77%), Idaho (76%), Colorado (71%), and North Dakota (52%). The proportion of residents with profound ID ranged from none to 85%. States reporting the highest proportions of residents with profound ID included Tennessee (85%), Delaware (82%), Wisconsin (82%), Virginia (76%), Mississippi (73%), Pennsylvania (72%), Georgia (72%), and Wyoming (72%).

Figure 4.2 Percent of People with IDD Living in PRFs by Level of Intellectual Disability and State on June 30, 2016



Data not available for Arizona, Kentucky and Massachusetts.

Age and Level of Intellectual Disability for People Admitted or Discharged in FY 2016

This section describes the ages and levels of intellectual disability of people who were newly admitted, readmitted or discharged in FY 2016 (See **Table 4.6** and **Table 4.7**).

Admissions and Discharges by Age

There were large age differences between current residents and people admitted, readmitted, or discharged from PRFs in 2016. While only 4% of the people in PRFs on June 30, 2016 were ages 21 years or younger, people in that age group were 30% of all people newly admitted, 17% of all people readmitted, and 11% of people who were discharged in FY 2016 (See **Figure 4.3a**). Similarly, only 19% of PRF residents were between 22 and 39 years, people in this age group were 43% of all people newly admitted, 61% of people readmitted, and 38% of people discharged. Conversely, an estimated 31% of PRF residents on were between 40 and 54 years, people in this age group were 18% of all people newly admitted, 13% of people readmitted, and 23% of people discharged. Finally, 46% of people living in a PRF were 55 years or older, people in that age group were 9% of all people newly admitted, 8% of people readmitted, and 27% of people who were discharged.

Admissions and Discharges by Level of ID

There were large differences in level of intellectual disability between PRF residents on June 30, 2016 and people admitted, readmitted or discharged from PRFs during FY 2016 (See **Figure 4.3b**). More than half (53%) of PRF residents on June 30, 2016 had profound ID. A much smaller proportion of people who were newly admitted (11%), readmitted (10%) or discharged (27%) in FY 2016 had profound ID. While 19% of current PRF residents had severe ID, the proportions were 11% of people who were newly admitted, 11% of people readmitted, and 10% of people who were discharged. The patterns were reversed for people with no, mild or moderate ID. Of the PRF residents, 14% had moderate ID compared with 27% of those newly admitted, 29% of those readmitted, and 22% of those discharged. Similarly, while 14% of PRF residents had mild or no ID, 42% of people who were newly admitted, 48% of people who were readmitted, and 36% of people who were discharged had no or mild ID.

Most PRF residents had profound IDD and were 40 years old or older. Most new admissions and readmissions were for people with no, mild or moderate ID who were 39 years old or younger. In FY 2016, there were

- 141 readmissions of people ages 39 years or younger compared with 806 discharges (17%),

Table 4.6 Age and Level of Intellectual Disabilities for Current, Newly Admitted, Readmitted and Discharged Residents of PRFs in FY 2016

Characteristic	On June 30, 2016		New Admissions		Readmissions		Discharges	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Reporting Facilities	100		70		42		91	
Age								
0-14 years	74	0%	45	5%	1	1%	20	1%
15-18 years	264	2%	107	12%	9	5%	73	5%
19-21 years	328	2%	130	14%	21	12%	91	6%
0-21 years	666	4%	282	30%	31	17%	184	11%
22-39 years	3,407	19%	397	43%	110	61%	622	38%
40-54 years	5,427	31%	164	18%	24	13%	368	23%
55-62 years	4,278	24%	51	6%	9	5%	241	15%
63+ years	3,770	21%	32	3%	6	3%	199	12%
Age Unknown	8	0%	0	0%	0	0%	5	0%
Level of ID								
Mild or None	2,390	14%	384	42%	87	48%	587	36%
Moderate	2,460	14%	253	27%	52	29%	354	22%
Severe	3,308	19%	106	11%	20	11%	163	10%
Profound	9,328	53%	100	11%	18	10%	440	27%
IDD Level Unknown	166	1%	80	9%	3	2%	74	5%

- 39 readmissions of people ages 40 years or older compared with 813 discharges (5%),
- 139 readmissions of people with no, mild or moderate ID compared with 941 discharges (15%), and
- 38 readmissions of people with severe or profound ID compared with 603 discharges (6%).

groups. However, there were more admissions or readmissions of people 21 years or younger than there were discharges in FY 2016 (313 admissions or readmissions versus 184 discharges). Overall, 85% of the people 21 years or younger who were admitted or readmitted were between the ages of 15 and 21 years.

Finally, discharges outnumbered admissions plus readmissions for each level of ID, and for most age

Figure 4.3a Age Distribution for June 30, Newly Admitted, Readmitted, and Discharged PRF Residents in FY 2016

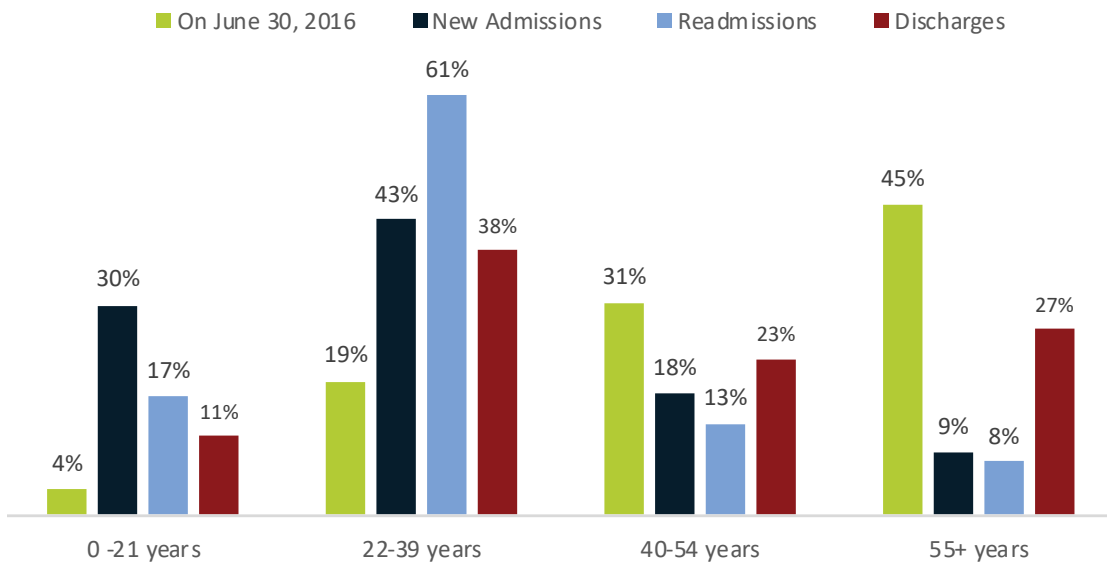
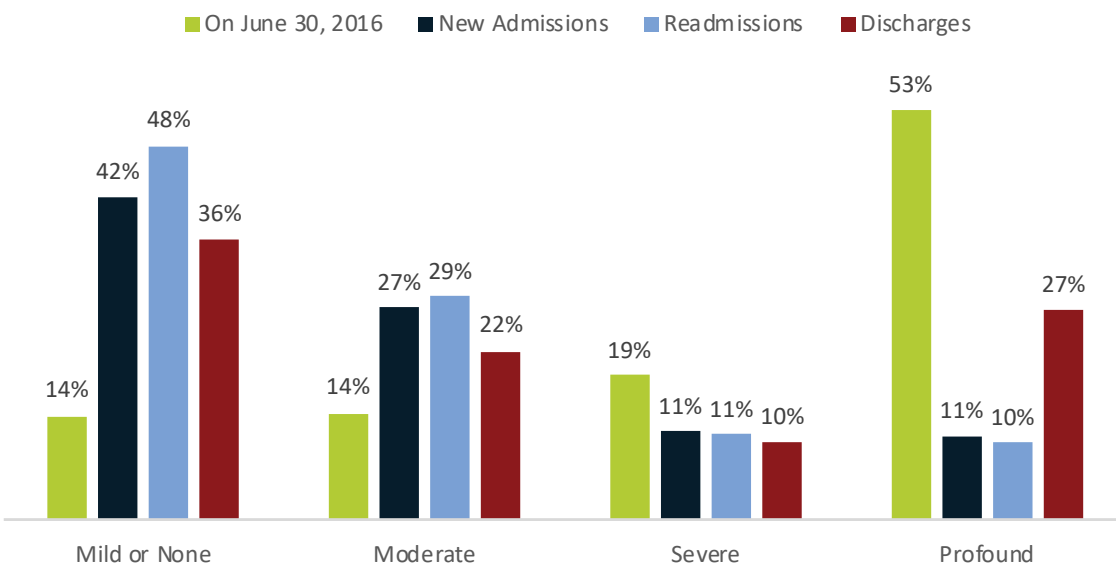


Figure 4.3b Level of Intellectual Disabilities for current, newly admitted, readmitted, and discharged PRF residents



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

Fewer facilities reported on new admissions (70 facilities), readmissions (42 facilities) and discharges (87 facilities) than responded to other parts of the FY 2016 PRF survey (100 facilities). Altogether, those facilities reported on 905 new admissions, 180 readmissions and 1,419 discharges. The prior or

subsequent setting type was unknown for 92 new admissions, 0 readmissions and 35 discharges (See **Table 4.7** and **Figure 4.4**).

People newly admitted to PRFs in FY 2016 came from many different types of settings. The most common settings were mental health facilities (17%), correctional facilities (16%), family homes (16%), "other" settings (16%), group homes of 1 to 6 people (12%), or state IDD facilities of 16 or more people

Table 4.7 Previous Residence for People Admitted or Readmitted to PRFs and Subsequent Residence of People Discharged from PRFs 2016 (in Percent)

Setting Type	New Admission	Readmissions	Discharges
Number of reporting facilities	70	42	87
Total Reported (Re)Admissions/Discharges	905	180	1419
Family home	16%	12%	11%
Host or foster family home	2%	2%	2%
Own Home (Independent/Supported/Semi-independent Living)	1%	1%	2%
Group home (1-6 res.)	12%	23%	22%
Group home (7-15 res.)	3%	2%	4%
State IDD facility (16+ res.)	11%	4%	32%
Nonstate IDD facility (16+ res.)	3%	2%	4%
Mental health facility	17%	21%	3%
Correctional facility	16%	3%	3%
Nursing facility	2%	1%	1%
Other	16%	29%	17%

Previous residence was unknown for 92 admissions and 0 readmissions. Subsequent residence was unknown for 35 discharges.

Figure 4.4 Known Previous Residence for People Admitted or Readmitted to PRFs and Subsequent Residence of People Discharged from PRFs in 2016 (in percent)

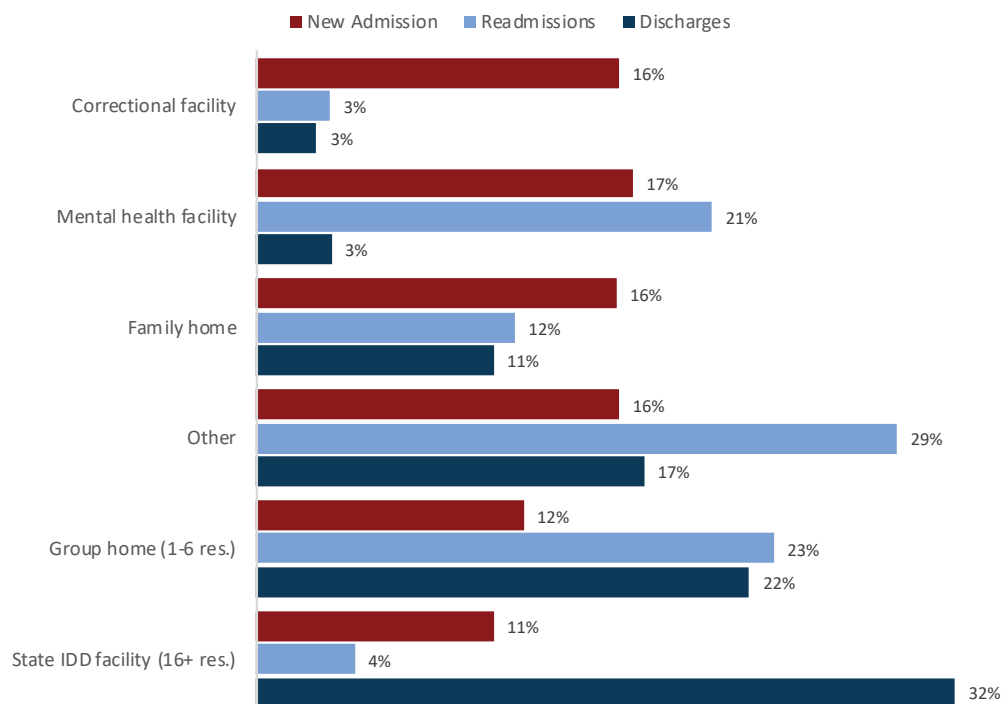


Table 4.8 PRF Staff Characteristics and Outcomes in 2016

	¹ Full-Time Equivalents	Percent	Staff FTE Per Resident
Staff Complement			
Physicians/Nurses	5,349	10	0.33
Teachers/Aides	229	0.4	0.01
Psychologists/Other QIDP	1,510	3	0.09
OT/PT/Speech	914	2	0.06
Direct Support Professionals	32,048	59	1.99
Administrative/Management	2,712	5	0.17
Facility Support	11,948	22	0.74
Total FTE Staff	54,710	100	3.39
Staff Outcomes			
DSP Vacancy Rate (%)		11%	
DSP Turnover Rate (%)		33%	
FLS Vacancy Rate (%)		10%	
FLS Turnover Rate (%)		17%	
DSP Starting Hourly Wage	\$12.96		
DSP Average Hourly Wage	\$15.99		
FLS Starting Salary	\$36,396		
FLS Average Salary	\$43,374		

N=92 facilities reporting ¹ FTE Full-time Equivalent (1 person working 40 hours per week or a combination of 2 or more people working a combined 40 hours per week).

(11%). Of the people readmitted to PRFs, 29% came from an “other” setting, 23% came from an IDD group home serving six or fewer people, 21% came from a mental health facility and 12% came from the home of a family member. Of the people discharged from PRFs in FY 2016, most moved to other state IDD facilities of 16 or more people (32%), IDD group settings of 6 or fewer people (22%), an “other” setting (17%), or family homes (11%).

There were notable differences for some residence types in the proportion of admissions or readmissions compared to the proportion of discharges. For example, while 16% of all new admissions to PRFs were from a correctional facility, only 3% of readmissions were from those settings and 3% of discharges were to those settings. Both admissions (17%) and readmissions (21%) from mental health facilities were more common than discharges (3%) to mental health facilities. There were also more new admissions from family homes (16%) than there were readmissions from (12%) or discharges to family homes (11%). Finally, while only 12% of the people newly admitted to PRFs came from group homes of six or fewer people, 23% of readmissions and 22% of discharges were to group homes of six or fewer people.

PRF survey respondents reported that 32% of all people discharged transferred from one PRF to another. Such transfers sometimes are related to facility closures or downsizing efforts. In the RISP survey (Table 4.1), states were instructed not to count people who moved from one PRF to another PRF as admissions or discharges.

STAFFING CHARACTERISTICS AND OUTCOMES

Staffing characteristics and outcomes were reported for 92 PRFs (See **Table 4.8**). Reporting PRFs employed 54,710 full-time equivalent (FTE) staff on June 30, 2016. One FTE is 40 staff hours worked per week whether those hours are worked by one employee or shared by two or more employees. Of the PRF employees, 59% (32,048 FTEs) were direct support professionals, 22% were facility support staff (working for example in the kitchen, laundry, or maintenance departments), 10% were physicians or nurses, 5% were administrators or managers, 3% were psychologists or other degreed professionals, 2% were therapists (such as occupational, physical or speech therapists), and fewer than 1% were teachers or teacher aides. Overall, PRFs employed 3.39 FTE staff per resident. They employed 1.99 FTE direct support staff per resident on June 30, 2016.

Staff turnover rates were computed as the total number of staff who left during the year divided by the total staff complement (including vacant positions) on June 30, 2016. Average turnover rates were 33% for direct support professionals and 17% for front line supervisors (FLS) for FY 2016.

Vacancy rates were computed as the total number of vacant positions on June 30, 2016 divided by the number of current staff plus the number of vacancies to be filled. An estimated 11% of DSP positions and 10% of FLS positions were vacant on June 30, 2016.

In FY 2016, starting wages for DSPs were \$12.96 (\$26,962 annually) and average wages for DSPs were \$15.99 (\$33,256). The average FLS starting annual salary was \$36,696 and the average annual salary was \$43,374.

STATUS OF PUBLIC RESIDENTIAL FACILITIES

PRFs Open on June 30, 2016

FY 2016 PRF surveys were returned for 100 of the 115 PRFs tracked by the RISP project (an 87% response rate, See **Table 4.9**). Responding facilities served 17,749 people with IDD (93% of the estimated 19,081 total). They served an average of 181 people, 177 of whom had IDD. Facilities ranged in size from 22 people (Grand Junction Regional Center in Colorado) to 495 people (Hunterdon Development Center in New Jersey). The facilities opened on average in 1950. The oldest facility was the Columbus Developmental Center in Ohio, which opened in 1857. The newest facility was the Mississippi Adolescent Center in Mississippi, which opened in 2011.

The year-end populations of reporting PRFs declined by an average of 6% between June 30, 2015 and June 30, 2016. Seventy-six facilities reported a population decline, including 21 that reported a decline of 10% or more. The largest population decline between June 30, 2015 and June 30, 2016 was at Montgomery Developmental Center in Ohio (declining 56%, from 84 to 37 residents). Facilities that increased in size by more than 10% were Higginsville Habilitation Center in Missouri (increasing 48%, from 41 to 58 residents) and Southwest Idaho Treatment Center in Idaho (increasing 32%, from 19 to 25 residents).

Daily per person expenditures averaged \$708 (\$258,420 per year) in the reporting facilities and ranged from \$212 (\$77,380 per year) in Maryland's Holly Center to \$1,666 (\$608,090 per year) in California's Fairview Development Center in Costa Mesa. Twelve facilities (14%) reported daily per person expenditures of less than \$400, 41 PRFs reported expenditures between \$400 and \$699, 26 reported expenditures between \$700 and \$999, and 16 reported expenditures of more than \$1,000 per person per day.

Admissions or readmissions between July 1, 2015 and June 30, 2016 averaged 12 per facility with a range from zero in 22 facilities to 108 at California's Porterville Development Center. Discharges averaged

15 with a range from 0 in 10 facilities to 124 at Florida's Developmental Disabilities Defendant Program, and 75 at California's Porterville Development Center. Deaths averaged six per facility, ranging from zero in ten facilities to 26 in Connecticut's Lower Fairfield County Center in Norwalk.

PRFs Closures and Projected Closures

Table 4.10 lists the names and disposition of 238 PRFs that closed, converted to serving a different population, converted from state-operation to private operation or downsized to fewer than 16 people with IDD on or before June 30, 2016. Some facilities on the list merged, split off, or changed names during the years they were in operation.

Closures between July 1, 2015 and June 30, 2016 included:

- Marshall Habilitation Center (Marshall, MO) closed December 2015
- Brooklyn DDSO (Brooklyn, NY) closed December 2015
- Broome DDSO (Binghamton, NY) closed March 2016
- Southern Oklahoma Resource Center (Pauls Valley, OK) closed July 2015
- Clover Bottom Development Center (Nashville, TN) closed October 2015
- Northern Virginia Training Center (Fairfax, VA) closed March 2016

**FISCAL YEAR 2016 WAS
THE FIRST TIME SINCE 1910
THAT THERE WERE FEWER
THAN 20,000 PEOPLE
LIVING IN PRFs.**

Table 4.9 Open PRFS on June 30, 2016: People Served, Movement Patterns, Average Daily Per Person Cost, Admissions, Discharges and Deaths By State and Facility Name

State	Facility Name (City) *	Year Opened	(Projected) Closure Date	Residents With IDD June 2016	All Residents June 2016	Average Daily with IDD FY 2016	Residents With IDD June 2015	% Change 2015-16	Average Daily Per Person Cost (\$)	Admissions/Readmissions	Discharges	Deaths
AR	Arkadelphia Human Dev. Ctr. (Arkadelphia)	1968		116	116	116	117	-0.9	377	5	5	2
AR	Booneville HDC (Booneville)	1972		122	122	121	122	0.0	385	11	11	0
AR	Conway HDC (Conway)	1959		469	469	472	478	-1.9	390	14	4	19
AR	Jonesboro HDC (Jonesboro)	1970		108	108	107	102	5.9	323	26	19	1
AR	Southeast Arkansas HDC (Warren)	1978		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
AZ	Arizona Trng. Program (Coolidge)	1952		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
CA	Canyon Springs (Cathedral City)	2001		46	46	48	51	-9.8	880	11	15	1
CA	Fairview Dev. Ctr. (Costa Mesa)	1959	Dec 2019	229	229	248	271	-15.5	1,666	2	41	12
CA	Porterville Dev. Ctr. (Porterville)	1953	Dec 2021	349	349	355	325	7.4	1,342	108	75	9
CA	Sonoma Dev. Ctr. (Eldridge)	1891	Dec 2018	342	342	374	399	-14.3	1,247	0	39	18
CO	Grand Junction Regional Ctr. (Grand Junction)	1919		22	22	27	29	-24.1	1,135	DNF	6	1
CO	Wheat Ridge Regional Ctr. (Wheatridge)	1912		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
CT	Northwest Ctr. (Torrington)	1984		38	38	38	38	0.0	DNF	0	0	0
CT	Hartford Regional Center (Newington)	1965		33	33	34	36	-8.3	1,206	3	4	2
CT	Lower Fairfield County Ctr. (Norwalk)	1976		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	21
CT	Southbury Trng. School (Southbury)	1940		261	261	270	291	-10.3	1,325	0	21	9
DE	Stockley Ctr. (Georgetown)	1921		51	51	DNF	52	-1.9	1,085	1	0	1
FL	Developmental Disabilities Defendant Program (DDDP, Chattahoochee)	1977		85	85	88	116	-26.7	448	97	124	0
FL	Sunland Ctr. (Marianna)	1961		302	302	307	311	-2.9	335	13	15	12
FL	Tacachale Ctr. / Sequin Unit (Gainesville)	1921		371	371	383	395	-6.1	426	1	15	10
GA	East Central Regional Hospital (Gracewood & Augusta)	1921		206	206	214	224	-8.0	1,267	0	12	6
GA	Georgia Regional Hospital of Atlanta (Decatur)	1968		35	278	38	43	-18.6	388	0	0	8
IA	Glenwood Resource Ctr. (Glenwood)	1876		231	231	235	238	-2.9	847	3	7	3
IA	Woodward Resource Ctr. (Woodward)	1917		143	143	147	153	-6.5	1,020	4	12	2
ID	Southwest Idaho Treatment Center (Nampa)	1918		25	26	23	19	31.6	849	13	7	0
IL	Choate Dev. Ctr. (Anna)	1873		172	172	170	167	3.0	605	29	23	1
IL	Fox Dev. Ctr. (Dwight)	1965		105	105	109	110	-4.5	799	2	2	3
IL	Kiley Dev. Ctr. (Waukegan)	1975		191	191	188	187	2.1	799	10	3	3
IL	Ludeman Dev. Ctr. (Park Forest)	1972		390	392	395	401	-2.7	799	13	18	6
IL	Mabley Dev. Ctr. (Dixon)	1987		106	106	105	101	5.0	799	7	1	1

DNF Did not furnish * See state notes in the Appendix.

Table 4.9 continued Open PRFS on June 30, 2016: People Served, Movement Patterns, Average Daily Per Person Cost, Admissions, Discharges and Deaths By State and Facility Name

State	Facility Name (City) *	Year Opened	(Projected) Closure Date	Residents With IDD June 2016	All Residents June 2016	Average Daily with IDD FY 2016	Residents With IDD June 2015	% Change 2015-16	Average Daily Per Person Cost (\$)	Admissions/Readmissions	Discharges	Deaths
IL	Murray Dev. Ctr. (Centralia)	1964	DNF	208	208	215	221	-5.9	771	3	2	4
IL	Shapiro Dev. Ctr. (Kankakee)	1879		478	478	487	496	-3.6	711	20	24	14
KS	Kansas Neurological Institute (Topeka)	1960		145	145	141	144	0.7	488	6	1	4
KS	Parsons State Hospital (Parsons)	1952		165	165	163	169	-2.4	422	11	12	3
KY	Bingham Gardens (Louisville)	1873		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
KY	Hazelwood Ctr. (Louisville)	1971	2017	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
LA	Louisiana Special Education Center (Alexandria)	1952		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
LA	Pinecrest Supports and Services Center (Pineville)	1918		435	435	421	410	6.1	722	60	25	10
MA	Hogan Regional Ctr. (Hawthorne)	1967		117	117	120	123	-4.9	797	1	0	7
MA	Wrentham Dev. Ctr. (Wrentham)	1907		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MD	Holly Ctr. (Salisbury)	1975		58	58	58	64	-9.4	212	1	2	5
MD	Potomac Ctr. (Hagerstown)	1978		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MS	Boswell Regional Ctr. (Sanatorium)	1976		96	96	101	107	-10.3	386	34	41	4
MS	Ellisville State School (Ellisville)	1920		277	289	321	305	-9.2	377	3	21	10
MS	Hudspeth Regional Ctr. (Whitfield)	1974		243	243	246	254	-4.3	307	2	12	1
MS	Mississippi Adolescent Center (Brookhaven)	2011		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MS	North Mississippi Regional Ctr. (Oxford)	1973		233	235	238	249	-6.4	303	1	9	8
MS	South Mississippi Regional Ctr. (Long Beach)	1978		124	124	131	138	-10.1	335	5	17	2
MO	Bellefontaine Habilitation Ctr. (St. Louis)	1924		121	121	121	126	-4.0	680	0	3	2
MO	Higginsville Habilitation Ctr. (Higginsville)	1956		58	58	50	41	41.5	929	22	3	2
MO	Southeast Missouri Residential Services (Poplar Bluff and Sikeston)	1992		62	62	62	62	0.0	592	0	0	0
MO	Southwest Community Services (Nevada)	1973		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		118	118	DNF	127	-7.1	641	0	5	4
MT	Montana Developmental Ctr. (Boulder)	1905	June 2017	22	22	36	43	-48.8	831	1	17	0
NE	Sheridan Cottages ICF (Beatrice)	1875		115	115	116	116	-0.9	1,133	0	0	1
NV	Desert Regional Ctr. (Las Vegas)	1975		47	47	47	47	0.0	DNF	23	24	1
NJ	Green Brook Regional Ctr. (Green Brook)	1981		106	106	106	107	-0.9	838	8	3	6

DNF Did not furnish * See state notes in the Appendix.

Table 4.9 continued Open PRFS on June 30, 2016: People Served, Movement Patterns, Average Daily Per Person Cost, Admissions, Discharges and Deaths By State and Facility Name

State	Facility Name (City) *	Year Opened	(Projected) Closure Date	Residents With IDD June 2016	All Residents June 2016	Average Daily with IDD FY 2016	Residents With IDD June 2015	% Change 2015-16	Average Daily Per Person Cost (\$)	Admissions/Readmissions	Discharges	Deaths
NJ	Hunterdon Dev. Ctr. (Clinton)	1969		495	495	499	500	-1.0	708	17	4	18
NJ	Vineland Dev. Ctr. (Vineland)	1888		362	362	375	388	-6.7	900	0	16	10
NJ	New Lisbon Dev. Ctr. (New Lisbon)	1914		220	220	242	268	-17.9	1,026	0	37	11
NJ	Woodbine Dev. Ctr. (Woodbine)	1921		294	294	319	342	-14.0	968	0	34	14
NY	Bernard M. Fineson Dev. Ctr. (Hillside; Howard Park)	1970	Mar 2017	77	77	DNF	116	DNF	DNF	5	42	DNF
NY	Sunmount DDSO (Tupper Lake)	1965		160	173	DNF	173	DNF	DNF	25	37	DNF
NY	Valley Ridge (Norwich)	2000		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NC	Black Mountain Ctr. (Black Mountain)	1982		87	154	86	80	8.8	490	13	0	6
NC	Caswell Ctr. (Kinston)	1914		327	328	327	338	-3.3	686	4	2	13
NC	J. Iverson Riddle Dev. Ctr. (Morganton)	1963		284	284	280	286	-0.7	575	9	6	5
NC	Murdoch Ctr. (Butner)	1957		422	431	423	433	-2.5	654	28	20	10
NC	O'Berry Ctr. (Goldsboro)	1957		212	212	214	219	-3.2	715	0	1	6
ND	Life Skills and Transition Center (Grafton)	1904		75	75	80	79	-5.1	867	18	21	1
OH	Cambridge Dev. Ctr. (Cambridge)	1965		79	79	78	72	9.7	485	30	18	0
OH	Columbus Dev. Ctr. (Columbus)	1857		94	94	95	95	-1.1	581	9	17	1
OH	Gallipolis Dev. Ctr. (Gallipolis)	1893		50	56	62	67	-25.4	639	4	18	3
OH	Montgomery Dev. Ctr. (Huber Heights)	1981	June 2017	37	37	37	84	-56.0	503	0	45	2
OH	Mount Vernon Dev. Ctr. (Mount Vernon)	1948		73	73	86	96	-24.0	577	9	27	4
OH	Northwest Ohio Dev. Ctr. (Toledo)	1977		81	81	85	96	-15.6	607	15	14	0
OH	Southwest Ohio Dev. Ctr. (Batavia)	1981		102	145	98	98	4.1	523	57	51	2
OH	Tiffin Dev. Ctr. (Tiffin)	1975		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
OH	Warrensville Dev. Ctr. (Warrensville)	1975		91	91	90	95	-4.2	636	22	22	4
OH	Youngstown Ctr. (Mineral Ridge)	1980	June 2017	32	32	51	71	-54.9	543	0	39	0
PA	Ebensburg Ctr. (Ebensburg)	1957		230	230	226	238	-3.4	781	0	4	4
PA	Hamburg Ctr. (Hamburg)	1960		84	84	88	92	-8.7	1,277	0	4	4
PA	Polk Ctr. (Polk)	1897		234	234	240	240	-2.5	1,197	2	2	12
PA	Selinsgrove Ctr. (Selinsgrove)	1929		233	233	234	247	-5.7	938	2	4	12
PA	White Haven Ctr. (White Haven)	1956		124	124	124	127	-2.4	1,087	2	1	4
SC	Coastal Ctr. (Ladson)	1968		150	150	151	152	-1.3	443	11	10	3
SC	Midlands Ctr. (Columbia)	1956		135	135	140	143	-5.6	443	10	5	13
SC	Pee Dee Regional Ctr. (Florence) and Thad E. Saleeby Ctr. (Hartsville)	1971		193	193	189	186	3.8	443	27	8	7
SC	Whitten Ctr. (Clinton)	1920		188	188	190	192	-2.1	443	10	12	2
SD	South Dakota Dev. Ctr. (Redfield)	1902		132	132	132	140	-5.7	512	20	28	0

DNF Did not furnish * See state notes in the Appendix.

Table 4.9 continued Open PRFS on June 30, 2016: People Served, Movement Patterns, Average Daily Per Person Cost, Admissions, Discharges and Deaths By State and Facility Name

State	Facility Name (City) *	Year Opened	(Projected) Closure Date	Residents With IDD June 2016	All Residents June 2016	Average Daily with IDD FY 2016	Residents With IDD June 2015	% Change 2015-16	Average Daily Per Person Cost (\$)	Admissions/Readmissions	Discharges	Deaths
TN	Greene Valley Dev. Ctr. (Greeneville)	1960	May 2017	60	60	71	88	-31.8	1,465	0	21	7
TX	Abilene State School (Abilene)	1957		293	293	306	321	-8.7	516	5	22	11
TX	Austin State School (Austin)	1917		184	184	187	192	-4.2	788	1	4	5
TX	Brenham State School (Brenham)	1974		264	264	272	279	-5.4	471	14	16	13
TX	Corpus Christi State School (Corpus Christi)	1970		220	220	221	221	-0.5	547	10	4	7
TX	Denton State School (Denton)	1960		458	458	457	458	0.0	476	23	10	13
TX	El Paso State Ctr. (El Paso)	1973		107	107	105	106	0.9	563	7	5	1
TX	Lubbock State School (Lubbock)	1969		191	191	197	201	-5.0	520	9	12	7
TX	Lufkin State School (Lufkin)	1962		295	295	302	308	-4.2	473	19	18	14
TX	Mexia State School (Mexia)	1946		256	256	244	256	0.0	721	54	10	6
TX	Richmond State School (Richmond)	1968		328	328	326	330	-0.6	472	14	8	8
TX	Rio Grande State Ctr. (Harlingen)	1973		61	61	65	71	-14.1	543	4	11	3
TX	San Angelo State School (Carlsbad)	1969		217	DNF	211	214	1.4	543	28	19	6
TX	San Antonio State School (San Antonio)	1978		229	229	231	229	0.0	433	14	9	5
UT	Utah State Dev. Ctr. (American Fork)	1931		191	191	191	191	0.0	511	16	2	9
VA	Central Virginia Trng. Ctr. (Lynchburg)	1911	2020	192	192	163	233	-17.6	1,134	3	30	14
VA	Southeastern Virginia Trng. Ctr. (Chesapeake)	1975		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
VA	Southwestern Virginia Trng. Ctr. (Hillsville)	1976	June 2018	98	98	110	123	-20.3	639	0	19	6
WA	Fircrest (Seattle)	1959		209	209	DNF	196	6.6	684	8	8	6
WA	Lakeland Village School (Medical Lake)	1915		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
WA	DSHS Rainier School (Buckley)	1939		296	313	303	317	-6.6	619	1	0	10
WA	Yakima Valley School (Selah)	1958		64	64	65	67	570.0	DNF	0	0	3
WI	Central Wisconsin Ctr. (Madison)	1959		204	204	207	214	-4.7	864	0	1	9
WI	Southern Wisconsin Ctr. (Union Grove)	1919		132	135	139	138	-4.3	991	0	1	5
WY	Wyoming Life Resource Ctr. (Lander)	1912		67	67	68	70	-4.3	802	1	0	4

DNF Did not furnish * See state notes in the Appendix.

Table 4.10 Final Status of PRFs No Longer in Operation as of June 30, 2016

State	Facility Name at Closure, Downsizing or Conversion	Year Opened	Final Status	
			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	2016	
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	
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 Hospital (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

Table 4.10 continued Final Status of PRFs No Longer in Operation as of June 30, 2016

State	Facility Name at Closure, Downsizing or Conversion	Year Opened	Final Status	
			Year	Disposition ¹
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	
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) ¹	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) ¹	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	

Table 4.10 continued Final Status of PRFs No Longer in Operation as of June 30, 2016

State	Facility Name at Closure, Downsizing or Conversion	Year Opened	Final Status	
			Year	Disposition ¹
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	
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	

Table 4.10 continued *Final Status of PRFs No Longer in Operation as of June 30, 2016*

State	Facility Name at Closure, Downsizing or Conversion	Year Opened	Final Status	
			Year	Disposition ¹
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	Springfield Regional Ctr. (Springfield)	1967	1990	
MT	Eastmont Human Services Ctr. (Glendive)	1969	2003	
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
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	Bronx DDSO (Bronx)	1971	1992	
NY	Brooklyn DDSO (Brooklyn)	1972	2015	
NY	Broome DDSO (Binghamton)	1970	2016	
NY	Capital District DDSO (Schenectady)	1973	2015	
NY	Central New York DDSO (Syracuse)	1851	1998	
NY	Craig DDSO (Sonyea)	1935	1988	
NY	Finger Lakes DDSO (Rochester)	1969	2013	
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	

Table 4.10 continued Final Status of PRFs No Longer in Operation as of June 30, 2016

State	Facility Name at Closure, Downsizing or Conversion	Year Opened	Final Status	
			Year	Disposition ¹
OH	Broadview Ctr. (Broadview Hghts.)	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	Orient Ctr. (Orient)	1898	1984	
OH	Springview Developmental Ctr. (Springfield)	1975	2005	
OH	Western Reserve Psychiatric Hab. Ctr. (Northfield)	1978	1990	
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	2015	Closed
OR	Columbia Park Hospital & Trng. Ctr. (The Dalles)	1963	1977	
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	Zamborano 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	2015	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	

Table 4.10 continued Final Status of PRFs No Longer in Operation as of June 30, 2016

State	Facility Name at Closure, Downsizing or Conversion	Year Opened	Final Status	
			Year	Disposition ¹
VT	Brandon Trng. School (Brandon)	1915	1993	
VA	Eastern State Hospital (Williamsburg)		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	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	
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.

Projected closures by Fiscal Year include:

FY 2017 (July 1, 2016 – June 30, 2017)

- Ella Grasso Center (Stratford, CT, listed on **Table 4.10**)
- Montana Developmental Center (Boulder, MT)
- Bernard M. Fineson Developmental Center (Hillside; Howard Park, NY)
- Montgomery Developmental Center (Huber Heights, OH)
- Youngstown Center (Mineral Ridge, OH)
- Greene Valley Developmental Center (Greeneville, TN)

FY 2018 (July 1, 2017 – June 30, 2018)

- Hazelwood Center (Louisville, KY)
- Southwestern Virginia Training Center (Hillsville, VA)

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

- Sonoma Developmental Center (Eldridge, CA)

FY 2020 (July 1, 2019 – June 30, 2020)

- Fairview Development Center (Costa Mesa, CA)
- Central Virginia Training Center (Lynchburg, VA)

FY 2021 or later

- Porterville Development Center (Porterville, CA)

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 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).
- Beatrice State Developmental Center (Beatrice, NE) is one campus with four ICF/IID units.
- 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 Sequin Unit at the Alachua Retarded Development Center was combined with the Tacachale Community of Excellence (Gainesville, FL) on the PRF survey
- The two campuses of East Central Regional Hospital (Gracewood & Augusta, GA) were combined for the PRF survey

Table 4.11 Operational Status of PRFs by State on June 30, 2016 with Projected Closures to June 2021

State	Operating Between 1960 and 2015	Closed, Converted or Downsized ¹		Open June 30, 2016	Projected to Close July 2016 - June 2021
		1960 to 2015	FY 2016		
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	10	0	5	1
DE	1	0	0	1	0
DC	3	3	0	0	0
FL	10	7	0	3	0
GA*	12	10	0	2	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	10	8	0	2	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	11	1	7	0
MT	2	1	0	1	1
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	21	2	22	1
NC	6	1	0	5	0
ND	2	1	0	1	0
OH	22	12	0	10	2
OK	4	3	1	0	0
OR	3	3	0	0	0
PA	23	18	0	5	0
RI	3	3	0	0	0
SC	5	0	0	5	0
SD	2	1	0	1	0
TN	5	3	1	1	1
TX	15	2	0	13	0
UT	1	0	0	1	0
VT	1	1	0	0	0
VA	8	4	1	3	2
WA	6	2	0	4	0
WV	4	4	0	0	0
WI*	3	0	0	3	0
WY	1	0	0	1	0
Reported US Total	374	230	6	139	12
% of Total		61%	2%	37%	3%

* See additional state notes in the Appendix. ¹ Downsized facilities serve 15 or fewer people with IDD.

- Thad E. Saleeby Ctr. (Hartsville, SC) combined with the Pee Dee Regional Ctr. (Florence, SC) for the PRF survey

TRENDS IN PUBLIC RESIDENTIAL FACILITY UTILIZATION

Public Residential Facility Closures

Of the 374 PRFs operating between 1960 and 2016, 230 (61%) closed by June 30, 2015, 6 (2%) closed between July 1, 2015 and June 30, 2016, and 139 were open as of June 30, 2016 (See **Table 4.11**). Twelve PRFs were scheduled to close between July 2016 and June 2021. States with the most PRF closures between 1960 and 2016 were Connecticut (10 PRFs closed), Georgia (10), Illinois (10), Indiana (11), Michigan (13), Missouri (12), New York (23), Ohio (12), and Pennsylvania (18).

The rate of PRF closures in the United States varied by year (See **Figure 4.5**). Only 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 81 during the decade of the 1990's with 53 closures between 1990 and 1994 and 40 closures between 1995 and 1999. The rate of PRF closures declined substantially after the turn of the 21st century, with only 22 closures between 2000 and 2004, and 17 closures between 2005 and 2009. However, around the time of the Great Recession, the pace of PRF closures increased again to 35 closures between 2010 and 2014. States are currently forecasting 23 PRF closures between 2015 and 2019.

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). Data for selected years are shown on **Table 4.12**.

The average daily population of PRFs increased from 2,429 in 1880 to 101,396 by 1939, and to an all-time high of 194,650 people in 1967 (See **Figure 4.6a**). Between 1967 and 1987, the PRF population declined by 51% to 95,886 as nearly 100,000 people moved from a PRF to another living arrangement. Between 1987 and 2000, the average daily population of PRFs declined by another 50% to 47,872 people. Between

Figure 4.5 PRFs Closed, Downsized, or Converted to Non-IDD Use or Nonstate Operation Between 1960 and 2016 with Projected Closures for 2016 to 2024 in 5-Year Intervals

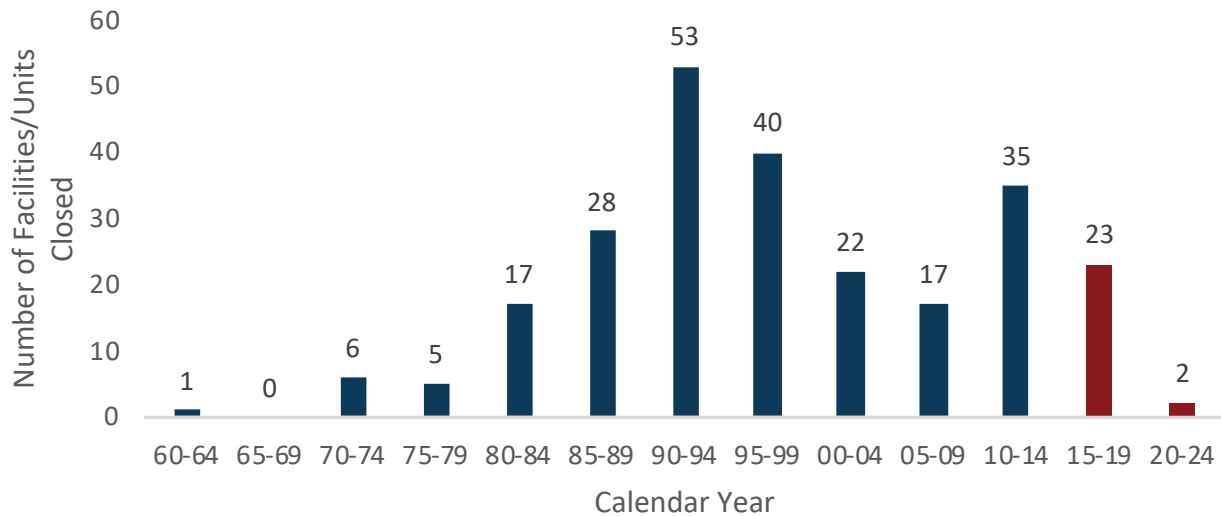


Table 4.12 Estimated Number and Proportion of People with IDD Living in PRFs by Level of Intellectual Disability on June 30 of Selected Years 1964 to 2016

Year	Average Daily Population			Percent in Psychiatric Settings	US Population (100,000)	Per 100,000 of the Population		
	State IDD	State Psychiatric	Total			State IDD	State Psychiatric	Total
1890	5,103				629.8	8.1		
1910	19,499				922.3	21.1		
1923	47,963				1,119.5	42.8		
1930	68,035				1,232.2	55.2		
1935	89,760				1,272.5	70.5		
1940	106,944				1,321.6	80.9		
1945	114,018				1,399.3	81.5		
1950	124,304	23,905	148,209	16%	1,513.3	82.1	15.8	97.9
1955	138,831	34,999	173,830	20%	1,650.7	84.1	21.2	105.3
1960	163,730	37,641	201,371	19%	1,806.7	90.6	20.8	111.5
1965	187,305	36,285	223,590	16%	1,650.7	113.5	22.0	135.5
1970	186,743	31,884	218,627	15%	2,050.5	91.1	15.5	106.6
1975	162,654	22,881	185,535	12%	2,159.7	75.3	10.6	85.9
1980	131,345	9,405	140,750	7%	2,277.3	57.7	4.1	61.8
1985	109,614	4,536	114,150	4%	2,384.7	46.0	1.9	47.9
1990	84,239	1,487	85,726	2%	2,499.7	33.7	0.6	34.3
1995	63,762	1,381	65,143	2%	2,630.8	24.2	0.5	24.8
2000	47,872	488	48,360	1%	2,823.9	17.0	0.2	17.1
2005	40,532	396	40,928	1%	2,961.9	13.7	0.1	13.8
2006	38,810	361	39,171	1%	2,990.0	13.0	0.1	13.1
2007	37,172	782	37,954	2%	3,020.0	12.3	0.3	12.6
2008	35,651	300	35,951	1%	3,018.0	11.8	0.1	11.9
2009	33,682	417	34,099	1%	3,074.4	11.0	0.1	11.1
2010	31,654	873	32,527	3%	3,087.5	10.3	0.3	10.5
2011	29,809	864	30,673	3%	3,115.9	9.6	0.3	9.8
2012	28,146	1,075	29,221	4%	3,139.1	9.0	0.3	9.3
2013	24,779	1,151	24,875	5%	3,161.3	7.5	0.4	7.9
2014	22,437	1,295	23,557	5%	3,188.6	7.0	0.4	7.4
2015	21,084	2,094	23,178	9%	3,214.2	6.5	0.7	7.2
2016	19,502	2,044	21,546	9%	3,231.3	6.0	0.6	6.6

¹ Number of people with IDD in psychiatric settings not reported by year: 2000 (NY); 2001 (NJ,NY,VA); 2002 (NJ,NY,VA); 2003 (CO,NY,VT); 2004 (IN,NJ); 2005 (CO,NJ,VT); 2006 and 2007 (CO,CT,NJ,VT); 2008 (CT, IN, NJ, VT); 2009 (CT, NJ, VT); 2010 (CA, CO, CT, ID, NC); 2011 (CO, DE, ID, MA, NC, VT); 2012; 2013 (AR, CO, GA, HI, ID, IA, KS, ME, MA, MS, MT, NH, NM, NY, OH, OK,TN, TX, UT, VA, WV); 2014 (GA, HI, ID, IA, KY, ME, MA, MS, MT, NH, NM, NY,OH,OK,RI, TX); 2015 (ID, MA, MT, NH, NM, NY, OH, OK, SC, TX); 2016 (ID, MA, MS, MT, NH, NM, NY, OH, OK)

2000 and 2016, the average daily PRF population declined by 59% to 19,502 people. There were fewer people with IDD living in PRFs in 2016 than at any time since 1910.

People with IDD in State-Operated Psychiatric Facilities

There have always been more people with IDD in PRFs than in state-operated psychiatric facilities. However, states also serve some people with IDD

in state-operated psychiatric facilities. There were 23,905 people with IDD living in state-operated psychiatric facilities in 1950, the first year data are available (See **Figure 4.6b**). 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. Between 1961 and 1977, the number of people with IDD in psychiatric facilities dropped by 63% to 15,524 people. The number continued to decline reaching 7,865 people in 1982, 3,106 people in 1986, 1,933 people in 1988 and a

Figure 4.6a Average Daily Population of PRFs from 1880 to 2016

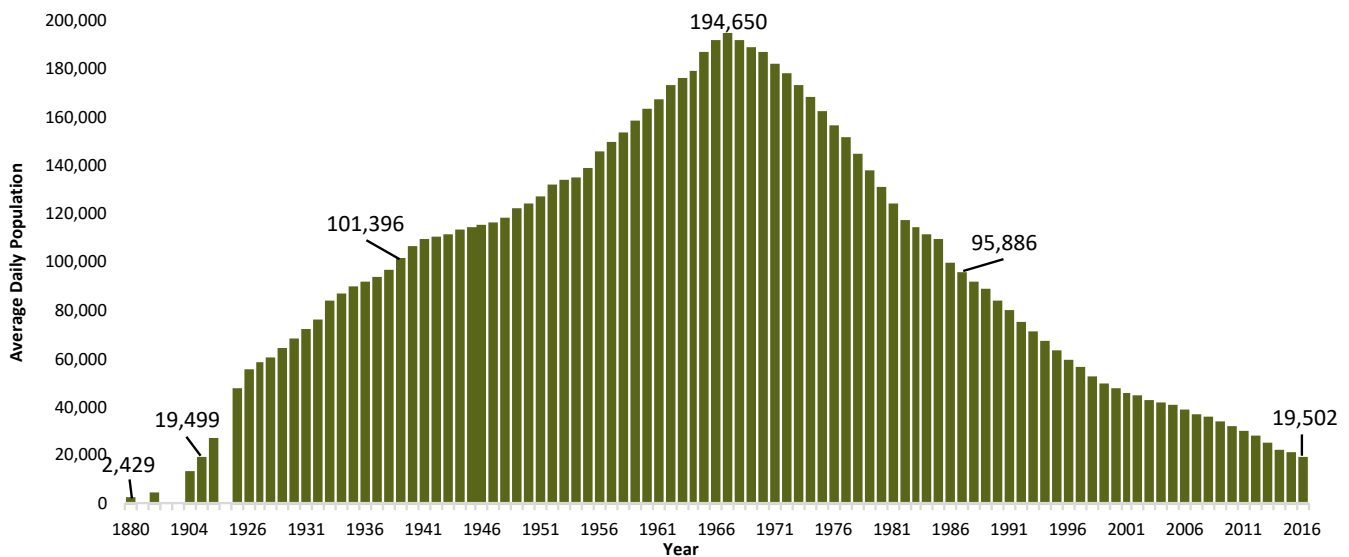
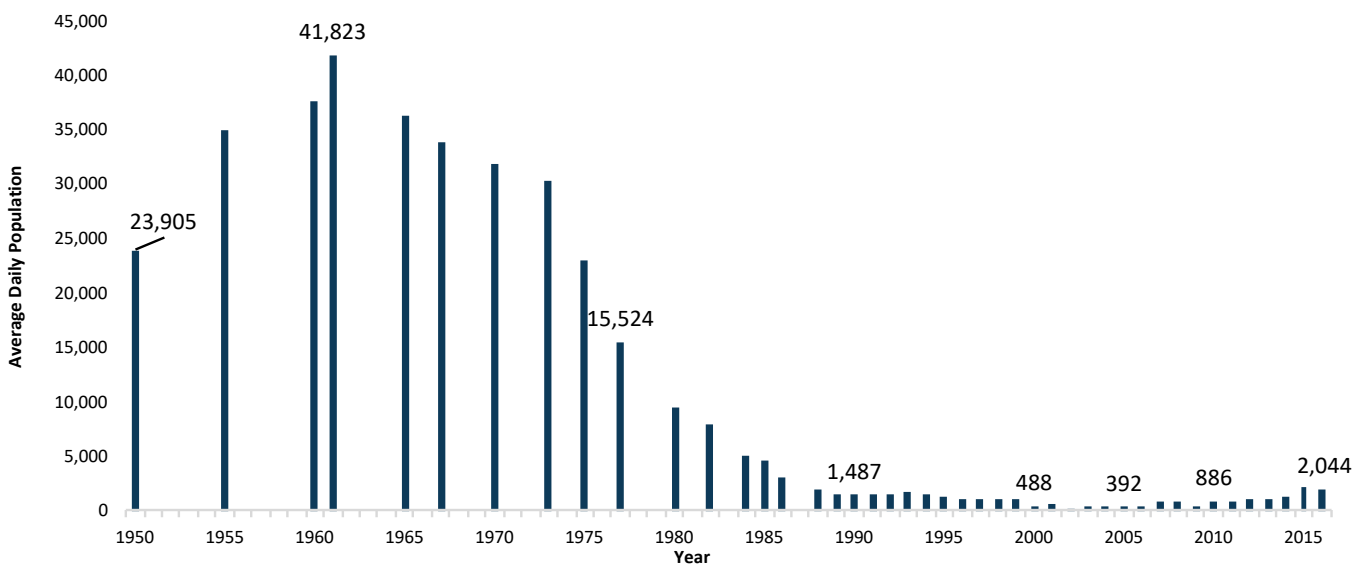


Figure 4.6b People with IDD in State Operated Psychiatric Facilities Selected Years 1950 to 2016



low of 267 people in 2002. Unlike PRFs however, the number of people with IDD in state-operated psychiatric facilities did not continue to decline. Instead, the number grew to 886 people in 2010 and to 2,044 people in 2016.

Between 2000 and 2016, an average of six states per year (range 0 to 21 states) were unable to furnish data on the number people with IDD living in state-operated psychiatric facilities. Without an alternative data source we are unable to estimate what the total might have been had all states reported. As a result, the reported totals are likely smaller than the actual totals.

Several factors contributed to the changing utilization of state-operated psychiatric facilities to serve people with IDD. For example, 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 between 1967 and 2000.

The reason that the number of people with IDD in state-operated psychiatric facilities increased since 2010 is unknown. Possible factors include increased recognition of depression, anxiety or other mental health disorders in people with IDD, shortages of community based mental health services for people with IDD, state policy decisions limiting or prohibiting new admissions to state-operated IDD facilities, and/or movement of some people with IDD from PRFs to psychiatric facilities as PRFs closed.

Rate of Change in the Number of People with IDD in PRFs or Psychiatric Facilities

Another way to look at people with IDD in PRFs and state-operated psychiatric facilities is to compare average annual numeric change to average annual percentage change (See **Figure 4.7**). The numeric decline in people with IDD in PRFs or state-operated psychiatric facilities was highest between 1975 and 1980 with an average decline of 8,957 people per year. The average annual decline was 5,320 people from 1980 to 1985, and 5,685 people from 1985 to 1990. The average annual decline slowed to 1,486 people per year between 2000 and 2004 but increased to 1,680 per year between 2005 and 2009, and 2,073 people per year from 2010 to 2014. The average annual decline for 2015 and 2016 was

Figure 4.7 Average Annual Change in the Number of People with IDD in PRFs and State Psychiatric Facilities in Five Year Intervals 1965 to 2016 with Linear Trendlines

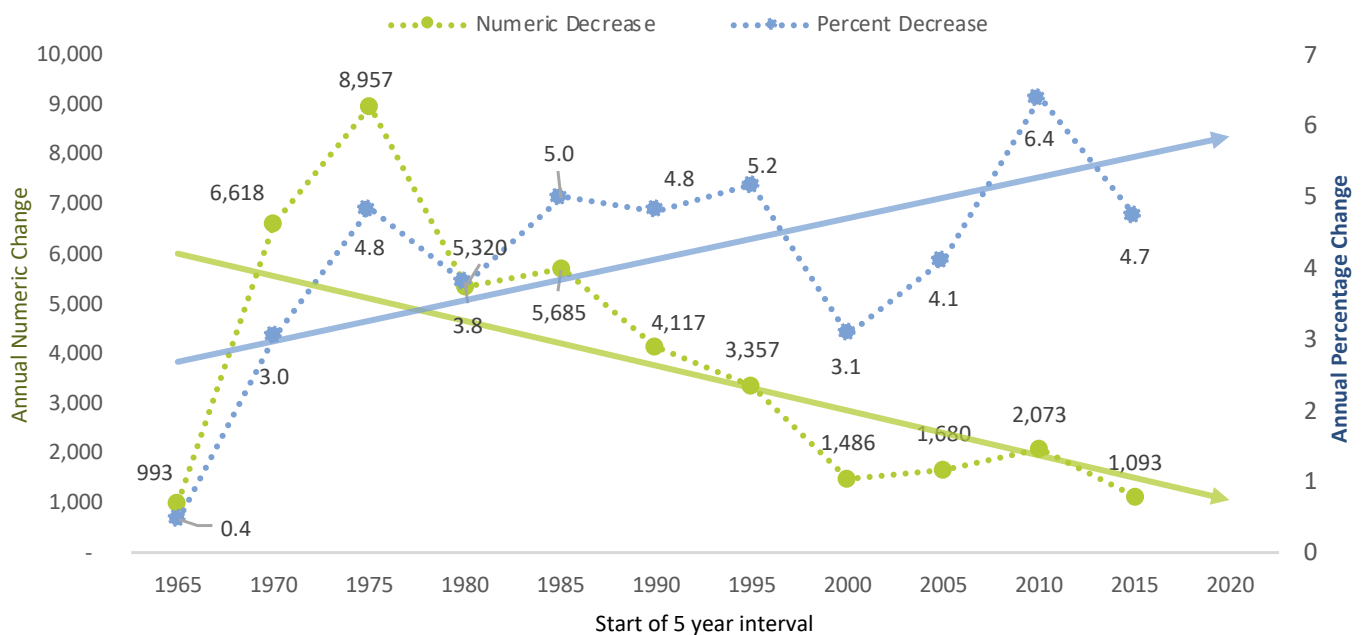


Table 4.13 Percent of PRF Residents with Prior Involvement with the Criminal Justice System 2010 to 2016

State	Average Daily Population									% change	
	1980	1985	1990	1995	2000	2005	2010	2015	2016	1980-2016	2010-2016
N States	51	51	51	51	51	51	50	49	48	48	33
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	89	-87	-25
AR	1,550	1,254	1,260	1,262	1,229	1,079	1,067	913	900	-42	-16
CA	8,812	7,524	6,768	5,494	3,879	3,307	2,149	1,077	965	-89	-55
CO	1,353	1,125	466	241	129	110	DNF	28	39	-97	DNF
CT	2,944	2,905	1,799	1,316	992	847	705	493	443	-85	-37
DE	518	433	345	308	256	123	71	54	52	-90	-27
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	780	-79	-19
GA	2,535	2,097	2,069	1,979	1,510	1,202	802	259	252	-90	-69
HI	432	354	162	83	0	0	0	0	0	-100	N/A
ID	379	317	210	139	110	94	68	24	23	-94	-66
IL	6,067	4,763	4,493	3,775	3,237	2,833	2,183	1,723	1,670	-72	-23
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	377	-69	-28
KS	1,327	1,309	1,017	756	379	360	340	311	316	-76	-7
KY	907	671	709	679	628	489	170	263	132	-85	-22
LA	3,171	3,375	2,622	2,167	1,749	1,571	1,144	453	467	-85	-59
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	127	-95	-8
MA	4,531	3,580	3,000	2,110	1,306	1,089	759	478	422	-91	-44
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	1,005	-39	-24
MO	2,257	1,856	1,860	1,492	1,286	1,152	671	410	345	-85	-49
MT	316	258	235	163	131	84	52	52	40 ^e	-87	-23
NE	707	488	466	414	401	372	182	114	115	-84	-37
NV	148	172	170	160	157	93	47	47	47	-68	0
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	1,537	-79	-43
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	542	-96	-73
NC	3,102	2,947	2,654	2,288	1,939	1,736	1,515	1,328	1,311	-58	-13
ND	1,056	763	232	156	144	140	120	82	80	-92	-33
OH	5,045	3,198	2,665	2,150	1,996	1,728	1,376	923	806	-84	-41
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	926	-87	-22
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	670	-78	-15
SD	678	557	391	345	196	172	149	139	136	-80	-9
TN	2,074	2,107	1,932	1,669	948	680	416	127	54	-97	-87
TX	10,320	9,638	7,320	5,459	5,431	4,977	4,337	3,241	3,124 ^d	-70	-28
UT	778	706	462	357	240	230	215	208	201	-74	-7
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	412	-88	-66
WA	2,231	1,844	1,758	1,320	1,143	973	914	777	673	-70	-26
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	357 ^d	-83	-20
WY	473	413	367	151	113	98	83	72	68	-86	-18
Estimated US Total	131,345	109,614	84,239	63,762	47,872	40,532	31,654	22,084	19,502	-85	-38

^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.

1,093. There was a clear overall downward trend in the number of people with IDD in PRFs and state-operated psychiatric facilities.

In comparison, there was a clear upward trend over time in the average proportion decline of people with IDD in PRFs and state-operated psychiatric facilities. The number of people with IDD in PRF or state-operated psychiatric facilities declined by an average of at least 3% per year between 1975 and 2016. The average annual decline increased from 4.8% per year between 1975 and 1979 to 5.2% between 1995 and 1999. More modest average annual declines were observed from 2000 to 2005 (3.1%), and 2005 to 2009 (4.1%). Between 2010 and 2014, as the number of PRF closures per year increased, the average percentage decline in the population reached a high of 6.4% per year. The average annual percentage decline for 2015 and 2016 was 4.7%.

Average Daily Population of PRFs by State

State trends in the average daily population of PRFs from 1980 to 2016 are shown on **Table 4.13**. Fifteen states closed all of their PRFs between 1980 and 2016: Alabama, Alaska, the District of Columbia, Hawaii, Indiana, Maine, Michigan, Minnesota, New Hampshire, New Mexico, Oklahoma, Oregon, Rhode Island, Vermont, and West Virginia. Six additional states reduced their average daily population more than 90%: Tennessee (97%), Idaho (94%), North Dakota (92%), Massachusetts (91%), Georgia (90%), and Delaware (90%). The remaining states reduced their average daily population by between 39% and 89%. The number of states with average daily PRF populations of more than 1,000 people declined from 32 in 1980 to 5 in 2016. States with more than 1,000 people with IDD in PRFs or state psychiatric facilities in 2016 were Illinois (1,670 people), Mississippi (1,005), New Jersey (1,537) and Texas (3,124).

The average daily population of PRFs decreased 38% from 31,654 to 19,502 people between 2010 and 2016. Four states closed their last PRF (Indiana, Minnesota, Oregon, and Oklahoma) between 2010 and 2016. Three states reduced their average daily populations to fewer than 50 people by FY 2016:

Idaho (23 people), Montana (40), and Nevada (47). Only 19,502 people remained in PRFs on June 30, 2016. With the support and advice of states who have already closed their last PRF, the goal of closing the last of the PRFs by 2030 may be in reach.

Trends in Admissions, Discharges and Deaths

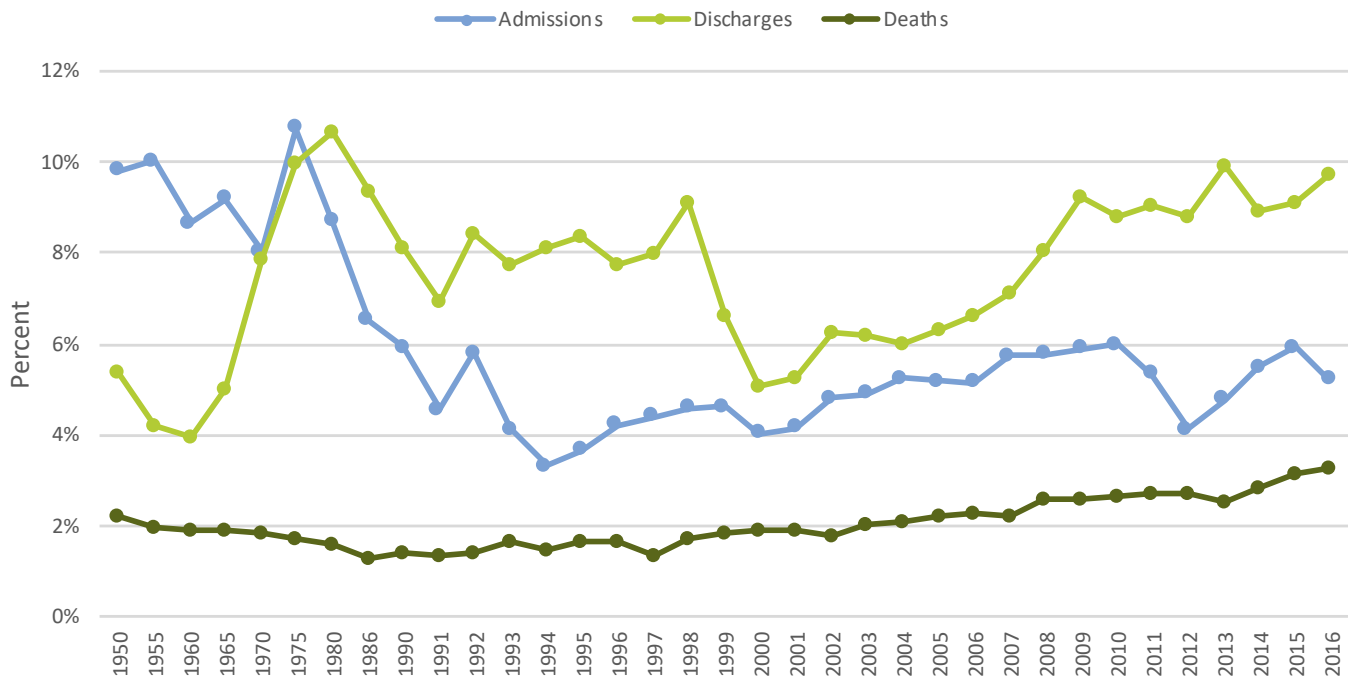
Table 4.14 shows annual admissions, discharges, and deaths for PRFs for selected years between 1950 and 2016. Transfers between PRFs are not included nor are admissions, discharges and deaths for state-operated psychiatric facilities. In 1950, PRFs reported an average daily population of 124,304 with 12,197 admissions (10% of the average daily population), 6,672 discharges (5%), and 2,761 deaths (2.2%). In 2016, the average daily population was 19,502 with 1,014 admissions (5%), 1,897 discharges (10%), and 635 deaths (3.3%).

There were 12,197 people with IDD admitted to PRFs in 1950. By 1975, annual admissions had

Table 4.14 Change in Estimated Average Daily Population and Annual Admissions, Discharges and Deaths in PRFs Selected Years 1950-2016

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
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)
1986	100,190	6,535	9,399	1,322	(4,186)
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)
2006	38,810	1,994	2,559	886	(1,451)
2007	37,172	2,128	2,637	821	(1,330)
2008	35,651	2,056	2,879	918	(1,741)
2009	33,682	1,981	3,111	870	(2,000)
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)

Figure 4.8 Annual PRF Admissions, Discharges and Deaths as a Proportion of the Average Daily Population, Selected Years 1980 to 2016



increased to 18,075 people before beginning to drop. Annual admissions to PRFs dropped to fewer than 5,000 people per year by 1991, fewer than 2,000 people by 2000 and fewer than 1,100 by 2016. Annual admissions as a proportion of the average daily population declined from 10% to 7% between 1950 and 1986 and reached a low of 3% in 1994. Admissions remained between 4% and 6% of the average daily PRF population from 1995 to 2016 (See **Figure 4.8**).

In 1950, 6,672 people with IDD were discharged from PRFs. The number of annual discharges increased to 18,095 people by 1975. As the total population of PRFs declined the number of annual discharges also declined. Annual discharges declined from 9,399 people in 1986, to 5,337 people in 1995 to 3,111 in 2009 and 1,897 in 2016. Annual discharges as a proportion of the average daily population increased from below 5% from 1950 to 1970 to a high of 11% in 1980. Discharges as a proportion of the average daily population declined to between 5% and 7% from 1999 to 2006, but increased to between 8% and 10% between 2007 and 2016.

There were 2,761 deaths of PRF residents with IDD in 1950. The deaths per year increased to a high of

3,635 in 1967 before beginning a steady decline. Total deaths declined to fewer than 1,000 per year in 1996, and continued to decline reaching 635 in 2016. The trend for annual deaths as a proportion of the average daily population was somewhat different. Deaths as a proportion of the daily population declined from 2.2% in 1950 1.3% in 1986. However, rather than continuing to decline, deaths as a proportion of the average daily PRF population increased reaching 2.2% by 2005, and 3.3% by 2016. The increase in deaths as a proportion of the average daily population is probably related, at least in part, to changes in the demographic characteristics people in PRFs (See **Table 4.16** for details).

Trends in Average Annual per Person Expenditures

Average annual per person expenditures for people living in PRFs were \$746 in 1950 (\$7,553 in 2016 inflation adjusted dollars, See **Table 4.15**). In 1970, one year before enactment of the ICF/IID program, average annual per person expenditures were \$28,782. ICF/IID regulations, court decisions and settlement agreements drove increases in expenditures with their requirements to reduce overcrowding, upgrade staffing levels, increase

Table 4.15 Annual Per Person Expenditures for People with IDD Living in PRFs Selected Years 1950-2016

Year	Cost (\$)	Cost (\$1=2016)
1950	746	7,553
1955	1,286	11,608
1960	1,868	15,203
1965	2,361	18,015
1970	4,635	28,782
1975	10,155	45,696
1980	24,944	72,587
1985	44,271	99,167
1990	71,660	133,288
1995	85,760	135,501
2000	113,863	159,409
2005	148,811	184,525
2006	167,247	199,024
2007	176,226	204,422
2008	188,318	207,150
2009	196,710	218,348
2010	195,197	216,669
2011	226,106	241,933
2012	237,149	249,006
2013	246,063	253,445
2014	228,592	230,877
2015	263,196	265,828
2016	278,858	278,858

Includes all state-operated IDD facilities of 16 or more people. * Source: Inflation <https://data.bls.gov/cgi-bin/cpicalc.pl>

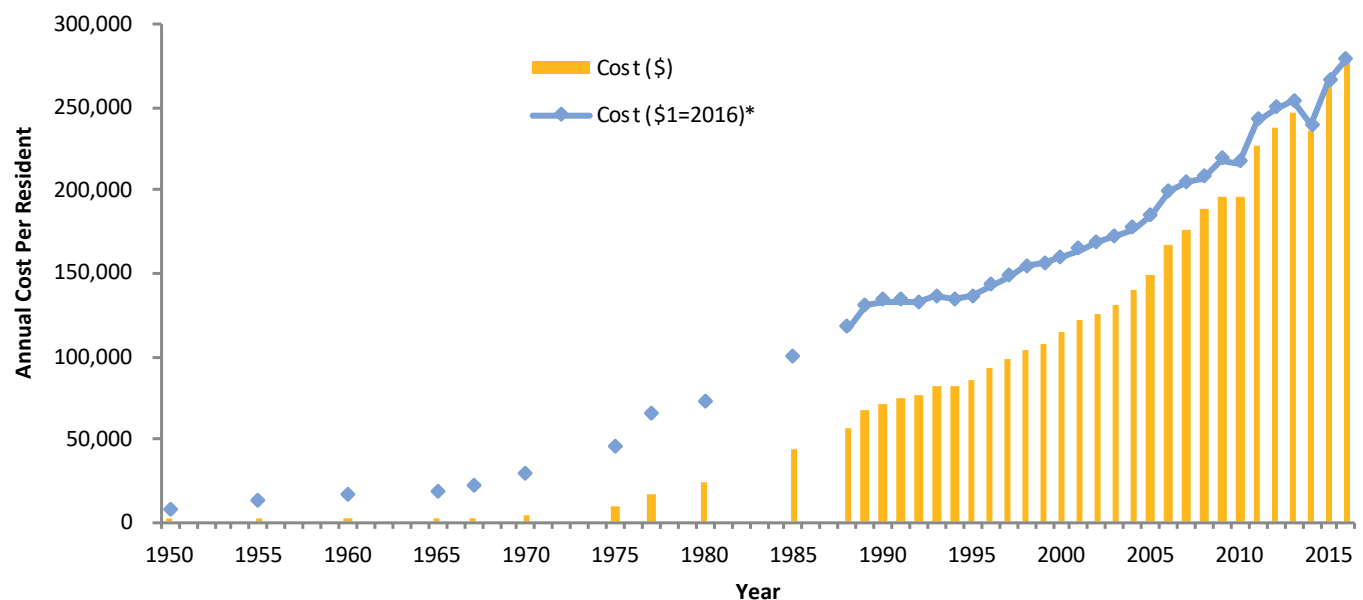
participation in meaningful daily activities and improve physical environments. By 1977, more than 70% of all PRFs were ICF/IID certified and annual per person expenditures had more than doubled to \$64,091. Between 1985 and 2016, as the populations of PRFs declined, per person costs increased as fixed costs (e.g., grounds, utilities, food service, laundry, physical plant and so forth) were shared by fewer people. Average annual expenditures for people living in PRFs rose from \$99,167 in 1985, to \$278,858 in 2016 (See **Figure 4.9**).

Characteristics and Experiences of People with IDD Living in PRFs

Age

Between 1950 and 1964 the proportion of PRF residents 21 years or younger increased from 39% (48,354 people) to a high of 49% (88,205, See **Figure 4.10**). The number of people 21 years or younger peaked at 91,592 in 1965. The proportion PRF residents 21 years or younger declined to 40% (63,516 people) in 1970, 30% (39,954) in 1979, 20% (23,239) in 1985, and 10% (8,170) in 1990. The proportion continued to decline reaching a low

Figure 4.9 Average Annual Per Person Expenditures for State-Operated IDD Facilities Serving 16 or More People, Selected Years 1950-2016



* Source: Inflation <https://data.bls.gov/cgi-bin/cpicalc.pl>

of 2.1% (623 people) in 2012 but then began to increase and was 3.7% (714 people) in 2016.

The age composition of people living in PRFs has been steadily shifting from young to old (See **Table 4.16** and **Figure 4.11**). The proportion (and

estimated number) of residents who were 63 years or older on June 30 was 4% (6,044 people) in 1977

- 8% (4,119 people in 1998 and
- 21% (4,103 people) in 2016

Figure 4.10 Average Daily Population of PRFs and Percent 21 Years or Younger, 1950 to 2016

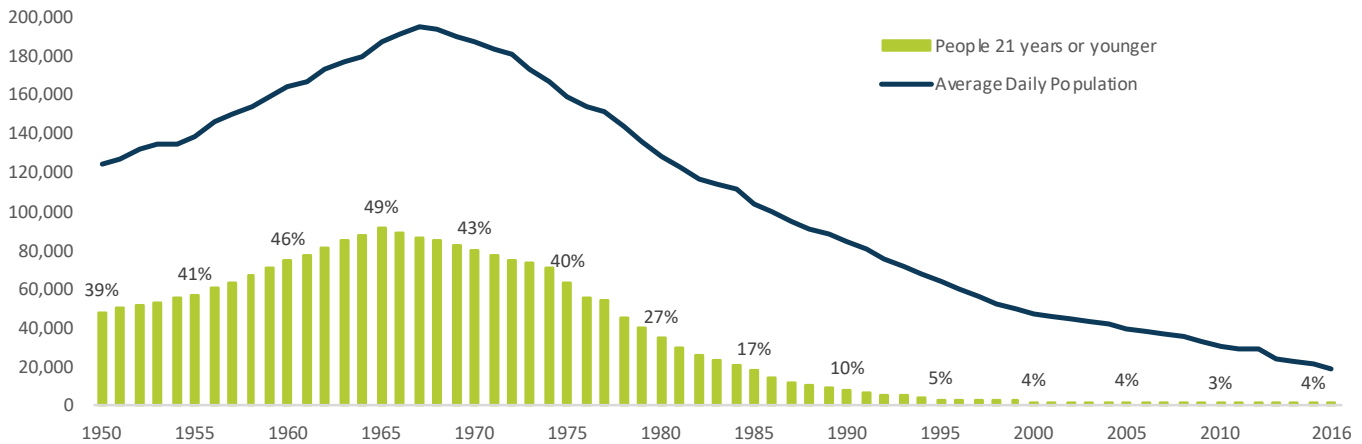


Table 4.16 PRF Population Characteristics June 30th of Selected Years 1977 to 2016

Characteristic (Percent in reporting facilities)		Year						
		1977	1987	1998	2008	2012	2014	2016
Estimated total residents		151,112	94,695	51,485	35,035	26,503	21,866	19,081
Gender	Male	57%	57%	60%	63%	63%	64%	63%
	Female	43%	43%	40%	37%	37%	36%	37%
Age	0-21 Years	36	13	5	5	4	4	4
	22-39 Years	41	54	38	23	19	19	19
	40-62 Years	19	27	49	61	59	58	55
	63+ Years	4	6	8	12	17	19	21
	Unknown					2	0	0
Level of Intellectual Disability	Mild/No ID	10	7	8	14	12	14	14
	Moderate	16	10	10	12	13	14	14
	Severe	28	20	18	16	16	17	19
	Profound	46	63	65	58	58	54	53
	Unknown					1	2	1
Other Conditions	Epilepsy			46	44	45	47	40
	Autism					17	18	19
	Cerebral Palsy	19	21	24	23	19	19	15
	Blind			16	15	13	15	15
	Deaf			8	7	7	5	6
	Alzheimers					3	2	2
	2 or More			57	66	61	55	48
Needs assistance or supervision with...	Dressing	56	61	70	53	65	55	64
	Transferring					45	48	58
	Toileting	34	47	60	57	56	35	58
	Eating	21	38	56	51	60	48	56
	Walking	23	30	39	39	43	39	41
Communication Cannot ...	Express needs verbally	44	55	60	58	57	47	52
	Understand verbal requests				34	31	44	29
Psychiatric and Behavior	Receives Mood, Anxiety or Behavior Medication				50	52	52	54
	Psychiatric Disorder			34	52	54	51	50
	Behavior Disorder	25	41	44	52	52	52	42

The proportion and estimated number of residents ages 40 to 62 years was

- 19% (28,711 people) in 1977
- 49% (25,568 people) in 1998 and
- 55% (10,575 people) in 2016

Level of Intellectual Disability

As the census of large state IDD facilities declined from its peak of 194,650 in 1967, the distribution of people by level of intellectual disabilities also changed (See **Figure 4.12**). Between 1964 and 1977, the total census declined from 179,629 to 151,112 but number of people with profound ID increased from 48,492 (27% of the 1964 total) to 68,886 (46% of the 1977 total). The proportion with profound ID continued to increase until it reached 65% in 1998. Since 1998 both the number and proportion of residents with profound ID has decreased. While the number of people with mild, moderate or no IDD decreased from 8,804 in 1998 to 5,429 in 2016, the proportion in those categories increased from 17% to 28%.

- The proportion (and estimated number) of PRF residents who had profound ID was
 - 46% (68,886 people) in 1977
 - 65% (33,259 people) in 1998
 - 53% (10,048 people) in 2016
- The proportion (and estimated number) of PRF residents with mild or no ID was
 - 10% (15,700 people) in 1977
 - 8% (3,913 people) in 1998
 - 14% (2,763 people) in 2016

Other Characteristics of PRF Residents

The most common monitored conditions other than intellectual disability of people in PRFs in 1998 were epilepsy (46% of the people), cerebral palsy (24%), blindness (16%), and deafness (8%). Between 1998 and 2016 the proportion of PRF residents with epilepsy declined from 46% to 40%, the proportion with cerebral palsy declined from 24% to 15%, and the proportion who were deaf declined from 8% to 6%. The proportion who were blind remained steady at between 13% and 16% of the people in PRFs between 1998 and 2016. Questions about autism spectrum disorder and Alzheimer’s disease were added to the PRF survey in 2012. Between 2012 and 2016, the proportion of PRF residents with ASD

Figure 4.11 Estimated Number and Proportion of People in PRFs by Age Group on June 30 of Selected Years 1977 to 2016

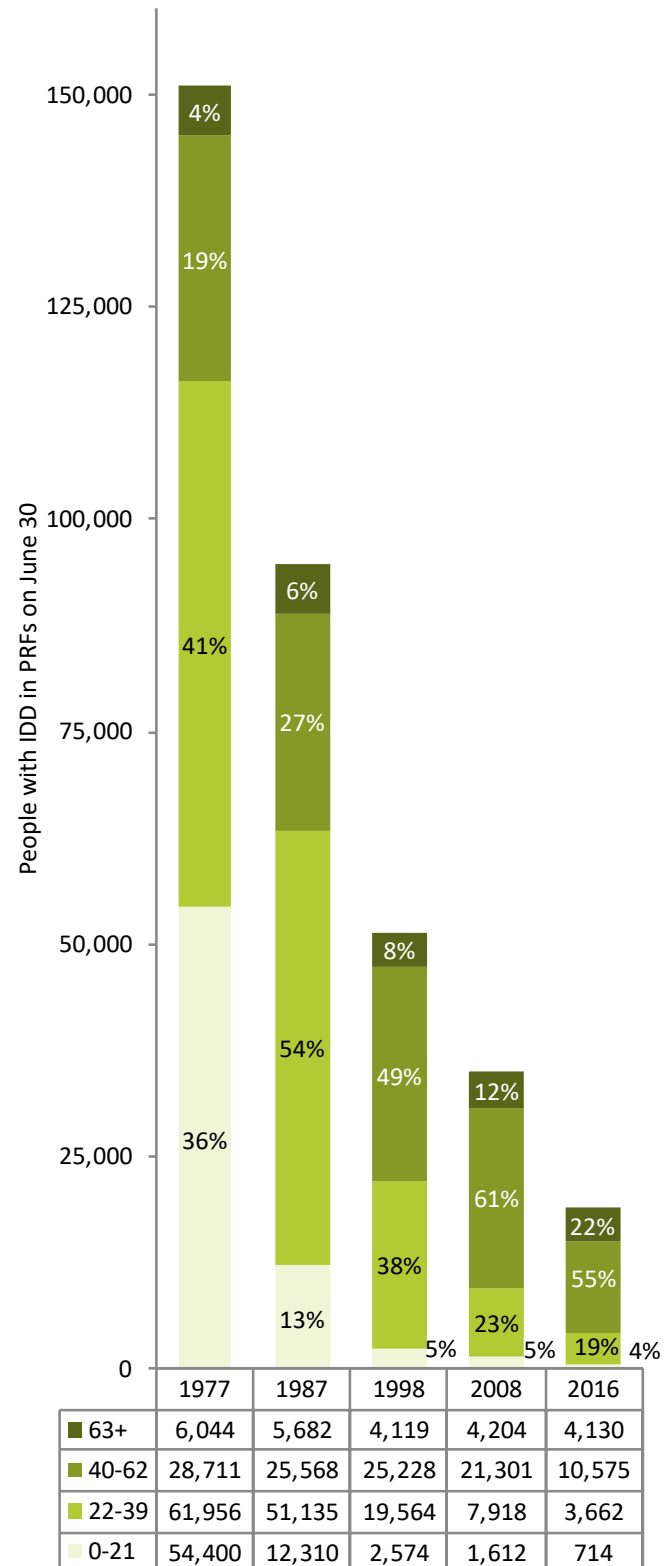
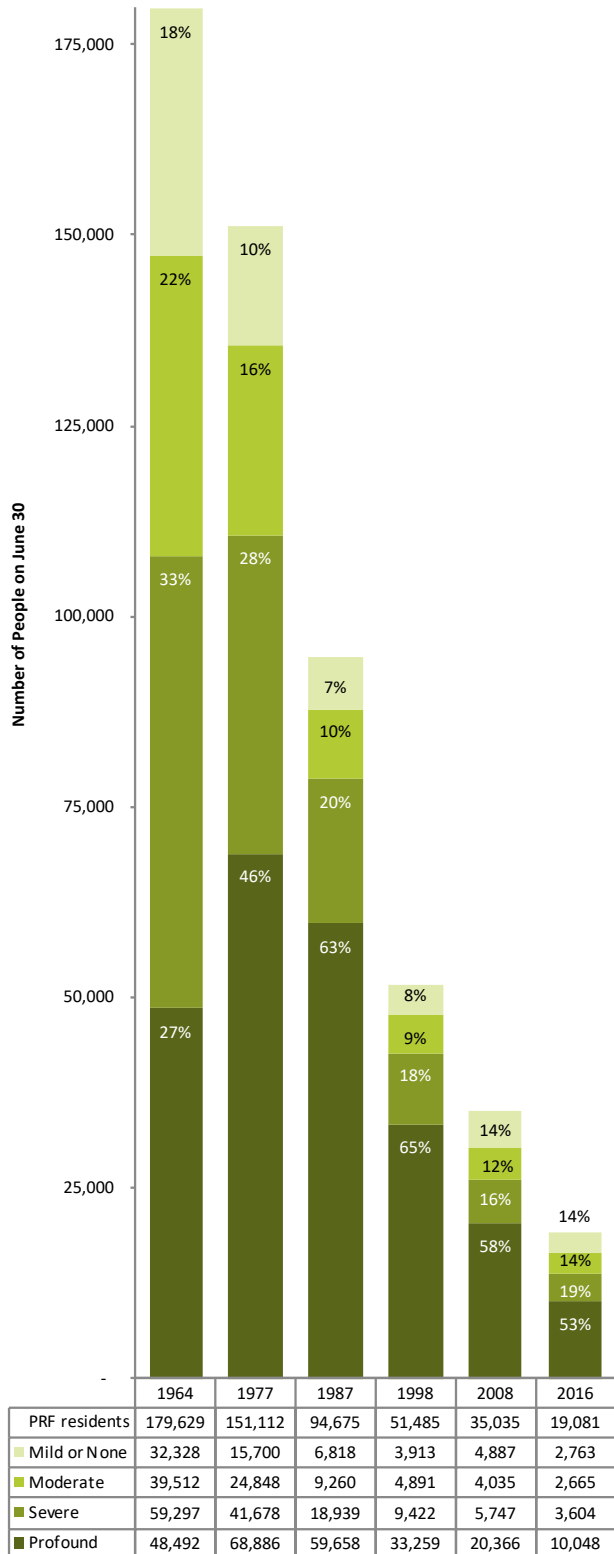


Figure 4.12 Estimated Number and Proportion of People with IDD Living in PRFs by Level of Intellectual Disability on June 30 of Selected Years 1964 to 2016



This figure excludes people whose level of ID was unknown. The source for 1964 data was Scheerenberger (1965).

increased from 17% to 19%, while the proportion with Alzheimer’s declined from 3% to 2%.

The proportion of PRF residents needing help or assistance with

- dressing ranged from 53% in 2008 to 70% in 1998, and was 64% in 2016
- transferring increased from 45% in 2012 to 58% in 2016
- toileting ranged from 34% in 1977 to 60% in 1998, and was 58% in 2016
- eating increased from 21% in 1977 to 60% in 2012, and was 56% in 2016
- walking increased from 23% in 1977 to 43% in 2012, and was 41% in 2016

The percent of PRF residents who could not express their needs verbally increased from 44% in 1977 to 60% in 1998, and declined to 52% in 2016. The proportion who could not understand verbal requests ranged from 29% to 44% between 2008 and 2016.

The proportion of PRF residents receiving medications for mood, anxiety or to address a behavioral challenge increased from 50% in 2008 to 54% in 2016. The proportion with a psychiatric disorder ranged from 34% and 50% between 1998 and 2016. The proportion of PRF residents with a behavior disorder requiring intervention increased from 25% in 1977 to 52% between 2008 and 2014, and was 42% in 2016.

Criminal Justice System Involvement 2010-2016

Questions about involvement in the criminal justice system were added to the PRF survey in 2010 and were asked every other year between 2010 and 2016. Between 2010 and 2016, the proportion of PRF residents who had been found to be incompetent to stand trial was between 1.7% and 5.5% with the highest proportion reported in 2016 (See **Table 4.17** and **Figure 4.13**). The proportion who had engaged in a behavior that led to contact with the criminal justice system between 3.7% and 5.5% with the highest proportion reported in 2016. The proportion of PRF residents who were under the jurisdiction of a criminal court for a reason other than those listed ranged from 1.6% to 3.0% with the highest proportion reported in 2016. The proportion who had been charged with a crime and had been court ordered to a PRF for competency training was between 0.5% and 4.0%

with the highest rate reported in 2014. Finally, the proportion of PRF residents under parole supervision on June 30 was less than half of one percent between 2010 and 2016.

Short-term Admissions 2010-2016

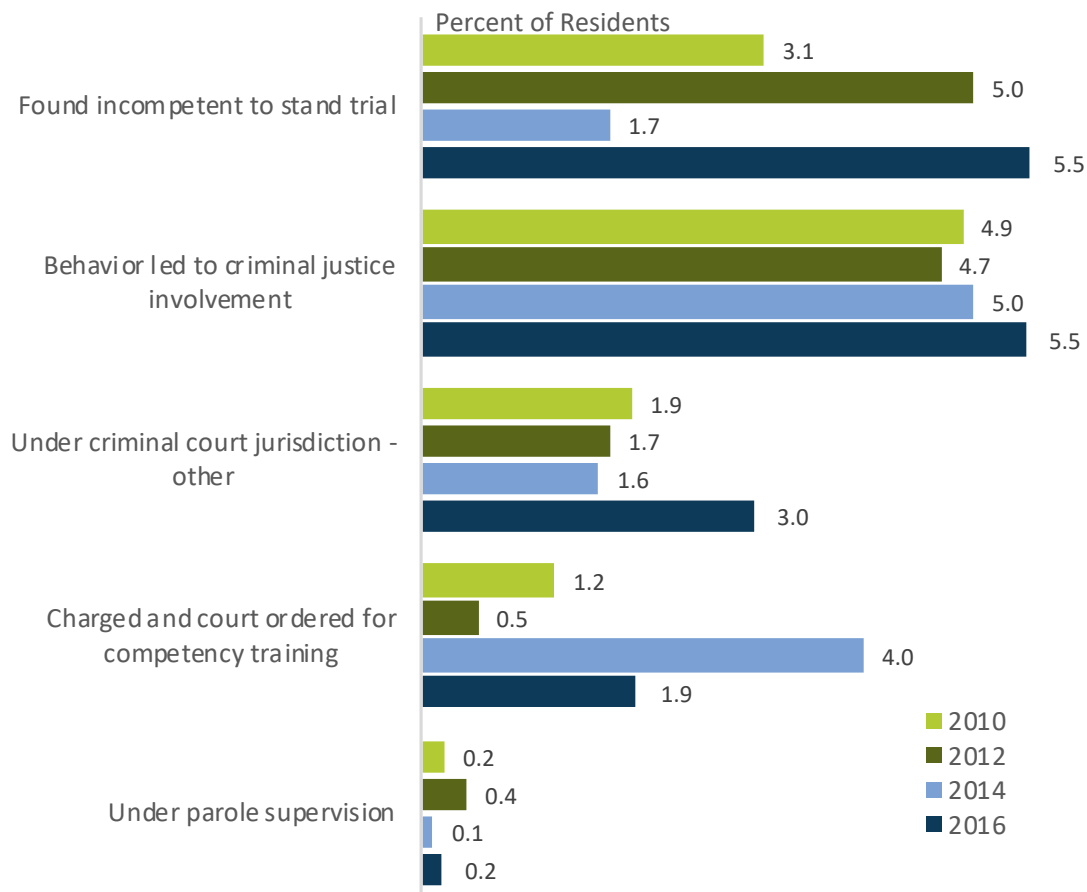
Questions about short-term admissions were added to the PRF survey in 2010. This question asked about the number of short-term stays rather than about the number of unique people who had a short-term

stay (See **Table 4.18** and **Figure 4.14**). The most common type of short-term stay was for respite. The number of respite stays was estimated to be 779 in 2010 (3.8 per 100 year end residents), 531 in 2012 (3.1), 479 in 2014 (2.3) and 510 (3.1) in 2016. The rate of short-term stays for evaluation purposes ranged from 2.0 per 100 residents to 2.4 per 100 residents between 2010 and 2016. Very few short-term stays for people needing crisis housing were reported (52 in 2010, 17 in 2012, 32 in 2014 and 3 in 2016).

Table 4.17 People Living in PRFs With Prior Involvement in the Criminal Justice System as of June 30, 2010, 2012, 2014 and 2016

Type of Involvement with the Criminal Justice System	2010		2012		2014		2016	
	N	%	N	%	N	%	N	%
Found incompetent to stand trial	465	3.1	791	5.0	251	1.7	865	5.5
Behavior led to criminal justice involvement	732	4.9	756	4.7	725	5.0	859	5.5
Under criminal court jurisdiction - other	292	1.9	260	1.7	227	1.6	471	3.0
Charged and court ordered for competency training	186	1.2	83	0.5	584	4.0	305	1.9
Under parole supervision	26	0.2	58	0.4	18	0.1	26	0.2
N of Reporting Facilities	92		79-83		71-79		90	

Figure 4.13 Percent of PRF Residents with Prior Involvement with the Criminal Justice System 2010 to 2016



Previous and Subsequent Residence 1985-2016

Tables 4.19 through 4.21 and Figures 4.15 through 4.17 show changes in the former residence of people admitted, or readmitted to a PRF, and in the subsequent residence of people discharged from PRFs between 1985 through 2016. 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, board and care)

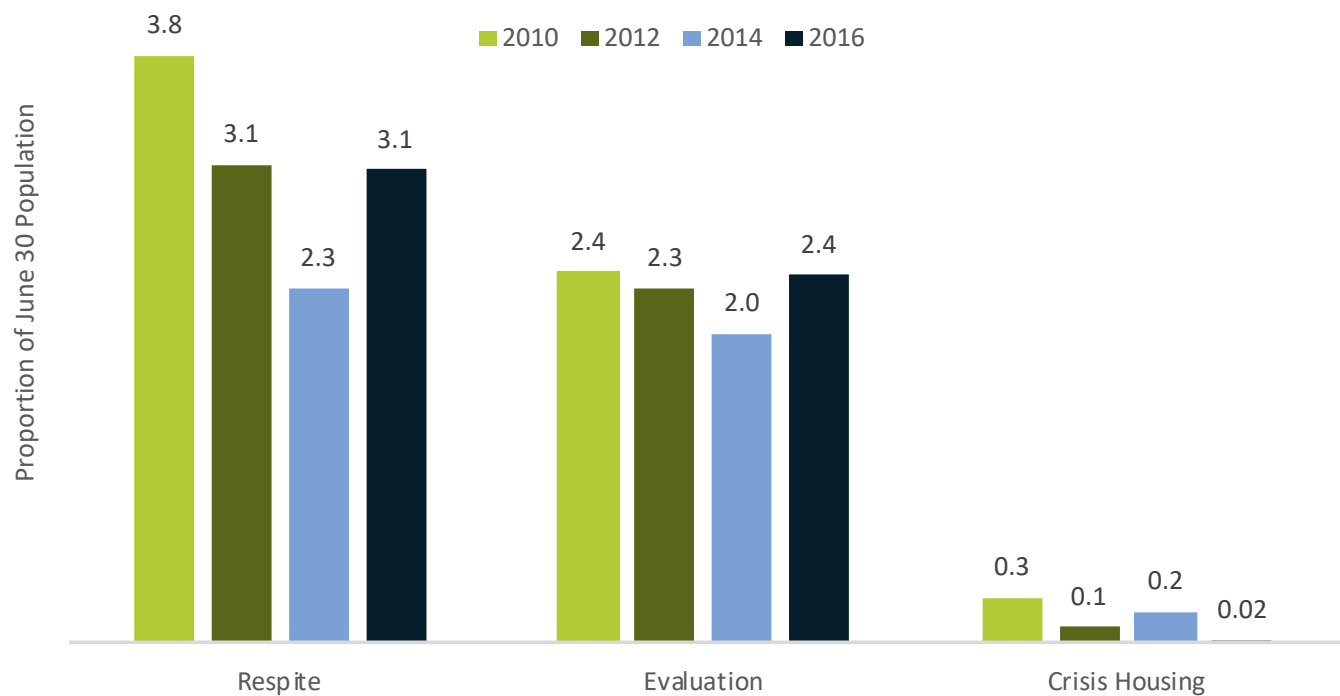
New Admissions

In 1985, 47% of all people newly admitted to PRFs from known setting types came from an individualized setting (mostly family homes; See **Table 4.19** and **Figure 4.15**). The proportion coming from individualized settings declined over time and was 23% in 2016. In 1985, 28% of people newly admitted to PRFs came from an IDD facility serving 16 or more people (nearly all

Table 4.18 Short-Term Admissions (Number and Per Year End Residents) to PRFs by Type in 2010, 2012, 2014, and 2016

Short-Term Admission Type	2010		2012		2014		2016	
	N	%	N	%	N	%	N	%
Year End Residents	31,101		26,503		21,600		16,679	
Respite	779	3.8	531	3.1	479	2.3	510	3.1
Evaluation	488	2.4	398	2.3	412	2.0	396	2.4
Crisis Housing	52	0.3	17	0.1	32	0.2	3	0.02
N of Reporting Facilities	98		86		68-75		95	

Figure 4.14 Short-Term Admissions as a Proportion of the June 30 PRF Population by Admission Type 2010, 2012, 2014, 2016



came for facilities of 64 or more people). By 2016, the proportion coming from a large IDD facility declined to 16% (with most coming from another PRF). In 1985, 19% of people who were newly admitted to PRFs came from a non-IDD facility (primarily mental health facilities). By 2016 the proportion coming from non-IDD facilities had increased to 43% with an equal number coming

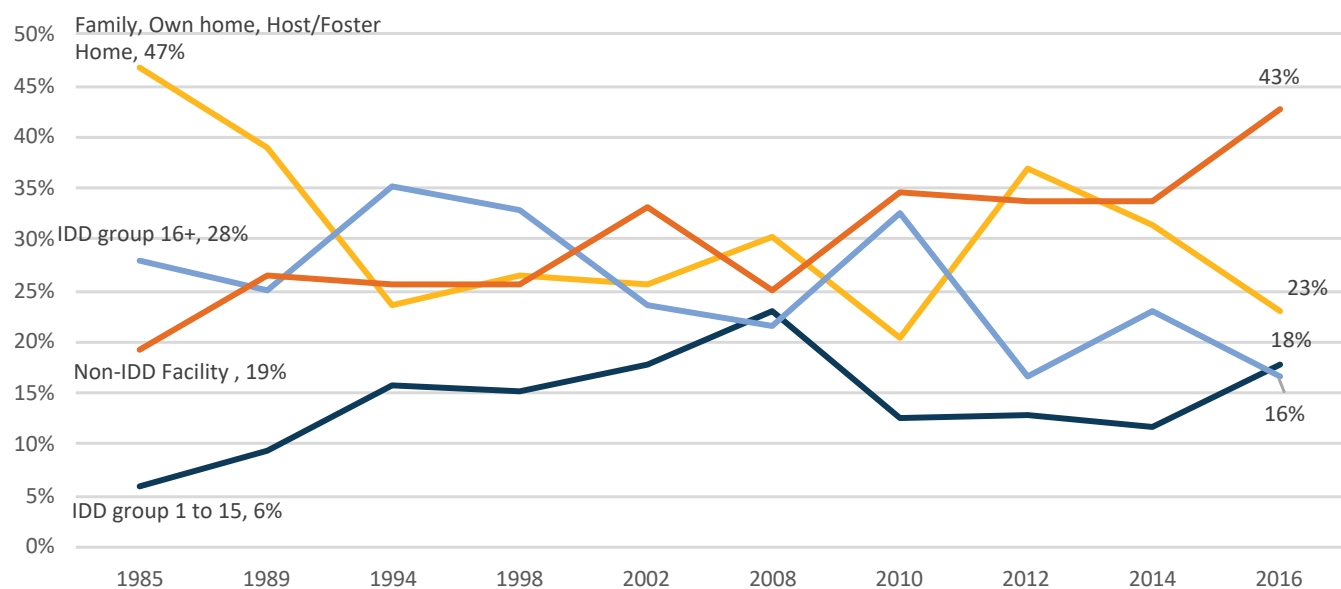
from mental health facilities and correctional facilities. In 1985 only 6% of people admitted to PRFs previously lived in an IDD group home of 15 or fewer people. By 2016, 18% came IDD settings of 15 or fewer people (most came from group homes of 6 or fewer people).

Table 4.19 Previous Place of Residence of Persons Newly Admitted to Large State Facilities (in Percent) for Selected Years 1985 to 2016

Previous Residence Type (Size)	Year									
	1985	1989	1994	1998	2002	2008	2010	2012	2014	2016
Home of parents or relative	39	29	19	21	19	21	15	24	23	15
Foster/host family home	4	5	0	2	3	3	2	2	1	1
Own Home Independent/Supported/Semi-independent Living	1	1	2	2	3	4	3	6	2	1
Group home (1-6 res.)								6	9	11
Group home (7-15 res.)								5	1	3
Group home (1 to 15 total)	6	8	14	14	16	22	12		10	13
Group IDD facility (16-63 res.)	4	4	3	4	3	4	11			
Nonstate IDD facility (64+ res.)	21	19	23	25	14	13	18			
State IDD facility (64+ res.)	2	0	5	2	5	4	2			
State IDD facility (16+ res.)								12	17	10
Nonstate IDD facility (16+ res.)								3	2	3
Mental health facility	14	16	16	12	16	13	16	14	16	15
Correctional facility	2	3	4	10	13	8	16	13	10	15
Nursing facility	2	3	2	2	1	2	1	2	1	2
Boarding homes/Board and care	1	2	1	1	0	0	0	0	0	0
Unknown/Other	7	10	7	6	7	6	4	14	18	25
Total	100	100	97	101	100	100	100	100	100	100

Note: Previous residence was reported by 70 facilities for 905 (86.9%) of an estimated 1,014 new admissions in FY 2016. In FY 2016, own home was merged with Independent/Supported/Semi-Independent Living and Boarding Homes/Board and Care was removed.

Figure 4.15 Previous Place of Residence for People Newly Admitted to a Large State IDD Facilities in Percent Selected Years: 1985 to 2016



Readmissions

In 1985, 49% of all people readmitted to PRFs came from an individualized setting (mostly family homes; See **Table 4.20** and **Figure 4.16**). By 2016, the proportion readmitted from an individualized settings had declined to 21%. The proportion readmitted from an IDD setting of 16 or more people declined from 16% in 1985 to 9% in 2016. The proportion readmitted from a non-IDD facility (primarily mental health facilities) increased from

13% to 34%. In 1985, 22% of people readmitted to PRFs came from an IDD group home of 15 or fewer people. By 2016, 36% came from IDD settings of 15 or fewer people (nearly all from group homes of 6 or fewer people).

Discharges

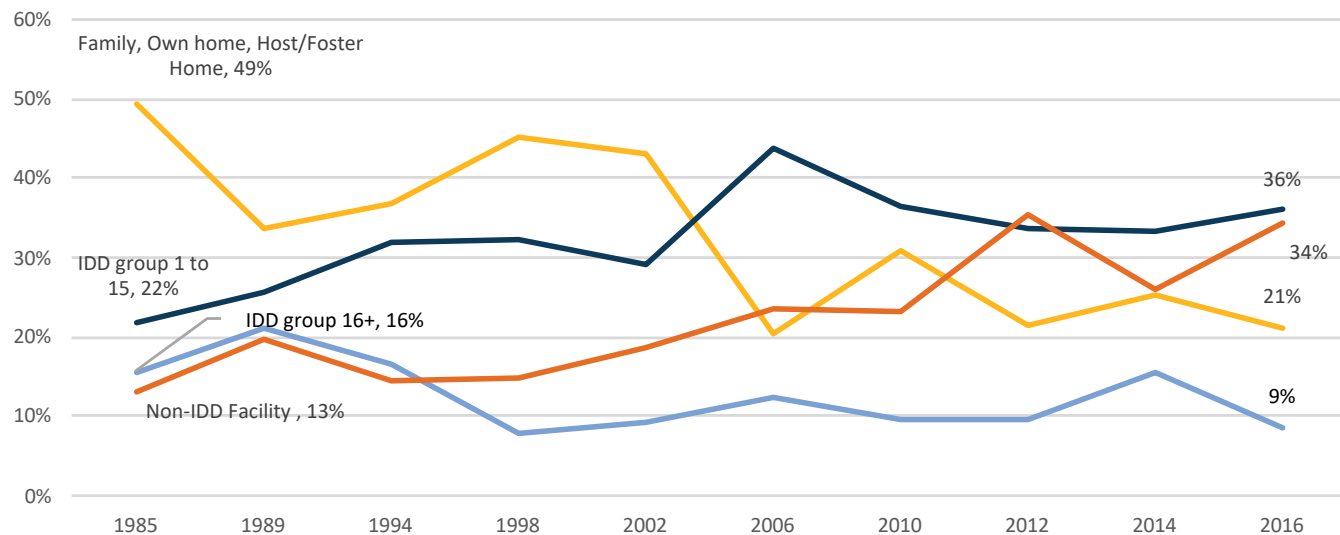
The proportion of people discharged from PRFs to an IDD group setting of 15 or fewer people declined

Table 4.20 Previous Place of Residence of Persons Readmitted to Large State Facilities (in percent): Selected Fiscal Years 1985 to 2016

Previous Residence Type (Size)	Year									
	1985	1989	1994	1998	2002	2006	2010	2012	2014	2016
Home of parents or relative	37	20	27	34	28	11	14	12	7	12
Own Home - Independent/Supported/Semi-independent Living	1	1	3	4	6	8	11	6	10	1
Foster home	7	9	5	6	7	1	2	0	2	2
Group home (1-6 res.)								16	19	23
Group home (7-15 res.)								12	6	2
Group home (15 or fewer res.)	20	23	30	31	27	41	32	28	25	26
Group IDD facility (16-63 res.)	4	2	5	3	3	4	3			
Nonstate IDD facility (64+ res.)	3	3	2	1	1	1	2			
State IDD facility (64+res.)	7	14	9	5	5	7	3			
State IDD facility (16+ res.)								4	10	4
Nonstate IDD facility (16+ res.)								4	2	2
Mental health facility	9	13	8	9	8	7	11	19	11	21
Nursing facility	2	3	2	3	4	6	2	7	5	1
Correctional facility	0	1	3	3	4	8	8	4	4	3
Boarding homes/Board and care	1	1	1	0	1	1	0	0	0	
Unknown/Other	10	10	6	3	7	6	12	16	26	29
Total	100	100	100	100	100	100	100	100	100	100

Excludes people whose previous setting was not known.

Figure 4.16 Previous Place of Residence for People with IDD Readmitted to a Large State Facility (in Percent): Selected Years 1985 to 2016



from 42% in 1985 to 31% in 2016 with most moving to a setting of 6 or fewer people (See **Table 4.21** and **Figure 4.17**). The proportion of people discharged from PRFs to an individualized setting declined from 27% in 1985 to 17% in 2016. Most people moving to an individualized setting between 1985 and 2002, and in 2016 moved to the home of a family member. The proportion of people discharged from PRFs to

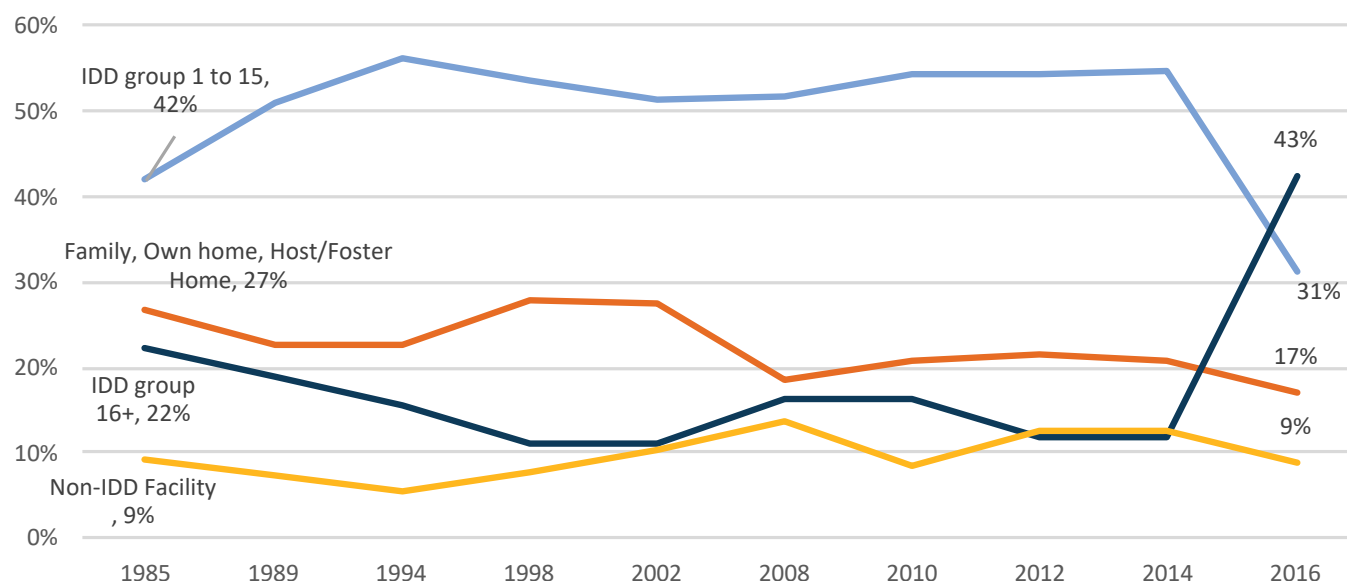
another IDD facility of 16 or more people declined from 22% in 1985 to 12% in 2014, but increased to 43% in 2016. In 2016 most of the moves to an IDD facility of 16 or more people were from one PRF to another PRF. Finally, the proportion of people discharged from PRFs who moved to a non-IDD facility was 9% in both 1985 and in 2016 and did not vary much from year to year.

Table 4.21 Subsequent Residence of People with IDD Discharged From a Public IDD Facility: Selected Years 1985 to 2016

New Place of Residence	Percent of People Discharged by Year									
	1985	1989	1994	1998	2002	2006	2010	2012	2014	2016
Independent/Supported/Semi-independent Living	1	2	5	9	7	8	11	10	10	2
Home of parents or relative	17	12	9	11	14	7	8	8	7	10
Foster/host family home	7	7	9	6	4	2	1	2	2	2
Group home (1-6 res.)								44	44	22
Group home (7-15 res.)								6	6	4
Group home (15 or fewer res.)	40	49	56	51	46	47	51	50	50	25
Group IDD facility (16-63 res.)	7	5	4	4	2	6	5			
Nonstate IDD facility (64+ res.)	10	10	9	6	7	7	9			
State IDD facility (64+res.)	4	3	2	1	1	1	1			
State IDD facility (16+ res.)								2	2	31
Nonstate IDD facility (16+ res.)								9	9	4
Nursing facility	4	2	3	3	4	6	5	2	2	1
Correctional facility	0	1	0	0	3	2	2	7	7	3
Mental health facility	1	1	1	2	2	4	2	2	2	3
Boarding homes/Board and care	3	2	1	3	1	1	0	1	1	
Unknown/Other	4	4	6	5	9	10	6	8	8	20

Blank spaces indicate years the survey did not ask about a residence type.

Figure 4.17 Subsequent Residence of People with IDD Discharged From a Public IDD Facility Selected Years 1985 to 2016



Excludes people whose subsequent residence was other or unknown (which was much higher in 2016 than previously)

Services Provided by PRFs to People Not Living in PRFs 2000-2016

PRFs have historically provided some services to people with IDD living in other settings (See **Table 4.22** and **Figure 4.18**). The average number of direct services provided to people not living in the PRF declined from 5.5 per facility in 2000 to 2.0 per facility in 2016. The proportion of facilities reporting they provided none of the listed services to non-residents increased from 9% in 2000 to 46% in 2016. In 2000, the most common types of services provided to non-residents were respite (reported by 56% of facilities), behavioral assessment and intervention (51%), crisis supports (44%) and dental services (41%). By 2016, the proportion of PRFs offering any of those services had declined by more than half. The most common services provided by PRFs to non-residents in 2016 were behavioral assessment and intervention (26% of facilities), dental (26%), and crisis support (19%).

The number of topics on which PRF staff assist or train community service providers declined from an average of 4.1 per PRF in 2000 to an average of 1.3 per PRF in 2016 (See **Table 4.23** and **Figure 4.19**).

The proportion of PRFs that provided no training or technical assistance to community service providers increased from 8% to 64% between 2000 and 2016. In 2000, the most common topics in which training or technical assistance were provided by PRF staff were behavioral assessment and intervention (offered by 54% of PRFs), assistive technology assessment and intervention (38%), crisis support services (35%), and health services (26%). The proportion of PRFs offering training or technical assistance on any of these topics dropped by more than half by 2016. The most common topics in 2016 were behavioral assessment and intervention (offered by 22% of PRFs), crisis support services (17%), and consultant health services (10%).

The decline in provision of direct services to people not living in PRFs and in provision of training or technical assistance by PRF staff are signs of a changing system. Many states have taken advantage of flexible Medicaid funding options to shift from institution-based to community-based models of supports and no longer rely on PRFs for any of these functions. The remaining states still have work to do to build a robust infrastructure to serve people with IDD in home and community-based settings.

Table 4.22 Percent of PRFs Providing Services to People Not Living On-Campus by Type of Service 2000 to 2016

Type of Service	Year									
	2000	2002	2004	2006	2008	2010	2012	2014	2016	
Behavioral assessment and intervention	51	48	40	53	51	52	33	29	26	
Dental	41	39	34	43	32	38	32	24	26	
Crisis support	44	41	30	40	42	37	26	22	19	
Recreation	24	25	16	48	29	27	20	16	15	
Respite	56	50	38	17	46	38	23	21	14	
Family support/Home visitation by staff	38	41	24	36	44	39	20	18	11	
Assistive technology assessment and intervention	33	29	30	39	35	21	20	12	11	
Personal/Social Counseling				19	24	21	10	18	10	
Diagnostic services	36	30	26	32	33	21	19	17	10	
Vocational training	25	31	26	9	29	24	21	20	9	
Consultant health services	29	28	25	32	25	22	14	22	7	
Physical therapy	20	18	15	13	18	19	12	11	7	
Other	15	11	10	10	7	9	12	5	7	
Medical and/or nursing treatment	22	25	18	25	22	16	17	12	6	
Audiological assessment and intervention	26	26	21	23	17	19	6	10	6	
Speech services	19	20	20	25	14	21	18	10	5	
Self-help or developmental classes	15	13	11	13	20	17	8	7	5	
Primary health care	10	8	8	25	7	9	10	11	4	
Sex education	9	11	8	24	9	9	4	4	2	
Offer none of the listed services	9	8	21	6	18	18	41	42	46	
Average number of services provided	5.5	4.9	4.0	5.1	4.8	4.4	3.3	2.8	2.0	

N = 78-94 facilities reporting. Each facility could report offering multiple types of services.

Figure 4.18 Percent of PRFs Offering Behavioral Assessment, Dental, Crisis Support, or Respite Services to People with IDD not Living On-Campus 2000 to 2016

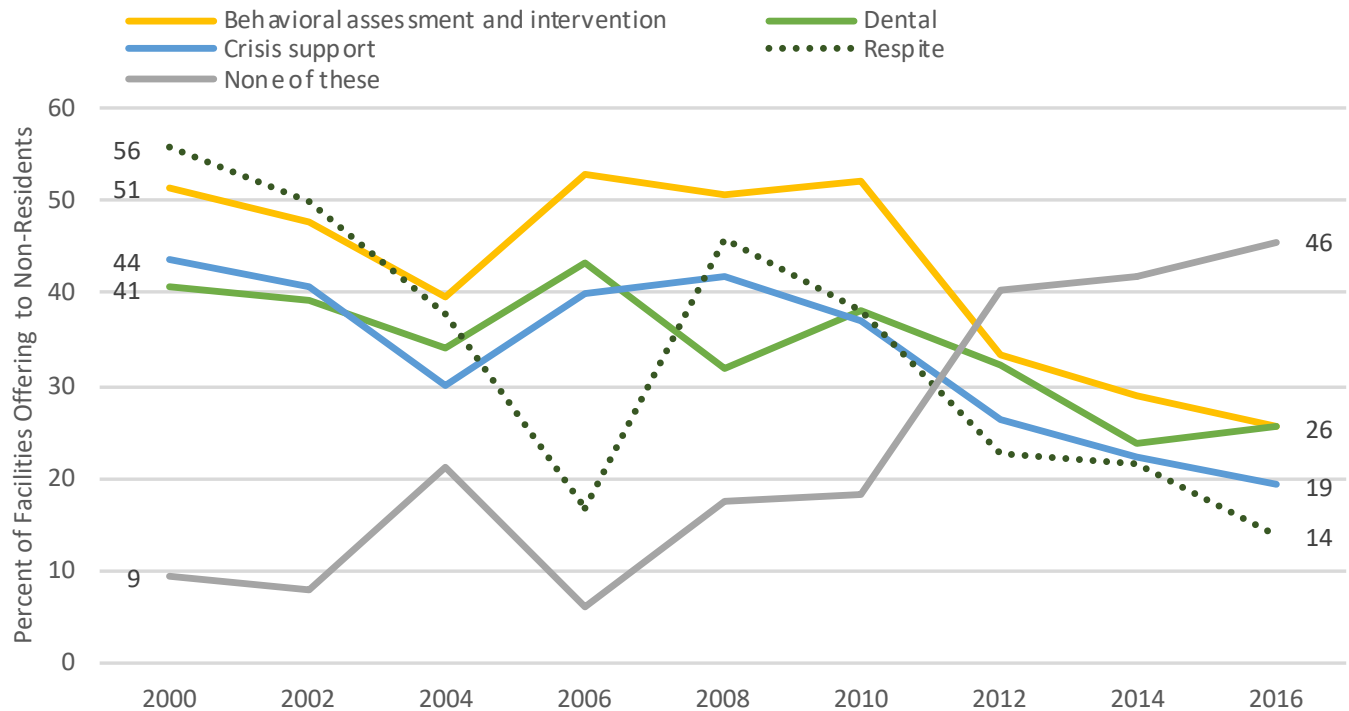


Table 4.23 Percent of PRFs Offering Training or Technical Assistance to Community Service Providers by Topic 2000 to 2016

Training/Technical Assistance Topic	Year									
	2000	2002	2004	2006	2008	2010	2012	2014	2016	
Behavioral assessment and intervention	54	44	33	47	44	39	26	31	22	
Crisis support services	35	35	26	36	35	27	19	25	17	
Consultant health services	26	33	19	26	18	22	12	14	10	
Assistive technology assessment and intervention	38	34	22	31	32	25	18	15	9	
Respite	9	8	8	15	4	10	4	7	8	
Dental services	10	10	10	13	8	16	8	7	7	
Personal/Social Counseling				13	9	15	5	13	7	
Family support/Home visitation by staff	24	16	15	17	10	17	14	17	5	
Diagnostic services	20	21	15	17	24	18	8	8	5	
Recreation	17	16	10	8	9	13	6	11	5	
Physical therapy	17	20	14	9	11	18	12	10	5	
Speech services	20	24	15	12	11	17	12	11	5	
Self-help or developmental classes	19	18	13	10	11	15	8	10	5	
Medical and/or nursing treatment	20	20	15	19	22	13	12	9	4	
Primary health care	11	10	6	13	8	12	6	3	4	
Audiological assessment and intervention	15	16	8	9	6	13	8	6	4	
Other	9	10	6	8	7	6	5	6	4	
Vocational training	20	16	9	8	17	11	10	10	3	
Sex education	15	9	10	15	7	10	2	6	3	
No services provided to people not living at the facility	8	9	21	29	34	49	55	53	64	
Average number of services provided	4.1	3.6	2.5	3.1	2.8	3.0	2.0	2.1	1.3	

N = 69-92 facilities reporting for indirect services

Figure 4.19 Percent of PRF's Providing Training or Technical Assistance to Outside Organizations by Topic 2000-2016

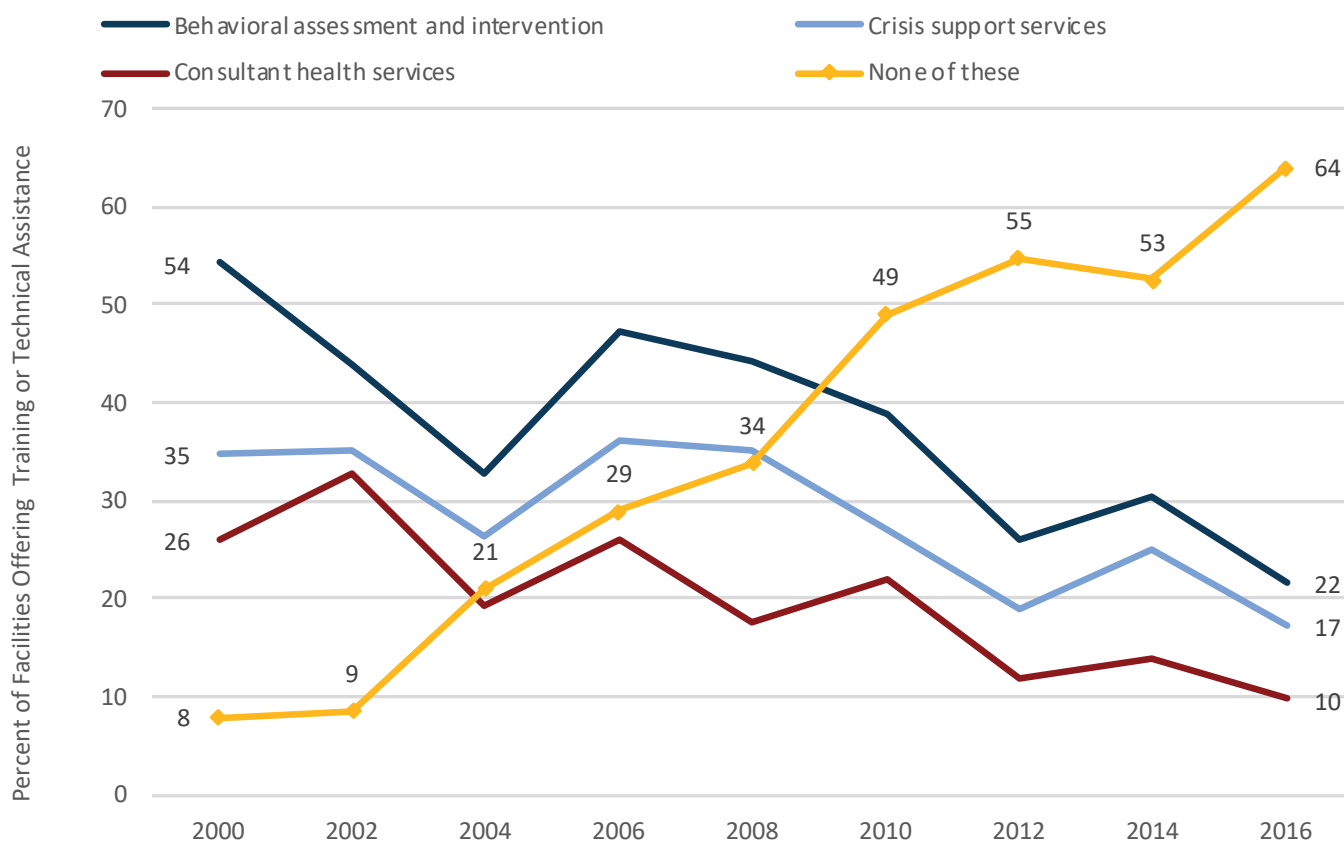


Table 4.24 Direct Support Professional and Frontline Supervisor Vacancy and Turnover Rates, Wages and Salary in Large State-Operated IDD Facilities Between FY 2004 and FY 2016

Staffing Characteristics	Year						
	2004	2006	2008	2010	2012	2014	2016
DSP Vacancy Rate (%)	6%	7%	7%	6%	8%	8%	11%
DSP Turnover Rate (%)	29%	27%	30%	24%	33%	33%	33%
DSP Starting Hourly Wage	\$10.1	\$11.1	\$11.4	\$12.0	\$12.0	\$12.5	\$13.0
DSP Average Hourly Wage	\$12.5	\$13.2	\$14.1	\$14.8	\$14.7	\$14.8	\$16.0
FLS Vacancy Rate	7%	5%	6%	6%	7%	8%	10%
FLS Turnover Rate	18%	13%	12%	10%	14%	14%	17%
FLS Starting Salary	\$27,397	\$29,914	\$30,979	\$35,228	\$33,118	\$34,732	\$36,396
FLS Average Salary	\$33,299	\$35,783	\$36,924	\$42,590	\$38,062	\$41,132	\$43,374

DSP Direct Support Professional; FLS Frontline Supervisor

PRF Staffing Characteristics 2004-2016

As the number and size of PRFs declined between 2004 and 2016, staffing outcomes also changed (See **Table 4.24**). Vacancy rates for Direct Support Professional (DSP) positions increased from 6% in 2004 to 11% in 2016 and DSP turnover rates increased from 24% in 2010 to 33% in 2016. DSP starting and average wages increased slightly from \$10.12 and \$12.53 in 2004 to \$12.96 and \$15.99 in 2016.

Similar changes occurred for Front Line Supervisors (FLS). FLS vacancy rates increased from 5% in 2006 to 10% in 2016. Turnover rates for FLS were at a low of 10% in 2010, but were 17% in 2016. FLS starting and average salaries increased from \$27,397 and \$33,299 respectively in 2004 to \$36,396 and \$43,374 respectively in 2016. ■



SECTION FIVE

STATE NOTES AND PROFILES

FY 2016

SECTION 5: STATE NOTES AND PROFILES

STATE NOTES

Alabama

In FY 2015, people waiting for, but not receiving LTSS were excluded from the count of people living in the home of a family member. For FY 2014 and FY 2016, those individuals were counted.

Alaska

The ICF/IID recipients served by the Alaska IDD agency live in another state.

Arizona

In FY 2016, Arizona changed the way they reported the number of people in family home versus other settings by age (21 and under and 22 and over), so numbers may differ than in the past (See **Table 2.7**).

Arizona manages ICF/IID settings within their 1115 Managed Care Demonstration Waiver.

California

The age categories reported for large state-operated IDD facilities in California were 22 to 31 years, 32 to 41 years, 42 to 51 years, 52 to 61 years, and more than 61 years.

Colorado

Changes in the caseload between FY 2014 and FY 2016 reflect year-to-year variations in the number of people enrolling in Supported Living Services. Colorado's two state-operated facilities of 16 or more people (Grand Junction Regional Center and Wheat Ridge Regional Center) operate units both on the campus and in the community. The people in nonstate "other" facilities live in Personal Care Alternative settings alone or with one other service recipient. The setting is often the home of a relative.

Connecticut

The waiting list is not limited to people requesting Medicaid Waiver. 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.

Connecticut reported six state-operated ICF/IID facilities with 16 or more people two of which closed before June 30, 2016. Admissions and readmissions reflect individuals entering all regional centers.

Delaware

Beginning in FY 2013, people receiving Family Support Specialist services were counted as living in the home of a family member.

Florida

The total number of people in IDD Group Settings does not include 956 people for whom setting size was unknown.

Georgia

For FY 2016, the Gracewood and Augusta Campuses of the East Central Regional Hospital submitted a combined PRF survey.

On **Table 2.9**, an estimated 284 people living in state-operated ICF/IID facilities are not shown.

Idaho

Idaho redesigned its children's IDD Waiver program resulting in a large increase in the number of people ages birth to 21 years receiving Waiver-funded supports beginning in FY 2015. Some nonstate group homes serve multiple populations. Only people with IDD in those homes are reported.

Illinois

Prior to FY 2016, some people who were receiving Medicaid Waiver-funded supports were included in the Medicaid Waiver waiting list count. The number of people waiting dropped in FY 2016 due to an administrative clarification.

People living in PRFs who are 21 years old are reported with the 22 years or older group.

Indiana

Indiana expanded its Family Supports Waiver to serve more people ages 21 years or younger. This change reduced the length of time that individuals and their families wait for services. Because the

Family Supports Waiver has an annual cap on the costs of an individual's service, and does not include a residential component, average Waiver expenditures per person also declined.

Kansas

Two people living large state-operated ICF/IID settings are not Medicaid-eligible. Their services are state-funded.

Between FY 2013 and FY 2016, the number of people in ICF/IID settings was reported for both state and nonstate facilities, but expenditures were reported only for nonstate facilities. Average per person expenditures were calculated based only on people in nonstate facilities and are therefore underestimated.

Kentucky

The number of people on the IDD caseload with services funded through the state general fund was estimated.

The number of Type II (Group Home) and Type III (Host/Family Foster Care) residences was estimated based on the total number of providers, assuming residences were at or near capacity.

As many as 10,000 Waiver recipients live in their own home or the home of a family member. However the number of Waiver recipients in own home versus home of a family member is not available.

Alternate data sources were used for number of ICF/IID recipients by age (AHCA, 2017a).

The Outwood and Oakwood IDD facilities were privatized prior to FY 2016 and but were not removed from the RISP list of open list of public residential facilities until FY 2016.

Maine

Setting size information was not available for 275 people in IDD Group Settings.

Four short-term state-operated facilities are not counted for the RISP report since no residents stay for more than 90 days.

Medicaid expenditures for FY 2013 were based on the authorized budget, but for FY 2014-2016 were based on paid claims.

Maryland

People living in "nonstate other" settings receive Community Coordination Services, Behavior Support Services (BSS), Residential, Individual Family Care (IFC), or self-directed supports.

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

Beginning in FY 2015, the number of service recipients by setting type does not include people 21 years or younger receiving LTSS while living with a family member.

Michigan

Michigan used FY2015 data for FY2016.

Setting size information was not available for 8,303 people in IDD Group Settings (See **Table 1.7**).

The "nonstate other" category includes 1,216 people eligible for Medicaid or State funded LTSS of whom 26 are homeless, in prison, or living in other institutional settings.

Michigan began reporting the number of 1915(b/c) waiver recipients in FY 2011 accounting for the jump in waiver recipients for that year.

Minnesota

Minnesota used FY2015 data for FY2016.

Nonstate other settings include Customized Living (Assisted Living) and Board and Care. Most Customized Living arrangements are Medicaid Waiver-funded.

In FY 2015, 416 family foster care homes were reclassified as corporate foster care settings with shift staff while still serving the same individuals at the same address. Nonstate group homes are corporate foster care settings where people with IDD or other health conditions reside. Minnesota tracks the number of people who receive long-term supports and services for settings of 1-4 people typically, and under certain circumstances up to five people with IDD or other mental and physical health

conditions. Setting size information based on claims is not available for settings of 1-3 and 4-6 people, but is reported for settings of 1-6 people. The most reliable number for people with IDD in nonstate group homes is for setting size 1-6.

Mississippi

Alternate data sources were used for the number of people with IDD in nursing homes (AHCA, 2017c).

ICF/IID recipients and expenditures by age and by setting size only include state-operated ICF/IID settings from FY 2013 through FY 2016. The IDD agency oversees state-operated ICF/IID, but the Department of Health oversees nonstate-operated ICF/IID.

Missouri

State general revenue funds are appropriated for in-home supports and services to families through regional autism projects.

The use of host/foster family homes expanded beginning in FY 2013.

Missouri received a large appropriation in FY 2015 to eliminate its in-home waiting list. MO also received supplemental funding late in FY 2014 to attend to increased demand for crisis placements.

Montana

Children ages 1-3 receiving Part C and/or Social Services Block Grant (Title XX) funding are included in the caseload beginning in FY 2016.

People waiting for services who received case management services were not included in the caseload in FY 2014. All people with DD served by the state IDD agency who are 16 years or older are entitled to Medicaid State Plan-funded Case Management services.

Prior to FY 2013, the number of nonstate group home settings serving one to three people was significantly over counted. The numbers reported from FY 2013 onward have been corrected.

Nebraska

The number of large state-operated facilities varies across tables because the Beatrice State Development Center is sometimes reported as a

single campus and other times as four separately licensed buildings.

Nevada

Nevada does not recognize or offer “group home” services for people with IDD.

The “nonstate other” category includes hospitals, correctional/ incarceration facilities, and rehabilitation centers serving 16 or more people. Those settings served multiple populations not just people with IDD.

New Hampshire

New Hampshire used FY2015 data for FY2016.

New Hampshire updated their ICF/IID expenditure data for FY 2015 and FY 2016. The average annual per person expenditures for FY 2014 and FY 2015 were reported incorrectly in the FY 2014 and FY 2015 RISP report.

New Jersey

The IDD agency caseload decreased between FY 2014 and FY 2015 as 2,000 people who were not receiving or requesting services were moved off the caseload because they declined to seek eligibility.

The caseload and people living in the family home decreased from FY 2013 to FY 2014 because services for children were moved to the Division of Children and Family.

Twelve people with developmental disabilities are housed in a separate building at an ICF/IDD as they have been convicted of crimes and have been court ordered to be in a disability rehabilitation setting. These people are reported as living in an “Other Funded” facility.

ICF/IID recipients and expenditures included only state-operated ICF/IID settings by age from FY 2013 through FY 2016.

New Mexico

The number of nonstate-operated ICF/IID, group homes, and host/foster family settings are estimated based on reports from five providers operating residences with 1 to 4 occupants, assuming those settings operate at or near capacity.

The transition to a new Third Party Assessor produced extended delays in processing DD Waiver claims,

delaying services for people waiting for Medicaid Waiver-funded supports in FY 2015 and FY 2016.

Alternative data sources were used for ICF/IID residents (AHCA, 2017a).

New York

The number of people waiting to live in a non-family setting includes only those who indicated they wanted to move within two years from when they were last interviewed by Office for People with Developmental Disabilities (OPWDD) staff.

The methodology used to estimate the number of Medicaid Waiver recipients in family or non-family settings by age changed for FY 2016.

New York operated 6 large IDD residential campus facilities and 18 community ICF/IID facilities serving 16 people or more people as of June 30, 2016. The 18 state-operated community ICF/IID facilities are not included in the sample for the PRF survey.

North Carolina

The number of settings and recipients in nonstate settings for FY 2016 was reported by six of the eight Local Management Entities/Managed Care Organizations (LME-MCO).

North Carolina increased the use of (b)(3) services under its Medicaid 1915 b/c waiver in FY 2016.

Expenditures were reported for most but not all people in ICF/IID settings.

North Carolina has four state-operated ICF/IID facilities with 16 or more individuals: Caswell Center, J. Iverson Riddle Development Center, Murdoch Developmental Center, and O'Berry Neuro-Medical Treatment Center (OBNMTC). The Black Mountain Center, a large state-operated Skilled Nursing Facility, is not ICF/IID certified and is not counted on **Table 1.8**.

North Dakota

Medicaid Waiver recipients receiving day and employment services but not in-home or residential services are include in the count of Waiver recipients, but their living arrangements are not reported.

Ohio

Setting size information was not available for 950 people in Nonstate Other IDD Group Settings in FY 2016 (See **Table 1.7**). Those people are counted in the total on **Table 1.9**. Those individuals live in other, unknown or temporary living arrangements.

The waiting list included people waiting for Medicaid Waiver-funded supports who were not already Medicaid Waiver or ICF/IID recipients. It included some people living in non-family settings.

Oklahoma

Oklahoma has four Medicaid Waivers. For two waivers, total annual expenditures are capped at a rate similar to that paid for services in a nonstate institution. The other two comprehensive Waivers serve only people with high needs and have higher annual expenditure caps.

Oregon

Oregon began offering home and community based services through the Medicaid State Plan 1915(k) funding authority in FY 2015. Total Medicaid Waiver recipients and expenditures declined as recipients moved from Waiver to State Plan 1915(k) funding.

Pennsylvania

All Medicaid Waiver recipients with housing services in FY 2016 were included in the setting type and total recipient sections. Expenditures and cost per person only included people with Waiver funding on June 30, 2016.

South Carolina

The Pee Dee Regional & Thad E. Saleeby Centers submitted one joint PRF survey for FY 2015 and FY 2016 (See **Table 4.23**).

Tennessee

The people counted as waiting to live in a setting other than the home of a family member are those with a crisis or urgent need.

Texas

The fiscal year ends on August 31 (rather than June 30) in Texas.

Texas uses an interest list, instead of a waiting list. Anyone can sign up for the interest list. People on the list are not evaluated for eligibility until their name is reached.

Alternative data sources were used for the number of people in nursing facilities (AHCA, 2017c).

Washington

The number of people in Own Home settings was lower in FY 2014 and FY 2015 because data were not available for all funding authorities.

Washington adopted and 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.

Wisconsin

Wisconsin used FY2015 data for FY2016.

Setting size information was not available for 34 people in IDD Group Settings (See **Table 1.7**).

Total caseload reported increased in FY 2015 due to inclusion of children not receiving services.

The number of adults in own home and family home settings is estimated based on a ratio, derived from functional screening data collected from each individual annually, but it is not specific to June 30.

Beginning in FY 2014, the number of people living in own home, family home and nonstate other settings includes LTSS recipients whose services are not funded by a Waiver. Prior to FY 2013, only waiver recipients in those settings were counted.

There are three large state-operated IDD facilities in WI (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 be in the facility beyond 90 days.

Wyoming

Only people receiving Medicaid Waiver-funded supports are counted in the nonstate group home, host/foster family home, and own home setting types. LTSS recipients with IDD in those settings whose supports were funded by another funding authority are not included.

In FY 2014, Wyoming completed their waiver redesign project, which included several cost cutting measures. Since most participants that were actively enrolled during FY 2015 did not have complete plans, providers did not bill for services. As a result, expenditures declined temporarily even as the number of participants increased.

STATE PROFILES

Profiles for each state and for the United States describe LTSS recipients and expenditures for people with IDD in FY 2016 and trends in the provision of LTSS by state IDD agencies in selected years from FY 1977 to FY 2016.

Reading the State Profiles

Unless otherwise noted, the profile shows values furnished by the state IDD agency. 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. The 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.

Figure 1 shows the number people living in Medicaid Intermediate Care Facilities for People with Intellectual Disabilities (ICF/IID) between 1977 and 2016 and the number of Medicaid Waiver recipients with IDD between 1982 and 2016.

Figure 2 shows the average annual per person Medicaid ICF/IID and Waiver expenditures for the year ending June 30, 2016.

Figure 3 shows the number of LTSS recipients with IDD living in various residential settings on June 30, 2016. Setting types include the home of a family member, a person's own home, a host/foster family home, and IDD group settings by the number of LTSS recipients per home (1 to 3, 4 to 6, 7 to 15, or 16 or more people). Data may be shown for the 1 to 6 people category even if a state did not furnish complete data for settings of 1 to 3 people and 4 to 6 people.

The table shows the number of LTSS recipients with IDD living in settings of various types and sizes, and the number of people on the IDD agency caseload, or receiving or waiting for LTSS by year. It also shows average annual per person Medicaid Waiver and ICF/IID expenditures, and Medicaid Waiver and ICF/IID recipients per 100,000 of the state's population.

Data on ICF/IID and Medicaid Waiver recipients and expenditures for years not shown can be viewed in the Chart Gallery of the RISP.umn.edu website. Survey questions and operational definitions can be found in the Publications section of the same website. See the FY 2016 report text for details about methodological changes that may have changed values reported from one year to the next (particularly for the waiting list questions). ■

RISP Profile FY 2016

Alabama

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

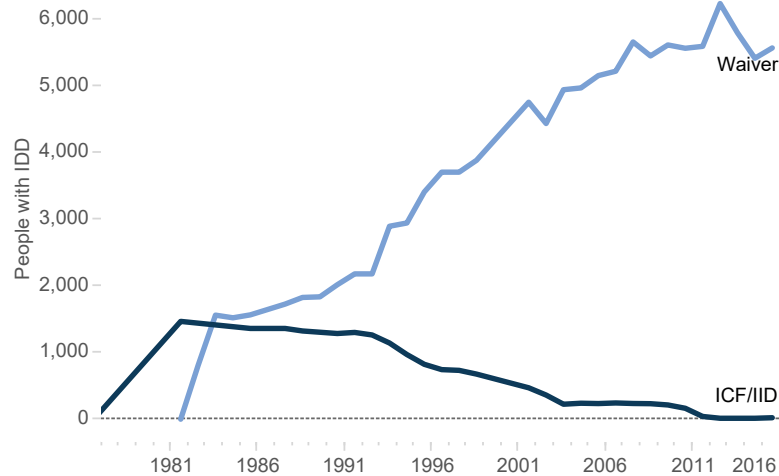


Figure 2: Medicaid Spending Per Person FY 2016

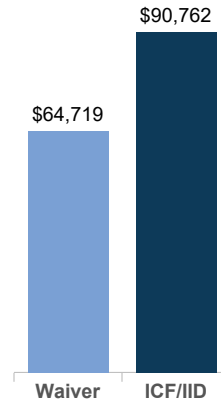


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

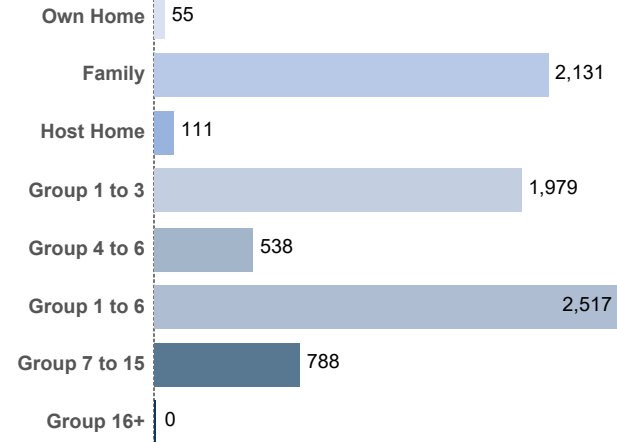


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				222	213	127	110	132	96	55
	Family				3,441	3,659	1,895	2,324	2,512	480	2,131
	Host Home				247	220	166	205	210	175	111
	Group 1 to 3				1,202	1,715	2,110	2,047	1,931	2,055	1,979
People in Congregate Settings	Group 4 to 6				399	488	527	467	403	447	538
	Group 1 to 6	49	121	295	1,601	2,203	2,637	2,514	2,334	2,502	2,517
	Group 7 to 15	61	183	585	897	907	816	709	644	742	788
	Group 16+	1,995	1,639	1,258	214	173	0	0	0	0	0
People Served by the DD Agency *	Caseload (known to the DD agency)							9,246	9,018	8,893	8,904
	LTSS Recipients (1)	2,105	1,943	2,138	6,622	7,375	6,495	5,862	5,832	3,995	5,602
	Waiting for Medicaid Waiver				807	2,372	2,901	2,975	3,186	3,432	3,324
People in Non-DD Settings *	Nursing Facility (s)			1,321	971	777	854	901	926	935	935
	Psychiatric Facility (2)			0	0	0	0	0	0	50	73
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$6,136	\$44,111	\$48,505	\$51,517	\$50,434	\$54,844	\$59,742	\$64,719
	ICF/IID Expenditures per Person			\$56,475	\$113,534	\$162,893	\$19,232	\$127,455	\$78,035	\$67,563	\$90,762
	Waiver Recipients per 100,000			49.4	109.2	117.7	116.2	129.2	119.7	111.6	114.7
	ICF/IID Residents per 100,000			31.5	5.3	4.5	0.9	0.3	0.3	0.3	0.5

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

(2) Includes only state operated psychiatric facilities until 2013.

(s) Data may be from an outside source.

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

DNF = Did Not Furnished.

PD = Partial Data.

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

RISP Profile FY 2016

Alaska

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

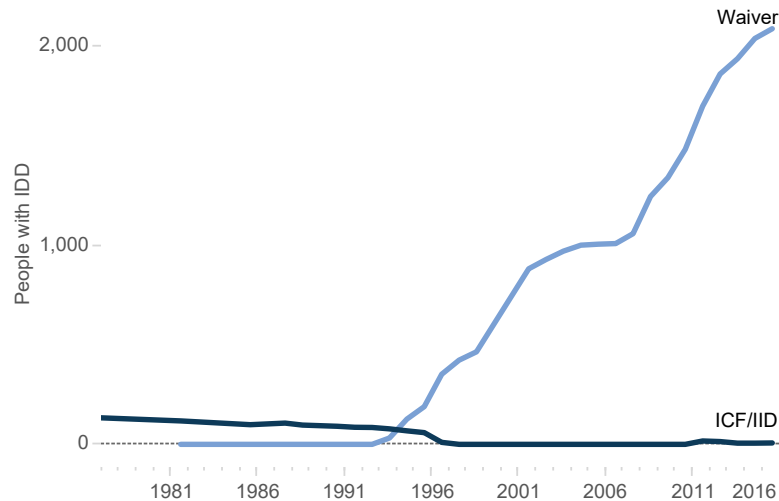


Figure 2: Medicaid Spending Per Person FY 2016

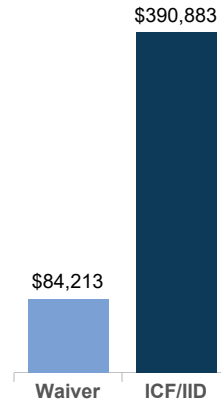


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

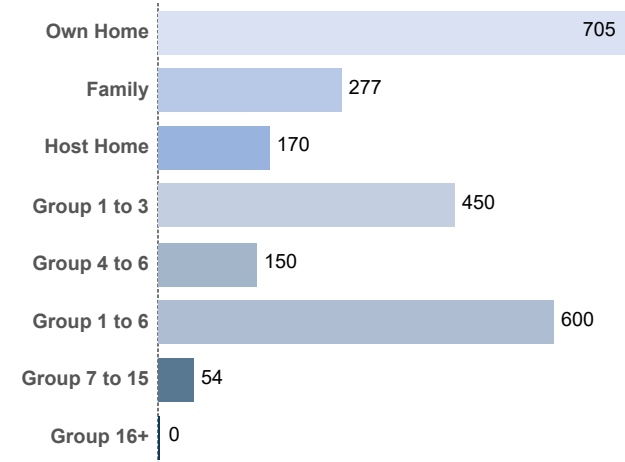


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				224	399	473	205	411	687	705
	Family				3,700	231	292	332	332	282	277
	Host Home				172	209	218	165	203	198	170
	Group 1 to 3				239	234	300	200	400	400	450
People in Congregate Settings	Group 4 to 6				201	106	128	150	128	150	150
	Group 1 to 6	53	122	291	440	340	428	350	528	550	600
	Group 7 to 15	17	38	37	0	5	0	50	0	58	54
	Group 16+	173	88	51	0	11	0	15	0	0	0
People Served by the DD Agency *	Caseload (known to the DD agency)							2,477	2,714	2,793	2,636
	LTSS Recipients (1)	243	248	379	4,536	1,195	1,421	1,131	1,480	1,781	1,813
	Waiting for Medicaid Waiver				1,400	662	461	613	679	743	537
People in Non-DD Settings *	Nursing Facility (s)			48	8	20	10	0	0	0	0
	Psychiatric Facility (2)			1	0	0	0	0	0	0	0
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$0	\$62,822	\$75,164	\$78,988	\$81,214	\$73,950	\$82,287	\$84,213
	ICF/IID Expenditures per Person			\$109,041	\$0	\$0	\$179,453	\$227,985	\$509,213	\$420,989	\$390,883
	Waiver Recipients per 100,000			0.0	151.1	189.1	232.8	253.7	263.6	276.8	282.1
	ICF/IID Residents per 100,000			16.0	0.0	0.0	2.3	1.9	0.8	0.8	0.9

(1) Long Term Supports and Service (LTSS) recipients may include imputed values; Until 2012 LTSS recipients may include people in nursing homes or psychiatric facilities who were not on the IDD agency caseload.
 (2) Includes only state operated psychiatric facilities until 2013.
 (s) Data may be from an outside source.

Settings by size includes ICF/IID, group homes, and nonstate other.
 DNF = Did Not Furnish.
 PD = Partial Data.
 * See state notes and the RISP report for further explanation.



RISP Profile FY 2016

Arizona

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

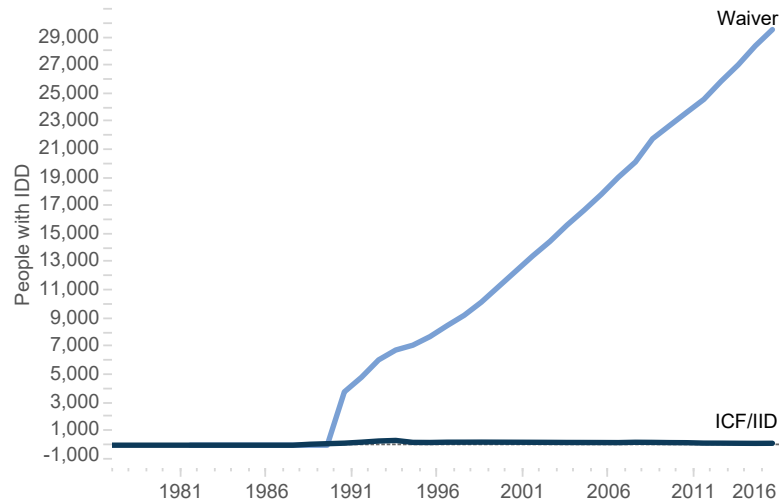


Figure 2: Medicaid Spending Per Person FY 2016

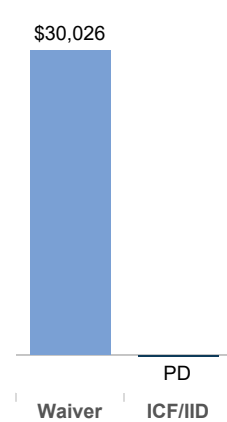


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

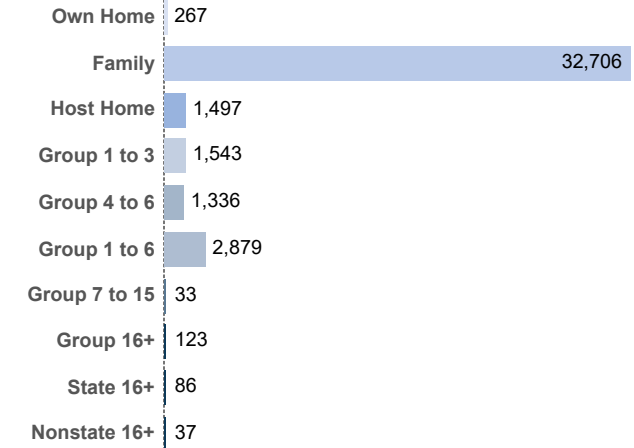


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				434	454	439	456	282	265	267
	Family				20,914	26,185	27,983	28,198	29,369	31,151	32,706
	Host Home				749	1,166	1,281	1,543	1,462	1,397	1,497
	Group 1 to 3				1,342	1,422	1,463	1,494	1,575	1,626	1,543
People in Congregate Settings	Group 4 to 6				1,058	1,117	1,166	1,182	1,242	1,090	1,336
	Group 1 to 6	120	689	2,263	2,400	2,539	2,629	2,676	2,817	2,716	2,879
	Group 7 to 15	116	137	91	40	32	25	25	25	33	33
	Group 16+	1,216	907	238	181	153	143	141	134	122	123
People Served by the DD Agency *	Caseload (known to the DD agency)							33,079	33,933	35,685	37,433
	LTSS Recipients (1)	1,452	1,733	2,592	24,718	30,529	32,573	33,149	34,189	35,786	37,605
	Waiting for Medicaid Waiver				173	29	79	414	238	184	211
People in Non-DD Settings *	Nursing Facility (s)			89	53	49	73	40	39	37	50
	Psychiatric Facility (2)			0	0	2	0	0	0	DNF	0
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$21,112	\$23,866	\$26,632	\$26,030	\$27,305	\$29,139	\$29,119	\$30,026
	ICF/IID Expenditures per Person			\$33,590	\$99,082	DNF	\$220,223	\$185,859	\$217,216	\$210,019	PD
	Waiver Recipients per 100,000			101.2	281.6	356.0	375.6	390.8	402.2	416.2	426.8
	ICF/IID Residents per 100,000			3.9	3.2	2.9	2.3	2.2	2.0	1.9	2.0

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

(2) Includes only state operated psychiatric facilities until 2013.

(s) Data may be from an outside source.

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

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PD = Partial Data.

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RISP Profile FY 2016

Arkansas

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

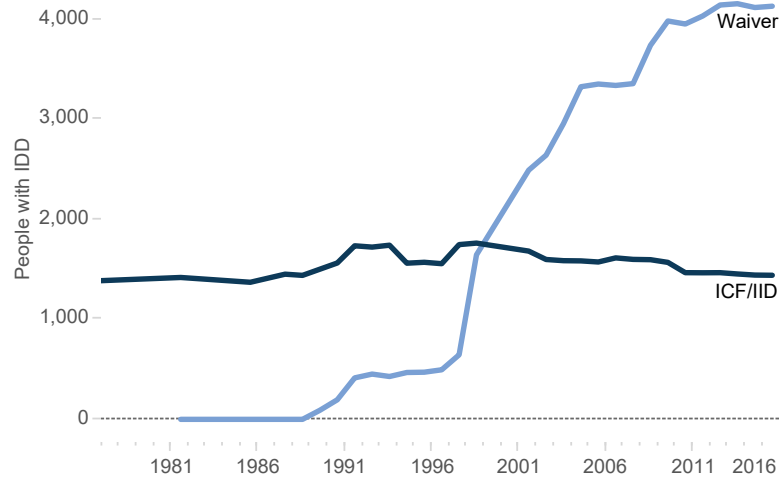


Figure 2: Medicaid Spending Per Person FY 2016



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

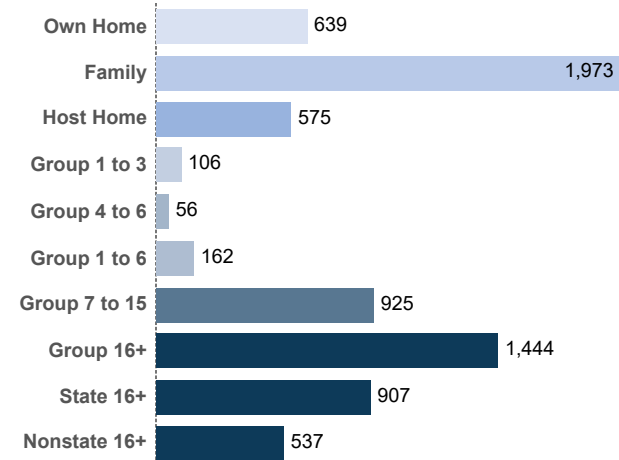


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				534	641	642	633	639	616	639
	Family				1,567	2,023	1,994	2,044	2,054	1,973	1,973
	Host Home				436	574	560	568	570	542	575
	Group 1 to 3				184	113	111	112	115	108	106
People in Congregate Settings	Group 4 to 6				61	53	53	56	56	56	56
	Group 1 to 6	12	42	228	245	166	164	168	171	164	162
	Group 7 to 15	134	148	773	835	865	867	936	940	932	925
	Group 16+	1,767	1,505	1,403	1,580	1,604	1,504	1,461	1,427	1,450	1,444
People Served by the DD Agency *	Caseload (known to the DD agency)							DNF	DNF	DNF	9,463
	LTSS Recipients (1)	1,913	1,695	2,404	5,197	5,873	6,328	5,824	5,832	5,682	5,735
	Waiting for Medicaid Waiver				DNF	1,522	2,180	2,580	2,959	2,838	3,161
People in Non-DD Settings *	Nursing Facility (s)			1,100	900	0	597	614	622	616	638
	Psychiatric Facility (2)			0	0	0	0	DNF	DNF	0	0
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$2,168	\$22,709	\$35,050	\$42,887	\$43,565	\$45,727	\$49,675	\$52,091
	ICF/IID Expenditures per Person			\$52,234	\$88,845	\$101,207	\$106,855	\$111,166	\$121,978	\$123,671	PD
	Waiver Recipients per 100,000			8.3	119.8	136.7	136.9	140.1	140.2	138.4	138.4
	ICF/IID Residents per 100,000			66.0	57.1	53.9	49.7	49.6	49.0	48.5	48.3

(1) Long Term Supports and Service (LTSS) recipients may include imputed values; Until 2012 LTSS recipients may include people in nursing homes or psychiatric facilities who were not on the IDD agency caseload.
 (2) Includes only state operated psychiatric facilities until 2013.
 (s) Data may be from an outside source.

Settings by size includes ICF/IID, group homes, and nonstate other.
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 * See state notes and the RISP report for further explanation.



RISP Profile FY 2016

California

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

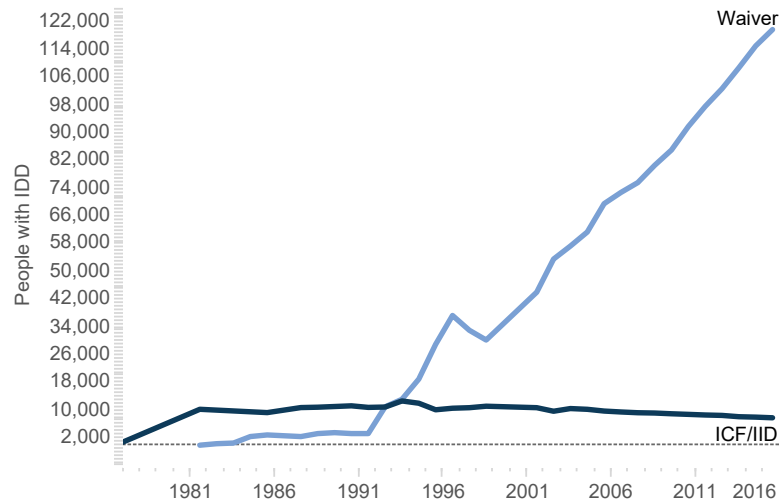


Figure 2: Medicaid Spending Per Person FY 2016

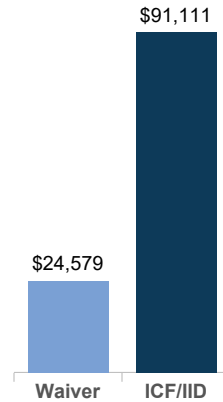


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

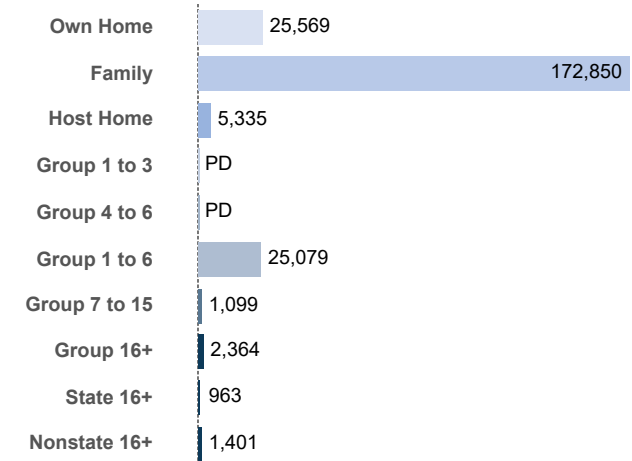


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				17,671	21,627	23,097	23,763	24,510	25,097	25,569
	Family				149,386	133,809	140,887	145,176	152,592	162,156	172,850
	Host Home				3,901	3,559	3,892	4,160	4,472	4,968	5,335
	Group 1 to 3				DNF	DNF	DNF	PD	PD	PD	PD
People in Congregate Settings	Group 4 to 6				DNF	6,235	DNF	PD	PD	PD	PD
	Group 1 to 6	6,942	8,759	17,046	23,994	25,329	25,593	25,618	25,487	25,338	25,079
	Group 7 to 15	1,947	2,592	3,074	1,487	1,229	1,152	1,181	1,176	1,129	1,099
	Group 16+	17,291	15,715	12,331	5,820	3,993	3,390	3,192	2,660	2,532	2,364
People Served by the DD Agency *	Caseload (known to the DD agency)							231,836	240,037	249,643	259,463
	LTSS Recipients (1)	26,180	27,066	32,451	202,261	189,546	199,168	203,090	210,951	221,455	232,389
	Waiting for Medicaid Waiver				0	0	0	0	0	0	0
People in Non-DD Settings *	Nursing Facility (s)			1,075	6,902	1,217	1,157	1,060	1,077	1,079	1,112
	Psychiatric Facility (2)			0	0	DNF	0	64	44	38	34
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$16,086	\$19,252	\$22,740	\$21,534	\$23,030	\$23,394	\$24,241	\$24,579
	ICF/IID Expenditures per Person			\$25,966	\$62,671	\$78,119	\$82,731	\$79,619	\$83,589	\$87,087	\$91,111
	Waiver Recipients per 100,000			11.1	170.4	229.0	257.3	268.7	281.0	294.7	305.9
	ICF/IID Residents per 100,000			37.5	28.7	24.4	22.9	22.1	21.2	20.4	19.9

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

(2) Includes only state operated psychiatric facilities until 2013.

(s) Data may be from an outside source.

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

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RISP Profile FY 2016

Colorado

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

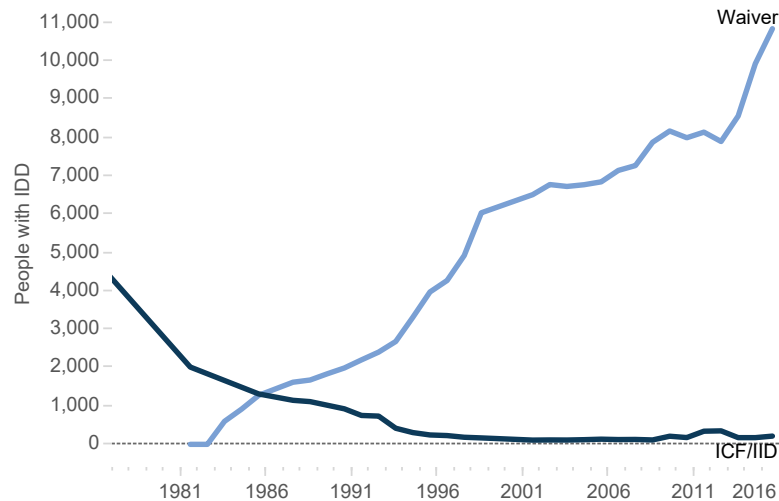


Figure 2: Medicaid Spending Per Person FY 2016

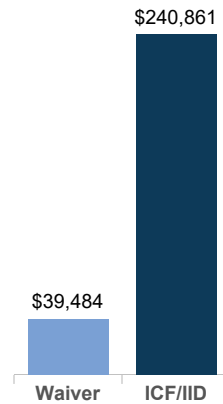


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

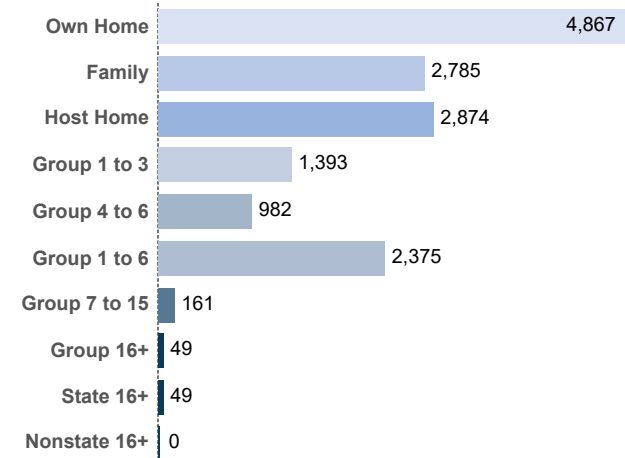


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				865	729	1,020	3,884	3,884	4,799	4,867
	Family				5,628	7,017	5,807	2,580	3,210	4,483	2,785
	Host Home				0	2,492	2,204	2,460	2,605	2,710	2,874
	Group 1 to 3				33	DNF	2,118	937	1,192	1,267	1,393
People in Congregate Settings	Group 4 to 6				646	1,370	110	1,018	998	932	982
	Group 1 to 6	119	670	1,819	679	1,370	2,228	1,955	2,190	2,199	2,375
	Group 7 to 15	421	670	910	499	203	207	166	154	126	161
	Group 16+	2,111	1,960	666	105	67	296	168	PD	29	49
People Served by the DD Agency *	Caseload (known to the DD agency)							21,833	22,085	24,883	19,567
	LTSS Recipients (1)	2,651	3,300	3,395	7,776	11,878	11,857	11,233	12,211	14,346	13,111
	Waiting for Medicaid Waiver				940	1,562	1,794	3,712	3,712	3,314	3,199
People in Non-DD Settings *	Nursing Facility (s)			428	161	97	95	240	160	153	64
	Psychiatric Facility (2)			0	DNF	DNF	0	DNF	0	0	0
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$26,450	\$36,110	\$41,127	\$40,630	\$41,583	\$41,529	\$39,818	\$39,484
	ICF/IID Expenditures per Person			\$60,300	\$481,362	\$134,414	\$115,258	\$123,606	\$253,725	\$233,314	\$240,861
	Waiver Recipients per 100,000			59.0	145.2	162.6	157.0	150.0	160.0	182.0	195.8
	ICF/IID Residents per 100,000			27.5	2.6	4.2	6.6	6.7	3.3	3.2	3.0

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

(2) Includes only state operated psychiatric facilities until 2013.

(s) Data may be from an outside source.

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

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RISP Profile FY 2016

Connecticut

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

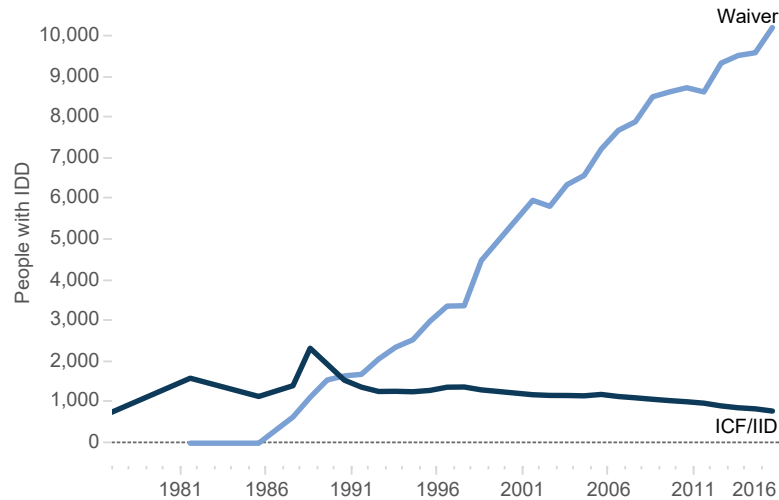


Figure 2: Medicaid Spending Per Person FY 2016

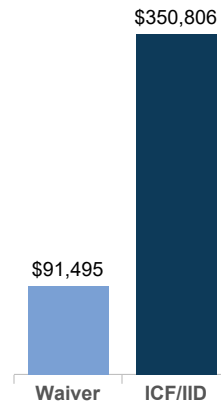


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

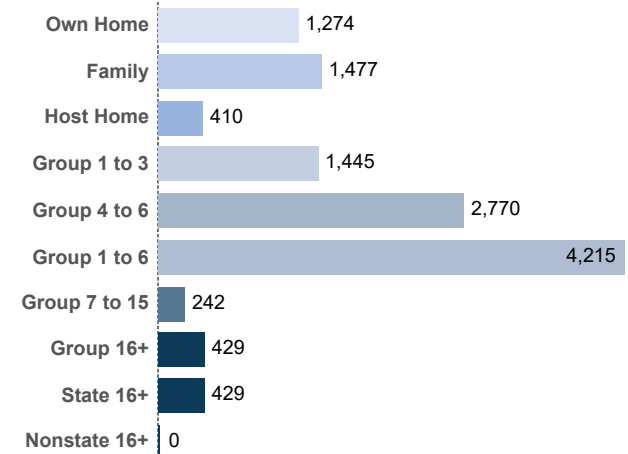


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				859	1,388	1,349	1,292	1,138	1,131	1,274
	Family				7,546	7,896	1,381	1,416	1,459	1,516	1,477
	Host Home				542	497	458	469	459	442	410
	Group 1 to 3				742	1,293	1,431	1,330	1,393	1,447	1,445
People in Congregate Settings	Group 4 to 6				2,685	2,696	2,654	2,678	2,673	2,741	2,770
	Group 1 to 6	251	353	3,113	3,427	4,000	4,085	4,008	4,066	4,188	4,215
	Group 7 to 15	364	540	570	472	354	338	288	278	254	242
	Group 16+	3,881	3,660	1,652	839	686	612	552	521	468	429
People Served by the DD Agency *	Caseload (known to the DD agency)							15,918	16,280	16,328	16,724
	LTSS Recipients (1)	4,496	4,553	5,335	13,685	14,821	8,599	8,025	7,921	8,012	8,047
	Waiting for Medicaid Waiver				680	531	612	618	682	638	650
People in Non-DD Settings *	Nursing Facility (s)			482	411	382	376	388	375	343	339
	Psychiatric Facility (2)			3	0	DNF	0	6	4	3	5
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$37,205	\$64,000	\$74,492	\$83,454	\$79,539	\$72,733	\$91,574	\$91,495
	ICF/IID Expenditures per Person			\$135,666	\$188,575	\$279,101	\$257,596	\$321,368	\$295,726	\$313,240	\$350,806
	Waiver Recipients per 100,000			50.3	187.5	241.7	240.6	259.9	265.1	267.4	285.8
	ICF/IID Residents per 100,000			47.1	33.2	29.3	27.4	25.5	24.2	23.5	12.0

(1) Long Term Supports and Service (LTSS) recipients may include imputed values; Until 2012 LTSS recipients may include people in nursing homes or psychiatric facilities who were not on the IDD agency caseload.
 (2) Includes only state operated psychiatric facilities until 2013.
 (s) Data may be from an outside source.

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RISP Profile FY 2016

Delaware

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

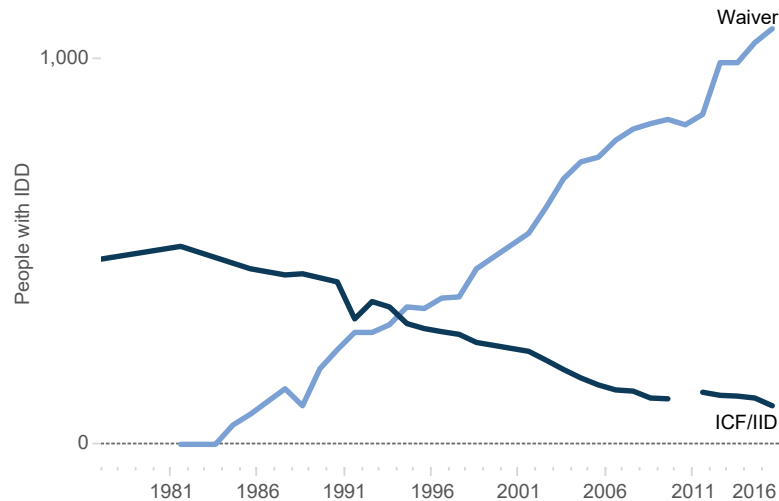


Figure 2: Medicaid Spending Per Person FY 2016

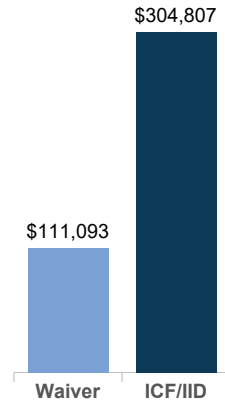


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

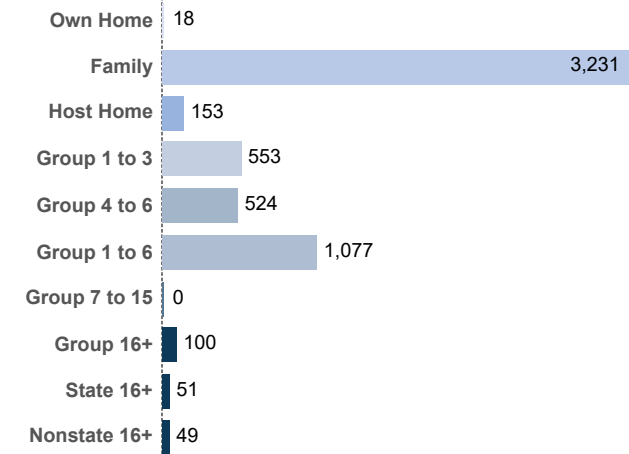


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				25	27	20	18	18	18	18
	Family				1,691	2,149	2,428	2,610	2,798	3,014	3,231
	Host Home				206	145	132	135	126	135	153
	Group 1 to 3				207	259	283	443	439	684	553
People in Congregate Settings	Group 4 to 6				340	467	474	525	564	389	524
	Group 1 to 6	179	148	278	547	726	757	968	1,003	1,073	1,077
	Group 7 to 15	9	10	89	0	0	23	0	0	0	0
	Group 16+	622	606	332	172	118	135	127	125	120	100
People Served by the DD Agency *	Caseload (known to the DD agency)							3,679	3,936	4,204	4,657
	LTSS Recipients (1)	810	764	699	2,641	3,165	3,458	3,858	4,070	4,360	4,579
	Waiting for Medicaid Waiver				7	174	17	0	0	0	0
People in Non-DD Settings *	Nursing Facility (s)			60	60	43	29	7	46	66	58
	Psychiatric Facility (2)			0	11	7	3	2	3	2	2
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$19,204	\$73,563	\$105,893	\$110,326	\$92,656	\$104,642	\$113,696	\$111,093
	ICF/IID Expenditures per Person			\$56,016	\$150,125	\$260,454	\$264,574	\$246,191	\$239,307	\$355,098	\$304,807
	Waiver Recipients per 100,000			36.0	86.8	93.8	93.2	106.8	105.7	110.0	113.1
	ICF/IID Residents per 100,000			61.9	20.4	13.1	14.7	13.7	13.4	12.7	10.5

(1) Long Term Supports and Service (LTSS) recipients may include imputed values; Until 2012 LTSS recipients may include people in nursing homes or psychiatric facilities who were not on the IDD agency caseload.
 (2) Includes only state operated psychiatric facilities until 2013.
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RISP Profile FY 2016

District of Columbia

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

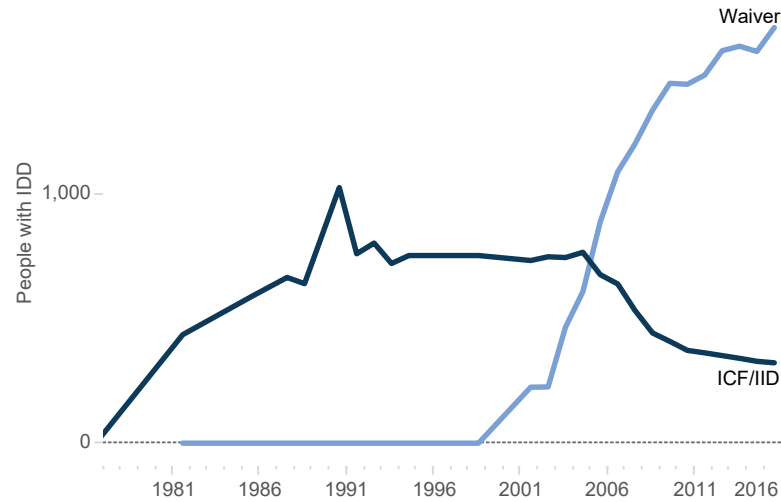


Figure 2: Medicaid Spending Per Person FY 2016

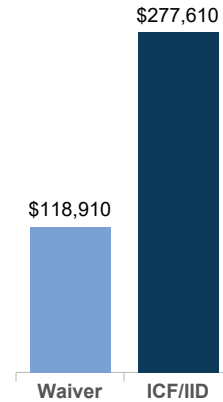


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

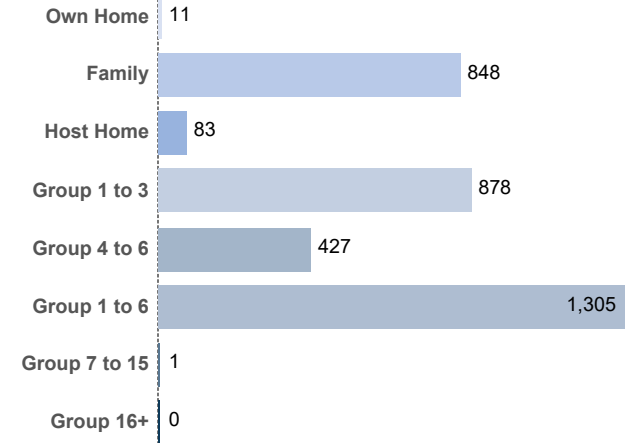


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				22	28	19	18	15	13	11
	Family				540	510	715	727	798	799	848
	Host Home				82	72	81	104	88	83	83
	Group 1 to 3				DNF	687	789	785	811	842	878
People in Congregate Settings	Group 4 to 6				DNF	487	489	471	465	433	427
	Group 1 to 6	28	139	646	933	1,193	1,278	1,256	1,276	1,275	1,305
	Group 7 to 15	0	76	304	118	52	0	0	9	7	1
	Group 16+	960	671	137	0	0	0	15	0	17	0
People Served by the DD Agency *	Caseload (known to the DD agency)							2,120	2,197	2,225	2,275
	LTSS Recipients (1)	988	886	1,087	1,695	1,855	2,099	2,120	2,186	2,194	2,248
	Waiting for Medicaid Waiver				0	0	0	0	0	0	0
People in Non-DD Settings *	Nursing Facility (s)			34	1	15	6	5	4	3	6
	Psychiatric Facility (2)			1	0	0	0	6	5	2	4
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$0	\$14,914	\$96,271	\$99,524	\$93,107	\$100,606	\$117,425	\$118,910
	ICF/IID Expenditures per Person			\$36,860	\$103,254	\$169,585	\$173,206	\$237,523	\$268,393	\$290,985	\$277,610
	Waiver Recipients per 100,000			0.0	110.6	240.3	233.9	243.9	242.1	234.1	245.2
	ICF/IID Residents per 100,000			171.7	139.3	68.0	57.4	54.5	51.8	48.9	47.4

(1) Long Term Supports and Service (LTSS) recipients may include imputed values; Until 2012 LTSS recipients may include people in nursing homes or psychiatric facilities who were not on the IDD agency caseload.
 (2) Includes only state operated psychiatric facilities until 2013.
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RISP Profile FY 2016

Florida

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

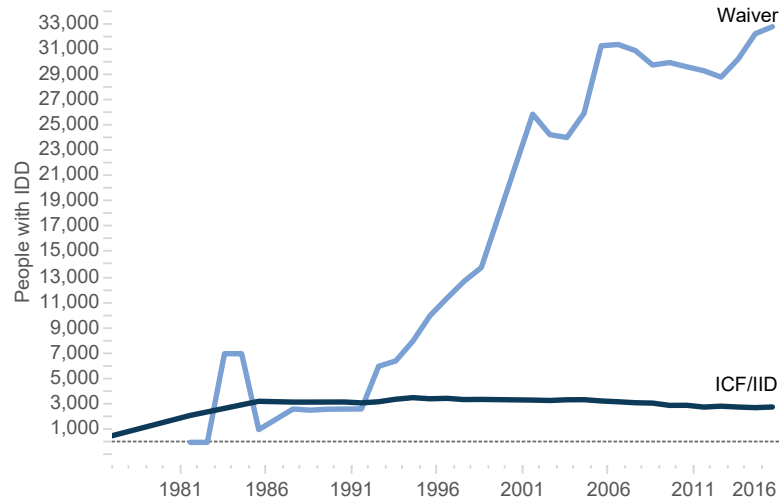


Figure 2: Medicaid Spending Per Person FY 2016

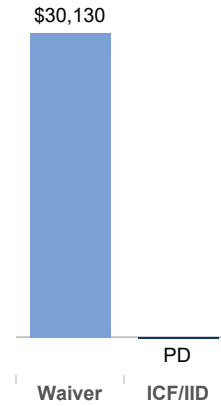


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

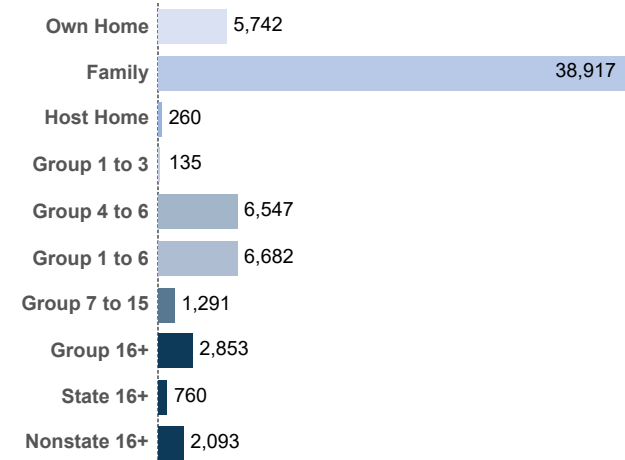


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				4,012	5,326	5,883	5,872	5,742	5,743	5,742
	Family				31,173	36,218	37,082	37,424	37,323	38,377	38,917
	Host Home				0	DNF	7,254	323	308	284	260
	Group 1 to 3				236	359	696	534	516	442	135
People in Congregate Settings	Group 4 to 6				4,515	5,704	6,343	6,198	6,375	5,442	6,547
	Group 1 to 6	791	937	1,987	4,751	6,063	7,039	6,732	6,891	5,884	6,682
	Group 7 to 15	1,008	1,474	2,244	1,286	1,233	1,642	1,606	1,647	1,811	1,291
	Group 16+	6,304	5,649	4,628	3,347	2,925	2,764	2,876	2,919	2,651	2,853
People Served by the DD Agency *	Caseload (known to the DD agency)							55,442	55,366	57,112	57,317
	LTSS Recipients (1)	8,103	8,060	8,859	44,569	DNF	62,118	55,000	54,906	54,814	56,701
	Waiting for Medicaid Waiver				3,100	3,835	4,311	22,432	21,165	21,331	20,486
People in Non-DD Settings *	Nursing Facility (s)			212	284	309	308	336	306	287	285
	Psychiatric Facility (2)			4	0	0	28	41	33	27	24
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$6,842	\$25,536	\$31,124	\$29,975	\$29,131	\$28,319	\$27,553	\$30,130
	ICF/IID Expenditures per Person			\$53,117	\$89,374	\$114,326	\$117,219	\$112,665	\$117,173	\$121,843	PD
	Waiver Recipients per 100,000			19.8	146.2	159.6	151.9	147.5	152.2	159.2	159.3
	ICF/IID Residents per 100,000			24.0	18.9	15.5	14.4	14.6	14.0	13.5	13.2

(1) Long Term Supports and Service (LTSS) recipients may include imputed values; Until 2012 LTSS recipients may include people in nursing homes or psychiatric facilities who were not on the IDD agency caseload.
 (2) Includes only state operated psychiatric facilities until 2013.
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RISP Profile FY 2016

Georgia

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

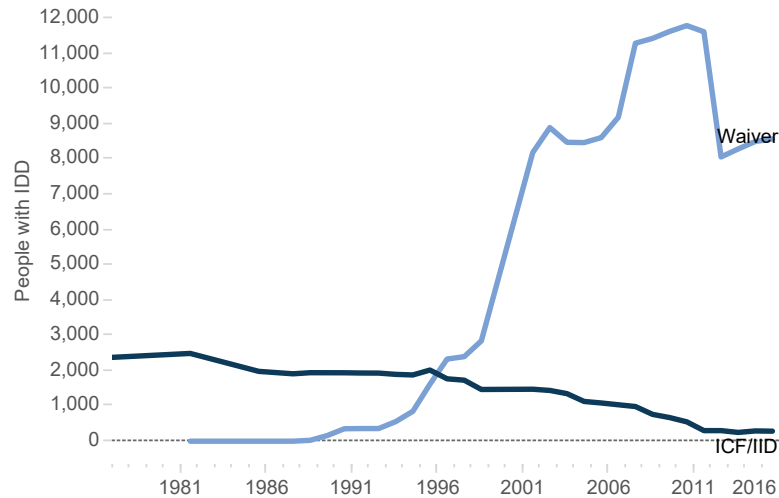


Figure 2: Medicaid Spending Per Person FY 2016

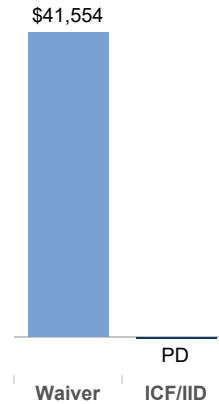


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

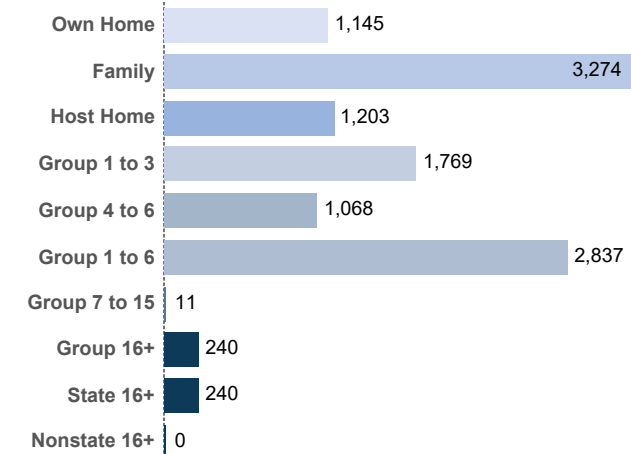


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				2,228	3,316	1,366	1,151	1,148	1,156	1,145
	Family				4,123	5,344	5,495	2,925	3,080	3,105	3,274
	Host Home				542	1,240	1,044	1,186	1,215	1,235	1,203
	Group 1 to 3				1,004	1,155	DNF	1,805	1,845	1,912	1,769
People in Congregate Settings	Group 4 to 6				598	1,225	DNF	990	996	987	1,068
	Group 1 to 6	96	709	1,608	1,602	2,380	DNF	2,795	2,841	2,899	2,837
	Group 7 to 15	236	138	11	0	0	DNF	11	11	11	11
	Group 16+	2,994	2,710	2,292	1,300	751	DNF	593	249	267	240
People Served by the DD Agency *	Caseload (known to the DD agency)							8,308	15,632	16,576	17,389
	LTSS Recipients (1)	3,326	3,557	3,911	9,795	13,031	11,414	8,661	8,544	8,697	8,994
	Waiting for Medicaid Waiver				1,441	1,640	2,735	7,074	7,337	8,070	8,070
People in Non-DD Settings *	Nursing Facility (s)			1,941	1,576	754	1,095	1,095	1,174	974	972
	Psychiatric Facility (2)			6	0	0	0	DNF	DNF	DNF	DNF
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$14,348	\$25,986	\$30,311	\$35,041	\$38,132	\$42,315	\$41,853	\$41,554
	ICF/IID Expenditures per Person			\$56,424	\$88,878	\$137,249	\$19,525	\$203,440	\$121,015	\$159,081	PD
	Waiver Recipients per 100,000			5.3	93.4	120.1	117.1	80.7	82.2	83.3	83.2
	ICF/IID Residents per 100,000			29.3	12.4	6.9	3.0	2.5	2.5	2.8	2.8

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

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RISP Profile FY 2016

Hawaii

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

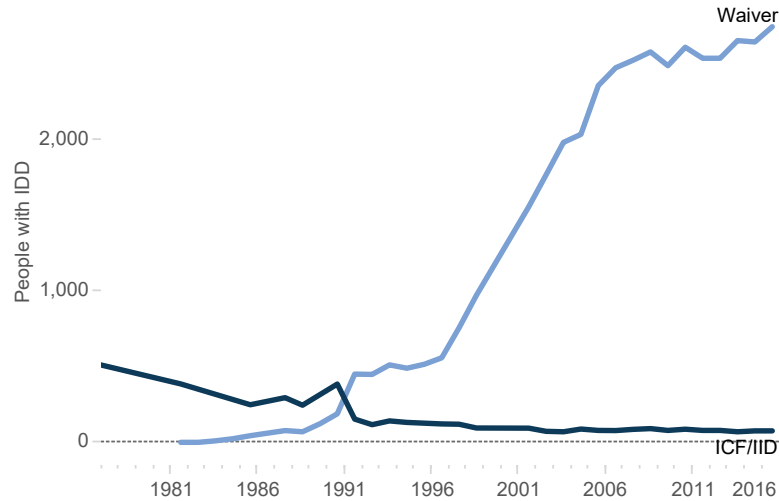


Figure 2: Medicaid Spending Per Person FY 2016

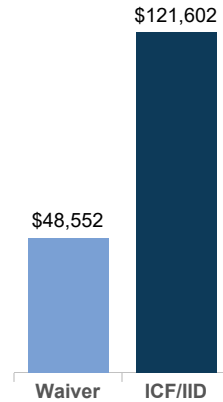
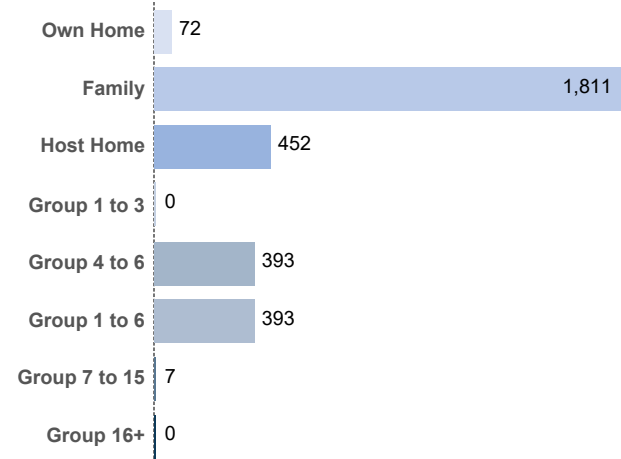


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type



Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				150	48	123	123	180	78	72
	Family				2,108	1,584	2,202	2,202	2,078	2,241	1,811
	Host Home				740	554	669	669	448	486	452
	Group 1 to 3				3	3	0	0	0	0	0
People in Congregate Settings	Group 4 to 6				164	163	227	227	239	341	393
	Group 1 to 6	366	445	948	167	166	227	227	239	341	393
	Group 7 to 15	18	12	7	8	8	7	7	0	7	7
	Group 16+	543	400	146	0	0	0	0	0	0	0
People Served by the DD Agency *	Caseload (known to the DD agency)							3,281	2,756	3,349	3,322
	LTSS Recipients (1)	927	857	1,101	3,173	2,360	3,281	3,228	3,113	3,153	2,735
	Waiting for Medicaid Waiver				0	0	0	0	0	0	0
People in Non-DD Settings *	Nursing Facility (s)			138	103	87	53	61	61	68	68
	Psychiatric Facility (2)			0	0	0	0	DNF	DNF	5	6
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$16,148	\$35,279	\$40,088	\$40,452	\$40,452	\$39,210	\$39,744	\$48,552
	ICF/IID Expenditures per Person			\$19,406	\$97,790	\$114,104	\$97,653	\$105,467	\$125,732	\$121,602	\$121,602
	Waiver Recipients per 100,000			16.7	160.0	183.4	182.7	181.2	187.5	185.2	192.7
	ICF/IID Residents per 100,000			34.0	6.9	5.8	5.7	5.6	4.9	5.3	5.3

(1) Long Term Supports and Service (LTSS) recipients may include imputed values; Until 2012 LTSS recipients may include people in nursing homes or psychiatric facilities who were not on the IDD agency caseload.
 (2) Includes only state operated psychiatric facilities until 2013.
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RISP Profile FY 2016

Idaho

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

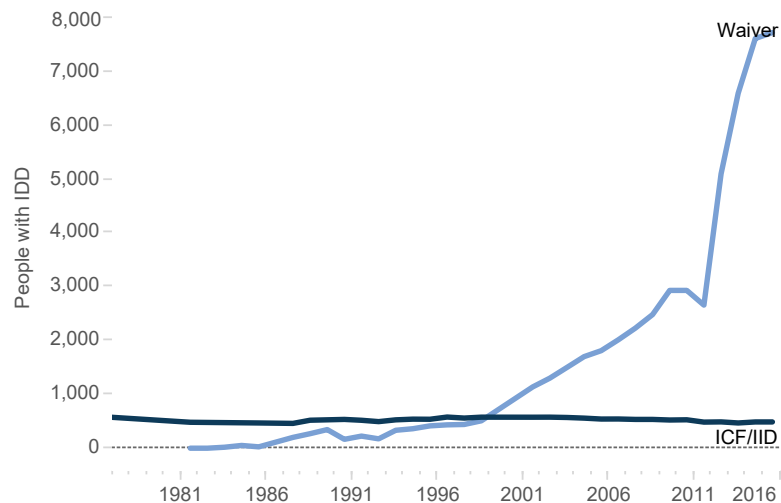


Figure 2: Medicaid Spending Per Person FY 2016

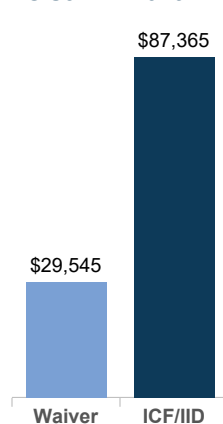


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

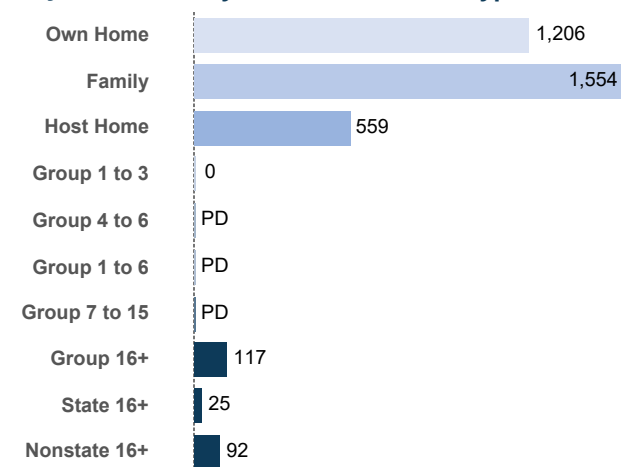


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				1,228	1,437	942	1,286	DNF	1,483	1,206
	Family				8,992	12,791	1,182	1,182	DNF	DNF	1,554
	Host Home				1,215	1,729	1,694	627	614	575	559
	Group 1 to 3				38	23	0	4	0	0	0
People in Congregate Settings	Group 4 to 6				205	196	DNF	PD	PD	PD	PD
	Group 1 to 6	42	41	342	243	219	DNF	PD	PD	PD	PD
	Group 7 to 15	76	180	475	507	515	DNF	PD	PD	PD	PD
	Group 16+	698	639	649	280	461	141	PD	PD	PD	117
People Served by the DD Agency *	Caseload (known to the DD agency)							5,100	6,599	7,393	10,151
	LTSS Recipients (1)	816	860	1,466	12,465	17,152	4,595	3,822	3,884	6,897	4,020
	Waiting for Medicaid Waiver				0	0	0	0	0	0	0
People in Non-DD Settings *	Nursing Facility (s)				125	233	49	98	112	126	113
	Psychiatric Facility (2)			0	0	DNF	0	DNF	DNF	DNF	DNF
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$13,018	\$29,689	\$33,827	DNF	\$14,858	\$15,616	\$25,854	\$29,545
	ICF/IID Expenditures per Person			\$63,995	\$97,655	\$126,447	\$37,585	\$99,877	\$101,931	\$87,365	\$87,365
	Waiver Recipients per 100,000			15.9	119.1	187.1	DNF	316.4	403.7	460.2	459.0
	ICF/IID Residents per 100,000			51.5	39.1	33.4	30.4	30.2	28.7	29.5	29.0

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

(2) Includes only state operated psychiatric facilities until 2013.

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Updated 3/12/2018

RISP Profile FY 2016

Illinois

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

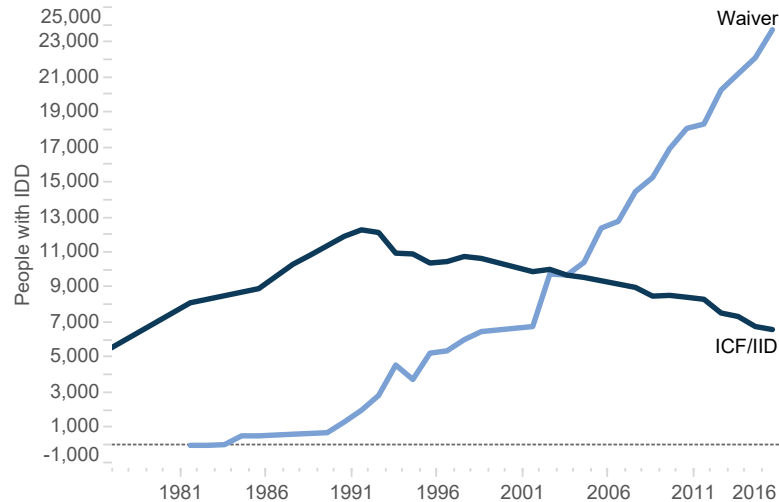


Figure 2: Medicaid Spending Per Person FY 2016

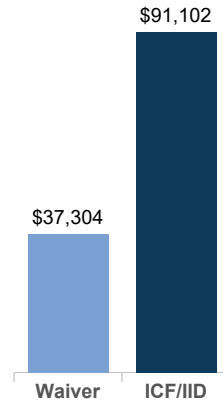
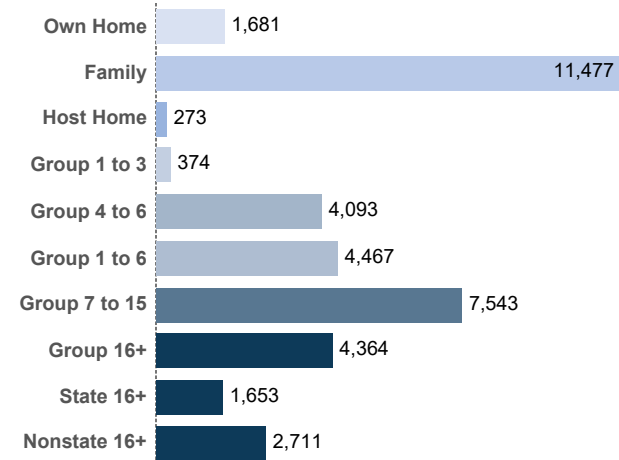


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type



Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				3,775	3,999	DNF	767	709	733	1,681
	Family				11,324	11,996	DNF	10,416	11,258	11,390	11,477
	Host Home				245	254	244	260	216	255	273
	Group 1 to 3				76	155	403	470	516	559	374
People in Congregate Settings	Group 4 to 6				3,640	3,844	4,366	3,931	4,355	4,651	4,093
	Group 1 to 6	69	331	897	3,716	3,999	4,769	4,401	4,871	5,210	4,467
	Group 7 to 15	101	387	3,824	6,463	7,703	8,202	7,193	7,242	7,467	7,543
	Group 16+	13,228	12,170	11,824	6,660	5,545	5,223	5,116	4,773	4,535	4,364
People Served by the DD Agency *	Caseload (known to the DD agency)							50,859	53,645	54,771	41,571
	LTSS Recipients (1)	13,398	12,888	16,545	31,183	33,496	30,173	28,153	29,310	29,591	29,805
	Waiting for Medicaid Waiver				DNF	15,042	12,076	22,999	22,000	17,566	9,725
People in Non-DD Settings *	Nursing Facility (s)				635	DNF	1,094	1,094	212	185	171
	Psychiatric Facility (2)			7	0	0	0	1	0	0	0
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$12,631	\$34,341	\$31,002	\$32,223	\$31,335	\$34,084	\$37,476	\$37,304
	ICF/IID Expenditures per Person			\$30,741	\$71,743	\$74,255	\$82,468	\$75,714	\$85,307	\$93,742	\$91,102
	Waiver Recipients per 100,000			11.6	81.9	132.1	142.6	157.6	164.8	172.2	185.5
	ICF/IID Residents per 100,000			103.5	75.2	66.8	64.8	58.7	57.1	52.8	51.7

(1) Long Term Supports and Service (LTSS) recipients may include imputed values; Until 2012 LTSS recipients may include people in nursing homes or psychiatric facilities who were not on the IDD agency caseload.
 (2) Includes only state operated psychiatric facilities until 2013.
 (s) Data may be from an outside source.

Settings by size includes ICF/IID, group homes, and nonstate other.
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RISP Profile FY 2016

Indiana

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

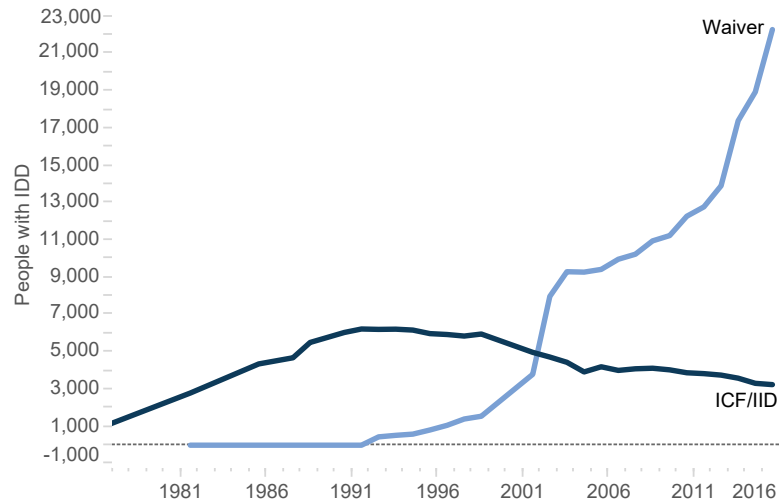


Figure 2: Medicaid Spending Per Person FY 2016

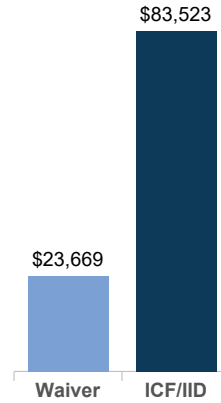
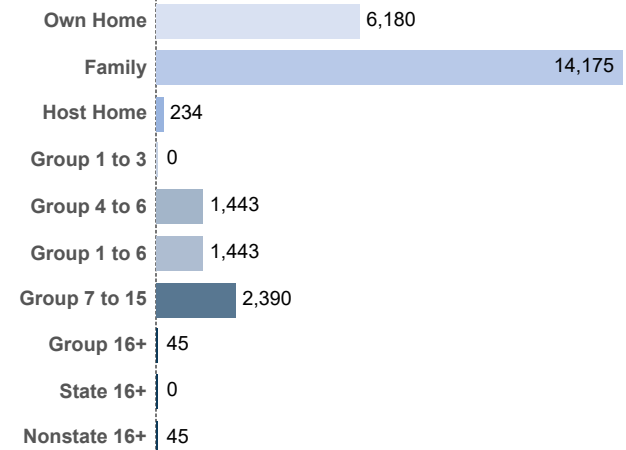


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type



Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				6,553	4,404	5,136	3,778	5,492	5,936	6,180
	Family				5,048	5,881	6,888	7,850	10,682	12,756	14,175
	Host Home				316	248	207	204	206	221	234
	Group 1 to 3				0	479	0	0	0	0	0
People in Congregate Settings	Group 4 to 6				3,254	1,682	1,657	1,527	1,605	1,456	1,443
	Group 1 to 6	466	487	2,015	3,254	2,151	1,657	1,527	1,605	1,456	1,443
	Group 7 to 15	172	243	2,424	0	2,525	2,447	2,554	2,339	2,454	2,390
	Group 16+	4,218	3,231	2,648	736	510	290	272	163	46	45
People Served by the DD Agency *	Caseload (known to the DD agency)							19,294	22,323	27,414	29,948
	LTSS Recipients (1)	4,856	3,961	7,087	15,907	15,719	18,284	16,185	20,589	22,869	24,467
	Waiting for Medicaid Waiver				DNF	17,142	DNF	5,109	3,533	2,579	1,934
People in Non-DD Settings *	Nursing Facility (s)			2,587	1,697	1,533	1,553	1,527	1,624	1,579	1,568
	Psychiatric Facility (2)			0	0	12	106	74	74	66	63
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$0	\$40,755	\$45,301	\$38,321	\$38,372	\$33,262	\$32,025	\$23,669
	ICF/IID Expenditures per Person			\$32,960	\$80,963	\$77,683	\$77,926	\$77,526	\$78,030	\$82,352	\$83,523
	Waiver Recipients per 100,000			0.0	148.0	173.4	195.6	211.8	263.9	286.3	336.2
	ICF/IID Residents per 100,000			107.8	62.7	62.3	58.7	57.2	54.5	50.1	49.0

(1) Long Term Supports and Service (LTSS) recipients may include imputed values; Until 2012 LTSS recipients may include people in nursing homes or psychiatric facilities who were not on the IDD agency caseload.
 (2) Includes only state operated psychiatric facilities until 2013.
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RISP Profile FY 2016

Iowa

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

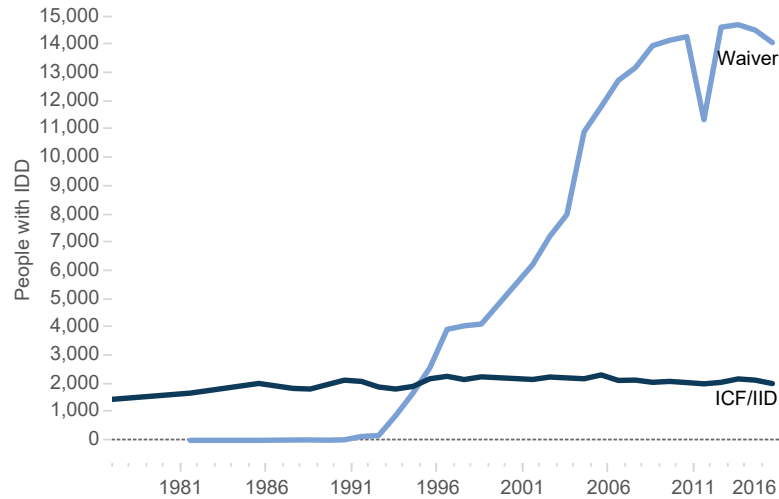


Figure 2: Medicaid Spending Per Person FY 2016

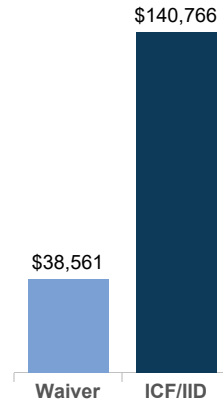
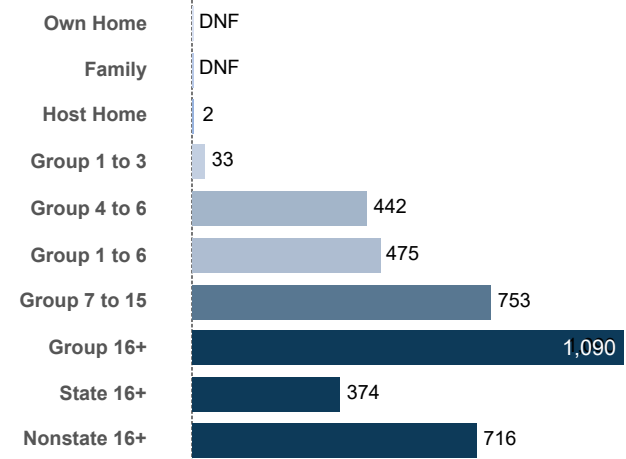


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type



Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				4,866	5,863	DNF	DNF	DNF	DNF	DNF
	Family				4,145	5,411	DNF	DNF	DNF	DNF	DNF
	Host Home				6	3	4	5	2	2	2
	Group 1 to 3				DNF	0	18	18	24	26	33
People in Congregate Settings	Group 4 to 6				DNF	380	467	493	508	497	442
	Group 1 to 6	94	211	1,860	694	380	485	511	532	523	475
	Group 7 to 15	296	588	1,571	1,060	798	920	908	872	782	753
	Group 16+	3,109	3,742	2,997	1,724	2,405	1,431	1,380	1,304	1,139	1,090
People Served by the DD Agency *	Caseload (known to the DD agency)							14,588	14,991	14,950	14,557
	LTSS Recipients (1)	3,499	4,541	6,428	12,495	14,860	14,838	12,097	12,709	11,711	11,623
	Waiting for Medicaid Waiver				79	94	0	0	0	0	DNF
People in Non-DD Settings *	Nursing Facility (s)			1,379	808	619	634	664	DNF	DNF	670
	Psychiatric Facility (2)			6	0	0	0	1,394	1,406	1,317	1,464
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$2,842	\$20,258	\$24,238	\$34,121	\$29,462	\$32,143	\$35,157	\$38,561
	ICF/IID Expenditures per Person			\$64,095	\$114,002	\$137,290	\$150,719	\$141,670	\$129,320	\$133,463	\$140,766
	Waiver Recipients per 100,000			0.7	368.6	465.3	369.5	473.7	473.9	465.2	449.5
	ICF/IID Residents per 100,000			76.3	73.6	68.5	65.1	64.9	70.0	68.3	64.2

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

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RISP Profile FY 2016

Kansas

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

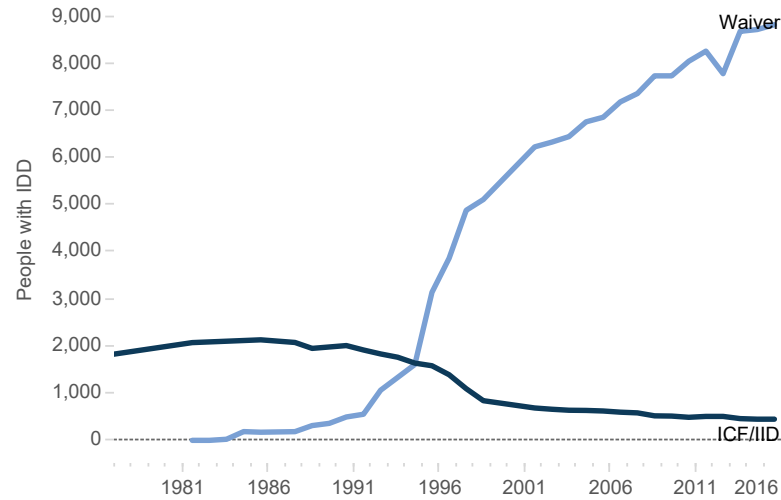


Figure 2: Medicaid Spending Per Person FY 2016

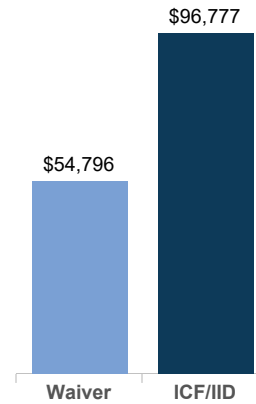


Figure 3: Caseload, Long Term Supports and Service Recipients, Medicaid Recipients, and Residents of Large Facilities on June 30, 2016
(Setting data by size and type is not available)

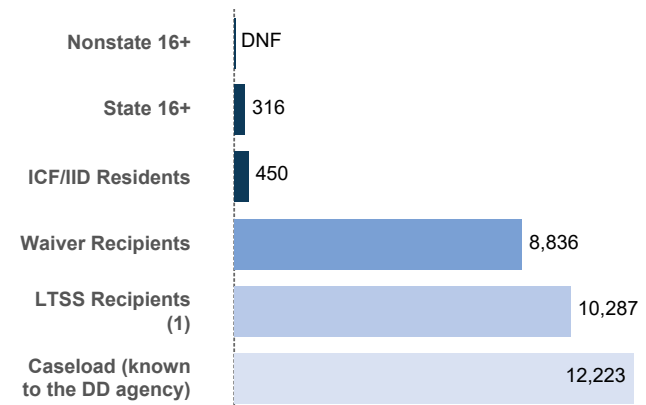


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016	
People in Individualized Settings	Own Home				1,774	2,561	DNF	82	DNF	DNF	DNF	
	Family				1,590	2,591	2,811	2,811	DNF	DNF	DNF	
	Host Home				141	227	82	82	DNF	DNF	DNF	
	Group 1 to 3				1,873	650	1,910	PD	PD	PD	PD	
People in Congregate Settings	Group 4 to 6				1,275	1,493	DNF	PD	PD	PD	PD	
	Group 1 to 6	220	184	764	3,148	2,143	DNF	PD	PD	PD	PD	
	Group 7 to 15	406	482	533	327	477	DNF	PD	PD	PD	PD	
	Group 16+	2,080	2,209	1,698	427	347	334	PD	PD	PD	PD	
People Served by the DD Agency *	Caseload (known to the DD agency)							9,045	11,689	12,131	12,223	
	LTSS Recipients (1)	2,706	2,875	2,995	7,407	8,346	9,045	8,488	6,664	9,971	10,287	
	Waiting for Medicaid Waiver				1,194	1,287	DNF	DNF	2,995	3,392	3,387	
People in Non-DD Settings *	Nursing Facility (s)			31	0	432	262	262	245	114	121	
	Psychiatric Facility (2)			4	0	0	0	DNF	8	DNF	DNF	
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person				\$23,481	\$32,107	\$36,224	\$39,917	\$43,946	\$46,019	\$47,378	\$54,796
	ICF/IID Expenditures per Person				\$48,846	\$105,345	\$119,983	DNF	\$124,703	\$132,551	\$144,952	\$96,777
	Waiver Recipients per 100,000				19.9	246.7	271.6	286.7	269.4	299.4	300.0	303.9
	ICF/IID Residents per 100,000				80.8	23.2	18.1	17.6	17.6	15.9	15.5	15.3

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

(2) Includes only state operated psychiatric facilities until 2013.

(s) Data may be from an outside source.

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

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PD = Partial Data.

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

Updated
2/14/2018

RISP Profile FY 2016

Kentucky

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

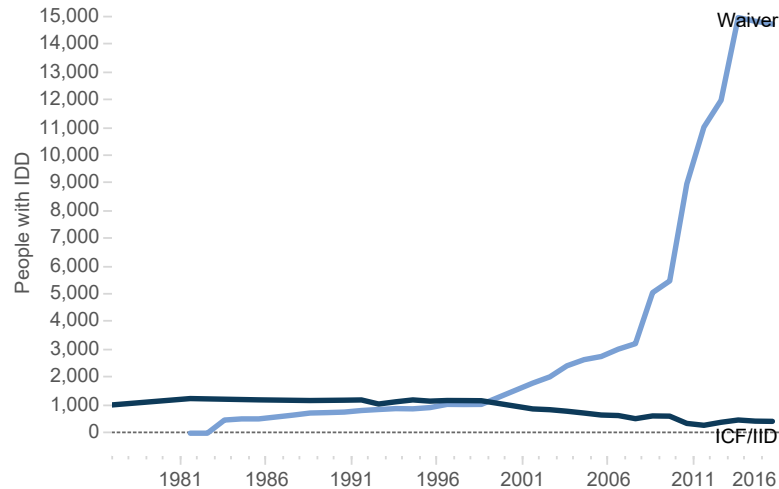


Figure 2: Medicaid Spending Per Person FY 2016

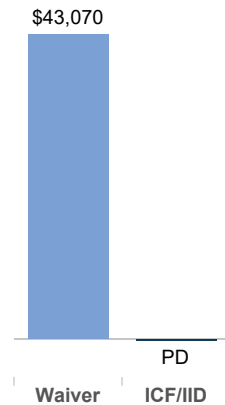


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

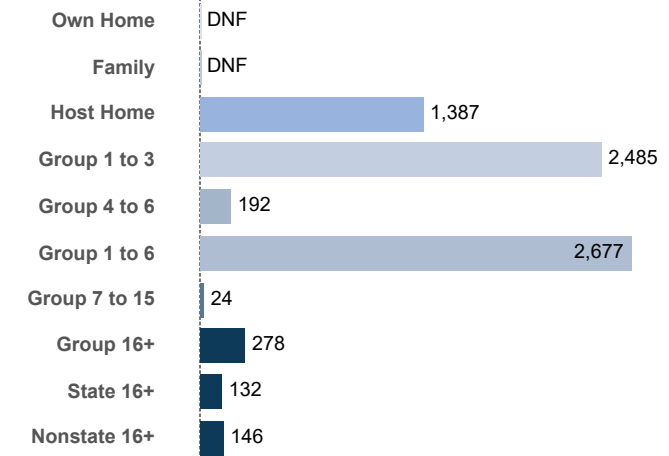


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016	
People in Individualized Settings	Own Home				770	297	261	327	327	DNF	DNF	
	Family				1,073	1,506	1,135	1,599	DNF	DNF	DNF	
	Host Home				512	644	761	767	1,069	1,249	1,387	
	Group 1 to 3				1,850	2,275	2,372	2,547	2,721	3,001	2,485	
People in Congregate Settings	Group 4 to 6				44	0	103	131	159	295	192	
	Group 1 to 6	44	112	747	1,894	2,275	2,475	2,678	2,880	3,296	2,677	
	Group 7 to 15	29	63	150	114	24	6	0	24	23	24	
	Group 16+	1,585	1,685	1,244	703	591	279	352	456	398	278	
People Served by the DD Agency *	Caseload (known to the DD agency)							DNF	DNF	18,000	14,768	
	LTSS Recipients (1)	1,658	1,860	2,141	5,066	5,337	5,190	5,765	6,355	13,959	13,712	
	Waiting for Medicaid Waiver				288	295	802	DNF	1,974	1,964	2,276	
People in Non-DD Settings *	Nursing Facility (s)	217			450	850	273	191	647	696	736	
	Psychiatric Facility (2)			5	0	0	0	242	DNF	376	362	
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person				\$21,335	\$59,076	\$48,463	\$36,794	\$38,282	\$36,765	\$40,048	\$43,070
	ICF/IID Expenditures per Person				\$54,924	\$148,208	\$236,622	\$457,827	\$445,347	\$318,989	\$323,036	PD
	Waiver Recipients per 100,000				20.5	63.6	126.6	252.2	273.4	339.9	336.0	332.8
	ICF/IID Residents per 100,000				32.1	17.4	14.2	6.5	9.0	10.2	9.8	9.6

(1) Long Term Supports and Service (LTSS) recipients may include imputed values; Until 2012 LTSS recipients may include people in nursing homes or psychiatric facilities who were not on the IDD agency caseload.
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RISP Profile FY 2016

Louisiana

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

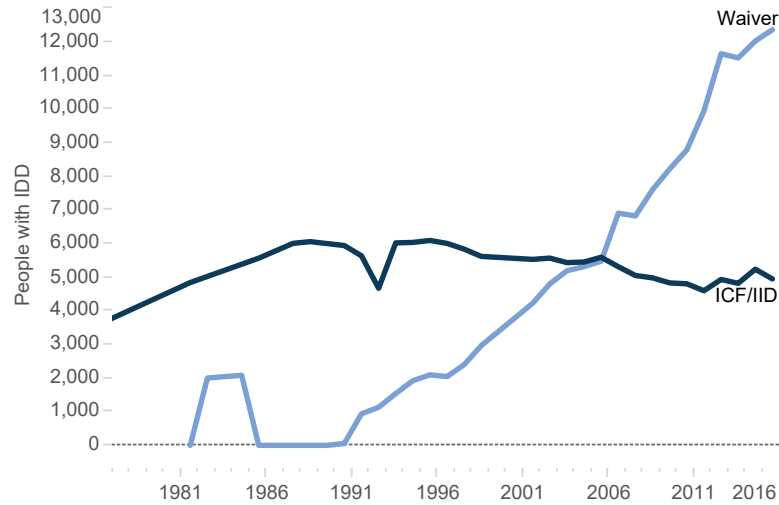


Figure 2: Medicaid Spending Per Person FY 2016

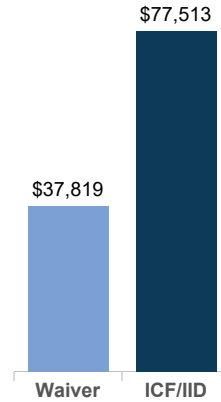


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

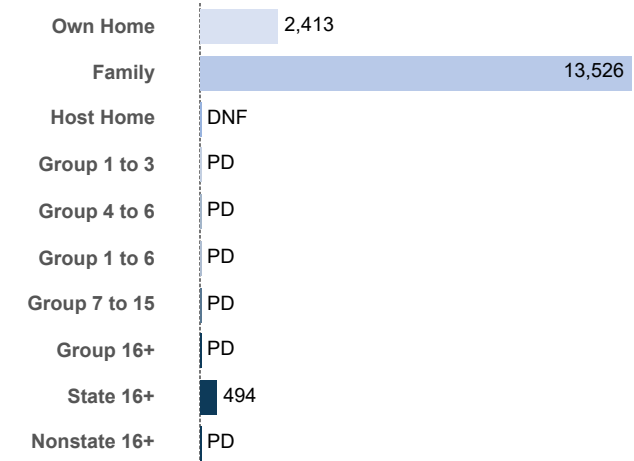


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				1,891	2,340	2,468	2,420	2,408	2,408	2,413
	Family				6,512	13,894	15,946	14,938	13,462	13,870	13,526
	Host Home				53	54	0	0	DNF	DNF	DNF
	Group 1 to 3				37	0	0	0	PD	PD	PD
People in Congregate Settings	Group 4 to 6				2,026	2,861	3,035	1,728	PD	PD	PD
	Group 1 to 6	39	85	2,224	2,063	2,861	3,035	1,728	PD	PD	PD
	Group 7 to 15	112	185	222	1,030	346	181	1,675	PD	PD	PD
	Group 16+	4,298	4,785	5,418	2,470	1,631	1,388	1,401	PD	PD	PD
People Served by the DD Agency *	Caseload (known to the DD agency)							11,399	44,902	48,305	50,071
	LTSS Recipients (1)	4,449	5,055	7,864	14,019	21,126	23,545	22,299	28,997	30,404	29,921
	Waiting for Medicaid Waiver				DNF	DNF	DNF	10,756	12,906	13,085	14,289
People in Non-DD Settings *	Nursing Facility (s)			1,252	677	382	511	549	439	434	598
	Psychiatric Facility (2)			0	0	16	16	DNF	DNF	DNF	DNF
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$3,643	\$45,489	\$48,370	\$40,901	\$38,769	\$38,710	\$38,450	\$37,819
	ICF/IID Expenditures per Person			\$39,948	\$77,963	\$97,633	\$100,133	\$79,065	\$80,932	\$73,201	\$77,513
	Waiver Recipients per 100,000			1.3	117.7	181.6	216.4	252.1	248.2	257.8	264.4
	ICF/IID Residents per 100,000			140.0	120.7	106.7	100.0	106.8	103.8	112.3	105.9

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

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RISP Profile FY 2016

Maine

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

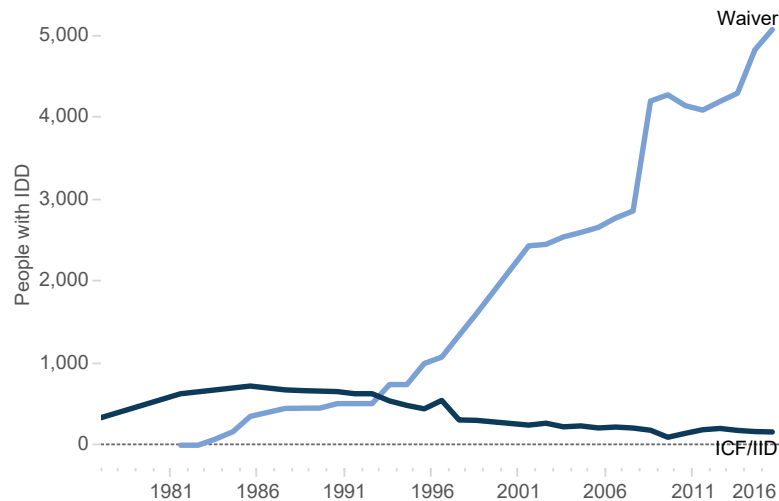


Figure 2: Medicaid Spending Per Person FY 2016

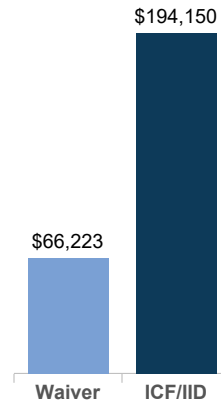


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

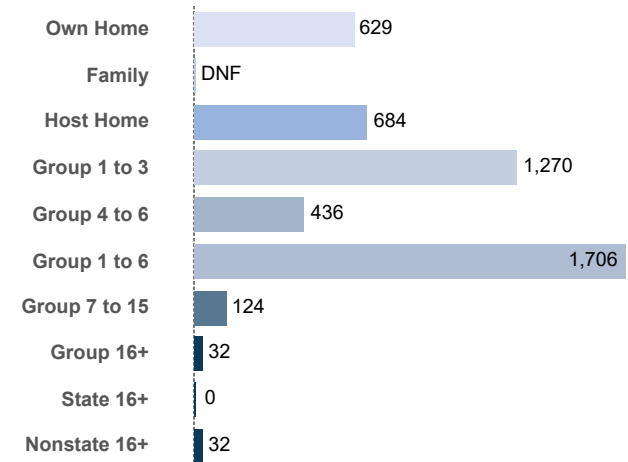


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				568	303	541	400	310	384	629
	Family				599	387	1,563	1,575	1,342	136	DNF
	Host Home				728	418	793	753	714	524	684
	Group 1 to 3				939	1,201	1,304	PD	1,261	PD	1,270
People in Congregate Settings	Group 4 to 6				996	657	775	PD	498	PD	436
	Group 1 to 6	429	524	1,259	1,935	1,858	2,079	2,116	1,759	1,638	1,706
	Group 7 to 15	75	179	187	202	65	116	113	114	124	124
	Group 16+	989	761	572	49	32	117	58	58	32	32
People Served by the DD Agency *	Caseload (known to the DD agency)							5,648	5,925	6,499	6,541
	LTSS Recipients (1)	1,493	1,464	2,018	4,081	3,063	5,261	5,113	4,404	3,143	3,586
	Waiting for Medicaid Waiver				105	337	85	725	957	1,153	1,264
People in Non-DD Settings *	Nursing Facility (s)			190	112	72	49	DNF	DNF	7	10
	Psychiatric Facility (2)			2	0	0	3	DNF	DNF	0	0
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$24,558	\$74,951	\$71,657	\$70,976	\$78,360	\$62,832	\$62,105	\$66,223
	ICF/IID Expenditures per Person			\$83,983	\$236,310	\$623,838	\$225,031	\$171,104	\$189,312	\$173,489	\$194,150
	Waiver Recipients per 100,000			41.2	197.0	322.8	308.5	316.8	323.9	364.0	382.1
	ICF/IID Residents per 100,000			53.1	17.9	7.3	14.2	15.4	12.9	12.6	12.2

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RISP Profile FY 2016

Maryland

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

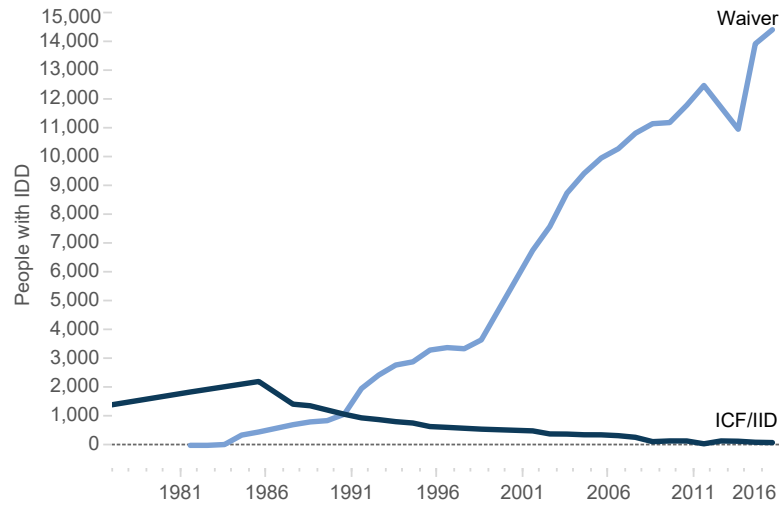


Figure 2: Medicaid Spending Per Person FY 2016

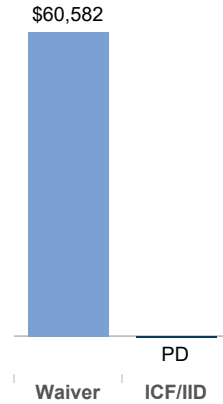


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

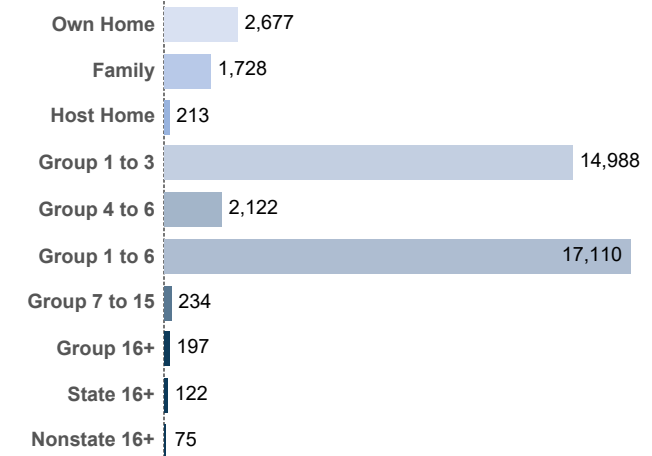


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				1,509	1,747	2,014	2,195	2,368	2,542	2,677
	Family				2,139	2,228	2,215	2,215	2,198	2,215	1,728
	Host Home				251	216	208	213	210	212	213
	Group 1 to 3				2,819	3,544	3,660	5,936	5,891	17,007	14,988
People in Congregate Settings	Group 4 to 6				1,663	1,629	1,757	1,853	1,950	2,048	2,122
	Group 1 to 6	62	352	3,325	4,482	5,173	5,417	7,789	7,841	19,055	17,110
	Group 7 to 15	71	163	0	313	256	236	219	240	274	234
	Group 16+	3,238	2,731	1,159	392	144	54	277	185	228	197
People Served by the DD Agency *	Caseload (known to the DD agency)							24,480	24,902	24,911	24,912
	LTSS Recipients (1)	3,371	3,246	4,484	9,086	9,764	10,385	12,908	13,042	24,528	22,159
	Waiting for Medicaid Waiver				7,710	2,770	4,065	5,276	5,660	5,547	5,441
People in Non-DD Settings *	Nursing Facility (s)			537	843	DNF	241	0	0	268	279
	Psychiatric Facility (2)			9	0	0	0	0	0	0	0
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$39,722	\$39,383	\$52,511	\$55,000	\$65,135	\$50,814	\$58,588	\$60,582
	ICF/IID Expenditures per Person			\$58,134	\$171,896	\$163,291	DNF	\$376	\$74,500	\$183,138	PD
	Waiver Recipients per 100,000			22.3	168.5	194.0	212.2	197.8	183.6	232.0	239.7
	ICF/IID Residents per 100,000			22.2	6.6	2.7	DNF	2.6	2.4	1.8	DNF

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

(2) Includes only state operated psychiatric facilities until 2013.

(s) Data may be from an outside source.

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

DNF = Did Not Furnished.

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RISP Profile FY 2016

Massachusetts

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

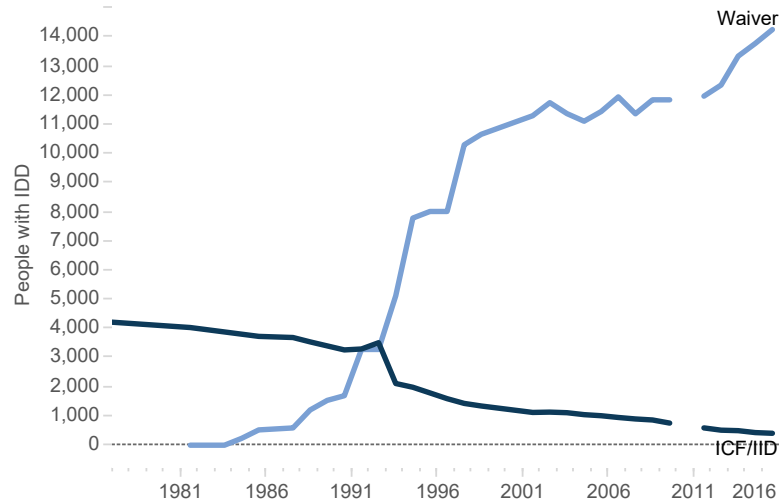


Figure 2: Medicaid Spending Per Person FY 2016

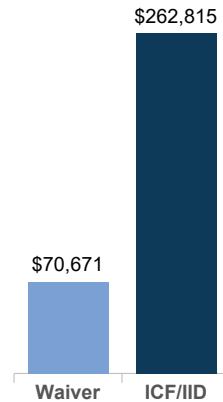


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

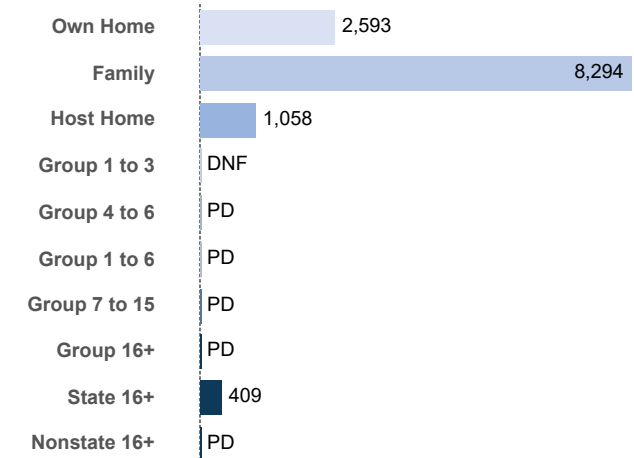


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				1,308	2,114	638	2,696	2,696	2,551	2,593
	Family				19,665	19,916	21,000	19,000	19,000	6,948	8,294
	Host Home				934	1,569	2,807	3,296	3,296	2,074	1,058
	Group 1 to 3				1,725	1,447	DNF	2,430	2,428	DNF	DNF
People in Congregate Settings	Group 4 to 6				5,334	5,024	DNF	6,435	6,435	PD	PD
	Group 1 to 6	282	911	3,440	7,059	6,471	7,809	8,865	8,863	PD	PD
	Group 7 to 15	1,012	1,129	1,661	885	1,188	799	652	652	PD	PD
	Group 16+	6,429	4,682	2,694	1,092	786	580	516	497	433	PD
People Served by the DD Agency *	Caseload (known to the DD agency)							34,447	34,447	35,438	36,491
	LTSS Recipients (1)	7,723	6,722	7,795	30,943	32,044	34,000	35,025	35,004	22,899	22,062
	Waiting for Medicaid Waiver				372	0	DNF	0	0	DNF	0
People in Non-DD Settings *	Nursing Facility (s)			1,600	1,056	712	367	253	253	455	267
	Psychiatric Facility (2)			8	0	0	0	DNF	DNF	DNF	DNF
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$33,546	\$55,719	\$56,241	DNF	\$57,879	\$66,108	\$84,031	\$70,671
	ICF/IID Expenditures per Person			\$101,183	\$203,152	\$49,492	\$21,483	\$237,736	\$245,836	PD	\$262,815
	Waiver Recipients per 100,000			28.4	173.9	181.1	180.4	184.8	198.1	203.1	209.5
	ICF/IID Residents per 100,000			54.6	16.4	11.6	8.9	7.7	7.4	6.4	6.0

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

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RISP Profile FY 2016

Michigan

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

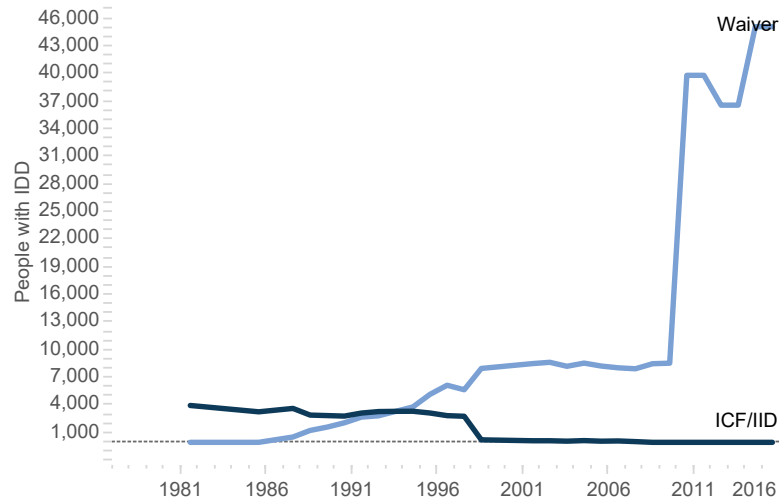


Figure 2: Medicaid Spending Per Person FY 2016

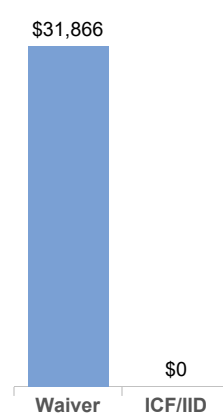


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

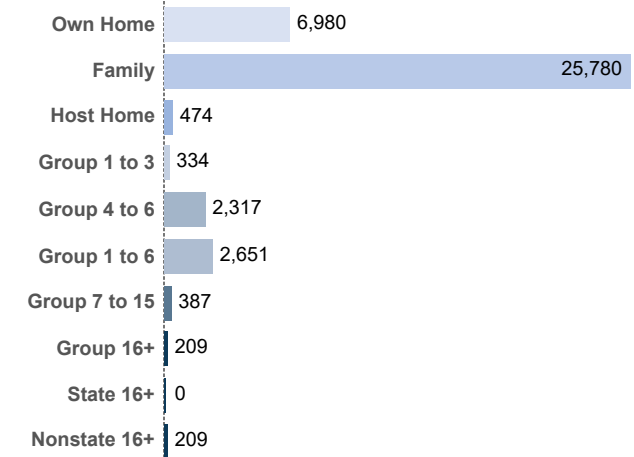


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				2,612	6,319	7,571	6,412	6,194	6,980	6,980
	Family				9,421	19,431	25,772	20,431	19,879	25,780	25,780
	Host Home				766	564	600	177	33	474	474
	Group 1 to 3				DNF	1,110	DNF	492	128	334	334
People in Congregate Settings	Group 4 to 6				DNF	7,439	DNF	3,634	1,937	2,317	2,317
	Group 1 to 6	1,306	3,529	7,513	10,729	8,549	DNF	4,126	2,065	2,651	2,651
	Group 7 to 15		1,868	0	0	1,904	DNF	640	290	387	387
	Group 16+	9,002	5,705	1,013	190	754	DNF	341	194	209	209
People Served by the DD Agency *	Caseload (known to the DD agency)							DNF	DNF	45,115	45,115
	LTSS Recipients (1)	1,306	11,102	8,526	23,718	37,521	47,546	38,575	36,179	44,784	44,784
	Waiting for Medicaid Waiver				0	DNF	DNF	DNF	DNF	0	0
People in Non-DD Settings *	Nursing Facility (s)				357	509	609	609	607	411	411
	Psychiatric Facility (2)			0	0	0	0	DNF	0	0	0
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$27,632	\$38,448	\$48,974	DNF	\$32,363	\$32,363	\$31,866	\$31,866
	ICF/IID Expenditures per Person			\$116,394	\$109,363	\$0	\$0	\$0	\$0	\$0	\$0
	Waiver Recipients per 100,000			22.7	85.0	86.9	403.1	369.9	369.3	454.7	454.4
	ICF/IID Residents per 100,000			30.4	1.9	0.0	0.0	0.0	0.0	0.0	0.0

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

(2) Includes only state operated psychiatric facilities until 2013.

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RISP Profile FY 2016

Minnesota

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

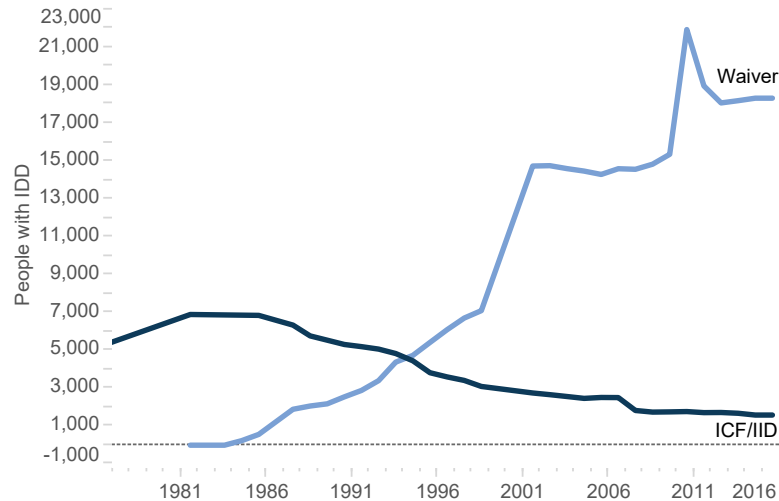


Figure 2: Medicaid Spending Per Person FY 2016

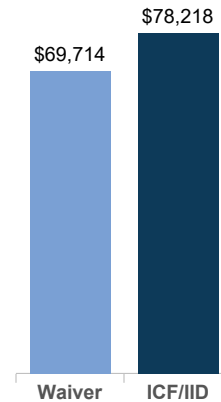


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

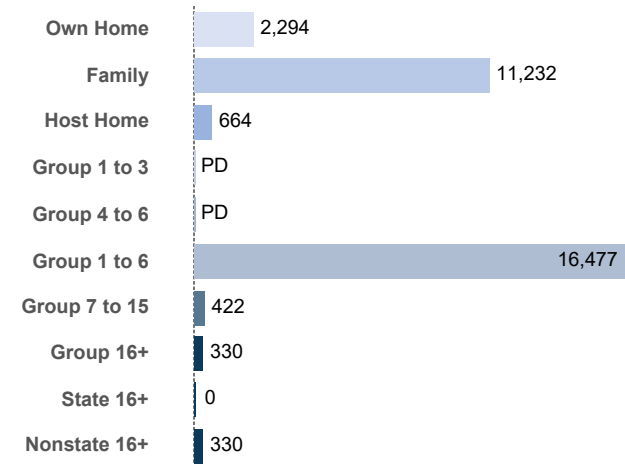


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				2,092	2,418	1,384	2,716	2,638	2,294	2,294
	Family				15,231	14,678	10,332	11,003	11,009	11,232	11,232
	Host Home			525	1,507	922	1,438	1,168	953	664	664
	Group 1 to 3				833	1,067	DNF	PD	PD	PD	PD
People in Congregate Settings	Group 4 to 6				6,909	8,800	DNF	PD	PD	PD	PD
	Group 1 to 6	286	652	4,504	7,742	9,867	DNF	9,461	15,780	16,477	16,477
	Group 7 to 15	911	1,805	1,853	1,027	589	DNF	452	436	422	422
	Group 16+	4,985	4,612	3,027	838	401	DNF	387	379	330	330
People Served by the DD Agency *	Caseload (known to the DD agency)							31,104	31,282	31,486	31,486
	LTSS Recipients (1)	6,182	7,069	9,909	28,437	28,875	25,586	31,059	31,251	31,474	31,474
	Waiting for Medicaid Waiver				3,855	3,243	2,718	3,630	3,575	3,564	3,564
People in Non-DD Settings *	Nursing Facility (s)			827	246	218	218	154	155	155	155
	Psychiatric Facility (2)			0	0	0	0	18	4	DNF	DNF
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$31,103	\$58,640	\$65,005	\$64,076	\$64,252	\$65,503	\$69,714	\$69,714
	ICF/IID Expenditures per Person			\$50,162	\$69,387	\$96,195	\$87,415	\$71,034	\$73,867	\$78,218	\$78,218
	Waiver Recipients per 100,000			57.6	281.9	289.5	352.5	333.3	333.2	333.6	331.8
	ICF/IID Residents per 100,000			120.0	48.1	33.1	32.0	31.8	30.9	29.0	28.8

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RISP Profile FY 2016

Mississippi

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

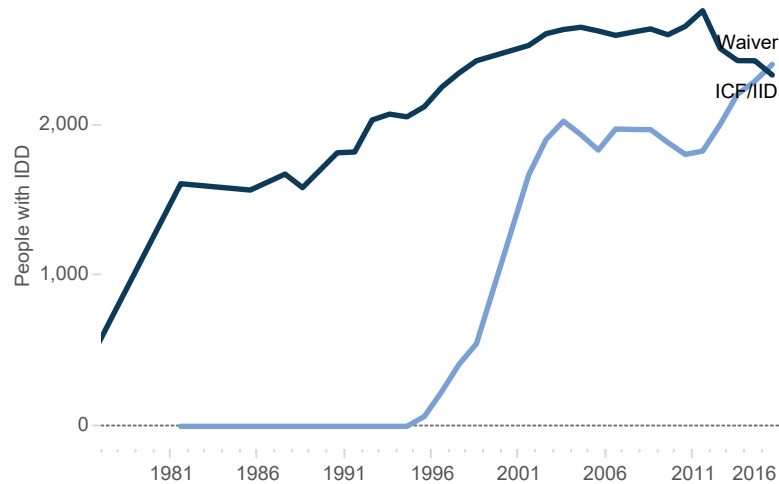


Figure 2: Medicaid Spending Per Person FY 2016

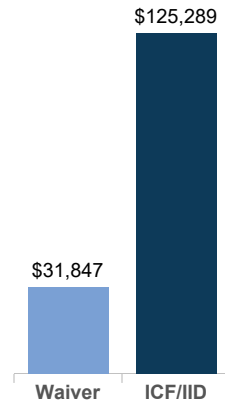


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

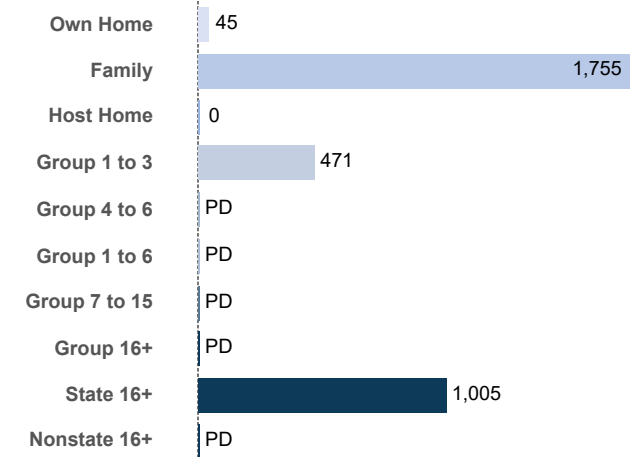


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				127	60	15	26	26	26	45
	Family				1,378	1,693	1,087	1,680	DNF	1,700	1,755
	Host Home				0	0	0	0	DNF	0	0
	Group 1 to 3				437	309	184	254	285	622	471
People in Congregate Settings	Group 4 to 6				123	80	128	158	PD	318	PD
	Group 1 to 6	17	67	310	560	388	312	412	PD	940	PD
	Group 7 to 15	102	210	115	718	682	652	605	PD	717	PD
	Group 16+	2,055	2,201	2,081	2,036	2,036	2,173	1,944	PD	1,778	PD
People Served by the DD Agency *	Caseload (known to the DD agency)							DNF	DNF	7,140	6,554
	LTSS Recipients (1)	2,174	2,478	2,506	4,819	4,859	4,396	4,667	4,786	5,161	5,007
	Waiting for Medicaid Waiver				DNF	DNF	DNF	DNF	DNF	1,828	1,441
People in Non-DD Settings *	Nursing Facility (s)			300	172	140	140	371	346	426	381
	Psychiatric Facility (2)			0	0	0	0	DNF	DNF	6	DNF
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$0	\$18,814	\$18,869	DNF	\$24,558	\$31,502	\$31,086	\$31,847
	ICF/IID Expenditures per Person			\$23,736	\$78,761	\$103,469	\$97,753	\$112,743	\$118,589	\$87,115	\$125,289
	Waiver Recipients per 100,000			0.0	66.4	83.6	DNF	67.1	73.8	76.7	80.6
	ICF/IID Residents per 100,000			70.2	90.9	63.6	92.6	84.0	81.3	81.3	54.0

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

(2) Includes only state operated psychiatric facilities until 2013.

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Updated 3/12/2018

RISP Profile FY 2016

Missouri

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

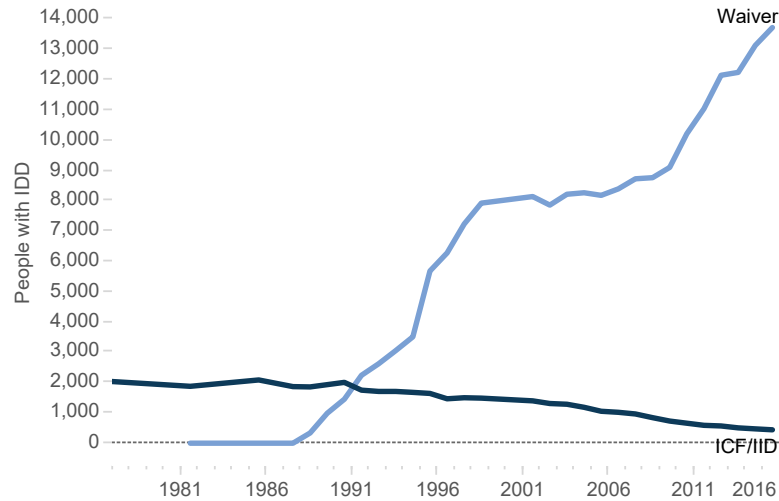


Figure 2: Medicaid Spending Per Person FY 2016

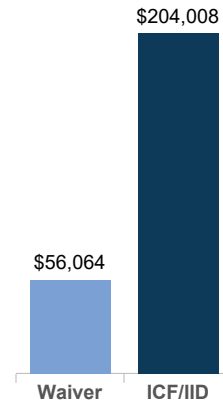


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

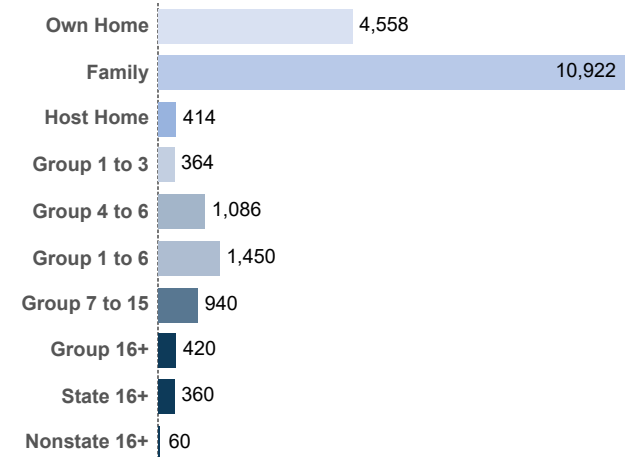


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				2,391	3,230	3,984	4,131	4,170	4,363	4,558
	Family				7,644	6,199	8,089	8,955	9,599	10,136	10,922
	Host Home				41	19	20	208	375	397	414
	Group 1 to 3				492	422	468	355	351	330	364
People in Congregate Settings	Group 4 to 6				330	1,276	1,156	1,197	1,112	1,033	1,086
	Group 1 to 6	599	470	1,368	1,313	1,698	1,624	1,552	1,463	1,363	1,450
	Group 7 to 15	1,059	1,180	1,700	1,224	976	1,108	1,126	1,072	1,080	940
	Group 16+	4,847	4,331	2,804	1,351	766	623	575	546	469	420
People Served by the DD Agency *	Caseload (known to the DD agency)							31,369	32,219	33,289	34,802
	LTSS Recipients (1)	6,505	5,981	5,872	13,964	12,888	16,869	16,578	17,225	17,808	18,704
	Waiting for Medicaid Waiver				491	206	200	1,113	898	356	262
People in Non-DD Settings *	Nursing Facility (s)			1,400	878	DNF	1,045	1,078	1,064	1,051	1,148
	Psychiatric Facility (2)			10	69	425	376	259	253	DNF	DNF
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$19,541	\$31,379	\$50,864	\$48,362	\$50,223	\$54,582	\$53,333	\$56,064
	ICF/IID Expenditures per Person			\$51,212	\$216,630	\$183,157	\$183,845	\$171,805	\$176,976	\$181,689	\$204,008
	Waiver Recipients per 100,000			43.9	142.5	153.0	183.3	201.0	201.9	215.9	225.2
	ICF/IID Residents per 100,000			38.9	20.4	12.2	9.8	9.4	8.3	7.8	7.2

(1) Long Term Supports and Service (LTSS) recipients may include imputed values; Until 2012 LTSS recipients may include people in nursing homes or psychiatric facilities who were not on the IDD agency caseload.
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RISP Profile FY 2016

Montana

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

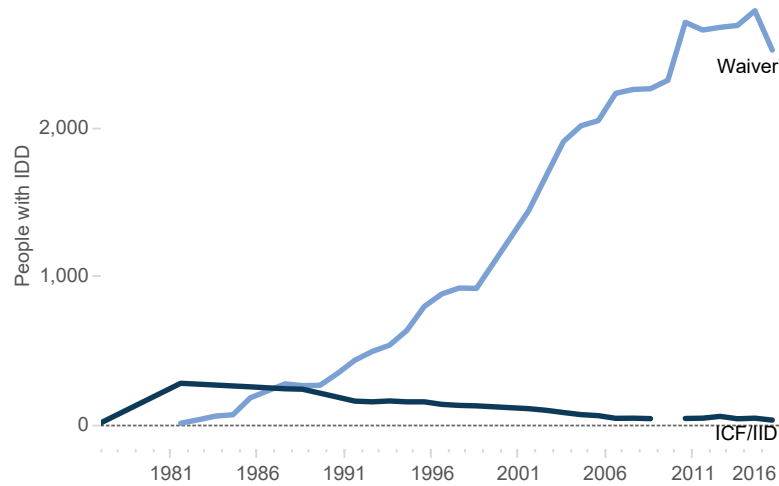


Figure 2: Medicaid Spending Per Person FY 2016

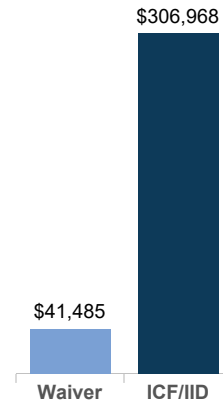


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

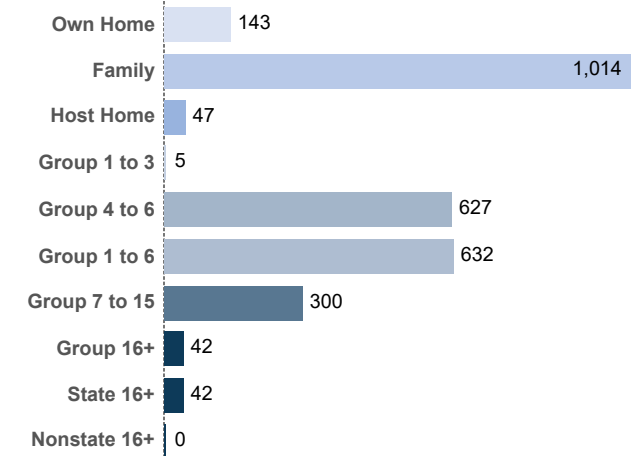


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				586	650	100	100	150	100	143
	Family				2,068	2,400	800	750	670	710	1,014
	Host Home				181	240	42	45	43	50	47
	Group 1 to 3				226	200	650	6	5	5	5
People in Congregate Settings	Group 4 to 6				286	380	661	504	536	708	627
	Group 1 to 6	86	93	615	512	600	1,311	510	541	713	632
	Group 7 to 15	339	415	523	398	400	415	632	632	725	300
	Group 16+	340	273	422	79	55	55	53	51	55	42
People Served by the DD Agency *	Caseload (known to the DD agency)							3,367	2,699	3,195	3,514
	LTSS Recipients (1)	765	781	1,560	3,824	4,345	2,803	2,374	2,087	2,353	2,178
	Waiting for Medicaid Waiver				560	691	635	676	705	953	1,233
People in Non-DD Settings *	Nursing Facility (s)			232	163	DNF	80	89	114	95	120
	Psychiatric Facility (2)			1	1	0	0	DNF	DNF	DNF	DNF
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$21,670	\$28,619	\$42,448	\$34,060	\$34,240	\$44,731	\$43,110	\$41,485
	ICF/IID Expenditures per Person			\$71,236	\$156,333	\$0	\$267,531	\$153,688	\$218,028	\$215,506	\$306,968
	Waiver Recipients per 100,000			43.9	216.2	235.5	265.4	264.6	263.7	270.9	243.0
	ICF/IID Residents per 100,000			24.4	8.4	DNF	5.5	6.6	5.0	5.3	3.8

(1) Long Term Supports and Service (LTSS) recipients may include imputed values; Until 2012 LTSS recipients may include people in nursing homes or psychiatric facilities who were not on the IDD agency caseload.
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RISP Profile FY 2016

Nebraska

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

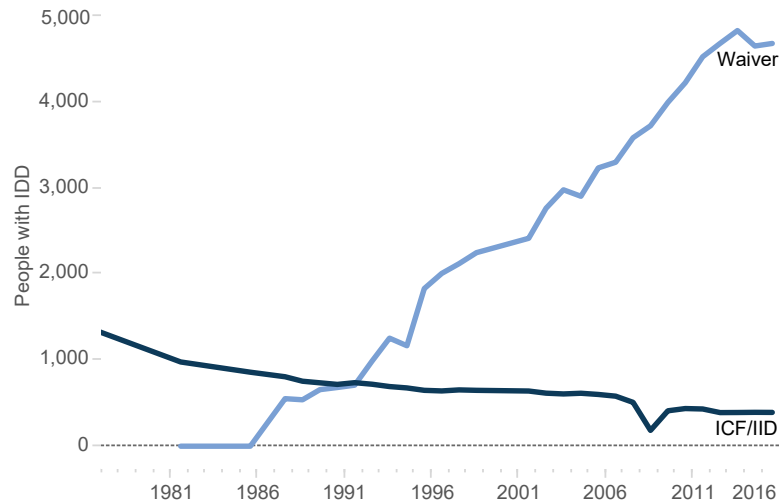


Figure 2: Medicaid Spending Per Person FY 2016

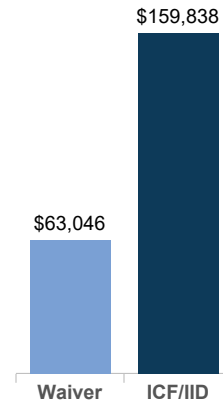


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

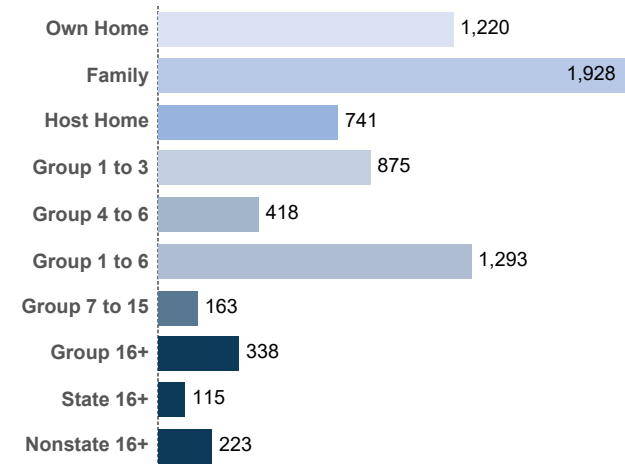


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				779	1,132	1,322	1,330	1,385	1,373	1,220
	Family				210	904	1,130	1,347	1,302	1,426	1,928
	Host Home				244	404	574	708	730	705	741
	Group 1 to 3				933	1,025	904	1,198	883	1,130	875
People in Congregate Settings	Group 4 to 6				494	520	658	447	500	250	418
	Group 1 to 6	195	344	1,399	1,427	1,545	1,562	1,645	1,383	1,380	1,293
	Group 7 to 15	551	398	308	213	89	121	100	172	191	163
	Group 16+	1,553	980	717	607	402	380	345	333	331	338
People Served by the DD Agency *	Caseload (known to the DD agency)							8,537	8,431	8,592	7,979
	LTSS Recipients (1)	2,299	1,722	2,424	3,480	4,476	5,396	5,477	5,324	5,433	5,684
	Waiting for Medicaid Waiver				1,227	1,639	1,875	1,775	1,811	1,838	2,149
People in Non-DD Settings *	Nursing Facility (s)			613	117	379	307	205	228	177	177
	Psychiatric Facility (2)			0	0	0	0	2	1	2	4
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$28,652	\$40,819	\$51,323	\$52,951	\$37,452	\$36,005	\$35,358	\$63,046
	ICF/IID Expenditures per Person			\$42,086	\$96,500	\$83,283	\$130,002	\$83,396	\$81,743	\$79,978	\$159,838
	Waiver Recipients per 100,000			42.9	165.3	219.0	244.2	250.8	257.0	245.5	245.7
	ICF/IID Residents per 100,000			45.1	35.0	22.6	23.3	20.9	20.8	20.8	20.6

(1) Long Term Supports and Service (LTSS) recipients may include imputed values; Until 2012 LTSS recipients may include people in nursing homes or psychiatric facilities who were not on the IDD agency caseload.
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RISP Profile FY 2016

Nevada

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

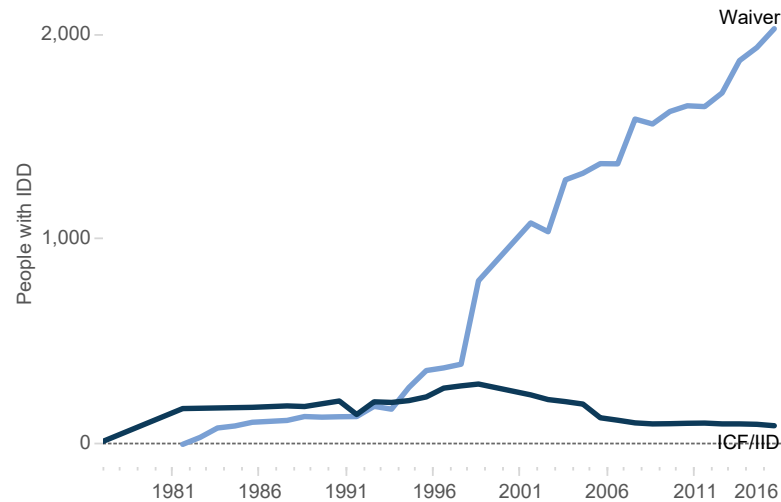


Figure 2: Medicaid Spending Per Person FY 2016

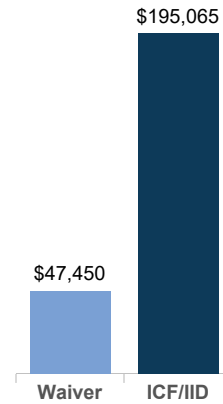


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

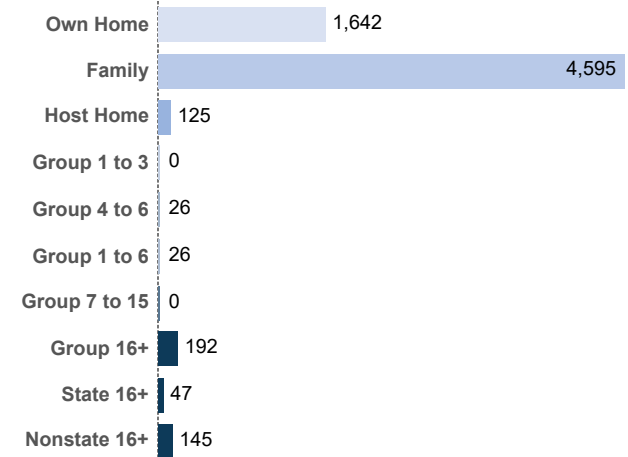


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016	
People in Individualized Settings	Own Home				1,293	1,348	1,530	1,597	1,635	1,662	1,642	
	Family				2,418	3,621	3,826	3,879	4,122	4,371	4,595	
	Host Home				39	70	75	71	80	85	125	
	Group 1 to 3				0	0	10	0	0	0	0	
People in Congregate Settings	Group 4 to 6				90	36	36	45	35	33	26	
	Group 1 to 6	61	116	389	90	36	46	45	35	33	26	
	Group 7 to 15	20	25	15	0	0	6	0	0	0	0	
	Group 16+	166	160	177	107	107	152	170	174	181	192	
People Served by the DD Agency *	Caseload (known to the DD agency)							5,744	6,028	6,332	6,580	
	LTSS Recipients (1)	247	301	581	3,947	5,182	5,716	5,762	6,046	6,332	6,580	
	Waiting for Medicaid Waiver				407	109	188	620	739	712	752	
People in Non-DD Settings *	Nursing Facility (s)			31	31	88	81	87	98	114	112	
	Psychiatric Facility (2)			0	0	0	0	0	0	0	0	
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person				\$16,563	\$32,379	\$44,517	\$47,680	\$43,985	\$49,786	\$49,085	\$47,450
	ICF/IID Expenditures per Person				\$59,019	\$134,379	\$182,906	\$171,590	\$177,377	\$185,757	\$178,629	\$195,065
	Waiver Recipients per 100,000				10.5	54.9	60.3	59.9	61.6	66.1	67.1	69.1
	ICF/IID Residents per 100,000				16.5	8.2	3.7	3.8	3.6	3.5	3.4	3.1

(1) Long Term Supports and Service (LTSS) recipients may include imputed values; Until 2012 LTSS recipients may include people in nursing homes or psychiatric facilities who were not on the IDD agency caseload.
 (2) Includes only state operated psychiatric facilities until 2013.
 (s) Data may be from an outside source.

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RISP Profile FY 2016

New Hampshire

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

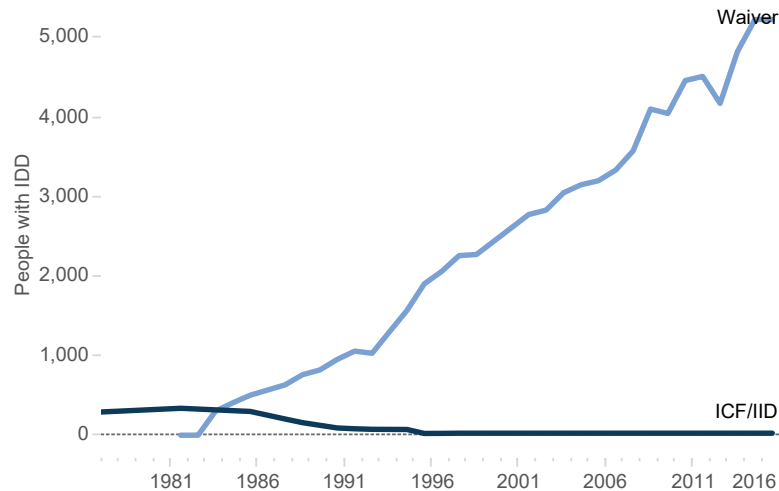


Figure 2: Medicaid Spending Per Person FY 2016

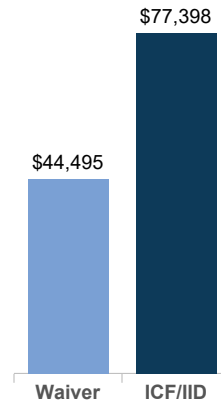


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

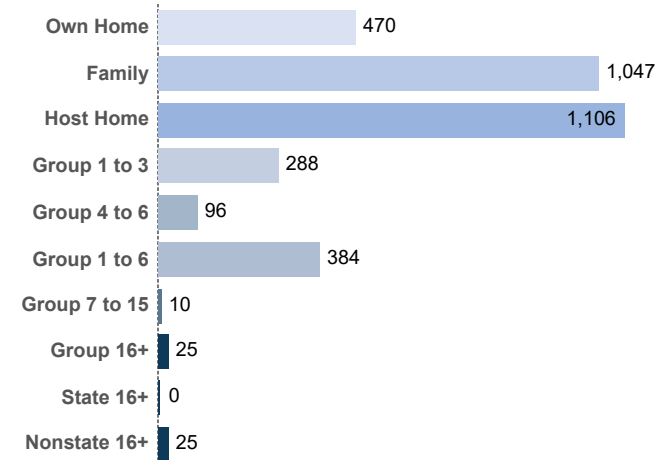


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				334	434	478	485	488	470	470
	Family				424	506	924	849	902	1,047	1,047
	Host Home				1,016	1,139	933	1,194	1,204	1,106	1,106
	Group 1 to 3				283	310	227	296	265	288	288
People in Congregate Settings	Group 4 to 6				78	75	62	80	84	96	96
	Group 1 to 6	62	152	1,147	361	385	289	376	349	384	384
	Group 7 to 15	81	141	132	22	22	12	18	18	10	10
	Group 16+	694	651	25	25	25	25	25	25	25	25
People Served by the DD Agency *	Caseload (known to the DD agency)							4,415	4,913	5,235	5,235
	LTSS Recipients (1)	837	944	1,304	2,182	2,511	2,749	2,947	2,986	3,042	3,042
	Waiting for Medicaid Waiver				119	19	49	242	79	79	79
People in Non-DD Settings *	Nursing Facility (s)			26	87	61	84	85	79	108	108
	Psychiatric Facility (2)			1	0	0	0	DNF	DNF	DNF	DNF
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$41,047	\$40,366	\$43,152	\$42,493	\$47,488	\$43,202	\$44,495	\$44,495
	ICF/IID Expenditures per Person			\$74,815	\$93,931	\$124,423	\$126,168	\$73,648	PD	\$88,793	\$77,398
	Waiver Recipients per 100,000			86.4	240.8	307.8	342.2	315.8	364.3	393.4	392.2
	ICF/IID Residents per 100,000			8.2	1.9	1.9	1.9	1.9	1.9	1.9	1.9

(1) Long Term Supports and Service (LTSS) recipients may include imputed values; Until 2012 LTSS recipients may include people in nursing homes or psychiatric facilities who were not on the IDD agency caseload.
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RISP Profile FY 2016

New Jersey

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

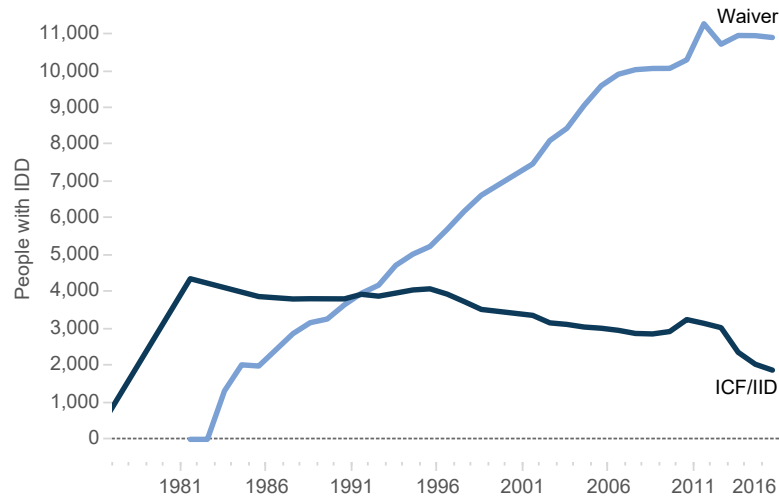


Figure 2: Medicaid Spending Per Person FY 2016

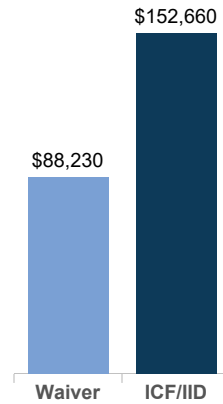


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

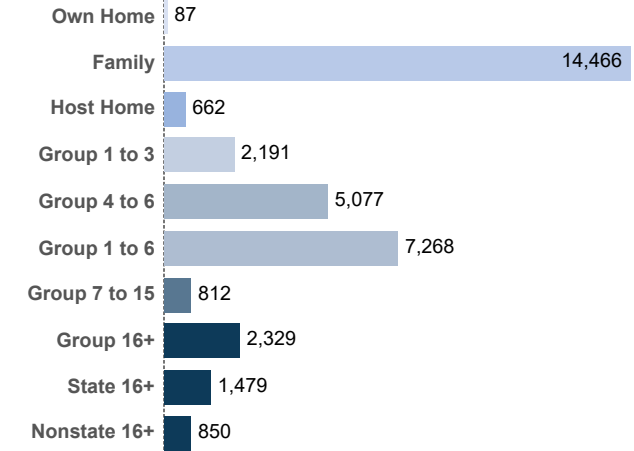


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				782	728	125	134	124	97	87
	Family				23,095	30,134	30,529	16,275	15,615	13,248	14,466
	Host Home				1,432	1,126	999	907	804	728	662
	Group 1 to 3				1,404	3,598	2,100	2,133	2,210	2,207	2,191
People in Congregate Settings	Group 4 to 6				2,956	4,329	4,167	4,292	4,375	4,905	5,077
	Group 1 to 6	280	1,076	3,954	4,359	7,927	6,267	6,425	6,585	7,112	7,268
	Group 7 to 15	197	439	0	782	931	1,437	945	922	842	812
	Group 16+	8,836	7,216	4,932	3,783	3,671	3,240	3,534	2,846	2,394	2,329
People Served by the DD Agency *	Caseload (known to the DD agency)							43,500	29,000	25,330	26,523
	LTSS Recipients (1)	9,313	8,731	8,886	34,233	44,517	43,700	28,220	26,896	24,421	25,624
	Waiting for Medicaid Waiver				3,384	DNF	DNF	3,932	3,765	3,664	3,201
People in Non-DD Settings *	Nursing Facility (s)			210	714	DNF	1,043	1,070	919	868	856
	Psychiatric Facility (2)			6	DNF	0	60	61	49	41	45
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$25,035	\$43,995	\$55,351	\$65,316	\$65,968	\$75,146	\$79,925	\$88,230
	ICF/IID Expenditures per Person			\$74,922	\$185,243	\$211,403	\$213,240	\$229,696	\$280,909	\$249,110	\$152,660
	Waiver Recipients per 100,000			47.1	104.1	114.7	127.4	120.7	122.8	122.5	122.1
	ICF/IID Residents per 100,000			49.2	35.0	33.3	35.6	34.1	26.5	22.8	16.5

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

(2) Includes only state operated psychiatric facilities until 2013.

(s) Data may be from an outside source.

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RISP Profile FY 2016

New Mexico

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

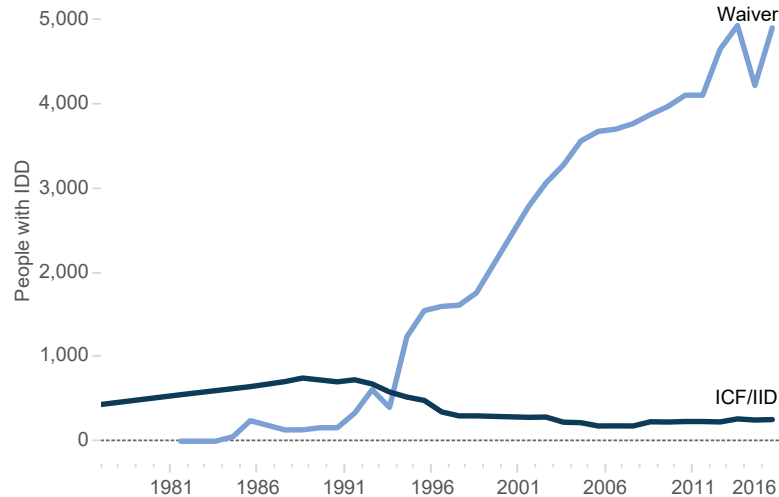


Figure 2: Medicaid Spending Per Person FY 2016

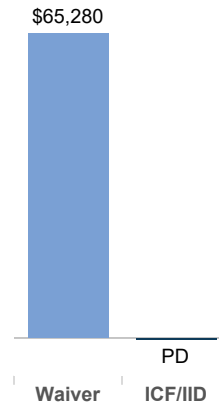


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

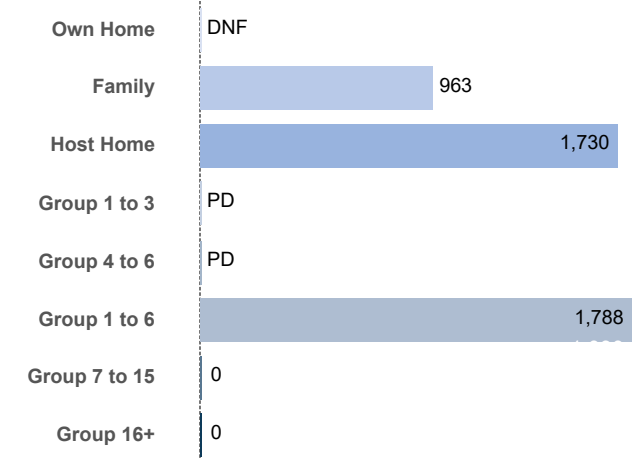


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				471	451	274	70	DNF	DNF	DNF
	Family				942	1,565	651	1,160	944	985	963
	Host Home				391	422	0	1,915	1,808	1,844	1,730
	Group 1 to 3				737	752	2,934	PD	PD	674	PD
People in Congregate Settings	Group 4 to 6				206	363	134	PD	PD	1,144	PD
	Group 1 to 6	113	139	396	943	1,115	3,068	246	1,789	1,818	1,788
	Group 7 to 15	100	155	360	130	120	120	120	0	0	0
	Group 16+	581	552	473	0	0	0	0	0	0	0
People Served by the DD Agency *	Caseload (known to the DD agency)							11,534	10,674	11,328	11,751
	LTSS Recipients (1)	794	846	1,229	2,877	3,673	4,222	3,511	5,663	4,722	5,744
	Waiting for Medicaid Waiver				3,359	4,998	4,998	6,248	6,133	6,365	6,516
People in Non-DD Settings *	Nursing Facility (s)			88	110	103	109	96	99	100	81
	Psychiatric Facility (2)			0	0	0	0	DNF	DNF	DNF	DNF
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$19,944	\$62,374	\$73,966	\$69,489	\$64,504	\$56,052	\$44,878	\$65,280
	ICF/IID Expenditures per Person			\$49,249	\$96,016	\$108,309	\$106,937	\$109,070	\$97,692	\$104,308	PD
	Waiver Recipients per 100,000			10.3	185.2	193.3	197.3	223.6	237.0	202.9	236.2
	ICF/IID Residents per 100,000			45.6	11.4	11.1	11.2	11.0	12.7	12.1	12.3

(1) Long Term Supports and Service (LTSS) recipients may include imputed values; Until 2012 LTSS recipients may include people in nursing homes or psychiatric facilities who were not on the IDD agency caseload.
 (2) Includes only state operated psychiatric facilities until 2013.
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RISP Profile FY 2016

New York

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

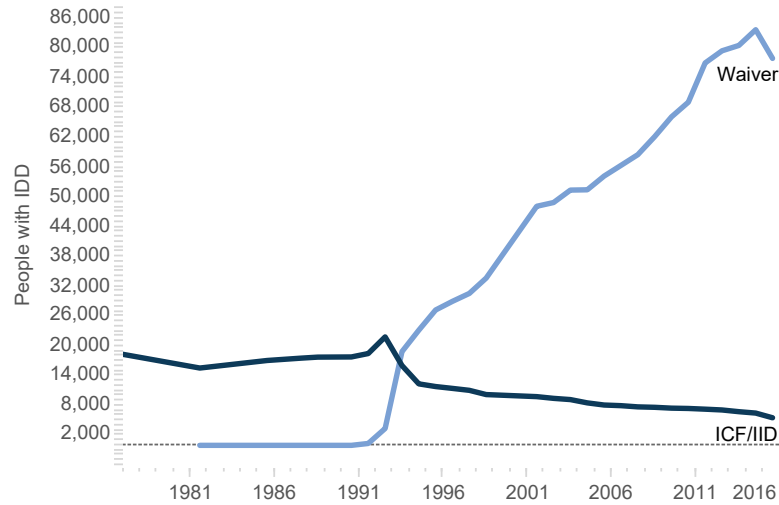


Figure 2: Medicaid Spending Per Person FY 2016

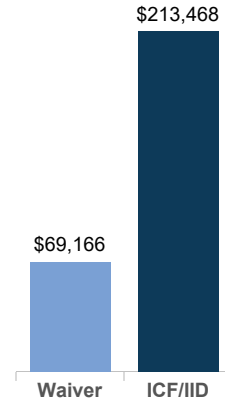


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

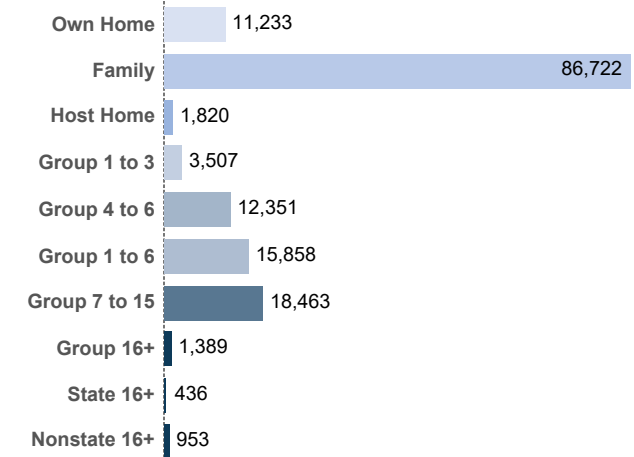


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				7,690	7,911	9,109	9,481	10,350	10,894	11,233
	Family				79,476	76,814	78,744	81,178	80,686	83,052	86,722
	Host Home				3,322	2,471	2,307	2,178	2,059	1,949	1,820
	Group 1 to 3				3,234	3,313	3,348	3,366	3,390	3,481	3,507
People in Congregate Settings	Group 4 to 6				8,769	11,420	11,697	11,784	12,067	12,201	12,351
	Group 1 to 6	3,496	4,271	6,165	12,030	14,703	15,045	15,150	15,457	15,682	15,858
	Group 7 to 15	1,817	5,609	15,751	19,039	18,788	18,822	18,533	18,588	18,462	18,463
	Group 16+	21,239	15,437	9,130	3,348	2,941	2,623	1,408	1,615	1,661	1,389
People Served by the DD Agency *	Caseload (known to the DD agency)							128,271	128,635	131,789	135,428
	LTSS Recipients (1)	26,552	25,317	31,046	124,905	123,628	128,551	128,949	129,217	131,914	135,638
	Waiting for Medicaid Waiver				5,273	3,864	6,971	DNF	0	0	0
People in Non-DD Settings *	Nursing Facility (s)			1,550	1,215	DNF	1,901	1,901	1,791	1,552	1,581
	Psychiatric Facility (2)			20	0	0	0	DNF	DNF	DNF	DNF
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$0	\$61,363	\$72,031	\$70,973	\$67,038	\$60,814	\$60,959	\$69,166
	ICF/IID Expenditures per Person			\$92,299	\$317,721	\$450,043	\$444,470	\$380,254	\$214,260	\$205,740	\$213,468
	Waiver Recipients per 100,000			0.0	267.4	341.5	393.7	404.5	408.0	423.0	394.8
	ICF/IID Residents per 100,000			98.6	44.4	38.7	37.2	36.3	34.3	32.8	28.1

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

(2) Includes only state operated psychiatric facilities until 2013.

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RISP Profile FY 2016

North Carolina

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

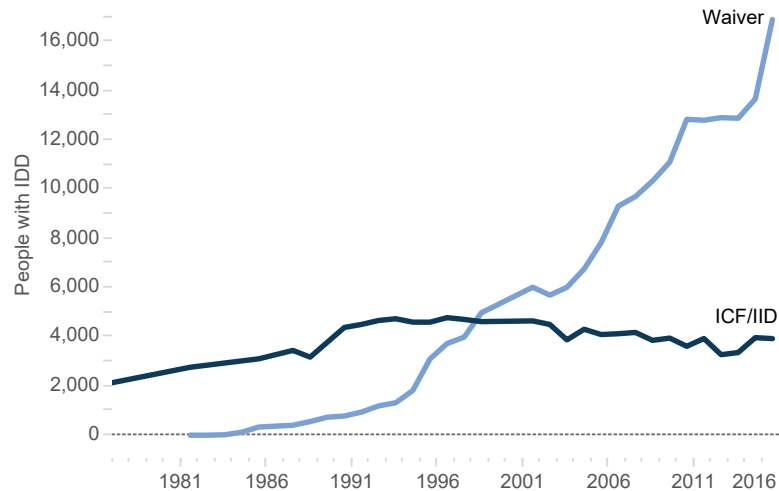


Figure 2: Medicaid Spending Per Person FY 2016

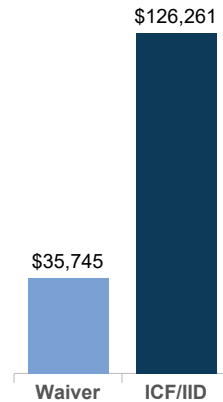


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

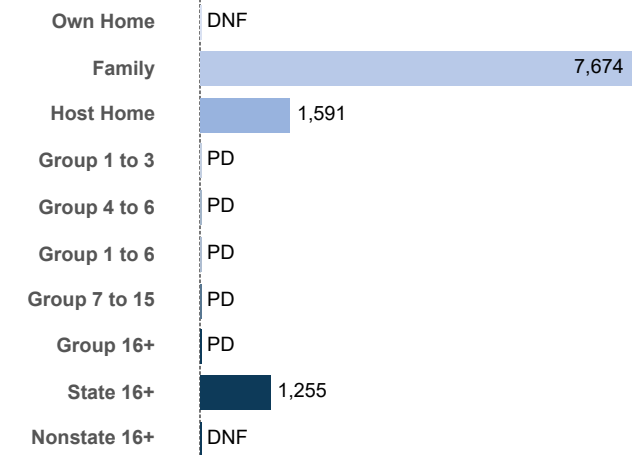


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				2,292	1,486	1,536	1,536	DNF	DNF	DNF
	Family				17,058	13,389	13,765	13,765	DNF	DNF	7,674
	Host Home				295	1,128	1,400	1,400	DNF	DNF	1,591
	Group 1 to 3				DNF	DNF	DNF	PD	PD	PD	PD
People in Congregate Settings	Group 4 to 6				DNF	1,526	DNF	PD	PD	PD	PD
	Group 1 to 6	239	484	2,643	5,815	3,575	3,280	PD	PD	PD	PD
	Group 7 to 15	153	179	251	1,062	346	DNF	PD	PD	PD	PD
	Group 16+	4,032	3,778	3,134	2,468	2,170	DNF	PD	PD	PD	PD
People Served by the DD Agency *	Caseload (known to the DD agency)							21,138	25,026	34,458	29,142
	LTSS Recipients (1)	4,424	4,441	6,028	28,990	22,094	26,727	21,824	24,381	28,975	20,394
	Waiting for Medicaid Waiver				DNF	397	8,425	9,900	9,130	9,569	10,687
People in Non-DD Settings *	Nursing Facility (s)			465	531	4,258	4,086	752	DNF	717	805
	Psychiatric Facility (2)			4	91	DNF	86	76	92	DNF	322
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$16,450	\$39,530	\$54,831	\$48,422	\$34,266	\$58,661	\$50,432	\$35,745
	ICF/IID Expenditures per Person			\$57,292	\$103,802	\$124,544	\$134,533	\$65,334	\$140,706	\$99,183	\$126,261
	Waiver Recipients per 100,000			11.6	77.8	116.3	131.3	131.1	129.5	136.1	166.5
	ICF/IID Residents per 100,000			65.0	49.6	41.4	40.3	33.2	33.8	39.5	31.1

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

(2) Includes only state operated psychiatric facilities until 2013.

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RISP Profile FY 2016

North Dakota

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

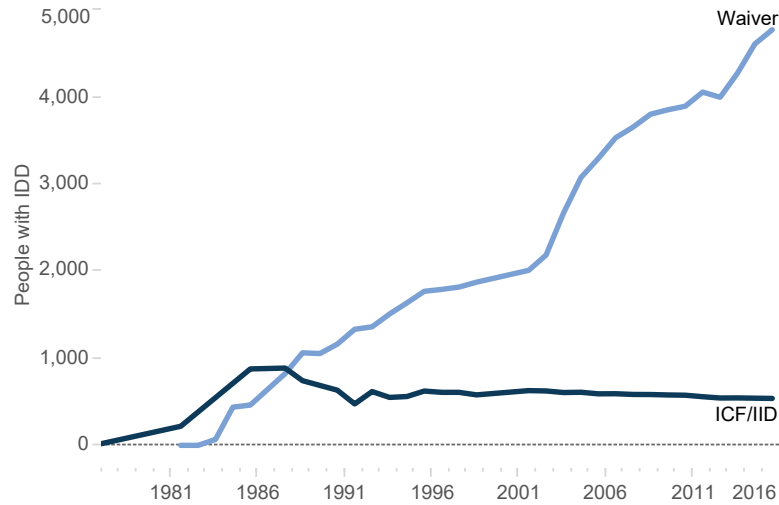


Figure 2: Medicaid Spending Per Person FY 2016

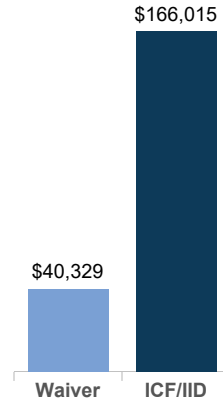


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

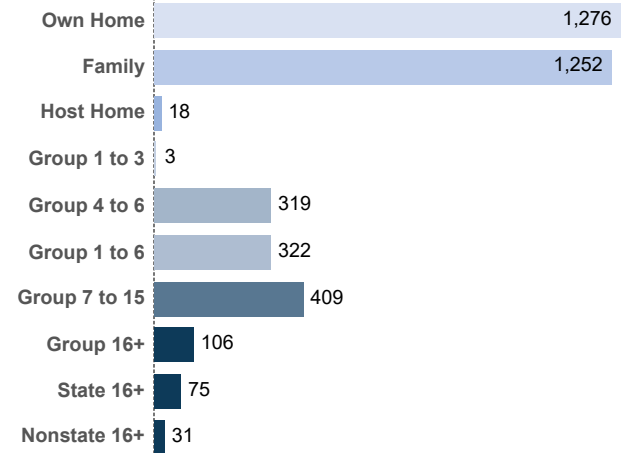


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				1,070	1,267	1,126	1,159	1,241	1,262	1,276
	Family				569	907	1,225	1,159	1,037	1,031	1,252
	Host Home				27	27	20	23	24	24	18
	Group 1 to 3				0	0	0	0	0	3	3
People in Congregate Settings	Group 4 to 6				192	251	241	258	268	287	319
	Group 1 to 6	23	12	965	192	251	241	258	268	290	322
	Group 7 to 15	47	146	595	536	487	520	486	469	437	409
	Group 16+	1,306	1,076	278	194	145	124	117	116	109	106
People Served by the DD Agency *	Caseload (known to the DD agency)							4,175	5,062	4,970	7,204
	LTSS Recipients (1)	1,376	1,234	1,838	2,588	3,084	3,356	3,202	3,155	3,153	3,383
	Waiting for Medicaid Waiver				0	0	0	0	0	0	0
People in Non-DD Settings *	Nursing Facility (s)			182	118	193	100	108	122	119	122
	Psychiatric Facility (2)			1	0	0	0	8	2	5	1
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$14,046	\$18,683	\$25,336	\$31,933	\$35,531	\$39,473	\$39,169	\$40,329
	ICF/IID Expenditures per Person			\$64,077	\$107,014	\$155,783	\$165,596	\$175,601	\$177,745	\$151,157	\$166,015
	Waiver Recipients per 100,000			26.6	483.3	573.3	580.2	552.9	578.4	609.4	630.1
	ICF/IID Residents per 100,000			99.8	95.8	86.1	79.9	75.2	73.7	61.2	61.2

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

(2) Includes only state operated psychiatric facilities until 2013.

(s) Data may be from an outside source.

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

DNF = Did Not Furnished.

PD = Partial Data.

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

RISP Profile FY 2016

Ohio

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

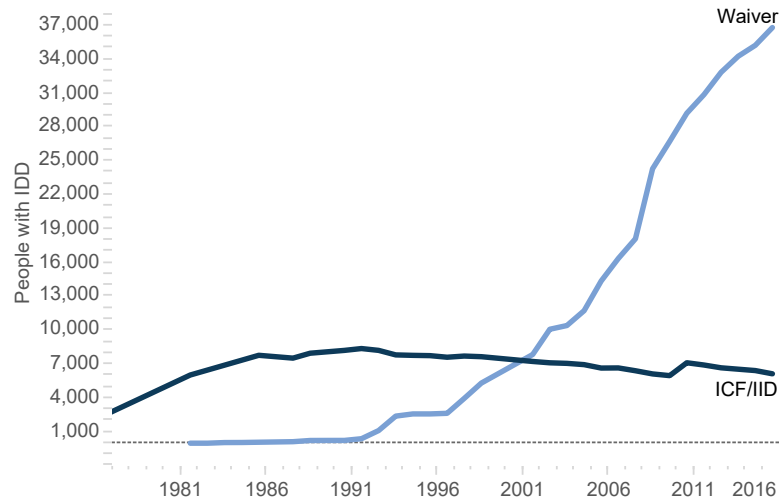


Figure 2: Medicaid Spending Per Person FY 2016

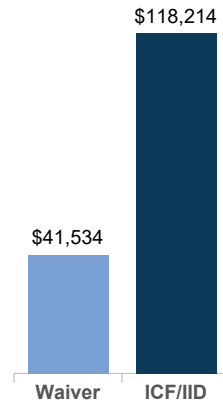


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

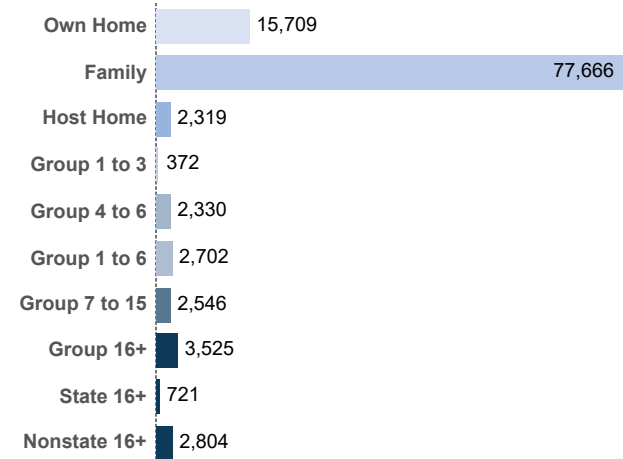


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				3,110	11,032	13,641	14,837	15,326	15,651	15,709
	Family				12,831	19,939	58,851	69,358	71,969	73,518	77,666
	Host Home				908	892	2,123	2,309	2,239	2,312	2,319
	Group 1 to 3				DNF	DNF	873	392	390	386	372
People in Congregate Settings	Group 4 to 6				DNF	432	2,245	2,251	2,234	2,238	2,330
	Group 1 to 6	620	1,347	3,707	2,660	3,623	3,118	2,643	2,624	2,624	2,702
	Group 7 to 15	768	1,587	2,993	2,609	2,817	2,618	2,660	2,668	2,614	2,546
	Group 16+	9,429	7,938	6,907	4,752	3,861	4,364	4,116	3,984	3,856	3,525
People Served by the DD Agency *	Caseload (known to the DD agency)							100,699	101,240	103,063	105,417
	LTSS Recipients (1)	10,817	10,872	13,607	26,870	42,164	86,677	100,699	101,244	103,130	105,417
	Waiting for Medicaid Waiver				DNF	DNF	DNF	31,630	29,660	30,526	31,467
People in Non-DD Settings *	Nursing Facility (s)			2,823	DNF	DNF	1,962	1,962	1,521	1,427	1,406
	Psychiatric Facility (2)			0	0	0	0	DNF	DNF	DNF	DNF
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$0	\$40,623	\$40,984	\$40,194	\$40,183	\$40,133	\$40,691	\$41,534
	ICF/IID Expenditures per Person			\$45,433	\$144,425	\$127,512	\$112,557	\$113,544	\$115,103	\$114,418	\$118,214
	Waiver Recipients per 100,000			0.0	102.4	231.7	267.5	283.9	295.6	303.5	317.0
	ICF/IID Residents per 100,000			75.1	60.7	51.9	60.0	57.7	56.5	54.8	52.9

(1) Long Term Supports and Service (LTSS) recipients may include imputed values; Until 2012 LTSS recipients may include people in nursing homes or psychiatric facilities who were not on the IDD agency caseload.
 (2) Includes only state operated psychiatric facilities until 2013.
 (s) Data may be from an outside source.

Settings by size includes ICF/IID, group homes, and nonstate other.
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RISP Profile FY 2016

Oklahoma

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

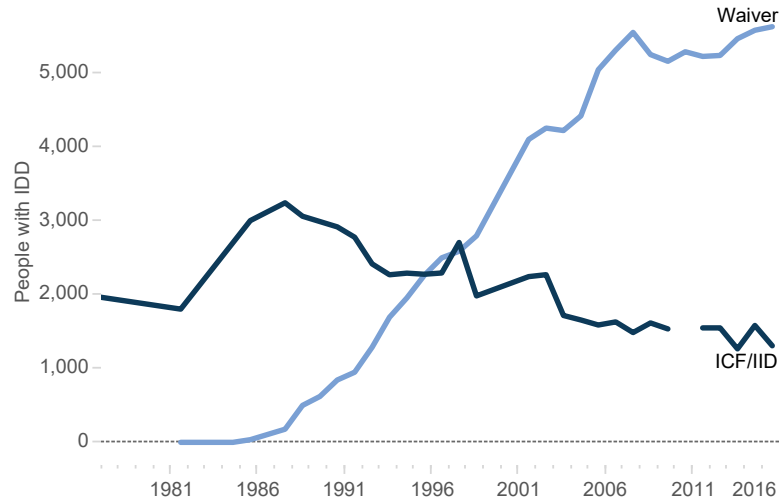


Figure 2: Medicaid Spending Per Person FY 2016

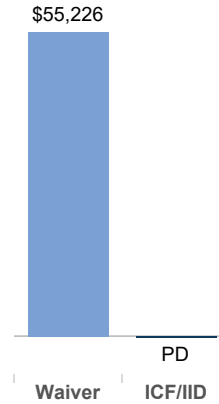


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

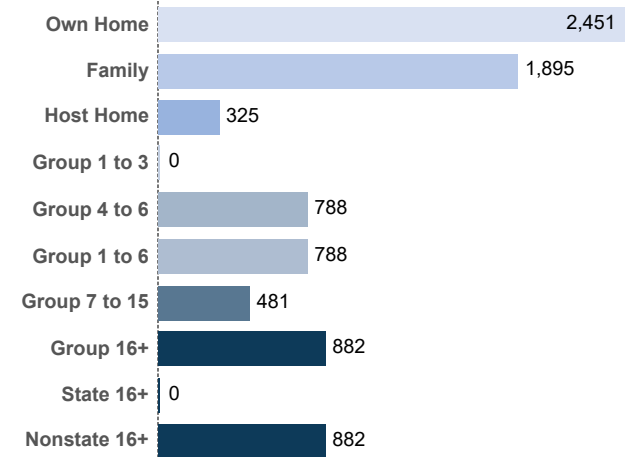


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				2,300	1,636	1,667	1,732	1,898	2,414	2,451
	Family				4,460	2,516	2,363	2,383	2,460	1,969	1,895
	Host Home				542	429	407	399	376	350	325
	Group 1 to 3				21	0	0	0	0	0	0
People in Congregate Settings	Group 4 to 6				802	740	752	PD	PD	818	788
	Group 1 to 6	11	6	720	823	743	752	PD	PD	818	788
	Group 7 to 15	19	86	283	326	461	574	PD	PD	598	481
	Group 16+	3,082	2,920	3,852	1,270	1,091	1,009	PD	PD	967	882
People Served by the DD Agency *	Caseload (known to the DD agency)							14,347	14,550	13,809	14,279
	LTSS Recipients (1)	3,112	3,012	4,855	9,721	6,876	7,087	6,837	6,806	7,116	6,822
	Waiting for Medicaid Waiver				3,853	5,737	6,808	7,044	6,980	6,943	7,050
People in Non-DD Settings *	Nursing Facility (s)			1,850	805	406	315	597	522	1,320	1,358
	Psychiatric Facility (2)			0	0	0	0	DNF	DNF	DNF	DNF
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$14,002	\$47,916	\$54,334	\$52,451	\$53,048	\$55,197	\$56,059	\$55,226
	ICF/IID Expenditures per Person			\$38,008	\$73,396	\$80,516	\$78,921	\$72,066	\$72,869	\$61,678	PD
	Waiver Recipients per 100,000			26.6	124.5	137.5	136.9	136.0	140.9	142.6	143.4
	ICF/IID Residents per 100,000			91.8	46.7	40.9	40.6	40.2	32.6	40.4	DNF

(1) Long Term Supports and Service (LTSS) recipients may include imputed values; Until 2012 LTSS recipients may include people in nursing homes or psychiatric facilities who were not on the IDD agency caseload.
 (2) Includes only state operated psychiatric facilities until 2013.
 (s) Data may be from an outside source.

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RISP Profile FY 2016

Oregon

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

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

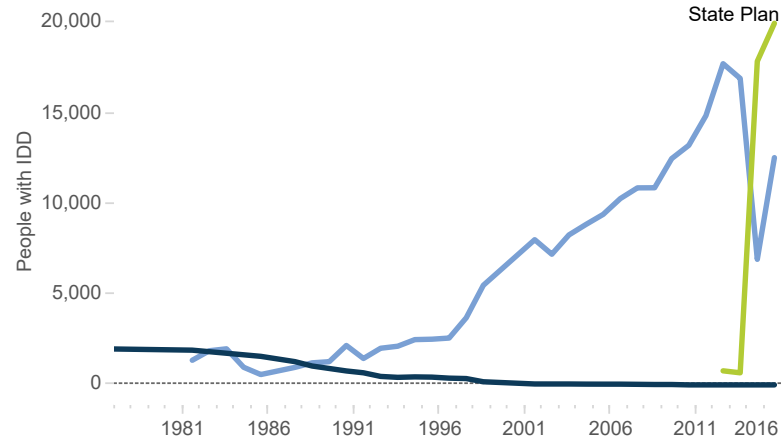


Figure 2: Medicaid Spending Per Person Fiscal Year 2016

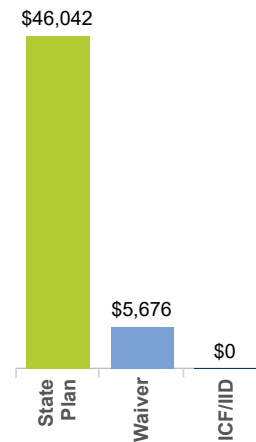


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

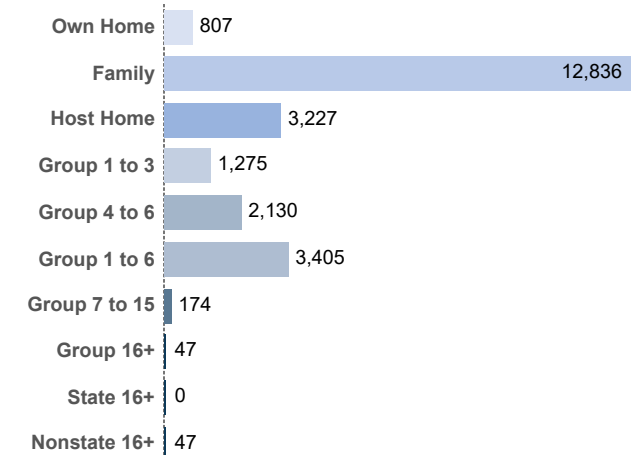


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

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

(1) Long Term Supports and Service (LTSS) recipients may include imputed values; Until 2012 LTSS recipients may include people in nursing homes or psychiatric facilities who were not on the IDD agency caseload.
 (2) Includes only state operated psychiatric facilities until 2013.
 (s) Data may be from an outside source.

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RISP Profile FY 2016

Pennsylvania

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

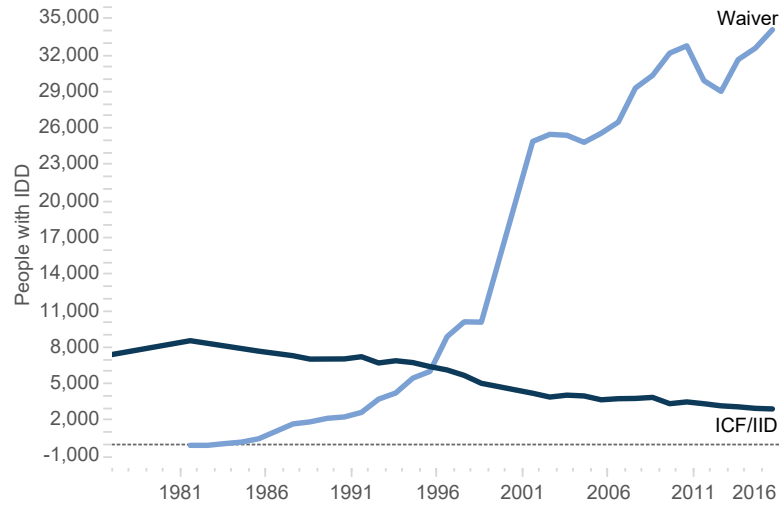


Figure 2: Medicaid Spending Per Person FY 2016

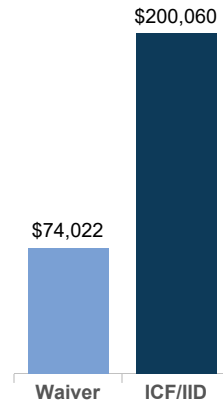


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

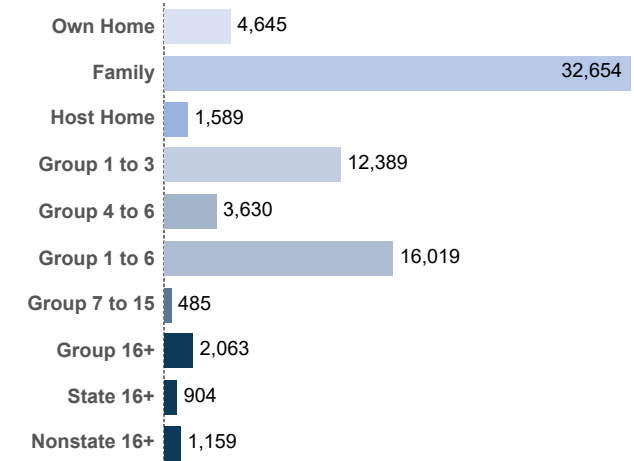


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				1,519	5,168	4,656	4,761	4,442	4,521	4,645
	Family				13,699	32,417	29,009	27,880	31,478	31,775	32,654
	Host Home				1,600	1,434	1,590	1,589	1,480	1,553	1,589
	Group 1 to 3				236	4,715	DNF	PD	PD	12,551	12,389
People in Congregate Settings	Group 4 to 6				8,065	3,838	DNF	PD	PD	3,679	3,630
	Group 1 to 6	1,078	2,588	7,809	8,301	9,553	DNF	PD	PD	16,230	16,019
	Group 7 to 15	1,310	1,075	813	1,296	2,014	DNF	PD	PD	483	485
	Group 16+	14,318	11,904	6,289	3,224	2,993	DNF	PD	PD	2,201	2,063
People Served by the DD Agency *	Caseload (known to the DD agency)							53,170	56,264	61,713	57,517
	LTSS Recipients (1)	16,706	15,567	14,911	29,639	53,579	57,309	53,170	56,275	56,763	57,505
	Waiting for Medicaid Waiver				5,149	1,613	1,979	5,814	7,360	5,493	7,812
People in Non-DD Settings *	Nursing Facility (s)			509	DNF	DNF	1,549	1,549	1,625	1,919	2,344
	Psychiatric Facility (2)			0	0	0	77	66	64	115	226
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$51,479	\$41,809	\$50,788	\$60,618	\$69,558	\$68,625	\$70,756	\$74,022
	ICF/IID Expenditures per Person			\$65,671	\$142,243	\$174,983	\$172,884	\$175,097	\$181,040	\$195,382	\$200,060
	Waiver Recipients per 100,000			19.5	200.3	253.7	234.8	227.6	247.9	254.9	267.1
	ICF/IID Residents per 100,000			59.4	32.6	26.9	DNF	25.4	24.7	23.6	23.4

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

(2) Includes only state operated psychiatric facilities until 2013.

(s) Data may be from an outside source.

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RISP Profile FY 2016

Rhode Island

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

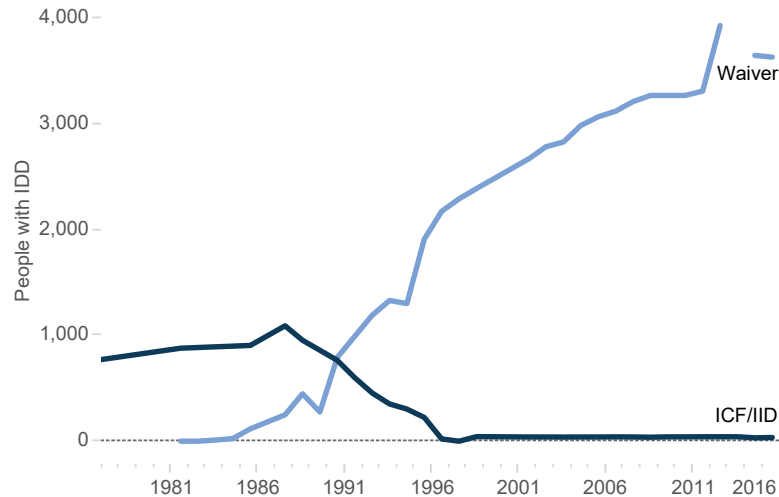


Figure 2: Medicaid Spending Per Person FY 2016

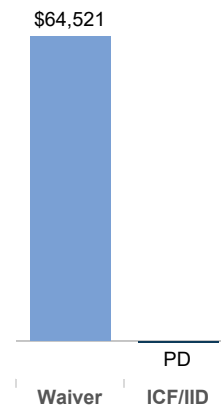


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

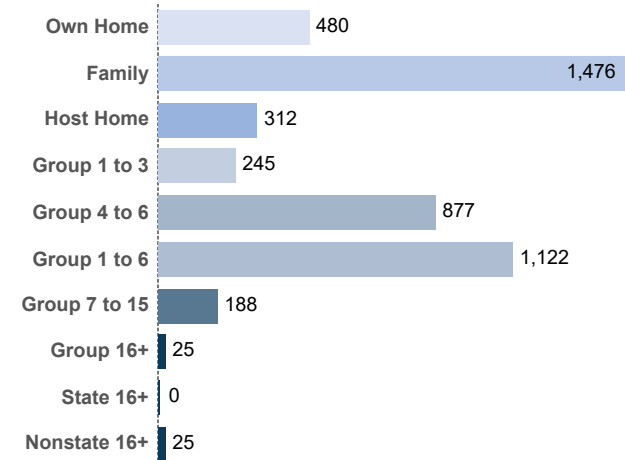


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				757	680	676	466	474	488	480
	Family				696	879	1,380	1,760	1,472	1,502	1,476
	Host Home				65	166	183	229	247	267	312
	Group 1 to 3				331	254	162	324	312	258	245
People in Congregate Settings	Group 4 to 6				817	927	949	957	913	873	877
	Group 1 to 6	0	153	826	1,148	1,177	1,111	1,281	1,225	1,131	1,122
	Group 7 to 15	98	228	345	177	147	166	210	206	253	188
	Group 16+	972	631	196	23	42	54	54	25	25	25
People Served by the DD Agency *	Caseload (known to the DD agency)							3,641	3,648	4,016	4,089
	LTSS Recipients (1)	1,070	1,012	1,367	2,866	3,091	3,614	4,000	3,649	3,666	3,603
	Waiting for Medicaid Waiver				0	0	0	0	0	362	0
People in Non-DD Settings *	Nursing Facility (s)			40	91	92	44	99	168	6	6
	Psychiatric Facility (2)			0	0	0	0	0	DNF	0	0
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$18,079	\$72,064	\$74,206	\$61,418	\$53,086	PD	\$52,921	\$64,521
	ICF/IID Expenditures per Person			\$86,564	\$176,700	\$279,563	\$218,085	\$235,022	\$214,398	\$247,742	PD
	Waiver Recipients per 100,000			79.0	277.9	311.1	315.7	374.4	DNF	345.9	344.4
	ICF/IID Residents per 100,000			76.3	3.7	3.9	4.0	4.0	4.0	3.0	3.3

(1) Long Term Supports and Service (LTSS) recipients may include imputed values; Until 2012 LTSS recipients may include people in nursing homes or psychiatric facilities who were not on the IDD agency caseload.
 (2) Includes only state operated psychiatric facilities until 2013.
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RISP Profile FY 2016

South Carolina

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

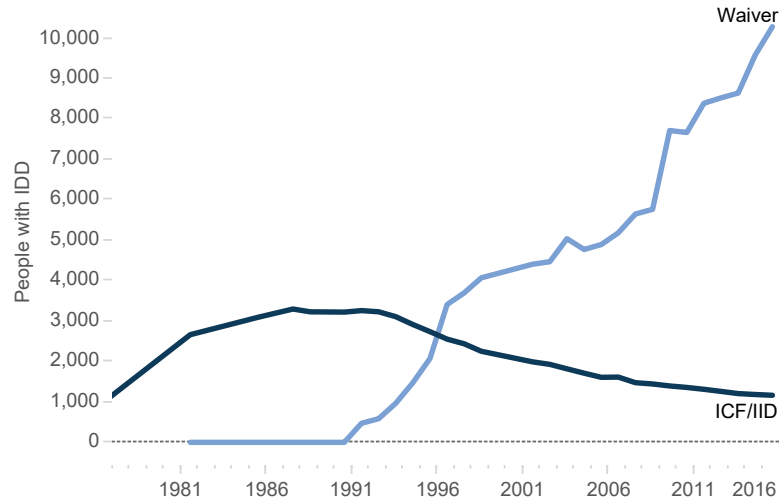


Figure 2: Medicaid Spending Per Person FY 2016

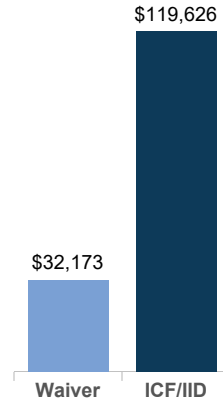


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

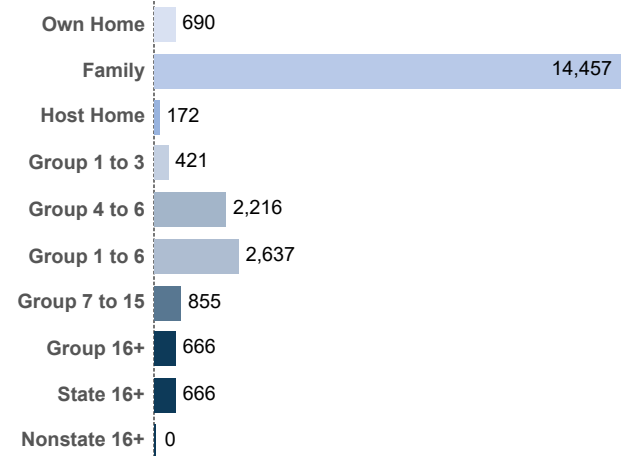


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				569	668	668	662	663	664	690
	Family				13,306	12,238	12,427	12,361	12,735	13,437	14,457
	Host Home				141	139	160	159	164	172	172
	Group 1 to 3				517	368	328	335	361	370	421
People in Congregate Settings	Group 4 to 6				1,436	1,998	2,057	2,107	2,104	2,179	2,216
	Group 1 to 6	9	3	927	1,953	2,366	2,385	2,442	2,465	2,549	2,637
	Group 7 to 15	135	191	973	910	897	890	891	865	867	855
	Group 16+	3,982	3,519	2,291	933	767	745	721	701	673	666
People Served by the DD Agency *	Caseload (known to the DD agency)							31,474	32,399	34,373	35,983
	LTSS Recipients (1)	4,126	3,713	4,191	17,812	17,075	17,481	17,236	17,593	18,363	19,479
	Waiting for Medicaid Waiver				1,768	335	295	9,050	6,903	6,150	4,426
People in Non-DD Settings *	Nursing Facility (s)			98	223	181	206	356	241	432	265
	Psychiatric Facility (2)			0	0	0	0	0	0	DNF	0
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$0	\$32,895	\$29,356	DNF	\$29,689	\$29,911	\$29,326	\$32,173
	ICF/IID Expenditures per Person			\$45,519	\$94,295	\$100,695	\$114,938	\$170,338	\$84,471	\$116,963	\$119,626
	Waiver Recipients per 100,000			0.0	112.2	166.9	DNF	178.6	178.9	195.9	207.4
	ICF/IID Residents per 100,000			90.6	40.2	30.2	27.8	26.4	25.0	24.2	23.5

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

(2) Includes only state operated psychiatric facilities until 2013.

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Updated
3/12/2018

RISP Profile FY 2016

South Dakota

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

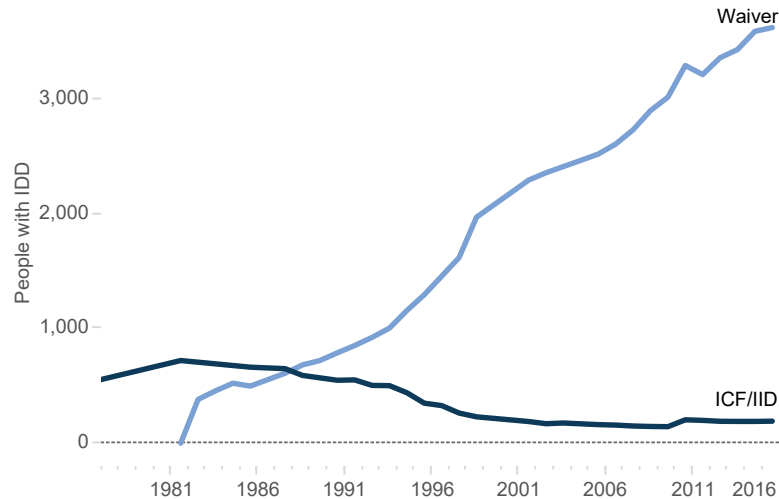


Figure 2: Medicaid Spending Per Person FY 2016

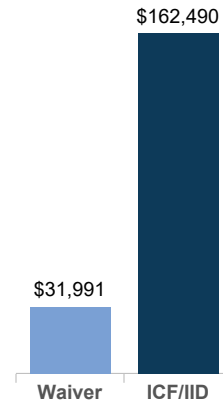


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

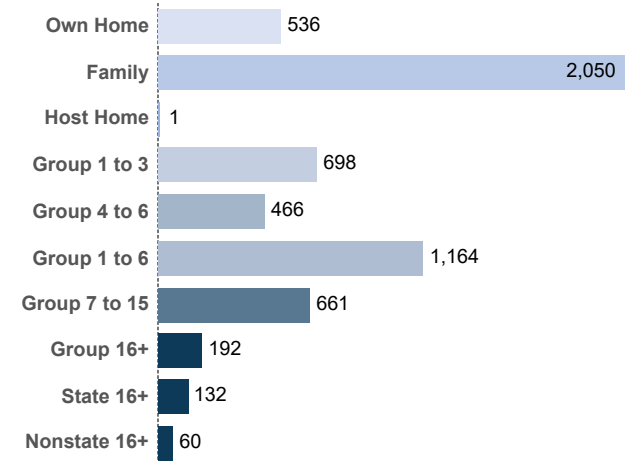


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				597	527	557	569	555	536	536
	Family				761	1,033	1,161	1,656	1,738	1,988	2,050
	Host Home				7	5	4	4	1	2	1
	Group 1 to 3				568	725	747	744	754	702	698
People in Congregate Settings	Group 4 to 6				304	514	404	406	431	507	466
	Group 1 to 6	10	8	555	872	1,239	1,151	1,150	1,185	1,209	1,164
	Group 7 to 15	242	471	739	586	416	585	649	647	623	661
	Group 16+	925	736	378	185	144	199	191	190	190	192
People Served by the DD Agency *	Caseload (known to the DD agency)							4,219	4,316	4,550	4,604
	LTSS Recipients (1)	1,177	1,215	1,672	3,008	3,364	3,822	4,219	4,316	4,548	4,604
	Waiting for Medicaid Waiver				5	2	0	0	0	0	0
People in Non-DD Settings *	Nursing Facility (s)			225	185	144	134	96	93	88	87
	Psychiatric Facility (2)			1	21	31	31	0	0	0	0
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$16,921	\$29,625	\$31,893	\$31,645	\$31,257	\$31,345	\$31,512	\$31,991
	ICF/IID Expenditures per Person			\$48,534	\$126,015	\$170,305	\$150,624	\$153,675	\$161,201	\$166,872	\$162,490
	Waiver Recipients per 100,000			112.1	317.9	370.7	385.8	397.9	402.4	418.4	418.9
	ICF/IID Residents per 100,000			78.1	21.8	17.7	23.9	22.6	22.3	21.8	22.2

(1) Long Term Supports and Service (LTSS) recipients may include imputed values; Until 2012 LTSS recipients may include people in nursing homes or psychiatric facilities who were not on the IDD agency caseload.
 (2) Includes only state operated psychiatric facilities until 2013.
 (s) Data may be from an outside source.

Settings by size includes ICF/IID, group homes, and nonstate other.
 DNF = Did Not Furnished.
 PD = Partial Data.
 * See state notes and the RISP report for further explanation.



RISP Profile FY 2016

Tennessee

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

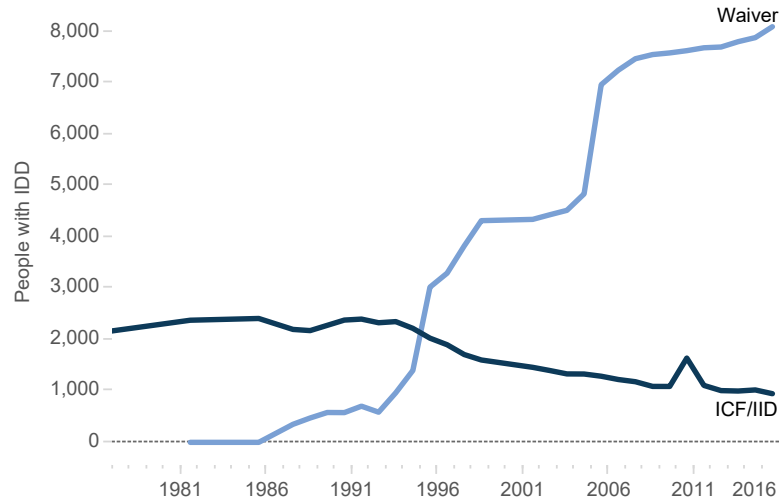


Figure 2: Medicaid Spending Per Person FY 2016

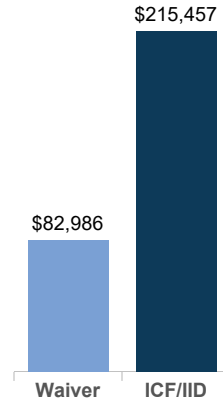


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

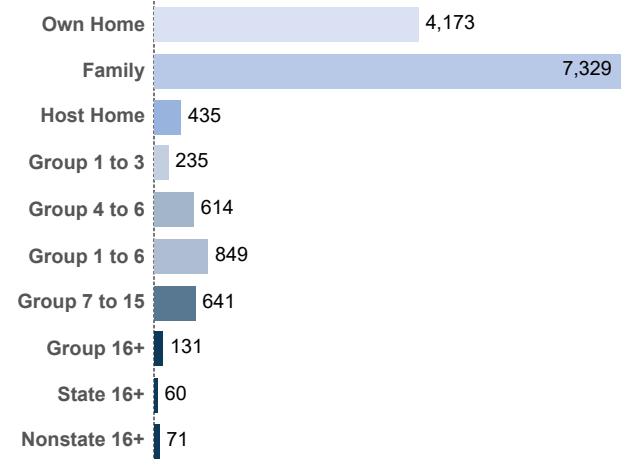


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				2,420	3,347	3,647	3,807	3,982	4,077	4,173
	Family				3,363	3,950	2,928	2,788	2,737	7,082	7,329
	Host Home			161	240	317	338	336	344	376	435
	Group 1 to 3				309	233	233	259	220	239	235
People in Congregate Settings	Group 4 to 6				371	357	558	609	606	580	614
	Group 1 to 6	210	343	654	680	610	791	868	826	819	849
	Group 7 to 15	495	729	1,401	892	649	733	656	668	732	641
	Group 16+	2,500	2,456	2,167	806	528	351	253	226	196	131
People Served by the DD Agency *	Caseload (known to the DD agency)							20,624	20,341	21,799	25,159
	LTSS Recipients (1)	3,205	3,528	4,383	8,401	9,401	9,219	8,708	8,783	13,282	13,558
	Waiting for Medicaid Waiver				1,491	1,158	1,654	7,165	6,494	6,277	5,769
People in Non-DD Settings *	Nursing Facility (s)			883	895	369	420	646	614	567	567
	Psychiatric Facility (2)			5	29	35	11	DNF	DNF	DNF	DNF
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$19,672	\$73,704	\$75,936	\$78,659	\$81,194	\$82,385	\$84,952	\$82,986
	ICF/IID Expenditures per Person			\$42,017	\$217,565	\$207,079	\$200,917	\$220,444	\$211,419	\$210,345	\$215,457
	Waiver Recipients per 100,000			11.7	89.9	119.4	119.0	118.5	119.1	119.4	121.6
	ICF/IID Residents per 100,000			48.1	81.1	17.1	17.2	15.5	15.3	15.5	14.1

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

(2) Includes only state operated psychiatric facilities until 2013.

(s) Data may be from an outside source.

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

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PD = Partial Data.

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

RISP Profile FY 2016

Texas

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

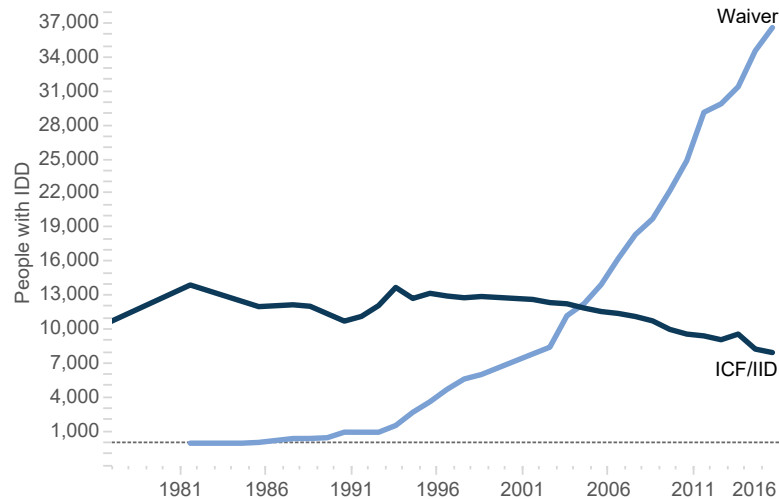


Figure 2: Medicaid Spending Per Person FY 2016

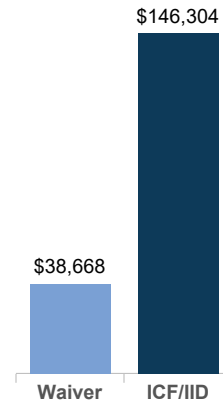


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

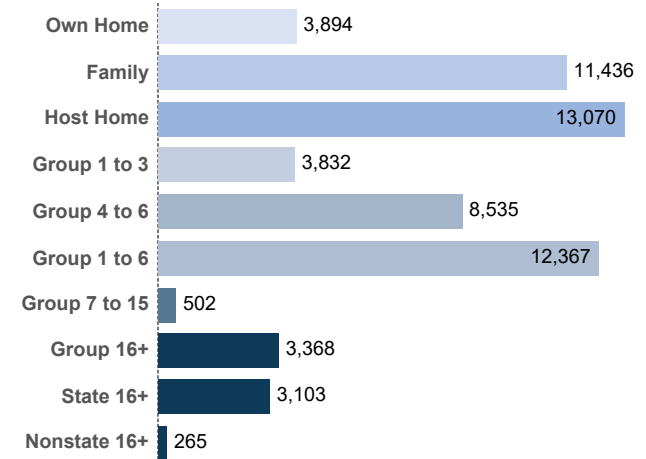


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				2,396	3,605	3,485	4,316	2,936	3,648	3,894
	Family				3,277	5,080	9,238	9,645	10,397	10,944	11,436
	Host Home				3,168	5,665	9,738	11,090	10,637	12,094	13,070
	Group 1 to 3				DNF	DNF	DNF	PD	PD	PD	3,832
People in Congregate Settings	Group 4 to 6				DNF	4,420	DNF	PD	PD	PD	8,535
	Group 1 to 6	101	76	1,987	8,153	4,420	11,283	12,357	11,886	12,151	12,367
	Group 7 to 15	434	1,053	793	689	567	555	551	553	533	502
	Group 16+	14,370	14,634	9,660	6,568	5,057	4,361	4,047	3,738	3,521	3,368
People Served by the DD Agency *	Caseload (known to the DD agency)							DNF	DNF	DNF	DNF
	LTSS Recipients (1)	14,905	15,763	12,440	24,251	24,394	40,596	42,006	41,079	42,891	44,632
	Waiting for Medicaid Waiver				DNF	DNF	DNF	DNF	DNF	DNF	DNF
People in Non-DD Settings *	Nursing Facility (s)			3,258	1,145	DNF	1,936	1,934	1,881	2,227	2,492
	Psychiatric Facility (2)			0	0	0	0	DNF	DNF	DNF	DNF
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$14,767	\$34,128	\$41,022	\$36,270	\$36,813	\$36,524	\$35,820	\$38,668
	ICF/IID Expenditures per Person			\$41,055	\$67,570	\$96,981	\$108,735	\$119,283	\$112,535	\$133,992	\$146,304
	Waiver Recipients per 100,000			5.6	53.9	88.5	112.0	113.2	116.7	126.0	131.6
	ICF/IID Residents per 100,000			62.1	52.2	39.9	36.3	34.1	35.7	29.8	28.3

(1) Long Term Supports and Service (LTSS) recipients may include imputed values; Until 2012 LTSS recipients may include people in nursing homes or psychiatric facilities who were not on the IDD agency caseload.
 (2) Includes only state operated psychiatric facilities until 2013.
 (s) Data may be from an outside source.

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RISP Profile FY 2016

Utah

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

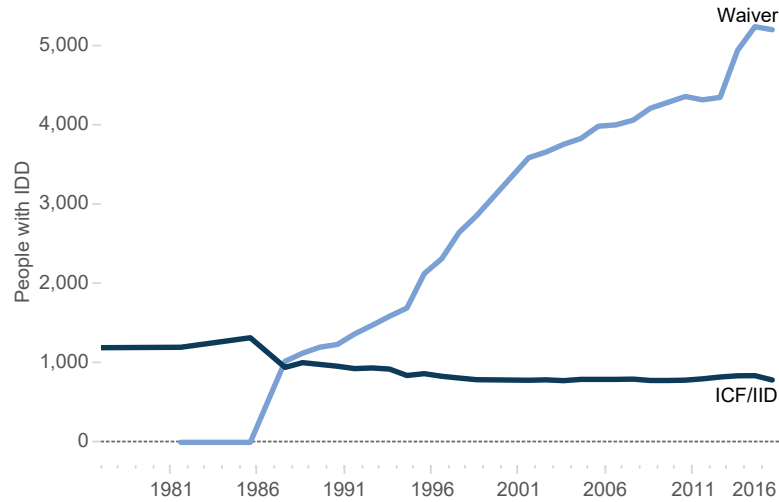


Figure 2: Medicaid Spending Per Person FY 2016

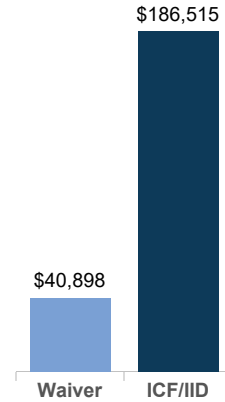


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

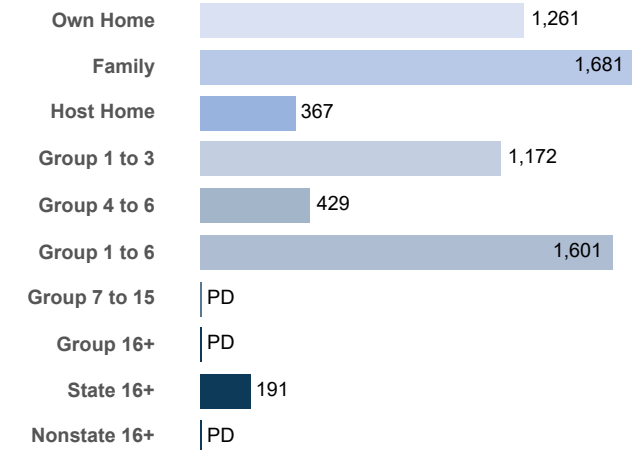


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				612	885	985	1,006	1,158	1,244	1,261
	Family				1,614	1,843	1,814	1,828	2,009	2,139	1,681
	Host Home				247	263	269	278	307	339	367
	Group 1 to 3				816	893	909	925	1,093	1,135	1,172
People in Congregate Settings	Group 4 to 6				311	341	348	353	400	415	429
	Group 1 to 6	68	50	782	1,127	1,233	1,257	1,278	1,493	1,550	1,601
	Group 7 to 15	95	145	340	160	172	162	162	71	74	PD
	Group 16+	1,217	1,155	948	754	739	773	760	814	763	PD
People Served by the DD Agency *	Caseload (known to the DD agency)							6,512	6,896	7,234	7,669
	LTSS Recipients (1)	1,380	1,350	2,070	4,514	5,135	5,427	5,350	5,852	6,161	5,746
	Waiting for Medicaid Waiver				244	1,822	1,834	1,886	1,821	1,914	2,387
People in Non-DD Settings *	Nursing Facility (s)			283	248	95	167	92	81	34	34
	Psychiatric Facility (2)			0	0	0	0	0	0	0	0
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$16,207	\$26,854	\$34,643	\$36,007	\$37,432	\$36,078	\$36,657	\$40,898
	ICF/IID Expenditures per Person			\$74,849	\$72,435	\$73,959	\$96,976	\$78,989	\$81,094	\$86,178	\$186,515
	Waiver Recipients per 100,000			85.5	155.2	155.1	151.3	150.0	167.9	174.9	170.5
	ICF/IID Residents per 100,000			54.2	32.2	28.2	28.1	28.4	28.5	28.1	6.6

(1) Long Term Supports and Service (LTSS) recipients may include imputed values; Until 2012 LTSS recipients may include people in nursing homes or psychiatric facilities who were not on the IDD agency caseload.
 (2) Includes only state operated psychiatric facilities until 2013.
 (s) Data may be from an outside source.

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RISP Profile FY 2016

Vermont

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

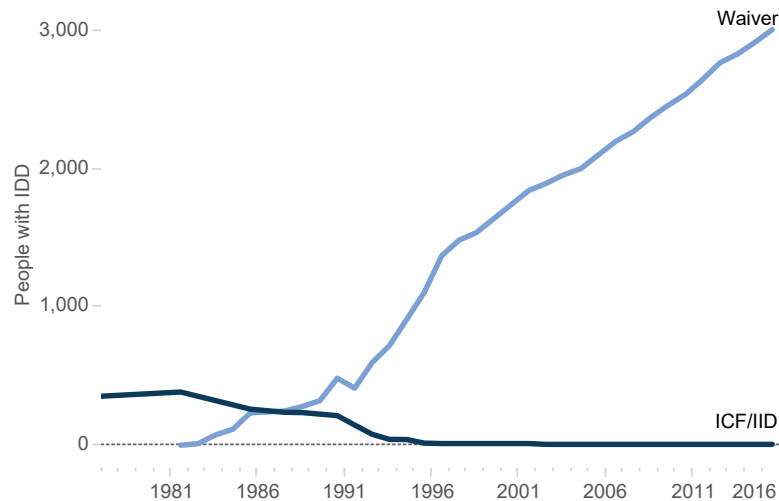


Figure 2: Medicaid Spending Per Person FY 2016

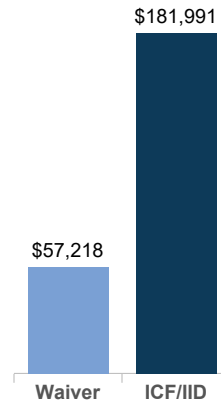


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

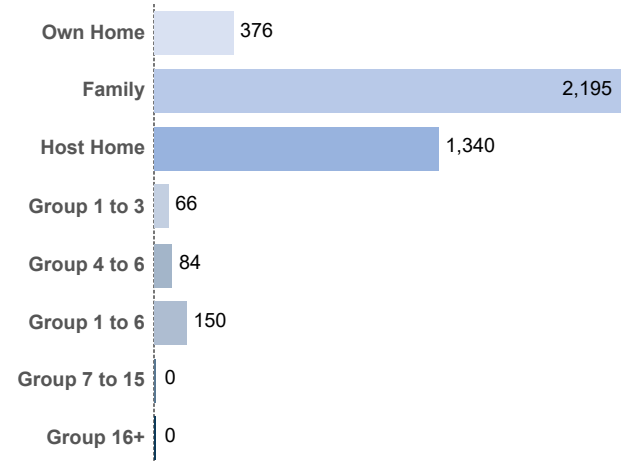


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				184	236	248	283	317	359	376
	Family				1,369	1,852	1,955	2,036	2,045	2,124	2,195
	Host Home				979	1,237	1,300	1,307	1,319	1,352	1,340
	Group 1 to 3				42	56	47	67	56	57	66
People in Congregate Settings	Group 4 to 6				73	75	90	81	85	86	84
	Group 1 to 6	262	322	504	115	131	137	148	141	143	150
	Group 7 to 15	143	120	0	0	0	0	0	0	0	0
	Group 16+	517	356	160	0	0	0	0	0	0	0
People Served by the DD Agency *	Caseload (known to the DD agency)							4,245	4,283	4,408	4,486
	LTSS Recipients (1)	922	798	664	2,563	3,238	3,442	3,774	3,822	3,978	4,061
	Waiting for Medicaid Waiver				0	0	0	0	0	0	0
People in Non-DD Settings *	Nursing Facility (s)			91	27	28	32	32	34	30	27
	Psychiatric Facility (2)			1	DNF	DNF	0	0	0	0	0
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$21,144	\$46,017	\$54,040	\$53,461	\$54,388	\$56,065	\$56,672	\$57,218
	ICF/IID Expenditures per Person			\$92,297	\$157,468	DNF	\$211,131	\$191,744	\$212,504	\$224,622	\$181,991
	Waiver Recipients per 100,000			85.5	321.5	393.1	423.2	442.0	452.1	465.9	481.9
	ICF/IID Residents per 100,000			37.9	1.0	1.0	1.0	1.0	1.0	1.0	1.0

(1) Long Term Supports and Service (LTSS) recipients may include imputed values; Until 2012 LTSS recipients may include people in nursing homes or psychiatric facilities who were not on the IDD agency caseload.
 (2) Includes only state operated psychiatric facilities until 2013.
 (s) Data may be from an outside source.

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RISP Profile FY 2016

Virginia

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

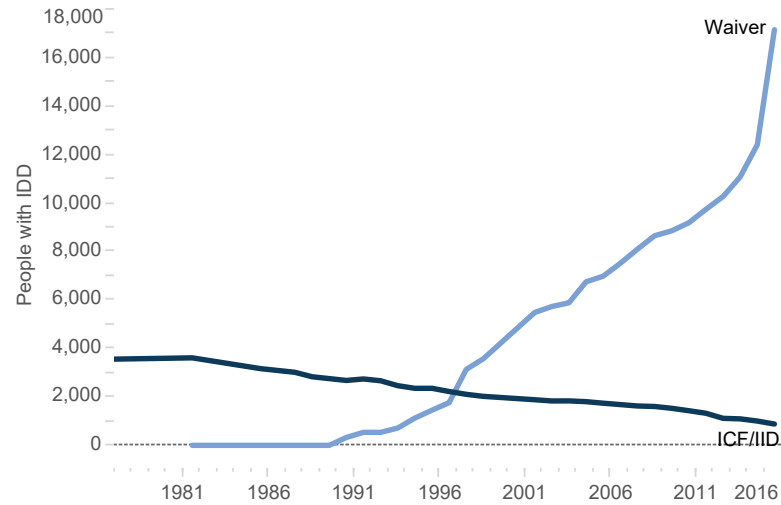


Figure 2: Medicaid Spending Per Person FY 2016

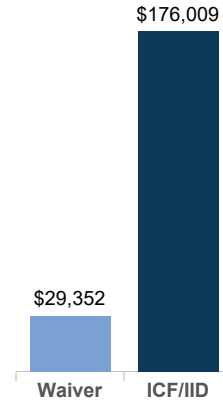


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

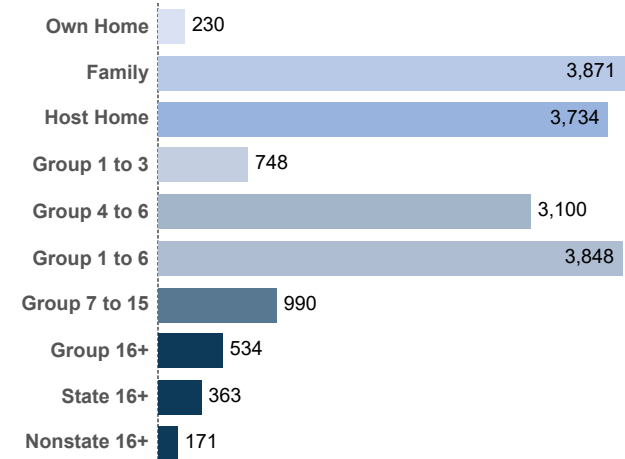


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				1,735	1,656	1,235	209	216	252	230
	Family				3,213	1,071	1,445	1,445	3,247	3,252	3,871
	Host Home				351	578	801	1,285	1,373	1,491	3,734
	Group 1 to 3				DNF	1,093	372	477	523	677	748
People in Congregate Settings	Group 4 to 6				DNF	1,240	2,166	2,523	2,824	3,028	3,100
	Group 1 to 6	123	161	223	DNF	2,333	2,538	3,000	3,347	3,705	3,848
	Group 7 to 15	153	281	394	DNF	411	594	1,060	1,097	1,010	990
	Group 16+	4,441	3,778	2,667	DNF	2,646	3,165	963	789	654	534
People Served by the DD Agency *	Caseload (known to the DD agency)							10,018	18,054	19,517	25,620
	LTSS Recipients (1)	4,717	4,220	3,284	DNF	8,695	11,023	7,973	10,069	10,364	13,209
	Waiting for Medicaid Waiver				2,028	4,395	4,649	6,672	8,576	10,339	10,877
People in Non-DD Settings *	Nursing Facility (s)			1,993	762	864	933	935	1,563	836	1,657
	Psychiatric Facility (2)			9	148	345	312	312	DNF	DNF	DNF
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$810	\$43,142	\$60,885	\$61,761	\$55,803	\$66,506	\$58,538	\$29,352
	ICF/IID Expenditures per Person			\$56,732	\$126,770	\$176,590	\$49,302	\$270,991	\$204,652	\$201,104	\$176,009
	Waiver Recipients per 100,000			5.2	99.3	110.8	119.2	124.5	133.3	148.2	204.2
	ICF/IID Residents per 100,000			42.7	23.9	19.1	16.2	13.5	11.9	9.3	5.6

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

(2) Includes only state operated psychiatric facilities until 2013.

(s) Data may be from an outside source.

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RISP Profile FY 2016

Washington

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

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

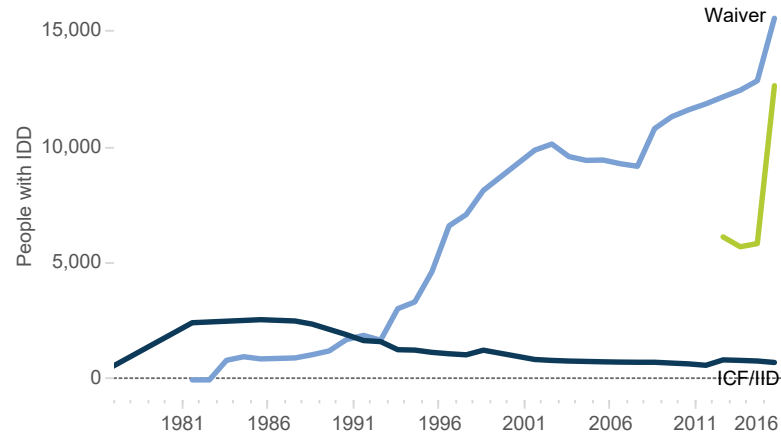


Figure 2: Medicaid Spending Per Person Fiscal Year 2016

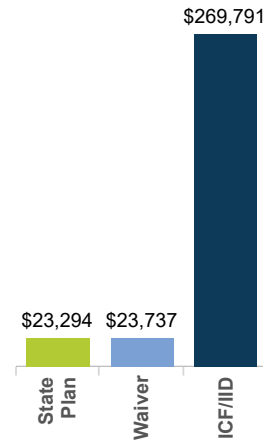


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

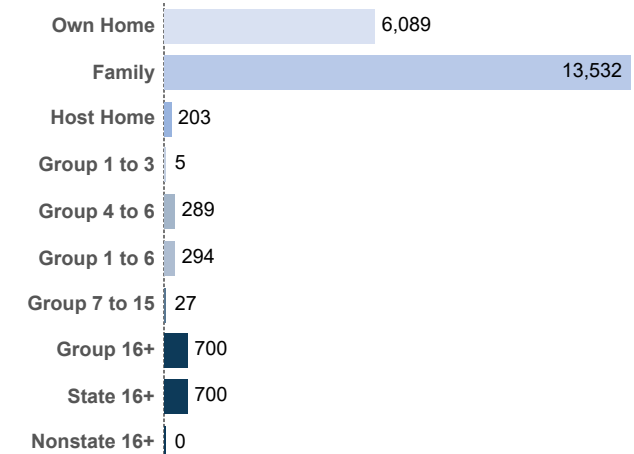


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				3,724	3,727	6,370	6,307	3,701	3,951	6,089
	Family				12,994	14,442	11,148	10,075	11,495	12,385	13,532
	Host Home			521	214	129	96	891	828	877	203
	Group 1 to 3				42	89	DNF	257	1,586	948	5
People in Congregate Settings	Group 4 to 6				1,711	2,015	DNF	1,866	737	1,224	289
	Group 1 to 6	102	194	3,549	1,753	2,104	DNF	2,123	2,323	2,172	294
	Group 7 to 15	347	473	402	307	169	DNF	284	120	229	27
	Group 16+	3,979	3,067	2,046	1,201	1,061	DNF	1,092	1,129	941	700
People Served by the DD Agency *	Caseload (known to the DD agency)							39,937	40,809	42,374	44,594
	LTSS Recipients (1)	4,428	3,734	6,518	20,193	21,632	21,236	20,772	19,596	20,555	20,855
	Waiting for Medicaid Waiver				DNF	DNF	DNF	1,081	1,270	1,033	671
People in Non-DD Settings *	Nursing Facility (s)			700	365	329	294	0	0	0	0
	Psychiatric Facility (2)			2	0	0	22	37	37	38	38
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$17,427	\$36,706	\$37,018	\$46,302	\$47,060	\$48,323	\$56,013	\$23,737
	ICF/IID Expenditures per Person			\$81,681	\$158,544	\$195,388	\$213,619	\$193,173	\$222,930	\$239,059	\$269,791
	Waiver Recipients per 100,000			34.6	150.5	168.7	172.5	175.0	176.8	179.8	213.9
	ICF/IID Residents per 100,000			38.9	12.7	10.8	9.1	12.4	11.9	10.7	10.3

(1) Long Term Supports and Service (LTSS) recipients may include imputed values; Until 2012 LTSS recipients may include people in nursing homes or psychiatric facilities who were not on the IDD agency caseload.
 (2) Includes only state operated psychiatric facilities until 2013.
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RISP Profile FY 2016

West Virginia

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

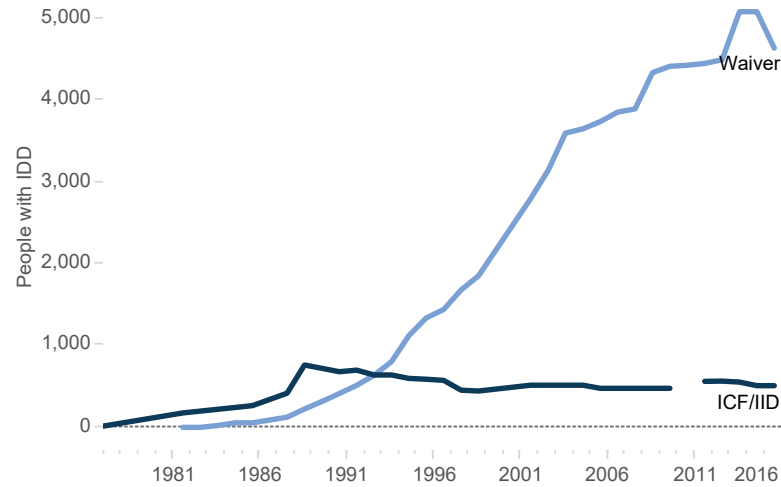


Figure 2: Medicaid Spending Per Person FY 2016



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

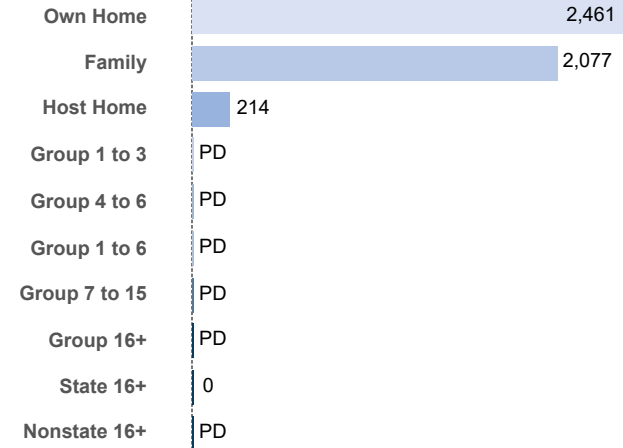


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				737	753	32	0	0	0	2,461
	Family				2,343	2,846	2,994	3,027	3,051	3,051	2,077
	Host Home				335	165	156	105	103	103	214
	Group 1 to 3				128	218	1,165	1,248	1,016	PD	PD
People in Congregate Settings	Group 4 to 6				170	171	DNF	311	PD	222	PD
	Group 1 to 6	24	29	446	298	389	DNF	1,559	PD	1,238	PD
	Group 7 to 15	32	24	409	555	500	DNF	726	PD	425	PD
	Group 16+	950	978	373	59	47	DNF	78	PD	0	PD
People Served by the DD Agency *	Caseload (known to the DD agency)							4,524	4,524	4,524	DNF
	LTSS Recipients (1)	1,006	1,031	1,228	4,327	4,700	5,338	5,495	5,566	5,033	6,004
	Waiting for Medicaid Waiver				210	409	646	832	977	977	1,274
People in Non-DD Settings *	Nursing Facility (s)			211	DNF	DNF	329	268	279	183	213
	Psychiatric Facility (2)			2	22	0	0	31	31	DNF	22
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$24,310	\$47,540	\$55,553	\$68,330	\$74,696	\$83,123	\$70,658	PD
	ICF/IID Expenditures per Person			\$23,085	\$106,992	\$131,226	\$116,483	\$118,919	\$121,499	\$133,521	PD
	Waiver Recipients per 100,000			22.9	200.8	238.1	239.7	242.2	274.5	275.4	253.1
	ICF/IID Residents per 100,000			37.8	28.3	25.7	DNF	30.5	29.9	27.4	27.8

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

(2) Includes only state operated psychiatric facilities until 2013.

(s) Data may be from an outside source.

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

DNF = Did Not Furnished.

PD = Partial Data.

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

RISP Profile FY 2016

Wisconsin

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

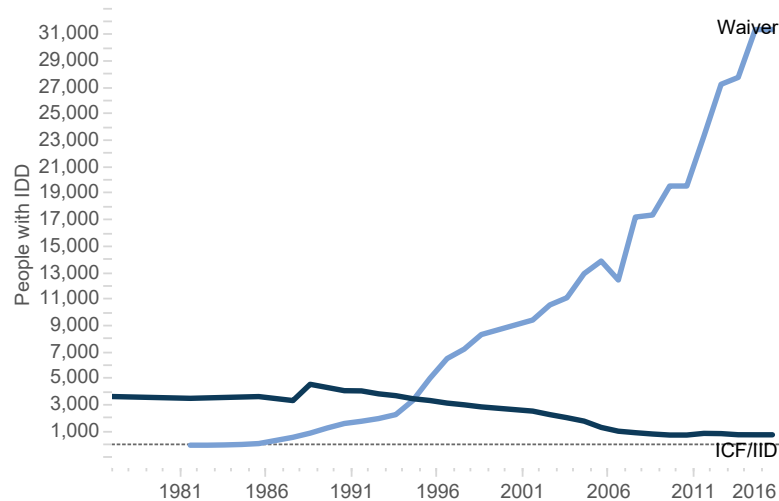


Figure 2: Medicaid Spending Per Person FY 2016



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

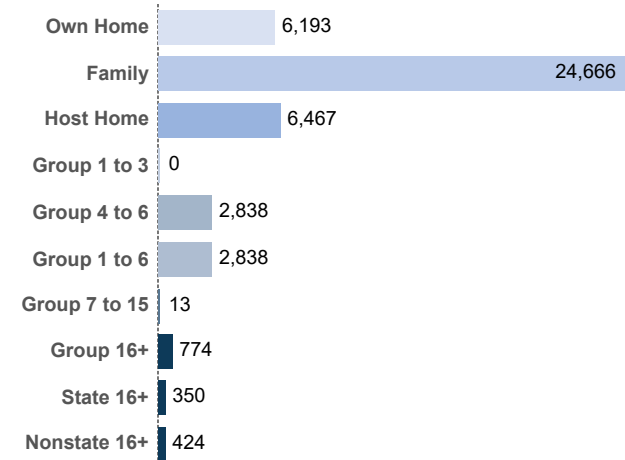


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				5,677	5,823	4,307	5,444	5,320	6,193	6,193
	Family				2,152	7,663	11,524	13,904	21,393	24,666	24,666
	Host Home				3,390	1,280	5,085	5,367	5,800	6,467	6,467
	Group 1 to 3				0	0	0	0	0	0	0
People in Congregate Settings	Group 4 to 6				1,016	2,858	2,465	2,596	2,561	2,838	2,838
	Group 1 to 6	194	324	4,655	1,016	2,858	2,465	2,602	2,561	2,838	2,838
	Group 7 to 15	960	1,282	1,510	1,083	2,040	28	31	22	13	13
	Group 16+	4,494	4,079	4,059	1,755	722	867	846	769	774	774
People Served by the DD Agency *	Caseload (known to the DD agency)							30,765	31,297	41,007	41,007
	LTSS Recipients (1)	5,648	5,685	10,224	15,073	20,386	24,324	28,194	35,939	40,985	40,985
	Waiting for Medicaid Waiver				DNF	4,783	924	2,252	2,169	1,890	1,890
People in Non-DD Settings *	Nursing Facility (s)			995	89	153	34	34	28	22	22
	Psychiatric Facility (2)			2	0	0	0	0	0	0	0
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$18,340	\$33,071	\$35,420	\$36,561	\$33,504	\$35,159	\$33,098	\$33,098
	ICF/IID Expenditures per Person			\$41,217	\$108,328	\$188,655	\$176,258	\$185,235	\$197,658	\$179,771	\$179,771
	Waiver Recipients per 100,000			33.2	234.6	344.9	408.6	475.7	483.5	545.1	544.4
	ICF/IID Residents per 100,000			83.3	32.9	13.5	15.6	15.3	13.7	13.6	13.6

(1) Long Term Supports and Service (LTSS) recipients may include imputed values; Until 2012 LTSS recipients may include people in nursing homes or psychiatric facilities who were not on the IDD agency caseload.
 (2) Includes only state operated psychiatric facilities until 2013.
 (s) Data may be from an outside source.

Settings by size includes ICF/IID, group homes, and nonstate other.
 DNF = Did Not Furnished.
 PD = Partial Data.
 * See state notes and the RISP report for further explanation.



RISP Profile FY 2016

Wyoming

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

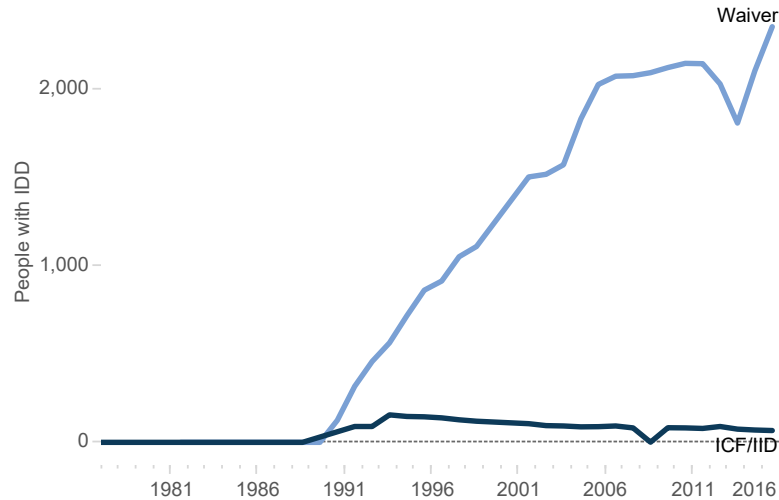


Figure 2: Medicaid Spending Per Person FY 2016

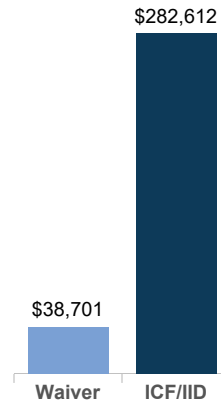


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

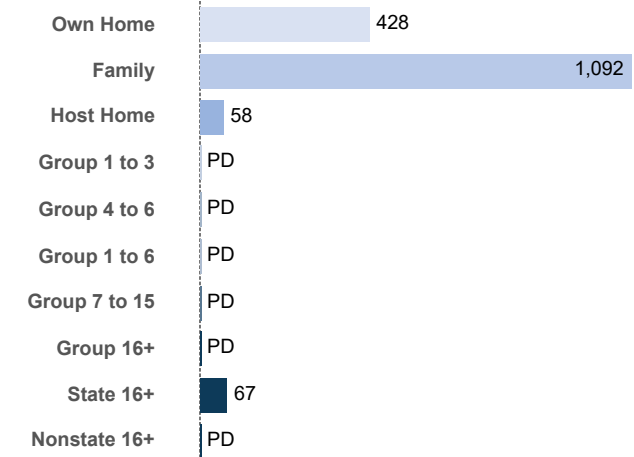


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				102	253	216	202	155	390	428
	Family				748	933	744	932	885	1,002	1,092
	Host Home				142	84	63	100	67	65	58
	Group 1 to 3				107	276	DNF	PD	PD	PD	PD
People in Congregate Settings	Group 4 to 6				393	495	DNF	PD	PD	PD	PD
	Group 1 to 6	28	17	222	500	771	1,036	PD	PD	PD	PD
	Group 7 to 15	70	93	180	125	87	91	PD	PD	PD	PD
	Group 16+	584	519	290	120	83	79	PD	PD	PD	PD
People Served by the DD Agency *	Caseload (known to the DD agency)							2,035	2,102	2,110	2,222
	LTSS Recipients (1)	682	629	692	1,737	2,211	2,262	2,125	1,888	2,178	2,287
	Waiting for Medicaid Waiver				0	120	387	587	513	317	182
People in Non-DD Settings *	Nursing Facility (s)			49	45	45	25	21	20	22	27
	Psychiatric Facility (2)			0	0	0	8	9	6	4	9
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$6,768	\$41,068	\$42,463	DNF	\$47,947	\$52,403	\$42,405	\$38,701
	ICF/IID Expenditures per Person			\$140,278	\$208,355	\$222,932	\$364,021	\$218,226	\$232,689	\$275,184	\$282,612
	Waiver Recipients per 100,000			27.2	360.7	377.6	373.0	349.3	310.4	360.0	403.1
	ICF/IID Residents per 100,000			13.0	17.3	14.7	13.7	15.4	12.8	11.9	11.4

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

(2) Includes only state operated psychiatric facilities until 2013.

(s) Data may be from an outside source.

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

DNF = Did Not Furnished.

PD = Partial Data.

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

Updated 3/12/2018

RISP Profile FY 2016

United States

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

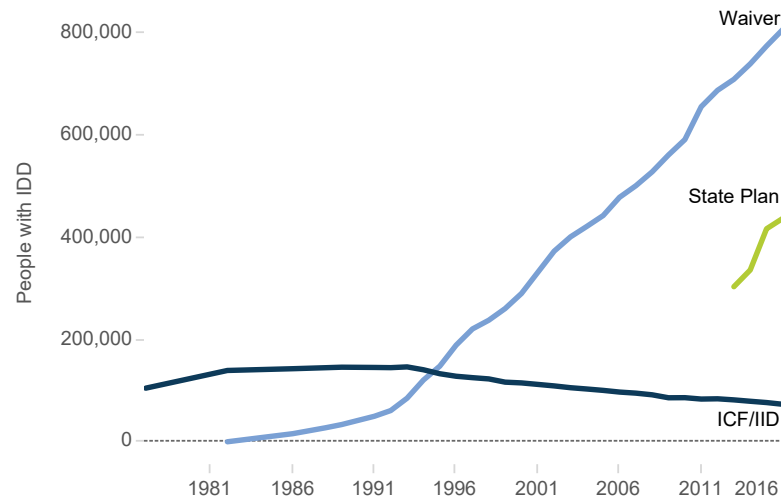


Figure 2: Medicaid Spending Per Person Fiscal Year 2016

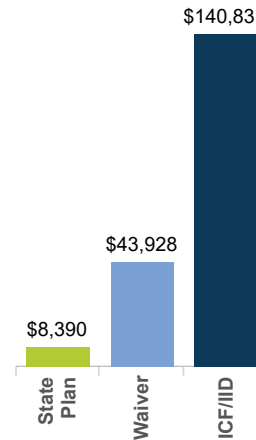


Figure 3: People Served by IDD Agencies on June 30, 2016 by Residence Size and Type

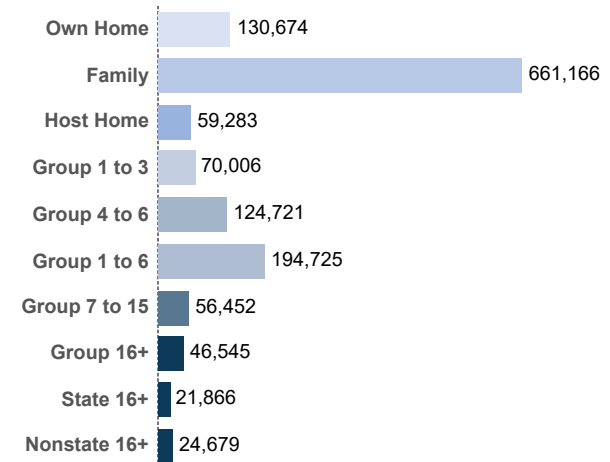


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				101,143	127,455	122,665	127,582	130,674	137,010	146,974
	Family				533,048	592,180	634,988	631,258	661,166	698,566	714,910
	Host Home				35,386	40,060	58,753	57,150	59,283	61,715	63,750
	Group 1 to 3		15,702		49,037	62,584	68,781	64,381	70,006	92,576	87,403
People in Congregate Settings	Group 4 to 6		17,486		107,573	105,290	116,159	126,187	124,721	123,774	122,792
	Group 1 to 6	20,400	33,188	108,479	156,610	167,874	184,940	190,567	194,725	216,350	210,195
	Group 7 to 15	20,024	30,515	53,475	52,888	55,682	56,409	55,778	56,452	54,136	53,166
	Group 16+	207,356	180,146	127,408	67,066	57,028	50,671	50,206	46,545	41,374	39,705
People Served by the DD Agency *	Caseload (known to the DD agency)							1,320,367	1,370,654	1,464,526	1,488,732
	LTSS Recipients (1)	247,780	243,849	289,362	946,141	1,040,279	1,138,121	1,112,542	1,148,844	1,209,151	1,228,700
	Waiting for Medicaid Waiver				73,828	115,059	79,102	245,474	209,523	199,447	193,828
People in Non-DD Sett..	Nursing Facility (s)	42,242	40,538	39,208	30,027	31,832	28,064	24,611	24,219	24,883	26,381
	Psychiatric Facility (2)	15,524	7,865	1,594	392	873	1,139	2,716	2,150	3,504	3,715
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person		\$901	\$22,319	\$38,679	\$44,396	\$44,160	\$43,365	\$43,686	\$44,112	\$43,928
	ICF/IID Expenditures per Person	\$5,798	\$14,886	\$55,630	\$119,162	\$146,999	\$143,996	\$149,813	\$139,281	\$138,859	\$140,831
	Waiver Recipients per 100,000		6.0	20.2	149.7	191.8	219.3	224.6	232.1	241.1	251.2
	ICF/IID Residents per 100,000	48.2	60.8	58.2	34.4	28.4	27.2	26.3	25.3	24.3	23.2

(1) Long Term Supports and Service (LTSS) recipients may include imputed values; Until 2012 LTSS recipients may include people in nursing homes or psychiatric facilities who were not on the IDD agency caseload.
 (2) Includes only state operated psychiatric facilities until 2013.
 (s) Data may be from an outside source.

All U.S. data are estimates with imputed values for missing data.
 Group includes ICF/IID, group homes, and nonstate other.
 * See state notes and the RISP report for further explanation.





SECTION SIX

APPENDIX

FY 2016

APPENDIX: REFERENCES, RESOURCES AND DATA SOURCES

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- 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
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A note to readers: A note to readers: The surveys and operational definitions for FY 2016 can now be found online on <https://risp.umn.edu/publications>.