



In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends 2019

Residential Information Systems Project

INSTITUTE *on* COMMUNITY INTEGRATION | **rtc** *on* community living | UNIVERSITY OF MINNESOTA

A UNIVERSITY CENTER *for* EXCELLENCE *in* DEVELOPMENTAL DISABILITIES



LONG-TERM SUPPORTS AND SERVICES FOR INDIVIDUALS WITH INTELLECTUAL OR DEVELOPMENTAL DISABILITIES: STATUS AND TRENDS THROUGH FISCAL YEAR 2019

RESIDENTIAL INFORMATION SYSTEMS PROJECT (RISP)

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PREFACE

The Residential Information Systems Project (RISP) at the University of Minnesota maintains data on long-term supports and services (LTSS) recipients with intellectual and developmental disabilities (IDD). This report describes the status and trends in publicly funded LTSS for the year ending June 30, 2019 (Fiscal Year 2019). This report includes all of the tables and figures including in typical annual reports but the text is abbreviated. Other materials including FY 2019 state profiles, infographics, surveys and survey instructions, and an interactive chart builder are available online at www.risp.umn.edu. Most historical RISP reports can also be downloaded from the RISP website.

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

Sheryl Larson, RISP Principal Investigator

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

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TECHNICAL USER'S GROUP

NASDDDS Research Committee

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

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ACRONYMS

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

INTRODUCTION

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

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

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

In 1977 and 1982, the University of Minnesota conducted national censuses of all state and non-state residential facilities for people with IDD (Bruininks, Hill & Thorsheim, 1982; Hauber, et al., 1984). The use of public (state-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.

The RISP project has described LTSS for people with IDD receiving supports funded through the Medicaid ICF/IID and HCBS Waiver funding authorities annually since 1982. As Medicaid added new LTSS funding

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

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

This Annual RISP report describes Medicaid and state funded LTSS managed by, or under the auspices of, state IDD agencies in Fiscal Year (FY) 2019 (July 1, 2018 through June 30, 2019) and examines trends across time. The RISP report describes six dimensions of LTSS:

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

Study Methodology

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

Prior to 2007, the annual RISP survey of state IDD Directors were collected via a paper survey. The first online survey was used from 2007-2012. The online data collection system was redesigned and new features were added in 2013. State data providers and project staff can view previous year's data for each data element, and can assign special codes to indicate estimates, external data sources used, data imputed by project staff, and alternative dates if data were not available for the requested date. State data providers may enter notes to help research staff and readers of the report to interpret the data correctly, or to record reasons for changes. Data proofing tools were added for the 2015 survey to assist states to identify possible arithmetic errors, inconsistencies within or across survey sections, and large year-to-year changes requiring explanation. Additional refinements were made as the online database moved to its current platform for the FY 2017 survey.

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

The PRF survey includes questions about characteristics such as age, gender, race, ethnicity and types of disabilities of people in residence on

June 30, admissions, readmissions, discharges, and deaths during year, facility closures and planned closures, and average daily per person expenditures. Survey data are analyzed using Microsoft Excel and SPSS 23.0 software. Missing or inconsistent responses are confirmed in follow-up communications with the survey respondents.

Definitions

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

Estimated Values are individual data elements whose value is estimated by the survey respondent. An "e" designates a value estimated by the state respondent.

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

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

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

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

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

- “Partial Data” (PD) signifies instances when some, but not all, of the data required for a computation were furnished by the state. Partial totals are reported for psychiatric facilities.
- Additional codes specify whether data were missing for state-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, 2018. Data flagged with the “d” footnote are from the immediately preceding or subsequent data year or in a few cases from a data other than June 30.

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

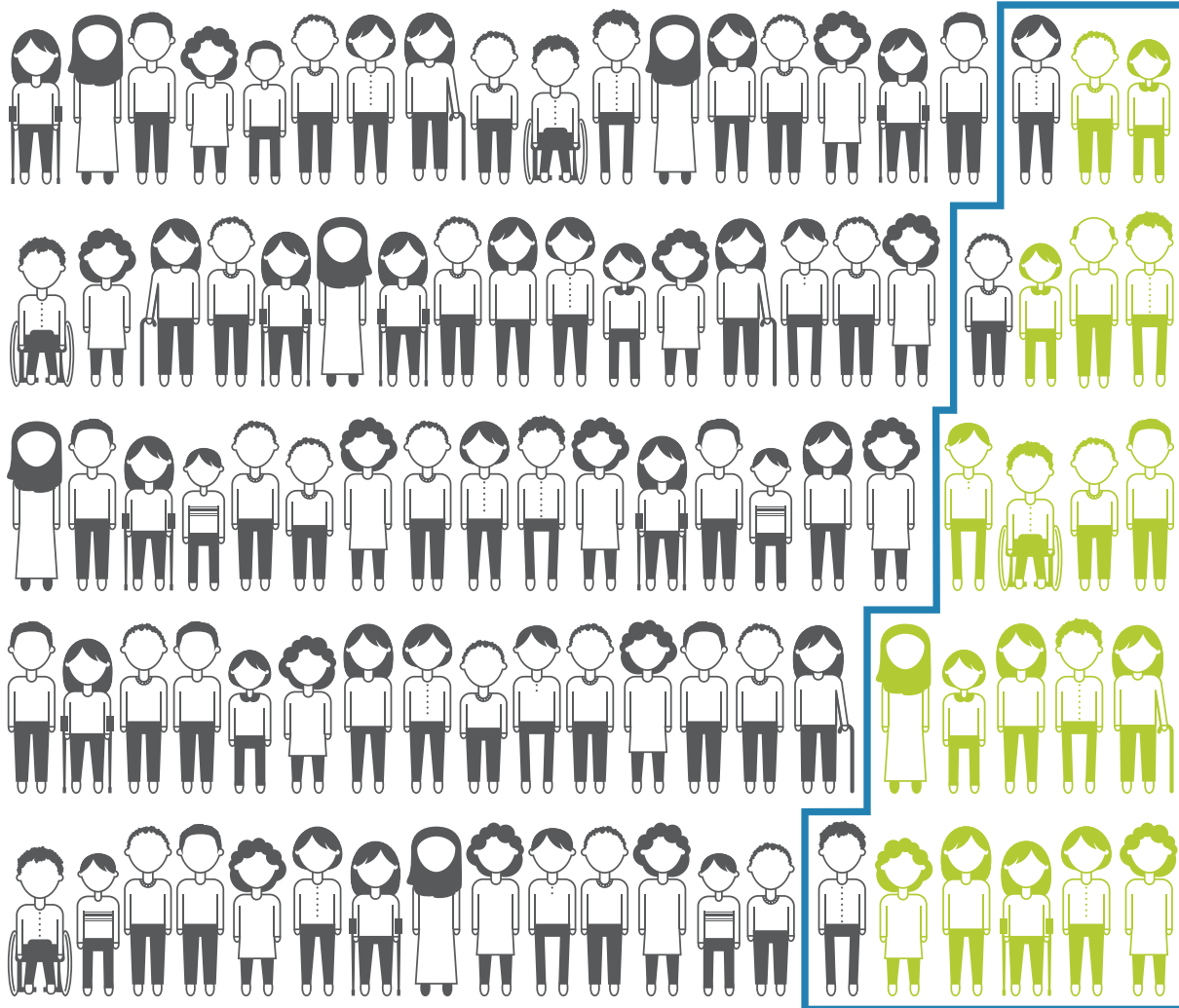
United States Estimated Totals include imputations by project staff to replace missing data based on historical trends, national distributions of setting sizes, secondary data sources, and other questions on the survey. Rows or columns of tables are labeled as estimated totals when they contain imputed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

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

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

People with IDD in the United States

7.39 million people in the United States had Intellectual or Developmental Disabilities (IDD) in 2019



22% 1.58 million people with IDD were known to or served by state IDD agencies

19% 1.40 million people with IDD received long-term supports or services through state IDD agencies

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).

SECTION 1: 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 (LTSS) with IDD.

How many people with IDD were in the United States, how many were known to state IDD agencies, and how many received long-term supports and services?

There were an estimated 7.39 million people with IDD (22.5 per 1,000 of the population) in the United States on June 30, 2019 (See **Table 1.1**). Including people with IDD in congregate settings,

- 5.26 million people (71%) were 21 years or younger
- 2.13 million people (29%) were 22 years or older

An estimated 1,581,104 people (21% of the people with IDD in the US) were known to or served by state IDD agencies (See **Table 1.2**). Of those,

- 607,899 people (38%) were 21 years or younger
- 973,205 people (62%) were 22 years or older

An estimated 1,375,623 people (19% of the people with IDD in the US) received LTSS (See **Table 1.3**).

Where did people with IDD receiving LTSS live?

An estimated 1.38 million of the 1.58 million people known to state IDD agencies (87%) received LTSS (See **Figure 1.1**), excluding people with IDD living in nursing homes or psychiatric facilities.

- 62% (849,104 people) lived in the home of a family member (See **Table 1.4** and **Figure 1.2**)
- 11% (153,079 people) lived in a home they owned or leased (See **Table 1.4**)
- 5% (64,869 people) lived in a host or foster family home (See **Table 1.5**)
- 20% (308,571 people) lived in a group home or facility (See **Table 1.6**).

An estimated 26,869 people with IDD lived in nursing homes and at least 1,784 people lived in a psychiatric facility (See **Table 1.10**). Including people with IDD living in nursing homes or psychiatric facilities,

- 60% of LTSS recipients lived with a family member,

- 11% lived in their own home,
- 5% lived with a host or foster family,
- 6% lived in a group setting of 3 or fewer people,
- 10% lived in a group setting of 4 to 6 people,
- 4% lived in a group setting of 7 to 15 people,
- 2% lived in an IDD facility of 16 or more people, and
- 2% lived in a nursing home or psychiatric facility (See **Figure 1.6**).

How many people with IDD lived in non-family settings of various sizes?

Of the 236,915 non-family settings in which LTSS recipients with IDD lived,

- 83% (196,459 settings) were home to three or fewer people
- 14% (32,378 settings) were home to 4 to 6 people
- 3% (6,070 settings) were home to 7 to 15 people
- 0.4% (844 settings) were home to 16 or more people (See **Table 1.7**)

Of the 526,517 people with IDD living in non-family settings,

- 54% (286,183 people) lived in a setting shared by three or fewer people
- 29% (153,262 people) lived in a setting shared by 4 to 6 people
- 10% (52,979 people) lived in a setting shared by 7 to 15 people
- 7% (34,209 people) lived in a setting shared by 16 or more people (See **Table 1.8**)

What was the average size of non-family settings in which LTSS recipients with IDD lived?

The average non-family residence was shared by 2.2 people with IDD (See **Table 1.9** and **Figure 1.3**).

In non-state settings, there were an average of:

- 1.4 people per own home setting,
- 1.6 people per host/foster family home,

2019

- 3.5 people per non-state group home (other than ICF/IID), and
- 8.7 people per non-state ICF/IID.

In state-run settings, there were an average of

- 5.4 people per Home and Community Based Waiver funded group home,
- 10.5 people per other group setting, and
- 76.4 people per ICF/IID facility

An average of 54% of people in non-family settings lived in a home shared by 1 to 3 people and 83% lived in a home shared by 6 or fewer people (See **Figure 1.4**).

How many people with IDD received long-term support or services per 100,000 of the population?

Overall, an average of 419 people with IDD per 100,000 of the population received LTSS (See **Figure 1.5**). Of those

- 67 per 100,000 lived in group settings of six or fewer people,

- 16 per 100,000 lived in group settings of 7 to 15 people,
- 10 per 100,000 lived in group settings of 16 or more people,
- 259 per 100,000 lived with a family member,
- 47 per 100,000 lived in a home they owned or leased,
- 20 per 100,000 lived with a host or foster family

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 115,204 people with IDD (21% of people 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 (See **Figure 1.7**).



Table 1.1 United States Population and People with IDD by Age and State on June 30, 2019

State	2019 US Population by age			Estimated Population with IDD					
	Age 0-17	Age 18-21	Age 22 +	Not in Congregate Settings (NHIS)				In Congregate Settings	Total All Ages
				Age 0-17	Age 18-21	Age 22+	Total		
AL	1,085,597	276,338	3,541,250	75,883	2,183	27,976	106,042	2,245	108,287
AK	179,749	39,120	512,676	12,564	309	4,050	16,924	445	17,369
AZ	1,639,648	404,319	5,234,750	114,611	3,194	41,355	159,160	1,575	160,735
AR	699,012	165,253	2,153,539	48,861	1,305	17,013	67,179	3,152	70,331
CA	8,891,064	2,100,622	28,520,537	621,485	16,595	225,312	863,393	29,381	892,774
CO	1,256,320	290,841	4,211,575	87,817	2,298	33,271	123,386	1,064	124,450
CT	727,432	200,152	2,637,703	50,847	1,581	20,838	73,267	3,679	76,946
DE	203,946	51,857	717,961	14,256	410	5,672	20,337	566	20,903
DC	127,901	42,351	535,497	8,940	335	4,230	13,505	411	13,916
FL	4,231,955	1,037,165	16,208,617	295,814	8,194	128,048	432,055	12,724	444,779
GA	2,503,029	619,638	7,494,756	174,962	4,895	59,209	239,065	3,497	242,562
HI	300,187	63,999	1,051,686	20,983	506	8,308	29,797	428	30,225
ID	449,355	95,709	1,242,001	31,410	756	9,812	41,978	838	42,816
IL	2,814,679	665,556	9,191,586	196,746	5,258	72,614	274,617	16,598	291,215
IN	1,567,421	390,769	4,774,029	109,563	3,087	37,715	150,365	5,607	155,972
IA	721,830	185,254	2,247,986	50,456	1,464	17,759	69,679	3,582	73,261
KS	700,301	172,475	2,040,538	48,951	1,363	16,120	66,434	2,727	69,161
KY	1,001,825	244,462	3,221,386	70,028	1,931	25,449	97,408	1,273	98,681
LA	1,084,886	256,583	3,307,325	75,834	2,027	26,128	103,988	5,355	109,343
ME	246,353	64,704	1,033,155	17,220	511	8,162	25,893	4,025	29,918
MD	1,332,287	309,540	4,403,853	93,127	2,445	34,790	130,363	3,054	133,417
MA	1,351,777	402,981	5,137,745	94,489	3,184	40,588	138,261	7,656	145,917
MI	2,142,822	556,062	7,287,973	149,783	4,393	57,575	211,751	10,495	222,246
MN	1,302,669	281,757	4,055,206	91,057	2,226	32,036	125,319	6,897	132,216
MS	698,420	186,431	2,091,298	48,820	1,473	16,521	66,814	3,810	70,624
MO	1,372,695	327,994	4,436,739	95,951	2,591	35,050	133,593	3,200	136,793
MT	226,524	59,405	782,849	15,834	469	6,185	22,488	995	23,483
NE	475,096	108,986	1,350,326	33,209	861	10,668	44,738	1,065	45,803
NV	690,737	147,635	2,241,784	48,283	1,166	17,710	67,159	857	68,016
NH	256,020	73,791	1,029,900	17,896	583	8,136	26,615	263	26,878
NJ	1,938,024	433,955	6,510,211	135,468	3,428	51,431	190,327	9,231	199,558
NM	473,850	114,410	1,508,569	33,122	904	11,918	45,944	1,595	47,539
NY	4,022,096	1,005,205	14,426,260	281,145	7,941	113,967	403,053	33,772	436,825
NC	2,293,972	603,697	7,590,415	160,349	4,769	59,964	225,082	9,380	234,462
ND	176,706	43,583	541,773	12,352	344	4,280	16,976	990	17,966
OH	2,574,847	643,615	8,470,638	179,982	5,085	66,918	251,984	10,213	262,197
OK	952,229	234,416	2,770,326	66,561	1,852	21,886	90,298	2,873	93,171
OR	862,816	213,729	3,141,192	60,311	1,688	24,815	86,815	4,157	90,972
PA	2,632,325	672,285	9,497,379	184,000	5,311	75,029	264,340	7,925	272,265
RI	203,575	68,663	787,123	14,230	542	6,218	20,991	1,200	22,191
SC	1,112,300	292,420	3,743,994	77,750	2,310	29,578	109,637	4,099	113,736
SD	215,269	44,084	625,306	15,047	348	4,940	20,335	1,403	21,738
TN	1,510,752	368,140	4,950,282	105,602	2,908	39,107	147,617	1,904	149,521
TX	7,396,631	1,662,287	19,936,963	517,025	13,132	157,502	687,659	17,773	705,432
UT	930,308	202,816	2,072,834	65,029	1,602	16,375	83,006	1,474	84,480
VT	113,559	41,797	468,633	7,938	330	3,702	11,970	121	12,091
VA	1,857,605	471,217	6,206,697	129,847	3,723	49,033	182,602	6,344	188,946
WA	1,662,965	375,311	5,576,617	116,241	2,965	44,055	163,261	10,132	173,393
WV	358,818	89,585	1,343,744	25,081	708	10,616	36,405	852	37,257
WI	1,263,412	324,602	4,234,420	88,312	2,564	33,452	124,329	5,639	129,968
WY	134,189	32,022	412,548	9,380	253	3,259	12,892	562	13,454
US Total	72,967,785	17,759,588	237,512,150	5,100,448	140,301	1,876,346	7,117,095	269,103	7,386,198

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

Table 1.2 People Known to or Served by State IDD Agencies by Age on June 30, 2019

State	Number of People ¹			% of People	
	Birth-21	22+ years	All Ages	Birth-21	22+ years
N States	46	46	46	46	46
AL	63	8,081	8,144	1	99
AK	1,027	1,910	2,937	35	65
AZ	29,527	14,943	44,470	66	34
AR	DNF	DNF	DNF	DNF	DNF
CA	153,306	141,299	294,605	52	48
CO	7,688	12,597	20,285	38	62
CT	4,181	12,945	17,126	24	76
DE	1,551	3,483	5,034	31	69
DC	95	2,304	2,399	4	96
FL	16,469	44,638	61,107	27	73
GA	DNF	DNF	DNF	DNF	DNF
HI	904	2,637	3,541	26	74
ID	4,999	4,845	9,844	51	49
IL	9,766	33,434	43,200	23	77
IN	12,269	22,135	34,404	36	64
IA	13,985	12,070	26,055	54	46
KS	4,352	9,186	13,538	32	68
KY	5,699	9,350	15,049	38	62
LA	12,840	27,723	40,563	32	68
ME	317	5,630	5,947	5	95
MD	4,504	19,492	23,996	19	81
MA	13,359	26,402	39,761	34	66
MI	17,771	32,471	50,242	35	65
MN	11,941	22,974	34,915	34	66
MS	2,223 ^l	3,786 ^l	6,009 ^l	37	63
MO	17,305	21,843	39,148	44	56
MT	1,675	2,748	4,423	38	62
NE	636	4,707	5,343	12	88
NV	3,911	5,290	9,201	43	57
NH	DNF	DNF	DNF	DNF	DNF
NJ	0	24,861	24,861	0	100
NM	3,068	6,641	9,709	32	68
NY	45,353	93,323	138,676	33	67
NC	15,514	21,200	36,714	42	58
ND	3,623	2,994	6,617	55	45
OH	53,188	54,028	107,216	50	50
OK	674 ^l	7,120 ^l	7,794 ^{e,l}	9	91
OR	12,226	16,968	29,194	42	58
PA	15,283	43,761	59,044	26	74
RI	332	4,565	4,897	7	93
SC	22,806	20,959	43,765	52	48
SD	DNF	DNF	DNF	DNF	DNF
TN	3,562 ^l	12,471 ^l	16,033 ^l	22	78
TX	DNF	DNF	DNF	DNF	DNF
UT	3,011	5,935	8,946	34	66
VT	1,423	3,188	4,611	31	69
VA	11,345	15,596	26,941	42	58
WA	23,242	25,179	48,421	48	52
WV	2,032	3,795	5,827	35	65
WI	13,190	36,852	50,042	26	74
WY	964	1,869	2,833	34	66
Reported Total	583,199	910,228	1,493,427	39	61
Estimated Total	607,899	973,205	1,581,104	38	62

^d Other date (data from previous or next year). DNF Did not furnish. ^e Estimate. ^l One or more component value imputed by RISP staff. ¹ The caseload total includes people with IDD who receive services, are waiting for services or are known to but not receiving services under the auspices of the state IDD agency.



Table 1.3 LTSS Recipients with IDD by Setting Type, Type of Operation, and State on June 30, 2019

Setting Type	Non-State Settings							State-Operated Settings			Estimated LTSS Recipients*
	Family home	Own home	Host /Foster Family Home	Group not ICF/IID	ICF/IID	Other	Unknown	Group Waiver	ICF/IID	Group Other	
N States	39	39	47	47	51	48	50	51	51	51	51
AL	2,640	40	0	3,349	15	0	0	0	0	0	6,044
AK	643 ^e	546	83	712	0	0	446 ^e	0	0	0	2,430
AZ*	29,231 ^{e,i}	257	1,516	3,133	34	10	0	128	0	0	34,322
AR	1,973	639	575	1,106	518	0	0	0	917	0	6,167
CA	230,744 ⁱ	26,670	3,446	23,760	6,804	0	0	0	326	0	291,750
CO	8,380 ⁱ	1,596 ⁱ	3,314	730	24	2,109	0	108	144	0	18,001
CT	4,744	1,439	390	3,931	340	200	0	180	324	0	11,548
DE	3,765	51	99	999	70	0	0	0	49	0	5,033
DC	876	8	92	1,051	308	10	0	0	0	0	2,345
FL	41,242	5,880	301	9,407	2,049	939	1,289	0	519	127	61,753
GA	DNF	DNF	DNF	DNF	112 ^s	DNF	0 ⁱ	0 ⁱ	153	59	13,694
HI	2,558	71	468	317	62	0	0	0	0	0	3,476
ID	1,719	DNF	509	184	418 ^s	0	6,392	0	14	0	9,236
IL	13,011	1,961	322	9,401	4,740	0	0	0	1,640	0	31,075
IN	21,361	1,757 ^e	325	5,880 ^e	3,081	0	0	0	0	0	32,404
IA	DNF	DNF	0	1,529	1,098	338	15,338	0	331	0	19,152
KS	DNF	DNF	DNF	DNF	106	DNF	0 ^{e,i}	0	300	0	9,590
KY	10,722	DNF	2,203	2,808	407	0	0	0	0	0	16,044
LA	DNF	2,265	9	0	3,993	0	10,582	0	497	0	17,346
ME	DNF	DNF	2,419	4,161	191	109	2,060	0	0	3	8,943
MD	DNF	DNF	236	6,316	0	0	10,299	0	93	0	16,944
MA	9,998	2,747	880	9,145	0	0	15,363	1,039	342	41	39,555
MI	29,603	10,077	464	9,194 ^e	0	457	0	0	0	0	49,795
MN	14,447 ^e	3,575 ^e	900	8,400	1,013	6,130	0	348	5	0	34,818
MS	2,551 ^e	179 ^e	0	913	870 ^s	0 ^{PD}	0	113	1,383	0	6,009
MO	12,858	4,982	522	1,714	73 ^e	0	0	211	310	0	20,670
MT	DNF	DNF	46	825	0	1,048	783	0	0	11	2,713
NE	DNF	DNF	1,237	1,159	240	0	2,395	0	105	0	5,126
NV	5,020	1,815	203	0	42	47	0	0	40	0	7,167
NH	1,179	408	1,984	1,742	25	0	0	0	0	6	7,118
NJ	13,925	52	436	8,062	60	600	0	0	1,263	0 ⁱ	24,398
NM	3,470	319	0	1,188	269	0	0	71	4	0	5,321
NY	DNF	12,023	1,495	25,232	3,891	0	75,695	6,342	279	0	124,957
NC	19,784 ⁱ	369 ^e	2,362 ^e	4,274 ^e	2,981	366 ^e	2,965	0	1,026	129	34,258
ND	3,288	1,379	12	348	466	0	0	0	71	0	5,564
OH	79,213	16,063	2,339	2,645	4,542	1,492	0	0	629	0	106,923
OK	DNF	DNF	DNF	DNF	1,376 ^s	DNF	5,321 ^e	0	52	0	6,749
OR	15,087	711	3,378	3,064	0	0	0	0	0	87	22,327
PA	23,342 ⁱ	3,407	1,471	11,868	1,821	1,945 ^e	51	0	719	0	44,593
RI	1,715	522	383	1,025	30	0	0	130	10	0	3,815
SC	17,833	688	187	3,068	480	0	0	15	673	0	22,944
SD	DNF	DNF	DNF	DNF	67 ^s	0	DNF	0	114	0	3,995
TN	DNF	DNF	625	5,331	798 ^e	0	3,860	0	150	0	15,242
TX	10,886	3,423	13,800	8,738	4,597	0	1,589	0	2,925	0	45,958
UT	1,982	1,341 ^e	464	1,963 ^e	552 ^s	0	0	0	180	0	6,482
VT	2,295	527	1,410	136	6	0	219	0	0	0	4,478
VA	6,047	1,041	1,750	5,390	538	0	0	0	78	0	14,844
WA	44,499	13,212	992	4,062	30	1,238	0	359	623	0	34,292
WV	3,205	857	190	1,364	492	0	0	0	0	0	6,114
WI	31,172	7,387	7,030	3,750	85	18	0	0	298	0	49,740
WY	1,114	496	40	599	0	5	44	0	52	11	2,361
Reported US Total	728,122	130,780	60,907	203,973	49,714	17,061	154,691	9,044	16,638	474	
Estimated US Total	849,104	153,079	64,869	216,411	49,758	16,227	0	8,969[*]	16,732	474	1,375,623

DNF Did not furnish. PD Partial data. ^a Missing values (DNF) assumed to be zero. ^d Other date (data from previous or next year). ^e Estimate. ⁱ One or more component value imputed by RISP staff. * Estimated total excludes people in nursing homes and psychiatric facilities. Some states reported people in family home and own home together.

Table 1.4 Reported and Estimated LTSS Recipients with IDD in Family or Own Home Settings by State and Setting Size on June 30, 2019

State	Reported People by Setting Type and Size				Estimated Totals			% of Estimated	
	Family Home	Own Home 1 to 3	Own Home 4 to 6	Own Home Total	All Settings	Family Home	Own Home	Family home	Own home
N States	39	34	36	39	51	51	51	51	51
AL	2,640	40	0	40	6,044	2,640	40	44%	1%
AK	643 ^e	546	0	546	2,430	643	729	26%	30%
AZ	29,231 ^{e,i}	242	15	257	34,322	29,231	257	85%	1%
AR	1,973	613	26	639	6,167	2,175	704	35%	11%
CA	230,744 ⁱ	26,670	0	26,670	291,750	230,744	26,670	79%	9%
CO	8,380 ⁱ	1,596 ^j	0 ⁱ	1,596 ^j	18,001	9,976	1,596	55%	9%
CT	4,744	1,439	0	1,439	11,548	4,744	1,439	41%	12%
DE	3,765	51	0	51	5,033	3,765	51	75%	1%
DC	876	8	0	8	2,345	876	8	37%	0%
FL	41,242	5,880	0	5,880	61,753	42,131	6,007	68%	10%
GA	DNF	DNF	DNF	DNF	13,694	8,156	1,604	60%	12%
HI	2,558	71	0	71	3,476	2,558	71	74%	2%
ID	1,719	DNF	DNF	DNF	9,236	7,004	1,107	76%	12%
IL	13,011	1,021	940	1,961	31,075	13,011	1,961	42%	6%
IN	21,361	1,757 ^e	0 ^e	1,757 ^e	32,404	21,361	1,757	66%	5%
IA	DNF	DNF	518	DNF	19,152	8,671	7,185	45%	38%
KS	DNF	DNF	DNF	DNF	9,590	4,291	1,412	45%	15%
KY	10,722	DNF	0	DNF	16,044	9,006	1,620	56%	10%
LA	DNF	2,265	0	2,265	17,346	10,582	2,265	61%	13%
ME	DNF	DNF	DNF	DNF	8,943	1,391	669	16%	7%
MD	DNF	DNF	DNF	DNF	16,944	5,717	4,582	34%	27%
MA	9,998	DNF	DNF	2,747	39,555	24,542	2,923	62%	7%
MI	29,603	DNF	DNF	10,077	49,795	29,603	10,077	59%	20%
MN	14,447 ^e	3,575 ^e	0	3,575 ^e	34,818	14,447	3,575	41%	10%
MS	2,551 ^e	16 ^e	163 ^e	179 ^e	6,009	2,551	179	42%	3%
MO	12,858	4,982	0	4,982	20,670	12,858	4,982	62%	24%
MT	DNF	DNF	DNF	DNF	2,713	1,703	82	63%	3%
NE	DNF	DNF	DNF	DNF	5,126	1,160	1,225	23%	24%
NV	5,020	1,201	614	1,815	7,167	5,020	1,815	70%	25%
NH	1,179	408	0	408	7,118	1,582	507	22%	7%
NJ	13,925	52	0	52	24,398	13,925	52	57%	0%
NM	3,470	319	0	319	5,321	3,470	319	65%	6%
NY	DNF	12,023	0	12,023	124,957	75,695	12,023	61%	10%
NC	19,784 ⁱ	369 ^e	0	369 ^e	34,258	19,784	518	58%	2%
ND	3,288	1,379	0	1,379	5,564	3,288	1,379	59%	25%
OH	79,213	14,934	1,129	16,063	106,923	79,213	16,063	74%	15%
OK	DNF	DNF	DNF	DNF	6,749	3,474	672	51%	10%
OR	15,087	711	0	711	22,327	15,087	711	68%	3%
PA	23,342 ⁱ	3,407	0	3,407	44,593	23,342	3,411	52%	8%
RI	1,715	522	0	522	3,815	1,715	522	45%	14%
SC	17,833	688	0	688	22,944	17,833	688	78%	3%
SD	DNF	DNF	DNF	DNF	3,995	1,452	536	36%	13%
TN	DNF	DNF	DNF	DNF	15,242	7,720	618	51%	4%
TX	10,886	DNF	DNF	3,423	45,958	11,355	3,571	25%	8%
UT	1,982	1,341 ^e	0	1,341 ^e	6,482	1,982	1,341	31%	21%
VT	2,295	527	0	527	4,478	2,295	553	51%	12%
VA	6,047	1,041	0	1,041	14,844	6,047	1,041	41%	7%
WA	44,499	7,872	5,340	13,212	34,292	13,776	13,212	40%	39%
WV	3,205	857	0	857	6,114	3,205	857	52%	14%
WI	31,172	DNF	DNF	7,387	49,740	31,172	7,387	63%	15%
WY	1,114	DNF	DNF	496	2,361	1,135	506	48%	21%
Reported US Total	728,122	98,423	8,745	130,780					
Estimated US Total	849,104	142,595	10,600	153,079	1,375,623	849,104	153,079	62%	11%

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. ⁱ One or more component value imputed by RISP staff. Some states reported a combined total people in own home and family home settings in one category and DNF for the other. Distributions are estimated in the estimated total columns.



Table 1.5 Host or Foster Family Homes and LTSS Recipients with IDD in Them by Setting Size and State on June 30, 2019

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	38	40	39	50	47	41	41	41	46	51	49	47
AL	0	0	0	0	0	0	0	0	0	0	0	0
AK	83	0	83	0	0	83	83	0	83	0	0	83
AZ	1,024	1	1,025	0	0	1,025	1,512	4	1,516	0	0	1,516
AR	575	0	575	0	0	575	575	0	575	0	0	575
CA	DNF	DNF	DNF	0	0	DNF	DNF	DNF	3,446	0	0	3,446
CO	1,657	0	1,657	0	0	1,657	3,314	0	3,314	0	0	3,314
CT	265	0	265	0	0	265	390	0	390	0	0	390
DE	91	0	91	0	0	91	99	0	99	0	0	99
DC	70	0	70	0	0	70	92	0	92	0	0	92
FL	DNF	DNF	DNF	DNF	0	DNF	66	139	205	96	0	301
GA	DNF	DNF	DNF	0	0	DNF	DNF	DNF	DNF	0	0	DNF
HI	294	0	294	0	0	294	468	0	468	0	0	468
ID	363	18	381	0	0	381	471	38	509	0	0	509
IL	242	0	242	0	0	242	322	0	322	0	0	322
IN	251	5	256	0	0	256	305	20	325	0	0	325
IA *	0	0	0	0	0	0	0	0	0	0	0	0
KS	DNF	DNF	DNF	0	DNF	DNF	DNF	DNF	DNF	0	DNF	DNF
KY	DNF	0	DNF	0	0	DNF	2,203	0	2,203	0	0	2,203
LA	9	0	9	0	0	9	9	0	9	0	0	9
ME	1,405	11	1,416	2	0	1,418	2,348	46	2,394	25	0	2,419
MD	234	0	234	0	0	234	236	0	236	0	0	236
MA	880	0	880	0	0	880	880	0	880	0	0	880
MI	DNF	DNF	DNF	0	0	DNF	DNF	DNF	464	0	0	464
MN	668 ^e	14 ^e	682	0	0	682	843 ^e	57 ^e	900	0	0	900
MS	0	0	0	0	0	0	0	0	0	0	0	0
MO	473	0	473	0	0	473	522	0	522	0	0	522
MT	DNF	DNF	DNF	0	11	11	DNF	DNF	DNF	0	46	46
NE	974	12	986	1	0	987	1,171	58	1,229	8	0	1,237
NV	165	1	166	0	0	166	199	4	203	0	0	203
NH	1,013	0	1,013	0	0	1,013	1,984	0	1,984	0	0	1,984
NJ	227	0	227	0	0	227	436	0	436	0	0	436
NM	0	0	0	0	0	0	0	0	0	0	0	0
NY	817	58	875	0	0	875	1,256	239	1,495	0	0	1,495
NC	991	0	991	0	343 ^e	1,334 ^e	1,037 ^e	0	1,037 ^e	0	1,325	2,362 ^e
ND	12	0	12	0	0	12	12	0	12	0	0	12
OH	2,057	0	2,057	0	0	2,057	2,339	0	2,339	0	0	2,339
OK	DNF	DNF	DNF	0	DNF	DNF	DNF	DNF	DNF	0	DNF	DNF
OR	685	724	1,409	16	0	1,425	1,058	2,287	3,345	33	0	3,378
PA	1,189	0	1,189	0	0	1,189	1,471	0	1,471	0	0	1,471
RI	383	0	383	0	0	383	383	0	383	0	0	383
SC	148	0	148	0	0	148	187	0	187	0	0	187
SD	DNF	DNF	DNF	0	0	DNF	DNF	DNF	DNF	0	0	DNF
TN	DNF	0	DNF	0	DNF	DNF	625	0	625	0	0	625
TX	DNF	DNF	DNF	0	0	DNF	DNF	DNF	13,800	0	0	13,800
UT	406 ^e	0	406 ^e	0	0	406 ^e	464	0	464	0	0	464
VT	1,261	0	1,261	0	0	1,261	1,410	0	1,410	0	0	1,410
VA	1,750	0	1,750	0	0	1,750	1,750	0	1,750	0	0	1,750
WA	596	15	611	0	0	611	921	71	992	0	0	992
WV	124	0	124	0	0	124	190	0	190	0	0	190
WI	DNF	DNF	DNF	0	DNF	0 ^{PD}	DNF	DNF	7,030	0	0	7,030
WY	DNF	DNF	40	0	0	40	DNF	DNF	40	0	0	40
Reported US Total	21,382	859	22,281	19	354	22,654	31,631	2,963	59,374	162	1,371	60,907
Estimated US Total	40,386	1,380	41,766	26	0	41,792	59,852	4,853	64,705	164	0	64,869

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

Table 1.6 Group LTSS Settings and People with IDD Living in them by Setting Size and State on June 30, 2019

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	37	35	39	40	41	41	41	38	42	41	43	47
AL	979	109	1,088	75	0	1,163	2,323	469	2,792	572	0	3,364
AK	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	712 ^f
AZ	767	300	1,067	10	2	1,079	1,798	1,302	3,100	96	109	3,305
AR	99	20	119	99	25	243	106	56	162	925	1,454	2,541
CA	1,141	PD	PD	PD	PD	6,351 ^f	2,819	PD	PD	PD	PD	30,890 ^f
CO	1,056	198	1,254	19	2	1,275	2,110	809	2,919	143	53	3,115
CT	670	583	1,253	23	5	1,281	1,602	2,866	4,468	171	336	4,975
DE	265	90	355	0	2	357	639	360	999	0	119	1,118
DC	557	87	644	0	0	644	969	400	1,369	0	0	1,369
FL	PD	PD	1,406	204	55	1,665	258	7,916	8,174	1,659	2,269	13,041 ^f
GA	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD
HI	0	179 ^e	179 ^e	1	0	180	0	371	371	8	0	379
ID	0	21	21	66	51	138	0	PD	PD	PD	94	616 ^f
IL	131	970	1,101	827	43	1,971	230	4,159	4,389	7,116	4,276	15,781
IN	1,721 ^e	347 ^e	2,068 ^e	312 ^e	2	2,382 ^e	4,842 ^e	1,769 ^e	6,611 ^e	2,300 ^e	50	8,961 ^e
IA	78	91	169	100	233	502	853	548	1,401	701	1,194	3,296
KS	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD
KY	106	14	120	3	6	129	2,648	184	2,832	21	362	3,215
LA	1	268	269	249	11	529	1	1,512	1,513	1,949	1,028	4,490
ME	321	507	828	164	4	996	663	2,315	2,978	1,421	65	4,464
MD	1,770	521	2,291	20	2	2,313	3,970	2,198	6,168	148	93	6,409
MA	PD	PD	PD	0	2	PD	PD	PD	10,225	0	342	10,567
MI	PD	PD	PD	PD	PD	PD	215 ^e	6,954 ^e	7,169 ^e	1,531 ^e	494 ^e	9,651 ^f
MN	PD	PD	3,712	28	10	9,629 ^f	PD	PD	9,259	260	247	15,896 ^f
MS	17	237 ^e	254 ^e	38	12	304	27	1,037 ^e	1,064 ^e	503	1,712	3,279
MO	113	196	309	102	8	419	284	858	1,142	803 ^e	363	2,308 ^e
MT	8	83	91	49	0	140	23	426	449	387	0	1,884 ^f
NE	457	90	547	24	3	574	723	357	1,080	120	304	1,504
NV*	14	4	18	0	28	46	19	24	43	0	86	129
NH	1,213	27	1,240	5	1	1,246	1,630	83	1,713	35	25	1,773
NJ	947 ^e	1,443	2,390 ^e	70	8	2,468 ^e	1,926	5,608	7,534	513	1,938	9,985
NM	PD	PD	343	15	1	359	PD	PD	1,361	155	16	1,532
NY	2,169	2,637	4,806	1,901	33	6,740	3,987	13,394	17,381	17,213	1,150	35,744
NC	345 ^e	891	1,236 ^e	45 ^e	25 ^e	1,438 ^f	284 ^e	2,601 ^e	2,885 ^e	521 ^e	1,840	8,776 ^f
ND	0	68	68	50	2	120	0	367	367	417	101	885
OH	202	521	723	283	65	1,071	364	2,477	2,841	2,272	2,703	9,308 ^f
OK	PD	PD	PD	PD	PD	211 ^f	PD	PD	PD	PD	PD	PD
OR	528	359	887	15	14	916	1,418	1,612	3,030	96	25	3,151
PA	4,637 ^e	704 ^e	5,341 ^e	48 ^e	21 ^e	7,355 ^f	9,282	2,995	12,277	379	1,752	16,353 ^f
RI	43	188	231	21	1	253	118	894	1,012	153	30	1,195
SC	172	574	746	101	5	852	431	2,308	2,739	824	673	4,236
SD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD
TN	PD	PD	PD	PD	1	PD	4,907	786 ^e	5,693 ^e	516 ^e	70 ^e	6,279 ^e
TX	PD	PD	PD	41	16	PD	PD	PD	12,712	429	3,119	16,260
UT	866 ^e	101	967 ^e	PD	PD	PD	1,394 ^e	510 ^e	1,904 ^e	PD	PD	2,695 ^f
VT	42	17	59	0	0	59	57	85	142	0	0	142
VA	0	1,114	1,114	94	3	1,211	0	5,081	5,081	735	190	6,006
WA	707	320	1,027	174	7	1,544 ^f	1,218	1,594	2,812	1,589	673	6,312 ^f
WV	PD	PD	707	54	0	761	1,242	214	1,456	400	0	1,856
WI	0	PD	PD	PD	PD	PD	0	PD	PD	PD	PD	4,151 ^f
WY	PD	PD	PD	PD	PD	606 ^f	PD	PD	PD	PD	63	667 ^f
Reported US Total	22,169	18,907	47,053	5,530	752	63,751	55,426	0 101,465	0 185,513	0 48,574	0 31,804	296,904
Estimated US Total	46,190	28,800	74,990	6,044	844	81,950	83,736	137,809	221,545	52,815	34,209	308,571

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. ¹ 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.

Table 1.7 Non-Family Residential Settings for LTSS Recipients with IDD by Type of Operation and Setting Size on June 30, 2019

Setting Size	Non-State Settings							State-Operated Settings							Total Settings ¹						
	1-3	4-6	1-6	7-15	16+	Total	1-3	4-6	1-6	7-15	16+	Total	1-3	4-6	1-6	7-15	16+	Total			
	41	42	44	45	47	45	50	50	50	51	51	51	51	41	42	44	45	47	45		
N States																					
AL	1,019	109	1,128	75	0	1,203	0	0	0	0	0	0	1,019	109	1,128	75	0	1,203			
AK	324	DNF	324	DNF	0	324	0	0	0	0	0	0	324	PD	324	PD	0	324			
AZ	1,950	300	2,250	8	1	2,259	6	4	10	2	1	13	1,956	304	2,260	10	2	2,272			
AR	1,287	26	1,313	99	20	1,432	0	0	0	0	5	5	1,287	26	1,313	99	25	1,437			
CA	1,140	3,882	5,022	124	24	6,347 ^f	1	0	1	0	3	4	1,141	3,882	5,023	124	27	6,351 ^f			
CO	4,308	187	4,495	0	0	4,495	1	11	12	19	2	33	4,309	198	4,507	19	2	4,528			
CT	2,371	555	2,926	19	1	2,946	3	28	31	4	4	39	2,374	583	2,957	23	5	2,985			
DE	407	90	497	0	1	498	0	0	0	0	1	1	407	90	497	0	2	499			
DC	635	87	722	0	0	722	0	0	0	0	0	0	635	87	722	0	0	722			
FL	DNF	DNF	DNF	DNF	DNF	DNF	0	0	0	0	3	3	PD	PD	PD	PD	PD	PD			
GA	DNF	DNF	DNF	DNF	1	DNF	0	0	0	0	2	2	PD	PD	PD	PD	3	PD			
HI	365	179	544	1	0	545	0	0	0	0	0	0	365	179	544	1	0	545			
ID	363	39	402	65	51	518	0	0	0	1	0	1	363	39	402	66	51	519			
IL	957	1,179	2,136	827	36	2,999	0	0	0	0	7	7	957	1,179	2,136	827	43	3,006			
IN	3,729	352	4,081	312	2	4,395	0	0	0	0	0	0	3,729	352	4,081	312	2	4,395			
IA	15,416	110	15,526	100	231	15,857	0	0	0	0	2	2	15,416	110	15,526	100	233	15,859			
KS	0	17	17	5	0	22	0	0	0	0	2	2	0	17	17	5	2	24			
KY	106	14	120	3	6	129	0	0	0	0	0	0	106	14	120	3	6	129			
LA	2,275	268	2,543	249	8	2,800	0	0	0	0	3	3	2,275	268	2,543	249	11	2,803			
ME	DNF	DNF	DNF	DNF	DNF	DNF	4	0	4	0	0	4	PD	PD	PD	PD	PD	PD			
MD	2,004	521	2,525	20	0	7,018	0	0	0	0	2	2	2,004	521	2,525	20	2	7,020			
MA	DNF	DNF	DNF	0	0	DNF	DNF	DNF	DNF	0	2	257	PD	PD	PD	0	2	PD			
MI	DNF	DNF	DNF	DNF	DNF	DNF	0	0	0	0	0	0	PD	PD	PD	PD	PD	PD			
MN	4,062	117	7,676	28	10	13,593 ^f	27	85	112	0	0	112	4,089	202	7,788	28	10	13,705 ^f			
MS	16	247	263	0	6	269	17	25	42	38	6	86	33	272	305	38	12	355			
MO	2,578	193	2,771	102	2	2,875	80	3	83	0	6	89	2,658	196	2,854	102	8	2,964			
MT	8	83	91	48	0	150 ^f	0	0	0	1	0	1	8	83	91	49	0	151 ^f			
NE	1,431	102	1,533	25	2	1,560	0	0	0	0	1	1	1,431	102	1,533	25	3	1,561			
NV	1,020	156	1,176	0	27	1,203	0	0	0	0	1	1	1,020	156	1,176	0	28	1,204			
NH	2,634	26	2,660	5	1	2,666	0	1	1	0	0	1	2,634	27	2,661	5	1	2,667			

Table 1.7 Non-Family Residential Settings for LTSS recipients with IDD by Type of Operation and Setting Size on June 30, 2019

Setting Size	Non-State Settings						State-Operated Settings						Total Settings ¹					
	1-3	4-6	1-6	7-15	16+	Total	1-3	4-6	1-6	7-15	16+	Total	1-3	4-6	1-6	7-15	16+	Total
	NJ	1,226	1,443	2,669	70	3	2,742	0	0	0	0	5	5	1,226	1,443	2,669	70	8
NM	DNF	27	324	15	1	340	0	1	19	0	0	19	PD	28	343	15	1	359
NY	2,856	2,236	5,092	1,490	28	6,610	130	459	589	411	5	1,005	2,986	2,695	5,681	1,901	33	7,615
NC	1,463	891	2,354	45	20	2,958 ^f	0	0	0	0	5	5	1,463	891	2,354	45	25	2,963 ^f
ND	1,391	68	1,459	50	1	1,510	0	0	0	1	1	1	1,391	68	1,459	50	2	1,511
OH	14,384	799	15,183	283	57	15,523 ^f	0	0	0	8	8	8	14,384	799	15,183	283	65	15,531 ^f
OK	DNF	DNF	106	16	0	210 ^f	0	0	0	1	1	1	PD	PD	106	16	1	211 ^f
OR	1,924	1,062	2,986	31	14	3,031	0	21	21	0	0	21	1,924	1,083	3,007	31	14	3,052
PA	9,233	704	9,937	48	17	11,947 ^f	0	0	0	4	4	4	9,233	704	9,937	48	21	11,951 ^f
RI	948	163	1,111	20	1	1,132	0	25	25	1	0	26	948	188	1,136	21	1	1,158
SC	402	574	976	101	0	1,077	5	0	5	0	5	10	407	574	981	101	5	1,087
SD	DNF	DNF	DNF	DNF	DNF	DNF	0	0	0	0	1	1	PD	PD	PD	PD	PD	PD
TN	DNF	84	84	47	1	132	0	37	37	1	0	38	PD	121	121	48	1	170
TX	0	736	736	41	3	780	0	2	2	0	13	15	0	738	738	41	16	795
UT	2,494	101	2,595	5	0	2,600	0	0	0	0	1	1	2,494	101	2,595	5	1	2,601
VT	1,824	17	1,841	0	0	1,841	0	0	0	0	0	0	1,824	17	1,841	0	0	1,841
VA	2,791	1,114	3,905	94	2	4,001	0	0	0	1	1	1	2,791	1,114	3,905	94	3	4,002
WA	5,335	1,313	6,648	174	3	7,161 ^f	32	54	86	0	4	90	5,367	1,367	6,734	174	7	7,251 ^f
WV	981	16	1,688	54	0	1,742	0	0	0	0	0	0	981	16	1,688	54	0	1,742
WI	DNF	DNF	DNF	2	2	2,709 ^f	0	0	0	0	3	3	PD	PD	PD	2	5	2,712 ^f
WY	0	0	536	0	0	1,140 ^f	0	0	0	2	2	2	0	0	536	0	2	1,142 ^f
Reported US Total	97,657	20,187	122,971	4,701	583	146,011	306	756	1,080	478	112	1,925	97,963	20,943	124,051	5,179	695	147,936
Estimated US Total	196,043	31,444	227,487	5,592	732	234,989	416	934	1,350	478	112	1,926	196,459	32,378	228,837	6,070	844	236,915

DNF Did not furnish. PD Partial data. ^g Other date (data from previous or next year). ^e Estimate. ^f Total is larger than component parts due to unknown settings or sizes. 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 1.8 Residence Size and Type of Operation for LTSS Recipients with IDD not Living with a Family Member by State on June 30, 2019

Setting Size	People in Non-State Settings							People in State-Operated Settings							Total People						
	Total							Total							Total						
	1-3	4-6	1-6	7-15	16+	1-3	4-6	1-6	7-15	16+	1-3	4-6	1-6	7-15	16+	1-3	4-6	1-6	7-15	16+	
N States	37	44	37	45	47	36	50	50	51	51	51	51	51	51	51	36	43	37	45	47	
AL	2,363	469	2,832	572	0	3,404	0	0	0	0	0	0	0	0	2,363	469	2,832	572	0	3,404	
AK	629	DNF	629	DNF	DNF	PDF	0	0	0	0	0	0	0	0	629	PD	629	PD	PD	PD	
AZ	3,536	1,300	4,836	80	34	4,950 ^f	16	21	37	16	75	128	3,552	1,321	4,873	96	109	5,078	109	5,078	
AR	1,294	82	1,376	925	537	2,838 ^f	0	0	0	0	917	917	1,294	82	1,376	925	1,454	3,755	1,454	3,755	
CA	29,488	19,011	51,945	1,277	654	53,876 ^f	1	0	1	0	325	326	29,489	19,011	51,946	1,277	979	54,202	979	54,202	
CO	7,019	754	7,773	0	0	7,773	1	55	56	143	53	252	7,020	809	7,829	143	53	8,025	53	8,025	
CT	3,423	2,720	6,143	141	16	6,300 ^f	8	146	154	30	320	504	3,431	2,866	6,297	171	336	6,804	336	6,804	
DE	789	360	1,149	0	70	1,219	0	0	0	0	49	49	789	360	1,149	0	119	1,268	119	1,268	
DC	1,069	400	1,469	0	0	1,469	0	0	0	0	0	0	1,069	400	1,469	0	0	1,469	0	1,469	
FL	DNF	DNF	DNF	DNF	DNF	DNF	0	0	0	0	646	646	PD	PD	PD	PD	PD	PD	PD	PD	
GA	DNF	DNF	DNF	DNF	144	PD	0	0	0	0	212	212	PD	PD	PD	PD	PD	PD	PD	PD	
HI	539	371	910	8	0	918	0	0	0	0	0	0	539	371	910	8	0	918	8	918	
ID	470	38	508	90	94	692	0	0	0	14	0	14	470	38	508	104	94	706	94	706	
IL	1,573	5,099	6,672	7,116	2,636	16,424	0	0	0	0	1,640	1,640	1,573	5,099	6,672	7,116	4,276	18,064	4,276	18,064	
IN	6,904	1,789	8,693	2,300	50	11,043 ^f	0	0	0	0	0	0	6,904	1,789	8,693	2,300	50	11,043	50	11,043	
IA	DNF	1,066	DNF	701	863	PD ^f	0	0	0	0	331	331	PD	1,066	PD	701	1,194	PD	1,194	PD	
KS	DNF	66	DNF	40	0	PD	0	0	0	0	300	300	PD	66	PD	40	300	PD	300	PD	
KY	4,851	184	5,035	21	362	5,418 ^f	0	0	0	0	0	0	4,851	184	5,035	21	362	5,418	362	5,418	
LA	DNF	1,512	DNF	1,949	531	PD	0	0	0	0	497	497	PD	1,512	PD	1,949	1,028	PD	1,028	PD	
ME	DNF	DNF	DNF	1,446	65	PD	3	0	3	0	0	3	PD	PD	PD	1,446	65	PD	65	PD	
MD	DNF	2,198	DNF	148	0	PD ^f	0	0	0	0	93	93	PD	2,198	PD	148	93	PD	93	PD	
MA	880	0	12,772	0	0	12,772	DNF	DNF	1,080	0	342	1,422	PD	PD	13,852	0	342	14,194	342	14,194	
MI	DNF	DNF	DNF	DNF	DNF	DNF	0	0	0	0	0	0	PD	PD	PD	PD	PD	PD	PD	PD	
MN	4,418	563	13,381	260	247	13,888 ^f	46	307	353	0	0	353	4,464	870	13,734	260	247	14,241	247	14,241	
MS	16	1,076	1,092	0	870	1,962 ^f	27	124	151	503	842	1,496	43	1,200	1,243	503	1,712	3,458	1,712	3,458	
MO	5,589	846	6,435	803	53	7,291 ^f	199	12	211	0	310	521	5,788	858	6,646	803	363	7,812	363	7,812	
MT	DNF	426	DNF	376	0	PD ^f	0	0	0	11	0	11	PD	426	PD	387	0	PD	0	PD	
NE	DNF	415	DNF	128	199	PD ^f	0	0	0	0	105	105	PD	415	PD	128	304	PD	304	PD	
NV	1,419	642	2,061	0	46	2,107 ^f	0	0	0	0	40	40	1,419	642	2,061	0	86	2,147	86	2,147	
NH	4,022	77	4,099	35	25	4,159	0	6	6	0	0	6	4,022	83	4,105	35	25	4,165	25	4,165	
NJ	2,414	5,608	8,022	513	675	9,210	0	0	0	0	1,263	1,263	2,414	5,608	8,022	513	1,938	10,473	1,938	10,473	
NM	319	98	1,604	155	16	1,775 ^f	0	4	75	0	0	75	319	102	1,679	155	16	1,850	16	1,850	

Table 1.8 Residence Size and Type of Operation for LTSS Recipients with IDD not Living with a Family Member by State on June 30, 2019

Setting Size	People in Non-State Settings							People in State-Operated Settings							Total People												
	1-3			4-6		7-15		16+		1-3			4-6		7-15		16+		1-3			4-6		7-15		16+	
	1-3	4-6	7-15	16+	Total	1-3	4-6	7-15	16+	Total	1-3	4-6	7-15	16+	Total	1-3	4-6	7-15	16+	Total	1-3	4-6	7-15	16+	Total		
NY	DNF	11,358	DNF	13,459	893	PD ^f	335	2,275	2,610	3,754	257	6,621	1,690	2,601	4,291	1,500	1,155	1,155	1,155	1,155	1,690	2,601	4,291	1,500	1,155	1,155	1,155
NC	1,690	2,601	4,291	521	685	5,497	0	0	0	0	1,155	1,155	1,155	1,155	1,155	1,690	2,601	4,291	1,500	1,155	1,690	2,601	4,291	1,500	1,155	1,155	
ND	1,391	367	1,758	417	30	2,205	0	0	0	0	71	71	71	71	71	1,391	367	1,758	417	101	1,391	367	1,758	417	101	2,276	
OH	17,637	3,606	21,243	2,272	2,074	25,589	0	0	0	0	629	629	629	629	629	17,637	3,606	21,243	2,272	2,074	17,637	3,606	21,243	2,272	2,074	26,218	
OK	DNF	DNF	DNF	DNF	0	PD	0	0	0	0	52	52	52	52	52	0	0	0	0	0	0	0	0	0	0	0	52
OR	3,187	3,812	6,999	129	25	7,153 ^f	0	87	87	0	0	87	87	87	87	3,187	3,899	7,086	129	25	3,187	3,899	7,086	129	25	7,240	
PA *	14,160	2,995	17,155	379	1,033	18,567 ^f	0	0	0	0	719	719	719	719	719	14,160	2,995	17,155	379	1,033	14,160	2,995	17,155	379	1,033	19,286	
RI	1,023	762	1,785	145	30	1,960	0	132	132	8	0	140	140	140	1,023	894	1,917	153	30	1,023	894	1,917	153	30	2,100		
SC	1,291	2,308	3,599	824	0	4,423 ^f	15	0	15	0	673	688	688	688	688	1,306	2,308	3,614	824	673	1,306	2,308	3,614	824	673	5,111	
SD	DNF	DNF	DNF	DNF	DNF	DNF	0	0	0	0	114	114	114	114	114	0	0	0	0	0	0	0	0	0	0	0	114
TN	DNF	641	DNF	511	70	PD	0	145	145	5	0	150	150	150	0	786	786	786	70	0	0	0	0	0	0	0	786
TX	0	3,964	29,925	429	204	30,558 ^f	0	10	10	0	2,915	2,925	2,925	2,925	2,925	0	3,974	29,935	429	3,119	0	3,974	29,935	429	3,119	33,483	
UT	3,199	510	3,709	59	0	3,768	0	0	0	0	180	180	180	180	180	3,199	510	3,709	59	180	3,199	510	3,709	59	180	3,948	
VT	1,994	85	2,079	0	0	2,079	0	0	0	0	0	0	0	0	0	1,994	85	2,079	0	0	1,994	85	2,079	0	0	2,079	
VA	2,791	5,081	7,872	735	112	8,719 ^f	0	0	0	0	78	78	78	78	78	2,791	5,081	7,872	735	190	2,791	5,081	7,872	735	190	8,797	
WA	9,943	6,714	16,657	1,589	50	18,296 ^f	68	291	359	0	623	982	982	982	982	10,011	7,005	17,016	1,589	673	10,011	7,005	17,016	1,589	673	19,278	
WV	2,289	214	2,503	400	0	2,903 ^f	0	0	0	0	0	0	0	0	0	2,289	214	2,503	400	0	2,289	214	2,503	400	0	2,903	
WI	0	0	14,417	13	72	14,502 ^f	0	0	0	0	298	298	298	298	298	0	0	14,417	13	370	0	0	14,417	13	370	14,800	
WY	0	0	536	0	0	536 ^f	0	0	0	0	63	63	63	63	63	0	0	536	0	63	0	0	536	0	63	599	
Reported US Total	103,635	92,188	261,214	40,966	13,465	315,645	719	3,615	5,485	4,484	16,187	26,156	143,120	95,803	286,691	45,450	28,892	341,801									
Estimated US Total	285,167	148,787	433,838	48,495	18,009	500,342	1,016	4,475	5,491	4,484	16,200	26,175	286,183	153,262	439,329	52,979	34,209	526,517									

DNF Did not furnish. PD Partial data. ^u 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 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 1.9 LTSS Settings and Recipients Not Living with a Family Member by Setting Size and Per 100,000 of the Population by State on June 30, 2019

State	Estimated Settings	Estimated LTSS Recipients ¹	People Per Setting	% in Settings of		State Population in 100,000's	People in LTSS Settings Per 100,000
				3 or Fewer People	6 or Fewer People		
AL	1,203	3,404	3	69	83	49	69
AK	1,027	1,787	2	76	97	7	244
AZ	2,272	5,091	2	70	96	73	70
AR	1,511	3,992	3	36	38	30	132
CA	27,810	61,006	2	54	95	395	154
CO	4,528	8,025	2	87	98	58	139
CT	2,985	6,804	2	50	93	36	191
DE	499	1,268	3	62	91	10	130
DC	722	1,469	2	73	100	7	208
FL	7,221	19,622	3	37	79	215	91
GA	2,405	5,538	2	56	85	106	52
HI	545	918	2	59	99	14	65
ID	1,202	2,232	2	68	78	18	125
IL	3,006	18,064	6	9	37	127	143
IN	4,395	11,043	3	63	79	67	164
IA	5,804	10,481	2	73	82	32	332
KS	2,212	5,299	2	53	84	29	182
KY	3,409	7,038	2	92	95	45	158
LA	2,803	6,764	2	34	56	46	146
ME	2,928	7,552	3	49	80	13	562
MD	7,020	11,227	2	76	98	60	186
MA	6,005	15,013	3	52	98	69	218
MI	9,960	20,192	2	53	90	100	202
MN	13,705	20,371	1	67	98	56	361
MS	355	3,458	10	1	36	30	116
MO	2,964	7,812	3	74	85	61	127
MT	253	1,010	4	14	62	11	95
NE	2,689	3,966	1	78	89	19	205
NV	1,204	2,147	2	66	96	31	70
NH	3,584	5,536	2	97	99	14	407
NJ	2,784	10,473	4	23	77	89	118
NM	604	1,851	3	18	91	21	88
NY	16,863	49,262	3	35	63	195	253
NC	4,873	14,474	3	42	77	105	138
ND	1,511	2,276	2	61	77	8	299
OH	16,682	27,710	2	68	81	117	237
OK	684	3,275	5	27	65	40	83
OR	3,052	7,240	2	44	98	42	172
PA	11,990	21,251	2	75	90	128	166
RI	1,158	2,100	2	49	91	11	198
SC	1,514	5,111	3	26	71	51	99
SD	1,237	2,543	2	49	67	9	287
TN	3,180	7,522	2	81	92	68	110
TX	14,905	34,603	2	59	90	290	119
UT	2,636	4,500	2	71	82	32	140
VT	2,095	2,183	1	96	100	6	350
VA	4,002	8,797	2	32	89	85	103
WA	7,870	20,516	3	54	88	76	269
WV	1,743	2,909	2	79	86	18	162
WI	10,739	18,568	2	73	94	58	319
WY	567	1,226	2	56	87	6	212
Estimated US Total	236,915	526,519	2	54	83	3,282	160

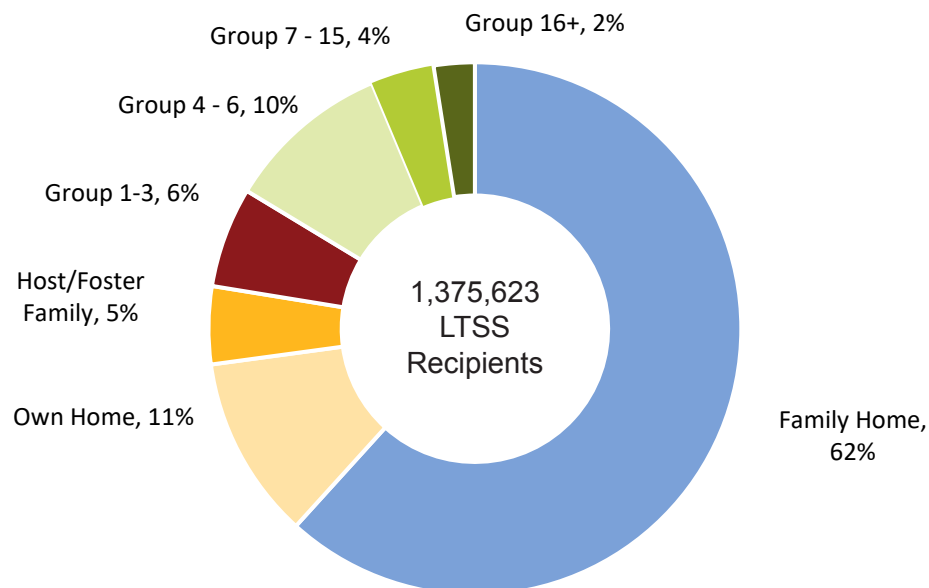
¹ Table includes people in group homes, host/foster family homes, own homes, and "other" IDD settings. It excludes people in family homes, nursing homes, psychiatric settings.

Table 1.10 People with IDD in Psychiatric Facilities or Nursing Homes by State or Non-State Operation and State; People per 100,000 in Nursing Homes or Psychiatric Facilities and Total LTSS Recipients on June 30, 2019

State	People with IDD Psychiatric Facilities			People with IDD in Nursing Homes			Estimated Nursing Home per 100,000	Estimated Total LTSS Recipients
	State	NonState	Total	State	Non-State	Estimated Total		
N States	29	27	27	34	33	51	51	51
AL	63 ^e	0	63	0	401	1,141 ^s	23	7,248
AK	0	0	0	0	0	17 ^s	2	2,447
AZ	0	0	0	0	36	36	1	34,358
AR	DNF	DNF	DNF	DNF	DNF	586 ^s	20	6,753
CA	0	31	31	0	1,052	1,052	3	292,833
CO	0	0	0	0	59	59	1	18,060
CT	0	3	3	0	303	303	8	11,854
DE	1	0	1	8	78	86	9	5,120
DC	8	0	8	0	3	3	0	2,356
FL	71	4	75	0	256	256	1	62,084
GA	DNF	DNF	DNF	DNF	DNF	1,060 ^s	10	14,754
HI	0	1	1	0	48	48	3	3,525
ID	DNF	DNF	DNF	DNF ^f	DNF ^f	126 ^s	7	9,362
IL	0	0	0	0	107	107	1	31,182
IN	37	0	37	0	1,431	1,431	22	33,872
IA	5	46	51	0 ^l	293	570 ^s	18	19,773
KS	79	64	143	0	97	97	3	9,830
KY	DNF ⁱ	0	DNF ^f	DNF	DNF	706 ^s	16	16,750
LA	0	42	42	10	814	824	18	18,212
ME	DNF	DNF	DNF	DNF	DNF	153 ^s	11	9,096
MD	12	0	12	8	339	347	6	17,303
MA	DNF	DNF	DNF	0	406 ^l	406 ^s	6	39,961
MI	DNF	DNF	DNF	DNF	DNF	963	10	50,758
MN	DNF	DNF	DNF	0	174	174	3	34,992
MS	DNF	DNF	DNF	DNF	DNF	395 ^s	13	6,404
MO	121	0	121	DNF	DNF	1,055 ^s	17	21,846
MT	DNF	DNF	DNF	DNF	DNF	131	13	2,844
NE	0	13	13	0	196	196	10	5,335
NV	0	0	0	0	129	129	4	7,296
NH	DNF	DNF	DNF	DNF	DNF	93 ^s	7	7,211
NJ	32	DNF	DNF	0 ^l	DNF	1,140 ^s	13	25,570
NM	DNF	DNF	DNF	DNF	DNF	84 ^s	4	5,405
NY	DNF	DNF	DNF	DNF	DNF	1,776	9	126,733
NC	114	65	179	96	2	824 ^s	8	35,261
ND	1	DNF	1 ^{PD}	0	104	104	14	5,669
OH	DNF	DNF	DNF	0	1,375	1,375 ^s	12	108,298
OK	DNF	DNF	DNF	DNF	DNF	494 ^s	13	7,243
OR	0	0	0	0	104	104	3	22,431
PA	85	186	271	0	2,440 ^e	2,440	19	47,304
RI	DNF	DNF	DNF	0	123	123	12	3,938
SC	DNF	DNF	DNF	0	294	294	6	23,238
SD	DNF	DNF	DNF	DNF	DNF	95 ^s	11	4,090
TN	DNF	DNF	DNF	0	497	497 ^s	7	15,739
TX	441	DNF	DNF	DNF	DNF	3,145 ^s	11	49,544
UT	DNF	DNF	DNF	DNF	DNF	173 ^s	6	6,655
VT	0	0	0	0	32	32	5	4,510
VA	204	0	204	81	53	134	2	15,182
WA	40	11	51	327	275	602	8	34,945
WV	DNF	DNF	DNF	DNF	DNF	232 ^s	13	6,346
WI	DNF	DNF	DNF	0	627	627	11	50,367
WY	4	0	4	0	0	24 ^s	4	2,389
Reported US Total	1,318	466	1,311	530	12,148			
Estimated US Total						26,869	8	1,404,276

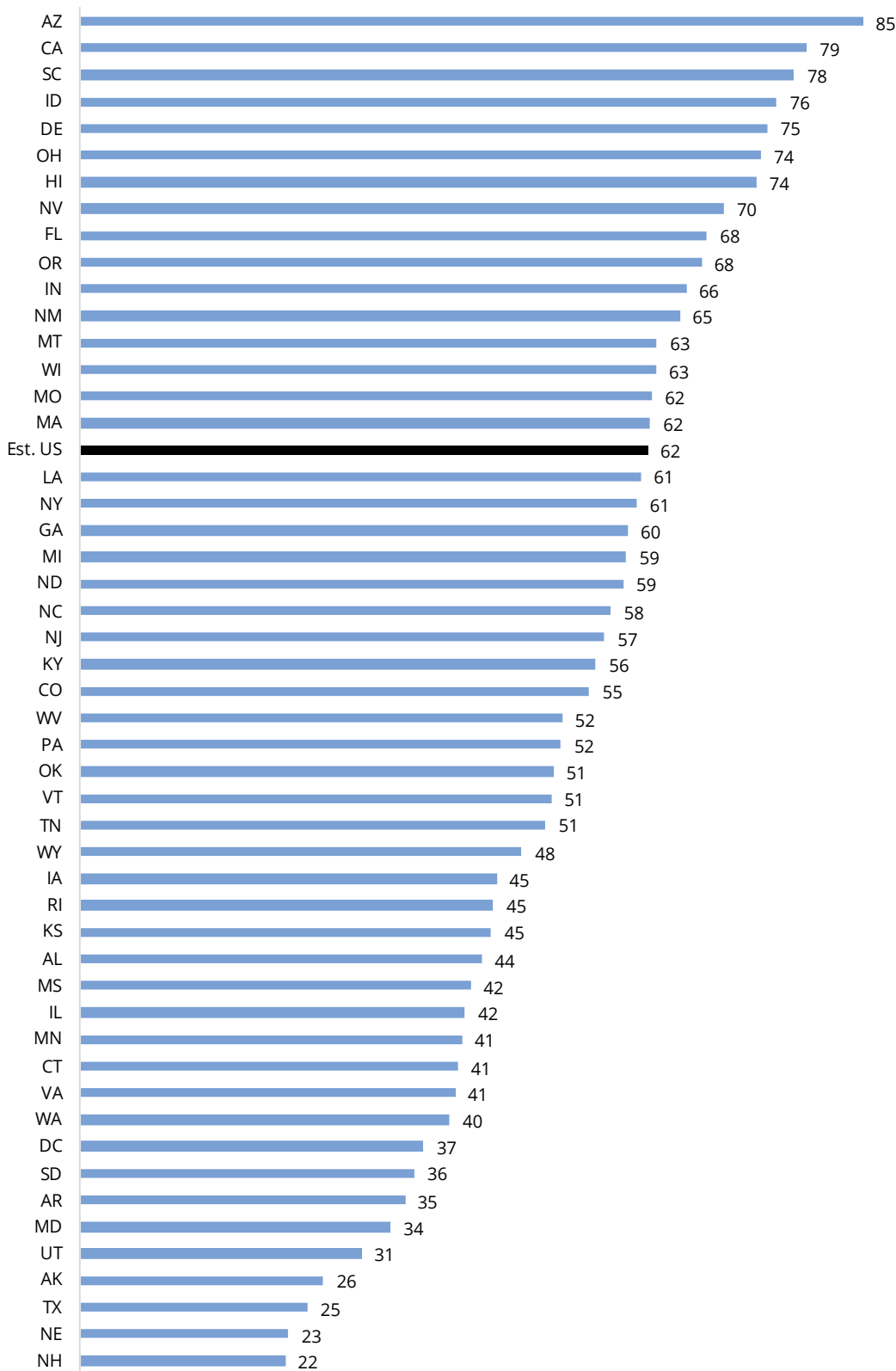
DNF Did not furnish. PD Partial data. ^a Missing values (DNF) assumed to be zero. ^d Other date (data from previous or next year). ^e Estimate. ^f Total is larger than component parts due to unknown settings or sizes. ^s Source APHA 2017c. * See state notes in Appendix.

Figure 1.1 LTSS Recipients with IDD by Residence Type and Size (Excluding people in Nursing Homes and Psychiatric Facilities) on June 30, 2019



The total includes people in settings of unspecified size or type. Percentages are based on settings of known type and size. Figure excludes people with IDD in nursing homes or psychiatric facilities

Figure 1.2 Estimated Percent of LTSS Recipients with IDD Living with a Family Member by State on June 30, 2019



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

Figure 1.3 LTSS Recipients with IDD per Setting by Setting Type on June 30, 2019

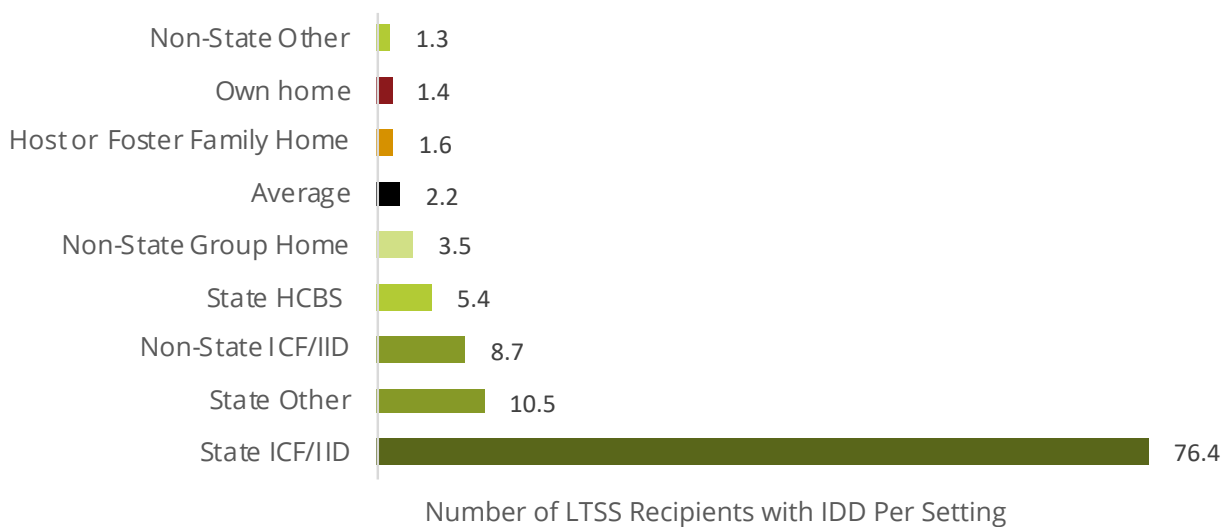


Figure includes people in group homes, host/foster family homes, own homes, and other IDD settings. It excludes people in family homes, nursing homes, psychiatric settings.

Figure 1.4 Percent of People not Living with Family Members who lived in Settings of 1 to 3 or 1 to 6 People by State on June 30, 2019

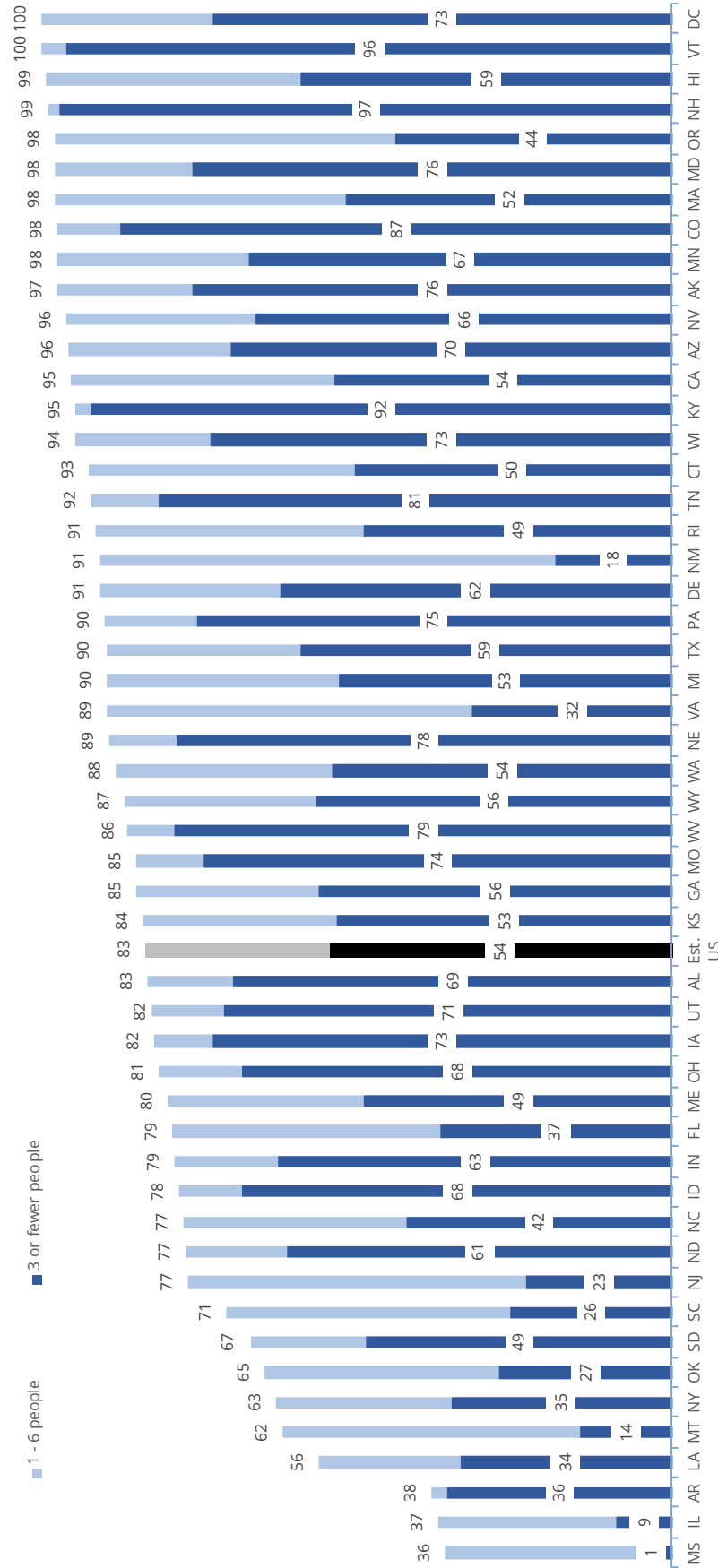


Figure 1.5 Estimated LTSS Recipients with IDD Per 100,000 of the Population by Setting Type and State on June 30, 2019

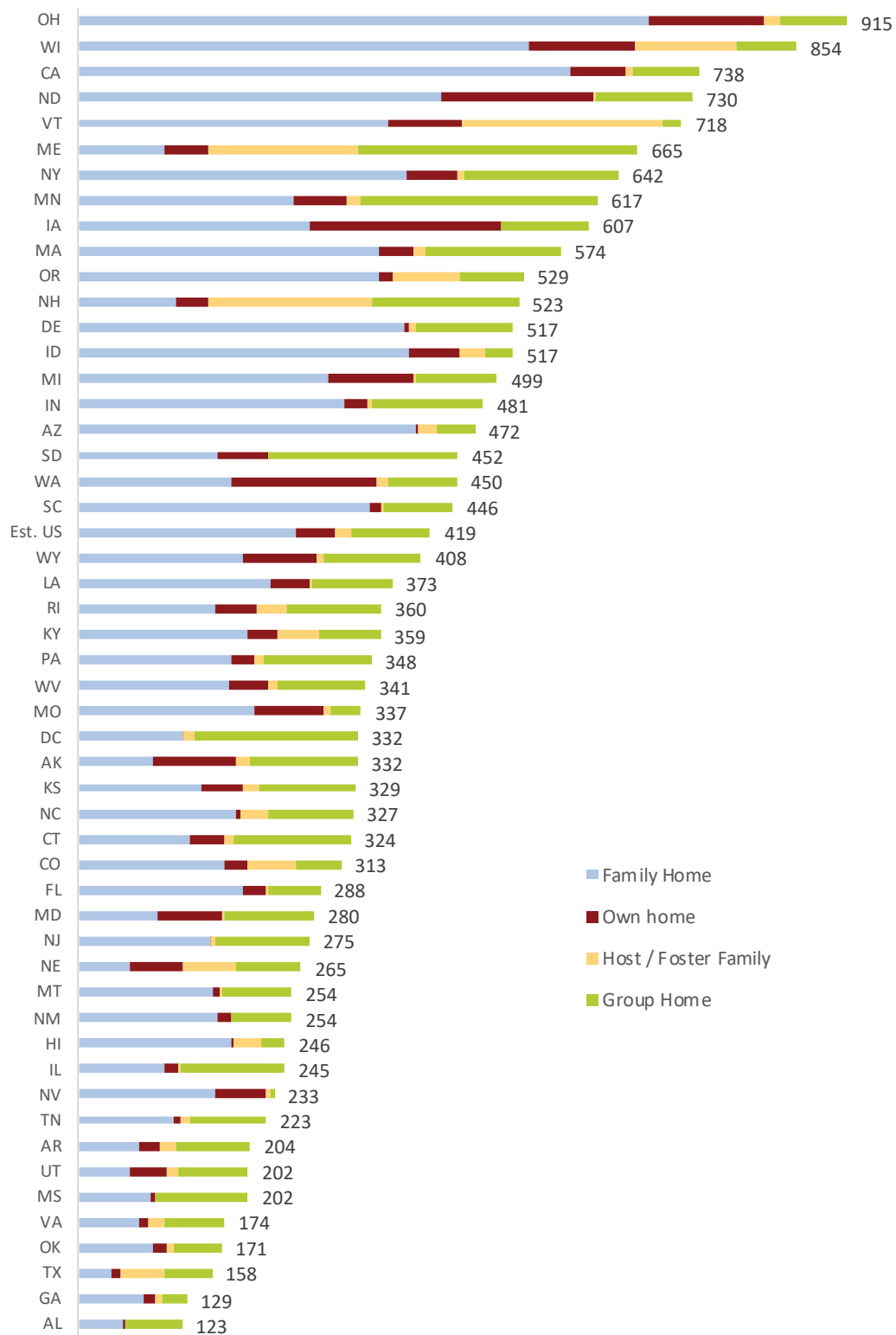
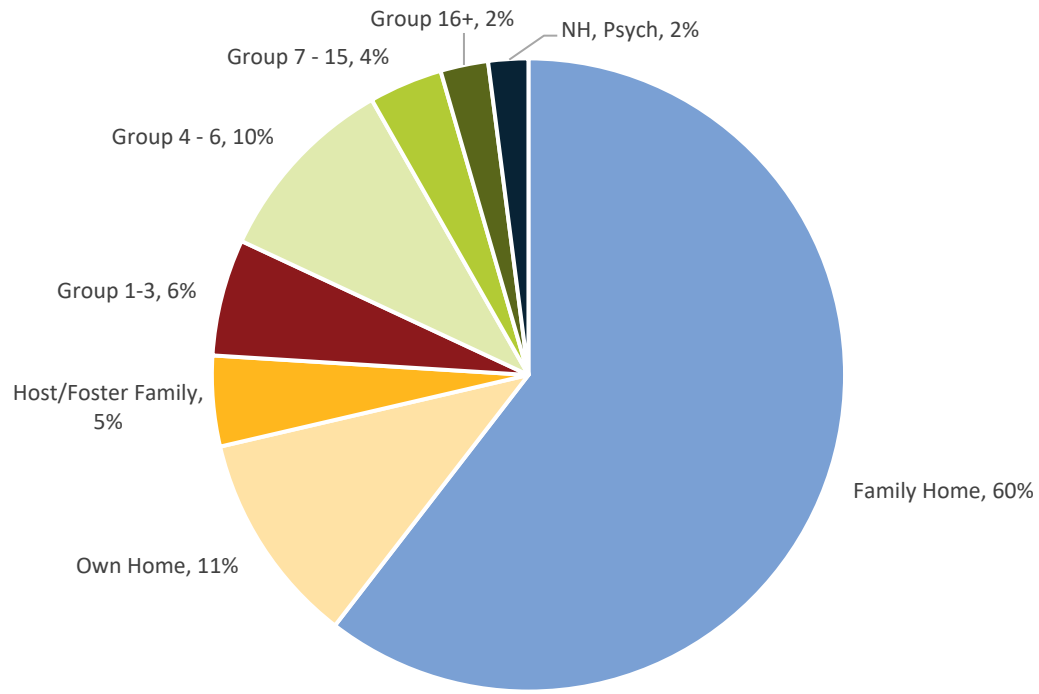
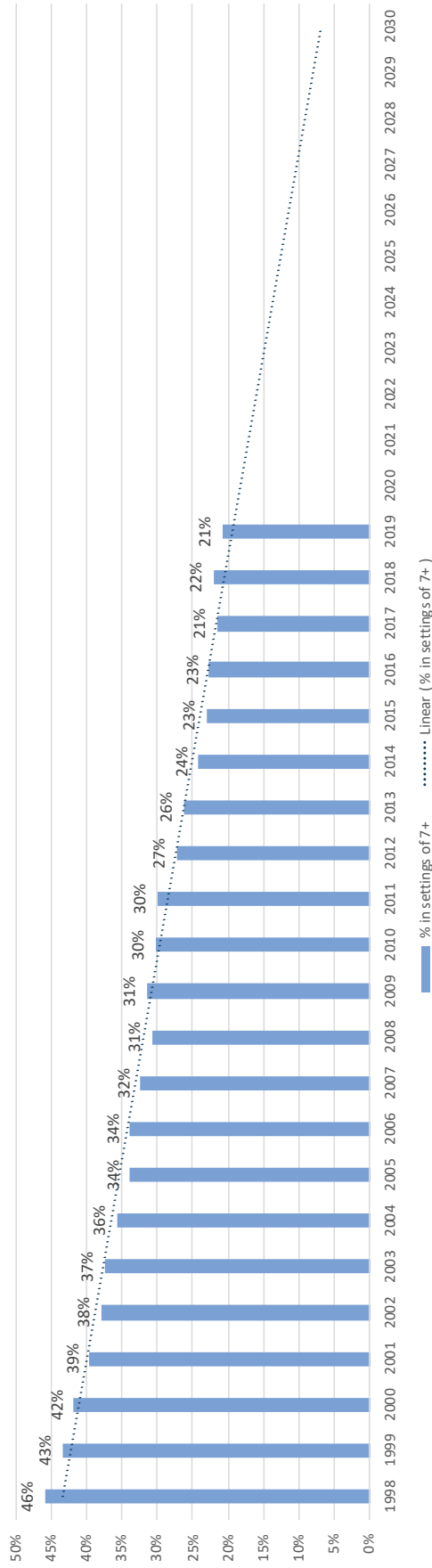


Figure 1.6 Estimated Percent of LTSS Recipients with IDD in Family Home, LTSS Settings, Psychiatric Facilities or Nursing Homes by Residence Type and Size on June 30, 2019



Estimated total people = 1,402,290

Figure 1.7 Percent of People in Nonfamily Settings who Live in Congregate Settings of 7 + People 1998 to 2019 with Linear Projections to 2030



SECTION 2: MEDICAID LTSS RECIPIENTS AND EXPENDITURES

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

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

In 2019, all 50 states and the District of Columbia provided LTSS to people with IDD funded by one or more Medicaid Home and Community-Based Services Waivers (See **Figure 2.1**). Of those,

- 47 states used Medicaid 1915(c) Home and Community-based Services (HCBS) Waivers
- 11 states used Medicaid 1115 Demonstration Waivers
- 8 states used Medicaid managed care waivers (1915a, b, or b/c)

In 2019, 49 states and the District of Columbia provided Medicaid State Plan funded LTSS to people with IDD. Of those,

- 48 states used the Medicaid Intermediate Care Facilities for Individuals with Intellectual Disabilities funding authority
- 35 states used the State Plan Targeted Case Management funding mechanism
- 7 states used Medicaid State Plan 1915(k) Community First Choice
- 7 states used Medicaid State Plan 1915(i) Home and Community-based Services

In 2019, 46 states reported using state or local non-Medicaid funding to provide LTSS for people with IDD.

How many people with IDD received LTSS through Medicaid or state funding authorities in FY 2019?

In Fiscal Year 2019, an estimated

- 930,356 people with IDD received LTSS through a Medicaid Waiver funding authority
- 219,532 people with IDD received LTSS through a Medicaid State Plan HCBS funding under the 1915(i) or 1915(k) authorities

- 269,051 people with IDD received LTSS funded by state or local dollars not matched by Medicaid
- 67,498 people with IDD received supports in a Medicaid ICF/IID
- 240,425 people on state IDD agency caseloads received no Medicaid or state funded LTSS (See **Figure 2.2**)

People could receive LTSS funded by more than one funding source.

Medicaid Home and Community Based Services Waiver

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

On June 30, 2019, 997,854 people with IDD were receiving services funded either by a Medicaid Waiver or by the ICF/IID program (See **Table 2.1**).

An estimated 194,983 people with IDD living with a family member or in their own home and not already getting Medicaid Waiver funded supports, were waiting for Medicaid Waiver funded LTSS. Of those,

- 30% (58,172 people) were waiting for Medicaid Waiver funds to move to another setting.
- 17% (33,766 people) received Medicaid State Plan Targeted Case Management services while waiting for Medicaid Waiver funded supports.

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

Seven 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 20% to serve every person with IDD on the June 30, 2019 Medicaid Waiver waiting list.

The proportion increase in the number of Medicaid Waiver plus ICF/IID recipients required to serve all people living with a family member and waiting for Medicaid Waiver funded supports declined from 29% in 2013 to 20% in 2019 (See **Figure 2.3**).

Where did Medicaid Waiver recipients with IDD live?

Of the people with IDD getting LTSS funded by a Medicaid Waiver

- 56% lived with a family member
- 25% lived in a group setting
- 13% lived in a home they owned or leased
- 6% lived with a host or foster family (See **Table 2.2**)

How old were Medicaid Waiver recipients with IDD?

In 2019, there were an estimated 930,356 people with IDD getting LTSS funded by a Medicaid HCBS Waiver (See **Table 2.3**). Of those people,

- 26% (240,641 recipients) were 21 years or younger
- 74% (689,647 recipients) were 22 years or older

How many people per 100,000 of the population received Medicaid HCBS Waiver funded supports?

- There were 283 Medicaid Waiver recipients with IDD per 100,000 of the United States' population (See **Figure 2.4**).
- The number of Medicaid Waiver recipients with IDD ranged from 75 people per 100,000 in Nevada to more than 650 people per 100,000 in North Dakota, Oregon, and Wisconsin.

What proportion of Medicaid Waiver recipients lived with a family member by age?

- An estimated 206,833 Medicaid Waiver recipients who were 21 years or younger (90%) lived with a family member. Only 23,786 (10%) lived in another setting (See **Table 2.4** and **Figure 2.5**).
- An estimated 291,672 Medicaid Waiver recipients who were 22 years or older (46%) lived with a family member while 345,665 (54%) lived in another setting.

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

- An estimated 77% of the 153,079 LTSS recipients who lived in a home of their own received Medicaid Waiver-funded supports (See **Table 2.5**).
- An estimated 59% of the 849,104 LTSS recipients who lived with a family member received Medicaid Waiver-funded supports.

What proportion of total FY 2019 Medicaid Waiver expenditures for people with IDD were for people 22 years or older?

Fiscal Year 2019 Medicaid Waiver expenditures for people with IDD were \$45.08 billion (\$137 per U.S. resident; See **Table 2.6**).

Of the \$42.15 billion in Medicaid Waiver expenditures for which age was reported,

- 10% (\$4.20 billion) was for people 21 years or younger
- 90% (\$37.95 billion) was for people 22 years or older

Average annual Medicaid Waiver expenditures in reporting states were \$48,458 per year-end recipient with IDD.

How did FY 2019 Medicaid Waiver expenditures for people with IDD differ by state?

- Average annual Medicaid Waiver expenditures per state resident were \$137 in FY 2019 (See **Figure 2.6**).
- Average annual Medicaid Waiver expenditures ranged from \$34 per state resident in Oregon to \$349 per state resident in Vermont. (*Oregon shifted most of its Medicaid spending for people with IDD from the Medicaid Waiver funding authority to the Medicaid State Plan funding authority.*)

How did average annual per person Medicaid waiver expenditures for people with IDD differ by age and living arrangement in FY 2019?

Of the Medicaid Waiver expenditures reported by recipient age and residence type, average FY 2019 Medicaid Waiver expenditures were,

- \$18,182 per recipient 21 years or younger
 - \$14,231 for people 21 years or younger living in the home of a family member
 - \$46,329 for people 21 years or younger living in other settings
- \$58,857 per recipient 22 years or older
 - \$26,852 for people 22 years or older living in the home of a family member
 - \$73,072 for people 22 years or older living in other settings (See **Table 2.7** and **Figure 2.7**)

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

How many ICF/IIDs of various sizes were operating on June 30, 2019?

On June 30, 2019, there were 5,937 ICF/IID settings in the United States (See **Table 2.8**). Of those,

- 4% (219 ICF/IID) were state-run including
 - 27% (60 facilities) serving 6 or fewer people
 - 23% (51 facilities) serving 7 to 15 people
 - 49% (108 facilities) serving 16 or more people
- 96% (5,718 ICF/IID) were non-state including
 - 64% (3,661 facilities) serving 6 or fewer people
 - 30% (1,730 facilities) serving 7 to 15 people
 - 6% (327 facilities) serving 16 or more people

There were no ICF/IID facilities of any size reported in Alaska, Michigan, Montana, or Oregon. In addition, there were no ICF/IID facilities of 16 or more people in Alabama, the District of Columbia, Hawaii, Idaho, Vermont, or West Virginia.

How many people lived in ICF/IIDs of various sizes?

An estimated 66,485 people lived in an ICF/IID on June 30, 2019 (See **Table 2.9**). Of those,

- 25% (16,732 people) lived in a state-run ICF/IID
 - 1% (251 people) lived in an ICF/IID housing 6 or fewer people
 - 4% (607 people) lived in an ICF/IID housing 7 to 15 people
 - 95% (16,732) lived in an ICF/IID housing 16 or more people
- 75% (49,758 people) lived in a non-state ICF/IID

- 39% (19,303) lived in an ICF/IID housing 6 or fewer people
- 32% (15,907) lived in an ICF/IID housing 7 to 15 people
- 29% (14,548) lived in an ICF/IID housing 16 or more people

What proportion of LTSS recipients with IDD who did not live with a family member lived in an ICF/IID?

Overall, 10% of LTSS recipients getting services from a non-state entity lived in an ICF/IID (See **Figure 2.8**) including

- 4% of LTSS recipients living in non-state settings of 6 or fewer people
- 33% of LTSS recipients living in non-state settings of 7 to 15 people
- 81% of LTSS recipients living in non-state settings of 16 or more people.

Overall, 64% of LTSS recipients with IDD living in a state-run setting lived in an ICF/IID including

- 25% of LTSS recipients living in a state-run setting of 6 or fewer people
- 14% of LTSS recipients living in a state-run setting of 7 to 15 people
- 98% of LTSS recipients living in a state-run setting of 16 or more people

How old were people living in an ICF/IID in Fiscal Year 2019?

- Of the people living in an ICF/IID 92% were 22 years old or older (See **Table 2.10**).
- There were 20.6 people living in an ICF/IID per 100,000 of the population (See **Figure 2.9**).

What were FY 2019 Medicaid ICF/IID expenditures?

Total Fiscal Year 2019 ICF/IID expenditures were \$9.46 billion (\$28.8 per United States resident). Average annual ICF/IID expenditures were \$140,210 per year-end recipient (See **Table 2.11**).

The average was

- \$125,579 for recipients 21 years or younger in 31 reporting states

- \$139,468 for recipients 22 years or older in 37 reporting states (See **Table 2.12**)

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

An estimated 997,854 Medicaid LTSS recipients with IDD lived in an ICF/IID or received Medicaid Waiver funded LTSS in Fiscal Year 2019 (See **Table 2.13** and **Figure 2.10**). Of those,

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

Total Medicaid ICF/IID plus Waiver expenditures for people with IDD were \$54.55 billion in FY 2019. Of the total,

- 83% (\$45.08 billion) was for Medicaid Waiver recipients
- 17% (\$9.46 billion) was for people in ICF/IID

How do living arrangements and average annual expenditures for ICF/IID and HCBS Waiver recipients differ by age?

Amongst adults 22 years or older,

- 345,665 people got Medicaid Waiver funded supports provided in a setting other than the home of a family member
- 291,672 people got Medicaid Waiver funded supports provided in the home of a family member
- The living arrangements for 52,310 Medicaid Waiver recipients 22 year or older were not reported.
- 62,032 people living in an ICF/IID (See **Figure 2.11**)

Amongst people 21 years or younger,

- 206,833 people got Medicaid Waiver funded supports provided in the home of a family member
- 23,786 people got Medicaid Waiver funded supports provided in a setting other than the home of a family member
- The living arrangements for 10,022 Medicaid Waiver recipients 21 years or younger were not reported.
- 5,466 people lived in an ICF/IID

Average annual per person expenditures for adults 22 years or older were

- \$139,468 for people living in an ICF/IID
- \$73,072 for Waiver recipients living in a setting other than the home of a family member
- \$26,852 for Waiver recipients living with a family member (See **Figure 2.12**)

Average annual per person expenditures for people 21 years or younger were

- \$125,579 for people living in an ICF/IID
- \$46,329 for Waiver recipients living in a setting other than the home of a family member
- \$14,231 for Waiver recipients living with a family member

How did Medicaid benefit ratios vary by state?

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 (See **Table 2.14**).

- 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.

States with the lowest state Medicaid benefit ratios for FY 2019

- Oregon (0.31)
- Washington (0.43)
- Nevada (0.45)
- Florida (0.53)
- California (0.54)

States with the highest state Medicaid benefit ratios for FY 2019

- West Virginia (4.57)
- Maine (4.54)
- New Mexico (3.76)
- Vermont (3.03)
- Iowa (3.02)

Table 2.1 People with IDD Living with Family Members Waiting for Medicaid Waiver-Funded LTSS, Total ICF/IID and Medicaid Waiver Recipients and Growth Needed to Serve those Waiting by State on June 30, 2019

State	People Waiting for Medicaid Waiver Funded LTSS			Estimated Medicaid Waiver + ICF/IID Recipients	Increase Needed to Serve All Waiting (%)
	Number Waiting	Gets Targeted Case Management	Waiting to Move from Family Home		
N States	44	40	28	51	44
AL	2,100	0	DNF	6,059	35
AK	652	0	142	2,444	27
AZ	270	0	0	35,028	1
AR	3,305	N/A	DNF	6,167	54
CA	0	0	0	138,420	0
CO	2,895	0	2,895	13,432	22
CT	304	242	111	10,602	3
DE	0	0	0	1,764	0
DC	0	N/A	0	2,345	0
FL	21,631	DNF	1,712	37,428	58
GA	DNF	DNF	DNF	13,635	DNF
HI	0	0	0	3,007	0
ID	0	N/A	0	9,226	0
IL	14,827	N/A	2,481	30,001	49
IN	1,666	N/A	DNF	32,404	5
IA	DNF	DNF	DNF	15,094	DNF
KS	3,742	1,770	DNF	9,839	38
KY	9,760	DNF	DNF	15,108	65
LA	0	0	0	17,120	0
ME	1,856	DNF	DNF	5,830	32
MD	5,198	4,326	387	15,379	34
MA	0	0	0	17,399	0
MI	DNF	N/A	DNF	49,589	DNF
MN	26 ^e	26 ^e	DNF	24,465	0
MS	2,095	DNF	DNF	4,952	42
MO	0	0	0	15,796	0
MT	DNF	DNF	DNF	2,656	DNF
NE	1,742	303	0	5,161	34
NV	82	82	DNF	2,396	3
NH	0	0	0	7,152	0
NJ	673	N/A	DNF	20,992	3
NM	5,066	400 ^e	DNF	4,912	103
NY	0	0	6,138	91,843	0
NC	10,344	2,428 ^e	1,369 ^e	33,951	30
ND	0	N/A	0	5,561	0
OH	22,811	3,890	DNF	46,020	50
OK	5,569 ^{e,i}	0	DNF	6,670	83
OR	0	0	0	28,170	0
PA	7,186	6,133	1,627	39,542	18
RI	0	N/A	0	3,990	0
SC	15,340	DNF	210	12,037	127
SD	DNF	DNF	DNF	3,806	DNF
TN	DNF	N/A	DNF	11,555	DNF
TX	DNF	DNF	DNF	47,314	DNF
UT	3,129	N/A	1,506	6,033	52
VT	0	0	0	3,194	0
VA	13,080	25	7,256	14,959	87
WA	13,476	N/A	DNF	19,401	69
WV	1,032	DNF	DNF	6,125	17
WI	572	0	DNF	39,447	1
WY	395	395	0	2,434	16
Reported US Total	170,824	20,020	25,834		
Estimated US Total	194,983	33,766	58,172	997,854	20

DNF Did not furnish. ^a 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.



Table 2.2 Medicaid Waiver Recipients with IDD by Reported Residence Type and State on June 30, 2019

	Family Home	Own Home	Host/ Foster Family	Group Settings				Setting Type Unknown
				Non-State IDD	Non-State Other	State IDD	Group Total	
N States	44	41	47	47	46	51	44	50
AL	2,640	40	0	3,349	0	0	3,349	0
AK	643 ^e	546	83	712	0	0	712	446
AZ*	29,231	272	1,554	3,205	10	128	3,343	0
AR	1,925	639	570	1,027	0	0	1,027	0
CA	76,880	11,218	1,469	19,935	0	0	19,935	0
CO	6,257	386 ⁱ	3,180	730	2,109	108	2,947	0 ⁱ
CT	4,126	1,364	379	3,796	83	180	4,059	0
DE	438	51	95	997	0	0	997	0
DC	876	8	92	1,051	10	0	1,061	0
FL	19,459	5,268	374	9,241	386	0	9,627	0
GA	DNF	DNF	DNF	DNF	DNF	0 ⁱ	PD	0 ⁱ
HI	2,029	65	468	305	0	0	305	0
ID	1,719	DNF	509	184	0	0	184	6,379
IL	12,002	1,961	322	9,303	0	0	9,303	0
IN	21,361	1,757 ^e	325	5,880 ^e	0	0	5,880 ^e	0
IA	5,295	6,776	0	1,462	116	0	1,578	0
KS	3,501	1,160	464	2,378	0	0	2,378	1,681 ⁱ
KY	10,722	DNF	2,152	2,779	0	0	2,779	0
LA	DNF	2,265	9	0	0	0	0	10,582 ⁱ
ME	DNF	DNF	1,499	2,451	DNF	0	PD	1,227
MD	24	3,951	225	6,062	0	0	6,062	5,693
MA	2,921 ^e	1,430	594	8,263	0	1,039	9,302	2,799
MI	29,117	DNF	DNF	DNF	DNF	0	PD	20,472
MN	10,674 ^e	2,063 ^e	900	8,400	822 ^e	348	9,570	0
MS	1,712	137	0	866 ^e	0 ^{PD}	113	979 ^e	0
MO	7,665	4,982	516	1,714	0	211	1,925	0
MT	1,703	DNF	46	825	DNF	0	PD	82
NE	DNF	DNF	1,228	1,157	0	0	1,157	2,395
NV	762	1,399	153 ^e	0	0	0	0	0
NH	1,179	408	1,984	1,742	0	0	1,742	0
NJ	11,179	52	436	8,062	0	0	8,062	0
NM	3,195	215	0	1,167	0	71	1,238	0
NY	47,284 ^e	6,245 ^e	1,488	25,197	0	6,342	31,539	0
NC	19,784 ⁱ	323 ^e	1,955	4,194	1,902 ^e	0	6,096	606
ND	3,288	1,379	12	348	0	0	348	0
OH	19,245	14,976	1,171	2,645	453	0	3,098	0
OK	DNF	DNF	DNF	DNF	0	0	PD	5,242 ^e
OR	15,018	707	3,367	3,061	0	0	3,061	0
PA	19,430	2,605	1,417	11,594	1,440	0	13,034	28
RI	1,715	522	383	1,025	0	130	1,155	0
SC	7,045	641	182	3,002	0	15	3,017	0
SD	DNF	DNF	DNF	DNF	0	0	PD	DNF
TN	DNF	DNF	625	5,331	DNF	0	PD	3,860
TX	10,886	3,423	13,800	8,738	0	0	8,738	0
UT	1,927	1,317	458	1,942	0	0	1,942	0
VT	1,099	208	1,410	136	0	0	136	0
VA	6,047	1,041	1,750	5,390	0	0	5,390	0
WA	11,625	9,620	136	1,684	218	359	2,261	0
WV	3,326	857	69	1,364	0	0	1,364	0
WI	21,337	7,362	6,652	3,712	1	0	3,713	0
WY	1,114	496	40	599	5	0	604	44
Reported US Total	459,405	100,135	54,541	187,005	7,555	9,044	203,604	61,536
Estimated US Total	499,139	118,428	57,634	204,967	8,040	8,969 *	221,976	10,852

DNF Did not furnish. ^d Other date (data from previous or next year). ^e Estimate. * See state notes in Appendix. Many states were unable to report residence type for all Waiver recipients. Please refer to Table 2.3 for an estimate of the total number of Waiver recipients. Medicaid Waiver authorities include 1115, 1915 (a), 1915 (a/c), 1915 (b), 1915 (b/c) and 1915 (c). 2 10,852 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 2019

State	Waiver Recipients			Percent 22 years or older	State Population in 100,000's ^s		Recipients per 100,000 by Age		
	Birth to 21 years	22 years or older	All Ages		Birth to 21 years	22 years or older	Birth to 21 years	22 years or older	All Ages
N states	45	45	50	45	51	51	45	45	50
AL	63	5,981	6,044	99	14	35	5	169	123
AK	DNF	DNF	2,430	DNF	2	5	DNF	DNF	332
AZ	22,205	12,704	34,909	36	20	52	1,086	243	480
AR	DNF	DNF	4,737	DNF	9	22	DNF	DNF	157
CA	56,722	74,389	131,111	57	110	285	516	261	332
CO	3,173	10,060	13,233	76	15	42	205	239	230
CT	368	9,560	9,928	96	9	26	40	362	278
DE	67	1,578	1,645	96	3	7	26	220	169
DC	32	2,005	2,037	98	2	5	19	374	289
FL	4,700	30,028	34,728	86	53	162	89	185	162
GA	DNF	DNF	13,370 ⁱ	DNF	31	75	DNF	DNF	126
HI	564	2,381	2,945	81	4	11	155	226	208
ID	4,673	4,118	8,791 ^e	47	5	12	857	332	492
IL	2,117	21,471	23,588	91	35	92	61	234	186
IN	11,873	17,450	29,323	60	20	48	606	366	436
IA	4,277	9,375	13,652	69	9	22	472	417	433
KS	1,752	7,681	9,433	81	9	20	201	376	324
KY	5,705	9,246	14,951	62	12	32	458	287	335
LA	2,678	10,178	12,856	79	13	33	200	308	277
ME	302	5,329	5,631	95	3	10	97	516	419
MD	328	14,960	15,288	98	16	44	20	340	253
MA	290	16,756	17,046	98	18	51	17	326	247
MI	17,353	32,236	49,589	65	27	73	643	442	497
MN	5,951	17,179	23,130	74	16	41	376	424	410
MS	DNF	DNF	2,715	DNF	9	21	DNF	DNF	91
MO	2,752	12,653	15,405	82	17	44	162	285	251
MT	327	2,329	2,656	88	3	8	114	298	249
NE	305	4,475	4,780	94	6	14	52	331	247
NV	164	2,150	2,314	93	8	22	20	96	75
NH	2,192	4,935	7,127	69	3	10	665	479	524
NJ	-	19,729	19,729	100	24	65	-	303	222
NM	407	4,238	4,645	91	6	15	69	281	222
NY	20,810 ^e	66,263 ^e	87,073 ^e	76	50	144	414	459	448
NC	11,562	18,278	29,840	61	29	76	399	241	285
ND	3,096	1,999	5,095	39	2	5	1,405	369	669
OH	5,910	34,939	40,849	86	32	85	184	412	349
OK	DNF	DNF	5,321	DNF	12	28	DNF	DNF	134
OR	11,773	16,397	28,170	58	11	31	1,094	522	668
PA	4,446	32,492	36,938	88	33	95	135	342	289
RI	5	3,956	3,961	100	3	8	2	503	374
SC	2,246	8,638	10,884	79	14	37	160	231	211
SD	DNF	DNF	DNF	DNF	3	6	DNF	DNF	DNF
TN	1,187	9,369	10,556	89	19	50	63	189	155
TX	6,658	32,388	39,046	83	91	199	73	162	135
UT	1,355	4,498	5,853	77	11	21	120	217	183
VT	318	2,870	3,188	90	2	5	205	612	511
VA	2,072	12,271	14,343	86	23	62	89	198	168
WA	4,988	13,903	18,891	74	20	56	245	249	248
WV	1,551 ⁱ	4,065 ⁱ	5,616 ⁱ	72	4	13	346	303	313
WI	6,832	32,232	39,064	83	16	42	430	761	671
WY	667	1,689	2,356	72	2	4	401	409	407
Reported US Total	236,816	661,421	926,810	71	907	2,375	261	278	282
Estimated US Total	240,641	689,647	930,356	74	907	2,375	265	290	283

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).

Table 2.4 Medicaid Waiver Recipients with IDD Living in Family Homes or Other LTSS Settings by Age and State and Percent by Age Living in Family Home on June 30, 2019

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	39	39	38	38	37	37
AL	DNF	DNF	DNF	DNF	DNF	DNF
AK	643	0	0	1,719	0	0
AZ	21,489	8,478	988	4,543	96	65
AR	DNF	DNF	DNF	DNF	DNF	DNF
CA	55,027	41,102	1,694	33,284	97	55
CO	2,805	4,731	500	5,905	85	44
CT	310	3,816	58	5,564	84	41
DE	42	396	25	1,105	63	26
DC	20	856	14	1,163	59	42
FL	3,719	15,740	1,297	13,972	74	53
GA	DNF	DNF	DNF	DNF	DNF	DNF
HI	528	1,501	35	878	94	63
ID	DNF	DNF	DNF	DNF	DNF	DNF
IL	1,688	10,314	429	11,157	80	48
IN	11,618	9,743	255	7,707	98	56
IA	1,837	3,458	2,440	5,917	43	37
KS	1,216	2,285	366	5,064	77	31
KY	5,605	5,117	DNF	DNF	DNF	DNF
LA	DNF	DNF	DNF	DNF	DNF	DNF
ME	DNF	DNF	DNF	DNF	DNF	DNF
MD	11	15	317	14,945	3	0
MA	290	2,921	0	14,131 ^e	0	17
MI	15,333	13,784	2,020	18,452	88	43
MN	5,353 ^e	5,321 ^e	598 ^e	11,858 ^e	90	31
MS	DNF	DNF	DNF	DNF ^e	DNF	DNF
MO	2,343	5,370	375	7,165	86	43
MT	DNF	DNF	27	926	DNF	DNF
NE	148	2,247	157	2,228	49	50
NV	42	720	122	1,431	26	33
NH	DNF	DNF	DNF	DNF	DNF	DNF
NJ	0	11,179	0	8,550	0	57
NM	393	3,278	14	960	97	77
NY	20,101 ^e	27,791 ^e	709 ^e	38,472 ^e	97	42
NC	9,075	10,709	3,375	7,964	73	57
ND	3,039	249	57	1,682	98	13
OH	5,236	17,263	674	17,676	89	49
OK	DNF	DNF	DNF	DNF	DNF	DNF
OR	10,744	10,287	1,304	6,487	89	61
PA	3,829	15,832	617	16,660	86	49
RI	3	1,690	2	2,266	60	43
SC	2,173	4,872	73	3,751	97	57
SD	DNF	DNF	DNF	DNF	DNF	DNF
TN	DNF	DNF	DNF	DNF	DNF	DNF
TX	3,346	8,261	3,197	23,599	51	26
UT	688	1,239	682	3,035	50	29
VT	185	914	137	1,952	57	32
VA	1,731	4,316	500	7,681	78	36
WA	4,631	6,577	357	7,326	93	47
WV	1,314	2,202	DNF	DNF	DNF	DNF
WI	6,701	14,636	131	17,596	98	45
WY	588	526	79	1,163	88	31
Reported US Total	203,844	279,736	23,625	335,934	90	45
Estimated US Total ²	206,833	291,672	23,786	345,665	90	46

DNF Did not furnish. ^a Other date (data from previous or next year). ^e Estimate. * See state notes in Appendix. This table shows the number of people by age and setting for whom Waiver expenditures were reported. ¹ Other settings include own home, host or foster family home, and all group settings. Medicaid Waiver authorities include 1115, 1915 (a), 1915 (a/c), 1915 (b), 1915 (b/c) and 1915 (c). ² An estimated 40,073 people are not accounted for in the Estimated totals on this table.

Table 2.5 Medicaid Waiver and LTSS Recipients with IDD in Own Home or Family Settings by State on June 20, 2019

State	All LTSS Recipients		Waiver Recipients		% with Waiver Funding ¹	
	Own Home	Family Home	Own Home	Family Home	Own Home	Family Home
N States	39	39	41	44	38	39
AL	40	2,640	40	2,640	100	100
AK	546	643 ^e	546	643 ^e	100	100
AZ	257	29,231 ^{e,i}	272	29,231	106	100
AR	639	1,973	639	1,925	100	98
CA	26,670	230,744 ⁱ	11,218	76,880	42	33
CO	1,596 ⁱ	8,380 ⁱ	386 ⁱ	6,257	24	75
CT	1,439	4,744	1,364	4,126	95	87
DE	51	3,765	51	438	100	12
DC	8	876	8	876	100	100
FL	5,880	41,242	5,268	19,459	90	47
GA	DNF	DNF	DNF	DNF	DNF	DNF
HI	71	2,558	65	2,029	92	79
ID	DNF	1,719	DNF	1,719	DNF	100
IL	1,961	13,011	1,961	12,002	100	92
IN	1,757 ^e	21,361	1,757 ^e	21,361	100	100
IA	DNF	DNF	6,776	5,295	DNF	DNF
KS	DNF	DNF	1,160	3,501	DNF	DNF
KY	DNF	10,722	DNF	10,722	DNF	100
LA	2,265	DNF	2,265	DNF	100	DNF
ME	DNF	DNF	DNF	DNF	DNF	DNF
MD	DNF	DNF	3,951	24	DNF	DNF
MA	2,747	9,998	1,430	2,921 ^e	52	29
MI	10,077	29,603	DNF	29,117	DNF	98
MN	3,575 ^e	14,447 ^e	2,063 ^e	10,674 ^e	58	74
MS	179 ^e	2,551 ^e	137	1,712	77	67
MO	4,982	12,858	4,982	7,665	100	60
MT	DNF	DNF	DNF	1,703	DNF	DNF
NE	DNF	DNF	DNF	DNF	DNF	DNF
NV	1,815	5,020	1,399	762	77	15
NH	408	1,179	408	1,179	100	100
NJ	52	13,925	52	11,179	100	80
NM	319	3,470	215	3,195	67	92
NY	12,023	DNF	6,245 ^e	47,284 ^e	52	DNF
NC	369 ^e	19,784 ⁱ	323 ^e	19,784 ⁱ	88	100
ND	1,379	3,288	1,379	3,288	100	100
OH	16,063	79,213	14,976	19,245	93	24
OK	DNF	DNF	DNF	DNF	DNF	DNF
OR	711	15,087	707	15,018	99	100
PA	3,407	23,342 ⁱ	2,605	19,430	76	83
RI	522	1,715	522	1,715	100	100
SC	688	17,833	641	7,045	93	40
SD	DNF	DNF	DNF	DNF	DNF	DNF
TN	DNF	DNF	DNF	DNF	DNF	DNF
TX	3,423	10,886	3,423	10,886	100	100
UT	1,341 ^e	1,982	1,317	1,927	98	97
VT	527	2,295	208	1,099	39	48
VA	1,041	6,047	1,041	6,047	100	100
WA	13,212	44,499	9,620	11,625	73	26
WV	857	3,205	857	3,326	100	104
WI	7,387	31,172	7,362	21,337	100	68
WY	496	1,114	496	1,114	100	100
Reported US Total	130,780	728,122	100,135	459,405	77	63
Estimated US Total	153,079	849,104	118,428	499,139	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. ¹ Proportion of recipients who received services funded by a Waiver. Medicaid Waiver authorities include 1115, 1915 (a), 1915 (a/c), 1915 (b), 1915 (b/c) and 1915 (c).



Table 2.6 Medicaid Waiver Expenditures for Recipients with IDD, Per Recipient and Per State Resident by Age and State in FY 2019

State	Waiver Expenditures (\$)			FY 2019 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	50	40	41	50	51	51
AL	DNF	DNF	350,722,756 ^s	6,044	DNF	DNF	58,028	49	72
AK	DNF	DNF	181,935,470	2,430	DNF	DNF	74,871	7	249
AZ	411,586,829	766,603,423	1,178,190,252	34,909	18,536	60,343	33,750	73	162
AR	DNF	DNF	180,988,989	4,737	DNF	DNF	38,208	30	60
CA	530,998,359	3,281,261,826	3,812,260,185	131,111	9,361	44,110	29,077	395	96
CO	59,803,539	475,958,852	535,762,390	13,233	18,848	47,312	40,487	58	93
CT	12,143,369	781,494,644	793,638,013	9,928	32,998	81,746	79,939	36	223
DE	3,560,417	151,228,072	154,788,489	1,645	53,141	95,835	94,096	10	159
DC	2,432,052	252,336,989	254,769,040	2,037	76,002	125,854	125,071	7	361
FL	87,172,543	1,144,790,111	1,231,962,654	34,728	18,547	38,124	35,475	215	57
GA	DNF	DNF	697,001,307 ^s	13,370 ⁱ	DNF	DNF	51,132	106	66
HI	13,291,487	131,682,225	144,973,712	2,945	23,566	55,305	49,227	14	102
ID	65,981,211	219,553,923	285,535,135	8,791 ^e	14,120	53,316	32,480	18	160
IL	74,296,596	922,474,056	996,770,652	23,588	35,095	42,964	42,258	127	79
IN	91,593,004	598,489,296	690,082,300	29,323	7,714	34,297	23,534	67	103
IA	124,819,470	552,854,428	677,673,898	13,652	29,184	58,971	49,639	32	215
KS	29,073,160	374,269,572	403,342,732	9,433	16,594	48,727	42,759	29	138
KY	199,550,474	513,231,007	712,781,481	14,951	34,978	55,508	47,675	45	160
LA	43,634,434	464,967,040	508,601,474	12,856	16,294	45,684	39,561	46	109
ME	11,871,488	438,832,537	450,704,025	5,631	39,310	82,348	80,040	13	335
MD	12,900,495	1,048,612,382	1,061,512,877	15,288	39,331	70,094	69,434	60	176
MA	5,309,742	1,550,886,645	1,556,196,387	17,046	18,309	92,557	91,294	69	226
MI	556,190,305	1,426,911,727	1,983,102,032	49,589	32,052	44,265	39,991	100	199
MN	284,856,517	1,389,631,852	1,674,488,369	23,130	47,867	80,891	72,395	56	297
MS	DNF	DNF	120,885,828	2,715	DNF	DNF	44,525	30	41
MO	81,468,484	952,763,072	1,034,231,556	15,405	29,603	75,299	67,136	61	169
MT	7,011,236	114,774,340	121,785,576	2,656	21,441	49,281	45,853	11	114
NE	21,540,404	307,330,598	328,871,002	4,780	70,624	68,677	68,801	19	170
NV	9,978,203	115,016,838	124,995,041	2,314	60,843	53,496	54,017	31	41
NH	18,840,681	255,247,760	274,088,441	7,127	8,595	51,722	38,458	14	202
NJ	-	1,418,241,123	1,418,241,123	19,729	N/A	71,886	71,886	89	160
NM	18,278,885	370,387,666	388,666,551	4,645	44,911	87,397	83,674	21	185
NY	435,118,486	6,076,458,922	6,511,577,408	87,073 ^e	20,909	91,702	74,783	195	335
NC	180,307,442	1,087,224,851	1,267,532,292	29,840	15,595	59,483	42,478	105	121
ND	DNF	DNF	212,556,844 ^s	5,095	DNF	DNF	41,719	8	279
OH	113,995,582	1,721,690,345	1,835,685,927	40,849	19,289	49,277	44,938	117	157
OK	DNF	DNF	313,337,170	5,321	DNF	DNF	58,887	40	79
OR	39,728,836	105,156,253	144,885,089	28,170	3,375	6,413	5,143	42	34
PA	109,171,127	3,301,949,958	3,411,121,084	36,938	24,555	101,623	92,347	128	266
RI	68,109	258,076,608	258,144,717	3,961	13,622	65,237	65,172	11	244
SC	87,633,322	336,447,966	424,081,288	10,884	39,018	38,950	38,964	51	82
SD	DNF	DNF	134,642,122 ^s	DNF	DNF	DNF	DNF	9	152
TN	28,769,603	739,157,987	767,927,591	10,556	24,237	78,894	72,748	68	112
TX	232,074,862	1,233,898,641	1,465,973,503	39,046	34,857	38,097	37,545	290	51
UT	40,295,053	254,011,492	294,306,545	5,853	29,738	56,472	50,283	32	92
VT	20,707,037	197,214,847	217,921,884	3,188	65,116	68,716	68,357	6	349
VA	DNF	DNF	978,058,990 ^s	14,343	DNF	DNF	68,191	85	115
WA	25,669,480	593,288,460	618,957,940	18,891	5,146	42,673	32,765	76	81
WV	DNF	DNF	299,138,028 ^s	5,616 ⁱ	DNF	DNF	53,265	18	167
WI	65,652,751	1,422,103,983	1,487,756,734	39,064	9,610	44,121	38,085	58	256
WY	12,745,332 ^e	97,604,292	110,349,624 ^e	2,356	19,108	57,788	46,838	6	191
Reported Total	4,195,289,542	37,951,379,045	45,083,504,516 -	930,356	18,182	58,857	48,458	3,282	137

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

Table 2.7 Medicaid Waiver Expenditures and Average per Recipient by Age, Living Arrangement, and State in FY 2019

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		35	33	35	33	34	32	32	33
AL		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
AK		21,513,359	0	0	160,195,460	33,458	N/A	N/A	93,191
AZ		331,225,262	312,919,165	80,361,567	453,684,259	15,414	36,910	81,338	99,864
AR		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
CA		424,232,010	860,333,244	106,766,348	2,420,928,582	7,710	20,932	63,026	72,736
CO		30,153,573	57,114,778	29,649,966	418,842,384	10,750	12,072	59,300	70,930
CT		4,307,096	87,076,592	7,836,272	604,966,620	13,894	22,819	135,108	108,729
DE		608,520	8,970,702	2,951,897	142,257,369	14,489	22,653	118,076	128,740
DC		480,511	48,232,105	2,085,767	210,164,016	24,026	56,346	148,983	180,709
FL		34,918,176	390,515,008	52,254,367	754,275,103	9,389	24,810	40,289	53,985
GA		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
HI		11,577,239	65,711,136	921,384	62,557,642	21,927	43,778	26,325	71,250
ID		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
IL		34,398,173	263,022,668	39,898,423	659,451,388	20,378	25,502	93,003	59,107
IN		84,562,799	185,362,160	7,030,205	413,127,136	7,279	19,025	27,569	53,604
IA		48,115,802	97,866,158	76,703,669	454,988,270	26,193	28,301	31,436	76,895
KS		16,797,835	62,862,289	12,571,691	308,153,698	13,814	27,511	34,349	60,852
KY		193,707,147	178,174,512	DNF	DNF	34,560	34,820	DNF	DNF
LA		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
ME		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MD		156,963	339,214	12,743,533	1,048,273,167	14,269	22,614	40,200	70,142
MA		5,589,202	279,648,622	0	1,352,863,636	19,273	95,737	N/A	95,737 ^e
MI		474,941,294	341,081,553	81,249,011	1,085,830,175	30,975	24,745	40,222	58,846
MN		209,666,641	270,099,164	75,189,876	1,119,532,688	39,168 ^e	50,761 ^e	125,736 ^e	94,412 ^e
MS		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MO		33,896,299	131,246,213	47,702,313	821,946,129	14,467	24,441	127,206	114,717
MT		DNF	DNF	1,836,184	54,247,006	DNF	DNF	68,007	58,582
NE		4,153,409	72,074,634	17,386,995	235,255,963	28,064	32,076	110,745	105,591
NV		649,774	11,674,850	9,328,429	103,341,989	15,471	16,215	76,463	72,217
NH		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NJ		0	DNF	0	DNF	N/A	DNF	N/A	DNF
NM		16,833,277	230,045,451	1,445,608	140,342,216	42,833	70,179	103,258	146,190
NY		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NC*		97,037,347	305,903,353	61,041,261	534,059,353	10,693	28,565	18,086	67,059
ND		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
OH		76,807,294	472,714,359	37,188,288	1,248,975,985	14,669	27,383	55,176	70,659
OK		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
OR		33,549,445	60,303,329	6,179,390	44,852,924	3,123	5,862	4,739	6,914
PA		40,421,387	687,395,114	68,749,740	2,614,554,843	10,557	43,418	111,426	156,936
RI		14,115	51,056,996	53,995	207,019,612	4,705	30,211	26,998	91,359
SC		84,785,044	190,093,296	2,848,278	146,354,670	39,018	39,018	39,018	39,018
SD		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
TN		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
TX		107,879,849	291,864,123	124,983,933	936,736,545	32,241	35,330	39,094	39,694
UT		10,248,862	27,858,666	32,003,054	219,597,029	14,897	22,485	46,925	72,355
VT		8,978,960	43,555,560	11,396,947	147,083,959	48,535	47,654	83,189	75,350
VA		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
WA		8,349,982	52,070,540	17,319,497	541,217,919	1,803	7,917	48,514	73,876
WV		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
WI		60,175,396	DNF	5,477,355	DNF	8,980	DNF	41,812	DNF
WY		11,235,010 ^e	30,393,977	1,510,322 ^e	67,210,315	19,107 ^e	57,783	19,118 ^e	57,790
Reported total		2,521,967,052	6,167,579,532	1,034,665,565	19,732,888,049				
Estimated US Total						14,231	26,852	46,329	73,072

DNF Did not furnish. N/A Not applicable. PD Partial data. ^a Missing values (DNF) assumed to be zero. ^d Other date (data from previous or next year). ^e Estimate. ^f Total is larger than component parts due to unknown settings or sizes. ^g 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).

Table 2.8 Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) by Size, Type of Operation and State on June 30, 2019

Size	State-Operated				Nonstate-Operated				All Facilities			
	1-6	7-15	16+	Total	1-6	7-15	16+	Total	1-6	7-15	16+	Total
N States	51	51	51	51	49	48	48	50	49	48	48	50
AL	0	0	0	0	0	2	0	2	0	2	0	2
AK	0	0	0	0	0	0	0	0	0	0	0	0
AZ	0	0	0	0	0	0	1	1	0	0	1	1
AR	0	0	5	5	0	33	4	37	0	33	9	42
CA	1	0	3	4	DNF	DNF	DNF	1,177	DNF	DNF	DNF	1,181
CO	3	10	2	15	5	0	0	5	8	10	2	20
CT	1	0	4	5	59	4	0	63	60	4	4	68
DE	0	0	1	1	0	0	1	1	0	0	2	2
DC	0	0	0	0	68	0	0	68	68	0	0	68
FL	0	0	2	2	38	20	51	109	38	20	53	111
GA	0 ⁱ	0 ⁱ	1 ^{e,i}	1 ^s	0	0	1	1 ^s	0	0	2	2
HI	0	0	0	0	16 ^e	1	0	17	16	1	0	17
ID	0	1	0	1	21	40	0 ⁱ	61	21	41	0	62
IL	0	0	7	7	31	147	30	208	31	147	37	215
IN	0	0	0	0	154	307	2	463	154	307	2	463
IA	0	0	2	2	50	44	24	118	50	44	26	120
KS	0	0	2	2	17	5	0	22	17	5	2	24
KY	0	0	0	0	1	3	6	10	1	3	6	10
LA	0	0	3	3	269	249	8	526	269	249	11	529
ME	0	0	0	0	1	11	4	16	1	11	4	16
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	1	0	0	1	103	28	10	141	104	28	10	142
MS	7	38	6	51	0	0	6	6	7	38	12	57
MO	0	0	6	6	0	6	1	7	0	6	7	13
MT	0	0	0	0	0	0	0	0	0	0	0	0
NE	0	0	1	1	6	1	2	9	6	1	3	10
NV	0	0	1	1	4	0	1	5	4	0	2	6
NH	0	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	27	15	1	43	28	15	1	44
NY	4	1	5	10	81	257	27	365	85	258	32	375
NC	0	0	4	4	299	28	13	340	299	28	17	344
ND	0	0	1	1	46	23	1	70	46	23	2	71
OH	0	0	8	8	143	220	56	419	143	220	64	427
OK	0	0	1 ⁱ	1 ^s	DNF	DNF	DNF	88 ^s	DNF	DNF	DNF	89
OR	0	0	0	0	0	0	0	0	0	0	0	0
PA	0	0	4	4	123	25	17	165	123	25	21	169
RI	2	0	0	2 ^{i,s}	0	0	1	1	2	0	1	3
SC	0	0	5	5	0	59	0	59	0	59	5	64
SD	0	0	1	1 ^s	0	0	1	1 ^s	0	0	2	2
TN	37	1	0	38	84	47	1	132	121	48	1	170
TX	2	0	13	15	736	41	3	780	738	41	16	795
UT	0	0	1	1	0	DNF	DNF	DNF	0	DNF	DNF	DNF
VT	0	0	0	0	1	0	0	1	1	0	0	1
VA	0	0	1	1	35	25	2	62	35	25	3	63
WA	0	0	4	4	4	1	0	5	4	1	4	9
WV	0	0	0	0	16	54	0	70	16	54	0	70
WI	0	0	3	3	0	2	2	4	0	2	5	7
WY	0	0	1	1	0	0	0	0	0	0	1	1
Reported US Total	59	51	107	217	2,438	1,698	280	5,681	2,497	1,749	387	5,898
Estimated US Total	60	51	108	219	3,661	1,730	327	5,718	3,721	1,781	435	5,937

DNF Did not furnish. ^d 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.

Table 2.9 People Living in an ICF/IID by Type of Operation, Setting Size and State on June 30, 2019

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	48	47	48	51	48	47	48	51
AL	0	0	0	0	0	15	0	15	0	15	0	15
AK	0	0	0	0	0	0	0	0	0	0	0	0
AZ	0	0	0	0	0	0	34	34	0	0	34	34
AR	0	0	917 ^{e,i}	917 ^{e,i}	0	317	201	518	0	317	1,118	1,435
CA	1	0	325 ^e	326 ^e	DNF	DNF	DNF ^e	6,804	DNF	DNF	DNF	7,130
CO	13	78	53	144	24	0	0	24	37	78	53	168
CT	4	0	320	324	307	33	0	340	311	33	320	664
DE	0	0	49	49	0	0	70	70	0	0	119	119
DC	0	0	0	0	308	0	0	308	308	0	0	308
FL	0	0	519	519	200	257	1,592	2,049	200	257	2,111	2,568
GA	0 ⁱ	0 ⁱ	153 ^{e,i}	153 ^s	0	0	112	112 ^s	0	0	265	265
HI	0	0	0	0	54	8	0	62	54	8	0	62
ID	0	14	0	14	DNF	DNF	0	418 ^s	DNF	DNF	0	432
IL	0	0	1,640	1,640	151	2,051	2,538	4,740	151	2,051	4,178	6,380
IN	0	0	0	0	771	2,260	50	3,081	771	2,260	50	3,081
IA	0	0	331	331	213	438	447	1,098	213	438	778	1,429
KS	0	0	300	300	66	40	0	106	66	40	300	406
KY	0	0	0	0	24	21	362	407	24	21	362	407
LA	0	0	497	497	1,513	1,949	531	3,993	1,513	1,949	1,028	4,490
ME	0	0	0	0	5	121	65	191	5	121	65	191
MD	0	0	93	93	0	0	0	0	0	0	93	93
MA	0	0	342	342	0	0	0	0	0	0	342	342
MI	0	0	0	0	0	0	0	0	0	0	0	0
MN	5	0	0	5	506	260	247	1,013	511	260	247	1,018
MS	38	503	842	1,383	0	0	870	870 ^s	38	503	1,712	2,253
MO	0	0	310	310	0	41 ^e	32	73 ^e	0	41	342	383
MT	0	0	0	0	0	0	0	0	0	0	0	0
NE	0	0	105	105	32	9	199	240	32	9	304	345
NV	0	0	40	40	24	0	18	42	24	0	58	82
NH	0	0	0	0	0	0	25	25	0	0	25	25
NJ	0	0	1,263	1,263 ^j	0	0	60	60	0	0	1,323	1,323
NM	4	0	0	4	98	155	16	269	102	155	16	273
NY	15	7	257	279	434	2,583	874	3,891	449	2,590	1,131	4,170
NC	0	0	1,026	1,026	1,775	521	685	2,981	1,775	521	1,711	4,007
ND	0	0	71	71	254	182	30	466	254	182	101	537
OH	0	0	629	629	752	1,732	2,058	4,542	752	1,732	2,687	5,171
OK	0	0	52 ⁱ	52 ^s	DNF	DNF	DNF	1,376 ^s	DNF	DNF	DNF	1,428
OR	0	0	0	0	0	0	0	0	0	0	0	0
PA	0	0	719	719	584	204	1,033	1,821	584	204	1,752	2,540
RI	10	0	0	10 ^s	0	0	30	30	10	0	30	40
SC	0	0	673	673	0	480	0	480	0	480	673	1,153
SD	0	0	114	114 ^s	0	0	67	67 ^s	0	0	181	181
TN	145 ^e	5 ^e	0	150 ^e	353 ^e	375 ^e	70 ^e	798 ^e	498	380	70	948
TX	10	0	2,915	2,925	3,964	429	204	4,597	3,974	429	3,119	7,522
UT	0	0	180	180	0	DNF	DNF	552 ^s	0	DNF	DNF	732
VT	0	0	0	0	6	0	0	6	6	0	0	6
VA	0	0	78	78	174	252	112	538	174	252	190	616
WA	0	0	623	623	18	12	0	30	18	12	623	653
WV	0	0	0	0	92	400	0	492	92	400	0	492
WI	0	0	298	298	0	13	72	85	0	13	370	383
WY	0	0	52	52	0	0	0	0	0	0	52	52
Reported US Total	245	607	15,786	16,638	12,702	15,158	12,704	49,714	12,947	15,765	28,490	66,352
Estimated US Total	251	607	15,874	16,732	19,303	15,907	14,548	49,758	19,554	16,514	30,422	66,485

DNF Did not furnish. ^a Other date (data from previous or next year). ^e Estimate. ^s Source (ACHA CASPER data, 2019) * See state notes in Appendix. Estimated by setting size and type are as of June 30, 2019.

Table 2.10 People Living in an ICF/IID Per 100,000 of the Population by Age and State in FY 2019

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	50	50	51	50	50	51
AL	14	35	49	0	15	15	0	0	0
AK*	2	5	7	DNF	DNF	14	DNF	DNF	2
AZ	20	52	73	2	117	119	0	2	2
AR	9	22	30	276	1,154	1,430	32	54	47
CA	110	285	395	208	7,101	7,309	2	25	18
CO	15	42	58	14	185	199	1	4	3
CT	9	26	36	2	672	674	0	25	19
DE	3	7	10	0	119	119	0	17	12
DC	2	5	7	2	306	308	1	57	44
FL	53	162	215	121	2,579	2,700	2	16	13
GA	31	75	106	33 ^s	232 ^s	265 ^l	1	3	2
HI	4	11	14	0	62	62	0	6	4
ID	5	12	18	23	55	78	4	4	4
IL	35	92	127	264	6,149	6,413	8	67	51
IN	20	48	67	267	2,814	3,081	14	59	46
IA	9	22	32	166	1,276	1,442	18	57	46
KS	9	20	29	7 ⁱ	399 ^{i,s}	406	1	20	14
KY	12	32	45	4	153	157	0	5	4
LA	13	33	46	311	3,953	4,264	23	120	92
ME	3	10	13	1	198	199	0	19	15
MD	16	44	60	4 ^{i,s}	87 ^s	91 ^s	0	2	2
MA	18	51	69	0	353	353	0	7	5
MI	27	73	100	0	0	0	0	0	0
MN	16	41	56	58	1,277	1,335	4	31	24
MS	9	21	30	227 ^s	2,010 ^s	2,237 ^l	26	96	75
MO	17	44	61	0	391	391	0	9	6
MT	3	8	11	0	0	0	0	0	0
NE	6	14	19	37	344	381	6	25	20
NV	8	22	31	6	76	82	1	3	3
NH	3	10	14	25	0	25	8	0	2
NJ	24	65	89	0	1,263	1,263	0	19	14
NM	6	15	21	18	249	267	3	17	13
NY	50	144	195	567	4,203	4,770	11	29	25
NC	29	76	105	475	3,636	4,111	16	48	39
ND	2	5	8	92	374	466	42	69	61
OH	32	85	117	452	4,719	5,171	14	56	44
OK	12	28	40	86 ^s	1,342 ^s	1,428	7	48	36
OR	11	31	42	0	0	0	0	0	0
PA	33	95	128	108	2,496	2,604	3	26	20
RI	3	8	11	16 ^s	21 ^s	37 ^s	6	3	3
SC	14	37	51	24	1,129	1,153	2	30	22
SD	3	6	9	89 ^s	92 ^s	181	34	15	20
TN	19	50	68	38	961	999	2	19	15
TX	91	199	290	1,182	7,086	8,268	13	36	29
UT	11	21	32	13	167	180	1	8	6
VT	2	5	6	1	5	6	1	1	1
VA	23	62	85	112	504	616	5	8	7
WA	20	56	76	0	428	428	0	8	6
WV	4	13	18	58 ^s	451 ^s	509 ^l	13	34	28
WI	16	42	58	2	381	383	0	9	7
WY	2	4	6	3	75	78	2	18	13
Reported US Total	907	2,375	3,282	5,394	61,659	67,067	6	26	20
Estimated US Total	907	2,375	3,282	5,466	62,032	67,498	6	26	21

DNF Did not furnish. aSource U.S. Census Bureau, Population Division (2019) for population data; ^d Other date (data from previous or next year). ^e Estimate. sACHA, 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.

Table 2.11 ICF/IID Expenditures, Recipients, Expenditure Per Person, and Expenditures Per State Resident by State in Fiscal Year 2019

State	ICF/IID Recipients	ICF/IID Expenditures	Expenditures per ICF/IID Recipient	State Population (100,000)s	Expenditures per State Resident (\$)
N States	51	51	48	51	51
AL	15	1,424,431	94,962	49	0
AK*	14	3,001,924	214,423	7	4
AZ	119	946,656	7,955	73	0
AR	1,430	155,447,068 ^s	108,704 ^s	30	52
CA	7,309	548,750,628	75,079	395	14
CO	199	48,315,059	242,789	58	8
CT	674	307,158,246	455,724	36	86
DE	119	32,702,197	274,808	10	34
DC	308	89,363,078	290,140	7	127
FL	2,700	331,590,954	122,811	215	15
GA	265 ⁱ	31,333,140 ^s	118,238 ⁱ	106	3
HI	62	8,203,830	132,320	14	6
ID	78	7,784,799	99,805	18	4
IL	6,413	607,588,464	94,743	127	48
IN	3,081	271,649,036	88,169	67	40
IA	1,442	400,593,401	277,804	32	127
KS	406	27,065,365	66,663	29	9
KY	157	36,578,422	232,984	45	8
LA	4,264	334,237,605	78,386	46	72
ME	199	43,648,150	219,337	13	32
MD	91 ^s	14,258,678 ^s	156,689 ⁱ	60	2
MA	353	102,257,338	289,681	69	15
MI	0	0	N/A	100	0
MN	1,335	106,380,245	79,686	56	19
MS	2,237 ⁱ	238,465,158 ^s	106,600 ⁱ	30	80
MO	391	83,969,348	214,755	61	14
MT	0	0	N/A	11	0
NE	381	64,374,783	168,963	19	33
NV	82	14,941,553	182,214	31	5
NH	25	4,128,098	165,124	14	3
NJ	1,263	431,747,571	341,843	89	49
NM	267	28,890,543	108,204	21	14
NY	4,770	985,696,836	206,645	195	51
NC	4,111	568,064,638	138,182	105	54
ND	466	89,713,481	192,518	8	118
OH	5,171	704,651,325	136,270	117	60
OK	1,428	81,821,526 ^s	57,298 ^s	40	21
OR	0	0	N/A	42	0
PA	2,604	580,767,082	223,029	128	45
RI	37 ^s	11,069,477 ^s	299,175 ^s	11	10
SC	1,153	149,615,641	129,762	51	29
SD	181	31,709,944 ^s	175,193 ^s	9	36
TN	999	198,048,295	198,247	68	29
TX	8,268	1,015,874,142	122,868	290	35
UT	180	42,429,604	235,720	32	13
VT	6	1,132,206	188,701	6	2
VA	616	186,761,581 ^s	303,184 ^s	85	22
WA	428	125,993,123	294,376	76	17
WV	509 ⁱ	71,071,746 ^s	139,630 ^{i,s}	18	40
WI	383	113,912,238	297,421	58	20
WY	78	20,592,936 ^e	264,012 ^e	6	36
Reported US Total	67,067	9,355,721,588	139,498	3,282	29
Estimated US Total	67,498	9,463,885,494	140,210	3,282	29

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

Table 2.12 Annual ICF/IID Recipients, Expenditures and Expenditures Per Person by Age and State in Fiscal Year 2019

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	50	50	40	40	31	37
AL	0	15	0	1,424,431	N/A	94,962
AK	DNF	DNF	DNF	DNF	DNF	DNF
AZ	2	117	58,140	888,516	29,070	7,594
AR	276	1,154	DNF	DNF	DNF	DNF
CA	208	7,101	12,384,099	536,366,529	59,539	75,534
CO	14	185	3,024,193	45,290,867	216,014	244,816
CT *	2	672	911,449	306,246,797	455,724	455,724
DE	0	119	0	32,702,197	N/A	274,808
DC	2	306	0	89,363,078	0	292,036
FL	121	2,579	13,527,778	318,063,176	111,800	123,328
GA	33 ^s	232 ^s	DNF	DNF	DNF	DNF
HI	0	62	0	8,203,830	N/A	132,320
ID *	23	55	1,485,158	6,299,641	64,572	114,539
IL	264	6,149	18,494,784	589,093,680	70,056	95,803
IN	267	2,814	25,583,571	246,065,465	95,819	87,443
IA	166	1,276	27,139,623	373,453,778	163,492	292,675
KS	7 ⁱ	399 ^{i,s}	DNF	DNF	0	0
KY	4	153	937,448	35,640,974	234,362	232,948
LA	311	3,953	31,355,371	302,882,234	100,821	76,621
ME	1	198	286,445	43,361,705	286,445	218,999
MD	4 ^{i,s}	87 ^s	DNF	DNF	DNF	DNF
MA	0	353	0	102,257,338	N/A	289,681
MI	0	0	0	0	N/A	N/A
MN	58	1,277	4,932,474	101,447,771	85,043	79,442
MS	227 ^s	2,010 ^s	DNF	DNF	DNF	DNF
MO	0	391	0	83,969,348	N/A	214,755
MT	0	0	0	0	N/A	N/A
NE	37	344	4,655,765	59,719,019	125,831	173,602
NV	6	76	990,862	13,950,691	165,144	183,562
NH	25	0	4,128,098	0	165,124	N/A
NJ	0	1,263	0	431,747,571	N/A	341,843
NM	18	249	1,944,717	26,945,826	108,040	108,216
NY	567	4,203	118,486,658	867,210,178	208,971	206,331
NC	475	3,636	50,422,014	517,642,624	106,152	142,366
ND	92	374	DNF	DNF	DNF	DNF
OH	452	4,719	61,547,305	643,104,020	136,167	136,280
OK	86 ^s	1,342 ^s	DNF	DNF	DNF	DNF
OR	0	0	0	0	N/A	N/A
PA	108	2,496	23,185,003	557,582,079	214,676	223,390
RI	16 ^s	21 ^s	4,208,101	3,593,860	263,006 ^s	171,136 ^s
SC	24	1,129	3,149,409	146,466,232	131,225	129,731
SD	89 ^s	92 ^s	DNF	DNF	DNF	DNF
TN	38	961	5,279,408	192,768,887	138,932	200,592
TX	1,182	7,086	151,939,266	863,934,876	128,544	121,921
UT	13	167	3,064,360	39,365,244	235,720	235,720
VT	1	5	188,701	943,505	188,701	188,701
VA	112	504	DNF	DNF	DNF	DNF
WA	0	428	0	125,993,123	N/A	294,376
WV	58 ^s	451 ^s	DNF	DNF	DNF	DNF
WI	2	381	83,347	113,828,891	41,674	298,763
WY	3	75	580,826 ^e	20,012,110 ^e	193,609 ^e	266,828 ^e
Reported Total	5,394	61,659	573,974,372	7,847,830,089		
Estimated US Total	5,466	62,032	596,626,913	7,813,546,650	125,579	139,468

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

Table 2.13 ICF/IID and Medicaid Waiver Recipients and Expenditures Total and Percent by Funding Authority and State in FY 2019

State	Total ICF/IID + Waiver		% of Recipients		% of Expenditures	
	Recipients	Expenditures (\$)	Waiver	ICF/IID	Waiver	ICF/IID
N States	50	51	50	50	51	51
AL	6,059	352,147,187	100%	0%	100%	0%
AK	2,444	184,937,395	99%	1%	98%	2%
AZ	35,028	1,179,136,908	100%	0%	100%	0%
AR	6,167	336,436,057	77%	23%	54%	46%
CA	138,420	4,361,010,813	95%	5%	87%	13%
CO	13,432	584,077,449	99%	1%	92%	8%
CT	10,602	1,100,796,258	94%	6%	72%	28%
DE	1,764	187,490,686	93%	7%	83%	17%
DC	2,345	344,132,118	87%	13%	74%	26%
FL	37,428	1,563,553,608	93%	7%	79%	21%
GA	13,635	728,334,447	98%	2%	96%	4%
HI	3,007	153,177,542	98%	2%	95%	5%
ID	8,869	293,319,933	99%	1%	97%	3%
IL	30,001	1,604,359,116	79%	21%	62%	38%
IN	32,404	961,731,336	90%	10%	72%	28%
IA	15,094	1,078,267,299	90%	10%	63%	37%
KS	9,839	430,408,097	96%	4%	94%	6%
KY	15,108	749,359,903	99%	1%	95%	5%
LA	17,120	842,839,079	75%	25%	60%	40%
ME	5,830	494,352,175	97%	3%	91%	9%
MD	15,379	1,075,771,555	99%	1%	99%	1%
MA	17,399	1,658,453,725	98%	2%	94%	6%
MI	49,589	1,983,102,032	100%	0%	100%	0%
MN	24,465	1,780,868,613	95%	5%	94%	6%
MS	4,952	359,350,986	55%	45%	34%	66%
MO	15,796	1,118,200,904	98%	2%	92%	8%
MT	2,656	121,785,576	100%	0%	100%	0%
NE	5,161	393,245,785	93%	7%	84%	16%
NV	2,396	139,936,594	97%	3%	89%	11%
NH	7,152	278,216,539	100%	0%	99%	1%
NJ	20,992	1,849,988,694	94%	6%	77%	23%
NM	4,912	417,557,094	95%	5%	93%	7%
NY	91,843	7,497,274,244	95%	5%	87%	13%
NC	33,951	1,835,596,930	88%	12%	69%	31%
ND	5,561	302,270,325	92%	8%	70%	30%
OH	46,020	2,540,337,252	89%	11%	72%	28%
OK	6,749	395,158,696	79%	21%	79%	21%
OR	28,170	144,885,089	100%	0%	100%	0%
PA	39,542	3,991,888,166	93%	7%	85%	15%
RI	3,998	269,214,194	99%	1%	96%	4%
SC	12,037	573,696,929	90%	10%	74%	26%
SD	DNF	166,352,066	DNF	DNF	81%	19%
TN	11,555	965,975,885	91%	9%	79%	21%
TX	47,314	2,481,847,645	83%	17%	59%	41%
UT	6,033	336,736,149	97%	3%	87%	13%
VT	3,194	219,054,090	100%	0%	99%	1%
VA	14,959	1,164,820,571	96%	4%	84%	16%
WA	19,319	744,951,063	98%	2%	83%	17%
WV	6,125	370,209,774	92%	8%	81%	19%
WI	39,447	1,601,668,972	99%	1%	93%	7%
WY	2,434	130,942,560	97%	3%	84%	16%
Reported Total	993,877	54,439,226,104	93%	7%	83%	17%
Estimated US Total	997,854	54,547,390,010	93%	7%	83%	17%

^d 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).

Table 2.14a FY 2019 Medicaid Expenditures for People with IDD, Federal Matching Percentage, and Federal Share by Funding Authority and State

State	Total FY 2019 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 ^s	1,424,431	352,147,187	72%	252,099,517	1,023,881	253,123,398
AK	181,935,470	3,001,924	184,937,395	50%	90,967,735	1,500,962	92,468,697
AZ	1,178,190,252	946,656	1,179,136,908	70%	822,494,615	660,861	823,155,475
AR	180,988,989	155,447,068 ^s	336,436,057	71%	127,615,336	109,605,728	237,221,064
CA	3,812,260,185	548,750,628	4,361,010,813	50%	1,906,130,092	274,375,314	2,180,505,406
CO	535,762,390	48,315,059	584,077,449	50%	267,881,195	24,157,530	292,038,725
CT	793,638,013	307,158,246	1,100,796,258	50%	396,819,006	153,579,123	550,398,129
DE	154,788,489	32,702,197	187,490,686	58%	89,080,775	18,820,114	107,900,890
DC	254,769,040	89,363,078	344,132,118	70%	178,338,328	62,554,155	240,892,483
FL	1,231,962,654	331,590,954	1,563,553,608	61%	749,895,667	201,839,414	951,735,081
GA	697,001,307 ^s	31,333,140 ^s	728,334,447	68%	471,312,284	21,187,469	492,499,753
HI	144,973,712	8,203,830	153,177,542	54%	78,169,825	4,423,505	82,593,331
ID	285,535,135	7,784,799	293,319,933	71%	203,101,141	5,537,327	208,638,469
IL	996,770,652	607,588,464	1,604,359,116	50%	501,475,315	305,677,756	807,153,071
IN	690,082,300	271,649,036	961,731,336	66%	455,178,285	179,179,704	634,357,989
IA	677,673,898	400,593,401	1,078,267,299	60%	406,129,967	240,075,625	646,205,593
KS	403,342,732	27,065,365	430,408,097	57%	230,308,700	15,454,323	245,763,023
KY	712,781,481	36,578,422	749,359,903	72%	510,850,487	26,215,755	537,066,243
LA	508,601,474	334,237,605	842,839,079	65%	330,590,958	217,254,443	547,845,401
ME	450,704,025	43,648,150	494,352,175	65%	290,794,237	28,161,786	318,956,023
MD	1,061,512,877	14,258,678 ^s	1,075,771,555	50%	530,756,439	7,129,339	537,885,778
MA	1,556,196,387	102,257,338	1,658,453,725	50%	778,098,194	51,128,669	829,226,863
MI	1,983,102,032	0	1,983,102,032	64%	1,278,109,260	0	1,278,109,260
MN	1,674,488,369	106,380,245	1,780,868,613	50%	837,244,184	53,190,122	890,434,307
MS	120,885,828	238,465,158 ^s	359,350,986	76%	92,344,684	182,163,534	274,508,218
MO	1,034,231,556	83,969,348	1,118,200,904	65%	676,387,438	54,915,954	731,303,391
MT	121,785,576	0	121,785,576	66%	79,818,267	0	79,818,267
NE	328,871,002	64,374,783	393,245,785	53%	172,920,373	33,848,261	206,768,634
NV	124,995,041	14,941,553	139,936,594	65%	81,084,283	9,692,585	90,776,869
NH	274,088,441	4,128,098	278,216,539	50%	137,044,221	2,064,049	139,108,270
NJ	1,418,241,123	431,747,571	1,849,988,694	50%	709,120,562	215,873,786	924,994,347

Table 2.14a FY 2019 Medicaid Expenditures for People with IDD, Federal Matching Percentage, and Federal Share by Funding Authority and State

State	Total FY 2019 Expenditures			Federal Matching Percentage (%) ¹	Federal Share of Total Expenditures (\$)		
	Waiver (\$)	ICF/IID (\$)	Combined		Waiver	ICF/IID	Combined
NM	388,666,551	28,890,543	417,557,094	72%	280,850,450	20,876,306	301,726,756
NY	6,511,577,408	985,696,836	7,497,274,244	50%	3,255,788,704	492,848,418	3,748,637,122
NC	1,267,532,292	568,064,638	1,835,596,930	67%	851,274,687	381,512,211	1,232,786,898
ND	212,556,844 ^s	89,713,481	302,270,325	50%	106,278,422	44,856,741	151,135,163
OH	1,835,685,927	704,651,325	2,540,337,252	63%	1,158,134,251	444,564,521	1,602,698,772
OK	313,337,170	81,821,526 ^s	395,158,696	62%	195,459,727	51,040,268	246,499,995
OR	144,885,089	0	144,885,089	63%	90,640,111	0	90,640,111
PA	3,411,121,084	580,767,082	3,991,888,166	52%	1,782,310,766	303,450,800	2,085,761,567
RI	258,144,717	11,069,477 ^s	269,214,194	53%	135,706,678	5,819,224	141,525,902
SC	424,081,288	149,615,641	573,696,929	71%	302,030,693	106,556,260	408,586,953
SD	134,642,122 ^s	31,709,944 ^s	166,352,066	57%	76,355,547	17,982,709	94,338,257
TN	767,927,591	198,048,295	965,975,885	66%	505,833,904	130,454,412	636,288,316
TX	1,465,973,503	1,015,874,142	2,481,847,645	58%	853,049,981	591,137,163	1,444,187,145
UT	294,306,545	42,429,604	336,736,149	70%	205,161,093	29,577,677	234,738,769
VT	217,921,884	1,132,206	219,054,090	54%	117,438,103	610,146	118,048,249
VA	978,058,990 ^s	186,761,581 ^s	1,164,820,571	50%	489,029,495	93,380,791	582,410,286
WA	618,957,940	125,993,123	744,951,063	50%	309,478,970	62,996,562	372,475,532
WV	299,138,028 ^s	71,071,746 ^s	370,209,774	74%	222,379,210	52,834,736	275,213,946
WI	1,487,756,734	113,912,238	1,601,668,972	59%	883,281,173	67,629,696	950,910,869
WY	110,349,624 ^e	20,592,936 ^e	130,942,560	50%	55,174,812	10,296,468	65,471,280
Reported Total	45,083,504,516⁰	9,355,721,588⁰	54,439,226,104	50%	22,541,752,258	4,677,860,794	27,219,613,052
Estimated US Total/Average	45,083,504,516	9,463,885,494	54,547,390,010	55%	24,795,927,484	5,205,137,022	30,001,064,506

⁰ 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 2019 State Medicaid Expenditures, Federal Income Taxes, and State Medicaid Benefit Ratios by Funding Authority and State

State	State Proportion of Total Federal Expenditures			Federal Business and Individual income Tax Paid		State Medicaid Benefit Ratio ²
	Medicaid Waiver	ICF/IID	Combined	Billions (\$) ⁵	Percent (%)	
N states	51	51	51	51	51	51
AL	1	0	1	26	0.8	1.11
AK	0	0	0	5	0.2	2.01
AZ	3	0	3	46	1.3	2.06
AR	1	2	1	30	0.9	0.91
CA	8	5	7	464	13.5	0.54
CO	1	0	1	59	1.7	0.57
CT	2	3	2	55	1.6	1.15
DE	0	0	0	20	0.6	0.63
DC	1	1	1	27	0.8	1.01
FL	3	4	3	206	6.0	0.53
GA	2	0	2	90	2.6	0.63
HI	0	0	0	9	0.3	1.06
ID	1	0	1	11	0.3	2.13
IL	2	6	3	158	4.6	0.59
IN	2	3	2	58	1.7	1.25
IA	2	5	2	25	0.7	3.02
KS	1	0	1	25	0.7	1.15
KY	2	1	2	34	1.0	1.81
LA	1	4	2	39	1.1	1.62
ME	1	1	1	8	0.2	4.54
MD	2	0	2	78	2.3	0.79
MA	3	1	3	118	3.4	0.81
MI	5	0	4	81	2.3	1.82
MN	3	1	3	99	2.9	1.04
MS	0	3	1	11	0.3	2.84
MO	3	1	2	62	1.8	1.35
MT	0	0	0	6	0.2	1.45
NE	1	1	1	25	0.7	0.94
NV	0	0	0	23	0.7	0.45
NH	1	0	0	12	0.3	1.35
NJ	3	4	3	137	4.0	0.78
NM	1	0	1	9	0.3	3.76
NY	13	9	12	301	8.7	1.43
NC	3	7	4	87	2.5	1.62
ND	0	1	1	7	0.2	2.64
OH	5	9	5	140	4.1	1.32
OK	1	1	1	25	0.7	1.12
OR	0	0	0	34	1.0	0.31
PA	7	6	7	138	4.0	1.73
RI	1	0	0	14	0.4	1.15
SC	1	2	1	27	0.8	1.72
SD	0	0	0	8	0.2	1.36
TN	2	3	2	68	2.0	1.08
TX	3	11	5	268	7.8	0.62
UT	1	1	1	24	0.7	1.14
VT	0	0	0	4	0.1	3.03
VA	2	2	2	83	2.4	0.81
WA	1	1	1	98	2.9	0.43
WV	1	1	1	7	0.2	4.57
WI	4	1	3	52	1.5	2.10
WY	0	0	0	4	0.1	1.67
Estimated US Total/Average	100	100	100	3448	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.

Figure 2.1 Funding Authorities Used by States to Provide LTSS to People with IDD on June 30, 2019

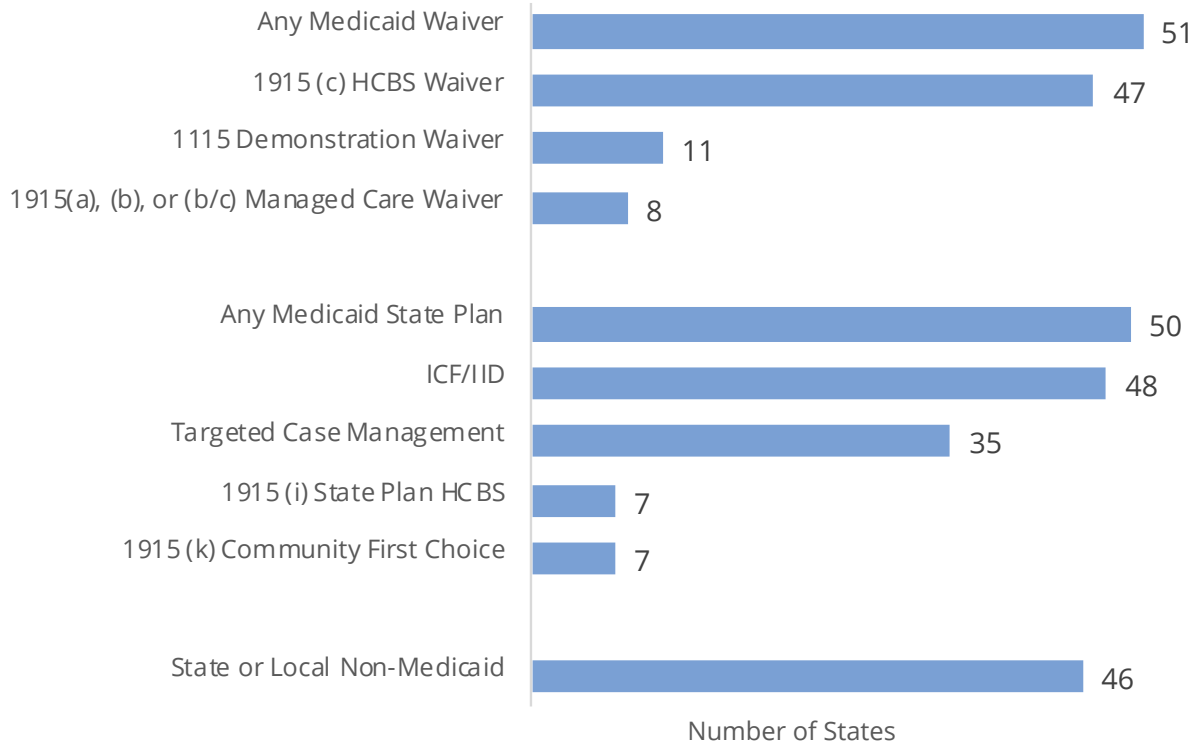
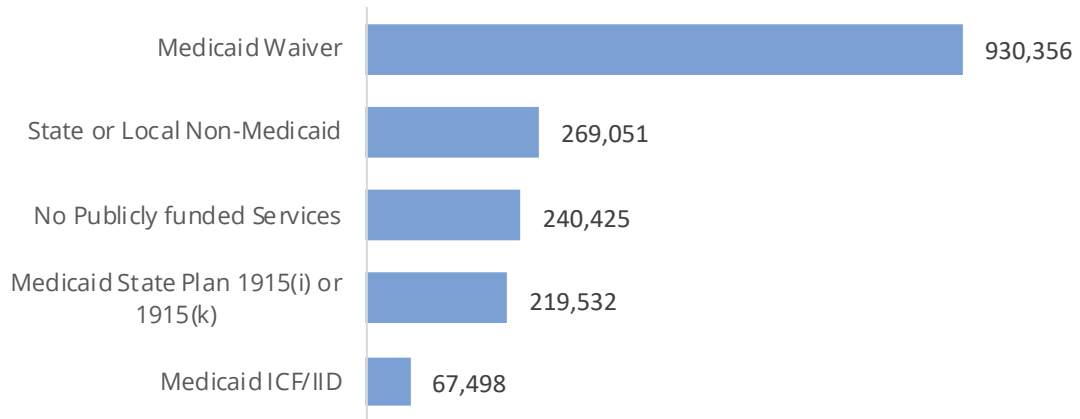


Figure 2.2 Estimated LTSS Recipients with IDD by Funding Authority on June 30, 2019



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

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 2019; and Percent Growth Needed to Serve Those Waiting

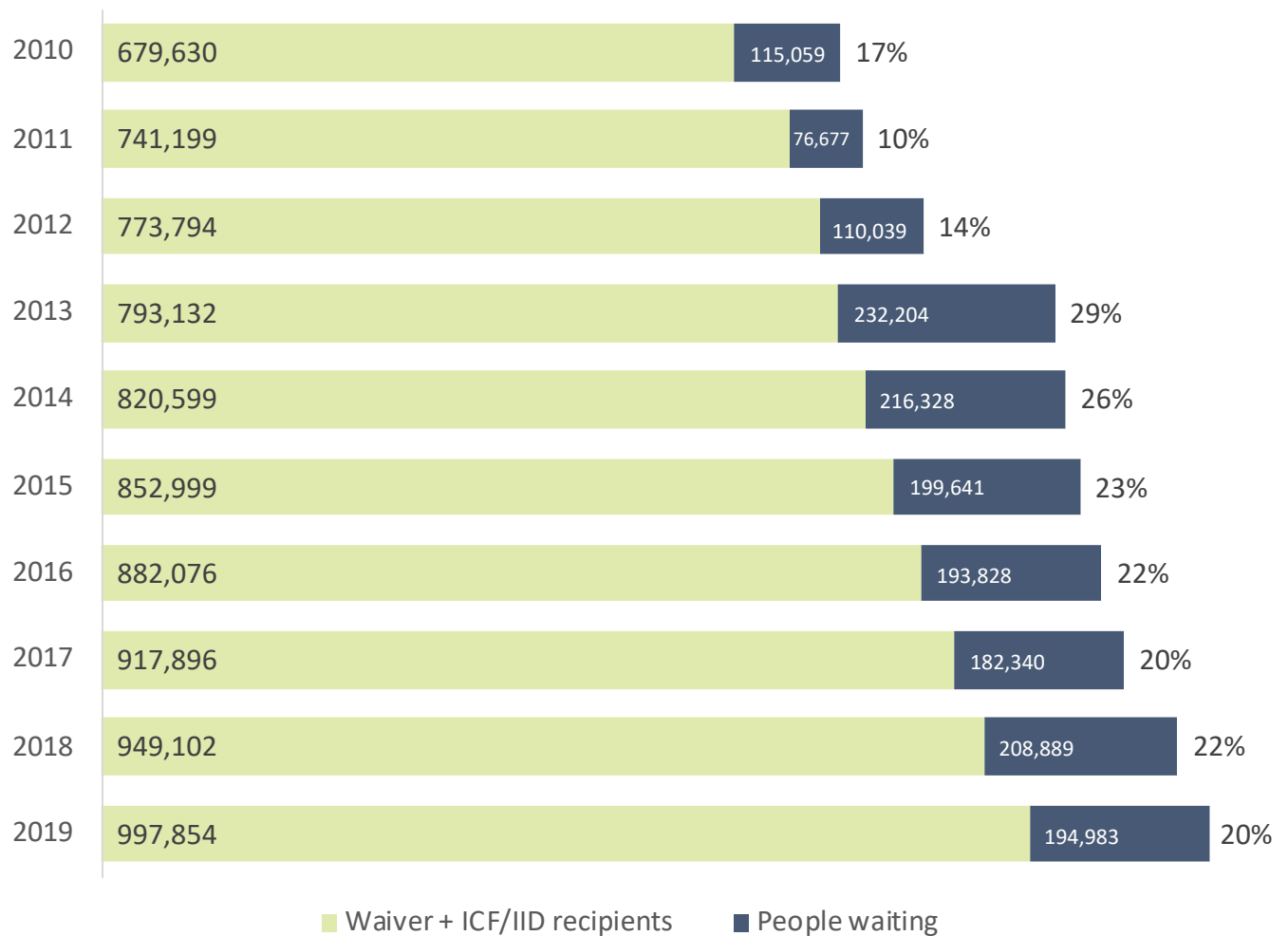
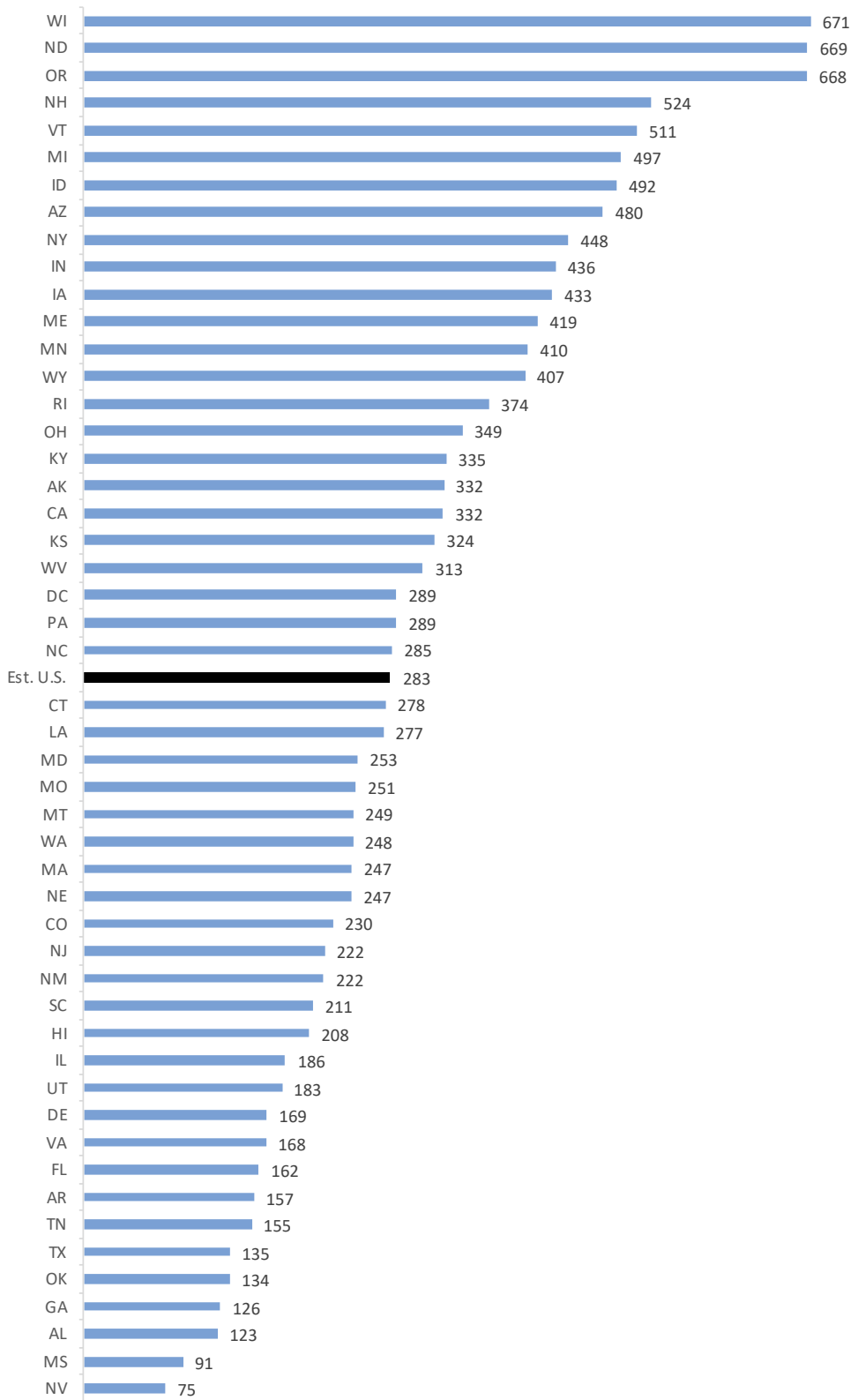
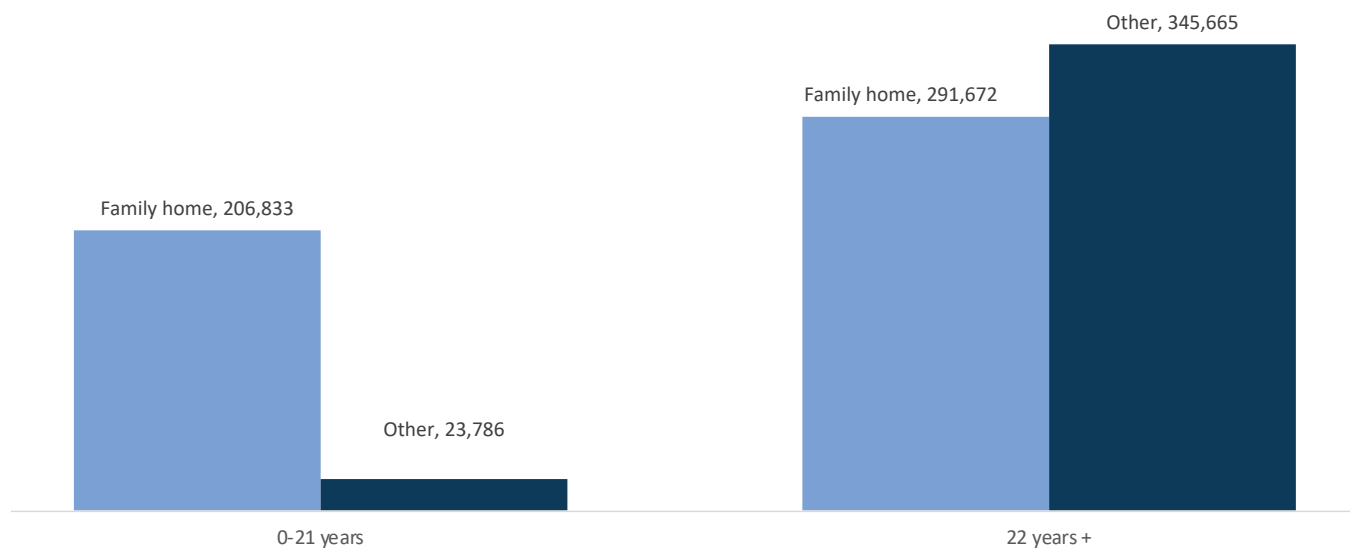


Figure 2.4 Wavier Recipients with IDD Per 100,000 of the Population by State in FY 2019



South Dakota did not report the number of Wavier Recipients for 2019

Figure 2.5 Estimated Number of Waiver Recipients With IDD Living With A Family Member or In Another Setting by Age on June 30, 2019



An estimated 40,073 Waiver recipients are not accounted for on this graph.

Figure 2.6 Annual Medicaid Waiver Expenditures for People with IDD per State Resident by State FY 2019

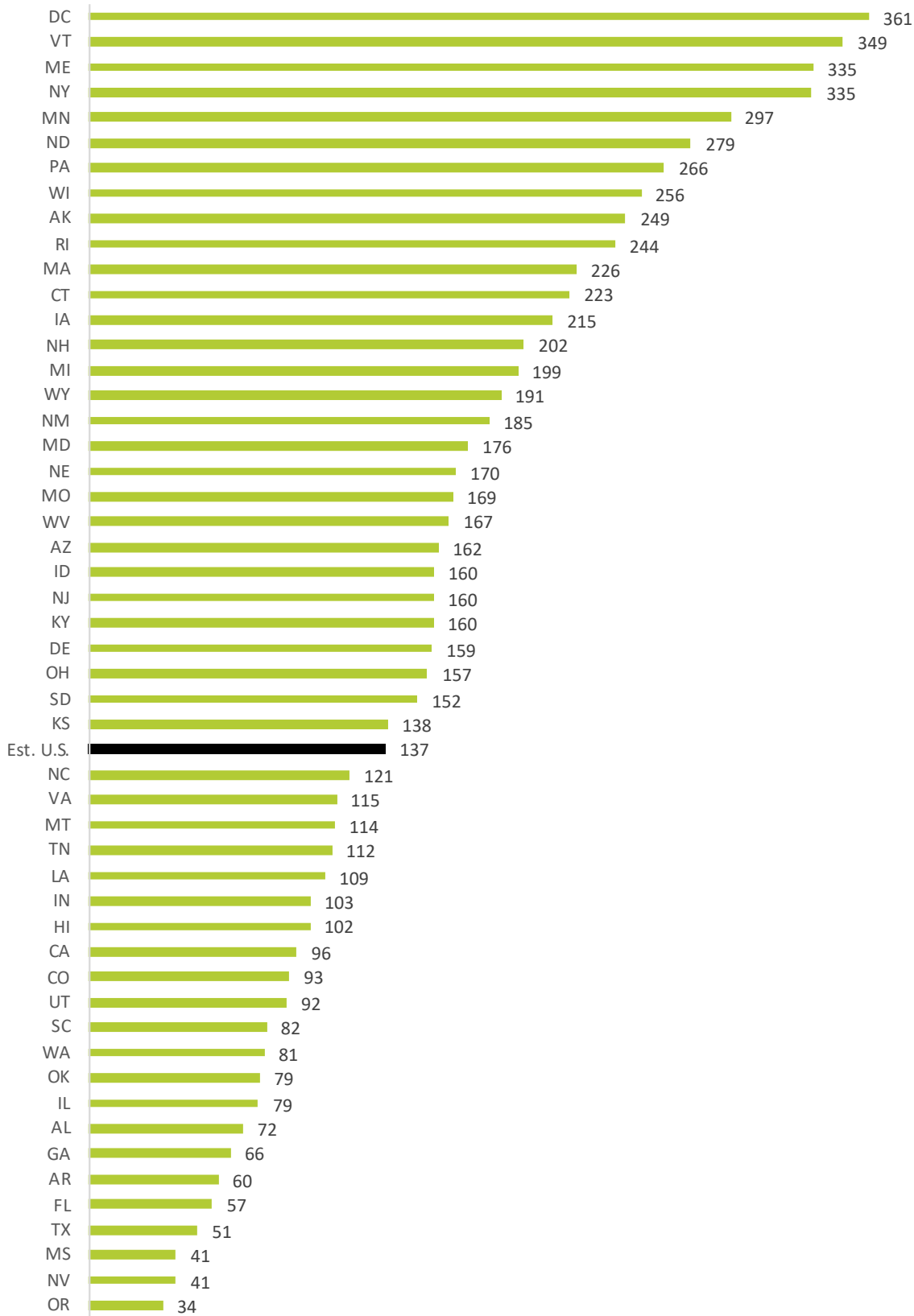
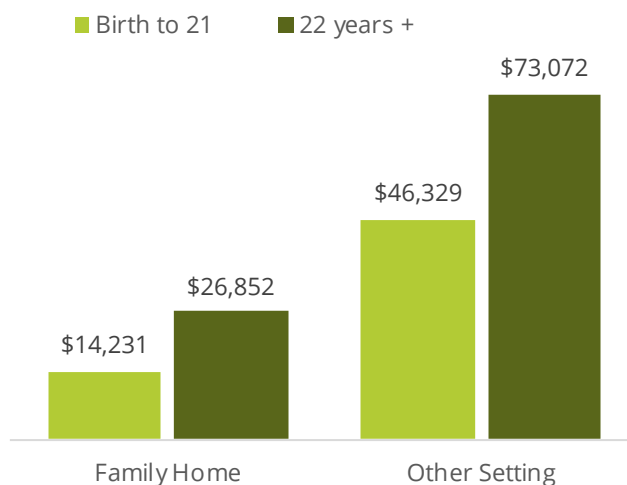
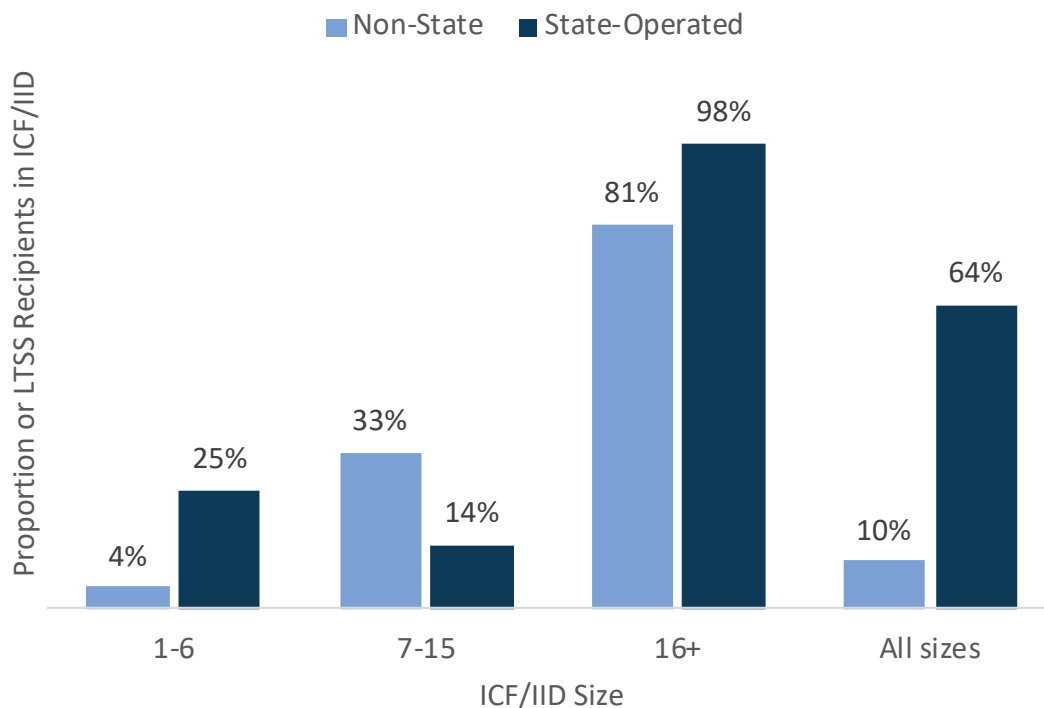


Figure 2.7 Estimated Average Annual Per Person Medicaid Waiver Expenditures by Age and Living Arrangement in FY 2019



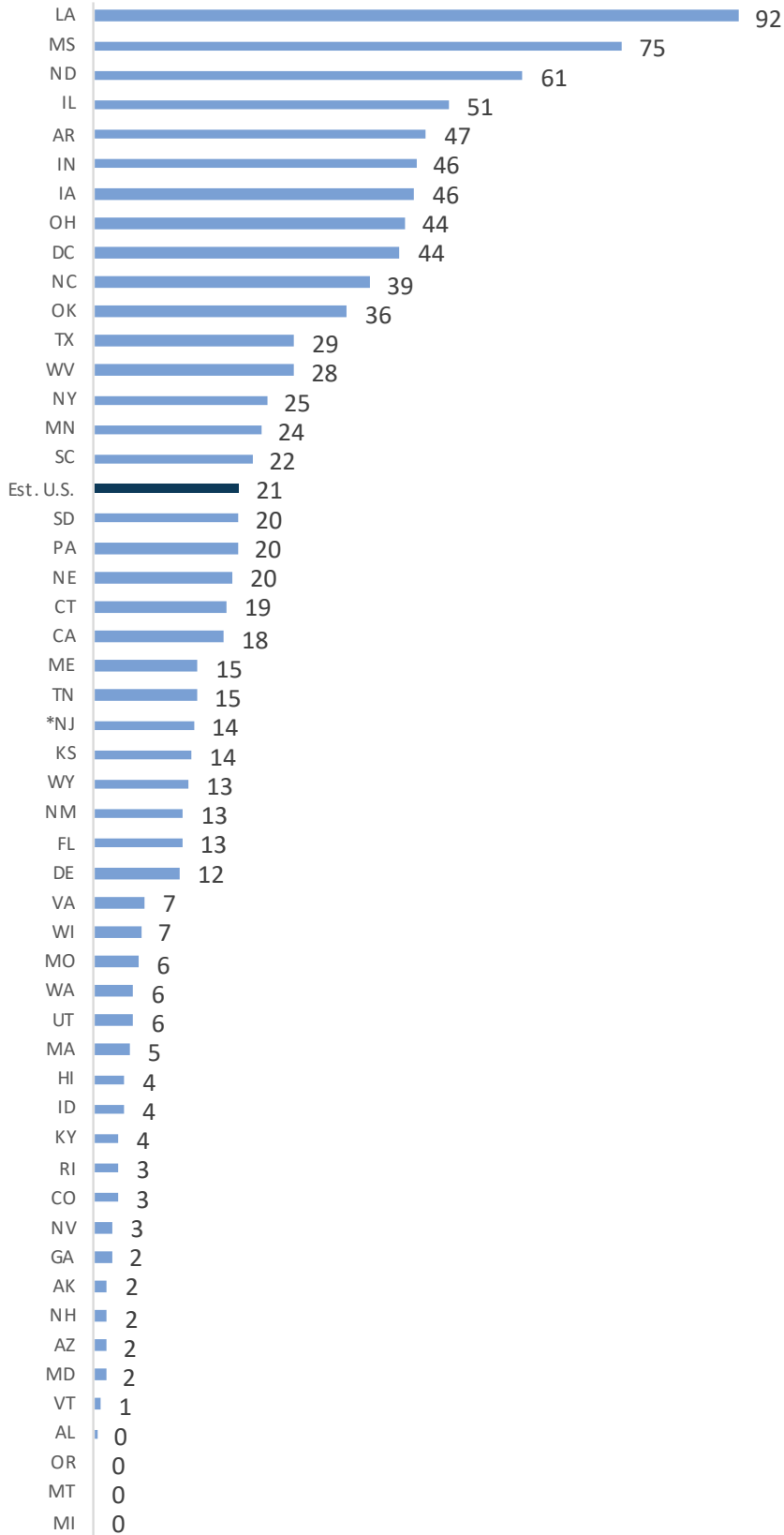
These US estimates are based on 32 states providing complete age and residential setting breakdowns for Waiver recipients and expenditures.

Figure 2.8 Proportion of LTSS Recipients not living with family members who live in an ICF/IID by Type of Operation and Setting Size on June 30, 2019



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.

Figure 2.9 ICF/IID Residents Per 100,000 of the Population by State in FY 2019



ICF/IID Intermediate Care Facility for Individuals with Intellectual Disabilities

Figure 2.10 Distribution of ICF/IID and Waiver Expenditures and Recipients in FY 2019

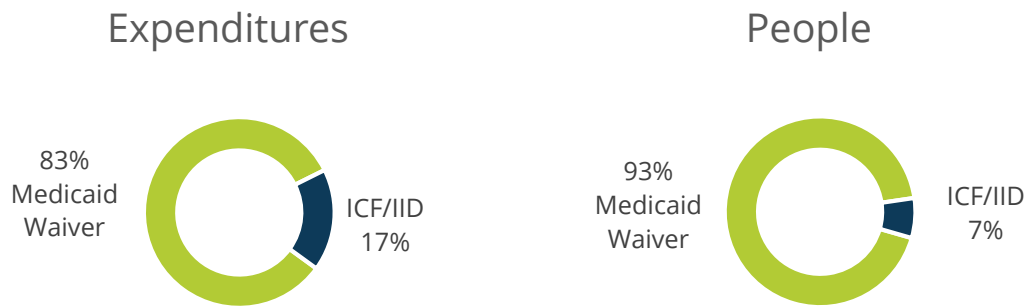


Figure 2.11 Estimated Medicaid LTSS Recipients with IDD by Age, Funding Authority and Living Arrangement in FY 2019

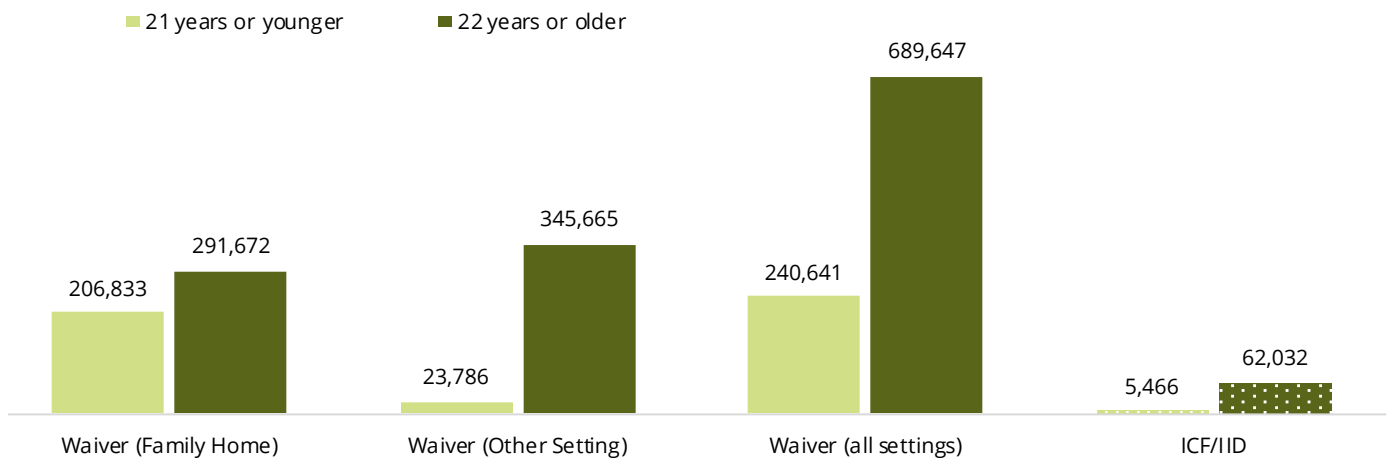
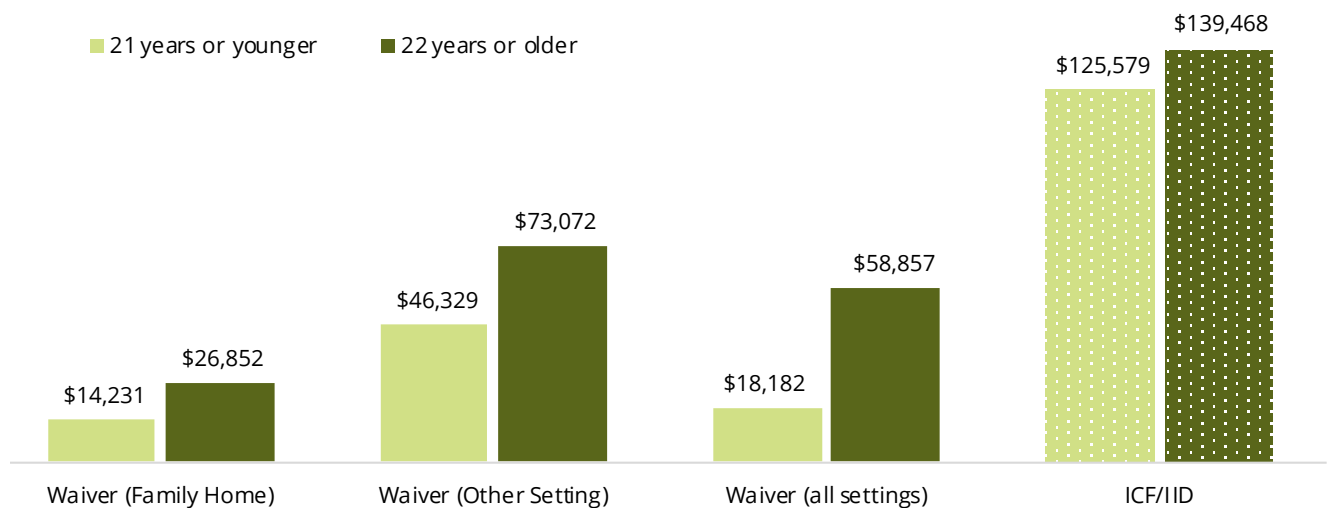


Figure 2.12 Estimated Annual Per Person Medicaid Expenditures by Age, Funding Authority and Living Arrangement in FY 2019



SECTION 3 TRENDS IN LONG-TERM SUPPORTS AND SERVICES

Section 3 describes trends in LTSS recipients and expenditures for people with IDD.

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

Between 1998 and 2019, the total number of LTSS recipients with IDD more than doubled increasing from 639,691 to 1,401,640 (See **Figure 3.1**). The number of LTSS recipients with IDD living in

- The home of a family member increased from 325,650 to 849,104 people.
 - Of the people living with a family member, the proportion who received Medicaid Waiver funded supports increased from 25% to 59%.
- A home of their own increased from 62,669 to 153,079 people
- A host/foster home or IDD group setting of three or fewer people increased from 63,279 to 148,605 people
- An IDD group setting of 4 to 6 people increased from 73,658 to 137,809 people
- An IDD group setting of 7 to 15 people decreased from 53,940 to 52,815 people
- An IDD facility, Nursing Home, or Psychiatric Facility of 16 or more people decreased from 114,495 to 60,228 people

How have IDD residential settings changed?

Between 1977 and 2019, the number of places other than the home of a family member in which LTSS recipients with IDD lived increased from 11,008 to 236,915 settings (See **Table 3.1**).

- The proportion of settings in which six or fewer people lived increased from 63% (6,898 facilities) to 97% (228,837 facilities)
- The number of settings operated by a non-state entity increased from 10,543 to 234,989.
- The proportion non-state settings serving six or fewer people increased from 65% (6,855 facilities) to 97% (227,487 facilities).
- The number of state-run settings increased from 465 to 1,926.

- The proportion state-run settings serving six or fewer people increased from 9% (43 facilities) to 70% (1,350 facilities).

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

Between 1977 and 2019, the number of LTSS recipients living in non-family IDD settings increased from 247,780 to 526,517 people (See Table 3.2). The number (and proportion) living in settings of

- 6 or fewer people increased from 20,400 (8%) to 439,329 (83%)
- 7 to 15 people increased from 20,024 (8%) to 52,979 (10%)
- 16 or more people decreased from 207,356 (84%) to 34,209 (6%).

Between 1977 and 2019, the average size of all non-family IDD settings declined from 22.5 to 2.2 people per setting. The average size of

- State-run IDD settings declined from 335.1 to 13.6 people per setting.
- Non-state IDD settings declined from 8.7 to 2.1 people per setting.

What are the trends in the use of state-run IDD settings?

- The proportion of people with IDD living in state-run IDD settings declined from 63% (155,804 people) in 1977 to 5% (26,175 people) in 2019 (See **Figure 3.2**).
- Of people living in an IDD facility of 16 or more people, the proportion living in a state-run setting decreased from 75% in 1977 to 47% in 2019 (See **Figure 3.3**).
 - If the number of people living in state-run settings of 16 or more people continues to decline at the rate it did from 2000 through 2019, there will be no people in those settings by 2028 (See **Figure 3.4**).

- If the number of people living in non-state settings of 16 or more people continue to decline at the rate from 2000 through 2019, there will be no people in those settings by 2045.

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

Between 1980 and 2019, the proportion of Medicaid expenditures for ICF/IID and Waiver funded services for people with IDD decreased from 11.9% to 8.9% (See **Table 3.3**).

Between 1982 and 2019, the number of people with IDD on June 30

- Receiving Medicaid Waiver funded supports increased from 1,381 to 908,029 people (See **Table 3.4**).
- In a Medicaid ICF/IID setting declined from 140,752 to 66,485 people (See **Table 3.6**).

Between 1982 and 2019,

- Annual Medicaid Waiver expenditures increased from \$5.9 million to \$45.1 billion in 2019 inflation adjusted dollars (See **Table 3.5** and **Figure 3.5b**)

- Annual ICF/IID expenditures from \$8.9 billion to \$9.5 billion in 2019 inflation adjusted dollars (See **Table 3.7** and **Figure 3.5b**).

In 2019 inflation adjusted dollars, between 1982 and 2019, average annual per person Medicaid expenditures for

- Waiver funded services for people with IDD increased from \$4,305 to \$48,458 (See **Figure 3.5c**).
- ICF/IID services for people with IDD increased from \$63,086 to \$140,210.

In 2019 inflation adjusted dollars,

- In 1982, annual per person ICF/IID expenditures (\$63,086) were 14.6 times higher than annual per person Waiver expenditures (\$4,305).
- By 2019, annual per person ICF/IID expenditures (\$140,210) were 2.89 times higher than annual per person Waiver expenditures (\$48,458).

Expenditures for Medicaid ICF/IID and Waiver funded services differ in important ways. For example, Medicaid Waiver expenditures exclude room and board costs while those expenditures are included for ICF/IID.

Table 3.1 Non-Family IDD Residences by Type of Operation and Setting Size on June 30 of Selected Years 1977 to 2019

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%

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.

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 2019

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%
1998	197,602	47,296	36,599	285,542	69%	4,720	6,646	51,485	62,851	8%	202,266	53,942	87,735	348,394	58%
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%

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.

Table 3.3 Medicaid Expenditures for ICF/IID and Waiver Recipients with IDD as a Proportion of All Medicaid Expenditures Select Years 1980 to 2019

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	\$420	\$43	10%
2013	\$438	\$42	10%
2014	\$480	\$42	9%
2015	\$527	\$44	8%
2016	\$549	\$46	8%
2017	\$577	\$48	8%
2018	\$586	\$49	8%
2019	\$614	\$55	9%

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

Table 3.4 Estimated Medicaid Waiver Recipients with IDD by State on June 30 Selected Years, 1982 to 2019

State	1982	1987	1992	1997	2002	2007	2012	2017	2018	2019	% Change 2012 vs 2019
AL	0	1,570	2,184	3,713	4,764	5,230	5,604	5,622	3,895	6,029	8%
AK	0	0	0	353	884	1,011	1,703	2,093	2,167	2,430	43%
AZ	0	0	4,832	8,508	13,471	19,066	24,617	30,982	33,154	34,325	39%
AR	0	0	415	496	2,494	3,342	4,037	4,138	4,365	4,737	17%
CA	0	3,027	3,360	37,478	44,205	73,024	97,868	124,081	117,014	109,502	12%
CO	0	1,389	2,204	4,276	6,516	7,148	8,147	12,184	12,657	12,770	57%
CT	0	0	1,693	3,371	5,972	7,692	8,638	9,979	9,885	9,928	15%
DE	0	81	290	379	547	788	855	1,031	1,211	1,581	85%
DC	0	0	0	0	225	1,090	1,479	1,796	2,027	2,037	38%
FL	0	2,631	2,637	11,399	25,921	31,425	29,353	33,812	34,556	34,728	18%
GA	0	0	359	2,332	8,190	9,194	11,621	8,579	8,579	13,370	15%
HI	0	56	452	560	1,560	2,481	2,544	2,367	2,832	2,867	13%
ID	0	55	225	434	1,139	2,015	2,660	8,113	8,234	8,804	231%
IL	0	664	2,006	5,400	6,787	12,800	18,355	22,810	23,138	23,588	29%
IN	0	0	0	1,067	3,802	9,976	12,786	25,099	27,117	29,323	129%
IA	0	4	137	3,932	6,228	12,751	11,359	12,716	13,214	13,649	20%
KS	0	135	555	3,872	6,239	7,195	8,274	8,891	9,124	7,503	-9%
KY	0	609	819	1,040	1,807	3,033	11,046	17,392	15,134	15,653	42%
LA	0	0	939	2,048	4,232	6,915	9,957	12,085	12,540	23,438	135%
ME	0	400	509	1,078	2,440	2,781	4,101	4,948	5,229	5,177	26%
MD	0	685	1,972	3,392	6,768	10,294	12,489	15,283	15,004	15,955	28%
MA	0	593	3,288	8,027	11,315	11,962	11,987	15,354	16,381	17,046	42%
MI	0	3	2,741	6,199	8,550	8,089	39,838	45,115	49,589	49,589	24%
MN	0	1,423	2,890	6,097	14,735	14,593	18,963	21,792	21,792	23,207	22%
MS	0	0	0	231	1,673	1,978	1,831	2,690	2,638	2,828	54%
MO	0	0	2,241	6,282	8,143	8,396	11,041	14,152	14,723	15,088	37%
MT	21	210	444	891	1,452	2,242	2,668	2,796	2,740	2,656	-0%
NE	0	0	710	2,010	2,419	3,304	4,531	4,592	4,666	4,770	5%
NV	0	129	136	374	1,083	1,372	1,652	2,152	2,219	2,314	40%
NH	0	541	1,059	2,063	2,779	3,339	4,519	5,387	6,442	5,313	18%
NJ	0	2,596	3,971	5,705	7,486	9,923	11,297	11,874	15,636	19,729	75%
NM	0	220	334	1,603	2,794	3,711	4,115	4,616	4,624	4,648	13%
NY	0	0	379	29,019	48,165	56,401	77,047	82,656	85,055	86,556	12%
NC	0	328	939	3,726	6,013	9,309	12,800	21,786	33,241	31,510	146%
ND	0	724	1,334	1,792	2,011	3,535	4,059	4,956	4,908	5,027	24%
OH	0	100	397	2,646	7,858	16,362	30,872	39,180	40,202	38,490	25%
OK	0	70	949	2,497	4,100	5,308	5,223	5,625	5,625	5,242	0%
OR	1,360	832	1,458	2,586	8,017	10,287	14,865	21,200	24,140	22,153	49%
PA	0	1,203	2,705	8,931	24,969	26,558	29,963	34,911	35,874	36,514	22%
RI	0	136	993	2,178	2,674	3,126	3,316	4,354	3,738	3,775	14%
SC	0	0	471	3,412	4,410	5,186	8,394	10,929	10,759	10,885	30%
SD	0	596	852	1,457	2,295	2,609	3,215	3,625	3,625	3,625	13%
TN	0	213	704	3,293	4,340	7,244	7,680	8,137	7,835	9,499	24%
TX	0	70	968	4,753	7,873	16,301	29,193	37,582	39,285	36,847	26%
UT	0	0	1,367	2,315	3,589	4,003	4,319	4,960	5,285	5,644	31%
VT	0	196	413	1,372	1,844	2,200	2,649	3,070	3,166	2,853	8%
VA	0	0	537	1,764	5,491	7,523	9,754	12,511	13,100	14,228	46%
WA	0	886	1,918	6,643	9,900	9,317	11,898	16,900	17,671	23,642	99%
WV	0	124	513	1,441	2,796	3,852	4,447	4,514	4,634	5,616	26%
WI	0	190	1,812	6,558	9,474	12,504	23,396	33,060	35,779	39,064	67%
WY	0	0	318	916	1,507	2,079	2,150	2,401	2,394	2,277	6%
Estimated US Total	1,381	22,689	62,429	221,909	373,946	501,864	688,410	846,878	878,842	908,029	32%
N States	2	35	47	50	51	51	51	51	51	51	51

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

Table 3.5 Estimated Medicaid Waiver Expenditures (in \$1,000s) for People with IDD by State Selected Fiscal Years 1982 to 2019

State	1982	1987	1992	1997	2002	2007	2012	2017	2018	2019	% change 2012-2019
AL	0	8,326	12,400	72,327	120,395	253,259	288,701	380,161	362,746	350,723	21%
AK	0	0	0	17,668	51,866	70,955	134,516	176,258	187,000	181,935	35%
AZ	0	0	98,716	203,898	386,529	556,450	640,785	982,473	1,101,033	1,178,190	84%
AR	0	0	11,250	12,063	53,077	91,380	173,135	225,030	237,513	180,989	5%
CA	0	30,400	54,049	355,246	853,788	1,532,880	2,107,489	3,383,876	3,391,877	3,812,260	81%
CO	0	25,455	60,192	133,282	205,028	268,080	331,010	453,993	482,569	535,762	62%
CT	0	7	83,575	222,364	386,547	454,125	720,878	929,152	959,340	793,638	10%
DE	0	846	5,105	16,279	34,181	75,090	94,329	135,182	142,550	154,788	64%
DC	0	0	0	0	1,648	19,678	147,196	218,864	238,618	254,769	73%
FL	0	12,850	20,246	131,805	496,921	908,572	879,855	1,004,430	1,068,863	1,231,963	40%
GA	0	0	10,250	63,130	286,390	263,542	407,212	356,495	647,325	697,001	71%
HI	0	565	4,385	11,721	34,728	97,000	102,910	102,074	121,835	144,974	41%
ID	0	568	1,188	9,996	27,804	60,937	64,425	249,874	253,914	285,535	343%
IL	0	12,840	79,600	116,000	140,200	416,200	591,460	923,395	955,156	996,771	69%
IN	0	0	0	33,301	198,630	402,597	489,971	741,069	645,274	690,082	41%
IA	0	0	774	48,271	127,081	275,728	387,580	565,174	573,760	677,674	75%
KS	0	638	13,737	93,519	189,358	247,334	330,269	489,936	522,395	403,343	22%
KY	0	10,974	19,821	29,430	91,756	163,060	406,429	655,991	665,582	712,781	75%
LA	0	0	1,785	44,291	129,015	258,220	407,248	473,862	468,866	508,601	25%
ME	0	5,674	13,250	60,067	136,461	230,661	291,071	346,241	381,553	450,704	55%
MD	0	21,708	72,327	140,673	251,357	495,386	686,894	1,003,268	1,007,146	1,061,513	55%
MA	0	13,278	90,000	280,000	483,391	587,453	876,814	1,483,297	1,515,881	1,556,196	77%
MI	0	80	81,039	162,809	538,109	316,274	445,712	0	1,983,102	1,983,102	345%
MN	0	13,170	95,381	260,223	699,687	889,902	1,215,081	1,554,310	1,554,310	1,674,488	38%
MS	0	0	0	631	20,699	39,461	43,976	94,711	114,590	120,886	175%
MO	0	0	65,792	154,768	235,897	379,435	533,967	889,123	923,876	1,034,232	94%
MT	375	3,596	10,827	22,500	42,005	68,412	90,871	114,648	113,620	121,786	34%
NE	0	0	25,522	58,901	108,402	140,172	239,921	291,120	298,298	328,871	37%
NV	0	1,489	2,400	4,877	24,367	61,585	78,767	104,967	114,343	124,995	59%
NH	0	13,518	44,400	89,427	117,922	143,209	192,025	0	264,074	274,088	43%
NJ	0	35,888	108,601	180,006	402,988	496,612	737,871	1,047,873	1,206,524	1,418,241	92%
NM	0	1,410	8,829	46,295	157,256	247,597	285,949	356,395	372,764	388,667	36%
NY	0	712	34,496	1,114,423	2,125,806	3,449,069	5,468,225	5,615,944	5,943,273	6,511,577	19%
NC	0	3,059	13,833	106,199	254,337	377,747	619,805	1,063,758	1,262,953	1,267,532	105%

Table 3.5 Estimated Medicaid Waiver Expenditures (in \$1,000s) for People with IDD by State Selected Fiscal Years 1982 to 2019

State	1982	1987	1992	1997	2002	2007	2012	2017	2018	2019	% change 2012-2019
ND	0	5,438	18,975	30,176	47,531	71,823	129,617	199,935	194,815	212,557	64%
OH	0	1,131	12,824	90,058	245,009	660,978	1,240,863	1,635,258	1,750,098	1,835,686	48%
OK	0	392	39,375	93,593	222,356	253,401	273,952	310,647	310,647	313,337	14%
OR	1,869	8,306	58,604	105,178	361,705	385,762	597,868	90,153	143,198	144,885	-76%
PA	0	35,975	133,681	415,399	977,487	1,199,739	1,816,306	2,705,916	3,129,240	3,411,121	88%
RI	0	5,648	14,367	107,962	160,859	245,521	203,663	209,184	242,805	258,145	27%
SC	0	0	4,961	51,300	142,500	185,700	291,243	329,786	346,471	424,081	46%
SD	0	6,153	16,257	38,739	58,935	81,945	101,739	115,968	115,968	134,642	32%
TN	0	1,853	14,431	72,738	205,314	525,964	604,098	682,075	684,445	767,928	27%
TX	0	1,828	39,755	159,896	321,671	566,475	1,058,827	1,515,458	1,544,336	1,465,974	38%
UT	0	0	23,000	50,794	88,991	113,867	155,515	244,217	263,698	294,307	89%
VT	0	4,840	14,154	47,980	74,856	109,071	141,617	198,042	214,158	217,922	54%
VA	0	0	15,975	67,430	198,911	394,326	602,412	821,443	911,721	978,059	62%
WA	0	12,068	39,974	105,006	214,490	315,624	550,896	56,035	560,798	618,958	12%
WV	0	777	13,200	43,660	120,218	203,371	303,862	0	304,222	299,138	-2%
WI	0	3,503	39,078	155,238	312,785	439,299	855,374	1,222,445	1,338,173	1,487,757	74%
WY	0	0	12,508	33,428	56,957	87,041	98,497	92,449	97,827	110,350	12%
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	42,235,143	45,083,505	53%
N States	2	36	47	50	51	51	51	51	51	51	5100%

Data for all years 1982 to 2016 can be viewed in the Chart Gallery of the RISP.umn.edu website. ^d Other date (data from previous or next year). ^e Estimate. ^f One or more component value imputed by RISP staff. DNF Did not furnish. ^g 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 2019

State	1977	1982	1987	1992	1997	2002	2007	2012	2017	2018	2019	% change 2012-2019
AL	0	1,470	1,364	1,304	745	472	244	41	22	25	15	-63%
AK	135	118	107	86	10	0	0	0	0	0	0	N/A
AZ	0	0	0	214	214	207	185	148	42	140	122 i	-18%
AR	1,385	1,420	1,453	1,737	1,558	1,684	1,616	1,467	1,425	1,435	1,430 s	-3%
CA	0	10,374	10,871	10,923	10,681	10,839	9,598	8,726	7,649	7,101	7,130 e	-18%
CO	4,537	2,017	1,149	754	229	111	125	343	173	203	168	-51%
CT	687	1,598	1,414	1,378	1,377	1,192	1,148	993	742	707	664	-33%
DE	477	513	439	325	292	241	141	135	118	120	119	-12%
DC	0	436	666	761	754	734	640	363	319	309	308	-15%
FL	370	2,128	3,180	3,118	3,476	3,338	3,205	2,806	2,770	2,700	2,612 i	-7%
GA	2,369	2,491	1,913	1,935	1,770	1,475	1,034	300	143	275	265 s	-12%
HI	524	387	296	154	122	94	78	79	79	73	62	-22%
ID	583	482	461	519	579	576	543	487	455	444	432 s	-11%
IL	5,353	8,144	10,346	12,311	10,500	9,923	9,213	8,344	6,593	6,512	6,380	-24%
IN	1,026	2,798	4,690	6,234	5,938	4,981	4,012	3,839	3,179	3,159	3,081	-20%
IA	1,432	1,673	1,840	2,088	2,268	2,157	2,123	2,002	1,765	1,441	1,429	-29%
KS	1,810	2,078	2,081	1,921	1,395	688	599	509	433	440	406	-20%
KY	999	1,250	1,187	1,200	1,180	876	637	523	422	735	407	-22%
LA	3,682	4,849	6,016	5,645	6,014	5,539	5,320	4,604	4,639	4,653	4,490	-2%
ME	310	630	677	630	548	246	222	202	159	196	191	-5%
MD	1,367	1,851	1,429	954	624	502	336	54	92	95	93	72%
MA	4,242	4,041	3,698	3,304	1,598	1,125	952	594	396	385	342	-42%
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	1,441	1,018	-41%
MS	491	1,614	1,678	1,825	2,256	2,534	2,601	2,765	2,169	2,125	2,253 s	-19%
MO	2,051	1,878	1,868	1,751	1,466	1,398	1,020	590	421	406	383 e	-35%
MT	0	290	253	170	148	119	54	55	12	6	0	N/A
NE	1,356	980	808	739	643	642	582	433	348	382	345	-20%
NV	0	175	188	146	275	242	118	104	91	84	82	-21%
NH	288	339	204	81	23	25	25	25	23	20	25	0%
NJ	525	4,366	3,815	3,942	3,948	3,370	2,963	2,426	1,463	1,385	1,323 i	-45%
NM	426	553	709	730	348	284	182	234	266	283	273	17%
NY	18,601	15,577	17,567	18,497	11,472	9,815	7,995	7,288	4,895	5,110	4,170	-43%
NC	2,073	2,762	3,445	4,502	4,777	4,645	4,124	3,930	4,406	4,243	4,007	2%

Table 3.6 Estimated ICF/IID Recipients by State, June 30, Selected Fiscal Years 1977 to 2019

State	1977	1982	1987	1992	1997	2002	2007	2012	2017	2018	2019	% change 2012-2019
ND	0	219	888	476	609	629	593	559	539	528	537	-4%
OH	2,488	6,040	7,535	8,384	7,615	7,240	6,667	6,926	5,814	5,370	5,171	-25%
OK	1,978	1,803	3,242	2,776	2,292	2,243	1,630	1,549	1,307	1,416	1,428 ^s	-8%
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	2,751	2,540	-26%
RI	763	881	1,093	602	21	40	41	42	34	37	40 ^s	-5%
SC	1,017	2,665	3,300	3,261	2,555	1,992	1,615	1,313	1,158	1,171	1,153	-12%
SD	540	721	650	552	328	189	158	199	192	176	181 ^s	-9%
TN	2,149	2,377	2,198	2,399	1,900	1,460	1,223	1,108	997	1,034	948 ^e	-14%
TX	10,486	13,959	12,211	11,187	12,985	12,684	11,447	9,467	7,939	7,872	7,522	-21%
UT	1,193	1,199	945	930	833	783	794	801	190	778	732 ^s	-9%
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	693	616	-54%
WA	440	2,464	2,539	1,695	1,126	880	767	629	738	700	653 ⁱ	4%
WV	0	176	417	699	574	515	477	562	514	517	498 ^s	-11%
WI	3,696	3,548	3,378	4,110	3,187	2,580	1,059	895	922	519	383	-57%
WY	0	0	0	90	139	106	93	79	62	59	52	-34%
Estimated US Total	106,166	140,752	146,641	146,260	126,697	110,572	96,427	85,384	71,018	70,260	66,485	-22%
N States	42	49	49	51	51	50	50	48	48	48	47	49

Data for all available years available in the Chart Gallery Section of the RISP.umn.edu website. ^b Non-State only. ^c State only. ^d Other date (data from previous or next year). ^e Estimate. ^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. ⁱ See state notes in Appendix.

Table 3.7 Estimated Medicaid ICF/IID Expenditures (in \$1,000s) by State, Selected Years 1982 to 2019 (not inflation adjusted)

State	1982	1988	1992	1997	2002	2007	2012	2017	2018	2019	% change 2012-2019
AL	31,076	54,014	80,701	58,306	60,516	31,522	10,586	1,990	2,033	1,424	-87%
AK	6,830	9,038	10,384	2,032	0	161	3,051	2,736	2,617	3,002	-2%
AZ	0	0	0	0	0	0	32,593	1,336	1,221	947	-97%
AR	34,603	51,087	88,047	105,950	28,958	146,960	168,540	0	171,345	155,447 ^s	-8%
CA	87,544	269,638	316,072	380,655	663,954	824,990	821,840	696,318	654,499	548,751	-33%
CO	(1,194)	43,403	55,495	23,575	19,202	22,647	39,533	43,853	44,762	48,315	22%
CT	41,722	109,464	192,888	188,190	213,455	240,165	284,642	194,535	200,961	307,158	8%
DE	8,281	15,246	26,543	31,233	31,219	26,647	17,462	32,392	33,174	32,702	87%
DC	7,350	40,108	51,774	74,258	79,480	85,051	69,494	92,289	89,216	89,363	29%
FL	48,048	130,435	181,802	248,208	310,393	319,288	328,460	331,591	331,591	331,591	1%
GA	48,271	84,730	115,391	127,303	110,659	105,885	67,117	0	33,587	31,333 ^s	-53%
HI	10,962	14,290	6,571	11,628	8,572	8,683	7,715	4,437	8,324	8,204	6%
ID	12,490	23,130	35,545	43,454	57,714	59,702	23,064	0	47,056	7,785	-66%
IL	120,855	243,824	499,573	580,152	720,932	696,183	688,115	586,802	613,172	607,588	-12%
IN	37,326	86,777	272,735	304,187	338,947	318,531	294,064	269,363	270,721	271,649	-8%
IA	52,267	88,710	150,456	178,213	192,996	276,651	301,739	206,347	231,887	400,593	33%
KS	40,647	69,568	102,523	94,468	65,863	65,288	64,412	40,556	41,087	27,065	-58%
KY	39,053	47,597	59,843	75,691	97,888	151,886	130,481	147,232	155,706	36,578	-72%
LA	97,076	165,291	260,925	422,009	362,343	442,023	467,517	352,396	342,022	334,238	-29%
ME	15,699	30,613	62,854	45,548	50,370	71,664	74,915	40,200	41,484	43,648	-42%
MD	53,170	83,621	65,023	63,699	61,628	68,466	123	25,780	31,087	14,259 ^s	11489%
MA	125,500	198,722	385,149	254,062	198,023	206,612	165,995	97,514	97,484	102,257	-38%
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	114,406	106,380	-35%
MS	20,579	32,524	62,156	119,386	178,043	255,287	270,287	196,141	237,953	238,465 ^s	-12%
MO	35,207	71,080	106,866	155,768	230,169	105,836	108,468	89,799	84,554	83,969	-23%
MT	0	10,179	13,124	15,809	14,061	10,632	11,320	5,759	10,788	0	N/A
NE	21,336	25,477	32,910	36,896	47,671	66,940	57,654	62,084	68,761	64,375	12%
NV	5,661	9,523	16,670	22,845	30,309	21,390	17,955	18,627	15,966	14,942	-17%
NH	6,339	14,142	6,127	1,299	1,953	2,522	3,154	0	3,588	4,128	31%
NJ	122,552	237,997	276,342	373,077	462,969	628,421	650,873	461,199	448,782	431,748	-34%
NM	12,078	23,587	39,164	21,729	18,993	21,263	24,809	26,785	28,813	28,891	16%
NY	797,385	1,158,161	1,715,103	2,010,006	2,472,622	3,057,177	3,382,395	1,060,094	965,311	985,697	-71%
NC	79,192	158,440	278,485	363,153	416,623	466,789	444,383	398,948	549,825	568,065	28%

Table 3.7 Estimated Medicaid ICF/IID Expenditures (in \$1,000s) by State, Selected Years 1982 to 2019 (not inflation adjusted)

State	1982	1988	1992	1997	2002	2007	2012	2017	2018	2019	% change 2012-2019
ND	498	40,216	39,980	43,653	54,683	61,655	92,146	71,114	90,387	89,713	-3%
OH	36,634	278,624	468,322	391,631	962,507	697,689	757,788	716,348	671,977	704,651	-7%
OK	32,395	83,725	111,773	100,900	112,292	127,291	113,228	0	72,128	81,822 ^s	-28%
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	602,232	580,767	-0%
RI	28,759	60,548	90,368	10,401	7,244	7,810	9,160	2,708	7,889	11,069 ^s	21%
SC	36,020	94,198	165,299	174,750	174,843	157,180	150,914	140,018	140,057	149,616	-1%
SD	14,890	22,005	29,221	20,194	18,448	20,149	29,594	31,198	31,807	31,710 ^s	7%
TN	56,831	77,504	111,715	212,774	252,512	243,129	216,276	203,300	185,901	198,048	-8%
TX	233,539	357,823	468,605	640,849	811,722	906,152	1,047,598	1,113,101	1,185,871	1,015,874	-3%
UT	23,711	27,666	39,659	45,047	54,883	58,134	63,278	40,106	72,058	42,430	-33%
VT	13,421	11,335	17,841	1,479	1,631	0	1,212	1,151	1,367	1,132	-7%
VA	78,609	106,785	153,992	159,667	216,052	231,030	288,116	243,550	205,733	186,762 ^s	-35%
WA	72,202	119,320	182,045	128,968	127,817	114,854	106,120	192,150	237,685	125,993	19%
WV	1,982	8,662	15,031	52,705	47,513	57,354	65,414	0	68,976	71,072 ^s	9%
WI	63,845	89,337	193,185	201,998	226,014	131,158	197,496	132,954	146,977	113,912	-42%
WY	0	0	2,556	17,778	15,543	20,007	20,745	18,713	14,464	20,593 ^e	-1%
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	9,709,292	9,355,722^o	-28%
N States	48		49	50	51	50	51	50	50	50	50

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

Figure 3.1 Number and Percent of LTSS Recipients with IDD by Living Arrangement Type and Size: Select Years 1998 to 2019

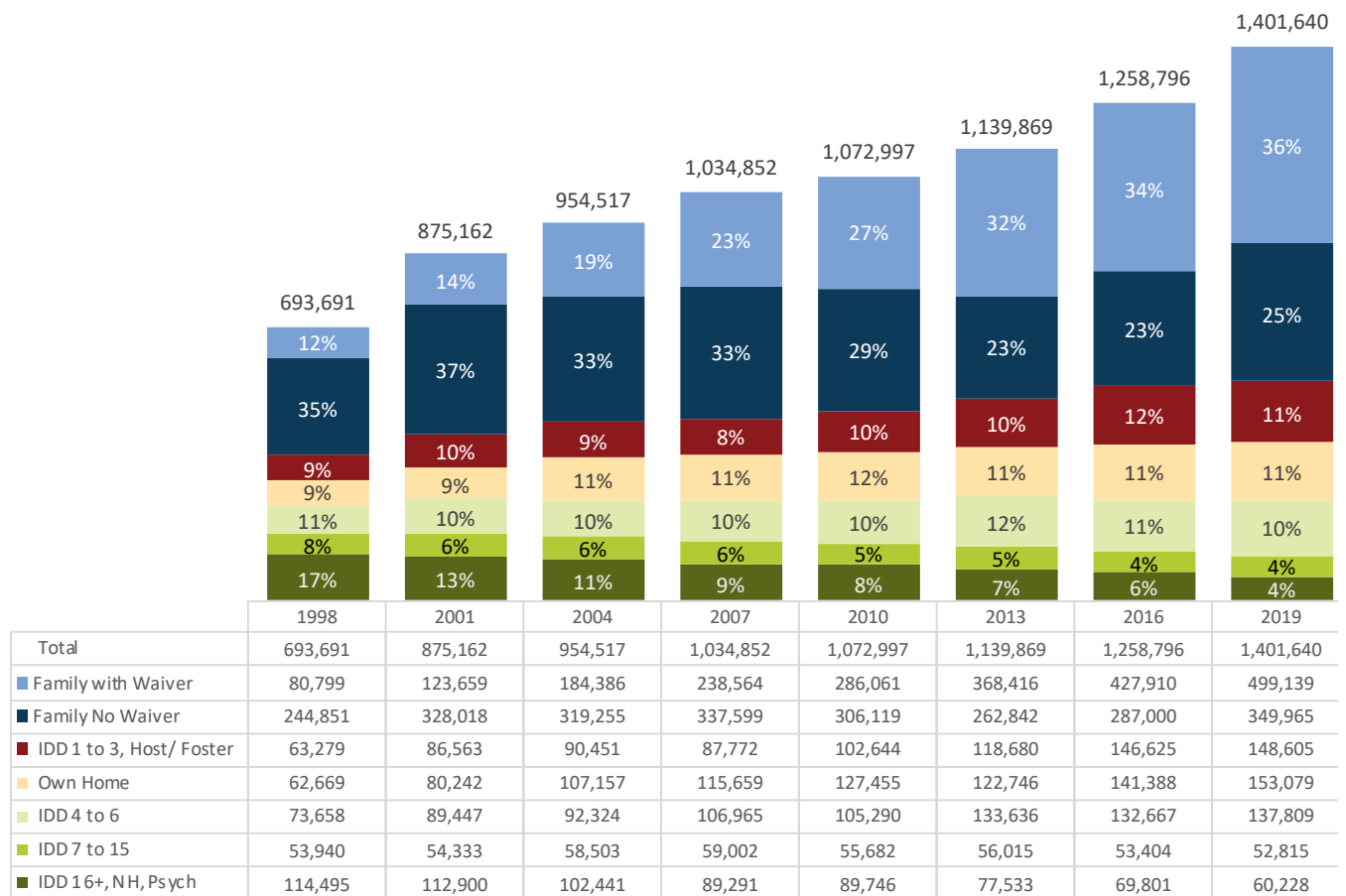


Figure 3.2 People with IDD in Non-family LTSS Settings by Type of Operation on June 30 Selected Years 1977 to 2019

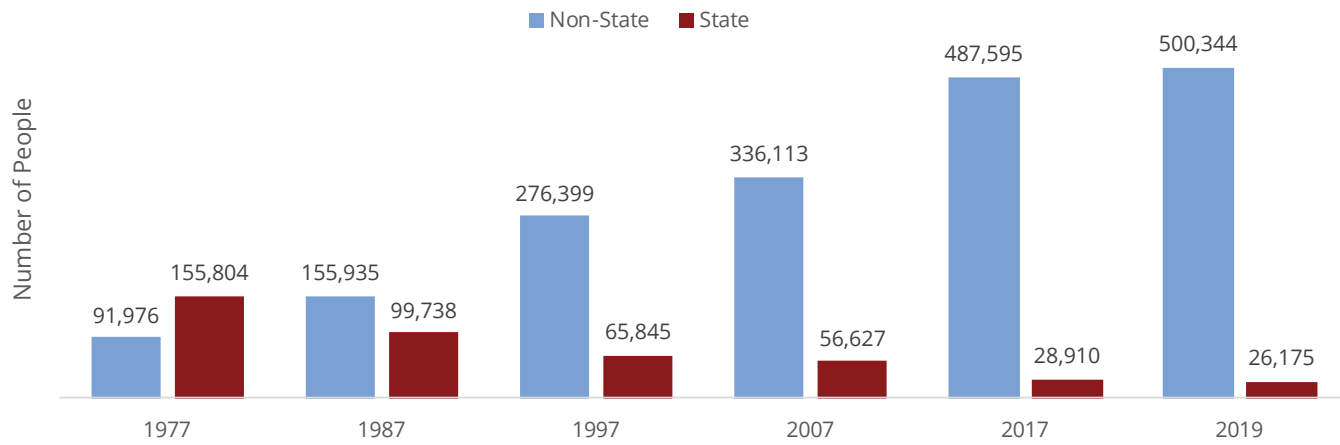


Figure 3.3 Proportion of People with IDD Living in IDD Settings of 16 or more people who Live in Nonstate Settings Selected Years 1977 to 2019

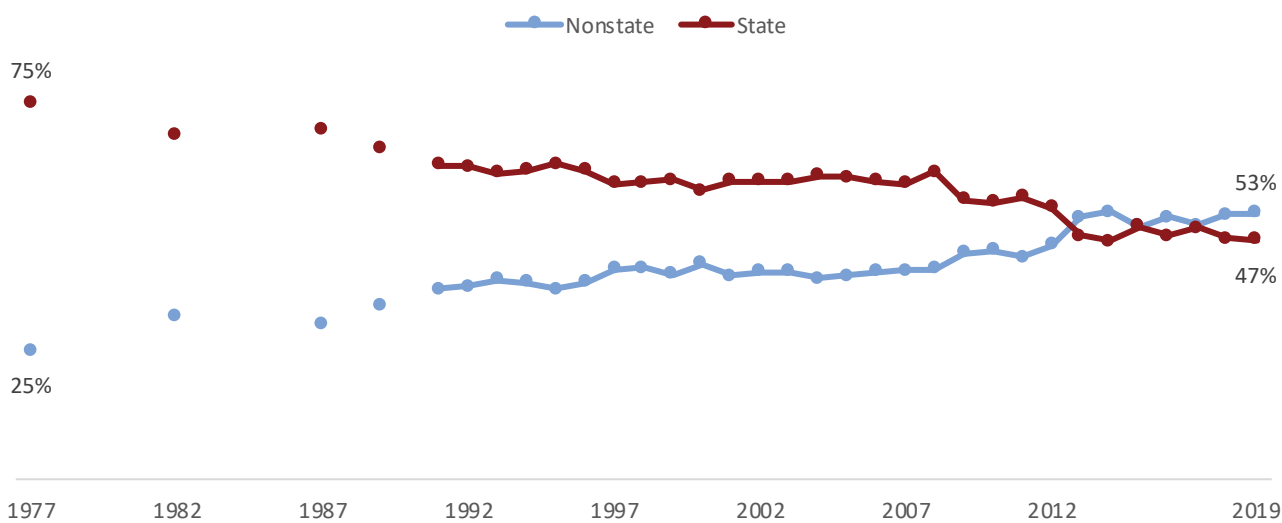


Figure 3.4 Number of LTSS Recipients with IDD in State and Nonstate-Operated Settings of 16+ People June 30, 2000 to 2019 with Linear Projections to 2045

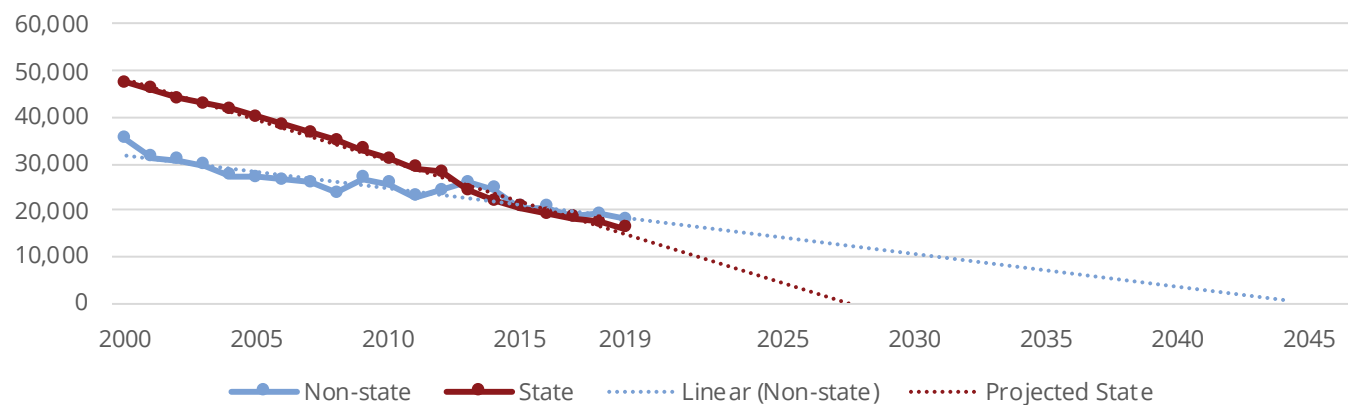


Figure 3.5a Medicaid ICF/IID and HCBS Waiver Recipients with IDD for Fiscal Year 1982 to 2019

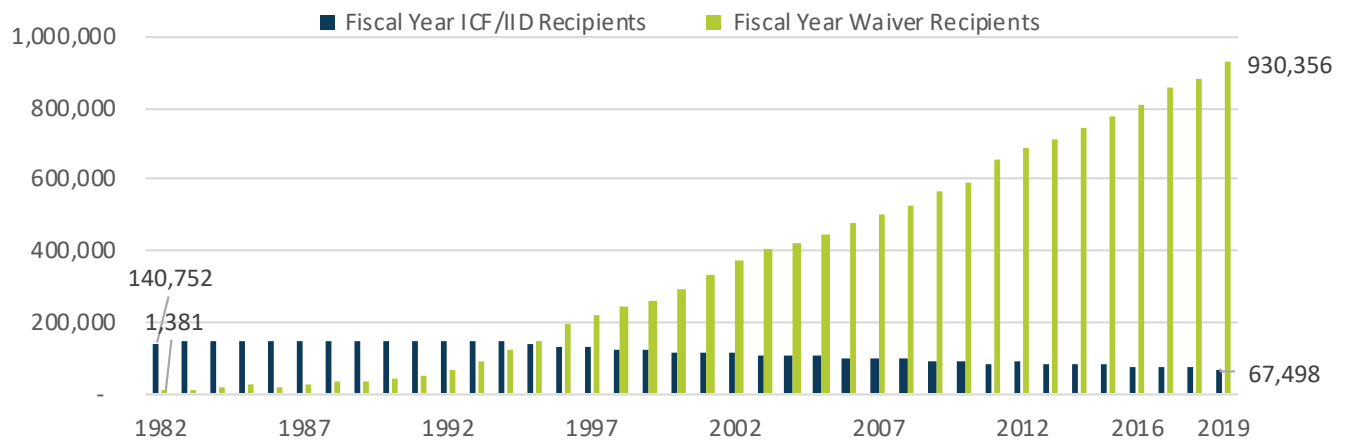


Figure 3.5b Medicaid ICF/IID and HCBS Waiver Expenditures in Billions for People with IDD From 1982 to 2019

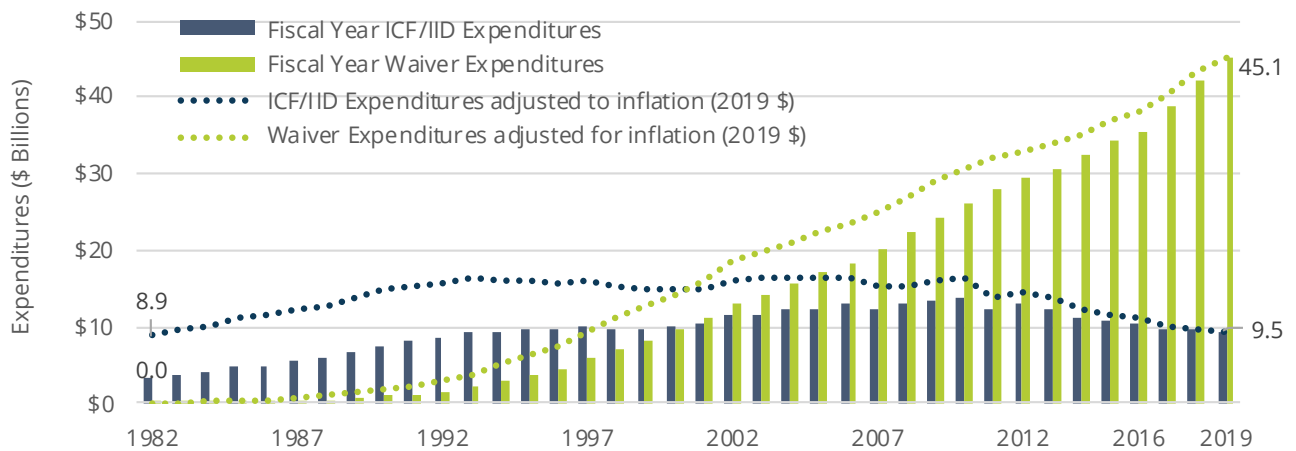
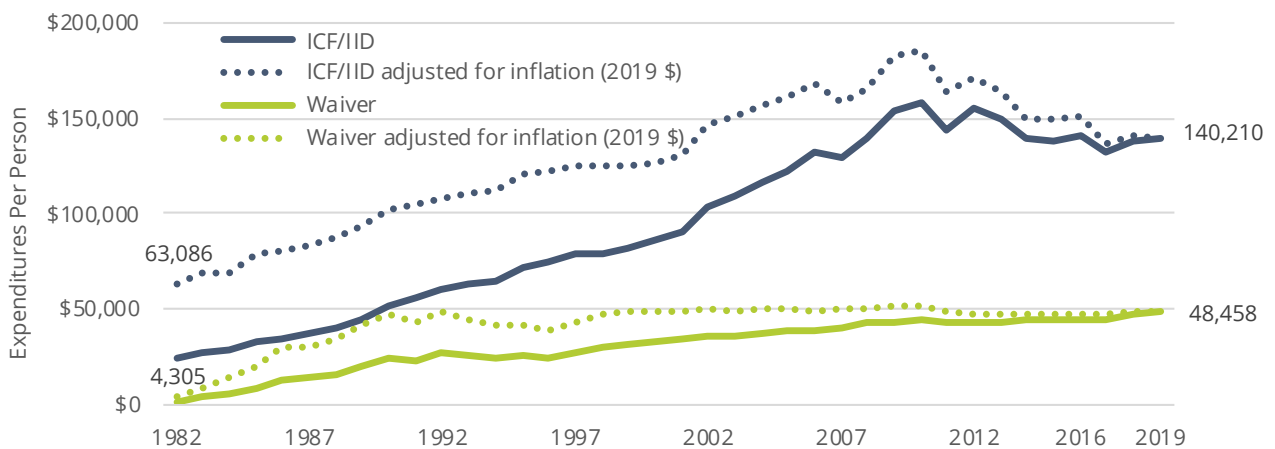


Figure 3.5c Average Annual Per Person ICF/IID and Waiver Expenditures For People with IDD From 1982 to 2019



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

Section 4 examines the status of and national trends in the use of state-run IDD facilities of 16 or more people (also called Public Residential Facilities, or PRF) or in state-run psychiatric facilities.

What was the census of PRFs in 2019 and how did it change between June 30, 2018, and June 30, 2019?

The daily census of PRFs decreased from 17,353 on June 30, 2018, to 16,200 on June 30, 2019 (a reduction of 7%; See **Table 4.1**).

The average daily population of PRFs in FY 2019 was 16,862.

Average daily per person costs for PRFs certified as Intermediate Care Facilities for Individuals with Intellectual Disabilities were \$822 for FY 2019. The average was \$645 in PRFs that were not ICF/IID certified.

Census changes for PRFs during FY 2019 included an estimated

- 1,014 admissions or readmissions
- 1,264 discharges
- 577 deaths
- 484 short-term admissions (less than 90 days)

What were the characteristics of people in PRFs on June 30, 2019?

Of the 16,200 people in PRFs, 10,407 (64%) were male (See **Table 4.2**).

Of the people in PRFs on June 30, an estimated

- 5% were birth to 21 years old
- 22% were 22 to 39 years old
- 47% were 40 to 62 years old
- 26% were 63 years or older

Race of people in PRFs was

- 69% white
- 20% Black or African American
- 7% Hispanic or Latino
- 3% were another race or multiple races

Of the people in PRFs

- 17% had mild or no intellectual disability
- 16% had moderate intellectual disability

- 17% had severe intellectual disability
 - 49% had profound intellectual disability
 - 1% had an unknown level of intellectual disability
- Of the people in PRFs,
- 39% had epilepsy
 - 23% had autism
 - 16% had cerebral palsy
 - 61% had a behavioral disorder requiring planned intervention
 - 7% had previous involvement in the criminal justice system at some time.

How did states differ in the age and level of intellectual disability of people living in PRFs?

- The proportion of June 30 residents ages 63 years or older ranged from 0 in Idaho to 79% in Arizona (See **Table 4.3** and **Figure 4.1**)
- The proportion of June 30th residents with profound intellectual disabilities ranged from 0 in Arizona, New York, Idaho, and Wyoming to 86% in Delaware (See **Table 4.4** and **Figure 4.2**)
- The proportion of people with no, mild or moderate ID and the proportion who were 39 years or younger was highly correlated by state ($r = 0.69$; See **Figure 4.2b**). States that served a higher proportion of people with no, mild or moderate ID also served a higher proportion of people 39 years or younger.

What were the characteristics of people who moved into or out of PRFs in 2019?

People ages 21 years or younger were 5% of the June 30, 2019, PRF population, but were

- 29% of all admissions or readmissions
- 15% of all discharges (See **Table 4.5** and **Figure 4.3**)

People with no or mild intellectual disabilities were 17% of the June 20, 2019, PRF population, but were

- 52% of new admissions or readmissions
- 43% of discharges (See **Figure 4.4**)

Where did people with IDD live before moving to PRFs?

Of the people newly admitted or readmitted to PRFs (See **Table 4.6** and **Figure 4.5**)

- 29% came from a criminal justice setting
- 18% came from the home of a family member
- 16% came from a group IDD setting of 6 or fewer people
- 14% came from a mental health facility
- 8% came from another (e.g., nursing home, hospital, boarding home or assisted living setting) or unknown setting
- 5% came from their own home or a host or foster family home
- 10% came from a group IDD setting of 7 or more people

Where did people live after they left PRFs?

Of the people who moved from a PRF to another setting

- 40% went to a group IDD setting of six or fewer people
- 17% went to a criminal justice setting
- 10% went to a group IDD setting of 7 or more people
- 9% went to a mental health facility
- 8% went to the home of a family member
- 8% went to their own home or a host or foster family home
- 8% went to another (Nursing home, Hospital or Assisted Living) or unknown setting

What were the staffing characteristics and outcomes for PRFs in 2019?

On June 30, 2019, PRFs employed an estimated

- 26,960 direct support professionals (1.82 full time equivalent staff per resident)
- 2,692 front line supervisors (0.18 full time equivalent staff per resident; See **Table 4.7**)

Vacancy rates on June 30, 2019, were

- 13% for direct support professionals
- 8% for frontline supervisors

Crude separation rates (turnover) for FY 2019

- 36% for direct support professionals
- 25% for frontline supervisors

Hourly wages for direct support professionals were \$14.65 to start and \$16.79 on average.

Annual salaries for frontline supervisors were \$40,618 to start and \$47,452 on average.

What were the trends in closures of PRFs?

Of the 376 PRFs operating between 1960 and 2019,

- 264 closed before July 1, 2018 (See **Table 4.10**)
- 3 closed, were privatized or reduced their population to 15 or fewer people between July 1, 2018, and June 30, 2019 (Sonoma Developmental Center in Eldridge California, Hazelwood Center in Louisville, Kentucky, and Hamburg Center in Hamburg Pennsylvania; See **Table 4.9**).
- 109 were open on June 30, 2019, 8 of which anticipated closing by June 30, 2024 (See **Table 4.8**).

On June 30, 2019, there were no PRFs serving people with IDD in 18 states: 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.

Between 2015 and 2019, 25 PRFs closed, were privatized, or reduced their census to 15 or fewer people with IDD (See **Figure 4.6**).

How has the number of people with IDD living in PRFs changed?

The average daily PRF population declined from a peak of 194,650 in 1967 to 16,862 in 2019 (See **Figure 4.7a**).

The average population of people with IDD in state-run psychiatric facilities declined from 41,823 in 1961 to 1,318 people on June 30, 2019 (**Figure 4.7b**). Data on state-run psychiatric facilities was provided by only 29 states for 2019.

Between 2010 and 2019, the average daily population of PRFs declined by an average of 47% from 31,654 to 16,862 people See **Table 4.11**)

The average annual change in the number of people in PRFs was 1,110 between 2015 and 2020. In percent, the average annual change was 4.8% (See Figure 4.8). The numeric change per year continues to decline, but the average annual change in percent remains around 5% per year.

Changes in movement into and out of PRFs between 1967 (the year the average daily population was highest) and 2019 included

- A reduction in the number of people admitted from 14,904 per year in 1967 to 1,014 per year in 2019 (See **Table 4.13**).
- A reduction in the number of people discharged from 11,665 per year in 1967 to 1,264 per year in 2019.
- A reduction in the number of annual deaths from 3,635 in 1967 to 577 in 2019.

As a proportion of the average daily PRF population (See **Figure 4.9**),

- The number of annual admissions declined from 11% in 1975 to 7% in 2019.
- The number of annual discharges declined from 11% in 1978 to 6% in 2019.
- The number of deaths increased from 1% (several years) to 3% in 2019.

The number of annual deaths in PRFs as a percentage of deaths plus discharges increased from a low of 11% in 1980 to 31% in 2019 (See **Figure 4.9b**).

How has average annual per person cost for people living in PRFs changed?

Average annual per person costs for people living in PRFs in 2019 dollars increased from \$7,914 in 1950 to \$281,952 in 2019 (See **Table 4.14** and **Figure 4.10**)

How have the characteristics of people living in PRFs changed?

The number (and percentage) of people 21 years or younger in PRFs declined from 91,592 (49% of all residents) in 1965 to 758 (5% of all residents) in 2019 (See **Figure 4.11**).

Of the people in PRFs, the percent who were

- Male increased from 57% in 1977 to 64% in 2019 (See **Table 4.15** and **Figure 4.12**).
- 63 years or older increased from 4% in 1977 to 26% in 2019.

Of the people in PRFs, the percent with

- No or mild ID increased from 10% in 1977 to 17% in 2019 (See **Figure 4.13**).
- Epilepsy declined from 46% in 1998 to 39% in 2019.
- Autism increased from 19% in 2016 to 23% in 2019.
- Cerebral palsy decreased from 19% in 1977 to 16% in 2019.
- A behavior disorder requiring planned care increased from 25% in 1977 to 61% in 2019.

How have the places people come from when they are admitted to a PRF changed, and how have the places they go when they leave a PRF changed?

Between 2016 and 2019,

- The percent of June 30 residents who had previous involvement with the criminal justice system increased from 4% to 7%.
- The percent of people admitted from a correctional facility increased from 17% to 29% (See **Table 4.16**).
- The percent of people discharged to a correctional facility increased from 3% to 17% (See **Table 4.17**).

Between 1989 and 2019, the proportion of people admitted to a PRF from

- The home of a family member, their own home, or a host or foster family home decreased from 35% to 23% (**Figure 4.14**).
- An IDD group residence of 16 or more people decreased from 23% to 5%
- A non-IDD specific facility (a mental health facility, correctional facility, nursing home, assisted living facility or boarding home) increased from 34% to 51%.

Between 1989 and 2019 the proportion of people leaving a PRF who moved to

- The home of a family member, their own home or a host or foster family home decreased from 22% to 16% (See **Figure 4.15**).
- An IDD group home of 15 or fewer people decreased from 49% to 43%.

- An IDD facility of 16 or more people decreased from 18% to 7%.
- A non-IDD specific facility (a mental health facility, correctional facility, nursing home, assisted living facility or boarding home) increased from 11% to 34%.

How have the services provided by PRF staff to people with IDD not living in a PRF changed?

Between 2000 and 2019, the average number of services offered by PRFs to people not living in them decreased from 5.5 to 1.4 per facility (See **Table 4.18** and **Figure 4.16**)

The percent of PRFs offering services to non-residents between 2000 and 2019 declined

- From 51% to 31% for behavioral assessment or intervention services.
- From 56% to 19% for respite services.
- From 41% to 24% for dental services.
- From 44% to 23% for crisis supports.

How have PRF staffing outcomes changed?

Between 2004 and 2019,

- The vacancy rate for DSPs increased from 6% to 13% and for frontline supervisors increased from 7% to 8% (See **Table 4.19** and **Figure 4.17**).
- The annual turnover rate increased from 29% to 36% for DSPs, and from 18% to 25% for frontline supervisors.

Table 4.1 PRF Daily Population, Admissions, Discharges, Deaths and per Person Expenditures by State for Fiscal Year 2019

State	Average Daily Population	Admissions	Discharges	Deaths	June 30 Residents			Short-term Admissions	Average Daily Per Person ICF/ IID Cost ¹
					2018	2019	1-Year % Change		
N States	48	47	47	47	51	51	51	44	31
AL	0	0	0	0	0	0	0%	0	N/A
AK	0	0	0	0	0	0	0%	0	N/A
AZ	77	0	0	4	80	75	-6%	0	772
AR	905	36	64	24	917	917 ^{e,i}	0%	52	404
CA	395	117	285	4	534	325 ^e	-39%	0	1,241
CO	23	9	9	1	50	53	6%	0	1,129
CT	185	2	3	22	347	320	-8%	1	1,249
DE	49	1	0	2	50	49	-2%	11	1,306
DC	0	0	0	0	0	0	0%	0	N/A
FL	685	103	131	31	698	646	-7%	0	431
GA	DNF	DNF	DNF	DNF	175	212 ⁱ	21%	DNF	DNF
HI	0	0	0	0	0	0	0%	0	N/A
ID	17	5	10	0	23	0	0%	7	1,340
IL	1,667	123	85	33	1,664	1,640	-1%	0	451
IN	0	0	0	0	0	0	0%	0	N/A
IA	DNF	0 ^{PD}	0 ^{PD}	0 ^{PD}	346	331	-4%	DNF	DNF
KS	299	12	8	8	305	300	-2%	0	469
KY	0	0	0	0	112	0	0%	0	0
LA	499	61	44	10	526	497	-6%	5	698
ME	0	0	0	0	0	0	0%	0	0
MD	94	85	75	5	95	93	-2%	0	861
MA	359	6	13	35	385	342	-11%	11	944
MI	0	0	0	0	0	0	0%	0	N/A
MN	0	0	0	0	0	0	0%	0	N/A
MS	1,426	36	89	19	899	842	-6%	32	401
MO	308	0	7	11	321	310	-3%	5	681
MT	0	0	0	0	0	0	0%	0	N/A
NE	106	11	12	4	109	105	-4%	0	800 ^e
NV	40	20	21	0	41	40	-2%	0	761
NH	0	0	0	0	0	0	0%	0	N/A
NJ	1,298	0	11	51	1,325	1,263	-5%	DNF	1,054
NM	0	0	0	0	0	0	0%	0	N/A
NY	DNF	DNF	DNF	DNF	261	257	-2%	DNF	DNF
NC	1,142	51	49	54	1,280	1,155	-10%	75	826
ND	70	14	5	5	68	71	4%	4	1,050
OH	640	46	53	21	650	629	-3%	131	709
OK	51	DNF	DNF	DNF	0	52 ⁱ	0%	DNF	DNF
OR	0	0	0	0	0	0	0%	0	N/A
PA	742	4	30	34	779	719	-8%	0	1,093
RI	0	0	0	0	0	0	0%	0	N/A
SC	673	44	40	33	672	673	0%	DNF	477
SD	114	DNF	DNF	DNF	115	114	-1%	DNF	DNF
TN	0	0	0	0	0	0	0%	0	N/A
TX	2,912	134	104	84	2,969	2,915	-2%	0	828
UT	180	9	4	10	185	180	-3%	2	664
VT	0	0	0	0	0	0	0%	0	N/A
VA	78	0	51	7	155	78	-50%	1	738
WA	744	3	22	31	668	623	-7%	92	919
WV	0	0	0	0	0	0	0%	0	N/A
WI	300	0	0	10	308	298	-3%	53	856
WY	61	15	15	4	67	63	-6%	2	914
Reported US Total	16,139	947	1,240	557	17,179	16,187	-6%	484	832
Estimated US Total	16,862	1,014	1,264	577	17,353	16,200	-7%	484	822

Source: RISP 2018 survey ¹Arizona reported average costs of \$772 per person for people in Medicaid Waiver funded state operated settings of 16+ people, Florida reported average daily costs of \$533 for people in other funded 16+ person state-operated settings and North Carolina reported average daily costs of \$489 per person in other funded state operated settings of 16+ people. Oklahoma reported that their last state operated facility closed in 2014. The 51 people listed were reported in the CASPER data system as living in a public ICF/IID.

Table 4.2 Characteristics of People with IDD Living in PRFs on June 30, 2019

Characteristic	Reported Total	Percent of People	Estimated Total	Reporting facilities
Residents on June 30	14,795	91%	16,200	96
Gender				
Male	9,504	64%	10,407	
Age				
0-21 Years	692	5%	758	95
22-39 Years	3,200	22%	3,504	
40-62 Years	6,996	47%	7,661	
63+ Years	3,905	26%	4,276	
Race				
White	10,007	69%	11,163	93
Black/African American	2,949	20%	3,290	
Hispanic/Latino	1,026	7%	1,145	
Other Race or Multiple Races	412	3%	460	
Level of Intellectual Disability				
Mild/No ID	2,551	17%	2,794	95
Moderate	2,434	16%	2,666	
Severe	2,456	17%	2,690	
Profound	7,246	49%	7,936	
Unknown	105	1%	115	
Other Conditions				
Epilepsy	5,467	39%	6,266	90
Autism	3,269	23%	3,747	90
Cerebral Palsy	2,251	16%	2,580	90
Behavior Disorder	8,673	61%	9,940	90
Involved with criminal justice system	932	7%	1,161	86

Source: PRF Survey

Table 4.3 Number of People with IDD in PRF's by Age and State on June 30, 2019

State	Age in Years						Total People
	0-18	19-21	0-21	22-39	40-62	63+	
AZ	0	0	0	0	16	59	75
AR	51	47	98	291	405	121	915
CA1	0	15	15	178	112	23	328
CO	0	5	5	26	11	6	48
CT	0	0	0	12	150	158	320
DE	0	1	1	9	25	14	49
FL	0	15	15	105	303	223	646
GA	0	0	0	4	63	56	123
ID	0	3	3	9	3	0	15
IL	1	25	26	378	919	310	1,633
IA	4	6	10	100	143	78	331
KS	18	16	34	75	150	41	300
LA	71	26	97	136	152	86	471
MD	0	2	2	36	39	16	93
MA	0	0	0	7	90	237	334
MS	46	26	72	249	388	132	841
MO1	0	0	0	26	170	112	308
NE	0	0	0	16	56	32	104
NV	0	0	0	24	14	2	40
NJ	0	0	0	67	808	397	1,272
NY	2	8	10	127	55	4	196
NC	21	12	33	119	554	426	1,132
ND	11	9	20	17	21	13	71
OH	23	32	55	225	252	96	628
PA	0	3	3	24	197	293	517
SC	0	0	0	43	76	27	146
SD	6	7	13	63	25	2	103
TX	82	74	156	723	1,389	642	2,910
UT	6	3	9	46	90	33	178
VA	1	1	2	4	21	18	45
WA	4	3	7	56	211	184	458
WI	0	0	0	0	61	52	113
WY	1	5	6	5	27	12	50
Reported US Total	348	344	692	3,200	6,996	3,905	14,793
Estimated US Total	381	377	758	3,504	7,661	4,276	16,200

Data Source: PRF Survey, N = 95 facilities, DNF Data not furnished. 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.

Table 4.4 Level of Intellectual Disability of People Living in Large State IDD Facilities by State (In Percent) on June 30, 2019

State	Level of Intellectual Disability (Percent)					Number of People
	Mild +	Moderate	Severe	Profound	Unknown	
AZ	0	100	0	0	0	75
AR	20	17	17	46	0	915
CA	71	12	4	9	3	328
CO	58	25	0	17	0	48
CT	7	12	25	55	0	320
DE	0	8	6	86	0	49
FL	25	17	11	46	0	646
GA	13	4	11	72	0	123
ID	53	40	7	0	0	15
IL	15	21	19	45	1	1,633
IA	22	20	23	34	0	331
KS	16	19	18	47	0	301
LA	21	21	15	41	1	471
MD	35	14	15	35	0	93
MA	6	11	22	61	0	334
MS	3	7	17	73	0	841
MO	13	19	29	39	0	309
NE	20	17	20	42	0	104
NV	23	28	30	20	0	40
NJ	11	8	13	69	0	1,272
NY	88	9	1	0	3	194
NC	5	10	18	66	0	1,132
ND	45	15	8	24	7	71
OH	21	37	16	26	0	628
PA	8	11	16	65	0	517
SC	16	21	8	53	1	146
SD	47	36	11	5	2	103
TX	20	18	16	46	0	2,909
UT	14	13	16	56	1	178
VA	0	4	18	78	0	45
WA	8	17	18	47	10	458
WI	4	7	32	58	0	113
WY	20	18	62	0	0	50
Reported US Total	17	16	17	49	1	14,792
Estimated US Total	17	17	17	49	0	16,200

Data Source: PRF 2019 Survey. N = 95 facilities DNF Data not furnished. 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.

Table 4.5 Age and Level of Intellectual Disabilities for Current, Newly or Readmitted, and Discharged Residents of PRFs in 2019

Characteristic	June 30, 2019 Residents		New & Readmissions		Discharges	
	Number	Percent	Number	Percent	Number	Percent
Reporting Facilities	95		75		79	
Age						
0-18 years	348	2%	165	17%	109	9%
19-21 years	344	2%	127	13%	82	7%
0 -21 years	692	5%	292	29%	191	15%
22-39 years	3,200	22%	479	48%	489	39%
40-62 years	6,996	47%	191	19%	365	29%
63+ years	3,905	26%	35	4%	184	15%
Age Unknown	0	0%	0	0%	9	1%
Level of ID						
Mild or None	2,551	17%	516	52%	515	43%
Moderate	2,434	16%	252	25%	251	21%
Severe	2,456	17%	100	10%	120	10%
Profound	7,246	49%	79	8%	296	25%
IDD Level Unknown	105	1%	48	5%	20	2%

Data Source: PRF Survey

Table 4.6 Previous Residence for People Admitted or Readmitted to PRFs and Subsequent Residence Type for People Discharged from PRFs 2019 (in Percent)

Setting Type	(Re) Admissions	Discharges
Number of reporting facilities	73	77
Total Reported (Re)Admissions/Discharges	955	1,177
Family home	18	8
Own, Host or Foster Family Home	5	8
IDD facility 1-6 residents	16	40
IDD facility 7-15 residents	5	3
IDD facility 16+ residents	5	7
Mental health facility	14	9
Correctional facility	29	17
Nursing home, Assisted Living, Boarding Home	8	8

Data Source: PRF survey, Previous residence was unknown for 43 (re)admissions (5%). Subsequent residence was unknown for 32 discharges (3%).

Table 4.7 Staff Characteristics and Outcomes in PRFs in FY 2019

Type of Staff	N Facilities	N FTE staff	FTE staff per resident
Direct Support Professionals (DSP)	89	26,960	2
Front Line Supervisors (FLS)	89	2,692	0
Turnover and Vacancy Rate		Rate	
DSP Vacancy Rate (%)	85	13	
DSP Turnover Rate (%)	85	36	
FLS Vacancy Rate (%)	85	8	
FLS Turnover Rate (%)	85	25	
Wages or Salary		Average	
DSP Starting Hourly Wage	87	15	
DSP Average Hourly Wage	87	17	
FLS Starting Salary	86	40,618	
FLS Average Salary	86	47,452	

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

Table 4.8 PRFs Open on June 30, 2019: 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 2019	All Residents June 2019	Average Daily IDD Population 2019	Residents With IDD June 2018	% Change 2018-2019	Average Daily Per Person Expenditures (\$)	Admissions/Readmissions	Discharges	Transfers	Deaths
AR	Arkadelphia Human Dev. Ctr. (Arkadelphia)	1968		116	116	116	116	0	405	2	5	7	0
AR	Booneville HDC (Booneville)	1972		129	127	127	124	4	395	16	0	10	1
AR	Conway HDC (Conway)	1959		469	471	477	471	-0	405	39	4	8	17
AR	Jonesboro HDC (Jonesboro)	1970		105	105	105	109	-4	400	4	0	4	3
AR	Southeast Arkansas HDC (Warren)	1978		96	96	96	DNF	DNF	430	8	2	3	0
AZ	Arizona Trng. Program (Coolidge)	1952		75	75	77	DNF	DNF	772	0	0	0	4
CA	Canyon Springs (Cathedral City)	2001		47	47	47	49	-4	1,270	7	0	8	1
CA	Fairview Dev. Ctr. (Costa Mesa)	1959	2020	43	43	91	104	-59	2,160	2	2	58	1
CA	Porterville Dev. Ctr. (Porterville)	1953	Dec 2021	238	238	256	269	-12	1,076	82	5	107	1
CO	Grand Junction Regional Ctr. (Grand Junction)	1919		22	22	22	21	5	1,367	6	1	3	2
CO	Wheat Ridge Regional Ctr. (Wheatridge)	1912		26	26	DNF	DNF	DNF	DNF	5	0	6	0
CT	Northwest Ctr. (Torrington)	1984		36	36	36	DNF	DNF	904	0	0	0	0
CT	Hartford Regional Center (Newington)	1965		46	51	46	45	2	1,350	1	0	0	1
CT	Lower Fairfield County Ctr. (Norwalk)	1976		65	65	65	67	-3	904	0	0	0	2
CT	Southbury Trng. School (Southbury)	1940		173	173	185	198	-13	1,250	0	0	7	18
DE	MAC Ctr. at Stockley (Georgetown)	1921		49	48	49	50	-2	1,324	1	0	0	2
FL	Developmental Disabilities Defendant Program (DDDP, Chattahoochee)	1977		86	86	107	DNF	DNF	89	0	103	1	DNF
FL	Sunland Ctr. (Marianna)	1961		243	243	256	260	-7	14	0	14	17	9
FL	Tachahale Ctr. / Sequin Unit (Gainesville)	1921		317	317	326	337	-6	1	0	8	13	10
GA	East Central Regional Hospital (Gracewood & Augusta)	1921		123	123	105	147	-16	0	0	24	9	8
GA	Georgia Regional Hospital of Atlanta (Decatur)	1968	2020	29	DNF	DNF	DNF	DNF	DNF	0	DNF	DNF	DNF
IA	Glenwood Resource Ctr. (Glenwood)	1876	2024	200	200	205	212	-6	887	3	0	2	13

Table 4.8 PRFs Open on June 30, 2019: 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 2019	All Residents June 2019	Average Daily IDD Population 2019	Residents With IDD June 2018	% Change 2018-2019	Average Daily Per Person Expenditures (\$)	Admissions/Readmissions	Discharges	Transfers	Deaths
IA	Woodward Resource Ctr. (Woodward)	1917		131	131	131	DNF	DNF	1,153	8	0	4	7
ID	Southwest Idaho Treatment Center (Nampa)	1918	2021	15	15	19	19	-21	1,177	10	0	15	0
IL	Choate Dev. Ctr. (Anna)	1873		150	150	150	190	-21	775	17	14	28	1
IL	Fox Dev. Ctr. (Dwight)	1965		85	85	89	92	-8	775	0	2	0	9
IL	Kiley Dev. Ctr. (Waukegan)	1975		201	201	198	195	3	810	15	3	7	5
IL	Ludeman Dev. Ctr. (Park Forest)	1972		368	368	376	382	-4	810	4	DNF	11	7
IL	Mabley Dev. Ctr. (Dixon)	1987		111	111	109	107	4	667	8	0	1	3
IL	Murray Dev. Ctr. (Centralia)	1964		242	242	231	225	8	810	25	4	5	4
IL	Shapiro Dev. Ctr. (Kankakee)	1879		476	477	511	469	1	743	31	5	23	7
KS	Kansas Neurological Institute (Topeka)	1960		139	139	138	DNF	DNF	497	4	1	3	4
KS	Parsons State Hospital (Parsons)	1952		162	162	161	DNF	DNF	DNF	9	0	7	2
LA	Louisiana Special Education Center (Alexandria)	1952		66	66	66	DNF	DNF	656	6	0	2	2
LA	Pinecrest Supports and Services Center (Pineville)	1918		405	405	398	393	3	722	9	0	33	8
MA	Hogan Regional Ctr. (Hawthorne)	1967		99	118	99	107	-7	1,072	0	0	0	8
MA	Wrentham Dev. Ctr. (Wrentham)	1907		235	235	248	DNF	DNF	880	1	0	1	27
MD	Holly Ctr. (Salisbury)	1975		49	51	49	DNF	DNF	308	4	0	0	5
MD	Potomac Ctr. (Hagerstown)	1978		44	44	45	39	13	803	19	0	14	0
MS	Boswell Regional Ctr. (Sanatorium)	1976		84	84	95	95	-12	380	6	10	10	3
MS	Ellisville State School (Ellisville)	1920		228	232	237	237	-4	383	14	0	12	11
MS	Hudspeth Regional Ctr. (Whitfield)	1974		198	198	195	217	-9	300	7	0	6	13
MS	Mississippi Adolescent Center (Brookhaven)	2011		32	32	31	DNF	DNF	425	14	DNF	17	DNF
MS	North Mississippi Regional Ctr. (Oxford)	1973		205	205	208	207	-1	322	11	9	3	2

Table 4.8 PRFs Open on June 30, 2019: 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 2019	All Residents June 2019	Average Daily IDD Population 2019	Residents With IDD June 2018	% Change 2018-2019	Average Daily Per Person Expenditures (\$)	Admissions/Readmissions	Discharges	Transfers	Deaths
MS	South Mississippi Regional Ctr. (Long Beach)	1978		94	94	99	104	-10	371	2	0	11	1
MO	Bellefontaine Habilitation Ctr. (St. Louis)	1924		106	107	107	112	-5	761	0	0	2	4
MO	Higginsville Habilitation Ctr. (Higginsville)	1956		45	49	45	48	-6	1,030	0	1	0	2
MO	Southeast Missouri Residential Services (Poplar Bluff and Sikeston)	1992		59	59	59	60	-2	572	0	0	0	0
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		98	98	49	104	-6	849	0	3	2	4
NE	Sheridan Cottages ICF (Beatrice)	1875		104	104	106	103	1	975	11	8	12	4
NV	Desert Regional Ctr. (Las Vegas)	1975		40	40	40	41	-2	DNF	20	0	21	0
NJ	Green Brook Regional Ctr. (Green Brook)	1981		85	85	92	95	-11	1,245	0	0	1	9
NJ	Hunterdon Dev. Ctr. (Clinton)	1969		444	444	450	457	-3	895	0	0	1	12
NJ	Vineland Dev. Ctr. (Vineland)	1888		189	189	194	196	-4	1,152	1	0	0	8
NJ	New Lisbon Dev. Ctr. (New Lisbon)	1914		301	301	305	313	-4	1,018	8	0	10	10
NJ	Woodbine Dev. Ctr. (Woodbine)	1921		253	253	256	260	-3	1,234	6	0	1	12
NY	Summount DDSO (Tupper Lake)	1965		150	150	DNF	152	DNF	DNF	31	0	35	0
NY	Valley Ridge (Norwich)	2000		46	24	DNF	45	2	DNF	10	0	8	0
NC	Caswell Ctr. (Kinston)	1914		300	301	306	314	-4	774	5	0	3	16
NC	J. Iverson Riddle Dev.Ctr. (Morganton)	1963		268	268	274	277	-3	663	9	0	10	8
NC	Murdoch Ctr. (Butner)	1957		389	393	392	405	-4	741	37	0	36	17
NC	O'Berry Ctr. (Goldsboro)	1957		175	175	180	188	-7	1,108	0	0	0	13
ND	Life Skills and Transition Center (Grafton)	1904		71	71	DNF	68	4	1,050	14	4	5	5
OH	Cambridge Dev. Ctr. (Cambridge)	1965		50	50	59	67	-25	704	7	1	21	3

Table 4.8 PRFs Open on June 30, 2019: 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 2019	All Residents June 2019	Average Daily IDD Population 2019	Residents With IDD June 2018	% Change 2018-2019	Average Daily Per Person Expenditures (\$)	Admissions/Readmissions	Discharges	Transfers	Deaths
OH	Columbus Dev. Ctr. (Columbus)	1857		116	116	114	115	1	642	26	0	23	2
OH	Gallipolis Dev. Ctr. (Gallipolis)	1893		50	50	51	51	-2	810	20	0	22	2
OH	Mount Vernon Dev. Ctr. (Mount Vernon)	1948		71	71	70	70	1	746	15	0	11	3
OH	Northwest Ohio Dev. Ctr. (Toledo)	1977		76	76	DNF	DNF	DNF	DNF	3	0	17	0
OH	Southwest Ohio Dev. Ctr. (Batavia)	1981		102	102	105	DNF	DNF	621	24	0	28	1
OH	Tiffin Dev. Ctr. (Tiffin)	1975		76	76	75	76	0	611	21	0	15	6
OH	Warrensville Dev. Ctr. (Warrensville)	1975		87	89	89	DNF	DNF	792	35	0	31	4
PA	Ebensburg Ctr. (Ebensburg)	1957		DNF	DNF	DNF	211	DNF	DNF	DNF	DNF	DNF	DNF
PA	Polk Ctr. (Polk)	1897	Nov 2022	196	196	202	208	-6	1,042	1	0	2	11
PA	Selinsgrove Ctr. (Selinsgrove)	1929		209	209	210	222	-6	1,025	1	2	10	6
PA	White Haven Ctr. (White Haven)	1956	Nov 2022	112	112	112	121	-7	1,008	0	2	3	8
SC	Coastal Ctr. (Ladson)	1968		146	146	146	DNF	DNF	474	5	5	2	6
SC	Midlands Ctr. (Columbia)	1956		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
SC	Pee Dee Regional Ctr. (Florence) and Thad E. Saleeby Ctr. (Hartsville)	1971		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
SC	Whitten Ctr. (Clinton)	1920		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
SD	South Dakota Dev. Ctr. (Redfield)	1902		103	103	107	116	-11	592	15	0	28	0
TX	Abilene State School (Abilene)	1957		263	263	264	269	-2	935	3	1		8
TX	Austin State School (Austin)	1917		179	179	178	177	1	935	4	7	2	7
TX	Brenham State School (Brenham)	1974		248	248	249	254	-2	935	8	1	6	5
TX	Corpus Christi State School (Corpus Christi)	1970		188	188	194	205	-8	935	3	1	8	10
TX	Denton State School (Denton)	1960		448	448	447	449	-0	935	18	2	11	10
TX	El Paso State Ctr. (El Paso)	1973		95	95	95	94	1	935	3	0	1	1
TX	Lubbock State School (Lubbock)	1969		188	188	183	184	2	935	13	3	3	7

Table 4.8 PRFs Open on June 30, 2019: 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 2019	All Residents June 2019	Average Daily IDD Population 2019	Residents With IDD June 2018	% Change 2018-2019	Average Daily Per Person Expenditures (\$)	Admissions/Readmissions	Discharges	Transfers	Deaths
TX	Lufkin State School (Lufkin)	1962		280	280	284	289	-3	935	4	1	6	7
TX	Mexia State School (Mexia)	1946		246	246	227	240	3	935	47	8	40	2
TX	Richmond State School (Richmond)	1968		315	315	320	321	-2	935	9	2	4	10
TX	Rio Grande State Ctr. (Harlingen)	1973		63	63	61	62	2	935	5	2	5	0
TX	San Angelo State School (Carlsbad)	1969		191	191	191	202	-5	935	15	2	14	9
TX	San Antonio State School (San Antonio)	1978		206	206	215	223	-8	935	2	3	9	8
UT	Utah State Dev. Ctr. (American Fork)	1931		178	176	180	185	-4	664	10	123	30	4
VA	Central Virginia Trng. Ctr. (Lynchburg)	1911	April 2020	45	45	65	86	-48	1,402	4	0	41	4
VA	Southeastern Virginia Trng. Ctr. (Chesapeake)	1975		DNF	DNF	DNF	73	DNF	DNF	DNF	DNF	DNF	DNF
WA	Fircrest (Seattle)	1959		DNF	DNF	DNF	176	DNF	DNF	DNF	DNF	DNF	DNF
WA	Lakeland Village School (Medical Lake)	1915		174	186	180	160	9	980	25	0	1	11
WA	DSHS Rainier School (Buckley)	1939		219	293	264	276	-21	867	1		68	7
WA	Yakima Valley School (Selah)	1958		65	78	69	56	16	996	3	0	0	1
WI	Central Wisconsin Ctr. (Madison)	1959		DNF	DNF	DNF	189	DNF	DNF	DNF	DNF	DNF	DNF
WI	Southern Wisconsin Ctr. (Union Grove)	1919		113	123	132	131	-14	963	0	0	0	6
WY	Wyoming Life Resource Ctr. (Lander)	1912		51	59	56	58	-12	725	3	DNF	7	4

Data Source: PRF Survey

Table 4.9 Final Status of PRFs Closed, Privatized, Converted for Use by Another Population, Downsized to Less than 16 people, Merged or Otherwise No Longer in Operation as of June 30, 2019

State	Facility Name at Closure, Downsizing or Conversion	Year Opened	Final Status	
			Fiscal Year	Disposition ¹
AL	Albert P. Brewer Dev. Ctr. (Daphne)	1973	2004	
AL	Glen Ireland II Ctr. (Tarrant City)	1986	1996	
AL	J.S. Tarwater Dev. Ctr. (Wetumpka)	1976	2004	
AL	Lurleen B. Wallace Dev. Ctr. (Decatur)	1971	2003	
AL	Wm. D. Partlow Dev. Ctr. (Tuscaloosa)	1923	2011	
AK	Harborview Ctr. (Valdez)	1967	1997	
AZ	Arizona State Hospital (Phoenix)	1978	1994	
AZ	Arizona Trng. Program (Phoenix)	1973	1988	
AZ	Arizona Trng. Program (Tucson)	1970	1995	
AR	Alexander Human Dev. Ctr. (Alexander)	1968	2011	
CA	Agnews Dev. Ctr. (San Jose)	1966	2009	
CA	Camarillo Ctr. (Camarillo)	1968	1997	
CA	DeWitt State Hospital (Auburn)	1946	1972	
CA	Lanterman Dev. Ctr. (Pomona)	1927	2014	
CA	Modesto State Hospital (Modesto)	1947	1962	
CA	Napa State Hospital Forensic Unit (Napa)	1995	2000	
CA	Patton State Hospital (Patton)	1963	1982	
CA	Sierra Vista (Yuba City)	2000	2009	
CA	Sonoma Dev. Ctr. (Eldridge)	1891	2019	Closed
CA	Stockton Ctr. (Stockton)	1972	1996	
CO	Pueblo State Regional Ctr. (Pueblo)	1935	1988	
CT	Bridgeport Ctr. (Bridgeport)	1965	1981	
CT	Clifford Street Group Home (Hartford)	1982	1995	
CT	Ella Grasso Ctr. (Stratford)	1981	2017	Closed
CT	John Dempsey Ctr. (Putnam)	1964	1997	
CT	Mansfield Trng. School (Mansfield)	1917	1993	
CT	Martin House Group Home (Norwalk)	1971	2000	
CT	Meridan Ctr. (Wallingford)	1979	2016	Downsized
CT	Mystic Ctr. (Groton)	1979	2010	
CT	New Haven Ctr. (New Haven)	1962	1994	
CT	Seaside Ctr. (Waterford)	1961	1996	
CT	Waterbury Ctr. (Cheshire)	1971	1989	
DC	Bureau of Forest Haven (Laurel, MD)	1925	1990	
DC	D.C. Village (Washington, DC)	1975	1994	
DC	St. Elizabeth's Hospital (Washington, DC)	1987	1994	
FL	Community of Landmark (Miami)	1966	2005	
FL	Florida State Hospital Unit 27 now with DDDP (Chattahoochee)	1976	2015	Merged
FL	Gulf Coast Ctr. (Fort Meyers)	1960	2010	
FL	N.E. Florida State Hospital (MacClenny)	1981	2000	
FL	Seguin Unit now with DDDP (Gainesville)	1989	2015	Merged
FL	Sunland Trng. Ctr. (Orlando)	1960	1984	
FL	Sunland Trng. Ctr. (Tallahassee)	1968	1983	
GA	Brook Run (Atlanta)	1969	1997	
GA	Central State Hospital (Milledgeville)	1842	2012	Converted

Table 4.9 Final Status of PRFs Closed, Privatized, Converted for Use by Another Population, Downsized to Less than 16 people, Merged or Otherwise No Longer in Operation as of June 30, 2019

State	Facility Name at Closure, Downsizing or Conversion	Year Opened	Final Status	
			Fiscal Year	Disposition ¹
GA	Georgia Regional Hospital (Savannah)	2000	2005	
GA	Gracewood State School and Hospital, now East Central (Gracewood)	1921	2015	Merged
GA	Northwest Regional Hospital (Rome)	1971	2011	
GA	River's Crossing (Athens)		1996	
GA	Rose Haven (Thomasville)	1968	2000	
GA	Southwestern Development Center (Bainbridge)	1967	2000	
GA	Southwestern State Hospital (Thomasville)	1967	2013	
GA	West Central Georgia Regional Hospital (Columbus)	2000	2004	
HI	Kula Hospital (Kula)	1984	1994	
HI	Waimano Trng. School and Hospital (Pearl City)	1921	1999	
IL	Alton Mental Health & Dev. Ctr. (Alton)	1914	1994	
IL	Bowen Ctr. (Harrisburg)	1966	1982	
IL	Dixon Ctr. (Dixon)	1918	1987	
IL	Elgin Mental Health & Dev. Ctr. (Elgin)	1872	1994	
IL	Galesburg Ctr. (Galesburg)	1959	1985	
IL	Howe Dev. Ctr. (Tinley Park)	1973	2010	
IL	Jacksonville Dev. Ctr. (Jacksonville)	1851	2012	
IL	Lincoln Dev. Ctr. (Lincoln)	1866	2002	
IL	Meyer Mental Health Ctr. (Decatur)	1967	1993	
IL	Singer Mental Health & Dev. Ctr. (Rockford)	1966	2002	
IN	Central State Hospital (Indianapolis)	1848	1995	
IN	Evansville State Hospital (Evansville)	1890	2011	
IN	Fort Wayne Dev. Ctr. (Fort Wayne)	1890	2007	
IN	Logansport State Hospital (Logansport)	1888	2012	Converted
IN	Madison State Hospital (Madison)	1910	2012	Converted
IN	Muscatatuck Dev. Ctr. (Butlerville)	1920	2005	
IN	New Castle Ctr. (New Castle)	1907	1998	
IN	Norman Beatty Memorial Hospital (Westville)	1951	1979	
IN	Northern Indiana Ctr. (South Bend)	1961	1998	
IN	Richmond State Hospital (Richmond)	1890	2010	
IN	Silvercrest State Hospital (New Albany)	1974	1995	
KS	Norton State Hospital (Norton)	1963	1988	
KS	Winfield State Hospital (Winfield)	1884	1998	
KY	Frankfort State Hospital and School (Frankfort)	1860	1973	
KY	Bingham Gardens (Louisville)	1873	2019	Privatized
KY	Hazelwood Ctr. (Louisville)	1971	2018	Privatized
KY	Bluegrass Oakwood ICF/IID (Somerset)	1972	2006	Privatized
KY	Outwood ICF/IID (Dawson Springs)	1962	1994	Privatized
LA	Acadiana Region Supports and Services Center (Iota)	1972	2011	Privatized
LA	Bayou Region Supports and Services Center (Thibodaux)	1982	2010	Closed
LA	Columbia Dev. Ctr. (Columbia)	1970	2009	Downsized
LA	Leesville Dev. Ctr. (Leesville)	1964	2012	Downsized
LA	Metropolitan Development Center	1967	2007	
LA	North Lake Supports and Services Center (Hammond)		2012	Privatized

Table 4.9 Final Status of PRFs Closed, Privatized, Converted for Use by Another Population, Downsized to Less than 16 people, Merged or Otherwise No Longer in Operation as of June 30, 2019

State	Facility Name at Closure, Downsizing or Conversion	Year Opened	Final Status	
			Fiscal Year	Disposition ¹
LA	Northeast Supports and Services Center (Ruston)	1959	2010	
LA	Northwest Louisiana Dev. Ctr. (Bossier City)	1973	2012	
ME	Aroostook Residential Ctr. (Presque Isle)	1972	1995	
ME	Elizabeth Levinson Ctr. (Bangor)	1971	1998	
ME	Pineland Ctr. (Pownal)	1908	1995	
MD	Great Oaks Ctr. (Silver Springs)	1970	1996	
MD	Henryton Ctr. (Henryton)	1962	1985	
MD	Highland Health Facility (Baltimore)	1972	1989	
MD	Joseph Brandenburg Ctr. (Cumberland)	1978	2011	
MD	Rosewood Ctr. (Owings Mills)	1887	2009	
MD	Victor Cullen Ctr. (Sabillasville)	1974	1992	
MD	Walter P. Carter Ctr. (Baltimore)	1978	1990	
MA	Belchertown State School (Belchertown)	1922	1992	
MA	Berry Regional Ctr. (Hawthorne)	1967	1994	
MA	Glavin Regional Ctr. (Shrewsbury)	1974	2013	Closed
MA	Medfield State Hospital (Medfield)	1898	1994	
MA	Monson Dev. Ctr. (Palmer)	1898	2012	
MA	Paul A. Dever Dev. Ctr. (Taunton)	1946	2001	
MA	Templeton Dev Ctr (Baldwinsville)	1967	2015	Closed
MA	The Fernald Ctr. (Waltham)	1848	2014	Downsized
MA	Worcester State Hospital (Worcester)	1833	1994	
MI	Alpine Regional Ctr. for DD (Gaylord)	1960	1981	
MI	Caro Regional Mental Health Ctr. (Caro)	1914	1997	
MI	Coldwater Regional Ctr. for DD (Coldwater)	1935	1987	
MI	Fort Custer State Home (Augusta)	1956	1972	
MI	Hillcrest Regional Ctr. for DD (Howell)	1959	1982	
MI	Macomb-Oakland Regional Ctr. for DD (Mt. Clemens)	1967	1989	
MI	Mount Pleasant Ctr. (Mount Pleasant)	1937	2009	
MI	Muskegon Regional Ctr. for DD (Muskegon)	1969	1992	
MI	Newberry Regional Mental Health Ctr. (Newberry)	1895	1992	
MI	Northville Residential Trng. Ctr. (Northville)	1972	1983	
MI	Oakdale Regional Ctr. for DD (Lapeer)	1895	1992	
MI	Plymouth Ctr. for Human Development (Northville)	1960	1984	
MI	Southgate Regional Ctr. (Southgate)	1977	2002	
MN	Brainerd Regional Human Services Ctr. (Brainerd)	1958	1999	
MN	Faribault Regional Ctr. (Faribault)	1879	1998	
MN	Fergus Falls Regional Treatment Ctr. (Fergus Falls)	1969	2000	
MN	MN Ext. Treatment Options Program (Cambridge)	1997	2011	Converted
MN	Moose Lake Regional Treatment Ctr. (Moose Lake)	1970	1994	
MN	Owatonna State Hospital (Owatonna)	1945	1972	
MN	Rochester State Hospital (Rochester)	1968	1982	
MN	St. Peter Regional Treatment Ctr. (St. Peter)	1968	1996	
MN	Willmar Regional Treatment Ctr. (Willmar)	1973	1996	
MO	Albany Regional Ctr. (Albany)	1967	1989	

Table 4.9 Final Status of PRFs Closed, Privatized, Converted for Use by Another Population, Downsized to Less than 16 people, Merged or Otherwise No Longer in Operation as of June 30, 2019

State	Facility Name at Closure, Downsizing or Conversion	Year Opened	Final Status	
			Fiscal Year	Disposition ¹
MO	Hannibal Regional Ctr. (Hannibal)	1967	1991	
MO	Joplin Regional Ctr. (Joplin)	1967	1992	
MO	Kansas City Regional Ctr. (Kansas City)	1970	1993	
MO	Kirksville Regional Ctr. (Kirksville)	1968	1988	
MO	Marshall Habilitation Ctr. (Marshall)	1901	2015	
MO	Midtown Habilitation Ctr. (St. Louis)		2004	
MO	Northwest Habilitation Ctr. (St. Louis)	2002	2012	
MO	Poplar Bluff Regional Ctr. (Poplar Bluff)	1968	1992	
MO	Rolla Regional Ctr. (Rolla)	1968	1984	
MO	Sikeston Regional Ctr. (Sikeston)	1969	1992	
MO	Southwest Community Services (Nevada)	1973	2017	Converted
MO	Springfield Regional Ctr. (Springfield)	1967	1990	
MT	Eastmont Human Services Ctr. (Glendive)	1969	2003	
MT	Montana Developmental Ctr. (Boulder)	1905	2017	Downsized
NV	Sierra Regional Ctr. (Sparks)	1977	2008	
NH	Laconia State School and Trng. Ctr. (Laconia)	1903	1991	
NH	New Hampshire Hospital, Brown Building (Concord)	1842	1990	
NJ	Ctr. at Ancora (Hammonton)		1992	
NJ	E.R. Johnstone Trng. & Research Ctr. (Bordentown)	1955	1992	
NJ	Edison Habilitation Ctr. (Princeton)	1975	1988	
NJ	North Jersey Dev Ctr (Totowa)	1928	2014	Closed
NJ	North Princeton Ctr. (Princeton)	1975	1998	
NJ	Woodbridge Dev Ctr (Woodbridge)	1965	2015	Closed
NM	Fort Stanton Hospital and Trng. Ctr. (Fort Stanton)	1964	1995	
NM	Los Lunas Hospital and Trng. Ctr. (Los Lunas)	1929	1997	
NM	Villa Solano-Hagerman Residential School (Roswell)	1964	1982	
NY	Bernard M. Fineson Dev. Ctr. (Hillside; Howard Park)	1970	2017	Closed
NY	Bronx DDSO (Bronx)	1971	1992	
NY	Brooklyn DDSO (Brooklyn)	1972	2015	
NY	Broome DDSO (Binghamton)	1970	2016	
NY	Capital District DDSO (Schenectady)	1973	2015	Closed
NY	Central New York DDSO (Syracuse)	1851	1998	
NY	Craig DDSO (Sonyea)	1935	1988	
NY	Finger Lakes DDSO (Rochester)	1969	2013	Closed
NY	Gouverneur (New York)	1962	1978	
NY	Hudson Valley DDSO (Thiells)	1911	2000	
NY	J.N. Adams (Perrysburg)	1960	1993	
NY	Long Island DDSO (Commack)	1965	1993	
NY	Long Island Suffolk DDSO (Melville)	1965	1992	
NY	Manhattan Ctr. (New York)	1972	1992	
NY	Newark Ctr. (Newark)	1878	1991	
NY	Rome Ctr. (Rome)	1894	1989	
NY	Sampson State School (Willard)	1961	1971	
NY	Staten Island (Staten Island)	1987	2012	

Table 4.9 Final Status of PRFs Closed, Privatized, Converted for Use by Another Population, Downsized to Less than 16 people, Merged or Otherwise No Longer in Operation as of June 30, 2019

State	Facility Name at Closure, Downsizing or Conversion	Year Opened	Final Status	
			Fiscal Year	Disposition ¹
NY	Taconic DDSO (Wassaic)	1930	2013	Closed
NY	Valatie (Valatie)	1971	1974	
NY	Westchester NY DDSO (Tarrytown)	1979	1988	
NY	Western NY DDSO (West Seneca)	1962	2011	
NY	Willowbrook State School (Staten Island)	1947	1988	
NY	Wilton DDSO (Wilton)	1960	1995	
NC	Black Mountain Ctr. (Black Mountain)	1982	2020	Converted
NC	Broughton Ctr. (Morganton)	1883	1994	
ND	San Haven State Hospital (Dunseith)	1973	1987	
OH	Apple Creek Dev. Ctr. (Apple Creek)	1931	2006	
OH	Athens Mental Health & Dev. Ctr. (Athens)	1975	1994	
OH	Broadview Ctr. (Broadview Hghts.)	1967	1992	
OH	Cambridge Mental Health Ctr. (Cambridge)	1978	1990	
OH	Central Ohio Psychiatric Hospital (Cleveland)	1978	1994	
OH	Cleveland Ctr. (Cleveland)	1976	1988	
OH	Dayton Ctr. (Dayton)	1979	1983	
OH	Dayton Mental Health Ctr. (Dayton)	1978	1994	
OH	Massillon State Hospital (Massillon)	1978	1994	
OH	Montgomery Dev. Ctr. (Huber Heights)	1981	2017	
OH	Orient Ctr. (Orient)	1898	1984	
OH	Springview Developmental Ctr. (Springfield)	1975	2005	
OH	Western Reserve Psychiatric Hab. Ctr. (Northfield)	1978	1990	
OH	Youngstown Ctr. (Mineral Ridge)	1980	2017	
OK	Hisson Memorial Ctr. (Sand Springs)	1964	1994	
OK	Northern Oklahoma Resource Center (Enid)	1909	2014	Closed
OK	Robert M. Greer Memorial Ctr. (Enid)	1992	2000	Privatized
OK	Southern Oklahoma Resource Center (Pauls valley)	1952	2016	Closed
OR	Columbia Park Hospital & Trng. Ctr. (The Dalles)	1963	1977	
OR	Eastern Oregon Trng. Ctr. (Pendleton)	1964	2009	
OR	Fairview Trng. Ctr. (Salem)	1908	2000	
PA	Allentown Mental Retardation Unit (Allentown)	1974	1988	
PA	Altoona Ctr. (Altoona)	1982	2006	
PA	Clarks Summit Mental Retardation Unit (Clarks Summit)	1974	1992	
PA	Cresson Ctr. (Cresson)	1964	1982	
PA	Embreeville Ctr. (Coatesville)	1972	1997	
PA	Hamburg Ctr. (Hamburg)	1960	2019	Closed
PA	Harrisburg Mental Retardation Unit (Harrisburg)	1972	1982	
PA	Hollidaysburg Mental Retardation Ctr. (Hollidaysburg)	1974	1976	
PA	Laurelton Ctr. (Laurelton)	1920	1998	
PA	Marcy Ctr. (Pittsburgh)	1975	1982	
PA	Mayview Mental Retardation Unit (Mayview)	1974	2001	
PA	Pennhurst Ctr. (Pennhurst)	1908	1988	
PA	Philadelphia Mental Retardation Unit (Philadelphia)	1983	1989	
PA	Somerset Mental Retardation Unit (Somerset)	1974	1996	

Table 4.9 Final Status of PRFs Closed, Privatized, Converted for Use by Another Population, Downsized to Less than 16 people, Merged or Otherwise No Longer in Operation as of June 30, 2019

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

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

Table 4.10 Operational Status of PRFs by State on June 30, 2019 with Projected Closures through June 2024

State	Operating Between 1960 and 2018	Closed, Converted or Downsized ¹		Open June 30, 2019	Projected to Close July 2019 - June 2024
		1960 to 2018	FY 2019		
AL	5	5	0	0	0
AK	1	1	0	0	0
AZ	4	3	0	1	0
AR	6	1	0	5	0
CA	13	9	1	3	2
CO	3	1	0	2	0
CT	15	11	0	4	0
DE	1	0	0	1	0
DC	3	3	0	0	0
FL	10	7	0	3	0
GA	13	11	0	2	1
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	4	1	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	13	0	5	0
MT	2	2	0	0	0
NE	1	0	0	1	0
NV	2	1	0	1	0
NH	2	2	0	0	0
NJ	11	6	0	5	0
NM	3	3	0	0	0
NY	45	40	0	5	0
NC	6	2	0	4	0
ND	2	1	0	1	0
OH	22	14	0	8	0
OK	4	4	0	0	0
OR	3	3	0	0	0
PA	23	18	1	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	0	2	1
WA	6	2	0	4	0
WV	4	4	0	0	0
WI	3	1	0	2	0
WY	1	0	0	1	0
Reported US Total	376	264	3	109	8
% of Total	100%	70%	1%	29%	2%

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

Table 4.11 Average Daily Population and People Per 100,000 of the US Population of PRFs and People with IDD in State-Operated Psychiatric Facilities, Selected Years 1890-2019

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				630	8		
1910	19,499				922	21		
1923	47,963				1,119	43		
1930	68,035				1,232	55		
1935	89,760				1,273	71		
1940	106,944				1,322	81		
1945	114,018				1,399	81		
1950	124,304	23,905	148,209	16%	1,513	82	16	98
1955	138,831	34,999	173,830	20%	1,651	84	21	105
1960	163,730	37,641	201,371	19%	1,807	91	21	111
1965	187,305	36,285	223,590	16%	1,651	113	22	135
1967	194,650	33,850	228,500	15%	1,987	98	17	115
1970	186,743	31,884	218,627	15%	2,051	91	16	107
1975	162,654	22,881	185,535	12%	2,160	75	11	86
1977	151,532	15,524	167,056	9%	2,202	69	7	76
1980	131,345	9,405	140,750	7%	2,277	58	4	62
1985	109,614	4,536	114,150	4%	2,385	46	2	48
1987	95,886 ⁱ	2,520 ⁱ	98,406	3%	2,428	39	1	41
1990	84,239	1,487	85,726	2%	2,500	34	1	34
1995	63,762	1,381	65,143	2%	2,631	24	1	25
1997	56,161	1,075	57,236	2%	2,680	21	0	21
2000	47,872	488	48,360	1%	2,824	17	0	17
2005	40,532	396	40,928	1%	2,962	14	0	14
2006	38,810	361	39,171	1%	2,990	13	0	13
2007	37,172	782	37,954	2%	3,020	12	0	13
2008	35,651	300	35,951	1%	3,018	12	0	12
2009	33,682	417	34,099	1%	3,074	11	0	11
2010	31,654	873	32,527	3%	3,087	10	0	11
2011	29,809	864	30,673	3%	3,116	10	0	10
2012	28,146	1,075	29,221	4%	3,139	9	0	9
2013	23,724	1,151	24,875	5%	3,161	8	0	8
2014	22,262	1,295	23,557	5%	3,189	7	0	7
2015	21,084	2,094	23,178	9%	3,214	7	1	7
2016	19,502	2,044	21,546	9%	3,231	6	1	7
2017	18,516	1,964	20,480	10%	3,257	6	1	6
2018	17,596	1,660	19,256	9%	3,255	5	1	6
2019	16,862	1,318	18,180	7%	3,282	5	0	6

Data Source: RISP survey, ¹Number of states not reporting on psychiatric settings by year: 2000 (1); 2001 (3); 2002 (3); 2003 (3); 2004 (2); 2005 (3); 2006, 2007 and 2008 (4); 2009 (3); 2010 (5); 2011 (6) 2012 (0); 2013 (21); 2014 (16); 2015 (10); 2016 (9); 2017 (14); 2018 (17); 2019 (22) ⁱData imputed based on adjacent years



Table 4.12 Average Daily PRF Population by State Selected Years 1980 to 2019

State	Average Daily Population										% Change 2010- 2019
	1980	1985	1990	1995	2000	2005	2010	2015	2018	2019	
N States	51	51	51	47	42	42	40	37	32		31
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	83	77	-35
AR	1,550	1,254	1,260	1,262	1,229	1,079	1,067	913	905	905	-15
CA	8,812	7,524	6,768	5,494	3,879	3,307	2,149	1,077	660	395	-82
CO	1,353	1,125	466	241	129	110	DNF	28	24	23	DNF
CT	2,944	2,905	1,799	1,316	992	847	705	493	361	185	-74
DE	518	433	345	308	256	123	71	54	49	49	-31
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	698	685	-29
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	21	17	-75
IL	6,067	4,763	4,493	3,775	3,237	2,833	2,183	1,723	1,662	1,667	-24
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	346	DNF	DNF
KS	1,327	1,309	1,017	756	379	360	340	311	301	299	-12
KY	907	671	709	679	628	489	170	263	266	0	N/A
LA	3,171	3,375	2,622	2,167	1,749	1,571	1,144	453	509	499	-56
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	94	-32
MA	4,531	3,580	3,000	2,110	1,306	1,089	759	478	379	359	-53
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	964	1,426	8
MO	2,257	1,856	1,860	1,492	1,286	1,152	671	410	317	308	-54
MT	316	258	235	163	131	84	52	52	0	0	N/A
NE	707	488	466	414	401	372	182	114	109	106	-42
NV	148	172	170	160	157	93	47	47	45	40	-15
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	1,362	1,298	-52
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	1,205	1,142	-25
ND	1,056	763	232	156	144	140	120	82	68	70	-42
OH	5,045	3,198	2,665	2,150	1,996	1,728	1,376	923	660	640	-53
OK	1,818	1,505	935	618	391	368	270	16	0	51	-81
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	825	742	-38
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	672	673	-14
SD	678	557	391	345	196	172	149	139	117	114	-23
TN	2,074	2,107	1,932	1,669	948	680	416	127	0	0	-100
TX	10,320	9,638	7,320	5,459	5,431	4,977	4,337	3,241	2,964	2,912	-33
UT	778	706	462	357	240	230	215	208	188	180	-16
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	187	78	-93
WA	2,231	1,844	1,758	1,320	1,143	973	914	777	681	744	-19
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	314	300	-33
WY	473	413	367	151	113	98	83	72	61	61	-26
Estimated US Total	131,345	109,614	84,239	63,762	47,872	40,532	31,654	21,084	17,596	16,862	-47

Data Source: RISP Survey, d Other date (Usually a different fiscal year or the previous year). e Estimate. DNF Did not furnish. N/A No people in large state facilities in 2010, 2015, or both. * See state notes in the Appendix. Oklahoma reported closing its last state run IDD facility in 2015. The 51 people listed for 2019 are in an ICF/IDD facility run by a public entity other than the state.

Table 4.13 Change in Estimated Average Daily Population and Annual Admissions, Discharges and Deaths in PRFs Selected Years 1950-2019

Year	Average Daily Population	Annual Number of			Net 1 year Change
		Admissions	Discharges	Deaths	
1950	124,304	12,197	6,672	2,761	
1955	138,831	13,906	5,845	2,698	5,363
1960	163,730	14,182	6,451	3,133	4,598
1965	187,305	17,225	9,358	3,585	4,282
1967	194,650	14,904	11,665	3,635	(396)
1970	186,743	14,979	14,702	3,496	(3,219)
1975	168,214	18,075	16,807	2,913	(1,645)
1980	128,058	11,141	13,622	2,019	(4,500)
1985	109,614	6,276	8,619	1,508	(3,851)
1990	84,732	5,034	6,877	1,207	(3,050)
1995	63,697	2,338	5,337	1,068	(4,067)
2000	47,872	1,936	2,425	915	(1,404)
2005	40,532	2,106	2,561	909	(1,364)
2010	30,602	1,833	2,690	820	(1,677)
2011	29,809	1,593	2,690	810	(1,907)
2012	27,665	1,141	2,436	747	(2,042)
2013	24,779	1,184	2,453	630	(1,899)
2014	22,437	1,235	1,997	643	(1,406)
2015	21,084	1,248	1,921	661	(1,334)
2016	19,502	1,014	1,897	635	(1,518)
2017	18,516	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)

Data Source: RISP Survey

Table 4.14 Annual Per Person Expenditures for People with IDD in PRFs Selected Years 1950-2019

Year	Cost (\$)	Cost (\$1=2019) ^s
1950	746	7,914
1955	1,286	12,267
1960	1,868	16,134
1965	2,361	19,162
1970	4,635	30,543
1975	10,155	48,256
1980	24,944	77,392
1985	44,271	105,188
1990	71,660	140,171
1995	85,760	142,188
2000	113,863	169,047
2005	148,811	194,801
2010	195,197	228,381
2011	226,106	257,761
2012	237,149	263,235
2013	246,063	270,670
2014	235,856	254,724
2015	263,196	284,252
2016	278,858	298,378
2017	253,187	263,314
2018	274,173	279,656
2019	281,952	281,952

Data Sources: RISP Survey, s: Inflation <https://data.bls.gov/cgi-bin/cpicalc.pl>

Table 4.15 PRF Population Characteristics June 30 of Selected Years 1977 to 2019 (in percent)

Characteristic (Percent)	Year									
	1977	1987	1998	2008	2014	2016	2017	2018	2019	
Estimated total residents	151,112	94,695	51,485	35,035	21,600	19,081	18,239	17,353	16,200	
Gender	Male	57%	57%	60%	63%	64%	58%	64%	64%	64%
Age	0-21 Years	36	13	5	5	4	4	4	4	5
	22-39 Years	41	54	38	23	19	19	20	21	22
	40-62 Years	19	27	49	61	58	55	52	50	47
	63+ Years	4	6	8	12	19	21	24	25	26
Race	White							71	70	
	Black/African American							19	20	
	Hispanic/Latino							7	7	
	Other Race or Multiple Races							3	3	
Level of Intellectual Disability	Mild/No ID	10	7	8	14	14	14	14	14	17
	Moderate	16	10	10	12	14	14	14	15	17
	Severe	28	20	18	16	17	14	16	17	17
	Profound	46	63	65	58	54	53	55	54	49
Other Conditions	Epilepsy			46	44	47	40	39	37	39
	Autism					18	19	19	20	23
	Cerebral Palsy	19	21	24	23	19	15	17	16	16
	Behavior Disorder	25	41	44	52	51	42	44	58	61
Prior Criminal Justice Involvement					5	4	5	5	7	
Short Term Stays					3	5	4	3	4	

Data Source: PRF Survey

Table 4.16 Previous Place of Residence of Persons (Re) Admitted to Large State IDD Facilities (in Percent) for Selected Years 1985 to 2019

Previous Place of Residence	Year									
	1985	1989	1994	1998	2002	2008	2012	2016	2018	2019
Home of parents or relative	39	29	19	21	19	21	24	17	18	18
Own, Host or Foster Family Home	5	7	2	4	5	7	8	4	3	5
Group home (1-6 res.)							6	12	18	16
Group home (7-15 res.)							5	3	3	5
Group home (15 or fewer res.)	6	8	14	14	16	22	11	15	21	20
State or Nonstate IDD Facility (16+ res.)	26	23	32	31	22	20	14	14	6	5
Mental health facility	14	16	16	12	16	13	14	17	18	14
Correctional facility	2	3	4	10	13	8	13	17	22	29
Nursing home, Assisted Living, Boarding Home	9	15	10	8	9	8	16	17	12	8

Source: PRF Survey

Table 4.17 Subsequent Residence of People with IDD Discharged From a Public IDD Facility: Selected Years 1985 to 2019

New Place of Residence	Year												
	1985	1989	1994	1998	2002	2008	2010	2012	2014	2016	2017	2018	2019
Home of parents or relative	17	12	9	11	14	7	8	10	8	11	8	6	8
Own, Host/Foster family home	9	9	13	16	11	10	12	15	13	3	6	5	8
Group home (1-6 res.)								35	47	22	50	57	40
Group home (7-15 res.)								9	6	4	6	2	3
Group home (15 or fewer res.)	40	49	56	51	46	47	51	44	54	26	55	59	43
Group IDD facility (16+ res.)	21	18	16	11	10	15	15	18	12	35	9	5	7
Mental health facility	1	1	1	2	2	4	2	2	2	3	4	7	9
Correctional facility	0	1	0	-	3	2	2	1	7	3	8	9	17
Nursing home, Assisted Living, Boarding Home	11	9	10	11	14	17	11	10	5	19	10	10	8
Total (may not add to 100 due to rounding)	100	100	105	100	99	100	100	100	100	100	100	100	100

Data Source: PRF Survey, Percentages exclude unknown.

Table 4.18 Percent of PRFs Providing Services to People Not Living On-Campus by Type of Service 2000 to 2019

Type of Service	Year												
	2000	2002	2004	2006	2008	2010	2012	2014	2016	2017	2018	2019	
Behavioral assessment and intervention	51	48	40	53	51	52	33	29	26	21	16	31	
Dental	41	39	34	43	32	38	32	24	26	24	8	24	
Crisis support	44	41	30	40	42	37	26	22	19	12	12	23	
Respite	56	50	38	17	46	38	23	21	14	14	13	19	
Consultant health services	29	28	25	32	25	22	14	22	7	10	8	19	
Vocational training	25	31	26	9	29	24	21	20	9	15	4	13	
Other	15	11	10	10	7	9	12	5	7	8	8	12	
Average number of services provided	6	5	4	5	5	4	3	3	2	1	1	1	

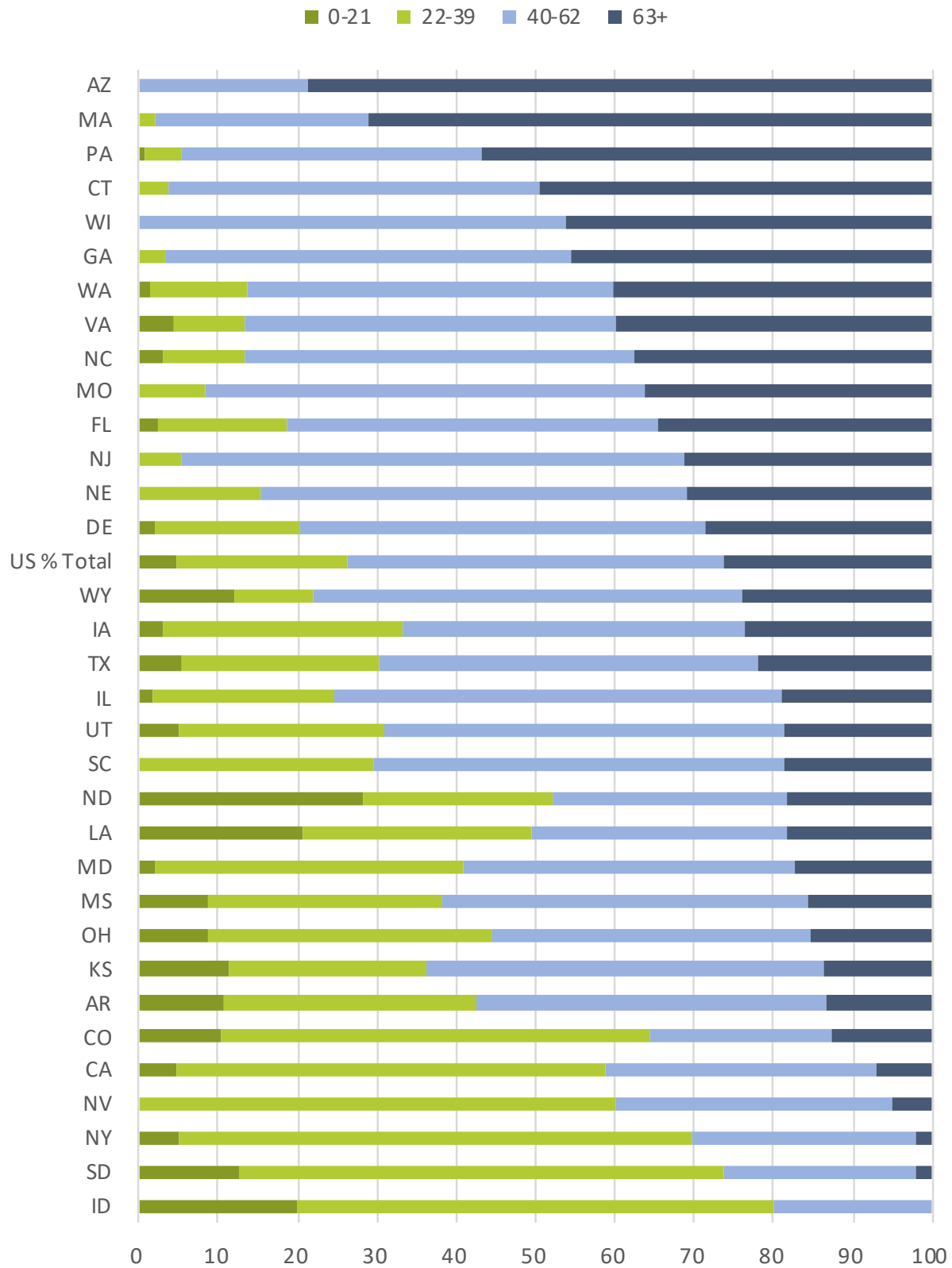
Data Source: PRF Survey, N = 91 facilities reporting. Each facility could report offering multiple types of services.

Table 4.19 Staff Characteristics in Large State-Operated IDD Facilities Selected Years 2004 to 2019

Staffing Characteristics	Year										
	2004	2006	2008	2010	2012	2014	2016	2017	2018	2019	
DSP Vacancy Rate (%)	6%	7%	7%	6%	8%	8%	11%	12%	14%	13%	
DSP Turnover Rate (%)	29%	27%	30%	24%	33%	33%	33%	40%	41%	36%	
DSP Starting Hourly Wage	\$10	\$11	\$11	\$12	\$12	\$12	\$13	\$14	\$15	\$15	
DSP Average Hourly Wage	\$13	\$13	\$14	\$15	\$15	\$15	\$16	\$16	\$17	\$17	
FLS Vacancy Rate	7%	5%	6%	6%	7%	8%	10%	10%	10%	8%	
FLS Turnover Rate	18%	13%	12%	10%	14%	14%	17%	17%	16%	25%	
FLS Starting Salary	\$27,397	\$29,914	\$30,979	\$35,228	\$33,118	\$34,732	\$36,396	\$38,123	\$41,604	\$40,618	
FLS Average Salary	\$33,299	\$35,783	\$36,924	\$42,590	\$38,062	\$41,132	\$43,374	\$47,678	\$48,127	\$47,452	

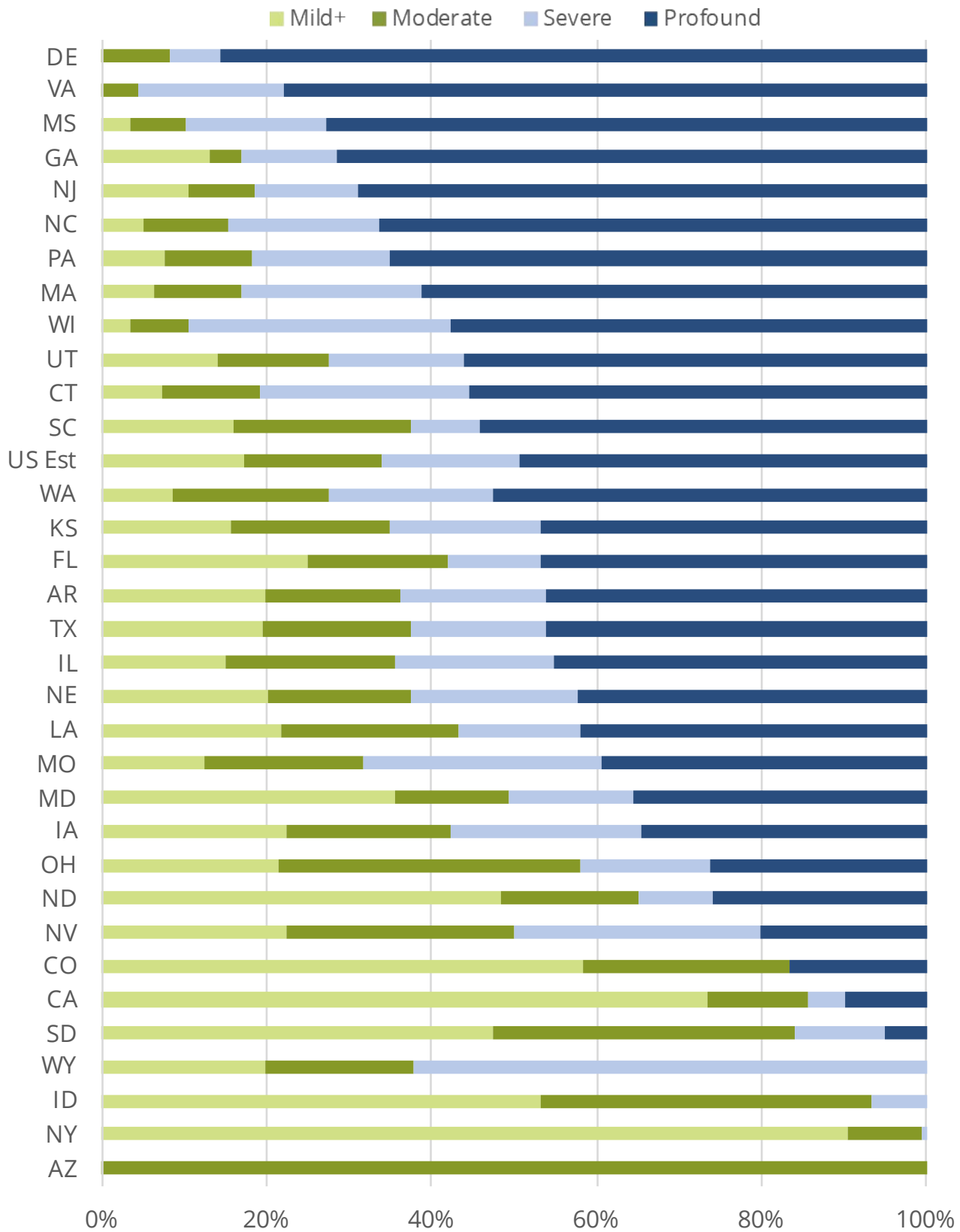
Data Source: PRF Survey, DSP Direct Support Professional; FLS Frontline Supervisor

Figure 4.1 Age of People Living in PRF's by State on June 30, 2019



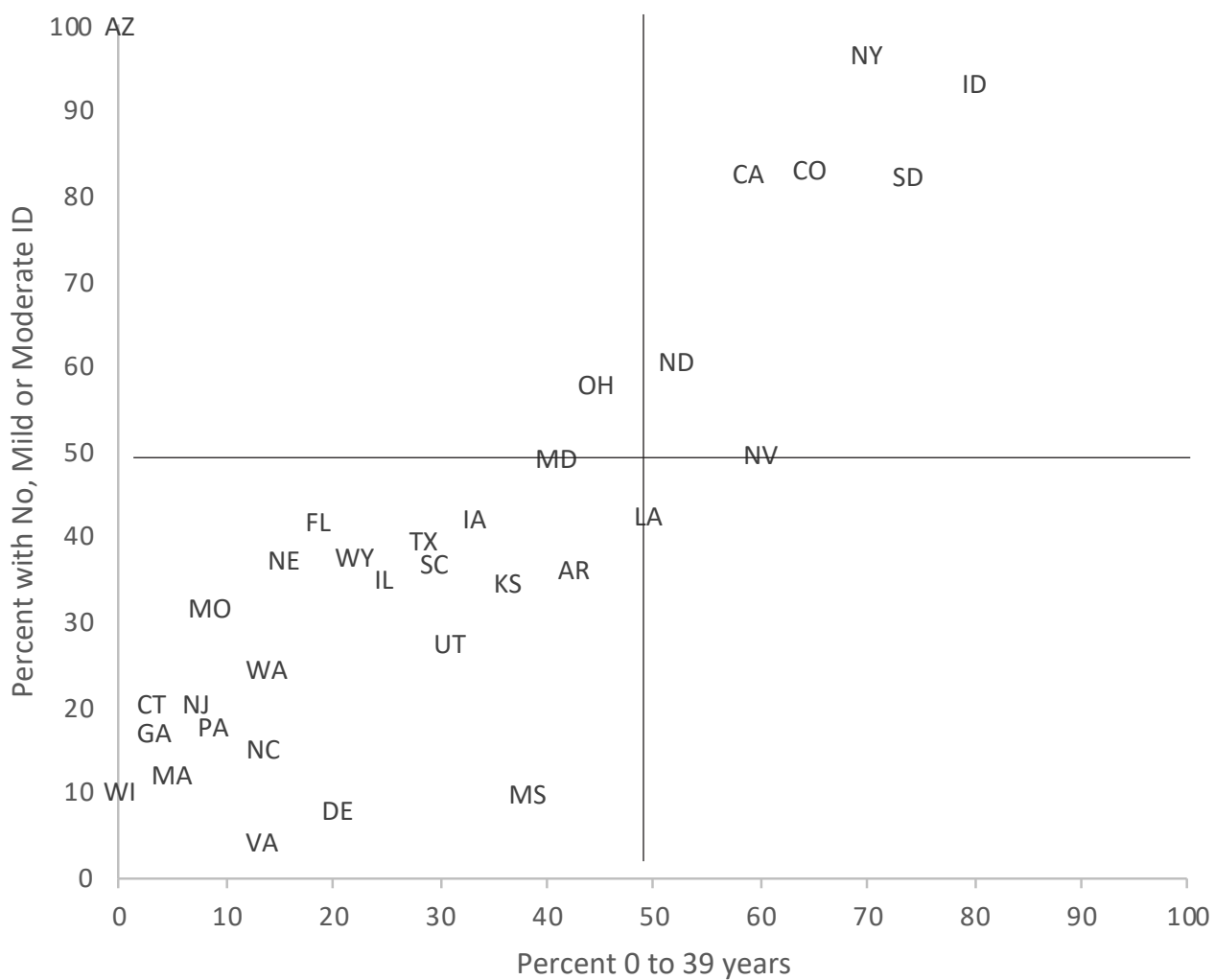
Data Source: PRF Survey

Figure 4.2a Level of Intellectual Disability (in Percent) of People in PRFs by State on June 30, 2019



Data Source: PRF Survey

Figure 4.2b Scatterplot of Age and Level of ID for People Living in PRFs on June 30, 2019 by State



Data Source: PRF Survey, Pearson $r = 0.69$

Figure 4.3 Age Distribution for June 30, Newly Admitted, Readmitted and Discharged PRF Residents in FY 2019

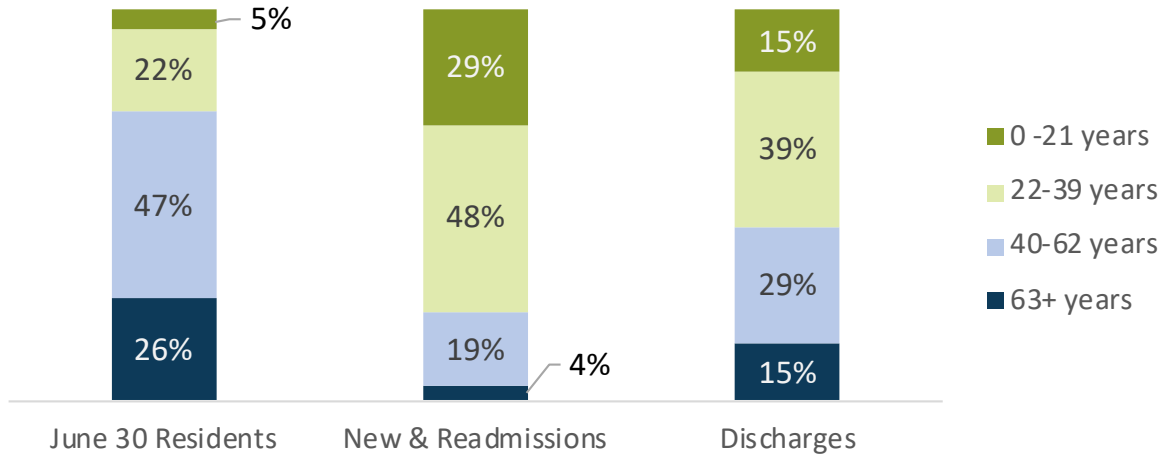


Figure 4.4 Level of Intellectual Disabilities for June 30, Newly Admitted, Readmitted and Discharged PRF Residents in FY 2019

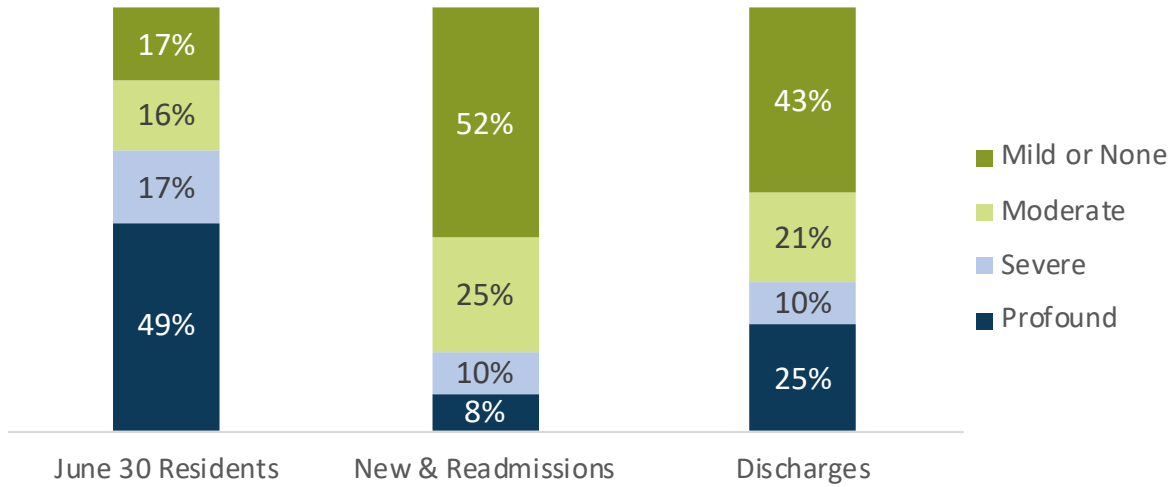


Figure 4.5 Previous and Subsequent Residence For People Admitted or Readmitted to and Discharged from PRFs in 2019 (in percent)

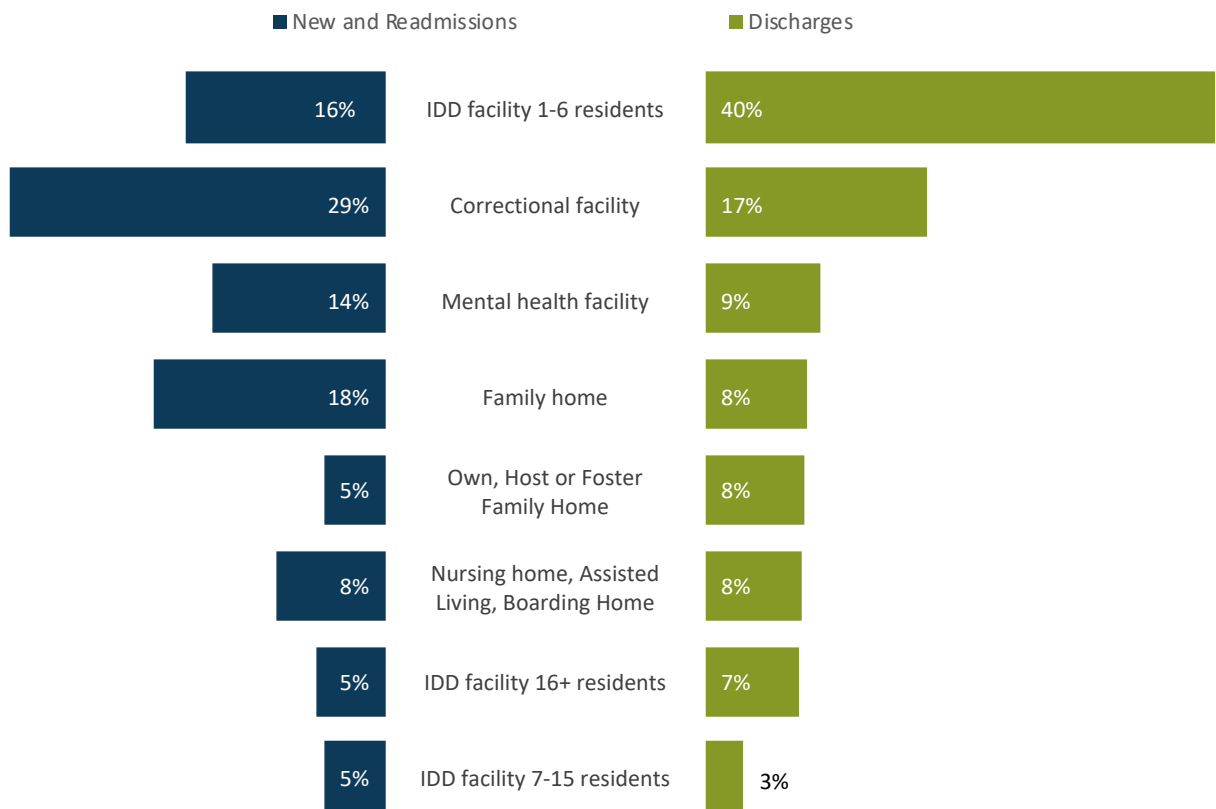


Figure 4.6 PRFs Closed or Converted to Non-IDD Use or Nonstate Operation Between 1960 and 2019 and Projected Closures by 2024 in 5-Year Intervals

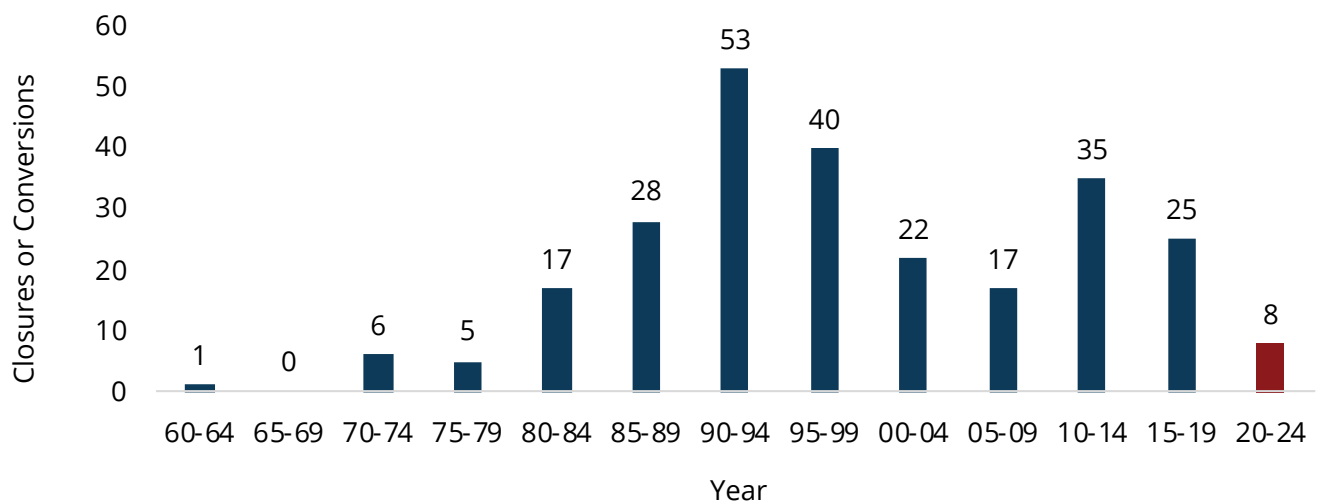


Figure 4.7a Average Daily Population of PRFs from 1880 to 2019

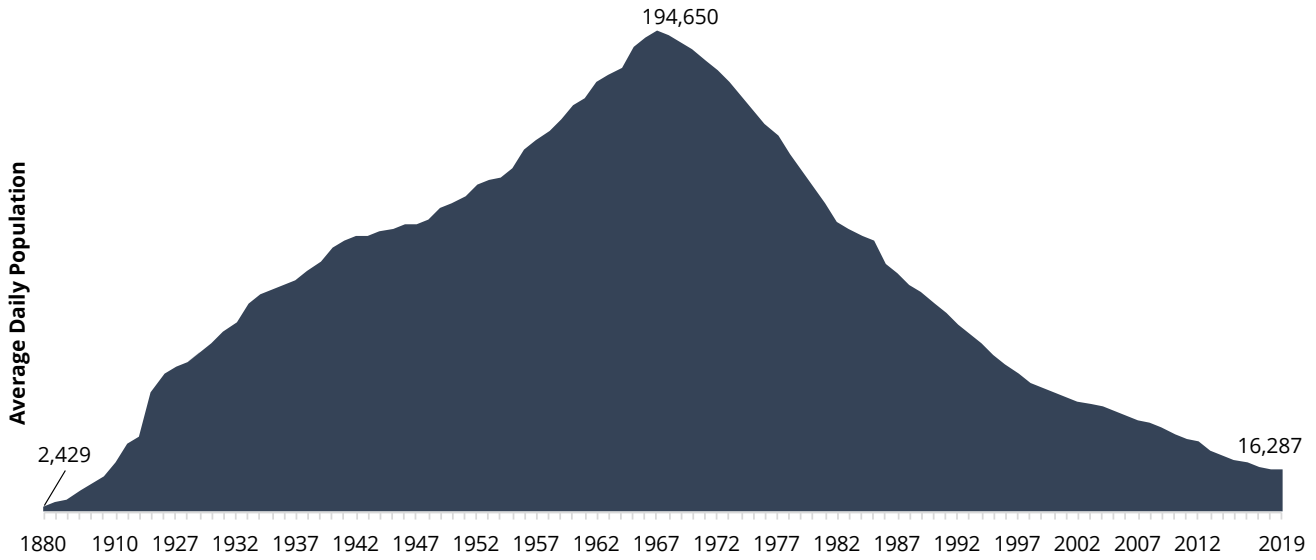


Figure 4.7b People with IDD in State Operated Psychiatric Facilities Selected Years 1950 to 2019

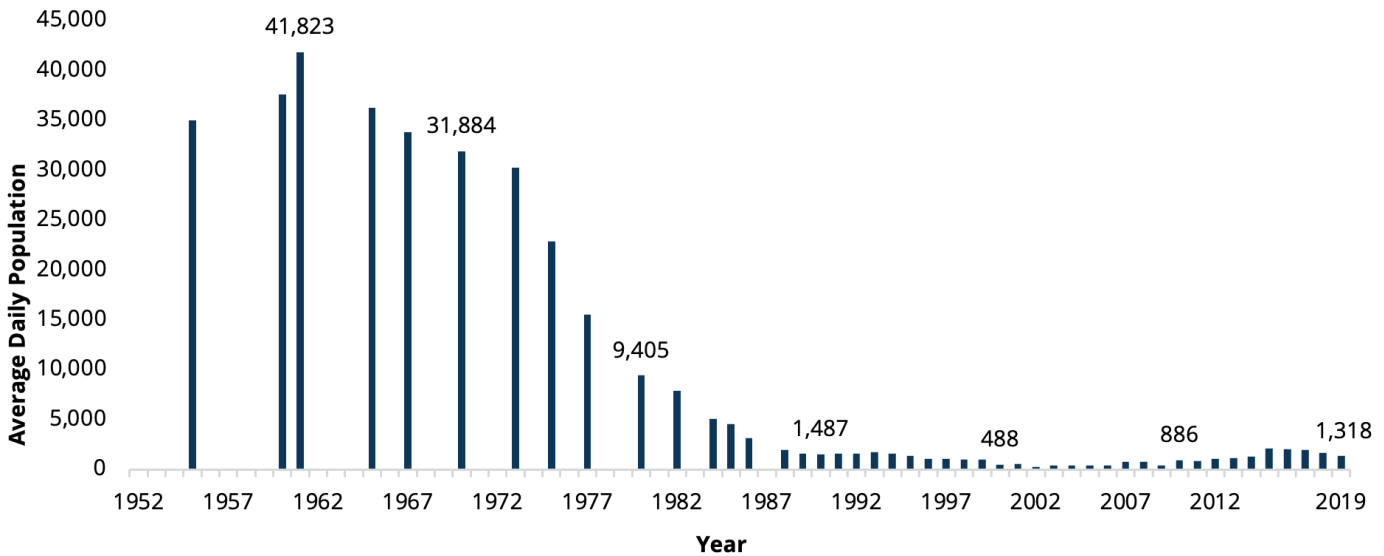
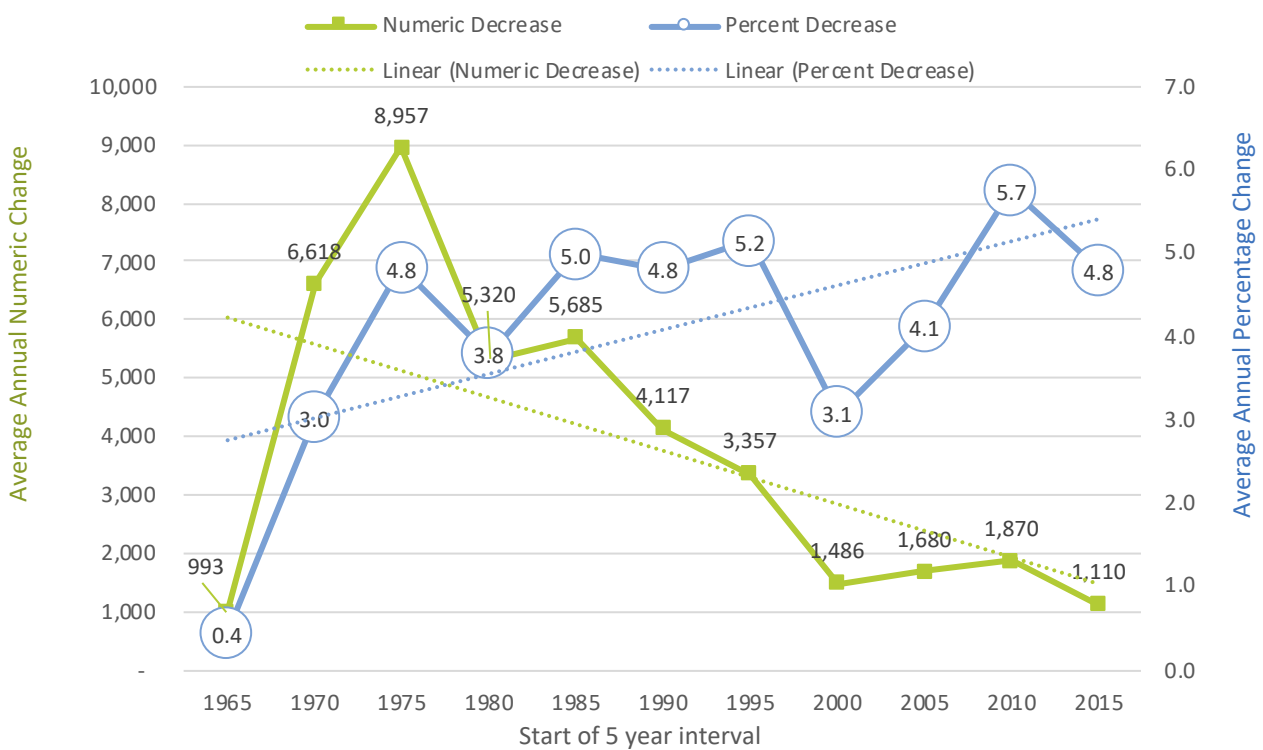
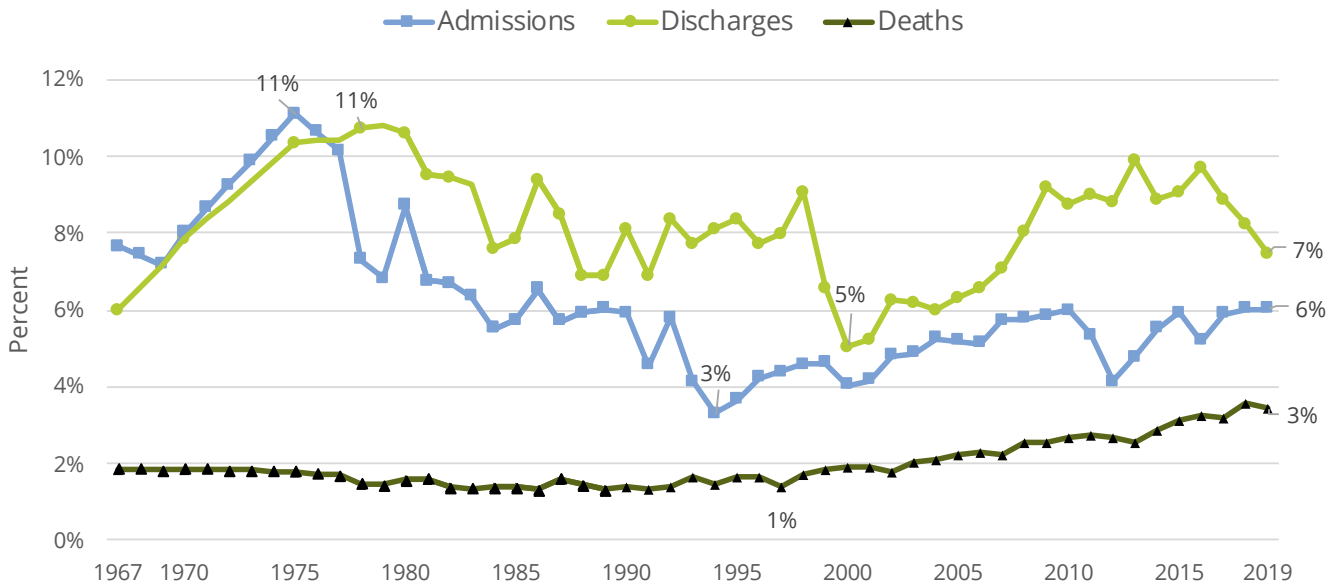


Figure 4.8 Average Annual Change in the Number of People with IDD in PRFs and State Psychiatric Facilities in Five Year Intervals 1965 to 2019 with Linear Trendlines



Data Source: RISP Survey

Figure 4.9a Annual PRF Admissions, Discharges and Deaths as a Proportion of the Average Daily Population, 1967 to 2019



Data Source: RISP Survey

Figure 4.9b Number of Deaths as a Proportion of all Leavers and Trend Line 1967 to 2019

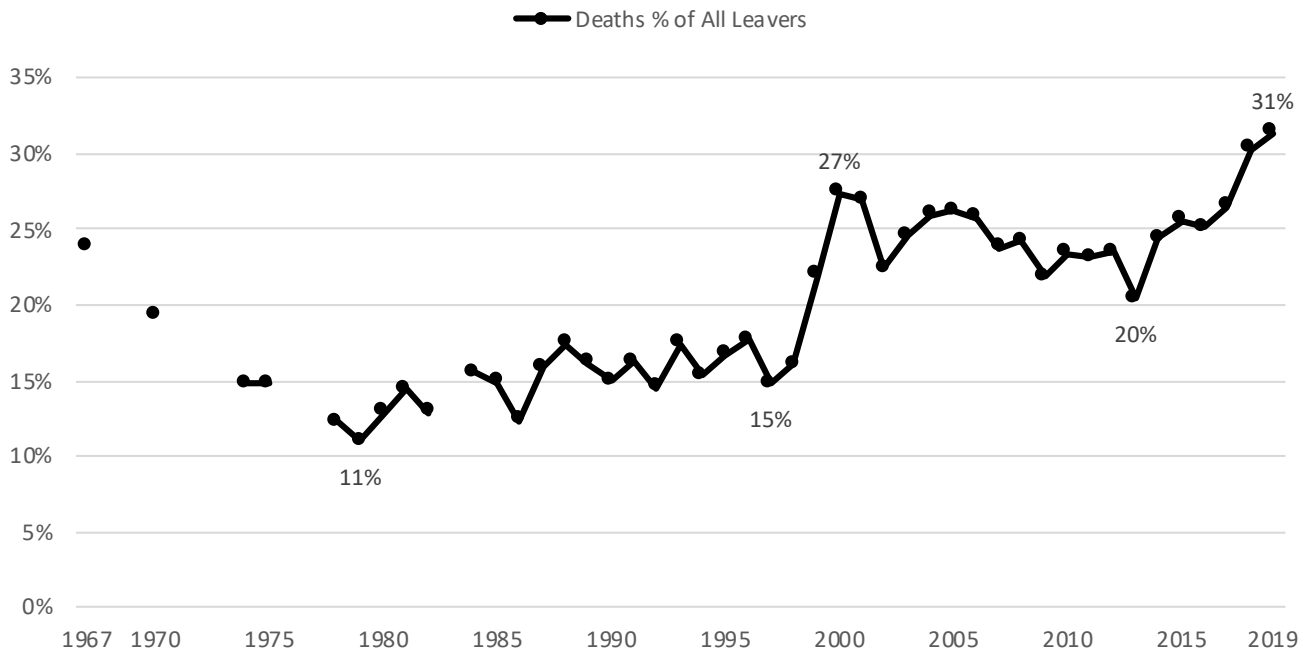
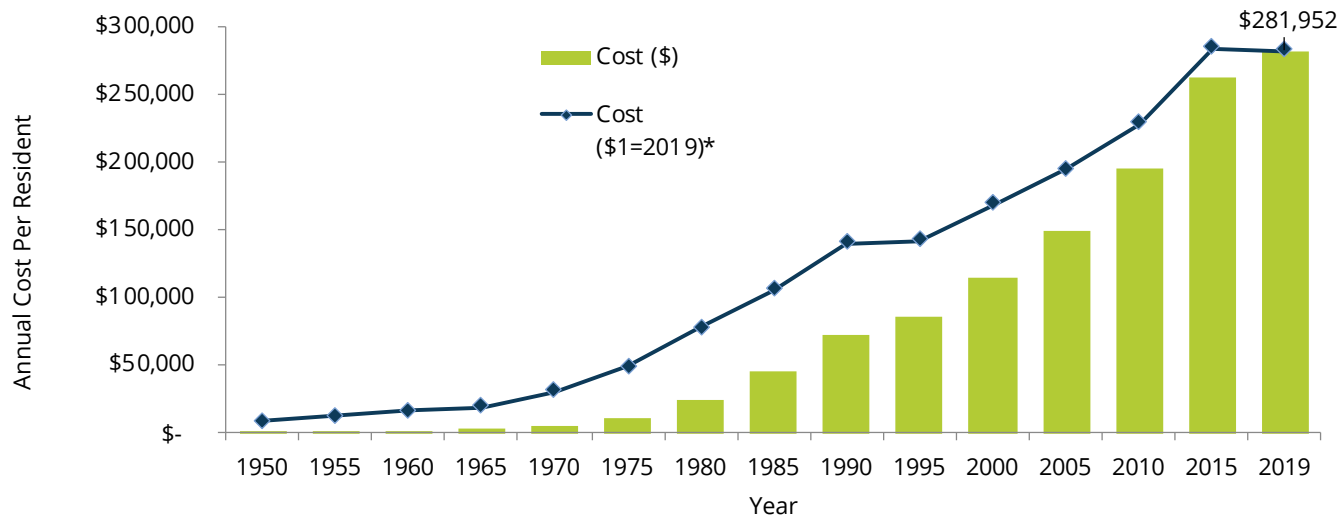
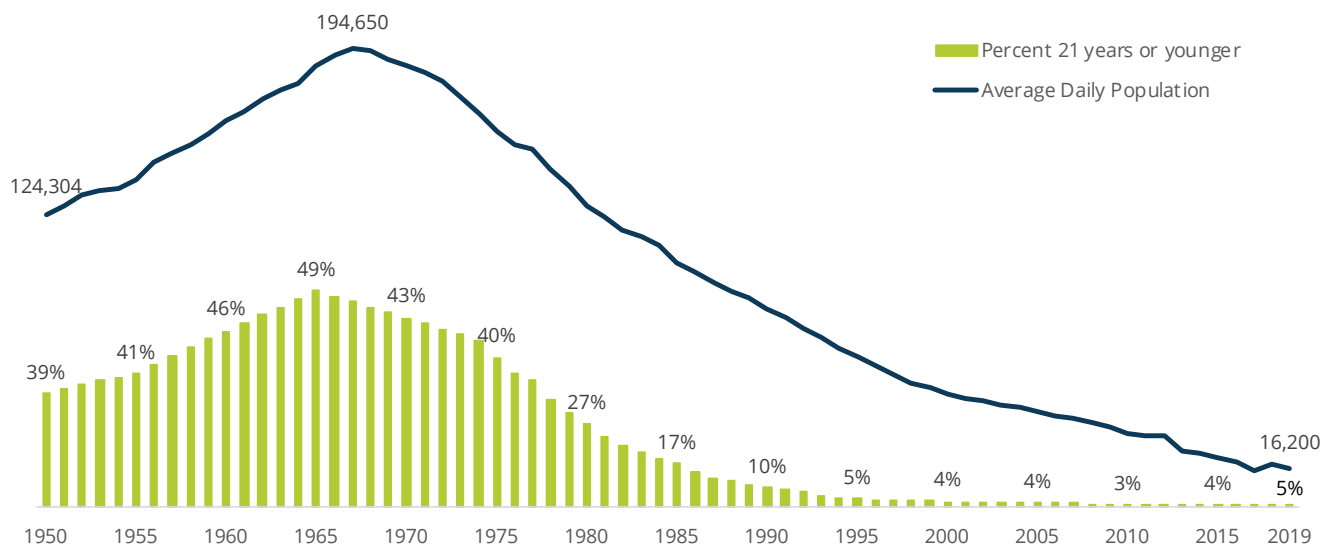


Figure 4.10 Average Annual Per Person Expenditures for PRF's, Selected Years 1950-2019



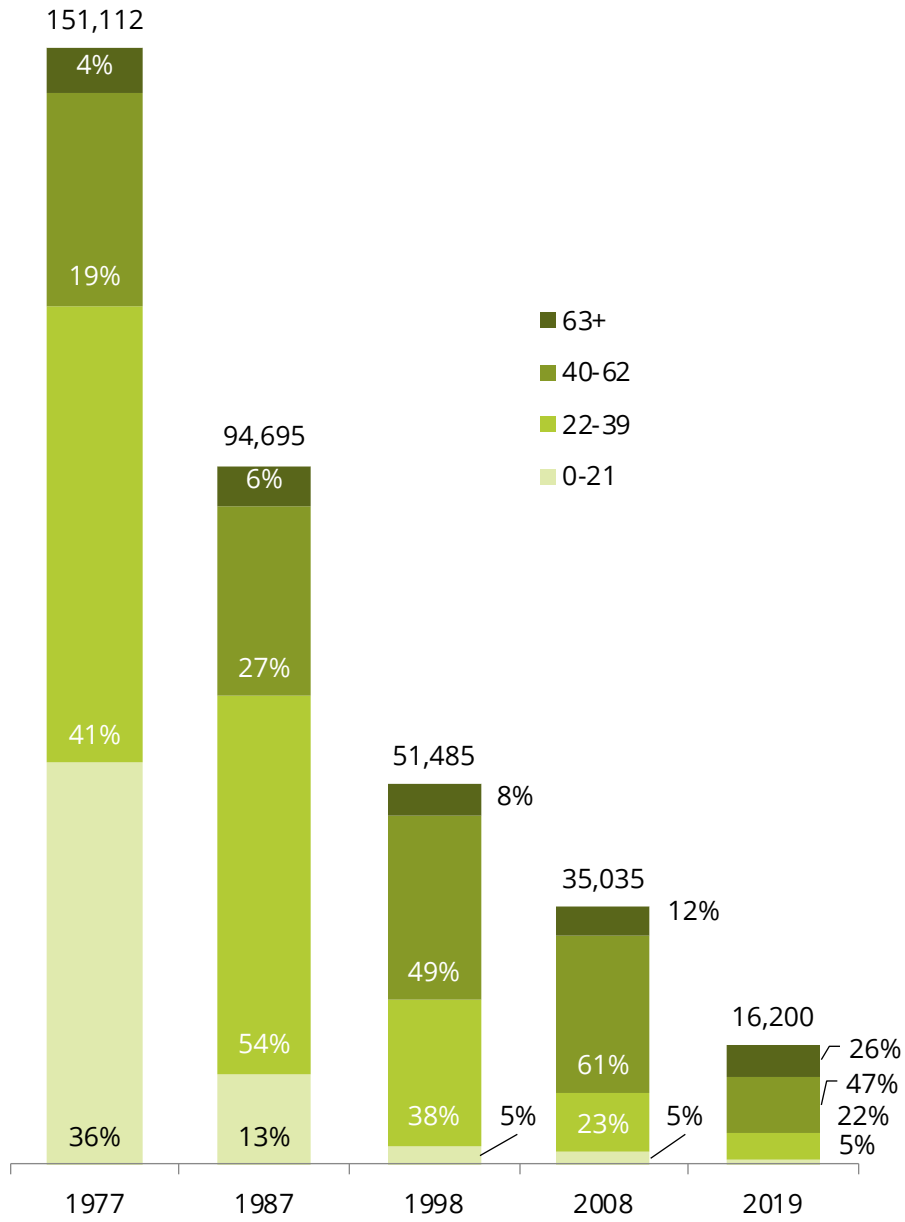
Data Sources: RISP Survey, ⁵ <https://www.usinflationcalculator.com/>

Figure 4.11 Average Daily Population of PRFs and Percent 21 Years or Younger, 1950 to 2019



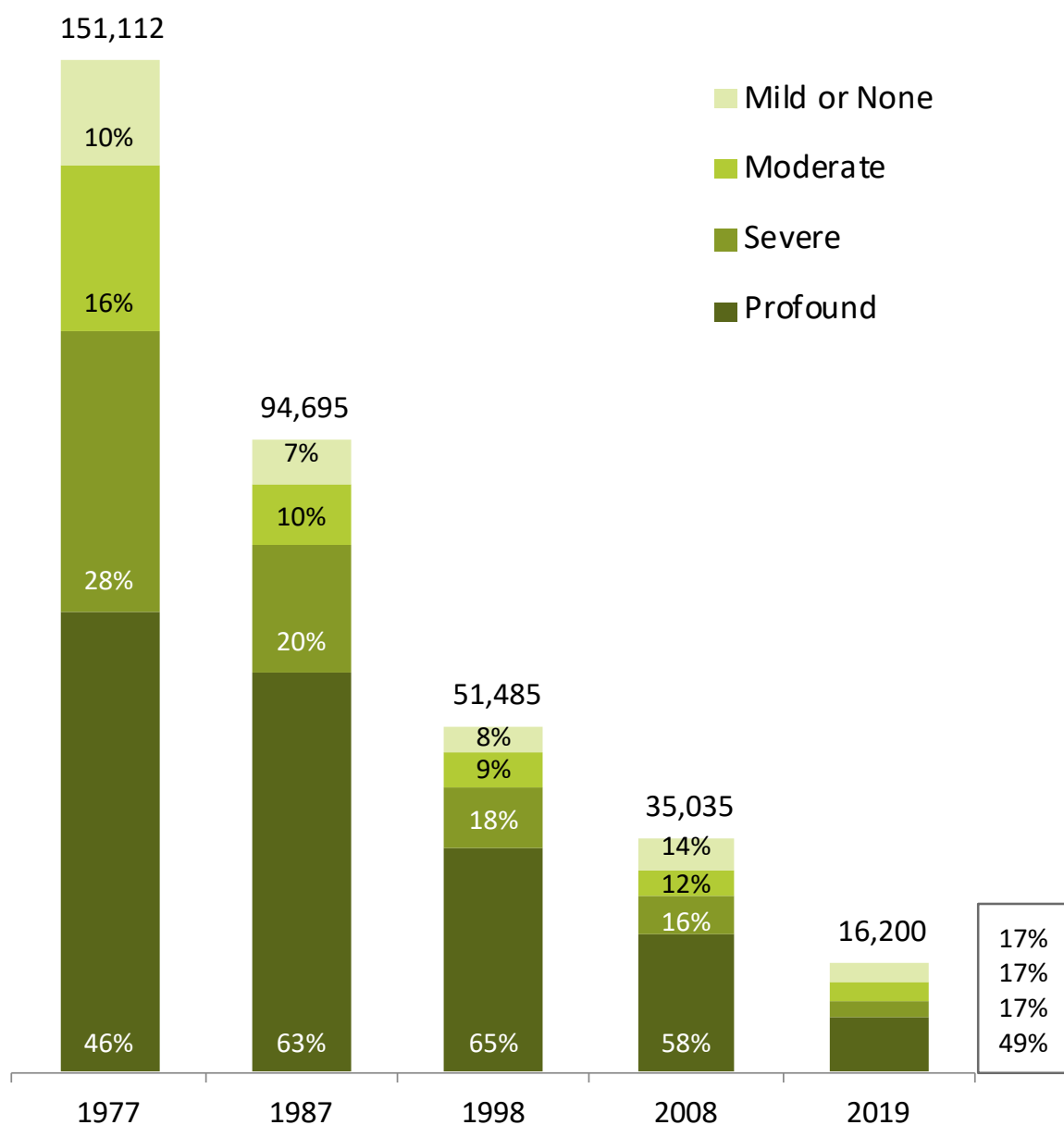
Data Source: RISP Survey

Figure 4.12 Estimated Number of People in PRFs by Age Group on June 30 of Selected Years 1977 to 2019



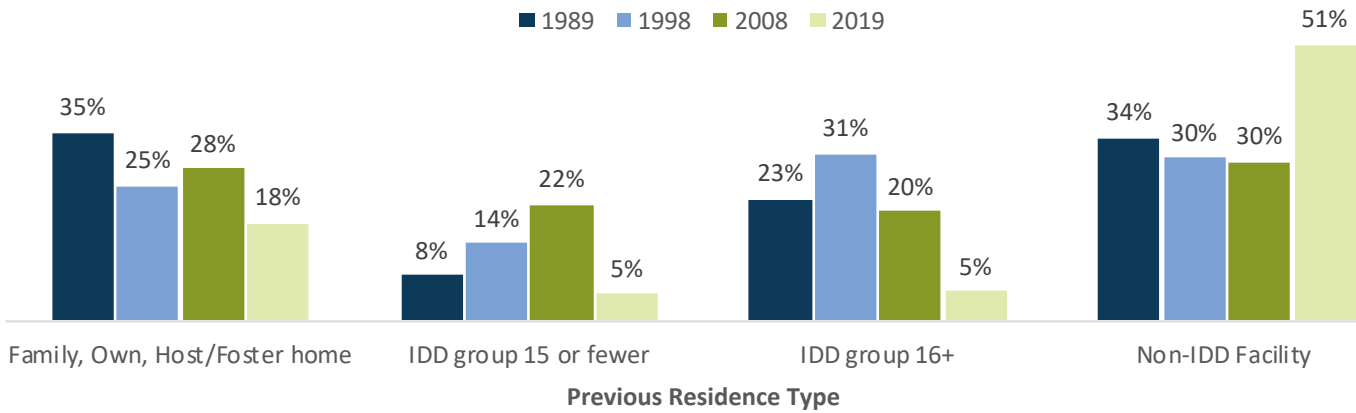
Data Source: PRF Survey. Some surveys had incomplete data on age.

Figure 4.13 Estimated Number and Proportion of People with IDD Living in PRFs by Level of Intellectual Disability on June 30 of Selected Years 1977 to 2019



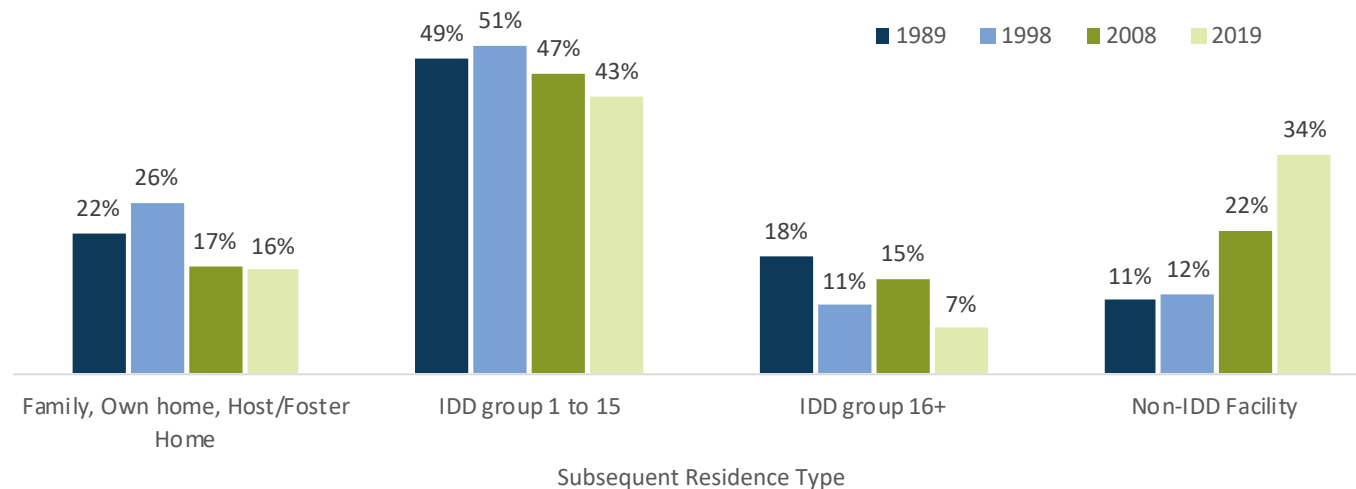
Data Source: PRF survey, This figure excludes people whose level of ID was unknown. Percentages for 2018 were mild or no 14%, moderate 15%, severe 17% and profound 54%.

Figure 4.14 Previous Place of Residence for People (Re)Admitted to a Large State IDD Facilities in Percent Selected Years: 1989 to 2019



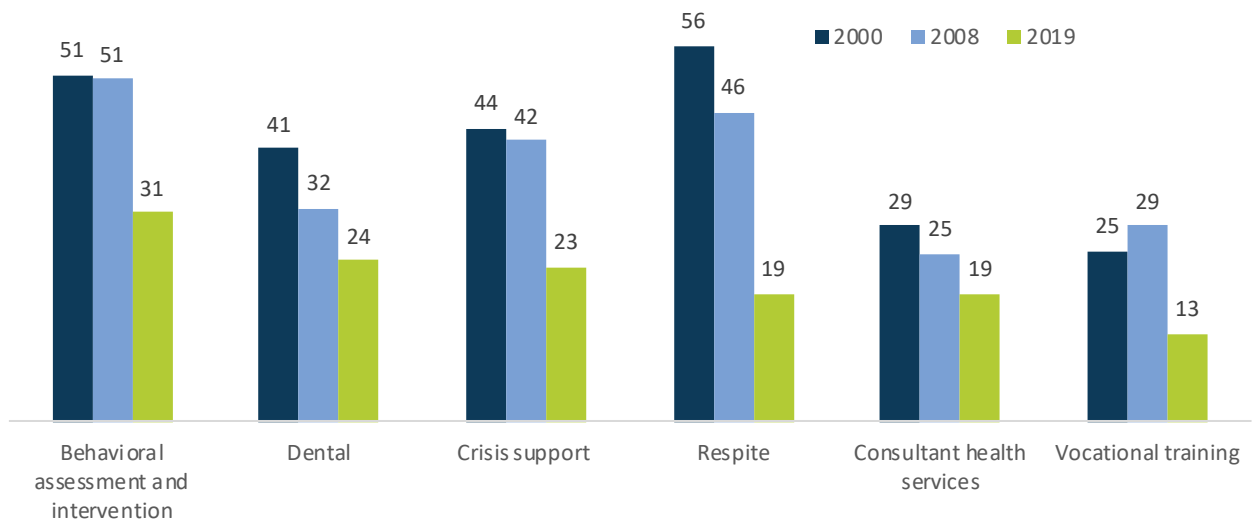
Source PRF Survey, Non-IDD Facilities include mental health facilities, correctional facilities, nursing homes, assisted living facilities, and boarding homes

Figure 4.15 Subsequent Residence of People with IDD Discharged From a Public IDD Facility Selected Years 1989 to 2019



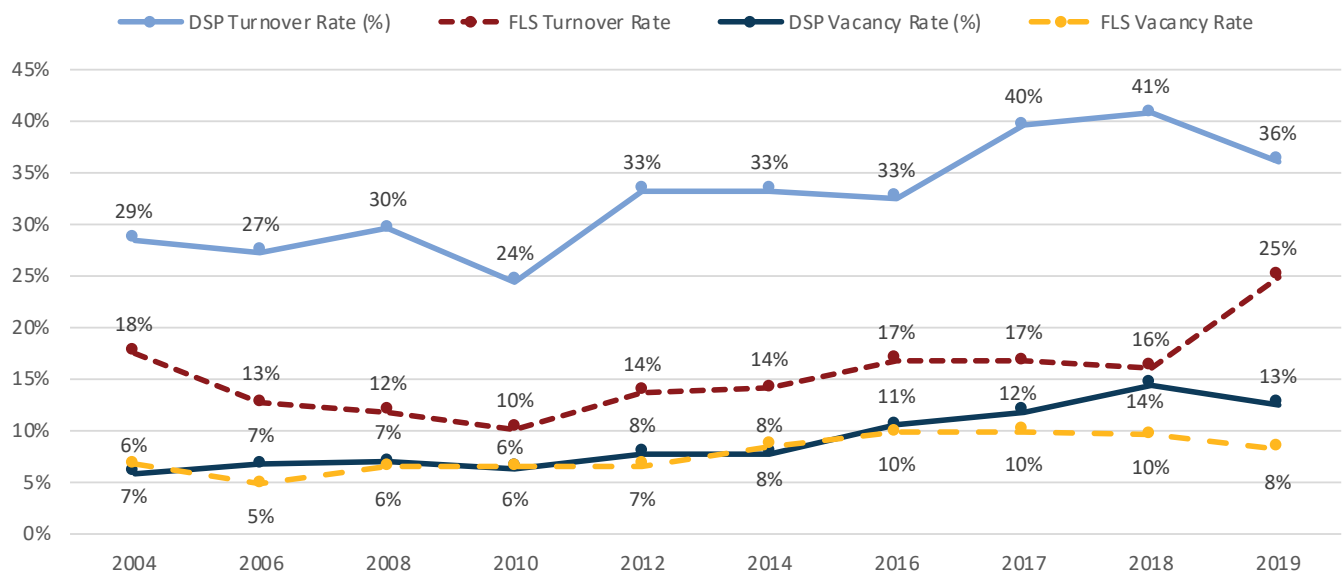
Source PRF Survey, Non-IDD Facilities include mental health facilities, correctional facilities, nursing homes, assisted living facilities, and boarding homes

Figure 4.16 Percent of PRFs Offering Supports to People with IDD not Living On-Campus 2000 to 2019



Data Source: PRF Survey

Figure 4.17 Direct Support Professional and Frontline Supervisor Turnover Rates in PRFs Selected Years 2004 to 2019



APPENDIX

STATE NOTES

State Notes describe variations from the survey definitions, alternative data sources used, reasons for large year-to-year changes, and other factors affecting data interpretation.

Alabama**Alaska**

Alaska's Group Home settings are licensed to provide services to people with IDD, mental health support needs, and seniors and do not exclusively serve HCBS recipients. Alaska does not operate ICF/IIDs, but 14 people from Alaska lived in ICF/IIDs in other states. Waiver recipients and expenditures by age assume that people ages 21 and younger lived with a family member and that people ages 22 years or older lived in other settings. Alaska's Community First Choice 1915(k) program began on October 1, 2018.

Arizona

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

Arkansas

Nursing home data are from AHCA (2019c). Some data on waiver recipients, ICF/IIDs, and waitlist are from Arkansas's Department of Human Services 2019 Annual Statistical Report (Gillespie, 2019).

California**Colorado**

People in nonstate "other" settings receive Individual Residence Services in settings of three or fewer people but not in host or foster family homes. People receiving Supported Living Services (SLS) may live in their own homes or with family members. Since FY 2018, SLS recipients have been reported together in the family home category. In FY 2017, the last year for which separate data were available, 39% of the combined SLS recipients lived with a family member and 61% lived in their own home.

Colorado's two state-run ICF/IID facilities (Grand Junction Regional Center and Wheat Ridge Regional Center) operate units both on a campus and in the community.

Connecticut

Beginning in FY 2019, CT began reporting actual Waiver and ICF/IID expenditures rather than claims. Beginning in FY 2019, some services for people under the age of 21 were funded through state funds not tied to DDS.

Delaware

In FY 2019 Delaware began providing targeted case management to waiver recipients not living in family homes. Some services previously funded only by the state are now covered under the HCBS Lifespan Waiver (which includes family support services).

District of Columbia

More people aged out of schools and enrolled onto waivers in FY 2019. DC reported two people under age 22 as enrolled ICF/IIDs, but they did not receive services in FY 2019.

Florida

FY 2019 saw a significant increase in people under age 22 living outside of family homes receiving waiver services, as well as their associated expenditures. Many of these people received crisis supports, so their numbers fluctuate year-to-year. The number of people 22 years and older receiving waiver services in family homes increased, as did their expenditures, due to program growth, rate increases, and as a result of Florida's minimum wage increasing. People listed as living in "other" nonstate-run settings include those in mental health group homes, and hospitals. People listed as living in "other" state-run settings were in prisons and/or jails.

Georgia

The Gracewood and Augusta campuses of the East Central Regional Hospital have both SNF and ICF/IID services. The Georgia Regional Hospital at Atlanta (in

Decatur) has SNF services. Data on state-run settings are from external sources (Office of Performance Analysis, n.d.) or from previous year reporting. Nursing home data are from AHCA (2019c).

Hawaii

The method for including people in their own homes changed in FY 2019, which accounts for changes in this living setting. This method will continue to be used going forward. It is not possible at this time, however, to report on the number of people in their own homes as of June 30th; instead, annual counts are reported. DDD does not track group home setting size. Based on available data, all group homes are reported as having 4–6-person capacity. Cost calculations methods also changed, which explains changes in waiver spending. Non-Medicaid state funds are provided through the Long-Term Adult Supports and Resources (LASR) program.

Idaho

Settings are reported by license or certification size. Some settings were not operating at capacity on June 30, 2019. Data on waiver recipients and state plan recipients are combined. People reported as on the IDD caseload but not receiving services may have moved in to or out of Idaho, stopped receiving services, or were approved for services but were waiting to get an approved plan.

Illinois

Illinois's count of people on the IDD caseload but not receiving LTSS includes 2,012 people already selected for services but who have not started receiving them yet, 515 people who were ineligible for services (people in PRFs and other residential settings, people living out of state, people who are deceased, and people with no needs listed), and 2,961 people who qualify for waiver services but have not demonstrated a need yet. The count of people on Illinois's waiting list includes 2,012 people already selected for services but not yet receiving them and 2,961 people who qualify for waiver services but have not demonstrated a need yet. Before FY 2019, Illinois's surveys included some people with primary diagnoses of mental health disorders who lived in PRFs. Beginning in FY 2019, Illinois will report only on people with IDD in PRFs.

Indiana

People on the IDD caseload but not receiving funded LTSS were incorrectly reported in FY 2017-2018. This was corrected for FY 2019 to show that there were no people in this category. Indiana did not track group home or own home setting details prior to 2019. Numbers reported for 2019 are estimates. Waiver enrollment increased in 2019.

Iowa

Variation between previous reporting years and FY 2018 is due to a change in reporting methods that include a more detailed data source. Number of settings per size is duplicated if a provider has more than one setting type. For example, a provider with an ICF/ID may also serve individuals in a community-based group home or supported community living services within their own home.

Kansas

The number of recipients of state-funded non-Medicaid services (broken out by age) is reported as an estimate because the data is self-reported, potentially includes duplicate recipients across services, and cannot be accurately broken out by age because many of the state-funded services are available to children and adults. The expenditures per person are also reported as estimates because they were based on estimated values for the calculation. During SFY 2019, there were two ICF/ID facilities that closed. Since not all of the people living in these facilities were placed in other ICF/IIDs, the total number of people living in ICF/IIDs of 7-15 people decreased significantly.

Kentucky

Kentucky reports the total number of providers for nonstate group home and host/foster family home; the number of settings by size was imputed based on the total number of recipients living in settings of each size. In FY 2018, an estimated 10,664 Waiver recipients on the Michelle P Waiver lived in family homes or homes of their own, but Kentucky could not differentiate the number in family homes versus own home settings—these 10,664 are therefore reported in Unknown Setting Type. ICF/ID recipients by age includes only people in nonstate ICF/ID. Nursing home data are from AHCA (2019c).

Louisiana

People do not receive state-funded IDD services when they are in nursing homes. 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 (Jackson; a psychiatric facility with 3 ICF/IID-certified units).

Maine

All data reported from Maine encompasses the entire fiscal year for FY2019. FY2019 reports only individuals with ID/DD served by the state IDD agency, which exclusively serves people ages 18 and over. This accounts for the significant reduction in the number of people ages 21 and under in reporting for FY2019. Four state-run IDD facilities where stays are limited to 90 days or less (Crisis Homes) are reported as "Other" state-run settings.

Maryland

Maryland's counts of people living in and outside of family homes are not complete as their data system does not track living situation of all waiver recipients. Some children receiving waiver supports moved from family to group homes as a result of Maryland's family support services changing. A managed care organization (MCO) manages Maryland's state plan HCBS 1915(i) and 1915(k) plans and does not share that data with Maryland's Developmental Disabilities Administration in time for them to report in RISP. Moving forward, the MCO will share this data earlier for reporting in RISP. 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>).

Massachusetts

The number of LTSS recipients ages 21 and younger living with a family member have not been reported since 2015. People living in host/foster settings before 2019 were counted as living in a family

home. When reporting on people living in ICF/IIDs and their associated expenditures, Massachusetts included 11 people temporarily admitted for crisis stabilization. Settings coded as "other" include nursing homes, housing under Massachusetts's Department of Mental Health, jails, prisons, and private pay settings. People reported as living in "unknown" settings includes children receiving LTSS as Massachusetts's data system does report on residence type for children. Nursing home data are from AHCA (2019c).

Michigan

Michigan began reporting the number of 1915(b/c) waiver recipients in FY 2011 accounting for the jump in waiver recipients for that year. Nursing home data are from AHCA (2019c). People who received state-funded non-Medicaid LTSS received Medicaid-covered services during a period of non-coverage, such as spenddown.

Minnesota

Non-state "Other" settings include Customized Living (Assisted Living) and Board and Lodging. Most Customized Living arrangements are Medicaid Waiver funded. In Minnesota, waiver-funded group homes are typically limited to four or fewer people (with certain exceptions allowing for five people). Claims data do not distinguish between settings of 1-3 and 4-6 people. There may be a few people on the IDD waiver waitlist who are enrolled in an alternative waiver program and residing in a foster care setting. Minnesota offers HCBS under state plan authorities 1905(a) and 1915(g). RISP did not collect information on these funding authorities, so people receiving these services were counted as receiving 1915(i) and 1915(k) services in the FY 2019 survey.

Mississippi

The number of waiver recipients living in group homes was estimated for FY 2019. The reported number of people receiving waiver supports while living in their own homes includes some people living in group homes due to how Mississippi organizes their data. In 2018, MS 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. Four of the five large state-run ICF/IID facilities also provide IDD Waiver Support Coordination (case management) and 1915(i) Targeted Case Management. Setting counts are estimates as Mississippi's data counted setting size based on licensed capacity, not number of residents living there. 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. People receiving services in family homes were estimated. For 2018 and 2019, Mississippi only provided ICF/IID expenditure data on state-run ICF/IIDs (the only ICF/IIDs under the DD agency's supervision). Nursing home data and nonstate ICF/IID data are from AHCA (2019c).

Missouri

Group home numbers are trending downward and will continue to do so as Missouri is no longer developing new group homes, and individuals are choosing the supported living service. Waiver expenditures for people ages birth to 21 years increased in FY 2019 in part due to more families choosing self-direction over residential services. Waiting lists for Waiver-funded supports in Missouri were eliminated in FY 2015. Beginning in FY 2015, all of the people reported to be waiting were actually moving through the assessment and provider selection process.

Montana

New data availability for the Part C program allowed for more accurate reporting on youth on the caseload but not receiving LTSS in FY 2019. People reported in nonstate-run "other" settings includes people in supported living and assisted living. Decreases in waiver expenditures for people ages birth to 21 years were due to the Autism waiver being phased out. Montana's last state-run ICF/IID closed in FY 2018.

Nebraska

Nebraska is not able to distinguish people living in their own or family homes, so they are reported together as living in unknown settings. A significant

factor that decreased the number of LTSS recipients living in family homes was a change in level of care eligibility requirements. In-home residential/adult companion services were replaced by supported family living, which became eligible for the day waiver and led to more people living with family to receive services. A policy change also allowed family members (not parents/guardians) to become DSPs, leading to more LTSS enrollees to live with family. Some people reported as living in unknown settings were living in family homes or their own homes but were not coded as such until after FY 2019. State-funded non-Medicaid LTSS in FY 2019 expenditures were supplemental funding given to waiver recipients. Beatrice State Development Center houses four separately licensed ICF/IID buildings on a campus. From FY 2011 to FY 2016, each building was reported as a separate facility.

Nevada

The non-state "other" category includes assisted living, correctional, emergency housing, hospital, rehabilitative training center, and transitional housing settings as well as people experiencing homelessness.

New Hampshire

Some data on nonstate-run settings and expenditures are taken from New Hampshire's FY 2020 survey as their data system made several key improvements between completing the 2019 and 2020 surveys. Nursing home data are from AHCA (2019c).

New Jersey

Most children in New Jersey (people ages 21 and under) with IDD who receive LTSS are served by the Department of Children and Families. Around 100 children with IDD remain on the caseload of the Division on Developmental Disabilities (DDD). The number of persons funded on Medicaid waivers and related expenditures experienced increases due to the New Jersey Supports Program. DDD began enrolling persons onto that program in FY 2016 which carried into subsequent FYs. Three people supported by DDD are housed in a specialized unit at one of its ICF/IIDs. This unit is used by the courts as an alternative to incarceration for individuals with IDD who have been convicted of crime(s). Associated costs for persons served there are not eligible

2019

for federal match. They are reported as residing in an “other” state-run setting. Reported ICF/IID expenditures are only for state-run ICF/IIDs. Nursing home data are from AHCA (2019c).

New Mexico

All supported living facilities in New Mexico are required to have 4 or fewer people each. People receiving family support are required to have 2 or fewer supported people in a setting. These limits were used to estimate the number of family and IDD-specific settings in New Mexico. Not all people living with families receive family support. Expenditures for state-funded non-Medicaid LTSS are estimates based on the number of individuals receiving State General Funds for day or residential services.

New York

The 6,138 people waiting to move to a setting other than the home of a family member in FY 2019 are people who expressed interest in Office for People with Developmental Disabilities supported housing. They may or may not currently live in family home or own home setting.

North Carolina

In FY 2019, much of North Carolina’s nonstate-run LTSS for people with IDD were managed by seven local management entity/managed care organizations (LME/MCO). Not all LME/MCOs provided complete data for all data points requested in RISP, so data are often inconsistent year-to-year. In FY 2018 and 2019, the following data were reported on by the corresponding number of LME/MCOs:

- ICF/IID: 2/7 (FY 2018: 3/7)
- Group homes: 3/7 (FY 2018: 3/7)
- Host/foster family homes: 4/7 (FY 2018: 3/7)
- Own home: 6/7 (FY 2018: 2/7)
- Other homes: 5/7 (FY 2018: 5/7)

Furthermore, data on residence size for nonstate settings is provided by LME/MCO that may not have access to accurate information on facility size. As a result, the reported number of facilities may be an undercount. A change in the number of people reported in state-run settings for 16+ residents under “Other” funding authorities is due to a change in coding the more properly associated people in

ICF-funded residences. People in Black Mountain and O’Berry Centers were included in counts of people in state-run facilities beginning in FY 2018.

North Dakota

Ohio

People on the agency caseload but not receiving funded LTSS may be on the waitlist, in school, receiving early intervention, or other locally funded services. It includes some people living in non-family settings. Everyone on Ohio’s waiver waitlist was moved to a transitional list and to be assessed by their county board of developmental disabilities by December 31, 2020. This change significantly reduced the waitlist. State-funded expenditures do not include funds allocated through county boards, which provide many services through local dollars. Nursing home data are from AHCA (2019c).

Oklahoma

Oklahoma Developmental Disabilities Services contracts with a nonstate-operated organization to manage the Greer Center, an ICF/IID, formerly state-operated, that provides mostly (but not exclusively) short-term crisis residential services to people with IDD. The Greer Center is reported as a nonstate-operated ICF/IID. ICF/IID data are from AHCA (2019a) and Mathematica (Murray, 2021). Data on Oklahoma’s caseload, people receiving waiver services, waiting list, and state-funded services are from other years’ data and Oklahoma’s Department of Human Services 2019 annual report (Martin, Wagner, & White, n.d.).

Oregon

Changes made in Oregon’s waiver program allowed more children to receive funding. As a result, fewer children were served by state-funded non-Medicaid plans. Nonstate-run home sizes are reported by how many people homes are licensed to support, not the number of people living there.

Pennsylvania

Rhode Island

Rhode Island's DD agency does not utilize a waiting list. ICF/IID data come from AHCA (2019a) and Murray (2021).

South Carolina

Own home settings could only be reported by the number of contracts held. There is no way to determine through the data the number of people served through each contract. Nursing home data are from AHCA (2019c).

South Dakota

South Dakota did not furnish data for the FY 2019 survey. ICF/IID data are from AHCA (2019a). Some waiver data are from Mathematica (Murray, 2021).

Tennessee

The 8,327 people reported in unknown settings either live with family members or in their own home since Tennessee's data system does not distinguish between these settings. Tennessee stopped accepting applications its 1915(c) Waiver on June 30, 2016 and no longer maintains a waiting list for 1915(c) Waiver-funded services. People on the referral list for services under the 1115 Waiver have not been screened for eligibility. The number of people ages 21 and under receiving waiver services increased significantly, along with their associated expenditures, due to increased enrollment in Tennessee's Employment and Community First (ECF) Choices program.

Texas

Texas's reported data is from August 31 rather than June 30 as that is the end of their state fiscal year. All ICF/IID settings in the 1-6 people size category are licensed for six people. Nursing home data are from AHCA (2019c).

Utah

ICF/IID recipients and expenditures, and age breakdowns are reported only for state-run settings.

Vermont

People receiving state-funded, non-Medicaid LTSS represent an unduplicated count of people getting Flexible Family Funding, Family Managed Respite, Bridge Program, and TCM. Waiver recipients are reported based on how many received services on June 30, 2019 rather than the full FY.

Virginia

Data on nonstate Medicaid Waiver-funded settings and Waiver expenditures are from a Kaiser Family Foundation Report (O'Malley Watts et al., 2020). The Southwest Virginia Training Center and Central Virginia Training Center closed in February, 2019.

Washington

The number of people with IDD in Own Home settings varies from year to year because data were not available for all funding authorities each year. 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. Expenditure data were provided for 428 of 653 ICF/IID recipients.

West Virginia

ICF/IID and nursing home data are from AHCA (2019a; 2019c).

Wisconsin

Setting size information was not available for LTSS recipients living in their own home or in a non-state other setting. Until FY 2014, Wisconsin reported only Waiver recipients living in own home, family home and nonstate "Other" settings. Since then, all LTSS recipients living in nonstate settings (including group homes and host or foster family homes) have been reported. Some children with IDD in state-run settings receive Medicaid State Plan funded services who are not on the DD 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. Nursing home data are from AHCA (2019c). In FY 2019, the waiver reimbursement increased as a result of rate rebasing. State-funded, non-Medicaid LTSS fluctuate greatly from year to year depending on requests for funding and availability of the funding. This year, requests were higher therefore expenditures were higher.

Public Residential Facility Survey Notes

Arizona

- Arizona Training Program at Coolidge: With respect to closure, the facility closure date is dependent on the number of members still living at the facility and the effectiveness of the cost per member. Closure Year is set for 2030.

California

- Sonoma Developmental Center: Complete information is not available. The facility closed in the middle of fiscal year.

Colorado

- Grand Junction Regional Center: With respect to other direct services provided to the community, Community Support team and Transition Support team were listed.

Connecticut

- Hartford Regional Center: There is a Step-Down unit on campus which temporarily supports up to 6 people at a time with ID who are in behavior crisis. The individuals are admitted from various settings, including hospital emergency rooms, residential CLAs, and their homes. Their stay cannot exceed 180 days.

Illinois

- Choate Mental Health and Developmental Center: For discharged residents, the “Other” intellectual disabilities were 2 diagnoses, Unspecified F79.

- William W. Fox Development Center: Per diem was \$775 until April 2019; then \$810. For “Other” direct services provided to the community, at this time, Fox Center does not provide any direct services to non-residents. However, if a person formerly living at Fox transfers to the community, they offer technical assistance for up to 1 year following discharge to help preserve the community placement. They offer assistance in behavioral, health, and dental services.

Kansas

- Kansas Neurological Institute: For “Other” direct services provided to the community, wheelchair seating clinic was listed.

Massachusetts

- Charles V. Hogan Regional Center: They did not have any new or readmitted residents who were not here for short term evaluation and treatment. They did not discharge any residents who were not there for short term evaluation and treatment. For direct services provided to the community, ‘Other’ included recreational areas available to community groups. These include the auditorium, gym and adapted gym.
- Wrentham Developmental Center: For direct services provided to the community, ‘Other’ included Assistive Technology services, Adaptive Physical Education, OT/PT Evaluations, and Orientation & Mobility Services.

Maryland

- Holly Center: For current resident ID level, since 6/30/19, 1 individual with moderate and 1 individual with severe level of IDD have been admitted. For new admissions since 6/30/19, there was 1 22-year-old and 1 57-year-old individual.

North Dakota

- Life Skills and Transition Center: DSPs that left and/or are vacant are FTE, not head count.

Nevada

- Desert Regional Center: For current resident’s ID, there was 1 individual with Cerebral Palsy. For new/readmissions ID, there were 4 with Cerebral Palsy & 1 with Prader Willi Syndrome. For settings discharged to, 7 were hospital and 2 were elopement. For direct services provided to the community, ‘Other’ included dietary.

New York

- Sunmount Development Center: For current resident’s ID level, 2 are missing and excluded. For race/ethnicity, there are 18 who are missing

and are excluded. One new/readmitted resident is missing ID level and is excluded. One discharged resident is missing ID level and is excluded.

- Valley Ridge: For current resident's race/ethnicity, 7 are missing and are excluded. For discharged resident ID level, 1 individual is missing and are excluded.

North Carolina

- Murdoch Developmental Center: For additional diagnoses and conditions, the Neuro-Meds are not included. The paid per diem rate is \$756.36.
- J. Iverson Riddle Developmental Center: For additional diagnoses and conditions, the Neuro-Meds are not included.
- O'Berry Neuro-Medical Treatment Center: For additional diagnoses and conditions, the Neuro-Meds are not included.

South Carolina

- Coastal Regional Center: Per diem day funded to DDSN from HHS.

South Dakota

- South Dakota Developmental Center: For current resident ID level, for none, 2 listed as F84.0 Autism, 5 listed as R41.83 borderline.

Texas

- All Centers: The categories "Unspecified" and "Not Indicated" were added to the paper version of the surveys submitted. They were coded as "Unknown".

- Mexia State Supported Living Center: For current resident's ID level, there was 1 with borderline that they coded as "None". For new/readmitted resident's ID level, there were 4 with borderline that they coded as "None". For discharged resident's ID level, there were 6 with borderline that they coded as "None".

Utah

- Utah State Developmental Center: For current resident's ID level, they coded those with borderline as "None". For discharged resident's ID level, the "Unknown" had a IQ of 96.

Washington

- Lakeland Village: For current resident's ID level, data were incomplete. Of the 40 unknown, most are profound.
- Yakima Valley School: For new/readmissions, the 3 individuals were respite for longer than 90 days. For direct services, those checked are provided to clients using their respite program. With respect to closure, the facility is scheduled for closure when the long-term resident count is 12.

Wyoming

- Wyoming Life Resource Center: For staffing, they are working on staffing up for a new facility that they are building on the campus. They have 94 staff and are needing to hire 93 people to fill vacancies.

REFERENCES, RESOURCES AND DATA SOURCES

REFERENCES

- ADA (n.d.) Olmstead: Community Integration for Everyone. Retrieved April 2018 from: www.ada.gov/olmstead/
- American Health Care Association (2019a). *Long Term Care (LTC) Stats: Intermediate care facilities for individuals with intellectual disabilities (ICF/IID) Facility and Resident Characteristics Report: CASPER June 29, 2019*. Washington DC: Author.
- American Health Care Association (2019b). *LTC Stats: Nursing Facility Operational Characteristics as of June 30, 2019*. Source: Center for Medicare & Medicaid Services Certification and Survey Provider Enhanced Reporting (CASPER). Washington, DC: Author.
- American Health Care Association (2019c). *LTC Stats: Nursing Facility Patient Characteristics as of June 30, 2019*. Source: Center for Medicare & Medicaid Services Certification and Survey Provider Enhanced Reporting (CASPER). Washington, DC: Author
- Americans with Disabilities Act of 1990. (1990). retrieved from: www.ada.gov/pubs/ada.htm.
- Bershadsky, J., Taub, S., Engler, J., Moseley, C. R., Lakin, K. C., Stancliffe, R. J., ..., & Bradley, V. (2012). Place of residence and preventive health care for intellectual and developmental disabilities services recipients in 20 states. *Public Health Reports*, 127(5), 475-485.
- Baio, J., Wiggins, L., Christensen, D. L., Maenner, M. J., Daniels, J., Warren, Z., ..., & Durkin, M. S. (2018). Prevalence of autism spectrum disorder among children aged 8 years—autism and developmental disabilities monitoring network, 11 sites, United States, 2014. *MMWR Surveillance Summaries*, 67(6), 1.
- Blatt, B., and Kaplan, F.M. (1966). *Christmas in purgatory: A photographic essay on mental retardation*. Allyn and Bacon. Republished in 1974, Syracuse, New York: Human Policy Press.
- Bronson, J., Maruschak, L.M., and Berzofsky, M. (2015). *Disabilities among prison and jail inmates, 2011-12*. Washington DC: U.S. Department of Justice, Bureau of Justice Statistics.
- Bruininks, R. H., Hill, B. K., & Thorsheim, M. J. (1982). Deinstitutionalization and foster care for mentally retarded people. *Health & social work*, 7(3), 198-205.
- Cheatham, L. P., Randolph, K. A., & Boltz, L. D. (2020). Youth with disabilities transitioning from foster care: Examining prevalence and predicting positive outcomes. *Children and Youth Services Review*, 110, 104777.
- CMS, Centers for Medicare and Medicaid Services (2013, May 3). *Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) Nomenclature Change (Qualified Intellectual Disabilities Professional QIDP)*. Memorandum from the CMS Survey and Certification Group to State Survey Agency Directors <https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/Policy-and-Memos-to-States-and-Regions-Items/Survey-and-Cert-Letter-13-28>
- CMS (2014) *Final Regulation: 1915(i) State Plan HCBS, 5-Year Period for Waivers, Provider Payment Reassignment, Setting Requirements for Community First Choice, and 1915(c) Waivers - CMS-2249-F/ CMS-2296-F 42 CFR § 441*. Retrieved from: www.medicare.gov/medicaid/hcbs/guidance/hcbs-final-regulation/
- Division of Medical Services. (2019). *South Dakota Home and Community Based Services Statewide Transition Plan*. South Dakota Department of Social Services. https://dss.sd.gov/docs/medicaid/hcbs/View_SD_Statewide_Transition_Plan_2.6.19.pdf
- General Accounting Office (1970). *Report to Congress: Questionable claims under Medicaid program for care of persons in state institutions for mentally retarded in California*. Washington, DC: General Accounting Office.

- Gettings, R.M., & Mitchell, D. (1980). *Trends in capital expenditures for mental retardation facilities: A state-by-state survey*. Washington, DC: National Association of State Mental Retardation Program Directors.
- Gettings, R.M. (1990). *Eliminating inappropriate nursing home placements: An analysis of federal-state implementation of OBRA-87's PASARR requirements*. Alexandria, VA: National Association of State Mental Retardation Program Directors, Inc.
- Gillespie, C. (2019). 2019 Statistical Report. Arkansas Department of Human Services: Little Rock, AR.
- Internal Revenue Service (IRS) Data Book. (n.d.). *Table 5, Gross Collections, by Type of Tax and State, Fiscal Year 2019*. Washington DC: Author. Retrieved from <https://www.irs.gov/statistics/soi-tax-stats-gross-collections-by-type-of-tax-and-state-irs-data-book-table-5>
- Irvin, C.V., Bohl, A., Stewart, K., Williams, S.R., Steiner, A., Denny-Brown, N., Wysocki, A., Coughlin, R., Slayter, E. & Springer, C. (2011). Child welfare-involved youth with intellectual disabilities: Pathways into and placements in foster care. *Intellectual and Developmental Disabilities, 49*, 1-13.
- John F. Kennedy Presidential Library and Museum (n.d.). *JFK and people with intellectual disabilities*. Webpage <http://www.jfklibrary.org/JFK/JFK-in-History/JFK-and-People-with-Intellectual-Disabilities.aspx>. Viewed March 9, 2016.
- Kugel, R, & Wolfensberger, W. (Eds., 1969). *Changing patterns in residential services for the mentally retarded*. Washington, D.C.: President's Committee on Mental Retardation.
- Lakin, K.C. (1979). *Demographic studies of residential facilities for the mentally retarded: An historical review of methodologies and Findings*. Minneapolis: University of Minnesota, Department of Psychoeducational Studies. Available online at <https://risp.umn.edu/archive>
- Lakin, K.C., Doljanac, R., Byun, S.Y., Stancliffe, R.J., Taub, S., & Chiri, G. (2008). Factors Associated with Expenditures for Medicaid Home and Community-based Services (HCBS) and Intermediate Care Facilities for Persons with Mental Retardation (ICF/MR) Services for Persons with Intellectual and Developmental Disabilities. *Intellectual and Developmental Disabilities, 36*, 200-214.
- Larson, S.A., Lakin, K.C., & Hill, S.L. (2012). Behavioral outcomes of moving from institutional to community living for people with intellectual and developmental disabilities: U.S. studies from 1977 to 2010. *Research and practice for persons with severe disabilities, 37*(4), 1-12.
- Larson, S.A., Lakin, K.C., Anderson, L.L., Kwak, N., Lee, J.H., Anderson, D. (2001). Prevalence of mental retardation and developmental disabilities: Estimates from the 1994/1995 National Health Interview Survey Disability Supplements. *American Journal on Mental Retardation, 106*, 231-252.
- Lewis, E., Eiken, S., Amos, A., & Saucier, P. (2018). *The growth of managed long-term services and supports programs: 2017 update*. Washington, DC: Truven Health Analytics. Retrieved March 7, 2018 from <https://www.medicaid.gov/medicaid/managed-care/downloads/ltss/mltssp-inventory-update-2017.pdf>.
- Livermore, G. A., Bardos, M., & Katz, K. (2017). Supplemental security income and social security disability insurance beneficiaries with intellectual disability. *Social Security Bulletin, 77*(1), 17-ii.
- Martin, D., Wagner, J., & White, C. (n.d.). *Oklahoma Department of Human Services 2019 Annual Report*. Oklahoma Department of Human Services. https://oklahoma.gov/content/dam/ok/en/okdhs/documents/okdhs-report-library/s19034_dhs2019annualreport_ccr_11122019.pdf
- Medicaid.gov (n.d.). Money follows the person. Retrieved from <https://www.medicaid.gov/medicaid/ltss/money-follows-the-person/index.html> August 21, 2017.

- Minnesota Governor's Council on Developmental Disabilities (2016). V. The reawakening 1950-1080b. 1950-1970 Improving the institutions. *Video: Senator Robert Kennedy visiting institutions ("snake pits") in New York*. St. Paul, MN: Author. Webpage <http://mn.gov/mnddc/parallels/five/5b/4.html>. Viewed March 9, 2016.
- Murray, Caitlin, Tourtellotte, A., Lipson, D. & Wysocki, A. (2021). "Medicaid Long Term Services and Supports Annual Expenditures Report: Federal Fiscal Year 2019." Chicago, IL: Mathematica.
- Texas Health and Human Services. (2020). Medicaid Waiver Programs Interest List Study. <https://www.hhs.texas.gov/reports/2020/09/medicaid-waiver-programs-interest-list-study>
- U.S. Department of Education (2021). *IDEA Section 618 Data Products: State Level Data Files Part B Child Count and Educational Environments 2018*. Retrieved Dec 4, 2021 from <https://www2.ed.gov/programs/osepidea/618-data/state-level-data-files/index.html#bcc>
- National Core Indicators. (2020). National Core Indicators 2019 Staff Stability Survey Report. <https://www.nationalcoreindicators.org/resources/staffstability-survey/>
- National Institute of Mental Health. (1966). *Patients in mental institutions, 1965*. Washington, DC: U.S. Government Printing Office.
- Office of Performance Analysis. (n.d.). *Annual IDD Mortality Report, CY 2020*. Georgia Department of Behavioral Health and Developmental Disabilities. <https://dbhdd.georgia.gov/organization/be-informed/reports-performance/mortality-reports>
- Office of Special Education and Rehabilitative Services (2020). *IDEA Section 618 Data Products: State Level Data Files*. Washington, DC: U.S. Department of Education. Downloaded March 10, 2020 from <https://data.ed.gov/dataset/idea-section-618-state-part-b-child-count-and-educational-environments/resources?resource=c49009eb-a269-4131-9bbe-7d8a3f67f649>
- O'Keefe, J., Saucier, P., Jackson, B., Cooper, R., McKenney, E., Crisp, S., & Moseley, C. (2010). *Understanding Medicaid home and community services: A primer*, 2010 edition. US Department of Health and Human Services and RTI International.
- O'Malley Watts, M., Musumeci, M., & Chidambaram, P. (2020). Medicaid Home and Community-Based Services Enrollment and Spending. *Issue Brief*. San Francisco, CA: Kaiser Family Foundation.
- Olmstead v. L.C.*, 527 U.S. 581 (1999). <https://tile.loc.gov/storage-services/service/ll/usrep/usrep527/usrep527581/usrep527581.pdf>
- Patrick, M. E., Shaw, K. A., Dietz, P. M., Baio, J., Yeargin-Allsopp, M., Bilder, D. A., ..., & Maenner, M. J. (2021). Prevalence of intellectual disability among eight-year-old children from selected communities in the United States, 2014. *Disability and Health Journal*, 14(2), 101023.
- Peebles, V., & Bohl, A. (2014). The HCBS taxonomy: a new language for classifying home- and community-based services. *Medicare & Medicaid Research Review*, 4(3). Retrieved from https://www.cms.gov/mmrr/Briefs/B2014/MMRR2014_004_03_b01.html.
- Social Security Administration. (2019). *Annual Report of the Supplemental Security Income Program*. Baltimore, MD: Office of the Chief Actuary.
- State of the States in Intellectual and Developmental Disabilities*. (n.d.). www.stateofthestates.org
- Tichá, R., Lakin, K. C., Larson, S. A., Stancliffe, R. J., Taub, S., Engler, J., ... & Moseley, C. (2012). Correlates of everyday choice and support-related choice for 8,892 randomly sampled adults with intellectual and developmental disabilities in 19 states. *Intellectual and Developmental Disabilities*, 50(6), 486-504.
- U.S. Census Bureau, Population Division. (2019). *Annual Estimates of the Resident Population: April 1, 2010 to July 1, 2019*. Downloaded March 10, 2022 from <https://factfinder.census.gov>.

U.S. Census Office. *A compendium of the Tenth Census*. Washington, D.C.: U.S. Government Printing Office, 1883.

Winsor, J., Timmons, J., Butterworth, J., Migliore, A., Domin, D., Zalewska, A., & Shepard, J. (2019). *StateData: The national report on employment services and outcomes*. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.

Zablotsky, B., & Black, L. I. (2020). Prevalence of children aged 3–17 years with developmental disabilities, by urbanicity: United States, 2015–2018. *National Health Statistics Reports, Number 139*. Retrieved from: <https://www.cdc.gov/nchs/data/nhsr/nhsr139-508.pdf>

Zablotsky, B., Black, L.I., Maenner, M.J., & Blumberg, S.J. (2017). Estimated Prevalence of Children with Diagnosed Developmental Disabilities in the United States 2014-2016. *National Center for Health Statistics Data Brief*, No. 291. Washington DC: U.S. Department of Health and Human Services. Retrieved from: <https://www.cdc.gov/nchs/data/databriefs/db291.pdf>

HISTORICAL DATA: RESIDENTIAL INFORMATION SYSTEMS PROJECT REPORTS

Historical data in this report are from the following reports. RISP reports for Fiscal Years 1988 through 2017 can be viewed or downloaded from <https://risp.umn.edu/publications>.

Alba, K., Bruininks, R.H., Lakin, K.C., Larson, S.A., Prouty, R.W., Scott, N., & Webster, A. (2008). *Residential services for persons with developmental disabilities: Status and trends through 2007*. R.W. Prouty, K. Alba & K.C. Lakin, (Eds.). Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

Anderson, L.L., Bachman, S., Blake, E.M., Bruininks, R.H., Burwell, B., Lafrenz, L., Lakin, K.C., Polister, B., Prouty, R.W., & Sandlin, J., (1996). *Residential services for persons with developmental disabilities: Status and trends through 1995*. R.W. Prouty & K.C. Lakin, (Eds.). Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

Anderson, L.L., Blake, E.M., Bruininks, R.H., Lakin, K C, Polister, B., Prouty, R.W., & Sandlin, J., (1997). *Residential services for persons with developmental disabilities: Status and trends through 1996*. R.W. Prouty & K.C. Lakin, (Eds.). Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

Anderson, L.L., Bruininks, R.H., Clayton, C., Lakin, K.C., Larson, S.A., Polister, B., Prouty, R.W., & Sandlin, J., (1999). *Residential services for persons with developmental disabilities: Status and trends through 1998*. R.W. Prouty & K.C. Lakin, (Eds.). Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

Anderson, L.L., Bruininks, R.H., Clayton, C., Lakin, K.C., Larson, S.A., Polister, B., Prouty, R.W., & Sandlin, J., (2000). *Residential services for persons with developmental disabilities: Status and trends through 1999*. R.W. Prouty & K.C. Lakin, (Eds.). Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

Anderson, L.L., Bruininks, R.H., Lakin, K.C., Polister, B., Prouty, R.W., & Sandlin, J., (1998). *Residential services for persons with developmental disabilities: Status and trends through 1997*. R.W. Prouty & K.C. Lakin, (Eds.). Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

- Anderson, L.L., Larson, S.A., Kardell, Y., Hallas-Muchow, L., Aiken, F., Hewitt, A., Agosta, J., Fay, M.L., & Sowers, M. (2015). *Supporting Individuals with Intellectual or Developmental Disabilities and their Families: Status and Trends through 2013*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
- 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.
- Bachman, S., Bruininks, R.H., Burwell, B., Kwak, N., Lakin, K.C., Larson, S.A., Mangan, T., Moore S, Polister, B., & Prouty, R.W. (1995). *Residential services for persons with developmental disabilities: Status and trends through 1994*. R.W. Prouty & K.C. Lakin, (Eds.). Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
- Breedlove, T., Bruininks, R.H., Coucouvanis, K., Lakin, K.C., Larson, S.A., Polister, B., & Prouty, R.W. (2004). *Residential services for persons with developmental disabilities: Status and trends through 2003*. R.W. Prouty, Smith, G., & K.C. Lakin, (Eds.). Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
- Bruininks, R.H., Byun SY, Alba K, Lakin, K.C., Larson, S.A., Prouty, R.W., & Webster, A. (2007). *Residential services for persons with developmental disabilities: Status and trends through 2006*. In: R.W. Prouty, Smith, G., & K.C. Lakin, (Eds.). Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
- Bruininks, R.H., Byun SY, Coucouvanis, K., Lakin, K.C., Larson, S.A., & Prouty, R.W. (2005). *Residential services for persons with developmental disabilities: Status and trends through 2004*. R.W. Prouty, Smith, G., & K.C. Lakin, (Eds.). Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
- Bruininks, R.H., Coucouvanis, K., Lakin, K.C., & Prouty, R.W. (2006). *Residential services for persons with developmental disabilities: Status and trends through 2005*. R.W. Prouty, Smith, G., & K.C. Lakin, (Eds.). Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
- Bruininks, R.H., Coucouvanis, K., Lakin, K.C., Larson, S.A., Polister, B., Prouty, R.W., & Smith J. (2003). *Residential services for persons with developmental disabilities: Status and trends through 2002*. R.W. Prouty, Smith, G., & K.C. Lakin, (Eds.). Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
- Bruininks, R.H., Hauber, F.A. & Kudla, M.J. (1979). *National survey of community residential facilities: A profile of facilities and residents in 1977*. Minneapolis: University of Minnesota, Department of Psychoeducational Studies.
- Bruininks, R.H., Kwak, N., Lakin, K.C., Larson, S.A., Polister, B., Prouty, R.W., & Smith J. (2001). *Residential services for persons with developmental disabilities: Status and trends through 2000*. R.W. Prouty, Smith, G., & K.C. Lakin, (Eds.). Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
- Bruininks, R.H., Kwak, N., Lakin, K.C., Larson, S.A., Polister, B., Prouty, R.W., & Smith J. (2002). *Residential services for persons with developmental disabilities: Status and trends through 2001*. Prouty, R.W., Smith, G., & Lakin, K.C. (Eds.). Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

- Clumpner, J.L., Krantz, G.C., & Bruininks, R.H., (1979). *Directory of state-run residential facilities serving mentally retarded people in 1979*. Minneapolis: University of Minnesota, Department of Psychoeducational Studies.
- Hauber, F.A., Bruininks, R.H., Hill, B.K., Lakin, K.C., & White, C.C. (1984). *National census of residential facilities: Fiscal year 1982*. Minneapolis: University of Minnesota, Department of Educational Psychology.
- Hauber, F.A., Bruininks, R.H., Wieck CA, Sigford, B.B., & Hill, B.K., (1981). *1978-1979 in-depth national interview survey of public and community residential facilities for mentally retarded persons: Methods and procedures*. Minneapolis: University of Minnesota, Department of Psychoeducational Studies.
- Krantz, G.C., Bruininks, R.H., & Clumpner, J.L. (1978). *Mentally retarded people in state-run residential facilities: Year ending June 30, 1978*. Minneapolis: University of Minnesota, Department of Psychoeducational Studies.
- Krantz, G.C., Bruininks, R.H., & Clumpner, J.L. (1979). *Mentally retarded people in state-run residential facilities: Year ending June 30, 1979*. Minneapolis: University of Minnesota, Department of Psychoeducational Studies.
- Krantz, G.C., Bruininks, R.H., & Clumpner, J.L. (1980). *Mentally retarded people in state-run residential facilities: Year ending June 30, 1980*. Minneapolis: University of Minnesota, Department of Psychoeducational Studies.
- Krantz, G.C., Clumpner, J.L., Rotegard, L.L. & Bruininks, R.H., (1980). *Mentally retarded people in state-run residential facilities: Year ending June 30, 1980*. Minneapolis: University of Minnesota, Department of Psychoeducational Studies.
- Lakin, K.C. (1979). *Demographic studies of residential facilities for the mentally retarded: An historical review of methodologies & findings*. Minneapolis, University of Minnesota, College of Education.
- Lakin, K.C., Blake, E.M., Prouty, R.W., Mangan, T., & Bruininks, R.H., (1993). *Residential services for persons with developmental disabilities: Status and trends through 1991*. Minneapolis: University of Minnesota Center on Residential Services and Community Living, Institute on Community Integration/UAP.
- Lakin, K.C., Hill, B.K., & Bruininks, R.H., (1985). *An analysis of Medicaid's Intermediate Care Facility for the Mentally Retarded (ICF-MR) program*. Minneapolis: University of Minnesota, Department of Educational Psychology.
- Lakin, K.C., Hill, B.K., Chen, T.H., & Stephens S.A. (1989). *Persons with mental retardation and related conditions in mental retardation facilities: Selected findings from the 1987 National Medical Expenditure Survey (Report No. 29)*. Minneapolis: University of Minnesota, Center for Residential and Community Services.
- Lakin, K.C., Hill, B.K., Street, H., & Bruininks, R.H., (1986). *Persons with mental retardation in state-run residential facilities: Years ending June 30, 1984 and June 30, 1985 with longitudinal trends from 1950 to 1985*. Minneapolis: University of Minnesota, Department of Educational Psychology.
- Lakin, K.C., Hill, B.K., White, C.C. & Wright EA. (1987). *Medicaid's Intermediate Care Facility for the Mentally Retarded (ICF-MR) program: An update (Report No. 25)*. Minneapolis: University of Minnesota, Department of Educational Psychology.
- Lakin, K.C., Jaskulski, T.M., Bruininks, R.H., Menke JM, White, C.C., & Wright EA. (1989). *Medicaid services for persons with mental retardation and related conditions*. Minneapolis: University of Minnesota, Institute on Community Integration.
- Lakin, K.C., Larson, S.A., Salmi, P., & Scott, N. (2009). *Residential services for persons with developmental disabilities: Status and trends through 2008*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

- Lakin, K.C., Larson, S.A., Salmi, P., & Webster, A. (2010). *Residential services for persons with developmental disabilities: Status and trends through 2009*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
- Lakin, K.C., Prouty, R.W., White, C.C., Bruininks, R.H., & Hill, B.K., (1990). *Intermediate care facilities for persons with mental retardation (ICF/IIDs-MR): Program utilization and resident characteristics (Report No. 31)*. Minneapolis: University of Minnesota, Center for Residential and Community Services.
- Lakin, K.C., White, C.C., Prouty, R.W., Bruininks, R.H., & Kimm, C. (1991). *Medicaid institutional (ICF-MR) and home and community-based services for persons with mental retardation and related conditions (Report No. 35)*. Minneapolis: University of Minnesota, Center on residential Services and Community Living.
- Larson, S.A. & Lakin, K.C. (1995). *Status and changes in Medicaid's Intermediate Care Facility for the Mentally Retarded (ICF-MR) program: Results from analysis of the Online Survey Certification and Reporting System*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
- Larson, S.A., Eschenbacher, H.J., Anderson, L.L., Taylor, B., Pettingell, S., Hewitt, A., Sowers, M., & Bourne, M.L. (2017). *In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends through 2015*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
- Larson, S.A., Eschenbacher, H.J., Anderson, L.L., Taylor, B., Pettingell, S., Hewitt, A., Sowers, M., & Bourne, M.L. (2018). *In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends through 2016*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
- Larson, S.A., Eschenbacher, H.J., Anderson, L.L., Taylor, B., Pettingell, S., Hewitt, A., Sowers, M., & Fay, M.L. (2017). *In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and trends through 2014*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
- Larson, S.A., Eschenbacher, H.J., Taylor, B., Pettingell, S., Sowers, M., & Bourne, M.L. (2020). *In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2017*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
- Larson, S.A., Eschenbacher, H.J., Anderson, L.L., Taylor, B., Pettingell, S., Hewitt, A., Sowers, M., & Fay, M.L. (2017). *In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and trends through 2014*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
- Larson, S.A., Hallas-Muchow L, Aiken F, Hewitt A, Pettingell S, Anderson, L.L., Moseley, C., Sowers, M., Fay, M.L., Smith, D., Kardell, Y., & Agosta, J. (2014). *Supporting individuals with intellectual or developmental disabilities and their families: Status and trends through 2012*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
- Larson, S.A., Hallas-Muchow, L., Aiken, F., Taylor, B., Pettingell, S., Hewitt, A., Sowers, M., & Fay, M.L. (2016). *In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and trends through 2013*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. DOI: 10.13140/RG.2.1.4153.0004

- Larson, S.A., Ryan A, Salmi, P., Smith, D., & Wuorio, A. (2012). *Residential services for persons with developmental disabilities: Status and trends through 2010*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
- Larson, S.A., Salmi, P., Smith D, Anderson, L.L., & Hewitt A. (2013). *Residential services for persons with intellectual or developmental disabilities: Status and trends through 2011*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
- Larson, S.A., van der Salm, B., Pettingell, S., Sowers, M., & Anderson, L.L., (2021). Long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2018. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
- Mangan, T., Blake, E.M., Prouty, R.W., & Lakin, K.C. (1993). *Residential services for persons with mental retardation and related conditions: Status and trends through 1992*. Minneapolis: University of Minnesota Research and Training Center on Residential Services and Community Living, Institute on Community Integration (UAP).
- Mangan, T., Blake, E.M., Prouty, R.W., & Lakin, K.C. (1994). *Residential services for persons with mental retardation and related conditions: Status and trends through 1993*. Minneapolis: University of Minnesota Research and Training Center on Residential Services and Community Living, Institute on Community Integration.
- Reichard, A., Haile, E., & Morris, A. (2019). Characteristics of Medicare beneficiaries with intellectual or developmental disabilities. *Intellectual and Developmental Disabilities*, 57(5), 405-420.
- Rotegard, L.L. & Bruininks, R.H., (1983). *Mentally retarded people in state-run residential facilities: Years ending June 30, 1981 and June 30, 1982*. Minneapolis: University of Minnesota, Department of Educational Psychology.
- Thorsheim, M.J. & Bruininks, R.H., (1978). *Admissions and readmission of mentally retarded people to residential facilities*. Minneapolis: University of Minnesota, Department of Psychoeducational Studies.
- White, C.C., Lakin, K.C., & Bruininks, R.H., (1989). *Persons with mental retardation and related conditions in state-run residential facilities: Year ending June 30, 1988 with longitudinal trends from 1950 to 1988 (Report No. 30)*. Minneapolis: University of Minnesota, Department of Educational Psychology.
- White, C.C., Lakin, K.C., Bruininks, R.H., & Li, X. (1991). *Persons with mental retardation and related conditions in state-run residential facilities: Year ending June 30, 1989 with longitudinal trends from 1950 to 1989*. Minneapolis: University of Minnesota, Department of Educational Psychology.
- White, C.C., Lakin, K.C., Hill, B.K., Wright E.A., & Bruininks, R.H., (1988). *Persons with mental retardation in state-run residential facilities: Year ending June 30, 1987 with longitudinal trends from 1950 to 1987 (Report No. 26)*. Minneapolis: University of Minnesota, Department of Educational Psychology.
- White, C.C., Lakin, K.C., Hill, B.K., Wright, E.A., & Bruininks, R.H., (1987). *Persons with mental retardation in state-run residential facilities: Year ending June 30, 1986 with longitudinal trends from 1950 to 1986 (Report No. 24)*. Minneapolis: University of Minnesota, Department of Educational Psychology.
- White, C.C., Prouty, R.W., Lakin, K.C., & Blake E.M. (1992). *Persons with mental retardation and related conditions in state-run residential facilities: Year ending June 30, 1990 with longitudinal trends from 1950 to 1990 and a directory of large state-run residential facilities*. Minneapolis: University of Minnesota, Center on Residential Services and Community Living/Institute on Community Integration (UAP).
- Wieck, C.A. & Bruininks, R.H. (1980). *The cost of public and community residential care for mentally retarded people in the United States*. Minneapolis: University of Minnesota, College of Education.

HISTORICAL DATA: OTHER SOURCES

Data on the history of LTSS and services for people with IDD prior to 1977 came from the following sources:

- Data on state IDD and psychiatric facilities for 1950 to 1968 from the National Institute of Mental Health’s surveys of “Patients in Institutions;”
- Data on state IDD facilities for FYs 1969 and 1970 from surveys conducted by the Office on Mental Retardation Coordination, now the Administration on Intellectual and Developmental Disabilities in the US Department of Health and Human Services;
- Data on large state IDD facilities for 1971 through 1977 from surveys of the National Association of Superintendents of Public Residential Facilities for People with Mental Retardation, now the APDDA; and
- Data on psychiatric facilities for 1969 to 1977 come from the National Institute of Mental Health’s surveys of “Patients in State and County Mental Hospitals.”

Medicaid Waiver Expenditures

1982-1991 Smith, G., & Gettings, R. (1991). The Waiver Program and Services for People with Developmental Disabilities: An Update. Alexandria, VA: National Association of State Mental Retardation Program Directors, Inc.

1992 Burwell, B. (1993). Personal Communication with K. Charlie Lakin.

2010 Eiken, S., Burwell, B., Gold, L. & Sredl, K. (2011). Medicaid 1915(c) Waiver Expenditures: 2011 Update Period. Cambridge, MA: Thompson Reuters.

2012 Eiken, S., Sredl, K., Gold, L., Kasten, J., Burwell, B., and Saucier, P. (2015). Medicaid Expenditures for long-term services and supports in FFY 2012. Cambridge, MA: Thomson Reuters; Washington, DC: Centers for Medicaid and Medicare Services.

2013-2016 Eiken, S., Sredl, K., Burwell, B., & Saucier, P. (2016). Medicaid expenditures for long-term services and supports (LTSS) in FY 2016. Downloaded from <https://www.medicaid.gov/medicaid/long-term-services-supports/reports-evaluations/index.html>

2017-2018 zurray, Caitlin, Alena Tourtellotte, Debra Lipson, and Andrea Wysocki. “Medicaid Long Term Services and Supports Annual Expenditures Report: Federal Fiscal Years 2017 and 2018.” Chicago, IL: Mathematica, January 7, 2021.

ICF/IID Expenditures

1980-1989 Eiken, S. (personal communication, April 15, 2015).

1990-1991 Burwell, B. (1992, January). Medicaid Long Term Expenditures for FY 1991. Lexington, MA: SysteMetrics/McGraw-Hill.

1992 Burwell, B. (1994, February). Medicaid Long Term Expenditures in FY 1993. Cambridge, MA: SysteMetrics A MEDSTAT Division.

1993 Burwell, B. (1999, April). Medicaid Long Term Expenditures in FY 1998. Cambridge, MA: The MEDSTAT Group.

1994-1999 Burwell, B. (1999, April). Medicaid Long Term Expenditures in FY 1999. Cambridge, MA: The MEDSTAT Group. Medicaid ICF-MR expenditures by state FY 1995 to FY 2000: Data from the HCFA 64 report. The Medstat Group.

2000 Burwell, B. (2001). Table B Medicaid ICF-MR expenditures by state FY 1995 to FY 2000: Data from the HCFA 64 report. The Medstat Group.

2001-2003	Burwell, B., Sredl, K., Eiken, S. (2007). Medicaid Long-Term Care Expenditures in FY 2006. Cambridge, MA: Thomson Reuters.	2015	Eiken, S., Sredl, K., Burwell, B., Woodward, R. (2017). Medicaid expenditures for long-term supports and services (LTSS) in FY 2015. Washington, DC: Truven Analytics. Retrieved from: www.medicaid.gov/medicaid/ltss/downloads/reports-and-evaluations/ltss-expenditures-ffy2015-final.pdf
2004	Eiken, S., Sredl, K., Burwell, B., and Gold, L. (2010, August). Medicaid Long-Term Care Expenditures in FY 2009. Cambridge, MA: Thomson Reuters.		
2005	Eiken, S., Sredl, K., Burwell, B., and Gold, L. (2011, October). Medicaid Expenditures for Long-Term Services and Supports: 2011 Update. Cambridge, MA: Thomson Reuters.	2016-2018	Murray, Caitlin, Alena Tourtellotte, Debra Lipson, and Andrea Wysocki. "Medicaid Long Term Services and Supports Annual Expenditures Report: Federal Fiscal Years 2017 and 2018." Chicago, IL: Mathematica, January 7, 2021.
2006	Eiken, S., Sredl, K., Gold, L., Kasten, J., Burwell, B., & Saucier, P. (2013, October). Medicaid Expenditures for Long Term Services and Supports in 2011. Truven.	2018	American Health Care Association (2018a). Long Term Care (LTC) Stats: Intermediate care facilities for individuals with intellectual disabilities (ICF/IID) Facility and Resident Characteristics Report: CASPER June 30, 2018. Washington DC: Author.
2007-2011	Eiken, S., Sredl, K., Gold, L., Kasten, J., Burwell, B., & Saucier, P. (2015, April). Medicaid Expenditures for Long-Term Services and Supports in FFY 2012. Truven.		American Health Care Association (2018b). LTC Stats: Nursing Facility Operational Characteristics as of July 1, 2018. Source: Center for Medicare & Medicaid Services Certification and Survey Provider Enhanced Reporting (CASPER). Washington, DC: Author.
2011	Braddock, D., Hemp, R., Rizzolo, M.C., Tanis, E.S., Haffer, L., & Wu, J. (2015). The State of the States in Intellectual and Developmental Disabilities: Emerging from the Great Recession. Washington, DC: American Association on Intellectual and Developmental Disabilities (AAIDD).		American Health Care Association (2018c). LTC Stats: Nursing Facility Patient Characteristics as of July 1, 2018. Source: Center for Medicare & Medicaid Services Certification and Survey Provider Enhanced Reporting (CASPER). Washington, DC: Author.
2012-2014	Eiken, S., Sredl, K., Burwell, B., Saucier, P. (2016). Medicaid expenditures for long-term supports and services (LTSS) in FY 2014. Washington, DC: Truven Analytics. Retrieved from: www.medicaid.gov/Medicaid/ltss/downloads/ltss-expenditures-2014.pdf		