

HOW MANY PEOPLE HAVE IDD?



HOW MANY PEOPLE WITH IDD GET
PAID SUPPORTS?



WHERE DO PEOPLE
WHO GET PAID SUPPORTS

LIVE?



HOW DO THE PLACES PEOPLE LIVE
DIFFER BY AGE AND
BY STATE?



HOW HAVE THE PLACES
PEOPLE WITH IDD LIVE
CHANGED?



**Residential Information
Systems Project**

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

Status and Trends Through June 30, 2020



LONG-TERM SUPPORTS AND SERVICES FOR INDIVIDUALS WITH INTELLECTUAL OR DEVELOPMENTAL DISABILITIES: STATUS AND TRENDS THROUGH 2020

RESIDENTIAL INFORMATION SYSTEMS PROJECT (RISP)

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TABLE OF CONTENTS

Acknowledgements.....	2
State Contacts	3
RISP National Advisory Group	6
Technical Users Group.....	7
Acronyms.....	8
EXECUTIVE SUMMARY	9
INTRODUCTION	21
The Policy Context	21
The Residential Information Systems Project (RISP)	27
SECTION 1: IN-HOME AND RESIDENTIAL LONG-TERM SERVICES AND SUPPORTS	33
Estimating Prevalence of IDD in the United States	33
IDD Agency Caseloads.....	37
Long-Term Services and SupportS Settings	39
SECTION 2: MEDICAID AND STATE LTSS FUNDING AUTHORITIES	64
State Utilization of LTSS Funding Authorities.....	64
LTSS Recipients with IDD by Funding Authority	64
People with IDD Waiting for Medicaid Waiver-funded Supports.....	64
Living Arrangements for People Receiving Medicaid Waiver-funded LTSS.....	68
Medicaid Waiver Utilization Rates by Age and State	71
Medicaid Waiver Expenditures.....	75
Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID).....	80
ICF/IID Expenditures.....	84
Medicaid Waiver and ICF/IID Recipients and Expenditures	89
Other Funding Authorities.....	95
A Short History of LTSS for People with IDD: Role of the Medicaid Program	97
SECTION 3: HISTORICAL PERSPECTIVES AND TRENDS IN LTSS	109
Trends in Types of Living Arrangements	109
Trends in Residence Size and Type of Operation.....	110
Trends in Medicaid Recipients and Expenditures	113
Trends in deaths of people on state IDD agency caseloads.....	121

SECTION 4: STATUS AND TRENDS IN LARGE STATE-RUN IDD FACILITIES	125
Status of Public Residential Facilities (PRF) Serving 16 or More People with IDD	125
Characteristics of People Living In PRFs	127
PRF Admissions and Discharges	131
PRF Staffing Characteristics and Outcomes	135
PRF Status by Facility as of June 30, 2020	135
Trends in Public Residential Facility Utilization	140
Trends in Average Annual per Person Expenditures	149
Trends in Characteristics of People with IDD Living in PRFs	150
Trends in PRF Admissions, Readmissions, and Discharges	153
SECTION 5: STATE NOTES	161
State Profiles	161
State Notes	161
SECTION 6: References, Resources and Data Sources	172
References	172
Historical Data: Residential Information Systems Project Reports	175
Historical Data: Other Sources	180

LIST OF TABLES

Table A: Long-Term Supports and Services Used by People with IDD.....	22
Table 1.1a United States Population, with ASD, ID, or DD IDD for Children 0-17 Years by State on June 30, 2020	35
Table 1.1b United States Population by Age and Estimated Number of Adults with Intellectual or Developmental Disabilities by Living Arrangement and State on June 30, 2020.....	36
Table 1.2a People Known to or Served by State IDD Agencies by Age on June 30, 2020	37
Table 1.2b Deaths per 1,000 people on State IDD Agency Caseloads July 1, 2019 - June 30, 2020	38
Table B: Living Arrangements for LTSS Recipients with IDD	40
Table 1.3 LTSS Recipients with IDD in IDD Settings by Setting Type, Type of Operation, and State on June 30, 2020	41
Table 1.4 Reported and Estimated LTSS Recipients with IDD in Family Home, Own Home or Unknown Settings Setting Size and State on June 30, 2020.....	43
Table 1.5 Host or Foster Family Homes and LTSS Recipients with IDD in Them by Setting Size and State on June 30, 2020	46
Table 1.6 Group LTSS Settings and People with IDD Living in Them by Setting Size and State on June 30, 2020	47
Table 1.7 Number of Settings Other than Family Homes in Which LTSS Recipients Live by Type of Operation and Setting Size on June 30, 2020.....	49
Table 1.8a LTSS Recipients with IDD not Living with a Family Member in Non-State Settings by Setting Size and State on June 30, 2020.....	50
Table 1.8b LTSS Recipients with IDD not Living with a Family Member in State-Operated Settings by Setting Size and State on June 30, 2020.....	51
Table 1.8c LTSS Recipients with IDD not Living with a Family Member by Setting Size and State on June 30, 2020	52
Table 1.9 LTSS Recipients per Setting, per 100,000 of the Population and Proportion of People in Non-Family Settings Living in Settings of 1-3 or 4-6 People	54
Table 1.10 People with IDD in State-Run and Nonstate Psychiatric Facilities and Nursing Homes by State on June 30, 2020	58
Table 2.1 People with IDD Living with Family Members Waiting for Medicaid Waiver-Funded LTSS, and Growth Needed to Serve those Waiting by State on June 30, 2020	66
Table 2.2 Medicaid Waiver Recipients with IDD by Reported Residence Type and State on June 30, 2020	69
Table 2.3 Number of Medicaid Waiver Recipients with IDD Total and per 100,000 of the Population by Age and State in FY 2020	70

Table 2.4 Medicaid Waiver Recipients with IDD Living in Family Homes or Other LTSS Settings by Age and State in FY 2020	73
Table 2.5 Estimated Percent of June 30, 2020 LTSS Recipients Living in Own Home or Family Home Settings whose Services were HCBS Waiver-Funded.....	76
Table 2.6 Medicaid Waiver Expenditures for Recipients with IDD, Per Recipient and Per State Resident by Age and State in FY 2020	77
Table 2.7 Medicaid Waiver Expenditures and Average per Recipient by Age, Living Arrangement, and State in FY 2020	79
Table 2.8 Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) by Size, Type of Operation, and State on June 30, 2020.....	81
Table 2.9 People Living in an ICF/IID by Type of Operation, Setting Size, and State on June 30, 2020	83
Table 2.10 People Living in an ICF/IID Per 100,000 of the Population by Age and State in FY 2020	85
Table 2.11 Estimated ICF/IID Expenditures, Recipients, Expenditure Per Person, and Expenditures Per State Resident by State in Fiscal Year 2020.....	87
Table 2.12 ICF/IID Recipients, Expenditures and Expenditures Per Person by Age and State in Fiscal Year 2020.....	88
Table 2.13 ICF/IID and Medicaid Waiver Recipients and Expenditures Total and Percent by Funding Authority and State in FY 2020	90
Table 2.14a FY 2020 Medicaid Expenditures for People with IDD, Federal Matching Percentage, and Federal Share by Funding Authority and State.....	93
Table 2.14b FY 2020 State Medicaid Expenditures, Federal Income Taxes, and State Medicaid Benefit Ratios by Funding Authority and State	94
Table 2.15 FY 2020 LTSS Recipients with IDD Funded through 1915 (i) or 1915(k), Targeted Case Management or Other State Plan HCBS Funding Authorities.....	96
Table 2.16 FY 2020 People on State IDD Caseloads getting State-Funded LTSS or No LTSS Funding.....	98
Table 3.1 Non-Family IDD Residences by Type of Operation and Setting Size on June 30 of Selected Years 1977 to 2020	110
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 2020.....	111
Table 3.3 Medicaid Expenditures for ICF/IID and Waiver Recipients with IDD as a Proportion of All Medicaid Expenditures Select Years 1980 to 2020.....	113
Table 3.4 Estimated Medicaid Waiver Recipients with IDD by State on June 30th Selected Years, 1982 to 2020	116
Table 3.5 Estimated Medicaid Waiver Expenditures (in \$1,000s) for People with IDD by State Selected Fiscal Years 1982 to 2020.....	118
Table 3.6 Estimated ICF/IID Recipients by State, June 30, Selected Fiscal Years 1977 to 2020.....	119

Table 3.7 Estimated Medicaid ICF/IID Expenditures (in \$1,000s) by State, Selected Years 1982 to 2020 (not inflation adjusted).....	120
Table 3.8 Deaths per 1,000 People on State IDD Agency Caseloads FY 2018 to FY 2020	122
Table 4.1 PRF Daily Population, Admissions, Discharges, Deaths and per Person Expenditures by State for Fiscal Year 2020.....	126
Table 4.2 Characteristics of People with IDD Living in PRFs on June 30, 2020.....	127
Table 4.3 Number of People with IDD in PRFs by Age and State on June 30, 2020	128
Table 4.4 Level of Intellectual Disability of People Living in PRFs by State on June 30, 2020	130
Table 4.5 Age and Level of Intellectual Disabilities for Current, Newly or Readmitted, and Discharged Residents of PRFs in 2020.....	133
Table 4.6 Previous Residence for People Admitted or Readmitted to PRFs and Subsequent Residence Type for People Discharged from PRFs 2020.....	134
Table 4.7 Staff Characteristics and Outcomes in PRFs in FY 2020	135
Table 4.8 PRFs Open on June 30, 2020: Projected Closure Date, Population, Per Person Expenditures, Admissions, Discharges and Deaths By State and Facility Name	136
Table 4.9 Operational Status of PRFs by State on June 30, 2020 with Projected Closures through June 2024.....	140
Table 4.10 Average Daily Population and People Per 100,000 of the US Population of PRFs and People with IDD in State-Operated Psychiatric Facilities, Selected Years 1890-2020.....	143
Table 4.11 Average Daily PRF Population by State Selected Years 1980 to 2020	146
Table 4.12 Change in Estimated Average Daily Population and Annual Admissions, Discharges and Deaths in PRFs Selected Years 1950-2020	147
Table 4.13 Annual Per Person Expenditures for People with IDD in PRFs Selected Years 1950-2020	149
Table 4.14 PRF Population Characteristics June 30th of Selected Years 1977 to 2020 (in percent).....	150
Table 4.15 Previous Place of Residence of Persons (Re) Admitted to PRFs (in Percent) for Selected Years 1985 to 2020	153
Table 4.16 Subsequent Residence of People Discharged From PRFs: Selected Years 1985 to 2020	154
Table 4.17 Percent of PRFs Providing Services to People Not Living On-Campus by Type of Service 2000 to 2020	156
Table 4.18 Staff Characteristics in PRFs Selected Years 2004 to 2020.....	157

LIST OF FIGURES

Figure 1.1 Estimated Total LTSS Recipients with IDD by Residence Type and Size on June 30, 2020.....	42
Figure 1.2 Estimated Percent of LTSS Recipients with IDD Living with a Family Member by State on June 30, 2020	44
Figure 1.3 Percent of People not Living with Family Members who lived in Settings of 1 to 3 or 1 to 6 People by State on June 30, 2020	56
Figure 1.4 LTSS Recipients with IDD per Setting by Setting Type on June 30, 2020	57
Figure 1.5 Estimated LTSS Recipients with IDD Per 100,000 of the Population by Setting Type and State on June 30, 2020.....	58
Figure 1.7 Percent of People in Non-Family Settings who Live in Congregate Settings of 7+ People 1998 to 2020 with Linear Projections to 2030.....	60
Figure 2.1 Funding Authorities Used by States to Provide LTSS to People with IDD on June 30, 2020.....	65
Figure 2.2 Estimated LTSS Recipients with IDD by Funding Authority on June 30, 2020.....	65
Figure 2.3 Total Medicaid ICF/IID and Waiver Recipients; People in Own or Family Home Waiting for Waiver Funding on June 30 of 2010 to 2020; and Percent Growth Needed to Serve Those Waiting.....	67
Figure 2.4 Waiver Recipients with IDD per 100,000 and Percent who are 22 Years or Older	72
Figure 2.5 Estimated Number of Waiver Recipients With IDD Living With A Family Member or In Another Setting by Age between July 1, 2019 and June 30, 2020.....	74
Figure 2.6 Annual Medicaid Waiver Expenditures for People with IDD per State Resident by State FY 2020	78
Figure 2.7 Estimated Average Annual Per Person Medicaid Waiver Expenditures by Age and Living Arrangement in FY 2020	80
Figure 2.8 Proportion of LTSS Recipients in Non-Family State- or Nonstate-Operated Settings of Various Sizes who Live in an ICF/IID on June 30, 2020	84
Figure 2.9 ICF/IID Residents per 100,000 of the Population by State in FY 2020	86
Figure 2.10 Distribution of ICF/IID and Waiver Expenditures and Recipients in FY 2020.....	89
Figure 2.11 Estimated Medicaid LTSS Recipients with IDD by Age, Funding Authority and Living Arrangement in FY 2020	91
Figure 2.12 Estimated Annual per Person Medicaid Expenditures by Age, Funding Authority, and Living Arrangement in FY 2020.....	91
Figure 3.1 Number and Percent of LTSS Recipients with IDD by Living Arrangement Type and Size: Select Years 1999 to 2020.....	109

Figure 3.2 People with IDD in Non-family LTSS Settings by Type of Operation on June 30 Selected Years 1977 to 2020	111
Figure 3.3 Proportion of People with IDD Living in IDD Settings of 16 or more people who live in Non-State Settings Selected Years 1977 to 2020	112
Figure 3.4 Number of LTSS Recipients with IDD in State and Nonstate-Operated Settings of 16+ People June 30, 2000 to 2020 with Linear Projections to 2045	112
Figure 3.5a Medicaid ICF/IID and HCBS Waiver Recipients with IDD from 1982 to 2020	114
Figure 3.5b Medicaid ICF/IID and HCBS Waiver Expenditures in Billions for People with IDD From 1982 to 2020	114
Figure 3.5c Average Annual Per Person ICF/IID and Waiver Expenditures For People with IDD From 1982 to 2020	114
Figure 3.6 Deaths per 1,000 Children and Adults on IDD Agency Caseloads Fiscal Years 2018, 2019 and 2020.....	121
Figure 4.1 Percent of People Living in PRFs in Age Groups by State on June 30, 2020	128
Figure 4.2 Level of Intellectual Disability (in Percent) of People in PRFs by State on June 30, 2020	130
Figure 4.3 Scatterplot of Age and Level of ID for People Living in PRFs on June 30, 2020 by State.....	132
Figure 4.4 Age Distribution for June 30, Newly Admitted, Readmitted and Discharged PRF Residents in FY 2020.....	132
Figure 4.5 Level of Intellectual Disabilities for June 30, Newly Admitted, Readmitted and Discharged PRF Residents in FY 2020	133
Figure 4.6 Previous and Subsequent Residence For People Admitted or Readmitted to or Discharged from PRFs in 2020	134
Figure 4.7 PRFs Closed or Converted to Non-IDD Use or Nonstate Operation Between 1960 and 2020 and Projected Closures by 2024 in 5-Year Intervals	141
Figure 4.8 Average Daily Population of Large State-Run IDD Facilities from 1880 to 2020.....	142
Figure 4.9 Average Daily Population of PRFs and Percent 21 Years or Younger, 1950 to 2020.....	144
Figure 4.10 Average Annual Change in the Number of People with IDD in PRFs and State Psychiatric Facilities in Five Year Intervals 1965 to 2020 with Linear Trendlines	145
Figure 4.11 Annual PRF Admissions, Discharges, and Deaths as a Proportion of the Average Daily Population, 1967 to 2020.....	148
Figure 4.12 Number of Deaths as a Proportion of all Leavers and Trend Line 1967 to 2020	148
Figure 4.13 Percent of PRF Residents by Age Group on June 30 of Selected Years 1977 to 2020.....	151
Figure 4.14 Estimated Percent of People with IDD Living in PRFs by Level of Intellectual Disability on June 30 of Selected Years 1977 to 2020.....	151

Figure 4.15 Previous Place of Residence for People (Re)Admitted to a Large State IDD
Facilities in Percent Selected Years: 1989 to 2020 153

Figure 4.16 Subsequent Residence of People with IDD Discharged From a Public IDD
Facility Selected Years 1989 to 2020 154

Figure 4.17 Direct Support Professional and Frontline Supervisor Turnover Rates in PRFs
Selected Years 2004 to 2020 157



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, 2020 (Fiscal Year 2020).

The RISP project reports are transitioning from being a print product to a primarily web-based product. For FY 2020, this technical report includes the Executive Summary, text, tables, figures, and references. State profiles, historical information about state run facilities of sixteen or more people, and the 2020 survey and operational definitions can be viewed or downloaded from www.risp.umn.edu. Historical RISP reports can be downloaded from the RISP website or the University of Minnesota Libraries Digital Conservancy <https://conservancy.umn.edu/search?spc.page=1&query=RISP>.

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

Sheryl Larson, RISP Principal Investigator

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TECHNICAL USERS GROUP

NASDDDS Research Committee

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

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ACRONYMS

ACL	Administration on Community Living
ADA	Americans with Disabilities Act
ADDM	Autism and Developmental Disabilities Monitoring
AHCA	American Health Care Association
AIDD	Administration on Intellectual and Developmental Disabilities
APDDA	Association of Professional Developmental Disabilities Administrators
ARPA	American Rescue Plan Act of 2021
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	Data not furnished
FFP	Federal Financial Participation
FMAP	Federal Medical Assistance Percentage
FY	Fiscal year (FY 2020 is July 1, 2019, to June 30, 2020, unless otherwise specified)
HCBS	Home and Community-Based Services (Medicaid)
ICF/IID	Intermediate Care Facility for Individuals with Intellectual Disabilities
ICI	Institute on Community Integration (University of MN's UCEDD)
ID	Intellectual disabilities
IDD	Intellectual and developmental disabilities
IDEA	Individuals with Disabilities Education Act
LTSS	Long-term supports and services
MCO	Managed care organization
MFP	Money Follows the Person
NASDDDS	National Association of State Directors of Developmental Disabilities Services
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)
PD	Partial data
PASRR	Preadmission Screening and Resident Review
PHE	2020 – 2023 Covid-19 Public Health Emergency
PRF	Public residential facility (a state-run 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
SSI	Supplemental Security Income
UCEDD	University Centers of Excellence in Developmental Disabilities

EXECUTIVE SUMMARY

People with intellectual or developmental disabilities (IDD) in the United States live in settings such as homes of their own, with a family member, with a host or foster family, or in a provider-owned or -operated setting.

Living Arrangements for Long-Term Services and Supports Recipients with IDD on June 30, 2020

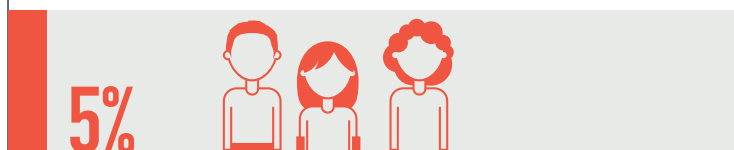
Family Home | a residence shared by a person with ID/DD and their related family members.



Own Home | a home owned or rented by one or more adults with ID/DD



Host or Foster Family Home | a home owned or rented by an individual or family that provides supportive services to one or more people with ID/DD



Group Home | a residence of six or fewer people owned, rented or managed by the organization or agency that provides services to the people in the home



Institution | a residence of seven or more people owned, rented, or managed by the organization or agency that provides services to people in the facility



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, 2020.

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

In 2020, there were an estimated 6.1 million children ages birth to 17 years with intellectual disability (ID), autism spectrum disorder (ASD) or developmental delay including children living in nursing homes, IDD institutions, and psychiatric facilities. That is a prevalence rate of 83.5 per 1,000. An estimated 3.2 million of those children had ID and/or ASD, a prevalence rate of 20.7 per 1,000. Of the 3.2 million children with ID and/or ASD, an estimated 20% were on the caseloads of state IDD agencies.

There were an estimated 2,275,551 adults 18 years or older with IDD of whom 44% were on the caseloads of state IDD agencies.

An estimated 644,948 children and youth ages birth to 21 years and an estimated 1,005,401 adults 22 years or older were on state IDD agency caseloads as of June 30, 2020.

How many people on IDD agency caseloads died in 2020?

An estimated 14,362 people on IDD agency caseloads passed away in 2020. Of those who died, 1,159 were ages 0 to 21 years and 12,963 were 22 years and older. Overall state IDD agencies reported 10.5 deaths per 1,000 people on their caseloads (2.2 per 1,000 for people ages 0 to 21 and 17.0 per 1,000 for those 22 and older).

Where did people with IDD receiving LTSS live?

An estimated 1.43 million people in the United States received one or more long-term support or service (LTSS) in addition to case management provided by or under the auspices of state IDD agencies (87% of the people known to state IDD agencies) on June 30, 2020. Of those,

- 62% (876,058 people) lived in the home of a family member.

- 22% (305,047 people) lived in a group home, Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID), or other group setting;
- 11% (154,634 people) lived in a home they owned or leased; and
- 5% (66,042 people) lived in a host or foster family home.

An additional 25,749 people with IDD lived in nursing homes and at least 2,254 more people lived in psychiatric facilities. The number of people with IDD in psychiatric facilities is an undercount due to incomplete data.

How many LTSS recipients lived together in non-family settings?

LTSS recipients with IDD who did not live with a family member lived in their own homes, host/foster family homes, group homes, ICF/IIDs, and other group settings. This does not include people in nursing homes or psychiatric facilities.

There were an estimated 231,734 non-family residences (1,935 were state-run and 229,799 were non-state run) in which LTSS recipients with IDD lived. Of those settings,

- 83% (192,104 settings) were home to three or fewer people,
- 14% (33,196 settings) were home to four to six people,
- 2% (5,605 settings) were home to seven to 15 people, and
- 0.4% (829 settings) were home to 16 or more people (721 nonstate and 108 state-run settings).

An estimated 525,763 people with IDD lived in non-family settings. Of those,

- 55% (286,740 people) lived in a setting shared by three or fewer people,
- 29% (153,761 people) lived in a setting shared by 4 to 6 people,
- 9% (49,011 people) lived in a setting shared by 7 to 15 people, and

- 7% (36,251 people) lived in a setting shared by sixteen or more people (20,929 in non-state facilities and 15,322 in state-run facilities).

What was the average size of non-family settings?

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

In non-state settings, there were an average of

- 1.4 people per own home setting,
- 1.6 people per host/foster family home,
- 3.4 people per non-state group home (other than ICF/IID), and
- 8.7 people per non-state ICF/IID.

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

- 5.1 people per group home (other than ICF/IID),
- 8.4 people per “other” group setting, and
- 69.2 people per ICF/IID.

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

An estimated 113,819 people with IDD (20% of those living in places other than the home of a family member) lived in IDD group settings shared by seven or more people, nursing homes or psychiatric facilities on June 30, 2020. This is a decrease from 115,677 (21%) on June 30, 2019.

SECTION 2 SUMMARY: MEDICAID LTSS RECIPIENTS AND EXPENDITURES

Section 2 describes the Medicaid and state authorities that funded LTSS for people with IDD.

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

In 2020, all fifty states and the District of Columbia provided Medicaid Waiver-funded LTSS authorized under Sections 1115, or 1915(a), (b), (b/c) or (c) of the Social Security Act. Of those states,

- 47 states used Medicaid 1915(c) Home and Community-based Waivers.
- 13 states used Medicaid 1115 Demonstration Waivers.
- 7 states used Medicaid managed care waivers (1915a, b, or b/c).
- 48 states provided institutional services to people with IDD through the Medicaid ICF/IID funding authority
- States using Medicaid state plan HCBS funding authorities included:
- 36 states used the Targeted Case Management authority.
- 7 states used Medicaid State Plan 1915(k) Community First Choice.

- 7 states used Medicaid State Plan 1915(i) Home and Community-Based Services.
- 26 states provided HCBS through another state plan funding authority.
- 47 states funded LTSS for people with IDD through state or local public dollars not matched by federal Medicaid funds.

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

Of the 1.65 million people with IDD known to or served by state IDD agencies,

- 68% (954,314 people) received LTSS through a Medicaid Waiver funding authority,
- 28% (467,490 people) received Medicaid State Plan Targeted Case Management services,
- 13% (277,908 people) received state- or locally funded LTSS,
- 10% (226,280 people) received no Medicaid or state-funded LTSS,
- 8% (166,937 people) received other Medicaid state plan HCBS-funded LTSS,
- 5% (104,092 people) received LTSS through the 1915(i) or 1915(k) state plan HCBS authorities, and

- 3% (64,445 people) received supports in a Medicaid ICF/IID.

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

Medicaid Waiver

This section describes services funded through a Section 1915(c) HCBS Waiver, an 1115 Demonstration Waiver, or a 1915 (a), (b), (a/c), or (b/c) Managed Care Waiver.

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

An estimated 174,785 people with IDD were living with a family member on in a home of their own and waiting for Medicaid Waiver-funded LTSS. Of those,

- 26% (45,933 people) were waiting to move to a different setting and
- 19% (32,669 people) received Medicaid State Plan-funded Targeted Case Management services while waiting.

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

The number of Medicaid Waiver plus ICF/IID recipients with IDD would have to increase by 18% to serve every person with IDD on the Medicaid Waiver waiting list.

Where did Medicaid Waiver recipients with IDD live?

Of the estimated 921,443 Medicaid Waiver recipients with IDD on June 30, 2020,

- 56% (519,404 people) lived with a family member,
- 24% (223,658 people) lived in a group setting,
- 13% (119,490 people) lived in a home they owned or leased, and
- 6% (58,891 people) lived with a host or foster family.

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

Of the 954,314 people with IDD who had a claim for Medicaid Waiver-funded LTSS in FY 2020,

- 25% (241,361 recipients) were 21 years or younger, of whom
 - 90% lived in the home of a family member and
 - 10% lived in their own home, a host or foster family home, or a group setting.
- 75% (712,953 recipients) were 22 years or older, of whom
 - 45% lived in the home of a family member and
 - 55% lived in their own home, a host or foster family home, or a group setting.

In FY 2020, there were 288 Medicaid Waiver recipients with IDD per 100,000 of the United States' population. There were:

- 264 Medicaid Waiver recipients with IDD per 100,000 of the population ages 21 years or younger,
- 297 Medicaid Waiver recipients with IDD per 100,000 of the population ages 22 years or older, and
- The number of adult Medicaid Waiver recipients per 100,000 of the population ranged from a low of 102 per 100,000 in Nevada to a high of 768 per 100,000 in Wisconsin. Rates also varied for children.

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

- 77% (119,490 LTSS recipients) living in their own home received Medicaid Waiver-funded supports.
- 59% (519,404 LTSS recipients) living in the home of a family member received Medicaid Waiver-funded supports.

What were total FY 2020 Medicaid Waiver expenditures for children and adults with IDD?

Estimated Medicaid Waiver expenditures for people with IDD were \$47.4 billion (\$143 per U.S. resident) of which:

- 9% (\$4.1 billion) was for people 21 years or younger and
- 91% (\$40 billion) was for people 22 years or older.

What were the average annual per recipient Medicaid Waiver expenditures for people with IDD in FY 2020?

Average annual Medicaid Waiver expenditures were \$49,764 per person with IDD. Average expenditures were:

- \$17,814 per recipient 21 years or younger overall,
 - \$14,659 for people 21 years or younger living in the home of a family member, and
 - \$55,076 for people 21 years or younger living in other settings.
- \$60,172 per recipient 22 years or older overall,
 - \$29,243 for people 22 years or older living in the home of a family member, and
 - \$85,189 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 facilities and recipients were there as of June 30, 2020?

There were 5,814 ICF/IID settings in the United States on June 30, 2020. Of those,

- 4% (230 ICF/IID) were state-run including:
 - 23% (53) serving six or fewer people,
 - 31% (72) serving seven to 15 people, and
 - 46% (105) serving 16 or more people.
- 96% (5,584 ICF/IID) were non-state operated including:
 - 63% (3,516) serving six or fewer people,
 - 31% (1,739) serving seven to 15 people, and
 - 6% (329) serving 16 or more people.

There were no ICF/IIDs of any size reported in Alaska, Michigan, Montana, or Oregon. There were no ICF/IIDs of sixteen or more people in Alabama, the District of Columbia, Hawaii, New Mexico, Vermont, or West Virginia.

How many people lived in state or non-state ICF/IID on June 30, 2020?

An estimated 64,445 people lived in ICF/IIDs on June 30, 2020. Of those,

- 25% (15,919 people) lived in state-run ICF/IIDs including:
 - 1% (219) in a setting of six or fewer people,
 - 4% (613) in a setting of seven to 15 people, and
 - 95% (15,127) in a setting of 16 or more people.
- 75% (48,526 people) lived in a non-state ICF/IID including:
 - 38% (18,648) in a setting of six or fewer people,
 - 32% (15,676) in a setting of seven to 15 people, and
 - 29% (14,202) in a setting of 16 or more people.

How old were people living in ICF/IIDs?

Of the 64,902 people living in ICF/IIDs at any time during FY 2020 (19.6 people per 100,000 of the population),

- 7% (4,384 people) were 21 years or younger (4.8 people per 100,000 of the population), and
- 93% (60,518 people) were 22 years or older (25.2 people per 100,000 of the population).

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

Of the 36,251 people living in IDD settings of sixteen or more people, 81% (29,329 people) lived in an ICF/IID including:

- 99% (15,127 of 20,929 people) in state-run IDD facilities, and
- 68% (14,202 of 15,322 people) in non-state IDD facilities.

What were FY 2020 Medicaid ICF/IID expenditures?

Total ICF/IID expenditures were \$9.38 billion (\$28.29 per United States resident). Average annual ICF/IID expenditures were \$144,469 per year-end recipient. The average was:

- \$129,404 for recipients 21 years or younger and
- \$150,112 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 2020?

An estimated 1,019,216 Medicaid LTSS recipients with IDD lived in an ICF/IID or received Medicaid Waiver-funded LTSS. Of those,

- 94% received Medicaid Waiver-funded LTSS and
- 6% lived in ICF/IIDs.

Total Medicaid ICF/IID plus Waiver expenditures for people with IDD were \$56.8 billion in FY 2020. Of the total,

- 83% (\$47.4 billion) was for Medicaid Waiver recipients and
- 17% (\$9.38 billion) was for people in ICF/IIDs.

State Plan and State- or Locally Funded Services and No LTSS

We are reporting the number of people getting LTSS through funding authorities other than the Medicaid Waiver or ICF/IID for the first time. Because we do not have historical data for all states, we are not reporting estimated totals. Therefore, people in these categories are undercounted.

How many people received state plan services?

In 2020, a total of 102,595 people in 46 reporting states received LTSS through either 1915 (i) or 1915 (k) Medicaid State Plans funding authorities. Of them,

- 39% were 21 years or younger and
- 61% were 22 or older.

A total of 163,452 people in 34 reporting states received State Plan HCBS through other funding authorities. Of them,

- 37% were 21 years or younger and
- 63% were 22 or older.

A total of 467,490 people in 39 reporting states received Targeted Case Management services. Of them,

- 45% were 21 years or younger and
- 55% were 22 or older.

How many people received state- or locally funded services?

In 2020, 277,123 people in 42 reporting states received state- or locally funded services. Of them,

- 58% were 21 years or younger and
- 42% were 22 or older.

How many people on state IDD agency caseloads did not receive services?

Some people on IDD agency caseloads on June 30, 2020, did not receive LTSS. This includes people on waitlists, people whose services were authorized but had not yet been initiated, and those who deferred services until a later time. These individuals were eligible for services.

In 2020, 220,313 people on IDD agency caseloads in 34 reporting states were not receiving services. Of them,

- 61% were 21 years or younger and
- 39% were 22 or older.

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

Section 3 summarizes trends in LTSS for people served by state IDD agencies.

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

Between 1999 and 2020, the number of June 30th LTSS recipients with IDD increased 97% from 728,704 to 1,434,307. The number of LTSS recipients with IDD living in

- The home of a family member increased 147% from 355,192 to 876,058 people. The proportion living with a family member who received Medicaid Waiver-funded supports increased from 23% to 59%;
- A home of their own increased 138% from 65,006 to 154,634 people;
- A host/foster home increased 107% from 31,884 to 66,042;

- An IDD group setting of three or fewer people increased 142% from 34,082 to 82,587 people;
- An IDD group setting of 4 to 6 people increased 71% from 80,464 to 137,294 people;
- An IDD group setting of 7 to 15 people decreased 7% from 52,863 to 48,955 people; and
- An IDD facility of sixteen or more people, a nursing home or psychiatric facility decreased 44% from 109,213 to 61,505 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 2020, the number non-family IDD settings increased from 11,008 to 231,734 settings.

- The proportion serving six or fewer people increased from 63% (6,898 facilities) to 97% (225,300 facilities).
- The proportion serving seven to 15 people decreased from 22% (2,405) to 2% (5,605).
- The proportion serving 16 or more people decreased from 15% (1,705) to less than 1% (829).

How has the number of people with IDD living in settings other than the home of a family member changed between 1977 and 2020?

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

- Six or fewer people increased from 8% (20,400 people) in 1977 to 84% (440,501 people) in 2020,
- Seven to 15 people increased from 8% (20,024 people) in 1977 to 9% (49,011 people) in 2020, and
- Sixteen or more people decreased from 84% (207,356 people) in 1977 to 7% (36,251 people) in 2020.

Of the people living in non-family IDD settings, the proportion living in state-run settings decreased from 63% (155,804 people) in 1977 to 5% (24,836 people) in 2020.

Between 1977 and 2020, the average size of all non-family IDD settings declined from 22.5 to 2.3 people per setting. The average size of

- State-run IDD settings decreased from 335.1 to 12.8 people per setting.

- Non-state IDD settings decreased from 8.7 to 2.2 people per setting.

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

Between 1982 and 2020, the number of people with IDD

- Receiving Medicaid Waiver-funded supports increased from 1,381 to 954,314 people, and
- In a Medicaid ICF/IID setting decreased from 140,752 to 64,902 people.

Total expenditures for people with IDD

- Receiving Medicaid Waiver-funded services increased from \$6.1 million to \$47.4 billion in 2020 inflation-adjusted dollars.
- In ICF/IID settings increased from \$9.1 billion to \$9.4 billion in 2020 inflation-adjusted dollars.

Average annual per person Medicaid expenditures for

- Waiver-funded services for people with IDD increased from \$4,390 to \$49,669 in 2020 inflation-adjusted dollars.
- ICF/IID services increased from \$64,340 to \$144,469 in 2020 inflation-adjusted dollars.

How has the number of people with IDD waiting for Medicaid Waiver-funded LTSS changed?

The number of people with IDD living with a family member or in their own home waiting for Medicaid Waiver-funded LTSS decreased 25% from 232,204 people in 2013 to 174,785 people in 2020. The number waiting to move to a residence other than the home of a family member decreased 57% from 107,204 in 2013 to 45,933 in 2020.

How has the number of deaths per 1,000 people on IDD agency caseloads changed?

Between FY 2018 and FY 2020, the number of deaths per 1,000 people on state IDD agency caseloads

- Across all ages increased 3% from 10.2 to 10.5 per 1,000 people,
- For people 21 years or younger decreased 20% from 2.7 to 2.2 per 1,000 people, and
- For people 22 years or older increased 10% from 15.4 to 17.0 per 1,000 people.

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

Section 4 examines the status of and trends in the number of people with IDD living in state-run IDD facilities serving 16 or more people (public residential facilities, or PRF) or in state-run psychiatric facilities.

How did the number of people living in PRFs change during FY 2020?

An estimated 15,322 people with IDD lived in a PRF on June 30, 2020 (down 5% from 16,200 on June 30, 2019). The average daily population for FY 2020 was 15,937. The number of people per facility ranged from 16 to 647 and averaged 160 (88 facilities reporting).

In 2020, PRFs had an estimated

- 888 admissions or readmissions,
- 878 discharges,
- 645 deaths, and
- 508 short-term admissions (less than 90 days).

People ages 21 years or younger were 5% of the PRF population on June 30, 2020, but were

- 29% of all admissions or readmissions and
- 20% of all discharges

People with mild or no intellectual disabilities were 17% of the population on June 30, but were

- 54% of the people admitted or readmitted and
- 49% of the people discharged from PRFs in FY 2020.

In 72 reporting facilities of the people newly admitted or readmitted to PRFs in FY 2020,

- 23% came from correctional facilities;
- 17% came from the home of a family member;
- 17% came from a group IDD setting of 6 or fewer people;
- 16% came from a psychiatric unit or facility;
- 10% came from a nursing home, assisted living facility or boarding home;
- 9% came from a group IDD setting of 7 or more people; and

- 7% came from their own home or a host or foster family home.

In 68 reporting facilities of the people who moved from a PRF to another setting in FY 2020,

- 36% went to a group IDD setting of six or fewer people;
- 15% went to a correctional facility;
- 14% went to a nursing home, assisted living or boarding home;
- 13% went to their own home or a host or foster family home;
- 11% went to the home of a family member;
- 7% went to a group IDD setting of seven or more people; and
- 4% went to a psychiatric unit or facility.

What were the characteristics of people with IDD living in PRFs in 2020?

On June 30, 2020, of the people living in PRFs, an estimated

- 5% were 21 years or younger, 23% were 22 to 39 years, 46% were 40 to 62 years and 27% were 63 years or older;
- 17% had mild or no intellectual disabilities (ID), 16% had moderate ID, 17% had severe ID, and 49% had profound ID;
- 7% were of Hispanic origin;
- 68% were white, 20% were black or African American, and 3% were another race or two or more races. Race was not specified for the 7% who were Hispanic;
- 38% had epilepsy, 23% had autism, and 16% had cerebral palsy; and
- 60% received medications for mood, anxiety, or behavior, had a psychiatric disorder, or had a behavior disorder.

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

Vacancy rates on June 30, 2020, were

- 14% for direct support professionals (DSPs, up from 6% in 2006)
- 8% for frontline supervisors (up from 5% in 2006)

Crude separation rates (turnover) for FY 2020 were

- 36% for DSPs (up from 29% in 2006)
- 26% for frontline supervisors (up from 13% in 2006)

How has the number of PRFs changed?

Of the 376 PRFs operating between 1960 and 2020,

- 266 closed before July 1, 2020,
- 3 closed between July 1, 2019, and June 30, 2020,
- 107 were open on June 30, 2020, 6 of which anticipated closing by June 30, 2024.

On June 30, 2020, there were no PRFs serving sixteen or more people with IDD in: Alabama, Alaska, the

District of Columbia, Hawaii, Indiana, Kentucky, Maine, Michigan, Minnesota, Montana, New Hampshire, New Mexico, Oklahoma, Oregon, Rhode Island, Tennessee, Vermont, and West Virginia.

How has utilization of PRFs changed?

The average daily PRF population declined from a peak of 194,650 in 1967 to 15,937 in 2020. The number of people in state-run psychiatric units or facilities declined from 33,850 in 1967 to 1,470 in 2020.

The number of PRFs decline from 376 in 1960 to 107 at the end of FY 2020. Three PRFs closed during FY 2020 and 6 more had plans to close by June 30, 2024.

The rate of discharges from PRFs as a percentage of the average daily population declined from 7.5% in 2019 to 5.6% in 2020. Deaths as a proportion of discharges plus deaths increased from 31% in 2019 to 43% in 2020.

Average annual per person expenditures for people in PRFs in inflation adjusted dollars increased from \$284,772 in 2019 to \$313,188 in 2020.







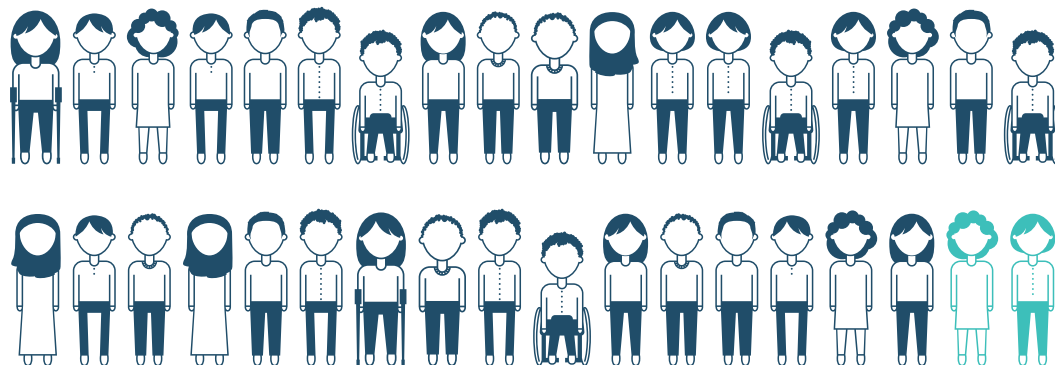
Introduction

FY 2020

People with IDD in the United States

8.38 million people in the United States had an intellectual and/or developmental disability in 2020.

2.88 million children had a developmental delay (but not ID and/or ASD)



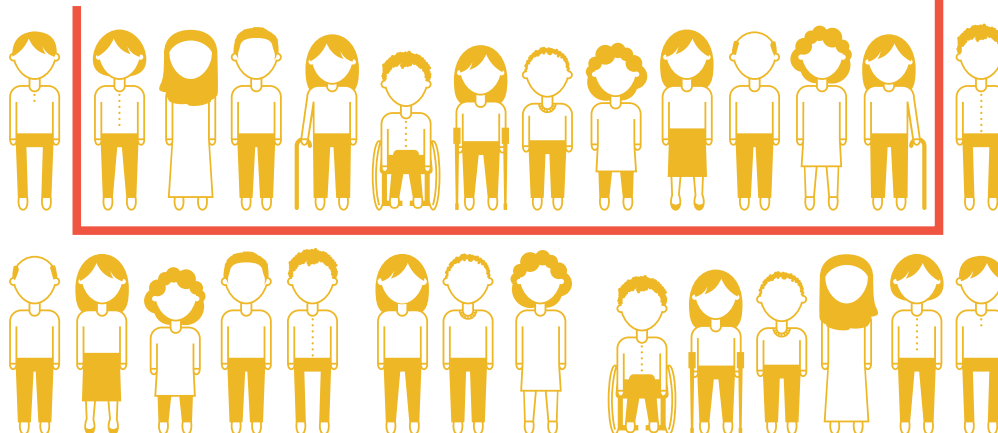
3.22 million children had an intellectual disability or Autism Spectrum Disorder (ASD)



20% of children were known to state IDD agencies

44% of adults were known to state IDD agencies

2.28 million adults had an intellectual and/or developmental disability



Note: IDD prevalence rates for people 17 years or younger from 2016 National Health Interview Survey (NHIS) were 6.99% in 2016 (Zablotsky et al., 2017). IDD prevalence rates for people 18 years or older from the 1994/1995 NHIS-Disability Supplement were 0.79% (Larson, et al., 2001).

INTRODUCTION

People with intellectual or developmental disabilities (IDD) should 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 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, income and assets, the type or amount of support needed, or the way supports are delivered.

LTSS assist people to participate fully in all aspects of community life including:

- Activities of daily living such as dressing, bathing, and eating;
- Household activities such as shopping, cooking, cleaning, and money management;
- Developing and maintaining relationships;
- Identifying and pursuing personal interests such as hobbies, sports, clubs, or worship;
- Health and Wellness (physical, emotional, and spiritual);
- Employment;
- Formal and informal learning opportunities;
- Making decisions about where and with whom to live; schedules and activities; and about how to spend earnings and other resources;
- Civic participation such as voting and paying taxes; and
- Traveling to and from work, school, or other places.

Full participation may require a different combination of informal and formal supports for each person. **Table A** describes some of the more common types of LTSS available to support full participation 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.

THE POLICY CONTEXT

LTSS in the United States for people with IDD may be funded by Medicaid; state, or local governments without Medicaid matching dollars; or the individual or family privately. LTSS are influenced by Medicaid statute and regulations (including the 2014 Home and Community-Based Services rule, and the 2024 Access Rule), as well as federal laws such as the Rehabilitation Act of 1973, the Americans with Disabilities Act of 1990, the Workforce Innovation and Opportunity Act of 2014, the Supreme Court's 1999 *Olmstead* decision, and other federal and state legislative actions, judicial decisions, and policies. A few of these influences are briefly described here. A more detailed description of the Medicaid program can be found at the end of Section 2 of this report.

The 2020 – 2023 Covid-19 Public Health Emergency: Impact on LTSS Landscape

The Covid-19 Public Health Emergency (PHE) of 2020 to 2023 had an immediate impact on the service delivery systems supporting people with IDD across the country. With little notice, the ways people received services and supports changed dramatically, with lockdowns limiting their access to community services and supports. States needed to act quickly to ensure access to personal protective equipment for people receiving services and direct support professionals (DSPs) and needed to devise strategies to ensure service continuity in unprecedented times. Everyone experienced disruption in their daily routines. People with IDD experienced more pronounced adverse impacts than other populations, leading many to question whether significant systemic changes, including reducing reliance on congregate settings, were needed to improve health and well-being (Landes et al., 2020).

The early months of the pandemic were marked with agility at both the state and federal levels to ensure a flexible Medicaid response heretofore unseen. The Centers for Medicare & Medicaid Services (CMS) readily made available emergency

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

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

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

authorities to aid states in their pivot to mitigate the spread of Covid-19 while striving to support people needing ongoing supports to remain in their homes and experience as few service disruptions as possible. Every state invoked a variety of Medicaid waivers and authorities to ensure service continuity, including 1135 waiver(s) and emergency state plan amendments. For Medicaid Home and Community-Based Services (HCBS), the most often used tool was the 1915(c) Appendix K.

States used Appendix K for many purposes, such as:

- Augmenting provider payment rates,
- Providing bonuses for DSPs who were working tirelessly to keep people with IDD safe,
- Increasing permissive use of technology both for the delivery of services and quality oversight,
- Permitting family members to be paid for rendering services, and
- Adjusting provider qualifications and settings in which services were delivered.

These flexibilities not only provided essential authority for supporting people with IDD throughout the pandemic, but they also created a laboratory for innovation, providing states an opportunity to accelerate new ways of thinking about helping people engage in their communities.

Despite these efforts, the pandemic exacerbated an ongoing crisis in the availability of DSPs. Many flexibilities and increased public investments were aimed at shoring up the catastrophic shortage of staff for HCBS nationally.

The 1135 waivers and the Emergency State Plan Amendments terminated upon expiration of the PHE. States could continue Appendix K flexibilities for six months beyond the expiration of the PHE. The Biden Administration announced that the PHE would expire on May 11, 2023, putting the sunset date in November 2023 for Appendix Ks.

The Covid-19 PHE underscored the urgent need to reduce the reliance on institutional services and expand access to high-quality HCBS to improve outcomes for people with LTSS needs. Consequently, Congress passed and President Biden signed the American Rescue Plan Act (ARPA) in March of 2021. Section 9817 of that statute provided states with

an enhanced match rate for one year for qualified HCBS. This provision resulted in the single greatest investment in HCBS since its inception. With these resources, states were required to supplement, not supplant, resources for HCBS and allowed to make any investments (with CMS approval) to strengthen HCBS. States have until March 31, 2025, to expend these resources. State use of the ARPA resources includes a heavy, almost universal commitment to increasing wages for DSPs. Every state has made or plans to make investments in this workforce. In addition to wages or other forms of compensation, states are building career ladders, making improvements to benefit offerings, and enhancing strategies to both recruit and retain workers in the field.

States also are addressing waiting lists, increasing service offerings, and improving quality and data systems. The impacts on the service delivery system for people with IDD will influence the service delivery system features for many years to come.

All of this happened as the 2014 HCBS final rule provisions were being implemented.

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

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

The HCBS rule describes characteristics of settings that qualify for Medicaid HCBS funding, and details additional requirements for services provided in provider-owned or -controlled settings. For example, people 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 homes, control over their schedules and activities, and access to food and visitors at any time. The settings component of the rule provoked significant controversy, lawsuits, and debate about whether intentional communities, farmsteads, and other congregate settings could be funded by HCBS authorities. In the end CMS abandoned its original requirement that all such settings would automatically be subject to “heightened scrutiny.” It removed requirements for residential settings regarding the size of the setting but requires that all provider operated settings to support access to community life.

Most provisions of the regulation became effective on March 17, 2014. However, states had until March 17, 2023, to fully implement the settings portion of the rule. After that date, each state needed to be fully compliant with the 2014 rule with oversight and monitoring strategies established to ensure ongoing compliance with the regulations. CMS permitted states to submit corrective action plans if they required additional time to meet the compliance requirements by the rule’s effective date. CMS received such requests from more than half of the states, so additional work has been underway to achieve full compliance in some settings.

Through a series of site visits related to state heightened scrutiny submissions, CMS identified key themes that require attention within states to better meet the entirety of the HCBS governing regulations. Areas for improvement needed across states include:

- Improved development and use of the person-centered service plan,
- Monitoring and oversight to ensure that leases and residency agreements include tenancy protections and are not used as tools for restriction and coercion for people living in provider-owned and -operated settings,
- DSP understanding about expectations outlined in the regulation, and
- Opportunities for meaningful choice of and engagement in community-integrated activities.

While the compliance date for the entirety of the rule has passed, the efforts to ensure ongoing compliance is essential. States have built key provisions for continuous quality improvement and monitoring to ensure continued achievement of the tenets of these important civil rights protections.

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

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

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

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

The United States Department of Justice’s (DOJ) enforcement of the *Olmstead* Decision has produced pivotal settlement agreements or consent decrees in several states that continue to shape the availability and delivery of HCBS. Notably, the Rhode Island, Virginia, and Oregon agreements contain specific requirements related to the nature and settings of services. See the DOJ *Olmstead* website for more information (<https://www.ada.gov/olmstead/>). DOJ continues to work with states, including through litigation, on issues related to *Olmstead*.

State Litigation and Policy Initiatives

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

Using Long-Term Supports and Services Data to Inform Public Policy

Policymakers are charged with creating systems to respond to the support needs of current and future generations of people 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 system 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 RISP can help answer key questions about service delivery systems at the state and national levels such as:

- How many children and adults in the US 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 setting types and sizes differ by state, recipient age, funding authority, and over time?
- How do expenditures for services differ by funding authority, setting type, and recipient age?

During these years of tumult in the LTSS system, RISP's importance has never been greater. The impacts of the pandemic, the investments through ARPA spending plans, and the full implementation of the HCBS final rule promise to shape service delivery systems. These data are essential to understand where those changes manifest within IDD service delivery systems.

Medicaid Basics

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

Rules and statutes that apply to all Medicaid programs are largely but not exclusively contained in Section 1902 and Section 1903 of the Social Security Act. Medicaid state plan services and eligibility groups (mandatory and optional) serve as the backbone for state's Medicaid programs. States' waivers are deviations from standard practice that states may choose to request to address the needs of specific groups of recipients.

Medicaid's rules, statutes, State Plan services, and eligibility groups support and guide all state Medicaid programs. Each state uses a unique combination of waivers and individualized services to meet the local needs of its citizens. All states must offer eligible recipients a set of mandatory benefits such as inpatient and outpatient hospital services, home health services, and laboratory and x-ray services (see <https://www.medicaid.gov/medicaid/benefits/mandatory-optional-medicaid-benefits/index.html> for a list of state plan benefits). States can choose whether to offer optional State Plan benefits such as occupational, physical, or speech therapy; personal care services; services in an ICF/IID; and other state plan home and community-based services. State plan services, whether mandatory or optional, must be available to all state Medicaid beneficiaries who need the service in sufficient amount, duration, and scope to achieve their purpose (O'Keeffe et al., 2010). States are not allowed to maintain waiting lists for state plan benefits and state plan benefits must be uniformly available statewide.

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

Eligibility criteria. States are required to cover individuals within specific financial parameters (mandatory eligibility groups). States may elect to cover additional groups or people of specified income and/or resource levels (optional eligibility groups). In an HCBS 1915(c) waiver, a Special Income Level (SIL) group (further at 42 CFR 435.217) can be identified for whom income and resources are counted differently for eligibility purposes. In addition to being financially eligible, Medicaid

HCBS waiver participants must meet the clinical requirement of “institutional level of care.” States also may choose to apply additional diagnostic or age-related eligibility restrictions.

Services offered and service definitions. Service and program definitions vary from state to state. For example, many states offer a service called “Family Support.” What is included under that label, however, can be vastly different (ranging from a single service such as respite to an intensive array of 24-hour in-home support). Some Waiver-funded services include annual or lifetime caps on expenditures for participants.

Populations served. States designate the populations to be served in their Medicaid Waiver programs. Some waivers target only people with IDD 18 years and older while others serve only children or all people regardless of age. The age break between child and adult services ranges from 18 to 22 years. Some Waivers target people with a specific diagnosis such as autism spectrum disorder or intellectual disabilities while others define eligibility in terms of functional support needs. While 1915(c) waivers originally were limited to a single population, states now have the option to include individuals with IDD, people with physical disabilities, older adults, and people with mental health diagnoses in a single Waiver.

Medicaid authority options. Medicaid authorities include state plan services, demonstration waivers, managed care Waivers, and other Waiver options. States may elect to offer Medicaid-funded services through various service delivery models such as fee for services or managed care.

These options result in quite different Medicaid programs and LTSS offerings from state to state. Because each state’s program is different, it is important to understand the state-specific landscape to understand the full array of supports and services available to people with IDD.

RISP collects a common core set of data from all state IDD agencies. However, interpreting the data properly requires an understanding of the state variations in eligibility criteria, service definitions, populations served and funding options. For example, the proportion of service recipients with IDD who live with a family member may differ

depending on whether the IDD system serves both children and adults or only adults because children are more likely than adults to live with a family member. Throughout this report, the narrative includes key considerations for interpreting specific tables and figures. Additional details about the survey questions and their operational definitions can be found at risp.umn.edu. In the appendix there are state notes describing state-specific factors for interpreting the tables and charts. RISP project staff members are available to assist you to understand the findings (email: risp@umn.edu). As you examine specific findings, you may also want to check state IDD agency websites, or with the IDD agency directors for clarification. State-specific information is available on the following websites:

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

THE RESIDENTIAL INFORMATION SYSTEMS PROJECT (RISP)

RISP is an Administration on Community Living (ACL) Longitudinal Data Project of National Significance (PNS) that maintains records on residential, in-home, and community-based supports for people with IDD. RISP reports chronicle the history of institutionalization, deinstitutionalization, and the development of community-based LTSS for people with IDD in the 50 U.S. states and the District of Columbia. There are two other PNS data projects focusing on people with IDD: one on LTSS expenditures at the University of Kansas (State of the States, <https://stateofthestates.ku.edu/>) and one on employment and day services at the University of

Massachusetts (State Data <https://www.thinkwork.org/statedata>).

RISP 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 and the National Association of State Directors of Developmental Disabilities Services (NASDDDS).

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

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

RISP has described LTSS for people with IDD receiving supports funded through the Medicaid ICF/IID and HCBS Waiver funding authorities annually since 1982. As Medicaid added new LTSS funding authorities, the project adjusted survey items to differentiate funding authorities in finer detail. In 2013, at the request of AIDD and in consultation with state IDD agency directors, 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 homes of family members. 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 CDC Healthy People

2020 monitoring needs, we incorporated questions on children living in institutional settings into our annual data collection protocol. Finally, to respond to technical assistance requests from AIDD and other federal and state agencies, we incorporated data from our ongoing prevalence studies that estimate the number of people with IDD by age and state into the annual RISP report.

In 2021, RISP published a joint report with the University of Massachusetts – Boston's ThinkWork! Project and the University of Colorado, Boulder's (now housed at the University of Kansas) State of the States project called *30 Years of Community Living* in collaboration with a team of advocates with IDD. That book, available on the ACL website (www.ACL.gov/30years), translates key research findings from RISP and the other projects into an easy-to-use report for the public.

This annual RISP report describes Medicaid- and state-funded LTSS managed by, or under the auspices of, state IDD agencies in Fiscal Year (FY) 2020 (July 1, 2019, through June 30, 2020) and examines trends across time. The RISP report describes six dimensions of LTSS:

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

Study Methodology

Annual RISP surveys are distributed to state IDD directors and designated data staff. RISP staff review prior year study findings and provide instructions for completing the survey for respondents via an annual webinar. The staff provide individual assistance

to state respondents, review incoming surveys to identify missing data and inconsistencies, and work with states to ensure the published data is as accurate as possible.

Prior to 2007, the annual RISP surveys of state IDD directors were collected via a paper survey. The first online survey was used from 2007-2012. The online data collection system was redesigned, and new features were added in 2013. Surveys are now collected primarily via the RISP project's secure online data portal. State data providers and project staff can view previous years' 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 requested data were not available in states' data systems. State staff 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 in FY 2015 to assist states to identify possible arithmetic errors, inconsistencies within or across survey sections, and large year-to-year changes requiring explanation. Additional refinements were made as the online database moved to its current platform for the FY 2017 survey.

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

The PRF survey includes questions about characteristics such as age, gender, race, ethnicity, and types of disabilities of people in residence on June 30, admissions; readmissions, discharges, and deaths during year; facility closures and planned closures; and average daily per person

expenditures. Survey data are analyzed using Microsoft Excel and SPSS 23.0 software. Missing or inconsistent responses are confirmed in follow-up communications with the survey respondents.

Definitions

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

Estimated Values are individual data elements whose value is estimated by the survey respondent. 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 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 supports or services in addition to case management provided by, or under the auspices of, state IDD agencies.

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

- If a state did not provide data for an item on the current year's survey, but a value was provided for a prior or subsequent year, data from the adjacent year is used and flagged "d" for other date.
- If a state does not furnish data for two or more years in a row, missing data are flagged "Data Not Furnished" (DNF).

- “Partial Data” (PD) signifies instances when some, but not all, of the data required for a computation were furnished by the state.
- Additional codes specify whether data was missing for state-run settings, non-state settings, or both.
- “Not Applicable” (N/A) is used only in reference to expenditures when a state did not use a particular program, setting, or funding source.

Other Sources. The reference section lists other data sources referenced in this report. Data from other sources is identified by the “s” footnote and the data source is specified.

Other Date. The footnote “d” indicates that the state provided data from a date other than June 30, 2020. Data flagged with the “d” footnote are from the immediately preceding or subsequent data year or from a date other than June 30.

The **Reported Total** row shows the sum of the values provided by all reporting states.

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

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

State Notes. States have considerable flexibility in how they administer 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 2020 RISP survey and survey item operational definitions are available at RISP.umn.edu.

New Data in the FY 2020 Report

The FY 2020 report includes several new tables and figures.

Prevalence for Children. Prior to 2020, the data we used to estimate the number of children with ID, autism spectrum disorder (ASD), and developmental delays (DDelay) came from a Centers for Disease Control and Prevention (CDC) report that used the National Health Interview Survey (NHIS) to report a combined prevalence estimate for these conditions (Zablotsky et al., 2017). A more recent CDC NHIS report (Zablotsky et al., 2023) provided separate prevalence estimates for these conditions allowing us to refine our tables. For 2020, in addition to using the combined prevalence rate, we also used separate rates for ASD, ID and DDelay from the 2019 to 2021 NHIS. To accommodate the increased detail, we split **Table 1.1** into two parts with **Table 1.1a** focusing on children and **Table 1.1b** focusing on adults.

Deaths. The Covid-19 public health emergency began in the United States in March 2020. In response, we added questions about deaths amongst children and adults on the caseloads of IDD state agencies for 2018, 2019 and 2020 to the FY 2020 RISP survey. For this report, we added **Table 1.2b** (for FY 2020 deaths) and **Table 3.8** and **Figure 3.6** (for trends from 2018 to 2020).

Additional Funding Authorities. Previously, we reported recipients and expenditures for Medicaid ICF/IID services and Medicaid HCBS Waiver funded services in Part 2 of this report. Beginning with the FY 2020 report, we added **Table 2.15** to show LTSS recipients getting Medicaid 1915(i) State Plan HCBS and 1915(k) Community First Choice (reported together), other Medicaid State Plan HCBS, or Medicaid Targeted Case Management (TCM). We added **Table 2.16** to show LTSS recipients whose services were state- or locally funded and to show the number of people on state IDD agency caseloads who did not receive any LTSS during the fiscal year. We previously reported Medicaid 1915(i) and (k) recipients on the state profiles. A few states that used other Medicaid State Plan HCBS reported those people with their 1915 (i) and (k) because there was no place on the survey to report them until 2020. Beginning in 2020, the state profiles show 1915(i) and (k) and other state plan HCBS as separate categories.



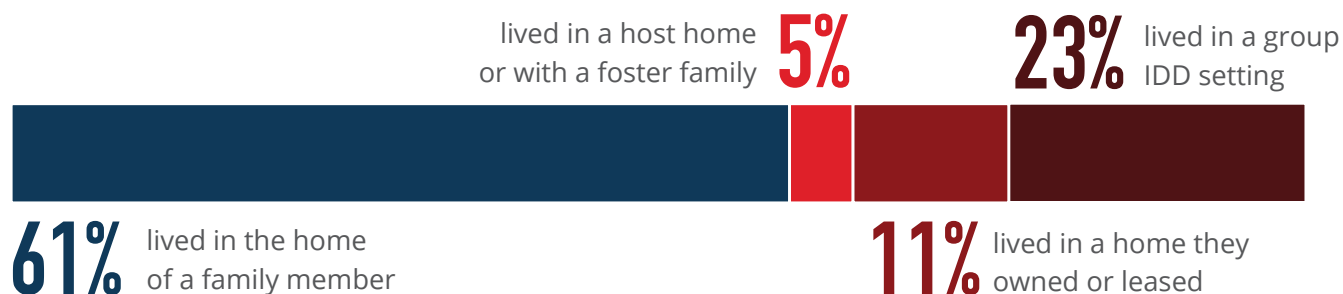
SECTION ONE

In-Home and Residential Supports

FY 2020

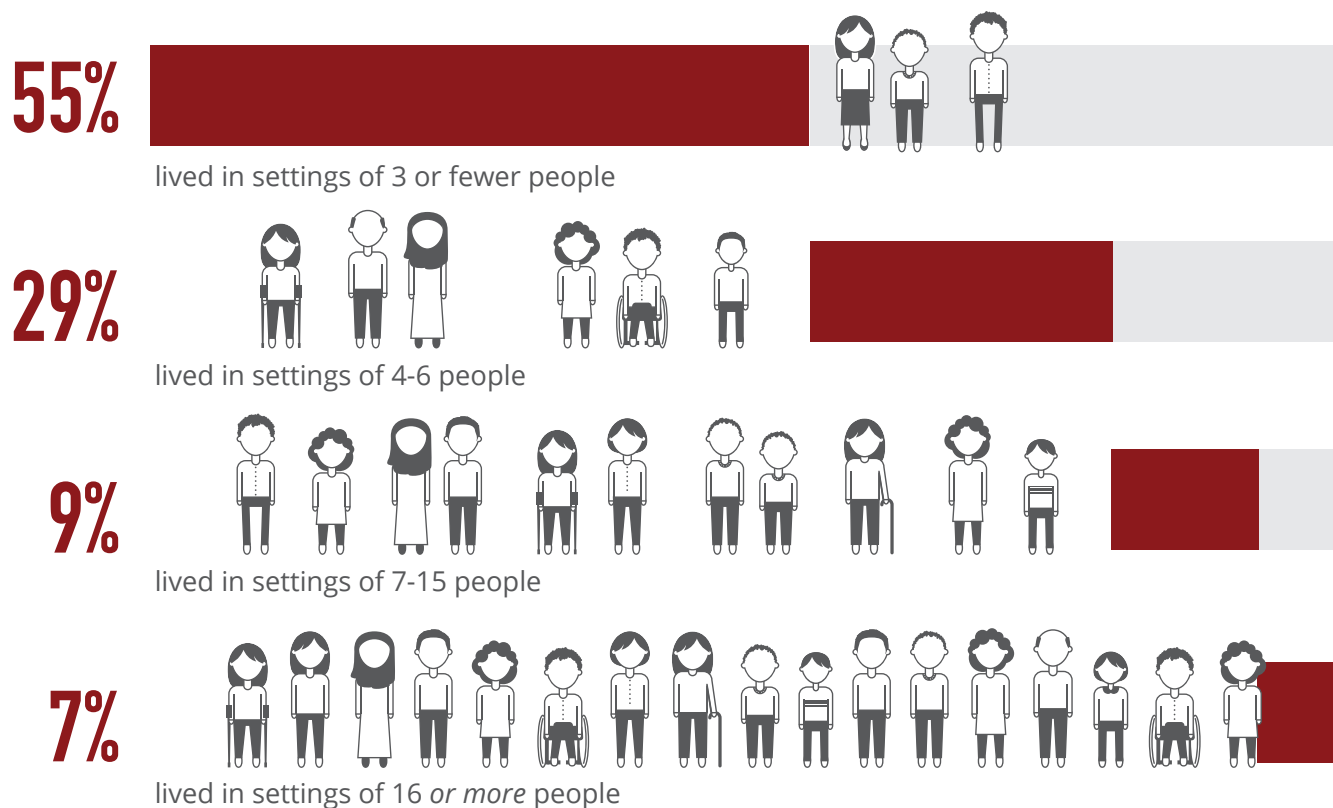
Where do people served by state IDD agencies live?

An estimated 1,429,824 people received long-term supports and services (LTSS) from state IDD agencies as of June 30, 2020



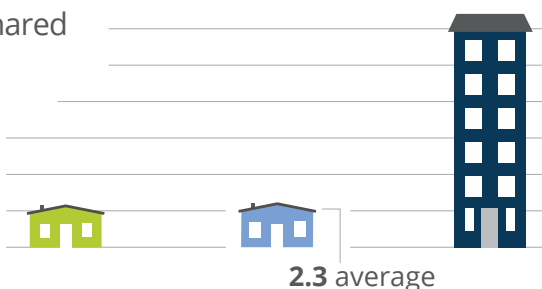
Note: These percentages exclude nursing home and psychiatric facilities

Of the estimated 525,763 LTSS recipients not living with a family member:



Those served by non-state providers shared a home with an average of **2.2 people**.

2.2 people per setting
in nonstate settings



12.8 people per setting
for state-operated settings

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

ESTIMATING PREVALENCE OF IDD IN THE UNITED STATES

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

Public Health Surveillance

The CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network reviews educational and health records to estimate prevalence rates for autism spectrum disorder (ASD) for eight-year-old children in eleven states. For 2020, the overall prevalence rate for ASD was 27.6 per 1,000 (Maenner et al., 2023). Of the children with ASD, 37.9% also had an intellectual disability. Black children with ASD (50.8%) were more likely than White children with ASD (31.8%) to also have an intellectual disability. (U.S. Department of Education, 2023).

Administrative Prevalence

The number of people with IDD in the United States can also be estimated from records from agencies providing or administering services to people with disabilities. In the 2020-2021 school year, an estimated 882,000 students ages 3 to 21 years had ASD, 487,000 had a developmental delay, 426,000 had an intellectual disability, and 125,000 had multiple disabilities. For every 1,000 children in school, 40 had one of these disabilities (18 per 1,000 had ASD, 10 per 1,000 had developmental delay, 9 per 1,000 had an intellectual disability and 3 per 1,000 had multiple disabilities; U.S. Department of Education, 2023b). In 2020, an estimated 0.5% of students with ASD, 0.2% of students with developmental delays, 0.9% of students with intellectual disabilities, and 5.0% of children with multiple disabilities were educated at home, or while living in a hospital, residential facility, or correctional facility, (U.S. Department of Education, 2023a).

Administrative data sets maintained by other federal and state agencies can also be used to estimate the

administrative prevalence of various disabilities. For example, a study using Adoption and Foster Care Reporting System data for forty-six states, DC, and Puerto Rico estimated 2.6% of the children in the child welfare system in 1999 had ID (Slayter & Springer, 2011). In that study, of the 17,714 children in the child welfare system with IDD, 4,789 (27.1%) lived in a group home or institution. Another study using the 2014 data from the same database reported that 3.7% of 7,117 youth ages 18 to 21 years in the foster care system had a diagnosis of ID (Cheatham, Randolph, & Boltz, 2020). A study using Medicaid claims data for 2016 identified 39,143 youth 21 years or younger with ASD or ID living in a foster care setting (Shea et al., 2024).

In an analysis of the 31 million adults receiving care through Medicaid fee-for-service arrangements in 2016, an estimated 483,595 (1.56%) had IDD or related conditions (Reichard, Haile & Morris, 2019). Of the 7.5 million Supplemental Security Insurance beneficiaries in 2022, 223,007 children ages birth to 17 years and 218,212 adults 18 to 64 years had ASD; 208,572 children and 42,229 adults had developmental disabilities; and 82,324 children and 816,279 adults had intellectual disabilities (SSA, 2023).

U.S. Population-Based Surveys

Several U.S. population-based surveys managed by the National Center for Health Statistics include questions that might be used to identify and describe people with disabilities. The U.S. Department of Justice used the National Inmate Survey to describe the prevalence of disabilities among prison and jail inmates. That survey asks three of the six disability questions from the American Community Survey (on hearing, vision, and cognitive impairments). It also asks about difficulties walking or climbing stairs, dressing, bathing, and living independently. In 2011, 2.9% of state and federal prisoners and 5.8% of jail inmates had three or more of the listed disabilities (Bronson et al., 2015). However, it is unknown how many of those people had IDD.

The National Health Interview Survey (NHIS) is an annual nationally representative survey of the civilian non-institutionalized U.S. population. In 1994 and 1995, the National Center on Health Statistics (NCHS) fielded a disability supplement to the annual NHIS survey (NHIS-D) that allowed researchers to identify sample members with ID and/or DD based on having three or more substantial functional limitations as defined in the Developmental Disabilities Act of 1997. In 1995, the prevalence of ID and/or DD was estimated to be 7.9 per 1,000 (0.79%) for adults 18 years or older (Larson, et al., 2001).

The NHIS 2019 through 2021 survey was used to update the prevalence rates for ID, ASD, and developmental delay in children 3-17 years (Zablotsky et al., 2023). The 2020 NHIS prevalence estimates for children were 22.0 per 1,000 for intellectual disability, 34.9 per 1,000 for ASD, 58.6 per 1,000 for other developmental delays, and 83.4 per 1,000 for any of these. These parent-reported estimates are more than twice as high as the rates of ID, ASD or developmental delays reported for students by the U.S. Department of Education.

Estimating IDD Prevalence from NHIS Data

We applied the 2020 NHIS prevalence for children (Zablotsky et al., 2023) to U.S. Census reports of the 2020 U.S. population by age (U.S. Census Bureau, Population Division, 2023) to estimate the number of children with IDD in the United States. Based on these prevalence rates, we estimate that there were 2.55 million children with ASD, 1.61 million children with ID, and 4.28 million children with developmental delay in the non-institutionalized U.S. population, with 6.1 million children having one or more of these disabilities (see **Table 1.1a**). Since the NHIS sample frame excludes people living in congregate settings, we added 5,784 children with IDD living in ICF/IID, nursing homes, or psychiatric facilities to the total for an estimate of 6,102,824 children with ASD, ID, and/or developmental delay. We applied the U.S. Census ADDM estimate that 37.9% of children with ASD also have ID (Maenner, et al., 2023) to compute that an estimated 3,221,498 children birth to 17 years in the United States had ASD, ID, or both.

We applied the 1994-1995 NHIS-D prevalence rate of 7.9 per 1,000 for IDD in adults (Larson et al., 2001). We estimate that there were 2,040,912 adults with IDD in the U.S. non-institutionalized population in 2020 (see **Table 1.1b**). We added 234,768 adults living in IDD settings with four or more people, 24,663 adults with IDD living in nursing homes, and 2,254 adults with IDD living in psychiatric facilities to estimate that there were 2,275,551 adults with IDD in the United States. Adding children with ID, ASD, or both to the number of adults we estimate that there were 5,497,049 people with ID, ASD, or IDD (for adults) in the U.S. Adding children with developmental delays increases the estimated total to 8,378,375.

Estimating the Number of Children Eligible for IDD Services as Adults

The impact of differences in the operational definition of disability is illustrated in a 2019 Social Security Administration (SSA) report that found that only 53% of youth deemed eligible for Supplemental Security Income (SSI) at age 17 based on the SSA childhood definition of disability (a functional definition similar to the DD Act definition) continue to be eligible for benefits when the adult criteria focusing on impairments in substantial gainful employment was imposed at age 18 (Social Security Administration, 2019).

We do not have current population-based estimates of IDD in adults and cannot estimate the number of children who might be eligible for IDD services at age 18 directly. We can, however, generate an estimated range. Considering the dramatic increase in the diagnosis of ASD, the 1995 prevalence rate for IDD in adults (7.9 per 1,000) would be a conservative estimate the number of individuals who at age 18 might meet state IDD eligibility. A more contemporary estimate can be derived by combining 2020 NHIS prevalence rates for ID and/or ASD for children with SSA estimates of the proportion of children who retain SSI eligibility after the age 18 disability redetermination. As computed above, an estimated 3,221,498 children had ID and/or ASD in 2020 (a rate of 44 per 1,000). SSA reported that 53% of child SSI recipients lose eligibility at the age 18 disability redetermination. Forty-seven percent of 3,221,498 is 1,514,104 (a prevalence rate of 20.7 per 1,000). Therefore, we estimate that between 7.9

Table 1.1a United States Population, with ASD, ID, or DD IDD for Children 0-17 Years by State on June 30, 2020

Estimated People Ages 0-17							
Group	U.S. Population	Autism Spectrum Disorder ¹	Intellectual Disability ¹	Developmental Delay ¹	Unduplicated ASD, ID, DDelay	Birth to 21 years in ICF/IID, NH, Psych ²	Total ID, ASD, DDelay
Prevalence Rate Per 1,000		35	22	59	83		
AL	1,107,113	38,638	24,356	64,877	92,333	95	92,428
AK	179,388	6,261	3,947	10,512	14,961	0	14,961
AZ	1,609,526	56,172	35,410	94,318	134,234	3	134,237
AR	699,251	24,404	15,384	40,976	58,318	299	58,617
CA	8,711,118	304,018	191,645	510,472	726,507	119	726,626
CO	1,264,138	44,118	27,811	74,078	105,429	16	105,445
CT	736,717	25,711	16,208	43,172	61,442	4	61,446
DE	206,405	7,204	4,541	12,095	17,214	33	17,247
DC	114,384	3,992	2,516	6,703	9,540	3	9,543
FL	4,198,955	146,544	92,377	246,059	350,193	35	350,228
GA	2,491,634	86,958	54,816	146,010	207,802	123	207,925
HI	299,366	10,448	6,586	17,543	24,967	0	24,967
ID	462,706	16,148	10,180	27,115	38,590	69	38,659
IL	2,813,039	98,175	61,887	164,844	234,607	206	234,813
IN	1,592,949	55,594	35,045	93,347	132,852	406	133,258
IA	740,266	25,835	16,286	43,380	61,738	376	62,114
KS	708,564	24,729	15,588	41,522	59,094	34	59,128
KY	1,021,936	35,666	22,483	59,885	85,229	9	85,238
LA	1,087,209	37,944	23,919	63,710	90,673	310	90,983
ME	252,274	8,804	5,550	14,783	21,040	10	21,050
MD	1,362,022	47,535	29,964	79,814	113,593	4	113,597
MA	1,366,194	47,680	30,056	80,059	113,941	28	113,969
MI	2,162,729	75,479	47,580	126,736	180,372	5	180,377
MN	1,317,461	45,979	28,984	77,203	109,876	48	109,924
MS	683,680	23,860	15,041	40,064	57,019	228	57,247
MO	1,379,301	48,138	30,345	80,827	115,034	0	115,034
MT	234,102	8,170	5,150	13,718	19,524	0	19,524
NE	485,377	16,940	10,678	28,443	40,480	61	40,541
NV	691,288	24,126	15,208	40,509	57,653	32	57,685
NH	256,849	8,964	5,651	15,051	21,421	37	21,458
NJ	2,007,684	70,068	44,169	117,650	167,441	230	167,671
NM	478,533	16,701	10,528	28,042	39,910	17	39,927
NY	4,113,114	143,548	90,489	241,028	343,034	835	343,869
NC	2,284,289	79,722	50,254	133,859	190,510	385	190,895
ND	183,001	6,387	4,026	10,724	15,262	116	15,378
OH	2,591,886	90,457	57,021	151,885	216,163	439	216,602
OK	948,655	33,108	20,870	55,591	79,118	92	79,210
OR	866,604	30,244	19,065	50,783	72,275	5	72,280
PA	2,649,152	92,455	58,281	155,240	220,939	217	221,156
RI	209,785	7,321	4,615	12,293	17,496	17	17,513
SC	1,103,965	38,528	24,287	64,692	92,071	19	92,090
SD	217,412	7,588	4,783	12,740	18,132	76	18,208
TN	1,526,367	53,270	33,580	89,445	127,299	47	127,346
TX	7,278,805	254,030	160,134	426,538	607,052	414	607,466
UT	947,565	33,070	20,846	55,527	79,027	24	79,051
VT	118,595	4,139	2,609	6,950	9,891	0	9,891
VA	1,886,339	65,833	41,499	110,539	157,321	185	157,506
WA	1,680,592	58,653	36,973	98,483	140,161	0	140,161
WV	360,784	12,591	7,937	21,142	30,089	70	30,159
WI	1,281,418	44,721	28,191	75,091	106,870	1	106,871
WY	135,514	4,729	2,981	7,941	11,302	2	11,304
US Total	73,106,000	2,551,399	1,608,332	4,284,012	6,097,040	5,784	6,102,824

¹ Source: U.S. Census Bureau, 2023. ² The prevalence of Autism Spectrum Disorder (ASD), Intellectual Disability (ID) and Developmental Delay (DDelay) per 1,000 in children 17 years or younger are from the 2019-2021 National Health Interview Survey (Zablotsky et al., 2023). ³ 2020 RISP data used to identify people 21 years or younger with IDD living in ICF/IID, nursing homes and psychiatric facilities. For states that did not report recipients in nursing homes and ICF/IID by age, age data are from AHCA, 2020.

Table 1.1b United States Population by Age and Estimated Number of Adults with Intellectual or Developmental Disabilities by Living Arrangement and State on June 30, 2020

State	United States Population		Estimated Adults with IDD by Living Arrangement						
	Age 18-21	Age 22 +	Noninstitutionalized Adults			IDD Settings w/4+ people	Nursing Home	Psychiatric Facility	Total
			Age 18-21	Age 22+	Total				
AL	297,050	3,620,116	2,347	28,599	30,946	1,052	1,009	DNF	31,998
AK	38,534	515,469	304	4,072	4,377	1,084	21	DNF	5,461
AZ	398,595	5,143,381	3,149	40,633	43,782	1,364	117	DNF	45,146
AR	167,968	2,144,305	1,327	16,940	18,267	1,884	609	DNF	20,151
CA	2,181,858	28,645,247	17,237	226,297	243,534	26,913	1,036	30	270,447
CO	304,958	4,204,618	2,409	33,216	35,626	939	47	DNF	36,565
CT	202,543	2,666,684	1,600	21,067	22,667	3,195	271	2	25,862
DE	54,899	728,644	434	5,756	6,190	438	51	2	6,628
DC	42,628	532,533	337	4,207	4,544	392	3	4	4,936
FL	1,070,778	16,268,454	8,459	128,521	136,980	12,860	266	19	149,840
GA	627,352	7,592,922	4,956	59,984	64,940	3,067	1,073	225	68,007
HI	69,201	1,086,704	547	8,585	9,132	346	38	0	9,478
ID	106,023	1,270,377	838	10,036	10,874	1,293	138	DNF	12,167
IL	687,216	9,312,253	5,429	73,567	78,996	15,723	105	0	94,719
IN	392,034	4,800,545	3,097	37,924	41,021	3,878	1,298	35	44,899
IA	189,123	2,260,980	1,494	17,862	19,356	4,952	673	136	24,308
KS	174,809	2,054,507	1,381	16,231	17,612	2,486	81	60	20,098
KY	243,728	3,240,172	1,925	25,597	27,523	636	701	544	28,159
LA	258,708	3,311,840	2,044	26,164	28,207	4,179	491	42	32,386
ME	66,151	1,043,934	523	8,247	8,770	709	102	7	9,479
MD	326,053	4,489,149	2,576	35,464	38,040	2,361	332	12	40,401
MA	411,088	5,252,635	3,248	41,496	44,743	9,064	215	DNF	53,807
MI	566,763	7,347,839	4,477	58,048	62,525	9,755	481	DNF	72,280
MN	298,105	4,090,928	2,355	32,318	34,673	10,653	163	DNF	45,326
MS	178,422	2,099,177	1,410	16,583	17,993	2,813	403	0	20,806
MO	342,866	4,432,746	2,709	35,019	37,727	1,781	0	107	39,508
MT	55,462	794,661	438	6,278	6,716	846	88	DNF	7,562
NE	111,381	1,364,746	880	10,781	11,661	730	173	11	12,391
NV	152,283	2,261,043	1,203	17,862	19,065	751	110	0	19,816
NH	73,883	1,046,797	584	8,270	8,853	124	90	DNF	8,977
NJ	479,121	6,802,189	3,785	53,737	57,522	7,854	911	DNF	65,376
NM	115,654	1,523,335	914	12,034	12,948	849	96	DNF	13,797
NY	1,110,073	14,978,062	8,770	118,327	127,096	30,781	2,705	DNF	157,877
NC	596,397	7,558,702	4,712	59,714	64,425	7,958	750	179	72,383
ND	48,539	547,554	383	4,326	4,709	744	121	DNF	5,453
OH	656,676	8,550,886	5,188	67,552	72,740	7,940	1,316	DNF	80,680
OK	229,222	2,781,476	1,811	21,974	23,785	2,638	476	DNF	26,423
OR	214,685	3,155,967	1,696	24,932	26,628	3,158	50	0	29,786
PA	727,815	9,625,733	5,750	76,043	81,793	5,114	2,278	253	86,907
RI	73,827	813,767	583	6,429	7,012	1,027	114	2	8,039
SC	286,804	3,727,656	2,266	29,448	31,714	3,720	307	DNF	35,434
SD	48,816	620,439	386	4,901	5,287	1,436	101	DNF	6,723
TN	376,648	5,007,825	2,976	39,562	42,537	1,244	467	DNF	43,781
TX	1,716,117	20,150,583	13,557	159,190	172,747	14,372	3,114	368	187,119
UT	218,719	2,105,332	1,728	16,632	18,360	1,278	159	DNF	19,638
VT	38,572	485,910	305	3,839	4,143	85	25	0	4,228
VA	496,703	6,248,351	3,924	49,362	53,286	5,281	83	158	58,567
WA	389,967	5,634,722	3,081	44,514	47,595	7,059	539	49	54,654
WV	94,718	1,338,214	748	10,572	11,320	544	218	DNF	11,864
WI	324,461	4,287,839	2,563	33,874	36,437	4,756	627	DNF	41,193
WY	30,646	410,691	242	3,244	3,487	533	21	9	4,020
US Total	18,364,642	239,978,639	145,081	1,895,831	2,040,912	234,639	24,663	2,254	2,275,551

* Source: U.S. Census Bureau, 2023. A prevalence rate of 0.79 per 1,000 was used to estimate the number of adults with intellectual or developmental disabilities in the noninstitutionalized US population based on analyses from the 1994/1995 National Health Interview Survey Disability Supplement (NHIS; Larson et al., 2001). ² Using the NHIS exclusions criteria, people in IDD settings of four or more people, ICF/IID, nursing homes and psychiatric facilities were excluded from the sample and are added separately here. ³ People ages 18 to 21 in nursing homes are included in the child estimate.

Table 1.2a People Known to or Served by State IDD Agencies by Age on June 30, 2020

State	Number of People ¹			Percent	
	Birth-21	22+ years	All Ages	Birth-21	22+ years
N States	43	43	47	43	43
AL	63 ^j	8,081 ⁱ	8,144 ⁱ	1	99
AK	DNF	DNF	3,333	DNF	DNF
AZ	30,085	15,717	45,802	66	34
AR	DNF	DNF	DNF	DNF	DNF
CA	161,580	145,845	307,425	53	47
CO	8,430	12,892	21,322	40	60
CT	4,101	13,077	17,178	24	76
DE	DNF	DNF	5,082	DNF	DNF
DC	90 ^o	2,439 ^o	2,529 ^o	4	96
FL	16,410	45,967	62,377	26	74
GA	6,187 ^j	17,650 ^j	23,837	26	74
HI*	985	2,864	3,849	26	74
ID*	3,589	4,220	7,809	46	54
IL	8,822	33,293	42,115	21	79
IN	13,489	21,321	34,810	39	61
IA	17,420	14,137	31,557	55	45
KS	4,423	9,347	13,770	32	68
KY	5,564	9,836	15,400	36	64
LA	12,840 ^j	27,723 ^j	40,563 ^j	32	68
ME	881	7,682	8,563	10	90
MD	3,991	19,820	23,811	17	83
MA	14,693	25,794	40,487	36	64
MI	11,467	38,132	49,599	23	77
MN	12,449	23,244	35,693	35	65
MS	DNF	DNF	5,017	DNF	DNF
MO	17,622	22,359	39,981	44	56
MT	2,141	2,711	4,852	44	56
NE*	1,881	5,762	7,643	25	75
NV	2,735	4,674	7,409	37	63
NH	DNF	DNF	DNF	DNF	DNF
NJ	0	25,495	25,495	0	100
NM	2,993	6,926	9,919	30	70
NY	41,096	79,134	120,230	34	66
NC	15,514 ^j	21,200 ^j	36,714 ^j	42	58
ND	3,599	2,983	6,582	55	45
OH	93,846	62,575	156,421	60	40
OK	DNF	DNF	8,100 ^{o,j}	DNF	DNF
OR	13,116	17,900	31,016	42	58
PA	14,606	44,022	58,628	25	75
RI	464	4,696	5,160	9	91
SC	20,863	22,033	42,896	49	51
SD	DNF	DNF	DNF	DNF	DNF
TN	3,499	10,984	14,483	24	76
TX	DNF	DNF	DNF	DNF	DNF
UT	3,353	6,312	9,665	35	65
VT	1,413	3,236	4,649	30	70
VA	11,871	16,347	28,218	42	58
WA	23,665	25,627	49,292	48	52
WV	2,032 ^j	3,795 ^j	5,827	35	65
WI*	13,833	38,601	52,434	26	74
WY	971	1,874	2,845	34	66
Reported Total	628,672	928,327	1,578,531	40	59
Estimated Total	644,948	1,005,401	1,650,349	39	61

^o Other date (data from previous or next year). DNF Did not furnish. ^e Estimate. ⁱ One or more component value imputed by RISP staff. ^j The caseload includes people who receive case management services, receive one or more long-term support or service, are waiting for services or are known to state IDD agencies but not receiving services. It does not include people whose eligibility for services has not been determined, and does not always include people in nursing homes or psychiatric facilities. Imputations are shown only if they are based on a state-reported value in the previous or subsequent year. ^{*} See state notes in Appendix.

and 20.7 young adults per 1,000 may be eligible for IDD services at age 18. The exact number depends on state IDD eligibility criteria and state policy about whether a person with ASD who does not also have ID is eligible for IDD services.

IDD AGENCY CASELOADS

A state IDD agency caseload includes all people with IDD who receive publicly funded LTSS through or under the auspices of the state IDD agency. The agency caseload also includes people with IDD eligible for IDD services who had requested and were waiting for services, as well as people screened as eligible for services but not receiving publicly funded LTSS on June 30, 2020. In most states, the caseload excludes people who are deemed not eligible for the services managed by the IDD agency. The IDD agency caseload does not include people with IDD served by other state agencies such as a department of education, child welfare, vocational rehabilitation, corrections, or a state Medicaid office operating separately from the IDD agency unless those individuals were also served by or known to the state IDD agency or are residents of an ICF/IID.

On June 30, 2020, an estimated 1,650,349 people with IDD (20% of the estimated total people with IDD in the United States) were served by or known to their state IDD agency (see **Table 1.2a**). Of those served by state IDD agencies, 61% were 22 years or older. State IDD agencies served an estimated 644,948 children and youth ages 21 years or younger (20% of estimated US total). State IDD agencies served 1,005,401 adults 22 years or older (44% of estimated US total).

The proportion of the state IDD caseload who were adults varied widely by state. Adults comprised 90% or more of the IDD agency caseload in New Jersey (100% were 22 years or older), Alabama (99%), the District of Columbia (96%), Rhode Island (91%), and Maine (90%). States serving more children or youth than adults in Arizona (66% were 21 years or younger), Ohio (60%), Iowa (55%), North Dakota (55%), and California (53%).

State differences in the age distribution of people on the IDD agency caseload reflect differences in state policy and practice in which state agency administers services for various Medicaid funding

Table 1.2b Deaths per 1,000 people on State IDD Agency Caseloads July 1, 2019 - June 30, 2020

State	Number of People on the Caseload who Died			Estimated Number of People on Caseload ¹			Deaths per 1,000 on caseload		
	Birth-21	22+ years	All Ages	Birth-21	22+ years	All Ages	Birth to 21	22 years +	All Ages
N States	35	36	39	35	36	39	34	36	39
AL	DNF	DNF	DNF	DNF	DNF ⁱ	DNF	DNF	DNF	DNF
AK	DNF	DNF	22	DNF	DNF	3,333	DNF	DNF	6.6
AZ	298	293	591	30,085	15,717	45,802	9.9	18.6	12.9
AR*	3	0	24	1,107	4,745	5,852	2.7	0.0	4.1
CA	278	1,892	2,170	161,580	145,845	307,425	1.7	13.0	7.1
CO	15	168	183	8,430	12,892	21,322	1.8	13.0	8.6
CT	6	288	294	4,101	13,077	17,178	1.5	22.0	17.1
DE	4	40	44	1,566	3,516	5,082	2.6	11.4	8.7
DC	0	73	73	90 ^e	2,439 ^e	2,529 ^e	0.0	29.9	28.9
FL	68	1,001	1,069	16,410	45,967	62,377	4.1	21.8	17.1
GA	DNF	DNF	DNF	DNF ⁱ	DNF ⁱ	DNF ⁱ	DNF	DNF	DNF
HI	3	34	37	985	2,864	3,849	3.0	11.9	9.6
ID	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
IL	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
IN	23	368	391	13,489	21,321	34,810	1.7	17.3	11.2
IA	DNF	8	8	DNF	14,137	31,557	DNF	0.6	0.3
KS	9	183	192	4,423	9,347	13,770	2.0	19.6	13.9
KY	15	201	216	5,564	9,836	15,400	2.7	20.4	14.0
LA	DNF	DNF	DNF	DNF ⁱ	DNF ⁱ	DNF ⁱ	DNF	DNF	DNF
ME	0	109	109	881	7,682	8,563	0.0	14.2	12.7
MD	14	269	283	3,991	19,820	23,811	3.5	13.6	11.9
MA	13	638	651	14,693	25,794	40,487	0.9	24.7	16.1
MI	31	611	642	11,467	38,132	49,599	2.7	16.0	12.9
MN	25	472	497	12,449	23,244	35,693	2.0	20.3	13.9
MS	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MO	33	322	355	17,622	22,359	39,981	1.9	14.4	8.9
MT	2	36	38 ⁱ	2,141	2,711	4,852	0.9	13.3	7.8
NE	3	111	114	1,881	5,762	7,643	1.6	19.3	14.9
NV	6	61	67	2,735	4,674	7,409	2.2	13.1	9.0
NH	0	31	31	1,276	5,284	6,560	0.0	5.9	4.7
NJ	0	544	544	0	25,495	25,495	N/A	21.3	21.3
NM	13	55	68 ⁱ	2,993	6,926	9,919	4.3	7.9	6.9
NY	51	1,671	1,722	41,096	79,134	120,230	1.2	21.1	14.3
NC	DNF	DNF	DNF	DNF ⁱ	DNF ⁱ	DNF ⁱ	DNF	DNF	DNF
ND	5	89	94	3,599	2,983	6,582	1.4	29.8	14.3
OH	91	902	993	93,846	62,575	156,421	1.0	14.4	6.3
OK	DNF	DNF	86	DNF	DNF	8,100 ^{e,i}	DNF	DNF	10.6
OR	13	220	233	13,116	17,900	31,016	1.0	12.3	7.5
PA	48	895	943	14,606	44,022	58,628	3.3	20.3	16.1
RI	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
SC	DNF	DNF	111	DNF	DNF	42,896	DNF	DNF	2.6
SD	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
TN	4	236	240	3,499	10,984	14,483	1.1	21.5	16.6
TX	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
UT	4	84	88	3,353	6,312	9,665	1.2	13.3	9.1
VT	3	45	48	1,413	3,236	4,649	2.1	13.9	10.3
VA	12	300	312	11,871	16,347	28,218	1.0	18.4	11.1
WA	64	697	761	23,665	25,627	49,292	2.7	27.2	15.4
WV	DNF	DNF	DNF	DNF ⁱ	DNF ⁱ	DNF ⁱ	DNF	DNF	DNF
WI	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
WY	2	16	18 ⁱ	971	1,874	2,845	2.1	8.5	6.3
Reported Total	1,159	12,963	14,362	530,994	760,580	1,363,323	2.2	17.0	10.5

^d Other date (data from previous or next year). DNF Did not furnish. ^e Estimate. ⁱ One or more component value imputed by RISP staff. ¹ Number of people on the caseload is only shown for states reporting deaths for each age category. See Table 1.2a for full caseload information. *See state notes in Appendix.

authorities, whether the state IDD agency or another state agency manage services for children with IDD, and the menu of services offered.

Deaths Amongst People on IDD Agency Caseloads

Beginning with the FY 2020 survey we asked states to report the number of children and adults on their IDD caseloads who died during the fiscal year. For 2020, 35 states reported deaths for children, 36 states reported deaths for adults, and 39 states reported deaths overall (see **Table 1.2b**). States reported 1,159 deaths amongst children, 12,963 deaths amongst adults, and 14,362 deaths overall. We computed the rate of deaths per 1,000 people on the caseload for states that reported both deaths and the number of people on the IDD caseload. For FY 2020, which ended four months into the Covid-19 pandemic, states reported 2.2 deaths per 1,000 children, 17.0 deaths per 1,000 adults, and 10.5 deaths per 1,000 people on the IDD caseload overall. Since states vary widely in whether and how many children they serve, comparisons between states for deaths should focus on rates for adults only.

LONG-TERM SERVICES AND SUPPORTS SETTINGS

RISP compares LTSS provided by employees of a state agency (state-run) versus LTSS provided by employees of a private organization, local governmental agency, or managed care entity (non-state). For people with IDD who receive one or more LTSS in addition to case management, we ask states to report the type of setting in which the person lives. We include all LTSS recipients with IDD even if the services they receive are provided exclusively in employment, day habilitation, or community locations. We ask about five types of non-state residential settings:

Family Home: A residence shared by a person with IDD and their related family members in which the person with IDD receives LTSS (e.g., respite care, in-home services, homemaker services, personal assistance).

Own home: A home owned or rented by one or more persons with IDD in which the person(s) with

IDD receives LTSS. The own home category excludes residences owned, rented, or managed by a residential services provider or the provider's agent.

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

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

Non-state setting, type unknown: States are asked to report the total LTSS recipients with IDD for whom living arrangement is not known. Some states can report the total number of people living in their own home or the home of a family member combined but are not able to separate people in own home settings from those living with a family member.

We ask about two types of settings that can be either state-run or non-state operated:

Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID): Medicaid-certified institutions for 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.

IDD Group Home: A residence owned, rented, or managed by the service provider, or the provider's agent, to provide housing for persons with IDD in which staff provide support. This category excludes ICF/IID-certified facilities.

Finally, we ask about:

Other state settings: state-run residences not certified as a Medicaid ICF/IID or funded by a Medicaid HCBS Waiver.

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.

This report includes tables that combine residential settings into the following clusters (See **Table B**):

- IDD Group (Group home, ICF/IID, and other group settings),
- IDD Nonfamily (Own home, Host or Foster Family home, ICF/IID, Group home, and Other), and
- All IDD Settings (Family home, Own Home, Host/Foster Family Home, Group Home, ICF/IID and Other).
- All LTSS Settings (Family home, Own Home, Host/Foster Family Home, Group Home, ICF/IID, Other, nursing home, psychiatric facility, and setting type unknown).

Living Arrangements

Of the 1.65 million people on state IDD agency caseloads, an estimated 84% (1,401,821 people) received one or more LTSS in addition to case management (see **Table 1.3**). Of those people, an estimated

- 98% (1,376,985 people) received LTSS from a non-state entity, including:
 - 867,058 who lived in the home of a family member,
 - 154,634 who lived in a home they owned or leased,
 - 66,042 who lived in a host/foster family home,

- 216,347 who lived in a non-state IDD group home,
- 48,526 who lived in a non-state ICF/IID, and
- 15,378 who lived in another type of non-state setting.

- 2% (24,836 people) received LTSS while living in a state-run residential setting including:
 - 15,919 who lived in a state-run ICF/IID, and
 - 8,524 who lived in Medicaid Waiver funded state-run IDD group settings, and
 - 353 who lived in a state-run group residence funded by another funding authority.

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

- Family home in 34 states of 42 reporting states (Arizona, California, Connecticut, Delaware, Florida, Georgia, Hawaii, Idaho, Illinois, Indiana, Iowa, Kansas, Louisiana, Massachusetts, Michigan, Minnesota, Mississippi, Missouri, Nevada, New Jersey, New Mexico, New York, North Dakota, Ohio, Oregon, Pennsylvania, Rhode Island, South Carolina, Vermont, Virginia, Washington, West Virginia, Wisconsin, and Wyoming),
- Group homes (not ICF/IIDs) in four states (Alabama, the District of Columbia, Tennessee, and Utah),
- ICF/IID in four states (Arkansas, Oklahoma, North Carolina, and South Dakota),
- Host/family foster home in one state (Texas), and

Table B: Living Arrangements for LTSS Recipients with IDD

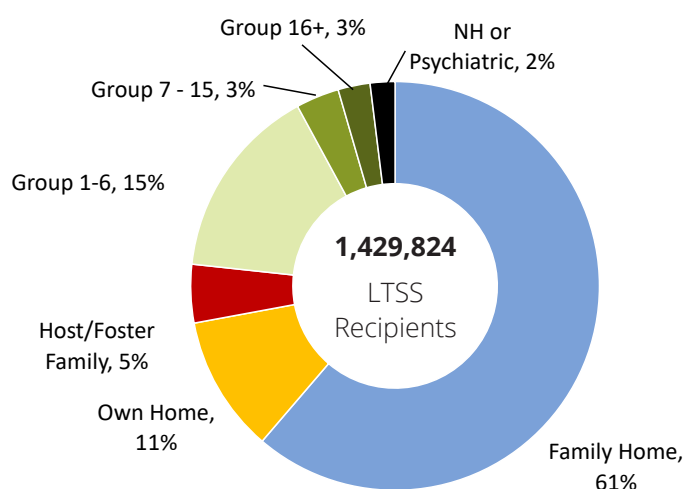
Residence Type	Service Operator		Setting Clusters			
	State Run	Non-state Entity	IDD Group	IDD Nonfamily Setting	Any IDD Residence	All Settings
Family Home		X			X	X
Own Home		X		X	X	X
Host/Foster Family Home		X		X	X	X
Group Home (Not ICF/IID)	X	X	X	X	X	X
ICF/IID	X	X	X	X	X	X
Other	X	X	X	X	X	X
Nursing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

Table 1.3 LTSS Recipients with IDD in IDD Settings by Setting Type, Type of Operation, and State on June 30, 2020

Setting Type	Non-State Settings							State-Operated Settings			Estimated LTSS Recipients ¹
	Family home	Own home	Host /Foster Family Home	Group not ICF/IID	ICF/IID	Other	Unknown	Waiver	ICF/IID	Other	
N States	42	41	47	47	51	45	45	51	51	51	51
AL	2,640 ⁱ	40 ⁱ	0 ⁱ	3,349 ⁱ	22	0	0	0	0	0	6,055
AK	271	755 ^{PD}	97 ^{PD}	840 ^e	14	0	1,356	0	0	0	3,333
AZ	30,698 ⁱⁱ	246	1,598	3,366	29	15	0	122	0	0	36,090
AR*	DNF	DNF	DNF	DNF	539 ^s	DNF	DNF	0	883	0	5,633
CA	243,357	26,920	3,603	23,661	6,535	0	0	6	258	0	304,340
CO*	DNF	DNF	3,461	571	24	2,552	10,071	102	140 ^e	0	16,921
CT*	4,919	1,406	387	3,862	319	180	18	172	302	0	11,565
DE*	3,775	64	98	1,031	70	0	0	0	48	0	5,086
DC	891	10	92	1,021	288	16	0	0	0	0	2,318
FL*	42,170	6,017	193	10,029	2,148	649	563	0	497	124	62,390
GA	16,253	1,759 ⁱ	1,567 ⁱ	3,746 ⁱ	113 ^s	153 ⁱ	0 ⁱ	0 ⁱ	101 ^s	59 ⁱ	23,751
HI	2,732	88	517	276	70	0	0	0	0	0	3,683
ID	1,827 ^s	DNF	1,827 ^s	175 ^{PD}	418	DNF	DNF	0	16	0	8,208
IL	13,411	1,770	318	9,403	4,605	0	0	0	1,613	0	31,120
IN	23,052	2,286 ^e	345	5,447 ^e	3,123	0	0 ^e	0	0	0	34,253
IA	10,133	8,057	181	4,580	1,109	111	0	0	321	0	24,597
KS	3,833 ^s	1,142	413	2,351	96	0	1,886	0	289	0	10,010
KY*	DNF	DNF	2,442	2,451	382	0	10,407	0	0	0	15,682
LA*	10,582 ⁱ	2,265 ⁱ	9 ⁱ	0 ⁱ	3,993 ⁱ	0	0 ⁱ	0	497 ⁱ	0	17,346
ME	DNF	DNF	1,785	2,138	191	110	2,328	0	0	4	6,556
MD*	DNF	DNF	DNF	6,318	0	0	9,888	0	93	0	16,299
MA*	25,423	2,686	826	9,200	0	0	1,238	1,004	309	43	40,172
MI*	29,603	10,077	464	9,164	0	588 ⁱ	DNF	0	0	0	49,896
MN*	15,303 ^s	3,651 ^e	1,002 ^s	8,241	955	6,123	0	322	0	0	35,597
MS*	2,473	67 ⁱ	0 ⁱ	900	686 ^s	0 ^{PD}	0	170	1,334	0	5,630
MO	12,443	5,044	528	1,486	72	0	0	200	287	0	20,060
MT*	DNF	DNF	42	853	0	DNF	1,877 ⁱ	0	0 ⁱ	11 ⁱ	2,783
NE	701	734	1,280	1,089	204	0	1,571	0	97	0	5,676
NV*	5,247	1,810	239	0	42	36	0	0	37	0	7,411
NH	960	351	0	1,748	25	0	3,470 ⁱ	0	0	6	6,560
NJ	15,231	47	399	7,724	53	570	0	0	1,193	3	25,220
NM	3,983 ^e	211 ^{ei}	0 ⁱ	950 ^{ei}	239 ^s	0 ⁱ	0	65	4	0	5,452
NY	75,695 ^s	12,230 ^e	1,378	25,202	3,567	0	0	6,084	271	0	124,427
NC	DNF	0 ^{PD}	0 ^{PD}	DNF	2,698 ^s	DNF	DNF	0	1,059 ^s	0 ⁱ	33,468
ND	3,451	1,437	13	333	463	0	0	0	62	0	5,759
OH	74,750	15,657	2,311	2,541	4,461	1,318	0	0	607	0	101,645
OK	DNF	DNF	DNF	DNF	1,386 ⁱ	DNF	DNF	0	0	0	6,663
OR	16,099	742	3,467	3,107	0	0	0	0	0	94	23,509
PA*	22,902	3,305	1,526	12,181	1,739	1,592	75	0	680	0	44,000
RI	1,717	511	406	1,010	29	0	0	122	0	0	3,795
SC	15,711 ^e	699	180	3,073	472	0	0	15	648	0	20,798
SD	DNF	DNF	DNF	DNF	67 ^s	DNF	DNF	0 ⁱ	98 ^s	0 ⁱ	4,301
TN*	4,210	DNF	688 ^s	5,196	789 ^e	0	4,050	0	148 ^e	0	15,061
TX	9,735	3,176	14,338	8,626	4,749	0	2,774	0	2,849	0	46,247
UT*	1,531	1,621	533	2,083	504 ^s	0	0	0	186	0	6,458
VT	2,314	558	1,396	143	6	0	225	0	0	0	4,636
VA	6,648	1,177	1,888	4,768	547	0	0	0	78	0	15,106
WA	16,932	13,345	916	2,232	1	1,290	0	212	514 ⁱ	0	35,442
WV	3,205 ⁱ	857 ⁱ	190 ⁱ	1,364 ⁱ	492 ^s	0	0 ⁱ	0	0	0	6,108
WI*	33,534	7,687	7,107	3,563	80	19	0	0	277	0	52,267
WY*	1,146	478	57	626	0	4	67	0	51	9	2,438
Reported US Total	811,491	140,983	60,107	202,018	48,414	15,326	51,864	8,596	15,847	353	
Estimated US Total	876,058	154,634	66,042	216,347	48,526	15,378	0	8,524	15,919	353	1,401,821

DNF Did not furnish. PD Partial data. ^e Other date (data from previous or next year). ^s Estimate. ⁱ One or more component value imputed by RISP staff. ⁱⁱ Data are from an alternate source (AHCA, 2020a). ¹ Estimated total excludes people in nursing homes and psychiatric facilities. Some states reported people in family home and own home in the setting unknown category because they could not differentiate between those setting types in their data system. * See state notes in Appendix.

Figure 1.1 Estimated Total LTSS Recipients with IDD by Residence Type and Size on June 30, 2020



The total includes estimates of residence type for people reported to be living in settings of unspecified size or type.

- Unknown in eight states (Alaska, Colorado, Kentucky, Maine, Maryland, Montana, Nebraska, and New Hampshire).

Adding in people with IDD living in nursing homes or psychiatric facilities, there were an estimated 1.43 million LTSS recipients with IDD in 2020 (see **Figure 1.1**). Of those, an estimated:

- 61% lived in the home of a family member,
- 15% lived in a group home shared by six or fewer people with IDD including,
 - 6% who lived in a home shared by one to three people, and
 - 9% who lived in a home shared by four to six people,
- 11% lived in a home they owned or leased,
- 5% lived with a host or foster family, and
- 8% lived in a facility housing seven or more people with disabilities including,
 - 3% who lived in an IDD group home serving seven to fifteen people



Table 1.4 Reported and Estimated LTSS Recipients with IDD in Family Home, Own Home or Unknown Settings Setting Size and State on June 30, 2020

State	Reported People by Setting Type and Size				Setting Type Unknown ¹	Estimated Totals			Percent	
	Family Home	Own Home 1 to 3	Own Home 4 to 6	Own Home Total		All IDD Settings	Family Home	Own Home	Family home	Own home
N States	42	31	31	41	45	51	51	51	51	51
AL	2,640 ⁱ	40 ⁱ	0 ⁱ	40 ⁱ	0	6,055	2,640	40	44%	1%
AK	271	DNF	DNF	755 ^{PD}	1,356	3,333	463	1,277	14%	38%
AZ	30,698 ^{ei}	229	17	246	0	36,090	30,698	262	85%	1%
AR	DNF	DNF	DNF	DNF	DNF	5,633	2,786	502	49%	9%
CA	243,357	26,920	0	26,920	0	304,340	243,357	26,920	80%	9%
CO	DNF	DNF	DNF	DNF	10,071	16,921	8,359	1,712	49%	10%
CT	4,919	1,406	0	1,406	18	11,565	4,937	1,406	43%	12%
DE	3,775	64	0	64	0	5,086	3,775	64	74%	1%
DC	891	10	0	10	0	2,318	891	10	38%	0%
FL	42,170	6,017	0	6,017	563	62,390	42,572	6,074	68%	10%
GA	16,253 ⁱ	DNF	DNF	1,759 ⁱ	0 ⁱ	23,751	16,253	1,759	68%	7%
HI	2,732	88	0	88	0	3,683	2,732	88	74%	2%
ID	1,827 ^e	DNF	DNF	DNF	DNF	8,208	5,183	931	63%	11%
IL	13,411	1,165	605	1,770	0	31,120	13,411	1,770	43%	6%
IN*	23,052	2,274 ^e	12 ^e	2,286 ^e	0 ^e	34,253	23,052	2,286	67%	7%
IA	10,133	DNF	DNF	8,057	0	24,597	10,133	8,057	41%	33%
KS	3,833 ^e	DNF	DNF	1,142	1,886	10,010	4,767	1,420	48%	14%
KY	DNF	DNF	DNF	DNF	10,407	15,682	8,638	1,769	55%	11%
LA	10,582 ⁱ	2,265 ⁱ	0 ⁱ	2,265 ⁱ	0 ⁱ	17,346	10,582	2,265	61%	13%
ME	DNF	DNF	DNF	DNF	2,328	6,556	2,168	160	33%	2%
MD	DNF	DNF	DNF	DNF	9,888	16,299	7,911	1,384	49%	8%
MA	25,423	DNF	DNF	2,686	1,238	40,172	25,423	2,830	63%	7%
MI	29,603	DNF	DNF	10,077	DNF	49,896	29,603	10,077	59%	20%
MN	15,303 ^e	3,651 ^e	0	3,651 ^e	0	35,597	15,303	3,651	43%	10%
MS*	2,473	67	0	67 ⁱ	0	5,630	2,473	67	44%	1%
MO	12,443	5,044	0	5,044	0	20,060	12,443	5,044	62%	25%
MT	DNF	DNF	DNF	DNF	1,877 ⁱ	2,783	1,749	82	63%	3%
NE	701	725	9	734	1,571	5,676	990	1,037	17%	18%
NV*	5,247	1,153	657	1,810	0	7,411	5,247	1,810	71%	24%
NH	960	351	0	351	3,470 ⁱ	6,560	960	929	15%	14%
NJ*	15,231	47	0	47	0	25,220	15,231	47	60%	0%
NM	3,983 ^e	211 ⁱ	0 ⁱ	211 ^{ei}	0	5,452	3,983	211	73%	4%
NY	75,695 ^e	12,230 ^e	0	12,230 ^e	0	124,427	75,695	12,230	61%	10%
NC	DNF	DNF	DNF	0 ^{PD}	DNF	33,468	19,784	2,826	59%	8%
ND	3,451	1,437	0	1,437	0	5,759	3,451	1,437	60%	25%
OH	74,750	14,681	976	15,657	0	101,645	74,750	15,657	74%	15%
OK	DNF	DNF	DNF	DNF	DNF	6,663	2,134	926	32%	14%
OR	16,099	742	0	742	0	23,509	16,099	742	68%	3%
PA	22,902	3,305	0	3,305	75	44,000	22,977	3,305	52%	8%
RI	1,717	511	0	511	0	3,795	1,717	511	45%	13%
SC*	15,711 ^e	699	0	699	0	20,798	15,711	699	76%	3%
SD	DNF	DNF	DNF	DNF	DNF	4,301	1,445	569	34%	13%
TN*	4,210	DNF	DNF	DNF	4,050	15,061	7,633	607	51%	4%
TX	9,735	DNF	DNF	3,176	2,774	46,247	10,483	3,426	23%	7%
UT*	1,531	1,621	0	1,621	0	6,458	1,531	1,621	24%	25%
VT	2,314	558	0	558	225	4,636	2,431	581	52%	13%
VA	6,648	1,177	0	1,177	0	15,106	6,648	1,177	44%	8%
WA*	16,932	7,935	5,410	13,345	0	35,442	16,932	13,345	48%	38%
WV	3,205 ⁱ	857 ⁱ	0 ⁱ	857 ⁱ	0 ⁱ	6,108	3,205	857	52%	14%
WI*	33,534	DNF	DNF	7,687	0	52,267	33,534	7,687	64%	15%
WY	1,146	DNF	DNF	478	67	2,438	1,185	490	49%	20%
Reported US Total	811,491	97,480	7,686	140,983	51,864					
Estimated US Total	876,058	142,228	12,406	154,634	0	1,401,821	876,058	154,634	62%	11%

DNF Did not furnish. PD Partial data. ^e Other date (data from previous or next year). ^e Estimate. ⁱ Total is larger than component parts due to unknown settings or sizes. ⁱ One or more component value imputed by RISP staff. ¹ In the non-state setting section, some states reported a combined total people in own home and family home settings in one category and DNF for the other. Other states reported a combination of own home and family home in the setting type unknown. The setting type unknown category may also include other setting types such as group homes or host or foster family homes. Distributions are estimated in the estimated total columns. Percentages on this table do not include people in nursing homes or psychiatric facilities.

- 3% who lived in an IDD facility serving sixteen or more people, and
- 2% who lived in a nursing home or psychiatric facility.

Home of a Family Member

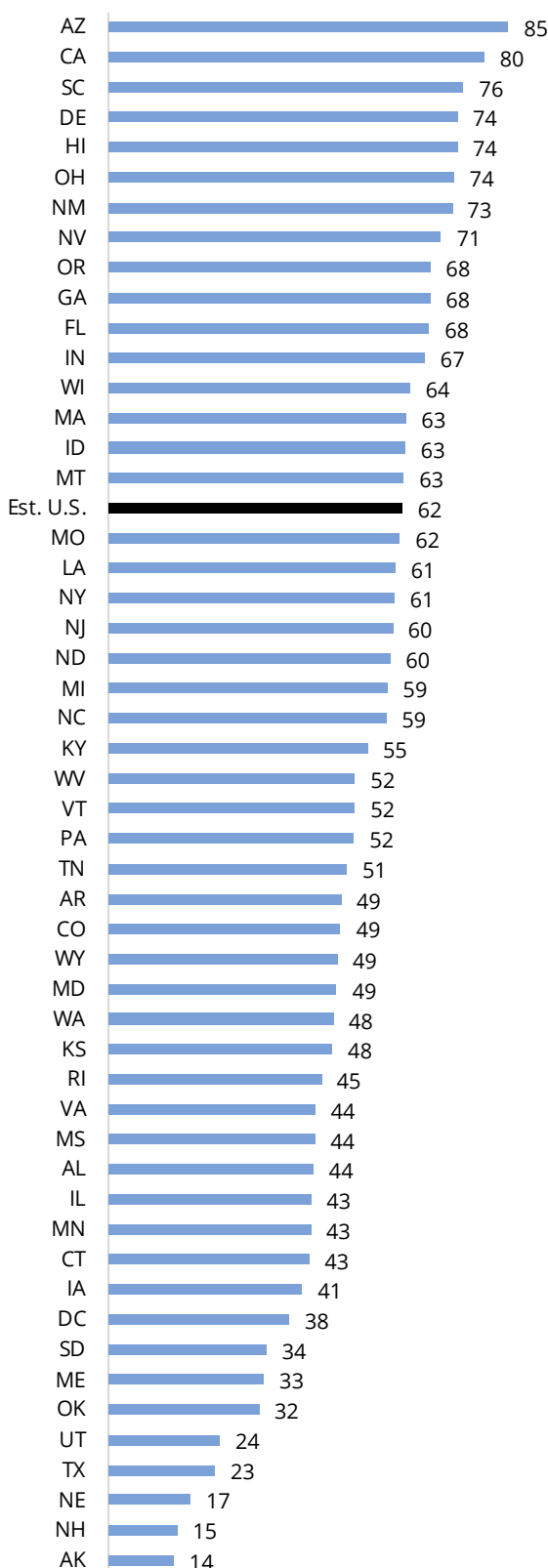
On June 30, 2020, an estimated 867,058 LTSS recipients with IDD (62% of those on state IDD caseloads) lived in the home of a family member (see **Table 1.4**). The proportion of LTSS recipients living in the home of a family member ranged from 14% in Alaska to 85% in Arizona (see **Figure 1.2**).

- States reporting three fourths or more LTSS recipients with IDD lived with family members were Arizona (85%), California (80%), and South Carolina (76%).
- States reporting one fourth or fewer LTSS recipients with IDD lived with family members were Alaska (14%), Nebraska (17%), New Hampshire (15%), Texas (23%), and Utah (24%).
- In Colorado, Kentucky, Maine, Maryland, and Montana, people living in family home settings and people living in their own home were combined and reported as living in an unknown setting type. In Tennessee, people in own home settings were combined with other people in unknown setting types. States were unable to report the residential living arrangements for 51,864 LTSS recipients with IDD based on the RISP residential types.
- States differ in the proportion of LTSS recipients living with family members based on whether the state IDD agency provides LTSS to children with IDD, and the proportion of LTSS recipients who are 21 years or younger. For example, in Arizona where 85% of LTSS recipients lived with a family member, 66% of LTSS recipients were 21 years or younger. Conversely, in Nebraska, where 17% of recipients lived with a family member, only 25% of LTSS recipients served by the state IDD agency were 21 years or younger. Variations may also be related to the use of different eligibility criteria for LTSS or differences in service options.

Own Home

An estimated 11% of LTSS recipients with IDD (154,634 people) lived in a home they owned or leased (Own Home) on June 30, 2020. Eleven states

Figure 1.2 Estimated Percent of LTSS Recipients with IDD Living with a Family Member by State on June 30, 2020



Estimates are included for states that did not report number of LTSS recipients living with a family member.

were not able to separately report the number of LTSS recipients who lived in their own homes.

Fewer than 2% of people lived in their own homes in Alabama, Arizona, Delaware, the District of Columbia, Mississippi, and New Jersey. States with the highest percentages of LTSS recipients with IDD in their own homes were Alaska (38%), Washington (38%), Iowa (33%), Missouri (25%) and Utah (25%).

Overall, 92% of people with IDD in their own homes lived alone or with one or two other LTSS recipients, while 8% lived with three to five other LTSS recipients. In 24 states, all the people in their own homes shared their home with two or fewer other LTSS recipients. By contrast, 41% of people with IDD in their own homes in Washington lived in own home settings shared by 4 or more LTSS recipients, as did 36% in Nevada and 34% in Illinois.

Host or Foster Family Home

There were an estimated 42,460 host or foster family homes in which people with IDD received LTSS on June 30, 2020. Of those homes, 41,521 served three or fewer people, and 939 served four or more people with IDD.

An estimated 66,042 people with IDD lived with a host or foster family on June 30, 2020 (see **Table 1.5**). Of those, an estimated:

- 94% (61,925 people) lived in homes shared by three or fewer people with IDD,
- 6% (4,061 people) lived in homes of four to six people with IDD, and
- Fewer than 1% (56 people) lived in homes of seven to fifteen people with IDD.

On average 1.6 people with IDD lived in each host or foster family home. The average number of LTSS recipients with IDD per host or foster family home was highest in Wisconsin (3.6 people per home) and Oregon (2.5).

IDD Group Settings

An estimated 305,087 people lived in 78,635 IDD group homes, ICF/IIDs, or other group IDD settings on June 30, 2020 (see **Table 1.6**). Group IDD settings do not include nursing homes or psychiatric facilities.

There were an estimated 78,635 IDD group settings on June 30, 2020. Of those,

- 54% (42,483 settings) served three or fewer people
- 38% (29,726 settings) served four to six people,
- 7% (5,597 settings) served seven to 15 people, and
- 1% (829 settings) served 16 or more people.



Table 1.5 Host or Foster Family Homes and LTSS Recipients with IDD in Them by Setting Size and State on June 30, 2020

Setting Size	Host/Family Foster Settings by Size						People in Host/Family Home by Setting Size					
	1-3	4-6	1-6	7-15	Unknown	Total	1-3	4-6	1-6	7-15	Unknown	Total
N States	31	35	34	48	44	33	38	38	42	51	50	47
AL	0 ⁱ	0 ⁱ	0 ⁱ	0 ⁱ	0	0 ⁱ	0 ⁱ	0 ⁱ	0 ⁱ	0 ⁱ	0 ⁱ	0 ⁱ
AK	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	97	0 ^{PD}	0	97 ^{PD}
AZ	1,064	2	1,066	0	0	1,066	1,589	9	1,598	0	0	1,598
AR	DNF	DNF	DNF	0	DNF	DNF	DNF	DNF	DNF	0	DNF	DNF
CA	DNF	DNF	DNF	DNF	DNF	DNF	3,603	0	3,603	0	0	3,603
CO	1,731	0	1,731	0	0	1,731	3,461	0	3,461	0	0	3,461
CT	267	0	267	0	0	267	387	0	387	0	0	387
DE	78	0	78	0	0	78	98	0	98	0	0	98
DC	72	0	72	0	0	72	92	0	92	0	0	92
FL	DNF	DNF	DNF	DNF	DNF	DNF	49	89	138	55	0	193
GA	DNF	DNF	DNF	0	0	DNF	DNF	DNF	DNF	0	1,366 ⁱ	1,567
HI	287	0	287	0	0	287	517	0	517	0	0	517
ID	DNF	DNF	DNF	0	0	DNF	DNF	DNF	DNF	0	1,827 ^e	1,827 ^e
IL	239	0	239	0	0	239	318	0	318	0	0	318
IN	262 ^e	7	269 ^e	0	0	269 ^e	317	28	345	0	0	345
IA	DNF	DNF	DNF	0	0	DNF	181	0	181	0	0	181
KS	DNF	DNF	DNF	0	DNF	DNF	DNF	DNF	DNF	0	413	413
KY*	DNF	0	DNF	0	0	DNF	2,442	0	2,442	0	0	2,442
LA	9 ⁱ	0 ⁱ	9 ⁱ	0	0 ⁱ	9 ⁱ	9 ⁱ	0 ⁱ	9 ⁱ	0 ⁱ	0 ⁱ	9 ⁱ
ME*	1,598	0	1,598	0	0	1,598	1,785	0	1,785	0	0	1,785
MD	DNF	DNF	DNF	0	0	DNF	DNF	DNF	DNF	0	0	DNF
MA*	826	0	826	0	0	826	826	0	826	0	0	826
MI	DNF	0	0 ^{PD}	0	0	DNF	464	0	464	0	0 ⁱ	464
MN	776 ^e	16 ^e	792 ^e	0	0	792 ^e	937 ^e	65 ^e	1,002 ^e	0	0	1,002 ^e
MS	0	0	0	0	0	0	0	0	0	0	0 ⁱ	0 ⁱ
MO	475	0	475	0	0	475	528	0	528	0	0	528
MT	DNF	DNF	DNF	0	0 ^{PD}	DNF	DNF	DNF	42	0	0	42
NE*	1,107	4	1,111	0	0	1,111	1,262	18	1,280	0	0	1,280
NV	195	0	195	0	0	195	239	0	239	0	0	239
NH	DNF	0	DNF	0	DNF	DNF	0	0	0	0	0	0
NJ	208	0	208	0	0	208	399	0	399	0	0	399
NM	0 ⁱ	0 ⁱ	0 ⁱ	0	0	0 ⁱ	0 ⁱ	0 ⁱ	0 ⁱ	0 ⁱ	0 ⁱ	0 ⁱ
NY	780	42	822	0	0	822	1,207	171	1,378	0	0	1,378
NC	DNF	DNF	DNF	0	0	DNF	DNF	DNF	DNF	0	0	0 ^{PD}
ND	13	0	13	0	0	13	13	0	13	0	0	13
OH	2,027	0	2,027	0	0 ⁱ	2,027 ⁱ	2,311	0	2,311	0	0	2,311
OK	DNF	DNF	DNF	0	0	DNF	DNF	DNF	DNF	0	0	DNF
OR	1,047 ^e	350	1,397 ^e	0	0	1,397 ^e	1,865	1,602	3,467	0	0	3,467
PA	1,280	0	1,280	0	0	1,280	1,526	0	1,526	0	0	1,526
RI	406	0	406	0	0	406	406	0	406	0	0	406
SC	142	0	142	0	0	142	180	0	180	0	0	180
SD	DNF	DNF	DNF	0	0	DNF	DNF	DNF	DNF	0	0	DNF
TN	DNF	0	0 ^{PD}	0	0	DNF	688 ^e	0	688 ^e	0	0	688 ^e
TX	DNF	DNF	DNF	0	DNF	DNF	DNF	DNF	14,338	0	0	14,338
UT	446	0	446	0	0	446	533	0	533	0	0	533
VT	1,245	0	1,245	0	0	1,245	1,396	0	1,396	0	0	1,396
VA	1,888	0	1,888	0	0	1,888	1,888	0	1,888	0	0	1,888
WA	819	2	821	0	0	821	907	9	916	0	0	916
WV	124 ⁱ	0 ⁱ	124 ⁱ	0 ⁱ	0 ⁱ	124 ⁱ	190 ⁱ	0 ⁱ	190 ⁱ	0 ⁱ	0 ⁱ	190 ⁱ
WI	DNF	DNF	1,966	0	0	1,966	DNF	DNF	7,107	0	0	7,107
WY	DNF	DNF	DNF	0	57	57	DNF	DNF	DNF	0	57	57
Reported US Total	19,411	423	21,800	0	57	21,857	32,613	1,991	56,188	55	3,663	60,107
Estimated US Total	41,521	931	42,452	8	0	42,460	61,925	4,061	65,986	56	0	66,042

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

Table 1.6 Group LTSS Settings and People with IDD Living in Them by Setting Size and State on June 30, 2020

Setting Size	Number of Group IDD Settings ¹						Number of People in Group IDD Settings					
	1-3	4-6	1-6	7-15	16+	All Sizes	1-3	4-6	1-6	7-15	16+	All Sizes
N States	31	31	34	37	38	38	35	34	39	40	40	47
AL	979	109	1,088	75	0	1,163	2,323	469	2,792	579	0	3,371
AK	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	854 ^f
AZ	971	266	1,237	11	2	1,250	2,191	1,155	3,346	85	101	3,532
AR	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD
CA	PD	PD	PD	117	PD	6,469 ^j	3,436	PD	PD	1,197	PD	30,460 ⁱ
CO	1,276	155	1,431	20	2	1,453	2,552	634	3,186	152	51 ^e	3,389 ^e
CT	695	564	1,259	19	5	1,283	1,636	2,751	4,387	135	313	4,835
DE*	277	120	397	0	2	399	709	322	1,031	0	118 ^e	1,149
DC*	542	92	634	0	0	634	930	395	1,325	0	0	1,325
FL	PD	PD	PD	PD	PD	PD	248	8,188	8,436	2,284	2,078	13,447 ^f
GA	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	4,172 ^f
HI	0	144	144	1	0	145	0	338	338	8	0	346
ID	PD	PD	PD	PD	PD	124 ⁱ	PD	PD	PD	PD	PD	609 ^f
IL	170	913	1,083	787	38	1,908	297	4,121	4,418	7,117	4,086	15,621
IN*	1,851	391 ^e	2,242 ^e	314	2	2,558 ^e	4,462	1,742 ^e	6,204 ^e	2,316	50	8,570 ^e
IA*	PD	PD	434	75	53	567 ^f	PD	PD	4,267	464	654	6,121 ^f
KS	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	2,736 ^f
KY*	101	12	113	3	8	124	2,312	156	2,468	24	341	2,833
LA	1	268	269	249	11	529	0	1,512	1,513	1,949	1,028	4,490
ME	862	103	965	15	10	990	1,724	490	2,214	159	70	2,443
MD	1,895	482	2,377	15	2	2,394	4,185	2,021	6,206	112	93	6,411
MA	PD	PD	PD	0	2	PD	PD	PD	10,247	0	309	10,556
MI	PD	PD	PD	PD	PD	0	692	6,971	7,663	1,578	511	9,752
MN*	PD	PD	3,827	23	8	9,738 ^f	PD	PD	9,087	224	207	15,641 ^f
MS	22 ^e	204	226 ^e	58	11	295 ^e	49	1,043	1,092	506	1,492	3,090
MO	107	158	265	94	8	367	264	701	965	748	332	2,045
MT	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	864 ^f
NE*	465	69	534	4	3	541	785	315	1,100	30	260	1,390
NV	16	5	21	0	22	43	16	24	40	0	75	115
NH	1,213	27	1,240	8	1	1,249	1,630	83	1,713	41	25	1,779
NJ	845 ^e	1,485	2,330 ^e	57	8	2,395 ^e	1,689	5,632	7,321	388	1,834	9,543
NM*	PD	PD	288	12	0	300	PD	PD	1,154 ^e	104	0	1,258
NY	2,168	2,684	4,852	1,849	28	6,729	4,000	13,593	17,593	16,516	1,015	35,124
NC*	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD
ND	0	75	75	44	2	121	0	397	397	368	93	858
OH	214	516	730	270	65	1,065	384	2,427	2,811	2,130	2,668	8,927 ^f
OK	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD
OR*	631	320	951	9	0	960	1,645	1,483	3,128	73	0	3,201
PA	4,872	707	5,579	42	21	5,642	9,605	2,988	12,593	331	1,676	16,192 ^f
RI	PD	PD	PD	PD	1	PD	PD	PD	PD	PD	29	1,161 ^f
SC	182	572	754	96	5	855	471	2,306	2,777	783	648	4,208
SD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD
TN	PD	PD	PD	PD	1	PD	4,884	711 ^e	5,595 ^e	467 ^e	71 ^e	6,133 ^e
TX	PD	PD	PD	41	16	790 ^f	PD	PD	12,736	454	3,034	16,224
UT	919	107	1,026	6	16	1,048	1,479	542	2,021	62	690	2,773
VT	57	17	74	0	0	74	68	81	149	0	0	149
VA	0	1,152	1,152	88	3	1,243	0	4,442	4,442	761	190	5,393
WA	969	203	1,172	12	4	1,537 ^f	1,456	893	2,349	96	514	4,249 ^f
WV	664	50	714	43	0	757	1,242	214	1,456	400	0	1,856
WI	0	641	641	1	5	647	0	3,563	3,563	7	350	3,939 ^f
WY*	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	690 ^f
Reported US Total	24,421	17,758	46,722	4,596	508	59,637	57,551	97,057	186,958	42,919	28,740	290,594
Estimated US Total	42,483	29,726	72,209	5,597	829	78,635	82,587	137,294	219,881	48,955	36,251	305,087

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

Of the 305,216 LTSS recipients with IDD living in group settings on June 30, 2020,

- 27% (82,587 people) lived in settings of three or fewer people,
- 45% (137,294 people) lived in settings of four to six people,
- 16% (48,955 people) lived in settings of seven to 15 people, and
- 12% (36,251 people) lived in facilities with 16 or more residents.

A key difference between Group Homes and Own Home settings is that Group Homes are provider-controlled. People in Medicaid HCBS funded provider-controlled settings must have protections against eviction as specified in a lease or other residency agreement. They must move to a different residence if they wish to select a different residential provider or if the current provider is no longer able to serve them. People living in their own homes can choose to remain in their home even if they decide to hire a different residential or in-home service provider.

Non-Family IDD Residential Settings

Tables 1.7 through **1.9** describe settings other than family homes in which LTSS recipients lived. These tables combine own home settings, host or foster family homes, IDD group homes, ICF/IIDs and other IDD congregate settings. They do not include nursing homes or psychiatric facilities. **Table 1.7** shows the number of non-state and state-run IDD settings in operation on June 30, 2020, by setting size.

Of the estimated 229,799 non-state IDD settings,

- 83% (191,714 settings) served one to three people,
- 14% (32,236 settings) served four to six people,
- 2% (5,128 settings) served seven to 15 people, and
- 0.3% (721 settings) served 16 or more people.

States reporting no non-state settings serving 16 or more people included Alabama, Colorado, the District of Columbia, Hawaii, Kansas, Maryland, Massachusetts, New Mexico, Oregon, South Carolina, Vermont, Washington, West Virginia, and Wyoming.

Of the estimated 1,935 state-run IDD settings:



Table 1.7 Number of Settings Other than Family Homes in Which LTSS Recipients Live by Type of Operation and Setting Size on June 30, 2020

	Non-State Settings							State-Operated Settings							Total Settings ¹						
Setting Size	1-3	4-6	1-6	7-15	16+	Size Unkn	Total	1-3	4-6	1-6	7-15	16+	Total	1-3	4-6	1-6	7-15	16+	Total		
N States	27	28	27	35	34	35	33	49	50	50	50	51	50	26	27	26	34	34	32		
AL	1,019	109	1,128	75	0	0	1,203	0	0	0	0	0	0	1,019	109	1,128	75	0	1,203		
AK	DNF	DNF	DNF	DNF	DNF	DNF	DNF	0	0	0	0	0	0	PD	PD	PD	PD	PD	PD		
AZ	2,189	269	2,458	8	1	0	2,467	7	3	10	3	1	14	2,196	272	2,468	11	2	2,481		
AR	DNF	DNF	DNF	DNF	DNF	DNF	DNF	0	0	0	0	5	5	PD	PD	PD	PD	PD	PD		
CA	PD	PD	PD	PD	PD	PD	DNF	2	3	5	0	2	7	PD	PD	PD	PD	PD	PD		
CO	PD	PD	PD	0	0	0	PD	0	8	8	20	2	30	PD	PD	PD	20	2	PD		
CT	2,365	537	2,902	15	1	0	2,918	3	27	30	4	4	38	2,368	564	2,932	19	5	2,956		
DE*	394	120	514	0	1	0	515	0	0	0	0	1	1	394	120	514	0	2	516		
DC*	624	92	716	0	0	0	716	0	0	0	0	0	0	624	92	716	0	0	716		
FL	PD	PD	PD	40	PD	PD	129	0	0	0	0	3	3	PD	PD	PD	40	PD	132		
GA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	0	0	0	2	2	PD	PD	PD	PD	PD	PD		
HI	375	144	519	1	0	0	520	0	0	0	0	0	0	375	144	519	1	0	520		
ID	DNF	DNF	DNF	PD	PD	54	123 ^f	0	0	0	0	1	1	PD	PD	PD	PD	PD	124 ^f		
IL	1,075	1,048	2,123	787	31	0	2,941	0	0	0	0	7	7	1,075	1,048	2,123	787	38	2,948		
IN*	4,336	401	4,737	314	2	0	5,053	0	0	0	0	0	0	4,336	401	4,737	314	2	5,053		
IA*	PD	PD	PD	75	51	5	PD ^f	0	0	0	0	2	2	PD	PD	PD	75	53	PD ^f		
KS	PD	PD	PD	PD	PD	PD	PD	0	0	0	0	2	2	PD	PD	PD	PD	PD	PD		
KY*	PD	PD	PD	3	8	0	PD	0	0	0	0	0	0	PD	PD	PD	3	8	PD		
LA	2,275	268	2,543	249	8	0	2,800	0	0	0	0	3	3	2,275	268	2,543	249	11	2,803		
ME	2,579	103	2,682	15	10	0	2,707	4	0	4	0	0	4	2,583	103	2,686	15	10	2,711		
MD	PD	PD	PD	15	0	DNF	PD ^f	0	0	0	0	2	2	PD	PD	PD	15	2	PD ^f		
MA	PD	DNF	PD	0	0	0	PD	0	0	254	0	2	256	PD	PD	PD	0	2	PD		
MI	DNF	DNF	DNF	DNF	DNF	DNF	DNF	0	0	0	0	0	0	PD	PD	PD	PD	PD	PD		
MN*	4,253	120	7,991	PD	PD	5,880	13,902 ^f	27	78	105	0	0	105	4,280	198	8,096	PD	PD	14,007 ^f		
MS	67	173	240	0	6	0	246	22	31	53	58	5	116	89	204	293	58	11	362		
MO	2,597	156	2,753	94	2	0	2,849	79	2	81	0	6	87	2,676	158	2,834	94	8	2,936		
MT	DNF	DNF	DNF	DNF	DNF	PD	DNF	0	0	0	1	0	1	PD	PD	PD	PD	PD	PD		
NE	2,252	75	2,327	4	2	0	2,333	0	0	0	0	1	1	2,252	75	2,327	4	3	2,334		
NV	1,003	168	1,171	0	21	0	1,192	0	0	0	0	1	1	1,003	168	1,171	0	22	1,193		
NH	PD	26	PD	8	1	PD	PD	0	1	1	0	0	1	PD	27	PD	8	1	PD		
NJ	1,100	1,485	2,585	57	PD	0	2,645	0	0	0	0	5	5	1,100	1,485	2,585	57	PD	2,650		
NM	0	33	271	12	0	0	283	0	1	17	0	0	17	0	34	288	12	0	300		
NY	PD	PD	PD	1,460	24	0	PD	130	466	596	389	4	989	PD	PD	PD	1,849	28	PD		
NC	DNF	DNF	DNF	DNF	DNF	DNF	DNF	0	0	0	0	4	4	PD	PD	PD	PD	PD	PD		
ND	1,450	75	1,525	44	1	0	1,570	0	0	0	0	1	1	1,450	75	1,525	44	2	1,571		
OH	PD	PD	PD	PD	PD	0	15,198	0	0	0	0	8	8	PD	PD	PD	PD	PD	15,206		
OK	DNF	DNF	DNF	DNF	DNF	DNF	88 ^f	0	0	0	0	0	0	PD	PD	PD	PD	PD	88 ^f		
OR	2,420	649	3,069	9	0	0	3,078	0	21	21	0	0	21	2,420	670	3,090	9	0	3,099		
PA	9,457	707	10,164	42	17	0	10,223	0	0	0	0	4	4	9,457	707	10,164	42	21	10,227		
RI	960	166	1,126	20	1	0	1,147	DNF	DNF	DNF	DNF	0	DNF	PD	PD	PD	PD	1	PD		
SC	411	572	983	96	0	0	1,079	5	0	5	0	5	10	416	572	988	96	5	1,089		
SD	DNF	DNF	DNF	DNF	DNF	DNF	2 ^f	0	0	0	0	1	1	PD	PD	PD	PD	PD	3 ^f		
TN	PD	PD	PD	PD	1	0	PD	0	37	37	1	0	38	PD	PD	PD	PD	1	PD		
TX	PD	PD	PD	41	3	PD	PD	0	2	2	0	13	15	PD	PD	PD	41	16	PD		
UT	2,842	107	2,949	6	15	0	2,970	0	0	0	0	1	1	2,842	107	2,949	6	16	2,971		
VT	1,840	17	1,857	0	0	0	1,857	0	0	0	0	0	0	1,840	17	1,857	0	0	1,857		
VA	3,065	1,152	4,217	88	2	0	4,307	0	0	0	0	1	1	3,065	1,152	4,217	88	3	4,308		
WA	5,798	1,231	7,029	12	0	349	7,390 ^f	69	17	86	0	4	90	5,867	1,248	7,115	12	4	7,480 ^f		
WV	1,645	50	1,695	43	0	0	1,738	0	0	0	0	0	0	1,645	50	1,695	43	0	1,738		
WI	DNF	PD	PD	PD	PD	PD	PD	0	0	0	0	3	3	PD	PD	PD	PD	PD	PD		
WY	DNF	DNF	DNF	DNF	DNF	PD	702 ^f	0	0	0	0	2	2	PD	PD	PD	PD	PD	704 ^f		
Reported US Total	58,391	10,053	72,274	3,633	209	6,288	96,891	348	697	1,315	476	1081,899	58,739	10,750	73,589	4,109	317	98,790			
Est.US Total	191,714	32,236	223,950	5,128	721	0	229,799	390	960	1,350	477	1081,935	192,104	33,196	225,300	5,605	829	231,734			

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

Table 1.8a LTSS Recipients with IDD not Living with a Family Member in Non-State Settings by Setting Size and State on June 30, 2020

Setting Size	People in Non-State Settings					Size Unknown	Total
	1-3	4-6	1-6	7-15	16+		
N States	40	44	41	44	44	48	40
AL	2,363	469	2,832	22	0	0	2,854
AK	0	14	866	0	0	2,210	3,076
AZ	3,994	1,167	5,161	64	29	0	5,254
AR	DNF	DNF	DNF	DNF	DNF	539	PD
CA	33,954	18,444	52,398	1,197	610	6,514	60,719
CO	DNF	595	DNF	0	0	10,071	PD
CT	3,421	2,614	6,035	104	15	18	6,172
DE*	871	322	1,193	0	70	0	1,263
DC*	1,032	395	1,427	0	0	0	1,427
FL	6,314	8,277	14,591	2,339	1,457	1,212	19,599
GA	DNF	DNF	DNF	DNF	DNF	9,294	PD
HI	605	338	943	8	0	0	951
ID	0	DNF	0	80	95	2,245	2,420
IL	1,780	4,726	6,506	7,117	2,473	0	16,096
IN*	7,053	1,782	8,835	2,316	50	0	11,201
IA*	181	47	12,505	464	333	736	14,038
KS	0	59	59	37	0	5,792	5,888
KY*	DNF	156	DNF	24	341	10,407	PD
LA	2,275	1,512	3,787	1,949	531	0	6,267
ME	DNF	490	DNF	159	70	2,328	PD
MD	DNF	2,021	DNF	112	0	9,888	PD
MA	826	0	12,712	0	0	1,238	13,950
MI	679	6,954	18,204	1,578	511	0	20,293
MN*	4,588	589	13,418	224	207	6,123	19,972
MS	67	900	967	0	686	0	1,653
MO	5,644	693	6,337	748	45	0	7,130
MT	DNF	DNF	DNF	DNF	DNF	2,730	PD
NE	2,772	342	3,114	30	163	1,571	4,878
NV	1,408	681	2,089	0	38	0	2,127
NH	1,981	77	2,058	41	25	3,470	5,594
NJ	2,135	5,632	7,767	388	638	0	8,793
NM	22	113	1,296	104	0	0	1,400
NY	17,100	11,471	28,571	13,025	781	0	42,377
NC	DNF	DNF	DNF	DNF	DNF	DNF	DNF
ND	1,450	397	1,847	368	31	0	2,246
OH	17,376	3,403	20,779	2,130	2,061	1,318	26,288
OK	DNF	DNF	DNF	DNF	DNF	DNF	DNF
OR	4,252	2,991	7,243	73	0	0	7,316
PA	14,436	2,988	17,424	331	996	1,667	20,418
RI	1,034	750	1,784	143	29	0	1,956
SC	1,335	2,306	3,641	783	0	0	4,424
SD	DNF	DNF	DNF	DNF	DNF	DNF	DNF
TN	5,572	565	6,137	465	71	4,050	10,723
TX	0	4,102	30,242	454	193	2,774	33,663
UT	3,633	542	4,175	62	504	0	4,741
VT	2,022	81	2,103	0	0	225	2,328
VA	3,065	4,442	7,507	761	112	0	8,380
WA	10,154	6,244	16,398	96	0	1,290	17,784
WV	2,289	214	2,503	400	0	0	2,903
WI	DNF	3,563	18,357	7	73	19	18,456
WY	0	0	0	DNF	DNF	1,232	PD
Reported US Total	136,353	103,468	359,319	38,203	13,238	88,961	410,760
Estimated US Total	285,817	149,392	435,209	44,789	20,929	0	500,927

DNF Did not furnish. PD Partial data. * See state notes in Appendix. † This table includes people in group homes, ICF/IIDs, host and foster family homes, own home, and IDD "other" settings. It excludes people living with a family member, in a nursing home or psychiatric setting. The number of people in Nonstate "other" settings is assumed to be 0 unless otherwise specified by the state.

Table 1.8b LTSS Recipients with IDD not Living with a Family Member in State-Operated Settings by Setting Size and State on June 30, 2020

Setting Size	People in State-Operated Settings					Size Unknown	Total
	1-3	4-6	1-6	7-15	16+		
N States	50	50	50	50	51	51	51
AL	0	0	0	0	0	0	0
AK	0	0	0	0	0	0	0
AZ	15	14	29	21	72	0	122
AR	0	0	0	0	883	0	883
CA	5	15	20	0	244	0	264
CO	0	39	39	152	51	0	242
CT	8	137	145	31	298	0	474
DE	0	0	0	0	48	0	48
DC	0	0	0	0	0	0	0
FL	0	0	0	0	621	0	621
GA	0	0	0	0	160	0	160
HI	0	0	0	0	0	0	0
ID	0	0	0	0	16	0	16
IL	0	0	0	0	1,613	0	1,613
IN	0	0	0	0	0	0	0
IA	0	0	0	0	321	0	321
KS	0	0	0	0	289	0	289
KY	0	0	0	0	0	0	0
LA	0	0	0	0	497	0	497
ME	4	0	4	0	0	0	4
MD	0	0	0	0	93	0	93
MA	0	0	1,047	0	309	0	1,356
MI	0	0	0	0	0	0	0
MN	48	274	322	0	0	0	322
MS	49	143	192	506	806	0	1,504
MO	192	8	200	0	287	0	487
MT	0	0	0	11	0	0	11
NE	0	0	0	0	97	0	97
NV	0	0	0	0	37	0	37
NH	0	6	6	0	0	0	6
NJ	0	0	0	0	1,196	0	1,196
NM	0	4	69	0	0	0	69
NY	337	2,293	2,630	3,491	234	0	6,355
NC	0	0	0	0	1,099	0	1,099
ND	0	0	0	0	62	0	62
OH	0	0	0	0	607	0	607
OK	0	0	0	0	0	0	0
OR	0	94	94	0	0	0	94
PA *	0	0	0	0	680	0	680
RI	DNF	DNF	DNF	DNF	0	122	122
SC	15	0	15	0	648	0	663
SD	0	0	0	0	98	0	98
TN	0	146	146	2	0	0	148
TX	0	8	8	0	2,841	0	2,849
UT	0	0	0	0	186	0	186
VT	0	0	0	0	0	0	0
VA	0	0	0	0	78	0	78
WA	144	68	212	0	514	0	726
WV	0	0	0	0	0	0	0
WI	0	0	0	0	277	0	277
WY	0	0	0	0	60	0	60
Reported US Total	817	3,249	5,178	4,214	15,322	122	24,836
Estimated US Total	923	4,369	5,292	4,222	15,322	0	24,836

DNF Did not furnish. PD Partial data. * See state notes in Appendix. ¹ This table includes people in group homes, ICF/IIDs, host and foster family homes, own home, and IDD "other" settings. It excludes people living with a family member, in a nursing home or psychiatric setting. The number of people in Nonstate "other" settings is assumed to be 0 unless otherwise specified by the state.

Table 1.8c LTSS Recipients with IDD not Living with a Family Member by Setting Size and State on June 30, 2020

Setting Size	Total People					Size Unknown	Total
	1-3	4-6	1-6	7-15	16+		
N States	39	43	40	43	44	48	40
AL	2,363	469	2,832	22	0	0	2,854
AK	0	14	866	0	0	2,210	3,076
AZ	4,009	1,181	5,190	85	101	0	5,376
AR	PD	PD	PD	PD	PD	539	PD
CA	33,959	18,459	52,418	1,197	854	6,514	60,983
CO	PD	634	PD	152	51	10,071	PD
CT	3,429	2,751	6,180	135	313	18	6,646
DE	871	322	1,193	0	118	0	1,311
DC	1,032	395	1,427	0	0	0	1,427
FL	6,314	8,277	14,591	2,339	2,078	1,212	20,220
GA	PD	PD	PD	PD	PD	9,294	PD
HI	605	338	943	8	0	0	951
ID	0	PD	0	80	111	2,245	2,436
IL	1,780	4,726	6,506	7,117	4,086	0	17,709
IN	7,053	1,782	8,835	2,316	50	0	11,201
IA	181	47	12,505	464	654	736	14,359
KS	0	59	59	37	289	5,792	6,177
KY	PD	156	PD	24	341	10,407	PD
LA	2,275	1,512	3,787	1,949	1,028	0	6,764
ME	PD	490	PD	159	70	2,328	PD
MD	PD	2,021	PD	112	93	9,888	PD
MA	826	0	13,759	0	309	1,238	15,306
MI	679	6,954	18,204	1,578	511	0	20,293
MN	4,636	863	13,740	224	207	6,123	20,294
MS	116	1,043	1,159	506	1,492	0	3,157
MO	5,836	701	6,537	748	332	0	7,617
MT	PD	PD	PD	PD	PD	2,730	PD
NE	2,772	342	3,114	30	260	1,571	4,975
NV	1,408	681	2,089	0	75	0	2,164
NH	1,981	83	2,064	41	25	3,470	5,600
NJ	2,135	5,632	7,767	388	1,834	0	9,989
NM	22	117	1,365	104	0	0	1,469
NY	17,437	13,764	31,201	16,516	1,015	0	48,732
NC	PD	PD	PD	PD	PD	PD	PD
ND	1,450	397	1,847	368	93	0	2,308
OH	17,376	3,403	20,779	2,130	2,668	1,318	26,895
OK	PD	PD	PD	PD	PD	PD	PD
OR	4,252	3,085	7,337	73	0	0	7,410
PA *	14,436	2,988	17,424	331	1,676	1,667	21,098
RI	PD	PD	PD	PD	29	122	2,078
SC	1,350	2,306	3,656	783	648	0	5,087
SD	PD	PD	PD	PD	PD	PD	PD
TN	5,572	711	6,283	467	71	4,050	10,871
TX	0	4,110	30,250	454	3,034	2,774	36,512
UT	3,633	542	4,175	62	690	0	4,927
VT	2,022	81	2,103	0	0	225	2,328
VA	3,065	4,442	7,507	761	190	0	8,458
WA	10,298	6,312	16,610	96	514	1,290	18,510
WV	2,289	214	2,503	400	0	0	2,903
WI	PD	3,563	18,357	7	350	19	18,733
WY	0	0	0	PD	PD	1,232	PD
Reported US Total	167,462	105,967	357,162	42,263	26,260	88,961	435,596
Estimated US Total	286,740	153,761	440,501	49,011	36,251	0	525,763

DNF Did not furnish. PD Partial data. * See state notes in Appendix. ¹ This table includes people in group homes, ICF/IIDs, host and foster family homes, own home, and IDD "other" settings. It excludes people living with a family member, in a nursing home or psychiatric setting. The number of people in Nonstate "other" settings is assumed to be 0 unless otherwise specified by the state.



- 20% (390 settings) served one to three people,
- 50% (960 settings) served four to six people,
- 25% (477 settings) served seven to 15 people, and
- 6% (108 settings) served 16 or more people.

There were no state-run IDD facilities of any size in Alabama, Alaska, the District of Columbia, Hawaii, Indiana, Kentucky, Michigan, Oklahoma, Vermont, and West Virginia. Other states with no state-run IDD facilities with sixteen or more people included Maine, Minnesota, Montana, New Hampshire, New Mexico, Oregon, Rhode Island, and Tennessee.

Of the 231,734 total non-family residences, an estimated:

- 83% (192,104 settings) served one to three people,
- 14% (33,196 settings) served four to six people,
- 2% (5,605 settings) served seven to 15 people, and
- 0.4% (829 settings) served 15 or more people.

LTSS Recipients Living in Settings Other than the Home of a Family Member

Excluding people living in nursing homes and psychiatric settings, an estimated 525,892 LTSS recipients lived in non-family settings on June 30, 2020 (see **Table 1.8a, b, c**). Setting size was not reported for 88,961 people living in non-state LTSS settings.

Of the 500,927 people in non-state settings, an estimated

- 57% (285,817 people) lived with three or fewer people,
- 30% (149,392 people) lived with four to six people,
- 9% (44,789 people) lived with seven to 15 people, and
- 4% (20,929 people) lived with 16 or more people.

Of the 24,836 people in state-run IDD settings, an estimated

Table 1.9 LTSS Recipients per Setting, per 100,000 of the Population and Proportion of People in Non-Family Settings Living in Settings of 1-3 or 4-6 People

State	Estimated Settings	Estimated LTSS Recipients in NonFamily 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	1,203	3,415	2.8	69	83	50	68
AK	1,432	2,870	2.0	62	92	7	391
AZ	2,481	5,392	2.2	75	97	72	75
AR	629	2,847	4.5	23	29	30	95
CA	29,448	60,983	2.1	56	96	395	154
CO	4,435	8,562	1.9	89	98	58	148
CT	2,956	6,628	2.2	52	93	36	184
DE*	516	1,311	2.5	66	91	10	132
DC*	716	1,427	2.0	72	100	7	207
FL	7,354	19,818	2.7	35	77	215	92
GA	3,105	7,498	2.4	59	88	107	70
HI	520	951	1.8	64	99	15	65
ID	1,410	3,025	2.1	55	87	18	164
IL	2,948	17,709	6.0	10	37	128	138
IN*	5,053	11,201	2.2	63	79	68	165
IA*	7,511	14,464	1.9	64	88	32	453
KS	2,205	5,243	2.4	52	85	29	178
KY*	4,065	7,044	1.7	91	95	45	156
LA	2,803	6,764	2.4	34	56	47	145
ME	2,711	4,388	1.6	84	95	14	322
MD	3,783	8,388	2.2	72	98	62	136
MA	5,307	14,749	2.8	39	98	70	210
MI	9,816	20,293	2.1	52	90	101	201
MN*	9,495	20,294	2.1	47	83	57	356
MS	362	3,157	8.7	4	37	30	107
MO	2,936	7,617	2.6	77	86	62	124
MT	282	1,034	3.7	18	61	11	95
NE	2,612	4,686	1.8	84	94	20	239
NV	1,193	2,164	1.8	65	97	31	70
NH	3,359	5,600	1.7	97	99	14	407
NJ	2,685	9,989	3.7	21	78	93	108
NM	462	1,469	3.2	41	93	21	69
NY	16,959	48,732	2.9	36	64	202	241
NC	3,688	13,684	3.7	39	67	104	131
ND	1,571	2,308	1.5	63	80	8	296
OH	16,261	26,895	1.7	69	82	118	228
OK	1,516	4,529	3.0	40	66	40	114
OR	3,099	7,410	2.4	57	99	42	175
PA	11,503	21,023	1.8	75	90	130	162
RI	1,171	2,078	1.8	50	91	11	189
SC	1,535	5,087	3.3	27	72	51	99
SD	1,028	2,856	2.8	47	68	9	322
TN	3,457	7,428	2.1	83	93	69	107
TX	16,040	35,764	2.2	59	90	291	123
UT	2,971	4,927	1.7	74	85	33	151
VT	1,857	2,205	1.2	96	100	6	343
VA	4,308	8,458	2.0	36	89	86	98
WA	8,186	18,510	2.3	62	96	77	240
WV	1,738	2,903	1.7	79	86	18	162
WI	8,349	18,733	2.2	75	98	59	318
WY	704	1,253	1.8	57	87	6	217
Estimated US Total	231,734	525,763	2.3	55	84	3,314	159

* Table includes people in group homes, host/foster family homes, own homes, and "other" IDD settings. It excludes people in family homes, nursing homes, psychiatric settings.

- 4% (923 people) lived in settings of three or fewer people,
- 18% (4,369 people) lived in settings of four to six people,
- 17% (4,222 people) lived in settings of seven to 15 people, and
- 62% (15,322 people) lived in settings of 16 or more people with IDD.

Of LTSS recipients with IDD not living with a family member, 95% (500,927 people) lived in non-state settings, and 5% (24,965 people) lived in state-run settings. States with the lowest proportion of people living in non-state settings were Mississippi (52%), New York (87%), and South Carolina (87%).

Of the 525,763 people living in settings other than the home of a family member, an estimated

- 55% (286,740 people) lived in settings of three or fewer people,

- 29% (153,761 people) lived in settings of four to six people,
- 9% (49,011 people) lived in settings of seven to 15 people, and
- 7% (36,251 people) lived in settings of 16 or more people.

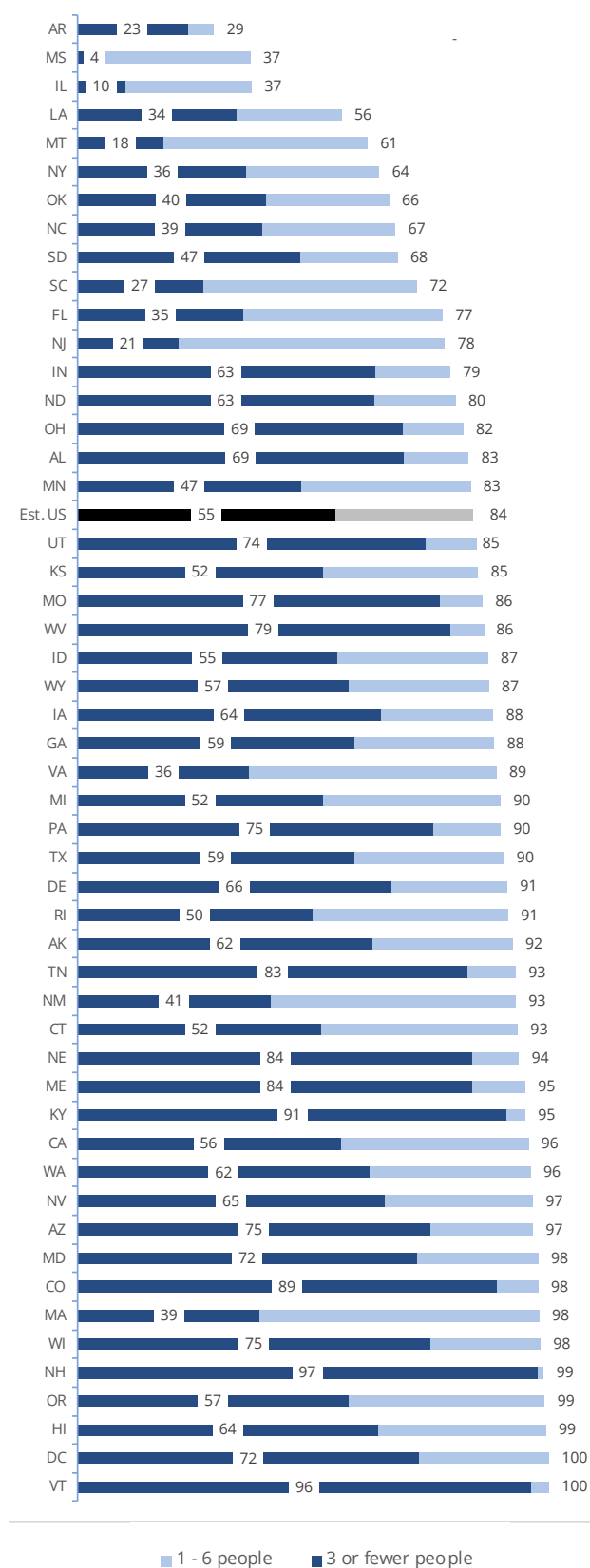
Alabama, Alaska, the District of Columbia, Hawaii, New Mexico, Oregon, Vermont, and West Virginia reported no people with IDD living in settings of sixteen or more people. States reporting that more than 10% of people non-family settings lived in a setting of sixteen or more people were Mississippi (47%), Illinois (23%), New Jersey (18%), Louisiana (15%), Utah (14%), South Carolina (13%), Florida (10%), and Ohio (10%).

Residential Setting Sizes

An estimated 525,763 people with IDD lived in 231,734 non-family settings on June 30, 2020 (an average of 2.3 people per setting; see **Table 1.9**).



Figure 1.3 Percent of People not Living with Family Members who lived in Settings of 1 to 3 or 1 to 6 People by State on June 30, 2020



States reporting the fewest people per setting were Vermont (1.2), North Dakota (1.5), Maine (1.6), Ohio (1.7), and Utah (1.7). States reporting the most people per setting were Mississippi (8.7), Illinois (6), Arkansas (4.5), New Jersey (3.7), and North Carolina (3.7).

To make it easier to compare state utilization of non-family residences for people with IDD, we computed the number of people with IDD in non-family settings per 100,000 of state population. There was an average of 159 people with IDD in LTSS settings other than the home of a family per 100,000 of state population. The number of LTSS recipients in non-family settings per 100,000 ranged from less than 70 per 100,000 in Alabama, Hawaii, and New Mexico to more than 350 per 100,000 in Alaska, Iowa, Minnesota, and New Hampshire.

On June 30, 2020, 84% of people living in a setting other than the home of a family member lived in a home shared by six or fewer LTSS recipients with IDD (see **Figure 1.3**). The proportion was 90% or greater in 25 states. The proportion was less than 50% in Arkansas (29%), Mississippi (37%), and Illinois (37%).

Overall, 55% of LTSS recipients not living with a family member shared a home with one or two other people. More than 90% of LTSS recipients lived in settings of three or fewer people in New Hampshire (97%), Vermont (96%), and Kentucky (91%). Fewer than 25% of LTSS recipients lived in settings of three or fewer people in Mississippi (4%), Illinois (10%), Montana (18%), New Jersey (21%), and Arkansas (23%).

Residential Setting Sizes by Setting Type

Overall, there were 2.3 LTSS recipients per setting in non-family settings (2.2 LTSS recipients per non-state setting, and 12.9 LTSS recipients per state-run setting; see **Figure 1.4**). The average number of people per setting by setting type and type of operation was:

- Own home (1.4 people per home)
- Host or Foster Family home (1.6 people)
- Non-state IDD group home (3.4 people)
- State-operated Waiver-funded IDD group home (5.1 people)

- Non-state ICF/IID (8.7 people)
- State-run ICF/IID (69.8 people)

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 a review of 30 years of deinstitutionalization research, 37 of 43 studies of people with IDD who moved from institutions to homes shared by six or fewer people showed improved adaptive behavior (daily living skills) for people who moved improved while less or no change was observed for people who remained in institutions (Larson, Lakin, & Hill, 2012). Setting size is a significant predictor of better outcomes in areas such as everyday choice, expenditures, and deaths due to Covid-19 (e.g., Bershadsky, et. al., 2012; Lakin et al., 2008; Ticha, et. al., 2012; Landes et al., 2020, 2021). People in the smallest settings typically have better outcomes than those living in larger settings in many areas.

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

On June 30, 2020, state IDD agencies provided LTSS to an average of 423 people with IDD per 100,000 of state population (see **Figure 1.5**). However, access to publicly funded LTSS for people with IDD varied widely across states. The states providing LTSS to the most people with IDD per 100,000 included Wisconsin (887 people per 100,000), Ohio

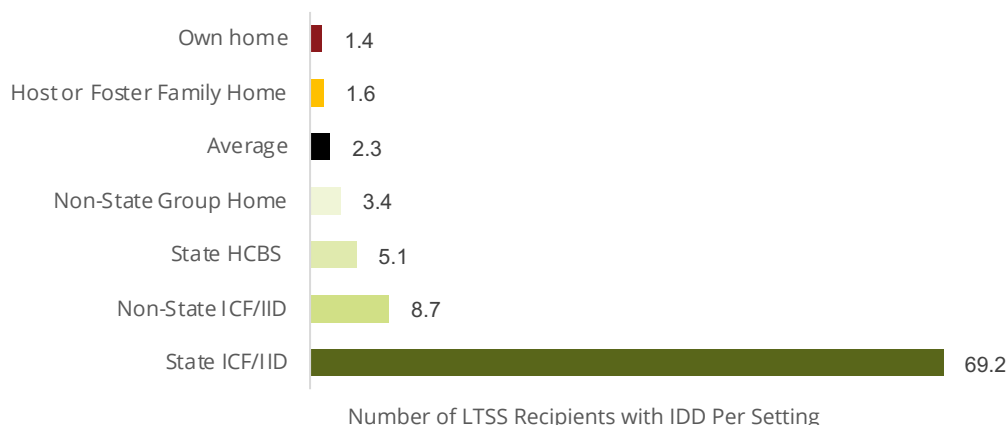
(861), Iowa (771), California (770), North Dakota (739), and Vermont (721). States providing LTSS to the fewest people with IDD per 100,000 were Alabama (121 people per 100,000), Texas (159), Oklahoma (168), Virginia (175), Arkansas (187), Mississippi (190), and Utah (197).

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

- Family home (average 264 per 100,000; range 36 per 100,000 in Texas to 634 in Ohio),
- Own home (47 per 100,000; range 1 in three states to 253 in Iowa),
- Host/foster family home (20 per 100,000; range less than 1 in four states to 228 in Vermont),
- Group setting one to six people (66 per 100,000; range 1 in Nevada to 215 in Minnesota),
- Group setting seven to 15 people (15 per 100,000; range less than 1 in six states to 82 in New York), and
- Group setting 16 or more people (11 per 100,000; range less than 1 in nine states to 49 in Minnesota and 50 in Mississippi).
- Group settings of any size (92 per 100,000; range 4 in Nevada to 274 in Minnesota).

LTSS utilization rates reflect differences in whether the state IDD agency administers LTSS for people ages 21 years or younger, historical patterns of institutional use and deinstitutionalization,

Figure 1.4 LTSS Recipients with IDD per Setting by Setting Type on June 30, 2020



¹ Figure includes people in group homes, host/foster family homes, own homes, and other IDD settings. It excludes people in family homes, nursing homes, psychiatric settings.

Figure 1.5 Estimated LTSS Recipients with IDD Per 100,000 of the Population by Setting Type and State on June 30, 2020

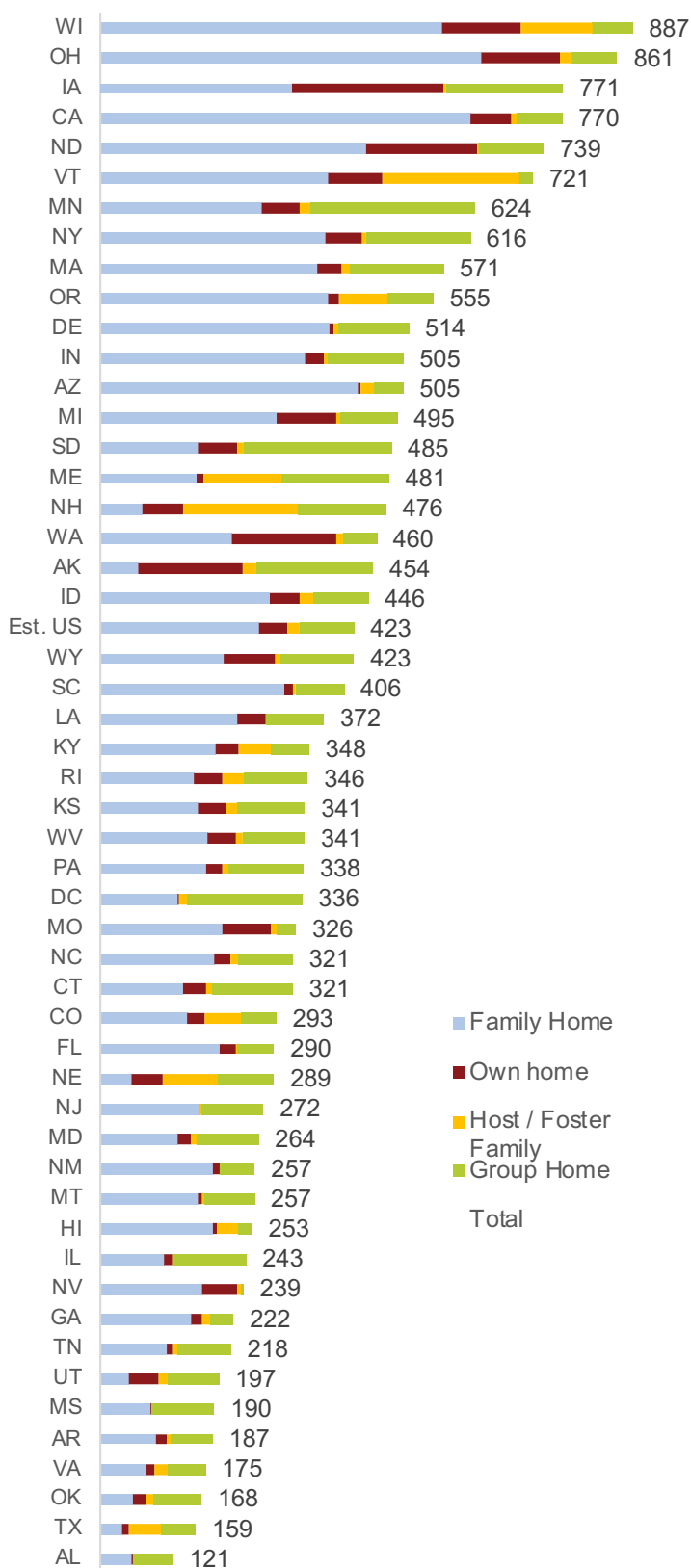


Table 1.10 People with IDD in State-Run and Nonstate Psychiatric Facilities and Nursing Homes by State on June 30, 2020

State	Psychiatric Facilities	Nursing Homes	Estimated Nursing Home per 100,000
N States	28	51	51
AL	DNF	1,104 [†]	22.0
AK	DNF	21 [§]	2.9
AZ	DNF	117 [§]	1.6
AR	DNF	609 [§]	20.2
CA	30	1,042	2.6
CO	DNF	47	0.8
CT	2	271	7.5
DE	2	82	8.3
DC	4	3	0.4
FL	19	266	1.2
GA	225 [‡]	1,173 [‡]	11.0
HI	0	38	2.6
ID	DNF	138 [§]	7.5
IL	0	105	0.8
IN	35	1,399	20.6
IA	136	715	22.4
KS	60	81	2.8
KY	544	703 [§]	15.6
LA	42 [‡]	491 [‡]	10.5
ME	7	10	0.7
MD	12 [‡]	332	5.4
MA	DNF	243	3.5
MI*	DNF	486	4.8
MN	DNF	163	2.9
MS	0	0	0.0
MO	107	0	0.0
MT	DNF	88 [§]	8.1
NE	11	185	9.4
NV	0	137	4.4
NH	DNF	102 [§]	7.4
NJ	DNF	1,141 [§]	12.3
NM	DNF	96 [§]	4.5
NY	DNF	3,026	15.0
NC	179 [‡]	750 [‡]	7.2
ND	DNF	123	15.8
OH	DNF	1,316 [§]	11.2
OK	DNF	476 [§]	12.0
OR	0	55	1.3
PA	253	2,283	17.6
RI	2	114	10.4
SC	DNF	309	6.0
SD	DNF	101 [§]	11.4
TN	DNF	467 [§]	6.8
TX	368	3,114 [§]	10.7
UT	DNF	167 [§]	5.1
VT	0	25	3.9
VA	158	134	1.6
WA	49	539	7.0
WV	DNF	218 [§]	12.2
WI	DNF	628	10.7
WY	9	21 [§]	3.6
Reported US Total	2,254	25,254	7.6
Estimated US Total		25,749	7.8

DNF Did not furnish. [§] Missing values (DNF) assumed to be zero. [†] Other date (data from previous or next year). [‡] Estimate. [§] Total is larger than component parts due to unknown settings or sizes. ^s Source APHA 2017c. * See state notes in Appendix.

lawsuits and consent decrees, and other factors such as the Federal Medicaid matching percentage.

State differences also exist in:

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

technology supports for Medicaid recipients (Tanis, Lulinski, Braddock, & Hemp, 2020; <https://stateofthestates.org/>).

People with IDD in Psychiatric Facilities and Nursing Homes

This section estimates the number of people with IDD receiving LTSS in state-run or non-state psychiatric facilities and nursing homes on June 30, 2020. Only 28 states reported the number of people with IDD living in psychiatric facilities while data were available for people with IDD in all states (either from the state or from an alternate source).

Psychiatric Facilities

While Medicaid funds are available for LTSS provided in most settings, they may not be used to fund services in “Institutes for Mental Disease”—also known as psychiatric facilities—for individuals 18 to 64 years old. Those services must be funded by state, local or private funds. A total of 2,254 people with IDD



in 22 reporting states were living psychiatric facilities on June 30, 2020 (see **Table 1.10**). These figures are an undercount because many states were unable to furnish complete information about psychiatric facilities. Lack of alternative data sources keeps us from estimating the total number of people with IDD in psychiatric facilities.

Nursing Homes

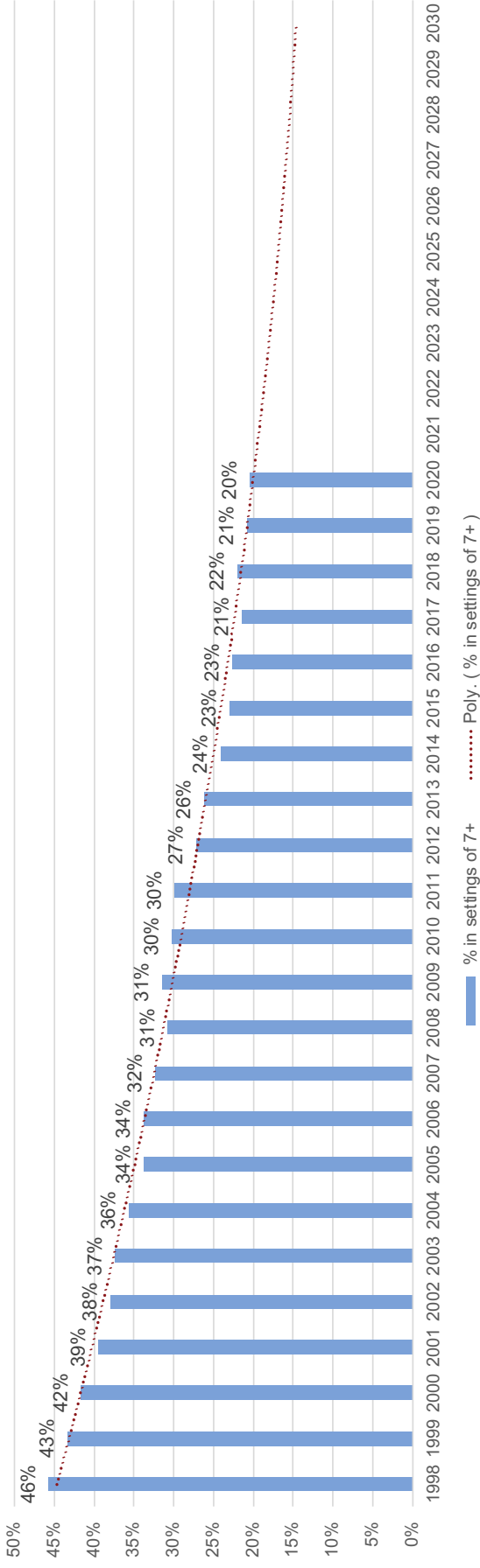
On June 30, 2020, there were an estimated 25,749 people with IDD living in nursing homes. For states that provided no or partial data, totals were estimated based on CMS CASPER nursing home data for residents identified as having ID and are identified by the superscript “s”(AHCA, 2020c).

States serving the greatest numbers of people with IDD in nursing homes were Texas (3,114), New York (3,026), and Pennsylvania (2,283). States reporting fewer than 50 people with IDD living in nursing homes were Alaska, Colorado, the District of Columbia, Hawaii, Maine, Mississippi, Missouri, Vermont, and Wyoming. When indexed by state population, states reporting more than 20 people with IDD living in nursing homes per 100,000 of the population were Alabama, Arkansas, Indiana, and Iowa.

Progress on Healthy People 2030 Objective DH-03

The Centers for Disease Control and Prevention Healthy People initiative establishes a set of objectives updated every 10 years to monitor progress toward improving the health of all Americans. RISP survey data are used to monitor progress on one Healthy People 2030 objective (see the Healthy People website at www.healthypeople.gov). Objective DH-03 for HP 2030 is to reduce the proportion of LTSS recipients with IDD who live in congregate care residences with seven or more people from 22.7% in 2016 to 11.5% by 2030. On June 30, 2020, an estimated 20% of LTSS recipients with IDD lived in IDD facilities of seven or more people, nursing homes, or psychiatric facilities (see **Figure 1.7**). This was a decrease from 23% in 2016. Between 1998 and 2020, the proportion living in settings of seven or more people declined from 46% to 20%.

Figure 1.7 Percent of People in Non-Family Settings who Live in Congregate Settings of 7+ People 1998 to 2020 with Linear Projections to 2030





SECTION TWO

Long-Term Supports and Services Funding Authorities

FY 2020

Medicaid HCBS Waiver-Funded Services in 2020

\$47.4 billion was expended to provide Medicaid Waiver funded supports to 954,314 people with IDD (\$49,669 per person)

Annual per person Medicaid Waiver expenditures

21 years and younger

\$17,814



22 years and older

\$60,172



In 2020, **954,314** people with IDD received Medicaid Home and Community-Based Waiver-funded supports.

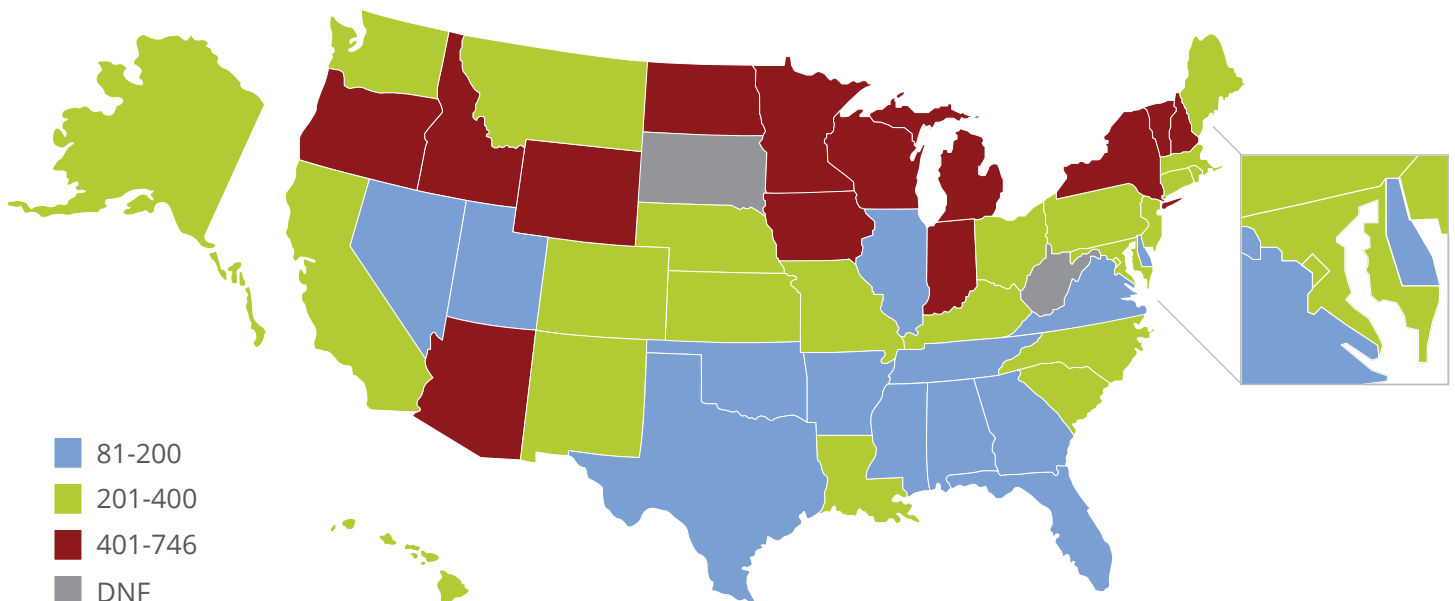


26% were 21 years or younger



74% were 22 years or older

In 2020, 288 people with IDD got Medicaid Home and Community-Based Waiver-funded supports for every 100,000 people in the United States.



2020 Medicaid Intermediate Care Facility for Individuals with Intellectual and Developmental Disabilities (ICF/IID)

\$9.38 billion was expended to provide ICF/IID-funded supports to 64,902 people with IDD (\$144,469 per person)

Annual per person ICF/IID expenditures

21 years and younger

\$129,404



22 years and older

\$150,112

In 2020, of the 64,902 people living in an ICF/IID settings:

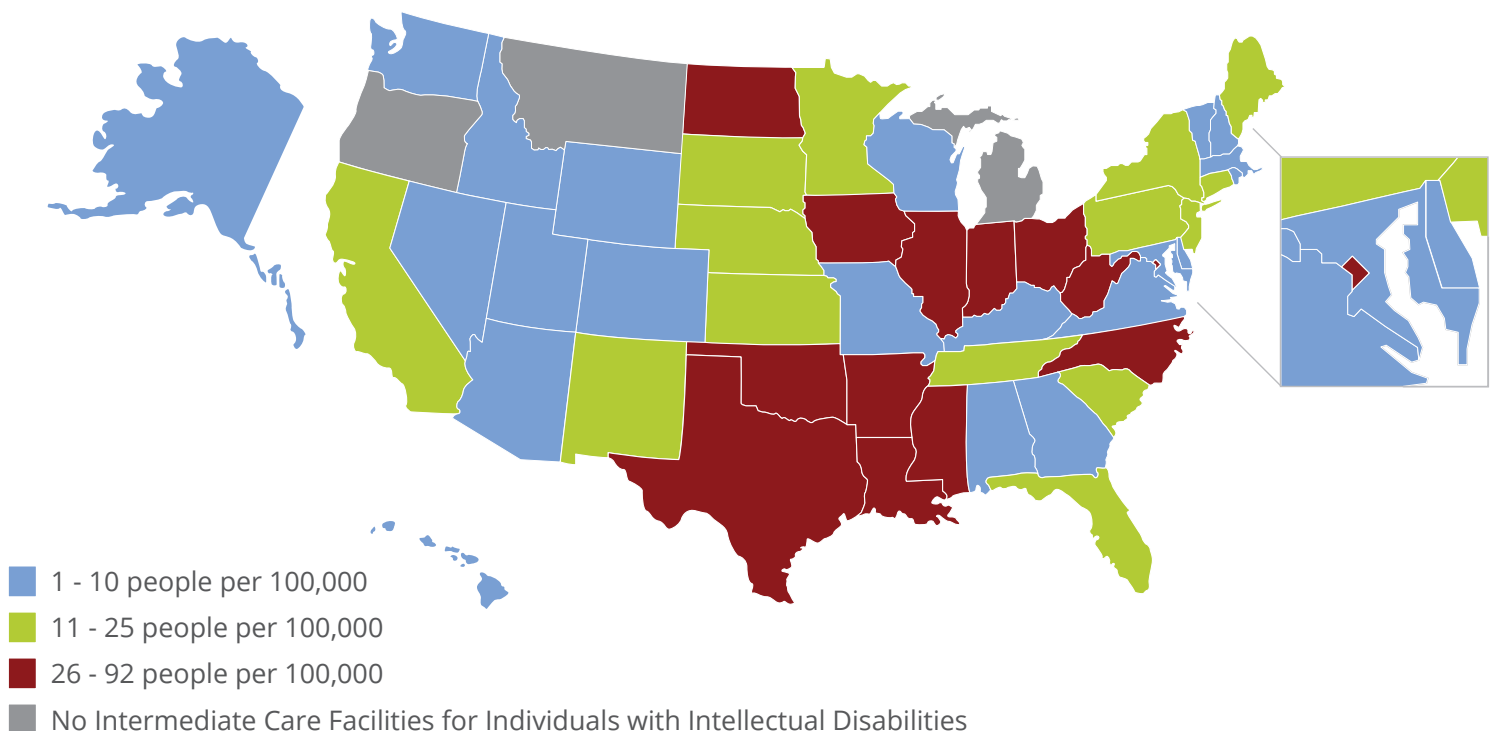


7% were 21 years or younger



93% were 22 years or older

In 2020, an average of 19.6 people per 100,000 of the population lived in an ICF/IID.



SECTION 2: MEDICAID AND STATE LTSS FUNDING AUTHORITIES

Medicaid offers an array of different mechanisms (or “authorities”) through which states can request matching federal funds to provide LTSS (see [Table C](#)). States can request flexibility in administration and in determining the type, amount, duration, and scope of services, as well as the design and delivery of services to be covered, consistent with federal regulations. The federal financial portion (called the Federal Medicaid Assistance Percentage, or FMAP) varies by state, based on per capita income and the size of the state. For FY 2020, state FMAP ranged from 56% in 15 states to 83% in Mississippi. In states with a 50% FMAP, every dollar the state spends on Medicaid-funded supports is matched by a dollar from the federal government.

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

STATE UTILIZATION OF LTSS FUNDING AUTHORITIES

In 2020, all 50 states and the District of Columbia funded LTSS for people with IDD through one or more Medicaid Waiver funding authority (see [Figure 2.1](#)). The number of states using Medicaid Waiver funding authorities included: 1915(c) Home and Community-based Waiver (47 states), 1115 Demonstration Waiver (13 states), and Medicaid Managed Care Waivers 1915(a), (b), or (b/c) (seven states). Waiver recipients described in this report may have received services funded by any of these Waiver funding authorities.

In 2020, 50 states and the District of Columbia reported using one or more Medicaid State Plan funding authorities to support LTSS for people with IDD. The number of states using State Plan funding authorities to support people with IDD included: Medicaid ICF/IID (48 states), Medicaid State Plan Targeted Case Management (36 states), Medicaid State Plan 1915(i) HCBS (seven states), State Plan 1915(k) Community First Choice (seven states),

and other state plan LTSS (26 states). Forty-seven states also reported funding LTSS for people with IDD through non-Medicaid, state, or local funding authorities.

LTSS RECIPIENTS WITH IDD BY FUNDING AUTHORITY

Of the 1.65 million people with IDD known to or served under the auspices of state IDD agencies, an estimated:

- 954,314 people received Medicaid Waiver-funded LTSS,
- 467,490 received Medicaid State Plan targeted case management,
- 277,908 received non-Medicaid, state- or locally funded LTSS,
- 166,937 received Medicaid State Plan LTSS through authorities other than 1915(i) or 1915(k),
- 104,092 received supports through Medicaid State Plan 1915(i) or 1915 (k) funding authorities,
- 64,445 lived in a Medicaid ICF/IID, and
- 226,280 did not receive public LTSS funding (see [Figure 2.2](#)).

Some people received supports through more than one funding authority. These numbers refer to people who received funded services through the listed funding authority any time between July 1, 2019, and June 30, 2020.

PEOPLE WITH IDD WAITING FOR MEDICAID WAIVER-FUNDED SUPPORTS

Forty-three states reported the number of people with IDD living with family members or in their own homes who had requested Medicaid Waiver-funded services but were waiting for those supports as of June 30, 2020 (see [Table 2.1](#)). People who already received Medicaid Waiver-funded supports who were asking for more or different supports, people living in an ICF/IID, and people not living with a family member or in their own home were not counted.

Number of People with IDD Waiting

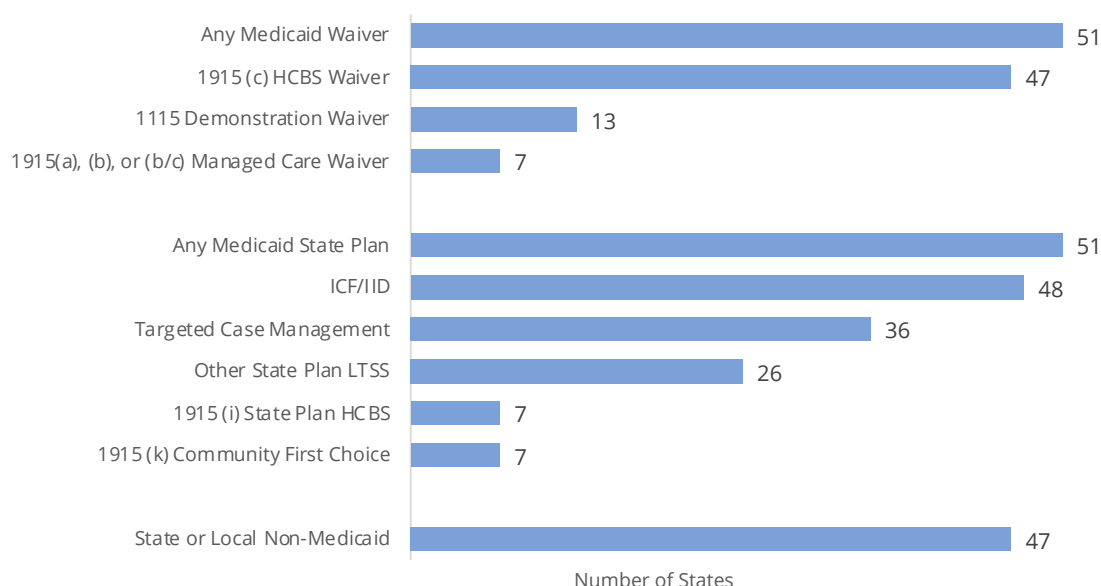
An estimated 174,785 people with IDD living with family members or in their own homes who were not already receiving Medicaid Waiver-Funded LTSS were waiting for LTSS on June 30, 2020.

Some states have shifted to offering Medicaid state-plan funded home and community-based supports for which waiting lists are not permitted for eligible individuals. Fifteen states (Arizona, California, Delaware, the District of Columbia, Hawaii,

Idaho, Louisiana, Massachusetts, Michigan, New Hampshire, New York, North Dakota, Oregon, Rhode Island, and Vermont) reported no people waiting for and not receiving Medicaid Waiver-funded supports in their own or family homes as of June 30, 2020.

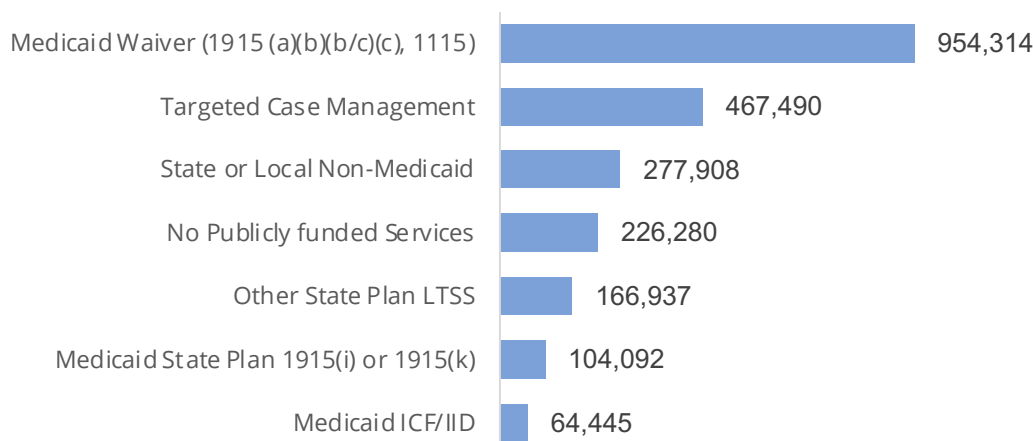
States reporting more than 10,000 people with IDD waiting for Medicaid Waiver-funded supports included Florida (22,986), South Carolina (18,946), Illinois (15,719), Washington (14,030), Virginia (13,080), and Kentucky (10,071). Those states, as well as Oklahoma (5,711 people waiting) New Mexico

Figure 2.1 Funding Authorities Used by States to Provide LTSS to People with IDD on June 30, 2020



Any Waiver category includes Medicaid 1915 (c) HCBS Waiver, 1915(a), (b), or (b/c) Managed Care Waiver, 1115 Demonstration Waiver

Figure 2.2 Estimated LTSS Recipients with IDD by Funding Authority on June 30, 2020



Some people receive services from more than one funding authority. Medicaid Waiver authorities include 1115, 1915 (a), 1915 (a/c), 1915 (b), 1915 (b/c) and 1915 (c); Figure does not show State Plan HCBS recipients or people getting Targeted Case Management Services

Table 2.1 People with IDD Living with Family Members Waiting for Medicaid Waiver-Funded LTSS, and Growth Needed to Serve those Waiting by State on June 30, 2020

State	People Waiting for Medicaid Waiver-Funded LTSS			Estimated June 30 Medicaid Waiver + ICF/IID Recipients	Increase Needed to Serve All Waiting (%)
	Number Waiting	Gets Targeted Case Management while waiting	Waiting to Move from Family Home		
N States	43	36	29	51	43
AL	2,100 ^j	420 ^j	693 ^j	6,055	35
AK*	766	DNF	DNF	2,567	30
AZ	0	DNF	0	35,959	0
AR	DNF	N/A	DNF	5,633	DNF
CA	0	0	0	115,675	0
CO	2,959	0	2,959	12,863	23
CT*	243	180	94	11,059	2
DE	0	0	0	1,960	0
DC	0	N/A	0	2,316	0
FL	22,986	DNF	2,138	37,118	62
GA	DNF	DNF	DNF	13,895	DNF
HI	0	0	0	3,025	0
ID	0	N/A	0	8,191	0
IL	15,719	N/A	2,936	29,990	52
IN	2,175	N/A	DNF	34,253	6
IA	DNF	DNF	DNF	24,272	DNF
KS	3,628	1,591	DNF	10,010	36
KY	10,071	DNF	DNF	15,682	64
LA	0 ^j	DNF	0 ^j	17,346	0
ME	196	1,400	DNF	6,465	3
MD	5,664	5,664	DNF	15,786	36
MA	0	0	0	14,394	0
MI	0	N/A	0	49,874	0
MN*	52 ^e	52 ^e	DNF	25,265	0
MS	2,527	694	0	4,779	53
MO*	997	982	167	15,088	7
MT	DNF	DNF	DNF	2,604	DNF
NE	2,019	400	0	5,297	38
NV	87	87	DNF	2,591	3
NH	0	0	0	6,544	0
NJ	520	N/A	DNF	22,871	2
NM	4,724	0	DNF	5,390	88
NY*	0	0	5,355	92,259	0
NC	DNF	DNF	DNF	33,597	DNF
ND	0	N/A	0	5,131	0
OH*	5,905	141	DNF	47,242	12
OK	5,711	DNF	DNF	6,663	86
OR	0	DNF	0	23,336	0
PA	6,782	5,662	1,358	39,268	17
RI	0	N/A	0	3,795	0
SC	18,946	DNF	208	12,240	155
SD	DNF	DNF	DNF	4,295	DNF
TN	DNF	N/A	DNF	10,851	DNF
TX	DNF	DNF	DNF	43,473	DNF
UT*	3,737	N/A	1,472	6,392	58
VT	0	0	0	2,926	0
VA	13,080	0	7,256	15,310	85
WA	14,030	N/A	0 ^j	25,160	56
WV	1,032 ^j	DNF	DNF	5,987	17
WI	414	0	DNF	40,717	1
WY	374	371	0 ^j	2,429	15
Reported US Total	147,444	17,644	24,636		
Estimated US Total	174,785	32,669	45,933	985,888	18

DNF Did not furnish. ^d Other date (data from previous or next year). ^e Estimate. ICF/IID: Intermediate Care Facilities for Individuals with Intellectual Disabilities. N/A - The state reported not using the State Plan Targeted Case Management funding authority. *See state notes in Appendix.

(4,724), Utah (3,737), and Mississippi (2,527) would have to increase the number of Waiver and ICF/IID recipients by more than 50% to serve everyone reported to be waiting for but not receiving Medicaid Waiver-funded supports.

People Receiving Targeted Case Management Services While Waiting

Of the people with IDD waiting for Medicaid Waiver-funded supports, an estimated 19% (32,669 people) in 13 states received Medicaid State Plan-funded Targeted Case Management (TCM) services while waiting. Four states with people waiting reported not providing TCM to people who were waiting. More than 90% of people waiting received TCM services in Maine, Maryland, Minnesota, Missouri, Nevada, and Wyoming. People waiting may have received LTSS funded by a Medicaid State Plan, or by a non-Medicaid state funding authority during their wait.

People Waiting to Move to a Group Setting

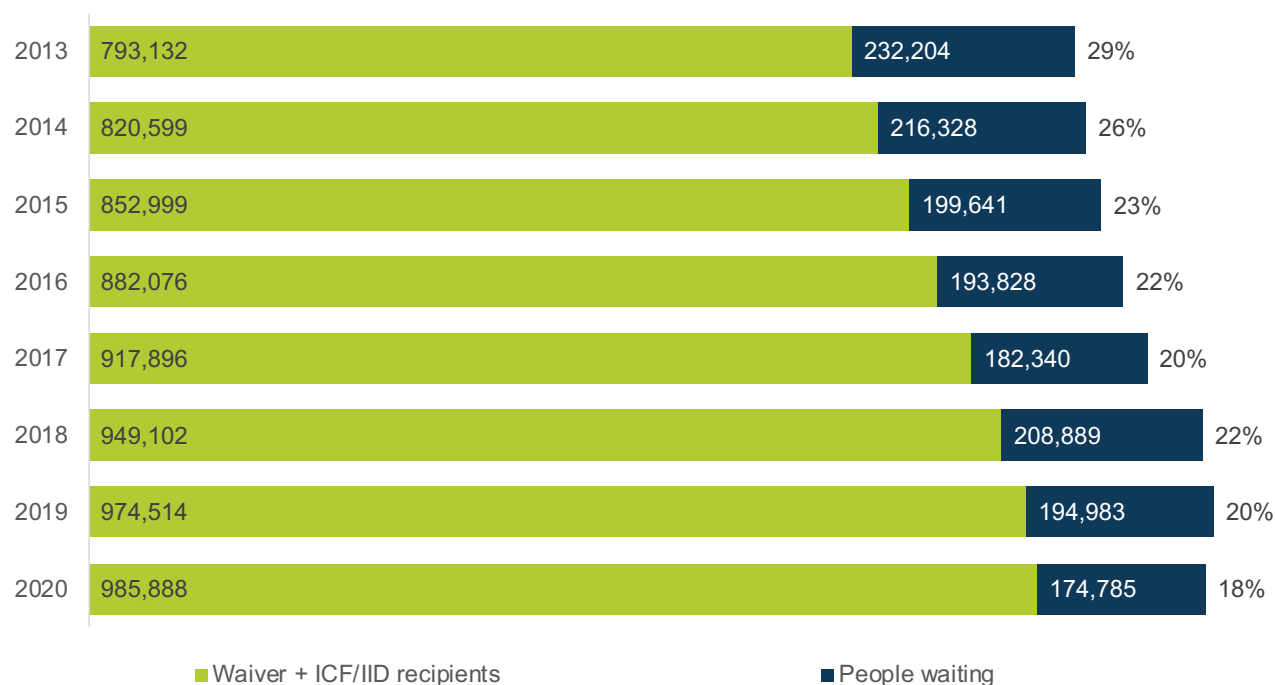
An estimated 45,933 people in thirteen states were waiting for Medicaid Waiver funding to enable them to move from their own homes or homes of family

members to a different setting. Colorado (100%) and Virginia (55%) reported that more than half of the people waiting planned to move to a non-family setting. New York reported people waiting to move from the home of a family member but reported no people on the Waiver waiting list. Those waiting are already getting Waiver-funded support but requesting services to enable them to move from the home of a family member.

Growth in Medicaid Funded LTSS Required to Serve All People Waiting

An estimated 985,888 people with IDD received Medicaid Waiver-funded supports or lived in an ICF/IID on June 30, 2020 (see **Figure 2.3**). To serve all 174,785 people waiting for Waiver-funded supports in states with waiting lists, the number of Waiver plus ICF/IID LTSS recipients would have had to increase by 18% overall. The proportion ranged from 0% in 16 states and less than 5% in five states to 155% in South Carolina (see **Table 2.1**). The percentage growth in service recipients needed to serve people waiting peaked at 29% in 2013 and declined to 18% in 2020. Prior to 2020, the last time the percentage was less than 20% was in 2012.

Figure 2.3 Total Medicaid ICF/IID and Waiver Recipients; People in Own or Family Home Waiting for Waiver Funding on June 30 of 2010 to 2020; and Percent Growth Needed to Serve Those Waiting



LIVING ARRANGEMENTS FOR PEOPLE RECEIVING MEDICAID WAIVER-FUNDED LTSS

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

We estimate that there were 921,443 Waiver recipients on June 30, 2020 (see [Table 2.2](#)). Nineteen states provided incomplete setting type data for HCBS Waiver recipients.

Home of a Family Member

An estimated 519,404 Medicaid Waiver recipients (56%) lived in the home of a family member. The proportion of Waiver recipients living with a family member ranged from 11% in Alaska to 85% in Arizona and exceeded 50% in 23 states.

Own Home

An estimated 119,490 Waiver recipients with IDD (13%) lived in a home they owned or leased on June 30, 2020. The proportion of Waiver recipients who lived in a home of their own ranged from less than one in Colorado, the District of Columbia, and New Jersey, to 57% in Nevada. In 20 states, fewer than 10% of Medicaid Waiver recipients with IDD lived in a home of their own. Only Nevada reported that more than 50% of recipients lived in their own homes.



Table 2.2 Medicaid Waiver Recipients with IDD by Reported Residence Type and State on June 30, 2020

	Family Home	Own Home	Host/ Foster Family	Group Settings			Group Total	Setting Type Unknown
				Non-State Group	Non-State Other	State IDD		
N States	42	40	45	45	43	51	42	43
AL	2,640 ⁱ	40 ⁱ	0 ⁱ	3,349 ⁱ	0	0	3,349 ⁱ	0 ⁱ
AK	271	755	97	840	0	0	840	590
AZ	30,698	262	1,573	3,260	15	122	3,397	0
AR	DNF	DNF	DNF	DNF	DNF	0	PD	DNF
CA	75,198	11,113	1,458	21,107	0	6	21,113	0
CO	6,013	0	3,461	571	2,552	102	3,225	0
CT	4,621	1,379	381	3,808	64	172	4,044	13
DE	680	64	97	1,001	0	0	1,001	0
DC	891	10	90	1,021	16	0	1,037	0
FL*	19,576	5,369	783	9,050	285	0	9,335	0
GA	DNF	DNF	DNF	DNF	DNF	0 ⁱ	PD	DNF
HI*	2,096	78	511	270	0	0	270	0
ID	1,827	DNF	506	DNF	DNF	0	PD	DNF
IL	12,374	1,770	318	9,310	0	0	9,310	0
IN	23,052 ^e	2,286 ^e	345	5,447	0	0	5,447	0
IA	9,964	7,931	180	4,552	110	0	4,662	0
KS	3,833	1,142	413	2,351	0	0	2,351	1,886
KY	DNF	DNF	2,442	2,451	0	0	2,451	10,407
LA	10,582	2,265 ⁱ	9 ⁱ	0	0 ⁱ	0	0 ⁱ	0 ⁱ
ME	DNF	DNF	1,785	2,052	109	0	2,161	2,328
MD	DNF	DNF	DNF	6,375	0	0	6,375	9,318
MA	2,848	1,379	560	8,294	0	1,004	9,298	0
MI	29,603	10,077	464	9,164	566 ⁱ	0	9,730	0
MN	11,672 ^e	2,162 ^e	1,002	8,241	911 ^e	322	9,474	0
MS	1,687	67	0	835	0 ^{PD}	170	1,005	0
MO	7,484	5,044	523	1,478	0	200	1,678	0
MT	1,703 ⁱ	DNF	46 ⁱ	825 ⁱ	DNF	0	PD	0 ⁱ
NE*	701	733	1,278	1,089	0	0	1,089	1,061
NV	886	1,434	183	0	9	0	9	0
NH	960	351	0	1,748	0	0	1,748	3,470 ⁱ
NJ*	13,455	47	399	7,724	0	0	7,724	0
NM	3,934 ^e	198	0	950 ^e	DNF	65	PD	DNF
NY	49,426 ^e	6,407 ^e	1,371	25,133	0	6,084	31,217	0
NC	DNF	DNF	DNF	DNF	DNF	0 ⁱ	PD	DNF
ND*	2,870	1,390	13	333	0	0	333	0
OH	24,383	13,602	1,148	2,541	500	0	3,041	0
OK	DNF	DNF	DNF	DNF	DNF	0	PD	DNF
OR*	16,031	741	3,460	3,104	0	0	3,104	0
PA	19,751	2,548	1,470	11,906	1,131	0	13,037	43
RI	1,717	511	406	1,010	0	122	1,132	0
SC	7,471	436	176	3,022	0	15	3,037	0
SD	DNF	DNF	DNF	DNF	0	0 ⁱ	PD	DNF
TN	DNF	DNF	688	5,196	0	0	5,196	4,050
TX	9,735	3,176	14,338	8,626	DNF	0	PD	DNF
UT	1,505	1,602	529	2,066	0	0	2,066	0
VT	1,116	265	1,396	143	0	0	143	0
VA	6,648	1,177	1,888	4,972	0	0	4,972	0
WA	12,531	9,845	140	1,697	220	212	2,129	0
WV	3,205	857 ⁱ	69 ⁱ	1,364	0 ⁱ	0	1,364 ⁱ	0 ⁱ
WI	22,476	7,658	6,705	3,520	1	0	3,521	0
WY	1,146	478	57	626	4	0	630	67
Reported US Total	459,260	106,649	52,758	192,422	6,493	8,596	207,511	33,233
Estimated US Total	519,404	119,490	58,891	208,325	6,809	8,524[*]	223,658	0

DNF Did not furnish. ⁱ Other date (data from previous or next year). ^e Estimate. ^{*} See state notes in Appendix. Many states were unable to report residence type for all Waiver recipients. Please refer to Table 2.3 for an estimate of the total number of Waiver recipients. Medicaid Waiver authorities include 1115, 1915 (a), 1915 (a/c), 1915 (b), 1915 (b/c) and 1915 (c). 2 31,239 Waiver recipients are not accounted for on this table.

Table 2.3 Number of Medicaid Waiver Recipients with IDD Total and per 100,000 of the Population by Age and State in FY 2020

State	Estimated FY 2020 Waiver Recipients			Percent 22 years or older	State Population in 100,000's ^s		Estimated 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	45	45	49	45	51	51	45	45	49
AL	63 ^j	5,981 ⁱ	6,044 ^j	99	14	36	4	165	120
AK	DNF	DNF	2,553	DNF	2	5	DNF	DNF	348
AZ	22,909	13,233	36,142	37	20	51	1,141	257	505
AR	568	3,643	4,211	87	9	21	65	170	140
CA	54,520	74,723	129,243	58	109	286	501	261	327
CO	3,354	10,420	13,774	76	16	42	214	248	239
CT	353	10,385	10,738	97	9	27	38	389	298
DE	DNF	DNF	1,842	DNF	3	7	DNF	DNF	186
DC	24	1,844	1,868	99	2	5	15	346	271
FL	4,271	30,381	34,652	88	53	163	81	187	161
GA	605 ^j	13,076 ^j	13,681 ^j	96	31	76	19	172	128
HI*	521	2,537	3,058	83	4	11	141	233	210
ID	3,589	4,220	7,809	54	6	13	631	332	425
IL	1,898	21,873	23,771	92	35	93	54	235	186
IN	13,202	17,928	31,130	58	20	48	665	373	459
IA	11,926	11,872	23,798	50	9	23	1,283	525	746
KS	1,670	7,781	9,451	82	9	21	189	379	322
KY	5,563	9,538	15,101	63	13	32	440	294	335
LA	2,678 ^j	10,178 ^j	12,856 ^j	79	13	33	199	307	276
ME	335	4,609	4,944	93	3	10	105	442	363
MD	342	15,351	15,693	98	17	45	20	342	254
MA	322	16,542	16,864	98	18	53	18	315	240
MI	10,962	35,998	46,960	77	27	73	402	490	466
MN	6,601	17,642	24,243	73	16	41	409	431	425
MS	DNF	DNF	2,759	DNF	9	21	DNF	DNF	93
MO	2,381	12,533	14,914	84	17	44	138	283	242
MT	339	2,265	2,604	87	3	8	117	285	240
NE*	386	4,486	4,872	92	6	14	65	329	248
NV	201	2,311	2,512	92	8	23	24	102	81
NH	2,192 ^e	4,343	6,535 ^e	66	3	10	663	415	474
NJ	0	21,625	21,625	100	25	68	0	318	233
NM	426	4,507	4,933	91	6	15	72	296	233
NY	21,608	69,208 ^j	90,816 ^e	76	52	150	414	462	450
NC	11,562 ^j	18,278 ^j	29,840 ^j	61	29	76	401	242	286
ND	2,970	2,276	5,246	43	2	5	1,283	416	673
OH	6,351	36,650	43,001	85	32	86	196	429	364
OK	DNF	DNF	5,261	DNF	12	28	DNF	DNF	133
OR*	11,736	17,710	29,446	60	11	32	1,085	561	695
PA	4,213	33,004	37,217	89	34	96	125	343	286
RI	5 ^j	3,956 ^j	3,961 ^j	100	3	8	2	486	361
SC	2,285	8,835	11,120	79	14	37	164	237	217
SD	DNF	DNF	DNF	DNF	3	6	DNF	DNF	DNF
TN	1,137	9,581	10,718	89	19	50	60	191	155
TX	4,889	34,186	39,075	87	90	202	54	170	134
UT	1,290	4,405	5,695	77	12	21	111	209	174
VT*	329	2,907	3,236	90	2	5	209	598	503
VA	2,263	12,571	14,834	85	24	62	95	201	172
WA	5,645	14,227	19,872	72	21	56	273	252	258
WV	DNF	DNF	DNF	DNF	5	13	DNF	DNF	DNF
WI	7,420	32,940	40,360	82	16	43	462	768	685
WY	693	1,724	2,417	71	2	4	417	420	419
Reported US Total	236,597	694,283	943,295	74	915	2,400	259	289	285
Estimated US Total	241,361	712,953	954,314	75	915	2,400	264	297	288

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

Host or Foster Family Home

An estimated 58,891 Waiver recipients with IDD (6%) lived with a host or foster family on June 30, 2020. The proportion of Waiver recipients with IDD who lived with a host or foster family ranged from less than 1% in Alabama, Louisiana, Mississippi, North Dakota, New Hampshire, and New Mexico to 48% in Vermont. In 33 states, fewer than 10% of Medicaid Waiver recipients with IDD lived with a host or foster family.

Group Settings

An estimated 223,658 Waiver recipients with IDD (24%) lived in group settings including an estimated 208,325 who lived in non-state, IDD group homes, 6,809 who lived in other non-state group settings, and 8,524 who lived in state-run group homes. The proportion of Waiver recipients living in group settings ranged from zero in Louisiana to 66% in Massachusetts. Besides Massachusetts, states in which 50% or more of Medicaid Waiver recipients

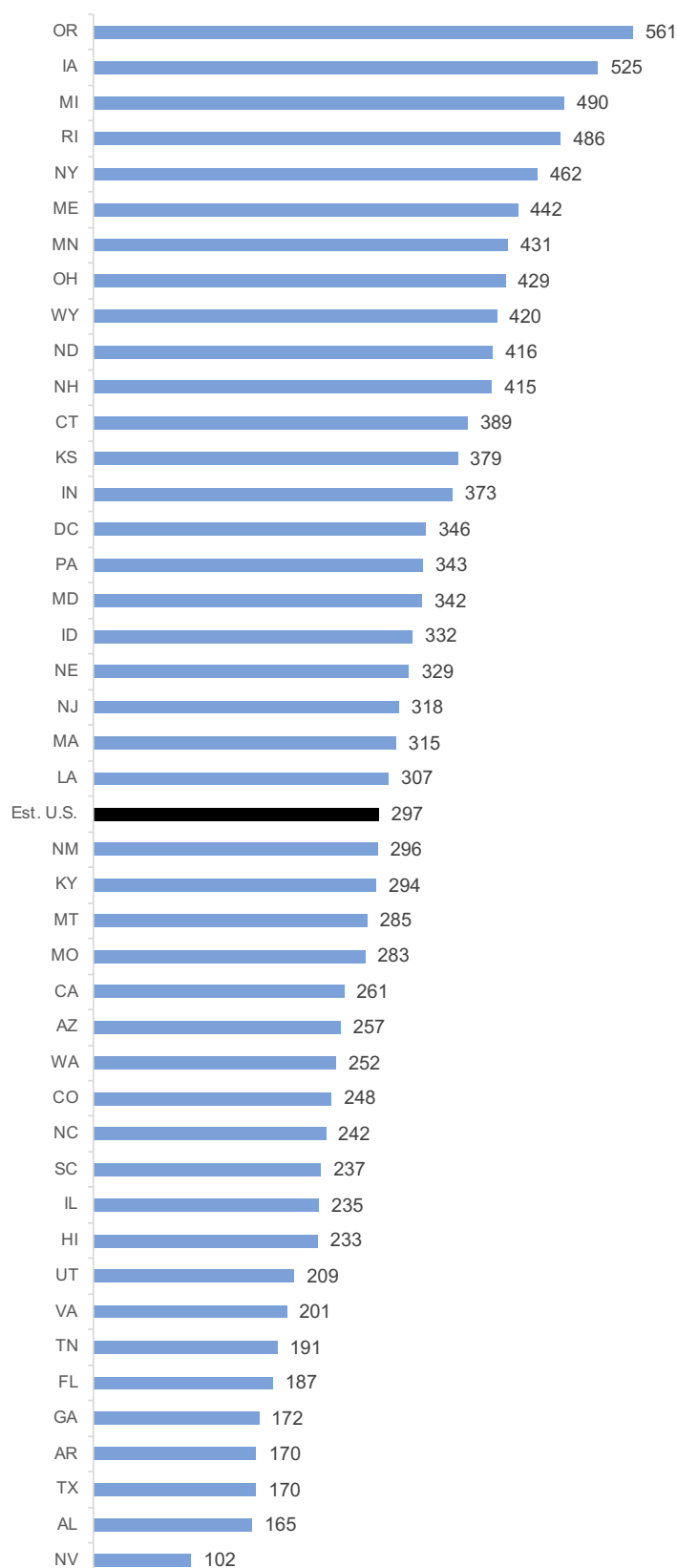
lived in a group setting included Alabama (56%), Delaware (54%), Tennessee (52%), and the District of Columbia (51%). Besides Louisiana, fewer than 10% of Medicaid Waiver recipients with IDD lived in group settings in Nevada (0.4%), Vermont (5%), North Dakota (7%), Ohio (7%), Arizona (9%), Hawaii (9%), Washington (9%), and Wisconsin (9%).

MEDICAID WAIVER UTILIZATION RATES BY AGE AND STATE

Age and expenditure data were provided for 954,314 people with IDD who had Medicaid Waiver expenditures between July 1, 2019, and June 30, 2020. Of those, an estimated 241,361 (25%) were 21 years old or younger and 712,953 (75%) were 22 years or older (see [Table 2.3](#)). In 14 states, 90% or more of Waiver recipients were 22 years or older. In Arizona (37%) and North Dakota (43%) fewer than 50% of Waiver recipients were 22 years or older.



Figure 2.4 Waiver Recipients with IDD per 100,000 and Percent who are 22 Years or Older



Number of adult waiver recipients not reported by Alabama, Alaska, Delaware, Georgia, Mississippi, Oklahoma, Rhode Island and South Dakota

Nationally, there were an estimated 288 Medicaid Waiver recipients with IDD per 100,000 of the population. Medicaid Waiver utilization rates for people with IDD ranged from 81 per 100,000 in Nevada to 746 per 100,000 in Iowa. Other states with utilization rates of more than 500 per 100,000 included Oregon (695), Wisconsin (685), North Dakota (673), Arizona (505), and Vermont (503).

Waiver utilization rates for children and youth with IDD 21 years or younger averaged 264 per 100,000 and ranged from 10 or fewer per 100,000 in New Jersey (0), Rhode Island (2), and Alabama (4) to more than 1,000 per 100,000 in Iowa (1,283), North Dakota (1,283), Arizona (1,141), and Oregon (1,085). Several states provide Medicaid Waiver-funded LTSS to young adults 18 to 21 years old but do not serve children younger than age 18.

Medicaid Waiver utilization rates for adults with IDD 22 years or older averaged 297 per 100,000 and ranged from 102 per 100,000 in Nevada to more than 500 per 100,000 in Wisconsin (768), Vermont (598), Oregon (561), and Iowa (525; see **Figure 2.4**). Seven states provided Medicaid Waiver-funded supports to fewer than 200 adults with IDD ages 22 years or older per 100,000 of the state population (Alabama, Arkansas, Florida, Georgia, Nevada, Tennessee, and Texas).

Access to Medicaid Waiver-funded LTSS differed by age and state of residence. In Arizona, Iowa, and North Dakota, utilization rates are more than twice as high for children as for adults. In Mississippi, Nebraska, New Jersey, Tennessee, Texas, and Wyoming, rates are 10 times higher for adults than for children.

Factors associated with differences in Waiver utilization include the extent to which state IDD agencies serve children, state policies regarding funding for Medicaid LTSS, historical use of ICF/IID versus Medicaid Waiver funding, and the extent to which the state uses Medicaid State Plan-, state- or locally funded LTSS for people with IDD.

Medicaid Waiver Recipients by Age and Living Arrangement

Living arrangements between July 1, 2019, and June 30, 2020, for Medicaid Waiver recipients were

Table 2.4 Medicaid Waiver Recipients with IDD Living in Family Homes or Other LTSS Settings by Age and State in FY 2020

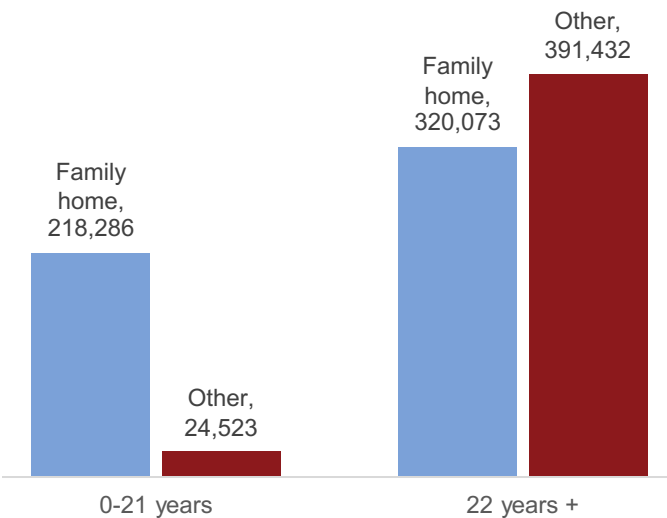
Age	Family Home		Other Settings ¹		% in Family Home	
	Birth to 21 years	22 years or older	Birth to 21 years	22 years or older	Birth to 21 years	22 years or older
N States	34	34	34	34	34	34
AL	DNF	DNF	DNF	DNF	DNF	DNF
AK	DNF	DNF	DNF	DNF	DNF	DNF
AZ	22,111	8,900	1,040	4,629	96	66
AR	DNF	DNF	DNF	DNF	DNF	DNF
CA	53,247	42,288	1,273	32,435	98	57
CO	2,934	4,447	564	6,370	84	41
CT	300	4,321	53	5,766	85	43
DE	DNF	DNF	DNF	DNF	DNF	DNF
DC	16	714	10	1,179	62	38
FL	3,338	15,928	933	14,453	78	52
GA	DNF	DNF	DNF	DNF	DNF	DNF
HI*	500	1,622	21	915	96	64
ID	DNF	DNF	DNF	DNF	DNF	DNF
IL	1,547	10,827	351	11,047	82	49
IN	12,809	10,243	393	7,685	97	57
IA	DNF	DNF	DNF	DNF	DNF	DNF
KS	1,316	2,517	354	5,264	79	32
KY	5,480 ^e	5,395 ^e	83 ^e	4,143 ^e	99	57
LA	DNF	DNF	DNF	DNF	DNF	DNF
ME	140	2,188	242	3,415	37	39
MD	DNF	DNF	DNF	DNF	DNF	DNF
MA	322	2,848	0	14,474	0	16
MI	9,128	9,379	1,834	26,619	83	26
MN*	5,995 ^e	5,677 ^e	606	11,965	91	32
MS	DNF	DNF	DNF	DNF	DNF	DNF
MO	2,078	5,418	303	7,115	87	43
MT	DNF	DNF	DNF	DNF	DNF	DNF
NE*	228	607	158	3,879	59	14
NV	67	819	136	1,491	33	35
NH	0	960	2,192	3,383	0	22
NJ*	0	13,455	0	8,170	0	62
NM	412	3,525	14	982	97	78
NY	20,709 ^e	29,155 ^e	896	38,201	96	43
NC	DNF	DNF	DNF	DNF	DNF	DNF
ND*	2,911	79	59	2,197	98	3
OH	5,660	19,240	691	17,410	89	52
OK	DNF	DNF	DNF	DNF	DNF	DNF
OR*	10,572	10,472	1,186	7,216	90	59
PA	3,548	16,385	665	16,619	84	50
RI	3 ⁱ	1,690 ⁱ	2 ⁱ	2,266 ⁱ	60	43
SC	2,220	5,047	65	3,788	97	57
SD	DNF	DNF	DNF	DNF	DNF	DNF
TN	DNF	DNF	DNF	DNF	DNF	DNF
TX	2,737	8,130	2,106	25,065	57	24
UT	421	1,077	869	3,328	33	24
VT*	187 ^e	929 ^e	142 ^e	1,978 ^e	57	32
VA	1,842	4,806	421	7,765	81	38
WA	5,265	6,810	396	7,709	93	47
WV	DNF	DNF	DNF	DNF	DNF	DNF
WI	7,273	15,204	147	17,737	98	46
WY	DNF	DNF	DNF	DNF	DNF	DNF
Reported US Total	185,316	271,102	18,205	326,658	91	45
Estimated US Total	218,286	320,073	24,523	391,432	90	45

DNF Did not furnish. ^e Other date (data from previous or next year). ⁱ Estimate. * See state notes in Appendix. This table shows the number of people by age and setting for whom Waiver expenditures were reported. The total reported by full year expenditures is different from the the June 30, 2020 total Waiver LTSS recipients. ¹ Other settings include own home, host or foster family home, and all group settings. Medicaid Waiver authorities include 1115, 1915 (a), 1915 (a/c), 1915 (b), 1915 (b/c) and 1915 (c).

reported by 34 states. Amongst Medicaid Waiver recipients 21 years or younger, an estimated 218,286 (90%) lived in the home of a family member and 24,523 (10%) lived in another type of residence. Amongst Medicaid Waiver recipients ages 22 years or older, an estimated 320,073 (45%) lived with a family member and 391,432 (55%) lived in another type of residence (see **Table 2.4** and **Figure 2.5**).

The proportion of child Medicaid Waiver recipients who lived with a family member averaged 90% but ranged from zero in Massachusetts, New Hampshire, and New Jersey to 99% in Kentucky. The proportion of Medicaid Waiver recipients 22 years or older who lived with a family member averaged 45%. Fewer than half lived with a family member in 22 states. More than half lived with a family member in 12 states.

Figure 2.5 Estimated Number of Waiver Recipients With IDD Living With A Family Member or In Another Setting by Age between July 1, 2019 and June 30, 2020.



Living arrangements by age and setting were reported by 34 states for people receiving Medicaid Waiver funded supports any time between July 1, 2019 and June 30, 2020.





Medicaid Waiver Recipients in Own Home or Family Home Settings

Of the 154,634 LTSS recipients living in their own home, an estimated 119,490 (77%) received supports funded by a Medicaid Waiver (see **Table 2.5**). All recipients living in their own home received Medicaid Waiver-funded supports in 19 states. In another seven states, 95% or more received Waiver-funded supports. Fewer than half of recipients living in their own home received Medicaid Waiver-funded supports in California (41%) and Vermont (47%). Arizona reported more people living in their own home and getting Waiver funded supports during FY 2020, than people living in their own home on June 30, 2020.

Of 876,058 LTSS recipients living with a family member, an estimated 519,404 (59%) received Medicaid Waiver-funded supports. All recipients living with a family member received Medicaid Waiver-funded supports in 16 states as did more than 95% of recipients in an additional four states.

In eight states, fewer than half of LTSS recipients living with a family member received Medicaid Waiver-funded supports.

LTSS recipients living in their own home or with a family member whose services were not funded by a Medicaid HCBS Waiver receive state- or locally funded LTSS or get LTSS funded by a Medicaid State Plan option.

MEDICAID WAIVER EXPENDITURES

In FY 2020, annual Medicaid Waiver expenditures for 954,314 recipients with IDD were \$47.4 billion, an average of \$49,764 per person per year (see **Table 2.6**). Annual per person Medicaid Waiver expenditures ranged from \$6,168 in Oregon (see state note regarding 1915(k) funding) to \$146,067 in the District of Columbia. Average per person expenditures also were more than \$90,000 in Massachusetts (\$105,805), Delaware (\$93,245), and Pennsylvania (\$92,593).

Table 2.5 Estimated Percent of June 30, 2020 LTSS Recipients Living in Own Home or Family Home Settings whose Services were HCBS Waiver-Funded

State	June 30, 2020 LTSS Recipients		FY 2020 Waiver Recipients 1		% with Waiver Funding	
	Own Home	Family Home	Own Home	Family Home	Own Home	Family Home
N States	41	42	40	42	39	40
AL	40 ⁱ	2,640 ⁱ	40 ⁱ	2,640 ⁱ	100	100
AK	755 ^{PD}	271	755	271	100	100
AZ	246	30,698 ^{aj}	262	30,698	107	100
AR	DNF	DNF	DNF	DNF	DNF	DNF
CA	26,920	243,357	11,113	75,198	41	31
CO	DNF	DNF	0	6,013	DNF	DNF
CT	1,406	4,919	1,379	4,621	98	94
DE	64	3,775	64	680	100	18
DC	10	891	10	891	100	100
FL	6,017	42,170	5,369	19,576	89	46
GA	1,759 ⁱ	16,253 ⁱ	DNF	DNF	DNF	DNF
HI*	88	2,732	78	2,096	89	77
ID	DNF	1,827 ^e	DNF	1,827	DNF	100
IL	1,770	13,411	1,770	12,374	100	92
IN	2,286 ^e	23,052	2,286 ^e	23,052 ^e	100	100
IA	8,057	10,133	7,931	9,964	98	98
KS	1,142	3,833 ^e	1,142	3,833	100	100
KY	DNF	DNF	DNF	DNF	DNF	DNF
LA	2,265 ⁱ	10,582 ⁱ	2,265 ⁱ	10,582 ⁱ	100	100
ME	DNF	DNF	DNF	DNF	DNF	DNF
MD	DNF	DNF	DNF	DNF	DNF	DNF
MA	2,686	25,423	1,379	2,848	51	11
MI	10,077	29,603	10,077	29,603	100	100
MN*	3,651 ^e	15,303 ^e	2,162 ^e	11,672 ^e	59	76
MS	67 ⁱ	2,473	67	1,687	100	68
MO	5,044	12,443	5,044	7,484	100	60
MT	DNF	DNF	DNF	1,703 ⁱ	DNF	DNF
NE	734	701	733	701	100	100
NV	1,810	5,247	1,434	886	79	17
NH	351	960	351	960	100	100
NJ*	47	15,231	47	13,455	100	88
NM*	211 ^{aj}	3,983 ^e	198	3,934 ^e	94	99
NY	12,230 ^e	75,695 ^e	6,407 ^e	49,426 ^e	52	65
NC	0 ^{PD}	DNF	DNF	DNF	DNF	DNF
ND*	1,437	3,451	1,390	2,870	97	83
OH	15,657	74,750	13,602	24,383	87	33
OK	DNF	DNF	DNF	DNF	DNF	DNF
OR*	742	16,099	741	16,031	100	100
PA	3,305	22,902	2,548	19,751	77	86
RI	511	1,717	511	1,717	100	100
SC	699	15,711 ^e	436	7,471	62	48
SD	DNF	DNF	DNF	DNF	DNF	DNF
TN	DNF	4,210	DNF	DNF	DNF	DNF
TX	3,176	9,735	3,176	9,735	100	100
UT	1,621	1,531	1,602	1,505	99	98
VT	558	2,314	265	1,116	47	48
VA	1,177	6,648	1,177	6,648	100	100
WA	13,345	16,932	9,845	12,531	74	74
WV	857 ⁱ	3,205 ⁱ	857 ⁱ	3,205 ⁱ	100	100
WI	7,687	33,534	7,658	22,476	100	67
WY	478	1,146	478	1,146	100	100
Reported US Total	140,983	811,491	106,649	459,260	76	57
Estimated US Total	154,634	876,058	119,490	519,404	77	59

DNF Did not furnish. ^d Other date (data from previous or next year). ^e Estimate. ⁱ One or more component value imputed by RISP staff. * See state notes in Appendix. Medicaid Waiver authorities include 1115, 1915 (a), 1915 (a/c), 1915 (b), 1915 (b/c) and 1915 (c). ¹ The number of Waiver recipients is based on the full fiscal year.

Table 2.6 Medicaid Waiver Expenditures for Recipients with IDD, Per Recipient and Per State Resident by Age and State in FY 2020

State	Waiver Expenditures (\$)			FY 2020 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	41	41	51	49	40	41	49	51	51
AL	3,655,780 ^j	347,066,976 ^j	350,722,756 ^j	6,044 ^j	58,028	58,028	58,028	50	70
AK	DNF	DNF	189,862,987	2,553	DNF	DNF	74,369	7	259
AZ	497,506,486	875,215,248	1,372,721,734	36,142	21,717	66,139	37,981	72	192
AR	17,094,572	201,825,891	218,920,463	4,211	30,096	55,401	51,988	30	73
CA	570,927,644	3,687,579,542	4,258,507,186	129,243	10,472	49,350	32,950	395	108
CO	72,296,890	540,904,961	613,201,850	13,774	21,555	51,910	44,519	58	106
CT*	18,101,964	945,140,539	963,242,504	10,738	51,280	91,010	89,704	36	267
DE	DNF	DNF	171,757,360	1,842	DNF	DNF	93,245	10	174
DC	2,843,998	270,008,608	272,852,606	1,868	118,500	146,425	146,067	7	396
FL	85,594,131	1,103,370,350	1,188,964,481	34,652	20,041	36,318	34,312	215	55
GA	DNF	DNF	710,426,180 ^j	13,681 ^j	DNF	DNF	51,928	107	66
HI*	10,922,892	128,583,883	139,506,775	3,058	20,965	50,683	45,620	15	96
ID*	48,261,487	232,456,447	280,717,935	7,809	13,447	55,084	35,948	18	153
IL	73,088,555	1,045,661,339	1,118,749,894	23,771	38,508	47,806	47,064	128	87
IN	98,675,646	772,075,673	870,751,319	31,130	7,474	43,065	27,971	68	128
IA	104,538,478	571,619,297	676,157,775	23,798	8,766	48,149	28,412	32	212
KS	30,088,771	392,686,560	422,775,331	9,451	18,017	50,467	44,733	29	144
KY	202,047,809	524,731,199	726,779,008	15,101	36,320	55,015	48,128	45	161
LA	43,634,434 ^j	464,967,040 ^j	521,139,532 ^j	12,856 ^j	16,294	45,684	40,537	47	112
ME	15,193,886	279,140,139	294,334,026	4,944	45,355	60,564	59,534	14	216
MD	12,742,058	1,054,856,257	1,067,598,316	15,693	37,257	68,716	68,030	62	173
MA*	7,494,059	1,776,805,703	1,784,299,762	16,864	23,273	107,412	105,805	70	254
MI	216,042,378	803,614,894	1,019,657,272	46,960	19,708	22,324	21,713	101	101
MN	342,806,320	1,469,123,991	1,811,930,311	24,243	51,932	83,274	74,740	57	318
MS	DNF	DNF	127,150,356	2,759	DNF	DNF	46,086	30	43
MO	75,205,208	1,007,895,809	1,083,101,017	14,914	31,586	80,419	72,623	62	176
MT	DNF	DNF	126,789,326	2,604	DNF	DNF	48,690	11	117
NE*	24,844,818	332,029,627	356,874,445	4,872	64,365	74,015	73,250	20	182
NV	12,042,087	132,950,573	144,992,660	2,512	59,911	57,529	57,720	31	47
NH	18,840,681	267,133,082	285,973,763	6,535 ^e	8,595	61,509	43,760	14	208
NJ	0	1,817,697,562	1,817,697,562	21,625	N/A	84,055	84,055	93	196
NM	19,117,606	403,014,845	422,132,451	4,933	44,877	89,420	85,573	21	199
NY	485,143,232	6,394,213,424	6,879,356,656	90,816 ^e	22,452	92,391	75,750	202	341
NC	180,307,442 ^j	1,087,224,851 ^j	1,267,532,292 ^j	29,840 ^j	15,595	59,483	42,478	104	121
ND	DNF	DNF	170,179,794	5,246	DNF	DNF	32,440	8	218
OH	139,147,421	2,072,658,809	2,211,806,230	43,001	21,910	56,553	51,436	118	187
OK	DNF	DNF	351,791,348	5,261	DNF	DNF	66,868	40	89
OR*	53,824,687	127,806,494	181,631,182	29,446	4,586	7,217	6,168	42	43
PA	117,462,128	3,328,562,296	3,446,024,424	37,217	27,881	100,853	92,593	130	265
RI	68,109 ^j	258,076,608 ^j	258,144,717 ^j	3,961 ^j	13,622	65,237	65,172	11	235
SC	93,663,904	362,153,433	455,817,337	11,120	40,991	40,991	40,991	51	89
SD	DNF	DNF	144,690,116 ^j	DNF	DNF	DNF	DNF	9	163
TN	29,555,429	758,279,618	787,835,047	10,718	25,994	79,144	73,506	69	114
TX	180,737,154	1,399,493,888	1,580,231,042	39,075	36,968	40,938	40,441	291	54
UT	50,980,097	271,979,799	322,959,896	5,695	39,519	61,743	56,709	33	99
VT*	21,118,518	201,285,403	222,403,921	3,236	64,190	69,242	68,728	6	346
VA	DNF	DNF	1,017,642,686 ^j	14,834	DNF	DNF	68,602	86	118
WA*	36,869,946	705,752,093	742,622,039	19,872	6,531	49,607	37,370	77	96
WV	DNF	DNF	312,400,323	DNF	DNF	DNF	DNF	18	174
WI	79,949,248	1,444,251,757	1,524,201,005	40,360	10,775	43,845	37,765	59	259
WY	12,152,996	99,875,271	112,028,267	2,417	17,537	57,932	46,350	6	194
Reported Total	4,104,588,950	39,959,769,780	47,399,587,263						
Estimated Total			47,399,587,263	954,314	17,810	60,082	49,669	3,314	143

DNF Did not furnish. ^a Other date (data from previous or next year). ^e Estimate. ^j Imputed value s U.S. Census Bureau, Population Division (2020); Murray, et al., (2023) (Total Waiver expenditures). * See state notes in Appendix. Medicaid Waiver authorities include 1115, 1915 (a), 1915 (a/c), 1915 (b), 1915 (b/c) and 1915 (c). US estimated expenditures per person calculated based only on states providing data for all elements by age.

Annual Medicaid Waiver expenditures for recipients with IDD ages 21 years or younger were \$4.1 billion (\$17,814 per person per year). The average ranged from zero in New Jersey and \$4,586 in Oregon to \$118,500 in the District of Columbia. Other states reporting averages of more than \$50,000 per year for recipients 21 years or younger included Nebraska (\$64,365), Vermont (\$64,190), Nevada (\$59,911), Alabama (\$58,028), Minnesota (\$51,932), and Connecticut (\$51,280). Other states reporting per person averages of less than \$10,000 per year included Washington (\$6,531), Indiana (\$7,474), New Hampshire (\$8,595), and Iowa (\$8,766).

Annual Medicaid Waiver expenditures for recipients with IDD ages 22 years or older were \$40 billion, (\$60,172 per recipient per year). The average ranged from \$7,217 in Oregon to \$146,425 in the District of Columbia. Other states with averages of more than \$90,000 per person included Massachusetts (\$107,412), Pennsylvania (\$100,853), New York (\$92,391), and Connecticut (\$91,010).

Total FY 2020 Medicaid Waiver expenditures for people with IDD averaged \$143 per United States resident (see **Figure 2.6**). Highest expenditures per state resident were reported for the District of Columbia (\$396), Vermont (\$346), New York (\$341), Minnesota (\$318), and Connecticut (\$267). Lowest per capita expenditures were reported for Oregon (\$43), Mississippi (\$43), Nevada (\$47), Texas (\$54), and Florida (\$55). Some state differences in average per person expenditures can be explained by recent shifts from Medicaid Waiver to Medicaid State Plan HCBS funding and by differences in the number of children served by the state IDD agencies. However, those factors do not fully account for the vast state differences in investments in HCBS Waiver-funded supports for people with IDD.

Waiver Expenditures by Age and Residence Type

For FY 2020, 29 states provided complete information about recipients and expenditures for Medicaid HCBS Waiver-funded supports by age and residence type (see **Table 2.7**). Per person Medicaid Waiver expenditures varied dramatically by age and living arrangement. Of the \$47.4 billion in Medicaid Waiver expenditures for FY 2020, age and residence type were known for \$35.3 billion (74% of the

Figure 2.6 Annual Medicaid Waiver Expenditures for People with IDD per State Resident by State FY 2020

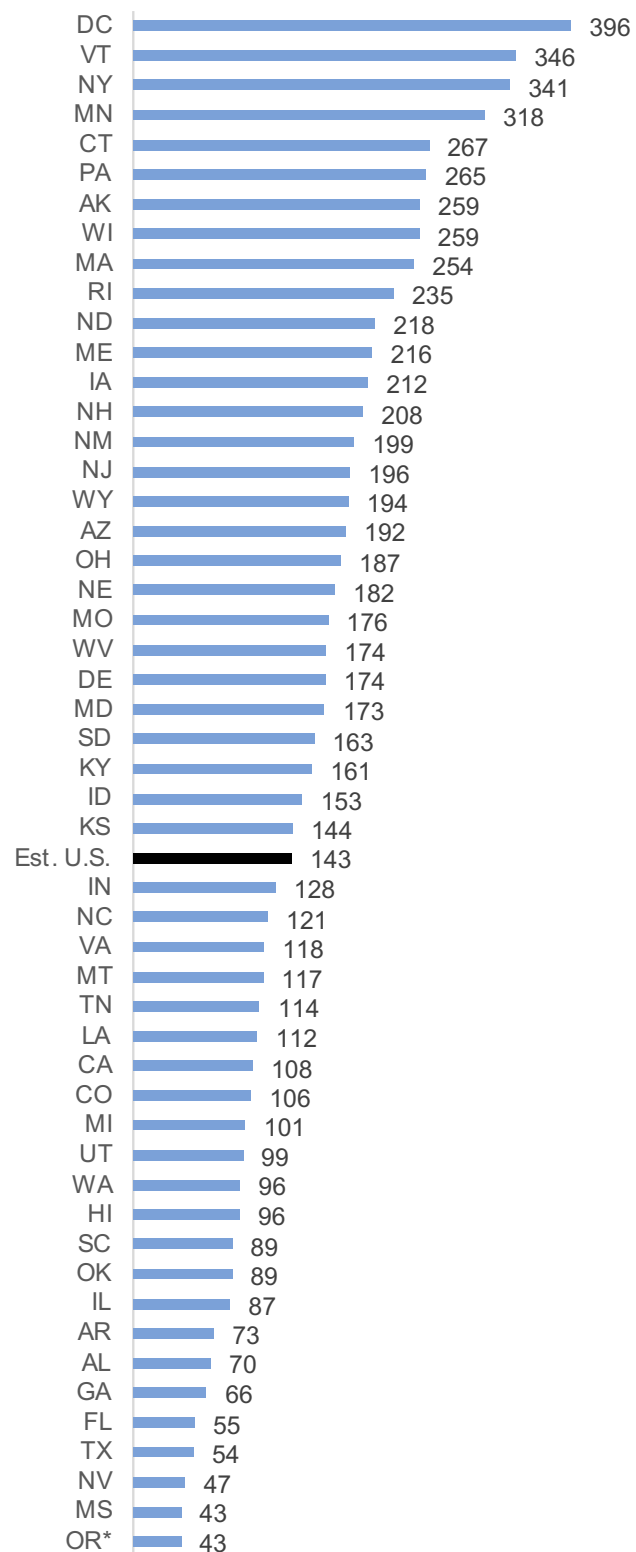


Table 2.7 Medicaid Waiver Expenditures and Average per Recipient by Age, Living Arrangement, and State in FY 2020

Setting	Annual Waiver Expenditures (\$)				Average Per Person Expenditures (\$)			
	Family Home		Other Settings		Family Home		Other Settings	
Age	Birth to 21	22 years +	Birth to 21	22 years +	Birth to 21	22 years +	Birth to 21	22 years +
N States	32	29	31	29	30	29	29	29
AL	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
AK	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
AZ	396,745,627	364,764,860	100,760,859	510,450,388	17,943	40,985	96,885	110,272
AR	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
CA	473,597,758	971,810,550	97,329,886	2,715,768,991	8,894	22,981	76,457	83,730
CO	35,253,431	58,802,329	37,043,459	482,102,632	12,015	13,223	65,680	75,683
CT	10,204,400	123,865,846	7,897,564	821,274,693	34,015	28,666	149,011	142,434
DE	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
DC	741,380	50,485,847	2,240,794	225,099,693	46,336	70,708	224,079	190,924
FL	30,601,003	381,441,105	54,993,128	721,929,245	9,167	23,948	58,942	49,950
GA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
HI	9,876,317	64,397,816	1,162,854	64,069,789	19,753	39,703	55,374	70,022
ID	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
IL	35,529,902	296,741,195	37,558,653	748,989,052	22,967	27,408	107,005	67,800
IN	90,312,406	182,686,254	8,363,240	589,389,419 ^e	7,051	17,835	21,281	76,693 ^f
IA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
KS	18,981,509	65,871,148	11,375,796	317,549,461	14,424	26,171	32,135	60,325
KY	197,009,291 ^e	190,113,469 ^e	5,037,798 ^e	334,617,730 ^e	35,951 ^e	35,239 ^e	60,696 ^e	80,767 ^e
LA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
ME	1,043,498	28,398,265	14,150,389	250,743,045	7,454	12,979	58,473	73,424
MD	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MA*	7,494,059	291,965,304	0	1,492,516,791	23,273	102,516	N/A	103,117
MI	183,813,024	149,145,542	32,229,354	654,469,352	20,137	15,902	17,573	24,587
MN*	253,017,455	290,275,592	89,788,865	1,178,848,399	42,205 ^e	51,132 ^e	148,166	98,525
MS	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MO	34,210,261	128,370,213	40,994,947	879,525,597	16,463	23,693	135,297	123,616
MT	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NE*	3,466,358	20,595,862	21,378,461	311,433,764	15,203	33,931	135,307	80,287
NV	1,017,119	12,059,334	11,024,968	120,891,239	15,181	14,724	81,066	81,081
NH	0	DNF	DNF	DNF	N/A	DNF	DNF	DNF
NJ	0	DNF	0	DNF	N/A	DNF	N/A	DNF
NM	17,103,805	248,719,400	2,013,801	154,295,445	41,514	70,559	143,843	157,124
NY	407,251,928	1,027,579,061	77,891,304	5,366,669,208	19,665 ^e	35,245 ^e	86,932	140,485
NC	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
ND*	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
OH	89,758,008	567,025,974	49,389,413	1,505,632,835	15,858	29,471	71,475	86,481
OK	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
OR*	44,796,520	71,754,353	9,028,167	54,199,307	4,237	6,852	7,612	7,511
PA	41,188,103	663,070,495	76,274,025	2,665,491,801	11,609	40,468	114,698	160,388
RI	14,115	51,056,996	53,995	207,019,612	4,705	30,211	26,998	91,359
SC	90,999,504	206,880,405	2,664,400	155,273,028	40,991	40,991	40,991	40,991
SD	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
TN	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
TX	92,831,039	308,383,568	88,863,003	1,078,452,659	33,917	37,932	42,195	43,026
UT*	8,154,743	23,892,270	42,825,354	248,087,530	19,370	22,184	49,281	74,546
VT*	8,902,349	44,591,352	12,216,169	156,694,051	47,606 ^e	47,999 ^e	86,029 ^e	79,218 ^f
VA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
WA*	10,235,128	50,297,505	25,872,690	670,127,630	1,944	7,386	65,335	86,928
WV	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
WI	74,239,108	DNF	5,710,141	DNF	10,207	DNF	38,845	DNF
WY	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
Reported total	2,668,389,147	6,935,041,909	966,133,478	24,681,612,385				
Estimated US Total					14,659	29,243	55,076	85,189

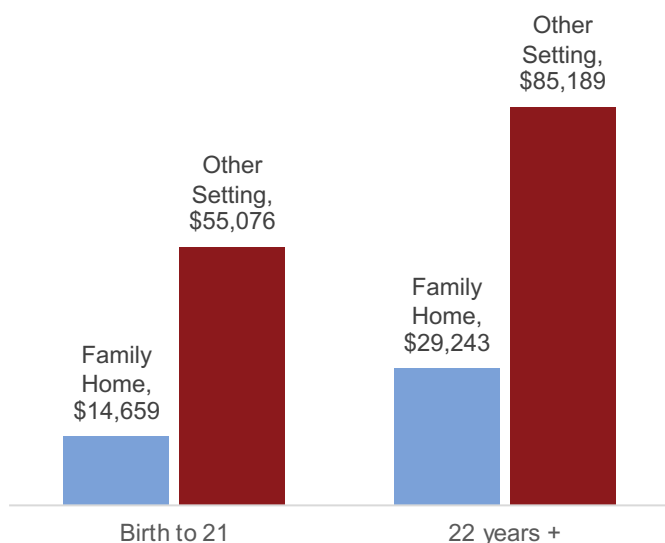
DNF Did not furnish. N/A Not applicable. PD Partial data. * Missing values (DNF) assumed to be zero. ^e Other date (data from previous or next year). ^f Estimate. [†] Total is larger than component parts due to unknown settings or sizes. [‡] One or more component value imputed by RISP staff. * See state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

total). Estimated average per person expenditures are based only on states providing recipient and expenditure data by living arrangement and age.

Estimated average annual per person Medicaid Waiver expenditures for recipients living with a family member were \$14,659 for children and youth through age 21 and \$29,243 for adults (see **Figure 2.7**). Estimated averages for recipients living in other settings were \$55,076 for children and youth through age 21 and \$85,189 for adults.

Medicaid Waiver expenditures are higher for adults than for children in part because children with disabilities are entitled free and appropriate educational services authorized under the Individuals with Disabilities Education Act while there are no comparable entitlement programs for adults. Furthermore, expenditures for adults include resources to pay for employment and day training and habilitation. Average per person expenditures were lower for recipients living with a family member than for recipients living in other settings in part because of unreimbursed hours of support provided by family caregivers to family members with IDD living with them would be financed with public dollars if those individuals lived in other settings.

Figure 2.7 Estimated Average Annual Per Person Medicaid Waiver Expenditures by Age and Living Arrangement in FY 2020



These US estimates are based on 32 states providing complete age and residential setting breakdowns for Waiver recipients and expenditures.

Estimated annual average per recipient Medicaid HCBS Waiver expenditures for children and youth through age 21 living with a family member ranged from \$1,944 in Washington to \$47,606 in Vermont. Expenditures for recipients 21 years or younger living in other settings ranged from \$7,612 in Oregon to \$224,079 in the District of Columbia. For adults 22 years or older living with a family member, the averages ranged from \$6,852 in Oregon to \$102,516 in Massachusetts. Finally, for adults living in other settings, average expenditures ranged from \$7,511 in Oregon to \$190,924 in the District of Columbia.

State variations are due in part to state differences in the array of service options and variations in the frequency and intensity of services available to individuals.

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

While the overwhelming majority of LTSS recipients with IDD receive Medicaid Waiver-funded supports, Medicaid continues to offer an institutional option for people with IDD through the Medicaid ICF/IID program. All ICF/IID facilities are considered institutions under the 2014 Medicaid HCBS final rule. However, unlike Medicaid Waiver-funded services, access to ICF/IID services is an entitlement for people with IDD who meet level-of-care eligibility criteria in the 48 states (all states except Michigan, Montana, and Oregon) that opt to include ICF/IID services in their Medicaid State Plan. Alaska does not operate any ICF/IIDs, but they do send some people with IDD to ICF/IIDs in other states.

ICF/IIDs by Size and Type of Operation

There were an estimated 5,814 ICF/IIDs on June 30, 2020 (see **Table 2.8**). Alaska, Michigan, Montana, and Oregon reported no ICF/IIDs. Ten states reported having only one or two ICF/IID facilities. States with the most ICF/IID facilities were California (1,108), Texas (790), and Louisiana (529). Seventeen states reported no state-run ICF/IIDs. Seven states reported no non-state ICF/IIDs.

Of the 5,812 ICF/IIDs, 230 (4%) were state-run, and 5,584 (96%) ICF/IIDs were run by a non-state

Table 2.8 Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) by Size, Type of Operation, and State on June 30, 2020

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	46	47	46	50	46	47	46	50
AL	0	0	0	0	0	2	0	2 ⁱ	0	2	0	2
AK	0	0	0	0	0 ⁱ	0 ⁱ	0 ⁱ	0 ^s	0	0	0	0
AZ	0	0	0	0	0	0	1	1	0	0	1	1
AR	0	0	5	5	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
CA	3	0	2	5	DNF	2	DNF	1,103	DNF	2	DNF	1,108
CO	3	10	2	15	5	0	0	5	8	10	2	20
CT	1	0	4	5	58	2	0	60	59	2	4	65
DE*	0	0	1	1	0	0	1	1	0	0	2	2
DC	0	0	0	0	61	0	0	61	61	0	0	61
FL	0	0	2	2	38	40 ^o	51	129 ^o	38	40	53	131
GA	0 ⁱ	0 ⁱ	1 ⁱ	1 ^s	0 ⁱ	0 ⁱ	1 ⁱ	1 ^s	0	0	2	2
HI	0	0	0	0	16	1	0	17	16	1	0	17
ID	0	0	1	1	DNF	DNF	DNF	54 ^s	DNF	DNF	DNF	55
IL	0	0	7	7	30	146	29	205	30	146	36	212
IN	0	0	0	0	155	312	2	469	155	312	2	469
IA	0	0	2	2	17	20	16	54	17	20	18	56
KS	0	0	2	2	16	5	0	21	16	5	2	23
KY	0	0	0	0	3	3	8	14	3	3	8	14
LA	0 ⁱ	0 ⁱ	3 ⁱ	3 ⁱ	269 ⁱ	249 ⁱ	8 ⁱ	526 ⁱ	269	249	11	529
ME	0	0	0	0	0	12	3	15	0	12	3	15
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	0	0	0	0	0	0	0	0	0	0	0
MN	0	0	0	0	104	23	8	135	104	23	8	135
MS	4	58	5	67	0	0	6 ⁱ	6	4	58	11	73
MO	0	0	6	6	0	6	1	7	0	6	7	13
MT	0 ⁱ	0	0	0 ⁱ	0 ⁱ	0 ⁱ	0 ⁱ	0	0	0	0	0
NE	0	0	1	1	6	1	2	9	6	1	3	10
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	0	2	2	0	0	7	7
NM	1	0	0	1	33	12	0	45	34	12	0	46
NY	2	3	4	9	79	239	24	342	81	242	28	351
NC	0 ⁱ	0 ⁱ	4 ⁱ	4 ⁱ	DNF	DNF	DNF	330 ^s	DNF	DNF	DNF	334
ND	0	0	1	1	51	19	1	71	51	19	2	72
OH	0	0	8	8	145	212	57	414 ⁱ	145	212	65	422
OK	0	0	0	0	DNF	DNF	DNF	88 ^s	DNF	DNF	DNF	88
OR	0	0	0	0	0	0	0	0	0	0	0	0
PA	0	0	4	4	127	19	17	163	127	19	21	167
RI	0	0	0	0	0	0	1	1	0	0	1	1
SC	0	0	5	5	0	58	0	58	0	58	5	63
SD	0 ⁱ	0 ⁱ	1 ⁱ	1 ^s	0 ⁱ	0 ⁱ	2 ⁱ	2 ^s	0	0	3	3
TN	37	1	0	38	84	47	1	132	121	48	1	170
TX*	2	0	13	15	731	41	3	775	733	41	16	790
UT	0	0	1	1	0 ⁱ	0 ⁱ	15 ⁱ	15 ^s	0	0	16	16
VT*	0	0	0	0	1	0	0	1	1	0	0	1
VA	0	0	1	1	36	25	2	63	36	25	3	64
WA	0	0	4	4	1	0	0	1	1	0	4	5
WV	0	0	0	0	23 ⁱ	43 ⁱ	0 ⁱ	66 ^s	23	43	0	66
WI	0	0	3 ⁱ	3 ⁱ	0	1	2	3	0	1	5	6
WY	0	0	1	1	0	0	0	0	0	0	1	1
Reported US Total	53	72	104	229	2,094	1,540	266	5,474	2,147	1,612	370	5,703
Estimated US Total	53	72	105	230	3,516	1,739	329	5,584	3,569	1,811	434	5,814

DNF Did not furnish. ⁱ Other date (data from previous or next year). ^e Estimate. ^s Other Source (AHCAa CASPER data, 201x). Totals for 16+ state operated may differ those reported on Table 4.10 because Table 4.10 includes state operated facilities not certified as ICF/IID. See State Notes for more information.

entity. All ICF/IIDs in Alabama, Arizona, the District of Columbia, Hawaii, Indiana, Kentucky, Maine, Minnesota, New Hampshire, Oklahoma, Rhode Island, Vermont, and West Virginia were run by a non-state entity. All ICF/IIDs were state-run in Maryland, Massachusetts, and Wyoming.

Overall, 61% of the ICF/IIDs served six or fewer people, 31% served seven to 15 people, and 7% served 16 or more people. Of the state-run ICF/IIDs, 23% served six or fewer people, 31% served seven to 15 people, and 46% served 16 or more people. Of the non-state ICF/IIDs, 63% served six or fewer people, 31% served seven to 15 people and 6% served 16 or more people.

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

LTSS Recipients in ICF/IIDs by Size and Type of Operation

On June 30, 2020, an estimated 64,445 people lived in ICF/IIDs (see **Table 2.9**). Fewer than 100 people lived in ICF/IIDs in 13 states (Alabama, Alaska, Arizona, Hawaii, Maryland, Michigan, Montana, Nevada, New Hampshire, Oregon, Rhode Island, Vermont, and Wyoming). By contrast, more than 2,000 people lived in ICF/IIDs in 11 states: Texas (7,598), California (6,793), Illinois (6,218), Ohio (5,068), Louisiana (4,490), New York (3,838), North Carolina (3,757), Indiana (3,123), Florida (2,645), Pennsylvania (2,419), and Mississippi (2,020).

An estimated 15,919 (25%) people in ICF/IIDs lived in state-run facilities while 48,526 (75%) lived in non-state facilities. An estimated 18,867 (29%) of people in ICF/IIDs lived in settings of one to six people, 16,289 (25%) lived in facilities of seven to 15 people, and 29,329 (46%) lived in settings of 16 or more people. However, 95% of those in state-run settings



Table 2.9 People Living in an ICF/IID by Type of Operation, Setting Size, and State on June 30, 2020

Size	State-Operated				Non-State				Total			
	1-6	7-15	16+	Total	1-6	7-15	16+	Total	1-6	7-15	16+	Total
N States	51	51	51	51	46	47	46	51	46	47	46	51
AL	0	0	0	0	0	22	0	22	0	22	0	22
AK*	0	0	0	0	14 ⁱ	0 ⁱ	0 ⁱ	14	14	0	0	14
AZ*	0	0	0	0	0	0	29	29	0	0	29	29
AR	0	0	883	883	DNF	DNF	DNF	539 ^g	DNF	DNF	DNF	1,422
CA	14	0	244	258	DNF	21	DNF	6,535	DNF	21	DNF	6,793
CO	13	76	51 ^e	140 ^e	24	0	0	24	37	76	51	164
CT	4	0	298	302	300	19	0	319	304	19	298	621
DE*	0	0	48	48	0	0	70 ^e	70	0	0	118	118
DC	0	0	0	0	288	0	0	288	288	0	0	288
FL	0	0	497	497	173	593	1,382	2,148	173	593	1,879	2,645
GA	0 ⁱ	0 ⁱ	101 ⁱ	101 ^s	0 ⁱ	0 ⁱ	113 ⁱ	113 ⁱ	0	0	214	214
HI	0	0	0	0	62	8	0	70	62	8	0	70
ID	0	0	16	16	DNF	DNF	DNF	418	DNF	DNF	DNF	434
IL	0	0	1,613	1,613	147	2,056	2,402	4,605	147	2,056	4,015	6,218
IN	0	0	0	0	774	2,299	50	3,123	774	2,299	50	3,123
IA	0	0	321	321	47	126	231	1,109	47	126	552	1,430
KS	0	0	289	289	59	37	0	96	59	37	289	385
KY	0	0	0	0	17	24	341	382	17	24	341	382
LA	0 ⁱ	0 ⁱ	497 ⁱ	497 ⁱ	1,513 ⁱ	1,949 ⁱ	531 ⁱ	3,993 ⁱ	1,513	1,949	1,028	4,490
ME	0	0	0	0	0	141	50	191	0	141	50	191
MD	0	0	93	93	0	0	0	0	0	0	93	93
MA	0	0	309	309	0	0	0	0	0	0	309	309
MI	0	0	0	0	0	0	0	0	0	0	0	0
MN	0	0	0	0	524	224	207	955	524	224	207	955
MS	22	506	806	1,334	0	0	686 ^e	686 ^e	22	506	1,492	2,020
MO	0	0	287	287	0	46	26	72	0	46	313	359
MT	0 ⁱ	0	0 ⁱ	0 ⁱ	0 ⁱ	0 ⁱ	0 ⁱ	0	0	0	0	0
NE	0	0	97	97	33	8	163	204	33	8	260	301
NV	0	0	37	37	24	0	18	42	24	0	55	79
NH	0	0	0	0	0	0	25	25	0	0	25	25
NJ	0	0	1,193	1,193	0	0	53	53	0	0	1,246	1,246
NM	4	0	0	4	135	104	0	239	139	104	0	243
NY	8	29	234	271	418	2,368	781	3,567	426	2,397	1,015	3,838
NC	0 ⁱ	0 ⁱ	1,099 ^{e,i}	1,059 ^s	DNF	DNF	DNF	2,698 ^s	DNF	DNF	DNF	3,757
ND	0	0	62	62	279	153	31	463	279	153	93	525
OH	0	0	607	607	757	1,643	2,061	4,461	757	1,643	2,668	5,068
OK	0	0	0	0	DNF	DNF	DNF	1,386 ^s	DNF	DNF	DNF	1,386
OR	0	0	0	0	0	0	0	0	0	0	0	0
PA	0	0	680	680	593	150	996	1,739	593	150	1,676	2,419
RI	0	0	0	0	0	0	29	29	0	0	29	29
SC	0	0	648	648	0	472	0	472	0	472	648	1,120
SD	0 ⁱ	0 ⁱ	98 ⁱ	98 ^s	0 ⁱ	0 ⁱ	67 ⁱ	67 ⁱ	0	0	165	165
TN*	146 ^e	2 ^e	0	148 ^s	347 ^e	371 ^s	71 ^e	789 ^e	493	373	71	937
TX*	8	0	2,841	2,849	4,102	454	193	4,749	4,110	454	3,034	7,598
UT	0	0	186	186	0 ⁱ	0 ⁱ	504 ⁱ	504 ^s	0	0	690	690
VT*	0	0	0	0	6	0	0	6	6	0	0	6
VA	0	0	78	78	178	257	112	547	178	257	190	625
WA	0	0 ⁱ	514	514 ⁱ	1	0	0	1	1	0	514	515
WV	0	0	0	0	92 ⁱ	400 ⁱ	0 ⁱ	492 ^s	92	400	0	492
WI	0	0	277	277	0	7	73	80	0	7	350	357
WY	0	0	51	51	0	0	0	0	0	0	51	51
Reported US Total	219	613	15,055	15,847	10,907	13,952	11,295	48,414	11,126	14,565	26,350	64,261
Estimated US Total	219	613	15,127	15,919	18,648	15,676	14,202	48,526	18,867	16,289	29,329	64,445

DNF Did not furnish. d Other date (data from previous or next year). e Estimate. s Source (ACHA CASPER data, 2020) * See state notes in Appendix.

were in settings of 16 or more people compared with 29% of those in non-state settings.

Nearly all the people living in ICF/IIDs of one to six people (99%) or seven to 15 people (96%) were in non-state facilities, while 53% of people living in ICF/IID of 16 or more people lived in a non-state facility.

All people in ICF/IIDs were in settings of 16 or more people in Arizona, Delaware, Georgia, Maryland, Massachusetts, New Hampshire, New Jersey, Rhode Island, South Dakota, Utah, Washington, and Wyoming. Between 75% and 99% of people in ICF/IIDs were in settings of 16 or more people in Kansas, Kentucky, Missouri, Nebraska, and Wisconsin.

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

Until 1981, the ICF/IID was the only Medicaid-funded residential option specifically for people with IDD. Once Medicaid began funding Home and Community-Based Services in 1981, the use of ICF/IIDs began to decline. By June 30, 2020, only 12% of LTSS recipients with IDD who did not live with a family member lived in ICF/IIDs (10% of people in non-state settings, and 64% of people in state-run settings; see **Figure 2.8**). Among people living in non-family settings of six or fewer people, 4% of those in a non-state setting and 24% of those in a state-run setting lived in ICF/IIDs. Among people living in facilities serving seven to 15 people, 35% of those in non-state settings and 15% of those in state-run settings lived in ICF/IIDs. Among people with IDD in facilities of 16 or more people, 68% of those

in non-state settings and 99% of those in state-run settings lived in ICF/IIDs.

ICF/IID Recipients by Age

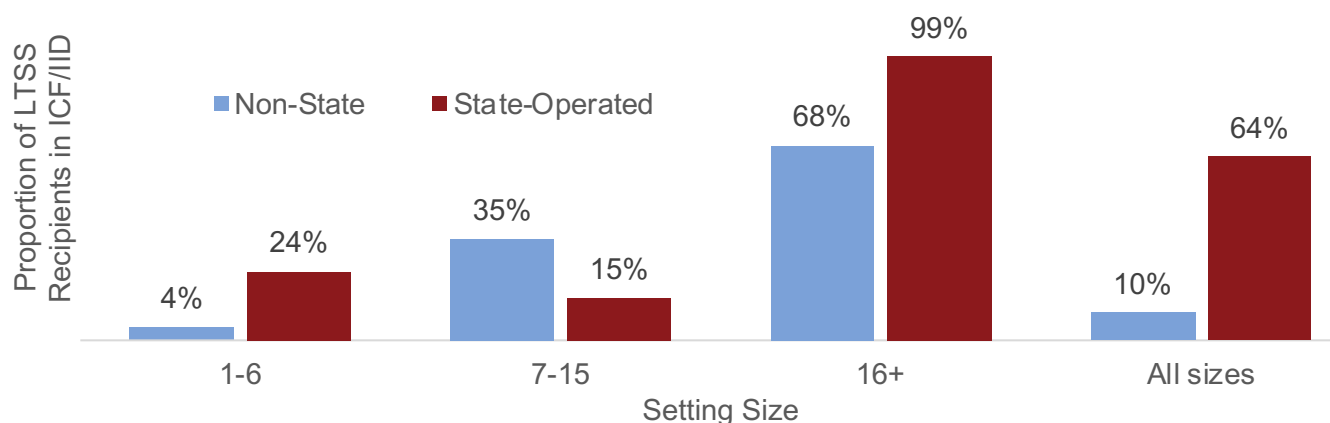
Of the people living in ICF/IIDs in FY 2020, an estimated 4,384 (7%) were 21 years or younger and 60,518 (93%) were 22 years or older (see **Table 2.10**). There were no people 21 years or younger in ICF/IIDs in Alabama, Alaska, Hawaii, Massachusetts, Michigan, Missouri, Montana, New Jersey, Oregon, Vermont, Washington, or Wisconsin. Three percent or fewer ICF/IID recipients were 21 years or younger in Arizona, California, Connecticut, the District of Columbia, Florida, Illinois, Kentucky, and South Carolina. By contrast, 100% of people living in ICF/IIDs in New Hampshire and 59% in Rhode Island were 21 years or younger.

An estimated 20 people with IDD per 100,000 of the U.S. population lived in ICF/IIDs on June 30, 2020 (see **Figure 2.9**). ICF/IID utilization rates ranged from zero in Michigan, Montana, and Oregon to 90 per 100,000 in Louisiana, 59 per 100,000 in North Dakota, and 49 per 100,000 in Illinois. ICF/IID utilization rates averaged 5 per 100,000 for children and youth 21 years or younger and 25 per 100,000 for adults 22 years or older.

ICF/IID EXPENDITURES

Estimated FY 2020 ICF/IID expenditures were \$9.38 billion (see **Table 2.11**). Expenditures ranged

Figure 2.8 Proportion of LTSS Recipients in Non-Family State- or Nonstate-Operated Settings of Various Sizes who Live in an ICF/IID on June 30, 2020



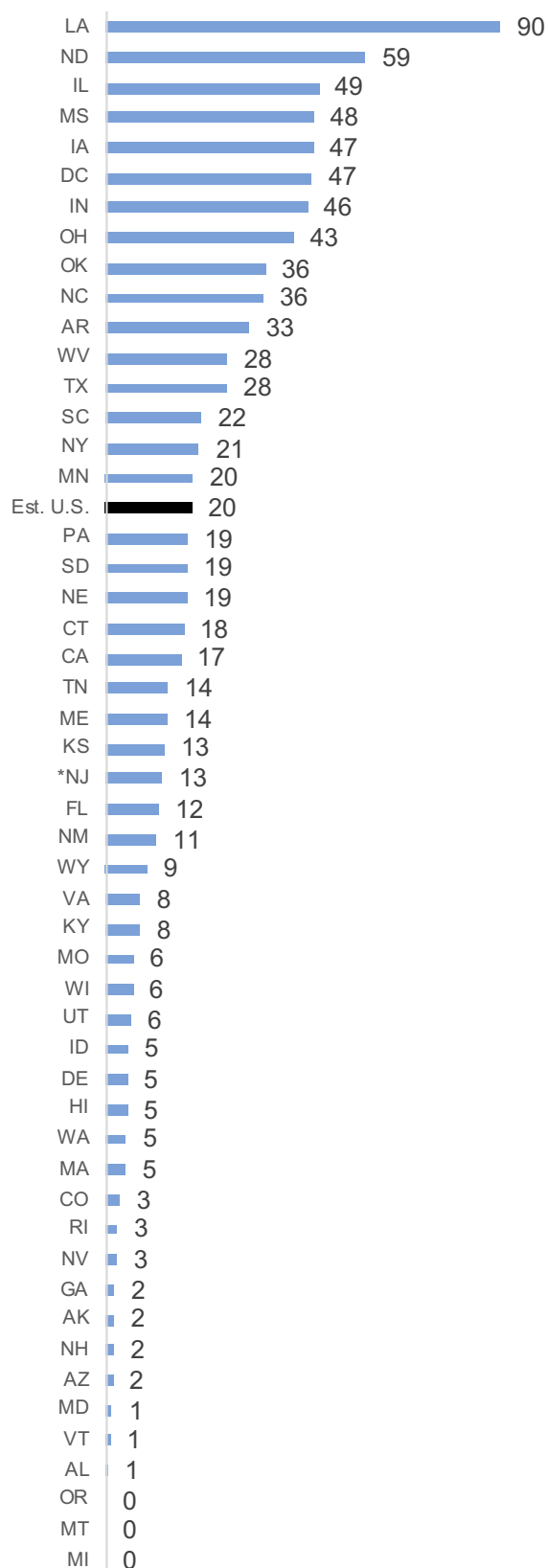
This figure includes people in group homes, ICF/IIDs, host and foster family homes, own home, and IDD "other" settings. It excludes people living with a family member, in a nursing home or psychiatric setting.

Table 2.10 People Living in an ICF/IID Per 100,000 of the Population by Age and State in FY 2020

Age	Population in 100,000s ^a			ICF/IID Residents			ICF/IID Residents per 100k		
	Birth to 21 years	22+ years	All Ages	Birth to 21 years	22+ years	All Ages	Birth to 21 years	22+ years	All Ages
N States	51	51	51	49	49	51	49	49	51
AL	14	36	50	0 ^s	26 ^s	26 ^s	0	1	1
AK*	2	5	7	0 ^j	14 ⁱ	14	0	3	2
AZ	20	51	72	3	108	111	0	2	2
AR*	9	21	30	128	860	988	15	40	33
CA	109	286	395	111	6,617	6,728	1	23	17
CO	16	42	58	16	172	188	1	4	3
CT	9	27	36	4	634	638	0	24	18
DE*	3	7	10	DNF	DNF	48	DNF	DNF	5
DC	2	5	7	3	322	325	2	60	47
FL*	53	163	215	19	2,579	2,598	0	16	12
GA	31	76	107	23 ^s	191 ^s	214 ^s	1	3	2
HI	4	11	15	0	70	70	0	6	5
ID*	6	13	18	16	75	91	3	6	5
IL	35	93	128	206	6,012	6,218	6	65	49
IN	20	48	68	270	2,853	3,123	14	59	46
IA	9	23	32	222	1,290	1,512	24	57	47
KS	9	21	29	33 ^s	361 ⁱ	394	4	18	13
KY*	13	32	45	7	344	351	1	11	8
LA	13	33	47	310 ^s	3,896 ^s	4,206 ^s	23	118	90
ME	3	10	14	10	181	191	3	17	14
MD	17	45	62	4 ^s	87 ^s	91 ^s	0	2	1
MA	18	53	70	0	317	317	0	6	5
MI	27	73	101	0	0	0	0	0	0
MN	16	41	57	48	1,092	1,140	3	27	20
MS*	9	21	30	DNF	DNF	1,407	DNF	DNF	48
MO	17	44	62	0	382	382	0	9	6
MT	3	8	11	0	0	0	0	0	0
NE	6	14	20	39	324	363	7	24	19
NV	8	23	31	5	74	79	1	3	3
NH	3	10	14	25	0	25	8	0	2
NJ*	25	68	93	0	1,196	1,196	0	18	13
NM	6	15	21	17	226	243	3	15	11
NY	52	150	202	514	3,807	4,321	10	25	21
NC	29	76	104	385 ^s	3,372 ^s	3,757 ^s	13	45	36
ND*	2	5	8	102	361	463	44	66	59
OH	32	86	118	439	4,629	5,068	14	54	43
OK	12	28	40	92 ^s	1,349 ^s	1,441 ^s	8	48	36
OR	11	32	42	0	0	0	0	0	0
PA	34	96	130	96	2,338	2,434	3	24	19
RI	3	8	11	17	12	29	6	1	3
SC	14	37	51	17	1,103	1,120	1	30	22
SD	3	6	9	76 ^s	89 ^s	165 ^s	29	14	19
TN	19	50	69	47	934	981	2	19	14
TX	90	202	291	414	7,651	8,065	5	38	28
UT*	12	21	33	16	170	186	1	8	6
VT	2	5	6	0	6	6	0	1	1
VA	24	62	86	112	561	673	5	9	8
WA	21	56	77	0	358	358	0	6	5
WV	5	13	18	70 ^s	428 ^s	498 ^s	15	32	28
WI	16	43	59	0	357	357	0	8	6
WY	2	4	6	2	52	54	1	13	9
Reported US Total	915	2,400	3,314	3,918	57,880	63,253	4	24	19
Estimated US Total	915	2,400	3,314	4,384	60,518	64,902	5	25	20

DNF Did not furnish. ^aSource U.S. Census Bureau, Population Division (2019) for population data; ⁱ Other date (data from previous or next year). ^s Estimate. ^hACHA, 2019 CASPER data for ICF/IID residents. * See state notes in Appendix. Number of ICF/IID recipients by age includes all fiscal year ICF/IID recipients and may differ from estimates by size and type which are based on data as of June 30.

Figure 2.9 ICF/IID Residents per 100,000 of the Population by State in FY 2020



from \$783,182 in Arizona to \$1.1 billion in Texas. Delaware, Rhode Island, and Utah only reported expenditures for people in state-run ICF/IID. North Dakota only reported ICF/IID expenditures for people in non-state ICF/IID.

Per Person ICF/IID Expenditures

Estimated FY 2020 per person ICF/IID expenditures averaged \$144,469 and ranged from \$7,056 in Arizona to \$390,833 in Delaware. Ten states reported per person annual ICF/IID expenditures of less than \$100,000. Seven states (Delaware, Kentucky, Massachusetts, New Jersey, Washington, Wisconsin, and Wyoming) reported per person annual ICF/IID expenditures of more than \$300,000. Most expenditures for people in ICF/IID settings in Arizona were captured under their 1115 Demonstration as Waiver expenditures.

Expenditures per State Resident

Annual ICF/IID expenditures averaged \$28 per state resident nationally and ranged from less than \$1 per state resident in Alabama, Arizona, Michigan, Montana, and Oregon to \$138 per state resident in the District of Columbia. Eleven additional states reported average expenditures of \$1 to \$10 per state resident, including Alaska, Colorado, Georgia, Hawaii, Idaho, Kansas, Maryland, Nevada, New Hampshire, Rhode Island, and Vermont. Besides the District of Columbia, only North Dakota (\$126) reported expenditures exceeding \$100 per state resident.

Expenditures by Age

For FY 2020, 39 states reported ICF/IID recipient and expenditure data for people 21 years or younger and 22 years or older. Average per person expenditures in reporting states were \$129,404 for people 21 years or younger and \$150,112 for people 22 years or older (see **Table 2.12**). Among states with 10 or more ICF/IID recipients 21 years or younger, average per person expenditures ranged from \$53,637 in Iowa to \$266,600 in Colorado. Amongst states reporting 10 or more ICF/IID recipients 22 years or older, annual per person expenditures ranged from \$6,713 in Arizona to \$387,476 in Kentucky.

Table 2.11 Estimated ICF/IID Expenditures, Recipients, Expenditure Per Person, and Expenditures Per State Resident by State in Fiscal Year 2020

State	ICF/IID Recipients	ICF/IID Expenditures	Expenditures per ICF/IID Recipient	State Population (100,000) ^o	Expenditures per State Resident (\$)
N States	51	51	48	51	51
AL	26 ⁱ	2,294,487 ^s	88,250	50	0
AK	14	2,969,922	212,137	7	4
AZ*	111	783,182	7,056	72	0
AR	988	193,142,365	195,488	30	64
CA	6,728	513,066,085	76,258	395	13
CO	188	51,990,548	276,545	58	9
CT	638	164,783,662	258,282	36	46
DE*	48	18,759,997	390,833	10	19
DC	325	95,056,999	292,483	7	138
FL	2,598	347,302,426	133,681	215	16
GA	214 ⁱ	37,088,431 ^s	173,310	107	3
HI	70	8,582,055	122,601	15	6
ID*	91	8,862,060	97,385	18	5
IL	6,218	684,214,893	110,038	128	53
IN	3,123	279,015,815	89,342	68	41
IA	1,512	139,308,911	92,136	32	44
KS	394	26,897,505	68,268	29	9
KY	351	135,711,908	386,644	45	30
LA	4,206 ⁱ	402,790,168 ^s	95,766	47	86
ME	191	26,977,602	141,244	14	20
MD	91 ^s	15,256,229 ^s	167,651	62	2
MA	317	105,080,321	331,484	70	15
MI	0	0	N/A	101	0
MN	1,140	100,355,457	88,031	57	18
MS*	1,407	171,026,640	121,554	30	58
MO	382	81,735,110	213,966	62	13
MT	0	0	N/A	11	0
NE	363	62,414,452	171,941	20	32
NV	79	17,741,145	224,571	31	6
NH	25	4,128,098	165,124	14	3
NJ*	1,196	429,271,845	358,923	93	46
NM	243	31,326,680	128,916	21	15
NY	4,321	905,397,822	209,534	202	45
NC	3,757 ⁱ	568,064,638 ⁱ	138,182	104	54
ND*	463	98,413,294	212,556	8	126
OH	5,068	734,569,207	144,943	118	62
OK	1,441 ^s	94,523,939 ^s	65,596	40	24
OR	0	0	N/A	42	0
PA	2,434	596,650,525	245,132	130	46
RI*	29	7,801,961	269,033	11	7
SC	1,120	159,035,421	141,996	51	31
SD	165 ⁱ	35,677,899 ^s	216,230	9	40
TN	981	199,107,553	202,964	69	29
TX	8,065	1,103,849,697	136,869	291	38
UT*	186	43,336,275	232,991	33	13
VT	6	1,389,083	231,514	6	2
VA	673	165,774,322 ^s	246,321	86	19
WA	358	113,000,000 ^e	315,642	77	15
WV	498 ⁱ	67,713,291	135,970	18	38
WI	357	123,847,712	346,912	59	21
WY	54	19,389,515 ^e	359,065	6	34
Reported US Total	63,253	9,195,477,151	145,376	3,314	28
Estimated US Total	64,902	9,376,357,677	144,469	3,314	28

ⁱ Includes non-state operated ICF/IIDs only ^s Includes only state operated ICF/IIDs. ^e Other date (data from previous or next year). ^o Estimate. ⁱ One or more component value imputed by RISP staff. DNF Did not furnish. ^s Other Sources: U.S. Census Bureau, Population Division (2018); ACHA (2018a) ICF/IID recipients; Murray et al, (2023) ICF/IID expenditures. *See state notes in Appendix.

Table 2.12 ICF/IID Recipients, Expenditures and Expenditures Per Person by Age and State in Fiscal Year 2020

State	ICF/IID Recipients		Annual Expenditures \$		Expenditures Per Person \$	
	Birth to 21 years	22 years +	Birth to 21 years	22 years +	Birth to 21 years	22 years +
N States	49	49	39	39	27	35
AL	0 ^s	26 ^s	0 ⁱ	2,294,487 ^j	N/A	88,250 ⁱ
AK	0	14	0 ⁱ	2,969,922 ^j	N/A	212,137 ^j
AZ*	3	108	58,140	725,042	19,380	6,713
AR	128	860	21,146,333	171,996,033	165,206	199,995
CA	111	6,617	7,010,958	506,055,127	63,162	76,478
CO	16	172	4,265,606	47,724,942	266,600	277,471
CT	4	634	17,782	164,765,880	4,445	259,883
DE	DNF	DNF	DNF	DNF	DNF	DNF
DC	3	322	0	95,056,999	0	295,208
FL	19	2,579	2,360,558	344,941,867	124,240	133,750
GA	23 ^s	191 ^s	DNF	DNF	DNF	DNF
HI	0	70	0	8,582,055	N/A	122,601
ID*	16	75	1,490,193	7,371,867	93,137	98,292
IL	206	6,012	26,133,462	658,081,431	126,861	109,461
IN	270	2,853	26,355,396	252,660,419	97,613	88,560
IA	222	1,290	11,907,392	127,401,519	53,637	98,761
KS	33	361	DNF	DNF	DNF	DNF
KY*	7	344	2,420,289	133,291,618	345,756	387,476
LA	310 ^s	3,896 ^s	DNF	DNF	DNF	DNF
ME	10	181	1,799,291	25,178,311	179,929	139,107
MD	4 ^s	87 ^s	DNF	DNF	DNF	DNF
MA	0	317	0	105,080,321	N/A	331,484
MI	0	0	0	0	N/A	N/A
MN	48	1,092	4,484,496	95,870,960	93,427	87,794
MS	DNF	DNF	DNF	DNF	DNF	DNF
MO	0	382	0	81,735,110	N/A	213,966
MT	0	0	0	0	N/A	N/A
NE	39	324	4,591,122	57,823,330	117,721	178,467
NV	5	74	777,115	16,964,030	155,423	229,244
NH	25	0	4,128,098	0	165,124	N/A
NJ*	0	1,196	0	429,271,845	N/A	358,923
NM	17	226	2,175,398	29,151,282	127,965	128,988
NY	514	3,807	95,226,334	810,171,488	185,265	212,811
NC	385 ^s	3,372 ^s	DNF	DNF	DNF	DNF
ND*	102	361	DNF	DNF	DNF	DNF
OH	439	4,629	64,962,925	669,606,282	147,979	144,655
OK	92 ^s	1,349 ^s	DNF	DNF	DNF	DNF
OR	0	0	0	0	N/A	N/A
PA	96	2,338	18,206,752	578,443,773	189,654	247,410
RI	17	12	4,208,101	3,593,860	247,535	299,488
SC	17	1,103	2,385,531	156,649,890	140,325	142,022
SD	76 ^s	89 ^s	DNF	DNF	DNF	DNF
TN	47	934	6,781,544	192,326,009	144,288	205,917
TX	414	7,651	55,263,239	1,048,586,458	133,486	137,052
UT*	16	170	3,333,560	40,002,715	208,347	235,310
VT	0	6	0	1,389,083	N/A	231,514
VA	112	561	DNF	DNF	DNF	DNF
WA	0	358	0	113,000,000 ^e	N/A	315,642 ^e
WV	70 ^s	428 ^s	DNF	DNF	DNF	DNF
WI	0	357	0	123,847,712	N/A	346,912
WY	2	52	718,130 ^e	18,671,385	359,065 ^e	359,065
Reported Total	3,918	57,880	372,207,745	7,121,283,052		
Estimated US Total	4,384	60,518	371,388,156	7,128,496,811	129,404	150,112

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

MEDICAID WAIVER AND ICF/IID RECIPIENTS AND EXPENDITURES

Total estimated combined Medicaid Waiver and ICF/IID expenditures for 1,019,216 recipients were \$56.8 billion in FY 2020 (see [Table 2.13](#)). An estimated 94% of combined recipients received Medicaid Waiver-funded Home and Community-Based Supports while 6% received supports while living in an ICF/IID (see [Table 2.13](#) and [Figure 2.10](#)). In 41 of the 51 states, Medicaid HCBS Waiver recipients were 90% or more of the combined recipients. Exceptions were Mississippi (66% were HCBS Waiver recipients), Louisiana (75%), Oklahoma (78%), Illinois (79%), Arkansas (81%), Texas (83%), the District of Columbia (85%), North Carolina (89%), and Ohio (89%).

An estimated 83% of the combined expenditures for FY 2020 were for Medicaid HCBS Waiver recipients while 17% were for ICF/IID recipients. Twenty-two states reported that 90% or more of their combined expenditures were for HCBS Waiver recipients. Those states were Alabama, Alaska, Arizona, Colorado,

Figure 2.10 Distribution of ICF/IID and Waiver Expenditures and Recipients in FY 2020

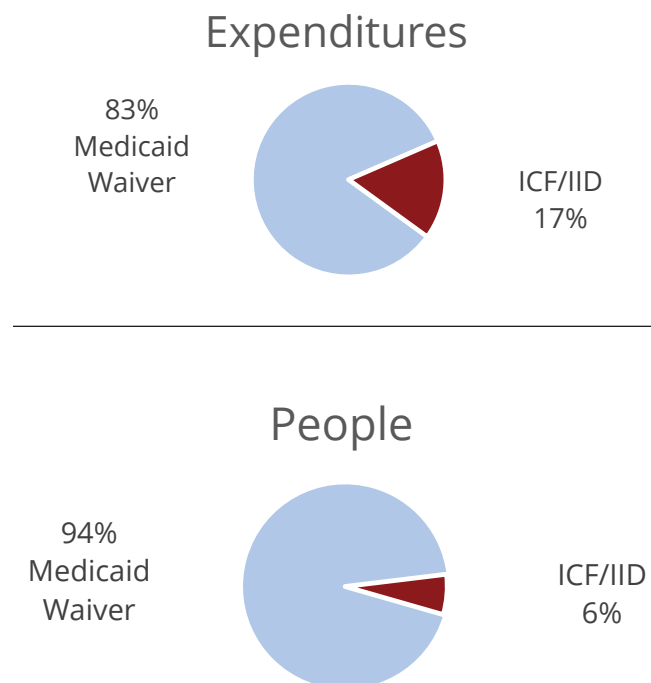


Table 2.13 ICF/IID and Medicaid Waiver Recipients and Expenditures Total and Percent by Funding Authority and State in FY 2020

State	Total ICF/IID + Waiver		% of Recipients		% of Expenditures	
	Recipients	Expenditures (\$)	Waiver	ICF/IID	Waiver	ICF/IID
N States	49	51	49	49	51	51
AL	6,070	353,017,243	100%	0%	99%	1%
AK	2,567	192,832,909	99%	1%	98%	2%
AZ*	36,253	1,373,504,916	100%	0%	100%	0%
AR	5,199	412,062,828	81%	19%	53%	47%
CA	135,971	4,771,573,271	95%	5%	89%	11%
CO	13,962	665,192,398	99%	1%	92%	8%
CT	11,376	1,128,026,165	94%	6%	85%	15%
DE	1,890	190,517,357	97%	3%	90%	10%
DC	2,193	367,909,605	85%	15%	74%	26%
FL	37,250	1,536,266,907	93%	7%	77%	23%
GA	13,895	747,514,611	98%	2%	95%	5%
HI	3,128	148,088,830	98%	2%	94%	6%
ID*	7,900	289,579,995	99%	1%	97%	3%
IL	29,989	1,802,964,787	79%	21%	62%	38%
IN	34,253	1,149,767,134	91%	9%	76%	24%
IA	25,310	815,466,686	94%	6%	83%	17%
KS	9,845	449,672,836	96%	4%	94%	6%
KY*	15,452	862,490,916	98%	2%	84%	16%
LA	17,062	923,929,700	75%	25%	56%	44%
ME	5,135	321,311,627	96%	4%	92%	8%
MD	15,784	1,082,854,545	99%	1%	99%	1%
MA	17,181	1,889,380,083	98%	2%	94%	6%
MI	46,960	1,019,657,272	100%	0%	100%	0%
MN	25,383	1,912,285,768	96%	4%	95%	5%
MS	4,166	298,176,996	66%	34%	43%	57%
MO	15,296	1,164,836,127	98%	2%	93%	7%
MT	2,604	126,789,326	100%	0%	100%	0%
NE	5,235	419,288,897	93%	7%	85%	15%
NV	2,591	162,733,805	97%	3%	89%	11%
NH	6,560	290,101,861	100%	0%	99%	1%
NJ*	22,821	2,246,969,407	95%	5%	81%	19%
NM	5,176	453,459,131	95%	5%	93%	7%
NY	95,137	7,784,754,478	95%	5%	88%	12%
NC	33,597	1,835,596,930	89%	11%	69%	31%
ND*	5,709	268,593,088	92%	8%	63%	37%
OH	48,069	2,946,375,437	89%	11%	75%	25%
OK	6,702	446,315,287	78%	22%	79%	21%
OR	29,446	181,631,182	100%	0%	100%	0%
PA	39,651	4,042,674,949	94%	6%	85%	15%
RI	3,990	265,946,678	99%	1%	97%	3%
SC	12,240	614,852,758	91%	9%	74%	26%
SD	DNF	180,368,015	DNF	DNF	80%	20%
TN	11,699	986,942,600	92%	8%	80%	20%
TX	47,140	2,684,080,739	83%	17%	59%	41%
UT*	5,881	366,296,171	97%	3%	88%	12%
VT	3,242	223,793,004	100%	0%	99%	1%
VA	15,507	1,183,417,008	96%	4%	86%	14%
WA	20,230	855,622,039	98%	2%	87%	13%
WV	DNF	380,113,614	DNF	DNF	82%	18%
WI	40,717	1,648,048,717	99%	1%	92%	8%
WY	2,471	131,417,782	98%	2%	85%	15%
Reported Total	1,006,548	56,595,064,414	94%	6%	84%	16%
Estimated US Total	1,019,216	56,775,944,941	94%	6%	83%	17%

^a Other date (data from previous or next year). ^e Estimate. ^f Sum of setting size data substituted for reported value. ^g Source ACHA (2017a) * See state notes in Appendix. Medicaid Waiver authorities include 1115, 1915 (a), 1915 (a/c), 1915 (b), 1915 (b/c) and 1915 (c).

Delaware, Georgia, Hawaii, Idaho, Kansas, Maine, Maryland, Massachusetts, Michigan, Minnesota, Missouri, Montana, New Hampshire, New Mexico, Oregon, Rhode Island, Vermont, and Wisconsin.

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

Living arrangements varied depending on age and Medicaid funding authority (see **Figure 2.11**). Across all funding authorities and setting types, adults outnumbered children. Overall, 25% of all HCBS Waiver recipients and 7% of ICF/IID recipients were children. Amongst HCBS Waiver recipients, however, children comprised 41% of those living with a family

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

Of the children who were HCBS Waiver recipients, 90% lived with a family member. Of the adults who were HCBS Waiver recipients, 45% lived with a family member and 55% lived in another type of setting.

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

Average annual per person expenditures varied by both age and living arrangement (see **Figure 2.12**). Across all funding authorities and setting types,

Figure 2.11 Estimated Medicaid LTSS Recipients with IDD by Age, Funding Authority and Living Arrangement in FY 2020

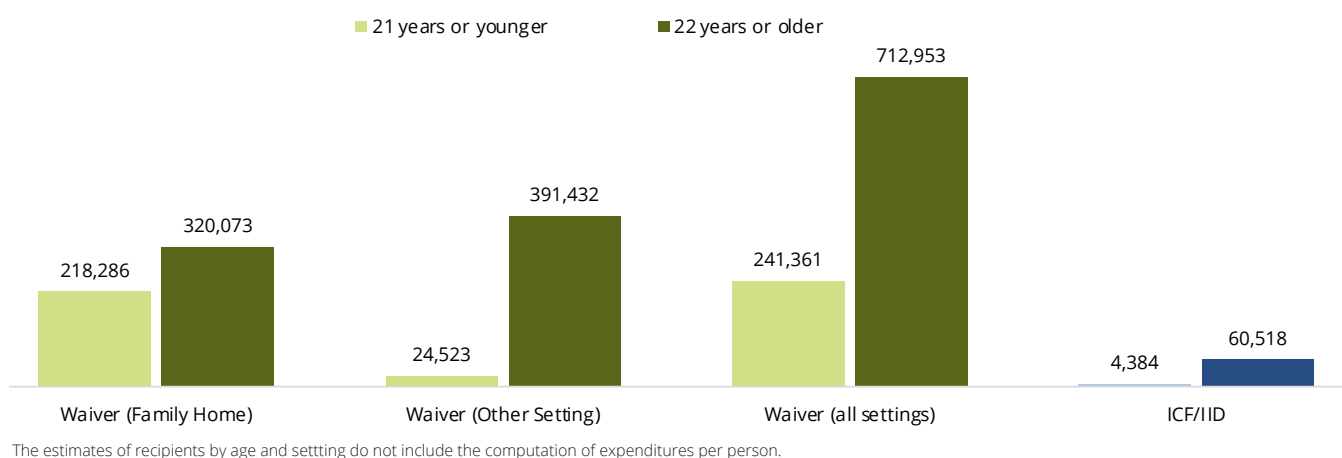
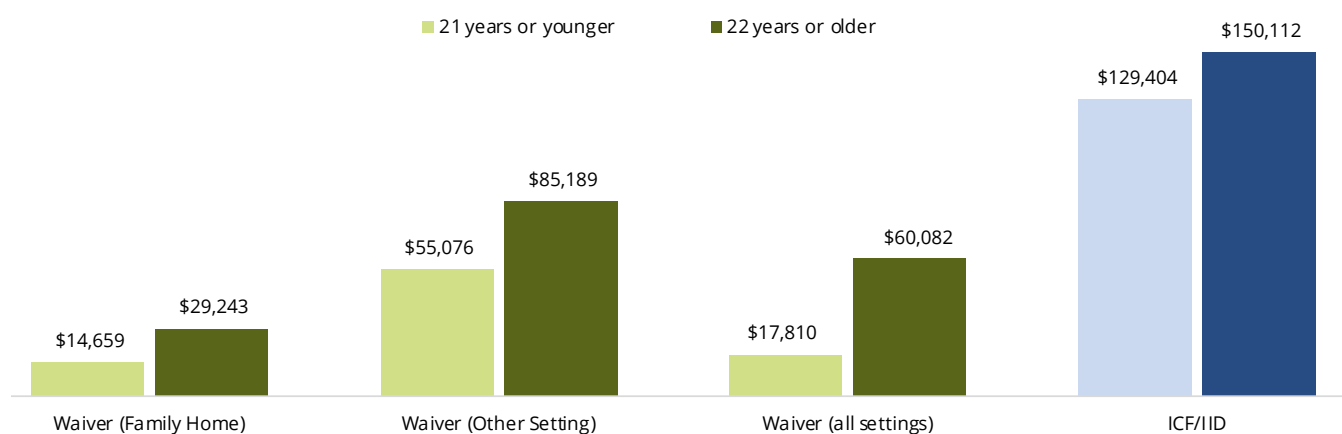


Figure 2.12 Estimated Annual per Person Medicaid Expenditures by Age, Funding Authority, and Living Arrangement in FY 2020



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

average expenditures were lower for children than for adults. Average annual per person expenditures for ICF/IID settings were \$135,756 for children compared with \$151,563 for adults. Across HCBS waiver settings, average per person expenditures were \$17,931 for children and \$60,191 for adults.

Average annual HCBS Waiver expenditures for people living with family (\$15,374 for children and \$30,494 for adults) were lower than those for people living in any other setting (\$59,971 for children and \$93,670 for adults). Average annual expenditures were lower for children than adults in part because children are entitled to a free appropriate public education paid for by other sources.

Annual per person expenditures for ICF/IID residents are higher than for Medicaid Waiver recipients for several reasons. For example, ICF/IID services are offered 24 hours per day every day for all recipients. The hours of service HCBS Waiver recipients get are based on their individualized service plan and for many are less than that. The benefit package for people living in an ICF/IID is fixed whereas the services provided to people getting HCBS Waiver-funded services

are individualized based on the person's needs. Other reasons for differences include that ICF/IID expenditures include room and board costs and some medical services that are not covered for HCBS recipients. By design, Medicaid HCBS Waivers cannot be used to fund room and board expenses. Waiver recipients live with family members or have their room and board expenses covered by SSI, state funds, their own income, and/or other resources.

Medicaid Expenditures and Benefits by State

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

Federal Medicaid Expenditures

Federal Medicaid reimbursement rates vary by states based on factors such as state wealth. The Federal Medicaid Assistance Percentage (FMAP) is the proportion of Medicaid expenditures paid by



Table 2.14a FY 2020 Medicaid Expenditures for People with IDD, Federal Matching Percentage, and Federal Share by Funding Authority and State

State	Total FY 2020 Expenditures			Federal Matching Percentage (%) ¹	Federal Share of Total Expenditures (\$)		
	Waiver (\$)	ICF/IID (\$)	Combined		Waiver	ICF/IID	Combined
N States	51	51	51	51	51	51	51
AL	350,722,756 ^d	2,294,487 ^e	353,017,243	78%	274,159,978	1,793,600	275,953,579
AK	189,862,987	2,969,922	192,832,909	56%	106,702,999	1,669,096	108,372,095
AZ	1,372,721,734	783,182	1,373,504,916	76%	1,046,288,505	596,941	1,046,885,447
AR	218,920,463	193,142,365	412,062,828	78%	169,926,063	149,917,104	319,843,167
CA	4,258,507,186	513,066,085	4,771,573,271	56%	2,393,281,039	288,343,140	2,681,624,178
CO	613,201,850	51,990,548	665,192,398	56%	344,619,440	29,218,688	373,838,128
CT	963,242,504	164,783,662	1,128,026,165	56%	541,342,287	92,608,418	633,950,705
DE	171,757,360	18,759,997	190,517,357	64%	110,027,765	12,017,654	122,045,419
DC	272,852,606	95,056,999	367,909,605	76%	207,913,686	72,433,433	280,347,119
FL	1,188,964,481	347,302,426	1,536,266,907	68%	804,572,264	235,019,551	1,039,591,816
GA	710,426,180 ^d	37,088,431 ^e	747,514,611	74%	522,163,242	27,259,997	549,423,239
HI	139,506,775	8,582,055	148,088,830	60%	83,243,693	5,120,912	88,364,605
ID	280,717,935	8,862,060	289,579,995	77%	214,861,507	6,783,021	221,644,528
IL	1,118,749,894	684,214,893	1,802,964,787	56%	630,303,690	385,486,671	1,015,790,361
IN	870,751,319	279,015,815	1,149,767,134	72%	627,289,250	201,002,993	828,292,243
IA	676,157,775	139,308,911	815,466,686	67%	455,730,340	93,894,206	549,624,546
KS	422,775,331	26,897,505	449,672,836	65%	276,325,956	17,580,209	293,906,166
KY	726,779,008	135,711,908	862,490,916	78%	567,032,982	105,882,430	672,915,412
LA	521,139,532 ^d	402,790,168 ^e	923,929,700	73%	380,744,542	294,278,497	675,023,039
ME	294,334,026	26,977,602	321,311,627	70%	206,033,818	18,884,321	224,918,139
MD	1,067,598,316	15,256,229 ^e	1,082,854,545	56%	599,990,253	8,574,001	608,564,254
MA	1,784,299,762	105,080,321	1,889,380,083	56%	1,002,776,466	59,055,140	1,061,831,607
MI	1,019,657,272	0	1,019,657,272	70%	716,411,199	0	716,411,199
MN	1,811,930,311	100,355,457	1,912,285,768	56%	1,018,304,835	56,399,767	1,074,704,602
MS	127,150,356	171,026,640	298,176,996	83%	105,763,666	142,259,959	248,023,625
MO	1,083,101,017	81,735,110	1,164,836,127	72%	778,208,081	58,726,677	836,934,757
MT	126,789,326	0	126,789,326	71%	89,995,063	0	89,995,063
NE	356,874,445	62,414,452	419,288,897	61%	217,407,912	38,022,884	255,430,796
NV	144,992,660	17,741,145	162,733,805	70%	101,683,352	12,441,865	114,125,217
NH	285,973,763	4,128,098	290,101,861	56%	160,717,255	2,319,991	163,037,246
NJ	1,817,697,562	429,271,845	2,246,969,407	56%	1,021,546,030	241,250,777	1,262,796,807
NM	422,132,451	31,326,680	453,459,131	79%	333,104,717	24,719,883	357,824,600
NY	6,879,356,656	905,397,822	7,784,754,478	56%	3,866,198,441	508,833,576	4,375,032,017
NC	1,267,532,292	568,064,638	1,835,596,930	73%	928,213,898	415,993,734	1,344,207,632
ND	170,179,794	98,413,294	268,593,088	56%	95,726,134	55,357,478	151,083,612
OH	2,211,806,230	734,569,207	2,946,375,437	69%	1,531,012,273	508,468,805	2,039,481,078
OK	351,791,348	94,523,939 ^e	446,315,287	72%	254,063,712	68,265,189	322,328,900
OR	181,631,182	0	181,631,182	67%	122,473,906	0	122,473,906
PA	3,446,024,424	596,650,525	4,042,674,949	58%	2,014,201,276	348,742,232	2,362,943,508
RI	258,144,717	7,801,961	265,946,678	59%	152,692,600	4,614,860	157,307,460
SC	455,817,337	159,035,421	614,852,758	77%	350,523,532	122,298,239	472,821,771
SD	144,690,116 ^d	35,677,899 ^e	180,368,015	64%	92,341,232	22,769,635	115,110,867
TN	787,835,047	199,107,553	986,942,600	71%	562,593,007	142,182,703	704,775,710
TX	1,580,231,042	1,103,849,697	2,684,080,739	67%	1,060,177,006	740,572,762	1,800,749,768
UT	322,959,896	43,336,275	366,296,171	74%	240,249,867	32,237,855	272,487,721
VT	222,403,921	1,389,083	223,793,004	60%	133,575,795	834,283	134,410,078
VA	1,017,642,686 ^d	165,774,322 ^e	1,183,417,008	56%	571,915,190	93,165,169	665,080,358
WA	742,622,039	113,000,000 ^e	855,622,039	56%	417,353,586	63,506,000	480,859,586
WV	312,400,323	67,713,291	380,113,614	81%	253,481,622	54,942,564	308,424,186
WI	1,524,201,005	123,847,712	1,648,048,717	66%	999,266,179	81,194,560	1,080,460,739
WY	112,028,267	19,389,515 ^e	131,417,782	56%	62,959,886	10,896,908	73,856,794
Estimated US Total/Average	47,399,587,263	9,376,357,677	56,775,944,941	61%	29,008,547,405	5,738,330,899	34,746,878,304

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

Table 2.14b FY 2020 State Medicaid Expenditures, Federal Income Taxes, and State Medicaid Benefit Ratios by Funding Authority and State

State	Percent of Total Federal Expenditures			Federal Business and Individual income Tax Paid		State Medicaid Benefit Ratio ²
	Medicaid Waiver	ICF/IID	Combined	Billions (\$) ¹	Percent (%)	
N states	51	51	51	51	51	51
AL	0.9	0.0	0.8	25.9	0.8	1.04
AK	0.4	0.0	0.3	5.4	0.2	1.94
AZ	3.6	0.0	3.0	48.3	1.4	2.11
AR	0.6	2.6	0.9	31.0	0.9	1.01
CA	8.3	5.0	7.7	459.1	13.6	0.57
CO	1.2	0.5	1.1	57.6	1.7	0.63
CT	1.9	1.6	1.8	51.9	1.5	1.19
DE	0.4	0.2	0.4	20.4	0.6	0.58
DC	0.7	1.3	0.8	31.2	0.9	0.88
FL	2.8	4.1	3.0	205.9	6.1	0.49
GA	1.8	0.5	1.6	88.7	2.6	0.60
HI	0.3	0.1	0.3	8.6	0.3	1.00
ID	0.7	0.1	0.6	11.5	0.3	1.88
IL	2.2	6.7	2.9	152.8	4.5	0.65
IN	2.2	3.5	2.4	58.1	1.7	1.39
IA	1.6	1.6	1.6	24.1	0.7	2.22
KS	1.0	0.3	0.8	23.7	0.7	1.21
KY	2.0	1.8	1.9	35.9	1.1	1.83
LA	1.3	5.1	1.9	35.5	1.1	1.85
ME	0.7	0.3	0.6	8.1	0.2	2.72
MD	2.1	0.1	1.8	79.1	2.3	0.75
MA	3.5	1.0	3.1	117.6	3.5	0.88
MI	2.5	0.0	2.1	76.9	2.3	0.91
MN	3.5	1.0	3.1	95.5	2.8	1.10
MS	0.4	2.5	0.7	11.0	0.3	2.19
MO	2.7	1.0	2.4	63.2	1.9	1.29
MT	0.3	0.0	0.3	6.6	0.2	1.33
NE	0.7	0.7	0.7	23.6	0.7	1.06
NV	0.4	0.2	0.3	23.2	0.7	0.48
NH	0.6	0.0	0.5	11.7	0.3	1.36
NJ	3.5	4.2	3.6	128.6	3.8	0.96
NM	1.1	0.4	1.0	9.6	0.3	3.63
NY	13.3	8.9	12.6	285.2	8.4	1.49
NC	3.2	7.2	3.9	86.1	2.5	1.52
ND	0.3	1.0	0.4	6.8	0.2	2.17
OH	5.3	8.9	5.9	138.1	4.1	1.44
OK	0.9	1.2	0.9	23.3	0.7	1.35
OR	0.4	0.0	0.4	34.5	1.0	0.35
PA	6.9	6.1	6.8	136.3	4.0	1.69
RI	0.5	0.1	0.5	13.7	0.4	1.12
SC	1.2	2.1	1.4	27.0	0.8	1.71
SD	0.3	0.4	0.3	8.0	0.2	1.41
TN	1.9	2.5	2.0	65.4	1.9	1.05
TX	3.7	12.9	5.2	257.1	7.6	0.68
UT	0.8	0.6	0.8	24.5	0.7	1.08
VT	0.5	0.0	0.4	4.4	0.1	2.97
VA	2.0	1.6	1.9	84.4	2.5	0.77
WA	1.4	1.1	1.4	99.2	2.9	0.47
WV	0.9	1.0	0.9	6.7	0.2	4.49
WI	3.4	1.4	3.1	49.4	1.5	2.13
WY	0.2	0.2	0.2	4.5	0.1	1.58
Estimated US Total/Average	100.0	100.0	100.0	3,384.7	100.0	1.00

² The State Medicaid Benefit Ratio compares the proportion of the total federal business and individual income tax paid by the state to the proportion of total ICF/IID plus Medicaid Waiver federal reimbursements received by the state for people with IDD. A value of less than 1 indicates that the state received a lower proportion of federal Medicaid ICF/IID and Waiver reimbursements than the proportion of federal income taxes paid. A value greater than 1 indicates that the state receives a higher proportion of federal Medicaid ICF/IID and Waiver reimbursements than the proportion of federal income taxes paid by the state.

the federal government. The average FMAP for FY 2020 was 61% (ranging from 56% in 15 states to 83% in Mississippi).

The federal Medicaid expenditures for people with IDD were estimated by multiplying the state's FMAP by ICF/IID and HCBS expenditures. Total Medicaid ICF/IID and Waiver expenditures for people with IDD in FY 2020 were an estimated \$56.8 billion, of which an estimated \$34.7 billion was reimbursed by the federal government. The Federal Medicaid program paid an estimated \$29 billion of the \$47.4 billion Medicaid Waiver expenditures and an estimated \$5.7 billion of the \$9.3 billion in Medicaid ICF/IID expenditures in FY 2020. Combined, the Federal Medicaid program paid an estimated \$34.7 of the \$56.8 billion ICF/IID and HCBS Waiver expenditures for people with IDD in FY 2020.

Proportion of Federal Expenditures by State

The first three columns on **Table 2.14b** show the percent of all federal Medicaid ICF/IID and HCBS Waiver expenditures received by each state for people with IDD. Of the \$29 billion in federal Medicaid Waiver expenditures for people with IDD, the proportion going to each state ranged from 0.2% for Wyoming to 13.3% for New York.

Of the \$5.7 billion in federal Medicaid ICF/IID reimbursements paid in FY 2020, less than 0.02% went to Arizona and Vermont while more than 5% went to Texas (12.9%), New York (8.9%), Ohio (8.9%), North Carolina (7.3%), Illinois (6.7%), Pennsylvania (6.1%), Louisiana (5.1%), and California (5%).

Combined proportions of Medicaid HCBS and ICF/IID expenditures by state ranged from 0.2% in Wyoming to 12.6% in New York.

The proportion of federal Medicaid expenditures allocated to each state varied by state population with the more populous states getting higher proportions than less populous states. The proportion also varied based on the state's total ICF/IID and HCBS Waiver expenditures. For example, New York, which spent 89% of its combined ICF/IID plus HCBS Waiver expenditures for people getting HCBS Waiver services received 13.3% of all federal Waiver expenditures and 8.9% of all ICF/IID expenditures. By contrast, Texas, which spent 41% of its combined expenditures on HCBS Waiver

recipients received 3.7% of Waiver expenditures and 12.9% of ICF/IID expenditures.

Federal Income Tax Paid

The second set of columns on **Table 2.14b** show total business and individual income taxed paid by each state and the proportion of total federal business and individual income taxes paid by each state. The totals shown do not include unemployment insurance, railroad retirement tax, estate and trust income tax, estate tax, gift tax, or excise tax. Totals also exclude taxes paid by U.S Armed Service members overseas, people in Puerto Rico, people in other nations, and undistributed taxes. In FY 2020, states paid a total of \$3.4 trillion in federal business and individual income taxes. The proportion paid varied by state ranging from 0.2% or less by Alaska, Montana, Vermont, and Wyoming to 13.6% by California.

State Medicaid Benefit Ratios

State Medicaid benefit ratios compares the proportion of federal Medicaid ICF/IID and Waiver reimbursements received by each state with the proportion of federal income taxes paid by each state. A state Medicaid benefit ratio of 1.0 indicates that the proportion of federal Medicaid ICF/IID plus Waiver reimbursements for a state is equal to the proportion of federal income taxes paid by the state. A ratio higher than 1.0 indicates that the state received a higher proportion of federal Medicaid ICF/IID and Waiver reimbursements for recipients with IDD than the proportion it paid of total federal income taxes. A ratio of less than 1.0 indicates that the state received a lower proportion of all federal Medicaid ICF/IID and Waiver reimbursements for people with IDD than the proportion it paid of total federal income taxes.

For FY 2020, state Medicaid benefit ratios ranged from 0.35 for Oregon to 4.49 for West Virginia. Overall, 35 states had Medicaid benefit ratios of 1.0 or higher and 16 states had ratios of less than 1.0. The relative benefit states got from the federal Medicaid program correlated with FMAP ($r = 0.36$). States for whom the federal government paid a higher share of Medicaid expenditures got proportionately more out of Medicaid than they paid in federal business and Income taxes. An estimated 12.9% of the differences between states in the

benefit ratio could be explained by differences in the state's FMAP ($R^2 = 0.129$). For example, of the 16 states with a benefit ratio of less than 1.0, eight had an FMAP of 56% (California, Colorado, Illinois, Maryland, Massachusetts, New Jersey, Virginia, and Washington). These wealthier states got less back in federal Medicaid reimbursements than they paid in business and personal income taxes.

States that provided HCBS Waiver plus ICF/IID services to more recipients per 100,000 of the state's population were more likely to have a positive Medicaid benefit ratio ($r = 0.39$). An estimated 15.6% of state-to-state variation in the Medicaid benefit ratio could be accounted for by the number of ICF/IID plus HCBS Waiver recipients per 100,000 of the state population ($R^2 = 0.156$). The three states serving the fewest people with IDD per 100,000 benefited least: Nevada served 83 people per 100,000 and had a benefit ratio of 0.48; Georgia served 130 people per 100,000 and had a benefit ratio of 0.6; and Alabama served 121 people per 100,000 and had a benefit ratio of 1.04. Conversely, Iowa served 793 people per 100,000 and had a benefit ratio of 2.22; North Dakota served 733 people per 100,000 and had a benefit ratio of 2.17, and Wisconsin served 691 people per 100,000 had had a benefit ratio of 2.13. These analyses do not include state and federal expenditures for Medicaid State Plan funded services for people with IDD.

OTHER FUNDING AUTHORITIES

Medicaid State Plan 1915(i) State Plan HCBS and 1915(k) Community First Choice

Seven states reported offering Medicaid 1915(i) State Plan HCBS-funded LTSS and seven reported offering Medicaid 1915(k) Community First Choice funded LTSS for people with IDD. Among the states offering 1915(i)- or (k)-funded LTSS, nine reported serving 104,092 people with IDD through these funding mechanisms in 2020 (see **Table 2.15**). Of the recipients for whom age was reported, 61% were 21 years or older. The number of people getting LTSS funded by Medicaid State Plan 1915(i) or (k) ranged from 154 in Alaska to 57,796 in New York.

Table 2.15 FY 2020 LTSS Recipients with IDD Funded through 1915 (i) or 1915(k), Targeted Case Management or Other State Plan HCBS Funding Authorities

State	State Plan 1915(i) or 1915(k) Recipients			"Other" State Plan HCBS Recipients			Targeted Case Management		
	Birth to 21 years	22 years +	Total	Birth to 21 years	22 years +	Total	Birth to 21 years	22 years +	Total
N States	42	42	46	34	33	34	35	35	39
AL	0	0	0	DNF	DNF	DNF	DNF	DNF	DNF
AK	DNF	DNF	154	DNF	DNF	191	DNF	DNF	2,272
AZ	0	0	0	0	0	0	0	0	0
AR	DNF	DNF	DNF	0	0	0	0	0	0
CA	24,796	33,000	57,796	1,574	5,067	6,641	136,082	117,943	254,025
CO	0	0	0	12,957	12,535	25,492	3,829	10,566	14,395
CT	0	0	0	0	0	0	0	0	0
DE	DNF	DNF	492	DNF	DNF	DNF	DNF	DNF	3,485
DC	0	0	0	0	0	0	0	0	0
FL	0	0	0	0	0	0	0	0	0
GA	DNF	DNF	0 i	DNF	DNF	DNF	DNF	DNF	DNF
HI	0	0	0	0	0	0	0	0	0
ID	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
IL	0	0	0	0	0	0	0	0	0
IN	0	0	0	0	0	0	0	0	0
IA	281	1,171	1,452	523	201	724	DNF	DNF	DNF
KS	0	0	0	DNF	DNF	DNF	1,632	7,688	9,320
KY	0	0	0	0	0	0	0	0	0
LA	0 i	0 i	0 i	DNF	DNF	DNF	DNF	DNF	DNF
ME	0	0	0	0	109	109	351	4,265	4,616
MD	DNF	DNF	DNF	DNF	DNF	DNF	3,641	18,108	21,749
MA	0	0	0	0	0	0	0	0	0
MI	0	0	0	0	0	0	10,210	25,622	35,832
MN	0	0	0	2,231	689	2,920	1,317	1,863	3,180
MS	DNF	DNF	851	0	0	0	DNF	DNF	1,045
MO	0	0	0	0	0	0	12,663	17,871	30,534
MT	0	0	0	0 i	294 i	294 i	DNF	DNF	DNF
NE	0	0	0	0	0	0	715	4,758	4,758
NV	0	0	0	95	578	673	2,735 e	4,674	7,409
NH	0	0	0	0	0	0	0	0	0
NJ	0	0	0	0	DNF	DNF	0	0	0
NM	0	0	0	0 i	0 i	0 i	DNF	DNF	DNF
NY	0	0	0	40,223	75,461	115,684	907	1,335	2,242
NC	0	0	0	DNF	DNF	DNF	DNF	DNF	DNF
ND*	2	63	65	0	0	0	0	0	0
OH	0	0	0	0	0	0	0	0	0
OK	0 i	0 i	0 i	DNF	DNF	DNF	DNF	DNF	DNF
OR	7,819	15,975	23,794	0	0	0	0	0	0
PA	0	0	0	DNF	DNF	DNF	12,212	6,640	18,852
RI	0	0	0	0	0	0	0	0	0
SC	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
SD	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
TN	0	0	0	0	0	0	0	0	0
TX	1,401	1,373	2,774	DNF	DNF	DNF	DNF	DNF	38,223
UT	0	0	0	DNF	DNF	DNF	0	0 i	0 i
VT	0	0	0	1,138	303	1,441	55	210	265
VA	0	0	0	DNF	DNF	DNF	2,263	12,571	14,834
WA*	5,416	11,298	16,714	0	0	0	0	0	0
WV	0 i	0 i	0 i	DNF	DNF	DNF	DNF	DNF	DNF
WI*	0	0	0	1,434	7,849	9,283	63	19	82
WY	0	0	0	0 i	0 i	0 i	247	125	372
Reported Total	39,715	62,880	104,092	60,175	103,086	163,452	188,922	234,258	467,490

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

Other Medicaid State Plan HCBS Funding Authorities

Although 1915(i), (j), and (k) were the first Medicaid funding mechanisms available to fund HCBS, states now have other Medicaid State Plan options through which they can offer LTSS. Eleven of the 26 states providing HCBS to people with IDD through other state plan funding mechanisms reported the number of LTSS recipients served. Those 11 states served 163,452 people. Of the recipients for whom age was reported, 63% were adults. The number LTSS recipients funded by Other Medicaid State Plan authorities per state ranged from 191 in Alaska to 115,684 in New York.

Medicaid State Plan-Funded Targeted Case Management Services

Of the 36 states that provided Medicaid State Plan targeted case management (TCM) to people with IDD in 2020, 20 reported providing Medicaid State Plan TCM services to 467,490 people. Of the TCM recipients for whom age was reported, 55% were adults. The number of TCM recipients per state ranged from 82 in Wisconsin to 254,025 in California.

State or Local non-Medicaid Funded LTSS

Among the 47 states that reported using state or local funds to pay for LTSS for people with IDD, 42 reported serving 277,123 recipients (see [Table 2.16](#)). Of the recipients for whom age was reported, 58% were children or youth 21 years or younger. The number of state or locally funded LTSS recipients with IDD per state ranged from four in Virginia to 135,622 in California.

People on State IDD Agency Caseloads Not Getting LTSS other than Case Management

A total of 220,313 people in 34 reporting states were on the caseload of state IDD agencies but did not get any LTSS other than case management. Amongst those whose age was reported 61% were children or youth ages 21 years or younger. Eight states reported that all the people on their caseloads received one or more LTSS in addition to case management. Amongst the other reporting states, the number of people who did not get LTSS

ranged from 336 in the District of Columbia to 55,205 in Ohio.

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

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

Institutionalization and Deinstitutionalization

The 1880 U.S. Census enumerated 76,895 people with IDD in the United States of whom 9,725 (13%) lived in institutions, almshouses, or prisons. The number of people with IDD living in institutional settings in the United States grew for the first six decades of the 20th Century. Most of those IDD institutions were state-run. In 1903, 15,511 people with IDD lived in institutions, 98.6% of whom lived in a state-run facility. By 1956, the average daily population of state-run IDD facilities had grown to 115,928. The number nearly doubled during the baby boom years from 1946 and 1964, reaching an all-time high of 194,650 people in 1967. In 1967, an estimated 33,850 additional people with IDD lived in state-run psychiatric facilities (the combined average daily population of state-run IDD and psychiatric facilities was 228,500 in 1967).

Despite their widespread use by the 1950s, families, parent associations, professionals, and policymakers protested that large state-run IDD institutions were overcrowded, understaffed, and sometimes unfit for human habitation. President John F. Kennedy, whose sister Rosemary had ID, urged Congress in 1963 to move away from providing services to people with IDD in custodial

Table 2.16 FY 2020 People on State IDD Caseloads getting State-Funded LTSS or No LTSS Funding

State	State-Funded LTSS			On Caseload, No LTSS		
	Birth to 21 years	22 years +	Total	Birth to 21 years	22 years +	Total
N States	38	36	42	34	33	34
AL	0 ⁱ	6 ⁱ	6 ⁱ	100 ^{ej}	2,000 ^{ej}	2,100 ^{ej}
AK	0	0	0	0 ⁱ	0 ⁱ	0 ⁱ
AZ	6,541	1,741	8,282	0	0	0
AR	0	0	0	411	242	653
CA	89,385	46,237	135,622	0	0	0
CO	3,212	839	4,051	2,251	2,272	4,523
CT	63	447	510	3,681	1,909	5,590
DE	DNF	DNF	1,057	0	0	0
DC	0	14	14	63	273	336
FL	704	2,263	2,967	11,895	14,398	26,293
GA	DNF	DNF	DNF	DNF	DNF	DNF
HI	0	107	107	0	0	0
ID	0	0	0	DNF	DNF	DNF
IL	1,671 ^e	3,014 ^e	4,685 ^e	8,724	5,958	14,682
IN	17	504 ^e	521 ^e	0	0	0
IA	DNF	DNF	DNF	DNF	DNF	DNF
KS*	6,389 ^e	13,804 ^e	20,193 ^e	2,779	1,465	4,244
KY	DNF	DNF	9,480	DNF	DNF	DNF
LA	DNF	DNF	5,681 ⁱ	DNF	DNF	DNF
ME	0 ⁱ	125 ⁱ	125 ⁱ	38	395	433
MD	764	3,463	4,227	3,536	4,069	7,605
MA	DNF	DNF	DNF	DNF	DNF	DNF
MI	189	445	634	319	728	1,047
MN	2,395	1,266	3,661	127	486	613
MS	0	0	0	DNF	DNF	DNF
MO	4,102	1,202	5,304	12,201	8,188	20,389
MT	0	8	8	DNF	DNF	DNF
NE	7	85	92	1,495	524	2,019
NV	1,312	1,365	2,677	767	1,173	1,940
NH	0	6	6	0	0	0
NJ	0	DNF	DNF	0	DNF	DNF
NM	34	260	294	2,516	1,933	4,449
NY	DNF	DNF	32,746 ⁱ	DNF	DNF	DNF
NC	1,567 ⁱ	4,099 ⁱ	5,666 ⁱ	7,334 ⁱ	6,263 ⁱ	13,597 ⁱ
ND*	581	47	628	201	277	478
OH*	DNF	DNF	DNF	43,705	11,500	55,205
OK	DNF	DNF	DNF	DNF	DNF	DNF
OR	3,139	5,796	8,935	3,599	4,067	7,666
PA	3,369	3,679	7,048	8,507	5,977	14,484
RI*	0	30	30	464	172	636
SC	DNF	DNF	DNF	DNF	DNF	DNF
SD	DNF	DNF	DNF	DNF	DNF	DNF
TN	2,418	1,792	4,210	DNF	DNF	DNF
TX	DNF	DNF	6,822	DNF	DNF	DNF
UT	3	44	47	2,044	1,693	3,737
VT	0	0	0	0	0	0
VA	0	4	4	DNF	DNF	13,190
WA	147	585	732	8,419	5,611	14,030
WV	DNF	DNF	DNF	DNF	DNF	DNF
WI	0	0	0	DNF	DNF	DNF
WY	51	DNF	51	276	98	374
Reported Total	128,060	93,277	277,123	125,452	81,671	220,313

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

institutions to providing services in community settings (John F. Kennedy Library). In 1965, after visiting the Willowbrook State School in New York, Senator Robert Kennedy reported that the children at the facility lived in filth and called the facility a “snake pit” (Minnesota Developmental Disabilities Council, 2016).

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

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

- having daily schedules defined by individual preferences and needs rather than by the needs of staff or a facility;
- spending time in a variety of different settings each week for work, learning, and leisure rather than remaining in the institution all day every day;
- taking breaks from normal routines to vacation, celebrate holidays, and enjoy seasonal activities;
- participating in inclusive activities in settings typical for people of similar age;
- being treated with respect and dignity with the right to make choices about both the little things (like what to wear or what to eat), and big things (like where to live and with whom);
- living, working, and playing in settings that included both males and females;
- 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). Federal and state legislative action during the 1960s and 1970s propelled a movement to deinstitutionalize services for people with IDD.

Introduction of Medicaid Funding

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

Intermediate Care Facilities for Individuals with Intellectual Disabilities

In 1967, a less medically oriented and less expensive form of long-term supports, the “Intermediate Care Facility” (ICF) program was authorized under Title XI of the Social Security Act. In 1971, the SNF and ICF programs were combined under Title XIX of the Social Security Act. Within the legislation, was a hardly noticed, scarcely debated amendment that authorized Federal Financial Participation (FFP) for “intermediate care” provided in public and private

facilities geared specifically to meet the needs of people with IDD. Medicaid facilities for people with IDD were initially called Intermediate Care Facilities for Individuals with Mental Retardation [sic] (ICF/MR), but because of Rosa's Law in 2010 are now referred to as Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID; Centers for Medicare and Medicaid Services, 2013b).

The ICF/IID legislation provided substantial federal incentives to states for upgrading the physical environment and the quality of care and habilitation in certified IDD facilities. It also neutralized incentives for states to place persons with IDD in SNFs by creating a federally subsidized alternative offering care that was more appropriate and habilitation in the form of active treatment. In the ensuing years, most state IDD facilities were certified as ICF/IIDs with two notable results: 1) nearly every state secured federal funding for large public IDD facilities, and 2) to maintain federal participation, states were compelled to invest substantial state dollars to bring their IDD facilities into conformity with ICF/IID standards. Forty states had at least one ICF/IID certified facility by June 30, 1977 (Krantz, Bruininks, & Clumper, 1979). Between 1978 and 1980, 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 type or severity of disability. As the law was implemented, families were able to enroll their children in a public school instead of placing them in an IDD facility or paying privately for educational services. The law also required a free appropriate public education for children with disabilities living in SNF, ICF/IID, and other institutions.

In the 1960s, states began to reduce the number of children living in state IDD facilities to reduce overcrowding as required by the ICF/IID standards, and to respond to the educational requirements of PL 94-142. The proportion of state IDD facility residents ages 21 years or younger peaked in 1965 at 49% (91,592 of 187,305 the people with IDD living in state facilities were children; NIMH, 1966). By 1977, the proportion of children in state IDD facilities

with 16 or more residents with IDD had dropped to 36% (54,098 of 151,532 total residents), and by 1987 the proportion was 13% (12,310 of 94,695). The proportion declined to 5% in 1998 and was 5% in FY 2020 (an estimated 732 of the average daily population of 15,904).

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

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

Downsizing ICF/IID Settings

Although Congressional debate about the ICF/IID program focused on large state facilities, the statute did not specifically limit ICF/IID coverage to only state facilities or to only large institutions. They simply restricted ICF/IID facilities to "four or more people in single or multiple units" (42 CFR 435.1010(b) (2)). The focus of the legislation was on improving the overall 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 15 people. Smaller facilities were given greater flexibility in meeting ICF/IID standards.

States varied in the rate at which they developed ICF/IID facilities serving four to 15 people. Some states developed hundreds, while others had none.

In 1982, two thirds (65%) of the 1,202 ICF/IIDs serving four to 15 people were 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 15 people. Following the publication of the guidelines, more states began to develop smaller ICF/IIDs. In the same year, Congress enacted legislation giving greater opportunity and flexibility to states to use Medicaid funding for community services through the HCBS waiver funding authority.

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” LTSS 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 equal to the increases in HCBS participants and expenditures. As the number of people in ICF/IID settings declined, those restrictions were relaxed and then dropped in 1994.

States specify in their 1915(c) Medicaid Waiver applications which Medicaid eligible population(s) will be served and which services will be available (e.g., homemaker, home health aide, personal care, day and residential habilitation, respite care, or

other services as approved by the Secretary of the U.S. Department of Health and Human Services; www.Medicaid.gov, 2016). Although not allowed to use HCBS reimbursements to pay for room and board, all states provide residential support services under categories such as personal care, residential habilitation, and in-home supports. HCBS recipients with IDD live with family members or use their own resources, usually cash assistance from other Social Security Act programs and state supplements to cover room and board costs.

While some Medicaid Waiver recipients live in host/foster family homes or group homes, most recipients live with family members or in a home they own or lease. With their flexibility and potential for promoting individualized services, Medicaid HCBS Waiver authorities have been the primary source of funding for home and community-based LTSS for more than three decades.

Balancing Medicaid Home and Community-Based and Institutional LTSS

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

Nursing Facility Reform

In the Omnibus Budget Reconciliation Act (OBRA) of 1987 (PL 100-203), Congress restricted admission to Medicaid-reimbursed nursing facilities to persons requiring specific levels of 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 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 Home and Community-Based Services Funding Authorities

Since 1999, Congress has added several additional Medicaid HCBS funding authorities allowing states to expand Medicaid-funded community services and reduce demand for institutional services. Many states operate HCBS programs for two or more different eligible populations. In February 2020, the Medicaid website (<https://www.medicaid.gov/Medicaid/section-1115-demo/demonstration-and-waiver-list/index.html>) listed 291 approved Section 1915(c) Home and Community-based Waivers, 53 approved 1115 Waivers, and 78 1915 (b) Waiver Authorities. Many states also offer HCBS under State Plan 1915(i), (j), or (k) funding authorities, though the eligibility criteria for those benefits may vary except for 1915(k), which must be offered to all individuals meeting an institutional level of care (including NF, ICF/IID and hospital). People with IDD are sometimes excluded from participating in those programs.

Supports for Families

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

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

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

Money Follows the Person

The Money Follows the Person (MFP) initiative authorized in the Deficit Reduction Act of 2005 is a federal demonstration program designed to help states reduce their use of institutional care while expanding options for people to receive care in the community. The legislation provided a system of flexible and augmented financing to assist states in moving people to smaller, more integrated, appropriate, and preferred settings. The program was amended by Section 2403 of Patient Protection and Affordable Care Act (P.L. 111-148), the Medicaid Extenders Act of 2019 (P.L. 116-3), the Medicaid Services Investment and Accountability Act of 2019 (P.L. 116-16 and was last expanded through the Sustaining Excellence in Medicaid Act of 2019 (P.L. 116-39).

MFP is the largest demonstration program in the history of Medicaid designed to transform LTSS. MFP grants enabled states to develop systems and services to help long-term residents of nursing facilities, ICF/IIDs, and Institutions for Mental Disease (i.e., psychiatric hospitals) to move to home or community-based settings. The program began in 2007, and by December 2016, it had supported more than 75,151 people with disabilities to move from institutions to community residences. Between January 2017 and December 31, 2018, an additional 18,640 people moved from institutions to community settings. As of April 2024, 45 states and the District of Columbia participated (<https://www.medicaid.gov/medicaid/long-term-services-supports/money-follows-person/index.html>).

In 2022, CMS issued a new funding opportunity for MFP. This effort, authorized under the Consolidated Appropriations Act of 2021 (CAA), made individual awards of up to \$5 million to states and territories

that were not already participating in MFP. These funds support states during the initial planning and implementation of their programs.

Additionally, CMS notified current MFP grantees that it is increasing the reimbursement rate for MFP “supplemental services.” CMS notes that supplemental services are now 100% federally funded with no state share. CMS also announced that it is expanding the definition of supplemental services to include additional services that can support an individual’s transition from an institution to the community, including short-term housing and food assistance. These changes will help to address barriers to community transition for eligible individuals in institutions, increase community transition rates, and increase the effectiveness of the MFP demonstration.

Medicaid Managed LTSS

Many states opt to use a capitated managed care model as an alternative to fee-for-service financing to manage some or all their Medicaid LTSS. There are several Medicaid authorities that states may use to implement a managed care service delivery model. These options may include various following authorities, depending on the specific contours of the state’s program design. States can amend their Medicaid State Plan under the 1932(a) federal authority to implement a managed care delivery system. Section 1915(a) and (b) Managed Care authorities also allow states to use managed care delivery systems. A hybrid program, concurrent 1915(b) and 1915(c) Waivers, also referred to as 1915(b/c) concurrent Waivers, allows states



to implement two types of Waivers at the same time if all federal requirements are met for both programs. For innovative demonstrations requiring authority not otherwise available through those noted above, states may propose to use an 1115 Research and Demonstration Waiver.

Managed care is a tool for use at state election within Medicaid. States must take significant care to ensure that managed care is appropriate for the goals of the state and, when such arrangements include IDD services, ensure a design and quality approach that recognizes the specific needs of the population and the need for careful state oversight and monitoring of managed care partners. This includes the essential articulation of required data, particularly those related to service delivery and setting and health and welfare, among others.

As states increasingly use managed care to deliver long-term services and supports to seniors and people with disabilities enrolled in Medicaid, CMS sought to provide additional requirements related to MLTSS programs and beneficiary protections while allowing states flexibility in program design and administration. They issued a final rule on April 25, 2016. CMS continues to refine expectations regarding data and quality, including for HCBS delivered through managed care. In 2022, CMS issued its recommended HCBS quality measure set to continually assess quality outcomes of individuals served in all HCBS (CMS, 2022).

Self-Directed Medicaid HCBS

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

In self-directed services, Medicaid recipients can choose their service provider and direct their supports and services. Recipients may directly manage budgeted Medicaid funds under some

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

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

Milestones in LTSS Policy

- **1965 Medicaid Program.** An anti-poverty program establishes Medicaid as an LTSS funder.
- **1971 Medicaid Intermediate Care Facilities for Individuals with Intellectual Disabilities.** This was the beginning of federal involvement in funding services for people with IDD, although still with an institutional focus. While many of the early ICF/IIDs were large, state-run institutions, funding was available to facilities serving four or more people who complied with the certification standards. During the 1970s, many smaller institutional settings opened, most commonly settings that housed six people.
- **Rehabilitation Act of 1973** prohibited discrimination based on disability in federally funded programs.
- **1975 PL 94-142** (Now the **Individuals with Disabilities Education Act**). PL 94-142 required school districts to provide an appropriate education to children with disabilities. This was the first time children with IDD could go to school in their communities instead of in residential institutions. Many states began to reduce the number of children living in state IDD facilities to reduce overcrowding as required by the ICF/IID standards, and to respond to the new educational requirements of PL 94-142.

- **1981 Medicaid Home and Community-Based Services Waiver.** The Medicaid HCBS Waiver started in 1981. It was an option states could use to fund LTSS in community settings other than ICF/IID-certified institutions. Initially, the program was a cost-saving measure more than a tool to support people with disabilities to live lives of their choosing in their communities. Participating states were required to demonstrate that their total Medicaid Waiver expenditures and the total number of people served grew no more than would be expected without the Waiver.
- **1987 Nursing Facility Reform.** With the Omnibus Budget Reconciliation Act (OBRA) of 1987, (PL 100-203) Congress restricted admission to Medicaid-reimbursed nursing facilities to persons requiring specific levels of 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 v. L.C.* decision established a right to “placement in the most integrated setting” under its interpretation of Title II of the ADA. 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 the creation of the 1915(i) funding authority and initial authorization of the Money Follows the Person program.
- **2010 Affordable Care Act.** This federal legislation authorized the Balancing Incentive Payments program, made modifications to the Medicaid 1915 State Plan LTSS option, and the Medicaid Waiver 1915(k) Community First Choice option, and extended funding for the Money Follows the Person program. It allows states to fund HCBS through Medicaid state plans and prohibits discrimination based on disability in federally funded health care.
- **2014 Medicaid Home and Community-Based Services Final Rule.** In 2014, CMS promulgated new rules that strengthen the requirements for integration, autonomy, choice and control, and person-centered services for Waiver recipients. All provisions of the rule became effective upon promulgation except those provisions related to HCBS settings. Implementation of the settings component of the rule was delayed several times to allow states time to assess their providers, and design and implement transition plans to bring all HCBS-funded service settings into compliance with the rule. The settings components of the rule went into effect on March 17, 2023.





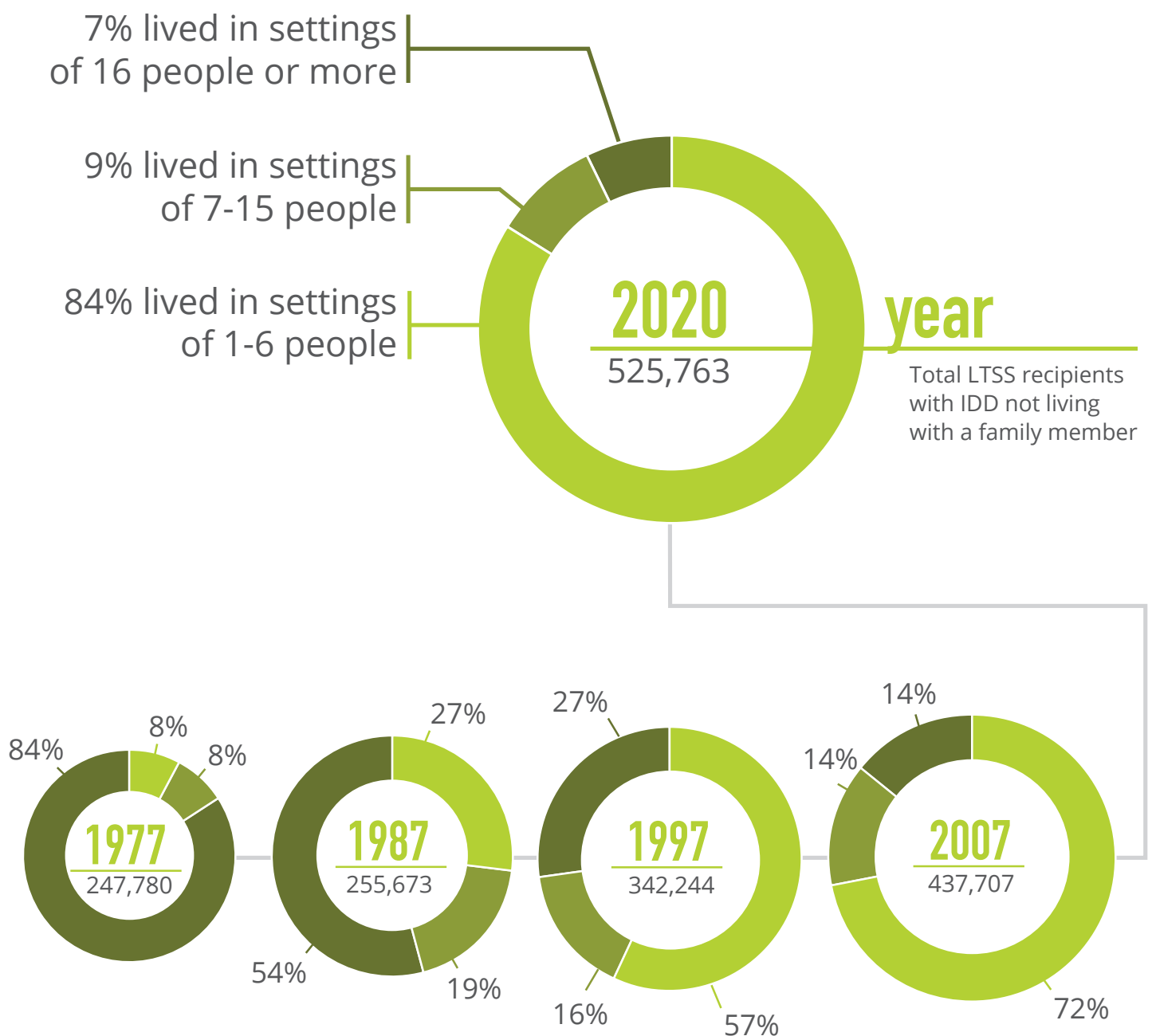
SECTION THREE

Historical Perspectives and Trends through 2020 in Long-Term Supports and Services

FY 2020

Change in the Total Number of People in Non-Family IDD Settings and Proportion in Settings of Different Sizes Between 1977 and 2020

Number of people with IDD living in non-family settings, and proportion
in settings of different sizes



SECTION 3: HISTORICAL PERSPECTIVES AND TRENDS IN LTSS

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

homes or psychiatric facilities, between 1999 and 2020 the total number of LTSS recipients with IDD increased 97% from 728,704 to 1,434,307 people (see **Figure 3.1**).

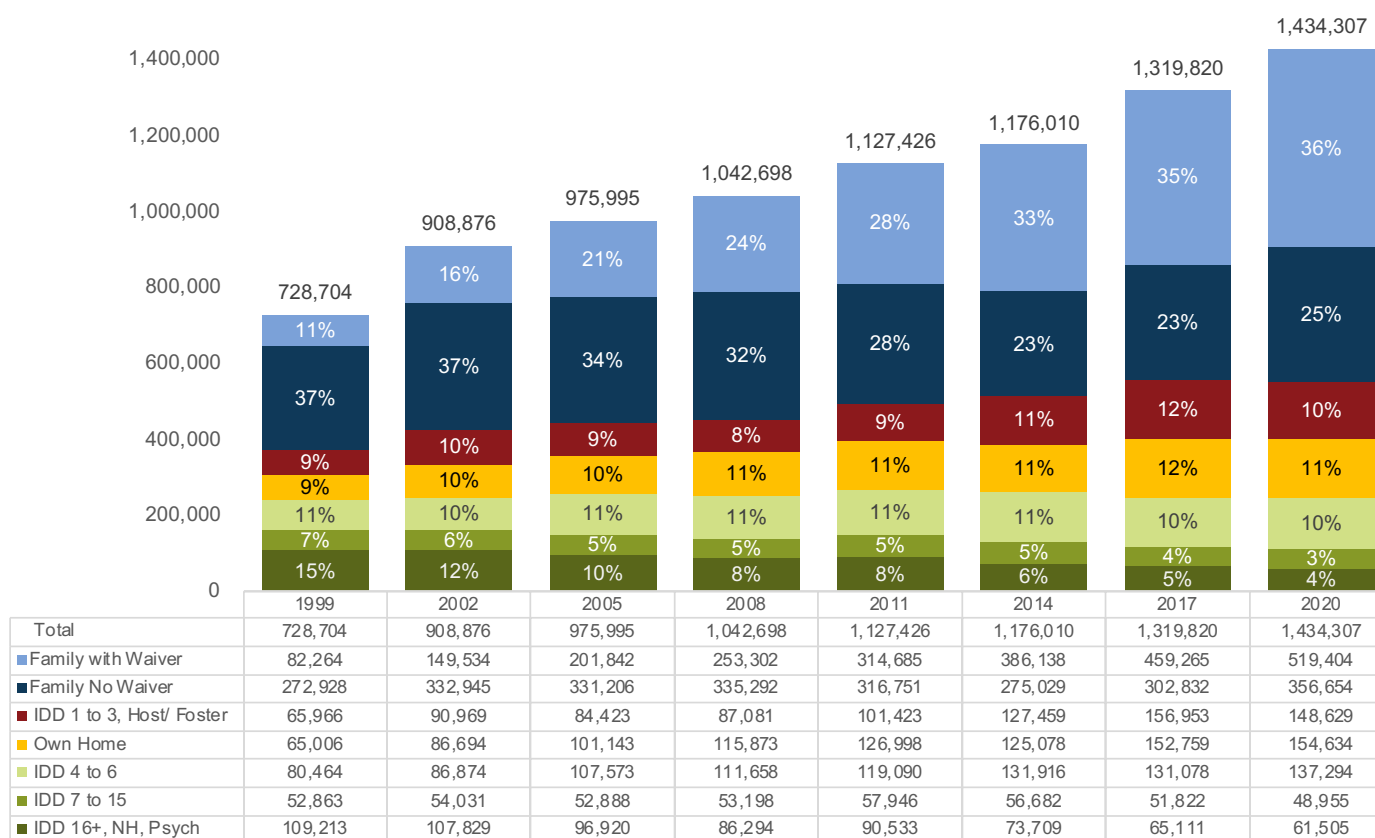
TRENDS IN TYPES OF LIVING ARRANGEMENTS

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

Family Home

The number of LTSS recipients with IDD who lived in the home of a family member increased by 147% from 355,192 in 1999 to 876,058 in 2020. The proportion of LTSS recipients who lived with a family member increased from 49% to 61%. The proportion LTSS recipients living with a family member who received Medicaid Waiver-funded supports increased from 23% in 1999 to 59% in 2020.

Figure 3.1 Number and Percent of LTSS Recipients with IDD by Living Arrangement Type and Size: Select Years 1999 to 2020



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

Non-Family Settings

Between 1999 and 2020, the number of LTSS recipients with IDD living in settings other than the home of a family member increased 49% from 373,512 to 558,249 people. The number of LTSS recipients with IDD living in their own home increased by 138% from 65,006 (9% of recipients) in 1999 to 154,634 (11%) in 2020. Amongst those living in group homes, host or foster family homes, IDD institutions, nursing homes, or psychiatric facilities, the proportion who lived in settings of:

- Three or fewer people increased 125% from 65,966 to 148,629 people,
- Four to six people increased 71% from 80,464 to 137,294 people,
- Seven to 15 people decreased 7% from 52,863 to 48,955 people, and
- 16 or more people decreased 44% from 109,213 to 61,634 people.

The proportion of LTSS recipients living in settings of seven or more people, including nursing homes or psychiatric settings, decreased from 22% in 1999 to just 7.7% in 2020.

TRENDS IN RESIDENCE SIZE AND TYPE OF OPERATION

The remainder of Section 3 focuses on trends in setting size, type of operation, and funding authorities for LTSS recipients with IDD from 1977 or the first year a service was tracked through 2020. Trends related to people living in state-run psychiatric facilities are covered in Section 4.

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

Number of Facilities by Size and Type of Operation

Between 1977 and 2020, the number of non-family settings serving LTSS recipients with IDD increased more than 20-fold from 11,008 to 231,734 (see **Table 3.1**). The number of non-family settings serving:

- One to six LTSS recipients increased 32-fold from 6,898 to 225,300,
- Seven to 15 LTSS recipients increased by 133% from 2,405 to 5,605, and

Table 3.1 Non-Family IDD Residences by Type of Operation and Setting Size on June 30 of Selected Years 1977 to 2020

Year	Number of Settings														
	Non-State					State-Operated					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%
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%
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%
2017	220,970	5,717	611	227,298	97%	1,315	646	121	2,082	63%	222,285	6,363	732	229,380	97%
2018	219,558	6,875	816	227,249	97%	1,348	530	119	1,997	68%	220,906	7,405	935	229,246	96%
2019	227,487	5,592	732	234,989	97%	1,350	478	112	1,926	70%	228,837	6,070	844	236,915	97%
2020	223,950	5,128	721	229,799	97%	1,350	477	108	1,935	70%	225,300	5,605	829	231,734	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.

- 16 or more LTSS recipients decreased by 51% from 1,705 to 829.

Between 1977 and 2020, the proportion of non-family settings serving

- One to six LTSS recipients increased from 63% to 97%,
- Seven to 15 LTSS recipients decreased from 22% to 2%, and

- 16+ LTSS recipients decreased from 15% to 0.4%.

LTSS Recipients with IDD by Residence Size and Type of Operation

Between 1977 and 2020, the number of LTSS recipients living in settings other than the home of a family member more than doubled, increasing from 247,780 to 525,892 (see **Table 3.2**). The number of LTSS recipients with IDD living in settings serving

Figure 3.2 People with IDD in Non-family LTSS Settings by Type of Operation on June 30 Selected Years 1977 to 2020

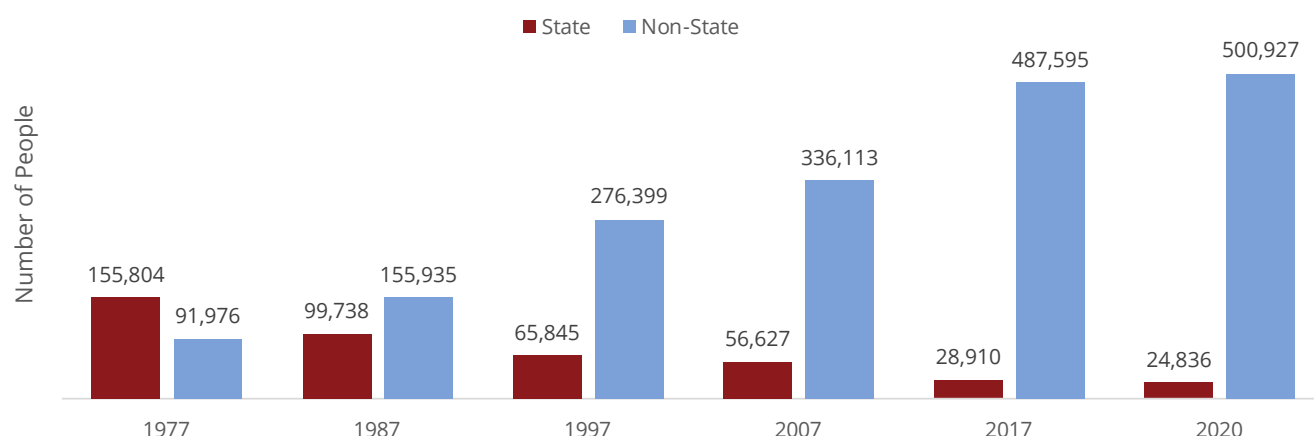


Table 3.2 People with IDD in LTSS Settings by Setting Size, and Proportion with 1 to 6 People on June 30 of Selected Years, 1977 to 2020

Year	Number of People with IDD ¹														
	Non-State					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%
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%
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	369,745	49,584	26,041	445,371	83%	5,317	6,431	24,165	35,913	15%	375,062	56,015	50,206	481,284	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%
2017	422,972	46,125	18,407	487,595	87%	4,975	5,696	18,239	28,910	17%	427,947	51,821	36,646	516,505	83%
2018	418,223	51,178	19,268	488,669	86%	5,385	5,018	17,557	27,960	19%	423,608	56,196	36,825	516,629	82%
2019	433,838	48,495	18,009	500,342	87%	5,491	4,484	16,200	26,175	21%	439,329	52,979	34,209	526,517	83%
2020	435,209	44,789	20,929	500,927	87%	5,292	4,222	15,322	24,836	21%	440,501	49,011	36,251	525,763	84%

¹ This table excludes people living with a family member, nursing home or psychiatric facility. It includes host or foster family settings, own home, and group settings including those certified as ICF/IID.

- One to six LTSS recipients increased 21-fold from 20,400 to 440,501,
- Seven to 15 LTSS recipients increased 145% from 20,024 to 49,011, and
- 16 or more LTSS recipients decreased 82% from 207,356 to 36,251.

Between 1977 and 2020, the proportion of LTSS recipients in non-family settings serving

- One to six LTSS recipients increased from 8% to 84%,
- Seven to 15 LTSS recipients increased from 8% to 9%, and
- 16 or more LTSS recipients decreased from 84% to 7%.

Between 1977 and 2020, the number of LTSS recipients with IDD living in state-run IDD settings of all sizes decreased from 155,804 to 24,836 (see

Figure 3.3 Proportion of People with IDD Living in IDD Settings of 16 or more people who live in Non-State Settings Selected Years 1977 to 2020

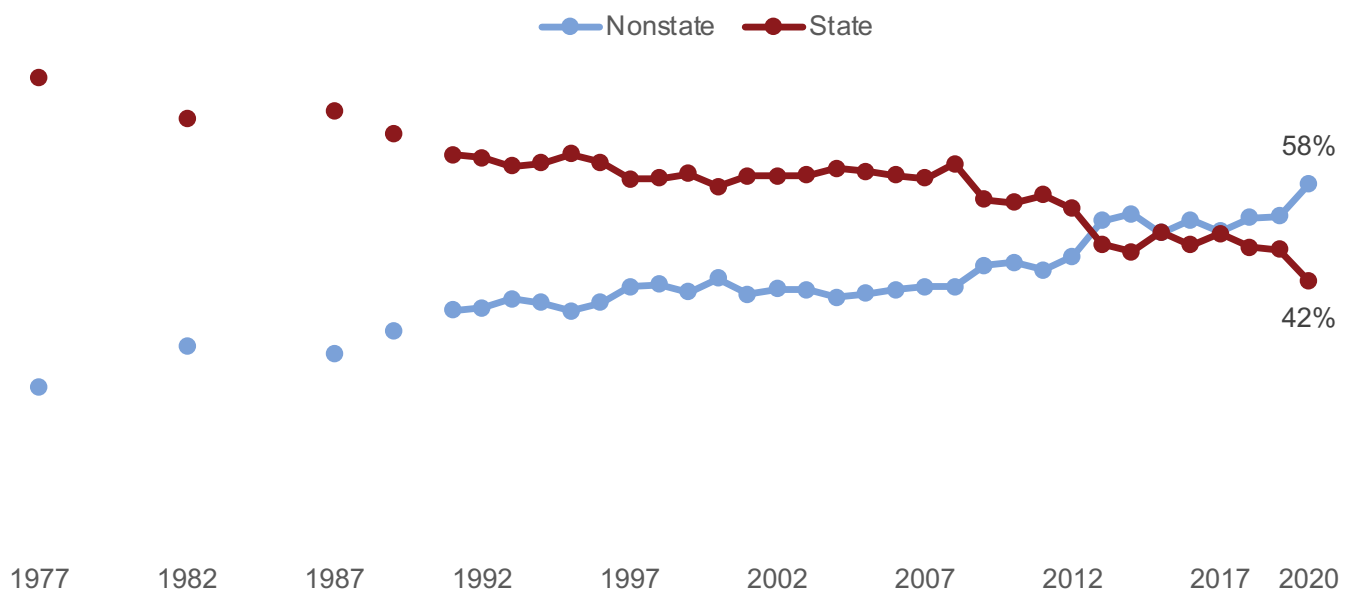


Figure 3.4 Number of LTSS Recipients with IDD in State and Nonstate-Operated Settings of 16+ People June 30, 2000 to 2020 with Linear Projections to 2045

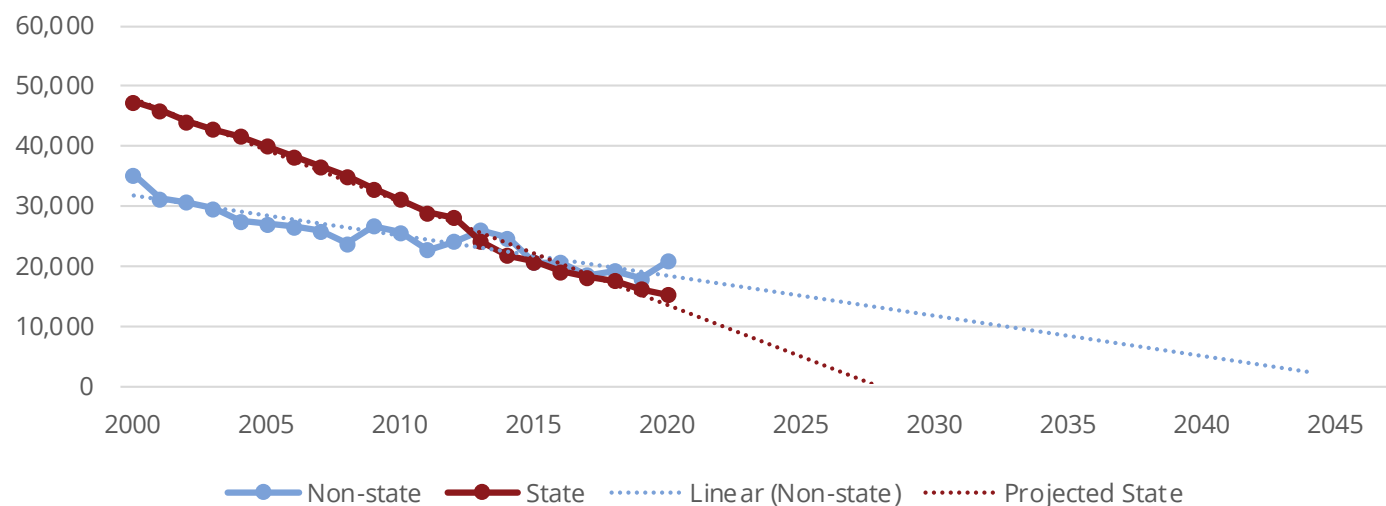


Figure 3.2). The number of LTSS recipients with IDD living in non-state settings of all sizes increased from 91,976 to 500,927. The proportion of people living in non-state settings of all sizes increased from 37% to 95%.

Between 1977 and 2020 of the people living in settings of sixteen or more people, the proportion living in non-state settings increased from 25% to 58% (see **Figure 3.3**).

Average Setting Size

The average number of LTSS recipients with IDD per non-family setting declined from 22.5 people in 1977 to 2.3 people in 2020. The average number of people per non-state setting declined from 8.7 in 1977 to 2.2 in 2020. The average number of people per state setting declined from 335.1 in 1977 to 12.9 in 2020.

Table 3.3 Medicaid Expenditures for ICF/IID and Waiver Recipients with IDD as a Proportion of All Medicaid Expenditures Select Years 1980 to 2020

Fiscal Year	Total Medicaid Expenditures (Billions) ¹	Medicaid ICF/IID and Waiver Expenditures for Persons with IDD (Billions)	Proportion of Total Expenditures for People with IDD (%)
1980	\$15	\$2	12%
1988	\$30	\$4	12%
1992	\$64	\$6	9%
1994	\$137	\$12	9%
1996	\$154	\$14	9%
1998	\$168	\$17	10%
2000	\$194	\$20	10%
2002	\$243	\$24	10%
2004	\$286	\$27	10%
2006	\$299	\$31	10%
2008	\$337	\$34	10%
2010	\$392	\$42	11%
2011	\$415	\$41	10%
2012	\$423	\$43	10%
2013	\$445	\$42	9%
2014	\$498	\$42	8%
2015	\$543	\$44	8%
2016	\$565	\$46	8%
2017	\$579	\$48	8%
2018	\$586	\$49	8%
2019	\$614	\$55	9%
2020	\$672	\$57	8%

¹Source <https://www.medicaid.gov/state-overviews/scorecard/annual-medicaid-chip-expenditures/index.html>

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

Figure 3.4 highlights trends in the number of people with IDD living in state-run and non-state IDD facilities serving 16 or more LTSS recipients with IDD and projects the number of people who will be living in those settings through 2045. The number of LTSS recipients with IDD living in non-state settings of 16 or more people dropped from 35,253 in 2000 to 20,929 in 2020 (a decrease of 14,324 people or 41%). The number of LTSS recipients with IDD in state-run settings of 16 or more people dropped from 47,329 in 2000 to 15,322 in 2020 (a decrease of 32,007 people or 68%). At these rates of decline, there would no longer be any LTSS recipients with IDD in state-run settings of 16 or more people by 2029, but there will continue to be people with IDD living in non-state settings of 16 or more people through 2045.

TRENDS IN MEDICAID RECIPIENTS AND EXPENDITURES

Total Medicaid expenditures for all populations grew from \$14.55 billion in 1980 to \$672 billion in 2020 (see **Table 3.3**). Medicaid ICF/IID and Waiver funding for people with IDD increased from \$1.74 billion in 1980 to \$56.6 billion in 2020. The proportion of Medicaid expenditures allocated to LTSS for people with IDD declined from 11.9% in 1980 to 8.4% in 2020.

Recipients

The number of people in ICF/IID settings peaked at 147,729 in 1993 but declined by 56% to 64,902 by 2020 (see **Figure 3.5a**). In 1982, there were 1,381 Medicaid Waiver recipients (1% of Medicaid Waiver plus ICF/IID LTSS recipients) and 140,752 people (99%) in ICF/IIDs. By June 30, 2020, the number of Medicaid Waiver recipients had grown to 954,314 (94% of Medicaid Waiver plus ICF/IID recipients) compared with 64,902 people in ICF/IID settings.

Expenditures

In 1982, Medicaid ICF/IID expenditures were \$3.35 billion (99.9% of combined expenditures) while Medicaid Waiver expenditures for people with IDD were \$2.24 million (see **Figure 3.5b**). By 2001, annual Medicaid Waiver expenditures exceeded

Figure 3.5a Medicaid ICF/IID and HCBS Waiver Recipients with IDD from 1982 to 2020

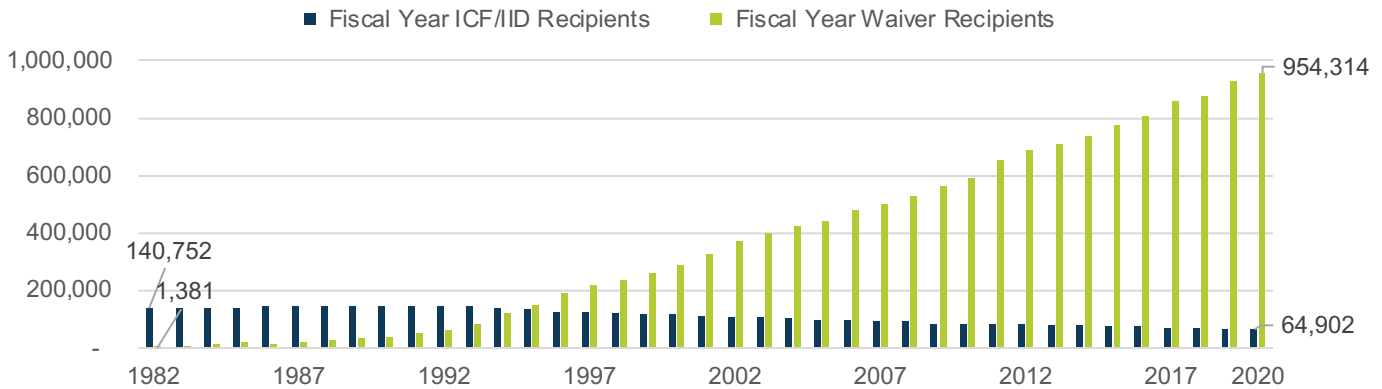


Figure 3.5b Medicaid ICF/IID and HCBS Waiver Expenditures in Billions for People with IDD From 1982 to 2020

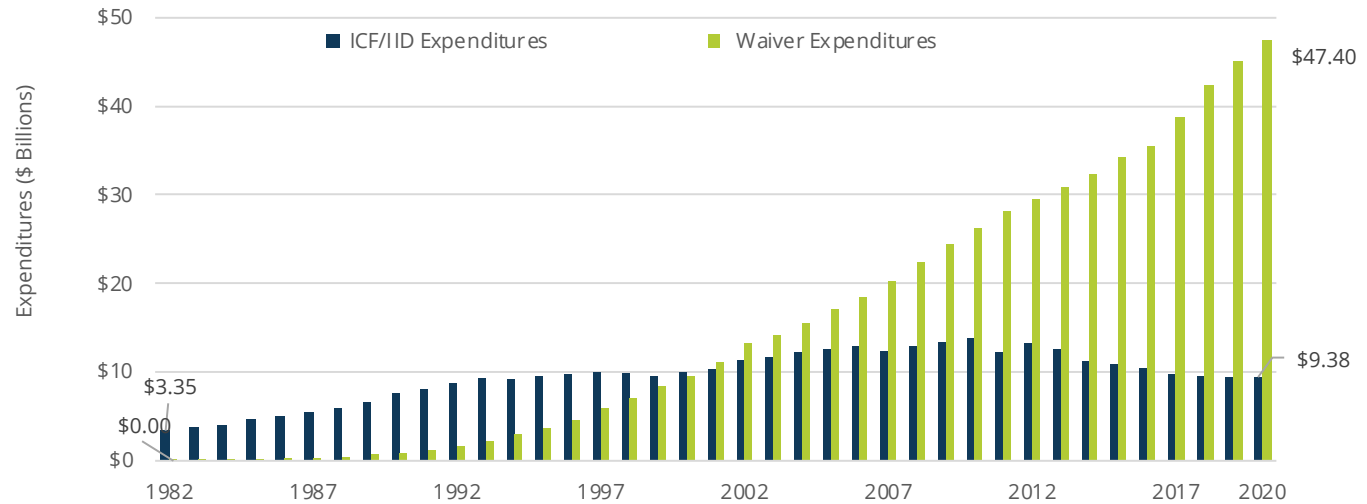
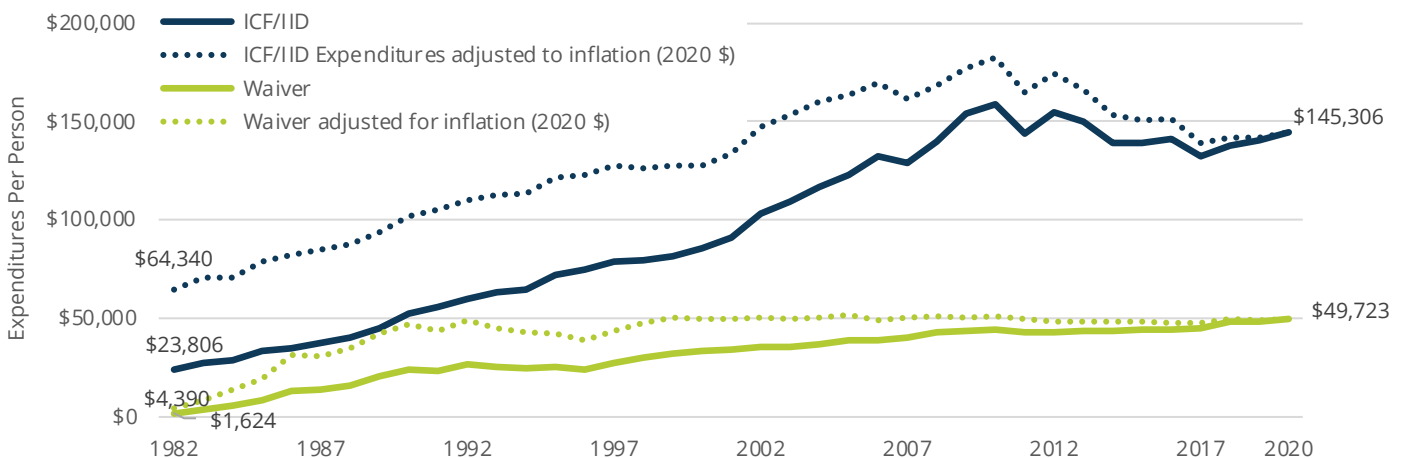


Figure 3.5c Average Annual Per Person ICF/IID and Waiver Expenditures For People with IDD From 1982 to 2020





annual ICF/IID expenditures (\$11.0 billion compared with \$10.35 billion). In 2020, annual Medicaid Waiver expenditures were \$47.4 billion (80% of combined expenditures) compared to \$9.38 billion for ICF/IID.

Annual per Recipient Costs

The average annual per person costs have always been higher for people in ICF/IID settings than for Medicaid Waiver recipients with IDD (see [Figure 3.5c](#)). In 1982, average annual per recipient expenditures were \$1,624 for Medicaid Waiver recipients (\$4,390 in 2020 inflation-adjusted dollars) and \$23,806 for people in ICF/IID settings (\$64,340 in 2020 inflation-adjusted dollars). In 2020, average annual per recipient expenditures had increased to \$49,723 for Medicaid Waiver recipients and to \$145,306 for people in ICF/IID settings. In both real and inflation-adjusted dollars the average annual per person expenditures for people in ICF/IIDs have declined since 2010. This is heavily influenced by the continued closures of expensive state-run ICF/IIDs (The number of state-run facilities

with sixteen or more people declined from 203 in 2010 to 103 in 2020).

Medicaid Participants and Expenditures by State

Tables 3.4 through **3.7** show trends in Medicaid Waiver and ICF/IID participants and expenditures by state for selected years 1982 to 2020. Data from each state for all available years can be viewed at the RISP website in the State Profiles.

Medicaid HCBS Waiver Recipients

In 1982, two states offered supports to people with IDD funded by a Medicaid Waiver authority. By 2002, all 51 states offered supports funded by one or more Medicaid Waiver authorities. The number of Waiver recipients grew from 1,381 on June 30, 1982, to 688,410 on June 30, 2012, and 921,443 on June 30, 2020 (see [Table 3.4](#)). Between 2012 and 2020, the number of Medicaid Waiver recipients grew in every state except Montana (which reported

Table 3.4 Estimated Medicaid Waiver Recipients with IDD by State on June 30th Selected Years, 1982 to 2020

State	1982	1987	1992	1997	2002	2007	2012	2017	2019	2020	% Change 2012 vs 2020
AL	0	1,570	2,184	3,713	4,764	5,230	5,604	5,622	6,029	6,029	8%
AK	0	0	0	353	884	1,011	1,703	2,093	2,430	2,553	50%
AZ	0	0	4,832	8,508	13,471	19,066	24,617	30,982	34,325	35,858	46%
AR	0	0	415	496	2,494	3,342	4,037	4,138	4,737	4,211	4%
CA	0	3,027	3,360	37,478	44,205	73,024	97,868	124,081	109,502	108,882	11%
CO	0	1,389	2,204	4,276	6,516	7,148	8,147	12,184	12,770	12,699	56%
CT	0	0	1,693	3,371	5,972	7,692	8,638	9,979	9,928	10,438	21%
DE	0	81	290	379	547	788	855	1,031	1,581	1,842	115%
DC	0	0	0	0	225	1,090	1,479	1,796	2,037	2,028	37%
FL	0	2,631	2,637	11,399	25,921	31,425	29,353	33,812	34,728	34,473	17%
GA	0	0	359	2,332	8,190	9,194	11,621	8,579	13,370	13,681	18%
HI	0	56	452	560	1,560	2,481	2,544	2,367	2,867	2,955	16%
ID	0	55	225	434	1,139	2,015	2,660	8,113	8,804	7,809	194%
IL	0	664	2,006	5,400	6,787	12,800	18,355	22,810	23,588	23,772	30%
IN	0	0	0	1,067	3,802	9,976	12,786	25,099	29,323	31,130	143%
IA	0	4	137	3,932	6,228	12,751	11,359	12,716	13,649	22,737	100%
KS	0	135	555	3,872	6,239	7,195	8,274	8,891	7,503	9,625	16%
KY	0	609	819	1,040	1,807	3,033	11,046	17,392	15,653	15,300	39%
LA	0	0	939	2,048	4,232	6,915	9,957	12,085	23,438	12,856	29%
ME	0	400	509	1,078	2,440	2,781	4,101	4,948	5,177	6,274	53%
MD	0	685	1,972	3,392	6,768	10,294	12,489	15,283	15,955	15,693	26%
MA	0	593	3,288	8,027	11,315	11,962	11,987	15,354	17,046	14,085	18%
MI	0	3	2,741	6,199	8,550	8,089	39,838	45,115	49,589	49,874	25%
MN	0	1,423	2,890	6,097	14,735	14,593	18,963	21,792	23,207	24,310	28%
MS	0	0	0	231	1,673	1,978	1,831	2,690	2,828	2,759	51%
MO	0	0	2,241	6,282	8,143	8,396	11,041	14,152	15,088	14,729	33%
MT	21	210	444	891	1,452	2,242	2,668	2,796	2,656	2,604	-2%
NE	0	0	710	2,010	2,419	3,304	4,531	4,592	4,770	4,996	10%
NV	0	129	136	374	1,083	1,372	1,652	2,152	2,314	2,512	52%
NH	0	541	1,059	2,063	2,779	3,339	4,519	5,387	5,313	6,519	44%
NJ	0	2,596	3,971	5,705	7,486	9,923	11,297	11,874	19,729	21,625	91%
NM	0	220	334	1,603	2,794	3,711	4,115	4,616	4,648	5,147	25%
NY	0	0	379	29,019	48,165	56,401	77,047	82,656	86,556	88,421	15%
NC	0	328	939	3,726	6,013	9,309	12,800	21,786	31,510	29,840	133%
ND	0	724	1,334	1,792	2,011	3,535	4,059	4,956	5,027	4,606	13%
OH	0	100	397	2,646	7,858	16,362	30,872	39,180	38,490	42,174	37%
OK	0	70	949	2,497	4,100	5,308	5,223	5,625	5,242	5,222	-0%
OR	1,360	832	1,458	2,586	8,017	10,287	14,865	21,200	22,153	23,336	57%
PA	0	1,203	2,705	8,931	24,969	26,558	29,963	34,911	36,514	36,849	23%
RI	0	136	993	2,178	2,674	3,126	3,316	4,354	3,775	3,766	14%
SC	0	0	471	3,412	4,410	5,186	8,394	10,929	10,885	11,120	32%
SD	0	596	852	1,457	2,295	2,609	3,215	3,625	3,625	4,130	28%
TN	0	213	704	3,293	4,340	7,244	7,680	8,137	9,499	9,914	29%
TX	0	70	968	4,753	7,873	16,301	29,193	37,582	36,847	35,875	23%
UT	0	0	1,367	2,315	3,589	4,003	4,319	4,960	5,644	5,702	32%
VT	0	196	413	1,372	1,844	2,200	2,649	3,070	2,853	2,920	10%
VA	0	0	537	1,764	5,491	7,523	9,754	12,511	14,228	14,685	51%
WA	0	886	1,918	6,643	9,900	9,317	11,898	16,900	23,642	24,645	107%
WV	0	124	513	1,441	2,796	3,852	4,447	4,514	5,616	5,495	24%
WI	0	190	1,812	6,558	9,474	12,504	23,396	33,060	39,064	40,360	73%
WY	0	0	318	916	1,507	2,079	2,150	2,401	2,277	2,378	11%
Estimated US Total	1,381	22,689	62,429	221,909	373,946	501,864	688,410	846,878	908,029	921,443	34%
N States	2	35	47	50	51	51	51	51	51	51	51

State data for all years since 1982 can be viewed in State Profiles on the RISP.umn.edu website. Medicaid Waiver authorities include 1115, 1915 (a), 1915 (a/c), 1915 (b), 1915 (b/c) and 1915 (c).

a decrease from 2,668 to 2,604; -2%). States reporting the greatest percentage growth between 2012 and 2020 were Idaho (growing by 194% from 2,660 to 7,809 recipients), Indiana (growing by 143% from 12,786 to 31,130 recipients), and North Carolina (growing by 133% from 12,800 to 29,840).

Medicaid HCBS Waiver Expenditures

Between 2012 and 2020, total Medicaid Waiver expenditures increased from \$29.54 billion to \$47.4 billion, an increase of 60% (see **Table 3.5**). Ten states posted increases of 100% or more in Medicaid Waiver Expenditures between 2012 and 2020. Those states were Arizona (increasing 114% from \$640.1 million to \$1.4 billion), California (increasing 102% from \$2.1 billion to \$4.3 billion), Idaho (increasing 336% from \$64.4 million to \$280.7 million), Massachusetts (increasing 103% from \$876.8 million to \$1.8 billion), Michigan (increasing 129% from \$445.7 million to \$1 billion), Mississippi (increasing 189% from \$44 million to \$127.2 million), Missouri (increasing 103% from \$534 million to \$1.1 billion),

New Jersey (increasing 146% from \$737.9 million to \$1.8 billion), North Carolina (increasing 105% from \$619.8 million to \$1.3 billion), and Utah (increasing 108% from \$155.5 million to \$323 million).

Medicaid Waiver expenditures decreased between 2012 and 2020 in Oregon, declining from \$597.7 million to \$181.6 million as the state shifted from primarily using 1915(c) HCBS Waiver to using state plan HCBS funding.

Medicaid ICF/IID Recipients

Between 2012 and 2020 the number of people with IDD living in ICF/IIDs decreased 25% from 85,384 to 64,445 people with 43 states reporting decreases (see **Table 3.6**). States reporting the largest decreases were Wisconsin (decreasing 60% from 895 to 357), Virginia (decreasing 53% from 1,326 to 625), Colorado (decreasing 52% from 343 to 164), and New Jersey (decreasing 49% from 2,426 to 1,246)



Table 3.5 Estimated Medicaid Waiver Expenditures (in \$1,000s) for People with IDD by State Selected Fiscal Years 1982 to 2020

State	1982	1987	1992	1997	2002	2007	2012	2017	2019	2020	% change 2012-2020
AL	0	\$8,326	\$12,400	\$72,327	\$120,395	\$253,259	\$288,701	\$380,161	\$350,723	\$350,723	21%
AK	0	0	0	17,668	51,866	70,955	134,516	176,258	181,935	189,863	41%
AZ	0	0	98,716	203,898	386,529	556,450	640,785	982,473	1,178,190	1,372,722	114%
AR	0	0	11,250	12,063	53,077	91,380	173,135	225,030	180,989	218,920	26%
CA	0	30,400	54,049	355,246	853,788	1,532,880	2,107,489	3,383,876	3,812,260	4,258,507	102%
CO	0	25,455	60,192	133,282	205,028	268,080	331,010	453,993	535,762	613,202	85%
CT	0	7	83,575	222,364	386,547	454,125	720,878	929,152	793,638	963,243	34%
DE	0	846	5,105	16,279	34,181	75,090	94,329	135,182	154,788	171,757	82%
DC	0	0	0	0	1,648	19,678	147,196	218,864	254,769	272,853	85%
FL	0	12,850	20,246	131,805	496,921	908,572	879,855	1,004,430	1,231,963	1,188,964	35%
GA	0	0	10,250	63,130	286,390	263,542	407,212	356,495	697,001	710,426	74%
HI	0	565	4,385	11,721	34,728	97,000	102,910	102,074	144,974	139,507	36%
ID	0	568	1,188	9,996	27,804	60,937	64,425	249,874	285,535	280,718	336%
IL	0	12,840	79,600	116,000	140,200	416,200	591,460	923,395	996,771	1,118,750	89%
IN	0	0	0	33,301	198,630	402,597	489,971	741,069	690,082	870,751	78%
IA	0	0	774	48,271	127,081	275,728	387,580	565,174	677,674	676,158	74%
KS	0	638	13,737	93,519	189,358	247,334	330,269	489,936	403,343	422,775	28%
KY	0	10,974	19,821	29,430	91,756	163,060	406,429	655,991	712,781	726,779	79%
LA	0	0	1,785	44,291	129,015	258,220	407,248	473,862	508,601	521,140	28%
ME	0	5,674	13,250	60,067	136,461	230,661	291,071	346,241	450,704	294,334	1%
MD	0	21,708	72,327	140,673	251,357	495,386	686,894	1,003,268	1,061,513	1,067,598	55%
MA	0	13,278	90,000	280,000	483,391	587,453	876,814	1,483,297	1,556,196	1,784,300	103%
MI	0	80	81,039	162,809	538,109	316,274	445,712	0	1,983,102	1,019,657	129%
MN	0	13,170	95,381	260,223	699,687	889,902	1,215,081	1,554,310	1,674,488	1,811,930	49%
MS	0	0	0	631	20,699	39,461	43,976	94,711	120,886	127,150	189%
MO	0	0	65,792	154,768	235,897	379,435	533,967	889,123	1,034,232	1,083,101	103%
MT	375	3,596	10,827	22,500	42,005	68,412	90,871	114,648	121,786	126,789	40%
NE	0	0	25,522	58,901	108,402	140,172	239,921	291,120	328,871	356,874	49%
NV	0	1,489	2,400	4,877	24,367	61,585	78,767	104,967	124,995	144,993	84%
NH	0	13,518	44,400	89,427	117,922	143,209	192,025	0	274,088	285,974	49%
NJ	0	35,888	108,601	180,006	402,988	496,612	737,871	1,047,873	1,418,241	1,817,698	146%
NM	0	1,410	8,829	46,295	157,256	247,597	285,949	356,395	388,667	422,132	48%
NY	0	712	34,496	1,114,423	2,125,806	3,449,069	5,468,225	5,615,944	6,511,577	6,879,357	26%
NC	0	3,059	13,833	106,199	254,337	377,747	619,805	1,063,758	1,267,532	1,267,532	105%
ND	0	5,438	18,975	30,176	47,531	71,823	129,617	199,935	212,557	170,180	31%
OH	0	1,131	12,824	90,058	245,009	660,978	1,240,863	1,635,258	1,835,686	2,211,806	78%
OK	0	392	39,375	93,593	222,356	253,401	273,952	310,647	313,337	351,791	28%
OR	1,869	8,306	58,604	105,178	361,705	385,762	597,868	90,153	144,885	181,631	-70%
PA	0	35,975	133,681	415,399	977,487	1,199,739	1,816,306	2,705,916	3,411,121	3,446,024	90%
RI	0	5,648	14,367	107,962	160,859	245,521	203,663	209,184	258,145	258,145	27%
SC	0	0	4,961	51,300	142,500	185,700	291,243	329,786	424,081	455,817	57%
SD	0	6,153	16,257	38,739	58,935	81,945	101,739	115,968	134,642	144,690	42%
TN	0	1,853	14,431	72,738	205,314	525,964	604,098	682,075	767,928	787,835	30%
TX	0	1,828	39,755	159,896	321,671	566,475	1,058,827	1,515,458	1,465,974	1,580,231	49%
UT	0	0	23,000	50,794	88,991	113,867	155,515	244,217	294,307	322,960	108%
VT	0	4,840	14,154	47,980	74,856	109,071	141,617	198,042	217,922	222,404	57%
VA	0	0	15,975	67,430	198,911	394,326	602,412	821,443	978,059	1,017,643	69%
WA	0	12,068	39,974	105,006	214,490	315,624	550,896	56,035	618,958	742,622	35%
WV	0	777	13,200	43,660	120,218	203,371	303,862	0	299,138	312,400	3%
WI	0	3,503	39,078	155,238	312,785	439,299	855,374	1,222,445	1,487,757	1,524,201	78%
WY	0	0	12,508	33,428	56,957	87,041	98,497	92,449	110,350	112,028	14%
Estimated US Total	2,243	304,961	1,654,887	5,964,966	13,224,202	20,177,966	29,538,694	36,841,952	45,083,505	47,399,587	60%
N States	2	36	47	50	51	51	51	51	51	51	51

State data for all years since 1982 can be viewed in State Profiles on the RISP.umn.edu website. ^a Other date (data from previous or next year). ^e Estimate. ⁱ One or more component value imputed by RISP staff. DNF Did not furnish. ^s Source: (Eiken et al., 2018). Medicaid Waiver authorities include 1115, 1915 (a), 1915 (a/c), 1915 (b), 1915 (b/c) and 1915 (c).

Table 3.6 Estimated ICF/IID Recipients by State, June 30, Selected Fiscal Years 1977 to 2020

State	1977	1982	1987	1992	1997	2002	2007	2012	2017	2019	2020	% change 2012-2020
AL	0	1,470	1,364	1,304	745	472	244	41	22	15	26 ¹⁵	-37%
AK	135	118	107	86	10	0	0	0	0	0	14	N/A
AZ	0	0	0	214	214	207	185	148	42	122	101 ⁱ	-32%
AR	1,385	1,420	1,453	1,737	1,558	1,684	1,616	1,467	1,425	1,430	1,422 ^j	-3%
CA	0	10,374	10,871	10,923	10,681	10,839	9,598	8,726	7,649	7,130	6,793	-22%
CO	4,537	2,017	1,149	754	229	111	125	343	173	168	164 ^e	-52%
CT	687	1,598	1,414	1,378	1,377	1,192	1,148	993	742	664	621	-37%
DE	477	513	439	325	292	241	141	135	118	119	118	-13%
DC	0	436	666	761	754	734	640	363	319	308	288	-21%
FL	370	2,128	3,180	3,118	3,476	3,338	3,205	2,806	2,770	2,612	2,645	-6%
GA	2,369	2,491	1,913	1,935	1,770	1,475	1,034	300	143	265	214 ^s	-29%
HI	524	387	296	154	122	94	78	79	79	62	70	-11%
ID	583	482	461	519	579	576	543	487	455	432	382 ^j	-22%
IL	5,353	8,144	10,346	12,311	10,500	9,923	9,213	8,344	6,593	6,380	6,218	-25%
IN	1,026	2,798	4,690	6,234	5,938	4,981	4,012	3,839	3,179	3,081	3,123	-19%
IA	1,432	1,673	1,840	2,088	2,268	2,157	2,123	2,002	1,765	1,429	1,535 ^j	-23%
KS	1,810	2,078	2,081	1,921	1,395	688	599	509	433	406	385	-24%
KY	999	1,250	1,187	1,200	1,180	876	637	523	422	407	382	-27%
LA	3,682	4,849	6,016	5,645	6,014	5,539	5,320	4,604	4,639	4,490	4,490 ^j	-2%
ME	310	630	677	630	548	246	222	202	159	191	191	-5%
MD	1,367	1,851	1,429	954	624	502	336	54	92	93	93	72%
MA	4,242	4,041	3,698	3,304	1,598	1,125	952	594	396	342	309	-48%
MI	5,760	4,002	3,683	3,180	2,899	173	151	0	0	0	0	N/A
MN	5,303	6,899	6,339	5,202	3,604	2,756	2,513	1,719	1,287	1,018	955	-44%
MS	491	1,614	1,678	1,825	2,256	2,534	2,601	2,765	2,169	2,253	2,020 ^j	-27%
MO	2,051	1,878	1,868	1,751	1,466	1,398	1,020	590	421	383	359	-39%
MT	0	290	253	170	148	119	54	55	12	0	0 ⁱ	N/A
NE	1,356	980	808	739	643	642	582	433	348	345	301	-30%
NV	0	175	188	146	275	242	118	104	91	82	79	-24%
NH	288	339	204	81	23	25	25	25	23	25	25	0%
NJ	525	4,366	3,815	3,942	3,948	3,370	2,963	2,426	1,463	1,323	1,246	-49%
NM	426	553	709	730	348	284	182	234	266	273	243 ^j	4%
NY	18,601	15,577	17,567	18,497	11,472	9,815	7,995	7,288	4,895	4,170	3,838	-47%
NC	2,073	2,762	3,445	4,502	4,777	4,645	4,124	3,930	4,406	4,007	3,757 ^s	-4%
ND	0	219	888	476	609	629	593	559	539	537	525	-6%
OH	2,488	6,040	7,535	8,384	7,615	7,240	6,667	6,926	5,814	5,171	5,068 ^j	-27%
OK	1,978	1,803	3,242	2,776	2,292	2,243	1,630	1,549	1,307	1,428	1,441 ^j	-7%
OR	1,989	1,918	1,284	668	373	51	41	0	0	0	0	N/A
PA	7,355	8,598	7,364	7,282	6,192	4,280	3,833	3,419	2,827	2,540	2,419	-29%
RI	763	881	1,093	602	21	40	41	42	34	40	29	-31%
SC	1,017	2,665	3,300	3,261	2,555	1,992	1,615	1,313	1,158	1,153	1,120	-15%
SD	540	721	650	552	328	189	158	199	192	181	165 ^s	-17%
TN	2,149	2,377	2,198	2,399	1,900	1,460	1,223	1,108	997	948	937 ^e	-15%
TX	10,486	13,959	12,211	11,187	12,985	12,684	11,447	9,467	7,939	7,522	7,598	-20%
UT	1,193	1,199	945	930	833	783	794	801	190	732	690 ^j	-14%
VT	352	385	238	146	12	12	6	6	6	6	6	0%
VA	3,558	3,616	3,018	2,743	2,225	1,885	1,684	1,326	658	616	625	-53%
WA	440	2,464	2,539	1,695	1,126	880	767	629	738	653	515 ^j	-18%
WV	0	176	417	699	574	515	477	562	514	498	492 ^j	-12%
WI	3,696	3,548	3,378	4,110	3,187	2,580	1,059	895	922	383	357	-60%
WY	0	0	0	90	139	106	93	79	62	52	51	-35%
Estimated US Total	106,166	140,752	146,641	146,260	126,697	110,572	96,427	85,384	71,018	66,485	64,445	-25%
N States	42	49	49	51	51	50	50	48	48	47	48	49

State data for all years since 1982 can be viewed in State Profiles on the RISP.umn.edu website. ^b Non-State only. ^c State only. ^d Other date (data from previous or next year). ^e Estimate. ^f Sum of setting data substituted for reported value. ^g One or more component value imputed by RISP staff. ^h Source: ACHA (2018a); Eiken, et al (2018). DNF Did not furnish. PD Partial Data.
 *See state notes in Appendix.

Table 3.7 Estimated Medicaid ICF/IID Expenditures (in \$1,000s) by State, Selected Years 1982 to 2020 (not inflation adjusted)

State	1982	1988	1992	1997	2002	2007	2012	2017	2019	2020	% change 2012-2020
AL	\$31,076	\$54,014	\$80,701	\$58,306	\$60,516	\$31,522	\$10,586	\$1,990	\$1,424	\$2,294 ^c	-78%
AK	6,830	9,038	10,384	2,032	0	161	3,051	2,736	3,002	2,970	-3%
AZ	0	0	0	0	0	0	32,593	1,336	947	783	-98%
AR	34,603	51,087	88,047	105,950	28,958	146,960	168,540	DNF	155,447	193,142	15%
CA	87,544	269,638	316,072	380,655	663,954	824,990	821,840	696,318	548,751	513,066	-38%
CO	-1,194	43,403	55,495	23,575	19,202	22,647	39,533	43,853	48,315	51,991	32%
CT	41,722	109,464	192,888	188,190	213,455	240,165	284,642	194,535	307,158	164,784	-42%
DE	8,281	15,246	26,543	31,233	31,219	26,647	17,462	32,392	32,702	18,760	7%
DC	7,350	40,108	51,774	74,258	79,480	85,051	69,494	92,289	89,363	95,057	37%
FL	48,048	130,435	181,802	248,208	310,393	319,288	328,460	331,591	331,591	347,302	6%
GA	48,271	84,730	115,391	127,303	110,659	105,885	67,117	DNF	31,333	37,088 ^c	-45%
HI	10,962	14,290	6,571	11,628	8,572	8,683	7,715	4,437	8,204	8,582	11%
ID	12,490	23,130	35,545	43,454	57,714	59,702	23,064	DNF	7,785	8,862	-62%
IL	120,855	243,824	499,573	580,152	720,932	696,183	688,115	586,802	607,588	684,215	-1%
IN	37,326	86,777	272,735	304,187	338,947	318,531	294,064	269,363	271,649	279,016	-5%
IA	52,267	88,710	150,456	178,213	192,996	276,651	301,739	206,347	400,593	139,309	-54%
KS	40,647	69,568	102,523	94,468	65,863	65,288	64,412	40,556	27,065	26,898	-58%
KY	39,053	47,597	59,843	75,691	97,888	151,886	130,481	147,232	36,578	135,712	4%
LA	97,076	165,291	260,925	422,009	362,343	442,023	467,517	352,396	334,238	402,790 ^c	-14%
ME	15,699	30,613	62,854	45,548	50,370	71,664	74,915	40,200	43,648	26,978	-64%
MD	53,170	83,621	65,023	63,699	61,628	68,466	123	25,780	14,259	15,256 ^c	12300%
MA	125,500	198,722	385,149	254,062	198,023	206,612	165,995	97,514	102,257	105,080	-37%
MI	152,838	213,105	180,561	519,144	27,648	28,824	0	0	0	0	N/A
MN	155,020	238,700	283,108	238,628	207,841	175,376	164,145	114,406	106,380	100,355	-39%
MS	20,579	32,524	62,156	119,386	178,043	255,287	270,287	196,141	238,465	171,027	-37%
MO	35,207	71,080	106,866	155,768	230,169	105,836	108,468	89,799	83,969	81,735	-25%
MT	0	10,179	13,124	15,809	14,061	10,632	11,320	5,759	0	0	N/A
NE	21,336	25,477	32,910	36,896	47,671	66,940	57,654	62,084	64,375	62,414	8%
NV	5,661	9,523	16,670	22,845	30,309	21,390	17,955	18,627	14,942	17,741	-1%
NH	6,339	14,142	6,127	1,299	1,953	2,522	3,154	DNF	4,128	4,128	31%
NJ	122,552	237,997	276,342	373,077	462,969	628,421	650,873	461,199	431,748	429,272	-34%
NM	12,078	23,587	39,164	21,729	18,993	21,263	24,809	26,785	28,891	31,327	26%
NY	797,385	1,158,161	1,715,103	2,010,006	2,472,622	3,057,177	3,382,395	1,060,094	985,697	905,398	-73%
NC	79,192	158,440	278,485	363,153	416,623	466,789	444,383	398,948	568,065	568,065 ^c	28%
ND	498	40,216	39,980	43,653	54,683	61,655	92,146	71,114	89,713	98,413	7%
OH	36,634	278,624	468,322	391,631	962,507	697,689	757,788	716,348	704,651	734,569	-3%
OK	32,395	83,725	111,773	100,900	112,292	127,291	113,228	DNF	81,822	94,524 ^c	-17%
OR	5,287	73,727	83,138	75,273	11,346	22,407	0	0	0	0	N/A
PA	326,340	384,252	502,755	527,594	506,212	584,411	580,876	603,230	580,767	596,651	3%
RI	28,759	60,548	90,368	10,401	7,244	7,810	9,160	2,708	11,069	7,802	-15%
SC	36,020	94,198	165,299	174,750	174,843	157,180	150,914	140,018	149,616	159,035	5%
SD	14,890	22,005	29,221	20,194	18,448	20,149	29,594	31,198	31,710	35,678 ^c	21%
TN	56,831	77,504	111,715	212,774	252,512	243,129	216,276	203,300	198,048	199,108	-8%
TX	233,539	357,823	468,605	640,849	811,722	906,152	1,047,598	1,113,101	1,015,874	1,103,850	5%
UT	23,711	27,666	39,659	45,047	54,883	58,134	63,278	40,106	42,430	43,336	-32%
VT	13,421	11,335	17,841	1,479	1,631	0	1,212	1,151	1,132	1,389	15%
VA	78,609	106,785	153,992	159,667	216,052	231,030	288,116	243,550	186,762	165,774 ^c	-42%
WA	72,202	119,320	182,045	128,968	127,817	114,854	106,120	192,150	125,993	113,000 ^c	6%
WV	1,982	8,662	15,031	52,705	47,513	57,354	65,414	DNF	71,072	67,713	4%
WI	63,845	89,337	193,185	201,998	226,014	131,158	197,496	132,954	113,912	123,848	-37%
WY	0	0	2,556	17,778	15,543	20,007	20,745	18,713	20,593	19,390 ^c	-7%
Estimated US Total	3,350,726	5,887,947	8,706,396	9,996,224	11,383,282	12,449,872	12,936,860	9,111,148	9,355,722	9,195,477	-29%
N States	48		49	50	51	50	51	50	50	50	50

^b Nonstate only. ^c Other date (data from previous or next year). ^e Estimate. DNF Did not furnish. PD Partial data. ^s Other Source (Eiken et al., 2017) State data for all years since 1982 can be viewed in State Profiles on the RISP.umn.edu website.

Two states reported increases in the total number of ICF/IID recipients between 2012 and 2020. The number of ICF/IID recipients increased in Maryland (increasing 72% from 54 to 93) and New Mexico (increasing 4% from 234 to 243).

Medicaid ICF/IID Expenditures

Total Medicaid ICF/IID expenditures decreased 29% overall between 2012 and 2020 from \$12.9 billion to \$9.2 billion (see **Table 3.7**). ICF/IID expenditures decreased in 28 states with the largest decreases in Arizona (decreasing 98% from \$32.6 million to \$783,000), Alabama (decreasing 78% from \$10.6 million to \$2.3 million), New York (decreasing 73% from \$3.38 billion to \$905.4 million), and Maine (decreasing 64% from \$74.9 million to \$27 million).

Twenty states reported increases in ICF/IID expenditures between 2012 and 2020. States reporting the largest increases were the District of Columbia (increasing 37% from \$69.5 million to \$95.1 million), Colorado (increasing 32% from \$39.5 million to \$52 million), and New Hampshire (increasing 31% from \$3.2 million to \$4.1 million). Maryland also had a large increase in ICF/IID expenditures, but their 2012 total may have not included all claims.

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

TRENDS IN DEATHS OF PEOPLE ON STATE IDD AGENCY CASELOADS

To track the impact of the Covid-19 pandemic on people with IDD, we retroactively requested data on the number of people on the IDD agency caseload who died during the fiscal year dating back to 2018 and 2019 as well as 2020 on the FY 2020 survey (see **Table 3.8**).

Between 2018 and 2020, the number of deaths per 1,000 people of all ages on IDD agency caseloads increased from 10.2 to 10.5 (3%). Out of 38 reporting states, 24 reported increases. The largest increases were reported by Arkansas (increasing 198% from 1.4 to 4.1 deaths per 1,000), Oklahoma (increasing 85% from 5.7 to 10.6), the District of Columbia (increasing 77% from 16.3 to 28.9), New York (increasing 76% from 8.1 to 14.3), and Nevada (increasing 39% from 6.5 to 9.0). Fourteen states reported decreases. The largest decreases were in Ohio (decreasing 34% from 9.6 to 6.3 deaths per 1,000), Michigan (decreasing 25% from 17.3 to 12.9), Alaska (decreasing 25% from 8.8 to 6.6), and New Mexico (decreasing 20% from 8.6 to 6.9).

Between 2018 and 2020, the number of deaths per 1,000 adults on state IDD caseloads increased from 15.5 to 17.0 (an increase of 10%; see **Figure 3.6**). The number of deaths per 1,000 children on state IDD agency caseloads declined from 2.7 to 2.2 (a decrease of 20%).

Figure 3.6 Deaths per 1,000 Children and Adults on IDD Agency Caseloads Fiscal Years 2018, 2019 and 2020

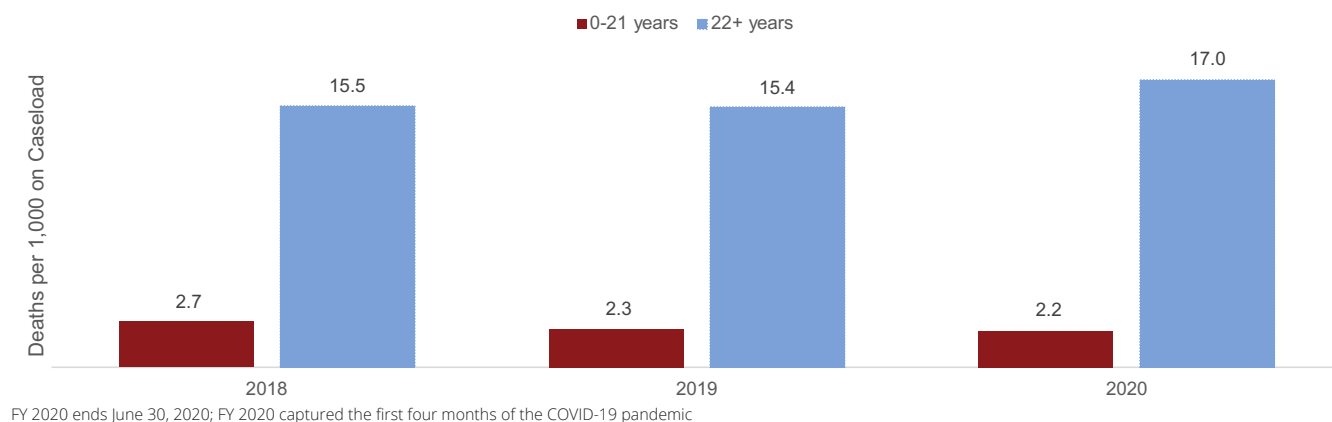


Table 3.8 Deaths per 1,000 People on State IDD Agency Caseloads FY 2018 to FY 2020

State	2018						2020					
	0 to 21 yrs	22+ yrs	All Ages	0 to 21 yrs	22+ yrs	All Ages	0 to 21 yrs	22+ yrs	All ages	0 to 21 yrs	22+ yrs	All Ages
N States	34	35	38	34	35	38	34	36	39	31	34	38
AL	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
AK	DNF	DNF	9	DNF	DNF	9	DNF	DNF	7	DNF	DNF	-25%
AZ	9	19	12	10	17	12	10	19	13	8%	-3%	3%
AR	2	1	1	1	0	0	3	0	4	25%	N/A	198%
CA	2	13	8	2	12	7	2	13	7	-28%	-1%	-7%
CO	1	10	7	1	13	8	2	13	9	122%	25%	27%
CT	4	18	15	3	22	17	1	22	17	-61%	19%	16%
DE	2	8	6	3	9	7	3	11	9	12%	44%	36%
DC	0	17	16	0	16	15	0	30	29	N/A	78%	77%
FL	5	19	15	4	19	15	4	22	17	-19%	13%	12%
GA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
HI	10	10	10	9	15	14	3	12	10	-70%	25%	-0%
ID	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
IL	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
IN	2	17	12	2	16	11	2	17	11	-3%	1%	-7%
IA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	1	0	DNF	DNF	DNF
KS	2	15	11	1	18	12	2	20	14	9%	30%	30%
KY	2	16	10	3	15	10	3	20	14	40%	28%	35%
LA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
ME	2	17	15	0	18	17	0	14	13	N/A	-16%	-16%
MD	0	14	11	2	11	10	4	14	12	602%	-4%	9%
MA	1	22	15	1	20	13	1	25	16	-31%	14%	7%
MI	2	26	17	1	19	13	3	16	13	78%	-38%	-25%
MN	2	17	12	2	18	13	2	20	14	-8%	19%	15%
MS	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MO	2	15	9	2	14	9	2	14	9	8%	-4%	-6%
MT	1	13	8	1	16	10	1	13	8	-15%	1%	-6%
NE	2	19	17	0	23	20	2	19	15	-26%	3%	-10%
NV	1	10	7	1	8	5	2	13	9	197%	29%	39%
NH	0	6	5	0	7	5	0	6	5	N/A	-7%	-4%
NJ	N/A	16	16	N/A	33	33	N/A	21	21	N/A	33%	33%
NM	4	11	9	5	10	8	4	8	7	2%	-25%	-20%
NY	1	12	8	1	12	8	1	21	14	68%	79%	76%
NC	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
ND	3	20	11	4	19	11	1	30	14	-45%	53%	33%
OH	2	17	10	1	13	6	1	14	6	-53%	-15%	-34%
OK	DNF	DNF	6	DNF	DNF	9	DNF	DNF	11	DNF	DNF	85%
OR	3	13	9	2	12	8	1	12	8	-70%	-7%	-17%
PA	4	18	14	3	18	14	3	20	16	-17%	14%	12%
RI	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
SC	DNF	DNF	2	DNF	DNF	3	DNF	DNF	3	DNF	DNF	5%
SD	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
TN	1	16	12	1	12	9	1	21	17	101%	38%	35%
TX	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
UT	2	11	8	3	13	10	1	13	9	-30%	17%	15%
VT	0	14	9	1	18	12	2	14	10	0%	2%	11%
VA	1	14	8	1	14	8	1	18	11	-4%	33%	31%
WA	6	16	13	6	25	16	3	27	15	-58%	67%	18%
WV	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
WI	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
WY	2	9	7	3	11	8	2	9	6	-5%	-7%	-7%
Reported Total	3	16	10	2	15	10	2	17	11	-20%	10%	3%

The rate of deaths per 1,000 people on the IDD agency caseload was only computed for states reporting both the number of deaths and the total number of people on their caseload



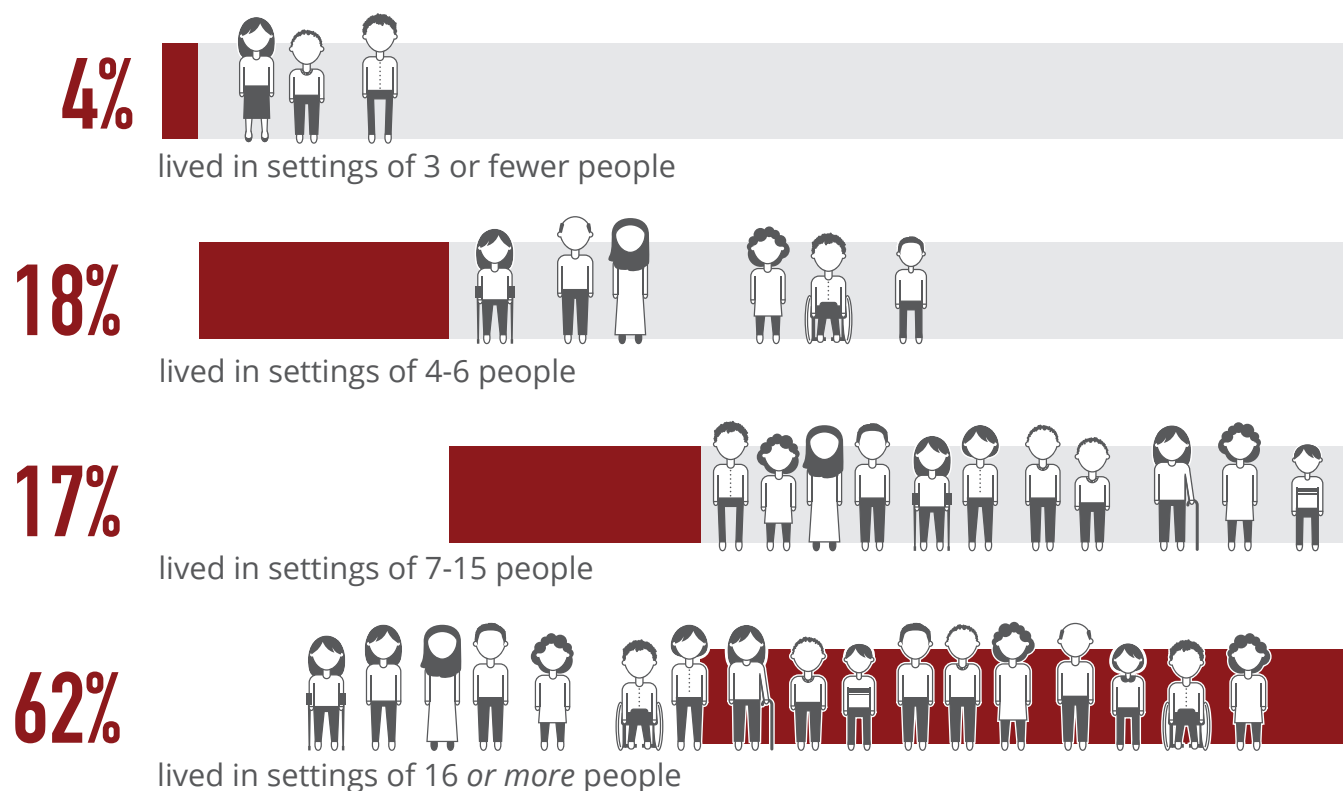
SECTION FOUR

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

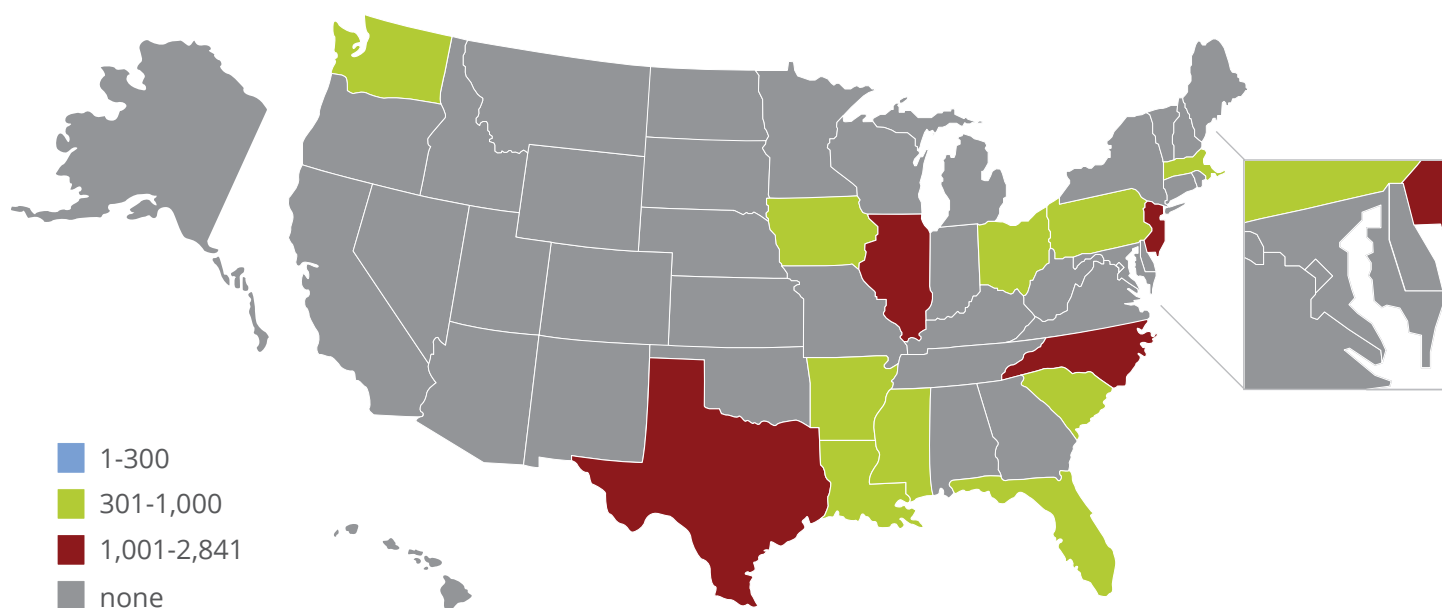
FY 2020

State-Operated Facilities Serving People with Intellectual or Developmental Disabilities on June 30, 2020

On June 30, 2020, 24,836 people lived in a state-operated residence.



In 2020, an average of 19.6 people lived in PRFs per 100,000 people.



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

Section 4 describes the status of state-run IDD facilities serving 16 or more people on June 30, 2020, and trends in utilization of those facilities. It describes trends in average daily and year-end populations, movement patterns (admissions, discharges, deaths, and short-term admissions), resident characteristics, previous residence of current residents, staff characteristics, and services provided to community residents.

Tables 4.1, 4.10, 4.11, 4.12, 4.13, and 4.14, and Figures 4.8, 4.9, and 4.10 use data from the annual RISP survey of State IDD Agency Directors.

The remaining tables and figures in Section 4 use data from the annual survey of facility administrators. FY 2020 surveys were returned by one or more facilities in all states with facilities except Arizona and Virginia.

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

By June 30, 2020, 18 states had closed, downsized, privatized, or converted all state-run IDD facilities

serving 16 or more people including Alabama, Alaska, the District of Columbia, Hawaii, Indiana, Kentucky, Maine, Michigan, Minnesota, Montana, New Hampshire, New Mexico, Oklahoma, Oregon, Rhode Island, Tennessee, Vermont, and West Virginia (see **Table 4.1**). The average daily population of PRFs in FY 2020 was 15,937.

The June 30 population of large state-run IDD facilities decreased from 16,200 in 2019 to 15,322 in 2020. Six states reported a decrease of 10% or more including California (-25%), Georgia (-25%), Massachusetts (-10%), North Dakota (-13%), South Dakota (-14%), and Washington (-17%). Of the states with open PRFs, 11 had fewer than 100 residents on June 30, 2020: Arizona (72), Colorado (51), Delaware (48), Idaho (16), Maryland (93), Nebraska (97), Nevada (37), North Dakota (62), South Dakota (98), Virginia (78), and Wyoming (60). The number of people living in PRFs increased in Idaho (14% increase from 14 to 16 people), North Carolina (6% increase from 1,155 to 1,228) and Utah (3% increase from 180 to 186).

Admissions, Discharges and Deaths

During FY 2020, an estimated 888 people were admitted or readmitted to PRFs (6% of the year's



Table 4.1 PRF Daily Population, Admissions, Discharges, Deaths and per Person Expenditures by State for Fiscal Year 2020

State	Average Daily Population	Admissions/ Readmissions	Discharges	Deaths	June 30 Residents			Short-term Admissions	Average Daily Per Person ICF/IID Cost ¹
					2019	2020	1-Year % Change		
N States	49	50	50	49	51	51	51	47	31
AL	0	0	0	0	0	0	0%	0	N/A
AK	0	0	0	0	0	0	0%	0	N/A
AZ	73	0	0	3	75	72	-4%	0	858
AR	880	8	11	21	917	883	-4%	11	414
CA	282 ^e	62	102	2	325	244	-25%	0	2,033
CO	24	22	22	8	53	51 ^e	-4%	0	1,091
CT	313	3	1	24	320	298	-7%	3	1,511
DE	47	0	0	2	49	48	-2%	0	1,098
DC	0	0	0	0	0	0	0%	0	N/A
FL	655	99	93	38	646	621	-4%	0	442
GA	DNF	DNF	DNF	DNF	212	160 ⁱ	-25%	DNF	626 ⁱ
HI	0	0	0	0	0	0	0%	0	N/A
ID	16	11	9	0 ⁱ	14	16	14%	0 ^{PD}	1,410 ⁱ
IL	1,627	99	77	49	1,640	1,613	-2%	0	502
IN	0	0	0	0	0	0	0%	0	N/A
IA*	325	6	8	8	331	321	-3%	0 ⁱ	1,051 ⁱ
KS	298	9 ^e	5 ^e	19 ^e	300	289	-4%	0	492
KY	0	0	0	0	0	0	0%	0	N/A
LA	443	67	32	14	497	497 ⁱ	0%	0	729
ME*	0	0	0	0	0	0	0%	0	N/A
MD*	92	66	65	1	93	93	0%	0	1,016
MA	330	2	9	37	342	309	-10%	10	DNF
MI	0	0	0	0	0	0	0%	0	N/A
MN	0	0	0	0	0	0	0%	0	N/A
MS	1,407	2	13	3	842	806	-4%	0	379
MO	279	1	9	22	310	287	-7%	2	712
MT	0 ⁱ	0 ⁱ	0 ⁱ	0 ⁱ	0	0 ⁱ	0%	0 ⁱ	N/A ⁱ
NE	100	5	6	6	105	97	-8%	0	975
NV	37	24	27	0 ⁱ	40	37	-8%	0 ⁱ	819
NH	0	0	0	0	0	0	0%	0	N/A
NJ	1,239	0	7	90	1,263	1,196	-5%	DNF	1,046
NM	0	0	0	0	0	0	0%	0	N/A
NY	DNF	0 ^{PD}	0 ^{PD}	DNF	257	234	-9%	0 ^{PD}	DNF
NC*	1,013 ⁱ	51 ⁱ	49 ⁱ	48 ⁱ	1,155	1,099 ⁱ	-5%	28 ⁱ	826 ⁱ
ND	67	7	9	8	71	62	-13%	6	1,116
OH	614	26	38	21	629	607	-3%	129	788
OK	0	0	0	0	52	0	0%	0	N/A
OR	0	0	0	0	0	0	0%	0	N/A
PA	700	6	10	35	719	680	-5%	0	1,134
RI	0	0	0	0	0	0	0%	0	N/A
SC*	653 ⁱ	29	10	31	673	648	-4%	DNF	477 ⁱ
SD	97	12 ⁱ	22 ⁱ	0 ⁱ	114	98 ⁱ	-14%	DNF	678 ⁱ
TN	0	0	0	0	0	0	0%	0	N/A
TX	2,862	107	85	96	2,915	2,841	-3%	0	846
UT	182	11	3	2	180	186	3%	0	652
VT	0	0	0	0	0	0	0%	0	N/A
VA	78	0	0	0	78	78	0%	0	652 ⁱ
WA	640	44	70	31	623	514	-17%	168	944
WV	0	0	0	0	0	0	0%	0	N/A
WI*	287	64	64	20	298	277	-7%	64	1,003
WY	51 ⁱ	13	14	2	63	60	-5%	0	984
Reported US Total	15,711	856	870	641	16,187	15,322	-5%	421	881
Estimated US Total	15,937	888	878	645	16,200	15,322	-5%	508	892

Data Source: RISP Survey d Other date (data from previous or next year). * Estimate. DNF Did not furnish. PRF - state run IDD setting of 16 or more people. Missing values replaced with values from PRF survey if available. 1 There is one PRF in Florida that is not an ICF/IID. The 2020 per diem for that facility is \$598.71.

average daily population). More than 100 people were admitted or readmitted to PRFs in Texas (107). Eleven states admitted 10% or more of their June 30, 2020, population within the same FY including Colorado (90%), Maryland (72%), Idaho (70%), Nevada (65%), Wyoming (25%), Wisconsin (22%), California (22%), Louisiana (15%), Florida (15%), South Dakota (12%), and North Dakota (10%). Admissions do not include transfers from one PRF to another.

There were an estimated 508 short-term admissions (lasting fewer than 90 days) in FY 2020. Two states reported more than 100 short-term admissions: Washington (168) and Ohio (129).

An estimated 878 people were discharged from a PRF in 2020. More than eighty people were discharged from PRFs in California (102), Florida (93), and Texas (85),

An estimated 645 people with IDD died while residing in a PRF in 2020. Three states reported deaths of more than 10% of their June 30, 2020, population: Colorado (33%), North Dakota (12%), and Massachusetts (11%).

Daily Per Person Expenditures

Estimated average daily per-person expenditures for FY 2020 were \$892 (\$325,580 per year) for ICF/IID certified PRFs. The average ranged from \$379 per day (\$138,306) in Mississippi to \$2,033 per day (\$741,884) in California. Twelve states had average daily per person PRF expenditures of more than \$1,000. Florida reported average daily costs of \$442 for ICF/IID certified facilities, and \$559 for other state-run facilities.

CHARACTERISTICS OF PEOPLE LIVING IN PRFS

FY 2020 PRF surveys were returned by 89 of the 107 PRFs in the 2020 sample frame (an 83% response rate, see [Table 4.2](#)). Responding facilities served 14,187 people with IDD (92% of the 15,322 estimated total residents). Response rates varied by survey item. Data for three facilities in Missouri and four facilities in South Carolina were reported by the state on a single survey.

Table 4.2 Characteristics of People with IDD Living in PRFs on June 30, 2020

Characteristic		Reported Total	Percent of People	Estimated Total	Reporting facilities
Residents on June 30		14,187	93%	15,322	89
Gender	Male	5,264	59%	9,039	89
	Female	8,923	41%	6,283	
Age	0-21 Years	673	5%	726	
	22-39 Years	3,201	23%	3,454	
	40-62 Years	6,468	46%	6,979	
	63+ Years	3,859	27%	4,164	
Race	White	9,623	68%	10,458	89
	Black/African American	2,865	20%	3,114	
	Hispanic/Latino	981	7%	1,066	
	Other Race or Multiple Races	431	3%	468	
Level of Intellectual Disability	Mild/No ID	2,307	17%	2,612	88
	Moderate	2,163	16%	2,449	
	Severe	2,264	17%	2,563	
	Profound	6,573	49%	7,442	
	Unknown	225	2%	255	
Other Conditions	Epilepsy	5,095	38%	5,746	84
	Autism	3,119	23%	3,518	84
	Cerebral Palsy	2,232	16%	2,517	84
	Behavior Disorder	8,200	60%	9,248	84
Involved with criminal justice system		737	6%	905	81
Short Term Stays in FY 2020		434	3%	508	85

Source: PRF Survey PRF - state run IDD setting of 16 or more people.

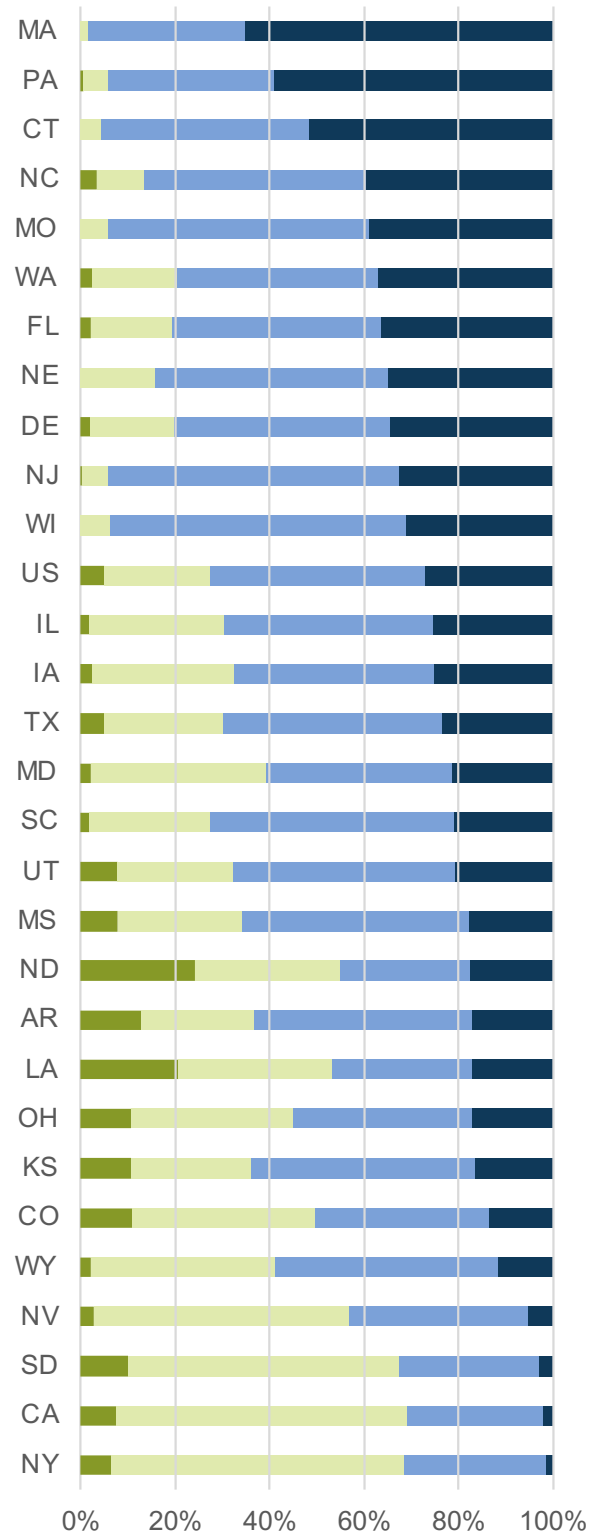
Table 4.3 Number of People with IDD in PRFs by Age and State on June 30, 2020

State	Age in Years						Total
	0-18	19-21	0-21	22-39	40-62	63+	
AZ	DNF	DNF	DNF	DNF	DNF	DNF	DNF
AR	45	42	87	166	314	120	687
CA	5	14	19	159	74	6	258
CO	2	10	12	43	41	15	111
CT	0	0	0	13	131	153	297
DE	0	1	1	8	21	16	46
FL	0	12	12	108	274	228	622
GA	0	0	0	60	55	0	115
ID	0	3	3	10	3	0	16
IL	2	19	21	368	559	327	1,275
IA	4	4	8	96	136	81	321
KS	14	15	29	71	131	46	277
LA	70	33	103	162	147	87	499
MD	1	1	2	35	37	20	94
MA	0	0	0	4	100	194	298
MS	37	25	62	208	377	141	788
MO	0	0	0	17	157	112	286
NE	0	0	0	15	48	34	97
NV	0	1	1	20	14	2	37
NJ	0	1	1	68	736	391	1,196
NY	3	9	12	118	57	3	190
NC	19	18	37	107	512	430	1,086
ND	6	9	15	19	17	11	62
OH	21	36	57	188	206	94	545
PA	0	1	1	17	105	179	302
SC	2	10	12	170	345	140	667
SD	3	6	9	53	27	3	92
TX	64	75	139	707	1,302	669	2,817
UT	11	3	14	45	85	38	182
VA	DNF	DNF	DNF	DNF	DNF	DNF	DNF
WA	3	12	15	109	261	227	612
WI	0	0	0	17	172	86	275
WY	0	1	1	20	24	6	51
Reported US Total	312	361	673	3,201	6,468	3,859	14,201
Estimated US Total	337	389	726	3,454	6,979	4,164	15,322

Data Source: PRF 2020 Survey. N = 89 facilities. DNF Data not furnished. PRF - state run IDD setting of 16 or more people. Did not provide data for FY2020: AZ and VA. All facilities with 16 or more people closed: AL, AK, DC, HI, IN, KY, ME, MI, MN, MT, NM, OR, RI, TN and WV.

Figure 4.1 Percent of People Living in PRFs in Age Groups by State on June 30, 2020

■ 0-21yrs. ■ 22-39 yrs. ■ 40-62 yrs. ■ 63+ yrs.



Data Source: PRF Survey: PRF - state run IDD setting of 16 or more people. All facilities with 16 or more people closed: AL, AK, DC, HI, IN, KY, ME, MI, MN, MT, NH, NM, OK, OR, RI, TN, VT and WV.

Of the people living in PRFs on June 30, 2020, 59% were male. An estimated 5% were 21 years or younger, 23% were 22 to 39 years, 46% were 40 to 62 years, and 27% were 63 years or older. An estimated 68% were white, 20% were Black or African American, 7% were Hispanic and 3% were another race, two or more races or unknown race. (Respondents told us they could only report these race/ethnicity categories.) Half (49%) of PRF residents had profound ID while 17% had severe ID, 16% had moderate ID, 17% had mild or no ID, and the level of ID was unknown for 2%.

An estimated 38% of PRF residents had epilepsy, 23% had ASD, 16% had cerebral palsy, and 60% had a behavior disorder requiring planned interventions. An estimated 905 (6%) people living in a PRF had been involved with the criminal justice system.

Age

There were substantial state-to-state differences in the ages of PRF residents (see **Table 4.3** and **Figure 4.1**). **Figure 4.1** excludes people whose age was unknown. An estimated 2% of PRF residents were

18 years or younger. The percentage ranged from 0% in 13 states to 14% in Louisiana. An estimated 3% of PRF residents were 19 to 21 years old. The percentage ranged from 0% to 1% in eight states to 19% in Idaho. Ten percent or more of PRF residents were 21 years or younger in Arkansas (13%), Colorado (11%), Idaho (19%), Kansas (10%), Louisiana (21%), North Dakota (24%), Ohio (10%), and South Dakota (10%).

An estimated 23% of PRF residents were 22 to 39 years. The percentage ranged from 1% in Massachusetts to 63% in Idaho. Other states reporting that 50% or more of PRF residents were ages 22 to 39 years included California (62%), New York (62%), South Dakota (58%), Nevada (54%), and Georgia (52%).

An estimated 46% of PRF residents were 40 to 62 years old. The percentage ranged from 19% in Idaho to 63% in Wisconsin. Other states reporting that more than 50% of PRF residents were 40 to 62 years old were New Jersey (62%), Missouri (55%), and South Carolina (52%).

Finally, an estimated 27% of PRF residents were 63 years or older. The percentage ranged from

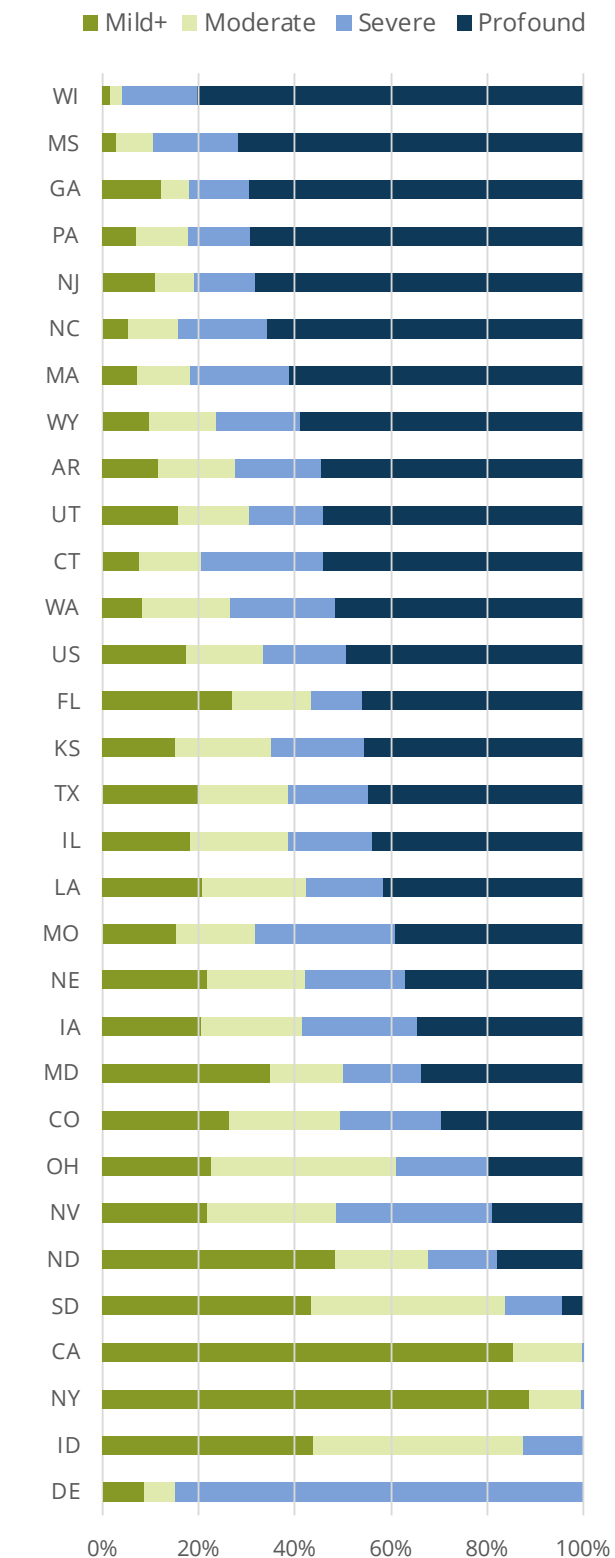


Table 4.4 Level of Intellectual Disability of People Living in PRFs by State on June 30, 2020

State	Level of Intellectual Disability					Number of People
	Mild+	Moderate	Severe	Profound	Unknown	
AZ	DNF	DNF	DNF	DNF	DNF	DNF
AR	80	109	123	375	0	687
CA	209	35	1	0	13	258
CO	24	21	19	27	20	111
CT	23	38	75	161	0	297
DE	4	3	39	0	0	46
FL	165	102	66	283	6	622
GA	14	7	14	80	0	115
ID	7	7	2	0	0	16
IL	230	257	219	556	13	1,275
IA	66	67	77	111	0	321
KS	43	56	55	129	0	283
LA	99	103	75	199	23	499
MD	32	14	15	31	0	92
MA	21	33	62	182	0	298
MS	22	60	139	567	0	788
MO	44	47	84	112	0	287
NE	21	20	20	36	0	97
NV	8	10	12	7	0	37
NJ	131	97	151	817	0	1196
NY	159	19	1	0	4	183
NC	57	111	203	712	3	1,086
ND	27	11	8	10	6	62
OH	122	211	103	108	1	545
PA	21	33	39	209	0	302
SC	DNF	DNF	DNF	DNF	DNF	DNF
SD	40	37	11	4	0	92
TX	561	526	466	1,260	4	2,817
UT	28	26	27	96	5	182
VA	DNF	DNF	DNF	DNF	DNF	DNF
WA	40	89	106	250	127	612
WI	4	7	43	221	0	275
WY	5	7	9	30	0	51
Reported US Total	2,307	2,163	2,264	6,573	225	13,532
Estimated US Total	2,612	2,449	2,563	7,442	255	15,322

Data Source: PRF 2020 Survey. N = 88 facilities DNF Data not furnished. PRF - state run IDD setting of 16 or more people. All facilities with 16 or more people closed: AL, AK, DC, HI, IN, KY, ME, MI, MN, MT, NM, OR, RI, TN and WV.

Figure 4.2 Level of Intellectual Disability (in Percent) of People in PRFs by State on June 30, 2020



Data Source: PRF Survey PRF - state run IDD setting of 16 or more people. Did not provide data for FY2020: AZ and VA. All facilities with 16 or more people closed: AL, AK, DC, HI, IN, KY, ME, MI, MN, MT, NH, NM, OK, OR, RI, TN, VT and WV..

0% in Idaho and Georgia to 65% in Massachusetts.

Other states reporting that more than 50% of PRF residents were 63 years or older were Connecticut (52%) and Pennsylvania (59%) as well.

Level of Intellectual Disability

Levels of intellectual disability of PRF residents also varied by state (see **Table 4.4** and **Figure 4.2**). **Figure 4.2** excludes people whose level of ID was unknown or not reported.

An average of 17% of people in PRFs had no or mild ID. The percentage ranged from 1% in Wisconsin to 89% in New York. Other states in which more than 25% of people had no or mild ID included California (85%), Colorado (26%), Florida (27%), Idaho (44%), Maryland (35%), North Dakota (48%), and South Dakota (43%).

An average of 16% of people in PRFs had moderate ID. The percentage ranged from 3% in Wisconsin to 44% in Idaho. Other states in which more than 25% of the people had moderate ID included Nevada (27%), Ohio (39%), and South Dakota (40%).

An average of 17% of people in PRFs had severe ID. The percentage ranged from 0% in California to 85% in Delaware. Other states in which 25% or more of the people had severe ID included Connecticut (25%), Missouri (29%), and Nevada (32%).

An average of 49% of people in PRFs had profound ID. The percentage ranged from 0% in California, Delaware, Idaho, and New York to 80% in Wisconsin. Eleven additional states reported that 50% or more of people in PRFs had profound ID including Mississippi (72%), Georgia (70%), Pennsylvania (69%), New Jersey (68%), North Carolina (66%), Massachusetts (61%), Wyoming (59%), Arkansas (55%), Connecticut (54%), Utah (54%), and Washington (52%).

Patterns of Age and Level of Disability

To further describe the patterns of age and level of disability by state we created a scatterplot showing the percent of PRF residents who had no, mild, or moderate ID (versus severe or profound ID) and the percent who were 39 years or younger (versus 40 years or older; see **Figure 4.3**). The correlation between age and level of ID in PRFs was ($r = 0.83$).

States serving more people with no, mild, or moderate ID also tended to serve more people with no, mild, or moderate ID, while states serving more people with severe or profound ID also tended to serve more people who were 40 years or older.

In two states (Ohio and Maryland), more than half of all people in PRFs had mild, moderate or no ID and fewer than half were ages 39 years or younger. For example, in Ohio, 61% had no, mild, or moderate ID, and 45% of PRF residents were 39 years or younger.

In five states (South Dakota, North Dakota, New York, California, and Idaho), more than half of the people in PRFs had mild, moderate or no ID and more than half were 39 years or younger. For example, in New York, 99% had no, mild, or moderate ID and 68% of residents were 39 years or younger.

In 20 states (Arkansas, Colorado, Connecticut, Delaware, Florida, Illinois, Iowa, Kansas, Massachusetts, Mississippi, Missouri, Nebraska, New Jersey, North Carolina, Pennsylvania, Texas, Utah, Washington, Wisconsin, and Wyoming), fewer than half of people in PRFs had no, mild, or moderate ID and fewer than half were 39 years or younger. For example, in Wisconsin, 4% had no, mild, or moderate ID and 6% were 39 years or younger.

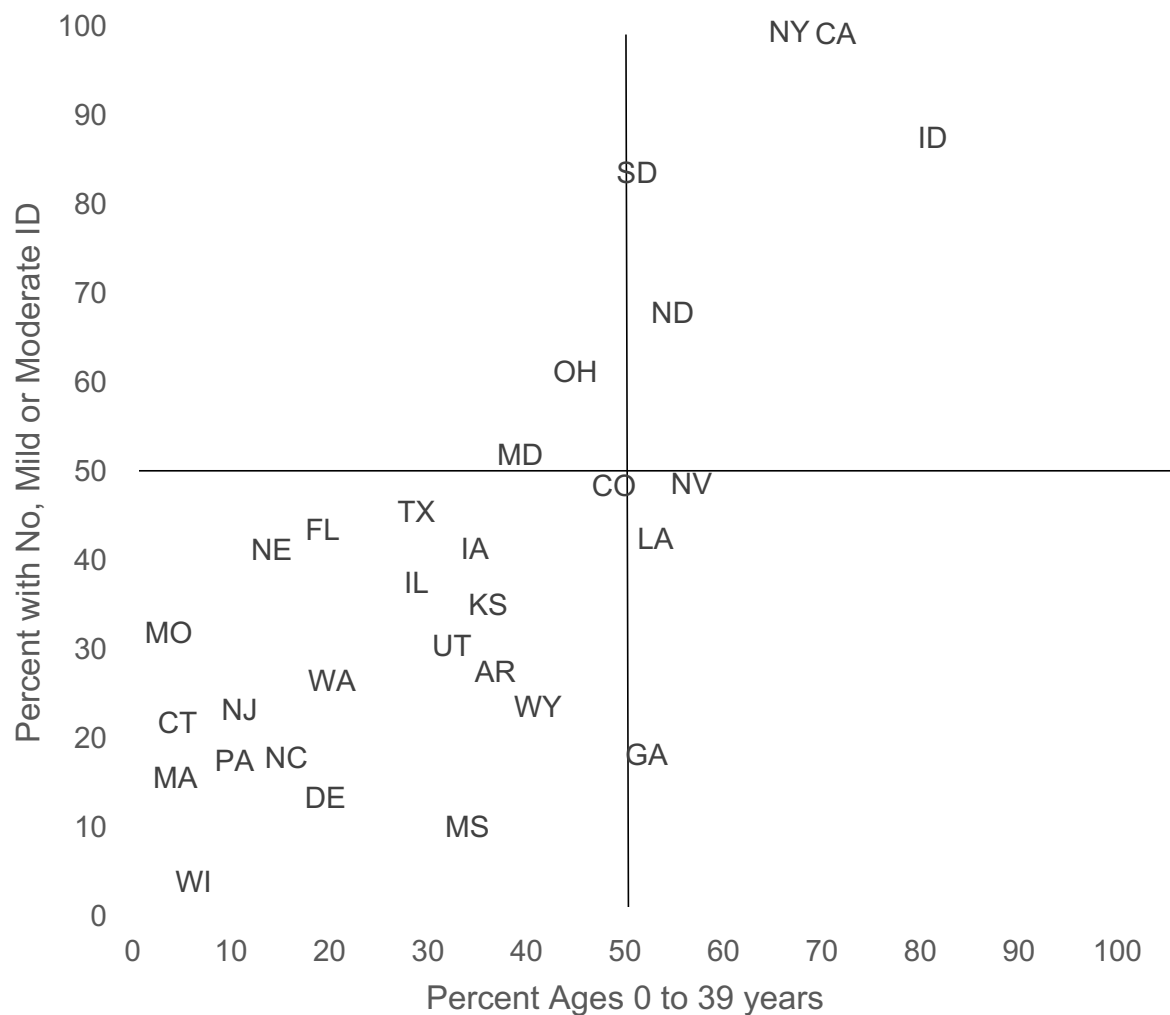
In three states (Georgia, Louisiana, and Nevada), fewer than half of residents had no, mild, or moderate ID and more than half were 39 years or younger. For example, in Georgia, 18% had no, mild, or moderate ID and 52% were 39 years or younger.

Differences in the profiles of states may reflect state policy decisions about the characteristics of people prioritized for admission to or discharge from PRFs, state differences in the effectiveness of community residential settings for certain groups, or the use of PRFs to serve specific groups (such as people who have had contact with the criminal justice system).

PRF ADMISSIONS AND DISCHARGES

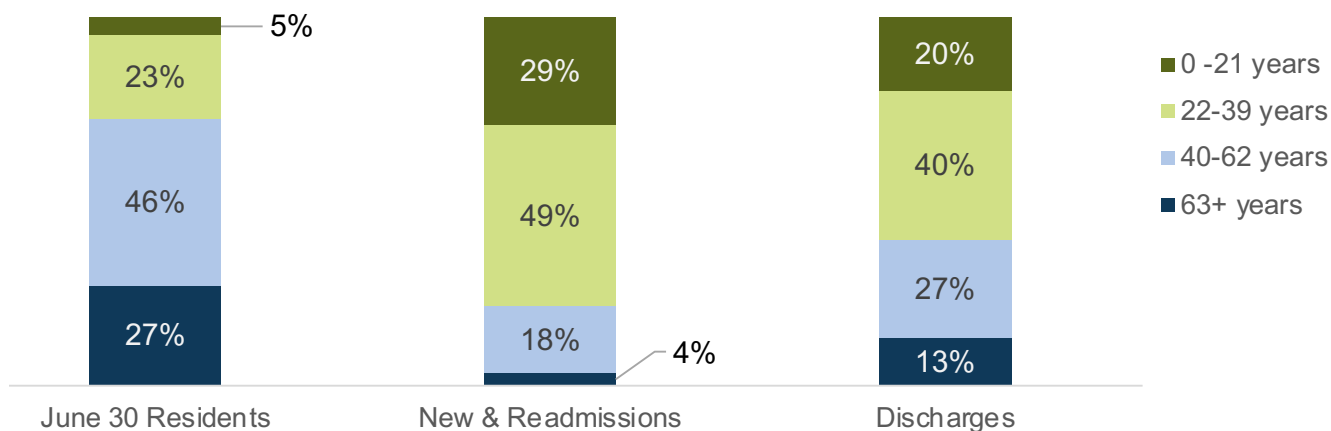
This section compares the age and level of intellectual disability for current PRF residents on June 30, 2020, new admissions and readmissions in FY 2020, and discharges in FY 2020. Age was reported for 14,201 of the estimated 15,451 PRF residents on June 30, 2020. Age information was

Figure 4.3 Scatterplot of Age and Level of ID for People Living in PRFs on June 30, 2020 by State



Data Source: PRF Survey, Pearson $r = 0.78$ PRF - state run IDD setting of 16 or more people. Did not provide data for FY2020: AZ and VA. All facilities with 16 or more people closed: AL, AK, DC, HI, IN, KY, ME, MI, MN, MT, NH, NM, OK, OR, RI, TN, VT and WV.

Figure 4.4 Age Distribution for June 30, Newly Admitted, Readmitted and Discharged PRF Residents in FY 2020



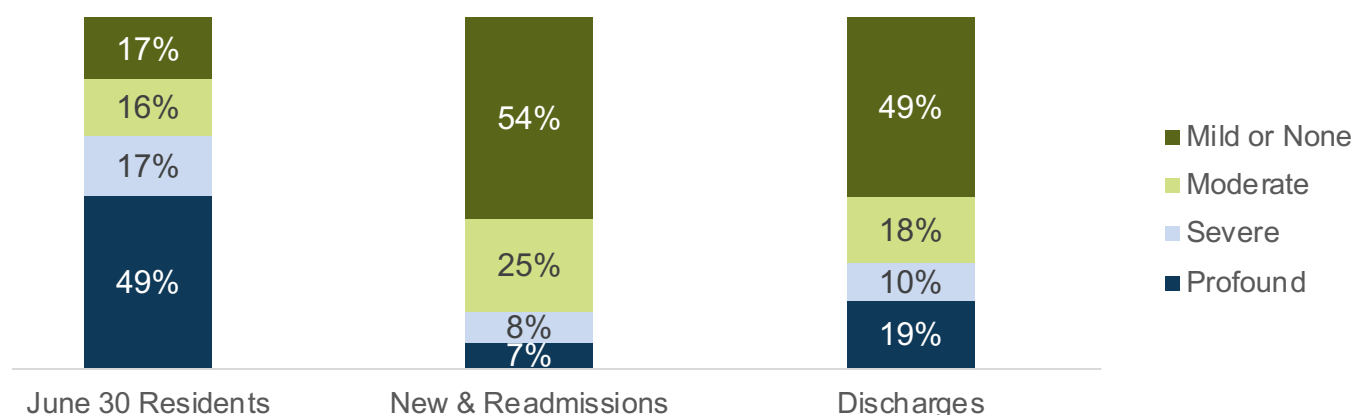
Data Source: PRF Survey. PRF - state run IDD setting of 16 or more people.

Table 4.5 Age and Level of Intellectual Disabilities for Current, Newly or Readmitted, and Discharged Residents of PRFs in 2020

Characteristic	June 30, 2020 Residents		(Re) Admissions		Discharges	
	Number	Percent	Number	Percent	Number	Percent
Reporting Facilities	89		74		70	
Age						
0-18 years	312	2%	134	16%	95	11%
19-21 years	361	3%	113	13%	83	9%
0-21 years	673	5%	247	29%	178	20%
22-39 years	3,201	23%	421	49%	360	40%
40-62 years	6,468	46%	153	18%	238	27%
63+ years	3,859	27%	30	4%	116	13%
Age Unknown	0	0%	0	0%	1	0%
Level of ID						
Mild or None	2,307	17%	443	54%	431	49%
Moderate	2,163	16%	207	25%	160	18%
Severe	2,264	17%	68	8%	91	10%
Profound	6,573	49%	58	7%	164	19%
IDD Level Unknown	225	2%	48	6%	30	3%

Data Source: 2020 PRF Survey. PRF - state run IDD setting of 16 or more people. This table shows reported sums rather than estimated totals.

Figure 4.5 Level of Intellectual Disabilities for June 30, Newly Admitted, Readmitted and Discharged PRF Residents in FY 2020



Data Source: PRF Survey. PRF - state run IDD setting of 16 or more people.

available for all 851 people admitted to PRFs in 2020, and 892 of the 893 people discharged from 74 PRFs.

Admissions and Discharges by Age and Level of ID

People who were admitted to or discharged from PRFs in 2020 were younger and less likely to have severe or profound ID than the average resident on June 30, 2020 (see **Table 4.5** and **Figure 4.4**). Of the people in residence on June 30, 2020, 73% were 40 years or older, 23% were 22 to 39 years, and 5%

were 21 years or younger. Of the people admitted or readmitted, 22% were 40 years or older, 49% were 22 to 39 years, and 29% were 21 years or younger. Of the people discharged, 40% were 40 years or older, 40% were 22 to 39 years, and 20% were 21 years or younger.

People who were 21 years or younger were 29% of admissions or readmissions but only 20% of discharges. People who were 22 to 39 years were 49% of admissions but only 40% of discharges. Half of all residents (46%) of PRFs on June 30, 2020,

were 40 to 62 years, but only 18% of those admitted and 27% of those discharged were in that age group. Finally, people 63 years or older were 27% of all residents on June 30, 2020, but only 4% of those admitted and 13% of those discharged. This suggests that PRFs are not being used primarily to serve people with aging caregivers.

Table 4.6 Previous Residence for People Admitted or Readmitted to PRFs and Subsequent Residence Type for People Discharged from PRFs 2020

Setting Type	(Re) Admissions	Discharges
Number of reporting facilities	72	68
Number of Reported (Re)Admissions/Discharges	814	859
Number with Residence Type Unknown	13	23
Family home	138	96
Own, Host or Foster Family Home	59	107
IDD facility 1-6 residents	133	303
IDD facility 7-15 residents	35	39
IDD facility 16+ residents	41	19
Mental health facility	132	32
Correctional facility	181	122
Nursing home, Assisted Living, Boarding Home	82	118

Data Source: 2020 PRF survey. PRF - state run IDD setting of 16 or more people. Previous residence was unknown for 13 (re)admissions (2%). Subsequent residence was unknown for 23 discharges (3%).

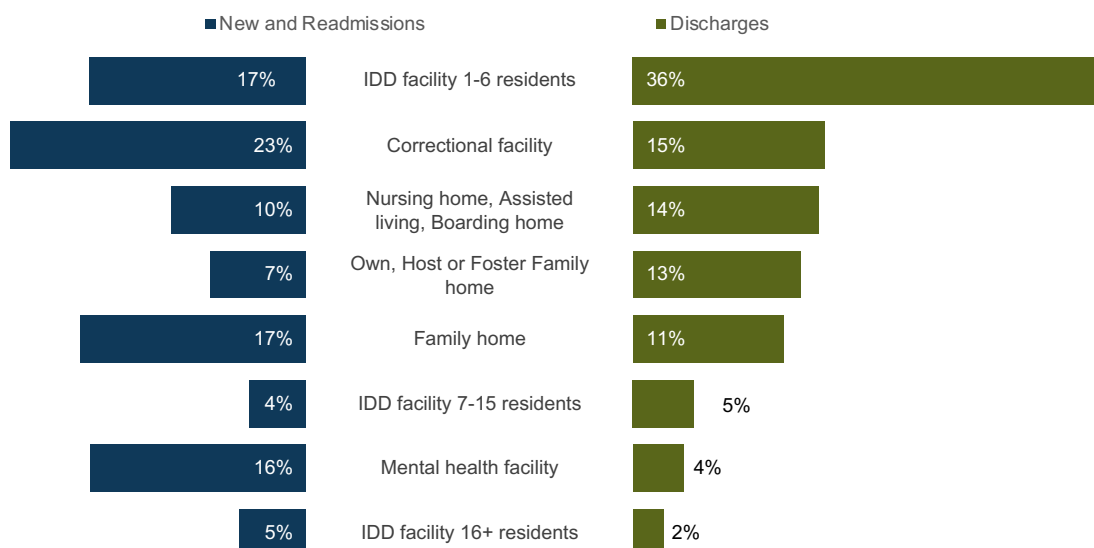
Differences in levels of intellectual disability were even more pronounced (see **Figure 4.5**). Of the people in residence on June 30, 49% had profound ID compared with 7% of those admitted and 19% of those discharged. By contrast, of the people in residence on June 30, only 17% had mild or no ID compared with 54% of those admitted and 49% of those discharged.

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

For FY 2020, 72 facilities reported previous residence for 801 of the estimated 888 people admitted to PRFs, and 68 facilities reported subsequent residence for 836 of the estimated 878 people leaving PRFs in 2020 (see **Table 4.6** and **Figure 4.6**).

In the reporting facilities for people admitted to PRFs in 2020, previous residential settings included a correctional facility (23%), the home of a family member (17%), a group home of six or fewer people (17%), a psychiatric unit or facility (16%), a nursing home, assisted living facility or boarding home (10%), their own home or a host or foster family home (7%), or an IDD facility of seven or more people (9%).

Figure 4.6 Previous and Subsequent Residence For People Admitted or Readmitted to or Discharged from PRFs in 2020



Data Source: PRF Survey

Table 4.7 Staff Characteristics and Outcomes in PRFs in FY 2020

Type of Staff	N Facilities	Reported N	Estimated N	FTE staff per resident
Direct Support Professionals (DSP)	82	25,954	28,207	1.84
Front Line Supervisors (FLS)	82	2,822	3,066	0.20
Turnover and Vacancy Rate		Rate		
DSP Vacancy Rate	81	14%		
DSP Turnover Rate	81	36%		
FLS Vacancy Rate	80	8%		
FLS Turnover Rate	80	26%		
Wage/Salary		Average		
DSP Starting Hourly Wage	82	\$15.31		
DSP Average Hourly Wage	82	\$17.34		
FLS Starting Salary	82	\$42,783		
FLS Average Salary	82	\$49,355		

Data Source: PRF Survey. PRF - state run IDD setting of 16 or more people. FTE Full time equivalent. (One FTE is 1 person working 40 hours per week or a combination of two more people working a combined 40 hours per week).

In the reporting facilities, for people discharged from a PRF in 2020, subsequent living arrangements included an IDD group home of six or fewer people (36%), a correctional facility (15%), a nursing home, assisted living facility or boarding home (14%), their own home or a host or foster family home (13%), the home of a family member (11%), an IDD facility of seven or more people (7%), or a psychiatric unit or facility (4%).

Half (395) of the people admitted come from and a third (272) of people discharged from PRFs go to non-IDD facilities. Most of the people coming from or moving to correctional facilities were in a handful of PRFs specializing in serving people involved in the justice system.

PRF STAFFING CHARACTERISTICS AND OUTCOMES

Staffing characteristics and outcomes were reported for 82 PRFs (see **Table 4.7**). Those PRFs employed 25,954 DSPs and 2,822 front line supervisors (FLS) on June 30, 2020. There were an estimated 28,207 DSPs and 3,066 FLS in PRFs. One FTE is 40 staff hours worked per week whether those hours are worked by one employee or shared by two or more employees. PRFs employed 1.84 FTE DSPs and 0.2 FLSs per resident.

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, 2020. Average turnover rates were 36% for DSPs and 26% for FLSs for FY 2020.

Vacancy rates were computed as the total number of vacant positions on June 30, 2020, divided by the number of current staff plus the number of vacancies to be filled. An estimated 14% of DSP positions and 8% of FLS positions were vacant on June 30, 2020.

In FY 2020, the average starting wage for DSPs was \$15.31 (\$31,845 for a full-time employee annually) and average wage for all DSPs was \$17.34 (\$36,066). The average FLS starting annual salary was \$42,783 and the average annual salary was \$49,355.

PRF STATUS BY FACILITY AS OF JUNE 30, 2020

Table 4.8 list all PRFs in the RISP sample frame that were still open and serving at least 16 people with IDD on June 30, 2020. There was an average of 160 people per facility on June 30, 2020. On June 30, 2020, the number of people per PRF ranged from 16 people in Southwest Idaho Treatment Center to 472 people in Shapiro Developmental Center (Illinois). Daily per person expenditures averaged \$833 (\$304,045 per year) and ranged from \$240 (\$87,600) for Holly Center in Maryland to \$1,410 (\$514,650) for the Southwest Idaho Treatment Center.

Between June 30, 2019, and June 30, 2020, the average PRF reduced their total population by eight people (-4%) The change between 2019 and 2020 ranged from an increase of 10 people for Gallipolis Developmental

Table 4.8 PRFs Open on June 30, 2020: Projected Closure Date, Population, Per Person Expenditures, Admissions, Discharges and Deaths By State and Facility Name

State	Facility Name (City)	Year Opened	(Projected) Closure Date	Residents With IDD June 2020	All Residents June 2020	Average Daily IDD Population 2020	Residents With IDD June 2019	% Change 2019- 2020	Average Daily Per Person Expenditures (\$)	Admissions/ Readmissions	Discharges	Transfers	Deaths
AR	Arkadelphia Human Dev. Ctr. (Arkadelphia)	1968		108	108	108	108	0	400	2	2	7	1
AR	Booneville HDC (Booneville)	1972		123	123	126	129	-5	425	4	7	2	1
AR	Conway HDC (Conway)	1959		456	460	463	469	-3	410	19	12	3	17
AR	Jonesboro HDC (Jonesboro)	1970		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
AR	Southeast Arkansas HDC (Warren)	1978		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
AZ	Arizona Trng. Program (Coolidge)	1952		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
CA	Canyon Springs (Cathedral City)	2001		47	47	48	47	0	1,403	9	9	0	0
CA	Porterville Dev. Ctr. (Porterville)	1953		206	238	210	238	-13	1,403	50	81	1	2
CO	Grand Junction Regional Ctr. (Grand Junction)	1919	June 2021	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
CO	Wheat Ridge Regional Ctr. (Wheatridge)	1912		111	111	116	116	-4	886	15	15	2	3
CT	Northwest Ctr. (Torrington)	1984		34	34	36	36	-6	904	0	0	0	2
CT	Hartford Regional Center (Newington)	1965		43	47	45	46	-7	904	1	0	0	4
CT	Lower Fairfield County Ctr. (Norwalk)	1976		63	63	63	65	-3	904	1	0	0	3
CT	Southbury Trng. School (Southbury)	1940		157	157	164	173	-9	1,250	0	0	1	15
DE	MAC Ctr. at Stockley (Georgetown)	1921		46	46	DNF	49	-6	DNF	0	1	0	2
FL	Developmental Disabilities Defendant Program (DDDP, Chattahoochee)	1977		88	88	89	86	2	571	81	71	7	1
FL	Sunland Ctr. (Marianna)	1961		240	240	242	243	-1	510	10	8	0	5
FL	Tacachale Ctr. / Sequin Unit (Gainesville)	1921		294	294	305	317	-7	460	0	4	0	19
GA	East Central Regional Hospital (Gracewood & Augusta)	1921		115	123	93	123	-7	626	0	8	0	4
IA	Glenwood Resource Ctr. (Glenwood)	1876	June 2024	192	192	196	200	-4	924	0	2	0	6
IA	Woodward Resource Ctr. (Woodward)	1917		129	129	119	131	-2	1,260	6	6	0	2
ID	Southwest Idaho Treatment Center (Nampa)	1918	June 2021	16	16	16	14	14	1,410	11	9	0	0
IL	Choate Dev. Ctr. (Anna)	1873		171	171	189	150	14	721	26	14	10	1
IL	Fox Dev. Ctr. (Dwight)	1965		80	80	85	85	-6	829	5	5	0	5
IL	Kiley Dev. Ctr. (Waukegan)	1975		106	196	198	200	-47	848	16	20	9	8
IL	Ludeman Dev. Ctr. (Park Forest)	1972		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
IL	Mabley Dev. Ctr. (Dixon)	1987		110	110	110	111	-1	848	8	4	0	5
IL	Murray Dev. Ctr. (Centralia)	1964		246	246	243	242	2	848	15	5	4	6
IL	Shapiro Dev. Ctr. (Kankakee)	1879		472	472	476	477	-1	848	29	19	3	12
KS	Kansas Neurological Institute (Topeka)	1960		131	131	132	139	-6	526	2	16	0	10
KS	Parsons State Hospital (Parsons)	1952		152	152	152	162	-6	457	7	14	5	9
LA	Louisiana Special Education Center (Alexandria)	1952		81	81	81	81	0	746	5	2	0	3

Table 4.8 PRFs Open on June 30, 2020: Projected Closure Date, Population, Per Person Expenditures, Admissions, Discharges and Deaths By State and Facility Name

State	Facility Name (City)	Year Opened	(Projected) Closure Date	Residents With IDD June 2020	All Residents June 2020	Average Daily IDD Population 2020	Residents With IDD June 2019	% Change 2019-2020	Average Daily Per Person Expenditures (\$)	Admissions/ Readmissions	Discharges	Transfers	Deaths
LA	Pinecrest Supports and Services Center (Pineville)	1918		418	418	412	405	3	815	9	34	0	11
MA	Hogan Regional Ctr. (Hawthorne)	1967		87	106	87	99	-12	1,077	DNF	DNF	DNF	12
MA	Wrentham Dev. Ctr. (Wrentham)	1907		211	211	223	235	-10	920	1	0	0	25
MD	Holly Ctr. (Salisbury)	1975		51	51	50	49	4	240	3	0	0	1
MD	Potomac Ctr. (Hagerstown)	1978		43	43	43	44	-2	964	20	21	0	1
MS	Boswell Regional Ctr. (Sanatorium)	1976		87	87	87	84	4	398	6	2	13	4
MS	Ellisville State School (Ellisville)	1920		214	217	230	228	-6	476	4	8	DNF	10
MS	Hudspeth Regional Ctr. (Whitfield)	1974		185	185	183	196	-6	300	1	9	0	2
MS*	Mississippi Adolescent Center (Brookhaven)	2011		29	29	30	30	-3	425	9	13	1	0
MS	North Mississippi Regional Ctr. (Oxford)	1973		185	185	197	205	-10	354	0	4	9	7
MS	South Mississippi Regional Ctr. (Long Beach)	1978		89	89	91	94	-5	382	2	6	0	1
MO	Bellevue Regional Ctr. (St. Louis)	1924		96	99	96	106	-9	779	0	0	0	10
MO	Higginsville Habilitation Ctr. (Higginsville)	1956		44	47	44	45	-2	1,030	0	0	0	1
MO	Southeast Missouri Residential Services (Poplar Bluff and Sikeston)	1992		59	59	59	60	-2	620	DNF	DNF	DNF	1
MO	Southwest Community Services (Nevada)	1973		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MO	St. Louis Dev. Disabilities Treatment Ctrs. (3: South County, St. Louis, and St. Charles Hab. Ctr.)*	2002		87	87	91	98	-11	944	1	2	0	0
NE	Sheridan Cottages ICF (Beatrice)	1875		97	97	100	104	-7	975	5	6	0	6
NV	Desert Regional Ctr. (Las Vegas)	1975		37	37	38	40	-8	879	24	27	0	0
NJ	Green Brook Regional Ctr. (Green Brook)	1981		74	74	81	85	-13	1,367	0	0	0	11
NJ	Hunterdon Dev. Ctr. (Clinton)	1969		431	431	440	444	-3	903	6	0	0	19
NJ	Vineland Dev. Ctr. (Vineland)	1888		176	176	183	189	-7	1,152	6	0	2	17
NJ	New Lisbon Dev. Ctr. (New Lisbon)	1914		279	279	290	301	-7	989	4	1	0	25
NJ	Woodbine Dev. Ctr. (Woodbine)	1921		236	236	245	253	-7	1,183	7	6	0	18
NY	Summit DDO (Tupper Lake)	1965		144	144	DNF	150	-4	DNF	27	26	0	1
NY	Valley Ridge (Norwich)	2000		46	46	DNF	47	-2	DNF	14	10	0	0
NC	Caswell Ctr. (Kinston)	1914		284	284	291	303	-6	844	2	4	0	14
NC	J. Iverson Riddle Dev. Ctr. (Morganton)	1963		269	269	266	268	0	710	11	4	0	6
NC	Murdoch Ctr. (Butner)	1957		366	379	385	388	-6	785	30	33	0	19
NC	O'Berry Ctr. (Goldsboro)	1957	June 2022	167	167	170	175	-5	1,125	1	0	0	9
ND	Life Skills and Transition Center (Grafton)	1904		62	62	67	72	-14	1,116	7	9	0	8
OH	Cambridge Dev. Ctr. (Cambridge)	1965		52	52	52	50	4	824	14	6	1	5

Table 4.8 PRFs Open on June 30, 2020: Projected Closure Date, Population, Per Person Expenditures, Admissions, Discharges and Deaths By State and Facility Name

State	Facility Name (City)	Year Opened	(Projected) Closure Date	Residents With IDD June 2020	All Residents June 2020	Average Daily IDD Population 2020	Residents With IDD June 2019	% Change 2019- 2020	Average Daily Per Person Expenditures (\$)	Admissions/ Readmissions	Discharges	Transfers	Deaths
OH	Columbus Dev. Ctr. (Columbus)	1857		114	114	114	116	-2	668	17	17	0	2
OH	Gallipolis Dev. Ctr. (Gallipolis)	1893		60	60	55	50	20	900	24	13	0	11
OH	Mount Vernon Dev. Ctr. (Mount Vernon)	1948		65	65	67	71	-8	839	13	15	2	2
OH	Northwest Ohio Dev. Ctr. (Toledo)	1977		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
OH	Southwest Ohio Dev. Ctr. (Batavia)	1981		101	101	98	102	-1	681	18	17	0	2
OH	Tiffin Dev. Ctr. (Tiffin)	1975		72	72	73	76	-5	734	21	16	5	4
OH	Warrensville Dev. Ctr. (Warrensville)	1975		81	81	85	89	-9	880	31	39	1	0
PA	Ebensburg Ctr. (Ebensburg)	1957		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
PA	Polk Ctr. (Polk)	1897	April	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
PA	Selinsgrove Ctr. (Selinsgrove)	1929		201	201	200	209	-4	1,144	4	3	0	9
PA	White Haven Ctr. (White Haven)	1956	Feb	203	203	107	112	-10	1,053	0	0	0	11
SC	4 SC Regional Centers (Coastal, Midlands, Pee Dee, and Whitten)	1968		647	647	653	659	-2	477	19	6	3	20
SD	South Dakota Dev. Ctr. (Redfield)	1902		92	92	97	103	-11	678	12	22	0	0
TX	Abilene State School (Abilene)	1957		259	259	259	263	-2	876	4	0	5	13
TX	Austin State School (Austin)	1917		175	175	178	179	-2	876	2	1	0	5
TX	Brenham State School (Brenham)	1974		240	240	244	248	-3	876	3	3	0	7
TX	Corpus Christi State School (Corpus Christi)	1970		181	181	187	188	-4	876	4	0	1	12
TX	Denton State School (Denton)	1960		432	432	440	448	-4	876	6	2	0	20
TX	El Paso State Ctr. (El Paso)	1973		99	99	98	95	4	876	4	1	1	0
TX	Lubbock State School (Lubbock)	1969		188	188	189	188	0	876	6	2	1	5
TX	Lufkin State School (Lufkin)	1962		264	264	267	280	-6	876	4	6	0	13
TX	Mexia State School (Mexia)	1946		238	238	233	246	-3	876	37	37	1	1
TX	Richmond State School (Richmond)	1968		304	304	309	315	-3	876	2	2	2	13
TX	Rio Grande State Ctr. (Harlingen)	1973		62	62	62	63	-2	876	2	3	0	0
TX	San Angelo State School (Carlsbad)	1969		183	183	183	191	-4	876	14	16	1	6
TX	San Antonio State School (San Antonio)	1978		192	192	199	206	-7	876	1	5	1	10
UT	Utah State Dev. Ctr. (American Fork)	1931		182	183	180	178	2	652	16	7	12	3
VA	Southeastern Virginia Trng. Ctr. (Chesapeake)	1975		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
WA	Fircrest (Seattle)	1959		213	213	213	213	0	884	16	5	DNF	7
WA	Lakeland Village School (Medical Lake)	1915		175	175	175	176	-1	1,027	8	4	0	16
WA	DSHS Rainier School (Buckley)	1939		161	161	190	218	-26	1,009	18	61	0	3
WA	Yakima Valley School (Selah)	1958		63	63	55	65	-3	996	3	0	0	5
WI	Central Wisconsin Ctr. (Madison)	1959		172	182	186	182	-5	976	0	2	0	8
WI	Southern Wisconsin Ctr. (Union Grove)	1919		103	115	109	113	-9	974	0	0	0	10
WY	Wyoming Life Resource Ctr. (Lander)	1912		51	57	51	51	0	944	4	2	0	2

Data Source: PRF Survey. PRF - state run IDD setting of 16 or more people. *Brookhaven in MS opened in 2011 and is not tracked elsewhere in this report. All facilities with 16 or more people closed: AL, AK, DC, HI, IN, KY, ME, MI, MN, MT, NM, OR, RI, TN and WV.

Center in Ohio (+20%) to a reduction of 94 people for Kiley Developmental Center in Illinois (-47%).

The number of admissions or readmissions for FY 2020 averaged 10 and ranged from zero in 13 facilities to 81 for the Developmental Disabilities Defendant Program in Florida. The number of discharges per PRF averaged 10 and ranged from zero for 17 facilities to 81 for Porterville Developmental Center in California. The number of transfers (in or out) averaged one per PRF and ranged from zero in 54 facilities to 13 for Boswell Regional Center in Mississippi. Finally, the number of deaths during FY 2020 averaged seven per PRF with a range from zero in 10 facilities to 25 in both the Wrentham Developmental Center in Massachusetts and New Lisbon Developmental Center in New Jersey.

PRF Closures and Projected Closures

The following facilities closed or have projected closing dates between July 1, 2019, and June 30, 2024.

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

- Georgia Regional Hospital (Savannah, Georgia)
- Black Mountain Center (Black Mountain, North Carolina) (converted to Skilled Nursing Facility)
- Central Virginia Training Center (Lynchburg, Virginia)

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

- Grand Junction Regional Center (Grand Junction, Colorado)
- Southwest Idaho Treatment Center (Nampa, Idaho)

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

- O'Berry Center (Goldsboro, North Carolina)

FY 2023 (July 1, 2022 – June 30, 2023)

- White Haven Center (White Haven, Pennsylvania)

FY 2024 (July 1, 2023 – June 30, 2024)

- Glenwood Resource Center (Glenwood, Iowa)
- Polk Center (Polk, Pennsylvania)



Methodology Notes

A list of all closed PRFs and the date they closed, converted to serving a different population, converted from state-operated to privately operated or downsized to fewer than 16 people can be viewed on the RISP website at RISP.UMN.edu.

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

- Colorado operates 23 ICF/IID units on two campuses: Grand Junction Regional Center (Grand Junction, CO) and Wheat Ridge Regional Center (Wheat Ridge, CO).
- Three facilities in Missouri (South County, St. Louis, and Saint Charles Habilitation Center submit a single PRF survey.
- Wisconsin reports three PRFs with 16 or more residents with IDD including the Northern Wisconsin Center in Chippewa Falls, which was converted to a short-term facility in 2005 but may have people who stay for more than 90 days.

Other facilities counted separately by state IDD agencies submit a combined PRF survey. For example:

- The Seguin Unit was combined with the Tacachale Community of Excellence (Gainesville, FL).
- The two campuses of East Central Regional Hospital (Gracewood and Augusta, GA) were combined.
- Four regional centers in South Carolina submit a single PRF survey (Pee Dee Regional Center, Costal Regional Center, Midlands, and Whitten).

TRENDS IN PUBLIC RESIDENTIAL FACILITY UTILIZATION

PRF Status by State

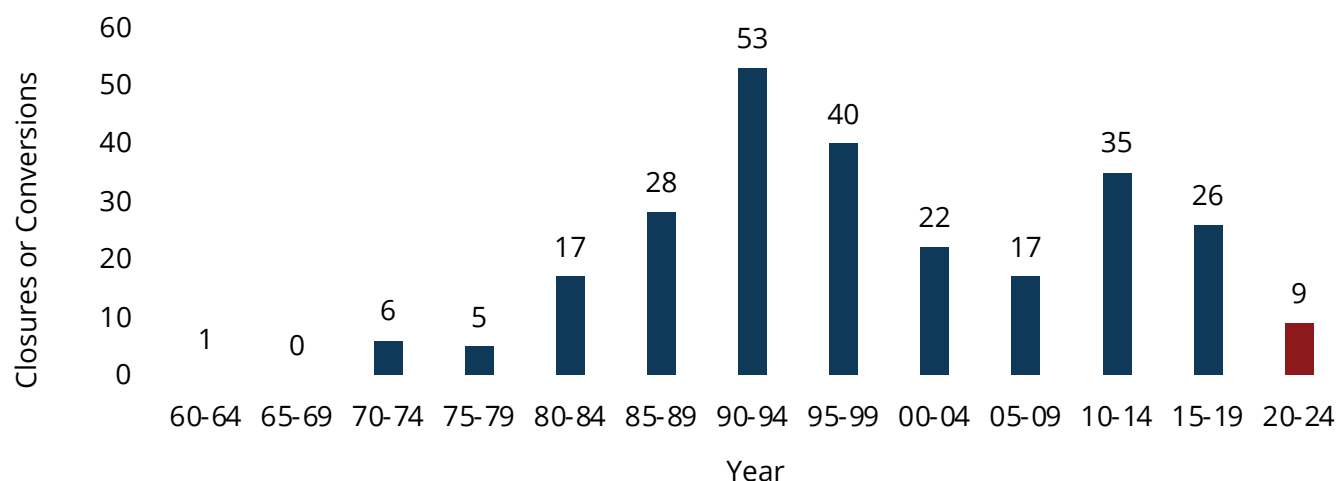
Of the 376 PRFs operating between 1960 and 2020, 266 (71%) closed, converted to a non-state facility, or downsized to 15 or fewer people before July 1, 2020 (see [Table 4.9](#)). Three facilities closed between July

Table 4.9 Operational Status of PRFs by State on June 30, 2020 with Projected Closures through June 2024

State	Operating Between 1960 and 2019	Closed, Converted or Downsized ¹		Open June 30, 2020	Projected to Close July 2020 - June 2024
		1960 to 2019	FY 2020		
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	10	1	2	0
CO	3	1	0	2	1
CT	15	11	0	4	0
DE	1	0	0	1	0
DC	3	3	0	0	0
FL	10	7	0	3	0
GA	13	11	0	2	0
HI	2	2	0	0	0
ID	1	0	0	1	1
IL	17	10	0	7	0
IN	11	11	0	0	0
IA	2	0	0	2	1
KS	4	2	0	2	0
KY	5	5	0	0	0
LA	11	8	0	3	0
ME	3	3	0	0	0
MD	9	7	0	2	0
MA	11	9	0	2	0
MI	13	13	0	0	0
MN	9	9	0	0	0
MS	6	0	0	6	0
MO	18	12	0	6	0
MT	2	2	0	0	0
NE	1	0	0	1	0
NV	2	1	0	1	0
NH	2	2	0	0	0
NJ	11	6	0	5	0
NM	3	3	0	0	0
NY	45	40	1	4	0
NC	6	2	0	4	1
ND	2	1	0	1	0
OH	22	14	0	8	0
OK	4	4	0	0	0
OR	3	3	0	0	0
PA	23	19	0	4	2
RI	3	3	0	0	0
SC	5	0	0	5	0
SD	2	1	0	1	0
TN	5	5	0	0	0
TX	15	2	0	13	0
UT	1	0	0	1	0
VT	1	1	0	0	0
VA	8	6	1	1	0
WA	6	2	0	4	0
WV	4	4	0	0	0
WI	3	1	0	2	0
WY	1	0	0	1	0
Reported US Total	376	266	3	107	6
% of Total	100%	71%	1%	28%	2%

Sources: PRF survey, RISP survey. PRF - state run IDD setting of 16 or more people. 1 Downsized - 15 or fewer people with IDD, Converted - no people with IDD. Facilities counted on Table 1.8 but not here Wisconsin 1; Wyoming 1. Facilities counted here but not on Table 1.8 Mississippi 1 (Brookhaven).

Figure 4.7 PRFs Closed or Converted to Non-IDD Use or Nonstate Operation Between 1960 and 2020 and Projected Closures by 2024 in 5-Year Intervals



Source: 2020 PRF Survey. PRF - state run IDD setting of 16 or more people.

1, 2019, and June 30, 2020, and 107 remained open on June 30, 2020. Six PRFs were scheduled to close between July 2020 and June 2024.

As of June 30, 2020, 18 states had closed all PRFs (Alabama, Alaska, the District of Columbia, Hawaii, Indiana, Kentucky, Maine, Michigan, Minnesota, Montana, New Hampshire, New Mexico, Oklahoma, Oregon, Rhode Island, Tennessee, Vermont, and West Virginia).

Nine states had closed none of their PRFs, three states had closed 1 to 25%, seven states had closed 26 to 50%, 12 states had closed 51 to 75% and five states had closed 76 to 99% of the PRFs that were open in 1960.

PRF Closures and Projected Closures 1960 through 2024

The rate of PRF closures in the United States has varied over time (see [Figure 4.7](#)). One PRF closed between 1960 and 1969. The number of closures increased to 11 between 1970 and 1979, and 45 between 1980 and 1989. The number of PRF closures peaked at 93 during the 1990s with 53 closures between 1990 and 1994 and 40 closures between 1995 and 1999. There were only 39 closures between 2000 and 2009. The number of closures increased to 61 between 2010 and 2019. Between 2020 and 2024, nine closures have happened or were expected. (RISP has not collected

and analyzed PRF survey data as of this report's publication.)

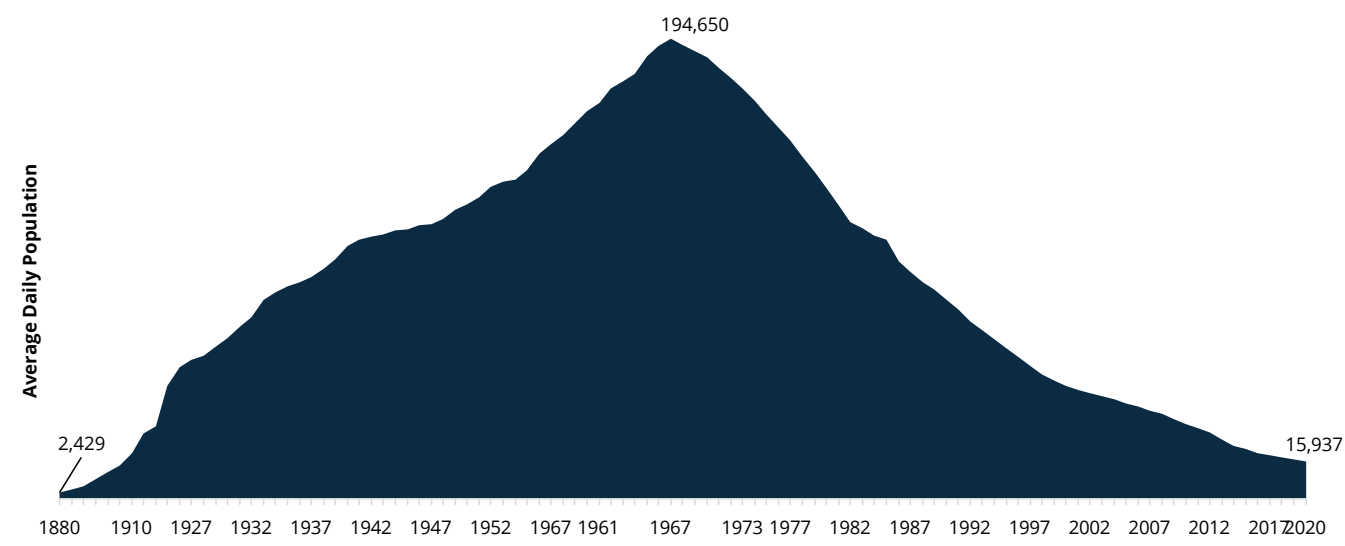
Average Daily Population of PRFs

RISP has historical data on the average daily population of state-run IDD facilities of 16 or more people for selected years since 1880 and annually since 1927 (Lakin, 1979). The average daily population of PRFs increased from 2,429 in 1880 to 106,944 in 1940 (see [Table 4.10](#) and [Figure 4.8](#)). The average daily population of PRFs peaked at 194,650 people in 1967. The average daily population of PRFs dropped to 151,532 in 1977, 95,886 in 1987, 56,161 in 1997, 37,172 in 2007, and 15,937 for FY 2020.

Utilization of PRFs per 100,000 of the Population

Changes in the utilization of PRFs for people with IDD per 100,000 of the population mirrored the trends in the average daily population of those facilities. In 1890, there were an estimated 8.1 people with IDD living in PRFs per 100,000 of the population. Utilization rates increased ten-fold by 1940 to 80.9 people with IDD per 100,000 of the population. Utilization rates of PRFs for people with IDD peaked in 1965 at 113.6 per 100,000. By 1980, the utilization rate had dropped by 49% to 57.7 people per 100,000. By 1995, the rate had dropped by another 57% to 24.2 per 100,000. Between 1995

Figure 4.8 Average Daily Population of Large State-Run IDD Facilities from 1880 to 2020



and 2007, the utilization rate dropped by 49% to 12.3 per 100,000. Between 2007 and 2017, the utilization rate dropped another 54% to 5.7 per 100,000 and was 4.8 people per 100,000 by 2020.

State-run Psychiatric Facilities

States have reported the number of people with IDD living in state-run psychiatric facilities since 1950 when there were 23,905 people with IDD living in those facilities. As with PRFs, the number of people with IDD in state psychiatric facilities rose in the 1950s reaching a peak of 41,823 people in 1961. The

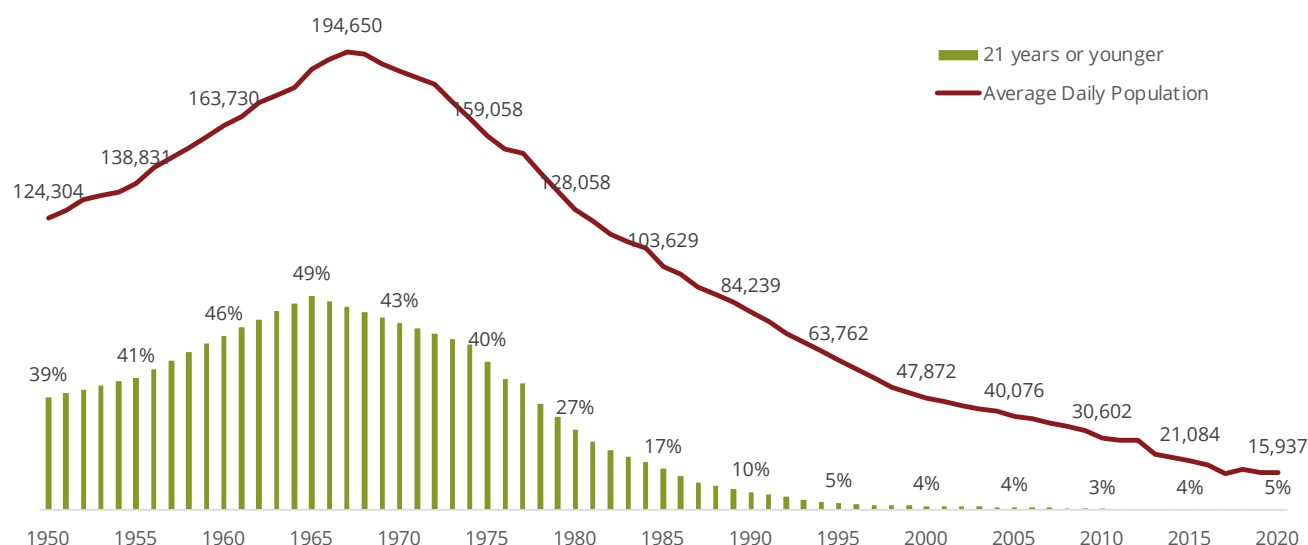


Table 4.10 Average Daily Population and People Per 100,000 of the US Population of PRFs and People with IDD in State-Operated Psychiatric Facilities, Selected Years 1890-2020

Year	Average Daily Population			Percent in Psychiatric Settings	US Population (100,000) ^s	People Per 100k of the Population		
	State IDD	State Psychiatric ¹	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
1967	194,650	33,850	228,500	15%	1,987.1	98.0	17.0	115.0
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
1977	151,532	15,524	167,056	9%	2,202.4	68.8	7.0	75.9
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
1987	95,886	2,520	98,406	3%	2,428.0	39.5	1.0	40.5
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
1997	56,161	1,075	57,236	2%	2,680.5	21.0	0.4	21.4
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	23,724	1,151	24,875	5%	3,161.3	7.5	0.4	7.9
2014	22,262	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	6.6	0.7	7.2
2016	19,502	2,044	21,546	9%	3,231.3	6.0	0.6	6.7
2017	18,516	1,964	20,480	10%	3,257.2	5.7	0.6	6.3
2018	17,596	1,660	19,256	9%	3,255.0	5.4	0.5	5.9
2019	16,862	1,318	18,180	7%	3,282.0	5.1	0.4	5.5
2020	15,937	1,470	17,407	8%	3,314.5	4.8	0.4	5.3

Data Source: RISP survey, PRF - state run IDD setting of 16 or more people. ¹Number of states not reporting on psychiatric settings by year: 2000 (1); 2001 (3); 2002 (3); 2003 (3); 2004 (2); 2005 (3); 2006, 2007 and 2008 (4); 2009 (3); 2010 (5); 2011 (6) 2012 (0); 2013 (21); 2014 (16); 2015 (10); 2016 (9); 2017 (14); 2018 (17); 2019 (22), 2020 (24) iData imputed based on adjacent years.

Figure 4.9 Average Daily Population of PRFs and Percent 21 Years or Younger, 1950 to 2020



Data Source: RISP Survey. PRF - state run IDD setting of 16 or more people.

number of people with IDD in psychiatric facilities dropped to 33,850 in 1977, 2,520 in 1987, and 1,075 in 1997, reaching an all-time low of 267 people in 2002. By 2007, the number of people with IDD in state-run psychiatric facilities had rebounded to 782 and was 1,470 in 2020. Reporting by states on the number of people with ID in state psychiatric facilities has declined since 2000 when 50 of 51 states reported. By 2020, only 27 state IDD agencies reported the number of people with IDD living in state operated psychiatric facilities.

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

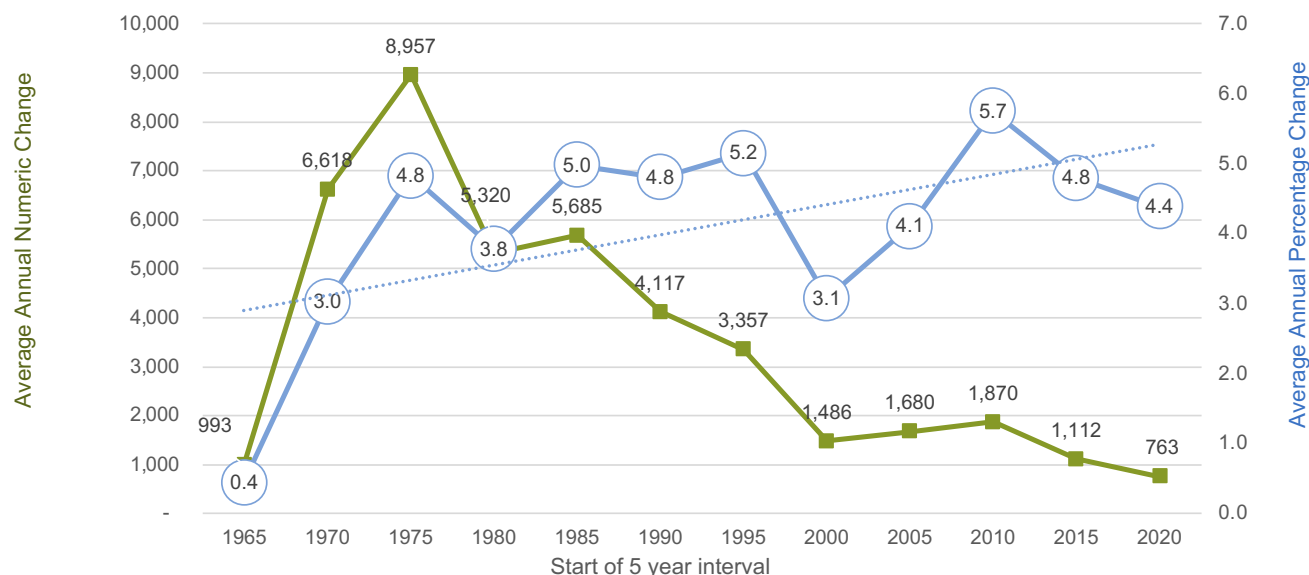
The reason for the increased use of psychiatric facilities between 2011 and 2020 compared to the previous decade is unknown, though some variation is likely due to differences in which states report this information each year. However, 16% of all admissions to PRFs in 2020 were from mental health facilities, and 4% of people discharged were sent to mental health facilities. It will be important to

continue to monitor the movement of people with IDD between PRFs and mental health facilities.

Children Living in PRFs

It is impossible to understand the history of deinstitutionalization for people with IDD without understanding how the age of people in PRFs changed over time. The percentage of people living in PRFs age 21 years or younger grew from 39% in 1950 to 49% in 1965 as the baby boom generation was born and survival rates for children with IDD increased. Half of the people in PRFs at their peak were children (see **Figure 4.9**). As the proportion of PRF residents who were children declined from 49% in 1965 to 10% in 1990, the total number of people in PRFs declined by 55% from 187,305 to 84,239. This period of rapid decline coincided with several major policy initiatives including a significant decline in admissions, the increasing use of federal Medicaid dollars to reform PRFs and decrease overcrowding in PRFs (through the ICF/IID program), the introduction of the Education for All Handicapped Children Act in 1973 (now the Individuals with Disabilities Education Act), and the introduction of Medicaid Waiver funding for services in Home and Community Based settings in 1981. By 1995, only 5% of PRF residents were 21 years or younger, and the pace of deinstitutionalization had slowed. The first 100,000 people left PRFs in the 25 years between

Figure 4.10 Average Annual Change in the Number of People with IDD in PRFs and State Psychiatric Facilities in Five Year Intervals 1965 to 2020 with Linear Trendlines



Data Source: RISP Survey. PRF - state run IDD setting of 16 or more people.

1965 and 1990. In the 25 years from 1990 and 2015, the PRF population declined by 63,155 people. Since 2015, the proportion of PRF residents ages 21 years or younger has remained steady at between 4% and 5% and the average daily population declined from 21,084 to 15,937.

Rates of Population Change in State IDD and Psychiatric Facilities

Another way to look at changes in the populations of PRFs and state psychiatric facilities is to compare average annual numeric change to average annual percentage change (see **Figure 4.10**). The numeric decline in people with IDD in PRFs or state psychiatric facilities was highest between 1975 and 1979 with an average decline of 8,957 people per year. The average annual numeric change was between 1,486 and 1,870 from 2000 through 2014 but dropped to 1,112 from 2015 to 2019 and to 763 in 2020.

Expressed as a percentage change in the population, the rate of population decline is accelerating. Between 1975 and 1979, the populations of state-run IDD and state psychiatric facilities declined at a rate of 4.8% per year. Between 1985 and 1994, the populations declined at a rate of about 5% per year. Between 2000 to 2004, the rate of decline dipped

to 3.1% per year. The average percentage decline peaked at 5.7% per year between 2010 and 2015, then dropped to 4.8% per year between 2015 and 2019 and to 4.4% in 2020.

State Trends in Average Daily Populations

State trends in the average daily population of PRFs from 1980 to 2020 are shown on **Table 4.11**. Between 1980 and 2020, the average daily population of PRFs dropped 88% from 131,345 to 16,052 and 18 states closed their last state-run IDD institution of sixteen or more people.

Eight states (Alabama, Indiana, Kentucky, Minnesota, Montana, Oklahoma, Oregon, and Tennessee) closed their last PRF between 2010 and 2020. All but one state reduced the number of people in PRFs between 2010 and 2020. States that reduced their PRF populations by 50% or more between 2010 and 2020 were California (87%), Connecticut (56%), Idaho (77%), Louisiana (61%), Massachusetts (57%), Missouri (58%), New Jersey (54%), Ohio (55%), and Virginia (93%).

Table 4.11 Average Daily PRF Population by State Selected Years 1980 to 2020

State	Average Daily Population										% Change
	1980	1985	1990	1995	2000	2005	2010	2015	2019	2020	
N States	51	51	51	47	42	42	40	37	31	31	30
AL	1,651	1,422	1,305	985	642	212	178	0	0	0	N/A
AK	86	76	58	33	0	0	0	0	0	0	N/A
AZ	672	538	360	183	166	138	119	95	77	73	-39
AR	1,550	1,254	1,260	1,262	1,229	1,079	1,067	913	905	880	-18
CA	8,812	7,524	6,768	5,494	3,879	3,307	2,149	1,077	395	282 ^e	-87
CO	1,353	1,125	466	241	129	110	DNF	28	23	24	DNF
CT	2,944	2,905	1,799	1,316	992	847	705	493	185	313	-56
DE	518	433	345	308	256	123	71	54	49	47	-34
DC	775	351	309	0	0	0	0	0	0	0	N/A
FL	3,750	2,268	1,992	1,502	1,508	1,341	963	848	685	655	-32
GA	2,535	2,097	2,069	1,979	1,510	1,202	802	259	DNF	DNF	DNF
HI	432	354	162	83	0	0	0	0	0	0	N/A
ID	379	317	210	139	110	94	68	24	17	16	-77
IL	6,067	4,763	4,493	3,775	3,237	2,833	2,183	1,723	1,667	1,627	-25
IN	2,592	2,248	1,940	1,389	854	456	205	0	0	0	N/A
IA	1,225	1,227	986	719	674	646	525	400	DNF	325	-38
KS	1,327	1,309	1,017	756	379	360	340	311	299	298	-12
KY	907	671	709	679	628	489	170	263	0	0	N/A
LA	3,171	3,375	2,622	2,167	1,749	1,571	1,144	453	499	443	-61
ME	460	340	283	150	0	0	0	0	0	0	N/A
MD	2,527	1,925	1,289	817	548	380	138	135	94	92	-33
MA	4,531	3,580	3,000	2,110	1,306	1,089	759	478	359	330	-57
MI	4,888	2,191	1,137	392	271	173	0	0	0	0	N/A
MN	2,692	2,065	1,392	610	42	29	25	0	0	0	N/A
MS	1,660	1,828	1,498	1,439	1,383	1,359	1,324	1,100	1,426	1,407	6
MO	2,257	1,856	1,860	1,492	1,286	1,152	671	410	308	279	-58
MT	316	258	235	163	131	84	52	52	0	0	N/A
NE	707	488	466	414	401	372	182	114	106	100	-45
NV	148	172	170	160	157	93	47	47	40	37	-21
NH	578	267	87	0	0	0	0	0	0	0	N/A
NJ	7,262	5,705	5,069	4,325	3,555	3,096	2,711	1,701	1,298	1,239	-54
NM	500	471	350	221	0	0	0	0	0	0	N/A
NY	15,140	13,932	7,694	4,552	2,466	2,233	2,019	648	DNF	DNF	DNF
NC	3,102	2,947	2,654	2,288	1,939	1,736	1,515	1,328	1,142	1,013 ^d	-33
ND	1,056	763	232	156	144	140	120	82	70	67	-44
OH	5,045	3,198	2,665	2,150	1,996	1,728	1,376	923	640	614	-55
OK	1,818	1,505	935	618	391	368	270	16	51	0	N/A
OR	1,724	1,488	838	462	62	43	22	0	0	0	N/A
PA	7,290	5,980	3,986	3,460	2,127	1,452	1,189	973	742	700	-41
RI	681	415	201	0	0	0	0	0	0	0	N/A
SC	3,043	2,893	2,286	1,788	1,129	953	786	681	673	653 ^d	-17
SD	678	557	391	345	196	172	149	139	114	97 ^d	-35
TN	2,074	2,107	1,932	1,669	948	680	416	127	0	0	N/A
TX	10,320	9,638	7,320	5,459	5,431	4,977	4,337	3,241	2,912	2,862	-34
UT	778	706	462	357	240	230	215	208	180	182	-15
VT	331	200	180	0	0	0	0	0	0	0	N/A
VA	3,575	3,069	2,650	2,249	1,625	1,524	1,197	534	78	78	-93
WA	2,231	1,844	1,758	1,320	1,143	973	914	777	744	640	-30
WV	563	498	304	94	0	0	0	0	0	0	N/A
WI	2,151	2,058	1,678	1,341	900	590	448	357	300	287	-36
WY	473	413	367	151	113	98	83	72	61	51 ⁱ	-39
Estimated US Total	131,345	109,614	84,239	63,762	47,872	40,532	31,654	21,084	16,139	15,937	-50

Data Source: RISP Survey. PRF - state run IDD setting of 16 or more people. 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 between 2010 and 2020. * See state notes in the Appendix. Oklahoma reported closing its last state run IDD facility in 2015. The 51 people listed for 2019 are in an ICF/IID facility run by a public entity other than the state.

Annual Number of Admissions, Discharges and Deaths

Table 4.12 shows annual admissions, discharges, and deaths for PRFs by state for selected years between 1950 and 2020. Transfers between PRFs are not included. In 1950, PRFs reported an average daily population of 124,304 with 12,197 admissions (10% of the average daily population), 6,672 discharges (5%), and 2,761 deaths (2.2%). In 2020, the average daily population was 16,052 with 888 admissions (6%), 878 discharges (5%), and 651 deaths (4%).

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

2,200 people. The number of annual admissions declined from 1,593 in 2011, to 888 by 2020.

The number of discharges per year grew from 6,672 in 1950 to a peak of 16,807 in 1975 before dropping below 10,000 by the early 1980's, to 6,887 by 1990 and to 2,425 by 2000. Annual discharges remained above 2,000 until 2014 when 1,997 people were discharged. Total discharges in 2020 were 878.

Annual deaths in PRFs peaked in 1967 at 3,635, dropped below 2,000 by the early 1980's, and below 1,000 by 2000. The number of deaths per year in PRFs declined from 915 in 2000 to 577 in 2019 but increased in 2020 to 645.

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

Admissions as a proportion of the average daily population ranged from 8% to 11% between 1967 and 1975. As the average daily population of PRFs declined, admissions as a proportion of the average daily population dropped from 11% in 1975 to 6% in 1990 and was between 3% and 6% of the average daily PRF population between 1990 and 2020 (see **Figure 4.11**).

Annual discharges as a proportion of the average daily population increased from 4% in 1960 to 11% by 1978. The proportion declined from 11% in 1980 to 7% by 1989. The proportion remained between 7% and 9% from 1990 and 1998 but dropped to 5% in 2000. The proportion rose to 10% in 2013 and 2016 before declining to 6% in 2020. For the first time since 1970s there were more admissions in 2020 than discharges (888 admissions, 878 discharges).

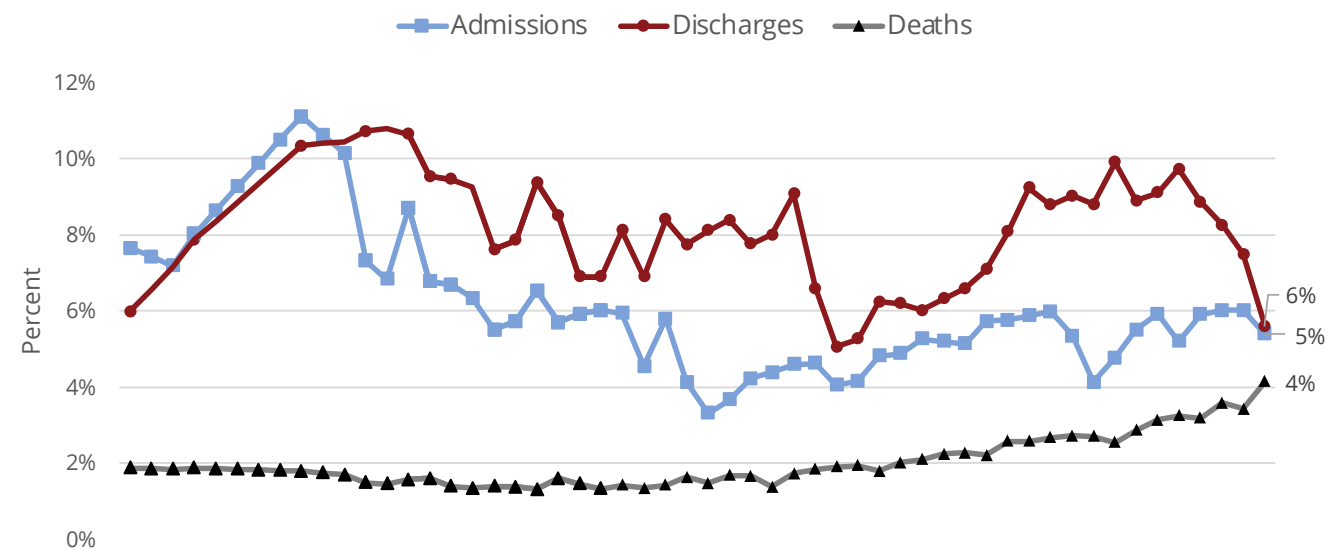
Deaths as a proportion of the daily population averaged 2% from 1950 through 1981. It was between 1 and 2% between 1981 and 1997. It averaged 1% from 1982 until 1995, 2% from 1995 through 2007, 3% from 2008 through 2017, and was 4% in 2020. The gradual increase in deaths as a proportion of the average daily population reflects the overall increase in age amongst people living in PRFs.

Table 4.12 Change in Estimated Average Daily Population and Annual Admissions, Discharges and Deaths in PRFs Selected Years 1950-2020

Year	Average Daily Pop.	Annual Number of			Net Change
		Admissions	Discharges	Deaths	
1950	124,304	12,197	6,672	2,761	
1955	138,831	13,906	5,845	2,698	5,363
1960	163,730	14,182	6,451	3,133	4,598
1965	187,305	17,225	9,358	3,585	4,282
1967	194,650	14,904	11,665	3,635	(396)
1970	186,743	14,979	14,702	3,496	(3,219)
1975	168,214	18,075	16,807	2,913	(1,645)
1980	128,058	11,141	13,622	2,019	(4,500)
1985	109,614	6,276	8,619	1,508	(3,851)
1990	84,732	5,034	6,877	1,207	(3,050)
1995	63,697	2,338	5,337	1,068	(4,067)
2000	47,872	1,936	2,425	915	(1,404)
2005	40,532	2,106	2,561	909	(1,364)
2010	30,602	1,833	2,690	820	(1,677)
2011	29,809	1,593	2,690	810	(1,907)
2012	27,665	1,141	2,436	747	(2,042)
2013	24,779	1,184	2,453	630	(1,899)
2014	22,437	1,235	1,997	643	(1,406)
2015	21,084	1,248	1,921	661	(1,334)
2016	19,502	1,014	1,897	635	(1,518)
2017	18,516	1,095	1,642	591	(1,138)
2018	17,596	1,059	1,453	632	(990)
2019	16,862	1,014	1,264	577	(827)
2020	15,937	888	878	645	(635)

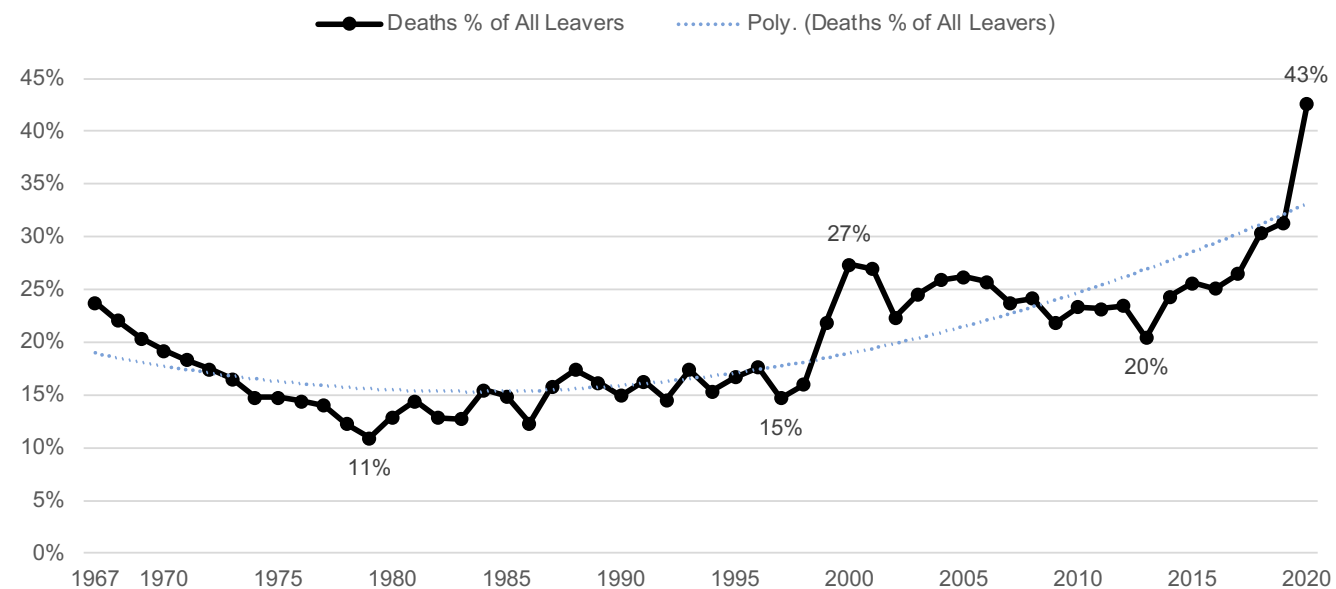
Data Source: RISP Survey. PRF - state run IDD setting of 16 or more people.

Figure 4.11 Annual PRF Admissions, Discharges, and Deaths as a Proportion of the Average Daily Population, 1967 to 2020



Data Source: RISP Survey PRF - state run IDD setting of 16 or more people.

Figure 4.12 Number of Deaths as a Proportion of all Leavers and Trend Line 1967 to 2020



Data Source: RISP Survey, PRF - state run IDD setting of 16 or more people.

We also looked at the number of deaths as a percentage of all deaths plus discharges (see **Figure 4.12**). This percentage was at its lowest level in 1979 at 11%. In the early 2000s there were higher than average rates of deaths as the rate climbed from 16% in 1998 to 27% in 2000 and 2001 but the rates subsequently dropped to below 25% from 2007

and 2016. Since then, the rates have been climbing reaching 30% in 2018, 31% in 2019 and 43% in 2020.

To facilitate comparisons with deaths of people on the caseload of state IDD agencies, we also computed deaths per 1,000 of the average daily population. The rates were 35.9 in 2018, 34.2 in 2019



Table 4.13 Annual Per Person Expenditures for People with IDD in PRFs Selected Years 1950-2020

Year	Cost (\$)	Cost (\$1=2020) ^s
1950	746	8,015
1955	1,286	12,418
1960	1,868	16,324
1965	2,361	19,408
1970	4,635	30,914
1975	10,155	48,844
1980	24,944	78,324
1985	44,271	106,693
1990	71,660	141,888
1995	85,760	145,793
2000	113,863	170,795
2005	148,811	197,918
2010	195,197	224,365
2011	226,106	254,052
2012	237,149	263,499
2013	246,063	270,399
2014	235,856	256,365
2015	263,196	283,007
2016	278,858	293,535
2017	253,187	261,018
2018	274,173	276,942
2019	281,952	284,772
2020	313,188	313,188

Data Sources: RISP Survey. PRF - state run IDD setting of 16 or more people. s: Inflation <https://data.bls.gov/cgi-bin/cpicalc.pl>

and 40.5 in 2020. The Covid-19 PHE may have had an impact on both discharges and deaths during the last four months of FY 2020.

TRENDS IN AVERAGE ANNUAL PER PERSON EXPENDITURES

Average annual per person expenditures for people living in PRFs were \$746 in 1950 (\$8,015 in 2020 inflation-adjusted dollars, see **Table 4.13**). In inflation-adjusted dollars, annual per person expenditures were \$30,914 in 1970, one year before enactment of the ICF/IID program. By 1980, inflation-adjusted expenditures had increased to \$78,324 and ICF/IID regulations, court decisions, and settlement agreements drove increases in expenditures with their requirements to reduce overcrowding, upgrade staffing levels, increase participation in meaningful daily activities, and improve physical environments. As the populations of PRFs declined, per person costs increased as fixed costs (e.g., grounds, utilities, food service, laundry, physical plant) were shared by fewer people and inflation-adjusted expenditures increased from \$106,693 in 1985, to \$293,535 in 2016. The average daily expenditures trend briefly decreased in 2017 but continued to increase after to \$313,188 in 2020.

Table 4.14 PRF Population Characteristics June 30th of Selected Years 1977 to 2020 (in percent)

Characteristic (Percent)		Year					
		1977	1987	1998	2008	2018	2020
Estimated total residents		151,112	94,695	51,485	35,035	17,557	15,322
Gender	Male	57%	57%	60%	63%	63%	64%
Age	0-21 Years	36	13	5	5	4	5
	22-39 Years	41	54	38	23	21	22
	40-62 Years	19	27	49	61	50	47
	63+ Years	4	6	8	12	25	26
Race	White					71	69
	Black/African American					19	21
	Hispanic/Latino					7	7
	Other Race or Multiple Races					3	3
Level of Intellectual Disability	Mild/No ID	10	7	8	14	14	17
	Moderate	16	10	10	12	15	16
	Severe	28	20	18	16	17	17
	Profound	46	63	65	58	54	49
Other Conditions	Epilepsy			46	44	37	38
	Autism					20	23
	Cerebral Palsy	19	21	24	23	16	16
	Behavior Disorder	25	41	44	52	58	60
Prior Criminal Justice Involvement						5	6
Short Term Stays						3	3

Data Source: PRF Survey. PRF - state run IDD setting of 16 or more people.

TRENDS IN CHARACTERISTICS OF PEOPLE WITH IDD LIVING IN PRFS

The characteristics of people living in PRFs continue to shift as the total number of people in those settings declines. The proportion of residents who were male remained steady at between 63% and 64% since 2008 (see **Table 4.14**). There has been a slight decrease in the proportion of residents who were White (decreasing from 71% in 2018 to 69% in 2020), with a corresponding increase in the proportion who were Black/African American (increasing from 19% in 2018 to 21% in 2020).

Age

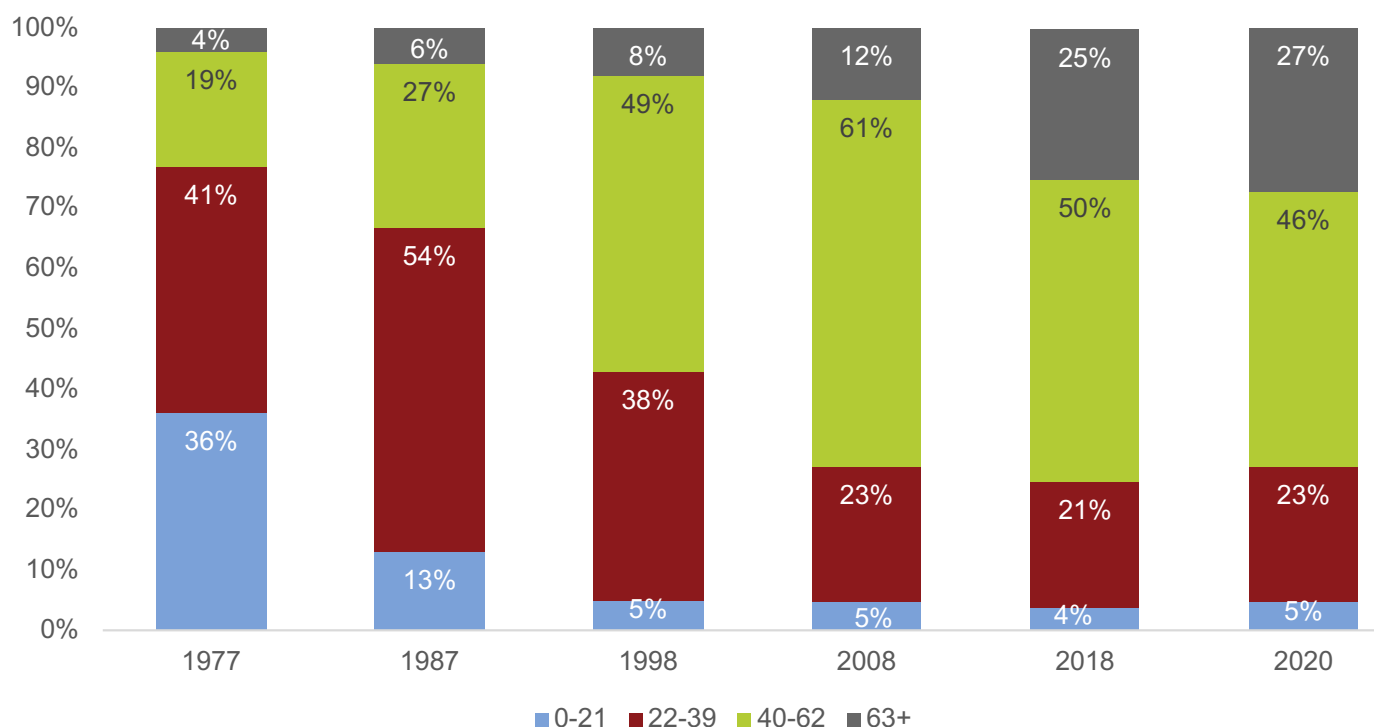
The age mix of people in PRFs shifted sharply between 1977 and 1998 as the proportion of people 21 years or younger and the proportion 22 to 39 years shrank and the proportion who were 40 to 62 years and 63 years or older grew (see **Figure**

4.13). Since 1998, the proportion who were 21 years or younger remained constant at 4% to 5% as the proportion ages 21 to 29 years leveled off to between 21% and 23%. Since 2008, the proportion ages 40 to 62 years shrank from 61% to 46% as the group ages 63 years or older continued to increase. Since 2018, more than 25% of all people in PRFs have been in the 63 years or older group.

Between 1977 and 2020, the number of people in PRFs

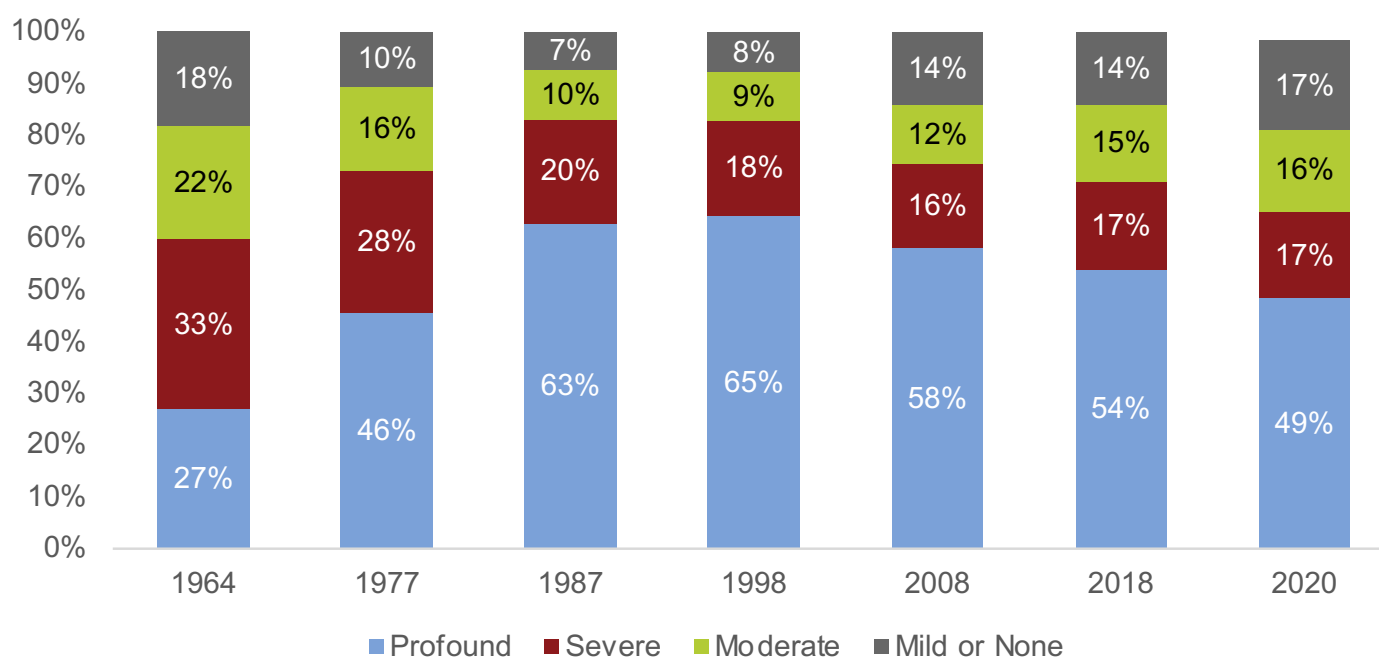
- Ages 21 years or younger declined from 54,400 to 726,
- Ages 22 to 39 years declined from 61,956 to 3,454,
- Ages 40 to 62 years declined from 28,711 to 6,979, and
- Ages 63 years or older declined from 6,044 to 4,164.

Figure 4.13 Percent of PRF Residents by Age Group on June 30 of Selected Years 1977 to 2020



Data Source: PRF Survey. PRF - state run IDD setting of 16 or more people.

Figure 4.14 Estimated Percent of People with IDD Living in PRFs by Level of Intellectual Disability on June 30 of Selected Years 1977 to 2020



Data Source: PRF survey. PRF - state run IDD setting of 16 or more people. This figure excludes people whose level of ID was unknown.

Level of Intellectual Disability

Between 1964 and 2020, the proportion of people in PRFs with no or mild ID decreased from 18% in 1964 to a low of 7% in 1987, but steadily increased to 17% in 2020 (see **Figure 4.14**). The proportion of people in PRFs with moderate ID decreased from 22% in 1964 to 9% in 1998 before increasing 16% in 2020. The proportion with severe ID decreased from 33% in 1964 to 16% in 2008 and was 17% in 2020. Finally, the proportion of people with profound ID increased from 27% in 1964 to 65% in 1998 but has been declining since then falling below 50% in 2020 (at 49%).

Between 1964 and 2020, the number of people living in PRFs with

- Mild or no ID decreased from 32,328 to 2,612,
- Moderate ID decreased from 39,512 to 2,449,
- Severe ID decreased from 59,297 to 2,563, and
- Profound ID decreased from 48,492 to 7,442.

Other Conditions and Characteristics

The proportion of people living in PRFs who had epilepsy decreased from 46% in 1998 to 38% in 2020 (see **Table 4.14**). The proportion who had ASD increased from 20% in 2018 to 23% in 2020. The proportion with cerebral palsy increased from 19% in 1977 to 24% in 1998, but then decreased to 16% by 2018 where it has remained. The proportion of people in PRFs who had a behavior disorder that required a planned intervention increased from 25% in 1977 to 60% in 2020. The proportion of people in PRFs who had prior involvement with the criminal justice system was 5% in 2018 and 6% in 2020. Short-term admissions as a proportion of the average daily population were between 3% and 4% between 2018 and 2020.

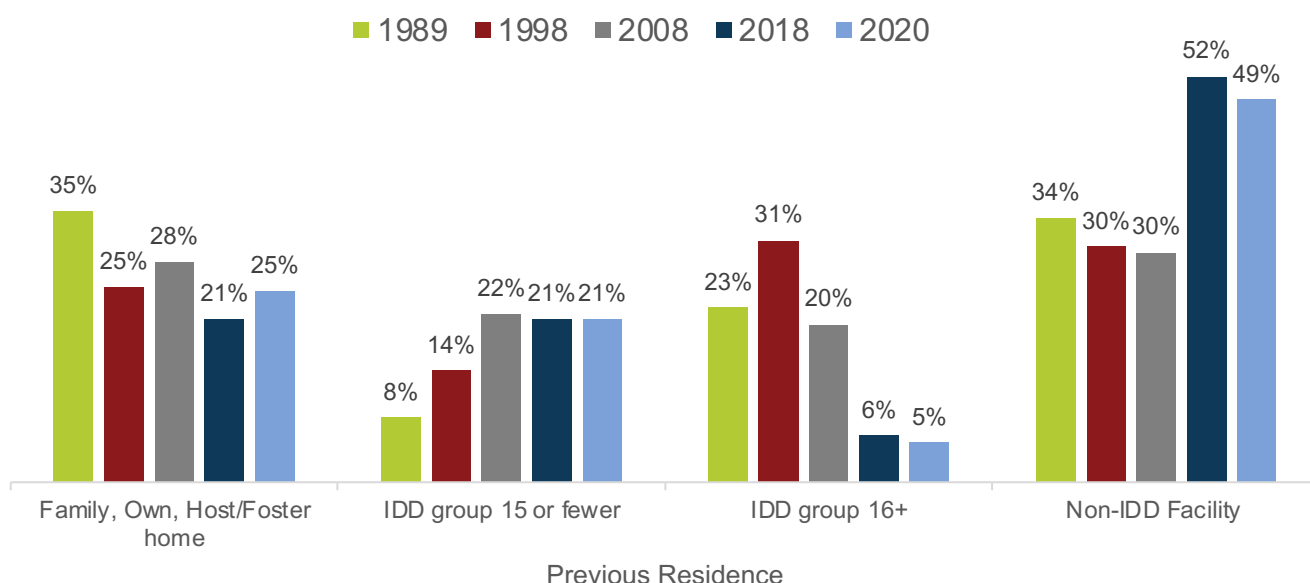


Table 4.15 Previous Place of Residence of Persons (Re) Admitted to PRFs (in Percent) for Selected Years 1985 to 2020

Previous Place of Residence (in percent)	Year										
	1985	1989	1994	1998	2002	2008	2012	2016	2018	2019	2020
Total Admissions	6,276	5,337	2,243	2,414	2,149	2,058	1,141	1,014	1,059	1,014	888
Home of parents or relative	39	29	19	21	19	21	24	17	18	18	17
Own, Host or Foster Family Home	5	7	2	4	5	7	8	4	3	0	7
Group home (1-6 res.)							6	12	18	5	17
Group home (7-15 res.)							5	3	3	16	4
Group home (15 or fewer res.)	6	8	14	14	16	22	11	15	21	5	21
State or Nonstate IDD Facility (16+ res.)	26	23	32	31	22	20	14	14	6	5	5
Mental health facility	14	16	16	12	16	13	14	17	18	29	16
Correctional facility	2	3	4	10	13	8	13	17	22	14	23
Nursing home, Assisted Living, Boarding Home	9	15	10	8	9	8	16	17	12	8	10

Source: PRF Survey. PRF - state run IDD setting of 16 or more people. Numbers do not include people whose previous residence was unknown (13 people in 2020).

Figure 4.15 Previous Place of Residence for People (Re)Admitted to a Large State IDD Facilities in Percent Selected Years: 1989 to 2020



Source PRF Survey. PRF - state run IDD setting of 16 or more people. Non-IDD Facilities include mental health facilities, correctional facilities, nursing homes, assisted living facilities, and boarding homes

TRENDS IN PRF ADMISSIONS, READMISSIONS, AND DISCHARGES

Previous and Subsequent Residence

Table 4.15 and **Figure 4.15** show changes in the former residence of people admitted or readmitted to a PRF. **Table 4.16** and **Figure 4.16** and the

subsequent residence of people discharged from PRFs from 1985 to 2020. For the figures, we excluded unknown and other settings and combined the remaining setting types into four categories:

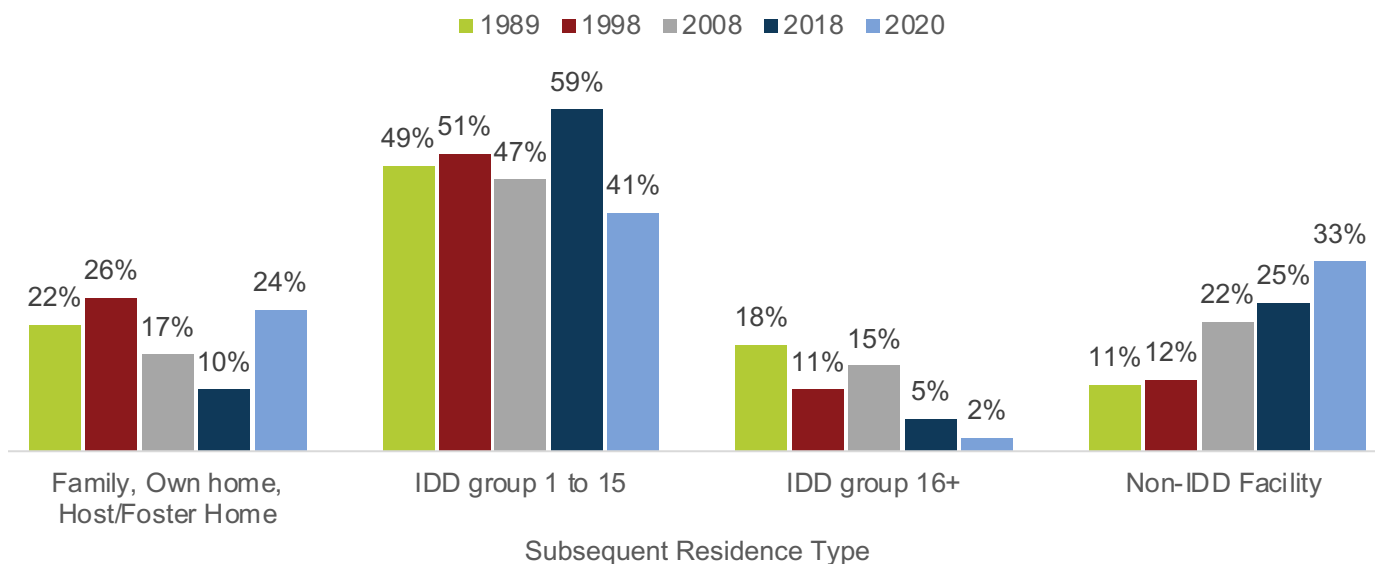
- Individualized settings (home of a family member, a host or foster family home, or own home),
- Group IDD settings of 15 or fewer people,

Table 4.16 Subsequent Residence of People Discharged From PRFs: Selected Years 1985 to 2020

New Place of Residence	Year													
	1985	1989	1994	1998	2002	2008	2010	2012	2014	2016	2017	2018	2019	2020
Total people discharged	8,619	6,122	5,490	2,414	2,785	3,111	2,690	2,436	1,997	1,897	1,642	1,453	1,264	878
Home of parents or relative	17	12	9	11	14	7	8	10	8	11	8	6	8	11
Own, Host/Foster family home	9	9	13	16	11	10	12	15	13	3	6	5	8	13
Group home (1-6 res.)								35	47	22	50	57	40	36
Group home (7-15 res.)								9	6	4	6	2	3	5
Group home (15 or fewer res.)	40	49	53	51	46	47	51	44	54	26	55	59	43	41
Group IDD facility (16+ res.)	21	18	15	11	10	15	15	18	12	35	9	5	7	2
Mental health facility	1	1	1	2	2	4	2	2	2	3	4	7	9	4
Correctional facility	0	1	0	0	3	2	2	1	7	3	8	9	17	15
Nursing home, Assisted Living, Boarding Home	11	9	9	11	14	17	11	10	5	19	10	10	8	14

Data Source: PRF Survey. PRF - state run IDD setting of 16 or more people. Percentages exclude people whose subsequent residence was unknown (23 people in 2020). Table does not include people who died.

Figure 4.16 Subsequent Residence of People with IDD Discharged From a Public IDD Facility Selected Years 1989 to 2020



Source PRF Survey. PRF - state run IDD setting of 16 or more people. Non-IDD Facilities include mental health facilities, correctional facilities, nursing homes, assisted living facilities, and boarding homes

- Group IDD settings of 16 or more people, and
- Non-IDD facilities (mental health facilities; correctional facilities; or nursing homes, assisted living facilities, and boarding homes).

Admissions

The proportion of PRF residents admitted or readmitted from an individualized setting such

as the home of a family member, a host or foster family home, or their own home decreased from 35% in 1989 to 25% in 2020. The proportion admitted from a group IDD setting serving 15 or fewer LTSS recipients increased from 8% to 21%. The proportion admitted from an IDD facility serving 16 or more LTSS recipients decreased from 23% to 5%. Finally, the proportion admitted from a non-IDD facility such as a mental health facility, correctional

facility, nursing home, or assisted living facility increased from 34% to 49%. This increase is driven by an increase in admissions from correctional facilities. This is related to a decrease in the number of facilities not serving people involved in the criminal justice system and continued operation of specialized facilities or units within facilities serving people involved with the criminal justice system.

Discharges

The proportion of PRF residents discharged to the home of a family member, their own home, or a host or foster family home was 22% in 1989 and 24% in 2020. The proportion who moved to an IDD group setting serving 15 or fewer LTSS recipients decreased from 49% in 1989 to 41% in 2020. By 2020, 36% moved to settings serving six or fewer LTSS recipients while only 5% moved to settings serving seven to 15 LTSS recipients. The proportion who moved to an IDD setting serving 16 or more people declined from 18% to 2%. Finally, the proportion who moved to an institution not specifically designed for people with IDD increased from 11% to 33%. There has been a slight increase in discharges to mental health facilities (from 1% in 1989 to 4% in 2020), and in discharges to

nursing homes, assisted living facilities or boarding homes (increasing from 9% in 1989 to 14% in 2020). However, the most prominent change has been in the proportion of people discharged to a correctional facility (increasing from 1% in 1989 to 15% in 2020).

Training and Technical Assistance Provided to People Outside of PRFs

Historically, PRFs provided services both to people living in them and to community members with IDD (see **Table 4.17**). However, this changed dramatically between 2000 and 2020. From 2000 to 2020,

- The proportion of PRFs providing behavioral assessment and intervention services to community members decreased from 51% to 20%;
- Those providing respite services decreased from 56% to 15%;
- Those providing crisis support services decreased from 44% to 17%;
- Those providing dental services decreased from 41% to 20%;



Table 4.17 Percent of PRFs Providing Services to People Not Living On-Campus by Type of Service 2000 to 2020

Type of Service	Year											
	2000	2002	2004	2006	2008	2010	2012	2014	2016	2018	2019	2020
Behavioral assessment and intervention	51	48	40	53	51	52	33	29	26	16	31	20
Dental	41	39	34	43	32	38	32	24	26	8	24	20
Crisis support	44	41	30	40	42	37	26	22	19	12	23	17
Respite	56	50	38	17	46	38	23	21	14	13	19	15
Consultant health services	29	28	25	32	25	22	14	22	7	8	19	11
Vocational training	25	31	26	9	29	24	21	20	9	4	13	11
Other	15	11	10	10	7	9	12	5	7	8	12	12
Average number of services provided	6	5	4	5	5	4	3	3	2	1	1	1

Data Source: PRF Survey. PRF - state run IDD setting of 16 or more people. N = 89 facilities reporting. Facilities could offer multiple types of services.

- Those providing consultant health services decreased from 29% to 11%; and
- Those providing vocational training decreased from 25% to 11%.
- Factors influencing these changes include a change in locus for technical assistance and services from PRFs to community settings, as well as increased enforcement of funding rules requiring money paid to PRFs to be spent only on the behalf of people residing in the PRF.

Staffing Characteristics

We have 16 years of data on how staffing characteristics and outcomes have changed in PRFs (see **Figure 4.17** and **Table 4.18**). Finding and keeping qualified DSPs and FLSs is one of the biggest challenges for LTSS providers. From 2004 to 2020, the average turnover rates for DSPs working in large state-run IDD facilities increased from 29% to 36% while vacancy rates increased from 6% to 14%. While the turnover rates were still a bit lower than in community residential settings, the vacancy rates comparable in 2020. A study of 3,000 HCBS providers in 27 states for 2020 reported that the national average turnover rate for DSPs was 44%, the average vacancy rates were 12% for full-time positions and 16% for part-time positions (National Core Indicators, 2022).

The similarities in vacancy rates are particularly notable since DSP starting and average hourly

wages for staff in PRFs kept pace with inflation between 2004 and 2020 with starting wages increasing from \$10.12 in 2004 (the equivalent of \$13.87 in 2020 dollars when adjusted for inflation) to \$15.31 in 2020. Average DSP wages increased from \$12.53 in 2004 (\$17.17 in inflation-adjusted dollars) to \$17.34 in 2020. Increases for DSPs working in other settings have not grown at this pace. Between 2004 and 2020, vacancy rates for DSPs more than doubled from 6% to 14%. DSP turnover rates increased from 29% to 36%. At \$13.24 in 2020, average hourly wages for DSPs working for community residential providers continue to be much lower than for DSPs working in large state-run IDD facilities (National Core Indicators, 2022).

Turnover rates for supervisors of DSPs working in PRFs increased from 18% in 2004 to 26% in 2020. Vacancy rates for FLS positions remained more constant (7% in 2004 and 8% in 2020). Between 2004 and 2020, starting salaries for FLSs increased from \$27,397 (\$37,536 in 2020 dollars) to \$42,783. Average salaries increased from \$33,299 (\$45,623 in 2020 dollars) to \$49,355.

Figure 4.17 Direct Support Professional and Frontline Supervisor Turnover Rates in PRFs Selected Years 2004 to 2020

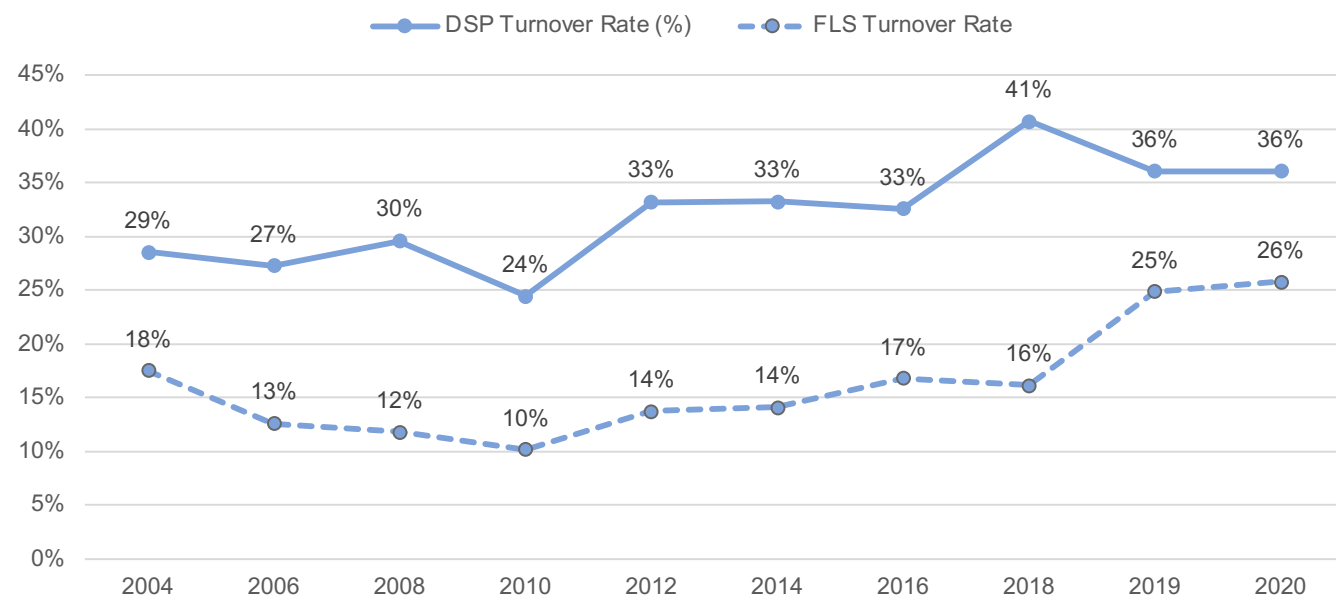


Table 4.18 Staff Characteristics in PRFs Selected Years 2004 to 2020

Staffing Characteristics	Year										
	2004	2006	2008	2010	2012	2014	2016	2017	2018	2019	2020
DSP Vacancy Rate (%)	6%	7%	7%	6%	8%	8%	11%	12%	14%	13%	14%
DSP Turnover Rate (%)	29%	27%	30%	24%	33%	33%	33%	40%	41%	36%	36%
DSP Starting Hourly Wage	\$10.12	\$11.06	\$11.35	\$11.95	\$11.99	\$12.49	\$12.96	\$13.77	\$14.78	\$14.65	\$15.31
DSP Average Hourly Wage	\$12.53	\$13.17	\$14.13	\$14.76	\$14.67	\$14.77	\$15.99	\$16.11	\$16.93	\$16.79	\$17.34
FLS Vacancy Rate	7%	5%	6%	6%	7%	8%	10%	10%	10%	8%	8%
FLS Turnover Rate	18%	13%	12%	10%	14%	14%	17%	17%	16%	25%	26%
FLS Starting Salary	\$27,397	\$29,914	\$30,979	\$35,228	\$33,118	\$34,732	\$36,396	\$38,123	\$41,604	\$40,618	\$42,783
FLS Average Salary	\$33,210	\$35,783	\$36,924	\$42,590	\$38,062	\$41,132	\$43,374	\$47,678	\$48,127	\$47,452	\$49,355

Data Source: PRF Survey. PRF - state run IDD setting of 16 or more people. DSP Direct Support Professional; FLS Frontline Supervisor



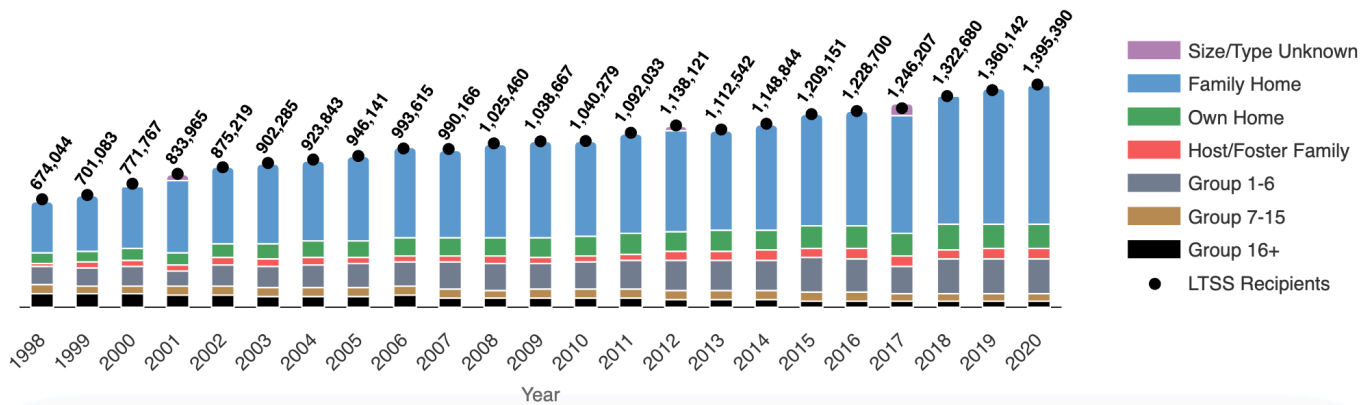
SECTION FIVE

STATE PROFILES AND NOTES

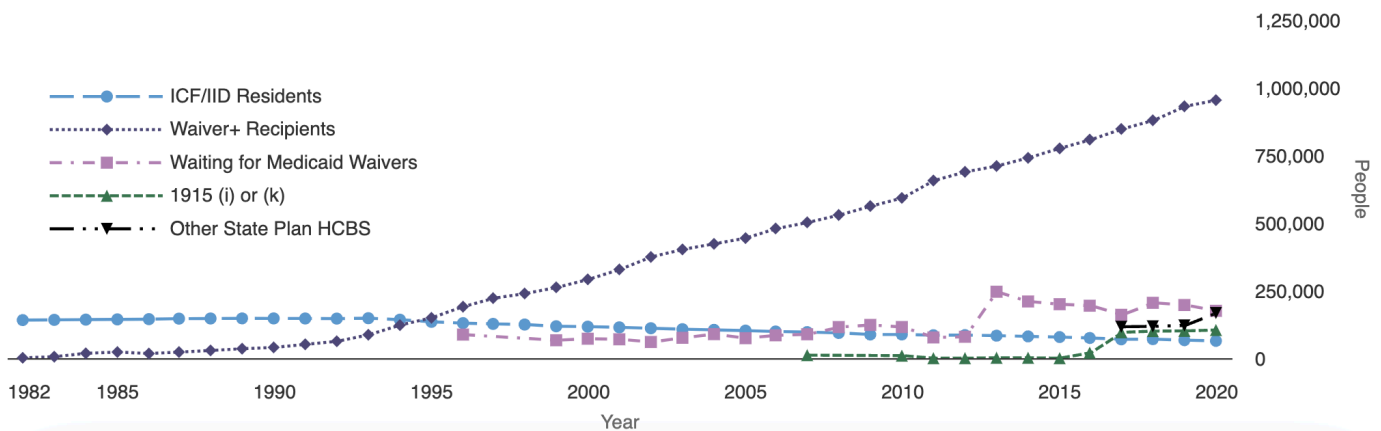
FY 2020

2020 United States Profile

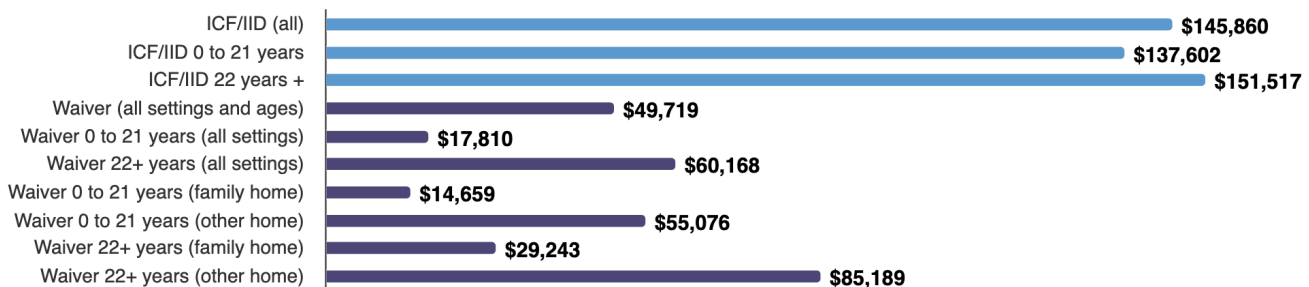
Long Term Supports and Services Recipients with IDD by Residence Type and Year



Medicaid Recipients by Funding Authority 1982 through 2020



Average Annual Per Person Spending by Age, Setting and Medicaid Authority in FY 2020



Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services;
 ICF/IID: Intermediate Care Facilities for Individuals with Intellectual Disabilities; Group:
 Number of people with IDD in a setting (ICF/IID, group home or other); Waiver+:
 Medicaid Authorities 1115, 1915 (a)(b) or (b)(c), 1915(c)



SECTION 5: STATE NOTES

State Profiles are posted on the RISP.umn.edu website and can be viewed or downloaded from the website.

STATE PROFILES

The state and United States profiles show longitudinal changes in residential settings for LTSS recipients with IDD, state IDD agency caseloads, Medicaid Waiver waiting lists and Medicaid recipients by funding authority. They also show expenditures per person by funding authority, setting type, and age. Blank spaces or breaks in a trend line indicate years in which a data element was not collected or for which a state provided incomplete or no data. Large year-to-year changes often reflect changes in state data sources or methodology, the addition or termination of a funding authority, or inclusion of a narrower or broader set of recipients. State Notes describe variations from the survey definitions, alternative data sources used, reasons for large year-to-year changes, and other factors affecting data interpretation.

IDD Agency Long Term Supports and Services Recipients by Residence Type

The first chart shows the number of LTSS recipients by residence type (family home, own home, host or foster family home, and group homes) by year. Group settings such as ICF/IID or Medicaid Waiver-funded group homes characterized by the number of people with IDD sharing the home (1 to 3, 4 to 6, 7 to 15 or 16 or more).

Caseload, LTSS and Medicaid Recipients and Waiting for Waivers

The second chart shows changes over time in the number of people served by state IDD agencies, the number of people with IDD receiving one or more LTSS in addition to case management, and the number of people with IDD waiting for Medicaid Waiver funded services while living with a family member or in their own home. The waiting list numbers do not include people who already live in a group home or another LTSS setting or who already receive some Medicaid Waiver funded supports. The chart also shows changes in the number of LTSS

recipients whose services are funded under the Medicaid ICF/IID program, or under one of several Medicaid Waiver funding authorities (1115, 1915 (a) (b) or (b/c), 1915(c)).

Average Annual Medicaid per Person Expenditures for FY 2020

The third chart shows average annual per person expenditures for people with IDD living in an ICF/IID, or who receive LTSS funded by specific Medicaid Waiver funding authorities (1115, 1915 (a) (b) or (b/c), 1915(c)). When available, for Medicaid Waiver recipients, annual per person expenditures are shown by recipient age as of June 30 (birth to 21 years or 22 years or older) and by living arrangement (family home or any other setting).

STATE NOTES

State Notes describe variations from the survey definitions, alternative data sources used, reasons for large year-to-year changes, and other factors affecting data interpretation. An asterisk next to the name of a state on the tables indicates data that are addressed by these state notes.

Alabama

Alabama did not complete the FY 2020 survey. Most data are from FY 2019. Alternate data for Waiver and ICF/IID expenditures are from Mathematica (Murray et al, 2023). Alternate data for ICF/IID and nursing home residents are from AHCA (2020a, 2020b, & 2020c).

Alaska

Alaska does not operate any ICF/IIDs, but some people on the IDD caseload live in ICF/IIDs in other states. Assisted living homes are licensed to provide services to elderly and adults with physical or mental disabilities. Some provide group home services to individuals 18 years or older funded by these HCBS waivers: Intellectual and Developmental Disabilities (IDD), Adults with Physical and Developmental Disabilities (APDD), or Children with Complex

Medical Conditions (CCMC). A decrease in IDD grant program funding contributed to an increase in the number of people waiting for services in FY 2020. Alternate data for Waiver and ICF/IID expenditures from Mathematica (Murray et al, 2023). Alternate data for ICF/IID and nursing home residents are from AHCA (2020a, 2020b, & 2020c).

Arizona

Arizona manages ICF/IID settings within their 1115 Managed Care Demonstration Waiver and reports ICF/IID recipients as being in Waiver-funded settings. Most ICF/IID expenditures are captured in the reports of Waiver expenditures. Alternate data for Waiver and ICF/IID expenditures are from Mathematica (Murray et al, 2023). Alternate data for ICF/IID and nursing home residents are from AHCA (2020a, 2020b, & 2020c).

Arkansas

Arkansas switched to managed care in FY 2020. FY 2020 data on living arrangements was not available from managed care organizations serving half of all recipients. The number of waiver recipients by residence are estimated based partial data. Reported deaths include only waiver recipients and people in large state-run facilities. ICF/IID recipients are reported for only state-run ICF/IIDs, but expenditures are reported for all ICF/IID recipients. Thus, the per person ICF/IID expenditures appear higher than what they were. Alternate data for LTSS recipients in nonstate settings and in large state-run IDD facilities are from Gillespie (2020). Alternate data for Waiver and ICF/IID expenditures are from Mathematica (Murray et al, 2023). Alternate data for ICF/IID and nursing home residents are from AHCA (2020a, 2020b, & 2020c). 1915(i) recipients are tracked by Arkansas Department of Behavioral Services and are not reported.

California

Colorado

Non-State operated “other” settings are community-based group homes, host homes, or individualized environments where the person lives alone, with family, or with one to two other service recipients in their own home, family home, or agency supported home. Colorado’s data system does not distinguish between people receiving services in their own or

family members’ homes. This is reflected in the FY 2020 data, but previous reports showed these people living in family homes. Colorado’s two state ICF/IID facilities (Grand Junction Regional Center and Wheat Ridge Regional Center) operate units both on a campus and in the community.

Connecticut

Non-state “other” settings include hospitals, mental health settings, and correctional facilities. The waiting list is not limited to people requesting Medicaid Waiver-funded supports. However, most people on Connecticut’s waiting list eventually move to a Waiver-funded residential setting. Some people on the waiting list are not eligible for Targeted Case Management services. Waiver spending in FY 2020 increased for people ages 0-21 due to school closures and thus an increase in in-home supports, as well as wage increases for in-home workers.

Delaware

Beginning in FY 2013, people receiving Family Support Specialist services were reported to be living in the home of a family member. Delaware has 120 group homes of four or more people. Their data system tracks these homes by their licensed size, not by how many people live there. In FY 2017, Delaware revised how it reported living arrangements for Waiver recipients. Before FY 2019, Waiver recipients living in settings other than the home of a family member were not counted. Delaware has one nonstate-run ICF/IID, the Mary Campbell Center, which housed 70 people in FY 2019; we report 70 people in FY 2020 as an estimate based on FY 2019 data. The Mary Campbell Center is not overseen by Delaware’s Division of Developmental Disabilities Services, so the people there were not previously counted in RISP as ICF/IID recipients, nor did we report on their expenditures. In FY 2020, people with IDD participating in Delaware’s 1115 Demonstration Waiver were not counted as LTSS recipients.

District of Columbia

Due to updated Waiver rules, residential habilitation (group homes) can no longer serve more than four people. The state funds out-of-state residential facilities, certain adaptive equipment, meals at day habilitation programs for adults who live with family members, and ICF/IID services for recipients 21 years or younger.

Florida

Nonstate-run “other” settings include mental health group homes, hospitals, and correctional facilities. The number of people reported in “other” Waiver-funded settings increased due to data system improvements. The number of group homes fluctuates year to year due to provider changes. The number of people living in host/foster family homes of four to six, seven to fifteen, and 16 or more people are estimated based on FY 2021 data. The number of people ages 0-21 living in Florida’s ICF/IIDs has decreased significantly in recent years as people age out of this category, and few to no young people are admitted to ICF/IIDs.

Georgia

Georgia was not able to provide FY 2020 data. The Gracewood and Augusta campuses of the East Central Regional Hospital have both SNF and ICF/IID services. The Georgia Regional Hospital at Atlanta (in Decatur) has SNF services. Data sources include the FY 2021 survey and Georgia’s FY 2020 PRF survey. External data sources included Mathematica for Waiver, State Plan, and ICF/IID expenditures (Murray et al, 2023), and AHCA for ICF/IID and nursing home residents (2020a, 2020b, & 2020c).

Hawaii

Hawaii’s caseload is reported for the entire FY, not just for June 30. Hawaii implemented a new data system in FY 2020, which resulted in some shifts in reporting due to more accurate data. Some Waiver participants were active in the Waiver system but did not have a billed service in FY 2020, which is why there are more participants reported in expenditures than total Waiver participants in the system. The 1115 Demonstration Waiver is not managed by Hawaii’s Developmental Disabilities Division and is thus not reported here.

Idaho

Idaho provided data for about half of the items on the FY 2020 survey. The number of people on the state IDD caseload did not include people living in ICF/IIDs. Settings are reported by license or certification size rather than actual occupancy. The significant decrease in expenditures for children on the Medicaid Waiver is the result of several factors. In FY 2020, DDA terminated the Children’s waiver and implemented the Medicaid State Plan-funded

Children’s DD Enhancement program. Children no longer must meet ICF/IID level of care to qualify for services. Medicaid Waiver expenditures increased as many children aged out of children’s services and due to a settlement agreement, which permits adult Waiver recipients to use their largest annual DD budget allocation since 2011 for services while DDA works to determine a court-approved budget allocation process. ICF/IID expenditures are reported only for a subtotal of recipients. Alternate data for Waiver and ICF/IID expenditures are from Mathematica (Murray et al, 2023). Alternate data for ICF/IID and nursing home residents are from AHCA (2020a, 2020b, & 2020c).

Illinois

Prior to FY 2016, the number of people with IDD reported to be waiting for services included some people who were already receiving Medicaid Waiver-funded supports. Beginning in FY 2016, only people living with a family member or in their own home who requested Medicaid Waiver-funded supports to begin within the next 12 months are counted. Before FY 2019, Illinois’s surveys included some people with primary diagnoses of mental health disorders who lived in PRFs.

Indiana

Information about people living in nonstate-run group homes was not reported until FY 2020. Data on people living in their own homes are estimates based on claims data.

Iowa

Variation between previous reporting years and FY 2020 is due to a change in reporting methods that include a more detailed data source. The number of non-state group home settings by size is based on the number of provider agencies and may, therefore, underestimate the total number of homes. PRF data on short-term or crisis admissions and per diem are from Iowa’s PRF surveys.

Kansas

The age breakdown of people receiving state or locally funded non-Medicaid LTSS and their associated expenditures were estimated by the Kansas Department of Aging and Disability Services based on the total reported amount.

Kentucky

All data are reported for the full FY rather than just for June 30. As a result, people who lived in more than one setting type during the fiscal year are counted more than once. People reported in unknown settings could live on their own or with family members because Kentucky's data system does not distinguish between residence types for people not receiving residential services. The state reports the total number of providers for group home and host or foster family home); the number of settings by size was imputed based on the total number of recipients living in settings of each size. ICF/IID recipients by age includes only people in nonstate ICF/IIDs. Alternate data for Waiver and ICF/IID expenditures are from Mathematica (Murray et al, 2023). Alternate data for ICF/IID and nursing home residents are from AHCA (2020a, 2020b, & 2020c).

Louisiana

Louisiana was only able to provide FY 2020 data on large, state-run institutions. Some data are imputed from Louisiana's FY 2019 RISP survey. Louisiana had three state-run facilities serving 16 or more people with ICF/IID licenses: Pinecrest Supports and Services Center (Pineville), Central Louisiana Supports and Services Center (Alexandria, previously known as the Louisiana Special Education and Transition Center), and East Louisiana State Mental Hospital (a psychiatric facility with three ICF/IID-certified units). Data on number of state-run settings and people living in them are from Louisiana's PRF surveys. Alternate data for Waiver and ICF/IID expenditures are from Mathematica (Murray et al, 2023). Alternate data for ICF/IID and nursing home residents are from AHCA (2020a, 2020b, & 2020c).

Maine

Maine's IDD agency mostly supports people ages 18 and older. The exception are some children that live in ICF/IIDs. Most children with IDD who receive LTSS are served by the Office of Children and Family Services and are not reported on the RISP survey. RISP data on people ages 0-21 only includes people ages 18 to 21 except ICF/IID data. Four short-term state-run IDD facilities are not counted since stays are limited to 90 days or less. A rise in nonstate-run host/foster settings in FY 2020 was driven by a new shared living option.

Maryland

The number of LTSS recipients reported FY 2015-2017 included people receiving only service coordination. People reported in unknown settings includes people living in their own or family homes as Maryland's data system does not distinguish between these groups. People in "non-state other" settings receive Community Coordination Services, Behavior Support Services (BSS), residential services, Individual Family Care (IFC), or self-directed supports. Before 2010, Maryland's reported number of people on the waitlist included those deferring services until later and those already receiving waiver services. Since 2010, their reported waitlist only includes those waiting for waiver services and not receiving other waiver services. The number of people served in FY 2020 increased because people receiving services through the state's 1915(i) and (k) programs were included and because Maryland added Community and Family Supports programs for people with IDD. Maryland has three state-run 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>). Alternate data for Waiver and ICF/IID expenditures are from Mathematica (Murray et al, 2023). Alternate data for ICF/IID and nursing home residents are from AHCA (2020a, 2020b, & 2020c).

Massachusetts

The number of people reported receiving services in host or foster family settings is a partial count since others receive these services through MassHealth and data on those people are not managed by the Department of Developmental Services. People reported in "other" settings include those in foster care, nursing homes, correctional facilities, and those experiencing homelessness. Expenditures for children receiving waiver services increased since FY 2019 due to an increase in participants, an increased budget, new legislation for family support, and Covid-19-related funding increases.

Michigan

Some data points that show decreases in people served and associated expenditures for FY 2020 are due to incomplete reporting by managed

care organizations, as well as changes in data management processes due to staff turnover in Michigan's IDD agency. Additionally, many people in Michigan temporarily stopped receiving services in FY 2020 due to the Covid-19 pandemic, restarting them in FY 2021. Many Michigan group homes closed early during the pandemic resulting in people moving to other settings including nursing homes. Michigan began reporting the number of 1915(b/c) waiver recipients in FY 2011 accounting for the jump in waiver recipients for that year. Michigan changed its 1915(b) waiver to an 1115 demonstration waiver in FY 2020.

Minnesota

Non-state "other" settings include Customized Living (assisted living) and Board and Lodging. Claims data do not distinguish between settings of one to three and four to six people. The numbers of Waiver recipients by residence type are estimates. In Minnesota, Waiver-funded group homes are typically limited to four or fewer people, with certain exceptions allowing for five people. There may be a few individuals on the IDD waiver waitlist who are enrolled in an alternative waiver program and residing in a foster care setting.

Mississippi

In FY 2020, Mississippi stopped providing state-run services other than case management funded by Medicaid 1915(c) and 1915(i) funding authorities. To ensure conflict-free case management, people previously receiving state-run IDD Waiver-funded residential services were transferred to certified private providers except for those living in one state-run facility. ICF/IID expenditure and recipient data only report on people in state-operated settings. Four of the five large state-run ICF/IID facilities also provide IDD Waiver Support Coordination (case management) and 1915(i) Targeted Case Management. The total number of LTSS recipients living with a family member increased as more people began using supports funded by the Medicaid 1915(j) funding authority. ICF/IID expenditures and recipients by age only include people in state-run ICF/IID.

Missouri

Missouri did not have a waiver waitlist between FY 2015 and FY 2019. It was reestablished in FY 2020.

Montana

Montana provided partial data for the FY 2020 RISP survey. Some data are from their FY 2019 survey. Since FY 2015, children ages 1-3 receiving Part C and/or Social Services Block Grant (Title XX) funding have been counted in the IDD agency caseload. People 16 years or older served by the state IDD agency are entitled to Medicaid State Plan-funded case management services. The nonstate "other" setting was an assisted living facility. In 2018, Montana began using new data reports that provided more accurate data than was previously available. This explains significant changes in data after FY 2017. Alternate data for Waiver and ICF/IID expenditures are from Mathematica (Murray et al, 2023). Alternate data for ICF/IID and nursing home residents are from AHCA (2020a, 2020b, & 2020c).

Nebraska

The number of children on the caseload increased due to policy changes allowing relatives to become providers. Some Nebraska group home providers changed operations in recent years to provide shared living supports, thus impacting the number of people reported in group homes and host or foster family homes. Nebraska's Aged & Disabled Waiver changed in FY 2020 to require nursing level of care for children. As a result, some children sought services under Nebraska's DD waiver, increasing the number of children supported by the waiver significantly. The level of care requirements also increased for the DD waiver, which led to a decrease in people receiving Waiver services in family homes. Beatrice State Development Center campus houses four separately licensed ICF/IID buildings. From FY 2011 to FY 2016, each building was reported as a separate facility.

Nevada

The count of people in their own homes includes 122 people who do not receive LTSS besides case management. The count of people in family homes includes 1,818 who did not receive LTSS besides case management. People in non-state "other" settings include people in jails, out-of-state ICF/IIDs, assisted living centers, hospitals, transitional living centers, and experiencing homelessness.

New Hampshire

Alternate data for Waiver and ICF/IID expenditures

are from Mathematica (Murray et al, 2023). Alternate data for ICF/IID and nursing home residents are from AHCA (2020a, 2020b, & 2020c).

New Jersey

The New Jersey IDD agency only serves adults. In FY 2020, three people with IDD housed in a separate building of a state-operated ICF/IID had been convicted of crimes and court-ordered to a disability rehabilitation setting. The number of own home settings are not known and is estimated to be one setting per recipient. Since FY 2013, ICF/IID expenditures and recipients by age have been reported only for state-operated ICF/IID settings. Significantly more people in family homes received Waiver services in FY 2020 due to ramp up of the "Supports Program" Waiver, which was implemented in FY 2017. Alternate data for Waiver and ICF/IID expenditures are from Mathematica (Murray et al, 2023). Alternate data for ICF/IID and nursing home residents are from AHCA (2020a, 2020b, & 2020c).

New Mexico

Non-state IDD group homes and supported living facilities in New Mexico serve a maximum of four people. It is not possible to differentiate between homes with one to three people and homes with four people. Claims data for supported living services were used to identify FY 2020 recipients and expenditures for LTSS recipients living in non-family settings. New Mexico's data system does not distinguish between those living in their own homes and family homes. Alternate data for Waiver and ICF/IID expenditures are from Mathematica (Murray et al, 2023). Alternate data for ICF/IID and nursing home residents are from AHCA (2020a, 2020b, & 2020c).

New York

Prior to FY 2018, the Office for People with Developmental Disabilities (OPWDD) used enrollment data to determine LTSS recipients in New York state. Starting in FY 2019, OPWDD transitioned to service utilization data, a more precise representation of the population supported by OPWDD. OPWDD does not have a waitlist for Medicaid Waiver Services. However, 5,355 people have expressed interest in OPWDD supported housing as of 06/30/2020. These

individuals may or may not currently live in a family home or their own home setting.

North Carolina

North Carolina was not able to provide data for the FY 2020 RISP survey. Data not reported from alternate sources are from FY 2019. People in Black Mountain and O'Berry Centers were included in counts of people in state-run facilities in FY 2020 but not in other recent years. Data on residence size for nonstate settings is provided by LME-Managed Care Organizations that may not have access to accurate information on facility size. As a result, the reported number of facilities may be an undercount. Alternate data for Waiver and ICF/IID expenditures are from Mathematica (Murray et al, 2023). Alternate data for ICF/IID and nursing home residents are from AHCA (2020a, 2020b, & 2020c).

North Dakota

Some people on the state caseload only received case management services. That number decreased in FY 2020 due to Covid-19 as case management required in-person visits. The number of waiver recipients who lived with family members decreased since many people chose not to continue in-home support during the early months of Covid-19. Before the 2020 survey, people receiving Infant Development were mistakenly excluded from counts of people in family homes on the Medicaid Waiver. They are now included. ICF/IID expenditures are only reported for recipients in non-state settings.

Ohio

People on the agency caseload but not receiving funded LTSS may be on the waitlist, in school, or receiving early intervention or other locally funded services. The waiting list includes people waiting for Medicaid Waiver-funded supports who are not already Medicaid Waiver or ICF/IID recipients. It includes some people living in non-family settings. State-funded expenditures do not include funds allocated through county boards, which provide many services through local dollars. Alternate data for Waiver and ICF/IID expenditures are from Mathematica (Murray et al, 2023). Alternate data for ICF/IID and nursing home residents are from AHCA (2020a, 2020b, & 2020c).

Oklahoma

Oklahoma was not able to provide data for the FY 2020 RISP survey. Data elements in this report are from external sources including a 2020 Oklahoma Developmental Disabilities Services annual report (n.d.) or from the FY 2019 survey. Alternate data for Waiver and ICF/IID expenditures are from Mathematica (Murray et al, 2023). Alternate data for ICF/IID and nursing home residents are from AHCA (2020a, 2020b, & 2020c).

Oregon

Previous years' reporting was based on licensed size of residential settings, but FY 2020 is reported based on number of people per home. Oregon began offering HCBS through the Medicaid State Plan 1915(k) funding authority in FY 2015. Total Medicaid Waiver recipients and expenditures declined shortly thereafter as recipients moved from Waiver to State Plan 1915(k) funding. FY 2020 was the first full year that case management was funded based on an individual's Medicaid eligibility rather than a procedure code entered by field staff. This, along with regular caseload growth, increased the number of Waiver recipients. An estimated 6,110 Waiver recipients received only case management services were included in the expenditures report and in the recipients by age counts.

Pennsylvania

Residences listed as "other" include personal care homes, friend's home, temporary homeless shelter, and other self-reported living arrangements on eligibility forms.

Rhode Island

The number of people ages 0-21 reported as on the caseload but not receiving LTSS has increased since FY 2017 due to a policy encouraging young people to apply for LTSS before age 17, though most will not choose to receive services until age 21 or 22. The rate of this increase is expected to level off after a few years. Rhode Island's DD agency does not utilize a waiting list. Data on waiver recipients and expenditures are from FY 2019. Reported ICF/IID expenditures include only state-operated ICF/IIDs.

South Carolina

Own home settings could only be reported by the number of contracts held. There is no way to

determine from the data the number of people served through each contract. PRF data on per diem and average daily residents are from South Carolina's PRF surveys.

South Dakota

South Dakota was not able to provide data for the FY 2020 RISP survey. Alternate data for Waiver and ICF/IID expenditures are from Mathematica (Murray et al, 2023). Alternate data for ICF/IID and nursing home residents are from AHCA (2020a, 2020b, & 2020c).

Tennessee

People reported in unknown settings may live in their own or family members' homes. People reported in family homes receive state-funded family services and are thus known to live in family homes. People in family homes are reported for the full fiscal year, not June 30. Tennessee stopped accepting applications for its 1915(c) Waiver on June 30, 2016, and no longer maintains a waiting list for 1915(c) Waiver-funded services. People on the referral list for services under the 1115 Waiver have not been screened for eligibility. The Harold Jordan Center had 12 people on June 30, 2020. Of them, five received Medicaid ICF/IID funding and seven received state funding. Alternate data for Waiver and ICF/IID expenditures are from Mathematica (Murray et al, 2023). Alternate data for ICF/IID and nursing home residents are from AHCA (2020a, 2020b, & 2020c).

Texas

The Texas fiscal year ends on August 31 rather than June 30. All ICF/IID settings in the 1-6 people category are licensed for six people. Alternate data for Waiver and ICF/IID expenditures are from Mathematica (Murray et al, 2023). Alternate data for ICF/IID and nursing home residents are from AHCA (2020a, 2020b, & 2020c).

Utah

People with urgent needs on Utah's waitlist in FY 2020 were provided temporary, one-time services as part of the CARES Act. Services included caregiver compensation, respite services, personal protective equipment, and assistive technology like tablets for telehealth and connecting virtually with friends and family. Increased expenditures for people on the

Waiver and living at home with family were due to rate increases, and, for people ages birth to 21, the addition of roughly 100 people to the Waiver. There appear to be fewer people living in family homes because some people living in their own homes were miscounted as living in family homes prior to the FY 2020 survey. ICF/IID recipients, expenditures, and age breakdowns are reported only for state-run settings. Alternate data for Waiver and ICF/IID expenditures are from Mathematica (Murray et al, 2023). Alternate data for ICF/IID and nursing home residents are from AHCA (2020a, 2020b, & 2020c).

Vermont

Vermont's only remaining ICF/IID closed during FY 2020. The date of birth cut off was incorrect for FY 2015 to 2017. This caused an undercount for those three years, resulting in an apparent increase in the number of children served and associated expenditures in FY 2020. Cost per person for people ages birth to 21 receiving state-funded services increased in FY 2020 due to un-duplicating cases and no longer including "Employment Program Base" numbers, which lowered the overall recipient count. The number of people receiving waiver services in family and non-family homes were reported based on June 30, 2020, while their associated expenditures were reported for all of FY 2020.

Virginia

Data on nonstate-run Medicaid waiver-funded settings and waiver expenditures are from a KFF report (O'Malley Watts et al., 2020). PRF per diem data are from Virginia's PRF survey. Alternate data for Waiver and ICF/IID expenditures are from Mathematica (Murray et al, 2023). Alternate data for ICF/IID and nursing home residents are from AHCA (2020a, 2020b, & 2020c).

Washington

Washington implemented Medicaid Community First Choice State Plan Services in FY 2016. Personal care services previously funded through a Medicaid Waiver are now funded through the Community First Choice State Plan option. Medicaid State Plan expenditures increased, and Medicaid Waiver expenditures decreased when the change was made. The number of people with IDD in own home settings varies from year to year because in some years data were not available for all funding authorities.

West Virginia

West Virginia was not able to provide data for the FY 2020 RISP survey. Most data are from their 2019 survey. Alternate data for Waiver and ICF/IID expenditures are from Mathematica (Murray et al, 2023). Alternate data for ICF/IID and nursing home residents are from AHCA (2020a, 2020b, & 2020c).

Wisconsin

Setting size information was not available for LTSS recipients living in their own homes or in non-state "other" settings. Until FY 2014, Wisconsin reported only Waiver recipients living in own home, family home, and nonstate "other" settings. Since then, all LTSS recipients living in nonstate settings (including group homes and host or foster family homes) have been reported. Some children with IDD in state-run settings receive Medicaid State Plan-funded services who are not on the IDD agency caseload are included as LTSS recipients. Large state-run IDD facilities in Wisconsin include Central Wisconsin Center in Madison and Southern Wisconsin Center in Union Grove. Though Northern Wisconsin Center was converted into a short-term stay facility in 2005, some residents may stay more than 90 days.

Wyoming

Nonstate "other" settings include an educational cooperative that provides both day and residential services to children with IDD ages 5 to 21 years. The number of nonstate-run group homes was estimated based on the number of people living in them. Alternate data for Waiver and ICF/IID expenditures are from Mathematica (Murray et al, 2023). Alternate data for ICF/IID and nursing home residents are from AHCA (2020a, 2020b, & 2020c).

Public Residential Facility Survey Notes

Arkansas

- Boonville Human Development Center: Data on discharges by level of IDD and age breakdowns are estimated. Four people transferred to other facilities in FY 2020.

California

- Canyon Springs Community Facility: The only new admissions were for people who transferred in

from FDC or PDC. For direct services provided to the community, 2017 data were used.

- Fairview Developmental Center: For direct services provided to the community, 2017 data were used.
- Sonoma Developmental Center: For direct services provided to the community, 2017 data were used.
- Porterville Developmental Center: The facility has two areas: the General Treatment Area (GTA) and the Secured Treatment Area (STA). Only GTA is closing in June 2021. STA will stay open.

Connecticut

- Hartford Regional Center: An estimated 18 DSPs left employment in FY 2020.

Illinois

- Elisabeth Ludeman Center: Five people transferred out from the facility: one went to another state-run IDD facility and four to a state-run MI facility.
- Choate Mental Health and Developmental Center: For current residents, unspecified ID was listed under 'unknown.'
- Ann Kiley Center: Other direct services provided to the community included behavioral assessment and technical assistance services.

Massachusetts

- Charles V. Hogan Regional Center: Did not discharge any residents other than those there for short-term evaluation and treatment in the "ESU" – Evaluation and Stabilization Unit. In FY 2020, six people from that unit returned to a group home or family home within 90 days. Other direct services provided to the community included recreational areas are available to community groups. These include their auditorium, gym, adapted gym, and pool.

Mississippi

- Ellisville State School: Some individuals who were discharged went to hospice settings.
- Boswell Regional Center: Boswell Regional Center operates several community homes not located on the campus. People living in those programs have access to the Regional Center amenities.

- North Mississippi Regional Center: Some individuals who were discharged went to in-patient hospice (hospital/institution).

Missouri

- Southeast Missouri Residential Services: Average costs per person per day were \$529 for Popular Bluff, \$615 for Sikeston.

North Dakota

- Life Skills and Transition Center: Twenty of the 32 reported admissions were for short term stays. Twenty of the 30 reported discharges were people who had been admitted for short-term stays.

Nevada

- Desert Regional Center: One person with an unknown level of ID had Prader-Willi Syndrome. One person with an unknown level of ID who was discharged had Fetal Alcohol Syndrome. Other direct services provided to the community included dietary consultations.

New York

- Sunmount Development Center: Other races/ethnicities included Asian or Pacific Islander (one person), and American Indian/Alaskan (one person). Race/ethnicity data were missing for 14 people. ID level was not available for six people who were new/readmitted and six people who were discharged.
- Valley Ridge: Data were missing for level of ID for two people, race/ethnicity for five people, and level of ID for two people who were admitted.

North Carolina

- Murdoch Developmental Center: Levels of ID were unknown for one current resident with ASD, two people with ASD who were admitted or readmitted, and for six people who were discharged (one had borderline ID and five had ASD).
- O'Berry Neuro-Medical Treatment Center: The person listed as having no ID has traumatic brain injury which occurred prior to 21st birthday. The current census includes both ICF and SNF beds. The ICF/IID is not admitting new people. Average daily per person expenditures were \$805.26 for the ICF/IID, \$564 for the SNF.

Ohio

- Mount Vernon Developmental Center: One individual was court ordered to the facility. Several others have been involved previously with the criminal justice system or came from jails.

South Dakota

- South Dakota Developmental Center: There are a total of 135 DSP positions. The number of vacancies is not known.

Texas

- Brenham State Supported Living Center: Twenty-three people who live in off-campus group homes receive services at Brenham Production Service (off-campus).
- Denton State Supported Living Center: The only service that they provide individuals living in the community is post-move monitoring for the first year after discharge. This is monitoring services and recommendation from the interdisciplinary team that is included in the community living discharge plan (CLDP). If within the first 90 days there is a potentially disruptive event that happens such as: police involvement, hospital/psych hospital admission, elopement, etc., the interdisciplinary team from the facility would meet and discuss with the provider if additional training would be needed and to share information to prevent the event from happening again. All other services are completed pre-move.
- San Angelo State Supported Living Center: Other direct services provided to the community included sex offender treatment.

Virginia

- Southeastern Virginia Training Center: Other direct services provided to the community included dental services for 281 people.

Wisconsin

- Southern Wisconsin Center: SWC no longer admits long-term residents. All new admissions were short-term only. In FY 2020, 15 short-term residents stayed longer than 90 days.
- Central Wisconsin Center for the Developmentally Disabled: There are 57 people who are on psych medications. One person was discharged to

hospice. Other direct services provided to the community included Outpatient Rehabilitation Technology Services. Average daily per person costs were \$1,198 for Short-term behavior units, and \$881 for Long-term care units and Medical short-term care units.

Wyoming

- Wyoming Life Resource Center: Other direct services provided to the community included assistive technology assessment and intervention.





SECTION SIX

APPENDICES

FY 2020

SECTION 6: 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.
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