

# In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends **2017**



**Residential Information Systems Project**





# **IN-HOME AND RESIDENTIAL LONG-TERM SUPPORTS AND SERVICES FOR PERSONS WITH INTELLECTUAL OR DEVELOPMENTAL DISABILITIES: STATUS AND TRENDS THROUGH 2017**

## **RESIDENTIAL INFORMATION SYSTEMS PROJECT**

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# TABLE OF CONTENTS

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Preface .....	1
Acknowledgements.....	2
State Contacts .....	3
RISP National Advisory Group .....	5
Technical User's Group .....	6
Acronyms.....	7
Executive Summary.....	8
Introduction .....	19
The Policy Context .....	19
The Residential Information Systems Project (RISP) .....	23
SECTION 1: IN-HOME AND RESIDENTIAL LONG-TERM SERVICES AND SUPPORTS (LTSS) .....	29
Estimating Prevalence of IDD in the United States .....	29
IDD Agency Caseloads.....	31
Long-Term Services and Support Settings.....	32
Progress on Healthy People 2020 DH-12 Goals.....	49
SECTION 2: LTSS FUNDING AUTHORITIES INCLUDING MEDICAID .....	57
State Utilization of LTSS Funding Authorities .....	57
LTSS Recipients with IDD by Funding Authority .....	58
People Living with a Family Member Waiting for Medicaid Waiver-Funded Supports.....	58
Living Arrangements for People Receiving Medicaid Waiver-Funded LTSS.....	60
Medicaid Waiver Utilization Rates .....	62
Medicaid Waiver Expenditures.....	69
Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID).....	72
ICF/IID Expenditures .....	77
Medicaid Waiver and ICF/IID Recipients and Expenditures .....	80
A Short History of LTSS for People with IDD: Role of the Medicaid Program.....	85
SECTION 3: HISTORICAL PERSPECTIVES AND TRENDS IN LTSS .....	95
Trends in Types of Living Arrangements .....	95
Trends in Residence Size and Type of Operation.....	97
Trends in Medicaid Recipients and Expenditures .....	99

SECTION 4: STATUS AND TRENDS IN LARGE STATE-OPERATED IDD FACILITIES ..... 109

    Status of Public Residential Facilities (PRFs) Serving 16 or More People with IDD in 2017 ..... 109

    Characteristics of People Living In PRFs in FY 2017 ..... 111

    PRF Admissions and Discharges ..... 115

    PRF Staffing Characteristics and Outcomes..... 117

    PRF Status by Facility as of June 30, 2017..... 118

    Trends in Public Residential Facility Utilization..... 131

    Trends in Average Annual per Person Expenditures..... 139

    Trends in Characteristics of People with IDD Living in PRFs..... 139

    Trends in PRF Admissions, Readmissions and Discharges ..... 142

SECTION 5: STATE NOTES AND PROFILES..... 150

    State Notes..... 150

    State Profiles ..... 155

SECTION 6: References, Resources and Data Sources ..... 210

    References..... 210

    Historical Data: Residential Information Systems Project Reports ..... 212

    Historical Data: Other Sources ..... 217

    RISP FY 2017 Survey | RISP FY 2017 Operational Definitions ..... 219

    Residential Information Systems Project | Operational Definitions | FY 2017 Survey..... 233

    Part 1: State-Operated Services ..... 238

    Part 2. Nonstate-Operated Living Arrangements ..... 239

    Part 3 Caseload, LTSS Recipients, and Expenditures..... 240

    Part 4 Medicaid Waiver Waiting List..... 241

    Part 5 Psychiatric, Nursing Facilities, and CDC Healthy People 2020 Monitoring ..... 241

    Frequently Asked Questions..... 242

## LIST OF TABLES

---

<b>Table A:</b> Long-Term Supports and Services Used by People with IDD.....	18
<b>Table 1.1</b> United States Population and People with IDD by Age and State on June 30, 2017 .....	30
<b>Table 1.2</b> People Known to or Served by State IDD Agencies by Age on June 30, 2017 .....	32
<b>Table B:</b> Living Arrangements for LTSS Recipients with IDD .....	33
<b>Table 1.3</b> LTSS Recipients with IDD by Setting Type, Type of Operation, and State on June 30, 2017 .....	34
<b>Table 1.4</b> LTSS Recipients with IDD Living with a Family Member by State on June 30, 2017 .....	36
<b>Table 1.5</b> LTSS Recipients with IDD in Own Home Settings by State and Setting Size on June 30, 2017 .....	37
<b>Table 1.6</b> Host or Foster Family Homes and LTSS Recipients with IDD in Them by Setting Size and State on June 30, 2017 .....	38
<b>Table 1.7</b> Group LTSS Settings and People with IDD Living in Them by Setting Size and State on June 30, 2017 .....	40
<b>Table 1.8</b> Non-Family Residential Settings for LTSS recipients with IDD by Type of Operation and Setting Size on June 30, 2017.....	41
<b>Table 1.9</b> Residence Size and Type of Operation for LTSS Recipients with IDD not Living with a Family Member by State on June 30, 2017 .....	43
<b>Table 1.10</b> LTSS Settings and Recipients with IDD Not Living with a Family Member by Setting Size and Per 100,000 of the Population by State on June 30, 2017 .....	44
<b>Table 1.11</b> People with IDD in State-Operated and Non-State Nursing Homes or Psychiatric Facilities by State on June 30, 2017.....	48
<b>Table 1.12</b> People with IDD 21 Years or Younger Living in Nursing Homes or other Congregate Settings of 4 or More People by State on June 30, 2017 .....	50
<b>Table C:</b> Medicaid Funding Authorities .....	56
<b>Table 2.1</b> 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, 2017 .....	59
<b>Table 2.2</b> Medicaid Waiver Recipients with IDD by Residence Type and State .....	61
<b>Table 2.3</b> Medicaid Waiver Recipients with IDD Total and per 100,000 by Age and State on June 30, 2017 .....	63
<b>Table 2.4</b> Medicaid Waiver Recipients with IDD Living in Family Homes or Other LTSS Settings by Age and State on June 30, 2017 .....	66
<b>Table 2.5</b> Medicaid Waiver and LTSS Recipients with IDD in Own Home or Family Settings by State on June 20, 2017.....	67

<b>Table 2.6</b> Medicaid Waiver Expenditures, Per Recipient with IDD and Per State Resident by Age and State in FY 2017 .....	68
<b>Table 2.7</b> Medicaid Waiver Expenditures and Average per Recipient by Age, Living Arrangement, and State in FY 2017 .....	70
<b>Table 2.8</b> Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) by Size, Type of Operation and State on June 30, 2017 .....	73
<b>Table 2.9</b> People Living in an ICF/IID by Type of Operation, Setting Size and State on June 30, 2017 .....	74
<b>Table 2.10</b> People Living in an ICF/IID Per 100,000 of the Population by Age and State on June 30, 2017 .....	76
<b>Table 2.11</b> ICF/IID Expenditures, Recipients, Expenditure Per Person, and Expenditures Per State Resident by State in Fiscal Year 2017 .....	78
<b>Table 2.12</b> Annual ICF/IID Expenditures Per Person by Age and State in Fiscal Year 2017 .....	79
<b>Table 2.13</b> ICF/IID and Medicaid Waiver Recipients and Expenditures Total and Percent by Funding Authority and State on June 30, 2017 .....	81
<b>Table 2.14a</b> FY 2017 Medicaid Expenditures for People with IDD, Federal Matching Percentage, and Federal Share by Funding Authority and State.....	84
<b>Table 2.14b</b> FY 2017 State Medicaid Expenditures, Federal Income Taxes, and State Medicaid Benefit Ratios by Funding Authority and State .....	85
<b>Table 3.1</b> Non-Family IDD Residences by Type of Operation and Setting Size on June 30 of Selected Years 1977 to 2017 .....	96
<b>Table 3.2</b> People with IDD in LTSS Settings by Setting Size, and Proportion with 1 to 6 People on June 30 of Selected Years, 1977 to 2017 .....	96
<b>Table 3.3</b> Medicaid Expenditures for ICF/IID and Waiver Recipients with IDD as a Proportion of All Medicaid Expenditures Select Years 1980 to 2017.....	99
<b>Table 3.4</b> Estimated Medicaid Waiver Recipients with IDD by State on June 30th Selected Years, 1982-2017.....	103
<b>Table 3.5</b> Estimated Medicaid Waiver Expenditures (in \$1,000s) for People with IDD by State Selected Years 1982 to 2017 .....	104
<b>Table 3.6</b> Estimated ICF/IID Recipients by State, Selected Years 1982 to 2017 .....	105
<b>Table 3.7</b> Estimated Medicaid ICF/IID Expenditures (in \$1,000s) by State, Selected Years 1982 to 2017 .....	106
<b>Table 4.1</b> PRF Daily Population, Admissions, Discharges, Deaths and per Person Expenditures by State for Fiscal Year 2017.....	110
<b>Table 4.2</b> Characteristics of People with IDD Living in PRFs on June 30, 2017 .....	111
<b>Table 4.3</b> Number of People with IDD in PRF's by Age and State on June 30, 2017 .....	112

<b>Table 4.4</b> Level of Intellectual Disability of People in PRF's (in percent) by State on June 30, 2017 .....	114
<b>Table 4.5</b> Age and Level of Intellectual Disabilities for Current, Admitted and Discharged Residents of PRFs for FY 2017 .....	115
<b>Table 4.6</b> Previous Residence for People Admitted or Readmitted to PRFs and Subsequent Residence Type for People Discharged from PRFs 2017 (in Percent) .....	116
<b>Table 4.7</b> Staff Characteristics and Outcomes in PRFs in FY 2017 .....	116
<b>Table 4.8</b> PRFs Open on June 30, 2017: Projected Closure Date, Population, Per Person Expenditures, Admissions, Discharges and Deaths By State and Facility Name .....	119
<b>Table 4.9</b> 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, 2017 .....	124
<b>Table 4.10</b> Operational Status of PRFs by State on June 30, 2017 with Projected Closures to June 2022 .....	130
<b>Table 4.11</b> 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 1890-2017 .....	132
<b>Table 4.12</b> Average Daily PRF Population by State Selected Years 1980 to 2017 .....	136
<b>Table 4.13</b> Change in Estimated Average Daily Population and Annual Admissions, Discharges and Deaths in PRFs Selected Years 1950-2017 .....	137
<b>Table 4.14</b> Annual Per Person Expenditures for People with IDD in PRFs Selected Years 1950-2017 .....	138
<b>Table 4.15</b> PRF Population Characteristics June 30th of Selected Years 1977 to 2017 (in percent) .....	140
<b>Table 4.16</b> Previous Place of Residence of Persons (Re) Admitted to Large State IDD Facilities (in Percent) for Selected Years 1985 to 2017 .....	143
<b>Table 4.17</b> Subsequent Residence of People with IDD Discharged From a Public IDD Facility: Selected Years 1985 to 2017 .....	143
<b>Table 4.18</b> Percent of PRFs Providing Services to People Not Living On-Campus by Type of Service 2000 to 2017 .....	145
<b>Table 4.19</b> Direct Support Professional and Frontline Supervisor Vacancy and Turnover Rates, Wages and Salary in Large State-Operated IDD Facilities Selected Years 2004 to 2017 .....	146

## LIST OF FIGURES

---

<b>Figure A.1</b> Key Elements of the Medicaid Program.....	20
<b>Figure 1.1</b> LTSS Recipients with IDD by Residence Type and Size on June 30, 2017 .....	35
<b>Figure 1.2</b> Percent of LTSS Recipients with IDD Living with a Family Member by State on June 30, 2017 .....	37
<b>Figure 1.3</b> LTSS Recipients with IDD per Setting by Setting Type on June 30, 2017 .....	45
<b>Figure 1.4</b> 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, 2017 .....	46
<b>Figure 1.5</b> Estimated LTSS Recipients with IDD Per 100,000 of the Population by Setting Type and State on June 30, 2017 .....	47
<b>Figure 1.6</b> Percent of LTSS Recipients with IDD in Family Home, LTSS Settings, Psychiatric Facilities or Nursing Homes by Residence Type and Size on June 30, 2017.....	49
<b>Figure 1.7</b> Number of People with IDD 21 Years or Younger Living in Nursing Homes or Congregate Settings of Four or More People June 30, 1997 to 2017 with Projections to 2020 .....	51
<b>Figure 2.1</b> Funding Authorities Used by States to Provide LTSS for People with IDD on June 30, 2017 .....	57
<b>Figure 2.2</b> Estimated LTSS Recipients with IDD by Funding Authority on June 30, 2017.....	58
<b>Figure 2.3</b> Total Medicaid ICF/IID and Waiver Recipients and People in Own or Family Home Waiting for Waiver Funding as of June 30, 2016 and June 30, 2017 .....	60
<b>Figure 2.4</b> Percent of Medicaid Waiver Recipients with IDD in Family Home, Own Home, Host or Foster Family Home, or Group Settings by State June 30, 2017.....	62
<b>Figure 2.5</b> Medicaid Waiver Recipients with IDD per 100,000 of the Population by Age and State on June 30, 2017 .....	64
<b>Figure 2.6</b> Estimated Number of Waiver Recipients by Age and Residence Type on June 30, 2017 .....	65
<b>Figure 2.7</b> Annual Medicaid Waiver Expenditures for People with IDD per State Resident by State FY 2017 .....	69
<b>Figure 2.8</b> Estimated Average Annual Per Person Medicaid Waiver Expenditures by Age and Living Arrangement in FY 2017 .....	71
<b>Figure 2.9</b> 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, 2017 .....	75
<b>Figure 2.10</b> People Living in an ICF/IID per 100,000 of the Population by State and Age on June 30, 2017 .....	77
<b>Figure 2.11</b> Distribution of ICF/IID and Waiver Expenditures and Recipients in FY 2017.....	80

<b>Figure 2.12</b> Estimated Medicaid LTSS Recipients with IDD by Age, Funding Authority and Living Arrangement on June 30, 2017 .....	82
<b>Figure 2.13</b> Estimated Annual Per Person Medicaid Expenditures by Age, Funding Authority and Living Arrangement in FY 2017 .....	82
<b>Figure 3.1</b> Number and Percent of LTSS Recipients with IDD by Living Arrangement Type and Size: Select Years 1998 to 2017 .....	95
<b>Figure 3.2</b> People with IDD in Non-Family LTSS Settings by Type of Operation on June 30 Selected Years.....	97
<b>Figure 3.3</b> Proportion of People with IDD in IDD Settings of 16 or more who Live in Nonstate Settings Selected Years 1977 to 2017 .....	98
<b>Figure 3.4</b> Number of LTSS Recipients with IDD in State and Nonstate-Operated Settings of 16+ People 1992 to 2017 with Linear Projections to 2037.....	98
<b>Figure 3.5a</b> Medicaid ICF/IID and HCBS Waiver Recipients with IDD From 1982 to 2017 .....	101
<b>Figure 3.5b</b> Medicaid ICF/IID and HCBS Waiver Expenditures in Billions for People with IDD From 1982 to 2017 .....	101
<b>Figure 3.5c</b> Average Annual Per Person ICF/IID and Waiver Expenditures For People with IDD From 1982 to 2017 .....	101
<b>Figure 4.1</b> Age of People Living in PRF's by State on June 30, 2017 .....	112
<b>Figure 4.2</b> Level of Intellectual Disability Distribution of People in PRFs by State on June 30, 2017 .....	114
<b>Figure 4.3</b> Age Distribution for June 30, Newly Admitted, Readmitted and Discharged PRF Residents in FY 2017 .....	115
<b>Figure 4.4</b> Level of Intellectual Disabilities for June 30, Newly Admitted, Readmitted and Discharged PRF Residents in FY 2017 .....	115
<b>Figure 4.5</b> Previous and Subsequent Residence For People Admitted or Readmitted to and Discharged from PRFs in 2017 (in percent) .....	117
<b>Figure 4.6</b> PRFs Closed or Converted to Non-IDD Use or Nonstate Operation Between 1960 and 2017 and Projected Closures for 2018 to 2024 in 5-Year Intervals.....	131
<b>Figure 4.7a</b> Average Daily Population of PRFs from 1880 to 2017 .....	133
<b>Figure 4.7b</b> People with IDD in State Operated Psychiatric Facilities Selected Years 1950 to 2016 .....	133
<b>Figure 4.8</b> Average Annual Change in the Number of People with IDD in PRFs and State Psychiatric Facilities in Five Year Intervals 1965 to 2017 with Linear Trendlines .....	134
<b>Figure 4.9</b> Annual PRF Admissions, Discharges and Deaths as a Proportion of the Average Daily Population, 1950 to 2017 .....	137
<b>Figure 4.10</b> Average Annual Per Person Expenditures for PRF's, Selected Years 1950-2017 .....	138
<b>Figure 4.11</b> Average Daily Population of PRFs and Percent 21 Years or Younger, 1950 to 2017 .....	139

**Figure 4.12** Estimated Number and Proportion of People in PRFs by Age Group on June 30 of Selected Years 1977 to 2017 ..... 141

**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 1964 to 2017 ..... 142

**Figure 4.14** Previous Place of Residence for People (Re)Admitted to a Large State IDD Facilities in Percent Selected Years: 1989 to 2017 ..... 144

**Figure 4.15** Subsequent Residence of People with IDD Discharged From a Public IDD Facility Selected Years 1989 to 2017 ..... 144

**Figure 4.16** Percent of PRFs Offering Behavioral Assessment, Dental, Crisis Support, Respite Services, or Vocational Training to People with IDD not Living On-Campus 2000 to 2017 ..... 145

**Figure 4.17** Direct Support Professional and Frontline Supervisor Turnover Rates in PRFs Selected Years 2004 to 2017 ..... 146



## PREFACE

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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, 2017 (Fiscal Year 2017).

Key changes for FY 2017 include:

- The survey was modified to allow states to report the number of people living in various types of non-state settings even if they were unable to report the size of those settings.
- Optional questions were added to allow states to report living arrangements for people receiving services funded by a Medicaid State Plan 1915(i) or 1915(k) funding authority.
- The Public Residential Facility Survey was condensed to focus on key questions. Specifically questions about reasons for involvement with the criminal justice system were condensed into a single item asking for the number of people who had been involved for any reason.

The FY 2017 surveys, operational definitions, reports and visualizations are available online at [resp.umn.edu](http://resp.umn.edu). Past RISP products listed at the end of this report can 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 [resp@umn.edu](mailto:resp@umn.edu). We continue to refine and expand our product offerings based on the requests and feedback we receive from readers.

Sherri Larson, RISP Principal Investigator

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Mark Sauro  
Joyce Wong

## Rhode Island

Brian Gosselin  
Anne LeClerc  
Joni Martell  
Donna Phillips  
Corinna Roy  
Evelyn Shapiro  
Kerri Zachi

## South Carolina

Darby Anderson  
Rufus Britt  
David Goldmintz  
Pat Maley  
Mary Poole  
Susan Simpson  
Angela Wright

## South Dakota

Barb Abeln  
Laura Ellenbacker  
Darryl Millner  
Alana Suiter

## Tennessee

April Darby  
Patricia Dodson  
Melinda Lanza  
Brad Turner

## Texas

Janie P. Eubanks  
Sonja Gaines  
Amanda Klekar  
Julia Marsh-Klepac  
David Mellinger  
Vicky Vanhorn

## Utah

Josip Ambrenac  
Tyler Black  
Amy Lewis  
Chad Midgley  
Angela Pinna  
Emily Weatherly

## Vermont

June E. Bascom  
Selina Hickman

## Virginia

Connie Cochran  
Zenna Fergusson  
Brenda Haley  
Kevin Hankins  
Cherice Jackson  
Maria Joson  
Kevin Meyer  
Melanie Murphy  
Heather Norton  
Cheri Stierer

## Washington

Marci Arthur  
Mark Eliason  
Jeff Flesner  
Connie Lambert-Eckel  
Upkar Mangat  
Evelyn Perez  
Shaw Seaman  
Tammy Winegar

## West Virginia

Steve Brady  
Roxanne Chaney  
Beth Morrison  
Pat S. Nisbet

## Wisconsin

Curtis Cunningham  
Jake Miller  
Cynthia Powell  
Michelle Prost  
Shelley Seeley  
Angela Witt

## Wyoming

Lee Grossman  
Colleen Noon  
Stephanie Wright

## **RISP NATIONAL ADVISORY GROUP**

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:

Catherine Arnold: Executive Director, Sibling Leadership Network.

Peter Berns: Chief Executive Officer, The Arc.

Julia Bascom: Executive Director, Autistic Self-Advocacy Network.

Curtis Decker: Executive Director, National Disability Rights Network.

Susan Havervamp: Director, Health Promotion and Healthcare Parity Program at the Ohio State University Nisonger Center.

Andrew Houtenville: Research Director, Institute on Disability at the University of New Hampshire.

Donna Meltzer: Chief Executive Officer, National Association of Councils on Developmental Disabilities.

Barbara Merrill: Chief Executive Officer, American Network of Community Options and Resources.

Maggie Nygren: Executive Director, American Association on Intellectual and Developmental Disabilities.

Ann Outlaw: Dissemination and TA Coordinator for the Center on Knowledge Translation for Disability and Rehabilitation Research (KTER).

Drew Smith: Partner, Community Bridges Consulting Group.

John Tschida: Associate Executive Director for Research and Policy, Association of University Centers for Disabilities.

## 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.

### Research Committee Membership

Mary Brogan, HI (2017-2019)  
 Beverly Buscemi, SC (2015-2017)  
 Evelyn Perez WA (2018-2020)  
 Terry Macy, DE (2016-2018)  
 John Martin, OH (2016-2018)  
 Bernie Simons, MD (2016-2018)  
 Lilia Teninty, OR (2016-2018)

### Members from Research Organizations

HSRI: Valerie Bradley  
 University of Minnesota: Amy Hewitt  
 University of Colorado: Rick Hemp  
 University of Massachusetts: John Butterworth

### NASDDDS Staff

Mary Sowers, Executive Director  
 Mary Lou Bourne, NCI Director

### Members of the RISP Subcommittee

Darby Anderson, SC  
 Marci Arthur, WA  
 Kathleen Haines, MI  
 Hope McGonigle, OH  
 Jacob Miller, WI  
 Joshua Negrini, CO  
 Christy Orcutt, OR  
 Hans Toegel, MA  
 Clayton Weidner, OH  
 Jeff Wieferich, MI

## ACRONYMS

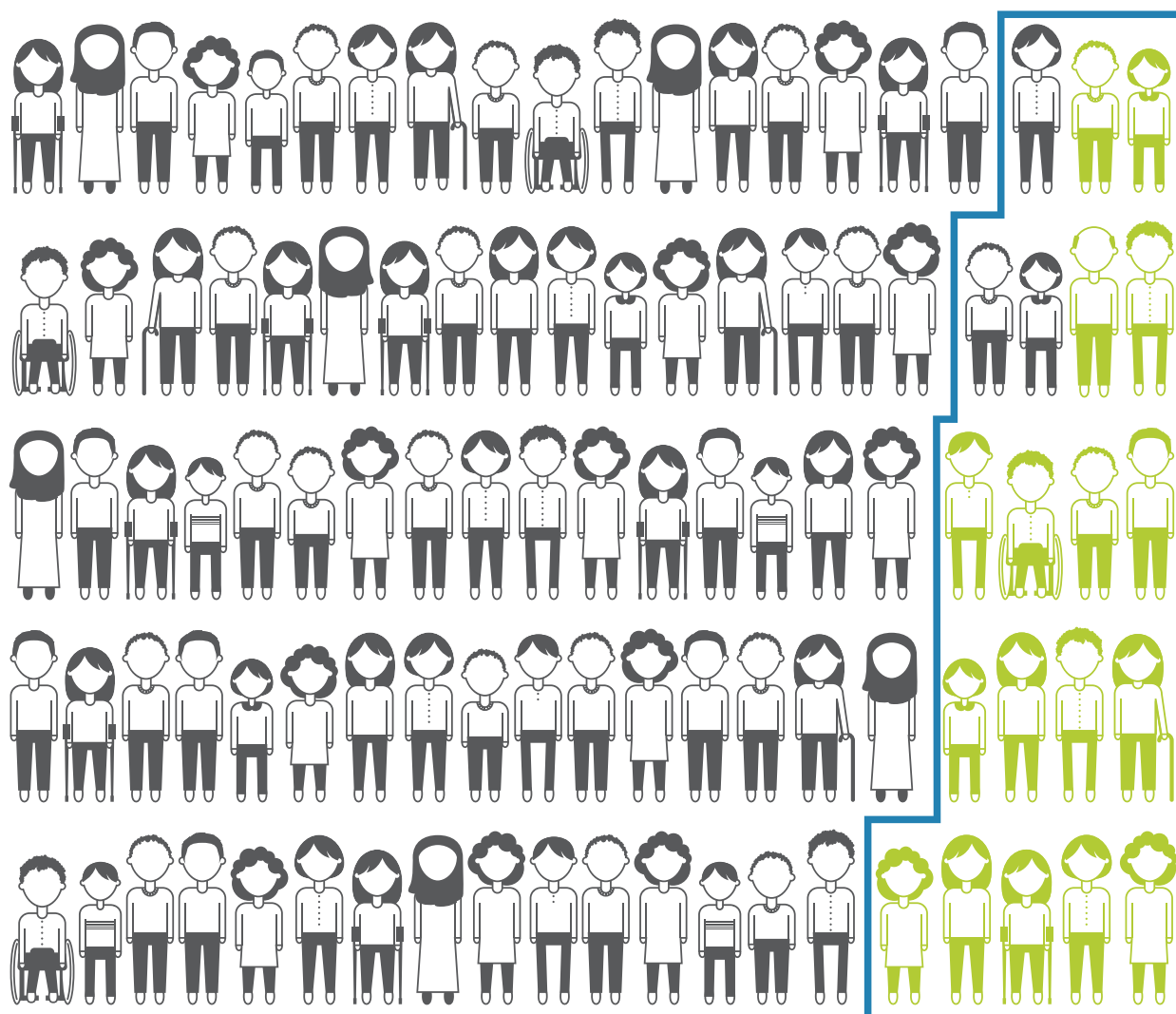
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<b>ACL</b>	Administration on Community Living
<b>ADA</b>	Americans with Disabilities Act
<b>AHCA</b>	American Health Care Association
<b>AIDD</b>	Administration on Intellectual and Developmental Disabilities (formerly ADD)
<b>APDDA</b>	Association of Professional Developmental Disabilities Administrators
<b>ASD</b>	Autism Spectrum Disorder
<b>CASPER</b>	Certification and Survey Provider Enhanced Reporting (CMS)
<b>CEHD</b>	College of Education and Human Development (University of Minnesota)
<b>CMS 64</b>	Centers for Medicare & Medicaid Services Quarterly Expense Report CMS, Centers for Medicare & Medicaid Services
<b>DD</b>	Developmental Disabilities
<b>DNF</b>	Did Not Furnish
<b>FFP</b>	Federal Financial Participation
<b>FMAP</b>	Federal Medical Assistance Percentage
<b>FY</b>	Fiscal Year (FY 2017 is July 1, 2016 to June 30, 2017 unless otherwise specified)
<b>HCBS</b>	Home and Community-Based Services (Medicaid)
<b>HSRI</b>	Human Services Research Institute
<b>ICF/IID</b>	Intermediate Care Facility for Individuals with Intellectual Disabilities
<b>ICI</b>	Institute on Community Integration (University of MN's UCEDD)
<b>ID</b>	Intellectual Disabilities
<b>IDD</b>	Intellectual and Developmental Disabilities
<b>IDEA</b>	Individuals with Disabilities Education Act
<b>LTSS</b>	Long-term supports and services
<b>MCO</b>	Managed Care Organization
<b>MFP</b>	Money Follows the Person
<b>NASDDDS</b>	National Association of State Directors of Developmental Disabilities Services
<b>NASUAD</b>	National Association of States United for Aging and Disabilities
<b>NHIS</b>	National Health Interview Survey
<b>NHIS-D</b>	National Health Interview Survey-Disability Supplement
<b>NIDILRR</b>	National Institute on Disability, Independent Living, and Rehabilitation Research
<b>OBRA-87</b>	Omnibus Budget Reconciliation Act of 1987
<b>OSCAR</b>	Online Survey, Certification and Reporting System (Medicaid)
<b>PASRR</b>	Preadmission Screening and Resident Review
<b>PD</b>	Partial data reported by state
<b>PRF</b>	Public residential facility (a state-operated IDD facility serving 16 or more individuals)
<b>QIDP</b>	Qualified Intellectual Disability Professional
<b>RISP</b>	Residential Information Systems Project (University of MN)
<b>RTC/CL</b>	Research and Training Center on Community Living for persons with Intellectual and Developmental Disabilities (University of MN)
<b>SNF</b>	Skilled Nursing Facility
<b>SSA</b>	Social Security Administration
<b>UCEDD</b>	University Centers of Excellence in Developmental Disabilities

## EXECUTIVE SUMMARY

People with intellectual or developmental disabilities (IDD) in the United States live in many different types of settings including homes of their own, with a family member, with a host or foster family, or in a provider-owned or operated setting. An estimated 17% of people with IDD in the United States were receiving Medicaid or State-funded long-term supports and services (LTSS) through state IDD agencies on June 30, 2017. This report describes LTSS recipients with IDD and public LTSS expenditures by recipient age (birth to 21 years or 22 years and older), residence type and size, funding source, and provider type (state or non-state).

# 7.38 million people in the United States had Intellectual or Developmental Disabilities (IDD) in 2017



**20%** 1.48 million people with IDD were known to or served by state IDD agencies

**17%** 1.28 million people with IDD received long-term supports or services through state IDD agencies



## SECTION 1 SUMMARY: IN-HOME AND RESIDENTIAL SUPPORTS

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Section 1 reports the prevalence of IDD, the number of people with IDD known to state IDD agencies, and the living arrangements of long-term supports and services recipients with IDD as of June 30, 2017

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

---

An estimated 7.38 million people with IDD (22.7 per 1,000 of the population) lived in the United States on June 30, 2017. An estimated 72% of those people were 21 years or younger. An estimated 1,478,425 people with IDD were known to or served by state IDD agencies (20% or 4.6 people per 1,000). Of the people served by state IDD agencies, 38% (567,535 people) were 21 years or younger and 62% (910,890 people) were 22 years or older.

### *Where did people with IDD receiving LTSS live?*

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An estimated 17% (1,278,602 people) of people with IDD in the United States received LTSS provided by or under the auspices of state IDD agencies (86% of the people known to state IDD agencies) on June 30, 2017. Of those,

- 60% (762,097 people) lived in the home of a family member
- 23% (296,097 people) lived in a group home, ICF/IID or other group setting
- 12% (152,759 people) lived in a home they owned or leased
- 5% (67,649 people) lived in a host or foster family home

An additional 25,576 people with IDD lived in nursing homes and an estimated 2,799 lived in a psychiatric facility. State IDD agencies managed services for some but not all individuals with IDD in psychiatric facilities or nursing homes.

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

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People with IDD who received LTSS and did not live with a family member resided in a variety of settings including: own home, host/foster family homes, group homes, Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID), and other group settings. The size of the estimated 229,380 non-family residences in which LTSS recipients with IDD lived varied. Of those settings,

- 85% (194,181 settings) were home to three or fewer people
- 12% (28,104 settings) were home to 4 to 6 people
- 3% (6,363 settings) were home to 7 to 15 people
- 0.3% (732 settings) were home to 16 or more people

An estimated 516,505 people with IDD lived in non-family settings. Of those,

- 58% (300,427 people) lived in a setting shared by three or fewer people
- 25% (127,519 people) lived in a setting shared by 4 to 6 people
- 10% (51,822 people) lived in a setting shared by 7 to 15 people
- 7% (36,736 people) lived in a setting shared by 16 or more people

What was the average size of non-family settings? The average non-family residence was shared by 2.3 people with IDD. In non-state settings, there were an average of

- 1.3 people per own home setting,
- 1.9 people per host/foster family home,
- 3.5 people per group home (other than ICF/IID), and
- 9.5 people per ICF/IID.

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

- 5.3 people per group home (other than ICF/IID),
- 15.7 people per “other” group setting, and
- 65.7 people per ICF/IID

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

An estimated 15,425 people with IDD age 21 years or younger lived in settings shared by four or more LTSS recipients. Of those,

- 8% (1,309 children and youth) lived in nursing homes and
- 92% (14,116 children and youth) lived in group homes shared by four or more people or in other congregate settings

## SECTION 2 SUMMARY: MEDICAID LTSS RECIPIENTS AND EXPENDITURES

Section 2 describes the Medicaid and state authorities through which LTSS for people with IDD are funded as of June 30, 2017. It describes the number of recipients, total expenditures, and expenditures per recipient for Medicaid Waiver and Intermediate Care Facilities for Individuals with Intellectual Disabilities. For Waiver recipients, it also describes recipients, expenditures and expenditures per recipient by age and living arrangement.

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

In 2017,

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

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

### *How many people with IDD received LTSS through Medicaid or state funding authorities in FY 2017?*

Of the 1,278,602 LTSS recipients with IDD,

- 67% (860,500 people) received LTSS through a Medicaid Waiver funding authority
- 18% (232,101 people) received LTSS through a Medicaid State Plan HCBS funding under the 1915(i) or 1915(k) authorities
- 16% (203,393 people) received state-funded LTSS
- 6% (73,855 people) received supports in a Medicaid ICF/IID
- 21% (267,134 people) received no Medicaid or state-funded LTSS

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

## Medicaid Waiver

### *How many people with IDD were waiting for Medicaid Waiver-funded supports on June 30, 2017?*

An estimated 182,340 people with IDD were living with a family member and waiting for Medicaid Waiver-funded LTSS. Of those,

- 35% (63,487 people) were waiting to move to a different setting
- 22% (39,960 people) received Medicaid State Plan-funded Targeted Case Management services while waiting.

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

The number of Medicaid Waiver plus ICF/IID recipients would have to increase by 20% to serve every person on the Medicaid Waiver waiting list.

### *Where did Medicaid Waiver recipients with IDD live on June 30, 2017?*

Of the 860,500 Medicaid Waiver recipients with IDD

- 53% (459,265 people) lived with a family member
- 26% (220,895 people) lived in a group setting
- 14% (118,997 people) lived in a home they owned or leased
- 7% (61,343 people) lived in a host or foster family home

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

Of the 860,500 Medicaid Waiver Recipients with IDD

- 25% (218,253 Medicaid Waiver recipients) were 21 years or younger, of whom
  - 85% (186,561 people) lived in the home of a family member
  - 15% (31,692 people) lived in own home, host or foster family home, or a group setting
- 75% (642,247 Medicaid Waiver recipients) were 22 years or older, of whom
  - 42% (272,704 people) lived in the home of a family member
  - 58% (369,543 people) lived in own home, host or foster family home or a group setting

There were 264 Medicaid Waiver recipients with IDD per 100,000 of the United States' population.

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

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

- 78% (118,997 LTSS recipients) living in their own home received Medicaid Waiver-funded supports
- 60% (459,265 LTSS recipients) living in the home of a family member received Medicaid Waiver-funded supports

### *What were total FY 2017 Medicaid Waiver expenditures for recipients with IDD? What proportion of FY 2017 Medicaid Waiver expenditures for recipients with IDD were for people 22 years or older?*

Estimated Medicaid Waiver expenditures for people with IDD in FY 2017 were \$38.71 billion (\$119 per U.S. resident) of which

- 10% (\$3.72 billion) was for people 21 years or younger
- 90% (\$34.99 billion) was for people 22 years or older

## *What were the average annual per recipient Medicaid Waiver expenditures for people with IDD in FY 2017? How did the average differ by age and living arrangement?*

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Average annual Medicaid Waiver expenditures were \$44,983 per year-end recipient with IDD in FY 2017. Average expenditures were

- \$17,033 per recipient 21 years or younger overall
  - \$11,363 for people 21 years or younger living in the home of a family member
  - \$50,411 for people 21 years or younger living in other settings
- \$54,481 per recipient 22 years or older overall
  - \$25,027 for people 22 years or older living in the home of a family member
  - \$76,216 for people 22 years or older living in other settings

## *How many ICF/IIDs were operating on June 30, 2017? How many people with IDD received services in ICF/ IID of different sizes?*

---

There were 6,084 ICF/IID settings operating on June 30, 2017. Of those,

- 5% (289 ICF/IID) were state-operated including
  - 25% (72) serving 6 or fewer people
  - 35% (102) serving 7 to 15 people
  - 40% (115) serving 16 or more people
- 95% (5,795 ICF/IID) were non-state including
  - 63% (3,640) serving 6 or fewer people
  - 31% (1,769) serving 7 to 15 people
  - 6% (336) serving 16 or more people

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

## *How many people lived in state or non-state ICF/IID of various sizes on June 30, 2017?*

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An estimated 73,855 people lived in an ICF/IID on June 30, 2017. Of those,

- 26% (18,987 people) lived in a state-operated ICF/IID including
  - 2% (304) in a setting of 6 or fewer people
  - 5% (939) in a setting of 7 to 15 people
  - 93% (17,744) in a setting 16 or more people
- 74% (54,868 people) lived in a non-state ICF/IID including
  - 43% (23,695) in a setting of 6 or fewer people
  - 29% (15,690) in a setting of 7 to 15 people
  - 28% (15,483) in a setting of 16 or more people

## *How old were people living in an ICF/IID?*

---

Of the 73,855 people living in an ICF/IID (22.7 people per 100,000 of the population)

- 7% (4,919 people) were 21 years or younger (5.4 people per 100,000 of the population)
- 93% (68,936 people) were 22 years or older (29.4 people per 100,000 of the population)

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

---

Of the 36,736 people living in IDD settings of 16 or more people, 90% (33,227 people) lived in an ICF/IID including

- 97% (17,744 of 18,497 people) in state-operated IDD facilities
- 84% (15,483 of 18,239 people) in non-state IDD facilities

### *What were FY 2017 Medicaid ICF/IID expenditures?*

---

Total ICF/IID expenditures in FY 2016 were \$ \$9.75 billion (\$30 per United States resident). Average annual ICF/IID expenditures were \$140,057 per year-end recipient. The average was

- \$101,707 for recipients 21 years or younger
- \$137,954 for recipients 22 years or older

### *What proportion of combined Medicaid ICF/IID and Waiver recipients and expenditures were for people in ICF/IID settings in FY 2017?*

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An estimated 934,355 Medicaid LTSS recipients with IDD lived in an ICF/IID or received Medicaid Waiver-funded LTSS. Of those,

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

Total Medicaid ICF/IID plus Waiver expenditures for people with IDD were \$48.5 billion in FY 2017. Of the total,

- 80% (\$38.71 billion) was for Medicaid Waiver recipients
- 20% (\$9.75 billion) was for people in ICF/IID

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

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

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

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Between 1998 and 2017, the number of LTSS recipients with IDD living in

- The home of a family member increased 134% from 325,650 to 762,097 people. The proportion living with a family member who received Medicaid Waiver-funded supports increased from 25% to 60%.
- A home of their own increased 144% from 62,669 to 152,759 people
- A host/foster home or IDD group setting of three or fewer people increased 148% from 63,279 to 156,953 people
- An IDD group setting of 4 to 6 people increased 78% from 73,658 to 131,078 people
- An IDD group setting of 7 to 15 people decreased 4% from 53,940 to 51,822 people
- An IDD facility, Nursing Home or Psychiatric Facility of 16 or more people decreased 43% from 114,495 to 65,111 people

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

Between 1977 and 2017, the number non-family IDD settings increased from 11,008 to 229,380 settings.

- The proportion of non-family IDD settings serving six or fewer people increased from 63% (6,898 facilities) to 97% (222,285 facilities).
- The proportion of non-state IDD settings serving six or fewer people increased from 65% (6,855 facilities) to 97% (220,970 facilities).
- The proportion of state-operated IDD settings serving six or fewer people increased from 9% (43 facilities) to 60% (1,315 facilities).

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

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

- 6 or fewer people increased from 8% (20,400 people) in 1977 to 83% (427,947 people) in 2017
- 7 to 15 people increased from 8% (20,024 people) in 1977 to 10% (51,822 people) in 2017
- 16 or more people decreased from 84% (207,356 people) in 1977 to 7% (36,736 people) in 2017

Of the people living in non-family IDD settings, the proportion living in state-operated settings declined from 63% (155,804 people) in 1977 to 6% (28,910 people) in 2017.

- Of the people in settings of 1 to 6 people, the proportion in a state-operated facility increased from 0.1% (216 people) in 1977 to 17% (4,975 people) in 2017.
- Of the people in settings of 7 to 15 people, the proportion in a state-operated facility increased from 1% (950 people) in 1977 to 20% (5,696 people) in 2017.
- Of the people in settings of 16 or more people, the proportion in a state-operated facility decreased from 99% (154,638 people) in 1977 to 63% (65,111) in 2017.

Between 1977 and 2017, the average size of all non-family IDD settings declined from 22.5 to 2.3 people per setting. The average size of

- State-operated IDD settings declined from 335.1 to 13.9 people per setting.
- Non-state IDD settings declined from 8.7 to 2.1 people per setting.

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

Between 1982 and 2017, the number of people with IDD

- Receiving Medicaid Waiver-funded supports increased from 1,381 to 860,500 people.
- In a Medicaid ICF/IID setting declined from 140,752 to 73,730 people.

Between 1982 and 2017 total expenditures for people with IDD

- Receiving Medicaid Waiver-funded services increased from \$2.2 million to \$36.5 billion.
- In ICF/IID settings increased from \$3.4 billion to \$9.8 billion.

Between 1982 and 2017, average annual per person Medicaid expenditures for

- Waiver-funded services for people with IDD increased from \$1,624 to \$44,983.
- ICF/IID services for people with IDD increased from \$23,806 to \$140,057.

In 1984, annual per person ICF/IID expenditures (\$66,774 in 2017 inflation adjusted dollars) were 5.12 times higher than annual per person Waiver expenditures (\$13,046 in 2017 inflation adjusted dollars). By 2017, annual per person ICF/IID expenditures (\$140,057) were 3.11 times higher than annual per person Waiver expenditures (\$44,983). Expenditures for ICF/IID and Medicaid Waiver-funded services differ in important ways. For example, Medicaid Waiver expenditures exclude room and board costs while those expenditures are included for ICF/IID.



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

---

The number of people with IDD living with a family member waiting for Medicaid Waiver-funded LTSS declined 21% from 232,204 people in 2013 to 182,340 people in 2017. The number waiting to move to a residence other than the home of a family member declined 41% from 107,204 in 2013 to 63,487 in 2017.

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

---

Between 1995 and 2017, the estimated number of people with IDD 21 years or younger living in IDD group settings of four or more people or in nursing homes declined 33% from 22,875 to 15,425 people.

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

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

### *How many people lived in PRFs on June 30, 2017? How did the number of people living in PRFs change during FY 2017?*

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An estimated 18,239 people with IDD lived in a PRF on June 30, 2017 (down 4% from 19,065 on June 30, 2016). The average daily population for FY 2017 was 18,516. The number of people per facility ranged from 24 to 495 and averaged 180 (94 facilities reporting).

During 2017, PRFs had an estimated

- 1,048 admissions or readmissions
- 1,642 discharges
- 591 deaths
- 1,042 short-term admissions (less than 90 days)

People ages 21 years or younger were only 4% of the PRF population on June 30, 2017, but they were

- 26% of all admissions or readmissions
- 13% of all discharges

People 63 years or older were 24% of the PRF population on June 30, 2017, but were

- 2% of new admissions or readmissions
- 11% of discharges

Of the people newly admitted or readmitted to PRFs in FY 2017

- 6% came from the home of a family member
- 21% came from their own home or a host or foster family home
- 18% came from a group IDD setting of 6 or fewer people
- 19% came from a group IDD setting of 7 or more people
- 17% came from a correctional facility
- 13% came from a mental health facility
- 6% came from another (Nursing home, Hospital or Assisted Living) or unknown setting

Of the people who moved from a PRF to another setting in FY 2017

- 6% went to the home of a family member
- 8% went to their own home or a host or foster family home
- 50% went to a group IDD setting of six or fewer people
- 14% went to a group IDD setting of 7 or more people
- 4% went to a mental health facility
- 8% went to a correctional facility
- 10% went to another (Nursing home, Hospital or Assisted Living) or unknown setting

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### *What were the characteristics of people with IDD living in PRFs in 2017?*

On June 30, 2017, of the people living in PRFs, an estimated

- 4% were 21 years or younger, 20% were 22 to 39 years, 52% were 40 to 62 years and 24% were 63 years or older.
- 14% had mild or no intellectual disabilities (ID), 14% had moderate ID, 16% had severe ID, and 56% had profound ID.
- 7% were of Hispanic origin.
- 70% were white, 20% were black or African American, and 3% were another race, two or more races. Race was not specified for the 7% who were Hispanic.
- 39% had epilepsy, 19% had autism, and 17% had cerebral palsy
- 56% received medications for mood, anxiety or behavior, had a psychiatric disorder, or had a behavior disorder.

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

Vacancy rates on June 30, 2017 were

- 12% for direct support professionals (up from 6% in 2006)
- 10% for frontline supervisors (up from 5% in 2006)

Crude separation rates (turnover) for FY 2017

- 40% for direct support professionals (up from 29% in 2006)
- 17% for frontline supervisors (up from 13% in 2006)

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### *How has the number of PRFs changed?*

Of the 376 PRFs operating between 1960 and 2017,

- 238 closed before July 1, 2016
- 22 closed, merged, downsized to less than 16 people or converted to a non-state facility between July 1, 2016 and June 30, 2017
- 119 were open on June 30, 2017, 10 of which anticipated closing by June 30, 2022.

On June 30, 2017, there were no PRFs serving people with IDD in 17 states: Alabama, Alaska, the District of Columbia, Hawaii, Indiana, Maine, Michigan, Minnesota, Montana, New Hampshire, New Mexico, Oklahoma, Oregon, Rhode Island, Tennessee, Vermont, and West Virginia.

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### *How has the census of PRFs changed?*

The average daily PRF population declined from a peak of 194,650 in 1967 to 18,516 in 2017. The average daily number of people with IDD in state-operated psychiatric facilities declined from 41,823 in 1961 to 267 in 2002 but increased to 1,964 people on June 30, 2017.





## Introduction

**FY 2017**

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

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

This adaptation of the Medicaid HCBS taxonomy originally appeared in Anderson, L.L., Larson, S.A., Kardell, Y., Taylor, B., Hallas-Muchow, L., Eschenbacher, H.J., Hewitt, A.S, Sowers, M, & Bourne, M.L. (2016). Supporting Individuals with Intellectual or Developmental Disabilities and their Families: Status and Trends through 2014. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. The Centers for Medicare and Medicaid Services detailed taxonomy for home and community-based services is available at [https://www.cms.gov/mmrr/Briefs/B2014/MMRR2014\\_004\\_03\\_b01.html](https://www.cms.gov/mmrr/Briefs/B2014/MMRR2014_004_03_b01.html)

## INTRODUCTION

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

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

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

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

Full participation is affected by the availability and competence of paid and non-paid support providers, the type and amount of supports provided, federal and state policies regarding LTSS oversight, operation, and funding, and the extent to which services are individualized to each person's family, community, and culture. LTSS in the United States for people with IDD may be

funded by Medicaid, state or local governments without Medicaid matching dollars or the individual or family privately.

## THE POLICY CONTEXT

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

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

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

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

Most provisions of the regulation became effective on March 17, 2014. However, states have until 2022 to implement the settings portion of the rule. By then, each state must have a transition plan approved by the Centers for Medicare & Medicaid Services (CMS) describing how services and settings currently funded through a Medicaid Waiver authority that are not fully compliant with the 2014 rule will be modified or how recipients in non-compliant settings will transition to a compliant service setting. As of February 2020, 46 states had received initial approval and thirteen states (Alaska, Arkansas, Delaware, the District of Columbia, Idaho, Kentucky, Minnesota, North Dakota, Oklahoma, Oregon, Tennessee, Washington and Wyoming) had received final approval from the CMS for their statewide transition plan (<https://www.medicaid.gov/medicaid/home-community-based-services/statewide-transition-plans/index.html>).

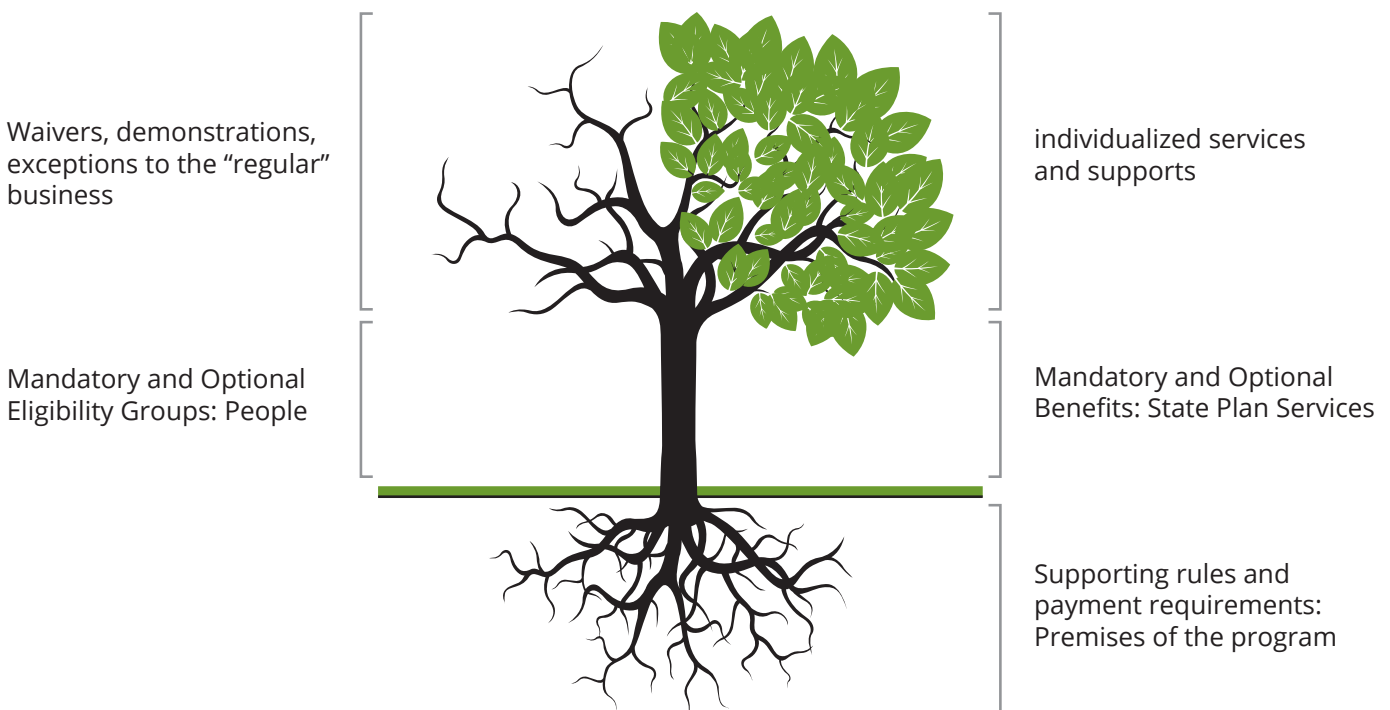
## The Americans with Disabilities Act and The Supreme Court’s Olmstead Decision Enforcement

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

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

- such services are appropriate;
- the affected persons do not oppose community-based treatment; and

**Figure A.1** Key Elements of the Medicaid Program



Adapted from NASDDDS 2019

- community-based services can be reasonably accommodated, taking into account the resources available to the public entity and the needs of others who are receiving disability services from the entity ([www.ada.gov/olmstead/olmstead\\_cases\\_by\\_issue.htm](http://www.ada.gov/olmstead/olmstead_cases_by_issue.htm)).

The United States Department of Justice's (DOJ) enforcement of the 2009 Supreme Court's Olmstead Decision has produced pivotal settlement agreements in several states that continue to shape the availability and delivery of HCBS. Notably, the Rhode Island, Virginia, and Oregon agreements contain very specific requirements related to the nature and settings of services. See the Department of Justice Olmstead website for more information (<https://www.ada.gov/olmstead/>).

## State Litigation and Policy Initiatives

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

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

Policymakers are charged with creating systems to respond to the support needs of current and future generations of individuals with IDD. As the settings in which services are delivered continue to shift from institutional to home and community-based settings, families, advocates, policymakers, and other stakeholders need accurate and timely information on publicly-funded supports to assess system performance, implement appropriate policies and practices, evaluate state service systems against national trends, and to track effective practices. Decision makers need information about the numbers

and ages of people served, the sizes and types of settings in which services are delivered, total and per-person expenditures, the types of Medicaid, state, and local funding authorities used, the characteristics and needs of service recipients, and of those waiting for services, and about individual and systems level performance outcomes. Information is also needed about the extent to which funded programs support valued personal outcomes such as opportunities to build authentic relationships and to participate in and contribute to communities.

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

- How many people have IDD?
- Of those people, how many are known to or served by the state IDD agencies?
- Where do people with IDD who receive LTSS live?
- How many people with IDD are waiting for Medicaid-funded LTSS?
- How do service settings types and sizes differ for recipients of different ages (i.e., children versus adults)?
- How do expenditures for services differ by funding authority, setting type, and recipient age?

## Medicaid Basics

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

The tree in **Figure A.1** illustrates key components of the Medicaid program. The roots represent the rules and statutes that apply to all Medicaid programs (largely but not exclusively contained at Section 1902 and Section 1903 of the Social



Security Act). The tree's trunk represents the Medicaid State Plan services and eligibility groups (mandatory and optional) which serve as the backbone for state's Medicaid programs. The branches of the tree represent waivers or deviations from standard practice that states may choose to request to address the needs of specific groups of recipients. Finally, the leaves on the tree represent the individually tailored supports and services available to individuals receiving services through the array of Medicaid funding authorities selected by the state.

The roots and trunk of the Medicaid "tree" support and guide all state Medicaid programs, but each state uses a unique combination of branches and leaves to meet the local needs of its citizens. All states must offer eligible recipients a set of mandatory benefits such as inpatient and outpatient hospital services, home health services, and laboratory and x-ray services (see <https://www.medicaid.gov/medicaid/benefits/mandatory-optional-medicaid-benefits/index.html> for a list of state plan benefits). States can choose whether to offer optional State Plan benefits such as occupational, physical, or speech therapy, personal care services, services in an Intermediate Care Facility for Individuals with Intellectual Disability (ICF/IID) and other State Plan Home and Community-based Services. State Plan services

(whether mandatory or optional) must be available to all state Medicaid beneficiaries who need the service in sufficient amount, duration and scope to achieve their purpose (O'Keeffe, et al., 2010). States are not allowed to maintain waiting lists for State Plan benefits and State Plan benefits must be uniformly available statewide.

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

- **Eligibility criteria.** States are required to cover individuals within specific financial parameters (mandatory eligibility groups). States may elect to cover additional groups and/or income and/or resource levels (optional eligibility groups). In an HCBS 1915(c) waiver, a Special Income Level (SIL) group (further at 42 CFR 435.217) can be identified for whom income and resources differently are counted differently for eligibility purposes. In addition to being financially eligible, Medicaid HCBS waiver participants must meet clinical "institutional level of care" requirements. States also may choose to apply additional diagnostic or age-related eligibility restrictions.



- **Service definitions.** Service and program definitions vary from state to state. For example, many states offer a service called “Family Support.” What is included under that label, however, can be very different (ranging a single service such as respite, to an intensive array of 24-hour in-home support). Some Waiver-funded services include annual or life-time caps on expenditures for participants.
- **Populations served.** States designate the populations to be served in their Medicaid Waiver program(s). Some waivers target only people 18 years and older while others serve only children or serve people of any age. The age break between supports for children and for adults ranges from 18 years to 22 years. Some waivers target people with a specific diagnosis such as autism spectrum disorder or intellectual disabilities while others define eligibility in terms of functional support needs. While 1915(c) waivers originally were limited to a single population, states now have the option to include individuals with IDD, people with physical disabilities, older adults, and people with mental health diagnoses in a single waiver.
- **Funding options.** Medicaid funding authorities include state plan services, demonstration waivers, managed care waivers, and other waiver options. States may elect to offer Medicaid funded services through various service delivery models such as fee-for-services or managed care authorities.

The RISP project collects a common core set of data from all state IDD agencies. However, interpreting the data properly requires an understanding of the state variations in eligibility criteria, service definitions, populations served and funding options. For example, differences in the proportion of service recipients with IDD who live with a family member are often related to differences in whether the IDD system serves both children and adults or only adults, because children are more likely than adults to live with a family member. Throughout this report, the narrative includes key considerations for interpreting specific tables and figures. Additional details about the survey questions and their operational definitions can be found in the appendix. Also in the appendix are state notes describing state-specific factors for interpreting

the FY 2017 tables and charts. RISP project staff members are available to assist you to understand the findings (email: [risp@umn.edu](mailto:risp@umn.edu)). As you examine specific findings, you may also want to check state IDD agency website, or with the IDD Agency director for clarification. State-specific information is available on the following websites:

- The National Association of State Directors of Developmental Disabilities Services website ([www.nasddds.org](http://www.nasddds.org)) lists state IDD agencies.
- The National Association of Councils on Developmental Disabilities website ([nacdd.org](http://nacdd.org)) lists state DD councils.
- The National Disability Rights Network website ([www.ndrn.org](http://www.ndrn.org)) lists member Protection and Advocacy (P&A) and Client Assistance Program (CAP) organizations.
- The ([risp.umn.edu](http://risp.umn.edu)) website publishes fact sheets, data visualizations, state profiles, and other resources.

## THE RESIDENTIAL INFORMATION SYSTEMS PROJECT (RISP)

RISP is an Administration on Intellectual and Developmental Disabilities (AIDD) Project of National Significance (PNS) that maintains longitudinal records of LTSS for people with IDD. RISP reports chronicle the history of institutionalization, deinstitutionalization, and the development of community-based LTSS for people with IDD in the 50 U.S. states plus the District of Columbia.

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

The RISP project, operating under a variety of names and funding sources, has collected and reported data on LTSS for people with IDD since 1977 and references historical records dating back to the 1880 U.S. Census. During the forty-three year history of the project, state- and federally-funded LTSS for people with IDD shifted from

being primarily provided in large segregated public IDD residential facilities to supporting people to participate fully in home and community settings.

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

The annual RISP report has described LTSS for people with IDD receiving supports funded through the Medicaid Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) and Home and Community-Based (HCBS) Waiver funding authorities since 1982. As Medicaid added new LTSS funding authorities, the project adjusted survey items to differentiate 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 Centers for Medicare and Medicaid Healthy People 2020 monitoring needs, we incorporated questions on children living in institutional settings into our annual data collection protocol. Finally, to respond to technical assistance requests from the Administration on Intellectual and Developmental Disabilities and other Federal and State agencies we added a table showing the estimated U.S. population with IDD by state.

This RISP report describes Medicaid and state-funded LTSS managed by, or under the auspices

of, state intellectual and developmental disabilities (IDD) agencies in State Fiscal Year (FY) 2017 (July 1, 2016 through June 30, 2017) 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, foster or host family home or group home)
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, and State Plan; State; or other)
6. Time (State Fiscal Year – July 1 to June 30 for most states)

## 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 FY 2015 and FY 2016 to assist states to identify possible arithmetic errors,



inconsistencies within or across survey sections, and large year-to-year changes requiring explanation. Additional refinements were made as the online database moved to its current platform for the FY 2017 survey.

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

The PRF survey includes questions about characteristics such as age, gender, race, ethnicity and types of disabilities of people in residence on June 30, 2017, admissions, readmissions, discharges, and deaths during FY 2017, 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 not receiving LTSS through the state IDD agency other than possibly case management 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.

**United States Estimated Totals** include imputations by project staff to replace missing data

based on historical trends, national distributions of setting sizes, secondary data sources, and information provided on other questions on the survey. Rows or columns of tables are labeled as estimated totals when they contain imputed data.

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

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

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

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

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

- If a state did not provide data for an item on the current year survey, but a value was provided for a prior or subsequent year, data from the adjacent year is used and flagged “d” other date.
- If a state does not furnish data for two or more years in a row, missing data will be flagged “Did Not Furnish” (DNF)
- “Partial Data” (PD) signifies instances when some, but not all, of the data elements required for a computation were furnished by the state.
- For a few tables, codes indicate which category of data are missing
- 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.** Appendix A lists other sources of data used in this report. Data from other sources is identified by the “s” footnote.

**Other Date.** The footnote “d” indicates that the state provided data from a date other than June 30, 2017. Data flagged with the “d” footnote are from the immediately preceding or subsequent data year. States with fiscal years ending on dates other than June 30 are indicated in the state notes section.

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

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

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

The FY 2017 RISP survey and operational definitions are available in in Section 6 following the references.



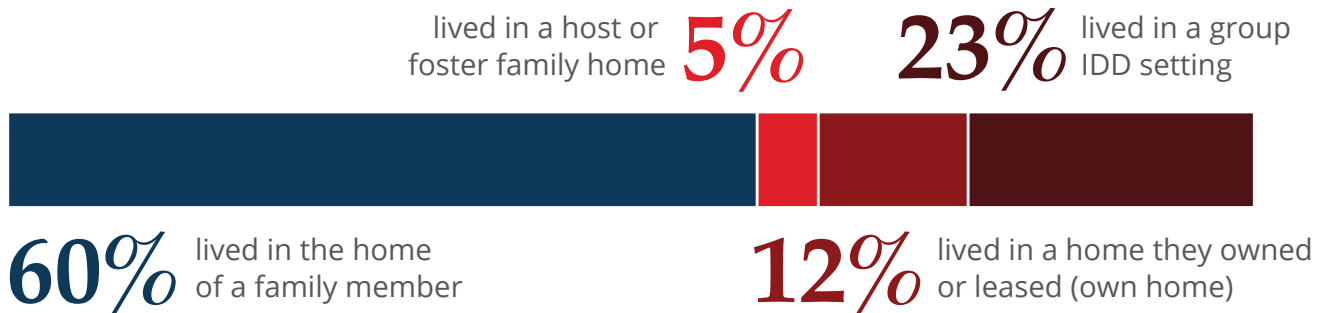
## SECTION ONE

# In-Home and Residential Supports

## FY 2017

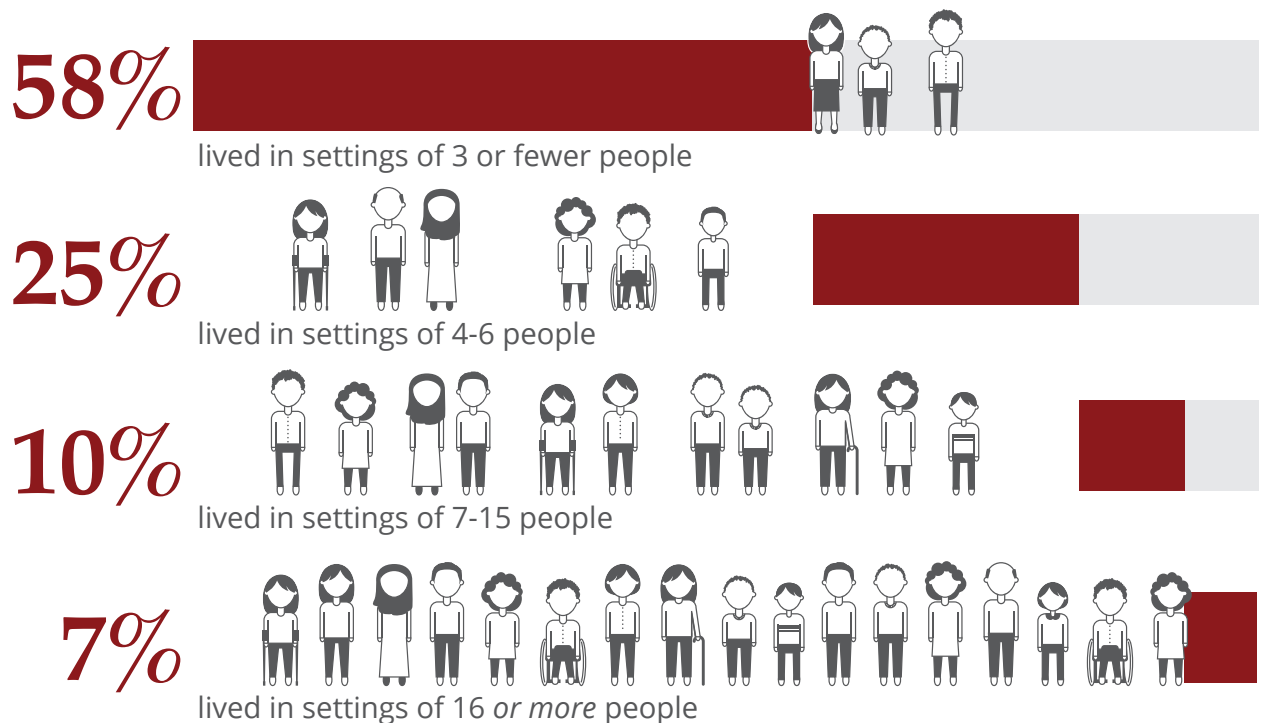
# Where People Served by State IDD Agencies Lived on June 30, 2017

An estimated 1,278,602 people received long-term supports and services (LTSS) from state IDD agencies:

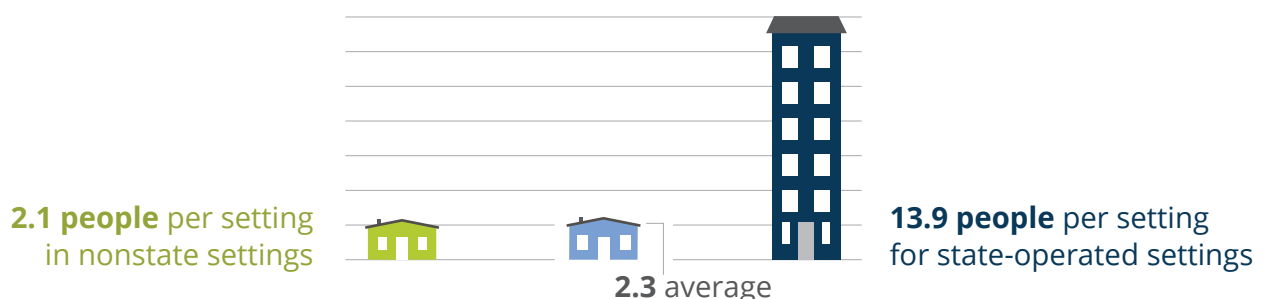


*Note: These percentages exclude nursing home and psychiatric facilities*

Of the estimated 516,505 LTSS recipients not living with a family member:



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





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

### ESTIMATING PREVALENCE OF IDD IN THE UNITED STATES

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

#### Public Health Surveillance

The CDC's Autism and Developmental Disabilities Monitoring Network (ADDM) network reviews educational and health records to estimate prevalence rates for Autism Spectrum Disorder (ASD) for 8-year-old children in eleven states. In 2014, they reported that 16.8 per 1,000 children had ASD of whom an estimated 31% also had intellectual disabilities (Baio, et al., 2018). The number of children with ID but not ASD was not reported.

#### Administrative Prevalence

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

The Office of Special Education and Rehabilitative Services (2020) also reports the number of students ages 6 to 21 years educated in correctional facilities, homebound or hospitals, or residential facilities by disability type. In 2018, 10,271 students with disabilities were in education while in correctional facilities including 760 students with ASD, ID, or multiple disabilities; 23,019 were homebound or in hospitals, including 8,320

students with ASD, ID or multiple disabilities, and 13,319 were educated in residential facilities including 4,854 students with ASD, ID or multiple disabilities. An estimated 13,934 (0.78%) of the 1.78 million students with ID, ASD or multiple disabilities ages 6 to 21 years received educational services while living in a residential school, homebound or hospital, or correctional facility.

Administrative data sets maintained by federal and state agencies can also be used to estimate the administrative prevalence of various disabilities. For example, a study using Adoption and Foster Care Reporting System data for 46 states, DC and Puerto Rico estimated 2.6% of the children in the child welfare system in 1999 had ID (Slayter & Springer, 2011). In that study, of the 17,714 children in the child welfare system with IDD, 4,789 (27.1%) lived in a group home or institution as did 125,633 of the 655,536 children identified as not having ID (19.2%).

In an analysis of the 31 million adults receiving care through Medicaid fee-for-service arrangements in 2016, an estimated 483,595 (1.56%) had IDD or related conditions (69,844 (0.23%) had ASD, 109,320 (0.35%) had CP, 338,005 (1.09%) had ID or related conditions such as chromosomal anomalies or congenital syndromes, 51,551 (0.16%) had learning disabilities, and 41,025 (0.13%) had other developmental delays; Reichard, Haile & Morris, 2019). In the 2010 Social Security Administration's National Beneficiary Survey, there were an estimated 1.3 million adults with intellectual disabilities receiving SSI and/or SSDI.

The RISP project uses administrative data from state developmental disabilities agencies to estimate the number of people with intellectual or developmental disabilities who receive publicly-funded long-term supports and services through or under the auspices of those agencies.

#### U.S. Population-Based Surveys

Several U.S. population-based surveys managed by the National Center for Health Statistics include questions that might be used to identify

**Table 1.1** United States Population and People with IDD by Age and State on June 30, 2017

State	Estimated Population with IDD						Estimated Total All Ages
	2017 US Population by age <sup>5</sup>		Not in Congregate Settings (NHIS) <sup>1</sup>			In Congregate Settings <sup>2</sup>	
	0-17 years	18+ years	0-17 years	18+ years	Total		
AL	1,098,696	3,776,051	76,799	29,831	106,630	2,179	108,809
AK	185,101	554,694	12,939	4,382	17,321	204	17,525
AZ	1,640,064	5,376,206	114,640	42,472	157,113	1,588	158,701
AR	706,968	2,297,311	49,417	18,149	67,566	3,073	70,639
CA	9,085,847	30,450,806	635,101	240,561	875,662	21,360	897,022
CO	1,264,389	4,342,765	88,381	34,308	122,689	1,082	123,771
CT	748,481	2,839,703	52,319	22,434	74,752	3,738	78,490
DE	204,783	757,156	14,314	5,982	20,296	581	20,877
DC	121,875	572,097	8,519	4,520	13,039	472	13,511
FL	4,191,249	16,793,151	292,968	132,666	425,634	11,119	436,753
GA	2,522,035	7,907,344	176,290	62,468	238,758	2,703	241,461
HI	305,549	1,121,989	21,358	8,864	30,222	421	30,643
ID	445,085	1,271,858	31,111	10,048	41,159	-21	41,138
IL	2,910,836	9,891,187	203,467	78,140	281,608	15,855	297,463
IN	1,577,326	5,089,492	110,255	40,207	150,462	5,251	155,713
IA	733,366	2,412,345	51,262	19,058	70,320	3,620	73,940
KS	715,632	2,197,491	50,023	17,360	67,383	1,511	68,894
KY	1,012,512	3,441,677	70,775	27,189	97,964	1,719	99,683
LA	1,109,393	3,574,940	77,547	28,242	105,789	10,836	116,625
ME	253,789	1,082,118	17,740	8,549	26,289	721	27,009
MD	1,348,340	4,703,837	94,249	37,160	131,409	2,638	134,047
MA	1,372,514	5,487,305	95,939	43,350	139,288	7,639	146,927
MI	2,182,341	7,779,970	152,546	61,462	214,007	7,719	221,726
MN	1,299,931	4,276,675	90,865	33,786	124,651	6,635	131,286
MS	719,494	2,264,606	50,293	17,890	68,183	3,366	71,549
MO	1,387,340	4,726,192	96,975	37,337	134,312	2,453	136,765
MT	228,736	821,757	15,989	6,492	22,481	731	23,211
NE	476,089	1,443,987	33,279	11,407	44,686	1,059	45,745
NV	686,685	2,311,354	47,999	18,260	66,259	349	66,608
NH	259,977	1,082,818	18,172	8,554	26,727	383	27,110
NJ	1,984,562	7,021,082	138,721	55,467	194,187	9,154	203,341
NM	492,517	1,595,553	34,427	12,605	47,032	1,143	48,175
NY	4,154,270	15,695,129	290,383	123,992	414,375	33,566	447,941
NC	2,307,857	7,965,562	161,319	62,928	224,247	5,635	229,882
ND	173,848	581,545	12,152	4,594	16,746	944	17,690
OH	2,611,283	9,047,326	182,529	71,474	254,003	9,610	263,613
OK	960,464	2,970,400	67,136	23,466	90,603	3,509	94,112
OR	875,017	3,267,759	61,164	25,815	86,979	2,031	89,010
PA	2,671,578	10,133,959	186,743	80,058	266,802	8,404	275,206
RI	207,816	851,823	14,526	6,729	21,256	1,066	22,322
SC	1,107,467	3,916,902	77,412	30,944	108,355	4,253	112,608
SD	214,671	654,995	15,006	5,174	20,180	1,406	21,586
TN	1,508,490	5,207,494	105,443	41,139	146,583	1,834	148,417
TX	7,349,563	20,955,033	513,734	165,545	679,279	15,652	694,931
UT	929,263	2,172,570	64,955	17,163	82,119	1,204	83,323
VT	117,399	506,258	8,206	3,999	12,206	139	12,345
VA	1,869,713	6,600,307	130,693	52,142	182,835	5,194	188,030
WA	1,643,522	5,762,221	114,882	45,522	160,404	3,129	163,533
WV	371,677	1,444,180	25,980	11,409	37,389	869	38,258
WI	1,288,013	4,507,470	90,032	35,609	125,641	4,226	129,867
WY	137,329	441,986	9,599	3,492	13,091	514	13,605
US Total	73,770,742	251,948,436	5,156,575	1,990,393	7,146,968	234,466	7,381,433

<sup>5</sup> U.S. Census Bureau, Population Division (2019). <sup>1</sup> 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). <sup>2</sup> 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 2017. The estimated totals do not account for state to state differences in prevalence rates.

and describe people with disabilities. The U.S. Department of Justice used the National Inmate Survey to describe the prevalence of disabilities among prison and jail inmates. That survey asks three of the six disability questions from the American Community Survey (hearing, vision, and cognitive impairments). It also asks about difficulties walking or climbing stairs, dressing or bathing, or living independently. In 2011, 2.9% of state and federal prisoners and 5.8% of jail inmates had three or more of the listed disabilities (Bronson et al., 2016). However, it is not sufficient to know the proportion of a population that have cognitive impairments because many conditions other than intellectual or developmental disabilities can cause cognitive impairments.

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

The estimated prevalence of ID, DD or ASD for children increased from 31.7 per 1,000 for children ages 5 to 17 years based on the 1995 NHIS-D to 69.9 per 1,000 for ID, ASD, or developmental delays in children ages 3 to 17 based on the 2016 NHIS. This increase is likely related to several factors.

Most notably, the three or more substantial functional limitations definition of developmental disabilities used by Larson, et al. (2001) was much more restrictive than the operational definition of developmental delays used by Zablotsky, et al. (2017). The dramatic increase in the estimated prevalence of ASD between 1995 and 2016 is also a contributing factor.

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

We applied the 1994/1995 NHIS-D prevalence rate of 7.9 per 1,000 for IDD in adults (Larson et al., 2001) and the 2016 NHIS prevalence of 69.9 per 1,000 for IDD in children (Zablotsky et al., 2017) to U.S. Census reports of the 2017 US population by age (U.S. Census Bureau, Population Division, 2019) to estimate the number of people with IDD in the U.S.. Since the NHIS sample frame excludes people living in congregate settings, we added 235,168 people with IDD in congregate settings of 4 or more people in FY 2017 resulting in an estimate of 7,382,136 people with IDD (22.7 per 1,000) in the U.S. in 2017 (See **Table 1.1**).

## IDD AGENCY CASELOADS

A state IDD agency caseload includes all people with IDD who receive publicly-funded long-term supports and services (LTSS) through or under the auspices of the state IDD agency. The agency caseload also includes people with IDD who had requested and were waiting for services, as well as people known to

**Table 1.2** People Known to or Served by State IDD Agencies by Age on June 30, 2017

State	Number of People <sup>1</sup>			% of People	
	Birth-21	22+ years	All Ages	Birth-21	22+ years
N States	46	46	47	46	46
AL	292	7,709	8,001	4	96
AK	973 <sup>d</sup>	1,663 <sup>d</sup>	2,636 <sup>d</sup>	37	63
AZ	26,541	13,596	40,137	66	34
AR *	63	2,892	2,955	2	98
CA	137,712	132,225	269,937	51	49
CO	7,835	11,268	19,103	41	59
CT	4,355	12,596	16,951	26	74
DE	1,357	3,263	4,620	29	71
DC	29 <sup>e</sup>	2,298	2,327	1	99
FL	16,502	42,223	58,725	28	72
GA	4,187 <sup>d</sup>	13,202 <sup>d</sup>	17,389 <sup>d</sup>	24	76
HI	548	2,302	2,850	19	81
ID *	4,518	3,595	8,113	56	44
IL	9,333	32,266	41,599	22	78
IN	9,531	19,747	29,278	33	67
IA	3,527	12,157	15,684	22	78
KS	4,273	8,762	13,035	33	67
KY	7,856	9,536	17,392	45	55
LA	12,723	26,109	38,832	33	67
ME	743	5,705	6,448	12	88
MD	5,577	19,176	24,753	23	77
MA	11,925	24,822	36,747	32	68
MI	DNF	DNF	DNF	DNF	DNF
MN	11,473 <sup>d</sup>	22,511 <sup>d</sup>	33,984 <sup>d</sup>	34	66
MS	DNF	DNF	5,933	DNF	DNF
MO	15,347	21,503	36,850	42	58
MT	439	2,357	2,796	16	84
NE	1,862	5,376	7,238	26	74
NV	2,618	4,172	6,790	39	61
NH	DNF	DNF	DNF	DNF	DNF
NJ	0	27,352	27,352	0	100
NM	2,948 <sup>d</sup>	6,522 <sup>d</sup>	9,470 <sup>d</sup>	31	69
NY	45,416 <sup>d</sup>	92,747 <sup>d</sup>	138,163	33	67
NC	9,987	17,795	27,782	36	64
ND	3,118	2,804	5,922	53	47
OH	53,597	53,217	106,814	50	50
OK	5,404 <sup>d</sup>	8,875 <sup>d</sup>	14,279 <sup>d</sup>	38	62
OR	11,001	15,725	26,726	41	59
PA	14,759	43,678	58,437	25	75
RI	5	4,349	4,354	0	100
SC	19,035	19,418	38,453	50	50
SD	1,591 <sup>d</sup>	3,013 <sup>d</sup>	4,604 <sup>d</sup>	35	65
TN	9,006	11,096	20,102	45	55
TX	DNF	DNF	DNF	DNF	DNF
UT	2,844	5,156	8,000	36	64
VT	1,324	3,214	4,538	29	71
VA	9,972 <sup>e</sup>	14,323 <sup>e</sup>	24,295	41	59
WA	26,369	20,658	47,027	56	44
WV	DNF	DNF	DNF	DNF	DNF
WI	6,697	29,505	36,202	18	82
WY	764	1,710	2,474	31	69
Reported Total	525,976	844,188	1,376,097	38	61
Estimated Total	567,535	910,890	1,478,425	38	62

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

state IDD agencies, but not receiving publicly funded LTSS on June 30, 2017. It does not include people with IDD served by other state agencies such as a department of education, child welfare, vocational rehabilitation, corrections, or a state Medicaid office operating separately from the IDD agency unless those individuals were also served by or known to the state IDD agency or residents of an Intermediate Care Facilities for Individuals with Intellectual or Developmental Disabilities (ICF/IID).

On June 30, 2017, an estimated 1,478,425 people with IDD (20% of the estimated total people with IDD in the United States) were served by or known to their state IDD agency (See **Table 1.2**). The majority (62%, 910,890 people) were 22 years or older. The proportion of the state IDD caseload who were adults varied widely by state. States in which adults comprised 90% or more of the IDD agency caseload were New Jersey (100%), Rhode Island (100%), the District of Columbia (99%), Arkansas (98%) and Alabama (96%). States that served more children or youth than adults were California (49%), North Dakota (47%), Idaho (44%), Washington (44%), and Arizona (34%).

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

Of the 1.48 million people served by state IDD agencies on June 30, 2017, an estimated 86% (1,278,602 people) received publicly funded long-term supports or services (17% of the people with IDD in the U.S.).

## LONG-TERM SERVICES AND SUPPORT SETTINGS

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



We track the places LTSS recipients live regardless which LTSS they receive or where the services are delivered (some LTSS recipients with IDD receive employment, day habilitation, or community supports but do not receive funded residential or in-home supports). LTSS recipients with IDD live in many different settings including:

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

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

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

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

**Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID):** Medicaid-certified institutions housing four or more people with IDD that provide comprehensive and individualized

health care and rehabilitation services to promote their functional status and independence 24 hours per day/365 days per year.

**Other non-state settings:** Residential settings other than own home, family home, host/foster family home, IDD group home or ICF/IID operated by a non-state entity in which a person with IDD lives and receives LTSS. Examples of non-state "other" settings include board care facilities, group facilities that do not exclusively serve people with IDD, and assisted living facilities.

**Non-state setting, type unknown:** Starting in 2017, the RISP survey included space for respondents to report non-state settings for which the type was unknown. These settings and the people with IDD living in them are included in estimated state and national totals but are not reported separately on tables.

**Other state settings:** State-operated residences not certified as a Medicaid ICF/IID or funded by a Medicaid Waiver authority in which LTSS recipients with IDD live.

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

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

**Table B:** Living Arrangements for LTSS Recipients with IDD

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

**Table 1.3** LTSS Recipients with IDD by Setting Type, Type of Operation, and State on June 30, 2017

Setting Type	Non-State Settings							State-Operated Settings			Estimated Total Recipients
	Family home	Own home	Host / Foster Family Home	Group not ICF/IDD	ICF/IDD	Other <sup>a</sup>	Unknown <sup>a</sup>	Group not ICF/IDD	ICF/IDD	Group Other <sup>a</sup>	
<b>N States</b>	44	44	46	47	49	45	42	51	51	51	51
AL	480	55	111	3,443	22	0	1,543	0	0 <sup>s</sup>	0	5,654
AK	277 <sup>d</sup>	705	170	654	0 <sup>s</sup>	0	287 <sup>d</sup>	0	0 <sup>s</sup>	0	2,093 <sup>d</sup>
AZ	34,451	265	1,543	2,967	42	7	0	145	0	0	39,420
AR	1,973	639	575	1,106	518	0	0	0	907	0	5,718
CA	181,533	25,968	5,825	20,185	6,856	0	0	0	793	0	241,160
CO	3,219	5,120	3,009	757	24	1,408	0	131	124	0	13,792
CT	4,555	1,455	376	3,856	364	218	0	274	378	0	11,476
DE	3,413	18	100	1,003	70	0	0	0	48 <sup>s</sup>	0	4,652
DC	893	15	85	1,016	319	0	0	0	0 <sup>s</sup>	0	2,328
FL	38,917 <sup>d</sup>	5,742	260	7,886	2,180	956 <sup>d</sup>	0	0	590	134	56,665 <sup>d,e</sup>
GA	3,274 <sup>d</sup>	1,145 <sup>d</sup>	1,203 <sup>d</sup>	2,825 <sup>d</sup>	DNF	23 <sup>d</sup>	109 <sup>d</sup>	0	143	67	8,789 <sup>d</sup>
HI	2,108	77	358	276	79	0	0	0	0	0	2,898 <sup>e</sup>
ID	1,610 <sup>e</sup>	1,206 <sup>d</sup>	546 <sup>e</sup>	376	430 <sup>s</sup>	0	4,375	0	25 <sup>s</sup>	0	8,568 <sup>e</sup>
IL	12,578	1,983	304	9,355	4,933	0	0	0	1,660	0	30,813
IN	17,035	6,449	253	661	3,179	0	0	0	0	0	27,577
IA	DNF	DNF	139	484	1,414	0	DNF	59	351	0	15,336 <sup>i</sup>
KS	DNF	DNF	DNF	DNF	131	DNF	8,891	0	302	0	9,324 <sup>e</sup>
KY	DNF	DNF	1,590	2,897	154	0	DNF	0	268	0	17,814 <sup>i</sup>
LA*	13,526 <sup>d</sup>	DNF	DNF	DNF	4,129	559	DNF	0	510	0	32,749 <sup>d</sup>
ME	DNF	729	729 <sup>e</sup>	1,777 <sup>e</sup>	159	DNF	DNF	0	0	6	6,448
MD	1,728 <sup>d</sup>	3,847	210	6,045	0 <sup>s</sup>	0	11,036	0	92	0	22,958 <sup>d</sup>
MA	7,046	2,702	1,029	8,849	0 <sup>s</sup>	0	0	1,071	396	48	21,141
MI	DNF	DNF	DNF	DNF	DNF	DNF	DNF	0 <sup>i</sup>	0 <sup>s</sup>	0 <sup>i</sup>	44,784 <sup>i</sup>
MN	13,475 <sup>d</sup>	3,471 <sup>d</sup>	873 <sup>d</sup>	8,318 <sup>d</sup>	1,170 <sup>d</sup>	6,224 <sup>d</sup>	0	359 <sup>d</sup>	13 <sup>d</sup>	0	33,903 <sup>d</sup>
MS	2,382 <sup>e</sup>	78	0	528	683 <sup>s</sup>	0	DNF	321	1,486	35	4,830
MO	11,278	4,748	460	1,986	80	0	0	227	341	0	19,120
MT	1,014 <sup>d</sup>	143 <sup>d</sup>	47 <sup>d</sup>	928	0 <sup>s</sup>	0	DNF	0	12	0	2,146 <sup>i</sup>
NE	2,148	1,177	845	1,248	239	0	0	0	109	0	5,766
NV	4,745	1,621	193	0	43	140	0	0	48	0	6,790
NH	DNF	DNF	DNF	DNF	23 <sup>s</sup>	DNF	DNF	0 <sup>i</sup>	0 <sup>s</sup>	6 <sup>i</sup>	3,175 <sup>i</sup>
NJ	13,922	79	600	8,366	61	653	0	0	1,402	0	25,083 <sup>e</sup>
NM	1,424 <sup>d</sup>	DNF	DNF	1,144 <sup>d</sup>	249 <sup>d</sup>	0	1,427 <sup>d</sup>	65 <sup>d</sup>	3 <sup>d</sup>	0 <sup>d</sup>	5,613 <sup>i</sup>
NY	89,066 <sup>d</sup>	11,734 <sup>d</sup>	1,692	24,388	4,456	0	0	6,542	439	0	138,347 <sup>e,i</sup>
NC*	DNF	208	2,204 <sup>e</sup>	4,159	3,264	DNF	638	0	1,142	181	24,619 <sup>i</sup>
ND	1,268	1,293	16	303	470	0	0	0	69	0	3,419
OH	79,382	15,899	2,433	2,645	5,139	641 <sup>e</sup>	0	0	675	0	106,814 <sup>e</sup>
OK	1,895 <sup>d</sup>	2,451 <sup>d</sup>	325 <sup>d</sup>	844 <sup>d</sup>	1,307 <sup>d</sup>	DNF	0	0 <sup>d</sup>	0 <sup>d</sup>	0 <sup>d</sup>	6,822 <sup>d</sup>
OR	17,687	709	3,292	3,015	0 <sup>s</sup>	0	0	0	0 <sup>s</sup>	96	24,799
PA*	22,189 <sup>e</sup>	3,485	1,532	11,787	1,969	2,055	43	0	858	0	43,918 <sup>e</sup>
RI	1,560	510	346	1,100	26	0	0	146	8	0	3,696 <sup>d</sup>
SC	15,685	704	168	3,069	501	0	0	0	657	0	20,784
SD	2,050 <sup>d</sup>	536 <sup>d</sup>	1 <sup>d</sup>	1,825 <sup>d</sup>	60 <sup>d</sup>	0	0 <sup>e</sup>	0	132 <sup>d</sup>	0 <sup>d</sup>	4,604 <sup>d</sup>
TN	7,292	4,084	462	623	837	0	0	0	160	0	13,458
TX	11,571 <sup>d</sup>	3,821 <sup>d</sup>	13,624 <sup>d</sup>	8,566	4,910	0	0	0	3,029	0	45,521
UT	1,667	1,229	400	1,715	583 <sup>s</sup>	0	638 <sup>e</sup>	0	190	0	6,422 <sup>e</sup>
VT	2,237	546	1,360	144	6	14	0	0	0 <sup>s</sup>	0	4,307 <sup>e</sup>
VA	3,871 <sup>d</sup>	230 <sup>d</sup>	3,734 <sup>d</sup>	4,491 <sup>d</sup>	318	0 <sup>d</sup>	DNF	0 <sup>d</sup>	549	0	13,193 <sup>id</sup>
WA	15,956	5,647	202	2,113	43	0	0	3	695	0	24,659
WV	3,438	857	214	123	514	14	0	0	0 <sup>s</sup>	0	5,160 <sup>d</sup>
WI	26,701	6,512 <sup>e</sup>	6,718	3,283	601	16	0	0	321	0	44,152 <sup>e</sup>
WY	1,144	456	50	633	0 <sup>s</sup>	10	0	0	62	7	2,362
<b>Reported US Total</b>	<b>683,663</b>	<b>130,348</b>	<b>60,206</b>	<b>173,762</b>	<b>52,555</b>	<b>12,938</b>	<b>28,987</b>	<b>9,343</b>	<b>18,987</b>	<b>580</b>	
<b>Estimated US Total</b>	<b>762,097</b>	<b>152,759</b>	<b>67,649</b>	<b>197,890</b>	<b>54,868</b>	<b>14,429</b>	<b>0</b>	<b>9,343</b>	<b>18,987</b>	<b>580</b>	<b>1,278,602</b>

DNF Did not furnish. PD Partial data. <sup>a</sup> Missing values (DNF) assumed to be zero. <sup>d</sup> Other date (data from previous or next year). <sup>e</sup> Estimate. <sup>f</sup> Total is larger than component parts due to unknown settings or sizes. <sup>i</sup> One or more component value imputed by RISP staff. \* See state notes in Appendix.

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

On June 30, 2017, an estimated 1.28 million people with IDD received LTSS (See **Table 1.3**) in settings other than nursing homes or psychiatric facilities. Of those people, an estimated

- 98% (1,249,692 people) received LTSS from a non-state entity, including:
  - 762,097 who lived in the home of a family member,
  - 152,759 who lived in a home they owned or leased,
  - 67,649 who lived in a host/foster family home,
  - 197,890 who lived in a non-state IDD group home,
  - 54,868 who lived in a non-state ICF/IID, and
  - 14,429 who lived in another type of non-state setting, and
- 2% (28,910 people) received LTSS while living in a state-operated residential setting including:
  - 18,987 who lived in a state-operated Medicaid-certified ICF/IID, and
  - 9,343 who lived in a Medicaid Waiver-funded state-operated IDD group settings, and
  - 580 who lived in a state-operated group residence funded by another funding authority

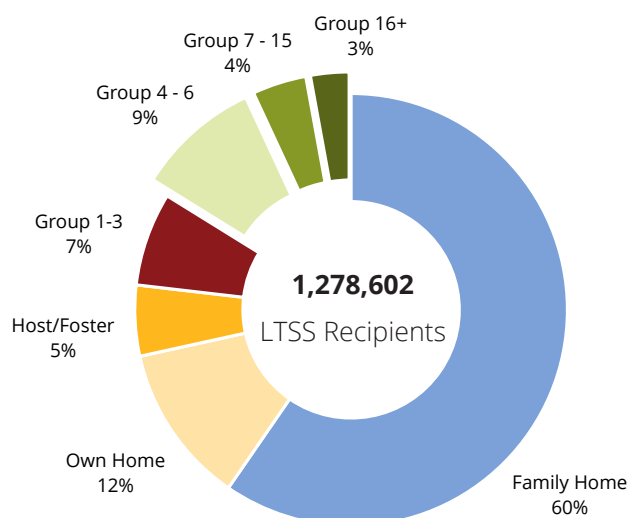
The most common living arrangements for LTSS recipients with IDD by state were:

- Family home in 29 states (Arizona, Arkansas, California, Connecticut, Delaware, Florida, Georgia, Hawaii, Illinois, Indiana, Minnesota, Mississippi, Missouri, Montana, Nebraska, Nevada, New Jersey, New York, Ohio, Oregon, Pennsylvania, Rhode Island, South Carolina, South Dakota, Tennessee, Vermont, Washington, West Virginia, Wisconsin, and Wyoming),
- Group homes in six states (Alabama, the District of Columbia, Maine, Massachusetts, Utah, and Virginia),
- Own Home settings in four states (Alaska, Colorado, North Dakota, and Oklahoma),
- Host/family foster home in one state (Texas), and
- Unknown due to missing data in ten states (Idaho, Iowa, Kansas, Kentucky, Louisiana, Maryland, Michigan, New Hampshire, New Mexico, and North Carolina).

As **Figure 1.1** shows, of the LTSS recipients with IDD:

- 60% lived in the home of a family member,
- 24% lived in a non-family setting of 3 or fewer people including
  - 12% in an “own home” setting,
  - 7% in an IDD group setting of 3 or fewer people,
  - 5% in a host/foster family home, and
- 16% lived in an IDD group setting of four or more people including:
  - 9% in an IDD group setting of 4 to 6 people,
  - 4% in an IDD group setting of 7 to 15 people, and

**Figure 1.1** LTSS Recipients with IDD by Residence Type and Size on June 30, 2017



**Table 1.4** LTSS Recipients with IDD Living with a Family Member by State on June 30, 2017

State	LTSS Recipients Served by State IDD Agencies		
	Estimated Total	Number Living with Family	% Living with Family
N States	51	44	44
AL *	5,654	480	8
AK	2,093 <sup>d</sup>	277 <sup>d</sup>	13
AZ	39,420	34,451	87
AR	5,718	1,973	35
CA	241,160	181,533	75
CO	13,792	3,219	23
CT	11,476	4,555	40
DE	4,652	3,413	73
DC	2,328	893	38
FL	56,665	38,917 <sup>d</sup>	69
GA	8,789 <sup>d</sup>	3,274 <sup>d</sup>	37
HI	2,898	2,108	73
ID	8,568 <sup>e</sup>	3,290 <sup>e</sup>	38
IL	30,813	12,578	41
IN	27,577	17,035	62
IA	15,336 <sup>i</sup>	DNF	DNF
KS	9,324	DNF	DNF
KY	17,814 <sup>i</sup>	DNF	DNF
LA	32,749 <sup>j</sup>	13,526 <sup>d</sup>	41
ME	6,448	DNF	DNF
MD	22,958	1,728 <sup>d</sup>	8
MA	21,141	7,046	33
MI	44,784 <sup>i</sup>	DNF	DNF
MN	33,903 <sup>d</sup>	13,475 <sup>d</sup>	40
MS	4,830	2,382 <sup>e</sup>	49
MO	19,120	11,278	59
MT	2,146 <sup>j</sup>	1,014 <sup>d</sup>	47
NE	5,766	2,148	37
NV	6,790	4,745	70
NH	3,175 <sup>j</sup>	DNF	DNF
NJ	25,083	13,922	56
NM	5,613 <sup>j</sup>	1,424 <sup>d</sup>	25
NY	138,347 <sup>e</sup>	89,066 <sup>d</sup>	64
NC	24,619 <sup>j</sup>	DNF	DNF
ND	3,419	1,268	37
OH	106,814	79,382	74
OK	6,822 <sup>d</sup>	1,895 <sup>d</sup>	28
OR	24,799	17,687	71
PA	43,918	22,189 <sup>e</sup>	51
RI	3,696	1,560	42
SC	20,784	15,685	75
SD	4,604 <sup>d</sup>	2,050 <sup>d</sup>	45
TN	13,458	7,292	54
TX	45,521	11,571 <sup>d</sup>	25
UT	6,422 <sup>e</sup>	1,667	26
VT	4,307	2,237	52
VA	13,193 <sup>d</sup>	3,871 <sup>d</sup>	29
WA	24,659	15,956	65
WV	5,160	3,438	67
WI	44,152	26,701	60
WY	2,362	1,144	48
Reported US Total	1,275,640	683,663	
Estimated US Total	1,278,602	762,097	60

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

- 3% in an IDD group setting of 16 or more people.

## Home of a Family Member

On June 30, 2017, an estimated 762,097 LTSS recipients with IDD lived in the home of a family member (See **Table 1.4**). The proportion of LTSS recipients living in the home of a family member ranged from 8% in Alabama and Maryland to 87% in Arizona (See **Figure 1.2**).

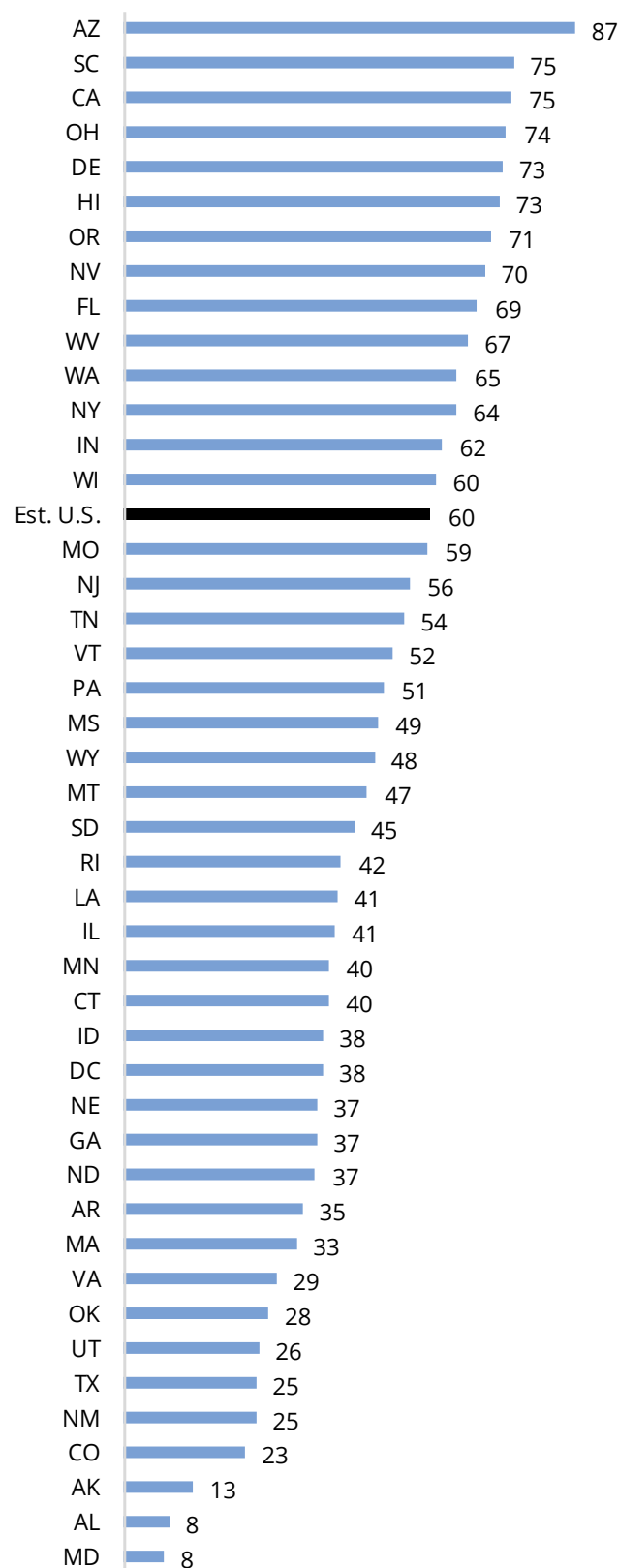
- States reporting the greatest proportion of LTSS recipients with IDD living with family members were Arizona (87%), South Carolina (75%), California (75%), Ohio (74%), Delaware (73%) and Hawaii (73%).
- States reporting the smallest proportion of LTSS recipients with IDD living with family members were Maryland (8%), Alabama (8%), and Alaska (13%).

Differences in the proportion of LTSS recipients living with family members are often related to whether the state IDD agency provides LTSS to children with IDD, and to the proportion of LTSS recipients who are 21 years or younger. For example, in Arizona where 87% of LTSS recipients lived with a family member, 66% of LTSS recipients served by the state IDD agency were 21 years or younger. Conversely, in Alabama where 8% of recipients lived with a family member, only 4% of LTSS recipients served by the state IDD agency were 21 years or younger. Similarly, in Maryland, where 8% of recipients lived with a family member, only 23% were 21 years or younger. Variations may also be related to the use of different eligibility criteria or the availability of different service options.

## Own Home

An estimated 30% of LTSS recipients with IDD (152,729 of 516,505 people) who did not live with a family member lived in a home they owned or leased (Own Home) on June 30, 2017 (See **Table 1.5**). Fewer than 2% of people in non-family settings lived in Own Home settings in North Carolina (1.8%), Delaware (1.5%), Alabama (1.3%), the District of Columbia (1.0%), or New Jersey (0.7%). More than half of LTSS recipients with IDD in non-family settings lived in Own Home settings in Nevada (79%), Tennessee (66%), Washington (65%), Indiana (61%), Missouri (61%), North Dakota (60%), and Ohio (58%).

**Figure 1.2** Percent of LTSS Recipients with IDD Living with a Family Member by State on June 30, 2017



Note: Family home data not available from IA, KS, ME, MI, NC, and NH.

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

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

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

**Table 1.6** Host or Foster Family Homes and LTSS Recipients with IDD in Them by Setting Size and State on June 30, 2017

Setting Size	Host/Family Foster Settings by Size						People with IDD by Setting Size					
	1-3	4-6	1-6	7-15	Unknown	Total	1-3	4-6	1-6	7-15	Unknown	Total
N States	40	41	40	43	43	40	41	40	43	45	46	46
AL	57	0	57	1	0	58	104	0	104	7	0	111
AK	170 <sup>d</sup>	0 <sup>d</sup>	170	0	0	170	170 <sup>d</sup>	0 <sup>d</sup>	170	0 <sup>d</sup>	0	170
AZ	1,058	0	1,058	0	0	1,058	1,539	4	1,543	0	0	1,543
AR	575	0	575	0	0	575	575	0	575	0	0	575
CA	DNF	0	DNF	0	0	DNF	5,825	0	5,825	0	0	5,825
CO	1,505 <sup>e</sup>	0	1,505	0	0	1,505	3,009	0	3,009	0	0	3,009
CT	251	0	251	0	0	251	376	0	376	0	0	376
DE	100	0	100	0	0	100	100	0	100	0	0	100
DC	65	0	65	0	0	65	85	0	85	0	0	85
FL	50 <sup>d</sup>	39 <sup>d</sup>	89	7 <sup>d</sup>	0	96	52 <sup>d</sup>	141 <sup>d</sup>	193	67 <sup>d</sup>	0	260
GA	927 <sup>d</sup>	0 <sup>d</sup>	927 <sup>d</sup>	0 <sup>d</sup>	0	927 <sup>d</sup>	1,203 <sup>d</sup>	0 <sup>d</sup>	1,203 <sup>d</sup>	0 <sup>d</sup>	0	1,203 <sup>d</sup>
HI	281	2	283	0	0	283	350	8	358	0	0	358
ID	388	16	404	0	0	404	DNF	DNF	1,116 <sup>e</sup>	0	0	1,116 <sup>e</sup>
IL	228	0	228	0	0	228	304	0	304	0	0	304
IN	193	2	195	0	0	195	245	8	253	0	0	253
IA *	137	0	137	0	0	137	139	0	139	0	0	139
KS	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
KY	936 <sup>e</sup>	0	936 <sup>e</sup>	0	0	936	1,590 <sup>e</sup>	0	1,590	0	0	1,590
LA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
ME	695	0	695	0	0	695 <sup>e</sup>	729 <sup>e</sup>	0	729 <sup>e</sup>	0	0	729 <sup>e</sup>
MD	202	0	202	0	0	202	210	0	210	0	0	210
MA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	1,029 <sup>e</sup>	0 <sup>e</sup>	0 <sup>e</sup>	1,029
MI	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MN	640 <sup>d</sup>	15 <sup>d</sup>	655 <sup>d</sup>	0	0	655 <sup>d</sup>	812 <sup>d</sup>	61 <sup>d</sup>	873 <sup>d</sup>	0	0	873 <sup>d</sup>
MS	0	0	0	0	0	0	0	0	0	0	0	0
MO	424	0	424	0	0	424	460	0	460	0	0	460
MT	DNF	DNF	DNF	DNF	DNF	DNF	47 <sup>d</sup>	0 <sup>d</sup>	47 <sup>d</sup>	0 <sup>d</sup>	0 <sup>d</sup>	47 <sup>d</sup>
NE	688	2	690	0	0	690	832	13	845	0	0	845
NV	137	3	140	0	0	140	181	12	193	0	0	193
NH	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NJ	286	0	286	0	0	286	600	0	600	0	0	600
NM	DNF	DNF	DNF	0	0	DNF	DNF	DNF	DNF	0	0	DNF
NY	919 <sup>d</sup>	56 <sup>d</sup>	975	0 <sup>d</sup>	0	975 <sup>d</sup>	1,465 <sup>d</sup>	227 <sup>d</sup>	1,692	0 <sup>d</sup>	0	1,692
NC	505	0	505	0	837	1,342	669 <sup>e</sup>	DNF	DNF	DNF	1,535 <sup>e</sup>	2,204 <sup>e</sup>
ND	16	0	16	0	0	16	16	0	16	0	0	16
OH	2,170	0	2,170	1	0	2,171	2,426	0	2,426	7	0	2,433
OK	325 <sup>d</sup>	0 <sup>d</sup>	325 <sup>d</sup>	0 <sup>d</sup>	0	325 <sup>d</sup>	325 <sup>d</sup>	0 <sup>d</sup>	325 <sup>d</sup>	0 <sup>d</sup>	0	325 <sup>d</sup>
OR	716	645	1,361	23	0	1,384	1,076	2,078	3,154	47	91	3,292
PA	1,220	0	1,220	0	0	1,220	1,532	0	1,532	0	0	1,532
RI	346	0	346	0	0	346	346	0	346	0	0	346
SC	132	0	132	0	0	132	168	0	168	0	0	168
SD	1 <sup>d</sup>	0 <sup>d</sup>	1 <sup>d</sup>	0 <sup>d</sup>	0	1 <sup>d</sup>	1	0 <sup>d</sup>	1 <sup>d</sup>	0 <sup>d</sup>	0	1 <sup>d</sup>
TN	369	0	369	0	0	369	462	0	462	0	0	462
TX	DNF	DNF	DNF	0	0	DNF	DNF	DNF	DNF	0	0	13,624 <sup>d</sup>
UT	350 <sup>e</sup>	0	350	0	0	350	400	0	400	0	0	400
VT	1,191	0	1,191	0	0	1,191	1,360	0	1,360	0	0	1,360
VA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	3,734 <sup>d</sup>
WA	110	11	121	4	0	125	115	52	167	35	0	202
WV	166 <sup>d</sup>	0 <sup>d</sup>	166	0 <sup>d</sup>	0	166	214 <sup>d</sup>	0 <sup>d</sup>	214	0 <sup>d</sup>	0	214
WI	1,699	0	1,699	0	0	1,699	6,718 <sup>e</sup>	0	6,718	0	0	6,718
WY	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	50 <sup>e</sup>	0 <sup>e</sup>	0 <sup>e</sup>	50
Reported US Total	20,228	791	21,019	36	837	21,892	36,830	2,604	40,390	163	1,626	60,776
Estimated US Total	33,668	1,160	34,828	52	0	34,879	62,294	5,193	67,486	163	0	67,649

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



Overall, 97.4% of people with IDD in Own Home settings lived with two or fewer other LTSS recipients, while 2.6% shared their home with three or more other LTSS recipients. In 26 states, all of the people in Own Home settings shared their home with two or fewer other LTSS recipients. By contrast, 47% of people with IDD in Own Home settings in Illinois shared their home with three or more other LTSS recipients, as did 36% in Nevada.

## Host/Family Foster Home

An estimated 13.1% of LTSS recipients with IDD (67,649 people) not living with a family member lived in a host or foster family home (See **Table 1.6**) on June 30, 2017. Of the LTSS recipients with IDD living in Host or Family Foster Homes, an estimated:

- 92.1% (62,294 people) lived in homes shared by three or fewer people with IDD,
- 7.7% (5,193 people) lived in homes of four to six people with IDD, and
- 0.2% (163 people) lived in homes of seven to fifteen people with IDD.

LTSS recipients with IDD lived in an estimated 34,879 Host or Foster Family Homes on June 30, 2017. Of those settings, 96.5% were home to three or fewer LTSS recipients with IDD, 3.3% were home to four to six LTSS recipients, and 0.1% were home to more than six people with IDD. The average Host or Family Foster Home served 1.9 people with IDD. The average number of LTSS recipients with IDD per home was 1.0 people in seven states but was 2.0 or more people in Colorado, Florida, New Jersey, Oregon, and Wisconsin.

## Group IDD Settings

An estimated 57.3% of LTSS recipients with IDD (296,097 people) who did not live with a family member lived in an IDD group setting (See **Table 1.7**) such as an IDD group home, Medicaid Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID), or other group settings. Group IDD settings do not include Own Homes, Host or Foster Family Homes, or Family Homes, nor do they include Nursing Homes or Psychiatric Facilities.

There were an estimated 76,569 IDD group settings on June 30, 2017. Of those,

- 57% (43,868 settings) served three or fewer people
- 34% (25,658 settings) served four to six people,
- 8% (6,311 settings) served 7 to 15 people, and
- 1% (732 settings) served 16 or more people.

While 91% of IDD group settings housed six or fewer LTSS recipients, the proportion varied by state ranging from less than half in Arkansas (49%), and Indiana (49%) to more than 95% in 18 states.

An estimated 57.3% of LTSS recipients not living with a family member (296,097 people) lived in IDD group settings on June 30, 2017. Of those,

- 30% (89,303 people) lived in settings of three or fewer people,
- 40% (118,398 people) lived in settings of 4 to 6 people,
- 17% (51,669 people) lived in settings of 7 to 15 people, and
- 12% (36,736 people) lived in facilities with 16 or more residents.

Overall, 70% (207,702 people) of those living in IDD group settings lived in settings of six or fewer



**Table 1.7** Group LTSS Settings and People with IDD Living in Them by Setting Size and State on June 30, 2017

Setting Size	Number of Group Settings <sup>1</sup>						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	40	40	42	42	43	43	39	38	41	40	43	46
AL	1,030	119	1,149	78	0	1,227	2,279	429	2,708	757	0	5,008 <sup>f</sup>
AK	193 <sup>d</sup>	192 <sup>d</sup>	385	19 <sup>d</sup>	10 <sup>d</sup>	414	450 <sup>d</sup>	150 <sup>d</sup>	600	54 <sup>d</sup>	0 <sup>d</sup>	941 <sup>f</sup>
AZ	692	295	987	4	2	993 <sup>e</sup>	1,624	1,378	3,002	33	126	3,161
AR	99	20	119	99	25	243	106	56	162	925	1,444	2,531
CA	PD	PD	5,233	129	65	5,427	PD	PD	24,650	1,005	2,179	27,834
CO	706 <sup>e</sup>	203 <sup>e</sup>	909	21	2	932	1,413	830	2,243	158	43	2,444
CT	704	565	1,269	31	5	1,305	1,660	2,804	4,464	236	390	5,090
DE	262	92	354	0	2	356	584	408	992	0	118	1,121 <sup>f</sup>
DC	535	86 <sup>e</sup>	621	0	0	621	893	442	1,335	0	0	1,335
FL	124 <sup>d</sup>	1,124 <sup>d</sup>	1,248	319 <sup>d</sup>	60 <sup>d</sup>	1,627	135 <sup>d</sup>	6,547 <sup>d</sup>	6,682	1,291 <sup>d</sup>	2,817 <sup>d</sup>	11,746 <sup>f</sup>
GA	964 <sup>d</sup>	259 <sup>d</sup>	1,223 <sup>d</sup>	1 <sup>d</sup>	3 <sup>d</sup>	1,227 <sup>d</sup>	1,769 <sup>d</sup>	1,068 <sup>d</sup>	2,837 <sup>d</sup>	11 <sup>d</sup>	PD	PD <sup>f</sup>
HI	10	64 <sup>e</sup>	74	6	0	80	0	348 <sup>e</sup>	348	7	0	355
ID*	0	23	23	72	46	141	PD	PD	PD	PD	257	831 <sup>f</sup>
IL	135	921	1,056	831	43	1,930	236	4,153	4,389	7,187	4,372	15,948
IN	0	312	312	326	2	640	0	1,403	1,403	2,387	50	3,840
IA	8	102	110	76	24	210	23	489	512	733	1,063	2,308
KS	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD
KY	907 <sup>e</sup>	30 <sup>e</sup>	937 <sup>e</sup>	3	6	946 <sup>e</sup>	2,717	180	2,897	23	399	3,319
LA	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD
ME	693	109	802	12	1	815 <sup>e</sup>	1,352 <sup>e</sup>	445 <sup>e</sup>	1,797 <sup>e</sup>	129	16	1,942 <sup>e</sup>
MD	1,643	487	2,130	24	2	2,156	3,786	2,079	5,865	180	92	6,137 <sup>u</sup>
MA	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	396	10,364 <sup>f</sup>
MI	DNF	PD	DNF	PD	DNF	PD	DNF	DNF	DNF	DNF	DNF	DNF
MN	PD	PD	9,677 <sup>d</sup>	36 <sup>d</sup>	10 <sup>d</sup>	9,723 <sup>d</sup>	PD	PD	15,539 <sup>d</sup>	323 <sup>d</sup>	250 <sup>d</sup>	16,084 <sup>d</sup>
MS *	95	153 <sup>d</sup>	248	62 <sup>d</sup>	14 <sup>d</sup>	324 <sup>d</sup>	113	PD	PD	PD	1,621 <sup>e</sup>	3,053 <sup>u</sup>
MO	135	216	351	112	8	471	356	977	1,333	901	400	2,634
MT	PD	PD	PD	PD	0 <sup>d</sup>	151 <sup>f</sup>	PD	PD	PD	PD	0 <sup>d</sup>	940 <sup>f</sup>
NE	425	103	528	26	3	557	727	421	1,148	140	308	1,596
NV	0	5	5	0	59	64	0	25	25	0	206	231
NH	PD	PD	PD	DNF	PD	PD	PD	DNF	DNF	DNF	PD	PD
NJ	1,097 <sup>e</sup>	1,340 <sup>e</sup>	2,437	87	10	2,534 <sup>e</sup>	2,193 <sup>e</sup>	5,357 <sup>e</sup>	7,550 <sup>e</sup>	752 <sup>e</sup>	2,180	10,482
NM	PD	PD	PD	11 <sup>d</sup>	2 <sup>d</sup>	PD	PD	PD	1,321 <sup>d</sup>	108 <sup>d</sup>	32 <sup>d</sup>	1,461 <sup>d</sup>
NY	2,119 <sup>d</sup>	2,524 <sup>d</sup>	4,643	1,963 <sup>d</sup>	35 <sup>d</sup>	6,641	3,904 <sup>d</sup>	12,827 <sup>d</sup>	16,731	17,882 <sup>d</sup>	1,212 <sup>d</sup>	35,855 <sup>f</sup>
NC	388	777	1,165	48	19	1,261 <sup>f</sup>	193 <sup>e</sup>	1,253 <sup>e</sup>	1,446	102 <sup>e</sup>	1,663 <sup>e</sup>	8,773 <sup>f</sup>
ND	3	62	65	49	2	116	9	332	341	402	99	842
OH	202	520	722	292	73	1,087	364	2,455	2,819	2,487	3,153	9,100 <sup>f</sup>
OK	0 <sup>d</sup>	140 <sup>d</sup>	140 <sup>d</sup>	51 <sup>d</sup>	30 <sup>d</sup>	221 <sup>d</sup>	0 <sup>d</sup>	788 <sup>d</sup>	788 <sup>d</sup>	481 <sup>d</sup>	882 <sup>d</sup>	2,151 <sup>d</sup>
OR	456	383	839	17	14	871 <sup>f</sup>	1,208	1,759	2,967	118	24	3,111 <sup>f</sup>
PA	6,289 <sup>e</sup>	794 <sup>e</sup>	7,083	56 <sup>e</sup>	24 <sup>e</sup>	7,163	10,862	3,388 <sup>e</sup>	14,250	433 <sup>e</sup>	1,986 <sup>e</sup>	16,712 <sup>f</sup>
RI	106	193	299	19	1	319 <sup>d</sup>	259	842	1,101	153	26	1,280
SC	159	577	736	103	5	844	404	2,316	2,720	850	657	4,227
SD	532 <sup>d</sup>	93 <sup>d</sup>	625 <sup>d</sup>	73 <sup>d</sup>	2 <sup>d</sup>	700 <sup>d</sup>	698 <sup>d</sup>	466 <sup>d</sup>	1,164 <sup>d</sup>	661 <sup>d</sup>	192 <sup>d</sup>	2,017 <sup>d</sup>
TN	110	150	260	77	1	338	266	647	913	634	73	1,620
TX	1,577 <sup>d</sup>	1,974 <sup>d</sup>	3,551	41 <sup>d</sup>	16 <sup>d</sup>	3,610 <sup>f</sup>	4,027 <sup>d</sup>	8,743 <sup>d</sup>	12,770	473 <sup>d</sup>	3,249 <sup>d</sup>	16,505 <sup>f</sup>
UT	756	85 <sup>d</sup>	841	PD	PD	864 <sup>f</sup>	1,218	446 <sup>d</sup>	1,664 <sup>d</sup>	PD	PD	2,488 <sup>u</sup>
VT	46	17	63	0	0	63	64	86	150	0	14	164
VA	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	5,358 <sup>f</sup>
WA	6	780	786	19	4	839 <sup>f</sup>	14	1,812	1,826	157	695	2,854 <sup>f</sup>
WV	6 <sup>d</sup>	139 <sup>d</sup>	145	52 <sup>d</sup>	0 <sup>d</sup>	197	14 <sup>d</sup>	637 <sup>d</sup>	651	0 <sup>d</sup>	0 <sup>d</sup>	651
WI	0	562	562	1	20	583	0	3,283	3,283	8	914	4,221 <sup>f</sup>
WY	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	712 <sup>f</sup>
Reported US Total	23,212	16,590	54,712	5,246	650	60,831 <sup>f</sup>	45,920	72,069	159,386	42,181	33,598	261,377
Estimated US Total	43,868	25,658	69,526	6,311	732	76,569	89,303	118,398	207,702	51,659	36,736	296,097

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



**Table 1.8** Non-Family Residential Settings for LTSS recipients with IDD by Type of Operation and Setting Size on June 30, 2017

Size	Non-State Settings						State-Operated Settings						Total Settings <sup>1</sup>					
	1-3	4-6	1-6	7-15	16+	Total	1-3	4-6	1-6	7-15	16+	Total	1-3	4-6	1-6	7-15	16+	Total
N States	30	32	31	41	43	31	46	46	46	47	48	49	30	32	31	41	43	31
AL	1,142	119	1,261	79	0	1,340	0	0	0	0	0	0	1,142	119	1,261	79	0	1,340
AK	716	192	908	19	10	937	0	0	0	0	0	0	716	192	908	19	10	937
AZ	1,909	292	2,201	0	1	2,202	6	3	9	4	1	14	1,915	295	2,210	4	2	2,216
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	PD	PD	PD	129	61	DNF	0	0	0	0	4	4	PD	PD	PD	129	65	PD
CO	PD	PD	PD	0	0	2,403 <sup>f</sup>	2	9	11	21	2	34	PD	PD	PD	21	2	2,437 <sup>f</sup>
CT	2,406	526	2,932	23	1	2,956	4	39	43	8	4	55	2,410	565	2,975	31	5	3,011
DE	380	92	472	0	1	473	0	0	0	0	1	1	380	92	472	0	2	474
DC	615	86	701	0	0	701	0	0	0	0	0	0	615	86	701	0	0	701
FL	PD	1,163	PD	326	57	DNF	0	0	0	0	3	3	PD	1,163	PD	326	60	PD
GA	2,839	268	3,107	1	0	3,108	0	0	0	0	3	3	2,839	268	3,107	1	3	3,111
HI	368	66	434	6	0	440	0	0	0	0	0	0	368	66	434	6	0	440
ID	PD	PD	PD	72	45	DNF	0	1	1	0	1	2	PD	PD	PD	72	46	PD
IL	963	1,128	2,091	831	36	2,958	0	0	0	0	7	7	963	1,128	2,091	831	43	2,965
IN	3,772	390	4,162	326	2	4,490	0	0	0	0	0	0	3,772	390	4,162	326	2	4,490
IA	PD	PD	PD	76	22	DNF	8	9	17	0	2	19	PD	PD	PD	76	24	PD
KS	PD	PD	PD	PD	PD	DNF	0	0	0	0	2	2	PD	PD	PD	PD	PD	PD
KY	PD	PD	PD	0	2	DNF	0	0	0	3	4	7	PD	PD	PD	3	6	PD
LA	PD	PD	PD	PD	PD	DNF	0	0	0	0	3	3	PD	PD	PD	PD	PD	PD
ME	PD	PD	PD	12	1	DNF	4	0	4	0	0	4	PD	PD	PD	12	1	PD
MD	5,505	489	5,994	24	0	6,018	0	0	0	0	2	2	5,505	489	5,994	24	2	6,020
MA	PD	PD	PD	PD	PD	DNF	PD	PD	PD	PD	2	262 <sup>u</sup>	PD	PD	PD	PD	PD	PD
MI	PD	DNF	DNF	DNF	DNF	DNF	PD	PD	DNF	PD	PD	0 <sup>u</sup>	PD	PD	PD	PD	PD	PD
MN *	PD	PD	13,515	36	10	13,561 <sup>d</sup>	27	89	116	0	0	116	PD	PD	13,631	36	10	13,677 <sup>d</sup>
MS	57	109	166	0	8	166	95	45	140	62	6	208	152	154	306	62	14	374
MO	2,382	209	2,591	112	2	2,705	76	7	83	0	6	89	2,458	216	2,674	112	8	2,794
MT	PD	PD	PD	PD	0	DNF	0	0	0	1	0	1	PD	PD	PD	PD	0	PD
NE	2,157	106	2,263	26	2	2,291	0	0	0	0	1	1	2,157	106	2,263	26	3	2,292
NV	918	149	1,067	0	58	1,125	0	0	0	0	1	1	918	149	1,067	0	59	1,126
NH	PD	DNF	DNF	DNF	PD	DNF	PD	PD	PD	DNF	DNF	1 <sup>u</sup>	PD	PD	PD	PD	PD	PD
NJ	1,462	1,340	2,802	87	5	DNF	0	0	0	0	5	5	1,462	1,340	2,802	87	10	PD
NM	PD	PD	PD	11	2	DNF	PD	PD	PD	0	0	DNF	PD	PD	PD	11	2	PD
NY	PD	2,130	PD	1,514	29	DNF	110	450	560	449	6	1,015	PD	2,580	PD	1,963	35	PD
NC	933	777	1,710	48	14	2,748 <sup>f</sup>	0	0	0	0	5	5	933	777	1,710	48	19	2,753 <sup>f</sup>
ND	1,312	62	1,374	49	1	1,424	0	0	0	0	1	1	1,312	62	1,374	49	2	1,425
OH	14,932	729	15,661	293	65	DNF	0	0	0	0	8	8	14,932	729	15,661	293	73	PD
OK	PD	PD	PD	51	30	DNF	0	0	0	0	0	0	PD	PD	PD	51	30	PD
OR	1,879	1,006	2,885	40	14	2,940 <sup>f</sup>	0	22	22	0	0	22	1,879	1,028	2,907	40	14	2,962 <sup>f</sup>
PA *	10,994	794	11,788	56	19	11,863	0	0	0	0	5	5	10,994	794	11,788	56	24	11,868
RI	951	170	1,121	17	1	1,139	11	23	34	2	0	36	962	193	1,155	19	1	1,175
SC *	378	577	955	103	0	1,058	0	0	0	0	5	5	378	577	955	103	5	1,063
SD	1,069	93	1,162	73	1	1,236	0	0	0	0	1	1	1,069	93	1,162	73	2	1,237
TN	2,587	115	2,702	76	1	2,779	2	35	37	1	0	38	2,589	150	2,739	77	1	2,817
TX	PD	PD	PD	PD	3	3,595 <sup>f</sup>	0	2	2	0	13	15	PD	PD	PD	PD	16	3,610 <sup>f</sup>
UT	2,226	85	2,311	PD	PD	2,333 <sup>f</sup>	0	0	0	0	1	1	2,226	85	2,311	PD	PD	2,334 <sup>f</sup>
VT	1,750	17	1,767	0	0	1,767	0	0	0	0	0	0	1,750	17	1,767	0	0	1,767
VA	PD	PD	PD	PD	PD	DNF	PD	PD	PD	PD	PD	DNF	PD	PD	PD	PD	PD	PD
WA	5,655	898	6,553	23	0	6,606 <sup>f</sup>	1	0	1	0	4	5	5,656	898	6,554	23	4	6,611 <sup>f</sup>
WV	1,029	139	1,168	52	0	1,220	0	0	0	0	0	0	1,029	139	1,168	52	0	1,220
WI	PD	PD	PD	1	17	DNF	0	0	0	0	3	3	PD	PD	PD	1	20	PD
WY	PD	PD	PD	PD	PD	DNF	0	0	0	0	1	1	PD	PD	PD	PD	PD	PD
Reported US Total	74,573	14,342	99,137	4,691	541	90,014 <sup>f</sup>	346	734	1,080	551	118	2,010	74,919	15,076	100,217	5,242	659	92,024
Estimated US Total	193,746	27,224	220,970	5,717	611	227,298	435	880	1,315	646	121	2,082	194,181	28,104	222,285	6,363	732	229,380

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

people. More than 95% of people in IDD group settings lived in settings of six or fewer people in Arizona, the District of Columbia, Hawaii, Minnesota, Oregon and West Virginia. Fewer than 25% of people in IDD group settings lived in settings of six or fewer people in Iowa (22.2%), North Carolina (16.5%), Nevada (10.8%), and Arkansas (6.4%).

## Non-Family IDD Residential Settings

**Tables 1.8 through 1.10** report on LTSS recipients with IDD living in settings other than the home of a family member. Non-family residences include own home settings, host or foster family homes, IDD group homes, ICF/IID certified facilities and other IDD congregate settings. They do not include nursing homes or psychiatric facilities (see the state notes in Section 5 for exceptions). Overall, an estimated:

- 84.7% (194,181 settings) housed 1 to 3 LTSS recipients,
- 12.3% (28,104 settings) served 4 to 6 LTSS recipients,
- 2.8% (6,363 settings) served 7 to 15 LTSS recipients, and
- 0.3% (732 settings) served 16 or more LTSS recipients.

On June 30, 2017, of the settings in which LTSS recipients with IDD lived, 1% (2,082 settings) were state-operated, and 99% (227,297 settings) were operated by a non-state entity. Of the estimated 2,082 state-operated settings:

- 20.9% (435 settings) in 12 states served 1 to 3 people,
- 42.3% (845 settings) in 13 states served 4 to 6 people,
- 31.0% (646 settings) in 10 states served 7 to 15 people, and
- 5.8% (121 settings) in 34 states served 16 or more people.

There were no state-operated IDD facilities in Alabama, Alaska, the District of Columbia, Hawaii, Indiana, Michigan, Oklahoma, Vermont and West Virginia. Other states with no state-operated IDD facilities with 16 or more people included Maine, Minnesota, Montana, New Mexico, Oregon, Rhode Island, and Tennessee.

Of the estimated 227,298 non-state IDD settings,

- 85.2% (193,746 settings) served 1 to 3 people,

- 12.0% (27,224 settings) served 4 to 6 people,
- 2.5% (5,717 settings) served 7 to 15 people, and
- 0.3% (611 settings) served 16 or more people.

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

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

An estimated 516,505 people lived in non-family IDD settings on June 30, 2017 (See **Table 1.9**). Of those,

- 58.2% (300,427 people) lived in settings of 3 or fewer people,
- 24.7% (127,519 people) lived in settings of 4 to 6 people,
- 10.0% (51,822 people) lived in settings of 7 to 15 people, and
- 7.1% (36,736 people) lived in settings of 16 or more people.

Alabama, Alaska, the District of Columbia, Hawaii, Montana, and West Virginia reported no people with IDD living in settings of 16 or more people. States reporting that 20% or more of people in non-family settings lived in a setting of 16 or more people were Arkansas (38.6%, 1,444 people), Illinois (24.0%, 4,372 people), and Mississippi (66.2%, 1,621 people). Other states with more than 3,000 people in settings of 16 or more people included Ohio (3,153 people) and Texas (3,249 people).

Of the 516,505 people in non-family settings, 5.6% (28,910 people) lived in state-operated settings, and 94.4% (487,595 people) lived in non-state settings. Fewer than 80% of all people in non-family settings lived in non-state settings in Arkansas (75.9%), Mississippi (24.8%), and New Mexico (67.3%).

Of the 487,595 people in non-state non-family settings, an estimated

- 61.4% (299,537 people) lived with three or fewer people,
- 25.3% (123,435 people) lived with 4 to 6 people,
- 9.5% (46,125 people) lived with 7 to 15 people, and
- 3.8% (18,497 people) lived with 16 or more people.

**Table 1.9** Residence Size and Type of Operation for LTSS Recipients with IDD not Living with a Family Member by State on June 30, 2017

Size	People in Non-State Settings										People in State-Operated Settings										Total People					Reported Total
	1-3					4-6					7-15					16+										
	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	1-3	4-6	1-6	7-15	16+			
N States	33	31	33	38	43	43	46	46	47	47	49	49	49	49	49	49	49	49	49	33	31	33	38	43		
AL	2,438	429	2,867	764	0	5,174 <sup>f</sup>	0	0	0	0	0	0	0	0	0	0	0	0	0	2,438	429	2,867	764	0		
AK	1,325	150	1,475	54	0	1,816 <sup>f</sup>	0	0	0	0	0	0	0	0	0	0	0	0	0	1,325	150	1,475	54	0		
AZ	3,413	1,369	4,782	0	42	4,824	15	13	28	33	84	145	145	145	145	145	145	145	3,428	1,382	4,810	33	126			
AR	1,294	82	1,376	925	537	2,838	0	0	0	0	0	907	907	907	907	907	907	907	1,294	82	1,376	925	1,444			
CA	PD	PD	56,443	1,005	1,386	58,834	0	0	0	0	0	793	793	793	793	793	793	793	PD	PD	56,443	1,005	2,179			
CO	PD	PD	PD	0	0	10,318	5	49	54	158	43	255	255	255	255	255	255	255	PD	PD	PD	158	43			
CT	3,479	2,601	6,080	174	15	6,269	12	203	215	62	375	652	652	652	652	652	652	652	3,491	2,804	6,295	236	390			
DE	702	408	1,110	0	70	1,191	0	0	0	0	0	48	48	48	48	48	48	48	702	408	1,110	0	118			
DC	993	442	1,435	0	0	1,435	0	0	0	0	0	0	0	0	0	0	0	0	993	442	1,435	0	0			
FL	5,929	6,688	12,617	1,358	2,093	17,024	0	0	0	0	0	724	724	724	724	724	724	724	5,929	6,688	12,617	1,358	2,817			
GA	4,079	1,106	5,185	11	0	5,305 <sup>f</sup>	0	0	0	0	0	210	210	210	210	210	210	210	4,079	1,106	5,185	11	210			
HI	427	356	783	7	0	790	0	0	0	0	0	0	0	0	0	0	0	0	427	356	783	7	0			
ID	PD	PD	PD	PD	233	5,278 <sup>f</sup>	0	1	1	0	0	24	25	25	25	25	25	25	PD	PD	PD	PD	257			
IL	1,590	5,086	6,676	7,187	2,712	16,575	0	0	0	0	0	1,660	1,660	1,660	1,660	1,660	1,660	1,660	1,590	5,086	6,676	7,187	4,372			
IN	6,392	1,713	8,105	2,387	50	10,542	0	0	0	0	0	0	0	0	0	0	0	0	6,392	1,713	8,105	2,387	50			
IA	PD	PD	PD	733	712	DNF	23	36	59	0	0	351	410	410	410	410	410	410	PD	PD	PD	733	1,063			
KS	PD	PD	PD	PD	PD	PD	0	0	0	0	0	302	302	302	302	302	302	302	PD	PD	PD	PD	PD			
KY	PD	PD	PD	0	154	DNF	0	0	0	0	23	245	268	268	268	268	268	268	PD	PD	PD	23	399			
LA	PD	PD	PD	PD	PD	PD	0	0	0	0	0	510	510	510	510	510	510	510	PD	PD	PD	PD	PD			
ME	2,804	445	3,249	129	16	6,643 <sup>f</sup>	6	0	0	0	0	0	0	0	0	0	0	0	2,810	445	3,255	129	16			
MD	7,834	2,088	9,922	180	0	21,138 <sup>f</sup>	0	0	0	0	0	92	92	92	92	92	92	92	7,834	2,088	9,922	180	92			
MA	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	396	1,515 <sup>f</sup>	1,515 <sup>f</sup>	1,515 <sup>f</sup>	1,515 <sup>f</sup>	1,515 <sup>f</sup>	1,515 <sup>f</sup>	1,515 <sup>f</sup>	PD	PD	PD	PD	PD			
MI	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF			
MN	PD	PD	19,483	323	250	20,056 <sup>d</sup>	47	325	400	0	0	372	372	372	372	372	372	372	PD	PD	19,883	323	250			
MS	78	PD	PD	PD	683	606 <sup>f</sup>	113	248	361	543	938	1,842	1,842	1,842	1,842	1,842	1,842	1,842	191	PD	PD	PD	1,621			
MO	5,365	949	6,314	901	59	7,274	199	28	227	0	341	568	568	568	568	568	568	568	5,564	977	6,541	901	400			
MT	PD	PD	PD	PD	0	PD	0	0	0	12	0	12	12	12	12	12	12	12	PD	PD	PD	PD	0			
NE	2,731	439	3,170	140	199	3,509	0	0	0	0	109	109	109	109	109	109	109	109	2,731	439	3,170	140	308			
NV	1,224	615	1,839	0	158	1,997	0	0	0	0	48	48	48	48	48	48	48	48	1,224	615	1,839	0	206			
NH	PD	DNF	DNF	DNF	PD	DNF	PD	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	PD	PD	PD	PD	PD			
NJ	2,872	5,357	8,229	752	778	9,759	0	0	0	0	1,402	1,402	1,402	1,402	1,402	1,402	1,402	1,402	2,872	5,357	8,229	752	2,180			
NM	PD	PD	PD	108	32	140 <sup>f</sup>	PD	PD	68	0	0	68	68	68	68	68	68	68	PD	PD	PD	108	32			
NY	16,814	10,801	27,615	13,732	923	42,300 <sup>e</sup>	289	2,253	2,542	4,150	289	6,981	6,981	6,981	6,981	6,981	6,981	6,981	17,103	13,054	30,157	17,882	1,212			
NC	909	PD	PD	PD	340	DNF	0	0	0	0	0	1,323	1,323	1,323	1,323	1,323	1,323	1,323	909	PD	PD	PD	1,663			
ND	1,318	332	1,650	402	30	2,082	0	0	0	0	69	69	69	69	69	69	69	69	1,318	332	1,650	402	99			
OH	17,838	3,306	21,144	2,494	2,478	26,757	0	0	0	0	0	675	675	675	675	675	675	675	17,838	3,306	21,144	2,494	3,153			
OK	2,776	788	3,564	481	882	4,927 <sup>d</sup>	0	0	0	0	0	0	0	0	0	0	0	0	2,776	788	3,564	481	882			
OR	2,993	3,741	6,734	165	24	7,016	0	96	96	0	0	96	96	96	96	96	96	96	2,993	3,837	6,830	165	24			
PA *	15,879	3,388	19,267	433	1,128	20,871 <sup>f</sup>	0	0	0	0	0	858	858	858	858	858	858	858	15,879	3,388	19,267	433	1,986			
RI	1,098	729	1,827	129	26	1,982	17	113	130	24	0	154	154	154	154	154	154	154	1,115	842	1,957	153	26			
SC	1,276	2,316	3,592	850	0	4,442	0	0	0	0	0	657	657	657	657	657	657	657	1,276	2,316	3,592	850	657			
SD	PD	PD	PD	PD	661	60	2,422 <sup>d</sup>	0	0	0	0	132	132	132	132	132	132	132	PD	PD	PD	PD	192			
TN	4,806	507	5,313	620	73	6,006	6	140	146	14	0	160	160	160	160	160	160	160	4,812	647	5,459	634	73			
TX	PD	PD	PD	PD	230	30,921	0	10	10	0	0	3,019	3,029	3,029	3,029	3,029	3,029	3,029	PD	PD	PD	PD	33,950			
UT	2,847	446	3,293	PD	PD	4,565 <sup>f</sup>	0	0	0	0	0	190	190	190	190	190	190	190	2,847	446	3,293	PD	PD			
VT	1,970	86	2,056	0	14	2,070	0	0	0	0	0	0	0	0	0	0	0	0	1,970	86	2,056	0	14			
VA	PD	PD	PD	PD	PD	8,773 <sup>f</sup>	PD	PD	PD	PD	PD	340	549 <sup>f</sup>	549 <sup>f</sup>	549 <sup>f</sup>	549 <sup>f</sup>	549 <sup>f</sup>	549 <sup>f</sup>	PD	PD	PD	PD	PD			
WA	5,666	1,971	7,637	192	0	8,005	3	0	3	0	0	695	698	698	698	698	698	698	5,669	1,971	7,640	192	695			
WV	1,085	637	1,722	0	0	1,722	0	0	0	0	0	0	0	0	0	0	0	0	1,085	637	1,722	0	0			
WI	PD	PD	PD	8	593	17,130	0	0	0	0	0	321	321	321	321	321	321	321	PD	PD	PD	8	914			
WY	PD	PD	PD	PD	PD	1,149	0	0	0	0	0	69	69	69	69	69	69	69	PD	PD	PD	PD	1,218			
Reported US Total	132,244	59,371	266,554	37,305	16,980	425,055 <sup>f</sup>	735	3,515	4,346	5,019	18,239	28,904 <sup>f</sup>	28,904 <sup>f</sup>	28,904 <sup>f</sup>	28,904 <sup>f</sup>	28,904 <sup>f</sup>	28,904 <sup>f</sup>	28,904 <sup>f</sup>	132,904	62,217	270,347	41,769	33,412			
Estimated US Total	299,537	123,435	422,972	46,125	18,497	487,595	891	4,084	4,975	5,696	18,239	28,910	28,910	28,910	28,910	28,910	28,910	28,910	300,427	127,519	427,947	51,822	36,736			

DNF Did not furnish. PD Partial data. \* Other data (data from previous or next year). <sup>f</sup> Estimate. <sup>d</sup> Total is larger than component parts due to unknown settings or sizes. <sup>e</sup> One or more component value imputed by RISP staff. \* See state notes in Appendix. \* This table includes people in group homes, ICF/IID, 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 1.10** LTSS Settings and Recipients with IDD Not Living with a Family Member by Setting Size and Per 100,000 of the Population by State on June 30, 2017

State	Estimated Settings	Estimated Recipients	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	1,669 <sup>j</sup>	4,159	2.5	71 <sup>i</sup>	82 <sup>i</sup>	49	85
AK	1,000 <sup>i</sup>	1,627 <sup>d</sup>	1.6	87 <sup>i</sup>	97	7	220
AZ	2,216 <sup>e</sup>	5,066	2.3	70 <sup>i</sup>	97	70	72
AR	1,437	3,745	2.6	35	37	30	125
CA	27,719 <sup>j</sup>	59,627	2.2	66 <sup>i</sup>	95	395	151
CO	6,380 <sup>i</sup>	10,614	1.7	89	98	56	189
CT	3,011	6,921	2.3	50	91	36	193
DE	474	1,239	2.6	58 <sup>i</sup>	90	10	129
DC	701 <sup>e</sup>	1,448	2.1	69 <sup>i</sup>	100	7	209
FL	6,989 <sup>j</sup>	17,748 <sup>d,e</sup>	2.5	38 <sup>i</sup>	76	210	85
GA	3,136 <sup>i</sup>	5,575 <sup>d</sup>	1.8	74 <sup>i</sup>	94	104	53
HI	440 <sup>c</sup>	790 <sup>c</sup>	1.8	54	99	14	55
ID	2,221 <sup>i</sup>	5,278 <sup>e</sup>	2.4	65 <sup>i</sup>	93 <sup>i</sup>	17	307
IL	2,965	18,295	6.2	9 <sup>i</sup>	37	128	143
IN	4,490	10,542	2.3	61	77	67	158
IA	5,442 <sup>j</sup>	9,064 <sup>i</sup>	1.7	73 <sup>i</sup>	80 <sup>i</sup>	31	288
KS	1,482 <sup>j</sup>	3,478 <sup>e</sup>	2.3	59	83 <sup>i</sup>	29	119
KY	3,608 <sup>i</sup>	7,150 <sup>i</sup>	2.0	91 <sup>i</sup>	94 <sup>i</sup>	45	161
LA	6,434 <sup>i</sup>	19,223 <sup>d</sup>	3.0	45 <sup>i</sup>	78 <sup>i</sup>	47	410
ME	2,314 <sup>i</sup>	3,675	1.6	83 <sup>i</sup>	95	13	275
MD	8,568 <sup>j</sup>	13,973 <sup>d</sup>	1.6	83 <sup>i</sup>	98	61	231
MA	5,191 <sup>i</sup>	14,095	2.7	48	83	69	205
MI	9,482 <sup>j</sup>	19,004 <sup>i</sup>	2.0	62	90	100	191
MN	13,677 <sup>j</sup>	20,686 <sup>d</sup>	1.5	68 <sup>i</sup>	97	56	371
MS *	382 <sup>j</sup>	3,131	8.2	6	31 <sup>i</sup>	30	105
MO	2,794	7,845	2.8	71 <sup>i</sup>	83	61	128
MT	280 <sup>i</sup>	1,132 <sup>i</sup>	4.0	45 <sup>i</sup>	86	11	108
NE	2,292	3,644	1.6	76 <sup>i</sup>	88	19	190
NV	1,126	2,045	1.8	60	90	30	68
NH	953 <sup>i</sup>	2,114 <sup>i</sup>	2.2	82 <sup>i</sup>	96	13	157
NJ	3,476 <sup>i</sup>	11,161 <sup>e</sup>	3.2	26 <sup>e</sup>	74	90	124
NM	1,133 <sup>i</sup>	3,251 <sup>i</sup>	2.9	64 <sup>i</sup>	96 <sup>i</sup>	21	156
NY	16,652 <sup>j</sup>	50,098 <sup>d,j</sup>	3.0	36 <sup>i</sup>	62	198	252
NC	2,827 <sup>j</sup>	11,376 <sup>i</sup>	4.0	53	83	103	111
ND	1,425	2,151	1.5	61	77	8	285
OH	16,593 <sup>j</sup>	27,432 <sup>e</sup>	1.7	67 <sup>i</sup>	79	117	235
OK	2,433 <sup>j</sup>	5,006 <sup>d</sup>	2.1	57 <sup>i</sup>	73	39	127
OR	2,962	7,112	2.4	43 <sup>i</sup>	97	41	172
PA	11,878 <sup>j</sup>	21,725 <sup>e</sup>	1.8	73 <sup>i</sup>	89	128	170
RI	1,175 <sup>d</sup>	2,136 <sup>d</sup>	1.8	52	92	11	202
SC	1,063	5,099	4.8	25	70	50	101
SD	1,237 <sup>d</sup>	2,554 <sup>d</sup>	2.1	48 <sup>i</sup>	67	9	294
TN	2,817	6,220	2.2	78 <sup>i</sup>	89	67	93
TX	11,922 <sup>j</sup>	34,601	2.9	61 <sup>i</sup>	89 <sup>i</sup>	283	122
UT	2,489 <sup>j</sup>	4,335 <sup>e</sup>	1.7	76	86	31	140
VT	1,779 <sup>j</sup>	2,070 <sup>i</sup>	1.2	95 <sup>i</sup>	99	6	332
VA	2,949 <sup>j</sup>	9,322 <sup>d</sup>	3.2	56 <sup>i</sup>	85	85	110
WA	6,611	8,715	1.3	67 <sup>i</sup>	90	74	118
WV	1,220 <sup>d</sup>	1,722 <sup>d</sup>	1.4	63 <sup>d</sup>	100 <sup>i</sup>	18	95
WI	7,311 <sup>i</sup>	17,452 <sup>e</sup>	2.4	75 <sup>i</sup>	95 <sup>i</sup>	58	301
WY	555 <sup>i</sup>	1,229	2.2	59	86 <sup>i</sup>	6	212
<b>Estimated US Total</b>	<b>229,380</b>	<b>516,505</b>	<b>2.3</b>	<b>58</b>	<b>83</b>	<b>3,257</b>	<b>159</b>

DNF Did not furnish. PD Partial data. <sup>d</sup> Other date (data from previous or next year). <sup>e</sup> Estimate. <sup>i</sup> One or more component value imputed by RISP staff. This table uses estimated totals for settings and people.\* See state notes in Appendix. <sup>1</sup> Includes people in group homes, host/foster family homes, own homes, and other IDD settings. Excludes people in family homes, nursing homes, psychiatric settings.

Of the 28,910 people in state-operated IDD settings, an estimated

- 3.1% (891 people) lived in settings of 3 or fewer people,
- 14.1% (4,084 people) lived in settings of 4 to 6 people,
- 19.7% (5,696 people) lived in settings of 7 to 15 people, and
- 63.1% (18,239 people) lived in settings of 16 or more people with IDD.

Of the 300,427 people in settings of three or fewer people, 99.7% lived in non-state settings.

Of the 127,519 people in settings of 4 to 6 people, 97% lived in non-state settings.

Of the 51,822 people in settings of 7 to 15 people, 89% lived in non-state settings.

Of the 36,736 people in settings of 16 or more people, 50% lived in non-state settings.

An estimated 516,505 people with IDD lived in 229,380 non-family settings on June 30, 2017 (an average of 2.3 people per setting; See **Table 1.10** and **Figure 1.3**). The average number of LTSS recipients per setting ranged from 1.2 in Vermont to 8.2 in Mississippi. States with the fewest people per setting included Vermont (1.2), Washington (1.3), West Virginia (1.4), North Dakota (1.5) and Minnesota (1.5). States serving the largest number of people with IDD per setting included Mississippi (8.2), Illinois (6.2), South Carolina (4.8), Montana (4.0) and North Carolina (4.0).

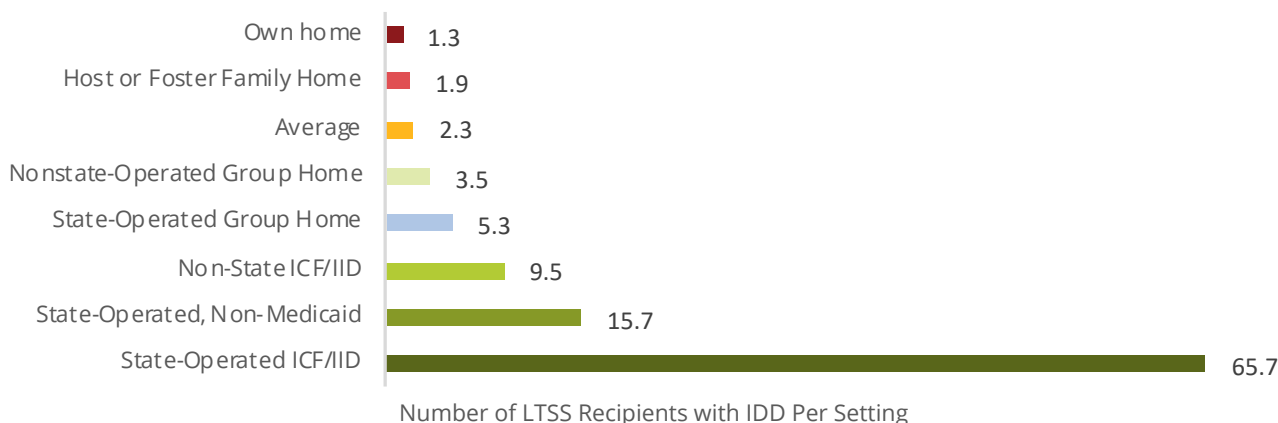
Overall, an estimated 2.1 LTSS recipients lived in each non-state setting, and 13.9 LTSS recipients lived in each state-operated setting. The average number of people per setting by setting type and type of operation was:

- Own home (1.3 people per home)
- Host or Foster Family home (1.9)
- Non-state IDD group home (3.5)
- Non-state ICF/IID (9.5)
- State-Operated IDD group home (5.3)
- State-Operated ICF/IID (65.7)
- State-Operated, Non-Medicaid funded (15.7)

On June 30, 2017, more than half (58%) of people with IDD not living with a family member lived alone or shared their home with one or two other LTSS recipients (See **Figure 1.4**). The proportion living in settings of 3 or fewer people ranged from 6% in Mississippi to 95% in Vermont. Other states with very low proportions in settings of three or fewer include Illinois (9%), South Carolina (25%) and New Jersey (26%).

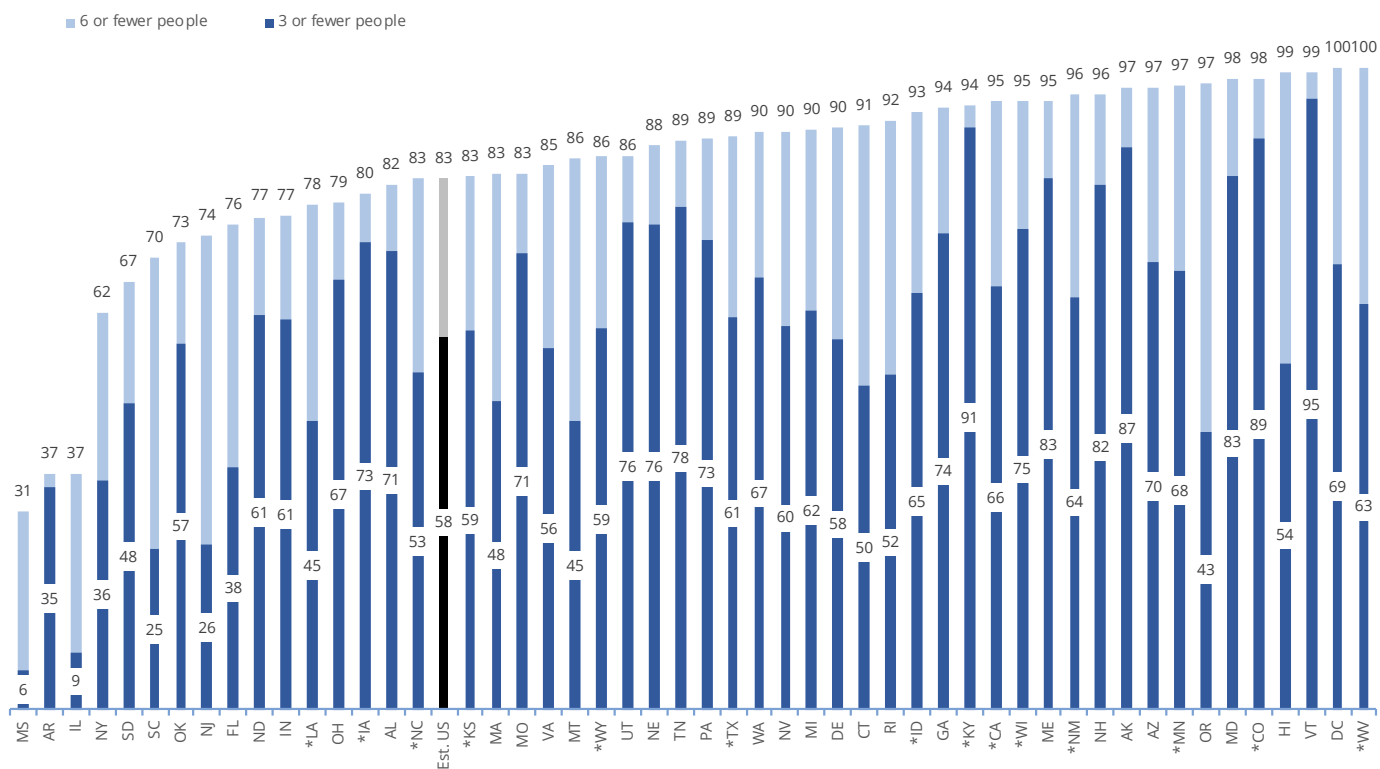
On June 30, 2017, 83% of all people living in a setting other than the home of a family member lived in a home shared by six or fewer LTSS recipients with IDD. The proportion living in settings of six or fewer people ranged from 31% in Mississippi to 100% in the District of Columbia and West Virginia. The proportion was 90% or greater in 23 states. In Arkansas and Illinois, 37% of people LTSS not living with a family member lived in settings of six or fewer people.

**Figure 1.3** LTSS Recipients with IDD per Setting by Setting Type on June 30, 2017



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

**Figure 1.4** Percent of People not Living with Family Members who lived in Settings of 1 to 3 or 1 to 6 People by State on June 30, 2017



\* % in settings of six or fewer known, but breakdown for settings of 1-3 versus 4-6 imputed based on national estimates.

The 2014 Medicaid HCBS rule does not require provider-operated Waiver-funded residences and vocational programs to be of a specific size, but it does require them to be community-based, inclusive (not segregated by disability) and to use individualized, person-centered planning and practices. In a review of 30 years of deinstitutionalization research, 37 of 43 studies, people with IDD who moved from institutions to homes shared by six or fewer people showed improved adaptive behavior (daily living skills) while less or no change was observed for people who remained in institutions (Larson, Lakin & Hill, 2012). Setting size is a significant predictor of better outcomes in areas such as everyday choice and expenditures (e.g., Bershadsky, et. al., 2012; Lakin, et. al., 2008; Ticha, et. al., 2012). People in settings of three or fewer people had better outcomes than those living in larger settings in many areas.

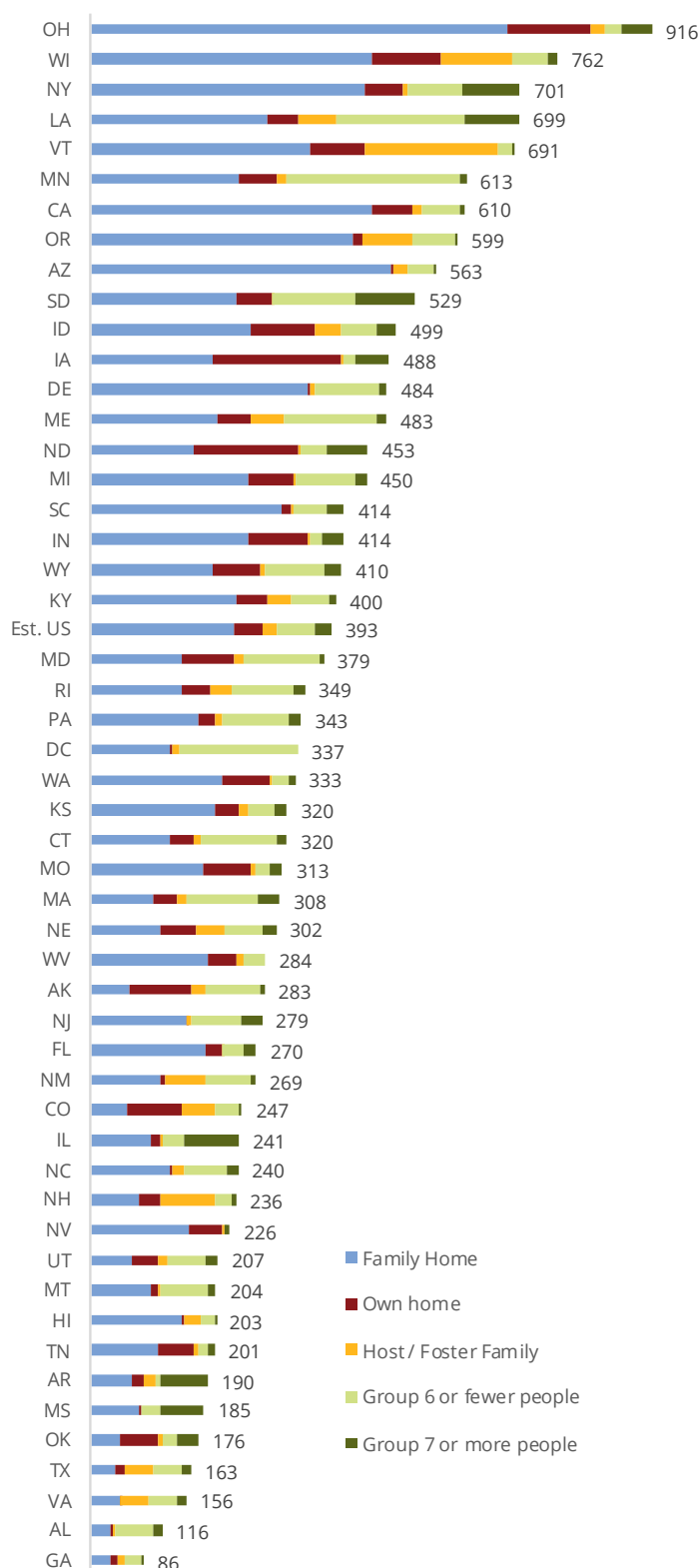
## Utilization of IDD LTSS Settings per 100,000 of the Population by Setting Type

On June 30, 2017, states IDD agencies provided LTSS to an estimated 393 people with IDD per 100,000 of the population (See **Figure 1.5**). Rates ranged from 86 per 100,000 in Georgia to 916 per 100,000 in Ohio. States with the utilization rates of less half of the national average included Georgia (86 per 100,000), Alabama (116), Virginia (156), Texas (163), Oklahoma (176), Mississippi (185), and Arkansas (190). Only Ohio had a utilization rate for LTSS services from a state IDD agency that was more than double the national average.

Overall, there were 234 LTSS recipients with IDD living with a family member per 100,000 of the population, ranging from 31 per 100,000 in Alabama to 681 per 100,000 in Ohio. In addition to Ohio, the only other state to report providing LTSS utilization rates for people living with a family member of more twice the national average was Arizona (491 per



**Figure 1.5** Estimated LTSS Recipients with IDD Per 100,000 of the Population by Setting Type and State on June 30, 2017



100,000). State IDD agencies reporting utilization rates of less than half the national average for LTSS recipients include: New Mexico (113), Nebraska (112), Tennessee (109), Massachusetts (103), Illinois (98), Montana (97), Mississippi (80), New Hampshire (79), Utah (67), Arkansas (66), Alaska (63), Colorado (57), Oklahoma (48), Virginia (46), Texas (41), Georgia (32), and Alabama (31).

An estimated 159 people with IDD received LTSS in a setting other than the family home per 100,000 of the U.S. population. Rates ranged from 53 per 100,000 in Georgia to 410 per 100,000 in Louisiana. Besides Georgia, other states serving fewer than 100 people per 100,000 of the population included Hawaii (55), Nevada (68), Arizona (72), Florida (85), Alabama (85), Tennessee (93) and West Virginia (95). Besides Louisiana, the only other states serving more than double the number of people per 100,000 as the national average were Minnesota (371), and Vermont (332).

The average number of LTSS recipients with IDD per 100,000 of the population (and range across states) varied by setting type as follows:

- Host/foster family home (21 per 100,000; range 0 in Mississippi to 218 in Vermont)
- Own home (47 per 100,000 average; range 1 in New Jersey to 210 in Iowa)
- Group setting 1 to 6 people (64 per 100,000; range 1 in Nevada to 283 in Minnesota)
- Group setting 7 to 15 people (16 per 100,000; range less than 1 in 9 states to 90 in New York) and
- Group setting 16 or more people (11 per 100,000; range less than 1 in six states to 54 in Mississippi)

Some state IDD agencies were much more likely to provide LTSS to people with IDD than others. LTSS utilization rates reflect differences in which state IDD agency administers LTSS for people ages 21 years or younger, historical patterns of institutional use and deinstitutionalization, lawsuits and consent decrees, and other factors not measured through the RISP survey.

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

This section estimates of the number of people with IDD receiving LTSS in state-operated or non-state

**Table 1.11** People with IDD in State-Operated and Non-State Nursing Homes or Psychiatric Facilities by State on June 30, 2017

	Psychiatric Facilities			Nursing Homes		
	State	NonState	Reported Total	State	Non-State	Estimated Total
N States	38	28	51	36	34	51
AL	61	0	61	0	932	932
AK	0 <sup>d</sup>	0 <sup>d</sup>	0 <sup>d</sup>	0 <sup>d</sup>	0 <sup>d</sup>	0 <sup>d</sup>
AZ	0	0	0	0	51	51
AR	0	0	0	DNF	DNF	648 <sup>s</sup>
CA	0	36	36	0	1,089	1,089
CO	0 <sup>d</sup>	0 <sup>d</sup>	0 <sup>d</sup>	0 <sup>d</sup>	51	51
CT	3	0	3	0	305	305
DE	2	0	2	7	46	53
DC	27	0	27	0	3	3
FL	1	5	6	0	288	288
GA	240 <sup>d</sup>	DNF	240 <sup>a</sup>	0 <sup>d</sup>	DNF	1,053 <sup>s</sup>
HI	3	0	3	0	63 <sup>e</sup>	63 <sup>e</sup>
ID	0	0	0	DNF	DNF	146
IL	0	0	0	0	143	143
IN	56	0	56	0	1,355	1,355
IA	12	262	274	DNF	1,061	1,061
KS	21	0	21	0	123	123
KY	409	0	409	DNF	DNF	708 <sup>s</sup>
LA	34	DNF	34 <sup>a</sup>	17	441	458
ME	DNF	DNF	0 <sup>a</sup>	0	82	82
MD	DNF	DNF	0 <sup>a</sup>	6	281	287
MA	DNF	DNF	0 <sup>a</sup>	0	DNF	440 <sup>s</sup>
MI	DNF	DNF	0 <sup>a</sup>	DNF	DNF	744 <sup>s</sup>
MN	DNF	DNF	0 <sup>a</sup>	0 <sup>d</sup>	147 <sup>d</sup>	147 <sup>d</sup>
MS	DNF	DNF	0 <sup>a</sup>	DNF	DNF	426 <sup>s</sup>
MO	175	0	175	0	0	0
MT	DNF	DNF	0 <sup>a</sup>	DNF	DNF	112 <sup>s</sup>
NE	0	9	9	0	181	181
NV	0	0	0	0	118	118
NH	DNF	DNF	0 <sup>a</sup>	DNF	DNF	90 <sup>s</sup>
NJ	43	DNF	43 <sup>a</sup>	0	822	822
NM	DNF	DNF	0 <sup>a</sup>	DNF	DNF	81 <sup>s</sup>
NY	DNF	DNF	0 <sup>a</sup>	DNF	DNF	1,645 <sup>d</sup>
NC	281	DNF	281 <sup>a</sup>	96	DNF	829 <sup>s</sup>
ND	5	DNF	5 <sup>a</sup>	0	106	106
OH	DNF	DNF	0 <sup>a</sup>	0	DNF	1,401 <sup>s</sup>
OK	DNF	DNF	0 <sup>a</sup>	0 <sup>d</sup>	1,358 <sup>d</sup>	1,358 <sup>d</sup>
OR	0	0	0	0	130	130
PA	63	161	224	0	2,373 <sup>e</sup>	2,373 <sup>e</sup>
RI	0	0	0	0	45	45
SC	DNF	DNF	0 <sup>a</sup>	DNF	275	430 <sup>s</sup>
SD	0 <sup>d</sup>	0 <sup>d</sup>	0 <sup>d</sup>	0 <sup>d</sup>	87 <sup>d</sup>	87 <sup>d</sup>
TN	29	DNF	29	0	451	451
TX	430 <sup>d</sup>	DNF	430 <sup>a</sup>	DNF	DNF	2,757 <sup>s</sup>
UT	0 <sup>d</sup>	DNF	0 <sup>a</sup>	DNF	DNF	162 <sup>s</sup>
VT	0	0	0	0	39	39
VA	0 <sup>e</sup>	353 <sup>e</sup>	353 <sup>e</sup>	0 <sup>e</sup>	1,037 <sup>e</sup>	1,037 <sup>e</sup>
WA	40	9	49	112	304	416
WV	22 <sup>d</sup>	DNF	22 <sup>d</sup>	DNF	DNF	210 <sup>s</sup>
WI	0	0	0	0	18	18
WY	7	DNF	7	DNF	DNF	22 <sup>s</sup>
Reported US Total	1,964	835	2,799	238	13,805	25,576
Estimated US Total				334	25,104	25,576

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



psychiatric facilities or nursing homes on June 30, 2016. Some states were not able to report on people receiving LTSS through a managed care organization or in settings licensed by an entity other than the state IDD agency.

### Psychiatric Facilities

While Medicaid funds are available for LTSS provided in most settings, they may not be used to fund services in “Institutes for Mental Disease” for individuals 18 to 64 years old. Those services must be funded by state, local or private funds. Half of all states (N=26) reported no people with IDD living psychiatric facilities. In the other 25 states a total of 2,799 people with IDD lived in state or non-state psychiatric facilities on June 30, 2017 (See **Table 1.11**). Totals reflect partial data for states reporting people with IDD only for state-operated or only for non-state psychiatric facilities.

### Nursing Homes

An estimated 25,576 people with IDD lived in nursing homes on June 30, 2017. An estimated 1% (334 people) lived in state-operated nursing home and 99% (25,104 people) lived in non-state nursing homes. Thirty-six states reported people with IDD in state-operated nursing homes and 34 states reported people with IDD in non-state nursing

homes. All but two states (Alaska and Missouri) reported people with IDD living in a nursing home. States with more than 1,000 people with IDD living in nursing homes included Texas (2,757), Pennsylvania (2,373), New York (1,645), Ohio (1,401), Oklahoma (1,358), Indiana (1,355), California (1,089), Iowa (1,061), Georgia (1,053), and Virginia (1,037).

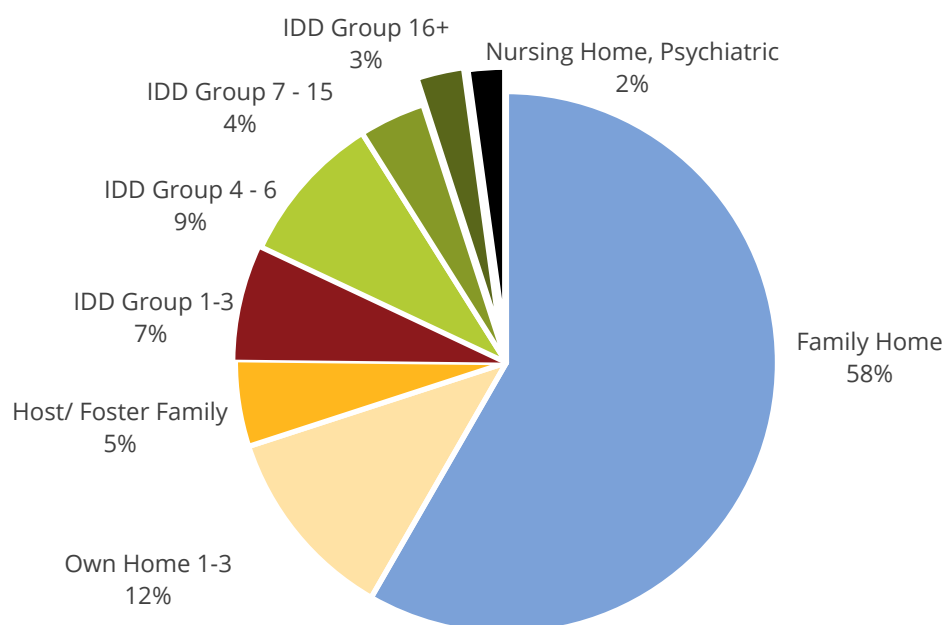
Estimated total for states providing incomplete information about people in nursing facilities were estimated based on a combination of data from FY 2016, and Centers for Medicare and Medicaid Services CASPER data for nursing homes on June 30, 2017 (AHCA, 2017c).

Including people in nursing homes and psychiatric facilities, an estimated 1,306,977 people with IDD received LTSS on June 30, 2017. Of those, 2% lived in a nursing home or psychiatric facility, 23% lived in a group IDD setting of any size, 12% lived in their own home, 5% lived in a host or foster family home, and 58% lived with a family member (See **Figure 1.6**).

## PROGRESS ON HEALTHY PEOPLE 2020 DH-12 GOALS

The Centers for Disease Control Health People establishes a set of objectives updated every 10

**Figure 1.6** Percent of LTSS Recipients with IDD in Family Home, LTSS Settings, Psychiatric Facilities or Nursing Homes by Residence Type and Size on June 30, 2017



years to monitor progress toward improving the health of all Americans. Current objectives are listed on the Healthy People 2020 website at [www.healthypeople.gov](http://www.healthypeople.gov). The following objectives from the Disability and Health section specifically address living arrangements for people with IDD:

- DH-12 Reduce the number of people with disabilities living in congregate care residences.
- DH-12.1 Reduce the number of adults with disabilities aged 22 years and older living in congregate care residences that serve 16 or more persons.
- DH-12.2 Reduce the number of children and youth with disabilities aged 21 years and under living in congregate care residences.

Congregate settings were defined as

- Non-family residential settings (state or non-state settings of any size, type or funding authority)
- In which four or more individuals with IDD live



**Table 1.12** People with IDD 21 Years or Younger Living in Nursing Homes or other Congregate Settings of 4 or More People by State on June 30, 2017

	Setting Type		Total
	Congregate	Nursing Home	
N States	31	31	28
AL	2	0	2
AK	0 <sup>d</sup>	0 <sup>d</sup>	0 <sup>d</sup>
AZ	0	5	5
AR	199	0	199
CA	1,824	5	1,829
CO	224	0	224
CT	113	1	114
DE	88	18	106
DC	0	0	0
FL	830	20	850
GA	DNF	DNF	DNF
HI	DNF	0	DNF
ID	DNF	DNF	DNF
IL	223	0	223
IN	316	106	422
IA	174	54	228
KS	DNF	DNF	DNF
KY	DNF	DNF	DNF
LA	DNF	4	DNF
ME	85	2	87
MD	DNF	2	DNF
MA	DNF	DNF	DNF
MI	DNF	DNF	DNF
MN	364 <sup>d</sup>	0 <sup>d</sup>	364 <sup>d</sup>
MS	DNF	DNF	DNF
MO	43	0	43
MT	DNF	DNF	DNF
NE	31	10	41
NV	19	17	36
NH	DNF	DNF	DNF
NJ	DNF	DNF	DNF
NM	DNF	DNF	DNF
NY	1,039 <sup>d</sup>	203 <sup>d</sup>	1,242 <sup>d</sup>
NC	DNF	DNF	DNF
ND	103 <sup>d</sup>	1 <sup>d</sup>	104 <sup>d</sup>
OH	439	DNF	DNF
OK	DNF	DNF	DNF
OR	211	48	259
PA	164 <sup>e</sup>	9 <sup>e</sup>	173 <sup>e</sup>
RI	0	0	0
SC	DNF	DNF	DNF
SD	138 <sup>d</sup>	0 <sup>d</sup>	138 <sup>d</sup>
TN	36	DNF	DNF
TX	DNF	DNF	DNF
UT	DNF	DNF	DNF
VT	2	0	2
VA	202 <sup>d</sup>	127 <sup>d</sup>	329 <sup>d</sup>
WA	27	6	33
WV	DNF	DNF	DNF
WI	68	0	68
WY	17	DNF	DNF
Reported US Total	6,981	638	7,619
Estimated US Total	14,116	1,309	15,425

DNF Did not furnish. <sup>d</sup> Other date (data from previous or next year). <sup>e</sup> Estimate. On this table all settings with 4 or more people other than nursing homes are considered "other" congregate settings.

- In which rotating (or shift) staff members provide supports and services.

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

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

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

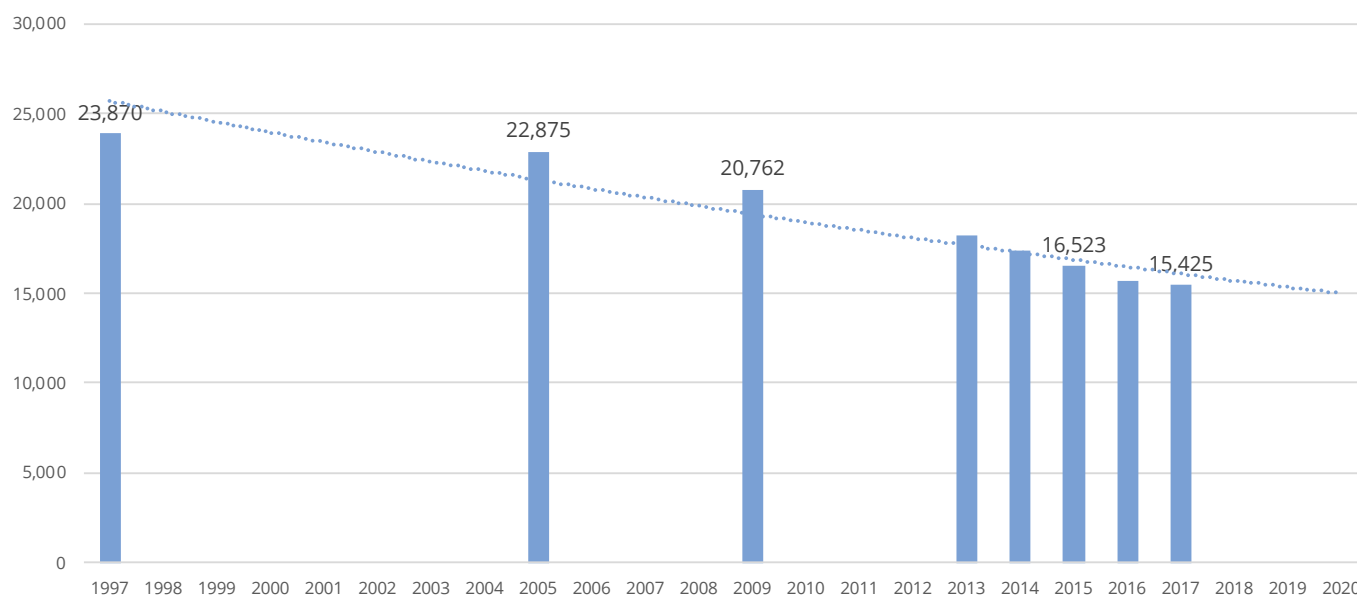
On June 30, 2017, the number of children and youth 21 years or younger living in a congregate

setting serving four or more LTSS recipients was 15,425. This total included 1,309 children and youth in nursing homes, 5,041 in ICF/IID settings and an estimated 9,074 in other types of congregate settings (See **Table 1.12** and **Figure 1.7**).

The number of children and youth in congregate settings has been tracked since 1977. From 1977 to 1996, every other year a survey of state-operated public residential facilities asked about children and youth in those facilities. The RISP project conducted special surveys in 1997, 2005 and 2009 asking state IDD agencies to report the number of children and youth in any congregate settings of four or more people. Beginning in 2013, questions about the age of LTSS recipients served by state IDD agencies were embedded in the annual RISP survey.

The number of children and youth in state-operated facilities of 16+ people declined from 90,942 in 1977 to 25,328 in 1987. The number of children and youth in congregate settings of 4 or more people estimated based on special surveys in 1997, 2005 and 2009 were 23,870, 22,875, and 20,762. Based on annual RISP surveys, the estimated number of children and youth with IDD in congregate settings of four or more people declined from 18,197 in 2013 to 15,425 in 2017.

**Figure 1.7** Number of People with IDD 21 Years or Younger Living in Nursing Homes or Congregate Settings of Four or More People June 30, 1997 to 2017 with Projections to 2020



Note: Data for 1997, 2005 and 2009 were based on one time special surveys. Data from 2013 and beyond were from the annual RISP survey.







## SECTION TWO

# Long-Term Supports and Services Funding Authorities

**FY 2017**

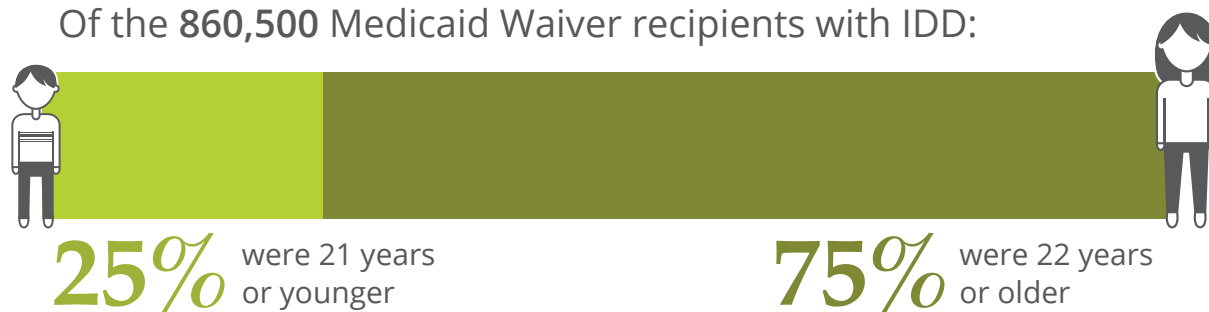
# Medicaid Waiver Recipients and Expenditures 2017

**\$38.7 billion** expended to provide Medicaid Waiver funded supports to 806,500 people with IDD (\$44,983 per person)

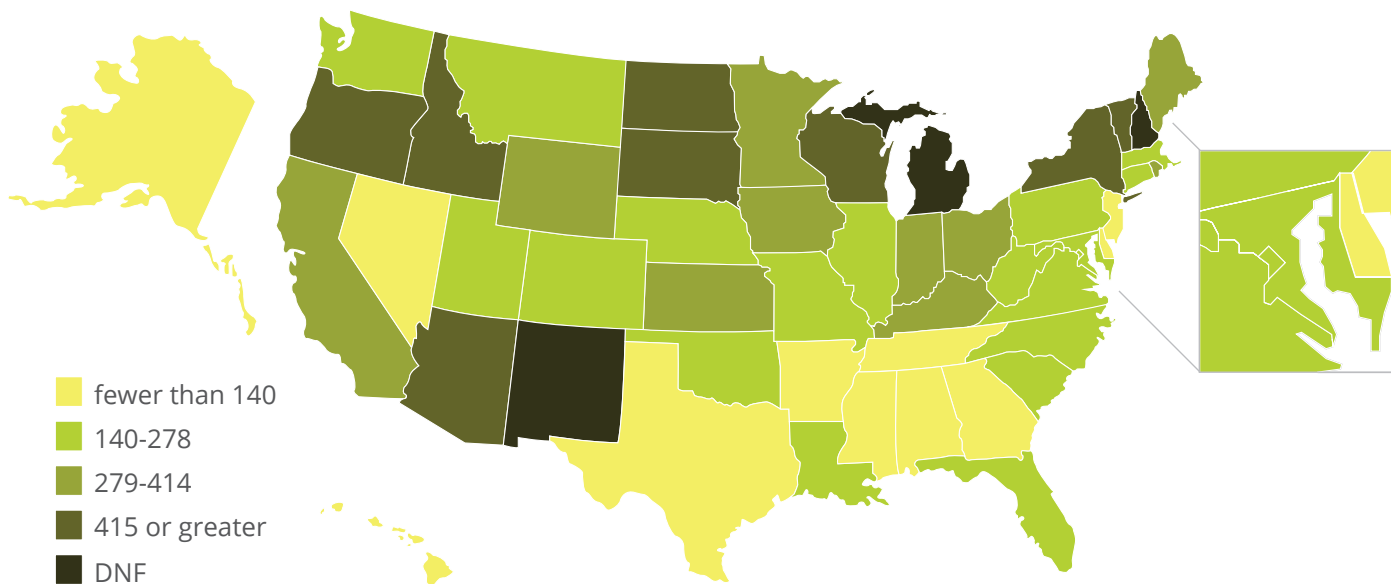
## Annual per person Medicaid Waiver expenditures



Of the 860,500 Medicaid Waiver recipients with IDD:



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



# Medicaid Intermediate Care Facilities for Individuals with Intellectual Disabilities ICF/IID 2017

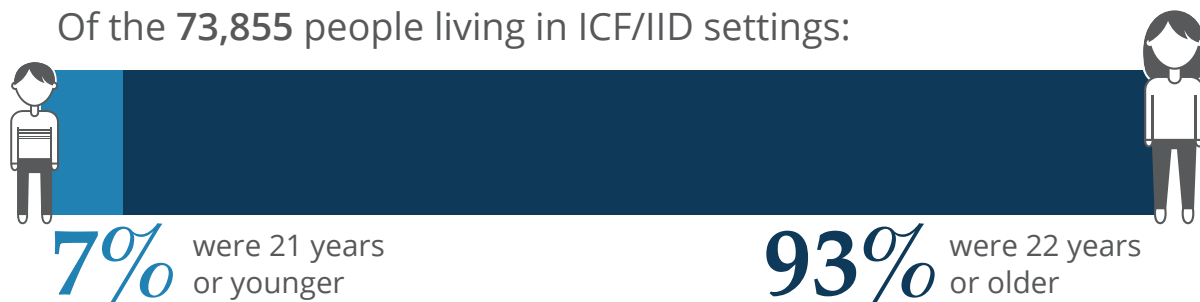
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**\$9.8 billion** expended to provide Medicaid ICF/IID services to 73,855 people with IDD (\$140,057 per person)

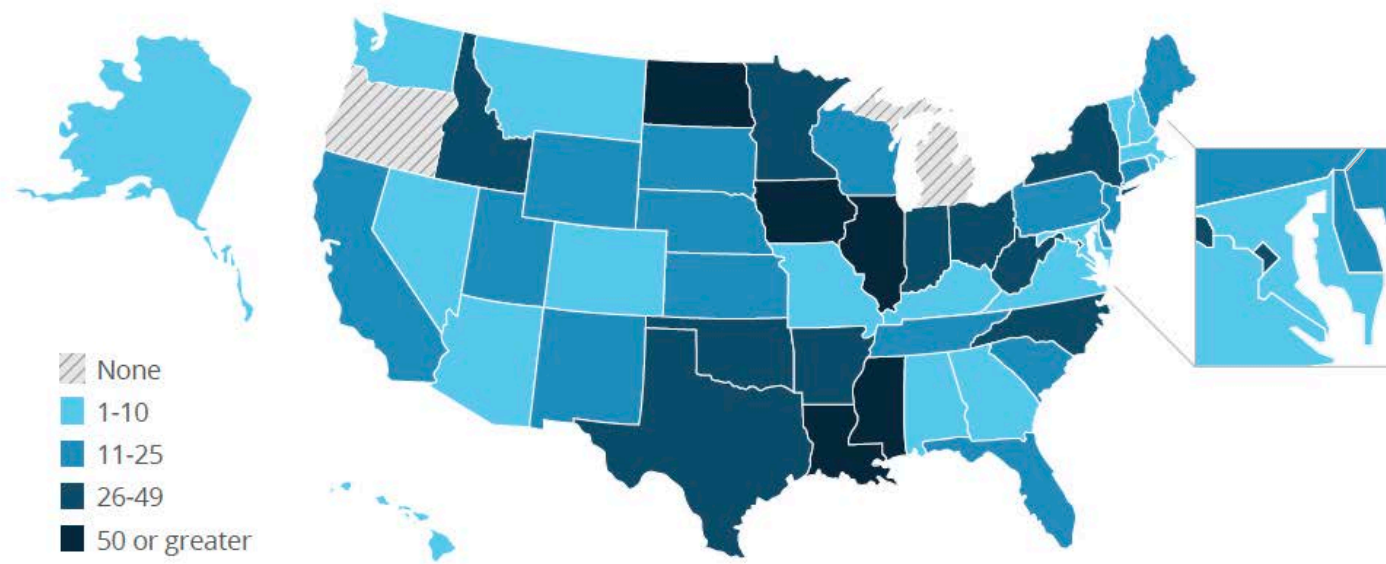
Annual per person ICF/IID expenditures



Of the 73,855 people living in ICF/IID settings:



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





**Table C:** Medicaid Funding Authorities

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

## SECTION 2: LTSS FUNDING AUTHORITIES INCLUDING MEDICAID

Medicaid offers an array of different mechanisms (or “authorities”) through which states can request matching federal funds to provide LTSS (see **Table C**). States can request flexibility in administration and in determining the type, amount, duration, and scope of services, as well as the design and delivery of services to be covered, consistent with federal regulations. The federal financial portion (called the Federal Medicaid Assistance Percentage - FMAP) varies by state, based on per capita income and the size of the state. For FY 2017, state FMAP ranged from 50% in 13 states to 75% in Mississippi. In states with a 50% FMAP, every dollar the state spends on Medicaid funded supports is matched by a dollar from the federal government.

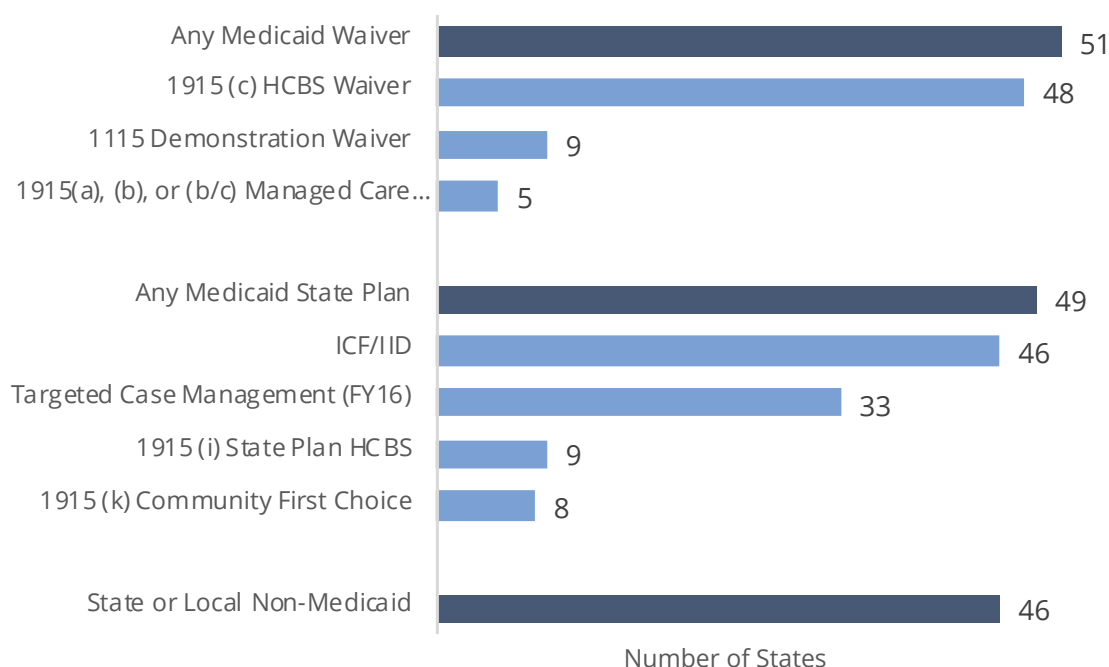
States use unique blends of these funding authorities to support LTSS for people with IDD. Meaningful comparisons of Medicaid programs across states requires consideration of the funding authorities, eligibility criteria, and the menu of services covered under each authority by each state.

### STATE UTILIZATION OF LTSS FUNDING AUTHORITIES

In 2017, all 50 states and the District of Columbia funded LTSS for people with IDD through one or more Medicaid Waiver funding authority (See **Figure 2.1**). The number of states using Medicaid Waiver funding authorities included: 1915(c) Home and Community-based Waiver (48 states), 1115 Demonstration Waiver (9 states), and Medicaid Managed Care Waivers 1915(a), (b), or (b/c) (5 states).

In 2017, 49 states reported using one or more Medicaid State Plan funding authority to support LTSS for people with IDD. The number of states using State Plan funding authorities included: Medicaid ICF/IID (46 states), Medicaid State Plan Targeted Case Management (33 states), Medicaid State Plan 1915(i) HCBS (9 states), and State Plan 1915(k) Community First Choice (8 states). Forty-six states also reported funding LTSS for people with IDD through non-Medicaid, state funding authorities.

**Figure 2.1** Funding Authorities Used by States to Provide LTSS for People with IDD on June 30, 2017



## LTSS RECIPIENTS WITH IDD BY FUNDING AUTHORITY

Of the 1.48 million people with IDD known to, or served under the auspices of state IDD agencies in FY 2017, an estimated 860,500 received Medicaid Waiver-funded LTSS, 73,855 lived in a Medicaid ICF/IID, 232,101 received supports through Medicaid State Plan 1915(i) or 1915 (k) funding authorities, 203,393 received non-Medicaid state-funded LTSS, and 267,134 did not receive LTSS funding. Some people received supports through more than one funding authority.

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

Forty-four states reported the number of people with IDD living with a family member who had requested Medicaid Waiver-funded services but were waiting for those supports as of June 30, 2017 (See **Table 2.1**). People who already received Medicaid Waiver-funded supports who were asking for different supports, people living in an ICF/IID and people not living with a family member were not counted.

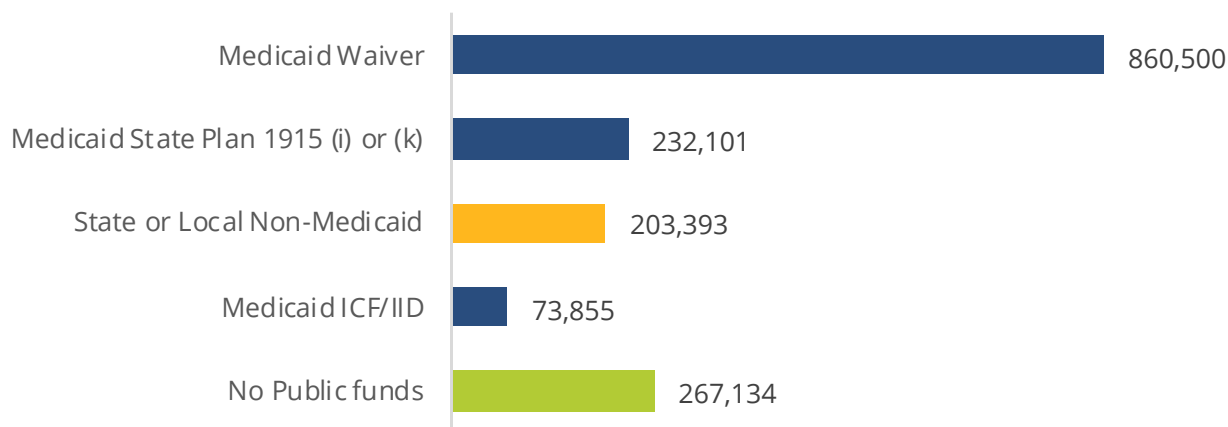
## Number of People with IDD Waiting

An estimated 182,340 people with IDD living with a family member were waiting for Medicaid Waiver-Funded LTSS on June 30, 2017. Thirteen states (California, Delaware, the District of Columbia, Hawaii, Idaho, Massachusetts, New York, North Dakota, Oregon, Rhode Island, South Dakota, Vermont and Washington) reported not having a waiting list or reported no people waiting for Medicaid Waiver-funded supports. States reporting more than 10,000 people with IDD waiting for Medicaid Waiver-funded supports included Florida (20,723), Illinois (10,778), Louisiana (15,259), Ohio (31,770 people), and Virginia (11,691).

## People Receiving Targeted Case Management Services While Waiting

Of the people with IDD waiting for Medicaid Waiver-funded supports, an estimated 22% (39,960 people) in sixteen states received Medicaid State Plan-funded Targeted Case Management Services (TCM) while waiting. Twenty states reported not providing TCM to people who were waiting. More than 90% of people waiting received TCM services in Maine, Maryland, Montana, Minnesota, Missouri, Nevada, West Virginia, and Wyoming. People waiting may have received LTSS funded by a Medicaid State Plan, or by a non-Medicaid state funding authority during their wait.

**Figure 2.2** Estimated LTSS Recipients with IDD by Funding Authority on June 30, 2017



Some people receive services from more than one funding authority. Medicaid Waiver authorities include 1115, 1915 (a), 1915 (a/c), 1915 (b), 1915 (b/c) and 1915 (c). For FY '17 Medicaid State Plan Home and Community Based Services authorities included 1915(i) and 1915(k) but did not include Targeted Case Management.

**Table 2.1** People with IDD Living with Family Members Waiting for Medicaid Waiver-Funded LTSS, Total ICF/IID and Medicaid Waiver Recipients and Growth Needed to Serve those Waiting by State on June 30, 2017

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	36	30	51	44
AL	2,451	DNF	1,283	5,644	43
AK	527 <sup>d</sup>	0 <sup>d</sup>	292 <sup>d</sup>	2,100	25
AZ	161	1	5	31,233	1
AR	2,802	DNF	DNF	5,586	50
CA	0	0	0	131,683	0
CO	3,052	0	3,051	12,373	25
CT	419	285	228	10,730	4
DE *	0	0	0	4,482	0
DC	0	0	0	2,128	0
FL	20,723	DNF	1,536	36,512	57
GA	DNF	DNF	DNF	8,854	DNF
HI	0	0	0	2,446	0
ID	0	0	0	8,568	0
IL	10,778	0	4,785	29,718	36
IN	1,573	0	DNF	28,278	6
IA	DNF	DNF	DNF	14,424	DNF
KS	3,711	DNF	DNF	9,324	40
KY	2,229	DNF	DNF	17,814	13
LA	15,259	1,067	DNF	17,018	90
ME	1,141	1,141	DNF	5,107	22
MD	5,812	5,569	5,401	15,375	38
MA	0	0	0	15,750	0
MI	DNF	DNF	DNF	45,115	DNF
MN	29 <sup>d</sup>	29 <sup>d</sup>	DNF	23,298	0
MS	1,437	296	47	4,176	34
MO	247	231	124	14,576	2
MT	1,233 <sup>d</sup>	DNF	DNF	2,810	44
NE	1,766	513	DNF	4,966	36
NV	745	745	607 <sup>d</sup>	2,243	33
NH	DNF	DNF	DNF	5,410	DNF
NJ	2,830	DNF	DNF	13,276	21
NM	4,834 <sup>d</sup>	DNF	DNF	4,870	99
NY	0 <sup>d</sup>	0 <sup>d</sup>	6,099 <sup>d</sup>	94,940	0
NC	9,402 <sup>e</sup>	25	228 <sup>e</sup>	25,296	37
ND	0	0	0	5,426	0
OH	31,770	5,468	DNF	44,994	71
OK	7,050 <sup>d</sup>	0 <sup>d</sup>	0 <sup>d</sup>	7,011	101
OR	0	0	0	21,200	0
PA	8,499	7,503	2,857	37,762	23
RI	0	0	0	4,362	0
SC	6,094	DNF	234	12,087	50
SD	0 <sup>d</sup>	0	0	3,820	0
TN	DNF	0	DNF	9,188	DNF
TX	DNF	DNF	DNF	46,172	DNF
UT	2,752	0	1,513	5,150	53
VT	0	0	0	3,076	0
VA	11,691	DNF	DNF	13,378	87
WA	0	0	0	20,635	0
WV	1,274 <sup>d</sup>	1,274 <sup>d</sup>	60 <sup>d</sup>	5,028	25
WI	DNF	10	DNF	33,983	DNF
WY	182	182	DNF	2,474	7
<b>Reported US Total</b>	<b>162,473</b>	<b>24,339</b>	<b>28,350</b>		
<b>Estimated US Total</b>	<b>182,340</b>	<b>39,960</b>	<b>63,487</b>	<b>934,355</b>	<b>20%</b>

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

## People Waiting to Move to a Non-family Setting

An estimated 63,487 people (35%) were waiting for Medicaid Waiver funding to enable them to move from the home of a family member to their own home, a host or foster family home, a group home, or another non-family setting. States reporting that more than half of people waiting wanted to move to a non-family setting were Colorado (99%), Maryland (91%), Nevada (81%), Alabama (62%), Utah (56%), and Alaska (55%).

## Growth in Medicaid Funded LTSS Required to Serve All People Waiting

An estimated 934,355 people with IDD received Medicaid Waiver-funded supports or lived in an ICF/IID on June 30, 2017 (See **Figure 2.3**). To serve all of the people waiting for Waiver-funded supports in states with waiting lists, the number of Waiver-funded or ICF/IID LTSS recipients would have to increase by 20% overall, with the proportion ranging from 1% in Arizona to 99% in New Mexico and 101% in Oklahoma.

## LIVING ARRANGEMENTS FOR PEOPLE RECEIVING MEDICAID WAIVER-FUNDED LTSS

The RISP survey asks about Medicaid Waiver recipients by age, living arrangement, and operating entity (state or non-state). It also asks for the number of people for whom Medicaid Waiver

expenditures are reported. In many states, the number of people for whom expenditure data are provided differs from the number of recipients reported by age because recipient characteristics and living arrangements are reported for people on June 30, 2017 but expenditures are reported for all of FY 2017. Except in the expenditures section, this report refers to total Medicaid Waiver recipients as of June 30, 2017.

Of the 860,500 Medicaid Waiver recipients on June 30, 2017, 60% (459,265) lived with a family member, 14% (118,997) lived in their own home, 7% (61,343) lived with a host or foster family, and 26% (220,895) lived in a group IDD setting (See **Table 2.2** and **Figure 2.4**). An estimated 30,546 Medicaid Waiver recipients with IDD in eleven states lived unknown setting types.

## Home of a Family Member

The majority of Medicaid Waiver recipients lived in the home of a family member. The number of Medicaid Waiver recipients living with a family member ranged from 77 in Maryland to 90,430 in California. The proportion of Waiver recipients living with a family member ranged from 1% in Maryland to 84% in Arizona and exceeded 50% in 17 states. There is a modest correlation between the proportion of Waiver recipients living with a family member and the proportion who are 21 years or younger ( $r = .43$ ) with states serving a higher proportion of Waiver recipients 21 years or younger also serving a higher proportion of recipients in the home of a family member.

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



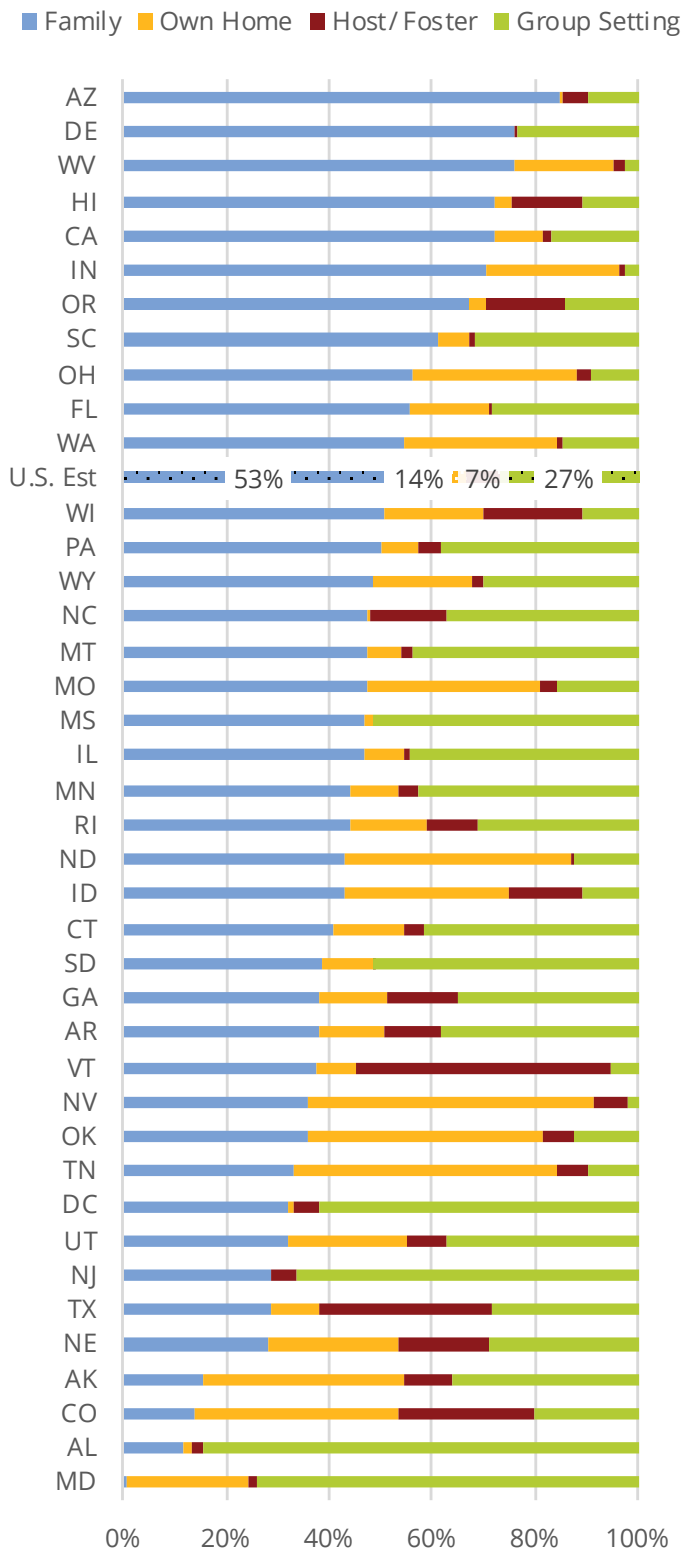
**Table 2.2** Medicaid Waiver Recipients with IDD by Residence Type and State

	Family Home	Own Home	Host/ Foster Family	Group Settings			Group Total	Unknown
				Non-State IDD	Non-State Other	State IDD		
N States	45	45	45	46	44	49	44	42
AL	480	55	111	3,437	0	0	3,437	1,539
AK	277 <sup>d</sup>	705 <sup>d</sup>	170 <sup>d</sup>	654 <sup>d</sup>	0	0	654 <sup>d</sup>	287 <sup>d</sup>
AZ	26,229	265	1,528	2,920	7	145	3,072	0
AR	1,925	639	570	1,027	0	0	1,027	0
CA	90,430	11,648	1,566	20,437	0	0	20,437	0
CO	1,575	4,549	3,009	757	1,408	131	2,296	0
CT	4,106	1,391	376	3,739	97	274	4,110	6
DE	3,367	0	5	992	0	0	992	0
DC	529	15	85	1,016	0	0	1,016	0
FL	18,735 <sup>d</sup>	5,152 <sup>d</sup>	250 <sup>d</sup>	7,882 <sup>d</sup>	956 <sup>d</sup>	0	8,838 <sup>d</sup>	0
GA	3,274 <sup>d</sup>	1,145 <sup>d</sup>	1,203 <sup>d</sup>	2,825 <sup>d</sup>	23 <sup>d</sup>	0	2,848 <sup>d</sup>	109 <sup>d</sup>
HI	1,674	65	320	252	0	0	252	0
ID	1,610	1,206 <sup>d</sup>	546	376	0	0	376	4,375
IL	11,530	1,983	304	9,248	0	0	9,248	0
IN	17,406 <sup>e</sup>	6,449 <sup>e</sup>	234 <sup>e</sup>	661 <sup>e</sup>	0	0	661 <sup>e</sup>	349
IA	DNF	DNF	DNF	DNF	DNF	59	PD	DNF
KS	DNF	DNF	DNF	DNF	DNF	0	PD	8,891
KY	DNF	DNF	1,590	2,897	0	0	2,897	12,905 <sup>e</sup>
LA	10,017 <sup>d</sup>	2,362 <sup>d</sup>	DNF	DNF	0 <sup>d</sup>	0	PD	DNF
ME	DNF	729 <sup>e</sup>	729 <sup>e</sup>	1,777 <sup>e</sup>	<sup>e</sup>	0	1,777 <sup>e</sup>	DNF
MD	77	3,531	205	5,846	4,989	0	10,835	0
MA	2,763	1,351	674	7,807	DNF	1,071	PD	DNF
MI	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MN	9,555 <sup>d</sup>	1,946 <sup>d</sup>	873 <sup>d</sup>	8,318 <sup>d</sup>	806 <sup>d</sup>	359 <sup>d</sup>	9,483 <sup>d</sup>	0 <sup>d</sup>
MS	1,788	70	0	467	0	321	788	0
MO	6,661	4,746	454	1,894	0	227	2,121	0
MT	1,014 <sup>d</sup>	143 <sup>d</sup>	47 <sup>d</sup>	926	0	0	926	DNF
NE	1,338	1,165	844	1,245	0	0	1,245	0
NV	794	1,220	138	0	0	0	0	0
NH	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NJ	3,852	0	589	7,433	0	0	7,433	0
NM	1,424 <sup>i</sup>	DNF	DNF	1,481 <sup>d</sup>	0	65 <sup>d</sup>	1,546 <sup>d</sup>	1,427 <sup>d</sup>
NY	43,149 <sup>d</sup>	5,751 <sup>d</sup>	1,684 <sup>d</sup>	24,317 <sup>d</sup>	DNF	6,542	PD	DNF
NC	6,553 <sup>e</sup>	105 <sup>e</sup>	2,009	3,533	465 <sup>e</sup>	0	3,998	638 <sup>e</sup>
ND	1,268	1,293	16	303	0	0	303	0
OH	22,096 <sup>e</sup>	12,399	1,190	2,462	338	0	2,800	0
OK	1,895 <sup>d</sup>	2,445 <sup>d</sup>	325 <sup>d</sup>	645 <sup>d</sup>	0 <sup>d</sup>	0 <sup>d</sup>	645 <sup>d</sup>	0
OR	14,235	691	3,225	2,980	0	0	2,980	0
PA	17,729	2,577	1,443	11,454	1,193	0	12,647	20
RI	1,560	510	346	1,089	0	146	1,235	0
SC	7,119	651	160	2,999	0	0	2,999	0
SD	1,453 <sup>d</sup>	365 <sup>d</sup>	1 <sup>d</sup>	1,809 <sup>d</sup>	0	0	1,809 <sup>d</sup>	0
TN	2,656	4,081	462	623	11	0	634	0
TX	11,571 <sup>d</sup>	3,821 <sup>d</sup>	13,624 <sup>d</sup>	8,566 <sup>d</sup>	0 <sup>d</sup>	0	8,566 <sup>d</sup>	0
UT	1,640	1,209	399	1,712	0	0	1,712	0
VT	1,029	219	1,360	144	0	0	144	0
VA	3,871 <sup>d</sup>	230 <sup>d</sup>	1,360 <sup>d</sup>	4,493 <sup>d</sup>	0 <sup>d</sup>	0 <sup>d</sup>	4,493 <sup>d</sup>	DNF
WA	11,291	6,062	214	2,315	0	3	2,318	0
WV	3,438	857	96 <sup>d</sup>	123	0 <sup>d</sup>	0	123	0
WI	16,947	6,492	6,382	3,239	0	0	3,239	0
WY	1,144	456	50	633	10	0	643	0
<b>Reported US Total</b>	<b>393,074</b>	<b>102,744</b>	<b>50,766</b>	<b>169,753</b>	<b>10,303</b>	<b>9,343</b>	<b>149,603</b>	<b>30,546</b>
<b>Estimated US Total <sup>1</sup></b>	<b>459,265</b>	<b>118,997</b>	<b>61,343</b>	<b>199,843</b>	<b>11,709</b>	<b>9,343</b>	<b>220,895</b>	<b>0</b>

DNF Did not furnish. <sup>d</sup> Other date (data from previous or next year). <sup>e</sup> Estimate. \* See state notes in Appendix. <sup>1</sup> US estimated totals include Waiver recipients for whom setting type was not known. In 2017, residence type was unknown or not reported for 164,062 waiver recipients with IDD. Medicaid Waiver authorities include 1115, 1915 (a), 1915 (a/c), 1915 (b), 1915 (b/c) and 1915 (c)



**Figure 2.4** Percent of Medicaid Waiver Recipients with IDD in Family Home, Own Home, Host or Foster Family Home, or Group Settings by State June 30, 2017



Eleven states did not report setting type for all Waiver recipients (IA, KS, KY, LA, ME, MA, MI, MT, NH, NM, and NY)

## Own Home

An estimated 118,997 Waiver recipients with IDD (14% of the total) lived in a home they owned or leased on June 30, 2017. The proportion of Waiver recipients who lived in a home of their own ranged from zero in Delaware and New Jersey to 57% in Nevada. In 18 states, fewer than 10% of Medicaid Waiver recipients with IDD lived in a home of their own, whereas in Nevada and Tennessee more than 50% of recipients lived in a home of their own.

## Host or Family Foster Home

An estimated 61,343 Waiver recipients with IDD (7% of the total) lived with a host or foster family on June 30, 2017. The proportion of Waiver recipients with IDD who lived with a host or foster family ranged from none in Delaware, South Dakota and Mississippi to 26% in Colorado, 36% in Texas, and 49% in Vermont. In 30 states fewer than 10% of Medicaid Waiver recipients with IDD lived with a host or foster family.

## Group Settings

An estimated 220,895 Waiver recipients with IDD lived in group settings including 199,843 who lived in a non-state group home, 9,343 who lived in a state-operated group home, and 11,709 who lived in another type of non-state group setting. States in which 50% or more of Medicaid Waiver recipients lived in a group setting included Alabama (84%), Maryland (74%), New Jersey (63%), the District of Columbia (62%) and South Dakota (50%). Fewer than 10% of Medicaid Waiver recipients with IDD lived in a group setting in Tennessee (8%), Ohio (7%), Vermont (5%), West Virginia (3%), Indiana (3%) and Nevada (0%).

## MEDICAID WAIVER UTILIZATION RATES

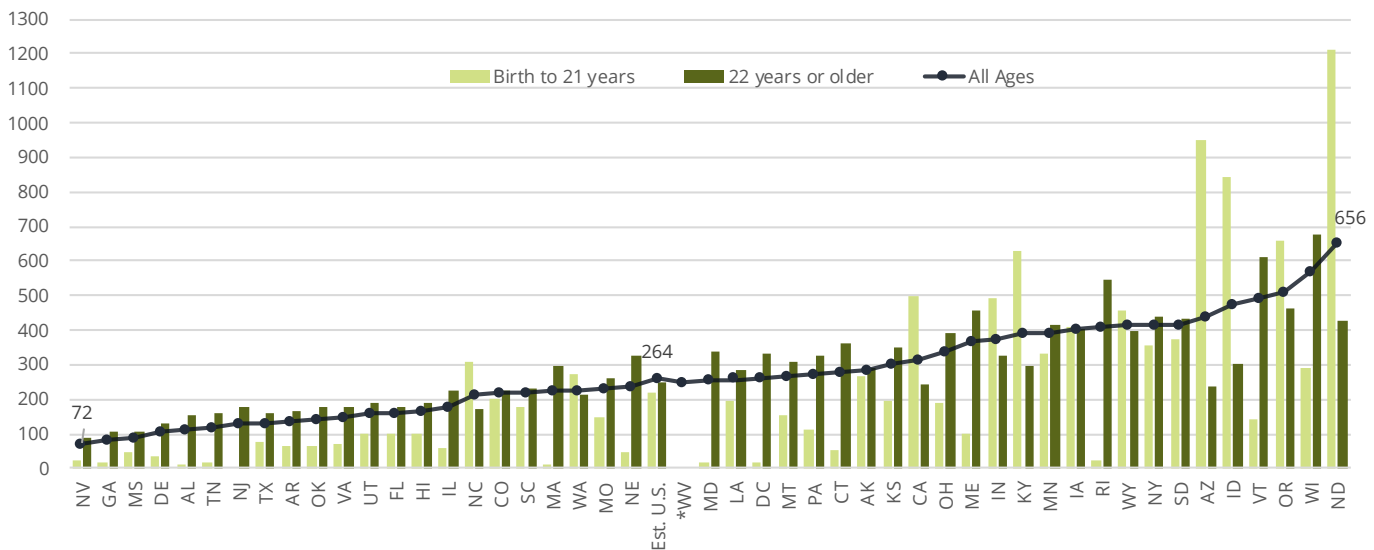
On June 30, 2017, an estimated 218,253 (25%) Medicaid Waiver recipients with IDD were 21 years old or younger and 642,247 (75%) were 22 years old or older (See **Table 2.3** and **Figure 2.5**). Fifteen states (Alabama, Connecticut, Delaware, the District of Columbia, Georgia, Illinois, Maine, Maryland, Massachusetts, Nebraska, New Jersey, Rhode Island, Tennessee, and Vermont) reported that 90% or

**Table 2.3** Medicaid Waiver Recipients with IDD Total and per 100,000 by Age and State on June 30, 2017

Age	Number Waiver Recipients			Percent 22 years or older	State Population in 100,000's <sup>s</sup>		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	47	47	48	47	51	51	47	47	48
AL	146	5,476	5,622	97	14	35	11	156	115
AK	601 <sup>d</sup>	1,492 <sup>d</sup>	2,093 <sup>d</sup>	71	2	5	270	289	283
AZ	19,143	11,839	30,982	38	20	50	949	237	442
AR	541	3,597	4,138	87	9	21	62	168	138
CA	55,489	68,592	124,081	55	112	284	497	242	314
CO	3,091	9,093	12,184	75	16	41	199	224	217
CT	485	9,494	9,979	95	10	26	51	361	278
DE	88	943	1,031	91	3	7	35	133	107
DC	26	1,770	1,796	99	2	5	16	333	259
FL	5,165	28,647	33,812	85	51	158	100	181	161
GA	610 <sup>d</sup>	7,969 <sup>d</sup>	8,579 <sup>d</sup>	93	31	73	20	109	82
HI	372	1,995	2,367	84	4	11	100	189	166
ID	4,518	3,595	8,113	44	5	12	846	304	473
IL	2,146	20,664	22,810	91	36	92	60	224	178
IN	9,603	15,496	25,099	62	20	47	492	329	376
IA	3,779	8,937	12,716	70	9	22	411	401	404
KS	1,745	7,146	8,891	80	9	20	198	352	305
KY	7,856	9,536	17,392	55	12	32	631	297	390
LA	2,615	9,470	12,085	78	13	33	194	284	258
ME	321	4,627	4,948	94	3	10	101	455	370
MD	289	14,994	15,283	98	17	44	17	341	253
MA	259	15,095	15,354	98	18	51	15	297	224
MI	DNF	DNF	DNF	DNF	27	72	DNF	DNF	DNF
MN	5,268 <sup>d</sup>	16,524 <sup>d</sup>	21,792 <sup>d</sup>	76	16	40	333	414	391
MS	420	2,270	2,690	84	9	21	48	108	90
MO	2,520	11,632	14,152	82	17	44	148	264	231
MT	439	2,357	2,796	84	3	8	155	307	266
NE	268	4,324	4,592	94	6	13	46	324	239
NV	174	1,978	2,152	92	8	22	21	91	72
NH	DNF	DNF	DNF	DNF	3	10	DNF	DNF	DNF
NJ	0	11,874	11,874	100	24	66	0	180	132
NM	DNF	DNF	DNF	DNF	6	15	DNF	DNF	DNF
NY	18,549 <sup>d</sup>	64,107 <sup>d</sup>	82,656 <sup>d</sup>	78	52	147	358	437	416
NC	8,857 <sup>e</sup>	12,929 <sup>e</sup>	21,786	59	29	74	310	174	212
ND	2,673	2,283	4,956	46	2	5	1,214	427	656
OH	6,030	33,150	39,180	85	32	84	187	393	336
OK	742 <sup>d</sup>	4,883 <sup>d</sup>	5,625 <sup>d</sup>	87	12	28	63	177	143
OR	7,056	14,144	21,200	67	11	31	656	461	512
PA	3,854	31,057	34,911	89	34	95	115	328	273
RI	60	4,294	4,354	99	3	8	22	548	411
SC	2,484	8,445	10,929	77	14	37	181	231	218
SD	981 <sup>d</sup>	2,644 <sup>d</sup>	3,625 <sup>d</sup>	73	3	6	375	435	417
TN	282	7,855	8,137	97	18	49	15	161	121
TX	6,730 <sup>d</sup>	30,852 <sup>d</sup>	37,582	82	89	194	76	159	133
UT	1,150	3,810	4,960	77	11	20	103	192	160
VT	225	2,845	3,070	93	2	5	142	612	492
VA	1,698	10,813	12,511	86	23	61	73	176	148
WA	5,408	11,492	16,900	68	20	54	271	212	228
WV	DNF	DNF	4,514	DNF	5	14	DNF	DNF	249
WI	4,683	28,377	33,060	86	16	42	292	677	570
WY	764	1,637	2,401	68	2	4	459	397	414
Reported US Total	200,203	587,043	791,760	74	909	2,349	220	250	243
Estimated US Total	218,253	642,247	860,500	75	909	2,349	240	273	264

DNF Did not furnish. <sup>d</sup> Other date (data from previous or next year). <sup>e</sup> Estimate. <sup>s</sup> 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).

**Figure 2.5** Medicaid Waiver Recipients with IDD per 100,000 of the Population by Age and State on June 30, 2017



\*Age breakdowns not available for WV; NM, MI, and NH did not furnish this data

more of Waiver recipients were 22 years or older. Three states (Arizona, Idaho and North Dakota) reported that fewer than 50% of Waiver recipients were 22 years or older.

On June 30, 2017, there were an estimated 264 Medicaid Waiver recipients with IDD per 100,000 of the population. Medicaid Waiver utilization rates ranged from 72 per 100,000 in Nevada to 656 per 100,000 in North Dakota. States reporting utilization rates more than twice the national average included North Dakota (656 per 100,000), Wisconsin (570), Oregon (512), and Vermont (492). States reporting utilization rates of less than half the national average included New Jersey (132 per 100,000), Tennessee (121), Alabama (115), Mississippi (90), Georgia (82) and Nevada (72). Differences in Medicaid Waiver utilization rates may be due variations in state wealth, fiscal priorities or utilization rates for other funding authorities such as state plan HCBS.

### Waiver Utilization Rates by Age

Waiver utilization rates for children and youth with IDD 21 years or younger averaged 240 per 100,000 of the population and ranged from 0 in New Jersey to 1,214 per 100,000 in North Dakota. States with utilization rates for children and youth of more than double the national average included North Dakota

(1,214 per 100,000), Arizona (949), Idaho (846), Oregon (656), Kentucky (631), California (497), and Indiana (492). Twenty-three states reported Medicaid Waiver utilization rates for children and youth of less than half of the national average. States with the lowest utilization rates for children and youth included Illinois (60 per 100,000), Connecticut (51), Mississippi (48), Nebraska (46), Delaware (35), Rhode Island (22), Nevada (21), Georgia (20), Maryland (17), the District of Columbia (16), Tennessee (15), Massachusetts (15), Alabama (11), and New Jersey (0). Many of these states provide Medicaid Waiver-funded LTSS to young adults 18 to 21 years old but do not serve children younger than age 18.

Medicaid Waiver utilization rates for people with IDD 22 years or older averaged 273 per 100,000 of the population and ranged from 91 per 100,000 in Nevada to 677 per 100,000 in Wisconsin. States with Medicaid Waiver utilization rates for adults of more than twice the national average included Wisconsin (677 per 100,000), Vermont (612), and Rhode Island (548). States with utilization rates for adults of less than half the national average included Delaware (133 per 100,000), Georgia (109), Mississippi (108) and Nevada (91).

Nationally, states provided Medicaid Waiver-funded LTSS to children with IDD at a slightly lower rate than



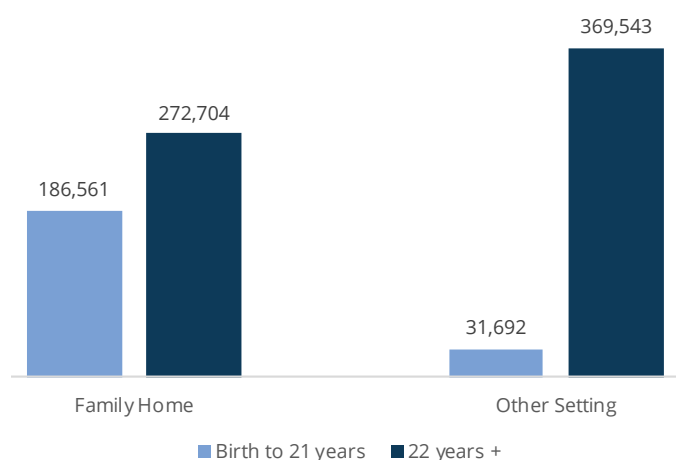
for adults (240 per 100,000 versus 273 per 100,000). Utilization rates were higher for children than for adults in eleven states. States in which utilization rates for children were more than twice the rates for adults included Arizona (four times more likely), Idaho (2.8 times more likely), North Dakota (2.8 times more likely), Kentucky (2.1 times more likely), and California (2.1 times more likely).

Medicaid Waiver utilization rates for adults were higher than for children and youth in 36 states, and were more two times higher for adults in 22 states. States in which the Medicaid Waiver utilization rate for adults was more than 10 times higher than the rate for children or youth included Rhode Island (adults were 25 times more likely), District of Columbia (21 times more likely), Massachusetts (20 times more likely), Maryland (19 times more likely), Alabama (14 times more likely), and Tennessee (11 times more likely). Many of these states provided Medicaid Waiver-funded LTSS to very few children youth, perhaps only serving youth ages 18 to 21 rather than children and youth ages birth to 21 years. It is possible that other state agencies such as Children and Family Services or Child Welfare were responsible for providing LTSS to children with IDD in those states.

## Medicaid Waiver Recipients by Age and Living Arrangement

In June 30, 2017, of the estimated 218,253 Medicaid Waiver recipients 21 years or younger 186,561 (85%) lived in the home of a family member while 31,692 (25%) lived in other settings on June 30, 2017 (See **Table 2.4** and **Figure 2.6**). All Medicaid Waiver

**Figure 2.6** Estimated Number of Waiver Recipients by Age and Residence Type on June 30, 2017



**Table 2.4** Medicaid Waiver Recipients with IDD Living in Family Homes or Other LTSS Settings by Age and State on June 30, 2017

Age	Family Home		Other Settings <sup>1</sup>		% in Family Home	
	Birth to 21 years	22 years or older	Birth to 21 years	22 years or older	Birth to 21 years	22 years or older
N States	37	37	37	37	37	37
AL	5	475	141	5,001	3	9
AK	277 <sup>d</sup>	0 <sup>d</sup>	325 <sup>d</sup>	1,442 <sup>d</sup>	46	0
AZ	16,303	9,988	2,840 <sup>e</sup>	1,851 <sup>e</sup>	85	84
AR	DNF	DNF	DNF	DNF	DNF	DNF
CA	53,755	36,675	1,734	31,917	97	53
CO	1,845	0	1,318	9,093	58	0
CT	408	3,698	77	5,796	84	39
DE	1,289	2,078	0	1,085	100	66
DC	20	707	9	1,109	69	39
FL	4,284	14,807	881	13,840	83	52
GA	DNF	DNF	DNF	DNF	DNF	DNF
HI	356	1,337	16	658	96	67
ID	DNF	DNF	DNF	DNF	DNF	DNF
IL	1,692	9,565	454	11,099	79	46
IN	9,300	8,106	303	7,390	97	52
IA	DNF	DNF	DNF	DNF	DNF	DNF
KS	DNF	DNF	DNF	DNF	DNF	DNF
KY	DNF	DNF	DNF	DNF	DNF	DNF
LA	DNF	DNF	DNF	DNF	DNF	DNF
ME	DNF	DNF	DNF	DNF	DNF	DNF
MD	35	53	254	14,941	12	0
MA	259	7,046	0	8,049	100	47
MI	DNF	DNF	DNF	DNF	DNF	DNF
MN	4,657 <sup>d</sup>	4,898 <sup>d</sup>	611 <sup>d</sup>	11,626 <sup>d</sup>	88	30
MS	DNF	DNF	DNF	DNF	DNF	DNF
MO	2,085	4,726	439	6,910	83	41
MT	DNF	DNF	DNF	DNF	DNF	DNF
NE	108	1,230	160	3,094	40	28
NV	60	734	114	1,244	34	37
NH	DNF	DNF	DNF	DNF	DNF	DNF
NJ	0	3,852	0	8,022 <sup>e</sup>	0	32
NM	DNF	DNF	DNF	DNF	DNF	DNF
NY	17,870 <sup>d</sup>	26,520 <sup>d</sup>	679 <sup>d</sup>	37,587 <sup>d</sup>	96	41
NC	6,378 <sup>e</sup>	6,865 <sup>e</sup>	1,763 <sup>e</sup>	5,691 <sup>e</sup>	78	55
ND	1,047	221	64	1,548	94	12
OH	5,436	16,238	594	16,912	90	49
OK	436 <sup>d</sup>	1,459 <sup>d</sup>	304 <sup>d</sup>	3,418 <sup>d</sup>	59	30
OR	5,971	8,264	1,085	5,880	85	58
PA	3,342	14,605	512	16,452	87	47
RI	33	1,506	27	2,788	55	35
SC	2,404	4,715	80	3,730	97	56
SD	892 <sup>d</sup>	560 <sup>d</sup>	91 <sup>d</sup>	2,084 <sup>d</sup>	91	21
TN	104	2,613	178	5,242	37	33
TX	4,440 <sup>d</sup>	7,862 <sup>d</sup>	2,662 <sup>d</sup>	24,041 <sup>d</sup>	63	25
UT	528	1,112	622	2,698	46	29
VT	114	915	111	1,930	51	32
VA	1,468	4,171	230	6,642	86	39
WA	3,732	7,929	1,676	3,563	69	69
WV	DNF	DNF	DNF	DNF	DNF	DNF
WI	4,594	12,353	89	16,024	98	44
WY	685	459	60	1,089	92	30
Reported US Total	156,212	228,342	20,503	301,486	88	43
Estimated US Total <sup>1</sup>	186,561	272,704	31,692	369,543	85	42

DNF Did not furnish. <sup>d</sup> Other date (data from previous or next year). <sup>e</sup> Estimate. \* See state notes in Appendix. This table shows the number of people by age and setting for whom Waiver expenditures were reported. <sup>1</sup> 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)



**Table 2.5** Medicaid Waiver and LTSS Recipients with IDD in Own Home or Family Settings by State on June 20, 2017

State	All LTSS Recipients		Waiver Recipients		% with Waiver Funding <sup>1</sup>	
	Own Home	Family Home	Own Home	Family Home	Own Home	Family Home
<b>N States</b>	44	44	45	45	44	44
AL	55	480	55	480	100	100
AK	705	277 <sup>d</sup>	705 <sup>d</sup>	277 <sup>d</sup>	100	100
AZ	265	34,451	265	26,229	100	76
AR	639	1,973	639	1,925	100	98
CA	25,968	181,533	11,648	90,430	45	50
CO	5,120	3,219	4,549	1,575	89	49
CT	1,455	4,555	1,391	4,106	96	90
DE	18	3,413	0	3,367	0	99
DC	15	893	15	529	100	59
FL	5,742	38,917 <sup>d</sup>	5,152 <sup>d</sup>	18,735 <sup>d</sup>	90	48
GA	1,145 <sup>d</sup>	3,274 <sup>d</sup>	1,145 <sup>d</sup>	3,274 <sup>d</sup>	100	100
HI	77	2,108	65	1,674	84	79
ID	1,206 <sup>d</sup>	1,610 <sup>e</sup>	1,206 <sup>d</sup>	1,610	100	100
IL	1,983	12,578	1,983	11,530	100	92
IN	6,449	17,035	6,449 <sup>e</sup>	17,406 <sup>e</sup>	100	100
IA	DNF	DNF	DNF	DNF	DNF	DNF
KS	DNF	DNF	DNF	DNF	DNF	DNF
KY	DNF	DNF	DNF	DNF	DNF	DNF
LA	DNF <sup>0</sup>	13,526 <sup>d</sup>	2,362 <sup>d</sup>	10,017 <sup>d</sup>	DNF	74
ME	729	DNF	729 <sup>e</sup>	DNF	100	DNF
MD	3,847	1,728 <sup>d</sup>	3,531	77	92	4
MA	2,702	7,046	1,351	2,763	50	39
MI	DNF	DNF	DNF	DNF	DNF	DNF
MN	3,471 <sup>d</sup>	13,475 <sup>d</sup>	1,946 <sup>d</sup>	9,555 <sup>d</sup>	56	71
MS	78	2,382 <sup>e</sup>	70	1,788	90	75
MO	4,748	11,278	4,746	6,661	100	59
MT	143 <sup>d</sup>	1,014 <sup>d</sup>	143 <sup>d</sup>	1,014 <sup>d</sup>	100	100
NE	1,177	2,148	1,165	1,338	99	62
NV	1,621	4,745	1,220	794	75	17
NH	DNF	DNF	DNF	DNF	DNF	DNF
NJ	79	13,922	0	3,852	0	28
NM	DNF	1,424 <sup>d</sup>	DNF	1,424 <sup>i</sup>	DNF	100
NY	11,734 <sup>d</sup>	89,066 <sup>d</sup>	5,751 <sup>d</sup>	43,149 <sup>d</sup>	49	48
NC	208	DNF	105 <sup>e</sup>	6,553 <sup>e</sup>	50	DNF
ND	1,293	1,268	1,293	1,268	100	100
OH	15,899	79,382	12,399	22,096 <sup>e</sup>	78	28
OK	2,451 <sup>d</sup>	1,895 <sup>d</sup>	2,445 <sup>d</sup>	1,895 <sup>d</sup>	100	100
OR	709	17,687	691	14,235	97	80
PA	3,485	22,189 <sup>e</sup>	2,577	17,729	74	80
RI	510	1,560	510	1,560	100	100
SC	704	15,685	651	7,119	92	45
SD	536 <sup>d</sup>	2,050 <sup>d</sup>	365 <sup>d</sup>	1,453 <sup>d</sup>	68	71
TN	4,084	7,292	4,081	2,656	100	36
TX	3,821 <sup>d</sup>	11,571 <sup>d</sup>	3,821 <sup>d</sup>	11,571 <sup>d</sup>	100	100
UT	1,229	1,667	1,209	1,640	98	98
VT	546	2,237	219	1,029	40	46
VA	230 <sup>d</sup>	3,871 <sup>d</sup>	230 <sup>d</sup>	3,871 <sup>d</sup>	100	100
WA	5,647	15,956	6,062	11,291	100	71
WV	857	3,438	857	3,438	100	100
WI	6,512 <sup>e</sup>	26,701	6,492	16,947	100	63
WY	456	1,144	456	1,144	100	100
<b>Reported US Total</b>	<b>130,348</b>	<b>683,663</b>	<b>102,744</b>	<b>393,074</b>	<b>79</b>	<b>57</b>
<b>Estimated US Total</b>	<b>152,759</b>	<b>762,097</b>	<b>118,997</b>	<b>459,265</b>	<b>78</b>	<b>60</b>

DNF Did not furnish. <sup>d</sup> Other date (data from previous or next year). <sup>e</sup> Estimate. <sup>i</sup> One or more component value imputed by RISP staff. Unknown values distributed according to national proportions. \* See state notes in Appendix. <sup>1</sup> 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).

recipients 21 years or younger in Massachusetts and Delaware lived in the home of a family member as did more than 95% of Waiver recipients 21 years or younger in Wisconsin (98%), California (97%), Indiana (97%), South Carolina (97%), New York (96%) and Hawaii (96%). Fewer than 50% of Medicaid Waiver recipients 21 years or younger lived in the home of a family member in Alaska (46%), Utah (46%), Tennessee (37%), Nevada (34%), Maryland (12%), Alabama (3%), and New Jersey (0%).

Of 642,247 Medicaid Waiver recipients 22 years or older, 272,704 (42%) lived in the home of a family member, and 369,543 (58%) lived in other types of settings. States serving more than half of Waiver recipients with IDD ages 22 years or older in the home of a family member were Arizona (84%), Washington (69%), Hawaii (67%), Delaware (66%), Oregon (58%), South Carolina (56%), North Carolina (55%), California (53%), Indiana (52%), and Florida (52%). Fewer than 20% of Waiver recipients 22 years or older lived in the home of a family member in North Dakota (12%), Alabama (9%), Alaska (0%), Colorado (0%), and Maryland (0%).

## People in Own Home or Family Home Settings Receiving Medicaid Waiver-Funded Supports

On June 30, 2017, of the 152,759 LTSS recipients with IDD living in a home of their own, 118,997 (78%) received supports funded by a Medicaid Waiver. All recipients living in their own home received Medicaid Waiver-funded supports in 18 states. In another eight states, 90% received Medicaid Waiver-funded supports. Fewer than half of recipients living in their own home received Medicaid Waiver-funded supports in New York (49%), California (45%), and Vermont (40%). None of the LTSS recipients living in a home of their own received Medicaid Waiver-funded supports in Delaware and New Jersey.

Of 762,097 LTSS recipients with IDD living with a family member, 459,265 (60%) received Medicaid Waiver-funded supports (See **Table 2.5**). All recipients living with a family member received Medicaid Waiver-funded supports in 14 states as did more than 90% of recipients in additional five states. In eleven states (Colorado, Florida, Maryland, Massachusetts, Nevada, New Jersey, New York, Ohio,



**Table 2.6** Medicaid Waiver Expenditures, Per Recipient with IDD and Per State Resident by Age and State in FY 2017

State	Waiver Expenditures (\$)			FY 2017 Waiver Recipients	Expenditures per Recipient (\$)			State Population <sup>s</sup> (100,000)	Expenditures per State Resident (\$)
	Birth to 21	22 Years +	Total		Birth to 21	22 years +	Total		
N States	44	44	47	48	44	44	47	51	47
AL	20,042,929	360,117,913	380,160,842	5,622	137,280	65,763	67,620	49	78
AK	25,701,813 <sup>d</sup>	150,555,938 <sup>d</sup>	176,257,752 <sup>d</sup>	2,093 <sup>d</sup>	42,765	100,909	84,213	7	238
AZ	341,814,931	640,657,754	982,472,685	30,982	17,856	54,114	31,711	70	140
AR	21,325,700	203,704,045	225,029,745	4,138	39,419	56,632	54,381	30	75
CA	532,946,927	2,850,928,800	3,383,875,727	124,081	9,605	41,564	27,272	395	86
CO	58,213,696	395,779,282	453,992,978	12,184	18,833	43,526	37,261	56	81
CT	29,187,769	899,964,569	929,152,338	9,979	60,181	94,793	93,111	36	259
DE	12,538,306	122,643,438	135,181,744	1,031	142,481	130,057	131,117	10	141
DC	1,267,545	217,596,060	218,863,605	1,796	48,752	122,936	121,862	7	315
FL	77,187,822	927,241,918	1,004,429,740	33,812	14,944	32,368	29,706	210	48
GA	16,063,804 <sup>d</sup>	340,430,926 <sup>d</sup>	356,494,730 <sup>d</sup>	8,579 <sup>d</sup>	26,334	42,719	41,554	104	34
HI	10,665,125 <sup>e</sup>	91,408,720 <sup>e</sup>	102,073,845	2,367	28,670	45,819	43,124	14	72
ID	163,649,315	86,224,618	249,873,933	8,113	36,222	23,985	30,799	17	146
IL	72,130,107	851,265,323	923,395,430	22,810	33,611	41,196	40,482	128	72
IN	79,945,802	661,123,153	741,068,955	25,099	8,325	42,664	29,526	67	111
IA	82,961,454	482,212,069	565,173,523	12,716	21,953	53,957	44,446	31	180
KS	67,678,541	422,257,726	489,936,267	8,891	38,784	59,090	55,105	29	168
KY	213,772,454	442,218,402	655,990,856	17,392	27,211	46,374	37,718	45	147
LA	50,743,785	423,118,486	473,862,272	12,085	19,405	44,680	39,211	47	101
ME	12,162,015	334,079,362	346,241,377	4,948	37,888	72,202	69,976	13	259
MD	8,784,965	994,482,690	1,003,267,655	15,283	30,398	66,325	65,646	61	166
MA	4,870,563	1,478,426,586	1,483,297,149	15,354	18,805	97,941	96,607	69	216
MI	DNF	DNF	DNF	DNF	DNF	DNF	DNF	100	DNF
MN	247,727,300 <sup>d</sup>	1,306,582,380 <sup>d</sup>	1,554,309,680 <sup>d</sup>	21,792 <sup>d</sup>	47,025	79,072	71,325	56	279
MS	DNF	DNF	94,710,728	2,690	PD	PD	35,208	30	32
MO	73,815,692	815,306,985	889,122,677	14,152	29,292	70,092	62,827	61	145
MT	10,352,334	104,295,794	114,648,128	2,796	23,582	44,249	41,004	11	109
NE	16,929,439	274,190,359	291,119,798	4,592	63,170	63,411	63,397	19	152
NV	7,628,433	97,338,928	104,967,361	2,152	43,842	49,211	48,777	30	35
NH	DNF	DNF	DNF	DNF	DNF	DNF	DNF	13	DNF
NJ	0	1,047,872,743	1,047,872,743	11,874	0	88,249	88,249	90	116
NM	DNF	DNF	DNF	DNF	DNF	DNF	DNF	21	DNF
NY	303,392,919 <sup>d</sup>	5,312,551,079 <sup>d</sup>	5,615,943,998	82,656 <sup>d</sup>	16,356	82,870	67,944	198	283
NC	161,973,332	901,784,249	1,063,757,581	21,786	18,288	69,749	48,828	103	104
ND	DNF	DNF	199,934,648	4,956	PD	PD	40,342	8	265
OH	108,205,865	1,527,052,618	1,635,258,483	39,180	17,945	46,065	41,737	117	140
OK	19,001,930 <sup>d</sup>	291,645,170 <sup>d</sup>	310,647,099 <sup>d</sup>	5,625 <sup>d</sup>	25,609	59,727	55,226	39	79
OR	13,446,222	76,707,199	90,153,420	21,200	1,906	5,423	4,253	41	22
PA	95,581,197	2,610,335,189	2,705,916,386	34,911	24,801	84,050	77,509	128	211
RI	1,201,968	207,982,164	209,184,132	4,354	20,033	48,436	48,044	11	197
SC	74,955,384	254,830,200	329,785,584	10,929	30,175	30,175	30,175	50	66
SD	8,369,671 <sup>d</sup>	107,598,396 <sup>d</sup>	115,968,067 <sup>d</sup>	3,625 <sup>d</sup>	8,532	40,695	31,991	9	133
TN	21,103,353	660,971,801	682,075,154	8,137	74,835	84,147	83,824	67	102
TX	233,509,694 <sup>d</sup>	1,281,948,268 <sup>d</sup>	1,515,457,962	37,582	34,697	41,552	40,324	283	54
UT	37,286,784	206,930,644	244,217,428	4,960	32,423	54,313	49,237	31	79
VT	14,880,937	183,160,581	198,041,518	3,070	66,138	64,380	64,509	6	318
VA	57,451,701	763,991,381	821,443,082	12,511	33,835	70,655	65,658	85	97
WA	DNF	DNF	56,034,831	16,900	PD	PD	3,316	74	8
WV	DNF	DNF	DNF	4,514	DNF	DNF	PD	18	DNF
WI	50,026,384	1,172,418,296	1,222,444,680	33,060	10,683	41,316	36,977	58	211
WY	9,886,120	82,562,421	92,448,541	2,401	12,940	50,435	38,504	6	160
<b>Estimated US Total</b>	<b>3,717,479,844</b>	<b>34,990,268,915</b>	<b>38,707,748,759</b>	<b>860,500</b>	<b>17,033</b>	<b>54,481</b>	<b>44,983</b>	<b>3,257</b>	<b>119</b>

DNF Did not furnish. <sup>d</sup> Other date (data from previous or next year). <sup>e</sup> Estimate. <sup>s</sup> U.S. Census Bureau, Population Division (2019). \* See state notes in Appendix. Medicaid Waiver authorities include 1115, 1915 (a), 1915 (a/c), 1915 (b), 1915 (b/c) and 1915 (c).

South Carolina and Vermont), fewer than half of the recipients living with a family member received Medicaid Waiver-funded supports.

## MEDICAID WAIVER EXPENDITURES

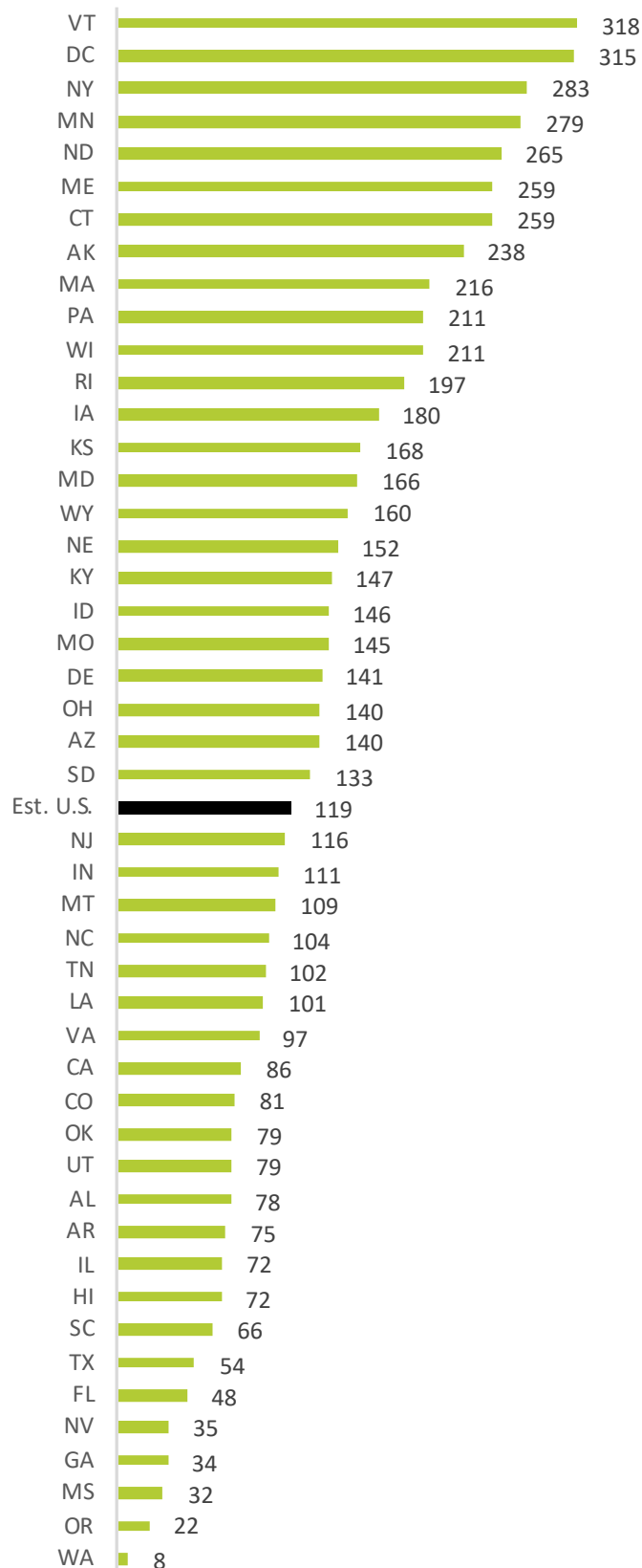
In FY 2017, annual Medicaid Waiver expenditures for 860,550 recipients with IDD were \$38.71 billion, an average of \$44,983 per person per year (See **Table 2.6**). Annual per person Medicaid Waiver expenditures ranged from \$3,316 in Washington and \$4,253 in Oregon, to \$93,111 in Connecticut, \$96,607 in Massachusetts, \$121,862 in the District of Columbia and \$131,117 in Delaware.

Annual Medicaid Waiver expenditures for 218,253 recipients with IDD ages 21 years or younger were \$3.72 billion (\$17,933 per person per year). Average per person Waiver expenditures for recipients 21 years or younger ranged from zero in New Jersey and \$1,901 in Oregon (see state note regarding 1915(k) funding) to \$142,481 in Delaware and \$137,280 in Alabama. Other states reporting average annual per person expenditures of more than \$50,000 per year for recipients 21 years or younger included Tennessee (\$74,835), Vermont (\$66,138), Nebraska (\$63,170) and Connecticut (\$60,181).

Annual Medicaid Waiver expenditures for 642,247 recipients with IDD ages 22 years or older were \$34.99 billion, (\$54,481 per recipient per year). Average annual per person expenditures ranged from \$5,423 in Oregon (see state note) to \$122,936 in the District of Columbia and \$130,057 in Delaware. Twenty-six states reported average annual per person expenditures for adults of \$50,000 or more.

Total FY 2017 Medicaid Waiver expenditures for people with IDD averaged \$110 per United States resident (See **Figure 2.7**). Highest per capita expenditures were reported for Vermont (\$318), the District of Columbia (\$315), New York (\$283), Minnesota (\$279), North Dakota (\$265), Maine (\$259) and Connecticut (\$259). Lowest per capita expenditures were reported for Texas (\$54), Florida (\$48), Nevada (\$35), Georgia (\$34), Mississippi (\$32), Oregon (\$22) and Washington (\$8). Oregon and Washington have shifted the majority of their LTSS expenditures from the Medicaid Waiver to a Medicaid State Plan option.

**Figure 2.7** Annual Medicaid Waiver Expenditures for People with IDD per State Resident by State FY 2017



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

**Table 2.7** Medicaid Waiver Expenditures and Average per Recipient by Age, Living Arrangement, and State in FY 2017

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	31	29	32	29	30	27	29	29
AL	84,741	7,184,456	19,958,187	352,933,457	16,948	15,125	141,547	70,573
AK	10,783,135 <sup>d</sup>	0	14,918,679 <sup>d</sup>	150,555,938 <sup>d</sup>	38,928 <sup>d</sup>	N/A <sup>d</sup>	45,904 <sup>d</sup>	104,408 <sup>d</sup>
AZ	279,154,206	256,073,958	62,660,725 <sup>e</sup>	384,583,796 <sup>e</sup>	17,123	25,638	22,064 <sup>e</sup>	207,771 <sup>e</sup>
AR	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
CA	422,767,427	709,751,853	110,179,500	2,141,176,947	7,865	19,352	63,541	67,086
CO	25,152,881	0	33,060,815	395,779,282	13,633	N/A	25,084	43,526
CT	22,889,814	114,744,721	6,297,955	785,219,847	56,102	31,029	81,792	135,476
DE	DNF	DNF	0	DNF	PD	PD	N/A	PD
DC	588,107	35,504,705	679,437	181,376,825	29,405	50,219	75,493	163,550
FL	30,055,452	260,851,523	47,132,370	666,390,395	7,016	17,617	53,499	48,150
GA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
HI	9,919,087 <sup>e</sup>	53,803,006	746,038	37,605,714	27,863 <sup>e</sup>	40,242	46,627	57,152
ID	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
IL	35,610,996	231,492,417	36,519,111	619,772,906	21,047	24,202	80,439	55,840
IN	69,266,423	147,990,818	10,679,379	513,132,335	7,448	18,257	35,245	69,436
IA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
KS	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
KY	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
LA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
ME	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MD	772,234	1,614,169	8,012,731	992,868,520	22,064	30,456	31,546	66,453
MA	4,870,563	4,314,054	0	1,474,426,586	18,805	612	N/A	183,181
MI	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MN	173,465,141 <sup>d</sup>	238,972,026 <sup>d</sup>	74,262,159 <sup>d</sup>	1,067,610,354 <sup>d</sup>	37,248 <sup>d</sup>	48,790 <sup>d</sup>	121,542 <sup>d</sup>	91,830 <sup>d</sup>
MS	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MO	23,542,036	100,630,409	50,273,240	714,454,780	11,291	21,293	114,518	103,394
MT	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NE	2,489,006	33,736,397	14,440,443	240,453,962	23,046	27,428	90,253	77,716
NV	1,049,463	11,211,336	6,578,970	86,127,592	17,491	15,274	57,710	69,234
NH	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NJ	0	DNF	0	DNF	N/A	PD	N/A	PD
NM	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NY	DNF	DNF	DNF	DNF	PD	PD	PD	PD
NC*	98,909,891	294,849,456	533,740,076	355,621,197	15,508 <sup>e</sup>	42,950 <sup>e</sup>	302,745 <sup>e</sup>	62,488 <sup>e</sup>
ND	DNF	DNF	DNF	DNF	PD	PD	PD	PD
OH	76,308,874	394,100,945	31,896,991	1,132,951,672	14,038	24,270	53,699	66,991
OK	5,091,702 <sup>d</sup>	33,534,120 <sup>d</sup>	13,910,226 <sup>d</sup>	258,189,876 <sup>d</sup>	11,678 <sup>d</sup>	22,984 <sup>d</sup>	45,757 <sup>d</sup>	75,538 <sup>d</sup>
OR	10,631,598	40,082,880	2,814,623	36,624,319	1,781	4,850	2,594	6,229
PA	38,000,323	544,348,097	57,580,874	2,065,987,092	11,371	37,271	112,463	125,577
RI	486,557	31,480,364	1,513,207	176,501,800	14,744	20,903	56,045	63,308
SC	72,541,362	142,276,423	2,414,022	112,553,777	30,175	30,175	30,175	30,175
SD	DNF	DNF	DNF	DNF	PD	PD	PD	PD
TN	3,000,547	79,462,484	18,102,806	581,509,317	28,851	30,410	101,701	110,933
TX	131,093,541 <sup>d</sup>	265,199,313 <sup>d</sup>	99,003,842 <sup>d</sup>	1,002,000,635 <sup>d</sup>	29,526 <sup>d</sup>	33,732 <sup>d</sup>	37,192 <sup>d</sup>	41,679 <sup>d</sup>
UT	8,598,838	23,735,667	28,687,946	183,194,977	16,286	21,345	46,122	67,900
VT	5,560,249	41,883,574	9,320,688	141,277,007	48,774	45,774	83,970	73,201
VA	43,570,110	169,087,630	13,881,590	594,903,751	29,680	40,539	60,355	89,567
WA	DNF	DNF	DNF	DNF	PD	PD	PD	PD
WV	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
WI	44,610,592	DNF	5,415,692	DNF	9,711	PD	60,850	PD
WY	DNF	DNF	DNF	DNF	PD	PD	PD	PD
Reported total	1,650,864,898	4,267,916,799	1,314,682,322	17,445,784,657				
Estimated US Total	2,119,874,654	6,825,078,041	1,597,605,190	28,165,190,874	11,363	25,027	50,411	76,216

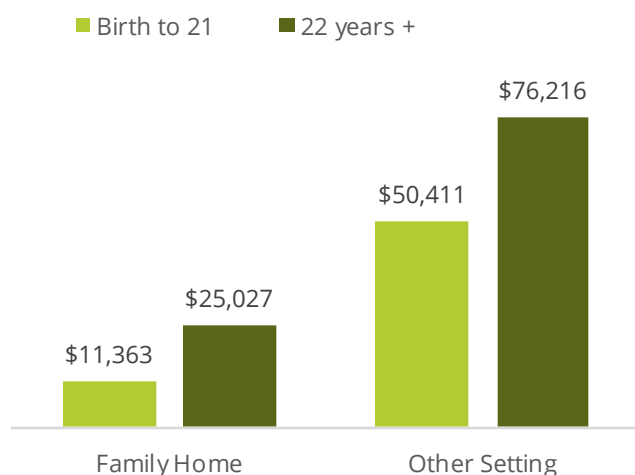
DNF Did not furnish. N/A Not applicable. PD Partial data. \* Missing values (DNF) assumed to be zero. <sup>d</sup> Other date (data from previous or next year). <sup>e</sup> Estimate. <sup>f</sup> Total is larger than component parts due to unknown settings or sizes. <sup>†</sup> One or more component value imputed by RISP staff. \* See state notes in Appendix. Average Spending per person is calculated with full reported data only. Medicaid Waiver authorities include 1115, 1915 (a), 1915 (a/c), 1915 (b), 1915 (b/c) and 1915 (c).

## Waiver Expenditures by Age and Residence Type

Between 27 and 30 states reported annual Medicaid Waiver expenditures by age and living arrangement for FY 2017 (See **Table 2.7**). While not necessarily representative of expenditures by age and living arrangement nationally, these figures illustrate important differences in per person Medicaid Waiver expenditures for people of different ages living in different residential settings. U.S. estimated totals have been adjusted to maintain the national proportion of recipients by age as reported on **Table 2.3**.

Estimated average annual per person Medicaid Waiver expenditures were lower for children and youth than for adults in both family home settings (\$11,363 versus \$25,027) and other residential settings (\$50,411 versus \$76,216; **See Figure 2.8**). Medicaid Waiver expenditures are higher for adults than for children in part because children with disabilities are entitled free and appropriate educational services authorized under the Individuals with Disabilities Education Act while there are no comparable entitlement programs for adults. For 2017, the US Department of Education projected that special education services for 6.7 million children and youth with disabilities ages 3 to 21 years would cost an average of \$11,137 per student (US Department of Education, 2016).

**Figure 2.8** Estimated Average Annual Per Person Medicaid Waiver Expenditures by Age and Living Arrangement in FY 2017



Estimated average annual per person Medicaid Waiver expenditures were lower for recipients living with a family member than for recipients living in other settings for both children (\$50,411 versus \$11,363) and adults (\$76,216 versus \$25,027). These differences are due, at least in part, to unreimbursed hours of support provided by family caregivers to family members with IDD living with them that would be financed with public dollars if those individuals lived in other settings.

### Waiver Recipients Living with a Family Member

In FY 2017, annual Medicaid Waiver expenditures for children and youth with IDD living with a family member averaged \$11,363 per person in 31 reporting states. Per person expenditures ranged from \$1,781 in Oregon to \$56,102 in Connecticut.

Average annual Medicaid Waiver expenditures for adults with IDD living in the home of a family member were \$25,027 (more than double the average for children) in 28 reporting states. Average annual per person expenditures for adults living with a family member ranged from \$612 in Massachusetts to \$50,219 in the District of Columbia.

### Waiver Recipients Living Settings Other than the Home of a Family Member

Annual per person Medicaid Waiver expenditures for children and youth 21 years or younger living in settings other than the home of a family member averaged \$50,411 and ranged from \$2,594 in Oregon (see state note) to \$302,745 in North Carolina. Other states with per person expenditures less than half the national average included Arizona (\$22,064) and Colorado (\$30,175). In addition to North Carolina, other states with per person expenditures of more than twice the national average were Tennessee (\$101,701), Pennsylvania (\$112,463), Missouri (\$114,518), Minnesota (\$121,524) and Alabama (\$141,547).

Annual per person Medicaid Waiver expenditures for adults 22 years or older living in settings other than the home of a family member averaged \$76,216 and ranged from \$6,229 in Oregon to \$207,771 in Arizona. In addition to Oregon, South Carolina (\$30,175) reported average annual expenditures of less than half the national average. In addition to Arizona, the District of Columbia (\$163,550) and

Massachusetts (\$183,181) reported average annual expenditures of more than double the national average.

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

While most LTSS recipients with IDD receive Medicaid Waiver-funded supports, an estimated 73,855 recipients with IDD lived in a Medicaid Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) on June 30, 2017. Medicaid ICF/IID facilities of all sizes are considered institutions under the 2014 Medicaid Waiver rule. However, unlike Medicaid Waiver services, access to ICF/IID services is an entitlement for people with IDD who meet level of care eligibility criteria in the 49 states (all states except Michigan and Oregon) that opt to include ICF/IID services in their Medicaid State Plan. Alaska reported funding ICF/IID services for seven individuals in 2017 but those services were provided in another state.

### ICF/IID Facilities by Size and Type of Operation

There were an estimated 6,084 ICF/IIDs on June 30, 2017 (See **Table 2.8**). Alaska and Oregon reported no ICF/IID facilities. Fifteen states reported having only one or two ICF/IID facilities. States with the most ICF/IID facilities were California (1,193), Texas (801), and Louisiana (541).

Of the 6,084 ICF/IID facilities, 289 (5%) were state-operated, and 5,795 (95%) were operated by a non-state entity. There were no ICF/IID facilities in Alaska, Georgia, Maryland, Massachusetts, Montana, Oregon, or Wyoming operated by non-state entities. All ICF/IID facilities in Alabama, Arizona, California, the District of Columbia, Hawaii, Indiana, Louisiana, Maine, New Hampshire, Oklahoma, Vermont and West Virginia were operated by a non-state entity. There were no state-operated ICF/IID in Alabama, Alaska, Arizona, the District of Columbia, Hawaii, Indiana, Maine, Michigan, New Hampshire, Oklahoma, Oregon, Vermont, or West Virginia. All ICF/IID facilities were state-operated in Georgia, Maryland, Massachusetts, Montana, and Wyoming.

Of the 6,084 ICF/IID facilities, 3,712 (61%) served six or fewer LTSS recipients with IDD, 1,871 (31%) served 7 to 15 recipients, and 451 (7%) served 16 or more recipients. There were no non-state operated ICF/IID facilities serving 16 or more recipients in Alabama, the District of Columbia, Hawaii, Indiana, Montana, Vermont, or West Virginia. In 17 states, fewer than 10% of ICF/IID facilities served 15 or fewer LTSS recipients with IDD. All ICF/IID facilities in Arizona, Delaware, Georgia, Maryland, New Hampshire, New Jersey, South Dakota and Wyoming served 16 or more people.

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

On June 30, 2017, an estimated 73,855 people lived in an ICF/IID (See **Table 2.9**). Fewer than 100 people lived in an ICF/IID in Alaska (0 people), Oregon (0), Vermont (6), Montana (12), Alabama (22), New Hampshire (23), Rhode Island (34), Arizona (42), Wyoming (62), Hawaii (79), Nevada (91), and Maryland (92). By contrast, more than 2,000 people lived in an ICF/IID in Mississippi (2,169 people), Florida (2,770), Pennsylvania (2,827), Indiana (3,179), North Carolina (4,406), Louisiana (4,639), New York (4,895), Ohio (5,814), Illinois (6,593), California (7,649), and Texas (7,939).

Of the 73,855 people in ICF/IID, 18,987 (26%) lived in state-operated facilities and 54,868 (74%) lived in non-state facilities. There were no people in state-operated ICF/IID in Alabama, Arizona, the District of Columbia, Hawaii, Indiana, Maine, New Hampshire, Oklahoma, Vermont and West Virginia. All of the people in ICF/IID were in state-operated settings in Maryland, Massachusetts, Montana and Wyoming as were 96% of ICF/IID residents in New Jersey. Other states in which more than 50% of ICF/IID residents lived in a state-operated facility included Washington (94%), Colorado (84%), Missouri (81%), Kansas (70%), Mississippi (69%), South Dakota (69%), Mississippi (69%), Arkansas (64%), Kentucky (64%), Virginia (63%), South Carolina (57%), Nevada (53%), and Connecticut (51%).

On June 30, 2017, an estimated 32% of all ICF/IID residents (23,999 people) lived settings of six or fewer people, 23% (16,629 people) lived in settings of 7 to 15 people, and 45% (33,227 people) lived in settings of 16 or more people. All of the people living

**Table 2.8** Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) by Size, Type of Operation and State on June 30, 2017

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	50	51	51	51	49	48	49	50	48	48	49	50
AL	0	0	0	0 <sup>s</sup>	0	2	0	2 <sup>s</sup>	0	2	0	2
AK	0	0	0	0 <sup>s</sup>	0	0 <sup>d</sup>	0 <sup>d</sup>	0 <sup>s</sup>	0	0	0	0
AZ	0	0	0	0	0	0	1	1	0	0	1	1
AR	0	0	5	5 <sup>s</sup>	0	33	4	37	0	33	9	42
CA	0	0	4	4	1,179	0	10	1,189	1,179	0	14	1,193
CO	2	12	1	15	5	0	0	5 <sup>s</sup>	7	12	1	20
CT	1	0	4	5	57	4	0	68 <sup>s</sup>	58	4	4	73
DE	0	0	1	1 <sup>s</sup>	0	0	1	1 <sup>s</sup>	0	0	2	2
DC	0	0	0	0 <sup>s</sup>	61	0	0	67 <sup>s</sup>	61	0	0	67
FL	0	0	2	2	39 <sup>d</sup>	3 <sup>d</sup>	48 <sup>d</sup>	90	39	3	50	92
GA	0	0	2	2	0 <sup>d</sup>	0 <sup>d</sup>	0 <sup>d</sup>	0 <sup>d</sup>	0	0	2	2
HI	0	0	0	0	16	1	0	17	16	1	0	17
ID	1	0	1	2	22	41	0	63 <sup>s</sup>	23	41	1	65
IL	0	0	7	7	38	155	30	223	38	155	37	230
IN	0	0	0	0	160	318	2	480	160	318	2	480
IA	0	0	2	2	70	45	22	137	70	45	24	139
KS	0	0	2	2 <sup>s</sup>	17	7	0	24 <sup>s</sup>	17	7	2	26
KY	0	3	4	7	0	0	2	2	0	3	6	9
LA	0	0	2	2	326	203	7	539	326	203	9	541
ME	0	0	0	0	3	12	1	16	3	12	1	16
MD	0	0	2	2 <sup>s</sup>	0	0	0	0 <sup>s</sup>	0	0	2	2
MA	0	0	2	2 <sup>s</sup>	0	0	0	0 <sup>s</sup>	0	0	2	2
MI	0 <sup>s</sup>	0 <sup>s</sup>	0 <sup>s</sup>	0 <sup>s</sup>	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MN	3 <sup>d</sup>	0	0	3 <sup>d</sup>	120 <sup>d</sup>	36 <sup>d</sup>	10 <sup>d</sup>	166 <sup>d</sup>	123	36	10	169
MS	1	62	6	69	0 <sup>d</sup>	0 <sup>d</sup>	8 <sup>d</sup>	8 <sup>d</sup>	1	62	14	77
MO	0	0	6	6 <sup>s</sup>	0	6	1	7 <sup>s</sup>	0	6	7	13
MT	0	1	0	1 <sup>s</sup>	0	0	0	0 <sup>s</sup>	0	1	0	1
NE	0	0	1	1	6	1	2	9 <sup>s</sup>	6	1	3	10
NV	0	0	1	1 <sup>s</sup>	5	0	1	6 <sup>s</sup>	5	0	2	7
NH	0 <sup>s</sup>	0 <sup>s</sup>	0 <sup>s</sup>	0 <sup>s</sup>	DNF	DNF	1	1 <sup>s</sup>	DNF	DNF	1	1
NJ	0	0	5	5 <sup>s</sup>	0	0	2	2	0	0	7	7
NM	DNF	0	0	1 <sup>s</sup>	22 <sup>d</sup>	11 <sup>d</sup>	2 <sup>d</sup>	39 <sup>d</sup>	DNF	11	2	40
NY	5	10 <sup>d</sup>	6 <sup>d</sup>	21	62 <sup>d</sup>	319 <sup>d</sup>	28 <sup>d</sup>	417	67	329	34	438
NC	0	0	4	4	255	26	13	294	255	26	17	298
ND	0	0	1	1	43	26	1	70	43	26	2	71
OH	0	0	8	8	142	229	64	435	142	229	72	443
OK	0	0	0	0	19 <sup>d</sup>	35 <sup>d</sup>	30 <sup>d</sup>	84	19	35	30	84
OR	0	0	0	0 <sup>s</sup>	0	0	0	0 <sup>s</sup>	0	0	0	0
PA	0	0	5	5	124	30	19	173	124	30	24	178
RI	2	0	0	2 <sup>s</sup>	0	0	1	1 <sup>s</sup>	2	0	1	3
SC	0	0	5	5	0	61	0	61	0	61	5	66
SD	0 <sup>d</sup>	0 <sup>d</sup>	1 <sup>d</sup>	1 <sup>s</sup>	0 <sup>d</sup>	0 <sup>d</sup>	1 <sup>d</sup>	1 <sup>s</sup>	0	0	2	2
TN	37	1	0	38 <sup>s</sup>	76	51	1	132 <sup>s</sup>	113	52	1	170
TX	2 <sup>d</sup>	0 <sup>d</sup>	13 <sup>d</sup>	15	740 <sup>d</sup>	41 <sup>d</sup>	3 <sup>d</sup>	786	742	41	16	801
UT	0	0	1	1 <sup>s</sup>	0 <sup>d</sup>	DNF	DNF	17 <sup>s</sup>	0	DNF	DNF	18
VT	0	0	0	0 <sup>s</sup>	1	0	0	1 <sup>s</sup>	1	0	0	1
VA	17	13	3 <sup>d</sup>	33	14	14	2	30	31	27	5	63
WA	0	0	4	4	6	1	0	7 <sup>s</sup>	6	1	4	11
WV	0	0	0	0 <sup>s</sup>	16 <sup>d</sup>	52 <sup>d</sup>	0 <sup>d</sup>	68 <sup>s</sup>	16	52	0	68
WI	0	0	3	3	0	1	17	18	0	1	20	21
WY	0	0	1	1 <sup>s</sup>	0	0	0	0 <sup>s</sup>	0	0	1	1
Reported US Total	71	102	115	289	3,640	1,764	335	5,794	3,711	1,866	450	6,083
Estimated US Total	72	102	115	289	3,640	1,769	336	5,795	3,712	1,871	451	6,084

DNF Did not furnish. <sup>d</sup> Other date (data from previous or next year). <sup>e</sup> Estimate. <sup>s</sup> Other Source (AHCAa CASPER data, 2018). Totals for 16+ state operated may differ from what is reported on Table 4.11 because this table reports only ICF/IID facilities.



**Table 2.9** People Living in an ICF/IID by Type of Operation, Setting Size and State on June 30, 2017

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	47	46	48	49	47	46	48	49
AL	0	0	0	0 <sup>s</sup>	0	22	0	22	0	22	0	22
AK	0	0	0	0 <sup>s</sup>	0	0	0	0 <sup>s</sup>	0	0	0	0
AZ	0	0	0	0	0	0	42	42	0	0	42	42
AR	0	0	907	907	0	317	201	518	0	317	1,108	1,425
CA	0	0	793	793	6,161	0	695	6,856	6,161	0	1,488	7,649
CO	11	92	21	124	24	0	0	24	35	92	21	148
CT	3	0	375	378	327	37	0	364	330	37	375	742
DE	0	0	48	48 <sup>s</sup>	0	0	70	70	0	0	118	118
DC	0	0	0	0 <sup>s</sup>	319	0	0	319	319	0	0	319
FL	0	0	590	590	215	65 <sup>d</sup>	1,900 <sup>d</sup>	2,180	215	65	2,490	2,770
GA	0	0	143	143	0 <sup>d</sup>	0 <sup>d</sup>	DNF	DNF	0	0	PD	PD
HI	0	0	0	0	72	7	0	79	72	7	0	79
ID	1	0	24	25 <sup>s</sup>	DNF	DNF	0	430 <sup>s</sup>	PD	PD	24	455
IL	0	0	1,660	1,660	177	2,128	2,628	4,933	177	2,128	4,288	6,593
IN	0	0	0	0	798	2,331	50	3,179	798	2,331	50	3,179
IA	0	0	351	351	312	390	712	1,414	312	390	1,063	1,765
KS	0	0	302	302	74	57	0	131	74	57	302	433
KY	0	23	245	268	0	0	154	154	0	23	399	422
LA	0	0	510	510	1,882	1,666	581	4,129	1,882	1,666	1,091	4,639
ME	0	0	0	0	14	129	16	159	14	129	16	159
MD	0	0	92	92	0	0	0	0 <sup>s</sup>	0	0	92	92
MA	0	0	396	396	0	0	0	0 <sup>s</sup>	0	0	396	396
MI	0 <sup>s</sup>	0 <sup>s</sup>	0 <sup>s</sup>	0 <sup>s</sup>	DNF	DNF	DNF	DNF	PD	PD	PD	PD
MN	13 <sup>d</sup>	0	0	13 <sup>d</sup>	597 <sup>d</sup>	323 <sup>d</sup>	250 <sup>d</sup>	1,170 <sup>d</sup>	610	323	250	1,183
MS	5	543	938	1,486	DNF	DNF	683 <sup>e</sup>	683 <sup>s</sup>	PD	PD	1,621	2,169
MO	0	0	341	341	0	48	32	80	0	48	373	421
MT	0	12	0	12	0	0	0	0 <sup>s</sup>	0	12	0	12
NE	0	0	109	109	33	7	199	239	33	7	308	348
NV	0	0	48	48	25	0	18	43	25	0	66	91
NH	0 <sup>s</sup>	0 <sup>s</sup>	0 <sup>s</sup>	0 <sup>s</sup>	DNF	DNF	23 <sup>d</sup>	23 <sup>s</sup>	PD	PD	23	23
NJ	0	0	1,402	1,402	0	0	61	61	0	0	1,463	1,463
NM	3 <sup>d</sup>	0	0	3 <sup>d</sup>	109 <sup>d</sup>	108 <sup>d</sup>	32 <sup>d</sup>	249 <sup>d</sup>	112	108	32	252
NY	27	123 <sup>d</sup>	289 <sup>d</sup>	439	365	3,185 <sup>d</sup>	906 <sup>d</sup>	4,456	392	3,308	1,195	4,895
NC	0	0	1,142	1,142	634	101 <sup>e</sup>	335 <sup>e</sup>	3,264	634	101	1,477	4,406
ND	0	0	69	69	236	204	30	470	236	204	99	539
OH	0	0	675	675	730	1,947	2,462	5,139	730	1,947	3,137	5,814
OK	0	0	0	0 <sup>d</sup>	108 <sup>d</sup>	317 <sup>d</sup>	882 <sup>d</sup>	1,307 <sup>d</sup>	108	317	882	1,307
OR	0	0	0	0 <sup>s</sup>	0	0	0	0 <sup>s</sup>	0	0	0	0
PA	0	0	858	858	611	230	1,128	1,969	611	230	1,986	2,827
RI	8	0	0	8	0	0	26	26	8	0	26	34
SC	0	0	657	657	0	501	0	501	0	501	657	1,158
SD	0 <sup>d</sup>	0 <sup>d</sup>	132 <sup>d</sup>	132 <sup>d</sup>	0 <sup>d</sup>	0 <sup>d</sup>	60 <sup>d</sup>	60 <sup>d</sup>	0	0	192	192
TN	146	14	0	160	340	424	73	837	486	438	73	997
TX	10 <sup>d</sup>	0 <sup>d</sup>	3,019 <sup>d</sup>	3,029	4,195	473 <sup>d</sup>	230 <sup>d</sup>	4,910	4,205	473	3,249	7,939
UT	0	0	190	190	0 <sup>d</sup>	DNF	DNF	583 <sup>s</sup>	0	PD	PD	773
VT	0	0	0	0 <sup>s</sup>	6	0	0	6	6	0	0	6
VA	77	132 <sup>e</sup>	340 <sup>e</sup>	549	73	129	116	318	150	261	456	867
WA	0	0	695	695	30	13	0	43	30	13	695	738
WV	0	0	0	0 <sup>s</sup>	514	0	0	514	514	0	0	514
WI	0	0	321	321	0	8	593	601	0	8	914	922
WY	0	0	62	62	0	0	0	0 <sup>s</sup>	0	0	62	62
Reported US Total	304	939	17,744	18,987	18,981	15,167	15,188	52,555	19,279	15,563	32,599	71,399
Estimated US Total	304	939	17,744	18,987	23,695	15,690	15,483	54,868	23,999	16,629	33,227	73,855

DNF Did not furnish. <sup>d</sup> Other date (data from previous or next year). <sup>e</sup> Estimate. <sup>s</sup> Source (ACHA CASPER data, 2018) \* See state notes in Appendix. For 2017 a size unknown option was added to the data collection. The size unknown values are not displayed separately but are reflected in the totals.

in an ICF/IID in Vermont, the District of Columbia, and West Virginia lived in a facility serving six or fewer recipients, as did 91% of people in Hawaii, and 81% of people in California. Just over half of the people living in an ICF/IID lived in a setting of six or fewer people in Texas (53%) and Minnesota (52%).

The majority ICF/IID residents in 27 states, and all ICF/IID residents in Arizona, Delaware, Maryland, Massachusetts, New Hampshire, New Jersey, South Dakota, and Wyoming lived in a facility serving 16 or more people. Other states in which 90% or more of all ICF/IID recipients lived in a setting serving 16 or more people included Wisconsin (99%), Kentucky (95%), Washington (94%), and Florida (90%). No people lived in an ICF/IID of 16 or more people in Alabama, Alaska, the District of Columbia, Hawaii, Montana, Oregon, Vermont, and West Virginia. Fewer than 10% ICF/IID residents lived in a facility of 16 or more people in Indiana (2%), Idaho (5%) and Tennessee (7%).

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

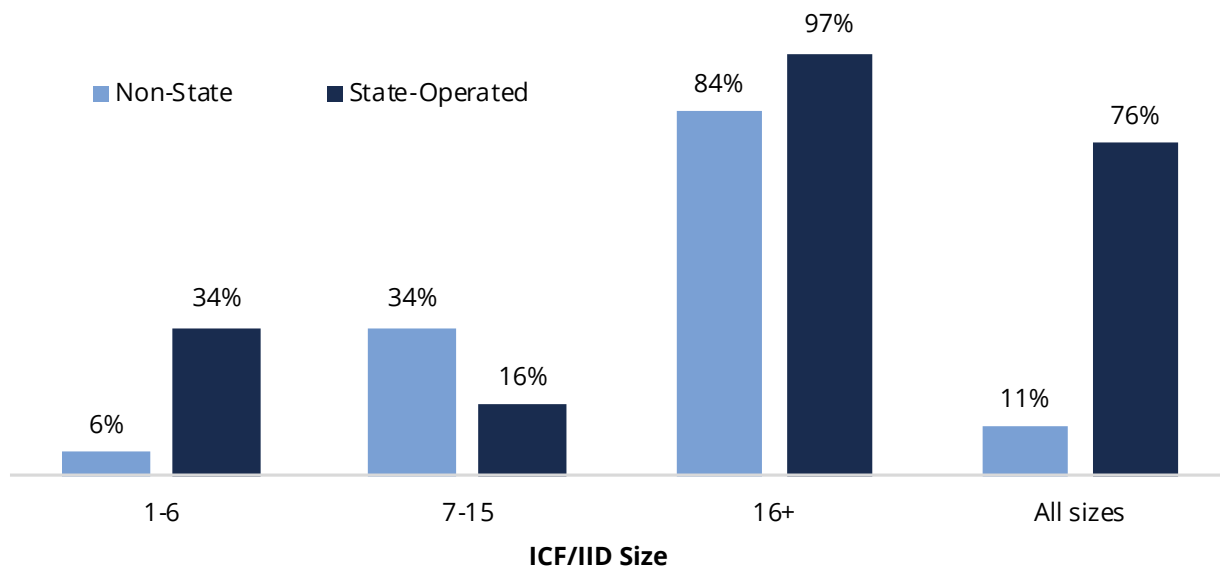
Overall, 11% of people living in non-state group settings, and 76% of people living in state-operated group settings lived in an ICF/IID (See **Figure 2.8**). Of

the people with IDD living in facilities of 16 or more people, 97% of those in state-operated settings and 84% of those in non-state settings lived in an ICF/IID. Among people living in facilities serving 7 to 15 people with IDD, 16% of those in state-operated settings, and 34% of those in non-state settings lived in an ICF/IID. Finally, among people living in group settings serving six or fewer people with IDD, 34% of those in a state-operated setting, and 6% of those in a non-state setting lived in an ICF/IID.

### ICF/IID Recipients by Age

Of the 73,855 people living in an ICF/IID on June 30, 2017, an estimated 4,919 (7%) were 21 years or younger and 68,936 (93%) were 22 years or older (See **Table 2.10**). There were no people 21 years or younger in ICF/IID facilities in Alabama, Delaware, Hawaii, Massachusetts, Missouri, Montana, New Jersey, or Wyoming. Fewer than 3% of ICF/IID recipients were 21 years or younger in California, Connecticut, the District of Columbia, Kentucky, Maine, South Carolina, Tennessee, Utah, Washington or Wisconsin. By contrast, 43% of ICF/IID residents in South Dakota, and 96% in New Hampshire were 21 years or younger.

**Figure 2.9** 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, 2017



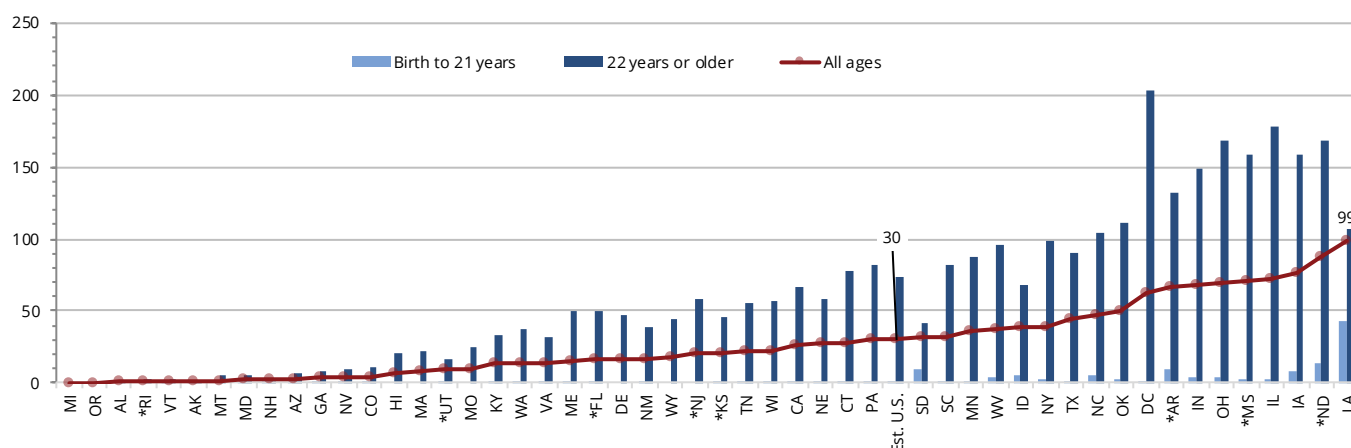
This figure includes people in group homes, ICF/IIDs, host and foster family homes, own home, and IDD "other" settings. It excludes people living with a family member, in a nursing home or psychiatric setting.

**Table 2.10** People Living in an ICF/IID Per 100,000 of the Population by Age and State on June 30, 2017

Age	Population in 100,000s <sup>s</sup>			ICF/IID Residents			ICF/IID Residents per 100k		
	Birth to 21 years	22+ years	All Ages	Birth to 21 years	22+ years	All Ages <sup>1</sup>	Birth to 21 years	22+ years	All Ages
N States	51	51	51	47	47	51	47	47	51
AL	14	35	49	0	22	22	0	1	0
AK*	2	5	7	3 <sup>d</sup>	4 <sup>d</sup>	7 <sup>d</sup>	1	1	1
AZ	20	50	70	6	133	139	0	3	2
AR	9	21	30	DNF	DNF	1,425	DNF	DNF	47
CA	112	284	395	117	7,485	7,649 <sup>g</sup>	1	26	19
CO	16	41	56	27	162	189	2	4	3
CT	10	26	36	1	740	742 <sup>g</sup>	0	28	21
DE	3	7	10	0	118	118	0	17	12
DC	2	5	7	1 <sup>s</sup>	331	332	1	62	48
FL	51	158	210	121	2,579	2,770 <sup>g</sup>	2	16	13
GA	31	73	104	22 <sup>s</sup>	253 <sup>s</sup>	275 <sup>s</sup>	1	3	3
HI	4	11	14	0	79	79	0	7	6
ID	5	12	17	90 <sup>s</sup>	365 <sup>s</sup>	455 <sup>s</sup>	17	31	27
IL	36	92	128	273	6,380	6,653	8	69	52
IN	20	47	67	266	2,913	3,179	14	62	48
IA	9	22	31	254	1,454	1,765 <sup>g</sup>	28	65	56
KS	9	20	29	DNF	DNF	433	DNF	DNF	15
KY	12	32	45	12 <sup>s</sup>	410	422	1	13	9
LA	13	33	47	578	4,061	4,639	43	122	99
ME	3	10	13	2	157	159	1	15	12
MD	17	44	61	3 <sup>s</sup>	89	92	0	2	2
MA	18	51	69	0 <sup>s</sup>	396	396	0	8	6
MI	27	72	100	0 <sup>s</sup>	0 <sup>s</sup>	0 <sup>s</sup>	0	0	0
MN	16	40	56	54 <sup>d</sup>	1,387 <sup>d</sup>	1,441 <sup>d</sup>	3	35	26
MS	9	21	30	80 <sup>c</sup>	1,406 <sup>c</sup>	2,169 <sup>g</sup>	9	67	73
MO	17	44	61	0 <sup>s</sup>	424	424	0	10	7
MT	3	8	11	0	14	14	0	2	1
NE	6	13	19	34	340	374	6	25	19
NV	8	22	30	15 <sup>s</sup>	76	91	2	3	3
NH	3	10	13	22 <sup>s</sup>	1 <sup>s</sup>	23 <sup>s</sup>	7	0	2
NJ	24	66	90	0 <sup>s</sup>	1,402 <sup>c</sup>	1,463 <sup>g</sup>	0	21	16
NM	6	15	21	18 <sup>s</sup>	236 <sup>s</sup>	254 <sup>s</sup>	3	16	12
NY	52	147	198	655	5,087	5,742	13	35	29
NC	29	74	103	521	2,989	4,406 <sup>g</sup>	18	40	43
ND	2	5	8	100 <sup>b</sup>	370 <sup>b</sup>	539 <sup>g</sup>	45	69	71
OH	32	84	117	406	5,408	5,814	13	64	50
OK	12	28	39	82 <sup>s</sup>	1,304 <sup>s</sup>	1,386 <sup>s</sup>	7	47	35
OR	11	31	41	0 <sup>s</sup>	0 <sup>s</sup>	0 <sup>s</sup>	0	0	0
PA	34	95	128	110	2,741	2,851	3	29	22
RI	3	8	11	0 <sup>c</sup>	8 <sup>c</sup>	34 <sup>g</sup>	0	1	3
SC	14	37	50	23	1,135	1,158	2	31	23
SD	3	6	9	83 <sup>d</sup>	109 <sup>d</sup>	192 <sup>d</sup>	32	18	22
TN	18	49	67	27	1,024	1,051	1	21	16
TX	89	194	283	515	8,075	8,590	6	42	30
UT	11	20	31	13 <sup>c</sup>	177 <sup>c</sup>	773 <sup>g</sup>	1	9	25
VT	2	5	6	1	5 <sup>s</sup>	6	1	1	1
VA	23	61	85	DNF	DNF	867	DNF	DNF	10
WA	20	54	74	2	748	750	0	14	10
WV	5	14	18	DNF	DNF	514 <sup>e</sup>	DNF	DNF	28
WI	16	42	58	1	922	923	0	22	16
WY	2	4	6	0 <sup>s</sup>	73	73	0	18	13
Reported US Total	909	2,349	3,257	4,538	63,592	73,862	5	27	23
Estimated US Total	909	2,349	3,257	4,919	68,936	73,855	5	29	23

DNF Did not furnish. <sup>b</sup> Nonstate only. <sup>c</sup> State only. <sup>d</sup> Other date (data from previous or next year). <sup>e</sup> Estimate. <sup>g</sup> Sum of setting size data substituted for reported value. <sup>s</sup> Source U.S. Census Bureau, Population Division (2017) for population data; ACHAa, 2017 CASPER data for ICF/IID residents. \* See state notes in Appendix. 1 The reported number of ICF/IID recipients by age when imputed uses ACHAa CASPER data for proportions.

**Figure 2.10** People Living in an ICF/IID per 100,000 of the Population by State and Age on June 30, 2017



ICF/IID Intermediate Care Facility for Individuals with Intellectual Disabilities; \* State reported partial data, AHCA ICF/IID data used for estimate.

An estimated 23 people with IDD of all ages per 100,000 of the U.S. population lived in an ICF/IID on June 30, 2017 (See **Figure 2.10**). ICF/IID utilization rates ranged from zero in Michigan and Oregon to 99 per 100,000 in Louisiana. Other states with utilization rates more than double the national average were Mississippi (73), North Dakota (71), Iowa (56), Illinois (52), Ohio (50), Indiana (48), the District of Columbia (48) and Arkansas (47).

An estimated 5 children and youth 21 years or younger per 100,000 of the population lived in an ICF/IID on June 30, 2017. Fewer than 10 children and youth per 100,000 of the population lived in an ICF/IID in forty states. States with ICF/IID utilization rates for children and youth of more than 10 per 100,000 included North Dakota (45), Louisiana (43), South Dakota (32), Iowa (28), North Carolina (18), Idaho (17), Indiana (14), New York (13), and Ohio (13).

An estimated 29 adults 22 years or older per 100,000 of the population lived in an ICF/IID on June 30, 2017. Fewer than 10 adults per 100,000 of the population lived in an ICF/IID in Alabama, Alaska, Arizona, Colorado, Georgia, Hawaii, Maryland, Massachusetts, Michigan, Montana, Nevada, New Hampshire, Oregon, Rhode Island, Utah and Vermont. States with ICF/IID utilization rates for adults exceeding twice the national average included Louisiana (122 per 100,000), Illinois (69), North Dakota (69), Mississippi (67), Iowa (65), the District of Columbia (62), and Indiana (62).

## ICF/IID EXPENDITURES

Total FY 2017 ICF/IID expenditures were \$9.76 billion nationally and ranged from \$1.15 million in Vermont to \$1.11 billion in Texas (See **Table 2.11**). Michigan and Oregon reported no ICF/IID expenditures for FY 2017. States reporting ICF/IID expenditures for state-operated settings only included Mississippi, New Jersey, Rhode Island, and Utah (See the c superscript). North Dakota reported ICF/IID expenditures for non-state settings only (See the b superscript).

### Per Person ICF/IID Expenditures

Estimated FY 2017 per person ICF/IID expenditures averaged \$140,057 and ranged from \$56,159 in Hawaii to \$411,355 in Montana. Only Hawaii had expenditures less than half the national average. In addition to Montana, seven states reported per person ICF/IID expenditures of more than double the national average including Maryland (\$280,215), Virginia (\$280,912), New Jersey (\$328,958), Rhode Island (\$338,446), Kentucky (\$348,892), and Alaska (\$390,883). Three of the states with very high per person expenditures had fewer than 15 people living in an ICF/IID including Rhode Island (8 people), Alaska (7 people), and Montana (14 people).

### Expenditures per State Resident

Annual ICF/IID expenditures averaged \$30 per state resident nationally and ranged from less than \$1

**Table 2.11** ICF/IID Expenditures, Recipients, Expenditure Per Person, and Expenditures Per State Resident by State in Fiscal Year 2017

State	ICF/IID Expenditures	ICF/IID Recipients	Expenditures per ICF/IID Recipient	State Population (100,000)	Expenditures per State Resident (\$)
N States	43	51	43	51	43
AL	1,990,000 <sup>e</sup>	22	90,455 <sup>e</sup>	48.7	0.4 <sup>*</sup>
AK <sup>*</sup>	2,736,179 <sup>d</sup>	7 <sup>d</sup>	390,883 <sup>d</sup>	7.4	3.7 <sup>d</sup>
AZ	DNF	139	DNF	70.2	DNF
AR	DNF	1,425	DNF	30.0	DNF
CA	696,318,455	7,602	91,597	395.4	17.6
CO	43,852,672	189	232,025	56.1	7.8
CT	194,535,040	741	262,530	35.9	54.2
DE	32,392,106	118	274,509	9.6	33.7
DC	92,289,465	332	277,980	6.9	133.0
FL	331,590,954 <sup>d</sup>	2,700 <sup>d</sup>	122,811 <sup>d</sup>	209.8	15.8 <sup>d</sup>
GA	DNF	275 <sup>s</sup>	DNF	104.3	DNF
HI	4,436,551	79	56,159	14.3	3.1
ID	DNF	455 <sup>s</sup>	DNF	17.2	DNF
IL	586,801,868	6,653	88,201	128.0	45.8
IN	269,363,408	3,179	84,732	66.7	40.4
IA	206,346,760	1,708	120,812	31.5	65.6
KS	40,555,846	433	93,662	29.1	13.9
KY	147,232,438	422	348,892	44.5	33.1
LA	352,395,681	4,639	75,964	46.8	75.2
ME	31,130,732	159	195,791	13.4	23.3
MD	25,779,812	92	280,215	60.5	4.3
MA	97,513,672	396	246,247	68.6	14.2
MI	0 <sup>i</sup>	0 <sup>s</sup>	0 <sup>i</sup>	99.6	0.0 <sup>i</sup>
MN	114,405,788 <sup>d</sup>	1,441 <sup>d</sup>	79,393 <sup>d</sup>	55.8	20.5 <sup>d</sup>
MS	196,140,609 <sup>c</sup>	1,486 <sup>c</sup>	131,992 <sup>c</sup>	29.8	65.7 <sup>c</sup>
MO	89,799,361	424	211,791	61.1	14.7
MT	5,758,970	14	411,355	10.5	5.5
NE	62,084,449	374	166,001	19.2	32.3
NV	18,627,060	91	204,693	30.0	6.2
NH	DNF	23 <sup>s</sup>	DNF	13.4	DNF
NJ	461,198,628 <sup>c</sup>	1,402 <sup>c</sup>	328,958 <sup>c</sup>	90.1	51.2 <sup>c</sup>
NM	DNF	254 <sup>s</sup>	DNF	20.9	DNF
NY	1,060,094,472	5,742	184,621	198.5	53.4
NC	398,947,721	3,510	113,660	102.7	38.8
ND	71,114,213 <sup>b</sup>	470 <sup>b</sup>	151,307 <sup>b</sup>	7.6	94.1 <sup>b</sup>
OH	716,347,503	5,814	123,211	116.6	61.4
OK	DNF	1,386 <sup>s</sup>	DNF	39.3	DNF
OR	0	0 <sup>s</sup>	0	41.4	0.0
PA	603,229,690	2,851	211,585	128.1	47.1
RI	2,707,569 <sup>c</sup>	8 <sup>c</sup>	338,446 <sup>c</sup>	10.6	2.6 <sup>c</sup>
SC	140,017,628	1,158	120,913	50.2	27.9
SD	31,198,086 <sup>d</sup>	192 <sup>d</sup>	162,490 <sup>d</sup>	8.7	35.9 <sup>d</sup>
TN	203,299,532	1,051	193,434	67.2	30.3
TX	1,113,101,471	8,590	129,581	283.0	39.3
UT	40,105,797 <sup>c</sup>	190 <sup>c</sup>	211,083 <sup>c</sup>	31.0	12.9 <sup>c</sup>
VT	1,150,508	6	191,751	6.2	1.8
VA	243,550,368	867	280,912	84.7	28.8
WA	192,149,670	750	256,200	74.1	25.9
WV	DNF	514 <sup>e</sup>	DNF	18.2	DNF
WI	132,953,712	923	144,045	58.0	22.9
WY	18,713,002	73	256,342	5.8	32.3
<b>Reported US Total</b>	<b>9,073,957,447</b>	<b>71,369</b>			
<b>Estimated US Total</b>	<b>9,751,782,147</b>	<b>73,855</b>	<b>140,057</b>	<b>3,257.2</b>	<b>29.9</b>

<sup>a</sup> Nonstate only. <sup>c</sup> State only. Expenditures and recipients are for state or nonstate settings only. <sup>d</sup> Other date (data from previous or next year). <sup>e</sup> Estimate. <sup>i</sup> One or more component value imputed by RISP staff. DNF Did not furnish. <sup>s</sup> Source: U.S. Census Bureau, Population Division (2018); ACHA (2018a). <sup>\*</sup> See state notes in Appendix.



**Table 2.12** Annual ICF/IID Expenditures Per Person by Age and State in Fiscal Year 2017

	Annual Expenditures \$		Expenditures Per Person \$	
	Birth to 21 years	22 years +	Birth to 21 years	22 years +
N States	37	37	25	35
AL	0	1,990,000 <sup>a</sup>	0	90,455 <sup>e</sup>
AK	1,143,086 <sup>d</sup>	1,593,093 <sup>d</sup>	381,029 <sup>d</sup>	398,273 <sup>d</sup>
AZ	DNF	DNF	DNF	DNF
AR	DNF	DNF	DNF	DNF
CA	6,040,904	690,277,551	51,632	92,221
CO	5,627,006	38,225,666	208,408	235,961
CT	262,845	194,272,195	262,845	262,530
DE	0	32,392,106	0	274,509
DC	338,350	91,951,115	338,350	277,798
FL	13,527,778 <sup>d</sup>	318,063,176 <sup>d</sup>	111,800 <sup>d</sup>	123,328 <sup>d</sup>
GA	DNF	DNF	DNF	DNF
HI	0	4,436,551	0	56,159
ID	DNF	DNF	DNF	DNF
IL	17,473,987	569,327,881	64,007	89,236
IN	24,994,574	244,368,834	93,965	83,889
IA	24,449,925	181,896,835	96,260	125,101
KS	DNF	DNF	DNF	DNF
KY	DNF	DNF	DNF	DNF
LA	41,271,664	311,124,017	71,404	76,613
ME	393,938	30,736,794	196,969	195,776
MD	DNF	DNF	DNF	DNF
MA	0	97,513,672	0	246,247
MI	DNF	DNF	0	0
MN	4,719,082 <sup>d</sup>	109,686,706 <sup>d</sup>	87,390 <sup>d</sup>	79,082 <sup>d</sup>
MS	11,155,283 <sup>c</sup>	184,985,326 <sup>c</sup>	139,441 <sup>c</sup>	131,569 <sup>c</sup>
MO	0	89,799,361	0	211,791
MT	0	5,758,970	0	411,355
NE	3,820,002	58,264,447	112,353	171,366
NV	2,949,126	15,677,934	196,608	206,289
NH	DNF	DNF	DNF	DNF
NJ	0	461,198,628 <sup>c</sup>	0	328,958 <sup>c</sup>
NM	DNF	DNF	DNF	DNF
NY	109,301,896 <sup>d</sup>	950,792,577 <sup>d</sup>	166,873 <sup>d</sup>	186,906 <sup>d</sup>
NC	36,103,746	362,843,975	69,297	121,393
ND	DNF <sup>b</sup>	DNF <sup>b</sup>	DNF <sup>b</sup>	DNF <sup>b</sup>
OH	50,115,838	666,231,665	123,438	123,194
OK	DNF	DNF	DNF	DNF
OR	0	0	0	0
PA	19,715,466	583,514,224	179,232	212,884
RI	0 <sup>c</sup>	2,707,569 <sup>c</sup>	0 <sup>c</sup>	338,446 <sup>c</sup>
SC	2,781,006	137,236,622	120,913	120,913
SD	11,267,784 <sup>d</sup>	19,930,302 <sup>d</sup>	135,756 <sup>d</sup>	182,847 <sup>d</sup>
TN	4,072,513	199,227,019	150,834	194,558
TX	58,513,351 <sup>d</sup>	1,054,588,120 <sup>d</sup>	113,618 <sup>d</sup>	130,599 <sup>d</sup>
UT	2,744,080 <sup>c</sup>	37,361,717 <sup>c</sup>	211,083 <sup>c</sup>	211,083 <sup>c</sup>
VT	191,751	958,757	191,751	191,751
VA	DNF	DNF	DNF	DNF
WA	402,033	191,747,637	201,017	256,347
WV	DNF	DNF	DNF	DNF
WI	22,924	132,930,788	22,924	144,177
WY	0	18,713,002	0	256,342
Reported Total	453,399,939	8,092,324,831		
Estimated US Total	512,746,223	9,150,134,423	101,707	137,954

Note: This table only includes values if the state reported participants and expenditures by age. US averages are based only on states that provided complete data by age. c State only. d Other date (data from previous or next year). e Estimate. i One or more component value imputed by RISP staff. s Source, ACHA (2017a). DNF Did not furnish. N/A Not Applicable - no ICF/IID settings. PD Partial data, calculation incomplete and not included in reported totals. \* See state notes in Appendix.

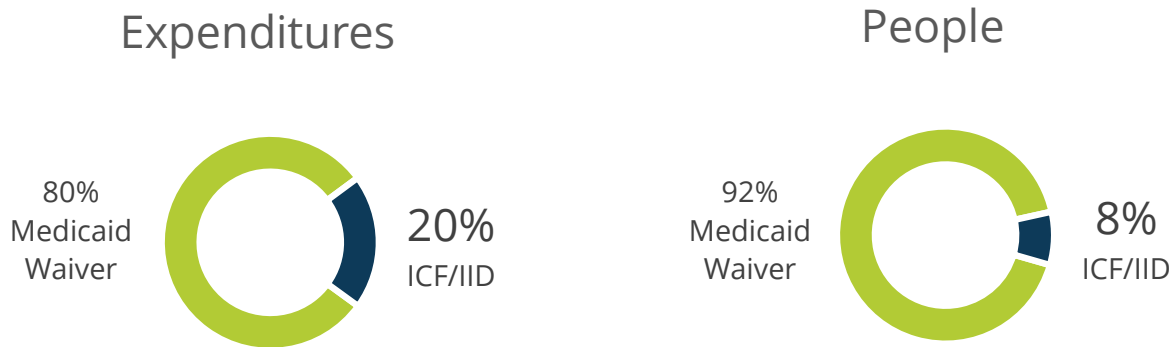
per state resident in Alabama to \$133 per state resident in the District of Columbia. Fifteen states reported average expenditures of less than \$15 per state resident including Alabama, Alaska, Colorado, Hawaii, Kansas, Maryland, Massachusetts, Michigan, Missouri, Montana, Nevada, Oregon, Rhode Island, Utah and Vermont. States with expenditures more than twice the national average including Ohio (\$61), Iowa (\$61), Mississippi (\$66), Louisiana (\$75), North Dakota (\$94) and the District of Columbia (\$133).

## Expenditures by Age

Total FY 2017 ICF/IID expenditures were \$512.7 million for people 21 years or younger and \$9.15 billion for people 22 years or older. Annual per person expenditures averaged \$101,707 for people 21 years or younger and \$137,954 for people 22 years or older (See **Table 2.12**). For children 21 years or younger, only Wisconsin (\$22,924) reported per person expenditures of less than half the national average while five states reported per person expenditures more than double the national average (Colorado, \$208,408, Utah, \$211,083, Connecticut, \$262,845, the District of Columbia, \$338,350 and Alaska, \$381,029). For adults 22 years or older, Hawaii (\$56,159) reported per person expenditures of less than half the national average while five





**Figure 2.11** Distribution of ICF/IID and Waiver Expenditures and Recipients in FY 2017

states reported per person expenditures of more than double the national average (the District of Columbia, \$277,798, New Jersey, \$328,958, Rhode Island, \$338,446, Alaska, \$398,273, and Montana, \$411,355).

## MEDICAID WAIVER AND ICF/IID RECIPIENTS AND EXPENDITURES

Total combined Medicaid Waiver and ICF/IID expenditures for 944,355 recipients were \$48.5 billion in FY 2017 (See **Table 2.13**). In FY 2017, 8% of the recipients and 20% of expenditures were for people in an ICF/IID (See **Figure 2.11**). In 36 states more than 90% of all Medicaid Waiver plus ICF/IID recipients received Medicaid Waiver funded LTSS. States serving the highest proportion of LTSS recipients in ICF/IID settings were Texas (19%), Oklahoma (20%), Illinois (23%), Arkansas (26%), Louisiana (28%), and Mississippi (36%).

In 15 states, more than 90% of Medicaid Waiver plus Medicaid ICF/IID expenditures were for Medicaid Waiver recipients. States reporting the highest proportion of combined expenditures for people for people in ICF/IID were Texas (42% of expenditures), Louisiana (43%), Mississippi (67%) and Washington (77%). The majority of Medicaid LTSS expenditures in Washington were for people receiving State Plan Home and Community-based LTSS (expenditures not shown).

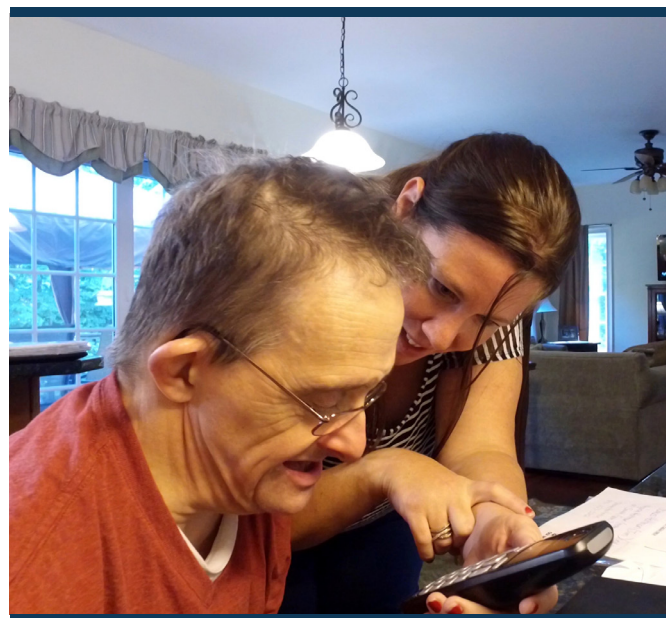
## Medicaid Waiver and ICF/IID Recipients by Age and Type of Residence

In FY 2017, there were substantially more adults than children in Medicaid Waiver-funded LTSS

settings (624,247 adults versus 218,253 children), and in ICF/IID settings (66,328 adults versus 5,041 children; **See Figure 2.12**). The proportion of recipients ages 22 years or older was 59% for Waiver recipients living with a family member, 92% for Waiver recipients living in another setting, and 90% for ICF/IID residents.

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

In FY 2017, annual per person Medicaid expenditures were higher for adults than for children in both Medicaid Waiver-funded settings (\$54,481 for adults and \$17,033 for children) and ICF/IID facilities (\$137,954 for adults versus \$101,707 for children;



**Table 2.13** ICF/IID and Medicaid Waiver Recipients and Expenditures Total and Percent by Funding Authority and State on June 30, 2017

State	Total ICF/IID + Waiver		% of Recipients		% of Expenditures	
	Recipients	Expenditures (\$)	Waiver	ICF/IID	Waiver	ICF/IID
N States	48	42	48	48	42	42
AL	5,644	382,150,842 <sup>e</sup>	100	0	99	1
AK	2,100 <sup>d</sup>	178,993,931 <sup>d</sup>	100	0	98	2
AZ	31,121	PD	100	0	PD	PD
AR	5,563	PD	74	26	PD	PD
CA	131,683	4,080,194,182	94	6	83	17
CO	12,373	497,845,650	98	2	91	9
CT	10,720	1,123,687,378	93	7	83	17
DE	1,149	167,573,850	90	10	81	19
DC	2,128	311,153,070	84	16	70	30
FL	36,512 <sup>d</sup>	1,336,020,694 <sup>d</sup>	93	7	75	25
GA	8,854 <sup>s</sup>	PD	97	3	PD	PD
HI	2,446	106,510,396	97	3	96	4
ID	8,568 <sup>s</sup>	PD	95	5	PD	PD
IL	29,463	1,510,197,298	77	23	61	39
IN	28,278	1,010,432,363	89	11	73	27
IA	14,424	771,520,283	88	12	73	27
KS	9,324	530,492,113	95	5	92	8
KY	17,814	803,223,294	98	2	82	18
LA	16,724	826,257,953	72	28	57	43
ME	5,107	377,372,109	97	3	92	8
MD	15,375	1,029,047,467	99	1	97	3
MA	15,750	1,580,810,821	97	3	94	6
MI	PD	PD	PD	PD	PD	PD
MN	23,233 <sup>d</sup>	1,668,715,468 <sup>d</sup>	94	6	93	7
MS	4,176 <sup>c</sup>	290,851,337 <sup>c</sup>	64	36	33	67
MO	14,576	978,922,038	97	3	91	9
MT	2,810	120,407,098	100	0	95	5
NE	4,966	353,204,247	92	8	82	18
NV	2,243	123,594,421	96	4	85	15
NH	PD	DNF	PD	PD	DNF	DNF
NJ	13,276 <sup>c</sup>	1,509,071,371 <sup>c</sup>	89	11	69	31
NM	PD	DNF	PD	PD	DNF	DNF
NY	88,398	6,676,038,470	94	6	84	16
NC	25,296	1,462,705,302	86	14	73	27
ND	5,426 <sup>b</sup>	271,048,861 <sup>b</sup>	91	9	74	26
OH	44,994	2,351,605,986	87	13	70	30
OK	7,011 <sup>s</sup>	PD	80	20	PD	PD
OR	21,200 <sup>s</sup>	90,153,420	100	0	100	0
PA	37,762	3,309,146,076	92	8	82	18
RI	4,362 <sup>c</sup>	211,891,701 <sup>c</sup>	100	0	99	1
SC	12,087	469,803,212	90	10	70	30
SD	3,817 <sup>d</sup>	147,166,153 <sup>d</sup>	95	5	79	21
TN	9,188	885,374,686	89	11	77	23
TX	46,172	2,628,559,433	81	19	58	42
UT	5,150 <sup>c</sup>	284,323,225 <sup>c</sup>	96	4	86	14
VT	3,076	199,192,026	100	0	99	1
VA	13,378	1,064,993,450	94	6	77	23
WA	17,650	248,184,501	96	4	23	77
WV	5,028 <sup>e</sup>	DNF	90	10	DNF	DNF
WI	33,983	1,355,398,392	97	3	90	10
WY	2,474	111,161,543	97	3	83	17
<b>Estimated US Total</b>	<b>934,355</b>	<b>48,459,530,905</b>	<b>92</b>	<b>8</b>	<b>80</b>	<b>20</b>

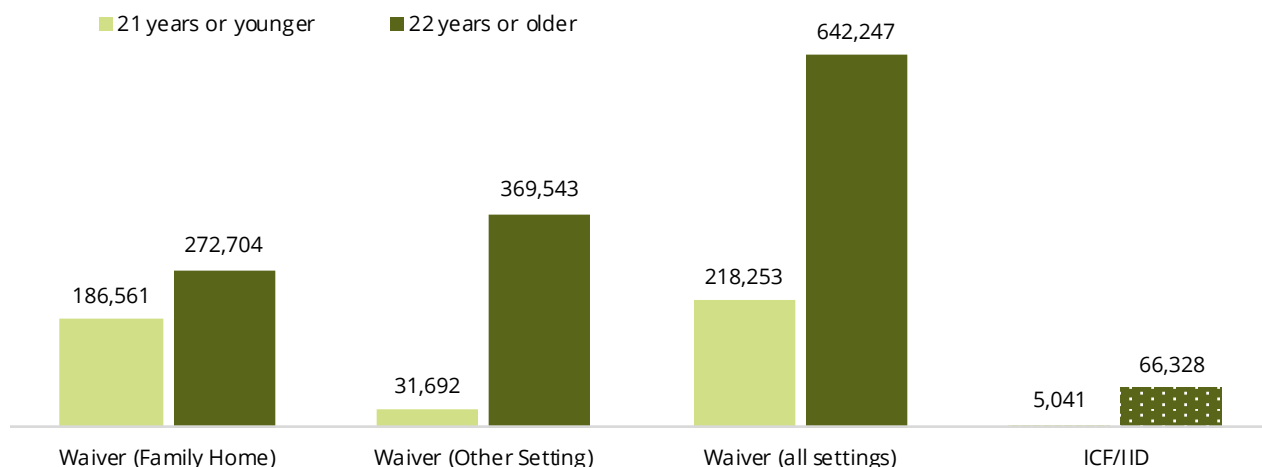
<sup>d</sup>Other date (data from previous or next year). <sup>e</sup> Estimate. <sup>s</sup> Sum of setting size data substituted for reported value. <sup>□</sup> Source ACHA (2017a) \* See state notes in Appendix. Medicaid Waiver authorities include 1115, 1915 (a), 1915 (a/c), 1915 (b), 1915 (b/c)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

See **Figure 2.13**). Average annual Medicaid Waiver expenditures were higher for recipients 22 years or older than for recipients 21 or younger living with a family member (\$25,027 versus \$11,363) or living in other settings (\$76,216 versus \$50,411). Annual per person expenditures for ICF/IID residents are likely higher than for Medicaid Waiver recipients at least in part because ICF/IID expenditures include room and board costs and several types of medical services that are not bundled into the cost for Medicaid Waiver-funded LTSS.

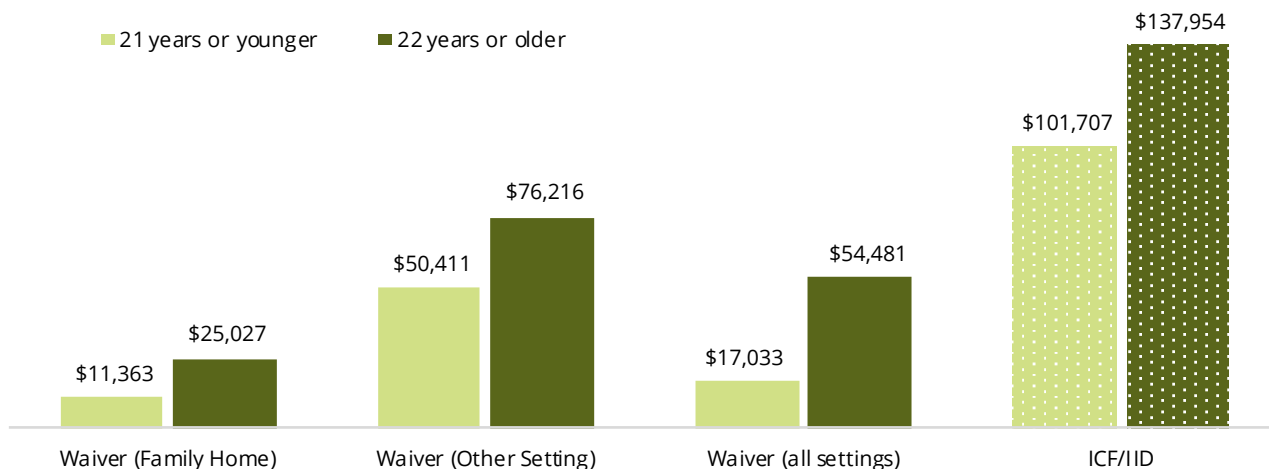
## Medicaid Expenditures and Benefits by State

**Table 2.14a** shows total Medicaid Waiver and ICF/IID expenditures, Federal Medicaid Assistance Percentages, and Federal Medicaid expenditures for ICF/IID and Waiver services for recipients with IDD in 2017. **Table 2.14b** shows the proportion of Federal Medicaid Waiver, ICF/IID, and combined expenditures for each state, total 2017 Federal Income taxes paid by each state and the proportion of Federal Income

**Figure 2.12** Estimated Medicaid LTSS Recipients with IDD by Age, Funding Authority and Living Arrangement on June 30, 2017



**Figure 2.13** Estimated Annual Per Person Medicaid Expenditures by Age, Funding Authority and Living Arrangement in FY 2017



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

taxes paid by each state. The state Medicaid Benefit ratio is the proportion of Federal Medicaid Waiver plus ICF/IID reimbursements received divided by the proportion of Federal Income taxes paid by each state. Overall the State Medicaid Benefit Ratio is one for the nation as a whole.

### Federal Medicaid Expenditures

Federal Medicaid reimbursement rates vary by states based on factors such as state wealth. The Federal Medicaid Assistance Percentage (FMAP) is the proportion of total Medicaid expenditures reimbursed by the Federal government. The average FMAP for FY 2017 was 59% (ranging from 50% in 13 states to 75% in Mississippi).

The Federal share of Medicaid ICF/IID and Waiver expenditures for people with IDD were estimated by multiplying the state's Federal Medicaid Assistance Percentage (FMAP) by the total Medicaid ICF/IID and Waiver expenditures. Combined Medicaid ICF/IID and Waiver expenditures for people with IDD in FY 2017 were an estimated \$48.5 billion, of which an estimated \$28.8 billion was reimbursed by the Federal government. Federal Medicaid reimbursements were an estimated \$23.0 billion in FY 2017 for Medicaid Waiver-funded supports and an estimated \$5.8 billion for services in an ICF/IID.

### Proportion of Federal Expenditures by State

We computed the estimated proportion of the total \$23.0 billion in federal reimbursements for Medicaid Waiver-funded LTSS and the \$5.8 billion in federal reimbursements for Medicaid ICF/IID LTSS paid to each state in FY 2017 (See **Table 2.14b**). Of the \$28.8 billion of federal ICF/IID plus Medicaid Waiver reimbursement to states, the proportion paid to each state ranged from 0.2% for Wyoming, Oregon and Hawaii to 11.6% for New York. Of the 23.8 billion in federal Medicaid Waiver reimbursements, 0.1% went to Washington and 0.2% went to Wyoming, Hawaii, and Oregon, while more than 5% went to Pennsylvania (5.9%), California (7.1%) and New York (11.6%). Of the 5.8 billion in federal Medicaid ICF/IID reimbursements paid in FY 2017, less than 0.1% went to Vermont, and less than 2% to Alaska, Rhode Island, and Alabama while more than 5% went to Illinois (5.2%), Pennsylvania (5.4%) California (6.0%), Ohio (7.7%), New York (9.1%) and Texas (10.8%). Because the proportions of Medicaid

reimbursement dollars received by each state is influenced by total state population, we then indexed these percentages to total Federal income taxes paid by each state.

### Federal Income Tax Paid

In FY 2017, states paid a total of \$3.4 trillion in federal business and individual income taxes. The proportion paid varied by state ranging from 13.0% by California, 8.0% by Texas, and 7.9% by New York, to less than 0.2% paid by Montana (0.18%), Alaska (0.16%), Vermont (0.13%), and Wyoming (0.13%).

### State Medicaid Benefit Ratios

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

For 2017, state Medicaid Benefit Ratios ranged from 0.17 for Washington to 3.55 for Maine. Twenty-three states had ratios of 1.0 or higher, 19 states had ratios of less than 1.0 and nine states provided only partial Medicaid expenditure data. States receiving less than half the proportion of federal Medicaid ICF/IID and Waiver reimbursements than they paid in federal taxes included Washington (0.17), Oregon (0.21), Nevada (0.44), and Florida (0.50). States that received more than twice the proportion of Medicaid ICF/IID plus Waiver reimbursements for recipients with IDD than the proportion of the total federal taxes paid included Iowa (2.10), Mississippi (2.18), North Dakota (2.41), Vermont (2.89) and Maine (3.55).

**Table 2.14a** FY 2017 Medicaid Expenditures for People with IDD, Federal Matching Percentage, and Federal Share by Funding Authority and State

State	Total FY 2017 Expenditures			Federal Matching Percentage (%) <sup>1</sup>	Federal Share of Total Expenditures (\$)		
	Waiver (\$)	ICF/IID (\$)	Combined		Waiver	ICF/IID	Combined
N States	47	43	42	51	47	43	42
AL	380,160,842	1,990,000 <sup>e</sup>	382,150,842	70	266,720,847	1,396,184	268,117,031
AK	176,257,752 <sup>d</sup>	2,736,179 <sup>d</sup>	178,993,931	50	88,128,876	1,368,090	89,496,965
AZ	982,472,685	DNF	PD	69	680,264,087	DNF	PD
AR	225,029,745	DNF	PD	70	156,823,229	DNF	PD
CA	3,383,875,727	696,318,455	4,080,194,182	50	1,691,937,864	348,159,228	2,040,097,091
CO	453,992,978	43,852,672	497,845,650	50	227,087,288	21,935,106	249,022,394
CT	929,152,338	194,535,040	1,123,687,378	50	464,576,169	97,267,520	561,843,689
DE	135,181,744	32,392,106	167,573,850	54	73,268,505	17,556,521	90,825,027
DC	218,863,605	92,289,465	311,153,070	70	153,204,524	64,602,626	217,807,149
FL	1,004,429,740	331,590,954 <sup>d</sup>	1,336,020,694	61	613,706,571	202,602,073	816,308,644
GA	356,494,730 <sup>d</sup>	DNF	PD	68	242,024,272	DNF	PD
HI	102,073,845	4,436,551	106,510,396	55	56,069,163	2,436,997	58,506,161
ID	249,873,933	DNF	PD	72	178,684,850	DNF	PD
IL	923,395,430	586,801,868	1,510,197,298	51	473,701,856	301,029,358	774,731,214
IN	741,068,955	269,363,408	1,010,432,363	67	494,589,421	179,773,138	674,362,559
IA	565,173,523	206,346,760	771,520,283	57	320,679,457	117,081,152	437,760,609
KS	489,936,267	40,555,846	530,492,113	56	275,393,176	22,796,441	298,189,617
KY	655,990,856	147,232,438	803,223,294	70	462,211,157	103,739,976	565,951,133
LA	473,862,272	352,395,681	826,257,953	62	295,121,423	219,472,030	514,593,453
ME	346,241,377	31,130,732	377,372,109	64	222,910,199	20,041,965	242,952,164
MD	1,003,267,655	25,779,812	1,029,047,467	50	501,633,828	12,889,906	514,523,734
MA	1,483,297,149	97,513,672	1,580,810,821	50	741,648,575	48,756,836	790,405,411
MI	DNF	0 <sup>i</sup>	PD	65	DNF	0	PD
MN	1,554,309,680 <sup>d</sup>	114,405,788 <sup>d</sup>	1,668,715,468	50	777,154,840	57,202,894	834,357,734
MS	94,710,728	196,140,609 <sup>c</sup>	290,851,337	75	70,682,616	146,379,736	217,062,353
MO	889,122,677	89,799,361	978,922,038	63	562,014,444	56,762,176	618,776,620
MT	114,648,128	5,758,970	120,407,098	66	75,163,313	3,775,581	78,938,893
NE	291,119,798	62,084,449	353,204,247	52	150,945,615	32,190,787	183,136,402
NV	104,967,361	18,627,060	123,594,421	65	67,882,392	12,046,120	79,928,512
NH	DNF	DNF	PD	50	DNF	DNF	PD
NJ	1,047,872,743	461,198,628 <sup>c</sup>	1,509,071,371	50	523,936,372	230,599,314	754,535,686
NM	DNF	DNF	PD	71	DNF	DNF	PD
NY	5,615,943,998	1,060,094,472	6,676,038,470	50	2,807,971,999	530,047,236	3,338,019,235
NC	1,063,757,581	398,947,721	1,462,705,302	67	711,441,070	266,816,236	978,257,306
ND	199,934,648	71,114,213 <sup>b</sup>	271,048,861	50	99,967,324	35,557,107	135,524,431
OH	1,635,258,483	716,347,503	2,351,605,986	62	1,019,093,087	446,427,764	1,465,520,850
OK	310,647,099 <sup>d</sup>	DNF	PD	60	186,201,871	DNF	PD
OR	90,153,420	0	90,153,420	64	58,121,910	0	58,121,910
PA	2,705,916,386	603,229,690	3,309,146,076	52	1,401,123,505	312,352,333	1,713,475,838
RI	209,184,132	2,707,569 <sup>c</sup>	211,891,701	51	106,725,744	1,381,402	108,107,146
SC	329,785,584	140,017,628	469,803,212	71	235,137,121	99,832,569	334,969,690
SD	115,968,067 <sup>d</sup>	31,198,086 <sup>d</sup>	147,166,153	55	63,712,856	17,140,228	80,853,084
TN	682,075,154	203,299,532	885,374,686	65	443,076,020	132,063,376	575,139,396
TX	1,515,457,962	1,113,101,471	2,628,559,433	56	851,384,283	625,340,406	1,476,724,689
UT	244,217,428	40,105,797 <sup>c</sup>	284,323,225	70	170,707,982	28,033,952	198,741,934
VT	198,041,518	1,150,508	199,192,026	54	107,853,411	626,567	108,479,977
VA	821,443,082	243,550,368	1,064,993,450	50	410,721,541	121,775,184	532,496,725
WA	56,034,831	192,149,670	248,184,501	50	28,017,416	96,074,835	124,092,251
WV	DNF	DNF	PD	72	DNF	DNF	PD
WI	1,222,444,680	132,953,712	1,355,398,392	59	715,252,382	77,791,217	793,043,599
WY	92,448,541	18,713,002	111,161,543	50	46,224,271	9,356,501	55,580,772
<b>Estimated US Total/Average</b>	<b>38,707,748,759</b>	<b>9,751,782,147</b>	<b>48,459,530,905</b>	<b>59</b>	<b>23,008,417,145</b>	<b>5,796,593,156</b>	<b>28,805,010,301</b>

<sup>b</sup> Nonstate only. <sup>c</sup> State only. <sup>d</sup> Other date (data from previous or next year). <sup>e</sup> Estimate. DNF Did not furnish. PD Partial data, calculation incomplete and not included in reported totals.

\* Source: Internal Revenue Service (2017). \* See state notes in the Appendix. <sup>1</sup> Source: <https://www.govinfo.gov/content/pkg/FR-2015-11-25/pdf/2015-30050.pdf>. Medicaid Waiver authorities include 1115, 1915 (a), 1915 (a/c), 1915 (b), 1915 (b/c) and 1915 (c)



**Table 2.14b** FY 2017 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 <sup>2</sup>
	Medicaid Waiver	ICF/IID	Combined	Billions (\$)	Percent (%)	
N states	47	43	42	51	51	42
AL	1.2	0.0	0.9	26.6	0.8	1.19
AK	0.4	0.0	0.3	5.4	0.2	1.96
AZ	3.0	DNF	PD	43.9	1.3	PD
AR	0.7	DNF	PD	32.5	1.0	PD
CA	7.4	6.0	7.1	440.5	13.0	0.55
CO	1.0	0.4	0.9	56.7	1.7	0.52
CT	2.0	1.7	2.0	57.5	1.7	1.15
DE	0.3	0.3	0.3	17.1	0.5	0.63
DC	0.7	1.1	0.8	28.3	0.8	0.91
FL	2.7	3.5	2.8	192.9	5.7	0.50
GA	1.1	DNF	PD	94.3	2.8	PD
HI	0.2	0.0	0.2	9.4	0.3	0.73
ID	0.8	DNF	PD	10.4	0.3	PD
IL	2.1	5.2	2.7	162.3	4.8	0.56
IN	2.1	3.1	2.3	58.9	1.7	1.35
IA	1.4	2.0	1.5	24.6	0.7	2.10
KS	1.2	0.4	1.0	25.6	0.8	1.38
KY	2.0	1.8	2.0	35.1	1.0	1.90
LA	1.3	3.8	1.8	42.7	1.3	1.42
ME	1.0	0.3	0.8	8.1	0.2	3.55
MD	2.2	0.2	1.8	71.2	2.1	0.85
MA	3.2	0.8	2.7	113.0	3.3	0.83
MI	DNF	0.0	PD	82.7	2.4	PD
MN	3.4	1.0	2.9	104.4	3.1	0.94
MS	0.3	2.5	0.8	11.7	0.3	2.18
MO	2.4	1.0	2.1	71.9	2.1	1.02
MT	0.3	0.1	0.3	6.1	0.2	1.53
NE	0.7	0.6	0.6	25.5	0.7	0.85
NV	0.3	0.2	0.3	21.6	0.6	0.44
NH	DNF	DNF	PD	12.1	0.4	PD
NJ	2.3	4.0	2.6	143.8	4.2	0.62
NM	DNF	DNF	PD	9.0	0.3	PD
NY	12.2	9.1	11.6	268.4	7.9	1.47
NC	3.1	4.6	3.4	82.9	2.4	1.39
ND	0.4	0.6	0.5	6.6	0.2	2.41
OH	4.4	7.7	5.1	142.1	4.2	1.22
OK	0.8	DNF	PD	27.1	0.8	PD
OR	0.3	0.0	0.2	32.3	1.0	0.21
PA	6.1	5.4	5.9	139.8	4.1	1.45
RI	0.5	0.0	0.4	14.9	0.4	0.86
SC	1.0	1.7	1.2	26.6	0.8	1.48
SD	0.3	0.3	0.3	7.9	0.2	1.21
TN	1.9	2.3	2.0	69.1	2.0	0.98
TX	3.7	10.8	5.1	271.0	8.0	0.64
UT	0.7	0.5	0.7	22.5	0.7	1.04
VT	0.5	0.0	0.4	4.4	0.1	2.89
VA	1.8	2.1	1.8	87.2	2.6	0.72
WA	0.1	1.7	0.4	85.9	2.5	0.17
WV	DNF	DNF	PD	7.0	0.2	PD
WI	3.1	1.3	2.8	53.1	1.6	1.76
WY	0.2	0.2	0.2	4.4	0.1	1.49
<b>Estimated US Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>3,399.0</b>	<b>100.0</b>	<b>1.00</b>

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

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

This history section was originally authored by K. Charlie Lakin and published in earlier RISP annual reports.

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

### Institutionalization and Deinstitutionalization

The 1880 U.S. Census enumerated 76,895 people with IDD living in the United States of whom 9,725 (13%) lived in institutions, almshouses, or prisons. The number of people with IDD living in institutional settings in the United States grew for the first six decades of the 20<sup>th</sup> Century, and most of those institutions were state-operated. In 1903, 15,511 people with IDD lived in institutions 98.6% of whom lived in a state-operated facility. The average daily population of state-operated IDD facilities increased 10 fold between 1903 and 1946 to 115,928. The number nearly doubled again during the baby boom years from 1946 and 1964, reaching an all-time high of 194,650 people in 1967. In 1967, an estimated 33,850 additional people with IDD lived in state-operated psychiatric facilities (the combined average daily population of state-operated IDD or psychiatric facilities was 228,500 in 1967).

Despite their widespread use, by the 1950s families, parent associations, professionals, and policy makers protested that large state-operated IDD institutions were overcrowded, understaffed, and sometimes unfit for human habitation. President



John F. Kennedy, whose sister Rosemary had intellectual disabilities, urged Congress in 1963 to move away from providing services to people with IDD in custodial institutions to providing services in community settings (JFK Library). In 1965, after visiting the Willowbrook State School in New York, Senator Robert Kennedy reported that the children at the facility lived in filth and called the facility a “snake pit” (MN DD Council, 2016).

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

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

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

human needs (such as food, clothing, personal hygiene, shelter, and transportation) and

- living, working and playing in physically accessible environments, with modifications or accommodations supporting full participation.

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

## Introduction of Medicaid Funding

Before 1965, there was no federal funding for LTSS for persons with IDD. In 1965, Medicaid was enacted as Medical Assistance, Title XIX of the Social Security Act. Medicaid is a state-federal partnership in which the federal government covers at least half of the service costs for eligible recipients. Initially, Medicaid funded long-term supports for people living in Skilled Nursing Facilities (SNF). Many state-operated facilities were converted to Medicaid SNFs once the Medicaid program was in place, and the number of people in Medicaid certified facilities increased rapidly. However, federal officials grew concerned that some people in SNFs were receiving more and more costly medical care than they needed. They were also concerned that the services offered in SNFs did not meet the developmental needs of children and adults with IDD (e.g., The Arc of the United States 1975).

## Intermediate Care Facilities for Individuals with Intellectual Disabilities

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

Facilities/Mental Retardation [sic] (ICF/MR) but because of Rosa's Law in 2010 are now referred to as Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID; CMS, 2013b).

The ICF/IID legislation provided substantial federal incentives to states for upgrading the physical environment and the quality of care and habilitation in certified IDD facilities. It also neutralized incentives for states to place persons with IDD in SNFs by creating a federally subsidized alternative offering care that was more appropriate and habilitation in the form of active treatment. In the ensuing years, most state IDD facilities were certified as Intermediate Care Facilities with two notable results: 1) nearly every state secured federal funding for large public IDD facilities, and 2) to maintain federal participation, states were compelled to invest substantial state dollars to bring their IDD facilities into conformity with ICF/IID standards. Forty states had at least one ICF/IID certified facility by June 30, 1977 (Krantz, Bruininks & Clumper, 1979). Between 1978 and 1980, nearly a billion state dollars were invested in facility improvements to meet ICF/IID standards (Gettings & Mitchell, 1980).

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

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

94,695). The proportion declined to 5% in 1998 and was 4% in FY 2017.

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

- a. created direct incentives for maintaining people in large state facilities by financing more than half of the costs of those services;
- b. diverted funds that could otherwise have been spent on community program development into facility renovations required to maintain eligibility for federal financial participation;
- c. promoted the development of large private ICF/IID facilities; and,
- d. promoted organizational inefficiency and individual dependency by promoting a single uniform standard for care and oversight for all people in ICF/IID settings irrespective of the nature and degree of their disabilities and/or their relative capacity for independence

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

### Downsizing ICF/IID Settings

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

States varied in the rate at which they developed ICF/IID facilities serving four to 15 people. Some states developed hundreds, while others had none. In 1982, nearly two-thirds (65%) of the 1,202 ICF/IIDs serving 4 to 15 people were located in Minnesota, New York, Michigan, and Texas. Some states and national organizations argued that the uneven

distribution of the smaller ICF/IID facilities reflected a lack of clear and consistent policy guidelines for certifying ICF/IID participation and/or a lack of support for those facilities in some regions.

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

## Medicaid Home and Community-Based Services

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

Regulations for the 1915(c) HCBS Waiver program were first published in March 1985. Initially, states were required to demonstrate reductions in the number of recipients of, and total expenditures for, Medicaid-funded institutional settings such as an ICF/IID roughly equal to the increases in HCBS participants and expenditures. As the number of people in ICF/IID settings declined, those restrictions were relaxed and then dropped in 1994.

States specify in their 1915(c) Medicaid Waiver applications which Medicaid eligible population will be served and which services will be available (e.g., homemaker, home health aide, personal care, day and residential habilitation, respite care or other services as approved by the Secretary of the U.S. Department of Health and Human Services; [www.Medicaid.gov](http://www.Medicaid.gov), 2016). Although not allowed to use

HCBS reimbursements to pay for room and board, all states provide residential support services under categories such as personal care, residential habilitation, and in-home supports. HCBS recipients with IDD live with family members or use their own resources, usually cash assistance from other Social Security Act programs and state supplements to cover room and board costs.

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

## Balancing Medicaid Home and Community-Based and Institutional LTSS

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

## Nursing Facility Reform

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

Despite state alternative disposition plans for moving persons with IDD out of nursing facilities, and preadmission screening and resident review

(PASRR), class action court cases established that the requirements of OBRA-87 were not always achieved (See Roland, et. al., v Cellucci, et. al., 1999, in Massachusetts, and Olesky et. al. v. Haveman et. al., 1999, in Michigan, Gettings, 1990).

### Expansion of Medicaid Waiver Funding Authorities

Since 1999, Congress has added several additional Medicaid Home and Community-based services funding authorities allowing states to expand Medicaid-funded community services and reduce demand for institutional services. Many states operate HCBS programs for two or more different eligible populations. In February 2020, the Medicaid website [www.medicaid.gov/medicaid/hcbs/authorities/index.html](http://www.medicaid.gov/medicaid/hcbs/authorities/index.html) listed 291 approved Section 1915(c) Home and Community-based Waivers, 53 approved 1115 Waivers, and 78 1915 (b) Waiver Authorities. Many states also offer HCBS under State Plan 1915(i), 1915(j) or 1915(k) funding authorities, though people with IDD are sometimes excluded from participating in those programs.

### Supports for Families

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

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

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

### Money Follows the Person

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

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

### Medicaid Managed LTSS

Many states have opted to use a capitated managed care model as an alternative to fee-for-service financing to manage some or all of their Medicaid LTSS (MLTSS). Section 1115 Research and Demonstration Projects allow states the flexibility to test new or existing approaches for financing and delivering Medicaid services, including the option to provide home and community-based services through a managed care entity. Similarly, states can



amend their Medicaid State Plan under the 1932(a) federal authority to implement a managed care delivery system. Section 1915(a) and (b) Managed Care authorities also allow states to use managed care delivery systems. A hybrid program (concurrent 1915(b) and 1915(c) waivers – also referred to as 1915(b)/(c) waivers) allows states to implement two types of waivers at the same time as long as all federal requirements were met for both programs.

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

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

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

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

The number of states offering MLTSS programs for adults with IDD increased from eight in 2012 to 19 in 2017 (Lewis et al, 2018). Of those states, nine covered Medicaid HCBS funded services and six covered ICF/IID services. The number of

states offering MLTSS programs for children with disabilities increased from eight in 2012 to 11 in 2017. Texas is the only state with an MLTSS program specifically for children.

## Self-Directed Medicaid HCBS

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

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

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

## Milestones in LTSS Policy

- **1965 Medicaid Program.** An anti-poverty program establishing Medicaid as a funder of long-term supports and services.
- **1971 Medicaid Intermediate Care Facilities for Individuals with Intellectual Disabilities.** This was the beginning of federal involvement in funding services for people with IDD although

still with an institutional focus. While many of the early ICF/IID certified facilities were large state-operated institutions, funding was available to settings of four or more people who complied with the certification standards. During the 1970s, a large number of smaller institutional settings were opened, with those that housed six people being the most common.

- **Rehabilitation Act of 1973** prohibited discrimination based on disability in federally funded programs.
- **1975 PL 94-142 (Now the Individuals with Disabilities Education Act).** PL 94-142 required school districts to provide an appropriate education to children with disabilities. This was the first time children with IDD could go to school in their communities instead of in residential institutions. Many states began to reduce the number of children living in state IDD facilities to reduce overcrowding as required by the ICF/IID standards, and to respond to the new educational requirements of PL 94-142.
- **1981 Medicaid Home and Community-based Services Waiver.** The Medicaid Home and Community-based Services Waiver started in 1981. It was an option states could use to fund LTSS in community settings other than ICF/IID certified institutions. Initially, the program was a cost saving measure more than a tool to support people with disabilities to live lives of their choosing in their communities. Participating states were required to demonstrate that their total Medicaid Waiver expenditures and the total number of people served grew no more than would be expected without the Waiver.
- **1987 Nursing Facility Reform.** With the Omnibus Budget Reconciliation Act (OBRA) of 1987, (PL 100-203) Congress restricted admission to Medicaid-reimbursed nursing facilities to persons requiring specific levels of medical/nursing services. People who did not need nursing services were required to move to other appropriate residential settings, except that individuals living in a specific nursing home for longer than 30 months could choose not to move.
- **1990 Americans with Disabilities Act.** The ADA is the landmark Civil Rights legislation for people with disabilities that prohibits discrimination based on disability with the goal of making sure that people with disabilities have access to the same opportunities as their fellow citizens. It required businesses and other organizations to make reasonable accommodations to allow all people including those with disabilities to access and use their settings and services.
- **1999 Supreme Court Olmstead Decision.** The Supreme Court in their 1999 Olmstead Decision established a right to “placement in the most integrated setting” under its interpretation of Title II of the Americans with Disabilities Act. The decision holds that people should not be required to live in institutions to have their medical needs met unless there are no integrated options available. The ADA coupled with the Olmstead decision pushed the service system to focus more on individualized supports and services that offer people greater choice and control over their lives.
- **2005 Deficit Reduction Act.** This legislation contained several provisions affecting LTSS. Among those provisions was creation of the 1915(i) funding authority and initial authorization of the Money Follows the Person program.
- **2009 Affordable Care Act.** This Federal legislation authorized the State Balancing Incentive Payments program, made modifications to the Medicaid 1915 State Plan LTSS option, and the Medicaid Waiver 1915(k) Community First Choice option, and extended funding for the Money Follows the Person program.
- **2014 Medicaid Home and Community-based Services (HCBS) Rule.** In 2014, the Centers for Medicare and Medicaid Services promulgated new rules that strengthen the requirements for integration, autonomy, choice and control, and person-centered services for Waiver recipients. All provisions of the rule became effective upon promulgation except those provisions related to HCBS settings. States have until 2022 to implement transition plans to bring all HCBS funded service settings into compliance with the rule.







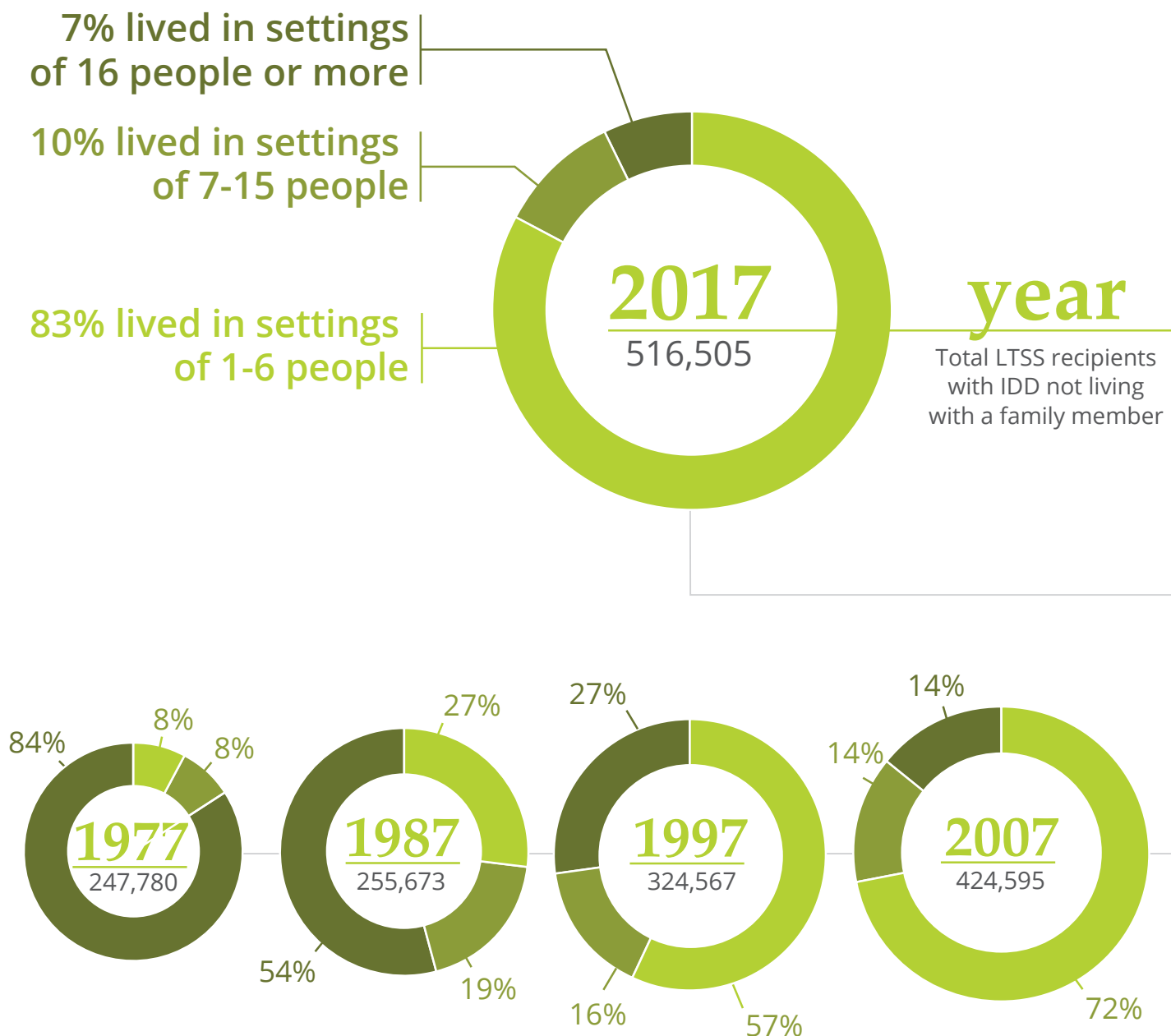
### SECTION THREE

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

**FY 2017**

## Change in the Total Number of People in Non-Family IDD Settings and Proportion in Settings of Different Sizes Between 1977 and 2017

Proportion of people living in non-family IDD settings



## SECTION 3: HISTORICAL PERSPECTIVES AND TRENDS IN LTSS

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

member, in their own home or in a host/foster family home has only been collected since 1998. Including people with IDD living in nursing homes or psychiatric facilities, between 1998 and 2017 the total number of LTSS recipients with IDD increased 90% from 693,691 to 1,319,819 people (See **Figure 3.1**).

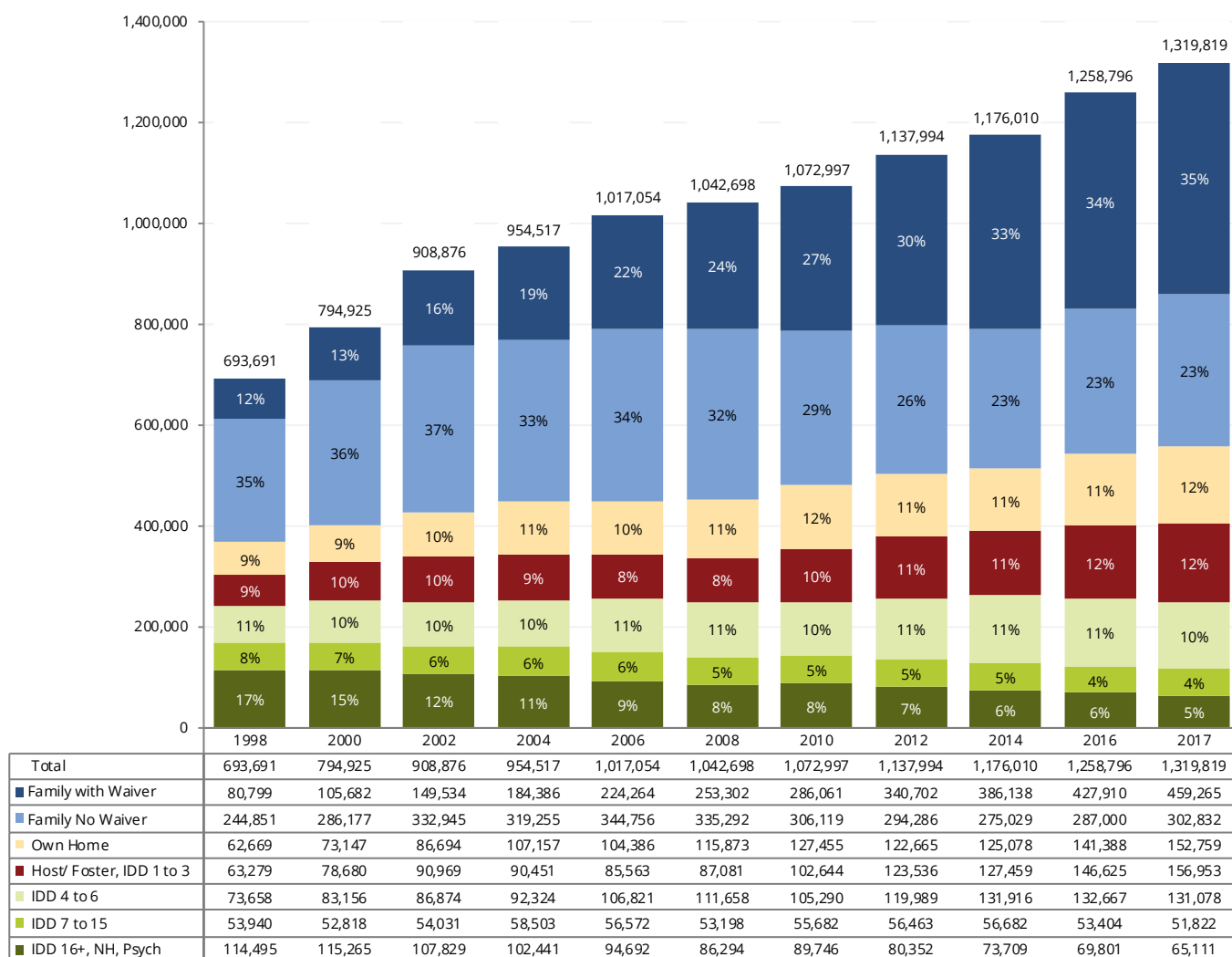
### TRENDS IN TYPES OF LIVING ARRANGEMENTS

Data on the size of non-family residential settings for people with IDD have been collected since 1977 but annual data on people living in the home of a family

#### Family Home

The number of LTSS recipients with IDD who lived in the home of a family member increased by 134% from 325,650 in 1998 to 762,097 in 2017. The proportion of LTSS recipients who lived with a family

**Figure 3.1** Number and Percent of LTSS Recipients with IDD by Living Arrangement Type and Size: Select Years 1998 to 2017



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

**Table 3.1** Non-Family IDD Residences by Type of Operation and Setting Size on June 30 of Selected Years 1977 to 2017

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%
1998	93,756	5,420	1,271	102,627	91%	1,194	672	272	2,138	56%	94,950	6,092	1,543	104,765	91%
2002	116,189	5,880	1,026	123,095	94%	1,634	713	233	2,580	63%	117,823	6,593	1,259	125,675	94%
2003	135,700	6,320	849	142,869	95%	1,707	771	234	2,712	63%	137,407	7,091	1,083	145,581	94%
2004	139,963	5,173	831	145,967	96%	1,621	703	229	2,553	63%	141,584	5,876	1,060	148,520	95%
2005	144,084	4,987	782	149,853	96%	1,542	718	209	2,469	62%	145,626	5,705	991	152,322	96%
2006	149,114	6,436	849	156,399	95%	1,506	737	201	2,444	62%	150,620	7,173	1,050	158,843	95%
2007	158,365	6,092	784	165,241	96%	1,683	733	217	2,633	64%	160,048	6,825	1,001	167,874	95%
2008	161,830	6,214	791	168,835	96%	1,628	734	215	2,577	63%	163,458	6,948	1,006	171,412	95%
2009	164,379	5,659	764	170,802	96%	1,637	732	205	2,574	64%	165,682	6,391	969	173,042	96%
2010	176,596	7,086	833	184,516	96%	1,501	692	203	2,396	63%	178,097	7,778	1,036	186,912	95%
2011	191,457	5,259	885	197,601	97%	1,485	701	200	2,386	62%	192,942	5,960	1,085	199,987	96%
2012	193,008	5,518	879	199,213	97%	1,315	685	187	2,165	61%	194,323	6,203	1,066	201,378	96%
2013	196,416	5,555	1,176	203,146	97%	1,258	710	167	2,135	59%	197,674	6,265	1,343	205,281	96%
2014	194,505	5,931	808	201,244	97%	1,330	723	148	2,201	60%	195,835	6,654	956	203,445	96%
2015	218,487	6,311	774	225,573	97%	1,231	709	149	2,089	59%	219,718	7,020	923	227,662	97%
2016	220,405	5,926	615	226,946	97%	1,284	706	140	2,130	60%	221,689	6,632	755	229,076	97%
2017	220,970	5,717	611	227,298	97%	1,315	646	121	2,082	63%	222,285	6,363	732	229,380	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 2017

Year	Number of People with IDD <sup>1</sup>														
	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%
2003	269,907	46,961	29,639	346,507	78%	5,554	7,385	42,835	55,774	10%	275,461	54,346	72,474	402,281	68%
2004	289,456	49,248	27,495	366,199	79%	5,540	6,810	41,653	54,003	10%	294,996	56,058	69,148	420,202	70%
2005	285,671	46,027	27,005	358,703	80%	5,471	6,980	40,061	52,512	10%	291,142	53,007	67,066	411,215	71%
2006	293,755	53,458	26,559	373,772	79%	5,429	7,089	38,305	50,823	11%	299,184	60,547	64,864	424,595	70%
2007	310,874	51,842	25,846	388,562	80%	5,417	7,078	36,650	49,145	11%	316,291	58,920	62,496	437,707	72%
2008	320,065	45,039	23,818	388,922	82%	5,360	6,994	35,035	47,389	11%	325,425	53,424	57,462	436,866	74%
2009	316,036	51,400	26,695	394,131	80%	5,427	7,048	32,909	45,384	12%	321,463	58,448	59,604	439,515	73%
2010	348,039	49,711	25,712	423,677	82%	5,156	6,875	31,101	43,132	12%	353,195	56,586	56,813	466,809	76%
2011	342,339	51,273	22,796	419,783	82%	5,059	6,786	28,969	40,814	12%	347,398	58,059	51,765	460,597	75%
2012	360,804	50,069	24,168	435,041	83%	5,386	6,394	28,120	39,900	13%	366,190	56,463	52,288	474,941	77%
2013	369,745	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	18,497	487,595	87%	4,975	5,696	18,239	28,910	17%	427,947	51,822	36,736	516,505	83%

<sup>1</sup> 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.

member increased from 47% to 58%. The proportion LTSS recipients living with a family member who received Medicaid Waiver-funded supports increased from 25% in 1998 to 60% in 2017.

## Non-Family Settings

Between 1998 and 2017, the number of LTSS recipients with IDD living in settings other than the home of a family member (including nursing homes and psychiatric facilities) increased 52% from 368,041 to 557,772 people. The number of LTSS recipients with IDD living in their own home increased by 144% from 62,669 (9% of recipients) in 1998 to 152,759 (12%) in 2017. Amongst those living in other settings, the proportion who lived in settings of:

- 3 or fewer people increased 148% from 63,279 to 156,953 people,
- 4 to 6 people increased 78% from 73,658 to 131,078 people,
- 7 to 15 people declined 4% from 53,940 to 51,822 people, and
- 16 or more people declined 43% from 114,495 to 65,111 people.

The proportion of LTSS recipients living in settings of 7 or more people, including nursing homes or psychiatric settings declined from 23% in 1998 to just 9% in 2017.

## TRENDS IN RESIDENCE SIZE AND TYPE OF OPERATION

The remainder of Section 3 focuses on trends in setting size, type of operation and funding authorities for LTSS recipients with IDD from 1977 or the first year a service was available or tracked through 2017 (excluding nursing homes and psychiatric facilities). Trends related to people living in state-operated psychiatric facilities are covered in Section 4.

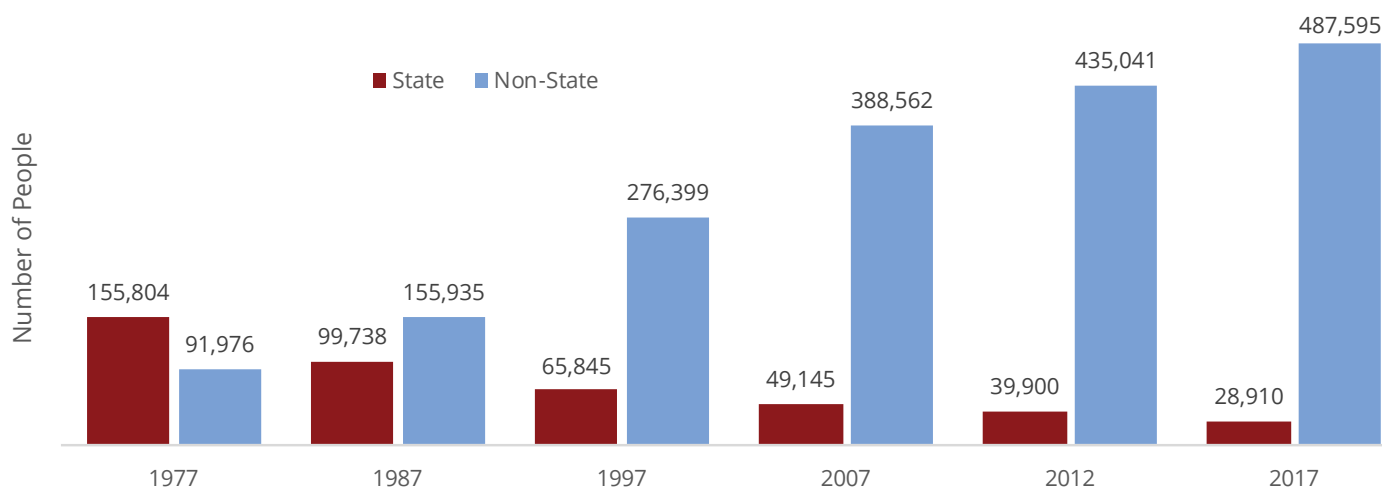
**Tables 3.1 and 3.2 and Figures 3.2 through 3.4** show changes in the size and type of operation of settings other than the home of a family member, nursing homes or psychiatric facilities in which LTSS recipients with IDD lived, and in the number of LTSS recipients in those settings.

### Number of Facilities by Size and Type of Operation

Between 1977 and 2017, the number of non-family settings serving LTSS recipients with IDD increased more than 20 fold from 11,008 to 229,380 (See **Table 3.1**). The number of non-family settings serving:

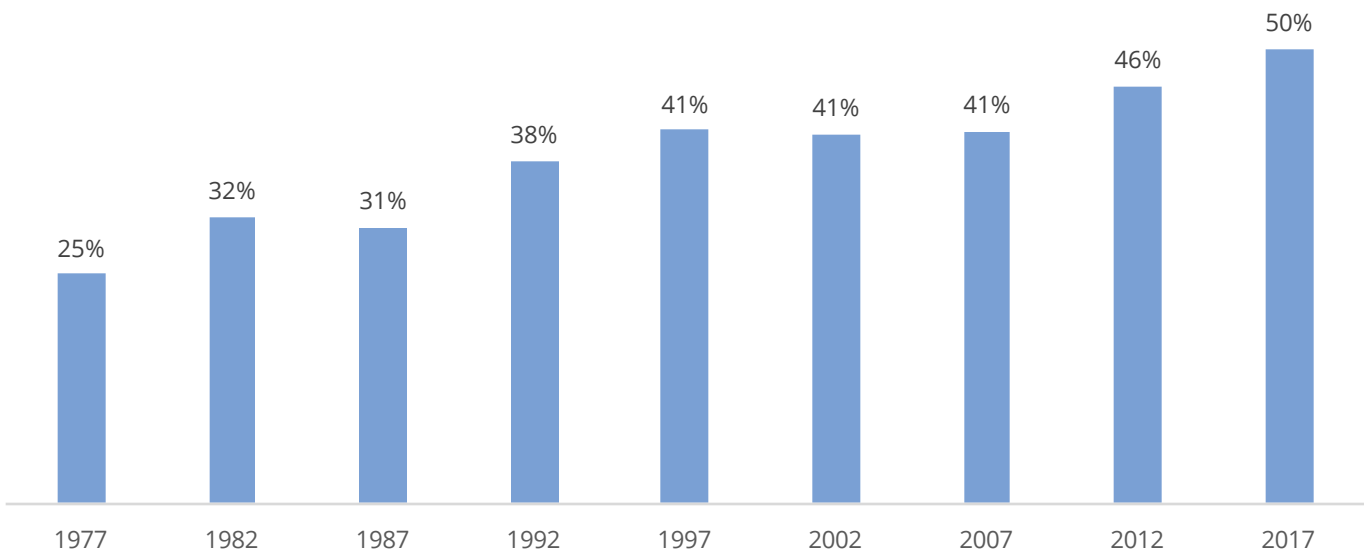
- 1 to 6 LTSS recipients increased 31 fold from 6,898 to 222,285,
- 7 to 15 LTSS recipients increased by 165% from 2,405 to 6,363, and
- 16 or more LTSS recipients decreased by 57% from 1,705 to 732.

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

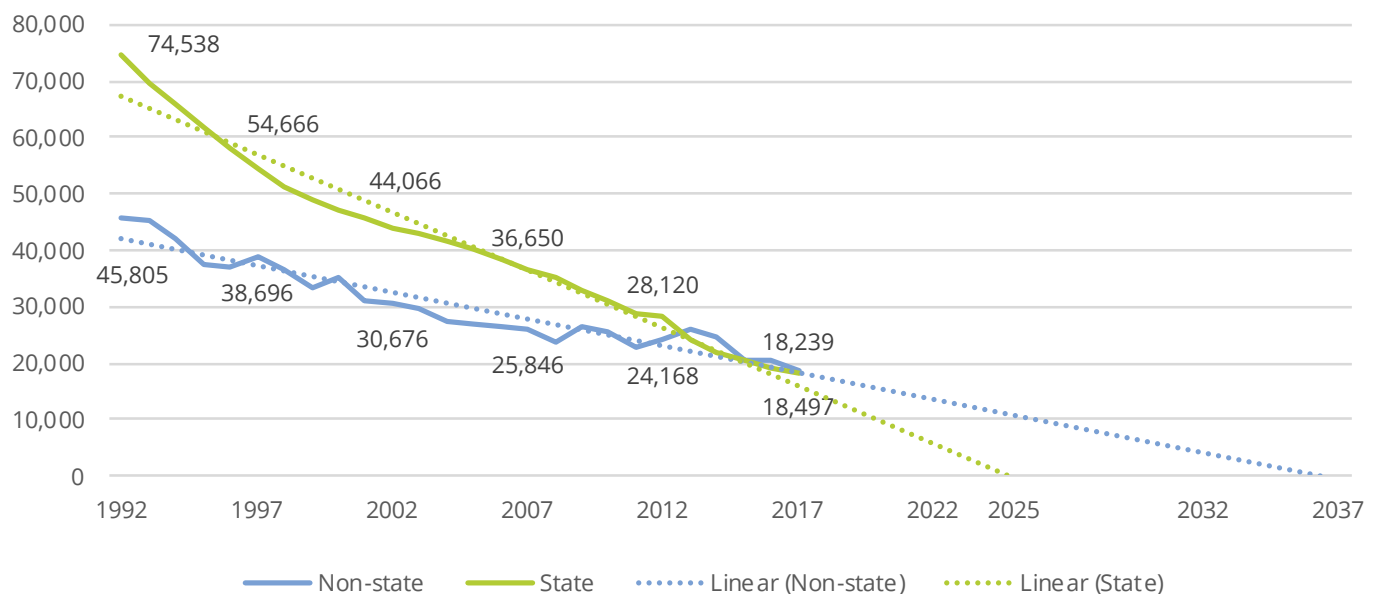




**Figure 3.3** Proportion of People with IDD in IDD Settings of 16 or more who Live in Nonstate Settings  
Selected Years 1977 to 2017



**Figure 3.4** Number of LTSS Recipients with IDD in State and Nonstate-Operated Settings of 16+ People  
1992 to 2017 with Linear Projections to 2037



Between 1977 and 2017, the proportion of non-family settings serving

- 1 to 6 LTSS recipients increased from 63% to 97%
- 7 to 15 LTSS recipients decreased from 22% to 3%
- 16+ LTSS recipients decreased from 15% to 0.3%

### LTSS Recipients with IDD by Residence Size and Type of Operation

Between 1977 and 2017, the number of LTSS recipients living in settings other than the home of a family member more than doubled increasing from

247,780 to 516,505 (See **Table 3.2**). The number of LTSS recipients with IDD living in settings serving

- 1 to 6 LTSS recipients increased 20 fold from 20,400 to 427,947
- 7 to 15 LTSS recipients increased 159% from 20,024 to 51,822
- 16 or more LTSS recipients decreased 5.6 fold from 207,356 to 36,736

Between 1977 and 2017, the proportion of LTSS recipients in non-family settings serving

- 1 to 6 LTSS recipients increased from 8% to 83%
- 7 to 15 LTSS recipients increased from 8% to 10%
- 16 or more LTSS recipients decreased from 84% to 7%

Between 1977 and 2017, the number of LTSS recipients with IDD living in state-operated IDD settings declined from 155,804 to 28,910 (See **Figure 3.2**). The number of LTSS recipients with IDD living in non-state settings increased from 91,976 to 487,595.

Between 1977 and 2017, the proportion of LTSS recipients living in non-state settings increased from 37% to 94%. The proportion in non-state settings serving

- 1 to 6 LTSS recipients remained at 99%
- 7 to 15 LTSS recipients decreased from 95% to 89%
- 16 or more LTSS recipients doubled from 25% to 50% (See **Figure 3.3**).

## Average Setting Size

The average number of LTSS recipients with IDD per setting declined from 22.5 people in 1977 to 2.3 people in 2017. The average number of people per non-state setting declined from 8.7 in 1977, to 7.6 in 1987, 3.5 in 1997 and 2.3 in 2017. The average number of people per state-operated setting declined from 335.1 in 1977, to 108.5 in 1987, 33.0 in 1997, 18.7 in 2007, and 13.9 in 2017.

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

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

in non-state settings of 16 or more people dropped from 45,805 in 1992 to 18,497 in 2017 (a decrease of 27,308 people or 60%). The number of LTSS recipients with IDD in state-operated settings of 16 or more people dropped from 74,538 in 2007 to 18,239 in 2017 (a decrease of 56,299 people or 76%). At these rates of decline, there would no longer be any LTSS recipients with IDD in state-operated settings of 16 or more people by 2025, but it wouldn't be until 2037 that there would no longer be any people with IDD in non-state-operated IDD settings of 16 or more people if current trends continue.

## TRENDS IN MEDICAID RECIPIENTS AND EXPENDITURES

Total Medicaid expenditures for all populations grew from \$14.55 billion in 1980 to \$576.64 billion in 2017 (See **Table 3.3**). Medicaid ICF/IID and Waiver funding for people with IDD increased from \$1.74 billion in 1980 to \$48.46 billion in 2017. The proportion of Medicaid expenditures allocated to LTSS for people with IDD declined from 11.9% in 1980 to 8.4% in 2017.

**Table 3.3** Medicaid Expenditures for ICF/IID and Waiver Recipients with IDD as a Proportion of All Medicaid Expenditures Select Years 1980 to 2017

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

\* RISP data 1 Source Eiken et al (2017). 2 Source: Eiken et al. (2018), [www.medicaid.gov/medicaid/ltss/reports-and-evaluations/](http://www.medicaid.gov/medicaid/ltss/reports-and-evaluations/) 3 Source: <https://www.kff.org/medicaid/state-indicator/total-medicaid-spending/> Medicaid Waiver authorities include 1115, 1915 (a), 1915 (a/c), 1915 (b), 1915 (b/c) and 1915 (c).

## Recipients

The number of people in ICF/IID settings peaked at 147,729 in 1993, but declined by 50% to 73,855 by 2017 (See **Figure 3.5a**). In 1982, there were 1,381 Medicaid Waiver recipients (1% of Medicaid Waiver plus ICF/IID LTSS recipients) and 140,752 people (99%) in an ICF/ IID. By June 30, 2017, the number of Medicaid Waiver recipients had grown to 860,500 (92% of Medicaid Waiver plus ICF/IID recipients) compared with 73,855 people in ICF/IID settings. The number of Medicaid Waiver recipients with IDD first exceeded the number of ICF/IID residents in 1995.

## Expenditures

In 1982, Medicaid ICF/IID expenditures were \$3.35 billion (99.9% of total expenditures) while Medicaid Waiver expenditures for people with IDD were \$2.24 million (See **Figure 3.5b**). By 2001, annual Medicaid Waiver expenditures exceeded annual ICF/IID expenditures (\$11.0 billion compared with \$10.35 billion). In 2017, annual Medicaid Waiver expenditures were \$38.71 billion (80% of combined expenditures) compared to \$9.75 billion for ICF/IID.

## Annual per Recipient Costs

The average annual per person costs have always been higher for people in ICF/IID settings than for Medicaid Waiver recipients with IDD (See **Figure 3.5c**). In 1982, average annual per recipient expenditures were \$1,624 for Medicaid Waiver recipients (\$4,110 in 2017 inflation adjusted dollars) and \$23,806 for people in ICF/IID settings (\$60,229 in 2017 inflation adjusted dollars). In 2017, average annual per recipient expenditures had increased to \$44,983 for Medicaid Waiver recipients and to \$140,057 for people in ICF/IID settings.

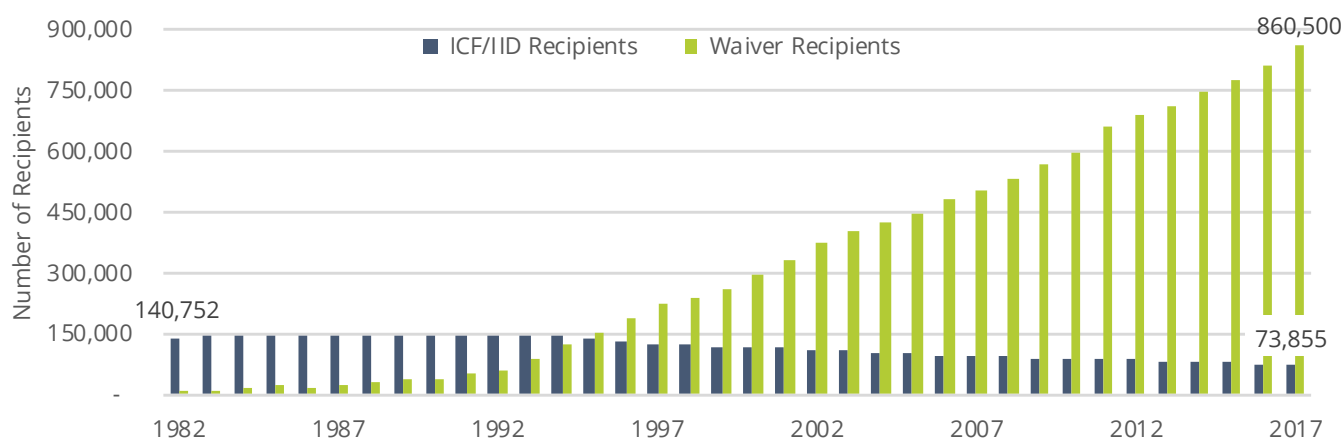
## Medicaid Participants and Expenditures by State

**Tables 3.4 through 3.7** show trends in Medicaid Waiver and ICF/IID participants and expenditures by state for selected years 1982 to 2017. Data for each state for all available years can be viewed at [RISP.umn.edu](http://RISP.umn.edu).

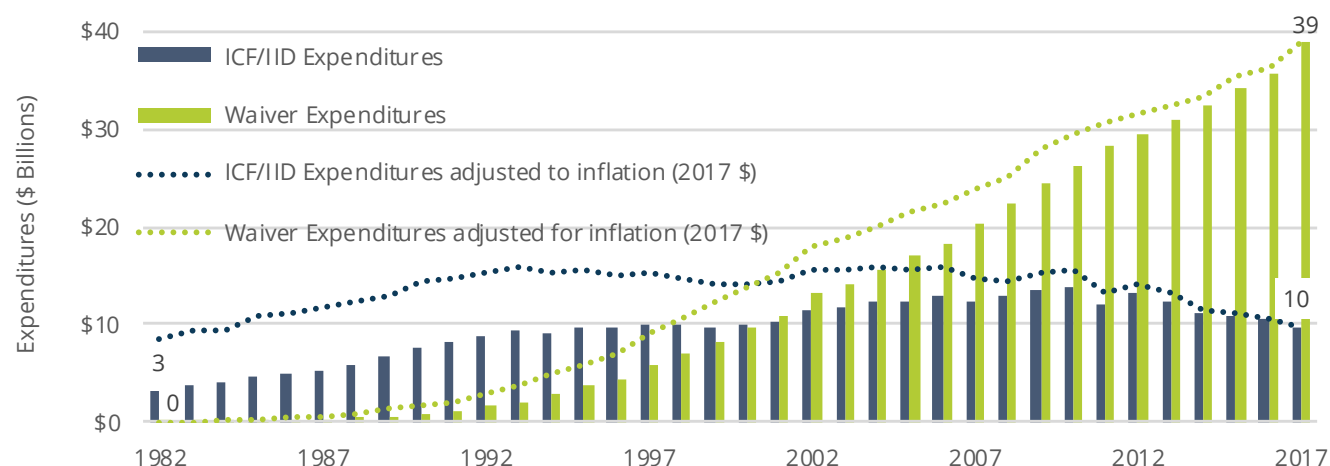
Between 2012 and 2017, the total number of Medicaid Waiver recipients with IDD increased



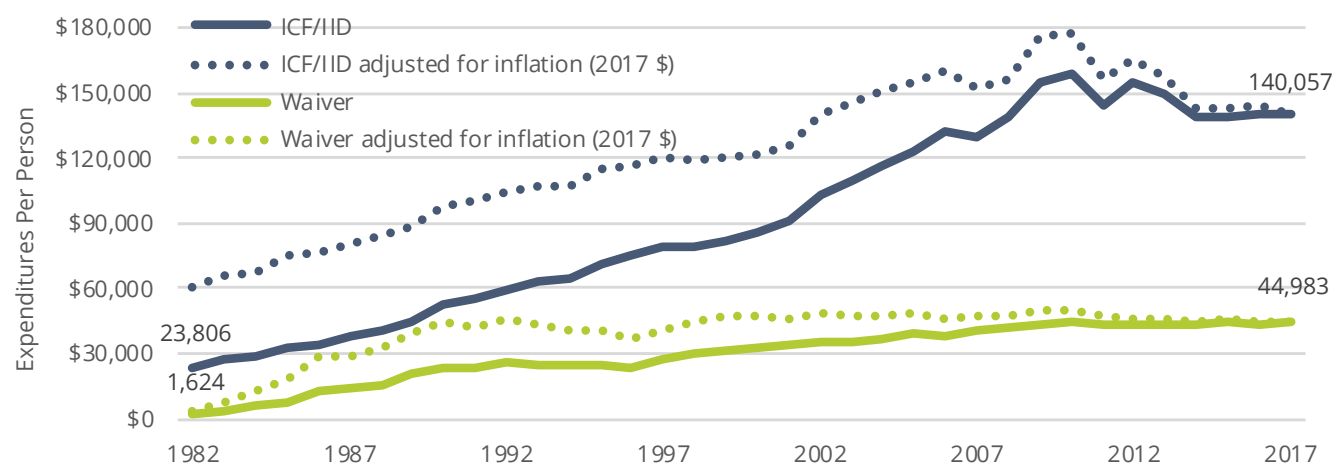
**Figure 3.5a** Medicaid ICF/IID and HCBS Waiver Recipients with IDD From 1982 to 2017



**Figure 3.5b** Medicaid ICF/IID and HCBS Waiver Expenditures in Billions for People with IDD From 1982 to 2017



**Figure 3.5c** Average Annual Per Person ICF/IID and Waiver Expenditures For People with IDD From 1982 to 2017



from 688,410 to 860,500, an increase of 25% (See **Table 3.4**). Between those years the number of Medicaid Waiver recipients grew in every state except Georgia (which reported a decrease from 11,621 to 8,579; 26%), and Hawaii (which reported a decrease from 2,544 to 2,257; 7%). States reporting the greatest percentage growth in Medicaid Waiver recipients were Idaho (growing by 305% from 2,660 to 8,113 recipients), Indiana (growing by 96% from 12,786 to 25,099 recipients), North Carolina (growing by 70% from 12,800 to 21,786 recipients), Kentucky (growing 57% from 11,046 to 17,392 recipients), and Colorado (growing 50% from 8,147 to 12,184 recipients). Other states reporting growth in the number of recipients of between 40% and 50% included Mississippi (47%), Oregon (43%), Washington (42%), and Wisconsin (41%).

Between 2012 and 2017, total Medicaid Waiver expenditures increased from \$29.54 billion to \$36.49 billion, an increase of 24% (See **Table 3.5**). Medicaid Waiver expenditures declined between 2012 and 2017 in five states including Washington (declining 90% from \$550.9 million to \$56.0 million), Oregon (declining 85% from \$597.9 million to \$90.2 million), Georgia (declining 12% from \$407.2 million to \$356.5 million), Wyoming (declining 6% from \$98.5 million to \$92.4 million) and Hawaii (declining 1% from \$102.9 million to \$102.1 million). Washington and Oregon both reported a shift from primarily using the Medicaid Waiver funding authorities for people with IDD to using a Medicaid State Plan HCBS funding authority.

Seven states reported increases in total Medicaid Waiver expenditures for people with IDD between 2012 and 2017 of more than 60% including Idaho (increasing 288% from \$64.4 million to \$249.9 million), Mississippi (increasing 115% from \$44.0 million to \$94.7 million), North Carolina (increasing 72% from \$619.8 million to \$1.05 billion), Massachusetts (increasing 69% from \$876.8 million to \$1.48 billion), Missouri (increasing 67% from \$554.0 million to \$889.1 million), California (increasing 61% from \$2.11 billion to \$3.38 billion), and Kentucky (increasing 61% from \$406.4 million to \$656.0 million).

Between 2012 and 2017, total ICF/IID recipients decreased 14% from 85,384 to 73,855 nationally with 40 states reporting declines (See **Table 3.6**). States

reporting the largest declines in the number of ICF/IID recipients between 2012 and 2017 included Montana (declining from 75% from 55 to 14 people), New Jersey (declining 54% from 3,153 to 1,463 people), Georgia (declining 52% from 300 to 143 people), and Alabama (declining 46% from 41 to 22 people).

Six states reported increases in the total number of ICF/IID recipients between 2012 and 2017. The largest increases were reported in New Mexico (increasing 9% from 234 to 254 people), North Carolina (12% increasing from 3,925 to 4,406 people), Washington (increasing 19% from 629 to 750 people), and Maryland (increasing 70% from 54 to 92 people). States with smaller increases included Louisiana (1%), and Wisconsin (3%).

Total Medicaid ICF/IID expenditures declined 25% overall between 2012 and 2017 from \$12.9 billion to \$9.8 billion (See **Table 3.7**). ICF/IID expenditures decreased in 24 states with the largest decreases in Alabama (decreasing 81% from \$10.6 million to \$1.9 million), Rhode Island (decreasing 70% from \$9.2 million to \$2.7 million), New York (decreasing 69% from \$3.38 billion to \$1.06 billion), Maine (decreasing 58% from \$74.9 million to \$31.1 million), and Montana (decreasing 49% from \$11.3 million to \$5.8 million). Thirteen states reported increases in ICF/IID expenditures between 2012 and 2017. States reporting the largest increases were Delaware (increasing 86% from \$17.4 million to \$32.4 million), Washington (81% increase from \$106.1 million to \$192.1 million), the District of Columbia (increasing 33% from \$69.5 million to \$92.3 million), and Kentucky (increasing 13% from \$130.5 million to \$206.3 million). Maryland also appeared to have a very large increase in ICF/IID expenditures but their 2012 total may have not included all claims.

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



**Table 3.4** Estimated Medicaid Waiver Recipients with IDD by State on June 30th Selected Years, 1982-2017

State	1982	1987	1992	1997	2002	2007	2012	2016	2017	% change 2012-2017
AL	0	1,570	2,184	3,713	4,764	5,230	5,604	5,580	5,622	0
AK	0	0	0	353	884	1,011	1,703	2,093	2,093	23
AZ	0	0	4,832	8,508	13,471	19,066	24,617	29,580	30,982	26
AR	0	0	415	496	2,494	3,342	4,037	4,135	4,138	3
CA	0	3,027	3,360	37,478	44,205	73,024	97,868	120,084	124,081	27
CO	0	1,389	2,204	4,276	6,516	7,148	8,147	10,846	12,184	50
CT	0	0	1,693	3,371	5,972	7,692	8,638	9,941	9,979	16
DE	0	81	290	379	547	788	855	1,077	1,031	21
DC	0	0	0	0	225	1,090	1,479	1,670	1,796	21
FL	0	2,631	2,637	11,399	25,921	31,425	29,353	32,830	33,812	15
GA	0	0	359	2,332	8,190	9,194	11,621	8,579	8,579	-26
HI	0	56	452	560	1,560	2,481	2,544	2,753	2,367	-7
ID	0	55	225	434	1,139	2,015	2,660	7,726	8,113	205
IL	0	664	2,006	5,400	6,787	12,800	18,355	23,744	22,810	24
IN	0	0	0	1,067	3,802	9,976	12,786	22,298	25,099	96
IA	0	4	137	3,932	6,228	12,751	11,359	14,091	12,716	12
KS	0	135	555	3,872	6,239	7,195	8,274	8,836	8,891	7
KY	0	609	819	1,040	1,807	3,033	11,046	14,768	17,392	57
LA	0	0	939	2,048	4,232	6,915	9,957	12,379	12,085	21
ME	0	400	509	1,078	2,440	2,781	4,101	4,881	4,948	21
MD	0	685	1,972	3,392	6,768	10,294	12,489	14,424	15,283	22
MA	0	593	3,288	8,027	11,315	11,962	11,987	14,274	15,354	28
MI	0	3	2,741	6,199	8,550	8,089	39,838	45,115	(1)	-1
MN	0	1,423	2,890	6,097	14,735	14,593	18,963	18,316	21,792	15
MS	0	0	0	231	1,673	1,978	1,831	2,408	2,690	47
MO	0	0	2,241	6,282	8,143	8,396	11,041	13,722	14,152	28
MT	21	210	444	891	1,452	2,242	2,668	2,533	2,796	5
NE	0	0	710	2,010	2,419	3,304	4,531	4,686	4,592	1
NV	0	129	136	374	1,083	1,372	1,652	2,033	2,152	30
NH	0	541	1,059	2,063	2,779	3,339	4,519	(1)	(1)	-1
NJ	0	2,596	3,971	5,705	7,486	9,923	11,297	10,922	11,874	5
NM	0	220	334	1,603	2,794	3,711	4,115	4,916	(1)	-1
NY	0	0	379	29,019	48,165	56,401	77,047	77,955	82,656	7
NC	0	328	939	3,726	6,013	9,309	12,800	16,892	21,786	70
ND	0	724	1,334	1,792	2,011	3,535	4,059	4,776	4,956	22
OH	0	100	397	2,646	7,858	16,362	30,872	36,817	39,180	27
OK	0	70	949	2,497	4,100	5,308	5,223	5,625	5,625	8
OR	1,360	832	1,458	2,586	8,017	10,287	14,865	12,548	21,200	43
PA	0	1,203	2,705	8,931	24,969	26,558	29,963	34,147	34,911	17
RI	0	136	993	2,178	2,674	3,126	3,316	3,638	4,354	31
SC	0	0	471	3,412	4,410	5,186	8,394	10,288	10,929	30
SD	0	596	852	1,457	2,295	2,609	3,215	3,625	3,625	13
TN	0	213	704	3,293	4,340	7,244	7,680	8,090	8,137	6
TX	0	70	968	4,753	7,873	16,301	29,193	36,671	37,582	29
UT	0	0	1,367	2,315	3,589	4,003	4,319	5,203	4,960	15
VT	0	196	413	1,372	1,844	2,200	2,649	3,010	3,070	16
VA	0	0	537	1,764	5,491	7,523	9,754	17,176	12,511	28
WA	0	886	1,918	6,643	9,900	9,317	11,898	15,586	16,900	42
WV	0	124	513	1,441	2,796	3,852	4,447	4,634	4,514	2
WI	0	190	1,812	6,558	9,474	12,504	23,396	31,460	33,060	41
WY	0	0	318	916	1,507	2,079	2,150	2,360	2,401	12
<b>Estimated US Total</b>	1,381	22,689	62,429	221,909	373,946	501,864	688,410	807,462	860,500	25
N States	2	35	47	50	51	51	51	50	51	

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



**Table 3.5** Estimated Medicaid Waiver Expenditures (in \$1,000s) for People with IDD by State Selected Years 1982 to 2017

State	1982	1987	1992	1997	2002	2007	2012	2016	2017	% change 2012-17
AL	0	\$8,326	\$12,400	\$72,327	\$120,395	\$253,259	\$288,701	\$361,133	\$380,161	32
AK	0	0	0	17,668	51,866	70,955	134,516	176,258	176,258 <sup>d</sup>	31
AZ	0	0	98,716	203,898	386,529	556,450	640,785	888,160	982,473	53
AR	0	0	11,250	12,063	53,077	91,380	173,135	215,395	225,030	30
CA	0	30,400	54,049	355,246	853,788	1,532,880	2,107,489	2,951,587	3,383,876	61
CO	0	25,455	60,192	133,282	205,028	268,080	331,010	428,244	453,993	37
CT	0	7	83,575	222,364	386,547	454,125	720,878	935,172	929,152	29
DE	0	846	5,105	16,279	34,181	75,090	94,329	119,647	135,182	43
DC	0	0	0	0	1,648	19,678	147,196	198,579	218,864	49
FL	0	12,850	20,246	131,805	496,921	908,572	879,855	989,156	1,004,430	14
GA	0	0	10,250	63,130	286,390	263,542	407,212	356,495	356,495 <sup>d</sup>	-12
HI	0	565	4,385	11,721	34,728	97,000	102,910	133,664	102,074	-1
ID	0	568	1,188	9,996	27,804	60,937	64,425	228,263	249,874	288
IL	0	12,840	79,600	116,000	140,200	416,200	591,460	885,747	923,395	56
IN	0	0	0	33,301	198,630	402,597	489,971	527,782	741,069	51
IA	0	0	774	48,271	127,081	275,728	387,580	543,363	565,174	46
KS	0	638	13,737	93,519	189,358	247,334	330,269	484,173	489,936	48
KY	0	10,974	19,821	29,430	91,756	163,060	406,429	636,053	655,991	61
LA	0	0	1,785	44,291	129,015	258,220	407,248	468,162 <sup>e</sup>	473,862	16
ME	0	5,674	13,250	60,067	136,461	230,661	291,071	332,802	346,241	19
MD	0	21,708	72,327	140,673	251,357	495,386	686,894	873,835	1,003,268	46
MA	0	13,278	90,000	280,000	483,391	587,453	876,814	1,008,756	1,483,297	69
MI	0	80	81,039	162,809	538,109	316,274	445,712	1,437,649 <sup>d</sup>	DNF	DNF
MN	0	13,170	95,381	260,223	699,687	889,902	1,215,081	1,276,890 <sup>d</sup>	1,554,310 <sup>d</sup>	28
MS	0	0	0	631	20,699	39,461	43,976	76,687	94,711	115
MO	0	0	65,792	154,768	235,897	379,435	533,967	769,305	889,123	67
MT	375	3,596	10,827	22,500	42,005	68,412	90,871	105,082	114,648	26
NE	0	0	25,522	58,901	108,402	140,172	239,921	295,435	291,120	21
NV	0	1,489	2,400	4,877	24,367	61,585	78,767	96,467	104,967	33
NH	0	13,518	44,400	89,427	117,922	143,209	192,025	232,932 <sup>d</sup>	DNF	DNF
NJ	0	35,888	108,601	180,006	402,988	496,612	737,871	974,961	1,047,873	42
NM	0	1,410	8,829	46,295	157,256	247,597	285,949	320,915	DNF	DNF
NY	0	712	34,496	1,114,423	2,125,806	3,449,069	5,468,225	5,391,832	5,615,944	3
NC	0	3,059	13,833	106,199	254,337	377,747	619,805	603,810 <sup>e</sup>	1,063,758	72
ND	0	5,438	18,975	30,176	47,531	71,823	129,617	192,609	199,935	54
OH	0	1,131	12,824	90,058	245,009	660,978	1,240,863	1,529,159	1,635,258	32
OK	0	392	39,375	93,593	222,356	253,401	273,952	310,647	310,647 <sup>d</sup>	13
OR	1,869	8,306	58,604	105,178	361,705	385,762	597,868	71,228	90,153	-85
PA	0	35,975	133,681	415,399	977,487	1,199,739	1,816,306	2,527,639	2,705,916	49
RI	0	5,648	14,367	107,962	160,859	245,521	203,663	234,726	209,184	3
SC	0	0	4,961	51,300	142,500	185,700	291,243	330,996	329,786	13
SD	0	6,153	16,257	38,739	58,935	81,945	101,739	115,968	115,968 <sup>d</sup>	14
TN	0	1,853	14,431	72,738	205,314	525,964	604,098	671,359	682,075	13
TX	0	1,828	39,755	159,896	321,671	566,475	1,058,827	1,418,007 <sup>d</sup>	1,515,458	43
UT	0	0	23,000	50,794	88,991	113,867	155,515	212,793	244,217	57
VT	0	4,840	14,154	47,980	74,856	109,071	141,617	172,227	198,042	40
VA	0	0	15,975	67,430	198,911	394,326	602,412	504,150	821,443	36
WA	0	12,068	39,974	105,006	214,490	315,624	550,896	369,959	56,035	-90
WV	0	777	13,200	43,660	120,218	203,371	303,862	DNF	DNF	DNF
WI	0	3,503	39,078	155,238	312,785	439,299	855,374	1,118,256	1,222,445	43
WY	0	0	12,508	33,428	56,957	87,041	98,497	91,333	92,449	-6
Estimated US Total	2,243	304,961	1,654,887	5,964,966	13,224,202	20,177,966	29,538,694	35,470,093	36,485,557	24
N States	2	36	47	50	51	51	51	51	51	

Data for all years 1982 to 2016 can be viewed in the Chart Gallery of the RISP.umn.edu website. <sup>a</sup> Other date (data from previous or next year). <sup>e</sup> Estimate. <sup>1</sup> One or more component value imputed by RISP staff. DNF Did not furnish. <sup>s</sup> Source: (Eiken et al., 2018). Medicaid Waiver authorities include 1115, 1915 (a), 1915 (a/c), 1915 (b), 1915 (b/c) and 1915 (c).

**Table 3.6** Estimated ICF/IID Recipients by State, Selected Years 1982 to 2017

State	1977	1982	1987	1992	1997	2002	2007	2012	2016	2017	% change 2012-2017
AL	0	1,470	1,364	1,304	745	472	244	41	22	22	-46
AK	135	118	107	86	10	0	0	0	7	7	N/A
AZ	0	0	0	214	214	207	185	148	137 <sup>s</sup>	139	-6
AR	1,385	1,420	1,453	1,737	1,558	1,684	1,616	1,467	1,425	1,425	-3
CA	0	10,374	10,871	10,923	10,681	10,839	9,598	8,726	7,918 <sup>s</sup>	7,649 <sup>s</sup>	-12
CO	4,537	2,017	1,149	754	229	111	125	343	215 <sup>s</sup>	189	-45
CT	687	1,598	1,414	1,378	1,377	1,192	1,148	993	790 <sup>s</sup>	742 <sup>s</sup>	-25
DE	477	513	439	325	292	241	141	135	118 <sup>s</sup>	118	-13
DC	0	436	666	761	754	734	640	363	323	332	-9
FL	370	2,128	3,180	3,118	3,476	3,338	3,205	2,806	2,791 <sup>s</sup>	2,770 <sup>s</sup>	-1
GA	2,369	2,491	1,913	1,935	1,770	1,475	1,034	300	284 <sup>s</sup>	143 <sup>c</sup>	-52
HI	524	387	296	154	122	94	78	79	76	79	0
ID	583	482	461	519	579	576	543	487	488	455	-7
IL	5,353	8,144	10,346	12,311	10,500	9,923	9,213	8,344	6,615	6,653	-20
IN	1,026	2,798	4,690	6,234	5,938	4,981	4,012	3,839	3,249	3,179	-17
IA	1,432	1,673	1,840	2,088	2,268	2,157	2,123	2,002	2,011	1,765 <sup>s</sup>	-12
KS	1,810	2,078	2,081	1,921	1,395	688	599	509	314 <sup>c</sup>	433	-15
KY	999	1,250	1,187	1,200	1,180	876	637	523	DNF	422	-19
LA	3,682	4,849	6,016	5,645	6,014	5,539	5,320	4,604	4,956	4,639 <sup>o</sup>	1
ME	310	630	677	630	548	246	222	202	162	159	-21
MD	1,367	1,851	1,429	954	624	502	336	54	DNF	92	70
MA	4,242	4,041	3,698	3,304	1,598	1,125	952	594	409	396	-33
MI	5,760	4,002	3,683	3,180	2,899	173	151	0	0 <sup>d</sup>	0 <sup>c</sup>	N/A
MN	5,303	6,899	6,339	5,202	3,604	2,756	2,513	1,719	1,591 <sup>d</sup>	1,441	-16
MS	491	1,614	1,678	1,825	2,256	2,534	2,601	2,765	2,337 <sup>s</sup>	2,169 <sup>s</sup>	-22
MO	2,051	1,878	1,868	1,751	1,466	1,398	1,020	590	442 <sup>s</sup>	424	-28
MT	0	290	253	170	148	119	54	55	42 <sup>s</sup>	14	-75
NE	1,356	980	808	739	643	642	582	433	393	374	-14
NV	0	175	188	146	275	242	118	104	91	91	-13
NH	288	339	204	81	23	25	25	25	25	23	-8
NJ	525	4,366	3,815	3,942	3,948	3,370	2,963	2,426	1,477 <sup>o</sup>	1,463 <sup>s</sup>	-40
NM	426	553	709	730	348	284	182	234	274	254	9
NY	18,601	15,577	17,567	18,497	11,472	9,815	7,995	7,288	5,555	5,742	-21
NC	2,073	2,762	3,445	4,502	4,777	4,645	4,124	3,930	3,925 <sup>s</sup>	4,406 <sup>s</sup>	12
ND	0	219	888	476	609	629	593	559	539 <sup>s</sup>	539 <sup>s</sup>	-4
OH	2,488	6,040	7,535	8,384	7,615	7,240	6,667	6,926	6,147	5,814	-16
OK	1,978	1,803	3,242	2,776	2,292	2,243	1,630	1,549	1,307 <sup>s</sup>	1,386	-11
OR	1,989	1,918	1,284	668	373	51	41	0	0	0	N/A
PA	7,355	8,598	7,364	7,282	6,192	4,280	3,833	3,419	2,991	2,851	-17
RI	763	881	1,093	602	21	40	41	42	35 <sup>c</sup>	34 <sup>s</sup>	-19
SC	1,017	2,665	3,300	3,261	2,555	1,992	1,615	1,313	1,165	1,158	-12
SD	540	721	650	552	328	189	158	199	192	192	-4
TN	2,149	2,377	2,198	2,399	1,900	1,460	1,223	1,108	947 <sup>s</sup>	1,051	-5
TX	10,486	13,959	12,211	11,187	12,985	12,684	11,447	9,467	7,997 <sup>s</sup>	8,590	-9
UT	1,193	1,199	945	930	833	783	794	801	191 <sup>c</sup>	773 <sup>s</sup>	-3
VT	352	385	238	146	12	12	6	6	6	6	0
VA	3,558	3,616	3,018	2,743	2,225	1,885	1,684	1,326	881 <sup>s</sup>	867	-35
WA	440	2,464	2,539	1,695	1,126	880	767	629	751	750	19
WV	0	176	417	699	574	515	477	562	509	514	-9
WI	3,696	3,548	3,378	4,110	3,187	2,580	1,059	895	687	923	3
WY	0	0	0	90	139	106	93	79	67	73	-8
<b>Estimated US Total</b>	<b>106,166</b>	<b>140,752</b>	<b>146,134</b>	<b>146,260</b>	<b>126,697</b>	<b>110,572</b>	<b>96,427</b>	<b>85,384</b>	<b>74,614</b>	<b>73,855</b>	<b>-14</b>
N States	42	49	49	51	51	50	50	48	47	49	

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

**Table 3.7** Estimated Medicaid ICF/IID Expenditures (in \$1,000s) by State, Selected Years 1982 to 2017

State	1982	1988	1992	1997	2002	2007	2012	2016	2017	% change 2012-2017
AL	\$31,076	\$54,014	\$80,701	\$58,306	\$60,516	\$31,522	\$10,586	\$1,997	\$1,990 <sup>e</sup>	-81
AK	6,830	9,038	10,384	2,032	0	161	3,051	2,736	2,736 <sup>d</sup>	-10
AZ	0	0	0	0	0	0	32,593	DNF	DNF	DNF
AR	34,603	51,087	88,047	105,950	28,958	146,960	168,540	DNF	DNF	DNF
CA	87,544	269,638	316,072	380,655	663,954	824,990	821,840	712,849	696,318	-15
CO	-1,194	43,403	55,495	23,575	19,202	22,647	39,533	40,224	43,853	11
CT	41,722	109,464	192,888	188,190	213,455	240,165	284,642	150,496	194,535	-32
DE	8,281	15,246	26,543	31,233	31,219	26,647	17,462	30,481	32,392	86
DC	7,350	40,108	51,774	74,258	79,480	85,051	69,494	89,668	92,289	33
FL	48,048	130,435	181,802	248,208	310,393	319,288	328,460	DNF	331,591 <sup>d</sup>	1
GA	48,271	84,730	115,391	127,303	110,659	105,885	67,117	DNF	DNF	DNF
HI	10,962	14,290	6,571	11,628	8,572	8,683	7,715	9,242	4,437	-42
ID	12,490	23,130	35,545	43,454	57,714	59,702	23,064	42,634 <sup>d</sup>	DNF	DNF
IL	120,855	243,824	499,573	580,152	720,932	696,183	688,115	602,642	586,802	-15
IN	37,326	86,777	272,735	304,187	338,947	318,531	294,064	271,366	269,363	-8
IA	52,267	88,710	150,456	178,213	192,996	276,651	301,739	283,081	206,347	-32
KS	40,647	69,568	102,523	94,468	65,863	65,288	64,412	13,162	40,556	-37
KY	39,053	47,597	59,843	75,691	97,888	151,886	130,481	DNF	147,232	13
LA	97,076	165,291	260,925	422,009	362,343	442,023	467,517	384,154	352,396	-25
ME	15,699	30,613	62,854	45,548	50,370	71,664	74,915	31,452	31,131	-58
MD	53,170	83,621	65,023	63,699	61,628	68,466	123	DNF	25,780	20,853
MA	125,500	198,722	385,149	254,062	198,023	206,612	165,995	107,491	97,514	-41
MI	152,838	213,105	180,561	519,144	27,648	28,824	0	0	0 <sup>i</sup>	N/A
MN	155,020	238,700	283,108	238,628	207,841	175,376	164,145	DNF	114,406 <sup>d</sup>	-30
MS	20,579	32,524	62,156	119,386	178,043	255,287	270,287	202,216	196,141 <sup>c</sup>	-27
MO	35,207	71,080	106,866	155,768	230,169	105,836	108,468	88,948	89,799	-17
MT	0	10,179	13,124	15,809	14,061	10,632	11,320	12,279	5,759	-49
NE	21,336	25,477	32,910	36,896	47,671	66,940	57,654	62,816	62,084	8
NV	5,661	9,523	16,670	22,845	30,309	21,390	17,955	17,751	18,627	4
NH	6,339	14,142	6,127	1,299	1,953	2,522	3,154	1,935	DNF	DNF
NJ	122,552	237,997	276,342	373,077	462,969	628,421	650,873	461,348	461,199 <sup>c</sup>	-29
NM	12,078	23,587	39,164	21,729	18,993	21,263	24,809	DNF	DNF	DNF
NY	797,385	1,158,161	1,715,103	2,010,006	2,472,622	3,057,177	3,382,395	1,185,815	1,060,094	-69
NC	79,192	158,440	278,485	363,153	416,623	466,789	444,383	398,985	398,948	-10
ND	498	40,216	39,980	43,653	54,683	61,655	92,146	77,031 <sup>b</sup>	71,114 <sup>b</sup>	PD
OH	36,634	278,624	468,322	391,631	962,507	697,689	757,788	726,662	716,348	-5
OK	32,395	83,725	111,773	100,900	112,292	127,291	113,228	DNF	DNF	DNF
OR	5,287	73,727	83,138	75,273	11,346	22,407	0	0	0	N/A
PA	326,340	384,252	502,755	527,594	506,212	584,411	580,876	598,381	603,230	4
RI	28,759	60,548	90,368	10,401	7,244	7,810	9,160	DNF	2,708 <sup>c</sup>	-70
SC	36,020	94,198	165,299	174,750	174,843	157,180	150,914	139,364	140,018	-7
SD	14,890	22,005	29,221	20,194	18,448	20,149	29,594	31,198	31,198 <sup>d</sup>	5
TN	56,831	77,504	111,715	212,774	252,512	243,129	216,276	201,883	203,300	-6
TX	233,539	357,823	468,605	640,849	811,722	906,152	1,047,598	1,153,752 <sup>d</sup>	1,113,101	6
UT	23,711	27,666	39,659	45,047	54,883	58,134	63,278	37,490	40,106 <sup>c</sup>	-37
VT	13,421	11,335	17,841	1,479	1,631	0	1,212	1,092	1,151	-5
VA	78,609	106,785	153,992	159,667	216,052	231,030	288,116	82,724	243,550	-15
WA	72,202	119,320	182,045	128,968	127,817	114,854	106,120	202,613	192,150	81
WV	1,982	8,662	15,031	52,705	47,513	57,354	65,414	DNF	DNF	DNF
WI	63,845	89,337	193,185	201,998	226,014	131,158	197,496	134,006	132,954	-33
WY	0	0	2,556	17,778	15,543	20,007	20,745	18,935	18,713	-10
Estimated US Total	3,350,726	5,887,947	8,706,396	9,996,224	11,383,282	12,449,872	12,936,860	10,507,955	9,751,782	-25
N States	48		49	50	51	50	51	51	50	50

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



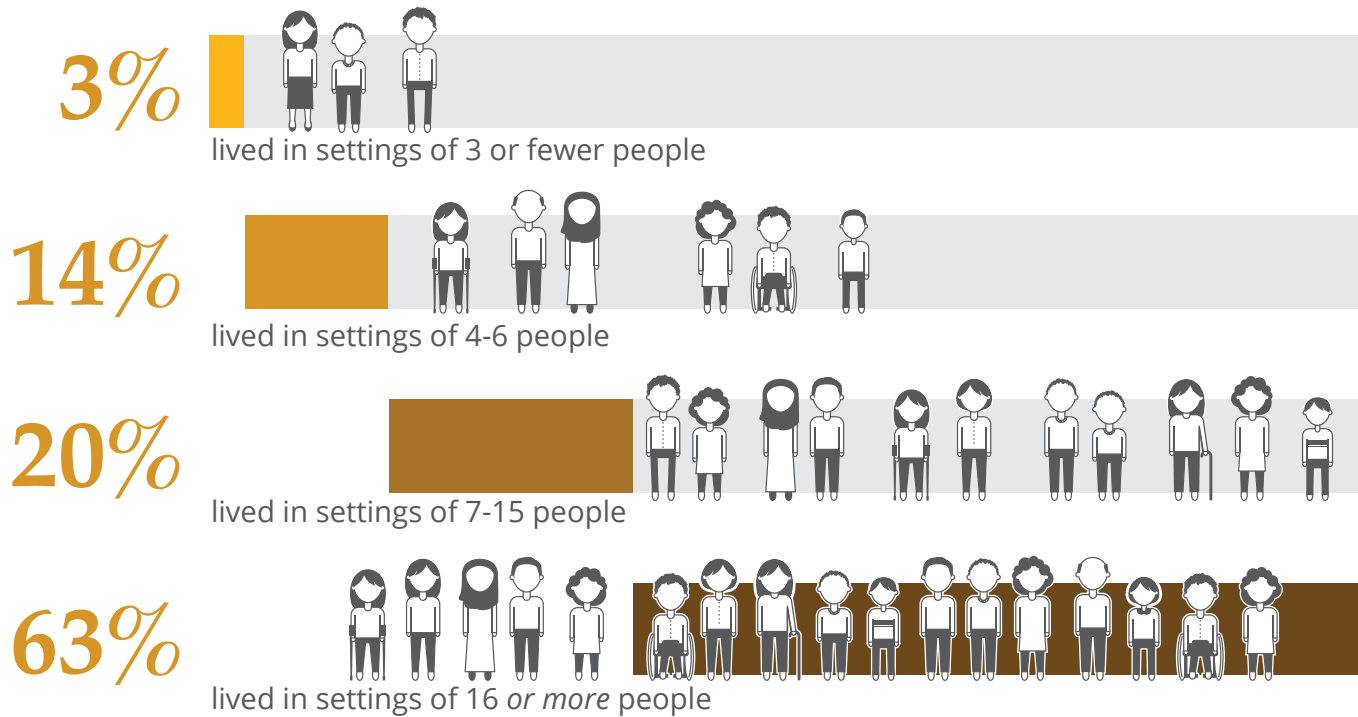
## **SECTION FOUR**

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

**FY 2017**

# State-Operated Facilities Serving People with Intellectual or Developmental Disabilities on June 20, 2017

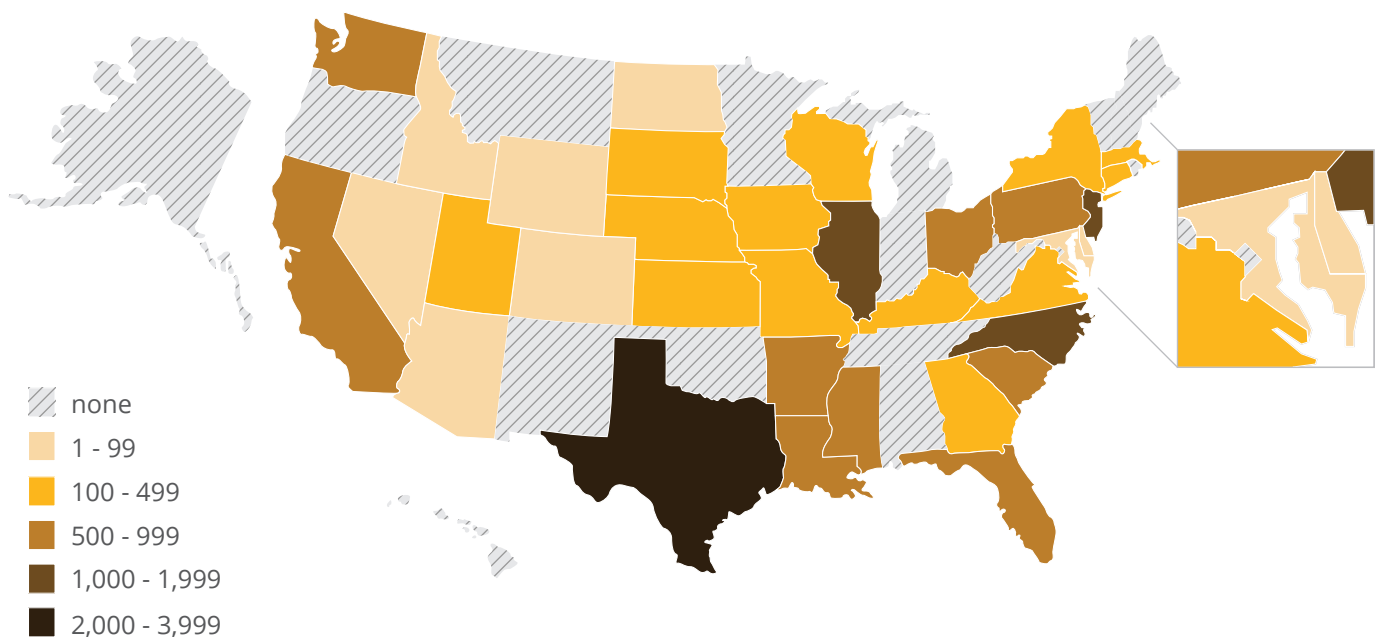
Of the 28,910 people with IDD living in state-operated settings,



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

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

By 2017, there were 18,239 people with IDD living in 119 PRFs in 34 states.





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

Section 4 describes the status of state-operated IDD facilities serving 16 or more people (Public Residential Facilities, or PRFs for short) on June 30, 2017 and trends in utilization of PRFs. It describes trends in average daily and year-end populations, movement patterns (admissions, discharges, deaths and short-term admissions), resident characteristics, previous residence of PRF current residents, staff characteristics, and services provided to community residents.

This section also lists PRFs open on June 30, 2017, and PRFs that had closed, downsized to fewer than 15 residents, privatized or converted to a different purpose by June 30, 2017. By June 30, 2017, seventeen states had closed, downsized, privatized or converted all of the PRFs that previously served people with IDD including: Alabama, Arkansas, the District of Columbia, Hawaii, Indiana, Maine, Michigan, Minnesota, Montana, New Hampshire, New Mexico, Oklahoma, Oregon, Rhode Island, Tennessee, Vermont and West Virginia. Of the remaining 35 states, 2017 PRF survey data were available for one or more facility in all states except Arizona, Kentucky, and Nebraska.

Tables 4.1, 4.10, 4.11, 4.12, 4.13, and 4.14, and Figures 4.6, 4.7, 4.8, 4.9, and 4.10 use data from the annual RISP survey of State IDD Agency Directors. The remaining tables and figures in Section 4 use data from the annual survey of administrators of large state-operated IDD facilities (PRF survey) fielded in with the cooperation of with the Association of Public and Private Developmental Disabilities Administrators (APDDA). The tables in Section 4 except Tables 4.8 and 4.9 provide state level data only for states with one or more open PRF as of June 30, 2017.

### STATUS OF PUBLIC RESIDENTIAL FACILITIES (PRFS) SERVING 16 OR MORE PEOPLE WITH IDD IN 2017

The average daily PRF population was 18,807 people in FY 2017 (See [Table 4.1](#)). The June 30 population declined 4% from 19,187 in 2016

to 18,239 in 2017. Two states, Montana and Tennessee reported closing their last PRFs in FY 2017. Between June 30, 2016 and June 30, 2017, five states reported small increases in the number of people in PRFs: North Carolina (5%), Wyoming (3%), Louisiana (3%), Nevada (2%), and Illinois (less than 1%). Six states reported a decline of 10% or more in the number of residents between June 30, 2016 and June 30, 2017 including Colorado (-12%), Connecticut (-13%), Georgia (-13%), California (-18%) and Maryland (-25%). Of the states with open PRFs, eight had fewer than 100 June 30, 2017 residents: Maryland (92), Arizona (84), North Dakota (69), Wyoming (69), Delaware (48), Nevada (48), Colorado (43), and Idaho (24).

### Admissions

During FY 2017, an estimated 1,048 people were admitted or readmitted to PRFs for stays of more than 90 days (6% of the year's average daily population). More than 100 people were admitted or readmitted to PRFs in Texas (145), Illinois (113), and California (108). Ten states admitted more than 10% of their June 30, 2017 population including Louisiana (12%), California (14%), Florida (14%), South Dakota (15%), Colorado (16%), Maryland (21%), North Dakota (28%), Wyoming (32%), Nevada (40%), and Idaho (54%). Admissions and readmissions do not include transfers from one PRF to another.

### Discharges

An estimated 1,642 people were discharged from a PRF in 2017 (9% of the average daily population). More than 100 people were discharged from PRFs in California (248), Ohio (241), Texas (141), and Florida (130). Eight states reported discharging more than 20% of their June 30, 2017 population: Idaho (83%), Nevada (38%), Ohio (36%), North Dakota (32%), California (31%), Wyoming (25%), Colorado (23%), and South Dakota (21%).

In FY 2017, eleven states discharged more than 20% of their average daily PRF population: Tennessee (39 people discharged, 65% of the average daily population), Nevada (24 people,



**Table 4.1** PRF Daily Population, Admissions, Discharges, Deaths and per Person Expenditures by State for Fiscal Year 2017

State	Average Daily Population	Admissions	Discharges	Deaths	June 30 Residents			Short -term Admissions	Average Daily Per Person Cost <sup>1</sup>
					2016	2017	1-Year % Change		
N States	36	35	34	34	36	36	36	32	34
AZ	86	0	0	2	86	84	-2%	0	DNF
AR	905	45	57	11	907	907	0%	102	404
CA	899	108	248	28	963	793	-18%	0	1,083
CO *	23	7	10	1	49	43	-12%	0	688
CT	402	3	34	18	429	375	-13%	1	928
DE	49	1	0	4	51	48	-6%	5	1,085
FL	724	98	130	22	760	724	-5%	8	475 <sup>2</sup>
GA	210 <sup>e</sup>	0	18	15	241	210 <sup>e</sup>	-13%	0	626
ID	29	13	20	0	25	24	-4%	9	849
IL	1,657	113	77	29	1,653	1,660	0%	0	425
IA	417	6	17	11	374	351	-6%	0	920
KS	301	19	20	6	316	302	-4%	0	896
KY	265	20	13	11	254 <sup>i</sup>	245	-4%	8	1,063
LA	487	62	52	11	494	510	3%	0	689
MD	92	19	16	5	122	92	-25%	1	816
MA	388	18	17	22	409	396	-3%	19	764
MS	989	37	85	31	1,005	938	-7%	53	343
MO	335	1	3	17	360	341	-5%	16	642
MT	0	0	0	0	42	0	-100%	0	853
NE	111	1	1	7	115	109	-5%	DNF	954
NV	48	19	18	0	47	48	2%	0	618
NJ	1,438	0	30	45	1,477	1,402	-5%	DNF	875
NY	363 <sup>i</sup>	DNF	DNF	DNF	436	289	-34%	DNF	DNF
NC	1,153	49	35	41 <sup>d</sup>	1,255	1,323	5%	81	659
ND	74	19	22	3	75	69	-8%	9	867
OH	702	41	241	18	721	675	-6%	172	560
PA	878	16	23	39	904	858	-5%	0	988
SC	663	36	26	20	666	657	-1%	52	443
SD	136 <sup>d</sup>	20 <sup>d</sup>	28 <sup>d</sup>	0	132	132 <sup>d</sup>	0%	0	482
TN	0	0	59	1	60	0	-100%	0	1,481
TX	3,026 <sup>d</sup>	145	141	88	3,103	3,019	-3%	0	837
UT	190	17	12	6	191	190	-1%	0	511
VA	354 <sup>d</sup>	31 <sup>d</sup>	DNF	DNF	363 <sup>d</sup>	340 <sup>i</sup>	-6%	DNF	943
WA *	714	62	19	26	700 <sup>e</sup>	695	-1%	318	767
WI	329 <sup>d</sup>	0	0	15	335	321	-4%	73 <sup>d</sup>	870
WY	79	22	17	6	67	69	3%	0	802
Reported US Total	18,516	1,048	1,489	559	19,187	18,239	-5%	927	694
Estimated US Total	18,807	1,048	1,642	591	19,187	18,239	-5%	1,042	694

Data Source: RISP Survey <sup>d</sup> Other date (data from previous or next year). <sup>e</sup> Estimate. DNF Did not furnish. <sup>i</sup> One or more component value imputed by RISP staff. \* See state notes in the Appendix. N/A Not applicable. <sup>1</sup> Per person costs are ICF/IID expenditures except in Arizona in which ICF/IID are combined with 1115 Waiver services and Georgia. <sup>2</sup> In Florida average daily costs were \$380 for people in ICF/IID certified PRFs, and \$475 for people in other facilities. Missing values replaced with values from PRF survey if available. If average daily population is not reported by the state, a simple average of year end 2016 and year end 2017 population is reported. Admissions and readmissions combined on the PRF survey beginning in 2017.

**Table 4.2** Characteristics of People with IDD Living in PRFs on June 30, 2017

Characteristic		Reported Total	Percent of Year End People	Estimated Total	N Reporting facilities
Residents on June 30, 2017		15,497		18,239	91
Gender	Male	9,891	64	11,641	91
	Female	5,606	36	6,598	
Age	0-21 Years	613	4	721	91
	22-39 Years	3,067	20	3,610	
	40-62 Years	8,110	52	9,545	
	63+ Years	3,702	24	4,357	
Race	White	10,777	70	12,740	90
	Black/African American	3,027	20	3,578	
	Hispanic/Latino	1,023	7	1,209	
	Other Race or Multiple Races	458	3	541	
Level of Intellectual Disability	Mild/No ID	2,191	14	2,579	91
	Moderate	2,119	14	2,494	
	Severe	2,430	16	2,860	
	Profound	8,570	55	10,086	
	Unknown	188	1	221	
Other Conditions	Epilepsy	5,720	39	7,072	84
	Autism	2,779	19	3,391	85
	Cerebral Palsy	2,488	17	3,076	84
	Behavior Disorder	8,061	56	10,762	81
Involved with criminal justice system		776	5	996	81
Short Term Stays in FY 2017		454	6	1,042	86

Data Source: PRF 2017 survey except estimated total short-term stays which were estimated based on responses from state IDD Directors

51%), Montana (20 people, 48%), Virginia (128 people, 35%), Colorado (16 people, 33%), Idaho (7 people, 28%), North Dakota (21 people, 28%), Ohio (182 people, 25%), South Dakota (28 people, 21%). Florida (154 people, 20%), and California (194 people, 20%).

## Deaths

An estimated 591 people with IDD (3% of the June 30 population) died while residing in a PRF in 2017. Only Texas reported more than 50 deaths (88). Four states reported no deaths in FY 2017 (Idaho, Montana, Nevada, and South Dakota). Four states reported deaths of more than 6% of their June 30, 2017 population including: Wyoming (9%), Delaware (8%), Georgia (7%), and Nebraska (6%).

## Short-Term Admissions

There were an estimated 1,042 short-term admissions lasting fewer than 90 days in FY 2017 (6% of the June 30 population). The number of people with short-term admissions may be less than the number of short-term admissions because some people had multiple short-term stays. Sixteen states reported no short-term admissions in FY 2017. Three states reported

more than 100 short-term admissions including: Washington (318), Ohio (172), and Arkansas (102). Five states reported readmissions numbering more than 12% of their June 30 population during FY 2017 including: Washington (46%), Idaho (38%), Ohio (25%), Wisconsin (23%), and North Dakota (13%).

## Daily per Person Expenditures

Average daily per-person PRF expenditures for FY 2017 were \$694 (\$253,310 per year). The average ranged from \$343 per day (\$125,195) to \$1,481 per day (\$540,565). States with average daily per person PRF expenditures of more than \$1,000 included: Tennessee (\$1,481), Delaware (\$1,085), California (\$1,083), and Kentucky (\$1,063). States with average daily per person PRF expenditures of less than \$500 included: South Dakota (\$482), Florida (\$475), South Carolina (\$443), Illinois (\$425), Arkansas (\$404), and Mississippi (\$343).

## CHARACTERISTICS OF PEOPLE LIVING IN PRFS IN FY 2017

Of the people living in PRFs on June 30, 2017, 64% were male, 4% were 21 years or younger

(721 people), 20% were 22 to 39 years (3,610), 52% were 40 to 62 years (9,545), and 24% were 63 years or older (4,357; See **Table 4.3**). Of the residents, 70% were white, 20% were black or African American, and 3% were another race, two

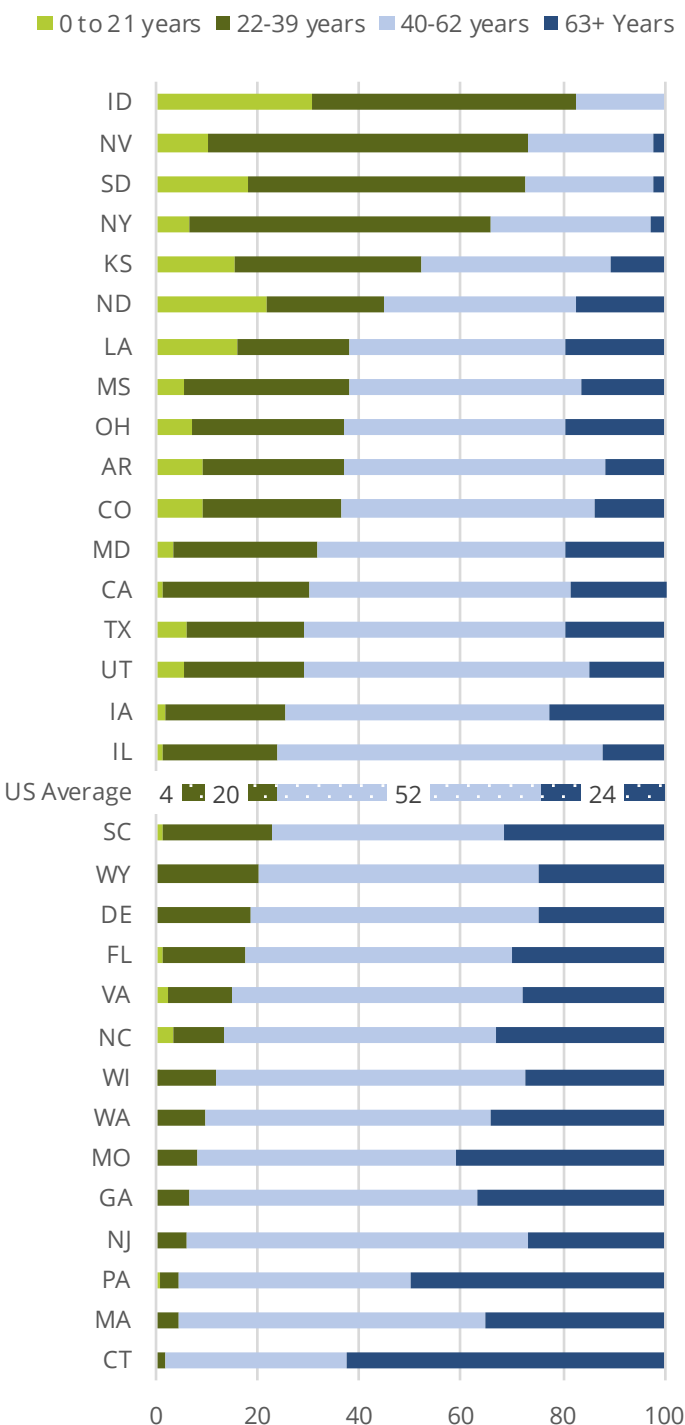
or more races or unknown race. Seven percent of PRF residents were of Hispanic origin. More than half (55%) of PRF residents had profound intellectual disabilities while 16% had severe intellectual disabilities, 14% had moderate

**Table 4.3** Number of People with IDD in PRF's by Age and State on June 30, 2017

State	Age in Years (Percent)							Reported Total
	0-18	19-21	0-21	22-39	40-62	63+	unknown	
AZ	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
AR	46	30	76	222	418	94	0	810
CA	0	12	12	227	394	149	5	787
CO	0	2	2	6	11	3	0	22
CT	0	0	0	5	97	170	0	272
DE	0	0	0	9	27	12	0	48
FL	1	9	10	113	370	211	0	704
GA	0	0	0	14	117	77	0	208
ID	1	6	7	12	4	0	0	23
IL	2	15	17	257	740	139	0	1,153
IA	1	3	4	52	113	50	0	219
KS	17	8	25	59	60	17	0	161
KY	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
LA	44	23	67	92	177	82	0	418
MD	0	3	3	26	44	18	0	91
MA	0	0	0	5	71	41	0	117
MS	28	21	49	290	411	145	0	895
MO	0	0	0	27	170	138	0	335
NE	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NV	1	4	5	30	12	1	0	48
NJ	0	0	0	85	941	375	0	1,401
NY	1	13	14	133	70	6	0	223
NC	29	12	41	133	704	441	0	1,319
ND	12	3	15	16	26	12	0	69
OH	14	21	35	143	209	95	0	482
PA	2	3	5	32	393	427	0	857
SC	4	7	11	162	345	239	0	757
SD	9	13	22	66	30	3	0	121
TX	99	77	176	702	1,556	585	0	3,019
UT	7	3	10	45	107	28	0	190
VA	1	5	6	37	163	80	0	286
WA1	0	0	0	16	95	58	0	169
WI	0	1	1	38	199	90	0	328
WY	0	0	0	13	36	16	0	65
<b>Percent</b>	<b>2</b>	<b>2</b>	<b>4</b>	<b>20</b>	<b>52</b>	<b>24</b>	<b>0</b>	<b>15,597</b>
<b>Estimated US Total</b>	<b>373</b>	<b>344</b>	<b>717</b>	<b>3,610</b>	<b>9,545</b>	<b>4,357</b>	<b>0</b>	<b>18,239</b>

Data Source: PRF 2017 Survey. N = 99 facilities DNF Data not furnished. <sup>1</sup> Data is for only 1 of 4 facilities. No state-operated facilities with 16 or more people in FY2017: AL, AK, DC, HI, IN, ME, MI, MN, MT, NM, OK, OR, RI, TN, VT and WV.

**Figure 4.1** Age of People Living in PRF's by State on June 30, 2017



Age data were not reported for AZ, KY, and NE.



intellectual disabilities, 14% had mild or no intellectual disabilities, and the level of intellectual disabilities was unknown for 1%.

Other conditions reported for people living in PRFs included epilepsy (39%), autism (19%), cerebral palsy (17%), blindness (15%) or a behavior disorder requiring planned interventions (56%). An estimated 996 (5%) of the people living in a PRF had been involved with the criminal justice system.

## Age

There were dramatic state-to-state differences in the ages of PRF residents (See **Table 4.3** and **Figure 4.1**). Twenty-three states reported one or more resident ages 19 to 21 years, and twenty states reported one or more resident ages 18 years or younger. States with twenty or more PRF residents 18 years or younger included Texas (99), Arkansas (46), Louisiana (44), Mississippi (28), and North Carolina (29). Three additional states reported 20 or more PRF residents 21 years or younger including Ohio (35), Kansas (25), and South

Dakota (22). PRFs in nine states reported serving no people younger than 22 years: Connecticut, Delaware, Georgia, Massachusetts, Missouri, New Jersey, Washington, and Wyoming.

Only Indiana (30%) and North Dakota (22%) reported that more than 20% of PRF residents were 21 years or younger. More than half of PRF residents were 39 years or younger in five states: Kansas (52%), New York (66%), South Dakota (73%), Nevada (73%), and Idaho (83%).

More than 50% of all PRF residents were 63 years or older in Connecticut (63%), and Pennsylvania (50%). More than 90% of all PRF residents were 40 years or older in Connecticut (98%), Massachusetts (96%), Pennsylvania (96%), New Jersey (94%), Georgia (93%), Missouri (92%), Washington (91%). Between 75% and 90% of PRF residents were 40 years or older in Wisconsin (88%), North Carolina (87%), Virginia (85%), Florida (83%), Delaware (81%), Wyoming (80%), South Carolina (77%) and Illinois (76%). The proportion 40 years or older was between 50% and 75% in eleven additional states.

## Level of Intellectual Disability

There were notable state-to-state differences in the distribution of PRF residents by level of intellectual disability (See **Table 4.4** and **Figure 4.2**). Overall, 14% of PRF residents had moderate ID, and 14% had mild ID. The proportion of residents with no, mild or moderate ID ranged from 5% in Wisconsin and 6% in Delaware to 87% in New York. Other states reporting that more than half of all PRF residents had no, mild or moderate ID included South Dakota (84%), Idaho

(74%), Colorado (68%), Kansas (58%), Nevada (54%) and North Dakota (51%).

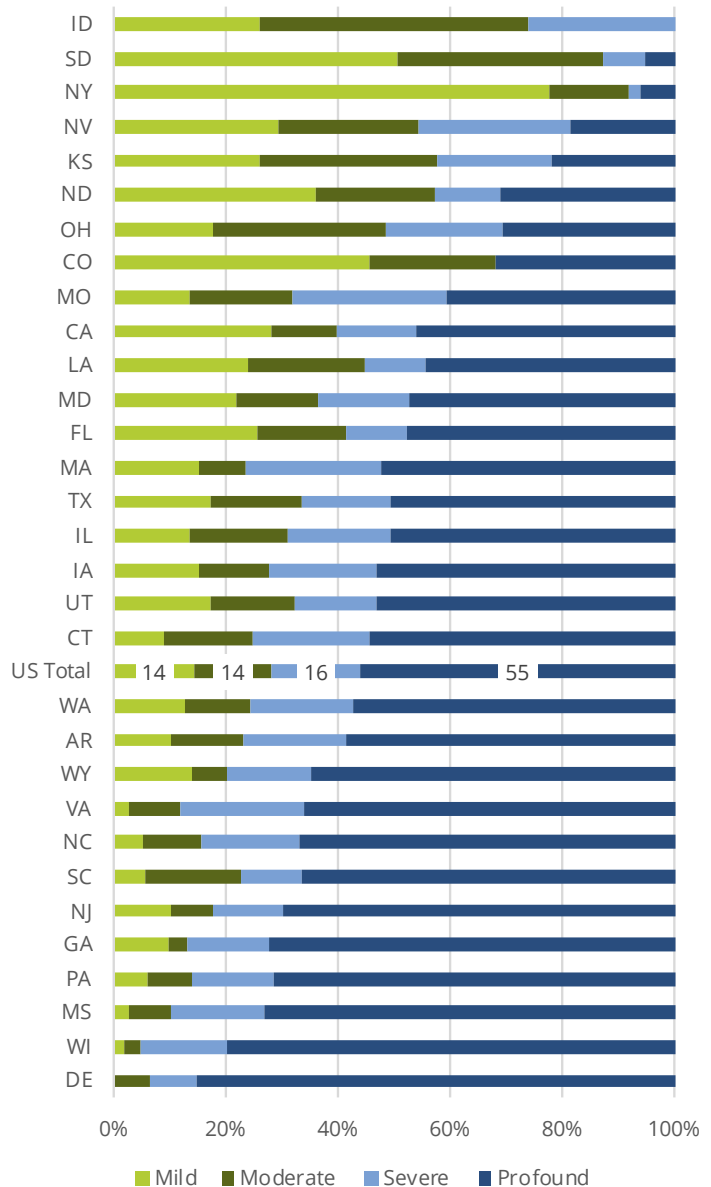
Overall, 16% of PRF residents had severe intellectual disability, and 56% had profound ID. The proportion with severe intellectual disability ranged from none in Colorado to 26% in Idaho and 27% in Missouri and Nevada. The proportion with profound ID ranged from none in Idaho to 71% in Pennsylvania and Georgia, 73% in Mississippi, 79% in Wisconsin, and 85% in Delaware. Of the 32 reporting states, 19

**Table 4.4** Level of Intellectual Disability of People in PRFs (in percent) by State on June 30, 2017

State	Level of Intellectual Disability (Percent)					Number of People
	Mild	Moderate	Severe	Profound	Unknown	
AZ	DNF	DNF	DNF	DNF	DNF	DNF
AR	10	13	19	58	0	810
CA	25	11	12	41	11	787
CO	45	23	0	32	0	22
CT	9	16	21	54	0	272
DE	0	6	8	85	0	48
FL	25	16	11	48	0	704
GA	10	3	14	71	1	208
ID	26	48	26	0	0	23
IL	13	18	18	50	1	1,153
IA	15	13	19	53	0	219
KS	26	32	20	22	0	161
KY	DNF	DNF	DNF	DNF	DNF	DNF
LA	24	21	11	44	1	418
MD	22	14	16	47	0	91
MA	15	8	23	50	5	117
MS	3	7	17	73	0	895
MO	13	18	27	41	0	336
NE	DNF	DNF	DNF	DNF	DNF	DNF
NV	29	25	27	19	0	48
NJ	10	7	13	70	0	1,401
NY	74	13	2	6	5	223
NC	5	10	18	66	1	1,319
ND	32	19	10	28	12	69
OH	18	31	21	30	0	482
PA	6	8	15	71	0	857
SC	6	17	11	66	0	657
SD	49	36	7	5	3	121
TN	DNF	DNF	DNF	DNF	DNF	DNF
TX	17	16	16	50	1	3,019
UT	17	15	15	53	0	190
VA	3	9	22	66	0	286
WA	12	12	18	57	1	169
WI	2	3	16	79	1	328
WY	14	6	15	65	0	65
<b>Reported US Total</b>	<b>14</b>	<b>14</b>	<b>16</b>	<b>55</b>	<b>1</b>	<b>15,498</b>
<b>Estimated US Total</b>	<b>2,579</b>	<b>2,494</b>	<b>2,860</b>	<b>10,086</b>	<b>221</b>	<b>18,239</b>

N = 91 facilities reporting. States with no PRFs are not shown

**Figure 4.2** Level of Intellectual Disability Distribution of People in PRFs by State on June 30, 2017





reported that more than half of all PRF residents had profound intellectual disability.

## PRF ADMISSIONS AND DISCHARGES

A total of 121 PRFs reported the ages and level of intellectual disability for PRF residents as of June 30, 2017, 69 facilities reported the number of admissions or readmissions, and 80 facilities reported the number of discharges in PRF's during 2017.

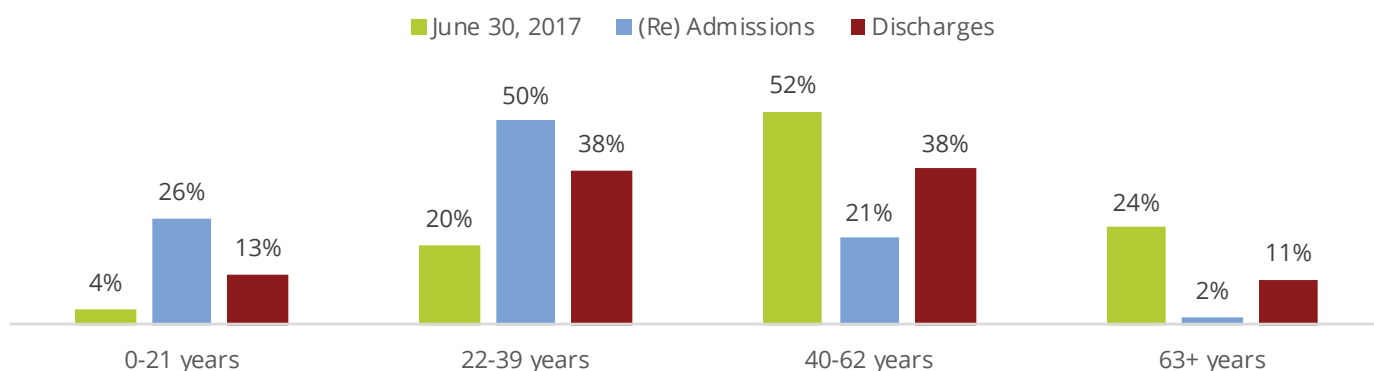
### Admissions and Discharges by Age and Level of ID

People who were admitted or discharged from PRFs in 2017 differed in age and level of disability from current residents on June 30, 2017 (See **Table 4.5** and **Figures 4.3** and **4.4**). Of the people living in a PRF on June 30, 2017, 76% were 40 years or older,

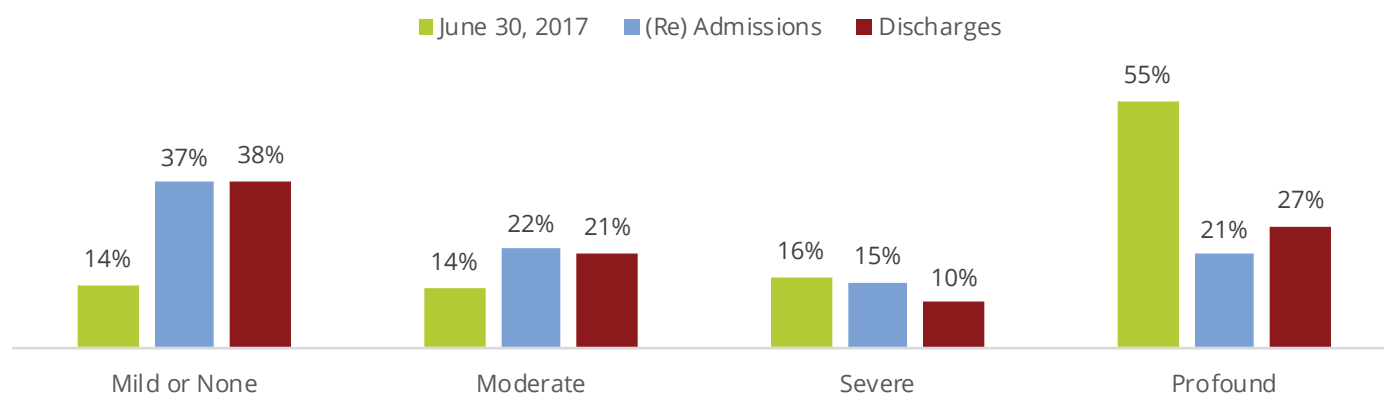
**Table 4.5** Age and Level of Intellectual Disabilities for Current, Admitted and Discharged Residents of PRFs for FY 2017

Characteristic	June 30, 2017		(Re) Admissions		Discharges	
	Est N.	Percent	Number	Percent	Number	Percent
Number of Facilities	121		69		80	
<b>Age</b>						
0-18 years	373	2%	143	14%	80	6%
19-21 years	344	2%	124	12%	87	7%
0-21 years	717	4%	267	26%	167	13%
22-39 years	3,610	20%	508	50%	504	38%
40-62 years	9,545	52%	216	21%	510	38%
63+ years	4,357	24%	22	2%	149	11%
Age Unknown	0	0%	1	0%	4	0%
<b>Level of ID</b>						
Mild or None	2,579	14%	424	37%	505	38%
Moderate	2,494	14%	253	22%	288	21%
Severe	2,860	16%	168	15%	136	10%
Profound	10,086	55%	239	21%	368	27%
IDD Level Unknown	221	1%	57	5%	47	3%

**Figure 4.3** Age Distribution for June 30, Newly Admitted, Readmitted and Discharged PRF Residents in FY 2017



**Figure 4.4** Level of Intellectual Disabilities for June 30, Newly Admitted, Readmitted and Discharged PRF Residents in FY 2017



20% were 22 to 39 years, and 4% were 21 years or younger. Of the people admitted or readmitted 23% were 40 years or older, 50% were 22 to 39 years, and 25% were 21 years or younger. Of the people discharged, 49% were 40 years or older, 38% were 22 to 39 years, and 13% were 21 years or younger.

People 21 years or younger were 26% of admissions or readmissions but only 13% of discharges. People 22 to 39 years were 50% of admissions but only 38% of discharges. More than half of all residents (52%) of PRFs on June 30, 2017 were 40 to 62 years, but only 21% of those admitted and 38% of those discharged were in that age group. Finally, people 63 years or older were 24% of all residents on June 30, 2017, but only 2% of those admitted and 11% of those discharged.

Of the people living in PRFs on June 30, 2017, 14% had mild or no ID, 14% had moderate ID, 16% had severe ID and 55% had profound ID. More than half (59%) of all people admitted to PRFs in 2017 had no, mild or moderate ID while 15% had severe ID and 21% had profound ID. Similarly, more than half (59%) of all people discharged had no, mild or moderate ID compared with 10% who had severe ID and 27% who had profound ID.

People with mild or no ID were 37% of those admitted or readmitted and 38% of those discharged from PRFs in 2017. People with moderate ID were 22% of those admitted and 21% of those discharged. People with severe ID were 15% of those admitted or readmitted compared to 10% of those discharged. Finally, while people with profound ID were 55% of current residents, they were only 21% of those admitted and 27% of those discharged in 2017.

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

For FY 2017, 67 facilities reported previous residence for 881 of the estimated 1,048 people admitted to PRFs, and 77 facilities reported subsequent residence for 1,227 of the estimated 1,642 people leaving PRFs (See **Table 4.6** and **Figure 4.5**).

In 2017, 27% of people admitted to PRFs had been living with a family member (6%), or in their own home or with a host or foster family (21%) prior

**Table 4.6** Previous Residence for People Admitted or Readmitted to PRFs and Subsequent Residence Type for People Discharged from PRFs 2017 (in Percent)

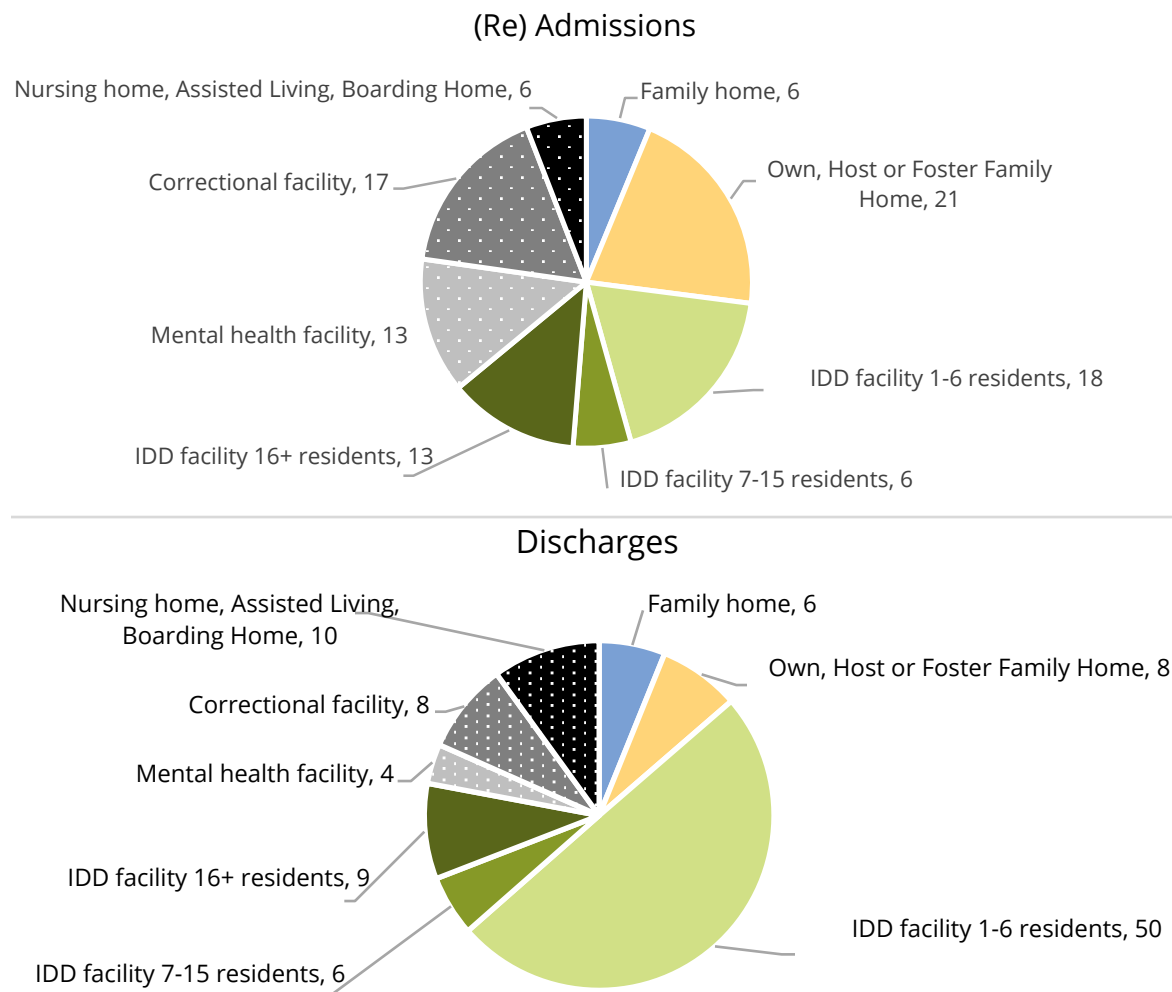
Setting Type	Admissions	Discharges
Number of reporting facilities	67	77
Total Reported (Re)Admissions/Discharges	881	1,227
Family home	6	6
Own, Host or Foster Family Home	21	8
IDD facility 1-6 residents	18	50
IDD facility 7-15 residents	6	6
IDD facility 16+ residents	13	9
Mental health facility	13	4
Correctional facility	17	8
Nursing home, Assisted Living, Boarding Home	6	10
Previous residence was unknown for 54 (re)admissions (6%). Subsequent residence was unknown for 84 discharges (7%).		

**Table 4.7** Staff Characteristics and Outcomes in PRFs in FY 2017

Type of Staff	N Facilities	N FTE staff	FTE staff per resident
Direct Support Professionals (DSP)	83	27,487	2
Front Line Supervisors (FLS)	83	3,333	0
Turnover and Vacancy Rate	Rate		
DSP Vacancy Rate (%)	81	12	
DSP Turnover Rate (%)	81	40	
FLS Vacancy Rate (%)	77	10	
FLS Turnover Rate (%)	77	17	
Wages or Salary	Average		
DSP Starting Hourly Wage	81	\$14	
DSP Average Hourly Wage	81	\$16	
FLS Starting Salary	78	\$38,123	
FLS Average Salary	78	\$47,678	
FTE Full time equivalent. (One FTE is 1 person working 40 hours per week or a combination of two more people working a combined 40 hours per week.			

to being admitted. More than one-third (37%) of people admitted to PRFs had been living in a group home (18% were living in a group home of six or fewer people; 6% were living in a group home of 7 to 15 people, and 13% were living in a facility of 16 or more residents). The final third (36%) of people admitted came from an institution not specifically designed to serve people with IDD including 13% who had been in a mental health hospital or facility, 17% who had been in a correctional facility, and 6%

**Figure 4.5** Previous and Subsequent Residence For People Admitted or Readmitted to and Discharged from PRFs in 2017 (in percent)



who had been in a nursing home, assisted living facility or boarding home.

In FY 2017, 14% of the people discharged from PRFs moved to the home of a family member (6%) or their own home or the home of a host or foster family (8%). Almost two-thirds (64%) moved to an IDD group setting including 50% who moved to a setting serving 6 or fewer LTSS recipients, 6% who moved to a setting serving 7 to 15 LTSS recipients with IDD, and 9% who moved to a setting serving 16 or more LTSS recipients with IDD. The remaining 22% moved to a facility not specifically designed to serve people with IDD including 4% who moved to a mental health facility or hospital, 8% who moved to a correctional facility, and 10% moved to a nursing home, assisted living facility or boarding home.

A higher proportion of people who were discharged moved to a group IDD setting serving six or fewer people than the proportion who had been admitted or readmitted from that type of facility (50% versus 18%). A lower proportion of people who were discharged moved to an own home or foster family home (8% versus 21%), mental health facility or hospital (4% versus 13%), or a correctional facility (8% versus 17%) than the proportion of people admitted or readmitted from those settings.

## PRF STAFFING CHARACTERISTICS AND OUTCOMES

Staffing characteristics and outcomes were reported for between 77 and 83 PRFs (See **Table 4.7**). PRFs employed 27,487 full-time equivalent (FTE)

direct support professionals and 3,333 front line supervisors on June 30, 2017. One FTE is 40 staff hours worked per week whether those hours are worked by one employee or shared by two or more employees. PRFs employed 1.88 FTE direct support professionals and 0.23 front line supervisors per June 30, 2017 resident.

Staff turnover rates were computed as the total number of staff who left during the year divided by the total staff complement (including vacant positions) on June 30, 2017. Average turnover rates were 39.5% for direct support professionals and 11.7% for front line supervisors for FY 2017.

Vacancy rates were computed as the total number of vacant positions on June 30, 2017 divided by the number of current staff plus the number of vacancies to be filled. An estimated 16.6% of DSP positions and 9.9% of FLS positions were vacant on June 30, 2017.

In FY 2017, starting wages for DSPs were \$13.77 (\$28,649 annually) and average wages for DSPs were \$16.11 (\$33,518). The average FLS starting annual salary was \$38,123 and the average annual salary was \$47,678.

## PRF STATUS BY FACILITY AS OF JUNE 30, 2017

FY 2017 PRF surveys were returned for 98 of the 110 PRFs tracked by the RISP project (an 88% response rate, See **Table 4.8**). Responding facilities served 16,426 people with IDD (90% of the estimated total residents of 18,516 on June 30, 2017). They served an average of 170 people with IDD. Facilities served between 22 people and 478 people with IDD. The facilities opened on average in 1950. The oldest facility was the Columbus Developmental Center in Ohio, which opened in 1857. The newest facility was the Mississippi Adolescent Center in Mississippi, which opened in 2011.

The year-end populations of reporting PRFs declined by an average of 3% between June 30, 2016 and June 30, 2017. Seventy-one facilities reported a population decline, including 16 that reported a decline of 10% or more. The largest population decline between June 30, 2016 and June 30, 2017 was at Bernard M. Fineson Developmental

Center in New York (declining 70%, from 77 to 23 residents). Facilities that increased in size by more than 10% were Hartford Regional Center in Connecticut, (increasing 46%, from 33 to 48 residents) Columbus Developmental Center in Ohio (increasing 15%, from 95 to 109 residents), and Southeastern Virginia Training Center (increasing 11% from 65 to 72 residents).

Daily per person expenditures averaged \$777 (\$283,605 per year) in the reporting facilities and ranged from \$296 (\$108,040 per year) in Mississippi's Hudspeth Regional Center to \$2,115 (\$771,975 per year) in California's Fairview Development Center in Costa Mesa. Nine facilities (11%) reported daily per person expenditures of less than \$400, 22 (26%) reported expenditures between \$400 and \$700, 42 (50%) reported expenditures between \$701 and \$1,000, and 11 reported expenditures of more than \$1,000 per person per day.

Admissions or readmissions between July 1, 2016 and June 30, 2017 averaged 12 per facility with a range from zero in 14 facilities to 92 at California's Porterville Development Center. Discharges averaged 15 per facility with a range from 0 in 7 facilities to 102 at California's Porterville Development Center. Deaths averaged 6 per facility, ranging from zero in twelve facilities to 40 in the Southwest Ohio Development Center.



**Table 4.8** PRFs Open on June 30, 2017: Projected Closure Date, Population, Per Person Expenditures, Admissions, Discharges and Deaths By State and Facility Name

State	Facility Name (City)	Year Opened	Estimated Closure	Population				Average Daily Per Person Cost (\$)	Admissions	Discharges	Transfers	Deaths
				With IDD June 2017	Any disability June 2017	Average daily with IDD 2017	With IDD June 2016	% Change 2016-17				
AR	Arkadelphia Human Dev. Ctr. (Arkadelphia)	1968		110	110	113	114	-4	3	9	1	0
AR	Booneville HDC (Booneville)	1972		128	128	124	122	5	11	5	0	0
AR	Conway HDC (Conway)	1959		467	473	468	468	-0	19	12	3	11
AR	Jonesboro HDC (Jonesboro)	1970		105	105	105	108	-3	27	30	DNF	DNF
AR	Southeast Arkansas HDC (Warren)	1978		96	93	DNF	DNF	DNF	7	3	DNF	DNF
AZ	Arizona Trng. Program (Coolidge)	1952		83	83	85	86	-3	0	0	DNF	DNF
CA	Canyon Springs (Cathedral City)	2001		48	48	46	46	4	14	11	0	0
CA	Fairview Dev. Ctr. (Costa Mesa)	1959	Dec 2019	162	166	192	216	-25	3	50	1	7
CA	Porterville Dev. Ctr. (Porterville)	1953	Dec 2021	321	321	338	350	-8	92	102	13	6
CA	Sonoma Dev. Ctr. (Eldridge)	1891	Dec 2018	256	260	307	342	-25	0	71	1	14
CO	Grand Junction Regional Ctr. (Grand Junction)	1919		22	22	24	28	-21	0	6	0	0
CO	Wheat Ridge Regional Ctr. (Wheatridge)	1912		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
CT	Northwest Ctr. (Torrington)	1984		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
CT	Hartford Regional Center (Newington)	1965		48	48	48	33	45	15	0	0	0
CT	Lower Fairfield County Ctr. (Norwalk)	1976		68	68	DNF	DNF	DNF	14	1	DNF	1
CT	Southbury Trng. School (Southbury)	1940		224	224	239	261	-14	0	22	0	15
DE	Stockley Ctr. (Georgetown)	1921		48	48	48	51	-6	2	1	0	4
FL	Developmental Disabilities Defendant Program (DDDP, Chattahoochee)	1977		79	79	77	85	-7	82	87	DNF	1
FL	Sunland Ctr. (Marianna)	1961		275	275	285	302	-9	8	27	DNF	8
FL	Tacachale Ctr. / Seguin Unit (Gainesville)	1921		350	350	361	371	-6	7	15	0	13
GA	East Central Regional Hospital (Gracewood & Augusta)	1921		178	178	192	206	-14	0	18	0	10
GA	Georgia Regional Hospital of Atlanta (Decatur)	1968		30	30	33	35	-14	0	0	0	5
IA	Glenwood Resource Ctr. (Glenwood)	1876		219	219	219	231	-5	1	9	0	4
IA	Woodward Resource Ctr. (Woodward)	1917		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
ID	Southwest Idaho Treatment Center (Nampa)	1918		23	25	26	24	-4	12	13	DNF	DNF
IL	Choate Dev. Ctr. (Anna)	1873		149	177	174	143	4	23	23	8	2
IL	Fox Dev. Ctr. (Dwight)	1965		99	99	99	105	-6	5	8	0	3
IL	Kiley Dev. Ctr. (Waukegan)	1975		195	195	190	191	2	19	13	1	3



**Table 4.8** PRFs Open on June 30, 2017: Projected Closure Date, Population, Per Person Expenditures, Admissions, Discharges and Deaths By State and Facility Name

State	Facility Name (City)	Year Opened	Estimated Closure	Population				Average Daily Per Person Cost (\$)	Admissions	Discharges	Transfers	Deaths
				With IDD June 2017	Any disability June 2017	Average daily with IDD 2017	With IDD June 2016	% Change 2016-17				
IL	Ludeman Dev. Ctr. (Park Forest)	1972		388	388	389	392	-1	9	8	1	6
IL	Mabley Dev. Ctr. (Dixon)	1987		109	109	108	106	3	6	0	0	3
IL	Murray Dev. Ctr. (Centralia)	1964	TBD	213	213	210	208	2	17	9	0	3
IL	Shapiro Dev. Ctr. (Kankakee)	1879		478	478	478	478	0	28	22	0	7
KS	Kansas Neurological Institute (Topeka)	1960		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
KS	Parsons State Hospital (Parsons)	1952		161	161	159	165	-2	17	20	0	1
KY	Bingham Gardens (Louisville)	1873		DNF	24	DNF	DNF	DNF	DNF	DNF	DNF	DNF
KY	Hazelwood Ctr. (Louisville)	1971	Sept 2017	DNF	100	DNF	DNF	DNF	DNF	DNF	DNF	DNF
LA	Louisiana Special Education Center (Alexandria)	1952		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
LA	Pinecrest Supports and Services Center (Pineville)	1918		418	418	430	433	-3	41	47	0	10
MA	Hogan Regional Ctr. (Hawthorne)	1967		117	117	116	117	0	6	DNF	DNF	9
MA	Wrentham Dev. Ctr. (Wrentham)	1907		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MD	Holly Ctr. (Salisbury)	1975		52	52	52	57	-9	0	0	0	5
MD	Potomac Ctr. (Hagerstown)	1978		39	39	39	38	3	19	18	0	0
MS	Boswell Regional Ctr. (Sanatorium)	1976		93	93	92	96	-3	22	19	2	4
MS	Ellisville State School (Ellisville)	1920		263	263	294	277	-9	2	12	0	15
MS	Hudspeth Regional Ctr. (Whitfield)	1974		225	225	223	243	-7	7	14	16	4
MS	Mississippi Adolescent Center (Brookhaven)	2011		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MS	North Mississippi Regional Ctr. (Oxford)	1973		215	218	229	233	-8	1	16	0	3
MS	South Mississippi Regional Ctr. (Long Beach)	1978		110	110	119	124	-11	5	14	0	5
MO	Bellevue Habilitation Ctr. (St. Louis)	1924		117	124	117	121	-3	0	1	0	3
MO	Higginsville Habilitation Ctr. (Higginsville)	1956		48	48	56	56	-14	0	4	0	4
MO	Southeast Missouri Residential Services (Poplar Bluff and Sikeston)	1992		61	61	61	61	0	DNF	DNF	DNF	2
MO	St. Louis Dev. Disabilities Treatment Ctrs. (South County, St. Charles Hab. Ctr.)	2002		109	110	109	109	0	0	2	0	5
NE	Sheridan Cottages ICF (Beatrice)	1875		108	109	112	115	-6	1	1	DNF	7
NV	Desert Regional Ctr. (Las Vegas)	1975		48	48	47	47	2	19	18	0	0

**Table 4.8** PRFs Open on June 30, 2017: Projected Closure Date, Population, Per Person Expenditures, Admissions, Discharges and Deaths By State and Facility Name

State	Facility Name (City)	Year Opened	Estimated Closure	Population				Average Daily Per Person Cost (\$)	Admissions	Discharges	Transfers	Deaths
				With IDD June 2017	Any disability June 2017	Average daily with IDD 2017	With IDD June 2016	% Change 2016-17				
NJ	Green Brook Regional Ctr. (Green Brook)	1981		102	102	103	106	-4	DNF	2	DNF	2
NJ	Hunterdon Dev. Ctr. (Clinton)	1969		477	477	485	495	-4	4	1	DNF	21
NJ	Vineland Dev. Ctr. (Vineland)	1888		207	207	214	220	-6	DNF	6	DNF	7
NJ	New Lisbon Dev. Ctr. (New Lisbon)	1914		338	338	350	362	-7	DNF	17	DNF	7
NJ	Woodbine Dev. Ctr. (Woodbine)	1921		277	277	285	294	-6	1	10	DNF	8
NY	Bernard M. Fineson Dev. Ctr. (Hillside; Howard Park)	1970	Dec 2017	23	23	50	77	-70	0	52	0	0
NY	Sunmount DDSO (Tupper Lake)	1965		155	155	158	160	-3	37	39	DNF	DNF
NY	Valley Ridge (Norwich)	2000		45	45	46	46	-2	10	11	0	0
NC	Black Mountain Ctr. (Black Mountain)	1982		85	149	87	87	-2	8	1	0	9
NC	Caswell Ctr. (Kinston)	1914		328	329	327	328	0	9	2	0	6
NC	J. Iverson Riddle Dev. Ctr. (Morganton)	1963		280	280	280	284	-1	6	4	1	7
NC	Murdoch Ctr. (Butner)	1957		425	428	432	422	1	36	20	0	13
NC	O'Berry Ctr. (Goldsboro)	1957		201	201	205	212	-5	1	3	0	9
ND	Life Skills and Transition Center (Grafton)	1904		69	69	74	75	-8	19	22	0	3
OH	Cambridge Dev. Ctr. (Cambridge)	1965		70	70	71	79	-11	26	35	0	0
OH	Columbus Dev. Ctr. (Columbus)	1857		109	109	106	95	15	39	23	0	2
OH	Gallipolis Dev. Ctr. (Gallipolis)	1893		55	57	53	55	0	17	16	0	1
OH	Mount Vernon Dev. Ctr. (Mount Vernon)	1948		80	80	78	73	10	21	10	0	4
OH	Northwest Ohio Dev. Ctr. (Toledo)	1977		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
OH	Southwest Ohio Dev. Ctr. (Batavia)	1981		100	100	98	98	2	29	32	1	40
OH	Tiffin Dev. Ctr. (Tiffin)	1975		68	89	83	69	-1	0	3	1	1
OH	Warrensville Dev. Ctr. (Warrensville)	1975		96	DNF	DNF	DNF	DNF	32	25	DNF	2
PA	Ebensburg Ctr. (Ebensburg)	1957		220	230	214	230	-4	3	8	0	5
PA	Hamburg Ctr. (Hamburg)	1960	June 2018	76	77	76	83	-8	DNF	1	DNF	6
PA	Polk Ctr. (Polk)	1897	2022	220	220	220	235	-6	9	7	0	11
PA	Selinsgrove Ctr. (Selinsgrove)	1929		224	224	224	233	-4	5	5	0	9
PA	White Haven Ctr. (White Haven)	1956	2022	117	117	122	124	-6	1	1	0	7
SC	Coastal Ctr. (Ladson)	1968		149	149	152	150	-1	4	5	0	0
SC	Midlands Ctr. (Columbia)	1956		129	129	135	135	-4	9	8	DNF	7
SC	Pee Dee Regional Ctr. (Florence) and Thad E. Saleeby Ctr. (Hartsville)	1971		188	188	189	193	-3	12	10	DNF	7

**Table 4.8** PRFs Open on June 30, 2017: Projected Closure Date, Population, Per Person Expenditures, Admissions, Discharges and Deaths By State and Facility Name

State	Facility Name (City)	Year Opened	Estimated Closure	Population				Average Daily Per Person Cost (\$)	Admissions	Discharges	Transfers	Deaths	
				With IDD June 2017	Any disability June 2017	Average daily with IDD 2017	With IDD June 2016						% Change 2016-17
SC	Whitten Ctr. (Clinton)	1920		191	191	194	188	2	420	11	5	DNF	3
SD	South Dakota Dev. Ctr. (Redfield)	1902		121	121	121	132	-8	498	9	20	DNF	DNF
TX	Abilene State School (Abilene)	1957		282	282	288	293	-4	830	7	3	0	12
TX	Austin State School (Austin)	1917		180	180	182	184	-2	830	0	0	3	7
TX	Brenham State School (Brenham)	1974		259	259	263	264	-2	830	14	6	2	11
TX	Corpus Christi State School (Corpus Christi)	1970		208	208	212	220	-5	830	4	5	1	9
TX	Denton State School (Denton)	1960		447	447	447	458	-2	830	9	6	4	18
TX	El Paso State Ctr. (El Paso)	1973		95	95	100	107	-11	830	4	9	0	6
TX	Lubbock State School (Lubbock)	1969		185	185	188	191	-3	830	10	9	1	7
TX	Lufkin State School (Lufkin)	1962		298	298	296	295	1	830	14	8	2	3
TX	Mexia State School (Mexia)	1946		246	246	236	256	-4	830	41	47	3	4
TX	Richmond State School (Richmond)	1968		319	319	320	328	-3	830	8	15	4	3
TX	Rio Grande State Ctr. (Harlingen)	1973		60	60	59	61	-2	830	7	7	0	0
TX	San Angelo State School (Carlsbad)	1969		213	213	209	217	-2	830	16	21	7	2
TX	San Antonio State School (San Antonio)	1978		227	227	226	229	-1	830	11	5	1	6
UT	Utah State Dev. Ctr. (American Fork)	1931		190	190	190	191	-1	578	17	2	DNF	6
VA	Central Virginia Trng. Ctr. (Lynchburg)	1911	June 2020	144	144	167	192	-25	994	9	51	0	6
VA	Southeastern Virginia Trng. Ctr. (Chesapeake)	1975		72	72	67	65	11	840	13	6	DNF	DNF
VA	Southwestern Virginia Trng. Ctr. (Hillsville)	1976	June 2018	70	70	81	98	-29	762	0	23	1	4
WA	Fircrest (Seattle)	1959		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
WA	Lakeland Village School (Medical Lake)	1915		169	179	183	169	0	776	2	0	9	13
WA	DSHS Rainier School (Buckley)	1939		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
WA	Yakima Valley School (Selah)	1958		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
WI	Central Wisconsin Ctr. (Madison)	1959		196	209	209	204	-4	DNF	DNF	DNF	DNF	8
WI	Southern Wisconsin Ctr. (Union Grove)	1919		132	132	132	135	-2	896	9	5	0	7
WY	Wyoming Life Resource Ctr. (Lander)	1912		65	74	74	67	-3	852	5	1	0	6

Transfers averaged 1 per facility with a range from 0 in 47 facilities to 16 for Mississippi's Hudspeth Regional Center.

## Projected PRF Closures

The following facilities projected closing between July 1, 2017 and June 30, 2022. One facility in Illinois reported plans to close but did not specify a date.

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

- Hazelwood Center (Louisville, KY)
- Bernard M. Fineson Developmental Center (Hillside, NY)
- Hamburg Center (Hamburg, PA)
- Southwestern Virginia Training Center (Hillsville, VA)

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

- Sonoma Developmental Center (Eldridge, CA)

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

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

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

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

- Porterville Development Center (Porterville, CA)
- Polk Center (Polk, PA)
- White Haven Center (White Haven, PA)

## PRFs Closures and Projected Closures

**Table 4.9** lists the names and disposition of 243 PRFs that closed, converted to serving a different population, converted from state-operation to private operation or downsized to fewer than 16 people with IDD on or before June 30, 2017. Some facilities on the list merged, split off, or changed names during the years they were in operation.

Closures between July 1, 2016 and June 30, 2017 included:



**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, 2017

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



**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, 2017

State	Facility Name at Closure, Downsizing or Conversion	Year Opened	Final Status	
			Fiscal Year	Disposition <sup>1</sup>
GA	Brook Run (Atlanta)	1969	1997	
GA	Central State Hospital (Milledgeville)	1842	2012	Converted
GA	Georgia Regional Hospital (Savannah)	2000	2005	
GA	Gracewood State School and Hospital, now East Central (Gracewood)	1921	2015	Merged
GA	Northwest Regional Hospital (Rome)	1971	2011	
GA	River's Crossing (Athens)		1996	
GA	Rose Haven (Thomasville)	1968	2000	
GA	Southwestern Development Center (Bainbridge)	1967	2000	
GA	Southwestern State Hospital (Thomasville)	1967	2013	
GA	West Central Georgia Regional Hospital (Columbus)	2000	2004	
HI	Kula Hospital (Kula)	1984	1994	
HI	Waimano Trng. School and Hospital (Pearl City)	1921	1999	
IL	Alton Mental Health & Dev. Ctr. (Alton)	1914	1994	
IL	Bowen Ctr. (Harrisburg)	1966	1982	
IL	Dixon Ctr. (Dixon)	1918	1987	
IL	Elgin Mental Health & Dev. Ctr. (Elgin)	1872	1994	
IL	Galesburg Ctr. (Galesburg)	1959	1985	
IL	Howe Dev. Ctr. (Tinley Park)	1973	2010	
IL	Jacksonville Dev. Ctr. (Jacksonville)	1851	2012	
IL	Lincoln Dev. Ctr. (Lincoln)	1866	2002	
IL	Meyer Mental Health Ctr. (Decatur)	1967	1993	
IL	Singer Mental Health & Dev. Ctr. (Rockford)	1966	2002	
IN	Central State Hospital (Indianapolis)	1848	1995	
IN	Evansville State Hospital (Evansville)	1890	2011	
IN	Fort Wayne Dev. Ctr. (Fort Wayne)	1890	2007	
IN	Logansport State Hospital (Logansport)	1888	2012	Converted
IN	Madison State Hospital (Madison)	1910	2012	Converted
IN	Muscatatuck Dev. Ctr. (Butlerville)	1920	2005	
IN	New Castle Ctr. (New Castle)	1907	1998	
IN	Norman Beatty Memorial Hospital (Westville)	1951	1979	
IN	Northern Indiana Ctr. (South Bend)	1961	1998	
IN	Richmond State Hospital (Richmond)	1890	2010	
IN	Silvercrest State Hospital (New Albany)	1974	1995	
KS	Norton State Hospital (Norton)	1963	1988	
KS	Winfield State Hospital (Winfield)	1884	1998	
KY	Frankfort State Hospital and School (Frankfort)	1860	1973	
KY	Bluegrass Oakwood ICF/IID (Somerset)	1972	2006	Privatized
KY	Outwood ICF/IID (Dawson Springs)	1962	1994	Privatized
LA	Acadiana Region Supports and Services Center (Iota)	1972	2011	Privatized
LA	Bayou Region Supports and Services Center (Thibodaux)	1982	2010	Closed
LA	Columbia Dev. Ctr. (Columbia)	1970	2009	Downsized

**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, 2017

State	Facility Name at Closure, Downsizing or Conversion	Year Opened	Final Status	
			Fiscal Year	Disposition <sup>1</sup>
LA	Leesville Dev. Ctr. (Leesville)	1964	2012	Downsized
LA	Metropolitan Development Center	1967	2007	
LA	North Lake Supports and Services Center (Hammond)		2012	Privatized
LA	Northeast Supports and Services Center (Ruston)	1959	2010	
LA	Northwest Louisiana Dev. Ctr. (Bossier City)	1973	2012	
ME	Aroostook Residential Ctr. (Presque Isle)	1972	1995	
ME	Elizabeth Levinson Ctr. (Bangor)	1971	1998	
ME	Pineland Ctr. (Pownal)	1908	1995	
MD	Great Oaks Ctr. (Silver Springs)	1970	1996	
MD	Henryton Ctr. (Henryton)	1962	1985	
MD	Highland Health Facility (Baltimore)	1972	1989	
MD	Joseph Brandenburg Ctr. (Cumberland)	1978	2011	
MD	Rosewood Ctr. (Owings Mills)	1887	2009	
MD	Victor Cullen Ctr. (Sabillasville)	1974	1992	
MD	Walter P. Carter Ctr. (Baltimore)	1978	1990	
MA	Belchertown State School (Belchertown)	1922	1992	
MA	Berry Regional Ctr. (Hawthorne)	1967	1994	
MA	Glavin Regional Ctr. (Shrewsbury)	1974	2013	Closed
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

**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, 2017

State	Facility Name at Closure, Downsizing or Conversion	Year Opened	Final Status	
			Fiscal Year	Disposition <sup>1</sup>
MN	Moose Lake Regional Treatment Ctr. (Moose Lake)	1970	1994	
MN	Owatonna State Hospital (Owatonna)	1945	1972	
MN	Rochester State Hospital (Rochester)	1968	1982	
MN	St. Peter Regional Treatment Ctr. (St. Peter)	1968	1996	
MN	Willmar Regional Treatment Ctr. (Willmar)	1973	1996	
MO	Albany Regional Ctr. (Albany)	1967	1989	
MO	Hannibal Regional Ctr. (Hannibal)	1967	1991	
MO	Joplin Regional Ctr. (Joplin)	1967	1992	
MO	Kansas City Regional Ctr. (Kansas City)	1970	1993	
MO	Kirksville Regional Ctr. (Kirksville)	1968	1988	
MO	Marshall Habilitation Ctr. (Marshall)	1901	2015	
MO	Midtown Habilitation Ctr. (St. Louis)		2004	
MO	Northwest Habilitation Ctr. (St. Louis)	2002	2012	
MO	Poplar Bluff Regional Ctr. (Poplar Bluff)	1968	1992	
MO	Rolla Regional Ctr. (Rolla)	1968	1984	
MO	Sikeston Regional Ctr. (Sikeston)	1969	1992	
MO	Southwest Community Services (Nevada)	1973	2017	Converted
MO	Springfield Regional Ctr. (Springfield)	1967	1990	
MT	Eastmont Human Services Ctr. (Glendive)	1969	2003	
MT	Montana Developmental Ctr. (Boulder)	1905	2017	Downsized
NV	Sierra Regional Ctr. (Sparks)	1977	2008	
NH	Laconia State School and Trng. Ctr. (Laconia)	1903	1991	
NH	New Hampshire Hospital, Brown Building (Concord)	1842	1990	
NJ	Ctr. at Ancora (Hammonton)		1992	
NJ	E.R. Johnstone Trng. & Research Ctr. (Bordentown)	1955	1992	
NJ	Edison Habilitation Ctr. (Princeton)	1975	1988	
NJ	North Jersey Dev Ctr (Totowa)	1928	2014	Closed
NJ	North Princeton Ctr. (Princeton)	1975	1998	
NJ	Woodbridge Dev Ctr (Woodbridge)	1965	2015	Closed
NM	Fort Stanton Hospital and Trng. Ctr. (Fort Stanton)	1964	1995	
NM	Los Lunas Hospital and Trng. Ctr. (Los Lunas)	1929	1997	
NM	Villa Solano-Hagerman Residential School (Roswell)	1964	1982	
NY	Bronx DDSO (Bronx)	1971	1992	
NY	Brooklyn DDSO (Brooklyn)	1972	2015	
NY	Broome DDSO (Binghamton)	1970	2016	
NY	Capital District DDSO (Schenectady)	1973	2015	Closed
NY	Central New York DDSO (Syracuse)	1851	1998	
NY	Craig DDSO (Soyea)	1935	1988	
NY	Finger Lakes DDSO (Rochester)	1969	2013	Closed
NY	Gouverneur (New York)	1962	1978	
NY	Hudson Valley DDSO (Thiells)	1911	2000	

**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, 2017

State	Facility Name at Closure, Downsizing or Conversion	Year Opened	Final Status	
			Fiscal Year	Disposition <sup>1</sup>
NY	J.N. Adams (Perrysburg)	1960	1993	
NY	Long Island DDSO (Commack)	1965	1993	
NY	Long Island Suffolk DDSO (Melville)	1965	1992	
NY	Manhattan Ctr. (New York)	1972	1992	
NY	Newark Ctr. (Newark)	1878	1991	
NY	Rome Ctr. (Rome)	1894	1989	
NY	Sampson State School (Willard)	1961	1971	
NY	Staten Island (Staten Island)	1987	2012	
NY	Taconic DDSO (Wassaic)	1930	2013	Closed
NY	Valatie (Valatie)	1971	1974	
NY	Westchester NY DDSO (Tarrytown)	1979	1988	
NY	Western NY DDSO (West Seneca)	1962	2011	
NY	Willowbrook State School (Staten Island)	1947	1988	
NY	Wilton DDSO (Wilton)	1960	1995	
NC	Broughton Ctr. (Morganton)	1883	1994	
ND	San Haven State Hospital (Dunseith)	1973	1987	
OH	Apple Creek Dev. Ctr. (Apple Creek)	1931	2006	
OH	Athens Mental Health & Dev. Ctr. (Athens)	1975	1994	
OH	Broadview Ctr. (Broadview Hgts.)	1967	1992	
OH	Cambridge Mental Health Ctr. (Cambridge)	1978	1990	
OH	Central Ohio Psychiatric Hospital (Cleveland)	1978	1994	
OH	Cleveland Ctr. (Cleveland)	1976	1988	
OH	Dayton Ctr. (Dayton)	1979	1983	
OH	Dayton Mental Health Ctr. (Dayton)	1978	1994	
OH	Massillon State Hospital (Massillon)	1978	1994	
OH	Montgomery Dev. Ctr. (Huber Heights)	1981	2017	
OH	Orient Ctr. (Orient)	1898	1984	
OH	Springview Developmental Ctr. (Springfield)	1975	2005	
OH	Western Reserve Psychiatric Hab. Ctr. (Northfield)	1978	1990	
OH	Youngstown Ctr. (Mineral Ridge)	1980	2017	
OK	Hisson Memorial Ctr. (Sand Springs)	1964	1994	
OK	Northern Oklahoma Resource Center (Enid)	1909	2014	Closed
OK	Robert M. Greer Memorial Ctr. (Enid)	1992	2000	Privatized
OK	Southern Oklahoma Resource Center (Pauls valley)	1952	2016	Closed
OR	Columbia Park Hospital & Trng. Ctr. (The Dalles)	1963	1977	
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	

**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, 2017

State	Facility Name at Closure, Downsizing or Conversion	Year Opened	Final Status	
			Fiscal Year	Disposition <sup>1</sup>
PA	Embreeville Ctr. (Coatesville)	1972	1997	
PA	Harrisburg Mental Retardation Unit (Harrisburg)	1972	1982	
PA	Hollidaysburg Mental Retardation Ctr. (Hollidaysburg)	1974	1976	
PA	Laurelton Ctr. (Laurelton)	1920	1998	
PA	Marcy Ctr. (Pittsburgh)	1975	1982	
PA	Mayview Mental Retardation Unit (Mayview)	1974	2001	
PA	Pennhurst Ctr. (Pennhurst)	1908	1988	
PA	Philadelphia Mental Retardation Unit (Philadelphia)	1983	1989	
PA	Somerset Mental Retardation Unit (Somerset)	1974	1996	
PA	Torrance Mental Retardation Unit (Torrance)	1974	1998	
PA	Warren Mental Retardation Unit (Warren)	1975	1976	
PA	Wernersville Mental Retardation Unit (Wernersville)	1974	1987	
PA	Western Ctr. (Cannonsburg)	1962	2000	
PA	Woodhaven Ctr. (Philadelphia)	1974	1995	Privatized
RI	Dorothea Dix Unit (Cranston)	1982	1989	
RI	Dr. Joseph H. Ladd Ctr. (N. Kingstown)	1908	1994	
RI	Zambrano Memorial Hospital (Wallum Lake)	1967	1989	
SD	Custer State Ctr. (Custer)	1964	1996	
TN	Arlington Dev. Ctr. (Arlington)	1969	2010	
TN	Clover Bottom Dev. Ctr. (Nashville)	1923	2016	Closed
TN	Greene Valley Dev. Ctr. (Greeneville)	1960	2017	Closed
TN	Harold Jordan Habilitation Ctr. (Nashville)	1979	2003	
TN	Winston Ctr. (Bolivar)	1979	1998	
TX	Ft. Worth State School (Ft. Worth)	1976	1996	
TX	Travis State School (Austin)	1961	1996	
VT	Brandon Trng. School (Brandon)	1915	1993	
VA	Eastern State Hospital (Williamsburg)	1773	1990	
VA	Northern Virginia Trng. Ctr. (Fairfax)	1973	2016	Closed
VA	Southside Virginia Trng. Ctr. (Petersburg)	1939	2014	
VA	Southwestern State Hospital (Marion)	1887	1988	
VA	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

<sup>1</sup> 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.



- Ella Grasso Center (Stratford, CT)
- Southwest Community Resources (Nevada, MO)
- Montana Developmental Center (Boulder, MT)
- Montgomery Developmental Center (Huber Heights, OH)
- Youngstown Center (Mineral Ridge, OH)
- Greene Valley Developmental Center (Greeneville, TN)

In addition, the state of New York clarified that 16 ICF/IID facilities not named on **Table 4.8** that previously had 16 or more people had fewer than 16 residents as of June 30, 2017.

## Methodology Note

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

- Colorado operates 23 ICF/IID units on two campuses: Grand Junction Regional Center (Grand Junction, CO) and Wheat Ridge Regional Center (Wheat Ridge, CO).
- Wisconsin reports three PRFs with 16 or more residents with IDD including the Northern Wisconsin Center in Chippewa Falls, which was converted to a short-term facility in 2005 but may have people who stay for more than 90 days.
- Other facilities counted separately by state IDD agencies submit a combined PRF survey. For example,
  - The Seguin Unit was combined with the Tacachale Community of Excellence (Gainesville, FL).
  - The two campuses of East Central Regional Hospital (Gracewood & Augusta, GA) were combined.
  - Thad E. Saleeby Ctr. (Hartsville, SC) was combined with the Pee Dee Regional Ctr. (Florence, SC).

**Table 4.10** Operational Status of PRFs by State on June 30, 2017 with Projected Closures to June 2022

State	Operating Between 1960 and 2017	Closed, Converted or Downsized <sup>1</sup>		Open June 30, 2017	Projected to Close July 2017 - June 2022
		1960 to 2016	FY 2017		
AL	5	5	0	0	0
AK	1	1	0	0	0
AZ	4	3	0	1	0
AR	6	1	0	5	0
CA	13	9	0	4	3
CO	3	1	0	2	0
CT	15	11	1	4	0
DE	1	0	0	1	0
DC	3	3	0	0	0
FL	10	7	0	3	0
GA	13	10	0	3	0
HI	2	2	0	0	0
ID	1	0	0	1	0
IL	17	10	0	7	0
IN	11	11	0	0	0
IA	2	0	0	2	0
KS	4	2	0	2	0
KY *	5	3	0	2	1
LA *	11	8	0	3	0
ME	3	3	0	0	0
MD *	9	7	0	2	0
MA	11	9	0	2	0
MI	13	13	0	0	0
MN	9	9	0	0	0
MS	6	0	0	6	0
MO	18	13	1	6	0
MT	2	1	1	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	23	16	6	1
NC	6	1	0	5	0
ND	2	1	0	1	0
OH	22	12	2	8	0
OK	4	4	0	0	0
OR	3	3	0	0	0
PA	23	18	0	5	3
RI	3	3	0	0	0
SC	5	0	0	5	0
SD	2	1	0	1	0
TN	5	4	1	0	0
TX	15	2	0	13	0
UT	1	0	0	1	0
VT	1	1	0	0	0
VA	8	5	0	3	2
WA	6	2	0	4	0
WV	4	4	0	0	0
WI	3	0	0	3	0
WY	1	0	0	1	0
<b>Reported US Total</b>	<b>376</b>	<b>238</b>	<b>22</b>	<b>119</b>	<b>10</b>
<b>% of Total</b>	<b>100%</b>	<b>63%</b>	<b>6%</b>	<b>32%</b>	<b>3%</b>

\* See additional state notes in the Appendix. <sup>1</sup> 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.



## TRENDS IN PUBLIC RESIDENTIAL FACILITY UTILIZATION

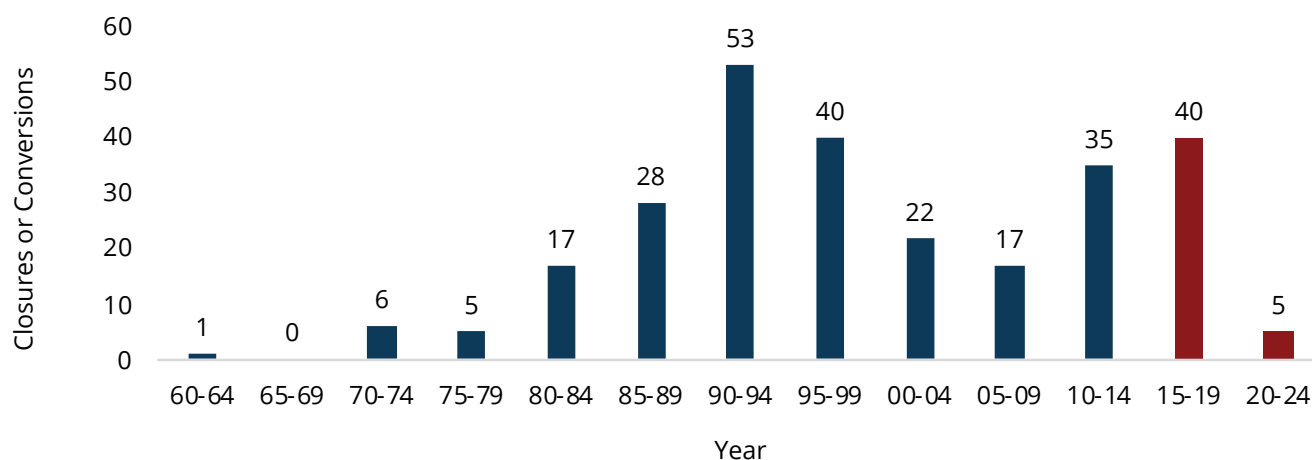
### PRF Status by State

Of the 376 PRFs operating between 1960 and 2017, 238 (63%) closed by June 30, 2016, 22 (6%) closed between July 1, 2016 and June 30, 2017, and 119 (32%) were open on June 30, 2017 (See **Table 4.10**). Ten PRFs were scheduled to close between July 2017 and June 2022.

As of June 30, 2017, seventeen states had closed all large PRFs serving people with IDD (Alabama, Alaska,

the District of Columbia, Hawaii, Indiana, Maine, Michigan, Minnesota, Montana, New Hampshire, New Mexico, Oklahoma, Oregon, Rhode Island, Tennessee, Vermont and West Virginia). Seven states had closed between 76% and 99% of all PRFs (Connecticut, Georgia, Maryland, Massachusetts, Missouri, New York, and Pennsylvania). Thirteen states had closed between 50% and 75% of all PRFs (Arizona, California, Connecticut, Florida, Illinois, Kentucky, Louisiana, Nevada, New Jersey, North Dakota, Ohio, and Virginia). Two states (Colorado and Washington) had closed between 25% and 49% of PRFs. Three states had closed fewer than 25% but at least one PRF (Arkansas, North Carolina and

**Figure 4.6** PRFs Closed or Converted to Non-IDD Use or Nonstate Operation Between 1960 and 2017 and Projected Closures for 2018 to 2024 in 5-Year Intervals



Texas). Eight states had not closed a PRF by June 30, 2017 (Delaware, Idaho, Iowa, Mississippi, Nebraska, South Carolina, Utah, and Wyoming). Wisconsin had one facility designated to serve only short-term admissions that was still reported as open by the state IDD agency.

## PRF Closures and Projected Closures 1960 through 2024

The rate of PRF closures in the United States has changed over time (See **Figure 4.6**). One PRF closed between 1960 and 1969. The number of closures increased to 11 between 1970 and 1979,

**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 1890-2017

Year	Average Daily Population			Percent in Psychiatric Settings	US Population (100,000) <sup>a</sup>	People Per 100k of the Population		
	State IDD	State Psychiatric <sup>1</sup>	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 <sup>i</sup>	2,520 <sup>i</sup>	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	18,807	1,964	20,771	9%	3,257	6	1	6

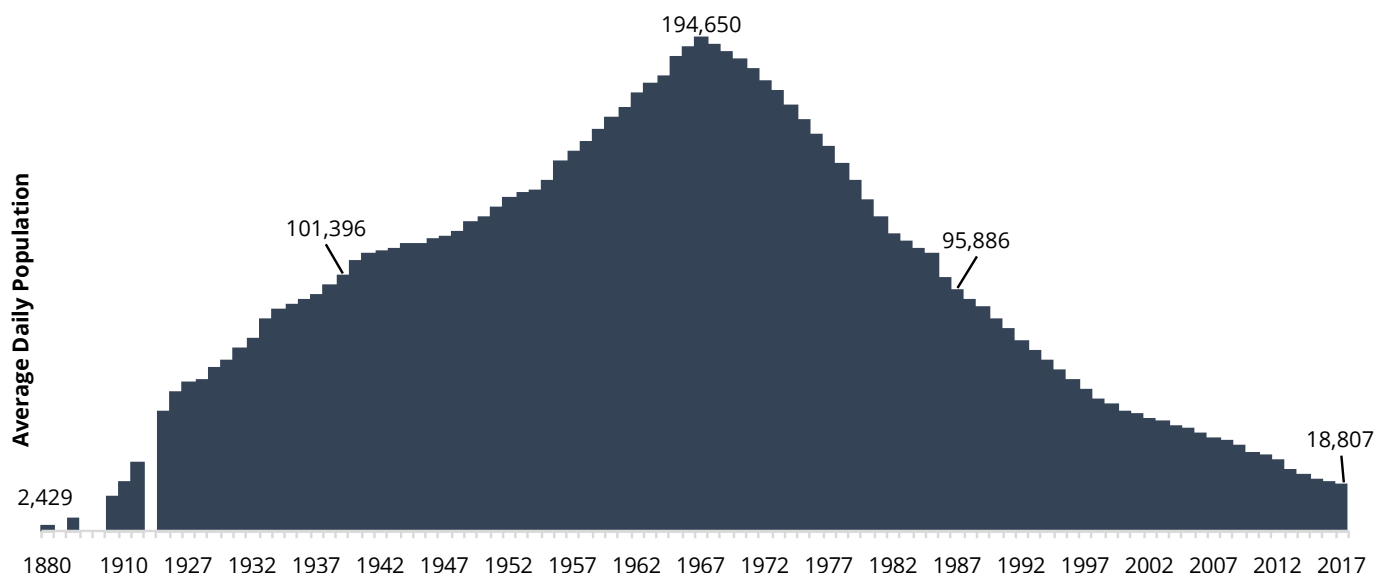
<sup>a</sup> Number of states not reporting on psychiatric settings by year: 2000 (1); 2001 (3); 2002 (3); 2003 (3); 2004 (2); 2005 (3); 2006, 2007 and 2008 (4); 2009 (3); 2010 (5); 2011 (6) 2012 (0); 2013 (21); 2014 (16); 2015 (10); 2016 (9); 2017 (14) iData imputed based on adjacent years

and 45 between 1980 and 1989. The number of PRF closures peaked at 93 during the decade of the 1990's with 53 closures between 1990 and 1994 and 40 closures between 1995 and 1999. The rate of PRF closures declined substantially in the first decade of the 21st century, with only 39 closures in the decade of the 2000s. The pace of PRF closures increased again as the nation faced the Great Recession of 2008. There were 35 closures between 2010 and 2014 with 40 closures or projected closures between 2015 and 2019. Five closures are planned between 2020 and 2024.

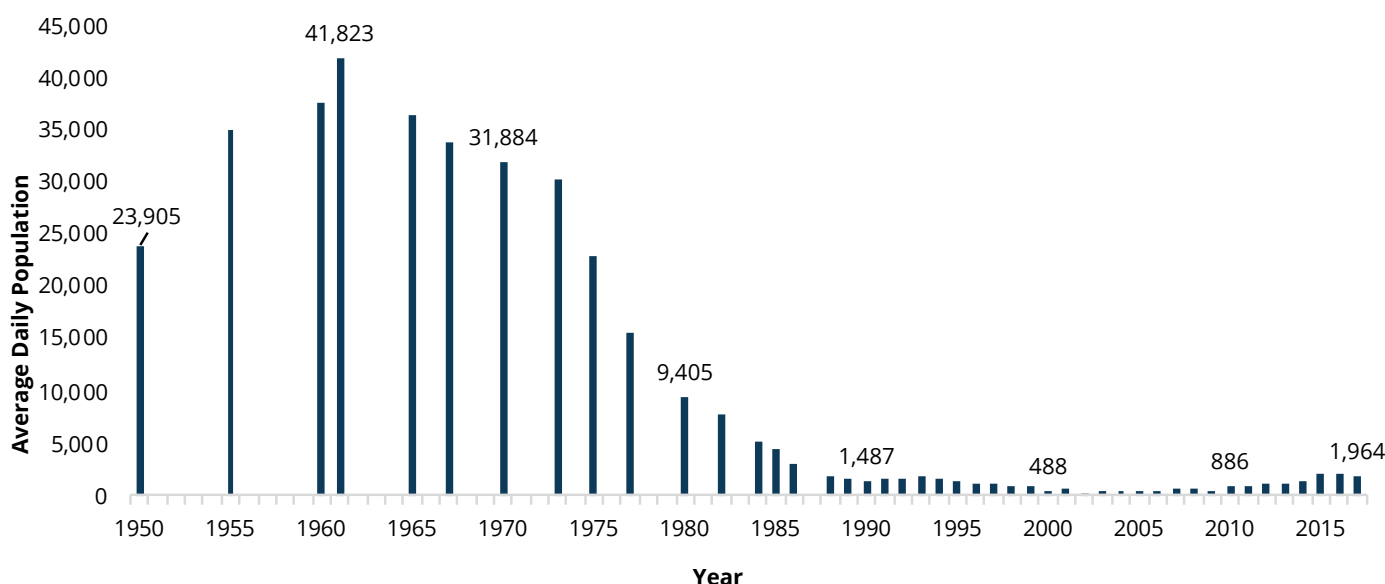
## Average Daily Population of PRFs

The RISP project has historical data on the average daily population of state-operated IDD facilities of 16 or more people for selected years since 1880, and annually since 1927 (Lakin, 1979). The average daily population of PRFs increased from 2,429 in 1880 to 106,944 in 1940 (See **Table 4.11** and **Figure 4.7a**). The average daily population of PRFs peaked at 194,650 people in 1967. Average daily population of PRFs dropped to 151,532 in 1977, 95,886 in 1987, 56,161 in 1997, 37,172 in 2007, and 18,807 in 2017.

**Figure 4.7a** Average Daily Population of PRFs from 1880 to 2017



**Figure 4.7b** People with IDD in State Operated Psychiatric Facilities Selected Years 1950 to 2016



## Utilization of PRFs per 100,000 of the Population

The utilization of PRFs for LTSS for people with IDD per 100,000 of the population mirrored the trends in the average daily population of those facilities. In 1890, there were an estimated 8.1 people with IDD living in PRFs per 100,000 of the population. By 1940 utilization rates had increased to 80.9 people per 100,000. Utilization rates peaked in 1965 at 113.6 people per 100,000. By 1980 (25 years later) utilization rates had declined to 57.7 people per 100,000. By 1995 (15 years) utilization rates had declined to 24.2 per 100,000. By 2007 (12 years) utilization rates had declined to 12.3 people per 100,000. Finally, by 2017, (10 years) utilization rates were 5.8 per 100,000 (lowest in 120 years).

## State-Operated Psychiatric Facilities

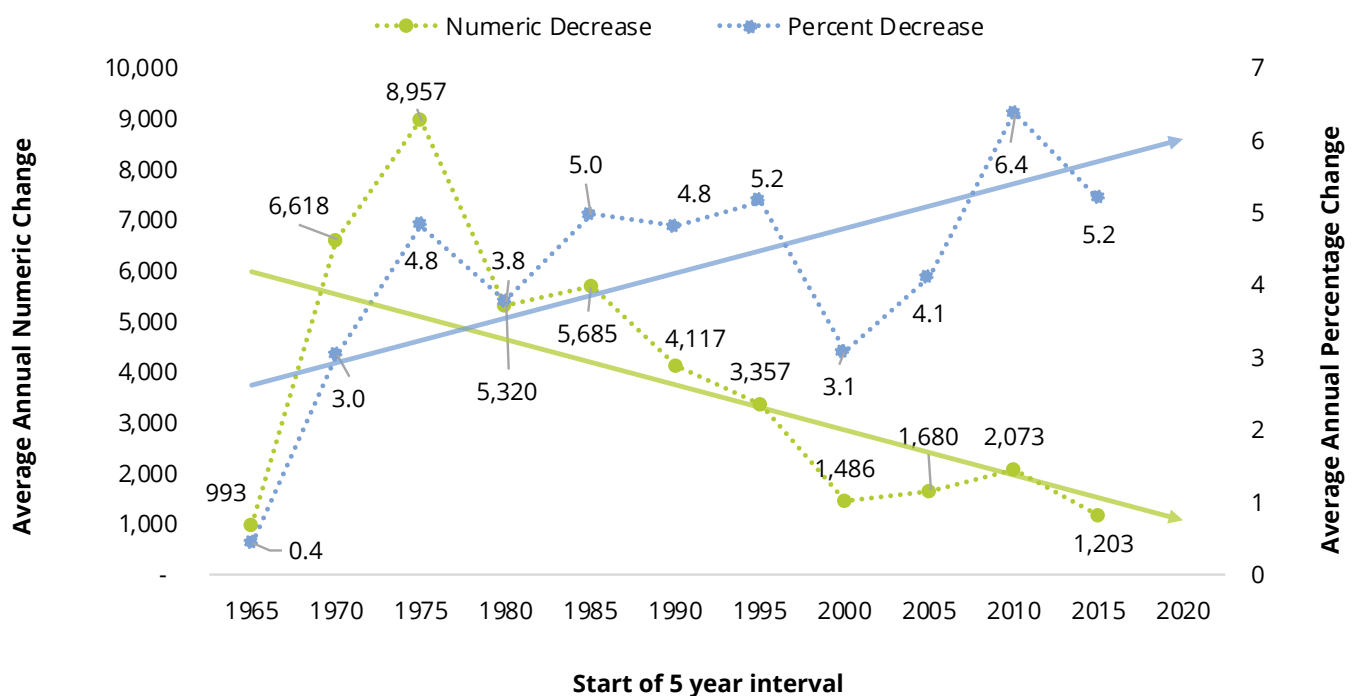
States have reported the number of people with IDD living in state-operated psychiatric facilities since 1950 when there were 23,905 people with IDD living in those facilities (See **Figure 4.7b**). As with PRFs, the number of people with IDD in state psychiatric facilities rose in the 1950s reaching a peak of 41,823 people in 1961. The number of people with IDD in

psychiatric facilities dropped to 33,850 in 1977, 2,520 in 1987, and 1,075 in 1997, reaching an all-time low of 267 people in 2002. By 2007 the number of people in state-operated psychiatric facilities had rebounded to 782, and was 1,964 in 2017.

Legislation in the late 1960s and early 1970s allowed states to obtain federal Medicaid cost sharing for institutional services provided in ICF/IIDs and in nursing homes, but prohibited use of Medicaid funding people for ages 18 to 64 years in facilities for “mental disease.” This provided a significant incentive for states to move people with IDD from psychiatric facilities to separate IDD units or IDD facilities and contributing to the reduction of people with IDD in psychiatric facilities since 1967. Caution is warranted, however, in using the estimates for people with IDD in state psychiatric facilities since 2000 as the number of states reporting on this population has fluctuated from year to year with an average of six states not reporting per year.

The reason that the number of people with IDD in state-operated psychiatric facilities increased since 2010 is unknown. Possible factors include increased recognition of depression, anxiety or other mental health disorders in people with IDD, shortages

**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 2017 with Linear Trendlines





of community-based mental health services for people with IDD, state policy decisions limiting or prohibiting new admissions to state-operated IDD facilities, and/or movement of some people with IDD from PRFs to psychiatric facilities as PRFs closed.

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

Another way to look changes in the populations of PRFs and state-operated psychiatric facilities is to compare average annual numeric change to average annual percentage change (See **Figure 4.8**). The numeric decline in people with IDD in PRFs or state-operated psychiatric facilities was highest between 1975 and 1980 with an average decline of 8,957 people per year. The average annual decline for 2015 through 2017 was 1,203 people per year.

In comparison, there was a clear upward trend over time in the average annual percent decrease in the number of people with IDD in PRFs and state-operated psychiatric facilities. The number of people with IDD in PRF or state-operated psychiatric facilities declined by an average of 3% per year between 1975 and 1980. The average annual decline was between 4.8% and 5.2% between 1985 and 1995, before dropping to 3.1% between 2000 and 2005. The average annual decline peaked at 6.4%

per year between 2010 and 2015, and was 5.2% between 2015 and 2017.

### State Trends in Average Daily Populations

State trends in the average daily population of PRFs from 1980 to 2017 are shown on **Table 4.12**. Between 1980 and 2017, the average daily population of PRFs dropped 86% from 131,345 to 18,807. In addition to the seventeen states that closed all PRFs during this period, ten states reduced their total PRF populations by 90% to 99%, fifteen states reduced their average daily populations by 75 to 89%, seven states reduced their average daily populations by 50% to 74%, and two reduced their populations by less than 50%.

Between 2010 and 2017, one state reduced their PRF population to 0 (Tennessee), one reduced their population by 75% to 99%, six reduced their populations by 50% to 74%, fourteen reduced their populations by 25% to 49%, ten reduced their populations by 0.1% to 24%, and two increased their populations between 2010 and 2017.



**Table 4.12** Average Daily PRF Population by State Selected Years 1980 to 2017

State	Average Daily Population									% change	
	1980	1985	1990	1995	2000	2005	2010	2015	2017	1980- 2017	2010-2017
N States	51	51	51	47	42	42	40	37	34	51	34
AL	1,651	1,422	1,305	985	642	212	178	0	0	-100	N/A
AK	86	76	58	33	0	0	0	0	0	-100	N/A
AZ	672	538	360	183	166	138	119	95	86	-87	-28
AR	1,550	1,254	1,260	1,262	1,229	1,079	1,067	913	905	-42	-15
CA	8,812	7,524	6,768	5,494	3,879	3,307	2,149	1,077	899	-90	-58
CO	1,353	1,125	466	241	129	110	DNF	28	23	-98	DNF
CT	2,944	2,905	1,799	1,316	992	847	705	493	402	-86	-43
DE	518	433	345	308	256	123	71	54	49	-91	-31
DC	775	351	309	0	0	0	0	0	0	-100	N/A
FL	3,750	2,268	1,992	1,502	1,508	1,341	963	848	724	-81	-25
GA	2,535	2,097	2,069	1,979	1,510	1,202	802	259	210	-92	-74
HI	432	354	162	83	0	0	0	0	0	-100	N/A
ID	379	317	210	139	110	94	68	24	29	-92	-57
IL	6,067	4,763	4,493	3,775	3,237	2,833	2,183	1,723	1,657	-73	-24
IN	2,592	2,248	1,940	1,389	854	456	205	0	0	-100	N/A
IA	1,225	1,227	986	719	674	646	525	400	417	-66	-21
KS	1,327	1,309	1,017	756	379	360	340	311	301	-77	-11
KY	907	671	709	679	628	489	170	263	265	-71	56
LA	3,171	3,375	2,622	2,167	1,749	1,571	1,144	453	487	-85	-57
ME	460	340	283	150	0	0	0	0	0	-100	N/A
MD	2,527	1,925	1,289	817	548	380	138	135	92	-96	-33
MA	4,531	3,580	3,000	2,110	1,306	1,089	759	478	388	-91	-49
MI	4,888	2,191	1,137	392	271	173	0	0	0	-100	N/A
MN	2,692	2,065	1,392	610	42	29	25	0	0	-100	N/A
MS	1,660	1,828	1,498	1,439	1,383	1,359	1,324	1,100	989	-40	-25
MO	2,257	1,856	1,860	1,492	1,286	1,152	671	410	335	-85	-50
MT	316	258	235	163	131	84	52	52	0*	-100	N/A
NE	707	488	466	414	401	372	182	114	111	-84	-39
NV	148	172	170	160	157	93	47	47	48	-68	2
NH	578	267	87	0	0	0	0	0	0	-100	N/A
NJ	7,262	5,705	5,069	4,325	3,555	3,096	2,711	1,701	1,438	-80	-47
NM	500	471	350	221	0	0	0	0	0	-100	N/A
NY	15,140	13,932	7,694	4,552	2,466	2,233	2,019	648	361	-98	-82
NC	3,102	2,947	2,654	2,288	1,939	1,736	1,515	1,328	1,153	-63	-24
ND	1,056	763	232	156	144	140	120	82	74	-93	-38
OH	5,045	3,198	2,665	2,150	1,996	1,728	1,376	923	702	-86	-49
OK	1,818	1,505	935	618	391	368	270	16	0	-100	N/A
OR	1,724	1,488	838	462	62	43	22	0	0	-100	N/A
PA	7,290	5,980	3,986	3,460	2,127	1,452	1,189	973	878	-88	-26
RI	681	415	201	0	0	0	0	0	0	-100	N/A
SC	3,043	2,893	2,286	1,788	1,129	953	786	681	663	-78	-16
SD	678	557	391	345	196	172	149	139	136	-80	-9
TN	2,074	2,107	1,932	1,669	948	680	416	127	0	-100	-100
TX	10,320	9,638	7,320	5,459	5,431	4,977	4,337	3,241	3,026 <sup>d</sup>	-71	-30
UT	778	706	462	357	240	230	215	208	190	-76	-12
VT	331	200	180	0	0	0	0	0	0	-100	N/A
VA	3,575	3,069	2,650	2,249	1,625	1,524	1,197	534	351	-90	-71
WA	2,231	1,844	1,758	1,320	1,143	973	914	777	714	-68	-22
WV	563	498	304	94	0	0	0	0	0	-100	N/A
WI	2,151	2,058	1,678	1,341	900	590	448	357	329 <sup>d</sup>	-85	-27
WY	473	413	367	151	113	98	83	72	79	-83	-5
Estimated US Total	131,345	109,614	84,239	63,762	47,872	40,532	31,654	21,084	18,807	-86	-41

<sup>d</sup> Other date (Usually a different fiscal year or the previous year). \* Estimate. DNF Did not furnish. N/A No people in large state facilities in 2010, 2015, or both. \* See state notes in the Appendix.

**Table 4.13** Change in Estimated Average Daily Population and Annual Admissions, Discharges and Deaths in PRFs Selected Years 1950-2017

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)
1986	100,190	6,535	9,399	1,322	(4,186)
1990	84,732	5,034	6,877	1,207	(3,050)
1995	63,697	2,338	5,337	1,068	(4,067)
2000	47,872	1,936	2,425	915	(1,404)
2005	40,532	2,106	2,561	909	(1,364)
2006	38,810	1,994	2,559	886	(1,451)
2007	37,172	2,128	2,637	821	(1,330)
2008	35,651	2,056	2,879	918	(1,741)
2009	33,682	1,981	3,111	870	(2,000)
2010	30,602	1,833	2,690	820	(1,677)
2011	29,809	1,593	2,690	810	(1,907)
2012	27,665	1,141	2,436	747	(2,042)
2013	24,779	1,184	2,453	630	(1,899)
2014	22,437	1,235	1,997	643	(1,406)
2015	21,084	1,248	1,921	661	(1,334)
2016	19,502	1,014	1,897	635	(1,518)
2017	18,807	1,095	1,642	591	(1,138)

## Annual Number of Admissions, Discharges and Deaths

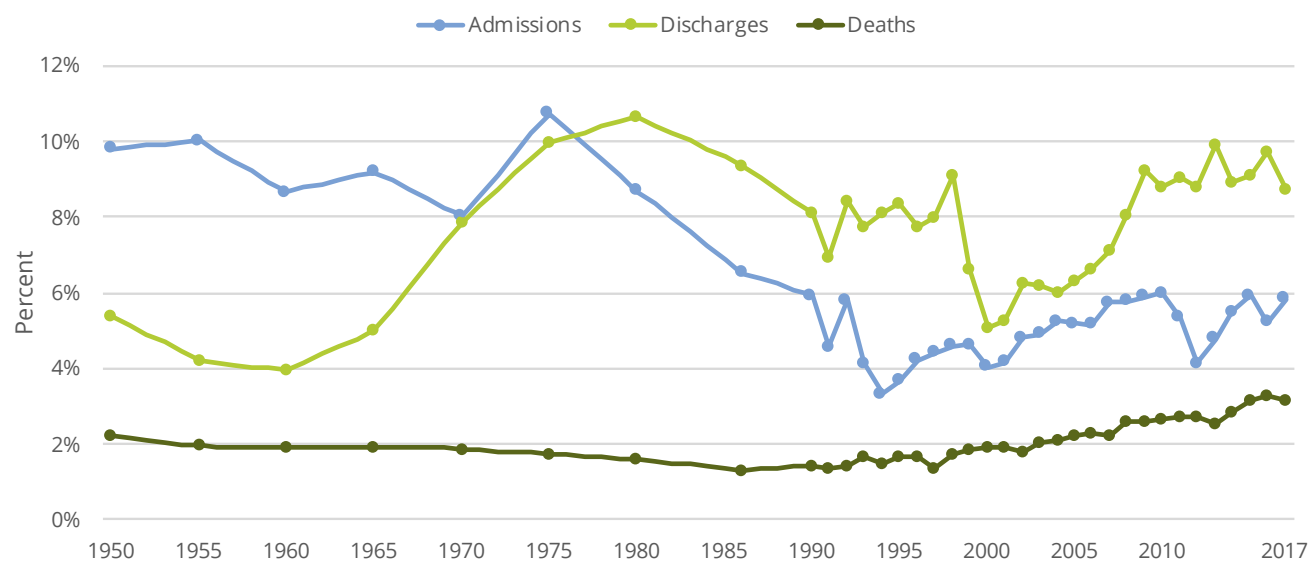
**Table 4.13** shows annual admissions, discharges, and deaths for PRFs for selected years between 1950 and 2017. Transfers between PRFs are not included. In 1950, PRFs reported an average daily population of 124,304 with 12,197 admissions (10% of the average daily population), 6,672 discharges (5%), and 2,761 deaths (2%). In 2017, the average daily population was 18,807 with 1,095 admissions (6%), 1,642 discharges (9%), and 591 deaths (3%).

The number of annual PRF admissions grew from 12,197 in 1950 to a peak of 18,075 in 1975. The number dropped to 6,535 by 1986 and to 1,936 by 2000. Between 2000 and 2010 annual admissions held steady at between 1,800 and 2,200 people. In 2011 there were 1,593 admissions. Since then there have been between 1,000 and 1,300 admissions per year with 1,095 admissions in 2017.

The number of discharges per year grew from 6,672 in 1950 to a peak of 16,807 in 1975 before dropping below 10,000 by the early 1980's, to 5,034 by 1990 and to 2,425 by 2000. Annual discharges remained above 2,000 until 2014 when 1,997 people were discharged. Total discharges in 2017 were 1,642.

Annual deaths in PRFs, peaked in 1967 at 3,635, dropped below 2,000 in the early 1980's, and below 1,000 by 2000. The number of deaths per year in PRFs

**Figure 4.9** Annual PRF Admissions, Discharges and Deaths as a Proportion of the Average Daily Population, 1950 to 2017



declined from 915 in 2000 to 591 in 2017. Since 2005, of the people who were discharged or who died in PRFs, between 20% and 26% died while the rest were discharged. Deaths as a proportion of average daily residents hovered around 2% from 1970 through 2007, but has exceeded 3% since 2015.

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

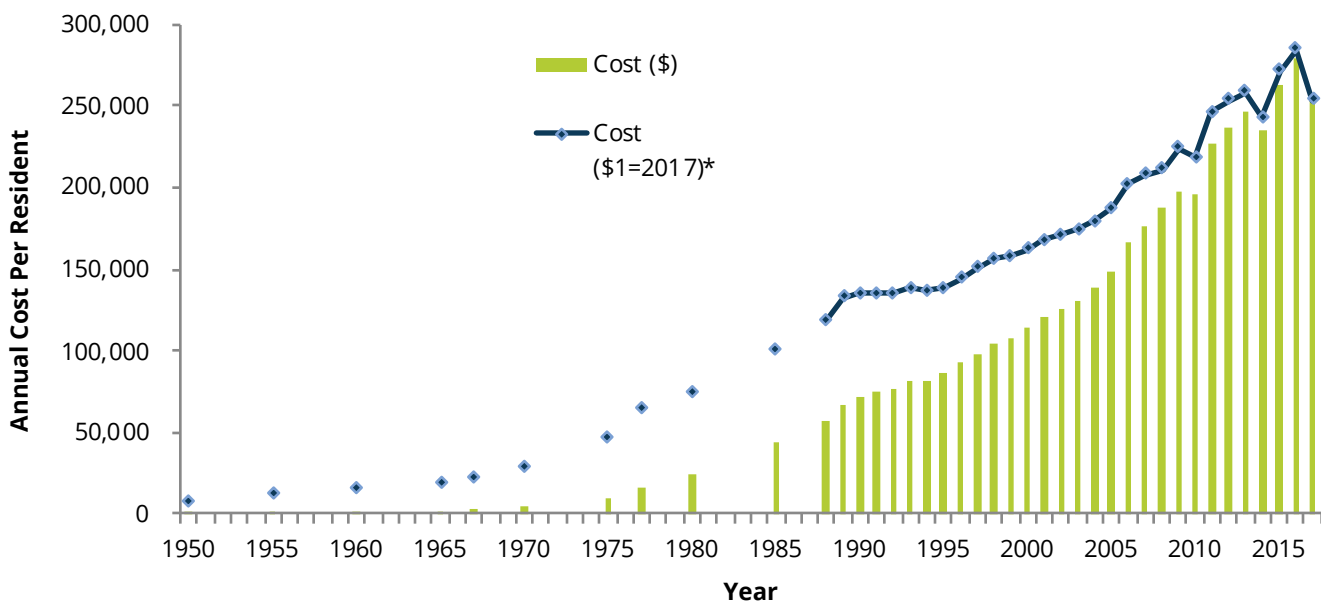
Admissions as a proportion of the average daily population ranged from 8% to 11% between 1950 and 1975. As the average daily population of PRFs declined, admissions as a proportion of the average daily population dropped from 11% in 1975 to 6% in 1990 and averaged 4% and 6% of the average daily PRF population between 1990 and 2017 (See **Figure 4.9**).

Annual discharges as a proportion of the average daily population was 3.9% in 1960 but increased to 10% by 1975. Discharges as a proportion of the average daily population of PRFs increased to a high of 11% in 1980, hovered between 7% and 9% from 1990 and 1998. The rate of discharges hovered between 5% and 7% from 1999 to 2006, before again increasing to between 7% and 10% from 2007 to 2017.

**Table 4.14** Annual Per Person Expenditures for People with IDD in PRFs Selected Years 1950-2017

Year	Cost (\$)	Cost (\$1=2017) <sup>s</sup>
1950	746	7,672
1955	1,286	11,788
1960	1,868	15,465
1965	2,361	18,298
1970	4,635	29,246
1975	10,155	46,407
1980	24,944	73,835
1985	44,271	100,938
1990	71,660	135,438
1995	85,760	138,074
2000	113,863	161,686
2005	148,811	187,501
2006	167,247	202,368
2007	176,226	207,946
2008	188,318	210,916
2009	196,710	224,249
2010	195,197	218,621
2011	226,106	246,456
2012	237,149	253,749
2013	246,063	258,367
2014	235,856	242,932
2015	263,196	271,092
2016	278,858	284,435
2017	253,187	253,187

**Figure 4.10** Average Annual Per Person Expenditures for PRF's, Selected Years 1950-2017



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

Discharges as a proportion of the average daily population declined to between 5% and 7% from 1999 to 2006, but increased to between 8% and 10% between 2007 and 2016.

Deaths as a proportion of the daily population declined from 2.2% in 1950 1.3% in 1986. Deaths as a proportion of the average daily population grew from 1.3% in 1986 to 2% in 2003, and were above 3% from 2015 to 2017. The increase in deaths as a proportion of the average daily population is probably related, at least in part, to the increasing age of people remaining in in PRFs.

## TRENDS IN AVERAGE ANNUAL PER PERSON EXPENDITURES

Average annual per person expenditures for people living in PRFs were \$746 in 1950 (\$7,672 in 2017 inflation adjusted dollars, See **Table 4.14**). In 1970, one year before enactment of the ICF/IID program, average annual per person expenditures were \$29,246 in 2017 inflation adjusted dollars. ICF/IID regulations, court decisions and settlement agreements drove increases in expenditures with their requirements to reduce overcrowding, upgrade staffing levels, increase participation in meaningful daily activities and improve physical

environments. By 1980, more than 70% of all PRFs were ICF/IID certified and annual per person expenditures had increased to \$73,835 in 2017 inflation adjusted dollars. As the populations of PRFs declined, per person costs increased as fixed costs (e.g., grounds, utilities, food service, laundry, physical plant and so forth) were shared by fewer people. Average annual expenditures for people living in PRFs rose from \$100,938 (in 2017 inflation adjusted dollars) in 1985, to \$252,564 in 2017.

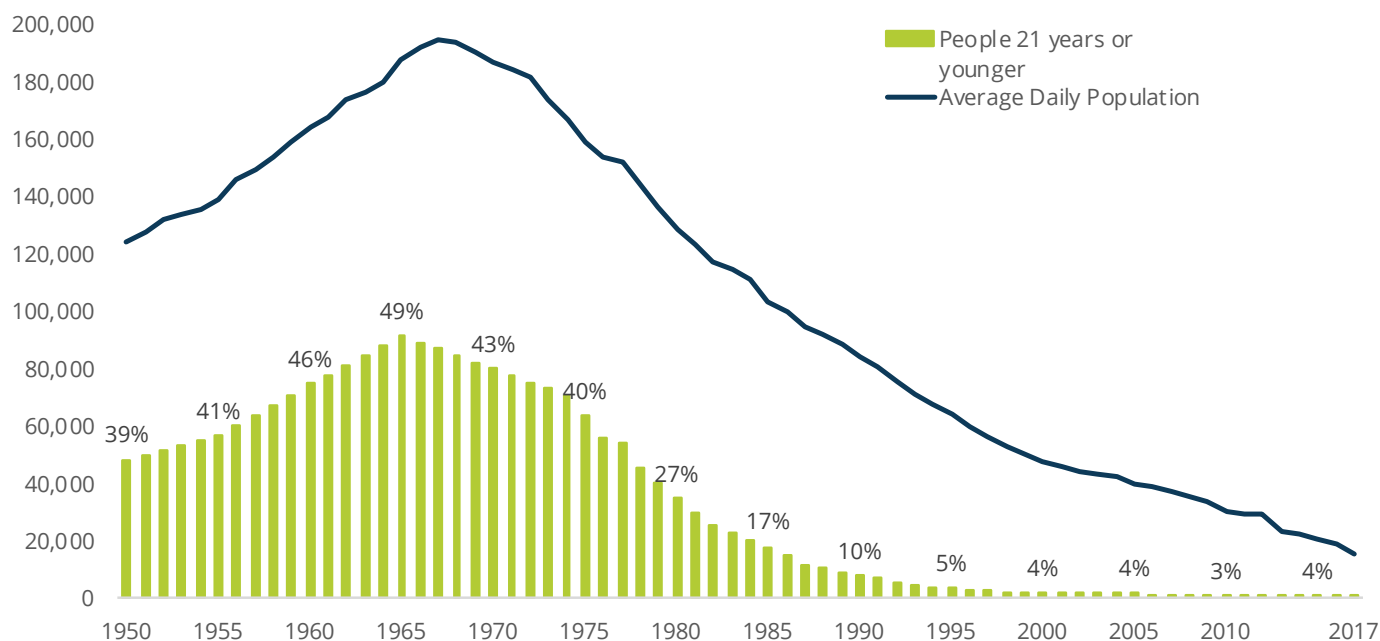
## TRENDS IN CHARACTERISTICS OF PEOPLE WITH IDD LIVING IN PRFS

### Age

Between 1950 and 1964 the proportion of PRF residents 21 years or younger increased from 39% to a high of 49% in 1964 before beginning to decline (See **Figure 4.11**). The proportion declined to 40% in 1975, 29% in 1979, 20% in 1983, 10% in 1989, and 5% in 1996. The proportion of PRF residents 21 years or younger dipped below 4% in 2006, and below 3% in 2010 reaching a low of 2.1% in 2012. The proportion grew to 4% in 2017.

**Table 4.15** shows changes in the characteristics of people living in PRFs between 1977 and 2017 (also

**Figure 4.11** Average Daily Population of PRFs and Percent 21 Years or Younger, 1950 to 2017





see **Figure 4.12**). The proportion of residents who were male increased from 57% in 1977 to 64% in 2017.

The proportion of PRF residents who were ages 22 to 39 years declined from 41% in 1977 to 20% in 2017. The proportion ages 40 to 62 years increased from 19% in 1977 to 49% in 1998, and 61% in 2008 but declined to 52% in 2017. Finally, the proportion of residents who were 63 years or older increased from 4% in 1977 to 8% in 1998, 12% in 2008, and to 24% in 2017.

Between 1977 and 2017, the number of people in PRFs

- Ages 21 years or younger declined from 54,400 to 721
- Ages 22 to 39 years declined from 61,956 to 3,610
- Ages 40 to 62 years declined from 28,711 to 9,545
- Ages 63 years or older declined from 6,044 to 4,357



**Table 4.15** PRF Population Characteristics June 30th of Selected Years 1977 to 2017 (in percent)

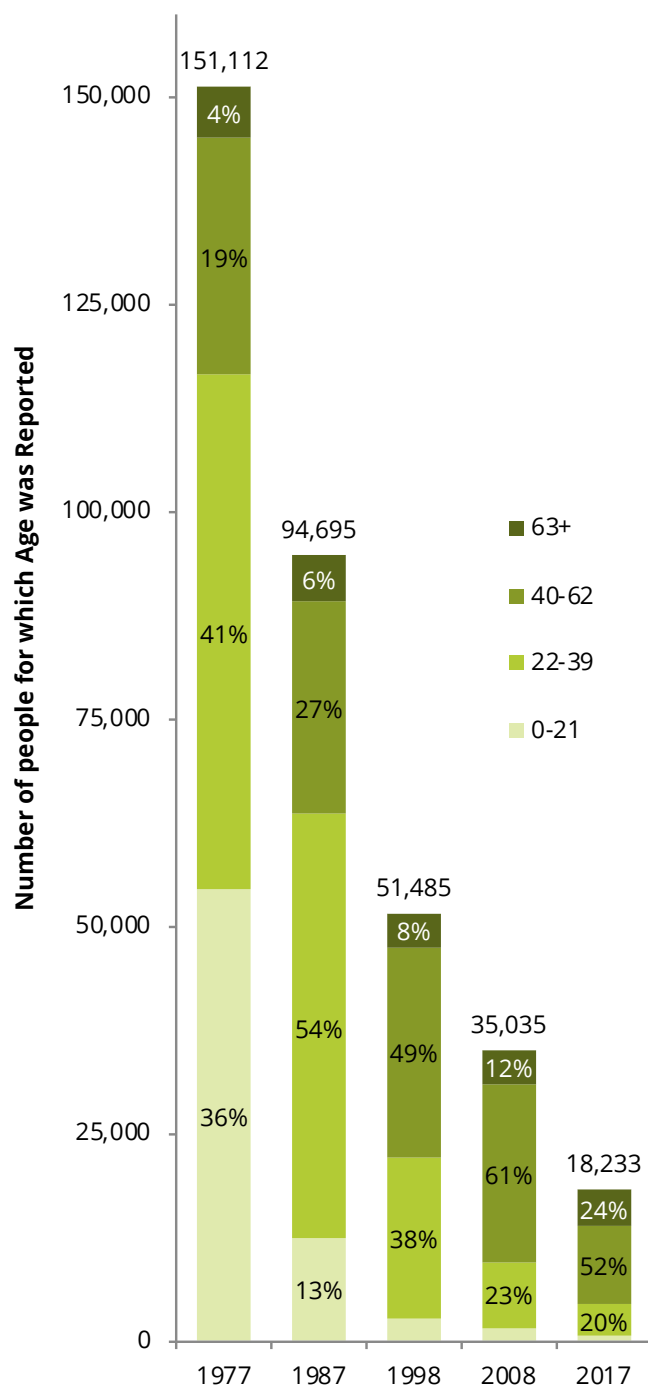
Characteristic (Percent)		Year					
		1977	1987	1998	2008	2016	2017
Estimated total residents		151,112	94,695	51,485	35,035	19,081	18,239
Gender	Male	57%	57%	60%	63%	63%	64%
	Female	43%	43%	40%	37%	37%	36%
Age	0-21 Years	36	13	5	5	4	4
	22-39 Years	41	54	38	23	19	20
	40-62 Years	19	27	49	61	55	52
	63+ Years	4	6	8	12	21	24
	Unknown					0	0
Level of Intellectual Disability	Mild/No ID	10	7	8	14	14	14
	Moderate	16	10	10	12	14	14
	Severe	28	20	18	16	19	16
	Profound	46	63	65	58	53	55
	Unknown					1	1
Other Conditions	Epilepsy			46	44	40	39
	Autism					19	19
	Cerebral Palsy	19	21	24	23	15	17
	Blind			16	15	15	
	Deaf						
Psychiatric and Behavior	Receives Mood, Anxiety or Behavior Medication				50	54	
	Psychiatric Disorder			34	52	50	56
	Behavior Disorder	25	41	44	52	42	
Prior Criminal Justice Involvement						4	5
Short Term Stays						5	6

Questions about psychiatric conditions and behavioral support needs were condensed into a single item for 2017

## Level of Intellectual Disability

The proportion of PRF residents with no, mild or moderate IDD dropped from 40% in 1964 to 17% in 1998 but increased to 28% in 2017. Between 1964

**Figure 4.12** Estimated Number and Proportion of People in PRFs by Age Group on June 30 of Selected Years 1977 to 2017



Age not reported for all people present on June 30.

and 2017, the proportion of PRF residents with severe intellectual disabilities declined from 33% to 16%, and the proportion with profound intellectual disabilities increased from 27% to 55%.

Between 1964 and 2017, the number of people living in PRFs with

- Mild or no intellectual disabilities decreased from 32,328 to 2,579
- Moderate intellectual disabilities decreased from 39,512 to 2,494
- Severe intellectual disabilities decreased from 59,297 to 2,860
- Profound intellectual disabilities decreased from 48,492 to 10,086

## Other Conditions and Characteristics

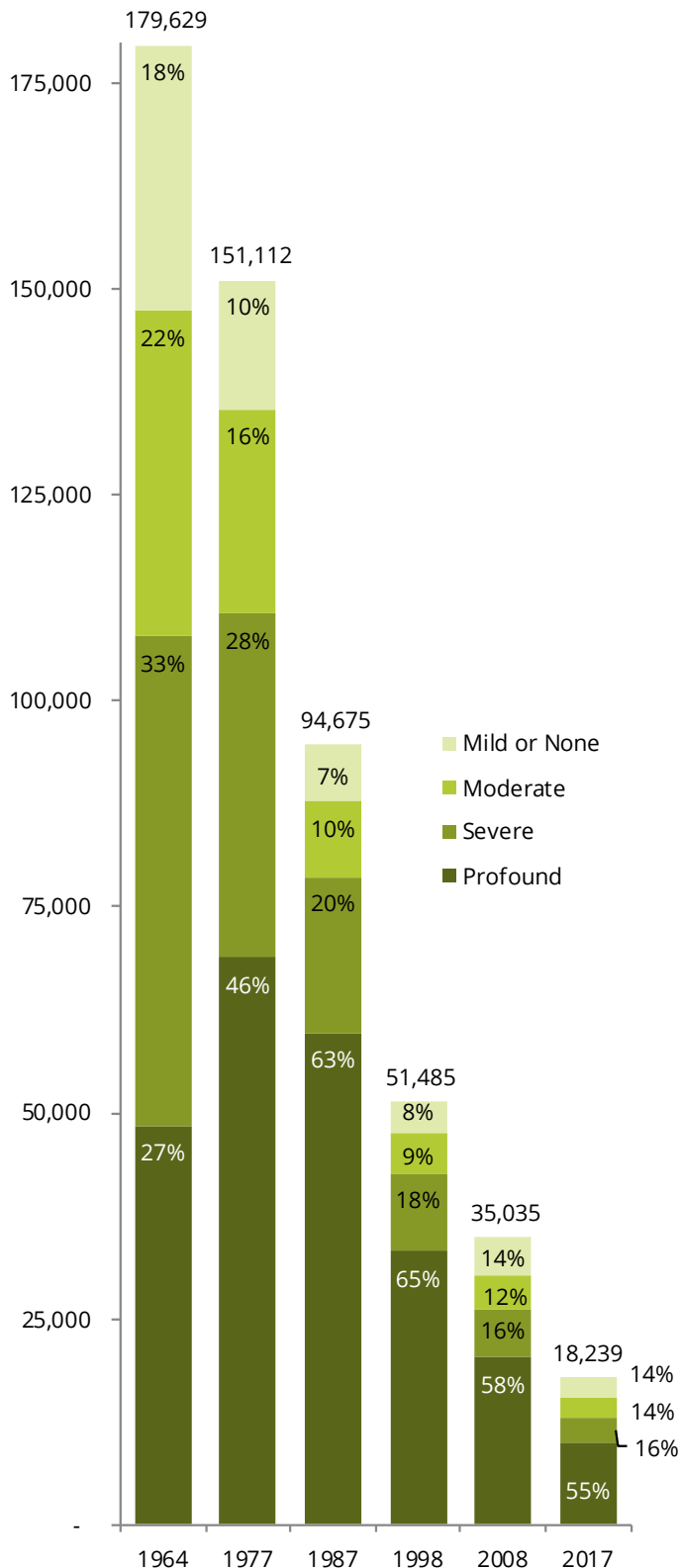
The proportion of people living in PRFs who had epilepsy declined from 45% in 1998 to 39% in 2017. The proportion who had autism was 19% in both 2016 and 2017. The proportion with cerebral palsy declined from 19% to 17% between 1977 and 2017. The proportion who were blind declined from 16% in 1998 to 15% in 2016 (the last year it was monitored).

For 2017 three questions about psychiatric needs and challenging behavior were reduced to a single question that asked the proportion of residents who had a behavior disorder that required a planned intervention. Facilities reported that 56% of PRF residents had this need. This is similar to the 50% to 54% reporting needing medication for mood, anxiety or behavior modification, the proportion with the psychiatric disorder, or the proportion with a behavior disorder reported in 2008 and 2016.

PRF's reported a slight increase in the number and proportion of residents who had prior involvement with the criminal justice system between 2016 and 2017. The number increased from 856 to 996, and the proportion increased from 5% to 6%. The number of short-term stays increased from 909 in 2016 to 1,042 in 2017. The ratio of current residents to short-term stays increased from 5 in 2016 to 6 in 2017.

The 2017 PRF survey was shortened so that it could be fielded annually instead of every other

**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 1964 to 2017



year. Responses to questions that appeared on the survey for the last time in 2016 are summarized here. In 2016, the proportion of PRF residents needing help or assistance with dressing was 64%, toileting was 58%, eating was 56%, walking was 41%, transferring was 58%. In 2016, 52% of PRF residents could not communicate their needs verbally, and 29% could not understand verbal requests. In 2016, 5.5% of PRF residents had been found incompetent to stand trial, 5.5% had exhibited behavior that led to criminal justice system involvement, 1.9% were charged and court ordered for competency testing, 0.2% were under parole supervision, and 3% were under the jurisdiction of the criminal courts for another reason. Finally, of the 909 short-term admissions in 2016, 56% were for respite services, 44% were for evaluations, and less than one percent were for crisis housing.

## TRENDS IN PRF ADMISSIONS, READMISSIONS AND DISCHARGES

### Previous and Subsequent Residence

**Tables 4.16** and **4.17** and **Figures 4.14** and **4.15** show changes in the former residence of people admitted or readmitted to a PRF, and in the subsequent residence of people discharged from PRFs from 1985 to 2017. For the figures, we excluded unknown and other settings and combined the remaining setting types into four categories:

**Table 4.16** Previous Place of Residence of Persons (Re) Admitted to Large State IDD Facilities (in Percent) for Selected Years 1985 to 2017

Previous Place of Residence	Year							
	1985	1989	1994	1998	2002	2008	2012	2017
Home of parents or relative	39	29	19	21	19	21	24	21
Own, Host or Foster Family Home	5	7	2	4	5	7	8	6
Group home (1-6 res.)							6	20
Group home (7-15 res.)							5	6
Group home (15 or fewer res.)	6	8	14	14	16	22	11	25
State or Nonstate IDD Facility (16+ res.)	26	23	32	31	22	20	14	13
Mental health facility	14	16	16	12	16	13	14	13
Correctional facility	2	3	4	10	13	8	13	17
Nursing home, Assisted Living, Boarding Home	9	15	10	8	9	8	16	6

Note: Previous residence for newly admitted and readmitted residents combined in 2017. People in unknown setting types not included for 2017.

**Table 4.17** Subsequent Residence of People with IDD Discharged From a Public IDD Facility: Selected Years 1985 to 2017

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

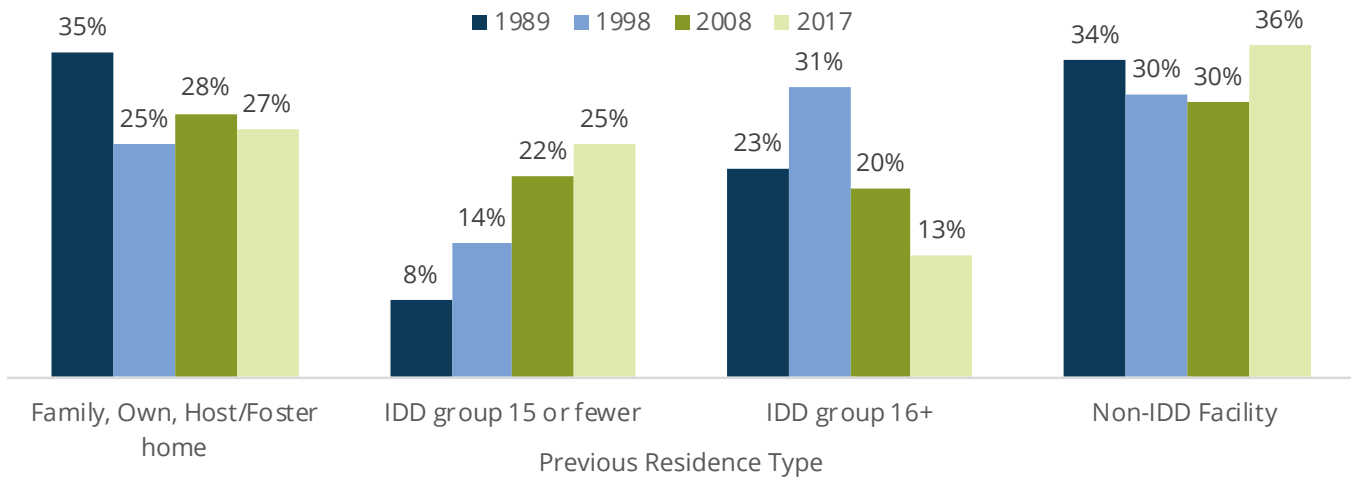
For 2012 through 2017 the percentages exclude unknown. Blanks indicate the setting was not listed on the survey

- Individualized settings (home of a family member, a host or foster family home, or own home)
- Group IDD settings of 15 or fewer people
- Group IDD settings of 16 or more people
- Non-IDD facilities (mental health facilities, correctional facilities, nursing homes, board and care)

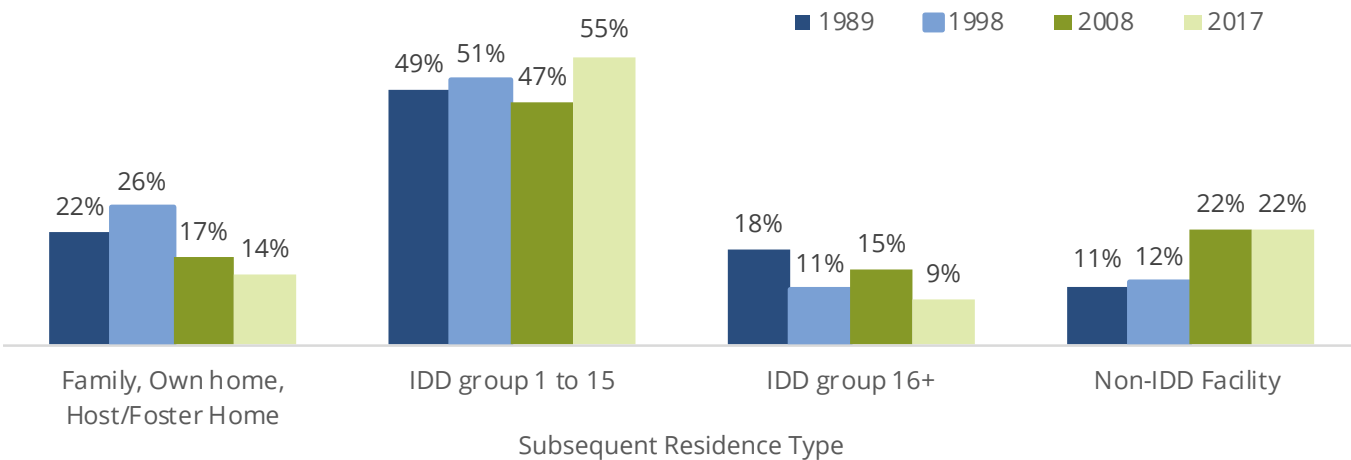
## Admissions

The proportion of PRF residents admitted or readmitted from an individualized setting such as the home of a family member, a host or foster family home or their own home decreased from 44% in 1985 to 27% in 2017. The proportion admitted from a group IDD setting serving 15 or fewer LTSS recipients increased from 6% to 25%. The proportion admitted from an IDD facility serving 16 or more LTSS recipients declined from 26% to 13%. Finally, the proportion admitted from a non-IDD facility such as a mental health facility, correctional facility,

**Figure 4.14** Previous Place of Residence for People (Re)Admitted to a Large State IDD Facilities in Percent Selected Years: 1989 to 2017



**Figure 4.15** Subsequent Residence of People with IDD Discharged From a Public IDD Facility Selected Years 1989 to 2017



Excludes people whose subsequent residence was unknown

nursing home, assisted living facility or boarding home increased from 25% to 36%.

## Discharges

The proportion of PRF residents discharged to the home of a family member, their own home, or a host or foster family home declined from 26% in 1989 to 14% in 2017. During those years the proportion moving to an IDD group setting serving 15 or fewer LTSS recipients increased from 49% to 55%, the proportion moving to another large IDD setting declined from 18% to 9%, but

the proportion moving to an institution not specifically designed for people with IDD increased from 11% to 22%. In 2017, 4% of those who left went to a mental health hospital or facility, 8% moved to a correctional facility, and 10% moved to a nursing home, assisted living setting or a boarding home.

## Training and Technical Assistance Provided to People Outside of PRFs

The PRF survey has asked facilities to report on the services offered directly to people with IDD

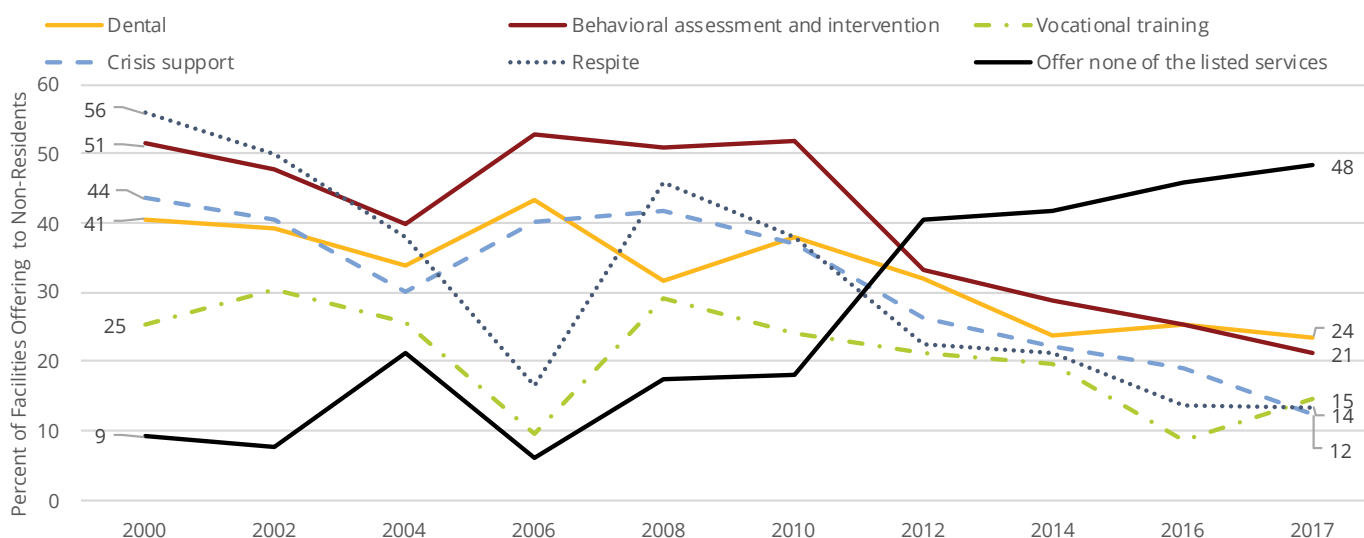


**Table 4.18** Percent of PRFs Providing Services to People Not Living On-Campus by Type of Service 2000 to 2017

Type of Service	Year									
	2000	2002	2004	2006	2008	2010	2012	2014	2016	2017
Dental	41	39	34	43	32	38	32	24	26	24
Behavioral assessment and intervention	51	48	40	53	51	52	33	29	26	21
Vocational training	25	31	26	9	29	24	21	20	9	15
Respite	56	50	38	17	46	38	23	21	14	14
Crisis support	44	41	30	40	42	37	26	22	19	12
Consultant health services	29	28	25	32	25	22	14	22	7	10
Other	15	11	10	10	7	9	12	5	7	8
Recreation	24	25	16	48	29	27	20	16	15	
Family support/Home visitation by staff	38	41	24	36	44	39	20	18	11	
Assistive technology assessment and intervention	33	29	30	39	35	21	20	12	11	
Personal/Social Counseling				19	24	21	10	18	10	
Diagnostic services	36	30	26	32	33	21	19	17	10	
Physical therapy	20	18	15	13	18	19	12	11	7	
Medical and/or nursing treatment	22	25	18	25	22	16	17	12	6	
Audiological assessment and intervention	26	26	21	23	17	19	6	10	6	
Speech services	19	20	20	25	14	21	18	10	5	
Self-help or developmental classes	15	13	11	13	20	17	8	7	5	
Primary health care	10	8	8	25	7	9	10	11	4	
Sex education	9	11	8	24	9	9	4	4	2	
Offer none of the listed services	9	8	21	6	18	18	41	42	46	48
Average number of services provided	6	5	4	5	5	4	3	3	2	1
N = 89 facilities reporting in 2017. Each facility could report offering multiple types of services. In 2017, only the services with data were asked about.										

N = 89 facilities reporting in 2017. Each facility could report offering multiple types of services. In 2017, only the services with data were asked about.

**Figure 4.16** Percent of PRFs Offering Behavioral Assessment, Dental, Crisis Support, Respite Services, or Vocational Training to People with IDD not Living On-Campus 2000 to 2017



who did not live in the facility since 2000 (See **Table 4.18** and **Figure 4.16**). The proportion of PRFs reporting they did not provide any services to people not living in the facility increased from 9% in 2000 to 48% in 2017 as states shifted their

technical assistance and services out of PRFs and into community-based settings. The proportion of facilities offering respite services (the most popular service offered to non-residents in 2000) declined from 56% in 2000 to 14% in 2017. The

proportion offering behavioral assessment and intervention supports declined from 51% in 2000 to 21% in 2017. Similarly, the proportion offering crisis support services declined from 44% to 14%. The declines were not quite as steep for dental services (declining from 41% of facilities in 2000 to 21% in 2017 offering the service), or for vocational services (declining from 25% of facilities to 15% in 2017).

## Staffing Characteristics

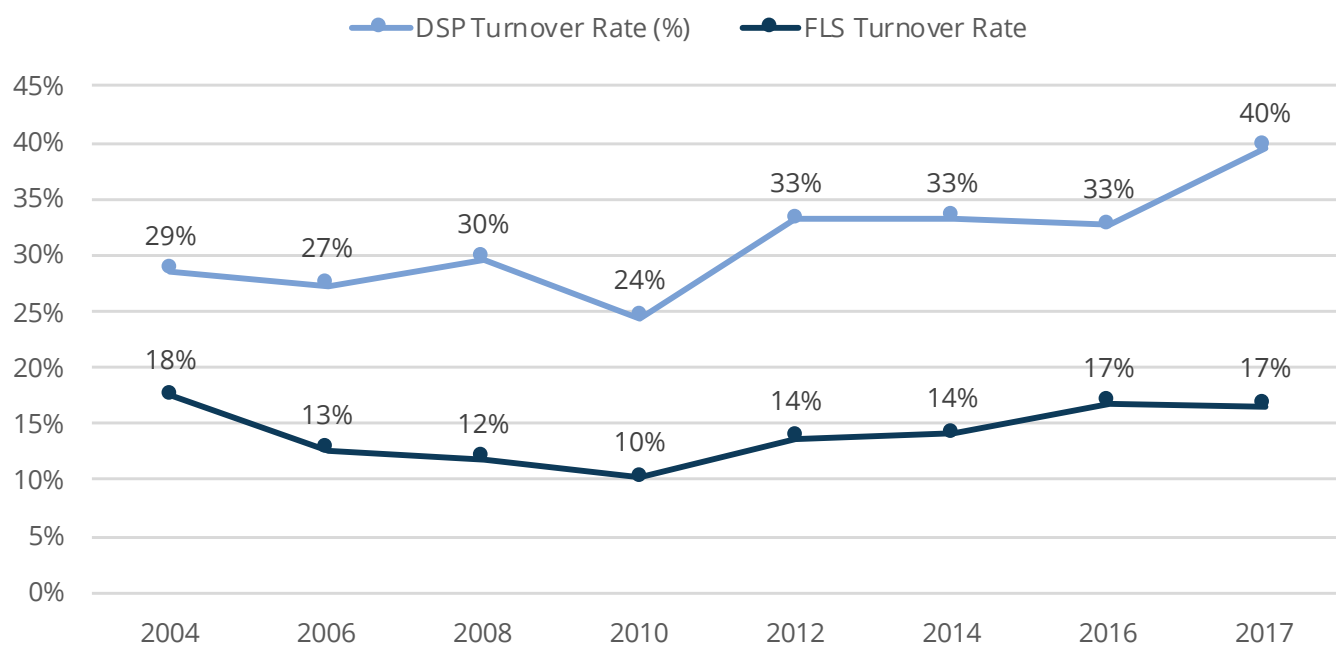
As the number and size of PRFs declined between 2004 and 2017, staffing outcomes also changed (See **Table 4.19** and **Figure 4.17**). Finding and keeping qualified direct support professionals and frontline supervisors is one of the most commonly mentioned challenges for LTSS providers. DSP starting and average hourly wages kept pace with inflation between 2004 and 2017 with starting wages increasing from \$10.12 in 2004 (the equivalent of \$13.07 in 2017 dollars when adjusted to inflation)

**Table 4.19** Direct Support Professional and Frontline Supervisor Vacancy and Turnover Rates, Wages and Salary in Large State-Operated IDD Facilities Selected Years 2004 to 2017

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

DSP Direct Support Professional; FLS Frontline Supervisor

**Figure 4.17** Direct Support Professional and Frontline Supervisor Turnover Rates in PRFs Selected Years 2004 to 2017



to \$13.77 in 2017. Average DSP wages increased from \$12.53 in 2004 (\$16.18 in inflation adjusted dollars) to \$16.11 in 2017. Between 2004 and 2017 vacancy rates for DSPs doubled from 6% to 12% and DSP turnover rates increased from 29% to 40%. At 40% the turnover rates in PRFs are similar to those reported for community-based LTSS providers.

Similar trends were seen for frontline supervisors. Between 2004 and 2017, starting salaries for frontline supervisors increased from \$27,397 to \$38,123, and average salaries increased from \$33,299 to \$47,678. During those years, vacancy rates for frontline supervisors increased from 7% to 10%. Turnover rates for supervisors remained between 10% and 18% between 2004 and 2017.





## SECTION FIVE

# STATE NOTES AND PROFILES

**FY 2017**



## SECTION 5: STATE NOTES AND PROFILES

### STATE NOTES

#### Alabama

In FY 2015 and FY 2017, people waiting for, but not receiving LTSS were excluded from the count of people living in the home of a family member. For FY 2014 and FY 2016, those individuals were counted.

#### Alaska

All ICF/IID recipients from Alaska live in other states. Alaska reported ten non-state group homes with 16 or more people, but zero people living in settings of that size.

#### Arizona

In FY 2016, Arizona changed the way they reported the number of people in family home versus other settings by age (21 and under and 22 and over), so numbers may differ than in the past (See **Table 2.7**). Arizona manages ICF/IID settings within their 1115 Managed Care Demonstration Waiver and reports ICF/IID and waiver group settings together.

#### Arkansas

Arkansas reported a caseload of 2,955 people and 5,718 LTSS recipients.

#### California

California reported recipients by age in its large state-operated IDD facilities in the following categories 22 to 31 years, 32 to 41 years, 42 to 51 years, 52 to 61 years, and more than 61 years.

#### Colorado

Colorado's two state-operated facilities (Grand Junction Regional Center and Wheat Ridge Regional Center) operate units both on the campus and in the community. Non-state "other" facilities are Personal Care Alternative settings in which a person lives alone or with one other service recipient. The setting is often the home of a relative.

#### Connecticut

The waiting list is not limited to people requesting Medicaid Waiver-funded supports. However most people on Connecticut's waiting list eventually move to a Waiver-funded residential setting. Some people

on the waiting list are not eligible for Targeted Case Management services. ICF/IID recipients and expenditures by age included only state-operated ICF/IID settings from FY 2013 through FY 2016.

#### Delaware

Beginning in FY 2013, people receiving Family Support Specialist services were counted as living in the home of a family member. In FY 2017, waiver recipients living in settings other than the home of a family member were not counted. In FY 2017, Delaware revised its reporting for waiver recipients by setting type.

#### District of Columbia

State-funded non-Medicaid expenditures cover non-waiver out of state residential facilities, certain adaptive equipment, and meals at day habilitation programs for adults who live with family members.

#### Florida

FY 2018 data was used for ICF/IID by age and expenditures.

#### Georgia

For FY 2017, the Gracewood and Augusta Campuses of the East Central Regional Hospital submitted a combined PRF survey (see Section 4 of the report). AHCA (2018a) reported one non-state ICF/IID with 121 residents in FY 2017, the state agreed to use ACHA data for ICF/IID in FY 2016 and FY 2017. The FY 2016 ICF/IID residents was reported as zero in the RISP report, but AHCA data indicates 284 residents.

#### Hawaii

No people were waiting for Medicaid Waiver-funded services on June 30, 2017.

#### Idaho

The total number of people on the state IDD caseload for FY 2017 included only people receiving Medicaid 1915(c) Waiver-funded supports. It did not include people living in an ICF/IID.

### **Illinois**

Prior to FY 2016, the number of people waiting for services included some people who were already receiving Medicaid Waiver-funded supports. Beginning in FY 2016, only people living with a family member or in their own home who requested Medicaid Waiver-funded supports to begin within the next 12 months are counted. For age breakdowns in Section 4 on large state-operated facilities, people 21 years old are reported with the 22 years or older group.

### **Indiana**

Beginning in FY 2014, Indiana expanded its Family Supports Waiver to serve more people ages 21 years or younger. This change reduced the length of time that individuals and their families wait for services. Because the Family Supports Waiver has an annual cap on the costs of an individual's service, and does not include a residential component, average Waiver expenditures per person also declined.

### **Iowa**

Beginning in FY 2017, Iowa was able to separate out people living in host or foster family settings more reliably resulting in higher numbers of people reported in those settings.

### **Kansas**

In FY 2016, the reported ICF/IID expenditures and average per person expenditures excluded services provided in state-operated ICFs/IID.

### **Kentucky**

The number of group home (Type II) and Host/Family Foster Care (Type III) residences was imputed based on the total number of providers, assuming residences were at or near capacity. In FY 2017, an estimated 12,905 Waiver recipients lived in family homes or homes of their own but Kentucky could not report the number in family homes versus own home settings.

### **Louisiana**

Louisiana had three state-operated facilities serving 16 or more people with ICF/IID licenses: Pinecrest Supports and Services Center (Pineville), Central Louisiana Supports and Services Center (Alexandria) previously known as the Louisiana Special Education

and Transition Center, and East Louisiana State Mental Hospital (a psychiatric facility with 3 ICF/IID certified units). In FY 2017 Louisiana served an estimated 12,085 people in non-state own home or family home settings combined, however the number by setting type could not be estimated.

### **Maine**

The estimated number of LTSS recipients in non-state settings increased in FY 2017 because people in unknown setting types were counted for the first time. Setting sizes for people living in non-state group settings other than ICF/IIDs were estimated. Four short-term state-operated IDD facilities are not counted since stays are limited to 90 days or less.

### **Maryland**

People with IDD living in "unknown" settings receive Community Coordination Services, Behavior Support Services (BSS), Residential, Individual Family Care (IFC), or self-directed supports. In FY 2017, there were an estimated 11,036 LTSS recipients in unknown settings. Starting in FY 2015, Maryland included people receiving case management services, which explains the increase in LTSS recipients, particularly in unknown setting types. Maryland has three state-operated facilities of 16 or more people. One of those, the Secure Evaluation and Therapeutic Treatment Program (SETT Unit), was not described in this report. A description of Maryland's facilities can be found online (<https://dda.health.maryland.gov/Pages/Facilities.aspx>).

### **Massachusetts**

Beginning in FY 2015, the reported number of LTSS recipients in non-state settings excludes people 21 years or younger living with a family member.

### **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.

### **Minnesota**

Data reported are from the FY 2018 survey. Non-state "other" settings include Customized Living (Assisted Living) and Board and Care. Most Customized Living arrangements are Medicaid Waiver-funded. In FY 2015, 416 family foster care

homes were reclassified as corporate foster care settings with shift staff while still serving the same individuals at the same address. 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.

### Mississippi

AHCA (2018a) was the source for data on the number of people with IDD in nursing homes. The IDD agency receives data regarding state-operated ICF/IID. The IDD agency does not receive private or non-state ICF/IID data. From FY 2013 to FY 2017, the reported ICF/IID recipients and expenditures by age and setting size only included state-operated ICF/IID settings.

### Missouri

Waiting lists for Waiver-funded supports in Missouri were eliminated in FY 2015. In FY 2017, all of the people reported to be waiting were actually moving through the assessment and provider selection process. State general revenue funds are appropriated for in-home supports and services to families through regional autism projects.

### Montana

Since FY 2015, children ages 1-3 receiving Part C and/or Social Services Block Grant (Title XX) funding have been counted in the IDD agency caseload. Since FY 2016, it has not been possible to differentiate between non-state group homes with 1 to 3 people from group homes with 4 to 6 people. People 16 years or older served by the state IDD agency are entitled to Medicaid State Plan-funded Case Management services.

### Nebraska

Beatrice State Development Center campus houses four separately licensed ICF/IID buildings. From FY 2011 to FY 2016, each building was reported as a separate facility.

### Nevada

The “non-state other” category includes hospitals, correctional/ incarceration facilities, and similar facilities of 16 or more people. In FY 2017, 57 people on the IDD agency caseload lived in those settings.

### New Hampshire

New Hampshire was unable to furnish data for the FY 2017 RISP report. FY 2017 data on people with IDD in nursing homes and ICF/IID facilities came from AHCA (2018a) reports.

### New Jersey

Data from FY 2010 forward has been adjusted to reflect the transfer of children’s services to another state department.

### New Mexico

Non-state IDD group homes in New Mexico serve a maximum of four people. It is not possible to differentiate between homes with 1 to 3 people and homes with 4 to 6 people. In FY 2017, an estimated 1,427 people receiving services under the MiVia Waiver lived in their own home or with a family member, but separate counts by setting type are not available.

### New York

While there is not a waiting list for Medicaid Waiver funding in New York, in FY 2017, an estimated 6,099 current service recipients with IDD indicated that they would like to move to supported housing within the next two years. New York reduced the number of state-operated ICFs/IID serving 16 or more people from 20 in March 2016 to six in March 2017. Three of those facilities were in the sample frame for the RISP FY 2017 Public Residential Facility Survey.

### North Carolina

North Carolina increased the use of (b)(3) services under its Medicaid 1915 b/c waiver in FY 2016. The number of settings and recipients in non-state settings for FY 2017 was reported by five of the seven Local Management Entities/Managed Care Organizations (LME-MCO). Three of those five LME-MCOs reported all setting as size unknown. FY 2017 expenditures and age breakdowns were reported for 3,510 of 4,406 people in ICF/IID settings.

North Carolina has four state-operated ICF/IID facilities with 16 or more individuals: Caswell Center,

J. Iverson Riddle Development Center, Murdoch Developmental Center, and O’Berry Neuro-Medical Treatment Center (OBNMTC). The Black Mountain

Center, a large state-operated Skilled Nursing Facility, is not ICF/IID certified.

### **North Dakota**

Medicaid Waiver recipients receiving day and employment services but not in-home or residential services are included in the count of Waiver recipients, but their living arrangements are not reported.

### **Ohio**

The waiting list included people waiting for Medicaid Waiver-funded supports who were not already Medicaid Waiver or ICF/IID recipients. It included some people living in non-family settings.

### **Oklahoma**

Oklahoma has four Medicaid Waivers. For two waivers, total annual expenditures are capped at a rate similar to that paid for services in a non-state institution. The other two comprehensive Waivers serve only people with high needs and have higher annual expenditure caps.

### **Oregon**

Oregon began offering home and community-based services through the Medicaid State Plan 1915(k) funding authority in FY 2015. Total Medicaid Waiver recipients and expenditures declined as recipients moved from Waiver to State Plan 1915(k) funding. Changes to improve the accuracy of reporting resulted in an increase in the number of 1915(c) recipients and expenditures reported in FY 2017.

### **Pennsylvania**

In FY 2017, the estimated number of LTSS recipients living with a family member declined because Pennsylvania stopped reporting residential settings for individuals receiving case management but no other long-term services or supports.

### **Rhode Island**

State reported 5 children on the caseload, but 215 children on the caseload getting no services, and 60 children getting waiver-funded services.

### **South Carolina**

The Pee Dee Regional & Thad E. Saleeby Centers submitted one joint RISP Public Residential Facility

Survey for FY 2015-2017 (See **Table 4.23**), but they are on two campuses so they are counted separately elsewhere in the report.

### **Tennessee**

Tennessee stopped accepting applications its 1915(c) Waiver on June 30, 2016 and no longer maintains a waiting list for 1915(c) Waiver-funded services. People on the referral list for services under the 1115 Waiver have not been screened for eligibility.

### **Texas**

The Texas fiscal year ends on August 31 (rather than June 30). Nursing home data were from AHCA (2018c).

### **Utah**

ICF/IID recipients and expenditures, and age breakdowns are reported only for state-operated settings. Expenditures for 45 children and 538 adults in non-state ICF/IID settings were not reported. Nursing home data were from AHCA (2018c).

### **Vermont**

The number of people in own home settings increased in FY 2017 to include LTSS recipients who receive services other than in-home support (e.g., employment supports, clinical services). The number of Medicaid Waiver recipients ages 21 and younger was a slight undercount from FY 2015 to FY 2017 due to a glitch in the formula. The total caseload on the state profile for 2013 through 2017 was updated to include people in transition between settings or in crisis housing and to account for differences between data sources for various data elements on the survey. This change will be reflected throughout the report beginning in 2018.

### **Virginia**

Virginia reported 17 new state-operated ICF/IID facilities serving 4 to 6 people and 13 new state-operated ICF/IID settings serving 7 to 15 people in FY 2017. FY 2016 data was used for Virginia for state and non-state settings when the reported numbers did not align with the updated caseload number for FY 2017.

## Washington

Washington implemented Medicaid Community First Choice State Plan Services in FY 2016. Personal care services previously funded through a Medicaid Waiver are now funded through the Community First Choice State Plan option. Medicaid State Plan expenditures increased and Medicaid Waiver expenditures decreased when the change was made. The number of people with IDD in Own Home settings varies from year to year because in some years, data were not available for all funding authorities.

## West Virginia

Nursing home data were from AHCA (2018c).

## Wisconsin

Setting size information was not available for LTSS recipients living in their own home or in a non-state other setting. Until FY 2014, Wisconsin reported only Waiver recipients living in own home, family home and non-state other settings. Since then all LTSS recipients in those settings have been reported.

Large state-operated IDD facilities in WI 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

No notes



## STATE PROFILES

The state and United States profiles show longitudinal changes in residential settings for LTSS recipients with IDD, state IDD agency caseloads, Medicaid Waiver waiting lists and Medicaid recipients by funding authority. They also show FY 2017 expenditures per person by funding authority, setting type, and age. Blank spaces or breaks in a trend line indicate years in which a data element was not collected or for which a state provided incomplete or no data. Large year-to-year changes often reflect changes in state data sources or methodology, the addition or termination of a funding authority, or inclusion of a narrower or broader set of recipients. The State Notes describe variations from the survey definitions, alternative data sources used, reasons for large year-to-year changes, and other factors affecting data interpretation. Additional national and state data can be viewed in the RISP project's Chart Gallery at <https://risp.umn.edu/viz>. Survey questions and operational definitions can be found in the Publications section of the RISP website.

### IDD Agency Long Term Supports and Services Recipients by Residence Type

The first chart shows the number of long-term supports and services (LTSS) recipients by residence type (family home, own home, host or foster family home, and group homes) by year. Group settings such as ICFs/IID or Medicaid Waiver-funded group homes are broken down according to the number of people with IDD sharing the home (1 to 3, 4 to 6, 7 to 15 or 16 or more).

### Caseload, LTSS and Medicaid Recipients and Waiting for Waivers

The second chart shows changes over time in the number people served by state IDD agencies, the number of people with IDD receiving one or more LTSS in addition to case management, and the number of people with IDD waiting for Medicaid Waiver-funded services while living with a family member or in their own home. The waiting list numbers do not include people who already live in a group home or another LTSS setting or who already receive some Medicaid Waiver-funded supports. The chart also shows changes in the number of LTSS recipients whose services are funded under the Medicaid ICF/IID program, or under one of several Medicaid Waiver funding authorities (1115, 1915 (a) (b) or (b/c), 1915(c)).

### Average Annual Medicaid per Person Expenditures for FY 2017

The third chart shows average annual per person expenditures for people with IDD living in an ICF/IID, or who receive LTSS funded by specific Medicaid Waiver funding authorities (1115, 1915 (a)(b) or (b/c), 1915(c)). When available, for Medicaid Waiver recipients, annual per person expenditures are also broken down by recipient age as of June 30 (birth to 21 years or 22 years or older) and by living arrangement (family home or any other setting).

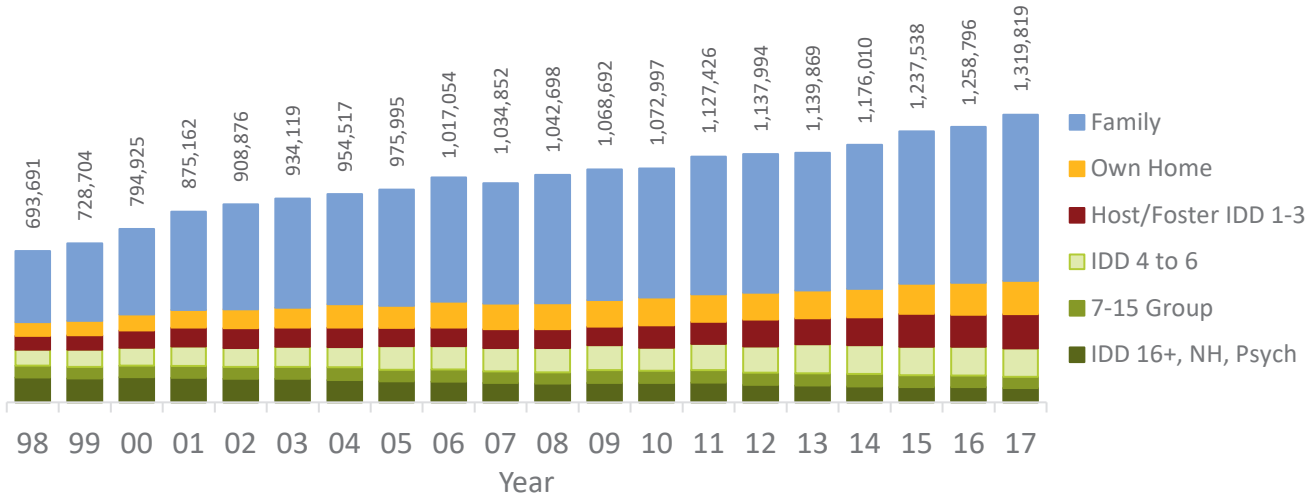
# United States

Fiscal year 2017

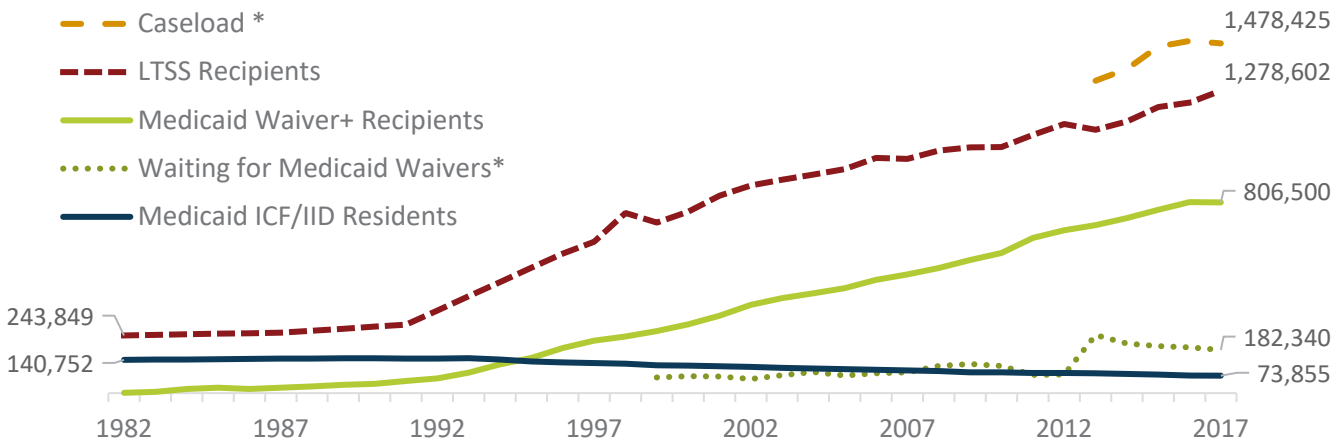
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## Long Term Supports and Services Recipients with IDD by Residence Type and Year

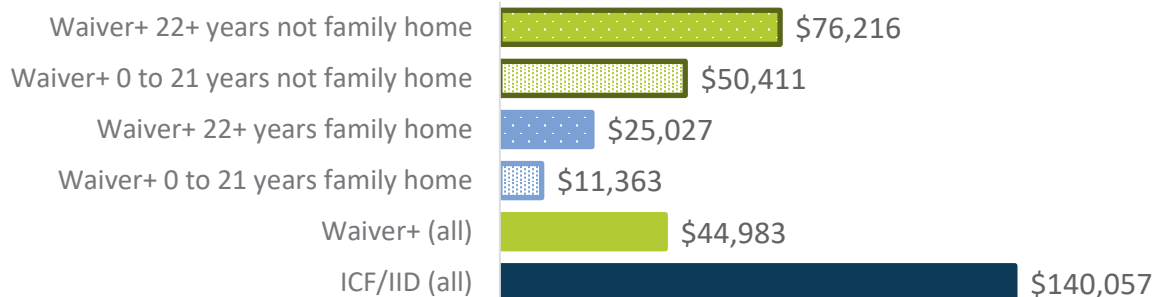


## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2017



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

## Average Spending Per Person by Medicaid Authority in Fiscal Year 2017



Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

ICF/IID: Intermediate Care Facilities for Individuals with Intellectual Disabilities

Group: Number of people with IDD in a setting (ICF/IID, group home or other)

Waiver+: Medicaid Authorities 1115, 1915 (a)(b) or (b)(c), 1915(c)

For more see [risp.umn.edu](http://risp.umn.edu)

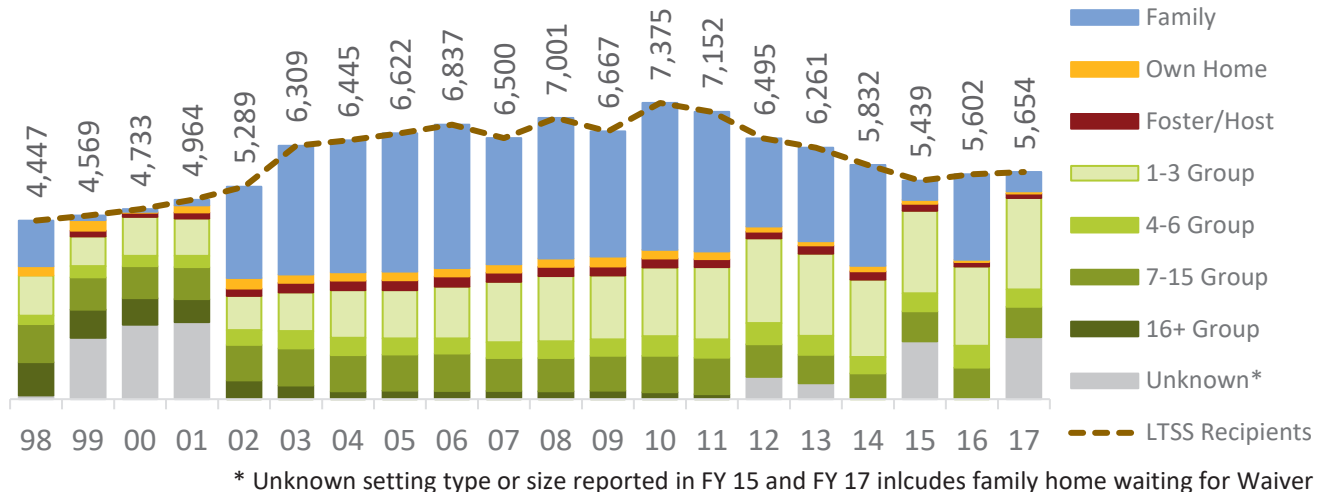
# Alabama

Fiscal year 2017

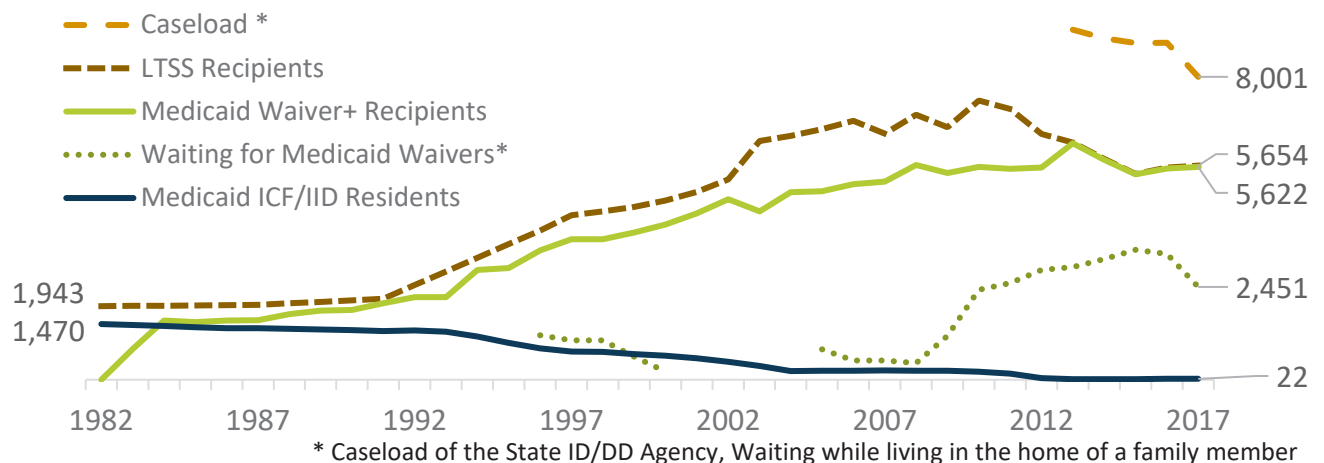
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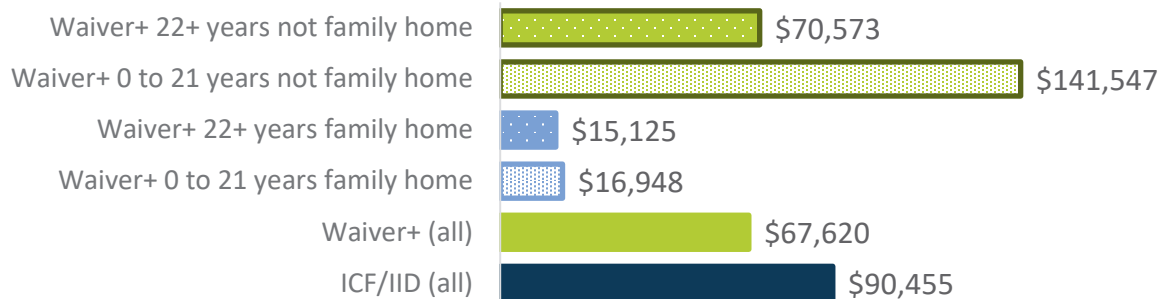
## IDD Agency Long Term Supports and Services Recipients by Residence Type



## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2017



## Average Spending Per Person by Medicaid Authority in Fiscal Year 2017



Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

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Group: Number of people with IDD in a setting (ICF/IID, group home or other)

Waiver+: Medicaid Authorities 1115, 1915 (a)(b) or (b)(c), 1915(c)

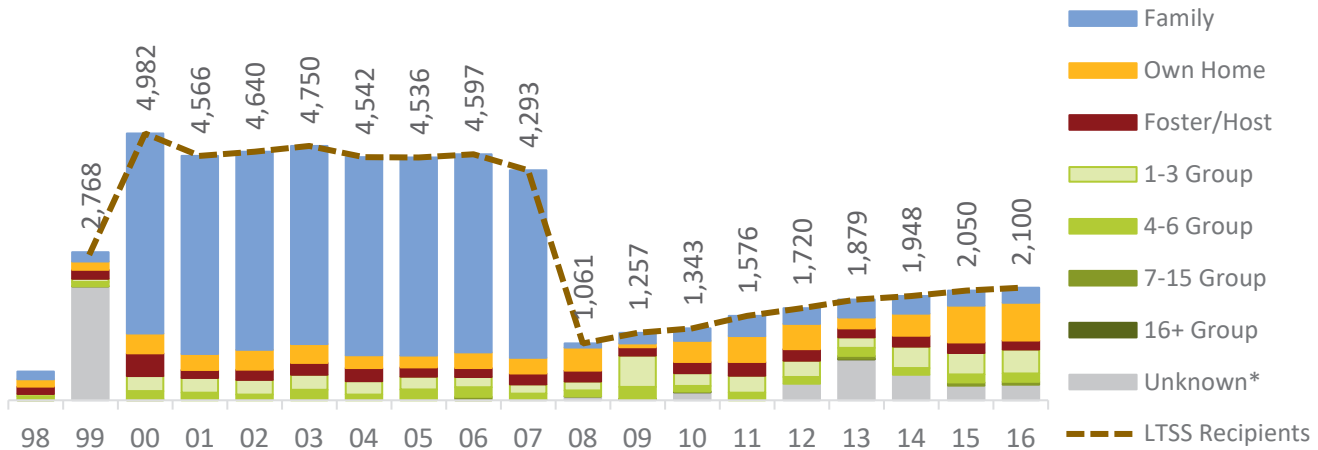
For more see [risp.umn.edu](http://risp.umn.edu)

# Alaska

Fiscal year 2017 not available, FY 2016 presented when available.  
Residential Information Systems Project

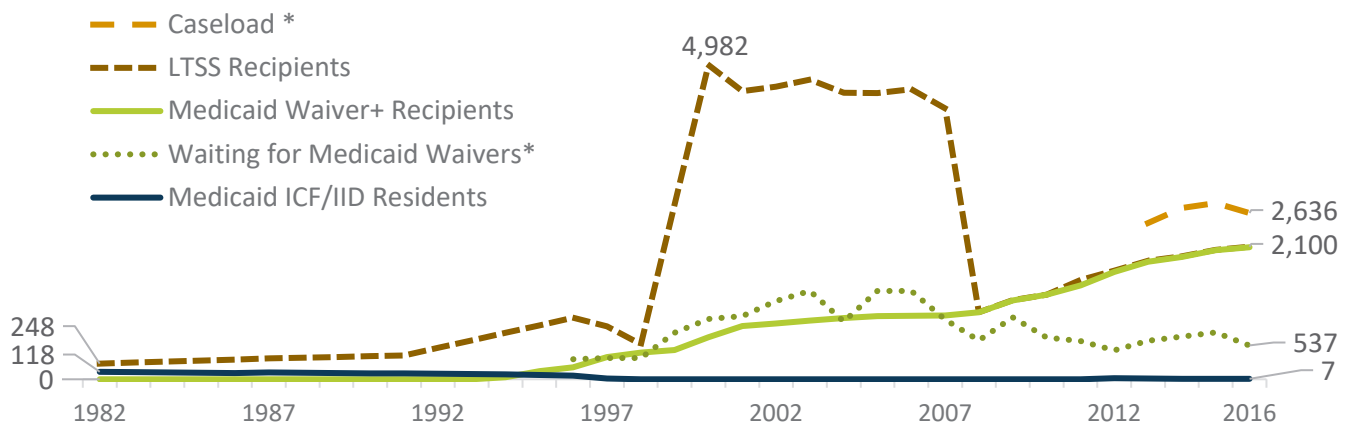


## IDD Agency Long Term Supports and Services Recipients by Residence Type



\* Unknown setting type or size reported in FY 2017 and gaps in all other years

## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2016



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

## Average Spending Per Person by Medicaid Authority in Fiscal Year 2016



All seven ICF/IID recipients are out of state.

Waiver+ by age in family home or not family home spending per person not available.

Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

ICF/IID: Intermediate Care Facilities for Individuals with Intellectual Disabilities

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Waiver+: Medicaid Authorities 1115, 1915 (a)(b) or (b)(c), 1915(c)

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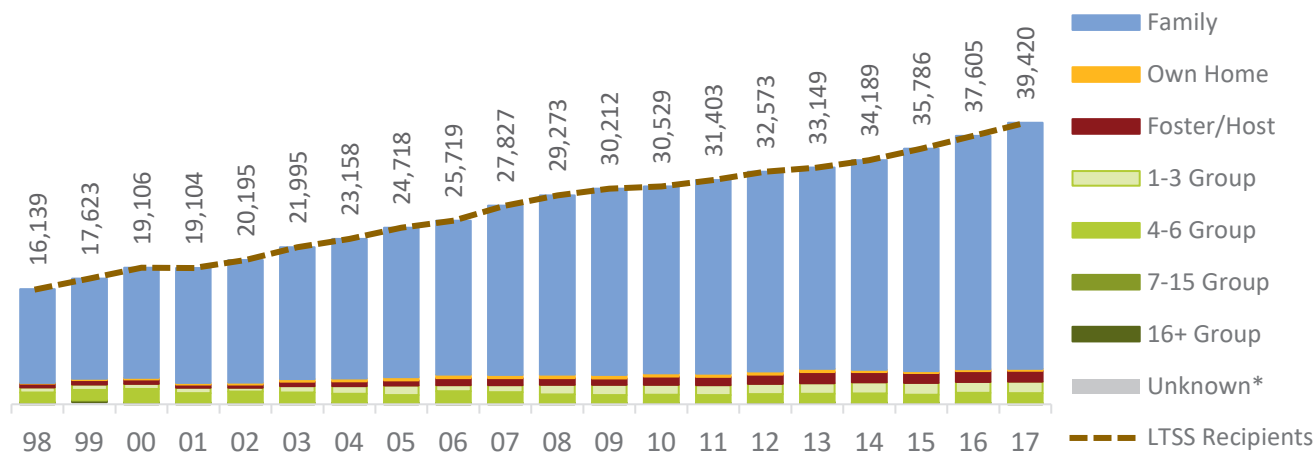
# Arizona

Fiscal year 2017

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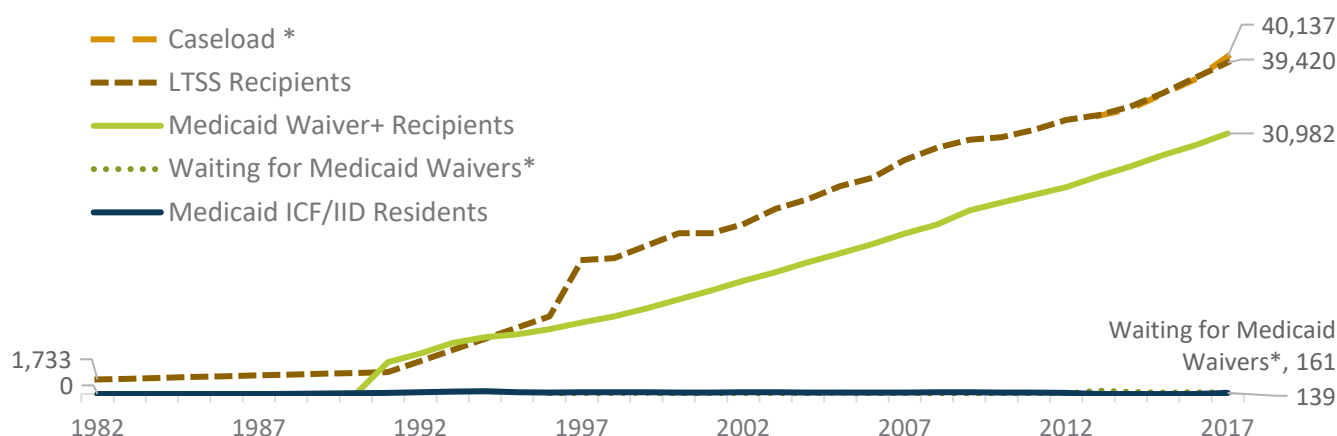


## IDD Agency Long Term Supports and Services Recipients by Residence Type



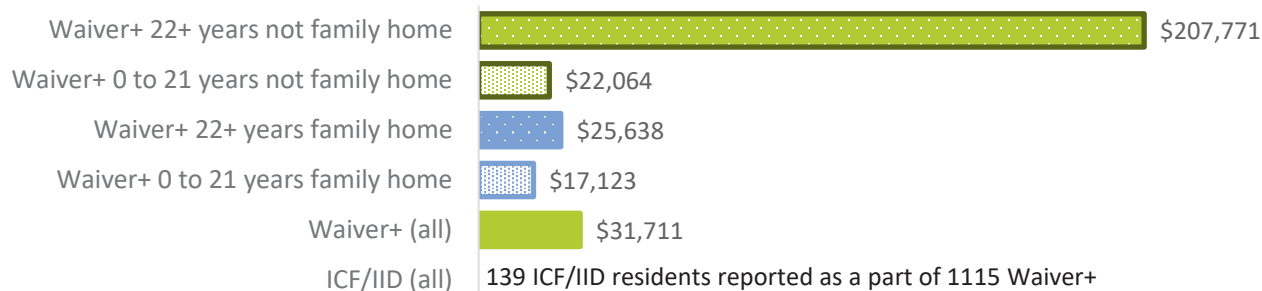
\* Unknown setting type or size reported in FY 2017 and gaps in all other years

## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2017



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

## Average Spending by Medicaid Authority Per Person in Fiscal Year 2017



Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

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Waiver+: Medicaid Authorities 1115, 1915 (a)(b) or (b)(c), 1915(c)

For more see [risp.umn.edu](http://risp.umn.edu)



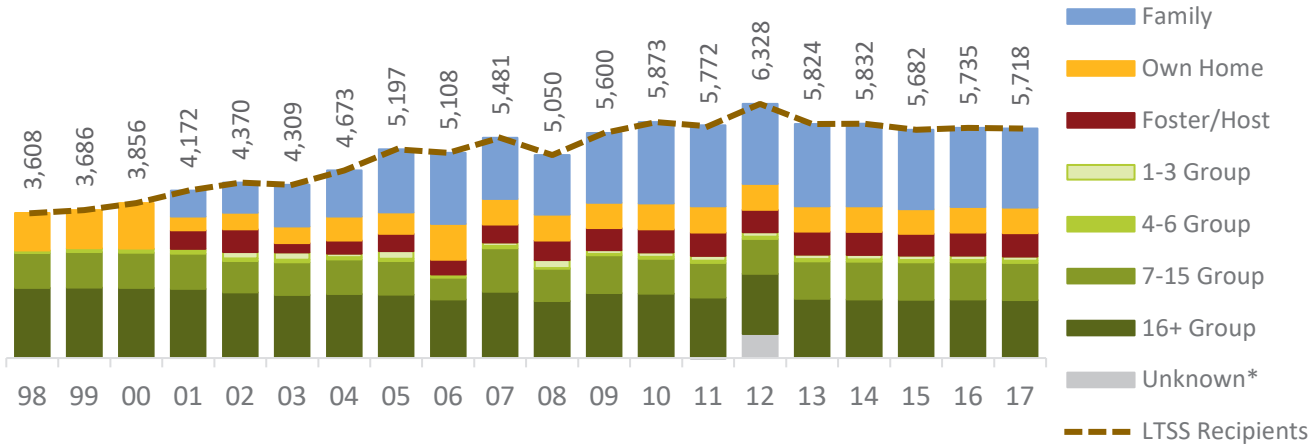
# Arkansas

Fiscal Year 2017

Residential Information Systems Project

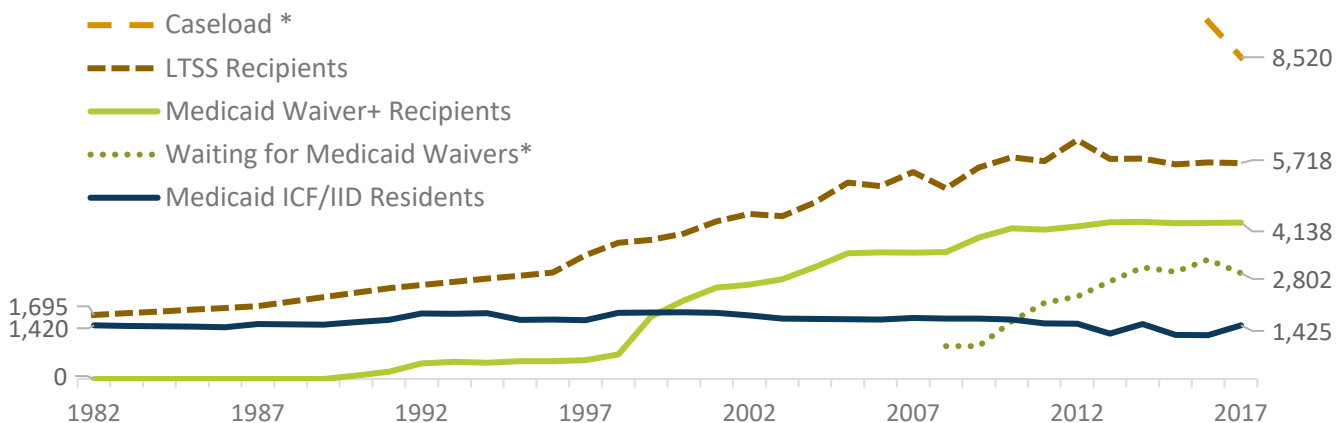


## IDD Agency Long Term Supports and Services Recipients by Residence Type



\* Unknown setting type or size reported in FY 2017 and gaps in all other years

## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2017



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

## Average Spending Per Person by Medicaid Authority in Fiscal Year 2017



Waiver by age in family home or not family home spending per person not available.

Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

ICF/IID: Intermediate Care Facilities for Individuals with Intellectual Disabilities

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Waiver+: Medicaid Authorities 1115, 1915 (a)(b) or (b)(c), 1915(c)

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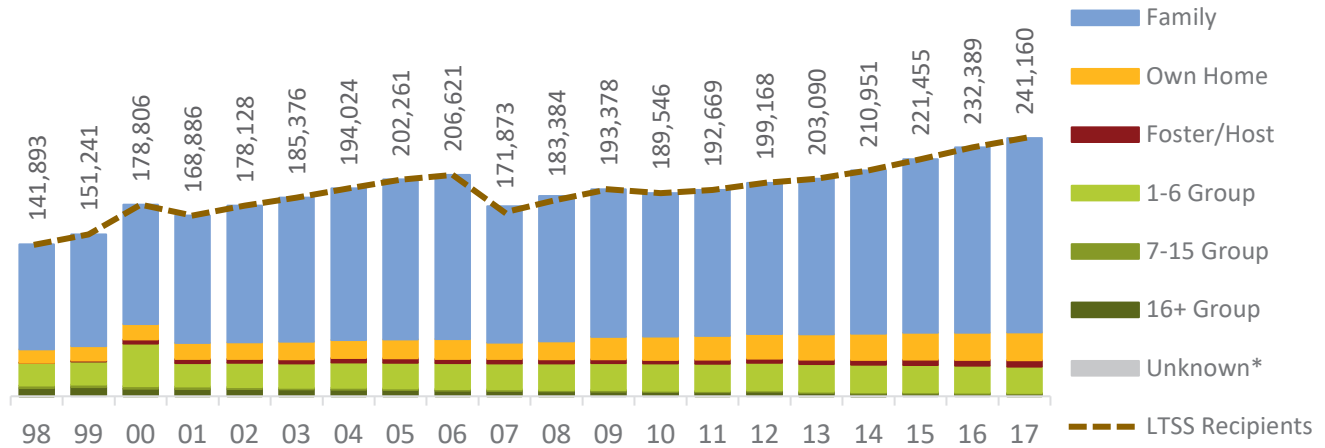
# California

Fiscal Year 2017

Residential Information Systems Project

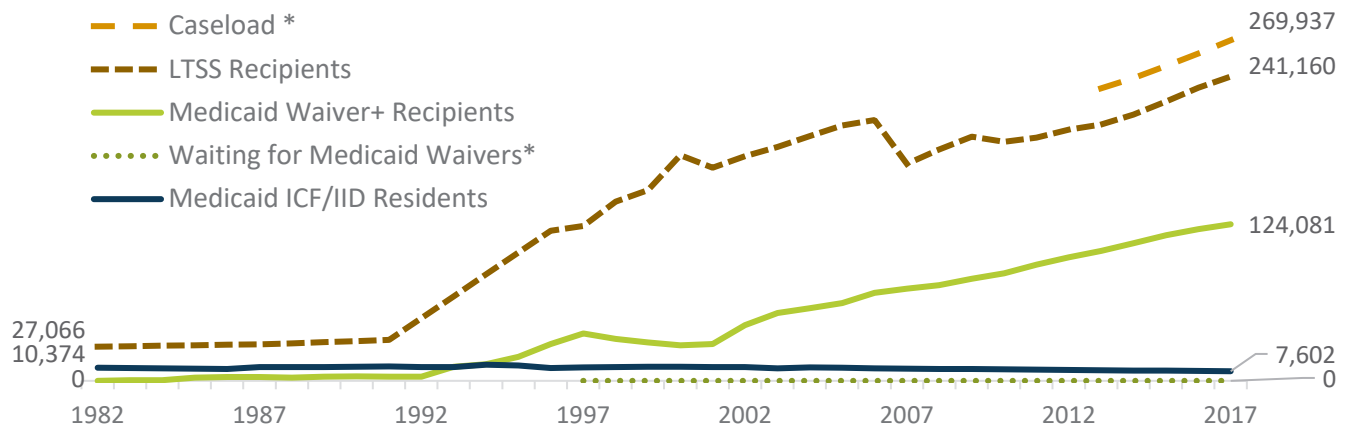


## IDD Agency Long Term Supports and Services Recipients by Residence Type



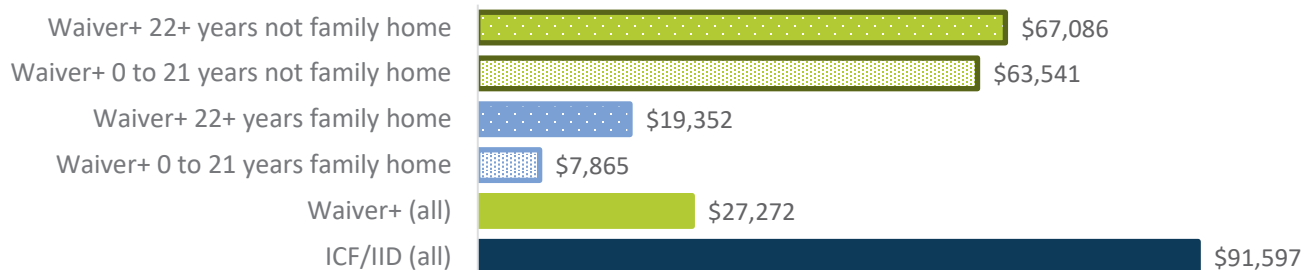
\* Unknown setting type or size reported in FY 2017 and gaps in all other years

## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2017



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

## Average Spending Per Person by Medicaid Authority in Fiscal Year 2017



Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

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Waiver+: Medicaid Authorities 1115, 1915 (a)(b)or (b/c), 1915(c)

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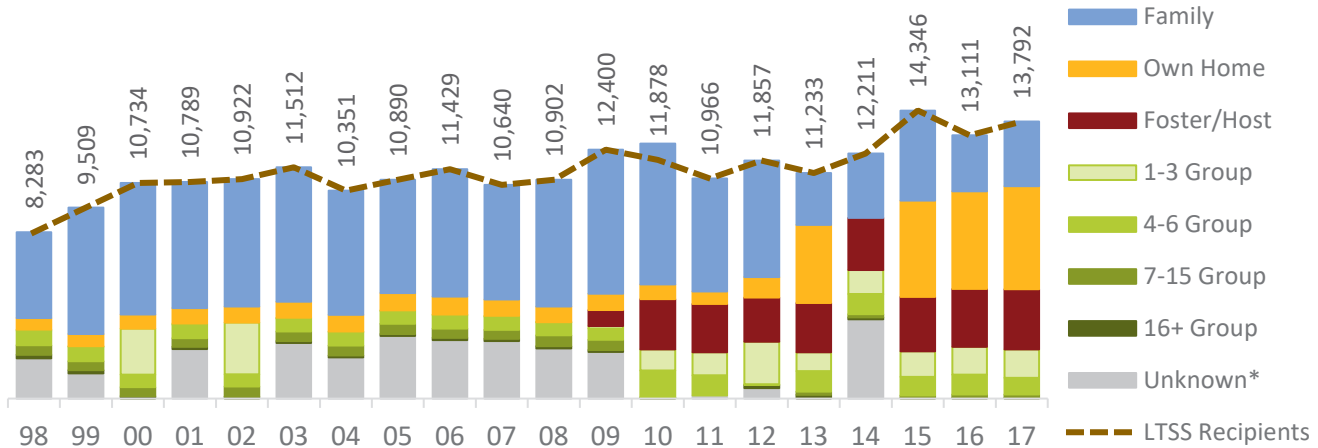
# Colorado

Fiscal Year 2017

Residential Information Systems Project

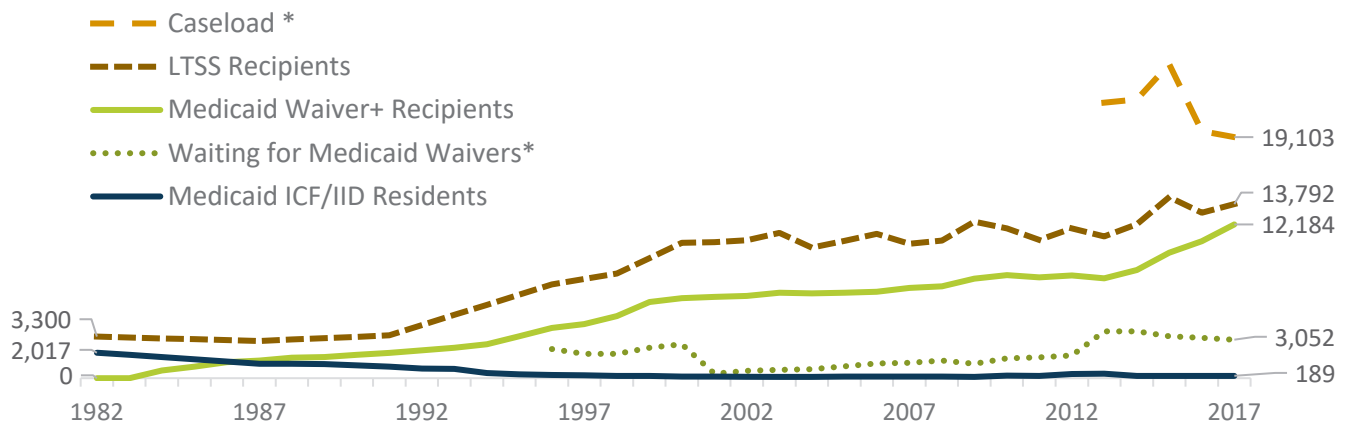


## IDD Agency Long Term Supports and Services Recipients by Residence Type



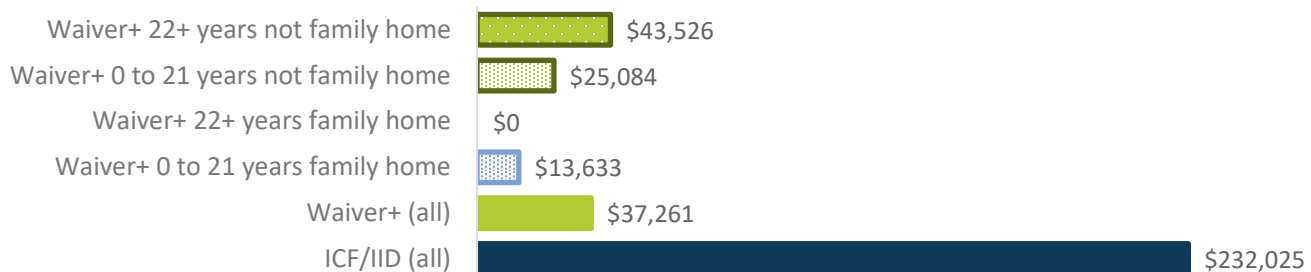
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## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2017



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

## Average Spending Per Person by Medicaid Authority in Fiscal Year 2017



Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

ICF/IID: Intermediate Care Facilities for Individuals with Intellectual Disabilities

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Waiver+: Medicaid Authorities 1115, 1915 (a)(b)or (b/c), 1915(c)

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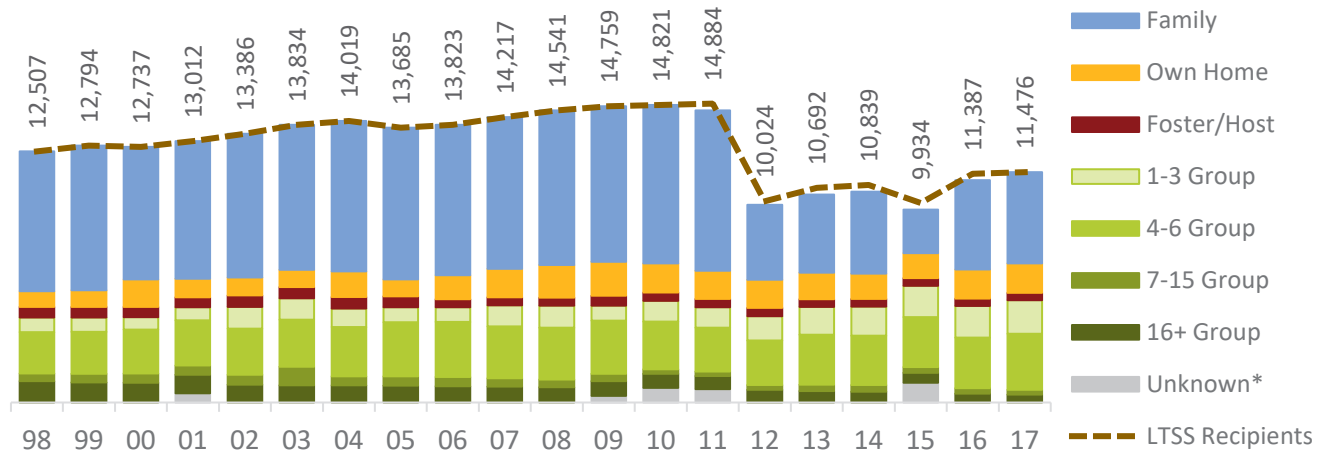
# Connecticut

Fiscal Year 2017

Residential Information Systems Project

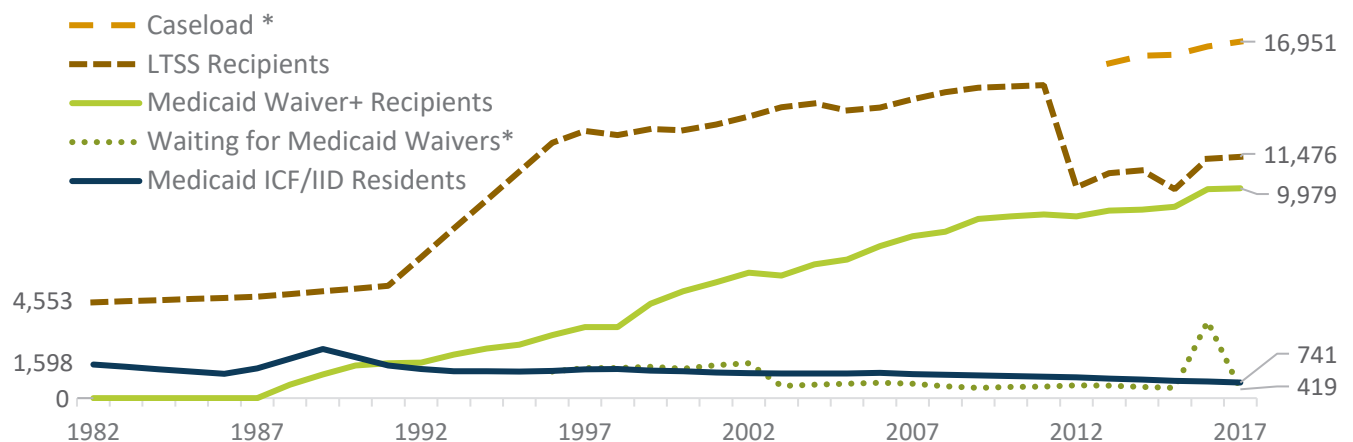


## IDD Agency Long Term Supports and Services Recipients by Residence Type



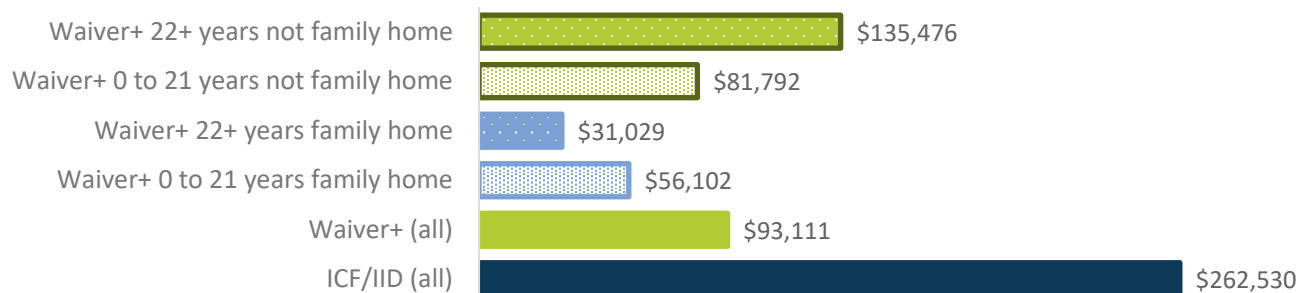
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## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2017



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

## Average Spending Per Person by Medicaid Authority in Fiscal Year 2017



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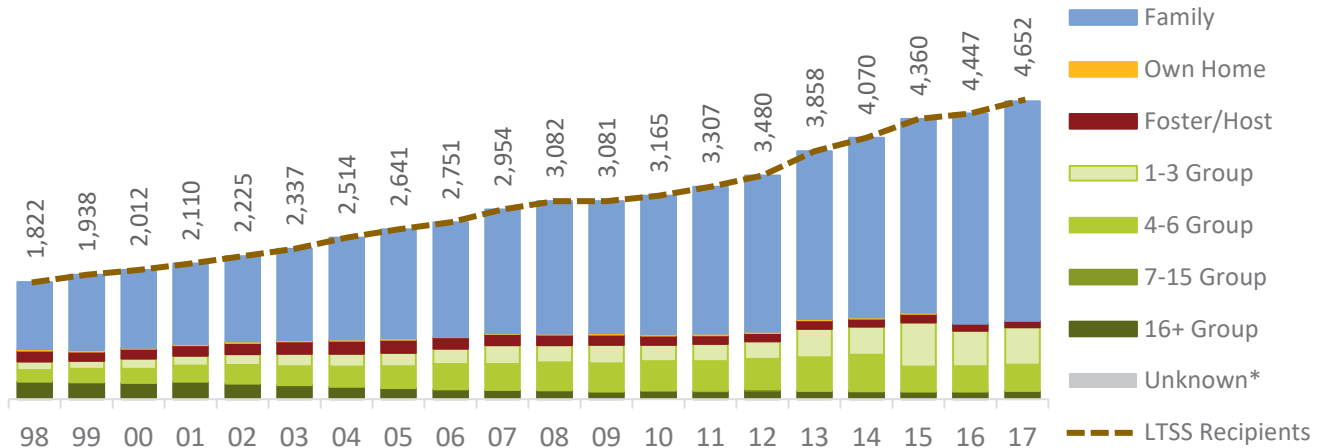
# Delaware

Fiscal Year 2017

Residential Information Systems Project

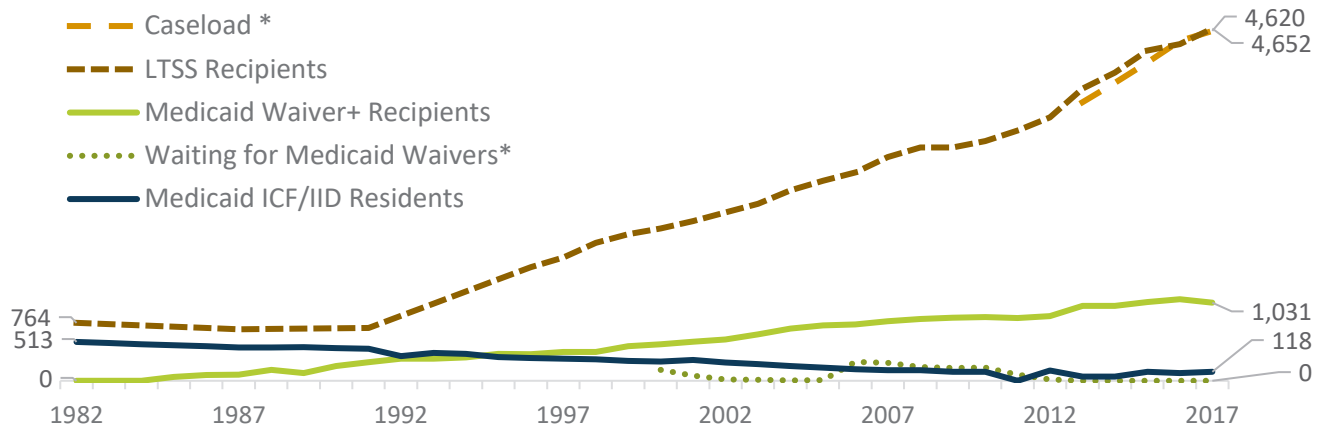


## IDD Agency Long Term Supports and Services Recipients by Residence Type



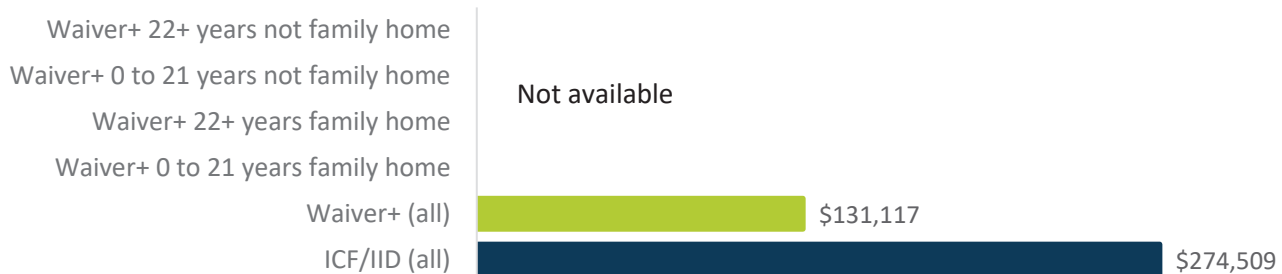
\* Unknown setting type or size reported in FY 2017 and gaps in all other years

## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2017



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

## Average Spending Per Person by Medicaid Authority in Fiscal Year 2017



Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

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Waiver+: Medicaid Authorities 1115, 1915 (a)(b) or (b)(c), 1915(c)

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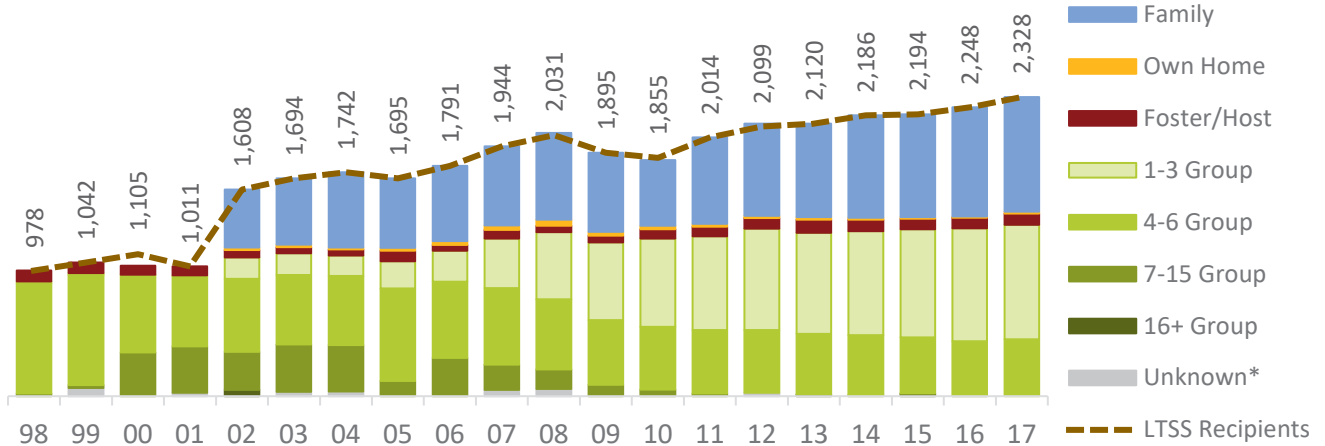
# District of Columbia

Fiscal Year 2017

Residential Information Systems Project

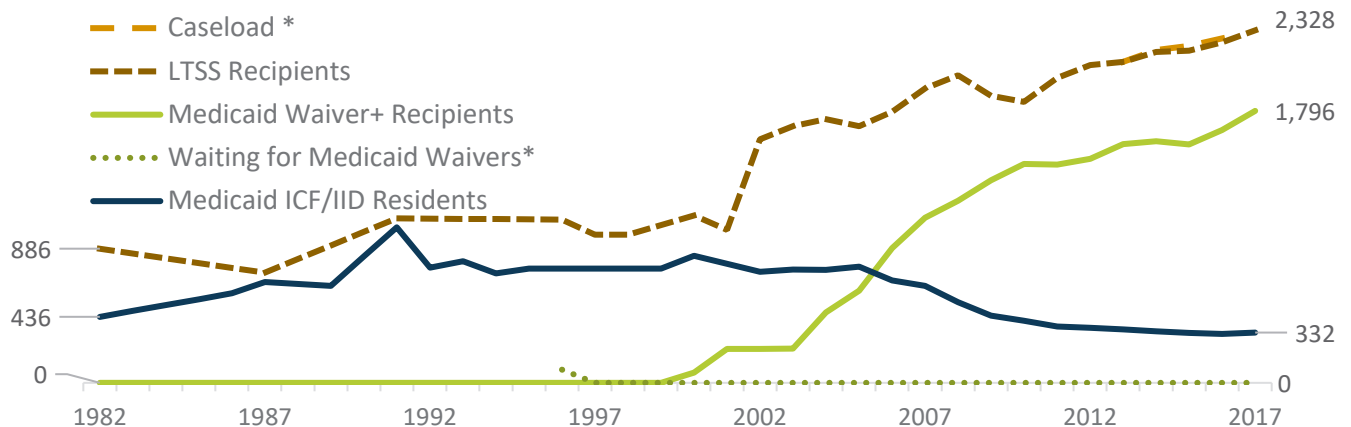


## IDD Agency Long Term Supports and Services Recipients by Residence Type



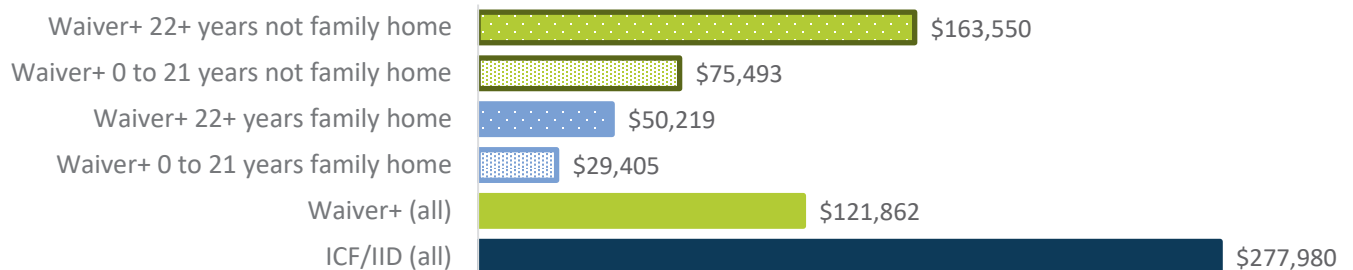
\* Unknown setting type or size reported in FY 2017 and gaps in all other years

## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2017



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

## Average Spending Per Person by Medicaid Authority in Fiscal Year 2017



Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

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Waiver+: Medicaid Authorities 1115, 1915 (a)(b)or (b)(c), 1915(c)

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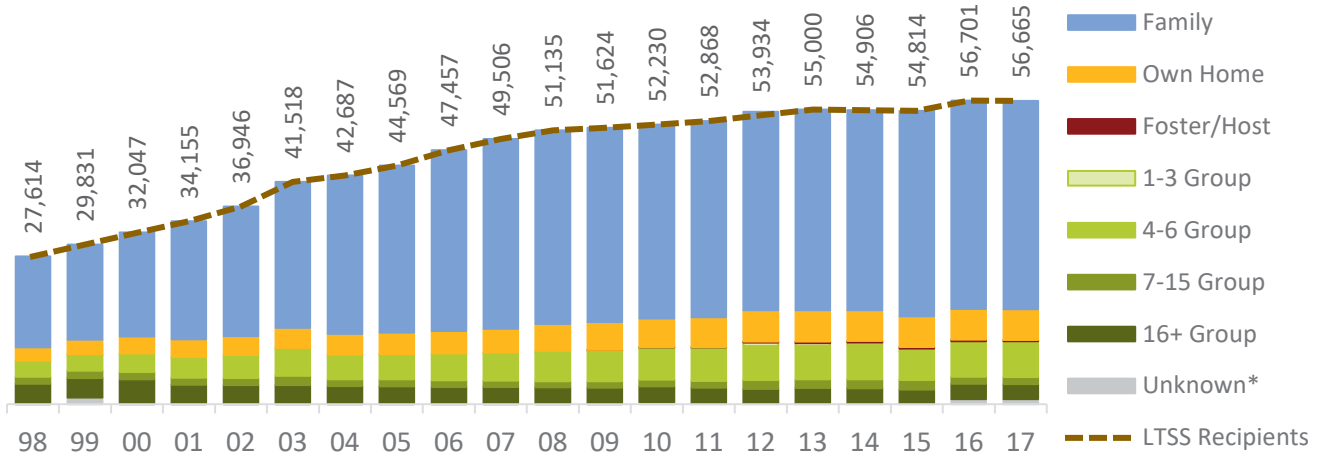
# Florida

Fiscal Year 2017

Residential Information Systems Project

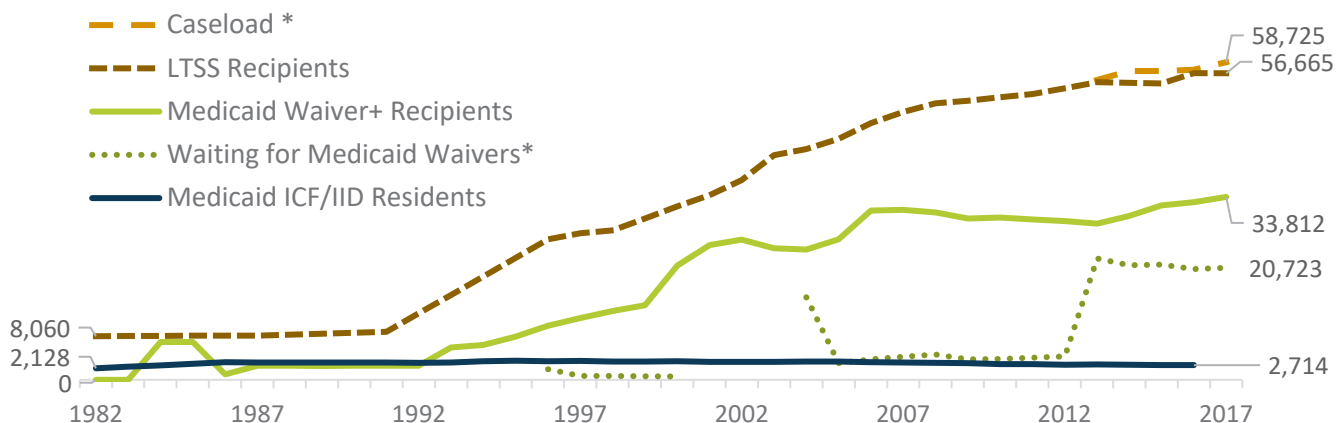


## IDD Agency Long Term Supports and Services Recipients by Residence Type



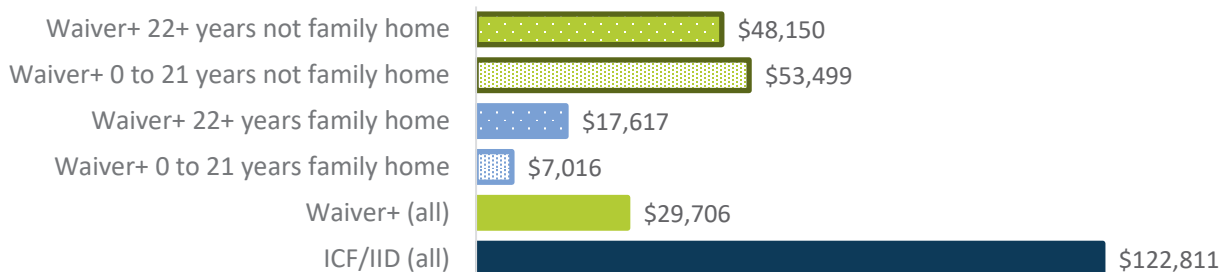
\* Unknown setting type or size reported in FY 2017 and gaps in all other years

## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2017



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

## Average Spending Per Person by Funding Authority in Fiscal Year 2017



Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

ICF/IID: Intermediate Care Facilities for Individuals with Intellectual Disabilities

Group: Number of people with IDD in a setting (ICF/IID, group home or other)

Waiver+: Medicaid Authorities 1115, 1915 (a)(b)or (b/c), 1915(c)

For more see [risp.umn.edu](http://risp.umn.edu)

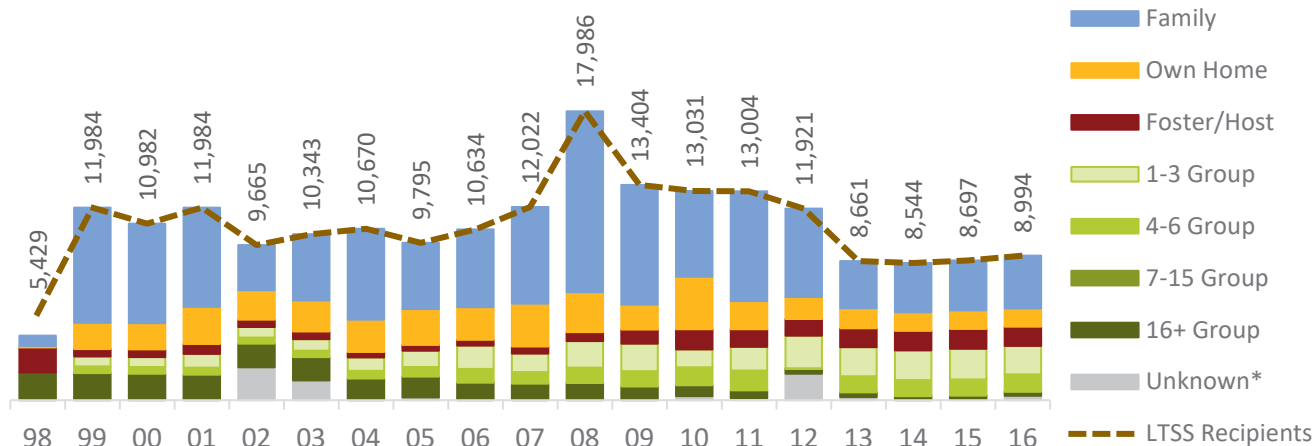
# Georgia

Fiscal year 2017 not available, FY 2016 presented when available.

## Residential Information Systems Project

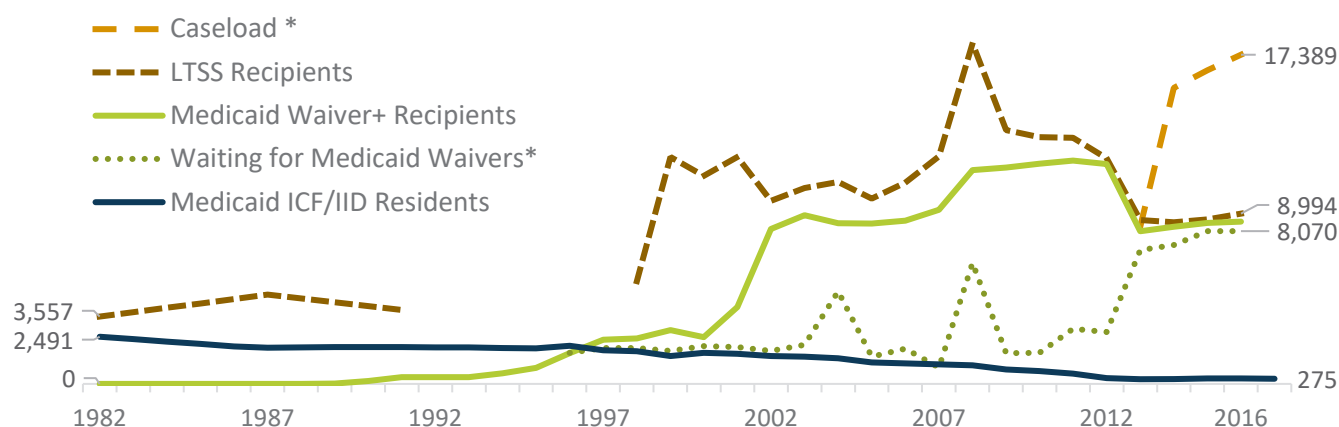


### IDD Agency Long Term Supports and Services Recipients by Residence Type



\* Unknown setting type or size reported in FY 2017 and gaps in all other years

### Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2016



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

### Average Spending Per Person by Medicaid Authority in Fiscal Year 2016



Waiver by age in family home or not family home spending per person not available.

Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

ICF/IID: Intermediate Care Facilities for Individuals with Intellectual Disabilities

Group: Number of people with IDD in a setting (ICF/IID, group home or other)

Waiver+: Medicaid Authorities 1115, 1915 (a)(b)or (b/c), 1915(c)

For more see [risp.umn.edu](http://risp.umn.edu)

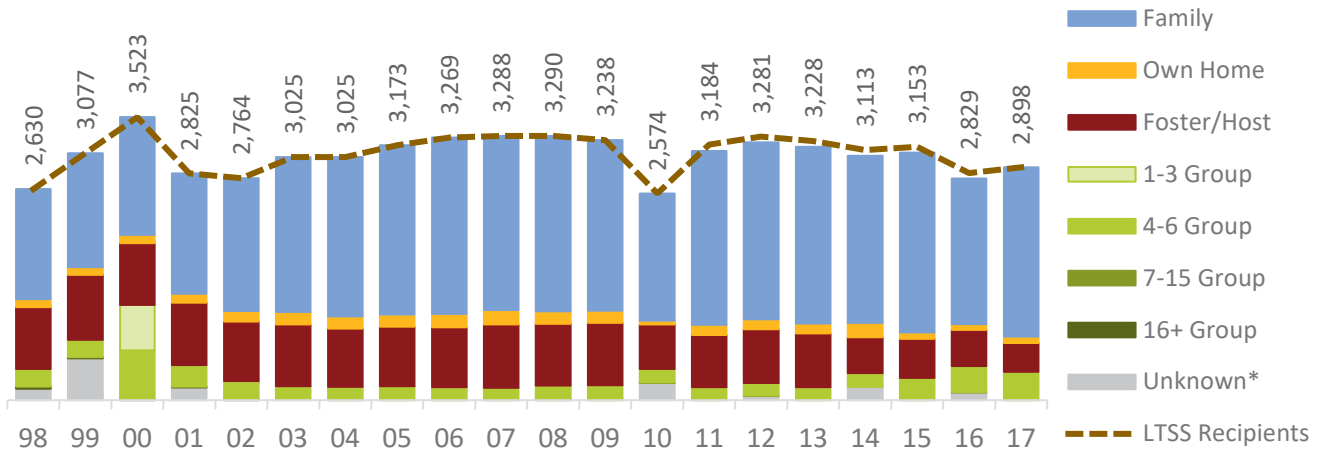
# Hawaii

Fiscal Year 2017

Residential Information Systems Project

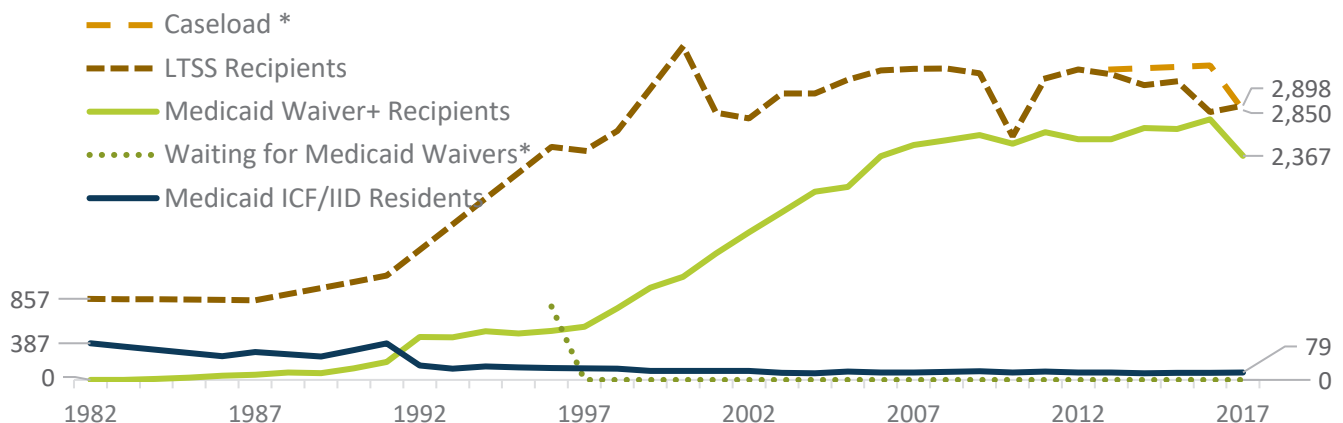


## IDD Agency Long Term Supports and Services Recipients by Residence Type



\* Unknown setting type or size reported in FY 2017 and gaps in all other years

## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2017



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

## Average Spending Per Person by Medicaid Authority in Fiscal Year 2017



Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

ICF/IID: Intermediate Care Facilities for Individuals with Intellectual Disabilities

Group: Number of people with IDD in a setting (ICF/IID, group home or other)

Waiver+: Medicaid Authorities 1115, 1915 (a)(b) or (b)(c), 1915(c)

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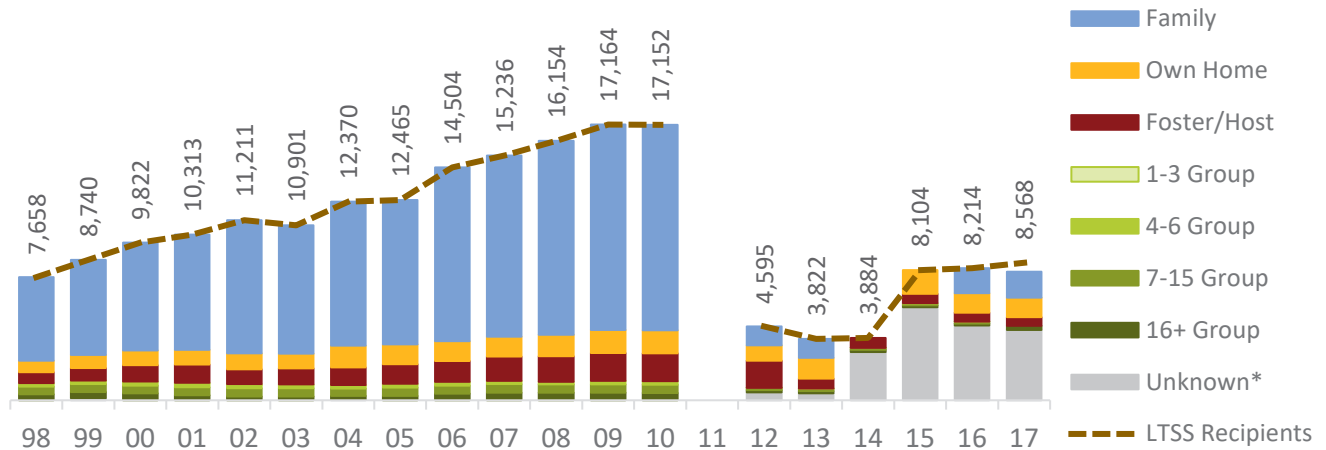
# Idaho

Fiscal Year 2017

## Residential Information Systems Project

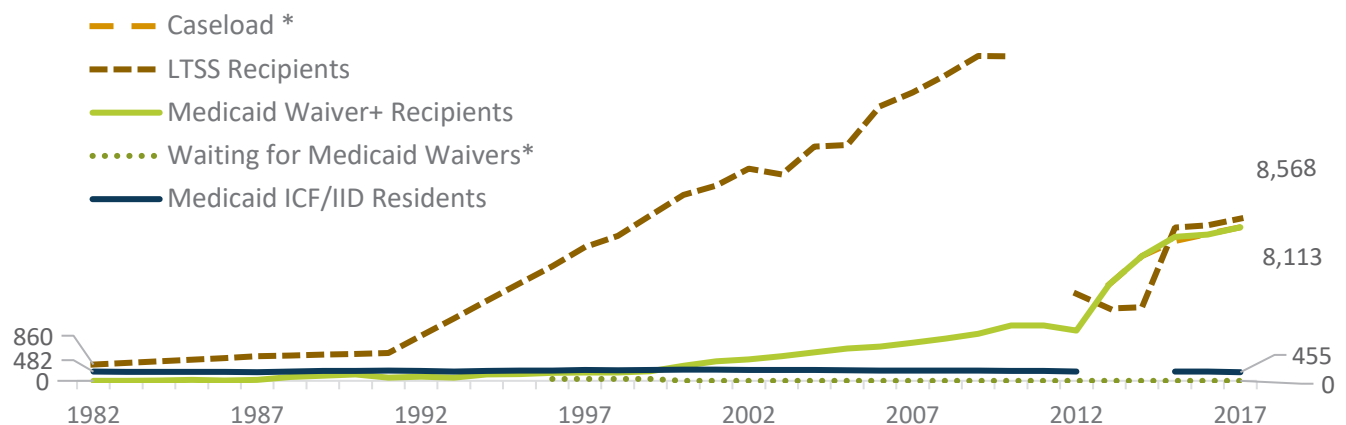


### IDD Agency Long Term Supports and Services Recipients by Residence Type



\* Unknown setting type or size reported in FY 2017 and gaps in all other years

### Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2017



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

### Average Spending Per Person by Medicaid Authority in Fiscal Year 2017



Waiver by age in family home or not family home spending per person not available.

Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

ICF/IID: Intermediate Care Facilities for Individuals with Intellectual Disabilities

Group: Number of people with IDD in a setting (ICF/IID, group home or other)

Waiver+: Medicaid Authorities 1115, 1915 (a)(b) or (b)(c), 1915(c)

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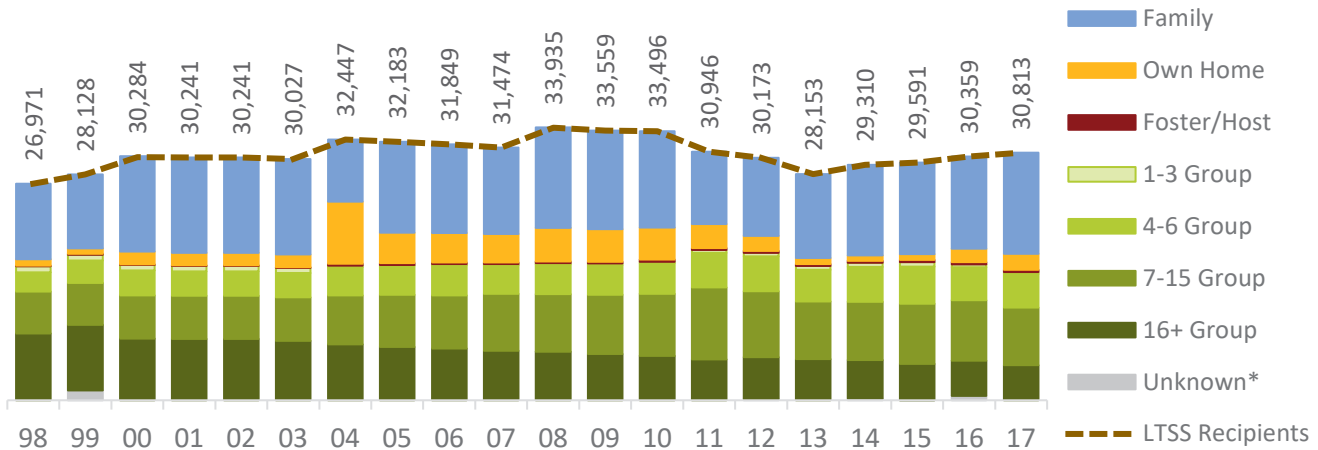
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Fiscal Year 2017

Residential Information Systems Project

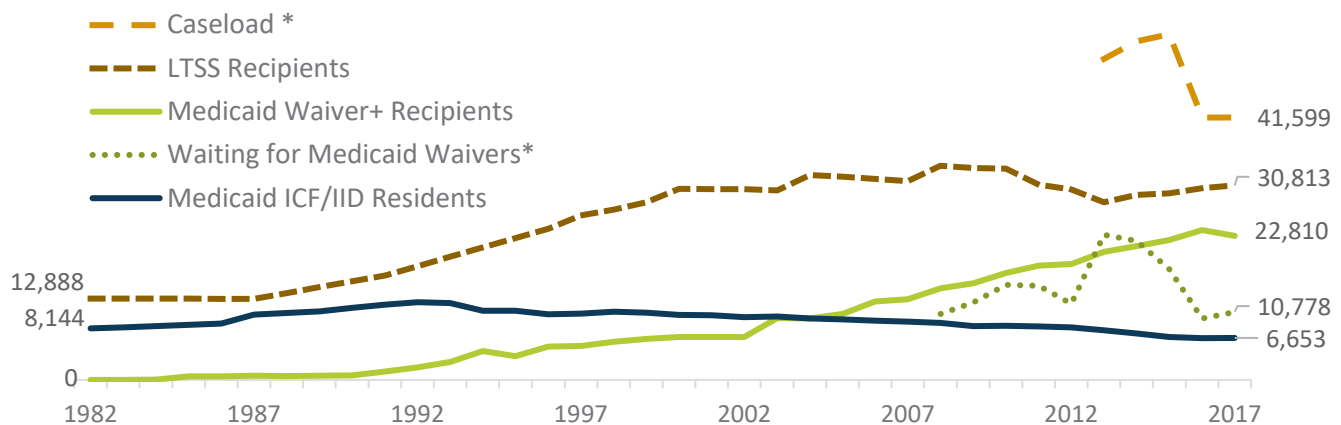


## IDD Agency Long Term Supports and Services Recipients by Residence Type



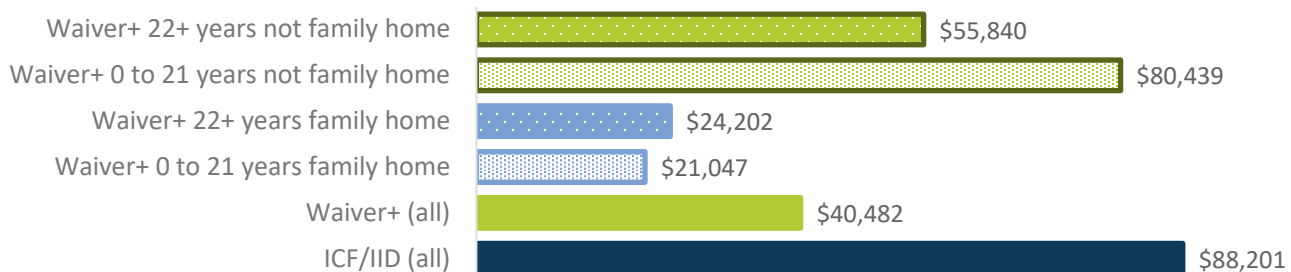
\* Unknown setting type or size reported in FY 2017 and gaps in all other years

## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2017



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

## Average Spending Per Person by Medicaid Authority in Fiscal Year 2017



Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

ICF/IID: Intermediate Care Facilities for Individuals with Intellectual Disabilities

Group: Number of people with IDD in a setting (ICF/IID, group home or other)

Waiver+: Medicaid Authorities 1115, 1915 (a)(b) or (b)(c), 1915(c)

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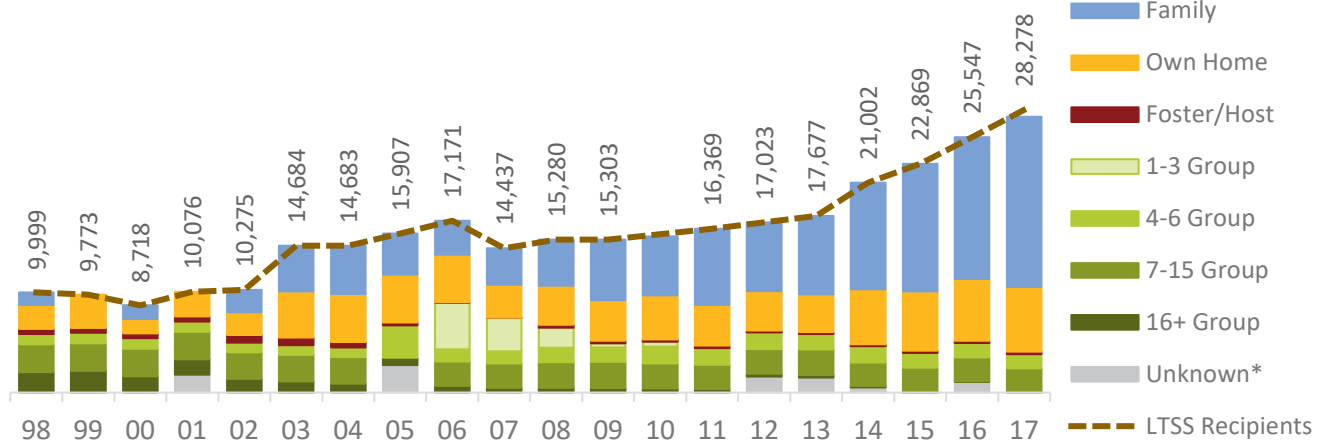
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Fiscal Year 2017

Residential Information Systems Project

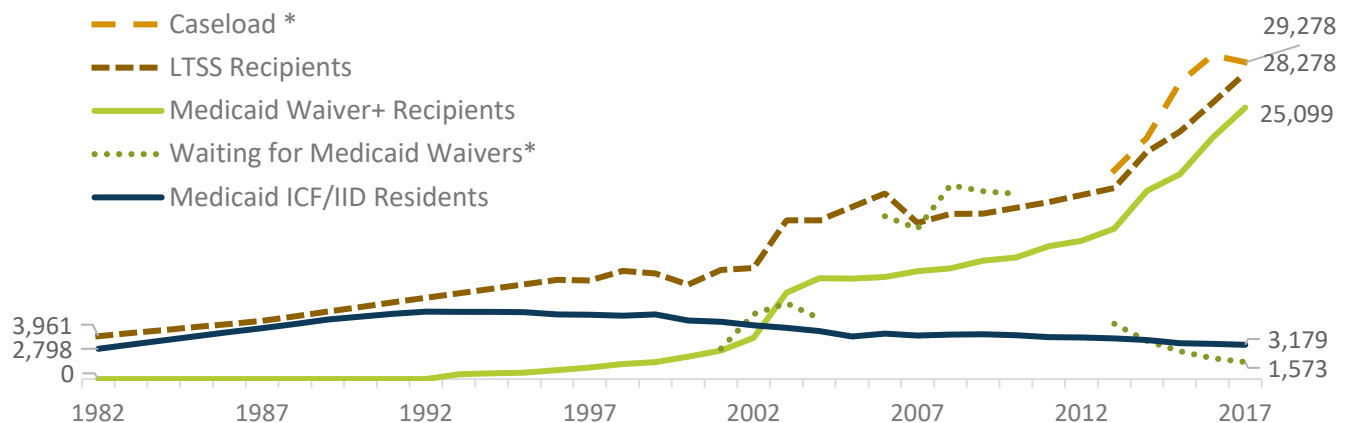


## IDD Agency Long Term Supports and Services Recipients by Residence Type



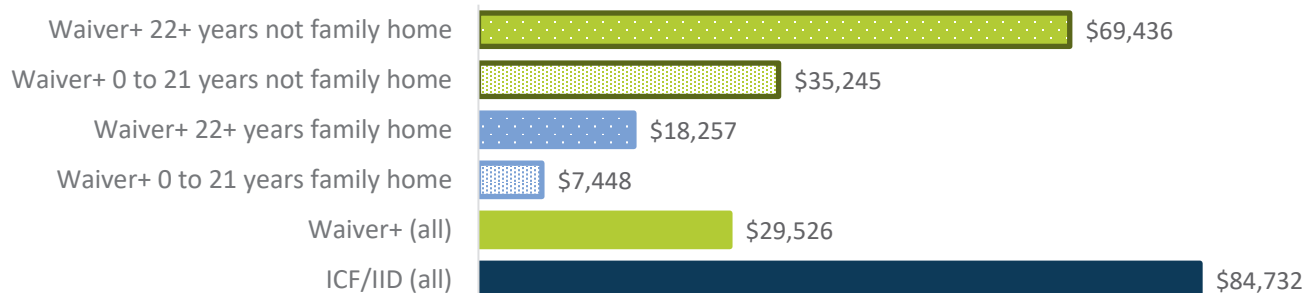
\* Unknown setting type or size reported in FY 2017 and gaps in all other years

## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2017



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

## Average Spending Per Person by Medicaid Authority in Fiscal Year 2017



Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

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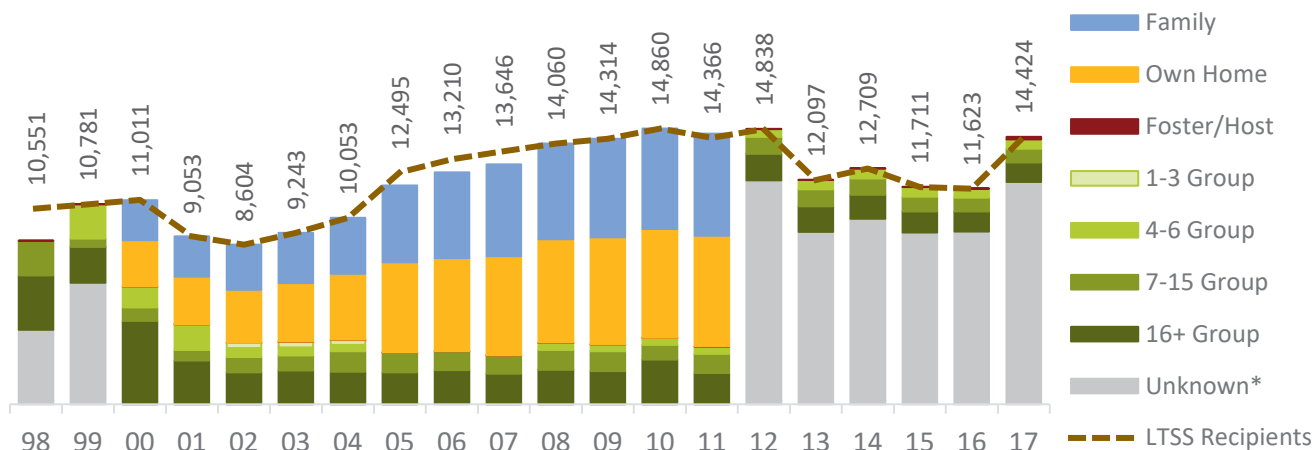
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Fiscal Year 2017

Residential Information Systems Project

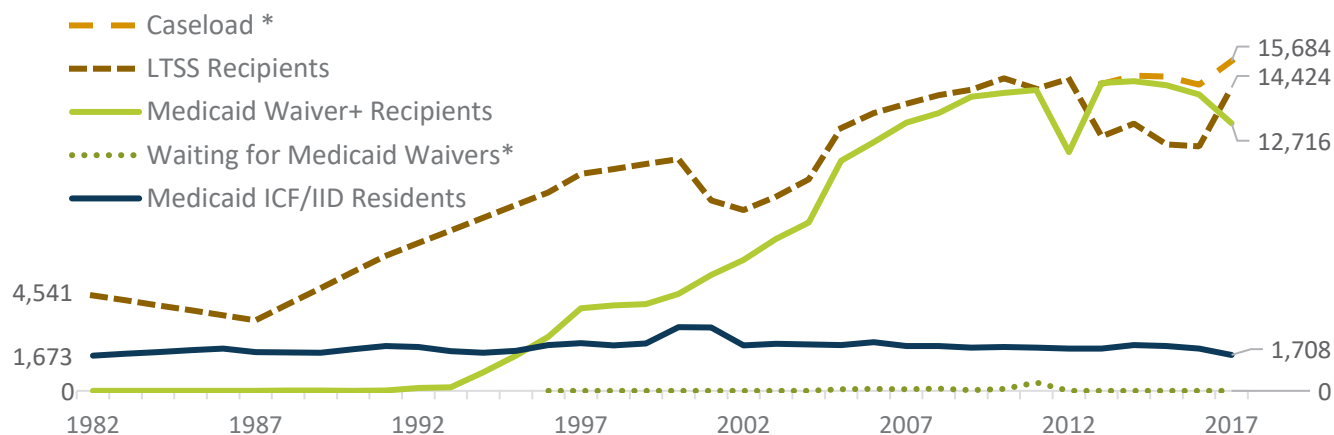


## IDD Agency Long Term Supports and Services Recipients by Residence Type



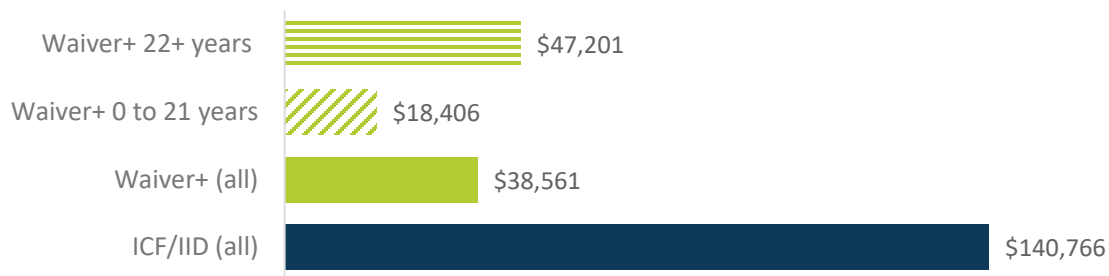
\* Unknown setting type or size reported in FY 2017 and gaps in all other years

## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2017



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

## Average Spending Per Person by Medicaid Authority in Fiscal Year 2017



Waiver by age in family home or not family home spending per person not available.

Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

ICF/IID: Intermediate Care Facilities for Individuals with Intellectual Disabilities

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Waiver+: Medicaid Authorities 1115, 1915 (a)(b) or (b)(c), 1915(c)

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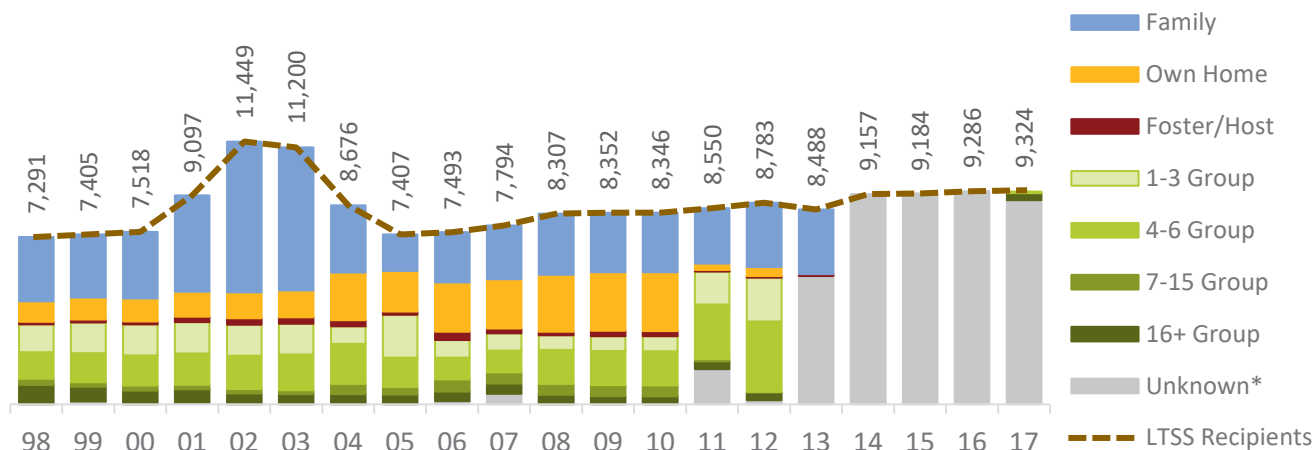
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Fiscal Year 2017

Residential Information Systems Project

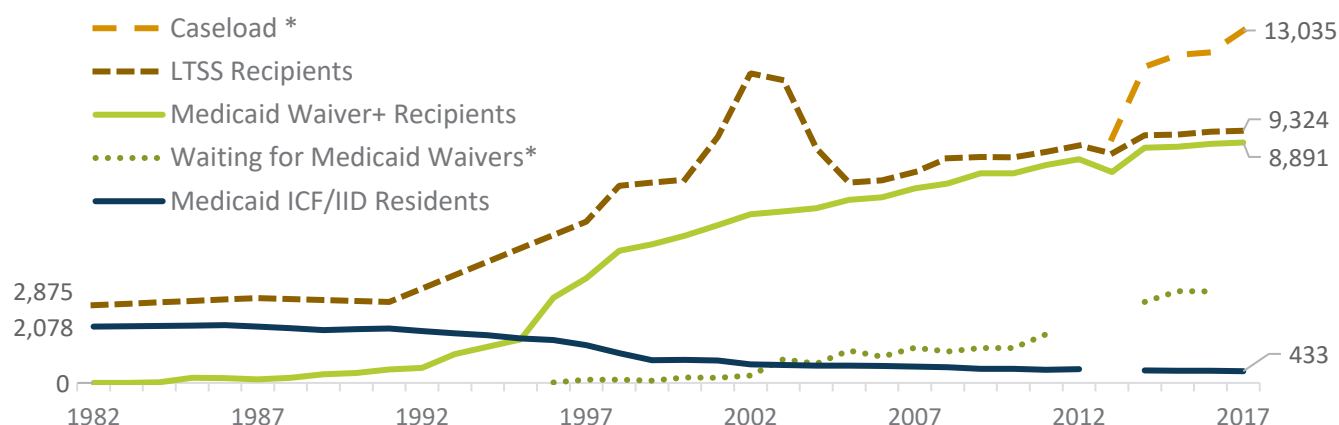


## IDD Agency Long Term Supports and Services Recipients by Residence Type



\* Unknown setting type or size reported in FY 2017 and gaps in all other years

## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2017



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

## Average Spending Per Person by Medicaid Authority in Fiscal Year 2017



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Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

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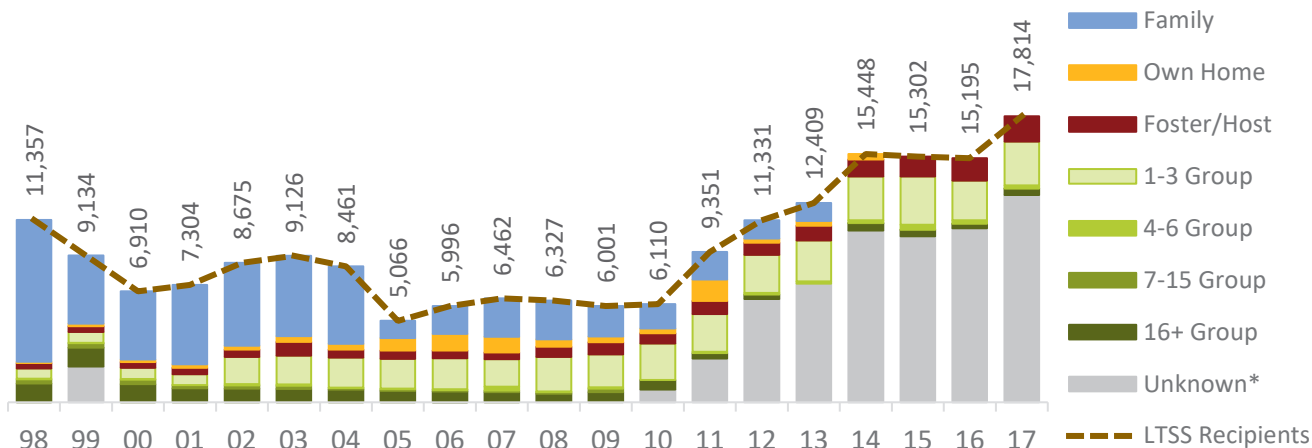
# Kentucky

Fiscal Year 2017

Residential Information Systems Project

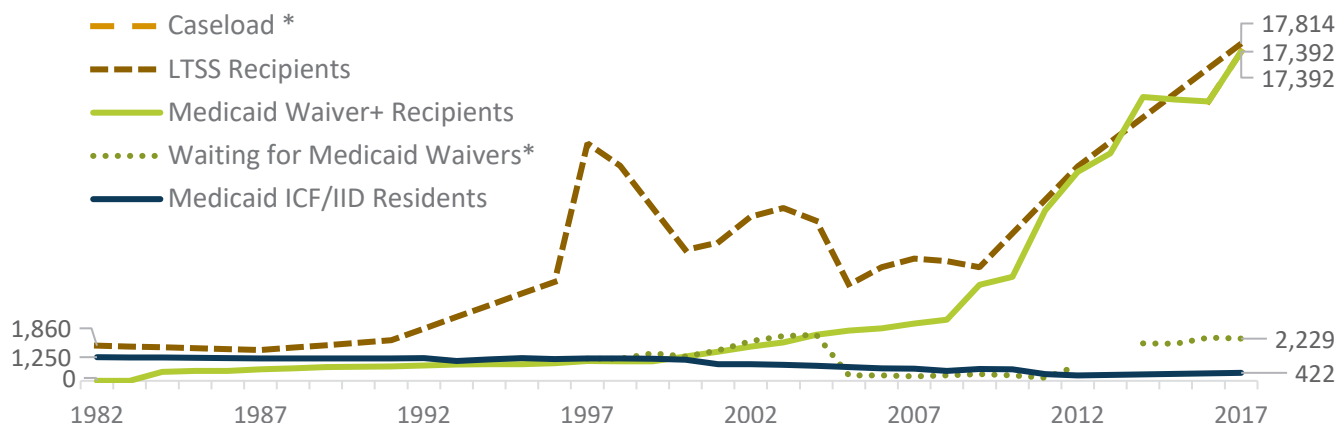


## IDD Agency Long Term Supports and Services Recipients by Residence Type



\* Unknown setting type or size reported in FY 2017 and gaps own home and family home

## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2017



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

## Average Medicaid Spending Per Person in Fiscal Year 2017



Waiver by age in family home or not family home spending per person not available.

Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

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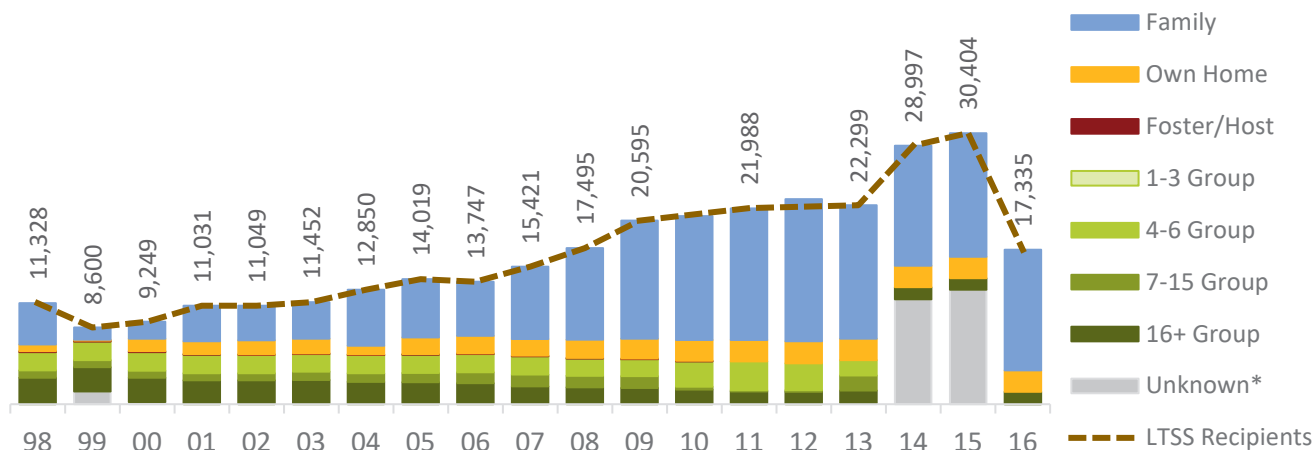
# Louisiana

Fiscal year 2017 not available, FY 2016 presented when available.

Residential Information Systems Project

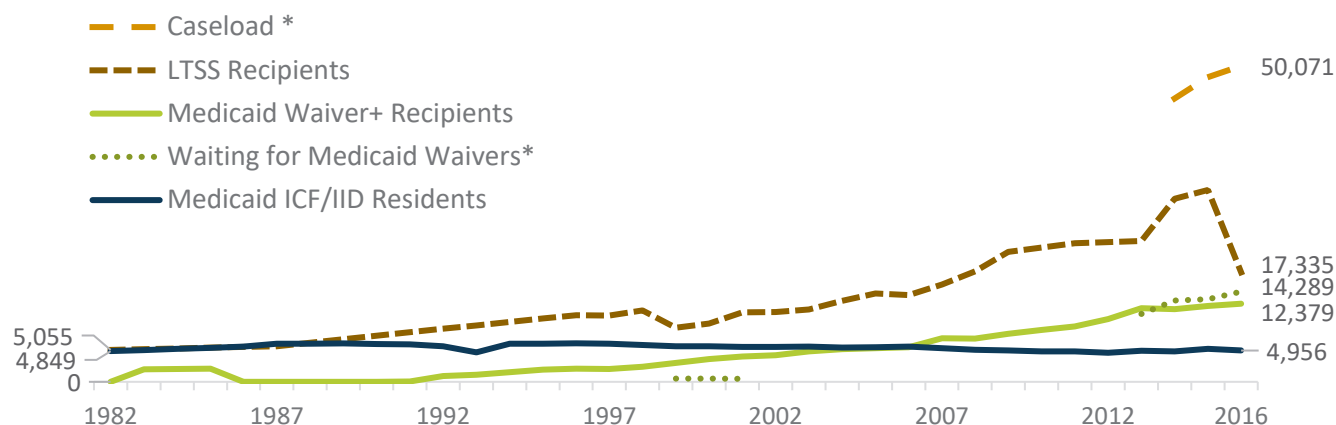


## IDD Agency Long Term Supports and Services Recipients by Residence Type



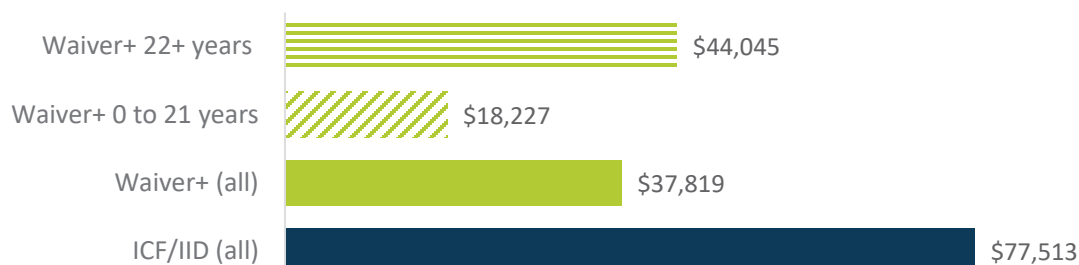
\* Unknown setting type or size reported in FY 2017 and gaps in all other years

## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2016



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

## Average Medicaid Spending Per Person in Fiscal Year 2016



Waiver by age in family home or not family home spending per person not available.

Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

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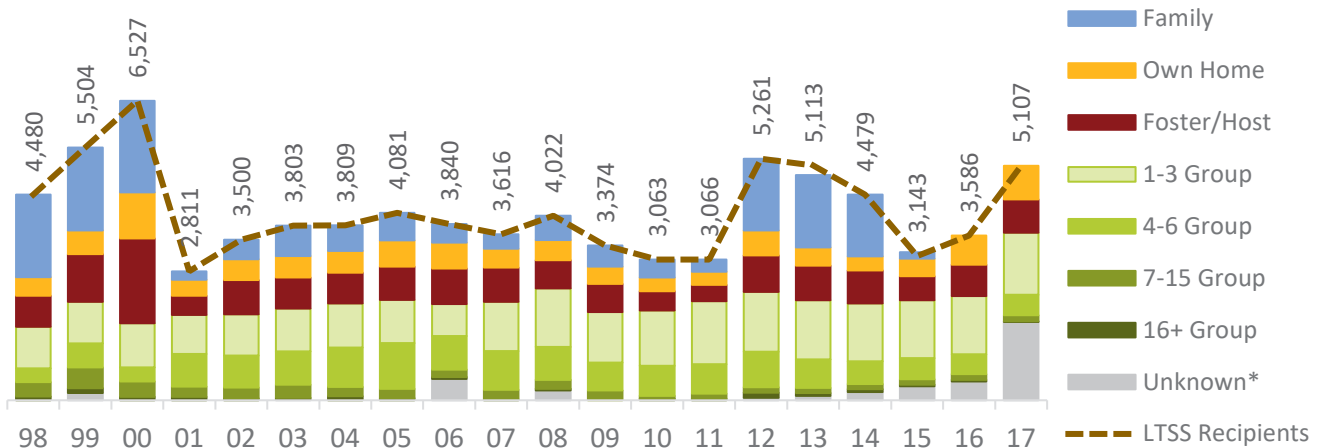
# Maine

Fiscal Year 2017

Residential Information Systems Project

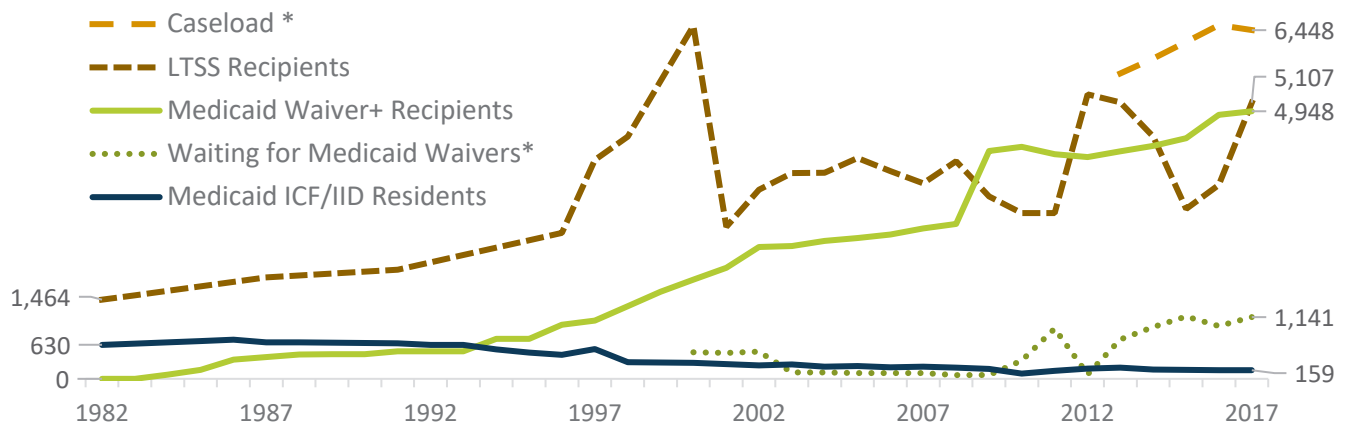


## IDD Agency Long Term Supports and Services Recipients by Residence Type



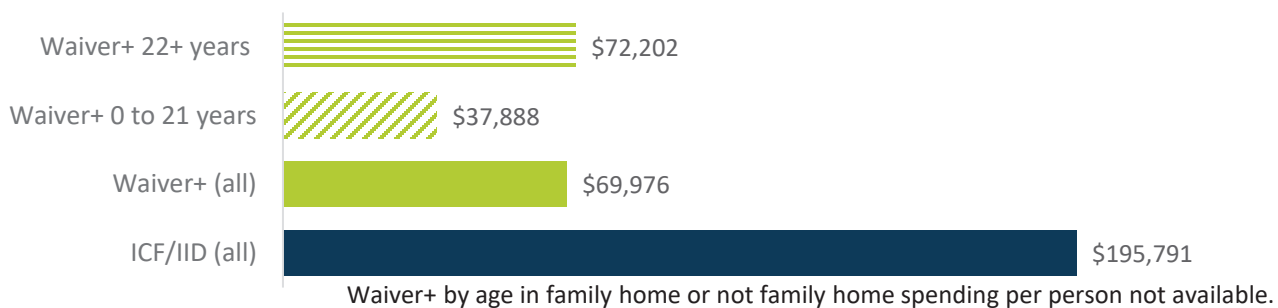
\* Unknown setting type or size reported in FY 2017 and gaps in all other years

## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2017



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

## Average Spending Per Person by Medicaid Authority in Fiscal Year 2017



Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

ICF/IID: Intermediate Care Facilities for Individuals with Intellectual Disabilities

Group: Number of people with IDD in a setting (ICF/IID, group home or other)

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# Maryland

Fiscal Year 2017

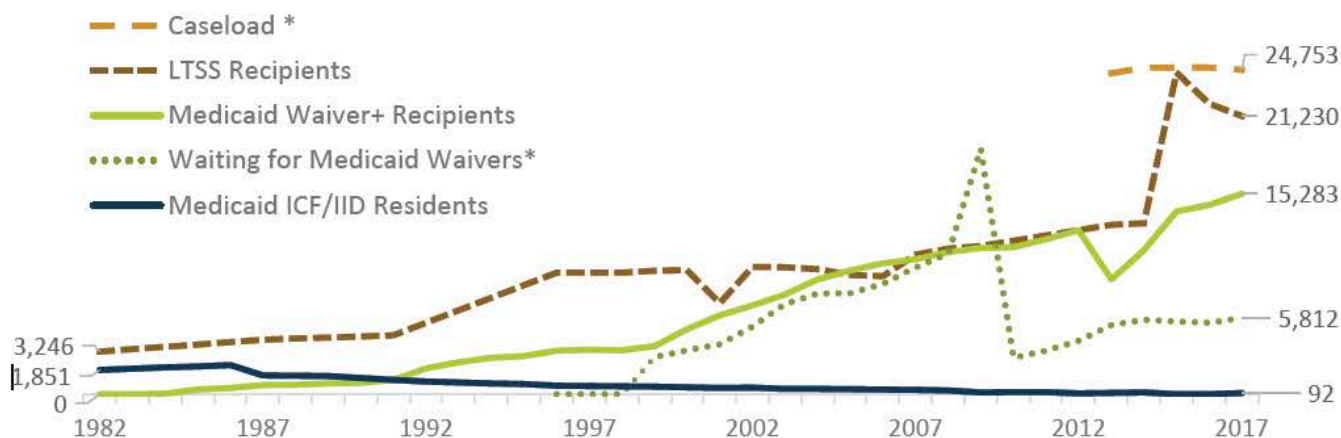
Residential Information Systems Project

## IDD Agency Long Term Supports and Services Recipients by Residence Type



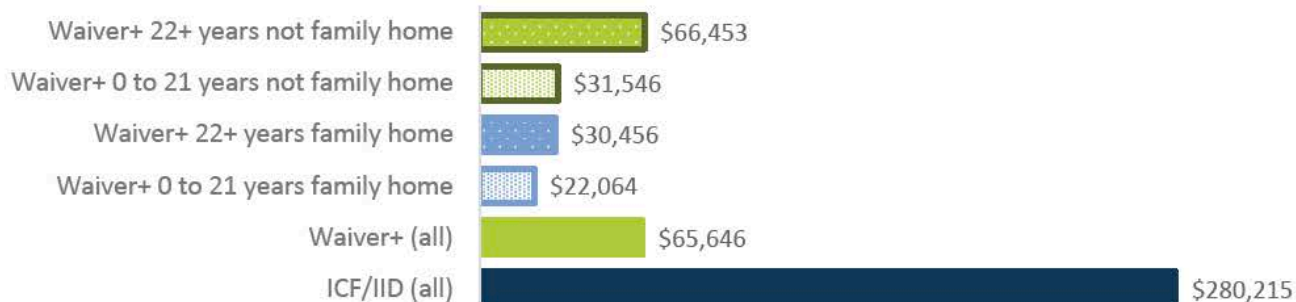
\* Unknown setting type or size reported in FY 2017 and gaps in all other years

## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2017



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

## Average Spending Per Person by Medicaid Authority in Fiscal Year 2017



Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

ICF/IID: Intermediate Care Facilities for Individuals with Intellectual Disabilities

Group: Number of people with IDD in a setting (ICF/IID, group home or other)

Waiver+: Medicaid Authorities 1115, 1915 (a)(b) or (b)(c), 1915(c)

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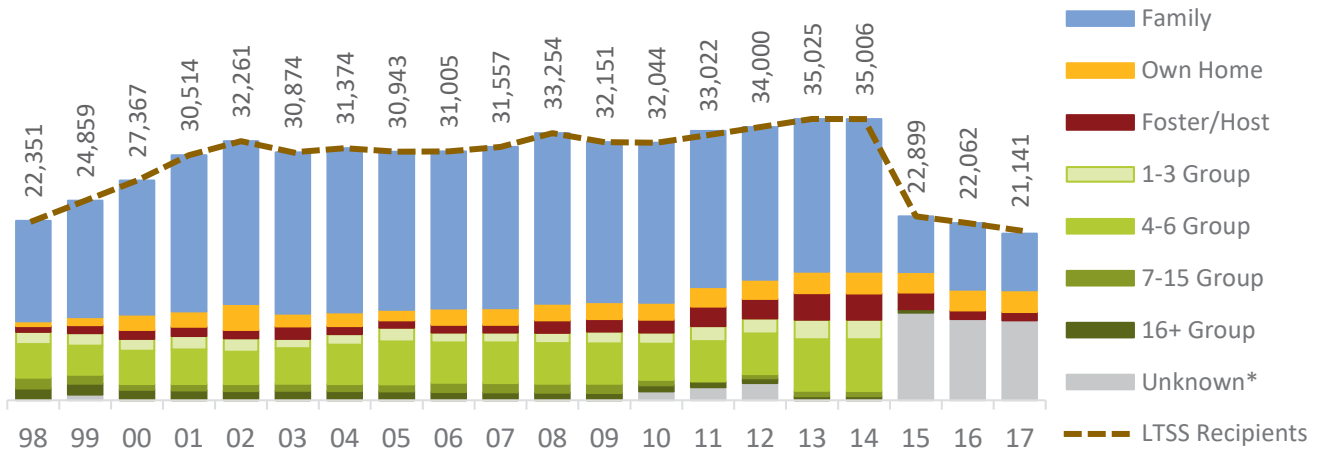
# Massachusetts

Fiscal Year 2017

Residential Information Systems Project

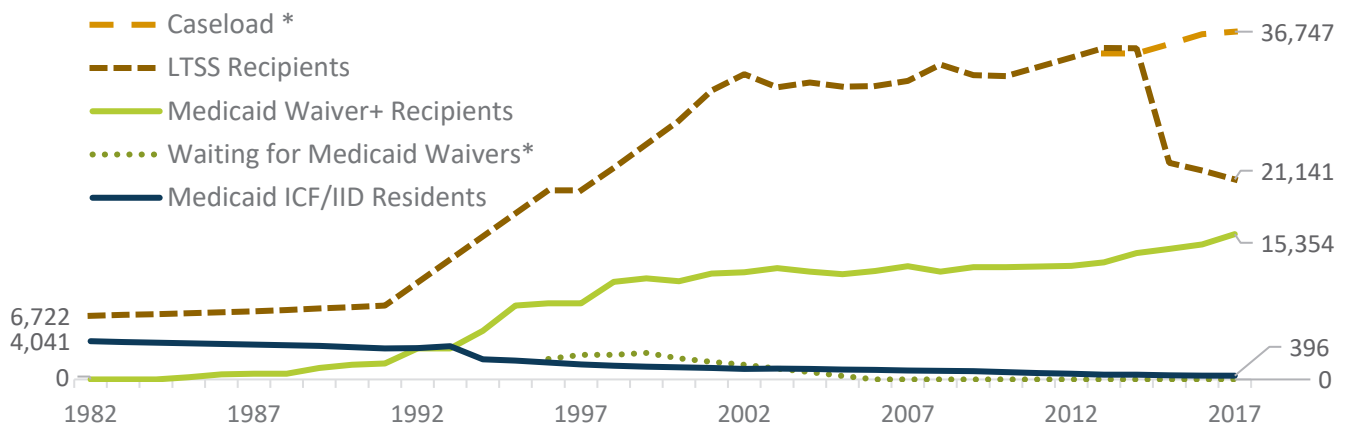


## IDD Agency Long Term Supports and Services Recipients by Residence Type



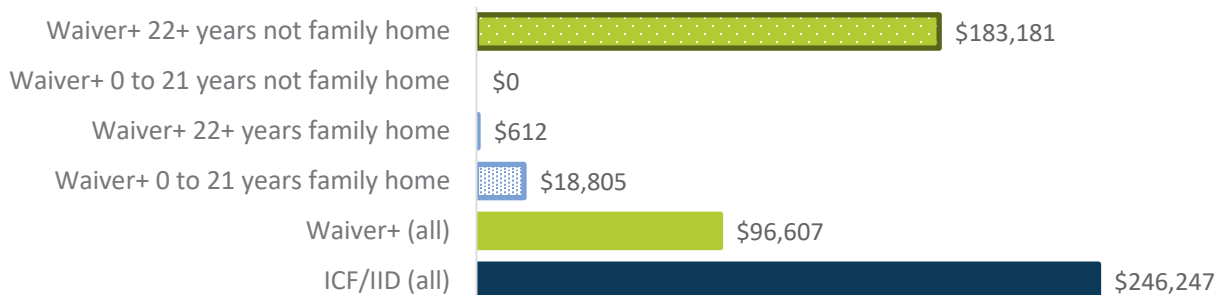
\* Unknown setting type or size reported in FY 2017 and gaps in all other years

## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2017



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

## Average Spending Per Person by Medicaid Authority in Fiscal Year 2017



Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

ICF/IID: Intermediate Care Facilities for Individuals with Intellectual Disabilities

Group: Number of people with IDD in a setting (ICF/IID, group home or other)

Waiver+: Medicaid Authorities 1115, 1915 (a)(b) or (b)(c), 1915(c)

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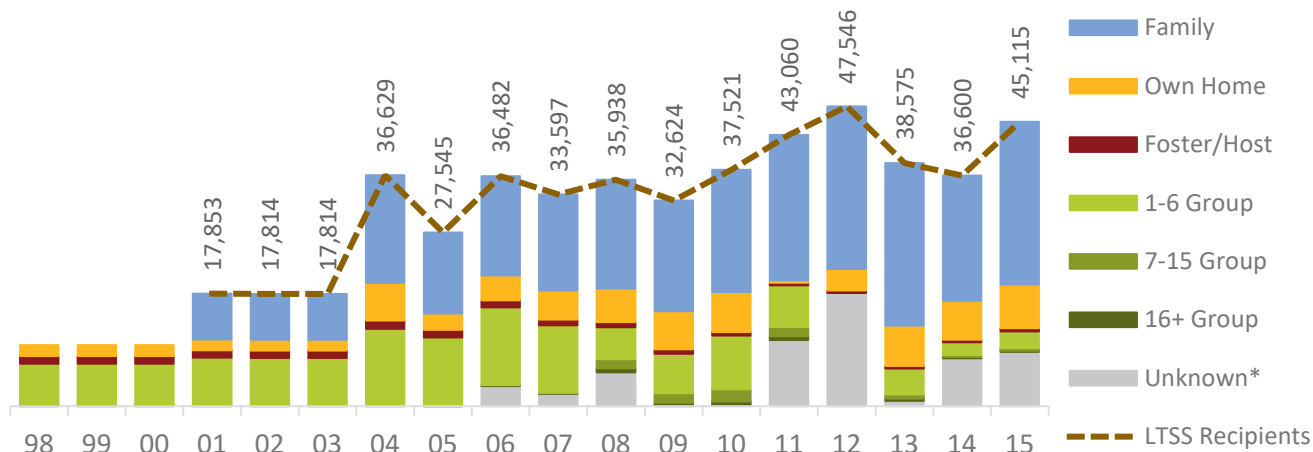
# Michigan

Fiscal year 2017 not available, FY 2015 presented when available.

Residential Information Systems Project

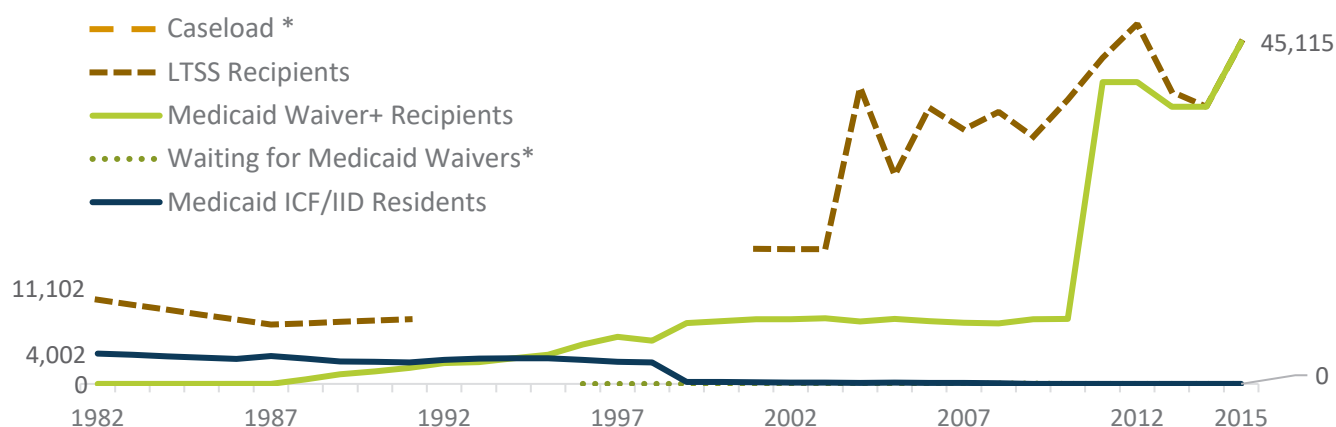


## IDD Agency Long Term Supports and Services Recipients by Residence Type



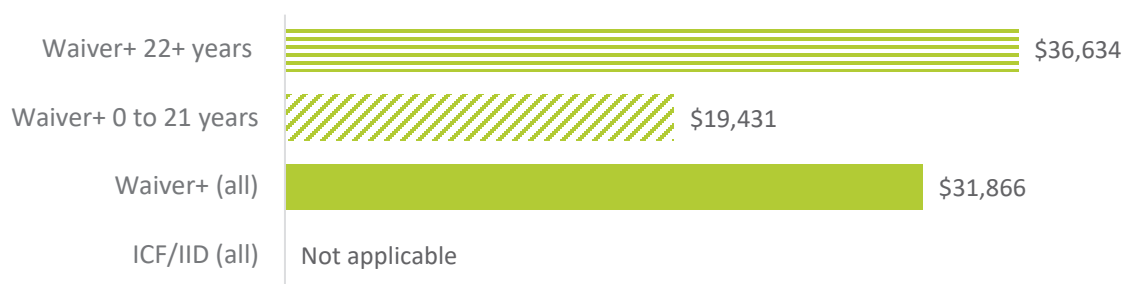
\* Unknown setting type or size reported in FY 2017 and gaps in all other years

## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2015



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

## Average Spending Per Person by Medicaid Authority in Fiscal Year 2015



Waiver by age in family home or not family home spending per person not available.

Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

ICF/IID: Intermediate Care Facilities for Individuals with Intellectual Disabilities

Group: Number of people with IDD in a setting (ICF/IID, group home or other)

Waiver+: Medicaid Authorities 1115, 1915 (a)(b)or (b/c), 1915(c)

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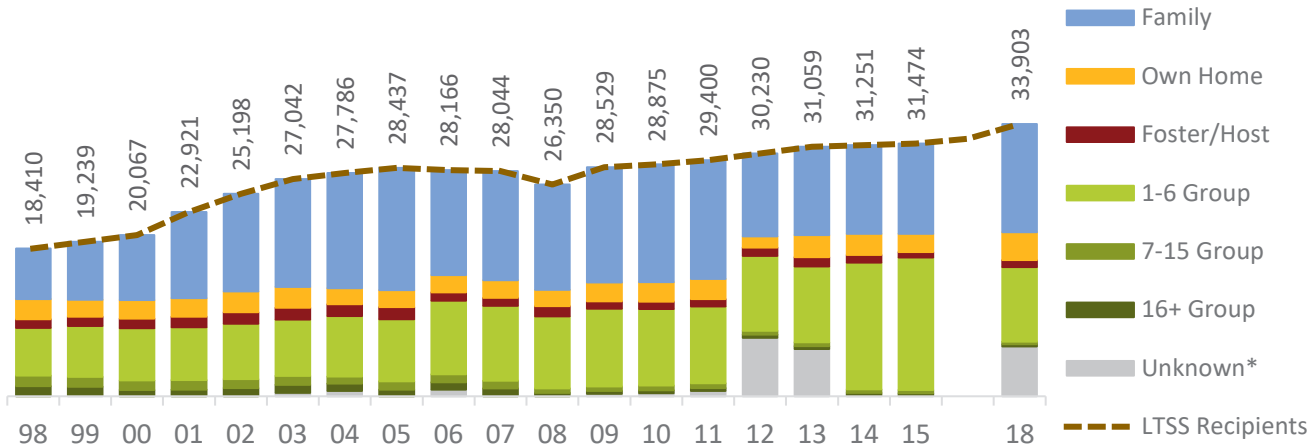
# Minnesota

Fiscal year 2018 data

Residential Information Systems Project

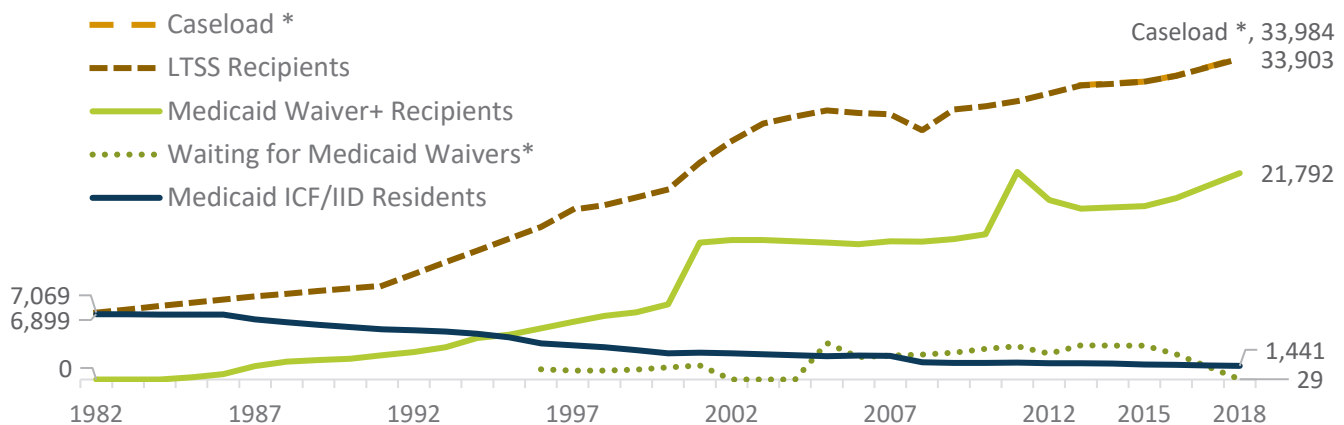


## IDD Agency Long Term Supports and Services Recipients by Residence Type FY 2018



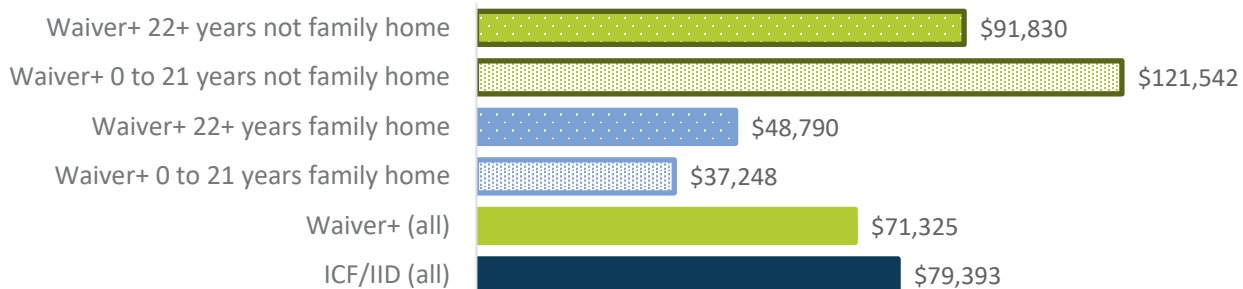
\* Unknown setting type or size reporting started in FY 2017 and gaps in all other years

## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2018



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

## Average Spending Per Person by Medicaid Authority in Fiscal Year 2018



Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

ICF/IID: Intermediate Care Facilities for Individuals with Intellectual Disabilities

Group: Number of people with IDD in a setting (ICF/IID, group home or other)

Waiver+: Medicaid Authorities 1115, 1915 (a)(b) or (b)(c), 1915(c)

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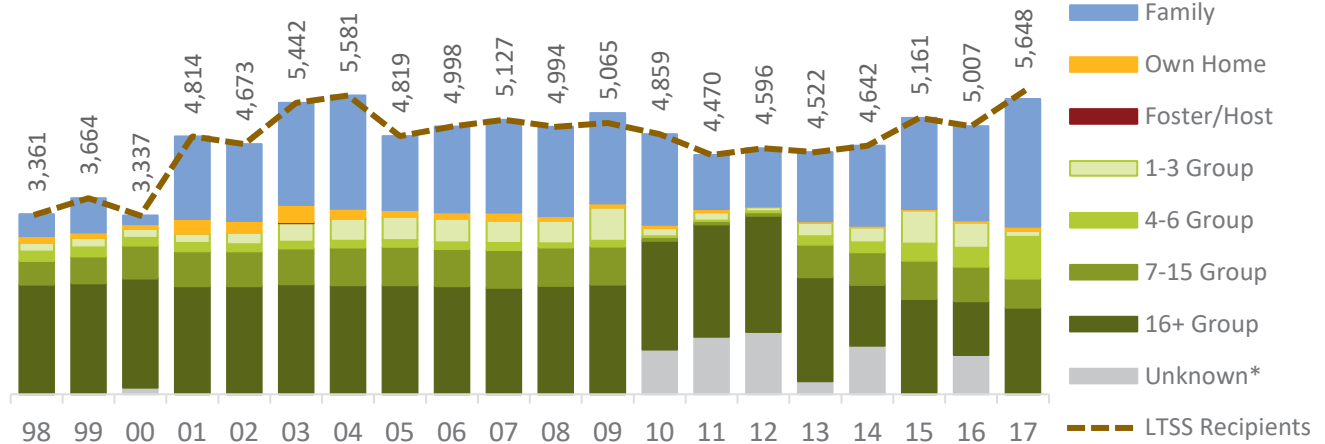
# Mississippi

Fiscal Year 2017

Residential Information Systems Project

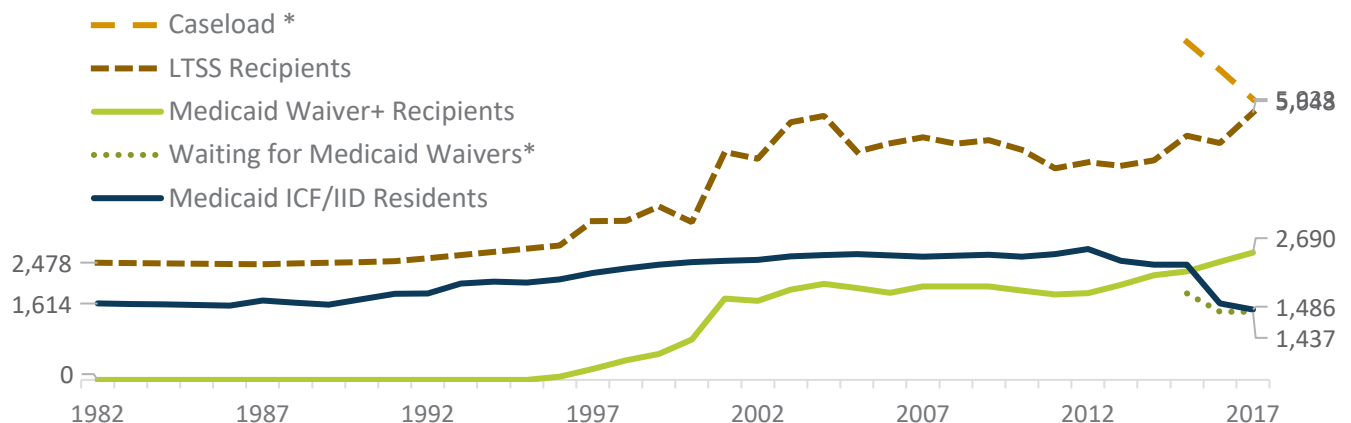


## IDD Agency Long Term Supports and Services Recipients by Residence Type



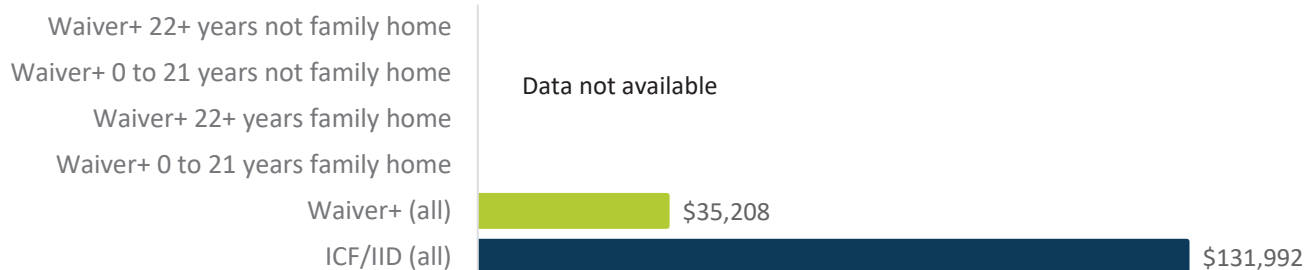
\* Unknown setting type or size reported in FY 2017 and gaps in all other years

## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2017



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

## Average Spending Per Person by Medicaid Authority in Fiscal Year 2017



Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

ICF/IID: Intermediate Care Facilities for Individuals with Intellectual Disabilities

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Waiver+: Medicaid Authorities 1115, 1915 (a)(b)or (b/c), 1915(c)

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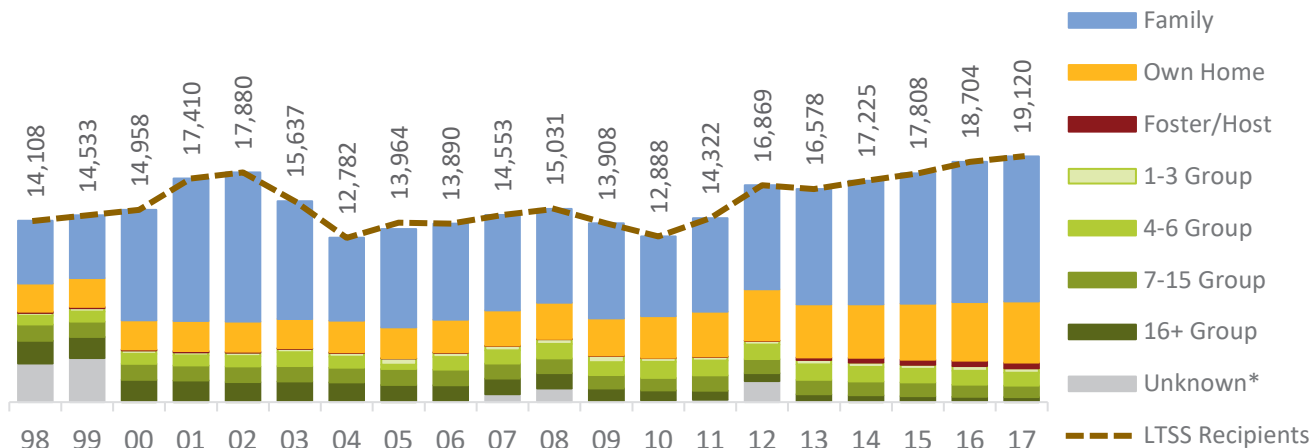
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Fiscal Year 2017

Residential Information Systems Project

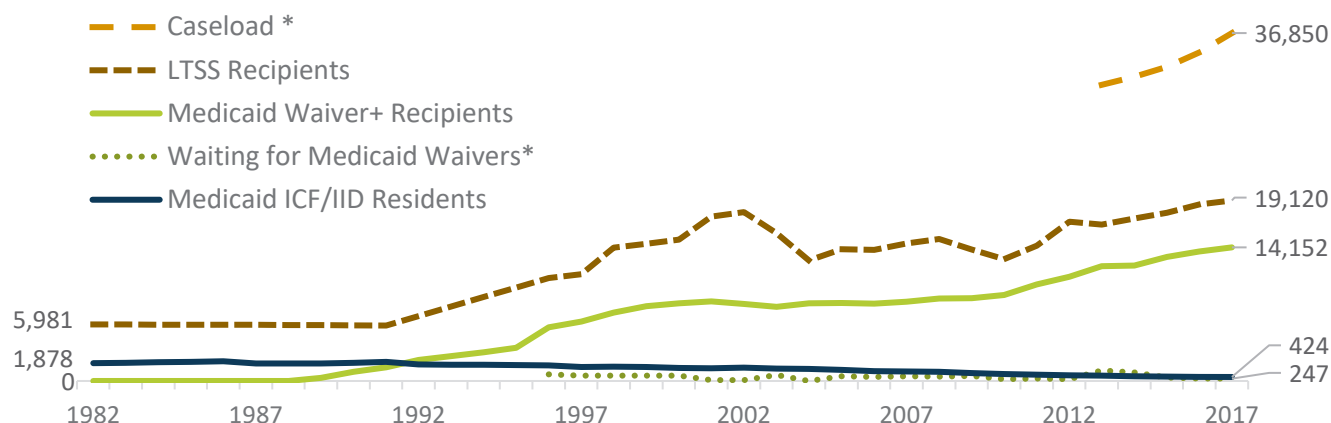


## IDD Agency Long Term Supports and Services Recipients by Residence Type



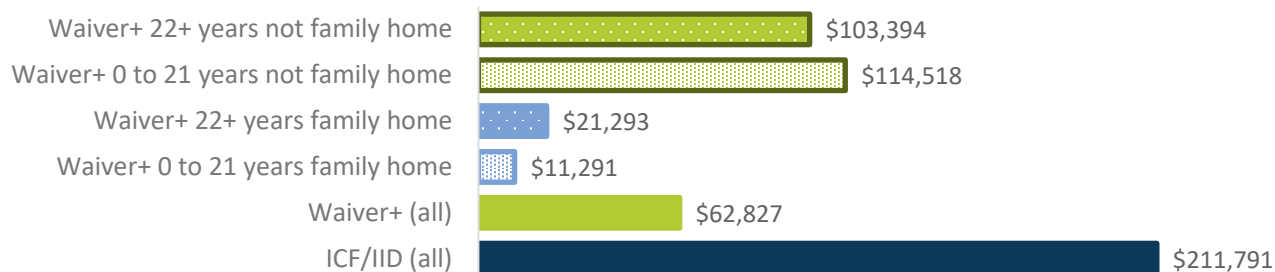
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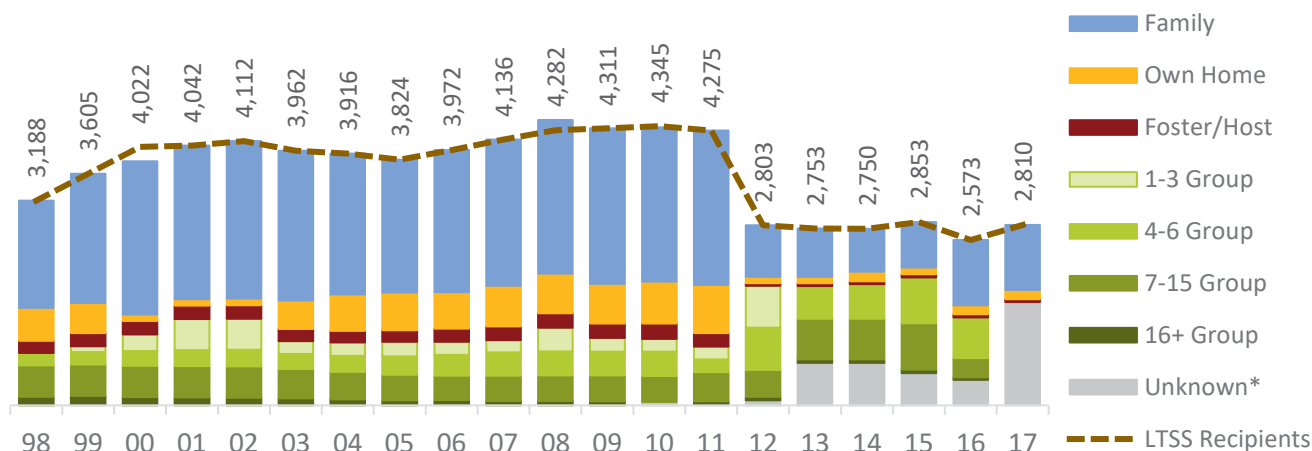
# Montana

Fiscal Year 2017

Residential Information Systems Project

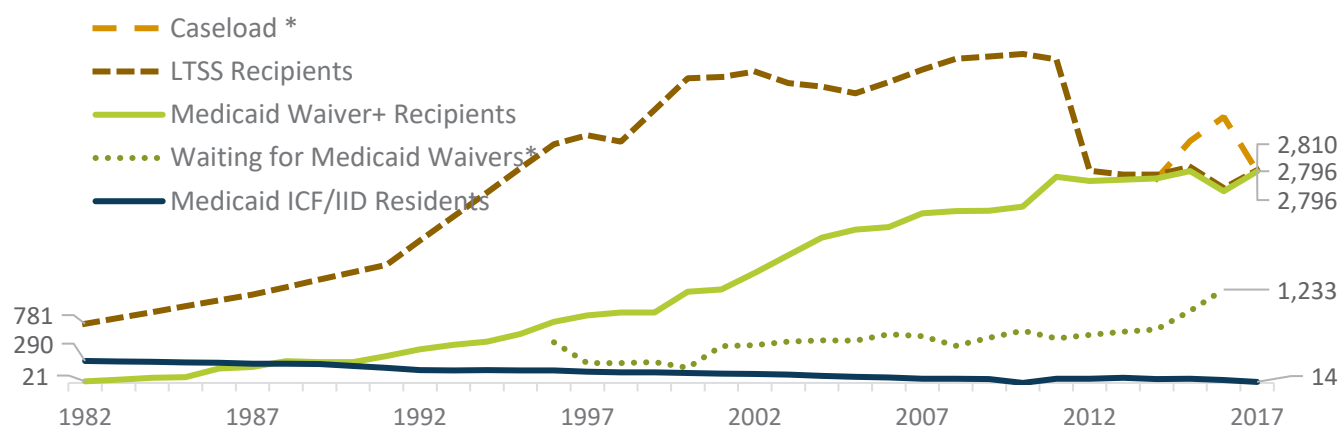


## IDD Agency Long Term Supports and Services Recipients by Residence Type



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## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2017



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

## Average Spending Per Person by Medicaid Authority in Fiscal Year 2017



Waiver by age in family home or not family home spending per person not available.

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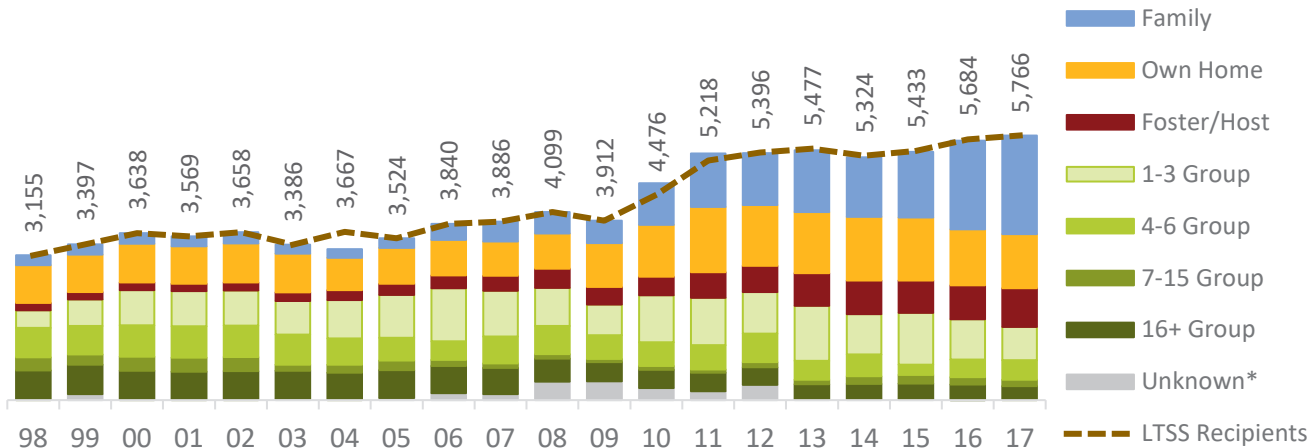
# Nebraska

Fiscal Year 2017

Residential Information Systems Project

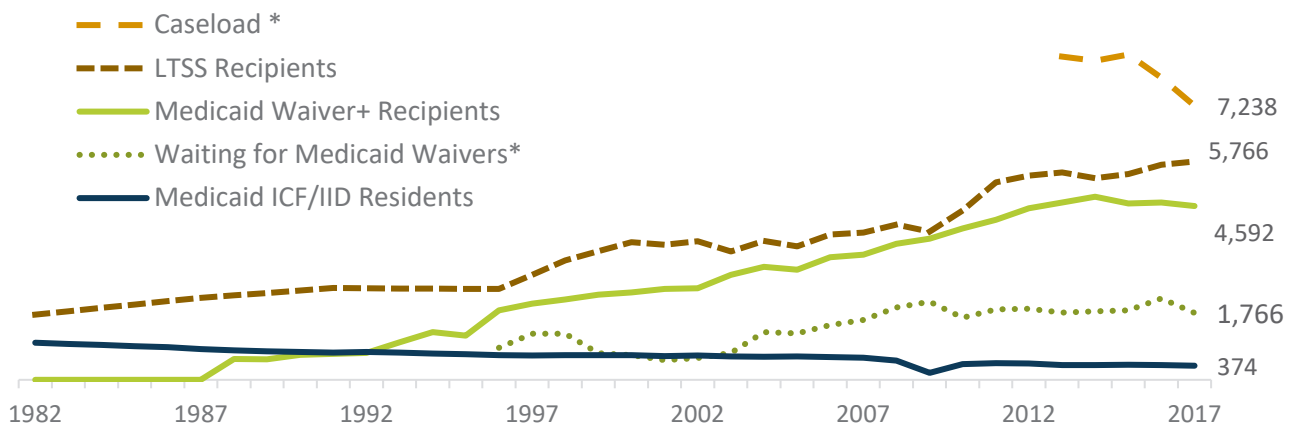


## IDD Agency Long Term Supports and Services Recipients by Residence Type



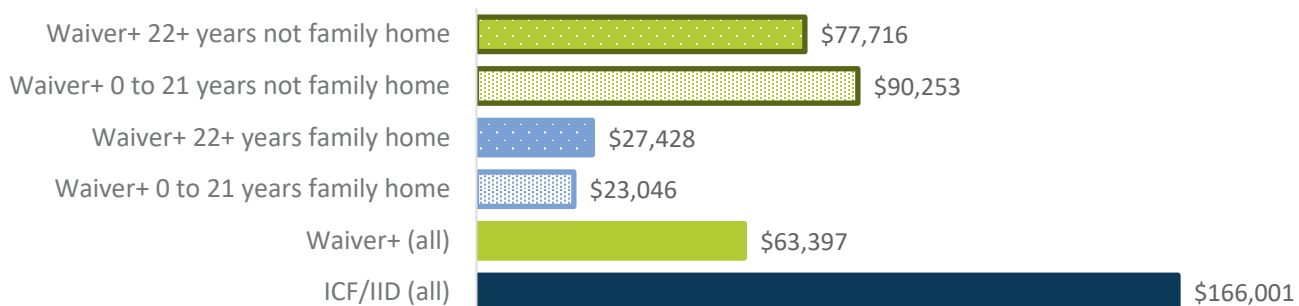
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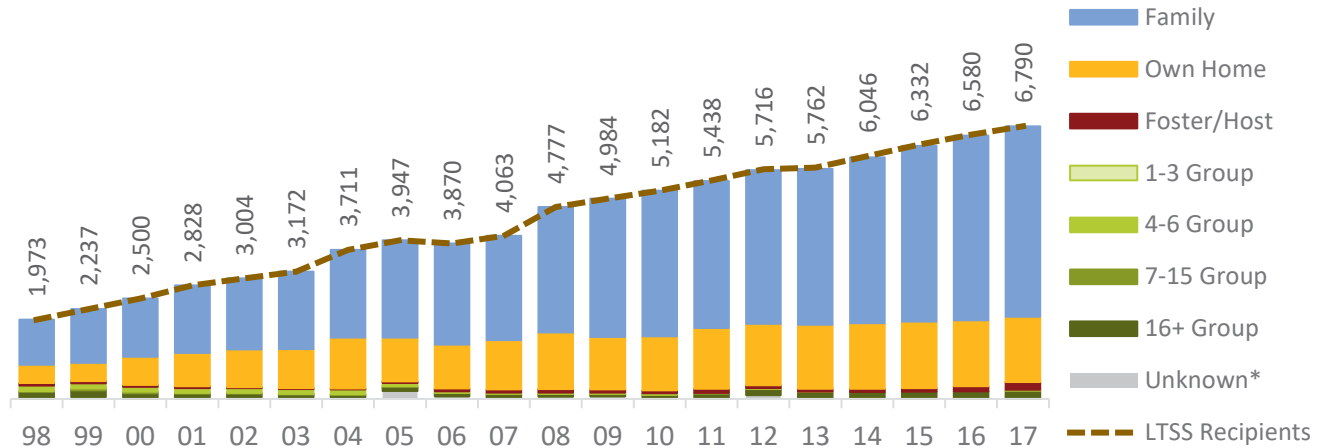
# Nevada

Fiscal Year 2017

Residential Information Systems Project

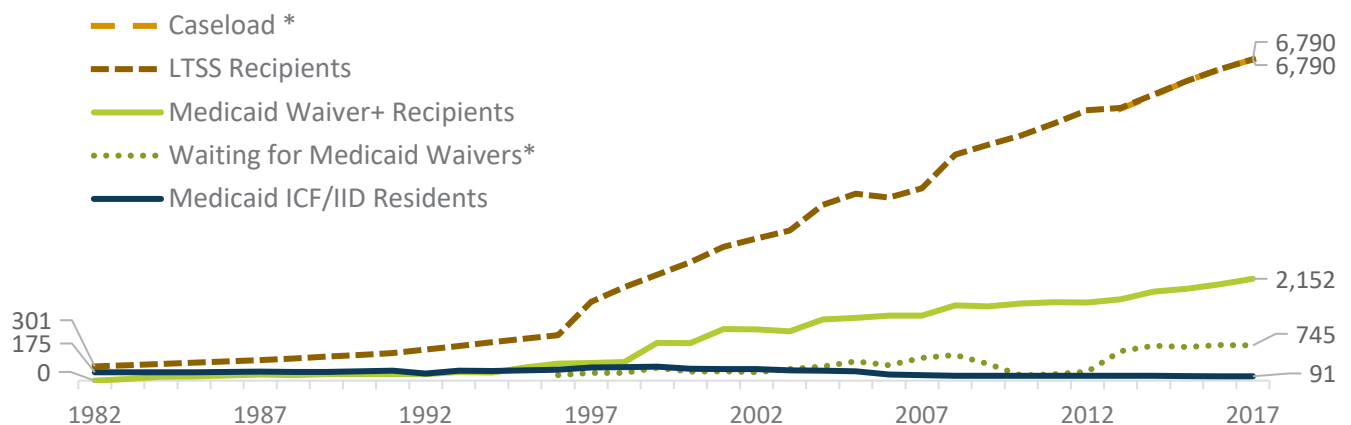


## IDD Agency Long Term Supports and Services Recipients by Residence Type



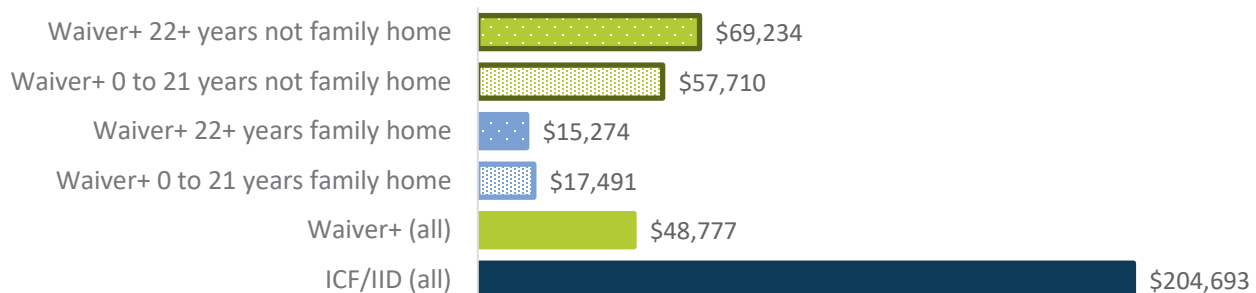
\* Unknown setting type or size reported in FY 2017 and gaps in all other years

## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2017



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

## Average Spending Per Person by Medicaid Authority in Fiscal Year 2017



Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

ICF/IID: Intermediate Care Facilities for Individuals with Intellectual Disabilities

Group: Number of people with IDD in a setting (ICF/IID, group home or other)

Waiver+: Medicaid Authorities 1115, 1915 (a)(b) or (b)(c), 1915(c)

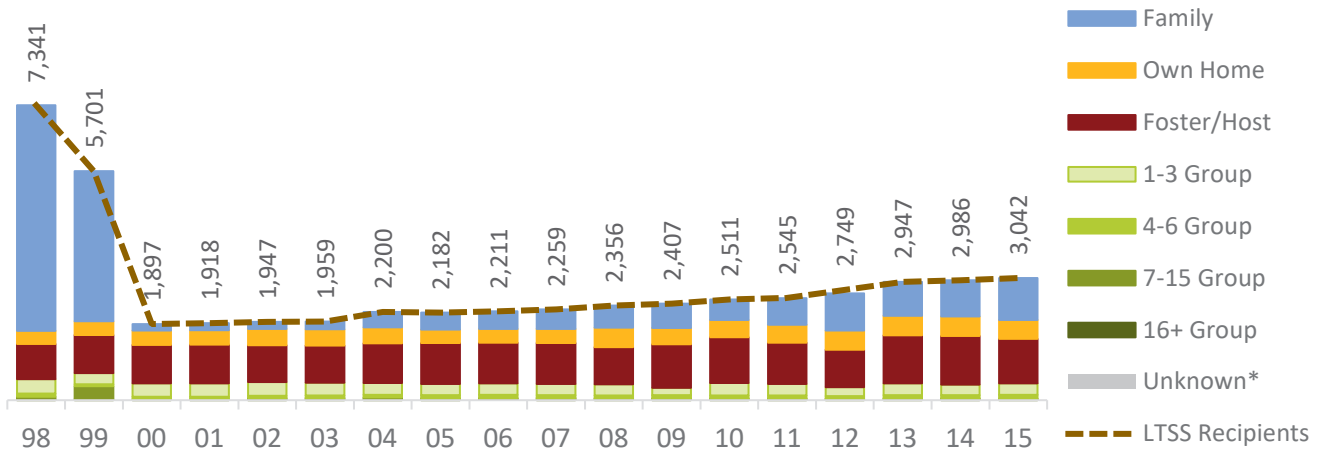
For more see [risp.umn.edu](http://risp.umn.edu)

# New Hampshire

Fiscal year 2017 and 2016 not available, FY 2015 presented.  
Residential Information Systems Project

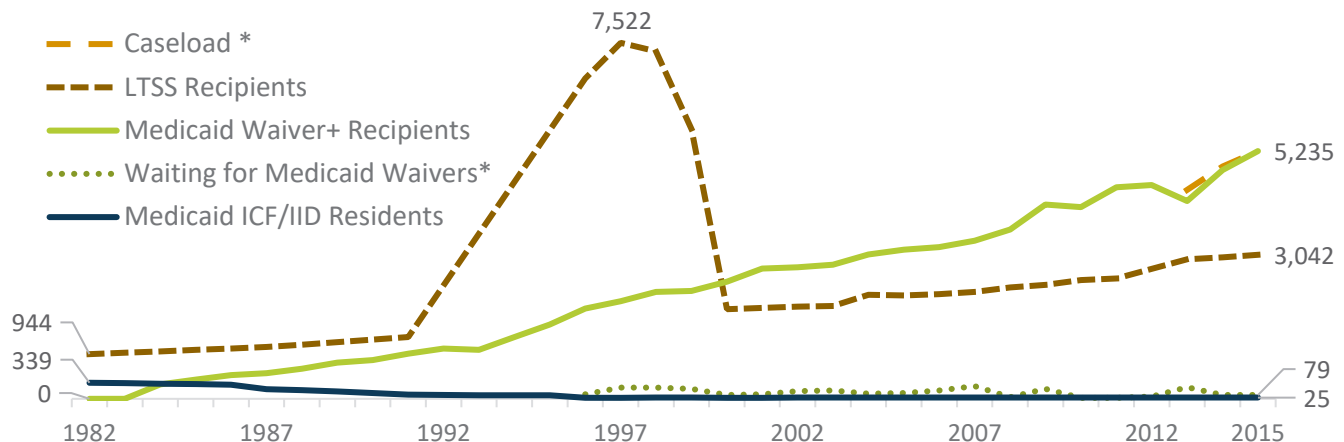


## IDD Agency Long Term Supports and Services Recipients by Residence Type



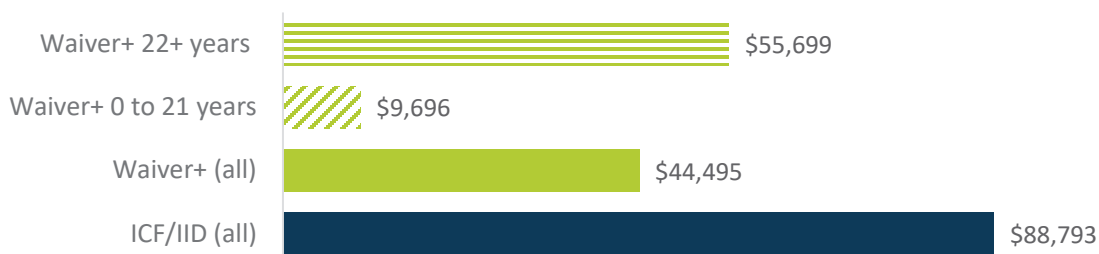
\* Unknown setting type or size reported in FY 2017 and gaps in all other years

## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2015



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

## Average Spending Per Person by Medicaid Authority in Fiscal Year 2015



Waiver by age in family home or not family home spending per person not available.

Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

ICF/IID: Intermediate Care Facilities for Individuals with Intellectual Disabilities

Group: Number of people with IDD in a setting (ICF/IID, group home or other)

Waiver+: Medicaid Authorities 1115, 1915 (a)(b) or (b)(c), 1915(c)

For more see [risp.umn.edu](http://risp.umn.edu)

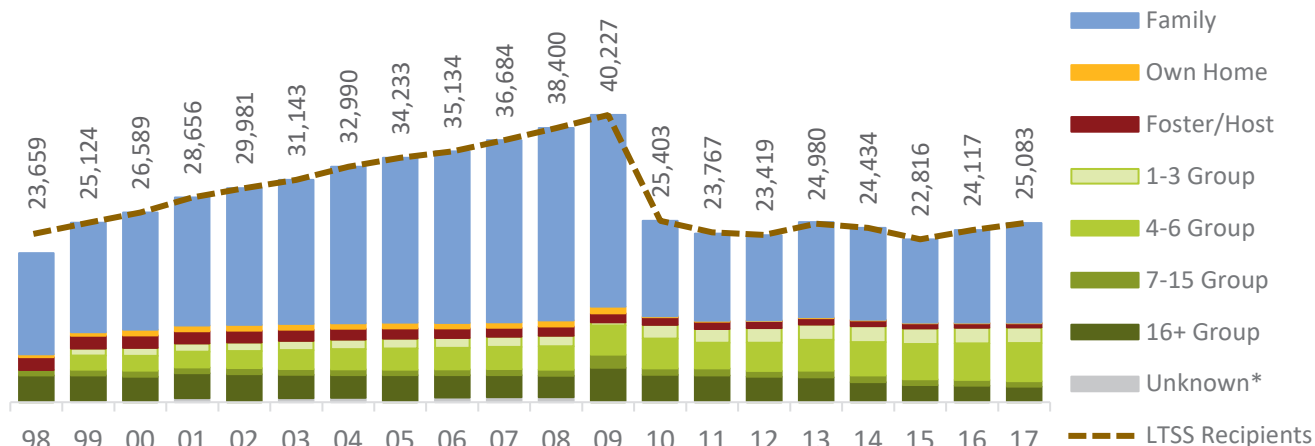
# New Jersey

Fiscal Year 2017

Residential Information Systems Project

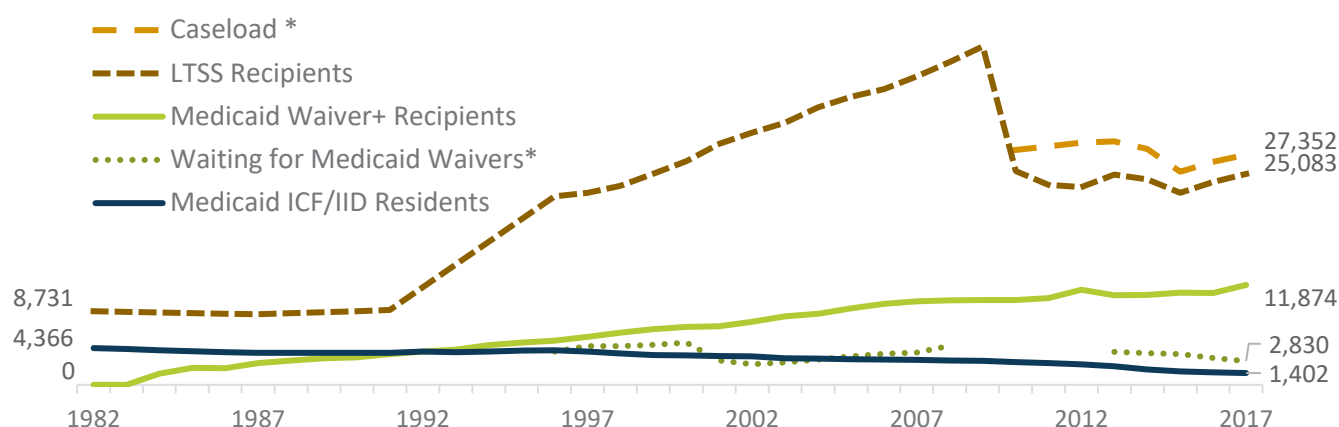


## IDD Agency Long Term Supports and Services Recipients by Residence Type



\* Unknown setting type or size reported in FY 2017 and gaps in all other years

## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2017



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

## Average Spending Per Person by Medicaid Authority in Fiscal Year 2017



Waiver by age in family home or not family home spending per person not available.

Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

ICF/IID: Intermediate Care Facilities for Individuals with Intellectual Disabilities

Group: Number of people with IDD in a setting (ICF/IID, group home or other)

Waiver+: Medicaid Authorities 1115, 1915 (a)(b) or (b)(c), 1915(c)

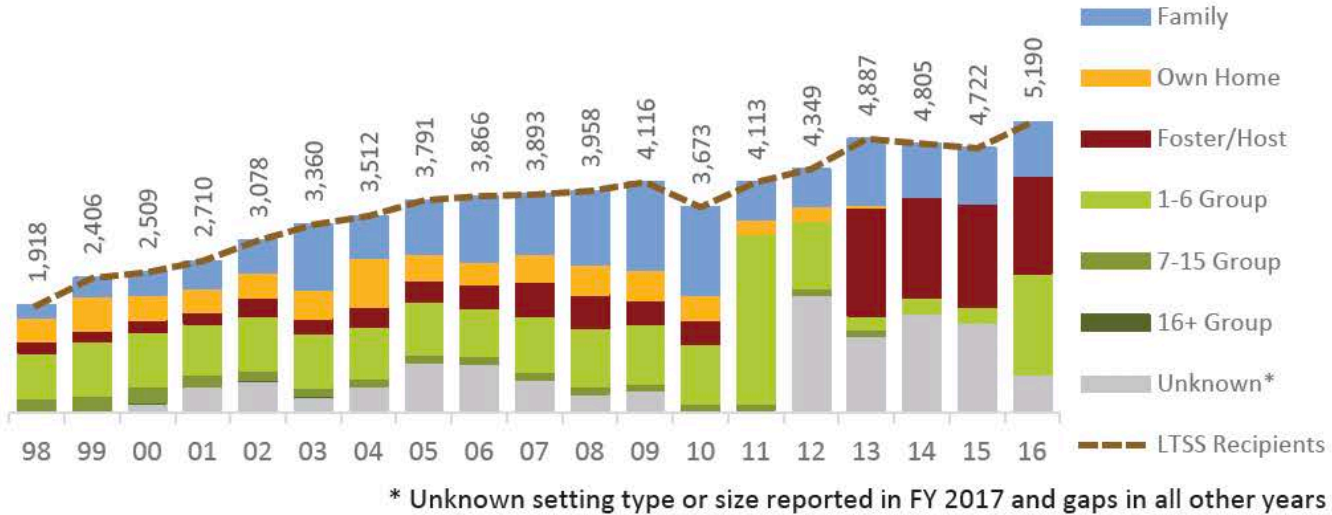
For more see [risp.umn.edu](http://risp.umn.edu)

## New Mexico

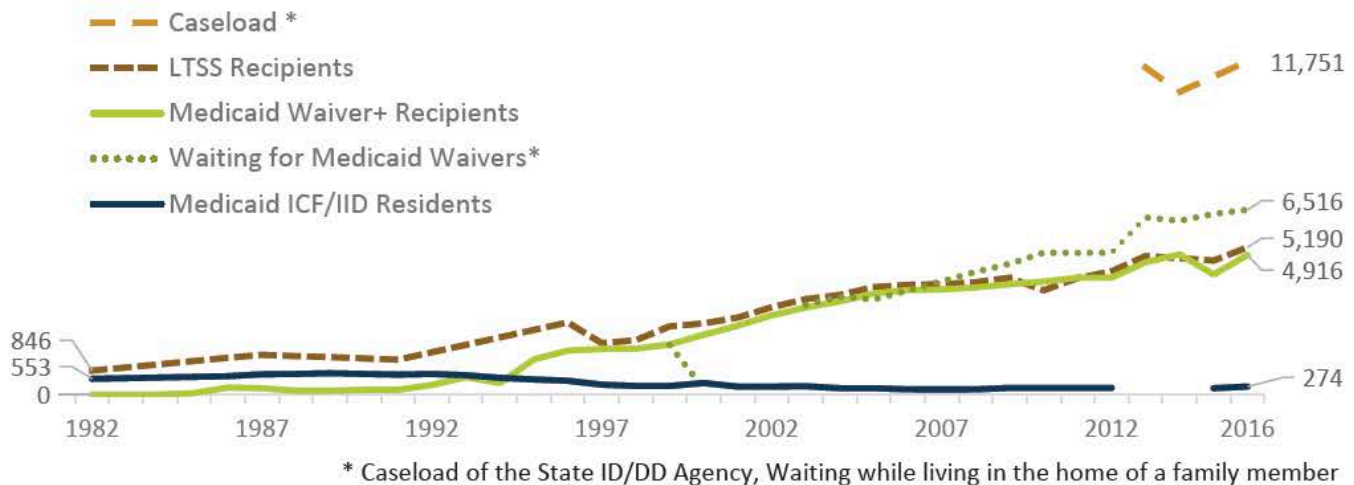
Complete Fiscal year 2017 not available, FY 2016 presented when available.  
Residential Information Systems Project



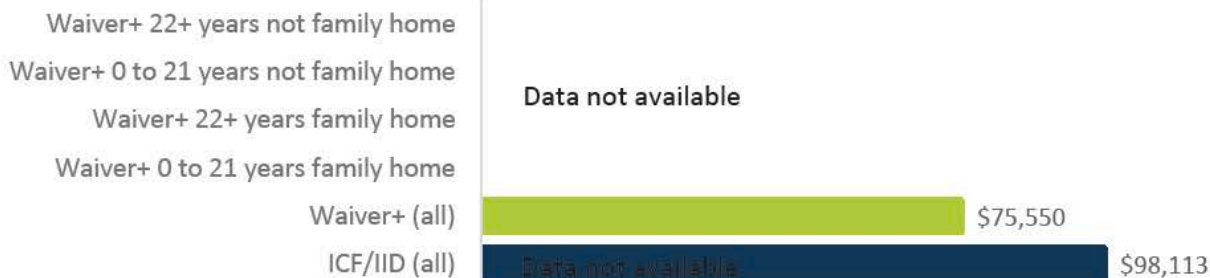
### IDD Agency Long Term Supports and Services Recipients by Residence Type



### Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2016



### Average Spending Per Person by Medicaid Authority in Fiscal Year 2016



Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services  
ICF/IID: Intermediate Care Facilities for Individuals with Intellectual Disabilities



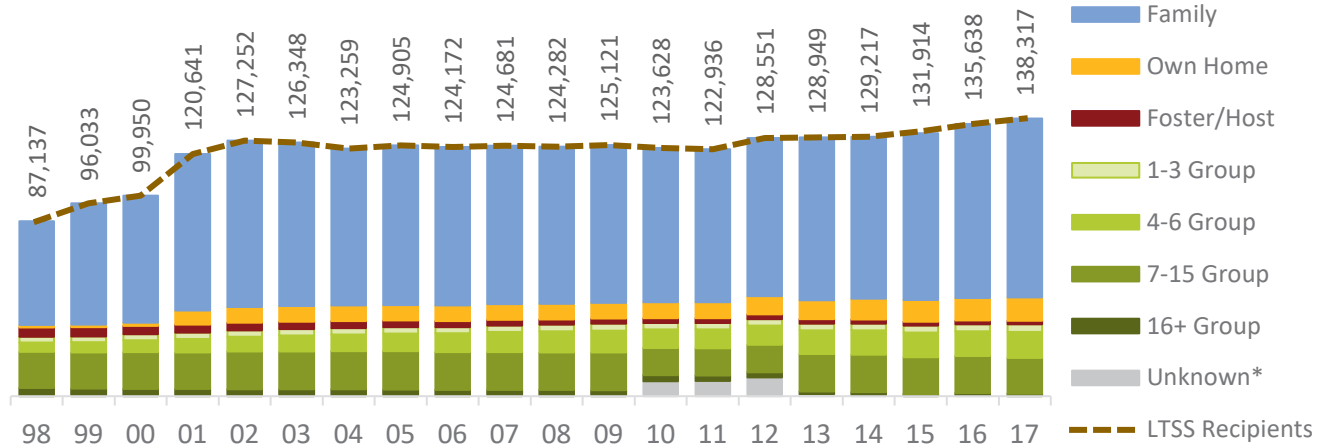
# New York

Fiscal Year 2017

Residential Information Systems Project

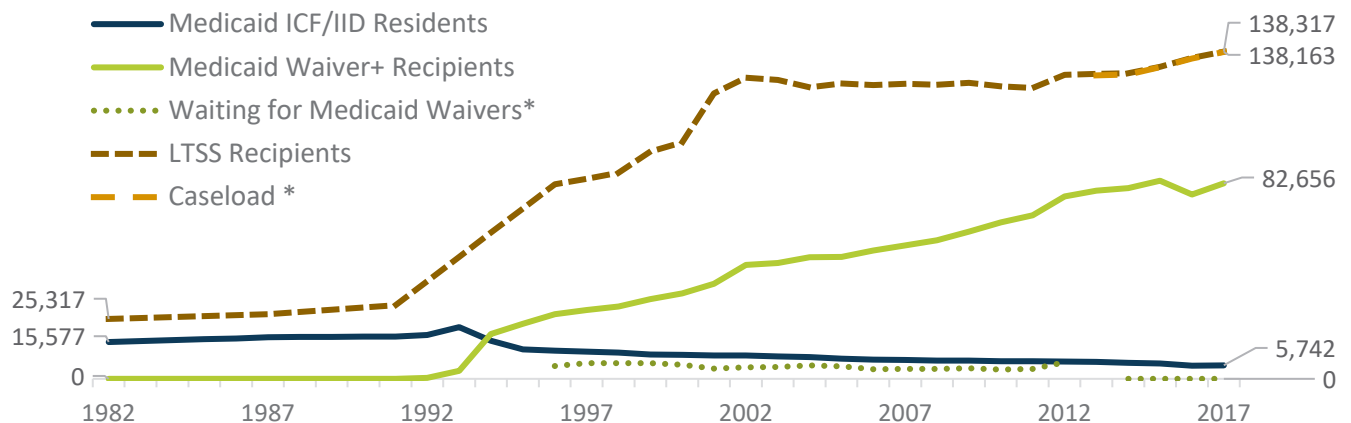


## IDD Agency Long Term Supports and Services Recipients by Residence Type



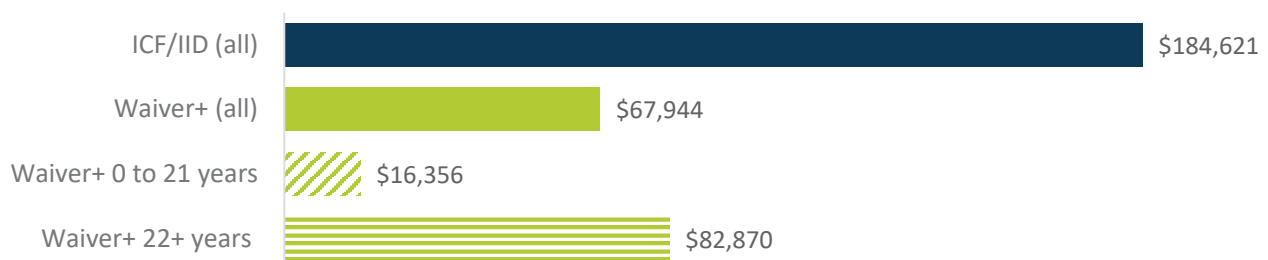
\* Unknown setting type or size reported in FY 2017 and gaps in all other years

## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2017



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

## Average Spending Per Person by Medicaid Authority in Fiscal Year 2017



Waiver by age in family home or not family home spending per person not available.

Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

ICF/IID: Intermediate Care Facilities for Individuals with Intellectual Disabilities

Group: Number of people with IDD in a setting (ICF/IID, group home or other)

Waiver+: Medicaid Authorities 1115, 1915 (a)(b)or (b/c), 1915(c)

For more see [risp.umn.edu](http://risp.umn.edu)

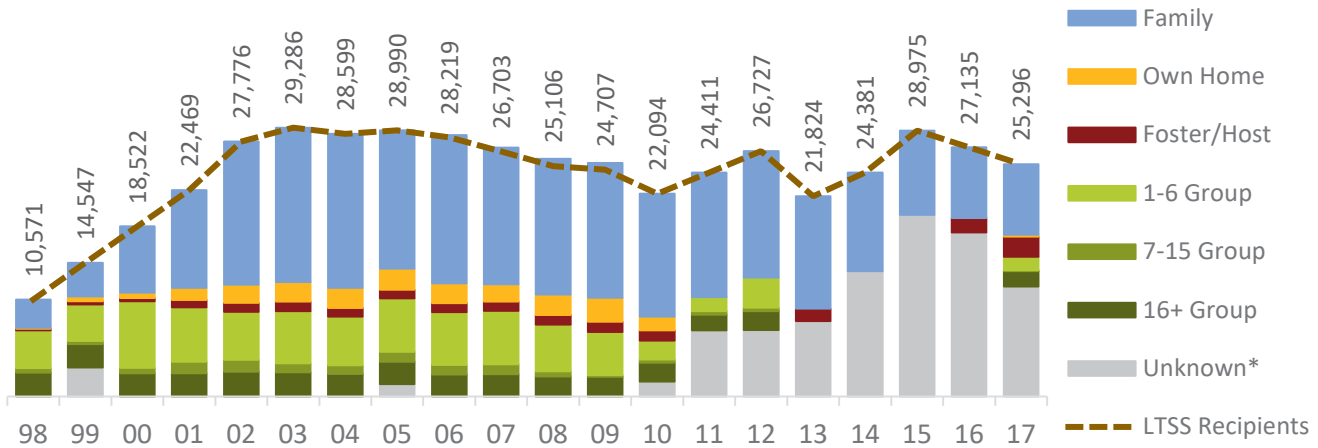
# North Carolina

Fiscal Year 2017

Residential Information Systems Project

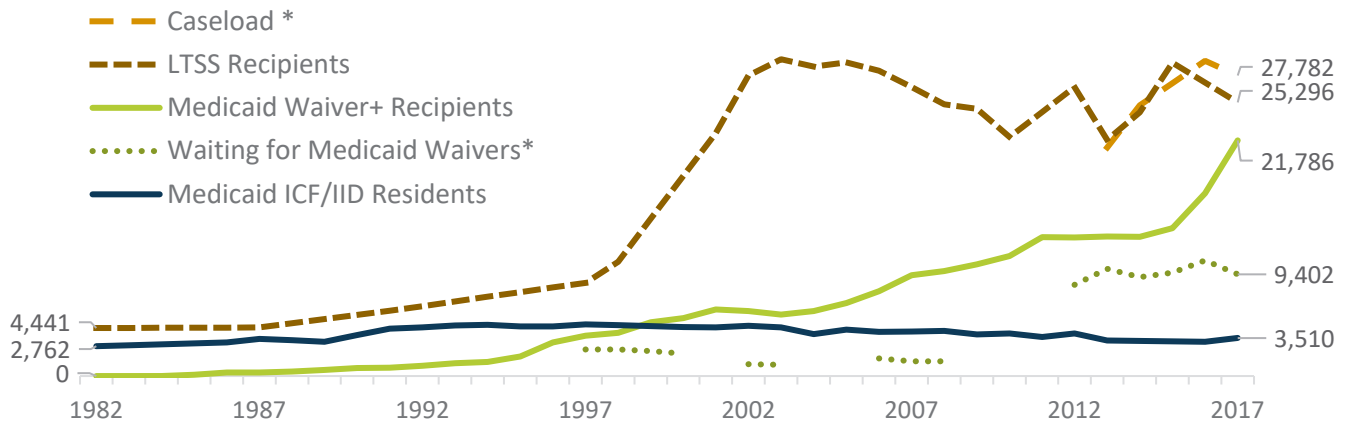


## IDD Agency Long Term Supports and Services Recipients by Residence Type



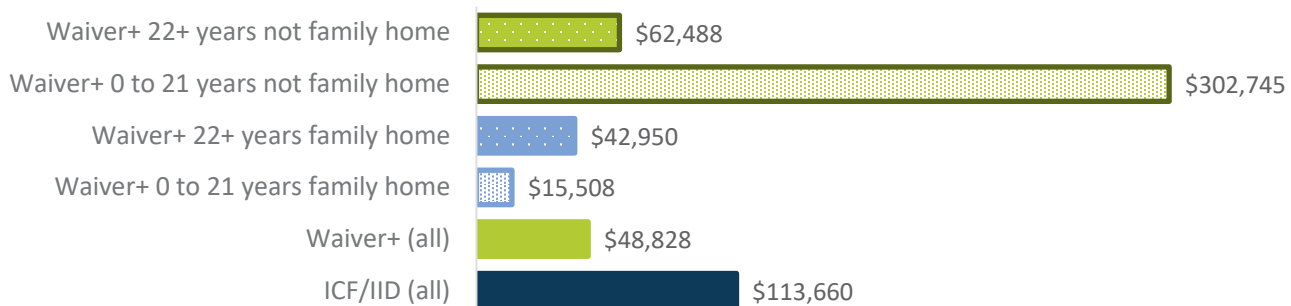
\* Unknown setting type or size reported in FY 2017 and gaps in all other years

## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2017



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

## Average Spending Per Person by Medicaid Authority in Fiscal Year 2017



Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

ICF/IID: Intermediate Care Facilities for Individuals with Intellectual Disabilities

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Waiver+: Medicaid Authorities 1115, 1915 (a)(b)or (b)(c), 1915(c)

For more see [risp.umn.edu](http://risp.umn.edu)

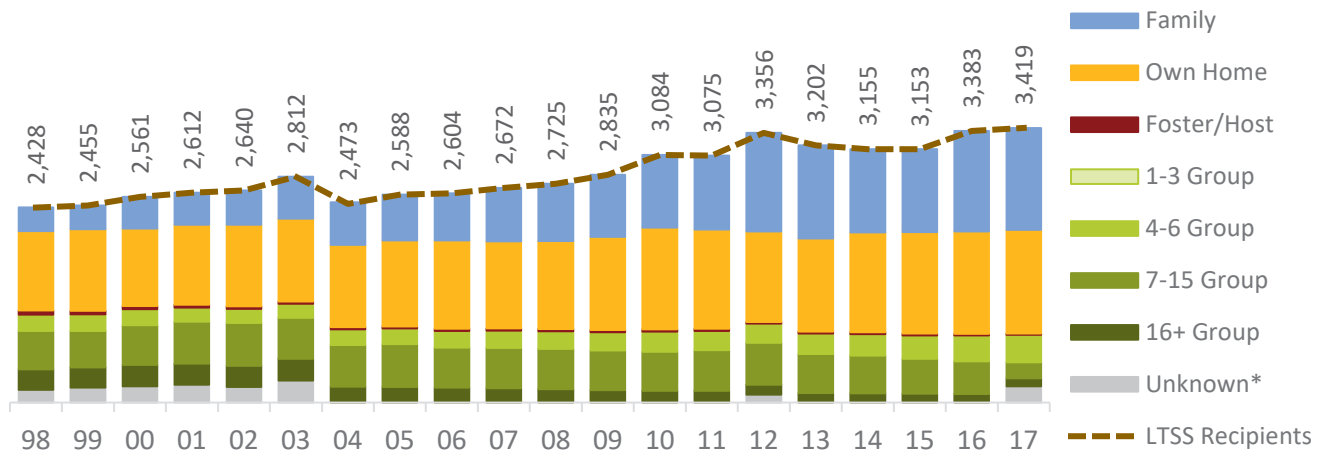
# North Dakota

Fiscal Year 2017

Residential Information Systems Project

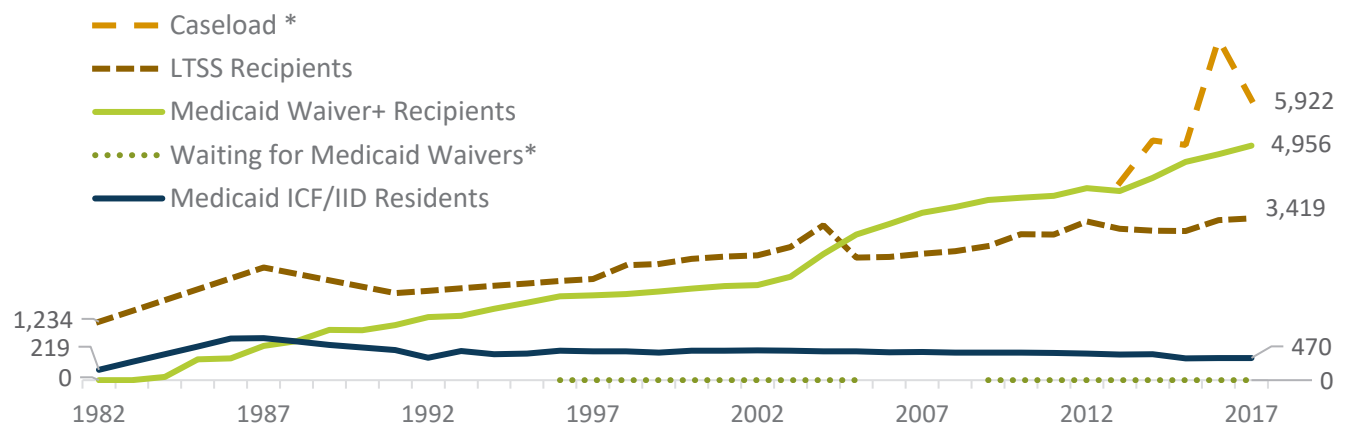


## IDD Agency Long Term Supports and Services Recipients by Residence Type



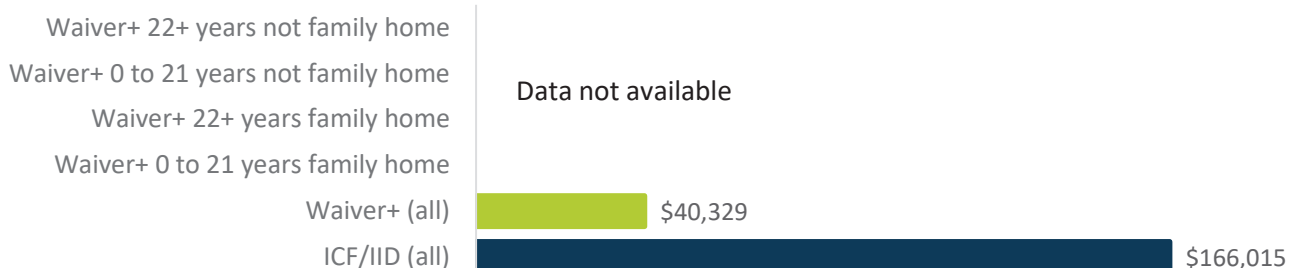
\* Unknown setting type or size reported in FY 2017 and gaps in all other years

## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2017



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

## Average Spending Per Person by Medicaid Authority in Fiscal Year 2016



FY 2017 expenditures and Waiver by age in family home or not family home spending per person not available.

Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

ICF/IID: Intermediate Care Facilities for Individuals with Intellectual Disabilities

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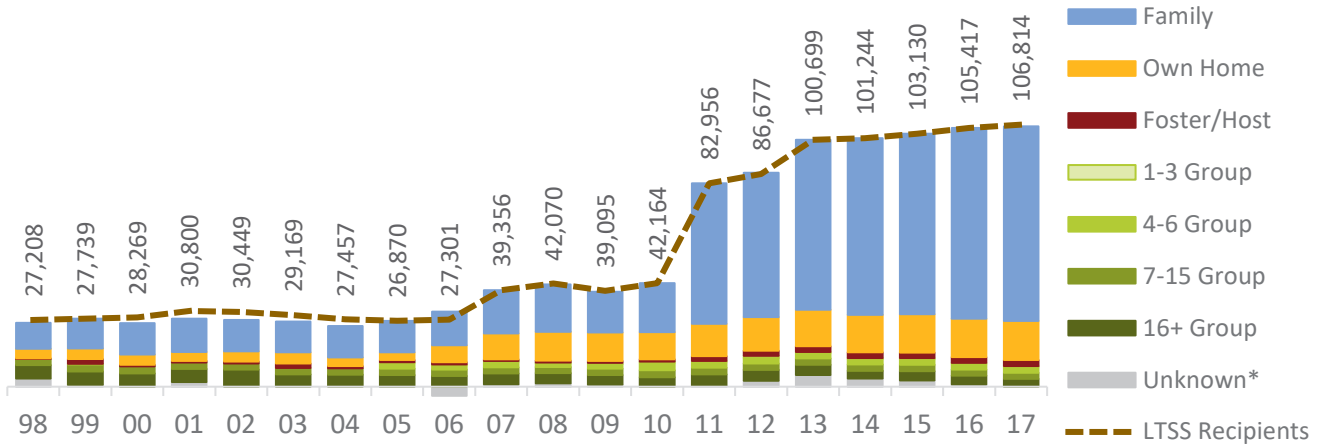
# Ohio

Fiscal Year 2017

Residential Information Systems Project

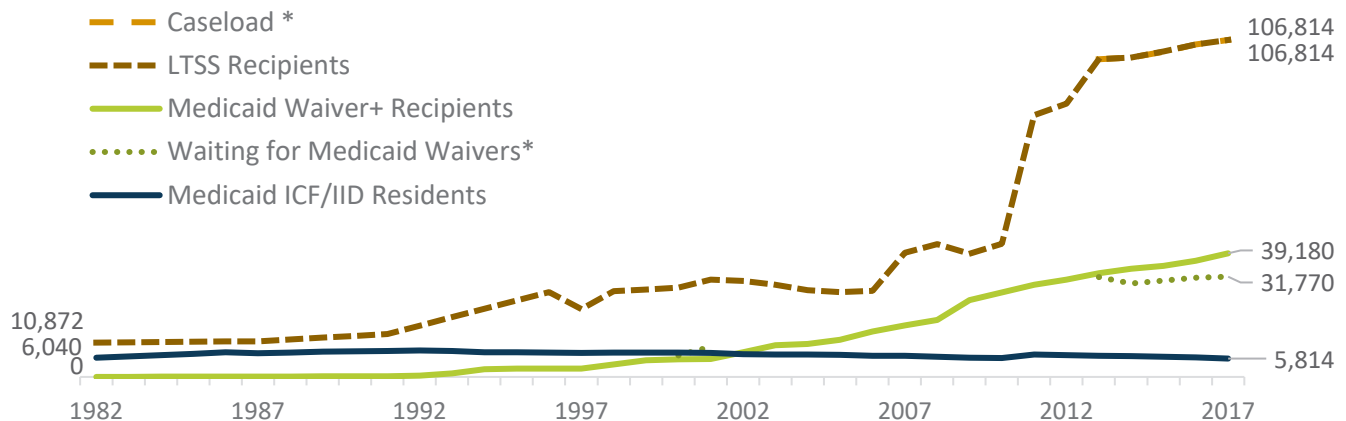


## IDD Agency Long Term Supports and Services Recipients by Residence Type



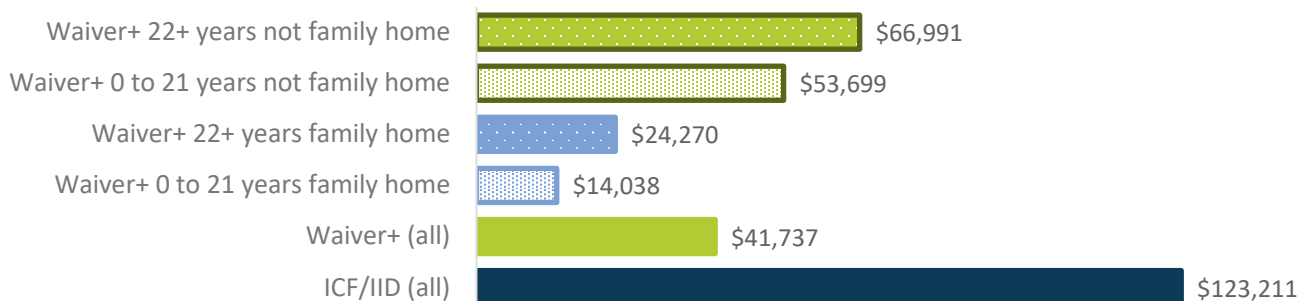
\* Unknown setting type or size reported in FY 2017 and gaps in all other years

## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2017



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

## Average Spending Per Person by Medicaid Authority in Fiscal Year 2017



Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

ICF/IID: Intermediate Care Facilities for Individuals with Intellectual Disabilities

Group: Number of people with IDD in a setting (ICF/IID, group home or other)

Waiver+: Medicaid Authorities 1115, 1915 (a)(b) or (b)(c), 1915(c)

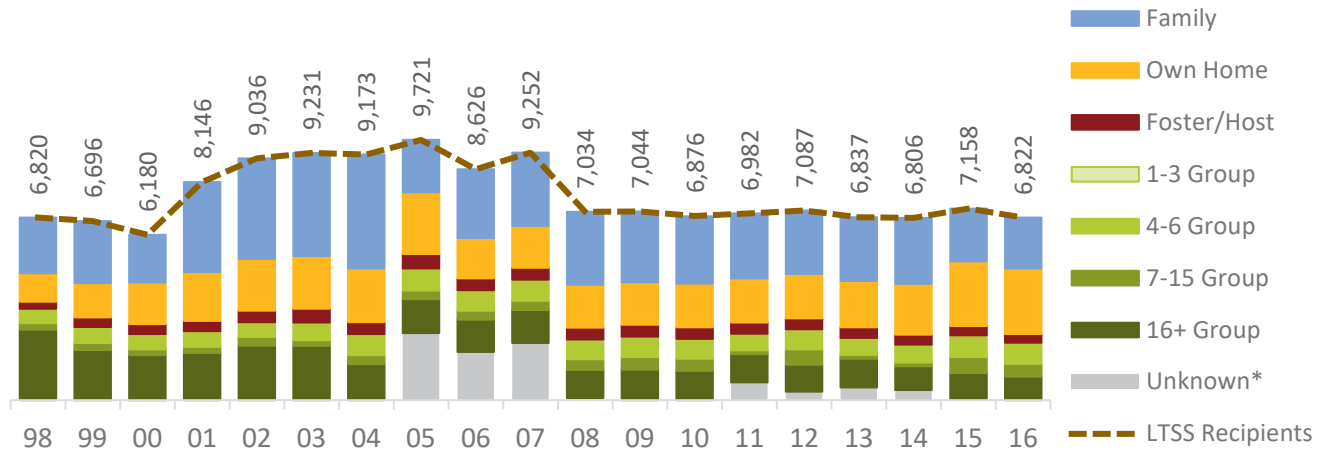
For more see [risp.umn.edu](http://risp.umn.edu)

# Oklahoma

Fiscal year 2017 not available, FY 2016 presented when available.  
Residential Information Systems Project

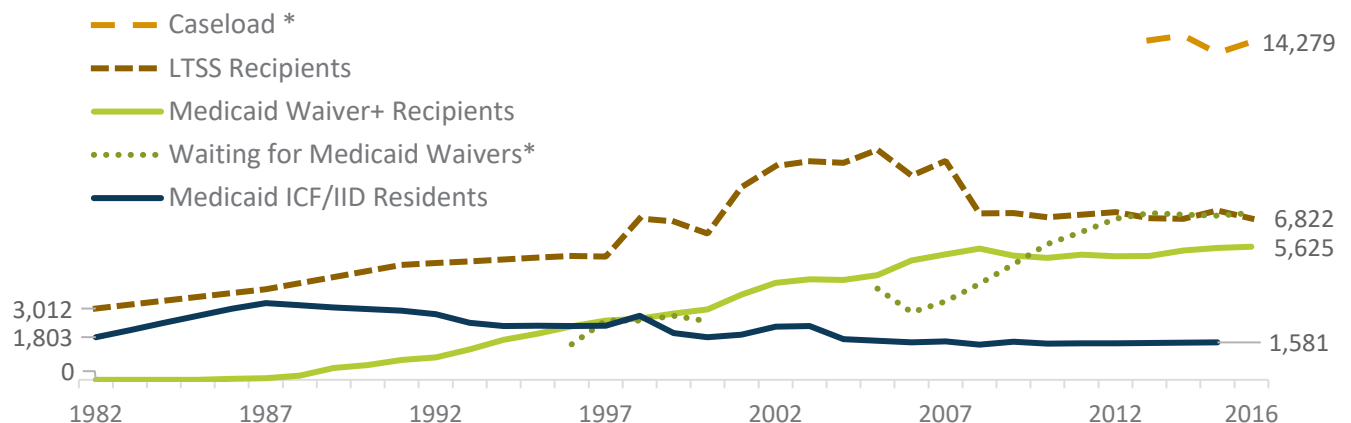


## IDD Agency Long Term Supports and Services Recipients by Residence Type



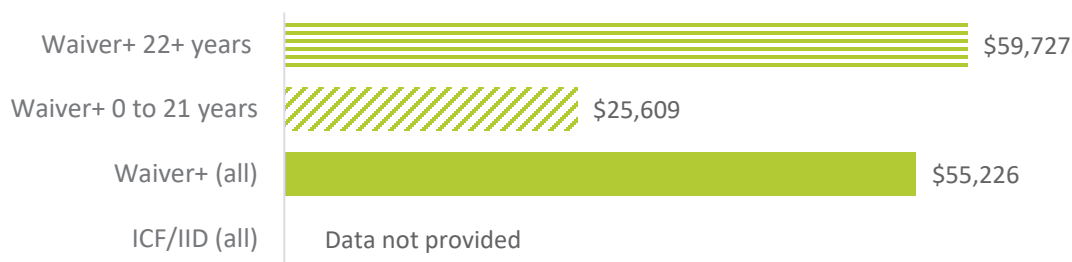
\* Unknown setting type or size reported in FY 2017 and gaps in all other years

## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2016



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

## Average Spending Per Person by Medicaid Authority in Fiscal Year 2016



Waiver by age in family home or not family home spending per person not available.

Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

ICF/IID: Intermediate Care Facilities for Individuals with Intellectual Disabilities

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Waiver+: Medicaid Authorities 1115, 1915 (a)(b)or (b/c), 1915(c)

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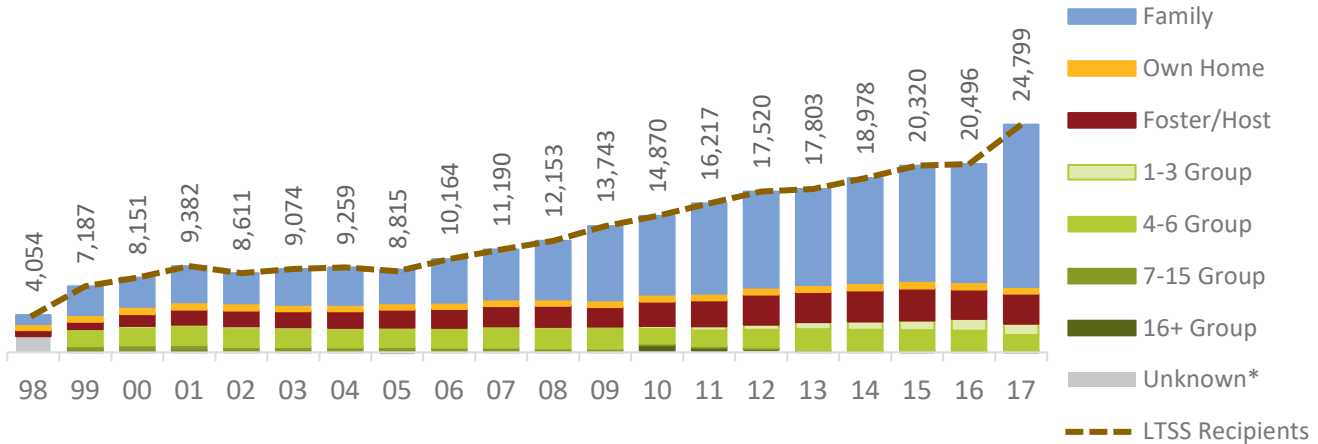
# Oregon

Fiscal Year 2017

Residential Information Systems Project

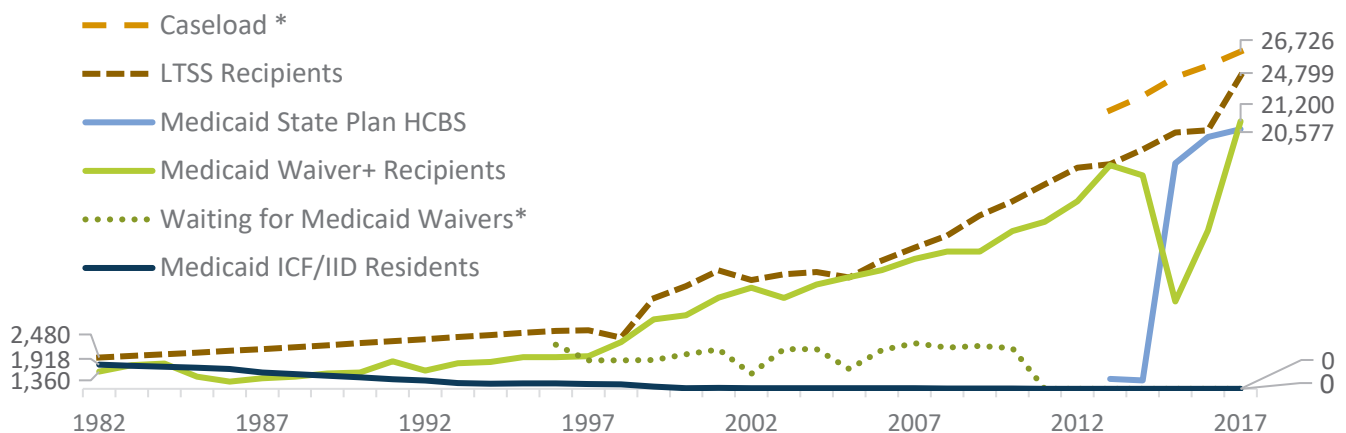


## IDD Agency Long Term Supports and Services Recipients by Residence Type



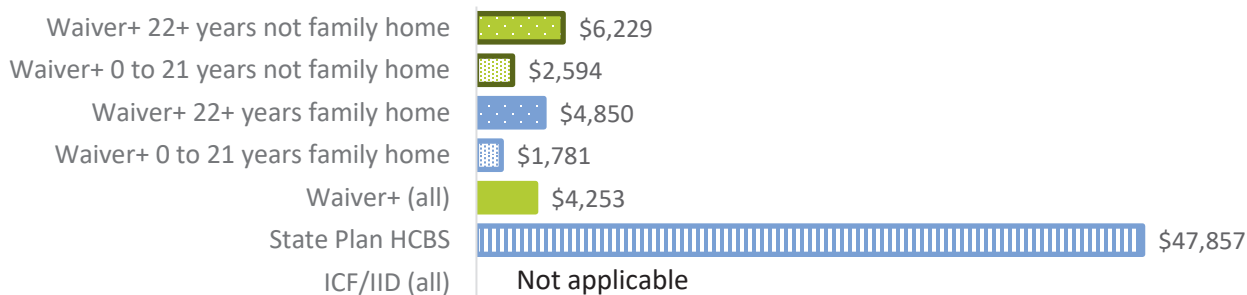
\* Unknown setting type or size reported in FY 2017 and gaps in all other years

## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2017



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

## Average Spending Per Person by Medicaid Authority in Fiscal Year 2017



Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

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For more see [risp.umn.edu](http://risp.umn.edu)



# Pennsylvania

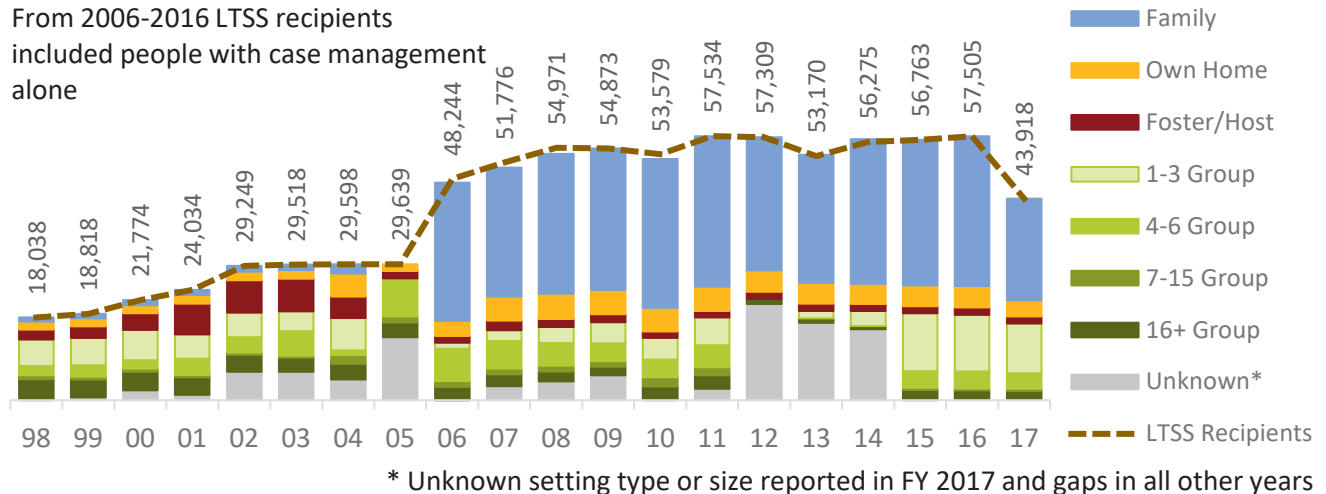
Fiscal Year 2017

Residential Information Systems Project

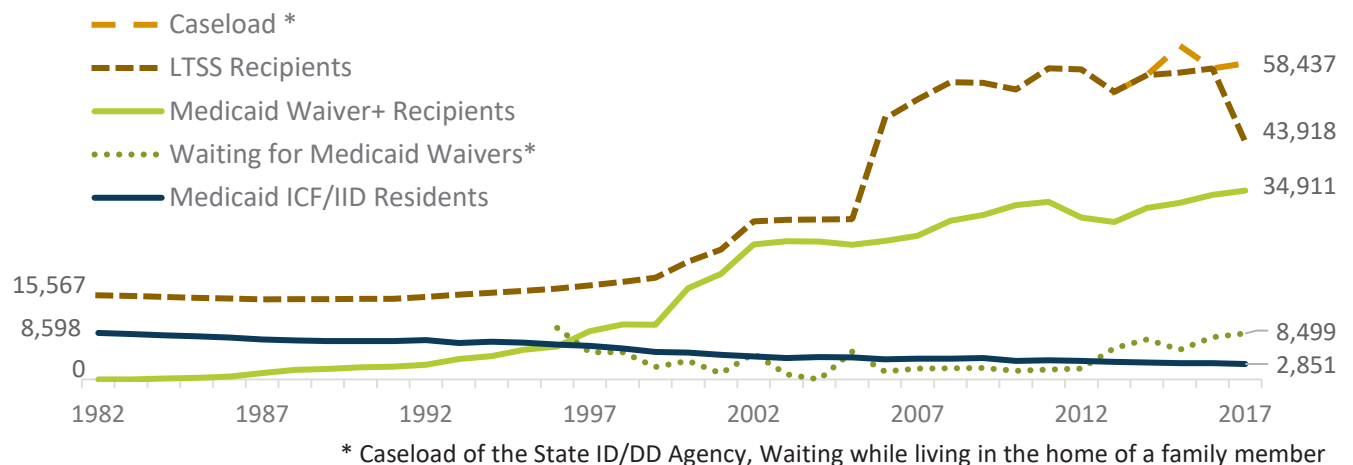


## IDD Agency Long Term Supports and Services Recipients by Residence Type

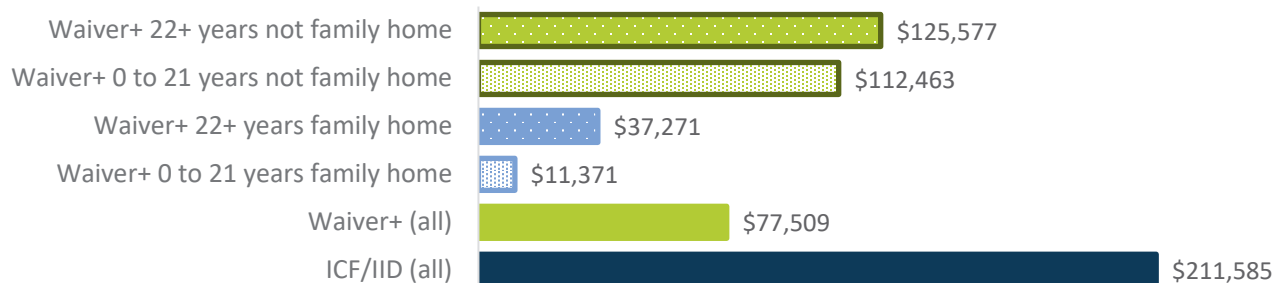
From 2006-2016 LTSS recipients included people with case management alone



## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2017



## Average Spending Per Person by Medicaid Authority in Fiscal Year 2017



Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

ICF/IID: Intermediate Care Facilities for Individuals with Intellectual Disabilities

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Waiver+: Medicaid Authorities 1115, 1915 (a)(b) or (b)(c), 1915(c)

For more see [risp.umn.edu](http://risp.umn.edu)

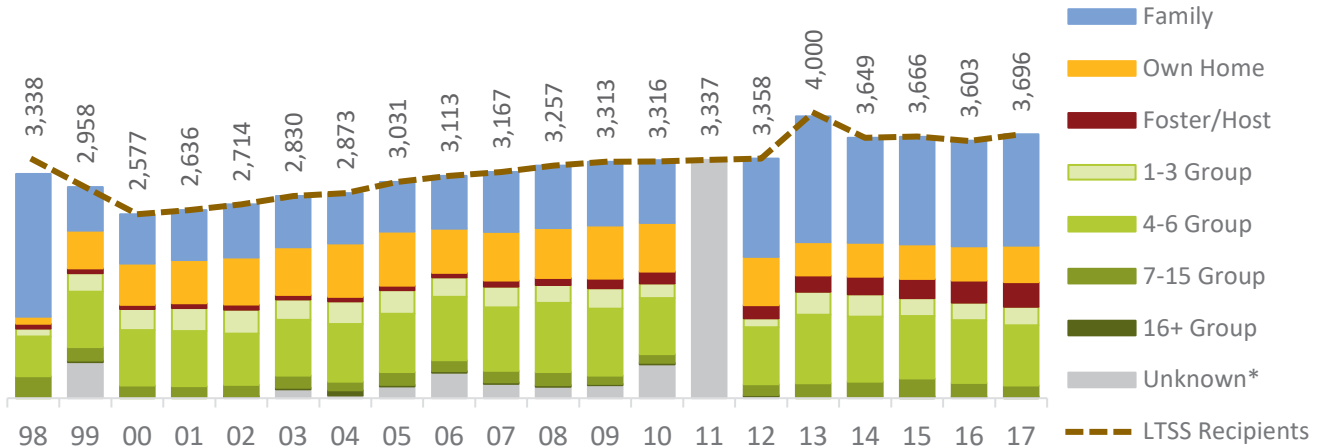
# Rhode Island

Fiscal Year 2017

Residential Information Systems Project

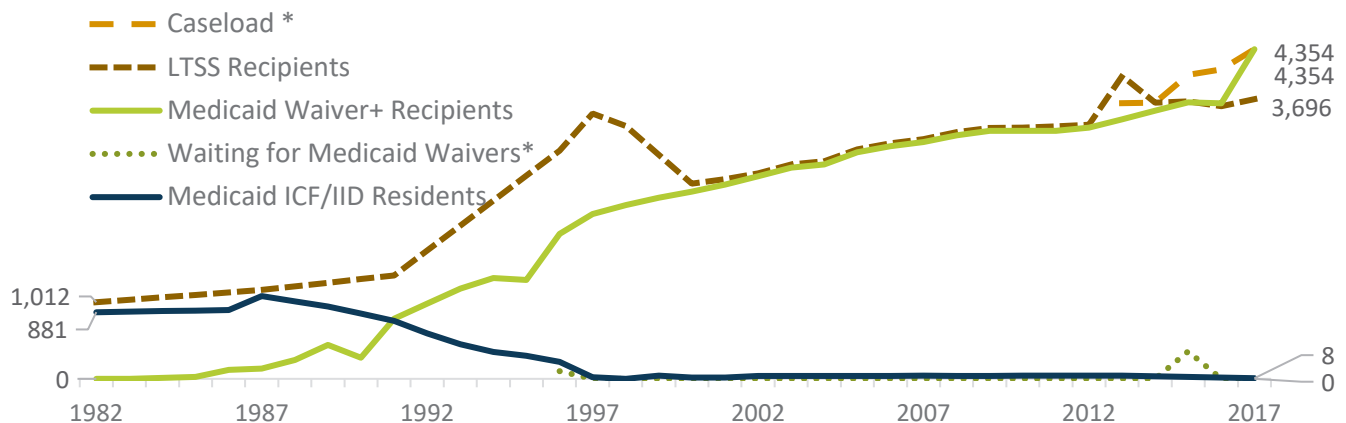


## IDD Agency Long Term Supports and Services Recipients by Residence Type



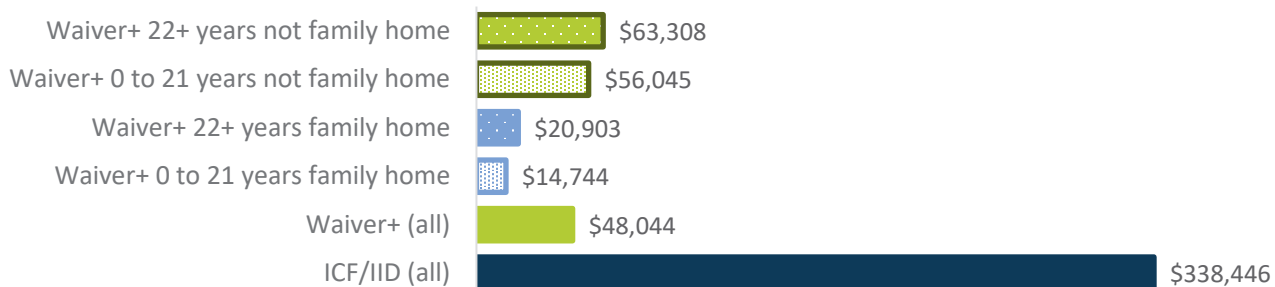
\* Unknown setting type or size reported in FY 2017 and gaps in all other years

## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2017



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

## Average Spending Per Person by Medicaid Authority in Fiscal Year 2017



Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

ICF/IID: Intermediate Care Facilities for Individuals with Intellectual Disabilities

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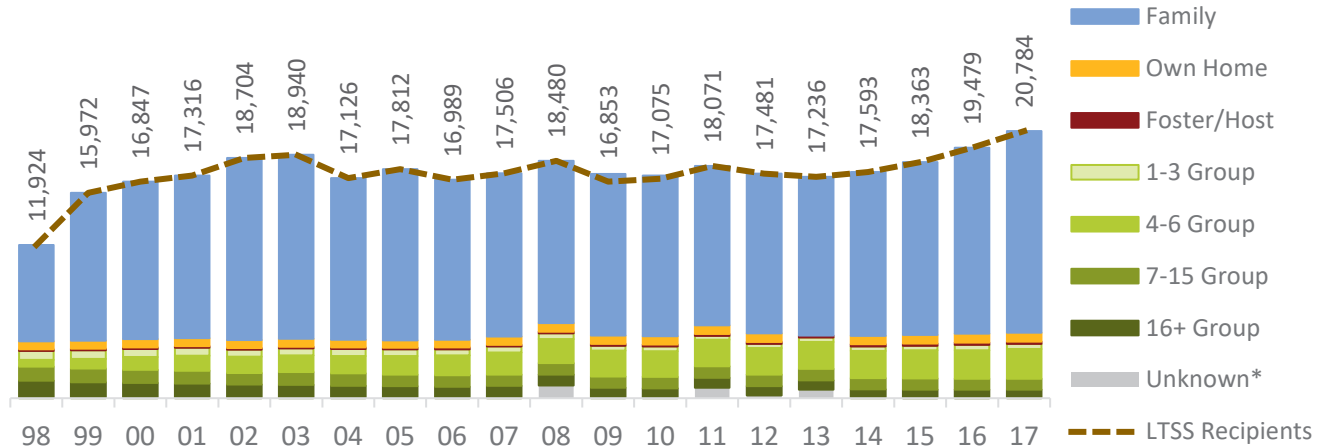
# South Carolina

Fiscal Year 2017

Residential Information Systems Project

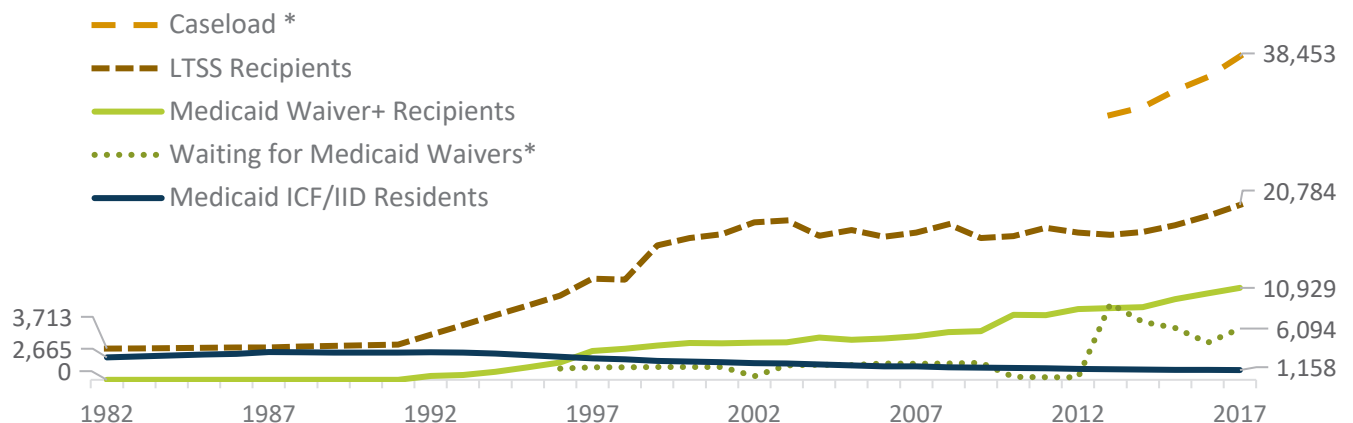


## IDD Agency Long Term Supports and Services Recipients by Residence Type



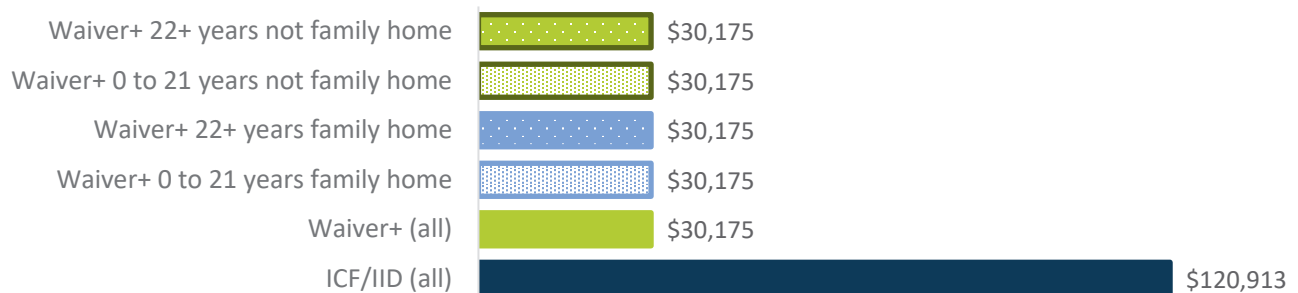
\* Unknown setting type or size reported in FY 2017 and gaps in all other years

## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2017



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

## Average Spending Per Person by Medicaid Authority in Fiscal Year 2017



Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

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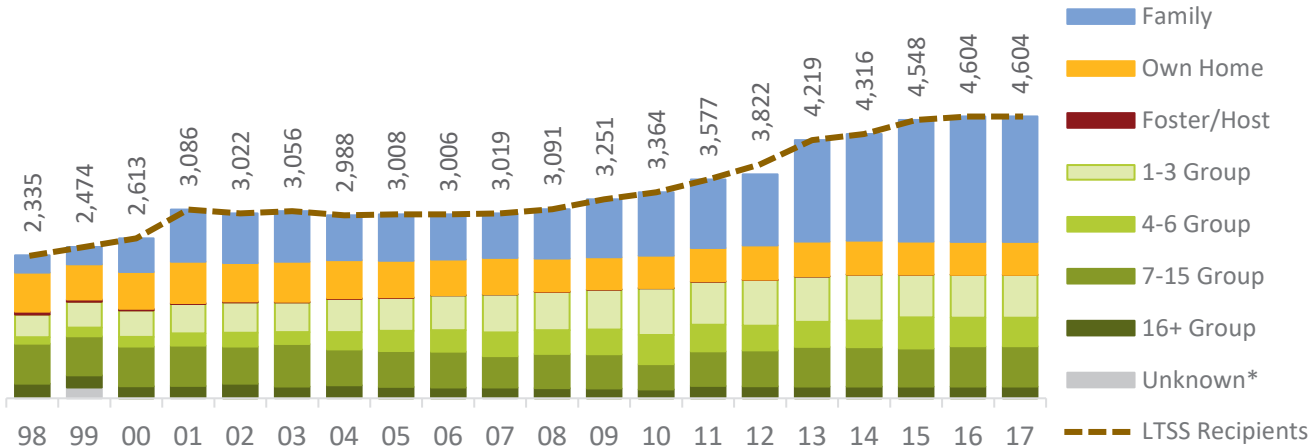
# South Dakota

Fiscal Year 2017

Residential Information Systems Project

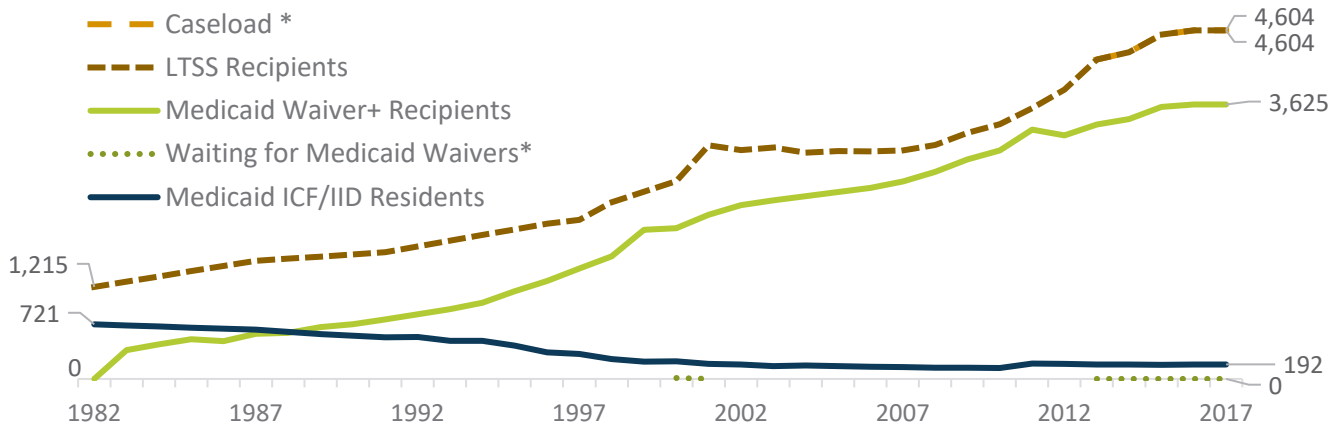


## IDD Agency Long Term Supports and Services Recipients by Residence Type



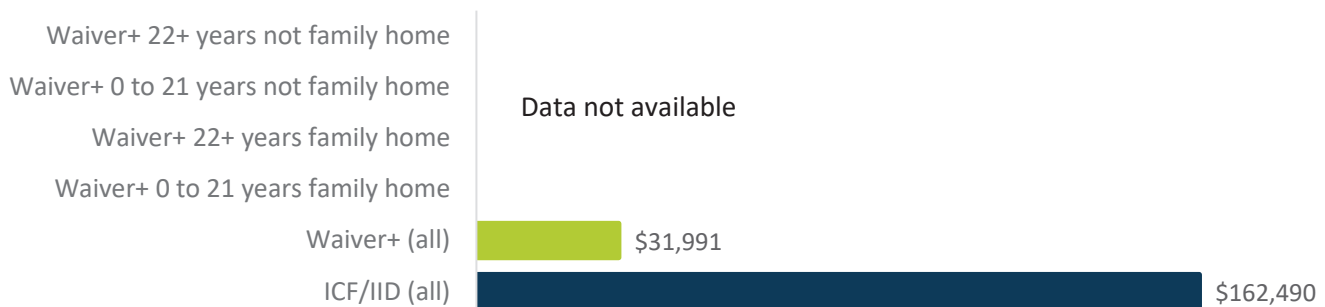
\* Unknown setting type or size reported in FY 2017 and gaps in all other years

## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2017



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

## Average Spending Per Person by Medicaid Authority in Fiscal Year 2017



Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

ICF/IID: Intermediate Care Facilities for Individuals with Intellectual Disabilities

Group: Number of people with IDD in a setting (ICF/IID, group home or other)

Waiver+: Medicaid Authorities 1115, 1915 (a)(b) or (b)(c), 1915(c)

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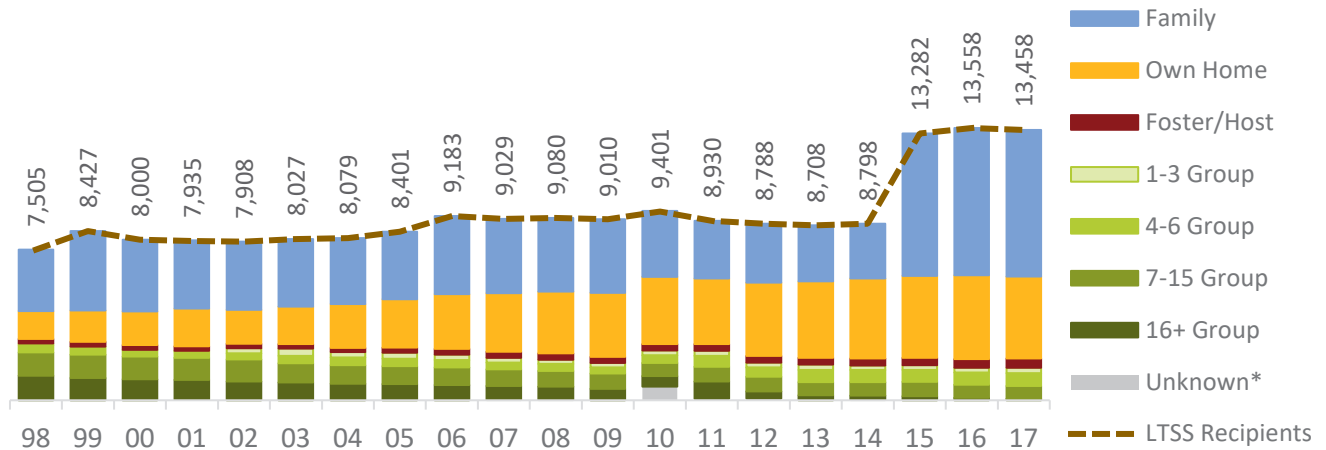
# Tennessee

Fiscal Year 2017

Residential Information Systems Project

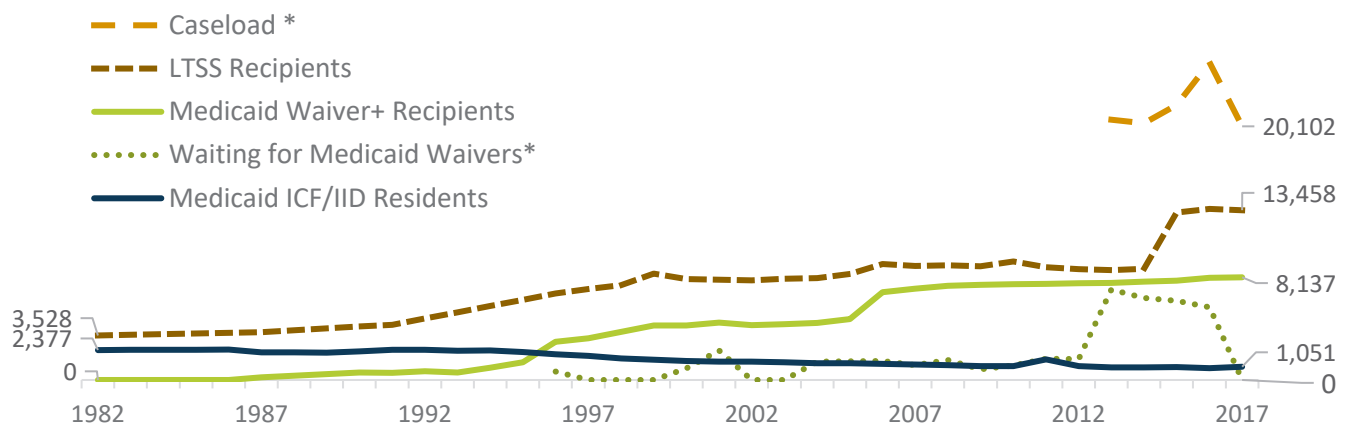


## IDD Agency Long Term Supports and Services Recipients by Residence Type



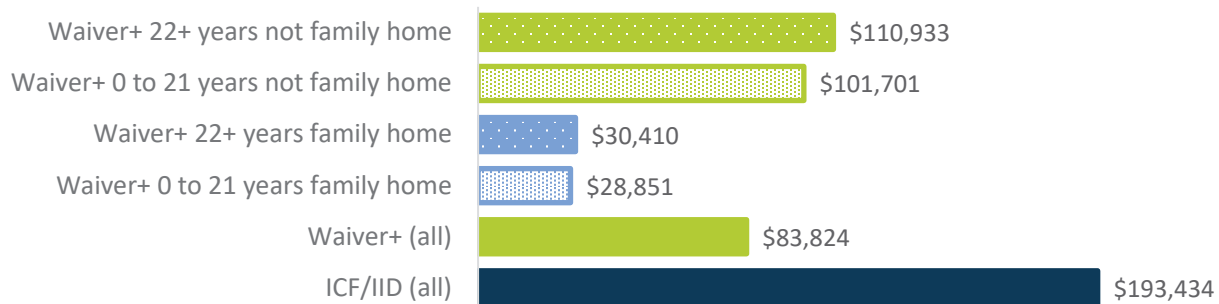
\* Unknown setting type or size reported in FY 2017 and gaps in all other years

## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2017



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

## Average Spending Per Person by Medicaid Authority in Fiscal Year 2017



Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

ICF/IID: Intermediate Care Facilities for Individuals with Intellectual Disabilities

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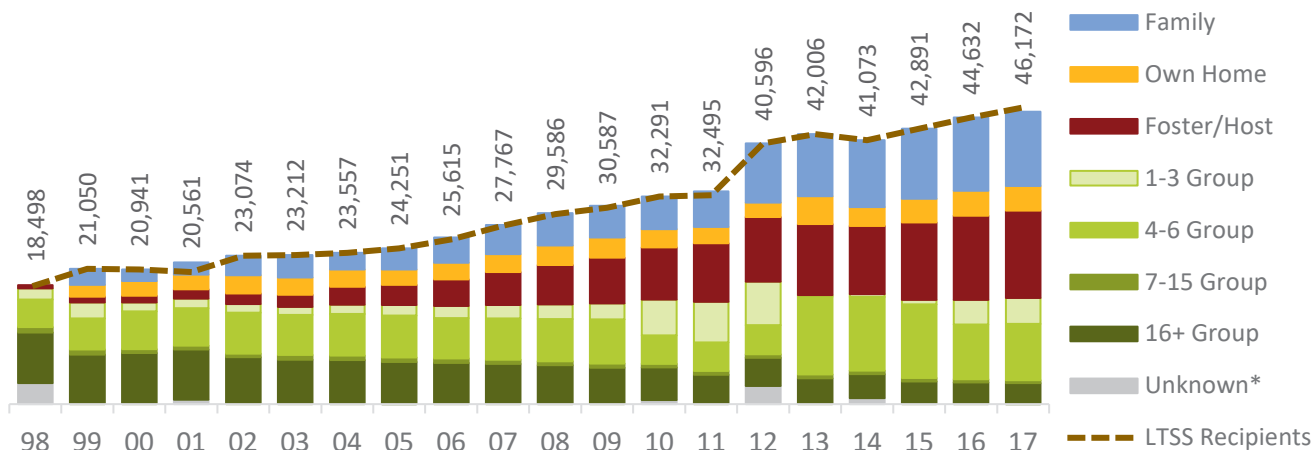
# Texas

Fiscal Year 2017

Residential Information Systems Project

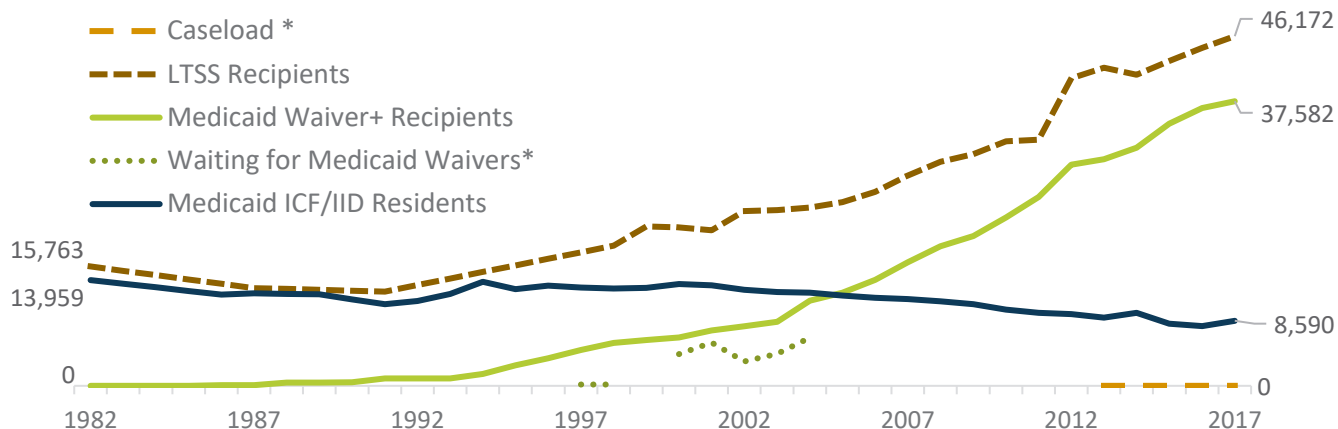


## IDD Agency Long Term Supports and Services Recipients by Residence Type



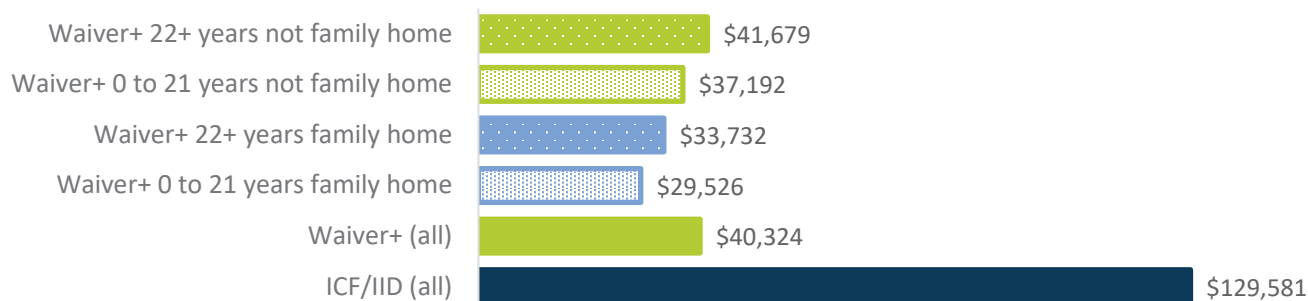
\* Unknown setting type or size reported in FY 2017 and gaps in all other years

## LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2017



\* Caseload of the State ID/DD Agency not available, Waiting while living in the home of a family member

## Average Spending Per Person by Medicaid Authority in Fiscal Year 2017



Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

ICF/IID: Intermediate Care Facilities for Individuals with Intellectual Disabilities

Group: Number of people with IDD in a setting (ICF/IID, group home or other)

Waiver+: Medicaid Authorities 1115, 1915 (a)(b) or (b)(c), 1915(c)

For more see [risp.umn.edu](http://risp.umn.edu)



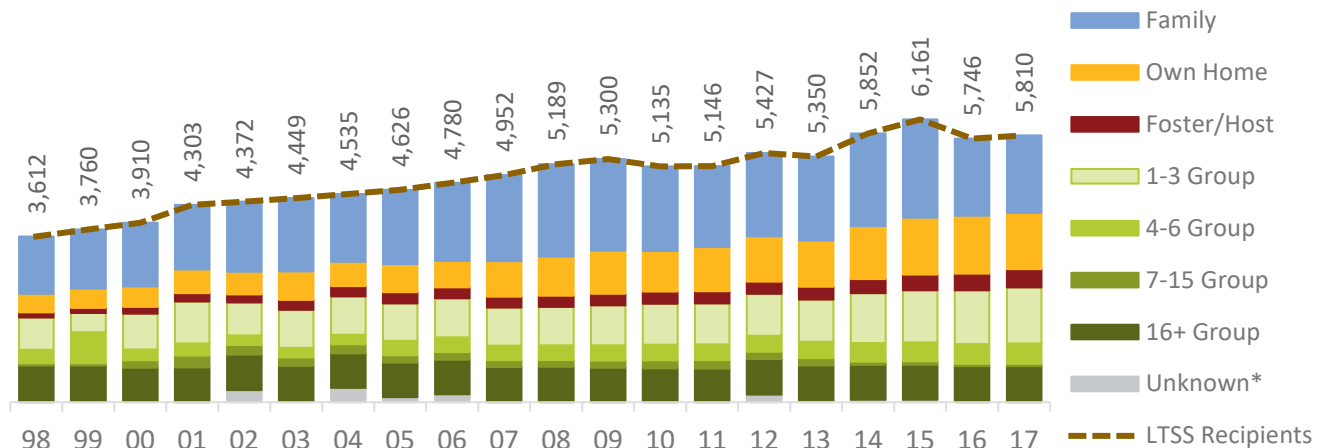
# Utah

Fiscal Year 2017

Residential Information Systems Project

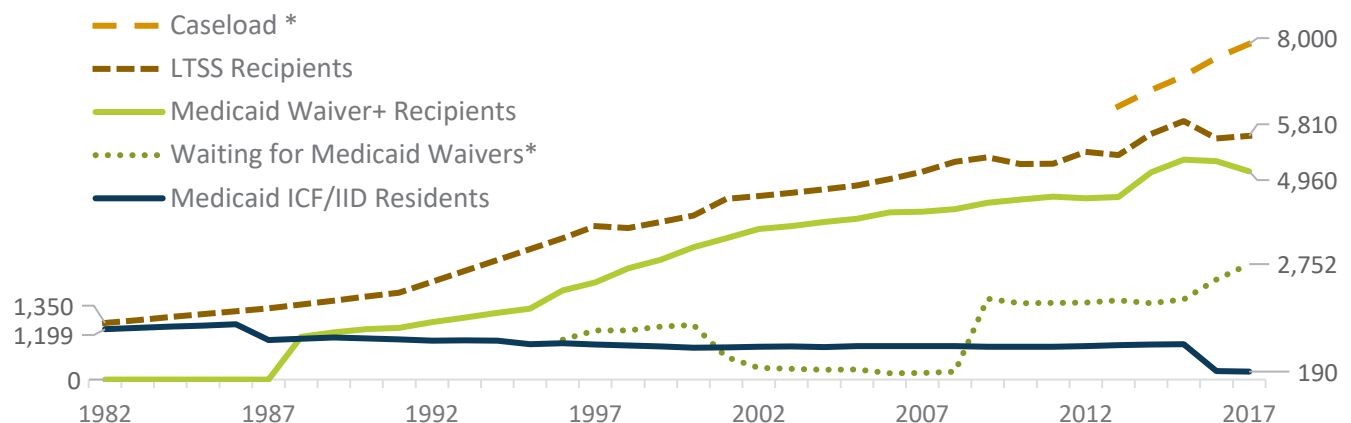


## IDD Agency Long Term Supports and Services Recipients by Residence Type



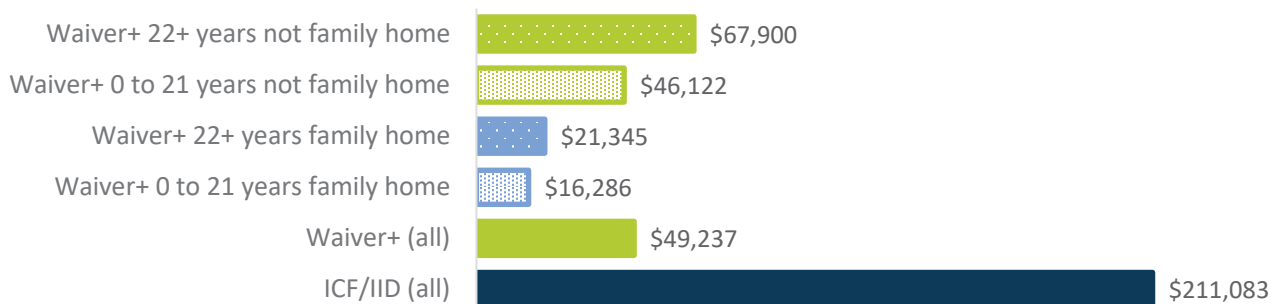
\* Unknown setting type or size (2017), otherwise indicated by gaps with LTSS recipients (1998-2016)

## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2017



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

## Average Spending Per Person by Medicaid Authority in Fiscal Year 2017



Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

ICF/IID: Intermediate Care Facilities for Individuals with Intellectual Disabilities

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Waiver+: Medicaid Authorities 1115, 1915 (a)(b) or (b)(c), 1915(c)

For more see [risp.umn.edu](http://risp.umn.edu)

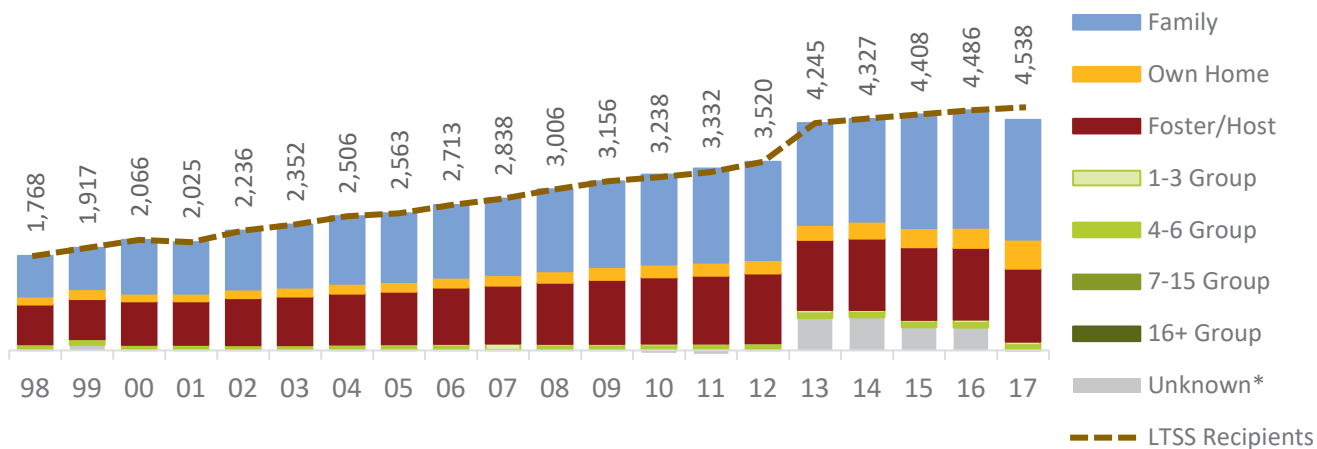
# Vermont

Fiscal Year 2017

Residential Information Systems Project

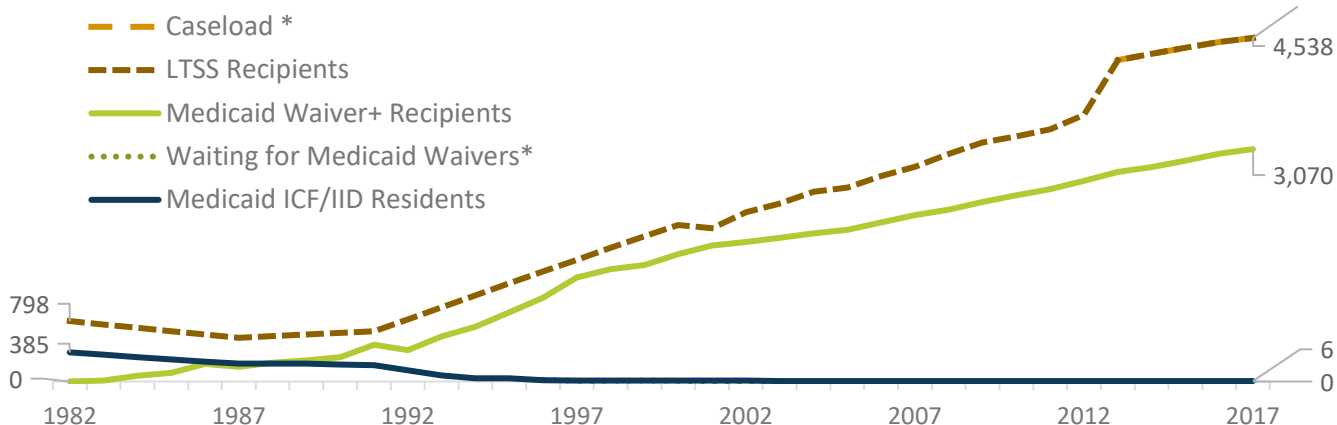


## IDD Agency Long Term Supports and Services Recipients by Residence Type



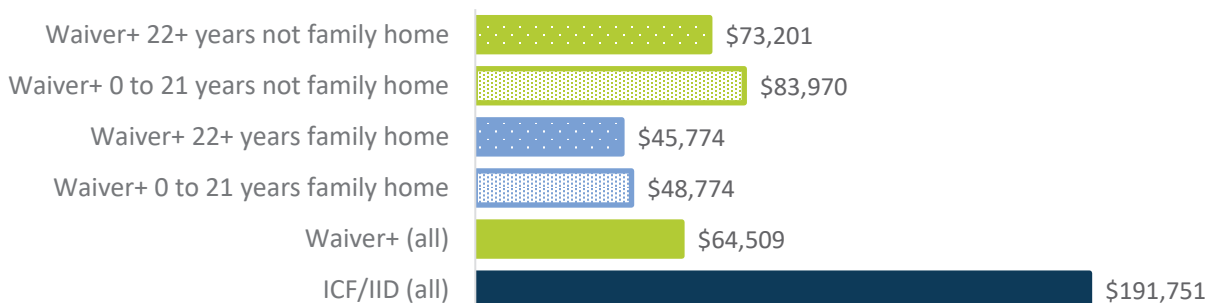
\* Unknown setting type or size reported in FY 2017 and gaps in all other years

## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2017



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

## Average Spending Per Person by Medicaid Authority in Fiscal Year 2017



Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

ICF/IID: Intermediate Care Facilities for Individuals with Intellectual Disabilities

Group: Number of people with IDD in a setting (ICF/IID, group home or other)

Waiver+: Medicaid Authorities 1115, 1915 (a)(b) or (b)(c), 1915(c)

For more see [risp.umn.edu](http://risp.umn.edu)

# Virginia

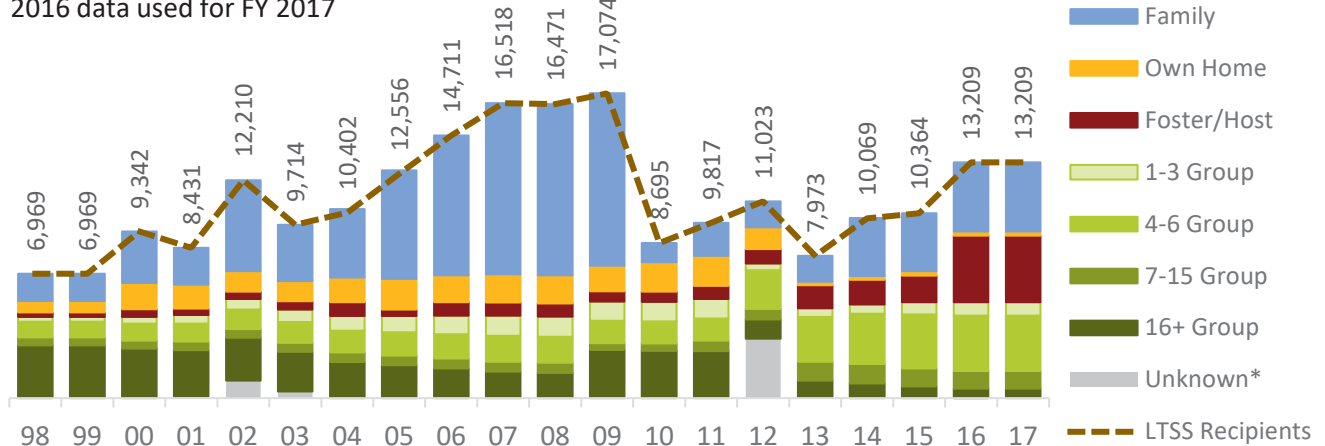
Fiscal Year 2017

Residential Information Systems Project



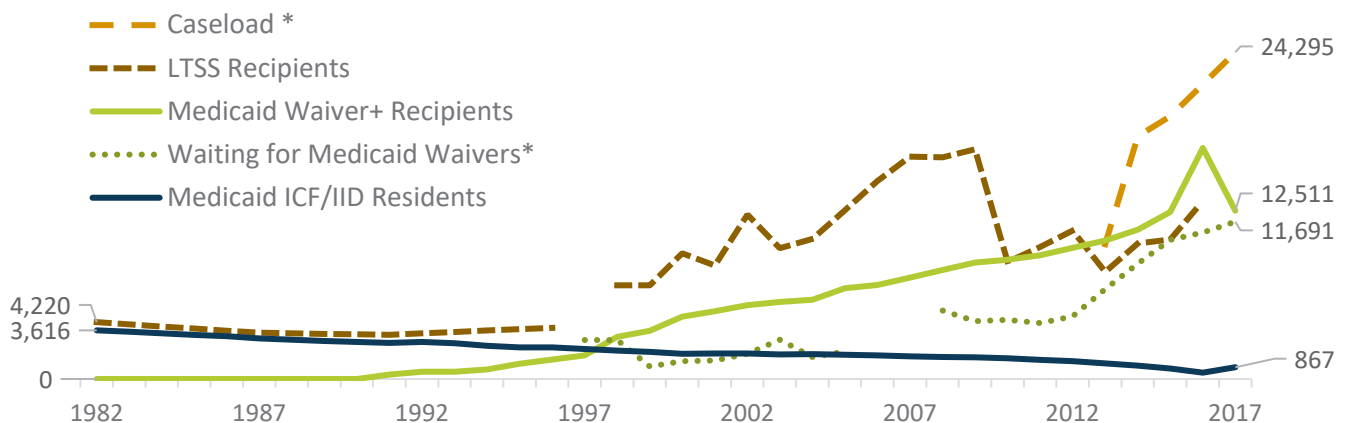
## IDD Agency Long Term Supports and Services Recipients by Residence Type

2016 data used for FY 2017



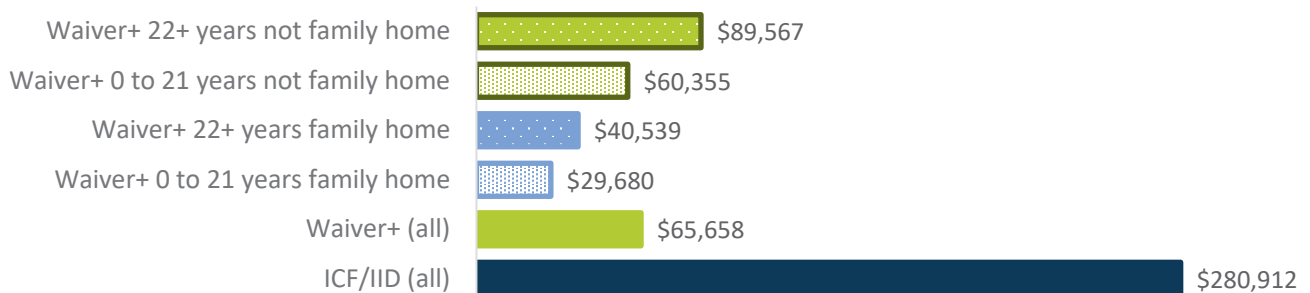
\* Unknown setting type or size reported in FY 2017 and gaps in all other years

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\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

## Average Spending Per Person by Medicaid Authority in Fiscal Year 2017



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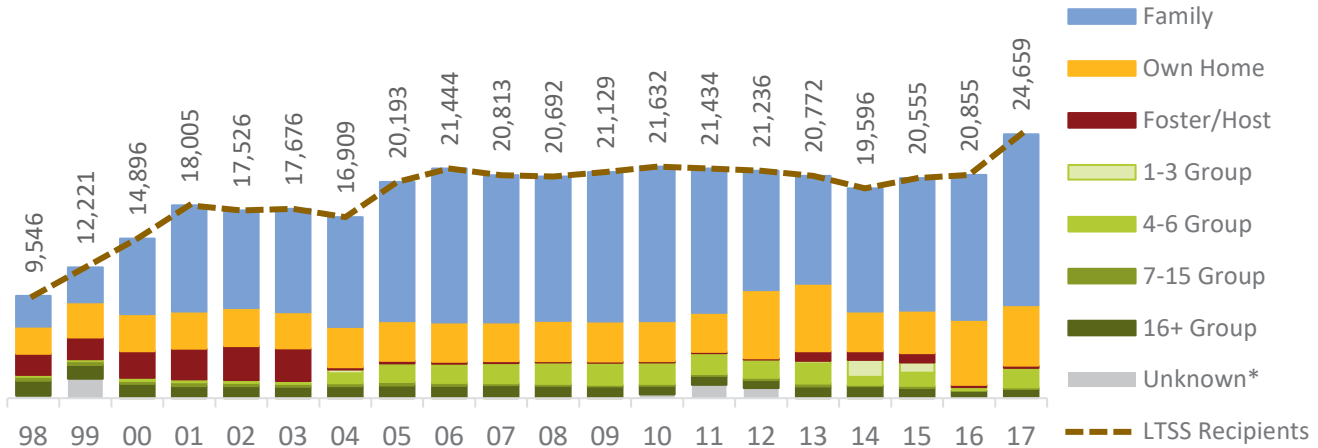
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Fiscal Year 2017

Residential Information Systems Project

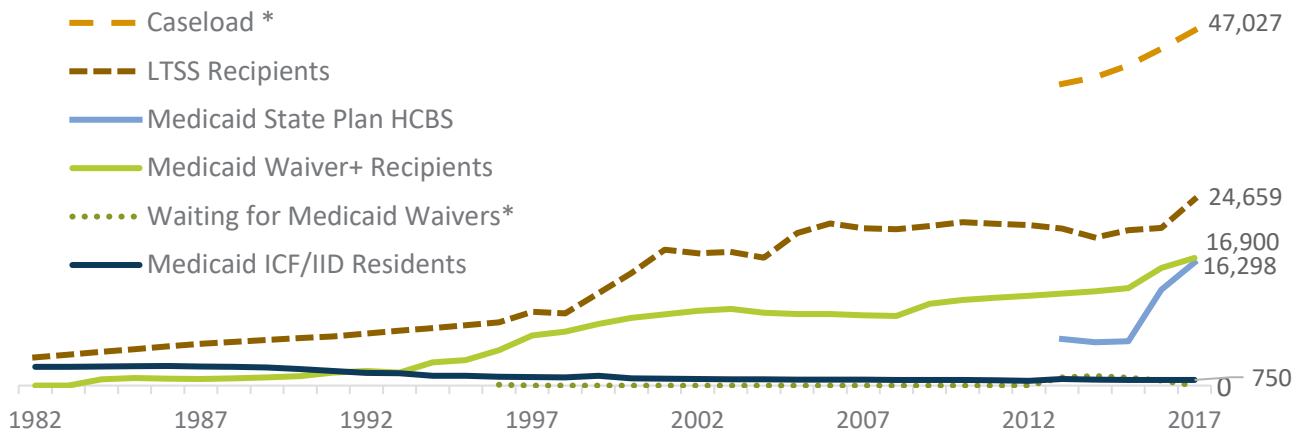


## IDD Agency Long Term Supports and Services Recipients by Residence Type



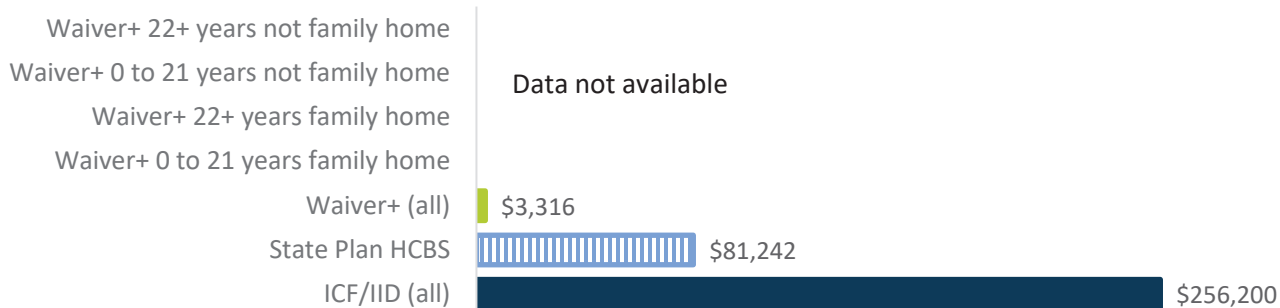
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## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2017



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

## Average Spending Per Person by Medicaid Authority in Fiscal Year 2017



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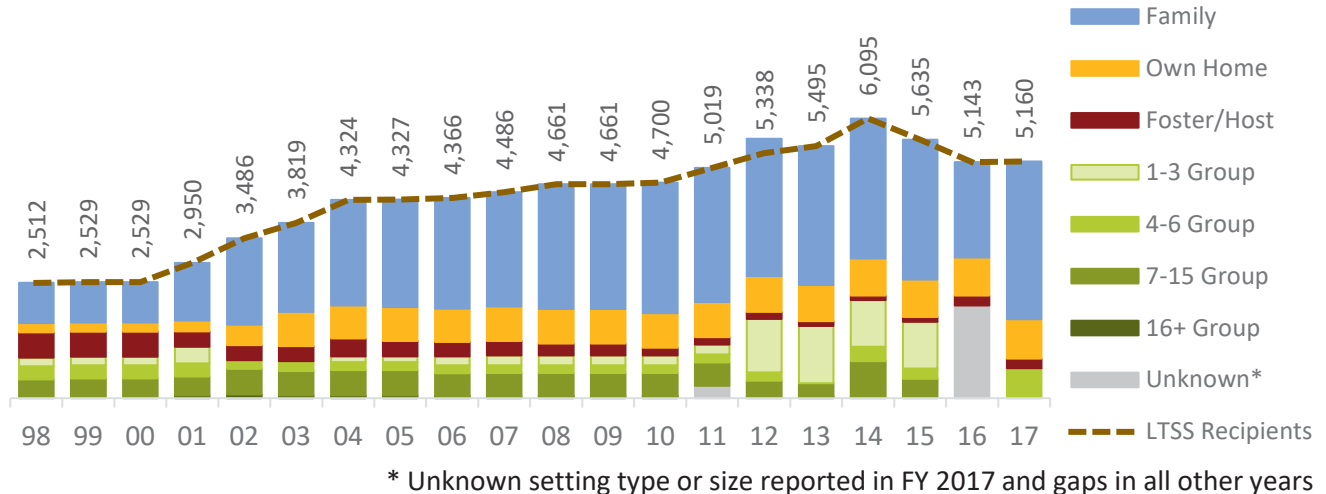
# West Virginia

Fiscal Year 2017

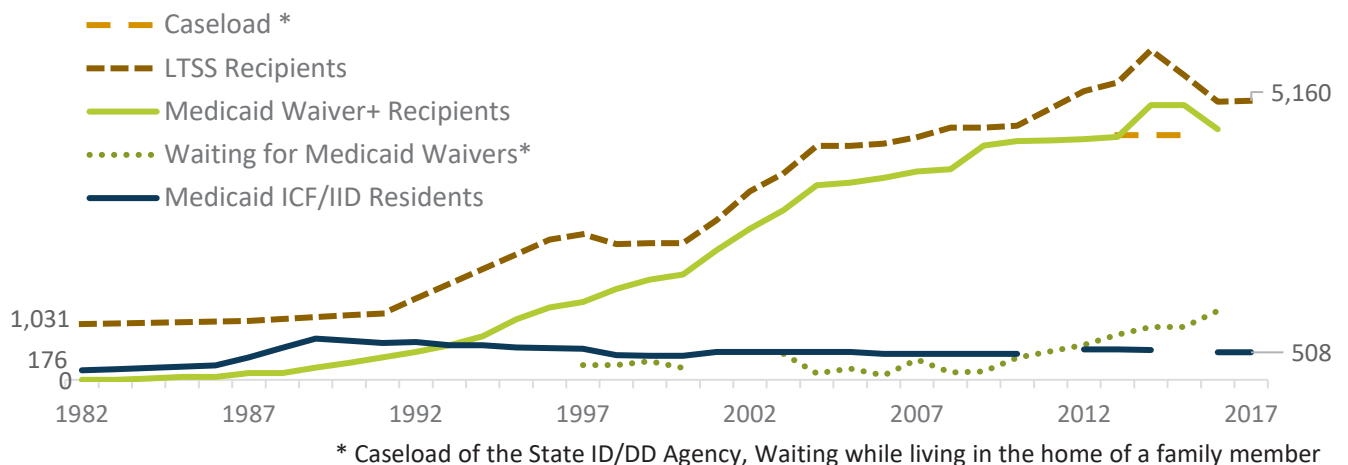
Residential Information Systems Project



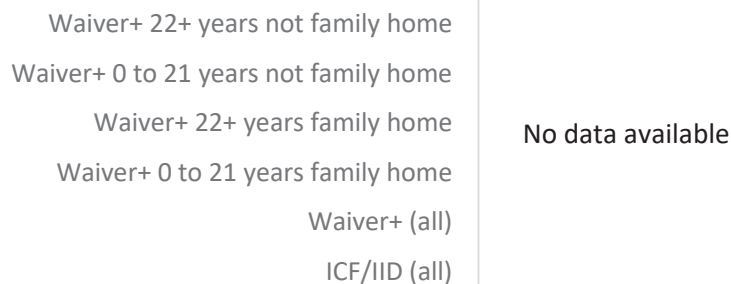
## IDD Agency Long Term Supports and Services Recipients by Residence Type



## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2017



## Average Spending Per Person by Medicaid Authority in Fiscal Year 2017



Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

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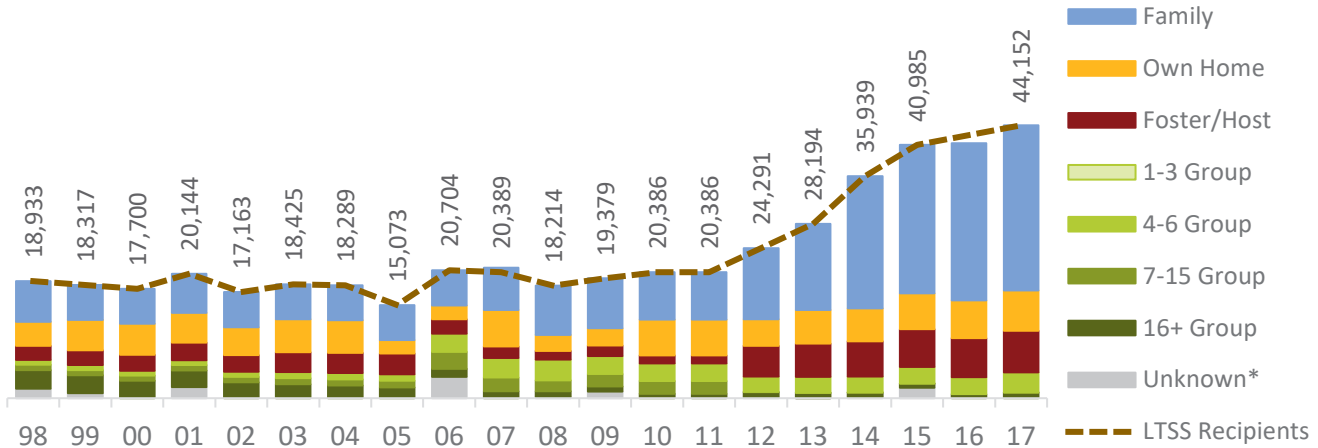
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Fiscal Year 2017

Residential Information Systems Project

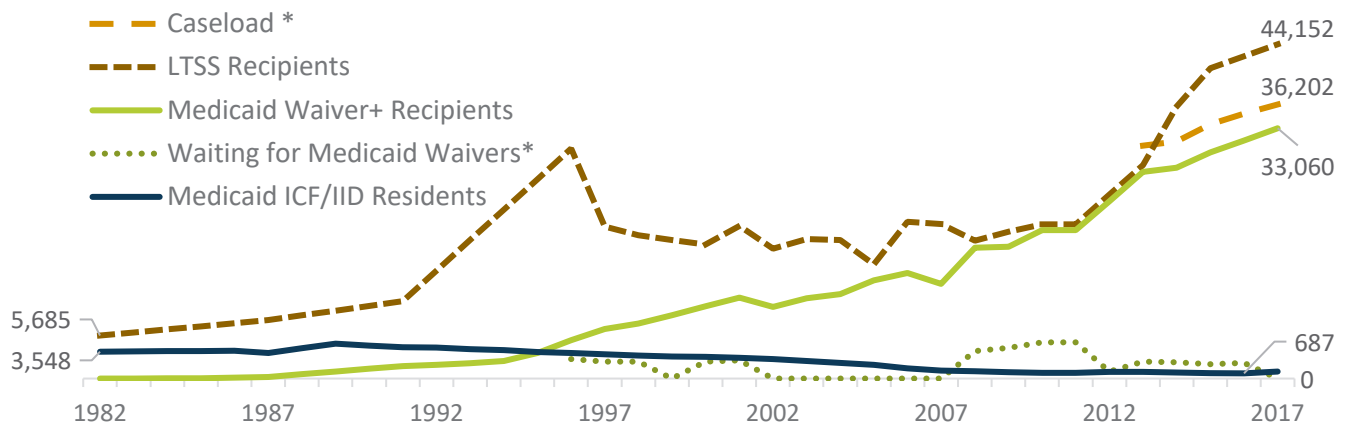


## IDD Agency Long Term Supports and Services Recipients by Residence Type



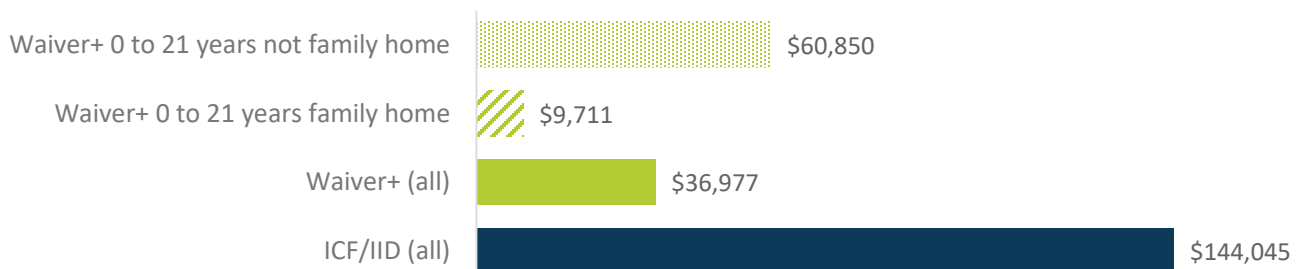
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## Caseload, LTSS and Medicaid Recipients and Waiting for Waivers\* 1982-2017



\* Caseload of the State ID/DD Agency, Waiting while living in the home of a family member

## Average Spending Per Person by Medicaid Authority in Fiscal Year 2017



Waiver by age in family home or not family home spending per person not available.

Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

ICF/IID: Intermediate Care Facilities for Individuals with Intellectual Disabilities

Group: Number of people with IDD in a setting (ICF/IID, group home or other)

Waiver+: Medicaid Authorities 1115, 1915 (a)(b) or (b)(c), 1915(c)

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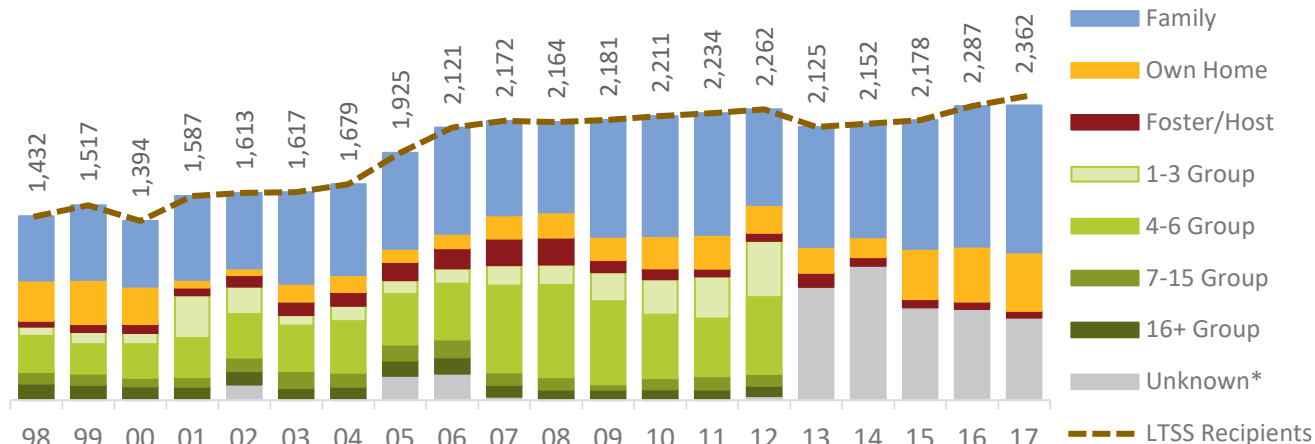
# Wyoming

Fiscal Year 2017

Residential Information Systems Project

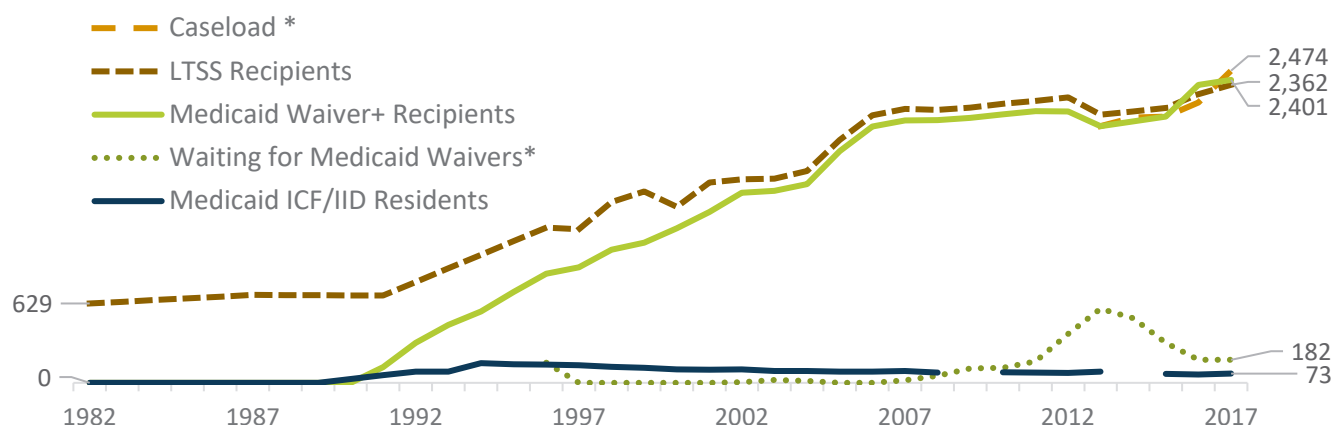


## IDD Agency Long Term Supports and Services Recipients by Residence Type



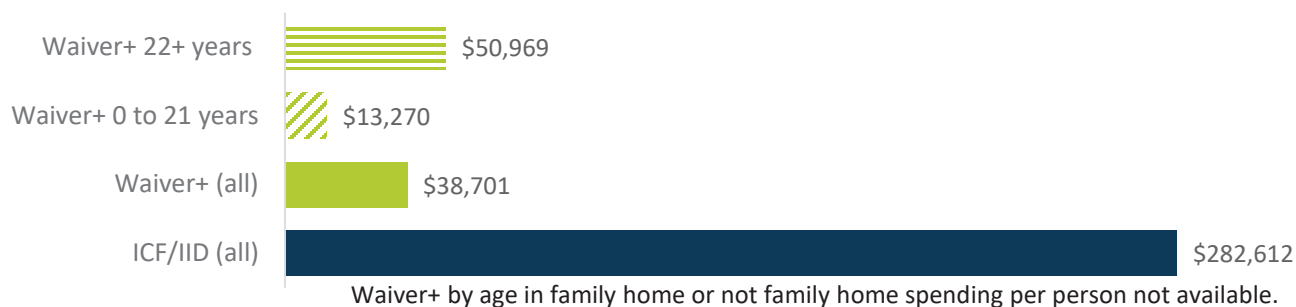
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## SECTION SIX

# APPENDICES

## FY 2017

## SECTION 6: REFERENCES, RESOURCES AND DATA SOURCES

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## HISTORICAL DATA: OTHER SOURCES

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

- Data on state IDD and psychiatric facilities for 1950 to 1968 from the National Institute of Mental Health's surveys of "Patients in Institutions;"
- Data on state IDD facilities for FYs 1969 and 1970 from surveys conducted by the Office on Mental Retardation Coordination, now AIDD;
- Data on large state IDD facilities for 1971 through 1977 from surveys of the National Association of Superintendents of Public Residential Facilities for People with Mental Retardation, now the APDDA; and
- Data on psychiatric facilities for 1969 to 1977 come from the National Institute of Mental Health's surveys of "Patients in State and County Mental Hospitals."

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## FY 2017 (July 1, 2016 – June 30, 2017) Residential Information Systems Projects (RISP) Survey

### Background

**About:** This is a survey of the University of Minnesota's Residential Information Systems Project ([RISP](#)). It is part of a 40-year longitudinal study tracking Medicaid and state-funded long-term supports and services ([LTSS](#)) provided under the auspices of State Intellectual and Developmental Disability ([IDD](#)) Agencies. The survey is fielded annually in conjunction with the National Association of State Directors of Developmental Disabilities Services ([NASDDDS](#)) and Human Services Research Institute ([HSRI](#)). It is used to create state and national profiles of LTSS recipients, settings, and expenditures.

**Timeline:** FY 2017 surveys are due March 30, 2018. Late responses may not be included in our FY 2017 annual report. Questions reference June 30, 2017, or the period from July 1, 2016 through June 30, 2017.

**Target Populations:** Parts 1 and 2 of the survey ask about people, served by [State IDD Agencies](#), who receive one or more Medicaid or state-funded long-term support or service ([LTSS](#)) in addition to case management or service coordination ([LTSS Recipients](#) with [IDD](#)). This group includes people receiving in-home or residential supports, as well as people receiving other types of LTSS such as day habilitation or vocational services even if the person does not receive services in their home or in a residential facility. It also includes people served by the [State IDD Agency](#) who live in Nursing Homes or [Psychiatric Facilities](#).

Parts 3 through 5 include a broader target population.

- People on the [State IDD Agency Caseload](#) (Parts 3 and 4). This group includes [LTSS Recipients](#) with [IDD](#) plus people with [IDD](#) receiving only case management or services coordination services, people waiting for services, and people known to the [State IDD Agency](#) but not currently receiving LTSS. It does not include people whose eligibility for services has not been determined.
- All people with [IDD](#) (Part 5), whether on the [State IDD Agency Caseload](#) or not, who live in [Nursing Homes](#), [Psychiatric Facilities](#), or other [Congregate Settings](#) housing four or more LTSS recipients (for people birth through age 21 years), or housing 16 or more LTSS recipients (for people ages 22 years and older).

### Survey Changes for FY 2017

1. We added one new question, and added additional response options for a few others.
  - a) **New:** Part 5 includes a new question about the total number of people with [IDD](#) ages 22 and over who live in [Congregate Settings](#) of 16 or more people, regardless of whether or not they are on the caseload of the [State IDD Agency](#).
  - b) **Added:** Parts 1 and 2 includes spaces to record the number of [LTSS recipients](#) with [IDD](#) whose [residence type is unknown](#), or who are in settings of an [unknown size](#).
  - c) **Added:** Part 2C includes spaces to record residence type for [LTSS recipients](#) with [IDD](#) whose supports are funded by [Medicaid State Plan HCBS](#) (1915i or 1915k).
2. Definition clarifications / changes:
  - a) Part 1 (state-operated LTSS) clarifies that the "Other" Funding Authority is anything other than Medicaid Waiver or ICF/IID.
  - b) Part 3 (expenditures and people by expenditure) clarifies Medicaid State Plan to mean 1915(i) and 1915(k), but not Targeted Case Management.

## FY 2017 (July 1, 2016 – June 30, 2017) Residential Information Systems Projects (RISP) Survey

### Instructions

This survey should be completed by the state director of IDD services, or his or her designee. Please consult your state's Medicaid office, or other relevant state agencies, as needed to provide accurate responses.

Complete responses are important to ensure that your state's system is accurately portrayed. We estimate values not provided when we compute estimated United States totals. We prefer to use estimates provided by states whenever possible. If you do not furnish complete information, the charts and graphs for your state may be incomplete or inaccurate.

The RISP survey is designed for online use. The online survey offers many tools, such as access to responses to previous year surveys, notes about data sources and explanations about specific values, interactive and context based instructions, and automated validation checks to confirm the accuracy of the reported data.

### General Instructions

- Do not leave questions blank.
- Enter "0" when there are no people/settings/expenditures in a particular category or Funding Authority.
- Provide totals, even if you are unable to provide breakdowns by type of operation, age, setting type, or setting size.
- Use a "DNF" (Data Not Furnished) to indicate that you are unable to furnish a value, and you do not have a reasonable estimate that you could use.
- Use an "e" to designate estimated numbers.
- If the data are from a date other than June 30, 2017, please specify the date.
- Leave notes to explain anything the reader of the technical report needs to know to interpret the data correctly.
- Shaded boxes show values that are automatically computed in the online version of the survey.
- Definitions for words can be found in the end of the Word version of the survey, or by a dotted underline in the online version.

### Online Survey Instructions

The web-based survey has been reorganized to mirror the Word version more closely to make data entry easier.

#### Expand

In the **Expand** menu, you can designate a value as an estimate (**e**), add notes, change the data date, or specify that you are unable to furnish a value (**DNF**). You can also see previous year data, validation warnings about possible data errors, and calculations used in the report.

- Use **Notes**
  - If a value has changed substantially from the previous year, or from the trend in recent years
  - If you used a definition different from the operational definition provided
  - If you used a different methodology, or categorized people differently, than in the past
  - To help readers correctly interpret your response
  - To explain why you were only able to answer part of a question
  - To help the person completing the survey in subsequent years know how you arrived at the value
- As notes are entered, they are added to a notes menu. Once a note is added, it can be selected from the list to apply it to other survey items.
- Previous year data can be found in the **Expand** menu. If you notice inaccuracies in data from previous years, please let your RISP staff team member know (You can find the name of the staff assigned to your state at the end of the survey). We will update the database, and use the revised data for subsequent reports and products.

## FY 2017 (July 1, 2016 – June 30, 2017) Residential Information Systems Projects (RISP) Survey

- **Validation Warnings** about possible errors have been added. Details about each warning can be viewed by clicking the expand button in the section titled “Validation checks that need your attention.”

**Notes** can be designated as private or public.

- **Private detail** – not for publication, but helpful for RISP staff or state staff who enter data, or
- **Public detail** – for publication in the state notes section of RISP reports and other products so that readers can correctly interpret your data

### Tips for using the Online Survey

- **Login.** The system automatically tracks all entries by login ID. Each person should have his or her own user name and password. Please do not use another person's ID to log in. Contact a RISP team member to get a new person added for your state.
- **Definition of Terms.** Definitions for selected terms can be viewed by moving your cursor over the term with a dotted underline. Additional instructions about specific survey items can be found in the “**Operational Definitions**” document.
- **Save.** The save button is on the top of each screen. You will receive a message if there are changes before you move to another screen to remind you to save the data. Data saves can be done frequently.
- **Expand button.** Codes, explanatory notes, historic data, and warnings about potentially incorrect data are all found under the “Expand” button. You can also specify the following for each response: “e” for estimates; “DNF” for did not or unable to furnish.
- **Alternate Date.** By default, we assume that the data you provide is correct as of June 30, 2017. If you are reporting data from a different date (such as data from a previous year), please note that date in the Expand section.
- **Computed values** have a shaded background. Some computed totals could only be changed by returning to the screen where the component value(s) were first entered. Entering a zero in the total of a row or column will often make the remaining cells zero.

Your assigned RISP project staff member is available by phone or email, and will contact you during the editing process if we find missing or possibly incorrect information, or notice a change from previous years that has not been explained in your comments. Thank you for your ongoing support of this Administration on Intellectual and Developmental Disabilities (US Health and Human Services) Data Project of National Significance.

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## FY 2017 (July 1, 2016 – June 30, 2017) Residential Information Systems Projects (RISP) Survey

### Funding Authorities

This section asks about federal and state **Funding Authorities** used to finance **long-term supports and services** for people with IDD as of June 30, 2017.

- Please respond “yes” to indicate any **Funding Authorities** for which you had expenditures in FY 2017 for people with IDD.
- Saying “no” will trigger the survey software to fill in 0’s for subsequent questions about the **Funding Authority**. You will not be able to enter recipients, settings, or expenditures for a **Funding Authority** if you say “no.”
- If you selected “no” by mistake, return to this section and change your “no” to a “yes” to enable data entry in other parts of the survey.
- If you are unsure, please verify your responses with your **State IDD Agency Director** or Medicaid office.

Which of these <b>Funding Authorities</b> were used to finance <b>long-term supports and services</b> for people with IDD on the <b>State IDD Agency Caseload</b> as of June 30, 2017?		Yes/No
<b>Medicaid Waiver</b>	1115 Demonstration Waiver	
	1915 (a) (b) or (b/c) Managed Care Waiver with LTSS	
	1915 (c) Home and Community Based Services Waiver	
<b>Medicaid State Plan HCBS</b>	1915(i) State plan Home and Community Based Services	
	1915(k) Community First Choice	
<b>Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID)</b>		
<b>State Non-Medicaid</b>	State funding for LTSS for people with IDD not matched with Federal Medicaid funds	

### Part 1: State-Operated IDD Recipients and Settings on June 30, 2017

**State-Operated IDD Settings** are residential settings staffed by state employees that serve people with IDD.

- Include state-operated IDD facilities and IDD units of facilities serving multiple populations such as Nursing Homes or Psychiatric Facilities.
- Multiple units, cottages, or homes located on a single campus should be counted as a single setting. Units, cottages, or homes located on different campuses should be counted separately.
- **Setting size** is based on number service recipients living in the facility/on the campus as of June 30. Do not count “empty beds” in determining setting size (for example, a campus licensed to serve up to 20 people that has 12 people in residence on June 30 should be listed in the 7-15 people category).

#### 1A. How many **State-Operated IDD Settings** served people on the **IDD Agency Caseload** on June 30, 2017 (by Facility Size and **Funding Authority**)?

State-Operated IDD Settings	Facility Size (Number of Service Recipients)						
<b>Funding Authority</b>	1-3	4-6	1-6 Total	7-15	16+	Size Unknown	All Sizes
<b>Medicaid Waiver</b> 1115; 1915 (a) (b) (b/c); and 1915 (c)							
<b>Medicaid ICF/IID</b>							
<b>Other</b>							
Total							

# FY 2017 (July 1, 2016 – June 30, 2017) Residential Information Systems Projects (RISP) Survey

## 1B. How many people with IDD lived in **State-Operated** IDD Settings on June 30, 2017 (by Setting Size and Funding Authority)?

People in <b>State-Operated</b> IDD Settings	Facility Size (Number of Service Recipients)						Total People
Funding Authority	1-3	4-6	1-6 Total	7-15	16+	Size Unknown	Total People
Medicaid Waiver 1115; 1915 (a) (b) (b/c); and 1915 (c)							
Medicaid ICF/IID							
Other							
Total							

## 1C. Describe people with IDD and daily costs in **State-Operated** IDD Settings serving 16 or more people for the Year ending June 30, 2017 by Funding Authority

State Operated IDD Settings serving 16 or more people with IDD are also known as <b>Public Residential Facilities (PRF)</b>	Medicaid Waiver	Medicaid ICF/IID	Other Funding Authority	Total
<b>ADMISSIONS/READMISSIONS</b> between July 1, 2016 and June 30, 2017 (Do not include short-term respite or crisis admissions of 90 days or less or transfers between <b>PRFs</b> )				
<b>SHORT-TERM respite or crisis ADMISSIONS to PRFs</b> (for stays of 90 days or less)				
<b>DISCHARGES</b> number of people who moved out of the facility between July 1, 2016 and June 30, 2017 (excluding short-term respite or crisis stays and transfers between <b>PRFs</b> )				
<b>DEATHS</b> People who died between July 1, 2016 and June 30, 2017 while living in a PRF.				
<b>AVERAGE DAILY RESIDENTS</b> between July 1, 2016 and June 30, 2017.				
<b>PER DIEM</b> (average daily per person cost of care). Enter N/A if there were no <b>PRFs</b> in a Funding Authority category on June 30, 2017.				

**Part 1** Data date if not June 30, 2017:

Respondent Name: \_\_\_\_\_ Phone: \_\_\_\_\_ Email: \_\_\_\_\_

## FY 2017 (July 1, 2016 – June 30, 2017) Residential Information Systems Projects (RISP) Survey

### Part 2. Nonstate-Operated LTSS Recipients and Settings on June 30, 2017

#### Section Instructions

**Nonstate-Operated settings** LTSS settings staffed by employees of an entity other than the state.

**Setting Size** Number of service recipients living in the setting as of June 30, 2017. Do not count empty beds (for example, a campus licensed to serve 20 people with 12 people in residence on June 30 should be listed in the 7-15 people category).

#### Nonstate-Operated Living Arrangement Types

Type I: **ICF/IID**. Medicaid Intermediate Care Facilities for Individuals with Intellectual Disabilities.

Type II: **IDD Group Home**. A residence owned, rented, or managed by the residential services provider, or the provider's agent, to provide housing for persons with IDD in which staff provide care, instruction, supervision, and other support for residents with IDD. Include corporate foster care settings and provider-owned or controlled housing.

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

Type IV: **Own Home**. A home owned or leased by one or more persons with IDD as the person(s)' own home, in which they receive personal assistance, instruction, supervision, and other supports. Do not include provider-owned or controlled housing. Include people sharing a home with a spouse/partner or other unrelated individuals. Do not include people living with a related family member.

Type V: **Family Home**. A residence of a person(s) with IDD who receives one or more long-term support or service such as respite care, personal assistance, day habilitation, or in-home supports in addition to case management services while living with a related family member.

Type VI: **Other Setting Type**. Other residential settings in which LTSS recipients with IDD on the caseload of the state IDD agency live. Other settings may include settings such as nonstate-operated hospitals, Nursing Homes, Psychiatric Facilities, assisted living facilities, board and care facilities, farmsteads, intentional, or gated communities. Do not include Type I ICF/IID settings or Type II IDD Group Homes in this category.

Type VII: **Unknown Setting Type**. The type of setting in which a LTSS recipient with IDD lives is not known (for questions 2B and 2C).

#### 2A. In how many different **Nonstate-Operated** settings did **LTSS Recipients** with IDD live on June 30, 2017 (By Setting Size and Setting Type)?

Number of Nonstate-Operated Settings	Setting Size (Number of Service Recipients)						
Residence Type	1-3	4-6	1-6 Total	7-15	16+	Size Unknown	Total Settings
I. <b>ICF/IID</b>							
II. <b>IDD Group Home</b>							
III. <b>Host/ Foster Family Home</b>							
IV. <b>Own Home</b>							
V. <b>Family Home</b>	Not requested						
VI. <b>Other Settings</b> (specify)							
Total							
Other Setting type(s):							



## FY 2017 (July 1, 2016 – June 30, 2017) Residential Information Systems Projects (RISP) Survey

**2B. How many LTSS recipients with IDD were served by nonstate entities on June 30, 2017 (By Setting Size and Residence Type)?**

LTSS Recipients in Nonstate Settings	Setting Size (Number of Service Recipients)						
Residence Type	1-3	4-6	1-6 Total	7-15	16+	Size Unknown	Total People
I. ICF/IID							
II. IDD Group Home							
III. Host/ Foster Family Home							
IV. Own Home							
V. Family Home	Not requested						
VI. Other Setting Types (specify)							
VII. Unknown Setting Type	Not requested						
Total							
Other setting type(s):							

**2C. Of the LTSS Recipients with IDD living in each setting type, how many received services funded by a Medicaid Waiver (1115, 1915 (a), (b) or (b/c), 1915 (c)) or State Plan Home and Community Based Services (1915 (i) or 1915 (k)) Funding Authority? For each setting type, note the unduplicated total number of people with IDD who receive Medicaid Waiver and/or Medicaid State Plan funded LTSS.**

Number of people in Nonstate Settings who receive Medicaid Waiver and/or Medicaid State Plan funded LTSS	Medicaid Waiver 1115; 1915 (a) (b) (b/c); 1915 (c)	In development: Not required	
		Medicaid State Plan 1915(i) or 1915(k)	Unduplicated Total
I. ICF/IID		Not applicable	
II. IDD Group Home			
III. Host/ Foster Family Home			
IV. Own Home			
V. Family Home			
VI. Other Setting Types (specify)			
VII. Unknown Setting Type			
Total in Nonstate settings			

**Part 2** Data date if not June 30, 2017:

Respondent Name: \_\_\_\_\_ Phone: \_\_\_\_\_ Email: \_\_\_\_\_

## FY 2017 (July 1, 2016 – June 30, 2017) Residential Information Systems Projects (RISP) Survey

This is what you reported in Parts 1 and 2 (for those using the online survey)

LTSS Recipients Living in <b>State-Operated</b> Settings (Part 1B)	Total Part 1
LTSS Recipients in <b>Nonstate</b> Settings (Part 2B)	Total Part 2
<b>Total LTSS Recipients</b>	LTSS recipients

### Part 3: IDD Agency Caseload, LTSS Recipients, and Expenditures

This section asks about Medicaid and State **LTSS** expenditures for people on the **State IDD Agency Caseload**, by **Funding Authority**, age, and living arrangement (family home or other).

#### State IDD Agency Caseload

- **Include**
  - People with IDD known to the **State IDD Agency** who receive one or more **long-term support or service** in addition to case management
  - People receiving only case management or service coordination services
  - People waiting for services, and
  - People known to the **State IDD Agency** but not receiving **LTSS**
- **Do not include** people whose eligibility for services has not been determined.

#### 3. How many people with IDD were on the **State IDD Agency Caseload** on June 30, 2017 (By Age)?

Provide an unduplicated total.

<b>State IDD Agency Caseload</b>	21 years or younger	22 years or older	Total All Ages
Number of People			

#### LTSS Recipients with IDD and Expenditures by Recipient Age and Living Arrangement

Report recipients and expenditures for FY 2017 (July 1, 2016 through June 30, 2017) for each **Funding Authority**. Medicaid expenditures include the Federal and the State/Local share. Annual per person expenditures are automatically computed in the on-line version of the survey.

#### 3A: Medicaid Waiver Recipients and Expenditures by Age for FY 2017

<b>Medicaid Waiver</b> 1115, 1915 (a)(b)or (b/c), 1915 (c)	21 years and younger	22 years and older	Total All Ages	Recipients Parts 1 & 2
Recipients				
Expenditures				
Expenditures per person				

#### 3B. Medicaid Waiver Recipients and Expenditures by Living Arrangement and Age for FY 2017

<b>Medicaid Waiver</b> 1115, 1915 (a)(b)or (b/c), 1915 (c)		21 years and younger	22 years and older	Total All Ages
Home of a Family Member	Recipients			
	Expenditures			
	Expenditures per person			
Other (non-family) Setting	Recipients			
	Expenditures			
	Expenditures per person			
Total Recipients by Living Arrangement				
Total Recipients by Age in 3A				

## FY 2017 (July 1, 2016 – June 30, 2017) Residential Information Systems Projects (RISP) Survey

### 3C: Medicaid State Plan Home and Community Based Services Recipients and Expenditures by Age

Medicaid State Plan HCBS 1915(i) or 1915(k)	21 years and younger	22 years and older	Total All Ages	Recipients (Part 2)
Recipients				
Expenditures				
Expenditures per person				

### 3D: Medicaid Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) Recipients and Expenditures by Age

Medicaid ICF/IID	21 years and younger	22 years and older	Total All Ages	Recipients (Parts 1 and 2)
Recipients				
Expenditures				
Expenditures per person				

### 3E: State-Funded Non-Medicaid LTSS Recipients and Expenditures by Age

State-Funded Non-Medicaid	21 years and younger	22 years and older	Total All Ages
Recipients			
Expenditures			
Expenditures per person			

### 3F: People with IDD on the State IDD Agency Caseload but not receiving funded LTSS on June 30, 2017

No Medicaid or State-Funded LTSS	21 years and younger	22 years and older	Total All Ages
People with IDD			

**Part 3** Data date if not June 30, 2017:

Respondent Name: \_\_\_\_\_ Phone: \_\_\_\_\_ Email: \_\_\_\_\_

## FY 2017 (July 1, 2016 – June 30, 2017) Residential Information Systems Projects (RISP) Survey

Part 4: **Medicaid Waiver** Waiting List

4. How many people with IDD living with a **Family Member**, or in **Own Home** settings, were waiting for **Medicaid Waiver**-funded services on June 30, 2017?

- **Include people waiting for *Medicaid Waiver*-funded LTSS who**
  - Lived with a family member, or in their own home, as of June 30, 2017 and who
  - Did not receive Medicaid-funded LTSS other than case management/service coordination
- **Do not include people**
  - Living in an **ICF/IDD**, or in another non-family setting (such as a Skilled Nursing Facility) or
  - Already receiving **Medicaid Waiver**-funded services in addition to case management/service coordination

People Waiting for <b>Medicaid Waiver</b> 1115, 1915 (a)(b) or (b/c), 1915 (c) funding	Number of People
How many people with IDD living in their own home or the home of family member were waiting for (but not receiving) <b>Medicaid Waiver</b> -funded LTSS on June 30, 2017?	
a. Of the people waiting, how many were receiving case management (including Targeted Case Management) services?	
b. Of the people waiting, how many were waiting to move to a setting other than the home of a family member?	

## Part 5 Psychiatric, Nursing Facilities and Other Congregate Settings

*This section includes all people with IDD living in your state whether they are served by the **State IDD Agency** or not.*

5A. How many people with IDD lived in state or nonstate operated Nursing Homes or **Psychiatric Facilities** on June 30, 2017? **Note:** Include people with IDD on the **State IDD Agency Caseload** who live in Nursing Homes or **Psychiatric Facilities**.

Number of People with IDD	State-Operated	Nonstate-Operated	Total People
In Nursing Homes			
In <b>Psychiatric Facilities</b>			

**About this Section:** The Centers for Disease Control (CDC) uses the data you report here to monitor national progress toward the Healthy People 2020 goals of reducing the number of children and adults with IDD living in congregate settings. It is very important that we receive data from all of the states on these questions.

**Congregate Settings** are

- State- or nonstate-operated non-family residential settings, such as **PRFs, ICF/IID, IDD Group Homes, Nursing Homes, Psychiatric Facilities, Other Group Settings** or similar facilities.
- In which rotating (or shift) staff members provide supports and services

For people ages 21 years or younger, report the number of LTSS recipients with IDD in **Congregate Settings** of four or more people.

For people ages 22 years or older, report the number of LTSS recipients with IDD in **Congregate Settings** of 16 or more people.

## FY 2017 (July 1, 2016 – June 30, 2017) Residential Information Systems Projects (RISP) Survey

**Congregate Settings** do not include **Own Home** settings.

People in **Congregate Settings** do not include people with IDD who:

- Live with birth or adoptive parents, or other family members (**Family Home**)
- Live in **Host/Foster Family Settings** in which no shift staff work
- Live only part of the year in a residential PreK-12 school
- Live in correctional or juvenile justice facilities
- Receive only respite services from a **Congregate Setting**
- Live in other states (do count people who live in your state whose services are paid by another state)

**5B: How many people with IDD 21 years or younger lived in **Congregate Settings** of four or more people on June 30, 2017?**

People with IDD ages 21 years or younger in <b>Congregate Settings</b> of four or more people	People
Nursing homes	
Other <b>Congregate Settings</b>	
Total	

**5C: How many people with IDD 22 years or older lived in Nursing homes or other **Congregate Settings** of 16 or more people on June 30, 2017?**

People with IDD ages 22 years or older in <b>Congregate Settings</b> of 16 or more people	People
In Nursing homes	
In Other <b>Congregate Settings</b>	
Total	

**Part 5:** Data date if not June 30, 2017:

Respondent Name: \_\_\_\_\_ Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Thank you for completing the RISP survey. After you submit your responses, the RISP project team will review your data and your responses to any **validation warnings**. You can view **validation warnings** online by clicking “Expand,” or by viewing the Validation Summary. We will contact you if we have any questions about your responses. Contact your assigned RISP staff member listed at the end of the survey or contact the RISP project team at ([RISP@umn.edu](mailto:RISP@umn.edu)) if you have questions.

### Abbreviations

<b>“d”</b>	The data are correct as of a date other than June 30, 2017
<b>“e”</b>	Estimate
<b>DNF</b>	Data not furnished
<b>HCBS</b>	Home and Community Based Services
<b>HSRI</b>	Human Services Research Institute
<b>ICF/IID</b>	Intermediate Care Facility for Individuals with Intellectual Disabilities
<b>IDD</b>	Intellectual or Developmental Disabilities
<b>LTSS</b>	Long-term supports and services
<b>NASDDDS</b>	National Association of State Directors of Developmental Disabilities Services
<b>PD</b>	Partial Data reported
<b>PRF</b>	Public residential facility (a state-operated IDD facility serving 16 or more individuals)
<b>RISP</b>	Residential Information Systems Project

## FY 2017 (July 1, 2016 – June 30, 2017) Residential Information Systems Projects (RISP) Survey

### Glossary

**Alternate Date** By default, we assume that the data you provide is correct as of June 30, 2017. If you are reporting data from a different date (such as data from a previous year), please note that date in the Expand section.

**Annotate Data** Designate a value as an estimate, from a different date, or to record that a value cannot be furnished.

**Average Daily Residents** Computed as either the average of people in a setting on June 30, 2016 and June 30, 2017, or the running average number of residents between those dates.

**Computed values** have a shaded background. Some computed totals could only be changed by returning to the screen where the component value(s) were first entered. The computed values will appear when all component elements have been reported.

### Congregate Settings

- State or nonstate non-family residential settings (any Funding Authority), such as group homes, ICF/IID, Nursing Homes, Psychiatric Facilities, or any other similar facility) in which rotating (or shift) staff members provide supports and services.
- **People in Congregate Settings does not include people who:**
  - Live with birth or adoptive parents, or other family members
  - Live in **Host/Foster Family Settings** in which no shift staff work
  - Live only part of the year in a residential PreK-12 school
  - Live in correctional or juvenile justice facilities
  - Receive only respite services from a **Congregate Setting**
  - Live in other states (do count people who live in your state whose services are paid by another state)

**Expand** In the **Expand** menu, you can designate a value as an **estimate**, add notes, change the data date, or specify that you are unable to furnish a value (**DNF**). You can also see previous year data, **validation warnings** about possible data errors, and calculations used in the report

**Funding Authorities** Federal, state, or local statutes that authorize funding for long-term supports and services. The RISP survey asks about the following **Funding Authorities**

- **Medicaid Waiver** Funding authorized in Sections 1115; 1915 (a) (b) (b/c); or 1915 (c) of the Social Security Act
- **Medicaid State Plan Home and Community Based Services** Funding authorized in Sections 1915(i) or 1915(k) of the Social Security Act
- **Intermediate Care Facilities for Individuals with Intellectual Disabilities** (ICF/IID)
- **State Funded-Non-Medicaid** Funding authorized by state or local jurisdictions that are not matched with Federal Medicaid funds

**Home and Community-Based Services (HCBS)** Long-Term Supports and Services provided in community settings designed to prevent the need for institutional placement, or to support a person to move out of an institution.

**IDD** Intellectual or developmental disabilities as defined in your state for service eligibility purposes. Some states require service recipients to have a condition such as an intellectual disability, autism, cerebral palsy, epilepsy, spina bifida, or a closely related condition. Other states define eligibility for IDD services based on the **Developmental Disabilities Assistance and Bill of Rights Act of 2000** definition, or based on the presence of specific functional limitations present before a specific age.

### IDD Agency Caseload

- **Include**
  - People with IDD known to the **State IDD Agency** who receive one or more long-term supports and services in addition to case management
  - People receiving only case management or service coordination
  - People waiting for services, and



## FY 2017 (July 1, 2016 – June 30, 2017) Residential Information Systems Projects (RISP) Survey

- People known to the **State IDD Agency** but not receiving **LTSS**

- **Do not include**

- People whose eligibility for services has not been determined
- People who receive services from another government agency, such as education or child welfare, unless they also are served by the State IDD Agency.

**In development: Not required** Items marked “In development” are optional. We will use annotations on tables to reflect when data from “In development” items are reported, but will not designate totals as DNF based on whether these items are completed or not.

**Long-Term Supports and Services (LTSS)** can be provided in an institution such as an **ICF/IID**, Nursing Home or Psychiatric facility or can be provided in **Home and Community-Based Settings**. LTSS include, but are not limited to, residential supports, in-home supports, personal care assistance, family supports, day or employment supports, case management, behavioral supports, support for participant direction, therapeutic services, non-Medical transportation, equipment, technology and modifications, home delivered meals, community transition services, family and caregiver training, respite, and financial management services.

**LTSS Recipients** People with **IDD** served by **State IDD Agencies** who receive one or more Medicaid or state-funded **LTSS** in addition to case management or service coordination.

- **Include** people receiving **LTSS** such as day habilitation, vocational services, or transportation even if they do not also receive in-home or residential services and people served by or under the auspices of the **State IDD Agency**.
- **Include** people with IDD living in Nursing Homes or **Psychiatric Facilities** in parts 1 and 2 if they are on the IDD Agency caseload, and in Part 5 whether or not they are on the IDD Agency caseload.

**Did Not Furnish** A value that is not available, and for which a reasonable estimate cannot be made.

**Estimate** An exact value is unavailable. The state’s best approximation of what the value would be if it had been available. Estimates can be the value for the item in the previous or subsequent fiscal year, but an estimate can be carried forward for only one year.

**Expand** A section of the online survey where users can add annotations, notes, and different dates. The menu also allows users to see previous year data, validations related to warnings about possible data errors, and calculations used in the report.

- **Private Detail** A note that is not for publication, but is helpful for RISP staff or other people from your state who enter data.
- **Public Detail** A note for publication in the state notes section of the RISP technical report, and with state profiles, to help readers correctly interpret your data.

**Nonstate-Operated Settings** LTSS settings in which services are provided by people who are not employees of the state government.

**Other Date** A date other than June 30, 2017, or a Fiscal Year ending on a date other than June 30, 2017.

**Other Funding Authority** (Part 1) State-Operated **LTSS** funded by a source other than Medicaid Waiver or ICF/IID.

**Other Setting Type** (Part 2) Settings in which **LTSS recipients** with IDD live other than an ICF/IID, group home, own home, host/foster family home, or family home. Other settings include, but are not limited to, Nursing Homes and Psychiatric Facilities.

**Partial Data** Used in the RISP technical report to indicate that a state furnished some, but not all, of the data needed to compute a value.

**Psychiatric Facilities** Residential facilities providing LTSS to persons with a primary diagnosis of a Psychiatric disorder (for example a mental health facility). Report only the number of people with IDD living in those settings.

**Public Residential Facilities (PRF)** State-Operated IDD Facilities with 16 or more residents (includes IDD units in state-operated facilities serving other populations).

## FY 2017 (July 1, 2016 – June 30, 2017) Residential Information Systems Projects (RISP) Survey

**Setting size** Number of long-term services and supports recipients living in the same home, facility, or campus as of June 30, 2017 (Categories include 1 to 3 people, 4 to 6 people, 7 to 15 people, or 16 or more people). Do not count “empty beds” in determining setting size.

**State IDD Agency** the state entity responsible for overseeing Medicaid or State-funded long-term supports and services for people with IDD.

**State-Operated IDD settings** residential facilities staffed by employees of the state government.

**State-Operated Settings, “Other” Funding Authority** – LTSS settings staffed by employees of the state-government that are funded by a source other than Medicaid **ICF/IID** or a **Medicaid Waiver**.

**Unknown Setting Size** (Part 2, Questions 2A) Number of LTSS settings of each type for which the setting size is unknown. (Part 2, Question 2B) Number of people with IDD living in a setting type of an unknown size.

**Unknown Setting Type** (Part 2, Type 7, Questions 2B and 2C) Number of LTSS recipients on the caseload of the State IDD Agency living in a nonstate-operated setting, for whom residential setting type is unknown. If one or more people are reported to live in an unknown setting type, totals for all setting types will be coded as estimates.

**Warnings** Validations and computation checks have been built into the RISP online survey. They alert users about values that are inconsistent with previous values or other survey responses, and about possible arithmetic or data entry errors.

### RISP Project Staff Members

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The RISP team can be reached at [risp@umn.edu](mailto:risp@umn.edu) or Research and Training Center on Community Living, University of Minnesota, 210 Pattee Hall, 150 Pillsbury Drive SE, Minneapolis, MN 55455. Phone 612-624-6328, Fax 612-625-6619.

# RESIDENTIAL INFORMATION SYSTEMS PROJECT OPERATIONAL DEFINITIONS | FY 2017 SURVEY

## Survey Overview and Definitions

The RISP project is directed by Sheryl Larson at the University of Minnesota. The data collection team for FY 2017 includes Lynda Anderson and Heidi Eschenbacher from the University of Minnesota, and Brittany Taylor from the Human Services Research Institute. Each state is assigned a specific staff member for ongoing project communication. You can see who is assigned to your state in the survey introduction at <https://risp.umn.edu/survey-dashboard>.

RISP technical assistance is available to state staff and the public. See the RISP website for contact information: <https://risp.umn.edu/contactus>. General RISP questions can be emailed to [risp@umn.edu](mailto:risp@umn.edu). Someone from the RISP project team will get back to you as soon as possible.

Technical Assistance is available about:

- How to interpret a specific finding in the annual technical report
- Comparisons between two or more states, or comparing a state to the nation as a whole
- How RISP findings relate to a story being developed by the press or media
- How to use RISP findings in policy development, strategic planning, and policy advocacy
- Other topics

## Abbreviations and Acronyms

CMS 64	Centers for Medicare & Medicaid Services Quarterly Expense Report
FY	State Fiscal Year July 1 to June 30, or as specified by states with different fiscal years
HCBS	Home and Community-Based Services
HSRI	Human Services Research Institute
IDD	Intellectual and Developmental Disabilities
ICF/IID	Intermediate Care Facility for Individuals with Intellectual Disabilities
LTSS	Long-term supports and services

NASDDDS	National Association of State Directors of Developmental Disabilities Services
NHIS-D	National Health Interview Survey-Disability Supplement
PD	Partial data reported
PRF	Public residential facility (a state-operated IDD facility serving 16 or more individuals)
RISP	Residential Information Systems Project (University of MN)
RTC	Research and Training Center on Community Living (University of MN)

## Special designators for the RISP survey and annual technical report

“d” Other date.

If the provided data was not from June 30, please specify the alternate date used.

“e” Estimate.

The reported value is the closest available approximation when the exact value is not known. A value reported in FY 2016 can be used as an estimate for FY 2017 by designating the date as June 30, 2016. Do not use values originally reported in FY 2015 or earlier as estimates.

“DNF” Data not furnished

Use the DNF code **only** if a value is not known or not available, and it cannot be estimated. Please limit the use of the DNF code. If the state does not provide a value or an estimate, project staff must impute the value to generate the US estimated totals. Do not use zero “0” to reflect unknown values.

“i” imputed. For use by the RISP team only.

No value, or incomplete data were provided. RISP project staff estimated the value so that a US estimated total could be computed. Imputed values are based on previously

reported data, and/or proportional estimates based on states with complete data.

“N/A” Not applicable.

This code is only used in reference to per-person expenditures for services provided in state-operated IDD facilities of 16 or more people for states that do not operate any facilities of that type. On all of the other questions, indicate that you do not use the service with a “0,” meaning no participants/facilities/expenditures etc.

“PD” – Partial Data. For use by the RISP team only in data analysis.

PD is noted on tables that include values computed using two or more survey items when some, but not all, of the components were reported by the state.

“s” Other source. For use by the RISP team only.

- Publicly available data from a federal data source are used for values such as the total state population by age, total income taxes paid by the state, and Federal Medical Assistance Percentages.
- Reports published quarterly by the American Health Care Association based on the Centers for Medicare and Medicaid Services CASPER reports are used as estimates if the state does not furnish complete data on the number of ICF/IID recipients, and number of people with IDD in Nursing Homes.
- IBM Watson (formerly Truven) has a contract with the Centers for Medicare and Medicaid Services to publish an analysis Medicaid long-term supports and services program expenditures as reported by states in their quarterly CMS 64 forms for each Federal Fiscal Year. However, those reports generally are based on date of payment rather than date of service, and are subject to revision for up to 2 years after the fiscal year ends. CMS no longer allows preliminary data to be released. The IBM Watson reports are usually not released until after the RISP technical report is published.

## Key Definitions

### Intellectual Disability

According to the American Association on Intellectual and Developmental Disabilities (AAIDD), intellectual disability is characterized by significant limitations both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior, which covers a range of everyday social and practical skills. This disability originates before the age of 18. The term intellectual disability covers the same population of individuals who were diagnosed previously with mental retardation in number, kind, level, type, duration of disability, and the need of people with this disability for individualized services and supports. Every individual who is, or was, eligible for a diagnosis of mental retardation is eligible for a diagnosis of intellectual disability. Alternative definitions are offered by the American Psychological Association (APA) in the DSM V, and by the World Health Organization (WHO) in the International Classification of Diseases and Related Health Problems. The International Statistical Classification of Diseases in Related Problems (ICD) version 10 (<http://www.icd10data.com/>) defines codes used in health care settings. States may use one of these definitions, or may use another definition in rule and statute.

### Developmental Disability (DD)

According to Congress, under the Developmental Disabilities Assistance and Bill of Rights Act of 2000 “developmental disability” is a severe, chronic disability of an individual that:

1. is attributable to a mental or physical impairment or combination of mental and physical impairments;
2. is manifested before the individual attains age 22;
3. is likely to continue indefinitely;
4. results in substantial functional limitations in 3 or more of the following areas of major life activity:
  - a. Self-care
  - b. Receptive and expressive language
  - c. Learning
  - d. Mobility

- e. Self-direction
  - f. Capacity for independent living, or
  - g. Economic self-sufficiency; and
5. reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated." [http://www.acl.gov/Programs/AIDD/DD\\_History/index.aspx](http://www.acl.gov/Programs/AIDD/DD_History/index.aspx)

## Related Conditions

States vary in which related conditions qualify an individual for IDD agency services. In some states people with a condition closely related to intellectual disabilities that results in the need for the same type, intensity, and duration of support as needed by a person with intellectual disabilities are eligible for IDD services. Common related conditions include autism spectrum disorder, cerebral palsy, down syndrome, spina bifida, hydrocephalus, epilepsy, and fragile X syndrome.

## Age

RISP defines children and youth as people ages birth to 21 years, and adults as people 22 years or older on June 30, 2017. These age groups were selected in cooperation with the NASDDDS Research Committee knowing that the age cutoff for children and youth varies by state. For the RISP survey, please use the 0-21 year age group if possible to permit meaningful comparisons across states. If your state uses a different age cutoff, or for some other reason you are unable to report using the 0-21 year group, please specify the age cutoff you used.

People born on or before June 30, 1995 should be reported in the ages birth to 21 years (21 years includes up to a person's 22<sup>nd</sup> birthday). People born after June 30, 1995 (i.e. born on or after July 1, 1995) should be reported for the 22 years or older.

## Long-Term Supports and Services

Long-Term Supports and Services (LTSS) assist people experiencing ongoing difficulties as a result of aging, chronic illness, or disability to perform activities of daily living (such as eating, bathing, and dressing), instrumental activities of daily living (such

as cooking, housekeeping, and managing money or medications), and to participate in employment, educational, recreation, and community activities of their choice.

LTSS include, but are not limited to, residential supports, in-home supports, personal care assistance, family supports, day or employment supports, case management, behavioral supports, support for participant direction, therapeutic services, non-medical transportation, equipment, technology and modifications, home delivered meals, community transition services, family and caregiver training, respite, and financial management services.

- **Behavior Supports:** Supports to prevent or reduce behavior-related issues or mitigate crisis needs. Includes services provided by professional staff, as well as preemptive solutions.
  - Examples: Mental health assessment, crisis intervention, behavioral support, counseling, assertive community treatment
- **Case Management:** Services to assist an individual or family to identify the supports they need, establish eligibility for funded supports, access needed supports, and monitor the extent to which available supports meet the needs of the individual.
  - Examples: Case management, service coordination
- **Day Habilitation & Employment:** Services provided to support the individual in community-based activities (i.e., supported employment, day programs, education)
  - Examples: Job development, supported employment (individual, group, competitive), prevocational services, day habilitation, and early start programs
- **Environmental Modifications and Technology:** Services to accommodate physical disabilities
  - Examples: Personal emergency response systems, home modifications (such as ramps, bathroom modifications), vehicle modifications or repairs, other adaptive equipment, augmentative communication devices, and similar services
- **Family Caregiver Support:** Services provided to help the family caring for an individual with IDD



- Examples: Home-delivered meals, home health aide, homemaker/chore, caregiver counseling, caregiver training
- **In-home Services:** Services to direct skills development and training to the individual living in the home of a family member, or the person's own home.
  - Examples: Home-based habilitation and training
- **LTSS Medical Supports:** Medical care needed to help individuals with disabilities to remain in their home, the home of a family member, or another home or community residential setting.
  - Examples: OT, PT, speech and language therapies, skilled and private-duty nursing
- **Participant-Directed Supports:** Assistance to individuals/families who self-direct services. Such assistance may include the development of the person-centered plan, managing individual budgets, recruiting workers, and accessing generic services and supports.
  - Examples: Financial management services, participant training, goods and services, other, interpreter
- **Personal Care Supports:** Direct one-to-one services to the individual provided in, or out of, home to provide instrumental support, community integration or skill training
  - Examples: Companion services, personal care/assistance
- **Residential Services:** Services provided to a person with IDD who lives in a setting other than the home of a family member while receiving funded supports.
  - Examples: Residential habilitation, group home, semi-independent living services, supported living services, shared living, corporate foster care, host home, family foster care
- **Respite:** Temporary relief from caregiving responsibilities for family caregivers
  - Examples: Respite (in home, out of home), individual support (day or night)
- **Transportation:** Supports to transport an individual to a community-based activity, including day services, employment services, or other community-based activities.
  - Examples: Community transportation services, non-medical transportation

## Funding Authorities

The survey asks about the **funding authorities** used in your state to finance **long-term supports and services** for people with IDD as of June 30, 2017. We cluster funding authorities into four broad categories: Medicaid Waiver, Medicaid State Plan Home and Community Based Services (HCBS), Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID), and non-Medicaid state funding sources.

**Medicaid Waivers.** Under the Social Security Act, certain provisions give the Secretary of Health and Human Services the authority to waive otherwise applicable provisions of the Medicaid statute. The RISP survey asks about people with IDD who receive LTSS funded by one or more of the following authorities:

### 1115 Demonstration Waivers

Section 1115 Waivers allow states to test experimental, pilot, or demonstration projects that promote the objectives of the Medicaid and CHIP programs. They give states additional flexibility to design and improve their programs to demonstrate and evaluate policy approaches such as expanding Medicaid eligibility criterion, providing services not typically covered by Medicaid, and using innovative service delivery systems that improve care, increase efficiency, and reduce costs.

### Managed Care Waivers

Several Medicaid authorities allow states to contract with Managed Care Organizations (MCOs) to manage Medicaid-funded services and supports, rather than using a fee-for-service financing structure. The authorities monitored by the RISP project include:

- **1915(a) Managed Care Waiver.** This authority allows states to enroll Medicaid recipients voluntarily into a managed care program as an alternative to offering those services using a fee-for-service model.
- **1915(b) Managed Care Waiver.** This authority allows states to mandate certain groups of Medicaid recipients to receive services through enrollment in a managed care program.
- **1915(b)/(c) Managed Care with Home and Community Based services.** This authority allows



states to operate a 1915(c) Home and Community Based Services Waiver concurrently with a managed care wavier authority.

### 1915(c) Home and Community Based Services Waivers

This funding authority allows states to provide Medicaid-funded long-term supports and services to eligible recipients in a home or community-based setting rather than in a Medicaid-funded institution. 1915(c) waivers can target specific populations, and each waiver includes a specified menu of covered services that assist in diverting people from entering institutional settings and/or transitioning individuals from institutional settings into their homes and community. States may operate several different 1915(c) waiver programs targeting different populations or service menus.

**Medicaid State Plan.** Medicaid State Plan services include acute care, institutional long-term supports and services, and home and community based LTSS. Do not report on State Plan Targeted Case Management except in the waiting list question.

- 1915(i) State Plan Home and Community-Based Services. The 1915(i) State Plan option allows states to target HCBS benefits to one or more Medicaid eligible population, define needs-based eligibility criteria, and provide a combination of acute care medical services such as dental services, and skilled nursing services, as well as LTSS, such as respite, case management, supported employment, or environmental modifications. This authority allows states to offer self-directed LTSS services. However, states must ensure that the benefit is available to all eligible individuals in the state.
- 1915(k) Community First Choice. The 1915(k) funding authority is a State Plan Option that permits states to provide home and community-based attendant services and supports to eligible Medicaid enrollees. Participants must require institutional levels of care to qualify. It provides increased federal matching dollars for expenditures. States must ensure that the benefit is available to all eligible individuals statewide.
- Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) is an optional institutional State Plan Medicaid benefit that funds comprehensive and individualized health care and

rehabilitation services to individuals to promote their functional status and independence.

### Other Funding Authorities

- State Non-Medicaid. State funded LTSS not eligible for federal Medical matching funds.
- “Other” funding (Used in Part 1). Any funding source other than Medicaid Waiver or Medicaid ICF/IID that funds state operated residential services for people with IDD.

### Time Frame

- Each survey covers one Fiscal Year. For most states, FY 2017 is July 1, 2016 to June 30, 2017.
- Most questions reference people or settings as of June 30, 2017, or the last day of the fiscal year.
- Contact your RISP staff if you want to have a different fiscal year assigned as the default date for the online RISP survey.
- Report expenditures for services delivered between July 1, 2016 and June 30, 2017.

### Populations of Interest

Parts 1 and 2 of the survey ask about people, served by State IDD Agencies, who receive one or more Medicaid or state-funded long-term support or service (LTSS) in addition to case management or service coordination (LTSS Recipients with IDD). This group includes people receiving in-home or residential supports, as well as people receiving other types of LTSS such as day habilitation or vocational services even if the person does not receive services in their home or in a residential facility. It also includes people served by the State IDD Agency who live in Nursing Homes or Psychiatric Facilities.

Parts 3 through 5 include a broader target population.

- People on the **State IDD Agency Caseload** (Parts 3 and 4). This group includes **LTSS Recipients** with IDD plus people with IDD receiving only case management or services coordination services, people waiting for services, and people known to the **State IDD Agency** but not currently receiving LTSS. It does not include people whose eligibility for services has not been determined.
- All people with IDD (Part 5), whether on the **State IDD Agency Caseload** or not, who live in

**Nursing Homes, Psychiatric Facilities**, or other **Congregate Settings** housing four or more LTSS recipients (for people birth through age 21 years), or housing 16 or more LTSS recipients (for people ages 22 years and older).

### Operating Entity

Operating entity refers to the organization that directly employs staff providing long-term supports and services. The organization may be **State-operated or Nonstate-operated**.

## PART 1: STATE-OPERATED SERVICES

**Part 1 Population of Interest: LTSS recipients with IDD** living in state-operated IDD residential facilities of all sizes or in IDD units of state-operated Nursing Homes or Psychiatric Facilities. Include IDD facilities or units managed by state agencies other than the State IDD Agency.

Setting size is based on number service recipients living in the facility/on the campus as of June 30. Do not count “empty beds” in determining setting size (for example, a campus licensed to serve up to 20 people that has 12 people in residence on June 30 should be listed in the 7-15 people category).

**Public Residential Facilities (PRF):** State-operated IDD residential facilities serving 16 or more people with IDD on one campus, or at one address. Multiple units located on a single institution campus are considered one facility regardless of the number of licensed units on the campus.

**Admissions or Readmissions** - The number of people with IDD admitted during FY 2017 (7/1/2016 to 6/30/2017) for stays of more than 90 days.

- Exclude transfers between large, state-operated IDD facilities with 16 or more people
- Exclude short-term admissions of 90 days or less for respite, crisis assessment or services or short-term emergency housing.

### Short-term Admissions in FY 2017

- Report the total number of admissions for respite, crisis assessment or services, or short-term emergency housing for stays of 90 days or less

- Count each **admission** of less 90 days or less (some individuals may have multiple short-term admission in a single year).

**Discharges** - the number of people with IDD who moved out of a PRF between July 1, 2016 and June 30, 2017.

- Include people released or discharged to a hospital, Nursing Home or other long-term care setting
- Exclude transfers to other large state operated IDD facilities
- Exclude people admitted for respite, crisis assessment or services or short-term emergency housing stays of 90 days or less

**Deaths** - the number of people who died while a resident of a PRF between July 1, 2016 and June 30, 2017

- Include any people who died prior to discharge, even if their death occurred during a temporary stay in a hospice, hospital, Nursing Home or other facility

### Average Daily Residents

- Average number of people living in any PRF in your state during the year.
- If not provided, average daily residents will be computed as the total number of PRF residents on June 30, 2016 plus the number of PRF residents on June 30, 2017 divided by 2.

**Per Diem** (average daily per person expenditures) in FY 2017

If a facility has more than one per diem rate, provide the average per diem paid across all residents with IDD.

Provide a single average for all facilities of the same type.

Include both state and federal Medicaid expenditures when computing the average.

## PART 2. NONSTATE-OPERATED LIVING ARRANGEMENTS

Part 2 Population of Interest: **LTSS recipients** on the State **IDD Agency Caseload** receiving LTSS from an employee of an entity other than the state.

Include all LTSS recipients with IDD who

- a. Receive one or more Medicaid or state-funded long-term support or service (LTSS) in addition to case management or service coordination
- b. Receive in-home or residential services,
- c. Receive day habilitation, vocational services or other LTSS even if they do not receive in-home or residential services,
- d. Live in an ICF/IID (even if it is licensed or monitored by an agency other than the State IDD Agency),
- e. Live in a nonstate-operated Nursing Home or Psychiatric Facility

All LTSS recipients with IDD on the State IDD Agency Caseload should be counted either in the state-operated residence or the nonstate-operated setting in which they live. Count LTSS recipients with IDD whose residence type is unknown in the Type VII Unknown Setting Type category.

### Nonstate-Operated Residences

**Type I: ICF/IID.** Medicaid Intermediate Care Facilities for Individuals with Intellectual Disabilities.

**Type II: IDD Group Home.** A residence owned, rented, or managed by the residential services provider, or the provider's agent, to provide housing for persons with IDD in which staff provide care, instruction, supervision, and other support for residents with IDD.

- Include corporate foster care settings in which services are provided by staff, none of whom consider the home their permanent residence.
- Excludes ICF/IID certified facilities.

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

**Type IV. Own Home.** A home owned or leased by one or more persons with IDD as the person(s)' own home, in which they receive personal assistance, instruction, supervision, and other supports.

- Include settings in which people with IDD
  - live alone or share a home with a spouse/partner or other unrelated individuals.
  - hold the title or lease in his or her own name; or is named on the lease,
  - can continue to live after discontinuing services from a particular provider, and
  - can substitute services from an alternative provider at any time.
- Do not include provider-owned or controlled housing (count those in Type II group homes).
- Do not include people living with a related family member (count those as Type V family home).

**Type V. Family Home.** A residence of a person(s) with IDD who receives one or more long-term support or service such as respite care, personal assistance, day habilitation, or in-home supports in addition to case management services while living with a related family member.

**Type VI. Other Setting.** Other residential settings in which LTSS recipients with IDD on the caseload of the state IDD agency live. Other settings may include settings such as nonstate-operated hospitals, Nursing Homes, Psychiatric Facilities, assisted living facilities, board and care facilities, farmsteads, intentional, or gated communities. Do not include Type I ICF/IID settings or Type II IDD Group Homes in this category. If you report people with IDD living in other residential settings, please describe the "other" settings.

**Type VII. Unknown Setting.** The type of setting in which a LTSS recipient with IDD lives is not known.

- People known to be homeless should be counted as living in an unknown setting.
- All people on the IDD Agency caseload who receive one or more LTSS, and who live in a nonstate setting, should be accounted for either in Types 1 through VI or in Type VII.
- If left blank, this question will be recoded to 0.

## Setting Size

Setting size is computed based on the total number of service recipients residing in the home/facility on June 30, 2017. Setting size categories include 1 to 3 people, 4 to 6 people, 7 to 15 people, and 16 or more people. Do not count empty beds (for example, a campus licensed to serve 20 people with 12 people in residence on June 30 should be listed in the 7-15 people category).

**2A. Number of facilities by setting size.** Homes or facilities that are clustered on a single campus or at a single address count as one facility. A facility or campus with multiple structures or licenses counts as one setting. For a facility in which 100 service recipients live, 10 of whom have IDD, report 1 facility of 16+ people and report 10 people living in a setting of 16+ people.

### Assumptions:

1. There are no ICF/IID settings serving fewer than four people.
2. There are no host/foster family homes serving sixteen or more service recipients.
3. There are no own home settings in which seven or more service recipients live.

An override function is available for the online survey if any of these assumptions are untrue in your state.

We do not count the number of family homes in which people live.

We report the total number of facilities by size across all types of state-operated settings, and across all non-family nonstate-operated settings.

- A total will be automatically computed if you provide a value of 0 or larger for all relevant setting types and sizes
- If complete setting type and size information are not provided, a DNF (did not furnish) or PD (Partial data) will appear in the report and on your state profile.
- Please enter a note explaining all DNF values.
- If you account for all LTSS recipients with IDD in state-operated and non-state operated settings

by using the size unknown, and/or setting type unknown fields we will report the totals rather than showing DNF or PD.

### 2B. Number of LTSS recipients by setting size.

Report the number of people with IDD living in settings of each size. If all service recipients in each setting have IDD, the number of people in a size category should be consistent with the number of settings in that size category. For example, if 100 people with IDD live in settings of 4 to 6 people, the total number of facilities serving 4 to 6 people should be between 17 (100 divided by 6) and 25 (100 divided by 4).

### 2C. Total Recipients by Funding Authority and Nonstate-Operated Residence Type

For each nonstate residential setting type, report the number of people with IDD whose services are funded by Medicaid Waiver (1115, 1915 a, b, b/c and c) and/or Medicaid State Plan HCBS (1915 i and k) funding authorities. Also, provide an unduplicated total number of Medicaid Waiver or Medicaid State Plan HCBS recipients for each residence type.

## PART 3 CASELOAD, LTSS RECIPIENTS, AND EXPENDITURES

3. The **IDD Agency Caseload** includes people with IDD known to or served by the auspices of the state IDD agency who:

- receive one or more LTSS in addition to case management or service coordination (LTSS Recipients)
- receive only case management or service coordination services
- are waiting for LTSS, and
- are known to the state IDD agency but not receiving LTSS as of June 30, 2017

Do not include people

- whose eligibility IDD services through the IDD agency has yet to be determined or
- who receive services through another state entity (such as child welfare, education, or income supports) unless they also meet the inclusion criteria above

If you provided complete data, total LTSS recipients reported in state-operated or nonstate-operated settings in Parts 1 and 2 are shown for your reference. The number of people on the IDD Agency Caseload should be equal to or greater than the total number of LTSS recipients reported in Parts 1 and 2.

### **3A through 3F People on the State IDD Agency Caseload Receiving Services, and Expenditures by Funding Authority.**

Report people on the caseload of your state IDD agency not receiving LTSS as of June 30, 2017 by age in question 3F.

Report the number of LTSS recipients and total LTSS expenditures by age and funding authority in questions 3A through 3E. Duplicate counts are allowed in questions 3A through 3E.

Questions 3A and 3B both ask about LTSS recipients whose services are funded by a Medicaid Waiver funding authority. Question 3A requests the number of Medicaid Waiver recipients and total Medicaid Waiver expenditures between July 1, 2016 and June 30, 2017 by age. Question 3B requests the number of Medicaid Waiver recipients and total Medicaid expenditures by living arrangement (family home or other) and age (21 years and younger or 22 years and older).

**Medicaid Expenditures** include both the state/local and federal match expenditures

**Per Recipient Expenditures.** The online survey automatically computes average per person annual expenditures for all categories in which complete information was provided. It is not necessary to compute these totals when completing the Word version of the survey. Please be sure that the expenditures you report are for the number of recipients you report in each category (even if you report expenditures for only a subgroup of recipients). Please verify that the computed average expenditures per recipient are plausible for each category.

## **PART 4 MEDICAID WAIVER WAITING LIST**

Part 4 population of interest: People on the **IDD Agency Caseload** waiting for **Medicaid Waiver-funded LTSS** while living in a **Family Home** or **Own Home** Setting as of June 30, 2017.

Include people waiting for Medicaid Waiver-funded LTSS who:

- Lived with a family member or in their own home as of June 30, 2017, and
- Did not receive Medicaid-funded LTSS, other than case management/service coordination as of June 30, 2017

Do not include people with IDD who:

- Lived in a setting other than a Family Home or Own Home or who
- Received Medicaid Waiver-funded LTSS as of June 30, 2017

Report the number of people waiting who received case management service/service coordination (including through State Plan Targeted Case Management) on June 30, 2017.

Also, report the number of people living with a family member who were waiting for Medicaid Waiver funding to move to another setting type (such as **Own Home**, **Host/Foster Family Home**, **IDD Group Home** or **Other**) as of June 30, 2017.

## **PART 5 PSYCHIATRIC, NURSING FACILITIES, AND CDC HEALTHY PEOPLE 2020 MONITORING**

Part 5 Population of Interest: All people with IDD living in congregate settings (whether on the **IDD Agency Caseload** or not).

### **Nursing Home**

A state or nonstate institution offering skilled nursing or medical care and related services; rehabilitation supports needed due to injury, disability, or illness; and/or long-term care including health-related care and services (above the level of room and board) not available in the community,



needed regularly due to a mental or physical condition. Admission to Medicaid Certified Nursing Homes requires a Preadmission Screening and Resident Review (PASSAR).

## Psychiatric Facility

Residential facilities designed for persons with a psychiatric disorder, (for example a mental health facility or institute for mental disease).

People living in an ICF/IID certified unit of a Nursing Home or Psychiatric Facility should be counted in the ICF/IID facility category.

**About this Section:** The Centers for Disease Control (CDC) uses the data you report here to monitor national progress toward the Healthy People 2020 goals of reducing the number of children and adults with IDD living in congregate settings.

It is very important that we receive data from all of the states on these questions.

If you are unable to furnish separate data for nursing homes and other congregate settings, enter the combined total and add a note saying that separate data are not available by type of congregate setting.

Congregate Settings are

- State- or nonstate-operated non-family residential settings, such as **PRFs**, **ICF/IID**, **Group Homes**, **Nursing Homes**, **Psychiatric Facilities**, **Other Group Settings** or similar facilities.
- In which rotating (or shift) staff members provide supports and services

For people ages 21 years or younger, report the number of LTSS recipients with IDD in **Congregate Settings** of four or more people.

For people ages 22 years or older, report the number of LTSS recipients with IDD in **Congregate Settings** of 16 or more people.

**Congregate Settings** do not include **Own Home** settings.

**People in Congregate Settings do not include people who:**

- Live with birth or adoptive parents, or other family members
- Live in **Host/Foster Family Settings** in which no shift staff work
- Live only part of the year in a residential PreK-12 school
- Live in correctional or juvenile justice facilities
- Receive only respite services from a **Congregate Setting**
- Live in other states (do count people who live in your state whose services are paid by another state)

## FREQUENTLY ASKED QUESTIONS

### Where do I go to complete the RISP survey online?

- The URL for the RISP survey is <https://risp.umn.edu/survey-dashboard>.
- If you have not previously done so, you will need to contact your state's assigned RISP team member for login information to access the survey. Please do not use someone else's login information.

### What if fewer people live in a facility on June 30 than the licensed capacity?

- Report only number of individuals with IDD residing in the facilities on June 30. Do not report the licensed capacity.

### What should we do when we cannot report a certain data element because it is not available?

- Report DNF to indicate that a data element is not available.
- Report totals whenever possible, even if you cannot provide subtotals. Examples:
  - If you know the number of people in settings of 1 to 6 people, but do not know how many are in settings of 1 to 3 and 4 to 6, report the 1-6 total, and enter DNF for 1 to 3 and 4 to 6.
  - If you know the total number of Medicaid Waiver recipients by age, but do not know how many people in each age group live in the home of a family member, report the totals by age, and enter DNF for the living arrangement component of the question.
- In reports using RISP data:



- For individual survey items, DNF indicates that a particular value was not provided.
- For tables that combine data from two or more separate elements, Partial Data (PD) indicates that at least one of the component values was reported, or DNF, if none of the component parts was reported.

### **What should we do if an entity other than the State IDD Agency manages some or all LTSS for people with IDD?**

- Please request the data from the other entity (e.g., the managed care organization, the State Medicaid Agency).
- If you report data from another entity, and would like readers of the report to know the source, please identify the source in the public notes.

### **What if the State IDD Agency does not collect or report certain data (ever, or for a specific year)?**

- Use the notes to explain why a data element is not available.
- Report data from the immediately prior year (if available). Do not repeat an estimate that is more than one year old.

### **Where do the Medicaid long-term care expenditure data used in the RISP report come from?**

- The annual RISP state survey has been the primary source for expenditures since these dates:
  - FY 1982 for 1915(c) Waivers (referred to as “Home and Community Based Waivers,” “regular ID/DD Waivers,” or Medicaid Section 2176 HCBS Waiver” in earlier years of the survey).
  - FY 1982 Medicaid 1115, 1915 (a/c), (b), or (b/c), and “other Waivers” serving people with IDD. This category also included OBRA (Nursing Home) ID/DD Waivers and Model Waivers for people with ID/DD from FY 1994 to FY 2008.
  - FY 1990 to FY 1995 Medicaid Community Supported Living Arrangement option (used by 8 states)
  - FY 2012 ICF/IID
  - FY 2013 Medicaid State Plan 1915(i) and 1915(k)
- Other sources for Medicaid Expenditures (used only when states are unable to furnish the data)
  - Until FY 2010, a CMS contractor published a report summarizing Medicaid Waiver and ICF/

IID expenditures based on CMS 64 reports in time to supplement data from non-reporting states for the annual RISP technical report. CMS no longer allows preliminary data to be released. This report is now released 21 to 24 months after the end of a fiscal year. As a result, the RISP technical report does not include data from the CMS 64 reports for the current year. Once they are released, those reports (currently produced by IBM Watson) are used to update our online database for states that furnished partial or no expenditure data.

- ICF/IID expenditures for FY 2011 are from the State of the States survey
- Expenditure data are updated as follows
  - States can provide updated expenditure data as it becomes available. Data provided by states is preferred.
  - Historical data that came from Truven or IBM Watson reports are updated in the RISP database for all applicable years when the IBM Watson reports are released.

### **What other data sources are used for the RISP technical report?**

- State populations by age are from US Census Data.
- Income taxes paid by state, and Medicaid federal match rates, are from the relevant federal databases.
- A summary of data from the Medicaid Certification and Survey Provider Enhanced Reporting (CASPER) reports for public and private ICF/IID and Nursing Homes is compiled quarterly by the American Health Care Association. Information from CASPER is used when a state is unable to furnish the number of people with IDD in ICF/IID or Nursing Home settings.
- The annual Public Residential Facility (PRF) survey is fielded by RISP staff to gather data about state-operated IDD facilities and IDD units in state operated Nursing Homes or Psychiatric Facilities. The sample frame for this survey was developed in 1977, and includes most, but not all, state-operated IDD facilities serving 16 or more people still in operation. Facilities are removed from the sample frame when they close, downsize to 15 or fewer people, are converted for use by a different population, or merge before June 30. The survey asks about the demographics of people served, and of those who enter or leave a facility during a

fiscal year. It also asks about facility characteristics such as the number of full-time equivalent staff.

### **Are duplicate counts ok?**

- Unduplicated counts should be used throughout the report, except that
  - Duplicated counts are acceptable in the expenditure section (Part 3), when service recipients receive LTSS services through more than one Medicaid or state funding authority (e.g., 1915(c) Waiver and State Plan HCBS).
- We compute the average per-person expenditure overall, and for subgroups of recipients, so it is important that the number of recipients reported matches the expenditures in each category.

### **Why do some totals differ from one table to the next in the annual RISP technical report?**

- Some totals could be calculated using items from more than one section of the survey. For example, the total number of Medicaid Waiver Recipients on June 30 is computed by summing the number of Waiver recipients in state-operated residences from Part 1 and the number served by non-state providers from Part 2. The number of recipients for whom expenditures were reported comes from Part 3. Totals for states that reported different numbers of people in Parts 1 and 2 than in Part 3 will not match.
- The survey asks for year-end recipients, but some states report recipients with expenditures in a fiscal year, regardless of whether they were recipients on June 30.
- By default, we report the data as it was reported on the survey. However, if the number of Waiver and ICF/IID recipients as of June 30 reported in Parts 1 and 2 are greater than the values in are reported in Part 3, Expenditures, then we use the number of people in Parts 1 and 2 as the total number of Waiver or ICF/IID recipients. The values from the expenditure section are used in conjunction with the expenditures, and for the total number of recipients so long as the number in Part 3 is greater than or equal to the number of people reported in Parts 1 and 2.

### **What is a validation check? What should I use it for?**

- Validation checks are used in the online survey. They warn the user of discrepancies such as values

that may have a misplaced decimal or a missing digit, large year-to-year changes, or inconsistencies between responses for questions in different sections of the survey.

- If you see a validation warning, look at the “Expand” menu to see “Validation checks that need attention.” Please correct data entry errors, or explain the reason for the discrepancy or notable change from previously reported values.

